

"It's A Scandal" -Daryl Hall on Doctors Denying Chronic Lyme

Singer/ Songwriter/ NY'er/ Dog-rescuer/ Champion for those suffering with Lyme and associated diseases



Growing up a musically-obsessed child in the 80's, [Daryl Hall](#) was one of my biggest inspirations. A masterful, inventive songwriter with an ocean of soul, he set me on the path to being an artist, to never waste a word, and to sing because I mean it.

With [six number ones](#) and five additional top ten hits throughout the 70's and 80's Daryl Hall and John Oates are the number one duo in music history. Still at the top of his game at 69 years old, Daryl has won legions of new fans with his hit MTV Live show [Live From Daryl's House](#).

In February of 2015, at my very sickest from [chronic Lyme](#) and [Bartonella](#), after it was [missed by eleven NYC doctors](#), I was homebound and in heart failure. On one of those terrifying, bleary days I caught the last half of a [Dan Rather interview](#) with Daryl.

Near the end, Rather asked, "What's the worst thing that's ever happened to you?"

Daryl exhaled, "Getting Lyme Disease is no fun, I'll tell you that right now."

"I have to speak with him," I thought. "He looks so good! I need to know how he got better."

So, here is my conversation with Daryl and with [Dr. Richard Horowitz](#), Daryl's esteemed [Lyme specialist](#), Board Certified Internist and Director of the Hudson Valley Healing Arts Center, in Hyde Park, New York, and New York Times best-selling author of [Why Can't I Get Better](#). His forthcoming book, [How Can I Get Better](#), will be out later this year.

Daryl, thank you for going on the record; many celebrities don't want to talk about this and I don't know why.

I don't either. I don't know why anybody would want to hide this, there's no stigma against it. It's something that's happening to everybody.

How and when did this all start for you?

About ten years ago, I started getting tremors, especially in my left hand and arm, with twitching, and I didn't know what that was. I've always had food allergies and spring allergies but then I got this very serious celery allergy. And that came out of the blue. And then finally I came down with this raging fever and really stiff neck and body.

What was the timeframe for all of the symptoms to surface?

This took place over the course of about a year.

I assume you were seeing doctors- what were they saying?

They told me it was the summer flu and all this nonsense. So I started talking to my family about it and my ex-wife, who has Lyme, said it sounded to her like Lyme. So I went to another doctor who finally did test me, and found I also had [ehrlichia](#). He gave me two weeks of Doxycycline only, and of course, old story, nothing happened. Except that the bull's-eye suddenly appeared. But I was not getting any better.

And then my sister found Dr. Joseph Burrascano for me, who was one of the few Lyme doctors practicing, and he was out in the Hamptons. He was the first [Lyme-literate doctor](#) that I went to and he gave me my diagnosis and started proper treatment. That went on for about a year.

What was the treatment?

I was [pulsing](#) oral antibiotics. I did not do an IV. I cycled through many different antibiotics, and slowly I started feeling better. Dr. Burrascano actually assessed me for Parkinson's because of my tremors, but thank God, I did not have it. It was Lyme.

Dr. Horowitz, is there a way to distinguish between Parkinson's and [Parkinsonism](#)? How common are tremors with Lyme and other tick-borne disease, and which infection seems to cause it?

Dr. Horowitz: Parkinson's disease is a clinical diagnosis, and the one common denominator underlying most chronic illness, especially neurological diseases like Parkinson's, is inflammation. We now know that different neurological diseases, including Parkinson's and Alzheimer's, as well as the symptoms of chronic Lyme disease are all influenced by inflammation, which can have multifactorial etiologies.

For example, inflammation could be due to different infections (like Lyme and Bartonella), autoimmune processes, environmental toxins, unhealthy bacteria in our colons (dysbiosis), an improper diet and/or nutritional deficiencies, as well as a lack of sleep.

