LYME DISEASE FOUNDATION
[redacted]
860-870-0070 Fax: 860-870-0080 www.Lyme.org 501(c)(3) Est. 1988
384-G Merrow Rd, Tolland, Ct 06084 2022

Mission
otecting people and pets from the wide variety of illnesses caused by Lyme disease and *other* vector-borne orders.
Anaplasmosis, babesiosis, cat scratch ease, Colorado tick fever, ehrlichiosis, ster's disease, tick paralysis, tularemia, Powassan encephalitis, Rocky Mountain tted fever, dengue/dengue hemorrhagic fever, West Nile virus, yellow fever, stern equine encephalitis, plague, Q-fever, relapsing fever, and tularemia.

2009

Dear Friends:

Lyme disease patients are often reduced to just numbers on a page. Somehow, the impact of this disease on their lives is often invisible to many of us. This book is the first of an ongoing educational campaign to rehumanize Lyme disease and show the impact this infection is having on families.

Lyme disease is a major problem for all people and employers in most states. About 400,000 people across the United States have been reported to the Centers for Disease Control and Prevention as confirmed cases. There may be a total of over 8-10 million cases in the United States to date.

The Lyme Disease Foundation (LDF) is the premier international scientific nonprofit dedicated to finding solutions to vector-borne disorders. We do this through education, research, and advocacy. The LDF is a partnership between the scientific, business, government, and public/patients communities.

Many people do not fully understand the serious nature of Lyme disease (LD) and other vector-borne disorders. These illnesses can disrupt lives, cause financial hardships, and interfere with school and work. LD patients often feel a sense of alienation and embarrassment due to their infection and are sometimes accused by family, friends, employers, and healthcare professionals, as wanting to have this "trendy disease" in order to gain attention or have an excuse to malinger. Patients can be left in medical limbo by physicians with opposing medical views. Conflicts are resulting in lawsuits and medical licensing disputes. Insurance company gate-keeping has bureaucrats and paid consultants micromanaging the physician/patient relationship and healthcare from a desk thousands of miles away from the patient. Sadly, we have been reduced to numbers on a page.

You are invited to submit your story for a future edition. A submission form is included at the beginning of this book. If you are interested in educating your friends and neighbors about the disease, please use our order form to purchase educational material.

Please read these stories carefully, Lyme disease *could* happen to someone *you love*!

Sincerely,
Karen V-Forschner
The Lyme Disease Foundation

LDF ORDER, DONATION, VOLUNTEER FORM

[redacted]

Name ____________________________________

email ____________________________________

Grade & class ___________________________ (List, if you are buying for your own school project)

Firm/Group ____________________________________

Address ____________________________________

City ____________________________________

State __________________ Zip _____________

Phone (____)_____-______ Fax (____)_____-______

Send the following items to a different address:

Items: ____________________________________

__ (Y/N). This is a gift from me to:

Name ____________________________________

Company ____________________________________

Address ____________________________________

City ____________________________________

State __________________ Zip _____________

Phone (____)_____-______ Fax (____)_____-______

I want to work with the LDF by:

- __ Running a Self-Help group.
- __ Legislation: ___Federal, ___State ______________. (name state)
- __ Developing Educational Material.
- __ Conducting a conference.
- __ Being on the Doctor referral list.
- __ Presenting LD information to the community.
- __ Other ____________________________________

Account number ____________________________________

Credit card type __Master Card __VISA __Am. Exp.

Cardholder name ____________________________________

Exp. Date ________ Cardholder signature __________________

DONATIONS - **The LDF is a 501(c)(3)**

Enclosed is a donation to help find solutions to Vector-borne diseases!

- __$ 25 Friend
- __$ 50 Supporter
- __$ 100 Sponsor, Professional/business
- __$ 250 Patron - *Complete below to receive a personal certificate*
- __$1,000 Scientific Circle - *Complete below to receive a personal certificate*
- __$____ Other

Special Donations

- In Honor of ____________________________________
- In Memory of ____________________________________

Acknowledgement is to be sent to (name & address):

____

____

Certificate: Print the name for a personal certificate.

Price includes handling & postage. Prices subject to change. U.S. funds. Delivery in 2 weeks. Minimum Credit Card order is $25

ITEMS	PRICE PER ITEM	QTY	TOTAL
CALL US FOR DELIVERY OUTSIDE OF U.S.			
Please *ENCLOSE PAYMENT!*		TOTAL	

A. TICK-KITS, BRACELETS, BROCHURES, & BOOKS

1 large poster, 2 brochures, 2 tick cards, 1 tick-kit, 1 bracelet. $20. **State your grade & class**

