

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Morris

Name: Carol



Total cost: \$26,000

Number of family members with LD: 3

Lost work/school: 1/2 time

Number of years sick: 5



In 1992 I had been diagnosed with Lyme disease from a huge ring and flu-like symptoms. I also had trouble coordinating my eyes, dizziness, headaches and fatigue. I had two weeks of amoxicillin with no improvement and four weeks of doxycycline but my eyes still were very painful and I couldn't keep them coordinated. I had night sweats and pains in my jaw and ears and neck. After 28 days of IV rocephin I was sent to Dr. Alan Steere in Boston. He verified the Lyme disease diagnosis, even though my test was negative. But he didn't give me more medication of any kind. I struggled for four years, in and out of episodes of fibromyalgia and rib pains sleeplessness and depression and concentration problems and headaches, becoming better at times and worse others. My hearing was affected, including now a ringing in one ear and all the while I was told by Steere these were left over symptoms.

Last year in July, 1996, while in Switzerland I had a sudden attack. The room spun. I couldn't walk, as if I were drunk...yet the hospital titer test again was negative. Back home my doctor had me get an M.R.I. The M.R.I physician saw white spots which he incorrectly diagnosed as mastoiditis. After a month of oral augmentin I suddenly nearly collapsed with heart skips, breathing problems, pains, stumbling, dizziness, stomach problems, sweats and electric shock, near fainting spells, rib pains and fibromyalgia...emergency room visits because I couldn't breathe properly and once my heart seemed to skip uncontrollably. All my earlier Lyme symptoms had come back doubly severe, including light phobia and sound phobia. And all other diseases I was tested for came up negative, not just once but several times.

My doctor put me back on IV immediately because by then I could not walk alone, had to be helped by my husband, could not drive or walk without stumbling. But in tens weeks of IV I was dramatically improved. I could walk better, drive, sleep better, heart stopping skipping, stomach aches diminished, and I could pursue my career as a writer.

It is obvious that IV helped...taking me from a totally incapacitated state, practically bedridden, to functioning, including at last almost getting rid of my fibromyalgia.

P.S. I'm still on oral antibiotic to maintain me

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Michigan

County: St. Clair

Name: Tonya 

Total cost: \$16,000

Number of family members with LD: 1

Lost work/school: work-8 months

Number of years sick: 8 months



HELLO, MY NAME IS TONYA  AND I AM A RESIDENT OF ST. CLAIR COUNTY.

IN SEPTEMBER OF 1994, I BECAME VERY ILL, FEELING VERY TIRED, VERY WEAK, EXPERIENCING ABDOMINAL, CHEST, NECK AND LOWER BACK PAIN, SEVERE HEADACHES, SWOLLEN KNEES AND ELBOWS. I ALSO NOTICES A FOREIGN RASH ON THE INSIDE OF MY LEFT CALF RESEMBLING THAT OF A BULLS-EYE. UNABLE TO WORK, I PROCEEDED TO DO EXTENSIVE RESEARCH ON MY OWN AND WAS CONVINCED I HAD LYME DISEASE. THE ONLY OBSTACLE LEFT WAS TO BE DIAGNOSED WITH THE DISEASE AND GET TREATMENT AS SOON AS POSSIBLE.

HAVING LYME DISEASE IS "HELL" IN ITSELF, BUT WORSE, IS THE EMPTY FEELING DOCTOR'S LEAVE YOU WHEN THEY DO NOT LISTEN TO WHAT YOU ARE TELLING THEM. OVER MY SEVEN MONTH JOURNEY, I WAS FALSELY DIAGNOSED WITH RINGWORM, SHINGLES AND A MINOR WEED RASH RESULTING IN THE "BULLS-EYE" RASH ON MY LEG. THE DOCTORS RAN SEVERAL HUNDRED TESTS, X-RAYS, BLOOD WORK, RADIATION INJECTIONS AND EKG'S ON ME TO FIND AN ANSWER. WHEN THE RESULTS WOULD COME BACK NEGATIVE THE DOCTORS EASILY GAVE UP. NOTHING WAS WRONG WITH ME. I WAS TOLD TO TAKE FOUR DIFFERENT MEDICATIONS AT ONE TIME TO EASE MY PAIN. I FELT LIKE A TINY MOUSE IN A CAGED WORLD ONLY WAITING TO BE INJECTED ONE MORE TIME WITH AN EXPERIMENTAL CURE.

AFTER SIX SPECIALISTS, FOUR OF WHICH ARE TRAINED IN INFECTIOUS DISEASE, A MEDICAL STUDENT AT THE UNIVERSITY OF MICHIGAN MEDICAL CENTER LISTENED TO WHAT I HAD TO SAY FOR OVER ONE AND A HALF HOURS. HE RAN THE CORRECT TESTS AND PUT FORTH THAT EXTRA EFFORT TO DIAGNOSE ME POSITIVEFOR LYME DISEASE. THAT DIAGNOSIS WAS MADE SIX MONTHS AFTER MY SYMPTOMS FIRST OCCURRED. AFTER THREE AND ONE HALF WEEKS OF HIGH VOLUME ANTIBIOTICS, I AM NOW ABLE TO MAINTAIN THE LIFE I ONCE LEAD, ONLY NOW I LEAD IT IN A SMARTER, MORE EDUCATED WAY.

I DO BELIEVE OUR DOCTORS IN THE MEDICAL FIELD ARE UNAWARE OF THE DISEASE BORNE BY TICKS. DOCTORS TODAY ARE TREATING THE SYMPTOMS OF LYME DISEASE AND NOT THE DISEASE ITSELF. THE WORLD IS CHANGING AND THE DISEASES OF TODAY ARE GREATER IN NUMBER. SOCIETY MUST REALIZE THAT FATAL DISEASES ARE SPREAD BY INSECTS THAT ARE NO LARGER THAN THE HEAD OF A PIN. MORE RESEARCH MUST BE CONSIDERED ESPECIALLY IN AREAS OF INCREASED WILDLIFE ACTIVITY. REJECTION BY DOCTORS AND HEALTH DEPARTMENT OFFICIALS ARE ONLY HURTING THE CHANCES OF IDENTIFYING A CURE FOR LYME DISEASE.

THANK YOU FOR YOUR TIME AND CONCERNS ABOUT LYME DISEASE. MAYBE BY BEING HERE WE CAN ALL LEARN SOMETHING FROM EACH OTHER.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Kansas
County: Johnson

Name: Carol 

Total cost: \$30,000/year

Number of family members with LD: 1

Lost work/school: 4 yrs.

Number of years sick: 16



Honorable Members of Congress:

For every face you see in this record, there are many more Lyme patients who are too sick and/or too disconnected to be a part of this record. Please listen to patients! We are sick, but that doesn't mean we are wrong! We are sick and that means we need your support and understanding more!

1. PLEASE ENCOURAGE DOCTORS TO RECOGNIZE AND TREAT LYME.
2. PLEASE GET INSURANCE COMPANIES TO COVER DOCTOR-PRESCRIBED LYME TREATMENTS.
3. PLEASE GET RESEARCH TO FIND A CURE FOR CHRONIC LYME.

I grew up on a farm in **north central Kansas** and graduated from the University of Kansas. I moved east with my husband and we lived in **New Jersey** for sixteen years and had two children. In Denville, our backyard opened up onto many square miles of woods. I may have contracted Lyme there in 1981, but not surprisingly for 1981, Lyme was not diagnosed. We moved back to Kansas in 1988 and in 1992, my family accompanied my husband on a two-year work assignment in **Europe**. There, in 1993, I went to the doctor with the characteristic EM rash and was diagnosed with **Borreliosis**, or Lyme disease. Several positive blood tests and many hellish avenues of neurological/muscular problems later, here I am with full-time Lyme, hoping for a **cure** and trying, meanwhile, to convince my insurance company to cover my doctor's prescribed treatment. I am fortunate that with help, I've been able to find doctors (in Europe and in the US), who recognize the seriousness of this infection. It is unfortunate that my health insurance provider (Metropolitan Life/UNITEDhealthcare) has (early 1995 to date) decided to stop coverage for my doctor's prescribed IV treatment of Lyme disease. I need this treatment; it helped me regain some losses from '93-'95. Before 1993, I energetically cared for my family and dependably served my community. I was also a teacher, grades 8-12, working ten-hour days, gratefully and enthusiastically impacting the lives of students.

