

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Maryland  
County: Baltimore

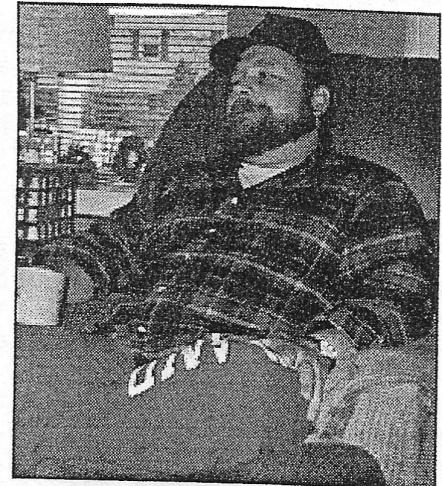
Name: Scott M. 

Total cost: \$600,000+

Number of family members with LD: 1

Lost work/school: 4 yrs, now on SS disability

Number of years sick: 11



Our involvement with Lyme began, technically, in July, 1986. We were camping in upstate New York. My husband, Scott, noticed a distinct bullseye rash on the top of his left hand. For three years (1986-1989) Scott suffered with fatigue, arthritis, and flu-like symptoms.

In 1989, I read about Lyme Disease in Readers Digest and realized that is what Scott must have. The local doctors disagreed. Scott's blood test was borderline, and he was not treated.

He continued to suffer and symptoms increased, until November 1, 1993. Scott collapsed at work and was rushed to the hospital. When I arrived, I said I believed it was the Lyme Disease, and was promptly told that Scott didn't have Lyme and had never had it.

For six months, Scott had test after test and saw doctor after doctor. We found out that very little was known about Lyme Disease by the medical community in our state.

In May, 1994, we finally found Dr. Richard Berg, an Infectious Disease physician. He listened to the whole story (he was the only one who had), and began to treat Scott for Lyme Disease. In June, 1994, Scott finally tested positive for Lyme.

You may ask - What is Scott's condition now? Well, unfortunately, but not surprisingly, Scott is doing very poorly. He hasn't worked since that day in November, 1993, almost four years ago. He hasn't driven in almost two years. He has symptoms too numerous to list (but anyone who is experienced with Lyme Disease knows exactly what they are). Physically and psychologically his prognosis is not good. Dr. Joseph Burrascano is Scott's Lyme physician and he is doing his best for him.

In other words, the Lyme Disease has invaded all parts of his body and is degenerating his brain. He is on IV antibiotics and takes about 70 pills each day for various reasons. Scott's quality of life is not very good.

Scott's brain disease due to the Lyme Disease has caused him to have less and less control over his body and thinking. He falls constantly and is very confused most of the time, and is in constant and terrible pain throughout his body.

In August, 1997, I was faced with a very difficult, heart-wrenching decision. I had to decided to place Scott in a nursing home so he could be cared for 24 hours a day by qualified individuals. Life is never the same after a decision like that is made. It was truly the best decision for Scott's sake, but a decision, nevertheless, that no one wants to make - for a parent or grandparent, let alone for your 42 year old husband.

I beg you who read this - Don't give up the fight to find a cure for Lyme Disease, reliable blood tests, treatment that works, and for those who do have Lyme - make the doctors listen and treat before anyone else gets like my husband.

I don't want any pity. But I demand, as a citizen of the United States, don't let my husband's life and death by Lyme be in vein. Do something now in a positive way that will make Lyme Disease at the forefront of the medical community in education and treatment.

DON'T FORGET THOSE OF US WITH LYME AND WITHOUT LYME, BUT WHOSE FAMILIES AND FRIENDS HAVE IT. WE HAVE MADE A SACRIFICE THAT WE WANT ACKNOWLEDGED AND URGE YOU TO TALK TO US AND LISTEN TO US AND MAKE A DIFFERENCE FOR US, OUR CHILDREN, AND FUTURE GENERATIONS.

I pray for the many Lyme Disease victims around the world, diagnosed and undiagnosed. As I say quite often, "We can't go back, we must go forward. Here we are, lets move on." May we all do that with the support and love of others, and be thankful for what and who we do have, and not dwell on what we have lost or been through.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey  
County: Union

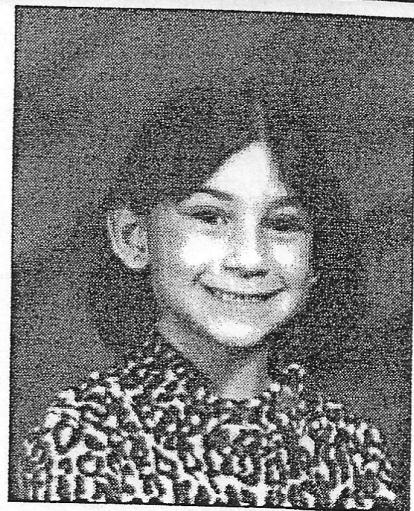
Name: Anne 

Total cost: \$4,000

Number of family members with LD: 2

Lost work/school: 60 days

Number of years sick: 1



Last November, when I was six my ear and head started hurting very badly every day. I cried a lot. My parents took me to a lot of doctors. My stomach and legs hurt me all the time but everyone said it was because I do gymnastics. I found out I have Lyme disease in June my ears and head hurt now but my legs still kill me, my don't hurt and I still can't do gymnastics. My chest hurts.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Union

Name: Eden 

Total cost: \$60,000+

Number of family members with LD: 2

Lost work/school: indefinate

Number of years sick: 12



The last 3 years I felt like I was losing my mind. I know I had either Alzheimer's or a Brain Tumor. My husband initially said that when you hit 40 this is what happens. At first I believed him but then he started getting REAL concerned. Something was definitely wrong but all the doctors & all the tests couldn't figure out what. I was so scared. I have a B.S in accounting, a masters of Science degree in Taxation & am working on a Ph.D. after college my IQ tested at 132 - I was recently (July 1997) tested at an IQ of 91. I spent 17 years running an international manufacturing company which employs 300 people. I had to leave it this summer because I can no longer function. The company is now up for sale - but it's hard to sell a company that's now nose diving & whose key employee doesn't go with the sale.

I'm doing extensive reading about Lyme Disease. For my daughter's suspected Lyme" (positive test results didn't come back for months) I found I had many of the symptoms being described. Years ago I had been told I had lupus, I had eye problems, stomach problems, sinusitis, knee surgery, Epstein-Barr etc etc just like my daughter. My regular ELISA test for Lyme showed negative. It wasn't until a "Lyme literate" doctor ordered Western Blots for both of us did we each get positive results. It's a crime that so many doctors will dismiss Lyme as a diagnosis based on the results of the ELISA test, which is known to be inaccurate. The stress of going undiagnosed for so many years was terrible. I now have stress of going undiagnosed for so many years was terrible. I now have the diagnosis of late stage neurologically Lyme Disease. My chance of completely recovering are very low. My chances would have been better if I was diagnosed & treated earlier. My 7 year old daughter is still in constant pain from her Lyme Disease. My 7 year old son has Tourette Syndrome. My kids need a mom not a space cadet. Please - Please - Please - get better testing for Lyme Disease and educate doctors PLEASE

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey  
County: Morris

Name: Jennifer 

Total cost: Hundreds of thousands

Number of family members with LD: 3

Lost work/school: 2 semesters

Number of years sick: 9



In the spring of 1987 I began suffering from vertigo, panic attacks, hair loss, photosensitivity, vision problems, sore glands, fatigue - pain in multiple joints. Was diagnosed as hypoglycemic, immunocompromised and suffering from exhaustion -

In 1992 Dec. after tentative diagnosis of M.S., depression and dementia - I asked for a Lyme disease test. I was one of the "elite" who was fortunate enough to have a positive test. I was treated for 6 weeks on I.V. Rocephin and told that my continuing symptoms were Post-Lyme Syndrome. I have been successfully treated with I.V. and oral and injections for the past 3 1/2 years. I continue with treatment and am able to maintain health on antibiotic treatment - I refuse other treatment - I do better on one month antibiotics - My two daughters and my dog have all had Lyme. My daughter continues to struggle like myself - My dog is dead -

We are struggling to pay for treatment. We are not yet bankrupt, but expect to be so before long

The lack of education regarding Lyme disease  
(in the County, the community, the Town Council -  
(Health Commission) politicians - M.D.s - emergency  
Rooms - is Appalling! and inexcusable  
and must be aggressively addressed.

The first and best line of defense against  
Lyme disease is education regarding L.d. Prevention  
is the best prevention - not even the schools  
or coaches teach or practice this - Many  
physicians smugly refer to Lyme disease as  
an "in disease" Lyme disease has robbed  
me and my family of health, happiness and  
finances (not to mention the alienation it  
causes in Society). Physicians are often the  
most arrogant and ignorant and teach  
myths and misinformation which is rampant -  
like the disease!!

"The absence of evidence is not evidence of  
absence" \_\_\_\_\_ | "

"Reality is a hanging judge."

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Michigan  
County: Clarkston

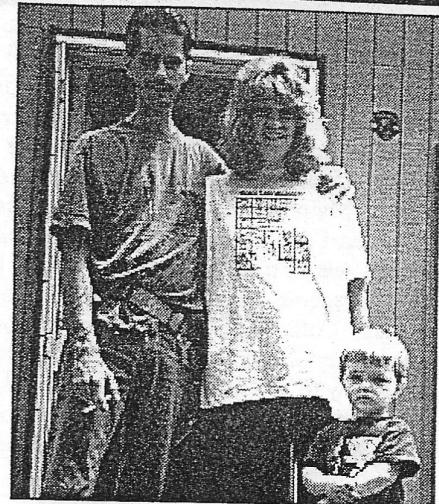
Name: Anita M. 

Total cost:

Number of family members with LD: 2

Lost work/school:

Number of years sick: 8



I am a 33 year old mother of two young children and I live in Clarkston, Michigan. Both my husband and I believe we contracted Lyme Disease during our stay in Traverse City, Michigan approximately eight years ago. It was soon after that period of time that our symptoms developed.

I had flu-like symptoms which would come and go. The number of symptoms and their intensity increased over the years, especially after each pregnancy. I was able to "fight" the symptoms and work full time as a legal secretary and still care for my one son at the time. Eventually, there did come a point in time where I was forced to end my employment due to the extreme fatigue, nausea, "brain fog", and lack of concentration. My family physician told me I was depressed and prescribed anti-depressants. Although my symptoms continued to worsen, I believed my physician and concluded it was due to "stress". After my three and a half year old was born, the disease brought my life to a complete halt. Within days of his birth, my symptoms increased in severity as well as developing more puzzling symptoms. Some of these symptoms included debilitating fatigue, joint pain, blurred vision, muscle pain, extreme weakness and heaviness of the arms and legs, severe nausea, dizziness and light-headedness, lack of concentration, confusion, word reversal, inside "jitters", heart palpitations, low grade fever, panic attacks, fits of crying, extreme irritability, shortness of breath and chest pains.

By the time my son was three months old, I was completely bedridden. I had to rely on a fulltime babysitter to come to the home to provide care for my two young children. I was bedridden for approximately two years and was unable to care of my youngest son for the first two and half years of his life. My family physician claimed I was suffering from post partum depression and again, prescribed anti-depressants. This is the same physician who informed me that Lyme Disease did not exist in Oakland County, Michigan, and that he did not know how "Dr. So-and-So" found his LD patients. Even after my diagnosis of Lyme Disease this same physician noted in my records that I was focusing too much on my physical symptoms and seeking too many doctors. He also wrote "I personally believe that this (major depression) is the patient's major problem - she refuses to accept it"!!!! As I sought out other physicians in my search for answers, they too labeled me as "depressed". A rheumatologist did however, inform me that I had a slightly elevated ANA, which is indicative of SLE. I was unaware of the fact this is also common in people with LD. I was told by several doctors that even if I did indeed have Lupus, I should not be this ill and most of my problems were "in my head".

