Pediatric Lyme disease: over- or under-diagnosed?

Townsend Letter for Doctors and Patients, Nov, 2006 by Marcus A. Cohen

In July 2004, the Lyme Disease Association (LDA) published my book-length report Lyme Disease Update. One chapter digested studies in medical journals on the difficulties in diagnosing Lyme, and it contained case histories of children with persistent infection. Because symptoms of Lyme can mimic symptoms of numerous other conditions, doctors had first diagnosed a few of these children with look-alike illnesses. The Lyme Disease Update elsewhere referred to similar cases, where parents bumped into roadblocks in their search for doctors unafraid to diagnose and treat pediatric Lyme.

The main sources of these barriers? Some state medical boards, most insurers, and certain physicians, who regard Lyme disease as over-diagnosed generally. They watch MDs specializing in chronic Lyme, tracking the number of patients these MDs diagnose with Lyme and how often they prescribe long-term antibiotics to handle the infection.

Curious to know if the situation with long-term pediatric Lyme had improved lately, I interviewed Pat Smith, president of the LDA, and Sandy Berenbaum, LCSW, BCD, a psychotherapist practicing in Brewster, New York, who has counseled children with Lyme since 1991. The interview with Pat Smith pinpoints conditions still bedeviling the diagnosis and treatment of pediatric Lyme disease and supplies an overview of various problems faced by children with Lyme. This interview also concentrates on difficulties encountered by physicians specializing in pediatric Lyme and offers an overview of activities by patients and groups around the US directed at improving diagnosis and treatment. Sandy Berenbaum's interview looks at pediatric Lyme from the perspective of a therapist experienced in helping children and parents cope with the numerous treatment and developmental problems involved; that interview gives a dramatic close-up of these problems through case histories. My final question to Ms. Berenbaum prompted a longer than expected reply on the use of integrative approaches in Lyme disease treatment.

An Interview with Pat Smith

MAC: Ms Smith, have conditions improved for diagnosing and treating Lyme in children over the past few years? If not, what are the main obstacles to improvement?

PS: Conditions have not really improved since 2004. One of the main obstacles to improvement stems from the Centers for Disease Control and Prevention (CDC) surveillance criteria and the misuse of these criteria by physicians, medical boards, insurers, even schools. Surveillance criteria are developed as an epidemiological tool to be able to compare the numbers from one state to another. They are very narrow criteria so the CDC can compare "apples to apples." The CDC is able to see trends in disease with those small but solid numbers. Clinical criteria for diagnosis need to be broader to include cases that physicians determine are Lyme through examination, history-taking, exclusion of other illnesses, and testing, if necessary, as an adjunct. The CDC has clearly delineated this distinction between surveillance and clinical criteria on its website and in testimony. It recommends that physicians make a clinical diagnosis.

The CDC changed its surveillance criteria at a 1994 conference with the Association of State and Territorial Public Health Laboratory Directors in Dearborn, Michigan, implementing a two-step testing protocol: first, an ELISA test, then, if positive, a follow-up Western Blot (WB). But the ELISA is highly insensitive. It should not be used as an initial screening test because it misses too many adults and children infected with Lyme. The WB, a better tool, was watered down at Dearborn. Two bands were removed, bands 31 and 34; these are bands that chronic patients often express. Under the present criteria, for surveillance purposes, patients must have only five out of ten specific bands on IgG and two out of three on IgM (excluding bands 31 and 34) to be considered positive by the CDC.

Furthermore, CDC surveillance criteria require an erythema migrans rash or positive serology and major system involvement--cardiac, neurological, skeletal. But research indicates that the classic bull's eye may only occur 50-60% of the time. Sometimes no rash occurs, or a rash that has a different appearance entirely may manifest.

Obtaining positive serology with the ELISA is a real problem as well. Antibody formation is dependent upon the immune system of each adult and child, and experts say the best results are obtained four to 12 weeks after the bite. Since early diagnosis and treatment ensure a better outcome for Lyme patients, that length of treatment delay may cause more prolonged suffering for patients or lead to development of chronic disease. Additionally, as demonstrated in research, results may be negative because antibodies can be bound up with antigen in complexes, and ELISAs only test for free antibody. There is a process for separating complexes and then testing, but it is not commercially available. A related problem is that polymerase chain reaction (PCR) tests, which are sensitive enough to detect genetic material from the Lyme spirochetes, the spiral-shaped bacteria responsible for Lyme disease, are not accepted by the CDC in diagnosing Lyme. Some doctors do use these tests to aid in diagnosis, and PCR results that are positive for Lyme disease should count in diagnosis (although a negative PCR does not rule out disease). CDC does accept PCRs for other diseases, including pertussis.

special problems still confront parents with sick children?