- **School Project material** - ***New.*** manufacturer-warranted-non-latex bracelet "DO-A-TICK-CHECK!" $6 each, 4 for $20.
- **Lyme Bracelets** - Glow-in-the-dark lyme-green
- **Tick Removal Kits** - Tick ID card, magnifying lens, precision tweezers, antiseptic wipe, & zip-lock bag. $10 each, 3 for $20.
- **Tick-Spread Diseases Brochure** - About ticks, LD symptoms/diagnosis/treatment, & other tick-borne disorders. $3 each, $50 for 10
- **Tick Wallet-Card** - Color 3-fold picture card. Diseases, prevention, removal, symptoms. $3 each, $50 for 100.
- **Lyme Disease & Pets*** - Information sheet of symptoms and treatment for cats, dogs, horses, and cows. $3 each.
- **Frequently Asked Questions*** - Questions and answers about diagnosis, treatment, and transmission. $3 each.
- **Insurance Questions** - Suggestions on how to get your insurance company to pay your medical claims. $3 each.
- **Everything You Need to Know about LD** (***Wiley & Sons***) - 270 page 2nd edition updated & expanded book with chapters o ticks, personal and property protection, LD (symptoms, diagnosis, testing, treatment), 100-year history of LD, *other* tick-borne disorders that infect people (ehrlichiosis, babesiosis, Rocky Mountain spotted fever, tularemia, and more), pets & tick-born disorders, and resources. Introduction by Dr. Willy Burgdorfer. **$25**
- **Many Faces of Lyme Disease** - Book of patients' writing about the impact tick-borne disorders on their lives. 6th ed. **$40**
- ***InStyle Parties*** - ***New.*** A complete guide to easy elegant entertaining. Donated by *InStyle Magazine*. **$20** (Retail $27.95).
- **Coloring Book** - Paper copy. You can copy and use with your kids or in the classroom. **$10**
- **Chronic Lyme Book** - 4" thick book of many older scientific LD articles that are still relevant. **$70**
- **Mosquito-Borne Disorder Brochure** - **In Process!** Watch out for *new* developments at www.Lyme.org!

***CDC approved** Prices and package combinations are subject to change without notice.

B. VIDEOS & POSTERS

- LD: What You Should Know* - 1 hr. Transmission, prevention, *microbiology*, diagnosis, symptoms, treatment, and *patient & researcher interviews*. A thorough discussion of aspects of the disease. **VHS $30**
- LD: What You Should Know (2 programs) - 30 min. edited version and a 60 min. original version of **What You Should Know** placed on one DVD set. The longer version covers transmission, prevention, *microbiology*, diagnosis, symptoms, treatment, and *patient & researcher interviews*. Thorough discussion of aspects of the disease. The shorter version is the same except it does not include the microbiology and interviews. **DVD $35.**
- Faces of Lyme Disease & *LD Video Quilt* - (2 programs) The ***Faces of Lyme Disease*** video is a 26 min. **Lifetime TV Network *Award-Winning*** documentary. Also included is the ***LD Video Quilt***, which is a 10 min. program of patients discussing their fears and hopes about Lyme disease. **DVD $35**
- LD: Facts for Kids* - Elementary School age kids. *Four* 18-minute DVD puppet programs (**2-English, 2-Spanish**). *Dr. Ticked-Off* and *WTIK: Do A Tick-Check*. Hosted by Luis (Emilio Delgado) from *Sesame Street*. ***Award winner at International Comm. Film & Video Festival. Broadcast nationwide as a PBS TV Special.*** Great for middle school Spanish class! This is equally enjoyed by groups of all ages. **DVD $30**
- **Satellite Medical Conference** - 3-hour 2-DVD set. Illinois Dept. of Health medically-accredited conference covering diagnosis, testing, treatment, & public health. Presenters: Doctors Burgdorfer, Burrascano, Liegner, Donta; Tom Forschner (LDF Executive Director), Mark Schmidt (Illinois Dept. of Health), & Renee Thaler (patient). Dr. Parenti of SmithKline Beecham discloses surprising results about seronegative disease & rashes discovered in the LD vaccine trials. **DVD $40**
- **Health Professionals Guide to Diagnosis & Treatment** - DVD, VHS. Doctors Joseph J. Burrascano, Jr., Craig Cleveland, Derrick DeSilva, and Kenneth Liegner discuss the state of the art of diagnosis and treatment. 1992. Nothing much has changed since. Leaders, historians, and others will find this very valuable. **DVD, VHS $25**
- *Poster Duo* (*What LD Is...*, LD Poster Guide)* - **What LD is . . .** is a large color (green background) poster with picture of symptoms & information on prevention. The **LD Poster Guide** is a poster with pictures of rashes, facial palsy, eye problems, and more, with extensive list of symptoms. **$25**

C. COMBINATION PROGRAMS

- **LD& the Scientific Method: An Investigative Survey*** - Middle School VHS program using LD to teach students about the scientific method. Includes: *LD: An Investigative Survey on Personal Prevention* video, *Teacher's Lesson Plans*, Survey Forms, and brochures that are used in the class exercise. **VHS $30**
- **Community Education Program*** - Great as a gift to a library, educator, or support group. Multi-piece program that is perfect for displays and healthfairs, and includes: a lightweight tabletop display, carrying case, *Poster Duo*, 100 brochures, 100 wallet cards, and 3 video programs - *LD: Facts for Kids* (DVD), *LD& Scientific Method* Program (VHS); *LD: What You Should Know* (DVD duo), & the *Satellite Medical Diagnosis & Treatment* (DVD). **$250** (a $310 value)
- **Workplace/Group Education Program*** - Multi-piece program designed to educate employees, employers, and other groups about tick-borne disorders. Includes: Instructional Handbook & video, *What You Should Know* DVD Duo set for group viewing, 100 tick wallet cards, 100 tick-borne brochures, Poster *Duo set*, and 5 bracelets. **$150** (a $290 value)
- **Self-Help/Support Group Program*** - Multi-piece program designed to help a person establish and run a self-help/ support group. Included are: *Running a Self-Help Group* 28-min. VHS video, two manuals on facilitating and running a group, sample brochures for reproduction, sample press releases, and Group posters. **$30**
- **Kids & Teens Educational Program*** - A great gift to a school, library, church, daycare, or educator. Multi-piece program for grades K-12 and includes: 500 wallet cards; Poster Duo set; 3 video programs (*Facts for Kids*-DVD, *LD & Scientific Method*-VHS, & *What You Should Know*-DVD duo); and a model school trip letter. **$250** (a $345 value)

