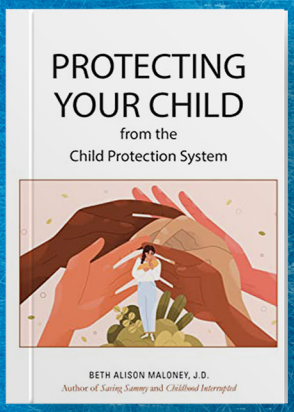
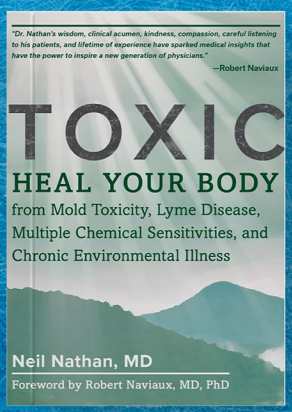
Looking for Answers? Additional books about Lyme disease.

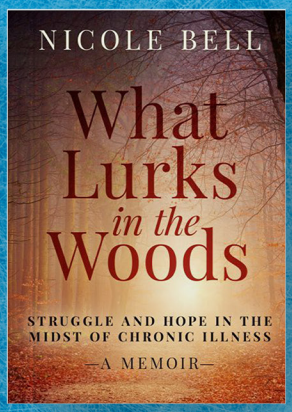
THE LYME TIMES

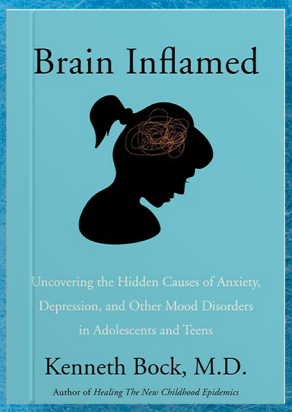
The Journal of LymeDisease.org

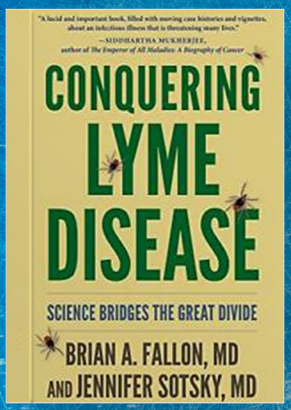
Special Issue: Lyme Disease Books

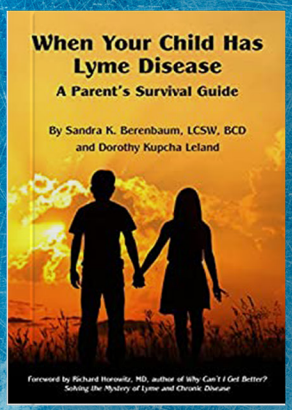


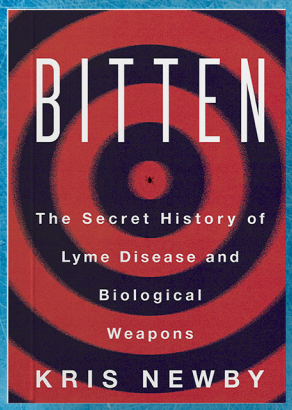


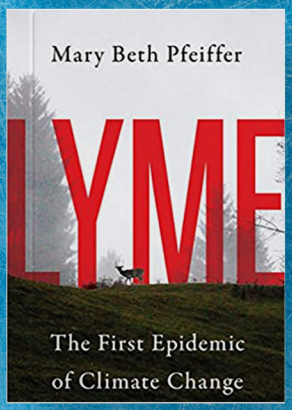


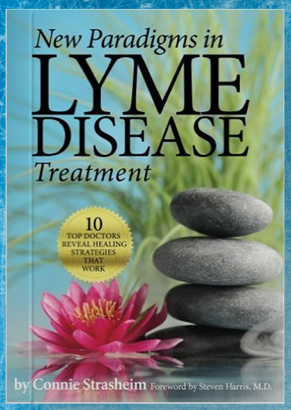


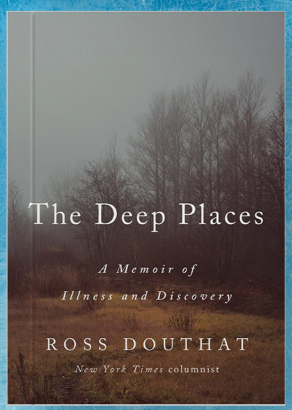


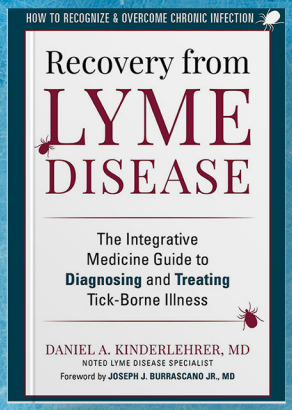


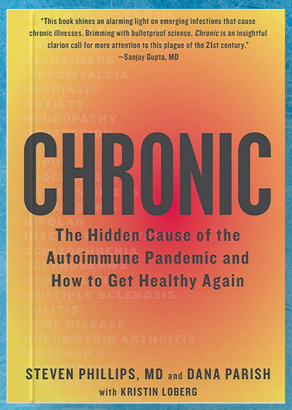












"Deep Places" Explores One Man's Lyme Fight

lymedisease.org
ADVOCACY, EDUCATION & RESEARCH

Special Issue

Who we are

LymeDisease.org is one of the oldest Lyme disease 501(c)(3) nonprofit organizations in the nation. We work to make the patient voice stronger, to support patient-centered research, to create legislative change, and to create a future where Lyme patients can receive the treatments they need to get well. We do this through patient empowerment and science-based advocacy—a powerful combination.

What we do

Education and outreach: Since 1989, LymeDisease.org has grown from publishing a single page newsletter into the largest communications network representing Lyme disease patients in the nation. Starting with our highly informative website, our content is widely distributed via blogs, social media, and our online quarterly journal, the Lyme Times. Members of the Board have published over 50 peer-reviewed publications.

The Lyme Times: *The Lyme Times* is our flagship publication. We inform the community about Lyme disease news, treatment approaches, research and political action through this quarterly journal.

Grassroots advocacy: Solving the critical health problems faced by Lyme patients requires grassroots involvement as well as local and national advocacy. We work with local advocates to help provide them with the tools they need for their long-term legislation efforts to succeed. For example, using our Voter Voice platform, citizens of Massachusetts sent thousands of messages to lawmakers in support of a Lyme-related insurance bill in their state. That important bill became law in August 2016. There is strength in numbers when we work together! We also promote grassroots efforts through our nationwide network of state-based internet groups.

Research: Our patient-powered research tool, MyLymeData, allows individuals with Lyme to pool their personal experiences to help drive research towards a cure. Science is based on evidence. Patients need more than hope–they need proof. The estimated 1-3 million patients suffering from chronic Lyme disease today can't wait years for clinical research trials. With over 5,500 patients enrolled, MyLymeData is in the top 10% of patient registries in the nation. We have published two of our large scale surveys on access to care and quality of life in peer-reviewed journals. LDo has funded research at Stanford, the University of Connecticut at New Haven, Stony Brook, and Johns Hopkins.

Symptom checker: In 2015, LymeDisease.org launched the Symptom Checklist, which helps patients determine whether they have been exposed to Lyme disease and assess whether they should see a healthcare practitioner. The checklist is designed to educate both patients and physicians. After completing the checklist, patients can take a print out of their results to their physicians to assist in diagnosis. Over 242,000 people have used the symptom checklist to help obtain an earlier diagnosis.

Physician directory: We provide patients with referrals to healthcare providers and we provide physicians with patient education tools. The physcians in our directory have been referred by patients who have been treated by them.

THE LYME TIMES

Published quaterly for members by
LymeDisease.org
www.lymedisease.org
Library of Congress No. 92-595999
ISSN No. 1552-7506
The Lyme Times

Chief Executive Officer & Principal Investigator MyLymeData: Lorraine Johnson, JD, MBA

Chief Operating Officer: Carolyn Cooper Degnan

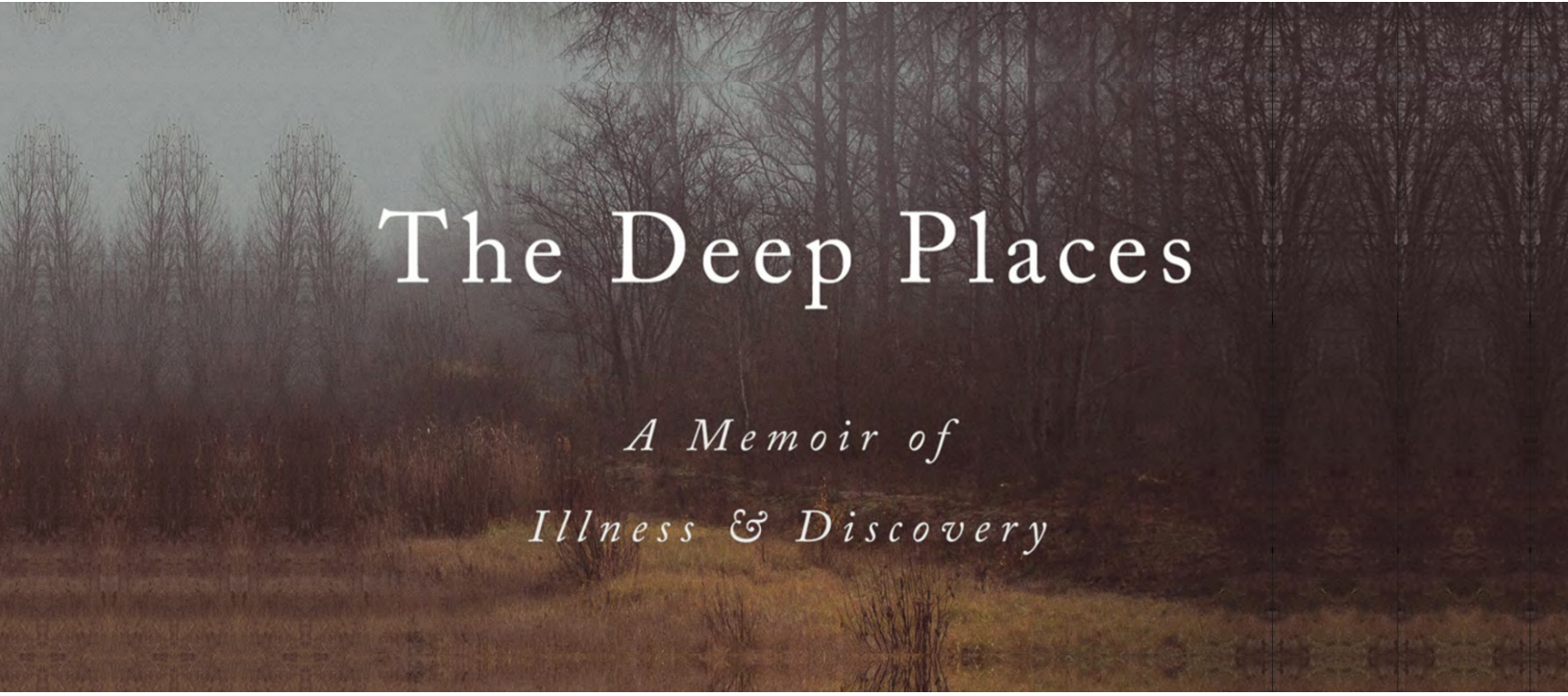
Vice-President, Director Of Communications: Dorothy Kupcha Leland

Layout Editor: Julia Higginson, M.A.

LymeDisease.org
President: Phyllis Mervin, EdM

Please go to www.lymedisease.org for membership information. PO Box 716, San Ramon, CA 94583

Contents



"Deep Places" Explores One Man's Lyme Fight

Author Ross Douthat shares how his life changed dramatically.

By Dorothy Kupcha Leland

Ross Douthat was a busy man. In addition to his regular opinion column in the New York Times, he wrote books, gave speeches, traveled, interviewed people, and was often interviewed himself.

In 2015, he and his wife had two kids and another on the way. They decided to leave Washington DC and relocate to Connecticut, where they had both grown up and still had family.

They found a rambling old country house that they fell in love with. After walking through the dwelling and briefly strolling around the property surrounding it, they made an offer which was accepted. Then, they returned to DC to prepare for the move.

And that's when Douthat's life changed dramatically.

It started with a stiff neck and an enlarged lymph node. ("Nothing to worry about," said an internist.) It progressed to migrating pain that moved from his head to his spine to his chest to his arms and legs. ("Maybe

drink more Gatorade–for the electrolytes," suggested a neurologist.) Other specialists prescribed sleeping pills and antidepressants. ("Stress," they declared. "Too much going on in your life.")

The Reason or the Symptom?

"I did feel stressed," Douthat remembers. "But the illness felt like the reason rather than the symptom."

He was tested for Lyme disease a couple of times, with negative results.

Meanwhile, the bizarre symptoms continued. Before he and his family left Washington, crushing chest pain sent him to the emergency room on two different occasions. Doctors there found nothing wrong with him. He followed up with various specialists, who theorized that his symptoms were psychosomatic.

As one infectious diseases doctor put it: "Look, I know it's hard to see, but you should feel happy. It's a good thing not to have a disease, you know.… And, if you need a mental health referral, we can definitely help with that."

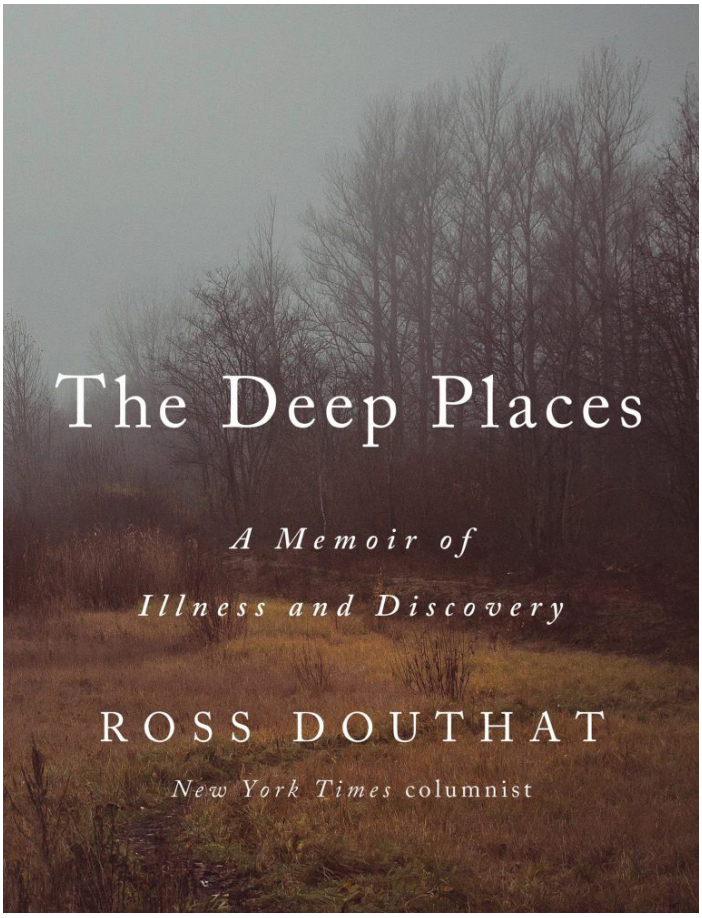
Caught in the Middle

In his recently published book, The Deep Places: A Memoir of Illness and Discovery, Douthat writes about being caught between what he was feeling in his body and what the doctors confidently proclaimed didn't exist.

> *By this point, I was deep into self-doubt about the reality of my experience. On the one hand, there was the pain, the burning, the vibrations, the feeling of invasion; I knew I'd never felt anything like this before. But what were mere feelings set against the certainties of so many doctors, the repeated negative readings of my blood?*

The family moved to the big country house, Douthat's condition continued to deteriorate, and he consulted new doctors in Connecticut.

First stop was a psychiatrist, who listened, took notes, and then surprised Douthat by saying, "I'm pretty sure you have a tick-borne disease, Ross." (Had a tick nailed him during his initial inspection of the Connecticut property? The timing certainly seemed



right.)

This sent him in search of Lyme specialists and to dig even deeper into learning about the illness: the problematic testing, difficulty of diagnosis, controversial treatments, and how mainstream medicine looks at Lyme with a mixture of disdain and denial.

Frustrating Illogic

He notes the frustrating illogic that Lyme patients face:

> *If you were a positive case with lingering, persistent symptoms after treatment, then your Lyme officially belonged to the past, and you no longer had a CDC-recognized disease. Instead, you had something called Post-Treatment Lyme Disease Syndrome (PTLDS), and the CDC's advice for anyone suffering through it was to basically keep on suffering.*

And he wonders:

> *If someone has an illness, takes a drug to treat it, and afterward retains exactly the same symptoms, why wouldn't you assume that they have simply continued to have the same disease? Why invent a mysterious "post-disease syndrome" to explain what is experienced by the patient as one continuous sickness?*

Douthat consulted different Lyme specialists that prescribed various antibiotic combinations. Some helped in some ways—but nothing got to the heart of the matter. He was still desperately ill.

At that point, Douthat started branching out into more alternative realms such as muscle testing, magnets, and a Rife machine—along with continuous heavy-duty prayer—and by the close of 2019, he was doing much better. "2020, I told myself, is going to be a good year."

Then he and other family members got nasty cases of COVID. And he writes:

> *The coronavirus era soon came to feel like a shattered mirror of the tick-borne epidemic and its controversies, with different pieces of the Lyme wars reflected and refracted in different aspects of the world-wide COVID crisis.*

In the following excerpt of "The Deep Places", Douthat expands on this comparison between Lyme and COVID-19.

The most direct parallel between the Lyme experience and the coronavirus drama, though, was in the swift proliferation of chronic cases from the new disease. These were the people, usually younger than the fatal cases, who got sick and didn't die but didn't seem to get better, either. They spent months bedridden and exhausted, they ran fevers that didn't break, they reported effects from the sickness not just in their throat or lungs but all over, in the heart and kidneys, joints and muscles, bowels and brain.

After months of illness, a female colleague, younger than me and doubtless healthier, still couldn't walk more than two blocks without pausing, short of breath. One of my college roommates who lived in Queens was sick for three weeks in March and seemed to quickly recover, only to find himself plagued by recurring chest pain, more in the heart than in the lungs, which sent him—like me, five years earlier—to emergency rooms and cardiologists with no result. When a New Yorker named Hannah Davis passed her four-month mark after infection, in late July of 2020, she tweeted a list of symptoms that reminded me of the letters that desperate Lyme patients sent to Allen Steere in the 1990s, begging to be taken seriously:

I still have a near-daily fever, loss of cognitive function, essential tremors, GI issues, severe headaches, heartrate of 150+, viral arthritis, heart palpitations, muscle aches, a feeling like my body has forgotten to breathe. Over the past 124 days I've lost all feeling in my arms & hands, had extreme back/kidney/rib pain, phantom smells (like someone BBQing bad meat), tinnitus, difficulty understanding text/reading, difficulty following conversations, sensitivity to noise & light, nonstop bruising. *Thinking* can cause headaches now.

Nobody knew exactly what to do for these "long-haul" COVID patients, and, as with Lyme patients there were plenty of stories about sufferers being dismissed and disbelieved, especially in cases where they had tested negative or (often, in those days) simply been unable to get a test to confirm their diagnosis.

At the same time, though, the scope and speed of COVID's airborne spread, the fact that there were so many of these long-haul patients all at once, seemed to create more sympathy and straightforward belief for their stories than in the slower-building tick-borne epidemic. So, perhaps, did the fact that doctors and nurses were disproportionately represented among early COVID cases, and thus among long-haulers, too.

In October of 2020, The Wall Street Journal covered some of these doctors, many of them months into a twilight existence of chronic fatigue and heart palpitations and headaches. One of

them, just two years removed from running the New York City Marathon, described going to a pulmonologist for her racing heartbeat and being told to try psychiatry and Xanax: "I said, 'I don't think so, I'm a psychiatrist.'" Another, an emergency physician in Atlanta, told the Journal that "this has absolutely changed my perspective . . . [on] the patients I see who come in with symptoms that are very real and I can't find any objective data to point me to a certain diagnosis."

So COVID offered a terrible crash-course education in the reality of chronic illness, the gap between what a disease was supposed to do in its "normal" presentation (symptoms in the throat and lungs for the coronavirus, a bull's-eye rash and fever and joint pain for Lyme) and how often the actual presentation is something else entirely, how many weird cascades a single invader can set off, how easily a previously healthy person can fall into a pit.

Who knows whether this education will change the way chronic illnesses are treated in the long run. Much of the medical theorizing about long-haul COVID, so far, has followed tracks familiar to Lyme patients—treating the recurring symptoms as problems of inflammation and tissue damage, a disturbed autonomic nervous system or an autoimmune cascade, which need to be managed palliatively or suppressed while the body is trained back to health through exercise or just recovers on its own.

For patients who don't seem to make much progress, there are grim comparisons to chronic fatigue syndrome, fibromyalgia, and, yes, "post-treatment" Lyme—but as with official discussions of those conditions, the possibility that a pathogen lingers is downplayed, and the assumption is that most of the suffering are fully in the aftermath of their infection.

Patience may well be the right approach for a lot of long-haul cases, who do seem to improve just by gradually building up their strength, slowly extending themselves in exercise as their hearts and lungs get back to normal. My colleague's case has been like that, and maybe my mother's as well: She feels okay six months after falling ill but gets chest pain and exhaustion when she does too much yard work.

On the other hand, people like Hannah Davis who have symptoms that seem to pop up randomly around the body, with kidney pain one day and neuropathies the next and brain fog all the while—it seems an awful lot like the way Lyme and other tick-borne travelers persist inside afflicted flesh, their effects cropping up all over long after the acute initial phase is done.

A virus is not a burrowing spirochete, but we know that viral infections, too, can persist and reappear. In the case of chronic fatigue syndrome, for instance, some doctors believe that the Epstein-Barr virus, often the triggering pathogen, sticks around to cause the ongoing immune disturbances, much as COVID-19 might in long-haul patients.

So to hear the term "post-COVID syndrome" already being tossed around to describe people whose COVID experience feels continuous, just months and months of the same feelings the virus gave them from the start—well, let's just say it sounds unfortunately familiar, and not necessarily a good sign for bringing them fully back to health.

Prominent Deniers of Chronic Lyme

Shortly after publication of his book, Douthat published three articles in the New York Times that drew upon his Lyme experiences.

1. How I Became a Sick Person (Oct. 24)
2. How I Became a Science Experiment (Oct. 31)
3. How I Became Extremely Open-Minded (Nov. 7)

On November 27, 2002 the newspaper published seven letters to the editor in response to Douthat's trio of articles. Three of the letter writers are prominent IDSA members, all well known deniers of chronic Lyme. Another one consults for Big Pharma. Any guesses about what those guys had to say about Douthat's columns?

I've read and reviewed a lot of books about Lyme disease. Douthat's book is one of the best. I highly recommend it.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

Doctors Told Nicole Bell Her Husband had Alzheimer's

He didn't. "What Lurks in the Woods: Struggle and Hope in the Midst of Chronic Illness" documents her family's difficult journey.

By Dorothy Kupcha Leland

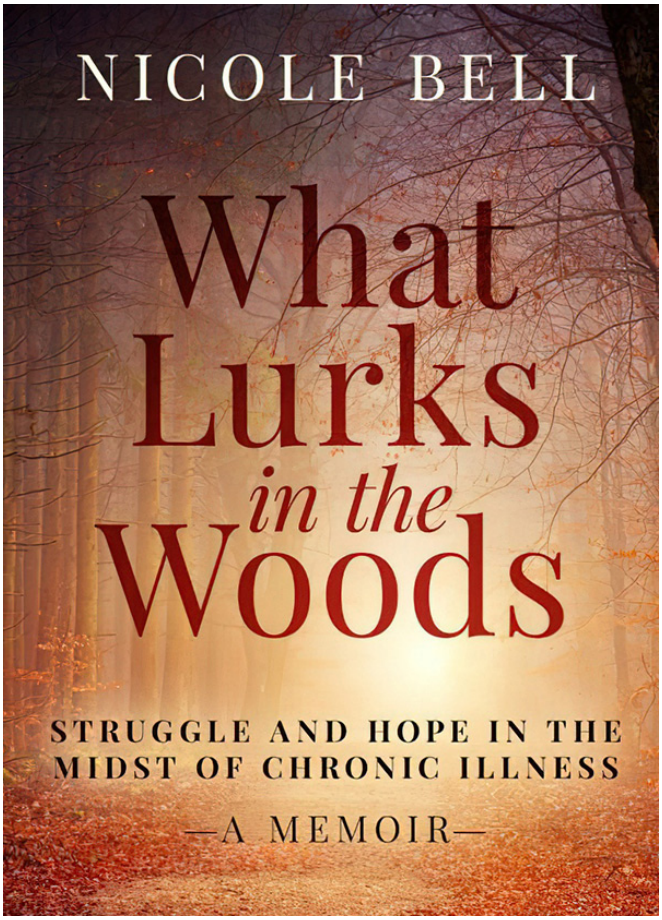
Nicole Bell had a life that many people would envy. She had an exciting, high-powered job, a handsome, smart, and loving husband, two beautiful children, and a great big house.

In fact, things pretty much seemed perfect — until one day, when it all began falling apart.

Her husband Russ started acting in a very peculiar manner. Forgetting to pick up the kids from school and daycare. Misplacing his wallet several times in a week.

Getting explosively angry with his wife and children over trivial matters.

But Nicole could always find a plausible explanation for it—he was stressed, he was depressed, he missed his former job.



Searching for the Cause

However, when he became utterly incapable of programing their household burglar alarm and videocassette recorder, Nicole could no longer deny that something was seriously wrong. Russ was an accomplished computer expert and electrical engineer—and now he was flummoxed by two tasks he'd flawlessly carried out for years.

Over her husband's objections, she took him to doctors for evaluation. All the physical tests—blood pressure, cholesterol, etc.—were normal. Nicole also wanted him checked for Lyme disease, since she'd heard that the infection can cause brain fog and memory issues. Furthermore, as a lifelong outdoorsman, Russ had pulled many ticks off himself through the years, though he'd never noticed a bull's-eye rash.

But her husband's Lyme test came back negative. And, after a battery of cognitive assessments showed serious deficits, eventually the doctors settled on the diagnosis of Alzheimer's disease.

Unfamiliar Terrain

In her new book, "What Lurks in the Woods: Struggle and Hope in the Midst of Chronic Illness, a Memoir," Nicole documents her family's difficult journey as they navigate this unfamiliar terrain.

Russ is despondent and becomes more impaired with each passing day. The kids are sad, confused, and scared of their father. Nicole, now the family's sole breadwinner, tries to hold things together with her job, the kids' schooling and Russ's medical needs.

One day, she's sitting in her car after work, and receives a phone call from her brother Scott. After years of complicated health issues, Scott's wife Jodi had recently found out that she in fact had Lyme disease. Scott tells his sister that he's been learning a lot about Lyme and thinks it might be at the root of Russ's problems.

"But we tested him and it came back negative," Nicole tells her brother. Scott encourages her to go online and order a kit for a specialized test. Here's what happens next.

Her powerful message deserves to be heeded.

An excerpt from Nicole Bell's book What Lurks in the Woods.

Why didn't this call [from Scott] come six months ago? I needed it then. I finally accepted the madness. I stopped raging against the machine. There was no way I could help him. Or was there?

Russ has advanced-stage Alzheimer's. Even the most progressive doctors are only having success with early-stage disease. No one can stop the fires once the whole forest is lit. Who am I to think that I can?

But what if Lyme truly is the cause? I've suspected it from the beginning, but his test said no. But everything Scott said makes perfect sense.

I heard that Lyme tests were horrible when I was working in diagnostics. PCR testing is a much better approach. It's very specific and reliable as long as there is enough target. Curing an

infection seems doable—much less daunting than treating a nebulous Alzheimer's fiasco. Or am I being naive?

The inner conflict consumed me. The leather seat pressed on my back, and I became aware that if it wasn't supporting me, I'd be lying on the ground, paralyzed.

