The Lyme-Autism Connection
by Tami Duncan and Bryan Rosner

To many parents, the discussion about whether Lyme disease and autism are connected is a moot point. It is really just semantics. The fact is that many children with autism have an active Lyme infection. Debate about whether Lyme causes autism, Lyme contributes to autism, or Lyme comes about after autism does nothing to help the many autistic kids who are testing positive for Lyme disease daily. If kids are infected, then they need to be treated. It's that simple.

Unfortunately, the Lyme disease diagnosis is often missed in autistic children. Many of these children are diagnosed only after the mother is first diagnosed. The message, then, is clear: if you are the mother of an autistic child, get yourself tested for Lyme disease, and if you have it, the probability that your child also has it is much higher. My story, excerpted below from The Lyme-Autism Connection, co-authored with Bryan Rosner, will help drive this point home.

It seems like yesterday when my beautiful baby boy was born. He was born right on time - on his due date, in fact. He was healthy and had a great APGAR score. He seemed happy to be in my inexperienced arms; I had never even held a baby before.

As I watched him begin to grow and develop, there were many times that I thought this boy must be some kind of genius. I swear I heard him say "Elmo" at just six months of age. He was my perfect little boy. A lady at work said she had never seen such great, fine motor skills, as he could take apart mechanical things that had just the tiniest of screws.

I had the usual arsenal of baby books to track his progress. He made most of the milestones on the check-off list. The things he hadn't accomplished, the doctor said it was "because he was a boy and they can just take longer." Okay...well, I didn't know any better. He was my first-born; who was I to question the decades of experience that the grandmas and doctors have?

When he was four and in pre-kindergarten, I noticed that he wasn't doing the same things as the other children. His speech seemed more slurred; his coloring was more scribbly. He was also notorious for playing alone on the playground or looking for bugs by himself. My poor baby, just like his mommy, had a hard time connecting with other kids. I asked the preschool teacher if she thought there was any problem. She said, "Oh no, don't worry about it. Sometimes the boys just take longer." Hmmm.

Kindergarten came, and more differences began appearing between him and the other children. My son couldn't jump, run fast, hop, read, or write his name. All of the other kids could do this. I finally realized that I couldn't listen to what other people were saying and had to go with my "mommy gut." I made a list of the things my son couldn't do. This list took up two pages. I presented this to his teacher, and she said I was right.

Finally, we got an evaluation for SID and speech. I remember my heart falling to my feet when I saw Miss Beth evaluate him. He could do much less than even I had thought. We walked away with a plan to start occupational therapy and speech therapy twice a week.

I thought we were all set; that we had our answer. But then in first grade, the gap between his skills and other children's widened even further. He was not reading well. He couldn't keep up in any subject except science. When I asked our school district for help, they told me they couldn't help him until he was three years behind the other kids. This was a lie. This lie enraged me enough to start telling everyone about it. By just a fluke, I told a total stranger in the cell phone store this story. His sister-in-law happened to be an advocate for children with special needs. This began our journey into the world of autism.

I took my son to one of the leading pediatric neurologists in Southern California. We walked out with an autism diagnosis. My son was seven years old when we got the diagnosis of autism spectrum disorder. It took me about one year to find information on biomedical treatments for him. At that point, he was eight years old. His age was past the “window of opportunity,” as many people call it. No chance for early intervention here. The mommy guilt set in "...I should have, would have, could have, if I had known...."
Lyme-Autism Connection

We began treatment with a DAN (Defeat Autism Now) doctor. Immediately, we began the gluten-free/casein-free diet. We tested and treated other issues such as metal toxicity, yeast overgrowth, viral issues, and vitamin/mineral deficiencies. At this time, my little guy flourished. He began reading and jumped from a kindergartento third-grade reading level in just three months. His tantrums, compliance, and behavioral issues diminished drastically. The progress we saw was amazing. He still had autism but was improving significantly. During this time, I started noticing that I was very tired, irritable and seemed to get sick a lot. I was getting ear and sinus infections and frequently having weird hallucinogenic dreams. I went to the doctor many times and was always hurried out with yet another antibiotic.

It wasn’t until November 2005 that I received my wake-up call. I woke up one Sunday morning with no voice. I went to a naturopath who worked in the office of my son’s DAN doctor, and she ran many labs. A few weeks later, the office faxed the lab results over to me. My voice had magically come back after two months, but I still wanted answers. I was shocked, to say the least, when my labs showed multiple infections. In fact, the test that was the most staggering was this Western Blot she ran. It showed that I was 100% positive for Lyme disease.

I had Lyme disease and the symptoms of it to boot.

