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

State: Connecticut
County: Hartford

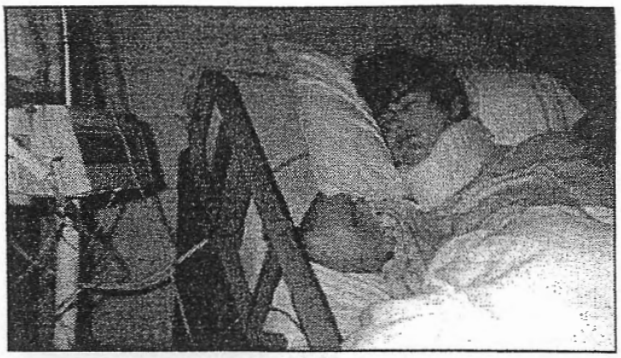
Name: Kari [redacted]

Total cost: $1,000,000

Number of family members with LD: 1

Lost work/school: 10th grade thru college+

Number of years sick: 9



Health Officials and the Media would lead you to believe that Lyme Disease is a benign nuisance that briefly interrupts your life (as a flu would) and is very simple to cure. I would like to tell you that is far removed from the truth for many of us with Lyme Disease.

My horrible journey with this disease began in Sept. 1988 when I came down with a terrible flu. I have never been the same. Once an active honor student, I was reduced to a bed ridden teen with difficulty remembering simple things. My life was full of PAIN and Suffering. Years went by and my treatments were constant. I have had a total of 3 years IV antibiotics and 6 years of ORal antibiotics. My body was so painful, my parents sent me to live in the warm desert of Arizona. We hoped and prayed this would alleviate my head pain and joints. That was 5 years ago. It was very hard to live alone, being so sick. My parents would fly out when I was extremely bad. In July of this year, 1997. I was forced to move back to Connecticut with my parents because I could no longer care for myself. It was disrovered that the Lyme had caused a swelling in the brain which triggered another condition called Chiari This past August

I had surgery in New York City to relieve the pressure in my head. I still have head pain. It is thought that this pain is still coming from the Lyme Disease. I have been going to a Community college since 1991 and have only completed less than 40 credits. I am a D.S.P. student and even with this special help, I have difficulty staying well enough to complete a semester. I will not give up and someday I will have a degree.

My family has exhausted all of their financial resources supporting me and my medical expenses. My Dad has retired and my mom has sold her business. They are preparing to sell their house and move with me anywhere in the country that I might feel better. I have applied for Social security, something none of of wanted me to have todo as we believe in personal responsibility. Unfortunately we have NO more money.

Finally, I would like to tell you how very frustrating it is to deal with a medical community that is constantly down playing it's seriousness. Even the health director for my town REFUSES to have ticks sent out for disease testing. She doesn't think that it is necessary as Lyme Disease is not a big deal.

I wish there was some way we could make all of these "professionals" understand that Lyme Disease is a Big Deal! It is painful, expensive, debilitating and can ruin your life.

In my opinion, much of this controversy stems from Grant money. If you follow the money you find the conflicting point of view, ie the people afflicted with this disease living it's horror vs. the "Ivory Tower" doctors who say it isn't so. It is my wish that none of you or your family members are ever afflicted with this preventable illness. When research money is available. Please grant it to those who are truely believing that this disease is serious and a cure must be found

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

State: Georgia
County:

Name: Davi[redacted]

Total cost: 2 Million

Number of family members with LD: 2

Lost work/school:

Number of years sick: Died

My father, David [redacted] died from Lyme Disease on December 10, 1995. He was 65 years old and had suffered endlessly for three years.

My father's symptoms were numerous. As a result of total dementia, his behavior was violent, yet he was completely unaware of his surroundings and incapable of communicating with us. He lost his ability to swallow food, recognize family members and to speak. He did not eat for three months and was fed through a tube. He was restrained in a bed for fourteen weeks. He went from a healthy 6'2" man to a 140lb. Skeleton

Due to the lack of understanding of this disease, my father's treatment was inappropriate and delayed. For instance he was straitjacketed and put into a psyche ward where he was given psychotic drugs. When my father was finally tested for Lyme, after my continued persistence, he tested positive. His MRI's showed multiple lesions on his brain.

At this time antibiotic treatment alone could not help my father. He would get a little better, only to relapse into further despair. His medical costs exceeded two million dollars. He saw over 100 doctors in his three years before he died. He was in seven different hospitals plus two rehabilitation homes.
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My father's case is not unique. There are hundreds of people too sick to be heard and also to desperate to fight. Lyme disease is a chronic and in most cases not curable. Without accurate tests the insurance companies can continue to deny that this disease exists as such. Doctors too can hide from the disease and continue to blame the patients for crazy behavior. Research is desperately needed now. Especially, if the most recent studies indicate that the mosquito can also spread this disease.
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On the day of my father's death, I promised him I would continue to let people know how devastating this disease can be. I am grateful that he no longers suffer from not only the horrors of the disease, but from the frustrations which we all faced from the medical profession.

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

State: New Jersey
County: Ocean County

Name: Ellen [redacted]

Total cost: $96,266

Number of family members with LD: 1

Lost work/school:

Number of years sick: 7 1/2

On February 26,1990, my life changed forever when I was bitten by a tick in Florida. On March 8, 1990, several days after the EM rash began, I became very ill. I was dismissed by a South Carolina Emergency Room doctor with a diagnosis of the flu even though I mentioned a tick bite, had an EM rash, asked about Lyme Disease, and was so dizzy that I couldn't walk without assistance. Several days later back in New Jersey, my physician said it could be Lyme Disease after hearing of my bite, symptoms, and seeing the rash. However, he said that TEN days of antibiotics would CURE the Lyme Disease and performed a Lyme test. One week after finishing the antibiotic, I was given another TEN days as symptoms still continued. Then, still presenting with dizziness, head pressure, severe neck pain and headaches; was told to see a psychiatrist because my test was negative and I had enough antibiotics to be CURED! After five months of dealing with this doctor and worsening symptoms, I went to an infectious disease specialist who also treated me inadequately.

At the end of 1990, after almost a year of allowing the disease to progress with little treatment, I went to Mayo Clinic in Minnesota to attempt to find help. I was told that there was NO Lyme Disease in Florida; and if I had ever had it, it would be cured after taking all those antibiotics. Mayo discovered nerve conduction abnormalities but said I would PROBABLY get better. They performed a spinal tap, but I found out years later that they decided not to test the fluid for Lyme as they decided I couldn't have had it. One positive note, they didn't find any other illness!

Eventually, a conservative Lyme knowledgeable physician diagnosed Lyme and treated me. However, I had been infected for so long and inadequately treated that the short regimens of antibiotics he prescribed only improved my symptoms of cranial neuritis, headaches, cognitive problems, back pain, intense neck pain, joint pain, difficulty sleeping, heart palpitations, difficulty swallowing due to esophageal spasms, and vision disturbances. All symptoms would worsen when he stopped the antibiotics for months at a time.

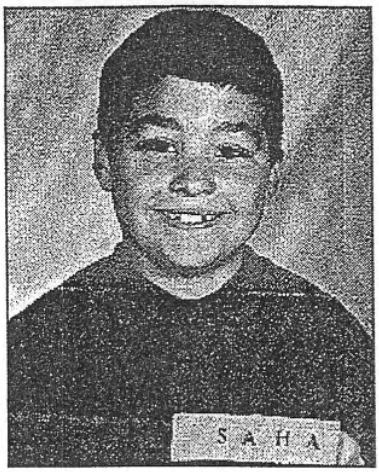
For the past few years, I've been treated aggressively. I've continued to slowly improve while taking continuous antibiotics, hoping for remission. I still have neck and muscle pain, cognitive problems, vision disturbances, and difficulty swallowing but at a lesser intensity.

Before March of 1990, I had no health problems and was an extremely active outdoor person who enjoyed hiking, skiing, camping, canoeing, gardening and swimming. Now I endure constant pain, cognitive problems and have accumulated medical bills amounting to over $96,000!

I feel like my life was ruined by a doctor who wouldn't admit that his THEORY of adequate Lyme treatment failed, and I went untreated for many months while the disease progressed to a possibly incurable state. Now, in addition to dealing with this devastating, painful disease; we Lyme patients watch our knowledgeable, compassionate, Lyme Disease physicians who strive to care for chronic patients be ridiculed and threatened. WHAT AN OUTRAGE!!! Teenagers are treated for acne with long-term antibiotics with no question but LYME PATIENTS are being denied treatment for a HORRIFIC INFECTION! Where is the sense in that!! Now a study is being done to investigate the possibility of persistent infection. It has already been proven to exist! Why not put the money where it would be of some value! Fund research to develop a reliable test and effective treatment for chronic Lyme!!!

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

State: Pennsylvania
County: Chester



Name: Christian [redacted]

Total cost: ?

Number of family members with LD: 2

Lost work/school: 6th grade

Number of years sick: 2 1/2

These are the Lyme disease symptoms that I have lived with for two and a half years: a flu like illness, heel pain, low grade fevers, rashes, sore throats, fatigue, constant headaches, stiff neck, joint pain, muscle pain, weight gain, blurry vision, stiffness of joints, shortness of breath, poor stamina, light sensitivity, difficulty concentrating, mood swings, lesions on skin, face pain, sleep disturbance, depression, dizziness, reversing letters and numbers, crying easily, lesions on brain, oxygen depletion of the brain. NOW MY STORY:

I am a twelve year old boy, who had never been sick until I moved to Chester County Pennslyvania. My first symptom hit me, in April 1995. At that time, I was misdiagnosed, and my symptoms went dormant until November 1995. Then, once again, I was misdiagnosed. My symptoms reappeared in April of 1996, and from that day on, I have always been sick, and have never been without symptoms. My Mom would find me, collapsed on the staircase, unable to move, I stayed so fatigued. My headaches hurt so bad that I wanted to bash my head in. My parents took me to a total of 14 different doctors (Some were in the same practice). I kept hearing the doctors say, "Well, Christian it sounds like Lyme disease, but your blood work is negative," or "You can't have Lyme disease, because your joints are not swollen." My Mom and Dad even took me to the big name hospitals, to see doctors we thought would help. All the doctors there could say was, " Sorry, lets just see how bad he gets." Then, two different M.R.I. tests showed that I have lesions on my brain, and a terrible thing happened. A neurologist, and an infectious disease doctor got together, and told my parents that I did not have Lyme disease, but they said that I did have something. They also said that I had been sick for so long, that I just keep on making myself sick. They suggested that I see a psychiatrist, and then they gave my Mom a prescription for happy, feel good drugs. Then they sent us on our way(We threw that prescription away). My parents counted 32 different symptoms of Lyme disease that I had, but it seemed like the doctor wouldn't listen. My Mom and Dad never gave up on me. My parents knew me better than any doctors, and they realized that I was a very sick kid. My Mom prayed for a doctor

to help me, and in September 1996, we found that doctor. I started taking an oral antibiotic (Biaxin), for 7 months as treatment. I was able to stay in school for most of 5th grade. My joint and arthritis pain, as well as many of my other symptoms left me, but my headaches never did. We went to New York, and I had a brain spec scan. The results showed that I was losing oxygen to the left side, right side, and the back of my head. My doctor started me on I.V. therapy (Rocephin). It's been five weeks since I started the I.V. therapy, and I'm just now starting to feel a change for the better. Now on some days my headaches are a one, and that's great compared to an 8 headache. I have not made it to 6th grade yet, I am being taught at home. I am hoping for a full recovery. It's hard being a kid and being worried to go outside in the sun because your headaches always get worse. Also, not being able to read because of my head pounding, or ride in a car because I'll get car sickness. So, please help the doctors not wait so long to treat if the symptoms sound like Lyme disease, and taste and smell like Lyme disease, please recognize and treat, so that other children will not have to end up with a pic line in their arm and their Moms having to cry.

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

State: Oregon
County: Union

Name: Shirley [redacted]

Total cost: Unknown

Number of family members with LD: 1

Lost work/school: 3 months

Number of years sick: 2-3

Spring + Summer 1988 - Felt an unusual Fatigue + weakness. Persistant RUQ abdominal pain.

Eventually went To ER For the pain. Abdominal CT done - considered normal. Did have a high amalaze Level (500 I think) at the time.

Saw 3 internist within The next Few weeks + was refered To a GI specialist who did Epstein Barr studies + diagnosed Epstein Barr. Regular internist poo hed all Findings + diagnoses + offered no help but labeled me depressed."

In The mean time I lost weight, was always Fatigued but not always able To sleep + began to develope a Fine Tremor + had taken a month off work For pancreatitis.

One morning I went To take off my Night gown + my neck + head Twisted + would not return to position. Was diagnosed with boiled muscle + given cervical Collar.

In the meantime I had experienced dry eyes, shoulder, Knee, hip + sternal pain + skipping heart beats. Idid not share These with a Dr. For Fear I would be passed around + poo hed Like I was with pancreatitis + not helped. However, I Felt That my vision was deteriova I went to Eye Dr. + was given Bi Focals. I already Felt dizzy - That made it worse. I was developing sensitivity to light + Forgetfulness - esp. short Term. I also had a persistant headache - I Felt in my sinuses + temples.

I went To a 4th internist who Treated The headache as a sinus infection with penicillin. I Felt The penicillin must have been "blanks" - I received no relief. He also sent me to a major Medical center in Seattle + They did MRI of The head + an endoscopy of The panceas... All which were normal. (They also did sinus x-rays which were normal).

I returned there For Follow-up + was given a perscription For depression + migrain Headaches. (which I did not take). I developed strep Throat (For real - a positive culture) + was Treated with penicillin, 500mg Twice a day. At The Time I Took it The sore Throat improved but The abdominal pain worsened. About a month later I was Feeling better

OVER

but had had some more weakness (poor grip), + Tingling in Face + hands on (R) side of my body,

I spent That Fall + winter seeing a Chiropractor. The headache + some of The body pain did improve.

In The meantime I was busy researching what it might be. I Thought it was M.S. My sister in Florida Told me it was Lyme.

I read an article in Readers Digest on Lyme + went to The library For more info. After reading the info, I recalled a day when I had been out picking raspberrys + saw a strange "Thing" clinging to my ankle. I squeezed + pulled + got it off + Then mashed it noticing it was Full of blood. It never occured to me at The Time That it was a Tick — all The ticks I had ever seen were Full grown, this Just looked like a little dark mole like skin tag.

After The research all The pieces fit but I had no positive relationship with a Dr I could Trust. I had been in contact with a peer at work who had a history of similar sorts + was seeing a Dr in San Francisco, as were her parents. I returned to the Dr who had seen me in The E.R. + Told him everything — he was reluctant to believe me but did have me tested For some tick born diseases Lyme + Rock Mt. Fever. They were negative.

He encouraged me to get counseling + eventually referred me to the Dr in San Francisco. That was Paul Lavoie. I saw (Dr Lavoie) him a Tolal of 3 Times over about a year + a half. I was Treated with oral Amoxicillin, Minocin + plaquinill. He also tried me on an antidepressant — non of The antidepres I took agreed with me. I ended up off work For 6 wks after I started Treatment with a mod. Nervous breakdown. My marriage was + had been breaking down.

After 3 months on plaquinill my lung over Feeling improved + I went off all drugs. My Son was diagnosed with a severe Form of cancer, + I spent The next year + a half battleing cancer (his) successfully. But my marriage ended. I did counseling For about 2-3 year.