I believe the motivations behind those who will tell you Lyme is generally "easy" (easily avoided, easily diagnosed, easily treated, etc.) are at best dishonest, deceptive, and dangerous. How these opinions can be taken seriously, is easily another difficulty in this very difficult illness. And please consider:

- Who profits when insured Americans are denied doctor-prescribed treatments?
- Who looks good when the disease is given premature limits and Lyme numbers are misleadingly low?
- Who profits when doctors are discouraged from recognizing and treating Lyme?
- Who loses when Lyme patients become disabled?

- 1. PLEASE ENCOURAGE DOCTORS TO RECOGNIZE AND TREAT LYME.**
- 2. PLEASE GET INSURANCE COMPANIES TO COVER DOCTOR-PRESCRIBED LYME TREATMENTS.**
- 3. PLEASE GET RESEARCH TO FIND A CURE FOR CHRONIC LYME.**

Thank you, Members of Congress, for your attention to this increasingly difficult problem.

Thank you, Lyme Disease Foundation, for making this means of communication available.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Pennsylvania

County: Chester

Name: Tamara



Total cost:

Number of family members with LD:

Lost work/school:

Number of years sick: 2



When I was diagnosis with lyme disease, that was the time my life started falling apart, the disease it self it steals your life, mind, body, every inch and part of your body, I've been suffering for 2 year now, and already I'm destroyed, it a living hell: I'm thirty five year old and feel like I'm 80 yr. old, pain is all way there, medication doesn't help, ~~I have~~ a needle in my arm and give my self my medication twice a day. Some part of the day I start to feel better, and then I get sick all over again, my family has been effected by this all so, I suffer from memory lose, anxiety, confusion, total lose of control it hard to write down and to explain what I'm going through, unless you have gone through it your self. I have five children three I've them under the age of 9, 7, 4, older one's 14, 16, life is hard not being able to do normal things with them. my husband has been my strong part of me, it hurts to think how much the disease is hurting people you love, I've gotten in touch with Jesus he's the only thing that keeps me going, I pray and pray that Jesus finds a cure for everyone who suffers with lymes, I right to go on I love life and my world seem doomed, but I won't let this disease win I will never give into it, God Bless & all of us who suffer with this disease

the first year of my illness I was sent to a doctor and he told my family doctor nothing is wrong with me, and he gave me some pill to take, I refused to take them the doctor thinks I'm crazy, ^{now} I am 2 years, And gotten sicker I am not crazy I'm just a victim of lyme DISEASE. I pray that all our crys to congress and the world are heard. we need help and so do our family's. I will never give up fighting. I won't let it win. to all the victim of lyme DISEASE keep the faith and don't give up try to live a life as best as you can my prayers go out to all. (God Hear's all our prayer)

there so much more to tell what this disease has done to my life and family but the paper can't hold it all and it goes on and on.

These are all my symptoms These are problem

Bell palsey

Dizziness

STIFF Neck

memory problems

anxiety

Joint pain

crying spells

lost in my own world

sever adaman pain

numbness

blured vision

can't walk or get out of bed sometime

Frustrated

intestell problems

trouble eating

I have all the

sinus infections

all the time

forget things I

read

always tired

Fatigue

Scared feeling

trouble sleeping

and coping

and gone through, small bowel ex rate, baren enema, blood work, mRI's - ultra sounds, many test of the rectum (I've had a histocytism) colons test, (I've had a cervical) HAD CANCER OF THE ~~RECTUM~~

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey
County: Camden

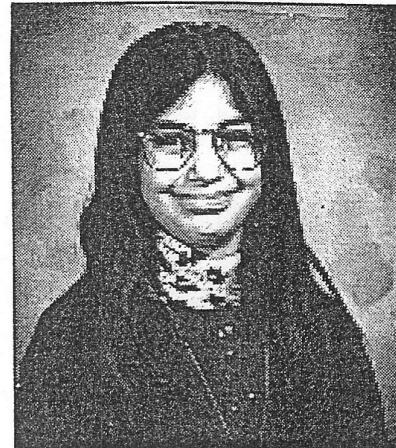
Name: Christina 

Total cost: thousands

Number of family members with LD: 3

Lost work/school: 20 weeks

Number of years sick: 4



Christina has been sick for four years. She has had one month of antibiotic therapy. She has frequent headaches, joint pain, muscle spasms, periods of confusion, ^{short pain} short-term memory loss, vision problems, to name a few of the symptoms she has. She has had many vials of blood taken and too many exposures to x-ray which show signs of her disease to have not been reported to the CDC as a case of Lyme. She has seen three rheumatology specialists and they all agree that she has chronic pain, however, they label her as having POST-Lyme syndrome. If it were post-lyme, why is she showing signs of a late stage Lyme victim? Getting a physician to admit to one of their patients is a true Lyme case is like pulling teeth (without novacaine). I believe they are scared of two things, retribution from the 'big brother' insurance companies and their own lack of

Knowledge of the disease.

Christina is an honor student at her school. When her symptoms are too much for her to bear, she must stay at home, take pain killers and she seldom eats. Luckily for her, our local school district understands her disability and she is protected by the Federal 504 law. Now, if her educators understand (and have researched this issue), why can't the people who are supposed to protect my child do the same? Will she have to become a complete cripple and be sentenced to a nursing home at the tender age of 10? There is an answer out there. She needs help from you desperately. If she had cancer you'd help. If she had MS or MD you'd help. She doesn't. She has Lyme - you should help. Make the medical community wake up, and research for a cure can't be too far away. Change the reporting criteria so the accurate figures will be known to all.

Christina is in pain. She is suffering yet through it all she tells me that she trusts adults to make her better. Don't make me lie to her and tell her you will, when you haven't.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey
County: Camden

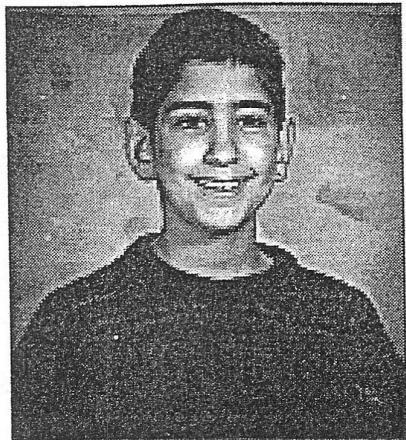
Name: James Gregory 

Total cost: thousands

Number of family members with LD: 3

Lost work/school: 6 weeks

Number of years sick: 2



James Gregory cut the grass at his grandmother's house on a Saturday. By Sunday night he had the tell-tale Lyme bulls-eye on his left shoulder. Was he given IV antibiotic therapy? No. He received oral antibiotic therapy. He suffers from extremely painful headaches, ^{chest pain} joint pain, short-term memory loss. He is twelve years old and in seventh grade. He takes acetomenefen with codeine when the pain is extreme and loses days at school. He awakens in the middle of the night screaming in pain because his muscles hurt so bad. He's tired of the doctor telling him he doesn't have Lyme anymore because he took antibiotics when he first was bitten. He asks, if this is true and I don't have Lyme, why do I suffer like this? He was a Boy Scout for 4 years and gave it up because he felt being a boy scout means going into the woods.

and camping, cleaning up or going on a nature walk, and he's had enough of those nasty germ-carrying ticks to last a life-time. He doesn't want to be exposed to them anymore. He was a BOY SCOUT! He gave it up because of a tiny insect which destroyed the normalcy of his life. He is scared every day because he never knows when the pain will hit him. He is scared at school because when he's told something, he doesn't always remember what he's been told and he fears getting into trouble. He has trouble studying for tests because he doesn't retain everything he's learned. My son wants to join the Army when he graduates from high school. He wants to protect the freedom of the American people. Greg needs protection now so he'll be able to fulfill his dream. Please help him now so he can help us in the future.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Wisconsin

County: Jefferson

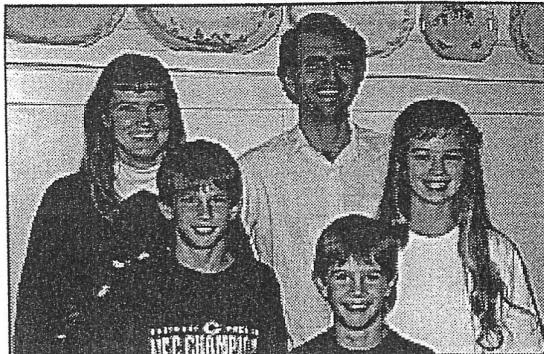
Name: Esther 

Total cost: \$146.00

Number of family members with LD: 4

Lost work/school:

Number of years sick: 2



My name is Esther , a wife, and mother of three young children. My story begins with two known tick bites from big ticks during a vacation to the family cabin close to Park Rapids, Minnesota in August of 1995. I thought it would be pretty safe there, since my mother-in-law has been going up there for more than 50 years. However, when we got there, we ended up moving trees that had blown down on the trail after a recent storm. It wasn't until March 1996, when I was 31 years old, that I had any problems.