My breath shallowed and quickened as if the weight of the decision sat on my chest. It should be easy. Order the damn kit.

But it was so much more than that. I was deciding if I wanted to bring hope back into my life. I had released it so reluctantly, so bitterly, but it was now gone. I wasn't sure I had the strength to bring it back and then lose it again.

Then his face flashed in front of me. This was Russ. This was the man I loved. Despite the awfulness of recent history, if I could get him back, I had to try. I couldn't live with myself if I didn't.

So, I peeled myself off the seat and stepped out of the car. My legs took a minute to stabilize as I walked into my office and settled into my desk. I booted up my laptop, and before I could change my mind, I opened Scott's email and ordered the kit. As I clicked the order button, I laughed at myself. Well, here's to hoping….

…[On] the first of December, I was sitting at my desk prepping for the following week when I saw the email pop up on my phone. The notification glared at me like a creepy clown at a carnival. Was it friend or foe?

I didn't want to open it at work, but I had to know. As I clicked on the file, I took a deep breath. Prepare yourself for both outcomes. You'll figure it out either way.

I read the report. "The highlighted microbes were detected in the submitted sample." There were two, *Borrelia burgdorferi* and *Bartonella henselae*.

My eyes stared at the bright yellow that surrounded the words. *Borrelia burgdorferi*—the bacteria that caused Lyme disease. *Bartonella henselae*—the bacteria that caused bartonellosis, or cat scratch fever.

The colloquial name made it seem nonthreatening, but I knew from my reading about Jodi's diagnosis that this other tick-borne illness was a beast in and of itself.

I sat there staring, mesmerized by the yellow glow. Suddenly, a thought snapped me out of my daze. I logged into my personal drive and pulled up our earlier results.

September 2016: Western blot negative for Borrelia burgdorferi. That was fifteen months ago. For fifteen months, I'd searched for answers that never came, and his brain continued to rot.

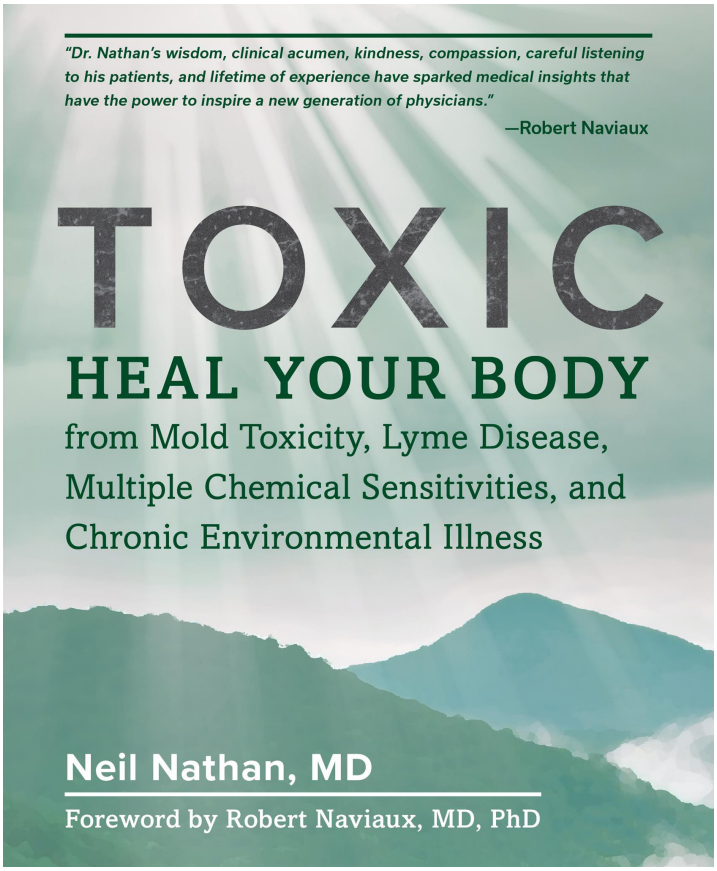
For fifteen months, I could have been researching, treating, and helping. Instead, for fifteen months, I'd been flailing, losing, and giving up. Fifteen fucking months.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

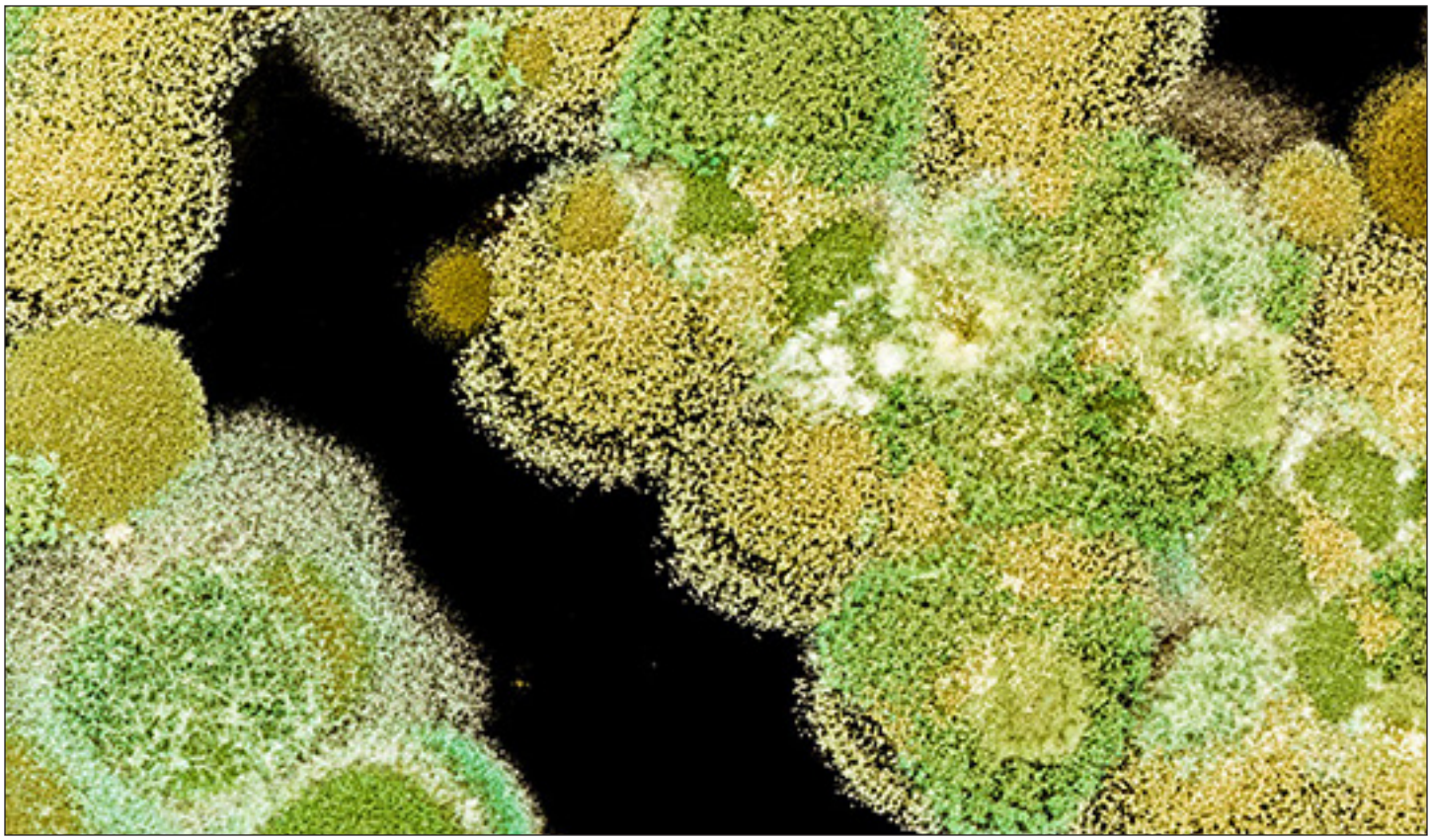
Genes and Environment Trigger New Chronic Illnesses

Dr. Neil Nathan's book, "Toxic" seeks to help "ultrasensitive" patients with mold toxicity, Lyme disease, multiple chemical sensitivities, and chronic environmental illness.

By Lonnie Marcum



When Dr. Nathan started treating patients 47 years ago, the model for medicine was much simpler—a standard diagnosis followed by a standard treatment. Now, he says, "The patients who come to see me today are a quantum leap



(or two) sicker than the ones who came to me in the late 1980s."

Today's patients are sicker, for longer, with a multitude of chronic ailments that weren't known to exist years ago. From autism to fibromyalgia to myalgic encephalomyelitis to mold toxicity—gone are the days of "take two aspirin and call me in the morning."

As Professor Robert Naviaux, MD, a world-renowned biomedical/genetics researcher, explains in his introduction, "These new chronic illnesses have both genetic and environmental causes. They are 'ecogenetic' diseases that occur because the chemistry of the environment is changing faster than our genes can adapt."

Dr. Nathan recounts the evolution of his own medical practice, progressively taking on more and more patients with whom no one else knew what to do. Now, 70% or more of his patients are classified as "ultrasensitive," meaning they react intensely to even minuscule exposure to medications and supplements.

The topics covered in the book are straight out of Dr. Nathan's real-world experience. While reading the book, I felt like someone was sharing with me all of their family's secret recipes. This book is full of hard-earned knowledge. It's a clear road map that combines the art and science of treating the sickest of the sick.

The book is organized in a way that makes it easy to return to time and time again. For instance, Chapters 8–20 provide a step-by-step guide on how to "reboot" every system of the body, arranged in the order in which they occur most frequently. So, whether you need to reset anything from your brain to your gut, it's in there.

Understanding Mold Toxicity

TOXIC also provides one of the easiest to understand and simplest methods for identifying and treating mold toxicity that I have ever read. Dr. Nathan explains how to identify the different types of mycotoxins (mold) and then clearly lays out a four-step process for treatment.

There is also an appendix devoted to troubleshooting mold toxicity issues for highly sensitive patients and a supplement guide.

I was especially interested in the contributions by Dr. Lawrence Afrin, one of the pioneers in mast cell research. I am forever grateful for his guidance and connecting me to the right specialists, which led to my own child's diagnosis of mast cell activation syndrome. Dr. Nathan estimates that 50% of his ultra-sensitive patients have a mast cell activation component to their illness.

Dr. Neil Nathan

The chapters on the cell danger response and genetics are incredibly detailed and precise and serve as proof of the science behind these complex illnesses.

> *The book is organized in a way that makes it easy to return to time and time again. For instance, Chapters 8–20 provide a step-by-step guide on how to "reboot" every system of the body, arranged in the order in which they occur most frequently. So, whether you need to reset anything from your brain to your gut, it's in there.*

Methylation

The chapter on methylation is a gift—believe me! This is one of the most poorly understood concepts in functional medicine today. No one understands this better than Dr. Nathan—he pioneered the first study on using a "simplified methylation protocol" in 2007. If taking vitamin B12 or folate makes you feel worse, you need to read this chapter!

If you've tried conventional treatment for Lyme disease, Bartonella, or mold yet continue to suffer from poor concentration, anxiety, headaches, insomnia, pain, ringing in the ears, strange sensations, increasing allergies to medication or food intolerance, and/or sensitivity to chemicals, you will find useful information in this book.

Dr. Nathan has been board-certified in fam-ily practice and pain management, is a founding diplomate of the American Board of Integrative Holistic Medicine, and is a board member of the International Society for Environmentally Ac-quired Illness (ISEAI). He recently retired from private practice after 50 years of seeing patients.

Dr. Nathan has lectured to medical audienc-es both nationally and internationally. He has written several books and has hosted an interna-tionally syndicated radio program/podcast, The Cutting Edge of Health and Wellness Today.

An excerpt from Dr. Neil Nathan's book Toxic.

While methylation is an important com-ponent of health and a common problem for patients suffering from chronic illnesses, it has been receiving an unusual amount of attention

Rich Van Konynenburg, PhD

lately, elevating its importance to heights that are, perhaps, out of proportion to the role that it plays. I am devoting a chapter to methylation in the hope that I can help put the whole concept into perspective

What Is Methylation?

While it may sound complicated, methylation is simply the biochemical process of adding a methyl group to a molecule. A methyl group consists of a carbon atom surrounded on three sides by hydrogen atoms, allowing the fourth side (to the left of the central carbon atom in Figure 14.1) to bind to another substance.

The process of methylation is basic to hundreds of important biochemical reactions in the body. The most important of these is creating glutathione, which is a central material in creating energy, detoxifying, and dealing with free radical buildup. The body uses methylation itself for detoxifying, repairing damaged DNA, converting serotonin to melatonin, and many other critical processes.

The most common symptoms of methylation deficiency, or an inability to methylate properly, are fatigue, cognitive impairment, pain, and insomnia.

Let's begin with a little history of how methylation rose to the top of the to-do lists of functional medicine physicians.

Amy Yasko, PhD,

How Methylation Came to Prominence

Rich Van Konynenburg, PhD, spent his career as a pioneering engineer who became a major troubleshooter for the Livermore National Laboratory. After his retirement, he became fascinated by the difficulties faced by patients with myalgic encephalopathy/chronic fatigue syndrome (ME/CFS) and fibromyalgia. He spent several years researching the biochemistry of these illnesses, and in 2003 he wrote a seminal paper suggesting that methylation chemistry, when not functioning properly, could explain virtually all of the clinical findings in ME/CFS.

This hypothesis was developed from the work of Amy Yasko, PhD, who was working with autistic children. Dr. Yasko suggested that autism was the form that illness took in younger patients and was similar to ME/CFS and fibromyalgia in adults and to neurodegenerative diseases in older patients.

This hypothesis was developed from the work of Amy Yasko, PhD, who was working with autistic children. Dr. Yasko suggested that autism was the form that illness took in younger patients and was similar to ME/CFS and fibromyalgia in adults and to neurodegenerative diseases in older patients.

Dr. Van Konynenburg was still having trouble convincing physicians to take his work seriously when I heard him speak at a medical meeting in

2007. I was so intrigued by the logic and simplicity of his ideas that when I got home from the meeting, I immediately placed fifty-one patients with ME/CFS and fibromyalgia on the five supplements that Dr. Van Konynenburg had developed from Dr. Yasko's work and that he described as a "simplified methylation protocol." Essentially, this protocol consisted of hydroxocobalamin (hydroxy-B12), a tiny dose of 5-methyltetrahydrofolate (5-MTHF), and several other supplements to support methylation chemistry.

After several months of taking these supplements, 70 percent of my patients noted definite improvements, and 20 percent reported that they felt markedly better.

> *This was the first time that Dr. Van Konynenburg's hypothesis had been tested, and he was delighted with our initial results.*

Dr. Van Konynenburg and I were fortunate to receive private funding for a more elaborate clinical study, and we entered thirty patients, all of whom met the criteria for ME/CFS and fibromyalgia, into a research project in which we measured their methylation chemistry and kept a detailed clinical symptom diary before giving them supplements. We gave all of them exactly the same supplements I had used in the pilot project and followed their clinical progress closely for nine months, measuring their methylation chemistry with a blood test from Health Diagnostic Laboratory every three months. The results were impressive. Despite the unusually long trial period, almost all of the patients participated for the entire duration.

> *Not a single patient who began the study had normal methylation chemistry, suggesting that Dr. Van Konynenburg's hypothesis about abnormal methylation chemistry playing a significant role in ME/CFS and fibromyalgia was valid.*

Dr. Neil Nathan and Dr. Van Konynenburg

By the end of six months, glutathione and SAM had risen to normal levels in almost every patient. After nine months, they were better still. More important, the patients had improved clinically: 77 percent reported improved energy, 65 percent reported improved sleep, 73 percent reported improved mental clarity, and 54 percent reported a decrease in pain. To put this differently, 83 percent told me that they had improved (defined by them as being 15 to 50 percent better), and of those who had improved, 27 percent reported that they were much better, defined as 50 to 100 percent better. The average improvement at six months was 48 percent and was statistically significant.

Dr. Van Konynenburg and I felt that we had begun to address the important questions: Does methylation play a role in ME/CFS and fibromyalgia, and if so, Is it treatable? The answer to both questions was a resounding yes!

The funding for this project did not, by design, include an institutional review board, which would have allowed us to submit these findings to a peer-reviewed journal. You can find the details in my book Healing Is Possible and in the December 2011 issue of the Townsend Letter.

Dr. Van Konynenburg and I presented this work at quite a few medical meetings, both national and international, and it received a good deal of attention. What followed was an explosion of interest in methylation as an important component of health and illness, and it came

to be viewed as a central area that needed to be addressed clinically. After all, the end product of methylation, as I have emphasized, is glutathione, which is essential for energy, detoxification, and oxidative chemistry. So methylation appears to be something that needs to be addressed early on in treatment, perhaps for everyone who is chronically ill.

Well, yes and no. As you might expect, in complex patients, it is more complicated than that.

Timing Methylation Treatment Correctly

In Chapter 8, I discussed the cell danger response (CDR). One important component of the CDR is that when a cell feels threatened, it intentionally shuts down methylation to deprive an infecting microbe of the capability to hijack the body's own methylation chemistry so that the microbe can reproduce. It therefore should come as no surprise that virtually all chronically ill and inflamed patients, in whom the CDR has been triggered, have measurably low methylation chemistry. But does that mean we should immediately provide all patients with the supplements to maximize methylation?

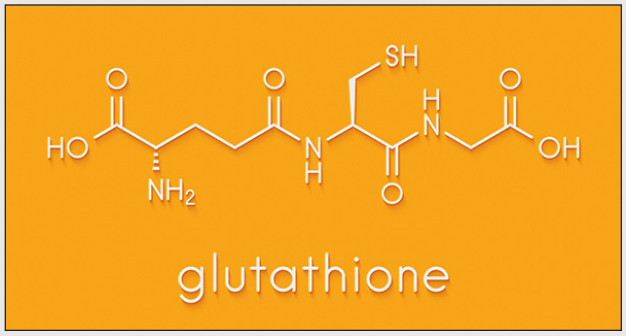
It turns out that the answer to that question is: It's all about timing.

Because the CDR is a protective mechanism, overriding that mechanism before the body is ready to move forward might not be a great idea, especially for sensitive patients. In my experience, approximately half of sensitive patients, if given vitamin B12 or folate (usually in the form of 5-MTHF), experience an intense worsening of their symptoms — even when given minuscule doses. I would like to emphasize that in our study of thirty patients, supplementing with only 200 micrograms of 5-MTHF improved every patient's ability to methylate. Some practitioners are recommending massive dosages of folate with the idea that if some is good, more is better. This is rarely true. In my practice, in fact, the opposite is far more common. Many of the patients who come to see me are on dosages of folate that are way too high, and they improve when we reduce the dosage dramatically or stop the supplement altogether.

> *I have found that once a patient has eased into treatment of the underlying main issue (usually mold toxicity or Lyme disease), he or she can take methylation supplements comfortably and with benefit later in the course of treatment.*

Unfortunately, some practitioners insist that because methylation is so important, especially to detoxification, patients must continue taking the supplements. Worse, they advise increasing the dosage even when a patient is clearly reacting badly. This is not wise. The vast majority of these patients will get worse — often much worse. The body is saying that it is not yet ready to begin this area of treatment.

I have found, however, that once a patient has eased into treatment of the underlying main issue (usually mold toxicity or Lyme disease), he or she can take methylation supplements comfortably and with benefit later in the course of treatment.



I worry that healthcare providers have escalated the importance of methylation in detoxification to the point that they are telling patients that if they can't methylate, they can't get better, so they have to keep taking their methylation supplements no matter how bad they feel.

Not so! Please keep in mind that the body has many avenues and organs of detoxification, so if methylation can't be started early on, the body can and does utilize other systems to detoxify. Sensitive patients who cannot take methylation supplements yet can begin treatment, improve,

Dr. Janette Hope, MD

and then initiate efforts to methylate better.

Another area I would like to address is the love affair that integrative practitioners are having with glutathione supplementation. While there is no question that glutathione is an essential component of health, its indiscriminate use is not always justified.

Many patients with mold toxicity, for example, get worse when given glutathione in any form: oral, IV, or topical. You may recall that in Chapter 3, I encouraged the use of oral glutathione as a prevocational agent to make urine testing for mycotoxins more accurate. At the same time, I cautioned that in sensitive patients, glutathione mobilizes molds (and other toxins) faster than their bodies can process those toxins, and the patients become more toxic. They experience this increase in toxicity as an intense exacerbation of their usual symptoms. This is not a reaction that these patients can override by pushing themselves to "ride it out," although many of them try anyway. It is important to recognize when this adverse reaction is occurring and to stop taking glutathione until the body is able to right itself.

A second concern I have is that many practitioners do not seem to realize that glutathione, as important as it is, is carefully monitored and regulated by the body. When glutathione is taken in any form, the body's biofeedback systems announce that it has plenty of glutathione on board now, so it can stop making glutathione using the process of methylation. What this means is that many patients who are taking glutathione are unwittingly turning off their ability to methylate, which is counterproductive in patients who already are not methylating well.

This is not to say that glutathione should not be used in treatment, but it is a plea to practitioners to make an effort to discern which patients might benefit from the use of glutathione and which should not be offered glutathione until they have improved. I have intentionally emphasized difficulties with methylation and the use of glutathione because these difficulties are common in my sensitive patients. I also want to make it clear that the use of glutathione in patients who have a stronger constitution can be quite helpful.

Janette Hope, MD, has described the use of intranasal glutathione being of great help in treating patients with mold toxicity. Many patients have found immediate and clear benefits from the use of oral or intravenous glutathione as well. My take-home message is simply to alert practitioners and patients to the possible downside of the use of glutathione and to advise you to be very careful when instituting treatment with this material.

The bottom line is that sensitive and toxic patients must approach methylation very carefully, and they and their healthcare practitioners must be mindful that this area of treatment may need to be postponed until they have begun to improve. While I believe that methylation is indeed important (heck, I helped put it on the map!), I urge patients and physicians to put its value into perspective and to always look for the greater context in which we view treatment.

Lonnie Marcum is a Licensed Physical Therapist and mother of a daughter with Lyme. She serves on a subcommittee of the federal Tick-Borne Disease Working Group. Follow her on Twitter: @LonnieRhea Email her at: lmarcum@lymedisease.org.

"Lyme Complex" Triggers Pandemonium in Immune System

Dr. Daniel Kinderlehrer's book, "Recovery from Lyme Disease: The Integrative Medicine Guide to Diagnosing and Treating Tick-Borne Illness" discusses how this happens.

By Dorothy Kupcha Leland

In 1996, Dr. Daniel Kinderlehrer had practiced integrative medicine for seventeen years, focusing heavily on food sensitivities, digestive issues, and nutritional supplementation.

Then, he suddenly developed a serious illness himself. It started with fever, chills, and muscle aches, which waxed and waned with alarming frequency. Eventually, this ailment would spin his life and medical practice into an entirely new direction.

During Kinderlehrer's initial search for what was wrong, he tested positive for Lyme disease. At first, that diagnosis brought relief. The standard medical advice was that a short course of antibiotics would clear the infection. Soon, he thought, he'd be good to go.

Uh-oh. That's not how things turned out.

"The Lab Must Be Wrong"

Kinderlehrer started the suggested treatment and promptly got worse. Intractable insomnia, anxiety, violent shaking of his body. Finally, he contacted a prominent physician with a reputation as an expert in Lyme disease.

Here's how he summarized the conversation later:

You don't have Lyme," [the expert] concluded.
Well, then, what do I have?" I was confused.
Something else," he replied.
But what about the lab tests?" I asked. "Using the western blot technique, the assay demonstrated the presence of antibodies highly specific for Lyme. I even repeated the tests one month later, and they confirmed the initial results. Isn't this the CDC criteria for the diagnosis of Lyme?"
The laboratory must have been wrong," he informed me.
Why do you think I don't have Lyme?" I responded.
Because if you had Lyme, you'd be better by now."

(Many people with persistent Lyme symptoms report being told something similar by doctors. I well recall the infectious disease "expert" my own family consulted early on in my daughter's illness. This prominent member of the Infectious Diseases Society of America stated point-blank that since she had completed thirty days of antibiotics with no change in symptoms, that "proved" she didn't have Lyme disease.)

New Book

At that point, Kinderlehrer set out to find answers for himself. In time, what he learned would be shared with hundreds of patients who eventually flocked to his practice, which now focuses entirely on tick-borne infections. And it led to a new book, Recovery from Lyme Disease: The Integrative Medicine Guide to Diagnosing and Treating Tick-Borne Illness.

Recovery from Lyme Disease has twenty-five chapters, divided into five sections:

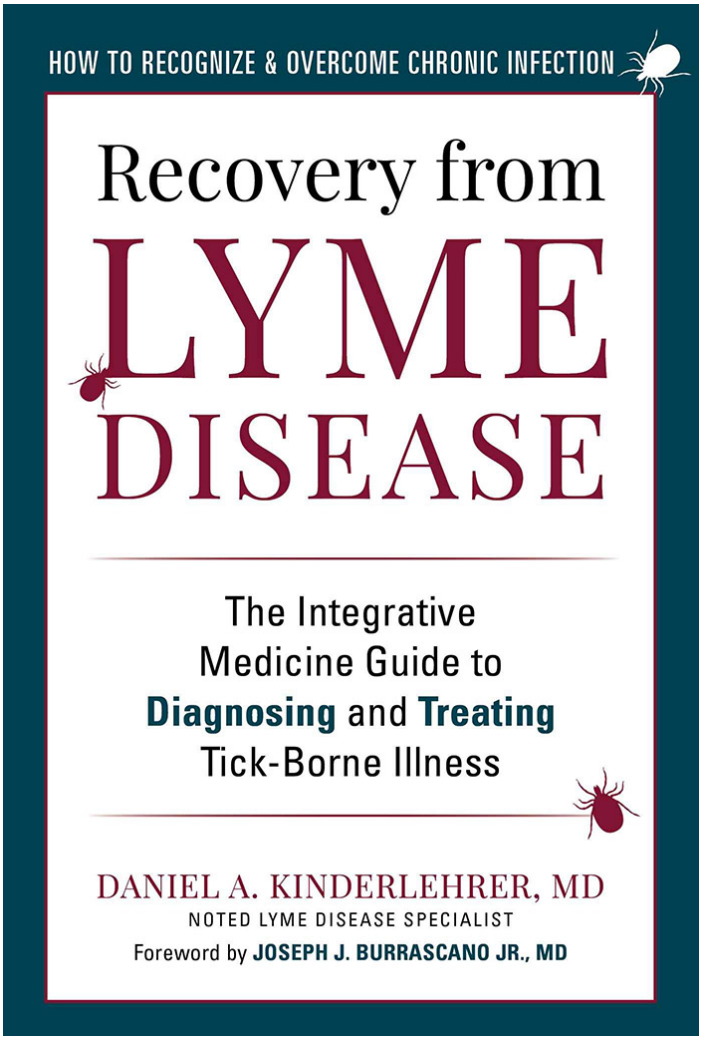
Section 1: Anatomy Lessons: Anatomy of an illness, an epidemic, and the Lyme wars

Section 2: Meet the Bugs" Explanation of the different microbes involved with what Kinderlehrer calls "Lyme disease complex," in which the Lyme bacterium, *Borrelia burgdorferi,* plays only one part

Section 3: It's all Connected: Endocrine dysfunction, gastrointestinal issues, nervous system disorders, inflammation, detoxification, fatigue, diet and nutrition

Section 4: What Else? Other considerations, alternative treatments, frequently asked questions

Section 5: The Challenge: Discussion of what it will take to get us where we want to go; appendices; acknowledgements



Chapter 18 (in Section 3) includes an excellent description of the immune system—particularly germane to COVID as well as to Lyme disease complex.

As the author puts it, "Lyme and its co-infections trigger pandemonium in the immune system, resulting in excessive systemic inflammation and auto-immunity as well as immune suppression. A multisystemic approach is necessary to control inflammation: avoiding allergic triggers, healing the gut, balancing hormones, calming the nervous system, enhancing detoxification—as well as treating infections."

