Patients
In The Lyme Light

Reflections on Lyme disease

A collection of adult and children's poems, drawings, artwork and resources.
Written with love from Lyme disease patients.
Acknowledgements

I would like to thank all the special help I received to make this publication become a possibility. Without the encouragement of Chaz, WildCondor and the many other people, I do not think I would have even tried to make a book of writings. Without Ann’s help with editing, this project would not have gotten off the ground. Ann was terrific to say the least. She offered a steady source of support and encouragement as well.

The book was intended to be a fundraiser for LLMD’s who needed extra support during the ordeal of legal battles. It is available now for anyone or any fund-raising activity for Lyme disease. I am grateful to have an opportunity to encourage others to get all the possible help that they can; the patients and families.

A few people read early drafts of the writings and provided encouragement. Thank you.

The final step was to print, scan and provide access to the book over an Internet site.

I would like to thank Dawn and Don for their support to have the book available. Without this help, I would be overwhelmed with printing costs. Finally, I would like to thank Karen for funding the printing of the few copies I needed to send out.

Last, but not least, I would like to thank all the writers and artists who contributed their work. The title was picked by everyone who made their suggestions.

I would also like to thank my mother who encouraged me to find the strength to get better and for her loving presence in my life. My daughter, who is a constant ray of sunshine. And, to my ex-boyfriend who did try to encourage me the best he could. And, of course, my LLMD and Lymenet who helped me to get well and without their help, of course I wouldn’t be writing this. Gigi, thank you for being there for me too!
In the Heart of Lyme
Reflections

(I wrote this poem one month after getting Lyme, not knowing what it was. I left a man whom I loved to go to NY. He warned me not to go because there was Lyme disease in the area. I arrived there on August 2, 2000 and got bit by a tick 2 weeks later. I have since left NY and came back to Seattle. We were together for a year and a half. Just recently, I left him after I got better. Our relationship ended abruptly and sadly) I think soulmates can be at odds, but I will always love this man in my heart.

I look up at the early, light blue sky,
Surrounded by the angelic white clouds,
I have a picture of you in my heart,
I've asked the angels to be with you today
And never leave you again.

I sit on my porch and stare
At the beauty around my soul (like we used to)
I hug you with all my tears,
And can't see through my transparent eyes.
I reflect on the revolving door of my life.

It's an illusion!
I chose that door not believing my heart
But, being afraid instead.
I may have walked through that time,
But, it was with hesitation and bitter resistance.
Now I am stuck in the door like a child,
Pounding my fist into a pillow and crying,
Not being heard.

I have been told I have an illness,
They put my head through a scan and once again,
They can't find out what is wrong with me.
I just pray that the angels will not leave me again.

I listen to the strong breeze whip through
The summer autumn sky,
Remembering me looking up to the sky above your bed.
We were so happy and alike in our spirits,
Pretending to be asleep with each other
As we held our bodies closely. Were we?
Your touch was so magical,  
It's on my mind when nobody is around.  
It is existing at this moment and for ten trillion more.  
You knew me like the wind knows  
The sky, trees, flowers and the wings of birds,  
It rippled through me as it touched the roots of my soul,  
As did our laughter.

I feel you are asleep now.  
It is very early where you lie.  
My heart of hearts feels tenderness for you.  
I guess I now understand unhappy endings  
Sad melancholy endings like in the movies.

As the leaves turn from green to red, where I sit  
My heart of hearts will always be with you.  
No matter what occurs in my life or yours.

Maybe love is eternal.  
The sky is still light blue,  
And there are still angelic white clouds.  
The weather has changed only a little  
Since I left sitting on this porch.

Nancy S. (Seattle)
Dear Friend,

I hope and pray that you get better. Lyme Disease and the co-infections (i.e. Babesiosis) are complicated issues. Please be assured that beginning your journey with a LLMD (Lyme Literate Medical Doctor) will be crucial to your health.

It may have been in the past you have had many symptoms and an excellent LLMD can help you with most if not all of the Lyme Disease issues. As time goes on, you will learn more and more about Lyme Disease (and the co-infections) and thus learn you’re about your body as well.

You will be able to see how everything relates and that understanding will help you. Be open to new ideas, and question how Lyme Disease works. Ask yourself," Does this relate to my illness?"

Don't ever quit. Believe in your doctors process. That is so important. Your symptoms and test results are your LLMD's map to your recovery. Little by little, like a castaway on an island, the clues unfold for you and your LLMD. The "ah ha's" begin, the feeling of awe as you move yourself out of this island and onto the land where you feel grounded. Be patient though, because like all lymies, we need a good LLMD to sort though all the complicated issues.

There may be times when you feel like you are over this thing. Your symptoms are crucial to your total healing. I have lived with denial about my disease, going back to work when I wasn't ready and getting sick again.

It also seems as though you could get more confused with too many answers from all kinds of help. Keep it simple. Know your body, step by step, and then let the healing begin. Know your LLMD, and look for one that has treated many cases of LD, some similar to yours.

As far as support goes, there is Lymenet, as Chazmyn mentioned in her letter. On Lymenet, you can gain additional information that can help you get better. Your LLMD is like a compass. Lymenet is similar to your friend who can direct you back to the main land.

As you read all the responses, perhaps your gut will help you too. A good LLMD, a good attitude about healing, and a solid patient history that your LLMD has about you is important. The true roadblocks will unfold by your testing results from reputable labs, your history, and known allergies. All this should come from one doctor. So reaching out is important - so you and your LLMD can find the true "ah ha's" together.

As you and your LLMD begin to get grounded in the healing process, may you find that your healing is a miracle...little by little, step by step. And, by all means, keep saying, "I will get better."

Painted Rabbit (WA)
How to Cope

My name is Chazmyn and I have Lyme Disease.

If you're reading this, then you must have also been bitten. I'm sorry you are not feeling well - but welcome to LymeLand.

Lyme is a baffling disease and you need all the help you can get to surf these waters. I would like to help and share a few things I've learned in my travels through Tickville. The most important thing is to have a good doctor. LLMD's or Lyme Literate Medical Doctors are your best bet for regaining your health. They treat lots of patients and are more experienced with the multitude of strange symptoms we have.

You will also need to do some things for yourself.

You need to rest. Rest. Rest. I know this is hard, people have lives and obligations - but you also have an obligation to yourself. You will not get any better unless you schedule some rest for yourself.

Drinking lots of fluids also helps. Water is best and helps wash out the toxins. Your doctor should also have you on some type of yeast treatment as the antibiotics destroy "good" bacteria along with the "bad."

Speaking of "bad bacteria", the Lyme germs cause a reaction when they die-off. The reaction is called a "herx" [Jarisch-Herxheimer Reaction] and involves pain, swelling and discomfort. Your doctor will advise you the best thing to do when this occurs. Some say to cut back on the antibiotics if the reaction is too severe.

You will also need some type of support group to help you with other questions and to help navigate the troubled waters. You will feel better when you realize you are not alone and that many, many others are in the same boat. There are a few Lyme support groups on the Internet. Lymenet is the best (in my opinion).

Keep a journal. Buy a small daily calendar and write down your symptoms each day. It only takes a moment, but will be very helpful in helping you keep track of when the "flare-ups" occur. This will enable you to have a semi-regular life on the "other days".

Patience. Depending upon how long after you were bitten - before you received treatment, the first few months can be slow going. It may be many days or weeks before you see improvement. Don't despair... It takes a while - but then one day you'll realize - you feel okay. For about five minutes. Then one day, you'll have a good ten minutes. On and on. Eventually, you'll even have an entire "good day". Don't be surprised, though, if the next day - you feel worse than ever. It's a two-steps forward, one step back process.

Lyme Disease can affect any or all organs, including the brain and heart. This is tough to hear - but you need to be aware. If you have symptoms like depression and rage, be sure to mention them to your doctor. Depression needs to be treated along with the Lyme Disease. It is very common. Having such a horrid disease IS depressing. Losing your health is a shock to your system. Some people, although not the majority, also experience rages and suicidal thoughts. Do not go through with these. Realize they are a by-product of the brain swelling. You will be
able to see your knees and feet swell--but not your brain. If you have strange impulses, hear voices, act in ways you never have before - let your doctor know. Don't be too embarrassed to mention it. This is NOT YOU - this is your brain on Lyme.

Research and learn about the disease, but always listen to your own instincts also. Friends and family usually have a hard time understanding how you can look perfectly normal but feel so horrible. They may say it's all in your head. It is. It's in your head, your heart, your internal organs, your joints and your muscles. And it moves. It travels throughout your body. This is good and this is bad. It's bad because it's extremely painful and confusing. It's good because just when you think you can't take it anymore--it moves to another area to torture you there. It can affect your elbow in the morning, and move to your knee by the afternoon. This is another reason why other doctors don't understand the disease. But this is also another "red-flag" indicating you have Lyme.

Take some time and discover things you can do to treat yourself when you are feeling bad. Books, movies, hobbies, hot baths, inspiring and uplifting friends, calming music, etc. Have them ready. Then when the bad times hit - you'll be prepared. It's lonely at 3AM when you're plagued with insomnia. Have something to help you. And insomnia and bad dreams are very common. Also, light sensitivity, sound sensitivity and being extremely sensitive to "everything" is common. Hang dark curtains up on your windows if you have trouble with "early awakening". Leave the harsh chemicals in the closet and clean with vinegar and baking soda. Listen to your body.

Avoid stress and stressful situations as much as humanly possible. Stress aggravates Lyme and also weakens your immune system.

