YeshTickvah

While most girls her age were enjoying a carefree life of school and friends, Chana was struggling with a disease whose existence many doctors refused to acknowledge. Chana reached out to me to share her story in the hopes it would help others in her situation learn where to turn. I am sure readers will be as incredibly inspired reading about her harrowing journey through late stage Lyme Disease as I was hearing it.*

**Not her real name.*

Can you tell us a little bit about yourself?

I am 20 years old. I was born and raised in Lakewood as the middle child in a large family k"h and attended wonderful local for elementary and high schools.

When did you first start feeling ill?

When I was in 6th grade, back in 2006, my symptoms began. I lost interest in many things that used to interest me and in all of the things that most girls my age were doing. As I child, I was very cheerful and active. I loved sports, day camp, and socialinteraction and had an engaging, energetic personality. My mother used to call me her sunshine.

All that came to an end in 6th grade. I grew withdrawn, sullen and lethargic. I lost my interest in school, and my grades began to drop.

Everyone chalked my metamorphosis to adolescence; they said it was a phase that I would get over. Welcome to teenagehood. No one thought that my disinterest was symptomatic of a deeper problem.

And it only got worse by the year. I wasn't growing out of the stage; I was growing more and more into it. I kept developing additional symptoms, many of which mimicked mono: fatigue, low energy, lethargy, etc.

This persisted for years.

What led you to seek a diagnosis?

As my tenth grade school year was about to begin, I told my mother that I didn't want to go to school anymore. It was just too hard and I was so tired all the time; I couldn't fathom facing another year of the same torture.

My mother suggested that I get tested for mono, which I did. I was relieved when the results came back positive and figured that that must have been what was holding me back all of these years. I went to a chiropractor who gave me herbal remedies for mono, but they didn't help, simply because it wasn't only the mono that was causing my symptoms. I didn't know that at the time, so I just assumed I would have to live with my mono until it went away on its own.

One day, in 11th grade, at exactly this time of year, I was helping my mother clean for Pesach when I began feeling muscle pain. I told my mother that my arms really hurt as I lifted and scrubbed.

While my mother didn’t react in front of me immediately, she was concerned and called my doctor. Once she set up an appointment, she told me that she felt it wasn’t normal for a girl of my age to experience such strong muscle pain from routine exertion. She feared I may have Lyme Disease, because she knew that could affect the muscles.

I went to the doctor and took the blood test. On Erev Pesach, mere hours before the *seder*, I got a call from the doctor’s office that I did indeed have Lyme Disease and needed to start antibiotics right away.

I began taking my medication and the transformation was amazing. The muscle pain all but went away and my energy was restored. I was thrilled; I had had Lyme, I was now cured, and life could go on, happily ever after.

I take it that was not the case?

Not at all. A month after I completed my antibiotics regimen, I experienced a relapse of all of the symptoms, aside for the muscle pain. Not only did the symptoms return, but they were doubled in intensity. I was doing everything I should in terms of diet, exercise and healthy lifestyle and yet the mere act of dragging myself out of bed in the morning required Herculean effort.

I went back to my pediatrician and described what was going on. The doctor’s response was, “I’m sorry, but we did everything we could. If you are still experiencing symptoms, it’s all in your head.”

He recommended I see a psychologist and was insistent that this was not Lyme Disease anymore, because the Lyme was surely out of my system.

By that point, it was already summer and I was preparing to head to camp as a staff member. I was determined to go with a positive attitude and was looking forward to my camp experience.

No more than a day into camp, I began feeling terribly sick. I wasn’t interested in any of the goings on or activities in camp, but because I was a staff member, I had to pretend to be interested. It was a really, really challenging summer.

I pulled through, because I knew I had made a commitment and I couldn’t just back out. As the summer wore on, I grew weaker and weaker and would call my mother asking her if I could come home. She encouraged me to stick it out and told me that as difficult as it was, I had a responsibility and therefore I had to stay. She was right, of course, and thanks to her encouragement I somehow made it through the summer. As soon as I came home, I slept for hours and hours, basically not emerging from my bed for three days.

Then came twelfth grade, the final and most exciting year of a girl’s formal schooling. I would go to school each day determined to make it work and then would come home, completely exhausted, pale and nauseous. I didn’t have the interest or energy to sit through classes and I was really, really suffering.

I knew this wasn't normal for someone as young as I was, and finally, my mother told me to stop trying to make it work and stay home for a few days to rest up. I was coming home early most days anyway, and on those days that I did make it through to the end, I was so, so sick afterward.

So I took her advice and I stayed home. A few days turned into a few weeks and then a few months.

