

LYME DISEASE: A COMPREHENSIVE APPROACH TO AN EVOLVING THREAT

FIELD HEARING OF THE COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS UNITED STATES SENATE ONE HUNDRED TWELFTH CONGRESS SECOND SESSION ON EXAMINING LYME DISEASE, FOCUSING ON A COMPREHENSIVE APPROACH TO AN EVOLVING THREAT

AUGUST 30, 2012 (Stamford, CT)

Printed for the use of the Committee on Health, Education, Labor, and Pensions



Available via the World Wide Web: <http://www.gpo.gov/fdsys/>

U.S. GOVERNMENT PRINTING OFFICE

75-786 PDF

WASHINGTON : 2012

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512-1800; DC area (202) 512-1800
Fax: (202) 512-2104 Mail: Stop IDCC, Washington, DC 20402-0001

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

TOM HARKIN, Iowa, *Chairman*

BARBARA A. MIKULSKI, Maryland	MICHAEL B. ENZI, Wyoming
JEFF BINGAMAN, New Mexico	LAMAR ALEXANDER, Tennessee
PATTY MURRAY, Washington	RICHARD BURR, North Carolina
BERNARD SANDERS (I), Vermont	JOHNNY ISAKSON, Georgia
ROBERT P. CASEY, JR., Pennsylvania	RAND PAUL, Kentucky
KAY R. HAGAN, North Carolina	ORRIN G. HATCH, Utah
JEFF MERKLEY, Oregon	JOHN MCCAIN, Arizona
AL FRANKEN, Minnesota	PAT ROBERTS, Kansas
MICHAEL F. BENNET, Colorado	LISA MURKOWSKI, Alaska
SHELDON WHITEHOUSE, Rhode Island	MARK KIRK, Illinois
RICHARD BLUMENTHAL, Connecticut	

PAMELA J. SMITH, *Staff Director, Chief Counsel*

LAUREN MCFERRAN, *Deputy Staff Director*

FRANK MACCHIAROLA, *Republican Staff Director*

C O N T E N T S

STATEMENTS

THURSDAY, AUGUST 30, 2012

	Page
Blumenthal, Hon. Richard, a U.S. Senator from the State of Connecticut, opening statement	1
Gillibrand, Hon. Kirsten E., a U.S. Senator from the State of New York	2
Harris, Dwight, Burlington, CT	5
Prepared statement	6
Reid, Katy, Ridgefield, CT	9
Prepared statement	10
Hopwood, Mark, Trumbull, CT	13
Prepared statement	15
Stafford, Kirby C., III, Ph.D., Chief Entomologist, Connecticut Agricultural Experiment Station, New Haven, CT	20
Prepared statement	22
Katz, Amiram, M.D., Assistant Clinical Professor of Neurology, Yale Univer- sity, Orange, CT	24
Prepared statement	25
Petrini, Joann, Ph.D., MPH, Director of Clinical Outcomes and Health Serv- ices Research, Department of Medical Education and Research, Western Connecticut Health Network, Danbury, CT	32
Prepared statement	34

ADDITIONAL MATERIAL

Statements, articles, publications, letters, etc.:	
Kris Newby, Senior Producer, UNDER OUR SKIN	44
The LymeDisease.Org	47
Letters to Senator Blumenthal	53

LYME DISEASE: A COMPREHENSIVE APPROACH TO AN EVOLVING THREAT

THURSDAY, AUGUST 30, 2012

U.S. SENATE,
COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Stamford, CT.

The committee met, pursuant to notice, at 10:05 a.m., in Gen Re Auditorium, University of Connecticut, Stamford, CT, Hon. Richard Blumenthal, presiding.

Present: Senator Blumenthal.

Also present: Senator Gillibrand.

OPENING STATEMENT OF SENATOR BLUMENTHAL

Senator BLUMENTHAL. Good morning, everyone. I'm going to officially call to order this hearing of the U.S. Senate Committee on Health, Education, Labor, and Pensions. I want to thank Senator Tom Harkin of Iowa for giving me this opportunity. He is the chairman of the committee.

I thank the committee staff and my staff for being so cooperative and helpful this morning. And I thank all of you for being here. I know we have a diverse array of people from different areas of interest, but we share a common concern with a disease that has really reached epidemic proportions.

There are about 40,000 cases of Lyme disease reported nationally each year. But that number is probably only about 10 percent of the actual number. One of the very pressing problems that needs to be addressed is the underreporting of Lyme disease, which results in part from the under-detection and lack of adequate diagnosis. And that, in turn, has led to divisions and schisms and disagreement within the scientific and medical community.

You are all aware of some of the dissention that has existed. Part of our objective this morning is to bring together people who really should have a common and shared concern. The objective of bringing people together is also the goal of the legislation that Senator Gillibrand and I have introduced in the U.S. Senate. We have, in all, 12 sponsors, co-sponsors, of this legislation, which would establish an advisory committee at the Federal level, giving patients a voice at the table, because too often, patients and victims have been marginalized in this process.

The inadequacy of diagnostic tools and techniques has left a lot of those patients without a voice because they haven't been given the proper attention. And so the advisory committee would give them a seat at the table. It would also invest in diagnostic research

and provide for education of doctors who all too often in other parts of the country are unaware, and even in Connecticut and New York and New England fail to appreciate the need for greater attention to it. And it would also improve reporting.

This bill is supported by a bipartisan coalition, I'm very proud to say. This hearing, I hope, will galvanize and energize support for it.

Again, I want to thank all of you for being here, and, most especially, my colleague and friend, Senator Gillibrand, who has come as far as any of us to be here today. But she has been such a consistent and courageous leader in this effort. I can't tell you how much her voice means in the U.S. Senate on this subject. She has really been a champion of all of you who are victims of this disease, as well as the scientists who have credibility in this area.

So I am really honored and pleased to welcome you, Senator Gillibrand, for being here today. I know your time is limited, so if you would give us the benefit of your views—and I know that she is reachable through email and many other means for anyone who doesn't have a chance to talk to her today. But we so appreciate your being here. Thanks so much.

STATEMENT OF SENATOR GILLIBRAND

Senator GILLIBRAND. Thank you, Senator Blumenthal, for holding this hearing. I couldn't agree with your opening statement more. I appreciate the fact that you are leading this effort in the Senate to really shine a light on the horrible disease and the effects of the diseases caused by tick-borne illnesses. I can tell you that families across New York have been suffering, often without a diagnosis.

We have so much work to do in terms of putting a very bright light on this issue, and I think this hearing is an excellent first step in that direction. I think our legislation would go a long way in bringing relief and bringing answers and bringing more dollars for research, development, and treatment.

I also want to acknowledge and thank the advocacy and support of groups from New York State that are here. We have the Tick-Borne Disease Alliance, the Empire State Lyme Disease Association, and the New York City Lyme Disease Support Group, and many support groups that are working across New York State to help raise awareness about tick-borne illnesses.

We are here today to bring awareness of Lyme disease and to support Senate bill 1381 to finally get a grip on the growing epidemic of tick-borne illnesses. From the farms of upstate New York to the beaches of Long Island to the parks in all five boroughs of New York City, tick-borne diseases are a public health crisis that truly knows no boundaries. Anyone can be a victim at any time, and it is a crisis that has been ignored for too long.

According to the U.S. Centers for Disease Control, Lyme disease remains the fastest growing vector-borne infectious disease in the United States. The CDC reports 30,000 cases of Lyme disease in 2009, but it acknowledges that actual numbers may be over, as Senator Blumenthal said, 10 times as high due to underreporting.

Another highly alarming factor in the growth of this disease is their place in our blood supply. The American Red Cross has now

confirmed at least 12 deaths nationwide from tick-borne diseases after it was transmitted by transfused blood. We need to ensure that our donor supply is thoroughly tested and free of disease to put a stop to these senseless infections.

Ending these diseases starts with prevention. But with no vaccines to prevent Lyme disease or the co-infections, we have a very long way to go. And the reality is that many people will continue to be infected every single year. Patient outcomes for tick-borne diseases are measurably better when these diseases are caught early. But there is a disagreement about proper diagnostic protocols and the lack of awareness of these diseases.

Each of the tick-borne diseases presents us with a complicated set of symptoms that varies from person to person. Each requires discrete testing and possibly different treatment protocols. Difficulties in identifying and diagnosing these diseases then lead to more difficulties when it comes to treatment. In fact, there is no standard and wholly effective treatment. And as with all progressive diseases, the patient will get sicker the longer the disease is left untreated.

Without a 100 percent reliable diagnostic and without a cure, education and awareness among doctors and patients, paired with research and heightened attention to the issue, are absolutely essential. That's why we are here, to hear more from those who have seen these diseases firsthand and know what is at stake in this fight.

I want to share one story from a New York family whose experience with Lyme disease is heartbreaking, but, unfortunately, all too common. Heidi Buono and her husband, Michael, live in East Greenbush, NY, near Albany, with their three children. It's about a stone's throw from where I live.

The family spent many wonderful times hiking throughout their bucolic woods behind their house and in the region. Heidi, the mom, began to experience many unexplained health problems, migraines, aches, pains, thyroid issues. She found ticks on her children frequently. The pediatrician told her not to worry about it. When her youngest daughter was two, Heidi removed an embedded tick. Within a week, her daughter was running a fever. The pediatrician said it was nothing and did not treat her child.

Four years ago, Heidi's health took a turn for the worse. She slept most days, barely able to leave her bed. She clung to the walls of her home just to get around. The internist tested Heidi for everything, but results were negative. She was declared healthy. But, of course, Heidi knew something was wrong. She couldn't afford any additional testing, and she could not visit specialists because they would not accept her insurance. Unable to work, she had to abandon her plans for returning to work to help pay for her children's college education.

Heidi's oldest son was an honor student at Columbia High School, and after the first week of his sophomore year, he became anxious, depressed, achy, and fatigued. He could not attend school. Like his mom, his blood work came back normal. He was put on anti-depressants and anti-anxiety medicines. Within 2 days, he was having suicidal thoughts, and the doctors wanted to place him in a psychiatric hospital. Finally, Heidi pleaded to have her son re-

tested for tick-borne diseases. The test came back positive for Lyme and several other tick-borne diseases.

Heidi's middle son has been sick since birth, has eye problems, and was diagnosed with learning disabilities. At 5 years old, he asked his mother, "Why can't I remember things?" Heidi believes he may have contracted tick-borne diseases in utero. This family is just like any other family throughout New York State and our Nation who are afflicted by tick-borne diseases and do not have answers.

One of the reasons why I am co-sponsoring S. 1381 is because we have to find them answers. Clearly, we need a better strategy than checking ourselves and our children for ticks. We need real investments in research to lead us to effective treatments, and we need to do a better job of educating families on the risks and emphasize prevention so they know what to do to protect themselves.

Our bill is the first step by the Federal Government to save more lives and one day rid us of tick-borne diseases. The bill takes the following measures: first, establishes a Tick-Borne Disease Advisory Committee; second, streamlines coordination between Federal agencies and private organizations; third, coordinates increased research and development around Lyme disease; fourth, develops more accurate and time sensitive diagnostic tools; fifth, increases public and physician education and establishes reports on Lyme disease that evaluate guidelines and research.

The time has truly come for all of us to join together and take strong action to eradicate tick-borne diseases and stop the needless suffering of so many families in Connecticut, in New York, and all around our country. It's time once and for all to take the right steps to give medical professionals and families better tools and resources that they desperately need to stop this horrible disease in its tracks and save more lives.

When we work together, guided by this common purpose, we will make progress and give more families more hope in their fight against these diseases. I hope you'll join Senator Blumenthal and me in support of our legislation so we can win.

Thank you.

Senator BLUMENTHAL. Thank you, Senator.

[Applause.]

Thank you for that very powerful testimony. I think you have really summarized the urgency that so many of us feel about developing diagnostic and treatment tools and the pernicious and insidious effects of this disease, the suffering it causes, the destruction of lives. The story that you told about that family, I think, will be mirrored by the three individuals who are going to follow you as witnesses here and then the experts who will follow them on the final panel.

So I really want to thank you for being here today.

Senator GILLIBRAND. Thank you, Senator.

Senator BLUMENTHAL. That was really excellent. Thank you.

[Applause.]

Our next panel, as I mentioned, will be patients, and they share with many in this room life stories that reflect the suffering and the pernicious impact of this disease. As often as I have heard these stories, I never cease to be moved by them. And that goes for

every one of the individuals in this room, not in this room, and on the witness panel. They are riveting and powerful, and, in a way, the most powerful case beyond all the words that may be spoken here.

These life stories, the changing lives as a result of this disease, I think, are really moving and inspiring, and, I might say, also, the courage that so many of you have demonstrated in the face of this terrible disease, the courage in the face of dismissiveness, often disregard, and, in a way, inaction as a result. So I've been working on this problem for some 10 or 15 years, and I'm glad that people have increasing courage to come forward as these individuals have done. I want to introduce them to you now.

Dwight Harris of Burlington, CT, was educated at UConn and has worked in real estate and development in Connecticut for many years. He suffered from undiagnosed Lyme disease for some years, having constantly resisted the kind of diagnoses of cardiac and psychiatric issues. Very often, as you know, improper, inaccurate diagnoses are given, and Dwight Harris can talk about his experience.

Katy Reid of Ridgefield was diagnosed with Lyme disease when she was in high school. I first came to know her at that time and saw her life change as she knew it. Her life changed forever. And she has overcome the disease. She has fought through it. She has fought through misdiagnosis and social stigma, and today she is a leader in the advocacy community, directing a support group for young Lyme patients.

Mark Hopwood is a small businessman and a father of three. His illness caused him to miss critical parts of his family life, and he can describe to you what that experience was like. He knows firsthand the challenges of raising a family and fighting through this disease, even as it was misunderstood and misdiagnosed.

I want to ask you to come forward, Katy, Mark, and Dwight—if you would come to the table here. And I'm going to ask, Dwight, that you go first.

Also, I just want to make everyone aware that we have two members of the State legislature here. Cathy Abercrombie, whom I saw earlier, is vice chairman of the Appropriations Committee, and she is a member of the Public Health Committee. We also have State Representative Gerry Fox here this morning. He is the chairman of the Judiciary Committee. And he, like Cathy, has been very instrumental on these issues, a leader in our State legislature.

Both of them have been leaders on this issue, and I'm really delighted that they are here today. And I'm sure that you can approach them during either the break or at the time when we finish. So thank you for being here, both Gerry and Cathy.

Mr. Harris.

STATEMENT OF DWIGHT HARRIS, BURLINGTON, CT

Mr. HARRIS. Yes, thank you. I know time is a concern this morning. We were asked to keep it brief. I think all of us have submitted some written testimony which probably exceeds the amount of time you'd like to hear from us.

But to summarize and get right to the point, or some of the points that I think are very important and critical, when we heard

the story that was recited earlier today, the interesting thing is—and just talking to these two lovely people that I just met—these stories are not unique. They are repeated time and time again with so many people that suffer from Lyme. So I appreciate the fact you have three of us. I think you probably could have 100 of us and you'd find many of the same things repeated.

I knew I had Lyme, or, at least, I believed I did, from day one. I had the telltale signs. It took 14 years before I could get any kind of medical agreement. By that time, it had deteriorated so bad it was practically untreatable. That was in 1994. I was at the point where I could hardly walk, talk—slurred speech, very little cognitive abilities. And, basically, I wouldn't be able to function or take care of myself if it wasn't for my devoted family.

Since then, I've gotten some treatments that are bringing me back to life. I still suffer about 3 days out of every week where I have great difficulty functioning. But before, I couldn't function for about 5 years straight. So I feel very fortunate at this point in time.

But the number of cases, I believe, are extremely underreported, because I had tests that came back negative. When it finally did come back positive, it didn't meet the criteria for the Centers for Disease Control to be reportable. So I think when you say there are at least 10 times more cases than what's reported, absolutely. I think it's probably much, much greater than that.

The difficult thing for me, which I understand from other people—they didn't know what they were suffering from. What was frustrating for me was I believed it, but I couldn't get anybody to help identify it. I also had great difficulty with my heart. "It must be in his mind," because I spent over \$100,000 in tests. "It must be emotional, must be psychiatric." And even though I was just as ill, it was gratifying to finally have it identified that this is the problem. You can't treat a problem until you can identify it. So I think that's the most important thing.

I think we have to get together. My treatments are not approved by the FDA and not approved by a lot of the medical profession. Yet I'm here, talking and walking today. I'm 64 years old, and if there's any ramifications, I don't care, because I had no life before.

I applaud all you're doing, and I really hope that this continues, because the saddest thing is that I've seen lots of young children misdiagnosed in the school system as having learning disabilities, having emotional difficulties, and it was Lyme disease. And when that was identified, the school said, "Oh, I'm so glad you got your child psychiatric help." No, it was of a physical nature. And that's sad when it affects our children.

Thank you.

[The prepared statement of Mr. Harris follows:]

PREPARED STATEMENT OF DWIGHT HARRIS

Thank you for permitting me to testify to you today about my experiences from infection with Lyme Disease and other associated tick infections.

I would like for you to know my medical history as it relates to this terribly debilitating disease as it is a story that is similar to so many victims I know. I was infected in 1994 and had the typical "Bulls Eye" associated with Lyme infection. I did not see a doctor while the "Bulls Eye?" was visible, but when my health started to deteriorate soon thereafter I sought medical advice. I reported the visual telltale signs of infection to my M.D. He ordered a blood test for Lyme and reported to me

that the result was negative. My health continued to deteriorate for the next 10 years at which time I was so physically incapacitated I was hospitalized with suspected heart impairment. At that time I had little muscle coordination, slurred speech, and cognitive difficulties. These symptoms would continue for long periods of time or be episodic, lasting for an hour at a time, but always persistent. I spent 1 week in the hospital at a cost exceeding \$70,000. I finally left against medical advice when I was told that my heart was erratic and I needed a pacemaker, but the remaining symptoms must be of a Psychiatric nature because 1 week of tests with many specialists could not identify a physiological basis for my condition. It was recommended that I be moved to the psychiatric ward for 2 to 3 weeks and be drugged to see if the symptoms disappeared while at the same time addressing my heart arrhythmia with a pacemaker. During my entire stay I persisted on my assertion that my condition must be connected to Lyme Disease. I was told that an additional blood test performed during my stay there was again negative. I left the hospital against medical advice with the complete support of my wife and family. I went back to visit the heart specialist that diagnosed my heart condition and asked him if he was aware of the impact of Lyme Disease on a human heart. He said he was ignorant about Lyme. It was at that point I was convinced I had made the right decision not to have a pacemaker installed, which as I understand it, is for life. It was now April 2004 and I continued to physically and mentally deteriorate. Every time I would see a doctor they wanted to rush me to the hospital for fear of a heart attack or stroke. I declined their invitation for the hospital visit every time. The remaining Lyme symptoms, other than chest pains and an irregular heartbeat, were always assumed to be emotional after looking at previous batteries of tests and completions of new tests. My work was almost impossible to perform. Besides having difficulty in work, I had very little quality of life. My family was very supportive of me, but I was almost becoming a vegetable in constant pain and suffering which greatly affected my life and the lives of the loved ones around me. I have seven children and I could barely manage the physical and mental strength to support them at graduations, wedding and other important functions, let alone serve the regular needs that children have for a father. Only a wife as strong, loving, and empathetic as mine could care for someone in my place. I have to say that my condition deteriorated to the point that I did not want to live. If I chose not to live in my condition the doctors would have appeared to have been correct in their original diagnosis when in fact, their incorrect diagnosis could have resulted in a tragedy. For the next 4 years I gave up searching for a Lyme literate doctor and succumbed to existing in life just for the sake of my family. Fortunately, I could work limited hours because I was self-employed. If I had to rely on outside employment I would be relegated to unemployment disability. My attorneys tried to convince me many times to go on welfare. My ability to reason and my business intellect was greatly impaired. I felt that if I accepted welfare and stopped striving to be productive at any level, I would continue a downward spiral to an existence that would be tantamount to purgatory.

In 2008 I made a friend who had been battling Chronic Lyme and she referred me to an excellent doctor that was extremely Lyme literate. My friend had not worked for 2 years, was almost bed-ridden every day, but now was slowly becoming a productive individual again. Thanks to her referral to this doctor I was able to start combating my disease. Thanks to Senator Blumenthal's work in Connecticut while he was Attorney General, this doctor was more comfortable treating Lyme with long term antibiotics. He immediately diagnosed Lyme Disease and informed me that the laboratory tests for Lyme Disease were not very often accurate. I asked him to have my blood tested anyway as he informed me that there were preferential tests and laboratories that might increase the level of reporting accuracy. My test came back positive, however, the level of infection was not high enough to be required to be reported to the Center for Disease Control even though I could hardly walk, speak, or reason, and was in incredible pain. This told me that whatever figures are reported for Lyme infection are grossly under-reported due to inaccurate testing or misdiagnosis. After 2½ years of treatment by this doctor I had some improvement, but still was very much incapacitated. During that time period I heard of other alternative treatments and inquired to him his thoughts on some of these treatments. He said he was not against alternative treatments, but he was familiar with many of them and that he did not see much success, however, one he identified as observing a high degree of success. I asked him if he could prescribe it for me. He could not do this as it was not FDA approved. I asked him why this was the case and it was, in his opinion, because it did not involve drugs and therefore pharmaceutical companies had no incentive to invest time and money for research and FDA approval. One and a half years ago I was fortunate to find someone to help me with this treatment and I am now getting my life and my family's life back

again. I am becoming productive, happy, and healthy. I am not on disability, I earn money, and I enjoy my children and grandchildren, and am very involved in charity and community work. In fact, I am on the board and or chairperson to foundations that oversee assets in excess of \$25 million. This past year I was awarded the "Citizen of the Year" award in my community. All this after I was perceived as physically and mentally challenged with little hope of recovery. Now, not only have I been able to recapture my life, but I am proud to say, I have significantly contributed positively to the lives of others. This has been made possible because I was fortunate to meet a Lyme victim, meet an M.D. who was not afraid to accept and treat Lyme patients, and an anonymous person who is willing to help Lyme victims with alternative medicine not accepted by most of the medical profession or the FDA. I am sure you know that much of the medical profession still does not believe in Chronic Lyme. It is because of this that insurance companies can decline benefits for most Lyme treatment except for early stages which requires 2 weeks of inexpensive antibiotics.

Now that I have been fortunate to receive successful treatment my heart goes out to all those victims that cannot afford to pay out-of-pocket when insurance companies decline coverage, who do not know where to find a Lyme literate doctor who can treat patients without fear of prosecution from States and medical boards, or who can find help with remedies outside FDA approval. The worse experience I had was not being able to have confirmation of my illness for so long. You cannot meet a challenge if you cannot identify it. Let's please learn how we can affectively identify this horrible disease, and then how we can treat it. We then must educate the medical profession, the public, and insurance companies, to give Lyme victims a chance for life. Living with untreated Chronic Lyme is not life to live. Aside from the personal pain and suffering, there is a tremendous cost associated with this disease. I know of many people that are totally disabled from this disease and society is picking up the check. Research with national attention and money will make lives and families whole again and will pay social and financial dividends way beyond your imagination. I have seven children across the country. Lyme is very prevalent in the Northeast, but there are many cases being reported West from here. Either the disease is spreading, or its awareness is increasing. Most doctors in other parts of this country are 20 years behind Lyme literacy here in the East. If Lyme in its early stages is identified, it can easily be treated with great success. The only reason I knew I was infected with Lyme was because my co-worker was infected with an identical "Bulls Eye" as mine at the same time. He was a veteran and was having a routine exam when the VA identified his Lyme infection. They prescribed 2 weeks of antibiotic treatment and to this day he has not had any Lyme symptoms. I figured that if I got sick I could go to a doctor and receive the same antibiotic treatment and be fine. The longer you wait, the harder it is to eradicate, and this is only if you have a Lyme literate medical profession with accurate testing. Look, my doctor said my test was negative, which was correct, but the test was wrong!

At this point in time, I am well and productive much of each week and I savor at the relief I have and the productive life I am leading compared to 10 years of almost complete incapacity to perform everyday tasks. A little help can go a long way. That is all we Lyme victims are looking for, a little help. I applaud Senator Blumenthal for all he has done in the past and his continuing effort. Please help him and all Lyme victims. By the way, my heart is medically sound without any pacemaker, and now my heart goes out to all Lyme victims who have not been as fortunate as me.

Thank for your time and attention to this matter.

Senator BLUMENTHAL. Thank you.

I know that each of you have written testimony, and I would welcome your submitting it for the record. We will make it part of the record. This hearing is a formal hearing of a congressional committee, and so it will be in the record, the formal proceedings of the U.S. Congress. Anything that you want to submit in writing, please feel free to do so.

And I will announce, also, at the end of this hearing that we will take submissions from anyone who is here or anyone who would like to submit statements for the record. We will make them part of the record. So we want to make this hearing as inclusive as possible, both for the scientific community and for laymen and patients and so forth.

So thank you for your testimony.
Katy. Thank you.

STATEMENT OF KATY REID, RIDGEFIELD, CT

Ms. REID. Thank you. I feel honored to be invited to talk to you today about my experience as a patient with Lyme disease. I most want for you to understand that this did not have to happen. I didn't have to be sick for over 11 years. It was a choice made by doctors in the State of Connecticut who ignored the possibility that my symptoms could be Lyme disease.

Instead, I spent years enduring stressful misdiagnoses from every type of specialist, with accompanying inaccurate medications and their frightening side effects. Finally, in 2002, I received a diagnosis and the start of treatment for not only Lyme disease but two co-infections, Babesia and Bartonella. Without a Lyme literate doctor's courage, I would not be standing here to tell my story.

In 2004, Senator Blumenthal invited me to speak to legislators about what it was like to be a college student suffering from Lyme disease, which was essentially impossible. I spoke about driving home every weekend to have my IV port cleaned and redressed. The student health staff at UConn were unwilling to handle those needs and made it clear that they felt chronic Lyme does not exist.

I explained how my school work suffered as inadequate classroom accommodations could not counter the effects of a brain that could no longer remember and fatigue so crippling that showering used all of my energy. It reminded me of high school, where, again, measures taken for Lyme disease by the school administration were disgracefully inappropriate. After 12 years at the top of my class, I finished my senior year at the alternative high school. I had surpassed the material being covered, and there was little they could do but warehouse me until graduation.

Friendships did little to negate that grief, disappearing quickly under the strain of this particular illness. I was excluded from group projects because they worried my failing memory would affect their grades. Sports teammates no longer found anything in common with me. And later, the endless traumas beyond their comprehension and the constant cancelled plans forced even my closest friends to move on.

After college, while receiving continued care for this illness, I began a support group for young adults. Attendees arrived from all over Connecticut, New Jersey, and New York. The sentiment support groups often acknowledge is that they are waiting until they are fully recovered before attempting any form of true social life. They find it easier to have no friends at all than to feel the weight of endlessly disappointing others.

Attendees discuss how they will not date, marry, or have children as a chronic Lyme disease patient. This reflects the rejection this illness has forced on them time after time and fear created by a lack of information. They don't want to burden a partner with the responsibilities of caretaking and still have no clear answer to other concerns, like whether Lyme can be spread through sexual transmission, because the research has not been completed.

So many young people take the failures of science and funding onto themselves, refusing to get close to anyone. Seventeen- and

eighteen-year-old girls have made the decision not to have children rather than risk the possibility of bringing a child into the world with a tick-borne illness.

How sad that our infirmed youth feel more personal responsibility in this regard than the medical world itself. How sad that patients like me, numbered in the thousands, have come to the conclusion that the medical community we once revered is failing to acknowledge the human anguish in front of them, and that any hope of progress has fallen to us on an individual level.

Money, determination, and, frankly, indignation have fueled my personal recovery. But as each symptom has slowly dissipated—night sweats, facial agnosia, bells palsy, hair loss, memory loss, debilitating fatigue, severe stomach problems, endocrine and hormone disruption, personality changes, and learning disabilities, to name just a few—what remains are the emotional side effects of an illness that I'm still told doesn't exist.

I testified in 2004, and I am here again today. I am thankful for the opportunity but wonder how many times we can document the pain of constituents without change. What more needs to happen before this illness is taken seriously? Families are falling apart and going broke over Lyme disease. Young adults unable to hold down jobs lay in bed, aging out of their parents' insurance policies. Some make the decision to live a half-functioning life because there are no clear or affordable options.

We are the State where this illness was first recognized in America. Yet we teach nothing about tick-borne disease prevention in our schools. In my early life, I had heard about Lyme disease as a joke from doctors, peers, and other parents. And now, unnecessarily, I have carried the burden of Lyme for over a third of my existence. I refuse to witness my pain played out in the children across Connecticut who are participating in sports, going camping, and playing with their dogs, completely unaware of the risk that awaits them.

I support this bill, and I support Senator Blumenthal.

Thank you.

[The prepared statement of Ms. Reid follows:]

PREPARED STATEMENT OF KATY REID, RIDGEFIELD, CT

I have always told people that I've been sick for over 11 years. But, there is something inherently wrong with that statement. It implies bad luck, chance, something beyond the realm of our control. But this experience was forced on me. It wasn't accidental. I didn't have to be sick for over 11 years but doctors in the State of Connecticut chose to ignore the possibility that my multitude of symptoms could be Lyme disease. They were more comfortable watching me suffer month after month than exploring the possibility that my mother suggested to them on our very first visit to the hospital—Lyme disease. I entered the emergency room with a stiff neck, facial palsy and high fever and left with a diagnosis of sinusitis. Why listen to the mother of a cross-country runner, Girl Scout, soccer and lacrosse player, hiker, camper and outdoor enthusiast? Because, really, when could I have been exposed? It didn't matter that she had seen my sister decline in a similar fashion and recover after a Lyme disease diagnosis, or that she herself had her health return with a long-term antibiotic regimen for the same illness. Without a bulls-eye rash, a known tick bite or the arthritic experience, the consideration was deemed ridiculous. Derogatory comments about Lyme not being contagious and veiled implications of Munchausen Syndrome abounded. The approved approach, instead, was to visit an expert in the field for each individual symptom, of which there were too many to keep count. Whether it was the endocrinologist, neurologist, gynecologist, psychiatrist, in-

ternist or pediatrician, they shook their heads when their protocol of choice failed and sent me off to the next one.

After years of stressful misdiagnoses, in addition to the experience of enduring illness, we were able to eventually find doctors willing to diagnose and treat not only the Lyme Disease I ended up having but also the two co-infections, Babesia and Bartonella. However, it was at a huge cost to both parties. The doctors risked their careers caring for me and my parents risked their savings on treatment plans and medications.

I feel so honored to be chosen to testify today, as I was in 2004 when I joined Senator Blumenthal to testify at a hearing on Lyme disease in Hartford. Honored, not because my story is unique, but because being given the opportunity to tell it gives meaning to the years I lost, bed-ridden and angry. And honored, also, because this illness stripped away the moments when I used to feel special or important and I cherish the times when those feelings return. I used to describe myself as social, smart, athletic. But Lyme disease took that all away. It made my previous grades impossible, A's became F's, I dropped out of varsity-level athletics due to fatigue, and I watched as major milestones of adolescence like prom, first job, first boyfriend, best friends, were ruined by symptomology and lack of understanding.

In 2004, I said that I wanted our State to care more about its children. Still angry from what this disease had unjustly cost me I sought a fresh start as far away as possible; California. When I came back after college, in part to receive continued care for this illness, not much had changed despite the continued efforts of patients and activists. I began a support group for young adults to be able to contribute to the community that had provided me with the information to advocate for my own care. Based in Ridgefield, our support group is geared towards young adults aged 16-30 and I can tell you that my experience is being retold through the lives of each person who walks through that door. Attendees arrive from all over Connecticut and others have their parents drive them from as far away as New Jersey and upstate New York. There are many more whose experiences leave them bed-ridden during the meeting times, with e-mails of apology awaiting me when I get back home. Parents contact me often; lost, struggling to understand an illness that has changed every aspect of the child they knew, hoping that my support group will return their loved ones some of what they've lost; whether its common compassion or a burgeoning friendship.

There are so many patient stories that recount the long-term suffering of misdiagnosed and undertreated Lyme patients that those who live in the world of chronic Lyme Disease have almost become numb to them. You simply need to go online, search for a book, or watch *Under Our Skin* to hear about the physical, emotional and psychological damage. In an effort not to be repetitious I have chosen to speak to you today about some of the lesser discussed, yet shockingly common experiences of the support group attendees. I will utilize my own illness memories to bring familiarity to the collective experience I have been witness to.

To begin with, while it is clear from the testimony of my fellow panelists, as well as my aforementioned scenarios, that there are many shortcomings of the medical world in terms of tick-borne diseases, these institutions are not the only ones that need reform in this regard. Schools, work environments and government assistance programs all fail when it comes to accommodating the needs created by chronic Lyme disease. They choose not to acknowledge its existence, let alone aid the sufferers.

In 2004 in my speech I wanted legislators to know what it was like to be a college student suffering from Lyme Disease in the State of Connecticut, which is, essentially, impossible. Every weekend I drove home to have my IV port cleaned and redressed. The student health staff at UConn was ill-equipped to handle my needs and the accompanying lectures about chronic Lyme disease not really existing added extra stress to an already stressful freshman year. Doctors had to carefully re-work my illness into another diagnosis in order for me to qualify for disability services, chronic fatigue being more universally accepted. But, disability services proved to be ineffective, anyway. Accommodations like note takers and extra time on tests were insignificant measures to counter the effects of a brain that could no longer remember and fatigue so crippling that showering used my daily allotment of energy. But, it's interesting how quickly these experiences become normalized. This wasn't the first time the educational system failed to understand my new needs. My senior year of high school, with a growing list of absences and slipping grades, I was moved to the Alternative High School. After 12 years at the top end of my class I finished my 13th, and final, year in a one-classroom school with a group of very troubled youth. Having previously surpassed the material of the classes they were teaching I spent most of the school hours doodling in a notebook or sleeping on the couch, essentially being in a holding pen 8 hours a day for 6 months until I was

allowed to graduate. I met some compassionate and wonderful people through that experience but it was not an appropriate placement. And I continue to feel repercussions from the transfer, being excluded from class reunions from the traditional high school to this day.

I would say that friends helped counterbalance the negative administrative portion of the school experience but, unfortunately, that was not the case. This highlights my next topic; the medical viewpoint of the nonexistence of chronic Lyme disease has infiltrated popular opinion in society, for everyone except for those who have experienced it firsthand. The alienation that young people feel can have a significantly negative impact, lasting beyond recovery. It is amazingly swift, the rate friendships disappear with the strain of this particular illness. When I was first diagnosed I watched this begin to happen. I was excluded from group projects because they worried my failing memory would affect their grades, teammates found they had nothing in common with me when I could no longer compete, and others, more bluntly, told me they just couldn't handle being around someone who was sick. They considered themselves experts in my disease and I was told after months of bed-ridden periods and dark moments of depression that "Lyme doesn't do that, and it certainly doesn't last this long." My closest friends stood by me but now, 11 years later, that is no longer true. Each one eventually grew tired of cancelled plans and the one-sided nature of having a friend undergoing continuous traumas beyond their comprehension. At 27 years old I can count the number of friends I have with less fingers needed to fill a hand, and half of them are my family members. When forming new relationships I have been conditioned to dread the moment they find out that I have had chronic Lyme Disease. When it inevitably comes up that I've been sick for a long period of time, sympathy abounds. But then, there's a moment of internal hesitation before I say my diagnoses, knowing that this will be the point in time where their opinion of my experience will change for the worse. Attendees of the support group often say that they are waiting until they are fully recovered before attempting any form of sociality. They find it easier to have no friends at all than to feel the weight of endlessly disappointing others. I hear them yearn, aloud, that they had some other illness that people wouldn't find so easy to judge. They talk about how they wish they had Cancer instead just so people wouldn't be so comfortable, even righteous, dismissing them at their lowest moment.