D. PACKETS

- Tick-borne Disease Historical Packet - ***New***. This includes 11 articles (including two 1895 articles on cases of LD in NY, 1945 article on cases from Illinois, and European cases), a 1989 article by Dr. Willy Burgdorfer, and a copy of a major historical out-of-print book on *Borrelia*. **$30**
- ***Journal of Spirochetal & Tick-Borne Diseases*** - Choose from listing on "www.Lyme.org" or "www.JSTD.org". **$10 per back issue.**
- Tick-Borne Disorder Packet - Brochures, medical articles, insurance information, pets, poster, and more. While these are older, they are still relevant and valid. **$40**
- LD Scientific Packet - Copies of a variety of scientific articles, including testing and treatment. While these are older, they are still relevant and valid. **$40**
- LD Chronic Packet - Chronic LD articles and more. While these are older, they are still relevant and valid. **$40**
- Tick-Borne disease & Pregnancy Packet - Copies of various scientific articles, abstracts related to tick-borne disorders, & implications for pregnancy. **$40**

*** CDC approved** Prices & combinations subject to change without notification.

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

Name:

State:

County:

Total cost:

Number of family members with LD:

Lost work/school:

Number of years sick:

To have your name included in this program please Complete this form and mail to:
Lyme Disease Foundation, [redacted]
I give permission to the LDF to use this information and photo in any way they deem useful.
Sign ______________________________ Date __________
Your Name (printed) ______________________________
Address ______________________________
City, State, Zip ______________________________
Phone Number (____) ____-__________

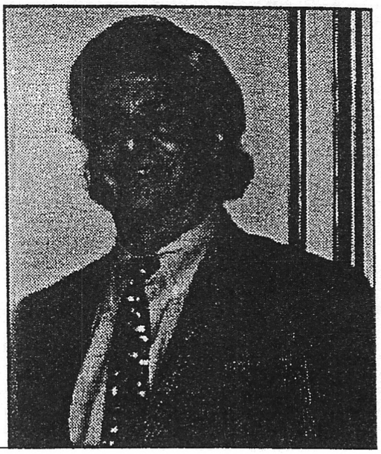
Many people do not fully understand the serious nature of Lyme disease. We now have an opportunity to more fully educate government officials, the media, businesses, and even the healthcare profession about how Lyme disease can disrupt lives, cause financial hardships, and interfere with school and work. LD patients often feel a sense of alienation and embarrassment due to the infection and are sometimes accused by family, friends, employers, and healthcare professionals, as wanting to have this "trendy disease" in order to gain attention or have an excuse to malinger. Patients can be left in medical limbo by physicians with opposing medical views. Worse yet, healthcare professionals are at odds with each other. Conflicts are resulting in lawsuits and medical licensing disputes. Insurance company gatekeeping has bureaucrats and paid consultants micromanaging the physician/patient relationship and healthcare from a desk thousands of miles away from the patient. We have been reduced to numbers on a page.

The LDF is now assembling the 2008 version of this book that re-humanizes tick-borne diseases from "just a bunch of numbers" to people with real faces and real lives. You are invited to participate! Please tell your story here - briefly and in a form easy to read. Handwriting is OK. Your story must be on the front and back of this form. No additional pages allowed.

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

State: New Jersey
County: Morris

Name: [redacted]



Total cost: $150,000

Number of family members with LD: 2

Lost work/school: Lost job & home

Number of years sick: 8

Infected 1989 Have been on MEGA Antibotics all these years. Lost my Job, which prior to becoming infected NEVER Lost a days work due to any reason! Was so ill I was unable to take care of myself. Unable to open mail, pay bills or keep up with social life. Lost my employ in 1992 Lost my insurance in June of 1990. Had owned Real Estate but Lost it due to inability to consentrate and pay Bills or make Phone calls to rent vacant property. Lost the home I lived in in 1993. I am still on I.V. therapy and mega oral and I.M. injection. Antibotic eye drops. Spend $1,200. per mo on Vit. Have 27 sections of I.V. DHNA DNHA cealation. 3 x week to Chropractor - Ozone I.V. oxygen into blood stream - Treated myself for Parasites. Use D.C. 3. Take Herbal tea.