Kinderlehrer gives good explanations of tests, treatments, and alternative approaches to dealing with these issues.

"Recovery from Lyme Disease: The Integrative Medicine Guide to Diagnosing and Treating Tick-Borne Illness" (Skyhorse Publishing), is available for ordering now.

Sometimes there is a moment in a person's life that, although seemingly insignificant at the time, heralds a drastic and unalterable change in everything that follows. For me, it was August 15, 1996.

The "insignificant event" was, I thought, a virus. I had a fever and chills. The fever was high, 104 degrees, and the chills made my teeth chatter and the bed shake. My body ached so much I felt like a discarded New England Patriot's tackling dummy.

But I had no other symptoms commonly associated with the flu, no cough or respiratory congestion, and influenza does not occur in the summer. I didn't have the upset stomach or diarrhea typical of a stomach bug, either. I never saw an insect bite, and I didn't notice a rash. For two days I was so sick I stopped worrying I would die, and started fearing that I would live. On the third day, it was all just a memory.

It seemed quite strange, but since I was able to resume full activity, including several three-mile runs, I didn't think much of it—until one week later, when

An excerpt from Dr. Daniel Kinderlehrer's book Recovery from Lyme Disease.

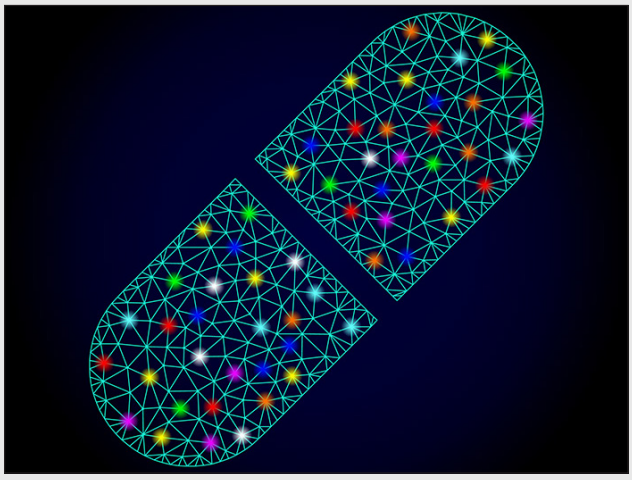
Sometimes there is a moment in a person's life that, although seemingly insignificant at the time, heralds a drastic and unalterable change in everything that follows. For me, it was August 15, 1996.

The "insignificant event" was, I thought, a virus. I had a fever and chills. The fever was high, 104 degrees, and the chills made my teeth chatter and the bed shake. My body ached so much I felt like a discarded New England Patriot's tackling dummy.

But I had no other symptoms commonly associated with the flu, no cough or respiratory congestion, and influenza does not occur in the summer. I didn't have the upset stomach or diarrhea typical of a stomach bug, either. I never saw an insect bite, and I didn't notice a rash. For two days I was so sick I stopped worrying I would die, and started fearing that I would live. On the third day, it was all just a memory.

It seemed quite strange, but since I was able to resume full activity, including several three-mile runs, I didn't think much of it—until one week later, when it hit again. Once more, the fever, chills, and muscle aches lasted two days and then went away. Still pretty strange, I thought, but since I felt well after this relapse I chose to ignore it.

Denial works well when you feel okay. But when the symptoms recurred for the third time a week later, the denial stopped working and I began to worry. This time I went to see a physician friend of mine. Upon examination, he palpated an enlarged spleen. He ordered some blood tests, and the laboratory reported a positive antibody test to Lyme. The diagnosis came as a relief. The cause of my problems was a simple bacterial infection. Two weeks of antibiotics would clear it, and then I could resume my normal life.



Was I in for a surprise!

I tolerated the antibiotics without difficulty, and the fever and chills did not return. But instead of feeling better, I felt worse. The next symptom that hit me, and hit me hard, was insomnia. One night I woke up at 4:00 a.m., and couldn't fall back to sleep. The next night I woke up at 3:00 a.m., the next at 2:00 a.m., and then 1:00 a.m., unable to go back to sleep. This went on for weeks. I only slept a few hours a night. I was exhausted. But even worse, I became consumed with anxiety.

I would lie awake through the dark hours of the night riddled with fear. Initially the apprehension focused on my sleeplessness, anticipating the difficulty of getting through the day in my worn-out state. Gradually the anxiety generalized into a constant dread that something terrible was about to happen—impending doom.

It wasn't rational. It wasn't something I could control with reason. It was just always there. It felt

like a black cloud was enveloping me, cutting me off from any future. It was pure existential terror. It was so intense that some nights, as I lay awake with insomnia, I shook so violently that I added disrupting the San Andreas fault to my list of fears—and I was living in Boston!

Although I'm a physician, I had little experience with Lyme. So I mustered what energy I could—I phoned a Lyme specialist in Boston at the Tufts-New England Medical Center, my alma mater, who was considered a world expert in Lyme disease and asked for advice. He listened courteously to my story as I described my history of symptoms and lab tests, but what he told me came as a shock.

You don't have Lyme," [the expert] concluded.

Well, then, what do I have?" I was confused.

Something else," he replied.

But what about the lab tests?" I asked. "Using the western blot technique, the assay demonstrated the presence of antibodies highly specific for Lyme. I even repeated the tests one month later, and they confirmed the initial results. Isn't this the CDC criteria for the diagnosis of Lyme?"

The laboratory must have been wrong," he informed me.

Why do you think I don't have Lyme?" I responded.

Because if you had Lyme, you'd be better by now."

My First Taste of Controversy

I thanked him for his time, hung up the phone, and tried to make sense out of what I had just heard. I considered this doctor's logic: if the cure didn't work, I didn't have the disease. I had had an acute illness with fever, chills, and muscle aches. I had blood tests that confirmed a diagnosis of Lyme. I lived in an area endemic for Lyme. I had seen deer ticks on our dog. I continued to feel terrible, but I didn't have Lyme because I wasn't better. I was getting my first taste of the controversies surrounding Lyme disease.

No Magic Pill

The bad news I learned on my journey is that there is no single treatment regimen that will cure any chronic illness—no magic pill, no simple injection. Healing from chronic illness requires a multipronged and multidimensional approach. Each person is different, and treatment protocols need to be individualized. It requires assembling the pieces of a puzzle, with each person presenting his or her own clues. There is no single recipe for success.

While Lyme has been the worst thing that has ever happened to me, it has also been the best. This experience has been profoundly humbling. There were times I felt so poorly that the only way I could get through the day was to tell myself that tomorrow I could commit suicide.

But Lyme has also blessed me with deep compassion and empathy for others who are suffering. Lyme has stirred in me a passionate commitment to help others who are challenged with this illness. Lyme has filled me with hope that each and every patient coming through my office door will get well. I can't think of anything more rewarding or more gratifying than helping people restore their well-being.

Healing from chronic illness requires a multipronged and multidimensional approach. Each person is different, and treatment protocols need to be individualized. There is no single recipe for success.

My medical practice is now limited to treating people with tick-borne infections. And despite living in Colorado, where the state Department of Health continues to deny that one can acquire Lyme disease, I have a long waiting list that keeps growing. There is a huge need out there for more Lyme literate practitioners, and I hope this book will help both physicians and patients better address this tremendous demand.

— — — — — — — — —

I am frequently asked how I treat Lyme disease. My answer is that I don't—I treat people, and they are all different.

There is no cookbook, even for treating early or acute Lyme disease. Ideally patients should

avoid any practitioner who uses a "one size fits all" approach. Treating Lyme patients effectively is complicated. This chapter will explain why.

Issues with Acute Lyme Disease

Acute Lyme disease would seem to be straightforward. A recent infection should be easily diagnosed and treated. But it often isn't.

Here's why:

1. Many people, perhaps most, do not observe a tick attachment.
2. A rash is often absent, missed, or ignored.
3. The early symptoms of acute Lyme disease may be absent or mild, or self-diagnosed as the flu, and therefore ignored by the patient.
4. The diagnosis of acute Lyme disease is often missed by medical practitioners.
5. The standard treatment recommended for acute Lyme disease is inadequate for eradicating the infection in many people.
6. Infection with the Lyme bacteria is frequently accompanied by co-infections that require different antibiotics as well as more aggressive treatment.
7. Some patients who present with acute Lyme are, unwittingly, suffering from chronic tick-borne infections that were acquired at some time in the past.
8. *Borrelia burgdorferi* (Bb) can suppress the immune system, resulting in persistent infection.
9. Although acute Lyme disease is characterized as being localized to the skin, Borrelia burgdorferi can spread systemically by the time the rash appears.
10. The previous chapter highlighted the several ways in which Bb has evolved to evade the immune system and resist antibiotics. In addition, not all Bb bacteria are the same; there are multiple strains of *Bb*, each with varying degrees of virulence and an affinity for different organs.

Chronic Infection is More Complicated

Chronic infection is a different ball game altogether. The majority of patients with chronic illness do not just have a long-term infestation with Bb. Rather, their Lyme disease complex* often includes other tick-borne infections, referred to as co-infections. Multiple studies have confirmed that ticks are veritable cesspools of microbes, and a single tick may harbor a handful of different bacteria.

For example, a collection of 286 ticks in upstate New York revealed that 64 percent had Bb, 20 percent had Anaplasma and 20 percent had Babesia; but 17 percent had Bb and Babesia, 16 percent had Bb and Anaplasma, and 5 percent had all three. One of the ticks had four pathogens: Bb, Babesia, Anaplasma, and B.miyamotoi. In fact, co-infection of ticks is the rule rather than the exception. Dr. Joseph Burrascano refers to these ticks as "nature's dirty needles."

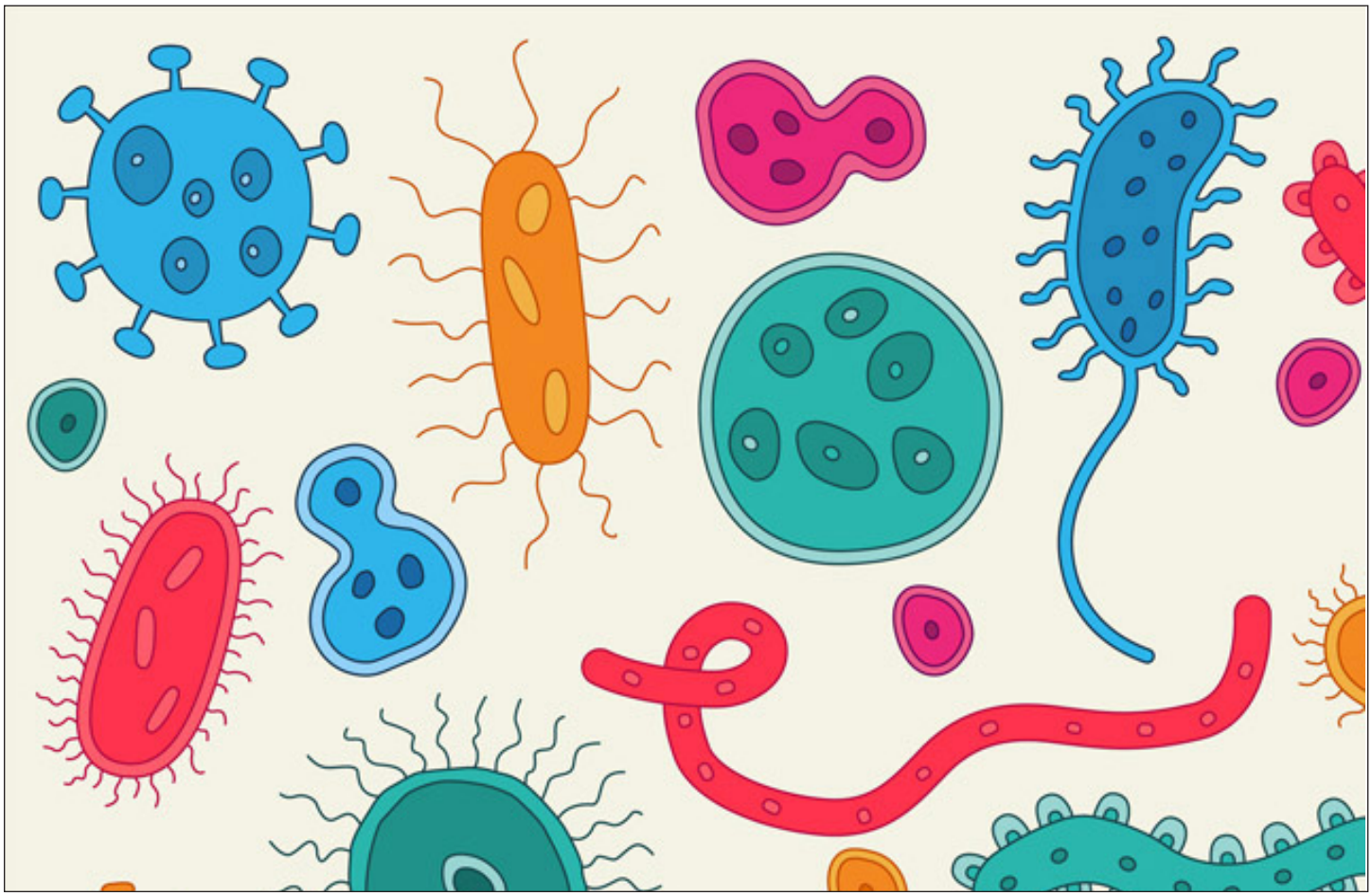
The presence of combined infections typically causes more severe symptoms than Bb by itself. The immune suppression from Bb infection is compounded by co-infections, and polymicrobial infections are more difficult to treat.

There is no cookbook, even for treating early or acute Lyme disease. Ideally patients should avoid any practitioner who uses a "one size fits all" approach.

Virtually all patients with Lyme disease complex are co-infected, and treatment of persistent infection with Bb will be unsuccessful unless therapy is also directed at these co-infections.

Many additional complications have been associated with Lyme disease complex:

1. Chronic inflammation associated with chronic infection results in many imbalances throughout the body. These will be discussed in detail in subsequent chapters.
2. Detoxification pathways get overloaded and fail to metabolize and excrete toxins efficiently. (See Chapter 19.)
3. Adrenal glands, which work hard to compensate for the ongoing stress, lose their reserve and in time become overtaxed, resulting in adrenal insufficiency. This not only induces fatigue, but also contributes to immune dysfunction. (See Chapter 15.)



4. Hypothyroidism is common—even people with normal thyroid gland function can present with symptoms of hypothyroidism. They often are converting too much of their T4 hormone to reverse T3, a form that blocks thyroid action at the cellular level, rather than making the usable form of the hormone. (See Chapter 15.)
5. Insulin resistance leads to elevated insulin levels, resulting in increased inflammation, fatigue, and immune suppression. (See Chapter 15.)
6. The autonomic nervous system, which regulates the body's automatic activities such as breathing, pulse, and body temperature, becomes destabilized. The resulting dysautonomia can cause chaotic manifestations: unstable blood pressure, both racing and slow pulse rates, difficulty breathing, heat and cold intolerance, anxiety, plus a host of other symptoms. (See Chapter 17.)
7. Immune imbalances may result in the development of food sensitivities, particularly to gluten. Some people also develop multiple chemical sensitivity syndrome (MCS). People with MCS react to low-dose exposures of chemicals such as perfumes, cleaning agents, and exhaust fumes, many of which are unavoidable in our current environment. (See Chapters 16 and 18.)
8. Immune dysregulation often results in autoimmunity, in which the immune system attacks its own cells.
9. Suppression of immune function from multiple tick-borne infections can lead to activation of microbes that were previously dormant. Many patients with Lyme disease complex experience reactivation of viral infections such as Epstein-Barr virus (EBV) and human herpes virus 6 (HHV6). (See Chapter 21.) People with chronic tick-borne infections seem particularly susceptible to complica-

tions from mold. Mold exposure is normally associated with respiratory symptoms such as congestion, sinus problems, and asthma; but reactions can also be systemic, resulting in migraine headaches, fatigue, joint pains, cognitive dysfunction, and depression. In other words, mold exposure can cause the same symptoms as Lyme disease complex. Complicating issues further, those molds most commonly associated with indoor water damage also excrete poisonous mold toxins. The symptoms of mold toxin exposure overlap with those of chronic infection, often resulting in severe inflammation and hormonal dysfunction, particularly suppressing the pituitary gland. (See Chapter 19.)

10. Histamine reactions, either due to increased release of histamine into the circulation, decreased metabolism of circulating histamine, or heightened sensitivity to histamine, can add to inflammatory symptoms. This condition is referred to as mast cell activation syndrome (MCAS). (See Chapter 18.)
11. *Bb* has an affinity for the nervous system, resulting in an array of neurological issues. A common problem is cognitive dysfunction, or brain fog, which, among other things, compromises the patient's capacity to make good therapeutic choices and follow through on treatment regimens. This issue is exacerbated by sleep disorders. (See Chapter 17.)
12. *Bb* and its co-infections, particularly Babesia and Bartonella, often cause neuropsychiatric disorders, particularly anxiety, depression, and irritability. Symptoms can be severe, resulting in panic attacks, suicidal ideation (and successful suicides), and rage episodes.
13. It is important to realize that these problems are not only a secondary response to illness, they can be a direct result of infection causing neuroinflammation and neurotransmitter imbalance. (See Chapter 17.)
14. People have very different physiologies, and their constitutions differ considerably. Genetic differences can impact detoxification, allergic dispositions, and autoimmune reactivity. There are also differences in each person's immune system, impacting their individual capacity to contain and eliminate infections.
15. By definition, people with Lyme disease complex have been sick for a long time. Many have been ill for years or decades before they receive a diagnosis, let alone find a practitioner willing to treat them. They often become weak and fragile, losing the rebound capacity of otherwise healthy people. As stated at the outset of this chapter, treating those with Lyme disease complex is complicated.

Risk Factors of Chronic Disease

Prior or ongoing exposures to mold and mold toxins, heavy metals, and chemical volatile organic compounds (VOCs) vastly impact a person's capacity to fight infection.

People also have enormously different tolerances to different antimicrobial agents, both herbal and pharmaceutical. Some patients have great difficulty taking any antimicrobials at all because they cannot tolerate the "die off," also known as a Herxheimer reaction.

A history of emotional trauma can result in immune dysfunction and difficulty fighting infection. Social and emotional support structures have been shown to enhance emotional well-being and boost immune competence. Lack of support adds an extra hurdle to treatment. (See Chapters 1 and 2.)

Physicians are taught in medical school, "When a patient presents with multiple symptoms, search for the common denominator that explains everything." This axiom applies well to acute illness: if a person has been healthy until two weeks ago and then develops fever, muscle aches, abdominal pain, nausea, and diarrhea, all these symptoms can be explained by a single pathogen.

Although Western medicine has done a good job of addressing acute illness, it has not been nearly as successful in addressing chronic disease. The "single-common-denominator" paradigm of illness no longer applies; there are usually multiple confounding issues. It takes detective work

to uncover the assorted imbalances and restore people to good health.

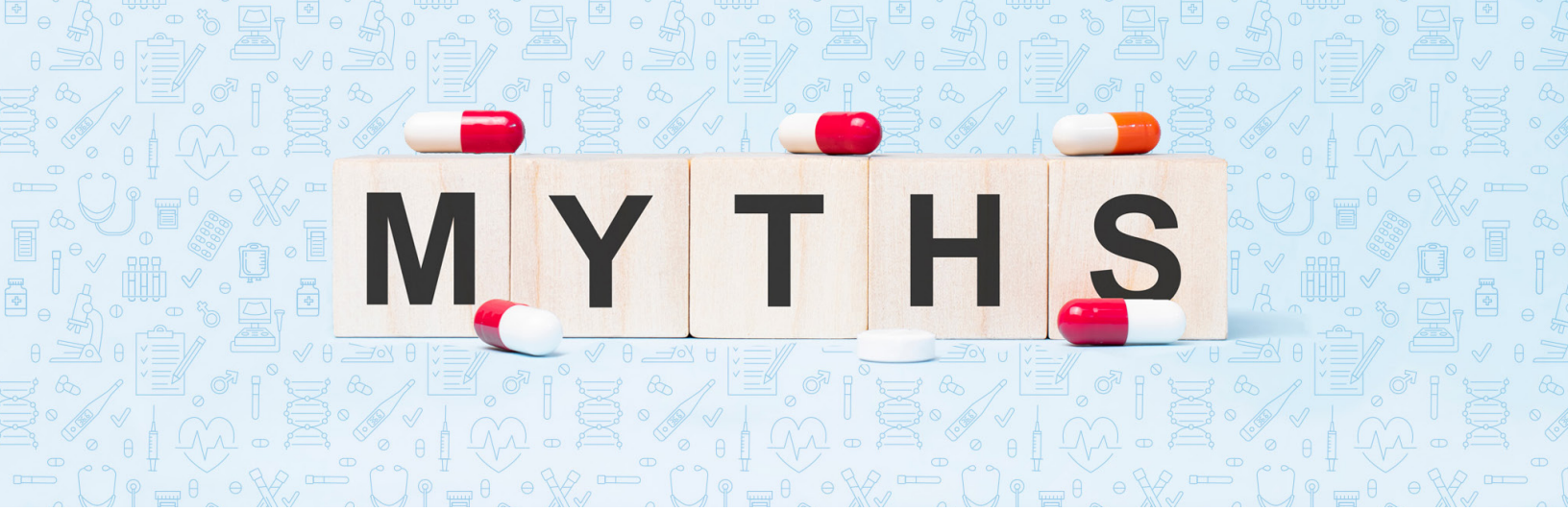
Awareness of these tick-borne infections is critical; equally essential is recognition that every patient is unique. The seed is important, but understanding the soil is equally relevant. Lyme disease complex is complicated. It takes a persistent sleuth to help people get better.

Take home points

1. Everybody is different, and treatment needs to be individualized.
2. The diagnosis of acute Lyme disease is often missed for multiple reasons.
3. Co-infections and toxic exposures increase the severity and duration of illness. *Bb* and co-infections may suppress immune function.
4. Most people with Lyme disease complex have co-infections.
5. Downstream issues of chronic infection complicate the clinical picture; endocrine, immunological, neurological, and gastrointestinal issues are common.
6. Emotional stress can make recovery more difficult while social support can promote healing.

Excerpted with permission from "Recovery from Lyme Disease: The Integrative Medicine Guide to Diagnosing and Treating Tick-Borne Illness" by Daniel A. Kinderlehrer, MD (Skyhorse Publishing), available now.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.



Chronic: The Hidden Cause of the Autoimmune Pandemic and How to Get Healthy Again

In their book, Chronic: The Hidden Cause of the Autoimmune Pandemic and How to Get Healthy Again.

By Dorothy Kupcha Leland

Chronic: The Hidden Cause of the Autoimmune Pandemic and How to Get Healthy Again is a long-awaited book by Dr. Steven Phillips and Dana Parish. The authors, a prominent Lyme doctor and a singer/songwriter/advocate who used to be his patient, are well known in the Lyme community. Given their connections with Lyme, it's initially curious that their book's title doesn't mention Lyme disease. But that omission is explained early on. In their text, Phillips and Parish use the term "Lyme+" for the dizzying constellation of microbes that can result in a wide variety of persistent symptoms and autoimmune conditions. Lyme disease by itself may be only one part of the complex picture.

Chronic is divided into two sections. The first part, "The Root," debunks commonly held myths about Lyme+ and shows how mainstream medicine has so often gotten its facts wrong. The second part, "The Remedy," offers practical advice on how to get properly diagnosed and discusses an assortment of treatments that may be useful.

The following excerpt is taken from the chapter titled, "The Myths That Get in the Way." (This passage includes two myths. The chapter explores many more.)

MYTH:

Long-term antibiotic therapy for Lyme is an unproven treatment that's highly dangerous.

FACT: Of course, we want to minimize risks to patients from treatments and maximize benefits. Therapies for most serious diseases can have serious side effects, but the risk of fatality from long-term antibiotic therapy is quite low. Far more deaths have been caused by Lyme+ than by its treatment. The risk

of fatal outcomes in the treatment of inflammatory diseases with immunosuppressive agents, and cancer with chemotherapy, is far higher than for antibiotic therapy, but the difference in those diseases is that they are accepted by the CDC as legitimate, therefore the risk is deemed justifiable.

But high rates of treatment failures using short-term antibiotic therapy are well documented in the medical literature. It has been clearly demonstrated in study after study that short-term antibiotics are simply not effective in many cases. This, coupled with published research proving bacterial persistence despite short-term antibiotics, makes the case for longer treatments until better treatments come along.

One of the earlier case reports revealing how Lyme disease can survive antibiotic treatment was published by the University of Chicago's Journal of Infectious Diseases in 1988. A group of Swiss scientists successfully grew *B. burgdorferi* from joint fluid three months after a fifteen-year-old girl was treated for Bell's palsy (facial paralysis) due to Lyme disease. She'd been bitten by a tick in Austria but experienced none of the typical symptoms—no rash, malaise, fever, or musculoskeletal pain. It wasn't until one side of her face drooped that doctors suspected Lyme, after which she underwent the conventional, two-week antibiotic treatment. After initially improving, she relapsed a couple of months later, developing sudden, unexplainable arthritis in her right knee. Her doctors finally found *B. burgdorferi* in her joint fluid and ordered another round of antibiotics, concluding that a two-week course of antibiotics for Lyme was inadequate.

In 1993, a more dramatic report was published out of the Department of Medicine at Fitzsimons Army Medical Center in Aurora, Colorado. There, a twenty-four-year-old patient with Lyme arthritis continued to relapse when the antibiotics were stopped. Despite years of oral and IV antibiotics, the researchers found *B. burgdorferi* in the patient's joint tissue and joint fluid—proof again that the bacteria can escape the assault of antibiotics. But the IDSA guidelines fail to take studies like these into account.

To understand the importance of considering novel treatments to address complicated health challenges—in this case, long-term anti-microbial therapy for Lyme+—it helps to consider other areas in medicine where out-of-the-box thinking eventually revolutionized the field, but only after hard-won battles. It was long thought, for example, that stomach ulcers were caused by diet and stress, for which bland foods, antacids, and meditation were prescribed, without benefits. Such patients went on to suffer, some requiring surgery, and some dying from bleeding ulcers or stomach cancer. In 1982, the Australian physicians Robin Warren and Barry Marshall found a link between *Helicobacter pylori* infection and ulcers, concluding that the bacteria—not spicy foods and a mean boss—were to blame.

In 1983, they presented a paper to the Australian Gastroenterological Society, but never finished their presentation because they were laughed off the stage. Barry Marshall took drastic steps. He had a baseline endoscopy of his stomach performed, which was normal, and then drank a batch of *H. pylori.* Soon after, he developed severe gastritis that was documented by another endoscopy. He then took antibiotics, which resolved his condition, documented again by endoscopy. It was because of this desperate tactic that Marshall and Warren were able to turn around medical dogma within fifteen years, which is light speed for a complete about-face in medical doctrine. In the past, other physicians had tried to change medical dogma but couldn't break through the medical community's wall of arrogance.

