

December 2021 (Revised 12/23) – David Danson

## New To Chronic Lyme?

After *finally* figuring out that you had Chronic Lyme, was your experience like mine?

1. Searched the internet for information. After a week my head was spinning. There is no pattern to the information. Where can I find information that I can trust?
2. Public (and family) are conditioned to think in terms of Acute Lyme. What's the problem with Lyme? Go see the doctor and get some antibiotics for 2-3 weeks. That advice comes from the CDC, and it is all over the internet. The terms Acute Lyme and Chronic Lyme mean the same thing to most people, it's just Lyme. That is not the case. Also, for those new to Lyme there is limited knowledge of co-infections.
3. After speaking to others who have Lyme, you find everyone has a different experience. Some people seem normal, and others are experiencing a variety of problems. Few, if any, can discuss their treatment in depth. Some get better, some treated for decades.
4. My primary care doctor cannot and has not helped me. He said I was in good health. Where can I get informed treatment by someone who knows *Chronic* Lyme? Every form of treatment seems to be controversial. Who can I trust? Where can I find help?

After receiving a positive response on a Western Blot test, a *Lyme literate* MD advised educating myself about Lyme before I started treatment. The intent of this document is to pay it forward. The knowledge gained by following the doctors' advice calmed my anxiety and made me a better patient.

When the Lyme books we read are written by doctors, wouldn't you assume they had the same academic training as our primary care doctors? We all know the cost and sacrifice a doctor makes to learn their trade. Imagine being a doctor, getting Lyme and discovering that you know nothing about Lyme. Doctors turn to their peers when sick, and they then experience the same hurdles we do. The Lyme journey changes their lives, making them special, because they become the canary in the coal mine, writing books, sending a message to their peers, and attempting to help us. But remember this. They are trying to treat the problem using the tools they know and trust, *pharmaceuticals*. Buhner, on the other hand, is not a doctor (He was a master herbalist, born into a family of doctors). He knocked his head against the wall of institutional arrogance for decades. He understood doctors are limited in their knowledge of and distrustful of herbals, knowledge that takes decades to acquire.

I like this quotation from Dr. Enid Haller because it justifies the effort taken to learn about Lyme. "There is a complete sense of relief when you discover the mystery of your illness because then you experience a release from passive helplessness to a positive, proactive self-determination. The systemic denial of chronic Lyme is a black eye on our medical system, on our country, and on the individuals still engaged in denial". Dr. Bessel van der Kolk (*The Body Keeps the Score*) states, "We must become aware of our inner experience and "befriend" ***what's going on inside us*** if we are to change how we feel".

*Chronic Lyme treatment is different from your life-long experience with healthcare.* You need to position yourself to make informed decisions. Learn about the critical role of foundation work. Understand why mold is a showstopper, and what mold does in/to your endocrine system when your immune system is Lyme compromised. (Mold spores mess up the chemical signal to your pituitary gland. The hormonal output of the pituitary is then out of balance.).

CDC guidelines put a doctors' license at risk if they deviate from CDC protocol (Attorneys watch for protocol violations). Understanding how CDC guidelines impact doctors/institutions practice, medical licensing and insurance helps control anxiety and expectations when dealing with doctors.

Below are books I have read that I found helpful. They may be of interest to you if you are trying to understand why Lyme and the coinfections are not like other health problems.

No single book gave me all the answers to my questions. Gaining knowledge and understanding the pathogens is a cumulative process.

A new book, #6 below, by Dr. Kinderlehrer, is my recommendation for a first read. If you read nothing else, this book will help you understand the challenge in front of you. I am not suggesting you use antibiotics. I chose not to. Dr. Kinderlehrer published a readable book, a balanced discussion containing information I did not find in other books. You and your family will benefit. If you read only one book, read his.