I call these multiple overlapping medical problems keeping Lyme patients sick, MSIDS. It stands for Multiple Systemic Infectious Disease Syndrome and it is a comprehensive map to identifying the factors that keep people sick so that they can achieve wellness. Infections and toxins on the MSIDS map drive inflammation, and in the case of tremors, Lyme combined with mercury toxicity and pesticide exposure, can all increase inflammation in the central nervous system, leading to amyloid production, which damages our nerve cells. This causes memory problems and tremors. If we want to control the symptoms of Lyme disease and decrease these neurological manifestations, we have to address all of the above overlapping causes of inflammation.

Daryl, did you continue on treatment after the first year?

Yes, Joe moved into research and I began treatment with Dr. Richard Horowitz, and I have been with him ever since. He is an extraordinary doctor, incredible.

Dr. Horowitz, how was Daryl when he first came to you and can you be specific about how you got his symptoms under control?

Dr. Horowitz: Daryl had intermittent symptom flares of fatigue, pain, sweats, palpitations and mild cognitive problems, that were keeping him from functioning at his full capacity, but he was a trooper, and always pushed through when he was performing and touring.

He responded to combinations of antibiotics that addressed the cell wall, cystic and intracellular forms of Lyme and co-infections (Babesia played a role in keeping him ill, as it does in many), and we found multiple abnormalities on the MSIDS map contributing to inflammation and sickness.

For example, apart from the infections, he would get hypoglycemic from time to time, because his diet was off with low adrenal function, especially when he was on the road touring for extended periods of time. We had to intermittently go in with antibiotics for symptom flares, although oftentimes, Daryl did fine with low dose herbal therapies. This was once the load of the bacteria and parasites were sufficiently knocked down.

Daryl, how are you now?

After treatment with him all these years, I am pretty much fine, except for occasional flareups. This spring, I had one and it was lengthy and it mimicked my original symptoms of stiff neck and aches and pains and arthritic feelings and heart palpitations, all the [typical Lyme symptoms](#).

Dr. Horowitz, why do patients seem to complain about springtime flares?

Dr. Horowitz: Sometimes it's due to a new tick bite, but Lyme and associated tick-borne infections tend to have a cyclical nature. For example, women who have been adequately treated may only flare around their menstrual cycle.

We see people with healthy immune systems that can be fine for extended periods of time (which is the case in those who have beaten down the majority of the infections with treatment), but then get a relapse with the change of season, or any new stressor, like an accident, having a family quarrel, or lack of sleep.

Daryl, do you think you were re-bitten?

No, definitely not. This just tends to happen to me about once a year.

What does Dr. Horowitz do for you when you have flareups?

He knows me pretty well at this point and knows to give me double doses of Omnicef. That seems to knock it back down for me.

Dr. Horowitz, as I know you treat with many different drugs and herbs, how did you come to choose Omnicef here?

Dr. Horowitz: Everyone responds differently to treatment. You have to take a careful history and see how people respond to different medications.

Some do well with cell wall drugs like Omnicef, implying that a certain percentage of the bacteria are in cell wall forms, causing illness. Others do well with intracellular drugs like doxycycline, Zithromax, rifampin or Dapsone, because intracellular bacteria are causing inflammation, making them sick.

Once you've figured out a patient's wiring, and the overlapping factors on the MSIDS map causing inflammation, you can get people better by addressing the specific abnormalities.

Daryl, how many doctors did you see that missed this?

Not that many because my ex-wife intervened pretty quickly, but probably about three, who did absolutely nothing for me. That was in a very short period of time and I was very lucky I started the proper regimen very soon. God knows, so many people go on like this for [years](#).

Dr. Horowitz, how many doctors and over what span of time is the average for people to find you?

Dr. Horowitz: The average patient who is sick for a long time tells me that they have seen at least between ten and twenty doctors over many years before seeing me. They are usually diagnosed with chronic fatigue syndrome, fibromyalgia, an autoimmune illness like rheumatoid arthritis and MS, dementia or a psychiatric illness, and told that its all in their head. When they see me, I confirm that it IS in their head. Infections and toxins in their brains are making them chronically ill.

Daryl, what do you say to the CDC, [Infectious Diseases Society of America](#) (IDSA) and other doctors who deny that chronic Lyme exists?

