# Lyme Disease

There is nothing that is easy about Lyme disease. From diagnosing - to treating - to living with Lyme disease – none of it is easy. My family of six all have had Lyme disease which is not surprising given that we lived in the woods in Connecticut for 14 years where the deer and our kids roamed free. Even our dog – a beautiful yellow lab – got Lyme disease.

I believe that Lyme disease is an epidemic that is not acknowledged by the medical community, largely because the standard testing for Lyme is so unreliable. People with Lyme are often misdiagnosed with chronic fatigue syndrome, MS, fibromyalgia, rheumatoid arthritis, or psychiatric problems. It could be many years before people receive the proper diagnosis and by that time their health has been in a downward spiral. The emotional toll of undiagnosed Lyme disease cannot be underestimated. There is nothing more defeating that going from doctor to doctor only to be told there is nothing wrong with you – when you are in fact very ill. Dr. Kinderlerher, a Lyme doctor told me that many people with Lyme feel so hopeless that they are suicidal. People with Lyme often look fine – which makes others doubt their symptoms. I got a lot more sympathy when my arm was in a cast – than I did when I had Lyme disease – because people could actually SEE the cast. Lyme can cause a lot of strain in families and with spouses – if the doctor can't find anything wrong with you then you must be fine. Children suffer the most since they have no baseline for what it is like to feel normal. They are at the mercy of adults and a medical community that often fails to properly diagnose and treat Lyme – leaving them to lose some very formative years of their lives. Children with Lyme are often diagnosed as having ADHD, learning problems, or just plain maligners. Lyme disease can change the trajectory of a child's life.

#### What is Lyme disease?

While many people have heard of Lyme disease – they are not always clear on what it is. Lyme disease is a bacterial infection from a tick bite. The bacteria is a spirochete (shaped like a cork screw) and its name is Borrelia burgdorferi. The catch is that you can get more than one infection from a tick bite, referred to as co-infections, which make you even sicker. Ticks can carry many bacteria, viruses, fungi and protozoa at the same time and transmit them in a single bite making them cesspools of infections. Different ticks carry different infections and live in different parts of the country. If you want to know which TBD's are prevalent where you live, ask a local vet since dogs serve as sentinels for tick diseases.

While it is beyond the scope of my handout to go into full detail – the following chart from The Lyme Disease Organization gives an overview of the most common co-infections.

## Symptoms of Lyme

The symptoms of Lyme are numerous and vary from person to person depending on what other coinfections are involved. What often starts as flu-like symptoms can develop into a multitude of other symptoms. The symptoms of Lyme overlap with many other illnesses making it hard to sort out. Lyme disease if often call the great imitator since it mimics many other diseases. Following is a partial list of symptoms:

- Flu-like illness any time of year
- Fatigue
- Fever
- Night sweats
- Headaches
- Frequent infections
- Sore throats and swollen lymph nodes
- Shortness of breath (air hunger), dry cough
- Joint pain in large joints
- Bell's palsy
- Gastrointestinal symptoms
- Brain fog/memory loss/cognitive impairment
- encephalitis
- Sleep impairment
- Psychiatric: mood swings/anxiety/panic attacks/depression
- Heart palpitations

# Diagnosing Lyme or Why Is It So Frigging Hard to Get a Diagnosis?

Lyme disease is or *should be* a clinical diagnosis – but most doctors rely on positive lab results and therein lies the problem. The standard lab tests for Lyme are in my opinion useless and not accurate. The other factor is that many people do not recall a tick bite or seeing a tick on them (not surprising since lymph ticks are the size of a pin head) nor do they develop a rash. It's also important to note that not everyone gets sick immediately after being bitten by an infected tick. Spirochetes can remain dormant in humans many months or even years. Dr. Crist, who specializes in tick-borne infections feels that trauma of some sort often sets things in motion and activates the disease. The trauma could be a car accident or some life changing event such as divorce, death in family, loss of job, moving etc.

The standard testing for Lyme is a two-tiered testing method which is recommended by the CDC (Center for Disease Control). The tests are so insensitive that they are estimated to be inaccurate in 35% - or as much as 50% of patients who have Lyme. Can you imagine any other disease, such as cancer, where you rely on a test that is only accurate 50% of the time?

First your doctor will order an ELISA test and if that is positive they will order a Western blot to confirm the disease. Well that makes no sense since the ELISA is so inaccurate. Without getting too technical I will try to explain why these are flawed. These tests don't measure the infection itself they measure antibodies that a patient's body makes in response to exposure to Lyme disease. Tests can be negative if not enough time has passed for antibodies to develop, the immune system is suppressed, or

the person is infected with a strain not measured by the test. During the first 4-6 weeks of illness most people have not yet developed the antibody that the test measures. That's why Lyme Literate Doctors, referred to as LLMD's, skip the ELISA and do the Western blot. The Western blot should be done by a lab that specializes in Lyme/tick-borne diseases.