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

State: New Jersey
County: Cape May

Name: Ella [redacted]
Total cost:

Number of family members with LD: 2

Lost work/school:

Number of years sick: 2 1/2

Ella was born the healthiest little butterball on Aug 8, 1995. after a long, hard pregnancy and the loss of her twin. I had my bullseye 2 years before she was born and still don't know for sure if she got it from me or on her own, since I did take her to work outdoors with me. We seem to be sick at same time. She was healthy up to Summer of 1996 (Coinsidently or not when I became chronicly sick) She had 105 fevers every few weeks, rashes, conjuctivitis, + swollen glands. Earaches, Stomache Her pediatrician was clueless + never mentioned lymes. She then developed major bloating w/ belly aches, would not eat, pale and dark circles, sensitive head + sore toes, wrists + knees. Just a year old she would complain to everyone she met + say "Boo Boo" pointing to her achy spots. I mentioned lymes tests to her dr. + he said "cant be"? When I asked why she dugs in her ears + said Boo Boo he said she just discovered her ears which ~~she~~ had told me the previous year! After I was finally diagnosed I first knew she had it too. She had even had many miniture bulls eyes the year before & was told she had hives along with her 105 fever, conjuctivitis & swollen glands. By this time she had tremors, chills & like a spell where she would stop whatever she was doing & go into a trance. Then continue as normal after a minute or so. I heard about Dr Charles Ray Jones in Hamden Conn. (a 4 hour trip) & took her immediately which happened to be during my first IV treatment & Major herxheimer & hooked to a heart monitor. Dr Jones diagnoses her immediatly & started her on oral meds which she has been on since July 1997. He feels she contracted it from me during pregnancy but she is fighting it on orals still (a year later) The question is always in my mind will she ever be the healthy baby she was again. Will she ever be Lyme free??

ITS JUST NOT FAIR!! SHE DESERVES a HEALTHY FUTURE!!!

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

State: New Jersey
County: Cape May

Name: NICOLE [redacted]

Total cost: Lost Count

Number of family members with LD: 2

Lost work/school: 4 years

Number of years sick: 5

I have been waiting for my mind to be better intact before sending my story but no one knows for sure when and if I will be my pre-lyme self again. It all started with what I thought was allergy to a masquito bit in 1993. I've had them several times (what I Now Know was a "Bulls eye"!) I worked at an outdoor Historical museum. My varied symtoms began (GI, Heart, aches + pains, glands etc) After several doctors gave me a clean bill of heath. I proceeded with my plan to have a baby with the help of fertility drugs. It was a miracle + I was pregnant the 2nd month. with twins! I was sick whole time with what I Now knew were lyme symtoms but being pregnant for first time the doctor first thought I was "obsessing"!! I lost the twin in 4th month of pregnancy and stayed in bed rest of pregnancy. I had

OVER

a beautiful chubby Baby girl (Ella Victoria [redacted] on Aug. 8, 1995. See her story also I soon became sicker than ever after few months of feeling good. I was diagnosed by a neurologist with "mono". I was told there was nothing that could be done. I lived sick with what I was told was "mono" for over a year with progressing neurologic and cardiac symptoms and had countless tests including MRI, 2)colonoscopy, 2)endoscopy, Cat scans GI + head, Upper + lower GI, & several Lymes tests + X-Rays + thousands of dollars of Blood tests. I finally decided I was dying. I compared my symptoms to Aids, (Fevers, Glands, infections, fatigue etc) the only one that didn't have was weight loss. Since I had gained 50 lb's in a few years. Immediately after the bulls eye. I finally saw an infectious disease dr. & my Lymes test was positive. I actually was happy ("They know whats wrong") after 2 months of oral antibiotics I was "cured" he said. He shrugged off my multiple symptoms still had (MAJOR ones) I saw a flyer about a Lyme support group + went that night & found out other people had this!! I went to Dr Anthony Lionetti & was immediately put on IV. I then relapsed + Started 2 IVs + an oral in Jan 98. & got deathly sick + developed psychiatric & more neurologic symptoms + meds were stopped until my mind settled down with help of Paxil. A counselor told me I could not be helped if I didn't admit I did not have lymes + my symptoms were anxiety. I had a grossly abnormal Brain Spect scan consistent with CNS. Lyme, and was stirred up by the new IV treatment. I sent a copy of spect scan + articles about neuro-psychiatric Lyme & hope she can help her next Lyme patient better. I just restarted treatment AGAIN, ONE DAY AT A Time!

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

State: Connecticut
County: Fairfield

Name: Maureen [redacted]

