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

Name: Charise [redacted]

State: California

County: Orange

Total cost: Undetermined

Number of family members with LD: 1

Lost work/school: not applicable

Number of years sick: 4 years



My experience with Lyme Disease started in October of 1995. I awoke with extreme pain all over my back. I never had any back problems prior to this date. I was a healthy, active, athletic 31 year old with a 6 month old son. I spent 2 years bouncing from doctor to doctor, ranging from orthopedics to rheumatologists. All doctors said yes, I tested positive for Lyme but none would put me on an antibiotic. My back symptoms started to get worse, along with new health problems, such as heart problems that mimic heart attack symptoms, arthritis in both knees, TMJ, & various problems with my central nervous system. Orthopedics wanted to perform a double fusion back surgery I refused. My rheumatologists told me I would need to learn to live with the pain. All the doctors I saw were aware of my positive Lyme tests but assumed me I did not have "active" Lyme Disease.

As my heart problems increased I was referred to a cardiologist and then sent to a cardiosurgeon. The surgeon believed I had heart disease based on my EKG's, stress tests, and echocardiogram. He performed an angiogram and found no clogged arteries. He sent me back to the cardiologists to figure out my problem. In the end, my insurance company spent over $20,000.00.

I began my own research and located a doctor in L.A. who had 10 years of experience with Lyme patients. He had been a Lyme patient himself so he can relate to all aspects of the disease. I began an oral antibiotic treatment plan on June 16, 1998 and will continue treatment up to 2 more years. I am currently 50-60% better and hope for a full recovery.

We have determined that I was bitten by a tick in Sept. of 1994 while vacationing in Maine. I was 8 weeks pregnant and unaware of the bite. I had no problems with my pregnancy. It was easy and wonderful. 3 months later I awoke with my first symptom.

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

State: New York
County: Rockland

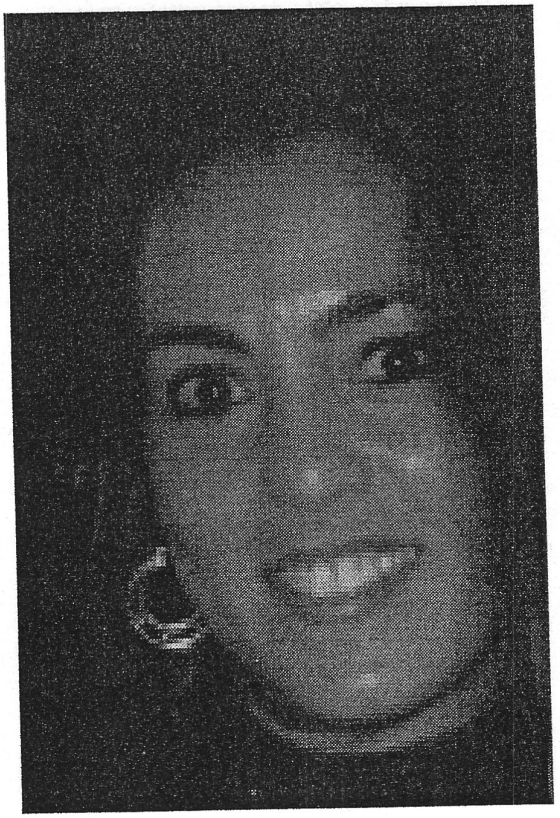
Name: Jean [redacted]

Total cost: $50,000+

Number of family members with LD: 1

Lost work/school:

Number of years sick: 8



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

State: California
County: Van Nuys



Name: Margaret [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 8

I was diagnosed with MS in August 1986, based primarily on lesions seen in an MRI. The usual blood tests were done, but no Lyme test. In fact, Lyme disease was never discussed, even though it was rampant on the East Coast (where I'd spent a lot of time) and parts of the Midwest (where I'd lived until recently) and I hiked frequently in the mountains surrounding LA.

Over the next 3 years, I tried various alternative therapies, the most beneficial being acupuncture. In 1989, I began to feel weaker and decided to give Western medicine another try. I found a neurologist through the Southern California chapter of the MS Society. In November my entire right side weakened considerably, and I underwent a five day IV Solumedrol treatment. Within the first few days my walking improved considerably, but the results did not last, and my walking and right-side strength quickly worsened.

The following summer I began to experience nightly leg cramps. Since the "kicking" seemed to stem from my knees and ankles, both right and left, this did not make MS sense to the neurologist. But the pain and spasticity had gotten so bad that I had another IV corticosteroid treatment; the spasticity became worse.

In the Spring of '95, while cruising around America On Line, I happened along a topic in the National MS Society folder "Any Good MS Docs Out There?" People from all over the country had written short notes about their neurologists, so I posted one about mine, stating that I had experienced more improvement from acupuncture and other alternate therapies, but he was personable and knowledgeable regarding MS.

A few days later I got an e-mail that began, "Don't give up hope. You may not have MS." I was 100% skeptical. In 9-1/2 years I thought I'd heard every cure in the book. But this e-mail was intelligent and articulate, even using words like "etiology," that I'd never heard before. Besides the author's name was Vincent Marshall, DVM. As a dog mom, I was intrigued. I replied with my real name and address, and a week or so later, received a thick envelope in the mail filled with Lyme information and testimonials. I read that "MS lesions" seen in an MRI are identical to those seen from Lyme disease, as well as neurosyphilus. I read about symptoms like hair loss, confusion and arthritic stiffness and pain that I had dealt for years, although whenever I'd brought them up to the neurologist, he'd said that those symptoms weren't MS related.

I made an appointment with an infectious diseases doc. He admitted that Lyme was not a familiar disease to him, because there was no Lyme disease in California. I asked him to please be open minded, and asked him to test my blood. The results were positive. He then called my neurologist to schedule a lumbar puncture. The day I had my spinal fluid drawn, the neurologist was flipping through my chart when he came upon the results of a Lyme test he'd given me six years before. The results had been borderline. My spinal fluid, too, came back positive.

I had a 28-day IV Rocephin treatment; four days after the end of the treatment, I was feeling pretty lousy and both the neurologist and ID docs phoned to tell me that although the Lyme diagnosis was clearly positive, the results of the blood and spinal fluid tests make it look like my main symptoms are not stemming from Lyme Disease but are probably still caused by MS.

I argued that even the latest research admits that it isn't what the numbers say that counts; it's the clinical findings. And clinically speaking, things started to turn around dramatically the next morning. The fatigue disappeared, my iliopsoasis muscle made a miraculous recovery–not quite effortless lifting my right leg from a standing or sitting position, but infinitely better than the last several years. My right leg wasn't nearly as heavy, so the drag was better, walking was easier and climbing stairs was no longer damn near impossible. The spasticity–the symptom I have long considered to be my worst and most painful–seemed to lessen nightly.

However, little by little, month after month, I again got weaker. I began using a cane or a walker to get around and the fatigue was again horrific. The doctors insisted that I shouldn't be too hopeful; I probably still have MS and besides the Lyme had gone untreated for so long now, I probably won't, or can't get much better anyway.

Then I heard about a doctor who honestly knows Lyme, it's symptomology and its treatment. I called one of his patients and got a referral. For the past year and a half, I've been treated by a true healer, who investigates the clinical facts, and has the courage to prescribe the most current, effective protocols. After 17 months of aggressive antibiotic therapy, many of the symptoms that have plagued me for the past 11 1/2 years are either gone or greatly reduced. To walk, I still use a cane, a wall or a friend's arm, but I am literally stronger every day. I am still experiencing problems with weakness on my right side, and nightly spasticity. Interesting that these are the two symptoms for which I was given Solumedrol, a corticosteroid.

I pray that the National Multiple Sclerosis Society will run a front page article in their newsletter encouraging all MSers to get tested for Lyme, especially newly diagnosed patients. Physicians must be taught the symptoms of Lyme; they must acknowledge Lyme's existence, learn to accurately test for it, learn to prescribe the antibiotics that work, and prescribe them for long enough to have a positive effect on chronic Lyme. Because I am living proof that aggressive, long-term abx work.

The cure for Lyme is no cake walk and I still have a long way to go. Granted, I don't know how much of the Lyme damage is permanent, but the way I look at it, nothing's permanent until I'm dead.

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

State Michigan
County St. Clair
Name Laura [redacted]
# of family members with LD 2 immediate, 1 extended
Total cost $ thousands Lost work/school Many Hours
years sick 10-12
Address [redacted]
City Port Huron
State Michigan Zip 48060
Daytime phone [redacted]



Ta ease
or ble.
W But,
we de a
se and
yo
Co nily
me
Se

ign
One Financial Plaza, Hartford, CT 06103
860-525-2000

(Me with my niece Lily

Your story here. Instructions and explanation follows.

I have chronic lyme disease and have suffered with it for over ten years. I am only 24 yrs. old and my life has had to be put on hold for lyme. I have bee to see so many doctors who didn't know what was wrong or misdiagnosed me and never tested for lyme. I went so long untreated that I suffer neurological problems, arthritis, constant pain and exhaustion. I have also had to deal with depression and anxiety for most of that time. I had to stop going to college and can only work part-time, because of this I have no insurance and have to live with my parents because I can only afford my medical bills and prescriptions. I am so afraid for my future and I hate to think that I'm a burden on my mom & dad. I also have a sister who suffers daily from lyme and she has a 10 month old baby girl who is the light of all our lives. My sister didn't know she had lyme when she got pregnant and now we don't know if Lily has lyme or not. Every night when I shed some tears while saying my prayers I pray that Lily will never know the devastation of lyme the way her mom and I have.

I give permission for the LDF to use this form in any way they deem useful
Sign Laura [redacted] Date 4/28/05

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

State: Michigan
County: Saginaw

Name: Shelly [redacted]



Total cost: Thousands

Number of family members with LD: 1

Lost work/school: 1 1/2 years

Number of years sick: 1 1/2

Let me begin by saying that my Lyme experience has ended with a healthy body. It began in September 1990 (soon after graduating college) with a tingling in my hand, that within two weeks had spread down my right side, then from my left foot up my left side. During that two-week period, I experienced spasms in my hand, arthritic symptoms and pain. Soon everything below my neck was numb and eventually grew weak and uncontrollable. For three months I could not dial the phone, button my clothes, or write my own name. Getting in and out of the bathtub was even difficult. My legs felt as if I was walking in a pool of finger jello all the time. At one point I also had bladder problems.

After I had seen a chiropractor, two medical doctors and an osteopath, I made an appointment with a neurologist. He ran several tests including a Lyme test (which was negative) and, of course, an MRI. My MRI showed abnormalities inside my spinal cord. The interpretation of the results were either a tumor or Multiple Sclerosis. He told me to come back in three months and he would do another MRI—if the lesions grew, it was a tumor; if not, it was MS. I asked about Lyme and he laughed at me.

I then saw another neurologist who did a spinal tap and concluded that my symptoms were the forerunner of MS. I also asked him about Lyme, and he said that Lyme did not affect people in that way. He recommended psychiatric counseling. He didn't feel I had a good attitude toward MS.

Shortly after the second diagnosis, I had heard of several people in my area with Lyme and started attending support group meetings. I made an appointment with Dr. Natole, and he determined that I had Lyme. At this time most of the numbness had disappeared. All that remained was the numbness in my hands. I was put on Suprax for 6 weeks and spent a month in bed. I was sleeping 18-20 hours a day, extreme nausea, disorientation, and loss of appetite. I was then put on Minocin for 2 months and felt much better.

Then IV Rochephrin followed for 9 weeks and I felt the best I ever had. I still suffered from memory loss and had an occasional herxheimer consisting of severe chest pains, blurred vision, difficulty breathing and cold sweats.

Following the Rochephrin was oral Minocin and Amoxicillan. During the end of 1991, I had another MRI done and the lesions had completely disappeared. In August 1992, I was taken off all medication and had no recurring symptoms. I have moved out of the Saginaw area to Rochester and work full time (plus) as an accountant. It appears the Lyme nightmare was left behind. I am once again normal (whatever that means) and live like everyone else. Fortunately for me (and the rest of us), Dr. Natole possessed the courage to take a stand against this unacknowledged disease and for that I say

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

State: Minnesota
County: St. Louis

Name: Deborah A. [redacted]

Total cost: Welfare

Number of family members with LD: 1

Lost work/school: 8 years

Number of years sick: 9 years



This is what I Looked like the Past 5 years !!!

I was bit on April 27 - 1989 while I was working for the city of Duluth as a gardener Tec. I was working up at Enger Tower removing the leaves off of the flower beds. That night I found a tick embeded above my Right elbow. I had St. Lukes Hospital remove the tick and verified it as a deer tick. 3 times the tick was squeezed trying to remove it. The 4th time they pulled it off. They put me on tetracyclin 500 mg 3 times a day for 10 days - about 3 weeks later I had a raise bump that was clear in the center and a Red ring around it. (Bullseye Rash) From that day on I got bit it has been a night mare!!!! I have gone thru the most night mare Pain and systoms from this dam disease !!! my tests are negative. I have headaces, muscle pain, spasims, Pain moving from joint to joint, night sweats, shooting pain, numbness, Swollen hands, face, left leg, swollen lymp node, fatigi, eye pain, diarra, low grade temp 95.3 that bounces up and down, memory problems, Bladde Problems, having trouble walk, going up and down stairs, my life is down the tuber and I am angry!! I am angry on how the system is treating people with Lyme Disease!!! what happen to the oath the doctors have taken to help People ???

OVER

I am sick of being called a liar!!! from people that have chossen to become a Dr. To help peple with illnesses. It makes me sick to know that people turn more to the money than to help people that are sick!!! I have lost all respect!!! for them!!

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

State: New Jersey
County: Morris

Name: Nancy [redacted]



Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 1 1/2

I'm a 57 year old divorced mother of 5 children and grandmother of 9. I live with my parents ages 81 & 83. I do house cleaning 5 days a week and feed-walk & house sit animals on the side.

