

Henry, Beverley

From: Jane Mills [clar teach@msn.com]

Sent: Wednesday, March 07, 2012 7:48 AM

To: PHC Testimony

I am responding to the state's request for public testimony regarding problems with Lyme testing and developing a State Lyme Task Force under House Bill 5335. I support improving Lyme Education and Research. I have well documented labs, which I have shared with doctors (and often saw their looks of amazement upon reading them) and the CT State Department of Health and am more than happy to share with you, which prove that my son, mother and I were infected with Lyme and co-infections but initially had negative labs due to the fact that multiple infections overwhelmed the immune system, which meant that our bodies could not fight the infections and therefore could not make antibodies to the Lyme or co-infections, so our labs were initially negative when tested for antibodies to Lyme, babesia and bartonella. I learned this from a well-respected researcher, and now have proof of it on our labs.

As we treated babesia (a cousin of malaria) that was only found on a research lab, Lyme bands started showing up and then we tested IGM positive on the Quest Western blot for Lyme because our bodies became stronger and could fight the Lyme, make the antibodies, and make the labs positive. Initially, as you will see if you care to read our story below, which I wrote several years ago, there were six of us all together who were sick who found each other due to the same mystery illness symptoms and 28 doctors tried to figure out why we were sick. These were brilliant doctors whose hands were tied due to initially negative labs.

Testing for Lyme, as well as co-infections, is hugely inadequate. One of the doctors we saw for my son, Dr. Krause, was quoted in the New York Times last spring as saying, "if you have Lyme and it is not being cured, suspect babesia." The NY Times article went on to indicate that babesia was being massively missed in the blood supply and that infants who had been given blood transfusions were dying due to not testing (or being able to test?) babesia in the blood supply.

Eva Sapi, from The University of New Haven, also tested ticks in 2008 for Lyme, and 90% of the ticks in the towns in CT where she collected ticks were positive for Lyme and 30% of the ticks tested were positive for babesia. The risk for Lyme and co-infections is clearly at epidemic proportions in CT when 90% of the ticks have Lyme and 30% babesia. When Lyme combines with babesia, it can be deadly. I hope that no other parent has to experience their child turning blue, as mine did, because he or she was infected with Lyme and babesia and it was not be detected. We were lucky, but others have not been that lucky. I went from having multiple negative labs, doctors who couldn't figure out why my entire family was sick, pain throughout my body, fatigue, night sweats, stabbing pains, twitching, and swollen joints, and almost losing my teaching career, to aggressively treating and now I am 98% well, have a renewed passion for teaching, as it was a passion that was almost taken away from me, and being successful once again in my teaching career.

Not only does testing for Lyme and co-infections need improvement, doctors need to be educated on the many symptoms of Lyme. At this point, there are at least ten people I know who I have shared that they had the same symptoms as mine or my son's prior to them finally getting a diagnosis of Lyme and/or co-infections from their doctor. A music teacher should not be able to recognize the symptoms of Lyme and co-infections before it is found by a doctor.

Please considered reading the full story below, which shows how easy even now it is for labs to miss Lyme and babesia and for doctors not to recognize the symptoms. We need better testing, better education, and a Lyme task force in Connecticut. Please let me know if you would like me to share our labs with you, which clearly demonstrate that typical Lyme, babesia and bartonella labs missed showing that we were infected. I have not had one doctor dispute this after reading our labs.

Sincerely,
Jane Mills

3/7/2012

Our story below was written about 4 years ago

History and Symptoms

My 7-year old son Stevie was the first of a series of ill people which would grow to include six people, 28 doctors searching to find the cause, and discussions with Alan Siniscalchi at the State Department of Health in Connecticut. When Stevie turned blue in gym class, my concern over finding the cause of his mysterious illness turned to desperation.

