



American protestors make their statement in front of the White House. Photo courtesy by Paul Mall

It's Our Turn Now: World-Wide Lyme Protest

by Lisa Hilton

Worldwide Protest Organizer Charlotte Therese Björnström from Sweden, recalls, "I started the Worldwide Lyme Protest after struggling hard for over 25 years to get help. I was stubbornly denied any treatment for Chronic Lyme and several co-infections. When I realized how widespread the same "non-treatment situation" was, and for what reasons treatment was being refused, and how inaccurate the diagnostic tests that are available are, I thought it's about time to do something BIG to change this problem globally. It's time to end the suffering of millions of people with these illnesses and other diseases that originate from tick-borne pathogens. The idea for a global protest seemed to come right in time. It spread like wildfire on the world wide web."

With this idea in mind, several Lyme Disease activists from my country came together to organize a Worldwide Lyme Protest. There are now over 20 countries involved. The following is a brief list of what several of the countries are doing on May 10 and May 11th as part of the Worldwide Lyme Protest.

Germany's "OnLyme-Aktion.org" will be coordinating the protest in Germany's. They have gained thousands of supporters and a joint signatory for an open letter to the German health minister. This letter, including thousands of signatures, will be handed to our health authorities on May the 10th. We are going to invite the press to cover this hand-over.

On Saturday the 11th of May we have organized a

demonstration in Berlin and invited anyone that would like to help. Our protest march will start at 2pm towards the Brandenburg Gate where several Lyme literate MDs will hold closing speeches. Alongside the demonstration we will hold a letter campaign for all those who are unable to join for the demonstration in Berlin. These letters are sent to our national reference centre for Lyme Borreliosis in Munich, one of the strongest official deniers of chronic Lyme Disease amongst the German government agencies."

The UK protest will be held at Department of Health, in London on Friday 10th May, 2013. Please stop by their website for more details! <http://worldwide-lyme-protest.org.uk/>. Please take the time to sign their petition too. <http://www.ipetitions.com/petition/uklymepetition/>

In Norway the demonstration will be held outside the Norwegian parliament on May 10th at 12:00 pm. Jordan Fisher Smith, from "Under our Skin" will be speaking at the Norway protest.

In the United States there are several states in the WWP this first year. States having protest events include: Alabama, Arizona, California, Connecticut, Florida, Illinois, Iowa, Kansas, Maine, Maryland, Massachusetts, Michigan, Minnesota, New Hampshire, New York, North Carolina, Ohio, Tennessee, Texas, Vermont, Virginia, and Wisconsin.

These state have a rally, protest or some other events planned such as public info booths, guest speakers, and even "Tommy the

Tick" will make appearances to hand out tick brochures to children.

It's never too late for states that aren't listed to participate. We are encouraging states that don't have an event to make sure they participate in "Ribbons Across America" where you hang a lime green ribbon on your mailbox, tree or front porch or in the "Samantha's Green Light Project," which encourages people to change the light bulb on the front porch to green.

Australia is having several Lyme awareness events in different states including: New South Wales, Australian Capital Territory, Victoria, South Australia, Western Australia, Northern Territory, and Tasmania. Keep up on the latest Lyme Disease updates in Australia here: <http://worldwide-lymeprotestaustralia.weebly.com/index.html>.

These are just several countries involved in the Worldwide Protest. To find out more information please visit: <http://worldwide-lymediseaseprotest.blogspot.com/>

Our hope with this protest is that Lyme disease and other tick-borne infections become accepted as Chronic, debilitating, and possibly fatal diseases. With several countries across the globe coming together, we are hoping to get media attention and make the statement that Lyme disease is everywhere, and those who suffer are not going to go away. Please come join us in helping spread awareness.

Just as the AIDS patients had to do in the 80's, Lyme disease patients are going to have to lead the charge in their own advocacy efforts.

Worldwide Lyme Protest's Mission Statement:

Worldwide Patients are raising awareness and protesting to highlight the following needs:

1. Recognition that Lyme disease (borreliosis) and other tick-borne infections such as Babesia, Bartonella, Rickettsia, and Ehrlichia, are serious and sometimes fatal illnesses.

2. Agreement that Lyme disease (borreliosis) should be listed as a reportable infection globally. Infection rates (in countries that monitor) reveal that Lyme is one of the fastest spreading tick-borne diseases across their countries. The only way to truly understand the full impact of infection and begin to reduce the incidence levels is to monitor the growth rate.

3. Educate the healthcare community regarding the accurate diagnosis of Lyme disease, which in some cases is limited to clinical presentation due to limitations of serological testing. We seek to bring awareness of the CDC caution with regards to criteria for blood tests: "This surveillance case definition was developed for national reporting of Lyme disease; it is NOT appropriate for clinical diagnosis"

4. Educate the healthcare community that Lyme should be included as a differential diagnosis in other illnesses that have no known cause; these include, but are not limited to: Motor Neuron Disease (MND) also known as Lou Gehrig's disease or Amyotrophic lateral

sclerosis (ALS), Multiple Sclerosis, Alzheimer's, Fibromyalgia, Seizures, and Bells Palsy.

5. Educate the healthcare community regarding affordable and effective treatment of both acute and chronic Lyme disease along with other tick-borne infections. This includes the need to update the outdated and flawed IDSA treatment guidelines and take into account the scientific research/treatment methods of ILADS.

