antibiotics were withdrawn. She wanted to try again, but the doctor refused. Alice and I wanted to give these questionable treatments and recommendations by these specialists some serious thought, since some members wanted us to be their personal advocates.

Finally, Alice came to me and said, "As I see it, we have to deal with infectious disease specialists if we are to get anywhere with this. They are few and far between. Unfortunately, you've had a problem with one. Alice then said, in her best native New Jersey accent, "So! Get over it!"

The next week, Alice and I sat in front of the big desk in Dr.Yerger's intimidating office. He had been surprisingly unfazed by the prospect of spending his lunch hour with us. Lunchtime was the only time he and his partner could arrange to meet with us on such short notice.

I was nervous, but took great pains not to show it. He and his partner were not in their regular office garb, but rather in very fine looking suits and expensive ties.

Dr. Yerger was especially cordial and graciously offered us a sandwich. He seemed quite pleasantly different from the way I remembered him when Dick was ill. We spent the next hour discussing ticks, Borrelia, our patient group, and their problems getting treatment. We all were quite polite although occasionally the discussion heated up slightly. At one point, I mentioned that Sharon Kurtz thought her antibiotic treatment was halted unnecessarily, and that she wanted to be retreated.

Dr. Yerger's partner interjected "We had to stop treatment when she developed a rash, a yeast infection."

"How do you know it was a yeast infection?" I asked. "Did you culture it?"

"No, actually, I did not."

I said, "Maybe the rash could have been a spirochete rash, not a fungus."

Dr. Yerger nodded a slow, almost imperceptible, nod, and then with a smile said to me, "It looks to me like you've been doing your homework!"

We heard later from a physician friend that these two doctors diagnosed and treated more cases of Borrelia after our visit than they had ever done previously. Shortly after our meeting, Dr. Yerger commented to Dr. Deal, "Bonnie and I buried the hatchet, and we are good friends now."

I agreed.

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DR. DEAL

One day during 1984 Dr. Deal called me and said that he had a patient in his practice that was being treated for severe mental disease by her psychiatrist. He said she appeared to be the most mentally depressed, emotionally vacant person he had ever observed in his practice. Her blood work indicated that she had an infection, and upon taking her history, he realized that most of her mental problems had begun shortly after a camping trip and a febrile illness that she thought was caused by insect bites on her legs. He decided to test her for Borrelia.

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Her tests came back highly positive for Borrelia even though this was long after her camping trip. He treated her with antibiotics, and a week later during a follow-up exam found that "she was a different woman!" She was alert, much happier, and claimed that her exhaustion and fuzzy thinking had cleared within two days of taking the antibiotics. This pattern continued every time she relapsed and was retreated.

It was brought to the attention of her psychiatrist, who thought it was a placebo effect. Dr. Deal disagreed because her blood work improved along with her depression each time she was treated. "After all", he reasoned, "Borrelia bacteria have an affinity for brain tissue, and if she has a brain infection, it could certainly explain her mental symptoms." (Further descriptions about the more recently discovered relationship of Borreliosis and mental disorders can now be found in Lyme borreliosis literature, Fallon, et al.)

On one occasion, I questioned Dr. Deal about all his efforts to help our group members. There were several people who could not afford the costs of getting blood drawn or being treated if they were positive. In these cases, he drew blood at no charge, and office visits for treatment cost a nominal twelve dollars. I knew he wasn't making any money and that it was costing him his time as well. "Why are you doing this?" I asked.

He sighed and said, "Many years ago, my wife and I lost our little girl when she was only six years old. She was diagnosed at the time with leukemia, but neither I nor my wife (a nurse) ever really believed that diagnosis. After seeing Dick's illness and all these others, I now believe that she probably died of Borrelia. Her blood work was almost identical to Dick's, and when I saw that his emergency room admitting diagnosis during his first high fevers was leukemia, it was like a flash-back of our daughter's illness."

"The week before she became ill with fevers, my wife and I had taken her on a lakeside vacation in Michigan. She played with a sick kitten all weekend and was constantly outdoors where she could easily have been bitten by ticks or fleas. Whatever it was, my wife and I felt there was a connection to those circumstances. And, although there are other disease possibilities, such as cat scratch fever (*Bartonella henselae*) from sick kittens, none match the overall clinical picture more closely than Borrelia." (B. henselae can be a co-infection in Lyme patients)

After all these years, there were tears in his eyes. Dr. Deal looked tired as he spoke. He would soon retire, and his patients would be hard-pressed to find another doctor of his mettle to take his place.

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He said slowly, "I think what you and your group are doing is very important, and the things you are observing need to be investigated, especially the Borrelia/MS connection."

"I'm ready to give up on that," I said dejectedly. "I already wrote to Dr. Byron Waksman, the head of the MS Society in New York last April, and he says I'm not the first to think of it. It's just an old spirochete/MS theory that dates back to 1911. It was eventually discarded in MS research circles."

"Maybe it shouldn't have been discarded so soon," Dr. Deal pondered. "I'm concerned enough about Dick's abnormal reflexes that I think he should see a neurologist." (Dick did so later but the neurologist suggested he was "faking" his abnormal reflexes in a subconscious desire to prove my theory.)

I said, "I've studied this for two years at the library, and written letters about it to MS physicians and researchers in the U.S., Canada, Europe, and elsewhere, and no one is taking it seriously except you, Dr. Burgdorfer and Dr. John Doll."

"What about Dr. Waksman, what else did he say?"

He told me that "hypothetically" I could be correct, but hypotheses need to be proven to become *fact*, and I have no way to prove it. So I give up! There's nothing more I can do."

"Well," he said with finality, "I think you might be correct, and if you don't keep trying do something about it now it could take another hundred years before they discover that Borrelia causes MS!"

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With Dr. Deal's encouragement and with the help of Dr. Byron Waksman, (National MS Society) by early October of 1984, I instigated a MS/Borrelia study. Dr. Waksman graciously arranged to have blood samples drawn by a neurologist at the University of Arizona's department of neurology in Tucson. He was concerned that "true MS" patients were difficult to diagnose, so he wanted to personally select a neurologist whom he deemed qualified. (I had already contacted this neurologist at an earlier date and he was definitely not interested).

"I already called him several months ago and he won't even talk to me!" I protested.

"Call him again," said Dr. Waksman pleasantly.

"I'm telling you, he doesn't believe me and he won't do this!" I wailed.

"Listen to me carefully," Dr. Waksman continued in a fatherly, calm, but very firm tone, "You call him ... again!"

So, I called. This time the neurologist was stiffly friendly and he agreed to provide serum samples from eight MS patients and four healthy controls, with the condition that I pay for all costs of having the blood tested for Borrelia. I agreed to his terms.

I arranged for a private laboratory in Texas, Austin Pathology, and a government laboratory, Rocky Mountain Laboratory in Montana to perform the tests. Both labs would test identical split serum samples. Drs. Ronald Johns' private lab and W. Burgdorfer's NIH lab would perform the serology.

Eight MS patients and four healthy controls were tested. This small study had the distinction of being the first MS/tick-borne relapsing fever Borrelia serological study ever performed in the entire world, said Dr. Waksman. (He later, in 1995 asked that I never forget that he helped me do the study)

The results revealed that two of the eight MS patients (25%) were positive for two different species of Borrelia: Lyme disease borrelia (*B.burgdorferi*) and Tick-borne relapsing fever borrelia (*B.hermsii*).

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Surprisingly, the Tucson neurologist concluded that because only two MS patients were positive, "Borrelia has nothing to do with MS." I strongly disagreed and wrote a lengthy letter to Dr. Waksman as to why.

Dr. Waksman wrote back and informed me that he was turning the study results and all of my past and present correspondence over to Yale University. He suggested that I contact someone in the neurology department at Yale for further help. I wrote to the doctor that he referred me to, a doctor I had spoken with the previous summer, one who at the time was very unreceptive, and not helpful at all.

Nevertheless, as Dr. Waksman advised, I cooperated with him. He was seemingly more interested now that he was complying with Dr. Waksman's request. He said he had applied for a grant from the MS society to study Lyme disease patients who developed neurological symptoms and signs.

I sent questionnaires and thirty-four serum samples to him from our relapsing fever Arizona group, where by now we had six MS or MS-like cases in our group. I received a couple of letters from him but no real help or encouragement, and never heard what happened to our serum samples or questionnaires.

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In briefly jumping ahead in this story; over a decade later, in 1994, I attempted to contact that same Yale University researcher, Dr. Stephen Casey (not real name) who was by now at another university, to tell him that my son, Doug, had just been diagnosed with MS, several years after his Borrelia infection.

I thought he would be stunned by the fact my 1982 prediction that Borrelia could later cause MS had now been supported by my son's tragic diagnosis of 'probable MS' by one neurologist and 'definite MS' by two other neurologists, would offer him ironic proof of the hypothesis. It was far beyond coincidence. Dr. Casey was an MS specialist who knew Doug's history and he was a Borrelia-savvy neurologist that Doug desperately needed to consult, I thought.

But, oddly, he did not return my calls. One of the other doctors in his department with whom I spoke told me that Dr. Casey was still focused on Borrelia and MS. The colleague, who sounded amazed upon hearing the news about my son, said he would personally relay my message. Soon, I did indeed receive a call from Dr. Casey. It was not friendly. His tone was flat, and he lacked any sign of compassion for Doug. He sounded aloof and he did not act surprised at my *Eureka* news. Polite but icy, he suggested dismissively that I contact the "Lyme Disease Foundation." Unlike his amazed colleague who had enthusiastically relayed my message to him, he didn't seem the least bit interested in any details and he did not offer any help at all for Doug.

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Paradoxically, by referring us to the Lyme Disease Foundation, he did not seem to differentiate Lyme disease borreliae from tick-borne relapsing fever borreliae, especially when the two by scholarly definition were supposedly two "different" disease entities.

I was not aware of anyone doing research studies regarding MS as a tick-borne relapsing fever complication, only Lyme disease and MS and, in the cases of neuro-LD, the diagnoses were not considered to be actual MS, but rather an "MS-like encephalomyelitis". Was it possible that he, like I, agreed with the concept that Borrelia is one single entity differing only in variant species and strains? If not, and my son had TBRF, not LD, why would he refer me to the Lyme Disease Foundation. TBRF was a very old disease and Lyme disease was described as a new disease. His dismissal and referral were indeed odd reactions to my call.

I knew that he had seen large numbers of neurologically impaired patients since I first contacted him twelve years earlier in 1982, some that had been diagnosed as having MS, and others evidenced MS-like symptoms and signs of MS. Yet, his cases had Lyme disease, not relapsing fever. I was puzzled at his reaction to my news and more so over his referral for me to consult the Lyme Disease Foundation. At that time (1995) it did not make sense.