I still get strange symptoms that aren't explained + must be careful to get enough rest + not get Too hot or too cold, drink plenty of water + Exercise.

I witness That it is only Through The grace of God I ever received Treatment + am not left in even worse shape.

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

State: New Jersey
County: Morris

Name: Mary Alice [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 3

I was bitten by a tick three years ago. I had a ring and a positive blood test. I suspect I got the tick from our outdoor cat. (We have deer in our yard.) I was treated with antibiotics, for several weeks and thought I was cured.

A year later I noticed my balance was poor and I had double vision. I did not connect it with Lyme.

Two years after the bite I began to ask my primary care doctor about my dizzyness and vision problems, reminding him of my Lyme history. He said he didn't think it was Lyme, and sent me to three opthomalogists, two ear specialists, two neurologists, a neurological opthomalogist, had a CAT scan and a spinal tap. I told all these doctors I had had Lyme. None suspected I still did.

Three years after the bite I really was feeling sick: cloudy headed, woosy, terrible balance, nystagmis, double vison, headaches, chills, tireaness and stiff joints I met someone who had the same set of symptoms who also was bitten by a tick three years ago. I suspected Lyme and went to a doctor in Mt. Kisco, NY

who treats many cases of Lyme. He gave me a blood test which was positive. I have been on antibiotics now for 10 weeks and am beginning to have some good days.

I know <u>many</u> people who have had Lyme. This is a huge problem in Morris County and the doctors seem to be in denial. Lyme is a frightening and incapacitating disease and needs to be taken seriously.

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

State: Iowa
County: Woodbury

Name: Rafelle Jessica [redacted]

Total cost: $150,000

Number of family members with LD: 3

Lost work/school: 7 yrs. of lost employment

Number of years sick: 13

"My Story"

This is a condesned version, and I will start where it began.... I moved to Dallas Texas with my 3½ year old son in 1983. I got a job working construction (house painting) I worked outside and in undeveloped areas for recreation, I went to the lakes and parks, in 1984 I started feeling fatigued, had a couple of allergic reactions to who knows what as the doctors didnt know, I was gaining wieght which acually I was swelling, my tooth, the front one, in which - had been knocked out, put back in and had a root canal a year earlier became infected. I was getting ear infections and vertigo. In 1985 I had knee surgery for a torn menicus disc., I started feeling unusually depressed and also became bulimic, In 1986 I moved back to Colorado... the fatigue was worse and now I was having pelvic pain, I took an aids test which was negative, but I was pregant & during pregnancy, I had water on the knee, it was tapped but not checked, my ears still bothered me, and now

I had neck pain and back pain and an overall uneasy feeling, during delivery, I developed Bell's palsy, a CT was done; it was OK. I fought fatigue neck pain, unusuall muscle pain and now I was having an irregular heartbeat. I was told this was "probably" stress related. In 1988 I was pregnant again, my Syptoms came and went, but fatigue was overwhelming and I was sleeping 10 to 11 hours and draging my feet at work (I was waitressing). I had a bicycle accident at 7½ mos. I now developed Insomnia and sound sensitivity, I was hospitalized for post partum depression and sleep deprivation for 10 days after the birth. — A few new syptoms; awful head pressure and face pain and pressure on the roof of my mouth, pressure in my chest and low body temperature, extreme jaw and teeth pain, nausea. Since 1989 to present time I have seen 25 or more physicans and dentists and oralsurgeons, I have had MRI's-brain-neck-CT's, head-sinus-barium enema-a sleep study-EEG-neucular bone scan-Colonostopy-physciatric testing-lower GI-upper GI-ultra sounds-spinal tap (blood patch) 5 teeth pulled 4 root canals, 5 TMJ devices made-echocaridiogram, 24 hr heart holter monitor. I'm sure there's a few more test I haven't mentioned, I have been raped by the medical profession, insulted & humiliated. I use the word rape to articulate my ordeal, I finally got diagnosed by a doctor in Missouri with Lyme's disease, day to day I have MS like syptoms (spelled suciaa) very bad dizzines & memory loss. Actually I can't fit all my syptoms on here. I am trying different antibiotics as I am having bad reactions to them - allergic it seems? my life is hour to hour going to the doctor and checking for damages from the drug ignorance of years past!

Sincerely,

[redacted]

1997

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

State: Iowa
County: Woodbury

Name: Caleb [redacted]

Total cost: Just starting

Number of family members with LD: 3

Lost work/school: Too many

Number of years sick: Sick off and on for 6 years

Caleb has recently been diagnosed with lymes disease our finacial costs are yet to be seen, as far as lymes related costs up until now, I would approximate $7,000.

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

State: Connecticut
County: Middlesex

Name: David [redacted]

Total cost: over $100,000

Number of family members with LD: 1 (+ dog)

Lost work/school: 1 yr (7th grade)

Number of years sick: 8

Underdiagnosis of Lyme Disease

(C) Frank [redacted] 1993-7 (November 1997)

This is a summary of Lyme disease as it affected my son, David. I am presenting this information with the hope that it may help others avoid the pain David has gone through.

When David had the classic Lyme rash (Erythema Migrans) in the summer of 1989 we did not recognize it as anything requiring medical attention.

In 1990 he started having intermittent incapacitating pain in his neck and lower head. It began as episodes a week to a month apart, with sudden onset of pain so bad he could not sit up for 1 to 2 hours, then decreasing over the next day.

In August 1990 he had a Lyme test (negative). In September he was referred to a neurologist. He had an X-ray of the cervical spine and an MRI of the "cervical spine and foramen magnum to rule out the possibility of a Chiari I malformation as well as the possibility of an AVM." Everything was "normal". The pediatrician said it was probably just "stress".

In January 1991 he had ankle pain and Achilles tendinitis in both ankles. He was also given another Lyme test (negative). During the next two months, he was also diagnosed with fatigue and viral infections. In November, he had an ear infection (otitis media) and was placed on Amoxicillin.

In September 1992, he again had Achilles tendinitis in both ankles, then plantar fasciitis. Our pediatrician said he would be back to normal in a week. He was in a wheelchair for 6 weeks due to the pain. He also started having other joint pain. We went to a chiropractor to get orthotics for his shoes, thinking that they might help. The chiropractor also had a Lyme test done (negative).

In October 1992 he was still suffering from the tendinitis, and also had a sore throat (strep test was negative), and eye problems. The pediatrician diagnosed photophobia and referred us to an ophthalmologist who diagnosed conjunctivitis.

Symptoms were so bad that he could not attend school. His teachers were telling us that he was too sick for school, and even though he wanted to continue, they could see the pain he was in. One teacher even said "If your doctor says there is nothing wrong, find another doctor."

At this time his symptoms included: fatigue, occasional headaches, neck pain, migratory joint pain, muscle pain, numbness, dry eyes, conjunctivitis, sore throat, nausea, stomach discomfort, and swollen lymph nodes. We live in a wooded area endemic for Lyme disease, 15 miles from Lyme, Connecticut. He spends a lot of time outdoors. Our dog had Lyme disease, was treated, and recovered.

Our pediatrician suspected Lyme, prescribed doxycycline, and ordered blood work with a Lyme test. Over the next few days, the symptoms got worse. Another doctor later told us that this was a Jarisch-Herxheimer reaction, common in spirochetal infections when antibiotics are started. When the **Lyme test came back negative the pediatrician told us to stop the antibiotics**, see an orthopedic surgeon, and send our son back to school, – and he **refused to do any other testing**.

We found another local doctor to continue the antibiotics, based on the symptoms, until our appointment with the orthopedic surgeon. After two weeks our son improved some. The orthopedic surgeon could not help, since it was not an orthopedic problem.

During this time, he developed **additional symptoms: loss of short-term memory, and perceptual difficulties. Later we realized that he also had gradually developed a lack of facial expression.**

We began searching for a doctor who could diagnose Lyme disease, or whatever it was that David had. After some searching, we found **two excellent doctors**. Family members referred us to their internist, and the Lyme Disease Foundation referred us to a pediatric neurologist with a lot of Lyme experience. **Both diagnosed Lyme disease**. We changed antibiotics to Amoxil, and after 3 more weeks David had improved a little more.

Since he had **neurological symptoms** that weren't responding (**short term memory loss, abnormal EEG**, etc.), we then changed to IV Claforan (every 8 hours).

Before Lyme treatment, the pain had evolved so that there was always pain between the very painful episodes. **After the first week of Claforan, he seemed much better, looked good, sleeping normally, more energy, no more neck pain (first time in 2 years), more facial expression, and started back with his tutor (doing well).**

Three days later he started having a reaction – getting red and unbearably itchy all over, and neither Benadryl, nor Atarax, nor reduced dosage, helped, **so we had to stop**. (No difficulty breathing, thank God.) Within a few days all the old symptoms started returning, first the neck pain, then the other joints, tiredness, etc.

After two very long weeks while the reaction got better and the Lyme got worse, he saw an allergist who desensitized him to the Claforan. This consisted of starting with a very very low dose rate and increasing it over about 8 hours. Every time itching appeared, the rate would be decreased for a while, the itching would stop, then the rate would be increased again.

After 7 more weeks of IV Claforan (every 8 hours) producing only gradual improvement (not as much as after the first week), our doctor added Biaxin orally.

After another 7 weeks, we saw only some improvement. Then his symptoms were neck pain, joint pain, arthritis, feeling awful, and fatigue. Some days were worse than others.

In May 1993, his PICC line (I.V. catheter) clotted and had to be removed. We continued with oral antibiotics (Suprax and Biaxin) for about a month, then our son started having a feeling of not getting enough air (not shortness of breath), and our doctor had us stop both antibiotics.

During 10 days with no antibiotics, symptoms gradually got worse, then suddenly got much worse. He woke up one night sick to his stomach, and soon had a terrible "hatchet-like" headache and swelling in his forehead. We saw the doctor on the second day, and started back on antibiotics, Minocin this time. He had some slow improvement while on Minocin.

After two months of Minocin, we switched to Zithromax. He continued improving. Although he missed a year of school, he had an excellent tutor and was able to continue with his class. In **December 1993 he was feeling well enough to resume sports** with his class. That spring he got an award for "Most Improved Player" on the school basketball team.

In 1996 he was doing well both academically and in sports. He stopped the antibiotics, and his teachers noticed he was not doing as well, for example missing things that he knew on a test. After resuming antibiotics, he is again doing well.

We have read everything available, and found no easy answers. David is one of hundreds of similar cases. **There are no studies that have proven that the serological tests are a reliable means of excluding a Lyme diagnosis. There are too many examples of long-term antibiotic requirements to believe that persistent infection is not a real problem.** We believe that if proper diagnosis and treatment had been further delayed, our son's recovery would have been longer and less likely.

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

State: Iowa
County: Woodbury

Name: Zachary A. [redacted]

Total cost: Just starting

Number of family members with LD: 3

Lost work/school: Too many

Number of years sick: Sick off and on for 7 years

Zachary has recently been diagnosed with lymes disease our finacial costs are yet to be seen, as far as lyme related costs up until now, I would approximate $7,000. to 9,000.

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

State: Massachessetts
County: Gloucester

Name: Elaine [redacted]

Total cost: ?

Number of family members with LD: 3

Lost work/school: 2 years

Number of years sick: 10

In 1987 I lived in South Plymouth, Ma. with my family I became very ill. I was extremely fatigued along with other symptoms, such as blurred vision, leg and knee pain with swelling and headaches. A doctor diagnosed me with Tic chronic fatigue syndrome. I then went to a blood specialist and he could find nothing wrong with me. However the symptoms persisted for a long time. The fatigue never went away completely. Also my knee continued to bother me off and on. In 1995, September and November, both my daughter and I were bitten by ticks. We both had Lyme disease. We thought my daughters disease went away and she was treated for 30 days. She had improvement but never regained her full energy and remained "sick". I have been on medication for Lyme ever since. My doctor and I have figured out that my diagnosis in 1987 was most likely mis-diagnosed Lyme. That explains my slow progress on the medication. We have made significant progress but will always have the disease because it wasn't treated right away in 1987. My oldest daughter

began showing strong symptoms of lyme this past summer. I began to remember that she had leg pain, fatigue and headaches since we lived in South Plymouth in '87. Although there was nothing medically wrong, she continued to have problems off and on that required tylenol and muscle pain soothers. I had her tested for lyme this fall. She tested positive. I had my younger daughter tested also (who had lyme in '95) She tested positive.

I am a single parent. I was going back to college, with a high honors associate degree. I was forced to quit because of lyme disease. I struggled, with the help of legal services, to get a disability through welfare. It took me 8 months to get it. I was denied SSI after meeting with 5 of their doctors, none of them familiar with lyme disease. I am too tired to fight with them and have no advocate to help me. Yet, I continue to feel sick. I am barely able to meet necessities with my family and have to live on $525/a month. My girls now need moral support, extra help in school and alot of T.L.C, and I find it difficult just keeping up with meals and laundry ext...

I would like to see more awareness of this disease. A little understanding would be nice. It would be great to get medical help without trying to explain to the doctor what lyme disease is.

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

State: Massachessetts
County: Gloucester

Name: Jennifer [redacted]

Total cost:

Number of family members with LD: 3

Lost work/school: 20 days

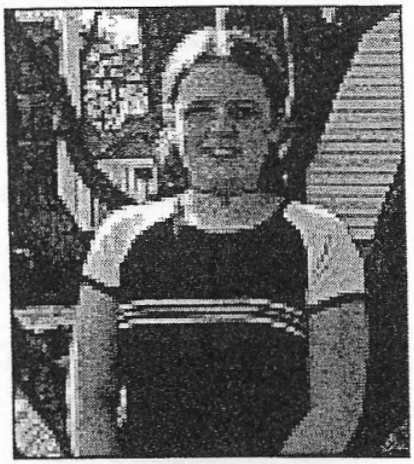
Number of years sick: 2

2 years ago I was bitten by a tick I had gotten very sick. I have gotten very tyard and have gotten pains in my legs. I also had stome trouble remember ing my homework and osher things for school. I took medecation for 30 days and felt better, Reas ently my mother had me tested agen for Lyme Disease because the symtons had beer coming back to me. Now the test results have came back positive and I am on more medecation. Iam 10 years old now and me, my sister, and my mother all have Lymes Disease. Some times it's hard to get things done because my hole family has Lyme Diseas and sometimes we all forget.

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

State: Massachessetts
County: Gloucester

Name: Michelle [redacted]



Total cost:

Number of family members with LD: 3

Lost work/school: Severe trouble in school

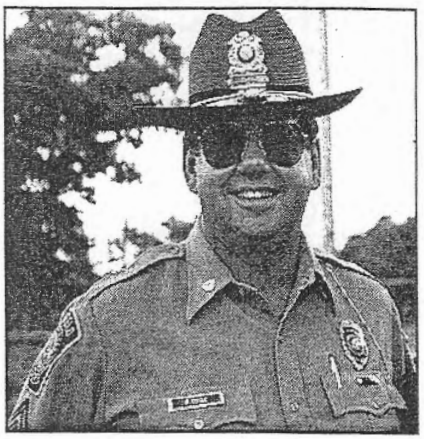
Number of years sick: 10

Hi my name is Michelle, I'm 13 years old. I've had Lyme Disease for ten years without knowing it. I, a month ago, got tested and it came back positive. We are suggesting that I got the Lyme disease from a tick in South Plymoth when we lived w/ my nana. I've had a lot of symtoms including, headaches (severe) muscle and joint pains, extreme fatigue, really bad memory loss and acedemic problems in School (lately). I am now on Tetracycline 3 times a day for a least 3 months. I hope to recover from this disease with the tetracycline but it might not come true since I've had Lyme for a long period of time.