6. We seek independent funding for research into tick-borne diseases. This Includes: Medical research into accurate Lyme testing and treatment and research of vector and reservoir hosts to determine what diseases they may carry and transmit.

In Australia we are also asking for:

7. Australian Health departments to come in line with the rest of the world and acknowledge that Babesia is a disease that can affect humans as well as animals.

8. Acknowledgement and Awareness that bacteria such as borrelia and Babesia can survive in donated blood supplies and be passed on via blood transfusions.

We would like to thank National Capital Lyme Disease Association for all their support in the WWP! <http://www.natcaplyme.org/> and Empire State Lyme <http://www.empirestate-lymediseaseassociation.org/>

Tick Bite Prevention

by Laura Wild

The outdoors is a beautiful place, so make sure you are always aware that ticks can be anywhere. You can get a tick on you from from your pet, another person, walking in grass, gardens, going to your mailbox, or doing just about anything outside. Keep away from edge habitat. Edge habitat is the zone of land between the woods and your lawn. The Spring/Summer 2013 Tick season is expected to be one of the worst on record. To prevent being bitten, I suggest you follow the following prevention tips.

PROPERTY

Put up fences around your property and have your lawn professionally treated by tick control experts. Take down bird-feeders, yes they are pretty, but song-birds can be loaded with ticks.

Clear away all brush, wood piles, wood chips, kindling, weeds, leaves and lawnmower waste from your house and yard. If you need an area to dump lawnmower waste, make sure it is as far as possible from high traffic areas of your lawn. Have your home inspected for mice, rats, bats, raccoons, opossum, moles, spiders etc, make sure there are no entrance points to your house, especially vents, pipes, loose or broken shingles in basements and attics for these critters. Keep your grass regularly mowed and trimmed short.

To protect your yard: Damminix Tick Tubes [http://www.ticktubes.com/Damminix Tick Tubes are biodegradable, cardboard tubes filled with permethrin treated cotton balls.](http://www.ticktubes.com/Damminix_Tick_Tubes_are_biodegradable_cardboard_tubes_filled_with_permethrin_treated_cotton_balls)

CLOTHING

Permethrin is the preferred tick repellent. DEET does not repel ticks well, only mosquitoes. DO NOT PUT PERMETHRIN ON YOUR SKIN, CLOTHES ONLY! To order permethrin Google permethrin spray. Let the Permethrin treated clothes fully dry before wearing them. Try wearing knee high gore

tex gaiters (tan color so you can see the ticks) sprayed with permethrin. Wear hiking boots or sneakers (no sandals) with the gaiters over them sprayed with permethrin. Sandals are fine if you are staying on pavement, out running errands or by a pool, but NOT for grass or backyard BBQ's.

Wear light colored clothing, shirts, shorts, socks, shoes, and carry a lint roller with you for hard to see spots. Have a buddy tick-check you every few hours. When you get home, put all your clothes in the dryer on the highest heat setting possible for one hour. Do not walk through your home with the clothes you have worn outdoors, especially your socks and shoes. Consider using Rynoskin socks <http://www.rynoskin.com/shop.htm> or Bug Shirt Pants and Shirt (tan or light color) also sprayed with permethrin. <http://www.bugshirt.com/>

For the head: If you have long hair, braid it and tie it up in a Buff or under a hat (light colored.) Buy a magnifying glass and have a buddy check your scalp and hair after any possible exposure. Buff USA can be located at <http://www.buff.es/en/index.php?p=USA>.

If you can't tolerate the permethrin, you can try Natrapel, citronella like herbal insect prevention. There are various natural tick repellents available, but it is not known yet how effective they are so use caution. Check yourself constantly and stay on trails and out of tall grass or underbrush and leaf litter, don't let trees or plants brush up against you. Stick to water sports, or very well worn paths when hiking, just too risky to go in the woods in most places. Be careful at the beach too!

PETS

Many veterinarians are now prescribing Doxycycline (antibiotic) for dogs and cats who are frequently outside as a method of prevention for the summer tick season. Your animal will take the pills daily until the weather gets cooler. This helps prevent Lyme disease, but is not a sure thing so

please follow the additional tips as well.

Make sure you keep your pets hair groomed short for the summer. Check your pet every single time they come in from being outdoors with a tick comb, lint roller, and a magnifying glass. Call in the tick experts, and keep your pets protected! If you are going to be traveling, talk to your veterinarian about some prophylactic Doxycycline for your pet in case he/she gets bit by a tick.

Don't let pets on your furniture without checking them! Try using a lint roller on your pets fur and checking them with a pet comb. Consider getting the Invisible Fence or keeping your dog/cat in a contained area so they cannot go back and forth between your property and the woods. Keep your animal on a leash when they are not in your yard and stick to well worn paths. If you do Invisible fence, have the perimeter of the zone brought in at least 10 yards from the woods/edge habitat.

TICK BITES

If you find a tick attached, proper removal is very important. Do not attempt to burn the tick, smother it in vaseline, or alcohol, doing this will cause the tick to regurgitate the contents of its stomach into your body, thus making you sick. Please do not use your fingers to remove or dispose of the tick. We do not want you in contact with a potentially disease-carrying tick. Do not squeeze the tick with your fingers. The contents of the tick can transmit a myriad of diseases. Instead, use a sterile tweezer, and gently grasp the tick as close to the head as possible, and pull out the entire tick. Put the tick in a clean glass vial or jar with a blade of grass. Label the jar with the patients name, the date, and location of the tick bite. Have the tick identified by your local health department, or send the tick to IgeneX labs for testing.