His referral was quite telling. Possibly he, like I, did not think TBRF and LD were any different after all. And maybe he thought that treatment for LD would help to arrest Doug's MS.

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LYME, CONNECTICUT – YALE UNIVERSITY

In November of 1984, Alice Holmgaard and I flew from Phoenix to Hartford, Connecticut, for Alice's rheumatology appointment. Before her appointment, we rented a car and drove to Lyme, Connecticut, to see Polly Murray, a woman who had meticulously documented disease patterns in herself and her family over many years beginning in the 1970's. She and another local woman, Judith Mensch, are credited with the initial discovery of what was later to become known as Lyme disease.

We wanted to meet these two ladies who had discovered Lyme disease, and compare Lyme disease symptoms with the kinds of symptoms we were observing in our group. Judith Mensch had been a co-discoverer in recognizing the disease and reporting it to state health officials at nearly the same time as Polly but she was unavailable the day we arrived, much to our disappointment.

As we traveled closer to Lyme, we began to see why everyone who visits there is enchanted with its beauty. We drove through woods and across stone bridges, the fall air just beginning to hint at winter. We met Polly at a little country store after calling her for directions. She said it would be easier for her to meet us and lead us in to her residence rather than having us chance getting lost in the maze of little country roads.

Alice had no trouble driving directly to the store, and there stood Polly to greet us as promised. She led us to one of the most storybook settings imaginable, her white, Victorian style, two-story home set in a clearing of woods. A large old wagon wheel stood near the end of the back driveway near a faded old barn, lending more charm to her spacious property. Inside her home we felt as though we had stepped back in time at least a generation. Polly is an artist of many media and her quilts, dolls and paintings adorned the charming old house.

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Uppermost in our minds of all our Lyme disease questions was, how to treat it. We didn't think the medical books were correct in stating that tick-borne borrelia was self-limiting or easily cured with antibiotics. Neither Alice nor I were of the opinion that there was much difference between Lyme disease borrelia and relapsing fever borrelia. It was just that LD was getting more attention than TBRF ever had and maybe we could learn from the new research, especially about treating the chronic cases.

We had the impression that the Lyme disease borrelia caused more arthritis type complications whereas our groups' relapsing fever borrelia evidenced more neurological problems similar to those in Europe. The similarities were more important than the differences.

Polly had been meeting periodically with Yale University researchers since the mid 1970's when the rheumatology department had taken up the investigation of her initial discovery of this new Lyme, Connecticut *juvenile arthritis disease.* She was well acquainted with ongoing research, but we were surprised to learn that our group in Arizona had implicated a great number of complications that had not yet been observed by pioneer Lyme physicians.

Polly readily believed that what we were describing was definitely a possibility with Lyme disease. She had already noticed many chronic health problems in her family and neighbors similar to our Arizona group's symptoms that she believed could be symptoms related to earlier tick bites. She had brought her ideas to the attention of Dr. Allen Steere, but he said that, as usual, she was way ahead of their research. It was true, much of what we were talking about wasn't yet published in Lyme arthritis literature, but most would later be in print.

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I told Polly that my eldest son had been plagued with epididymitis for several years after his (1996) relapsing fever, which I didn't connect with Borrelia until two male members of our group had recently described the same pattern after their tick exposures.

Polly suddenly realized that she knew of at least two such cases, but had not connected that with Lyme disease. Our afternoon was spent comparing notes about these two similar Borrelia infections and what we believed were complications of it. She was impressed with the high rate of MS cases among our group.

When Polly began talking of how Lyme disease was "spreading" out of Lyme and into areas of New York, Alice and I were incredulous. We were not of the opinion that the Lyme Borrelia bacterium was new at all. We knew that ticks have been in existence for eons, and spirochete bacteria were among the first anerobic bacteria on earth.

As we saw it, the only thing new about Lyme disease was that a new species of hard-bodied ticks was named as a new vector of the newly discovered (1982) *Borrelia burgdorferi* bacterium. Other species of hard-bodied ticks, lice, fleas and soft-bodied ticks had transmitted Borrelia to humans for at least a century before the new species and strains of *B. burgdorferi* were detected. Furthermore, Alice and I did not think it was 'spreading' but more likely it had been around, undetected, for a long time.

Polly was respectful of the current academic research reports of its "spread", and that is what she alluded to and described. She was open to our opinions, however.

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It is now a fact that LD occurs worldwide and that the bull's-eye rash, a definitive diagnostic hallmark of early LD had been observed in Europe earlier than 1909. (Afzelius, etal.) I had observed this type of palm-sized bull's-eye rash (magenta colored) on the left side of my husband's upper torso a few weeks after his initial relapsing fevers. To my knowledge or to the knowledge of Dr. Burgdorfer it had never been associated with relapsing fevers before. In the years following Dick's illness he had recurring rashes, as did others who reported such rashes in our support group.

The genus, Borrelia, and its variable species and strains are widespread. If TBRF and LD are collectively included within this diversely related spectrum, the vectors and diseases under that umbrella are universal in distribution.

After visiting Polly, we drove to Hartford where Alice was able to see a Lyme arthritis specialist who gave her his suggestions about treating her similar type of Borrelia. He, like many other early Lyme pioneers, had not heard of *Borrelia hermsii.*

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While in Hartford and New Haven I tried to contact some physicians at Yale University. I was successful in talking at great length with one, by phone. Dr. Gordon Hutchinson, M.D., was more than cordial, and he was fascinated to learn about Dick's tick-borne relapsing fever. He said, "Isn't that something rare that you get in the Rocky Mountains?"

"No, you can get it in many geographical locations, and I don't think it's rare at all, only rarely diagnosed properly," I responded. Then I launched into our long saga, to which he patiently listened. He seemed fascinated, and supportive in an, "I believe you" kind of astonishment. He suggested that we contact someone at an Arizona university about our findings.

Admittedly, he didn't know much about relapsing fever Borrelia, but as I told our story and compared the long-term complications we were observing in our newly formed Arizona support group to those of other spirochete diseases such as syphilis, yaws and leptosporosis, he became more interested. I said that I didn't think that Lyme disease was much different.

I told him about my son and others in our group having chronic epididymitis, and that my son had even had surgery that failed to cure it.

I cited some medical literature that stated epididymitis could be caused by spirochetes. He said he could recall only one case of epididymitis among the Lyme cases he had seen.

I promised to send him a news article about Dick's illness as well as some other anecdotal information I had collected. He, in turn, had some good ideas for treating my son's epididymitis that he offered to share with our family physician if he wanted to give him a call. (Dr. Deal later called him and enjoyed an informative conversation. When Brad was treated as suggested by Dr. Hutchinson, his epididymitis dramatically cleared up and has never relapsed.

Before hanging up the phone, Dr. Hutchinson said, "Are you keeping a log on all of this?"

"A what?" I queried.

"A log, you know, like writing everything that happens on a calendar."

"No, I have never thought of that," I said.

"I think you should; you might be glad you did one day. Jot down a note or two as things happen and it will be enough to jog your mind into remembering things if you ever have a need to." He also suggested that I contact the University of Arizona to investigate our Arizona Borrelia.

As soon as I got home, I bought a calendar. Dr. Hutchinson's name was the first to go on it.

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UNIVERSITY OF ARIZONA

Alice and I took Dr. Hutchinson's advice and arranged to drive to Tucson the first week of December (1984) to see a physician at the University of Arizona in an attempt to generate some research on behalf of our Borrelia group.

It took some extensive inquires for us to find just the right person to talk with at the University. We were getting to be both particular and very wary about "spinning our wheels" with people who would just comment on how interesting it all was and then do nothing.

Dr. Jacob L. Pinnas (M.D. Internal Medicine, Rheumatology, Allergy and Immunology) seemed to fit the bill perfectly. Once we met him, we knew we had picked the right person.

He was intrigued with our saga from the start and agreed that the western version of Lyme disease was not likely rare at all, but only going undiagnosed in countless numbers of people.

We cited some old literature dating back to the turn of the century that described early complications such as arthritis as well as eye, kidney, liver and neurologic problems, to name a few. We told him of people in our group who had developed *chronic* conditions such as lupus, collagen vascular-type disease, and multiple sclerosis or MS-like disease. Women had miscarriages and still-births that had been unexplained, and the facts are that all of the above-named things can be caused by spirochete infections. They were already described in very old medical literature as being the great imitators of countless diseases.

Spirochetes were famous for causing almost every disease imaginable. In fact, a famous physician, Sir William Osler, said, "Know syphilis in all its manifestations and habits and all things clinical shall be known unto you." In more recent years … "Know Borrelia spirochetes"… could be added to this quote and be accurate.

We knew that Dr. Pinnas understood what we told him even better than we did because he had a good background in infectious disease and internal medicine. He had been trained by CDC as an Epidemic Intelligence Service (EIS) officer. We were happy to find that someone with his background and stature found us credible.

Dr. Pinnas didn't rush us, and after listening for a short time, he invited everyone in his department to come in before our hour was up to listen to what we were describing. Most were genuinely interested, except for two medical students (one male and one female) who looked askance at each other, rolling their eyes and making sure that we noticed their droll, arrogant, skepticism; they left before our hour was up. Dr. Pinnas didn't let their lack of enthusiasm dampen his, however. He resolved to do everything within his power to help us.

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He assessed Alice's clinical picture and referred her to a Phoenix rheumatologist whom he thought would be very receptive to the idea of treating her with antibiotics for what appeared to be "infectious arthritis." He wrote a letter to the physician in support of our position. Unfortunately, the rheumatologist was not as receptive as he thought and not only that, he did not treat Alice with antibiotics but rather with standard arthritis drugs. Alice rapidly went downhill and began showing joint deformities. Antibiotics were the only thing that worked well for her, but this doctor refused to treat her with anything other than with gold salts and popular arthritis drugs of that era.

Dr. Pinnas asked that we send more information to him including slides of our Tahoe neighborhood and townhouse, and he invited me to bring some slides of ticks and spirochetes upon our next visit to the university. He asked me to give a presentation to his microbiology students at the University, but I declined, feeling unsure that I was ready for that.

Dr. Pinnas went to bat for us as best he could. He wrote letters in defense of our observations. Five years later, after we had moved to Memphis, I received a copy of a letter he sent to a Phoenix Lyme Foundation representative, James Bunch, in which he mentioned my efforts. He said that eventually he had to abandon his efforts because of a lack of funds and no real interest in Borrelia on a state level.

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DIRECTIVES AND STONEWALLS

Not long after Charles Thornton's newspaper article was published in the Arizona Republic newspaper, Dr. Burgdorfer informed me that he could no longer do serologic tests because his laboratory was primarily a research lab. I could only imagine that he had been pressured from someone in authority. He said it was the responsibility of local authorities. Conversely, local authorities refused to test the growing list of people who inquired about it.

