

# **Finding the Light in the Dark**

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***No Matter How Bad It Gets***

***There is HOPE***

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## INTRODUCTION

I wrote this book to provide support to people suffering from anxiety, depersonalization and derealization related to Lyme disease. Far too often people are not aware that these symptoms may be Lyme-related and therefore they go untreated or are painfully misdiagnosed.

Since my high school days, I suffered on and off from chronic anxiety and depersonalization, but never knew these were symptoms of neurologic Lyme disease. Unfortunately this is the case for many people.

After many years of battling with Lyme disease (but not even knowing this is what I had) and feeling like I was the walking dead, I am so happy to report to you that I am living again and have been symptom-free for six months!

I hope this book provides you with a deeper understanding of Lyme disease and offers you some guidance and support for your own healing process.

Please remember that no matter how bad it gets, there is HOPE.

My wishes for your healing,

Heather Levine

## CHAPTER ONE

### *THE BEGINNING*

When I was a little girl, I played in the woods all of the time. I loved the outdoors. I also loved animals and dreamed of being a veterinarian one day. I was pretty curious about everything and loved meeting new people. I guess you could say that I was really a very happy go-lucky kid.

When I was 10 years old, one day I was playing the woods in Connecticut and was bitten by a tick. I remember getting a red rash, but otherwise never really thought anything about it.

A couple of years later, we moved into New York City. I had a good group of friends, loved school, and continued to love meeting new people. I was a little bit of a trickster, and I remember some of my friends considering me the class clown. Mostly, I was a daredevil and lived life to the fullest!

Things started to change though during my teen years. I began to suffer from anxiety. Everyone around me felt that it was abnormal for a girl of 15 to be so anxious all of the time.

Not long afterwards, I developed an onset of depersonalization disorder. This is when you feel completely emotionally detached from the world and feel as if you are living in another dimension. Depersonalization is really scary. This went on for about a year and then all of a sudden it went away.

After high school --- during my time in college -- I was pretty much symptom free. I had some bouts of depression, but no anxiety for the most part. I traveled to Australia where I studied abroad and also lived in London shortly after college. I worked for two years

before attending law school. My life really took a turn for the worst when I started law school. Doctors were baffled by my symptoms. I had horrific migraines, ringing in my ears, and immense, pressure in the back of my head. I once passed out in a car dealership holding my head asking to be rushed to a hospital. The tests came out fine.

While clerking for a judge one summer I started to get strange brain zaps and creepy crawling sensations in my head, but didn't think much of it. One day when I was out to lunch with one of my co-workers, she asked me what was wrong. I told her that I was just having shooting zaps and it must just be a headache or something.

Neurologists put me on all sorts of medications for my headaches. I also had depression. Not one neurologist or psychiatrist ever thought my symptoms might be Lyme disease.

Later, towards the end of law school, my symptoms got really bad. The severe depression turned into immense anxiety *literally overnight*. It was horrendous. I walked into my law firm and knew something was wrong with me. I felt scared of people. Sounds felt too loud. And my boss came over to me and asked: "Are you okay? You haven't been acting like your usual self." I told him I was fine and then went home.

I called my boss the next day and told him I needed to take some time off.

## CHAPTER TWO

### *ANXIETY*

That time off from work was horrible. My anxiety was getting worse I ordered several tapes from an anxiety specialist and walked around with affirmations in New York City saying to myself, *I am fine. I am good. I am special.* But that didn't work. My thoughts at that point were so a part of my consciousness that it was hard to detach.

I called my friend and she recommended I see one of the top psychologists in the city for anxiety. I agreed.

I sat in the doctor's office and told him I was suffering from severe agoraphobia and social phobia. He then asked me when was the last time I dated someone. *Was he serious? Didn't he understand the severity of this?* I was such an outgoing person and now I was reduced to being a major social phobe.

Slowly my social phobia started to get even worse. I couldn't talk to anyone so I would just stay home for weeks on end and have everything under the sun delivered to my apartment. The weeks then turned into months.

I had so much anxiety that drinking alcohol and taking anti-anxiety medications seemed like a great way to escape the anxiety. Boyfriends had come and gone because of my immense anxiety. I wanted so much to love and be loved but I would just tell them that they deserved someone better than what I had become.

In fact, there was a point when I really felt like the men in my life were dating me, *but I wasn't dating them.* It was a really unfair situation. I was just incapable of being there for someone else. Some of the men would try to help me and give me advice on what to do, but I knew that I had to conquer what I was going through on my own.

I soon became scared to talk to people on the phone. I didn't know how to interact with anyone ... I didn't know what to say. I felt confused. I was as alone as one can get. My world was very small, and I knew there was a whole world I was slipping away from.

That summer I wanted to take the bar exam, but I was so anxiety ridden that I couldn't leave the house. I even became addicted to anti-anxiety pills my doctor had prescribed for me. I'll be honest ... my doctor was prescribing the pills like they were candy.

Day by day I felt farther and farther away from reality.

## CHAPTER THREE

### *DEPERSONALIZATION*

Later that summer, my anxiety turned into depersonalization *again*. I wasn't sure whether the depersonalization was a way for my body to protect itself from my immense anxiety, but I knew that I needed help.

I went to a top specialist and told him that I had depersonalization and that I was numb. I kept crying in the doctor's office and telling him that I couldn't feel the chair. My senses were completely off. I couldn't taste or touch anything and sounds were incredibly loud. What I didn't know was that I was slowly going crazy and the effects of Lyme disease were effecting my neurological system.