My story starts with a very strange illness from 3/5/96-3/22/96. The symptoms included...arm sensitive to touch, headache, achey to painful legs when walk on them too long, stuffy nose, sore neck glands on sides of neck, chills, achey arms, loss of appetite, sore throat, painful elbows at bed time, mucous in nose and throat, big toes felt like they swelled up, red rash on front side of legs above knees (not itchy or sore), tonsils swollen, mild chest pain, dry throat, knee cap hurt mildly when I walked and seemed like it moved, runny nose, and fevers off and on for three days that ranged from 101*-105* (as I read on the forehead thermometer).

After this strange illness, I had a cold with a stuffy and runny nose all week from 3/25/96-3/30/96. Starting 4/2/96, and almost every day after in April and early May 1996, were more symptoms, such as...throbbing pain in ear, red raised pimples on hand, knee cap felt loose, wrists and arm pain, jaw, ankle, finger, and leg pain, itchy legs, itchy knuckle on hand, sleepy hands, lower back pain, tender breasts, sore chest, and stomachaches.

My pains have been really mild from the start, and even today. However, they are noticeable enough. I had an Elisa Lyme test on 5/9/96 and the result was "negative". No antibiotic was given. Since 1996, the only time I notice any aches is pretty much during March and April. The flare-ups consist of sleepy arms, headaches, indigestion, and stuffy nose. My nose doesn't seem to smell very well anymore, unless I get really close to something.

Since May 1997, I have joined a Fibromyalgia Support Group, started working outside the house, help others who may have Lyme Disease, and am looking forward about life. I will be putting these stories about my family in my village library so that they may help others. I have also kept a daily diary on all of us so that other people could look at a daily record of symptoms and what triggered them. That was what I was looking for in helping to diagnose my youngest son's illness. This week I will be educating the school about Lyme Disease, by speaking in front of the 4th, 5th, and 6th grades. My children are in those grades in the elementary school. I also will be attaching a copy of these stories to the brochure called "Guide to Lyme Disease" and sending one to each family, and staff member in the elementary school. Since I work for Head Start and work with preschool children, I will be giving staff members the same brochure and stories. I'm also going to speak to the families about Lyme Disease and Fibromyalgia and the seriousness of these.

I have learned that you need to have a positive attitude when dealing with ill children. Our family has joined sports and other activities that have kept our minds and bodies preoccupied. We do a lot of movie watching and playing with pets. Most importantly, we talk about how we feel when we feel bad. My goal is to help other people. I'm always happy to share my experiences with other people.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Wisconsin

County: Jefferson

Name: Carolyn [REDACTED]

Total cost: \$272.50

Number of family members with LD: 4

Lost work/school:

Number of years sick: Almost 3



I'm Esther [REDACTED] mother of Carolyn [REDACTED], who is now 12 years old. Carolyn was 9 1/2 years old when she went on a Memorial Day weekend campout on 5/28/95- 5/29/95. My husband insisted on taking the kids on a campout even though our son, Brian, had a bad nine months previous to this weekend. I was on the verge of proving that Lyme Disease was truly the illness that Brian had. I felt really bad to let Carolyn and David, our other son who was 8 1/2 years old, go. The doctors wouldn't confirm a diagnosis for Brian at that time.

Carolyn, therefore, ended up going to Blue Mound State Park in Wisconsin for the weekend. Her story starts like this...On 6/22/95, she had a headache. On 6/24/95- saw a red pimple on her right leg on the panty line.

6/25/95- got headache towards evening when at Six Flags themepark in Illinois. She said she saw a pimple on her leg on her panty line.

6/27/95- I saw a warm, red, raised, oval rash where her pimple was on her leg. It wasn't itchy, but sore when her pants rub on it. It expanded during the day.

6/28/95- I drew a pen mark around the rash about 8:30p.m., and even took pictures of it. It was 1 inch wide by 2 3/4 inches long. I called Marshfield Clinic up and expressed my concern about Lyme Disease. They told me to put cortisone cream on the rash. I put Cortaid on it.

6/29/95- The rash had spread 1/4 inch wider overnight to 1 1/4 by 2 3/4 inches. It was only sore to the touch. I sprayed 2 % Benadryl Anti-Itch Spray on it about 7:45a.m.- to see if it would help with some pain if her underwear rubbed on it. I also put warm, wet compresses on the pimple to see if it was a boil or infected hair follicle, and then put anti-bacterial lotion on it. At 12p.m.-pimple is dark red now and rash is spreading up higher. It is now 2 inches wide by 3 inches long. At 8:20p.m.- the rash had spread more to 2 inches wide by 3 3/4 inches long. It still wasn't itchy. I didn't put anything on it for bedtime.

6/30/95- 7:40 a.m.- rash looks as if going away. It didn't spread last night. Rash not as red anymore, but pimple still red. Rash is still sore to the touch. 8:30 p.m.- itchy pimple- she is scratching it. Rash area looks a little redder again- not bigger though. Pimple isn't dark red anymore, but light colored. 10:20 p.m.- I put Cortaid on rash and covered it for bedtime.

7/1/95- The rash is gone, only pimple remains.

The pimple eventually disappears and the light, and short headaches start coming at the end of July 1995 and about 3-4 times every month in 1996.

The other symptoms that Carolyn has had so far, besides light to medium headaches, are...twisted ankles, knee pain, stomachaches, gushing nosebleed, arm pain when pushing or pulling, weak arm, foot pain, backaches, low grade fevers, sore throat, sleepy leg, loss of appetite, jaw pain, finger pain, shoulder pain, itching and swollen knuckle on finger, fatigue, leg pain below knees, and skin-tone bumps on arms that look like goosebumps. Her problems occurred only 3-4 times a month- a very mild case.

Her Elisa Lyme test taken on 5/9/96 had a result of 256. A Western Blot taken on 5/23/96 was "negative". No medicine was given. Carolyn was a healthy child who got sick only one or two times a year. Since she's turned 12 years old in January of 1998, she's had more frequent, and more severe flare-ups. Her body is starting to change now.

To this day, she's had no medicine. It was hard enough to convince the doctors that my son Brian had a real problem. I figured they would never take me seriously about my daughter. My will-power to fight was deteriorating.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Wisconsin
County: Jefferson

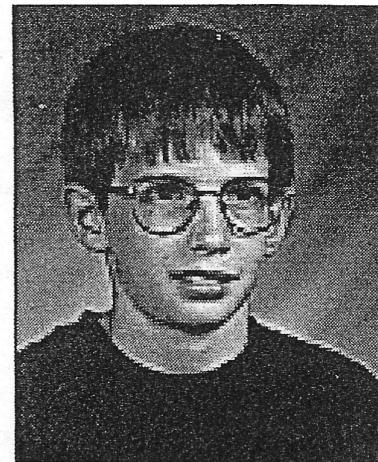
Name: David 

Total cost: \$1215.00

Number of family members with LD: 4

Lost work/school:

Number of years sick: 2 1/2



My name is Esther  mother of David . David was 7 1/2 years old when we went to a family cabin near Park Rapids, Minnesota in August of 1995. David had a known tick bite from a larger tick that you could see well. The only symptoms in September of 1995, that may be related to Lyme Disease, would be-headaches and 100*-101* fevers. He was pretty healthy until January 1996, when he got the flu. From 2/16/96-2/22/96, after a bad cough, he started with more symptoms that may have been related to Lyme Disease (but,I didn't realize it then). These symptoms included... stomachaches, headaches, stuffy nose, sniffling nose, and watery eyes. His pain was pretty strong.

He was healthy again up until 8/9/96, when his leg hurt above the knee. He had a hard time walking on it. He proceeded until 8/14/96 with headaches, stomachaches, sore throats, fevers of 100*-104*, and swollen tonsils. A strep test was taken- a "positive" result. Amoxicillin was given for 10 days. During late September 1996, he had a low-grade fever of 100*, a few headaches, and a sore and swollen throat.