For example, in 1940, Dr. A. Stone Freedberg, of Harvard, found the spiral-shaped bacteria in the stomachs of ulcer patients, but wasn't believed. In 1946, Dr. Constance Guion presented a paper on treating stomach ulcers with the antibiotic chlortetracycline, but her colleagues at Cornell Medical School denounced

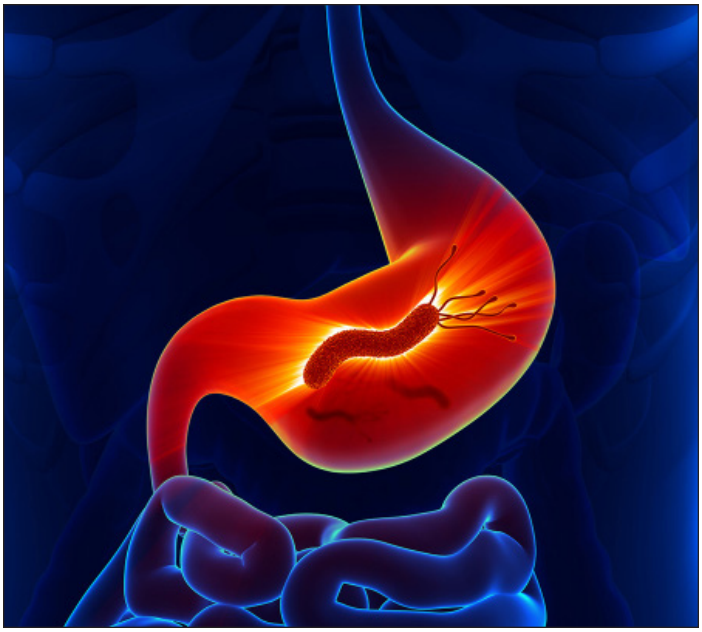
her so mercilessly that she ditched her thoughts of treating ulcers with antibiotics. And then there was John Lykoudis, a physician from a small town in Greece, who developed a bleeding ulcer and cured himself with antibiotics. Since they worked for him, he treated his ulcer patients with antibiotics too, and found they were effective. He soon had patients flying in from all over the world to have him treat their stomach ulcers with antibiotics. In the 1950s, he presented his work to professors at several Greek medical schools but was met with laughter. He then contacted the Greek minister of health, the prime minister of Greece, and eventually the chairmen of the department of medicine at Athens Medical School, to no avail. He was treated like a pariah. Unable to get his work published, he died without vindication, never getting to see Drs. Marshall and Warren win the 2005 Nobel Prize for their discovery. *

The state of medical dogma today regarding Lyme+ is worse than it was for stomach ulcers before Marshall and Warren took the stage. The Lyme+ doctrine is similarly based on obsolete, erroneous data, but far more riddled with financial conflicts of interest, as follows:

Big Pharma sells few cures, but it sells lots of bandages—very expensive bandages that require lifelong refills. No pharmaceutical company is interested in finding the cause of autoimmune disease and eradicating it. That wouldn't be profitable.

Obsolete, inaccurate Lyme blood tests still bring in big money for their patent holders, so why would they want to improve them? Why not just control the conversation, keep saying that they work fine?

The now defunct Lyme vaccine lined the pockets of certain physician researchers who continue to espouse the same medical doctrine that was required to get its FDA (Food and Drug Administration) approval (perhaps in the hopes that it would clear the way for a second Lyme vaccine). The belief that Lyme is easy to diagnose and easy to cure was a necessary prerequisite for vaccine approval because administering the Lyme vaccine to someone who still harbors *B. burgdorferi* in their body could be dangerous.



* In 1997, the CDC, with other government agencies, academic institutions, and the medical industry, launched a national education campaign to inform health care providers and consumers about the causal link between *H. pylori* and ulcers. Until word got out, millions suffered needlessly, including family members of our own, having no idea that their cure was an inexpensive prescription away. At the time the national education campaign spread the news, nearly 90 percent of patients were still subscribing to the old dogma and relentlessly popping antacids and avoiding their favorite foods to no avail.

The following is an excerpt taken from the chapter titled. "The Myths that Get in the Way"

MYTH: The medical establishment has no idea what causes Post-Treatment Lyme Disease Syndrome or what the best treatment for it is.

FACT: The medical establishment has no idea what causes Post-Treatment Lyme Disease Syndrome or what the best treatment for it is. If you've been dealing with chronic Lyme+, then chances are you've heard this statement. As previously noted, PTLDS is a misleading term given the wealth of published information that these organisms can persist—and indeed continue to

Authors Steven Phillips, MD, and Dana Parish.

thrive —despite drugs that were initially thought to kill them but don't. It's an illogical construct. Think about it: What are the chances that a second disease of mysterious origins (i.e., PTLDS or an autoimmune disease), but with the same symptoms as the first disease, would come and replace the first disease? What are the odds, in light of published evidence that the pathogens that cause the first disease survive after both short- and long-term antibiotics?

Consider also that there are numerous other chronic bacterial infections that require long-term combination antibiotic therapies: tuberculosis, leprosy, chronic coxiella, brucellosis, and Whipple's disease, to name a few, some of which are included in what we term Lyme+. Many of the other members of Lyme+ are no different and should be included in the same category.

"Because semantics guide patient care, we believe the term Post-Treatment Lyme Disease Syndrome is harmful, and in some cases fatal, and it should not be used.

The consequence of referring to patients with persistent symptoms of Lyme disease after a short course of antibiotics as having Post-Treatment Lyme Disease Syndrome is a fait accompli, in that such patients, now desperately searching for answers on the CDC website, may feel that antibiotics can't possibly help them. You may already believe this if you've ever gone to the CDC's website. But if someone with Lyme+ is led down the path of PTLDS, this will only delay care further and increase the likelihood of subsequent antibiotic treatment failure. Late-stage Lyme+ is difficult to treat. Because semantics guide patient care, we believe the term Post-Treatment Lyme Disease

Syndrome is harmful, and in some cases fatal, and it should not be used.

Excerpted from CHRONIC: The Hidden Cause of the Autoimmune Pandemic and How to Get Healthy Again © 2020 by Steven Phillips, MD, and Dana Parish. Reproduced by permission of Houghton Mifflin Harcourt. All rights reserved.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

CHRONIC:

The Hidden Cause of the Autoimmune Pandemic and How to Get Healthy Again

AUTHOR: DR. STEVEN PHILLIPS AND DANA PARISH

Chronic is divided into two sections. The first part, "The Root," debunks commonly held myths about Lyme+ and shows how mainstream medicine has so often gotten its facts wrong. The second part, "The Remedy," offers practical advice on how to get properly diagnosed and discusses an assortment of treatments that may be useful.

ORDER BOOK

"Brain Inflamed" Talks to Parents of Teens with Mental Health Problems

Neuropsychiatric symptoms might actually have physical roots.

By Dorothy Kupcha Leland

By the time they turn 18, as many as 50 percent of all children and teens will meet the diagnostic criteria for at least one mental health disorder.

So says Dr. Kenneth Bock, who has practiced integrative medicine in New York state for 35 years. During much of that time, he has focused on the needs of tweens and teenagers.

If you are a parent or family member of a young person suffering from what appears to be mental health problems, he urges you to remember this: "Not all conditions that present as psychological disorders are actually psychological disorders."

In fact, he's been able to help children and teenagers overcome such issues as anxiety, low energy, depression, emotional volatility, and behavior disorders by addressing the physical root causes of the conditions—too often overlooked by conventional approaches.

He shares this knowledge in his new book BRAIN INFLAMED: Uncovering the hidden causes of anxiety, depression, and other mood disorders in adolescents and teens.

As he states in his introduction, I've often found that a panic disorder is being caused by something no one has thought to investigate, like an immune system gone haywire, or low blood sugar, or an out-of-whack adrenal system. With proper treatment that addresses the source of the symptoms, these children's neuropsychiatric issues—the violent mood swings, brain fog, lethargy, anxiety, depression, tics and OCD—can lessen and even disappear.

Range of Conditions

The book introduces a concept Dr. Bock calls the Mood Dysregulation Spectrum. This term illustrates the vast range of conditions that can manifest as neu-

ropsychiatric symptoms but might actually have physical origins. Examples of such causes include gluten sensitivity, adrenal dysfunction, or infections such as Lyme disease and strep.

Notes Dr. Bock: "Being aware that there are multiple medical conditions that could contribute to your child's condition is the first step toward getting them better."

The book begins with an introduction to how the immune system works. Thus, we learn how inflammation can start in one part of the body, such as the gut, and then wreak havoc on a different part of the body, like the brain. Dysbiosis—an imbalance of intestinal flora—in fact can lead to a wide variety of problems, both physical and mental.

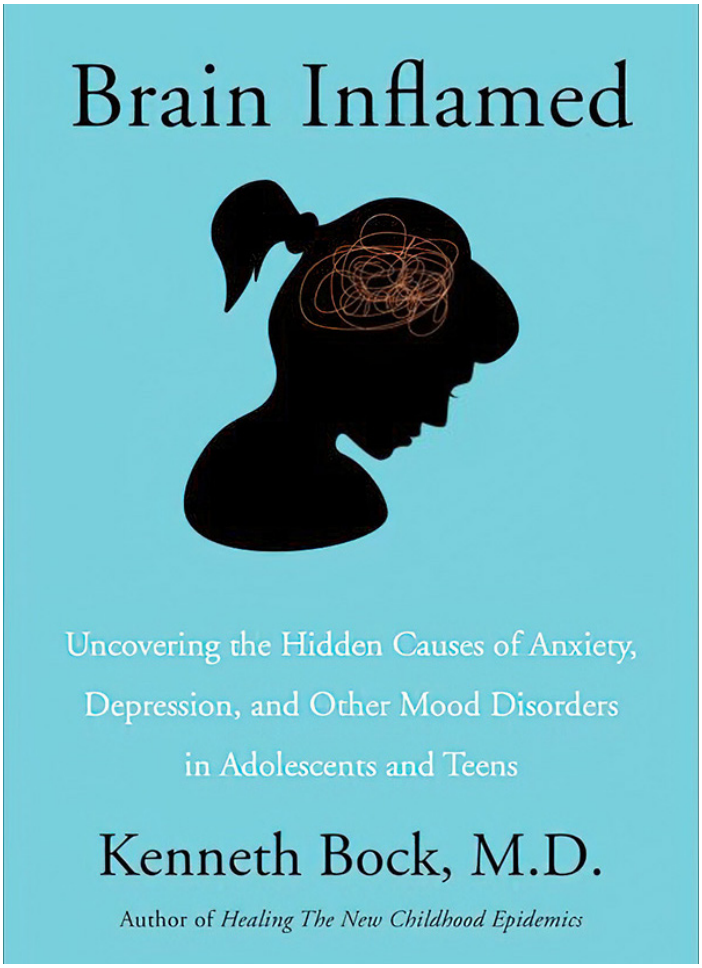
Sometimes inflammation leads to an autoimmune reaction in the brain—often called PANDAS or PANS—which can seemingly turn a child into a completely different person overnight. This illness can involve a terrifying constellation of symptoms, including the rapid onset of obsessive-compulsive behaviors, severe anxiety, mood swings, aggressiveness, and other abnormalities.

> *With proper treatment that addresses the source of the symptoms, these children's neuropsychiatric issues—the violent mood swings, brain fog, lethargy, anxiety, depression, tics and OCD—can lessen and even disappear.*

Dr. Bock proposes a new name for the condition: infection-triggered autoimmune brain inflammation, or ITABI. (I heartily agree with Dr. Bock on this. Neither PANS nor PANDAS mentions inflammation—one of the hallmarks of the condition. And PANDAS only refers to strep—too restrictive a definition for an illness with so many contributing factors.)

Mood Dysregulation Spectrum

The author delves into a variety of situations that can thrust a young person onto the Mood Dysregulation Spectrum—such as thyroid and adrenal imbalances, nutritional deficiencies, infections such as Lyme disease and Bartonella, and toxic exposures to mold, lead, or mercury.



One of the most intriguing parts of the book is its use of case studies to demonstrate the complexities of what these young people (and their parents!) have gone through to find answers. One particularly riveting account traces the experiences of Stacy, an adolescent whose myriad problems had started shortly after she was bitten by a tick at age 4.

For the next nine years, the girl suffered from panic attacks, periodic rages, severe anxiety, OCD, chronic sinusitis, mood disorder, ADHD, and involuntary jerking of her arms.

> *According to Dr. Bock, the risk of misdiagnosing a case of Lyme disease is especially high in children.*

Stacy had been tested for Lyme disease a few times—all negative. (But as we in the Lyme community have learned, a negative test doesn't necessarily mean you don't have it.)

Stacy's doctors tried a dozen different heavy-hit-

ting psychiatric drugs on her over the years, to no avail. When her parents finally brought her to Dr. Bock at age 13, he didn't let those previously negative Lyme tests stop him from investigating the possibility of tick-borne disease.

According to Dr. Bock, the risk of misdiagnosing a case of Lyme disease is especially high in children. "While neuropsychiatric symptoms often accompany the physical symptoms of Lyme disease in adults," he writes, "they can be the only signs of Lyme disease in kids: irritability, personality change, depression, brain fog, mood disorders, school phobia, insomnia, and anxiety."

Many Causes

I think it's important to note that the book's subtitle refers to the "causes" (plural) of these disorders, not their "cause" (singular). In Stacy's case, Dr. Bock's examination and testing found not only Lyme and Bartonella, but strep antibodies, vitamin D deficiency, reactivated Epstein-Barr virus, low thyroid function, and allergy to cats and pollen.

Working from the assumption that some combination of these factors was contributing to Stacy's physical and mental health issues, he devised a multi-faceted treatment plan. It didn't happen overnight, but in time, she made substantial improvements on issues that had plagued her for years.

Other case studies in the book highlight thyroid problems, low blood sugar, adrenal dysfunction, allergies, mold, exposure to toxins, food sensitivities, and nutritional deficiencies.

Dr. Bock says one of the most common nutritional deficiencies he sees is methylfolate, especially in patients with mood disorders. Methylfolate, a B vitamin, is needed for building the neurotransmitters responsible for happiness and emotional well-being. Without it, he says, the brain is primed for anxiety and depression.

An excerpt from Dr. Kenneth Bock's book Brain Inflammed.

This passage concerns the case of Stacy, an adolescent who experienced years of psychiatric symptoms which started after she was bitten by a tick at age 4.

By the time she first saw Dr. Bock at age 13, she'd already been prescribed these drugs: Ritalin, Focalin, Strattera, Lexapro, Venlafaxine, Lamictal, prednisone, Zyprexa, Zoloft, Ativan, sertraline and Seraquel. She had also had several doses of IVIG, a treatment for autoimmune conditions.

Signs of Brain Inflammation

Stacey's elementary school years were punctuated by hypervigilance, school phobia, paranoia, fear of contamination, and uncontrollable rages. Together with neurological symptoms, like the foot drag and the tics, and the OCD, all the symptoms and behaviors screamed brain inflammation to me. Here are some of the other clues I observed:

Chronic infections: In addition to multiple strep infections, Stacey had battled chronic sinusitis since early childhood. So many infections suggested a compromised immune system.

Food allergies: At some point, a doctor suggested that Stacey had a sensitivity to dairy and possibly egg whites, and sure enough her symptoms improved when she eliminated these foods, as well as gluten, from her diet (though she strayed from this diet once she felt better). Food sensitivities would point to the possibility of a leaky gut, which can cause widespread inflammation. If her symptoms improved once her gut health improved, that would suggest the gut could be a contributing factor in her neurological and psychological symptoms. For as we've read, a leaky gut can contribute to a leaky blood-brain barrier, which would put a patient at a higher than

average risk for brain inflammation. Increased permeability of the blood-brain barrier would make it easier for inflammatory elements, such as those triggered by Lyme disease, to get into the brain.

Stalled progress: The temporary nature of Stacey's improvement after IVIG told me that something was blocking the treatment's efficacy. Could it be that she wasn't getting a high enough dose? Typically, low doses of IVIG are used to treat immune deficiency conditions, whereas neurological autoimmunity and brain inflammation require higher doses. Stacey's first two IVIG treatments, the ones that had worked best, were administered at a high dosage, but perhaps to mitigate her severe headaches, her doctor had lowered the dose for the subsequent ones.

Dilated eyes: Stacey's pupils were massive the first time I saw her. Living with chronic anxiety means living in a perpetual state of fight or flight. The sympathetic nervous system is on high alert, and to me, that suggests brain inflammation, as dilated pupils are frequently seen during flares of ITABI. [Also known as PANS/PANDAS.]

Homicidal thoughts: Though Lyme patients typically report crushing exhaustion, there have been instances of people with Lyme committing violence against others or reporting homicidal or suicidal thoughts.

Co-infections

While ticks are the primary vector for Lyme disease, they frequently carry many other diseases as well, all of which can be transmitted at the same time. In fact, slightly over 50 percent of Lyme disease patients are also diagnosed with at least one co-infection such as Babesia, mycoplasma, or Bartonella.

Lyme disease can be bad; Bartonella can be worse. The same bacteria that causes cat-scratch fever, in which the lymph vessels become inflamed, Bartonella is treated relatively effectively with intracellular antibiotics when caught early. Unfortunately, because it can burrow into red blood cells, it doesn't always show up in bloodwork. When patients come in with symptoms like numbness or tingling feet, a doctor might test for Lyme, but if the Lyme titer is negative, they'll assume that whatever is ailing the person can't be tick-borne.

However, if they haven't checked the western blot, and they haven't tested for any of the common co-infections that travel with Lyme disease (which is especially important in patients who come from endemic areas, work with animals, or spend a lot of time outside), it's premature to rule out tick-borne diseases. And early detection is important; as with Lyme, the longer Bartonella is left in the bloodstream, the harder it is to eliminate.

The most distinguishing symptoms of Bartonella are soreness on the bottom of the feet, especially the heel; ice pick–like pain in and around the eyes; headaches; and violaceous striae, reddish-purplish tracks that look like stretch marks. But it can also cause intense joint pain, GERD, difficulty swallowing, and crawling, burning sensations in the skin. Another symptom of Bartonella is intense, violent anger, sometimes accompanied by homicidal thoughts.

The other co-infections that frequently travel with Lyme have overlapping symptoms. Babesia, however, is a protozoan parasite that invades the brain and nervous system and causes fever, chills, sweats, chest pain, and most notably, air hunger. Mycoplasma, a type of bacteria, can cause severe fatigue, dry cough, and generalized pain. The more co-infections you have, the more complicated it becomes to treat the Lyme disease.

Explosive Reaction

Stacey's explosive reaction to the ADHD and psych meds could have been caused by a new Bartonella infection if she'd been bitten by another tick. More likely, however, the cause was brain inflammation, which is often what I find in children who don't respond at all or have adverse reactions

to psychiatric meds. ADHD medicines increase dopamine levels. For a kid with brain inflammation, that's like throwing a lighted match on a vat of gasoline.

Some psychotropic meds are actually anti-inflammatory, which may be one of the mechanisms for their effectiveness in certain patients. Considered along with all of her history, Stacey's reaction to these medications seemed extremely relevant to me.

If she did have brain inflammation, I had to consider that she could also have an autoimmune problem. Some doctors will say that the symptoms of post-Lyme are residual, that like PANDAS and strep, Lyme disease can provoke a secondary autoimmune problem that persists even when the bacterial infection is gone. That's the big controversy when discussing persistent Lyme disease: is it a chronic infection, is it an infection with autoimmunity, or is it just a case of autoimmunity?

I think it's a combination. You can kill the infection and still be left with fragments of dead bacteria that can stimulate the immune system and cause an autoimmune reaction, and at the same time bacteria can instigate molecular mimicry that triggers autoimmunity in genetically susceptible individuals.

In fact, about half of patients with persistent Lyme symptoms, in particular neuropsychiatric symptoms, test positive for antineuronal antibodies—antibodies produced against nerve cells, especially when they break down and release their neural antigens. The presence of these antibodies points to evidence of autoimmune inflammation in the nervous system.

Over several decades, researchers have found emerging links between autoimmune disorders and neuropsychiatric disorders, prompting more investigation into whether a subset of what we currently diagnose as primary psychiatric disorders are in fact autoimmune disorders with psychiatric symptoms.

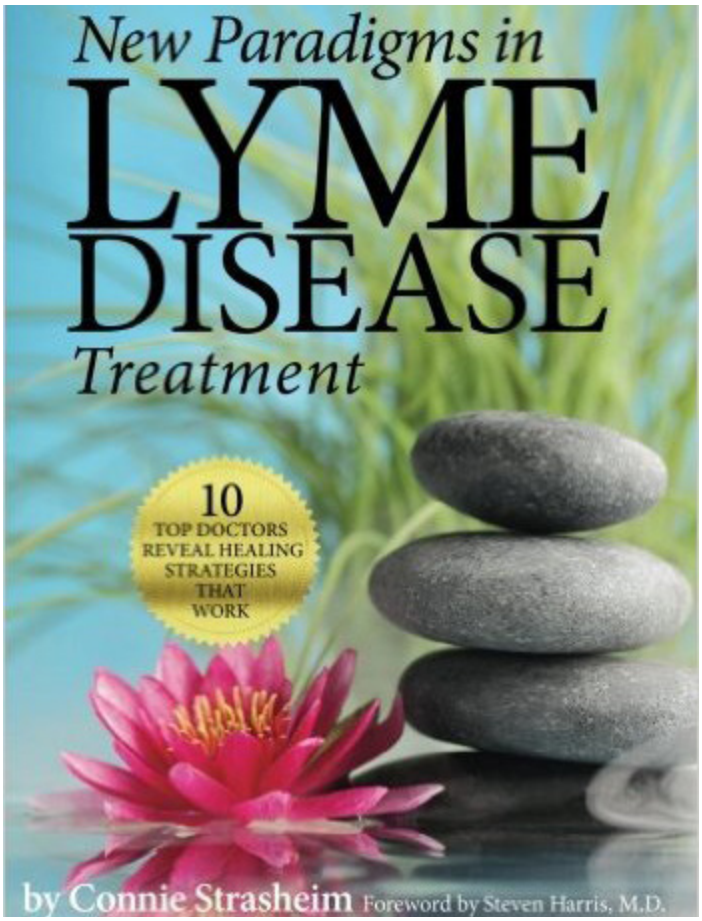
If I ran a Cunningham panel — a special test that measures the concentration of antibodies present in the blood — and the results revealed elevated antineuronal antibodies, it could indicate that Stacey's neuropsychiatric symptoms were being caused by an infection-triggered autoimmune reaction, which would also explain why IVIG had helped calm her neuropsych symptoms so dramatically.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

Symptom Patterns in Six Lyme-Related Infections

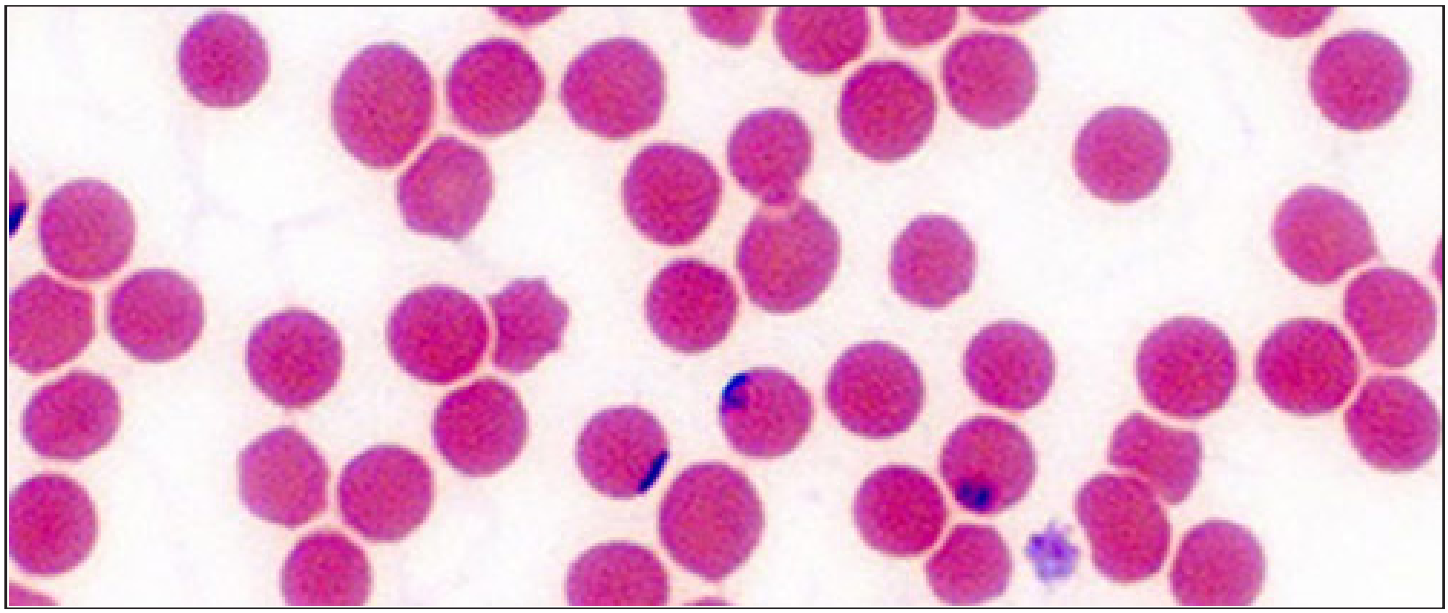
In "New Paradigms in Lyme Disease Treatment" 10 Top Doctors Reveal Healing Strategies

By Dorothy Kupcha Leland



When mainstream medicine talks about Lyme disease, it's usually couched in simple terms: A tick infected with one organism bites a person, causing a few specific symptoms. Treatment is a short course of doxycycline—and then you are good to go. Next!

Unfortunately, that's not the experience of many people with Lyme disease. Instead of being infected with one errant pathogen, they may have several illnesses at once, causing a weird complex of symptoms that are difficult to sort out. Instead of needing just a short course of one specific drug—well, things are more complicated than that.



NEW PARADIGMS IN LYME DISEASE TREATMENT:

10 Top Doctors Reveal Healing Strategies That Work

AUTHOR: CONNIE STRASHEIM

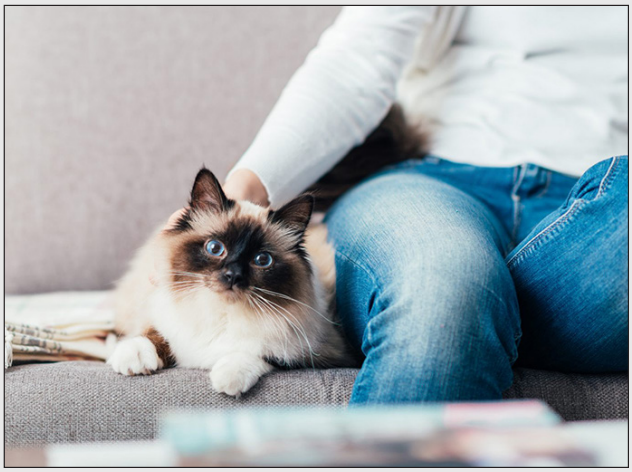
In the book **New Paradigms in Lyme Disease Treatment**, author Connie Strasheim interviews 10 doctors about their approach to treating Lyme-related illnesses.

ORDER BOOK

In the following excerpt, Dr. Wayne Anderson discusses six of the most commont Lyme-related infections.

These symptom patterns should only be used as a guideline for diagnosis since no two people are exactly the same, and symptoms will vary from person to person. Neurotoxins from these infections all cause inflammation in the brain and nervous system and cause similar symptoms and compromise the body's function in a similar way. Yet, each microbe often will manifest its own unique traits or personality.

Understanding the different symptom patterns that the microbes cause is especially important since lab tests for Lyme disease aren't adequate (although they have improved greatly in recent years). Diagnosis also can be complicated by the fact that people's immune systems respond differently to infection, according to their life stressors and metabolic strengths and weaknesses. Doctors should look for patterns in their patients and always appreciate that treating people with Lyme disease is about shades of gray, because the infections create symptom pictures that are never black and white.



Babesia or Babesia-Like Organism (BABLO) Symptom Patterns

Babesia, or Babesia-like organisms (BABLO) primarily affect the brain and autonomic nervous system. The first words that a patient with active Babesia-like organisms in his body might say are that he can't focus or think. His cognitive function is significantly compromised, and his mood is almost always affected. Both depression and anxiety are very common. A person with Babesia has a lot of emotional upheaval; fear is a dominant symptom.

Babesia also can affect the autonomic nervous system, which is responsible for much of the "automatic" functions of the body, such as heartbeat, breathing, etc. This means that the communication between the brain and body is affected, so any physical symptoms that patients have from Babesia can be related more to autonomic nervous system dysfunction rather than the organisms themselves. For instance, Babesia can cause postural orthostatic tachycardia syndrome (POTS); a racing heart at rest and/or an irregular heartbeat and heavy pounding heart at night, but the problem isn't in the heart. The problem is that the autonomic nervous system isn't functioning properly.