It isn't just friendships that get affected, though. Young adults sit around the table once a month in meeting and, devoid of emotion, discuss how they will not date, marry or have children as a chronic Lyme disease patient. In part, this is because they are afraid of the rejection this illness has forced on them time after time and, in part, this is a direct reflection of fear created by a lack of information and research. They don't want to burden a partner with the responsibilities of caretaking and share concerns of spreading the illness to others. The fact we know is that Lyme Disease is closely related to Syphilis. What we don't know, yet, is if it can also be spread through sexual transmission; the research has not been completed. So, many young people take the failures of science and funding onto themselves, refusing to get close to another in that way when the chance they could spread their pain, frustration and suffering to others is unclear. How sad that our infirm youth feel more personal responsibility in this regard than the medical world itself. The same logic applies to pregnancy. Seventeen- and eighteen-year-old girls have already made the decision not to have children rather than risk the possibility of bringing a child into the world with an illness they have so long felt the repercussions of. It is a concern I myself share, though I remain optimistic. Doctors always respond to my inquiries with a resounding "No, transmission in utero is impossible!" But, I find after a moment more of prodding that their certainty on the matter is based on their belief that this illness isn't even serious enough to consider that situation, not the presence of factual information backing their opinion. Other patients plod forward, hopeful, declaring that "Everything happens for a reason," the oft-spoken and seldom believed mantra of Lyme disease sufferers.

These stepping stones of adulthood that many take for granted are just one component of the circumstantial situations that are the repercussions of this illness. Families are falling apart under the strain, young adults are unable to hold down jobs while they lay in bed and age out of their parent's insurance policies, and the cost of out-of-pocket care means that though many come to understand what they need to get better, they are prohibited due to financial constraints. Imagine making a decision at 24 that you simply have to live a half-functioning life because there are no clear or affordable options available. Sometimes they find it easier to deal with a more universally accepted, yet inaccurate, misdiagnosis than struggle, alone, through the terrain of tick-borne illness.

Lyme Disease has irrevocably changed me. I have joined the masses of patients who have come to the conclusion that progress begins with us; the institutions we

once idolized failing to acknowledge the level of human anguish in front of them. Even when I step outside of the advocate arena I cannot leave these illnesses behind. My occupation has me in Bridgeport, CT working in the school system with approximately 80 youth. Not one of them has ever heard of ticks or Lyme disease. Being inner-city their doctors have deemed preventive discussion unnecessary despite the fact that they often visit parks, summer camps and travel with their families around the State. The awareness measures completed through the efforts of volunteers, such as the BLAST prevention program and our local task force, cannot reach these areas without funding for growth. We are the State where this illness was first recognized in America and we need to be the leaders in its prevention. It is hard to believe that we have nothing about this illness in our school health and science programs and health departments are not given the funding and educational programming necessary to teach their communities what personal safety in the State truly requires.

Money, determination and, frankly, indignation have fueled my personal recovery. But as each symptom has slowly dissipated I've said goodbye to night sweats, facial agnosia, bells palsy, hair loss, memory loss, debilitating fatigue, severe stomach problems, endocrine and hormone disruption, personality changes, learning disabilities, loss of word retrieval, to name just a few, only to greet the emotional side effects to having illnesses that have been deemed illegitimate. I testified in 2004 and I am here again today. I am thankful for the opportunity but wonder how many times we can document the pain of constituents without change. This bill is a great beginning and I'm here today in support of it, thankful to Senator Blumenthal and his continued efforts. My personal hope remains, as it has for the last 11 years, to witness the cessation of suffering of Lyme disease patients and to never again see the events of my life played out in the children I see participating in sports, camping, playing with their dogs, experiencing childhood in the State of Connecticut unaware of the risk that awaits them.

Senator BLUMENTHAL. Thank you, Katy.

[Applause.]

Mark.

STATEMENT OF MARK HOPWOOD, TRUMBULL, CT

Mr. HOPWOOD. I have been struggling with Lyme disease for more than 3 years. Before the onset of symptoms, I was a very active parent. I owned my own business, working 12 hours a day. I worked out 3 to 5 days a week, ran, played tennis, golf, and I'm an avid martial arts practitioner.

My symptoms started with just a little bit of lightheadedness and dizziness. I would climb a flight of stairs and I'd be out of breath, which was completely unusual for me. I started seeing doctors at that point, and my symptoms were escalating, and, eventually, they included extreme fatigue, where I just couldn't get out of bed, and migraines. I had problems with small motor skills. I had memory loss. I had delayed cognitive functioning. I had slurred speech. And I couldn't participate in normal everyday activities.

I'm married and have three young children. And my wife and two of my kids are here today. The youngest of my children, who is not here today, hasn't known a father without Lyme disease. I couldn't volunteer to coach a sport. I couldn't teach my daughter how to ride a bicycle. I couldn't give my son piggy-back rides. I couldn't carry a sleeping child from their car seat into their warm bed. My daughter would come home from first grade, and she would have stories and pictures she had drawn, and in them, my wife and other two kids were always central characters, but I was always in the background, sick and in bed.

I mentioned that I'm a small business owner who, during the most challenging economic climate in a generation, was forced to cut my hours in half and sometimes take weeks off at a time. I

never had a bull's-eye rash. I never found an embedded tick. I saw 10 different doctors over an 18-month period of time—two general practitioners, two otolaryngologists, an ophthalmologist, neurologist, cardiologist, homeopathologist, rheumatologist. I went through all of the “ists.” And I finally saw an infectious disease specialist.

And in that time of seeing all of those different doctors, I was diagnosed with anything from a sinus infection to anxiety and depression, all the way to a tumor that would require brain surgery. When I think about it now, I am so completely dumbfounded that the medical community is so misinformed and misled about the symptoms, the treatment, and testing for Lyme disease. We had one doctor recently tell us that you have just as much of a chance of getting struck by lightning as you do getting Lyme disease. Another doctor recently said that even if you send a tick away to be tested and it comes back positive for Lyme, they won't treat you unless you have symptoms. And this is just infuriating at some points.

But, for me, the most damage came from the doctor who diagnosed me with a tumor, for one, because I sat around for 6 months at a clip waiting for MRI results to see if this spot on an image grew; and, secondly, because he prescribed me multiple courses of prednisone, which essentially shut down my immune system and accelerated the Lyme disease attack on my body. And over that period of time, things were accelerating and degrading so quickly that my wife and I thought for sure that I was either going to be permanently disabled or I was going to die from this.

The infectious disease doctor was the first to suggest Lyme disease, and he sent a Western Blot test off to Stony Brook labs. And he informed me, basically, “I don't care what the test says when it comes back. I'm treating you for Lyme, because those tests are notoriously inaccurate.” I will forever be in debt to that doctor. My test did come back positive, and the response then was, “Oh, you're one of the lucky ones. This is going to help with insurance.”

So due to the fact that I am self-employed, I pay for my own private healthcare coverage. And when I add that cost to my co-pays uncovered, office visits, and medicines, over the last 12 months alone—and it's been a 3-year and 4-month battle to this point—so over just the last 12 months, I've spent \$30,000 in cash out-of-pocket in treatments. And this is in addition to what the insurance company actually paid on my behalf.

It's been 22 months since receiving the proper diagnosis and finding the right doctors, and I have made tremendous progress. I can now shoot hoops in the driveway with my son. I can give piggy-back rides to my youngest. And I am now an essential character in my daughter's wonderful stories.

However, each morning, I still awake wondering how I will feel that day. And it's incredibly unnerving not to know what kind of person you're going to be from one day to the next or what you'll be capable of. I struggle to play catch-up on 3 years worth of lost time, both at home and at work. And I have a daily fear that my health will decline once again or permanently, and I will become the shadow of a husband and father that I was just a few months ago.

Overall, I do feel blessed now that I have more good days than bad. However, as grateful as I am, I can't help but wonder how different my life would be had that first doctor or the second doctor or even the third doctor had some level of competence about the symptoms of this disease and made the proper diagnosis. My children wouldn't have to ask each and every morning, and they do, "How are you feeling today, Daddy?"—so that they will know what version of their father they'll get for the day.

And as everybody up here keeps repeating, obviously, my story is not rare, and I personally know far too many people who have had a similar or worse experience. And I am grateful as well that patients have a voice here today, as most of the dialog or lack thereof has completely excluded those who actually are suffering from this debilitating disease.

For too long, many Lyme patients have been marginalized and, in the worst, have been characterized as hysterics. And in my experience, long-term Lyme disease sufferers are extremely well educated on the disease and, in most cases, more so than their doctors and medical panelists that are making decisions on policy.

The thing about patients is that they have no institutional alliances. They have no industry ties. They have nothing financial to gain and no hidden agenda. Our only wish is for greater awareness, accurate testing, and effective treatments for Lyme disease and its related co-infections.

Thank you.

[The prepared statement of Mr. Hopwood follows:]

PREPARED STATEMENT OF MARK HOPWOOD

I have been struggling with Lyme disease for more than 3 years. Before the onset of symptoms, I was an active parent, worked 12 hours a day at my own business, worked out 3–5 times per week, was a runner, played tennis and golf, and was an avid martial arts practitioner.

My symptoms started with dizziness and fatigue and escalated to debilitating fatigue, migraine headaches, heart palpitations, difficulty with small motor skills, delayed cognitive processing, and short-term memory loss. I could not participate in normal every day activities.

I am married and have three young children. The youngest of whom hasn't known a father without Lyme disease. I could not volunteer to coach a sport, teach my daughter to ride her bike, give piggy back rides, or carry a sleeping toddler from the car into their warm bed. When my daughter would bring home the stories she had written for her 1st grade class, my wife and kids were central figures, but I was always in the background, sick and in bed.

I am a small business owner who, during the most challenging economic climate in a generation, was forced to cut my hours in half and sometimes miss work for weeks at a time. I am the sole bread winner for my family. My wife has been out of the workforce since she became pregnant with my now 9-year-old son. When I did feel well, I had to dedicate almost all of my time to catching up on work so that I could provide for my family. In my desire to provide, the most important things a man gives to his wife and children were sacrificed—time, attention, and being "present." Work always got the best version of me while my family always got the worst. Without a diagnosis and my health continuing to erode, my wife and I were preparing for the worst. We were trying to figure out how she could get back into the workforce while caring for three young children and a disabled husband.

I never had a bull's-eye rash and I never found an embedded tick. I went to 10 different doctors over an 18-month period before receiving the proper diagnosis. I was erroneously diagnosed with everything from a sinus infection, to depression, to a tumor. Looking back on it now, I am dumbfounded that so many doctors were so uninformed or misled about the symptoms, testing, and treatment for Lyme Disease. One doctor said, "You have as much of a chance of getting struck by lightning as you do contracting Lyme Disease." Another doctor diagnosed me with anxiety and depression after a 10-minute visit during which he never asked if I felt anxious or

depressed. The most damage came from a doctor who prescribed multiple courses of Prednisone, which provided temporary relief but ultimately caused the disease to accelerate its attack on my body. My wife became my primary care physician, doing research online, making appointments with two general practitioners, two otolaryngologists, an ophthalmologist, neurologist, cardiologist, homeopathologist, rheumatologist, and finally an infectious disease specialist. The infectious disease doctor was the first to suggest Lyme Disease and sent a Western Blot test off to Stony Brook Labs. He informed me, "Regardless of what the test shows, I'm still going to treat you for Lyme Disease because the tests are notoriously inaccurate." When my test came back positive, I was told "You are one of the lucky ones. This will help with insurance coverage."

Due to the fact that I am self-employed, I pay for private health care coverage. When I add the insurance premiums, co-pays, un-covered treatments, and medicine over the past 12 months alone, I have spent more than \$30,000 out-of-pocket. This is in addition to the medical costs my insurance company has paid on my behalf.

It's been 22 months since receiving the proper diagnosis and finding the right doctors. I have made tremendous progress but I am not nearly where I was prior to Lyme disease. With my improved health, my small business has regained its footing. More importantly, I can now shoot hoops with my oldest son, give piggy back rides to my youngest son, and I am now a central character in my daughter's wonderful stories. However, each morning I awake wondering how well I will feel that day. I struggle to find balance when trying to play catch-up on 3 years of lost time and opportunities at home and work. I still have a daily fear that my health will decline and I will revert to the shadow of a husband and father I was just a few months ago. Just days before writing this letter, I was in bed for 3 consecutive days, completely debilitated, without warning.

Overall, I feel blessed that I finally am having more good days than bad. However, as grateful as I am, I can't help but wonder how different my life would be had my doctors been more aware of, or had a reliable test for, vector-borne illnesses. If my first, second, or even third doctor had the proper diagnoses, my recovery would have only required a few dollars for 30 days of antibiotics. My children wouldn't have to ask every morning, "How are you feeling today Daddy?" trying to gauge which version of their father they will get today.

The most frightening aspect of my story is that it is not rare. I personally know far too many people who have had a similar or worse experience. I am grateful that patients have been given a voice here today as most of the dialogue (or lack thereof) has excluded those actually suffering from this debilitating disease. For too long, many Lyme patients have been marginalized or characterized as hysterics. In my experience, long-term Lyme patients are extremely well-educated on the disease and in some cases more so than some doctors and medical board members. We have no institutional allegiances, no industry ties, nothing financial to gain, and no hidden agenda. Our only wish is for greater awareness, accurate testing, and effective treatments for Lyme Disease and related co-infections.

Senator BLUMENTHAL. Thank you.

[Applause.]

Again, I really want to thank each of you for your very eloquent and moving stories and for the courage to come forward and talk about them. It's not easy to do.

Maybe I could ask a general question for all of you. We were talking a little bit before the session began, and I said we were going to have some experts following you. And then I sort of caught myself and said, "Well, you know, you really are the experts." The patients are the ones who bring a perspective to this discussion. The 3,000—and there are 3,000 patients, victims, every year. Again, that 3,000 probably is only one-tenth of the number every year who suffer from Lyme disease.

But I wonder if I could ask you what you think are the most needed steps that can be taken at the national level. Knowing about the bill that we've introduced, which I regard as just a kind of down payment, a first step, what do you think are the steps that ought to be taken through the National Institutes of Health or the Center for Disease Control, or other agencies that can and should

do more to develop research and treatments? I'll ask that as a general question.

Mr. HARRIS. Well, again, I think the most important thing is to be able to identify it. You know, there's a lot of talk about short-term Lyme, long-term Lyme, chronic Lyme. Forget how long it can exist. If you can at least identify it to begin with, that's a start. And I think that's been the biggest problem.

My concern is I think there are a lot of treatments out there, herbal, an array of things that may not be drug related necessarily. But once you have a good reliable way of identifying the disease, I think research should be done to see what could be done to alleviate the symptoms, even if it never goes away. I'm leading a life 3½ days a week. He's leading a life longer. You sound like you're doing better than both of us.

My experience has been unless pharmaceuticals do research, and the results can make them money, there's very little places to go to offer research where there's not money to be made. What has helped me would not make any money for any pharmaceutical company. Therefore, I believe that's the reason there's been no research, and yet it has changed my life incredibly.

[Applause.]

You know, a doctor who heard I was getting this treatment said,

"Well, you know, we don't know if there's going to be any long-term effects. You may not be able to have a baby in 20 years, Dwight. But you're 64. Don't worry about it."

At least, I have a little bit of my life back and I'm contributing. So I think that's the most important thing, identifying it and finding monies to do research for all things, from a practical point of view—and you'll probably get that from the patients—what seems to work and figure out why it works. Then figure out what the ill effects may be, if any.

Senator BLUMENTHAL. Anybody have anything—Katy?

Ms. REID. Doctor education and policy change, I would say, No. 1, because of the trickle-down effect that results from it. When young people are trying to do anything, it's all a result of the very beginning, where their primary care doctor found them and felt like their medical condition stood. Whether they're trying to get into disability services or get things covered by insurance, it all begins with that first visit to the doctor with the very beginning symptoms. I think that's where everything needs to change, and the rest will come as a byproduct of that.

Mr. HOPWOOD. And to add to that, the fact that you do have the CDC definition of what Lyme disease is, but based on their tests, is a really damaging thing, because these doctors—I've talked to them. I've talked to my pediatrician. I've talked to my own doctors. And they say, "Oh, well, this is what the CDC says Lyme disease is, and if you don't have it, you don't have it." Also the IDSA coming out and making claims as to what Lyme disease is or isn't—these are the things that these doctors are quoting to me, personally, and it's incredibly damaging.

If there was some standard that said, "Look, this is what it is. This is how it should be treated." There's clearly not enough research on it to define it in the way that you're defining it. So that falls right into doctor education.

And the second thing is a definitive test, because the tests now, as most of you know, don't actually test to see if you have the disease. It's whether or not you have the antibodies to the disease. So nobody really knows. And they're so inaccurate that, in some cases, they're almost useless. It's more useful to have a doctor that knows what they're talking about than the tests.

[Applause.]

Senator BLUMENTHAL. Katy alluded to the second area that I wanted to ask you about, insurance practices. I've talked to you over time about the insurance policies and the problems that each of you have encountered. I wonder if you could talk about that a little bit. Maybe we can begin with Katy.

Ms. REID. I believe that Lyme disease has become almost an elitist illness, because you need a certain level of affluence to recover from it, unfortunately. I see so many young people in the support group who literally know what they need to get better and cannot afford that. And I think that's disgraceful that people lay in bed and know exactly which doctors they need to go see, which medications they need to be on, and it's just too far out of their reach. It's just disgraceful.

Senator BLUMENTHAL. They can't afford it because—

Ms. REID. Insurance won't cover it, or they've aged out of insurance. They've been too infirmed to be able to hold down a job, yet they don't qualify for medical disability because Lyme is not recognized.

Senator BLUMENTHAL [continuing]. Right.

Mr. HARRIS. I've had people practically break down in tears that said, "Oh, my gosh, Dwight, I wish I could see some of the doctors you've seen, but my insurance company won't pay for it, and I can't get the help"—basically the same thing. I mentioned I spent over \$100,000 in a hospital in 1 week. Fortunately, Lyme wasn't mentioned so they covered it. If it was Lyme, I probably wouldn't have been.

But the treatment I'm getting now—that's another thing. It's very inexpensive. Yet the people that have told me about it are afraid for fear of prosecution for sharing with others. So I believe there are some alternative means of being treated, but we're not allowed to share it, or they've asked to remain anonymous, and I feel very sad about not being able to share that. But I do feel the insurance companies definitely use the opportunity not to pay insurance.

By the way, if I was identified, which I thought I had for 14 years and told the hospital—we spent \$100,000. That is still a cost. It wasn't to come out of my pocket. It came out of the insurance company's. But it is still a cost that has to be borne. If it was identified as Lyme to begin with, the insurance company could have saved \$100,000. You multiply that many times, then, hopefully, insurance premiums in general should come down. So there's a cost savings that's very important there.

Mr. HOPWOOD. For me, I've been more fortunate than most on what my insurance provider has covered. But it still is guiding what treatments I was receiving. For example, I've been on a PICC line for IV antibiotics on two separate occasions, once for 3 months and once for 6 months, and they covered it. However, the only IV

antibiotic they would allow was not the one that my doctor thought would be the best one for me, but not the one that would be covered. So there's been some of that.

Also, I'm on about \$300 to \$400 worth of naturopathic medicine that's not covered because it's not considered real medicine because a pharmaceutical company didn't develop it. And right now, I am trying to get approval for a third round of IV antibiotics, and we're waiting, but they're doubtful that it will be covered. And in that case, I would have to pay for that entirely out-of-pocket.

And then, last—and I think probably one of the most scandalous aspects of it—is that the good doctors, the doctors who are actually on the front lines who know what they're talking about, have been threatened by medical boards and by insurance companies—

[Applause]

Mr. HOPWOOD [continuing]. Out of accepting insurance. So now the doctors who really know what they're talking about, out of a threat to their own financial livelihoods, have to say, "I'm sorry, but I can't be affiliated with any of these insurance providers." So now I pay—there's one doctor we were considering going to. It was \$1,000 cash. I pay \$500 cash every time I go to see my doctor. So, again, that's the same thing. You're creating this thing where only the affluent—not that I'm particularly affluent. I just can stack it on my credit card.

Senator BLUMENTHAL. Well, we could go on with each of you, and, altogether, you have been enormously helpful. And I know that apart from this public forum, each of you have shared information with me and with my staff, which I tremendously appreciate, and I know that you speak for many others in the kind of eloquent witness that you've borne to the effects of this disease. So I want to thank each of you for being here today.

And insofar as there are young people, Katy, who may be in your support group and need help from my office, as you know, we give a lot of priority to helping people when they have problems with insurance companies. And we can't always win, but we fight as hard as we can. So if you want to talk further about some of those individual cases, I'd be happy to do so.

Ms. REID. Thank you.

Senator BLUMENTHAL. In the meantime, thank you so much for being here today. It has enormous meaning. Thank you.

Mr. HOPWOOD. Thank you.

Mr. HARRIS. Thank you, and thank you for your help.

[Applause.]

Senator BLUMENTHAL. We are enormously fortunate to be joined today by three of Connecticut's and the Nation's leading professionals in this area. Dr. Kirby Stafford has a Ph.D. in entomology and is currently the chief entomologist of the Connecticut Agricultural Experiment Station in New Haven, which, as you know, is nationally renowned. He has studied the deer tick extensively, and he brings a background focus on prevention through tick eradication.

Dr. Katz is a physician with years of experience in treating Lyme patients. He is a member of the Yale School of Medicine faculty. He is an assistant clinical professor there. He was educated at the

Sackler School of Medicine in Tel Aviv, Israel. He has written and spoken extensively and is highly regarded across the Nation.

Dr. Joann Petrini has a Ph.D. in health research and a master's in public health. She serves as director of Clinical Outcomes and Health Services Research at the Western Connecticut Health Network (WCHN), which is located in Danbury. WCHN has introduced the groundbreaking Lyme Disease Registry project, and it aims to collect broad data on different presentations of Lyme in hopes of improving detection and treatment. I have visited their facilities, and I've been very impressed by the work that they are doing. And, again, they are gaining a reputation across Connecticut and the country.

So I want to ask them to come forward, please.

[Applause.]

Dr. Stafford, why don't we begin with your testimony, if you would.

STATEMENT OF KIRBY C. STAFFORD, III, Ph.D., CHIEF ENTOMOLOGIST, CONNECTICUT AGRICULTURAL EXPERIMENT STATION, NEW HAVEN, CT

Mr. STAFFORD. Thank you, Senator, for the invitation to speak here this morning and provide some perspective on prevention, which I think is the first line that people should consider as they wrestle with this whole Lyme disease issue. I've heard from the patients, giving some of their personal stories here this morning. But please remember, too, that Lyme disease is actually a worldwide problem. It's very common for the Northern Hemisphere, ranging from the United States to Europe and even into Asia.

Here in the United States, it is the most important vector-associated disease. As you mentioned earlier, Senator, there's 30,000 to almost 40,000 cases reported by the Centers for Disease Control and Prevention every year, and yet that represents only about 10 percent of the actual diagnosed cases, because many cases simply are not reported. Lyme disease is caused by a bacterium, a spirochete called *Borrelia burgdorferi*, and is transmitted through the feeding of the blacklegged tick, or the deer tick, as most people know it, *Ixodes scapularis*. Out on the Pacific coast, the western blacklegged tick is the vector.

It's been a long story. Lyme disease was first described from a cluster of human cases in the Lyme area of Connecticut in the mid-1970s. And it took a few years, until 1982, when the actual causal organism, as well, the tick, were actually identified. The recognition of Lyme disease here in Connecticut has a long history. It's tied to our geologic history and changing landscape patterns, with the restoration of our habitat, reforestation, reestablishment of some key hosts here in New England. And so over the past three decades, we've seen the infected ticks expand their range from these very local foci in New England along the coast and as well as the upper Midwest, putting more people at risk of tick bite and getting Lyme disease.

By 2010, 94 percent of Lyme disease cases were reporting from 12 States, from Maine down to Virginia to Pennsylvania. Interestingly, Delaware and Connecticut had the highest incidence of disease with 73 and 55 cases per 100,000 respectively. And, actually,

for many, many years, Connecticut was the leading State in the country. But that has shifted as we see more and more States with more and more cases of Lyme disease. The other two States in the top 12, shall I say, are Minnesota and Wisconsin, where a separate distinct population of the blacklegged tick is also expanding its range.

Of course, this is not just Lyme disease. I want to mention that this tick also transmits the agents of human babesiosis and human granulocytic anaplasmosis. These are two emerging tick-borne infections that are also seeing a noticeable increase in human cases over this past decade. We know that the tick can carry multiple infections with any or all three of these pathogens, increasing the likelihood of co-infection for people that are bitten by the tick, which can complicate diagnosis and treatment.

Now, since the discovery of the Lyme disease agent back in the mid-1970s and its description in 1982, scientists—I am proud to say, at the Connecticut Agricultural Experiment Station—have been at the forefront of a lot of Lyme disease research. Some of the very first antibody tests for both humans and wildlife were developed at the Experiment Station. The actual first isolation of this bacterium from wildlife was done at the Experiment Station. We've done a lot of work on studying the ecology of the disease as well as tick control strategies.

Without a Lyme disease human vaccine, prevention comes down to basically preventing tick bite and controlling the tick, primarily in residential locations where people are at the highest risk. I want to focus the rest of my remarks on prevention, which is my main area of research. That research and that of some of my fellow researchers or investigators—we've examined a variety of vector control approaches to determine their efficacy in controlling ticks.

Chemical acaricides, that is, pesticides or insecticides, have been the mainstay for controlling ticks for both humans—biting ticks—and livestock for many years. And while we know that ground applications of these compounds can provide highly effective local tick control, there's a lot of environmental concerns with their use, and it's kind of restricted their acceptance and broad use. And some new approaches, obviously, were needed.

So some of these researchers—what we've looked at—the approaches include personal protection measures, which we know are effective but can be difficult sometimes for individuals to follow through; host management; vegetative and habitat modification; again, acaricide applications; host-targeted acaricides to mice through bait boxes and deer through 4-Poster stations; biological control—I've done a lot of work there—and control with botanically derived compounds.

Now, most of these approaches have had varying degrees of success. However, more work needs to be done. And, of course, as you all know, the incidence of Lyme disease continues to increase.

There has been an expanding interest in natural or organic or herbal products in recent years. There has been a growing organic land care movement. And so my research the past several years has focused on biological and natural tick control products with support from grants from the CDC.

For example, largely through our studies, an entomopathogenic fungus, *Metarhizium anisopliae*, has been registered with the U.S. Environmental Protection Agency and registered in most States for tick biological control to provide an alternative for those who do not want to use chemical insecticides. A product with this naturally occurring soil fungus is anticipated to be commercially available in 2014.

Just to highlight one other example involving vegetative management, our colleagues in Maine found that the blacklegged tick populations were twice as numerous in barberry-infested forests as in adjacent forests that did not have barberry. Similarly, the scientists at the Experiment Station found a significant difference in tick abundance between barberry-infested and barberry-free areas. We discovered that ticks in the Japanese barberry infestations had a much higher rate of infection with the Lyme disease agent, and that removal of this invasive plant could reduce the number of spirochete-infected ticks by nearly 60 percent.

But, unfortunately, there have been few studies that have integrated these approaches. But they do suggest that it is possible to get better tick control if you combine them. The problem is that the ecological dynamics of Lyme disease are very complex. You have a 2-year life cycle. You have many reservoir-competent and reservoir-incompetent hosts, and that complicates the effectiveness of any one approach.

So I and some of the other scientists at the Experiment Station will begin evaluating an integrated tick management approach to try to provide a better understanding of our ability to prevent Lyme disease and control ticks and reduce risk through a cooperative agreement that I just received from the CDC. And another thing we want to do with this project is try to quantify some of the outcomes of these interventions to try to get a better understanding of the interaction of these vertebrate reservoirs and how these techniques work or do not work.

Clearly, prevention and early diagnosis remain a key component in the management of Lyme disease. But without better approaches to reduce exposure to infected ticks, people will continue to contract Lyme disease and one or the other tick-associated illnesses. And I just want to wrap up by noting that many of these management techniques are available through my tick management handbook that is available on the Agricultural Experiment Station's Web site at www.ct.gov/caes.

Thank you.

[The prepared statement of Mr. Stafford follows:]

PREPARED STATEMENT OF KIRBY C. STAFFORD III, PH.D.

Lyme disease is one of the most important vector-associated diseases in the United States and the 5th most common nationally notifiable disease. There are around 30,000 to nearly 40,000 cases reported to the Centers for Disease Control and Prevention (CDC) each year, which likely represents only 10 percent of the diagnosed cases. The disease is caused by the bacterium, *Borrelia burgdorferi*, which is transmitted in the eastern and mid-western United States by the bite of the blacklegged tick, *Ixodes scapularis*, which is more commonly known as the deer tick. In 2010, 94 percent of Lyme disease cases were reported from 12 States: Connecticut, Delaware, Maine, Maryland, Massachusetts, Minnesota, New Jersey, New Hampshire, New York, Pennsylvania, Virginia, and Wisconsin. Delaware and Connecticut had the highest incidence of disease with 73.1 and 55.0 cases per 100,000

population, respectively. A related tick, the western blacklegged tick, is responsible for the transmission of the Lyme disease bacteria in the Pacific coastal States. The “deer” tick is also responsible for transmitting the agents of human babesiosis and granulocytic anaplasmosis, two emerging tick-borne infections in the United States that have also seen a notable increase in human cases in the past decade. Furthermore, *Ixodes scapularis* may have single or multiple infections with any three of these pathogens, which would increase the likelihood of co-infection and possibly complicate diagnosis and treatment.

Lyme disease was described from a cluster of human cases in the Lyme area of Connecticut in the mid-1970s. The identification of the Lyme disease agent and *Ixodes scapularis* as the vector for this pathogen followed in 1982. Since that time, scientists at The Connecticut Agricultural Experiment Station (CAES) have been at the forefront of Lyme disease related research, developing some of the first antibody tests, first isolating the pathogen from wildlife, studying the ecology of the disease, and evaluating many tick control strategies. Over the last three decades, we have seen infected ticks expand their range, putting more people at risk of tick bite and acquiring Lyme disease.

In the early 1980s, populations of *Ixodes scapularis* were identified at a number of coastal sites along the northeastern coast from northern Massachusetts to New Jersey, but few were present at inland locations, a pattern originating from past geologic history and land use patterns. Subsequently with restoration of habitat (re-forestation) and hosts in the 20th century, the northern population of *Ixodes scapularis* increased in abundance and expanded geographically from those early coastal sites. For example, we know from Experiment Station surveys of white-tailed deer that neither the tick nor the Lyme agent was present in northwestern Connecticut in 1980. That region of the State later had some of the highest rates of Lyme disease in Connecticut. The southern Mid-Atlantic States, such as Maryland and Virginia, have seen a steady, dramatic rise in reported Lyme disease cases this past decade. A separate, independent population of *Ixodes scapularis* in the upper mid-west has also been expanding southward. At least a few cases of Lyme disease have been reported from most States, the District of Columbia, and Canada, although in some cases the source of infection is unclear.

We find that individuals in suburban residential developments with adjacent wooded tracts, and those with rural homes in woodland environments, where there are abundant hosts for the tick, have the highest risk for Lyme disease. Consequently, tick bite prevention and the control of vector ticks in residential locations has been the main approach to reducing the risk of Lyme disease. My research and that of other investigators have studied a variety of vector control approaches to determine their efficacy in reducing tick abundance. My work has included personal protective measures, host management, vegetative or habitat modification, acaricide applications, host-targeted acaricides to mice and deer, biological control, and control with botanically-derived compounds. Most of these approaches have met with varying degrees of success, but more work needs to be done, and the incidence of Lyme disease continues to increase. The ecological dynamics of Lyme disease are complex, involving a 2-year life-cycle and many reservoir-competent and reservoir-incompetent hosts, complicating the effectiveness of any single tick management strategy.

While the ground application of acaricides can provide highly effective, local tick control, environmental concerns have restricted their acceptance and broad use. Interest in natural, organic, and herbal products have been on the rise in recent years and my research the past several years has focused on biological and “natural” product tick control with support from the CDC. Largely through our studies, an entomopathogenic fungus, *Metarhizium anisopliae*, has been registered with the U.S. Environmental Protection Agency (EPA) and the States for tick biological control. A product with this naturally occurring soil fungus is anticipated to be commercially available in 2014. Another example of the Experiment Station’s work is in vegetative management. A study conducted by our colleagues in Maine found that blacklegged tick populations were twice as numerous in barberry-infested forests as in adjacent forests without barberry. Our scientists at CAES had also found significant differences in tick abundance between barberry-infested and barberry-free areas. We discovered that ticks in Japanese barberry infestations had an elevated prevalence of infection with *B. burgdorferi* and that the removal of this invasive plant could reduce the number of spirochete-infected deer ticks by nearly 60 percent.

Few studies have been done using an integrated tick management approach to control ticks in the environment. I and other scientists at the Experiment Station will be evaluating an integrated tick management approach to control ticks and reduce the risk of Lyme disease through a new cooperative agreement with the CDC. We also hope to quantify the epidemiological outcomes of our interventions focusing

on ticks or vertebrate reservoirs to provide a better understanding of the ability of Lyme disease prevention and control strategies to reduce risk. Prevention remains a key component in the management of Lyme disease, but without better approaches to reduce exposure to infected ticks, many people will continue to contract Lyme disease or one of the other tick-associated diseases.

Information on the ticks, disease agents they transmit, personal protection measures, and various tick management strategies can be found in the Experiment Station's Tick Management Handbook at www.ct.gov/caes.

Senator BLUMENTHAL. Thank you.

[Applause.]

Dr. Katz.

STATEMENT OF AMIRAM KATZ, M.D., ASSISTANT CLINICAL PROFESSOR OF NEUROLOGY, YALE UNIVERSITY, ORANGE, CT

Dr. KATZ. Thank you, Senator Blumenthal, for giving me the opportunity to speak about this epidemic that we've been both involved with for the past 15 or 20 years. I think it's a great step that it reached the House level, because it is a national problem. And the numbers that I'm going to run by you will show that it is perhaps more than we even think it is.

With the 1 to 10 ratio of the reported versus diagnosed, we have another 1 to 10 ratio which is quite acceptable by the mainstream scientific community. This is the number of patients that, in spite of early diagnosis and adequate treatment, will develop chronic illness. So, best case scenario, if you have a bull's-eye rash, and you get antibiotics in a timely manner, still 1 out of 10 will go on to develop a chronic illness which we believe is autoimmune in nature.

Now, if we are going to add to this number, this proportion, the patients that are not diagnosed because they don't have a bull's-eye rash and because the tests are inaccurate and because of the schism in the medical community, then we are ending up, I believe, with the prevalence—not incidence, not number of cases per year—a cumulative number of about a half million of the American population are sick with a chronic illness which stemmed out of Lyme disease, and it's not an infection anymore.

There might be a role to the pathogen, either dividing or infective or inflammatory, but the disease can be ongoing and perpetuating without the presence of the spirochete. That's the reason why this terminology of chronic Lyme disease versus chronic infection is very misleading.

Recent studies, recent collaboration, between the group of Wormser and Klempner—Klempner did the extramural NIH study in the late 1990s—showed the sera of those patients who participated in the studies and were shown not to benefit from prolonged antibiotic treatment—with Dr. Aledini and Latov—that developed new assays to detect auto-antibodies. They found out that 60 percent of the patients that have “chronic,” Lyme disease do not benefit from prolonged antibiotic treatment based on those studies—are actually showing antibodies against neuronal elements, which are both central and peripheral.

So we are ending up with the morbidity which is inflammatory autoimmune of large proportions that is not addressed. And the mainstream medical community, even though it admits that it is present—and, actually, the first report about its presence came

from those colleagues—at this point, it became a debate which is just semantic: What is chronic? What is infection?

There is a disease. The disease is appreciated. More effort should be made to develop better assays, of course, to diagnose the tick disease when it is acute, but also to diagnose the chronic illness and to give it a better term than fibromyalgia, chronic fatigue, or—that's best case scenario—or psychiatric for this when they are not finding answers.

So we cannot ignore the magnitude of the problem. And I think that if we are talking about efforts that the government can offer, it should be divided into—streamed into three different directions. One should be the improvement of the testing. The tests are inaccurate. We need an accurate test that not only will tell us if the disease is there or not, but what is the level of infection. Is it acute or chronic? We don't have accurate tests to tell us, because if the test is accurate and we have serologic evidence, it's not necessarily requiring added antibiotic treatment. But if the test would tell us that there is active infection, then we know that we need to follow with antibiotics for various lengths of time.

The second avenue of support should be improved treatments. And with treatments, I'm not talking only about antibiotic treatment, but also I'm talking about addressing those autoimmune ailments which will add to the general health, because 5 percent of the population in the Nation are suffering from autoimmune illnesses. And by this effort, other people will benefit.