PS: Families may face various pressures when their children are treated for Lyme disease. Divorce cases with custody disputes sometimes hinge on proving a child has chronic Lyme, and the "proof" usually sought is CDC surveillance criteria positive. The parent having the child treated, usually the mother, is taken to court, though the parent is only following orders from physicians providing treatment. The parent may then discover that the state's child protective services inject themselves into the case. Fortunately, guidelines for treatment by the International Lyme and Associated Diseases Society have evolved into a second standard of care, which can be used to support the child's treatment. Officials in a number of states, educated by Lyme groups about this issue, can sometimes intervene when baseless charges are made.

Parents also have problems in schools that don't want to accept a diagnosis of chronic Lyme. These schools try to have school-appointed doctors make a determination, or they force a parent to see a physician chosen by the school district, since they often do not want to pay for accommodations that students with chronic disease may require.

In another area, parents are experiencing difficulty with treatment-related expenses. Often, two or more children in a family have Lyme. This entails hardship in getting appropriate testing and treatment; parents may have no insurance or limited insurance that requires them to see only "network" physicians, most of whom don't treat Lyme disease. Addressing that problem, the LDA has created the LymeAid 4 Kids program, serving children nationwide, to provide evaluation and initial treatment.

MAC: How are physicians faring under current conditions?

PS: Treating physicians, of course, also encounter problems if CDC surveillance criteria are improperly used for diagnostic purposes or if only Infectious Diseases Society of America) guidelines for treatment are recognized. State medical boards continue to investigate and charge physicians for long-term antibiotic treatment of persistent Lyme. Doctors who deny the existence of chronic infection continue to testify against them. Some MDs have been successful in their quest to prove there are two standards of care. Others have not been so fortunate and have had to deal with the imposition of restrictions on their practices and even revocation of their licenses.

As a result, physicians willing to treat children for chronic Lyme disease are scarce in most states. The LDA doctor referral line and email had been receiving over 1,000 requests per month for physicians, forcing LDA to develop an automated system so parents and patients could readily access Lyme-literate physicians nationwide. In the saddest cases, families have packed up and driven or flown crosscountry to already crowded practices to access medical care for their children. The children are the unfortunate victims, their childhoods stolen by an insidious disease that few want to recognize, diagnose, treat, or accommodate in any way.

MAC: Can you pinpoint the chief reasons for continuation of a situation that clearly discourages better diagnosis and treatment of Lyme in children?

PS: Besides the lack of funding, which has prevented the development of more definitive diagnostic tests, diagnostic problems remain because physicians don't heed the CDC's warnings not to use surveillance criteria for diagnosis, a fact stated on the CDC website. The issue is further clouded by CDC's testing warning, which appears to further blur the distinction between surveillance and diagnostic criteria and seems to require the two-step protocol (ELISA+, followed by WB) for clinical diagnosis. Bottom line: many doctors use the overly strict surveillance criteria to diagnose, and they often expect their peers to do the same. Insurance companies are also improperly using the surveillance criteria to deny reimbursement for diagnosis and for treatment of Lyme disease--again, despite CDC's warnings on their website not to do so!

Lastly, IDSA guidelines only address early Lyme disease; thus, patients with chronic illness are completely shut out from treatment when these guidelines are the ones solely recognized. In a current adult example, an infectious disease doctor in a hospital shut off IV treatment after two weeks to a woman, not even his patient, who was finally beginning to experience relief from her neurological symptoms, because he disagreed with the treatment. This is appalling, since IDSA has not allowed input into their guideline development from either the International Lyme and Associated Diseases Society (ILADS), an organization of clinicians specializing in Lyme disease, or from the LDA, a national organization representing patient interest, though each organization has requested input.

MAC: Can you provide a quick overview of political action to improve conditions?

PS: Lyme groups are pulling together, many under the auspices of the LDA, which has chapters and affiliates nationwide. LDA and its Time for Lyme affiliate are now supplying private research monies to open an endowed center at Columbia to study chronic Lyme disease, the first of its kind in the world. The groups are $200,000 away from opening the center.

Since Lyme disease receives only 44% of the amount of government funding given to West Nile Virus, despite the fact Lyme has almost eight times more reported cases, LDA partners nationwide are working together to promote HR 3427 in the US House of Representatives and S 1479 in the US Senate. These bills will provide $100 million for research, education, prevention, and surveillance improvement for Lyme and other tick-borne diseases. The House version has 77 co-sponsors to date.