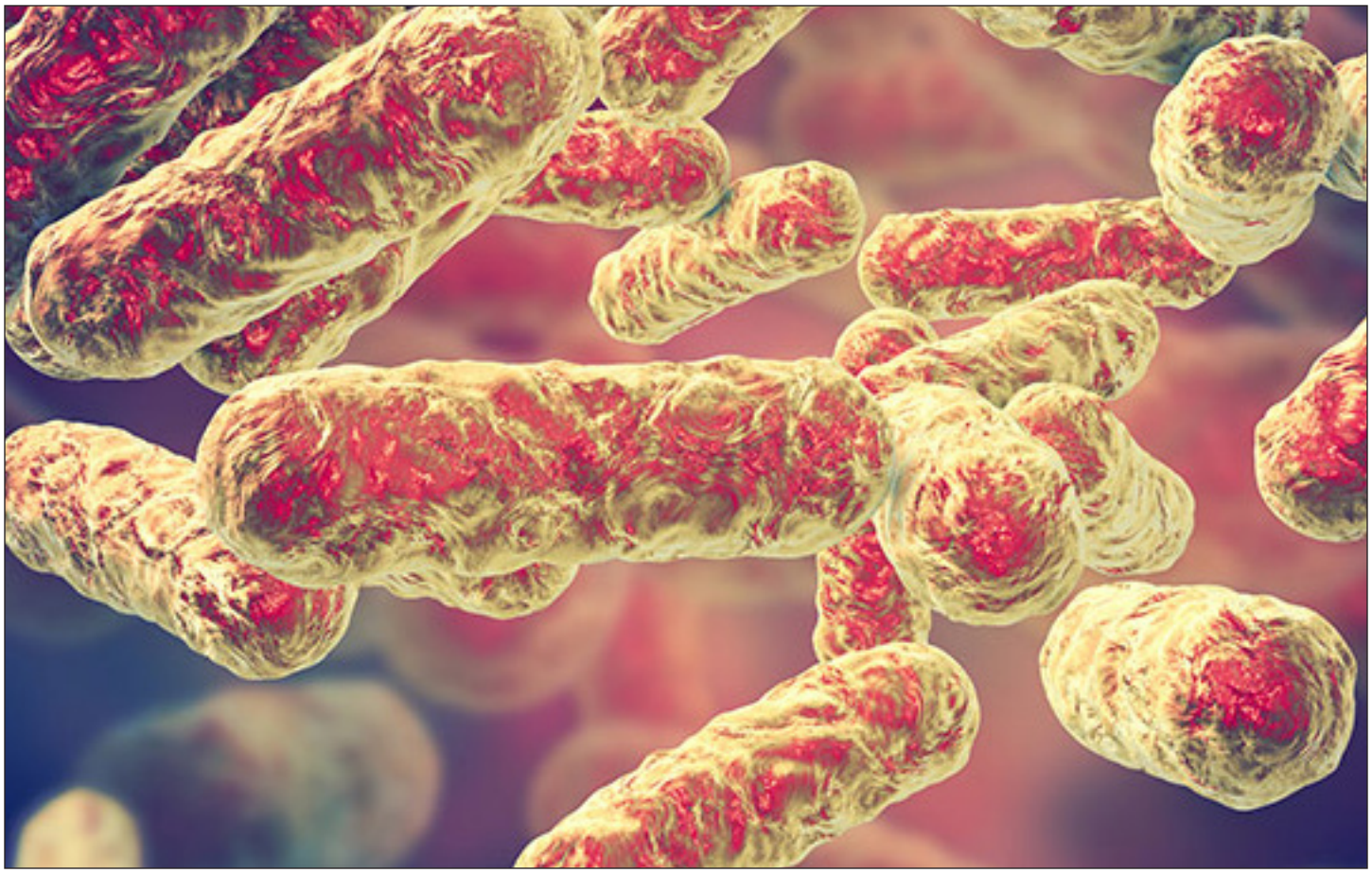
Shortness of breath is also common, because people with Babesia don't regulate their oxygen-saturation flow properly due to problems in the autonomic nervous system (ANS). Such people feel a sense of "air hunger" because the ANS isn't dilating their bronchial tubes or opening their diaphragm properly, because these parts of their body are not getting the signal to do so from the command center in brain.

Additional symptoms of Babesia include lots of drenching sweats and chills. Babesia is a relative of the malarial organism and is part protozoan and part bacteria. So as with malaria, people can get terrible chills and lots of sweats and basically feel like they are going crazy. People with Babesia are often quite chilled and can't get warm and will have to take a hot shower or jump in a bathtub to warm up. The temperature de-regulation is again related to a dysfunctional autonomic nervous system. So, people either can't get warm, or they get too hot. They turn down the thermostat at night because they are too hot, but then they get too cold while in bed and so turn it back up by a degree. They freeze when going to bed and throw the covers on; then, in the middle of the night, they get boiling hot and throw the covers off and drench their bedclothes in sweat.

Insomnia is common as Babesia affects the sleep center in the brain. Other symptoms include blurred vision, bowel-motility issues and bladder difficulties. People with Babesia will either have trouble starting their urinary stream or will go through episodes of incontinence. They may also have problems with bowel motility; usually constipation, but can also sometimes have diarrhea due to autonomic nervous system de-regulation. A dominant Babesia infection also can affect certain areas of the wrists, hands, ankles and feet. These areas can be painful, numb or experience temperature extremes.

Babesia does not generally cause pain in the body, so if a person has pain, then it's usually due to another problem. The picture is always complicated though because people with Babesia who have a compromised detoxification system will have pain in their body as a result of poor waste removal. But, the pain is not from the infection itself.

These are what I call clearly identifiable



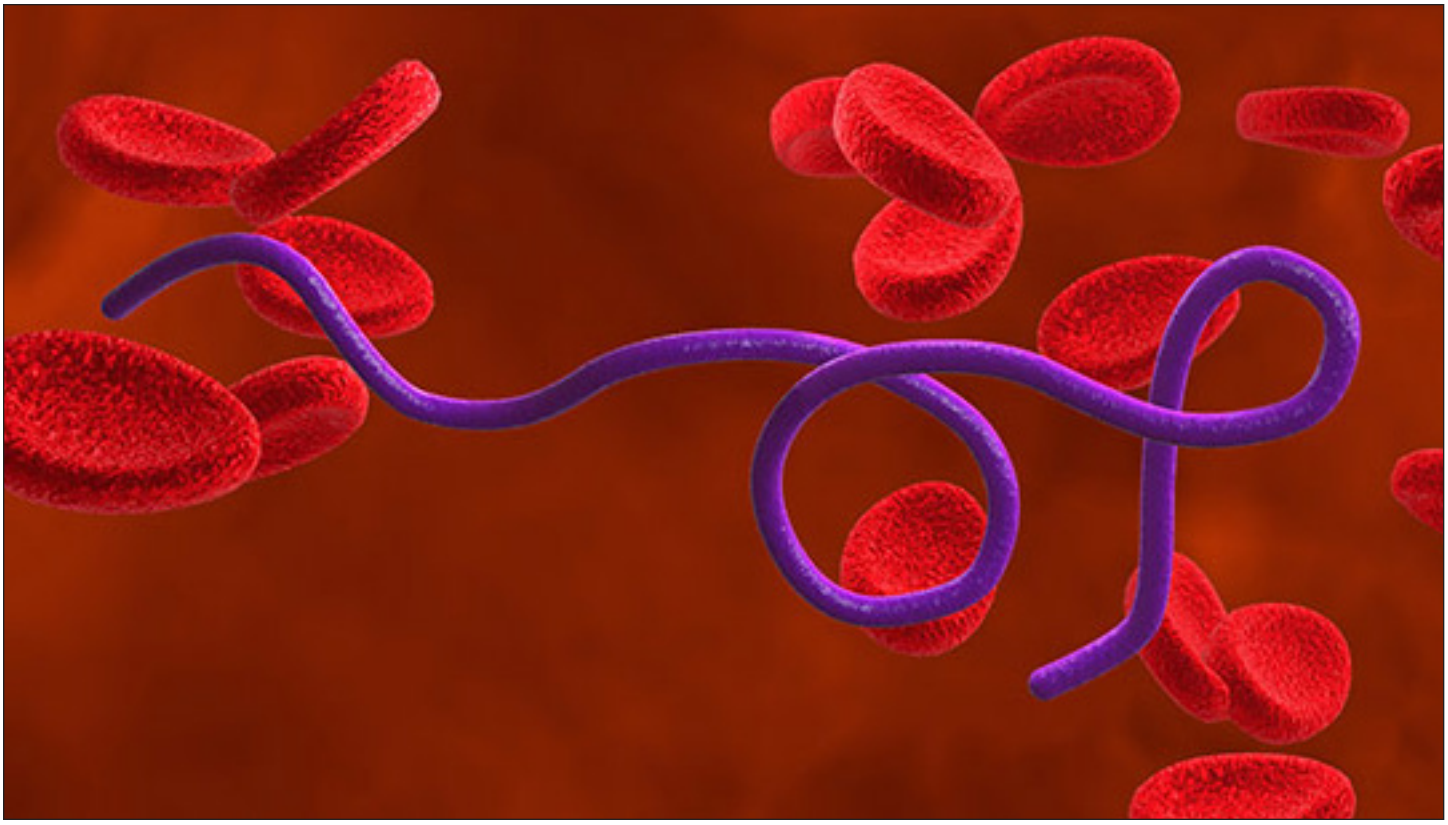
Babesia symptoms in those patients who have an immune system that is not terribly depleted or who don't have a compromised detoxification system or other conditions or infections that are currently active and which could complicate the symptom picture. The same holds true for the symptom patterns of all of the other infections described here.

Bartonella or Bartonella-Like Organism (BLO) Symptom Patterns

Many people have Bartonella or Bartonella-like (BLO) infections in their bodies. They are perhaps the most abundant infections in people because many veterinarians say that 80 percent of all house cats and nearly 100 percent of all hunting cats carry Bartonella microbes. Fleas bite cats and infect them with the Bartonella-like organisms, which are then transmitted to humans when they get bitten by the flea. Bartonella and BLO infections are therefore probably the most common of the vector-borne Lyme disease co-infections.

People who have active Bartonella symptoms have much more pain than people who are manifesting predominantly Babesia-related symptoms. The first thing out of their mouths is usually, "You have to help me with my pain." They have pain in their joints and the connective tissue around their joints. This joint pain will migrate to other areas of the body. So for instance, patients with active Bartonella might have knee pain, but just when they are about to go to the doctor for the pain, the pain will migrate to the left elbow. The hallmark symptom of Bartonella is sensitivity and tenderness on the bottom of the feet, especially the soles.

Generalized pain in the body, or pain that is sharp and severe, is often related to Bartonella. Bartonella can also cause headaches and ice



pick-like pain. Both Babesia and Bartonella cause headaches, but Bartonella headaches are worse. A Babesia headache produces more weird sensations in the head and pressure in the head. People with active Babesia infections will say, "I don't know if I'd really call what I have a headache. It's more like a pressure in the head." Babesia can cause migraines as can Bartonella, but Babesia migraines are generally less severe. Bartonella prefers the occipital areas of the head; the back of the head and neck are generally painful. So pain is a dominant characteristic of Bartonella.

All of these slow-growing intracellular infections affect the brain but create different symptom patterns, according to which infection is dominant or most active. I see more depression in people with active Babesia but less variability of mood, whereas people with active Bartonella may be irritable and anxious but then "flip over" into depression. Many people with Bartonella infections are misdiagnosed as having bi-polar disorder due to their fluctuating moods; they can easily go from being angry and irritable to being depressed.

Bartonella-like organisms can also stay on the surface of the organs and tissues and cause a wide array of symptoms. One such symptom is gastritis. In fact, most cases of gastritis that aren't caused by Helicobacter pylori infections are often caused by Bartonella, which is the second-most common cause of this condition. It can irritate the stomach so that people lose their appetite and/or get heartburn.

Many people with Bartonella infections are misdiagnosed as having bi-polar disorder due to their fluctuating moods; they can easily go from being angry and irritable to being depressed.[/pullquote]

Bartonella can cause a low-level, relapsing sore throat. People with active infections will periodically awaken with sore throats and wonder if they are coming down with a cold, but then the sore throat will go away.

Bartonella irritates the bladder and can cause frequent urination, interstitial cystitis, or other chronic inflammatory conditions of the urinary system.

Bartonella can also cause fevers, but for patients to be able to run a fever, they need to have

a relatively functional immune system, so not everyone who has a Bartonella infection will get a fever. Yet people will often feel hot, as if they have a fever, but their body temperature may be below normal.

Bartonella can affect the eyes and cause conjunctivitis, or inflammation of the outermost layer of the eye, which results in irritated, dry red eyes, as well as other eye problems.

Bartonella cause more skin-related problems than the other infections. Red bands or stretch marks on the skin called striae are common, as are acne and other skin problems.

Bartonella lives in the liver and spleen where it inflames these organs and compromises their functioning. When the liver and spleen are inflamed, the filtering capacity of the blood is affected, resulting in thick blood. People with Bartonella may have slightly elevated liver enzymes on lab tests. For instance, the alanine aminotransferase (ALT) test score may be just outside of the normal range and high only intermittently. The inflammation that Bartonella causes in the liver and spleen can compromise the body's detoxification system in a major way, though. When the spleen is compromised, the lymph glands may also become swollen, which then causes the lymph flow to become thick, sludgy and slow.

Borrelia Symptom Patterns

Borrelia symptom patterns are a bit harder to define because this organism isn't as aggressive as the others. The distinguishing symptom that it causes is fatigue; people who have active Borrelia symptoms tend to have more fatigue than those whose predominant symptoms are due to Bartonella or Babesia. People with active Babesia and Bartonella are much more restless than those with active Borrelia infections. All of the infections cause exhaustion; that is ubiquitous within the entire family of neurotoxin infections, but Babesia and Bartonella cause more restlessness, whereas people who are primarily manifesting Borrelia symptoms are often more tired. Feeling "wired and tired" is common with all the neurotoxin diseases, so I am really just focusing on the shades of gray here.

Borrelia causes pain, but the pain is much more diffuse and spread throughout the body. It also can be muscle-related and fibromyalgia-like, rather than primarily in the joints, as with Bartonella. However, doctors and patients need to keep an open mind when it comes to diagnosis and not over-generalize about symptom patterns. For instance, there is a subset of Borrelia patients who have arthritic-like symptoms and lots of inflammation in their joints, although I see this maybe less than 10 percent of the time.

The symptoms of Borrelia can be a mixture of a little of what's found in all of the other Lyme-related infections.

Borrelia affects the nervous system, but it's a bit more "ghost-like" in the symptoms that it causes, so it's not as defined or specific. If patients have been adequately treated for Babesia and Bartonella infections and have only 20 percent of their symptoms remaining, such as a bit of fatigue, achiness and brain fog, I might suspect that they still have some Borrelia microbes that need to be addressed.

Lyme microbes are smart and are looking for hiding places in the body; they want to be invisible and disguise themselves from the immune system. This means that they don't stay in the blood for long and quickly go to areas of poor circulation, to avoid being attacked by the immune system. Their goal is to lull the intracellular environment into complacency. For instance, Borrelia is able to change its form and alternate between the spirochete, cell-wall deficient and cyst forms as a way of confusing and hiding from the immune system.

Reprinted from New Paradigms in Lyme Disease Treatment with the kind permission of Connie Strasheim and Wayne Anderson ND. To learn more about the book and read more of Dr. Anderson's chapter, see: www.NewLymeTreatments.com

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

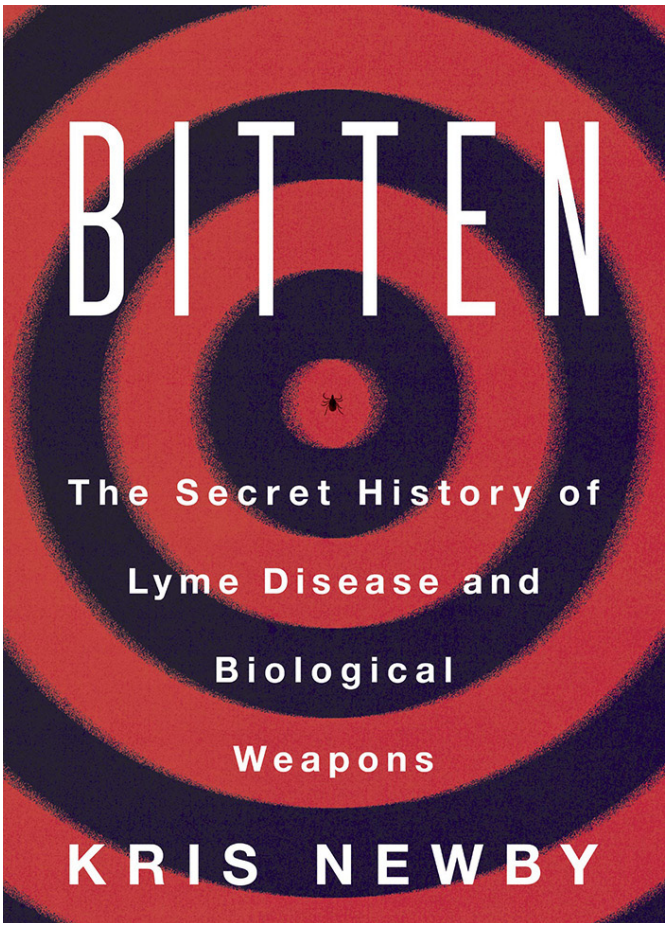
Is Lyme Disease a Bioweapons Experiment Gone Bad?

Kris Newby's book, Bitten: The Secret History of Lyme Disease and Biological Weapons, is a wakeup call.

By Dorothy Kupcha Leland

The mainstream "origin story" of Lyme disease in the United States goes like this: In the 1970s, a mysterious ailment afflicted a group of people in and around Lyme, Connecticut. Eventually, scientists determined it was caused by a spirochete transmitted by the bite of an Ixodes tick. A short course of antibiotics would resolve the issue. Mystery solved. Problem fixed.

Since then, that's basically the script followed by health officials, researchers who receive government funding to study Lyme disease, and the medical establishment.



Unfortunately, says science journalist Kris Newby, "the chasm between what researchers say about Lyme disease and what the chronically ill patients say they are experiencing has remained an open wound for decades."

And Newby knows what she's talking about.

In 2002, while vacationing on Martha's Vineyard in Massachusetts, she and her husband Paul were bitten by unseen ticks.

"These tick bites would rob us of our good health," Newby writes, "and send me on an investigation into an almost unimaginable possibility: that we were collateral damage in a biological weapons race that had started during the Cold War."

Upon their return to California, Newby and her husband got horribly sick. A succession of medical experts couldn't pinpoint the problem and eventually dismissed them as patients. This happened despite the fact that Newby had a positive Lyme test, which her doctors rejected as a false positive.

For readers not familiar with the issue, here it is in a nutshell: Hundreds of thousands of people get sick every year in the U.S. with Lyme and other tick-borne illnesses. But for complex reasons, patients have a devil of a time getting properly diagnosed and treated.

Newby's case was typical. She saw 10 doctors before stepping out of the medical mainstream and paying out of pocket for a physician who could recognize what she had and knew how to treat it. A point of contention in the controversy is whether the illness can persist after the patient receives a short course of antibiotics. Government/medical establishment folks say no. But patient experience says yes.

In time, Newby found her way to a physician who was familiar with tick-borne illnesses. This doctor diagnosed her with Lyme disease and babesiosis, both prevalent in ticks on Martha's Vineyard. Then, she began years of treatment that slowly brought her back to health.

Under Our Skin

During her recovery, Newby started working with film director Andy Abrahams Wilson, of Open Eye Pictures. They jointly researched what became the award-winning Lyme documentary Under Our Skin, which delves into the history of the Lyme disease controversy.

In the course of filming Under Our Skin, Newby

and Wilson struggled to find a government expert on Lyme disease willing to be interviewed on camera. The CDC, the NIH, and others declined.

"The politics of the disease were too charged," she writes, "and the government researchers seemed to want to steer clear of the controversy."

Then they met retired NIH researcher Willy Burgdorfer, the discoverer of the Lyme spirochete—Borrelia burgdorferi—for whom it is named. In contrast to others they had sought out, Burgdorfer seemed eager to talk.

"Willy told us that the U.S. government knows that Lyme disease can become chronic and that patients can relapse years after an initial infection," Newby writes, "and that the disease is particularly damaging to the neurological systems of children."

Lyme Disease Research – A Shameful Affair

Furthermore, Burgdorfer criticized the dozen or so researchers who have received most of the government funding for Lyme disease.

"The controversy in Lyme disease research is a shameful affair," he said on camera.

> *He stated that the work should instead be done by scientists "who don't know beforehand the results of their research."*

Then, Newby writes, "as soon as we turned off the camera and began packing up our gear, Willy told us with a smile, 'I didn't tell you everything.' But try as we might, we couldn't get him to say more."

Under Our Skin was released in 2008. Now, fast-forward to the present day. Newby's new book, Bitten: The Secret History of Lyme Disease and Biological Weapons, describes her years-long effort to understand who Burgdorfer was and to get to the bottom of what he hinted at that day.

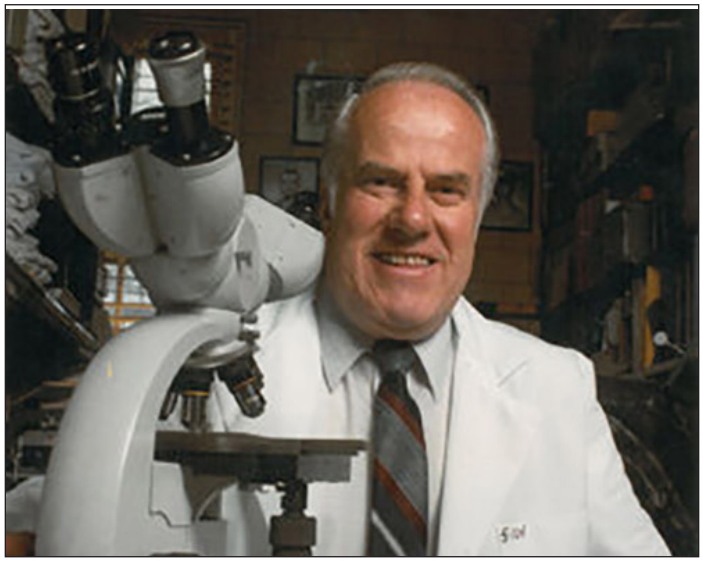
Turning Ticks Into Lethal Weapons

Burgdorfer grew up in Basel, Switzerland, and became fascinated with ticks while a PhD student at the Swiss Tropical and Public Health Institute. At the end of his training, in 1951, he took a position at the U.S. government's Rocky Mountain Laboratories in Montana. It held the most extensive collection of ticks in the country.

At first, it appeared that the job involved figuring out how to protect people and animals from tick-borne diseases. However, Burgdorfer was apparently soon disabused of that notion. During that Cold War era, the U.S. government was heavily involved in bioweapons research. Scientists sought ways to turn infectious microbes—such as anthrax, the plague, brucella, and tularemia—into potent military tools that could disable a huge population. (Perhaps the Russians?)

Newby writes about a particular meeting Burgdorfer attended in Canada: "After hearing from a roomful of entomological warfare experts … he now most certainly knew that he was no longer protecting humans from tiny eight-legged beasts. He was instead turning those beasts into lethal weapons."

Burgdorfer spent time at Fort Detrick, Maryland, where one of the buildings was nicknamed the "Anthrax Hotel." Another structure housed the "Eight Ball," a massive cloud chamber used for testing airborne bioweapons on animals and human volunteers.



Willy Burgdorfer

He brainstormed with entomologist James Oliver, who was working on a program to drop weaponized ticks out of airplanes. He traveled to England and Czechoslovakia to meet with scientists doing similar work.

Burgdorfer also experimented with ways to infect ticks with more than one pathogen at a time.

Documentation of Tick-borne Bioweapons Research

Newby meticulously documents all of this with massive archival research, discussions with many people knowledgeable about bioweapons research in the U.S., and another interview with Burgdorfer himself in 2013.

By then, advanced Parkinson's disease was stealing Burgdorfer's ability to speak clearly, and his health was failing. (In fact, he would die the following year.)

At this point in the book, the reader is itching to know: Will he give specifics? Was the outbreak of sickness in and around Lyme, Connecticut, in the 1970s connected to bioweapons research? Was there an accidental release of pathogens? Or a deliberate one?

> *In this final interview, Burgdorfer confirmed that he had been working on tick-borne bioweapons research—and insinuated there had been an accidental release of some sort.*

Newby writes, "It was frustrating that he still

Dr. Willy Burgdorfer, discoverer of microbe causing Lyme disease.

wouldn't disclose key details on the who, what, and where of the alleged bioweapons accident. He offered me more pieces of the puzzle, but for unknown reasons, he was holding back on the whole story."

Even more puzzle pieces would emerge in the months before his death. It turns out Burgdorfer had a trove of Lyme-related research notes that he had never relinquished to government archivists. He instead wanted them preserved for posterity in a university library. (They are now available online at Utah Valley University.) More complexities would surface after Burgdorfer's death, when his widow provided additional materials for the academic archive.

The Swiss Agent

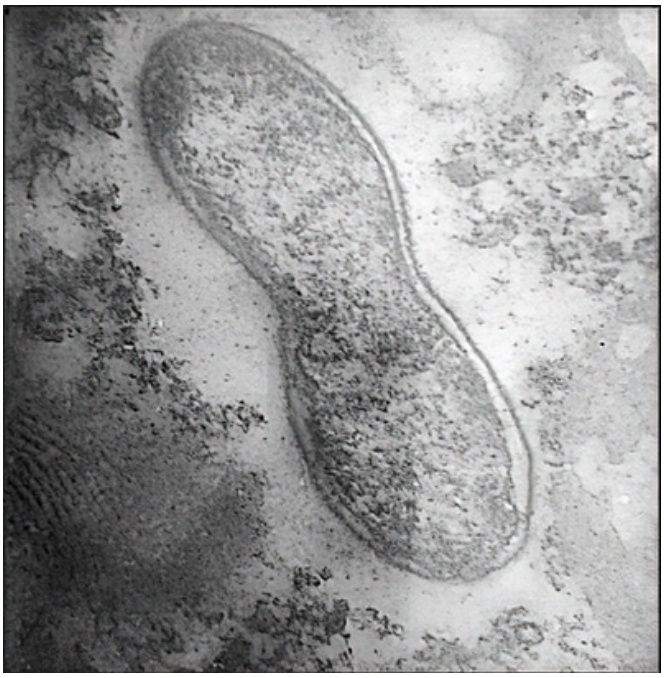
Newby went through these records with a fine-tooth comb. Most intriguing were Burgdorfer's references to something he dubbed the Swiss agent. Was this another pathogen? Could it be what makes Lyme disease so virulent? Why was it never mentioned in any of Burgdorfer's journal articles? Why wouldn't he talk about it?

The author does a stellar job of sifting through a huge collection of clues. But some answers remain tantalizingly out of reach. "If the outbreak was caused by a U.S. accident, we need it exposed," she writes. "If it was a hostile act by a foreign actor, then it shows how woefully unprepared we are for future attacks."

The Lyme community cares passionately about the true origin story of this burgeoning epidemic. Indeed, the microbe has been around for eons. Lyme spirochetes have been found in ticks that were encased in amber 15 million years ago. Lyme DNA is in the bones of "The Iceman," who lay frozen in the Alps for over 5000 years. But did something happen in the last half of the 20th century to ramp up this pathogen's virulence? And/or that makes it spread more easily? Newby's book certainly suggests that.

Burgdorfer died in 2014, leaving behind significant "dots" without connecting them all. The aforementioned James Oliver died in 2018, two years after giving a magazine interview about his bioweapons research at Fort Detrick. (He said one of his goals had been to figure out ways to distribute ticks to targeted geographic areas.) But like Burgdorfer, he stopped short of providing specifics.

Were these two men seeking to clear their consciences for the roles they played in bioweapons research? Their generation of scientists is dying off. Is anyone left who might offer clarity? Are there any



***Rickettsia helvetica*, aka the Swiss Agent, discovered by WIlly on his trip to Neuchatel.**

still-classified documents that hold the secrets?