In the fall of 2005, when Stevie was in first grade, he all of a sudden started reacting to his low food allergies by bloating and feeling unwell. The fifth doctor we went to (after having gone to an allergist and other MDs with no successful answers) said it had to do with his gall bladder not working properly and he gave him choline and beta food and he was suddenly able to tolerate the low food allergies again. Why this happened had us perplexed, but it was soon forgotten I am not certain that this incidence relates to our "mystery illness" but I am adding this because sudden food allergies and intolerances have been claimed by others ill with the same illness that we ended up having.

Shortly after the holidays in 2006, Stevie came down with a high fever and flu symptoms. Three months of ear infections followed. I was relieved when his ear infections finally cleared, but one day shortly after they cleared on the way to school, Stevie yelled from the back seat, "I have a pain in my arm!" The pain appeared to be a cramp and it lasted 20 minutes! This was the start of his pains. Stevie would be in the middle of doing something, and then he would yell in pain. I would ask where the pain was and the answer was always different, a finger, a toe, his head.

We then went to several doctors who went above and beyond looking for answers, but they were unable to find them. Stevie complained of chest pain, and the doctors ran tests, but found nothing. Nobody could explain the cramps, difficulty concentrating and remembering, throat complaints, shooting pains, occasional nausea, and fatigue that would even cause him to nod off during school productions. I had noted that my son kept sweating at night and I wondered why I couldn't figure out how many blankets to put on him, but did not realize at the time that this was a symptom. I asked a few doctors at this point if my son could have co-infections since chronic Lyme was considered, and was told that his symptoms didn't match for the co-infections (I assume now that this conclusion came from what they had been taught about these illnesses). Then, one day, I got the call to come to the nurse's office at school. Stevie had been running in gym and turned blue. Thanks to fast thinking on the nurse's part, his color had already returned back to normal by the time I got there.

Around the same time, Stevie started struggling in school. His teachers started questioning reading disabilities, processing, and memory issues. A psychological evaluation was suggested. How did my son suddenly go from being considered gifted, to not being able to keep up?

Near the end of the school year, Stevie had a sinus infection. His pediatrician gave him antibiotics and something wonderful happened! His symptoms started to go away! In fact, they vanished completely by the beginning of the summer. I had Stevie do a bit of reading that summer to get caught up and by fall, as confirmed on an evaluation, he had gone from below first grade level to grade four level!

But his gains were short-lived. Just prior to entering second grade, Stevie had an asthma attack and all of the symptoms suddenly flew back! When the labs kept turning up negative, and doctors continued to be baffled, I started what would end up being hundreds of hours searching the internet for the solution.

Around this same time, a relative of ours who I ran into said, "Jane, my kids have it too! They have the same symptoms as Stevie!"

So, we each went to our own doctors and let them know that this could be a group problem. Sue's (not real name) doctor did labs and we had some clues. There was a positive ANA and positive strep, but it did not appear to be scarlet fever. Again, we were stuck.

A short time later, in the fall of 2006, I had a sore throat that was gone by morning and wondered if I had "it". Things did not initially appear too out of the ordinary, but I was paying attention just in case. A few weeks later I had an ache in my hip. After running more labs, it turned out that most of us also had a positive strep. Then, one night, an odd sensation came. I woke up and my body was tingling all over. Then the stabbing pains came and I thought, people had looked at me like I had two heads when I told them about Stevie's stabbing pains, so this must be the same illness! I started getting very, very, tired. I had never been this tired in my life. My muscles ached, my body twitched, I was sweating every night and had low-grade fevers that would be very sporadic, sometimes two weeks apart. My doctor, who I saw once a year, and only if I had to, started seeing me for weekly visits trying to figure out what was going on and he ran lots of tests. My sedimentation rate was slightly high.

After calling the State Department of Health, Alan suggested that what I was describing sounded like babesia, a co-infection often found with Lyme. I looked it up on the internet and most symptoms matched mine and when my knees swelled, something that typically happens with Lyme infections, I thought, yes this has to be it. But in spite of monthly testing, I kept coming up negative on all tick-borne tests. Doctors continued down other paths for all of us because the clues were sparse on the labs, although labs continued to be given to me for many tick infections, all coming up negative.

