by Terri Reiser

(Editor's note: Terri shares her journey from a diagnosis of Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) to a diagnosis of Lyme disease. An interview with her Lyme disease specialist follows.)

About nine years ago I began to experience symptoms that I now know fit the profile for Lyme disease. I was working and living in Germany and had been for several years. I lived in a rural area and spent a lot of time outside hiking and walking my dog. I had a very stressful job and *ju st thought that the symptoms I had were due to stress*
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I was constantly feeling as if I had the flu. I would run low-grade temperatures, and by the last year I was there I had profound fatigue, frequent headaches, severe panic attacks and what I now know is Bell's palsy. My husband and I also went through several miscarriages. By the time I had resigned my position, I could barely make arrangements to fly home to Florida. I was also soon pregnant with my daughter. (A year after she was born, I found myself divorced.) I thought that a climate change would solve some of the stressful problems that I had. My daughter and I moved up here to Cape Cod, where we have been for the past 7 years. I was lucky to find a terrific family physician, Dr. Barry Conant. I did not know that he and his family nurse practitioner, Beth McGarry, would become so important to my little family.

Over the course of the next few years I continued to experience more and more symptoms of fatigue, joint and knee pain, and headaches. I did have sinus surgery for sinus disease and a deviated septum that was expected to cure the problem. It has helped my sinuses, but my other symptoms got worse after the surgery. I never really recovered from it and became very ill. My fatigue was overwhelming. I began the usual regimen of cures—yeast-free diet, mega-vitamin therapy, increased salt, more rest, more exercise, less exercise, melatonin. *You all know the hoops we jump through*
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I was tested right away for Lyme disease. In fact, I was tested throughout the next several years a total of 7 times. All the tests were for Lyme titers, and all were negative. Three different physicians diagnosed me with CFIDS/ME. I also was continuing to suffer from sinus infections and began to notice that when I was put on a regimen of Zithromax or Doxycycline or Biaxin, that by the end often in fourteen days, I felt better. The fog lifted. After several cycles of this, my doctor continued to keep me on Biaxin.

During the following year, I continued to slowly improve. I never told my doctor how bad my symptoms actually had been. I was just too afraid. I had such intense weakness and muscle spasms that I would fall down. One of the most frightening events was during a time when I had gone off medication**.** *I pulled a hot frying pan out of the oven with my bare hands, warned my daughter not to touch it, and then moved it to the back burner. I did not feel the burn*
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I then resumed taking Biaxin, and soon improved, only to have to go off of it for some other treatment. I hit bottom quickly. Within five days I was unable to get out of bed, I was unaware of being awake or asleep, and I had hallucinations. I called my doctor, who put me back on the Biaxin and told me he thought I had Lyme disease. I could not believe that I did, as I had never pulled a tick off of me or had a bull's-eye rash. I did not know that the symptoms I was experiencing were those of Lyme disease.

I was then referred to a Lyme disease specialist, Dr. Donta, and he ordered a Western-blot test and brain SPECT. Before the results were in, which were overwhelmingly positive, Dr. Donta made a clinical diagnosis of Lyme disease and added Plaquenil to the Biaxin. *At that point I experienced what is called a Jarisch-Herxheimer reaction, when you feel worse before you get better.* I was then in bed for two weeks in a lot of pain, but woke up one day and felt great for the next three weeks. I was able to travel to Florida and I was even able to do most of the driving. After a hike, my daughter and I each picked off five or six deer ticks off our clothing. By this time I was well aware that spraying with a good tick spray containing DEET is essential, along with other protective measures to repel ticks. I now have tick spray available wherever we go. I make sure our cat is treated to prevent ticks being brought into the home and also so he won't get Lyme disease.

After a few months of treatment, I began to feel much better and kept getting better. During this time I realized that my daughter had been complaining of knee pain, and light sensitivity, was sick with sinus infections and sore throats, and was emotionally unable to handle much stress. During our first few years on the Cape there had been several deer ticks removed from her and she was given a prophylactic course of antibiotics. We now know that this short treatment is usually not going to take care of Lyme disease. She is now under longer-term treatment for Lyme disease and is doing much better with a reduced school day, compliance in taking her medications, and more rest.

I continued the antibiotic and Plaquenil therapy for a year, at which time some symptoms that had disappeared returned. I did not experience the usual cyclical improvement and worsening of symptoms. At this point Dr. Donta changed my medication to tetracycline and I experienced another Herxheimer reaction that lasted about six weeks. Again, I woke up a few Saturdays ago and have felt pretty good since then.