It's mystifying to me. When something is impossible to understand, then conspiracy theories crop up. And you start asking why; what is all this virulent opposition to the reality of chronic Lyme disease? And I don't know what [the truth of it](#) is- why they're denying it— but I can certainly tell you that it is hurting a lot of people. It is hurting a lot of doctors and it is [hurting a lot of patients](#) that should be treated properly. It's a scandal, really.

It is very disturbing. I refer people to the brilliant documentary, [Under Our Skin](#), to get a handle on the corruption at play here. Do you want to weigh in on your feelings about this, Dr. Horowitz?

Dr. Horowitz: Daryl is, of course, right. There is a lot of denial going on here. We are in the middle of an epidemic where many people are getting sick and becoming disabled. I regularly hear stories that patients lose their jobs, families are torn apart, and they can't find anyone to help them.

Although the scientific literature clearly shows that the present diagnostic testing is inadequate with persistent infections causing chronic illness, there is a divide among doctors about how best to diagnose and treat these patients, and it has led to a virulent healthcare debate. The fall-out is that some doctors have lost their licenses for trying to help these sick patients, and many are also scared to treat them because of ramifications from the health insurance companies. We need to get everyone to the table quickly to sort this out. Lyme and associated co-infections are a major healthcare threat for our country.

Daryl, do fans come up and talk to you about Lyme disease?

They do, all the time. They ask me what to do and what doctor to go to and I refer them to the ILADS website. I tell them I go to Richard Horowitz and I reassure them that yes, I believe that you are truly sick. This is not a lie. You're not crazy, you're not a hypochondriac, because a lot of people are accused of that.

Did you ever have neuropsychiatric symptoms from Lyme?

Yes, not severe, but yes. I had cognitive issues and I still do when I get these occasional flareups. I get a little brain fog and I can't think as sharply as I normally do. Luckily, it does not last long for me. But yes, I went through a period where I was very disassociated, having issues with writing and things like that, hand-eye coordination.

Dr. Horowitz, what are the most common neuro-psych issues you see with Lyme and TBD and what is the best treatment for them?

Dr. Horowitz: Many of my patients complain of neurological symptoms like a stiff neck, headache, light and sound sensitivity, dizziness, memory and concentration problems, as well as symptoms of depression and anxiety.

We can even see a sudden onset of OCD and psychosis/schizophrenic-type symptoms. That's usually the case if someone is co-infected with multiple infections, like Babesia, which makes Lyme symptoms three times more severe; Bartonella which increases many underlying neuro-psych symptoms; and/or if someone has been exposed to environmental toxins like heavy metals and mold. The best treatment is to find all of the underlying infections making you sick, and detoxify from inflammatory cytokines and neurotoxins.

Daryl, did you have any anxiety, depression, or insomnia?

I had occasional insomnia. My ex-wife who has Lyme had horrible insomnia, she didn't sleep well for years. Luckily, that passed for me.

Dr. Horowitz, for patients with Lyme-induced insomnia, can you explain why this happens, what you recommend to treat it, and tell us how to treat it?

Dr. Horowitz: Sleep disorders are due to inflammation with tick-borne diseases, but you have to do a differential diagnosis to see if there are overlapping causes of insomnia.

For example, someone could have Lyme, causing a delayed sleep phase syndrome, where it takes them hours to fall asleep, and they get up in the late morning or afternoon, but they also could have other things interfering with sleep like drinking too much espresso late in the day (I wouldn't know anything about that), having an overactive bladder, being on stimulant medication with a long half-life, having sleep apnea, restless leg

syndrome, hormone abnormalities, such as low estrogen seen in menopause, or having elevated adrenal hormones at night keeping them up at night.

Others might have a chronic pain condition or do stimulating activities on the computer, interfering with their melatonin production. The key is to diagnose any and all overlapping causes of insomnia, and treat the tick-borne disorders, while using both medications and herbs to get people to sleep. Then the insomnia usually gets better over time.

Daryl, what do you make of the [IDSA](#) notion that four weeks of antibiotics is curative for Lyme?

I think it's a lie! Simple as that. It's a lie. And for some people, if they only have [borrelia](#), maybe they are cured in that short of time. But a large number of people are not, and it becomes chronic, and there are usually [co-infections](#) involved, and then they remain sick. Anybody who says otherwise is giving false information.