Take care of yourself and I hope you feel better soon. Please come and visit me and my friends at www.lymenet.org <http://www.lymenet.org> in the flash discussion section.

Yours in Healing and Harmony,
Chaz
32 WAYS TO FEEL BETTER WITH LYME DISEASE

Release all the heartache. Fly with the eagles, soar with the wind, set your spirit free. No more heartache. Freedom of the skies. Love yourself and give yourself a break, make peace with your family and let go of all burdens, release negative thoughts, go to a Lyme Literate doctor, realize your potential and never give up on your dreams, laugh at yourself, play with a child and don’t forget to discover your gifts. Paint, read, draw, run, jump skip and sing. Trust in your instincts, listen to your inner voice. Take off your coat of armor to let others realize your vulnerabilities...If you are tired, take that much needed nap. Naps are healing for our health. Release the tears, begin your healing...Love is life’s greatest gift, treasure it.

Written by Nancy, Laura, Gael, Andrea, Margaret & Sheryl
"Don'ts" to Live By

(This is wonderful - Here are my favorites!)

Don't undermine your self with by comparing yourself to others...
   it is because we are different that each of us is special.
Don't set your goals by what other people deem important;
   only you know what's best for you.
Don't take for granted the things closest to your heart;
   cling to them as you would your own life, for without them, life is meaningless.
Don't let life slip through your fingers;
   by living in the past or for the future, by living your life one day at a time you live all the days of your life.
Don't give up when you still have something to give;
   nothing is really over until the moment you stop trying.
Don't be afraid to admit that you are less than perfect;
   it is this fragile thread that binds us to each other.
Don't be afraid to encounter risks;
   it is by taking chances that we learn to be brave.
Don't diminish your dreams;
   to be without deems is to be without hope, to be without hope is to be without purpose.
Don't run through life so fast that you forget not only where you have been but where you are going;
   life is not a race, but a journey to be savored every step of the way.

The world cannot be discovered by a journey of miles, no matter how long, but by a spiritual journey, a journey of one inch, very humbling and peaceful by which we arrive at the ground by our own two feet, and learn to be home within ourselves.

Take a moment to remember that life is sacred...all of life...
A few short years on this planet and we are gone.
Do not spend time worrying about all that has gone wrong.
You will miss the lesson, the gift, the gift of life...and the privilege to live.

Laura P. (NY)
In Praise of the Internet and the Lymenet Flash Board
(Lymenet Flash can be reached at http://flash.lymenet.org)

"I have been on Amox for about a week and I have noticed I'm tired all the time. Could this be a herx? I have been tired since getting sick but never this bad. Thanks."

This is just one of the many messages posted online by people seeking advice and guidance. The terminology may look like Chinese to some, but to those belonging to this ever-growing group, it is just a normal conversation. The people on this and other similar websites are tied together by a common thread; they are all suffering from or affected by Lyme disease and/or other tick borne diseases.

Most have Lyme disease and many are also infected with one or more of the recognized co-infections, Babesiosis, Ehrlichiosis, and Bartonella, which can all be transmitted by the same tick bite. I should say "we" because I belong to this club of "Lymies," as we endearingly refer to each other.

Many here know my story, but others have heard only bits and pieces. I have been sick for about four and a half years, although the infection could have been in my system for much longer than that. I did not have a positive test until last summer when one finally turned up positive. I have been to many doctors, been on many medications, but I have not yet beaten the resilient bacteria that courses through my veins. My story is similar to many others and, like so many, the end is not yet in sight.

On this site, we gather together to support each other and be supported, to seek advice and get answers. In essence, we come together because we are alike and that likeness breeds understanding. A kind of understanding that others cannot have, no matter how hard they try, simply because they do not know what we know. They do not know what it feels like to have a body under attack by those microscopic enemies.

There is comfort in being with others who know what it is like to be told you are crazy, who have been bumped from doctor to doctor only to be told that nothing is wrong. Others who know enough about antibiotics and painkillers to become pharmacists and enough about this disease to be a better doctor than those we (not so endearingly) refer to as "ducks."

Here race, gender, and age do not matter. We are all equals. We do not even refer to one another by our real names most of the time but by our made-up screen names like Tincup, Lymetoo, mothertooeight, and runner21. We are like family, with short fights among members but with a deep sense of love, understanding, and acceptance.

Those who have been sick for years or even decades gather and give support and advice to those who are just beginning down this path. Those beginning new treatments can ask for any information or advice from those who have tried the treatment in the past. Articles are discussed, doctors are recommended, jokes are made, and hope is shared.

On this website, I have heard many disappointments when medicine does not work and too few triumphs when it does. I have posted my share of questions and learned so much from those who try to give me answers.
Through the challenge of dealing with the many components of Lyme disease, I have not only discovered an inner strength that I never knew I had, but I have met some amazing people. They give me the courage to keep fighting and the faith that someday I will be able to type the message, "I am well!"
Annie (MA)
(My Dad died last June and I’ve had a lot of problems dealing with it - recurring dreams, crying jags that last for days, trying to forgive myself and begging my Dad to forgive me for leaving him in NY when he seemed to be improving and I needed to get back home because I was so sick. His birthday is May 8th and to honor him, I have decided to quit smoking on that day because I know I will never ever pick up another smoke after making that promise to him (his spirit). But what I really want to share with you is a poem I came across after my Dad died. It’s called "I Wish You Enough..." and tells about a father & daughter in their last moments together.)

I Wish You Enough....
I wish you enough sun to keep your attitude bright.
I wish you enough rain to appreciate the sun more.
I wish you enough happiness to keep your spirit alive.
I wish you enough pain so that the smallest joys in life appear much bigger.
I wish you enough gain to satisfy your wanting.
I wish you enough loss to appreciate all that you possess.
I wish enough hellos to get you through the final goodbye.

Deb (NH)
Every year the Florida Folk Association has a song-writing contest. There are many wonderful entries and a couple of years ago I thought I might try my luck at it. Don't know what made me think I could do half the job the songwriters do. The song had to be about Florida of course.

I wrote a song about my momma and my daddy and how I came to be a half breed (Yankee and Rebel) from Florida named "Cracker" Crumbs. I had planned to play it to a soft, sweet tune on a dulcimer and sing it some day but, I never thought it complete, so it sits on the shelf.

I used some of the words from my song to fit into this poem below about the bad ducks meeting their fate in our Florida Gator Pit.

**A Ducks Fate in the Florida Gator Pit**

Rustlin' leaves of palm trees blowin', sweet scents of flowers flow.  
Gators eyes at twilight glowin', and swamp tides running low.  
Shore birds on the sandy beaches, beneath a sky so blue.  
A gator pit has come to be, just for a duck like you.  
Stone gray wonder, the manatee, the dolphins flyin' high.  
You misdiagnose just one more friend, and in the pit you'll fly.  
Skeeters hatching, wetlands hum,  
The gators eat ducks one by one.  
We tried to warn them, See the light!  
But they were never all that bright!  
Raging storms with lots of thunder, blowing winds will take you under.  
But don't fear that I say, old duck, you have just run out of luck.  
Hot summer heat, but it won't kill.  
Old slymie swamps, you'll git your fill.  
The bugs as big as dinner plates.  
But... the gator pit will be your fate.  
You can kiss yer butt good bye, for being such a duck.  
We only wanted you to help, but at that, you did suck.  

Rustlin' leaves of palm trees blowin1, sweet scents of flowers flow.  
Gators eyes at twilight glowin', and swamp tides running low.

Tincup
Rage from Lyme
Annie's Poem

Head hurts.
Mind aches.

Neck creaks.
Heart breaks.

Eyes blur.
Voice screams.

Ears ring.
Spirit dreams.

Legs cramp.
Muscle burns.

Feet swell.
Soul yearns.

Body weakens.
Time flies.

Smiles fade.
Soul dies.

Annie (MA)
Terter's Poem
(Lyme Literate Medical Doctor = LLMD)

Thanks to not having an LLMD,
Lymie Land is where I'll be...
Stuck inside this ditzy brain,
Can't remember my own name...

Aches and pains, I hurt all day.
Muscles, joints... don't waste away!
Antibiotics all around...
Pardon me while I feel down.

A miracle has come my way!
an LLMD has decided today...
To help me to find "the way"!
He's always there, to be sure,
To work with me to find a cure.

What comfort is my family,
And my insurance company!
How lucky do I have to be
With faith, and the security-
of all of these and an LLMD!

This poem was so much fun,
I just might write another one!

("forum" is the Lymenet Flash Board)

This is the greatest forum for Lyme-
I know, I post here all the time!
Tincup knows how to keep us in stitches
But she knows when to change the switches.

Knowledge she has lots, on ticks
And makes us laugh with all her tricks
I know I found the place for me
This will go down in history.

A place to learn, a place to vent,
In the field of Lyme, we are making a dent!
With deep regret I end my poem
Because I am not alone;
My kids are home from school on time...
if they new that I was talking about Lyme-
they'd kill me even though I rhymed!

       terter
The curse

The curse spoke to my body and flooded me with emotion:
"Go to the sun like a child,
Let the wind talk to your soul,
The sun shines brighter now.
Grab the sunlight in the meadow, idealistic one,
Allow yourself to be free and wild.
Let the wind lift up just the roots of your hair,
Allowing sweat to pour like tears.
Cry and lift the rainbow from your eyes.
Love and touch everything with compassion.
Burn and allow the fire to rage at the curse.
Now you can heal."

Heat is constructive to my soul.
Heat is the energetic color
That melts my curse and yours.
Stars glitter in the distance.
Shining through a black translucent sky.
Illuminate yourself in stars.
Pierce the curse so that you will be full
Of glitter and life and your dreams.
Glitter is present in my past,
And in my heels and in my eyes.
Glitter exists in healing and in movement.