And the third arm of the support would definitely go to Dr. Stafford's department, because if we don't have infecting ticks, we won't have the disease at all. But bear in mind that the National Geographic in November of last year described a frozen man from the Italian Alps that—5,300 years ago, he got struck by an arrow and died in the Alps and was perfectly preserved. And he was found in 1991, but only recently they did his autopsy. In his brain, they found *Borrelia burgdorferi*.

So this *Borrelia burgdorferi* has been with us for thousands and thousands of years. What makes it pathogenic now is another area of research and questioning.

Thank you.

[The prepared statement of Dr. Katz follows:]

PREPARED STATEMENT OF AMIRAM KATZ, M.D.

INTRODUCTION

Lyme disease is a tick borne spirochetal infection that causes a multi-systemic disease. When identified, diagnosed and treated in a timely manner, *most of the acute cases will recover and be cured*; however, about 10 percent of the infected individual will develop a chronic, antibiotic resistant condition, which is believed to be autoimmune (the immune system is confused and cannot differentiate between our healthy body and foreign antigens and starts attacking our own body). The autoimmune process attacks the brain, the peripheral nerves, the joints and the muscles and is better documented in the rheumatologic literature (Steere, et al. Autoimmune mechanisms in antibiotic treatment-resistant Lyme arthritis. *JAI*. 2001; 16:263–266). This chronic condition will vary in severity, from a very debilitating affliction to one with occasional aches and pains. *The very sick individuals cannot be gainfully employed, are usually bedridden and in addition to their physical ailments, may suffer from a severe cognitive deficit, with difficulties of memory and concentration along with psychiatric manifestations (depression, anxiety, OCD and even psychosis)* which are part of the neurologic complication of this condition (brain disease rather than a psychiatric condition). The percentage of chronic conversion in the

undiagnosed (and untreated) cases is probably much higher (see below). *The chronic condition can be managed (but not cured) in varying degrees of success.*

Lyme disease is a continued and escalating public health issue. In 2009 around 40,000 new cases of Lyme disease were reported in the United States, which is more than a 4-fold increase since reporting started in 1991. One fourth of the reported cases are from New England. (<http://www.cdc.gov/about/grand-rounds/archives/2011/pdfs/PHG>). There is a steady annual increase in the incidence of Lyme disease, except in years where no funding for reporting was available.

The ratio between reported and diagnosed cases is a source of major debate and ranges between 1:2 to 1:10. Accepting a ratio of 1:5 brings the number of diagnosed cases in 2009 to 200,000.

A major problem in assessing the magnitude of this serious public health issue is the undiagnosed cases. The reasons for failure to diagnose Lyme disease varies from lack of the typical telltale sign, the ECM rash; unreliable diagnostic tests; an atypical clinical presentation; a co-infection (another infectious disease transmitted by the same tick); etc. Many of the undiagnosed cases will go on to develop a chronic illness, which is usually no longer responding to short or long courses of antibiotics, since it becomes an ill-defined autoimmune disease (as discussed below). For future calculations, we will use the very conservative assumption that the annual undiagnosed cases for 2009 was 200,000, the same as the estimated diagnosed figure.

As early as 1990, Allen Steere, the “father” of Lyme disease, who was first to describe Lyme arthritis, found that even when timely diagnosed and adequately treated, about 10 percent of the patients develop “antibiotic resistant arthritis,” which is an autoimmune, chronic condition (Steere, A., et al. Lyme arthritis—an epidemic of oligoarticular arthritis in children and adults in three Connecticut communities. *Art Rheum* 1977;20:7–17; Steere, et al. Association of chronic Lyme arthritis with HLA-DR4 and HLA-DR2 alleles. *N Engl J Med*. 1990; 323:219–23. Steere, et al. Autoimmune mechanisms in antibiotic treatment-resistant Lyme arthritis. *JAI*. 2001; 16:263–66).

Similar estimates of autoimmunity were given in a more recent review of “chronic” Lyme disease (Feder HM, et al. A critical appraisal of “chronic Lyme disease.” *N Engl J Med* 2007;357:1422–30).

Based on the numbers listed above, a fair (and probably underestimated) statement is that since 2009, each year at least 40,000 patients are added to the chronically ill pool, which adds up to about 350,000 patients since reporting started in 1991.

Today, in 2012, it will be fair to expect that about 0.5 million patients in the United States are chronically ill due to Lyme disease (1 in 600 people), of them 125,000 live in New England (1 percent of the population), which is around 30,000 patients in Connecticut. These numbers are based on the 2010 Census (<http://2010.census.gov/2010census/data/>) and the CDC Lyme Disease incidence report: <http://www.cdc.gov/lyme/stats/chartstables/incidencebystate.html>).

Schism and polarization within the medical community, heated by patient activism, resulted in ignoring the problem, preventing our strong and capable medical and scientific communities from finding the long overdue answers.

Rather than continuing the true search for answers, Lyme disease research was derailed by unrelated agendas.

Not unlike the political arena the magnitude of the problem requires a bipartisan effort. Our brilliant and capable physicians and scientists should refocus only on one target—finding a solution to the problem.

ATTACHMENT.—THE DIAGNOSIS AND TREATMENT OF CHRONIC LYME DISEASE (AKA: POST-TREATMENT LYME DISEASE)

Patients with chronic illness and symptoms which can be seen in post-treatment (“chronic”) Lyme disease are usually seen by numerous physicians who are perplexed by the complexity of their symptoms. There are no conclusive studies assessing the prevalence (see above) of this condition, or its mechanisms, even though recent literature stemming from unprecedented collaboration between main stream authorities on Lyme disease (IDSA) and leading neuroscientists might have found a partial explanation to the neurologic aspect of the chronicity (Chandra, et al. Anti-neural antibody reactivity in patients with a history of Lyme borreliosis and persistent symptoms. *Brain Behav Imm*. 2010; 24:1018–24).

DIAGNOSIS

Before making a diagnosis of “Chronic” Lyme disease, a **relentless effort should be made to rule out other conditions which can have a similar clinical pic-**

ture. Over-diagnosis of Lyme disease, may lead to a **dangerous under-diagnosis of other conditions** and over treatment with antibiotics. Chronic Lyme disease *cannot be diagnosed* based on clinical symptoms solely. *It cannot be diagnosed by using tests which are not FDA approved.* Desperate patients and the lack of reliable diagnostic tests for Lyme disease (see below) led to the appearance of expensive, non-FDA approved laboratories and tests.

TESTING FOR LYME DISEASE

Direct Methods (none are FDA approved)—the direct identification of the pathogen can be done by:

1. Culture (growing the spirochete from a fluid or tissue sample obtained from a patient in a culture medium, which is very difficult and hard to reproduce. It is used mainly in research laboratories and recently by one commercial laboratory, which appears to have too many positive results (50 percent–70 percent).
2. PCR (polymerase chain reaction), enzymatic amplification the nucleic acid of the spirochete from the specimen until it reaches a detectable quantity that can be identified. This methodology is prone to contamination and false positives (the test is positive but there is no infection), but is the most commonly used direct method.
3. Dark field microscopy with immune fluorescence staining. Accurate, but available only in research labs and requires the presence of spirochetes in the specimen.

Serologic tests (FDA approved)—Indirect identification of the infection by measuring the immune response of the host. Will fail when the patient is immune deficient (is not making enough antibodies), or the number of pathogens is overwhelming (bad infection—where all the antibodies are tied to the spirochete and not enough are available for serologic detection).

1. ELISA (enzyme linked immune sorbent assay) is a colorimetric quantitative technique that measures the intensity of the immune response against the pathogen—the serum of the patient (which may contain antibodies against the spirochete) is mixed with a standardized amount of diced Lyme pathogens (antigens). After incubation, during which the antibodies bind to the antigens, a reagent that connects only to the antibody—antigen complexes is added. After the attachment, the reagent changes its color. The color intensity of the solution is then measured and converted to antibody concentration. The assay is accurate but it will be also positive with other spirochetal infections and in a variety of autoimmune conditions (false positive).

2. IFA (Immunofluorescent Assay)—similar to the ELISA, but uses a different color binding reagent (fluorescent).

3. C6 Peptide. Similar to the ELISA in process, but instead of having a diced spirochete solution as antigenic source, it uses only one protein (antigen) from the spirochetal coat—the C6 peptide—which is more specific and results in many less false positives. It also is supposed to correlate with a more recent infection.

4. Western blot (immunoblot). A qualitative technique that measures the presence of antibodies against the various proteins of the spirochete. The serum interacts with a strip of gel onto which a mixture of spirochetal proteins are applied. They are separated according to their size (the smaller migrates the farthest on the gel). This results in the smallest protein (with a molecular weight of 18kd) ending at one end of the strip and the largest protein (with a molecular weight of 93kd)—at the opposite. After the antibody—antigen complex is stained—there is a visible “band” at the location of each spirochetal protein against which antibodies were formed.

The CDC serologic criteria for reporting and surveillance—the “Two Tier” Approach. (Recommendations for test performance and interpretation from the Second National Conference on Serologic Diagnosis of Lyme Disease. MMWR *Morb Mortal Wkly Rep.* 1995;44:590–1).

- “A two-test approach for active disease and for previous infection using a sensitive enzyme immunoassay (EIA) or immunofluorescent assay (IFA) followed by a Western immunoblot was the algorithm of choice. All specimens positive or equivocal by a sensitive EIA or IFA should be tested by a standardized Western immunoblot. Specimens negative by a sensitive EIA or IFA need not be tested further. When Western immunoblot is used during the first 4 weeks of disease onset (early LD), both immunoglobulin M (IgM) and immunoglobulin G (IgG) procedures should be performed. A positive IgM test result alone is not recommended for use in determining active disease in persons with illness >1 month’s duration because the likelihood of a false positive test result for a current infection is high for these persons. If a patient with suspected early LD has a negative serology, serologic evidence of infection is best obtained by testing of paired acute- and convalescent-phase

serum samples. Serum samples from persons with disseminated or late-stage LD almost always have a strong IgG response to *Borrelia burgdorferi* antigens.

- It was recommended that an IgM immunoblot be considered positive if two of the following three bands are present: 24 kDa (OspC), 39 kDa (BmpA), and 41 kDa (Fla)—(Engstrom SM, Shoop E, and Johnson RC. Immunoblot interpretation criteria for serodiagnosis of early Lyme disease. *J Clin Microbiol* 1995;33:419–22).

- It was further recommended that an IgG immunoblot be considered positive if five of the following 10 bands are present: 18 kDa, 21 kDa (OspC), 28 kDa, 30 kDa, 39 kDa (BmpA), 41 kDa (Fla), 45 kDa, 58 kDa (not GroEL), 66 kDa, and 93 kDa—(Dressler F, Whelan JA, Reinhart BN, and Steere AC. Western blotting in the serodiagnosis of Lyme disease. *J Infect Dis* 1993;167:392–400.)

Unfortunately the inconsistencies of the test results between different laboratories and even in the same laboratory are so frequent—that it is difficult to trust their reports.

For example, a Western blot test can be run three times on the same specimen: the first, when ordered as such (Western blot); the second, if an ELISA with reflex Western blot is also ordered (meaning that the Western blot test will be automatically performed if the ELISA is positive); and for the third time, if a C6 peptide with reflex Western blot is ordered. It is not unusual to receive both a positive and a negative IgM and/or IgG Western blot reports, in the same patient, from the same sample. *A difference in one band turns the test from negative to positive and vice versa.*

The Western blot is usually interpreted visually, which results in a significant inter observer variability. One laboratory attempted to solve this problem by implementing a mechanized reading of the blot. This resulted in changing the test from a qualitative one to a quantitative one, with significant under interpretation.

It is clear that more accurate tests are needed and more so, a test that will tell us if the infection is active. Such a test, if accurate will cut down the number of cases treated with unnecessary prolonged antibiotic courses and prevent many patients from acquiring a chronic illness. When this test develops, it should be used widely in areas where Lyme is endemic, when patients present with an atypical illness.

What are the possible explanations of developing “chronic” Lyme disease?

1. **Persistent Lyme infection.** In spite of the IDSA’s treatment recommendations stating that 2 weeks (range 10–21 days) of oral antibiotics (doxycycline, amoxicillin, or cefuroxime), are sufficient to treat Lyme disease diagnosed by ECM (Bull’s eye) rash, there is culture-supported data, suggesting otherwise (Wormser, et al. The Clinical Assessment, Treatment, and Prevention of Lyme Disease, Human Granulocytic Anaplasmosis, and Babesiosis: Clinical Practice Guidelines by the Infectious Diseases Society of America *Clin Inf Dis* 2006;43:1089–134; Hunfeld, et al. Risk of culture-confirmed borrelial persistence in patients treated for erythema migrans and possible mechanisms of resistance. *Int J Med Microb* 2006; S1,233–241).

There should be more flexibility in the number of days of antibiotic treatment. ***Initial treatment should be extended if the diagnosis is firm and the patient’s condition did not improve.*** This is supported by recent studies conducted in mice and monkeys that show that even after prolonged antibiotic courses, the treated animals can contain infective spirochetes (Hodzic, et al. Persistence of *B. burgdorferi* following antibiotic treatment in mice. *Antimac Ag & Chemoth.* 2008; 52:1728–36. Embers ME, Barthold SW, Borda JT, et al. Persistence of *Borrelia burgdorferi* in Rhesus Macaques following antibiotic treatment of disseminated infection. *PLoS One.* 2012; 7:e29914)

2. **Persistent presence** of non-infective Lyme spirochetes after adequate antibiotic treatment leading to an ongoing disease. The immune system can attack a dead micro-organism or its fragments and in the process of the attack damage healthy surrounding tissues. Recently (July 2012), the Yale group led by Linda Bockenstedt, showed the presence of fragments of the spirochete long after the infection. It means that one doesn’t need the entire spirochete to cause an on-going damage. Persisting spirochetal antigens can do it (Bockenstedt, et al. Spirochete antigens persist near cartilage after murine Lyme borreliosis therapy. *J Clin Invest.* 2012;122:2652–60). If a dead spirochete or its fragments contains a protein which has some resemblance to one of our own body proteins—then it can start or perpetuate an autoimmune process (see below).

In this context, it was shown that inflammation can be triggered by some of the spirochetes lipoproteins (OspA, OspB). Inflammation is caused by irritating our immune cells that in turn secrete cytokines that damage our own tissues. So damage to the tissues can result from inactive spirochetes, just by the irritating nature of

the proteins they carry (Fallon, et al. Inflammation and central nervous system Lyme disease. *Neurobiology of Disease* 2010;37:534–41).

Persistent presence of the spirochete without causing any illness should be also considered. A recent discovery of *Borrelia burgdorferi* by PCR in the brain of the “Iceman” who lived in the Neolithic period in the Italian Alps 5,300 years ago raises the question of coexistence. The “Iceman” died from an arrow wound and was healthy otherwise. He was frozen for all those years until recently thawed for his autopsy (was found frozen in a glacier in 1991—Hall SH. Iceman Unfrozen. *National Geographic*. 2011; 220:118–33). It is possible that like some other pathogens, *B. burgdorferi* sits in our body inactive and then one day, due to one stimulus or the other becomes active again.

If the spirochete has been residing in our bodies since the Neolithic age, why is it reaching only now epidemic proportions? The answer is complex. Ecologic changes (reforestation, population shift to the suburbs, a change in the viral population that makes bacteria pathogenic, etc.). Decreased immunity due to a more “sterile” upbringing and increase in autoimmune diseases, in general (Jackson Nakazawa D. *The Autoimmune Epidemic*. Touchstone, NY 2008).

3. **Persistent/untreated infection of other tick borne agents**, transmitted by the same ticks (“co-infections”).

4. **Re-infection**. Living in a Lyme endemic area, where about 50 percent of the tick bites go undetected, unnoticed re-infection can result in a “chronic” picture. This includes the “co-infections.”

If after the infections are identified and treated adequately the patient continues to be symptomatic, there are two main processes that can explain the patient’s condition:

1. Residual damage from either of the above (e.g. brain damage resulting in white matter lesions leading to permanent neurologic deficits).

2. The post-Lyme autoimmune syndrome is probably the most common cause for the chronic illness, the rheumatologic aspects of which were described in the literature over 20 years ago (Steere, et al. Association of chronic Lyme arthritis with HLA-DR4 and HLA-DR2 alleles. *NEJM*. 1990; 323:219–23. Steere, et al. Autoimmune mechanisms in antibiotic treatment-resistant Lyme arthritis. *JAI*. 2001; 16:263–66).

It was also shown by Aledini and Latov that “Antibodies against OSPA epitops of *Borrelia burgdorferi* cross react with neuronal tissue” (*Journal of Neuroimmunology*. 2005; 159:192–95) explaining why the post-Lyme autoimmune syndrome is not only a rheumatological condition, but also a neurological.

Under the autoimmune category, the post-Lyme vaccination syndrome should be included (Latov, et al.—Neuropathy and cognitive impairment following vaccination with the OSPA protein of *Borrelia burgdorferi*. *J Periph Ner Sys* 2004;9:165–67).

A different group of researchers showed that Osp-A shares similar amino acid sequence with the streptococcal protein M, that is similar to a human muscle protein, myosin, that triggers human autoimmune conditions such as carditis (disease of the heart), arthritis and possibly other post-streptococcal conditions (Raveche, et al. Evidence of *Borrelia* autoimmunity-induced component of Lyme carditis and arthritis. *J Clin Microb*. 2005;43:850–56).

The recent collaboration between Latov, Aledini, Wormser and Klempner (who was the PI of the extramural NIH “chronic” Lyme study in the late 1990s—Klempner, et al. Two controlled trials of antibiotic treatment in patients with persistent symptoms and a history of Lyme disease. *NEJM* 2001;345:85–92), showed that the sera of patients with “chronic” Lyme disease contain anti-neuronal antibodies (Chandra, et al. Anti-neural antibody reactivity in patients with a history of Lyme borreliosis and persistent symptoms. *Brain Behav Imm*. 2010;24:1018–24).

Recent studies of proteomic patterns (a test for the patterns of protein components) generated by the cerebrospinal fluids of patients with “chronic” Lyme further supports that this disease entity is unique and cannot be “lumped” with other syndromes (Schutzer, S. E., et al. Distinct cerebrospinal fluid proteomes differentiate post-treatment Lyme disease from chronic fatigue syndrome. *Plos One* 2011;6:e17287).

In the past 3 years, we have found that many patients with “chronic” Lyme disease exhibit anti-neuronal antibodies and increased Cam II kinase activity (antibody mediated neuronal damage via calcium channel activation), as found in *Dr. Cunningham’s laboratory at the University of Oklahoma* (Kirvan, et al. Mimicry and autoantibody-mediated neuronal cell signaling in Sydenham chorea. *Nature Med*. 2003;9:914–20), supporting, again, the autoimmune nature of “chronic” Lyme.

We found that both the peripheral and central nervous system are targeted in post-Lyme and post-Lyme vaccine illnesses. Unlike the known autoimmune nature

of demyelinating neuropathy of large fibers, many of those patients experience immune neuropathies of sensory and autonomic ganglia.

TREATMENT

When facing “chronic” Lyme, with an autoimmune flavor, one should consider treatment with a combination of hydroxy chloroquine and a macrolide.

HYDROXYCHLOROQUINE + MACROLIDES

The rationale of the treatment is:

1. The hydroxychloroquine potentiates the antibiotic effects of macrolides, by increasing the pH in the lysosome (“Late and chronic Lyme disease”, Sam Donta. Medical Clinics of North America 2002; 86: 341–49. “Macrolide therapy of chronic Lyme disease,” Sam Donta. Medical Science Monitoring, 2003; 9(11):136–42).

2. Hydroxychloroquine has also immune modulating properties and is classified as a weak DMARD (disease modifying anti-rheumatic drug). It interferes with the functioning of T- and B-Lymphocytes, monocytes and macrophages by entering their lysosomes and increasing the lysosomal pH, which inhibits the ability of these cells to produce and release inflammatory cytokines and hydrolytic enzymes.

Clarithromycin possesses anti-inflammatory properties and potentiates the effects of hydroxychloroquine. I have seen many patients with intractable arthritis improve when macrolides are added (“Anti-inflammatory activity of macrolide antibiotics.” The Journal of Pharmacology and Experimental Therapeutics. January 2000, 156–63; Ianaro, et al.).

Immune modulation and anti-inflammatory properties are especially advantageous in the setting of post-Lyme autoimmune syndrome.

3. The combination of an anti-malarial and a macrolide treats Babesia, a common co-infection “Atovaquone and azithromycin for the treatment of Babesiosis” Krause, et al. *New England Journal of Medicine* 2000; 343: 1454–58).

BENZANTHINE PENICILLIN

When hydroxychloroquine/macrolide combination is not effective, cannot be tolerated (allergic reactions, GI side effects, tinnitus, contact dermatitis, psoriasis flair up, ophthalmologic contraindications, etc.), or when hydroxychloroquine has reached its maximal safe cumulative dosage (1,000G)—intramuscular benzanthine G penicillin (Bicillin LA) is an option (Marco AC and Accrdo S. Long-term treatment of chronic Lyme disease with benzanthine penicillin. *Ann Rheumat Dis* 1992;51:1007–08).

The mechanism of action of benzanthine penicillin (other than the obvious antimicrobial) is unknown. Why 3 percent of the daily intravenous dose of penicillin can achieve much better results when injected intramuscularly once a week?

One explanation is that the bacteriocidal signal it sends is not strong enough to activate defense mechanisms of the spirochete, but enough to suppress the expression of the outer surface proteins (mainly OspA and OspB) which are known to trigger inflammation (Rupprecht, et al. The pathogenesis of Lyme neuroborreliosis: from infection to inflammation. *Molecular Medicine*. 2008;14:205–12).

Another explanation is that Bicillin is an effective anti-streptococcal treatment and that the autoimmune morbidity is perpetuated by streptococcal presence.

I have had a significant number of patients with Chronic Lyme disease who did not get better on long courses of oral and/or intravenous antibiotics, but responded to weekly Bicillin shots within a month or two. This treatment is so benign, that I offer it now prior to hydroxychloroquine and clarithromycin, in spite of its poorly explained mechanism of action.

INTRAVENOUS IMMUNOGLOBULINS (IVIG)

Are not indicated for the treatment of Lyme disease per se. They are indicated when there is immune deficiency or neurologic conditions of autoimmune nature complicating Lyme disease.

Autoimmune diseases affect about 5 percent of individuals in developed countries. Autoimmunity is the patho-physiologic mechanism in neurologic conditions affecting the myelin of the peripheral and central nervous system, the basal ganglia, the post-synaptic membrane, the hippocampal pyramidal cells and Purkinje cells, among other targets, in a variety of autoimmune conditions of the nervous system.

Autoimmunity is believed to be a result of complex interactions between genetic traits and environmental factors. Infections and vaccinations are some of the more known environmental factors. Among other known mechanisms are myeloproliferative conditions and other neoplasms (through a paraneoplastic mechanism).

The outer surface protein A of *Borrelia burgdorferi* (OspA) is a lipoprotein with a molecular weight of 31kd that possesses immuno-stimulatory properties that can activate pro-inflammatory toll-like receptors of the immune system. Receptors of this kind are also expressed in a variety of neuronal elements including Schwann cells, microglia, astrocytes and oligodendroglia, which probably contribute to the development of inflammatory responses affecting the entire nervous system. The OspA has a partial amino acid sequence (165–73) homologous to that of HLFA–1 (human lymphocytic function associated antigen–1) that results in activation of T cells to this auto antigen ending in an autoimmune disease (autoimmune disease caused by “molecular mimicry” mechanism).

As discussed earlier, it was shown that certain sequence of amino acids on the OspA can trigger the formation of anti-neuronal autoantibodies (Aledini and Latov. Antibodies against OSP A epitops of *Borrelia burgdorferi* cross react with neuronal tissue. *Journal of Neuroimmunology*. 2005; 159:192–95). Osp–A shares similar amino acid sequence to the streptococcal protein M, that is similar to myosin and triggers immune carditis, arthritis and even Sydenham’s chorea (Raveche, et al. Evidence of *Borrelia* autoimmunity-induced component of Lyme carditis and arthritis. *J Clin Microb*. 2005;43:850–56).

Both Lyme disease and the Lyme vaccine (LYMERix—Latov, et al.—Neuropathy and cognitive impairment following vaccination with the OSP A protein of *Borrelia burgdorferi*. *J Periph Ner Sys* 2004;9:165–67) can trigger neurologic autoimmune disease. Since the Lyme vaccine is a pure preparation of OspA (coated onto aluminum hydroxide), it is reasonable to assume that this protein is also responsible for the autoimmune disease triggered by Lyme infection. This autoimmune disease is especially common in individuals with class II, MHC HLA DR4 (DRB1*0401), whose macrophages identify the amino acid sequence shared by the OspA and our body proteins as “non-self” attach to it and present it to the T & B lymphocytes.

Persisting presence of IgM antibodies reacting to the OspA, which is not reported by common laboratories (Western Blot band 31), might be an indicator of an autoimmune condition triggered by this protein. The fact that patients with this condition have a disease of both peripheral and central myelin, also supports the etiology (post-Lyme/LYMERix autoimmune), since it is uncommon for patients with “pure” MS, who have a disease of the central myelin, to have peripheral neuropathy. And vice versa, it is uncommon to have MS when having demyelinating neuropathy.

The most common Lyme associated autoimmune conditions affecting the central and peripheral nervous system myelin result in “white matter lesions” on brain MRI’s which are associated with a wide range of neuropsychiatric manifestations; damage to the basal ganglia/sub thalamic nucleus resulting in bizarre and disabling movement disorders and; peripheral nerve conditions such as Guillain Barre, CIDP and even multifocal motor neuropathy with block, but more frequently ganglioneuropathy of the sensory and autonomic nerves.

Intravenous immunoglobulins (IVIG) are widely used for treatment of a variety of diseases, but mainly in autoimmune neurologic conditions (Dalakas MC. Intravenous immunoglobulin in autoimmune neuromuscular diseases. *JAMA*. 291: 2367–75, 2004).

Their exact mechanism of their action is unknown, but there are several possibilities:

- a. They probably bind to the idiotypes via their anti-idiotypic variable portion, blocking the interactions between the idiotypes and idiotype antigens that usually lead to autoimmune disease.
- b. IVIG bind to the Fc receptors of the macrophages preventing phagocytosis and to the Fc receptors of the autoantibodies in the antigen-antibody complex, preventing activation of the complement.
- c. They bind to the C3 complement fraction and impeding the complement cascade.

The major advantage of IVIG therapy is achieving significant immunomodulation with arrest of the autoimmune process, which is comparable to high dose steroids or cytotoxic agents, *without immunosuppression* and its associated risks.

In multiple sclerosis, the effects of beta-interferons on susceptibility to infections are not clear. By modifying the host inflammatory response they can impair the body’s ability to fight infection. The recent natalizumab (Tysabri) experience (Warneke, et al. Natalizumab and Progressive Multifocal Leukoencephalopathy. *Arch Neur*. 2010; 67:923–930) showed that the only two patients receiving natalizumab that developed PML (progressive multi focal leukoencephalopathy), where those also receiving Avonex (beta-interferon 1–alpha). This means that the beta interferons are not so safe when patients have an ongoing infection.

Our view is that in conditions where autoimmune processes are linked to infections and it is not clear whether the infection is active or not, IVIG treatment should be tried first. High dose steroids and/or immunosuppressive agents should be considered as a treatment option only when IVIG fail, or contraindicated.

SELECTED PUBLICATIONS ON THE TOPIC

- Grzegorz S. Nowakowski, M.D.; and Amiram Katz, M Epilepsia partialis continua as an atypical presentation of cat scratch disease in a young adult. *NEUROLOGY* 2002;59:1815–16.
- Katz A. IVIG treatment in patients with Lyme associated movement disorder *Autoimm Rev.* 2006;15:106–09.
- Katz A. IVIG treatment in patients with Lyme and demyelinating disease. *Autoimm Rev.* 2006;15:302–05.
- Katz A, Zubal G, Westerveldt M, Blumenfeld H and Seibyl J. Neuropsychological Testing and SPECT/PET Ratio-Images In Patients with Lyme Encephalopathy—Pre- and Post-Antibiotic Treatment Studies. *JOI.* 2007;17:103.
- Katz, A and Berkley JM. Diminished Epidermal Nerve Fiber Density in Patients with Antibodies to Outer Surface Protein A (OspA) of *B. burgdorferi* Improves with Intravenous Immunoglobulin Therapy. *Neurology* 2009;72(S3):A55.
- Milone M, Katz A, Amato AA, et al. Sporadic late onset nemaline myopathy responsive to IVIG and immunotherapy. *Muscle & Nerve.* 2010;41:272–76.

Senator BLUMENTHAL. Thank you.

[Applause.]

Dr. Petrini.

STATEMENT OF JOANN PETRINI, Ph.D., MPH, DIRECTOR OF CLINICAL OUTCOMES AND HEALTH SERVICES RESEARCH, DEPARTMENT OF MEDICAL EDUCATION AND RESEARCH, WESTERN CONNECTICUT HEALTH NETWORK, DANBURY, CT

Ms. PETRINI. Good morning. On behalf of Western Connecticut Health Network, I really appreciate the opportunity to submit this testimony concerning the proposed legislation providing for the expansion of Federal efforts concerning prevention, education, treatment, and research activities related to Lyme and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee.

As an acute care two-hospital network, including Danbury Hospital, New Milford Hospital, and the Western Connecticut Health Network Biomedical Research Institute, home of the Nation's first hospital-based Lyme Disease Registry, we understand firsthand the complex nature of this disease and its varying effect on our patients. In 2009 and 2012, the Community Report Card for Western Connecticut reported that our region has among the highest rates of tick-borne illness in the United States, as Dr. Stafford has cited. It also reported Lyme disease to be a prevalent and high priority public health concern for the region.

Western Connecticut Health Network's Lyme Disease Registry was created from the greater Danbury community's express desire to explore Lyme disease more thoroughly, including the lingering symptoms associated with Lyme disease. We recognize that extremely valuable information, as we've heard this morning, can come from individual patient experiences. But it is most useful when these experiences are carefully combined and studied in a systematic format for a large number of patients.

The mission of the Lyme Disease Registry is to create a comprehensive database of patients with Lyme disease that will serve as the basis for multidisciplinary research leading to a better understanding of the course of the disease and how people are af-

fects, causes of persistent symptoms, and improved diagnosis and treatment. Through our interviews, we have heard the painful stories of people whose lives were devastated by this disease. We have heard how chronic Lyme disease has dramatically weakened people's health.

Despite these examples, those of us working with the Registry find ourselves walking a very fine line, even in the use of terminology. For example, if we use the term, chronic Lyme disease, we become discredited by many physicians. If we use the term, post-Lyme syndrome, we are discredited by those in the community who have been personally impacted. Based on our patient interactions, we believe that there is a protracted clinical course for Lyme disease for many people. But the controversy surrounding these long-term symptoms has created a polarizing tension between patients and providers.

The Registry staff work hard to stay focused on the goal of conducting meaningful and high quality research. Our research plans to date have been shaped by our local community task forces, specifically those in Brookfield, CT, through the regional HVCEO that focus on Lyme disease in conjunction with public health professionals. We currently have about 180 patients enrolled in the Lyme Disease Registry, but we continue to recruit people over the age of 5 years whose Lyme disease has been diagnosed by a healthcare provider. But we do not adhere to the CDC criteria. We can be reached, for those who are interested, at lyme.registry@westernconnecticuthealthnetwork.org.

We've been working to understand whether the protracted course of Lyme disease is homogeneous or heterogeneous. That is, does Lyme disease have a consistent or a variable clinical presentation? Specifically, we are working to understand whether the protracted symptoms may be caused by the genotype of the bacteria, or the tick, the genotype of the host, or the person, or a combination of the two. And, of course, all of this becomes confounded with co-infections.

As we've heard, Lyme disease and other tick-borne illnesses are dramatically underreported. This underreporting is due in part to the limitations in our ability to diagnose the disease. At the Registry, we are working on a new approach to Lyme diagnosis. The patented technology we are testing is potentially more sensitive than currently available tests. This test might be especially useful for detecting Lyme spirochetes in patients with lingering symptoms that are unresponsive to antibiotic treatment.

Our work has been conducted using the basic science platform of the Western Connecticut Health Network's Basic Science Research Institute and with the expertise of our Department of Pathology at Danbury Hospital. So we have the infrastructure needed, but for the Registry to be most successful, we need to increase enrollment and secure additional funding. We are currently collaborating with the CDC on ways to maximize the potential of the Registry, and we asked the Tick-Borne Diseases Advisory Committee to consider Western Connecticut Health Network's Lyme Disease Registry as a resource to support its work going forward.

We have had the distinct pleasure of touring Senator Blumenthal through our Lyme Disease Registry and would like to thank him

and other legislators here today for their commitment and ongoing dedication to this cause.

I'll just end with my recommendations, which are: We sincerely support the creation of the Tick-Borne Diseases Advisory Committee and strongly recommend, as you've stated, patients and their families be represented on this committee. This committee would bring a strong and united voice to this cause. One of the provisions in the proposed bill is the creation of a registry. We offer our Registry to serve as a resource to the advisory panel and any research questions that may emerge as you synthesize existing evidence and create new ideas for study.

And then, finally, funding for community-based participatory research projects focused on Lyme disease should be included in Federal research initiatives. While the support of Danbury Hospital and the community has been generous toward the Registry, our work has moved very slowly due to limited funding. Public funding for this type of community-based participatory research is desperately needed to move innovative research forward.

So, in conclusion, we offer the knowledge and expertise of our professional team to participate on the advisory committee or in any work groups to further prevention, research, and treatment of Lyme disease.

[The prepared statement of Ms. Petrini follows:]

PREPARED STATEMENT OF JOANN R. PETRINI, PH.D., MPH

Western CT Health Network appreciates the opportunity to submit testimony concerning Lyme disease and proposed legislation to provide for the expansion of Federal efforts concerning the prevention, education, treatment, and research activities related to Lyme and other tick-borne diseases, including the establishment of a Tick-Borne Diseases Advisory Committee. As an acute care two-hospital Network including Danbury Hospital, New Milford Hospital and the Western CT Health Network Biomedical Research Institute, home of the Nation's first hospital-based Lyme Disease Registry, we understand first-hand the complex nature of this disease and its varying affect on our patients.

The 2009 and 2012 *Community Report Card for Western Connecticut*, a collaborative publication looking at leading health indicators for the towns of Western Connecticut found our region has a higher rate of tick-borne illness than most other geographic areas in the Nation and also found Lyme disease to be a prevalent public health issue and a priority health concern for the region based on State case rates (1). The data collected in 2009 and again in 2012 via our Community Health report Card indicates that Lyme disease is an important and ongoing health issue for our community.

Western CT Health Network Lyme disease registry was created from the Greater Danbury community's expressed desire to explore Lyme disease more thoroughly, including the lingering symptoms associated with Lyme disease and unmet medical service needs of the community. We recognize that extremely valuable information can come from individual patient experiences, but it is most useful when these experiences are carefully combined and studied in a systematic format for a large number of patients.

The mission of the WCHN Lyme disease registry is to create a comprehensive database of patients with Lyme disease that will serve as the basis for multidisciplinary research leading to a better understanding of:

- The course of the disease and how people are affected;
- Causes of persistent symptoms; and
- Improved diagnosis and treatment.

Through our interviews we have met and heard the painful stories of people whose lives were devastated by this disease. We have heard how chronic Lyme disease has dramatically weakened people's health. This physical damage combined with the feelings of helplessness leave the lives of patients and their families in turmoil. Despite these examples, those of us working with the Registry find ourselves walking a very fine line, even in the use of terminology regarding the long-term ef-

fects of Lyme disease. For example, if we use the term chronic Lyme disease, we become discredited by many physicians. If we use the term post-Lyme syndrome we are discredited by the community that has been personally impacted. Based on our interactions with many patients, we believe that there is a protracted clinical course for many people following Lyme disease, but the controversy surrounding these long-term symptoms has created tension between patients and providers that can be polarizing.

The Registry staff work hard to stay focused on the goal of conducting meaningful and high quality research. Our research plans to date have been shaped by the impact of several community task forces in our area, specifically those in Brookfield, CT and through the regional HVCEO's Lyme Task Force that focus on this disease in conjunction with public health professionals. For inclusion in the Lyme disease registry, we do not require that patients have a diagnosis following the existing CDC criteria. We currently have about 180 patients enrolled, but we continue to recruit people over the age of 5 years of age who have had Lyme disease diagnosed by a healthcare provider (contact us at lyme.registry@wcthn.org).