In early 1996 I was waking up tired - I said my age & work too much. Then my knuckles were all hurting so much - I said arthritus - runs in family. My knees were now hurting - my work. I was having slurred speech and blurred vision - very forgetful - couldn't figure that out. My bones in arms were hurting, neck was very sore. Terrible headache for 6 wks. I was getting very weepy and could just fall asleep so easy in the afternoon. Finally in Aug '96 I couldn't take it any more and really thought I had Lyme I called my PCP for a Dr. I almost crawled

OVER

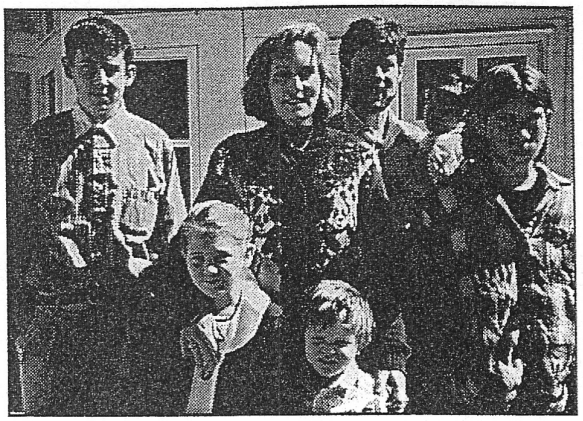
into his office. I read Lyme symtoms + decided I had Lyme - I had almost all of them. He took blood + sent me home (Fri at 5pm) on mon. I was told 2/3 the test came back I had Lyme - the rest of test came back then I had it before or a long time - I had it a long time. I was on antibiotic (Doxycycline) til Dec - get better then down hill back + forth. I got a new Dr. in Jan. and put on new antibiotic (Biaxin), acidophilis, CoQ10, high potency vitamin + Vitamin C. He didn't tell me don't take the first 2 together! Health food store told me you don't take them together. Also, the store told me I needed the acidophilis from ref., ~~high~~ also the CoQ10 50mg or higher. Dr didn't know either one came in different strengths! I hurt so much + was so tired - but I had to work to pay for my Dr visits and medications. As of July 97 I'm feeling good; But, I've never fully recovered - come 4 pm I'm tired - don't want to do anything else - I was always a work a holic - early up to work + work late every day! I was bitten by a tick in 95 but no rash. I feel like that's where my problem started. I don't wish this on anyone!! my father had a cousin from Shelter Island die from this - went in a coma etc.

I feel the Drs should go to the 10/27/97 "support meetings" to learn + Read the Lyme books.

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

State: Massachusetts
County: Barnstable

Name: Maureen [redacted]



Total cost: $200

Number of family members with LD: 1

Lost work/school:

Number of years sick: 2

In May of 1994, my family and I moved into our beautiful newly built house on a dirt road surrounded by wooded conservation area. We already had a pony and a barn cat and soon acquired two dogs. I often went for long walks with my children and the dogs in the woods.

In June of 1995 I noticed that my knees were very sore, mostly in the morning, to the point that I had difficulty walking down the stairs. I didn't pay too much attention to the pain because it would come and go and seemed to lessen in intensity as the summer wore on.

By the fall I was experiencing periods of extreme fatigue. I my youngest son who was then about 11/2 fell asleep in the car on the way into town to do errands. I would park the car and curl up on the seat to nap in the parking lot. I was usually up by 7 am and by 10 am felt like it should be 10 pm. because of how tired I felt. I evolved from an occasional coffee drinker to a coffee addict in an effort to get through the day.

OVER

My personality also began to change. Always somewhat "easy going" before, I gradually became very irritable & withdrawn. My husband still refers to that time as "the dark ages."

During this time I also had many other strange and varied symptoms that would come and go. My left hand and arm felt weak and would sometimes shake. One leg had loss of sensation. I had frequent heart palpitations which may have been from all the caffeine I was drinking. I had the sudden onset of a severe stiff neck that lingered for weeks then recurred on the other side. One of my more severe symptoms was blinding headaches that I woke up with. They incapacitated me for hours and usually resulted in vomiting. Dizziness and visual disturbances also began to plague me. The visual problems became one of the other most troubling symptoms I had. They usually only one eye was affected. I had a feeling of pressure in the eye and the sensation that I was seeing under water. Different kinds of light bothered me and I had trouble seeing digital numbers or flashing lights. This was a problem since I work as a maternity nurse with equipment that had displays and readouts that I sometimes couldn't see well.

To complicate matters we were in the process of adopting a special needs child from Korea. Physicals were required as part of the adoption requirements. During my physical I mentioned my troubling symptoms to my physician who then referred me to a neurologist. who could find nothing wrong. As my symptoms worsened I went to an opthalmologist and an allergist looking for answers. In the back of my mind was the thought that I could have lyme disease but I had never had the tell tale rash or flu-like symptoms that I could recall. In July of 1996 I asked my doctor for a lyme disease titer after attending a lecture on lyme disease I had heard about on the radio. Shortly after that I was diagnosed with lyme disease and began my many months of treatment. I am now hopefully recovered but fear for my family and others contracting this insidious disease.

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

State: Connecticut
County: Litchfield

Name: Linda [redacted]

Total cost: $250,000

Number of family members with LD: 1

Lost work/school: 2 yrs.

Number of years sick: 7



After going from doctor to doctor for many months, enduring many tests and receiving many different opinions, I finally had a positive Lyme test and found a physician who was willing to treat me, which isn't any easy task.

Until the time I started treatment and for several years after, I suffered with typical Lyme symptoms like fatigue & muscle aches, but my whole life was devistated by the neurologic and neuropsychiatric manifestations of having a severe brain infection. These included light-headedness, disorientation, constant headpressure, visual, auditory & spacial disturbances, such as the feeling that floors & walls are tipped, just to name a few.

Always thinking of myself as a very mentally stable and happy individual, it is very difficult to describe the severe psychiatric symptoms I experienced at this time. I felt as though I was going crazy. The anxiety and depression were

unlike anything I had ever experienced before. It felt as though someone or something had stepped into my body and taken control of my mind and body. Needless to say, it was a living hell. At one point, I even half-heartedly tried to commit suicide.

Thanks to the diligence and support of my doctor, I have a wonderful, very full and rewarding life now. After years of very aggressive antibiotic therapy, I have gotten back my life and sanity. The personal growth I have gained from this experience is immeasurable.

I am still on antibiotic therapy just to remain a functional person, but I am looking forward to the day when I can be totally healthy and antibiotic-free.

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

State: Texas
County: Travis



Name: Kay [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 23

In the summer of 1974 I was bitten repeatedly by deer ticks in Cedar Creek, Texas (Travis County). After a short period I experienced excruciating urethra spasms and a syphilitic looking rash. The next year, I spent many a day in the Otolaryngologist's office for infected tonsils that failed to respond to repeated prescriptions of penicillin. Finally, shots of gammaglobulin and penicillin seemed to clear it for a time.

I had a baby in 1977 that was born premature and jaundiced and we were both treated with IV antibiotics. My daughter received 2 liters of blood as well.

The years to follow were full of repeat illnesses and a host of diagnoses, including Spastic Colon, Pancreatitis, Irritable Bowel Syndrome, Spastic Urethra, Chronic Fatigue Syndrome, Arthritis, Tonsillitis, and multiple ovarian cysts, for which I had a Complete Hysterectomy in 1985. Compounding all this were severe, ongoing cognitive problems. I was told often that it was all in my head and I needed to consult a psychiatrist, which I did for 2 years.

At last, in 1994 I tested positive for Borellia Burgdoferi on the Elisa, Western Blot and Gundersen tests. Elevated spinal fluid values further confirmed the diagnosis.

I have been on antibiotics for years now and am currently taking Flagyl as well. My symptoms have improved greatly from the treatment, only to flare again when I try to stop.

I also tested positive for Babesiosis this year, one of the many co-infections which are now being tested for.

If not for the help I have received by way of support and education from people all over the country, I don't really care to think what might have happened. I feel I owe my life to these people and a few brave doctors who have gone out of their way to attempt to understand this multisystem disease. I deeply love the family members and friends who have had the compassion and wherewithal to stick by me and help me as well.

Of course the most important person of all is my dear husband. He has put in countless hours at the local hospital libraries here in Houston and has never failed me when I needed help the most.

OVER

This letter barely touches what my life has been like and I haven't cared to discuss the dozens of doctors that missed the diagnosis completely and treated me without a shred of compassion. To think this disease is over-diagnosed in Texas is ludicrous at best. I had to leave Houston, and even Texas, to get diagnosed.

We all have issues of treatment, employability, ethics and legalities which are far from being resolved. To all my friends on Compuserve, Prodigy and the Internet; I pray you never give up the struggle for legitimacy, treatment and recognition of the seriousness of this disease.

Much love to you all,
Kay [redacted]

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

State: Rhode Island
County: Newport

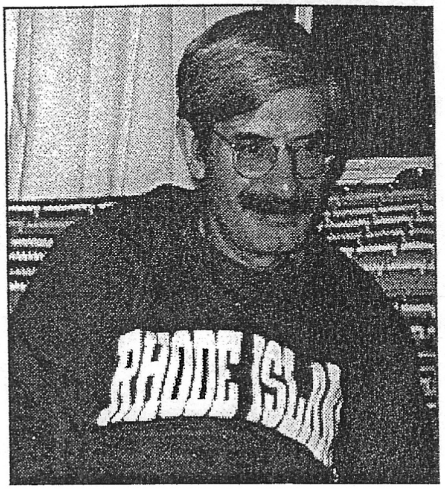
Name: Frank F. [redacted]

Total cost: Significant

Number of family members with LD: 2

Lost work/school: see below

Number of years sick: 10



I developed neurological signs and symptoms (s/s) and was seen by a prominent neurologist at Brigham & Women's Hospital in Boston, Mass. (Before the onset of my s/s I ran three miles a day, but after, I could not walk without extreme difficulty one hundred feet to the mail box.) I was diagnosed with Atypical MS based on my s/s and test results even though there was no demyelinating disease noted with the MRI. I was told to return in six months to see if there was any progression of s/s. My wife, who is a nurse, read an article concerning Lyme Disease in Outdoor Life Magazine and we decided to investigate further. I first saw a physician at Yale in the Lyme Disease Clinic of the Rheumatology Department. I was told I could not possibly have Lyme Disease as none of my joints were edematous and my "ELISA" was negative. (This test had been done by my primary physician at my insistence). No further tests were ordered and I was advised to see a neurologist again. I then saw another internist who suspected Lyme Disease. He ordered the appropriate Lab tests and the diagnosis of Lyme Disease was confirmed. This whole process took two and half (2½) years and I was seen by four doctors during this time frame before the correct diagnosis was made.

I was initially treated with IV antibiotics for six months followed by nine months of oral antibiotics. I have had two exacerbations since being initially treated and was on oral antibiotics for about a year with each exacerbation. I have not experienced an exacerbation for about two years.

I still have neurological deficits which include difficulty with walking, short term memory loss, fatigue both with and without exertion, tingling and numbness in [redacted] extremities, and periods of "just not feeling well."

I have chronic neurological Lyme Disease for which there is no cure at this time. If my disease had been diagnosed in the acute stage two weeks of oral antibiotics would have cured this disease. If Lyme had been [redacted] diagnosed earlier I am confident my s/s would not have been as severe and I may not have been left with persistent neurological deficit.

My life has changed significantly since now I must plan my day and pace my activities. I retired from my job at the earliest time possible. I was fortunate to be in a profession (ie. electronics engineering) where ~~my~~ physical labour was not required. Flexible work hours allowed me to work the hours in the day where I was most productive resulting in me being able to maintain my employment.

I continue to hear of incidences of delays in diagnosis and/or mis-diagnosis of Lyme Disease and the resulting consequences. I am amazed and concerned over the ignorance which still persists in the medical community about Lyme Disease. It is also of a grave concern to me that those treating Lyme Disease can not agree on diagnosis and treatment and instead of acting collaboratively are at odds causing further confusion within the medical community. This spills over into the insurance companies being [redacted] allowed to dictate treatment which does result in Lyme Disease patients not being treated appropriately.

I question what would have happened to me if my wife had not been persistent about investigating Lyme Disease and been satisfied with the diagnosis of Atypical MS. Would I be confined to a wheel chair, bed ridden or deceased? (Please think about this -- a thought which I continue to experience -- what if?)

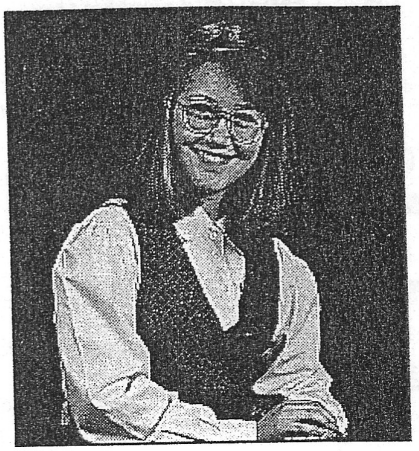
Sincerely,

[redacted]

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

State: Illinois
County: Lake

Name: Kerry [redacted]



Total cost: $100,000

Number of family members with LD: 1

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

Number of years sick: 2 1/2

A Fairy Story -- The Sandford family went on a camping trip into an area known as having deer ticks, but they went prepared with insect repellant, and they walked only on the paths, and they checked each night on their necks and legs for ticks. So when Kerry, 13 years old, discovered a bull's-eye rash on her buttock about 10 days after the camping trip, we went immediately to the doctor, who, of course, was very knowledgeable about Lyme Disease, and listened to the mother's request for testing and/or antibiotic therapy. He never would have said, off the cuff, that it was a spider bite, not to worry. So everything ended happily ever after.

Don't we wish ....

Then my 15 year old daughter Kerry's life would be so very much different, hopefully so very much kinder.

The experience has been an almost continuous chain of ignorance. Kerry's story is similar to many other people with Lyme. We have seen doctors in 8 states, driven thousands of miles (and flown quite a bit, too), spent thousands of dollars, and have prayed that our insurance company will continue to support Kerry's treatment.

For 18 months straight, Kerry had a very severe headache, day and night, which could not be alleviated by any medications. Her idea of relief now is when the headache isn't overwhelming everything else. She was hospitalized twice for 5 days, just to try and break the headache (it didn't work).

Kerry has a rare side effect - hyperacusis, or noise sensitivity. For weeks at a time, Kerry was unable to brush her hair or teeth, leave her room (much less the house), or even sleep on her mattress because of the pain any noise caused. The degree of her hyperacusis was frightening. She couldn't ride in a car, go in the kitchen, flush a toilet. Sounds that we find comforting and uplifting - breezes in the trees, birds singing - would start her shaking. Although it isn't as severe now as it was, she is still unable to go to movies or malls or school. We have just purchased earplugs, state of the art, costing $2,200, to help normalize her life a bit.

OVER

Four newspapers wrote stories about Kerry's hunger for reading during a library contest. The library asked people to read 100 books in a year - Kerry read more 1,100 books, including Plato, Dickens, Austen, and volumes of science fiction and fantasy. Now she is having difficulty with reading.

But this very intelligent girl, who should be enjoying her sophomore year in high school, hasn't been in school since the beginning of 8th grade. She was to be first chair in flute in the 8th grade band - playing the flute hurts her now. She took Irish step-dancing lessons for 7 years, was ready to move from the novice level to Open, a big achievement, but she can't tolerate the music or the pounding of the hard shoes anymore. Kerry was so excited about getting a driver's license, but reality is hitting that she won't be able to yet. As a gifted student, Kerry was looking forward to high school classes, to participating on the debate team - to dances and basketball games.