I had to make changes in my lifestyle when I became ill and have had to continue to make changes. I know what I can do, how much of it I can do, and I work with a therapist to deal with illness-management issues. I am now a member of the human race again, but not the superwoman I was many years ago. With that change has come a great understanding and appreciation for people with CFIDS/ME, Lyme disease, Fibromyalgia (FM), and brain injuries and infections. We all share so many of the same symptoms. We all have to go through such a trial, and we have no dream team to represent us. If we are lucky, we find a physician who takes the time to become "Lyme literate." Such was the good fortune that I have had.

I thought it would be a good idea for people with CFIDS (PWCs) to have correct and accurate testing done for Lyme disease, so I interviewed Dr. Donta (see interview below). If you have not had a Western-blot test done, you should. Keep an open mind, use the resources listed, and go for one more test. I had almost every single symptom of CFIDS/ME that I ever read or heard about, yet I found out I have Lyme disease.

P.S. I wish all of us good luck in our treatments and in our outlook for the future. I *believe there is a specialness about us beyond our illnesses*
, and we have to discover what that is and hang on tight to it. Whether it is your talent, your parenting, your faith or your ability to help another, use that to hang on. When I hit bottom again, and I will, I will read this paragraph, and hope that this information will help someone. I want to thank my healthcare professionals and their staff for all of their help, time and patience not only for myself, but for all of us with these particular health issues.

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Interview by Terri Reiser with SAM T. DONTA, M.D.

(Infectious Diseases and Biomolecular Medicine, Boston University Medical Center Professor of Medicine, Boston University School of Medicine)

Q: *Dr. Donta, would you please tell about your creden-tials and describe your interest and work with Lyme dis-ease?*

A: I have been an infectious-disease specialist for about thirty years now. I was head of infectious disease at the University of Iowa and at the University of Connecticut. I moved here for geographical reasons and continued my work in infectious diseases, including Lyme disease. We have been investigating toxins and the bacteria of Lyme disease. We have a toxin that we have isolated now that we're interested to see if it has anything to do with Lyme disease. I believe that if we can bring together our basic research with our clinical research that maybe we can advance the field significantly further.

Q: *What tests do you rely on to make a diagnosis and what other factors do you consider in making a diagno-sis?*

A: Lyme disease is still largely a clinical diagnosis that depends on a complex of symptoms, the most major of which are fatigue, musculoskeletal symptoms such as pains, shooting pains, joint pains, muscle pains and other, what I call, pure neurological symptoms and signs such as numbness, tingling, memory dysfunction, forgetfulness, mood disorders and a number of other

neurological signs such as headache. Additional symp-toms can include palpitations, skipping heartbeats, rapid heartbeats, dizziness, eye blurring, ear ringing or humming, urinary frequency, and irritable bowel. There is a whole complex of symptoms that by themselves don't give you much of a clue, but when you put them all together are diagnostic.

Now, one of the problems is that this group of symptoms can be interpreted to be due to other diseases that I call "Lyme-like" diseases such as fibromyalgia, chronic fatigue syndrome and, if you served in the Per-sian Gulf, Gulf War illness which is an identical multi--symptom illness. I think that the exciting and interest-ing thing is that we are faced with a group of disorders now that have similar symptoms and they should be telling us something about what is going on. If we can only get past the credibility issue and move to figuring out why patients have these illnesses then we would all be better off.

Q: *Which labs do you recommend that patients ask their doctors to send blood work to for determination of Lyme disease?*

A: Regarding Lyme disease, *the best test available now is the Lyme Western-blot*, though it is an indirect test.
It is one in which you use two different antibod-ies, that is the IgM antibody as well as the IgG anti-body
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to look for reactions. This technique basically spreads out the proteins of the bacteria so that you can see individual reactions by your immune system against these bacterial proteins. Some reactions are highly spe-cific for Lyme disease, that is we don't think anything else can cause that, and it tells us that you have been exposed to and infected by the Lyme bacteria. Other reactions may be common to other bacteria and you cannot use that to say that you do or you don't have Lyme disease. The CDC recommendation is to have a two-tiered system of testing where you just do a titer (Lyme titer blood test) and then you follow it with a Western-blot only if the titer is positive. This unfortu-nately was a very poor decision and is inaccurate be-cause *the titer test is negative in over 70 % of cases*
, in my experience, which have a positive Western -blot test. The Western-blot still misses 20% of peo-pie who have Lyme disease. There is no other way, there is no culture method that is 100% reliable and the PCR-DNA method is just not sensitive enough, proba-bly because these bacteria are hiding inside cells and they are not destroying those cells and coming out into the open. So between the Western-blot, and the PCR-DNA testing, which is not very sensitive, we don't have many good laboratory tools.

