

Statement at Lyme Next Forum, Skidmore College, May 21, 2012 INTO THE WOODS: THE PATIENT JOURNEY THROUGH LYME



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Hi, it's nice to be here. I just want to mention I went to college not far from here at the University at Albany, where I was a bio major. Back then, a mother and artist named Polly Murray had just begun documenting the strange set of symptoms afflicting neighbors in her town of Lyme, Connecticut. I was still in college here in Albany in 1975 when Murray reported those original patients to the Connecticut Department of Health. Polly Murray has described the loneliness of her journey, but today I am here to tell you that, decades later, new patients often travel the same lonely path as if Murray had never paved the way. Too many of us still spend years seeking help for what was, in the beginning, incontrovertible and curable Lyme disease, only to reap the whirlwind of late diagnosis and failed treatment --even in New York and other hyperendemic areas of the United States.

My own journey through Lyme started in 1993, when my husband Mark, our two sons, and I moved to Westchester County. Our lovely property in the hamlet of Chappaqua abutted a spruce forest, and we reveled in our new contact with nature --there were deer, squirrels, raccoons, mice and all sorts of other animals and birds.

From that point on, we all became increasingly sick. First there were headaches, joint pains, and an inexplicable weariness. With time, the symptoms intensified and multiplied: My knees became so painful that I had to sit down to descend the stairs in my house on my bottom, one step at a time. I developed dysphagia: I had so much trouble swallowing that I literally choked on my food. I developed peripheral radioneuropathy: My arms and legs buzzed, gently at first, and then increasingly painfully until it felt like electricity was running through me. The headaches became relentless. My eyes were painfully sensitive to light. I spent hours each day in a darkened room, in bed.

Meanwhile Mark, an avid tennis player, began stumbling and bumping into walls. He was an award-winning journalist, but he began struggling with memory and groping for words. Increasingly cognitively impaired, he was forced to leave his job after realizing that he'd spent hours trying to read a single, simple paragraph.

Our youngest son, David, began to sleep --first so long that he could not do his homework or see his friends; eventually, so much that he could not get to class. In the end he was sleeping 15 hours a day.

Hardest hit was Jason, our oldest, who suffered profound fatigue and shooting pains starting at age nine, late in the summer of '93. The doctors called these "growing pains" normal, and my son, though often fatigued, tried to keep going. Then in 1998, he developed a huge rash over his torso. I called the doctor's office and was told not to bring him in --since it wasn't in the shape of a literal bull's eye, it wasn't Lyme, they said. After that rash, Jason became increasingly ill, and never seemed to get well.

By 2000, at age 16, he was functionally disabled. He could not think, walk, or tolerate sound and light. On medical leave from high school, he spent his days in the tub in our darkened main-floor bathroom, drifting in a mental fog while hot water and steam eased his pain. As his condition worsened, as all sorts of lab tests came back negative, a raft of specialists at New York City's top teaching hospitals suggested diagnoses from migraine aura to parvovirus. Each diagnosis elicited a treatment, but none of them worked.

"What about Lyme disease?" I asked from time to time.

"There are too many symptoms here and he's way too sick for Lyme disease," responded the pediatrician, who told us he felt it was all psychological. Thankfully the psychiatrist we ultimately consulted --an academic scientist who literally wrote the book on child and adolescent psychiatry-- disagreed. At his insistence, the pediatrician drew fourteen vials of blood, testing for hormone imbalance, mineral deficiency, anemia, and a host of infections, including one tick-borne disease -- Lyme. A week later he called to tell us that just one test, a Lyme Western blot from Labcorp, had come back positive, with eight of ten bands highly lit.

Finally the head of infectious disease at Northern Westchester Hospital weighed in: In retrospect, he said, Jason had probably been misdiagnosed for years. I will never forget the way he phrased his grudging diagnosis: "I'll give it to you," he said, as if we had earned some coveted prize that others, whose confusing arrays of multi-system ailments could be explained in some other way, would never get. Unaware of the political turmoil over tick-borne disease, I didn't yet understand how rare it was for a doctor like him to diagnose late-stage Lyme disease in New York State. Jason was treated with eight weeks of intravenous Rocephin, but when he didn't get well, the Lyme diagnosis was revoked, and that doctor, too, consigned him back to psychiatry.