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

State: Connecticut
County: Litchfield

Name: Roger A. [redacted]



Total cost: $100,000+

Number of family members with LD: 2

Lost work/school: 6 months

Number of years sick: 8

My Lyme story begins like most chronic Lyme patients. Doctor after doctor did not know what was wrong with me. All told me that even though I had many Lyme symptoms since my test was negative, I didn't have Lyme Disease and would not treat me.

Thinking UConn Medical would be my savior, I went there. Another blood test was given and even though Dr. [redacted] didn't see me, he called and told me the test was negative so I didn't have Lyme.

By this time I was so ill I had to stop working. I finally found two local doctors to treat me by my symptoms. I immediately had a herxheimer reaction which is caused by the Lyme bacteria being killed off.

After calling the Lyme Disease group, I learned that many have gone through what I had and also were left untreated by UConn and other doctors who base their diagnosis on unreliable blood tests. Many of us then went on to late stage Lyme Disease due to not being treated sooner.

I firmly believe that if I hadn't found Dr. [redacted] and [redacted], I would be crippled today. I responded to long term antibiotic treatment and have returned to work full time. Everyone responds differently to treatment. Many of us need long term treatment because Lyme is a slow growing bacteria that is only killed when active.

We need politicians to help pass two bills- one that would allow doctors to treat their patients anyway they see fit. Now even though long term antibiotic treatment is working for many of us, our doctors are being criticized. Secondly, politicians must also pass a bill that would force insurance companies to pay for all treatment prescribed by a doctor for as long as it is needed. Now insurance companies have doctors on retainers mandating treatment to stop after four weeks. Insurance companies are interested in saving money and not looking at the fact that we are getting better with long term treatment.

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

State: Michigan
County: Jackson

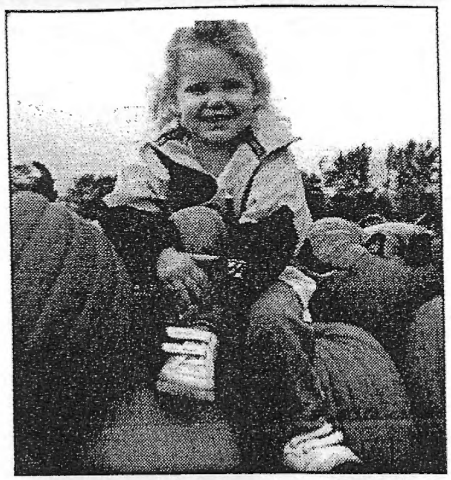
Name: Victoria [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 5 months



My name is Dawn [redacted] and this is our story. Our daughter Victoria was bitten by a Tic in late May of 1997. We found the tic at the stem of the neck,we pulled it out with tweezers and all of the tic came out. The tic couldnt of been there longer than a couple of hours. We called the family Doctor who said there was nothing to worry about. A couple of weeks had passed and we started to notice a big difference in her behavior. We checked the area of the bite and noticed it was not healing and there was light red rash around the area. We were somewhat aware of Lyme's disease as someone in our community has it. Fornuately for us they were willing to share their experience with us. We called their Physician and were able to get an apt. for Victoria. July of 1997 was her first appointment, we see the Doctor once a month which is about a 2½ hour drive there one way. Victoria's emotional state is not well, she gets very confused,angry,along with her crying spells. On top of her Lymes disease she has developed Alopecia (Hair Loss) and Candidiasis (Chronic Yeast). Victoria doesn't understand what is happening to her, she use to be such a good natured child who had so much energy and loved life. Victoria doesn't ucare when people look at her when she has an outburst, or they are staring at her hair but, I do. There are times when I will just break down and cry and it is her who comforts me," Itll be alright Ma". One thing I can say is God gave her a strong spirit. When she cries out in her sleep from the pain in her legs and stomach, I do wonder if and when this will be over for her and all of us! I do believe in the P & P method, The power of prayer and patience. In reality that is all you can do until they find the right combination of drugs that will work is pray and be patient. The financial burden is also difficul missing work,travel for treatment, the treatment itself, tests and bloodwork. We have only been doing this for a short time in comparission to most Lymes patients and to be honest I don't know how they muster up the strength to do it. In some ways i think it would be easier to deal with cancer or something else at least then you would know what you are dealing with and be able to face it head on, with Lymes there are so many strains of bacteria and so many other illnesses and side effects that can occur. The pain you feel watching someone you love go through so much

and knowing there is nothing you can do is incredible. The stress it creates in our lives is so great. David her Dad and I feel we are in constant turmoil and there is never a moments peace. Thank you for listening.

Emotionally, Financially,and Physically drained in Springport,MI.

Dawn

Dawn M. [redacted]

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

State: Maryland
County: Washington

Name: Carol [redacted]

Total cost: $20,000

Number of family members with LD: 2

Lost work/school: 6 months

Number of years sick: 10 minor symptoms, 2 yrs very ill

After 2 years of suffering from disabling neurological symptoms and after spending $20,000.00 on painful laboratory tests I was diagnosed with lyme disease. I am one of the fortunate lyme patients because I had a positive blood test that met the Centers for Disease Control (CDC) criteria. If I had not tested positive and had not had the massive antibiotic treatments needed for chronic lyme, today I would be in a nursing home at age 52.

My story is so similar to many with undiagnosed lyme disease. For years I complained of sporadic rashes, numbness & tingling of the extremities, facial and mouth pain, neck stiffness, vibrations and burning over my body, urinary tract infections, rapid heart beat, vertigo, ringing in the ears with ear pain, confusion and depression, feelings of electrical shocks, stabbing pains in the muscles and feelings of possible encephalitis. No wonder my doctor had a difficult time making a diagnosis. Two years later a neurologist from the Washington D.C. area agreed to test me for lyme after I convinced

him this could be a possibility. I am married to a Veterinarian and help to rehabilitate wildlife. I was frequently informed that I could not have lyme disease since I live in Western Maryland and there is no lyme disease in Washington County.

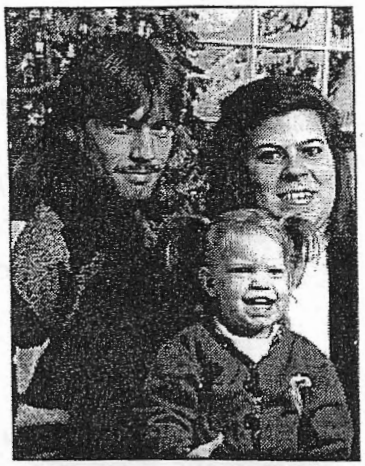
My IFA blood test came back 1 to 10,000 and all Western Blot tests met the CDC criteria. I had 30 days of IV Rocephin along with symptomatic treatments of Amoxicillin and Zithromax. I am once again leading a normal life thanks to my doctor [redacted] a lyme specialist in N.Y. who so graciously advised my doctor on proper treatment.

My daughter, a graduate from the Univ of Maryland and working in Washington D.C. suffered from abdominal problems along with constant r We had her tested for lyme and she was positive. After 6 months of amoxicillin she is fine and has been symptom free for 18 months. Our black lab, who suffered from arthritis, also tested positive.

For most people with chronic lyme disease one or two doses of antibiotic treatment will not cure this disease. Doctors must treat patients with long term antibiotics and possibly treat with antibiotics for life.

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

State: Connecticut
County: Middlesex



Name: Joanne [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 1

I had my daughter in January 1994. By right this should have been the happiest year in my life, but I got sick. It all started in June At first it was my left knee; it was swollen and I could hardly walk on it. I went to my local Emergency Room (ER) and the Physician Assistant (PA) told me I had hurt it in some way. He told me to take Advil for the pain and apply ice. I went back to the ER about a week later, this time it was for my right hand. My fingers were swollen twice their normal size, I could not bend them without hurting and my wrist was also quite swollen and hurt as well. This PA told me I had Carpal Tunnel Syndrome. He told me to take vitamin B6 and Advil. A few days later I was in pain all over; my joints were all swollen and very painful. When I went back to the ER and saw another PA, he said I had all the symptoms of rheumatoid arthritis and prescribed Naprosyn and sent me home. On July 1st I was in bed crying because I could not move one inch without shrieking in pain. My boyfriend took me to the ER and this time I saw a real Medical Doctor. He questioned me about Lyme Disease and if I had ever been tested. I told him no. He took my blood and prescribed an antibiotic. On July 8th I received the phone call I was dreading. The test was positive; I had Lyme Disease. The next six months of my life was agony. I could not take care of my daughter. Since the time I got sick my mother took care of her. I could not hold her, feed her, dress her, or most of all play with her. I was stuck in bed most of the time because it hurt to breath, let alone walk. My family took care of me as if I was the helpless infant. One day while I was reading the newspaper in bed, I found the number for the Bristol-Burlington Connecticut Lyme Disease Support Group. It was the members of the group that helped me through the most agonizing time in my life. If it was not for them I do not know where I would be today.

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

State: Michigan
County: Oakland

Name: Carol [redacted]

Total cost: $150,000

Number of family members with LD: 3

Lost work/school:

Number of years sick: 1992


Me & Daughter(also has Lyme) before Lyme


After Lyme

I am Now Totally disabled from Lyme Disease, I'm on Social Security Disability. Prior to my illness I worked in the Medical field and taught physicians Laboratory procedures in a family practice Residency training program.

my E.M. rash was missed by my primary care physician as Poison Ivy or a spider bite. I was given steroids both topically and orally-which is the worse thing to do for this disease as it allow it to decimate throughout your body and into your brain where it hides from the antibiotics and fools the body into not recognizing it as a foreign envador.

I went from a person who could do statistics ~~to~~ in her head to one that can't remember something 5 minutes after I have been told. My short range memory is very bad. I get on the road & forget where I'm going and can't remember to do the simplest things. My brain swells, my vision is very poor from this disease.

I picked this disease up in my own Wooded back yard after weeding by my bird feeder. The birds bring the nymph and larvae stage into the yard. as do squirrels, chipmonks, Ratcoons & Posium. ALL OF which we have in our back yard. I had a classic E.M. Rash with a bulls eye. IT TOOK 4 years to get a confirmed Diagnosis through PCR-DNA testing-by then IT was to Late to hope for a cure. I only pray for a remission OF the symptoms at this point.

my eldest daughter, the mother of 2 was bite by a Tick in Tennessee and has been diagnosed with Lyme. She was treated for over a year but still has the disease. She couldn't find a Lyme Literate Doctor in Tennessee to treat her and had to go to another state to be treated.

(over)

my Son, who lives in Germany picked up the disease in Europe. Yet you can't get the state of Michigan or the state of Tennessee or the Country of Germany to admit we have a problem.

With more money to educate Doctors and other citizen maybe others could be spared the horrors we all have had to endure.

With more money for research, maybe there can be a cure for us who seem to be incurable at the present time... or a vaccine can be made that will at least prevent others from sharing in our fate.

Please excuse my writing and spelling as both of these have been affected by my neurological dysfunction.

Many people think of this disease as a simple tick born disease that gets better with a treatment of antibiotics. I'm here to tell you that this is not the case myself as well as my family members have been treated various times with antibiotic therapy and yet we STILL test PCR-DNA positive for this disease. IT's not easily eradicated once it has established itself and disseminated throughout our bodies. I would Love to live to see my grandchildren grow up... but my biggest Wish + prayer is that my children can live to see their children grow up.

my family has been devistated by this disease!

Thank you for listening to my STORY [redacted]

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

State: Michigan
County: Oakland

Name: Carol [redacted]

Total cost: $90,000

Number of family members with LD: 1

Lost work/school: Now on disability

Number of years sick: 7

In the spring of 1991, I was out on sick leave from my employer, a hospital I had worked for sense 1983; as a teaching staff member for a Residency Training Program as a Medical Technologist with an advanced degree in Health Care Education who taught physicians laboratory skills they could use as a Family Practice Physician.

I was waiting to get ruptured Silicone Breast implants out and was quite ill with many symptoms including unexplained rashes and an elevated ANA.

One sunny day I was feeling a little better, so I decided to clean out our bird feeder in our back yard and got down on my knees to do so. A few weeks later, I had on my left knee a bulls eye rash, very typical of the E.M. Rash-but I didn't nor did my physician recognize this rash as Lyme Disease related. We knew it was different and felt it was a reaction to an insect bite but didn't recognize it as a Lyme related rash. After three weeks of spreading and itching he treated me with Medrol Pack (steroids) and the rash eventually went away.

Like many others with Lyme disease my symptoms were originally dismissed, i.e. pain in joints, major cognitive problems(especially short range memory and sleep Disturbances. I was told I was under stress because of having to deal with the ruptured Silicone Breast Implants and their explantation-but when they tried me on psychotrophic drugs I became worse not better.

I went to a Rheumotologist who diagnosed my problem as Atypical Connective Tissue Disease as many of the women with illness from silicone and toxic chemicals showed some of the symptoms I was having. I just kept getting worse, a nurse friend suggested that I see an Infectious Disease Physician - who diagnosed me with Histioplasmosis and treated me for this infection. This infection cleared up but I continued to feel worse. He again ran an infectious disease panel on me. This time the Eliza test for Lyme Disease was positive and the Western Blot was equivilical. I talked with Scientist in new Britain CT. and in California where they do the most accurate Lyme testing and came up positive for the PCR-DNA in my urine indicating active Lyme disease. My Rheumatologist had always felt that I was having cross reacting antibodies and a false positive reaction. With the positive PCR-DNA there was no question we were dealing with Lyme. This was four years

OVER

after the E.M. Rash on my knee. The Infectious Disease Doctor tried to treat me for the Lyme Disease-but because of decreased Hepatic (liver) and Kidney function (about 50% of normal) I am not able to detoxify very well and couldn't tolerate the antibiotic therapy very well. Because of the chemical exposure I'm allergic to Latex and Silicone, for this reason I can't seem to have I.V 's either. I have Toluene. Formaldehyde and Benzene in my body from the implants as do many other women who had ruptured implants. These agents are cancer causing and many women with this situation are coming down with Multiple Myeloma an incurable bone marrow cancer. My body is continuely trying to detoxify these chemicals and when antibiotics are added for the Lyme my system can't handle them for very long.

My Heart, Thyroid. Pituitary, Liver, Kidneys and Areenals are in very poor shape from the affects of the Lyme. If the Lyme Disease could have been caught earlier and treated sooner. I might not be disabled and on Social Security Disability: rather I might be back working at a profession that I loved dearly.

I am most thankful to finely have found a wonderful Doctor in Saginaw, Mi. who understands this disease and is willing to be educated on the other problems that I face i.e. Toxic Chemical Exposure and resulting Atypical Connective Tissue Disease. We are not able to treat me as aggressively as we would like to, but I thank God I have found a physician who understands Lyme Disease and the devastation that It causes.

I have a daughter in Tennessee who also has Lyme Disease, who was bitten by a tick in her yard while mowing her yard. She recognized the Rash as Lyme bur couldn't get a local Doctor to treat her long enough. She eventually ended up in Missouri to get treatment from a Lyme literate Doctor but it wasn't soon enough. She now also has Chronic Lyme Disease.