He was again healthy until 12/29/96, when he really started in with true signs of an illness that made me worry. Up until now, the illnesses that David experienced didn't make me think that it was Lyme Disease. He was a healthy child who only got sick during the winter like most healthy people do. Now his symptoms consisted of 100*-101* fevers, headaches, stomachaches, sore throats, chills, swollen tonsils, and a burst capillary below one eye. They came for about four days that week and then stopped. The next week it started again. By 1/14/96, I was convinced that he had Lyme Disease, or Fibromyalgia, like his brother. On 1/14/96 a Lyme Elisa test was done, along with a Sed rate, CBC, and a Monospot. On 1/23/97 the results came back. The Lyme IgM was 1.65, the Sed rate was 8, and the Monospot was "negative". A Western Blot was done since the Lyme IgM was high. Since David's symptoms were getting to be daily and more constant, and he did have a "positive" Lyme test, I wanted the doctor to treat him as soon as possible. I saw what waiting did to my other son and didn't want to see it again. I knew the doctor wasn't going to give David medicine "just because I asked", so I wanted my husband to "bug" the doctor about it (atleast my husband believed me that there was a problem). Two weeks worth of Amoxicillin was all we got for David.

David's legs and arms started hurting and falling asleep during this time, so I was sure that we had to keep pursuing medicine. I put him on 500 mg. of chewable Vitamin C tablets, along with Multi-Vitamins Complete, while he had problems. When the Western Blot result came back on 2/11/97, it was "negative". The doctor felt that he didn't need to give David any more medicine. I walked out of the office very upset, David walked home with me while the rest of the family drove. I predicted that he wouldn't do anything. My husband then saw what I had gone through with our first son getting sick. I immediately called up Marshfield Clinic in Marshfield, Wisconsin and set up an appointment with the same doctor that treated our son, Brian. I got a prescription for four weeks of Amoxicillin right away on 2/12/97. During the course of the medicine, David got better, only to have three flare-ups in the winter from January 1998 up until now in April. The flare-ups may last one or so weeks in length and may consist of headaches, stomachaches, sore and swollen tonsils, and fevers up to 103*. I've learned that rest is the most important thing for him besides a healthy diet. David, now 11 years old, is on no medication, and is enjoying all sports. I'm happy to have him back again.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Wisconsin
County: Jefferson

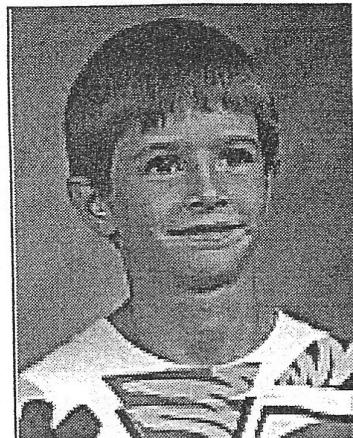
Name: Brian 

Total cost: \$9,794.00

Number of family members with LD: 4

Lost work/school:

Number of years sick: 3 1/2



My name is Esther , mother of Brian . Brian had gone on a camping trip for a few days in August 1994, with my husband and our two other children, to Governor Dodge State Park and Mirror Lake, both in Wisconsin. There was no known tick bite on any of the family. Brian had just turned six years old prior to the first symptoms that showed up in late October 1994. His story starts with a flu-like illness that got drastically strange and worse as the first month went by. He was given Amoxicillin for 10 days for a double ear infection. That helped the symptoms go away from December 1994 until the end of February 1995. Then the illness went wild.

From late February 1994-July 1995, Brian lived with the illness daily. His symptoms hit hard on his body. I was lucky to be a mother at home babysitting, or I would have never been able to work. I kept home from school a lot during the beginning of the illness, but sent him most of the time when he should have rested. My problem-I had no doctor telling me to keep him home. Since his story is very complicated, I'll list symptoms, doctors seen, and tests done up until now. We spent a lot of money out of our own pocket, and the insurance did eventually pay for some things.

Symptoms- headaches, migraines, sore throat, swollen tonsils, dry throat, eye pain, blurry vision, double vision, watery eyes, eyes sensitive to light, blood vessels in eye changed, stiff neck, swollen lymph nodes in neck, double ear infection, ringing in ears for four weeks, ear pain, nose pain, stuffy nose, runny nose, swollen adenoids, pain in cheek and chin when touched, jaw pain, rib soreness, stomachaches, digestive problems, nausea, diarrhea, backaches, swollen glands in groin area, dotted red rash on buttocks, finger pain, hives on fingers, sleepy and tingly legs, painful and weak legs, shooting pain in legs, chronic fatigue, intense itching all over body, bronchitis, chronic strep throat, seizure, difficulty sleeping, burst capillary on hand, moodiness.

Tests- allergy, sinus CAT scan, brain CAT scan, MRI on the brain, spinal tap, monospot, ear exam, comprehensive eye exam, Lyme Elisa, Western Blot, rheumatoid arthritis, and EEG.

Doctors- Pediatricians, General Practitioner, Neurologist, ENT, Ophthalmologist, and Rheumatologist.

It wasn't until 6/20/95, at the Marshfield Clinic in Marshfield, Wisconsin, that Brian got a diagnosis of having had Lyme Disease. He was treated with six weeks of Amoxicillin. During the weeks he got better to the point of running again and feeling healthy, like normal. After two weeks of feeling good while off the antibiotics, he had a febrile seizure. Due to a chronically sore and swollen throat, his tonsils and adenoids were taken out on 12/7/95. The symptoms came again for months until March 1996. .

OVER

I wanted a second opinion for Brian to see if he could have more medicine. I was steered toward a rheumatologist in Racine, Wisconsin. He diagnosed Brian as having Fibromyalgia, due to the Lyme Disease. Brian was healthy all summer and fall. The winter of 1996 brought a few flare-ups. The summer of 1997 was healthy, and this past winter of 1997 had two flare-ups, each lasting about a week or so long. The recent flare-ups consisted of headaches, stomachaches, and/or fevers, and/or leg pains. These symptoms may occur on their own, or with an illness, like strep throat or a cold.

I have never doubted Brian's complaints, nor I ever will. We've been through a lot together. My husband needed a diagnosis from a doctor before he believed that there was something wrong. This almost wrecked our marriage. The doctors needed a positive test and outward signs on the body before they would believe there was something wrong. My daughter, who was 9 years old at the time, couldn't understand why we couldn't buy things like we normally would. I tried explaining to her that there were doctor bills to pay. She didn't understand. My other son, who was 8 years old, was just great. He said that I could use the money from his bank to pay for doctor bills. (I didn't take him up on the offer, but I sure gave him a big hug.) Every time we went to a doctor, we hoped they could help us. One time Brian came to our car after a visit to a doctor and he said, "They didn't even give us any medicine." He said it in an upset way. Another time during a flare-up, when I was sick, he came and laid on my bed, and asked me, "Am I gonna die?" Brian was 7 years old when he asked this.

I am very thankful to the doctors, and people, that have been concerned and helpful, and to the school district in which we are involved. They have been very supportive.

All the doctors in Wisconsin should be aware of Lyme Disease, but they aren't. I hope that someday it will change.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Massachusetts
County: Norfolk

Name: Linda 

Total cost:

Number of family members with LD: 4

Lost work/school:

Number of years sick: 13



Linda



Grand-daughter (5) &
Daughter, Lisa (31)

I had Lyme Disease 10 yrs. before I was diagnosed by The Western Blot test. My Elisa was negative 6 mos. prior however The Elisa is 75% inaccurate but it is cheaper so insurance company's prefer that test.

I never felt well, always felt tired and had flu like symptoms. My profession was nurse anesthesia and this required physical stamina & mental alertness. I developed a Bell's palsy, nystagmus, irregular gait, dizziness, vertigo, neurological pain throughout my body, loss of memory, poor word finding, getting lost and extreme fatigue to name some of the symptoms.

I saw about 6 doctors before I was diagnosed with LD. It mimics so many other diseases and it is difficult to pull all this information together. I have had 26 operations some due to a poor immune system.

I have been on antibiotic treatment for 3 years, oral and intravenous. My veins were not very good so I had a port-a-cath inserted into my chest. The intravenous Rocephin gave me gall stones, and the intravenous Clafin caused my liver function tests to be abnormal.

I have been off antibiotics now for 4 mos. but my neurological symptoms & fatigue are all returning so it is time to resume antibiotic treatment.

My daughter Lisa (31) has LD for 5 years. She also needed IV Rx. She is doing poorly. Her husband Steve has LD & also my 5 yr. old grand daughter has LD. She has ADD/HD, anxiety disorder & obsessive compulsive disorder. It has been very hard on them all.

We run a self help group in Westwood, ma. Our group consists of about 10 people but we feel like a family offering support where we can in this devastating disease that robs your mind, energy leaving you with neurological damage, pain, fatigue & depression.

Please take us seriously & help us. & may God Bless You.

Linda



THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Middlesex

Name: Jay 

Total cost: Thousands

Number of family members with LD: 1

Lost work/school: Both

Number of years sick: 2 1/2



THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey
County: Morris

Name: Marion B. 

