THE MANY FACES OF LYME DISEASE
WE ARE <u>NOT</u> *JUST* NUMBERS!

State: Pennsylvania
County: Chester

Name: Christian [redacted]

Total cost: ?

Number of family members with LD: 2

Lost work/school: 6th grade

Number of years sick: 2 1/2

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

I am a twelve year old boy, who had never been sick until I moved to Chester County Pennslyvania. My first symptom hit me, in April 1995. At that time, I was misdiagnosed, and my symptoms went dormant until November 1995. Then, once again, I was misdiagnosed. My symptoms reappeared in April of 1996, and from that day on, I have always been sick, and have never been without symptoms. My Mom would find me, collapsed on the staircase, unable to move, I stayed so fatigued. My headaches hurt so bad that I wanted to bash my head in. My parents took me to a total of 14 different doctors (Some were in the same practice). I kept hearing the doctors say, "Well, Christian it sounds like Lyme disease, but your blood work is negative," or "You can't have Lyme disease, because your joints are not swollen." My Mom and Dad even took me to the big name hospitals, to see doctors we thought would help. All the doctors there could say was, " Sorry, lets just see how bad he gets." Then, two different M.R.I. tests showed that I have lesions on my brain, and a terrible thing happened. A neurologist, and an infectious disease doctor got together, and told my parents that I did not have Lyme disease, but they said that I did have something. They also said that I had been sick for so long, that I just keep on making myself sick. They suggested that I see a psychiatrist, and then they gave my Mom a prescription for happy, feel good drugs. Then they sent us on our way(We threw that prescription away). My parents counted 32 different symptoms of Lyme disease that I had, but it seemed like the doctor wouldn't listen. My Mom and Dad never gave up on me. My parents knew me better than any doctors, and they realized that I was a very sick kid. My Mom prayed for a doctor to help me, and in September 1996, we found that doctor. I started taking an oral antibiotic (Biaxin), for 7 months as treatment. I was able to stay in school for most of 5th grade. My joint and arthritis pain, as well as many of my other symptoms left me, but my headaches never did. We went to New York, and I had a brain spec scan. The results showed that I was losing oxygen to the left side, right side, and the back of my head. My doctor started me on I.V. therapy (Rocephin). It's been five weeks since I started the I.V. therapy, and I'm just now starting to feel a change for the better. Now on some days my headaches are a one, and that's great compared to an 8 headache. I have not made it to 6th grade yet, I am being taught at home. I am hoping for a full recovery. It's hard being a kid and being worried to go outside in the sun because your headaches always get worse. Also, not being able to read because of my head pounding, or ride in a car because I'll get car sickness. So, please help the doctors not wait so long to treat if the symptoms sound like Lyme disease, and taste and smell like Lyme disease, please recognize and treat, so that other children will not have to end up with a pic line in their arm and their Moms having to cry.

THE MANY FACES OF LYME DISEASE
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State: Oregon
County: Union

Name: Shirley [redacted]

Total cost: Unknown

Number of family members with LD: 1

Lost work/school: 3 months

Number of years sick: 2-3

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

Eventually went To ER For the pain. Abdominal CT done - considered Normal. Did have a high amalaze Level (500 I Think) at The Time. Saw 3 internist within The next Few weeks + was refered To a GI specialist who did Epstein Barr studies + diagnosed Epstein Barr. Regular internist poo had all Findings + diagnoses + offered no help but labeled me "depressed".

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

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

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

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

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

OVER

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

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

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

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

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

He encouraged me to get counseling + eventually refered me to The Dr in San Fransisco. That was Paul Lavoie.

I saw (Dr Lavoie) him a Tolal of 3 Times over about a year + a half.

I was Treated with oral Amoxicillin, Minocin + plaquinill. He also tried me on an antidepressant — non of The antidepres I took agreed with me. I ended up off work For 6 wks after I started Treatment with a mod. Nervous breakdow. My marriage was + had been breaking down.