My son in Germany also has Lyme Disease and picked it up in Germany or Austria. He doesn't have a positive test and is going through a living hell trying to get the antibiotics needed to keep him alive. I will have them write their stories and also send pictures of themselves and their families they both have two children each.

This Disease has touched my family's lives a great deal. I hope and pray that more people, doctors, researchers and the general public wake up and educate themselves to the horrors ans devastation that this disease causes.

My prayer is that research comes up with something that can help us with this disease and prevent it in others.

Enclosed is my picture, and bless you for caring.

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

State: Oregon
County: Marion

Name: Nona O. [redacted]

Total cost: $1,600

Number of family members with LD: 1

Lost work/school: (Retired) 10 years

Number of years sick: 10

May '85 "Good news, Mrs. [redacted], you definitely DON'T have Lyme disease." ---The young Kaiser-Permanente internist had known nothing about Lyme when I "caught it from a magazine" and asked for a test. He had gone out to a hall phone, but we still heard him call a specialist in infectious disease and ask about Lyme. Now he knew all about it, including its 100% accurate ELISA test! (I had read about Lyme in a Good Housekeeping article and recognized my symptoms.

The previous November I had cleared brush north of our house, and gotten a classic Lyme rash on the arm ("I've only your word you had it", another infectious disease specialist was later to tell me). Severe headaches, stiff neck and blackouts had followed in weeks, joint pains, then chronic fatigue in months. My K-P doctors tested everything, recognized everything, diagnosed everything---separately. They gradually doubled my thyroxin, to a dangerous level (caught by my son, and confirmed by an outside endocrinologist---apparently no one has ever explained to most M.D.s that one Graves disease patient in six has "mixed symptoms").

The Lyme test was negative, but I did get ten days of antibiotics.

The next two years saw more joint and muscle pains, often changing location; heart palpitations and chest pains; several neurological problems; blurred vision; hands and feet terribly swollen; right jaw swollen and painful. I was on crutches several times. Diagnosis? ---Rheumatoid arthritis. X-Rays and lab tests don't show any? ---then it's your heart, [redacted]. (But, doctor, you haven't so much as put a stethoscope to my chest!...)

Jul '90 Local TV told me of a Lyme support group in Portland. A doctor there, 12 years a Lyme sufferer himself, sent an info packet to my newest K-P doctor, who finally started me on Amoxicillin and Probenecid. My right eye's vision doubled. "Mrs. Ford, there is no such thing as double vision in one eye". Sheer ignorance; the literature recognizes at least 3 kinds.) The cataract grew very rapidly; K-P let it get over-ripe; I was blind in my right eye. I called all of the ophthalmologists in the Salem telephone directory, asking if they knew anything about the effects of Lyme on the eyes---none did! But three of them asked me to share if I got the information. Thru the doctor I had met in Portland, I did receive a packet of info on the subject. Copies were made and taken to the three doctors. I had one of them do a lens-implant June '93. Six months later he diagnosed Lyme unequivocally, from weird vision symptoms... showing brain involvement; my info packets had paid off! Most Lyme sufferers are not so lucky. Since then K-P has provided my BIAXIN long-term, but with every new doctor I am shifted to, it may be withdrawn. They have already used the state medical board to stop the Lyme practice of the only doctor in Oregon with extensive experience with Lyme. The reason?---he had a lot of Lyme patients! Might as well close down every oncologist who treats cancer...

Oct '97 Half the M.D.s in Oregon will still tell you, "There is no Lyme disease in Oregon", (one even shouted it at me), but many vets have been treating animals for over a decade. By CDC's own standards, there must be at least 2,000 people with Lyme in the state, and help is almost non-existent.

I have had three ELISA tests and one PCR...all negative, but my many, many, symptoms (including dyslexic tendencies) are far from negative and definitely not a figment of my imagination.

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

State: New Jersey
County: Monmouth

Name: Ann [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school: 1985

Number of years sick: 17

MY HISTORY IS LONG AND COMPLICATED.

IN 1980 I BECAME ILL WITH FLUÝ LIKE SYMPTOMS FOLLOWED BY BOUTS OF DEBILITATING FATIGUE, MIGRANES, SINISITIS, BRONCHITIS, AND A DIAGNOSIS OF IRITIS LATER DIAGNOSED AS INTERMEDIATE UVEITIS (INFLAMATION OF THE EYES WHICH WAS KNOWN TO CAUSE BLINDNESS AND WAS OF UNKNOWN ORIGIN) AS WELL AS GASTROINTESTINAL DISTRESS.

I WAS TREATED WITH ANTIBIOTICS AS CALLED FOR AND NUMEROUS DROPS FOR THE EYES.

BY 1984 THE EYE DISEASE WAS OUT OF CONTROLL AND I WAS GIVEN A LARGE DOSE OF STEROIDS TO HELP SAME. I HAD A SEVERE REACTION AND AND COULD NO LONGER FUNCTION IN THE WORK FIELD.

I WAS PUT ON FULL DISABILITY, SOUGHT OUT THE HELP OF A PSYCHOLOGIST WHOM GOT ME TO SEARCH FOR THE CAUSE OF MY EYE DISEASE IN ADDITION TO RETURNING TO SCHOOL WHICH I DID WITH THE BACKING OF VOCATIONAL REHABILITATION. UNFORTUNANELY BY 1988 THINGS WERE LOOKING BLEAK AGAIN. MY CONCENTRATION WAS FAILING ME AS WELL AS MY EYESIGHT AND THE CONSTANT ADVERSE REACTIONS TO EYE MEDICATIONS.

IN JUNE OF 1991 I BECAME EXTREMELY ILL WITH FLU LIKE SYMPTOMS AGAIN. THE MIGRANES INTENSIFIED AND NEUROLOGICAL SYMPTOMS WERE DEVELOPING. THE EYE DISEASE WAS OUT OF CONTROL. MY PHYSICIAN ONCE AGAIN INSISTED THIS HAD TO BE PSYCHOLOGICAL IN NATURE, NO ONE COULD HAVE THIS MUCH WRONG WITH THEM! PART OF ME WAN'T TO BELIEVE THIS WAS TRUE BUT THE OTHER KNEW IT WASN'T.

BY JUNE OF 1993 I HAD NOTED THAT A NUMBER OF MY SYMPTOMS MATCHED "ATTENTION DEFICIT DISORDER". A PSYCHIATRIST AGREED AND I HAD THIS CONFIRMED BY A NEUROLOGIST.

STILL NO MENTION OF LYME DISEASE

I WAS TREATED FOR ATTENTION DEFICITIT DISORDER (1/3 NORMAL D OSE OF CYLERT) WHICH WAS ENOUGH TO ORGANIZE MY MIND AND SEND ME ON A SEARCH FOR THE CAUSE OF THE EYE DISEASE.

I HAD NOW DEVELOPED CYSTIC MACULA EDEMA IN THE EYES AS WELL AS GLAUCOMA. AFTER RETURNING FROM THE NATIONAL INSTITUTE OF HEALTH IN BETHESDA, MARYLAND WITH PERMISSION FOR THE DOCTORS TO USE IMMURAN (an immunosuppresant) IN PLACE OF STEROIDS,I FINALLY OBTAINED DOCUMENTAION LINKING THE EYE DISEASE TO MULTIPLE SCHLEROSIS IN 5% OF THE CASES AND MAYBE LYME DISEASE. IMADE A LIST OF ALL DISEASES EVEN REMOTELY CONNECTED TO UVEITIS AND SET ABOUT ELIMINATING THEM. WITH THE HELP OF A FEW DOCTORS I FINALLY RECEIVED A CLINICAL DIAGNOSIS OF LYME DISEASE AND FINALLY IN DECEMBER OF 1995 WAS ADMITTED TO A HOSPITAL AND PUT ON RECEPHIN WITH DRAMATIC RESULTS. AT THIS POINT LESIONS ON THE BRAIN HAD BEEN CONFIRMED AS WELL AS RADICULITIS. I HAD RUPTURED A DISC, HAD DEMYELATING PLAQUES ON MY SPINAL CORD, FLUID IN THE SPHENOID CAVITY OF THE BRAIN AND WAS BADLY IN NEED OF AN EYE OPERATION WHICH NEEDED TO BE PERFORMED WITHOUT THE STANDARD USE OF STEROIDS PRIOR TO SAME.

TO DATE I HAVE HAD THREE EYE OPERATIONS WITHOUT THE USE OF STEROID THERAPY IN ADVANCE AND MY EYES ARE THE BEST THEY HAVE BEEN IN TEN YEARS. THE LAST MRI OF MY BRAIN CAME BACK NORMEL AND I NO LONGER HAVE SYMPTOMS OF ATTENTION DEFICIT DISORDER (at least I no longer require medication).

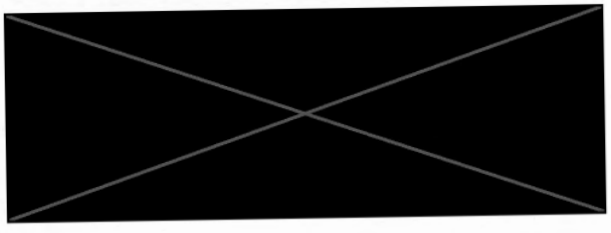
UNFORTUNATELY THE BATTLE GOES ON. I HAVE RELAPSED EACH TIME I HAVE BEEN TAKEN OFF MEDICATION AND SUFFER FROM CHRONIC UNREMITTING PAIN DUE TO NERVE DAMAGE AND POSSIBLY JOINT DISEASE. AS LONG AS THIS INFECTION REMAINS IN MY SYSTEM MY SIGHT IS AT RISK.

PCR TESTING HAS TWICE CONFIRMED THE DIAGNOSIS OF LYME DISEASE REGARDING MY CASE.

Please Note: 1/3 of All Cases of Intermediate Uveitis Are Considered To Be Lyme Disease Related

Article Dated 11/95

Plus Research Previously Done Dating Back To 1986



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

State: Maryland
County: Washington

Name: Mary [redacted]

Total cost: ?

Number of family members with LD: 1

Lost work/school: Retired

Number of years sick: 5

When your local Health Dept. says "There are no funds to test ticks for infection" , and when your local Health Dept. does not want to accept or look at your positive Lyme Test when you personally hand it to them, then something is terribly wrong. When you have deer ticks crawling across your kitchen table and coming off of vegetables you pick from your garden and many persons in your neighborhood are getting ill with symptoms known to be indicative of Lyme Disease, there is a great problem that needs to be dealt with and not put aside.

April - 1992- I had an engorged tick removed from my lower back - followed in a few days by a bulls-eye rash. Because Lyme Disease was unheard of in Western Maryland at the time, I did not seek medical help.

May - 1992- I was stricken with Bells Palsy, fatigue and joint pain and sent to emergency room for possible stroke. Put on 50 mg. Predisone and sent home. I immediately started therapy on my face.

Aug. - 1992- Flu-like symptoms weakened my body for 3 months.

Dec. - 1992- Severe Asthma attacks began, which I had never had asthma in my life. Put on 50 mg. Predisone and inhaler.

Feb. - 1993- Memory Loss, Poor Concentration, Blurred Vision, Eye pain and Joint Pain began a year of one problem after another with sleepless nights, weakness and low grade fevers.

Jan. - 1994- Severe Memory Loss, unable to do daily chores, teach Sunday School, Read Music and sing on the choir as I had done for 30 years. I went into deep depression and cried for my doctor to please test me for Lyme.

March- 1994 - Elisa Test - (Negative.) Sent to Rheumatologist, he said nothing could be done but put cortisone shots in my joints. I refused.

April - 1994- Was refered to Johns Hopkins and clinically diagnosed with Lyme Disease and ordered on anti-biotics for 30 days. Had Western Blot Test with 41K Positive.

June 1994- Had Spinal Tap - Protein Count marked High, my doctor said the test was fine, nothing wrong.

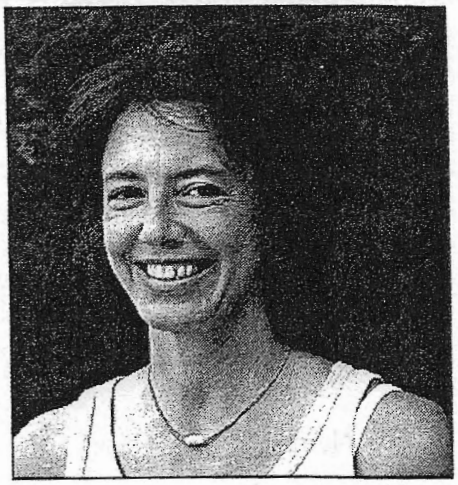
October- 1994 Relasped, Put on Doxycycline for 30 days.

October- 1995 Relasped again, doctor refused to give me anymore antibiotic Was told to live with it and I would probably be in a wheelchair in a few yrs. I began to study this strange disease called Lyme Disease and went over all my tests and immediately noticed one of the main symptoms was High Protein Count in Spinal Fluid. I became determined, I would not settle for a life in wheelchair.

(cont'd)

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

State: Maryland
County: Harford



Name: Virginia [redacted]

Total cost: $100,000+

Number of family members with LD: 1

Lost work/school: 7 years

Number of years sick: 7

Nightmare on Lyme Street

[redacted]

In July 1990, while living in an area endemic for Lyme disease, I found an engorged deer tick crawling off my hand. Subsequently I found a rash on my leg above the ankle. The physician diagnosed the erythema migrans rash and noted the two bites inside the center of the rash and prescribed a short course of doxycycline. The test for Lyme antibodies performed at this time returned negative. Later my blurred vision worsened, as did the numbness and paresthesias in my extremities. I had swollen glands, fever and chills, debilitating fatigue, and felt really sick as if I had been poisoned. Extensive evaluation for other illness proved negative.

During the eighth week after the tick bite, I converted from seronegative to seropositive for Lyme antibodies. A short course of intravenous Claforan was given. It helped, but after that my condition worsened. My leg dragged at times with numbness and severe shooting pain, swollen glands, fever and chills; and arthritis which slowly spread to several joints, and the cognitive dysfunction worsened. The neurologist ordered a lumbar puncture which was tested at the Hospital of University of Pennsylvania lab, and it returned positive for Lyme antibodies. This specimen was then sent to Dr. Steere of Tufts University for retesting and was returned "negative" for Lyme antibodies.

Three months later after my condition had further deteriorated, a friend drove me back to the neurologist: I was weak, my Lyme headache had worsened, the above symptoms had intensified. This time my reflexes when tested were unresponsive. My neurologist was alarmed and he prescribed intravenous Rocephin. I have improved slowly but considerably on lengthy regimens of antibiotics used separately and in combination. My vision for many months was blurred, but now is improved though not yet fully restored.

I am still not completely cured. I have given seven years of my life to this debilitating illness. I am still not completely cured. I have been mis-diagnosed by doctors who almost willfully refused to take my symptoms seriously. It has been an extremely expensive illness, simply because it was diagnosed so late in development. Though I met over and above the diagnostic criteria set by the Centers for Disease Control for diagnosing Lyme disease, yet based on Dr. Steere's one test result from his lab, I was not given the antibiotics I needed for treatment.