Around this time I went to see my niece. When I walked into the house she gave me the biggest hug and said, "I love you aunt Heather." I cried holding her tight in my arms. I couldn't feel her. I couldn't be present with her. Life was getting harder and harder for me. I felt like the walking dead.

I started to have many experiences where my heart would race, and I would get shooting pains in my back, but still the doctors kept saying it was purely anxiety or that it could be a case of fibromyalgia and it would go away.

One night I woke up and one of my arms was completely numb. When I visited the doctor, he told me that this was carpel tunnel syndrome. *But I barely type anymore. How can this be carpel tunnel?*

There were many nights I would excuse myself from the dinner table and lie on the bathroom floor and cry. I just could not stop the depersonalization! I couldn't see, feel, or taste anything. I wanted a life other than this one.

## CHAPTER FOUR

### *HELP ME!*

My life was stagnant. Every time I would get on the phone with my friends, they were going on with their lives. I was severely depressed and each day seemed like groundhog's day.

It seemed that everything that came out of my mouth was on auto pilot. I was like a robot. The strange part was that I was able to hear my own voice echo. I felt like an alien. I was someone else, certainly not me. Not Heather. I was being taken over by another force. I didn't know whose life I was living. I was in someone else's body and trying to break free.

I remember some doctor telling me that I was just commitment phobic.

I would go to Reiki retreats, Buddhist retreats, hang crystals over my head, see hypnotists and spiritual healers to help myself. Nothing worked. When I would meet people who I already knew, it was almost as if I was meeting them for the first time. *Did I have Alzheimer's?*

One night I went out with some people to an engagement dinner, I sat quietly at the table and just watched all of them. Smiling happy faces. *What was that like?* I felt like I hadn't laughed or smiled in years. *Why was I so distant from these people? Why?* It felt like they were in another world from me and somehow I could not push through the barrier to meet them. It was almost like I was in a glass case. I excused myself from the table and went into the bathroom and cried.

For a good five minutes I sat on the toilet crying my eyes out. "God please help me, God please help me. I am going to die!" I slid on the floor in the bathroom and sobbed. I couldn't stop the depersonalization. I couldn't see, feel, or taste anything. I wanted to

prick myself so hard so I could feel something. *Maybe I should get addicted to sleep and never wake up?* It felt like the end.

Then when I got home my mother told me I had to get *normal*. I had no idea what that was. I wanted to be normal. I wanted to shake this depersonalization off so much. *Help me! Someone help me!* I was scared. I was frightened. Everything seemed heavy in my apartment and hard to manage. I just wanted a different life, I wanted to purge everything and live out of a suitcase. I couldn't take care of myself anymore. Everything was so unmanageable. At this point I couldn't cognitively handle anything – like put on a shirt or take a shower.

I couldn't take care of myself and so I did just that – didn't take care of myself.

My whole family told all our friends that I had a nervous breakdown, but I knew it was way worse. *Was this really happening?* The strange part was that I knew it was happening so I couldn't be schizophrenic. *Or could I?* I started hearing crackling sounds and insane ringing in my ears. Something had truly taken over my body.

One night I found myself huddled at the end of the bed, rocking back and forth. My dog kept staring at me to walk her. My house was a complete mess and I started shaking.

I looked at all the things in my room and wondered *How did everything get there?* Everything felt completely unmanageable. Even lifting up a book was unmanageable. So this was hitting rock bottom? This was bad.

I crawled to the phone and asked my sister for help. She told me to get up, but I didn't know how. I was confused. I didn't know how to function. *How can I eat, move, etc.?* I tried reading, but for some reason I couldn't formulate sentences with the words on the page. *What was going on?*

My sister came into my apartment and everything was a mess. She started crying and gave me the biggest hug. "We're going to get you out of this," she said.

## CHAPTER FIVE

### *LYME TEST*

Two weeks later a friend of the family who had been suffering for Lyme disease for years called. She told me that what I had might be Lyme disease. She had similar symptoms to mine, but not as extreme.

I took a standard western blot medical test for Lyme (which usually comes out negative for many people with Lyme and I didn't know it at the time). One week later, I got the results. It came out negative. I decided I must be going crazy. Please note that it wasn't until I got a test several months later from Igenix when I finally knew I had Lyme and saw all the bands.

On that day I knew I couldn't be alone anymore. I felt one step away from dying and was suicidal. I had to move home (and I also couldn't afford rent anymore).

Every morning from that point on I would wake up in bed and open one eye to see if anything had changed. Everything was still the same. Life was passing me by. *What was going on?* There had to be a better way. But I knew that I couldn't function and wasn't able to be alone. I was scared to be alone, and I couldn't handle anything by myself.

Then one day I got a phone call from my mother telling my father that we were going to see a doctor at a hospital for my "nervous breakdown." (Everyone in my family thought I had a nervous breakdown but I knew it was so much more than that.)

I got into the hospital and met with the doctor. I told him that I was hearing echoing voices, ringing on and off in my ears, and that life felt too hard to go on with. I also told the doctor I was having creepy crawling sensations in my brain, brain zaps and tremors.

The result?