After 3 months on plaquinill my hung over Feeling improve. + I went off all drugs. My son was diagnosed with a severe Form of cancer. + I spent The next year + a half batteling cancer (his) successfully. But my marriag ended. I did counseling For about 2-3 year.

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

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

THE MANY FACES OF LYME DISEASE
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State: New Jersey
County: Morris

Name: Mary Alice [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 3

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

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

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

Three years after the bite I really was feeling sick: cloudy headed, woosy, terrible balance, nystagmis, double vision, headaches, chills, tiredness and stiff joints. I met someone who had the same set of symptoms who also was bitten by a tick three years ago. I suspected Lyme and went to a doctor in [redacted] who treats many cases of Lyme. He gave me a blood test which was positive. I have been on antibiotics now for 10 weeks and am beginning to have some good days.

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

[redacted]

THE MANY FACES OF LYME DISEASE
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State: Iowa
County: Woodbury

Name: Rafelle Jessica [redacted]

Total cost: $150,000

Number of family members with LD: 3

Lost work/school: 7 yrs. of lost employment

Number of years sick: 13

"My Story"

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

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

Sincerely, [redacted] 1997

THE MANY FACES OF LYME DISEASE
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State: Iowa
County: Woodbury

Name: Caleb [redacted]

Total cost: Just starting

Number of family members with LD: 3

Lost work/school: Too many

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

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

THE MANY FACES OF LYME DISEASE
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State: Connecticut
County: Middlesex

Name: David [redacted]

Total cost: over $100,000

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

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

Number of years sick: 8

Underdiagnosis of Lyme Disease

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

THE MANY FACES OF LYME DISEASE
WE ARE <u>NOT</u> *JUST* NUMBERS!

State: Iowa
County: Woodbury

Name: Zachary A. [redacted]

Total cost: Just starting

Number of family members with LD: 3

Lost work/school: Too many

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

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

THE MANY FACES OF LYME DISEASE
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State: Massachessetts
County: Gloucester

Name: Elaine [redacted]

Total cost: ?

Number of family members with LD: 3

Lost work/school: 2 years

Number of years sick: 10

In 1987 I lived in South Plymouth, Ma. with my family I became very ill. I was extremely fatigued along with other symptoms, such as blurred vision, leg and knee pain with swelling and headaches. A doctor diagnosed me with the chronic fatigue syndrome. I then went to a blood specialist and he could find nothing wrong with me. However the symptom persisted for a long time. The fatigue never went away completely. Also my knee continued to bother me off and on. In 1995, September and November, both my daughter and I were bitten by ticks. We both had Lyme disease. We caught my daughters disease right away and she was treated for 30 days. She had improvement but never regained her full energy and remained fatigued. I have been on medication for Lyme ever since. My doctor and I have figured out that my diagnosis in 1987 was most likely mis-diagnosed Lyme. That explains my slow progress on the medication. I have made significant progress but will always have the disease because it wasn't treated right away in 1987. My oldest daughter, began showing strong symtoms of lyme this past summer. I began to remember that she had leg pain, fatigue and headaches since we lived in South Plymouth in '87. Although there was nothing medically wrong, she continued to have problems off and on that required tylenol and subtle pain soothers. I had her tested for lyme this fall. She tested positive. I had my younger daughter tested also (who had lyme in '95). She tested positive.

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

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

THE MANY FACES OF LYME DISEASE
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State: Massachessetts
County: Gloucester

Name: Jennifer [redacted]

Total cost:

Number of family members with LD: 3

Lost work/school: 20 days

Number of years sick: 2

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

THE MANY FACES OF LYME DISEASE
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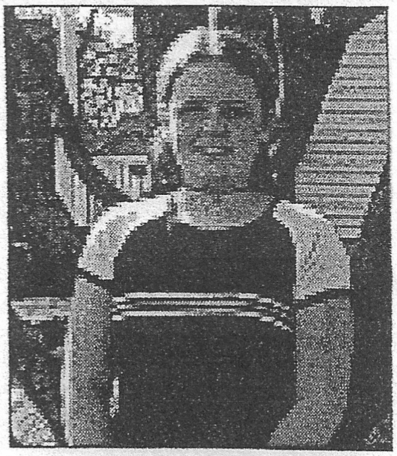