Movement, like a horse. Oh powerful horse,
Move us up and beyond the curse of the body.
Feel the warmth in the horses’ eyes and gallop,
So we can ride, ride life like a dream again.
Dream in energetic color.
Splashes of color, soaking up
The diseased landscape in your heart.
Feel the hot sun burning through
The ugly curse that consumes your body.
Laugh and lift the curse...
The sun will shine again.

Fall, fall into the perfect meadow,
Allow yourself to feel
The sweet, soft whiteness of nothing.
Look up to the clouds
And allow the Gods to laugh with you.
The gold on the leaf is evident now.
Dreams, healing and happiness are made of color.

Painted Rabbit
Ex-Marine still facing challenges
The News-Gazette, Champaign, Illinois, August 2001
By ERNST LAMOTHE JR.
(Published Online July 29, 2001)

RANTOUL - Danne Buchanan of Rantoul walks with a noticeable limp, suffers from constant fatigue, his eyes are highly sensitive to sunlight and his body twitches. That is a far cry from the man who five years ago could run 20 miles with 60 pounds of military gear on his back. Buchanan is showing the effects of osteoporosis and Lyme disease he says he contracted in the Marine Corps in 1994.

The disease, which claims muscle and joint pain, energy loss and fevers as some of its symptoms, is spread by bites from deer ticks.

The day he was infected with Lyme started out normally.

He was out patrolling on a training mission at Fort Bragg, N.C., and Buchanan, 34, didn't notice it until he got home the next day. He saw the bite and removed the tick from his arm with tweezers. Several days later, he felt sick.

"I didn't think anything of the bite at first, but I started coming down with flu-like symptoms and something didn't feel right," Buchanan said.

The bite started as a small red circle, then spread outward, becoming white in the center and spanning five inches. He was admitted to a naval hospital and stayed for 20 days while doctors gave him antibiotics. The upper east coast is known for bouts of Lyme, but North Carolina displays only moderate cases, according to the Centers for Disease Control.

After the pain remained, Buchanan asked for further treatment. Instead of getting support from the military he always wanted to join, he said, the Marines turned their back on him.

"They said life could be made very difficult on me if I kept asking for any more medication," he said. "I felt like I was betrayed." Military officials did not return calls seeking comment.

Buchanan took his case to the Department of Veterans Affairs last November, seeking a chance for full disability for Lyme and degenerative arthritis to his knees, an ailment also caused from military action, according to Buchanan. The response fell well short of his expectations.

In May, the VA Ratings Board sent a letter to Buchanan assigning him a 10 percent service-connected disability rate or $101 a month.

But intravenous medicine alone for six weeks cost double that amount. Ten percent means the board agreed there was painful or limited motion of a major or group of minor joints, according to VA reports. It's the most common level of disability for veterans, with more than 853,000 people. VA reports state a 20 percent evaluation was not warranted because Buchanan didn't have two or more major or minor incapacitating joints.
The percentage given for each case is set by law depending on the injury, not the extent of the person's disability. Nationally, Lyme accounts for 114 out of 2.3 million veterans' cases, according to the VA public affairs office. Any adjustments to the rates are based on whether there are loss of limbs, veterans who need constant assistance eating and bathing or service-related injuries that render employment impossible.

Buchanan said the amount the VA gave him hardly covers the $15,000 in medical costs for more than five different medications he has taken since leaving the military. He tries to take care of the bills a little at a time, but some remain unpaid. Carl Henderson, spokesmen for the VA in Chicago, said two steps are involved in determining the disability payment. First, the organization examines the individual's service records to determine if the injury was a result of active duty. Then the ex-soldier undergoes examination by VA doctors on the extent of the injury. Though Henderson wouldn't talk directly about Buchanan's case, he said the system is as objective as possible. Henderson said the evaluation never takes liability - whether the soldier caused the illness - into account and only focuses on giving veterans benefits for service-related injuries.

Through outpatient treatment reports, his service medical records from May 20, 1994, to Feb. 2, 1999, and VA examinations, Buchanan received the 10 percent compensation for Lyme, but the department rejected his arguments of adjustment disorder and arthritis. The military claims the knee injury is not service-related, according to the ratings board.

"How many 34-year-old people complain about having osteoporosis?" Buchanan said. "How can you not see the daily weight I carried on my back in the Marines and not connect it to my bad knees?"

The department allows every veteran to request an appeal within a year of receiving the original decision by writing a letter to the appellate board. The board takes up to 205 days to reassess the appeal, according to the VA public affairs office in Washington, D.C.

Buchanan didn't appeal because he said he didn't want to go through the same process that took more than six months and possibly be disappointed again. After he received an honorable discharge on Feb. 5, 1999, Buchanan set his sights on being a cop as another way to serve his country. However, the Las Vegas police department saw his military records and he was denied a job, Buchanan said. A sudden halt for a man who thought he would be in the military for 30 years. Hungry to live out his life's dream of defending his country after reading books about soldiers' bravery in war, he began his military career in the Marine Corps on April 9, 1991. Two years later, he joined reconnaissance school.

Like the Army Rangers or the Navy Seals, Recon is voluntary and each cadet can drop out at any time. Buchanan successfully completed the nine-week course, which included a "hell week" of running six miles a day and not sleeping until "they break you," he said. Buchanan said he used his strong wide-framed body on training missions to his advantage over smaller but quicker soldiers.

"For a guy my size it was great to make it through the program because the next biggest guy to me was 190 pounds," said Buchanan, who weighed 260 pounds after graduating.

He received Good Conduct Medals and awards as a sergeant for his technical work as a leader for the Marines. But now, there are obvious signs that his ailments have taken a toll on the former commanding officer.
The 6-foot 5-inch, 300-pound man, who used to carry those 190-pound soldiers on his back during Recon missions, struggles to pick up his 5-year-old daughter Danielle, and on some days walks with a cane. More severe cases of chronic neurologic problems have placed those afflicted with Lyme into wheelchairs, according to Dr. Joyce Beitel of Carle Clinic. The summer months have become more of a painful annoyance than restful pleasure. He wears protective sunglasses to shield his eyes.

Buchanan tried not to let these obstacles stop him.

He drove trucks for Creek Carrier in Lincoln, Neb., for a couple of years, a job made more difficult because he had to drive hours without taking medication that might make him drowsy. Buchanan missed numerous days of work due to doctor appointments and sickness. He went from earning $1,000 a week to $250 because he worked so few hours.

Buchanan's next step was looking to the government for help. He went to U.S. Rep. Tim Johnson, R-Urbana, with his hopes hinging on at least getting 20 percent of disability, which would qualify him for educational funding to receive training for a new job. That would pay for him to go to school and choose another career. Matt Bisbee, press secretary for Johnson, said the office is looking into his complaint. Buchanan said waiting is the hardest part. But few things have been easy the last seven years.

"I just want a chance to prove to people how Lyme can just tear at your life, and move toward fully supporting my family," he said.
My Story - by Terter

I was diagnosed with Lyme Disease about 11 years ago. I had 3 negative blood tests until finally my last Western Blot came up positive.

I was sent from doctor to doctor with my myriad of symptoms; each one passing me to someone else, pronouncing me "cured", telling me to never call or come in again, or sending me to a psychiatrist. I stopped counting when I saw over 30 doctors...but some of them did help me to the best of their abilities. I was admitted to hospitals and went to the ER more times than I want to admit. One of my doctors committed suicide while my family was under his care. I spoke at his funeral. His doctor said that he had Lyme psychosis himself.

I used to work in Occupational Therapy at a rehabilitation hospital, never knowing that I would soon become the patient that needed rehabilitation. My mind and my body were falling apart, bit-by-bit.

I am not sure what was scarier - having to use a wheelchair off and on for 5 years, because of my movement disorder caused by Lyme Disease which gave me temporary paralysis, or the cognitive problems caused by this insidious disease.

I had gotten lost in my own home, had forgotten how to use a key and turn on a light switch, and even how to match socks. I lost my ability to do math-couldn't manage my checkbook or household without help. I saw two neuropsychiatrists who referred me to cognitive therapy, where I re-learned some skills, and how to compensate for the ones that I have lost. I have suffered visual and auditory hallucinations as well.

I have had virtually every body system either affected or in pain. Lyme Disease gave me cardiac and thyroid problems, and joint, bone, muscle pain, with swelling, burning, throbbing and aching everywhere-even my scalp. I have had ringing in my ears, bowel and bladder incontinence, choking on food, apnea, difficulty walking, and safety issues too. I once put my bare hands in the woodstove to turn over a log, and put my finger under a bagel to cut it!

At the same time that I was so ill with this disease, my two daughters, mother and sister were also fighting Lyme Disease too. We never knew who was going to be on IV therapy, in the hospital, or who could help who, and when. My oldest daughter lost some vision in one eye and had drop attacks. My youngest had learning disabilities, and obsessive-compulsive behaviors. I couldn't even help her with her kindergarten homework, as I was unable to comprehend the instructions.

Thanks to our faith in God, some wonderful doctors along the way, and supportive family, we have recovered so much of our health. None of us are left unscathed, but we are thankful for how far we have come.

It is so very important for those with tick borne illness symptoms to get to an LLMD-a Lyme Literate Medical Doctor, as soon as possible. If I had been to one as soon as my symptoms began, I would not be on Social Security Disability today...left with a Myoclonic movement disorder, joint pain, and minor cognitive problems. Thank you, terter
HERE LIES...