He just dismissed me. In fact, all the doctors I met with just said it was my imagination and that I wanted attention. I had to wonder to myself, *Am I going crazy??*

Suddenly a nurse at the hospital put a bracelet on me and started to take me away from my parents. When she grabbed my hand, I flipped out.

I was just so scared to not be in control of my life and two people take hold of me and drag me back into the hospital. My parents kept telling me it was for my own good as they were crying in the waiting room. What had happened to their daughter?

When I got back into the hospital room, the nurse sedated me.

They put me in a gown and there I was ... in the hospital in the mental facility with a white gown and socks. My hair was a mess, and my face was unwashed. The window was cruddy and my life was gone.

I slept. I slept and I slept. There was nothing else to do. All I wanted to do was sleep and never wake up. After all, I was dead already.

The woman who I shared the room with slept all of the time. *Was that a reflection of me?* All I kept thinking was: *What is happening to me? I went from working in a law firm and writing long briefs to a white robe with my hair disheveled? Something has to be wrong here?*

The hospital didn't allow us to make phone calls. Even though I had depersonalization, I was a fighter and always tried to use the phone at night to call my sister. Of course, they always escorted me back into my room.

One day I was looking out the window and there was this family there -- all happy and smiling. *I will never have that*, I thought. *I was beyond repair. I was hopeless and my life was over.*

My family came to visit. I remember my dad bringing beautiful soaps and stuff. *Oh what was the point? This was what people on the outside used and I was awful. I looked*

*awful and felt awful.* Can you imagine? Your family bringing you soaps and coming out in a white robe?

No one knew that I was in the hospital other than my family. It was a taboo subject.

## CHAPTER SIX

### *THE FARM*

The doctors wanted to put me into a rehab for my anxiety. So my family started to look at places that would help re-teach me how to cognitively take care of myself. I needed to re-learn how to function. I was a liability to my parents at this point.

I told my mom to please commit me somewhere. I couldn't live like this.

I checked myself into a place in New England. It was a working farm where they held your hand and walked you through how to take care of yourself again. The farm was a place for schizophrenics. I remember growing up joking about these kinds of places. We called them, "the funny farm." But this was no joke at all. *Was this really happening?*

Before I went, I learned that every day the owner would wake us up at 6am to tend to the animals. The whole premise of this place was that it was to show us how to take care of ourselves again. With it being cognitively hard for me to put a shirt on, I knew this might be helpful.

As we drove up to the farm, four girls came out to greet me at the car. "I can't do this. I can't do this," I said to my dad, and then I got back into the car. My dad pulled me aside shaking me on the shoulders and said, "What choice do you have? You can't work. You can't put a shirt on. You can't take care of yourself anymore." He dropped me off and then I saw the car drive off in the distance.

Those months I lived in a house with a handful of girls with disorders ranging from bipolar to schizophrenia.

There was one girl \*Mary (name has been changed) who was detoxing from heroin. She couldn't be in her own skin, and had lots of ups and downs. Every day her room was

flooded with tons of candy, which was so enticing to me! At the time I didn't know it, but having Lyme makes you crave sugar because Lyme feeds on sugar.

Every night we would eat endless chocolate and we would talk to each other all through the night. Mary told me that her heroin addiction started with taking anti-anxiety medications. Those nights talking with Mary were like experiencing another world. I could see how someone could be so desperate just to numb the pain of anxiety. I told Mary that before I came to the rehabilitation farm, I was taking anti-anxiety medications to calm my anxiety. I knew though that things would get worse if I continued taking them – since I was becoming dependent on them.

I started writing in a journal about Mary's feelings and linking them to how similar they were to me being depersonalized. It was interesting because I realized that Mary used drugs to get rid of her anxiety, and I started going that route at one point, but then stopped. I started to realize that maybe the anxiety was too much for my body to handle so my body shut down and became numb and depersonalized.

Sometimes, I would sneak out of my room in the middle of the night and try to comfort Mary. I told her that she would be okay and that we would get out of this situation. What did I know? I was in the same boat. My life wasn't working either.

The owner of the place didn't really like me all that much. I'm such a wise ass. I think part of me was too smart for my own good. Some nights I would sneak in movies and popcorn to cheer up the girls. I would also make them holiday and birthday cards to cheer them up. I didn't know much about being schizophrenic or de-toxing from heroin, but in some respects the fact that I was there, made me not much different than these girls.

Every day was the same at the rehabilitation farm. There I was to face my own feelings. I ordered a bunch of self-help books at the center, and my room became a library of books ranging from Deepak Chopra to Debbie Ford. Sometimes the girls would come into my room and we would all do art therapy together. It was probably the worst time in my life, but looking back we were all really great people, just with unfortunate circumstances.

## CHAPTER SEVEN

### *HOME AGAIN*

When I left the rehabilitation farm to go home two and half months later, I was still stuck with depersonalization. One night I was crying because my family told me they couldn't handle it anymore and couldn't afford to help me financially being sick. I was sobbing because how could I work when I didn't know how to put a shirt on or make myself breakfast? At this point I still couldn't read, I didn't know how to really dress myself, and my IQ was below 80.

I had remembered that some nights when my anxiety was horrific at the rehabilitation center, I went into Mary's room and she would share books with me that had helped her. One night she took a bunch of books from her bookshelf and showed me the 12-step workbook as well as the "big book," which is what they call it in the meetings. She told me I could borrow them and off I went. Night after night, I couldn't put down this big book and the 12-step workbook. It really helped me.