One night, during my hours of search on the internet which kept leading me back to tick-borne infections, I discovered new research on babesia. What I learned was that lab testing for Tick infections is often poor. Many technicians are not properly trained to detect babesia on a blood smear, and sometimes it doesn't show up. The more I read, the more convinced I became that this is what we had. The stabbing pains were even listed as one of the symptoms for tick-borne infections, and in fact, looking at the list of symptoms, all of our symptoms were there!

I learned about the Fry lab, a new research lab that used a patent pending stain to detect babesia, Bartonella, and ehrlichiosis, all co-infections. My PCP kindly ordered the test and it was positive for babesia and Bartonella! Just prior to starting medication, my doctor and I checked for tender points that are commonly found with fibromyalgia patients, and I had 5 of them. Could the hidden cause behind much fibromyalgia and chronic fatigue be babesia and co/infections not being detected? I certainly felt I fit the bill for chronic fatigue and fibromyalgia and wondered if my situation of the labs not showing this tick combination illness could be the missing link between chronic fatigue and fibromyalgia and Lyme and co-infections. I started medication with azythromycin and mepron, medicine used to treat malaria-type infections such as babesia, and within a week, I was sleeping

soundly through the night for the first time in months. The fatigue started to lift. Then, I learned something truly amazing. When you are triple infected with babesia, Bartonella and Lyme, the labs can come up negative because a person can be too sick to fight the infections and create the antibodies needed to make the labs come up positive. I learned that bands for Lyme disease would probably start to show up after I started to kill the babesia because my body would be strong enough to fight the Lyme. And as predicted, after a month of babesia medication, Lyme bands started to show up and I was equivocal on some Lyme tests. After, clearing babesia, I then became IgM positive for Lyme on the Quest Western Blot, 11 months after first being infected! This was important as doctors have learned that IgM only happens for the first few months of being ill with Lyme. However, it makes sense that if your body is too overwhelmed with multiple infections to fight them, and if Bartonella suppresses the immune system, it is going to stay at IgM until it can fight the illness. Certainly my lab progression with the equivocal Elisa, followed by Lyme bands showing and then a positive IgM WB confirm this concept (labs showing this progression attached).

A crucial point I would like to make is that there are other labs which help validate a tick-borne infection. This is extremely important as these were the first abnormal labs that showed after a year of illness for my son other than something minor like slight protein in the urine (see attached labs).

We also have a genetic pattern that does not allow us to remove Lyme biotoxins well when they die, and according to one researcher, the killed off Lyme can "create severe hormone abnormalities and alter MSH, VEGF, Free testosterone, DHEA, Free T3 thyroid and VIP." Bartonella can also alter VEGF, TNF-a, IL-6, and IL-1b. Stevie's VEGF was very high when first tested and his VIP was low.

Additional routine labs that can be "off" when one has a tick-borne infection. As it is very clear to me that our present tests for tick-borne illness can miss a person who is multiple infected, I strongly believe that these additional labs should be routinely tested for by doctors when there is a question of a tick-borne infection. I know that by our being given the proper labs that insurance companies also saved thousands because we did not need to keep testing trying to figure out what was wrong with us.

One by one, the 6 of us tested positive for co-infections on the Fry lab. Stevie, the second one to treat, cleared most if not all of his babesia and Bartonella and just tested positive on an IgM Western Blot for Lyme after two years of being ill! Stevie also had seriously high eosinophilia for a year, up as high as 37, which only now has come down to 17 after the hidden Lyme finally turned positive and antibiotics treated the Lyme. Lyme, babesia and Bartonella can all produce eosinophilia. (See attached medscape article, Are Various Babesia Species a missed Cause for Hypereosinophilia?)

As Stevie had also contracted Lyme 5 years ago, with almost every band in IgM and IgG showing positive, we had thought that his babesia and Bartonella were from that infection until the IgM showed for Lyme on the Quest Western Blot. 5 doctors, for almost a year, tried to figure out the cause of the eosinophilia. The fact that they have gone from a high of 37 to 17, a few points over his baseline, shows that the IgM Lyme was finally being addressed. Now that Stevie has cleared all or most of his Bartonella and babesia, Lyme medications made a significant change in my son. The babesia and Bartonella needed to be addressed first and then he was able to test positive for Lyme IgM and fight it.