We have been working to uncover information that will help us understand whether the protracted course of Lyme disease is homogenous or heterogeneous. That is, does Lyme disease have a consistent or variable clinical presentation? Specifically, we are working to understand whether protracted symptoms may be caused by: (1) the genotype of the bacteria (or the tick); (2) the genotype of the host (the person); or (3) a combination of the two.

The CDC acknowledges the true number of human Lyme disease cases may actually be 6–12 times higher than number of reported cases. This underreporting is due, in part, to the limitations in our ability to diagnosis the disease. At the Registry, we are working on a new approach to Lyme diagnosis. The patented technology we are testing is potentially more sensitive than currently available blood tests. This test might be especially useful for detecting Lyme spirochetes in patients with lingering symptoms that are unresponsive to antibiotic treatment. Our work has been conducted at the Western Connecticut Health Network Biomedical Research Institute which provides the basic science platform needed to conduct our studies, in conjunction with the Department of Pathology at Danbury Hospital.

Thus, we have the infrastructure needed, but for the registry to be most successful, we need to increase our enrollment and secure additional funding. We are currently collaborating with the CDC on ways to maximize the potential of the registry and we ask that the Tick-Borne Diseases Advisory Committee consider the Western Connecticut Health Network Lyme Disease Registry as a resource to support its work going forward.

We have had the distinct pleasure of touring Senator Blumenthal through our Lyme disease registry and would like to thank him and other legislators here today for their commitment and ongoing dedication to this cause and will end with the following recommendations:

- We support the creation of a Tick-Borne Diseases Advisory committee and strongly recommend that patients and their families be represented on the committee. Such a committee would bring a strong and united voice to the cause.
- One of the provisions in the proposed bill is the creation of a Registry. We offer our registry to serve as a resource to the Advisory Panel as they synthesize existing evidence and create new ideas for study.
- Funding for community-based participatory research projects focused on Lyme disease should be included in Federal research initiatives. While the support of Danbury Hospital and the community has been generous, our work has moved slowly due to limited funding. Public funding for this type of community-based participatory research is desperately needed to move innovative research forward.

In closing, we offer the knowledge and experience of our professional team to participate on the Tick-Borne Diseases Advisory Committee and/or associated work groups to further prevention, research and treatment of Lyme disease.

ENDNOTES

1. ACT Department of Public Health Lyme Statistics—Available at: <http://ct.gov/dph/cup/view.asp?a=3136&Q=399694&dphPNavCtr=46973#46999>.
2. CDC. (2004). Lyme disease—United States, 2001–2002. *MMWR*, 53:365–9. Available at: <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5317a4.htm>.

Senator BLUMENTHAL. Thank you.

[Applause.]

Thank you, each of you, for your testimony. And I can tell you I read each of your testimonies last night, and I'm going to have

it made part of the record, your written testimony, as well as what you've just said.

I want to begin my questioning with you, Dr. Stafford, to talk a little bit about the escalating incidence of this disease. The word, escalating, actually, I have taken from Dr. Katz's testimony. He uses that word to describe what he's also mentioned is now a disease of epidemic proportions. And yet it is a relatively recent, or recently discovered disease.

I wonder if you can tell us whether you think it has existed for a long time. I know the bacterium has been found in some remains of early man, and yet the symptoms or the disease itself has been relatively recently discovered just maybe 30 or 40 years ago. Maybe you could talk a little bit about that.

Mr. STAFFORD. Well, Lyme disease—you know, the first case in Europe that was actually described was in 1909 in Sweden. And, obviously, Dr. Katz just referenced the ice man, who was found to have been infected with the Lyme disease organism over 5,000 years ago. And, actually, some tick specimens in Europe dating from the 1800s were found positive.

So Lyme disease has been around for a long time, and it was just this unique cluster of cases in Lyme that basically brought attention to this disease as a distinct clinical entity. And it lies in the past. I mean, it's very possible that the Native Americans and the early colonists may have suffered from Lyme disease.

You know, during our early history, the forests were essentially cleared for agriculture. The deer were hunted out. The tick largely disappeared. There was actually a Swedish naturalist named Peter Kalm who kept a journal of his travels through the 1750s in parts of New England. And he noticed back then how bad the ticks were. In the late 1800s, you couldn't find any ticks—no habitat, no host, no ticks.

They survived on isolated refuges in the islands off New England. There was a separate population that survived in the upper Midwest. So with reforestation and conditions being right, the tick began expanding its range, cases started being recognized, and the tick has been expanding every since.

This northern population of the tick has been heading south. It's now well into Virginia. You know, *Ixodes scapularis* is found throughout the whole eastern United States, but there are some distinct characters to this. This tick has high infection rates. It's carrying a spirochete that is, I guess, what you could call virulent in the sense that it readily causes human disease, and it continues to expand. How far it will go is unclear.

Senator BLUMENTHAL. So it is expanding across the country.

Mr. STAFFORD. It's expanding in the Midwest and New England. There aren't that many cases yet in the South. The dynamics there are a little different, and it's unclear. It's transmitted by a related tick out on the Pacific Coast. It's up in Canada. So what the full extent eventually will be and how many more people will be subject to getting Lyme disease is a little unclear, but it continues to expand.

In fact, anecdotally, I hear that a lot of veterinarians even more and more are picking up positives on their dogs down through Virginia and some of the southern States. And, ironically, in some of

the early years when Lyme was first expanding here in New England, one of the early detection techniques was canine serosurveys, because dogs pick up ticks. So the first indicators that become infected are dogs. So that's kind of a suggestion that there is still yet a leading edge perhaps in the expansion that is not yet reflected in human cases.

Senator BLUMENTHAL. To what extent do you think that climate disruption, the warming trends that have become more noticeable, contribute to the spread of the ticks and the disease?

Mr. STAFFORD. Well, with climate change, there are some issues there. The tick has, of course, been moving steadily north, and so we'll see expansion up in that direction. And it could have some impact on the disease only in the sense that we're not clear what it's going to do to the small mammal population and food resources for those animals. Remember, this is tied in—the presence of the tick is tied into the abundance of these animals, but it does come in cycles.

Dr. KATZ. And in a warm winter, we don't have a break. We don't have the freezing of the ticks. There are infections throughout the year.

Mr. STAFFORD. The adult ticks do survive through the winter, regardless. But, obviously, during warm days, they'll continue to be active, and that puts more and more people at risk. Nevertheless, the majority of people get Lyme disease in the summer months when the smaller nymph stage is active. It's very small, hard to detect. You heard Mark say earlier he never noticed a tick that bit him. And that is actually true of many people that actually come down with Lyme disease.

Senator BLUMENTHAL. Do you think that habitat control measures are a viable solution here? I remember seeing over the years various different kinds of contraptions that were supposed to give the deer food and at the same time destroy the ticks on the deer. Are any of these kinds of habitat controls really promising?

Mr. STAFFORD. Some of them are promising to the extent—we believe that, roughly, about three-quarters of people pick up the tick and acquire Lyme disease in their own residences. You can get it camping. You can get it hiking or some other place. But, the highest risk is actually right around the home. And so a lot of the research is focused on reducing the risk in that area.

We did find that treating deer—this approach—I'm not sure how practical on a wide scale it would be. But those 4-Posters where we were treating the deer in the town of Old Lyme, we actually had a statistical reduction in Lyme disease cases. So I think, more than anything else, it just points out the important dynamics of these hosts in keeping this disease going.

Senator BLUMENTHAL. Is there enough education of the general population to make them aware of preventive steps they can take, whether in terms of clothing or insect repellent, and also of the medical community as to their awareness of what the symptoms may be and what they should be looking for in the patients who come to them with symptoms? Those are two separate areas, and I'm going to ask Dr. Katz the same question, vis-à-vis, the medical community. But maybe you can begin with the question.

Mr. STAFFORD. Well, Senator, the CDC actually funded a number of local health department outreach activities. I know there are some here in the audience that were familiar with those. There were a lot of materials produced and a lot of outreach, and active surveillance was instituted as part of those.

Actually, the irony is that as we increased our educational efforts, the Lyme disease numbers went up, not down, because as more people became aware and we instituted active surveillance as part of those programs, more and more of the cases were actually detected. Although the goal was to try to reduce Lyme disease, we actually ended up detecting more of the cases that were there. So there were a lot of—

Senator BLUMENTHAL. You need to know what the dimensions of the problem are to fight it.

Mr. STAFFORD. To fight it, right. In other words, the baseline went up as a part of our educational outreach. And so there were a lot of people who became quite familiar with the techniques. There was one study that was done that showed that, statistically, in a case control study, the most effective method was actually tick checks and removing infected ticks before they have a chance to transmit. It was one statistical thing that really came up as having a significant impact on getting or not getting Lyme disease.

I'll just make one aside. As far as the education of the medical community goes, obviously, I think in their schooling they don't get much in the way of entomological training. And we do receive for testing at the Experiment Station a lot of ticks, but we also receive a lot of things that are not ticks for testing. So, in that regard, yes, there could be some more additional outreach to the medical community in terms of just simply recognizing tick bites and what a tick is and the risk a patient would have of actually coming down with the disease.

Senator BLUMENTHAL. You know, I'm not a scientist, and I'm not a doctor. I'm not a researcher. So I am not equipped professionally to draw conclusions about chronic Lyme or post-treatment Lyme, whatever the labels are that are given to them. But, first of all, I want to thank each of you for being here, because the scientific expertise that you bring to the subject is immensely valuable. I think it gives credibility to people who continue to suffer after they receive some treatment, and we know that there is a population of people who continue to suffer.

So I wonder, Dr. Katz, if you could comment on this educational factor, the potential need to create more awareness among the medical community as to what the continuing symptoms may be and their causes and what to do to treat them. Is there more that the Federal Government can do to create that awareness and education?

Dr. KATZ. I think that it will be hard to change education when the majority of the medical community follows a hard line of IDSA guidelines—you know, 30 days or 2 or 3 weeks of antibiotics. And in spite of the fact that there are some glimmers of hope here and there of describing a chronic illness, which is derived from Lyme disease, it's not yet a mainstream medical fact, which it should be.

And I think that, unfortunately, this animosity that began 10 years ago, 15 years ago, should end, because with all strict IDSA

doctors, you will find some stories that when it comes to their own family members, they will give more antibiotics than 3 weeks. There should be some flexibility, and if the patient is still having active symptoms at the end of the 3 weeks, they should get more treatment, because these are the ones that——

[Applause.]

Dr. KATZ [continuing]. This is the chance of getting them better. And I've seen many, many patients that came to see me after they were done with their primary care physician, with the 30 days, and 2 weeks later, they're having a recurrence of symptoms and bad symptoms, and they were given another course—science cannot be strict. It's not a mathematics of binaric zero or one, yes or no. There are exceptions to the rule, and there should be some flexibility. So that would be the first thing there should be a consensus on and education that would follow.

And the other should be this enormous public health issue of post-infectious or post-treatment. These are most likely autoimmune syndromes, which are, once again, prevalent. And based on my calculations—and they are not really extreme—about half a million Americans are chronically ill today after they have been infected with Lyme. So we need to open the door for this entity and to include it into the curriculum and education.

Senator BLUMENTHAL. Dr. Petrini, do you have any comments on that issue?

Ms. PETRINI. You know, obviously, this is not my area of expertise at all. But I can tell you one of the things just associated with a registry, one of the things I love most about it, is the sort of contagious impact that it has. And so one opportunity that is also available in addition to formal training are residency programs as well as medical education rotations. And to the extent that we can expose our residents before they become independent practitioners to the varying options out there, I think we can at least increase their awareness about alternatives. So I would add that.

Senator BLUMENTHAL. When you collect information for your Registry, do you distinguish between, say, chronic Lyme and short-term Lyme? Do you make distinctions based on time or efficacy of treatment?

Ms. PETRINI. No. The only criteria we have is that you're over 5 years of age and that you have had a diagnosis of Lyme disease by a healthcare provider. Now, I know that's limiting in some ways, as we've heard this morning, for people who have never had a diagnosis. We don't require serology. We will accept clinical presentation of the disease in some way. So, therefore, if we receive that documentation from a healthcare provider in some way—it just can't be self-diagnosed.

Given that it's a registry, we need to follow some protocol. We do not, though, stick to strict adherence to the CDC criteria. We heard very clearly about that as we were forming the Registry, that that would be very limiting. And so we've opened it up and are including, again, both acute infection and chronic infection in the Registry. And that we are including acute as well, I think it would be a very good comparison over time as we're able to look at the serology. So the answer is no.

Dr. KATZ. That would enable in the future to divide the different subpopulations.

Ms. PETRINI. The thing about a database, obviously, is you can stratify based on different presentations. So we felt like that was actually very flexible as, hopefully, more knowledge comes to us about the disease and we can then look at specific profiles that we can compare. So the database allows that flexibility with growing knowledge.

Senator BLUMENTHAL. In your view, what can be done to increase the reporting, the reliability and the completeness of reporting?

Ms. PETRINI. Dr. Stafford is probably the expert here. But it becomes an issue of, as I've heard, competing priorities. And so this has, obviously, been a disease that people take for granted as a problem in the area. We continue to collect data, but as we know, we continue to say it's underreported. The truth is, I think, at the public health level, it just becomes an issue of competing priorities, and this one hasn't necessarily risen.

Senator BLUMENTHAL. Do you talk to doctors? Do you talk to public health departments about this issue of underreporting?

Ms. PETRINI. To the extent that we can. We're really focused on the research. We try to stay very focused on the research. That's our goal. Our goal is to try to find some answers. Certainly, we do promote awareness of the Registry. Given the fact that the data are not available elsewhere, there was a need to create the Registry since it didn't exist. So I think in some ways, that's a message as well that there is a need for this, because it's not collected elsewhere.

Dr. KATZ. There should be a financial incentive, like a co-pay, \$20 for doing the paperwork. I'm sure it will improve reporting.

Senator BLUMENTHAL. Dr. Stafford, do you think the disagreement within the medical community inhibits the work to prevent Lyme disease? We've seen how it can sometimes impede treatment or insurance coverage. Do you think it also—the division of opinion—impedes the preventive steps?

Mr. STAFFORD. Well, I think this whole issue that the community has wrestled with—chronic or post-Lyme syndrome, and the patients that have obvious illness, and that it's hard to pinpoint exactly what it is or what stage it's at—has focused a lot of resources and attention on this whole diagnosis and treatment issue. Consequently, quite frankly, prevention often takes a back step because of that issue and the focus that has been on it.

And like other diseases, whether you're talking about heart disease or anything else, a lot of effort is made on prevention. But at the same time, a lot of resources are put into diagnosis and treatment after the person has the disease, as opposed to preventing it to begin with.

Ms. PETRINI. I would say it's stifling in many ways. As someone who, prior to coming to Danbury Hospital, didn't understand much about this disease, I was quickly educated by many. I still don't consider myself an expert, but I'm learning continuously. I was very surprised at how little we knew about this disease. I was really surprised. Maybe I shouldn't have been, but I was. I believe that because of the public discourse and because there isn't this sort of

open communication because of the stifling nature of this, I think it's really been prohibitive in many ways—probably hard to measure.

Senator BLUMENTHAL. We talked a little bit about the co-infection issue. Does that impede reporting, do you think, in other words, the possibility that there may be different variations of tick-borne diseases?

Ms. PETRINI. It's incredibly important to do this, so I'm really not sure about the extent that it impacts underreporting. We know that they are all underreported. But it's really important to not only have this big focus on Lyme disease, obviously, and I really congratulate you for opening it up to all tick-borne diseases. But, certainly, from a research perspective, we don't fully understand that impact of co-infections and whether or not that may distinguish between someone's course and whether it's protracted or not.

Senator BLUMENTHAL. Dr. Katz.

Dr. KATZ. I don't think that co-infections are interfering with the reporting, because they are harder to diagnose. For example, early cures—or acute disease people end up in the emergency room or they don't have clinical—but Babesia and Lyme are getting so close together now in the ticks that I believe that there are no misses because of diagnosis of co-infection. I think that there might be misses in the diagnosis of Lyme because of co-infection that changes the clinical course or the response to antibiotics, but not as far as reporting.

Senator BLUMENTHAL. Do you think, Dr. Katz, and all of you, that doctors who treat Lyme disease need more support in the sense of protection for their professional activities? I know there was a time when some of them contacted my office and said that they felt that some of the professional groups within their State were hostile to what they were doing. Is that a continuing problem?

Dr. KATZ. Well, I think it's a continuing problem. You know, one needs to be very cautious, and there is no room for any mistake, because if you make a minor mistake unrelated to tick-borne diseases, they will use this opportunity to get you off the map. I've had complaints from physicians in other States, hostile States, that were unbiased.

But I think Connecticut has been relatively—I didn't see any vendetta, as far as I'm concerned. People know me in Connecticut and I know them, and I didn't feel any hostile atmosphere, per se. But in other States, it could be different.

Senator BLUMENTHAL. And, finally, let me ask each of you: Are we making progress? You know, are we making any strides in combating and fighting this disease?

Dr. Stafford.

Mr. STAFFORD. Well, I think the research community has done a lot of work, and I think a lot of progress has been made. But yet at the same time, the Lyme disease numbers continue to move on. So, in that sense, no, we have not made enough progress.

Senator BLUMENTHAL. Because the numbers are increasing.

Mr. STAFFORD. The numbers are increasing. They do cycle. For example, in the past couple of years, the Lyme numbers have been down, and that's just simply the dynamics of the tick population that varies from year to year. But that steady path has been up

and probably will continue to go up despite the little minor annual fluctuations. But, yes, I think it's going to continue going, despite all the work that we've done, and we're just going to have to keep working at it to try to reverse that trend.

Some of the projects that have been funded—the purpose for that education outreach was with that kind of goal in mind. Lyme disease is a very complex disease. Since it's a vector-borne disease, it's out there in the wild. It makes it much more difficult to address. You're dealing with controversial issues ranging from the use of insecticides to deer management and control, which often gets a lot of opposition.

Just for example, we do know, at least, a few communities have had the luxury of completely eliminating the deer or reducing the deer in their community substantially, and the tick numbers and Lyme disease cases have either disappeared or dropped substantially. But that's something that may not be practical—it's one of the things I'd like to address—in most settings. Those were in geographically isolated sites like peninsulas or islands or something like that. It remains yet unknown whether it's an approach that can be even used in other communities, and it's something that we need to explore. But I would agree.

Dr. KATZ. I think that we have made some progress as far as understanding the nature of the illness and the nature of the chronic illness. As I mentioned, in some recent publications, there is initial dialog with the two groups, the two camps, which I think is progress. I feel that the scientific work is moving forward, and we have a better definition of some of the syndromes.

Senator BLUMENTHAL. Dr. Petrini.

Ms. PETRINI. As a lonely epidemiologist, I would say that when you have a disease and when you're talking about the persistent symptoms, when you don't have a clear case definition that is consistent from study to study, then you're really at the beginning of understanding what this is all about. And this is one of the things that we've—again, the strength of having a database is that you're able to look at different profiles.

But when you don't have an actual case definition of what you're talking about, really starting from scratch—we understand the symptoms—then you're really at the infancy of the research. And that's where I feel we are right now. So I'm feeling positive that there's some momentum here.

Senator BLUMENTHAL. Well, what I take from what each of you and what others have said this morning is there really is a role for more research, more development of tools to combat this disease, particularly diagnostic tools, to better find the disease before it engages with the human body, whether the diagnosis can be improved in the short-term. Certainly, I think the Federal Government can help to support that research through the resources it has, the NIH, the CDC.

I'm very hopeful that the measure that I proposed and that Senator Gillibrand has co-sponsored and others around the country—it is a bipartisan coalition. And in some of those States where it is spreading, there is an increased awareness for the need that we have to have better diagnostic tools. The advisory committee giving patients and victims a seat at the table, giving them a voice to be

heard, I think will help to increase awareness in the medical community.

But I think there's also the need to somehow bring the medical community together, because, again, I'm not a scientist, not a doctor, but the need for a common strategy is so striking here. The insurance companies, from what I've understood and heard here today, continue to be a problem, a problem in the sense that they are still resistant to providing coverage in many instances. And the legislation doesn't immediately address that issue, but it will, in terms of creating better diagnostic tools, which, in turn, could lead to better insurance coverage.

I think the collaboration between researchers, physicians, and prevention experts can be enhanced. And this hearing, I think, should be regarded as just the beginning of a more public approach to this problem on the part of officials who have a public responsibility to address this disease and its effects on our society, not just in the suffering and the loss of human productivity that we've heard, but also the cost in medical treatment and lost work hours and lost talents and skills.

So I think there is clearly a need to do more. And I can say that this hearing has certainly given me more evidence that I will need with my colleagues, and I know Senator Gillibrand will continue to be an ally in this effort.

I want to thank everyone who has come here today. Each of you have made a statement by being here. Each of you have sent a message. And I haven't seen this room as packed as it has been here. Speaking of the room, I want to thank UConn for loaning us this facility to use today.

And, finally, on behalf of the Senate committee, I invite you to submit additional comments.

Dr. Katz, the appendix that you attached is very, very useful in summarizing some of the findings, some of the diagnostic methods and so forth. And all of this testimony will be available on our Web site, my Senate Web site, after the hearing for public viewing for anyone who wants to go back and examine any of it.

So, again, my thanks to each of you. I hope that we will do this again in another part of the State, perhaps in another part of the country, because I think that this better reporting, better awareness, better education is a critical task that lies ahead.

And with that, I'm going to close the hearing. My thanks to everyone. This hearing is adjourned. Thank you.

[Additional material follows.]

ADDITIONAL MATERIAL

PREPARED STATEMENT OF KRIS NEWBY

CDC Allows Commercial Group to Set Lyme Disease Policy and Funding Without Transparency or Oversight

In early 2005, leaders of a commercial medical society formed an ad hoc group of 26 members whose initial aim was to discredit and remove a competitive set of Lyme disease treatment guidelines from the National Guidelines Clearing House.

This “Ad Hoc International Lyme Disease Group” convened during government-funded, closed-door meetings and had members who were researchers with significant commercial interests in Lyme disease tests and vaccines; CDC and NIH government officials; and foreign nationals. This group set Lyme disease policy and a national research agenda without public oversight or transparency, and subsequently, a large percentage of government grants were awarded to its own members. Part of the group’s stated mission was to run a covert “disinformation war” to ruin the reputations of the patients, physicians, and journalists who questioned the group’s research and motives.

These findings, and more, were recently revealed through a Freedom of Information Act request filed by the producers of UNDER OUR SKIN, a documentary about the politics and commercial interests surrounding Lyme disease. The Centers for Disease Control (CDC) took almost 5 years to fulfill this request, which included 1,400 pages of emails sent between the CDC, the NIH, and authors of the Infectious Diseases Society of America’s Lyme disease guidelines.

A number of improprieties were revealed in the CDC and NIH emails released in the FOIA request, including evidence that Ad Hoc International Lyme Disease Group members:

(1) Disproportionately received about a third of all Lyme-disease related government grants, at the same time several CDC and NIH employees associated with Lyme disease research were members of the Ad Hoc group. Since 1991, just 5 Ad Hoc group-affiliated organizations received more than \$88 million in government research grants.

(2) Allowed a researcher who owns a company that markets Lyme disease tests and vaccines to organize a CDC–NIH-sponsored meeting where Lyme disease government funding strategies were being determined. Shortly after he organized this meeting, his company’s government grant total approximately doubled, to over \$2M per year.

(3) Used their government positions to try to remove a competing medical society’s Lyme disease studies and guidelines.

(4) An NIH employee used his government credentials to orchestrate a “disinformation war,” through anonymous tips, blogs and press leaks, against physicians and researchers who seek to publish scientific findings that contradict those of the IDSA guidelines authors.

(5) Used their government titles and positions to block patient-backed Lyme disease legislation.

In summary, these newly disclosed emails show that the Ad Hoc International Lyme Disease Group, which is enabled by employees of the CDC and the NIH, has been operating outside of government regulations on transparency and public accountability for years. It appears to be steering millions of dollars of grants to group members, and it covertly has been trying to tarnish the reputations of patients, researchers and journalists who disagree with them, using their improper relationships with government employees.

I urge Congress to further investigate this matter so that scientific research on Lyme disease can proceed without the undue influence of commercial interests.

1. Ad Hoc International Lyme Group Members

Overlapping Members	IDSA 2006 Lyme Guidelines	Ad Hoc Int'l Lyme Group
Wormser GP	Lead author	Lead author
Dattwyler RJ	Author	Member
Nadelman RB	Author	Member
Fish D	Author	Member
Shapiro ED	Author	Member
Bockenstedt LK	Author	Member

Overlapping Members	IDSA 2006 Lyme Guidelines	Ad Hoc Int'l Lyme Group
Krause PJ	Author	Member
Steere AC	Author	Member
Halperin JJ	Author	Member
Klempner MS	Author	Member
Bakken JS	Author	Member
Dumler JS	Author	Member
Stanek	Author	
Strle	Author	
Guidelines consultants:		
Fingerle V (Slovenia)	Consultant	
Wilske B (Germany)	Consultant	
O'Connell S (UK)	Consultant	Member
Agger WA		Member
Aguero-Rosenfeld M	Consultant	
Artsob H (Canada)		Member
Auwarter P		Member
Baker, P (NIH)	(unofficial reviewer)	Member
Barthold B	Consultant	
Draper T		Member
Dumler JS	Consultant	Member
Feder HM Jr		Member
Gerber M	Consultant	
Green J	Consultant	Member
Johnson BJ (CDC)	Consultant	Member
Kaplan R	Consultant	
Lee J	Consultant	
McSweeney E		Member
Mead P (CDC)		Member
Morshed M (Canada)	Consultant	Member
Munoz J	Consultant	Member
Natelson BH	Consultant	
Nowakowski J	Consultant	
Philipp M	Consultant	
Piesman JF	Consultant	
Porwancher R		Member
Radolf JD		Member
Schwartz I		Member
Sigal L	Consultant	
Smith RP Jr		Member
Sood S		Member
Weinstein A	Consultant	Member
Wong SJ		Member
Zemel L	Consultant	Member

Grants to Idsa Lyme Guidelines Authors' Universities

U.S. gov't grants for tick-borne disease research 1991–June 2012

To Author's Univ.	Gov't Grants \$
NYMC	19,152,802
Wormser	
Dattwyler	
Nadelman	
YALE UNIV.	30,723,519
Fish	
Shapiro	
Bockenstedt	
Krause	
HARVARD/MASS GENERAL	4,654,229
Steere	
ATLANTIC HEALTH SYSTEMS	
Halperin	

U.S. gov't grants for tick-borne disease research 1991–June 2012—Continued

To Author's Univ.	Gov't Grants \$
BOSTON UNIV/NEMC	25,375,887
Klempner/Steere	1,774,026
UNIV. of MINN.	6,388,077
Bakken	
EUROPEAN UNIV.'s	
Stanek	
Strle	
Total	88,068,540
TOTAL LYME GRANTS	\$292,453,171
DIDSA TOTAL	30.11 percent

Source: <http://taggs.hhs.gov>.

2. Grants to Dattwyler-Affiliated Companies by Year

Dattwyler organized the CDC- and NIH-funded meeting on “Laboratory Diagnosis of Lyme Disease in 2007,” the same year his grant awards double.

Dattwyler is a founder and part-owner of **Biopeptides**, and holds a patent for a “multi-peptide assay for serodiagnosis of Lyme disease. This company markets Lyme-related wildlife & human vaccines and diagnostics kits.

1995: \$99,840
 1997: \$324,790
 1998: \$406,653
 1999: \$111,634
 2000: \$428,750
 2001: \$426,046
 2002: \$143,157
 2003: \$0
 2004: \$147,863
 2005: \$1,253,238
 2006: \$1,219,531
 2007: \$1,560,960
 2008: \$2,454,581
 2009: \$2,067,523
 2010: \$2,134,294
 2011: \$2,659,069

Source: <http://taggs.hhs.gov>.

3. PHIL BAKER, NIH LYME DISEASE PROGRAM OFFICER

“I am now more convinced than ever that pulling the ILADS guidelines is the only solution to this problem.”

Source: CDC NIH FOIA Highlights, page 17.

Credit: A sincere thanks to Lorraine Johnson for condensing 1,400 pages of emails into 40 of the most important ones.

4. EDWARD MCSWEEGAN, NIH, SUGGESTS THAT ROBERT ARONOWITZ OF UPENN WRITE AN ARTICLE ON THE POLITICS OF LYME DISEASE

Quote: **“Anyone know of any academic sociologists or historians interested in doing a paper on the politics of Lyme disease? Maybe Robert Aronowitz at UPenn?”**

Source: 002–Ad Hoc Plants Lyme Politics Article.png.

5. FEBRUARY 2007—EDWARD MCSWEEGAN, AN NIH EMPLOYEE WHO WAS DEMOTED FOR HARASSING AND STALKING LYME DISEASE ADVOCATES, DECLARES WAR ON LYME PATIENTS AND JOINS THE IDSA–CDC-LED AD HOC INTERNATIONAL LYME DISEASE GROUP

“If outer space is the military’s ultimate “high ground,” then cyberspace is the high ground in an information war. And what we have here is a war. Actually a

disinformation war. An insurgency against evidence-based medicine. It's time to start shooting back.

. . . Personally, I have been thinking that it might be useful to have a limited access Web site containing material to facilitate quick responses to reporters' questions and to facilitate the drafting of letters to legislators and editors."

Source: CDC NIH FOIA Highlights, page 12–13.

6. **March 2008**—CDC's Barbara Johnson works with NIH's Edward McSweeney and IDSA Lyme guidelines authors to lobby against a Lyme disease patient protection bill.

Subject: Maryland; Lyme Public Awareness Bill (HB 836).

Anyone have any contacts in the Maryland Dept. of Health who would be interested in knowing about this Maryland bill and the efforts of activists to kill it?—Ed

Ed,

This is the contact information for the State epidemiologist. Paul, is this current? If not, please send us both a link to the list of all the State epis.—Barbara"

Source: CDC–NIH–War–Emails–9–11–2.

LYMEDISEASE.ORG,
September 13, 2012.

A Federal Failure in Lyme Research, Guidelines, and Accountability: CDC and NIH Allow Private Interests of the IDSA to Set Federal Agenda in Lyme Research and Dictate Lyme Policy without Oversight

Submitted by Lymedisease.org (formerly the California Lyme Disease Association) on behalf of patients across the United States.

INTRODUCTION

The government has an obligation to represent the interests of the public, to act impartially in an open and transparent manner, and to be accountable for its actions. Disturbing new facts obtained in a Freedom of Information Request filed by Kris Newby, the investigative reporter who produced *Under Our Skin*, reveal that an ad hoc group composed of members of the Infectious Diseases Society of America (IDSA), a medical specialty society, along with members of the Centers for Disease Control & Prevention (CDC) and the National Institutes of Health (NIH), has been acting in violation of fundamental principles of ethics. This group has been covertly setting government Lyme policy, intentionally excluding other stakeholders, running afoul of government open meeting standards, and deliberately subordinating the public interests to those of a private medical society. The group's actions have resulted in implementation of faulty public health policymaking and have damaged Lyme patients throughout the nation who suffer from severely restricted access to care as a result of these policies. Their actions have also resulted in favoritism in Federal grant funding and suppression of the innovation critically needed by Lyme patients for improved diagnostic and treatment options. These acts of commission and omission represent serious breaches of the public trust and undermine the integrity of the scientific research agenda. The CDC and NIH have essentially abdicated their healthcare policy determinations to a Quasi-Governmental Lyme Organization, dominated by a private medical society with no government accountability or oversight.

BACKGROUND

According to copies of emails released pursuant to a FOIA request (Newby 2012), a rogue group of IDSA researchers and government officials formed an ad hoc organization in 2005, shortly after a meeting of members of the U.S. Department of Health and Human Services, the Public Health Service, CDC, and the National Center for Infectious Diseases/Board of Scientific Counselors (NCID BSC) held on May 12 and 13, 2005 in Atlanta, GA. (NCID BSC Minutes.) According to minutes of the NCID BSC meeting, the group was attended by 31 CDC/NCID staff members (12 of whom were IDSA members), 10 BSC members (6 of whom were IDSA members), 4 ex-officio members (3 of whom were IDSA members) and 3 Liaison Representatives (1 of whom was an IDSA member). Notable among the attendees were Lyle Peterson, director of the Division of Vector-borne Infectious Diseases (DVBID) and IDSA president Walter Stamm, who raised an alarm about a competitor organiza-

tion, the International Lyme and Associated Diseases Society (ILADS), whose Lyme guidelines had just been listed on the National Guidelines Clearinghouse. This government meeting then determined that “CDC researchers should focus on science and not on the concerns of patient groups; other groups may need to step in and assist DVBID with public interface.” Action items from NCID BSC meeting included updating IDSA guidelines, updating CDC guidelines for interpreting laboratory tests, and notifying physicians and other practitioners regarding availability of clinical and laboratory documents.

That same month a private conference chaired by Dr. Gary Wormser (who also chaired the IDSA Lyme guidelines) was held at Westchester County Medical Center. According to one member, Dr. Susan O’Connell, the goal of the group was to “counteract misinformation from groups such as ILADS, unorthodox laboratories and support groups.” At the meeting a “work plan” was established that included a mixture of private interest and public policy issues:

- Updating IDSA guidelines (Wormser 2006).
 - Critical appraisal of ILADS guidelines (Phil Baker NGC & Susan O’Connell’s “Independent Appraisal and Review of ILADS 2004 “Evidence-based guidelines for the management of Lyme disease”).
 - Critical appraisal of chronic Lyme disease (NEJM article) (Feder 2007).
 - Facts and Fiction about Lyme disease.
 - In-house tests commonly at variance with standard diagnostic methods (IGeneX NYDOH investigation; Susan Wong of NYDOH is a member of the group).
 - Research needs.
 - 2nd Banbury conference on serodiagnosis of Lyme disease to be held Sept. 2007
- Surveillance definition modifications.

No public notice was given and the meeting was clandestine. The participant list for the meeting, chaired by Dr. Wormser included principally IDSA researchers and CDC employees: Drs. Zemel, Fish, Bockenstedt, Munoz, Dumler, Steere, Barbara Johnson (CDC), Shapiro, Strle, Stanek, Bakken, Halperin, Klempner, Baker, Krause, Dattwyler, Nadelman, Fingerle, Weinstein, Wilske, McKenna, Mead (CDC), Feder, Artsob, Schwartz, Green, Nowakowski, Aguero-Rosenfeld, Morshed, Auewaeter, Baker, Smith, O’Connell, Sood, Wong (NYDOH), Draper. (See Attachment A to this submission.) Shortly after that meeting IGeneX lab was investigated pursuant to a complaint filed based on concerns with its laboratory interpretation method. (Susan Wong, a member of the group worked for the NYDOH which launched the investigation against IGeneX.) A second clandestine meeting, also chaired by Dr. Wormser, was held on January 15th and 16th, 2007 at Westchester Medical Center.

This group, which subsequently added two members of the NIH, Drs. Phil Baker and Ed McSweeney, to its membership ranks, proceeded to work on IDSA projects and government policy projects regarding Lyme disease.

During the course of the FOIA period, the group:

- Developed and published the IDSA guidelines;
- Secured the listing of the IDSA guidelines on the National Guidelines Clearinghouse;
- Lobbied the National Guidelines Clearinghouse to delist the ILADS guidelines from the site;
- Authored and published an article in the New England Journal of Medicine defending the IDSA guidelines;
- Worked to launch an investigation against a major Lyme disease diagnostic company, IGeneX;
- Orchestrated the Second Banbury conference on serodiagnosis held in September 2007 (Barbara Johnson of the CDC, Dr. Phil Baker of the NIH, and Dr. Ray Dattwyler of the IDSA organized it.); and
- Sought surveillance definition modifications.

Throughout the 2 years of emails circulated among the Quasi-Government Lyme Organization, three things are clear. First, there was no dividing line between the private enterprise interests of the IDSA, a medical society, and those of the public or the government. The anticompetitive agenda of the IDSA Lyme researchers was adopted unquestioningly by the CDC and NIH as their own. Second, neither the CDC nor the NIH exercised impartiality or sought the views of IDSA’s competitors, patients, or the public in making its public policy determinations regarding the IDSA and its competitors. Third, the public and the IDSA’s competitors were excluded from the meetings and communications. The group included government employees who worked to pursue the IDSA’s interests. Specifically, government employees reviewed IDSA guidelines drafts, helped get them listed on the National Guidelines Clearinghouse, worked to delist the guidelines of IDSA competitor

ILADS, reviewed drafts of the NEJM article, referred the NEJM article to the CDC press office to ensure that it was publicized, had the CDC press office request open access publication of the NEJM article from the publisher, and worked with a private IDSA researcher and grant recipient to host a scientific conference that would determine a research agenda and inform funding decisions.