Some of the Phoenix patients went to Tucson for help. There they were told that a "directive" had been issued forbidding further tests. When we called to inquire as to who issued the directive, we were told to ask CDC. CDC referred us to Dr. Burgdorfer. And, so the shameful, bureaucratic, stonewalling, shuffle went. The looming question was, "Why?" I pleaded with Dr. Burgdorfer to help and, after telling him about some of the tragic stories of debilitating illness and hardship, he compassionately relented and agreed to test "only a few, on an 'occasional' basis," and then "Only if you are really sure in your own mind that these people have Borrelia."

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In keeping my promise, I was careful to refer to his lab only the most heart-wrenching cases, and only those who fit the profile of definite tick-bite exposed relapsing fever patients. Many among this group had lost jobs due to illness and could not afford to have their blood drawn. Compassionately, my family physician offered to draw blood at no fee for these individuals.

Before the end of the year, 47 people reacted with elevated titers to *Borrelia hermsii* and/or *Borrelia burgdorferi* (Lyme disease). By now our small group of borreliosis victims had grown much larger due to word of mouth and Charles Thornton's May of 1984 news article. We could no longer just meet in our homes so we began holding our meetings at larger facilities such as church halls, senior citizen centers, or anywhere that did not charge a fee.

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Mr. Peacock, Dr. Burgdorfer's colleague, told me he was amazed because seventy-five percent of the blood sera we sent for tests had been "positive." He added, "The serum samples we get from Yale physicians are only about twenty-five percent positive."

After being contacted by Rusty Gerber, a CDC trained Epidemiology Intelligence Orricer (EIS), Dr. Burgdorfer agreed to send copies of the serology reports to our State Health Department, but he continued to address the reports to me.

Meanwhile, the Arizona Department of Health Services in Phoenix referred all of the inquiries generated by the news article to me. I finally had to demand that they stop giving out my phone number. They in turn demanded that Dr. Deal and I write up histories on all these callers and provide them with copies. At first I tried to comply and at one point took a hand-written anecdotal synopsis of several cases to the health department in person. Dr. Deal refused to do what he deemed was their work.

The day I took my list to ADPHS, Dr. Doll greeted me warmly and seemed impressed that our group was showing more evidence of high rates of MS occurring in Borrelia victims.

The brief informal meeting was cordial. One of Dr Doll's colleagues, named Mike told a story of how eight people, himself included, from Phoenix were sent to Tucson to investigate a bat cave. Seven of them slept inside the cave with the exception of one member of the group who decided to sleep outside. All seven of the cave dwellers became ill with very high fevers, whereas the lone outsider was fine.

Blood tests were immediately run on all of them during their high fevers, and Borrelia spirochetes were demonstrated on blood smears.

The demonstration of actual organisms on blood smears is a definitive diagnosis of Borrelia, and in this case the species was determined to be *Borrelia turicata.* That particular species of Borrelia is found primarily in the southwestern United States and is transmitted by *Ornithodoros turicata soft-bodied ticks.*

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Fifteen years later, I spoke with Dr. John Doll's wife and learned from her that the man who told me this story, Mike, had developed a debilitating case of MS and was forced to retire. He had moved to New Mexico and was living with his daughter, confined to a wheel chair and bed. I wondered if he had made any connection of his MS to his tick-borne borreliae infection and if he had ever tried treating it with antibiotics. I tried to contact him without success.

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By August, The Arizona Department of Health Services (ADHS) sent out a "MEMORANDUM" to all Arizona physicians regarding "Tick-Borne Relapsing Fever." It gave a description of the disease. I recognized the description as one I had read at the library regarding "louse-borne Borrelia," not "tick-borne." (There are some differences.) I thought that it was better than nothing.

Because of "recent publicity," ADPHS offered to review blood smears of anyone who experienced these symptoms and stated that they "may" do further serology on a "limited" number from such patients. We knew that Charles Thornton was interviewing them about a possible second news article, and he later said that he thought this might have influenced their new offer.

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One lady from our group, Sharon Kurtz, took them up on their offer. Because she had received a previous, highly positive serology report as well as a clinical diagnosis of *Borrelia hermsii* infection, she matched their necessary criterion so the public health officials agreed to investigate her case.

In addition to her high fevers immediately following a campout travel history near Payson, Arizona, she also described a sick parrot at her home that she admittedly had handled over the years previous to her fevers. She told of vacationing at Christopher Creek just outside Payson, Arizona where she had been bitten on her feet and legs by what she thought were ticks.

The Health Department officials decided to include a test for "psittacosis" (parrot fever) as well as for Borrelia. Her psittacosis titer came back at 1:32 (a very weak titer) while her two Borrelia tests were both positive at 1:256 and 1:512. Regardless of this proof of definite Borrelia antibodies in her blood at standardized (CDC) positive levels, they reported to her that she had had "psittacosis, not Borrelia."

Incredulously, she asked, "How can you say that when the psittacosis titer is so low and both Borrelia titers are so highly positive?" "The Borrelia tests are no good," was the clipped retort. (Those tests were the same tests used by CDC, Yale and Harvard.)

Sharon was so disgusted with that opinion and the rude treatment she experienced from public health officials, she decided to go back to college and study microbiology. She soon published an excellent paper on the relationship between MS and Borrelia. (Med. Hypoth., Vol. 21, Issue 3, Nov. 1986, pp 335-343)

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Patients reported to me that the health department officials turned down their requests for tests. One woman was told by Tucson officials that they had been issued a "directive" to not perform any Borrelia tests on Arizona people. I called local authorities and was told by one official that Dr. Burgdorfer's serologic tests were "no good" and "didn't work," so therefore they would no longer offer them to patients. As mentioned above, we knew that Dr. Burgdorfer's tests were the same tests that Yale and Harvard doctors were utilizing, so why would they be "no good" for Arizona? It was nonsense.

Is it any wonder that we did better on our own than with any help from our local public officials?

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"My tests are perfectly good and they do work! Dr. Burgdorfer thundered in response. "Perhaps if they knew what they were doing, they could convince themselves of this."

Dr. John Doll, the only person to sympathize with us at ADPHS, kindly suggested that I contact a Dr. Ron Johns in Austin, Texas, to see if he could do tests for us in his private lab. Dr. Johns had opened a private lab to test for things such as rabies and Dr. Doll thought he might be interested in this.

Dr. Ron Johns agreed to test for us after I made arrangements for Dr. Burgdorfer to send Borrelia antigen (necessary to set up the procedure) from his lab to Dr. Johns' laboratory. Our family physician offered to draw the blood free of charge to all who could not afford it. The lab costs were only thirty-five dollars, which I paid for those who could not afford it.

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Charles Thornton said that local health officials have a mandated responsibility to investigate and resolve infectious disease outbreaks of this nature and there appeared to be a blatant shirking of that responsibility in regard to our group. Drs. Doll and Burgdorfer were the only ones willing to listen and offer assistance.

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PASSING THE BUCK

On September 4, 1984, Charles Thornton's second elaborate news story hit the press and although this one was relegated to page one of section "B", it generated the same kind of interest as the first story and went out on the wire services. More calls and letters came in from all over the country.

Dr. Burgdorfer was furious. "Well, you really did it this time, didn't you?" he shot at me over the phone line. "You put my name in the newspaper!" he said angrily.

"I did not!" I retorted. "Charles Thornton did, after he called you for the interview."

"And, whose fault is that!?" he went on and on.

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What I was to learn the hard way is that conscientious scientists do not like to be quoted in the lay press without adhering to the specific protocol befitting each situation. I was an out of control loose cannon in the view of government administrators; I had incited an embarrassing, unfortunate situation for them with the news articles. Although mandated by law to address communicable disease among citizens, our local public health services employees were ill prepared to handle an epidemic of Borrelia. They did not have the time, money or educational expertise to do the job. Worse yet, patients were learning about it faster than they were.

The dilemma created great agitation between various public health officials, none of whom apparently wanted to hold the reins of this responsibility. Some officials resorted to intimidating patients with insulting remarks.

I received several calls from people who had contacted the Arizona Department of Health Services seeking help but were told by employees taking their calls that our group members had "parasite fantasy disease" and "syphilis, not Borrelia".

I called one such health official.

"I understand that you are telling people that our group members, including my husband, have syphilis."

"Well, some of them do", he said curtly. "Syphilis and Borrelia are both spirochete bacteria so the people in your group are just 'cross-reacting' to Borrelia on these tests, when they really have syphilis."

I said, "Wait just a minute, are you telling me that my husband has syphilis?" A woman had called me and said that he had actually told her that my husband had syphilis, not Borrelia. Now he confirmed it with me.

"He's an airline pilot, isn't he? He travels around a lot, doesn't he?" he remarked smugly.

I was disgusted, and told him so.

"What about the new bride?" I continued. "She had to be free of syphilis on her required blood tests before she could get married. (In those days venereal disease tests were required before marriage). She was bitten by a tick, and flushed the blood-filled tick down the toilet during her honeymoon. She was sick within a week."

"Well, obviously she had one last fling before going to the altar," He retorted.

"That's ridiculous!" I scoffed, "Borrelia spirochetes were 'positively identified' during the fevers of both my husband and the new bride and were clearly demonstrated on blood smears at the time of their fevers. So, in addition to the supporting factor of positive serologic tests performed by Dr. Burgdorfer himself, they both had absolute proof of Borrelia infection on thin smear slides at the time of their fevers."

"Oh, if they found spirochetes on blood smears, that proves they had syphilis" he said, triumphantly.

"No, that is not true," I said. "Syphilis spirochetes do not stain well with aniline dyes and therefore do not show up on blood smears, whereas Borrelia readily absorbs aniline dye stains and are quite identifiable by experts. That is one way to tell the difference. Any spirochete expert can tell you that!"

Now I realized that he did not know much about TBRF because the largest epidemic ever recorded in North America had occurred in his own state of Arizona at the Grand Canyon in 1973. At that time, the diagnostic proof criteria for identification of Borrelia was well described by K.M. Boyer, et.al., who stated that other spirochetes do not stain with aniline dyes.

He quickly changed the subject and suggested that these people had "conversion." People had already told me that the health department, in addition to the syphilis label, was describing our group members as psychological misfits that had, " hysteria" as well as "parasite fantasy disease."

I asked, "Do you mean *conversion hysteria*?"

"Yes," he replied.

"Sometimes people get obsessed with one main subject," he added, "and that becomes their main interest."

"Oh," I said, "And just what does your job consist of, anyway? Are you a psychologist or medical doctor?"

"No, I'm in zoonotic Disease."

"Just zoonotic disease… that's all?" I probed.

"Yes."

"Sounds like your 'main' interest," I countered.

He answered proudly, "Yes."