Before I knew it, I had been home from school for three whole months. During those months, I didn't leave the house. I didn't feel well at all, and it was a difficult time. I remember pushing myself to go to the mailbox one day and then coming inside exhausted. I had had enough activity for the day. Brushing my teeth was strenuous. All of those normal activities that we take for granted were giant challenges for me.

After those three months passed, with no sign of improvement, we realized we had to take further action. I couldn't continue like this, with so much of my life still ahead of me and so much still to accomplish. I knew I had to get to the bottom of this, but I didn't know how.

After having been told by your doctor that there was nothing left to do, where else could you turn?

We decided to try a new pediatrician; perhaps he would have more insight and be able to figure out what to do. We went to Dr. Eilenberg and described my symptoms, asking him what we should do. We were just so completely and utterly helpless at the time.

He looked at my records and asked me, "I see you were diagnosed with Lyme back in April; what treatment did your doctor prescribe?"

I told him that I had taken 30 days of oral antibiotics.

Dr. Eilenberg said, "Just from looking at your blood work, I can see that you have a very heavy case. Of course 30 days of oral didn't help; you would require months of IV antibiotics."

In a way, it was such a relief to have a doctor admit that there was something still wrong with me, and that there was a way out. I had been so scared that this would be my life forever.

He validated my difficulties and reassured me that this was most definitely not in my head. I would be back to myself once the treatment was finished. The thought of living a normal life again was surreal.

The only catch was that I had to find a doctor who would prescribe the IV medication; he couldn't do that.

What were your next steps?

My parents began calling infectious disease doctors and hospitals and describing my situation.

Every reaction we received was the same and it shocked me at the time.

"There is no such thing as late stage Lyme. There's nothing we can do for you."

The problem is that there are two schools of thought regarding Lyme disease and it is the most political and controversial disease today. According to the CDC (Center for Disease Control), there is nothing to do for Lyme Disease that has gone untreated for too long, so many doctors take that to mean that there is no such thing as late stage Lyme, and have no answers for suffering patients. They suggest the same 21-28 days of antibiotic for all Lyme disease patients regardless if they were infected with Lyme for one month or for a few years.

We were up against the medical establishment, knowing there was a way for me to feel better, but slamming into impenetrable brick walls at every turn we took.

Finally, we found one doctor willing to put me on IV treatment for a month. Immediately, I began feeling so much better. I was grateful to this doctor and amazed at how much energy I was capable of having. After a month, though, this doctor told me that I was cured and he refused to continue treatment any more.

At this point, I was desperate; I saw how much it could really help, but it wasn't enough. I would need many more months of this treatment in order to return my strength to its full capacity. It only made sense that if a person was ill for a long time with Lyme disease , they will require longer treatment.

After continued research, I learned that I would have to find a Lyme Literate medical doctor, which is a doctor who believes that late stage Lyme exists and is certified to treat it by ILADS (International Lyme and associated Diseases) These doctors are difficult to find because they tend to keep a low profile. The CDC and the mainstream medical establishment are against them, and they are therefore susceptible to lawsuits.

How did you find such a doctor?

We eventually got hold of a woman who had a list of most of the Lyme literate doctors in the country. We called her and told her how desperate we were. She took down our details and location and then got back to us with three doctors in our area who could help us. The first name she gave us was located in Mount Kisco, NY. We had to travel three hours *each way* every three weeks to see him and it cost a fortune for each and every visit. That would have been fine, except that it wasn't helping. This doctor insisted on putting me only on oral and we already knew that oral wouldn't work. When it comes to Lyme disease individuality rules, not all chronic Lyme patients can tolerate oral antibiotic.

We called back the woman who had referred us there, once again in desperation.

She gave us the next name on her list, a Lyme literate doctor who just happens to live in Jackson, NJ. Not only were we able to eliminate the exhausting travel, we finally saw the light at the end of the tunnel as this doctor turned out to be the *shaliach* sent by Hashem to engender my *refuah*. The doctor immediately put me on IV medication and I began getting better and better.

How are you today?

I went on medication for a year and a half andtoday I am a different person than I have been ever since the sixth grade, eight years ago.

I am completely off all treatment, medication and antibiotics. I see a homeopathic doctor, and I stay on top of my situation, making sure to eat healthy and sleep well. I do tire more easily than some others, but it doesn't hold me back from living a normal life, from getting involved in *chesed* projects and even starting my own.

My illness won't affect my future life - my ability to get married, to have children and to be an exceptional wife and mother. I continue to embrace life and take on responsibility and don't let my condition get in the way.