Here lies my heart,
strangely invaded, left
torn apart

By a disease some
say doesn't exist.
But we who have it
must insist.

Here lies my health,
once bitten, twice shy.
We measure our wealth in days gone by

Oh, but I am easily amused,
laugh with the jester
and with the fools,
mostly sunny with scattered blues.

Here lies my home.
Others like me roam
knowledge like a garden grown.

If you need a prayer or word,
here you can be seen and heard.
Vast halls of experience, rooms of pain,
much can and cannot be explained.

Here lies my hope.
Friends and neighbors from a wider scope,
a refugee when you just can't cope.

Wiser minds do oft prevail,
and some have been led out of hell,
wondering if it's the scariest disease because of its habits.
Or is it the most frightening because I have it?

A. Wryter
10/00
2nd Annual Halloween Submission
The Reality of Lyme Disease

(Written after Jacob warned his tutor that if he pushed himself too much he would crash, and when he did crash, she told him he had planned to get sick. He was very hurt. He had just tried to educate her on the nature of the disease, only to be accused of a psychological reaction to his own expectations.)

Don't plan to be sick. Such easy words from those who can live every day to the fullest, and not experience the frustration of a chronic illness.

Don't plan to be sick.

Don't plan to be sick, even though you haven't been well for the past 10 years. You have been sick since the age of 4, only to get better, then get sick again.

Every time you get better, you think this is the time that the sickness won't come back. This time the doctor knows what he is doing, this time you'll get the right medicine, and this nightmare will be forever gone. Then you can live like other people, and count on feeling well, and count on doing all the things other people do. But the nightmare returns again and again, and you find you can no longer trust your body, trust this disease, trust the doctor who knew he'd be able to fix you, because as soon as you trust, that trust is broken once more by pain and sickness returning. Don't plan to be sick.

One morning you wake up, and you feel an unusual feeling. You aren't sick. You tentatively put one foot on the floor, waiting for pain somewhere, and finding none, you stand on both feet. There is no familiar nausea, no head pain, your feet don't hurt, you stretch your arms and can feel both your hands. For the past several weeks you're health has been improving, but you never dreamed you could feel this good again. It has been slow, and the only way you realize how well you are now is by comparing where you were four weeks ago.

This is the best you've felt in months, and you rejoice. After weeks of nausea and fatigue, you are elated. The new medication is working. The doctor finally knew what to do. You have been taking your medicine faithfully, doing exactly what you are supposed to do, and it has paid off. You are out from under this dragging illness. You feel light on your feet, and you feel like doing everything. You want to go outside, but you want to stay inside and do all the things you've been wanting to do. You feel a great surge of energy, and know that this is how other people feel all the time, and realize why you couldn't do the things you should be doing all the time, because now you have wellness to compare it to.

This is what life is about. This is what every day should be. Your head is clear, it doesn't hurt. You can think, so you want to concentrate on something, just to remember how it feels to be in control of your mind. There is so much to do! You are happy. You are free. The world is a wonderful place. Life is great!

Day two, is much the same, and you wonder how you could've just lain around all these weeks and months. The world has too much to offer to waste it lying around. Maybe you weren't really sick at all. Maybe you've just been depressed, and think you've been sick. You forget very quickly how it feels to be sick, because it feels so wonderful to be well. There are more things to do, and you make plans to do all the things you've been thinking about for months. There is no limit.
Life is good. Day three, then day four, and day five, are all great, and you wonder again what made you lie around all that time. All those months of listlessness, were you really as sick as you thought? Why didn't you do all these things all this time? Go places, have fun, get caught up on your work. Laugh. Freedom. You barely glance at your old hangout, the couch, and you put away the comforter you always used.

"Not again, no never again, will I lie on that couch and be like I was before. I am a changed person. I am over this being sick thing. It's not going to happen. I am on the miracle drug. After 10 years of this, I will not let it return."

You are on a high, just from being able to do the things other people can always do.

Week two, and lying on the couch is just a bad dream. You'll never be there again.

Day fifteen, you awaken, and feel the pain before you even move your head. The room spins, and you try to sit up. You shuffle to the bathroom, on aching feet and ankles. This can't be happening. It will go away, you know it will. This wasn't going to happen again. What did you do wrong? Did you forget your medicine? No. Did you not get enough rest? No, you've been careful. Could it be the flu? Yeah, the flu, that has to be it. It is unacceptable to think the whole nightmare is back. Day two, you awaken to the same symptoms, day three and day four are worse. It isn't the flu, or it would be gone. Oh, why couldn't it have been the flu? The flu would be welcome, but not this. This doesn't go away in a few days. This is familiar. Why did it come back? What have you done? Were you a bad person? Are you being punished for something?

You didn't plan this, this return of symptoms, you didn't want this. Or did you? Maybe you knew that it couldn't last, so you set yourself up to get sick again? No, you didn't do that, you were much too busy and happy to think about it coming back.

Weeks turn into months, and nobody understands, because there for a few weeks you were a normal functioning person. You don't understand why it had to come back. You realize you cannot trust your body, you cannot trust this disease, you cannot trust your doctor to cure you, you cannot trust your family and friends to understand. After all, if you were well once, why isn't it happening again? Surely, it is something you've done wrong. And you are back down into the depths of the same old comforter on the couch, except this time, everyone is remembering what you were like when you were well, and by their accusing looks you know they can't understand why you just don't get up and act like you did before. .........................

Months later, you awaken one morning, to an unusual feeling. No nausea, no headpain, no spinning room, you tentatively take a step and your ankles don't hurt, you stretch your arms and can feel your hands. You remember another time, two times, three times, 28 times this has happened to you in the past 10 years, and you say to yourself, "I won't be tricked this time. This time I will not count on feeling well forever, I will not let my body trick me, the doctor trick me, and my family count on my feeling well again."

Day two, and day three, all goes well, and when someone asks how you are feeling because they notice you are more active, you shy away from any proclamations about feeling well, as it will only make a fool of you. You know from the past 28 or is it 78 or is it 278 times, that it doesn't last, so you fill each day with as much as you sensibly can, enjoying each moment of this good time, and wait for the good time to be over, as it always is.
Weeks later, after feeling great, and on top of the world, you awaken one morning to nausea, head pain and a spinning room. You have quit kidding yourself. This isn't the flu. You knew to expect it, but you didn't plan it. No, you don't plan to be sick. You just know you can no longer count on being well.

It is the reality of the disease. It is Lyme.

Judy Coleman - OH
Wings of Lyme
Nancy's Story

Lyme disease is the last thing I wanted after moving back to New York in August of 2000. After all, my childhood was all pleasant memories growing up on Long Island and camping Upstate. I could remember the lightning bugs as I unpacked my boxes. I felt like a child who had come back again for a long awaited vacation. It was the hot summer in August of 2000.

My camping adventures were almost twenty years before. But, now in 2000, my boyfriend, "M," and I bought a beautiful home in Claverak, NY. We purchased the house from an owner of a local newspaper. "How perfect," I thought. I studied communications in college and this seemed like a perfect fit.

I can remember driving back to the house after we landed in Albany and asking a local man about Lyme disease. He told me, "No, that is just on Long Island." Somehow I didn't believe him. For the next few weeks, I kept noticing many of the town people seemed sick and arthritic.

I have always been an energetic type person so Lyme disease scared me. Dad used to tell me I was one of the most energetic people he knew. I have worked in advertising - a real go-getter. I sold for advertising agencies, and I wrote copy. I was the mother of a wonderful, 19-yr.-old daughter, and I was just finishing up my teaching certificate.

One day after we moved there, I had plans to make the house magnificent. I had a book of ideas and pictures. The garden was my biggest project. I walked around our property with just my sandals on. Today, I know that was a big mistake.

"C," a friend of mine back in Seattle, had watched a special television show about Columbia County and the incredible amounts of Lyme disease there. He begged me to be careful. I listened and in the back of my mind decided to read up more on Lyme disease. I discovered in a medical journal that if a person gets bit, getting on antibiotics right away will rid one of the disease. Today I know this is a half-truth.

Besides worrying about Lyme disease, I had other problems as well at that time. I realized I had made a big mistake going to New York. Although I loved the countryside and this house, I could not forget my life in Seattle and a passionate romance I had with "C," who warned me about Lyme disease. I tried to heed his warnings by using Off and other insect repellents with DEET. I tried to forget him with painting, decorating and of course gardening on the 12 deer and tick infested acres.

I wrote poetry to try to let my feelings go. But, I could not forget him.

Two weeks after I arrived in New York, I found a tick on the back of my leg. The date was August 12, 2000. I went immediately to a doctor to remove it. I asked for antibiotics and they said, "NO, just wait to see if you get a bulls-eye rash." I couldn't sleep; somehow I knew I would probably wind up with Lyme disease.

The next day I went to the Emergency Room to try my luck. I wanted antibiotics and would stop at nothing until I got them. I was told by the resident doctor at the hospital that I was a "piece of work" and that I didn't need antibiotics. I didn't care what he thought; I had read in a medical journal, if you get on antibiotics within ten days of a bite, your chances of getting Lyme disease were pretty much non-existent. He finally gave in and gave me a small dosage of Doxycycline.
I was so happy that I wouldn't get Lyme disease and I faithfully took all my antibiotics and even got a Lymerix vaccine shot on the 15th of August. (What a mistake after knowing what I know now!) Lymerix prevents proper Lyme disease testing and can actually cause horrible permanent side effects in some people. Around the 29th of August, I had a second round of Lymerix. I thought I was fine. I went back to Seattle to visit my family.