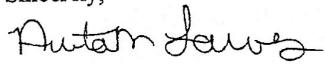
My family committed me to a psychiatric ward because they did not know what to do with me. I have heard comments such as: 1) you don't give a "darn" about your kids 2) most husbands would have left by now, 3) you just want attention, 4) You are like the boy who cried wolf, 5) nobody wants to hear it, 6) so-and-so has cancer/ms/lupus and they are doing just fine, 7) well, I have a bad back and get tired, but I still get on with my life, 8) you are sucking up your husband's health insurance, don't you care? 9) I know someone who has Lyme Disease but they can work, etc.!!!!!! It was everyone's opinion that I had severe mental problems. During my stay at the hospital, I had to defend myself to these physicians repeatedly and informed them that there was something terribly wrong with my body, and not my head. I recall being barely able to hold my head up during the group therapy sessions. If a worker asked how I was doing and I replied with something to the effect that I was not feeling well, their reply would be "Oh, stop focusing so heavily on your physical symptoms". I learned very quickly that my "ticket" out of the hospital would be a fake smile on my face and the claim that the Prozac was doing wonders. My family and the medical community continued to doubt my sanity thus far and I was literally on my own in Lyme Hell as I continued to search for a diagnosis.

One morning I was pleading with my husband to find help for my children and myself. I not only feared for myself being this ill, but my children as well should anything happen to me in their presence. My husband had already accepted the physician's diagnosis of depression and replied to my plea with "You just want attention". It was at that moment that I had a nervous breakdown and made a return trip to a psychiatric ward. Thank God that I was admitted to different hospital the second time. It was during my stay there that I was introduced to an infectious disease doctor. He ran numerous tests including Lyme Disease. Several of the bands came back positive!! My physician started intravenous antibiotics immediately which he continued for six months.. I was thrilled that I now had a name for this invisible disease.

After one year of treatment with this infectious disease doctor, I switched to another LLMD whom I believe to a very courageous and compassionate physician. I have remained on oral antibiotics continuously for the the last two years. Although I have made much progress, the road to recovery is a very long one. I continue to struggle with the symptoms on LD on a daily basis and face an uncertain future. It only took me at least seven years of learning how to live/function while feeling ill, one year of being completely bedridden, two visits to a psychiatric ward, 13 physicians, severed relationships with family and friends, witnessing my husband children suffer the loss of a wife and mother, the loss of my own self-worth and doubting my own sanity to find my diagnosis

..... Lyme Disease.

Sincerely,



Anita M. Lawes

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Maryland  
County: Baltimore

Name: M. David



Total cost: \$16,000

Number of family members with LD: 1

Lost work/school: 2 weeks

Number of years sick: 4 months



I found the embedded deer tick on July 11, 1997. I got sick with mild flu symptoms the following week. My primary care Dr. put me on doxycycline, 100 mg b.i.d. for 4 weeks. I did not get well. Instead I got worse. I saw the Ass't Chief of Medicine of Mercy Hospital in Baltimore, an I.D. specialist.

I had clear-cut neurologic symptoms at that point, but was seronegative due to having been put on doxycycline from the start. He discounted my symptoms almost entirely, but to cover himself he prescribed BIAxin. Within a week I was having a profound Herxheimer reaction with symptoms of meningitis. A prominent Baltimore Neurologist was called in - the symptoms alarmed him & he ordered an emergency lumbar puncture and ran a serology on the fluid. Of course, it was negative (I had been on antibiotics for 2 months by now); He pronounced that I had a virus - but not Lyme. I was taken off antibiotics at that point and got much worse. I finally talked to some Lyme literate people at the NJ Lyme Care Center & they gave me the IGENEX Lab's No. My primary Dr. had them send the Lyme Urine Antigen Test Kit and we started up on Ceftriaxone 2g/day. Within 3 days I was having a severe Herxheimer

OVER

and at day 6 we took urine samples. I tested highly positive at 110. However, the ID doctor was unimpressed and refused to order IV drugs.

By now I was losing my memory, getting lost in familiar places and beginning profound episodes of neuropathic pain, with almost total numbness in my rt. hand. I felt like I was becoming paralyzed. I finally was able to see Richard Berg, MD — an ID Lyme Literate Dr. — He immediately ordered IV Rocephin for a month. However, I lost at least 6 weeks of valuable time dealing with the Lyme illiterate ID Dr. Now my cognitive impairments are better — not cured. I suffer from severe neuropathic pain in my arms and I am unable to work full time. Of course, my final diagnosis was Neurologic Lyme Disease which should have been treated from the point of doxycycline failure with IV antibiotics. Maybe it would be able to work more if this had occurred. This has had a devastating effect on my family (I have 2 small children) and every other aspect of my life.



# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Michigan  
County: Saginaw

Name: Sherry R. 

Total cost:

Number of family members with LD: 2

Lost work/school:

Number of years sick: 3



Vacationing on Hilton Head Island, S.C. in 1988 I got bit by something and developed a rash that didn't go away for a long time. Shortly there after I developed carpal tunnel syndrome, in both hands & feet. I was diagnosed with multiple sclerosis, rheumatoid arthritis and possible scleroderma. I can still remember pushing my 3-yr-old in her swing with my fists, as my hands would uncurl with difficulty. I would lay on the floor with my young twins, trying to care for them dealing with symptoms of constant fatigue and pain. I was finally diagnosed with Lyme Disease and treated with long term antibiotics. I am now cured, or in a long-term remission, as the last time on antibiotics was 1991. I passed on LD to my son, David, either through the placenta or breast milk.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Michigan  
County: Saginaw

Name: David R.  (7 1/2)

Total cost:

Number of family members with LD: 2

Lost work/school:

Number of years sick: 5



I was diagnosed with Lyme Disease when I was 2 years old. Prior to that I had been hospitalized with fevers of unknown origin. I spent the next 3 years on antibiotics to treat my illness. My symptoms included: fever that lasted for a week once each month, headaches, severe leg pains that would wake me up almost nightly, stomach aches, general body aches with no diagnosis of arthritis, inability to settle down, and probable ADHD. I was beginning to develop leukemia at the time of my diagnosis with LD. The Lyme Disease has been cured, or I am in a long remission of 2 1/2 years standing. However, it has left me with many allergies, and a mild problem with ADD.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Michigan  
County: Oakland

Name: Betsy



Total cost: \$60-70,000

Number of family members with LD: 1

Lost work/school: 2 yrs

Number of years sick: 3



### Lyme Disease: In a Patient's Own Words

**Editor's note:** This is the first-person case history of a Lyme disease patient who contacted me online after reading the Lyme disease lecture notes. Her story is worthwhile reading, not only because it illustrates some exemplary features of this elusive disease, but because the patient-author is such an articulate and objective historian. It's too bad *all* patients cannot communicate their problems so well!

*—Ed Uthman, MD*

---

The way I was diagnosed was a long involved story, so I hope that you have the patience to read it. I will try to make it as concise and interesting as possible.

In August of 1994 I vacationed to Cape Cod, Massachusetts. (I live in Michigan). We also went to Lenox, Mass., for two days to hear the Tanglewood Music Festival. (Had been a life-long dream of mine, the Tanglewood excursion, being the music aficionado that I am). In order to get there, we walked three miles each way at night, through a dark, wooded, grassy area much of the way. Being in excellent physical shape, the hike was no problem for either of us. I did not use any insect repellent, as was three weeks pregnant at the time, and did not want to take any chances. (Also didn't know anything about this being a Lyme endemic area-had hardly heard of Lyme!) I never saw any ticks on me, but then never looked for any. Who knows, I could have been bitten on my neck, and who routinely checks the back of their neck? Interestingly enough, I do have a strange rash on the back of my neck which seems to come and go, but no doctor has ever confirmed that it is from the Lyme infection.

The pregnancy turned out to be a partial molar one, which was then diagnosed as trophoblastic disease. This required me to be on six months of methotrexate IM therapy until my HCG levels were normal. Prior to beginning the chemotherapy, I developed swollen glands in my jaw. (These swollen glands occurred eight weeks after my vacation) They disappeared after two days and I thought nothing of it. I read later that one of the early Lyme symptoms can be the onset of swollen glands. In retrospect, a shame that I didn't know that then, and wasn't treated at that point.

While on the chemotherapy I slowly developed strange symptoms which were not thought to be side effects from the chemo (according to the oncologist). It may have been reasonable to conclude that they were an emotional reaction to the trauma of being on chemotherapy, yet I didn't think this was the case. I felt as though I had an infection.

Once off the chemo, I thought that I would start feeling much better. Instead, I started developing more strange symptoms such as face pain, head pain, teeth pain, pressure sensations in my esophageal area, and finally two months later, arthritis in my knees, heart palpitations, dizziness as though they were upside down! The problem with this disease is that many of these symptoms are difficult to describe, and I consider myself to be a very articulate person. Each day brought more troubling symptoms in addition to those I had. So, I made the round of internists, neurologists, ENTs, etc. Most of whom thought my problems were psychological/emotional, or they just didn't know. I finally asked for a Lyme titre, and it was negative. I put that idea on the back burner for a while, assuming the test was the final word.

I then had a complete medical work-up via a top medical facility and everything was negative, yet I was feeling very ill. Finally, thanks to the Internet, I obtained some information about Lyme symptoms which seemed very similar to mine. My good friend who is a physician here in Michigan then called a doctor in New York who was willing to see me, and recommended that I take a Lyme urine antigen test first. My friend ordered this test for me and the samples came back highly positive. I then went to see a top infectious disease specialist here in town. He ran every test one can think of including the Lyme titers. He ordered the Elisa IgM and Elisa IgG, as well as the Western Blot IgM and IgG. The IgMs [ceftriaxone] for 42 days followed by doxycycline. No improvement noted, despite the fact that my Lyme titres (while still positive after subsequent testing) are less.

Wondering whether I actually had Lyme since not responding to treatment, I went to seek a second opinion. He concurred with the first doctor's diagnosis, saying that I definitely had the disease. He remarked that different antibiotics work for different patients, and we hadn't found the right one for me yet. So I am now on [penicillin G benzathine] injections and am hoping that I will finally respond to this treatment. In the meantime, I have been unable to work for the past eight months because I am too ill.

One thing I have learned from this is that many physicians treat patients as though they are either hypochondriacs (which I have never been before) or as having an anxiety based set of symptoms, when they don't know what else to call it. I am glad that I was persistent and insistent, to at least get some treatment. Incidentally, I did call the Massachusetts Dept. of Public health and spoke with an epidemiologist there who confirmed that I had visited a Lyme endemic area.  See back!

**Editor's afterword:** Some of the concepts concerning the clinical problems involved with Lyme disease are illuminated by this history:

- **The failure to obtain a solid history of a tick bite.** despite having an excellent historian. The long walk through the woods to the concert in an endemic area is an excellent teaser, but many patients may not even think to tell you about something like this when you quiz them about hiking, camping, golfing, etc. Getting what you need when taking a history seems like it should be easy, but I think you will find this is one of the more challenging aspects of clinical medicine.
- **The unreliability of lab tests for Lyme disease.** Her first test was negative, but the follow-up tests were all positive. Never let a lab result turn you away from a solid clinical diagnosis. If your experienced clinical eye points you in one direction, do not let the lab divert you. The lab just has a bit of the patient's blood. You have the whole patient and the cognitive advantage. Another challenge of clinical medicine is to get the most out of the lab without being a slave to it.
- **The frustration of the Lyme patient.** The disease can be just as confounding to the patient as it is to you, the doctor. The patient above expresses pride in how she took such good care of herself physically and seems to evince a sense of betrayal by her body, especially in light of the fact that her symptoms were so anatomically widespread and seemingly unrelated.
- **The ubiquitous red herring.** This will get you every time. This patient's physician had to deal with her documented partial hydatidiform mole. The mole is a fairly rare disease in the United States, and it is unlikely that this (or any) physician had much experience with it. In such a case, the typical doctor would not know what to expect from a patient carrying the diagnosis of mole. There would always be some uncertainty about whether the mole or the chemotherapy could be causing the symptoms, or whether a third alternative explanation should be sought. Getting past a red herring is a major challenge for a developing clinician.
- **The unreliability of treatment.** No infection will respond to antibacterial treatment 100% of the time, and Lyme disease is an exceptionally good example of that. Remember, you get no guarantees with any medical treatment, as you, as the physician, have to have a plan B ready in case plan A doesn't work.

-E.U.