Total cost: \$2,000

Number of family members with LD: 2

Lost work/school: Unsure

Number of years sick: 38



1959 PAINFUL WRISTS FOR 3 mos. \rightarrow birth of a son.
1960 FACIAL PAIN (RT) EVERY 3 mos. DURING PREGNANCY
(*THIS DTG, DEVELOPED JOINT PAINS)
1961 PAIN BOTH FEET (SOLES) FELT LIKE I WAS
WALKING ON MY BONES.
1966. WT. LOSS, ANOREXIA, MYRATOXIC JOINT PAINS
SPONTANEOUS PURPURA, DEPRESSION, CRIED A LOT.
FEARS OF IMPENDING DEATH. \rightarrow 8th mo. OF PREGNANCY
AFTER DELIVERY 55 DIFFERENT DX'S WERE TRIED
 \rightarrow NO RESULTS. AFTER A HOSPITAL STAY ATENTATIVE
DX: SOME TYPE OF LUPUS. VASCULITIS ALSO VISIBLE
PROBLEMS. 1990 DOUBLEVISION, BLURRED VISION XMO. NO
CAUSE.
1968 - HUSBAND DIED SUDDENLY LEAVING ME & 5 YOUNG
CHILDREN AGES 1 1/2 - 11 yrs. HAD TO WORK TO
SUPPORT MY FAMILY. I HAD JOINT PAINS AND
NON-PAINFUL PURPURA, WHICH I STILL HAVE. TOOK
A LOT OF TYLENOL OVER THE yrs.
1970 - 1996 WORKED IN THE PENAL SYSTEM AS A NURSE
APRIL 27, 1996 ALL MEDICAL DEPTS. WERE PRIVATIZED
ON THIS DAY I WAS ASSIGNED DUTIES WHICH RE-
QUIRED ME TO DO 71500 STAIRS. I SUBSEQUENTLY
DEVELOPED SHIN SPLINTS IN BOTH LEGS. FELLOVER
MY C4 & 5/31/96. TEARS, PAIN, INSOMNIA, AND I CEST
TOWARD POOR APPETITE FOR 3 1/2 mos.
1990 - 1996 HAD NUMEROUS TICKS ON ME DRIVING
TO WORK IN A WOODED AREA. 1996 A HAND BITE IN URBAN
TOWN.
1993 - INJURED RT. KNEE PERMANENTLY FROM
FALL ON ICE.

10/96 SAU PA IN MANAGEMENT M.D. who
HELPED ME INITIALLY but NO TESTS
WERE DONE, I ASKED HIM IF I COULD
HAVE L.D. - HE DIDN'T think so.

4/97 DEVELOPED RT FLANK PAIN. RT. mid - ST HIGH MUSCLE
PAIN - NON-STOP UNTIL 6/97; SAU A L.D. LITERATE
M.D., but NOT BEFORE I SAW A UROLOGIST, A
ORTHOPEDIST, GYN. SINCE 6/97 I'VE HAD A
CHEST X-RAY, MAMMOGRAM, PELVIC AND ABDOMINAL
ULTRASOUND, EKG. AND STRESS TEST.

AMOXICILLIN 1,000MG TID P.O. 6/97 TO 10/11/97;
I WAS FEELING GOOD; STARTING WALKING UP
TO 14 MI. / DAY, AND HAD MORE ENERGY, GOOD APP-
ETITE, SLEEPING WELL. SINCE THE MED. WAS
STOPPED THE JOINT PAINS ARE COMING BACK;
HEADACHES, NECK PAIN; APPETITE SOMETIMES
SLEEP PROBLEMS. HAD (1) DAY WHEN I COULD
BARELY WALK.

OVER THE YRS. I'VE HAD STABBING MUSCLE PAINS
FOR NO REASON

SINCE 5/97 I'VE HAD 4 TICKS ON ME.
DO NOT REMEMBER A TICK BITE 1959 ETC.
BUT WAS IN MANY WOODED AREAS, AND WE HAD PETS.
I NEVER HAD THE RASH OR BULL'S EYE.

1993 PECULIAR RASH ON BOTH LEGS WHILE VISITING IN
NEW ORLEANS, LA. THOUGHT IT WAS FROM PLANTAIN -
LASTED 6 MOS.

4/97-6/97 - RT FLANK PAIN - SENS. FIVE TO HOT &
CLOTHING PLUS SENSITIVE SCALP. BOTH STOPPED
WITH AMOXICILLIN.

I DO NOT HAVE THE COST FOR 1959 TO 1996.

NOTE: I ENJOY GOING TO L.D.S.C. - HAVE HEARD
THAT A LOT OF PHARMACISTS NEED TO BE EDUCATED. I
GIVE EVERYONE I MEET A CRASH COURSE IN L.D.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Massachusetts

County: Bristol

Name: Jennifer

Total cost: \$50,000+

Number of family members with LD: 2

Lost work/school: 220 days/3years

Number of years sick: 5 1/2



Jennifer was a happy, healthy, intelligent five year old when our nightmare began in March of 1992. She developed a large (6 inch) circular, red hot swelling on her right calf after a vacation trip to Poughkeepsie, N.Y. When I called her physician's office for an appointment, the nurse told me the swelling was an "allergic reaction, give her Benadryl, put ice on it and don't worry about it."

Within a week, she developed flu like symptoms which were diagnosed as a sinus infection which then became Mycoplasmic Pneumonia. She started breaking out in extremely painful blisters which would disappear rapidly, leaving behind red dots where the blisters had appeared. The pediatrician diagnosed another "allergic reaction". I have since learned from Jen's present Lyme Disease specialist that this rash is a second degree Erythema Migrans rash.

Migraines, stomach pain, photophobia, joint pain and fevers up to 103.0° became a daily occurrence. She would stay in one spot all day long with tears streaming down her face. I would call her physician and he would tell me to "give her Tylenol and leave her alone". I have since learned that this situation signals a patient is in a critical state and should be cared for immediately. My daughter was ignored.

Her grades in school started to decline and her teacher started to report that Jennifer was daydreaming in class. It should be noted that she could do simple addition, subtraction and could do remedial reading before entering school. At home, she started to show signs of Petit Mal type seizures which were diagnosed as such by a pediatric neurologist in February of 1993. Her electroencephalogram was abnormal and her neurologist believed it was caused by an organic illness. He called in several of infectious disease specialists who diagnose Lyme Disease. They treated her at Rhode Island Hospital with Rocephin IV for eight days and had her evaluated

for neuropsychiatric illness. From the testing, they found she had developed attention deficit disorder, short term memory loss and a cognitive learning problem, all typical of Lyme Disease.

This was in February of 1993. Eleven months after the initial rash. During those months, she was sent to two well known hospitals in Boston and to multiple departments in those institutions. She had a battery of blood tests which were reported to us as "negative" for all disease. In reality her Lyme IgM was positive for the disease in August of 1992. When we found out that the doctors had lied to us, we confronted them and asked why they didn't treat her. Their answer was "We didn't have enough proof." A positive IgM and typical pediatric Lyme symptoms weren't enough proof.

Now 5 1/2 years later, Jennifer struggles with arthritis, migraines, narcolepsy, cataplexy, fevers, seizures and learning problems. (Narcolepsy has an element called sleep paralysis. Sleep paralysis allows the patient the ability to hear and feel touch but the body can not move. Jennifer lived with the fear that someday she won't be able to come out of an attack, although the physicians tell her she'll always come out of it. Sleep paralysis is a temporary state but when you're locked inside that state, it is a terrifying experience). Jennifer goes to school in a wheelchair when she is able and continues to struggle with her learning problems.

It has to be noted that this illness affects the whole family. Financially, we barely make ends meet although my husband works three jobs with an income nearing the \$50,000. mark.

Jennifer's life has been ruined by information that doctors are taught by a certain specialist in Boston. Information from bias, flawed research. When confronted with true symptoms, these physicians become defensive and attack you with the mantra "Dr. _____ is the expert and you don't know what you're talking about." This "expert" should be investigated to find out where he is getting his grants. Could it be from the health insurance industry who profits from his research? What price does this misinformation cost? The cost are human lives!