Dr. Horowitz, what are your thoughts here? How long does it take you, on average, to get people either into remission or, at least, under control?

Dr. Horowitz: It is individualized and varies from person to person. If it is an acute case of Lyme, without associated co-infections, it can be relatively quick.

Those with chronic Lyme, who are very ill and have been sick for many years with multiple abnormalities on the MSIDS map, may require years of treatment to get better and/or get into remission. We have had some recent breakthroughs in treatments based on research coming out of Johns Hopkins University and Kim Lewis's lab at Northeastern University showing that [Lyme is a "persister" bacterium](#).

We recently published two new studies on the use of mycobacterium drugs (Dapsone and pyrazinamide) for Lyme, which are normally used for other persister bacteria (mycobacterium infections like leprosy and TB). They are turning out to be very helpful in a certain percentage of people who have failed all traditional therapies.

I just had one woman from Maine, sick for over 15 years, who finally got off of all of her antibiotics after using both of these drugs. I just spoke to her, and she is getting better off antibiotics for the first time in nearly two decades! These new therapies look very promising. They will be discussed in detail in my new book coming out, ["How Can I Get Better? An Action Plan for Treating Resistant Lyme and Chronic Disease"](#).

Daryl, did you have [Herxheimer](#) reactions during longterm antibiotic therapy?

Oh, yeah. I was getting them every three weeks on treatment at first. Lyme creates such roving symptoms. I'd feel arthritic in my hipbone, then tremors, then stiff neck, and sometimes a slight headache, or heart palpitations, and these things would all rove around my body. They are these intense but vague symptoms that move around, that's the best way I can describe it.

Dr. Horowitz, what are your top recommendations for getting through herxes/ detoxing?

Dr. Horowitz: Herxheimer reactions result from killing off the Lyme bacteria, with inflammatory molecules produced called cytokines, which are not being adequately removed from the body. The rule of thumb is to turn off the faucet and shut down the production of inflammatory molecules, and open up the drain, improving the functioning of the detoxification pathways of the body, to get rid of the toxins.

This can usually be accomplished using medications that control inflammation like low dose naltrexone (LDN), Plaquenil, and IVIG (immunoglobulin therapy), but also using natural approaches like doing a trial of giving up gluten and grains, avoiding allergic foods and nightshades (potatoes, tomatoes, eggplant and peppers), or doing an alkaline diet with lots of healthy fruits and vegetables, while using phytochemical supplements that also turn on anti-inflammatory genes in the body.

Tumeric (curcumin), green tea extract (EGCG), resveratrol (the red wine/grape extract), and broccoli seed extract (sulforaphane), combined with omega 3 fatty acids, can all help lower inflammation. We also have had success decreasing Herxheimer reactions by alkalizing (drinking lemons and limes in water, or taking Alka Seltzer Gold) while taking liposomal glutathione and/or clay/charcoal, which helps remove toxins from the body.

If you do all this while properly detoxifying, it helps the majority of patients. However, if you are on an antibiotic or herbal treatment that is causing a sustained Herx, and the above therapies do not help, you may need to take a break and rotate treatments.

Daryl, roving symptoms is a great way to describe Lyme and will help a lot of people who are going from doctor to doctor as each system of their body feels off, yet they get no answers. Hopefully, the lightbulb will go on and they will realize they need to be checked for Lyme by a Lyme specialist.

Exactly. Lyme is many things. One day you can feel like you have arthritis in your leg and the next day it feels fine and the next day you have brain fog. If you have any one of those symptoms and they are moving around your body, that is a big clue that you could have Lyme disease.

I know you live in Dutchess County, NY, which is a highly endemic area. Why don't you move to Hawaii?

I know people who do! One of the saddest things, and I used to be a hunter and a woodsman, is that I love the outdoors. I love nature. But it's been denied me. I can't walk in the woods anymore, my home is surrounded by a super-enforced deer fence so that even rodents don't get in, because mice and chipmunks carry ticks as well. I think one of the weirdest legacies of all this is that it's like a prison.