Now that I am Baruch Hashem feeling well and capable of living a normal life, I want to help others who are going through hard times. I am grateful every day when I wake up and am able to get out of bed without feeling tired! I know that Hashem has a purpose for me being alive and energetic today, so I try to make the most of my time. I love volunteering for different *chesed* projects. I especially like to help out with the YeshTickva Lyme Awareness and Support Organization.

I am also hoping that one day I can start an organization of my own. I think it would be geared towards seniors since I feel that there is a lack of programs to benefit seniors, but this is all just an idea right now, and I am not sure how it will play out exactly.

Can you tell us more about YeshTickva?

YeshTickva is a *frum* non-profit organization that offers a range of services and support for individuals suffering from Lyme Disease, especially late stage or chronic Lyme. We feel that with the proper knowledge and information, patients can make better decisions about their treatment and ultimately their general well-being. The organization began two years ago with thirteen women sitting around a dining room table, and now they have a whole website, a hotline, different support events and multiple calls a day, a number that increases during the busy tick season.

We have so far helped a large number of people receive correct diagnoses, find doctors, and benefit from emotional support and guidance. It's so painful to watch others suffer without knowing what to do, to have doctors deny that what you are experiencing is a real illness and to tell you that it is all in the head. Through YeshTickva, I can help others the way I needed to be helped all of these years.

What would you like to give over to others who may be in your situation?

First of all, it is important to create awareness of this situation. There are many people who may have Lyme Disease and not know it, suspect they have it or have symptoms that they don't realize may be Lyme. Lyme disease mimics other diseases such as Multiple sclerosis, Parkinson's, ALS, Fibromyalgia, Rheumatoid Arthritis, chronic Fatigue syndrome, or an array of mental disorders.

The difficult part of this disease is that we cannot rely on standard blood work and regular doctors diagnosis. Since Lyme disease is a recent illness, many doctors are unaware of how to diagnose Lyme properly since they have not learned it in medical school. There are more advanced tests out there today, more sensitive labs , and different tick borne diseases testing that can help diagnose many people that are suffering. Lyme is also a clinical diagnosis based on symptoms and supportive lab work. I want these people to know that their situation is not hopeless, as I once thought mine was, and that there are people they can reach out to for help.

. Anyone who feels they might have Lyme Disease, or know that they have it but are not sure where to turn, can contact YeshTickva at 347 389 5963, yeshtickva@thejnet.com, or www.yeshtickva.com They can also reach me through the Shopper.

How have your struggles made you stronger?

Having Lyme Disease has put me to the test physically, emotionally and spiritually. I can honestly admit that I am now physically healthier,emotionally stronger and spiritually more connected than I would have been otherwise. I also have a powerful sense of empathy and am able to relate to others going through challenges.

We live in a society today where people are afraid to ask questions and seek the help they need. There were times it was hard to have a positive attitude, and since I was so young when I first began suffering from Lyme, I was confused and had many questions.

"Why did Hashem make this happen to me?" "How am I expected to be happy at when I am ill?"

At first, it was hard for me to open up and ask what was on my mind, as I was afraid people would reject me or think I am dumb. Once I was able to develop the confidence to do so, though, I didn’t regret it. My teachers at seminary have encouraged me and taught me how to effectively get the answers to my questions. I honestly believe that if a person is spiritually connected, emotional and physical wellness will be easier to obtain. As a result of my Lyme, I have been made to seek out my true inner strength, and looking back at how much I have grown from my struggle is a truly fascinating experience.

Do you ever have this feeling of regret that you missed out on so much of your life?

I don’t regret missing out. My life was designed perfectly for me, and Hashem wanted this to happen. Why should I regret something over which I had no control?

What helped you get through the challenging times?

Having a consistent support system in place has helped me get through the challenges. I also found many books that have helped me to cope. I actually came across a list of questions called “30 day chronic illness challenge”, and I felt that by being forced to think up answers to these questions, I have gained insight into my personal thoughts regarding my journey through Lyme.

What is your message to our readers in general?

The best medication is prevention. If you or somebody you know has been bitten by a tick, don't ignore it. If Lyme disease is diagnosed in the early stages, one month of antibiotic is very often enough. Many people who were bitten never recall a tick bite or a rash. If you are experiencing any symptoms, neurological , rheumatoid, or other symptoms that your doctor can't seem to diagnose, look into Lyme disease. And If you are lucky to have been saved from the devastating effects of Lyme, say, "Thank you Hashem."

If you do know of someone who suspects they may be suffering from Chronic Lyme, let them know about YeshTickva. You may just be saving another person from years and years of pain and misery.