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Monmouth

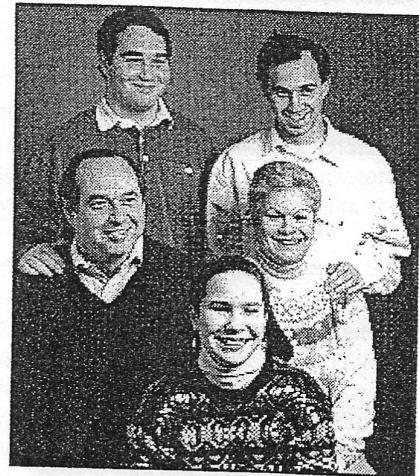
Name: Noelle

Total cost: \$70,000

Number of family members with LD: 1

Lost work/school: 1 1/2

Number of years sick: 4



J. D. Bleiweiss, M.D.
1245 Whitehorse-Mercerville Rd.
Suite 408
Trenton, New Jersey 08619

Dear Dr. Bleiweiss,

As you know, when we brought Noelle to you last fall, she was essentially incapacitated from the problems related to Lyme disease. The three months of treatment she had previously received from our local "Lyme expert" had failed to stem the progress of the disease, even despite the "magic" 28 days of IV antibiotics. While her previous doctor overlooked her actual condition and declared her "cured," you carefully assessed her condition and then attacked her illness. While she underwent a long and tumultuous period of progress and backsliding, your treatment has ultimately given her back her life, and she is now, essentially, symptom free.

Needless to say, we were shocked and saddened to learn, today, that you have decided to close your practice. We appreciate that this certainly had to be a most difficult decision for you. While Noelle's progress has been truly gratifying, there is always that fear in our hearts that she may again need the kind of concern and aggressive, individualized treatment you have given your Lyme patients. We feel we may never find doctor who can replace your unselfish devotion to your patients' total health, nor your relentless efforts to better understand Lyme disease and its treatments. You can certainly be proud of your record for helping your patients, many of whom other doctors had considered hopeless and abandoned. Should you decide to reopen your practice in the future, please be sure to consider Noelle your patient.

On a more personal note, if there is a way that Gayle and I can help or support you, either now or in the future, please ask. We join your other patients who feel that we owe you so much that we could never repay you. God bless you for being there when Noelle needed you most. We all wish you best of health and luck as you proceed.

Please refer to the "postscript" on the other side of this page.

Thomas R. Hull

Postscript:

Two days after the letter on the other side was written, Dr. John Bleiweiss was dead. Although he was "officially" considered a suicide victim, his death was actually the result of the Lyme controversy. He was persecuted as a doctor who healed his patients rather than follow the ineffective treatment regimens dictated by the insurance companies and their high profile doctors.

Dr. Bleiweiss, a Lyme victim himself, had dedicated his life to helping his Lyme patients. He had helped more than 1200 of the most seriously ill Lyme victims return to useful and productive lives by carefully customizing antibiotic treatments for each and teaching them how to strengthen their immune systems by taking vitamins, eating properly and taking care of themselves. He had patients that routinely came from as far away as Florida and Europe. Many of these patients, including my daughter, believe he had saved their lives... Dr. Bleiweiss recognized that the medical dogma on Lyme treatment did not lead to a "cure" for most victims. His research in medical journals was relentless as he worked to define new treatment protocols that would help his tough cases.

Often he told my daughter, Noelle, that she was one of his "most difficult cases" ...she always seemed to react differently to the treatment than he expected. But, he never gave up on her, as the other doctors had done. Despite medical evidence that Noelle had Lyme disease for ten years, she was not diagnosed until age 15. Then, her first two doctors treated her for 4 months for "sinus infections" and 4 months for Lyme using oral and IV antibiotics (for 28 days). She was declared "cured" even though she was clearly worse after their treatments!!! But then Dr. Bleiweiss watched her closely as he treated her with a variety of oral antibiotics (the insurance company wouldn't pay for additional IV antibiotics). After five months, she finally began to improve. He was so pleased to see her disease go into remission and so proud as she went back to high school and did so well!!! I can still remember the elated look on his face as she reported reduced neurological and other symptoms at each subsequent visit...

We later learned that Dr. Bleiweiss had been under attack for over seven years. Trumped up charges that had been disproven time and again in the courts brought him to the verge of financial ruin. Then, on Saturday, August 12, 1995, the "Trenton Times" published an article: "State seeks license of Lyme disease doctor." The information leaked to the press, again made the same old charges and indicated that he would lose his license! He was closing his office, clearly in response to this renewed legal attack. But then, seeing the article early that day, he was pushed to commit suicide. Yes, it was technically the bullet that ended his life, but it was those who have turned to the political "dark side" of the Lyme controversy that really pulled the trigger, killing this gifted healer.

No one will ever know what contribution Dr. Bleiweiss could yet have made to the sufferers of Lyme and other diseases. Unfortunately, his genius died with him. Publication of his book was also blocked, somehow, so even that legacy is now gone forever. After the death of Dr. Bleiweiss, my daughter relapsed twice, but she still managed to make up 1-1/2 years of high school. We were so proud when she graduated, on schedule, and in the top 10% of her class. We know that "Dr. B" would have been proud of her, as well. She is now doing very well in college...continues to suffer from Lyme symptoms...and we still live in fear that a relapse might come at any time.

Since Dr. Bleiweiss' death, the Lyme epidemic has continued. The current official statistics are misleading, however, since many doctors no longer report their Lyme cases for fear of being attacked, as was Dr. Bleiweiss. Every day, we think of "Dr. B." He could have helped many other friends and family members who are now also Lyme victims. One friend recently died from Lyme diseases due to the arrogant ignorance of his doctor, who wouldn't treat him! Even after two years, remembering the death of "Dr. B" still brings tears to our eyes...after all, he was the doctor who saved our daughter's life...and when he needed us, we could not help save his life!!! When will the politics of Lyme disease END so this terrible disease will be the subject of the attack, rather than the doctors who treat Lyme aggressively?????

Thomas R. 

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Connecticut
County: Windham

Name: Andrea 

Total cost: \$30,000+

Number of family members with LD: 1

Lost work/school: years

Number of years sick: 7



In the summer of 1989, I can clearly recall not feeling well. I felt as if I had a "flu-like" illness. My muscles ached, my joints hurt and I experienced terrible tension / migraine headaches. Along with a sore throat and a notorious, large expanding red rash. What happened to me over the next 6 months was worse than I ever imagined. As time grew closer to the Thanksgiving/Christmas holidays, I became weaker and my symptomology grew more complicated. By Christmas I suffered episodes of memory loss + confusion + weight loss. By January 1990 I was forgetting my way to work, what my work hours were and I was convinced I had a brain tumor or Alzheimer's disease. Unfortunately, I had a very unsupportive employer who would not cooperate with my physician (St. of CT-D.C.F.). I was fired in mid-January (1990) due to a doctor's note of "Clinical depression." From that point on I concentrated on my health and was seen by several physicians.

On March of 1990, I experienced a very alarming painful episode of Bell's Palsy on the left side of my face. Months of CT scans, MRI's and mis diagnosis of Lupus, maybe M.S. followed. On the Summer of 1990 I ran into a friend who expressed concern of my symptoms and suggested "Get tested for Lyme disease" I have had it 3 times myself, Bob [REDACTED] stated. I was tested and all the various test were positive! over the course of year's it's been I.V. + oral Antibiotics + spinal taps and months of physical therapy. I'm plagued with many symptoms. I was granted Social Security disability. I have short-term memory loss, Arthritis, Ocular Motor dysfunction + periods of chronic fatigue. I don't recall being bitten - but I did have the red rash. (Summer of '89). It's been 7 years since my diagnosis and I've learned to live with Lyme disease and function the best way possible. I've formed a network of Lyme friends such as Polly [REDACTED] of Old Lyme, CT. I also run a support group during April, May + June at the Putnam Public Library in Putnam, CT. I've graduate from College (1997) Bachelor degree + work part-time currently.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey

County: Morris

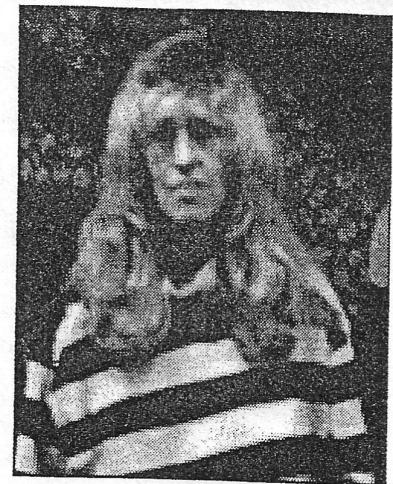
Name: Mindi 

Total cost: \$1,000's

Number of family members with LD: 1

Lost work/school: Both

Number of years sick: Since 1983



My name is Mindi  I'm 43 yrs old, and I have had Lyme disease since 1983. I will never forget the day, the time, the hour, of walking up in July 1983 unable to move my neck, pain, exhausted, Fever, chills, feeling flu-like in summer? That was the beginning of the worst days & months of my life to come. No-one diagnosed me with Lyme disease until 1991. By that time I was almost disabled, Arthritis, muscle pain, exhaustion, mental fog, No memory, focus, concentration, diarrhea, hives, hearing loss, vision loss, pain everywhere. Through the years since 1983 I was sent to every specialist, imaginable, no-one thought to test me for Lyme disease. I lost my family, friends, lover, work, income everything, I am unable to care for my most basic needs. I was told I did not have Lyme disease because my blood tests for years were negative for years. Since Lyme is supposed to be a clinical diagnosis, every doctor who told me I didn't have Lyme disease said soley on a Lyme test were negligent. No-one really listened to all of my symptoms & put things together that destroyed my life. Had I been diagnosed instead of 1991 I may not be writing this. In 1993 I found a doctor, who for the first time listened, and carefully examined my history, she diagnosed me Lyme, and has substantiated this with blood work. Besides being a brilliant physician, who puts her reputation and livelihood on the line each

time she goes to work, she is caring, compassionate, and I have witnessed countless patients of hers getting well. Because of my severe allergies, and insurance restrictions I am still severely disabled with lyme disease. Insurance companies will not pay for prolonged I.V. therapy which is what is necessary to control the symptoms of lyme disease (chronic). Most doctors are not lyme literate, nor are they compassionate, they refer people to psychiatrists when they don't know what's going on. I suffer from depression because I have lyme disease and have lost everything in my life.

WE ARE NOT JUST NUMBERS!

State: Maryland
County: Carroll

Name: Jena (Beagle-Lab mix)

Total cost:

~~11~~

Number of family members with LD: 2

Lost work/school: Died

Number of years sick: 2 months



Jena

4 1/2 yr old Beagle/Lab mix

Bite: July 22, 1997

DIED: September 13, 1997

- Jena received yearly Lyme vaccines.
- Jena was a family house pet. She only went outside to go to the bathroom. She was a companion dog.
- We found the tick and rash July 23rd by July 24th she was on high dose antibiotics.
- She had:
 - lameness
 - muscle weakness
 - loss of appetite
- Jena seemed to be coming out of it, when she went to bed and never woke up. Her little heart just gave out.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Texas

County: Williamson

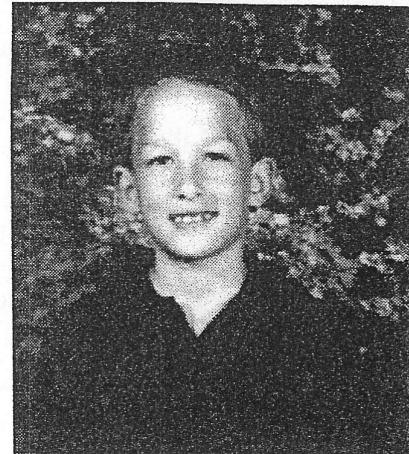
Name: David "Hunter" 

Total cost: \$25-30,000

Number of family members with LD: 2

Lost work/school: 1/2 year

Number of years sick: 3 years



My name is Lisa Johnson and my son's name is Hunter . Hunter is eight years old. In July, 1995 he had an EM rash on the upper left side of his chest. I had already had Lyme so I took Hunter to his doctor and told the doctor what I thought the rash could be. The doctor told me it was probably nothing. We would watch it. Unfortunately, I did not know then what I know now. We were leaving for a two week vacation. The EM rash disappeared. Hunter had occasional problems from then until March, 1997. I now realize these problems were probably caused by the Lyme. Hunter got really sick with the "flu" in March, 1997 and was never well afterwards. He had a rash and repeated infections. He missed a lot of school. He could not stay a whole day at school. He had sore throats, headaches and stomachaches. His math grade went from an A to a D in one six weeks. One day he passed out at school. He was dizzy a lot. He had no appetite at times and he lost weight. One day, a teacher found him with his head on the lunch room table instead of eating and sent him to the nurse. I knew there was something wrong but it did not seem like the doctor noticed all the visits to her office. In fact, I pointed out to her we had seen her something like 18 times in 10 months. I was frustrated so I took Hunter to another doctor that said he had allergies. Hunter got a stiff neck and swollen glands right after that. He was pale a lot and cried easily. He ran low grade fevers. We went back to Hunter's old doctor and she kept

saying he had viral syndrome to explain the repeated infections. At one point, she said he had an enlarged spleen. I insisted she do something. Finally, at my insistence she decided to do a mono test and a Lyme test. I had forgotten about the bite and since the doctor had told me it was alright I had assumed it was. Both tests were negative and the doctor gave Hunter no treatment. We waited one month. During this time I did a lot of research on Lyme Disease. One month later, when Hunter was sick again I told the doctor that Lyme tests were often negative even when the person was infected. She

said "I know." If she knew this why had yet another month gone by with no treatment? The school nurse and Hunter's teacher told me that he did not feel like being at school. I asked her to take Hunter out of school until we figured this out. She said she would not sign the papers for home schooling because "they learn so much more at school than academics" ignoring the fact that if he did not feel like being there he would learn nothing. She did agree reluctantly to treatment with oral antibiotics but we decided to find a doctor who knew about Lyme. We found a wonderful doctor in Connecticut named Dr. Charles Ray Jones. Another Lyme sufferer told us not only was he treating children but he was getting them well! The day Hunter saw him for the first time he had Bell's Palsy, arthritis, an enlarged liver and spleen, and conjunctivitis among other things. He has missed half a school year so far. He has a home tutor. He has problems with short term memory and comprehension as well as other cognitive problems. Dr. Jones diagnosed Hunter with chronic late stage lyme disease with brain involvement. He is on IV and oral antibiotics. He also has many other symptoms like tremors, blurred vision, double vision, skin and sound sensitivity, extreme fatigue, headaches, bladder dysfunction, muscle twitching, disorientation, auditory hallucinations, falling down, dropping things, letter and number reversals, eye pain, sweats, chills, hyperactivity, shooting pains and cough with shortness of breath among other things. He has had a positive blood culture and positive urine antigen tests. The positive urine antigen tests were after seven weeks of IV antibiotics. He has had positive bands on the Elisa test that are specific for Lyme disease. The most frustrating thing of all was when we went to an infectious disease specialist that I thought might help us if we had a problem and needed immediate help. It is a long way from Texas to Connecticut. She told us that "Hunter may have had lyme disease but that he should be well" and after a brief examination she said she saw nothing wrong. I was telling her a lot of things were wrong but it was like she did not hear me or did not believe me. It was obvious she had her mind made up about Lyme Disease before Hunter ever walked through the door and nothing I could say was going to change it. I believe Dr. Jones will get Hunter well if anyone can but it will take a while. Hunter is slowly getting better. Dr. Jones is a very good doctor who understands Lyme Disease. I do not understand why in this day and time doctors are not listening to patients and realizing that a short course of antibiotics is not working for a great number of people. It is clear that many patients benefit from long term antibiotic treatment. I am so thankful for the few brave and compassionate doctors like Dr. Jones who are willing to listen to patients and do what is right.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Michigan
County: Wayne

Name: Margaret 

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 7



In the later summer of 1988, I was pulling weeds near the canal that bordered our yard and was "bitten." I had no idea what was that caused the red, swollen donut shaped place on my shin. It itched but hurt when rubbed. After a couple of weeks, it had gradually gone away; I don't remember any other symptoms at that time and I had put it out of my mind.

Following my divorce in 1990, I began having visual problems followed by a week or so of hot flashes, stomach upsets, irritability and just "not feeling good." (I am fortunate in that I have not had the joint pain many suffer.) It wasn't until 1993 that I began seeing a pattern to these visual/stomach/etc. problems and began keeping closer tabs on what and how I was feeling. I mentioned the bulls-eye rash (after getting my first information about Lyme from a letter carrier friend who gave me a brief directive from the U.S. postal service with a warning about the disease and cautions for the carriers walking their routes.) to my family doctor on one of my many visits to him - he didn't even acknowledge my comment. The cycle of symptoms continued and in 1994 I went through a full battery of tests at the Wayne State University medical center: MRI, neurological, EEG, and so on and on. With no defining results it was suggested that I see a psychiatrist! The symptoms continued, more severe and new ones that included difficulty breathing, racing heart beat, anxiety attacks and severe depression.

I then moved to central Michigan and was seeing a new family physician. I think I wore him down because he finally agreed to a more complete check up (starting with another MRI, visual and hearing stress tests, etc.) and lupus and Lyme blood tests. When the technician drew my blood at the hospital lab, she commented "Boy, is your doctor in for it!" When I asked why, she said that the state of Michigan health department did not recognize Lyme Disease and that any doctor requesting even a test had to fill out forms and defend his request. At this same time a Saginaw doctor was going before the Medical Review Board because he was treating Lyme patients - that the Board said couldn't exist because Michigan didn't have Lyme disease.