Total cost: $50,000.00

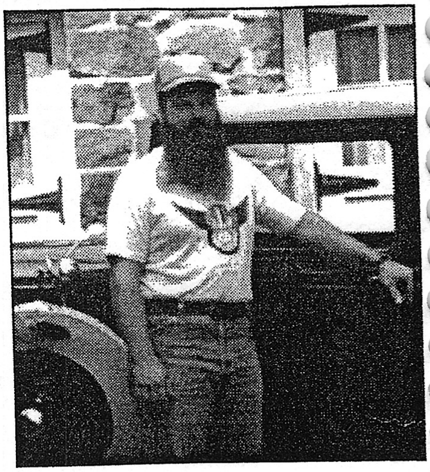
Number of family members with LD: 2

Lost work/school: 6 months

Number of years sick: 2 1/2 years

MY STORY BEGINS IN OCTOBER OF 1996, SOME 3 MONTHS BEFORE I BECAME ILL. IN OCTOBER MY BOYFRIEND, KEVIN, BECAME ILL AND WAS SUBSEQUENTLLY DIAGNOSED WITH LYME DISEASE. AT THAT TIME I WAS ACTIVE, YOUR TYPICAL WORKHORSE GOING TO GRADUATE SCHOOL, WORKING FULL TIME & TAKING CARE OF KEVIN. PRIOR TO LYME DISEASE WE WERE AN INDEPENDENT ACTIVE COUPLE. OUR IDEA OF A VACATION WAS HORSEBACK RIDING THROUGH THE WILDS OF THE ALASKAN RANGE FOR TWO WEEKS EACH YEAR. IN JANUARY OF 1996 I DEVELOPED SEVERE HEADACHES, VISUAL CHANGES OVERNITE, BALANCE PROBLEMS AND BLACK OUTS. UNFORTUNATELY WHEN I WENT TO MY PHYSICIAN THE COMBINATION OF ME STATING WHAT I THOUGHT WAS MY DIAGNOSIS, KEVIN'S ILLNESS & THE FACT I AM A NURSE SET HIM OUT TO PROVE IT WAS ANYTHING ELSE. I HAVE BEEN DIAGNOSED WITH CHRONIC FATIGUE, MS, EPSTEIN BAR VIRUS AND SOME I DON'T EVEN REMEMBER. SIX MONTHS LATER AFTER FIVE DOCTORS I FINALLY GOT DIAGNOSED WITH LYME & STARTED TREATMENT. BY THEN THE DELAY IN TREATMENT HAD RESULTED IN MORE SEVERE SYMPTOMS OF SEIZURES DISORDER, MEMORY PROBLEMS AND DANGEROUS BLACKOUTS. SINCE THEN I HAVE BEEN ON IV TREATMENT 3 TIMES, HAVE BEEN DENIED TREATMENT ON TWO OCCASSIONS, PRIVATE PAID FOR TREATMENT AND WAS DISABLED FOR 6 MONTHS. FORTUNATELY I HAVE THE FAMILY SUPPORT & A SUPPORTIVE EMPLOYER TO BE ABLE TO PRIVATE PAY TO GET THE IV TREATMENT WHICH ENABLED ME TO RETURN TO WORK & A FUNCTIONAL LEVEL. I FEAR FOR PATIENTS THAT DO NOT HAVE THE SUPPORT SYSTEMS THAT I HAVE. I FEAR FOR PATIENTS THAT DO NOT HAVE THE KNOWLEDGE OF THE INSURANCE GAME OR THE MEDICAL PROFESSION. I HAVE ALSO BEEN APPALLED NOT ONLY BY THE LACK OF COMPASSION BY THE MEDICAL COMMUNITY BUT BY THE GENDER BIAS FEMALE PATIENTS OFTEN ENCOUNTER. PERHAPS THE MOST DISTURBING DISCOVERY IS THE FALSE CLAIMS IN THE RESEARCH ARENA. THE NUMBER OF FLAWED STUDIES INDICATING LYME IS A BENIGN DISORDER IS DISTRUBING. THE PUBLIC AT LARGE DOES NOT HAVE THE ABILITY TO DISCERN THE GOOD RESEARCH FROM THE FLAWED AND THUS IS OFTEN MISINFORMED. I HAVE SEEN STUDIES PUBLISHED IN PERSTIGOUS JOURNALS WHICH WOULD NOT HAVE BEEN ACCEPTED AS A MASTERS THESIS. KEVIN & I CONTINUE OUR STRUGGLE, WE HAVE PERIODS OF RELATIVELY GOOD HEALTH THAT WE SEIZE & ENJOY. BUT THE PERIODS OF ILLNESS FROM CHRONIC LYME ARE PERSISTING. WE LOOK FORWARD TO A DAY WHEN WE BOTH ENJOY GOOD HEALTH AGAIN.

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



State: Pennsylvania
County: Berks

Name: David [redacted]

Total cost: $6,000

Number of family members with LD: 1

Lost work/school: 6 months

Number of years sick: 2

Hi, my name is David [redacted] and I have had Lyme Disease off and on for 14 months out of an 18 month period. In April of, 1996 I didn't feel good for two weeks and had severe headaches , nausea, felt di zzy, and my joints ached. I went to the doctor and he said that I was just probably tired and stressed. The day after I went to the doctor I took a shower and in the mirror I saw a "bullseye" on my buttocks cheek. At the time I was relieved because I thought I "only had Lyme Disease". Boy was I wrong.

That doctor gave me antibiotics that I was deathly allergic to, but I figured that out on my won because he figured it was the Lyme making me that sick. He gave me a different antibiotic but it was the same base medicine and made me sick again so I switched doctors. The new doctor put me on antibiotics for a month and said that the Lyme Disease was "now you see it, now you don't" so I didn't feel good and I was waiting for the symptoms to go away on thheir own. I didn't feel good throught the winter of 1996 but I just thought that was the way it was with Lyme. Then in March 1997 that I got all of the beginning symptoms back again. Headaches, nausea, dizziness, neck hurt so bad I couldn't move my head, knees hurt so bad I could hardly walk, I missed a lot of work AGAIN, called the second doctor I went to and told him I had all of the symptoms again, he told me to take Tylenol. So, I went back to the first doctor and he said he would give me a blood test. Blood test showed positive for Active Lyme Disease. He put me on an antibiotic immediately. I told the doctor I wanted to see a specialist. I saw Dr. DeBenedectis, a specialist, but before he could see me I was on antibiotics for 10 days and he wanted his won blood tests. His blood test came back negative because I was on a antibiotic for 10 days previously. He said I didn't have Lyme and wanted to test me for MS. The test really showed a false negative.