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Alice's husband, Don Holmgaard, thought we should sue the local public health officials for their persistent, insulting and slanderous statements. He consulted an attorney who said that suing bureaucrats for what we thought at the time was ineptness, was not an option. The lawyer did say, however, that Megan, the new bride and, my husband could definitely sue for the aspersions they had cast upon their morality by stating that they had syphilis, not Borrelia.

We decided that we had more important things to do than waste our time in court over a point that would not serve to accomplish what we wanted for our support group members. Don had become a forceful member of our group, and he continued to seek political support for our cause while Charles Thornton urged him on. Making this a political football contest was the best tactic, said Charles more than once. The two of them became good friends in the process of plotting their next moves.

Don worked consistently hard on behalf of our group but most of all he did so because of the growing concern he had for his wife, Alice. She had improved somewhat after our trip to Yale and Dr. Deal had consulted her Hartford rheumatologist for treatment advice. Alice was fine as long as she stayed on the antibiotics but, as soon as she was off them her symptoms would gradually return and were worse. Dr. Deal thought we should find a Lyme-savvy rheumatologist in the western states if possible.

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TEXAS LD EXPERT

My librarian friend Jean Crosier alerted us to a terrific Lyme arthritis specialist in Dallas, Texas, Eliot Goldings, MD, whose "Grand Rounds" (December 13, 1984) publication she spotted at her medical library. She gave contact information to me and I called him at Alice's request. He offered to see Alice immediately. She and Don made arrangements to travel to Dallas. They were not disappointed. Dr. Goldings spent considerable time with both of them.

Don related how he had Lyme disease too, but he was not ill with any chronic manifestations like Alice was. The one thing he did get was palm-sized recurring bull's eye type rashes that periodically appeared on his chest area, rashes that persisted for weeks. His rashes occurred on his chest, the only area other than his neck and head that were not submerged in his frequent hot-tub soaks. (Borrelia microbes quickly die at temperatures above 104 degrees so we assumed the rashes were evidence of the microbes seeking cool areas of the body) He soon learned that antibiotics promptly cleared the outbreaks.

Dr. Goldings was fascinated to learn of these recurring rashes. Most people don't get that pattern and some never recall any rashes at all. They discussed this at length.

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Little did either of them suspect on the day of that appointment that Don Holmgaard would die within weeks of that summer day in 1985. Although he had recently experienced unusual headaches, he was unaware that lurking in his head was a deadly form of brain cancer, a glio-blastoma brain tumor that would cause a stroke shortly after he and Alice returned home from Dallas. Don died in October of 1985 from his brain tumor. Ironically and tragically, Dr. Goldings was to die three years later at age forty from a brain tumor.

By now, I knew of six brain tumors related to Borrelia.

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On Sunday, March 24, 1985, I had read an article in the Arizona Republic newspaper about a high incidence of multiple sclerosis (MS) in the province of Saskatchewan, Canada. In the small town of Henribourg that is located about fifty miles north of Saskatoon, a local woman named Sylvia Hall noticed that six girls who had attended her local high school in the early 1940's later developed MS.

Subsequent investigations revealed that twenty-seven people who resided within a scope of five miles surrounding her community since 1941 had all developed MS. Some had since died. The article went on to state that.... "Not more than 300 people could have lived in the area."

If these numbers are correct, this focus of MS is nearly 10% of this population or about ten people in every one hundred. In the general population during the 1980's the rate of MS in the United States was roughly 1.2 people per *thousand*. (Please remember that at our Lake Tahoe townhouse building that consisted of only 4 units we had 3 cases of MS within a twenty year span of time and, that number equated to one in every *ten* people. University of Saskatchewan scientists had begun an investigation of Hall's claims in 1982, and looked into such things as the school well water, glaciers, soil, and base minerals.

Whatever environmental agent they were looking for was thought to have been present during World War II, because that's when all the MS patients had resided in the area. The Arizona Republic article went on to say that Hall thought that the bombing practice that took place on the area's dry lake bed might have stirred up toxic material that reached the town, three miles away. But the scientific team rejected her theory because these conditions were not matched in other "MS hotspots" such as the Orkney Islands off Scotland. The researchers said that genetic factors as well as environment are important because "local Indians have never had MS."

It had taken Sylvia Hall quite some time and many letters sent to universities to bring attention to the local problem. By the end of the article and three years of study no one was announcing any conclusions. I sympathized with her for having put forth such well-intentioned efforts, only to have nothing come of it.

It was intriguing to me that the scientific team had overlooked a common denominator between the Henribourg MS epidemic and other wartime MS epidemics: those that had occurred in such places as Iceland, the Faroe Islands and the Orkney Islands. All four of those places shared a common denominator, the concentrations of Borrelia-infected wartime "troops." Tick-borne spirochete and louse-borne spirochete infections were so common during wars that Borreliae (spirochetes) and typhus (rickettsiae) co-infections were collectively called, "trench fever" and "war fever."

British troops had been very closely linked to MS epidemics that had not existed before their wartime arrivals. After they left, MS was diagnosed in record numbers among the local populations of Iceland, the Orkney Islands and the Faroes over the next two decades.

No MS or Borrelia studies were conducted over the next twenty years to follow up on the British troops once they returned home.

I decided to call Sylvia Hall to ask her if her six high school girlfriends had dated any of the pilots who were running the target practice bombings near her town, and ask if her school experienced a lice epidemic (Borrelia recurrentis). I couldn't reach her, so I called the University of Saskatchewan.

The scientist I spoke with was very much interested, and I promised to send him more extensive information in a letter. I asked if he would forward my information on to Sylvia Hall. He agreed to do so, but I never heard from her or him again. I have no way of knowing if she ever received my request.

***

Researchers over the years have speculated and published theories about the possible reasons for these wartime-related MS epidemics. One observation that seemed plausible was that large numbers among the British troops had pet dogs. A popular theory was that because some studies had linked MS to dog and other pet ownership, "distemper virus" caused MS. Other like theories abounded but never proved correct, and they were soon out of fashion among the MS research community.

Borrelia bacteria spirochetes should have been the obvious suspected precursors of MS because of the rampant war fevers during World War II at which time the unanimous consensus among European, particularly German scientists, was that indeed MS was caused by *syphilis* spirochetes. Whether many of these MS experts of the day ever connected war fevers to louse or tick-borne Borrelia spirochetes is not known because, tragically, most of the European and German scientists who advanced the spirochete concept died in the holocaust along with their research publications. (See Vincent Marshal, DVM)

The snobbish attitude following the war was that spirochetes are unsavory by association; disgusting parasites that are transmitted through venereal contact between humans (syphilis), or from the infestation, fecal contamination and bites of lice, fleas and ticks (Borrelia). Certainly no country would lay claim (or blame) for such unspeakable disease parasites! No decent scientist would want to study Borrelia, regardless that this microbe had killed more humans than all wars combined in the history of the world.

In reference to "war fever" Borrelia infections and typhus, Lenin is credited with saying during the Russian Revolution that, "Either socialism will defeat the louse or the louse will defeat socialism." (Cited by A.G. BARBOUR-Biology of Borrelia Species).

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Another reason spirochetes disappeared from research circles was the advent of the antibiotic era. Scientists and government health agency officials assumed that with the use of antibiotics, all bacterial disease would be cured forever.

A public official in the United States, in an effort to explain the dried up funding, announced, "Spirochetes are a thing of the past." (Ralph Parker Memorial Address, Burgdorfer).

As a result, less than ten papers per year were published about Borrelia spirochetes between 1950 and 1982, before the new Borrelia species of Lyme disease B. burgdorferi was discovered. (Biology of Borrelia Species, Alan G. Barbour and Stanley F. Hayes, Microbiological Reviews, Dec. 1986, p.381. and Burgdorfer, W., A. G. Barbour, S. F. Hayes, J. L. Benach, E. Grunwaldt, and J. P. Davis. 1982. Lyme disease, a tick-borne spirochetosis? Science 216:1317-1319).

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Wartime Borrelia infections should have spurred *more* not *less* spirochete research regarding MS. Of interest, at present MS is more common in women than it is in men. But, during the 1940's, the years following the First World War and including the Second World War, MS was more common in men by a ratio of 3:2. (Textbook of Clinical Neurology, Fifth Edition, Israel S. Wechsler, W. B. Saunders Co., Philadelphia and London 1943).

MS is a disease that occurs almost exclusively between the ages of twenty and forty. It is thought that exposure to environmental agents such as toxins, viruses or other infections in a person whose immune system is altered due to hereditary causes can result in MS. The onset of MS following such mysterious exposures is thought to take anywhere from a few months to four decades.

Certainly the timing of the male MS ratio's being higher than that of females following and during World War I and World War II (1914 to 1945) could easily implicate one important facet of an MS/Borrelia link. During war years, men experienced more Borrelia exposures than women.

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Syphilis spirochetes dominated research during the 1940's. The long-term effects of those infections included MS-like neurological damage that could take several decades to develop. With Lyme borreliosis (LB) spirochetes can cause similar, insidious, long-term brain and other central nervous system damage such as; MS, ALS, Parkinsonism, dementia and more. (A.B. MacDonald, M.D,. et al., personal communication)

The neurological complications of TBRF were not followed up or documented in the ensuing years since the wars. Recently, with Lyme borreliosis (LB) patients experiencing mirror-image syphilis sequelae over the past three decades, it is not far-fetched to conjecture that in later years TBRF or LD neuro-borreliosis could evolve to not only MS-like encephalomyelitis, but to actual MS.

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MEDIA COVERAGE

Early in 1985 a free-lance book and magazine article author, Ted Schwarz, telephoned to ask me if he could do a small article about Dick's tick-bite illness. I was hesitant. Dick and I did not want any more publicity because of the onslaught of telephone calls and letters we received after the newspaper articles. We were already more involved than we wanted to be, but by now, thanks to Charles Thornton, we knew the importance of getting news media attention in order to involve government officials.

After thinking about it, I agreed to let him do an article, if Family Circle Magazine would agree not to give out our telephone number. I knew that one article in Family Circle magazine was worth thousands times more than my letters to individuals.

Family Circle agreed to field all potential inquiries for us that might result from their publication. The article was published August 13,1985, and Family Circle kept their promise, until one day I got a call from a representative.

"Mrs. Bennett, we want you to know that we have had over a thousand calls on your article, many of them media calls. I was surprised at that number. The Gary Collin's, 'Hour Magazine' television show producer really wants to talk with you, and we would like your permission to give her your phone number. We think their show is a quality afternoon talk show hosted by Gary Collins, and it will help get your tick-bite information out to the public."

I agreed to talk with the producer, and after talking with her, she was quite willing to honor my request of having an expert scientist or physician appear on the show with me to give the disease more credibility.

(Years later, Family Circle Magazine and Hour Magazine TV show featured my future colleague Karen Vanderhoof Forschner).

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When I arrived for the taping, I was introduced to Paul E. Lavoie, M.D., Rheumatologist, from San Francisco. The producer said he was the west coast medical expert. I had never met him but had heard good things about him from Dr. Burgdorfer.