Repairing the Open Wound

Newby's book raises important questions that deserve answers. Chief among them: precisely what was done to weaponize Lyme disease—and why won't the government come clean about it?

Lyme and other tick-borne pathogens are spreading throughout the world. In the U.S. alone, the number of people suffering from Lyme disease is projected to hit 2 million in 2020.

Yet, for the last 40+ years, our government's effort to solve the Lyme disease crisis has been lethargic at best. While the medical establishment minimizes their plight, patients have largely been left on their own to figure out (and pay for) Lyme-related medical care. Meanwhile, few research dollars have been devoted to finding more effective treatments.

The following is an excerpt form Kris Newby's book Bitten: The Secret History of Lyme Disease and Biological Weapons.

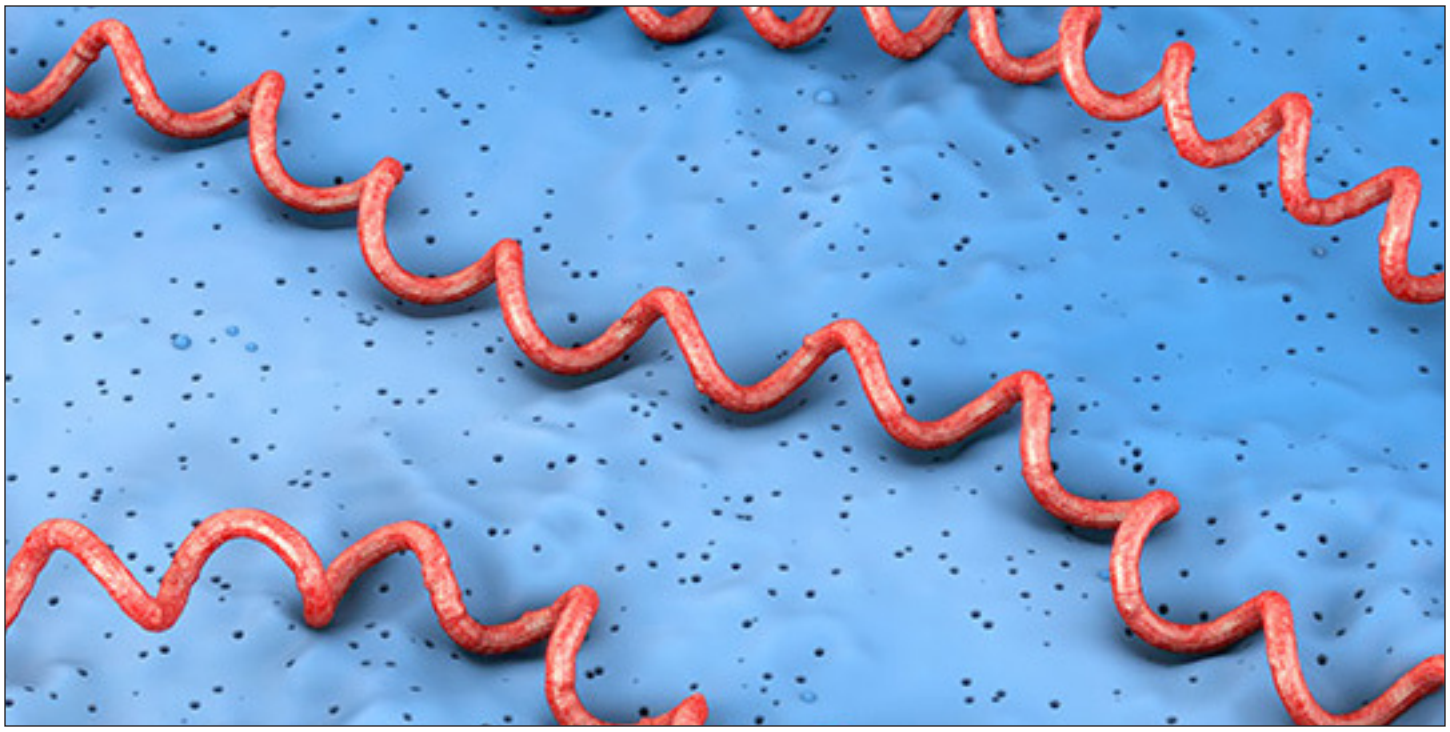
Diving straight back into his work at the lab, he began by analyzing the hundreds of Ixodes ricinus tick samples he'd brought home from Switzerland, searching for what was making the goatherds sick. He and the Swiss team found three microbes never before seen in this species of tick: an unidentified spotted fever rickettsia; a whip-tailed cattle protozoan similar to babesia, called Trypanosoma theileri; and the infectious larval stage of a parasitic deer worm, *Dipetalonema rugosicauda*.

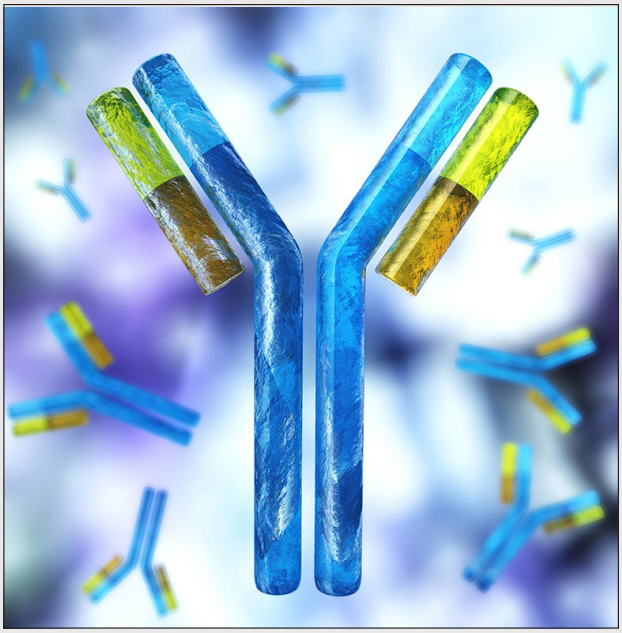
Willy sat at his microscope late into the night, snipping off tick legs and letting drops of their hemolymph fall onto a glass slide; mixing the drops with a stain that would make the rickettsias glow under a dark field microscope; and dissecting tick parts to see where the rickettsias hid inside the tick. Most established rickettsias evolve over time to find species-specific, competition-free niches within a tick.

But these rickettsias were everywhere, shimmering stars in Willy's microscopic galaxy. They floated in the tick's main body cavity, in the cell cytoplasm and nuclei, in the ovaries, and in all stages of tick sperm. It was worrisome. If the new organism could be transmitted from tick eggs to the thousands of newly hatched larvae, it would spread more rapidly into the ecosystem than most tick-borne diseases.

Under a higher magnification, Willy saw that the rickettsias existed in two form factors: a two-cells-fused-together (diplococcus) form and a sausage-like (rod) form. Both looked exactly like the newly discovered rickettsias he'd found on Long Island.

Next, he developed a fluorescent antibody test so that he could rapidly detect infected ticks, lab animals, or humans. First, he isolated a unique, identifying molecule from the surface of the microbe, labeled it as antigen C9P9, and mass-produced it in a flask filled with a growth medium.



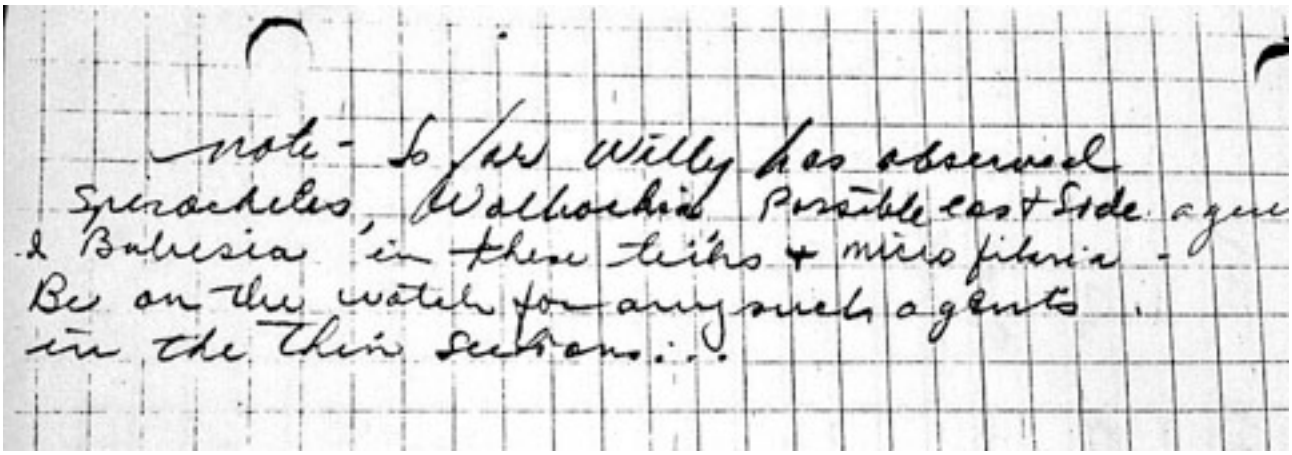


(Antigens are the "bad guys" to an immune system, and antibodies are essentially the beat cops on the lookout for them.

When antibodies bump into an invading germ's surface antigen, they bind to it, essentially placing a "Most Wanted" poster on it. They also send out a biochemical all-points bulletin to other parts of the body, with instructions to destroy the germ.) Next, he smeared the C9P9 antigen on a microscopic slide and added a drop of an animal's bodily fluids that had been mixed with a fluorescent dye. If the animal had recently been exposed to the germ, there would be antibodies that recognized C9P9 as an invader, and the dyed antibodies attached to the C9P9 antigens would glow like little neon lights under the ultraviolet illumination. That's how Willy would know that the animal had been infected.

On April 12, 1979, he quietly began testing Lyme patients' blood samples against the European Swiss Agent antigen and known disease-causing rickettsias. The blood samples reacted strongly only to the Swiss Agent antigen. This meant that the rickettsias from Switzerland and Long Island might be one and the same species or perhaps closely related.

With the discovery of the Lyme spirochete still two years away, Willy kept pursuing a hypothesis that the Lyme outbreak was caused by the same organism that was making the Swiss goatherds sick. By August 1980 he was confident enough with his experiments to share the test results with the East Coast investigators working on the disease outbreaks: John Anderson and Lou Magnarelli, from the Connecticut Agricultural Experiment Station; Jorge Benach, from the New York State Department of Health; and Allen



A note from a lab technician confirming that Willy had found spirochetes, Wolbachia, an East side agent (aka the Swiss Agent USA rickettsia), babesia, and microfilaria worms in the Lyme outbreak ticks.

Steere, from Yale University.

In his lab notes he referred to "Swiss Agent USA" as an "R. montana–like rickettsia organism" or the "East side agent." More blood and ticks were tested during the fall to make absolutely sure that this was the microbial culprit.

"I am excited to pursue further the possibility of a rickettsia etiology of Lyme disease," Allen Steere wrote to Rocky Mountain Lab's director, Robert N. Philip, on November 8, 1979. During the first quarter of 1980, the thrill of discovering a new disease started creeping into their correspondence. If it was true that the American Swiss Agent caused the Lyme outbreak, they'd go into the medical history books. Their finding would probably lead to tenure-track positions at a major university and a steady flow of research grants. They might even have a shot at a Nobel Prize.

On January 3, Willy wrote to Aeschlimann about testing he'd done on the Lyme arthritis patients: "I have done some preliminary serology with sera from patients and have found very strong reactions against the 'Swiss Agent.'"6 In February, his phone log read, "Steere patient sera tested again: Still very positive for Swiss Agent." In March, he wrote to Anderson and Steere again: "Most specimens, with a few exceptions, reacted only against antigens prepared from the Swiss Agent."7 In short, the disease clusters in Connecticut and Long Island seemed to have been caused by Swiss Agent USA.

Then, in April, the Swiss Agent USA rickettsia vanished. It was never again mentioned in talks, letters, interviews, or journal articles. The only clue to its demise was a cryptic note from Steere to Willy that read, "As mentioned in our telephone conversation, enclosed are the decoded results of serological tests against various rickettsia . . . I appreciated the chance to talk with you yesterday about the future directions for this work . . . I agree that any plans for manuscript writing are currently premature. I would not want anything in print that you would not find convincing."

Reading between the lines, it appears that Willy told Steere and Magnarelli that the Swiss Agent testing was unreliable. Benach recalls that Willy told him that he thought the new rickettsia was a harmless symbiont that didn't cause disease.

And about two years later, Willy announced that a spirochete was the causative agent of Lyme disease. Case closed.

There is, without a doubt, something suspicious about the sudden disappearance of the Swiss Agent USA from all correspondence.

None of the living researchers involved in the Swiss Agent discovery seem to recall or know why exactly it fell off the radar. Its absence from the scientific literature is equivalent to the missing

eighteen and a half minutes from Nixon's White House tapes. And it leaves us with the important question: Why?

From the book BITTEN by Kris Newby. Copyright © 2019 by Kris Newby. Published on May 14, 2019 by Harper Wave, an imprint of HarperCollins Publishers. Reprinted by permission.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

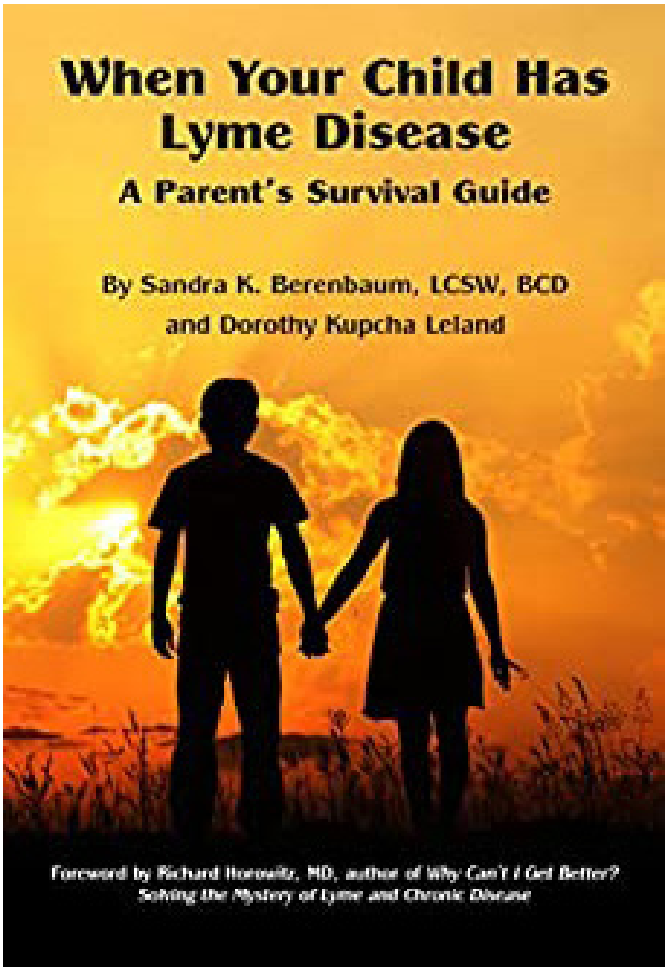
A Parent's Survival Guide for When your Child has Lyme Disease

A look at the many complex personal and family issues that arise with diagnosis.

By Dorothy Kupcha Leland

In 2005, out of the blue, my then-13-year-old daughter Rachel became so disabled from a mysterious pain condition that she needed to use a wheelchair. At that time, I didn't even know what Lyme disease was.

I also didn't know that our family had fallen into a huge medical controversy, what many have dubbed "The Lyme Wars." And I did not anticipate the many complex personal and family issues that would arise. We felt alone. But, in fact, we were part of a growing yet invisible group—families grappling with a disease



that is largely ignored by the medical establishment.

It was a long, hard, expensive slog but, eventually, our family got through it. We were guided by Internet research and online patient support groups. In time, we found our way to medical practitioners and treatments that put our daughter's health back on track and allowed her to leave that wheelchair behind for good. At that point, I entered the world of Lyme disease activism, trying to help change a system that drastically harms so many families.

Since then, I've regularly encountered parents who face the same issues my family did. Many of them are in even more daunting circumstances.

In the following excerpt, I discuss the frustrating process of trying to figure out what was causing my daughter's troubling symptoms.

As we continued on our merry-go-round of medical appointments, I noticed a disturbing pattern. Each time we saw a new practitioner, the conversation went something like this:

Nurse: "Please rate your pain on a scale of one to ten. One is hardly any pain at all and ten is the worst pain you can imagine."

Rachel, with no hesitation: "Ten."

Nurse (smiling and shaking her head): "Oh, no, dear. You don't understand. It's not a ten. You're not in that much pain. Ten is the worst pain you can possibly imagine."

Rachel, with no hesitation: "Ten."

Nurse, sighing: "I'll put down an eight."

Then she leaves the room.

It soon became obvious that this was a pervasive mindset. The practitioners had a mental image of what ten-out-of-ten pain looked like, and Rachel didn't match it. To them, she just looked like a normal girl sitting in a wheelchair. Because at that moment she wasn't howling in anguish, she couldn't possibly have excruciating pain. (One nurse said, "No dear, number ten pain would be at least equal to childbirth." As if my 13-year-old daughter had a frame of reference for that.)

Part of the problem was how they phrased it. They always said, "Ten is the worst you can imagine." I once pointed out that maybe this was the worst Rachel could imagine. The nurse glared at me and said, "Let her answer for herself."

I wanted to cry out to every medical person we saw: She feels like she's being stung by bees! We have to push her on a rolling office chair to get to the bathroom. Sometimes her foot feels like it's on fire. But they just seemed to want a data point for their chart.

Children with Lyme disease may experience many different kinds of pain. It can be difficult to figure out what's causing it. Many of them hurt for years, with little help or understanding from the medical system. And because children may not be adept at describing their pain, it is often underestimated.

Here's what one mother said about a daughter whose symptoms began at age 5:

I was told that the eye pain was because she was in kindergarten and starting to read, the joint pain was growing pains, and the fatigue was just her talking and getting attention or being lazy, and she needed more exercise.

Three years later, the girl's symptoms and pain intensified.

They mentioned psychiatric stuff and took her in a separate room to ask if this was attention-getting because maybe she had been molested (their theory). They said to wear supportive shoes. They gave her no good pain meds. They offered ibuprofen…. She was supposed to go to a special study for children with inexplicable pain (since she absolutely positively could not possibly have Lyme, because it "doesn't exist" in California) but somehow that never happened.

> *When a child is suffering and the doctors aren't helping, it's common for a parent to doubt herself.*

A New York mother recounts that her child,

Authors, Dorothy K. Leland and Sandra K. Berenbaum

whom I will call Becky, began to experience leg pain when she was 2 or 3 years old.

By age 6, Becky suffered from lots of muscle and joint pain, headaches, stomach aches…She was often unable to walk due to the pain in her legs and the extreme weakness that would hit. I got her crutches, which helped some when she needed them. At times she would be walking along the room and then just melt into the floor and scoot on her bottom to get to where she was going.

As the pain continued for years, her mother reports, Becky hated being asked to rate it on the one to ten scale. "She never really knew a life without pain. So it was difficult to rate something as none-to-horrible when all you knew was moderate-to-horrible." Finally, at age 14, Becky was diagnosed and treated for Lyme disease and her pain reduced significantly.

Lyme disease is named after Lyme, Connecticut, where it was first recognized in the 1970s. The area continues to be a hotbed for the infection. So, it shouldn't be a stretch for a doctor in that state to suspect Lyme disease in a sick child, especially when there's a known tick bite. Yet, that is not the experience of many families.

A Connecticut mother tells of her 3-year-old boy, who had been bitten by a tick. Soon, he experienced knee pain, rashes, and fevers that would come and go. "Because we had gotten the tick out right away and it wasn't engorged, we were told it couldn't possibly be Lyme disease."

The knee pain worsened. He no longer wanted to run and play, but rather sat listlessly all day. The mother pushed to have him evaluated for Lyme disease, but the doctors dismissed her concerns. When their son was still in pain nine months after the tick bite, the family finally took him to a physician more familiar with Lyme disease. This doctor found that the child indeed had Lyme. Antibiotic therapy has relieved many of the symptoms, though at this writing, treatment is on-going.

> *Lyme-related catastrophic illness is like a house on fire. Families need help battling the flames and rescuing their children.*

At this stage of the game, when a child is suffering and the doctors aren't helping, it's common for a parent to doubt herself. Am I doing everything I can to help my child? Is there something I've overlooked? God forbid, is this somehow my fault? Unfortunately, the medical establishment often creates or feeds these doubts.

The mother is usually the one who is most engaged with the afflicted child. She shares those sleepless nights, witnesses firsthand the child's anguish, and shuffles the youngster to medical appointments. Yet, her ideas about what might be going on are often dismissed by the so-called experts. They may say she is "overly engaged" with her child's health problems. Or, like in my case, that I somehow "wanted" my daughter in a wheelchair.

At one point, before we knew what was wrong with Rachel, I made an appointment to see a counselor myself. The stress of her deteriorating condition was taking a toll on me, too, and I needed help holding things together. The therapist told me flat out that I spent too much time thinking about my daughter's health. She said I needed to develop other interests. At the time, I was too flummoxed to reply.

But here's my response: "What if my child was trapped inside a house that was on fire, and I was trying to get her out? Would you say I was 'overly engaged' with her welfare? Would you say I should stop trying to save her and find myself a

hobby?" Lyme-related catastrophic illness is like a house on fire. Families need help battling the flames and rescuing their children.

Excerpted from When Your Child Has Lyme Disease: A Parent's Survival Guide

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

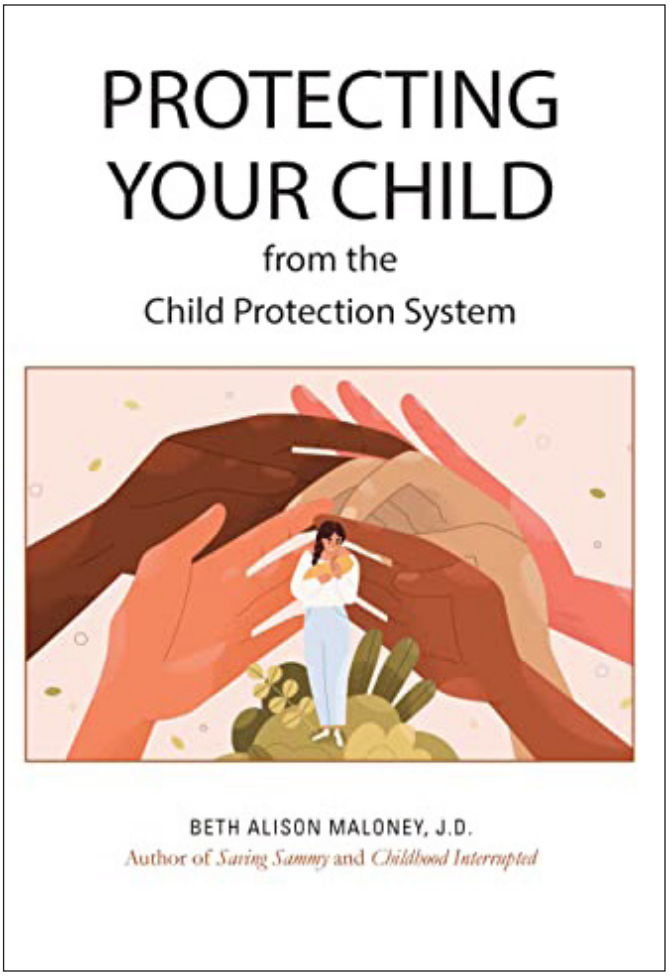
Protecting Your Child from the Child Protection System

What to do when parents of children with medically complex conditions are unjustly accused of harming their sick child.

By Dorothy Kupcha Leland

If your child has chronic Lyme disease, PANS/PANDAS, mast cell activation syndrome, POTS, or any number of other "medically complex conditions" – you have probably experienced being disbelieved by many people.

You may be a decent, well-intentioned parent doing everything you can to figure out your child's puzzling medical problems.



You may scour the internet to learn more about the child's condition, track the ups and downs of his or her symptoms, and carry binders full of medical records to appointments with various specialists—many of them far from your home.

But, in a cruelly ironic twist, those very activities can get you in trouble.

Physicians who have little experience with your child's medically complex condition may feel you are "over medicalizing" your child.

School officials may think you're intentionally keeping your child out of class for reasons they consider invalid.

Neighbors and even family members may believe you're exaggerating your child's health problems—and, in their opinion, going about things the wrong way.

And, unfortunately, any one of these people might report you to Child Protection Services. And then your problems will escalate dramatically.

Now, it goes without saying that sometimes children ARE abused by parents, and there is, of course, a legitimate role for CPS investigations.

But medically complex conditions are fraught with issues that can unfairly entangle parents—and the more they fight to free themselves, the more tied up in legal knots they may become.

For an idea of how bad things can get, consider what happened to then-teenager Justina Pelletier and her family. In 2013, her parents lost custody of their daughter after Boston Children's Hospital disagreed with how she was being treated at a different medical center. (Read more about Justina's situation here: https://www.lymedisease.org/justina-2/)

What to do?

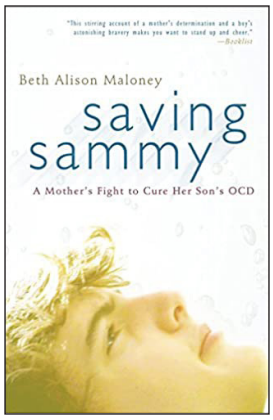
According to Beth Alison Maloney, there are things you can do now to minimize the possibility of running afoul of CPS in the future. And, if you're already caught up in the system, there are things you can do to get out of it.

Her thorough and well-researched advice on this subject is laid out in a new book called Protecting Your Child from the Child Protection System.

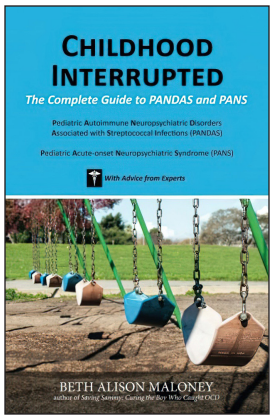
Maloney is an attorney and the mother of a child who suffered from the strep-caused autoimmune condition known as PANDAS—back before practically anybody even knew what that was.

Theirs was a complicated journey. But her son finally got better and now is a well-functioning adult. She wrote their family's story in her 2009 book, Saving Sammy: A Mother's Fight to Cure Her Son's OCD.

Beth Alison Maloney



In 2013, she wrote another instructive book, called Childhood Interrupted: The Complete Guide to PANDAS and PANS. It primarily focuses on the medical information you need to help your child recover from these conditions.



Over the past two decades, Maloney has worked as a lawyer, guardian ad litem, and nationwide consultant in the field of child protection laws. She has seen firsthand how innocent families are sometimes presumed guilty of all manner of abuse. She has seen the rise of "child abuse pediatricians"–specialists that she believes sometimes jump to unwarranted conclusions, to the detriment of the families involved.

She wrote this book so parents of sick children can

understand what they are potentially up against and how they can help themselves. As she states in the introduction, "Too much is at stake for you to plunge in without being informed."

An excerpt from Beth Alison Maloney's book Protecting Your Child From the Child Protection System.

Parents—overwhelmingly mothers—of medically complex children are highly vulnerable to being accused of abuse. Bruises, fractures, broken bones, violent rages, self-harm, persistent pain, and tubes to breathe, eat, or flush stools from the intestine may be the result of any number of complex medical conditions, but all may lead to false accusations of Medical Child Abuse.

Child abuse pediatricians, wholly unqualified in complex medicine, do not hesitate to assert that specialists' diagnoses are incorrect, and that prescribed medications, treatments, and interventions are unwarranted.

Child abuse pediatricians claim that symptoms, behaviors, and life-saving interventions are actually signs of abuse because the mother falsified, exaggerated, or "instigated" treatment.

They claim that diagnoses which cannot be "disproven" are particularly suspect and name, as examples, Mitochondrial Disease, Ehlers-Danlos Syndrome, and PANS/PANDAS.