By that time we were on-line with ALDF and AOLyme and the Lyme Disease Coalition and had information saying being on antibiotics before the blood test would make it come up a false negative. I still had all of the symptoms plus somedays my vision was good and some days it wasn't. The ALDF referred us to Dr. Tarpinian in Easton, PA. It's 120 miles round trip to Dr. Tarpinian but he is very good with Lyme Disease and didn't treat me like I was crazy in the head. He understood all of my symptoms and problems because the patients he deals with and he personally knows a doctor with Lyme Disease. I am presently on Ceftin 500MG twice daily which is $348.00 after insurance co-pays. I have had numerous blood test, antibiotic prescriptions, doctor visits which insurance is not willing to pay for. They deemed some of them unecessary. I have been on antibiotics for 6 months so far this year, missed a lot of work, thank God my wife and I run our own business at home, I developed muscle twitches, on medication for that and am also being treated for severe depression. I asked Dr. [redacted] how people who work in factories or people who are not in their own business with Lyme Disease get through dealing with the disease. He said he saw people lose their jobs, lose their homes and lose their families because noone understands the disease. As far as my situation with my job and my wife, I think one of the big things that is helping us is that fortunately through our business we have a computer that is on-line aand through that we got Dr. [redacted] name and talk to many, many other people in my same situation over the internet.

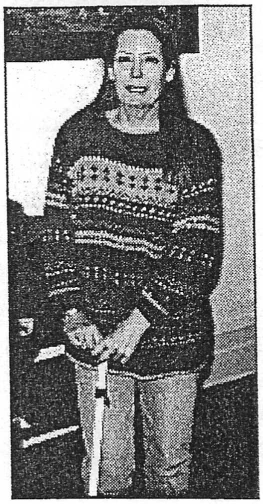
We don't know what's in store for the future. Dr. [redacted] said it could reoccur yearly for a minimum of 5 years, not at all or reoccur forever. We don't know what permanent damage, if any, is possible over the years. I can't do my normal daily routines anymore. We have to get people to mow the grass, plow the snow, paint the house, etc. because I am not able to do the things I used to before I got the Lyme Disease. My body won't allow me to. All I know is that Lyme Disease is a horrible disease and is not "in my head". I used to have a happy, active lifestyle but that is no more. I haven't found an eye doctor that understands Lyme Disease yet. I have "floaters" and "blurry spots" that affect my vision but the eye doctors never give me a solid answer about it. I think it's because they don't understand Lyme Disease.

Lyme Disease has definitely changed my life...and definitely not for the better.

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

State: New Jersey
County: Monmouth

Name: Ann [redacted]



Total cost:

Number of family members with LD: 1

Lost work/school: 1985

Number of years sick: 17

MY HISTORY IS LONG AND COMPLICATED.

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

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

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

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

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

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

STILL NO MENTION OF LYME DISEASE

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

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

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

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

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

(PLEASE NOTE: 1/3
OF ALL CASES OF
INTERMEDIATE UVEITIS
ARE CONSIDERED TO BE
LYME DISEASE RELATED)
-
ARTICLE DATED 11/95
PLUS RESEARCH PREVIOUSLY
DONE DATING BACK TO 1986

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

State: Maryland
County: Washington

Name: Mary [redacted]

Total cost: ?

Number of family members with LD: 1

Lost work/school: Retired

Number of years sick: 5

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

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

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

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

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

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

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

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

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

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

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

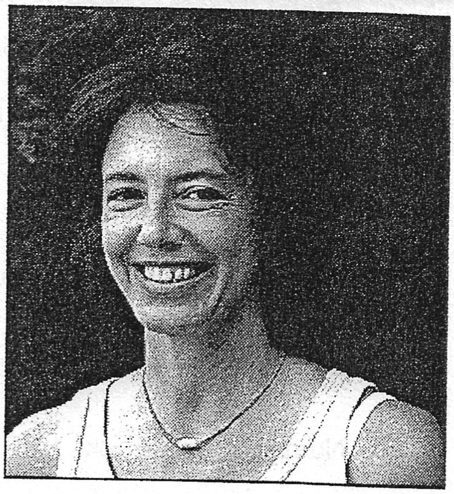
October- 1995 Relasped again, doctor refused to give me anymore antibiotic Was told to live with it and I would probably be in a wheelchair in a few yrs. I began to study this strange disease called Lyme Disease and went over all my tests and immediately noticed one of the main symptoms was High Protein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

(cont'd)

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

State: Maryland
County: Harford

Name: Virginia [redacted]



Total cost: $100,000+

Number of family members with LD: 1

Lost work/school: 7 years

Number of years sick: 7

Nightmare on Lyme Street

[redacted]

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

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

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

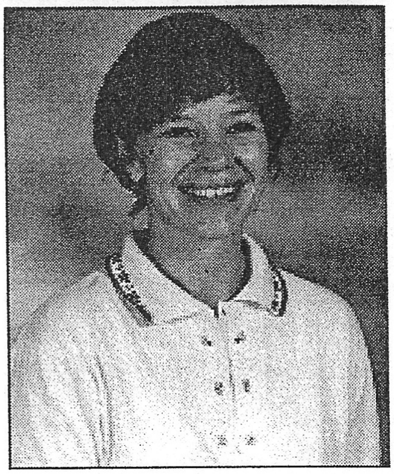
I am still not completely cured. I have given seven years of my life to this debilitating illness. I am still not completely cured. I have been mis-diagnosed by doctors who almost willfully refused to take my symptoms seriously. It has been an extremely expensive illness, simply because it was diagnosed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