I share in that sentiment with you. But given that, you don't consider moving?

No, I live where I live. I figure it out. I am careful, I am aware of it, I wear protection, I don't go wandering around in the woods anymore. I deal with it, it's a reality that I face.

I know you had to take a break from touring because of your Lyme disease. How long was that and how did you get back to being on the road?

It wasn't that long, maybe a month or so. But it was sheer willpower that I got back on the road. I just worked being sick. If I don't feel well, I let my adrenaline kick in and it pushes the symptoms down. I am used to dealing with this and also I feel that I am lucky. It never hit me so hard that I was totally out of action, my cognitive symptoms of brain fog were never intense enough or lasted long enough to cause me to stop completely. I was able to write and do the things I normally do.

Daryl, what was your lowest moment with Lyme?

Worrying that I would never get better, that this was going to stop my life. That was early on. Another low moment was when I was walking down the street in this little village near me in Dutchess County and it felt like there was a glass window between me and the world. I felt separated from the reality that I was in. It was a very disconcerting feeling, I felt totally disassociated and I thought to myself, "where is this going?" It was a very bad moment.

What has Lyme taught you?

It taught me to not trust the government and not to trust doctors. Most of them don't know what they're talking about. I hate to say that, I have a lot of friends who are doctors, specialists. But they tend to buy into the party line and they are not paying attention to what patients are saying and what's real. I really learned that. And in my younger days, I was always a bit body-sensitive, and the Lyme completely knocked that out of me. I know what it's like to actually have something. So, in some ways it was a growing-up process. I really learned how to deal with the things that happen in life.

Lyme teaches you about being in the moment.

Yes, exactly. And how to work under adversity, how to do my job no matter what. No matter how I felt, I am up on stage, nobody knows the difference and pretty soon I don't know the difference. I guess you could look at it, in one way, that a some good came out of it.

I really get that. Now I'm like, "I'm alive and I feel really good and I am so lucky."

Yeah, you learn to appreciate what you got.

Can you give some hope to people out there who are suffering from Lyme disease or who think they might be?

First of all, [find a Lyme-literate doctor](#). Do whatever it takes to find them and be diligent about it. And don't listen to any doctor who tells you your symptoms are imaginary, get to the bottom of it. Follow the regimen as prescribed by your Lyme-literate doctor, most of them know what the most effective protocol is for dealing with this, and be optimistic because it gets better. You will improve, for sure.

Agreed. I would add that whenever patients get an auto-immune diagnosis like RA, Fibromyalgia, Lupus, MS etc, that they ask their doctor what the root cause of this is. If they give no reasonable answers, I recommend patients seek a second opinion from a Lyme specialist, since Lyme can mimic all of these diseases.

Dr. Horowitz, what do you say to those suffering with Lyme?

Dr. Horowitz: There is definitely hope for those who are still sick and not getting better. I have seen over 12,000 chronically ill Lyme patients in the last 28 years, and by diagnosing and treating all of the abnormalities on the MSIDS map, the majority of people get better.

For some, its using a different combination of antibiotics and antimalarial medications. Many have Lyme and persistent co-infections like [Babesia](#), Bartonella and Mycoplasma and need all of the infections properly treated, or they won't improve.

That was the case with my wife, who is finishing up 12 months of a Dapsone protocol, and it's the best she has been during the 20 years of our marriage. For others, the key might be treating hormone abnormalities, getting

them on an allergen-free diet, getting them to sleep, or detoxing more (my wife also needed to do all of that to feel better). Everyone is different, but if you work with your healthcare provider and go through diagnosing and treating all of the 16 points on the MSIDS map, you should definitely see improvement. Do not give up!

For more information about Lyme and other tick-borne illness, visit Lymedisease.org, [Lyme Disease Challenge](#), and [Bay Area Lyme Foundation](#).

To find a referral for a Lyme specialist near you, visit: [Global Lyme Alliance](#) or [ILADS](#). Daryl Hall & John Oates are on tour all year long. Check [here](#) for tour dates.

Check out Daryl's restaurant and live music club, [Daryl's House](#).

Follow Dana Parish on Twitter: www.twitter.com/danaparish