

Case summaries:

Wagner Family – In our family all of us have been sick with Lyme, Babesiosis, Bartonella, Ehrlichiosis, Chlamydia pneumonia, and Mycoplasma. Our illness started slowly, after we moved to the suburbs, only to escalate after an illness experienced on a trip to New England. **What is important to know about our case is that there were multiple opportunities for this to have been diagnosed in our kids, and in me – but our diagnosis relied in the end, on our own research, and our ability to advocate for ourselves, and to pay for lyme literate physicians.** Our kids deteriorated in front of our eyes. I'm supplying copies of some data that illustrate the impact of these diseases on my son Sam and my daughter Sarah. My son's SPECT scan showed ABSENT areas of perfusion – that means no blood flow in areas of his brain. After 2.5 years of treatment and great improvement, last year, when he was off of antibiotics for a few months, we could see he was sliding... well, they happened to do the 1st grade cognitive testing in school, and the results illustrated blatantly what we had seen off the antibiotics. Look at his results – Spatial 92 percentile, Concepts 80th, Verbal 72nd and Memory – 26th percentile arriving at an IQ correlate of 108. You don't see disparities like that unless there is something terribly wrong. Back on the antibiotics he improved dramatically. After 3 years of comprehensive, individualized treatment, our children this year are functioning "normally". Most recently, we completed a follow-up neuro-cognitive evaluation of our children, and found that Sam's IQ has increased by 26 points, and Sarah's by 16 points. Dr. Brian Fallon's research (Columbia University Lyme and Related Tick Borne Disease Research Center) found a 22 point in IQ decline in children affected by Lyme which mirrors our experience. We don't know if we'll ever really be "cured" but we certainly know that with appropriate treatment, we can be functional and our children can develop as "normally" as possible.

Gallagher Family – mother and all 6 kids are symptomatic. Mother's symptoms started quite some time ago, with fatigue, aches and pains, night sweats, headaches, cognitive issues, memory issues... she spent years going from doctor to doctor with all kinds of diagnoses, and little relief. She finally found her way to a lyme literate physician just this past year, and **when tested came up flamingly positive according to the most conservative criteria, CDC positive, along with positive titers for Babesiosis as well.** Her children are also symptomatic and have been to the best of our academic hospitals over the years, including CHOP, with many diagnoses and again little relief. **Two of her daughters, who were both in "gifted" classes earlier in their school years, are now in special classes/and a school for learning disabilities, with one daughter having dyslexia and severe challenges reading due to tracking issues (documented lyme symptoms).** She also was diagnosed with Lyme and other coinfections. Both mother and daughter have started to improve since undergoing treatment earlier this year, but, due to the significant delays in treatment it is unclear what their prognosis will be. These children's lives have been robbed from them due to ignorance and lack of ability to appropriately assess for Lyme and other tick-borne diseases. **What is heartbreaking is that these parents must choose which child they can next afford to treat. Most recently, the brought their next daughter, whose symptoms had increased significantly this past year, and she also tested**

positive for Lyme disease.

Charen Family: Rebecca Charen started getting ill when she was in elementary school, similar to my daughter she started having serial infections, in one year she had 23 sinus infections. She has had 2 tick bites they knew about – the first one – she was not even tested, and not treated. **The second one she was tested, was positive, and was treated, for two weeks.** After that, things became much more serious – at about 11 years old, she began having all kinds of aches and pains and, developed asthma, started sleeping all day, was weak and fatigued and lost her voice, speaking only in a whisper. At 12, she started having dizzy spells, lost her balance and started having seizures. This is when she became wheelchair bound. During this time, her mother who is an RN, took her to the best hospitals in our region, CHOP, Dupont and she had lots of diagnoses, asthma, common immune deficiency, dysautonomia, etc, but she was never even evaluated for Lyme disease, let alone other tick co-infections. One night her father, who now carried his daughter around the house, was watching Mystery Diagnosis, and recognized in the episode all of his daughter's symptoms and yes, it was Lyme disease. Her mom started researching after that, and after attempts to get her tested for lyme **locally encountered rejection and denial** that this could be at the root of her problems.