There is a brain SPECT scan that I have been us-ing to see if there were changes typical of

Lyme dis-ease, which is to the temporal lobe and the frontal lobe although it can be to other areas as well. As far as that specificity, you can't use that to say, "That proves it's Lyme." It is like anything else in law and medicine, there is circumstantial evidence. So even with a positive Western-blot, that does not prove that your symptoms are actually due to Lyme disease, but it's compatible with it. When the Western-blot is positive in chronic disease, frequently it is the IgM that is positive, show-ing activity and this is interesting because IgM tradi-tionally had been thought to be a sign of *early* response to disease. But we have learned now, over the last ten to twenty years, that when you have a disease reactivate, that sometimes the IgM can come up again. I use this to follow patients that have IgM positivity to see if they are getting better, especially if clinically they're not get-ting better . *If we see the IgM getting better, that's a clue that we are making progress even though clini-cally it hasn't quite caught up with it yet.*
The SPECT scan also is something that you can repeat and it shows reversible changes, that is it comes back to normal. and that is a heartening sign about Lyme disease in that things are generally reversible.

Q: *In your estimation, what percentage of CFIDS or CFS patients actually have Lyme disease, and are you concerned about the number of patients who are in-fected with Lyme disease and not being treated?*

A: Regarding the issue of patients who have fibromyal-gia (PM) or CFS and how many of those have Lyme disease, I have not done an assessment of patients who have CFS to see what proportions of those have posi-tive Western-blots. A lot of those questions have been asked, but researchers have used the titers, for example, or a Western-blot technology, where the diagnosis can be missed, especially in this part of the state, where the one and only company does not do an IgM blot but only does an IgG blot.

So 1 think that we need to re-ask this question of the CFS patient and to screen patients from various parts of the United States with a Lyme disease Western-blot, recognizing the limitations of the blot as I have said before, to see how many of those have Lyme disease. I would say that if you have CFS or FM and you have prominent musculoskeletal symptoms and memory dysfunction and you live in an endemic area like here in the Northeast, or the mid-Atlantic states, that *operationally* you are better off being considered as if having Lyme disease. At least you have a chance of a definitive treatment and perhaps even cure with the antibiotic treatment as opposed to relying totally on symptomatic relief, exercise programs, and cognitive behavioral therapies to try and improve your control of the disease. This is not to belittle those symptomatic relief programs, but they don't get at the underlying cause.

Q: *What percentage of patients exhibit the classic signs of Lyme disease, such as a bull's-eye rash, after being bitten by a deer tick carrying the spirochete that causes Lyme disease? What happens in the process of con-tracting the bacteria from the deer tick?*

A: As far as the number of patients with Lyme disease who have a tick bite or a rash, those estimates are un-clear in my studies. About a third knew they had a deer-tick bite and about a third had a rash they thought was an unusual rash. The recent vaccine studies by Smith-Kline clearly show that half the patients who have rashes do not have a typical rash, and those are culture proven Lyme disease bacteria. So we have to get away from the idea that Lyme disease rashes are always bull's-eye rashes and are always big, because that is not the case. Once the tick has bitten the person and the bacteria have entered the body, you don't know which ticks are infected and which one is going to re-sult in persistent infection. Those bacteria enter the bloodstream and can stay around in the blood stream for a while, but then rapidly find their hiding place, which is probably in the nervous system along the spinal routes and the sensory ganglia as well as in the brain, probably the temporal and frontal lobes. Whether they go to other places like the peripheral nerve endings in the skin or whether they actually go to joint tissue itself, or if it's the nerves going to the joint tissue is unclear, but it certainly is a neurologic disease and not the rheumatologic disease that it was once thought to be.

Q: *What is your usual recommendation for treatment as far as choice of drugs and duration of treatment?*

A: The treatment of Lyme disease is basically antibi-otics at this point and it has to be the right antibiotics, not just sensitive by the test tube but probably antibi-otics that can get inside cells. The major ones that do that, or the only ones, are the tetracyclines. Doxycycline and Minocycline are the types of tetracycline. I prefer the old-fashioned tetracycline compound itself because it is a higher dose, less protein-bound and in clinical expe-rience appears to be more effective. The alternative is to use one of the erythromycin drugs. The newer ones are Clarithromycin, called Biaxin, and Azithromycin or Zithromax. They are more tolerable than the ery-thromycins, have high activity against the bacteria in the test tube and get inside cells. Now interestingly enough, once it gets inside cells the journey is not completed be-cause if these bacteria are living in an acid compart-ment, as I believe these bacteria are, then the ery-thromycin group doesn't seem to work as well in acid. I have taken to using a quinine drug (trade name Plaquenil, chemical name hydroxychlorquin) that has been used effectively for years for treating rheumatoid arthritis or lupus for reasons that aren't exactly understood. This does change the pH and acidity inside cells to allow the erythromycin type antibiotic to work more effectively.