Lyme groups have also successfully initiated and helped pass legislation and policies in a number of states to protect doctors treating chronic Lyme disease and to provide mandatory insurance for testing and long-term therapy. Rhode Island has the most comprehensive laws protecting physicians and mandating insurance coverage for long-term treatment. California had a law prohibiting disciplinary action against physicians solely for using alternative and complementary medicine, and advocates were recently successful in having Lyme-treating physicians included. This law follows the lines of a New York policy statement issued by the Office of Professional Medical Conduct, allowing Lyme doctors the same latitude allowed other physicians who quoting the New York statement "use treatment modalities not universally accepted by the medical profession"; such MDs can't be charged solely on the basis of non-traditional therapy. New Jersey now has Lyme-literate doctors on its medical review board. Addressing inequalities in schools, New Jersey has passed a law requiring certain in-services for teachers who have pupils with Lyme according to state-adopted guidelines. New Jersey also has the only state-adopted curriculum guidelines for students with Lyme. Connecticut has a law that requires insurance payment within specified treatment limits and then requires cases to be reviewed by various specialists.

MC: Closing thoughts?

PS: The medical aspects of the disease have become eclipsed by the political ones. Many in the Lyme community share the opinion that vested interests and certain physicians and researchers who feel that Lyme disease is over-diagnosed and over-treated are hiding behind the very science they tout, science that is meant to work for people, not prevent them from getting well. Until science catches up to what, in the broadest sense, is reality for tens of thousands of victims--chronic Lyme disease--sick patients need to be allowed to receive whatever effective treatment is available. Lives are at stake, including the lives of many of our children.

An Interview with Sandy Berenbaum

MAC: Sandy Berenbaum, you've been counseling children with Lyme disease for 15 years. Where do these children live? Where is your practice located?

SB: Children with Lyme disease, and their parents, currently make up the bulk of my practice. A year and a half ago, after I moved my home to Connecticut, I moved my primary office from Wappingers Falls to Brewster, New York, on the Connecticut border. That move made it possible for more Connecticut families to see me. Though the majority of my clients come from Connecticut and New York, I have had clients come to see me from New Jersey and New Hampshire, and have had contact with parents of children with Lyme from other states around the country. As is true with Lyme-literate physicians, there is also a shortage of Lyme-literate psychotherapists, an area that calls for very specialized knowledge and skills.

MAC: Can you run through the main difficulties encountered by the children and parents you see? Can you put a finger on what primarily causes these difficulties?

SB: The main difficulty is that children with chronic Lyme are very ill, with a complex illness that affects each child in a different way, with no predictability regarding the course of the illness. These children often do not look sick, so they do not get the compassion from people around them that they would get if they had another major, debilitating illness. Some can identify and articulate their symptoms--severe headaches, stomachaches, inability to sleep, profound fatigue. But those kids who have severe cognitive deficits, or problems with concentration and attention, often can't put their finger on what's wrong, can't put it into words. They know they are out of step with their peers, but don't know why. This is very confusing and isolating for these kids.

The kids I see have chronic Lyme. To a large extent, it became chronic because they were not diagnosed early. It took years for some of them to find the right doctor to figure out what was wrong. Now the illness is pervasive and very difficult to treat. Unlike adults with chronic Lyme, many of the children can't remember what being well was like. Their parents don't know how the brains of their kids would have been functioning had they not gotten sick; they don't know what "normal" is for their child.

Aside from the difficulty with the illness itself and the isolation from their peers who are well, children with Lyme are very often misunderstood in school. Instead of recognizing that they have special needs and require entitlements afforded them by federal and state education and civil rights law, many schools accuse these kids of malingering and hurl accusations at their parents. In districts that are not Lyme-knowledgeable, school meetings can be a nightmare. Parents, often ill with Lyme themselves, have to obtain the services of advocates and attorneys in order to get the accommodations their children need. A major problem, then, for children suffering from Lyme disease is their struggle to get to school, stay in school, and not be worn down by the hostile environment that school can be for these children. I am a strong advocate of mandatory Lyme disease education in the schools, particularly in states where Lyme is endemic.

MAC: Drawing from your counseling experience, can you recall a few cases that illustrate the core problems in diagnosing and treating pediatric Lyme?

SB: The first case that comes to mind provides a dramatic example of what Lyme can do to children and parents, and what a Lyme-literate psychotherapist can do to aid in obtaining a diagnosis. A 15-year-old boy was brought to see me by his parents. He was refusing to go to school, and he was psychotic, paranoid about peers in the school environment. He had been an honors student, but his grades had plummeted. He was unable to sleep. His parents did not know what was wrong, and no doctor had identified a medical problem. His pediatrician had specifically denied Lyme, when the titer was negative. I suggested pursuing the question of Lyme further with a Lyme-literate doctor. The diagnosis was confirmed by clinical diagnosis, not blood test, and treatment began. Three days on antibiotics that crossed the blood-brain barrier, and his psychosis disappeared, but then joint pains began. He was very ill for years, on homebound instruction for a year-and-a-half, with support services from the local high school, which had a very compassionate principal. Returning to school, and eventually graduating from an excellent college, he went on to law school. His family doctor had been wrong in not diagnosing his Lyme disease. Those in his school who thought he was malingering, or a behavior problem, had been wrong as well. It was a long haul, but his parents' willingness to pursue answers got him there.