She took her daughter to Dr. Ray Jones in CT in January of 2008. **Dr. Jones confirmed a Lyme diagnosis along with multiple co-infections.** At the time, Rebecca was having seizures every 15 minutes, and passing out continuously – she was wheelchair bound, and had been homeschooled for 3 years. When I met Rebecca it was about 6 months into treatment, she was already down to 3-5 seizures a day, and greatly improved. **But it took another full year of treatment before she was out of that wheelchair.** There have been setbacks along the way, and no one knows what her outcome will be, but she is now back in school, and functioning well, and enjoying her friends and life again – she is an amazing fighter. **However, her family had to sell their house to pay for IV antibiotics that the insurance company would not approve,** and they had to travel out of state to get access to care that could/would help her, her mother had to quit her job to care for her, and the family has shelled out virtually everything they owned and now live with her grandmother.

The Logue Family: In this case, Joe Logue, Manager of a significant family-owned business in the Williamsport PA area, where I spent a large part of my youth, started becoming ill about 10 years ago. Initially Joe and his wife suspected Lyme disease, and his family doctor suspected it as well and started him on antibiotics right away, while they also had an MRI and other testing done, including Lyme testing. However, the neurologist who read his MRI diagnosed him with MS, and **his lyme test was somehow “cancelled” though no one could say who did it.** They spent years trying to pursue the Lyme diagnosis but **got no support in the medical profession,** told over and over again it was MS, even though it was “atypical”. For 5 years he underwent MS treatment and continued to deteriorate with a variety of symptoms. Eventually, they got to someone who tested him and **he was positive for Lyme and for co-infections, with exceptionally high titers.** Since then, he has been undergoing treatment and is now progressing. He lost major functionality, all major organ systems were taxed, experienced much pain, neuro-cognitive and psychiatric symptoms – and he is still

walking only with the assistance of a walker, but has slowly began to regain stamina and functionality. This time last year he was spending nearly 16 hours a day in bed. This illness has reduced someone in his early 40's to an old man, a father of a young child, a head of a major business, and nearly destroyed his marriage, and his life. **They've had to spend more than \$50,000 out of pocket to access the care that is finally restoring functionality**, and that is on top of partial reimbursement for the doctor's visits.

Esposito Family – their daughter's journey started in October 2008 when she came down with a sore throat, and a fever that went on and on, followed by a rash, and malaise. The rash was diagnosed as Erythema Multiforma – no bulls-eye, but red swirls all over her body. **No treatment was recommended and no bloodwork was done (family doctor). This was prime tick season and no one mentioned this, no one even asked where she had been.** She continued to be fatigued all through the rest of the year, struggling on her soccer team, and complaining of aches and pains. And then her underlying asthma worsened. In January 2009, she had swollen, painful joints and a rheumatologist suspected RA, and ordered a Lyme Western Blot and she came back 10 out of 10 bands positive. At this point, she was treated with 28 days of antibiotics, and the doctor said to contact him should she have re-occurrence... **which she did in May when fatigue sent in and she spent a full week on the sofa.** When they called the rheumatologist, **he refused to see her and told her to see her family doctor.** And the family doctor said that **nothing could be done for her "malaise"**. At this point, the family knew they had to turn elsewhere. She is now being treated by a lyme knowledgeable doctor and functioning normally.

Ellman Family: In this case, the husband had a tick in his body for 15 days. Not knowing it was an embedded tick, he finally went to his dermatologist about this bump, and he said "no big deal there is a tick here but it's not a Lyme's tick". He didn't test him, but gave him a shot and dismissed him. A week later he had a stroke!!!!!! The daughter, who is a veterinarian, was furious and ensured that he had a Lyme test. And, his titer was sky high!