Now, a good day is when she'll go to the library for an hour or two by herself.

This disease has impacted her family life (the toll on us has been enormous), our finances, her education, her social life ("WHAT social life?" she asks), and ever so much more. Our dreams for our bright, cheerful, sociable daughter have changed drastically. We are unable to envision a future for her at this time - we have no idea as to whether she will ever get much better than she is now. Kerry wants to be like the other kids - to get up in the morning to grouse about going to school and taking tests, to dress for dates, to take her first solo car drive, to join a giggling group of friends to inspect the earrings at Claire's Boutique at the Mall.

Instead she lives a lonely life filled with pain and noises. And it's devastating to think that she may never get better, may never be able to live a normal life, may never be without pain. All from an insect no bigger than the period at the end of this sentence.

Much remains to be learned about this terrible illness - its cause, its cure, the impact it has on the victims and the families of the victims.

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

State: California
County: Calaueras

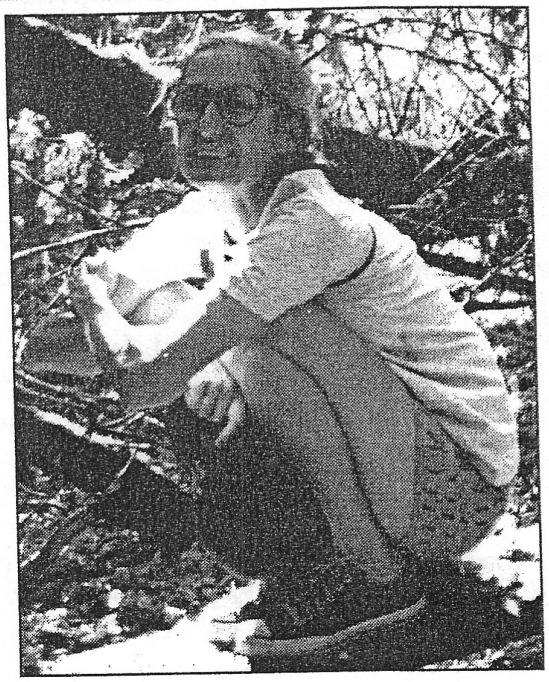
Name: Mary [redacted]

Total cost: $10,000

Number of family members with LD: 1

Lost work/school: 6 months on disability

Number of years sick: 2



My name is Mary Schnauffer. Pictured here - in shorts in the woods - happy always out doors - hiking, backpacking, camping, swimming in rivers and lakes, gardening, wildcraft-ing herbs. In the picture still able to squat - actually had a very good yoga practice. Also, I'm a R.N. practicing as a post anesthesia critical care nurse. I've been on disability since June of this year - and will likely be off many more months. Spent several months on crutches this summer due to swelling in one knee. I was just diagnosed - Shropostive - in June - but have had joint problems for 2 years - I'm the only family member with Lyme - Thankfully.

the cost is ongoing. I have work health insurance. Probably medical expenses close to $10,000. I live in rural Calaveras County, California.

I give permission for the LDF to use this information [redacted] 10-24-14

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

State: Maryland
County: Montgomery

Name: Patricia [redacted]

Total cost: $34,000

Number of family members with LD:

Lost work/school: 8 months

Number of years sick: 3+



I became very ill with terrible headaches and stiff neck. I never saw a tick or a bull ring (rash). I was in and out of the hospital twice and after seeing several neurologists, one finally tested me for Lyme disease because he saw a droopy eye lid. I tested positive and having headaches without a break for almost six weeks I had 2 MRI's and surgery on brain tissue which showed nothing.

I immediately went on IV antibiotics with a stint in my arm and home care for 21 days. I felt a little better, but not too much. I then went on oral antibiotics for 3 months and slowly recovered.

I have permanent problems. I now hear my heart beating constantly because the artery in my neck expanded and is pushing against my ear-drum. I have chronic fatigue which renders my activities every day. I must rest every day for at least an hour.

The whole sickness was a total nightmare and the pain so bad, sometimes unbearable. I had little sleep, anxiety attacks, lost 12 pounds in the first three weeks. My dog also got the disease at the same time even though he had gotten shots for it. I feel very lucky that I have not had a recurrance but I found a doctor who was willing to treat me.

Please find a cure. Please spend money for research. Please control the deer and mice population to stop the spread of Lyme disease. My life will never be the same and I always fear I will get infected again. People need IV and antibiotics if disease has spread to the brain tissue as mine did. People need long term treatment in many cases. I have talked to many long suffering people. Please give money to find a cure.

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

State: Oregon
County: Washington

Name: Konnie [redacted]



Total cost: $24,000

Number of family members with LD: 1

Lost work/school: 9-18 months of school

Number of years sick: 5

This story is told by Linda about her daughter Konnie's illness with Lyme disease.

In May of 1991, Konnie, who was 6 years old, was bit by a tick in Northern California. She presented with a bull's eye rash, and we had to go through 3 doctors in Washington state before she could receive any antibiotic treatment. The amount of antibiotic presecribed was only for 2 weeks.

In early 1992, Konnie began experiencing an increasing number of odd symptomns such as headaches, muscle and joint pains, rashes, sore throats, stomach pains and increasing fatigue. Remembering the encounter with the tick less than a year ago, I felt this could very well be a recurrence of Lyme. After going to various specialists in my HMO, Konnie finally was given a Lyme test. It came back positive; however, my child was denied treatment because of the belief that she had received "enough" antibiotic in 1991 to cure Lyme disease.

Konnie kept getting worse, and struggled valiantly in school despite being told there really wasn't anything wrong with her; I was told to see a psychiatrist; that I was crazy and somehow was responsible for Konnie's symptoms. Relatives and teachers were far from supportive. I could not believe that I had to fight for medical help for my daughter, and be treated like I was doing the wrong thing! I never received any help from the HMO.

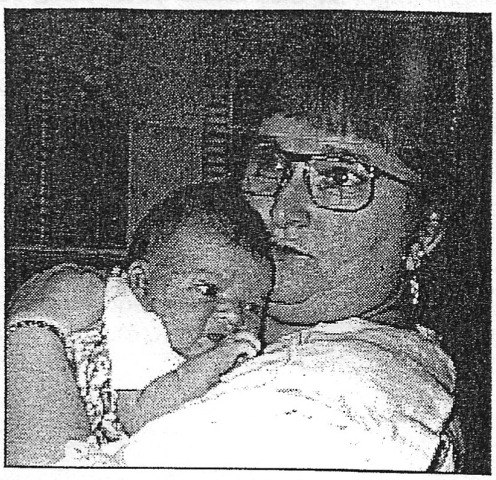
Finally in mid-1993, a friend read about a Lyme support group in the newspaper (it had just gotten started). After talking to the people there, we found a doctor who would treat Konnie immediately but he was in California. He did not understand how the existence of Lyme was denied and improperly treated in Oregon. I later found out that the CDC recognized Oregon as a Lyme endemic state; although it was the very last state to require mandatory testing (Dec. 1994).

Konnie has also gone to NJ to see a Lyme specialist, and a local doctor finally was willing to work with us. After 1.5 years of anitbiotic treatment, Konnie showed steady improvement and is almost symptom-free. She is acting like the normal little girl she always has been, only the disease took this from her. Just seeing her play like the other girls is precious to me. She will continue receiving antibiotics until she has no more problems. I have paid for all medical expenses for Lyme disease out of my own pocket.

I recently participated in protesting Dr. Allen Steere coming to teach doctors in Seattle how to treat Lyme. He believes that 4 - 6 weeks of antibiotics cures this disease or you probably didn't have it in the first place. He is wrong, and my little girl's experience prove it. I want to tell my story because I do not want any more people to have to go through what I have.

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

State: Michigan
County: Wayne



Name: Connie [redacted]

Total cost: $25,000

Number of family members with LD: 1

Lost work/school: 52 days

Number of years sick: 4

I was bitten 9-15-93 in my classroom, that had been mice infested for years. Four days later I ended up in ER. That was the first time I had ever heard the word Lyme. The ER physician told me I couldn't possibly have Lyme, because there aren't any deer in Wayne County. He drew blood because of my insistance and sent me on my way. My many symptons were definately early Lyme symptoms, including the bite on my face and an excruciating meningitis type headache. I was led to believe the antibiotics I was on for a sinus infection were the #1 cure and I would be "cured" in one month,...if indeed I had Lyme at all.

This was the beginning of a long hard road, that so far has lasted 4 years. My family physician was very willing to learn, but finding information was not easy. He along with thousands of other physicians in Michigan are very poorly informed about Lyme. He and I struggled along together with what information we could find. Meanwhile, I got progressively worse, the symptoms were so varied it was hard to keep track of the many things happening. While waiting for an appointment opening for a doctor 2 hours away. I saw an infectious disease specialist. Who left the room to look up the disease. She didn't believe in Urine Antigen testings and informed me that I had a thyroid condition. I had given her all my blood results and my thyroid was fine.

Phone calls to the Michigan Department of Public Health were absolutely useless. I was told ticks only bite in June, July and August, and since I had gotten bitten in September, there was no way I could possibly have been bitten by a "Lyme" tick. Every call for information was worse than the first. I was told there were ticks on Menominee county way up north, but when the animals cross county and state lines, the ticks get off !!!

It was almost impossible to work. I couldn't believe anyone could have that many symptoms at one time. I could not believe I was so ill and felt so terrible. My family doctor continued to help me as we both searched for information on Lyme. The doctor two hours away, and more Lyme testing confirmed I indeed did have Lyme.

Lyme disease has become a complete lifestyle change. Your entire life is turned upside down and your priorities change. I didn't choose Lyme, it chose me. This disease is extremely hard on not only the one infected, but everyone around me. I am the insurance earner and no matter what-----I had to work in order to be able to afford medicine.

Everytime I tried to make progress, or have a good day I would get a feeling of joy, only to realize another cycle will begin again. It never ends. The Michigan Department of Public Health could help us if they would admit Lyme is all over Michigan, not just in Menominee county. They could at least tell the doctors the truth so patients don't have to needlessly suffer while a doctor tries to find a disease that isn't here. Tourism is the the #1 reason why they deny Lyme. If they would just educate the citizens and health care providers things would be

easier all the way around. People could learn prevention and enjoy the outdoors and if they did happen to get bit, they would be able to get proper treatment immediately.

I feel like my stamina is nearly ZERO. I have a wonderful husband, son, daughter-in-law and two beautiful granddaughters who do not get nearly as much time from me as they should. But after a day of work I am hardly able to drive home, much less stop and see my girls. I do very little work at home my husband does as much as he can. On the weekends, I try to rest and refuel knowing Monday 7:30 a.m. will arrive sooner than expected. Again the neverending cycle begins.

There is no way I can put a cost to how much money my insurance company has spent for medicine, or what I have spent for vitamins and supplements to help boost my immune system. I originally kept track, then it became overwhelming. I just pray that I can last long

enough to enjoy the time I have missed with my family. Time is very precious when it just continually slips away from you. I do try to do as much as I can to help other Lyme patients. I know what it was like for me when there was nowhere to turn for help. If I had AIDS, there would be help everywhere, research, medicine, etc. I beg you to please help Lyme Disease Victims and their Families.

Addendum.

My very good friend is unable to do this letter at this time. She has been ill for 6 years, she has a daughter with Lyme. She is currently in the hospital, very ill, but she needs to be counted. She not only has Lyme, but Erlichia + Babesiosis. Her quality of life is unreal. She has 4 daughter + husband who have greatly suffered through this with her.

Thank you,

[redacted]

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

State: Oregon
County: Multnomah



Name: Linda [redacted]

Total cost: $100,000+

Number of family members with LD: 1

Lost work/school: 11 years

Number of years sick: 20

Linda [redacted] was a sales person with a 6 state territory when she received tick bites in Texas, Colorado and Oregon 16 years ago when she was 42. She had been in sales for about 15 years at that time. Following the bites, she began to develop symptoms that eventually went all over her body, including her heart, joints, muscles, spleen, liver and central and periperhal nervous systems. After about a year, she was unable to continue working due to her getting lost, and other distressing symptoms. She eventually became paralyzed , was unable to read and think enough to put a sentence together, and was nearly blind.

Her search for a diagnosis eventually led her to go to about 50 doctors. She received over 100 different types of tests, but nothing ever could be found wrong with her. The diagnoses given to her ranged from CFIDS, fibromyalgia to being "crazy and lazy". Psychiatrists, however, evaluated her and indicated that her problem was medical and not mental.

She finally came upon an article on Lyme disease in a doctor's waiting room, and eventually convinced doctors that this was her problem. She was so near death at one point that doctors and nurses in the ER were placing bets to see if she would make it through the night. She came back with a vengence! She later helped start a support group and made many local TV appearances.

Her symptoms abated enough after 2 years of antibiotics so that she could think more clearly, her arthritis pain became endurable and she could walk again, although not without a walker. Now, 8 years after antibiotic therapy, she is still on a walker, and has improved so that she is stable, although not symptom-free. She is currently on SSI, but it took her 1.5 years to receive payment checks even though the court ruled in her favor. She estimates that she has personally spent over $100,000 dollars in her search for a diagnosis and treatment.

She most recently participated in a demonstration in Seattle against Dr. Allen Steere who has held a 22 year monopoly on Lyme disease research money and direction. She was a true inspiration to the Lyme community who has had an increasingly difficult time in receiving appropriate care because of the conservative "standard of care" promulgated by this doctor.

