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

by Lisa Hilton

Worldwide Protest

Organizer Charlotte Therese Björström from Sweden, recalls, "I started 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 "Welt Lyme Aktion.org" will be coordinating the protest in Germany. 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 hand delivered to the German health authorities on May 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 who would like to help. Our protest march will start at 2pm downtown 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 Norwegian 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 midday.

It's never too late for states aren't invited 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 "Samuntha'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.lymeprotest.org.uk.

We 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 level 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 Bell’s 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 reservoir vectors 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.empirestatelymeseasassociation.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 from your pet, another person, walking in grass, gardening, going to your mailbox, or doing just about anything outside. Keep away from edge habitats. 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 songbirds are loaded with ticks.

Clear away brush, wood pile, wood chips, kindling, weeds, leaves and lawn refuse from your house and yard. If you need an area to dump lawnmower waste, it might be as far as possible from high traffic areas of your lawn. Have yard waste such as grass, fruit tree leaves, vines, mice, rats, bats, raccoons, opossum, moles, spiders etc., removed as soon as possible from your entrance points to your house, especially vents, piers, porches, and window shingles in basements and attics for these critters.

Keep your grass regularly mowed and trimmed short.

To protect your yard: Daminix Tick Tubes 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 dry fully before wearing them.

Try wearing knee high goe tex tights (tan color so you can see the ticks sprayed with permethrin. Wear hiking boots or sneakers (no sandals) with the goetiemms over them sprayed with permethrin. Sandals are fine if you are staying on pavement, out running or on a rocky trail but are NOT for grass or back yard 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 about 20 minutes, or as long as possible. This will help kill any that may have entered your yard.

For the head: If you have long hair, braid it and put 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 bought online at http://www.buffusa/en/index.php?

If you can't tolerate the permethrin, you can try Natrapel, citronella like get Nattapel, citronella like the tick on your calendar. Ticks like the woods. Keep a watchful eye on pets and check- ing 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.

If you are planning on hiking when they are not in your yard and stick to well worn paths. If you go off into the wild or have the perimeter of the yard brought in at least 10 yards to the woods/edge habitat.

TICK BITES

If you find a tick attached, proper removal is very important. Do not attempt to wriggle the tick, smother it in vinegar, 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 try 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 tweezers, and gently lift off the tick as close to the head as possible, and pull out entire body. If you are in a wooded area, clean brass var or jar with a blade of grass. Label the jar with the patient's name, the date, and location of the tick bite. Have the tick identified by your local health department, or send the tick to Igln quality labs for testing.

TREATMENT

All known tick bites must be treated immediately.

If you are sofa for a rash to appear, because it is not a new 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 10 days 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 pratician is to call the Tick Borne Disease Alliance at tbdalliance.org. The usual treatment for a fresh tick bite is Doxycycline (or a similar oral treatment) 100 mg per day for 4-6 weeks. Keep a watchful eye out for any new symp- toms 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) Lyme literate Medical Doctor (LLMD) if your primary care doctor does not feel comfortable. Remember, one tick bite can give you many other infections in addition to Lyme disease. Familiarize yourself with the terms babesiosis, cheliosis, har- tonella, 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 IgxEN, check this info at http://www.ingenex.com/files/ticktest.pdf

For an ILADS Lyme literate Medical Doctor, go to http://tbdalliance.org/treatment/find-a-medical-profes-sional.html

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!!

Q: Which one has Lyme Disease?

A: The child is far less likely to receive proper diagnosis and treatment from a knowledgeable doctor.

See www.txlida.org for more info
Please help Support Kim! She is so close to her goal of raising the needed funds for her Lyme disease treatment and medical expenses.

http://www.gofundme.com/1569z8

Kim’s dream is to become a doctor. Let’s join together and help her reach her goal.