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

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

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

State: Massachusetts
County: Plymouth



Name: Susan [redacted] RN

Total cost: $10,000

Number of family members with LD: 1

Lost work/school: Work 10

Number of years sick: 1 1/2

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

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

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

Please pay attention to Lyme Disease, No one should

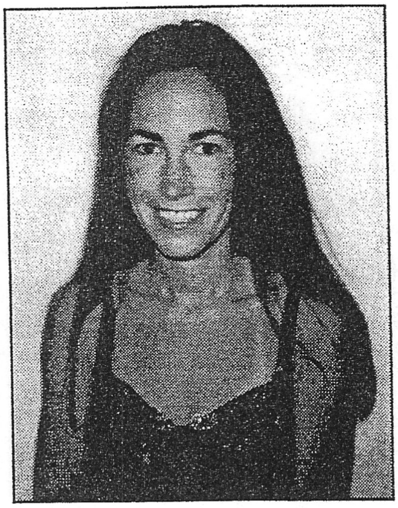
OVER

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

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

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

State: New Jersey
County: Somerset



Name: Caroline [redacted]
Total cost:

Number of family members with LD: 1

Lost work/school:

Number of years sick: 2 years

I began by having very odd symptoms - stomach problems, headaches, tiredness. I had never had any complaints like this before. then I had numbness in my arm and pins and needles all over my body. I heard from at least 20 doctors, "its stress and all in your head"! My parents turned against me and made me go to a psychologist. However, I kept pursuing doctors activily. Knowing that I was sick. Finally. after 2 years. I was diagnosed. To This day. My parents don't understand my dilemna. They think its in my head. They have pretty much left me on my own and offer little help with my life. I am 26 years old and my job. life and independence have been taken away. I suffer from achey muscles, knee problems. memory loss, vocal problems, eye problems etc. everyday. But, at least I'm assured that this problem is real and it has a name. I would love to be able to help others in my situation. I am always trying to convince my friends that this "tick borne illness" is a real threat. But, I feel like we need to do more because society still thinks they are invincable against this

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

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

After 11 doctors, including a rheumatologist, 2 internists, 3 ophthamologists, neurologist, neuro-psychologist, neuro-surgeon and infectious disease specialists 9 both clinical and academic) from Hagerstown, Frederick and Baltimore,It is very clear that doctors of all specialties need to educated in the complexities of this disease without the politics of peer pressure, Insurance Companies restrictions on medications, Real Estate supression of an unhealthy problem in their area and above all the criteria put on our local Health Dept. by the NIH.

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

People in Maryland are getting very ill,

It is not right that sick people have to fight to get well.

It is time for strong well individuals to step forward and realize that time is running out for them as they may be the next to get this disease and ask questions and find answers before its too late.

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

State: Missouri
County: Grundy

Name: Alice[redacted]

Total cost: ?

Number of family members with LD: 1

Lost work/school: 6

Number of years sick: 6

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

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

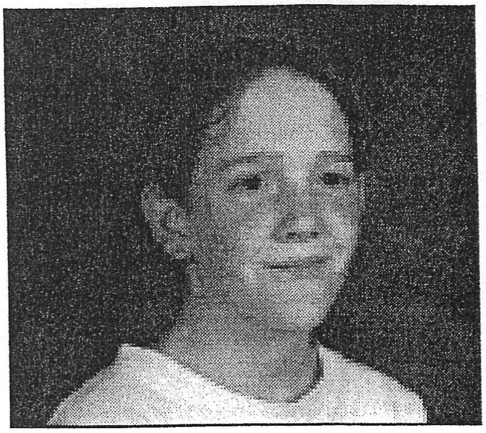
take her off of them

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

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

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

State: California
County: Contra Costa



Name: Wade [redacted]

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

Number of family members with LD: 1

Lost work/school: 1 year

Number of years sick: 2

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

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

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

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

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

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

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

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

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

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

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

State: Wisconsin
County: Washington

Name: Jon [redacted]

Total cost: $6,000

Number of family members with LD: 1

Lost work/school: weeks

Number of years sick: unsure-possibly 5 or 6


Jon is third from the left, top row.

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

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

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

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

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

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

State: Connecticut
County: Hartford

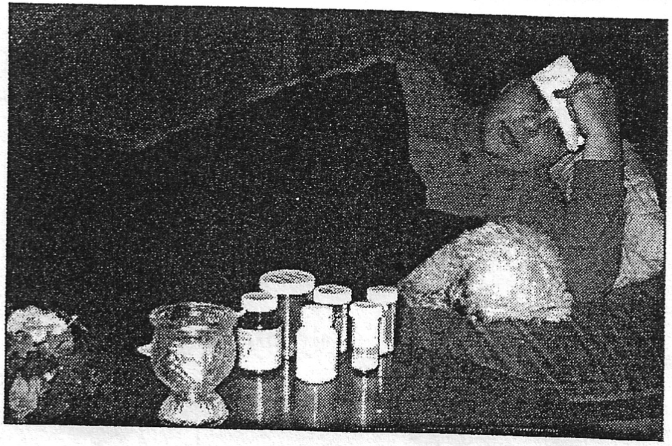
Name: Gia [redacted]

Total cost: $350,000

Number of family members with LD: 2

Lost work/school: 2 yrs.