Typed from an interview w. Linda by Lisa L. Stanley PhD.
Linda is unable to write much due to neurological damage

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

State: Connecticut
County: Fairfield

Name: Kevin [redacted]

Total cost: $70,000.00

Number of family members with LD: 4

Lost work/school: 5 months

Number of years sick: 2 1/2 years



I HAVE HAD LYME DISEASE FOR 2 1/2 YEARS NOW. MY STORY STARTS WITH MY JOB AT A MUNICIPAL HEALTH DEPARTMENT. MY TASKS TOOK ME OUT INTO FIELDS & SUBDIVISIONS TO COMPLETE SITE INSPECTION FOR SEPTIC SYSTEMS. I QUICKLY BEGAN TO REALIZE I HAD NUMEROUS RASHES ON MY FEET FOLLOWING SUCH INSPECTIONS. I WENT TO SEVERAL PHYSICIANS TO IDENTIFY THESE RASHES AND ALL DISCOUNTED THAT THEY WERE EM RASHES. IN AUGUST OF 1996 I WAS BITTEN BY A TICK ON THE BACK OF MY NECK WHILE AT WORK. I WAITED FOR THE TYPICAL RASH OR FLU LIKE SYMPTOMS, WHICH NEVER CAME. THEN IN LATE OCTOBER OF 1996 I BEGAN TO EXPERIENCE SLEEP DISORDER, GASTROINTESTINAL DISTRESS AND FATIGUE. THEN ON NOVEMBER 3RD I PASSED OUT A WORK. THE FIRST DOCTOR I SAW TOLD ME I WAS DRINKING TO MUCH COFFEE. LATER IN THE MONTH I DEVELOPED SEVERE HEADACHES, VISUAL CHANGES & EAR PROBLEMS. I WAS THEN TESTED FOR LYME DISEASE & I WAS LUCKY, I WAS CLEARLY POSITIVE. WITH THREE WEEKS OF ORAL DOXYCYCLINE I COULD NO LONGER SWALLOW OR SNEEZE. I STARTED ON 10 WEEKS OF IV ROCEPHIN AND IMPROVED BUT MY PROBLEMS CONTINUED. I TRIED ORALS, BICILLIN INJECTIONS FOR THE NEXT 1 1/2 YEARS ON & OFF. FINALLY I CAME OFF ALL MEDICATION FOR 9 MONTHS AND AM NOW EXPERIENCING A MAJOR RELAPSE. THE IMPLICATIONS OF CHRONIC INFECTION IS CLEARLY MISUNDERSTOOD BY THE MAJORITY OF PHYSICIANS. SINCE MY INITIAL DIAGNOSIS I HAVE HAD SEVERAL MYSTERIOUS RASHES ON MY FEET AFTER SITE INSPECTIONS AT WORK, BIOPSY RESULTS REVEAL THESE RASHES TO BE EM RASHES. THE IGNORANCE OF THIS DISEASE BY OUR HEALTH CARE PROFESSIONALS IS ASTOUNDING. MY CASE COULD HAVE BEEN PREVENTED OR CAUGHT MUCH EARLIER & TREATED MORE EFFECTIVELY.

THE IRONIC PART OF ALL THIS IS THAT MY GIRLFRIEND AND I MANIFESTED ALL THE SAME SYMPTOMS. THREE MONTHS AFTER I BECAME ILL SHE BECAME ILL AND IT TOOK HER SIX MONTHS TO BE DIAGNOSED!! THIS DISEASE HAS DEVASTATED OUR PERSONAL & PROFESSIONAL LIVES. THE DIFFICULTIES WE EXPERIENCED WITH DIAGNOSIS & TREATMENT HAVE BEEN NUMEROUS & DIFFICULT TO COPE WITH WHILE TRYING TO REGAIN OUR HEALTH. WE CONTINUE TO STRUGGLE AGAINST THIS DISEASE.

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

State: Pennsylvania
County: Chester

Name: Susan [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school: 1 1/2 years

Number of years sick: 1 1/2 years

Sept. 1996 returned to my job as a school counselor, after 6 days on the job I could hardly walk. My knee joints were so swollen + sore. Doctor immediately diagnosed Lyme. Took Rocephen IV 1 month. Then suprax for 10 months. Had all classic Lyme symptoms.

Now 1 1/2 yrs later I still have swollen knees - much pain. Just Drained yesterday (again) and synovial fluid is being sent for Lab testing. Dr. says Post Lyme Arthritis. Some days I can hardly walk. I take ANTI-depressants + ANTI Inflammatory meds.

I used to jog + do aerobics daily for years. I am 49 yrs. old and otherwise in great condition.

I have no idea how I got Lyme. Never saw a bullseye or bite.

I am on a leave of absence from school all 1997-98 year. It's almost over and I'm no better.

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

State: Kentucky
County: Jefferson

Name: Michael K. [redacted] MD

Total cost: >$100,000

Number of family members with LD: 1

Lost work/school: Disabled since 11/8/96

Number of years sick: >2

36 yo physician previously healthy. Undetermined tick bite probably 8/96 - developed persistent cough, fatigue, malaise, 20 lb wt loss 9-11/96. Placed on 10 days oral antibiotics multiple pulmonary tests negative. 2/97 developed tremors, fasciculations, imbalance, vertigo, diplopia, persistent fatigue misdiagnosed "MS", worsened x 2 on high dose steroids. Finally properly diagnosed by Dr Burrascano, now improving slowly on IV antibiotics x 16 months, going for hyperbaric oxygen treatment. Paying for own antibiotics because insurance refuses. Tremendous cost to self, family, unable to drive, work or walk independently!

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

State: New York
County: Westchester

Name: Dawn [redacted]

Total cost:

Number of family members with LD: 1 + dog

Lost work/school:

Number of years sick: 14



One November morning fourteen years ago, I found a tick on my scalp the morning after I'd been in the woods with my dogs. I didn't give it a further thought. But within a few weeks, my right knee began to swell. It became progressively more painful. I made no connection. On April 20, Good Friday, I awoke with a strange sense of forboding and as it turned out, with good reason. Later in the day, while playing tennis on my swollen knee, I ruptured the miniscus. By the next morning, my entire leg was purple with swelling. I nearly fainted from the pain.

An orthopedist diagnosed trauma to the knee. I hobbled around on crutches for a month until he agreed to investigate. In May I had arthroscopic surgery. The knee remained swollen. The doctor was at a loss to explain it . A rheumatologist he recommended also had no answer. My leg was so stiff I could not drive and could barely walk. Later in the summer while on Cape Cod, I consulted another orthopedist in order to obtain physical therapy. Noting the persistent swelling, he suggested I might want to be tested for the newly discovered Lyme disease (the first I'd heard of it.) He doubted I had it, however, since it usually affected more than one joint he said. I had the test and it was negative. Not knowing how little doctors actually understood about Lyme disease, nor how unreliable the tests are, I dismissed the possibility of being infected.

Time went on and my back began to ache. I became easily confused and my brain often felt fogged. I would have unexplained periods of weakness and intense fatigue. It became difficult to sleep at night because of pains in my joints. Sometimes for no apparent reason my whole body would ache and I would become so fatigued that I would have to lie down and would virtually pass out. I developed double vision in my right eye and intermittent ringing in my ears. I often had blinding headaches and a stiff neck. One night I awoke in panic. I could not take a deep breath because my entire upper body was in spasm. I would occasionally get fluttering and pain in my heart and nerve pains down my arms. Time and again I had to cancel plans or miss work.

Then a friend discovered that he had Lyme disease. But he seemed to have different symptoms so again I did not make a connection. Why should I? My test had been negative. Meanwhile, I was desperately seeking relief from every conceivable source. After mainstream medicine failed me, I consulted chiropractors, acupuncturists, massage therapists, and homeopaths. I tried a change in diet, took supplements and "miracle" herbs, studied yoga and had psychotherapy. I tried meditation, prayer, and visualization. My misery only increased. I was beginning to doubt my sanity. I was sure my friends and family thought I was imagining it all.

One day while on Cape Cod I had a sudden impulse to stop in at a clinic and be retested for Lyme. Lo and behold! Positive! The clinic physician prescribed Doxycycline. My symptoms only intensified. I didn't know where to turn. Then I learned about the Allen Steere Clinic in Boston, considered to be the DEFINITIVE AUTHORITIES on Lyme disease. Desperate, I called them and described my symptoms over the phone. The doctor's words were: "That's not Lyme disease. Lyme disease doesn't act that way." I broke down and cried with frustration. I KNEW I was infected.

That week, by strange coincidence, my husband met a rheumatologist on the golf course back in New York. The doctor agreed to take me on after having me tested again in the Yale and Brookhaven Labs. He told me it was the most positive test he had ever seen. But the intravenous Rocephin treatment he prescribed was not covered by insurance unless administered in a hospital. And so I was admitted to the Co-op Care Center of New York University Hospital, where I received Rocephin twice a day. When I began to show signs of improvement, the doctor stopped the treatment at the end of eleven days. What a relief to be cured! But about a year later, the symptoms gradually began to return. The doctor was nonplussed when I informed him of this but agreed to try Rocephin again, this time for 21 days at home since I was now covered by insurance. Once more, I seemed to be "cured" but by now had developed a severe yeast infection of the intestinal tract caused by the antibiotic. It is a condition which still plagues me and requires a highly restricted diet and an assortment of remedies to keep it under control.

I was again symptom free for several months. But when I suspected Lyme was on the rampage again, I had another test (Western blot in a California laboratory) and it was positive. I didn't want Rocephin again because of the side effects and took instead Suprax, prescibed by the doctor at the DOCS clinic where I was tested. My homeopath also treated me with two courses of a drug from Germany. But it was not more than a few months before I was in misery again. I went back to both doctors to request treatment which they both denied, declaring they couldn't do anything more for me. So I called my rheumatologist again, who fussed at me about patient loyalty but nevertheless prescribed penicillin, which proved to be once more merely a stopgap measure. When I began to feel wretched again, I decided to try an infectious disease doctor who told me frankly he couldn't help me but kindly referred me to a Lyme specialist in Princeton NJ. The number he gave me turned out to be incorrect and I didn't pursue it, hoping to find someone more local. Not long after that, I heard of a new treatment which involved oxidating the blood and which claimed to help Lyme sufferers. But it was untested and cost upwards of an uninsurable $4000. I decided to wait for proof of its effectiveness.

Recently, I got the brainstorm to check the computer for news of Lyme. I was astounded at the number of people whose stories are similar to mine. I was heartened to realize that I am not imagining these symptoms. I made contact with a Lyme support group and through them have finally found a Lyme literate doctor. It appears, however, that the only solution for the present time will be longterm antibiotics, something I had hoped to avoid. But the misery, the humiliation and embarrassment at being considered a malingerer, and the total disruption of my life necessitate it. Desperate situations require desperate measures.

It seems incredible that a disease which has caused so much anguish to so many people has had such limited funding for research. We are not imagining our pain. Every aspect of our lives at home and at work has been affected. Lyme is a dreadful and debilitating disease. WE NEED HELP!

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

State: New Jersey
County: Middlesex



Name: Madeline [redacted]

Total cost: $10,000

Number of family members with LD: 1

Lost work/school: yes

Number of years sick: 5

My name is Madeline. I am a wife and mother - 2 children. I work as a teacher-aide in an elementary school for special education. In the summer of '92 I started getting headaches, pain around the spleen area, several neck pain, dizziness and very, very tired. When I went to the doctor's office he told me I was fine. All my blood tests and exams came back that everything was perfect. He never checked for Lyme. After several visits I insisted on some tests like a Cat-Scan because I still wasn't any better. I only worked part-time so I got through a whole year of misery to finally being diagnosed with Lyme. But I was told by the doctor that read the Cat-Scan and took some of his own blood tests, like Lupus and Lyme, that because I lived in Catskill, that the Lyme test was ok even though it read positive on the result sheet. That set me back 6 months. If I didn't work part-time, I would have lost my job.

Finally, a third doctor started treating me with low doses of antibiotics. He put me on IV therapy after 6 months but

only because I begged him. He kept me on for less than 28 days and that was it. He felt I was cured. After relapsing I tried a fourth doctor who treated me with more IV therapy for 2 months - he fought hard with the insurance company for me because I was so sick.

Since that therapy I've been on my own & try vitamins, herbs, diet, special. Every day is pain but I get through because I have to raise 2 children and work and ~~so~~ take one day at a time. All the doctors say is that the damage is done and it'll take time and I have to live like this - pain, tired and miserable.

It has taken a toll on my marriage and my lifestyle. I'm in bed at 9:00 pm, before my kids even. I'm only 45 and I feel like 90. I don't know where I contracted Lyme but I'm glad my children did not get it or my husband - nobody should go through this kind of pain.

[redacted]

P.S. I can't write anymore because of the Lyme

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

State: New York
County: Suffolk

Name: Pat [redacted]



Total cost: Years of unemployment

Number of family members with LD: 2

Lost work/school: Had to quit good paying job.

Number of years sick: 21

In the summer of 1976, I had a weird rash on my back that did not affect me. But, went to the doctor anyway. He put a bandaid on it. Shortly after that I had blurred vision, numbness that spread all over my body, impaired balance, extreme fatigue, joint pains which moved all over my body, inner feelings of dread, stiff neck, foggy headed, etc. etc. I went to countless doctors over the years and was told, I was stressed out, or I was bored, or I needed to see "someone". In 1981, I went to a neurologist, head of Brooklyn Hosp. He took a spinal tap checking for M.S., negative, cat scan and blood tests normal.. everything normal.

Why do I feel like this???

I started doing my own research at the library and diagnosed myself with syphilis. The symptoms and "bug" are very much alike. I returned to the neuro doc and made him give me a second spinal to check for syphilis as the 'bug' also hides. He must have thought I was "bonko" by this point, but, he did it anyway. Negative, back to square one. His discharge paper at that time Feb. 1984, stated: Diagnosis: Possible demyelinating disease of the central or peripheral nervous system. He told me face to face that he thought I had "something" but didn't know what it was. He was the only doctor that told the truth. I had to quit my job, I dealt with alot of money and was getting unsure of myself. Besides all the days I had to take off work due to the fatigue. I thought maybe staying home would help me feel better. Didn't work, things only progressed.

In 1985, we moved to Long Island and I just continued to suffer. Reading a local paper, telling of the symptoms of Lyme, again, woke me up. This is it! I remember the rash in '76. I went to several doctors and had Lyme tests done over a period of 5 years or so. All negative. I was off and on antibiotics for sinus infections at that time. Then came the extreme dizziness. I had all kinds of tests done, MRI's of the brain, and E.E.G., E.N.G. (horrid test). Nothing. They could not find the source of the dizziness. In March 1994, I saw an ad in our local paper telling about a woman who was suing her Ins. co. for non-payment of I.V. therapy for Lyme Disease. It mentioned her symptoms and the doctors name treating her. I got an appointment immediately. He took 14 tubes of blood and sent them to different labs. All came back positive. 8 significant bands in the Western Blot test. I was so happy to finally put a name to what was causing me to feel so sick, I cried the rest of the day. My husband cried too. I was put on I.V. therapy for 6 months using several types of antibiotics, all powerful. I did not gain anything from the medication. Only left with high liver enzymes and tachycardia. I went for a second opinion to the most renowned Lyme doctor here on Long Island. He checked my records and told me there is no "cure" for Lyme Disease, some people get better, others don't. As far as he was concerned there was nothing else he could do for me.

I am now into my 21st year of suffering. I live day to day and do what I can, when I can. I no longer drive due to the dizziness, and must rely on others to take me anywhere. I miss that little bit of "freedom" I had.