The ~~IV~~ bi-cillin injections didn't work, and I have tried many different orals since then. I've been on IV Claforan since August of 1997, and I am hoping that this will help me improve.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut  
County: Fairfield

Name: Julie Leiss

Total cost: \$60,000

Number of family members with LD: 1

Lost work/school: both

Number of years sick: 3



In April 1995 I was camping at a KOA campground in Virginia. While gathering wood with my daughters we ran into an area infested with ticks. I saw one crawling on my daughter's arm and a few days later found one embedded in my arm. I inquired into the incidence of Lyme disease in Virginia and was told "that is something you have in Connecticut—don't worry about it here." Listening to that advice proved to be a terrible mistake. Later inquiries found that the men in the nearby Navy base were coming down with Lyme disease.

I remember not feeling well on the long drive home. A week later I came down with what I thought was a flu or virus—fever, chills, body aches and the constant urge to urinate. The spring turned into summer and I was plagued with a constant repertoire of sinus infections, stomach problems, fevers, bronchitis, fatigue, asthma attacks, joint pain, headaches, swollen lymph nodes, and later, tingling, numbness, burning sensations, weakness, abdominal pain, muscle spasms, eye pain and dryness and a terribly dry mouth.

In November after running a series of blood tests and ultra sounds my family physician diagnosed me with Lyme disease. I was given a month's dose of oral Doxycycline and pronounced cured. Although the medicine helped, four days after finishing the treatment the severe headaches came back, respiratory symptoms, weakness and chills. My family physician sent me to an infectious disease doctor in our area. He ignored my blood test results and symptoms, told me that I didn't have Lyme disease and made disparaging remarks against women. I left his office upset, depressed and furious. My condition continued to deteriorate—I couldn't move my neck, I would wake in the middle of the night with paralyzing chest pain, and I was so exhausted I had to crawl up the stairs. My hands were so weak I couldn't keep them on the steering wheel. I felt as if my head was in a vice grip. I would lose my car in the parking lot, put it into reverse instead of drive and vice versa. I would get so dizzy that I had many bruises from falling down and into things. I had blackouts and at times could barely walk. I couldn't remember the name of the little boy I was watching. I had to stop running my day care business since I could barely look after my own three children.

I sought help from two other doctors before I was finally put on intravenous antibiotics. My condition is now being treated aggressively because I have also been diagnosed with interstitial cystitis (which started with the onset of Lyme), a progressive disease which causes chronic inflammation of the bladder wall and for which there is no cure. On the IV treatment some of the symptoms gradually started to subside and I felt much better. However two months into the treatment program I had to have my gall bladder removed because it had become inflamed, a side effect of the medicine. Once the medicine was stopped, I had bladder spasms which were similar to childbirth contractions and intense knee pain and headaches. I developed an infection from the PICC stand now. I think it is frightening that when I stop the antibiotics the symptoms seem to return with a vengeance.

I plan on continuing on antibiotics until most of my symptoms disappear. I only hope they will. This insidious disease has disrupted my family life, cost me a business, ruined my bladder, taken away precious years from my life, and prevented me from being a capable parent to my children. I can only drive if my destination is within a few miles, because I still feel as if "I am in a fog." Before I became ill with this disease I must confess ignorance to the many symptoms of Lyme disease and the consequences of leaving a tick bite untreated. I am angry at the lack of knowledge many doctors have about this disease and the disparity among doctors in treating it.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

**State:** New Jersey

**County:** Morris

**Name:** Lorraine



Total cost: \$900 Insurance pays the rest

Number of family members with LD: 1

Lost work/school: 4 months

Number of years sick: 6 months



I am a 53 year old self employed jeweler and until I got Lyme disease last summer was living a healthy productive life. On June 20, 1997, after feeling a little sick for about 24 hours my fever shot up to 103.5°. I also had a severe headache, diarrhea, all my muscles and joint ached, I was extremely tired and weak, I couldn't concentrate or think, and I could not eat. I found a bite on my back with a 1 1/2" rash around it which grew to 7" in the next week and then faded away. On June 21 I started vomiting also.

On June 24, I saw Dr. [redacted] of Summit Medical Group, Summit, NJ who refused my request for a Lyme test. She treated me for an infected spider bite and said I also had a virus. When I was no better by July 14, Dr. [redacted] sent me to an infectious disease specialist Dr. [redacted] of Summit Medical Group, Summit, NJ, who recognized my symptoms as Lyme disease and started 100 mg Doxycycline twice daily for 14 days. He ordered tests for Lyme disease and my test results were very strongly positive. My condition improved, but Dr.

[redacted] refused to give me more than 2 weeks medication even though my symptom continued. At this time I was sleeping 10 to 14 hours a day, was confused, forgetful, weak and tired all the time, had a stiff neck, had ankle, shoulder, hip, knee and jaw pain that varied in severity each day, had little appetite, and my heart pounded when I walked up a flight of stairs, after which I had to lie down. I was unable to work.

After Dr. [redacted] refused me more medication I managed to get 2 weeks more Doxycycline from Dr. Richard Wilmot of Summit Medical Group, a Rheumatologist who told me he sees Lyme patients "down the road" who still suffer because they were not given medication long enough early on in their Lyme disease.

This gave me time to find the Morris Area Lyme Support Group through which I was able to find a doctor who takes my Lyme disease seriously. I continue to be on medication for 6 months now, and I eat a restricted diet and take many costly supplements to bolster my immune system. I presume I will stay on this path as my symptoms continue to subside. I will do whatever my Lyme doctor suggests, trying not to become a chronic Lyme disease patient. My doctor and I are doing all we can. It is time for the rest of the world to catch up. We need treatment, cure, and prevention.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey  
County: Middlesex

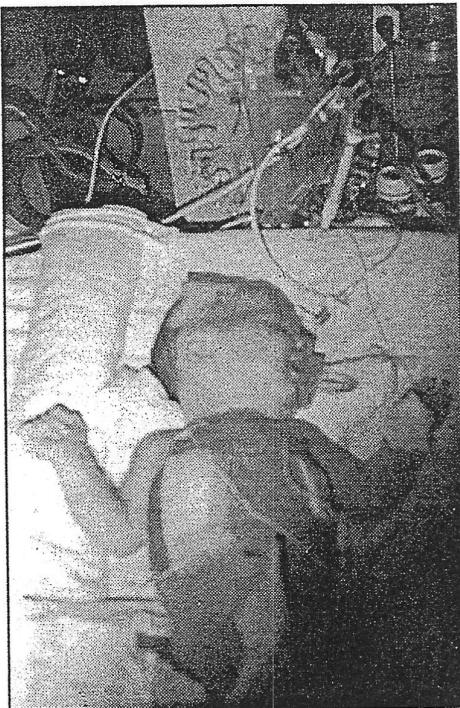
Name: Joanne, Micheal, &  
Maximillion 

Total cost: Bankruptcy

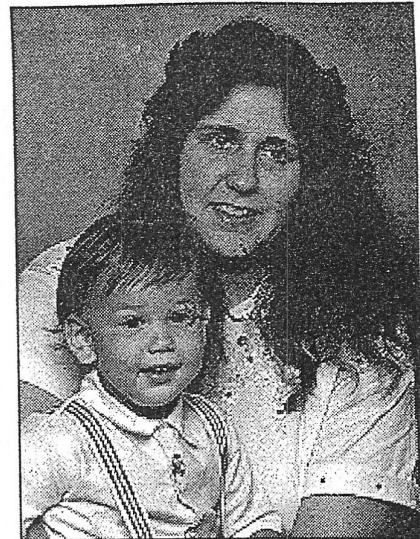
Number of family members with LD: 3

Lost work/school: 2 1/2

Number of years sick: 6



Maximillion March 13, 1993



Joanne 36, Maximillion 2 1/2



Michael Age 13

I was 6 months pregnant when I was bit, doctors said a allergic reaction. Maximillion was born March 13<sup>th</sup> 1993 this is how a baby looks at birth from full blown Lyme at this time we were told he had a staph virus, we're a western beach blood test was taken 1 1/2 months ago. He has 2 positive Jones the same I. S. have, mom was on life support for 4 days, then Ventilators and our local insurance company denied all our coverage because we chose life instead of death, we still fighting this disease doctors were surprised that I had Lyme and gave this disease to my child through birth, after saying doctors I mean Obstetrics. 9 months after mom & began getting sick they said doctor ~~can't~~ doctor told me never see doctor, need to be educated on this disease and not threatened to have their ~~license~~ license taken away we need people to help study for a test to say yes you have Lyme, not a Vaccine. how can we have a Vaccine. many people have this disease and are not aware of this. Insurance is another matter & needed A.V. Insurance said 30 days then you cured,

I nearly flipped out. I've been around out of hospital I've had a port put in my chest. My doctor felt I needed T.V. for 90 days to start, insurance said these doctors say 30 days (we are these doctors Texas) well ashees my doctor is here in New Jersey, and he makes the docs not some jerk straight I have a total of Six children I am so thankful for my wonderful doctor, he understand and cares and stands behind us too go. Now I'm able to care for my family and enjoy life itself again I layed in bed 3 months before anyone told me I had this disease a 14yr. old son took care of me and 5 of his siblings including an infant who was ill and a 18 month old. my own personal physician a doctor Segal in New Brunswick New Jersey is he loves the insurance money and tells us this vaccine is due out soon what are the side affects his answers all made of no sense I feel insurance waste there money on his research when they could have good doctors doing research that will help all of us who are live with this disease. It is no way a 30 day cure just a hell of away to live the rest of your life and for a child just starting out and for people who are late stage. We need help. and ~~can~~ leave our doctors alone  
Medicine needs of now.  
St. Peter's New Brunswick N.J.

This sheet was not used in my whole story

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Bergen

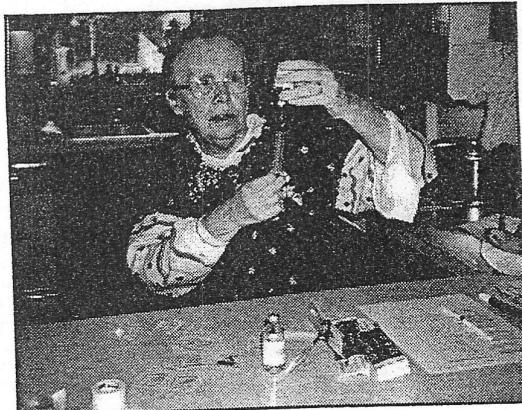
Name: Dorothy 

Total cost: \$6,000

Number of family members with LD: 1

Lost work/school: Permanent

Number of years sick: 2



As a Square Dance Caller, I worked on Sunday nights. But the first Sunday in December of 1995 will always remain in my memory, because sudden groin pain was so severe that I was unable to finish calling the evening's dance - this had never happened before, and although I was embarrassed, the pain overcame - I had no choice. At this point, we began the rounds of various doctors and tests. Of course, many symptoms disappeared without warning, and were forgotten; we didn't connect them to each other.

The groin pain resulted in a specialist suggesting a colonoscopy, which was unsuccessful and resulted in two Barium enema tests, with negative results. In January of 1996 my left foot had a numbness, and I visited a podiatrist who suggested different shoes (I've since discovered the word "fasciculation" which described my foot perfectly). In February of 1996 my vision was severely affected, but I blamed it on the temporary office work I was doing. While the vision didn't improve, at least the numb foot and the groin pain went away.

That June I attended a square dance convention in San Antonio, but found knee pain so disabling that much of my time was spent searching for elevators rather than stairs. Since I was travelling by train, I had to make special arrangements with Amtrak to use their disabled facilities (overnight). Someone at that point suggested WD 40 to be sprayed on my knee. With nothing to lose, I tried it, and it helped for awhile.

My condition continued to deteriorate, with total lack of energy or enthusiasm about anything, until October of 1996 when my depression was quite severe. At that point, I developed severe headaches that never ceased in a 24 hour period, and I wanted to kill myself. An MRI was performed one night at 11:30 because the pain was so severe I couldn't sleep. Negative again. Unable to walk upstairs to bed, I slept on the living room floor (day and night). Recently when I asked my daughter if I ever gave a reason for lying on the floor, she replied: "You said because it didn't move". For a two week period, with the headache being constant, friends and relatives came in and out of the house, trying to get me to eat, get dressed, etc. At one point, a friend dragged me to her chiropractor, because my headache also included a stiff neck, and this resulted in two things: (1) the headache went away and (2) he diagnosed me with Bell's Palsy.