I called the DAN doctor and said I wanted our whole family tested. Luckily, my daughter and husband were spared. But my little boy, at this time nine years old, still having autism, was positive for Lyme. In a twisted way, I was happy. Finally, we had another piece of his “autism puzzle.” You see, we had hit a wall or plateau with his current treatments. We had done almost everything and weren’t able to pull out any more improvements. This Lyme disease diagnosis provided a scary, yet realistic reality that we did have things to work at. If we treated the Lyme infection, we might be able to pull out more improvements.

These events are just the beginning of our story. When I look back at my health history, I believe that I was probably infected with Lyme disease around the age of 19. I can’t remember a tick bite (most Lyme sufferers do not remember being bitten), but I do remember a ringworm-looking rash, followed by an unexplained high fever and stiff neck that hospitalized me and left the doctors scratching their heads. Once the fever broke, everyone assumed I was fine, and we pursued this no more. I had to get back to college and back to my life. But the damage was done; I had acquired Lyme disease.

It appears that I gave Lyme disease to my little boy, without even knowing it. Both my son and I are still in the healing process, but I am happy to report that we are much improved. My son is on the verge of recovery; I can see this every day. His body is healing, and he is waking up from the fog of autism.

The term “Lyme disease” is probably not the most appropriate description of what is happening inside the bodies of autistic children such as my own. Jeff Wulfman, MD, of Vermont, was one of numerous physicians who presented at our recent Lyme Induced Autism (LIA) Foundation conference held on June 27-29, 2008 in Indian Wells, California. Dr. Wulfman refers to the disease in question as “Borrelia-Related Complex.” It’s a multi-factorial disease encompassing multiple infections such as Borrelia, Bartonella, Mycoplasma, Babesia, and Strep, to name a few. (In a future column, I plan to share more of the important information shared at our recent conference.)

Whether or not a particular child becomes victim to Borrelia-Related Complex depends on many factors, some of which we understand, some of which we do not. We know that factors such as environmental triggers, maternal health, and genetics play a role. And we know that these infections can be passed from mother to child during pregnancy.

The science of Borrelia-Related Complex is critically important and so are the associated studies currently taking place. However, for this column, I am focusing on the experiences of mothers. “An observant mother’s evidence may be questioned but should never be ignored” —Lancet, 1951. Many mothers are convinced that they are passing along Lyme disease to their newborns, and research is beginning to prove them right. Here is another moving story of congenital transmission, again, excerpted from The Lyme-Autism Connection.

A Long Journey

Who would have ever thought that time spent in the garden I loved so dearly would have caused us all so much pain...I have always been a person who loves the outdoors. I have always spent as much time in my yard as I can. So, when I was pregnant with my third child, it was no different. During my first trimester, I spent a considerable amount of time working in my garden at our suburban home near Albany, New York. I don’t remember a tick bite. I never had the “bulls-eye” rash. I just remember waking up one morning with extremely swollen glands in the right side of my neck, believing that I was going to come down with something. But then it just went away.

A few weeks after that, I became increasingly fatigued, and everything seemed to ache. I dismissed it as just pregnancy symptoms and never gave it a second thought. Then one morning, I woke up with what I thought was a pinched nerve in the right side of my back. I was about 14 weeks pregnant at the time. I had a strange, tingling sensation which extended down my leg. I was told to lie down and rest, which I did. The tingling began to progress to all four extremities. The next day, I began to lose fine motor function in my hands. I immediately went to the ER at a local hospital and was admitted to the neurology unit with suspected Guillain-Barre. During my time there, my symptoms progressed to include: numbness in all four extremities, face, and abdomen; tachycardia (fast heart rate), unsteady gait and balance difficulties; tinnitus (ringing in the ears); and a plethora of other bizarre symptoms. Around
this time, my parents’ (who were also my neighbors) dog was diagnosed with Lyme disease. I was convinced that I had Lyme disease, but none of the physicians felt that my symptoms were consistent with Lyme.

Despite my strange symptoms, my tests all came back relatively normal. I did have one positive Lyme ELISA and one equivocal ELISA and a slightly abnormal white blood cell count, but my MRI, lumbar puncture, and nerve conduction studies were all normal. The Western Blot eventually came back negative.

The day before my discharge, I began to experience terrible head and neck pain and the left side of my body had begun to twitch and move involuntarily. I was still discharged and returned home. A day after my discharge, I was back in the ER. I had begun vomiting and was unable to eat or stand upright due to the pain in my head and neck. I had lost ten pounds in less than a week, and the left side of my body was still twitching uncontrollably.

They ran more labs at the ER, which showed mild hypoglycemia, but were otherwise normal. I was told that there was nothing medically wrong with me and that I should “see someone to evaluate my level of stress.” I was discharged from the ER and sent home. A day after my discharge, I was back in the ER. I had begun vomiting and was unable to eat or stand upright due to the pain in my head and neck. I had lost ten pounds in less than a week, and the left side of my body was still twitching uncontrollably.