Many people do not know how devastating Lyme Disease can be. It is not a disease to be shelved at research labs. There has to be someone, someday who will find a real cure for us. I have lost the best years of my life. I am now 51. I want some quality years not quantity.

Does our government want a generation of disabled people?

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

State: Oregon
County: Washington

Name: Rita [redacted] Ph.D.



Total cost: $30,000+

Number of family members with LD: 1 (Mom)

Lost work/school: 8+

Number of years sick: 18+

I have had Lyme disease for many years and have been bitten by ticks on both East and West coasts. My latest exposure was in June of 1991, in Washington County, Oregon. Although I saw the tick and the rash, because it was believed that Lyme didn't exist in Oregon, my diagnosis was delayed. The cumulative effect of multiple exposures to the Lyme bacterium, made my disease much more difficult to manage. In addition, I recently found out that I had another tick-borne disease, Babesiosis, a malarial-like infection. I am the first reported Babesiosis case in Oregon. Only my personal research, and my insistence on diagnosis and treatment, got me any medical help in this state.

The symptoms that I had before this latest exposure involved many areas of my body, but I was able to deal with these problems somehow. Following the last bite, I went downhill rapidly especially in neurological areas. By December of that year, my goal was to simply wash the kitchen floor. I had full body pain, frightening neurological and cardiac symptoms, profound fatigue, and was in despair. The doctor who began treating me also had the disease and understood it very well; he was able to work with me in a long-term situation. Following 1 year of treatment, I could do a bit of my housework. After two years, I was functioning better, but still in much neurologic and arthritic pain. After over 6 years of antibiotic therapy, I am functioning well, but do appear to have persisting disease that always relapses at some point following antibiotic withdrawal.

Because of my health, I have never returned to paying work; I take care of my family and am doing a lot of volunteer work in the Lyme community. The work I used to do was in the academic arena (faculty at Baylor college of Medicine; 19 publications), teaching and tutoring, and sales. So you can understand that this disease has taken much from me professionally. But it has added a lot to my understanding of the reasons why there is so much difficulty in recognizing and properly taking care of patients with Lyme disease.

Presently, I am a Lyme support group leader covering the NW states, and am on the boards and committees of several Lyme organizations. I have set up various educational resource centers in the NW. Our main resource center is at Good Samaritan Hospital in Portland, OR where patients and doctors can call and receive information about Lyme and other tick-borne diseases; books and tapes can be borrowed free of charge. All of this has been done at my own expense. All this education is very important, but there are forces that are political that keep open-minded knowledge at bay.

And chief among them is fear. Let me explain as concisely as possible.

The predominating approach to diagnosing and treating Lyme disease is very conservative and almost "cookbook" in simplicity. Basically, it states that Lyme disease is very greatly overdiagnosed and overtreated. A patient, no matter how long they have been sick, nor how much damage has been done, "should" be cured within 4-6 weeks of antibiotic therapy. If one is not, then various other causes are said to exist such as "Post-Lyme disease, Pseudo-Lyme disease, MS, fibromyalgia, hyperchondriasis, etc. No culture studies have been done to substantiate these claims, but the academics who promulgate these ideas have held a lock on direction of money and, therefore, thought for over 22 years. This academic posturing has very real and damaging consequences in real life.

What has happened is that doctors who choose to deal with Lyme in any but the most conservative ways have had their licences suspended or limited. Many doctors are aware of this, and either will not treat Lyme at all because they fear consequences, or maintain a very low profile and will only take a few cases. This is exactly what has happened in the NW. As a support person for many years, most of my time is spent in trying to get doctors to help patients. Most doctors refuse because of what they know can happen should they decide to use their clinical judgement. I send many patients out of state if they have anything except early disease. Others go untreated all together or treat themselves. Disability claims for Lyme disease are not being settled in the light of current medical and clinical knowledge. And the CDC clearly recognizes Oregon and Washington as endemic for Lyme disease.

My story, in a very shortened form, then, is not only the story of how I have struggled with this disease; but it includes the struggles of the hundreds of Lyme patients that I represent in the NW. It also encompasses the very few doctors who even dare deal with Lyme and other tick-borne diseases here, and the political forces that exist nationwide that have kept a stranglehold on thought and research direction.

To have doctors treat their patients in an open-minded fashion, without fear of being turned into medical boards simply because they choose to treat a disease for longer than a month or two, is one of the key elements I feel is necessary to keep human suffering at a minimum, and to use that clinical expertise to get this disease under control.

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

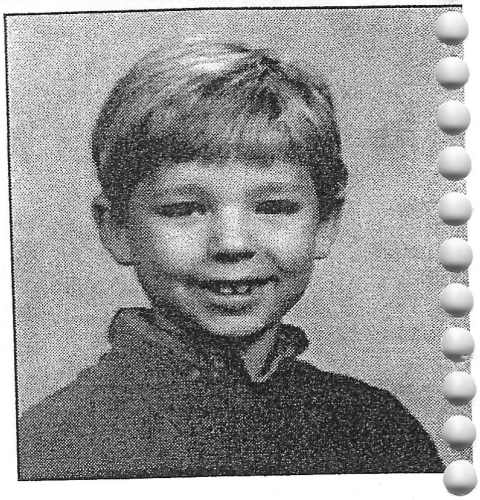
State: Michigan
County: Huron

Name: Marcus [redacted]
Total cost:

Number of family members with LD: 2

Lost work/school: 4 weeks

Number of years sick: 2 months



I detected an EM rash on my son Marcus in November of 1996. I thank God for that rash and being a chronic Lyme sufferer myself — I was very well educated (the hard way) on Lyme — I wasn't so lucky to have gotten the EM rash. By Dec. 96 positive for Lyme & Marcus' MRI of the brain showed two (2) lesions. After a few months of treatment - Marcus had no longer any symptoms. It has been over a year now - and Marcus seems to be doing well. Knowing a good Doctor that was educated about Lyme has helped me and in return has also saved our son from Chronic Lyme Disease — Too bad we had to go out of Michigan to get the help we needed!

Mary Sting
mother of Marcus Sting

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

State: Michigan
County: Huron

Name: Mary [redacted]
Total cost: Thousands

Number of family members with LD: 2

Lost work/school: Down to part time

Number of years sick: 4 ys +



Mary-2nd in from the right

To Whom it may concern:

I am a resident of Michigan-the upper Thumb area who's been forced to travel out of State for treatment, due to the State of Michigans refusal to admit we have a serious problem with Lyme Disease.

My story is a long one- I'll try to be brief.

Before seeing Dr. . I had been seen by seven different doctors. Symptoms listed below are accumulative over a 10 month period.

lower back pain
bowel problems(diarrhea)
neck pain and pressure
eye pain
severe fatigue, moody
laryngitis
severe muscle spasms
light headedness
worsening of symtoms w/menstrual cycle
unusual sensations in head
heart palpitations-MVP
sweats, chills-icy/hot sensations
loss of libido
upset stomach
shortness of breath
pressure in throat
some joint pain
muscle twitches
tingling, numbness & burning sensations in neck & arms
Bells Palsy
buzzing sound in ears
difficulty thinking
short term memory loss
motion sickness
thyroid lump

No known tick bite or initial rash

I thought myself to be well informed on Lyme--
"Rash - flu like symptoms - easily treated"---was I wrong! Not until a comment by a town local- Quote- " You don"t have something stupid like Lyme Disease" did we start investigating. Two women with-in two miles of my home had Lyme disease--one cured and one chronic. I made a call to one and explained my symptoms--we had very similar problems, and she was a documented case in Michigan.

Two of the last doctors I had seen were made aware of this- one had treated Lyme Disease in the past. Neither Dr. would talk about it-"the shade was pulled very fast with the mention of Lyme". Again referred to another specialist.

continued on page 2

My family and I had enough of the obvious run-around we were getting. From that point I made a call to my brother in New York to get info on Lyme Disease-was put in contact with a friend suffering with Lyme. I was given Dr. [redacted] number in P.A. - what a blessing to have found this compassionate Doctor and staff!

I had many clinical symptoms of Lyme Disease and also tested positive.

Started antibiotic treatment after ruling all else out.

Sept. 94: Fourth week of treatment - severe worsening of symptoms-improvement from then on

Jan. 96: Off Biaxin

April 96: On Biaxin due to increasing arthritic & muscle pain Third day on Biaxin-worsening of symptoms and then subsided

Aug. 96: EM rash on upper back(documented w/pictures)

Oct. 96: Check-up w/Dr. [redacted] - doing well with some fatigue occasional muscle soreness and light-headedness

Dec 97 off antibiotics – went down hill – back on meds – starting to improve

I am able to be a mother to my three children again and my husband and family have "their" Mary back.

I have prayed that the State of Michigan would let our compassionate Doctors treat their patients without fear of retribution.

Dr. [redacted] takes his oath very seriously--who's a better judge of that than patients like myself!

Thank you P.A. for being responsive to a health problem such as Lyme Disease-many people from my State appreciate it!

Sincerely

Mary [redacted]

Mary [redacted]

cc
Governor John Engler
of Michigan

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

State: Nevada
County: Washoe

Name: Harold A. [redacted]

Total cost: Difficult to judge

Number of family members with LD: 1

Lost work/school:

Number of years sick: 8



AIR FORCE ASSOCIATION
Aerospace Education Foundation

Contracted Lyme in Summer—Fall, 1989, probably in Sonoma County, California, where ticks and Lyme are rather prevalent. Possibly was infected before I found a tick and "Bullseye" rash behind my knee, as I already was experiencing what I have increasingly been able to identify as the symptoms. Knowing what I now understand, I would have insisted on antibiotic treatment at once, rather than wait for the tick to be tested (it was lost!) or the results of on-again, off-again, inconclusive tests, the way it has been through my testing history. The symptoms are extensive, wide ranging, fleeting, move around, and sometimes temporarily respond to new medication. They are of emotional, mental and physical nature, similar to those attributed to Chronic Fatigue Immune Dysfunctional Syndrome, although more extensive and so far lacking gastrointestinal disorders. Emotional problems are lassitude, depression, intolerance and a terribly "short fuse". Mental shortcomings are what you might expect: Difficulty in concentration, expression, memory, and spatial orientation (not accurately keeping track of distance to the ground, causing tripping;

The many, varied, mobile physical symptoms, although seemingly very real, are so far "more, in the mind". As examples, cardio-vascular discomfort always turns out to be unfounded, when checked; to this point, heart and blood pressure are the best thing about me. Although I have had great difficulty with my legs (particularly knees) and shoulders, there seems to as yet be no severe joint deterioration or nerve problems as a direct consequence. Places that have been sore and tender to the touch (sometimes outright painful) are: heels, knees, hips, elbows, shoulders, biceps and neck. There has been occasional paralysis of an arm (usually the right) or disfunction of both. The legs move and work poorly, and sometimes collapse with no warning. I have fallen possibly ten times, attributing about half to leg failure and half to tripping. The major damage sustained was in my left leg, with two thrombosis experiences/episodes from which I may have recovered except for vein valve damage. Throughout my difficulty all "just in case" tests proved favorable (MRI, Cat Scan, X Ray, and Ultra Sound - except during blood clots), but recently after a bad fall (1997), the MRI showed a herniated lower disc pinching a nerve to my right leg. An operation to remove the disc has apparently (hopefully) corrected this. I also sometimes experience blurred, shifting vision, seeming "spray" on exposed skin, fingers with stiffness/swelling. All in all, Lyme seems to be my major difficulty, leading to the only other things faulty in my physical condition. Please, find cure!

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

State: Connecticut
County: New London

Name: JoAnne B. [redacted]

Total cost: $80,000

Number of family members with LD: 2

Lost work/school: 38

Number of years sick: 5

To Whom it may concern:

I am writing this letter in hopes to increse the awareness of how devastating Lyme Disease can be to an individual and their family. I hope and pray that people who have the power to make a difference in this terrible disease will do so. Five years ago our immediate family consisted of four happy, healthy individuals, 2 parents approx. ages 36 years and 2 children ages 8 and 11 years. Oh course, we need to mention the very much loved 5 year old family dog. We worked hard and saved our money and finally our dream of a nice home in East Lyme, CT was fulfilled. Our lives were perfect and so complete. Slowly our dream was torn apart by this terrible disease. I was biten by a tick carrying Lyme Disease. My symptoms were as follows: intermitten fevers, severe headaches, loss of balance skills, light headedness, very weak and fatigued. Then I progressed to swollen joints: ankles, knees, hands, spine and neck. Then I lost my peripherial vision, my short term memory and finally I was becoming very short of breath upon the least physical exertion and passing out. Before this terrible disease hit I ran atleast 3 miles daily and if time permitted further. Also I worked out atleast 2 to 3 hrs, 3 times a week. I was in very good physical shape. Initially I went from physician to physician in hopes of getting better. Finally, a cardiologist diagnosed the Lyme Disease just by chance prior to performing cardiac surgery. I can no longer do the grocery shopping, cannot lift over 5 lbs. without cardiac pain and irregularities and sometime so severe that I pass out. I use to be very active and independent and now I am afriand to drive because of my vision loss and afriand to be alone incase I start having cardiac difficulties not to mention the fatigue and joint pain. I have tried many oral antibodics with initially improvement then it starts to plateau and then cease to cause improvement. Presently, I am on IV antibodics as well as oral antibodics with good results but now I am starting to plateau. I feel strongely that maybe if I was diagnosed sooner, if physician's understood this disease better and if the insurance Co. would not fight the treatment that I would be well now.

To add to this horrible life our worse nightmare has occured. Our healthy, beautiful son has Lyme Disease. His symptoms are no short term memory, problems speaking, very arthritic swollen joints of his neck, spine, shoulders, hands, feet and knees. He no longer can ride his bike or go to school secondary to the exhaustion, no balance, severe headaches, hot flashes so severe that he becomes sick, chest pain upon the least physical activity and there are days he cannot ascend or descend stairs or even walk.