A Local Pharmacist: this story illustrates that even the "classic" symptoms are being missed at best, or perhaps ignored. A local pharmacist started experiencing symptoms and then had a rash, a bulls eye rash. He went to his doctor who said it was nothing... he went to another doctor who called it "cellulitis", and eventually as symptoms progressed, he found his way to Doylestown ER, where they diagnosed the classic bulls-eye rash and recommended the standard treatment. As you can expect, after this treatment, symptoms persisted and continued to evolve. The pharmacist now travels out of state to a New York State lyme literate physician.

See attached Peter's Family Story

Many other teens: the stories are heartbreaking... with multiple suicide attempts, denials of IV antibiotics that were restoring functionality. Lives broken and destroyed due to lack of awareness and capacity to diagnose and adequately treat these diseases.

Matt's Story

My name is Montie Peters. My wife Helen and I have 4 fantastic children. Our twins Matt and Mike, middle son Mitchell and a daughter Darcie. We live in Point Township, Northumberland County, on a farm. Matthew was 12 going on 13 in 1997 and was always sick. He was on various antibiotics which would make him better, then when the antibiotics were done in days he would be sick again. Around Christmas of that year everyone in the family had the flu, Matt with his compromised immune system became very ill. His pediatricians in Lewisburg decided it was time for Matt to be in a hospital for examination. Hershey Medical was contacted and we took Matt to the appointment. Matt was admitted and was put through a barrage of tests. Matthew walked into Hershey and left several days later in a wheel chair. We had hundreds of dollars in prescriptions for him for reflex and respiratory ailments. Matt had been removed from all antibiotics since they were having no affect on him by not making him better. What we did not know was that those same antibiotics were keeping his Lyme disease partly in check.

Approximately one week later Matthew continued to deteriorate. He was a 182 pound football player and now weighed in at 113 pounds. On a late Saturday, very early Sunday morning as my wife and I stood by his bed, Matt was in the fetal position, barely responsive, ash in color something had to be done. My wife and I went back to our room and cried. It was frightly apparent that we were loosing our son. We called the pediatricians and met them at their office at 2:00 A.M. Sunday morning. When the doctor saw Matt he became very anxious and so concerned that he immediately contacted Geisinger Medical and Matthew was in their emergency an hour later. Matt was transferred up to the Janet Weis Children's hospital and met with the infectious disease team.

My mother Jean had kept a journal on all the things we were doing with Matt, doctors trips, med's etc. This helped to establish a time line for when Matt became very ill. The doctors at Geisinger read the journals and met with my wife and I and one thing became apparent, Matthew spiraled down to this point and the only real change was the antibiotics were removed. Geisinger put Matt back on a low level of antibiotics and a variety of other meds. Some of his new meds were Physiological drugs. My wife and I were questioned, did we love each other, did we fight in front of the children, were there money problems in our home-- this was just crazy, it made us furious. The only thing wrong in our life was the sick boy in that bed, concentrate on what is wrong with him. It was recommend that Matt see a physch counselor. We made the arraignments for a counselor in Lewisburg. Matthew had become abusive, both physically and verbally. Matt was in so much pain he didn't know what to do with himself. I took Matt to the counselor, checked in with a very nice lady and did a small interview with the counselor. Matt had a temole cough and they thought it was and imprinted tick similar to torettes and could be helped through physch therapy, and or hypnosis. Matthew wanted to be a doctor &om the time he was 7 years old. He asked me why this had happened to me daddy . Your heart is broken, you are a parent, you have all the answers, guess again. I told Matt that I thought this was a test in his life and when he was in med school and it was kicking bis butt he could look back on this and realize he could do anything. I was praying it was so.

At his point Matt's Story takes a turn.

