My Statement to Institute of Medicine, October 10, 2010

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Institute of Medicine Talk on The Human Face of Tick-Borne Disease

by Pamela Weintraub

Lyme disease entered my life in 1993, when my husband Mark, our two sons, and I moved to Westchester County, New York. At the time I was, as I am now, a science journalist specializing in biomedicine for the national consumer press. 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 erythema migrans 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 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 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 —babesiosis and anaplasmosis. 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. Two years later he was playing varsity basketball for his high school, and today he is a graduate of Brown University and earning his MFA in film.

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 and many speaking at this forum. My journey as a patient was contextualized by all this research, and often confirmed. For instance, I met large numbers of patients with classic, incontrovertible 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. 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 a Lyme rash had to look like a literal bull's eye. Patients reported going to doctors with a tick bite, early flu like symptoms, and sometimes even an erythema migrans rash, and being told to wait for a positive test before they could be treated. When patients tested positive, a significant percent were told they could still not be treated for Lyme disease until they developed gross objective disease signs like swollen knees or inflamed nerves—in other words, until they had advanced into the late stage of disease, when treatment was more likely to fail.

Other patients with known exposure and signs and symptoms of Lyme disease failed to test CDC positive on their Western blots. Take me: I had a positive ELISA and four CDC positive bands plus two additional Borrelia burgdorferi proteins, outer surface proteins A and B. Six bands in all, and the lab was Stony Brook. Still, I had to step outside the bounds of the medical mainstream to find a practitioner who recognized this alternate band pattern as Lyme disease. Patients in the South could have the trademark rash and objective disease signs --but they would be told there was no Lyme or clinically comparable Lymelike disease in their state, and be turned away.

Such patients, in aggregate, constitute what I think of as the chronic Lyme population: They had bona fide Lyme disease that would have been cured with early treatment. Instead of getting that treatment, they were diagnosed months or years too late. They were eventually treated for late stage Lyme disease in accordance with the Guidelines of the Infectious Diseases Society of America. And they failed the treatment.

Completing the community of patients covered by the meeting today are the coinfected—those with babesiosis, anaplasmosis, ehrlichiosis, or some other tick-borne infection. If you look at tick surveys from around the United States these diseases 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. 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.

As a group, these patients can be 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.

Unresolved Lyme and tick-borne disease can be a nightmare 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 --malingerers 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 early 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.

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 India for a black box therapy said to be based on stem cells. 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 has traumatized the patient community writ large.

No wonder patients are in such turmoil. The three largest patient advocacy organizations have staged a boycott of this forum because they say it is biased against them. To quote their press release, they "remain skeptical that the process will lead to a true understanding of the patients' needs." The history of the patient experience has robbed them of faith that anyone in government will understand their pain or address their plight. It has been almost 35 years since Polly Murray reported the strange set of symptoms in her town of Lyme to the Connecticut Department of Health. Back in 1976, Murray noted the loneliness of her journey, but decades later, new patients 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 classic Lyme disease, only to reap the whirlwind of late diagnosis and failed treatment—even in the most endemic areas of the United States.

In interviews with hundreds of these patients, I found that relapsing-remitting illness was an overriding hallmark of the chronic disease. Use of antibiotics was overwhelmingly the strategy patients preferred for fighting back, though which drug might work for which person was highly variable, suggesting a scenario that is outrageously complex. I myself had a relapsing-remitting illness. 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. Can we really dismiss this common experience as coincidence or a psychiatric disease?

I've heard it said that all Lyme patients want are more antibiotics, but that isn't true. Patients just want to get well, and any therapy that cures them would be embraced. No reasonable person would ever argue that the answer sought by future science should be endless antibiotic treatment for years on end—even if infection remains chronic at low level, as evidence suggests. To help these patients, medicine must acknowledge their pain. And science must deal with the complexity. Anyone who follows bioscience knows what’s happening out in Seattle, where the medical pioneer, Dr. Leroy Hood, is building data-driven P4 medicine --the personalized medicine of the future that any patient group this varied needs. As Dr. Ben Luft suggests, only a systems biology approach can target the full spectrum of infections, strains, and immune cascades for every patient involved.

We are long past the point where we can keep telling patients that they themselves are deluded because the science is state-of-the-art when, clearly, their diagnosis and treatment come from the century past. Yet hearing this bald assertion is part of the patient experience, too. Of course it gets them upset. We’ve all gotten stuck. We have academic scientists embroiled in a broad, dumbed-down fight with patients over the issue of chronicity while a revolution in bioscience has reframed the questions we need to ask.

I’ll end with a paraphrase of Tolstoy: Every early stage Lyme patient is pretty much the same, but each chronic patient takes a singular journey of one. For many years, this discomfiting fact has undermined the patient narrative. But with the advent of proteomics, genomics, and other 21st century tools, with greater powers of vision, the story told by bioscience and the story told by patients can finally converge.