After recognizing the similarities between Mary and me, I decided to start going to 12 step meetings. I was desperate. It was the last house on the block and I had nothing left.

Those first few days in the 12 steps were scary, mostly because it was my last hope. I couldn't listen to some of the speakers because my mind would race as I would look up at some of the slogans. *Was this for real? Was I in reality?* It all felt like a hellish dreamlike state. My anxiety was so severe that I became numb and the thoughts of feeling emotionally numb were so intense in my psyche that I had no where else to go.

But there was no other option. I was scared, and this depersonalization was going to have me for life. I had to do something or I was going to die into an abyss. *Please help me dear God, I'm frightened.*

I promised myself that I was going to do 90 meetings in 90 days which was the standard protocol for many people in the program.

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Going to those meetings was like being in a fight with myself. My body felt like it had been taken over by another force, and listening to the speakers honestly felt like an exorcism. They were taking the force out of me. I had to fight. I had to, even though I was scared ... even though I was terrified. There was no other option. I had tried everything.

Here I was -- dead – like a ghost -- but I was still trying to go into the real world that was around me. *Can't anyone hear me? Can't anyone understand me? Can't anyone understand this condition?* I was alone. I was alone in this depersonalization hell. I thought I would never have anyone understand me.

I kept going to the meetings, but it was like white knuckling it. I would tell myself, "Actions over thoughts." ACTIONS? Shoot this was tough. I could barely get out of bed.

I would stand up at the meetings and fight through it. What else was I to do? The depersonalization was just going to stay inside me and I couldn't fight it. There was no other way out of this other than to keep going.

They had sponsors at the meetings and thought this might be a good idea. I decided to get a sponsor and went to three meetings a day. Slowly, I started praying even when I didn't want to. In fact, I made sure that I did everything the opposite from what I wanted to do. I would drag myself to those three meetings a day, and I would call three people once a day. This was hard because I didn't know how to be around people. I would tell them that it was hard for me to talk to them and this actually put some ease into the conversation.

As I continued doing the 12 step program, I was beginning to believe in a higher power. I felt the steps were working to help me get out of depersonalization.

I eventually went off all anxiety medication, and started forcing myself to be around people all the time, and ...

**the depersonalization went away.**

Then slowly, after three months in the program, my anxiety went away and I started *feeling* again. What I mean by this is that I started to *have feelings* and wasn't numb anymore. The thing with this, however, was that I didn't know how to manage the feelings as they came in.

One day I was walking back from a 12 step meeting down Third Avenue and I got a surge of energy back in my system. I felt this surge in my arms, legs, and all through my body. All of the sudden I felt an intense wave of happiness. I started smiling and looked up and around at all the buildings. I was so happy to have my emotions back that I was crying. After years of anxiety, agoraphobia, and depersonalization everything was gone!

I remember a guy looking at me like I was nuts! Why was this girl so happy and then now crying? I honestly ran down the street and started touching everything from the subway post entrance to the few trees that lined the avenue. I could feel the paint on the subway post, the rough bark of the tree, the glass doors to the entrance of my apartment building, the soft supple skin on my face. It was truly extraordinary. I was physically and emotionally present!! It was honestly such an amazing breakthrough. At that point my anxiety was gone. Everything was gone. I was normal. Or so I thought.

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But the first three months in the 12 step program for anxiety were a dark period. They were dark days where nothing made me happy. I forgot how to laugh and every time I laughed, it wasn't genuine. The smile was fake too. I was out of touch with my body and being, and was like a robot. There were extreme highs and extreme lows as my body adjusted.

Since it had been a while since I had emotions, dealing with them was quite new for me and I didn't know how to manage them. A lot of people in the meetings say that in the first year it is not a good idea to enter into a relationship or make any significant

changes because the person is dealing with how to manage emotions without using drugs. In my case, I was essentially learning how to manage emotions that were once covered up with anxiety and depersonalization.

I didn't know what to do with sadness because obviously it was an uncomfortable feeling. Of course there always was an urge to want to take an anti-anxiety pill or do something to numb the feelings. But I guess when I felt sadness, I knew that I should pick up the phone and try to call a friend and tell her I was sad (to take the focus off myself). This is why it was so important to constantly try to get out of your self and ask other people how they are doing. This was a tremendous breakthrough.

It was pure luck and a matter of giving the 12 steps a shot for 90 days. What did I have to lose? By the 90<sup>th</sup> day, things were better.

Looking back now, I think it was being around people, calling people, and praying that helped me conquer depersonalization. Furthermore, the willingness to go through the dark and unknown was a big factor in helping me conquer it.

The problem was that Lyme was still eating me alive and I didn't know it.

## CHAPTER EIGHT

### *THE GREAT IMITATOR*

While I felt that I had conquered everything, I was still praying, calling my sponsor and going to two meetings a day. Mostly I was learning how to manage emotions. Sometimes I would cry, sometimes I would laugh, and sometimes I was scared to love people. But the good thing is that I started to care about people.

At this point, I had no symptoms whatsoever. I was so sure that I was fine that I started helping other people try to overcome anxiety by taking them through the 12 steps. I even started working again. Everything was okay.

Eight months later things took a turn.

I went to my stepsister's wedding, and after the wedding, I felt insanely tired. I felt as if my head was hit by a Mack truck. My head felt heavy and there was immense pressure in the back of my skull.