I was disappointed in the show because we did not include enough technical information about the disease. The interview had focused primarily on the drama of Dick's initial illness and the most elemental information such as how to tuck your pants in your socks to avoid ticks.

Gary Collins sensed my disappointment as I talked with my husband after the show and he approached us offstage.

"Bonnie," he said, kindly, "You can't get much information said about something this complex in what amounts to about an eight-minute segment of a show. What you really need is a four hour documentary." He was right. A nice guy and it was worth coming to the show just to meet him.

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My husband offered to drive Dr. Lavoie to the airport after the show. On our way we stopped for lunch and talked nonstop about Borrelia. Dr. Lavoie knew more about Borrelia than any physician I had ever talked with before. I decided that in addition to meeting Gary Collins, he was another good reason for me to have come for the taping.

Dr. Lavoie was the sort of medical expert I had been searching for since 1982. His knowledge about tick-borne relapsing fever Borrelia as well as Lyme disease Borrelia was extensive. One of his favorite observations was that Borrelia had finally solved the elusive cause of "hypochondria." Physicians had been taught to dismiss patients who complained of more than three symptoms as being hypochondriacs. Now, he realized nearly all of them had Borrelia.

Information about my University of Arizona MS/Borrelia study had appeared mysteriously in a Sacramento Bee article, and I later came to suspect that Dr. Lavoie was the one to furnish the information to their reporter. The Sacramento Bee article was one of the best I had seen, and it took up several pages of the Sunday, October 13, 1985, "Forum" section of the edition.

The article also mentioned that, "Epidemiologists at the Vienna Lyme symposium noted that the geographical correlation between the habitat of Ixodes ticks and MS is almost 100%."

Dr. Lavoie became a key friend, mentor, and a physician for Dick as well as a source of information and help for our entire Arizona support group throughout the next decade. We exchanged our ideas freely in those pre-internet/email days with letters and phone calls.

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My librarian friend Jean Crosier, who had been retrieving Borrelia articles for me since my first visit to the VA library in 1983, was still pulling up articles for me at the medical library. After learning that Dr. Lavoie would be actively involved with helping many members of our

support group, she agreed to send publications to him as soon as anything new came across her desk. He said he was thrilled to have his own personal librarian, and years later in appreciation he invited Jean to be his guest at a San Francisco Lyme disease meeting.

In those days the Lyme and TBRF borreliosis community was fairly small and there were often points of disagreement, but overall there was a sense of enthusiastic collaboration among many patients, physicians, and research scientists, as the scope of the two similar diseases and their later manifestations emerged.

Dr. Lavoie shared his discoveries and views with me and our support group, and he shared my information with his professional colleagues in the eastern United States by passing it on at symposiums and by forwarding copies of my letters to his colleagues to include Dr. Burgdorfer, Alan MacDonald, MD, Paul Duray, MD, Russell Johnson, PhD, Eva Asbrink, MD (Sweden), Alan Barbour, MD, Robert Lane, PhD, and, many others.

I was already acquainted with many of Dr. Lavoie's colleagues, including dermatologist Dr. Eva Asbrink. She had gifted me with a copy of her PhD. monograph about the skin manifestations of Borrelia. He also knew microbiologist Julie Rawlings, whom Dr. Ron Johns had hired to moonlight our serology at his private rabies lab in Texas, she charging the affordable fee of only $35.00 per test. The circle of collaboration was growing into what we good-naturedly referred to as our "Tick Clique."

Dr. Lavoie had been urging me and two of his patients to spearhead a Borreliosis foundation. In 1987 he suggested that I speak with Susan Smith, an author who was Dr. MacDonald's sister, and psychologist Dr. Lin Coonan Yeiser. Lin contacted me and we discussed the possibility but decided against it for the time being. She had just published a book, "Nannies Au Pairs, Mothers' Helpers." Her priorities such as promoting her book precluded the work a foundation would require.

Besides, I was at the point of giving up work regarding Borrelia because it seemed I had done enough, without much success. My goal of getting legitimate research interest in TBRF by now seemed hopeless. I was ready to quit. I had no idea at that time how much more work would be required of me in the years ahead once the later complications of tick-bites began to insidiously manifest amid my family and friends.

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CHARLES THORNTON - 1985

By spring of 1985, after we moved to Tennessee, Charles Thornton had been continuing to work throughout the last months of 1984 and through the summer of 1985 interviewing patients, doctors, health officials, and politicians in the preparation of his "Pulitzer Prize-worthy" public health story. This third story would be a massive, nine-week-long, Sunday paper serial-type publication. It would be an all encompassing coverage of a David and Goliath battle of desperately ill people, from all walks of life, versus the powers that be within the scientific, academic, pharmaceutical, medical, and political bureaucratic system and not to exclude the insurance industry. A collective system that he thought had failed in its duty to serve the people.

Mr. Thornton was particularly interested in my pursuit of TBRF as a cause of MS, especially in view of the high numbers of MS patients within our Arizona TBRF Borrelia group. He and Dr. John Doll talked at great length about this. He quoted Dr. Doll in his news article as saying, "She might be on to something."

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Thornton had once taken pre-med courses in Memphis when he aspired to become a physician, so being somewhat educated in the medical field he could see some logic in a possibility that Borrelia bacteria might very well have caused this MS and MS-like phenomenon among our members. He, like Dr. Doll, encouraged me to pursue it even after we moved to Tennessee. We still kept a townhouse in Scottsdale for our frequent visits home so I was often included in our support group's interviews with Thornton.

He questioned me about what I had learned in my discussions with Dr. Byron H Waksman. I told him that he helped me do the 1984 University of Arizona MS/ Borrelia study, and that although he had thought my theory could be "hypothetically correct," he had cautioned that Borrelia might be an MS masquerader and not true MS. But after Dr. Waksman heard about 25% of the selected "true" MS patients who had positive antibody tests for Borrelia he was very surprised and turned over my "Borrelia/MS serologic study" test results along with all my other correspondence to Yale University. He suggested that I keep in touch with the researchers there for more help.

Thornton pondered this for a moment and said, "Did you hear from anyone at Yale after that? "

"Yes, I corresponded briefly with the neurologist who had received my correspondence from Dr. Waksman. I later sent questionnaires and serum samples to him from members of our support group in an effort of cooperation, but our group never received any results or conclusions regarding these."

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Charles Thornton had purposely described my MS, "possible cause" implication in the first part of both the May 20th and September 4th articles. "This way, by publishing your statements, you can prove you said this 'way-back-when' just in case someone later proves that MS can be caused by tick-borne relapsing fever."

After this meeting with Thornton in the late summer of 1985, he promised to lend more support for my MS theory when he published his "next 'series' of articles in the Arizona Republic."

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I already knew Charles Thornton was delving deeper into our puzzle when he wrote a lengthy human-interest article about a woman with MS which was published on Sunday, October 7, 1984, less than a week after our second article. He managed to include an excellent description of the disease, the possible cause, genetics, treatments, ongoing research and more. He had interviewed some top experts, including Dr. Waksman, for the article.

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Mr. Thornton had continued to work on his extensive Borrelia patients' interviews throughout the winter of 1984/1985. He thought the story would be ready for publication by early spring. He planned to include the results of my MS/Borrelia University of Arizona study.

By spring his plan was sidetracked when he was offered the chance to travel to Brazil to brave the wilds of the Amazon and remote jungle areas in search of a story. His articles read like a novel, relating human interest experiences about medical aid amid primitive conditions. Before he was finished, the editors learned to save full pages for Mr. Thornton's articles because they could not decide what to leave out. He did not just tell a story, he invited the reader to experience it.

He called me at our Germantown, TN, home in July and said that the Borrelia articles were all but ready to print and needed only a couple more interviews from health officials. But later, he called again.

"I just received word", he said excitedly, "that I'm going to Afghanistan to cover a story about volunteer medical teams from the United States who are risking their lives working over there."

"No," I said incredulously, "Aren't you scared to death to go there?"

"Not at all!" he said confidently. "It's the most exciting thing I've ever done. I absolutely 'must' do it."

"I am sorry to say that my Borrelia articles (his planned nine-week series) will have to wait until I get back if I don't get them completed in time for a September 1st deadline."

Similar to his earlier trek to document volunteer medical personnel in South America, he optimistically set out on yet another dangerous adventure in pursuit of documenting the work of other brave individuals, a group of American medical personnel who were voluntarily working deep inside the war-torn nation of Afghanistan. They were compassionately offering medical treatments to the wounded rebels who were fighting the Soviet-backed government.

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When Charles traveled in Afghanistan, he dressed in Afghan-type clothing in the hope that he would blend in with the natives.

Meanwhile, it was a beautiful day just outside of Memphis, in Germantown, Tennessee where Dick and I had by now settled in after our move there, when the phone rang. It was a call from Alice Holmgaard in Phoenix. She was crying.

"Charles Thornton is dead! He was killed in Afghanistan!"

The news was devastatingly tragic. She had to also break the news to her husband Don who lay dying from his brain tumor. His good friend Charles was dead, a matter of weeks preceding Don's tortuous death in October.

Thornton was killed on September 19th in a troop ambush, when Soviet helicopters swooped down on the truck convoy in which he was riding.

News photographer Peter Schlueter, Thornton's partner, survived the ordeal by diving into a ravine in the darkness. He described about forty soldiers, assumed to be Soviets, who after landing (near Kandahar, Afghanistan), leaped out of the helicopters and aimed right at the truck which contained Thornton, Schlueter, a nurse from Miami, and 13 mujahideen guerrillas.

In addition to Charles Thornton, two of the mujahideen freedom fighters were killed.

The Soviets' news agency, TASS, reported that Thornton was a CIA agent, and was using his journalism status as a cover to get him into the country. The Soviets had captured the story Charles Thornton was carrying home, and it was published in the Soviet Union, but not in the United States.

In "TV GUIDE" one week later, I read a story with a warning threat that came too late for Charles Thornton. The leading caption read, "A Soviet Ambassador's Promise: THE NEXT JOURNALIST WE FIND IN AFGHANISTAN WILL BE KILLED." (TV GUIDE, September 28,1985, pp. 36-40).

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Dr. Robert Simon, an assistant professor of medicine at UCLA Medical School, was the founder of the International Medical Corps, (IMC) and the first American physician to sneak into Afghanistan after the 1979 Soviet invasion. Dr. Simon was irate at the lack of a meaningful response on the part of the State Department regarding Thornton.

The IMC was one of two private agencies that sponsored Thornton's trip. "Everything we have done has been with the disapproval of the State Department," said Simon. In addition to the tepid reaction, he was also concerned with the apparent lack of U.S. news coverage of Thornton's death. He said, "The death of Charles Thornton should have been on the front page of every major newspaper in this country." He planned to develop a Charles Thornton Clinic in Afghanistan.