It was shortly after my birthday on when I had Lyme disease symptoms. The definitive day was September 7th. I couldn't get out of bed in the morning and wanted to rest more than three quarters of the day. A friend of mine came over and I screamed at her, not understanding what was wrong with me. I had just gotten a new puppy for my birthday, and if wasn't for walking him and the other dog in the house, I wouldn't have gotten up at all. Except, perhaps to eat. But, even eating was lighter than usual. I lost 10 pounds in two weeks.

I received a call from the woman who helped sell us the house. "How are you, let's get together." I told her I couldn't; I was too sick and so very tired. "That is a symptom of Lyme disease," she told me. Those words were so loud to me, I then knew I had the dreaded plague. If it weren't for that call, I don't think I would have figured it out until "M" got back home from a business trip to Alaska; I just thought it was the muggy New York air making me sick. Even with the air conditioning, I was sweating at night.

I was alone in this big house with nobody to help me. I had two dogs to take care of. And this seemed liked a gigantic project. I hated the thought of the dogs bringing me in more ticks, so I made sure they were protected, and even then I didn't feel safe.

"M" would call me from Alaska every few days and ask how I was. I had been to many doctors. One told me I had diabetes. Another had my head scanned for a brain tumor because I couldn't keep liquids in my system.

Finally, I received another call from "C" in Seattle again. He told me to get to the best doctor I could immediately. I called around and found one through a friend of mine who seemed better after having Lyme disease and Babesia. I made my appointment and rested for days because I didn't have the energy to drive two hours away.

The doctor's office was in Hyde Park. As soon as I walked in the office, I felt better. The entire office had a healing feeling. The nurses, and Physician Assistant cared so much. I knew I would somehow get over this. My appointment, itself was healing! I talked about all the symptoms I had. Even hair falling out, numbness in hands and feet, frequent urination, extreme fatigue, weight loss, tingling muscles, stiffness in neck. I had twenty-one symptoms in all.

I began a course of antibiotics; 1500 mg Amoxicillin and 500 mg of Probenecid. I had another set of blood work done and when the results came back, I was alarmed to know I had Babesiosis too. I was put on quinine and Cleosine a few weeks after the Amoxicillin. I started to feel a little better.

A few weeks after I began the quinine, "M" came home from Alaska. I knew I didn't want to be in New York anymore. My heart had left him. He told me to leave. The next day I carried one suitcase and my puppy and boarded the plane for Seattle. I was crying the entire way home. I knew I was sick, but I didn't realize how bad it would get before I got better. It was Election Day 2000. I wanted to vote but somehow that didn't matter at the time.
I sat on the plane hoping my life would be okay. My daughter picked me up from the airport and was very puzzled as to why I would leave NY. The answer is two-fold and complicated.

First, Lyme disease had me feeling like I knew what I was doing. When I think back now, I was really pushing myself into truth. Honestly I did not have the energy to make this move now. Secondly, I was a strong woman; I would not live my life with man I didn't love anymore. My heart was with "C" in Seattle and I didn't know how to just let life unfold in New York. Maybe I knew I needed to recover back home in Seattle, too. It is difficult to recover when your heart doesn't belong in an environment.

I believe Lyme disease was just the beginning of all the other symptoms. Financially, I had just left all my security. But, then again, I am not one to live solely for money or security. I am an artist and I live in my heart.

For the next two years, I would call the LLMD (Lyme Literate doctor) in New York. I was put on antibiotic after the malaria type medications to get rid of the Babesia. I worked and was fired. Got another job but had to leave due to fatigue. I couldn't pay my bills. I struggled so much but kept my faith. I was now with the man I loved and I kept thinking that if we could get through these hard times, anything would be possible.

Things were rough. In 2001, "C" had to file bankruptcy and lost everything except the house we live in. I finally went back to work halftime as a teacher. Slowly, we are patching our lives up. This disease has cost both of us so much!

After two years, I am better. Thanks to my LLMD in New York mainly. This man put his life on the line for all his patients. And, for that I am inspired to write this. I will never forget the day he sounded so scared telling me, "I don't know if I can write you a prescription next month. The Board of Medicine may be taking my license away." It is for this reason, that I want to have all types of writings for his patients - to help them but to also help my doctor and those LLMD's who are fighting financially and spiritually. "C" thanks him too. He told me last night that he is so grateful to him for saving me life. Without my LLMD, we would not be here together.

Two days ago, I found out tests prove I don't have Babesia anymore! I am 90-95 percent better. I have fatigue and some tingling in my hands. I do not have Bell's Palsy anymore; my memory is better.

I say things like, "I am better, I used to look..." I am putting Lyme disease in my past and that is to me a sign that I am on my way back, here in my new life in Seattle.

Nancy (WA)
Most people measure out their lives in terms of events... "before I went to high school...after I got
married...when my children were born." My life is divided into "before Lyme disease"....and 
"after".

Before I got Lyme disease, I was an extraordinarily fit 40-year-old woman. Played softball, 
hiked, skied, ran...had three wonderful teenage daughters...a terrific husband...a job that I loved 
as a labor and delivery nurse on the night shift. Something happened to completely change my 
health, my life, my self-image...and that something is Lyme disease.

The bad respiratory bug I got around the holidays in 1995 dragged on for a while; I got better, 
but the muscle aches, the fatigue, and the flu-ish feeling didn't go away. February of 1996, I 
woke up to find I had gone deaf in one ear. A couple rounds of steroids (the customary 
treatment for sensory-neural hearing loss) triggered a strange assortment of neurological 
problems in addition to my already deteriorating health. Muscle twitches, numbness, tingling, 
cognitive problems...and I was SICK.

MRIs revealed nothing. Every blood test known to medicine (including Lyme disease) ..nothing. 
A lumbar puncture...nothing. In short, I was the sickest looking healthy person my doctor had 
ever seen. My weight was dropping rapidly, my hair started to fall out, my brain was gone. I 
had previously buzzed in and out of my doctor's office one a year for a physical; now I was in 
my doctor's office weekly, sometimes more often...sometimes having to be driven there, as I 
was too sick to drive.

My doctor (yes, I'm a walking poster child for the value of the primary care physician) all but 
turned himself inside out, and sent me to several neurologists, two infectious disease doctors, a 
rheumatologist, and ENT specialists (much to the dismay of my insurance company, I'm sure.)

Although I wasn't quite confidant in the diagnosis of chronic fatgue syndrome and fibromyalgia 
that I ultimately received, it DID seem to fit...except for the hearing loss, which all the specialists 
who concurred with my diagnosis of CFIDS seemed to ignore. As hard as it was to be sick, 
what was devastating was when my 15-year-old daughter began to develop similar symptoms a 
year after I was diagnosed with CFIDS.

TWO people? In one family?

Finally, late in 2000, a new onset of hearing loss in my good ear sent me to the world of closed-
captioning on TV. I couldn't use the phone, I couldn't work.

Another trip to Massachusetts Eye and Ear in Boston, and the specialist couldn't explain the 
hearing loss... except, he said, for one case of hearing loss like this that he had seen in Lyme 
disease.

That was enough for me. A referral to an infectious disease doctor (an LLMD) in December of 
2000, eight weeks of IV Rocephin, months and months of oral antibiotics... and I finally have my 
life back. The improvement has been slow... there have been a few mild setbacks, but now, five 
and one half years after the onset of symptoms, a year and a half after the initiation of 
antibiotics, I'm working full time, going to school at night, playing softball, skiing, and beginning 
to get my life back.
My doctor told me at the beginning of treatment that nobody ever recovers 100%; most get 50%
better, a few never get better at all. On rare occasions, a 90% recovery occurs, and that's about where I am. I'm still on antibiotics (Ceftin), have some lingering neuro symptoms, but I don't consider myself "sick" anymore. In fact, there are the few blessed days every month where I feel totally normal.

It's been a long, hard road, but one that's being traveled by many others right now. Were it not for the support of my husband, family, and friends, and for the persistence of one very special primary care doc (to whom I truly owe my life... thanks, JPH!), I don't think I'd be here to tell my story.

Lisa L. (MA)
Love and Light to all

What does He deal - but a bag of tricks
   Not seen by us - as to our Soul,
He sticks working and working - moving us on
To a better place - where Love will dawn.
   How many of us - really felt lonely
But our outside lives - were 'well' only?
How many of us - lived by these rules
   In the life we live - by all Its schools?
   How many of us - will sacrifice
Our own knowledge - for another's dice?
When the dice get rolled - this time around
We'll walk in our truth - without a sound.
When I'm done learning - what will I do
   But help all others - no matter who
God - I want to graduate!
So I can do my life's work - My Fate.
   Ha! I must be getting tired!
   Love and Light to all!

"Calming Wind"
I remember waking up on Saturday morning, October 21, 1995. My 6-month-old son had successfully slept through the night, allowing me seven hours of undisturbed sleep. It was going to be a good day. My husband John and I were going to a friend's wedding. We would spend the evening dancing and celebrating with friends.

As my thoughts were focused on what I was going to wear, I experienced a sharp deep pain in my back. I never had any back problems before this. Throughout my pregnancy I was fortunate to escape the typical back complaints. As I got out of bed the pain was unbearable. I couldn't walk. I was stiff as a board. I tried stretching but that only made it worse. I got into the shower hoping to get some relief, but there was no improvement. I remember thinking, "something seriously is wrong."