I remember my mom calling me to get out of bed. She screamed at me saying, "It's 4pm get out of bed! Stop being so lazy." I told her I couldn't move. It felt like my body was made out of a ton of 50-pound bricks. *Did I have chronic fatigue syndrome?* I was scared.

Soon after I started getting a head cold and went to see a doctor for the chronic fatigue and the cold. The doctor put me on antibiotics. Little did I know that these antibiotics would open Pandora's box!

I started getting dizzy, and felt like I was high all of the time. I felt so high that I couldn't even walk. The symptoms became unbearable!!

About three days after taking these antibiotics, I called the doctor crying asking him what he gave me. "Please doctor, please, whatever you gave me is making me have vertigo and everything around me is moving almost like I just got off a rollercoaster!"

He had no idea what to do and there I was with heart palpitations, tremors, shakiness in my extremities, nausea, hot and cold sweats, brain fog, tingling sensations (not like the positive ones from before), ringing in the ears, and numbness all down my extremities. What was this??!! I screamed, "Please help me!"

There were days I would wake up shaking and my bed was completely soaked in sweat. Was I dying?

I began having seizures and derealization.

Some days I was scared that I wouldn't make it through the night, so I just sat upright all night in my bed with the lights on waiting for the sun to rise. I would pray to God saying, "Please God, please just let me wake up in the morning." I always had the number for the nearest hospital by my bedside just in case I would start having shakes again.

Eventually I went on a mission to figure out what was wrong with me. People were throwing around the words multiple sclerosis, lupus, fibromyalgia, chronic fatigue syndrome, Epstein-Barr, hypothyroid, and diabetes. You name it. *Lupis? MS? Was I going to die?*

I got tested for most of these things, but the tests and the labs came out negative and I was right back to where I started. Again, I didn't know what was wrong with me!

Over time, the seizures and the derealization started getting worse and there were days when I couldn't walk outside. If I did I had to hold on to the side of a building. It was an all too common occurrence for me to be walking in New York City and have to beg someone to help me walk across the street or tell me how to get to my apartment building. The sidewalks would look almost cartoon-like as I was walking. I was literally living in a 24/7 fun (but of course not fun) house every day - feeling like I was high. My memory was also slowly going again.

Some nights I called some people from AA who I had met, but they didn't know how to help me. At this point I knew that continuing going to AA meetings wouldn't help. I knew I needed to find a support group with people that could help me through this illness. But what was it?

For months I went online and did massive research to find out what I might have. Eventually I began finding thousands of people with EXACTLY the same symptoms as I had. There they were ... the four words of doom: Chronic late stage Lyme.

## CHAPTER NINE

### *CHRONIC LATE STAGE LYME DISEASE*

Later that year I was tested for Lyme and it came out positive. It turned out that I also had a lot of co-infections including Babesia, Ehrlichia, Bartonella and Mycoplasma.

I was relieved in some ways because I thought I might have MS, or lupis, and really thought I was going to die any second. I was also sad though because even though I had found so many people with my same symptoms, I couldn't find anyone who had recovered.

(I want to mention here that Lyme has been coined as "the great imitator" because it mimics pretty much every single disease out there because it is in the neurological system -- which is why it's so frightening. In my case it mimicked diseases such as multiple sclerosis, lupis, fibromyalgia, and chronic fatigue syndrome.)

I also took a test that showed how damaged my cognitive skills were. I couldn't add or subtract numbers anymore. I think I even stopped the test because my heart was so broken. What was I to do? Here I was having graduated law school and now I couldn't even read or do simple math. It was just devastating. *How was I going to pay back my loans?*

That walk back was the longest walk home. I walked through the park and looked around at all these Manhattan mothers playing with their children. *Was I even living?* I just sat on a bench with my head in my hands and sobbed.

## CHAPTER TEN

### *THE POLITICAL SIDE OF LYME*

I went to see an infectious disease doctor who gave me a 30-day course of antibiotics (Doxycycline). According to the Centers for Disease Control, to eradicate a patient of Lyme, doctors are only supposed to give 30 days of antibiotics. However, there is controversy over this protocol.

The International Diseases Society of America (IDSA) states that Lyme can be eradicated in a 28 to 30-day course of antibiotics. The International Lyme and Associated Diseases Society (ILADS), however, thinks that a longer course of treatment is necessary if the disease has reached late stage. This is because in late stage Lyme the bacteria hides in the Lyme patient's tissue throughout their body, which makes it harder to treat. Furthermore, the bacteria changes into cyst form which makes it that much harder to eradicate.

The Infectious Disease Society of America simply will not even consider that Lyme is easy to get, needs prolonged antibiotic treatment until a patient is symptom free, and that the infection is hard to kill. They do not consider the co-infections (other bacteria ticks carry) that make Lyme even more virulent. The ISDA believes that if you still are symptomatic after a short course of antibiotics (normally 28 days) that you have what they call, "Post-Lyme syndrome." They will not call it Chronic Lyme disease, nor will they treat it any further. Their theories have been proven untrue by Lyme patients themselves. Many Lyme patients have had these 28-day treatments and, like myself, still remain sick.

The International Lyme and Associate Disease Society on the other hand are a group of Lyme-literate doctors that recognize that Lyme can be a long battle. ILADS has shown that in some people, long-term antibiotic treatment works. However, with some people the relapse rate is very high.