The counselor interviewed Matt and when she finisbed she took me aside and said that there is far more wrong with my son than she would ever be able to deal with. Your beat is broken again, you are lost what is going on with this boy. The counselor at that point asked me an odd question. Had we considered that Matt's problems could be Lyme disease. The nice lady that cbecked us in had symptoms similar to Matt and she had just been diagnosed with Lyme disease. I thought this is ridiculous, Matt had been in two of the premier hospitals in my area don't you think they would have found this. The next night our phone rang and it was my wife's cousin, who we only see twice a year, she bad meet a woman that day who had symptoms like Matt. It was the nice lady from the counselors office in Lewisburg. The following day one of the owners from my insurance agency came to my business because he bad heard that Matt was ill. This man informed me that he had Lyme disease and that he had gone undiagnosed for years. He gave me paperwork and information on Lyme disease and my wife and I set down with Matt and asked him some of the questions in this literature. After Matt was settled in bed, my wife looked at me and said "God is trying to tell us how to help Matt" . I talked to the gentleman from the insurance agency, he gave me the name of a specialist in upper New York. I contacted this specialist and begged them to see our son. I took Matthew away from Geisinger Medical and drove him to a doctor I had never met, who practiced in the basement of his home, for help with a disease I didn't know anything about. I was scared out of my mind. I will remember the drive to New York the rest of my life, what had I done. \$600.00 up ITont to see the doctor, the doctor did not take insurance, you paid every time you went. The specialist examined Matthew, took blood, asked questions and interviewed us. Two hours we were there. The specialist wanted to know what the diagnosis was on Matt and we informed him that it was thought to be in his head, he was on Physocialgial Meds and was being turned into someone we didn't know. The specialist informed us that Matthew was the poster child for Lyme disease. I wanted to know how this diagnosis was made since no blood tests were returned yet. The specialist informed us that Lyme Disease is diagnosed on a clinical diagnosis. What does that mean I inquired. He said close your eyes, standing in front of you is and animal, the animal weights two

tons, has a trunk and tusks, do you need to open your eyes to know it is an elephant.

The specialist sent Matt's blood away and scheduled a Brain Spect to be done. This test was Scheduled at Columbia Presbyterian Hospital in Manhattan. The brain spect is a test which shows the vascular picture of your brain. In Matt's case it showed that the vessels in his brain were closing up. It became imperative that Matt be put on a Pic-Line (a port in his arm running into his heart) so that antibiotics could be infused daily and get the maximum into his blood stream. Hershey Medical did the pic line and a care provider was chosen for the antibiotic. Physical therapy in our local town was contacted to help to see if we could get Matt walking again. Matt could use a walker but it was not a pretty sight.

Matthew was home schooled at my office at 5th and Arch Sts. in Sunbury. Twice a day I would take Matt out and make him use his walker, the muscles in his legs had gotten to a point that he could barely stand. He hated me for making him move he would hit me, spit on me, and call me names, this is my son, if I could have made a deal with the devil for my soul he would have had it the level of despair was indescribable. Matthew would not eat, it was like someone had switched off food in his head, he did not desire food, yet he had to eat. I tried to force feed him to eat, you cannot do this to your child no matter what you think. We made many trips to the specialist in New York and even destroyed a van from the constant running.

We had started an addition on our home, it was supposed to be a project for me and the 3 boys, then Matt got sick, if not for our son Mike that addition which still not finished, it wouldn't even be under a roof. The money going out our door was insane, we cashed in bonds, savings were gone, the Idds college money was spent, the only thing we had left was the fann and our home. We had a family meeting with the other children and told them we would sell everything we had and live in a trailer if it would make their brother better. Matthew's I.V. alone was over \$100,000 dollars. I remember the moment my wife and I met with the care provider and the insurance company realizing that Matt required long term care the proposal was that the care provider would take less of a payment and the insurance would pay a little more and they would put Matt into managed care and 100 % would be covered. I remember hearing my heart beat as they crunched the numbers and when all agreed my wife and I went into the hall and cried. We were done, at that low moment the major dollars were taken care of and we had a boy that required all of our energy. I took Matt to physical therapy, he hated this, anything that made him move his legs was painful, Matt would throw his walker and yell at us.