A week and a half after starting Ceftin, Stevie threw the covers off my bed at 6:00 to go to school.....this, from a child who was always tired and often needed to sleep in in the morning, sometimes begging to wait a few more hours to go to school so he could sleep, and my letting him do so because I knew he was ill. As of his report

card, his teachers noted "memory improvement", "maturity", "developing strong listening skills", and "improvement with productivity", all at the end of this trimester when he started to improve from Lyme, and indeed as he is also a student in my own class, he doubled the work he was doing in my class and got 100 on tests.

On a neuropsych evaluation he had been diagnosed with generalized anxiety disorder and ADHD in the fall of 2006 (while sick with babesia, Bartonella and Lyme). His anxiety and sometimes OCD-like behavior completely vanished one day after being on mepron and azythromycin for a month and there has been zero problems with anxiety since that day. Many of the ADHD symptoms have been dissipating since starting Ceftin for Lyme, and from the literature, ADHD is common misdiagnosis for those with tick-borne illness. See The ABC's of Lyme Disease included in this mailing. Although he has not been re-evaluated for ADHD, the symptoms have been vanishing and most of his specials teachers see no sign of it, although organization is still an issue and I believe his classroom teacher may still question ADHD. However, this is a kid who could easily have been medicated on ADHD drugs due to the complications caused by this illness and the lack of lab accuracy as well as the lack of recognition of how a neuropsych evaluation can give clues suggesting the possibility of neuro-Lyme. His neuropsych evaluation also showed a sensitivity to loud sounds and bright light and he showed a difference on low energy with weak muscles and tiring easily

On the Weschler IV, Stevie scored 150 for verbal comprehension, 119 for perceptual reasoning, 116 for working memory and 88 for Processing Speed. (attached) His GAI was 142 and FSIQ 127. After learning about how someone with a tick-borne illness can present on a neuropsych evaluation from a presentation done by Judith Leventhal, Ph.D. and Leo J Shea III, Ph. D. at the 3rd Annual Lyme Disease Symposium at the University of New Haven, I learned that a big red flag for tick-borne illness in a child is when there is a huge discrepancy in the evaluation, with someone in the 90% + range and then a very low range in another category, which is usually processing. So, here we had precisely this scenario on Stevie's neuropsych lab, 150 – 88. Teachers and most psychologists don't know this is a red flag, and I certainly did not know this, even after hundreds of hours or reading, until hearing the presentation.

My mother also had babesia, Bartonella and what appears to be Lyme. Two different labs officially show babesia and Bartonella. Lyme specific bands show, but it does not show a positive Western Blot as of yet, although I fully expect that she will eventually test positive for Lyme on a Western Blot after treating her babesia and Bartonella as Stevie and I did. Only after reading research, did I realize that the mysterious illness my mom had had five years prior could be the same as ours. Her disease had not progressed in the same fashion as ours. Her illness started with not being able to walk more than two steps before feeling like she was going to faint. Then, she had horrible pain in her back a few months later. Eventually she became foggy and even had a mini bells palsy. When a Lyme test came back negative, I had not known at the time that it could still mean she was positive. Upon recently finding her Christmas letter from 2003, she described in it a mystery illness that she had had that resembled Lyme and chronic fatigue. 5 doctors at the time were unable to find the cause of this illness. A few weeks after my mother started treating babesia with mepron and azythromycin, her mini bells palsy resolved. She presently struggles with neurological problems, balance issues, pain and fatigue. Simple things such as balancing her check book are now complex for her and she is no longer able to drive.