Unfortunately Lyme-literate doctors are not easily found and are not listed in local phone books. They are far and few between and many people have to travel distances once they find one. Primary doctors have never even heard the term, "Lyme-literate doctor," and many Lyme patients refer to their Lyme-literate doctors as "Dr. X" or "Dr. Y" because they don't want to lose their doctors in the political controversy.

This treatment controversy between the International Lyme and Associated Diseases Society and the International Diseases Society of America pits doctors against doctors, scientists against scientists, and the ones who suffer - the Lyme disease victims.

Testing is another issue. The Centers for Disease Control (CDC) states that Lyme disease is clinically diagnosed, but the National Institute of Allergy and Infectious Diseases (NIAID) recently stated that the testing is insensitive. Yet, to "confirm" Lyme disease, the tests are required. If the tests are insensitive, producing false negative/positive results, why are they necessary? And since the testing is inaccurate, this surely must mean the statistics are inaccurate.

Add to this, Lyme disease has been called "The Great Imitator," as it has up to 100 different symptoms that can mimic pretty much every single disease out there. Lyme can be hard for doctors to recognize since most Lyme patients don't have the same exact mix of symptoms. Doctors are not trained to diagnose Lyme and will not treat you unless you have a recollection of a tick bite and the classic bulls-eye rash. Even if you do have proof of a tick bite or rash, when Lyme is under-treated or a bite is never treated, symptoms can appear and/or reappear and will not abate without proper diagnosis and long-term treatment.

The doctor I saw was an infectious disease doctor who followed the ISDA protocols. (I didn't know yet about ILADS.)

## CHAPTER ELEVEN

### *SORRY, I CAN'T HELP YOU ANYMORE*

After the 30 days were up, I called the doctor's office crying saying that I still had derealization and that all my surroundings felt strange as if I was perceiving the world in a glass fish bowl. I said I felt constantly high or drunk. The secretary told me that this was normal, that she had too many Lyme patients, and that I couldn't call the doctor anymore. (I had called every day for a week after finishing up the 30 days of antibiotics.)

The doctor finally got on the phone and said that Lyme was out of my system and that he couldn't help me anymore. *If Lyme was out of my system then how come I was still sick?* I dropped onto the floor with the phone off the hook.

From that point on, I spent endless nights on the computer joining self-help groups, and trying to figure out how to cure Lyme. I spoke with other Chronic Lyme patients who had been through what I had been through. They recommended that I see a Lyme-Literate Medical Doctor (LLMD). These are doctors, as I mentioned, that are trained to handle chronic late stage neurological Lyme.

The interesting part is that when these Lyme patients would recommend a Lyme-literate physician, they would have to tell me to call "Dr. X" or "Dr. Y." This was because, as I explained in the previous chapter, they were scared to give out the doctor's full name because of the political environment around Lyme disease. In other words, prescribing long-term antibiotics was seen as a no-no.

When I called the Lyme-literate doctors at that time, many told me it would be a six-month waiting period. After calling several other doctors, some wanting \$900 to \$1,000 a visit, I realized the severity of the situation.

These doctors would want to pump me full of intravenous antibiotics, but my insurance company would deny the intravenous injections of antibiotics, and actually most of the treatments. I couldn't even afford insurance anymore. Heck, I couldn't afford food anymore.

Even so, I put myself on the waiting list.

I lived a life of never ending panic attacks, seizures, heart palpitations, night sweats, tingling sensations and derealization at this point. Although depersonalization was gone, Lyme had manifested itself in an entirely different way in my brain and neurological system.

My seizures were getting worse and so were some of the heart palpitations. Being rushed into emergency rooms became a normal occurrence for me. I remember one day walking to the car with my sister, and I started to feel my heart racing. Hoping it would pass, I ignored it. But as I sat there in the backseat of the car, my heart started racing so much that I thought I was going to die.

"Please, please help me—help me! Oh God please ... I don't want to die." I held my sister tight during that car ride. Someone called an ambulance. *Please. Oh God, Please.* "I love you guys. I think I'm having a heart attack!" *Oh please God not now! I don't want to die! I'm not ready!* I remember the car pulling to the side of the road and the ambulance coming to the car.

It was just Me and God. All I wanted was one more day to live. **I was not ready to die.**

Truth of the matter is, when are we ever ready? I had confronted some serious questions throughout my journey over the recent years. *What happens to us when we die? Is this the end? Is my life over? Is there a Heaven? Will I be able to go there? What is Life?* Someone without Lyme might think this is dramatic—but these questions came to me during the time when life was very scary for me, and near an end.

Sitting in the ambulance with my sister and her husband by my side, all I could think was, *Are these my last moments on earth? Why me God? Why me? I didn't want to go out this way.*

## CHAPTER TWELVE

### *A HIGHER POWER*

It seems dramatic but I did write some letters to my sister just in case that night was my last night on earth.

During those times with intense heart palpitations and tremors, I started putting aside my anger at God and really knew that it was time to become humble. If I was going to die tomorrow, where would I go? *Where would God take me?*

There were nights when now instead of a room overflowing with self-help books, I was on a new level. My room was filled now with books ranging from Christianity, to Judaism, to Buddhism, to Hinduism. Books with titles such as “Coping with Chronic Illness,” “How to Cope with Death,” “90 minutes in Heaven,” “Heaven is Real,” “What is Heaven Like?” etc.