DISCUSSION

Professional medical societies, including the IDSA, serve the economic interests of their members and members in turn sometimes bring their own economic and commercial interests to bear on the actions of their medical societies—for instance, in developing clinical guidelines. These are not entirely new phenomena. More than 20 years ago, Professor P. Kissam, an expert in healthcare antitrust law at the University of Kansas School of Law, described these interests:

Professional societies are organized to promote the economic and professional interest of their members, and their decisions regarding the economic behavior of professionals typically are made by groups of professionals who sit in judgment of their competitors. Further, although professional societies profess to be operated in the public interest, the modern social science analysis of “professionalism” indicates that collective professional decisions regarding economic behavior often are determined by a professional ideology and technology, to say nothing of economic interests that are not so clearly in the public interests. (Kissam 1984.)

In the case of Lyme disease, there are two competing medical paradigms and medical societies. The IDSA supports the view that Lyme disease is hard to catch, easy to cure and that any persistent manifestations in patients after a short treatment of antibiotics are caused by something other than the Lyme bacteria. (Wormser 2006) In their view, patients suffer from no more than the “aches and pains of daily living”. The opposing viewpoint is held by the International Lyme and Associated Diseases Society (ILADS). In ILADS’ view, Lyme disease can be difficult to diagnose and treat, may persist after short-term treatment and require additional treatment, and can severely interfere with the patient’s quality of life. (Cameron 2004) A survey of over 4,500 patients with chronic Lyme disease found that 25 percent had been on disability at some point in their illness. (Johnson et al. 2011) Data from this same survey showed that 60 percent of those who had tried the IDSA short-term treatment protocols had failed to regain their health and 80 percent of patients would not choose to be treated under the IDSA protocols.

Conflicting guidelines are not uncommon. According to the National Guidelines Clearinghouse, 25 other diseases have controverted guidelines and controversy is common when definitive studies are lacking. (Institute of Medicine 2011) Dr. Gordon Guyatt, an expert in evidence-based medicine agrees and describes the problem:

What tends to happen to experts is that they tend to develop strong beliefs and tend to select supporting evidence to back up their beliefs and this is how you have people making absolutely opposite recommendations. . . . Evidence is never enough—it is always evidence in the context of values and preferences that influence guidelines and clinical care. (Guyatt 2011)

The current state of the science in Lyme disease is “science-in-the-making” and acknowledging this provisionality is an *essential* feature of scientific integrity. The majority of IDSA guidelines recommendations generally (Khan et al. 2010; Lee et al. 2011) as well as the majority of the Lyme guidelines recommendations (38 of 71) are based on no more than “expert opinion.” (Johnson & Stricker 2010a). The IDSA misrepresents the current state of the proven science. They state that only “a few” patients remain ill after standard treatment while the true figure is 25 to 50 percent. (Stricker & Johnson 2011) They cite the NIH-funded trials as definitive proof that longer treatments are not effective when few human studies have been conducted—all with contradictory results and limited sample sizes. (Delong et al. 2012). Moreover, a monkey trial has demonstrated persistence of Lyme spirochetes after a treatment regimen modeled on the Klempner human trial. (Embers et al. 2012). Dr. Phil Baker was responsible for overseeing both the Klempner trials and the Embers trial, which was intended to be a fact check on the human trial. Both were funded at roughly the same time, but the Embers trial publication was delayed for 10 years. Dr. Baker was aware that this valuable piece of research had not been completed, yet continued to cite the NIH flawed trials as definitive proof that no further research in Lyme was necessary.

Science is supposed to be *truth generating*, but this can only happen when there is a free market of ideas and when contradictory viewpoints get a fair hearing. Scientific truth suffers when people or institutions within democratic societies “get hold

of some institutional position of power (a scientific journal, a research institute) and impose their favorite “line” of research there, leading to a dead end.” Labinger 2001; pg. 46.)

The impact of these failed government policies and the use of the Quasi-Government Lyme Organization that excluded divergent viewpoints and did so without public accountability or oversight has resulted in what Congressman Smith characterized as the lost decade at a recent congressional hearing that he chaired. A group of researchers who adhere to the IDSA party line are funded; while those who do not are silenced. The gravity of this situation was highlighted in the testimony of Stephen W. Barthold, Ph.D., Distinguished Professor, Department of Pathology, Microbiology and Immunology, Center of Comparative Medicine, School of Veterinary Medicine University of California, Davis at Congressman Smith’s House Hearing on July 17, 2012:

“Because of firmly entrenched opinion within the medical scientific community, evidence of persisting viable but non-cultivable spirochetes is slow to be accepted, and research proposals submitted to NIH that feature persistence following treatment are likely to receive prejudicial peer review in the contentious environment of Lyme disease*. Negative comments by peer reviewers of grant applications in the current financially austere NIH climate result in unfindable scores, if they are scored at all (triaged).” (Barthold 2012)

Dr. Barthold disclosed that in a recent unfunded R01 application, a peer reviewer identified the following as a major weakness:

“The lay public that has so far denied the validity of scientific data will misunderstand the significance of . . . [persisting non-cultivable *Borrelia burgdorferi*] . . . and use it as additional evidence to support the idea of treatment-resistant Lyme disease.”

If research in Lyme disease depends upon whether researchers adhere to the appropriate dogma rather than the pursuit of scientific truth, why bother? Why waste public treasury on trivial research that merely reinforces entrenched dogma? So deep is the culture of entrenched intellectual bias held by the bulk of the Lyme researchers funded by the NIH and CDC, who also sit as peer reviewers for government grant funding, that few speak out. Indeed, Dr Barthold prefaced his remark by acknowledging he had nothing left to lose given his pending retirement and stated:

“There is overwhelming evidence in a variety of animal species as well as humans that *B. burgdorferi* persists without treatment, but the crucial question is does it survive following treatment, and if so, do surviving spirochetes cause “chronic” Lyme Disease or PLDS? These questions cannot be answered by speculative and expensive human clinical trials motivated by firmly held dogmatism.”

Although the goal of peer review is to improve an article or fund more worthy scientific research, Dr. David Kaplan, professor of pathology at Case Western Reserve University states that rejections may occur “*if the reviewer feels that the paper threatens his or her own research or contradicts his or her beliefs*” and that it’s a “*problem that can very quickly become censorship.*” (Akst 2010) Dr. Brian Martin at the University of Wollongong, Australia says: “[A]nonymous peer review can be used to marginalize a challenging theory and, at the same time, the secrecy involved can reduce awareness that anything improper might be involved.” (Martin 2010)

The anonymity of peer review and the abuse of power by Lyme guidelines panel members with intellectual conflicts of interest has suppressed and silenced critical funding for Lyme disease that would address the needs of patients. An editor of a journal which published an article submitted by Dr. Stricker challenging IDSA theories remarked in an email on the aggressive tone of the comments after publication of the article, stating, “[t]his level of polarized debate was unique for our journal and my editor’s experience that spans four decades.”

By engaging in the clandestine activities of the Quasi-Government Lyme Organization, the CDC and NIH have given voice to one view of science and silenced another. The result has been a decade of research promoting the interests of the IDSA researchers and advancing the careers of those who participated in the group, while failing to further our understanding of the diagnosis and treatment of Lyme disease.

In the FOIA email communications, one government official Dr. Baker, refers to patients as “Lyme loonies”. Another government employee, Dr. McSweeney refers to the efforts of the group to suppress divergent points of view as “war”. No matter how you parse it, the profound favoritism demonstrated toward the IDSA, the targeting of the ILADS guidelines, and the attitude displayed toward patient groups is anything but impartial.

The CDC and NIH have an obligation to place the interests of the public above those of a private medical society and an obligation to act impartially. It is a basic obligation of public service. The Standards of Ethical Conduct for Employees provides: "Employees shall act impartially and not give preferential treatment to any private organization or individual." The standards further provide that "Employees shall endeavor to avoid any actions creating the appearance that they are violating the law or the ethical standards set forth in this part." (Standards of Ethical Conduct for Employees of the Executive Branch).

We call upon Congress to investigate and disband the Quasi-Government Lyme Organization. We also call upon Congress to install transparent, impartial, non-exclusionary process in all matters of public policy regarding Lyme disease. Finally, we ask that peer review of grant processes be impartial and not prejudiced or dominated by intellectual bias that suppresses research. This could be done by making sure that patients have a role in establishing the research agenda for Lyme disease and in making sure that patients and other scientific points of view are adequately represented in peer review. Patient Centered Outcomes Research Institute, established under the new healthcare reform, supports patients' full participation in research, including active roles in identifying and selecting research questions; reviewing research proposals for funding; and ensuring patient participation throughout the research process, including on research teams. We call upon the NIH and CDC to implement these practices which are designed to prevent grant programs from being driven by intellectual bias and furthering private interests rather than those of the public.

Respectfully submitted,

LORRAINE JOHNSON, JD, MBA,
Chief Executive Officer.

BIBLIOGRAPHY

- American Academy of Pediatrics (AAP). Classifying recommendations for clinical practice guidelines. *Pediatrics* [serial on the Internet]. 2004; 114(3): Available from: <http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list-uids=15342869>.
- American Medical Association (AMA). Principles of Medical Ethics. Principle VIII. Adopted 1957; revised 1980 and 2001.
- Akst J. I have your paper. *The Scientist Magazine*, August 1, 2010 available at <http://classic.the-scientist.com/?articles.view/articleNo/29962/>.
- Atkins D, Siegel J, Slutsky J. Making policy when the evidence is in dispute. *Health Aff (Millwood)*. 2005 Jan-Feb;24(1):102-13.
- Auwaerter PG, Bakken JS, Dattwyler RJ, Halperin JJ, Nadelman RB, O'Connell S, et al. Lyme disease antiscience ? Authors' reply. *The Lancet Infectious Diseases*. 2012;12(5):362-3.
- Testimony of Dr. Stephan Barthold, "Persistence of Non-Cultivable *Borrelia burgdorferi* Following Antibiotic Treatment: Critical Need for Further Research: "Global Challenges in Diagnosing and Managing Lyme Disease—Closing Knowledge Gaps" House Subcommittee on Africa, Global Health, and Human Rights (July 17, 2012).
- Cameron D, Gaito A, Harris N, Bach G, Bellovin S, Bock K, et al. Evidence-based guidelines for the management of Lyme disease. Expert review of anti-infective therapy. 2004;2(1 Suppl):S1-13.
- Delong AK, Blossom B, Maloney E, Phillips SE. Antibiotic retreatment of Lyme disease in patients with persistent symptoms: A biostatistical review of randomized, placebo-controlled, clinical trials. *Contemp Clin Trials*. 2012 Aug 19.
- Embers ME, Barthold SW, Borda JT, Bowers L, Doyle L, Hodzic E, et al. Persistence of *Borrelia burgdorferi* in Rhesus Macaques following Antibiotic Treatment of Disseminated Infection. *PLoS ONE*. 2012;7(1):e29914.
- Fallon BA. Lyme borreliosis: Neuropsychiatric aspects and neuropathology. *Psychiatric Annals*. 2006;36(2):120-28.
- Feder HM, Jr., Johnson BJ, O'Connell S, Shapiro ED, Steere AC, Wormser GP, et al. A critical appraisal of "chronic Lyme disease". *The New England Journal of Medicine*. 2007 Oct 4;357(14):1422-30.
- Guyatt, G. and Montori, V., EBM debate (March 21, 2011) available at <http://www.youtube.com/watch?v=KjLD5AkDOWs>.
- Infectious Diseases Society of America. Grading the Evidence 2011: Available from: <http://www.idsociety.org/Content.aspx?id=6000#grading>.
- Infectious Diseases Society of America. *Final Report of the Lyme Disease Review Panel of the Infectious Diseases Society of America*. April 22, 2010: Available from: http://www.idsociety.org/Lyme_Final_Report/.

- Johnson L, Aylward A, Stricker RB. Healthcare access and burden of care for patients with Lyme disease: a large United States survey. *Health Policy*. 2011 Sep;102(1):64–71.
- Johnson L, Stricker R. The Infectious Diseases Society of America Lyme guidelines: a cautionary tale about development of clinical practice guidelines. *Philosophy, Ethics, and Humanities in Medicine*. 2010;5(1):9. Available from: <http://www.peh-med.com/content/5/1/9>.
- Johnson L, Stricker RB. Final report of the Lyme disease review panel of the infectious diseases society of america: a pyrrhic victory? *Clin Infect Dis*. Nov 1;51(9):1108–9; author reply 9–1.
- Khan AR, Khan S, Zimmerman V, Baddour LM, Tleyjeh IM. Quality and strength of evidence of the Infectious Diseases Society of America clinical practice guidelines. *Clin Infect Dis*. 2010 Nov 15;51(10):1147–56.
- Kissam P. “Antitrust Boycott Doctrine,” 69 Iowa L. Rev. 1165 (1984).
- Klempner M, Hu L, Evans J, Schmid C, Johnson G, Trevino R, et al. Two controlled trials of antibiotic treatment in patients with persistent symptoms and a history of Lyme disease. *The New England journal of medicine*. 2001 Jul 12;345(2):85–92.
- Labinger J, Collins, H, editor. *The One Culture?: A Conversation about Science*. Chicago: University of Chicago Press; 2001.
- Lee DH, Vilemeyer O. Analysis of Overall Level of Evidence Behind Infectious Diseases Society of America Practice Guidelines. *Archives of internal medicine*. 2011 January 10, 2011;171(1):18–22.
- Maes E, Lecomte P, Ray N. A cost-of-illness study of Lyme disease in the United States. *Clin Ther*. 1998 Sep–Oct; 20(5):993–1008; discussion 992.
- Martin B, How to attack a scientific theory and get away with it (usually): the attempt to destroy an origin-of-AIDS hypothesis, *Science as Culture*, Vol. 19, No. 2, June 2010, pp. 215–39). Available at: <http://www.bmartin.cc/pubs/10sac.html>.
- Sackett D, Straus S, Richardson W, Rosenberg W, Haynes R. *Evidence-based medicine: how to practice and teach EBM*. 2nd ed. Edinburgh: Churchill Livingstone; 2000.
- Sniderman AD, Furberg CD. Why guideline-making requires reform. *Jama*. 2009 Jan 28;301(4):429–31.
- Standards of Ethical Conduct for Employees of the Executive Branch, Subpart A—General Provisions, §2635.101, Basic obligation of public service. (Codified in 5 CFR Part 2635 (1/1/99 Edition), as amended at 64 FR 2421–22 (Jan. 14, 1999) and 64 FR 13063–064 (Mar. 17, 1999)). Available at: <http://www.cdc.gov/maso/facm/pdfs/LAWS/ethicsstandards.pdf>.
- State of Connecticut Attorney General. *Press Release: Attorney General’s Investigation Reveals Flawed Lyme Disease Guidelines Process, IDSA Agrees to Reassess Guidelines, Install Independent Arbiter*. May 1, 2008; Available from: <http://www.ct.gov/AG/cwp/view.asp?a=2795&q=414284>.
- Stricker R, Johnson L. Lyme disease: The next decade. *IDR [serial on the Internet]*. 2011; 2011: Available from: http://www.dovepress.com/articles.php?article_id=6013.
- Tabarrok AT. Assessing the FDA via the Anomaly of Off-Label Drug Prescribing. *The Independent Review*. 2000, Summer Summer 2000;V(1):25–53.
- Newby, Kris, Written Submission of Testimony dated September 11, 2012 regarding results of FOIA request to CDC and NIH on Lyme activities to Congressional Field Hearing dated August 30, 2012, Chaired by Senator Richard Blumenthal.
- World Medical Association, Declaration of Helsinki (adopted 1964; revised 1975, 1983; and 1989). Available at <http://history.nih.gov/about/timelines/helsinki.html>.
- Wormser GP, Dattwyler RJ, Shapiro ED, Halperin JJ, Steere AC, Klempner MS, et al. The clinical assessment, treatment, and prevention of lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by the Infectious Diseases Society of America. *Clin Infect Dis*. 2006 Nov 1;43(9):1089–134.

ATTACHMENT A

Members of Quasi-Governmental Lyme Group

Researchers	Government Employees (NIH, CDC, NYDOH)
Gary Wormser (Invitor)* Larry Zemel* Durland Fish	Paul Mead (CDC)* Barbara Johnson (CDC)*

Members of Quasi-Governmental Lyme Group—Continued

Researchers	Government Employees (NIH, CDC, NYDOH)
Linda Bockenstedt*	Ed McSweegan (NIH)*
Jose Munoz*	Phil Baker (NIH)
Steve Dumlar*	Susan Wong (NYDOH)*
Allen Steer*.	
Eugene Shapiro*.	
France Strle.	
Gerold Stanek.	
Johan Bakkan*.	
John Halperin*.	
Mark Klempner*.	
Peter Krause*.	
Arthur Weinstien*.	
Donna McKenna.	
Hank Feder*.	
Ira Schwartz*.	
Jerry Green.	
John Nowakowski.	
Maria Agüero-Rosenfeld.	
Sunil, Sood*.	
Tom Draper (Med Advisor to city of Danbury & Cochair of the Task Force on Lyme Disease at Danbury).	
Raymond Dattwyler*.	
Robert Nadelman*.	
Volker Fingerle.	
Robert Smith*.	
Susan O'Connell*.	
Paul Auwaerter*.	

Bold members are authors of 2006 IDSA Lyme guidelines. Wormser GP, Dattwyler RJ, Shapiro ED, Halperin JJ, Steere AC, Klempner MS, et al. The clinical assessment, treatment, and prevention of Lyme disease, human granulocytic anaplasmosis, and babesiosis: clinical practice guidelines by the Infectious Diseases Society of America. Clin Infect Dis. 2006 Nov 1;43(9):1089–1134.

Asterisked members are authors of 2007 NEJM article. Feder HM, Jr., Johnson BJ, O'Connell S, Shapiro ED, Steere AC, Wormser GP, et al. A critical appraisal of "chronic Lyme disease". The New England Journal of Medicine. 2007 Oct 4;357(14):1422–30.

LETTERS TO SENATOR BLUMENTHAL

Nothing is more important in the fight against Lyme disease than hearing the voices of those affected. The following was provided by many patients, advocates, and stakeholders, and I am pleased to submit this testimony to the permanent record of the hearing of the Health, Education, Labor, and Pensions Committee, which took place on August 30, 2012, entitled "Lyme Disease: A Comprehensive Approach to an Evolving Threat."—Richard Blumenthal, U.S. Senate.

PAT SMITH, LYME DISEASE ASSOCIATION

SENATOR BLUMENTHAL & U.S. SENATE HELP COMMITTEE MEMBERS: My experiences with Lyme disease began about 27 years ago when, as a board of education member in my NJ township, I witnessed students and staff, in particular from one area of the community, develop a disease called Lyme disease, one which we in the public sector knew nothing about. I got the district to agree to put out information through the schools, after I spent weeks trying to find out what Lyme was and where I could find that information. I finally found what I needed on a local military installation, where some of the first cases of Lyme in NJ had been diagnosed and treated. It was the first time I heard about Juvenile Rheumatoid Arthritis, which had often been the initial diagnosis of the children who were later correctly diagnosed with Lyme.

A few years later, first one then another of my children developed Lyme disease. Fortunately, I was aware of the symptoms of Lyme and when my oldest daughter had symptoms which could be described at best as weird, I sent her to a hospital near her college, where they readily, without fanfare, diagnosed and treated her for Lyme disease. My youngest daughter was not so lucky. Her symptoms were vague and in the intervening years between the onsets of my daughters' health problems, suddenly those who had Lyme became pariahs, and the journey to get my youngest

daughter diagnosed and treated was a nightmare which I liken to a trek through Dante's Inferno, with each downward spiral worse than the previous one.

I had intended to raise my 3 children and reenter the work force when the last had finished elementary school. That was not to be, as my youngest became sick around 10 years old, and remained in the grips of a disease that took her through arthritis, petit mal and grand mal type seizures, temporal lobe type seizures, gastrointestinal problems, back and neck problems, memory loss, mental confusion, tachycardia, brachycardia, panic anxiety attacks, hallucinations, balance problems, eye problems, muscle pain, nerve pain, later morphea sclerodoma and a condition similar to POTS, and blackouts. If you are not familiar with some of those terms, welcome to our Lyme world of the 80s, 90s and later. I was a mother, not a doctor, but soon had to not only argue legally, scientifically and morally for treatments that worked but had to mix and dispense meds through pumps and hang IV drips. I remember worrying at 3 a.m. whether I would kill my daughter, as I carefully tapped air bubbles out of syringes on a "sterile" kitchen table.

The worst of times were the 3-4 years of seizures, where she was out of school, technically on home instruction, although many sessions had to be cancelled. The "episodes" she had were something no mother should have to deal with, and when a doctor finally gave me a name to put with it, I was ecstatic. A name meant the ability to deal with it. Temporal Lobe Seizures, he said. I searched for an expert on temporal lobe seizures in the U.S. and called him up. He was kind enough to listen to what I told him about my daughter, what her Lyme had triggered, what I had done, and when I finished my tale, he said, congratulations, you now know more about temporal lobe seizures than most doctors in the world. I was stunned and did as much research (no Internet then) as I could into what was happening to her, the different manifestations—the times when she spoke with no "affect," the times she spoke like a little girl, the times she just sat and stared for hours on end, the times she screamed for us and did not know we were there, the times she woke up screaming that she had "6" fingers (on one hand), counting them and showing her were useless in those times, there was no rationality during those episodes. I remember the nights I slept on a mattress on the floor beside her bed, so if she woke up in a seizure state, I would be there to calm her from the awful nightmares and assure myself instantly that the bloodcurdling screams were not someone killing her. These seizure states seemed to be controlled by a switch. They turned on, lasted 16 hours or so a day, and turned off. She, fortunately, was left with no memory of what occurred during them, we were not as fortunate. We were all exhausted, and my entire life was spent tied to my daughter and her terrible illness, trying to find people to help save her life. I wore a beeper (no cell phones yet) so my husband could beep me if I ran to the store and something happened. I rarely left home. Once I came back and found she had retreated into the fetal position. That is when I decided that if my daughter survived, I would never let a family go through this alone again. I have tried to keep that promise.

Fast forward to today, where after many years of antibiotic treatment and alternative treatments, my daughter has a life after graduating with honors from a prestigious college (ironically, the doctors associated with that college refuse to treat chronic Lyme patients) and has held corporate jobs in a medically-related field. Does she still have Lyme disease? Yes, I say that not as an "expert," but from the perspective of 121 mother years of experience and 24 grandmother years of experience of dealing with children with and without Lyme.

There is discourse out there from some who call themselves experts who know nothing about Lyme disease, or worse, do know, but are led by vested interest. They claim Lyme patients and their families think everyone has it. Not true. Two of my daughters have Lyme, one doesn't; all four of my granddaughters do not. I want to keep it that way.

Instead of entering the paid workforce, I devoted my life and energies to volunteer to help those afflicted with Lyme and help others avoid Lyme. To that end, I have spoken and/or testified in numerous State capitals across this country and in Washington, DC. I have met with leaders connected to all levels of government and all branches of the Federal Government and met with the military. My 12 years as a board of education member and board president taught me how government should operate, how it does operate, and how to get problems solved. The first issue requires educating people to the problem. I have done that, the next requires lobbying, I have done that—when that fails, it is time to rally those who have the same types of problems—I have done that, and I continue to do all of the above.

It is time now that government recognizes that Lyme has gone from an unknown infectious disease to one which has spread from a few States in the 70s & 80s to all States and to 65 countries throughout the world. It is time to recognize that in 2009, the Centers for Disease Control & Prevention, CDC, said that Lyme surpassed

HIV in incidence in the U.S. It is time to recognize that the testing used for Lyme disease is ancient—while scientists are mapping genomes and using DNA testing, Lyme doctors are forced by government agencies to diagnose by looking for antibodies that may take weeks to develop, if at all, or may not be testable when they do develop.

Patients are caught in the middle of vested interest “experts” who saturate the media with their take on the science of Lyme, shutting down discussion of all the aspects of the science, refusing to partake in any meaningful dialogue with those who hold different opinions based upon science the experts have decided is unworthy. These experts use their influence as medical journal reviewers and also walk the halls in State Capitols and in Washington, DC, and use their significant financial clout to make sure their message is heard and accepted. That leaves us, the patients, the families of patients, who are also advocates, to stand up for the patients who are physically, mentally, emotionally, and financially drained from Lyme disease, to try to get them the help they desperately need. The “experts” have decided that we too, the advocates, are crazy, unknowledgeable, unstable, and they use their bully pulpit to spread those lies with relish, trying to discredit the people in the trenches who are working to help humanity.

You have the ability to help patients and to prevent others from becoming patients. To borrow from a once popular TV series, “the truth is out there.” You need to uncover that truth, wresting it from those who would prevent it from reaching daylight, those whose gravy train will be derailed if that truth comes to light. On behalf of patients everywhere, I ask that you make that effort. Read the testimony from this hearing and for further details on the science, the reporting, the testing, the numbers, I ask that you go to the U.S. House Foreign Affairs Committee, Africa, Global Health & Human Rights Subcommittee Hearing Record on Lyme disease on July 17, 2012. There, you can find some measure of that truth and have a springboard for actions, which you as government officials, can take to end Lyme disease. Thank you.

DEBBIE SICILIANO AND DIANE BLANCHARD, LYME RESEARCH ALLIANCE

We at Lyme Research Alliance are determined to find the answers on tick-borne diseases through science and are raising private funding to do so. While it is our wish that the Federal Government will help to find these answers, we are concerned over how the research dollars have been spent. The prejudicial funding by our government has slowed the process down, and countless children and families are suffering because of it.

ALANA BOSSIDY, MERIDEN, CT 06450

When I was growing up, I can remember my mother having days where she would need to lie down; where she wouldn’t be able to move around much because of the achiness in her joints. Since I was so young, it was hard to understand why my vibrant mom was feeling like this. As of today, my mother has now been infected by strands of Lyme disease 3 different times.

When I was in college, my brother began feeling “under the weather.” The array of symptoms continued for a couple of weeks, and not soon after, I received a call that my brother was in the hospital with meningitis. When he was finally released, we knew that something was still wrong. My brother, who had always been the healthy one while we were growing up, was now sick all the time. On any given day, he would wake up to a full day of aching joints, anxiety attacks, memory loss, severe back and neck pain, migraines, and heart palpitations. The list of symptoms he was experiencing was endless. In the span of 5 months, my brother was sent to a range of different doctors including a neurologist, a rheumatologist, and a gastroenterologist. He had multiple CAT scans, MRIs, and tests. In the end he was diagnosed with Lyme disease. Today my brother will administer his intravenous medication, just as he has almost every day for the past 6 years.

In the summer of 2008, I started feeling really lousy. I was constantly tired. All I wanted to do was stay in bed. I started having trouble remembering things. I would forget how to get to the mall that I had gone to every week since I was a teenager. I would forget entire conversations I had with friends and family. I could no longer multitask without having anxiety. I had my first anxiety attack in August of that year. I was paranoid, fatigued, anxious, and nauseous. I had a constant headache, stiff neck, back pain, fever, and heart palpitations. I had night sweats, digestive problems, shortness of breath, and difficulty speaking and putting my thoughts into words. My list of symptoms was also endless. I was diagnosed with Lyme disease and “treated” with 5 weeks of medication that summer. Now, 4 years later, I have been on and off medication trying to diminish the symptoms that con-

tinuously pop up. In the past 4 years, I have seen a psychologist for my anxiety, a gastroenterologist for my digestive problems, and an infectious disease doctor who specializes in Lyme disease.

Lyme disease has changed the lives of my family and me. Our conversations swirl around how we're feeling on the particular day, whether we remembered to take our medication, and will we ever feel normal. Most days we forget what normal feels like. You learn to accept the days you feel sick and to cherish the days you aren't bothered by symptoms. I am sick of living a Lyme disease life. I am sick of worrying about my brother's health and the amount of medication he's had to intake. I am sick of going back on medication and worrying whether I will someday infect my own children with this horrible disease. I simply want my life back. Is that too much to ask?

MR. JEFFREY DICERA, MILFORD, CT 06460

A Long Case of Lyme Disease?

Even though I'm writing something right now, I'm not composing songs or scripting movies like I normally would at this time. My hands haven't been strong enough to allow the inspiration to follow through, and the people around me want to know what's going on. I never, ever thought I'd be writing a testimony about a chronic disease, especially Lyme. I was led to believe it was just a painful flu-like virus with an ugly rash. But now I can't think of anything better I could do for anyone but to explain it once more, and hopefully this time, make enough sense of it so we can do something.

I've lived in Connecticut all my life. I enjoyed playing outside a lot and was pretty nimble and active, sometimes bragging about it. Most of all, music was, and still is my life. When I was 7 years old, I was sent to the hospital by my pediatrician for a virus. It was mildly scary. It was like the flu, but with very sharp, sudden pains that migrated throughout my body. After about a week, I developed a rash on my leg, and we needed to see the doctor right away. They suspected it was Lyme.

We were sent to the hospital for all the necessary tests. Later that evening, the results came back 100 percent negative from five labs. At that point, it was diagnosed as a rare virus with a long name, which ruled out Lyme disease. I had taken a children's prescription of ibuprofen, or an equivalent, and after several weeks, the rash disappeared some time after the pain.

Things were normal again, so I resumed my life, writing songs for the first time. When I was around 9 years old, I developed an excruciating pain in my knee. Nothing showed but the pain was unbearable. The next day it was greatly swollen, several inches wider. My doctor referred me to the hospital once more for more tests, and again, it was another unusual virus. This occurred two more times that year, then never happened again.

In 1990, after surviving a car accident, I had experienced some post-traumatic symptoms for years after, which got worse, oddly enough during one of the best times of my life. I always say that I was afraid to enjoy something and I wondered if I made myself sick from the thought. After many years, I realized I didn't, not entirely anyway. From 1994–97, the symptoms developed to a disorder that eventually took over my daily function. As I was starting my first year in college, I had something wrong inside that I kept fighting. I fought to the point where I couldn't walk any more, missing classes, and eventually not leaving the house. I was sent to the emergency room with what they first thought was a stroke. After 3 days, tests came back that I had a potentially fatal chemical imbalance, based on two major chemicals that were almost absent. The cause was said to be from a growth spurt, which I never understood since I was always being outgrown throughout school. But the prognosis was a full recovery in 3 years, at the most. I was treated with antipsychotic meds. A year later, I was able to return to college and graduate.

From 1998–2008, I'd been on meds the whole time and could not yet grasp the independence from the meds. I developed some memory and focus problems, while also gaining a lot of weight. I realized I was strong enough without the meds, and made a vow and mission to get off the meds and become myself again. From 2008–10, I was weaned off the meds, eventually seeing happiness again. Focus returned, as did my memory, which really helps in this case.

In 2009, I started to feel occasional heart palpitations. I was concerned, but everyone else said it wasn't anything to worry about. I also developed a cough that lasted throughout 2010, followed by some muscle stiffness and occasional tremors. A lot of life-changing events occurred that year, prompting work on a new album. Yet I needed to take more action to get a new doctor and undergo an overdue routine physical.

In November 2010, I tested positive for Lyme disease. It was a shock, and yet it was a big relief! The doctor administered the Lyme test because of my recent symptoms, and the question came up, "Do you recall ever getting a tick bite?" All of a sudden, it hit me. I remembered the rash I got when I was 7. The doctor told me more about Lyme, that if not caught early, it spreads through the central nervous system and the brain. I began to consider that Lyme disease was possibly the cause for all the unusual ailments I experienced over the years.

So I was given a round of oral antibiotics for 4 weeks. The symptoms gradually progressed, plus I had trouble shaking colds for months, at the same time, still seizing opportunities to play and promote the new album. I found myself repeatedly calling the doctor's office for appointments, while getting hung up on, or a voice message saying they're closed, during business hours! Between the lack of due attention, and the disease itself, I was at this point full of anxiety, feeling helpless and invisible. Symptoms progressed and I became uncharacteristically irritable.

Meanwhile, I'm trying to build a fan base, while touring with two bands. Over the summer, being a drummer, I began to have trouble with my hands. They got bitter cold frequently and I had persistent joint pain. Nevertheless, I kept playing.

The doctor finally came through and more tests were done. Lyme came up negative, arthritis was negative in x-rays, yet the physical pain prompted a referral to a neurologist. At this point, my left (dominant) hand was going numb during shows, and I was having trouble carrying drums to gigs. The neurologist did a Nerve Conduction Study, and there was no damage. All doctors concluded there was no evidence of Lyme causing the symptoms. They said it was a reaction from Lyme when it was active. Rest, better diet, and better sleep would help to make a full recovery. Symptoms got worse, and I became less mobile.

Early this year, I was advised to be more proactive and find a Lyme specialist. I started to hear more stories like mine, and I read many things online, mainly because I wanted a name for whatever I was feeling. Most pain was accompanied by shortness of breath and sometimes fainting, severe chills and gasping for air. I couldn't sleep much and averaged about 3 hours a night for months. Yet the more I learned and experienced, the more I was convinced that I had this since I was 7.

In February 2012, I was referred to a specialist with great credentials. After another test for Lyme, I was promised a follow-up with more tests for co-infections. After winning a long battle getting coverage, I was stopped at the doctor's office and forced to pay before I could get the results. It turned out they didn't accept my coverage. Once we paid, the tests showed Lyme was present, but not active. No other tests were done for Lyme at this point, and I was referred back to the neurologist.

I was prescribed meds again, for inflamed nerve endings and anxiety. This proved to be a problem at shows. Shortly after, I lost most of the function of my left hand.

The effects persisted for weeks, and then months into today. I feared I would miss my shows, which I didn't. I performed those shows with a splint brace and reworked my drumming technique. As it stands now, I'm seeing an infectious disease specialist and have been tested for multiple diseases, including co-infections and non-Lyme I.D.s. I'm likely going to undergo tests for Lyme in the brain.

This is not just an illness. It's a social nightmare. After losing the ability to handwrite, to play most of my instruments, but reassurance that I can sustain playing drums, I lost my job and most of my friends, whom I've worked with and shared memories with for 8 plus years. My new album has been postponed since 2010, and I've hesitated to promote it for its own protection. My work is my mission in life, but more often now, I fear the worst. I know I can do better. Lyme, in any form, is serious, not only how deceiving it is but how many people are going through it. Whatever we do would change a lot of things for the better. For now, the best thing I can ask for is to be heard, and understood as myself again.

MS. LORI ESPOSITO, EASTON, CT 06612

My third try . . . cannot read, email, etc. without daily migraines, extreme fatigue, and flu like symptoms, due to undetected Lyme and Babesia. Insurance does not cover doctors for Lyme and denied by ltd. Only child is son now 10 and was ill since he was 2. Just want to be able to lift my head without pain and work again and have some normal fun and activity with my son. Please recognize how seriously disabling Lyme is and the need for insurance companies to also.

MRS. KRISTIN MARSHALL, MYSTIC, CT 06355

I have Lyme disease, I am a mother of two small kids, and I am slowly dying. I contracted Lyme disease 16 years ago, but was only diagnosed 2 years ago. My husband and children have watched me get worse by the day, to the point where

I can rarely get out of bed, play with my kids or take care of my family's basic needs like cooking and cleaning. I cannot work because of this disease.

Because I am unable to work we are in a low-income bracket and are recipients of Connecticut's Medicaid program which provides our entire family with full health insurance coverage. We are humbly grateful for all that this offers. It isn't enough, though, for someone with Lyme disease.

Doctors and medical professionals that follow the ILADS guidelines and properly treat Lyme disease do not accept health insurance, most of them for fear of losing their medical licenses for "over prescribing" antibiotics. So people like me who have no money to pay out-of-pocket are left to die a slow and miserable death.

The reasons for this are beyond my ability to put in to words here; I have a basic understanding of the controversy between the CDC, IDSA and ILADS but I lack the comprehension skills to describe it. The only way I can talk about it is to say that it is unconscionable what is happening to people like me with chronic Lyme disease.