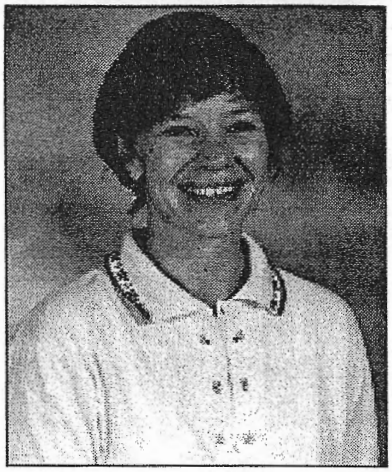
Lyme disease is a serious and growing problem throughout the world. For Dr. Steere to conclude that a "short course of antibiotics" is enough to treat Lyme disease, and when that short course does not completely resolve the condition, to assume that it was not Lyme disease to begin with, is an irrational, irresponsible, erroneous and dangerous assumption to make. Diagnosis cannot be based on one test from Dr. Steere's lab alone.

There is so much more than this that it can not be described here – all the ambulance rides and visits to the emergency room, all the IV sticks that I've had, PICC lines, Central line, all the nursing care visits, all the pharmacy calls, all the medicines I've taken for 7 years, all the physician visits, all the lab tests, all the days and nights spent alone without adequate food, and cold, all the critical looks from people seeing me wearing a hat and several sweatshirts in 90 degree weather trying to keep warm, all the strangers and friends who generously and graciously helped me when I couldn't do for myself, fixing meals, driving to doctors, cleaning my house, doing paperwork, food shopping, paying my bills, dressing me, there were times I couldn't even speak two words, and couldn't stand, and I was destitute with no income and no food and stood in a food line with an IV hanging out of my arm.

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

State: Massachusetts
County: Plymouth

Name: Susan [redacted] RN



Total cost: $10,000

Number of family members with LD: 1

Lost work/school: Work 10

Number of years sick: 1 1/2

I am a 44 year old nurse, wife and mother of two who lives in a coastal Massachusetts community. After 6 months of illness, 9 doctors, countless blood tests and a variety of diagnostic procedures (MRI, EEG, vision + hearing tests) I was finally diagnosed with sero-negative Lyme disease with brain changes noted on a SPECT scan. I have been on oral antibiotic treatment for 9 months and am about 50% better. The severe pain has diminished but the neurological symptoms are stubborn. There is not a part of my body that has not felt this disease, not a muscle, not an eyelash. It is truly all consuming.

My odyssey through this disease has had profound effects, not only on my mind and body, but on relationships as well. The months before diagnosis were pure torture, being so ill, getting worse month by month, with no one to validate you, not even my own profession, medicine. Depression and self-doubt are harder to deal with than the physical pain. I'll never know how those of us with Lyme find the strength to keep moving forward, there can be some awfully bad days.

As I continue to heal, be it ever so slowly, I remind myself that the only way past this, is through it. Supportive family and friends, a support group and an expert doctor are those that help me on my road to recovery.

Please pay attention to Lyme Disease, No one should

OVER

have to go through this. Early diagnosis and treatment can save countless numbers of dollars, mental and physical agony, and probably many relationships.

We must work to change the reporting requirements for Lyme Disease. There are many of us who do not fit the CDC's protocol for Lyme Disease. This not only invalidates us but is a disservice to the population in general, who deserve to know how widespread this disease is and where the high risk areas are.

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

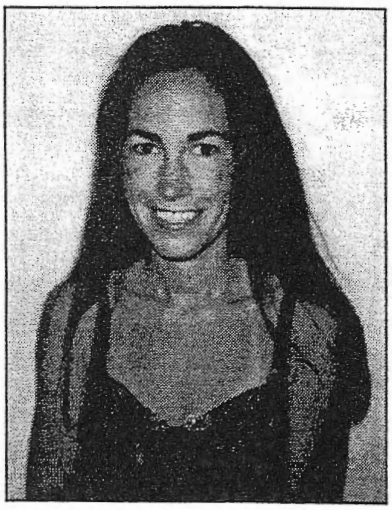
State: New Jersey
County: Somerset

Name: Caroline [redacted]
Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 2 years



I began by having very odd symptoms - stomach problems, headaches, tiredness. I had never had any complaints like this before. then I had numbness in my arm and pins and needles all over my body. I heard from at least 20 doctors, "it's stress and all in your head". My parents turned against me and made me go to a psychologist - However. I kept pursuing doctors actively. knowing that I was sick. Finally. after 2 years. I was diagnosed. To this day. My parents don't understand my dilemma. They think its in my head. They have pretty much left me on my own and offer little help with my life. I am sick headed and my job. life and independence have been taken away. I suffer from achey muscles, knee problems. memory loss, vocal problems, eye problems etc. every day. But, at least I'm assured that this problem is real and it has a name. I would love to be able to help others in my situation. I am always trying to convince my friends that this "tick borne illness" is a real threat. But, I feel like we need to do more because society still thinks they are invincible against this

Received a call from my doctor , requesting that I visit a Lyme Specialis and be part of his research testing. I began looking for a new doctor. I found a doctor who was familiar with Lyme Disease, looked over all my record and ordered a Western Blot, result Positive 1.32 was put on Amoxicillin for 6 weeks.

Because of late diagnosis and mis-reading of spinal tap, many problems associated with this disease have now become permanent with damage to the eyes, joints, bones and memory but I have been down to almost 0 and with antibiotics been brought back to a productive human being.

After 11 doctors, including a rheumatologist, 2 internists, 3 ophthamologists, neurologist, neuro-psychologist, neuro-surgeon and infectious disease specialists (both clinical and academic) from Hagerstown, Frederick and Baltimore,It is very clear that doctors of all specialties need to educated in the complexities of this disease without the politics of peer pressure, Insurance Companies restrictions on medications, Real Estate supression of an unhealthy problem in their area and above all the criteria put on our local Health Dept. by the NIH.

It is bad enough to go from a strong athletic individual to a weak pain ridden person with many health problems from the bite of an infected tiny insect but then to be demorilized and be pushed aside by those whom we are taught to trust.

People in Maryland are getting very ill,
It is not right that sick people have to fight to get well.
It is time for strong well individuals to step forward and realize that time is running out for them as they may be the next to get this disease and ask questions and find answers before its too late.

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

State: Missouri
County: Grundy

Name: Alice [redacted]

Total cost: ?

Number of family members with LD: 1

Lost work/school: 6

Number of years sick: 6

MY name is [redacted]. My wife [redacted] has lymes disease, we live in TRENTON, MISSOURI__in GRUNDY COUNTY. [redacted] has had lymes disease every since 1991, she was bitten by a dear tick, and at the time we didnt know anything about lymes disease. she had a job as cordinator over a bus , we use to take people to the BINGO HALLS AND TO THE CASINOS,and we never thought anything about it at the time until she started to become forgetful, and get very tired all the time , we just thought it was from the trips wearing her out all the time but we later found out that after a she had lymes disease and she had already went without any treatment for a year for it, and by then it had already done damage to her.

The doctors in MISSOURI dont believe there is any lymes disease here because of the CDC.saying there isnt any lymes here and it has been quit a struggle trying to keep her doctored for it, I now have to take her to a doctor in ILLINOIS to get doctored for it, and it is a 5 HOUR drive there and 5 HOURS back, they have been so much help SHE now has ENCEPHOLITIS(FLUID ON THE BRAIN) from LYMES DISEASE. She is in constant pain and has to take pain medicine around the clock and is unable to work, it is hard for her to stand up and walk and she cannot get any disability for it cause they say she doesnt have enough work credits and that I(JOE) work in a factory and make too much money for her to be eldigable for any SSI. OR SOCIAL SECURITY. SHE HAS BEEN unable to work every since she was bitten by the tick. If it wasnt for my insurance where i work we would be out in the cold, but they say that so many weeks of being on antibotics is enough and then the doctors take her off of them

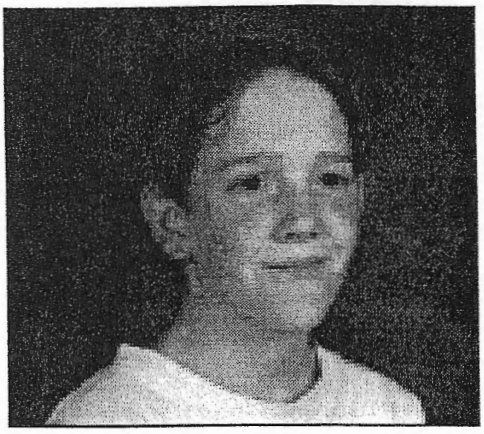
IT is very hard for anyone to understand how bad LYMES DISEASE can be unless it is YOURSELF OR A LOVED ONE that has it. MY WIFE has had a lot of problems every since she has been bitten by the tick.IT is very hard for her to do the house work and i have to help her but i dont care to do it for her .

THIS picture is of my wife [redacted] and you can see the TIPICAL LYME RING on her neck. I only hope that they will come with something that will get rid of LYMES DISEASE and real soon for there are too many people out there with it, and they may not know they have it is what is bad.

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

State: California
County: Contra Costa

Name: Wade [redacted]



Total cost: $20,000 (unreimbursed medical bills)

Number of family members with LD: 1

Lost work/school: 1 year

Number of years sick: 2

My name is Wade [redacted] I am in eighth grade, but I have a home teacher from the school district because of my Lyme disease. I always have a bad headache and painful joints. I feel terrible most of the time. It's hard to remember back to 6th grade when I was one of the fastest runners in my P.E. class. I loved to go fishing and hunting. I used to hike a lot then, and had fun doing things with my friends. Then one Monday morning in February 1996, I found an engorged tick in my hair near the base of my skull. The school nurse thought it was gross and flushed it down the toilet. When I told my parents they were very concerned and told me to tell them if I started feeling sick. I said, "Sure Mom," but figured it was no big deal.

When I started feeling bad a couple of weeks later, I thought I was just getting the flu. My mom took me to the doctor and pointed out that I might have Lyme because of the tick bite and the bad headaches. My doctor thought I probably had the flu or an allergy. He gave me Claritin, and would not give me antibiotics for Lyme disease like my mom asked. After a couple of weeks of taking Advil for my headaches, my mom took me back to the doctor because I was feeling worse. My doctor had an ELISA blood test done for Lyme and a nasal X-ray for sinus problems. The blood test was negative for Lyme so I was put on decongestants and Augmenton for 10 days. I started to feel better, but got worse again after I stopped the antibiotics. Mom took me to see a second pediatrician. I told her that it was very painful to walk now and that the headaches were much worse. The pediatrician also thought I had sinusitis and put me on Bactrim. Two days later I broke out in hives, so I was switched to Cefzil for a couple of weeks.

I was miserable in school, because my ankles would hurt so much after P.E. that I had to hang on to the chain link fence on the way back to class. My P.E. teacher thought I was trying to get out of exercising. My teachers just thought I wasn't paying attention in class, but I just couldn't concentrate. Mom hired a tutor to help me with homework which was very hard for me to do in the afternoons. By then I was taking Advil pills to school to try to keep the headaches and joint pains down. The Advil didn't help much but it worked better than Tylenol. I can tell you this story because my mom and dad began keeping a log of all my symptoms and medicines. Without looking back at the log, the past year and a half is just a blur of feeling terrible, going to the doctors, trying something else, and just going on feeling sick. I also want to say that I like my doctor a lot but I don't think he knows how to help me.

Mom asked him to do another blood test (Western blot). She had a friend who had Lyme and thought my symptoms sounded the same. The blood test was negative. School was out and we were about to go on a trip. My doctor was on vacation, but mom begged another doctor in the office to give me Amoxicillin to take on the trip. We drove across country, and at first I had trouble with motion sickness. I felt really terrible, and I hated being pushed in a wheel chair around Williamsburg and Washington DC. After a couple of weeks, I started to get better, and even went on a horseback ride in Wyoming. I still had the headaches, but they weren't so bad. My doctor gave me another month of Amoxicillin when I got back.

When school started, my doctor wouldn't refill the prescription until more tests were done, so I had another blood test which was negative. I was feeling so bad at school that I took 6 Advil during the day just to keep my headache down to a 6 (on a scale of 1-10, 10 being the worst). My doctor wrote a note excusing me from P.E., but my teacher would say things like "You're feeling up to this today aren't you Wade?" in front of everyone, so I would push myself to do the exercises and track. Next, I was referred to a doctor for Fibromyalgia. He didn't think I had Lyme, and the tests he did for rheumatoid arthritis were negative.

Because I had gotten better on Amoxicillin, he gave me 3 more months of it. By Christmas, I was beginning to feel OK again. I could go on hikes, and the headaches were almost gone. I was so happy that I was getting better. Two weeks after I stopped the Amoxocillin, I had a relapse. My parents took me to a Lyme specialist who told me that I might have Lyme or about 5 other dread diseases. He said we had to prove that I didn't have those other things, so I was sent to a psychiatrist, an ophthalmologist, and a very nice neurologist. I had more blood tests (all negative) an MRI which looked normal, and a spinal tap that **really** hurt (also negative). So I found out I don't have a tumor, cancer, MS, eye problems, and some other bad things. By this time I was having incredibly painful "hits" or stabbing pains in my chest, head, and knees, so I had an EEG and an EKG (both normal). My neurologist tried me on 8 different headache blockers to try and get rid of the headaches. None of them helped and some made me so sick I couldn't eat and felt dizzy a lot of the time. I was so sick I stopped going to school. My worst day was my last, when kids started making fun of me when I couldn't walk to the office because of my bad joints. Finally a teacher helped me, then my mom came to take me home. A teacher from the district was sent to our house for an hour each day to bring assignments, teach me things, and give me the tests. She helped me get through the 7th grade.

My doctor put me on 6 weeks of IV Rocephin in April 1997. My parents paid to have a urine test for the first several days of the IV treatment. I felt terrible at first, but after a couple of weeks, my headaches seemed to go down and the pains weren't so bad in my ankles and knees. It turned out that my urine sample from the 4th day of IV showed a strong positive result for Lyme. That positive test helped me feel that I could fight the spirochete. I had a real enemy I could focus on beating even if I couldn't punch it in the nose. I began to feel much better on the IV, but when I stopped, I still had symptoms of headaches, chest hits, and joint pains. I went on a low dose of Zithromax, but day by day I began to get worse again. I was so discouraged because I had counted on getting better with the IV. My joints were so bad I had to use a wheel chair, and I had as many as 20 hits in a day. It was a scary time. I was afraid to go in a pool because I might drown if I got a pain in my chest.

My dad had learned from the internet that Hyperbaric Oxygen Therapy (HBOT) was helping some people who had chronic Lyme. They took me to southern California to have a SPECT scan done at UCLA. That smoggy LA day, it took 9 people 11 stabs to get an IV line into my ankle! The scan showed that areas of my brain were not getting enough oxygen. I started HBOT at the Hyperbaric Oxygen Institute in San Bernadino. The people there were incredibly nice, and a kid from Canada, who was being treated for colitus, helped me learn how to clear my ears when I was being pressurized. At first I felt really terrible after the treatments, but after about 2 weeks I was feeling as well as when I finished the 6 weeks of IV treatment. I braved a second SPECT scan which indicated improvement in my brain.

My parents were running out of funds because our HMO wouldn't pay for SPECT scans and HBOT, so we returned to the Bay Area. The Lyme specialist recommended that I go off antibiotics for awhile. I got really bad again after three weeks. It took that long to find a hospital and doctor in our area that would give me HBOT for Lyme. I am slowly getting better on HBOT, and have recently started taking Doxycycline and Biaxin at the same time. A scientist who heard of my story, called to tell my dad that he had been cured of Lyme by taking those two antibiotics for two years.