Over the next 3 years I developed heart problems, neurological difficulties such as, short-term memory loss, vertigo, visual disturbances, chronic headaches, sore throats, persistent coughing and joint pain. It seemed unusual for a perfectly healthy female at 33 years of age to have so many unexplainable ailments. I had no previous history of health problems. I didn't drink or smoke. I was in good physical condition. I sought the help of numerous doctors to find out what was wrong with me. I consulted with orthopedics, rheumatologists, cardiologists, cardio-surgeons, infectious disease specialists, and internists. I went to physical therapy, chiropractic, and acupuncture for relief from the pain.

On the advice of many of the doctors and therapists, I spent endless hours at home exercising and stretching. None of it helped. I had numerous and expensive diagnostic tests' ranging from CAT scans, bone scans, MRIs EKGs, treadmill tests, nuclear scan, and an angiogram. The results were all positive for some sort of abnormality. The good news was that I had evidence that my complaints were justified. Several doctors ordered extensive blood tests. Each time, I tested positive for Lyme disease. I was advised by these doctors that a positive test was nothing to be concerned about. They explained that thousands of people test positive for Lyme disease without having the illness.

But I was sick, had classic symptoms and consistently positive Lyme tests. "Shouldn't Lyme be considered?" I thought, "instead of spending thousands of dollars on diagnostic tests and surgeries, wouldn't antibiotics be worth a try?" I didn't know enough at the time. The doctors acknowledged something was contributing to my declining health. However, they all ignored the possibility of Lyme disease.

My orthopedic specialist advised me I would need a double fusion back surgery to relieve my back pain. I was not convinced that major lumbar surgery was going to resolve all my medical issues. The other symptoms didn't seem to have any relation to a back problem. The positive Lyme test results stuck in my head.

I learned about Lyme disease during my three-year stay in Virginia in my mid 20's. I was aware that Lyme disease is transmitted by the bite of an infected tick. I remember Virginians talking about the seriousness of the disease and the importance of early intervention with proper antibiotics. I began doing my own research about the disease.
I couldn't remember being bitten by a tick. Nor did I have a bull's eye rash, which is commonly thought to signify a bite by a Lyme-infected tick. I have since learned it is common not to have a rash. Fortunately, I have a family member who is an orthopedic surgeon. I sought his opinion regarding my back ailments. He reviewed my diagnostic test results and advised against any back surgery. He shared with me a recent article from a medical journal about the relation between joint pain and Lyme disease. The article discussed how performing arthroscopic surgery on a patient did not resolve the problem of joint pain because the primary cause of the arthritis was the Lyme bacteria. (Borrelia burgdorferi).

I began my search to find a doctor. I wanted one who would have the knowledge and experience to treat what appeared to be an under-diagnosed and misunderstood disease in the medical community. As I was searching for a doctor, my heart problems were getting worse. I had numerous EKGs, all were abnormal. One particular cardiologist told me that the EKGs indicated I had suffered a heart attack. He asked me if I remembered ever having any symptoms that resembled a heart attack. I explained that I had three separate incidents in the past two months. He immediately referred me to a cardio-surgeon who ordered an angiogram. I authorized him to perform the angiogram. Before the procedure, I gave the surgeon the information I had learned about cardiac involvement in Lyme patients and how the bacterium attacks the heart. He was not convinced this was my problem. He explained to me the possibility of heart disease and the need to have stents or an angioplasty performed.

As I suspected, the angiogram was clear and there was no heart disease. I knew I needed to find a doctor who would seriously consider that my symptoms were a result from Lyme disease. If I continued with the doctors I had been seeing, I would never get well. I found a doctor who had experience treating Lyme patients. Several lab tests for tick-borne diseases were performed. The results were again positive for Lyme but also for a co-infection, ehrlichiosis. Ehrlichiosis is a bacterium that infects and invades the white blood cells. It can be treated with the same drugs used for treating Lyme.

I began an aggressive antibiotic treatment for Lyme and ehrlichiosis and showed significant signs of improvement. This gave me hope and I regained some of my life back. In January 2001, I began experiencing drenching night sweats, chills, and a chronic low-grade fever. These symptoms continued for several months. Over a six-week period I lost 25 pounds, 20 percent of my body weight. I went from size five to size zero. Even size zero was too big. My doctor suspected Babesiosis, a third tick-borne illness. Babesia is a parasite similar to malaria, and attacks the red blood cells. It requires a different form of drug treatment than Lyme and ehrlichiosis. I tested positive. My illness suddenly became more complicated.

I started a new regimen of powerful drugs immediately. Since beginning an appropriate treatment plan for all three illnesses, I have been able to reduce or eliminate some of my symptoms. I believe I have made progress in attacking the diseases. Whether I will ever be free from the diseases is unknown. Medical science is not conclusive on whether late-stage Lyme, along with co-infections can be cured. In fact, most in the medical community refuse to acknowledge the prevalence and the seriousness of tick-borne illnesses. These illnesses imitate many diseases, making a diagnosis difficult. Diseases such as Crohn's, ulcerative colitis, multiple sclerosis, rheumatoid arthritis, lupus and chronic fatigue syndrome are just a few of the mis-diagnoses.

More research on Lyme disease and the effect of co-infections needs to be completed. Another critical area in need of research is the effect of tick-borne diseases on children. Unfortunately, may become infected in more ways than adults. Like adults, the most common way is to be
bitten by an infected tick. Children, however, are also at risk through in-utero transmission or from breast milk. Children who suffer from tick-borne illnesses are plagued with symptoms similar to adults.

They may also have difficulty learning, impaired concentration, inability to pay attention, reading problems, overwhelmed by school work, confusion, uncharacteristic behavior outbursts, mood swings, fevers, chills, joint pain, stomach aches, headaches, nausea, asthma and allergies. We learned of these risks the hard way. In March 2002, our son was diagnosed with congenital Lyme and has since begun treatment.

The devastating affects of Lyme disease and other tick-borne illnesses plague an increasing number of people in our country. No matter where you live, you should be aware of the risks of a tick bite. Ticks and the diseases they carry do not distinguish between race and gender, rich and poor, young and old. Awareness and education is necessary.

If you are bitten by an infected tick, early intervention (in most cases) provides a successful recovery. When a delay in treatment occurs it becomes more difficult to eradicate, leaving long term consequences. It is important for doctors to make a clinical diagnosis, confirmed with laboratory data to determine if a person has Lyme disease.

Educated doctors are crucial for a successful diagnosis and treatment. In my case, the clinical evidence was present, along with repeated positive blood tests. Looking back, it appears to me that my doctors missed the obvious signs and failed to diagnose my illness correctly. It has been six years since that October morning.

I often wonder if my story would read differently if I had received prompt treatment. For now, my journey continues, along with my son. Tick season will soon be here again. I hope by sharing our story, it will help others protect themselves and their families from experiencing the debilitating and devastating effects of this disease. Websites, recommended reading and laboratories for tick analysis and testing.
I'm a former Lymie (third stage) who suffered for over 14 years with mild Lyme and for 4 years with severe Lyme after being infected for a second time.

Just thought I'd drop by and say I've been off abx for 7 months and symptom free for much longer. I'm feeling great; I'm back working full time and getting my life back. I used to spend all my time between the bed and the computer and you all were my only grip on sanity. Thank You.

I always wondered if anyone ever got better and swore that when and IF I beat the disease I'd be back. Well, here I am! Hang in there, I've been where you are... I could not walk for 18 months and thought/was told I may die. You will get better. Keep listening to your LLMD's and know that there IS HOPE.

Our LLMD's are our lifeline. I owe my life to my Doctor. He told me he'd make me better if I just did what he said. Despite all the criticism we both took from mainstream medicine, he was right. I see Abx like a cancer patient sees chemo, a necessary evil. It makes us sick but will eventually save us. Keep taking your meds no matter how bad it gets... my only advice.

FYI, I had 6 months of Zith. Six months of Zith and Metronidazole and 2 years of Suprax and Metronidazole. Two, three month rounds of Cholestyramine toward the end of the abx. really made me feel better. The yeast was a pain (similar symptoms of Lyme) and I'm still on weekly Diflucan, acidophilus and a no carb/sweet diet but am working/exercising/living and getting better every day. Candida is nothing compared to Lyme. My only lasting affect is a right knee with crepitus, a body that I'm working to get back in shape(I've lost the 17 Lyme pounds) and making new relationships because most family & friends left me. The new ones are better.

A warm, gentle hug to all the hurting Lymies out there.

God Bless You,

andigail,
Gainesville, FL.

Children in the Lyme Light
My Life Without Lyme Disease in This Family

This Lyme Disease is killing me...
Everybody’s had it, but luckily not me.

I know how to use a key... Why
can’t everyone else in my family?

I don’t want to live this life...
Especially when it causes so much strife.

One kind of bug is plenty for me...
Let’s make Lyme Disease, history!

-not in the Lymelife

Carlos S. Morales-
NJ Age 14
Once upon a time, a brother and sister lived in the Hudson River Valley of New York. The boy, Nick, and the girl, Monica, loved to run among the fields and catch butterflies, frogs and other animals and then let them go.

Every winter, they would go to Florida and visit other areas of the United States along the way. Sometimes they would discover new animals. Once, in Florida, they came across a scary alligator and you should have seen how very fast they ran back to the house! They were both great runners from all the sports and running and climbing they did all year round.

Alligators were totally new to them. Nick and Monica thought of catching one someday when they were older, but they were wise enough to stay far enough away while they looked at them from the water by the house.

Nick and Monica had dreams of exploring new areas of the United States. After all, discovering animals and new countryside was exciting. They would think of their adventures while they were at school. Their teachers loved their reports and stories of their trips. Nick and Monica were both excellent writers.