***

A short time after Charles Thornton's death, Ed Foster, an editor at the Arizona Republic, called me and said they were still planning to do the nine-week Borrelia series Charles had written. He said he would be in touch with me. Soon after that he called again and said that every tape recording, note, manuscript etc. that Charles had accumulated from interviewing our Borrelia group had "vanished".

"Whatever was in that story died with Charles Thornton," he said sadly. Then he added, "Would you consider doing this whole thing again with a new medical reporter?" Our group agreed to do so. I would be living in Germantown, Tennessee, by then.

***

After our move to Tennessee, I spoke with Ed Foster again and he said that most of Charles' story items had at last been found. The AZ Republic staff members were looking for a capable reporter to hire with this story uppermost in their minds. They finally hired a man, Peter Alshire, whom I spoke with on only one occasion. He never did the story. By this time Ed Foster had moved on to another newspaper.

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AWARENESS

In October of 1986 Dr. James Webb invited me to a Society of Vector Ecologists (SOVE) meeting in southern California. He was the scientist who had been interested in my husband's story, and who had introduced me to SOVE back in 1983. He would be in attendance, as would several other doctors whose names had by now become familiar to me. Most importantly, Dr. Burgdorfer would be giving a presentation about Lyme disease.

Dick and I flew from Memphis to Riverside. When we arrived at the meeting, we were greeted warmly by Drs. Webb (Orange County Vector Control), Burgdorfer (NIH, NIAID) and Dr. Robert Lane, PhD. (Entomology, Univ. Cal. Berkeley). We gathered around a warm fireplace and discussed TBRF and other tick-borne pathogens with the three of them, Dr. Webb taking photos of us. Dr. Burdorfer and Dr. Lane were sympathetic to our plight and offered to do what little they could to help. But these men were scientists, not MDs, and our primary concern was getting medical treatment before it was too late, as it already was for some.

We were grateful to learn the latest news about Lyme disease and other tick-borne diseases from Dr. Burgdorfer and other highly esteemed scientists such as Dr. Andrew Spielman (Harvard) and Dr. Robert Lane (Berkeley) and many others who spoke during the formal part of the meeting.

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During the lunch break I noticed that Dr. Burgdorfer was eating a whole-wheat sandwich. His manners were European-style impeccable. He looked out of place here. I pictured him dining on dishes of fine china, not a university cafeteria tray. He seemed contented enough, though, and it dawned on me at that moment that even though these famous scientists were a little more stiff and decorous than any group I had ever met, they were just like everyone else, doing their jobs in life. They were quite likeable, un-conceited people.

It was truly an honor for us to meet these fine doctors and have a first-hand look into their world of science, so it was well worth the trip to California. Dr. Webb took pictures of all of us and Dick took some pictures of me with Drs. Burgdorfer and Lane.

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ARIZONA VETERINARIAN DISCOVERS BORRELIA IN DOGS

At a dinner party in December of 1985, I was seated next to a veterinarian, Dr. Robert (Bob) Bartsch, who owned a very large, state-of-the-art, animal laboratory in Arizona. He knew that I was involved with tick-borne disease so he thought that I would be interested in his latest discovery. He had tested large numbers of dogs from San Antonio, Texas that he found to be infected with canine Ehrlichiosis caused by Rickettsia microbes, microbes that are aptly described as halfway between viruses and bacteria.

I was familiar with human granulocytic ehrlichiosis (HGE) because it is tick-borne and is sometimes a co-infection occurring in humans who are infected with Borrelia. Dr. Bartsch said that he did not think Borrelia infections were common in dogs, especially in Arizona.

"Have you tested any dogs for Borrelia?"

"No, I haven't because it is so rare, and I doubt my San Antonio or Arizona dogs would be infected since it is not endemic to Texas and Arizona."

Of course I did not believe it was rare at all. A friendly discussion took place throughout the dinner with each of us presenting our views.

Finally, I challenged him with a bet. "If you serologically test 100 of your HGE dogs from San Antonio, I will bet that at least twenty of them will have positive Borrelia titers."

He laughed incredulously at that suggestion but he good-naturedly agreed to the bet if I could procure some antigen for him. (Fresh antigen specific for Borrelia is necessary for setting up the procedure, and it is extremely difficult to obtain). If I could do that for him, he promised to hire a knowledgeable microbiologist to do the work.

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He was good for his word. After I found a source for the antigen, he hired a microbiologist, Cecile Fowler, to perform the tests. Dr. Bartsch and Cecile were surprised to find that 23 of 100 dogs from his San Antonio group were positive for Borrelia. By March of 1986 Cecile had found Borrelia in 3 Arizona dogs from Tucson and Chandler.

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Three years later, in April of 1989, I received a telephone call from the Arizona Department of Health Services.

"We have some exciting news to tell you, Mrs. Bennett; we have found Lyme disease in Arizona dogs!"

"Does 'we' mean Dr. Bob Bartch and Cecile Fowler?"

"How did you know that?" was the stunned response.

***

The public officials in charge of vector-borne disease at ADHS had been publicly embarrassed by a newspaper editorial that I had written about Arizona's public health officials (The Arizona Republic, April 18,1989, A-10) where I cited their view that, "Lyme disease doesn't exist in Arizona because they haven't found it in any ticks." (Technically speaking, ticks do not have Lyme disease, they only have the causative agent that once transmitted to animals and man can cause the disease). Furthermore, Arizona citizens did indeed have Lyme disease as well as tick-borne relapsing fever, regardless of the source.

The officials had repeatedly and steadfastly maintained to members of our support group and others that the Arizona residents who were already diagnosed with LD had contracted it ... "outside Arizona's borders while hiking in such states as California, Nevada, Utah and Colorado."

Of course they had all but ignored the scope of the real threat of *Borrelia hermsii* infections in Arizona such as the epidemic at the Grand Canyon in 1977 and the Tucson cave, seven-victims infected with *Borrelia turacatae*, from their own investigative colleagues' overnight venture; not to mention all the others in our support group that they tried in vain to ignore.

I wondered what would happen if LD ticks converged dead-center at the four corners area of the state borders where Utah, New Mexico, Colorado and Arizona meet. Would the LD ticks there know instinctively which way to turn? And what about California ticks? Had our public health experts posted signs, in Blythe for instance, "No ticks allowed beyond this border?" I know that is ridiculous, but that is what it boiled down to.

At the end of my editorial I suggested that, "If DPHS officials are serious about finding it in Arizona, maybe they should take a 'hike' and look harder."

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Four years later, although Borrelia burgdorferi was by then known to occur worldwide (except in Arizona according to our health officials), a paper published in Med Entomol. 1992 Nov. 29(6) 1060-2, describes a field study in Arizona's Hualapai Mountain Park. Ixodes (hard-bodied ticks) were collected by the authors who included my old telephone conversations friend Craig Levy of Arizona's ADHS. Two of 48 ticks were discovered to harbor Borrelia burgdorferi, a "first" in Arizona.

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ORAL SPIROCHETES AND MS

We had been living in Tennessee for over a year when, in July of 1986 my librarian friend Jean Crosier sent me a copy of an article from the British medical journal, "The Lancet". It was a medical hypothesis regarding an oral spirochete as a cause of multiple sclerosis by Derek Gay, M.D., pathology. (Frederick Gay).

Dr. Gay meticulously described in detail the migration of spirochetes from their oral origination to the brain. He further explained the processes involved in the damage caused by such spirochetes to *myelin*, the fatty tissue surrounding and protecting nerves within the central nervous system.

Myelin allows for brain signals to be transmitted smoothly to muscles in similar fashion as to how an electric wire is surrounded with protective materials that allow for uninterrupted conduction of electricity. Simply put, without myelin protection, brain signals can be short-circuited and over time nerve and muscle functions can be destroyed.

Upon receiving Jean Crosier's information I wrote a letter to Dr. Gay along with some enclosures, and explained in detail my observations of tick-borne *borreliae* spirochetes that I thought caused MS.

In my letter I quoted my favorite line from Oscar Felsenfeld's book, "Borrelia, Strains, Vectors, Human and Animal Borreliosis" where it described the concept that there is … "only *one* species of Borrelia and all Borrelia types we are speaking and writing about are mere variants of only one single microbial entity." Having been a dental assistant before I married, I was familiar with an oral spirochete, "Borrelia vincentii" a cause of Vincent's angina also sometimes referred to as gingivitis and trench mouth.

I agreed with Felsenfeld's statement in that all pathogenic Borrelia spirochetes are essentially the same by their very nature. It wasn't far-fetched for me to believe that oral spirochetes, as Dr. Gay suggested, could likely cause MS.

There were several possible candidates: *Treponema mucosum,* (cause of *pyorrhea*) as well as *Treponema vincentii, (also known as Borrelia vincentii).* Other forms of treponemes in the mouth include *T.denticola, T.macrodentium, T.oralis, and T.scoliodontium.* Treponeme spirochetes are more closely related to syphilis spirochetes and could be loosely called *siblings* where borreliae spirochetes are more like *first cousins* of syphilis treponeme spirochetes. All pathogenic spirochetes can cause multi-organ system manifestations such as heart, joints, cancer and autoimmune diseases. (The Silent Saboteurs, Unmasking Our Own Oral Spirochetes as the key to saving trillions in health care costs., William D Nordquist DMD MS and David J Krutchkoff DDS MS).

Some spirochetes are actually beneficial within the host while others are disease causing. But, likened to the discovery that human ulcers can be caused by a bacterium, *Helicobacter pylori*, that was previously thought to be normal flora in the stomach likewise ever advancing discoveries reveal the dangers versus benefits of a variety of microbes in our bodies.

***

Dr. Gay answered my letter immediately with a handwritten explanation of the similar qualities as well as the differences of various spirochetes within a closely related family, a classification which he said was being, "Actively reassessed at the moment". The spirochetes that interested him were *anaerobic (living in complete absence of oxygen)* whereas Borreliae are *microaerophilic (requiring very tiny amounts of oxygen for growth).*

He further cited recent Lyme disease literature published in 1985 and 1986 that indicated that the emerging neurological disorders of "demyelinating encephalopathy" and "Borrelia encephalomyelitis" within the Lyme disease arena were being "misdiagnosed" as MS.

I did not agree that these cases were necessarily misdiagnosed, because MS is an obscure diagnosis. Likewise, neurological Lyme disease and other tick-borne neurological complications feature obscure diagnoses. If tick-borne Borrelia is misdiagnosed as MS because it shares almost identical symptoms and signs of MS then, how can anyone conclude that tick-borne infections are not one of the actual causes of MS?