Sometimes I feel my life has been ruined, but then I talk to other people who have been struggling with Lyme for many years and haven't given up. My friend Stephanie Diers got Lyme in the 1960's when she was 12. She sends me pictures of herself and her husband who also has Lyme. My friend Bob Lane has been the biggest help in giving me the courage to get better. He has believed in my symptoms and helped my parents learn everything they can about the disease. It's bad enough feeling so terrible you don't even want to see your friends. The fact that doctors don't know what to do and HMO's won't pay for treatments like HBOT really gets you down. I know that my parents can't pay for any more HBOT, and I doubt that the HMO's will let me take Biaxin for two years until I'm cured. I feel lucky that I have a family and friends who haven't given up on me. I am part of a Kids in Creeks program, and it helps to look forward to when I will be able to help make San Pablo Creek a better place for frogs, newts, and fish.

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

State: Wisconsin
County: Washington

Name: Jon [redacted]

Total cost: $6,000

Number of family members with LD: 1

Lost work/school: weeks

Number of years sick: unsure-possibly 5 or 6

Jon is third from the left, top row.

I am 33 years old and live in West Bend, Wisconsin. I am married with 2 small children and work as a software developer in the Milwaukee metro area.

I have experienced years of problems associated with Lyme Disease and saw 7 doctors before I was actually diagnosed with Lyme Disease. Over the last few years I have had joint swelling and pain, kidney pain, dizziness, facial paralysis, fatigue, chest pain, muscle pain, headaches, tingling and numbness in arms and hands, blurry vision and other problems. Over time I have received diagnosis of Fibromyalgia, Irritable Bowel Syndrome, Rieters Syndrome, and other various conditions.

I finally was tested for Lyme by a doctor in the Emergency Room after my wife dialed 911 and had me transported to the hospital for chest pain. The younger doctor had ordered the test after my wife had explained the bizarre problems that I had encountered in previous months. It is my impression that many Lyme patients are viewed as hypochondriacs and are not taken seriously by medical professionals. I was very healthy and weightlifted each morning and jogged four miles a night before my Lyme problems began. My doctor was not even aware that facial paralysis was associated with Lyme, and the rheumatologist that I saw also missed the diagnosis. My wife and two small children are missing a once very healthy and active husband and father.

I drove 450 miles last week to see a Lyme literate doctor. That doctor stated that my old doctor was using a treatment that was about 15 years old and wasn't very effective. If I hadn't taken initiative and sought help and information from other Lyme patients via the internet, I would still be working with my old doctor today and receiving an ineffective treatment regiment. Because Lyme Disease can cause permanent damage to the heart, brain, joints, eyes, and other organs, it is extremely important to get treatment immediately. Unfortunately, most of the Lyme patients that offered me help also had the same experiences with multiple doctors and misdiagnosis.

Thank you to the Lyme Foundation for their physician referral help. The medical community has a LONG way to go in recognizing, diagnosing, treating, and curing Lyme Disease. There doesn't seem to be much awareness about the disease in my home state of Wisconsin, which is a region with a high incidence of the disease. Only action by the medical community, and our state and federal governments can change the situation in the future.

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

State: Connecticut
County: Hartford

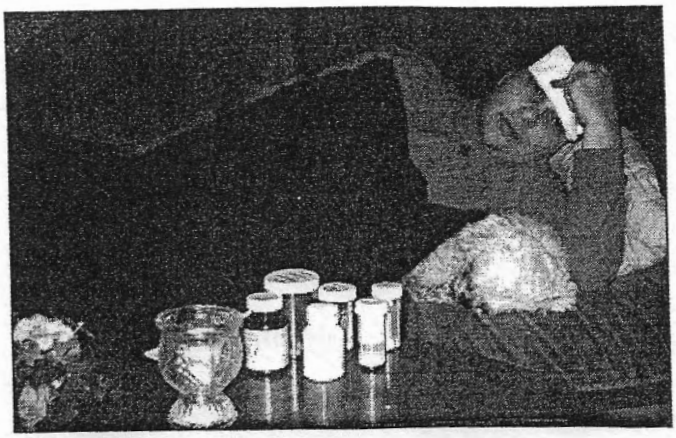
Name: Gia [redacted]

Total cost: $350,000

Number of family members with LD: 2

Lost work/school: 2 yrs.

Number of years sick: 5



my story started five agonizing years ago. my nightmare started with a rash on my back that my father said was a spider bite so I just let it go. I had no idea what Lyme Disease was, but I sure found out the hard way. After ten different doctors with ten different diagnosis I finally got two positive Lyme titers three years to late. I was treated with oral antibiotics for one year then started on IV antibiotics which finally started to improve my symtoms which included massive head pain twenty-four hours a day, burning in various parts of my body, joint pain and swelling, and deep depression. Unfortunately my insurance company played god and decided to take me off I.V. My symtoms began to intensify again and my head pain remained. In the summer of 1997 I found out I had Arnold Chiari malformation which is the spinal instability

to grow in the womb which needs Surgery.
Once again I am waiting for my Insurance company to approve the surgery. & I have lived the nightmare of Lyme Disease for five years now and it has been nothing less then unbelievable. It is the most Underrated, undertreated, and misdiagnosed disease, and it is time that those in power should start recognizing this and start helping wherever they can to help those who are needlessly suffering. This disease is second only to aids in infectious disease at this time when are those in power going to realize this, and help us my family has suffered for too long and my Son has been only a month who suffer in pain everyday, it is not fair for him and many other children who have been touched either indirectly or directly by this disease Please help us! This needs to start here and now Thank you for reading this letter.

[redacted]
(mother, wife, and Lyme Sufferer

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

State: Indiana
County: Adams

Name: Charile [redacted]

Total cost: $3,100

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

Dear Karen Forschner;

I just came across your information about the Campaign late last night on the internet.

I sincerely hope you may be able to include our family info in your first edition for Congress. I don't have time just now to go into all we've been through, but if our state of Indiana could be included in this small way, it may help demonstrate this is a problem for the entire nation, not just the northeast. I will send our story soon. thanks- [redacted]

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

State: Indiana
County: Adams

Name: Jean Porter [redacted]

Total cost: $34,000

Number of family members with LD: 5

Lost work/school: 7 months + misc.

Number of years sick: over 2 year

Dear Karen Forschner;

I just came across your information about the Campaign late last night on the internet.

I sincerely hope you may be able to include our family info in your first edition for Congress. I don't have time just now to go into all we've been through, but if our state of Indiana could be included in this small way, it may help demonstrate this is a problem for the entire nation, not just the northeast. I will send our story soon. Thanks-

[redacted]

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

State: Indiana
County: Adams

Name: Jason [redacted] (12)

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

Dear Karen Forschner:

I just came across your information about the Campaign late last night on the internet.

I sincerely hope you may be able to include our family info in your first edition for Congress. I don't have time just now to go into all we've been through, but if our state of Indiana could be included in this small way, it may help demonstrate this is a problem for the entire nation, not just the northeast. I will send our story soon. Thanks-

[redacted]

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

State: Indiana
County: Adams

Name: Ryan [redacted] (8)

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

Dear Karen Forschner;

I just came across your information about the Campaign late last night on the internet.

I sincerely hope you may be able to include our family info in your first edition for Congress. I don't have time just now to go into all we've been through, but if our state of Indiana could be included in this small way, it may help demonstrate this is a problem for the entire nation, not just the northeast. I will send our story soon. Thanks-

[redacted]

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

State: Indiana
County: Adams

Name: Nathan [redacted] (4)

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: At least 2 years

Dear Karen Forschner:

I just came across your information about the Campaign late last night on the internet.

I sincerely hope you may be able to include our family info in your first edition for Congress. I don't have time just now to go into all we've been through, but if our state of Indiana could be included in this small way, it may help demonstrate this is a problem for the entire nation, not just the northeast. I will send our story soon. Thanks-

[redacted]

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

State: New York
County: Cattaraugus

Name: Elizabeth [redacted]

Total cost: $200,000

Number of family members with LD: 1

Lost work/school: 6 months

Number of years sick: 3-4 before diagnosis

I am 58 years old, a former teacher and an outdoor enthusiast. I live in a rural area and love outdoor sports. My husband is a deer hunter. In April 1994 I read an article by John K. Bleiweiss, MD titled When To Suspect Lyme Disease. I matched symptoms he described for chronic Lyme, with many encephalitis type symptoms. I had been tested for all kinds of things by my doctor and was put on several anti-depressants as the only solution. It didn't help much.

In May 1994 I sought treatment from [redacted] since I could not find a W. New York doctor who took my claims seriously. Dr. Joseph had me take a urine antigen test before + after 1 month's treatment with Biaxin. (I was allergic to amoxycillan). The second urine antigen test showed that I was positive for Lyme. I continued treatment on more month + was symptom free for 8 months. I was treated again by my doctor here in NY with Vantin for 6 weeks. I have been symptom free since June 1995.

I suffered Lyme symptoms for 3-4 years before self-diagnosing + seeking treatment from a Lyme specialist. I am very grateful to Dr. Joseph.

P.S. I could have contacted several more Lyme patients in my area if I had received this form in time. Send me forms if hearing is delayed.

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

State: Connecticut
County: Fairfield

Name: Marie [redacted]

Total cost: >$150,000

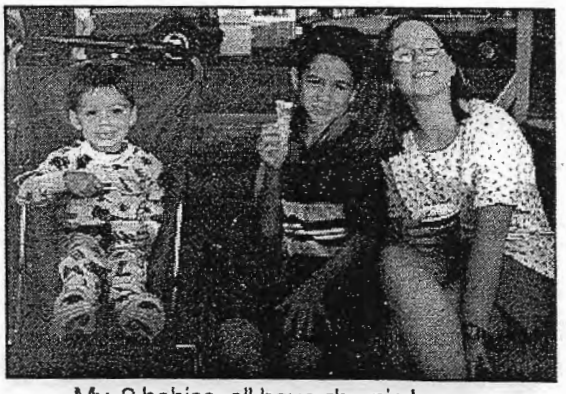
Number of family members with LD: 4
immediate, 16 extended

Lost work/school: immeasurable

Number of years sick: 5

My 3rd baby's Christening. We all have Lyme!

My family in 1989. In 1997, 16 of us have Lyme.



My 3 babies all have chronic Lyme.

I have Chronic Lyme Disease, with full neurological involvement. We believe I first contracted L.D. when pregnant with our third child. Unfortunately, I was misdiagnosed and mistreated with Lyme. Not only do I suffer daily these consequences, but so does my innocent baby son, who was born with Congenital Lyme Disease.

Despite treatment, length, expensive, & invasive treatment, I have constant battles with Lyme Disease. I have abnormal brain circulation, cognitive deficits, and nearly constant pain & fatigue.

I have 3 children with severe late stage chronic Lyme Disease. I watch my babies suffer, and worry about their future. I'm afraid to cry for them, because my tears would never stop. I am trying to teach them strength, and to help them find peace.

I have little or no energy to share with my husband, the only Lyme-free member of our family. He and I live on the edge of financial disaster - due to Lyme Disease.

My parents both have Lyme, 2 of my sisters have Lyme; one brother, one sister-in-law and one brother in law also have Lyme. Oh, and 5 nieces & nephews. We have all been diagnosed at different places, in different labs. This is so strange, and so scary, and - oh-so sad.

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

State: Connecticut
County: Fairfield

Name: Alyssa [redacted]

Total cost: >$150,000

Number of family members with LD: 4
immediate, 16 extended

Lost work/school: ongoing!

Number of years sick: 2 1/2

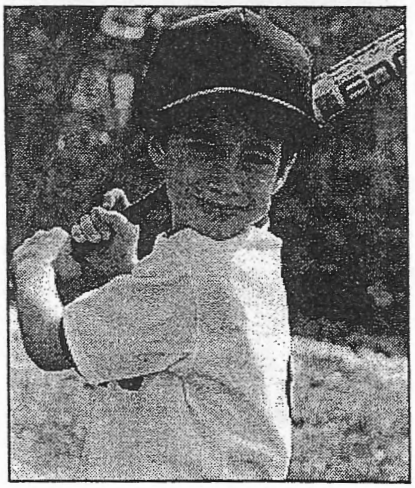
Nearly 11 years old.

Alyssa was bitten by a deer tick in the fall of 1994. She was diagnosed with Lyme Disease in March of 1995, months after she should have been diagnosed and treated. She appeared to respond well to heavy dosco of oral medication, and local pediatricians believed Alyssa to be well, despite frequent colds, flu, & fatigue.

She is currently enmeshed in a serious relapse. Lyme has invaded her entire neurological system. A gifted student at school, she has just been accepted as a Special Education student due to her brain limitations which affect her cognitive abilities. She suffers pain or fatigue, or emotional imtability on a daily basis. As a 1st year middle schooler, she should be giggling, and talking on the phone, and having boundless energy. This is not the case. Alyssa is a very sick child. Just when she should be testing her wings, her wings have been clipped by Lyme Disease.

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

State: Connecticut
County: Fairfield



Name: Paul [redacted] (7 1/2)

Total cost: >$150,000

Number of family members with LD: 4
immediate, 16 extended

Lost work/school: ongoing!

Number of years sick: 3 1/2

Paul contracted Lyme Disease when he was 4½ years old, in 1994. He had excruciating groin pain, leg, ears, and throat pain, skin sensitivity, head-aches, fatigue. After only one month of treatment Paul seemed well.

He sufferred a major relapse the following winter, endured many months of pain and fatigue. Paul seemed to gradually improve again on oral antibiotics. He relapsed again and again, finally being treated with excrutiatingly painful intramuscular injections of antibiotics.

Again, and again Paul seemed to improve. Now he has brain involvement, and is chronically ill. He cannot plan one day to the next when he will feel well. He is a strong fighter, rarely gives in to tears, rarely succombs to self-pity.

Paul experienced hyperbaric oxygen treatment this summer, and was incredibly brave and trusting while holding a heavy mask on his face, lying virtually still for his 1½ hr. long twice per day treatments.

He is loving and friendly, but is sick of being sick.

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

Name: Michael J. [redacted]

State: Maine

County: Piscataquis

Total cost: Undetermined

Number of family members with LD: 1

Lost work/school: Forced to retire early.

Number of years sick: 7

I STARTED HAVING PROBLEMS IN 1992 AFTER A YEARLY VISIT WITH FAMILY IN TOMS ~~RETVER~~ RIVER NEW JERSEY WHERE I LIVED PRIOR TO MOVING HERE. I WAS HAVING ACHES AND PAINS THAT SEEMED TO NOT WANT TO GO AWAY. I WAS GIVE A LYMES TEST AFTER I REQUESTED SERVERAL TIMES. IT WAS DRAWN ON THE 5TH OF THE MONTH AND RETURNED NEGATIVE ON THE EIGHTH OF THE SAME MONTH! I WAS NOW A FEMALE ALSO! I DID NOT FIND THIS OUT UNTIL YEARS LATER WHEN I REQUESTED MY MEDICAL RECORDS.

I CONTINUED TO GET WORST WAS TOLD I HAD RA AND WAS GIVEN MEDICATION THAT DID NOT SEEM TO WORK. AGAIN BACK TO DOCTOR, MORE MEDICATION NO RELIEF! THIS CONTINUED FOR SEVERAL YEARS AND I WAS STILL ASKING FOR A NEW LYMES TITHER. I WAS DENIED BECAUSE THE RA TEST SHOWED POSTIVE. MEANWHILE, MY DIABETES WAS CONSTANTLY HIGH AND I COULD NOT CONTROL IT! I WAS SENT TO A RA DOCTOR IN 1998 WHO SHOT MY KNEES FULL OF CORTISONE, NO RELIEF!