One day, the Nick got sick. He started to have lots of aches and pains, but his family doctor didn’t know what was wrong. He did some tests on Nick’s blood for Lyme disease. They came back negative.

Nick started to feel very tired. He missed days of school. One day he woke up and felt a tingling in his left hand. His mother started to worry. "What will be next?” she thought. "He has missed two weeks of school already!"

On the fifteenth day, his teacher called and asked Nick’s mother what was wrong. "Oh, he doesn't have any energy to go to school, and he keeps saying his muscles hurt, his back is sore and he won't eat anything." The teacher asked Nick's mother if he had a Lyme disease test. "Yes, and it came back negative," Mom replied.

Monica seemed to be doing fine, she didn't have any aches and pains at all. She was just sad. She missed playing with her brother very much. She ran and played in the fields by her house alone now. She also did nice things for Nick. One day, Monica made chicken soup out of a can and put it on the table by Nick's bedside. It just sat there. He didn't eat it.

The next day, she brought Nick a Nestle’s Crunch bar, his favorite. He just stared at it. Nick looked away from Monica and asked her, "What is wrong with me?" Monica ran downstairs crying and asked her dad, (who knew everything) "Dad, what is wrong with Nick? He looks so sick. Please do something for him."

Nick and Monica’s dad had a friend with whom he talked the next day. He found out that Lyme disease is not always found by family doctors. He came home with another doctor’s name who had an office thirty miles away. The doctor had a lot of experience treating people with disease you can get from a tick bite. Nick’s mom made an appointment. It would be in two weeks.

Monica felt sad for her brother and kept bringing him food to eat. She couldn’t even get him to eat his favorite food like the lemon meringue pie her grandmother brought over the night before. She started to cry and ran off into the tree house in the back yard. She stayed up there until late that evening. She started to draw butterflies that she remembered catching a few months ago
with her brother. She drew a few of them on a page when she heard her dad call her name. "Monica, are you up there?"

Dad climbed up the red, wooden stairs to the tree house. He had a smile on his face. He looked like Nick when he smiled. Monica wiped the tears from her right cheek. Dad gave her a big hug. A thunderstorm was coming. It was getting darker outside than Monica had ever imagined. Dad turned on the light inside the tree house and held her tightly. When Monica woke up, she was nestled in her dad’s strong arms. She felt safe.

The two weeks had gone by and Nick, his mother and father had an appointment with the Lyme disease doctor. Monica kept thinking about it while at school. She felt better knowing that her brother was getting help. She felt good about the short story she wrote that day in school in school. Maybe it was because she felt safe after her dad held her for hours the night before.

Monica ran home from school that day. Nick was sitting on the couch talking to Dad. "Monica, come in here. We are in here, hurry." Monica took off her shoes and ran toward her family.

Dad spoke softly but with a sad glow in his eyes. "The doctor thinks Nick has Lyme disease. He has many of the symptoms and he told us that he will get better. I want you to just love him and keep bringing him your soup. He needs to eat because he got bit by a tick that makes him lose his appetite for any food. Then Dad explained a disease called Babesiosis.

"I know you have been worried about him." Dad started to chuckle. "I have seen all the food you have been trying to get Nick to eat."

Nick chuckled too. He always knew that his family loved him. He felt warm inside and began to feel a joy, knowing he would get better.

Nick took the antibiotics and herbs that the Lyme doctor gave him and noticed within two months he had more energy. During that time, Monica gave him chicken soup every day.

One day, Nick came downstairs and told Monica, "I don't think I want chicken soup anymore. Can you bring me some steak?"

Monica asked her dad to barbeque Nick a steak. "Why of course, I would be glad too. It looks like your buddy is going to be ok."

Monica began to think of the butterflies again that she and Nick caught. She began to draw butterflies every day. She learned how to make the butterflies look real and put them all around her brother's room. He really liked that.

As time went on, Nick began to go back to school for half the day. His mother and his friends helped him to catch up. His teacher was extra nice. Nick found out later on that his teacher knew about Lyme disease because her son had also been sick. That is why she knew what to do.

One day, Nick’s teacher had him write a report on how to avoid getting Lyme disease. He did lots of research and read the report to his class. In the report, he gave details of how to use care when going outside.
Wearing proper clothing and noticing the signs of Lyme disease are essential. During the summer, he reported that Lyme disease was easier to get. During the warm months, ticks can attach to anyone who is not dressed properly or using repellent. He also talked about using sprays on clothes to prevent ticks from attaching to clothing. He did research and found out that guinea hens actually eat ticks along with the grass they cling to. He talked about how sick he was and how Babesiosis and Lyme disease are treatable if you get help right away.

Today, Monica and Nick have an indoor butterfly collection. They let the butterflies go outside and watch them fly away. Summertime is spent swimming and being extra careful to keep ticks away. "I don't ever want to go through that again," Nick said. "Me either," Monica shouted!
Here are Nick's notes on Lyme disease and other diseases you can get from the same tick bite.

Description of Lyme Disease:

Lyme disease is an infection caused by the bacterium Borrelia burgdorferi. The bacterium is spread by black-legged or deer ticks. The deer, get the bacteria from mice. These ticks are usually smaller than dog ticks and harder to detect. The smaller ticks, or nymphs, are about the size of a poppy seed; adult ticks are the size of a sesame seed.

According to some experts, infection occurs 24 to 72 hours after the tick attaches to the skin. Some people report that they were infected within a few hours. The early stages of the disease are usually associated with mild symptoms that may include:

**Early Lyme Disease Symptoms**

- swelling of lymph glands near the tick bite
- fatigue
- headache
- achy-ness
- joint pain
- chills
- and a flat, red, not-itchy rash (which can look like a bull's-eye) around the bite

It is extremely important to remember that during the beginning stages of Lyme Disease, not all symptoms will occur, including the classic bull's-eye rash. Only about 50% of people who get Lyme disease ever see a rash around the tick-bite.

The next stage of Lyme disease, called early disseminated stage, usually appears 2 weeks to 9 months after the tick bite, and may include:

- two or more areas of rash not at the site of the bite
- severe headache
- severe fatigue
- enlarged lymph nodes ("glands")
- stiffness, especially in the joints and neck
- sore throat
- sensitivity to light
- facial paralysis (Bell's palsy)
- tingling or numbness in the extremities
- irregular heart rhythm
- fever of 100 to 102 degrees Fahrenheit (37.78 to 38.89 degrees Celsius)
- meningitis

Two other diseases, Ehrlichiosis (HGE) and Babesiosis, also can be transmitted through tick bites, -sometimes by the same tick that carries Lyme disease! It is therefore necessary to test for and treat these diseases as well. The right blood tests can be ordered through a Lyme Literate Medical Doctor.
**Ehrlichiosis**

Ehrlichiosis symptoms are high fever, severe headache, fatigue and incapacitating muscle and joint stiffness.

**Babesiosis**

Babesiosis is a malaria-like disease also transmitted by tick bites. Symptoms include weakness, fatigue, fever, drenching sweats, muscle soreness, and headaches.

Over 150,000 cases of Lyme disease have been reported between 1982 and 2000. It is estimated that those numbers should be multiplied by 10 because there are lots more cases which go undiagnosed and unreported. (1)

Here are some ways you can keep ticks away from your house:
Keep lawns mowed and trimmed; clear brush, litter, and tall grass; and stack woodpiles off the ground.

Check your clothes and your pets for ticks before going in your house.
In addition, you can have a licensed professional spray your yard with insecticide in May and September to prevent ticks from multiplying.

Lyme Disease does not have to become a disabling condition. A good prognosis will rely on first on having an excellent Lyme Literate Medical Doctor, (an LLMD) to help your child over come Lyme Disease.

References:
1 Center of Disease Control, Statistics of Lyme Disease

Written by Painted Rabbit (WA), co-written by AJ (TX) and Annie C, (AR)
JD's Story

(Part of this was a letter written to another sick child. This was very therapeutic for this mom to write. I probably could have kept writing for hours. I just wonder how many kids feel that they just be alone in this struggle and have to deal with the stress that Lyme puts on a family.)

My name is J.D. My mom is writing this because I am only nine years old. If I could talk to you, in person, I would tell you that right now my body is different from the other kids in school. I am very much aware of this and I want to be normal again--soo bad. Even though people tell me that I'm Autistic, or ADHD, or Obsessive-compulsive, or laugh because I can't control the Tourettes, I am here inside this body and am very much aware of things being very wrong.

Most days I don't want to go to school because I don't want the other kids to laugh at me when I don't want to eat the same food that they eat. They call me anorexic, and even though I don't know what that means I know that they are making fun of me. The smell of food makes me gag and feel like throwing up.

They don't like me because I have to have everything in perfect order, and if I color a picture, and it's not perfect, I tear it up and recolor it. They laugh when my eyes blink uncontrollably, and then my head jerks, and sometimes I say things that I don't really mean- things that are really mean and hurt others people's feelings. I get sent to the office for saying things that I thought that I was just thinking.

I am afraid almost all of the time; I'm especially afraid of mice and the dark. I think and talk about death all of the time. My thoughts are usually very morbid, and even though I want to think different thoughts, I really don't seem to have very much control over it. I can be very loud and people tell me to shut up all of the time. I don't have any friends. I spend most of my time very, very afraid. Some people try to understand and be nice to me, but it doesn't last very long. I get real depressed because I am sure most of the time that this is just all my fault. I cry and say that I am just a bad kid and that I don't want to live. I ask my mom if God still loves me, and if I will go to hell, because I drew a picture about killing another little boy in my classroom. I am a very good artist.