1. Stephen Buhner, ***Healing Lyme, Third Edition***. As my first book, I found Mr. Buhner's book to be an eye opener. *There is an explanation for my problems!* Buhner has respect for the intelligence of mother nature and the bacteria we are dealing with. The content of the book is based on thousands of research papers and his years of experience treating Lyme, as a master herbalist. The book is readable by a knowledge seeking layman (not everyone will agree with that). He describes how this pathogen exists in our body, how it tricks the immune system and gets past the BBB, gaining access to our brain and much more. There are sections that are intended for doctors and only a medical professional will comprehend some content. No other book goes into the level of biology that this book does. I skimmed those highly technical sections, knowing that the details were beyond my comprehension. Reading the Afterword and Appendix One first might help you understand the author. Read more about Mr. Buhner at <https://www.stephenharrodbuhner.com>. ***I have the following concerns.*** Buhner advocates for one's ability to self-treat with his protocols. I started treating that way and changed my mind. There is more to successful herbal treatment than killing the bugs and this book is light on advice for diet, exercise and identifying organ stress. I also learned that *strategic* use of herbs requires the skill of a trained practitioner. I wasted dollars on the wrong herbs when I started self-treatment. Buhner suggests several herbal options for a symptom, but which herb is best for my body, and is the suggested dosage right for my body (his dosages are averages). Another example, how to determine which organs are stressed and blocking progress. Those organ needs must be

identified and supported for treatment to be effective. A trained practitioner will identify the stressed organ. Our body in treatment is constantly adapting, the bugs adapt, and the herbs taken to support the body must also be adjusted regularly. As a layman I had no awareness of the altered need or the new protocol. Buhner's book does not discuss this, but a skilled provider constantly adjusts protocol. When I read blogs on Facebook, I find many people think herbal treatment is like antibiotic treatment. I.E., the right combination of herbs will kill the bugs. That was not my experience.

2. Stephen Buhner, ***Healing Lyme Disease Coinfections***. I came to this book almost a year after reading *Healing Lyme*. The book opened my eyes to how different the coinfections are from *Borrelia*. My coinfections were *Bartonella* and *Babesia*. I had no idea they were so different from *Borrelia* and *required different treatment*. *Bartonella* turned out to be my toughest challenge. It was a long, hard battle to get *Bartonella* under control.
3. Dr. Richard Horowitz, MD, ***How Can I Get Better?*** This book is about treating chronic illness, of which Lyme is a large part of his patient base. Dr. Horowitz has years of experience treating patients with antibiotics. He goes into detail about the different antibiotics and the testing he does to monitor side effects. In my opinion this book is informative, and it makes you aware of the many challenges and duration of treatment with antibiotics. You must read between the lines to understand the cost of antibiotic treatment. But you will get the picture when you read about all the lab work. YouTube has a good interview with Dr. Horowitz, where he discusses challenges experienced during the 10 years of treatment he provided for his wife, who has Lyme. Think about that. Imagine enduring 10 years of antibiotics. This is an MD who is recognized as a Lyme expert. My take-away was to question the effectiveness of antibiotics in the treatment of Chronic Lyme. A book by Yolanda Hadid, who went to Dr. Horowitz (and *many, many* other "experts") for Lyme treatment, sheds light on the cost and experience of antibiotic treatment.
4. Dr. Neal Nathan, MD, ***Toxic, Heal Your Body***. Dr. Nathan deals with mold, heavy metals and other maladies that complicate Lyme treatment. Dr. Nathan addresses foundation work and why ***foundation work is a precursor to healing***. He makes the point that a good treatment protocol may be hijacked if foundation work is not addressed. I read this book because Dr. Nathan discusses how support systems in the body get stuck and need to be rebooted. Dr. Nathan treats with antibiotics, but he is open minded about options. He is an expert in the field and his book makes you aware of the difficult challenges of a doctor who sees so many seriously ill patients. He helped me understand the importance of immune system "*primary*" and "*secondary*" and the importance of treating primary. Those were two terms my doctor always used when checking me. She would say, "we have to figure out what is primary (which infection is the immune system fighting?)". I just wanted to kill all the bugs. Go strong, kill them all and get it over with. Dr. Nathan explained why *you must work in concert with your immune system (primary)*, or you may be working against it. This means you must treat "primary", or the

immune system may feel it is being attacked and be diverted from its focus on the “primary” infection it is fighting.