We also learned of another person in my town, Joan (not real name), a vice-president at a major insurance company, who had been to eight doctors already, but could not find the answers for her illness. She had been bitten by something while reading on her lawn. She developed a rash and then got very sick. Her doctors had tested her for Lyme, but it was negative. Just as had happened to me, her doctors gave her a course of doxycycline because it looked like she had Lyme in spite of negative labs, but it barely made a dent in her illness. (I later learned and experienced that this is because the co-infections need to be treated first or at the same time

as Lyme...note Dr. Krause confirmed this in his NY Times interview, June 2011). I shared what I had learned with her and she too tested positive on Fry labs. She started medication and her health started returning. At present, she is still struggling with these illnesses.

Our story includes six people that I know. There have been several other people that I have met in passing who have had very similar experiences and I shared what I learned but will never know their outcomes. I have had three people in the last two weeks tell me that they have symptoms like mine that the doctors are unable to explain. When explaining this illness to one of these people, a young lady responded, "You just described every symptom I have. And, my dog just came in with a tick on him the other day. My doctor thinks I have fibromyalgia." She lives in the southern part of the state on the shore.

As our story demonstrates, there is a serious lack of knowledge about these illnesses and when these tick-borne illnesses are combined, the labs can easily miss them due to the person being too sick to produce the antibodies to make the labs positive. These illnesses can be life-threatening. My son turned blue and survived, and I know how lucky we are. I have received e-mails about children who are not as lucky and have died. Educating the public and the medical establishment and letting them know of the threat is not something that can wait. We can't let more children and families suffer with the ignorance that surrounds these illnesses. In addition, a doctor recently told me he has been seeing lots of patients coming in with rashes. Unfortunately, as I speculated to Alan a year ago, if a music teacher can find 6 people with this illness who are being missed, then there have to be hundreds. The recent tick studies done by Eva Sapi now confirm this serious threat to the public.

Recent Tick Testing in Connecticut

At the third Annual Lyme Disease Symposium at the University of New Haven on May 17, 2008, Eva Sapi shared her recent tick studies with the audience. I am going to include a few of their significant findings (in my opinion) here:

Tick Collection and DNA Extraction 2003:

230 Ticks were collected at multiple sites in Southern Connecticut. 20% had Lyme, 30% had Bartonella, and 34% had babesia. Total single tick infection rate, 57% and coinfection rate, 22%.

Fairfield County Project (2007 Fall):

Study at school yards, public parks and playgrounds to evaluate exposure to children. Testing done in over 50 sites. As of Feb 2008, 522 deer tick samples collected and 481 tested for *Borrelia burgdorferi* infection. Overall Bb infection rate: 60%

My own questions are, if the tick infection rate for Lyme has increased from 20% to 60% in 4 years, could babesia and Bartonella also have tripled...could they be as high as 90% for Bartonella and 99% for babesia? The important thing about this study is that it confirms the huge risk to children from ticks that are not even found in the woods, but on playgrounds, parks and schoolyards.

Suggestions for Educating the Public:

Information on the CT Dept of Health web site with links for instance

<http://www.lymediseaseassociation.org/ABCsLYME.pdf>

Additional Suggestions:

Show the tick study results

State that there is evidence that when someone is dual or triple infected that none of the labs may show positive. (use any part of our story to illustrate this, if you want)

Have information on babesia, Lyme and Bartonella on your web-site, including sources for prevention, symptoms, and what to do if a tick is found on you.

www.Lymeassociation.org has good articles for parents. Include sources for parents and information for doctors and psychologists. People need to know that anxiety, ADHD and OCD-like behaviors can be from these infections.

Contact the media and put out a press release.

Consider suggesting the link between Lyme and co-infections that are missed on labs and chronic fatigue and fibromyalgia as part of the press release.

Consider offering a few training sessions for medical professionals. Obviously this is not training most have had. I have had medical professionals not know what babesia was when I brought it up and others ask me if that is found in Connecticut. If you don't know what it is, then you are not going to test for it, and then even if you do know what it is, as our situation shows, the tests can miss it.

E-mail medical professionals and send out a mailing to them with info.

E-mail schools with this information and suggest that this information be shared with all staff.

Sincerely,

Jane Mills

Music Teacher

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