Sometimes I can't hear what people are saying to me, but other times noise bothers me so much that I have to scream. I try so hard to be good, but something always happens. My teacher thinks that I am just lazy and not willing to work, but, honestly, I don't seem to be able to do today the exact same thing that I excelled in yesterday. I usually won't play at recess because the kids laugh at the way I run, and my muscles and joints hurt so bad. Sometimes the slightest touch will make me go into a rage. Sometimes I stutter. I will have to say the beginning of my sentence several times before I can get the rest of it out.

At home, I don't allow anyone in my bedroom. I know if anything has been moved in even the slightest little bit. I also obsess about germs. I won't allow my 2 year old nephew to touch me because he has a lot of baby germs. I now wear tinted glasses that help with the lights or the sunlight that hurts me so bad.

I love my family so much and I give them lots of hugs. We tell each other that we love each other all the time. I say that I am sorry a lot because I really don't mean to do some of the things that I do.
I was so afraid that I would die when I was in the hospital. I had a very high fever and my head hurt so bad. I was seeing things that my mom said weren't there, and all of the tests that I had to do hurt so much, and I couldn't understand why they were doing all of these things to me. I was having seizures and I know this scared my mom a lot.

My brothers and sisters try to help me out and ask the other kids to stop picking on me so much. I ask my mom every day (several times a day) if I really am getting better. It is so hard to believe that my life really actually is getting better.

I have an older stepsister who is 16. She is very obsessive-compulsive, and gets very depressed too. Her main phobia is about dying. She asks everyday if the pain in her leg means that she has cancer. She asks about dying several times a day. She also washes her hands about every 5 minutes. She gets bad headaches and her muscles hurt, too. She hasn't been sick as long as I have, but she knows that she is getting better too. She knows that without the help that she, too, could very well be as sick as me.

I know that most of the time those that are sick with this stuff feel that we are all alone, (even in a house full of people). This is so hard to live with. I'm glad that I have my family. It's real hard most of the time, but I can barely see the light at the end of the tunnel.

My mom and dad are sick too. Sometimes I hear them fight about what some of the doctors have said to them. Sometimes my mom cries and cries. I think it must be because of me, but she tells me that sometimes she just has to cry. Sometimes my mom has to stay in bed because she is so sick. She says that she hurts a lot of the time. Mom and Dad are both very forgetful. Dad sleeps most of the time these days. My parents seem to fight a lot about money these days.

All of us seem to be going to the doctor a lot and are taking a lot of medicine. Gosh, I hope the other 6 people that live in our house don't get sick too. I really like the wonderful Doctor that we go to in Missouri. My mom says that he is going to help us all.

We go to church and the people there pray for my family. We pray at home, too, and ask God to be with all the sick, hurt, and afraid people in the world.

JD (KS)
A maze of Lyme
TEST YOUR LYME DISEASE KNOWLEDGE

Find the word, and then circle it within the grid.

Yeast  Herx  Swelling  Thief
Itching  Dizzy  Aches  Cycle
Tick  Bitten  Bullseye  Fevers
Migrates  Pain  Nightmares  Web
Arthritis  Eyes  Insomnia  Twitching
Rash  Fatigue  Unexplained  Fog
Sad  Pals  LLMD  Flagyl
Lyme Disease  Burning  LymeNet
Cartoons and Drawings
Well, I am glad you finally made it to the office. Let’s see...
It says here you are experiencing horrible fatigue, swelling and joint pain,
irregular heartbeats and chest pain, insomnia, short term memory loss
and depression, mental fog and word disassociation,
horrible headaches, shooting pains.
Partial paralysis on the left side of your face,
I also see you’ve requested bloodwork, including
a Lyme Disease test, I am sorry ma’am, but-
WE DON’T HAVE LYME HERE!

Obviously,
the tick
didn’t know
that!
Please, I want to go to school. I hate Lyme Disease!
Roads of Healing

Resources for Patients who have Children with Lyme Disease
(and or co infections)
Books on Lyme Disease

Everything You Need to Know About Lyme Disease and Other Tick-Borne Disorders
by Karen Vanderhoof-Forschner, Sen. Joseph I. Lieberman, William Burgdorfer, PhD, MD (hon.)
Paperback, 237 pages
Published by John Wiley & Sons
Publication date: May 1997

The Widening Circle: A Lyme Disease Pioneer Tells Her Story
by Polly Murray
Hardcover, 321 pages
Published by St. Martins Pr (Trade)
Publication date: May 1996

Coping With Lyme Disease: A Practical Guide to Dealing With Diagnosis and Treatment
by Denise V. Lang with Joseph Territo, MD
Paperback, 272 pages
Published by Henry Holt (Paper)
Publication date: April 1997

Twice An Angel: Living and Dying with Lyme Disease: The Jenny Umphress Story
by Susan Umphress and Marilyn Nelson
Paperback, 342 pages
Published by Good Earth Publishers
Publication date: May 2000

Infectious Diseases of the Fetus and the Newborn Infant, 4th edition
Jack S. Remington, Jerome O. Klein, eds., Chapter 11: "Lyme Disease" by Tessa Gardner, MD
Published by Saunders, Philadelphia, 1995, pp 447-528
Important Websites
National Lyme disease organizations:

www.lymenet.org - Lymenet (National)
www.ILADS.org - International Lyme & Associated Diseases Society (National)
www.lymealliance.org - Lyme Alliance (National)
www.lyme.org/index2.html - Lyme Disease Foundation (National)

Government websites

www.nih.gov - NIH - National Institutes of Health
www.cdc.gov/ncidod/dvbid/ld82_97.pdf - CDC Statistics
www.cdc.gov/ncidod/dvbid/dvbid.htm - CDC Vector Borne Diseases
www.fda.gov/cdrh/lyme.html - FDA

Guidelines

www2.lymenet.org/domino/file.nsf/UID/guidelines - by Dr. Burrascano

Testing Laboratories

www.igenex.com - Igenex - testing
www.bbii.com - Boston Biomedical Labs. - testing
www.mdlab.com - Medical Diagnostic Laboratories (MDL)
www.bowen.org - Bowen Institute

Important Researchers

www.columbia-Lyme.org - Columbia University Center On Lyme and Dr. Brian Fallen's Study
www.MentalHealthandIllness.com - R. Bransfield MD
Other good Resource Websites

Here is an internet website with very extensive information for parents about how Lyme disease may effect their children:

http://www.lymesite.com/childrenandLyme.htm

www.geocities.com/HotSprings/Oasis/6455/lyme-links - Lots of Links -Art Doherty

www.geocities.com/ldbullseye - Lots of good information and good Links has a link to LDAOHio - the Lyme Disease Association of Ohio
Resource page for parents of children with Lyme Disease and other co-infections:

Some studies and Journal papers (abstracts etc.)

1. Explains how Lyme Disease can mimic attention deficit hyperactivity disorder (ADHD), depression, and multiple sclerosis.

2. Talks about cognitive disorders related to Lyme Disease.
Lyme disease. This may represent an infectious or postinfectious encephalopathy related to B. burgdorferi infection.

http://neuro.psychiatryonline.org/cqi/content/abstract/13/4/500


A Controlled Study of Cognitive Deficits in Children With Chronic Lyme Disease

Felice A. Tager, Ph.D., Brian A. Fallen, M.D., John Keilp, Ph.D., Marian Rissenberg, Ph.D., Charles Ray Jones, M.D. and Michael R. Liebowitz, M.D.

Received August 7, 2000; revised January 3, 2001; accepted January 10, 2001. From the Columbia University Department of Psychiatry, Division of Behavioral Medicine, New York, New York. Address correspondence to Dr. Tager, Columbia Presbyterian Medical Center, 622 West 168th Street, Box 427, New York, NY 10032. E-mail: ft49@columbia.edu

Although neurologic Lyme disease is known to cause cognitive dysfunction in adults, little is known about its long-term sequelae in children. Twenty children with a history of new-onset cognitive complaints after Lyme disease were compared with 20 matched healthy control subjects. Each child was assessed with measures of cognition and psychopathology. Children with Lyme disease had significantly more cognitive and psychiatric disturbances. Cognitive deficits were still found after controlling for anxiety, depression, and fatigue. Lyme disease in children may be accompanied by long-term neuropsychiatric disturbances, resulting in psychosocial and academic impairments. Areas for further study are discussed.

http://www.poughkeepsiejournal.com/saturday/opinion/stories/op032302s3.shtmI
Lyme study could help adolescents

In my psychotherapy practice, I have seen both adolescents and adults battling Lyme disease. If one or more family member is seriously ill, the effects on the family can be profound.

When the brain is affected, the patient's ability to succeed can be very limited. Adolescents who have problems with memory, concentration and other cognitive functions have difficulty learning. It is not clear to the adolescent, the parents, or the school exactly what is wrong, just that the student is not successful.

Studies published in psychiatric and medical journals have documented the complexities of Lyme. There have, however, been few that focused on adolescents.

Patrick McAuliffe, a doctoral candidate at Columbia University Teacher's College, has begun a study on the cognitive effects of Lyme disease in adolescents. His adviser for the study is Dr. Brian Fallen, a noted Lyme researcher.

Neuropsychological testing will be provided without charge to adolescents who qualify. Study results could help schools better understand the cognitive deficits these young people may have, thus promoting their school success. In addition, it could contribute significantly to professional literature, filling a gap that exists in our understanding of this complex illness, and how it affects our adolescents.

For further information on the study, contact Patrick at Patnain@optonline.net

Sandra K. Berenbaum, CSW-R, BCD, Wappingers Falls