MS patients being treated with expensive state-of-the-art MS drugs could actually have bacterial infections, not the *autoimmune, self-destructive, disease* known as MS. Therefore, these misdiagnosed MS patients should be treated with appropriate antibiotics, not immune response altering drugs. MS patients are not concerned with nomenclature; their urgent need is the arrest and eventual cure of a potentially crippling disease that insidiously besets them.

Since state of the art expensive MS drugs have never cured or even had any major long term impact on controlling the disease, and have been shown to cause serious side effects, shouldn't all MS patients opt instead to try simple, relatively safe and inexpensive tetracycline-type antibiotics just in case they have Borrelia spirochetoses?

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Minocycline and doxycycline have bacteriostatic and bactericidal as well as immune and inflammatory modulating and chelating effects. Both of these oral, low cost tetracycline type drugs can offer positive effects for neuroborreliosis and MS patients as well. Moreover, positive effects have been shown to work in at least 85% of cases without … "ill effects." (See: Emerging Therapies, Canada- 2003 study of 10 patients, Luann Metz et al.).

Dr. Gay didn't say whether he agreed or not with the latest Lyme disease literature but he did say near the end of his letter regarding the different types of spirochetes that, *"Nevertheless the similarities are probably more important than the differences and there is no doubt in my mind at all that the changes occurring in the brain in MS can only be produced by a 'spirochaete'."*

***

Five years after my 1986 correspondence with Dr. Gay, in 1991, Jean Crosier spotted another publication by Drs. Gay and Esiri in the medical journal "Brain" (1991) 114, 557-572 entitled *"Blood-Brain Barrier Damage in Acute Multiple Sclerosis Plaques, An immunocytological study by D. Gay and M. Esiri, Oxford University Press.* This article supported Dr. Gay's earlier work and as far as I was concerned proved his theory that MS is a spirochete infection. He again described how his (and Dr. Esiris') pathology study of MS patients' plaques offers an excellent example of the immune cascade, the view differing with the rule of thumb theories.

The results "... argued against specific humoral immune-mediated damage to myelin ..." (the immune-mediated damage to myelin being a popular concept among scientists in MS research circles), and "support the idea (Wisniewski and Bloom, 1975; Adams, 1989) that

myelin may be damaged as an innocent bystander rather than as a specific target in the inflammatory reactions which develop around and within the walls of cerebral vessels."

If complement and immunoglobulin are found in tissues or on micro-organisms "... this provides evidence that antibody has reacted with antigen and that complement has been fixed by the classical pathway."

Drs. Gay and Esiri further explain by stating, "It may not be assumed that the finding of complexed material in lesions is certain evidence that the complexes are the cause of the damage, but a primary pathological role for the complexes described here is suggested by their exclusive association with acute plaques and their disposition within HLA-DR +ve macrophages in the advancing borders of small hyperactive lesions. The presence of IGM in these complexes further supports this acute association."

I thought this research news should be shouted from the highest mountains, yet it appears it was buried in the archives of scientific publications and no one seemed to know about it.

It meticulously spells out and demonstrates a concept that would change the idea of MS being an "autoimmune" disease where the MS patient's immune system "attacks" its own body parts such as the myelin sheath. Instead, MS is a disease where the immune system is seeking to destroy "antigen(s)" the remnants of debris that don't belong in the body and myelin is damaged as "an innocent bystander".

Dr. Gay's earlier work can be confirmed by this new study in that the nature of spirochetes during an antigen/immune war can present precisely this scenario.

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In 1995, nine years after my first correspondence with Dr. Gay, I tried to contact him by telephone, but I was unable to locate him to let him know that my son Doug's probable MS had just been diagnosed by a Phoenix "Top Doc" neurologist at the Barrow Neurological Institute located in Phoenix, Arizona. This diagnosis was soon confirmed in Portland and Bend, Oregon, by two of his home-based neurologists.

I wanted Dr. Gay to know that Doug had had tick-borne relapsing fever borreliosis eleven years earlier when he and his friend Martin returned to college following a ski trip to Lake Tahoe.

As earlier mentioned, in the first chapter of this book, Martin, having experienced unexplained fevers that recurred, was serologically diagnosed with *Borrelia hermsii* a few months after Doug's diagnosis. He now ten years later, was very ill and lay in a coma dying from "adenoid cystic carcinoma," a cancerous tumor that began behind his eye and metastasized within his skull.

Doug was by now suffering many MS signs and symptoms; loss of vision in one eye, numbness, tingling, speech difficulty, gait problems, and had fallen to the floor on one occasion when his leg could not support him.

I thought this news of Doug's MS diagnosis and Martin's tumor manifesting in the identical time-lapse frame following their previous borreliae infections a decade earlier would be of great interest to Dr. Gay and would offer him more solid, convincing evidence of spirochetes causing MS and possibly Martin's tumor.

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Three years after my unsuccessful attempt to find a telephone number for Dr. Gay, my librarian friend Jean Crosier finally located his phone number, so I called him at his home in England.

Dr. Gay was cordial and said that he remembered me but his reaction to everything I said about MS and spirochetes had a flat tone. This was ominously similar to what I was detecting in the voices of my former medical and scientific friends in the United States, since the day that I began hearing rumors that government hierarchy officials had purportedly issued directives within public health agencies to cease contact with lay people such as myself regarding any connection between Lyme disease, Chronic Fatigue Syndrome and MS.

When I suggested to Dr. Gay that his medical spirochete hypothesis that he published way back in 1986 was very obviously true, he said in a quiet, resigned tone of voice, "That was a long time ago and, it has long since been forgotten."

This was my first chilling inkling that the health officials in Great Britain and elsewhere likely had the same controlling agenda as did our public health agencies' figureheads in America. (It is rumored that Great Britain works under the policies of our CDC in Atlanta) I got the feeling that Dr. Gay, although polite, was uncomfortable talking about this subject, so I quickly ended the call with a promise to send him a letter and include several enclosures, which I mailed immediately.

This time he did not respond right away as he had done so enthusiastically in 1986; that being a time when he had complimented me generously about my observations by stating that he was "fascinated" to read my spirochete research, and he added, "Congratulations on a fine piece of work!" Now, nine years later, with obvious solid evidence presented to him in support of his and my own views, he paradoxically did not respond at all.

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HARVARD UNIVERSITY – ANTHONY KOMAROFF, MD

In February of 1987 I received a letter from Dr. Anthony Komaroff, Director of the Department of Internal Medicine at Brigham and Women's Hospital and Harvard Medical School. He said that Mrs. Polly Murray had contacted him about the possibility that the illness labeled "chronic Epstein-Barr virus infection (CEBV)" might in some cases be borreliosis. He had been studying cases in his area of New England as well as at Lake Tahoe locations and was interested in learning what he could from me about the group of people I had identified in Tahoe.

Mrs. Murray had conversed with him about the nature of both relapsing fever and Lyme disease and she questioned his belief that borreliae are completely eradicated by treatment, and told him that might not be entirely correct.

I was more than happy to explain in great detail what I had learned and observed within the previous five years about Borrelia in Tahoe and Arizona as well. Besides, our group was already acquainted with news of the Tahoe CEBV epidemic as well as the Tucson and Denver reports of it. We were convinced that those epidemics were chronic TBRF, not chronic Epstein-Barr virus. This would be a great chance to explain our views.

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We had already received several phone calls and letters from people in Arizona and California who thought that the epidemic of EBV was one and the same as LD and TBRF Borrelia. On their behalf and for our own sakes we had contacted EBV experts in Tucson and Denver and in the Lake Tahoe area without having any notable impact on their notions that they were dealing with a virus, although we suggested it might be TBRF.

But, here at last we had a legitimate MD from Harvard who appeared to take our group's chronic syndrome seriously. I responded with a lengthy letter to Dr. Komaroff, taking him at his word that he would be interested in learning what I could tell him.

Dr. Komaroff responded within two weeks and again asked for more information from questionnaires that he enclosed for our group and he asked for medical records such as physical findings, lab reports and a list of symptoms. He said he would be discussing the matter further with Dr. Steere and "Dr Magnarelli, at your suggestion."

I had not recommended Dr. Steere to him but had suggested in my letter that he contact Dr. Louis Magnarelli because he was familiar with the problem of Borrelia serology tests cross-reacting with Epstein-Barr virus tests. It was difficult to determine if patients had Lyme disease or infectious mononucleosis (caused by the Epstein-Barr virus) based on such tests. I thought the cross-reactions might offer good clues into why his Tahoe CEBV patients were thought to have a virus when they more likely had Borreliosis or both.

The nature of Borrelia is to *cluster* in geographical locations such as New England for Borrelia burgdorferi, and Lake Tahoe for *Borrelia hermsii*, so not everyone has been exposed to it. The nature of EBV infections, however, is universal in distribution and nearly everyone has been exposed to it over a lifetime.

I remained convinced that the Lake Tahoe epidemic of chronic Epstein-Barr virus (CEBV) was a form of chronic borreliosis. I seized the chance to describe more to Dr. Komaroff about Borrelia. On April 14, 1987, I sent him our TBRF group's fatigue study questionnaires.

Dr. Komaroff once again answered promptly and said "they" would be doing blood tests of "chronic mononucleosis" patients that he had been studying in New England and Lake Tahoe for antibodies to Borrelia burgdorferi.

He said he would not need any more information from our group as it seemed they had a different complex of symptoms from his mononucleosis CEBV (aka chronic fatigue syndrome, CFS) group, but if they found high rates of positives they might well come back to our group for more information.

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I did not agree that their complex of symptoms were different at all; they were nearly identical to ours. I was disappointed to hear that they were testing only for *B. burgdorferi*, because the majority of our group as well as his Tahoe patients had resided in areas endemic for *B.hermsii*, TBRF not B.burgdorferi LD. Tests need to be specific as to species and strains to be accurate.

If my memory served correct, Dr. Magnarelli said the tests cross-reacted on LD patients with Epstein-Barr virus, and he had learned to tell the difference. I hoped that the patients Dr. Komaroff was testing were all from New England, not Tahoe, because the Tahoe victims would likely have had exposure to *Borrelia hermsii*, not necessarily *Borrelia burgdorferi*, with different borreliae species and strains, antigenically specific to Lake Tahoe.

Regardless of these differences, it was (and still is) common for Lyme disease experts and most physicians in the United States to label TBRF as the more popular "Lyme disease" whereas in Europe the term *borreliosis* is more correctly used.

Nevertheless, I was grateful to Dr. Komaroff for his efforts and interest in our patient group and to Polly Murray for her role in bringing us to his attention.

At the end of his letter he thanked me for pointing him in the right direction to pursue the literature that suggested a Borrelia/MS connection. It was good to hear that finally a physician of his high medical standing would consider this MS theory seriously.

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Two years later, during a private discussion regarding the Tahoe area "CFS" epidemic and his grant, Dr. Komaroff was quoted on page 357 in the book "Osler's Web," authored by Hillary Johnson, as stating, "I always believed this disease was connected in some way with lupus and multiple sclerosis."