# LABS used for Lyme testing:

#### IGeneX

www.lGeneX.com

Phone: 800-832-3200

The gold standard in testing for Lyme and other tick infections. The director of the lab was kind enough to spend almost an hour on the phone with me when I was at my wits end – and helped to point me in the right direction. This is the lab my family used.

• Stony Brook Lyme Disease Laboratory

www.medicine.stonybrookmedicine.edu

Phone: 631-444-3824

• Medical Diagnostic Laboratories

www.mdlab.com Phone: 877-269-0090

# Other methods for testing for Lyme:

- **Bio-meridian machine**: In a perfect world doctors would send patients for a bio-meridian screening. The bio-meridian that I use has all the frequencies of Lyme disease and co-infections and in my experience with my family has been very accurate. That's why I trained on it!!!
- Darkfield Microscope:

At the Clear Health centers, Dr. Haskell looks at your blood under a darkfield microscope. He can not only identify spirochetes in your blood – but can diagnose Lyme – based on the violet colored hue of the spirochete. Seeing is believing. I wish the darkfield microscope was used by more doctors.

 Columbia University Medical Center - Lyme & Tick Borne Diseases Research Center www.columbia-lyme.org Phone:646-774-7503

The center is a great resource for information and offers patients with persistent neurologic or neuropsychiatric symptoms attributed to Lyme a second opinion where an extensive evaluation is performed. People with Lyme often have a slow processing speed and visual tracking issues.

# **Treating Lyme Disease**

If one of the lab tests come back positive the standard treatment for Lyme is anywhere from 2-4-6 weeks of doxycycline. For a fresh infection this works well and the medical community is pretty

much in agreement on this approach. The controversary is over how to treat someone who has had Lyme disease for awhile and this is where things get very contentious. The Lyme world advocates for longer courses of antibiotics until the patient's issues are resolved. The CDC and mainstream medical community don't agree with this approach making it difficult for patients to get the care they need. My husband went to an KU infectious disease doctor who totally dismissed the idea of chronic Lyme. When I called another infectious disease practice in Kansas City — the receptionist told me that they will not see anyone who has had Lyme or thinks that they have had Lyme. Seriously?

While Lyme often becomes the focus or even obsession for chronically ill people – other important factors are should not be overlooked. If a person has been sick for while there is more than just Lyme disease involved – mold, viruses, heavy metals, parasites and teeth can all play a role and need to be addressed.

These are the various methods my family tried to treat Lyme

- Long-term antibiotics
- Hyperbaric Oxygen Therapy
- Homeopathics through the Hansa Center
- UVLRx IV Therapy
- Ozone Therapy
- Dr Zhang's herbal protocol

# **Long-term Antibiotics**

My family and I all did long term antibiotics – and I wish we didn't. While we all got some benefit from the antibiotics the damage they did to our guts was significant.

#### **Hyperbaric Oxygen Therapy**

I am a big believer in HBO Therapy. It is powerful and non-invasive with no side effects. With that being said it did not help us with our "Lyme" symptoms because we didn't know it at the time but we were dealing with a host of other parasites. HBO therapy has helped people with Lyme and it is effective with bacterial infections. I saw first hand how a man's foot was saved. He had an open wound that wouldn't heal – and had a date scheduled for amputation. After about 30 sessions of HBO therapy he foot healed and was saved from amputation. HBO therapy is also amazing for head injuries.

#### The Hansa Center

All 6 of us went to the Hansa Center – with 4 of us getting great results. The Hansa Center treats people with chronic illness using a unique approach that can get phenomenal results with homeopathies and various detox therapies. It's located in Wichita Kansas and people travel from all over the country to go there. The catch is that it is very expensive – costing around \$9,000 for an initial two-week visit. The other catch is that you don't know how many return visits will be needed. We got great results for one of our children after 4 visits (totaling 5 weeks) over an 18 month period. I saw other people get amazing results – including several young girls who had been wheelchair bound – get out of their wheelchairs. While the Hansa Center is not a Lyme clinic most of the people I met where there for Lyme disease. I

met so many people who had been to the Mayo Clinic and other various "top" medical facilities that had failed them – but at the Hansa Center they got results. I say if you have the time and money is not object – go for it.

# **Ozone Therapy at Clear Health Centers**

I am a big fan of ozone and I think it is a slam dunk when it comes to infectious disease. We did various ozone therapies with great results under Dr. Haskells supervision at the Clear Health Center in Utah. Ozone can help to reduce not only Lyme bacteria but viruses and mold. To learn more about the therapies visit <a href="https://www.ClearHealthCenters.com">www.ClearHealthCenters.com</a>

## Dr. Zhang's Herbal Protocol

Dr Qingcai Zhang has developed a Lyme protocol combining TCM (traditional Chinese medicine) with conventional western medicine with good results. "Of key importance is the fact that our herbal ingredients are more potent than raw herbs and less toxic that the pharmaceuticals used by WM to treat Lyme disease". While his clinic is located in New York City the good news is if you can't travel there he will do phone consults. His initial visit or phone consult is \$150 which does not include the herbal supplements which average around \$300 a month. Compared to other alternative Lyme treatments I think this is very affordable and a great option.