The situation would stretch anyone's credulity: Our formerly straight-A, basketball-playing son, after contracting Lyme disease, being misdiagnosed for years, and finally receiving antibiotic therapy for two months, had now developed a bizarre, unrelated psychiatric disorder whose symptoms were,

coincidentally, exactly the same as those of Lyme disease. Perhaps it is possible to believe this kind of explanation when served up by experts talking about other people's children; but it is the rare parent who would accept this decree for a child of his or her own --especially when your psychiatrist then weighs in saying he has never seen a psychiatric disease like this in his life.

My husband Mark and I, by now both quite ill now ourselves, faced a choice: Accept this unlikely story and give up on our son's future, or find one of the Lyme doctors said to treat more aggressively, in opposition to the mainstream views we had followed for years to the current, tragic state of affairs.

So in the summer of 2000 we bundled our boy into the car and headed up to New Haven, and the practice of the embattled pediatrician, Charles Ray Jones. Dr. Jones examined and tested Jason and told us he was so sick because he had contracted not only Lyme disease, but two common co-infections that ticks carry --Babesia and Anaplasma. Epidemiologically, it seemed like a reasonable call, given the many vacations we'd taken on Martha's Vineyard and Cape Cod, where Babesia was rife. Dr. Jones treated Jason with standard doses of doxycycline for anaplasma and Lyme disease, and with mepron and zithromax for babesia. Two weeks later --after years of freefall-- our son got out of the bathtub and began throwing a basketball around the family room.

Today he is a graduate of Brown University. He has also earned an MFA in film and is living out in Hollywood, pursuing his dream of becoming a screenwriter. Not a day goes by that I don't feel gratitude for the fact that my son has regained his life. I know how lucky we were to have this nightmare end.

Although my book, *Cure Unknown*, is in part a memoir, its focus is really what I found after I had dealt with my family's health problems sufficiently for me to sit back and peer through the eyes of the investigative and skeptical science journalist I had been for decades before Lyme swept us away.

For almost eight years, from 2000 to 2008, I interviewed patients, the Lyme doctors treating the sickest of them, and dozens of academic scientists, including most of those at the forefront of research.

My journey as a patient was contextualized by all this reporting, and often confirmed. For instance, I met large numbers of patients with classic presentations of Lyme disease who, like Jason, would probably have been cured with early treatment but who were instead diagnosed late, often very late, in the game.

You'll hear a lot of talk today about chronic patients --primarily those who are diagnosed late, and then receive and fail the standard antibiotic treatment recommended by the Infectious Diseases Society of

America, or IDSA --patients like Jason. I'll discuss them, too. But first I want to step back and talk about that uncontroversial patient, the acute patient --the individual who has just been infected with Lyme.

Routinely, patients that I interviewed reported going to their primary care doctors with the tick in hand and being told to throw the tick away and return only if symptoms emerged. Many patients told me of doctors who insisted, erroneously, that a Lyme rash had to look like a bull's eye, specifically. Patients from highly endemic Lyme regions reported going to doctors with a tick bite and flu-like symptoms in summer and fall, when flu symptoms are rare, yet being told to wait for a positive test before they could be treated.

The practice of asking probable patients to advance to later disease so a doctor can be 100 percent certain the diagnosis is Lyme has served to churn out new generations of chronic Lyme patients for decades now. Lyme disease is usually entirely curable if you treat it early, but most patients do not test positive on the standard two step diagnostic early on. A study from Johns Hopkins in 2007 found that up to 55 percent of patients with other laboratory evidence for Lyme disease test negative on the tests recommended by CDC, especially early in the course of the disease.

If you develop a flulike illness in summer or fall and you live in a Lyme endemic area, certainly if you have a Lyme rash, an erythema migrans, you should be treated for Lyme disease without waiting for the test: This is not controversial advice. The CDC says this. But because of all the heat surrounding this disease, such patients find they may be refused treatment until they are very ill.

This risky waiting game takes on new proportion in light of other disturbing, and NON-CONTROVERSIAL news from New York State, this time from disease ecologist Richard Ostfeld of the Carey Institute for Ecosystem Studies in Millbrook. Ostfeld has documented, this year, a rare event he calls an acorn inversion that is going to make new cases of Lyme disease spike.

Here is how it works: In the fall of 2010 there was a bumper crop of acorns, plentiful food for the white-footed mouse that is the primary reservoir for the Lyme disease spirochete, *Borrelia burgdorferi*. The acorns were so robust that the mice surged from the average of 20 mice an acre to 200 mice an acre in a single year. There was a commensurate increase in the larval, or baby, ticks that fed on the mice and acquired the infection in 2011. Ordinarily those ticks would fall off and the next year, as nymphs, or adolescents, they would again attach to the mice or other wildlife --and sometimes pets and people-- for another blood meal.