TREATMENT

All known tick bites must be treated immediately. Do not wait for a rash to appear, because it often never will. It is also a myth

that a tick needs to be attached for 24 hours to transmit infections. If your family doctor tells you to "wait and see" if you get sick or develop a rash, my advice would be to RUN out of that office and find a good Lyme Literate Medical Doctor (LLMD) immediately. DO NOT WAIT! The best place to find a Lyme literate practitioner is either ILADS.org or the Tick Borne Disease Alliance at tbdalliance.org.

The usual treatment for a fresh tick bite is Doxycycline (or a similar oral therapy) 400 mg per day for 4-6 weeks. Keep a watchful eye out for any new symptoms appearing, and mark the date you were bitten by the tick on your calendar. One tick bite can infect you with multiple infections in addition to Lyme disease, so be very watchful of your health over the following weeks, and follow up with an International Lyme and Associated Diseases Society (ILADS) trained Lyme Literate Medical Doctor (LLMD) if your primary care doctor is uncooperative.

Remember, one tick bite can give you many other infections in addition to Lyme disease. Familiarize yourself with the terms babesiosis, ehrlichiosis, bartonella, Rocky Mountain spotted fever and tularemia. Arm yourself with knowledge, make sure it is the CORRECT information, and pass this on to your friends, family and community.

LYME DISEASE TREATMENT GUIDELINES

❖ To test a tick via IgeneX, check this info at <http://www.igenex.com/files/ticktest.pdf>

❖ For an ILADS Lyme doctor referral, go to: <http://tbdalliance.org/treatment/find-a-medical-professional>

❖ For the main ILADS site, go to: http://www.ilads.org/lyme_disease/about_lyme.html

Please be careful out there! Have a great summer, but please, don't get a tick bite!!

pha

Public Health Alert

The PHA is committed to researching and investigating Lyme Disease and other chronic illnesses in the United States. We have joined our forces with local and nationwide support group leaders. These groups include the chronic illnesses of Multiple Sclerosis, Lou Gehrig's Disease (ALS), Lupus, Chronic Fatigue, Fibromyalgia, Heart Disease, Cancer and various other illnesses of unknown origins.

PHA seeks to bring information and awareness about these illnesses to the public's attention. We seek to make sure that anyone struggling with these diseases has proper support emotionally, physically, spiritually and medically.

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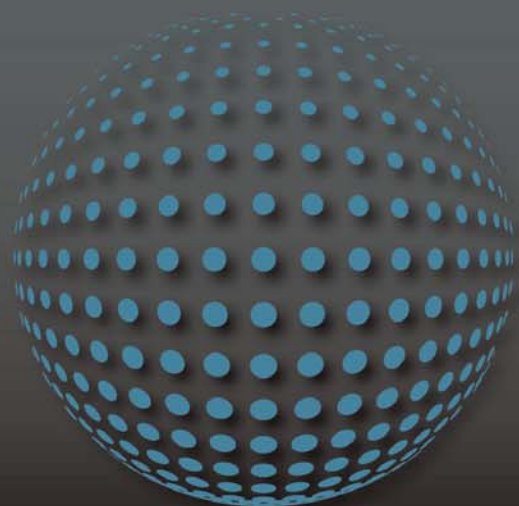
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A: They both do!

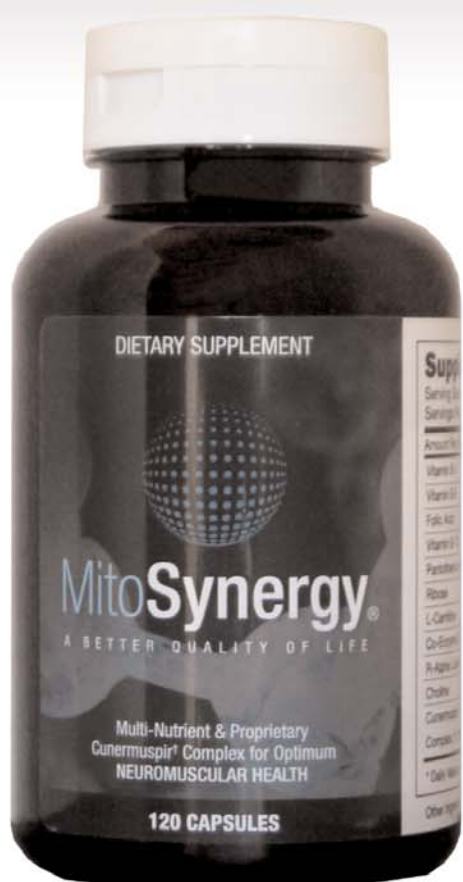
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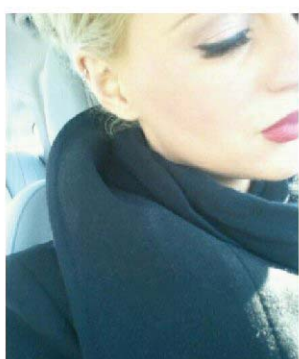
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Texas Woman Passes Lyme Disease to Her Children Via Pregnancy



by Shelley White

Oh, the number of debates surrounding Lyme. They are endless, and many are meaningless. There is one that is crucial to the health of children though, and that is the debate of whether or not you can pass Lyme to your child if you are infected while pregnant. People can waste time fighting about the subject all they want. What it really comes down to is the words of the women who have actually been pregnant while having Lyme. Today, Melinda Fulford from Texas is bravely speaking up about her personal experience on this topic by engaging in an interview with me. Melinda and her children have all been affected by Lyme, and she was infected with the disease before and during her pregnancies.