You can order his book *Lyme Disease and Modern Chinese Medicine* on amazon.

www.zhangclinicnyc.com Phone: 212-573-9584

# **Supplements**

- **BioPure** this site carries supplements developed by Dr. Klinghardt for Lyme disease such as the **BioPure CockTail** www.biopureus.com
- Results RNA sells a kit for Lyme disease *Ultimate Lyme Support System* This is a good company with high quality supplements that some people have had good results with. www.resultsrna.com
- Quicksilver

Top quality products that I really like a few of which can be helpful for Lyme including Biocidin LSF and artemisinin <a href="https://www.quicksilverlife.com">www.quicksilverlife.com</a>

#### Teeth

While most people don't know it -jawbone infections can be a hidden source of Lyme disease and why some people never get better. Lyme bacteria can get into your jaw via infected root canal teeth or cavitations from wisdom teeth. It wasn't until I had my cavitations cleaned out that I finally felt better — it was really life changing for me. If you have Lyme disease I would strongly suggest trying to find a biological dentist who is familiar with cavitations.

#### **Documentary**

A moving documentary on the devastating effects of Lyme disease. <u>www.Underourskin.com</u>

# Lyme and Coinfections Chart

| Coinfections   | Vector  | Causative Agent  | Endemic Area                  | Symptoms   |
|--|---|--|-------------------------------|--|
| Lyme Disease<br>(also called<br>STARI or<br>Masters'<br>Disease) | Deer Tick<br>Pacific Black-legged Tick<br>Lone Star Tick                          | Borrelia<br>burgdorferi<br>Borrelia lonestari<br>Other Borrelia? | Throughout<br>US              | Off season "flu" Rash (bull's-eye or other) Constitutional symptoms Musculoskeletal symptoms Wide range of neurologic symptoms, including Bell's Palsy |
| Babesiosis   | Deer Tick<br>Pacific Black-legged Tick  | Babesia microti<br>WA-1<br>New strain                            | Northeast<br>West Coast       | Fever<br>Hemolytic anemia<br>Constitutional symptoms<br>Possible death   |
| Ehrlichiosis   | Deer Tick<br>Pacific Black-legged Tick<br>American Dog Tick<br>Long Star Tick     | Anaplasma<br>phagocytophila                                      | Northeast<br>Upper<br>Midwest | Fever<br>Headache<br>Constitutional symptoms<br>Possible death   |
| Colorado Tick<br>Fever   | Rocky Mtn Wood Tick   | Colorado Tick<br>Fever virus                                     | Western US                    | Fever with remission<br>Second bout of fever   |
| Tick-borne<br>Relapsing<br>Fever                                 | Relapsing Fever Tick<br>(soft tick)   | Borrelia hermsii<br>Borrelia parkeri<br>Borrelia turicata        | Western US                    | Sudden onset high fever,<br>recurrent fevers<br>Petechial rashes<br>Joint and muscle aches   |
| Q Fever  | Brown Dog Tick<br>Rocky Mtn Wood Tick<br>Lone Star Tick                           | Coxiella burnetii  | Throughout<br>US              | Acute fever<br>Chills<br>Sweats  |
| Powassan Viral<br>Encephalitis                                   | Woodchuck Tick  | Flavivirus   | Eastern and<br>Western US     | Fever<br>Meningoencephalitis<br>10% fatality rate<br>50% neurologic sequelae   |
| Rocky<br>Mountain<br>Spotted Fever                               | American Dog Tick<br>Rocky Mtn Wood Tick<br>Relapsing fever Tick?<br>(soft ticks) | Rickettsia   | Throughout<br>US              | Sudden fever Maculopapular rash on soles of hands and feet that spreads over the entire body 3 to 5% fatality rate                                     |
| Tick Paralysis   | American Dog Tick<br>Rocky Mtn Wood Tick<br>Lone Star Tick                        | Neurotoxin<br>excreted from<br>tick's salivary<br>gland          | Throughout<br>US              | Fatigue<br>Flaccid paralysis<br>Tongue and facial paralysis<br>Convulsions<br>Death  |
| Tularemia  | American Dog Tick<br>Rocky Mtn Wood Tick<br>Lone Star Tick                        | Francisella<br>tularensis  | Throughout<br>US              | Indolent ulcers<br>Swollen lymph nodes<br>Deaths can occur   |
| Bartonella   | Cats<br>Ticks<br>Fleas  | Bartonella<br>quintana<br>Bartonella<br>henselae                 | Worldwide                     | Fever<br>Mild neurologic signs<br>Granulomatous lymphadenitis<br>Red popular lesion  |