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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 50lbs with each child. I think being overly exhausted was the thing that seemed to stand out the most. I was very sick during both my pregnancies. I had no idea about Lyme and just thought I was the same as I did when preg- nant. After my first 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 my second child. 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 me, but duringulated to that at the time. My first LLMD told me that pregnant women have a greater chance of getting symptoms, especially the actual birth. Maybe that’s why I had a touch wiped 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 tell me 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 preg- nant.

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 it, and one complaint is that her visual field is corrected fully. She can wear glasses, but her vision suff- fers 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 had many ear infec- tions, two cases of pneumo- nia under the age of four, allergies and asthma; as well as some emotional issues at one point. Her positive IGEMX test didn’t help us get treatment for her. She was very small, about three, when all we 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 con- sulting with him in the field, her doctor finally gave us 30 days of amoxicillin for her. I’m not supposed to take care of it, I really didn’t think that would “take care” of it. What else could we do? My first LLMD, Dr. H, believed that Lyme is passed to a child from an infected mother. He also believed it to be sexually transmitted. He said I had to take antibiotics 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 cure. How could this happen to us?

I am sure you have quite a strong and valid opinion on the debate sur- rounding this issue. Do you mind sharing that with me?

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 con- clusion.

Unless you have lived it, how would you know? People are too ingrained into blindly believing anything the medical community spouts 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 sup- ports 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 experi- ence.

What do your children think about the situation, knowing that their health problems exist because they were infected while pregnant with you?

They both know that it was something that couldn’t be helped. There has been some anger and resent- ment, 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 do things like other kids, with- out 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 I think 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 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 now know, what would be your advice to women with Lyme regarding pregnancy?

Of course I have 2 children, so for me I would not get pregnant. Adopt. If you feel like you MUST have a child, please take antibiotics while you are pregnant and future. I know they both wish it hadn’t happened, but I know they both also know I’m here to support them and help in any way I am able.

Wow. Your story will most certainly help the women who read this article. Once again Melinda, thank you for being 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 of it, 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 hor- rible feeling watching your “Pregnancy...” cont’d pg 7
When Should a Psychiatrist Suspect Lyme Disease?

In a published study (Hajej et al, Am J Psychiatry 2002;159:297-301), one-third of psychiatric inpa-
tients showed signs of past infection with the Lyme spirochete, Borrelia burgdor-
feri. The International Lyme and Associated Diseases Society (ILADS) has found that even severe neuropsy-
chiatric behavioral symptoms in this population can often be reversed or amelio-
rated when antibiotics are used along with the indicat-
ed psychiatric treatments.

Don’t miss this crucial diagnosis:

Patients with late-
tage Lyme disease may present with a variety of neurological and psychiatric problems, ranging from mild to severe. These include cog-
nitive losses such as memory impairment or loss (“brain fog”), dysesthesia and word-
finding problems, visual and spatial processing impairment (trouble finding things, getting lost), slowed process of information, psychosis, seizures, violent behavior, irritability, rage attacks / impulse dyscontrol, anxiety, depression, panic attacks, rapid mood swings that may mimic bipolarity (manic/depression), obses-
sive compulsive disorder (OCD), sleep disorders, attention deficit/hyperactivi-
ty disorder (ADD/ADHD)-
syndrome, and Autism-
spectrume.

Lyme disease is one of the fastest growing infec-
tious diseases in the nation. The Centers for Disease Control and Prevention (CDC) reported over 23,783 new cases in 2002, and the government agency esti-
mates 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 com-
plicated 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 psy-
chiatric and/or neurological symptoms.

Lyme disease sometimes begins as a flu-like ill-
ess. Common symptoms include headache, sore throat and joint pain. After infection, patients may develop cardiac or early neurological prob-
lems including meningitis, encephalitis and cranial neu-
ropathies. Look for eyelid drop, facial weakness, numbness or pain, shoulder drop, 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 atypical symptoms that are less common or occur in multiple joints. Most patients notice this to a psychiat-
trist only if directly asked.

At any time after a tick bite, patients may also exhibit cognitive symptoms such as memory and concentra-
tion impairments and word-finding difficulties, ADD/ADHD-like symp-
toms, 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 sys-
tem have been found in 15 -
48% 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 neuroborreliosis or Lyme encephalopathy. Usually the patient is totally unaware of its presence.