Number of years sick: 5



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

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

Thank you for reading this letter.

[redacted] , mother, wife, and Lyme sufferer

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

State: Indiana
County: Adams

Name: Charile [redacted]

Total cost: $3,100

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

Dear Karen Forschner:

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

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

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

State: Indiana
County: Adams

Name: Jean Porter [redacted]

Total cost: $34,000

Number of family members with LD: 5

Lost work/school: 7 months + misc.

Number of years sick: over 2 year

Dear Karen Forschner:

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

State: Indiana
County: Adams

Name: Jason [redacted] (12)

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

Dear Karen Forschner;

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

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

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

State: Indiana
County: Adams

Name: Ryan [redacted] **(8)**

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: over 1 year

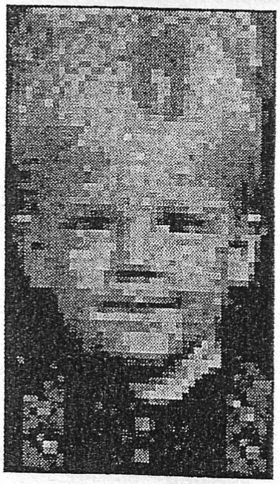
Dear Karen Forschner:

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

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

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

State: Indiana
County: Adams



Name: Nathan [redacted] **(4)**

Total cost: $925

Number of family members with LD: 5

Lost work/school:

Number of years sick: At least 2 years

Dear Karen Forschner;

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

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

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

State: New York
County: Cattaraugus

Name: Elizabeth [redacted]

Total cost: $200,000

Number of family members with LD: 1

Lost work/school: 6 months

Number of years sick: 3-4 before diagnosis

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

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

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

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

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

State: Connecticut
County: Fairfield

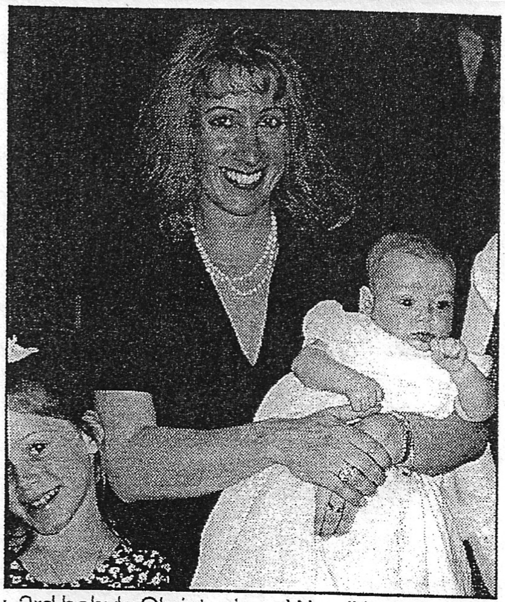
Name: Marie [redacted]

Total cost: >$150,000

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

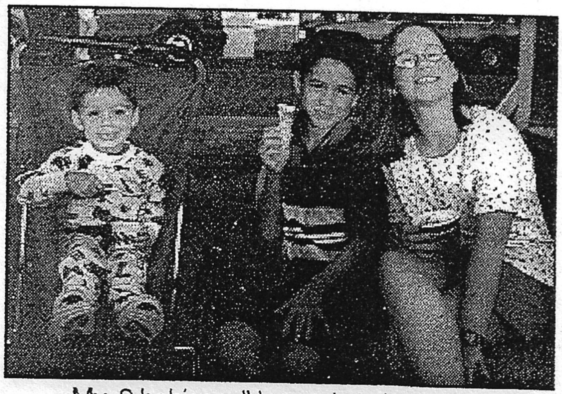
Lost work/school: immeasurable

Number of years sick: 5



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

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



My 3 babies all have chronic Lyme.

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

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

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

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

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

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

State: Connecticut
County: Fairfield

Name: Alyssa [redacted]

Total cost: >$150,000

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

Lost work/school: ongoing!

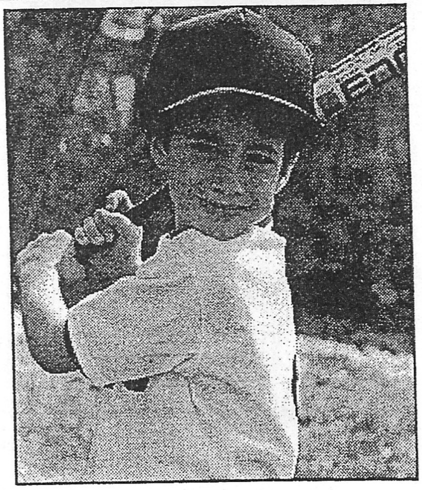
Number of years sick: 2 1/2

Nearly 11 years old.

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

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

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



State: Connecticut
County: Fairfield

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

Total cost: >$150,000

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

Lost work/school: ongoing!

Number of years sick: 3 1/2

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

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

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

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

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