FINALLY WENT TO THE VETERANS ADMINISTRATION WHEN I FOUND OUT I WAS ELIGIBILE FOR MEDICAL HELP AS I WAS 10 AND A HALF YEARS IN THE NAVY.

I FINALLY HAD A LYMES WESTERN BLOCK AND THE DOCTOR LOOKED AT MY WIFE WHO WAS PRESENT AND TOLD HER "THANK YOU FOR BEING SO PERSISTANT" HE THEN LOOKED AT ME AND STATED :"MIKE YOU HAVE LYMES AND YOU HAVE IT BIG TIME!" I STARTED MEDICATION AND WAS REMOVED FROM ALL OTHER MEDICATION. I WILL BE ON THIS MEDICATION FOR AT LEAST A YEAR, BUT, I WILL TELL YOU NOW, MY DIABETESE IS BACK TO NORMAL, I AM STARTING TO SHOW SIGNS OF RECOVERY. MY SHAKING HAS STOPPED MY ANKLE KNOBS HAVE GONE DONE OR DISAPPEARED. I AM ON THE ROAD TO RECOVERY. I WILL NOT BE ONE HUNDRED PER CENT BETTER, BUT I WILL BE 85 TO 90% BETTER.

I RETIRED FROM MY JOB WHICH PAID ME EXCELLENT WAGES BECUASE OF THIS LYMES MY WIFE AND I HAVE BEEN FORCED TO A LESSER INCOME EXSISTANCE.

I WAS REFUSED THE REQUESTED TEST BY 5 DOCTORS WHO NOW ALL SAY THEY DID NOT KNOW.

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

State: New Jersey
County: Gloucester

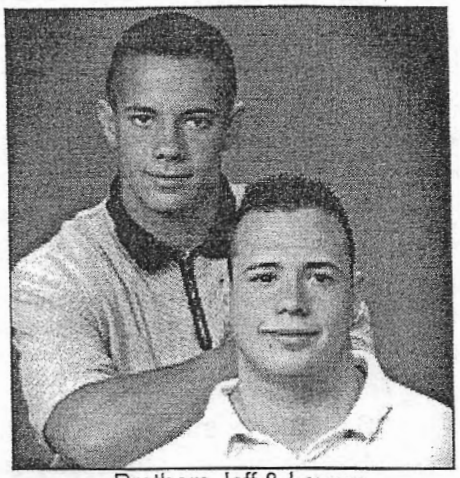
Name: Jeffrey [redacted]

Total cost: $20,000

Number of family members with LD: 2

Lost work/school: 1 month

Number of years sick: 6



Brothers Jeff & Lauren

Six years ago, my ten year old son Jeff was playing baseball on a spring day. Within a week he was bit by 2 ticks. I called our doctor, and was told to wait for a bulls eye to appear at the site of the tick bites. The bulls eye never developed, but something worse did. Within the next 2 months Jeff experienced headaches, fever, fatigue and swollen glands. I asked the doctor if it could be Lyme Disease, and was told "no" due to the lack of a bulls eye. Jeff was diagnosed with mononucleosis.

Meanwhile, Jeff's older brother Lauren injured his knee, requiring surgery. Months later Lauren's was not healing properly. Through blood tests the doctor learned Lauren tested positive for Lyme Disease, and he referred us to an infectious disease specialist. During Lauren's treatment, I told the doctor about Jeff's problems.

Jeff was twelve then. After two years of being diagnosed as having mononucleosis, he was still tired all the time. Jeff continued to suffer from headaches, fever and joint pain. The treatment for mono is bed rest. What twelve year old boy wants to spend the summer in bed, because he is too tired to get up?

Jeff was tested for Lyme Disease and the results showed he tested positive. The new doctor prescribed antibiotics. Neither the doctor nor the medication was covered by our insurance, so we were forced to use credit cards in order to pay for Jeff's treatment. Finally Jeff started to feel better, but Jeff got bit by another tick and had to go back on the medicine.

Through the years, Jeff's illness also caused problems at school. He had been an A-B student, but falling asleep during class didn't go over too well with his teachers. He was accused of staying up too late at night, and even drug use! Meanwhile, he was really in bed at 7:30 PM, just to be able to make it through the next day. And the only drugs he was taking were his prescriptions. Each year, I had to educate new teachers about Jeff's condition. Most didn't know anything about Lyme Disease, so I had to share copies of the literature I've collected. Only then are they convinced my son is not abusing drugs.

Jeff is 16 now. He still plays baseball and he now is on his high school wrestling squad. He's continued suffering from fatigue and knee pain. In the past six months he's been to a surgeon, a rheumtologist and a physical therapist for the pain, but none of them can come up with a reason or solution for his pain.

To be able to do the things he enjoys - Jeff must compensate for his condition. He'll take a nap so he can make it through an evening at the movies with friends. After paying sports, Jeff needs to ice his knees and take an anti-inflammatory. Normal every day activities like getting in and out of cars, or climbing up and down stairs are painful. After six years, Jeff's tired of going to doctors, without getting results, and is now resigned to living with pain, that might never go away.

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

State: California
County: Tuolumne

Name: Cindy [redacted]

Total cost: $8,300

Number of family members with LD: 4

Lost work/school: 1 1/2 yrs of work

Number of years sick: 2

I was an extremely healthy 38 yr. old woman until May 1994. Several months prior to that I was bit by a small red tick in my yard in Sonora, CA. I didn't think of Lyme because like all the other places , 'we didn't have it here'. My illness began with numbness and an array of other sensory disturbances. The numbness spread from my foot to most of my body including my face. Lyme ELISA titers were negative so at this point it was ruled out. I was sent to a neurologist who did an MRI, ANA, and a lumbar puncture. The MRI was abnormal with diffuse periventricular white matter, my ANA was slightly positive for Lupus, and my spinal was positive for oliogoclonal banding and an elevated Igg synthesis rate suggestive of multiple sclerosis. I was again told I did not have Lyme because the spinal tap would have been positive. My health continued to deteriorate. I cried uncontollably for months. It was very hard on my entire family. I became nearly bed ridden with fatigue, it was difficult to walk, and I was unable to work. I began doing extensive research into the field of Lyme disease and learned that all of my symptoms and lab results could be consistent with Neurologic Lyme. My family physician supported me in my belief , dispite the fact that 3 neurologists felt it was probably MS. At this time I was showing reactivity to specific Lyme protein bands.

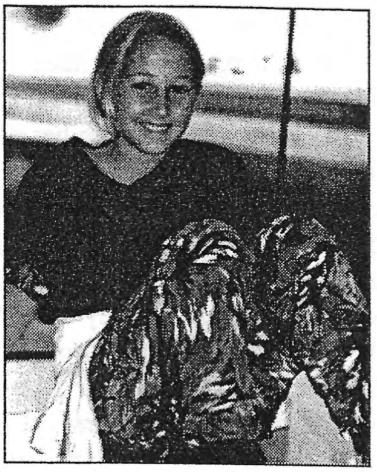
Five months into my illness I was started on IV rocephin at 2 gr. a day. After the initial worsening of symptoms I slowly began to improve. I remained on antibiotics (1st amoxicillin, then Azithromycin) for a total of 2 years and 3 months. Several times when I seemed to be symptom free I stopped the medication but within days my symptoms returned. Therefore I elected to stay on them many months after my symptoms resolved. I was seen by Dr. [redacted] in Dec. of 1996 at UCSF. It was mutually agreed that I would stop the antibiotics to see if there was a reoccurance of symptoms. I have remained symptom free for nearly 2 years now. It was a very devastating and hopeless feeling during my Lyme battle. I not only was fighting the disease but fighting for the doctors to believe that we indeed did have this disease in our county. One good thing did come out of all I had to go through though. If I hadn't studied the disease parameters in detail, I would have never realized that I was not the only family member suffering from Lyme disease.

All three of my children had it. One of my daughters, at that time age 10 had had it for 6 years undiagnosed. We Spent thousands of dollars on specialists, medical tests, and abdominal exploratory surgery on her before she was diagnosed in the summer of 1995 when I insisted she be tested. Her Lyme ELISA was positive at 1.4. The cutoff being 1.0. If more Physicians in this country and in particular this state and county would try to learn more about this disease and how it can manifest itself, they could save countless patients a whole lot of money and needless suffering. Many physicians only seem to see what they already know. It just isn't taken seriously here. I know we are not the only family in this county to have had Lyme Disease, but we are probably the only ones that really looked for it.

Every member in our family presented with a different set of symptoms, therefore how could it all be Lyme?!

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

State: California
County: Tuolumne



Name: Carly J. [redacted]

Total cost: $4,800

Number of family members with LD: 4

Lost work/school: 1 month

Number of years sick: 6 1/2

My daughter's story is a bit unique because the disease did not present itself as a typical Lyme infection. Unfortuately many of them don't and are therefore missed. For nearly two years the only presenting symptom was chronic hoarseness. It began approximately one year following the removal of an embedded nymphal tick from her ear at age four. The bite was sustained in Mono County while camping. She experienced severe episodes of chronic hoarseness followed by complete remissions. The initial attack was preceded by swollen lymph nodes, congestion, and cough. It lasted for many weeks. The episodes did not appear to be seasonal or allergic in nature. They did however progress in frequency, duration , and severity. She would loose her voice completely for weeks on end. The next symptoms to be noted were chest pains, frequently reoccurring swollen lymph nodes, and arthralgias involving her knees and ankles. This slow progression occurred over a three year period. Then in May of 1994 they exacerbated. She experienced severe acute and persistent abdominal pain. After four weeks of a low grade fever, abdominal pain, and nausea, a laparoscopy was done revealing swollen mesenteric lymph nodes surrounded by fluid. A diagnosis of mesenteric adenitis was made. During this illness she also experienced frequent chest pains, hoarseness with mucous, and loss of voice. After this her health continued to worsen. While camping two months later she experienced a severe case of respiratory dyspnea. She began gasping for air and started to panic. It was one thing after another with her health. 'Hot spots' on her arms and legs, malar rashes, acute localized muscle inflammation/severe pain, acute severe muscle cramps, and chronically swollen lymph nodes. Next she was sent to an orthopedist for the chronic knee and ankle pains. There she was diagnosed with Femoral Patella Disfunction syndrome, unknown etiology. By March of 1995 after again returning to her pediatrician for the hoarseness, he referred her to U.C. Davis Med. Clinic to the otolaryngology department. It had now been six years since the hoarseness began. It was there that I insisted on Lyme testing. During her illness I had been doing extensive research into Neurologic Lyme because I was suffering from it and had been for a year. The more I read the more I was convinced Carly also had it. Her ELISA came back positive at 1.4. The cutoff being 1.0. A repeat showed a level of 1.23 at which point the cut off was 1.2. In addition to these two positive ELISAs, a Western blot, both Igg and Igm combined showed positive bands at 41, 53, and 66 kDa.

Unfortunately, I was told that these tests showed she had been exposed in the past but wasn't having an active infection now.
What about the active symptoms?. Just like me I was going to have to fight to get my child's health back. Even her pediatrician told me that the test was probably wrong that we didn't have it in our county. To lift his blinders I sent him a copy of positive tick culturing done six miles from our house by Vector-Borne Disease Depart. of Health Services, Sacramento. Is it my job to educate physicians about a serious disease right here in my back yard? And is it my job to fight for my little girls health when I know what's wrong with her and they don't?
We ended up taking her to Sonoma, 200 miles from our home in Sonora to get her treated by a Dr. that was familiar with Lyme disease in children. She was on a lengthy course of antibiotics for 1 1/2 years. It took 10 weeks after starting the 500mg. Biaxin before we began to notice any improvement. It was a slow process but by the completion of antibiotics, she was symptom free. She has been off them now for 8 months. She is now a happy, healthy, normal and beautiful 13 yr. old.

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

State: California
County: Tuolumne

Name: Chelsea [redacted]

Total cost: $1,365

Number of family members with LD: 4

Lost work/school:

Number of years sick: 9 months

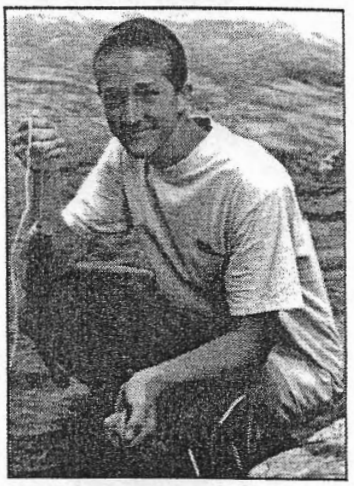
My third and youngest child to contract Lyme disease was my daughter Chelsea. She was 7 years old at the time of the tick bite. It occurred in March of 1996 while we were hiking a couple miles from our home located in Sonora, CA. It was in her posterior neck and wasn't discovered until it was engorged the following day. Her local physician treated her with liquid erythromycin for ten days. On May 26, 1996 she acquired yet another tick bite while visiting at her Grandfather's ranch in Hollister, CA. I sent this tick in for Borrelia burgdorferi culturing but was told it was negative. It had been over 2 1/2 months since the first tick bite and it was at this time that she began experiencing symptoms. They occurred despite the short course of antibiotics she had. She developed chest pains, stomach aches, and felt poorly. Her physician felt she probably had an allergy to milk and had me remove it from her diet and observe her. I did this for several weeks and continued to watch her suffer from the stomach aches and chest pains. She was also beginning to lose her reading and math skills and becoming forgetful. She returned to her doctor in late August and I requested she have an ELISA, and Western blots both IGG and IGM. Her physician knew our family history which included three other members with it. He still felt it was highly unlikely that she had it too. The first tests were performed a little over 5 months after the initial exposure and proved to be equivocal. Her serology was 1.15 and her Western blots both showed suspicious reactivity to 39, 41, and 93 kDa proteins. Her physician elected to wait four to six weeks and then retest her. These second two Western blots both IGG and IGM now met all the criteria required by Centers of Disease Control. She had 2 of the 3 required bands on her IGM and 5 of 10 required on her IGG. There is a small window of opportunity to catch such a striking lab profile as this. Now nearly seven months into the disease she could finally begin treatment. She took a six month course of Biaxin during which time I spent months fighting my insurance for coverage. They said, "Our review of current literature, Rahn et. al.,(**Annal of Internal Medicine 1991:114:472**), and Tierney et. al.: **Current Medical Diagnosis and Treatment 1997** edition, does not support the efficacy of using antibiotics beyond 30 days for the treatment of Lyme disease". In order for them to approve the continuation of antibiotics I had to do extensive research and send them copies of peer-reviewed studies which documented improved outcome with chronic (i.e.>30 days) Biaxin. I did this which I shouldn't have

had to! I knew that it had already been proven, why should I have to show them this proof? It's there responsibility to know the facts, not just pretend to with a lot of *academic logo.*

The outcome of Chelsea's story is a good one, but only because I knew the disease parameters and how they can manifest. I knew from the first presenting symptom of chest pains (70% of children with Lyme disease have chest pains) that she very likely had contracted Lyme disease. But months went by and a lot of expense had to be incurred prior to treating her. She has been off the antibiotics now for 7 months and has remained symptom free.