First of all, Melinda, thank you for speaking up about Lyme, especially about such an important issue. What has your personal experience been like with being pregnant while having Lyme disease?

You are welcome Shelley, glad I could help. Well, I guess I don't really know what it's like being pregnant without Lyme. Of course I went through the same symptoms as women without Lyme have like nausea, swollen feet/ankles, cravings and all, but I gained 50lb's with each child. I

think being overly exhausted was the thing that seemed to stand out for me. During both my pregnancies I had no idea about Lyme and just thought all women felt the same as I did when pregnant. After my 1st child (age 22) I never felt the same. I couldn't put my finger on what it was but I never felt quite like I did before the birth of baby number one. I'm not sure if women without Lyme feel this way, but it was a significant change for me. I never had the energy to play softball anymore, or do much strenuous physical exercise of any kind. My second pregnancy twelve years later was tougher on my body, but I attributed that to age. I knew it would be my last child, but I never knew what I was passing on to her. I had a friend at work that was pregnant the same time as I was and she had lots more energy than I did. She was younger and smaller than I, so I attributed it to that at the time. My first LLMD told me that pregnancy causes a relapse of symptoms, especially the actual birth. Maybe that's why they both wiped me out so much?

What does it feel like to have sick children? Although you had no clue you had Lyme disease while you were pregnant, I am sure you will agree that it is important for women who have Lyme disease, and want to have a baby, to know what it is like for a mother to see her children's health suffer as a direct result of having Lyme while pregnant.

It feels like their pain and unknown-future is my fault. My oldest has been fortunate to still function normally with the disease. My oldest daughter had some issues in high school with her joints and she was unable to do some of her cheerleading moves because of it, but for the most part she was and is functioning normally. She had a febrile

seizure when she was 10 months old due to high fever, but for the most part has been healthy. She has very poor vision though and has to use contacts to get it corrected fully. She can wear glasses, but her vision suffers for it. No one would ever guess she has Lyme. It is in her blood, but at least for now her immune system is able to control it.

My younger daughter hasn't been so fortunate. She has had many ear infections, two cases of pneumonia under the age of four, allergies and asthma; as well as some emotional issues at one point. Her positive IGENEX test didn't help us get treatment for her. She was very small, about three, when we all were tested and my LLMD at the time did not treat children. He gave us Dr. J as a referral, but after repeated attempts to contact him her primary care doctor gave up. After consulting with "experts" in the field, her doctor finally gave us 30 days of amoxicillin for it, and that supposed to take care of it. I really didn't think that would "take care" of it, but what else could I do? My first LLMD, Dr. H, believed that Lyme is passed to the child from an infected mother. He also believed it to be sexually transmitted. He said not right away, but with repeated exposure it will happen. My heart felt crushed. I had done this to my children. I had given them a disease that no one can say is cured for certain. How could this happen to us?

I am sure you have quite a strong and valid opinion on the debate surrounding this issue. Do you mind sharing that with us?

No I don't mind at all. I have had numerous doctors tell me that it is impossible to pass this disease that way. Well then I would like a plausible way to explain how both my children and myself have this disease. When you think about them being born

12 years apart, and the fact that one was born in Ft. Worth, TX and the other in Vernon, TX, and they both have this disease, how can you come to any other conclusion.

Unless you have lived it, how would you know? People are too ingrained into blindly believing anything the medical community puts out as fact. But when you think about it, they often change their minds about everything from how disease spreads to the food pyramid. There is research that supports Lyme being transferred from a mother to her baby during pregnancy, but they leave out that broader scope of research, and only show the research paid for and produced by the Infectious Disease Society of America (IDSA).

I also have a friend who believes it can be passed through breast feeding due to her own personal experience.

What do your children think of the situation, knowing that their health problems exist because you were infected while pregnant with them? To make it clear, you did not know you had Lyme while you were pregnant.

They both know that it was something that couldn't be helped. There has been some anger and resentment, but teens do that with a lot of things. At first I think it was easier for my oldest daughter to deny the disease. I mean if I didn't have it then it couldn't have been passed to her. She was afraid and with so many people already denying it, it was easier. I can understand that. She has since come around to believing me and asking some questions about what she should do if she gets sick.

My youngest was so very young that she knows nothing else but having the disease. She gets frustrated and angry about having to take so many medications

and about being in constant pain. She also gets headaches and the fatigue. She just wants to go do things like other kids, without the Lyme baggage. She doesn't blame me though. We have a pretty tight bond due to going through this mess together.

Actually, I think I've taken it the worst just due to the guilt and heaviness of heart I feel about their futures. I know they both wish it hadn't happened, but they understand that I would do anything to fix it if I could. They have a lot of compassion and empathy. I think they are grateful that they both can still walk and even run. Although it looms over them they try to just live life and enjoy their measure of health they have now. They both also know that I'm here to support them and help in any way I am able.

Knowing what you know now, what would be your advice to women with Lyme disease regarding pregnancy?

Of course I have 2 children, so for me I would not get pregnant. Adopt. If you feel you MUST have a child, please take antibiotics while you are pregnant and use a very good Lyme literate doctor to guide you through the pregnancy. (OR, just get a cat. Just kidding!)