Also during this period, I visited our family doctor, an internist, and unknown to me, he sent my blood for a Lyme test. Finally a neighbor took the bull by the horns and carted me off to the emergency room of the local hospital where they treated me for the Bell's Palsy, and took a blood test for the possibility of Lyme. Home from the hospital a few days later, I was phoned by the internist who said I had Lyme Disease and should begin antibiotics immediately. I was unresponsive, had no recollection of being bitten, never had a rash, and ignored him. Two days later I was back in the hospital (dehydration, among other things) and IV antibiotics were begun.

The doctor at the hospital (not my internist) was not familiar enough with Lyme to order follow-up oral meds after the 3 week IV was finished. I felt better for awhile, but in January of 1997 realized that even though I didn't want to believe it, I was really SICK. That was when I contacted 1 800 TICK BITE, got the name of a specialist, and went to work to heal myself. Yes, the patient must become actively involved! Dr [REDACTED] prescribed Suprax and I began a diary (which today is 16 pages of tiny print). At the end of a month, I felt worse than before, and we moved on to oral Doxycycline. Meanwhile, Dr [REDACTED] tried to get my insurance company to permit additional IV. While waiting for this approval, we moved on to Zithromax, which made a big difference in my health, so that I was able to take a vacation with minimal discomfort. Finally, in June of 1997 approval was granted and we began with Vancomycin which was toxic to me. Once we got back to Rocephin, improvement was quick (six more weeks). Then we went back to Doxy and Zith until October 1997, when I was discharged.

Today, February 1998, I still don't have my energy back, but am accomplishing more around the house than before. I've applied to Social Security for disability - the memory loss during LD was such that calling a square dance is impossible - memory is necessary. My vision is still poor, and I'm no longer driving at night - another reason not to be calling square dances, most of which are at night. Depression is gone at last, and I'd like to offer support to those who are suffering, as I did, with mental anguish and loss of feelings of self-worth, which many days was worse than the physical pain. Yes, I still have pain in my legs, and bear it during the daytime, then take Percodan at night to sleep.

We were able to backtrack from my first symptoms to estimate the actual bite probably took place in October 1995, because that was when I visited Toms River and helped my mother by clearing out gardening debris and tree branches from her backyard - without any protection, of course, never even dreaming about LD. Now I know better!

The photo enclosed was taken during my first session of Rocephin, November 1996. My hair stopped growing, my fingernails were breaking without cause, and I have dyslexia. My sense of humor is still intact, and the line that helps me a lot is:

**“Aside from that, how did you enjoy the play, Mrs. Lincoln?”**

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut  
County: Hartford

Name: Beverly 

Total cost:

Number of family members with LD: 1

Lost work/school: 1 week

Number of years sick: 1-2 years



I FEEL THAT I AM ONE OF THE LUCKIER LYME DISEASE STORIES, DUE TO A VERY PERCEPTIVE DOCTOR, GOOD ADVICE FROM A SUPPORT GROUP LEADER, AND AGGRESSIVE TREATMENT. FOUR YEARS BEFORE THE MAJOR SYMPTOMS, I WAS BIT BY A TICK. ONE WEEK LATER, I HAD A ROUTINE PHYSICAL FOR MY JOB. MY DOCTOR NOTICED THE BIG RED RAISED AREA ON MY LEG AND TREATED ME WITH ANTIBIOTICS. HE PUT IN MY CHART ? Lyme disease, WHICH I DID NOT SEE UNTIL YEARS LATER WHEN I HAD TO CHANGE DOCTORS. AT THAT TIME LAYMEN NEVER HEARD OF THIS DISEASE AND FEW DOCTORS HAD COME ACROSS IT. ABOUT 3-4 YEARS LATER, I BECAME VERY TIRED AND MY ARTHRITIC SYMPTOMS BECAME MORE SEVERE. GETTING OUT OF BED WAS A VERY DIFFICULT TASK. I WAS VERY LAME AND HAD NO ENERGY. I CONTINUED TO WORK, BUT STRUGGLED TO STAY AWAKE. I WENT TO MY DOCTOR (A DIFFERENT ONE FROM YEARS BEFORE) HE RAN A SERIES OF TESTS WITH NO INDICATION OF ANYTHING IN PARTICULAR. I ASKED HIM TO TEST ME FOR LYME DISEASE, WHICH I HAD ONLY HEARD OF IN THE FEW MONTHS BEFORE THAT TIME. HE DID SO RELUCTANTLY AND THE RESULTS WERE MIDDLE OF THE LINE, ACCORDING TO HIM. HE PUT ME ON A DOSE OF ANTIBIOTICS FOR A SHORT TIME WITH NO RESULTS. ABOUT THAT TIME, I HAD ALSO HEARD OF A PROGRESSIVE DOCTOR WHO WAS TREATING PEOPLE FOR LYME DISEASE. I GOT THIS INFORMATION FROM A LOCAL LYME DISEASE SUPPORT GROUP. THE NEW DOCTOR PUT ME ON MEGA DOSES OF ANITBIOTICS, WITH SOME SUCCESS. THIS WAS SHORT LIVED AND HE DECIDED TO TREAT ME INTRAVENOUSLY WITH I BELIEVE WAS ROSEFIN FOR SIX WEEKS. WHAT A DIFFERENCE!! IT HAS BEEN ABOUT FIVE YEARS SINCE THOSE TREATMENTS AND I AM STILL FEELING QUITE WELL. THERE HAVE BEEN SHORT TIMES I HAVE QUESTIONED SOME SYMPTOMS, BUT FOR THE MOST PART I AM FEELING WELL. I ONLY WISH OTHERS HAD AS POSITIVE RESULTS AS I HAVE. THERE ARE MANY PEOPLE IN MY AREA WHO ARE SUFFERING A GREAT DEAL.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Maine

County: Oxford

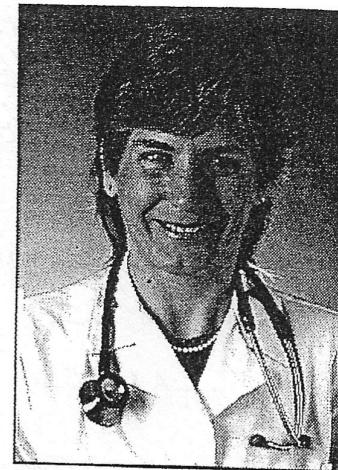
Name: Teresa [REDACTED] D.O.

Total cost: \$20,000

Number of family members with LD: 3

Lost work/school: 4 month

Number of years sick: 8



I was well until 1989 when I moved to Pa. Camping, Hiking, canoeing - were favorite activities. Fall 1989 severe flu-like symptoms followed by fatigue occurred. Every 2-4 months thereafter had stereotypic bouts of "flu" - low grade fevers, fatigue, muscle aching, knee pain, headaches, stiff neck, and difficulty concentrating. Saw several Doctors - Lyme tests negative. No treatments given. Changed work from full-time ER to Part time (No call, No nights) family practice. I didn't seem to have the stamina I'd used to have.

July 1997 [REDACTED] sided severe Neck pain + stiffness. Lost appetite, severe headaches, insomnia, cognitive problems - Anxiety, 12# wt loss, occ. diarrhea. Thought I had a depression until I realized <sup>how</sup> sick I felt. Received a call from Beth [REDACTED] - who had Lyme years ago. After doing my own research, I realized Lyme was the most likely diagnosis.

I found that 3 labs in the country that could do reliable testing. I was admitted to the hospital urgently one night after awakening to a numb & paralyzed R leg. The Neurologist, Infectious disease doctor & internist all told me they doubted I had Lyme disease, but placated me by doing the tests I ordered. A spinal tap was normal at the hospital lab, but Igenex showed a + PCR on the CSF and + Urine Antigen <sup>for Lyme</sup>. I have been on IV antibiotics for 2 months. have been totally disabled; although some improvement in last 2 weeks.

My R leg function loss was transient, but had prompt treatment not been instituted more permanent dysfunction could have occurred.

Only because I was a doctor, doing my own research and ordering my own tests was I able to get treatment. The articles I've read and lectures I've attended on Lyme, have not spoken adequately about the multisystem symptoms, the problems of diagnosis, and the need for prolonged treatment. Since my illness has been made public, people have come forward requesting testing. The number of positive test results here in Maine continues to boggle my mind. Funding is needed for better diagnostic tests, vaccine development, and effective treatments.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

Name: Michael Dirk



State: Maine

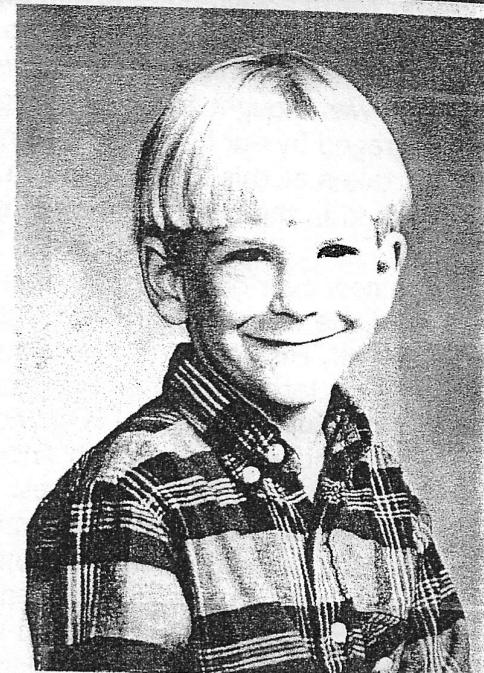
County: Androscoggin

**Total cost:** over \$200,000

**Number of family members with LD:** 3

**Lost work/school:** Yes

**Number of years sick:** Not known



Michael was diagnosed with Lyme disease shortly before his 6<sup>th</sup> birthday. We had never found a tick on him nor seen the bull's eye rash. He was tested because his mother suddenly developed neurological Lyme and Babesiosis. By the CDC criteria Michael's Western Blot was read as negative. But I had done my homework and knew that positive bands 31 and 34 were important and pointed to Lyme exposure. Although local doctors including specialists, advised us to ignore the test, telling us it was probably a false finding anyway and assuring us that Michael looked well. But after seeing the severe illness in his mother we chose to see an out of state pediatrician experienced in Lyme disease treatment for a second opinion. He was started on Suprax and within 3 days had flulike symptoms as we learned were common Herxheimer symptoms seen during Lyme treatment. He had fever 101.F, no appetite, sad, sleeping a lot, and complained of aching in leg and feet. After 3 days he was back to his usual energetic, cheerful self. About every month or two he'd have another 1-2 days of these same Herx symptoms, but did continually better each time.

It was interesting to note that things that we had considered normal childhood occurrences went away. He was no longer having his occasional nightmares, or night sweats. Shooting pains in the legs at night which had caused Michael to awaken screaming for the last two years were no longer happening. Since Michael was two he had been watched closely for growth delay being in the minus tenth percentile on the growth charts. During the first year of Lyme treatment he grew 4 inches putting him back in the normal range. Could all these changes just be coincidence, we asked, perhaps.

After six months of no symptoms we took Michael off his antibiotics. We were hoping we were done with Lyme. However, within one week the nightmares, the sweats, and afternoon tiredness were back. Leg pains began recurring, so severe he screamed and cried at night as we tried Tylenol, cold

packs, warm packs, holding him until he could fall back to sleep. He also began complaining of knee pain and bugs crawling on his right leg. He was then started on Zithromax which in one week caused total body hives. This reaction at first was thought to be an allergic reaction to the drug, but we were encouraged by our Lyme consultant to continue the Zithromax with Benadryl. LUAT taken at this time were high. The hives were a form of Herx reaction as is described in the medical literature.

It was now over one year since we had started Michael's treatment for Lyme disease. He tested negative for Babesia and Erhlichia, and appeared to be doing well. His antibiotics were stopped and a Lyme blood culture was done two weeks later. It came back positive and showed resistance to his old antibiotic Suprax. Michael is now on dual therapy. We decided not to opt for the wait and watch approach since Lyme had already demonstrated to us its potential for ruining human lives. We were not willing to gamble with our son's life. We understand that sometimes long term antibiotics are needed because of the long generation time of spirochetes, such as *Borrelia burgdorferi*. Many children with Lyme have not been as fortunate as Michael.