We need to be able to see Lyme literate medical professionals, bill our insurance, and have said insurance companies pay for our life-saving medications. That is the one result I pray for in this bill.

Please, please help me. Please.

MS. BETH CAPPALI, GREENWICH, CT 06830

I can testify to the devastating results of undiagnosed Lyme disease and the ongoing problems associated with the disease. For years I suffered cognitive, physical, and emotional disorders with no substantiated cause. I saw physicians, specialists, allergists, and immunologists at the local, regional, national, and finally, international level. I have been treated for every symptom from high blood pressure, high cholesterol, allergies, rashes, fevers, muscle weakness, joint pain, thyroid malfunctions, and a plethora of more minor ailments. All of these symptoms presented either simultaneously, separately, or in sequence. It wasn't until a diagnosis of Lyme and massive doses of antibiotics that I was able to resume some semblance of normal life. It has left me with ongoing anaphylactic responses to the most minute particles of cat dander proteins, respiratory issues, joint issues, and muscle spasms and that is considerably superior to the past 10 years.

These issues have caused great financial problems, emotional issues, familial constraints, physical realignment and confinement, along with fluctuating cognitive abilities and emotional ability. The autoimmune response appears to be untreatable at this time, but there is some hope with clinical trials in Canada. The trials in Japan and those in Los Angeles have proven futile.

This disease has caused great damage to my business, my husband, my children, my home and my friends. I cannot stress enough that the research into diagnosis and treatment for its ongoing effects must be a priority.

Thank you for this venue.

LISA STEIN, GLASTONBURY, CT 06033

I was diagnosed in 1996 with mono. I continued to have difficulties and could barely walk. I was in my 20s and I felt like I was in my 70s. I was dismissed by my doctors and diagnosed with fibromyalgia and depression. I pushed on and stopped going to the doctors because they weren't helpful. I continued to have ups and downs. During the downs I would have pain and emotional distress and would end up having to leave my job and change my profession. I was finally diagnosed with Lyme disease in 2006 when my pain one morning just flipped sides. My doctors thought it was a recent infection, so the treatment I received didn't stick. I started a new job and got sick all over again, bedridden for months again (for the 3rd time in my life, and my fourth job, once again lost due to my illness).

Lyme disease has affected me physically, neurologically, professionally, and socially. My friends have successful careers and relationships and children. I am not able to sustain any of those. I cannot keep up physically and I am not able to function neurologically.

I worked hard for my education and to be successful in my profession. Now I am ill and living at home with my parents and not financially independent. I don't have a family of my own. Lyme disease had changed my personality and my life. I wouldn't want to see anyone ever have to go through what I have been through. My COBRA insurance coverage ended and if I can find an insurance company to cover me, they do not cover my doctor visits to the Lyme specialist. It's difficult and I struggle not only financially but also physically and neurologically. It's frustrating to have different pains, not knowing if it is the Lyme disease or something else and needing to go to doctor appointments to have them say everything is normal. I repeatedly have to endure physical therapy, not from my activity but just from the

Lyme disease. The savings I worked so hard to save for my future, spent on doctors' bills and treatment. The damage from Lyme disease is done and I will never be able to return to my teaching profession, and although I'm hopeful, I may never have any profession. I may never have a personal relationship. I may never be able to have a family of my own. To think this could've been prevented if only my doctors were more knowledgeable, open minded and supportive to consider my condition was the result of Lyme disease and to provide the proper treatment. I would be successful in my career and personal life. I feel cheated out of my life and career (never mind just being able to hold a job). People don't realize how damaging Lyme disease really is, and it's frustrating to hear, "well you look great." (Probably from all the bed rest my body requires.) It's not about how I look, I'm constantly in pain. I'm not able to communicate effectively and I can only get my point across to you, if I had a few months to compose these few paragraphs.

TERESA HITCHCOCK, WINDSOR LOCKS, CT 06096

I have late stage Lyme disease which has affected every aspect of my life. Initially, I didn't realize that my symptoms were anything more than the common cold. But why did every sniffle turn into bronchitis or pneumonia? Why did it last months on end while picking up everything from pink eye to the flu? Because I was unaware that I was dealing with such a largely suppressed immune system from such a tiny bug.

Shortly after giving birth to my son in 2002, I found myself constantly landing in the doctor's office with a myriad of complications. A skin rash that would not clear up, a swollen knee that couldn't be relieved, a painful shoulder without cause, a numbing hand that became difficult to use, piercing migraines and plenty of sleepless nights. Missing time at work and struggling to keep up at home, I brought these increasing concerns to the attention of my Primary Care Physician. Why did the doctor tell me that I had "Mommy Stress Syndrome"? Why did the doctor have me go through Worker's Comp to address my hand and shoulder? Why didn't the doctor do any blood work? Because the doctor was unaware of the manifestations of Lyme disease.

Over the course of 6 years and nearly a dozen specialists, I did physical therapy, tried countless medications, had hand and knee surgery but still had no relief. At this point, cognition complications were becoming extremely frightening and I had lost all faith in the medical community. Out of desperation, I sought the help of a reputable Naturopath. He listened while I pleaded to regain my health and after just one visit and my first set of blood work, I finally had a diagnosis. Lyme disease—positive, positive, positive! I was so excited by the results, this meant I could take some antibiotics and be cured. Then why was I still so sick after 30 days of Doxycycline? Why wasn't my primary care physician able to continue the treatment? Why was it so hard to find a Lyme Literate Medical doctor? Because 30 days of antibiotics is clearly insufficient and medical guidelines tie the hands of willing doctors.

Being sick for so long caused my life to be turned upside down. At home, I felt distanced from my family. Unable to get out of bed to even sit at the park or toss a ball with my son. Unable to consume the simple pleasures of life. At work, my peers began to doubt my credibility. Being absent a lot caused frustration for them. I tolerated snide remarks and eventually felt as though I was under constant attack and unwelcome. Running out of sick time and FML protection with ongoing debilitation caused me to resign in October, 2011. This was by far, the hardest to accept. All my hard work down the drain and how will I sustain the loss of income. Why is this happening to me? Because I have an "invisible" illness that nobody understands.

Currently, I have Chronic Insomnia, fatigue so severe it's like wearing a 300 pound blanket that I can barely carry, profound muscle weakness that causes me to drop things and even fall down, painful muscle spasms, tremors, achy joints, cognitive complications including memory loss, brain fog, disorientation and blackouts, loss of word recall with stuttering, migraines, seizure-like events, heart complications causing palpitations and a recent bout of Pericarditis. I have lots of dizziness and have been diagnosed with Postural Orthostatic Tachycardia Syndrome after numerous fainting episodes. GI upset so bad that I was hospitalized after not being able to eat or drink for 10 days, urinary complications, loss of temperature control such as excessive sweating or freezing hands and feet, visual changes, light sensitivity, hearing loss, sound sensitivity, dental deterioration, hair loss, adrenal fatigue, vitamin deficiencies and so on. The list seems endless since the disease affects every system of the body. Why do I continue long-term antibiotics since it is unclear if I am getting better? Because without it, I may be confined to a wheelchair or have facial paralysis or be dead.

To sum it up, this has been a long difficult road. I have applied for Social Security disability only to be denied. I am sick and in financial ruin. Guess I can kiss my 800 credit score good-bye and just hope for a miracle to find a way to pay my health insurance premium, medical bills and to keep a roof over my head with food in it. And just when I thought it couldn't get any worse, it did. My biggest fear has reared its ugly head. I thought I'd get through my story without tears but this is so unbearable for me.

My son has shown subtle signs of Lyme symptoms in the past. I had suspicion of him contracting it congenitally and brought him to the Children's Hospital for evaluation when he was 6 years old. The specialist advised me not to worry. Stating that he'd be dead already if he was infected during pregnancy. Most women miscarry or the baby dies within days of birth. Austin is now 9 years old and progressively showing symptoms. I cannot sit by and watch this unfold without being proactive and putting up a fight. I recently heard evidence of infected newborns sustaining life. So why is there so little knowledge of congenital Lyme disease? (Your turn to answer)

It's time to pull every resource available to conduct proper research of tick-borne illnesses in order to provide appropriate testing and treatment. So many lives are counting on it.

CORINNE SILANO, TORRINGTON, CT 06790

In 2011 I was diagnosed as having Chronic Lyme Disease by a Naturopathic Physician (via a Western Blot test in which I had 9 out of 10 positive IGG bands). Prior to that, I had been tested for Lyme disease (Elisha test) on numerous occasions over the years by various doctors with the results being "false negatives". Doctors thought that I had everything from congestive heart failure to possible kidney issues. I am presently under the care of a Lyme Literate physician who believes that I have had this incapacitating disease since I was a child (I am now 51 years old). I also have Fibromyalgia as well as a result of the Lyme disease. In retrospect, it all made sense "knowing what I know now" and I needlessly suffered all those years, the doctors not knowing why I kept getting sick and why I had various symptoms (i.e. neuropathy and edema in my legs, severe vertigo etc.). The plethora of issues caused by this disease was the ultimate reason why I had to retire from my career of over 31 years in Law Enforcement (I was a Police Detective for the City of Torrington, Connecticut). The illness (over the years) caused me to miss work for extended periods of time and it was not until last year that it was discovered what was causing me to feel incapacitated to the point that I struggled just to make it to work, let alone make it through a day. Feeling the way that I did was certainly a safety issue for me in my job in the capacity of a police officer. It is also disheartening that insurance companies do not cover all the expenses for Lyme Literate doctors, when in fact people diagnosed with Chronic Lyme Disease experience the same symptoms as persons with Multiple Sclerosis, Parkinson's Disease etc. The disease also takes a toll on family members as well. Lyme disease has certainly changed my life, but I count my blessings that I finally discovered (through proper testing and unfortunately needless suffering) what has been causing me to feel so ill for so many years. Thank you Senator Blumenthal for being the voice of so many Lyme Sufferers throughout the country. God Bless.

STAN SOLARSKI, GUILFORD, CT 06437

Before all of this started I was 100 mph all day long, with no health issues. I'd get up at 5 a.m., go fishing, work on moderate sized house projects, work out 5 days a week, have no issues with aches, pains, mental clarity, energy, etc. It was many years ago, but I graduated in the top 2 portfolios in my class and won design awards—this all changed.

Fall 2007 I started having pains in my back near my right shoulder blade, I thought I pulled a muscle at the gym. By late fall 2007 I was very run down by the end of a work day, the pain in my right rear shoulder increased and I had shooting pains down my right arm and up my neck and I had a re-occurring upper respiratory infection. I was not overly concerned about myself—my wife was pregnant and due at the end of Feb 2008. I saw my PCP and he recommended a chiropractor. I did not go.

Jan. 2008 I saw my PCP for the re-occurring upper respiratory infection and they gave me levaquin, only because my wife was pregnant and due to this I had my first herx. I did not know what happened. I had extreme body aches and brain fog—it came on like a switch. I called my PCP, he had me come back in, did the Lyme test through Quest and found Lyme positive by the end of Jan. 2008.

Feb. 2008–March 2008—my PCP gave me doxy. I had little to no improvement—it was cyclical—I'd feel minimally better for ± 3 days and then worse.

March 2008–July 2008, I went to numerous doctors who told me nothing was wrong with me, meanwhile I was untreated and got horrendously worse—especially w/brain fog/de-realization/de-personalization.

July 2008–February 2009 (if I remember correct)—I saw Dr. Keszler in Madison. She helped a little at first, but then only gave me doxy for months while I continued to get worse.

Feb. 2009—current, I saw Dr. Weiss. He gave me 3x the amount of doxy I was on and he found I absorb only trace amounts of doxy. So this entire time it was like I went untreated. Dr. Weiss found through blood test at Ignex I am positive for Lyme and mycoplasma (he said I do not have signs of mycoplasma and some of the antibiotics he gave me would have addressed mycoplasma). Dr. Weiss clinically said I have bartonella and babesia due to harsh reactions I've had to antibiotics (rifampin/minocycline combo (I've completed 2 cycles of this) and zithromax/mepron combo (I completed 1 cycle of this)—and my symptom history. I think I did the gambit of antibiotics w/Dr. Weiss with the exception of picc line—which I am highly uncomfortable about (instead I did months of bicilin shots 3x per week). Dr. Weiss also found that I have Vit D deficiency (last checked my level was 43), high amounts of biofilm and confirmed active Lyme—all from recent various blood test. He also found abnormal spect image, but normal mris and mras. There was a suspect “thing” in my mra which could be nothing, or the very early stages of an aneurism. I need to have another mra around July 2010—can I get this through your office?

Current—I have been off antibiotics since 9/10. I continue to improve with the treatments of first an HPMP and now GB 4000 rife machines.

Note—have also been under treatment for the last year or so by 2 naturopaths. Dr. K with herbal remedies (great w/detox) and Dr. S with rife.

Current symptoms: Since mid-March (11) I started waking up to mild to severe back pain and now headaches and body aches (legs!!). These usually go away in around an hour of wake up, but sometimes the pain lessens but continues throughout the day. By mid-morning I sometimes get mild/moderate numbness in my hands, arms and cheeks—along w/a little brain haze (possibly because I started drinking coffee again—dumb). Usually when I leave work by 4 p.m. the numbness and haze gets slightly worse. I used to crash when I got home and sat down—this is from 2 months ago—I am now better from this. If I keep myself active it's not as bad but tough to do, but if I fall asleep, even for 10 minutes this somewhat clears up. Some days this does not happen—or is not as bad—and usually clears up (not 100 percent) by 8–9 p.m. This all is not as bad on weekends. The numbness and twitching were an issue in the past, gone away and have recently come back. My energy level is also slightly lower than original. I had occasional air starvation—but only when eating—this has stopped in the last month. Occasionally I have “restless leg” like symptoms in bed—usually after a rife.

I treat with the GB4000 every 4 days. I defiantly have a herx reaction (depending on the frequency used) and then feel better. I suspect that by treating this way I may be pulling out older symptoms by hitting the bugs a different way—I am currently on one of the lower settings/ways of treating with the machine.

Past symptoms:

Night sweats: moderate;

Freezing cold in warm air temperatures: moderate/severe;

Fatigue: moderate/severe;

Swollen Glands: mild/moderate;

Sore throat: moderate—used to wake up to this every day;

Bottom of foot pain—especially upon wake up: moderate;

Testicular pain: moderate;

UTIs: mild—not too bad, but never had this before. Had ± 10 ;

Loss of Libido: moderate/severe;

Heart pains: mild;

Heart palpitations: moderate;

Joint pain: mild to severe;

Muscle stiffness: mild—also had mild burning sensations in my neck/shoulders—sometimes throughout whole body;

Headaches: mild to severe. I used to wake up to a head ache every day. I've had severe burning headaches during herxes—similar to acid burn feeling;

Tingling/numbness/burning: mild to severe;

Vision: mild/moderate floaters;

Ears: mild to severe ringing;

Sound sensitivity: mild;

Vertigo: mild;
 Lightheadedness/Wooziness: mild to severe;
 Difficulty walking: mild—down stairs (during herx);
 Confusion/difficulty thinking: severe;
 Forgetfulness/bad short term memory: severe;
 Rage: severe;
 Disturbed sleep: severe insomnia/early waking—really messed up dreams—was on clonopin for months—even during the day due to anxiety;
 Word search/trouble writing/typing: moderate;
 Depression: moderate/severe; and
 Also—severe depersonalization, de-realization, weird perception, anxiety, panic attacks in stores (fluorescent lights).

MARIE SMITH, ANDOVER, CT 06232

I have had dozens of tick bites. In December, 2005, I had a small unidentified rash and was tested for Lyme and other tick-borne infections. That report came back with “exposure” to Babesia. Per CDC guidelines, I was not treated. Fast forward to April, 2007. I spent a day in ER with chest pains and extremely high blood pressure, but my heart checked out fine. Two weeks later, I had the results of blood work tests showing positive for Lyme and Babesia. Treatment began. Five years later, I am still battling these diseases by treating my symptoms while continuously searching with hopes of finding a cure. These chronic infections have left me at about forty percent ability compared to 7 years or so ago. The buildup of disabling fatigue, deep joint and muscle pain, along with headaches and panic attacks, are more than enough to drive me and everyone around me crazy, especially those that live with me. The remedy that helps me is to sleep, rest, recover, and repeat, for as much time as it takes to get functioning again. My contribution to this community has been greatly limited by these diseases. Recently, my symptoms have changed a bit and now include moments of dizziness/loss of balance. The ringing in my ears, however, is now somewhat tolerable. The bacteria lives and moves about my person taking up residence in my weak spots, attacking cells at those spots, until something causes them to move somewhere else. I have managed to live a good life in spite of my disability because of my supportive family and friends. Without them I do not know where I would be. Thank you for allowing me to share this with others.

ROSEMARY P. WALLINGFORD, CT 06492

In March 2010, I was diagnosed with ALS at Yale. I was a 49-year-old mother with a young son. I was completely devastated and was told to essentially “go home and die”. The neurologist also told me to not try antibiotics because they didn’t work and just made patients sick.

At the time, I didn’t know why he would even say anything about antibiotics so when my husband and I researched ALS we found out that it has similar symptoms as Lyme.

For the past few years I have been going to Lyme doctors. The first doctor was in Mt Kisco, NY. He was established and took insurance but was very paranoid about legal issues so he didn’t want to treat me with antibiotics very long. I did improve on IV ceftriaxone for 9 months but wasn’t cured.

The second doctor I tried was in CO at a clinic run by an hematologist that had been diagnosed with ALS but cured using antibiotics. Their treatment protocol was very aggressive and unfortunately too severe for my body to handle. The cost of seeing a doctor long distance was also prohibitive. Phone consults are not covered by my insurance.

I am now going to an osteopath who uses herbs, antibiotics and antiparasitic drugs and am doing ok. I am still weak and have trouble breathing sometimes but I can drive, eat normally and walk a mile a day.

If I didn’t have a chance to try antibiotics because the laws prohibited extended use of them, I don’t believe I would be here today sharing my story. I’m grateful for every moment I have to be with my family and to have the freedom to try drugs that might cure a fatal disease without fear of legal restriction or medical retribution for my doctor.

CHERYL RENN, GREENWICH, CT 06830

As a registered nurse I have found it very disconcerting and very frustrating trying to deal with both getting diagnosed and obtaining treatment for Lyme Disease. I recognized my symptoms 2 weeks after a camping trip in 2007. I did not get treatment until June of 2008. As a middle-aged woman doctors tossed my symptoms up

as menopause or hypochondria. Once I did find an Infectious Disease doctor who was able to diagnose me, she would only give me one round of antibiotics and insisted that I be seen by a neurologist for my neurological symptoms. She was angry and rude to me after I choose an out-of-plan Lyme's literate neurologist. I felt really belittled by this woman.

I had to fight for treatment with my insurance company after my initial treatment with Doxycycline. I even had to write letters to the Company president, the Insurance Commissioner after many appeals to my insurance company at that time (Healthnet).

The Lyme neurologist got me on track which brought me to remission but later he wouldn't see me because he got a bill from my insurance company. I always charged my fee so he got full payment from me. I dealt with the insurance company myself. Anyhow, my neurological symptoms returned and he wouldn't return my phone calls. He is very knowledgeable but he picks and chooses his cases and abandons the patients that don't suit him.

I am currently dealing with symptoms again. Mine always present neurologically and again I am frustrated by fearful doctors and the stigma attached to treating Lyme and the divide between those who treat and those who don't and the health insurance companies who now seemingly set practice guidelines.

Really a shame if you are not medically savvy or unable to rally for yourself.

Care costs are driven by ignorance.

LINDSAY ROLLIN, BETHEL, CT 06801

I didn't want to wake up yet! Another few minutes or maybe even hours! My back felt like it had sprouted roots that spread deep down to the depths of my mattress. As I opened my eyes, my attempt to sit up was halted by the excruciating pain radiating from the base of my head. A turn to look at my clock sent a worse shiver of pain into my neck, taking my breath away. Despite being exhausted, I felt like I had slept for decades, like Rip Van Winkle. Is this what being old feels like I wondered. I was only 31 years old but I felt more like 81 most days.

I rolled to the side trying to be careful to keep my head steady, which felt heavy like a bowling ball. My eyes burned from the early afternoon sunbeam, which shined directly into the space between the window and the blinds. My hunger helped drag me out of bed, so I wandered into the kitchen. I looked into all the cabinets and fridge and weighed out my options. Eggs were completely out of the question. I spotted some Honey Nut Cheerios and tried to make a plan—bowl, spoon, cereal, milk.

Too much work I decided as I retreated back to my bed, defeated. My journey to the kitchen had jump started the headache, which was a cross between the sensation of being hit in the back of the head with a baseball bat or as if my brain was one of those spongy creatures that expand when placed in water.

Finally reaching my bed, I sat down and lowered myself onto one elbow, then slowly rolled onto my back. I knew something was wrong. It felt like my gas tank was empty. I had been coasting—running on fumes. I could have probably used an oil change too. Too exhausted to sleep, my mind began to wander into the darker place. How can that doctor look me in the face and say that there wasn't anything to do. "Post-Lyme Syndrome," he said, "the damage is done. You'll just have to live with it."

The next few days were a blur—a flurry of self-despair. The unbelieving looks from people complete with comments such as, "But you look fine." Or "You really have to start taking better care of yourself, you are always sick!" like I was doing this on purpose. I surrendered 17 vials of blood for testing in one visit and still no answer. C'mon, early re-activation of mono for the past 7 weeks? If the early stage felt this awful, I couldn't wait for full blown mono. Another doctor wondered lupus, chronic fatigue, MS. All they seemed to be on consensus was that they didn't know what was making me feel like I had been hit by a truck or tried to make me feel better. In the game of hot potato, I was the potato, quickly being passed from one doctor to another—my primary to the neurologist, the rheumatoid specialist to the infectious disease and then back again. How can I fight when I don't know what I am fighting?

Frustration overwhelmed me. I knew this all started with a teeny tiny tick that I never even found. Lyme was well known but I hadn't even heard of Babesiosis. I later learned that the tiny parasites live in blood and destroy red blood cells. This is unfortunately just a snap shot of my Lyme journey, one of the memories that I would rather forget, a moment of time in a journey of at least 5 years in the making.

In our weakest moments, we sometimes make the most important decisions. I could be a victim and cry at the injustice. I could be patient and wait for a doctor

to give me all the answers. But that's not who I wanted to be. I had to take charge, educate myself, and be my own advocate. Empowerment is a better feeling than victimization. It was in that moment of not being able to get out of bed that I made the decision to not take this laying down!

I am currently pursuing a degree at Columbia University's Teacher's College and studying with one of the top reading and writing experts in the country, but I am plagued with ears ringing during lectures and difficulty recalling words. I am an intelligent woman who does not want to continue feeling this way while at the same time refusing to give in. I am tired of being derailed by mind numbing stiff necks that come out of nowhere. It is really hard to work on my studies when the light hurts my eyes, making reading my required work difficult. I am fed up with not having the same focus I did before becoming infected.

There is more. More feelings—why me? I'm not even an outdoorsy person. How can the government let all these people stay sick? Out of all the diseases, why did I have to get the one that is constantly put into question if it even exists? I already gave up the idea of breast feeding my future babies. I am at the point of even giving up on having my own kids, which has always been a top priority. Now I am dealing with the reality that no one wants to date someone who never feels good, that it is a really hard thing to understand when someone has chronic problems. At this point, it takes 100 percent of my energy to make it through school.

Although this is my reality at the moment, it does not have to be my permanent reality. It doesn't have to be like this for other people. Maybe we don't have to watch it slowly spread to other regions that thought they were safe. Maybe other women don't have to give up their dreams of being mothers. Maybe I can get better.

With research and better testing, I am hoping that other people won't be mistakenly given rounds of steroid treatments that make them sicker. If my Lyme had been detected at that point and doctors had the vital understanding that Lyme patients cannot tolerate steroids, that it makes them sicker and the Lyme stronger. With research, we can stop the controversy.

SHELLY FLYNN, A.N. FLYNN, MSW, COLCHESTER, CT 06415

DEAR MR. BLUMENTHAL: My story is not unlike those thousands, perhaps millions of people who have experienced Chronic Lyme disease. In November 2009, I was finally diagnosed, and properly treated for Lyme disease and its often accompanying co-infections. The arduous journey however, began long before November 2009.

My recollection of this journey begins in the summer of 1995, when on break from a rigorous Master's degree program, I found myself lying on my neighbor's front yard, completely out of breath, a mere 100 yards from my home. Always fit, and making time in my busy schedule for exercise, this overwhelming feeling of exhaustion and inability to catch my breath was completely foreign. Something was terribly wrong and I sought help from my primary care physician. I found some relief in the 7 day treatment of antibiotics, however, the improvement waned as the treatment ended. A second prescription was given, with the same result. And finally, a third round was prescribed, with the same level of temporary relief.

At the same time, pulmonary tests, cardiovascular tests, and blood tests were conducted—all with negative results. To my knowledge, Lyme tests were not conducted. Finally, without any answers to be found, the primary care physician recommended antidepressants. Fortunately, in the middle of my clinical study in social work, I fully recognized the DSM-IV diagnostic criteria for depression and knew that this wasn't the cause. I left his office with the goal of finding answers and refusing an unnecessary prescription.

I sought help from a number of practitioners including acupuncturists and naturopathic physicians, and was diagnosed with Chronic Fatigue Syndrome. Complementary modalities built my system enough to finish graduate school and secure employment as a Master's level social worker.

Fast forward 10 years. My health still a concern, however, I am determined to "fight through it", which practice can only remain effective for a while. In May 2006, I was carried out of my place of employment in an ambulance with a familiar cause: extreme shortness of breath and exhaustion. Again, pulmonary tests, cardiovascular tests, blood tests were conducted—all negative. Lyme tests were not performed.

I was released from the emergency room without any answers. Again, seeking the help from a different M.D. who also practiced homeopathy, I regained enough physical wellness to continue on with my life. In 2007, blood tests were finally conducted for Lyme disease. IGG negative; IGM positive indicating the presence of a non-recent infection. Three weeks of Doxycycline were prescribed which helped temporarily. Time went on. My system began to crash yet again and I still was unable to find an adequate treatment program.

Frustrated and after much research, I self-prescribed a very vigorous herbal protocol for chronic Lyme. This worked for 8 months before I began to crash again. Finally, feeling very angry with the inability of our medical system to correctly diagnose and treat Lyme properly, I sought the help of what is considered a Lyme Literate M.D. Unfortunately, this meant a 6 hour round trip to the office accompanied by out-of-network costs. Finally, in November, 2009, a diagnosis of Chronic Lyme, with the presence of co-infections was rendered. A rigorous treatment protocol involving antibiotics and what unfortunately is considered as “complementary” interventions was prescribed. Three years later, and after much self-education, I can say that I am feeling much better. I haven’t “crashed” in years though I know full well that I will always need a maintenance program due to the presence of a Lyme infection that possibly has a 15-year history in my body. I am also knowledgeable enough to demand an appropriate antibiotic treatment protocol for my son when his ELISA comes back negative yet the test report for the tick that was pulled from my son’s body and sent to the Connecticut Agricultural Experiment Station indicated a female engorged deer tick carrying the spirochetes that cause Lyme disease.

That being said, unanswered questions continue to plague my thoughts regarding my experience. How is it that Lyme originated in Connecticut, yet one needs to travel out-of-state for proper treatment? How is it that Lyme has reached near pandemic proportions and we continue to have inconsistent diagnostic criteria across State lines, labs tests that are less than accurate, a recommended treatment protocol that is ineffective, and physicians without the base knowledge of Chronic Lyme? How is it possible that Chronic Lyme is being questioned as a viable diagnosis? Why is it that co-infections are not routinely tested for when testing for the presence of a Lyme infection? How are patients able to navigate through barrier after barrier when they are feeling so incredibly ill?

Chronic Lyme I can battle, and successfully with the right interventions. I am a fighter who understands the research behind the disease. There are volumes of solid research on Lyme and it’s often accompanying co-infections. Science knows how the organism behaves and what treatment protocols are most effective. The data is available, but not being used. We appear to have a deficient health system regarding the diagnosis and treatment of Lyme that may not be acting in the best interest of the patient. And for what? I ask you to conduct some deep, critical thinking on the answers to this question.

KATHY LAWRENCE, MILFORD, CT 06460

On May 30, 2012, it was my decision to visit a rheumatologist for various symptoms that I was experiencing—which my regular physician was unable to diagnose. The rheumatologist sent me for a full blood analysis, and within 2 weeks she said that I have Lyme disease. I was prescribed Doxycycline. She told me to return to her office in 6 months, to re-evaluate my condition. First of all, the prescribed medication made me feel considerably more ill than before. I thought that in taking this medication, I would feel no other symptoms once the course was over. It has been 3 months now, as of writing, and my symptoms have not decreased in the slightest. I am frequently crippled with incurable pains. It is like a pinball effect on my body. The pains are very sporadic. Sometimes I think I just have a headache, but shortly after taking something for it (Tylenol) the pains jump elsewhere. I have had symptoms for a long time before I visited the rheumatologist, but they were not as severe or frequent. I once worked several jobs, but I am no longer able to sustain a working man’s regimen. I am stricken with pains and sickness more often than not. My appetite and digestion have been severely affected by this disease. I have unbearable migraines that affect my perception greatly, and force me to be unable to do anything but try to relax. I was told that there are no other options for my symptoms other than taking medications that don’t work, and instead make me just feel worse.

ALICIA COLON, STAMFORD, CT 06906

I’m a healthy 39-year-old female in the prime of my life. I had found what I thought was a scab on my arm because it hurt, I removed it and a large red bull’s eye appeared. A friend told me they thought it might be a tick and told me to save it and send it to the Health Department. I called my doctor immediately and told them I thought I had been bitten by a tick, and wanted to get on antibiotics, they said I would have to wait for the tick to come back. That took several weeks and it was positive for Lyme disease, they gave me a script for doxycycline and I was fine for many years. One day out of the blue I felt extremely ill, my body temperature dropped to 95, my ears were ringing, my eyes couldn’t handle any light, I couldn’t walk straight and was falling down, had extreme insomnia, had rapid weight loss, muscle spasms, depression, nervous system problems, rashes, my men-

strual cycle stopped, the list goes on. I ran from doctor to doctor saying I was extremely sick, they ran all kinds of tests, including Lyme disease tests, only to be told they were negative even though I had the symptoms. After a year of running around and still ill, I made it to a Lyme doctor and he did specialized tests which showed I had 3 bands on the Western Blot and also had 2 co-infections; bartonella and Babesia. The original doctors had one band showing on the tests (they never tested for co-infections), but said they didn't have to tell me because the CDC said 1 band means you don't have Lyme disease, what a horrible injustice! Huge flaw in our medical system! Thus the antibiotic regime started, orals, IV, shots, etc . . . Here I am 12 years later and still sick. Late stage Lyme disease does exist and co-infections do as well. More studies and research need to be done to fight this horrible disease, the medical community and doctors need to be better educated. This disease is now worldwide and is ruining people's lives, not to mention the strain it puts on our loved ones, the insurance companies and the Government. Lyme disease doesn't discriminate; anyone can get it, or a co-infection. These diseases are easily transmitted by insects, etc. and more needs to be done to protect our loved ones! Regards.

CAROL ROBLES, STRATFORD, CT 06614

In April 2012, I started to have chest pain. I have had this symptom for about a year and thought it could just be acid reflux disease; however the stabbing chest pains were happening more often. I started to become extremely tired, and I noticed that my legs would be swollen most of day. After going to the doctors and having abnormal EKG results, they thought it could be a blood clot or heart disease. I went for several testings all came back negative. My initial blood work proved there was something not right. My symptoms continued and even worsened. Some days I could not stand, I had cramps on my hands, legs, and even face at times. I had severe pain all over my body, headaches, pressure in my head, difficulties concentrating, stabbing pain on the side of head and noticed mood swings. I stayed away from family because I was easily annoyed by people. I repeated my visits to my doctor's office. Finally, my doctor tested me for Lyme disease, 3½ weeks later I received a phone call and she diagnosed me on July 12, 2012. After finishing my 29 days of antibiotics, I am still not the same. I still have many days where standing on my feet is painful and even notice that my concentration is not the same. I feel all of the symptoms daily. I am currently still educating myself about Lyme so I can rebuild my body to the way it was before. I thank God for the strength he gives me daily. Lyme disease has really affected my life and I am currently still awaiting my day where I can be back to normal.

MEREDITH LODGE, UNIONVILLE, CT 06085

I stayed back in 7th grade for not going to school enough. In 10th grade I dropped out and got my GED. I started college and made dean's list the first semester but "burned out/withdrew" because of poor attendance the second semester. My third semester I did great. That was in 1995—the year my knee was swollen for no apparent reason. I was diagnosed with Lyme disease in 2009.

I worked hard at school and at the jobs I held. But they all ended in Burnout. Or the flu. Until 2004, when I finally could not fake a full job anymore (I did try again in 2006.) I was able to hold on to a per diem job until I could not perform anymore.

I was tested and told I did not have Lyme disease at least three times from 1995–2009 when I got my diagnosis. Furthermore, when I did get the diagnosis, I asked the doctor to test me for other tick borne infections and he refused. A month later my blood tested positive.

There needs to be better testing and better treatment. I acknowledge it is unlikely I can be helped in my lifetime—I just can't afford proper treatment, only the rich can. I could have had I been diagnosed in 1995 but after 15 years, there was no chance for me anymore. I hope you can help the next generation. I hope they can get GOOD truthful testing and appropriate affordable care.

Suicide is the number one killer in Lyme Patients. I don't know if it is because of the chronic pain, isolation, or both, but I don't want another person to take their life because they are not treated properly or the medical establishment tells them their knee swelling is idiopathic—and their wrist pain, and the neck and shoulder pain is stress, and oh the migraines, just stress, and the sweating? That's a panic attack.

I don't think enough psychiatrists rule out physical illness. As a young 19-year-old who could not walk without a cane, I was told the numbness in my tongue, jaw, and hand was a panic attack. Please don't let our government treat the kids of

today as I was treated. The psychiatrist pills never made me better because I was not sick in the head, but had an infection.

GILLIAN SMITS, WEST SIMSBURY, CT 06092

I moved to the USA, from South Africa, in 1995 as a young mom with my husband and baby son. I knew nothing about the presence of ticks in America. In 1996, with a second child in tow, my family and I moved to CT from Boston, and in 1998 bought our first house in Simsbury. It was at this time, that I started gardening, and had my first of many tick bites. Since I did not know the difference between ticks, nor knew that they could carry disease, I had no clue that being bitten would change the course of my life forever.

In 1999, at the age of 34, I developed flu like symptoms which then passed, after which I developed colitis, which continued for 4 continuous months and for which doctors could not find the cause. Shortly after that, I developed symptoms of reflux and stomach problems which did not resolve and which were not related to diet. After that, I developed severe night sweats, fatigue and joint pain. I also started getting migraines. Each symptom was considered unrelated by my doctors and treated separately. No one told me that my symptoms could be related to a tick bite and so, because I still did not understand the dangers of ticks, I continued to garden, with no protection from ticks. In 2001, my youngest son of 5, was bitten by a tick and became very ill. He was diagnosed with Lyme disease by his pediatrician after a positive blood test and treated with antibiotics, but although he improved, he continued to suffer from profound fatigue. I was told that it could no longer be Lyme disease but took him to the doctor multiple times because he was so tired, that he could not play sports, or live a life like other children. He was bitten repeatedly from the age of 5 until the age of 12; however, every time I took him to his doctor, he would only get treated if his blood work was CDC positive, regardless of his symptoms. His fatigue persisted along with cognitive and memory issues and he was diagnosed with ADHD and needed special education. His last tick bite was in 2007, when he was refused treatment by his doctor again. In 2005, I was bitten yet again, this time knowing a little more about Lyme disease, I saved the tick. I sent the tick for testing at UConn, which revealed that this tick did indeed carry Lyme disease. I was denied treatment by my doctor, because my blood test was not positive, in spite of being symptomatic and was told that there was no possibility I could have Lyme, even though the tick was embedded in my skin and was dead when I found it. In 2006, my oldest son was bitten by a tick and was treated for Lyme disease, but continued to be symptomatic after treatment with joint pain, headaches and severe fatigue. He was bitten again in 2007 at a summer camp, and his symptoms worsened, but this time was denied treatment because his blood test was not CDC positive. In 2011 he developed a bull's eye rash with no evidence of a tick bite, by which time his fatigue was so profound that he would need to sleep every day after school. My youngest son, by this time had developed additional health problems, which were unexplained by his doctor, and was still suffering from profound, constant fatigue.