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

State: Massachusetts
County:

Name: Karen Sullivan, RN

Total cost:

Number of family members with LD: 1

Lost work/school: career & life

Number of years sick: Years





Karen Counts

Karen Sullivan is dead.
She died because she believed that she didn't count.
Her Lyme Disease went misdiagnosed as chronic fatigue syndrome for years. When she finally did find the answer and began getting help, she discovered to her shock that her loved ones saw her differently. Suddenly she was diseased, defective, untouchable. To her horror, she found that the very medical profession she had been a part of for over 20 years as a pediatric nurse was riddled with politics and a maze of red tape. When she lost her career to Lyme Disease, she lost the only place where she found a sense of self worth. When she lost her career, she also lost her insurance. When she lost her health, she lost her independence, and her independence was vital to her life. When it was time for those she had cared for to care for her, they didn't have the skills to handle the task. They didn't know how to give her the loving compassion and nurturing that she had spent her life giving to others as a pediatric nurse.
The message she got from all this was, "Karen doesn't count."
She was not just the victim of a bacteria, but a victim of today's Society - one where Lyme disease victims go misdiagnosed, and undiagnosed, not because of lack of science and knowledge, but because of the greed and the egos of doctors and insurance companies. In her world people turn to anger and callousness to hide their fear and feelings because they haven't been taught anything else.
Karen's life outside of Lyme Disease was far from perfect. Lyme Disease magnified the imperfections. It was a terrible thing for her to wake up one day and find that her entire body has been infected with a bacteria that had taken away her ability to function physically, mentally and

emotionally. But the abandonment of those who meant the most to her was devastating and the resulting hole in her soul, the loneliness, was more than she could bear.
She believed she was worthless. Her suicide note requested that her brain and any organs that could be used for science should be donated...but the coroner couldn't find any takers. It seemed to drive home the message she got that she didn't count.
We can't bring her back, but we can tell the world that "Karen Counts." We can send a message for all those suffering like Karen that they do count. Her story speaks to all whose lives have been affected by Lyme Disease. Join us in a vigil for Karen.

Send a message to Cindy McCormick at Cape Cod Times that says...
"Karen Sullivan Counts. My life, like hers, has been affected by Lyme Disease. Count me in on a vigil in her memory next Saturday night."
Tell Cindy you are placing a candle and sign out (or whatever you decide to do). Tell Cindy WHERE you live. Feel free to add that Karen's story reflects your very own saga with Lyme or anything else you would like her to know. Tell her of any Lyme related suicides you know of. She's collecting information right now for a comprehensive story on Lyme so this is a great opportunity for all of us to be heard.

[redacted]

Then next Saturday, November 1 at 6 p.m wherever in the world you are, light a candle and put up a sign that says "Karen Counts" in your window or in your yard. I'm putting out a candle in a paper sack that says "Karen Counts." And pray for all of us.
With sadness and sorrow,
Rae Record

Yes, Lyme Disease has devastated our family beyond words. We have been affected severely emotionally, medically and financially. We have had an insurance policy with BC/BS of CT for 21 years. The insurance co. refuses to pay for IV antibodics passed 30 days. Their refusal on our son was based on their opinion of him not having Lyme but diagnosing him with M.S. Their diagnosis was not based on the fact that the antibodics were making him better, or upon medical records that they never reviewed or even a physical exam of our son. Their decision was based upon financial concerns of their own and not on sound professional medical expertise. IV antibodics are approx. 8 to 10,000 dollars a month. My son has been on IV intermittently approx. 8 months and myself 3 months. This is just overwhelming emotionally to fear that you cannot get medical care to save your child's life here in the United Stated secondary to the insurance co., this is overwhelming financially. Families are forced to sell their homes, provide medical care only to certain members of their families.

As you can see how devastating this disease can be to a family. This is just one story of many. Please help the victims of Lyme Disease! You have the power to make a difference and all we ask is to get well again and go back to being productive individuals. This disease affects, young, old, innocent healthy people. Please again I ask please help us fight this terrible disease. You can make a difference.

Sincerely,

Paul, JoAnne, Paula, Jesse Sturges
East Lyme, CT

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

State: Maine
County: Penobscot

Name: Beatrice M. [redacted] MD



Total cost: over $100,000

Number of family members with LD: 1

Lost work/school: 2 yr

Number of years sick: 3 1/2

Begin at the beginning: I am well. A healthy, energetic internist and pediatrician practicing in rural Maine, struggling to maintain a balance between professional demands and the demands of a young family, I am accustomed to 40 hour days and sleepless nights. The stresses of life and death and birth and illness, of relationships and planning and unplanning and rolling with the punches are not strangers to me. Basically, I am a happy and optimistic realist by nature, not uncomplaining, but committed to family, friends and patients. I am also demanding professionally and attentive to details and subtleties as well as the big picture. In this telling, I include no discussion of the impact of this illness and its struggles on my family, though they are many. So far, despite recognizing lots of lemons, we have managed to make lemonade. Not everyone can do that.

1. Prior to 4/94 I am well.
2. Miscarriage 4/29/94
   complicated by significant blood loss (2 -3 units)
   complicated by unknown retained products of conception x 2 1/2 months
3. Ithaca trip 5/31/94 short excursion thru brush with shorts and sandles...bad choice.
   pinprick sensation R ankle persistent thru 6/2/94 brushed, looked, saw nothing.
4. RASH 6/3/94; deeply erythematous, increasing in size to spread over R foot dorsum and up to mid shin, becoming near circumferential, central area with bluish discoloration and almost vesicular appearance, rash slightly painful, foot and lower leg quite swollen; satellite on R posterior calf and shin not as large or deeply erythematous,. I now recognize this as a variation of the EM rash. It faded with cortisone cream over several days and was forgotten. heavy investment in getting back to normal on my part.
5. second gyn hemorrhage 7/2/94 - discover retained products
   D+C
6. unwellness begins 7/3/94in the middle of the night after D&C; nausea, achey, myalgia, chest pain
7. 1st Antibiotics 7/5/94 DOXY + METRO x 4 days; then TMP/SMZ DS based on culture lochia ultrasound -
8. pass more RPC 7/18/94 point from which I marked myself ill, though decreased work load and call because of unwellness from start of July.arthralgias, myalgias,inc. stiff neck, fevers, abd discomfort; sleep disturbance; energy wall; burning eyes great fatigue, malaise, struggle to finish what obligations I have for July ultrasound
9. OB/GYN consult 7/28/94 switch to HEPARIN, CLINDA, KEFLEX, some gyn improvement, no resolution, CT abd and pelvis -; 45 minutes of any activity exhausts me. low grade fevers, sleep disturbance, arthralgias, myalgias,etc... HYSTEROSCOPY and D+C 8/8/94
10. Vermont Consult 8/26/94; rec. do no more tests, take no meds. suggests it looks like it may be going to be CFS
11. Trial of CLINDA for 3 weeks 9/17/94 last time any improvement was on , not this time; trial of Zoloft no improvement
12. Remember RASH 11/ /94 +ELISA report –Western Blot
    Dx: keratoconjunctivitis also made 11/94
13. TREAT LYME 12/1-28/94 worse x 2 wks, herx like rxn then better x 1 1/2 wks, then much

"But you don't look sick... !"
The flush in my cheeks reflects fever, not wellness.
The circles under my eyes reflect illness, not my former lack of sleep or advancing age.
The bloat + weight gain I have experienced are unrelated to poor food choices.
"You look so good!"

"Thank you. You should have seen me when I felt well."

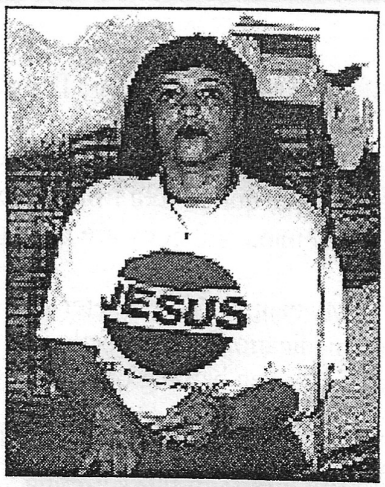
OVER

worse one week post D/C CEFTRIAXONE

14. Restart ABX 1/5/95 ceftriaxone and Biaxin
15. Consult ID 1/19/95 switch to DOXY - sort of plateau; report 0 bands +
16. STOP all meds 3/4/95 no sig. improvement and marked episode of fever rigors and nausea and vomiting; can't tolerate persistent nausea. was this a herx-like rxn?
17. RASH 3/23/95 similar to original not as severe, larger on L leg this time.
18. Consult Boston specialist 5/19/95 doubts Lyme, draws labs, recs investigate abd. possibilities; consider exercise and low dose amitriptyline; post infectious fatigue syndrome; now 2 bands I report WB -.(I later learn none of the history he uses is accurately recorded)
19. D+C, LAPAROSCOPY 6/23/95
20. RASH 7/27/95 similar to original not as severe again on legs one spot on arm
21. GI eval. 10 -11/95 identify spondylolysis on BE
22. No dx. - calling this post infectious chronic fatigue syndrome; I still think it's Lyme Borreliosis
23. Osteopaths for back 11/95 and on-going for about 2-3 months
24. Stop private practice 12/95; unable to perform duties required to maintain private practice; throughout 1995 worked Mon and Tues am's spend Wed on couch all day to recover enough to work Thurs. am to spend Fri, Sat, and Sun recovering enough to do it again. Took no call, limited social activities, aodl's; gradually realized not only not getting better, but getting worse. Decision to stop practicing made as a result
25. Start exercise 1/96 overall symptoms are worse now; not to pre December 94 but pretty bad. Prior to this unable to attempt activity beyond work and survive. Symptoms worsen, feel much worse with aerobic activity,except that it justifies the fatigue! Difficult to bounce back from exercise.
26. Review Case and data on Lyme Disease. Consult Specialist in Long Island re:LD ? 2/96. Obtain labs including CSF, urine, serum. for PCR, etc. WB 2 bands, IgM multiple bands; begin IV Doxycycline 4/96; nutritional regimen, vitamins, and Physical therapy for resistance training. Initially full hour just to stretch and completely wiped out afterwards. Recommended NO aerobics for time being.Generally worse after starting Doxy, esp. nausea. Begin to see clearer pattern of worsening perimenstrually and gradually see improvements in between.Herx like rxn's - q 4 wks.
27. Slowly improving through the summer. ~August start to be less well. End of October change to IV Ceftriaxone and build up to 4Gms 3 days weekly.Herx. Begin to improve. Dec. add Zithromax and hydroxychloroquine, BIG herx. Can see real improvements.
28. Increasing exercise tolerance through '96, though still difficult to do more than now more advanced program and the most basic aodl's consistently. Mild worsening of symptoms now seen mid cycle with more pronounced worsening perimenstrually.
29. 2/97 new tinnitus. Sick as a dog in March with sinusitis really sets me back even to have a cold!
30. 4/97 can more easily see improvements ; compared with last year at this time much better energy, many fewer sleepless nights, sleep has some benefit now, although I require much more than ever before. Still cannot sustain demanding activity for more than a couple of days at a time but this is still far better than previously and I recover a little more quickly if I do push myself. The energy wall has moved out a little farther .
31. 6/97 I am feeling fairly well, still fatigued, still ache but able to do more without major consequences.
32. 8/97 Not as well, severe headaches and fatigue, gradual worsening of symptoms since July increase meds to 5 days/ week and add azithromycin IV. At visit to Dr. B. start Mepron , 9/97 and plan for treatment break.
33. 11/3/97 Nearing treatment break and eagerly anticipating not having a 3-5 hour medication requirement each day. I am clearly better than I was a year ago, but still unable to sustain activities for more than 1 day at a time except on a very short term basis. This is not compatible with medical practice rurally, I wonder if it is compatible with any type of practice, or any employment. I am discouraged, but still hopeful. So tired and so tired of complaining. I need to be less preoccupied with my own well-being and that is nearly impossible.

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

State: Pennsylvania
County: Chester



Name: Dianita Marie [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school: 6

Number of years sick: 6

Hello my name is Dianita Marie Wilson, I am 42 years old and have been suffering with Chronic Lyme Disease for seven years now five years undiagnosed because Lyme Disease is very difficult to diagnose and has come to be known as The Great Imitator because it mimics so many other diseases. I have been diagnosed as having M.S, Lupus, Chronic Fatigue and so many others.

I had under gone so many tests such as Spinal Taps, EEGS, MRI' S, Cat Scans, series of blood tests, and many others.

I have been in hospitals, hooked up to I.V.s, also I have been on a cane off and on. Some days I can't even get out of bed. I experience these symptoms every day. Headaches, body aches, joint pains, skin rash, swollen knees and ankles. Some days, as I said are worst then others.

During the five years, I wasn't diagnosed with Lyme Disease and didn't receive the necessary antibiotic drug treatment, my physical condition deteriorated rapidly. joint and muscle pain became unbearable needed to depend on a cane to move around, in May 1995.

I was placed on home I. V. antibiotic therapy, then H.M.O insurance company took me off my antibiotic for five months causing my Lyme to go through out my body and to my brain. I had to have somebody with me at all time.

Then after five months of hell. I finally got back on my home I. V. antibiotic therapy, 6000 mgs a day 3 x's a day. The veins in my arms then collapsed. Causing my operation in April 1997 to have the Cather put in left breast. Leading directly to the main vein in my heart.

So I do my own dressing change, flush and Catheter change and also the home I.V. Antibiotic Therapy.

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The cause of my Lyme Disease was from a tick bite in my own front yard.

Just think a tick can take away your health as well as your sanity. One of the comments I receive quite often from people is you look health. Sick people are supposed to look sick. My mind and body are falling apart. I am spiritually coping with this disease.

My central line Catheter was implanted in my chest by a surgeon this April. The medication goes directly into the large vein in the heart. OnIy restriction is no swinging and when bathing or showering not getting it wet. I was trained by a nurse to do my dressing.

But inspite of this suffering I am going through, I have to get on with my life.

I have a husband Robert and a son "R.C." and I put these pains in perspective get out of the house, I call friends and do something to remind me that a lot of people out there are in need also. I thank God for being able to continue to help others. If I can help somebody then my living shall not be in vain and I thank the Lord for this extra strength.

God can do all things if we only believe and have faith in him. I can do all things through Christ which strengthen me.