When a better diagnostic and screening test is found, more accurate reporting of Lyme disease will begin. When the actual widespread incidence of Lyme disease is known, research dollars and effort will be directed toward finding a cure. Until then the darkness and fear of this medical nightmare continues.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey  
County: Middlesex

Name: Andrea 

Total cost: \$1000

Number of family members with LD: 1

Lost work/school: Lost job 3 yrs. ago

Number of years sick: 4

Let's start with insurance first. I became sick in '92' after sinus and several pain went through many of test all negative. Then anxiety set in along with pain attacks & belonged to RCHP ~~Physician~~ at the time just medication, then severe foot pain in and out of emergency room went to specialists, surgeons, knee doctors, also confusions, short term memory loss, hair loss, muscle pain. In '95' I had enough of RCHP, and come out of network (RCHP) paid on my own for a private doctor who diagnosed me with one look and saw left palsy and a rash on my chest with knew I'm late stage Lyme, all because doctors at RCHP would not listen to me and refused me when I asked for a Lyme test, he told me everyone is Lyme crazy, and go see a local shrink and ran off to ~~his~~ his baby shower given by his ~~ex~~ nurses. (that doctor)

So my doctor ~~know~~ has been treating me since 1995 and I'm still on medication, we need the medical board to ~~leave~~ our doctor who care and want to help us alone stop ~~the~~ threatening their license, or you there will be less on the hand like aids.

I'm mother 4 children who depend on me daily 24 hrs a day I need to function, I have not been able to work for 3 yrs. my job was a C.P. for a School like how could I help other people children when I can't function for my own. This disease makes us live in limbo. It's distorted my life for 5 yrs. I don't know ~~why~~ few people can see this disease the only disease when it's should be called the horrible disease.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

Name: Joshua 

State: Florida

County: Pinellas

Total cost: \$20,000

Number of family members with LD: 3

Lost work/school: weeks

Number of years sick: 8.5

Joshua got sick at 6 months of age. He would turn pale, vomit, sleep for 18 hours a day. He had fevers as high as 105, red rashes - never a bulls eye. We saw over 10 specialists who had no answers. On Joshua's 2nd birthday we were at All Childrens Hospital having a feeding tube placed. Over the next two years he would get better & then relapse. We noticed that every time he took antibiotics he would turn pink, eat, play etc. He had a positive Elisa test for Lyme but since the western blot was negative - we were told it's not Lyme. One doctor suggested we try Foster care and suggested I might be causing his problems. We were devastated when Joshua began holding his head & crying we had an MRI done & it showed white matter disease. Fearing a fatal disorder "leukodystrophy" we went to Johns Hopkins. They could not identify the problem but verified something was destroying brain cells. After several long periods of ~~medications~~ antibiotics he improved, got rid of the feeding tube etc. By all appearances he is a normal, happy kid but continued to have flu like spells. When I discovered that I had Lyme we retested him and he showed Lyme Antigens. We saw the infectious disease doctor who cared for our son as an infant. Joshua completed 2 months of Doxycycline with resolution of headaches, joint pain, hoarse voice, & nausea.

It is now 3 months since that time & Joshua is going downhill. We are seeking a doctor who handles his case but no one here treats kids with Lyme. We have had to fight this disease for 8 1/2 years. We are not going to quit now!

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

**State:** New Jersey  
**County:** Middlesex

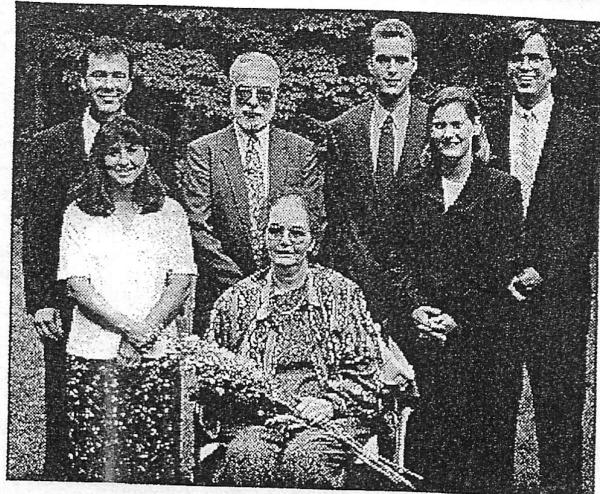
**Name:** Ann 

**Total cost:** up to \$500,000

**Number of family members with LD:** 1

**Lost work/school:** Forced to retire on disability

**Number of years sick:** 7+



### ANN'S FIGHT WITH LYME

#### How did it happen?

**I**n the summer of 1989, Ann developed a rash on her legs. Her doctor at our HMO treated it as if it was a topical rash with a cortisone ointment and gradually it disappeared. However, she gradually developed the classical symptoms of Lyme Disease—soreness in her joints, head symptoms—feelings of heat, movement, lightheadedness and dizziness, plus slight urinary incontinence. She suffered from frequent urinary pain and all the symptoms of bladder infections, but generally tested negative for bacterial infection. The bladder "infections" were treated off and on with antibiotics.

**F**inally, after persistently returning over and over again to the doctor to try to get relief from the persistent feeling of illness, she was tested for all sorts of possible diseases, including MS, among others; had MRIs, saw numerous specialists, and underwent too many tests to remember. After about a year of fruitless searching for a reason for her illness, the doctor finally prescribed the ELISA test for Lyme Disease. It tested positive and she was given the standard three-week dose of amoxicillin. Unfortunately, after about a week or so she developed a massive allergic reaction, with hives everywhere and eventually near total skin peeling. She was then given doxycycline for about a two-week period. Repeated bladder "infections" continued to plague her and usually resulted in a ten-day course of doxycycline. All the while the other Lyme symptoms continued to worsen.

**F**inally in the summer of 1991, she convinced the medical experts, primary care physician and her supervisor, at our HMO that she was still suffering from the Lyme infection. They finally agreed to prescribe a two-week course of the intravenous antibiotic Rocephin. After two weeks, she was so much improved, she convinced her primary care physician to continue the treatment for another week. Then after three weeks, most of the symptoms were gone and by strong and persistent argument, convinced the head of the medical unit to continue the treatment for another week. At this time, in July 1991, all of her symptoms were gone!

**U**nfortunately, this was the last time in her life that she was to be symptom free. The Lyme

### MCCHESNEY FAMILY

Chip Charles Dan Matt

Holly (Chip's wife) Darby (Matt's wife)

Ann (Lyme victim)

symptoms gradually returned over the next two months and then she was referred to the local university and medical school and their "Lyme expert". He observed her decline and diagnosed her as having a case of "fibromyalgia", prescribing low impact aerobics (which were impossible because of the dizziness) or swimming as treatment. Meanwhile, all of her symptoms were returning in generally more serious forms, muscle pain, severe urinary incontinence, dizziness and lightheadedness and difficulty in physical exertion, such as climbing stairs. When her head symptoms returned, he stopped the swimming and finally, in November, he prescribed a three-week course of IV antibiotic, Claforan. It helped to alleviate her symptoms, but not to the degree that the treatment in July did.

**W**ell before this point, our family decided to get out of the HMO, since we were thoroughly dissatisfied with their general lack of competence and the lack of any alternative to their treatment decisions about our healthcare. This situation was totally unacceptable. We planned to resume the appropriate treatment with another physician after the end of the policy year, since at that point, there was no alternative to paying the full price of any care outside the HMO. We decided not to go outside for IV treatment, costing about \$3-4000/month. We realize now that was probably a very bad decision.

**O**ur new doctor specialized in Lyme related cases and when Ann was first examined by him in late 1991, he prescribed an oral antibiotic to "carry her over" to 1992. Then he made every effort to treat her with IV antibiotics, using several different ones over three to four months. Then he used oral antibiotics, but was never able to eliminate all the symptoms, the most refractive one being the urinary incontinence. He even tried steroids, having heard that a doctor on the West Coast was having some success. These made the incontinence problem even worse, in fact, one day in the grocery store her incontinence was so bad that her urine ran out on the floor, after saturating the Depends and Serenity pads she always wore. Finally, our doctor recommended we seek help at one of his colleagues who had some success with especially difficult Lyme cases.

**S**tarting in early 1993, her new doctor started continued to try different antibiotics, both singly and in combinations, often pulsing them. He also changed them when they seemed to lose their effectiveness, which was generally after about six weeks or so. In addition to the drugs, he also recommended that several herbs, vitamins and minerals be part of the therapy. During this time, she was on IV therapy for several courses, one as long as five months. Unfortunately, she did not improve, gradually losing her mobility and becoming partially paralyzed on her right side. All the other symptoms gradually worsened, with brief periods of improvement when a new antibiotic was used. The improvement was always short lived. It seemed that when the organism became acclimated to the new antibiotic, it roared back stronger than ever. This course of treatment continued until the end of July 1995, when Ann slipped on a rug and fell, fracturing her hip. A couple of weeks later her physician committed suicide, leaving her without anyone who were familiar with her case.

**W**hile she was recovering from her surgery first in the hospital and then in a rehabilitation hospital, serious problems with orthostatic hypotension prevented her from having much physical therapy. She had a lot of tests to confirm her Lyme disease, including spinal puncture, PCR and others we can't remember. These were mostly negative, unfortunately the lab threw out her spinal fluid before the PCR could be run.

**I**n late 1995, we became frustrated with our primary care physician and again sought a Lyme expert. We found him in Westchester County, NY. He very carefully analyzed Ann's condition and after about three months decided the only alternative was to restart IV treatments. Since we lived so far away, we made arrangements to have a local doctor supervise the medication. When the managed care company refused to allow the IV medication, we decided to continue to try oral antibiotics. Since the 1995 hip fracture, Ann has never regained her mobility, being too dizzy to walk more than a few steps and being unable to use a wheel chair because of her paralysis. Due to her incapacity, she was forced take disability retirement from her position, which she loved, as an assistant professor of Nutritional Sciences at Rutgers University. She is confined to a hospital bed except to visit her doctor and on rare occasions when she is feeling up to going to church or for a short ride. She requires a full time attendant for all necessary daily activities (toileting, eating, bathing, etc.).

**R**ecently, a neurologist diagnosed Shy-Drager syndrome, a degenerative nerve disease. If this diagnosis is correct, it was probably caused by the long-term struggle with Lyme disease.

## What effect on the family?

**N**eedless to say this illness has had a devastating effect on her life and our family. She is confined to her bed and our home; cut off from her lifework, her associates and her students that provided her with mental and psychic stimulation and rewards. Before her hip fracture, her students would wheel her around on her desk chair and change the overheads during her lectures. They and she really enjoyed the stimulation and interaction of the learning process. Now, when Charles is not at work on weekends, he spends them caring for Ann.

**P**erhaps the only good thing is the decision of our youngest son to pursue a medical career by attending medical school. He was in denial about his mother's illness until the hip fracture, when he finally realized she was really ill and he would have to deal with it. Our other two sons were in college most of the time of her illness and seemed to never be really effected negatively.

## What did it cost?

**T**he cost of this illness in terms of the healthcare dollars is incalculable, I estimate the medications, tests and physician bills to date are between \$450-600,000. At the end of 1994, the total insured cost was more than \$250,000. That doesn't count the HMO cost before 1992, estimated to be about \$150,000.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Ohio  
County: Franklin

Name: Shirley 

Total cost: Unknown

Number of family members with LD: 1

Lost work/school: 6 months

Number of years sick: 1 1/2

In 1991, I acquired Lyme disease from a dog tick which fell onto my bed when a cat came into the house. The tick embedded itself on the inside of my thigh, and I found it a couple nights later. Fully engorged, it was removed improperly, and I went to a local doctor because the area had become infected. He prescribed a short course of doxycycline at a low dose and two weeks later, I still had symptoms (rause, light sensitivity and taste problems). I went back to the clinic to a different doctor and was prescribed 1 week's worth of amoxicillin. I still had symptoms, so I found a Lyme literate physician who treated me with a month's worth of Cefixime, followed by a month of Suprax and 12 weeks of IV's. 8 weeks of Rocephin and 4 weeks of Clefazime, I still had symptoms, so he referred me to a "lyme specialist" in Pennsylvania. I had amoxicillin/erathromycin for 2 1/2 yrs. and was fully functional, able to work again. I was so happy and grateful! I picked up from where I left off in 1991. I worked full time, pursued further education, got engaged and totally forgot about Lyme.

However, it was a little more difficult to forget about the optics (reunited I had contracted from Lyme Disease, I was treated at Ohio State University in 1991 and completely recovered from it also).