Reports alleging abuse by parents of medically fragile children generally arise from one of three situations:

1. Parental disagreement with a doctor,
2. Emergency department visits, or
3. Medical disagreements among doctors, when the physician whose opinion is not chosen files a report with CPS.

These situations can arise in either outpatient or inpatient care. Usually, the mother is reported. And when both parents are reported, the focus of the investigation will quickly shift to focus on the primary caretaker, which is usually the mother. She will be accused of weaponizing the medical system to harm her child. The buzz words in the initial reports usually include one or more of the following:

1. interference with care,
2. doctor shopping, or
3. over-medicalization.

The splintered nature of complex care is part of the reason for these reports. The conditions are not well understood and warrant multiple specialists.

Ideally, all of those specialists would be readily accessible, practice together in one close-knit group, have admitting privileges at hospitals near the children's homes, and see eye-to-eye about every recommendation.

But that is rarely the case. Different hospitals, in different cities, far from the child's home are much more likely. Medical opinions differ. Communication between experts is scattershot if it happens at all.

There are conflicting treatment recommendations. The child's pediatrician probably has no relationship with the experts or the hospitals. Physicians in emergency departments of local hospitals, where the children are often brought for stopgap help, have little familiarity with the diagnoses. Even when specialists do have admitting privileges, that will not ensure against claims of abuse. Child abuse pediatricians may wrest control of the patient's care from the specialist. So, you must do what you can to avoid situations and places that are rife with the possibility of accusations against parents.

Child abuse pediatricians, wholly unqualified in complex medicine, do not hesitate to assert that specialists' diagnoses are incorrect, and that prescribed medications, treatments, and interventions are unwarranted.

Medically fragile children do not succeed without extraordinary parenting skills. Those same skills often boomerang and are twisted into

allegations of abuse.

Parents of medically complex children function as Central Command. They learn medical terms, research the origins of their children's disorders, advocate for appropriate care, argue with insurance companies, schedule appointments, travel out of state to reach experts, and join parent groups on social media for much-needed support.

They are tasked with passing information and opinions back and forth between physicians at different institutions and practices who often do not communicate amongst themselves.

And when experts disagree, parents must make tough decisions on treatment paths, which will invariably rankle the egos of some providers whose suggestions are rejected in favor of others.

When reports for suspected Medical Child Abuse are made, CPS will seek the help of a child abuse pediatrician. And that pediatrician will start with the presumption that the child has been abused.

Guided by confirmation and anchor bias, the child abuse pediatrician will selectively gather evidence that confirms the presumption, disregard contradictory facts, and anchor an opinion by prioritizing the information that they assert is consistent with abuse.

All of the mother's words and actions will be filtered through the presumptive lens of abuse. Then, the CPS caseworker and government's prosecutor, having no independent knowledge of medicine, will move in lockstep with the child abuse pediatrician to remove the child from the mother's care.

Maloney's book is divided into six parts:

1. An overview of the Child Protection System and how it functions.
2. How to navigate the maze and what to do if you find yourself accused
3. The special challenges facing parents of medically complex children
4. Building a team—lawyer, family, friends
5. A deeper dive into the court system
6. Rebuilding your lives after being falsely accused of abusing your child.

No parent wants to think about the possibility of losing custody of their child–especially when that child is seriously ill. But parents of medically complex children should familiarize themselves with the issues involved and take steps to head off trouble.

Knowledge is power. And if you're falsely accused of abusing your child, you need all the power you can get.

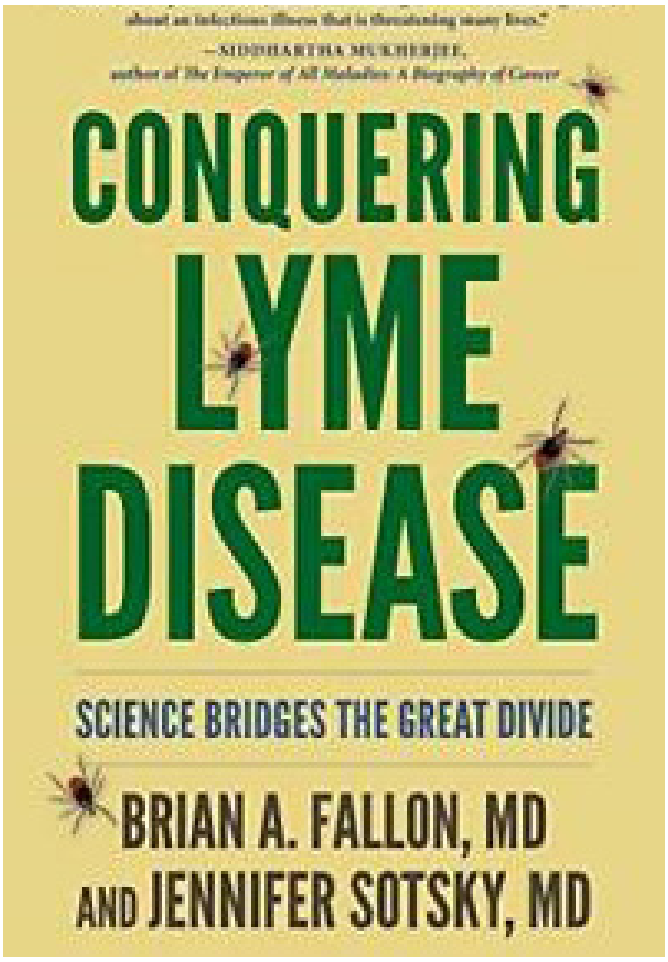
For more information, see Beth Alison Maloney's website: https://bethalisonmaloney.com/

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

How Might a Doctor Respond to a Patient with Relapsing Lyme Symptoms?

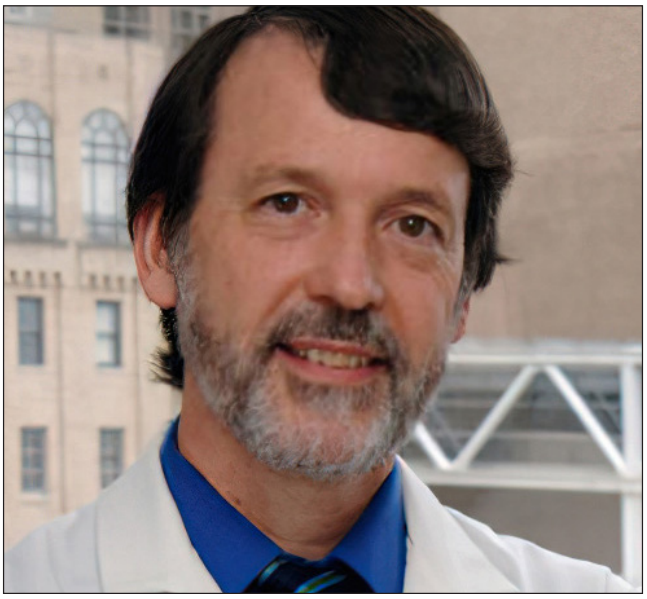
"Conquering Lyme Disease" and the deeply entrenched medical divide about the diagnosis and treatment of Lyme disease.

By Dorothy Kupcha Leland



For far too long, patients have gotten the short end of the stick in the so-called "Lyme wars" – the deeply entrenched medical divide about the diagnosis and treatment of Lyme disease.

In Conquering Lyme Disease: Science Bridges the Great Divide, co-authors Brian A. Fallon, MD, and Jennifer Sotsky, MD, put forth a different idea. They say that recent scientific advances are reshaping our understanding of the illness — and closing the gap between the two factions. They say there is cause for both doctors and patients to be optimistic about the future of Lyme disease treatment.



Brian A. Fallon, MD

Jennifer Sotsky, MD

In outlining the issue, however, they do not overlook the very real suffering that many patients have experienced at the hands of their medical practitioners. They assert that the politically charged climate surrounding Lyme disease can severely impact the physician-patient relationship.

Patients who remain ill after receiving standard Lyme treatment, the authors say, "may start to feel disbelieved, marginalized, or abandoned by the medical community."

In the following excerpt, Fallon and Sotsky explore how doctors sometimes respond to their patients with relapsing symptoms.

If one is confident in the wisdom of academic experts that one course of antibiotic treatment is curative for most patients, a reasonable approach by a health care provider when faced with a patient whose symptoms have not improved would include searching for another possible illness that has not yet been considered.

1. The patient may be depressed or overly anxious because there is a combination of low energy, irritability, and changes in sleep patterns.
2. The patient may have fibromyalgia because there is widespread pain.
3. The patient may have chronic fatigue syndrome because daily sleep intervals extend to twelve to fourteen hours and the patient's physical functioning has dramatically declined.

Consideration of these alternative explanations is reasonable and part of good medical practice, especially given that we now know that certain environmental triggers (such as infection) can lead to residual mood disorders, persistent fatigue, and musculoskeletal pain.

The problem is not that the physician is considering these other possibilities to enhance care of the patient; indeed, these other diagnostic considerations may provide new directions for treatment. The problem is that the physician may be completely opposed to the possibility that the patient may still have residual infection and/or that another course of antibiotic therapy might confer benefit.

The physician may take umbrage when patients bring in articles or relate anecdotes suggesting that repeated antibiotic treatment for some cases of Lyme disease may be necessary. The patient comes to feel shut out, unheard, and uncertain whom to trust. Even in instances in which

the doctor's recommendations might in fact have validity, the patient who feels unheard will remain doubtful about the doctor's judgment and unlikely to follow through.

When the patient's symptoms not only persist but become more numerous, the patient becomes alarmed and somatically preoccupied. Whereas when there is an explanation and plan of action, or even the sense that the doctor has absorbed the information and is giving it thought and attention, patients are better able to relax their vigilance. When the doctor responds by blaming or brushing the patient off, the patient will feel doubly traumatized. As a result of this physician-patient interaction, the subjective experience of pain and confusion imposed by the illness becomes compounded by a kind of physician-induced post-traumatic stress disorder.

Doctors are trained to be able to give answers and find solutions. When a patient presents with a litany of symptoms that do not fit into the doctor's known paradigms or that are unsupported by laboratory evidence, that doctor may be tempted to discount those aspects of the patient story that do not fit. The doctor may not want to treat that patient, knowing that he or she does not know how to help or fearing that engagement with this patient might take him into controversial medical waters.

Lyme disease is one of those illnesses that remind us of the value of old-school medicine: knowing the patient as a person, knowing how the current presentation fits into his or her life as a whole, and listening very carefully to the details of the clinical history.

The current climate in health care delivery poses particular challenges for the patient with a complex or atypical disease presentation, such as those manifest in many of our patients with late-stage post-treatment Lyme disease symptoms. The traditional functions of the physician—listening carefully to the patient's history in order to create a differential diagnosis and sitting by the patient's side to offer human comfort in the face of physical and mental suffering—have been marginalized to the periphery in favor of a checklist of questions and laboratory tests.

Instead of looking at the patient and listening, the physician of today is often found staring at a computer screen, typing in answers to questions that look good for the medical record but are not necessarily focused on unraveling the individual patient's complex presentation.

This means that doctors are deprived of an invaluable source of information: the patient him- or herself. Patients and their family members have important insights to provide the physician regarding their former functioning and how the current presentation differs from their habitual selves. Lyme disease is one of those illnesses that remind us of the value of old-school medicine: knowing the patient as a person, knowing how the current presentation fits into his or her life as a whole, and listening very carefully to the details of the clinical history.

Guidelines that were developed to convey and clarify the typical presentation and course of an illness fail to address the outliers whose lab values or clinical trajectory fall outside of the norm. Could this patient be an outlier? Could this patient have Lyme disease even if the presentation and course are atypical? Even if the lab tests are equivocal? Some physicians ask themselves such questions. Others do not.

Some doctors love the complicated patient, experiencing such encounters as a challenge, an opportunity for a "Dr. House" moment—finding the thread that unravels the disease and revealing the elusive diagnosis. Other doctors may feel quite uncomfortable evaluating patients who do not fit known patterns and whose symptoms seem to defy the doctor's expertise. Such encounters take time—a commodity that few doctors now have.

Why Would a Patient, Previously Well-Regarded by the Physician, Be So Readily Dismissed?

Aspects of Lyme disease itself may contribute

to the perplexing response of physicians. Patients generally appear healthier than they feel, and symptoms are not only subjective but also quite variable, so that the patient presents differently from visit to visit. One day the symptoms appear more neurologic—ranging from sharp stabbing pains or shooting pains to dizziness, migraines, and problems with short-term memory.

On another day, the symptoms appear more rheumatologic, with migrating joint and muscle pains. On yet another day, the patient appears to be much better symptomatically. In addition, the patient may be cognitively impaired, making it hard for him or her to retrieve details of symptom history and present them in an organized way.

The lack of consistency in the patient's presentation may make the patient appear flaky and unreliable. The multiplicity of presentations may suggest to the physician that the underlying diagnosis is more likely a somatic symptom disorder, a stress disorder, or even a fabrication for secondary gain.

How Does the Patient Feel?

Patients may come to feel like a pariah within the medical community, part of a marginalized group. Once "chronic Lyme disease" is in the medical chart, doctors and other health care providers may have an immediate negative bias: this patient is "bad news," won't respond well to interventions, and will have all kinds of preconceived and benighted notions of what is going on with them.

The experience of being disbelieved or even disliked by physicians can be not only demoralizing but also destructive to good patient care. Sensing the doctor's disbelief or distrust, the patient learns to screen his or her statements so as not to agitate the doctor and be further discredited. The net result is that the doctor ends up not hearing the full clinical picture and the patient ends up increasingly isolated.

Adding insult to injury, the same patient who has been told that "there is no such thing as chronic Lyme disease" may be dismayed and enraged to discover that past Lyme disease is an exclusion factor for life insurance. The patient then asks, "If chronic symptoms after Lyme disease don't exist or aren't serious, then why is a past history of Lyme disease a reason for exclusion from life insurance?"

Others may find that even when treatments (such as intravenous antibiotics) are prescribed by their doctors, insurance companies refuse to pay, citing articles or calling upon "experts" who diagnose and treat Lyme disease according to very narrow criteria. The medical controversy has the effect of adding substantially to the financial burden of the illness on patients.

> *The experience of being disbelieved and misrepresented over and over is inherently traumatizing.*

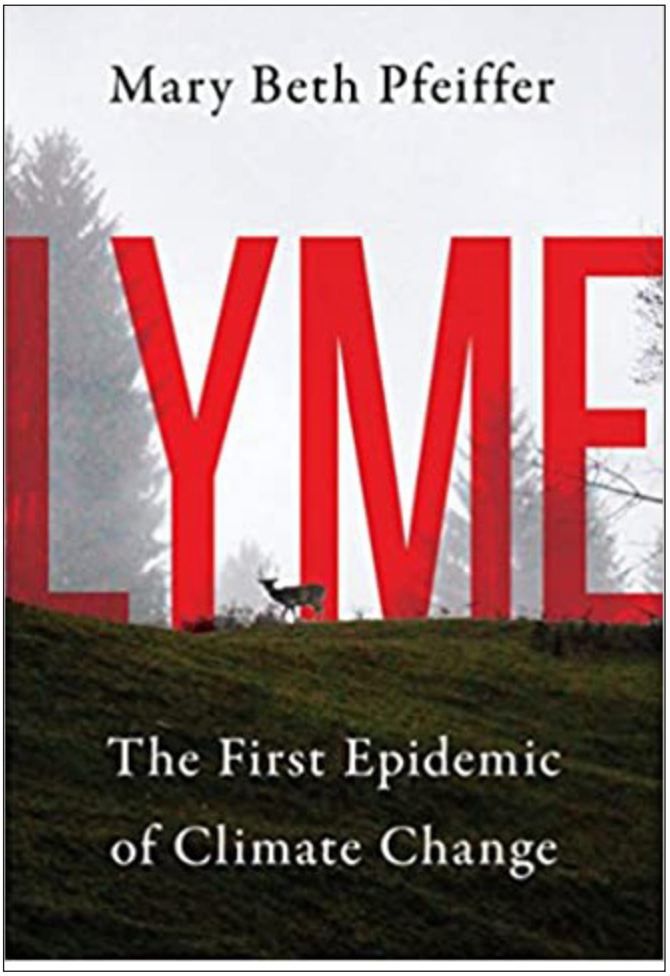
The experience of being disbelieved and misrepresented over and over is inherently traumatizing. Some patients, following eventual recovery from hard to diagnose and/or complex cases of Lyme disease, have identified this atmosphere of disbelief (and the resulting social isolation and self-doubt) as the single most stressful aspect of their illness experience.

Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

“American medicine pretends to understand the Lyme epidemic. It does not.”

"Lyme: The First Epidemic of Climate Change" takes comprehensive look at worldwide Lyme disease picture.

By Dorothy Kupcha Leland



Though investigative journalist Mary Beth Pfeiffer spoke in quiet, steady, well-modulated tones, her message packed a powerful punch. It was at once riveting, deeply moving, and profoundly disturbing.

“The management of Lyme disease by American medicine and government is, to use a word that investigative reporters do not use lightly, a scandal,” Pfeiffer asserted. “American medicine pretends to understand this epidemic. It pretends to have a handle on it. It does not.”

She delivered those words a few years ago, while on

Mary Beth Pfeirffer

a book tour for Lyme: The First Epidemic of Climate Change. Unfortunately, little that she spoke about at that time has changed.

She talked about many different aspects of the Lyme disease picture: infected ticks, which are showing up around the globe in places they've never survived before; differences among research scientists; the myths embraced by the medical establishment that make it difficult for Lyme patients to get appropriately diagnosed and treated.

Most compellingly, she shared heartbreaking examples of individuals and families impacted by these wrong-headed policies.

In the following excerpt from the book, Pfeiffer delves into the thorny issue of diagnostic testing.

In 2001, The New York Times Magazine ran an article that set the tone for how Lyme disease patients, specifically those who disagreed with treatment policy and protocols, would be viewed for years to come. Entitled "Stalking Dr. Steere," the five-thousand-word feature began, "Last year, Dr. Allen Steere, one of the world's most renowned medical researchers and rheumatologists, began to fear patients." Back in 1977, Steere was the curious doctor, then thirty-three, whose investigations of a cluster of illness in Lyme, Connecticut, led to the discovery of Lyme disease. Now, the people he had tried to help were turning on him. He was a proponent of short-course antibiotics, and they blamed him when they remained sick and were not believed. It was a good story line, and the Times ran with it.

If it wasn't perfectly clear from the get-go, Steere was the hero of this story, a man with "a gentle, almost artistic temperament," and a "quiet and reserved nature." He was a "virtuoso violinist," "a kind of Magellan of medicine." The villains, mean and menacing, were Lyme disease patients. They stalked him in "hordes," carrying signs when he spoke in public that said terrible things, the story said, like "How many more will you kill?" and "Steer Clear of Steere!" For all his efforts on behalf of patients, Steere was now fearful of them, beaten-down, displaying a "slightly ghostly" pallor. His stalkers thought they had a chronic form of Lyme infection, the article noted, but Steere, "the world's foremost expert," demurred, saying they suffered chronic fatigue, mental illness, or fibromyalgia.

> *The nascent movement that questioned Lyme disease treatment, of which the attack on Steere was part, was fueled by a novel, evolving, and effective way to organize dissent: the Internet.*

The nascent movement that questioned Lyme disease treatment, of which the attack on Steere was part, was fueled by a novel, evolving, and effective way to organize dissent: the Internet. Steere was a primary focus of complaints that sometimes turned ugly. This much was true. But for every patient who may have sent a threatening email—the article doesn't state how many Steere received—there were many more who were doing the real work of organizing a crusade. "The group did hold up signs and chanted things like 'Steer Clear of Steere,'" said a woman with a cane who handed out leaflets on Fifth Avenue in New York. "This was a group of ill people, along with their friends and family, that were out there to educate others about the controversies surrounding Lyme Disease," she wrote in a blog. Published letters to the editor—the Times said it received a "flood" of mail—ran four to two against the article with one writer asking, "Would you describe people who

are afflicted with H.I.V., epilepsy, diabetes, heart disease or cancer as 'stalkers' if they protested the loss of their medication?"

Among the pro-Steere writers was his good friend since age eighteen, the violinist Itzhak Perlman, whose daughter had been misdiagnosed with Lyme disease; Perlman called Steere an "outstanding physician." Nonetheless, in a portrayal with real and lasting ramifications, the misguided acts of some—no doubt unsettling to Dr. Steere—were cast as a guerrilla war of the many.

The venue in which the story was told—in America's paper of record—validated the image as an accurate representation of chronic Lyme sufferers and of their unsubstantiated claims. Physicians, already told that antibiotics were curative despite indications otherwise, were given license to dismiss and ignore long-term sufferers. Other news outlets could feel comfortable following suit. Seven years later, American Medical News ran an article on the controversy over Lyme disease that continues to this day. "I have observed among infectious diseases fellows that they don't want to see these patients," Dr. Paul Auwaerter, a Lyme traditionalist, was quoted as saying. "It has become a poisonous atmosphere."

Dr. Raymond Dattwyler

The fault is not solely among practitioners who rebuff Lyme cases. Patients insist they remain sick. Physicians do not know how to treat them. And the experts and public health officials who advise them have given neither permission nor tools to try. Chief among those tools is a clear-cut way to diagnose Lyme disease.

Eluding Capture

In May of 2016, the Canadian government

sponsored a conference on Lyme disease in Ottawa that brought together a rare coterie of Lyme disease players: patients, activists, general practitioners, field researchers, data collectors, and most significantly, a smattering of prominent physicians and scientists on both sides of the parallel universes of Lyme disease. A rare sight at any conference that featured grumbling patients was Dr. Raymond Dattwyler, a New York Medical College professor of microbiology with a double pedigree in Lymeland. He was second author of the 2006 Lyme treatment guidelines of the Infectious Diseases Society of America, the ones that have dictated care in the United States and worldwide and been used to discipline doctors who practice outside them. As significant, he was a member of a US Centers for Disease Control and Prevention panel that met in Dearborn, Michigan, in 1994 and, as he put it at the start of his lecture, "wrote the two-tier guidelines."

"And," he continued, "I'm going to actually tell you some of the problems with that right now."

Two-tiered testing for Lyme disease diagnosis is so named because it involves two sequential blood tests. The first measures antibodies to see if a patient's immune system has produced enough to indicate potential exposure. Then, if the first test is positive, a second one, called the West¬ern

blot, checks to see if antibodies bind to specific Borrelia burgdorferi proteins, producing smudges on a test strip, called bands. These bands also indicate exposure—but with a catch.

A low-key fellow with spectacles, cropped white hair, and red striped tie, Raymond Dattwyler then explained in eighteen minutes the flaws in the blood tests that have long defined who is and is not infected with Lyme disease. His manner was matter-of-fact, as if everyone had known this for years. The technology was based on cultures that missed distinctive proteins, he said, while including others not specific to B. burgdorferi. "That criteria (sic.) that was developed in the 1980s and the 1990s—there's a lot of problems with that." It is "not that good." You can be seropositive for the rest of your life, it doesn't mean you're infected."

> *"The biggest problem is not sensitivity," or too many false negatives, Dattwyler told me. "It's specificity—too many false positives."*

I have attended other conferences and conducted many interviews in which the flaws of the Lyme diagnostic were similarly vented. But the speakers were mainly patient advocates and, especially, Lyme practitioners—doctors who have been disparaged by guidelines adherents for making Lyme diagnoses in the face of tests that had come back negative. Dattwyler's comments, however, were coming from the side that had designed Lyme disease testing.

Under the diagnostic rules set by the panel on which he served, and adopted by the CDC in 1995, Lyme patients must achieve a minimum number of bands to test positive on the Western blot test—two out of three for one type of antibody or five out of ten for another. Get four of ten and, sorry, that is a negative. Yet the blot is curiously constructed, even arbitrary, designed to detect certain proteins while leaving out others that may be important. For one, it is skewed toward detecting one manifestation of Lyme disease over another. The five-of-ten-band scenario was modeled on a 1993 study showing the bands correctly diagnosed 96 percent of arthritis-related cases—but just 72 percent of neurological cases. The blot also includes a band that detects the flagella, common to many bacteria, along with bands that are far more indicative of *Borrelia burgdorferi*, something like a trunk on an elephant. Lyme doctors in the United States sometimes rely on these significant markers to diagnose the disease, ignoring the need for two of three or five of ten bands when symptoms and clinical judgment suggest Lyme disease.

When Dattwyler spoke, it had been two decades since the choices were made of what bands to include, what to leave out, and how many were needed for diagnosis, decisions that had immense consequences for multitudes. Here, at this conference in Ottawa, was one of the most powerful directors of Lyme policy and practice in the United States and the world agreeing the technology was flawed, old, in need of replacement. "We didn't have good definitions of what was in those Western blots," he told the gathering. "Those were just bands on a gel."

So what do those bands, or rather their absence, mean in real life? For a boy, sixteen, living near Boston, they meant seven weeks in a psychiatric hospital. After relapsing from a previous bout of Lyme disease, the boy had been ruled negative for Lyme disease after registering four of

the requisite five bands on the Western blot—as close to positive as humanly possible. Although Lyme disease is well known to cause serious psychiatric symptoms, doctors diagnosed the boy with "pure mental illness," not Lyme disease, according to an article in International Medical Case Reports journal. Enter a pathologist from New Milford, Connecticut, named Sin Hang Lee who had devised a test using DNA sequencing to search for the pathogen in human blood. When he submitted his findings on the boy's blood to the GenBank repository of genetic sequences of the National Institutes of Health, they perfectly matched the DNA footprint for Borrelia burgdorferi.

But as often happens with research that bucks traditional Lyme dogma, Lee's report was criticized in the scientific literature. While his test found Borrelia DNA, he was unable to culture the organism, leaving the case, as a 2017 letter in JAMA Internal Medicine put it, "unproven." Beyond this, however, even if the boy had been positive in two-tiered testing—and this is a comment on the fallibility of the technology itself—he likely would have been ruled a "false positive," with antibodies showing up from his previous infection. In short, Lyme testing is often a lose-lose proposition. Test negative and get no treatment. Test positive and get no treatment if already treated. This incenses Lee, a feisty former Yale professor who had escaped communist China in 1961 and is angry over the use of twin tests that miss many cases. What are the odds that the DNA he found in the boy's blood wasn't *B. burgdorferi* after hitting a match in the NIH GenBank? "It's mathematically almost impossible," he said.

Several months after the Ottawa conference, I reached out to Raymond Dattwyler, who is a tell-it-like it is kind of guy from the Bronx, where he was raised by working class, high-school educated parents, of which he is rightly proud. He was direct in his criticisms of the two tiers of Lyme testing, how they have been used, and said that they must go. "They were a stopgap measure. Those were never supposed to be cast in concrete. [They were] supposed to be used until something better came along," he told me. "Twenty years ago, I would've said they're fine. Now I say, 'Oh shit, we were wrong.' It doesn't look as good as we thought it was."

When I questioned the upshot of this flawed instrument—what it meant for sick, undiagnosed patients—Dattwyler lapsed into the qualifiers guideline authors have used to simultaneously acknowledge the testing regimen's flaws while defending its use. "The biggest problem is not sensitivity," or too many false negatives, Dattwyler told me. "It's specificity—too many false positives." The major flaw, in other words, was not the negative tests among people who actually had Lyme disease, although that is certainly a problem if you are one of them. The real problem—the one Lyme researchers have been far more concerned with, as I wrote in chapter 4—were people who were wrongly diagnosed with Lyme disease and treated with antibiotics when they did not have it. The false positives. The double test, the high bar, the bright bands on a Western blot—these were all designed to avoid just that, weeding out people early on who might have this or that antibody but not really Lyme disease. But what about all those missed cases, I asked, the people who did not manifest the typical rash and tested negative? "You miss the early thing," Dattwyler said bluntly, "because your tests suck and not everybody gets the rash and doctors don't realize the rash is variable."

"But later," he said, "you don't miss many at all."