To make things worse, in 2008, I was re-infected by a tick bite to the head, after a deer jumped on the roof of my car, and fell through the sun roof of my Toyota Sienna. A female deer, weighing approximately 300 lbs., as described by the police at the site of the accident, caused a severe concussion after which I became extremely ill with undiagnosed Lyme disease, yet again. In 2009, I was forced to close down my business due to severe, almost daily migraines. Repeated visits to doctors and specialists were of no help, and I was told they knew no reason for my constant debilitating headaches. Even though I questioned Lyme disease, my blood work from local labs was never CDC positive for Lyme, and so it was always ruled out of the equation. No doctor ever thought to put all my symptoms together and look at them being caused by a single disease.

In 2010, I started developing severe muscle pain in multiple areas of my body, and tendonitis, and then facial pain and jaw pain that became so bad that I could no longer chew or eat solid foods. By this time, I was in such pain I could no longer work. The joint pain had spread to my fingers, toes, feet, knees and back, and I also had severe neck pain in addition to the migraines. By May 2011 my finger joints began to swell, and I had dizziness and peripheral neuropathy in my feet and fingers in addition to many unexplainable symptoms. In June of 2011, I was finally diagnosed with Lyme disease by my cardiologist, who put the pieces of my health history together. During the 14 years of having undiagnosed Lyme disease, I also developed a heart arrhythmia in addition to my other classical symptoms and was diagnosed with ADD when I became affected cognitively by Lyme disease. Little did I know what the truth was at the time.

I started treatment immediately following my diagnosis in June 2011, and have found a Lyme Literate M.D. who continues to treat me. I have made definite progress in my health, but my entire nervous system has been affected by Lyme disease and I am not sure how permanent the damage may be. One of the most disturbing symptoms has been the on and off loss of my voice, which apparently only affects 2.5 percent of victims to Lyme disease. As a singer, this has been devastating to me, but I am thankful that I am still alive and am getting treatment. Every time I come off antibiotics, I lose my voice only to get it back when I go back on antibiotics. After 1 year of oral antibiotics, I am still sick enough to need IV treatment. My insurance will only pay for 1 month of IV antibiotics, and I will have to pay for the rest. As a widow with two children, who were recently also diagnosed with disseminated Lyme, I have a terrible financial burden imposed on me. If my children and I were only treated correctly in the beginning, this could all have been avoided. My doctor believes my children will make a full recovery, and that I will too, but only with long-term antibiotic therapy. Although I am disabled, I cannot take disability because I am a widow under the age of 50, and I need to work to get my health insurance for myself and my two children. I thought losing my husband to brain cancer at the age of 41 was the worst thing I would ever endure. I was wrong. Lyme disease has taken years away from me and my two children and it could all have been history, if doctors were only properly educated and the right treatment not withheld from us at the time.

I hope my story illustrates what can be the worst case scenario for a family when Lyme disease strikes. Doctors repeatedly say they don't believe in Lyme disease, but it happened to all three of us.

I will never again work in my garden nor go for a walk in the woods. I live in fear of not getting well and being bitten again. It's a terrible way to live. I hope my story will be a lesson as to what can happen when Lyme disease is left untreated.

PATTI VAUGHN, CHESHIRE, CT 06410

My story is like many others. I'm a Whitewater kayaker and this takes me into the woods to get to the river. On one trip home I found the tick on my head, went to the doctor after a couple weeks of not feeling well and there is my result. I have Lyme disease.

I've had a few rounds of antibiotics and at this point I only go to the doctor when I'm symptomatic. This has cut into my active life style and my quality of living. If there could be a definitive test, so you would know if you have the active infection or not would be helpful. Right now no matter what I test positive because they test for the antibodies that I will now always have in my system. My boyfriend has suffered with his Lyme for years and finally having to pay out of pocket to see doctors to get treatment.

EDWARD WALKER, GUILFORD, CT 06437

I was a vibrant husband, small business owner with a four children family, when I was literally struck down with Lyme disease in 1999. It attacked my central nervous system and changed my very being. Prior to diagnoses, which lasted a few months, I was hot then cold, dizzy, incapacitated with fatigue and mentally in a fog with a severe loss of my short term memory and, what I refer to as, Lyme induced ADD. My whole life as I knew it was upside down and you can imagine how it affected my family and my partner and our 30 employees at our small town firm. I have not recovered from most of these symptoms. I had to sell my half of the company, that I started, to my partner because I could not perform my duties as CEO. I, as of 2008 and the sale of my company, have had to retire from working at what I loved to do. I'm simply unable due to this debilitating illness. I'm sure there are, if not 100s, 1,000s of these stories.

JULIA MITCHELL, NEW CANAAN, CT 06840

Suddenly at the end of January this year my 4-year-old son Jack developed pain in his knees. Within one day my son was in excruciating pain all the time in both his knees and ankles. He could no longer stand up. He had to eat his food propped up whilst lying down as it was too painful to move him. Within a further 2 days he had chronic pain in his shoulder and could not turn his head.

After 5 days from the initial onset of pain he was diagnosed with Lyme disease. He was treated with 7 weeks of antibiotics. During the first 2 weeks the pain went away but he was too tired to walk by each afternoon. By the 3rd to 4th week of antibiotics he was symptom free.

We are praying that he has beaten his hideous disease.

It was June 3, 2011, I had plans to meet some friends for appetizers, I felt an odd tingling feeling in the tips of my left hand, didn't think much of it, maybe it was something I had done at work, a few moments later I had a "wave" of dizzy/lightheadedness come over me which lasted a moment.

I met my friends and was home by 11:00 p.m. I woke up the next morning June 4, 2011 the day that changed my life FOREVER! When I woke up I had NO feeling in the left side of my face and NO feeling in my left hand from my wrist down. Needless to say not only is this not a "normal" occurrence but it became very frightening, I was 38 at the time, a single mother of a then 15-year-old son that I have sole custody of and is my world. I just had to be okay! I waited the day to see if it was possibly just a bad migraine coming on, at 5:17 a friend brought me to the hospital, I explain what had happened how it came on out of nowhere etc. the doctor came back after a short time and said "I think it's just a migraine" I replied as I was crying "but I never got the headache" a few moments later they came in and said they were taking me for a CT Scan. Well not long after the scan the doctor returned and said something about finding something on my brain, at that moment I think I just shut down and did not hear anything else except I was going to ICU, I do know what ICU is but at that moment I could not even comprehend what anyone was saying nor what was going on. I was in the hospital for 4 days deteriorating SO rapidly fast, I just kept repeating "you don't understand I just want to go home to my son and dog" I was not getting any answers and when I did it was everything from a brain tumor to just a mass to your going to need brain surgery to you have to be seen by a brain surgeon.

I had debilitated SO quickly that I could not even walk 4 steps when I was released from the hospital 4 days later.

A few days later I had an MRI, however was not able to be left alone as I could no longer do anything. Soon after the MRI I went to see a Neurosurgeon, well I had a mass on my brain all right, a 21 mm mass!! That is the size of a golf ball, it is in the deep part of my brain that controls my breathing and swallowing the Neurosurgeon was so confused over what he saw, it did not fit any one diagnosis perfectly, he brought this to his peer group that meets once a week to see if he could gain any clarity. Needless to say as weak as I was I would NEVER just let someone cut into my brain. Upon waiting for the Neurosurgeon to speak with his peer group it was suggested by a friend that I should see a Lyme doctor. Listen, at the point I was at and how bad I was I would have gone to see anyone if I thought they could help. I was SO SO VERY lucky to get an appointment within that week. The doctor spent over an hour with me as well as I gave him a copy of the MRI for him to review, we spoke about how I had been feeling, and he did some balancing "tests" with me. He also asked me "why I had never gone back to him since 2007, when I tested positive for Lyme"? My response was "I could not afford it" I did 6 weeks of the doxycycline that he had written in 2007, felt better, realized there was no way I could afford \$250.00 every 2 months to see the doctor as he does not accept insurance due to how controversial Lyme and Lyme treatment is and how unrecognized Lyme is! Great lesson to learn, too bad it was at the expense of my life, health and quality of life! He looked at my MRI and yes has seen lesions on the brain but again this did not fit any description perfectly. I was put on medicine ASAP from him as he also wanted to "study" my MRI. I slept 18 hours a day ALL of June, July and August. I could not work, drive or even be left alone.

I returned to see the doctor 6 weeks after my original visit and the office manager did not even recognize me. I was able to sit up straight and walk somewhat better. Since the 6 weeks in between seeing him I had another MRI done, and the mass was now 10mm!!!! It had to be Lyme!!!! If it was cancer or a tumor it would not have shrunk that quickly or from the medicine alone. I spoke with the Neurosurgeon who said that with the rapid decrease in size based on the medication for Lyme that he believed in fact it was Lyme. WOW!!!! A Neurosurgeon that actually believed in Lyme!

I had gone through emotional ups and downs during those 3 months when I was not sleeping. Yes part denial still, part oh how I hate feeling this way, part I just want to be me again.

In August I had another MRI, the mass was down to 5mm, to the doctor it was GREAT news to me I was disappointed I wanted it 100 percent gone. My doctor was SO thrilled with 5mm, that actually going forward should it not grow again it will always show something, somewhat like a scar per say. Once I actually saw the MRI's 21mm to 10mm to 5mm I got a better understanding and was then "accepting" of the 5mm number.

I had the lap band surgery in 2008, the pills I need to take were much bigger than the size of my stomach at that time, needless to say I made the choice to have fluid release from the band as to be able to take my medication. I kinda thought taking care of a mass on my brain was far more important than dying thin!

You tell people you have Lyme and the first thing they say is so you have a lot of joint pain and the next is do you know when you got bitten or where you were. My answers to those questions are no I don't have joint pain I have a mass on my brain and no I have no idea when I got bitten or where I was.

I NEVER had joint pain until March of this year and let me tell you there are days getting out of bed that I feel far older then 39, one of my knees when I move it actually sounds like glass breaking in it.

I have survived a year since the day my life changed forever. I have learned to manage my care and take 32 pills a day, I try some days to put on a "happy" face, suck it up and "act" normal.

I would NOT wish/want anyone else to EVER go through what I have.

I NEVER EVER in a million years thought I would be doing as "good" as I am today. Lying in that hospital bed last June, I REALLY thought this is it, this is going to be the best my life is EVER going to get. I have learned to educate myself. I have tried battling insurance companies over the need for treatment and payment. I do NOT have the money to go to the doctor every 2 months and not proudly can say I am in collections for other things because I CHOOSE LIFE!! MY LIFE!!

Four months ago I was almost Lyme "free" my recent test now shows I am positive for 8 bands of Lyme!!! My doctor explained that means the Lyme has come out of its "cell" and is now in my blood stream which means it is "pulling" itself out! Can't honestly say I was happy to hear I have more bands but do have a better understanding.

Currently I am in constant pain, my eyesight has gotten worse, my balance is off (I fell 3 times in 1 week) I could fall asleep in an instant. I am constantly tired, still have 5mm mass on my brain and "Lyme brain" or "Lyme fog" so bad I write notes for EVERYTHING, I could be in the middle of a 10 minute conversation and in 1 second completely forget what I was speaking about, like a mental wall just came up. I have to try and focus harder to understand things that I used to just "get", forget common everyday words. As well as the mounting bills.

Why is more NOT being done? Why when someone donates blood do they not even test it? Why do LLMD'S not believe and prescribe 6 weeks of meds and "you're fine"? Why do the insurance companies refuse to recognize Lyme is REAL, it is debilitating, and kills?!? Why when you go to a GP due to lack of insurance to go to a LLMD, they don't do the proper test? Because it's cheaper and more "cost effective"? At what price, the suffering or in cases of death?!

When will enough be enough?

I personally have had enough but will continue to fight this battle every day of my life and hope that Lyme does in fact become recognized for what disease it truly is and all that goes with it.

I thank you for your time in reading my personal journey thus far.

DR. PHILLIP J. BAKER, PH.D., LYME, CT 06371

DEAR SENATOR BLUMENTHAL: There is much misinformation being disseminated on the internet and elsewhere about the diagnosis and treatment of Lyme disease.

First, there is abundant evidence indicating that, when used in endemic regions or in areas where the probability of contracting Lyme disease is significant, the two-tiered test recommended by the CDC—which is based on numerous studies using well-characterized reference specimens—is extremely sensitive and specific and performs well. Although it is falsely claimed that this test was developed ONLY for surveillance purposes, that is not the case; the CDC acknowledges its use for clinical diagnostic purposes when used in conjunction with other clinical signs symptoms, and even works closely with State Laboratories of Public Health to ensure the reliability and integrity of the data derived from such testing.

Second, the results of at least 4 peer-reviewed, NIH-supported clinical trials indicate that extended antibiotic therapy is of no benefit—and may even be unsafe—for the treatment of "chronic Lyme disease" a condition that has yet to be defined as a distinct clinical entity and one that can be distinguished from other non-infectious medical conditions with similar symptoms. Since there is NO published, peer-reviewed evidence to indicate that such treatment is both beneficial and safe, the recommendations of the IDSA—that have been supported by Lyme disease experts and organizations/panels throughout the world—should be considered valid and based on the best evidence available. Although some claim to have derived benefit from extended antibiotic therapy, it should be noted that in the largest clinical trial

conducted to date, a placebo effect of 38 percent was noted; furthermore, in a recent survey of more than 4,000 individuals by Johnson, about 40 percent claimed to have benefited from such treatment, a figure that is remarkably close to the reported placebo effect. It would be false and dishonest to assume that extended antibiotic therapy for the treatment of "chronic Lyme disease" is a proven fact.

TRACY CHRISTENSEN, LEDYARD, CT 06339

Hello, my name is Tracy Christensen, I'm 37 years old and I've been suffering from (late/chronic) Lyme disease since 2004. I went undiagnosed for over 2 years and because of this is why I'm in the condition I am in now. It started with feeling extremely exhausted and a lot of joint pain. I went to a doctor in CT and was told it was the flu. (I was not once ever tested for Lyme disease, nor was the disease ever mentioned to me.) This feeling went on for quite some time and I never seemed to feel better. I made a call to my primary care doctor and that was when I was tested for Lyme and tested positive. Given there can be false positives as well as false negatives with certain Lyme testing, I was then given a spinal tap and sure enough I definitely did have Lyme disease. Contrary to what many people think, there is not always a bull's-eye rash. I did not have a rash at all or remember being bitten by a tick. Once I was tested, I was put on Doxycycline for 30 days with no changes so I was put on a second round, and still no changes. I had EXTREME pain in my joints, especially my knees making it almost impossible for me to walk or try to stand up. I am constantly exhausted, I have memory problems, word retrieval problems, I have a lot of numbness in my right hand as well as sometimes trouble focusing and concentrating. I was then referred to someone named Dr. Sam Donta. I was given an appointment with Dr. Donta and he was so thorough and courteous and took the time to explain the disease to me. I was out of work for 12 weeks and I was put on THREE different medications for a year and a half. Tetracycline, Clarithromycin and Gabapentin. These did help, but unfortunately I took a turn for the worse and was admitted to the hospital in October of 2010 with spinal meningitis. I was literally fighting for my life. I was put in isolation as it was unclear if I had bacterial meningitis or viral meningitis, both of which are very contagious; however bacterial meningitis can be fatal. My mother would literally have to spoon feed me as I had absolutely no energy to lift a fork on my own. I had a 102 temperature for 3 days. It was an incredibly scary time. Being that I have Lyme disease also means I have a very weak immune system and am very susceptible to illness. Thankfully I had viral meningitis and was released after 4 days. During my stay I also had another spinal tap; this once again confirmed the fact that I still had Lyme disease. When you have Lyme disease that goes undiagnosed for too long, it's nearly impossible to get rid of. To this day, I still have a lot of trouble with my joints, and now it's mainly in my feet and ankles, I have a lot of memory problems, especially short term. My right hand is numb 85 percent of the time and it's painful to even make a fist with each hand, and I sometimes need assistance in standing up after sitting down for a period of time. I feel like I'm in a "fog" most days and have trouble remembering simple tasks or where I'm even going or how to get somewhere at times. Even with all of this I have a very physically demanding job in retail and I am on my feet 8 hours a day for 40 hours per week. I sometimes have to lift heavy things, but I do the best I can as I have to work. I have days where I feel like I will fall because my knees will want to just give out on me. I have fallen a few times. Thankfully each time was at home and my husband was there with me. As of present I am currently not on any prescribed medications as I'm waiting to get another appointment with Dr. Donta as I have just sent a follow-up to his office 2 days ago. I feel as if the disease has gotten into my feet, ankles, and brain as well as my nervous system. I need treatment and I wanted to share my story so that others know they are not the only ones suffering from this. There are many "Lymeers" out there and we need our voices to be heard so we can find a way to live a pain free life. But even with all I have been through with this debilitating disease, I continue to tell myself that I will not let the disease control me, I will do whatever I can, to control it! Much easier said than done. I very much miss the "me" I used to be.

JASON BOROWSKY, STRATFORD, CT 06614

It all started when I was about 7 years old, I can remember getting sick and being put on penicillin for 2 weeks and it wasn't soon after that my ankles started to hurt and then I failed 2nd grade. I had problems all through school and just felt like something just wasn't right. When I was 15 I was diagnosed with arthritis in my ankles and was told that it would worsen with time and leave me disabled, but why I had arthritis was a mystery. My first job I had I was in high school I had to quit

because of my arthritis in my ankles. My senior year of high school I wanted to become a fighter jet pilot in the air force and talked to an air force recruiter about joining but when he found out about my arthritis in my ankles he said I'm sorry but we can't take you. After high school I worked as a cook for 5 years and had to quit because of my arthritis and moved to back to Connecticut. I was working at a golf course, things were OK but still felt like something just wasn't right. Then I moved to Pennsylvania and worked a couple different jobs struggling all the way, then I was hired at a glass factory, a really great job but still I felt like something just wasn't right. My 2nd year working there my health went downhill and I went off on sick leave. Two years and about 15 doctors later I was diagnosed with Lyme disease and when I was I knew I had it since I was about 7 years old. I lost my job because my body was and still is messed up. I applied for disability back in 2008 and was denied and applied again in 2010 and was denied and now I'm in the appeal's process. I still feel sick, my arthritis is worse. My right leg is still swollen and hurts and my back pain is horrible. The doctors I see don't know what to do or how to treat me or discount everything I have to say. I had to sell everything I owned, lost a couple girlfriends and any chance of a normal life because of a Lyme infection that went undiagnosed for about 28 years. I LOST EVERYTHING AND THE AIR FORCE LOST ONE HELL OF A FIGHTER PILOT! Thank you, God bless you, and God bless America"

SHELLEY GERIAK, SEYMOUR, CT 06483

I got bit by a tick in May of 2011. My new dog I believe brought some in and came on my bed. I pulled it off but a piece was embedded and stuck. I also found one in the shower so I am not sure if I got bit by 2. I went to my doctor and saw the P.A. She tried to dig the rest out but couldn't and said it will fall out. Their policy was NOT to put me on any preventative doxycycline. I believe that would have helped me. She said wait for any symptoms and then come back and they would treat me. Four weeks to the day I developed a large red hot rash or hive but on opposite side of stomach where I was bit. I went to doctor and he put me on 3 weeks of doxy. I started with severe joint and stabbing pains in my thighs. I didn't feel better until the 3rd week of doxy. I then stopped it and 2 weeks later the symptoms came back so I was referred by that primary to an infectious disease doctor that then did the blood work through Quest and it came back positive for Lyme. He then prescribed 30 days of doxycycline. There was about a month lapse in any treatment before getting the appointment with the infectious disease physician. I then took the 30 days and felt better and a week after finishing them the symptoms came back. I called the doctor and he said he doesn't believe in chronic Lyme disease. I asked him to send me my blood work results in mail. It showed I tested positive to 2 IGG bands on western blot and 2 IGM bands. I researched it on the Web and it said if you test positive for 2 or more IGM Bands you have active Lyme. I then tried to find a Lyme literate doctor which was difficult and I learned how they don't advertise. They treat Lyme as they get flagged or watched by the medical board and or insurance companies for prescribing too much of antibiotics. I finally found and got an appointment with a Lyme literate doctor at end of September 2011, 4 months after I got bitten. He does not accept insurance and he put me on 3 heavy duty antibiotics as well as supplements. I never had fatigue or pain like that ever and you feel like you are going to die. I finally felt a little better end of November and kept checking all my blood work as I see him every 2 months. It is a year later and in April he changed the antibiotics and I still am testing one band for IGM which you need to have none to stop antibiotics. My fear is if get sick with an infection no antibiotic will be strong enough from being on them so long. I took Mepron, Azithromycin, and Ceftin for a good 7 months and now on Plaquenil, Biaxin and Cefitin . . . all daily and twice a day. It is now a year later and every time I stop antibiotics the symptoms and pain come back. It's very frustrating . . . I take probiotics and diflucan for yeast. I also developed a low thyroid and now take medicine for that and have a baker's cyst behind one knee . . . all from the Lyme . . . I then starting also seeing a holistic doctor that treats it with a Rife Machine. I never in a million years thought this was what Lyme was like. They are parasites that form cysts around themselves encapsulated to hide from antibiotics and almost impossible to kill them all. The AMA needs to change their criteria and make all tick bites treated no matter what with 3 weeks of doxy as soon as you get bit. I have had operations, 2 children natural childbirth and fell off a 15 foot deck and never had this type of pain and fatigue. It is an 11 on a scale of 1-10. Please help any way you can.

My family and friends have encouraged me for years to write a book about my 20 year struggle with Lyme disease. The reason I have chosen not to is twofold: first, I cannot dwell on my illness because I am afraid I would never let go of the sadness or anger and second, I am aware that my story is similar to thousands of other peoples. However, when I saw this opportunity, I thought I would take a moment to briefly share my journey which changed the course of my life forever.

I grew up in Greenwich, Connecticut and I was a very accomplished student and athlete. I was an All-State field hockey player, a leader in my class and a very happy, competitive young woman with lots of friends. In the fall of my senior year of high school, seemingly overnight, I became utterly depressed. I became socially withdrawn even though I had just been accepted early to UVA and won our State championship in field hockey. I also began to experience severe back pain, intense fatigue and other physical problems. But because they all did not develop at the same exact time and physical symptoms migrated, my family and I could only focus on the depression.

Over the course of the next 15 years, I dealt with a laundry list of serious physical problems but the constant undercurrent in my life was my major depression. I had to drop out of college twice and I was hospitalized for depression twice—the first time was a brief stint because I was a threat to myself; the second was a 4 month stay after a near successful suicide attempt. Regardless of the fact that I thankfully lived, my life as I knew it was over.

My family comes from the “pull yourself up by the boot straps” mentality and I was leading the charge in the belief that my problems were purely psychological. Although now in retrospect my family can list dozens of major physical symptoms that I was experiencing during that time period—arthritis and surgery in my knee, major joint pain, debilitating fatigue, random infections that never made sense, constant headaches, weight loss/gain, skin rashes, menstrual problems, multiple cervical dysplasias, hair loss, mouth sores, the list goes on and on—Lyme was never on the radar and the symptoms always came and went. My family and I never suspected an underlying ailment.

I was eventually diagnosed as bipolar with borderline personality disorder. At one point in time, I was taking upwards of 10 psychotropic at once, everything from lithium, depakote, risperdal, neurontin, ativan, trazadone. The best doctors in the NYC area put me on everything, but never questioned the fact that I had no family history of depression at all nor did they ever question the physical symptoms which were very apparent. By the age of 22, I could barely hold down a part-time job because I was a zombie. My Mom tells me now she used to pray every night that I would wake up in the morning. I was so doped up I could barely walk up a hill. Therapy was my full time job—for much of my early twenties, I went four times a week. After the hospitalizations and all of the therapy, my family had blown through my college money and my parents struggled to pay my medical bills.

This sounds crazy, but the greatest thing that ever happened to me was that I got bitten by a tick again in 2007. Because I was reinfected, I became so severely ill that no one could ignore the symptoms anymore. At first, the doctors thought I had mono, then MS or some type of lymphoma. I was so sick that I was vomiting regularly from headaches, I couldn't speak, I could barely walk, I lost almost all short-term memory and I lost weight rapidly. I developed papilledema (my brain swelled so much and put pressure on my optic nerves) and I nearly went blind.

We were desperate for answers and finally, I was led by a friend to Dr. Richard Horowitz and his brilliant P.A. Lauren Yunker. Although I had tested negative at two other labs over the previous 6 months, my Lyme test came back positive both for chronic and acute infections, even according to CDC standards. The rest of the story is like many others. I did months and months of IV treatment, along with injections and years of other treatment—both antibiotics and holistic.

The last time I swallowed a psychotropic was in November of 2007. I can honestly say that I have never felt a moment of depression since. Once the Lyme was cleared from my brain, my moods became stable and it was as if I finally came up from underwater. I continued with therapy for quite a while largely because I was seemingly dealing with PTSD. To realize that I literally lost 15 years of my life because of an infection that could have been dealt with relatively simply was almost too much to handle. For years, I had been told that I would forever be bipolar and I had completely adopted the identity of “crazy girl” who would never have any sort of future.

My life is amazing now. I am married to an incredible man and I have a son who is now 2½. I very much still deal with Lyme and now a lupus-like autoimmune con-

dition partly because I was sick with Lyme for so long. I am still in and out of treatment but I am so lucky to have the life that I am living.

Lyme is brutal on so many levels—not only can it literally destroy your life—physically, psychologically, socially, and financially but it is also completely isolating. I cannot tell you how many doctors belittled me, told me I was crazy or wouldn't touch me with a ten foot pole. And I certainly can say that you learn who your friends are when you have Lyme. People have a very difficult time understanding how a tick bite can lead to such devastation. I often still question who to share my story with. And the journey of treatment which is incredibly painful and brutal does not engender much sympathy from friends.

The thing that upsets my family most is that when someone like myself is ill with odd physical and psychiatric symptoms (particularly in the Northeast), Lyme should be one of the first thoughts in a doctor's mind. Why do doctors so freely and easily label children and adolescents with psychiatric diagnoses that will forever alter their lives but are so reluctant to even entertain that Lyme could be the cause? I am certainly not saying that psychiatric disorders are not prevalent or real, but the ease with which they diagnose children and the simultaneous resistance to entertaining that Lyme could cause such odd multisystemic problems is shocking and downright dangerous.

My story is a horrific one but it has a happy ending. I am now working to make sure that others don't go through what I experienced.

CHRISTY RYAN, ELLINGTON, CT 0602

It was 1997 when I got sick. I had gone to my local doctor with a bite on my leg with a circle around it. They told me that it was just a reaction to a mosquito bite. A few months later I got very sick. I had been walking my neighborhood every day for exercise (about three miles) and now I needed help from my husband to walk up one flight of stairs. Severe muscle weakness, tremors, irregular/fast heart beats, lack of appetite, trouble breathing and breathlessness, extreme teeth pain, trouble swallowing, word finding and memory issues, ulcerated colitis, headaches dizziness, problems sorting things etc. I was so weak I could not even hold a conversation for any length of time. I went to the same doctor again and they told me to go home, that I needed to eat more vegetables. So I tried to eat more vegetables and got sicker. They never once took a blood test to see if I had Lyme. I went years (over 8) going to different doctors. I saw about 25 different doctors ranging from family to neurologist, rheumatologist, infectious disease, endocrinologists, nutritionists, etc. I had many blood tests, brain scans, EMG, Heart monitors etc. I was told by almost every doctor I saw that . . . I was depressed, that I needed to be on antidepressants, they asked questions like . . . are you having trouble at home with your husband? Are you unhappy with your life? We can't find anything wrong with you, you are fine. I was in and out of emergency rooms a dozen times with heart issues. The doctors were more interested in writing me a prescription for antidepressants than finding out what was wrong. I had mentioned to them on several occasions that I thought I had Lyme and they would say . . . Lyme does not have symptoms like that. One neurologist did not even examine me and told me I was depressed and offered a prescription of . . . you guessed it, antidepressants. I am not sure when all these doctors became psychologists? Well thank God my mind still functioned and I knew I was truly sick. It was not in my head, it was not because I was a woman or that I was having trouble with my husband or I needed to eat more vegetables. That was all just a bunch of nonsense the doctors came up with so they did not have to tell me that, "they did not know". My diagnosis was purely by happen stance. My sister was visiting a relative in Nantucket and was telling her my story and she told my sister, "I know what is wrong with her, she has Lyme" My sister said, "How can you be so sure" Well she had been diagnosed a year earlier after 3 years of going through the same ordeal that I went through. Our stories were almost identical. She gave me the name of her doctor in Boston. I will not tell his name, because these Lyme doctors have had their licenses taken away from the non-believers, for just helping people. I made an appointment, I brought in my blood tests, told him my symptoms and he said, "You have Lyme". Eight years of fighting, arguing, pleading for relief, pleading for someone to believe me, pleading for my dignity and it was so simple and not simple at the same time. I sat there and cried in his office in front of him and God with relief that someone knew and that they believed me. All this time my Family and I suffered needlessly. I was put on antibiotics and a malaria drug for 2 years. I can function now, I can work now. I still have lingering problems every month, but I deal with it the best I can and I am so much better than before. I cannot thank my Doctor enough who believed me. I cannot thank my husband enough for being a rock and loving me

through it all. We need better testing, we need more education for Doctors, but most of all we need someone to believe us first.

KELLY SHARP, NOANK, CT 06340

Coming up on 1 year of IV antibiotics and I am finally starting to feel alive again. I've had painful arthritis in my hands for years which is now 90 percent better, not to mention a myriad of other ills. Lyme and all of its co-infection have gotten into my heart, my brain, bladder, bones, thyroid, kidneys and nerves. I can make it through the day much better now, and for that, I am grateful. I am not grateful to the doctor who dropped me after my Lyme diagnosis and subsequent treatment by a Lyme literate doctor. In 10 years he did not diagnose me because my ELISA was always negative. Every year, he told me, "You don't have Lyme". My insurance company dropped me as well, when I was finally diagnosed with a Western Blot at my own request. My wish is that the Lyme guidelines be changed so that chronic Lyme patients can be treated with long-term antibiotics, which are covered by insurance, for however long it takes to get better. All doctors should be educated in Lyme symptoms and treatment. Neither doctors nor insurance companies should be allowed to drop patients because they have Lyme. More government funding for research, including better testing of tick borne illnesses. If these things could be accomplished, we will have started to fight this modern day scourge. Thank you.

MR. AND MRS. MARSHA MARCINKO, WATERBURY, CT 06708

THE BEGINNING OF THE END AND BACK AGAIN

I've had several people ask me recently where my full story is. I suppose I've kind of been avoiding it because it's difficult to know where it begins, and it certainly hasn't ended. See, I've come to the realization that Lyme disease is not just the process of being infected, being properly diagnosed (or not), and being treated. It is much more complex than that. It is a stealthy and highly evolved bacterium that affects every person differently and to different degrees.

The severity of the infection is dependent on the presence of other co-infections or other underlying conditions such as genetics, the strength of your immune system, your diet, your mindset, your social and emotional well-being, stress levels, companionship, the list goes on. It is dependent on each individual person and their overall health. How it affects one person can be completely different from the next. Some people can harbor Lyme and not have symptoms for years, until the circumstances are just right. That's what happened to me.

I suppose my story begins as a young child. I was always small, pale, and I got sick a lot. Not an extremely large amount, but if there was something going around, I was sure to catch it. I had a few unexplained illnesses when I was young that resolved themselves. Fast forward to my teens, and the thing that sticks out to me is all I ate was sugar and bread. All I drank was sugar. I was an angry youth. I was depressed. And I generally walked around with a chip on my shoulder.

When I was 18, I decided to become a vegetarian. I read all the veggie books, cookbooks, studied nutrition; thought I was eating healthy. And I kind of was. I was eating organic food and whole grains, at least. But I smoked, I drank, I drank an insane amount of coffee with an even more insane amount of sugar. Sweets—couldn't stay away from them. I always felt tired, somewhat out of control, out of my body. Fifteen years later I went back to eating meat because my body was screaming for it.

What does all of this have to do with Lyme disease? Well, it sets up the stage for where I was physically, emotionally, mentally. I wasn't that bad—but I wasn't in a good place either. I wasn't taking care of myself. Eating was something I did to make my stomach shut up. Sleeping was something I did when I couldn't stay awake anymore.

I worked as a theatrical electrician, lighting designer, technical director, and stage manager for years. Working long hours for not a lot of pay. Loved that aspect of my life. It was my passion. Then I transitioned into working as an electrician in construction. Quickly moved up as a working foreman, estimator, project manager. Eventually I joined the IBEW electrical union.

I had a pretty good life aside from my ex-jerk who I wasted 9 miserable years on. I had a good career. I loved to go back-country hiking. I was in good shape. I started taking classes to learn how to meditate, do Clairvoyant readings and healings. I was finally coming into my own, learning to look within and heal, find personal growth. I decided to go on a Vision Quest in New Mexico in 2001 which turned out to be the most amazing life changing experience I've ever had. Unfortunately or fortunately, this is also where I believe I was infected with Lyme disease.

I don't know for sure when, where, or how I was infected. I never saw a tick. I never developed a bulls-eye rash. The only thing I remember is being attacked by at least 50 deer flies while getting water out on my quest. I had bites all over my body. So after that first day I wore my rain gear to go get water. It was plastic, covered my body, and didn't allow them in as easily. It was not long after this quest that my symptoms began to surface.

Most of them I just chalked up to getting older, having beat up my body as a kid and in my field of work. Aches and pains, joints cracking didn't seem unreasonable. Headaches I just assumed were because of stress. When I started to raise an eyebrow was when the twitching began. I would kick so violently in my sleep it would wake me. My whole body would jerk from the force. I just ignored it.

At one point, I had developed bursitis in my knee for no apparent reason, even doctors thought I was a little young for that. Then, I started to notice that I was dropping things. I always had good mechanical ability and strong hands from being an electrician for so long. At times, it was as if my hand just randomly decided it didn't want to continue holding what had been placed in it. A coffee cup. A tool. My keys.

Then, I started to have recurring vertigo where I couldn't drive because the whole world would spin. It would be bad for a few days, and then take about 2 weeks to completely go away. I would walk into walls. My balance was off. I was very fatigued. I couldn't seem to get a good night sleep between the twitching and the unbearable night sweats where I would wake up soaked and freezing.

Then I started having poor memory and moments of just feeling lost and stupid. I thought it was just because I hadn't been sleeping. I just kept ignoring all of it thinking it had obvious reasons. I started getting sick a lot, my ears would ring, my muscles would twitch. I'd get random pains. I had many more symptoms, tests, surgeries, and illness than what I list here.

Then, I developed a sort of rash on my arms in 2005. It was just little red bumps. Nothing I could recognize. And the lymph nodes under my arms and in my pelvis swelled and hurt. I didn't have a fever, but I felt something systemic was going on. I just didn't feel right. I looked up my symptoms online and saw Lyme disease. I thought, "I doubt it, I haven't had any ticks on me, but I'll ask the doc."

So I went to my doctor about the rash and lymph nodes and asked him to test me for Lyme. He refused, telling me there is no way it could be Lyme. I didn't have a tick or the bulls-eye rash, and there isn't any Lyme in California. He tested me for tuberculosis instead.

I went on with my life until I had an injury at work. I had somehow pulled my sternum and knocked my back out of whack, or so I was told by the doctors. Nothing they could do, nothing showed on the MRI and they told me to go back to work. But, I couldn't work for more than a couple hours without having the sharp pains radiating from my back around my ribcage, which always scared me and made me think I was having a heart attack. I couldn't work as an electrician anymore. Now I think it probably had to do with Lyme, but there's no way to definitively know.

Meanwhile, during all of this I had left my ex-jerk, gotten my own apartment, and was swept off my feet by the love of my life, my husband. He swept me right to Connecticut, where I began to work as an estimator/project manager for an electrical contractor. A few years later we were married. Hindsight, I realize that right before the wedding I had taken antibiotics for a sinus infection. By the time the wedding came around, I felt better than I had in years. I thought it was just because I was getting married!

About 6 months after our wedding my normal symptoms that I had been ignoring for years started to get worse. My knee swelled and hurt to walk on it, yet I hadn't done anything to hurt it. I was working overtime, and I was home sitting on my tail the whole time. How could I have hurt my knee? It got to the point where I couldn't drive my truck anymore because I couldn't push the clutch in.