5. ***Bullseye***, by Jonathan Edlow, MD. This is a history of the discovery of Lyme on multiple continents. The book also addresses the challenges faced by labs, professional controversies, and the history of Lyme research, worldwide. In many ways, Europe is ahead of the US in research and treatment, especially Germany. To me there is an unmentioned irony. One challenge scientists face is that the known protein markers for Lyme are like other disease protein markers, so they can't say from the tests that it is Lyme. They never flip the coin and suggest that maybe people tested with existing tests for other diseases are detecting Lyme proteins and receiving the wrong diagnosis. For a real-life example, check the Kris Kristofferson story. Diagnosed and treated for Alzheimer's when he had Lyme. Other examples show up often, specifically MS (another clinical diagnosis).
6. ***Recovery From Lyme Disease***, by Dr. Daniel Kinderlehrer, practicing in Colorado. This book was published after I reached remission (or thought I had). I find it refreshing to finally read the work of an LLMD who addresses the wide variety of treatments that are required/available because of the diversity found in patients with a wide range of problems. He discusses antibiotic/herbal/alternative treatment and uses clinical diagnosis with each patient to make his treatment decisions. His book is very readable and will help anyone trying to figure out what they are dealing with. He answered questions that I have not found addressed in other books (like, why is mold such a big deal, how Lyme is involved in thyroid disorders – an early pre-diagnosis challenge for me). Setting realistic expectations for treatment progress should be more informed after reading this book. Personally, I feel the book is a must read for anyone (including family members) with chronic Lyme, fibromyalgia, chronic fatigue, and MS.
7. Dr. Steven Phillips book, ***Chronic***, is about diseases of the autoimmune system. He explores the science behind common infections that are difficult to diagnose and treat, including *Borrelia*, *Bartonella* and many others. This book was published in 2020, after I had finished my search for answers. I picked up the book because my daughter has an auto immune disorder and RA, which I wanted to learn more about. It turned out the focus of the book is on Lyme+. *Chronic* is easy to read and is a good book for people new to Lyme. It is also a book which folks with MS, fibromyalgia, chronic fatigue, RA, and other diseases would benefit from reading. As often happens, Dr. Phillips had a personal life altering experience with Lyme. Buhner's book provides the most information about the biology of the pathogens and Dr. Kinderlehrer has better discussion of treatment. *Chronic* is about the impact of the pathogen on the immune system and treatment protocols. His motivation for writing the book is personal frustration with his peers in the medical community, which is the same frustration that we have.

Others in the field, like Dr. Jay Davidson (<https://drjaydavidson.com/about/>) are active on the internet and deliver webinars where specialists from many areas have round table discussions about their work. The diversity of skills and treatments discussed in the

webinars is, to me, evidence of how the lack of good lab tests for Lyme (I.E., evidence-based medicine) allows desperate people to seek any solution that helps. And that leaves people who are ill trying to figure out who is believable. Lack of local Lyme expertise is also a big, big problem. Local Lyme skillsets are rare and hard to find (even in a community where they exist). Most Lyme qualified doctors do not advertise because of the controversy over Lyme treatment within their peer community, the reality that there is no one method of treatment that works for everyone and they have more patients than they can handle. The pattern seems to be that people who try a treatment solution that doesn't work for them feel like they were taken advantage of, calling the provider a quack. I have observed that every treating doctor will have failures, and sometimes the failure is a breach of contract by, and unrealistic expectations of, *the patient*. It is a partnership.