Wow. Your story will most certainly help the women who read this article. Once again Melinda, thank you so much for offering your insight on this matter. Do you have any last words of wisdom or points you wish to add?

I certainly don't have answers to all this, but I can only tell you what I've been through and hope that it will help someone. Please take precautions if you have Lyme and want to have a baby of your own. It is a horrible feeling watching your *"Pregnancy" ... cont'd pg 7*

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What Psychiatrists Should Know About Lyme

Edited by ILADS

Psychiatrists:

Drs. Virginia T. Sherr and Debra J. Solomon

When Should a Psychiatrist Suspect Lyme Disease?

In a published study (Hajek et al, Am J Psychiatry 2002;159:297-301), one-third of psychiatric inpatients showed signs of past infection with the Lyme spirochete, *Borrelia burgdorferi*. The International Lyme and Associated Diseases Society (ILADS) has found that even severe neuropsychiatric behavioral symptoms in this population can often be reversed or ameliorated when antibiotics are used along with the indicated psychiatric treatments.

Don't miss this crucial diagnosis:

Patients with late-stage Lyme disease may present with a variety of neurological and psychiatric problems, ranging from mild to severe. These include cognitive losses such as memory impairment or loss ("brain fog"), dyslexia and word-finding problems, visual/spatial processing impairment (trouble finding things, getting lost), slowed processing of information, psychosis, seizures, violent

behavior, irritability, rage attacks / impulse dyscontrol, anxiety, depression, panic attacks, rapid mood swings that may mimic bipolarity (mania/depression), obsessive compulsive disorder (OCD), sleep disorders, attention deficit/hyperactivity disorder, (ADD/ADHD)-like syndrome, and Autism-like syndrome.

Lyme disease is one of the fastest growing infectious diseases in the nation. The Centers for Disease Control and Prevention (CDC) reported over 23,783 new cases in 2002, and the government agency estimates that the total number may be tenfold higher. The disease is caused by the bite of a deer tick infected with the *Borrelia burgdorferi* (Bb) spirochete and may be complicated by other parasites or coinfections. It is hard to diagnose because fewer than half of all Lyme patients recall a tick bite or develop the signature erythema migrans ("bullseye") rash. As a result, many patients go untreated and develop psychiatric and/or neurological symptoms.

Lyme disease sometimes begins as a flu-like illness accompanied by fever, headache, sore throat and joint pain. After infection, patients may develop cardiac or early neurological prob-

lems including meningitis, encephalitis and cranial neuropathies. Look for eyelid droop, facial weakness, numbness or pain, shoulder droop, sensory distortions or any other focal neurological signs. There may be a history of neck pain and stiffness or muscle twitching. Some patients may have arthritic symptoms in single or multiple joints. Most patients mention this to a psychiatrist only if directly asked.

At any time after a tick bite, patients may also exhibit cognitive symptoms such as memory and concentration impairments and word-finding difficulties, ADD/ADHD-like symptoms, learning disabilities, OCD, crying spells, rages, depression/bipolar disorder, panic/anxiety disorders and psychoses - all may be caused or exacerbated by Lyme disease.

Disorders of the nervous system have been found in 15 - 40% of late-stage (tertiary) Lyme patients (Caliendo et al, Psychosomatics 1995;36:69-74). When Lyme disease affects the brain, it is often referred to as Lyme neuroborreliosis or Lyme encephalopathy. Usually the patient is totally unaware of its presence.

Neuroborreliosis can mimic virtually any type of encephalopathy or psychiatric disorder and is often

compared to neurosyphilis. Both are caused by spirochetes, are multi-systemic, and can affect a patient neurologically, producing cognitive dysfunction and organic psychiatric illness. Such symptoms may be dormant, only surfacing years later. Dr. Brian Fallon, director of the Lyme Disease Research Program at Columbia University and principal investigator of the NIH-funded study of brain imaging and persistent Lyme disease, cites five questions that imply warning signs of possible Lyme encephalopathy:

* Are there markers of non-psychiatric disease such as erythema migrans rash, arthralgias or arthritis, myalgias, severe headaches, sound or light sensitivity, paresthesias, diffuse fasciculations, cardiac conduction defects, word finding problems, short-term memory loss, tremors, cranial neuropathies, and/or radicular or shooting pain?

* Is this psychiatric disorder atypical or unusual? For example, does a panic attack last longer than the expected 1/2 hour? Or is it a first-ever panic attack at age 50?

* Is there poor or paradoxical response or excessive side effect sensitivity to medications that are expected to

be helpful for particular psychiatric symptoms?

* Is this new-onset disease without psychological precipitants such as new stressors or secondary gain?

* Is there an absence of a personal history or family history of major psychiatric disturbances?

Negative answers to these questions do not rule out the presence of Lyme disease. But a "yes" to most of the questions, especially in a patient with an out-of-doors lifestyle or a pet, demands further clinical assessment. Dr. Fallon recommends Western blot serologic studies, lumbar puncture, neuropsychological testing, brain MRI and SPECT (single photon emission computerized tomography) scans. For more information, see www.columbia-lyme.org.