They ran more labs at the ER, which showed mild hypoglycemia, but were otherwise normal. I was told that there was nothing medically wrong with me and that I should “see someone to evaluate my level of stress.” I was discharged from the ER and sent home. A day after my discharge, I was back in the ER. I had begun vomiting and was unable to eat or stand upright due to the pain in my head and neck. I had lost ten pounds in less than a week, and the left side of my body was still twitching uncontrollably.

Things seemed to settle down a bit after that. I was still tired, and everything ached, and my feet were numb, but the most severe symptoms had dissipated. I was still convinced that I had Lyme disease, but no one would listen to what I had to say and that I should “see someone to evaluate my level of stress.” I was discharged from the ER and sent home. A day after my discharge, I was back in the ER. I found myself sitting in the ER at a different hospital. My symptoms had continued to progress, and I was becoming increasingly ill. My OB admitted me to the hospital for hyperemesis. I was given IV fluids and round-the-clock Demerol and Phenergan. I was given one dose of IV Rocephin because of the possibility of Lyme, but that was not continued. I was stabilized and sent home after a few days.

The abdominal pain was gone, but my symptoms were back. Not long after that, I saw an infectious disease doctor for possible Lyme disease. He ran a number of tests, including additional Lyme tests. My Western Blot was “negative,” but showed one reactive IgM band at the 23kd location. (I have since learned that this is considered to be equivocal by many Lyme-literate doctors.)
Lyme-Autism Connection

loss, strange visual disturbances, joint deformity in my hands, severe "brain fog," forgetfulness and word-finding difficulty, and many, many more strange symptoms. I couldn't remember what side of my car the gas tank was on, how to put the words together to say "chocolate milk," and even spaced out when I was driving and forgot where I was or where I was going. I was 27 years old at the time. I was evaluated for possible multiple sclerosis, lupus, and rheumatoid arthritis.

My tests all came back negative, and my symptoms continued to progress. I spent a considerable part of my pregnancy on methylprednisolone (a steroid) and had monthly level two ultrasounds. I had to withdraw from my classes and quit working. I was barely able to take care of my children or myself. It was a terrible time in my life.

In January 2006, my daughter was born, beautiful and healthy. My symptoms never went away, and I spent the next few months trying to continue with school at night, studying for the MCAT, and taking care of my children during the day, all the while fighting against my body and doctors who refused to listen. By that summer, I had gotten to the point that I was convinced that I would end up on disability for the rest of my life, or perhaps even worse. I had seen just about every type of specialist that exists, to no avail. I finally saw a very kind immunology and allergy physician in Albany. After performing a number of tests, he concluded that I might have hidden Lyme disease and should go see a physician in Boston who specialized in the disease. I attempted to contact the doctor several times, but never received a call back. Desperate, I once again began self-medicating with some leftover amoxicillin that I had. The response was nothing short of miraculous. Within a few days, my mind began to clear.

But, along with that, the pain in my body began to change. Instead of the intense aching, the pain became "cleaner and sharper," and the pain in my head and neck that I had experienced a year prior in the hospital returned. I was experiencing a Herxheimer reaction, which is a worsening of symptoms caused by the release of toxins by the dying bacteria. I eventually went to see my primary care physician who agreed with my self-diagnosis and began prescribing the medication for me. I was finally, after more than two years, diagnosed and being treated for Lyme disease.

Around this same time, my son began to display alarming developmental delays. He was started in Early Inter-vention when he was 18 months old and began speech therapy and special education and later physical therapy. He had global developmental delays and hypotonia (low muscle tone). He developed reflux. He was irritable and would often scream out at night as if he were in pain, but no one could explain why. By the age of two, he could not even say "mama" and had begun to socially withdraw. His therapist would come to the house to work with him, and he would lie on the floor and close his eyes. He refused to communicate with them in any way. I came across a study on Columbia's Lyme Research site and began to wonder. The study was looking at the prevalence of a Lyme-induced-autism-like syndrome. The children showed developmental delays consistent with autism symptoms, but when they were treated with antibiotics, they began to get better. Convinced that this was the root of my son's problems, I took him to see a pediatric infectious disease doctor at the local hospital. She informed me that not only did congenital Lyme not exist, but there was no way that I had Lyme disease. We left her office very quickly.

I began researching pediatric Lyme disease further and found Dr. Charles Ray Jones in New Haven, CT. I immediately scheduled an appointment with him. I took my son to see Dr. Jones, and he started him on amoxicillin. The response was once again, miraculous. My son went from being completely non-verbal, almost non-testable, and most likely heading towards an autism diagnosis, to virtually normal. We noticed a change almost immediately. It has only been about three months since he started his antibiotics, and he now no longer qualifies for Early Intervention services. His language, which had showed profound delays, is now within normal limits. He smiles and laughs and hugs us. He is just a different child now.