State: Massachessetts
County: Gloucester

Name: Michelle [redacted]

Total cost:

Number of family members with LD: 3

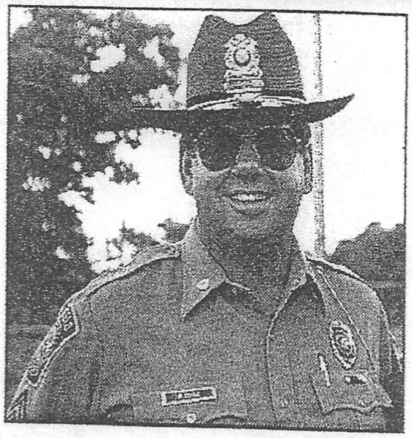
Lost work/school: Severe trouble in school

Number of years sick: 10

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

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

State: Connecticut
County: Litchfield



Name: Roger A. [redacted]

Total cost: $100,000+

Number of family members with LD: 2

Lost work/school: 6 months

Number of years sick: 8

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

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

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

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

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

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

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

State: Michigan
County: Jackson

Name: Victoria [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 5 months

My name is Dawn [redacted] and this is our story. Our daughter Victoria was bitten by a Tic in late May of 1997. We found the tic at the stem of the neck,we pulled it out with tweezers and all of the tic·came out. The tic couldnt of been there longer than a couple of hours. We called the family Doctor who said there was nothing .to worry about. A couple of weeks had passed and we started to notice a big difference in her behavior. We checked the area of the bite and noticed it was not healing and there was light red rash around the area. We were somewhat aware of Lyme's disease as someone in our community has it. Fornuately for us they were willing to share their experience with us. We called their Physician and were able to get an apt. for Victoria. July of 1997 was her first appointment, we see the Doctor once a month which is about a 2½ hour drive there one way. Victoria's emotional state is not well, she gets very confused,angry,along with her crying spells. On top of her Lymes disease she has developed Alopecia (Hair Loss) and Candidiasis (Chronic Yeast). Victoria doesn't understand what is happening to her, she use to be such a good natured child who had so much energy and loved life. Victoria doesn't ucare when people look at her when she has an outburst, or they are staring at her hair but, I do. There are times when I will just break down and cry and it is her who comforts me,." Itll be alright Ma". One thing I can say is God gave her a strong spirit. When she cries out in her sleep from the pain in her legs and stomach, I do wonder if and when this will be over for her and all of us! I do believe in the P & P method, The power of prayer and patience. In reality that is all you can do until they find the right combination of drugs that will work is pray and be patient. The financial burden is also difficul missing work,travel for treatment, the treatment itself, tests and bloodwork. We have only been doing this for a short time in comparission to most Lymes patients and to be honest I don't know how they muster up the strength to do it. In some ways i think it would be easier to deal with cancer or something else at least then you would know what you are dealing with and be able to face it head on, with Lymes there are so many strains of bacteria and so many other illnesses and side effects that can occur. The pain you feel watching someone you love go through so much and knowing there is nothing you can do is incredible. The stress it creates in our lives is so great. David her Dad and I feel we are in constant turmoil and there is never a moments peace. Thank you for listening.

