

FOREWORD

I BEGAN MY PRACTICE OF PRIMARY CARE INTERNAL MEDICINE IN 1981 in a small town in coastal New York, known for its natural beauty—untouched pine forests, wetlands, and many wild animals. It is also part of the coastal bird flyway, through which our feathered friends travel as they migrate from one hemisphere to the next. Ominously, it also is located just 30 miles across the water from Lyme, Connecticut.

Soon after I set up my office, in addition to seeing the usual ailments common to this type of medical practice, I did note that there was a surprisingly large population of patients with “strange” illnesses. How could a relatively young person have a degenerated right hip, while the left hip, obviously the same age, was fine? Why so many “atypical” cases of Lupus? And what about the many patients with unexplained brain fog and confusion, to the point of having difficulty making sentences? The nerve “tingles,” the insomnia, the fatigue, the head and body aches, the anxiety, the “depression” that always was associated with knee pains?

Well, as I was to find out a few years later, my little town would become noted for having the highest reported case rate of Lyme disease in the world!

Lyme disease is not a new illness. It has been recognized, in one form or another, for over a hundred years. In unraveling its history, one can see many instances of missed opportunities, unrecognized patterns and outright mistakes by scientists, physicians and government officials. Over

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time, a divide developed between the front-line, Lyme-treating physicians, and the scientists and physicians at our major institutions, both at the university level and in government.

How did this come to be? What have been the consequences? Could any of the troubles we are now facing in the Lyme Wars have been prevented?

My personal Lyme story began in the mid-1980s when the pathologist at my local hospital, the genius Dr. Alan MacDonald, one day invited me to his makeshift “skunkworks,” a little lab he created in an abandoned part of the hospital morgue. There he showed me his custom-built microscope, but more importantly he had me look through the eyepiece. And there they were—crazy looking undulating thread-like bacteria that he was able to grow out from the blood of many of my patients. Yes, they were *Borrelia burgdorferi*, the spirochetal bacterium known to cause Lyme disease.

As it turned out, Dr. Willi Burgdorfer had collected the actual ticks from which he discovered this germ, which was eventually named after him, from a spot within a bike ride from where I lived and worked! He and Dr. MacDonald became friends and colleagues and together they laid the foundation for the modern concept that Lyme disease is in fact an infectious disease.

To gain perspective, one must go back in time a few years. In 1975, after many calls from residents of Lyme, Connecticut, led by Ms. Polly Murray, the U.S. Centers for Disease Control sent Dr. Alan Steere, a rheumatologist and epidemiologist, to Connecticut to study this cluster of unusual rashes and painful swollen joints. Two years later he published a study of 51 cases of a new clinical entity and called it “Lyme Arthritis”. He recommended treatment with aspirin and steroids; he considered it self-limited and saw no benefit from treatment with antibiotics. After all, he is a rheumatologist and not an infectious disease specialist.

After the discovery by Dr. Burgdorfer, the need to treat this bacterial infection with antibiotics became accepted. But which antibiotics? At what does? And for how long?

Steere conceptualized Lyme as being an illness that displays both “major manifestations” and “minor manifestations”. He and his colleagues defined successful treatment as the elimination of the major symptoms (Bell’s palsy, acute carditis, inflammatory arthritis) even though, in Steere’s belief, they usually would resolve over time without treatment! They also basically dismissed the minor manifestations—the headaches, fatigue, body pains, confusion, nerve tingles and numbness, etc.

They assumed, without any proof, that the remaining minor symptoms reflected a non-infectious immune-mediated phenomenon, and called it the “post-Lyme syndrome.”