My life went well in the following four years. I had a job with a high distribution firm in Columbus. I never missed work. I spent too many hours. I enjoyed life to the fullest and did all that I could to make up for the time lost in 1991.

In July, 1996, I was riding with my fiancé a dairy farmer on his tractor. I rode for about two hours, then visited a friend in another rural area south of Columbus. I had sprayed repellent on myself before I visited the farm - just in case I carried the repellent in my car, too, and stayed it during visits to the farm during the summer months.

OVER

A couple of days after the farm visit, I started to feel like I did in 1991—nauseated, not well, numbness in legs and feet, <sup>burning</sup> pain in my back (I recognized this as probable Lyme disease). I had a place on my back that itched. However, I was on amoxicillin/ampicillin for a tooth infection, so I didn't seek medical attention. About three weeks later, after a rough July, the symptoms melted away, and I came back to my 100% self again. I thought that if I had Lyme, the penicillin Lyme meds took care of it.

About this time, I received a promotion at work. I did not want the position, others talked me into applying for the job. I was quite happy with the job I had and when I got the job, I didn't know why I applied. Then I realized that what I had was probably hyper pressure, and it affected my thinking processes at that time. After this bout of whatever this was, I developed hypersensitivity in all of my five senses - taste, smell, hearing, vision and touch became very acute. When I stepped into the shower, the water would feel two different temperatures on my body. Droopy eyelid appeared, but that was left over from 1991. I made little connection to Lyne at this point, and my life went along fairly well, except the panic attacks.

blood, so I didn't think it was a bite. A couple of days later, I had symptoms like I had in July. I wondered if it was Lyme, but didn't call anybody knowledgeable for help - like the LD F. I had early LD symptoms and he suggested I call the Lyme doc who treated me in 1991. I went to a local doctor and by the time I got there, I forgot to mention LD. She thought it was a tooth problem, because now 4 days later my teeth hurt. I left the office and thought, "I think I have LD and I don't want to be thus diagnosed." Still I didn't call anyone else. I went back to the doctor; I told her I thought something bit me & I could not make up my mind, but I got about it, "the Lyme". She called me. I still had swelling around my eyes but I'd made a decision on what to do. She already hit me neurologically and I couldn't make up my mind on what to do. I called a couple of my Lyme friends and they told me to call the Lyme specialist. Still I couldn't do it. I thought it was too late and this was only 1/2 days after the bite. Finally, I called, but the medication I did not help. I kept slipping till I finally had to quit my job. I did IV's, shots, and will never be like I was. I keep blaming myself, but I realize that Lyme affected me so quickly, I couldn't respond as normally would.

# THE MANY FACES OF LYME DISEASE WE ARE NOT JUST NUMBERS!

State: Connecticut  
County: Hartford

Name: Chris 

Total cost: \$100,000+

Number of family members with LD: 1

Lost work/school: 23 1/2 weeks

Number of years sick: 10 years



## LYMERHYME

I know I once said it,  
But now I forget it.  
To think is a difficult strain.  
My guess is you're thinking  
I must have been drinking,  
But it's Lyme disease in my brain!

I'm incredibly foggy,  
Feeling lifeless and groggy.  
I'm depressed and frightfully weepy.  
This disease has me yearning,  
While tossing and turning  
All night when I'm not even sleepy.

My joints are all achy.  
My heart's achy breaky.  
I've got this low grade afternoon fever.  
I was bit by a tick  
That's made me real sick;  
Now I'm a Lyme bug believer.

I know it's bacteria  
And not just hysteria,  
As purported by some academicians.  
It was found in my blood,  
This *burgdorferi* crud,  
And confirmed by five different physicians.

For me it's been chronic,  
and now histrionic.  
That my overall health's been affected.  
It's nearly five years,  
And now I have fears  
I will be forever infected.

So I'm suing Blue Cross  
For not covering the cost  
Of prescribed I.V. antibiotics.  
Dr. Schoen will be named,  
And partly blamed,  
As a consultant of misdiagnoses.

As part of my suit,  
I will mention, to boot,  
That Blue Cross denied life insurance  
Due to information  
On my application.  
(I mentioned the Lyme in concurrence.)

The firm kind of said,  
"We can't have you dead,  
So no life insurance there'll be.  
Since you have this disease,  
We say 'no thank you please',  
And we still will not pay for I. V."

It's sad but it's true  
That I have to sue;  
But I'm determined to get my bills paid for.  
My disease is insured  
For prescriptions incurred.  
That's what insurance was made for!

Interesting enough,  
Though it's been tough,  
From this illness I have something to gain.  
I've come to believe,  
Rather than grieve,  
There's some purpose in all of the pain.

Day after day,  
I press on my way,  
Helping others who I know are infected.  
It's become a life goal  
To assist in the toll.  
Perhaps that's why I was selected.

Yet, I pray for a cure  
As I try to endure  
This affliction of tick borne disease.  
It might be a miracle,  
Though not very empirical,  
That causes these symptoms to ease.

In conclusion I state  
That some docs I berate  
For their foolish denial of the facts.  
While as long as I live  
There is praise that I give  
For my doctor and his selfless acts.

It's he that's been treating,  
And I believe beating,  
This spirochete down to the core.  
Without him I'd died  
From borrelia inside.  
So I've dubbed him a saint evermore.

Still there will be those  
Who take payment for prose  
That is written on behalf of their greed.  
But they just may get  
This disease *a la tête*,  
And then a good doctor they'll need!

Perhaps there's a chance  
Of a tick in their pants  
To bite them while they're not suspecting.  
For when they are infected  
They'll be rejected  
And curtail what insurers are expecting.

Then they would know  
The life that is so  
Unbelievably changed and insulting.  
And they'd search for the cure,  
No longer to lure  
Insurance for third party consulting.

Now you've read in verse  
My Lyme rant and curse  
Of ill fated health to recover.  
Perhaps you can say,  
If you're feeling this way,  
There's some hope for you and for others.

Keep a good heart,  
With a positive start,  
Through the difficult maze of diagnosing.  
You'll be okay,  
Perhaps cured one fine day,  
With your doctor's antibiotic dosing.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: New Jersey  
County: Morris

Name: Patricia 

Total cost: Lots

Number of family members with LD: 1

Lost work/school: Have lost my job

Number of years sick: 14



Got Lyme on Memorial Day 1983. Had rash and flu and was told I had shingles. I saw over 35 doctors and specialists in the years that followed and was diagnosed with Chronic fatigue syndrome, ADD, ulcers, irritable bowel, depression, manic depression. I had various joint and muscle problems which were attributed to my efforts to keep fit - bicycling, hiking.

During the first twelve years I had long periods of being well interspersed with sick periods. My ability to concentrate varied with the degree of sickness or how well I felt. In 1992 I left an excellent job at AT&T and went on long term disability. In early 1996 I was diagnosed with Lyme and until June of 1997 was on oral antibiotics. In September 1997 I was put on Rocephin IV and am now getting 4 grams per day 4 days per week.

I now can get up and get dressed each day. I can also brush my teeth once and sometimes twice a day. I can occasionally cook for myself. I have trouble keeping up with my bills and have most all of them paid directly. I have trouble with even the simplest decisions. I can sometimes walk for 2 miles but other days can not put one foot in front of the other.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut

County: Fairfield

Name: Brian

Total cost: \$6,200

Number of family members with LD: 5

Lost work/school:

Number of years sick: 2 1/2



This photo was taken 4 months after moving to our new home. It's hard to tell that Dad already had late stage Lyme disease.

Three weeks after moving to area known to be endemic for disease carrying ticks, I developed flu-like symptoms and a small pink rash on my leg. I was bed-ridden with aches and fatigue. Concerned, my wife sent me to the doctor for the first time since I had known her. I was lucky. I had classic symptoms of Lyme disease, which were supported by my highly positive blood work. Unfortunately, I was treated for only three weeks, which is considered standard. For the most part I improved, but four months later I relapsed with debilitating fatigue and arthritis like symptoms. Lucky again, my blood work was still positive so it was easy for me to receive an additional month of antibiotics. When I continued to complain of sore joints and occasional headache and fatigue several months later, I was told I had a post Lyme syndrome. My symptoms would resolve in time. Given that my symptoms were more a nuisance than a disability, I was able to accept that diagnosis.

During the next year, several members of my family developed more serious cases of Lyme disease. As we began to see doctors who were more knowledgeable about the illness, I learned that post Lyme syndrome is a crock. Persisting symptoms most likely mean persisting infection. Three years after the initial infection, I was still experiencing symptoms and still testing positive for Lyme. I have been treated aggressively with antibiotics for the last 5 months, and I am feeling noticeably better. It's frustrating to think that even with clear cut symptoms and positive serology, I was unable to get adequate treatment early in the disease. Ignorance and undertreatment has caused my illness to become unnecessarily prolonged.

My story is unfortunate, but thankfully not serious. However the story of my family's struggle with Lyme disease has turned out to be a father's worst nightmare. Read on for the accounts of my wife and children. Lyme disease has completely overturned our life and has cost \$ 352,000 so far.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut

County: Fairfield

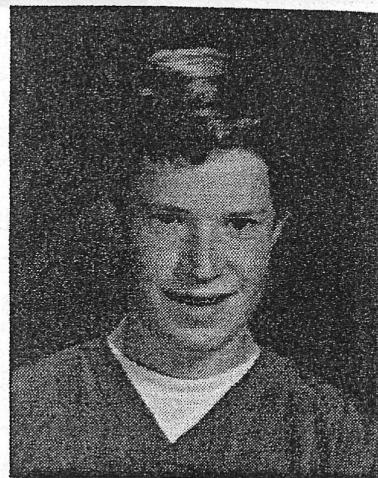
Name: Brian  (15)

Total cost: \$81,000

Number of family members with LD: 5

Lost work/school: Only goes part time

Number of years sick: 2



Brian was an exceptionally bright, outgoing and healthy child. At 12, he was a state high scorer on the SAT exam, which was given to 7th graders as part of the Johns Hopkins Program for Talented Youth. Active in football, swimming and church activities, he also wrote sports articles for the town newspaper, and played trombone, tuba and piano. He now suffers from chronic neurological Lyme disease. Now 15, he has had to give up sports and most of his other activities. He had to drop several of his advanced courses due to memory problems; poor concentration and dyslexia. He can manage a shortened day at school and needs classes in special education. He has had to give up many high school social activities. What follows is his story in his own words.

I had always been healthy until 1995 when I noticed joint pain in my fingers and toes, mild fatigue and an unusual case of clumsiness. My mother and sister were being treated for Lyme disease, so I was sent to a doctor quickly. After 6 weeks of treatment, I was relatively symptom free until December 1996. While on antibiotics for a bronchitis infection, I suffered a Jarisch-Herxheimer reaction to the medication. My mother recognized this as a response often associated with treatment for Lyme disease! I experienced massive fatigue, heavy arthritis and strange cognitive problems. I reversed my words, had difficulty spelling simple words and noticed memory deficit. The mild joint pain I experienced prior to this reaction (which I incorrectly attributed to growing pains and football injuries) became exacerbated. I was treated for six months beginning in January 1997, but progress was negligible and new symptoms emerged. My balance was severely off; I would fall if I closed my eyes. In June I underwent surgery to implant a permanent IV catheter in my chest. I have been on IV since then and have also undergone hyperbaric oxygen therapy. Improvement is painstakingly slow. I am in need of a 504 special education plan. I had to drop 3 advanced classes due to neurological difficulties which absolutely impact academic performance. Tests taken at my school indicate I can only process small pieces of simple information at a time. I expect to be on antibiotics for the foreseeable future and am concerned about how this will impact my admission to college. The scary part of this story is that my early symptoms were vague and easily explained by common childhood problems. Initial treatment was probably not aggressive enough, allowing the disease time to entrench itself in my brain. My illness, which is "invisible" to the public, has thrown my family a financial, physical and emotional curve ball. I thank you for your time in examining this disease and our stories.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut

County: Fairfield

Name: Erin 

Total cost: \$150,000

Number of family members with LD: 5

Lost work/school: 6 months

Number of years sick: 2 1/2



Before



After

Except for a few sore throats, I have never been sick. I kept a busy schedule. I got good grades, I swam competitively 10 hours a week and played 2 instruments. During a race on the 4<sup>th</sup> of July (in '95), I felt like my legs were too heavy to move. Two days later I was in the pediatrician's office because my parents thought it was LD. He gave me 3 weeks of amoxicillin, and took an Elisa blood test. It was negative, so treatment was stopped. At this time I was 10. 6 months later I started to have chills and headaches. I also experienced light sensitivity and needed sunglasses. My Lyme test was <sup>positive</sup> for an old bite and the new doctor said I had relapsed. I was given 4 weeks of I.V. Rocephin. My parents thought I should have more medicine but the doctor said I was fine and that kids respond better than adults. That's what we wanted to hear so we believed it. I felt fine for 7 months. Then started mild twitching, headaches, a swollen knee, and chills. I went to a Lyme pediatrician in 12/96 who started giving me medication. He took a Brain SPECT<sup>†</sup> which showed my brain was a mess. By 2/97 I was having terrible seizures. The seizures were so bad that we took all the furniture out of a room so I would not hurt myself when I had a seizure. A typical seizure would last several hours, and could not be contained. I was hospitalized for ~~3~~ days. I had many tests which showed nothing. They said I had psychological problems and was acting out because my mom was sick. We went to a Lyme literate psychologist who said I was coping beautifully with my disease and that Lyme was the cause. Soon after I developed narcolepsy. I would fall asleep 300-400 times a day. I was in a wheelchair because I would fall when I had narcolepsy. I didn't go to school during the 6 months that I had these symptoms. My family and I went to PA for HBO therapy for a month. This was helpful. I am almost 13 and go to school only part time. I go in a cab and have an aide because of the narcolepsy. I require specialized because it is hard to learn new things. I have been on an I.V. for 9 months and the road to recovery is a long one. I will never be completely cured and I will always have to worry about my Lyme disease coming back. Although I have missed out on opportunities with my friends I enjoy learning about the science behind this disease and would like to be a doctor.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut  
County: Fairfield

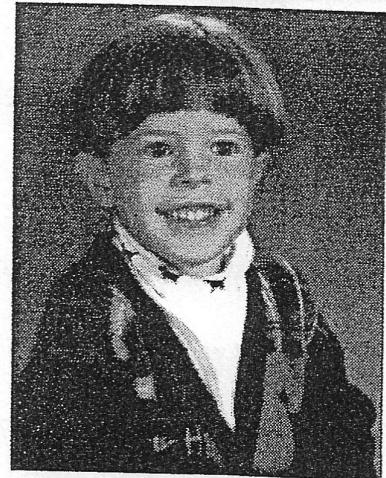
Name: Kevin  (5)

Total cost: \$18,000

Number of family members with LD: 5

Lost work/school:

Number of years sick: 2



LD can be extremely difficult to diagnose in kids who have trouble describing vague symptoms. They can appear quite healthy, like Kevin, who is 5.

I don't know how I got Lyme disease. I never went in the woods, but I did play on the grass. Mom had Dad were careful to check me when when I played outside, but never found a tick. I never had a rash and I never looked sick. I went to nursery school every day and was always full of energy. When I was 4, my Mom noticed that I seemed to be favoring one leg. My knee hurt, but it was not all the time. I could play. Whenever my knee hurt, my eyes hurt, too. I would mix up stories and get cranky. I tried to tell Mom that my brain was "sticky" but she didn't know what I meant. It didn't hurt, it just wouldn't work. I would climb up on the sink and put a wet washcloth on my head. On those days, my behavior was hyperactive and I would stutter. Luckily, my parents knew a doctor who was helping my sister with Lyme. He knows a lot about it. It is a very, very long drive to his office. He found arthritis in many of my joints, especially my knees and hands. No wonder I didn't like to use crayons! He understood about "sticky" brain and gave me big pills to swallow. I have had to take my medicine for almost one year. Now I feel better, but I have problems that look like ADD, with attention, and my hands hurt. In kindergarten I have to go to special ed. I use play doh to make my hands stronger so I can color and use scissors. They help me learn to concentrate and learn new things in small steps. It costs my school a lot of money. My parents worry that I will get re-infected at school and that we may miss it again. My Mom, sister and brother have been really sick. I get scared. Lyme disease is very bad. Please help us find a way to get better and to keep us safe from tick bites.

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Texas

County: Dallas

Name: Louise 

Total cost:

Number of family members with LD: 1

Lost work/school: 7 yrs

Number of years sick: 7



I am one of the many faces of Lyme Disease. I do not even know where to begin my story about how Lyme Disease has affected my life. I became ill the summer of 1990 approximately 2 weeks after spending a glorious week of summer camp in the mountains of Colorado with a group of teens from my church. I became extremely ill and went to an Internal Medicine Dr. at Baylor Hospital in Dallas, I had swollen glands visible wherever lymph nodes are. I went through 3 weeks of medical testing for everything from Rocky Mountain Spotted Fever to Strep throat, after 3 weeks of negative tests this Dr. sent me home with a prescription for Prozac and a diagnosis of Clinical Depression! I still had evidence of a rash, temp, extreme fatigue and flu like symptoms. I had NO signs what so ever of clinical depression!

I went to the head of Infectious Disease at Baylor who then put me through numerous other test, including surgery. He did say there was something wrong because I had an elevated ANA blood test. The symptoms continued, he treated the symptoms the best he could. I took up to 6 medications and remained ill. He did assure me that I was not depressed nor was I crazy! I continued seeing him for 5 years for Chronic Fatigue Syndrome, until one day when I was visiting with a Neurologist in my office building who had just done a radio program and detected Bells Palsy on the right side of my face, he suggested I may have Lyme Disease. After that conversation I called my Infectious Disease Specialist who suggested antibiotics for 3 weeks. I noticed some change and asked for another rx of antibiotics. He would only give me 6 weeks of antibiotics, not enough to effectively treat LD.

I continued to suffer missing out on many of my children's activities, unable to do any of the normal things I was used to doing.

In July of 1995 I was seeing Dr. Conrad Speece for manipulation of my back and sharing my story with him. He had studied LD and was sure that I may have been misdiagnosed. He started me on long term abx and within 4 months I was off of all of the other meds that my Infectious Disease Specialist had put me on. I began to feel so much better.

I had a relapse in Sept. of 96 and began seeing a LD Specialist. I have many long term symptoms as a result of Lyme Disease. I suffer from extreme joint pain, fatigue and "lyme fog". My neurological system has been affected and I have extreme headaches.

I am also unable to obtain any type of medical insurance and I am just praying that I do not have a catastrophic illness or accident.

I am unable to work full time and it is extremely difficult for me to enjoy life to its fullest!! As my email address suggested I am very TIKDatLYME!!!

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: California

County: Kings

Name: Rebekah



Total cost: \$4,000

Number of family members with LD: 1

Lost work/school: Senior year of college, plus 3 months so far

Number of years sick: 1



Me with my nephew Eric

### STATE WHERE CONTACTED LYME DISEASE:

Georgia

### COUNTY WHERE CONTACTED LYME DISEASE:

Floyd County

I got a tick bite in Rome, Georgia on Turkey Mountain in July or August of 1996. I also (foolishly) picked ticks off my employer's dog. (I was working as a nanny.)

Neither of these two things were anything I thought much of at the time, UNTIL

1. I started getting headaches...
2. I returned to school to student teach and couldn't stand the noise and didn't know what my supervising teacher was saying or doing.
3. I was in such depression my parents said to come home.
4. I came home and had hallucinations and seizures.
5. I couldn't sleep at night, OR wake up in the day.
6. I was angry at everything and everybody.
7. I couldn't read anymore.
8. I vomited a lot.
9. I couldn't walk down the street
10. My joints hurt.
11. Worst of all, I wanted to die.

I have been undergoing treatment with oral antibiotics since November 1, 1996.

Thankfully, I am getting better. I'm walking, taking dance and doing sewing, writing, crafts, and baby-sitting my nephew, and I don't want to die any more. I want to finish college soon, but every time I feel good for two to three weeks I get a real sick spell. Someday....

Rebekah



Further word from the mother on reverse:

Rebekah I believe would have died from Lyme disease, perhaps not directly, but as a result of the seizures she was having (which have completely disappeared after her undergoing antibiotic treatment.) Either, by having a seizure when driving up and down the mountain in Tennessee where she was in college; or by doing something foolish while undergoing her hallucinations. For example, one night she went outside and slept in an old car in front of our house. When she was sick, that seemed like a perfectly logical thing to do. After she got over the hallucinatory period of her Lyme disease, she said, "I could have been killed doing that!"

Barbara



# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Pennsylvania

County: Chester

Name: Maurene Patsy

Total cost: Could not estimate

Number of family members with LD: 1

Lost work/school: I have been unable to work for over 11 years. Will probably never be able again.

Number of years sick: Estimated to be over 25 years.

Have been treated for 6+ years.



Six years ago I was diagnosed with LUPUS and SJOGREN'S SYNDROME. My current symptoms had started with pain that was diagnosed as a heel spur. The first cortisone shot in the heel took away the pain completely for about three months. After that nothing that was done would stop the pain. I was put through a battery of test to determine the root cause of the trouble. During this time all my joints started to bother me with severe pain. The worse thing about the joint pain would be how quickly my joints would "freeze" on me. I could sit for less than a minute and if the phone rang I could hardly walk to the phone.

The Rheumatologists that I sought help from were both giving me a very negative prognosis. Exhaustion was also quite a problem for me at this time as it had been at times in the past. I have a friend who had done a lot of research (as an interested medical treatment consumer, not as a professional) on Lymes Disease. She convinced me to seek treatment for Lymes. I had been tested numerous times and had accepted the negative results. She drove me to Dr. DeMarco in Egg Harbor, NJ. Dr. Charlene DeMarco treats Lymes if you are symptomatic even if your blood test is negative. She is not participating in my medical plan so I've had to pay a portion of all her charges. She is also a long (1 1/2 hour) drive from my home.

My first LYME prophylactic was "Ceftin". On the oral medication only for three weeks I experienced my first Jarvish Herxheimer reaction. I was deathly ill, too weak to walk alone for 4 days. After six weeks of orals I was put on IV home administered. At first I was on 2 infusions a day, increased to 4 a day after a few weeks. I was on IV for three months. Even though my insurance company had given an OK to treatment they decided they would only pay for the first 2 months and I had already had three. I was taken off the infusions immediately not because it was prudent medicine but because of finances.

While treating me and delving into medical history Dr. DeMarco and also Dr. Buanoncontro (my present Lymes physician) are in agreement that I have had LD for probably 25 years. The cost of those illnesses to me and to my family are too huge to calculate. If indeed they are correct my symptoms started as neurological problems. I started having the "flu" in January and couldn't shake it. I was constantly getting what I thought was a backset of flu. Finally in April of that year I was hospitalized (in Wichita, Kansas) and test were run. All tests appeared to show that I had a brain tumor but no tumor could be found. After about a year of forgetfulness, depression, muddled thinking, exhaustion, etc. the symptoms subsided. Later, severe female trouble began and I had a hysterectomy. Later problems arose that led to a diagnosis of Canida which proved to be false. That was followed by heart problems. This involved an angiogram and was diagnosed as heart valve problems. After moving to this area I had severe exhaustion. After that I started having the foot problem and the cycle of LYME treatment began. Some of the more sever symptoms have been a huge weight gain and no amount of dieting would budge it. (On Optifast at the hospital for six weeks with a 2 pound loss). One year ago I took Phen-fen and lost what I wished to lose but with that gone I am up ten pounds and it won't budge. I am seeing a primary care physician who doubts that any of my problems are Lymes but is beginning to come around. I am driving all the way to Berlin, NJ for Lymes care. In this region, unless a Doctor or a close family member has had this disease they have their heads in the sand. I am also seeing a Naturopath. I have had periods during this entire 25 years that I was asymptomatic. Any stress, physical or emotional will start symptoms. I have not been symptom free in 2 years. My current problems are neurological.

I am writing this letter with pain so sever through my neck and head I can hardly see. I have no energy to face the day and yet I cannot remember a specific tick bite all those years ago. I know that I was diagnosed with Rocky Mountain spotted fever in 1957 when we lived in Arizona but I was only ill about a week. I know I am grateful to people like the Lymes foundation volunteers because I am too tired to fight. God bless you. I hope this helps.