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

Dawn [redacted]
Dawn M. [redacted]

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

State: Maryland
County: Washington

Name: Carol [redacted]

Total cost: $20,000

Number of family members with LD: 2

Lost work/school: 6 months

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

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

My story is so similar to many with undiagnosed lyme disease. For years I complained of sporadic rashes, numbness & tingling of the extremities, facial and mouth pain, neck stiffness, vibrations and burning over my body, urinary tract infections, rapid heart beat, vertigo, ring ing in the ears with ear pain, confusion and depression, feelings of electrical shocks, stabbing pains in the muscles and feelings of possible encephalitis. No wonder my doctor had a difficult time making a diagnosis. Two years later a neurologist from the Washington D.C. area agreed to test me for lyme after I convinced him this could be a possibility. I am married to a Veterinarian and help to rehabilitate wildlife. I was frequently informed that I could not have lyme disease since I live in Western Maryland and there is no lyme disease in Washington County.

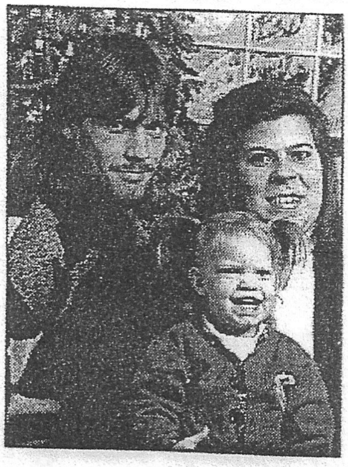
My IFA blood test came back 1 to 10,000 and all Western Blot tests met the CDC criteria. I've had 30 days of IV Rocephin along with symptomatic treatments of Amoxcillin and Zithromax. I am once again leading a normal life thanks to my doctor [redacted] a lyme specialist in N.Y. who so graciously advised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

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

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

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

State: Connecticut
County: Middlesex



Name: Joanne [redacted]

Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 1

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

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

State: Michigan
County: Oakland

Name: Carol [redacted]

Total cost: $150,000

Number of family members with LD: 3

Lost work/school:

Number of years sick: 1992


Me & Daughter(also has Lyme) before Lyme


After Lyme

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

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

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

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

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

(Over)

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

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

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

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

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

My family has been devistated by this disease!

Thank you for lestening to my story. [redacted]

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

State: Michigan
County: Oakland

Name: Carol [redacted]

Total cost: $90,000

Number of family members with LD: 1

Lost work/school: Now on disability

Number of years sick: 7

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

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

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

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

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

OVER

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

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

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

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

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

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

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

Enclosed is my picture, and bless you for caring.

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

State: Oregon
County: Marion

Name: Nona O. [redacted]

Total cost: $1,600

Number of family members with LD: 1

Lost work/school: (Retired) 10 years

Number of years sick: 10

May '88 "Good news, Mrs. [redacted] you definitely DON'T have Lyme disease." ---The young Kaiser-Permanente internist had known nothing about Lyme when I "caught it from a magazine" and asked for a test. He had gone out to a hall phone, but we still heard him call a specialist in infectious disease and ask about Lyme. Now he knew all about it, including its 100% accurate ELISA test! (I had read about Lyme in a Good Housekeeping article and recognized my symptoms.

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

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

The next two years saw more joint and muscle pains, often changing location; heart palpitations and chest pains; several neurological problems; blurred vision; hands and feet terribly swollen; right jaw swollen and painful. I was on crutches several times. Diagnosis? ---Rheumatoid arthritis. X-Rays and lab tests don't show any? ---then it's your heart, [redacted]. (But, doctor, you have never so much as put a stethoscope to my chest!...)

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

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

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

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

State: Connecticut
County: Hartford

Name: Kari [redacted]

Total cost: $1,000,000

Number of family members with LD: 1

Lost work/school: 10th grade thru college+

Number of years sick: 9

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

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

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

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

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

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

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

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

State: Georgia
County:

Name: Davi[redacted]

Total cost: 2 Million

Number of family members with LD: 2

Lost work/school:

Number of years sick: Died

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

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

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

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

THE MANY FACES OF LYME DISEASE
WE ARE <u>NOT</u> *JUST* NUMBERS!

State: New Jersey
County: Ocean County

Name: Ellen [redacted]

Total cost: $96,266

Number of family members with LD: 1

Lost work/school:

Number of years sick: 7 1/2

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

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

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

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

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

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