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

State: California
County: Tuolumne



Name: Colter [redacted]

Total cost: $3,300

Number of family members with LD: 4

Lost work/school:

Number of years sick: 8 months

The third member of our family to contract Lyme Disease was my son Colter. By the time he contracted it I was definitely onto this 'insidious spirochete'. In the middle of April, 1995 at which time Colter was 13 1/2 years old he had high tick exposure at my Dad's ranch in Hollister, CA. One month later he experienced flu-like symptoms which included stomach aches and fever. He was ill for about 1 week then recovered. Eight weeks after the initial tick exposure he passed out while playing his clarinet at band camp. He was a very healthy and physically fit boy who rode his mountain bike extensively so this was very unexpected. He was knocked unconscious and sustained a concussion. He spent the rest of the day in the hospital recovering, having X-rays, cat scans, and lab work. At this point I was highly suspicious that he had contracted Lyme. I expressed my concern to the E.R. doctor who promptly told me that this was not a symptom of Lyme disease. My son was released from the hospital and quickly recovered at home from his head trauma. Unfortunately, this did not turn out to be an isolated incident. Over the remainder of the summer he experienced this 'passing out' feeling a couple more times and by September they became frequent. Sometimes it occurred while playing his clarinet and sometimes while doing nothing. At this point, he was also beginning to experience a sleeping disorder. He would thrash around at night disrupting his bedding, knocking over lamps and rearranging things during the night. I never actually saw any of these episodes but saw the result of them in the morning. I returned to his pediatrician for evaluation. He informed me that my son may be suffering from a neurological disorder. Yes, that's what my concern was... neurological Lyme disease! I requested he have an ELISA, and Western blots, both IGG and IGM. He asked me what a Western blot was for!! Well, not surprisingly his Western blot came back positive with reactivity to 39, 41, and 93 kDa protein bands. He still wasn't convinced. Exposure in an endemic area, symptoms consistent with Lyme disease, two other family members currently under treatment for Lyme disease, and a positive test. What else was there to pursue? I did get him to write me a prescription for antibiotics and told him I would seek further advice from Dr. Katzel, a Lyme specialist in northern California.

Colter's story did have a happy ending. He was treated for three months and has remained symptom free for nearly two years. He has been in a high school Dixieland Band for nearly as long and is a very accomplished musician.

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

State: Michigan
County: Oakland

Name: Susan [redacted]

Total cost: $80,000

Number of family members with LD: 1

Lost work/school: Disabled

Number of years sick: 3

Lyme Disease—A Real Mid-life Crisis

In June, 1994, my life seemed rather uncomplicated, with the exception of the hot flashes and aches and pains that my tennis friends and I discussed . . . my sons had completed college, my full-time adult education position was very fulfilling, and my husband and I were preparing to travel more during our school holidays and enjoy more recreational hobbies.

We often visited Upper Michigan and northern Wisconsin; and on one particular June morning, my husband and I decided a stroll around the parameter of the dense 80 acres my brother and sister-in-law had just purchased was a must. Later that evening, I was puzzled with the "black raised scab" on my leg; I was advised to just scratch it off since it was a harmless wood tick--no need for concern over wood ticks!

Weeks later, Lake Tahoe was another scheduled holiday during the summer of '94. On this trip, not only did I find hiking more strenuous than usual, but playing a social tennis match and staying up after 9 p.m. proved difficult. I looked forward to seeing David Copperfield at Caesar's Palace; this would be special in celebration of my husband's birthday. After we were seated, the noise caused such extreme anxiety and "jitters" that a quick exit was necessary. It took at least twenty minutes for the symptoms to disappear. The abrupt departure from that event was the first of many difficult moments.

The following eight months shifted from a bad dream to a nightmare as the physical symptoms grew. I was first diagnosed with anemia by my gynecologist during an annual check-up; a pain management physician diagnosed fibromyalgia as the headaches and neck pain became more intense. Weight loss along with nausea and chills and fevers were common during this "change process"(eight visits to my general M.D. were made and I questioned him regarding the tick bite and possible Lyme , but was told tests were not necessary since there had been no bull's eye or rash, which were necessary for active Lyme disease—this was all due to menopause.) Other specialists pronounced low thyroid, rosachea, mitral prolapse, gastritis, Raynaud's disease, TMJ, hiatal hernia, and a thyroid disorder. By November the specialist's list was now over ten, each requesting tests and more tests.

Symptoms worsened weekly--mashed-potatoes and yogurt were two tolerable foods, severe migrating headaches would last for days, anxiety and heart palpitations would come and go at the most unexpected moments. I recall mentioning to my doctor that I was experiencing dementia, and his response, "What does a young woman like you know about dementia?" Driving and shopping under fluorescent lights became unbearable, as did working more than four consecutive hours. On one "better day," I asked my husband to play some tennis because this "menopause battle" was not going to win over me; but after five minutes, the fatigue was so severe that I struggled to walk from the court to the car. When friends would visit and I became the least bit excited, I had to leave the room and lie down in a quiet area, since excitement and laughter were no longer tolerable. Would the "old me" ever return? I did not want another doctor to mention the words depression and anxiety and, of course, menopause!

Christmas vacation and rest were helpful; and upon returning to school in January, I made the decision to visit no more doctors—life wasn't the same, but I would accept this and get on! However, a scheduled appointment with an infectious disease physician was still on the docket. Thank God my dear husband convinced me not to cancel!

The infectious disease physician's diagnoses were Lyme disease, parasites, anemia, and clamydia. At last. . .a diagnosis of Lyme disease and a good possibility of full recovery perhaps within thirty days! Needless to say, that short-term disease which I believed would be cured within a month became a long-term illness that changed several plans.

OVER

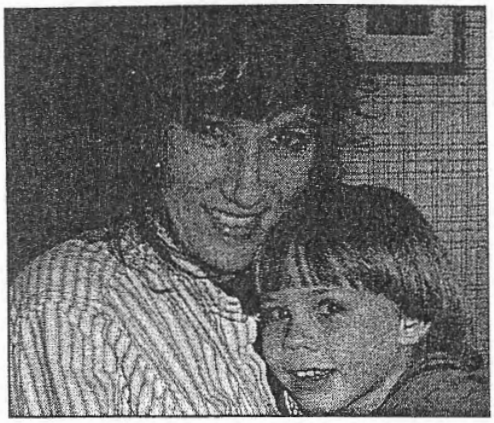
The "mid-life crises" did not end quickly; but knowing there was hope that the "old me" might still be inside my body as I began months of antibiotics, including IV therapy, and suffered as the severe Herxheimer reactions brought painful headaches and joint pains, fevers, heart palpitations, extreme fatigue, facial and teeth pain, and several other frightening new symptoms. I learned that with Lyme disease, patience is essential, along with a positive attitude and an optimistic, caring physician who understands each stage and offers hope and encouragement. Without support and prayer, at times it seemed impossible to continue to fight with so little strength and so many new symptoms bombarding daily. "No pain, no gain" was my hour by hour motto, and the difficult times shrunk from entire days to hours and even minutes on the better days.

It has been three years now and the Lyme journey has not yet ended; but with each new passing day and the added research, along with the support of family and caring Lyme friends (thank God for e-mail and a good support group), and prayer, my improvement continues and I anticipate full recovery or complete remission someday. My goal is to attempt to make this "journey" a bit easier for others who encounter these hardships along the way, and I anticipate the day when once again sports and evening activities will play a more vital role in my life.

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

State: New Jersey
County: Cape May

Name: Edina [redacted]



Total cost: $65,000

Number of family members with LD: 3

Lost work/school: 4 years

Number of years sick: 10

Looking back I realize that I acquired Lyme Disease first in 1989 and was reinfected several times in 1995 & 96. I was tested in 1996 by a clinic on the U.S. Coast Guard base. I explained my numerous symptoms and that I believed I might have Lyme Disease. My Elisa titer was negative and I was eventually passed along to the base psychiatrist where he diagnosed a Major Depression. I tried to explain that I felt my situation was more than psychological but the base was so uninformed I decided to seek a specialist.

By the time I was tested over a 7 month period with PCR's I became so ill I was afraid I was dying. I had dizziness, debilitating headaches, neck pain, confusion, memory loss, low grade & regular fevers. I suffered from nausea, knee

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pain and anxiety. I could not eat and was unable to care for my family nor myself. By 4pm daily I would be trembling, exhausted, feverish, and sick. I weighed around 100 lbs at 5'5". My family all kept asking me why I was so ill but I had no clear answers.

Finally in August '97 I got a Bull's Eye rash on my hip. Eventually I got satellite rashes throughout my entire upper body. In October 1997 I tested positive by PCR and that together with an equivical band 83 Western Blot gave Dr. [redacted] the diagnosis and he began me on IV treatment. I had all together 3 treatments each lasting 2½ months. I tested positive after both my 1st and 2nd treatment by PCR (urine).

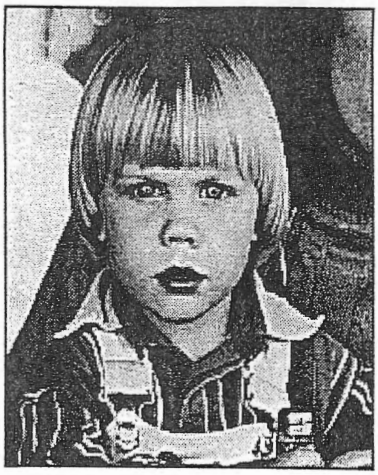
I feel even today I am afflicted with Lyme disease only I have decided to manage it with vitamins, minerals, herbs, rest, and the proper lifestyle. It is a frustrating situation because I have lost so much of myself. I used to be such a strong, healthy, and fit person. I used to run marathons and even an 80 mile race in 1987. I was in the service and got my airborne wings in 1990. By 1997, due to Lyme disease I could not even drive across a minor bridge without having a serious anxiety attack. Equally as upsetting is the loss of mental capacities.

Honestly, at this point I would endure almost any logical treatment if I was assured of a cure.

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

State: New Jersey
County: Cape May

Name: Kelly [redacted]



Total cost: $35,000

Number of family members with LD: 3

Lost work/school: 0

Number of years sick: 4 1/2

Our son Kelly is a beautiful blonde haired, blue eyed 4th year old. We realized at age 2 that he was chronically ill. He had been bitten numerous times by ticks but also could have contracted Lyme Disease from birth as I have had Lyme Disease since 1989. We had beaten a trail to our pediatrician when we decided to go to Children's Hospital Infectious Disease clinic. We saw Dr. [redacted] for a period of several months in which he did many tests eliminating all logical explanations except Lyme Disease. We finally insisted upon testing for Lyme Disease and an Elisa titer was negative. I begged Dr. to investigate further into Lyme Disease but he patted my hand and told me that I was "Lyme historical" and perhaps

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been had residual psychological problems from my own Lyme Disease.

Upon our disgust with this treatment we began testing for Lyme Disease at Dr [redacted] clinic in [redacted]. Further testing proved conclusively that Kelly had Lyme Disease with a positive urine PCR and a significant Lyme band on a Western blot test.

We then sought the care of a pediatrician, Dr. [redacted] in Connecticut and Kelly is under his care to this day. Unfortunately, by the time we found Dr. [redacted] we had a very sick child. He was gaunt with dark circles under his eyes which were often bloodshot and extremely light sensitive. He was often inconsolable with pain, nausea, dizziness, stuttering and stammering, no stamina and bladder trouble. He went days without eating. He was even affected psychologically.

Kelly was on IV medications in combination with orals for 9½ months. Currently he takes oral medication and 14 different vitamin, mineral, and herb supplements. His improvement has been impressive, however, we are uncertain as to how long he will remain okay. Kelly's strong character and will has benefitted him through a traumatic time. We are hopeful for our sons future but realize we will probably always be battling against Lyme Disease.

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

State: Illinois
County: Rock Island

Name: Joan [redacted]

Total cost: $15,000.00?

Number of family members with LD: 2

Lost work/school: ?

Number of years sick: 10+ years

If someone had told me ten years ago that the bite of a tick no bigger than a poppy seed could turn my life upside down, causing such physical and mental anguish, I would never have believed it. Having been in excellent health all my life and not one to complain. I self-doctored recurring rash areas on my upper legs and groin area during the fall and winter of 1986-87. The body aching, stiffness, and general run-down feeling I attributed to growing old -- 51!!

In August 1987 we were in Wisconsin on our 35th annual vacation. Two weeks later, while visiting a daughter in Florida, I noticed a 'peculiar' red-ringed bite on my arm. I told her one of her 'Fla' bugs must have bitten me because it was different than anything I'd had before. However, it didn't itch nor hurt so I did nothing about it. It did, however, stay there through September and reddened if I rubbed it and also another smaller one appeared a short distance away. During September I began experiencing extreme weakness and fatigue, constant sleeping, dizzy spells, low back pain, and a pain in my back after each swallow.

It was early October when my right knee became very and swollen and painful. Two weeks later the left knee was the same and I sought medical help. X-rays and blood work were all negative. The pain grew worse each day, moving to other joints and muscles, moving around my body, pain I found impossible to describe. In December, a second doctor (orthopedic) drained the fluid from my knees and injected steroids (the first of three in the next three months). More tests, all negative.

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By February I was a mess and tried to tell the rheumatologist I had been sent to that it wasn't just m y joints, something terrible was wrong with my whole body. I felt like I was going to die and nobody really cared or seemed to understand, I wanted to die many days, but, I looked okay. There was no physical evidence of anything wrong, no test indicated any problem.

Then, one test done in February was positive. It was a LYme titer! I had never heard the word before. The doctor said it was insignificant couldn't justify treatment. Two weeks later I read an article on Lyme and puzzle pieces seemed to fit together. The 1986 yearly fishing trip to Wisc., a rash, a red-ringed bite following the next year's trip, all of the joint and muscle pains, other symptoms, could it be Lyme? Had I been bitten in Wisc.and possibly again in Florida? I'll never know.

The rheumatologist adamently refused to treat me for Lyme and insisted I had sero-negative rheumatoid arthritis. I went to a large university research hospital in Iowa, and was told, "Yes, I'd been infected with LYme but until I got more symptoms I should be treated for arthritis. ?????

Where to go? Finally, in Oct. I visited another doctor (internist). He diagnosed Lyme, called the CDC and I received the 'standard' two week IV course of Rocephin. Cured? No. Better? A little .

A few months later everything intensified. Over the next year I was given several short courses of oral Doxycline - 200 mg. For a year I kept complaining, there were new symptoms. I was told I was thinking too much about Lyme. When I came in with a hand written list I was sent to a psychologist. Three months later I was told I shouldn't be leading a support group. Three months following that my knees swelled and the pain was back in a big way. I was sent to a Chicago doctor, and after one month of Amoxycillin, one month of Doxycycline, not improving and sed rate rising, I received another two week course of IV Rocephin, this time followed by a short course of 200 Doxycycline, but still not well.

That was 1991. Where am I today? Not real bad, but not good. The list of complaints and tests done would be really long but all tests were negative, except one just recently done, an EEG which showed seizure activity. Other tests include endoscopy, colonoscopy, thyroid, several EKG's, stress tests, thallium stress test, echo cardiogram, sleep lab and a brain MRI. I would have bladder infections monthly - - relating to the monthly cycle of Lyme????? I don't know.

I do know, as does my family, that I'm not the same Mom and Grandma I used to be. There is mo test to determine if the bacteria has all been destroyed, no test to say what is causing all of the lingering and new problems that I have. I pray the future is brighter in recognizing this horrible disease and then treating it in the appropriate manner to end suffering.