But in 2012, the acorn crop has crashed –so much so that the mice are dying in droves. Instead of 200 mice per acre, we are going to have 5 mice per acre. But what will happen to all those hungry ticks –all those nymphs now seeking another blood meal? Well, the mice may be gone, but the nymphs are still here. Without mice to attach to, these nymphs, the size of poppy seeds and hard to detect because they anesthetize the bite area, are going to be seeking other hosts. Those alternate hosts are us. Ostfeld predicts that the acorn inversion along with the warmer weather starting earlier in the year will cause Lyme cases in Saratoga Springs and the rest of the northeast to spike by about 20 percent.

Let me put this in perspective: The CDC says that about 90 percent of Lyme cases go unreported. In 2009, the last year for which CDC statistics are available, about 30,000 cases meeting the Agency's intentionally narrow surveillance definition were reported, suggesting 300,000 cases, at least.

I say at least because, as in ANY disease, there is quite a bit of variation --here largely caused by different strains of the spirochete. Many of the experts i spoke with contend that strain variation may mean that an unknown number of additional people will never meet the exact antibody pattern called for by the standard tests of the day, yet will still be infected and still have Lyme disease.

Another NON-CONTROVERSY to reckon with is this: The black-legged tick that transmits Lyme disease here in the Northeast also transmits other infections at the same time. A Columbia University study found that 71 percent of deer ticks in a suburb of New York harbored at least one pathogen, while 30 percent had at least two, and 5 percent had three infections. And like Lyme, many of these pathogens are on the rise. Foremost is Babesia, which is spreading so fast that, in areas like Cape Cod, Massachusetts and Eastern Long Island, it is almost as prevalent as Lyme disease. The malaria-like disease infects red blood cells and can cause fever, exhaustion, and drenching sweats. In the immune-compromised, untreated babesiosis can result in death. Disease that results from coinfection with Lyme and Babesia may be especially protracted and severe. Other tick-borne pathogens include Anaplasma, a bacterial infection that causes severe flu-like symptoms, and the Powassan virus, a truly scary pathogen notable for brain swelling and encephalitis, Powassan virus may lead to permanent neurological damage or death. The latter two are found in a small, but statistically significant number of ticks --a frightening risk if, like I did, you live on a property abutting the woods and are constantly exposed.

If you look at tick surveys from around the United States co-infections in ticks are widely reported, and they are well-known as human diseases, yet primary care physicians almost never consider or test for them, if indeed the possibility of Lyme itself is seriously considered.

As if all this isn't enough, a second spirochete --another *Borrelia*, this one a relapsing fever-- has been found in black-legged ticks throughout the northeast by scientists at Yale. There is no commercial lab test available for the organism. At the same time, the lonestar tick has moved from the Southern part of the United States all the way up the east coast. That tick has been associated with yet another suspected spirochetal, Lyme-like illness for which there is no test. In both cases, scientists are working to determine the human burden of disease that may result.

I think a real effort needs to be made to determine the whole suite of possible diseases patients with Lyme may be carrying --because having an unknowable, undiagnosable illness can be very much part of the patient experience on the ground. Patients like Jason can be very sick, and their disease can be refractory specifically because it isn't just Lyme.

Another number that has been repeated to me again and again by experts across the spectrum of opinion in other areas of Lyme and even mentioned in peer review is this: About 20 percent of patients who remain untreated for a year or more --so MANY of us-- will fail the one or two month course of antibiotic treatment in the IDSA guidelines. Twenty percent. This is the chronic Lyme population.

The cause of their ongoing illness may be controversial, but the fact that so many slip through the cracks and remain ill, according to my reporting, is not.

Also NOT controversial: Patients that fail standard treatment can become very ill. Mark Klempner of Boston University reports his cohort of chronic Lyme patients was as impaired as those with congestive heart failure or osteoarthritis and more impaired than those with type 2 diabetes or a recent myocardial infarction. Brian Fallon of Columbia reports pain equivalent to post-surgical pain and fatigue as severe as that seen in M.S. Patients can suffer stabbing, boring, shooting pains in their arms and legs, or impaired vision and hearing from damaged nerves. They can suffer heart damage.