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

State: Tennessee
County: Davidson

Name: Marie [redacted]



Total cost: $29,000

Number of family members with LD: 1

Lost work/school: work $20,000

Number of years sick: 5

In June of 1990 I discovered a tick on my back. It was surprising because my clothes and body had been sprayed with bug repellant. I had been out in the woods for 6 hours two days in a row as a performer at a Renaissance Festival. For a few days I felt a little under the weather but attributed it to the exhausting work. A few days after the bite I noticed a very large rash with central clearing around the bite area. Since it did not itch or hurt I did not seek medical treatment. I was unaware that what I had witnessed was a telltale sign of Lyme disease. About one month after the bite I began to have unexplainable pain in my right shoulder joint. A conversation with a friend convinced me to have a test for Lyme. The results of an ELISA were negative so I eliminated the possibility of Lyme disease. I didn't realize then that a negative test was not conclusive proof of lack of infection. At the time I was working as a wallpaper hanger, singing professionally, going to graduate school, and studying kung fu. This was very normal for me because I thrived on the amount of diverse activity. However, the fall following my bite I felt overwhelmed and dropped one of my graduate courses. I began to feel very stressed and irritable. I noticed occasional pain in my right knee and feelings of dizziness. Soon I began to cut back on work because I was exhausted. By spring 1991 I was experiencing almost constant pain in my joints, dizziness, extreme fatigue, chest pain, skin sensitivity and ringing in my ears. My friend who had previously suggested Lyme disease gave me some literature to read. I began to see the connection between the onset of my symptoms and the tick bite. Another ELISA came back negative. A third test was performed and this time a Western Blot was positive. I had to go out of state to be treated by a knowledgeable doctor. In the fall of 1991 he put me on a course of Biaxin which I continued for three and a half years. During my illness I was forced to discontinue kung fu training, stop working almost completely and reduce my course load to one class a semester. There were many days when simply walking down the hall in my house was overwhelming. I battled severe suicidal depression which was treated with Paxil. Medication was also used to treat insomnia. A former professional actress, I experienced difficulty speaking including stumbling over words and stuttering. Many times I had great trouble with my previously excellent memory. There were many days when I thought I would never feel good again. However, thanks to treatment I am now well, off medicine entirely and recently gave birth to a healthy child. This past spring (1997) I finally graduated with my Master of Arts degree. If I had not been fortunate enough to

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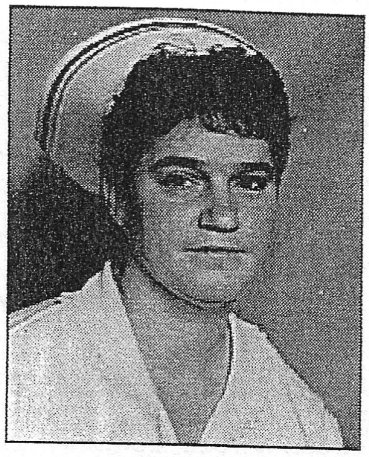
have a friend who informed me of this terrible disease and locate a doctor courageous enough to treat me, I believe that I would either be dead now or crippled, bedridden and severely mentally ill. Lyme disease is a real threat to our population. With proper diagnosis and treatment there is hope. My fear is that so many more will continue to suffer, with needless cost in terms of lives and productivity.

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

State: Wisconsin
County: Grant



Name: Jolinda [redacted]

Total cost: $100,000.00

Number of family members with LD: 1

Lost work/school: 6 months total

Number of years sick: 12 years with flare-ups

In the fall of 1986, I noticed a reddened raised rash on my wrist, after being out in the woods on our farm cutting firewood. The rash was about the size of a fifty cent piece, and had a light ring within it's border. I thought it was a ringworm at first but it didn't go away with topical ringworm treatments or with cow salve. In Dec. 1986, I became very ill with severe flu like symptoms; nausea, abdominal pain, chills, fever, dizziness, & loss of appetite. I went to a doctor who was not my regular pysician as my regular doctor was out of town. I doctored with this doctor for about 3½ months as he had ordered several expensive diagnostic tests due to my symptoms and elevated white count in the blood. After the tests were competed and the results back without conclusive diagnoses, he suggested the symptoms were due to Psycholgical nature, and that I was " a Chinese puzzle" and he couldn't help me, I am a very energetic person and had never been ill, only hospitalized to have our 3 children. To continue, I doctored from Dec.1986 to April 1988 with 2 different physicians, 2 Urologists(because of chronic kidney/bladder infections), 2 Gynocologists(because of inflammatory pelvic infections), and a Chiropractor to try adjustments to help deal with aching joints and muscles. Then in April 1988, I tried another Chiropractor. After a series of X-rays, he told me that stucturally there was no bone or muscle problems that could be causing my problems. After discussing my symptom, he then asked me if there was a possibility that I could have come in contact with with deer or if I had been bitten by a tick. I then told him of the rash in the fall of 1986. He then advised me to have a lyme Serology test done. I stoppped at the clinic that I initially had gone to when I first became ill. That doctor only ordered

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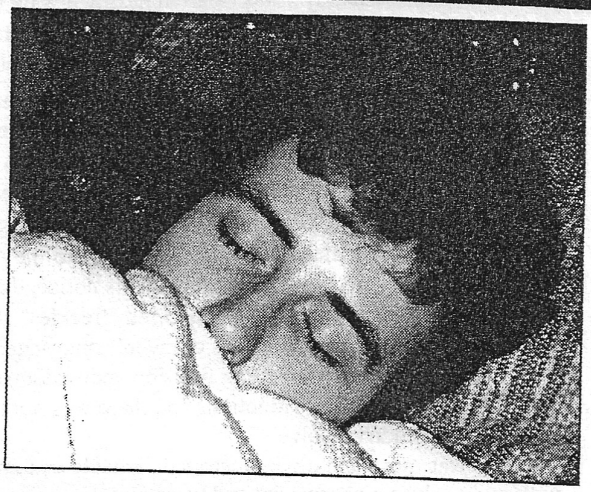
a CBC which did not usefully detect Lyme Disease. I then called another clinic which had a physician that had one case of Lyme. He agreed to run the Serology which came back positive. He advised me to see him. I went on another cycle of antibiotics(Amoxicillin, one of the many medications I had already used). He told me the test revealed a past exposure to Lyme Disease. We then discussed the rash I had. I continued to doctor with him until his death in 1990. I have had 6 surgeries up to that point, with either infections noted or physicians mystified by origin of the problems found. Each time I would ask the possibility of Lyme Disease being the cause, they would reply that it is not a problem in this area, which of course is very untrue. I have continued to have chronic exacerbations of infections of unknown origin, as well as generalized aching, chronic pain, and elevated white counts. These symptoms have been persistent over the past 12 years. Over the past 12 years my husband and I have spent over $100,000.00, with the first 4½ years out of our own pockets. We faced the possibility that I would continue with multiple medical problems well into the future. In 1992, I had a let up with chronic health problems. And to prevent me feeling like I was going out of my mind, as this is what doctors were pretty much saying with their diagnoses and suggestions of Psychological Stress, I furthered my education and became a Licensed Practical Nurse. I have had about 6 months total loss of work time over the past 12 years. I live on a dairy farm, & help when I can. Lyme Disease is a living hell, and to have doctors either not aware of or interested in looking into Lyme Disease and the frustration of not feeling well, is sad as well as dangerous. THe emotional and physical well being of persons afflicted with Lyme is tragic. I have been diagnosed with Fibromyalgia and Mastalgia. I have been told by specialists that I need to "learn to live with it", and medically I am at a point that I'm not suffering from a life threatening disease. It really upsets me that once a person has been treated, the doctors feel you don,t have future problems. I had one GI Specialist in UW Hospital that did express his concerns that the length of time between exposure and treatment, and that the medications used were not appropriate. He told me he is quite sure the problems I have at the present time are latent Lyme related problems. One of the more aggravating issues for me is that my primary physician does not acknowledge Lyme Disease and the ramifications of it.

To "deal" with the chronic pain I have sought some relief wwith 'alternative healing' products. I continue to have low grade temps, fatigue chills, achiness, and nausea. Faith in my religion, support from my family, and compassionate support from some of the physicians does help. Lyme Disease does affect the whole family!!

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

State: Illinois
County: Kane

Name: Jeanette [redacted]



Total cost: $250,000

Number of family members with LD: 1

Lost work/school: 1 1/2 mos

Number of years sick: 17

Perhaps the most important aspect of my story is that it is now 8 years since I was diagnosed with Lyme disease and on Labor Day of this year I began a severe, neurological relapse. This is in spite of well meaning physicians who treated me and told me I was cured. I continued to have those "little symptoms" that tell you that the illness is not gone and is just waiting for the chance to come back full force. I was able to find a physician who would continue treating me with oral antibiotics. This allowed me to continue to work for several years in spite of fatigue, headaches, etc., but left little or no energy to enjoy life. Unfortunately, one oral antibiotic after another would fail after a period of time and my physician would try another. Finally, he felt there were no others to try and he was reluctant to treat me with intravenous antibiotics because he felt that would be extreme and because he dislikes the hassles he gets from insurance companies when he orders intravenous therapies. So, in spite of my increasing symptoms and a severe headache that lasted from the end of May to the end of July, he did not change my medication.

On September 1st of this year the headache started again with a strength that would drop a bull elephant. I also developed fevers, chills, nausea, vomiting, swelling under my tongue and in my throat, spinning and dizziness, double vision, 35% hearing loss, weakness, extreme fatigue, shortness of breath, pain in my left knee, memory and thinking problems, etc. This landed me in two different hospitals (about $15,000.00 plus tests) in several weeks time being examined by an oral surgeon, an ear nose and throat specialist, a neurologist, 2 infectious disease specialists, and a rheumatologist all of whom scratched their heads and told me they were baffled. So while I continued to slide further and further down hill for a month they pondered more tests.

Finally, I was able to obtain the name of physician, only an hours drive from home, who was knowledgeable about Lyme disease and she started aggressive intravenous antibiotic treatment within days of her examining me. Two weeks after starting treatment I no longer have double vision and my hearing is somewhat improved. The spinning, dizziness and stamina have improved to the point where I was able to stand up and take my first shower under my own power in 6 weeks!

The bad news is that I have lost 7 weeks of work and am expected to be off for at least 6 more. Even then, I will probably have to start back part time until it is clear that my recovery is not in jeopardy. I do not want to relive this scenario again!

The other bad news is that my insurance company has flatly denied my claims for the intravenous antibiotics stating that they are unnecessary. All claims for Lyme disease intravenous antibiotics automatically go directly and immediately to the office of the medical director at my insurance company. Because I expect the cost to run over $30,000.00, I will make a formal appeal, but I'm not sure what my chances are against the all powerful insurance company. They have lots of resources. I will have to gather documentation and write the appeal myself.

Such is the state of treatment of patients with Lyme disease today. We need your help to rectify this.

If you have a couple more minutes, I'll tell you how it started.

In approximately 1980 I started having a wide range of unusual physical symptoms. I was 25 years old and the Director of Pharmacy Services at a medical clinic. I loved to camp and hike and fish and did so in Wisconsin, Minnesota, New York and Pennsylvania. My symptoms came on over several years, not all at once, and included left hip lameness that lasted a few weeks and went away, left knee lameness that lasted a couple months and went away, headaches that were so severe I would swear I had a brain tumor, visual disturbances, fatigue and shortness of breath, memory losses that at times were so severe I had to find excuses to avoid disclosing that I couldn't remember my long time friend's name, irritability and mood swings to the point that I was nearly divorced, depression that came and went at a moments notice, difficulty swallowing, loss of hair growth on my shins, tiny, bright, blood red "freckles" started appearing on my skin, twitches of my left eyelid, tremors of my left ring finger and so forth. My doctor ran a few tests and checked my swallowing function and reassured me that I was just overly concerned with my bodily functions and there was nothing wrong with me that a psychiatrist couldn't resolve.

I was more and more frustrated, irritable and impatient. I decided I was unhappy with my work as a pharmacist and went on to complete my MBA. I resigned my work at the clinic.

Over the next 9 years I was frequently treated with short regimens of oral antibiotics for what were thought to be sinus infections and 3 bouts of strep throat. But by late 1987 I was so fatigued, short of breath, irritable and unable to handle frustration that I resigned my job as Operations Manager for a clinical research laboratory. I thought I was just overworked and over stressed and needed to rest up and find a different job. In the mean time I took a part time position as a practicing pharmacist. This impacted my income and my benefits including retirement savings dramatically.

But in spite of resting up I didn't get better. I continued to limp along for about a year when I suddenly became extremely short of breath, extremely fatigued, confused, dizzy, with headaches and an ear ache. Because I was running only a low grade fever and I "looked fine", I was told that I had a virus and it would go away by itself. I couldn't make the physicians understand how wrong things were physically with me. They couldn't see the mental cloudedness, the weakness, the headaches, etc. They just wouldn't believe me.

Finally, about 8 physicians later, I found one who believed me and decided to check for Lyme disease.. Fortunately, my blood test was positive. Oral doxycycline antibiotic was started with no relief. Two weeks of intravenous antibiotics brought me back to the world of the living, but left me still symptomatic. More oral doxycycline antibiotic allowed me to relapse in a period of 3 months. Nine weeks of intravenous antibiotics again brought me back but left residual symptoms. Then no physician would order more antibiotics. A neurologist put me through $10,000.00 worth of tests and decided that I no longer had Lyme disease because my positive blood test only "showed that I used to have Lyme disease."

With an expensive trip out East for a consultation with a Lyme knowledgeable physician, I was able to convince a local MD to continue oral antibiotic treatment (a more potent one than doxycycline). That was about 6 years ago and I have more or less been on oral antibiotics since then. At times when I have attempted to stop them, my symptoms have worsened more and more rapidly. The end result being that I completely relapsed this September even while on the oral antibiotics. And that brings my story full circle.

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

State: Maryland
County: Carroll

Name: Robin [redacted]

Total cost: Astronomical

Number of family members with LD: 2

Lost work/school: Never worked

Number of years sick: 18 1/3



Name: Robin [redacted] Age 38 Lyme 18 1/3 yrs.
- 19 yr old Resident Camp Counselor Catoctin Mountains bitten July 1979
- went 9 yrs. not knowing what was wrong. Doctors told me too many ymptoms to be one thing, it must be in my head.
- 1988 Clinically diagnosed with Lyme Disease (I did not have a positive ter) but had all the symptoms.
- Took 2 more years to find a Doctor in Maryland who would work with r Joseph Burrascano Jr, East Hampton, New York. 8 hrs. is a long way to trave f you are in a medical emergency.
- I have lost my life since I was 19. I have a Bachelor of Science egree in Elementary Education. I was going for my Masters in Deaf Educatio ost the disease took too much of a toll for this to happen. I was also an interpreter for the deaf.
- I am unable to work as many days I can only move from chair to chair. I walk with the aid of 2 loftstrand crutches or a wheel chair
- I have had positive titers since original diagnosis.

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The Lyme has affected me:

Chronic Lyme Disease
Ischemic Heart Disease
High Blood Pressure
Immune Deficency (I have T + B cells No Killer Cells)
Cerebella Degeneration
Asthma
Neuropathy (all extremities)
Muscle weakness + lack of Coordination
Arthritis (all joints)
[redacted]
Tachardia
Menopause (age 29)
Reflex Sympathetic Dystrophy
Seizures
Memory Problems
Temperary paralysis
4 knee surgeries
Costochanodritis
severe headaches
Stomach problems
Lymphedemia
Lyme Colotis
Chronic pain

This has put a great strain on my family. I live with my parents.

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

State: Oregon
County: Lane

Name: Daniel [redacted] Ph.D.



Total cost: $20,000

Number of family members with LD: 1

Lost work/school: 3+ years

Number of years sick: 5+

I am a 37 year-old, educated professional recognized worldwide in my field and a victim of Lyme and other tick-borne diseases. I am also a victim of a medical establishment that is reluctant to test or treat for these diseases, and that is why I am writing you today.