I was on a mission to know what was after this life because living like this was no life at all. My life seemed over for the most part. Like a good lawyer, I would cross read sections of the bible with the Torah. I also visited rabbi’s, priests, and pastors and asked them what happens when we die.

Some had answers, and some were a little more vague. But I guess through my search and asking people I started believing that there must be some sort of after-life other than this one.

Although, this probably was the scariest time of my disease, it was actually the closest I got to God. It’s strange but I really found comfort in knowing that he would be there for me on the other side.

## CHAPTER THIRTEEN

### *THE EMERGENCY ROOM*

My eyes were raw from all the tears. I remember sitting in the emergency room staring at the ceiling at this little crack just wanting something to take me away from all this pain from all these years. Then the usual thought came to my mind, *Is this really happening? Is this what my life has become?*

The doctor came into the room, handed me a Tylenol and showed me brochures about the cure for the **common hypochondriac**. He asked me if I wanted to see the therapist on staff. It was times like this that I sunk into major despair.

The hospital business administrator came to my bedside. "Do you have insurance?" she asked.

"No, I don't," I replied. "I'm in the middle of insurance companies right now."

"Well when you're done please go to the check-out counter." She left.

I slowly put my clothes on and walked weakly to the receptionist area. She handed me the bill.

"That will be \$500. Will you be paying by credit card?"

I stood there too tired to even think, but \$500 dollars for two Tylenol and a doctor asking me to see a therapist? It was days like this that I just wanted to end it. There was no help out there for someone like me. This was a typical day in my Lyme life. **No one understood.**

## CHAPTER FOURTEEN

### *RELAPSE*

Six months later, I was sitting in the doctor's office (a Lyme-literate physician) getting my Lyme antibiotics and telling the doctor that I was relapsing. The office was flooded with Lyme patients. *What was going on?*

I sat in the doctor's office telling him yet again about the never-ending horrible brain fog, derealization, heart palpitations, hotness in the back of my neck, hot and cold sweats, tingling in my hands and feet, migraines and exhaustion. He said this was normal for Lyme disease, and then the nurses came into the room and wanted to take my blood. They were laughing and talking about what they were going to do for July 4th.

Tears began to swell up in me as I didn't even remember the last time I went out with friends or had a life for that matter. They were also laughing at me because my veins were too small and it was too hard to inject me with a needle.

That drive home from the doctor's office was the worst day of my life (well, I guess I had many of those). The words from my doctor that said, "You may have this for the rest of your life" really made me want to drive my car off the road. I had been sick for six years with everything imaginable with my neurological system and my brain. If he knew how I felt he wouldn't want to live either.

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A couple of weeks later it was my birthday. I was broke. I mean *really* broke. I sat in my room alone on my birthday with no friends but me and a candle. I sat there holding the candle praying to God to give me money for treatments, to give me hope, and to be there for me through all of this.

After I blew out the candle, I ran to my computer and bought myself my *first* birthday gift. It was an infrared sauna from Promolife. I had heard that infrared saunas were a very important tool for detoxing. Unfortunately, living in New York I was overwhelmed by the high prices of going to a spa to do an infrared sauna -- so I decided to buy an infrared sauna mat to use in the comfort of my own apartment.

As I clicked the button to pay, I literally had one eye open and was shaking. *Okay I can do this. I'll just pay it off when I'm better.*

That day I knew I had no choice but to seek help and get on the right track. Through months of research, I had been mostly finding stories of people who had acute Lyme disease, but not late stage like I had. After Googling everything under the sun, I finally found Perry Fields, US Track and Field Athlete, whose Lyme story was very similar to mine.

I was actually very skeptical about speaking with Perry at first. There are so many people on the Internet who prey on people with Lyme, trying to sell their products and claim to have a quick cure. Something inside me just told me to trust her and I went with it. I really had no other choice. I was up against a wall, flat broke, relapsed on antibiotics, and had tried everything else and that had no answers.

My family had really given up on me. I remember my them telling me that they couldn't handle me being sick. "Oh, Please, you guys are all I have. Please. Please help me." I remember saying this as I cried. They told me that "All this money had been spent these years on doctors and that I should be better by now. Call me when you're normal again." They then hung up the phone. The sad part is they were right. I still wasn't better. My eyes were puffy because of all the tears.

What was I going to do? My knees were weak as I dropped the cell phone and curled up in a fetal position on the floor. My eyes were raw from tears. Tear after tear just streamed down my face hitting the floor. I was too tired to wipe them. I kept asking God "Why me? Why me God? What did I do to deserve this? If I did something bad I'm sorry. I'm so so sorry."

Later, the phone kept ringing and I knew that it wasn't a friend or my mother to say that she changed her mind. I had lost all my friends by this time and just lost my family by my side.

It had been two years since I had left my job, and my old boss thought I'd fallen off the face of the earth because I disappeared. The only person it could possibly be was a creditor asking about my bill or my bank asking about the default payments on my student loans from law school. I stood still for a minute silently in my room asking God for advice. "God, please help me. I need to get better. I need to start making money. Please God help." A voice then said to me "Do whatever it takes no matter how crazy it is." (I watched Conversations of God not too long before that and knew that each one of us has a "guiding voice.")

I answered the phone and of course just as I predicted It was my bank asking me about the missed payment from my insanely high law school loan. I should have let it go to voicemail.