Even more devastating, especially to students and knowledge workers, are the cognitive and memory deficits. Testing hundreds of such patients, New York University neuropsychologist Leo Shea found specific deficits in concentration, short-term memory and processing speed. Fallon has objectified these impairments by tracing them to blood flow and metabolism deficits in the brain. Some scientists have called the impact of these impairments mild, but that does not remotely capture the experience for the patient herself --the angst of falling behind in school or feeling perpetually foggy and confused. Many patients report getting lost while driving around their own neighborhoods. Many patients have told me they could no longer remember enough to perform the detailed tasks of their jobs.

For me, the fatigue was the worst of it --during the years I had Lyme disease, I collapsed in a heap every afternoon while my children were in school, my exhaustion overwhelming and profound. Sure, there are studies that minimize these types of "subjective" symptoms as being almost irrelevant. But just because you can see evidence on the outside --for instance the rash or joint swelling-- doesn't mean the devastation on the inside can't also be measured in a reliable fashion or shouldn't be given primary weight as perhaps the most important and clinically relevant outcome of all.

Now finally to the core controversy: At the heart of the fight over Lyme disease is the debate over the chronic patients, the unlucky 20 or so percent of those who each year get diagnosed late and fail the standard treatment, staying sick. The big dispute in Lyme revolves around the cause of their illness: Have they failed the treatment because the antibiotic couldn't kill the infection, or because a secondary --still undefined-- immune syndrome has taken hold? Are the chronic patients persistently infected? Has the short-term treatment stamped out infection, leaving just tissue damage and immune dysfunction in its wake? Or is the ongoing illness some combination of all of the above?

To date, three human studies funded by the National Institutes of Health have failed to quell the debate over chronic infection. The conflict was stirred up further in 2012, following a Tulane University study finding "persisters"—living Lyme spirochetes-- embedded in the tissue of rhesus monkeys treated for months, suggesting infection stays active, after all. Related findings come from mice, guinea pigs, and dogs.

Do these recent monkey findings mean that the persister cells in the study have been proven as a cause of continued symptoms in humans to the standards demanded by academic science? No. That study has not been done. Science demands that we confirm these monkey findings in humans through rigorous studies --just as it demands that we determine immune components to the illness. Because these issues have not been settled, more research must be done.

I can tell you that I, personally, became convinced I was chronically infected because relapsing-remitting illness was an overriding hallmark of my own Lyme disease. I was infected for some seven years before diagnosis. I was treated and seemed to get better, but every time I stopped antibiotic treatment I relapsed like clockwork over the course of two to three months. I went through draining cycles of relapse followed by retreatment for four years before the recovery was sustained. I stopped taking antibiotics for Lyme disease in 2004, after dealing with these relapses, and I have been well since. Yet many others have been treated as or more aggressively, and remain sick --prolonged antibiotic treatment has not worked well for them. In the midst of so much disagreement and patient variation, and without more funding for research, each chronic patient embarks on a journey of one.

That journey can feel desperate and take years. Unresolved Lyme and tick-borne disease can be nightmares for parents, who bear the heartache of watching their children suffer along with the sense of helplessness and despair that comes from a medical community all too quick to dismiss their complaints: Take it from me. My two boys are better now, but both lost their childhood to Lyme and tick-borne disease. After a child has been allowed to slip through the cracks of early diagnosis and treatment, the stage is set for isolation and alienation as the child drops from clubs, sports teams, friendships and often, even school. In the wake of the child's decline, schools often push psychiatric interpretations, foisting inappropriate labels and discipline or help.

When the child doesn't respond to wrong-headed strategies, the schools may accuse parents of poor skills in parenting or even Munchausen by proxy, a diagnosis that has been called into disrepute by top experts in psychology and psychiatry, but still manages to rear its head as an accusation where mothers and Lyme disease are concerned.

What a chasm I found between the patients I interviewed and some physicians at teaching hospitals in the northeast. One well-known academic told me that virtually all Lyme patients are diagnosed early these days, and for the rare one who slips through the cracks to late stage disease, treatment response is guaranteed. "If the patient doesn't respond, he never had Lyme disease," the doctor said.

When, during grand rounds or training sessions, such doctors suggest the patients are bogus -- malingers too wimpy to handle stress, middle-aged suburban women with somatoform disorder, or hypochondriacs in search of the disease du jour-- they have poisoned the chance of timely diagnosis by predisposing front line primary care physicians to seek psychiatric explanations first. With antibiotic treatment off the table, such patients wander from family doctor to clinic to teaching hospital, from one specialist to the next --and then off the grid.