The next case exemplifies the unpredictability of this illness, particularly where co-infections are involved. A 15-year-old girl had been ill with Lyme and co-infections for many years when she started seeing me. A very bright, determined girl, she attempted to start school each year, on a reduced schedule. When her symptoms worsened, she would go back on homebound instruction. She worked very well with the home tutor when she was well enough, but there were weeks when she couldn't work at all. She had intractable daily headaches and problems sleeping, aside from other symptoms, which made life very difficult for her. A social girl, the isolation from her peers was particularly painful. Through counseling, she dealt with family issues as they arose, particularly her relationship with her sibling, also ill with Lyme with a different presentation of symptoms, which made for difficulties at times. A private person, who kept her feelings inside, she was able to talk about how frustrating the symptom flares and limitations on her functioning had become, rather than to bottle up those feelings. In the safe, therapeutic environment, she was also able to explore what she thought she could do in school without her Lyme worsening--to be a partner in planning an individualized school program and to come to accept accommodations--not easy for some children.

One comment here on the role of psychotherapy for children and families with Lyme disease: It is well known that a major illness in a family can put a heavy burden on a marriage. In families where children have chronic Lyme, it is not unusual for one parent to recognize the severity of the child's illness and press on to obtain an appropriate diagnosis and treatment plan, and the other parent to minimize it and think that the diagnosis is wrong or the treatment too extensive. Some may even not believe the complaints of the child, especially if extended family members or school officials express doubt. Family counseling, including parent counseling, can support the parents' marriage and make a profound difference in the atmosphere of a family facing a child's chronic Lyme disease.

My final example illustrates the problems that visible Lyme symptoms can produce for a child tic disorder, Bell's palsy, etc. It also touches on the nightmare school can be when the staff lacks understanding and respect for the child and the parents.

A boy, now 16, first came to me when he was ten-years-old. His primary symptoms at the time were anorexia and a motor tic, but he was able to attend school and do well academically. Assaulted on school grounds by a bully (an attack that left visible bruises throughout his body), the boy's Lyme symptoms worsened as the result of his physical and emotional trauma, and he was out of school for four years. His cognitive abilities and ability to concentrate significantly worsened, and he returned to school classified as a special education child, with an Individualized Education Plan, giving him support and accommodations. He was thrilled to be back in school, made friends easily, and was not a behavior problem at home or in school. Some teachers were wonderfully supportive, and the boy's level of learning and love for learning were superior in those classes. Other staff did not read his IEP; one of his teachers, not following the IEP directives, required the child to do work from which his IEP exempted him. This led to a grade lower than he deserved in that class, very upsetting for an academically motivated child. The boy was also penalized for failing to follow general sign-in instructions that were impossible for him to follow, given his organizational disabilities. He loved being back in school, but was deeply affected by the hostile environment school had become for him.

MAC: Long-term antibiotics are usually prescribed in cases of chronic Lyme for children and adults. Do you know of instances where integrative therapy has been tried?

SB: Many of my clients are treated by physicians who practice integrative medicine and are open to collaborating with other professionals. It is common for nutritional supplements to be used, together with traditional antimicrobial medications. Some physicians have incorporated the use of Chinese herbs as adjunctive treatment, and some Lyme-literate physicians have found that the combined effect of chronic Lyme and co-infections on the immune system makes patients more vulnerable to other conditions, calling for other types of treatments, for example, addressing heavy metal toxicity. I've spoken and written extensively about the need for a collaborative approach to treating chronic Lyme disease. One size does not fit all, and antibiotics are rarely enough in chronic Lyme. Psychotherapy and family therapy are very, very important for many children and families with this devastating illness, but other adjunctive therapies such as acupuncture, nutrition counseling, and hyperbaric oxygen have been helpful as well.

New Developments at Columbia University and the CDC

In my interview with Pat Smith, she referred to fundraising for an endowed chronic Lyme disease research center at Columbia University, the first of its kind in the world. The director is slated to be Brian Fallon, MD, Columbia University College of Physicians and Surgeons. This winter, I'll interview him for a Townsend Letter column, seeking his projections on how the center will operate and on its priorities in investigating Lyme disease. I'll also interview Pat Smith again. In July, the LDA obtained a meeting with the CDC director and high-ranking CDC staff in Washington, DC. The host was Congressman Christopher Smith. The agenda covered major problems in Lyme disease, foremost among them the rising number of Lyme cases nationally; chronic Lyme and the difficulties in getting prompt and adequate treatment; lack of funds to deepen scientific understanding of Lyme disease; and the need to increase public awareness of Lyme's impact on Americans. This column will report, too, on developments from the LDA-CDC meeting.

by Marcus A. Cohen