Other helpful tests may include PCR for *Borrelia burgdorferi* in blood, serum, cerebrospinal fluid (CSF) and urine, and/or *Borrelia* antigen testing in urine and CSF. Because blood tests at the top three general medical laboratories in the nation fail to detect 35% of Lyme antibodies, ILADS recommends use of laboratories that spe-

"Psychiatrists"... cont'd pg 7

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Cholestyramine

Of rising concern is a new theory regarding Lyme disease and its ability to produce a neurotoxin. This theory is headed by Dr. Shoemaker, a local doctor from Pocomoke, MD who has done extensive research in Lyme disease. He explains there is a neurotoxin released by *Borrelia burgdorferi* which the body may not be able to get rid of on its own.¹ He further explains the neurotoxin is able to persist in the body long after the bacteria.¹ This theory explains the many lasting symptoms Lyme patients suffer in chronic Lyme disease. This neurotoxin is responsible for many of the lasting symptoms patients experience including encephalopathy and inflammation. While the toxin cannot be directly measured as of yet, other biomarkers such as cytokine levels and hormone levels can be measured to characterize the effect of the biotoxin.^{1,4} Another test is termed a visual contrast sensitivity (VCS) test which can be used in the case of any biotoxin to measure the effect on the patient's vision.⁴

Many new treatments are being studied; and one such treatment which has shown great promise is Cholestyramine. This treatment is already being used by many patients and they are experiencing substantial improvements in their symptoms. The principal behind the mechanism is simple: sequester the toxin and excrete it. The human liver is naturally responsible for

removing toxins in our body. The Lyme toxin is shunted from the liver and released into the bile; but instead of it being excreted when we evacuate our bowels; it is instead reabsorbed in the intestines.¹ After, it is again transported through the hepatic system where it is recirculated to the bile and begins the cycle again.¹ This cycle could continue indefinitely all the while causing many symptoms. Cholestyramine has the ability to bind to the toxin and both are then excreted. Using cholestyramine on a daily basis depletes the toxin level at a dose-dependent rate.¹ Many see symptom improvement in 2-3 weeks.^{1,3}

Cholestyramine (Questran) available by prescription only was originally used to prevent the absorption of cholesterol, and more recently to help bind and remove the toxin produced in patients with *Clostridium difficile* infections.² Cholestyramine comes in a powder form which is mixed with a beverage of choice, soup, or other highly fluid food. It can be taken once daily up to four times a day.^{1,2} Since cholestyramine will bind to anything in the intestines, it should be taken at least one hour prior to any medication or vitamins, or four hours after.^{1,2}

Additionally, cholestyramine may prevent the absorption of fat soluble vitamins, so supplementing your diet with those is important.^{2,3} It is essential when taking cholestyramine, to increase fluid intake.^{1,2} The most frequent side effect



experienced is constipation which is generally mild and can be easily resolved with fluid intake or gentle laxatives.^{1,2} Welchol has a similar mechanism to that of cholestyramine, but is considerably less efficacious.³ Cholestyramine is widely available as a commercial product and as a compound from specialized pharmacies. Many patients have chosen to use the compound version as it does not contain the high sugar content and fillers which comprise the commercially available product.

With a low side effect profile, cholestyramine is a reasonable choice for patients not only suffering from chronic Lyme disease but any neurotoxin or biotoxin. Due to lack of financial interest from big pharmaceuticals, there are few human studies with Lyme disease on cholestyramine. The studies which have been performed

showed improvements in the Lyme patients in various aspects. This old drug may have just been given a new purpose which may prove key in chronic Lyme disease treatment.

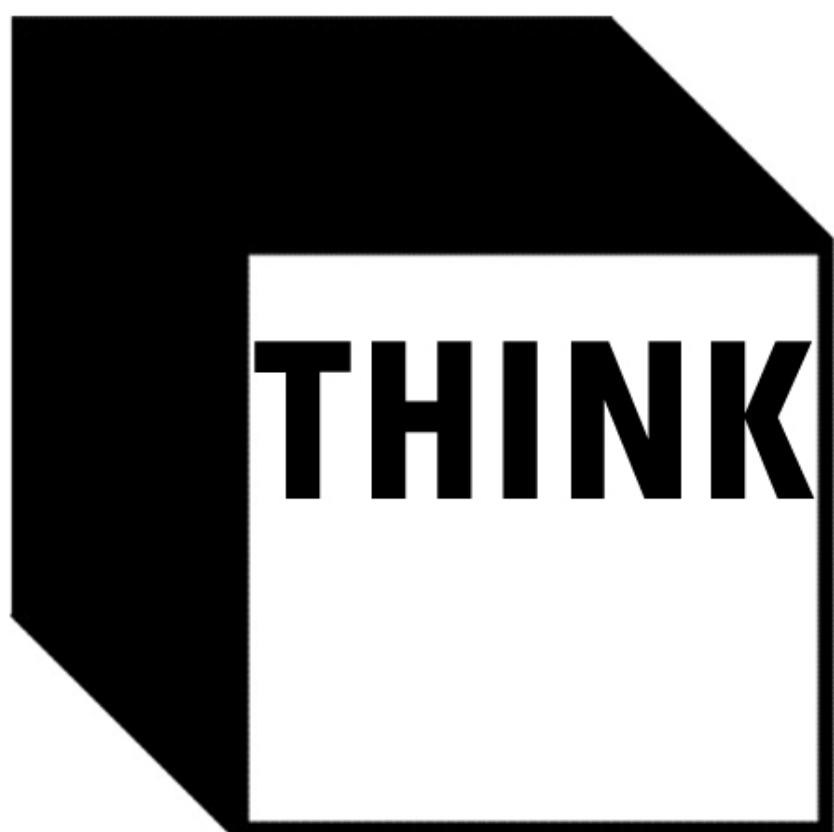
Cholestyramine is commercially available, however the sugar contained in this product may cause yeast overgrowth and will be detrimental to patients. We recommend that this medication be compounded so there are no unwanted additives such as sugar and artificial sweeteners.