The Upshot

In April of 1996, the New York State Department of Health wrote a letter to the CDC about its concerns over the new two-tiered technology. Agency officials had gone back and reviewed their Lyme disease cases from before two-tiered testing was adopted to see how the new criteria for diagnosing and counting Lyme disease cases would play out. Officials were concerned. "If we followed a case confirmation scheme which incorporated the new two-test requirement for serologic [blood test] confirmation on our 1995 cases, 1,237 cases

would not have been confirmed." That meant that 31 percent of all diagnosed cases in 1995 would have been ruled negative. The letter cited one case in particular: A patient had tested positive on the first tier and negative on the Western blot—a CDC negative overall—but had a form of facial paralysis that is a signal indicator of Lyme disease. "Do I confirm the case…?" the letter writer asked. Over time, the answer became crystal clear: You don't.

The warring camps and hunkered-down mentality that have dominated Lyme disease are a function of the diagnostics that Dr. Dattwyler spoke so frankly of at Ottawa and to me. Indeed, the major issue driving the Lyme controversy for two decades has been the lack of a dependable test to determine if someone is currently infected with Lyme disease. A 2013 Virginia law mandated that doctors inform potential Lyme patients, "current laboratory testing for Lyme disease can be problematic and standard laboratory tests often result in false negative and false positive results." Even when it works, the test indicates only the presence of antibodies—which can last long after a prior infection—and not of the pathogen itself. That glaring gap in the Lyme diagnosis paradigm has hurt patients who need care and, beyond this, hampered research: How can we reliably enroll patients in studies, know if antibiotics work, and chart the effects of treatment if tests fail in a portion of cases?

The better question might be why two-tiered testing has been so fiercely defended for so long, why its square pegs have been jammed into round holes. In 2012, I interviewed a leading Lyme disease researcher-physician who has long been allied with the Infectious Disease Society of America side. The researcher said, but later asked that I not use, this rather innocuous quote in regard to the test regime: "I don't think there's any question that everybody would like to have something better." In the world of Lyme disease politics, I learned, there was a distinct aversion to stepping outside the company line, which holds that the test is fine. Barbara Johnson, a CDC microbiologist with close ties to IDSA Lyme leaders, wrote this in a book chapter in 2012: "An extensive peer-reviewed scientific literature supports the rationale for and performance of two-tiered serological testing."

That statement works only if one believes the Lyme diagnostic's low accuracy—about half of tests are correctly positive at all stages—is normal and acceptable. This is a view the CDC has long embraced. "During the first few weeks of infection, such as when a patient has an erythema migrans rash," it has officially proclaimed, "the test is expected to be negative." The body simply hasn't produced enough antibodies. But the false negatives are okay, the CDC has held, because Lyme disease can be diagnosed based on early symptoms or by the Lyme disease rash. There are two problems with that.

First, a Lyme diagnosis is so controversial that many doctors want proof before treating. At three different points, the IDSA treatment guidelines advise physicians not to treat potential Lyme patients who do not have a rash or a positive test. In cases involving early neurologic, arthritic, and cardiac symptoms, the guidelines say symptoms simply "are too nonspecific to warrant a purely clinical diagnosis." Confirmation, they say, requires "laboratory support" or "serologic testing." This is an unambiguous way of telling physicians not to use their judgment, even in the face of symptoms and likely exposure.

Second, the CDC's study of 150,000 patients found the rash in 69.2 percent of cases; officially, the CDC maintains 70 to 80 percent of infections manifest it. But even a rash does not guarantee correct diagnosis since it may not look like the classic reddish "bull's eye" with a clear center. CDC photos show six variations, among many, including with a "bluish" hue, a "central crust," and "dusky centers." Just 9 percent of ninety-five people who developed Lyme rashes had the true bull's eye, according to a 2002 study in the Annals of Internal Medicine. At Johns Hopkins School of Medicine, researchers studying 165 early Lyme patients reported good news and bad: 87 percent actually had a rash—higher than the CDC estimates—but about a quarter of those were still ini-

tially misdiagnosed. Yet without this misnamed, sometimes misidentified, and often overlooked skin lesion, the guidelines insist on a positive test before diagnosis.

This is what happens in the real world. Because just 30 to 40 percent of tests are correctly positive in the early weeks of infection, because the rash is unpredictable, and because Lyme symptoms are common to other maladies, a share of people leave their doctors' office undiagnosed and untreated. Some go on to feel better, get on with their lives, and suffer crippling problems later on. That's the Lyme progression when it goes untreated. Recall that 10 to 20 percent of early treated patients suffer lingering problems. Most tragically, doctors have been encouraged, in cases with no rash, to allow infections to fester, then test later, even though patients may have symptoms and ticks may be active and infected locally. In patients without the rash, wrote Lyme pioneer Allan Steere and colleagues in 2016, "manifestations of Lyme borreliosis are typically diagnosed by recognition of characteristic clinical signs and symptoms along with serological testing." The keywords in that sen-tence: along with. Diagnose by symptoms, Steere is saying, but also have a positive test. The assertion was made in a review of the literature published in Nature Reviews Disease Primers, one of many recitations of previous studies that have hammered home the mainstream Lyme message.

The Lyme controversy would cease to exist if there was a better test and, moreover, a standard, predictable, and accepted way to culture Borrelia burgdorferi, namely to grow it from a sample of an infected person's blood.

The CDC's laissez faire pronouncements, its reassurances that a faulty technology works, and the advisories of the most esteemed names in Lyme disease, I'd argue, have made doctors complacent, believing, wrongly, that either a rash or, sooner or later, the twin tests will diagnose their Lyme cases. In fact, neither can be counted on to occur, most especially early on but later too. Further, reassurances that the tests work have stalled urgently needed research. If it isn't broke, as the saying goes

Roberta L. DiBiasi, a pediatrician, wrote somewhat more realistically on the tests than CDC's Barbara Johnson—if in somewhat dry medical prose—in a 2014 article in Current Infectious Disease Reports: "Many attempts have been made to evaluate serologic testing" for Lyme disease, she stated. "For even this basic measure of test validity, there is marked controversy in the medical literature."

When I began reporting on Lyme disease in 2012, I asked Gary Wormser, the lead author on the Lyme disease guidelines and the physician most associated with Lyme policy in the United States, if the tests worked. It was the last time he would speak with me. I subsequently wrote an article that questioned the validity of the tests. He said then, in a comment that captures the one-hand, other-hand nature of two-tiered Lyme diagnosis: "We don't recommend testing for people with the rash. A negative test doesn't prove anything. If you're sick six months, six years and you don't have a positive test, give me a break." This is the prevailing principle of Lyme diagnosis: The tests don't work early, but most certainly work later. No rash, no positive test, no Lyme disease. What's the issue?

Under this regime, nonrash patients with equivocal symptoms, such as flu-like illness, headache, and fever, may be told to return for testing if symptoms persist. Yet even then, cases may be missed. A CDC continuing education tutorial advises doctors that "convalescent phase" patients, the second stage after acute, will correctly test positive in standard two-tiered testing just 26 to 61 percent of the time—the range of four studies quoted that demonstrates the tenuous nature of Lyme diagnosis. Later on, patients with "early disseminated" Lyme disease, with symptoms like meningitis and facial palsy, the four studies reported, will be positive 73 to 88 percent of the time. That's better but misses potentially one in four cases. It isn't until the "late disseminated" phase that two-tiered testing reaches accuracy heights of 95 to 100 percent, the tutorial advises. Yet those are some of the toughest cases to treat.

In 2016, British researchers looked at eighteen

published studies and found the tests correctly positive just 54 percent of the time overall, a low figure that reflects early failure rates. Notably, these researchers found no standard definition of each Lyme stage—early, late, convalescent—which, they said, "prevented clear evaluation of test sensitivity." When they looked at results by manifestation, they found good results in arthritis cases—96 percent accuracy. But for neurological Lyme disease, which can lead to memory and cognitive problems, numbness in the extremities, or psychiatric disorders, the study said testing was correctly positive in 87 percent of cases overall, leaving a significant share of potentially impaired people undiagnosed.

Beyond this, studies that measure the accuracy of Lyme disease tests should be viewed skeptically. Some rely on a kind of circular logic, selecting patients on which to validate the tests who have been known to suffer Lyme disease—precisely because they had already tested positive in two-tiered testing. Researchers writing in Clinical Infectious Diseases in 2008 acknowledged this flaw: "It is problematic to determine the frequency" of positive tests in cases involving neurologic, cardiac, or joint problems because positive testing is "a part of the case definition." A CDC-led study also acknowledged, "the possibility of selection bias toward reactive samples cannot be discounted."

These and other flaws became eminently clear when a team led by Mariska Leeflang, a Dutch epidemiologist and testing expert, reviewed the methodology behind seventy-eight studies on the efficacy of Lyme disease tests. Leeflang's 2016 article in the journal BMC Infectious Diseases concluded that every one of those studies suffered from "a high risk of bias" in at least one of four categories. In the end, her team's exhaustive review did not find "sufficient evidence" to endorse current Lyme diagnostics. "These [study] designs are very likely to overestimate sensitivity and specificity," Leeflang told me–namely to inflate the test's ability to predict positive and negative results. In other words, the performance rates are best-case, not real-world, figures.

Then there is how this all plays out in fast-paced labs for a technology the CDC study called "complex (and) technically demanding." Dutch researchers looked at the performance of eight commercial versions of the first tier test and five of the second in 2011; they reported "widely divergent" results depending on which combination was used. In comparison to Lyme tests, antibody testing for HIV infection is a breeze. In 2017, two British researchers calculated the statistical probability of accuracy for each test in a head-to-head comparison. For late-stage Lyme disease—when two-tiered testing supposedly works best—Lyme tests falsely ruled patients negative 17 percent of the time. The HIV test was falsely negative in 0.1 percent of cases. Writing in the International Journal of Medicine in 2017, the researchers noted that was a 170-fold difference.

The Lyme controversy would cease to exist if there was a better test and, moreover, a standard, predictable, and accepted way to culture Borrelia burgdorferi, namely to grow it from a sample of an infected person's blood. To really know how well the test works, Leeflang told me, you need to measure test performance in people who are known to have Lyme disease and, as important, in people who don't. "You need a gold standard," she said. In 2013, a Lyme disease researcher at the University of New Haven in Connecticut, Eva Sapi, introduced a culture test, her results published in the International Journal of Medical Sciences. Sapi's methodology was challenged in an article by CDC's Johnson, who has published on, and has patents for, Lyme disease diagnostic technology. The CDC subsequently recommended against use of what I'm told was an imperfect study but a promising technology.

Instead, the agency has for many years upheld use of a diagnostic strategy that is indisputably flawed. "Until we can separate the infected from the uninfected and the cured from the uncured," wrote Elizabeth Maloney, a physician and author of the International Lyme and Associated Diseases Society guidelines, "arguments over diagnostic and therapeutic approaches will continue." Dattwyler hopes not. He has been working on a new

antibody test that, if approved and marketed, will more accurately diagnose infections. He acknowledged it would not distinguish current from past infection, as with the old test, which is a huge problem in areas where people are repeatedly infected. Beyond this, he volunteered that the test on which he has worked for a dozen years would likely make him some money. "It is going to change," he said. "It's going to change because I'm one of the guys leading the charge to change it."

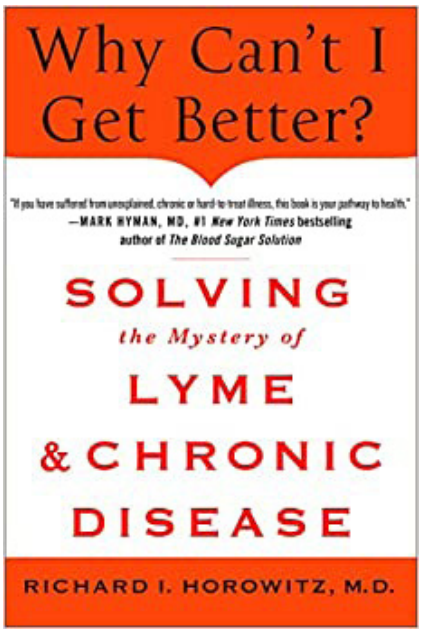
Dorothy Kupcha Leland is LymeDisease.org's Vice-president and Director of Communications. She is co-author of When Your Child Has Lyme Disease: A Parent's Survival Guide. Contact her at dleland@lymedisease.org.

Looking for Answers?

Additional books about Lyme disease

By Dorothy Kupcha Leland

DIAGNOSIS, TREATMENT AND HEALING MODALITIES

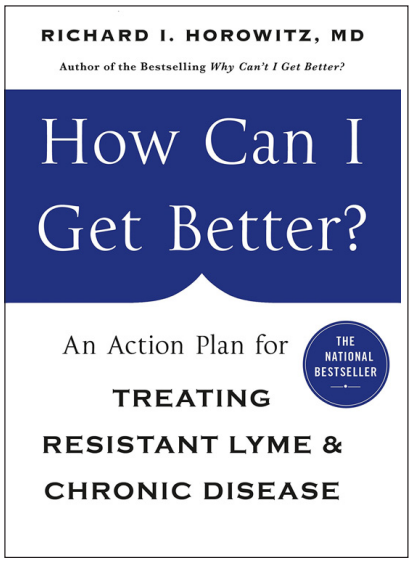


WHY CAN'T I GET BETTER? Solving the Mystery of Lyme & Chronic Disease

AUTHOR: RICHARD I. HOROWITZ, MD

Groundbreaking book by world-renowned expert in treating tick-borne diseases. Dr. Horowitz explains his process for diagnosing what he calls Multiple Systemic Infectious Disease Syndrome (MSIDS). It's a multifactorial model for treating chronic disease, which identifies up to 16 overlapping sources of inflammation and their downstream effects.

ORDER BOOK

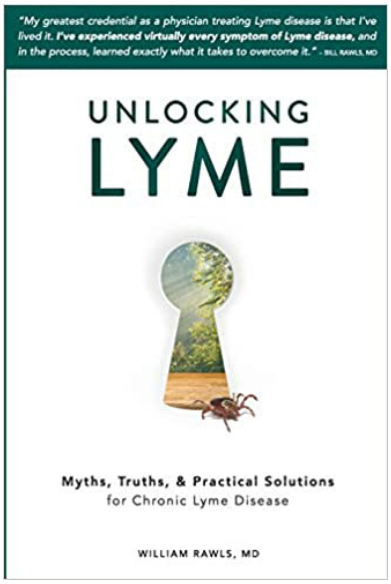


HOW CAN I GET BETTER? An Action Plan for Treating Resistant Lyme & Chronic Disease

AUTHOR: RICHARD I. HOROWITZ, MD

In this follow-up volume to his first book, Dr. Horowitz offers a direct, actionable step-by-step plan for implementing his 16-point MSIDS Diagnostic Map.

ORDER BOOK

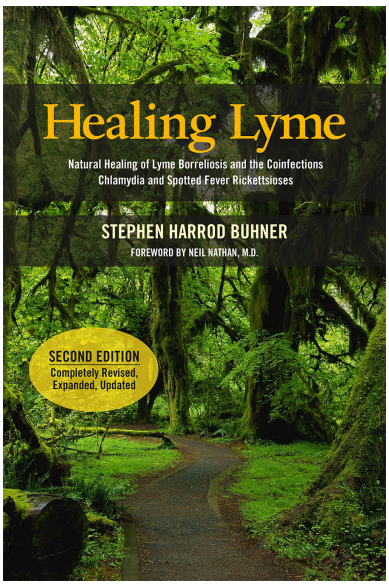


UNLOCKING LYME: Myths, Truths, and Practical Solutions for Chronic Lyme Disease

AUTHOR: WILLIAM RAWLS, MD

The author, a physician who overcame Lyme disease himself, offers an overview of holistic and non-toxic therapies for healing and symptom control (including pain, depression, insomnia).

ORDER BOOK

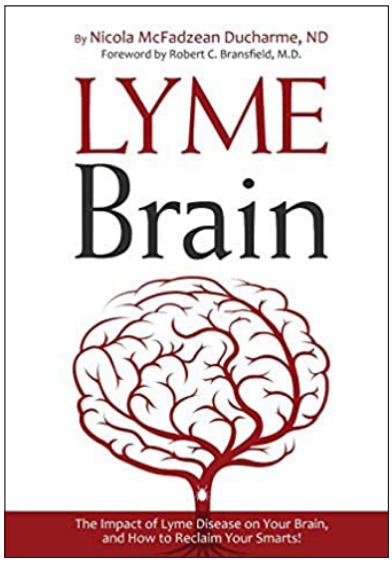


HEALING LYME: Natural Healing and Prevention of Lyme Borreliosis and Its Co-infections

AUTHOR: STEPHEN HARROD BUHNER

Master herbalist Buhner outlines the most potent herbal medicines and supplements that offer help, either alone or in combination with antibiotics, for preventing and healing Lyme disease.

ORDER BOOK

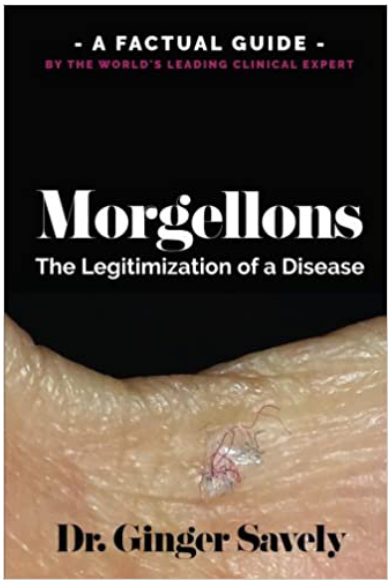


LYME BRAIN:The Impact of Lyme Disease on Your Brain, and How to Reclaim Your Smarts.

AUTHOR: NICOLA MCFADZEAN DUCHARME, ND

The author defines "Lyme brain" as a constellation of symptoms that can include short-term memory loss, difficulty with focus and concentration, and other assorted neurocognitive factors. It can be accompanied by anxiety and depression. This book offers strategies to combat this frustrating condition.

ORDER BOOK

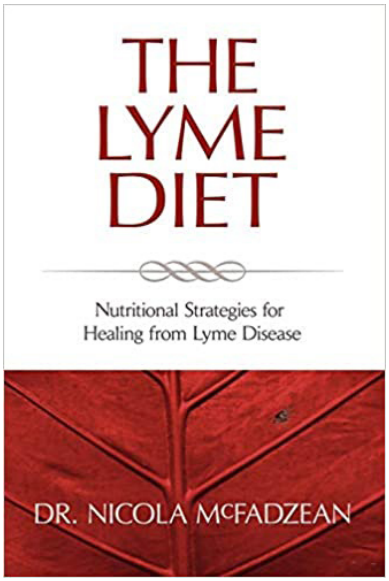


MORGELLONS:The Legitimization of a Disease

AUTHOR: DR. GINGER SAVELY

Morgellons disease afflicts a subset of Lyme disease patients. It's characterized by the presence of multicolored filaments that lie under, are embedded in, or project from skin. This book compiles what's known about this still-mysterious condition.

ORDER BOOK



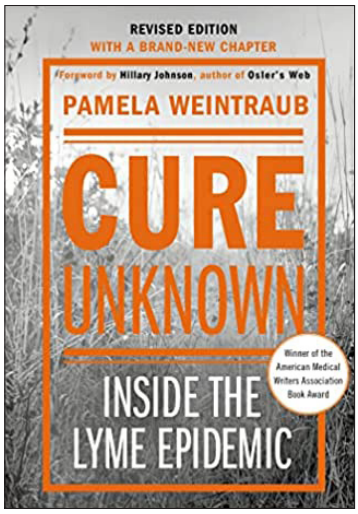
THE LYME DIET: Nutritional Strategies for Healing from Lyme Disease

AUTHOR: NICOLA MCFADZEAN, ND

Writes the author: "The role of nutrition is central not so much in the actual bug-killing, but in the underlying strength and resilience of your health. Immune support, inflammation management, hormone regulation and detoxification functions can all be vitally influenced by your nutritional intake."

ORDER BOOK

HISTORY AND SCIENCE

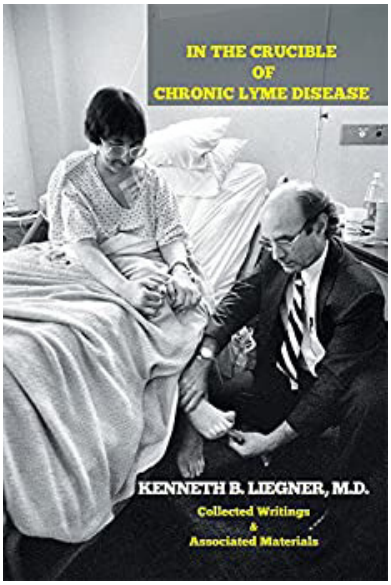


CURE UNKNOWN: Inside the Lyme Epidemic

AUTHOR: PAMELA WEINTRAUB

An investigation into the science, history, medical politics, and patient experience of Lyme disease told by a journalist whose entire family contracted the illness.

ORDER BOOK



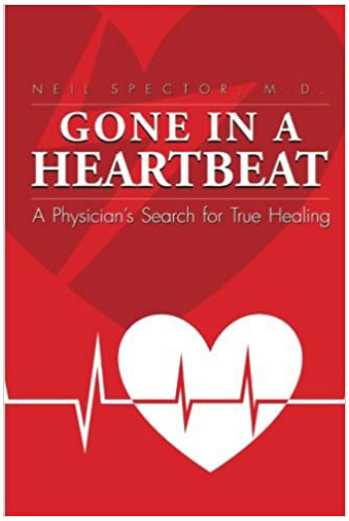
IN THE CRUCIBLE OF CHRONIC LYME DISEASE: Collected Writings & Associated Materials

AUTHOR: KENNETH B. LIEGNER, MD

Despite scientific studies, the CDC and IDSA dismiss any existence of chronic Lyme disease. In this book, Kenneth B. Liegner, M.D. has compiled into a single volume a compelling argument that the disease does exist.

ORDER BOOK

PERSONAL NARRATIVES

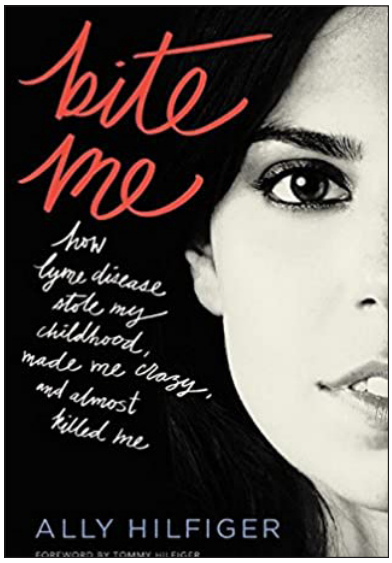


GONE IN A HEARTBEAT: A Physician's Search for True Healing

AUTHOR: NEIL SPECTOR, MD

Dr. Spector's case of Lyme disease went unrecognized for so long, he ultimately needed a heart transplant. After the publication of this gripping memoir, he went on to become one of the most beloved heroes in the Lyme community.

ORDER BOOK

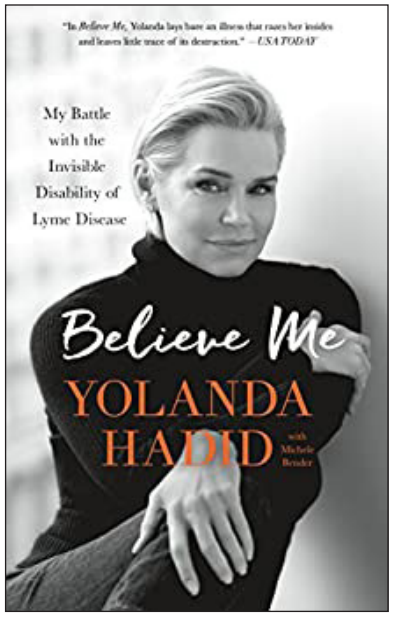


BITE ME:How Lyme Disease Stole My Childhood, Made Me Crazy and Almost Killed Me

AUTHOR: ALLY HILFIGER

Riveting first-person account of what it's like to be a young child—and then a teenager—with undiagnosed Lyme disease.

ORDER BOOK

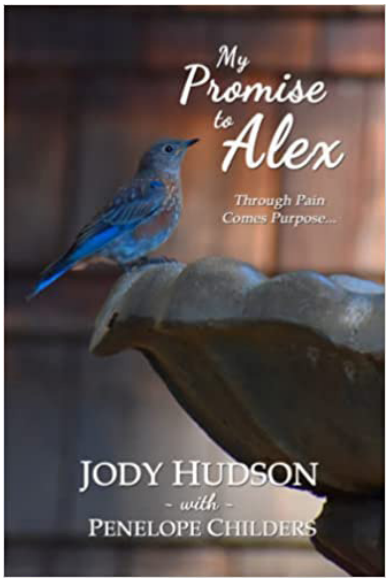


BELIEVE ME: My Battle with the Invisible Disability of Lyme Disease

AUTHOR: YOLANDA HADID

A former super-model and former cast member of "The Real Housewives of Beverly Hills," Hadid outlines how she never stopped trying to find answers to her health problems. Her memoir details how she criss-crossed the globe to try an astonishing array of alternative and ancillary treatments—ultimately ending up in a good place.

ORDER BOOK

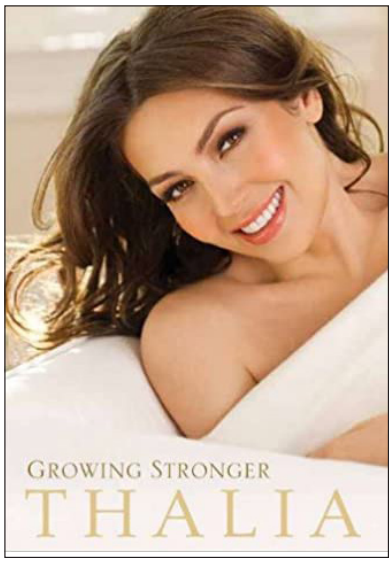


MY PROMISE TO ALEX

AUTHOR: JODY HUDSON

When eleven-year-old Alex Hudson complained that her leg hurt, her mother, Jody, thought it was just growing pains. But for the next ten years, Alex battled with what perplexed doctors deemed a medical mystery. Her mother Jody wrote this book and founded the Alex Hudson Lyme Disease Foundation in her daughter's memory.

ORDER BOOK



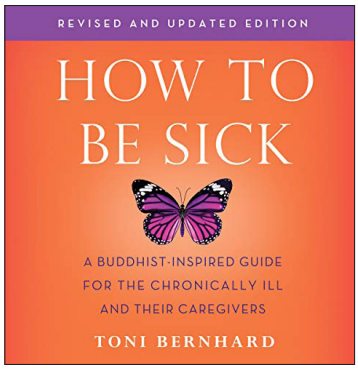
GROWING STRONGER

AUTHOR: THALIA

Entertainment superstar Thalia, a Mexican and American singer and actress, discusses her Lyme disease experience.

ORDER BOOK

MISCELLANEOUS

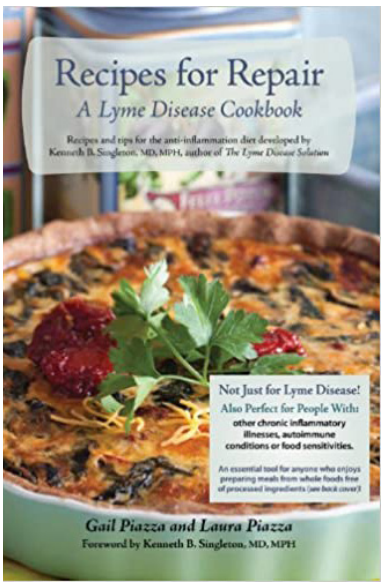


HOW TO BE SICK: A Buddhist-inspired guide for the chronically ill and their caregivers

AUTHOR: TONI BERNHARD

A book about how to "be" when you are sick. How to have a worthwhile existence, finding meaning, purpose and joy, even when chronic illness seems to have stolen your life away.

ORDER BOOK



RECIPES FOR REPAIR:A Lyme Disease Cookbook

AUTHOR: GAIL AND LAURA PIAZZA

This book offers 151 whole food recipes to reduce harmful inflammation caused by Lyme disease and chronic illnesses.

ORDER BOOK