Having treated many Lyme patients by then, I recognized that in disseminated disease, ten to fourteen day courses of antibiotics would either result in only a lessening of the illness, or an initial good outcome followed by a relapse. The patients would then respond again to a repeat course of antibiotics. Based on this experience, and looking through Dr. MacDonald’s microscope and using his *Borrelia* cultures, it became clear to me that short courses of antibiotics were prone to failure, and that these recurrent or persisting symptoms were due to an ongoing infection. I disagreed with Steere and formulated my own definition of “successful treatment”: clearing of all Lyme symptoms, both major and minor, with no relapse by three months after treatment ended.

How does one achieve this? The answer, based on a systematic treatment study I did in 1988, was to increase both the dose of the antibiotics that were then in use, and then to extend the duration of treatment out to several months. The data clearly demonstrated a direct relationship between treatment duration and success. My conclusions, presented at the 1990 International Congress on Lyme Disease in Stockholm:

“I conclude that each patient responds uniquely and must be managed individually, and more importantly, the duration of antibiotic therapy is just as important as which antibiotic is chosen in order to achieve a lasting remission.”

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My work was confirmed independently by many front-line, Lyme-treating physicians from all across America. They included such well known and admired physicians as Drs. John Drulle in New Jersey, Ed Masters in Missouri, and Paul LaVoie in California.

After Steere's original series of articles, the entity known as Lyme Arthritis received official U.S. government recognition. However, instead of assigning the study of this new entity to the infectious disease branch of the National Institutes of Health, immunologists and rheumatologists were given the job. Here began the split between university-based and government-supported researchers (who still claim that persisting symptoms post treatment are autoimmune because they believe, despite evidence to the contrary, that the Lyme infection could not possibly persist after several weeks of antibiotics), and the front-line Lyme-literate physicians who disagree with them.

But what about the patients? Patients with Lyme become torn between front-line Lyme-treating physicians and the University-based clinics. As a result, support groups sprang up all across the United States, and at the same time the first of many non-profit, national organizations formed to advocate for Lyme victims and their families.

Lyme-literate physicians and allied health practitioners eventually joined together to form the International Lyme and Associated Diseases Society (ILADS), a top-level professional organization that has been instrumental in raising the scientific bar, developing meaningful treatment guidelines, and educating physicians worldwide. Finally there is now a blend of hard science with common sense that had been lacking.

Where do we stand now? The Lyme Wars continue, but with a lot of hard work and sacrifice by many, patient and practitioner alike, the truth is getting out there and many more are becoming Lyme-aware. Through this wonderful book and the hard work and in-depth research it reflects, one can now be empowered to proceed on a foundation of knowledge and the security of knowing that you are not alone, that you are not just imagining your symptoms, and that you can be helped. I deeply respect

and appreciate this book and hope you enjoy reading it as much as I have. Please accept my best wishes, always!

Sincerely,

Joseph J. Burrascano Jr. M.D. ("Dr. B")

Dr. Burrascano is a well recognized specialist in the diagnosis and treatment of Lyme and associated complex infectious diseases, and the chronic illnesses that accompany them. With over twenty five years of experience and research in this field, he has appeared in and on virtually every form of media both here and abroad, has advised the CDC and NIH, testified before the U.S. Senate, an armed services joint subcommittee, and at various governor's councils.

He is also a founding member of the International Lyme and Associated Diseases Society, and currently is an active Board Member of the affiliated International Lyme and Associated Diseases Educational Foundation.

No longer in clinical practice, Dr. Burrascano works full time in the biotech arena to further medical research in tick-borne and other chronic illnesses.

Notable among many of his ongoing projects is his active involvement in the recent development of in vitro culturing methods of symbiotic Borrelia including the Borrelia responsible for Lyme Disease. This landmark achievement provides a new standard for diagnosing all stages of Lyme disease and can be used to follow the outcome of treatment. Dr. Burrascano is still recruiting practitioners for his ongoing project, "The Lyme and Associated Diseases Registry"™, which follows each selected patient from the beginning to the end of their illness, tracking symptoms, tests, treatments and outcomes. Finally, his lifelong interest in nutrition has come to bear with his present consultative work with various nutritional supplement suppliers.