At this point we discovered the internet and found a lyme support group with young people. Matthew was fascinated just being able for the first time to be able to talk to someone who was going through the same thing as him and realizing that he was not alone. He needed to be online and we used his access as a behavior modification tool to get him to behave and eat. We purchased a computer for our home and went online. Months went by and Matt slowly improved, but he improved. Frequent trips to the specialist in N.Y., physical therapy, and local doctors. I remember in late middle school when he stood at a dance with a girl and just moved back and forth, something my wife and I thought we would never see, this is just how devastating this disease can become.

It seemed that Matt had hit a plateau, he was better but far from normal something was still missing. The specialist in N.Y. said that roost of his cases were now showing a co infection call bebesis and recommend treating Matt for it. Matt was put on a drug call Mepron at a price of \$600.00 per bottle and is a derivative of mustard gas, horrible stuff. This along with the regime of antibiotics that he was on brought him up to his current level.

The affect that Matt's condition had on my family and my friends knew no bounds. In Matt's late senior year of high school I received a caU from the president of the school board, it was official Matthew was the valedictorian of his class. The board president is a close friend and had seen Matt at his worse, he informed me that he would not just give Matthew the award but had a speech to say about what he had been through. The board president could not complete the speech so overcome with emotion as were my family and mends in the stands. This disease not only devastated Matthew but affected mends, family, and community.

It took 5 years to bring Matt back to where he is today, our lives were changed forever, at one point in one of the hospitals some said to me that-you as a parent are only as happy as your sickest child, we lived this nightmare. There are many, many other stories in the 5 year struggle, but what is most important is the despair of no diagnosis, the huge financial outlay, we were moments from selling the farm and home we live on. For our family and Matthew everything that needed to or could be done was done. This is not the case with most people living with lyme disease. Most of the people who are diagnosed with lyme are treated with oral antibiotics and not for very long. Two weeks to 30 days of oral is very common and usually prescribed. Matthew was on an LV pic line for 10 1/2 months into his heart and oral meds to compliment that. Matthew had constant attention and all the love and support we and our family and mends could give. When we started this journey lyme disease was completely unknown to us, at this point in my little area I know 30 people who have lyme disease.

It is important that a change in attitude about lyme disease and its diagnosis take place. In Matt's case he has never tested positive in his blood for lyme disease. Matt's blood tests always were 1 band short of the

C.D.C criteria for lyme disease. If we had continued using that diagnosis Matt would not be the boy he is today, and possibly not even here. The bill that is being proposed is a step in the right direction.

As an update- Matt is now 23. My wife and I watched with pride as he led the procession into Bryce Jordan at Penn State as top of the class for the Pre Medical college of science. Currently Matt is attending Johns Hopkins in Baltimore and plans to specialize in pediatric oncology.

You are looking at the most thankful father in the world. Your whole life prioritizes around an event like this. The things that you thought were important become meaningless. Matt's recovery was a result of many things. I feel I must mention a few individuals. Michael, Matt's twin brother who we leaned on when times were tough, Mitchell Matt's little brother, who got lost, and little attention while all energy went to Matt, little sister Darcie who was only 6 and missed her birthday because Matt was in the hospital, my mother Jean, my family, our friends, our church who never stop praying for Matt, our school district, all the doctors, nurses, and counselors who helped to make Matthew better. In my marriage there is a wonderful and unique individual, my wife Helen. Helen worked to continue to bring money into our home while I ran Matt everywhere, we communicated by cell phone from doctor appointments and sessions, she is the compass in our family, she has my heart.

I want to thank the committee for hearing Matt's story. The task before you and before all of us is to truly make a difference. The proposed bill makes it easier for doctors to diagnose lyme disease and not be persecuted for doing so. The next time you are at the store, the mall or anywhere in public, take note of the amount of people, younger people who are walking around with canes or are in wheel chairs it may just scare you.

Thank you for listening

Matt's Dad