I contracted my initial tick bite while watching drift boats on the Willamette River, in July 1992 mere blocks from my home. While on a 105-mile bicycle ride several days later, I came down with flu-like symptoms including chills, fever and muscle and joint aches. Symptoms and a red rash around my navel persisted while enroute by car to a faculty position at a research university in the South, and I discovered the imbedded tick in my umbilical cavity while showering one evening some three weeks after arrival. I didn't know tick bites can be painless and commonly occur in obscure areas where they are unlikely to be noticed and I didn't know one tick can carry multiple diseases. After a very rough night with a 102-degree fever, aches, delirium and extreme fatigue, I checked into the emergency room where the tick was removed and I was diagnosed with a bacterial infection and prescribed antibiotics.

Instead of getting better from such a seemingly small incident, I became worse. Much worse. In the days that followed, I was clinically diagnosed with Lyme disease by a local practitioner and received the first of what was to become a two year-long course of antibiotics. In the meantime, I began to struggle with increasingly severe symptoms. Amidst the stresses and strains of starting a new job, I developed excruciatingly painful arthralgias and myalgias, tremors, weeping skin rashes and disturbed sleep. I became forgetful and had great difficulty in performing sequential tasks. I frequently had to excuse myself from lectures and dash down the hall to the restroom to vomit. I became terribly weak with debilitating fatigue and I experienced trouble with my eyes and perceptions. My vision blurred, my eyes became grainy and I developed many "floaters". But worst of all were changes in perception as I began to experience difficulty in writing, editing and proofreading text. I found I couldn't "see" errors and began to develop dyslexic letter reversals when writing. Even my handwriting deteriorated to the point where I had to provide my bank with a new exemplar to access my account. It became difficult to find the words I wanted in conversation and while lecturing and stress began to mount as I found myself searching for words in my very public position. Normally neat and groomed before my classes, I took extra shirts to work as I would drench 5-6 daily with heavy sweats. It became hard to regulate my temperature and my feet and hands would frequently be cold to the touch while my torso was feverish. For much of this time, I ran subnormal temperatures while dripping with perspiration.

When the soft-money for the position ran out, I returned home to continue my consulting business and received another year's treatment of oral antibiotics from my primary care provider. While the symptoms would occasionally improve for short periods, they always returned and I never quite regained my previous levels of good health. Thus began a steady decline which continues.

In time, I developed severe thyroid difficulties -- Graves disease, Hashimoto's thyroiditis and a toxic multinodular goiter. I responded poorly to steroid treatment and three treatments with large doses of radioactive iodine failed to address the thyroid difficulties. I developed several hundred unusual —>

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benign lipomas throughout my lower back and thighs, and found my energy dwindling to the point where I was frequently bed-bound and unable to do more than the simplest tasks. Neurological anomalies persisted.

I went from being an active, healthy, vibrant adult to one who could barely function. I went from living independently to living with my elderly parents as I found I was not well enough to consistently hold any job outside my home. In time, even my consulting business went by the board as I struggled with the constant, debilitating fatigue and pain of my symptoms. Previously, I had bicycled 8,000 - 12,000 miles annually. Now, I could barely get to the mailbox on my worst days. I went from riding 100 miles 3-4 times weekly to napping after a car drive to the grocery store.

And yet, the intermittent, remitting nature of my symptoms led to misunderstandings and disbelief as days of bed-rest were followed by 30-mile bicycle rides and "good" weeks, only to crash once again as I struggled to be "normal". It caused a sense of shame and diminished self-esteem. Friends doubted and abandoned me. Colleagues lost patience. Family stayed by me and supported me, and for that I will always be grateful.

As difficult as it has been to bear and struggle with the symptoms of these tick-borne diseases, it has been as bad or worse to deal with a medical profession that is mired in denial and dismissal. With the exception of the initial treating physician and my own primary care physician -- who was forced to leave her practice for making outside referrals -- I have been belittled, denigrated and suffered outright abuse by medical practitioners who accused me of malingering, hypochondria, and abuse of the medical profession. I was "fired" by my most recent internist for seeking outside referrals and repeatedly prescribed antidepressants with no clinical history of depression, a condition widely regarded as responsible for my constellation of symptoms.

In the past five years, I have seen more than 25 physicians seeking to alleviate my ills. Despite asking, begging and demanding to be tested to determine the possibility of continued tick-borne infections, I was universally refused. I was told I was depressed, diagnosed with lupus, rheumatoid arthritis, fibromyalgia, fibrocytis, a sleep disorder, that I needed surgeries. I have been yelled at, screamed at, sworn at and cursed by doctors who have ordered me to leave their offices after asking them to perform a simple blood test. I was told I could never have contracted Lyme or other tick-borne diseases because "We don't have them here," "Because you haven't been anywhere they are," "Because they are so rare," and -- despite previous medical documentation -- "Because you only *think* you were bitten by a tick and probably never were."

And now, after recent testing has shown I am positive for babesiosis and ehrlichiosis infections, I now must turn my efforts toward finding a physician out-of-state who is willing to treat me for these documented, detected illnesses and test for the presence of any remaining Lyme disease. Even the physician who finally administered these tests has asked me to seek treatment elsewhere.

As an individual I regret the pain, the loss in life-quality. I regret the time lost, the damage to my career and the cost to myself. As a respected policy analyst and researcher I regret the cost to the insurance company and society as many dead-ends were explored because of a refusal to consider Occam's razor and the most likely possibilities through the simplest and most cost-effective means -- timely blood-testing through proven and repeatable methods correlated with clinical presentation. And I regret my loss of faith and trust in a medical profession that has refused to acknowledge and treat a growing health threat, dooming countless others to a fate such as mine or worse. I can't see the situation getting better soon; the tick is an efficient vector for disease transmission and the incidence of infection is already widespread. How long will denial continue? What would you do if -- when -- you, a friend, a lover, spouse or child contract a painful, debilitating tick-borne disease? How high will the costs mount? How many more will suffer needlessly?

I am real. This is my story. Will it be yours?

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

State: New Jersey
County: Sussex

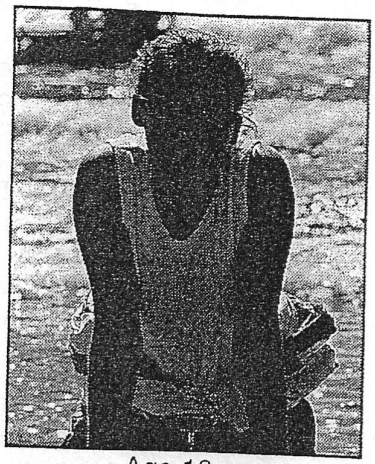
Name: Kristen [redacted]

Total cost: $350+

Number of family members with LD: 1

Lost work/school: 2 days

Number of years sick: 21 Months



Age 16

In August of 1992 our family moved from the Bay Area of Northern California to an acre and a quarter of wooded property in Northern New Jersey. During the next five years the only time I heard about deer ticks was when I'd take our dog to the vet.

In the Fall of 1994 daughter Kristen was selected by John's Hopkins University to take the SAT test. At age 12 she did quite well in school, played the piano, and was an accomplished Hobie Cat sailor racing as crew on Hobie 16's on nearby Lake Hopatcong. Two years later her grades fell below average during her freshman year, it took weeks instead of days to learn piano lessons, week after week she needed extra help with Algebra, and her back and knees hurt almost too much to race.

In July of 1996 Kristen found a swollen dead tick in her hair. Immediately I contacted the doctors office and described in detail the tick. Thinking I was speaking to a nurse, I believed the "receptionist" when she assured me it was only a "wood tick". During the following ten month period each symtom Kristen displayed was treated separtely by six different doctors.

It wasn't until May 1997 that Dr. A. Tiger, an orthopedist, saw her swollen knee and put the pieces together to spell "lyme disease". Her lab results all came back positive and showed an exposure of over three months with a diagnosis of late stage lyme disease. The MRI showed a torn cartilage in the left knee also swollen as a result of the lyme arthritis.

Kristen is being treated for post lyme depression with the drug Pamelor. Arthroscopic surgery was done 2/26/98 to repair torn cartilage. If the pain returns, we'll assume it's lyme arthrit

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On July 11, '96 Kristen came home from the lake complaining of a terrible headache. While showering she found a dead swollen tick in her hair line on the back of her neck. I was assured by the doctors office it was only a "wood tick"; nothing to worry about despite the headaches that continued for three days. Flu symtoms came and went without too much concern. Twelve days after the bite Kristen saw the doctor for a stiff and painful neck. That gradually went away but by August Bell's palsey set in affecting her left eye and smile. We thought it was a slight twitch and after three weeks it too disappeared. Come September field hockey practice seemed to be causing extreme low back pain so Dr. Lasser, orthopedist, excused her from gym as well as sports for a month.

A new symtom appeared in October. She could barely eat or open her mouth the pain was so intense. Our dentist Dr. Bush prescribed lorazepam, a muscle relaxent for TMJ.

Kristen sought extra help each week for Algebra but continued to be in a fog doing poorly. Her piano teacher decribed her as lethargic. During week days she found it difficult to fall asleep before one in the morning. On weekends she would sleep for 12-14 hours straight. During the winter of '97 she experienced four nosebleeds and several episodes of a sore throat.

April 6, '97 our daughter woke up at a friends with extreme pain in her left knee. Three days later the pain subsided but appeared quite swollen. We decided it was time to see orthopedist, Dr. Tiger, but not til after she returned from a school trip to Germany. By May 14th the swelling was nearly gone so we thought about cancelling the appointment. Thank goodness we kept the appointment. Dr. Tiger immediately suspected lyme disease so ordered lab tests as well as an MRI. The MRI showed a torn cartilage. The lab report showed 12 bands of positive KDA (lyme exposure). Two negative bands meant exposure was at least three months prior and that she was in the late stage of the disease.

Within hours I had Kristen in the office of Dr. McManus, infectious disease specialist. He prescribed amoxicillan 500mg three times a day for nine weeks. To prevent yeast infections she also took acidouphilus capsules.

Within ten days I read five books, dozens of pamphets, and called every number where I thought I might get answers or information on lyme disease. The guilt I felt as a mother was unbearable. I gained weight, cried, and worried. As a result I now have high cholesterol and high blood pressure.

Most of Kristen's symtoms subsided except for mild depression. Pamelor was prescribed in September '97. By February '98 surgery was performed to eliminate the returning pain in her left knee. So now we wait and wonder if the lyme disease is really gone and she can finally run free of pain.

So often we ask "why me". In August '97 we got an answer. Kristen convinced a 15 year old friend after worrying for weeks about tick bites that she should see a doctor. The girl displayed many symtoms of lyme including heart irregularities. She didnot, however, test positive for lyme disease. She did have a congenitive heart defect requiring a pacemaker immediately.

Please share the knowledge of lyme symtoms so we can eliminate delayed diagnosis and even save lives.

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

State: Maryland
County: Prince George

Name: Roberta [redacted]

Total cost:

Number of family members with LD: 4

Lost work/school: 2 years

Number of years sick: 3 1/2



PRIOR IQ LYME

EDUCATION

B.S. degree in General Biology, Spring 1996,
University of Maryland at College Park, MD

WORK EXPERIENCE

Student Research Fellowship June-August 1994
National Cancer Institute, Bethesda MD
Division of Cancer Treatment
* Established an assay used to screen patients with colon cancer
* Prepared vertical gels, cultured cell lines
* Examined tumor tissues, extracted DNA, PCR assays

Biological Science Aide June 1993-May 1994
United States Dept. of Agriculture, Beltsville, MD
Nutrient and Metabolism Interactions Laboratory
* Assisted with diabetic retinopathy research
* Prepared and distributed animal diets
* Sacrificed and dissected animals for analysis
* Collected blood samples for nutrient analysis

Research Assistant May 1990-August 1990
United States Dept. of Agriculture, Beltsville, MD
Entomology Laboratory
* Investigated gypsy moth pheromones and behavior
* Built, distributed, and gathered gypsy moth traps
* Collected burlap straps, moths and assessed trees for damage

Hospital Volunteer September-December 1994
American Red Cross, National Naval Medical Center
Bethesda, MD Pediatric Ward

National Service Fraternity September 1993-May 1994
Alpha Phi Omega, Epsilon Mu Chapter
University of Maryland at College Park, MD

Hospital Volunteer Sept. 1992-April 1993
Holy Cross Hospital, Kensington MD Medical Stroke Ward

Physical Therapy Aide April 1991-May 1991
Rehabilitation Associates of Maryland, Greenbelt MD

HONORS AND AWARDS

Golden Key Honor Society 1993
Phi Sigma Society, Beta Zeta Chapter 1993
National Agricultural Res. Scholarship 1991, 1993

ACTIVITIES

Pre-Med Society 1992-1994
Team Captain, Intramural Womens Basketball 1992-1994
Division I Basketball, Loyola College, 1991-1992
Lived in Europe, Summer, 1992
Traveled in Europe, 3 weeks, 1993
Marine Corp Marathon, 1993

CURRENTLY

Osarta is presently hospitalized, extremely underweight, not functioning anywhere near her prior abilities, and her total health is at risk. Undiagnosed Lyme disease with neurologic complications.

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

State: Maryland
County: Prince George

Name: Joseph [redacted]

Total cost:

Number of family members with LD: 4

Lost work/school: 3 1/2 years

Number of years sick: 3 1/2



Joe's story is not unlike many Lyme patients. In 1989 he had the flu, fever, rash, etc. and the doctors said it "was a viral infection and nothing can be done to treat viruses. In the course of 2 weeks the rash will disappear and the fever will lessen." And it did.

For 5 years the Lyme bacteria spread throughout Joe's body until it hit the brain. He began to have neurologic involvement - paralysis, dizziness, etc. and was hospitalized for 5 weeks at which point the doctors could not "label" what was wrong. We demanded a Lyme test and it was confirmed.

3 1/2 years later Joe receives IV antibiotics. He was entering his senior year of high school when he was hospitalized. He has not returned to school.

Our BCBS insurance has refused to pay for treatment since april 1997 saying it is "not medically necessary", even though the doctors say that it is! When we inquired how the insurance arrived at "not medically necessary" we are not able to find out. They won't pay for the treatment (practicing medicine) and are not accountable to anyone (patient) yet we must continue paying the premiums (approx. $600 month for our family).

Lyme patients are treated as "less than human" by doctors, insurance personell, and the public in general because of ignorance, lack of education, and the almighty dollar.

We will NEVER GIVE UP until, God willing, Joe is rid of this debilitating disease.