My family found our way to doctors who diagnosed infections clinically and treated empirically, all the while using modalities for symptomatic relief of chronic disease: These were the best of the Lyme doctors. They treated our babesiosis and addressed our Lyme relapses and, over the course of years, brought us back to health. We found them compassionate and responsible, but being the patient of such a doctor is stressful: He or she may be under investigation, and rarely takes insurance for fear of being profiled as an outlier and then delisted and further stigmatized, making the financial burden on the patient intense. Most of the doctors who helped my family get well are today under investigation or facing charges in New York State.

Other patients default to outright quackery: dangerous chemicals and mixtures; lethal levels of heat applied to internal tissues; risky doses of salt. Today, some patients are spending life savings on trips to clinics in India, Mexico, and elsewhere for a black box therapies said to be based on stem cells, intracellular heat, and more. A diaspora of the desperate and broke, many of these patients have come to the end of the line.

It is hard enough to be sick --but to be so sick for so long and also be a suspect-- to have your physical pain, your integrity, your very sanity called into question as you travel the medical landscape begging for help, well, let me tell you, that is a crushing course of events. In most other diseases, the sick person can focus on being a patient --on following through with treatment to try to get well. No one suggests the cancer patient is factitious, or the heart patient a sociopath. But in Lyme and tick-borne disease, the brutality of such rejection on top of real physical illness is yet another body blow.

Because I am the author of a book about Lyme disease, I hear often from patients. My personal nightmare has ended, but the tragedy of Lyme is a drumbeat that goes on. I just want to read a few of the emails I have received, with personal details changed to protect the privacy of these folks:

One mother sent this note about her son, infected with Lyme out on Long Island: The young man, a graduate of very prestigious university, eventually became so sick and felt so little recourse that he took out a 60,000 dollar loan on his own credit cards to pay a Lyme doctor who would treat him with a regimen of intravenous and oral antibiotics over the course of almost a year. Having finished the treatment, the young man is sicker than ever. "He is much worse!" the mother writes. "Yesterday, he spoke with his father and could not stop crying. On his facebook page, he wrote that he was 'too sick to be.' which scared me to death. He feels there is no hope, and nothing else to do."

Someone sent this note to me through my blog at *Psychology Today*, where I had written an article on neurological Lyme disease: "I have gone undiagnosed/misdiagnosed for 30 yrs and am now 48 yrs old. I believe I contracted this sometime in my teen years. I underwent four months of IV Rocephin and prior to that six months of oral antibiotics from a neurologist at a teaching hospital. I am a complete invalid and can barely get out of bed. I do not know were to turn. I went to a new support group just started for Lyme up the road from me. There were about 20 people at the first meeting and it was something out of a nightmare as we went around the room introducing ourselves. One woman was in a wheelchair and in severe pain from Lyme arthritis, another woman could not introduce herself and starting crying, another tried suicide, another started going blind and one woman even passed out and fell over in her chair."

And this, from a young woman who has gotten well after longer-term treatment for Lyme disease, though during her college years she was quite ill. She was dismissed by the dean of students, who insisted it was all in her head and would not allow her to take a lighter course load. As a result of her illness and exhaustion, this former straight A academic superstar barely passed her classes. She graduated, but says, "I lost my mentors, because my professors were told I was inventing the illness. What do I do now? How do I rebuild my life?"

As for my family, we are better now --we have moved from the epicenter of the epidemic in the northeast suburbs of New York City and live happily, in Brooklyn. I don't plan to leave the concrete again. But the emails keep hitting my inbox. They are dark, relentless, and so sad.

They tell me this: We need a campaign of awareness to prevent new generations of patients, our children, from slipping through the cracks of early, curable Lyme disease to chronic illness. We need tests that can reliably detect Lyme and other tick-borne disease within that early window of infection that is most curable and we need tests that can distinguish those with chronic Lyme from those with other chronic illnesses, like chronic fatigue syndrome or fibromyalgia.

If we don't know who has the disease, for sure, we cannot document the scope of the problem, and we cannot hope to solve it. Reliable, validated 21st century diagnostics must be the linchpin of any research initiative. When we have diagnostic tools in hand, we can treat our patients earlier and find true cures for the chronic group that has never gotten well.