I went to the doctor, and she sent me to an orthopedic surgeon. The first one I saw immediately gave me a cortisone shot, without X-rays or an MRI. Little did I know this would prove to be detrimental for Lyme. He arrogantly said, "You will walk out of here like you never had pain." As I was limping out, he saw me and said, "Feels better, right?" I winced in pain, and said, "No, it's actually worse." He gave me a disapproving look and said, "Give it time, you'll be fine in a couple hours."

Well, that didn't happen. It got much worse. I went to another orthopedic surgeon, who took an MRI and found there was a "chip" missing out of the bone on the side of my knee. He insisted I must have stepped hard or fell or did something to injure it. I insisted that wasn't possible. He dismissed it and said I must not remember. He said all he could do was surgery to try to clean it out and induce healing. So,

I scheduled the surgery. Little did I know at the time that both Lyme and Candida are capable of causing that type of damage.

A few weeks before the surgery, an accident happened at my workplace stopping all work, and I didn't know if I was going to keep my job or what was going to happen. So I cancelled the surgery. Meanwhile, I had made an appointment with a new general practitioner. I went for my normal first appointment physical. I'll never forget this day. It was in February 2010. Almost 10 years had passed without any answers. I went with a list of symptoms.

My new doctor, without ever doing a blood test, knew the moment she met me that I had Lyme disease, and suspected Erlichiosis. She had suffered herself with Lyme, and had to be on IV antibiotics to treat it for an extended period of time. She knew the ugly face of this disease first hand. She tested me, and it came back positive. She immediately started me on Doxycycline, and I started to have the Herxheimer Reaction.

I'll never forget seeing the PA at that doctor's office when I went for a follow up a month later and she said, "You must be feeling better now that you've been treated for Lyme disease." I just looked at her. I didn't know what to say. I was actually at my worst moment in treatment and I felt like I was going to die.

I was on antibiotics for 11 months. During that time I can't even begin to tell you the pain that I endured. The twitching, cramping, brain fog, loss of words, no sleep, anxiety, heart palpitations . . . it just didn't end. I had to continue to work, and often I was working 50 hours a week at a job that required me to be detail oriented and on point.

Probably the worst day I had was when I drove home from work, drove past my exit and kept driving to my last job. I got halfway there before I "woke up" and realized where I was. Then, I went to order Chinese food and I'm on the phone, staring at the menu, and I couldn't read, think, or speak. I had to hang up the phone. It was terrifying.

There were many times during treatment that I didn't know if I was going to make it; if I had it in me to keep fighting. And I did not have it anywhere near as bad as most do that encounter this disease. I have a high tolerance for pain. I didn't have the paralysis and complete disability that many endure. For that I am grateful.

But I did have my husband, my Mom, and a few friends (not all of them) that stood closely by me and cheered me on. They would not let me give up. They kept reminding me of how courageous I was, and how strong I was, and that they knew I could beat this thing. They kept my hope alive.

After 11 months, I started to feel worse, not better. I began to become concerned that the treatment wasn't working. I started doing some research and found some information on Candida (yeast). I found that symptoms are almost identical to Lyme symptoms, and that if not treated, it can kill you. My doctor had told me to cut out sugar and take probiotics while on antibiotics, and gave me Fluconazole to keep it in check. But, I don't think I ever realized how crucial it was to eat a strict diet during treatment. I just didn't listen.

I went for a follow-up and talked to her about it. She agreed, and told me to stop antibiotics; even though I had not gone 2 months symptom free. It saved my life. She did some tests and found that my Lyme test was now showing negative, and a Candida culture showed that I did have an infection. She put me on Fluconazole daily, and told me to adhere to a strict diet. This was probably the hardest part of treatment for me.

Everything I knew had to change. No more sugar, no more bread, no more alcohol, no more grains, no more milk or cheese. I thought I was going to starve.

But, after a couple weeks, I started to feel so much better, and I had already lost over 10 lbs. After 2 months, almost all of my symptoms had vanished and I felt better than I had in years. After 4 months, I had lost 30 lbs., my weight had stabilized, I was symptom free, energetic, and I had my life back. I was amazed. It came out of nowhere. I wasn't even expecting it, I had been sick for so long.

I decided to share my success on the forums, and found it was met with great resistance. Not only was I told that it would only be a matter of time before my "remission" would cease and Lyme would return, but the whole idea of Candida being an issue was completely dismissed. I was shocked. Appalled. Here I wanted to share what seemed to me to be a pretty important key to the puzzle, and I was told I didn't know what I was talking about. My own Lyme community was not supportive of me and my experience.

So, I decided to make my Web site, www.LivingLyme.com. I realized there was a voice that needed to be heard. Not only did I believe in and experience Hope and Success, but I knew that there were many people out there suffering with Candida

and being treated for Lyme. I knew that this information could help a lot of people get their lives back as much as possible.

I thought I was cured. So, I went off the diet. Within a week I started to feel sick again. This was when I realized that just because your symptoms are gone, does not mean that your body has completely healed. It takes a significant amount of time to completely restore your health. I was at the beginning, not the end.

For the next 6 months I struggled with diet, fighting Candida, diet, diet, diet, diet. This was my biggest struggle! Give me a pill or herb to take and I'll do it. But stick to a strict diet? I didn't have the time, the energy, or the will power to do that. And the most ridiculous part of it all is that I knew that when I stuck to the diet, I felt fantastic. And when I went off of it, I went way off of it, and got sick again.

It took me another 10 months of research and writing to finish the Web site. It evolved into much more than I could have ever anticipated. During that time, I learned more about this disease and about myself than I could have ever imagined. I learned so much more about Nutrition than I had in the 20 years of studying food and nutrition and alternative healing methods. I gained a much deeper understanding of the human body, and the mind-body connection. I learned what it means to surround yourself with allies.

The most valuable lesson I have learned is the importance of taking care of myself, inside and out. I am still grasping this, and embracing it. I still have much more to learn.

ZELMA BERUBE, COLCHESTER, CT 06415

I moved to CT with my husband in 1997—back to his hometown—after he separated from the USAF. We met while in the military; we both served in the USAF during Desert Storm. I got out of the service in 1992 and went back to school—I finished my Master in Public Administration in 1997. My son David was 2 years old and Dean was facing going to be deployed again so we decided he should get out and we should move to his home town in CT. I was able to find a good job in 1998. To my surprise, I also found out I was pregnant, totally not planned but very happy about it. Baby Daniel came December 31, 1998, we had bought a house and moved in beginning of February. And with all these great things happening, my NIGHTMARE started April 1999.

My story began on a day like any—waking up on a Monday morning to go to work. Baby Daniel was now just 3½ months old. It's mid-April and my husband and I had been doing a lot of yard work through the month getting the yard ready. I was planting in the front of the house on Sunday—I'm not much of a planter though—I'm a city girl by heart. Woke up and felt sore all over my body—achy—like I got run over by a truck or something. I couldn't believe that I was still in such bad shape from having the baby; I always worked out and was in pretty good shape before baby Daniel came.

Throughout the day, the achiness turned into severe pain all focused on my right side. It started from the top of my head all the way down to my right toe. Being Manager of the Children's Hospital Primary Care Center, I worked with great doctors. I talked to one of them and she took a look at me—saw a small red rash like on the inside of my right knee. Thought maybe I was having an allergic reaction to something that bit me while I was doing yard work. Gave me Benadryl and told me to go home and get some rest. I was feeling pretty awful so I decided to go home early as she suggested.

On my way driving home, I started losing control of my right side muscles of the face, everything started twitching. I had already left the hospital so I stopped at the nearest outpatient Emergency Room. While there, I started having this episode which made everyone think I was having a stroke. I lost complete functioning of my right side, I couldn't write, I couldn't walk. I still remember the nurse's comment "but she's only 32". They transported me via ambulance to the nearest Hospital. They did Neurological evaluations and a CT scan but everything was normal. After 14 hours I was able to walk out of there. Debilitated but had regained my right side functioning. All the doctors were baffled. I was baffled and couldn't get my head around what had happened to me. I had always been pretty healthy—even my pregnancies, I worked until the last day before I delivered.

The following months were a blur . . . these seizure-like episodes kept coming on and off and I was in and out of the emergency room. No one could figure out what was happening to me. I tried to continue to work but it was useless—the episodes would happen at work and I had everyone there scared not knowing what to do. They would happen while I was driving so I would pull over and wait until they passed and turned around and go home and go to bed. My Primary Care doctor and Neurologist initially told me it could be MS, a brain tumor, Lupus but after all the

tests were normal they had no answers. The Neurologist finally told me I was depressed and needed to take depression medication—maybe post-partum depression he said. I knew better . . . I was getting depressed of not knowing what was making me sick. It was now over 6 months later and I was exhausted of going from doctor to doctor and no help. My Primary Care doctor wouldn't even see me anymore when I had the episode, she just sent me to the ER. It was just sad. That's when I took control. I got copies of all my records and started looking for something. There it was the positive Lyme titer—but what is Lyme? I questioned.

I had never heard of Lyme before so there started my research. My Western Blot test was negative but as I read more and more I found that this was not unusual. I contacted the Lyme Disease Foundation and went over my symptoms which by now had expanded to my spine to the point that I could barely walk. They reassured me and told me this may be Neuro Lyme and I needed to see a Lyme Literate M.D. (LLMD) right away—so I got a list of them. One in NY, MA and CT. I thank god every day for having found my wonderful doctor. He saved my life. He not only diagnosed me with Lyme disease but I also had Babesiosis, another tick-transmitted disease. Although my CDC Lyme tests kept coming back negative, the positive Babesia test confirmed I was definitely bit by a tick. It was a painful treatment process. The Herx or healing crisis as they call it from the die-off of the bacteria; the long road to recovery. It took well over a year for me to start feeling like myself again but I did it. I did it when every one of my doctors had turned their backs on me. I did it with only the support from my family, my friends and my Lyme doctor.

I have had several relapses since and every time it gets more difficult. My first relapse was in 2003, this time I was able to get a positive Lyme test and PCR via the Igenex lab—I had many Lyme reactive bands but I still couldn't meet the CDC criteria for a positive test. My LLMD explained this controversy to me and I was baffled. I was able to get on IV treatment right away since my Neurological symptoms were very severe and I was again having the seizure-like episodes. It again took over a year to get back on track. I had started a new job with Hartford Hospital Patient Accounts Department in 2002 and I just couldn't believe I had to once again deal with this horrible disease. After many months of struggling, I continued to work but had to resign from my full-time position and took a part-time job at the Hospital so I could continue with my treatment and slow recovery.

My 2nd relapse came shortly after when I had finally regained my strength and had started to feel better. I started having some non-related issues of Endometriosis in 2005. This meant I had to go on hormone treatment but I knew that was going to be very difficult with the Lyme disease. I had never been able to go back on the birth-control pill. There was something about hormones and Lyme and although I couldn't make the connection, I knew that taking hormones just exacerbated all the Lyme symptoms. Sure enough as soon as I started the hormone treatment required to deal with the Endometriosis diagnosis, the seizure-like episodes were back. I was back with all the Neurological symptoms again and these continued while I dealt with this other disease. I finally found an OB Specialists that would listen and he allowed me to go through surgery and have a hysterectomy so I can get off the hormones. I continued to treat the Lyme but the antibiotics were now just keeping me feeling sick. I opted to see a Naturopathic doctor and started regular acupuncture treatment. It took 2+ years to get back on track but I finally felt like myself again and I was back!!

I had a long break from the ailments of Lyme and was finally starting to think I was finally done with this nasty disease. I still struggled from time to time with fatigue and aches and pains but I continued to seek care with my Acupuncture doctor and to maintain my immune system strong. I never felt better.

In 2011 some weird things started to happen. I had been able to go back to full-time work in 2007 and got a promotion in 2010, my stress level was at an all-time high. I was working out and continued with the natural treatments although I hadn't made it to see my Acupuncture doctor in a while. My schedule was just crazy busy with home and work.

One day on my way home from work, I just simply ran my fingers through my hair and was massaging my scalp when I felt a bald spot. I totally freaked out . . . my scalp was soft like a baby's bottom . . . totally no trace of any hair in that area. I had also been having a real tough time sleeping—actually I was not sleeping at all. I would lay in bed all night wide awake and then finally fall sleep at 3 a.m. or 4 a.m. then had to get up at 6:30 a.m. to go to work . . . I was miserable and exhausted. A friend recommended that I take a natural sleep aid called Melatonin—I researched it and it sounded harmless. I bought a bottle and tried it . . . slept like a baby the first couple of nights. About a week into taking this, I started to break into hives. I'm really not sure if this were caused by the Melatonin or not but I think there was something in them that triggered some type of reaction.

I dealt with the hives for about a week but they kept getting worse . . . spreading all over my body more and more. I bought Benadryl and all kinds of itch reliever and nothing would stop the itch and pain. Finally on a Friday I was home (good Friday I think) was helping my husband outside with the yard work and the burning got so BAD, I just couldn't take it anymore. The hives were all over in between my legs and I could barely walk! I went to the walk-in medical center in town. When I saw the doctor, he took a look at the bald spot—Alopecia he said—and the hives combination—maybe Lupus he said. I explained to him that I had history of Lyme disease but he wasn't so interested in that. He did blood work to test me for all kinds of stuff . . . and prescribed me some steroids to help deal with the hives. I wish I could go back to that day again and I would never take those STEROIDS . . . because that is what caused this relapse I am sure of it. I cannot prove it . . . but I know it. I took the steroids for a week on a progressive dose and on day #7, I started to have severe pains in the back of the head, my seizure-like episodes were back. I was back to square one—the Lyme bacteria was BACK!!

The seizures were BACK!! First thing I could think of was to go back to my Acupuncture doctor. He should be able to get me back on track again . . . I was so sure! I started going twice/week; he started researching what else he could do. I had a feeling I was in for a long road so I went to see a Primary Care Doctor to ask her to help me . . . brought all my records from my prior Lyme experiences. She was very skeptic about the Lyme diagnosis even though I had my positive test results from my DNA tests back in 2003. She ordered lab work to test for Lyme again and also wanted to order an MRI to see if something would show about what was happening in the brain. Marc was working so hard looking for alternative treatments but the Lyme was very busy. My symptoms were getting worse very quickly. It wasn't only the seizures now; I was starting to have all these cognitive issues too. At times I could barely speak—my tongue was numb and I couldn't enunciate my words anymore but I just couldn't think straight—my brain was getting full of Lyme bugs. I was a walking Lyme-time bomb!

It hadn't even been a month yet but it really felt like a year! In May 2011, I had to ask for a leave of absence from work so I can figure out what I was going to do. I was able to get 6 weeks. The MRI was normal and my Lyme tests were negative (what a surprise!) The doctor saw me at my worse on one of my visits where I could barely talk and walk—she wanted me to see a neurologist right away and asked if I would see an Infectious Disease doctor. I agreed but had my reservations—I knew this wouldn't be easy to sell my Lyme diagnosis all over again with negative tests results. I needed a Lyme Literate M.D. but how I can get one soon! I tried calling my old Lyme doctor and see if he would see me again—unfortunately he was out on a medical leave himself and closed his practice shortly after. So I was back to square one without a LLMD—and with neurological symptoms advancing so quickly on me. I know it is Lyme but how do I convince all these doctors that just don't understand this disease? I couldn't, my visit to the Neurologist was a bust—it was horrible to me and made me feel once again like this was all in my head—I got some horrible flashbacks to 1999—I left there and just cried!! The Infectious Disease visit didn't go any better. He was so sure it wasn't Lyme disease. He said that since I was already treated with IV antibiotics that should have been plenty to kill all the bacteria—again I just cried as I walked out of the office!

My acupuncture doctor hadn't given up though . . . he found something—he travel to NY to visit this natural Lyme specialists and he got information on this alternative treatment called “Carnivora” I read about it and what I read totally sold me—it is used in Europe for people with cancer and there have been cases of people with Lyme that have recovered with this. So this was my only hope! I went on the treatment and I was able to go back to work in July, my brain felt clear again . . . my neurological symptoms had gotten better and I was so happy!! I knew I still had a long road though so I continued to see Marc and continued the treatment.

Unfortunately in September, the seizures came back with a vengeance. I ended up in the emergency room with one of the worse seizure episodes. They finally talked me into going on seizure meds. The seizures were happening more often now so I had to agree. I found a neurologist who although she didn't believe in Lyme, she knew the seizures were real. Unfortunately the EEG and MRIs still weren't showing anything to help her so trying the seizure meds were our only option. It helped to an extent, it reduced the severity of the seizures and they weren't coming as often anymore. I still needed a Lyme doctor to get me on the antibiotic treatment. I knew that was my only way to get rid of these bugs in my brain.

I finally found a Lyme Specialists who would treat me in MA. I started treatment in March 2012. I went downhill very quickly after starting the treatment. The die-off from the Lyme bacteria or herx reaction was very severe and I was in bed once again. Two weeks into it, I had to stop the treatment so I can continue to work.

I knew I had to figure out how to do this as the Lyme was just running rampant and spreading more and more without the antibiotics. I tried the treatment again in mid-April but like clockwork, I went downhill again and just couldn't work. My doctor convinced me to take a leave of absence from work so I can do this the right way.

I went out on my short-term disability on 4/30/12 and haven't been able to get back on track since. I find it unbelievable that I still have so much Lyme bacteria left in me to kill. My doctor told me I would need at least 6 months to get back on track and be able to get back to work . . . I really hoped it wasn't going to take that long. It has been 4 months now and I'm still fighting to get better. My cognitive issues have continued to advance but this last month, I have finally started to . . . [TRUNCATED]

JANE POWELL, WILTON, CT 06897

I had bands on Western Blot. I had IV antibiotics. I then had neuropathy I legs, worsening fatigue, shortness of breath, palpitations, pain in joints severe and severe headaches. I continued to try to have a life, got married, could not go anywhere on honeymoon due to dizziness suffered constantly. Had 2 more children got divorced tried to take care of kids while sick and ex-husband threatening to take children they began with Lyme symptoms and oldest daughter was very ill. He used this against me and had DCF called. Even though a Lyme doctor had said they both had Lyme they had a Yale doctor take the stand against me and removed my children from the only home and mother they knew. I have cried every day 6 times a day for a year. I see them 1 hour a week because they accused me of Munchausen. I am fighting to get them back while I fight this disease. Help us!!!! In America we should have the right to take our child to whatever doctor we want not fear we will lose our kids. I don't even know how they are and if they will get worse like I did. Became sick one night when I had ringing in my ear the room turned upside down and I vomited. I had a fever and a headache for a few days. I then began having migraines a lot. I was 26 had a child, began having leg pains, dizziness, diarrhea, fatigue. No diagnosis for years. I remained always feeling sick. I had severe vertigo for 1 year I was out of work I was an ICU nurse. I was finally diagnosed with Lyme.

SANDRA BERENBAUM, SOUTHBURY, CT 06488

I became ill in 1984, with severe, debilitating migraine headaches. For 6 years, I searched for doctors that would find the cause, and be able to at least give me relief. By 1990, I had been to multiple doctors, including several prominent neurologists at major medical centers. No one had answers.

By 1990, the migraines were daily, with no medication providing relief. I also had severe cognitive problems, as well as sleep issues, and psychiatric issues. The most profound migraine led to my developing a severe Bell's palsy, and I finally had the diagnosis of Lyme disease.

A friend who was a physician had diagnosed himself with Lyme disease 6 months prior to my diagnosis, when 14 of his colleagues couldn't figure out what was wrong with him. I called my friend, and asked for help in finding someone who understood this strange disease that was so severely impacting my life. He led me to a doctor in an endemic area, out of the mainstream, who treated me for 4 years, with multiple antibiotics—orals, intramuscular injections, and 25 weeks of IV antibiotics.

Four years after the start of treatment, I became headache free. I was able to get restorative sleep. My cognitive functioning returned, and the psychiatric manifestations disappeared. I am symptom free today, with brain functioning far superior, at age 70, to how I was at age 45.

I am a psychotherapist, and as I learned about Lyme, I came to realize that many of my clients had undiagnosed Lyme disease. That was the cause, in many cases, of their psychiatric problems, behavioral issues, and poor school performance. Resolve the Lyme, and the functioning of my young clients returned.

I now have a full practice seeing Lyme disease patients and their families. Many, like me, went undiagnosed, were misdiagnosed, or undertreated for months or years. Consequently, the strain on these patients and their families is enormous.

It's hard to believe that now, almost 30 years after I went undiagnosed, this problem remains, and patients continue to suffer from the ignorance that is perpetrated by the IDSA, and the filtering down of the guidelines to physicians around the country.

Denial of Lyme as a chronic persistent infection continues. Patients remain undiagnosed, misdiagnosed, and misled, with no end in sight.

PAUL MIHALICK

My battle with Lyme disease began 7 years ago when I was rushed to the Emergency Room with symptoms of a heart attack. I was diagnosed with Pericarditis which is inflammation of the sack around the heart generally caused by a viral or bacterial infection. They could not tell me the cause.

The chest pains continued over the next 3 months and I saw several doctors and cardiologist's none of whom could pinpoint the cause.

Thankfully the chest pains diminished and were finally gone. Months later the chest pains returned and at times lasted for a week to a couple months. This continued over the course of 7 years.

New symptoms began to appear muscle weakness, sensitivity to light, pain throughout the rib cage and sternum. Numbness and tingling in the fingers, loss of balance and many more.

The strange thing was none of these symptoms were constant I might have them for a day or a week or a month and I might feel fine for a week to a month confusing the doctors.

I visited my Primary doctor over the course of 5 years with all these symptoms and was tested for Lyme disease twice which came back negative both times. I was sent to numerous specialist none of whom could tell me the cause of my mystery illness.

Finally after 5 years the chest pain and fatigue became so bad I could no longer work and had to leave my job as an automotive technician. At this time I also switched doctors. Thankfully my new doctor understood that the current testing for Lyme disease is only up to 50 percent accurate and recognized my symptoms were consistent with late stage infection with Lyme disease. He ordered a more detailed test that finally proved I had the disease.

I was so relieved to finally know what was causing my disabling symptoms now I could treat this Disease and get well. After 2 years of treatment I realized this was not going to happen easily. My infection with Lyme disease persisted along with the symptoms and even more new ones began to appear.

I did much research online about the Disease and joined a support group with many other people infected with the late stage form of this disease. What I began to realize is only 5-10 percent of patients were ever getting 100 percent well and many patients were dying.

My hope is that the public and doctors will better understand that there are 2 types of Lyme Disease, the acute form which is often easy to treat if caught early. And the Chronic late stage form of the infection that is much more difficult to treat and often a lifelong battle. Once we can accept the late stage persistent form of this infection we can begin to do real research in finding a cure. This would also help patients from not only suffering the disabling physical symptoms of the disease but also the emotional stress caused by Doctors and Family members who do not understand the Chronic Late Stage form of the infection.

KELLY MAIRSON COVENTRY, CT

My story began 5 years ago when I discovered a rash on my stomach. I didn't pay much attention to it and assumed it was just a bad case of poison ivy. It wasn't until 5 months later that I started to develop odd, quirky symptoms similar to MS that eventually got so bad that I passed out on my kitchen floor. Only to wake up so sick that I couldn't move from my bed for 3 weeks. My first doctor ran blood tests and basically said I looked fine to her and thought it would be a good idea for me to start a gratitude journal and write down the things I was thankful for. At that time my tests came out normal, including my Lyme test which only showed 2 reactive bands, so it was considered negative.

Every doctor that I went to could not find out what was wrong with me, including a pretty well respected infectious disease doctor here in CT. He said my story sounded like Lyme so he decided to treat me with 3 weeks of doxycycline and told me if I didn't feel better he would put me on IV. Well I felt worse. When I saw him again I thought he would be willing to treat me but he decided to change his mind and told me I didn't have Lyme I must be vitamin D deficient from lack of sunlight. He basically dismissed me and told me that I possibly could be depressed because most women my age get that way. He suggested I see someone to talk to. Which I did because at that point I honestly thought I was going crazy.

I went from being an active 39-year-old mom of 2 small children that exercised, walked my dogs, swam, played, worked and loved my life to someone who was too tired to even talk to a friend on the phone. My legs were numb, I had blurry vision, stabbing pains everywhere, ringing in my ears, headaches, twitching, swollen glands, hearing loss, joint pain, and fatigue. I moved from my couch to my bed for

5 months until I was able to see my brilliant Lyme doctor Steven Phillips of Wilton, CT.

He diagnosed me with Chronic Lyme Disease by my symptoms, history and blood tests. At this point I had gone 18 months from that initial rash before I had treatment. I was hoping to get rid of it for good but because I had gone so long without a diagnoses or medicine it became much harder to treat.

It has now been 5 years since this all began and I have to say I am not on my couch anymore, I have bad days and am still being treated but I have improved so much with the help of my now 2 incredible Lyme doctors. Without long-term treatment I don't know where I would have been. When I stop my medicine I get fevers and get very sick again. I know what I was like when I was really sick and I wasn't able to be a mom, work or function as a member of my community. And now I am back to living again. So, please, please understand that this disease is REAL and it is CHRONIC. This bill is so important to me so I strongly urge you to let it move forward and allow Chronic Lyme Disease to be recognized and all patients who have it the respect they deserve.

Thank you.

CINDY SWEET-HENRY

I, Cindy Sweet-Henry, was visiting Mayland, VA 6 years ago, without knowledge I was bitten by a tick. But, I remember scratching off a bump on my leg without looking. Got back home to California and got very sick with a rash all over my legs. They got so bad that I could not walk on them without being in much pain. Went to clinic after 3 weeks. Doctor's here in California have no idea what this rash was but put me on antibiotics for 2 weeks. I got a bit better. It seemed I was in and out of doctor's office trying to get an answer for feeling sick, losing weight, headaches, ringing in my ears, sinus infections again and again, aches throughout my body, vision blurred and double. Hands started freezing up on me. Working with children I started catching everything. For the last year at work before my boss let me go, due to dizzy spells and blackouts and just missing so much work due to sickness. I have spent so much money on doctor after doctor. I was told MS, but had remembered the thing I scratched off my leg. My husband showed me a tick crawling on him a few times. I didn't put the link together till later. The test my GP did said negative so he ruled it out. Then I heard about IGeneX and had blood work done there . . . POSITIVE! OK now I was trying to get a doctor to help me. None in California knew what to do and wouldn't believe it. Then up in the mountains here Sequoia's I contracted a tick in my belly button, with the perfect bulls eye rash. Doctors put me on antibiotics for 2 weeks. Note every time I was on antibiotics I felt better then would spiral down afterwards.

I would love to see this Lyme Disease to be exposed for all to have knowledge of this rapidly growing disease Babesiosis. I think of all the children out there. This crippling disease could be one in your family. I wouldn't wish this on my worse enemy. God Help Us! The word needs to get out so those infected can get appropriate medical help. That insurance umbrella could allow an extensive test to determine Lyme and not the same old test they have used for years. Hear the voices of the people. We care! Texas is doing something about the mosquito's! If we don't do something we will be seeing more deaths due to uneducated people in the high places. This isn't a plea for us but for the whole USA with this Disease. In God We Trust!

CDR MARK AND LYNN JOHNSON, CHESAPEAKE, VA 23322

A little background, I am a Commander in the United States Navy currently living in the Hampton Roads area of Virginia. My wife Lynn Johnson was diagnosed with Lyme disease approximately 2 years ago, after 15 years of going undiagnosed or misdiagnosed with MS. Lyme has ravaged her body. She was receiving treatment for this disease up until about 1 year ago when our insurance Tricare, decided the care she was receiving was "beyond the standard of care" and cut off treatment. Unfortunately when they did this Tricare also reversed payment for all the care that had been received up to that point. We are currently in our third level appeal with Tricare in regards to this decision, but that appeal is not the purpose of this letter to you.

I am aware of some of the groundbreaking legislation you championed in Connecticut in regards to the available care for patients undergoing treatment for Lyme disease. What you might not realize is that there is a whole subset of patients in this country, who because their insurance is provided by the Federal Government have very little options when it comes to the treatment of this debilitating disease. I am talking of course about our members of the military and their dependents.

The Defense Health Board was supposed to have reviewed the Department of Defense policy for the treatment of Lyme disease in 2008, but held off their review until the completion of the legal battles you fought in the State of Connecticut. As you well know those legal questions have been settled for some time now, but the DHB has neglected it's duties to perform a review of this policy refusing to acknowledge that the Infectious Disease Society of America guidelines have expired. By proxy, Tricare has used these same expired guidelines to deny my wife's first and second level appeals.

I am sure you are well aware of some of the debilitating effects Lyme disease can have on a patient and by extension that patient's family. I promise you my family is no different. I no longer recognize the person I am married to, she is a 40-year-old woman living in a 70 year old woman's body. Lyme disease and its treatment are difficult enough. The frustration she feels everyday of knowing exactly what is wrong with her but being denied proper treatment is almost unbearable. Fighting with our military healthcare provider has only compounded the amount of suffering my wife endures, depression, anxiety, hopelessness, helplessness, who do we turn to? Our own Senator Jim Webb, head of the Senate Armed Services Committee, has been limited in his assistance as he is not running for re-election and in the midst of a re-election year does not have time left to sponsor legislation. I think the only thing that allows her to make it through the day is the thought of our two children and her drive to make a difference in how military dependents are treated by Tricare in regards to the treatment of Lyme disease. Her doctors are telling her she has been getting by on pure adrenaline but there is not much left in the tank.

I urge your office to look into the disparity that exists when it comes to the medical options our troops and their families have for Lyme disease treatment when compared to the general public and especially to your constituents in the great State of Connecticut. What further alarms us, when we reached out to the Department of Defense Inspector General's Office, we were told they were starting their own investigation into this matter as they had recently viewed a memo issued within the Federal Government to Military Treatment Facilities telling them to no longer test, diagnose, or treat Lyme disease.

Why has the Defense Health Board neglected to perform their required statutory review of Lyme treatment guidelines? What are they afraid to find?

I can tell you from experience and personal observation there are many military families that are sacrificing everything they have to help get their loved ones treatment outside the military health care system. In many cases they suffer personal financial ruin, bankruptcy, loss of security clearance, and vastly decreased productivity at the important jobs they perform to defend this Nation of ours.

How many of our soldiers are in a war zone right now worrying about the health of their loved ones back home who are suffering the untreated effects of Lyme disease? Is this really the effective soldier we need on the front lines? I know from personal experience that I have been ineffective in my job over the last 2 years as I struggle to find my wife treatment for Lyme disease, all the while maintaining an ongoing appeal with Tricare to cover the care she already received.

Since Tricare cut my wife's treatment short her health has diminished greatly. She has severe neurological and cognitive issues, muscle wasting and more. She has no choice but to be the single military wife 5 days a week, in Hampton Roads, VA while I work in Washington DC. It's very difficult. She now has a secondary condition/diagnosis of CIDP. This is an autoimmune disorder that requires IVIG treatment regularly. Tricare tried their hardest to deny my wife this care in violation of their own policies in the process. We fought hard to access this care and reluctantly Tricare has agreed. Is this autoimmune condition related to years of untreated Lyme disease? Only research and time will tell, hopefully. I can tell you that Tricare will pay far more for IVIG for my wife then it would cost for antibiotics that might just heal her from this infection.

Since the time we filed the appeal of my wife's Lyme treatment with Healthnet/Tricare (just over 2 years ago) we have been subject to arbitrary and capricious discrimination with regards to receiving further healthcare for my wife, even care not related to Lyme disease. We have been treated like second class citizens by the very government I go to work for every day to defend. In fact we have neglected to treat our daughter for Lyme disease, even though she is blatantly positive by Center for Disease Control standards, because we fear the repercussions we might face. Words cannot describe the helplessness I feel in regards to not being able to provide my family with the healthcare they so desperately need.

I urge your staff to look into this matter and for you to sponsor legislation requiring the Defense Health Board to review Lyme disease treatment protocol for military members and their dependents.

Thank you for your time and service in this matter.

I have lost my home, am on food stamps, am tens of thousands of dollars in debt and am so ill that I have had to leave my career of 20 years almost 5 years ago to this day. I have four doctors attesting that I am disabled, neuro cognitive exams and work capacity function tests confirm my inability to perform even sedentary work on a part time basis; MRI's, EKG's and CT scans substantiate my disease but I receive no disability, not even from my private disability insurance policy I was protected under for being in upper management. Apparently, I do not have enough evidence.

I was earning a six figure income, had a college degree and prepared for my retirement years; chances are, now, I will be in the street, with nowhere to go, once my mom is gone. She is 76 years old, lives solely on her social security, and is now supporting me financially and taking care of me at a time when I should be taking care of her. To worsen matters, my son, we suspect, has it as well along with life threatening cardiac problems and will be needing open heart surgery, to be performed this summer. How can I take care of him when I cannot take care of myself? This is all too much for my elderly mother but I have nobody else.

I cannot even go inside a grocery store on most days; the noise is intolerable, I can hear every person in the store talking all at once; my vision becomes so impaired I become dizzy and disoriented and aside from the pain in the bottom of my feet preventing me to walk far enough to gather more than a few items, I sometimes get lost and am unable to find my escape to the front door. Any stimulation to the brain . . . noise, light, talking, music, makes me confused, impaired and unable to perform even the simplest of everyday tasks.

I need a doctor. I am getting worse, quickly. On an echo cardiogram, they found fluid in my lungs yet my Medicaid doctor won't treat me due to an admitted lack of knowledge to tick borne disease (her practice is in the same county as Lyme CT!) and apparently there is a law preventing non-medicare doctors from taking my money and accepting me as a cash patient because I am on medicare. So, I cannot receive treatment. Without treatment, I cannot get better. I am now trapped by a political disease and cannot crawl out despite doing everything right . . . I went to college, graduated at the top of my class, climbed the ladder in my career and I am now one step away from a tent and a cardboard sign. I now need a machine to breathe but insurance won't cover it. My mom continues to rack up her credit cards in order to pay.

A doctor openly admitted to me recently that in med school, she was shown a picture of borrelia burgdorferi and the extent of the explanation was . . . "this is what it is, although you will probably never see it in your careers. I just wanted you to know what it looked like". This is what infuriates Lyme sufferers more than anything! An epidemic and many doctors know less than their patients. Even more inexcusable is their refusal altogether to listen with an empathetic ear and even try to help us. Instead they label us crazy hypochondriacs and we are sent away with depression medications.

Being born and raised in the Lyme, CT area, I was exposed to and bitten many times by the deer ticks in the woods by my childhood home. Back in the 1960s and early 1970s we had no idea that these tiny creatures would someday destroy our lives. In retrospect, I was stricken by Lyme decades earlier but was never treated. The big controversy over chronic lyme fails to address the many with untreated lyme.

I recall laying in bed as a child, screaming in pain; the doctors' answer . . . growing pains. As an adolescent, they gave me shots of cortisone claiming it was bursitis. We never thought to ask why a 13 year old would have bursitis but now know cortisone harmed me more than helped.

I moved out west for college and was never properly diagnosed. They never heard of Lyme Disease out there and to this day, there are many on the west coast that still insist it is an east coast problem.

When I came home for a family visit in 2006, I found another tick, a fully engorged nymph deer tick. I was advised to keep an eye on it and see somebody if I felt any symptoms. Five weeks later and back in California, I became acutely ill and sought help from several doctors; not only would nobody treat me, but I was actually told by infectious disease doctors "if you are here to talk about Lyme, you are barking up the wrong tree!" My own PCP told me "go home where you came from, there is nothing we can do for you here" (he works at a major teaching hospital in S. Cal.).

There are so many underlying problems contributing to this epidemic it is difficult to know where to begin. The lack of training of our doctors, the laws protecting them to properly treat, the diagnostic dilemma . . . and the list goes on. Meanwhile,

I sit and wait to die or to be back on the street again, sick and alone and scared beyond imagination. What keeps me going? The hope that by some miracle, I will somehow get well enough again to help others who have fallen through the cracks and become victim of a disease that mainly for political reasons, continues to disable more and more people everyday.

[Editor's Note: See also: U.S. Department of Health and Human Services, Public Health Service, Center for Disease Control and Prevention, National Center for Infectious Diseases, Board of Scientific Counselors—Minutes of Meeting, May 12 and 13, 2005, Atlanta, GA at: www.cdc.gov/MasO/FACM/facmarchived.htm?url=20.]

[Whereupon, at 11:55 a.m., the hearing was adjourned.]