Since my blood test was negative, I "didn't have Lyme" and my doctor recommended an anti-depressant. Meanwhile, I continued gathering information about Lyme and tracking my cycles which were now at least once a month and lasted two to three weeks: wow, one week a month to feel relatively normal!

OVER

Some time after moving back to the metro Detroit area in 1996, I saw a Michigan Lyme hot-line number on a bumper sticker and this past October called the hot-line and was referred to Dr. Ledtke whose practice is made up mostly of Lyme patients. I drove two hours to his office, was clinically diagnosed with Lyme and am now in my third month of treatment. Although I haven't seen much progress yet, I am at last hopeful. After 10 years I am finally getting the attention and treatment I need.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New Jersey
County: Monmouth

Name: Ester 

Total cost: ?

Number of family members with LD: 1

Lost work/school: 4 months

Number of years sick: 1

I became sick 1 year ago. However I did not receive a definite diagnosis until 6 months after initial visit with numerous doctors. I started with severe fatigue and strep throat. The fatigue hit me so hard it changed my life. I could not do things that I could do in the past after visiting with m.d.'s, infectious disease specialist who told me I had Chronic Fatigue Syndrome, or stress related problems I finally found a Dr. who tested me for Lyme Disease. After a six months of joint pain, muscle pain, severe fatigue, depression, and lung problems I finally found out the answer to my debilitating disease. I have Lyme disease. I have lost four months of work and fear if I will ever be able to return to work full time and lead a normal life. I've received antibiotics since Nov. 1997 - however most people are ignorant to the severity of this disease; as you start

OVER

The antibiotics you become very sick and it takes months or even years for the bacteria to be killed off and hopefully it will go into remission.

People should be aware of two things

① When you start antibiotics you will not be well within 7 to 10 days!

* ② This is a disease that is treatable not curable.

I have pain in my body everyday.

My knees feel as if something is inside eating at them. My muscles in my neck are in pain. I have pain at times radiating down my arms. I've severe headaches; my ankles also hurt and are swollen at times. I've had trouble concentrating and I've become forgetful.

In the past I am a very upbeat positive person. This disease has brought me to tears on numerous occasions. Please help us educate people on this debilitating disease.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Michigan
County: Isabella

Name: Jeremy [REDACTED]

Total cost: \$80,000+

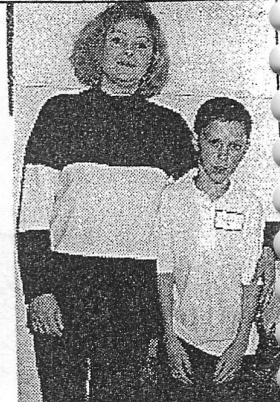
Number of family members with LD: 1

Lost work/school: numerous

Number of years sick: 6 1/2



Age 4 (before tick bite)



May '97 Age 10

To whom this should concern,
I hope you can imagine the nightmare that our entire family has had to endure unjustly for almost 7 years. I ended a before and after the illness photo to let you see what has happened. Jeremy was 5 years old when I, his mother, spotted a small tick on him, this was followed by a rash. Needless to say my pediatrician told me not to be alarmed because "he rarely has Lyme Disease in Michigan." I totally trusted his opinion and brushed it off my mind. Little did I realize how much suffering this would cause Jeremy the next 7 years or maybe his entire life.

Lyme disease creeps up on you and when its your child its even harder to diagnose. First he began to have flu-like illness (stiff neck - swollen glands and etc.) When he reached 1st grade (eye problems, muscle weakness - weight loss - body stiffness (legs knees.) We had him to many doctors during this time but they thought as we did, that maybe he had a child hood illness from school.

The problems really started to snowball in the second grade he became so rigid, stiff that he couldn't walk up the stairs. He had signs of anerixia - (muscles over 90% of his body) We began taking him to pediatric specialists all over Michigan. If we even mentioned Lyme disease we were looked at as if we were ignorant.

Doctors either were misinformed or uneducated in this disease. So they just pushed it aside. I did finally get 3 presumptive opinions or so called diagnoses of J.R.A. with no tests results to back it. I did treat him for 8 or 9 months and watched him go downhill more. Finally the Michigan Lyme support group gave me some contacts on reliable tests & doctors who understand and treat Lyme. I immediately sent out a fastig Lyme IgM Antigen test that came back highly positive for Lyme. In the meantime, a ^{Rheumatologist} pediatric specialist saw Jeremy and quickly ~~assured~~ that he had JRA even after I told him of the positive Lyme test. He became really angry with this idea of Lyme disease and said, "Lyme Disease isn't in Michigan only in Menominee County in the U.P."

I decided that I would not return for his next office visit and informed his office. I had an appointment the next week with a Doctor who was seeing Lyme patients and the results were great news but no antibiotic treatment. I guess that made him really upset though because I didn't accept his diagnosis (The Rheumatologist) because he filed a 32000 form with the Michigan Protective Services stating neglect in treating my son for the wrong disease. Ridiculous! Yes! Several Doctors stood behind me and got the charges dropped. I havint even had a chance to tell you about the pain and suffering that my son has been through. I insist that you please contact me ^{as this is} so I can let you know the "Rest of the Story".

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: New York

County: Westchester

Name: Audrey B. 

Total cost:

Number of family members with LD: 1

Lost work/school: Retired

Number of years sick: 22



My first encounter with a tick bite occurred in the fall of 1975. I noticed a "small scab" on the top of my head when I washed my hair. I could not remember bumping my head. It had been working in my yard. After 3 weeks of the "small scab" growing larger & larger, I removed it with great difficulty. Much to my surprise it was an engorged tick. This was verified by my daughter's science teacher. I called my Internist who told me to forget about it, my aches & pains were all in my head or maybe I had a cold. He did not see me. I took ASA and Ben Gay ointment & rested a lot. For the next 11 yrs. I was treated for "flu - arthritis - colds - generalized fatigue - sleep plagued fever". None of this was related to my tick bite because ticks didn't carry disease according to my doctor.

In the summer of 1987, a co-worker & I found rashes on our abdomens @ the same time because we were both scratching. We worked in a psychiatric hospital & had been on the grounds with some patients. Nobody had heard of Lyme's disease so we didn't tell our doctors or the employees health doctor. We took ASA when we developed aches, pains & runny noses.

I was finally treated for Lyme's Disease in January 93 when my primary J.M.D. decided that my signs & symptoms sounded like Lyme's Disease. He ordered a Lyme titer which was high so he put me on antibiotics.

As recently as August, 1997, I was put on antibiotics again, altho' my current HMO Doctor claimed I was suffering from an

Acute attack of asthma, which I had never experienced in my life. My symptoms were a sore throat and a severe cough. The fatigue was due to lack of sleep, he claimed so he gave me a cough medicine with codeine - also 5 mg doses of prednisone x 6 weeks.

To me, the worst part of this illness, is the chronic fatigue. I can live with the pain in my joints - the aspirin after breakfast gets me started in the morning. Fortunately I have a high tolerance for pain. I rarely missed work or school after returning to college for the nursing degree.

I have been given much stronger pain killers over the years but I seldom took them after reading their side effects.

I am a member of the older generation. I was taught that nothing interferes with your responsibilities. Currently, I am retired.

I have no idea what this cost.

THE MANY FACES OF LYME DISEASE

WE ARE NOT JUST NUMBERS!

State: Michigan
County: Emmet

Name: Kristin & Nancy 

Total cost: 1/2 Million

Number of family members with LD: 3

Lost work/school: yes

Number of years sick: 20+



It's been nine years since I first got treatment for Lyme. My daughter had almost exactly the same things going on so I took her to the Dr. who was treating me. She started treatment in Aug. of 1990. As you can see from the picture she recently got married but had to quit college because of Lyme and she didn't go back. It's sad, she was a good student. She did some modeling before her thyroid went nuts and the we got out of control. Right after the wedding is had her thyroid radiated and is now trying to regulate it with medication. As for me - well I'm still treating. This is my 9th year of it, 8 1/2 months on IV's. And a leg brace to prevent falling. I'm exhausted most of the time. I havent been able to work since 1993 and just started the process for SS disability. By Lyme Disease I was a windsurfer, worked full time at a cement plant and was a girl scout leader for 10 yrs. Now it's a good day when I can stand up long enough to get the dishes done. Thanks for caring enough to put this together.