Neuroborreliosis can mimic virtually any type of encephalopathy or psychiat-
ric disorder and is often compared to neurosyphilis. Both are caused by spiro-
chletes, are multi-systemic, and can affect a patient neuro-
logically, producing cogni-
tive 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 imag-
ing and persistent Lyme dis-
case, cites five questions that imply warning signs of pos-
sible Lyme encephalopathy:

* Are there markers of non-
psychiatric disease such as syphilis or tuberculosis, myal-
gias, severe headaches, smell or light sensitivity, posterior cruciate ligament tears, cerebral conduction defects, word finding prob-
lems, short-term memory loss, tremors, cranial neu-
ropathies, and/or peculiar or shooting pain?

* Is this psychiatric disor-
der 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 paradoxi-
cal response or excessive side effect sensitivity to med-
ications that are expected to be helpful for particular psy-
chiatric symptoms?

* Is this new-onset disease without psychological pre-
cipitants, or do the patient present with delusions or paras-
ores 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 recom-

dends Western blot sero-
logistic studies, lumbar puncture, neuropsychological testing, brain MRI and SPECT (single photon emis-
sion computerized tomogra-
phy) scans. For more infor-
mation, see www.columbia-
lyme.org.

Other helpful tests may include PCR for Borrelia burgdorferi in blood, smooth muscles, 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 anti-
body positives, ILADS recommends use of both DNA and antigen.

“Psychiatrists... must use these etiologic clues to guide their diagnostic thinking,” says Dr. Fallon. “If the patient is not improving, then it is time to consider Lyme disease. If the patient is improving, then it is time to consider whether Lyme disease is being missed.”

For more information about Lyme disease, visit www.lyme.org.

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To contact us today!!

email: publichealthalert@yahoo.com

Contact us today!!

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The International Lyme and Associated Diseases Society (ILADS) has presented several conferences on Lyme disease since 1995. In 2002, the Society funded a 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 syphilis or tuberculosis, myalgias, severe headaches, smell or light sensitivity, posterior cruciate ligament tears, cerebral conduction defects, word finding problems, short-term memory loss, tremors, cranial neuropathies, and/or peculiar 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?

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For more information about Lyme disease, visit www.lyme.org.
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. He further explains the neurotoxin is able to persist in the body long after the bacteria. 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. Another test is termed a visual contrast sensitivity (VCS) test which can be used in the case of any sensitivity (VCS) test which can be measured to characterize the effect of the biotoxin. 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 recirculated to the bile and begins the cycle again. 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. Many see symptom improvement in 2-3 weeks.

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. 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. 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. Additionally, cholestyramine may prevent the absorption of fat soluble vitamins, so supplementing your diet with those is 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@communiphyarmacymd.com.

References:
child suffered because they cannot physically or mentally handle what they are going through 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 disabilities, or other 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 at a much greater risk. I have no choice but to take what comes at this point in time. I keep your child from having to worry about how this bacte- ria is spreading through your body and I keep the choice safe from them. 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, I lived very close to Lake Texoma for a year or so and frequently found ticks on me, 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 test results came back positive. IGENEX lab. Everyone's test, except my mom's, came much later than when I was treated 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, unfortunate- ly.

After taking high dose IV Rocephin and oral Flagyl for four months I still was not better, so Dr. H said my case was too complicated and he just couldn't see me any more. 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 doc- tor 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 never get any better, just worse. I was told I'd be in a wheelchair soon. I went to physical therapy, was misdi- agnosed 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 a combination of antibiotics and vitamins and supplements, I was so sick for a year, and then that both of my children were too. As long as they can without this terrible disease to take their lives over like it's done mine. If it was possible I'd take all of them Lyme on myself. After all, I unwill- ingly 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 rela- tively free of any major com- plications of this disease."

“Psychiatrists”... "cont' from pg 5

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