Dr. Bill Rawls is an MD who personally had Lyme. His opinion about antibiotic treatment is well described on his web site. He does use his web site to sell herbal solutions (based on Buhner's protocol), as does Dr. Davidson. Dr. Rawls is called a quack by some on the internet (by those he couldn't help?). Dr. Rawls' website has an extensive list of resources. He lists lots of books on the subject and provides *a searchable list of local support groups that you may be able to network with*. Chapters 12 & 13 in his book, *Unlocking Lyme*, is a good discussion of antibiotic and herbal treatment considerations.

Another herbal solution mentioned on Facebook sites is from DesBio ([www.desbio.com](http://www.desbio.com)). I was not aware of this option until I was years into treatment. It is worth checking out, but I have no experience with their multi-step program. I'm sure there are others I am not aware of.

Dr. Marty Ross has many products and information on his website. I purchased Biocidin products to break up biofilm from the website. Search for his website with Google.

Dr. Neil Spector is a doctor who had Cardia Lyme. I had contact with Dr. Spector. His first question was "what are you doing about diet?". His interview on YouTube was interesting. Search for his name and Lyme on Facebook. Dr. Spector used his skill and knowledge in cancer research to investigate Lyme treatments. Videos on YouTube cover his findings. Unfortunately, Dr. Spector passed away in May of 2019 because of heart issues.

Effective treatment is complicated and slow. Buhner explains the challenge of treating adaptable pathogens in his books. Dr. Nathan, in his book, *Toxic*, addresses a component of the treatment process many people ignore, *Foundation Work*. Dr. Kinderlehrer doesn't use those words, but he does call out the need for same. In summary, it means a body in chaos cannot heal. The liver, kidneys, lymphatic system, endocrine system, methylation, gastrointestinal tract, immune system, and others must be relieved of stress and in balance. There are no shortcuts. Reaching balance is incredibly complex.

The challenge of finding a qualified health care professional when you are ill is draining, frustrating, and maddening. Add the reality of no insurance coverage and the stress gets

worse. I often find that people who are ill will not even consider Lyme treatment when I mention there is no insurance coverage. You are not alone with the frustration this brings. To locate a Lyme qualified provider, you can do a search on [www.ilads.org](http://www.ilads.org), but that did not work for me. My provider was found through old fashioned networking and good fortune, a chance meeting my wife had with an old friend at the right time (adult daughter in a wheelchair was able to return to work after treatment). Everyone has a different experience. All are challenging.

A final thought. Years of treatment experience, knowledge gained from books and the good fortune of working with a qualified doctor made me aware that herbal treatment is tailored to each individual. Reading blogs I find that many people approach herbal treatment with the same mindset as antibiotic treatment. My doctor is a Chiropractic Kinesiologist with a TBD (tick born disease) test kit. The AK skillset supports the strategic use of herbs, homeopathic and essential oils therapy. Herbs are part of a three-legged stool if you can visualize it that way. Diet (Food is thy medicine), exercise, and herbs work together to bring balance to the body, create a host environment that is uncomfortable for the pathogens and help the immune system do its job.

Muscle testing by the AK doctor identified the herb(s) my body needed at the right time. Dosages were adjusted at each visit (normally 4-6 weeks). Sometimes an herb was used for a week, sometimes a year. Over five years I used more than 95 herbs, many of which were proprietary herbal blends that are only available to doctors. The strategic use of herbs at the needed dosage avoids spending money on the wrong herbs. The saved herbal dollars (versus a Buhner based do it yourself treatment protocol) paid for the cost of the doctor, not to mention the advantages to my body.

Diet restrictions are necessary to take away food sources preferred by the pathogens, eliminate foods that are acidic or cause inflammation and add foods that improve gut health. Over five years I was in contact with three doctors. I found the differences in their focus on diet and exercise to be quite different. To one doctor diet was a priority, the second talked briefly about diet only and the third never mentioned either. I believe it is important foundation work. How can it not be? A good diet resource on the internet is Nick Polizzi. Do a Google search and check out his offerings. He surrounds himself with experts on the subject "Food is Thy Medicine". Nick was told he had Parkinsons and healed himself with diet.

I hope the above information is helpful as you navigate the Lyme Journey.