I have found in clinical practice over the past five years that this is an effective and nicely tolerated regi-men when you take it twice a day with food. The treat-ment duration is a key issue. Not only does it take a longer time to start having a response with treatment for Lyme disease, but it takes a minimum period of a number of months to get a good effective response. So if you concluded that one month of treatment was enough, you would be missing the boat. Usually we call it a three-month trial to even see if you *start* to get better, and once you start getting better we keep go-ing until you are all better, or until you reach a plateau and then we change you to another treatment program. Usually if you have been sick for more than a year, you need about a year and a half of antibiotic treatment ro-tating between one type of antibiotic and then another.

Regarding patients with CFS and how those symp-toms can mimic those of Lyme disease, as far as 1 know they are identical to Lyme so I can't tell one from the other. So are we facing a series of multi-symptom ill-nesses, some of which are Lyme disease and some of which are not Lyme disease? I suspect that there are other diseases besides Lyme that cause a Lyme-like ill-ness. Until we can discover those I don't know how to approach them, because if they are viruses they won't respond to antibiotics, but if they are Lyme or Lyme--like bacteria they will respond to certain antibiotics. That is why I would encourage people with CFS to ap-proach the possibility that they have Lyme disease.

Q: *What can a patient do who would like to be tested using your criteria? I understand that some people have a very difficult time finding a physician who will use the labs that you recommend.*

A: Regarding issues of HMO and primary-care physi-cians: if they are not willing to recommend referral to somebody who is more Lyme-literate then that becomes a problem. You can go through appeals and success-fully ask for a referral to somebody who knows more about Lyme disease. That physician may or may not be an infectious-disease physician, but there are also un-fortunately few physicians who are aware of the chronic Lyme-disease state.

As far as laboratory testing there are several labo-ratories that are probably adequate. The one I use is BBI North American Labs. (Their number is 1-800--866-6254.) Igenex in California does a very good Western-blot, and Cambridge Biotech also does a good Western-blot. Those are the main laboratories that are contracted with by organizations to do a
partial
blot so one would have to be aware of those possible limita-tions. (You want a full Western-blot) Keep in mind, a negative test doesn't exclude Lyme disease and a posi-tive test does not prove Lyme.

An Editorial Postscript on Lyme Diagnosis and Treatment

by Ken Casanova

Consideration should be given to whether a "CFIDS/ME" or "FM" Western-blot-*negative* patient has had prior tick exposure.

Anyone ill with Lyme disease for 1 to 2 months has progressed to a *chronic* Lyme-disease state. Antibi-otic treatment for chronic Lyme involves oral antibiotic therapy for 4 to 6 months; for more seriously ill pa-tients, or patients ill beyond one year. Dr. Joseph Bur-rascano, Jr. (another Lyme-disease expert), recom-mends intravenous antibiotics for 6 to 10 weeks or longer, followed by oral treatment or intramuscular in-
jections for many weeks or months
thereafter.

Because of the potential length and intensity of this treatment regime, it is sensible, to the extent possible, to try first to determine whether or not patients really have Lyme before committing them to treatment on an "operational" basis. There are other tests besides the Western-blot. According to Dr. Burrascano, "Antigen tests including PCR are now available... sensitivity re-mains poor, possibly less than 30%.. . Therefore, multi-ple specimens must be collected to increase yield..." There is also a Lyme Urine Antigen Test. Moreover, in a chapter from his new book, *The New Lyme Disease: Diagnostic Hints and Treatment Guidelines for Tick--Borne Illnesses,* Dr. Burrascano lists a series of fac-tors, signs, symptoms, and laboratory tests, that-—when evaluated together—can indicate the presence of Lyme as "Highly Likely," "Possible," or "Unlikely."

A patient should spend some time educating himself or herself on diagnostic methods, treatments, and who are the most experienced Lyme clinicians, based in part on their use of the most current diagnostic and treatment approaches.

You can obtain Dr. Burrascano's chapter men-tioned above, on the net at http://www.lymenet.org/. Also, here in Massachusetts, you may contact the Massachusetts Lyme Disease Coalition, P.O. Box 1916, Mash-pee, MA 02649, 1-508-563-7033, for further informa-tion.