Community Pharmacy compounds cholestyramine with xylitol and stevia (a natural plant sweetener). For more information on how Cholestyramine might be beneficial for you, call Community Compounding Pharmacy at 1-855-LymeRxS or send your inquiry to compounding specialist, Melissa Ruark at melissa@communitypharmacymd.com.

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1. Ryser, Carol Anne. *Borrelia (Lyme) Neurotoxin*. Health Centers of America. <http://www.healthcentersofamerica.com/information.cfm?id=146>.
2. Micromedex® Healthcare Series [Internet database]. Greenwood Village, Colo: Thomson Healthcare. Updated periodically.
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“Psychiatrists” ... con’t from pg 5

cialize in Lyme and other tick-borne illnesses.

Contact www.lymediseaseassociation.org for a listing of recommended labs. Blood tests should not be used to rule out Lyme disease when there is a strong clinical presentation. Dr. Robert Bransfield, a psychiatrist who specializes in infectious causes of neuropsychiatric illness, has developed a structured clinical interview to assess seronegative patients. See www.mentalhealthandillness.com

What to Do?

Screen patients for Lyme symptoms, especially those with complicated or atypical presentations. Be suspicious of Lyme if a patient mentions cognitive changes, extreme fatigue, weight changes, headaches, fibromyalgia, a history of "mono," "spider bites," multiple sclerosis, explosive rages or sudden mood swings. To elicit data about cognitive problems ask broad questions such as, "How do you think your brain is functioning?" or "How many things can you handle at one time?"

Consider Lyme disease in children with behavioral changes, fatigue, school phobias, academic problems, learning disabilities, headaches, sore throats, GI complaints and/or migrating pains. In teens, Lyme disease may be complicated by drug abuse.

The Lyme spirochete is slow growing and can be difficult to treat, so be sure the patient is treated with appropriate antibiotics for at least two to four weeks beyond symptom resolution. Most individuals with Lyme disease respond to antibi-

otics, but the treatment course is highly patient specific. ILADS has published evidence-based guidelines for the diagnosis and treatment of Lyme and associated tick-borne diseases (Expert Rev Anti-Infect Ther 2004;2(Suppl):S1-S13). For more information, visit the ILADS website at www.ilads.org.

Some of the common symptoms of late-stage (tertiary) Lyme disease and other tick-borne coinfections:

- * Profound fatigue
- * Chills, sweats and skin flushes
- * Night sweats
- * Migrating arthralgias
- * Muscle pains/twitching
- * Sleep disturbances
- * Severe headaches
- * Shifting neurologic pains
- * Tremors, shakiness
- * Numbness, tingling sensations, pain often shifting and unusual in type
- * Cranial nerve disturbance (Facial numbness, pain, tingling, paralysis, optic neuritis, trouble swallowing, distortion of smell or taste) See Category below.

The more severe neurological symptoms or disorders associated with late-stage Lyme disease:

- * Progressive dementias
- * Seizure disorders
- * Strokes
- * ALS-like syndrome (similar to Lou Gehrig's Disease)
- * Guillain-Barre-like syndrome
- * Multiple sclerosis-like syndrome
- * Parkinson's disease-like syndrome
- * Other extrapyramidal disorders
- * Visual disturbances or loss



Checklist of common cognitive impairments in Lyme disease (from Marian Rissenberg, Ph.D., clinical neuropsychologist)

Losses in fields of attention/executive functions such as inability to maintain divided or sustained attention, auditory and mental tracking and scanning, and memory retrieval can affect:

- * Memory functions (lost

items, missed appointments, retold stories)

- * Language functions (halting speech, disrupted participation in conversation)

- * Visual/Spatial Processing (Inability to find things, tendency to get lost, disorganization, difficulty reading, especially for enjoyment)

- * Abstract reasoning (Poor problem-solving/decision-making)

* Slowed processing speed (Familiar tasks take longer, can't follow conversations well).

Most or all of these impairments, if caused by neuroborreliosis, may improve with proper antibiotics combined with other appropriate symptomatic treatments.

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“Pregnancy” ...cont’d from pg 4

child suffer because they cannot physically or mentally do the things they want because of a disease you passed on to them. Watch the documentary 'Under Our Skin' so you can see more of what Lyme does to a child. There are more situations like mine in the film. I could have children in wheelchairs, with autism, or MANY other maladies that take away a normal life to a much greater degree. It's a very dangerous disease and depending on where the bacteria congregate, you are taking a huge risk. I have no choice but to take what comes at this point, but if you can keep your child from having to worry about how this bacteria will hit them next, make the choice save them from it. Thanks so much for taking the time to hear my story and I hope the best for everyone suffering from this disease.

Melinda was also kind enough to take the time to share her own personal health journey with Lyme disease.