Pat Norman  
(Legal voting name: Maurene Patsy Norman)

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

**State:** Connecticut

**County:** Fairfield

**Name:** Joseph 

Total cost: \$30,000+

Number of family members with LD: 3

Lost work/school: 9 weeks this year

Number of years sick: 1



### Our Story

November 1, 1997

Over the past year, I have been touched by Lyme Disease in many ways. Little did I know that Lyme Disease had played a silent part in our family for over 15 years. Like many Lyme Disease stories, this is a long one.

This past February, I started to become very dizzy and developed a strange mental fog. Unable to concentrate, I soon dropped out of my masters degree program which I was attending after work. As the weeks went on, my dizziness turned into a profound "seasickness" feeling which lasted for weeks. Unable to eat much, I started to loose weight. Soon I started to have anxiety problems, blurred vision, memory loss. In time, I started to have profound feelings of faintness. One night I ended up in the emergency room because I could barely keep from passing out. I had noticed how my symptoms would come and go just as someone had flipped a switch. Up until February, I was very happy with everything in my life, all was going well. At 27 years old, my life was suddenly falling apart.

After about three months of numerous tests, (including Lyme tests which I asked for) nothing was showing up. Not once did they mention Lyme Disease even though many of the medical technicians who administered tests mentioned it! My doctors didn't have a clue. At first they told me it was a inner ear virus. As time went on, my primary care physician kept inferring there were psychological reasons for my illness. He often pointed toward work as a source of stress. I was adamant about the fact that I loved my job as a engineer and found work to be very enjoyable. In fact, it was my inability to concentrate on projects which I had handled with ease just months before which led me to believe there was a physical problem with me. Something didn't fit the picture. It all came to a head when he prescribed an anti-depressant.

It wasn't until I started looking around on the Internet to find what could possibly be getting me so sick that I found a newsgroup about Lyme Disease. I couldn't believe that others were out there with the same problems I had. Through the net, I also started to meet many people who were misdiagnosed with Multiple Sclerosis and actually had Lyme. I had spent the past 15 years watching my mother slowly digress from the effects Chronic Progressive Multiple Sclerosis. She is now barely able to move her arms and is confined to an electric wheelchair. Over the years, our family has grown together to help her as best we can. I would read these stories to her, with the hope that maybe a miracle could fall upon our family. That day was a major turning point for my family and I.

Through the help of the Lyme Disease Foundation, I found a very knowledgeable doctor who has since helped me immensely. I still struggle on a daily basis to regain my health even after 6 months of antibiotics. Although I am MUCH improved after 5 months of antibiotic therapy, I am still plagued with various health problems. This disease has caused the loss of countless work days including a six week medical leave.

My Lyme doctor was very interested in my mom's health history. While growing up in Connecticut, she had Rheumatic fever as a young girl and was given Penicillin as a prophylactic treatment to prevent strep throat. She maintained a daily pill of penicillin for the next twenty years. In 1981 she stopped taking penicillin as recommended by her doctor, who told her he wasn't totally sure if she ever had Rheumatic fever so many years before. It was in that year that she began to lose strength in her leg. After many doctors and a few years later, she was finally diagnosed with Chronic Progressive MS. Over the years, she had strange growing rashes and periodic hair loss which no doctor could explain. She had a western blot Lyme test in 1987 which we were told was negative. We soon made her an appointment with my new Lyme Doctor. He gave her the latest round of current Lyme tests which, to our amazement, came back positive.

Later one evening, I came home to my parents who were both taken by emotion. After asking what was wrong, she told me that the antibiotics were helping her. Throughout the 15 year battle to fight her disease, not once did anything help her. She recently began to move her toes and fingers which she has not moved in many years. Although the road ahead will be a long one, we now have hope which had all but disappeared over the years. She is grateful to be given the opportunity for improvement.

After contracting Lyme, I was amazed at the many myths about the disease. Many people feel it is a arthritic disease when, in fact, it is a multi-systemic infection. In my case it had attacked my neurological system. I have never had one ache from it. Another misunderstanding is that it can be cured by 4 weeks of antibiotics. Some people need months of aggressive antibiotic therapy to help kill the spirochete. We need more government support for education, treatment research and insurance legislation to protect those who need treatments.

Please help me and the MANY other people who fight for their health every day because of this horrible disease.

There is more to the story than aching joints and a rash....much more!!

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

State: Connecticut

County: Fairfield

Name: Marcia 

Total cost: \$350,000+

Number of family members with LD: 3

Lost work/school: is disabled, cannot work

Number of years sick: 15+



### Our Story

November 1, 1997

Over the past year, I have been touched by Lyme Disease in many ways. Little did I know that Lyme Disease had played a silent part in our family for over 15 years. Like many Lyme Disease stories, this is a long one.

This past February, I started to become very dizzy and developed a strange mental fog. Unable to concentrate, I soon dropped out of my masters degree program which I was attending after work. As the weeks went on, my dizziness turned into a profound "seasickness" feeling which lasted for weeks. Unable to eat much, I started to lose weight. Soon I started to have anxiety problems, blurred vision, memory loss. In time, I started to have profound feelings of faintness. One night I ended up in the emergency room because I could barely keep from passing out. I had noticed how my symptoms would come and go just as someone had flipped a switch. Up until February, I was very happy with everything in my life, all was going well. At 27 years old, my life was suddenly falling apart.

After about three months of numerous tests, (including Lyme tests which I asked for) nothing was showing up. Not once did they mention Lyme Disease even though many of the medical technicians who administered tests mentioned it! My doctors didn't have a clue. At first they told me it was a inner ear virus. As time went on, my primary care physician kept inferring there were psychological reasons for my illness. He often pointed toward work as a source of stress. I was adamant about the fact that I loved my job as a engineer and found work to be very enjoyable. In fact, it was my inability to concentrate on projects which I had handled with ease just months before which led me to believe there was a physical problem with me. Something didn't fit the picture. It all came to a head when he prescribed an anti-depressant.

It wasn't until I started looking around on the Internet to find what could possibly be getting me so sick that I found a newsgroup about Lyme Disease. I couldn't believe that others were out there with the same problems I had. Through the net, I also started to meet many people who were misdiagnosed with Multiple Sclerosis and actually had Lyme. I had spent the past 15 years watching my mother slowly digress from the effects Chronic Progressive Multiple Sclerosis. She is now barely able to move her arms and is confined to an electric wheelchair. Over the years, our family has grown together to help her as best we can. I would read these stories to her, with the hope that maybe a miracle could fall upon our family. That day was a major turning point for my family and I.

Through the help of the Lyme Disease Foundation, I found a very knowledgeable doctor who has since helped me immensely. I still struggle on a daily basis to regain my health even after 6 months of antibiotics. Although I am MUCH improved after 5 months of antibiotic therapy, I am still plagued with various health problems. This disease has caused the loss of countless work days including a six week medical leave.

My Lyme doctor was very interested in my mom's health history. While growing up in Connecticut, she had Rheumatic fever as a young girl and was given Penicillin as a prophylactic treatment to prevent strep throat. She maintained a daily pill of penicillin for the next twenty years. In 1981 she stopped taking penicillin as recommended by her doctor, who told her he wasn't totally sure if she ever had Rheumatic fever so many years before. It was in that year that she began to lose strength in her leg. After many doctors and a few years later, she was finally diagnosed with Chronic Progressive MS. Over the years, she had strange growing rashes and periodic hair loss which no doctor could explain. She had a western blot Lyme test in 1987 which we were told was negative. We soon made her an appointment with my new Lyme Doctor. He gave her the latest round of current Lyme tests which, to our amazement, came back positive.

Later one evening, I came home to my parents who were both taken by emotion. After asking what was wrong, she told me that the antibiotics were helping her. Throughout the 15 year battle to fight her disease, not once did anything help her. She recently began to move her toes and fingers which she has not moved in many years. Although the road ahead will be a long one, we now have hope which had all but disappeared over the years. She is grateful to be given the opportunity for improvement.

After contracting Lyme, I was amazed at the many myths about the disease. Many people feel it is a arthritic disease when, in fact, it is a multi-systemic infection. In my case it had attacked my neurological system. I have never had one ache from it. Another misunderstanding is that it can be cured by 4 weeks of antibiotics. Some people need months of aggressive antibiotic therapy to help kill the spirochete. We need more government support for education, treatment research and insurance legislation to protect those who need treatments.

Please help me and the MANY other people who fight for their health every day because of this horrible disease.

There is more to the story than aching joints and a rash....much more!!

# THE MANY FACES OF LYME DISEASE

## WE ARE NOT JUST NUMBERS!

**State:** New York

**County:** Suffolk

**Name:** Susan 

Total cost: \$100,000

Number of family members with LD: 1

Lost work/school: 9 months

Number of years sick: 9 months

My story may seem shocking or absurd, but for myself and many others, it is a pitiful reality. My Lyme story began before I was even aware that I had the disease. In September 1996, I noticed an unusual red blotch on my ankle. I decided to see my doctor. This rash was not the typical "bullseye" rash that is associated with Lyme. But as I would come to find out, less than 50% of all Lyme patients ever get the "bullseye" rash. After seeing two doctors, neither of them could diagnose the rash and it eventually disappeared. I feel compelled to comment on where I was in my life just prior to my illness. I was at perhaps the best point in my life. I was finishing up my Master's degree, had a new wonderful apartment, and a fantastic job that I loved. The sad truth is that for myself and most other Lyme patients, my mental health was to be questioned by many doctors. In the beginning of January, I started feeling what I thought was a case of the office flu finally hitting me. I was feeling tired and a little achy. I had strangely started experiencing small bouts of mild dizziness. I went to the doctor and she told me that it was the flu and did a strep test. She called several days later to reveal that my strep test was positive and put me on the usual antibiotics. A few weeks later, I was at work and was still feeling very flu-like but nothing short of a coma kept me home from work. I started to feel weakness and stiffness in my neck. It quickly became difficult to hold my head up. I got up to try and make it to the break room and my legs buckled beneath me. I became so dizzy that I could hardly see. I was taken to the emergency room of the local hospital. The doctor said it was probably an ear infection and sent me home. The next two days were somewhat of a fog. I laid in my apartment, barely able to move. My legs seemed to just not work. I was dizzy beyond belief. Walking was a next to impossible feat. Over the next two days my condition worsened. I could not move the left side of my body. My jaw was stiff and I was only able to slur out a few words. My left side would barely respond to stimuli, and my sed rate (indicating inflammation) was 86. Normal is 0-20. The doctors suspected meningitis and gave my IV Rocephin until that was ruled out. I was put on steroids to reduce the inflammation (I did not know that steroids are the worst things to give to a Lyme patient). Over the next 6 days that I spent in the hospital, I was tested for



everything from Lupus to Multiple Sclerosis and everything was negative. I was sent home with a diagnosis of Vasculitis. About a week after my release from the hospital I received a call from the neurologist. He said that one of my tests had come back positive. They had found Lyme disease in my blood and in my spinal fluid. The neurologist felt that IV antibiotics would be needed because of the severity of my symptoms. He referred me to an infectious disease doctor for treatment. Despite the severity of my symptoms, my Lyme "counts" were not extremely high so I was put on oral antibiotics. After 3 weeks of oral medication, I still felt extremely sick. I was weak, had numbness in various parts of my body, had 10 days of a rapid pounding heart rate (a condition called Tachycardia), and a variety of other symptoms. The doctor had also found that I tested positive for exposure to Rocky Mountain Spotted Fever. I had also developed a facial palsy on one side of my face. The decision was made that I should have been on IV antibiotics. I was placed back in the hospital for 10 days. After the recognized 28 days of IV treatment, during which I had some improvement, my doctor said that it was time to stop treatment. If I was not cured with 28 days of IV, then maybe there was something mentally wrong with me. Well 5 weeks later I was back in a wheelchair and so sick that I could barely move. I finally found the doctor who has been treating me for the last five months. He admits when he does not know. He consults with other doctors and encourages me to get second opinions. He cannot promise me when I will get well and he explains the risk of IV treatment to me. But I could not stay sick and do nothing. I want my life back. I can only hope that I will be able to beat this disease. I am now fighting my HMO because they have decided to stop paying for my \$1000.00 a week treatment. My parents have been forced to use money from their savings to pay for my treatment and I have had to move back in with them. My case is a severe one, but there are others like me. There needs to be more research done in order to help those who are infected and the many who unfortunately will be infected in the future.