So, this is our story, our truth. I know that there are others out there with similar stories. Until more research is conducted and the disease is better understood, there will be even more who suffer. These past few years have been a powerful learning experience for me. My hope now is to spread the word about the tragedy of Lyme disease.

We are in the midst of an epidemic caused by a bacteria more sophisticated than our current technology and a disease that most doctors don't understand. I know that there are countless people out there suffering the way that we did who are told that they are "crazy" or who simply have their symptoms dismissed as nonsense. I cannot be silent about our experience and can only hope that I can alert enough people to this disease so that they may not suffer the way that we did. Please, educate yourselves. Ask questions. Don't ever doubt yourself. Don't ever give up for fighting for what you believe. If I had given up or had not had the strength to fight and question everything, my children and I would have faced a very grim fate. I know that we would not be where we are today. So, please, don't ever give up fighting and [do] help me to spread the word.
high numbers, why are just a few thousand parents talking about it? The number of affected children is estimated to be 250,000-300,000. Our Lyme literate doctors have been seeing children with Lyme disease who have “autistic” symptoms for years. However, the majority of doctors are missing the boat. Their utter refusal to learn and execute appropriate testing is unacceptable and forces parents to take matters into their own hands – that is, if the parents ever even become aware of the Lyme-autism connection.

Doctors specializing in autism have been warned from governing organizations, and even organizations within the autism community, that treating these kids for Lyme disease may place them at risk for losing their medical licenses due to the controversial and politically charged debate currently surrounding Lyme disease treatment policy in the United States. Given this regulatory constriction, and the hyper-focused attention on mercury as the only cause in autism, children are being misdiagnosed and given inappropriate treatment plans – not just a few children but possibly hundreds of thousands of children. Research on the synergistic relationship between Lyme, multiple-infections and mercury is being ignored. The experience and wisdom of an ever-increasing number of moms is being minimized. It is time for the medical community to step up and get educated on this disease paradigm that is destroying so many families.

Parents and a few brave physicians are beginning to pave the way. If you are a parent, are you going to look under every rock to find healing for your child? If you are a physician, are you going to wait ten years and see how this plays out, or are you going to learn as much as you can and begin helping our families? The message to parents and physicians is clear and growing louder each day: you can no longer ignore the Lyme-autism connection.

Tami Duncan
President of LIA Foundation
Website: www.liafoundation.org
E-mail: Tami@liafoundation.org

Journalist Bryan Rosner began studying and writing about Lyme disease after his five-year battle with the illness. The Lyme-Autism Connection, which he co-authored with Tami Duncan, is his fourth book on Lyme disease; his previous three explored alternative treatments for the disease. Bryan’s research focuses not only on treatments popular in the United States, but also successful healing modalities found throughout the world.

You can learn more about and purchase The Lyme-Autism Connection by visiting www.LymeAutismBook.com or calling BioMed Publishing Group at 530-541-7200.

Lyme-Autism Connection

LIQUI-D3 provides cholecalciferol, a highly bioavailable form of Vitamin D, in a nutritious, olive oil base. Vitamin D has been the subject of intensive research which has greatly increased our understanding of vitamin D deficiency. This research has also expanded the range of therapeutic applications available for cholecalciferol. Physiologic requirements for vitamin D may be as high as 4000 IU per day.

LIQUID3

A Dietary Supplement Providing 2000 IU of Cholecalciferol per Drop*

1 Fl. Oz. (30 ml)

<table>
<thead>
<tr>
<th>One Drop Provides:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calories: &lt;0.5</td>
</tr>
<tr>
<td>Calories from Fat: 0.5</td>
</tr>
<tr>
<td>Total Fat: 0.026g</td>
</tr>
<tr>
<td>Cholesterol: 0 mg</td>
</tr>
<tr>
<td>Total Carbohydrates: 0 mg</td>
</tr>
<tr>
<td>Protein: 0 mg</td>
</tr>
<tr>
<td>Vitamin D (as cholecalciferol): 2000 IU</td>
</tr>
</tbody>
</table>

Recommended Usage:
As a dietary supplement, one (1) drop daily or as directed by your health care professional.

LIQUID3 provides cholecalciferol, a highly bioavailable form of Vitamin D, in a nutritious, olive oil base. Vitamin D has been the subject of intensive research which has greatly increased our understanding of vitamin D deficiency. This research has also expanded the range of therapeutic applications available for cholecalciferol. Physiologic requirements for vitamin D may be as high as 4000 IU per day.

Rx Vitamins

For more information about our full product line or to place an order call:
1-800-Rx2-2222 or 914-592-2323
fax orders toll free to 1-888-800-8068
visit us at www.rxvitamins.com • email: info@rxvitamins.com

*This statement has not been evaluated by the Food and Drug Administration. This product is not intended to diagnose, treat, cure or prevent any disease.