When I was a child we

lived very close to Lake Texoma for a year or so and frequently found ticks on us, so I think I was about 8 years old when I got Lyme. We had no clue about Lyme disease at the time and just picked them off and never thought another thing about it. In certain seasons it was not uncommon to find several in a day. We did tick checks at night before baths. When my sister finally found a doctor who knew about Lyme, my mom, dad, sister and I were all tested; our tests were sent to the IGENEX lab. Everyone's test, except my mom's, came back positive for Lyme disease. This leads me to believe that we were all infected around the same time when I was young. My mother later tested positive as well.

For one thing, I believe I was bitten a second time by another tick that transmitted Lyme to me when I was in college at TWU. I had a bite show up on my upper leg/hip area. I thought it was probably a mosquito bite because it itched terribly. Then it got bigger and bigger and turned

into a rash. I went to the nurse practitioner on campus and she said it was shingles. Shingles? At 27? She gave me antiviral medication for it and it went away in about 3 weeks. Much later when I saw an ID doctor he believed that it wasn't shingles at all but the bull's eye rash from Lyme disease. He said the medication hadn't actually helped the rash. The rash had gone away on its own, since they only last around 3 weeks. This meant more bacteria for me. However, this information came much later than when I was pregnant, unfortunately.

After taking high dose IV Rocephin and oral Flagyl for four months I still was no better, so Dr. H said my case was too complicated and he just couldn't see me anymore. He was primarily a research doctor and was focused on that. He said I should find another doctor who could find out what was complicating my treatment. "Great," I thought. I went without a Lyme literate doctor for several years. I had to quit working and we filed bankruptcy, lost our home,

and were in a mess. I suffered through seeing local doctors that told me I'd never get any better, just worse. I was told I'd be in a wheelchair soon. I went to physical therapy, was misdiagnosed several times, got leg braces and pretty much just felt like things were never going to change.

After I got approved for disability I found a new doctor to see who accepted our insurance. My husband and I flew to PA to see him. He immediately put me on oral antibiotics and vitamins and supplements. I was so sick for a year, and then began to improve.

Meanwhile, my youngest began complaining of her legs hurting, headaches, and crying for no reason. She couldn't explain why she was upset. I asked my new doc if I could bring her for an assessment. He agreed and she tested positive on a regular western blot test (not from IGENEX) and was CDC positive. Her Lyme was hitting her hard. He began treating her too and every 3 months we both flew to PA to see him. Later we were able to just go every 6

months. Her immune function had improved significantly and she was feeling so much better. Mine, not so much.

Last year we quit going. We needed to get out of rent houses and have a home again. Due to that, we had no funds for traveling there. My daughter is still doing well, but has had several things that point to needing treatment again. I think I will always need treatment, to be honest. That is okay with me. I don't really care if I ever recover, I just hope with all my heart that both of my children will be able to function normally as long as they can without having this horrible disease take their lives over like it's done mine. If it were possible I'd take all their Lyme on myself. After all, I unwillingly shared it with them in the first place. I've had times of feeling guilty, time of feeling rage, times of sadness and pity, but mostly I feel blessed that they are still able to live their lives relatively free of any major complications of this disease. "

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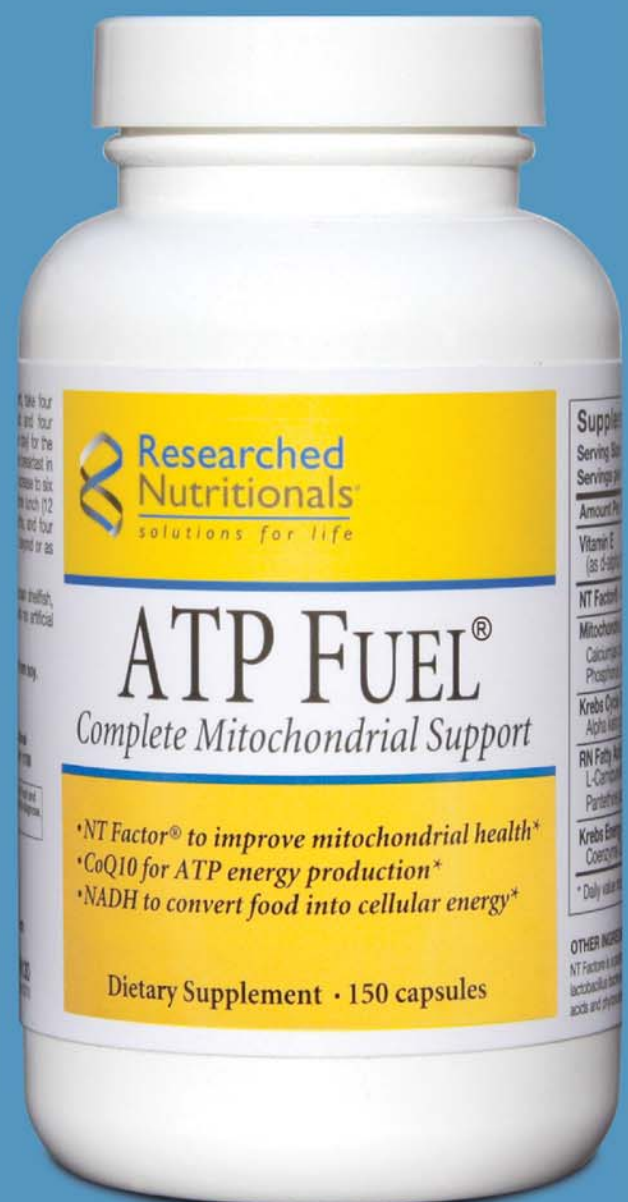
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