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**By the time I called Perry I had nothing left.** I think I even applied for another credit card to call her because the others were maxed out. Money had been spent all these years and I still wasn't better and I was up against a wall. Sometimes I would beg friends for some extra cash or my parents, but by this time everyone was so tired of me asking, and tired of me being sick. **I had lost everything and everyone.**

Perry provided me with the information I needed and then it was up to me to find people in New York City to do some of the treatments.

I started seeing alternative healers, and went off of antibiotics. Going off antibiotics was scary for me. I won't lie. It wasn't an easy task, but I just said to myself, "I'm dying anyway. What difference does it make? Let me try this for six months."

## CHAPTER FIFTEEN

### *RECOVERY*

Over the next six months I sold everything in my apartment from jewelry, to shoes, to my most prized possessions to afford alternative treatments. Everything was gone. I sold everything except my bed and my TV. It was scary because I didn't know how long it would take to get out of Lyme and I might run out of things to sell. I knew though that once I was able to get better I would be able to work again. Having constant brain fog and derealization makes it hard to have a job. Sometimes I rented out my apartment for the weekend for extra cash. I would also dog walk or even dog sit. These things helped me get some money together.

By going to alternative healers and following my own healing protocol, including eating organic foods, taking vitamins and minerals, going to yoga class, and praying, I started to get better. My cognitive skills returned and I was able to critically read again, and also add and subtract numbers.

Today I am happy to report that I am symptom free and have been for several years since writing this. My life is completely different now. I try to eat organic when I can, I go to yoga class to relax and de-stress, I am continuing to take vitamins and minerals (and sometimes aloe), and I always pray when I can... I am working again! I am so grateful that I am better and working! My colleagues are so impressed with my recovery. They saw me come from a place of near death to really living again. Today, I love helping people file disability claims and assisting them with other various disability legal matters.

A lot of people have asked me what was the most important thing I did during my time with Lyme. I tell them honestly and quite often getting better is a paradox. The paradox is spiritually understanding how temporary life is and that death is ultimately the best teacher that we have. What I mean by this is that during those nights when I was sick I dreamt everyday of having a life and living a life now (in the present moment at that time). The problem with this was that I was so physically sick that having a life seemed

impossible. Moreover, forcing my body and constantly reminding myself that we had to “get better now or else” was not helping my adrenals to relax. It was only when I really “let go” and focused on things other than this life (mainly Heaven) and just the beauty of the descriptions that I read was when my body began to get better. It is almost like our bodies need to be reminded that this life is temporary.

We truly are eternal beings and unfortunately our society keeps forgetting to tell us this. Time and time again we read in the news that another celebrity has died or someone that we know has passed away and we are shocked. Why? Why are we always shocked? Life is and always has been temporary. It was never supposed to be eternal. That is what heaven is for. Why isn't society preparing us for who we really are?

It was after really understanding the beauty of eternal life and the love that we have in Heaven, that my body began to heal. As these thoughts of Heaven permeated my body, some of the light and love began to change my thinking patterns. The hell that I experienced on this earth was replaced by love from my inner being and my heart.

I realized that all along during my journey with Lyme I had all the love and all of God inside me. Unfortunately, it was buried under layer and layers of thoughts, impressions, identities, shame, guilt, regrets, and fear (all things that God never gave me but rather our society). So, I guess the question would be well if society gave us those things and not God then wouldn't it be better to live in a cave somewhere? However, after healing I realized that it was in seeing the darkness that I could only experience the light. What I mean by this is that every thought I had was the opposite of love and it was experiencing and realizing this where I truly began to understand that I had all the unconditional love inside me.

The ironic part of life is that society teaches us that people, places, things bring us happiness. But, all these things are fleeting. The true happiness lies right within your heart where God dwells. He's been there since your birth. He is just waiting to hear you. Take the time to shut off the cell phones and be still. Hear all the chatter in your head. Let them go. Whether they are voices of your boss, mother, father, child etc. Let them

go. See the root of where and when you got the thought and then see them pass just like clouds. After a while of watching the thoughts leave watch the light appear and God's love come into your heart like the sun.

I have dreamed of where I am today for years. Lyme manifested itself in me in some pretty weird ways, but I know everything happens for a reason. It's strange, but I almost don't want to take back my Lyme. I would be such a different person than I am today. I am so thankful for all the people I met during my Lyme journey. There are so many wonderful resources out there such as the 12 step programs, temples, church, fellowships which are there to assist you where you are at energetically and meet likeminded people who are in a similar situation than you. It really provides encouragement being with others and knowing that you are not alone. There is someone out there that has your exact story and is going through the same thing.

I truly think that we are meant to be in fellowship with one another and love one another. I think sometimes our society is changing so rapidly with technology that there is a risk that we are losing touch of humanity at some points. Its important not to be alone too much. Go out there and be with people. As scary as it is they are your most important teachers and so is life.

I am so grateful for all the people I met on my journey. All the healers, friends and people that came into my life for a season that I loved.

My dream ultimately is to have a spa or rehabilitation center for people with Lyme to go to -- a place for Lymies to call home. It was everything I wanted when I was sick, alone and when my family couldn't understand this disease at all

Please remember no matter how bad it gets that there is hope. I feel that people in the Lyme community were my biggest support system and were like a family. You have helped me to save myself. We all save eachother. Love one another because we are all in this game together. The game of life.

Much Love, Heather