Nine and a half years after our initial correspondence, I wrote to Dr. Komaroff for the last time on October 7, 1996. It was a letter he could not ignore because it lent the most compelling support, if not positive proof, for my earlier 1982 hypothesis that TBRF could later cause MS.

I told him that my son Doug was diagnosed in 1995 as having MS and that his MS had manifested insidiously many years after his TBRF exposure(s) several years after I had predicted the possibility.

Dr. Komaroff was obviously taken aback by the news. He answered the letter, remarking that even though they had studied Lyme disease in his studies, *"It obviously remains possible that other borrelial infections that we have not looked for could play a role in MS."* He turned over my information to Dr. Eric Logigian.

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WINDING DOWN

Although I had gradually dropped out of the TBRF groups, my plans to give up work on Borrelia after our move to Tennessee were not working out, especially now after corresponding with Dr. Komaroff about the Tahoe/New England epidemics.

Dr. Burgdorfer thought I should at least stay informed about the new discoveries in the Lyme disease community because studies of tick-borne relapsing fever were as sparse as ever, and the two Borrelia syndromes were most definitely very much alike according to our support group data. Both LD and TBRF patients had things in common with the chronic fatigue illnesses that Dr. Komaroff had investigated. Dr. Burgdorfer encouraged me to keep up on things.

In 1987 Dr. Burgdorfer had encouraged me to write an editorial about my observation that TBRF patients demonstrated the same erythema migrans (EM) rash that was thought to be the hallmark of Lyme disease. I did so and it was published in two newsletters (SOVE, Orange County, California. and the LYME BORRELIOSIS NEWSLETTER , Biocheme, Vienna, Austria) I reserved the right to use it elsewhere so, I include it here:

Lyme Disease, A Misnomer

Is "Lyme disease" a new disease or merely a new name for the sequelae that have long been associated with an old, seldom diagnosed spirochetosis known as "relapsing fever," with recognition of more vectors and a newly discovered borrelia species.

Current clinical data on Lyme disease describe complications similar to those known to occur in relapsing fever: skin rashes, neurologic, cardiac, and arthritic complications. The differences are in the initial onset of the disease. Relapsing fever patients have relapsing fevers whereas Lyme disease victims initially usually experience milder flu-like symptoms. These symptoms including the clinically defined erythema chronic migrans (ECM) lesions and the late appearing arthritis have been shown to occur repeatedly in a relapsing fever-like fashion.

The clinical literature on Lyme spirochetosis considers the appearance of the ECM lesion as a "hallmark," even though less than 50% of patients experience this manifestation. Indeed, I have reasons to question the occurrence of this "hallmark" during the initial phase of Lyme disease, and consider it possible that ECM may develop months, even years after initial exposure to the spirochetes. It may occur more immediately in "sensitized" persons who are exposed to second or subsequent bites of infected arthropods. It may also occur simply as a later, spirochete-incited exacerbation in people not necessarily exposed to subsequent bites.

My husband, son, and a family friend contracted relapsing fever while vacationing at Lake Tahoe, Nevada. None of them experienced ECM lesions during or shortly after their original febrile illness. To my knowledge, ECM has not been known to occur in relapsing fever. Yet, all three experienced 10 months to 3 years later, ECM rashes on the trunk, inner thigh and underarm areas. They all denied second exposures to arthropod bites preceding the onset of these lesions.

This suggests that ECM can be a manifestation of relapsing fever, and is not necessarily the "hallmark" of Lyme disease. Hypothetically, if ECM is not the "first" manifestation of Lyme disease, first time exposure may b missed completely by physicians simply because patients don't qualify for the described criterion of ECM.

To the best of my knowledge, long term follow-up studies of relapsing fever patients have not been done. Therefore, ECM rashes would not likely be associated with this infection if they occurred months or even years later. Moreover, retrospective studies of Lyme disease patients who present with ECM may reveal earlier exposure or histories of relapsing fever that were never diagnosed as such.

The high prevalence of spirochetes and their pahogenicity, causing long term health effects, are now being recognized. Yet, differences between Lyme disease and other previously described borrelia infections are still in question. Serologic tests for Lyme disease cross-react with relapsing fever and other spirochetal diseases. Therefore many cases of reported Lyme disease could be other spirochetoses.

Many scientists like Dr. O. Felsenfeld (In, Borrelia: Strains, Vectors, Human and Animal Borreliosis, Warren H. Green Incl, 1971) advanced the concept that there is only one species of borrelia and that all borreliae types we are speaking and writing bout are mere variants of that single microbial entity. If this concept is true, it is a paradox that Lyme disease should be considered a separate disease entity rather than a type of relapsing fever – a disease already described by Hippocrates.

It may be a mistake to assume that Lyme disease is a new disease that is spreading, and is a separate entity from other types of borreliosis. It more likely has been around for a long time, with worldwide distribution, and with criteria for definitive clinical description and treatment as yet incomplete. It could become evident that Lyme diseas is a variant form of relapsing fever described centuries ago.

Because of the many similarities of "Lyme disease" to other types of borreliosis, a name change is in order – a name that would encompass the disease processes of all persistent borreliosis. How about "Chronic Borreliosis Syndrome" abbrevieated CBS?

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Dr. Lavoie was even more persistent than Dr. Burgdorfer about my staying in the loop of Borrelia and he continued to keep in touch with me by telephone with his latest news. Dick and I had already spent a great deal of our time with Borrelia, so I was willing to walk away from it so we could travel and enjoy golf. However, I promised to keep in touch with Dr. Burgdorfer and Dr. Lavoie and all the other good friends I had made among Borrelia experts within the medical and scientific world since Dick's illness in 1982.

Dick and I began taking advantage of our airline passes traveling to places we had always wanted to see, and we played golf. We were having the time of our lives. Our sons were on their own, one still in college out of state. We were free to enjoy each other completely with all the benefits of middle-age that we had religiously planned and saved for during our 26 years of marriage. It was a heady time for us.

But, when Dick was absent for days at a time with his airline-scheduled trips, I began thinking back on the years since he was ill. I didn't have many friends in the Memphis area yet.

***

By the summer of 1987, I began to actually miss working on Borrelia. I was no longer driven as I had been at first when fear of the unknown had spurred me to avidly pursue answers for the complications our family suffered, answers unknown to physicians of the day. But during the learning process for the sake of my family, I had figuratively been bitten by the Borrelia bug, a scientific subject that grew more fascinating every day.

Drs. Lavoie and Burgdorfer were correct in stating that I could not just erase Borrelia from my life.

I knew that I wasn't finished yet; I rationalized that there were too many loose ends to tie up. Maybe I could confine my Borrelia activities to only the times when Dick was working. He agreed that was a good idea. Little did we know then that my Borrelia days were most definitely not completely over.

Since 1982, I thought that I owed Dr. Burgdorfer a great deal of gratitude for all he had done to mentor me in my quest of answers, and for standing by our group even during the times when we knew he was being pressured by officials within his own laboratory, NIH, NIAID, CDC, Department of Health and Human Services and more, to cease his alliance with us.

I resolved to do something for him and set a lofty goal of trying to get him nominated for a Nobel Prize. I didn't know where to begin but, on September 24th, 1987, I decided to call Dr. Byron H. Waksman at the National MS Society in New York.

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DR BYRON WAKSMAN- DR. THOMAS WELLER- NOBEL PRIZE

Dr. Waksman was the most prominent medical doctor I knew at the time and I figured he would know what to do if anybody did. It had been three years since he had helped me with the University of Arizona MS patients' Borrelia serology study and he had been very generous with his time and advice in letters and phone calls.

I now sought his advice for how to go about nominating Dr. Burgdorfer for a Nobel Prize. As I mentioned earlier in chapter ten of this text, I had no idea at that time that his father, Selman A. Waksman, had won The Nobel Prize in Physiology or Medicine 1952.

Furthermore, over all the years of our communication with each other, Dr. Byron Waksman had never mentioned that fact to me before or after that day.

Dr. Waksman remembered me from three years earlier and we talked about a number of MS and Borrelia related subjects. I explained my desire to initiate a way to get Dr. Burgdorfer nominated for a Nobel Prize.

Dr. Waksman said I would have to contact an existing Nobel laureate in the field closest to Dr. Burgdorfer's work in infectious disease in order to merely have him considered to be nominated. Furthermore, I should be prepared for the fact that any letter from me to one of those people would be "lost in the shuffle". He didn't even think a letter from me would be read at all and more likely be thrown in the wastebasket without a glance.

***

I was disappointed to hear how difficult it would be for me to get Dr. Burgdorfer's name in front of the Nobel committee. I didn't know what to do. The next day I wrote Dr. Waksman a thank you letter and brought him up to date on some of the latest information and new ideas from my research efforts. I enclosed a copy of my "Lyme Misnomer" paper that Dr. Alan Barbour said was to be published in the fall issue of the International Lyme Newsletter.

I read a news article about a scientist, Dr. Barbara Mc Clintock who won The Nobel Prize in Physiology or Medicine, 1983. Her research was in genetic structure of maize, so she was not a person that could likely nominate Dr. Burgdorfer, his category being a new microbe, but I thought she or someone in her laboratory would likely know who I could consult.

On Saturday, September 26th I decided to telephone her laboratory's switchboard in Cold Spring Harbor, New York just to see if anyone working there on the weekend could suggest a scientist in the infectious disease category who could nominate Dr. Burgdorfer.

It was a little late in the day New York time. So, after the phone rang several rings without an answer I began to hang up the receiver. Just in time, I heard a delicate voice answer, "Cold Spring lab… Hello."

"I am trying to reach someone in your laboratory who might know who I can contact about getting Dr. W. Burgdorfer nominated by the Nobel committee for a Nobel Prize. It is my understanding that it would have to be someone in the infectious disease category because he discovered an infection-causing agent, Borrelia burgdorferi, the first new infectious bacterium to be recognized in over half a century."

"Well," she offered, "just off hand I can think of only a couple people, but I think your best bet is to contact Dr. Thomas Weller, who is currently head of the Tropical Public Health Department at Harvard. He was awarded The Nobel Prize for his work in successfully cultivating the polio virus; I believe it was in the middle 1950's. If you can wait just a minute I think I have his phone number.

"Yes, she said, "Here it is…."

"Oh, thanks a million!" I said gratefully. "And, by the way, what is your name?"

"Barbara."

"Not, 'Dr. Barbara Mc Clintock', are you?"

"Yes, I am Barbara Mc Clintock," she added softly.

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It took me a few days to get my nerve up to call Dr. Weller, but finally in early October of 1987, I picked up the telephone and dialed. A woman answered. It was Dr. Weller's wife. She was charming. After I explained my mission she suggested that I mail my information to their home address. She assured me that Dr. Weller would want to read it.

On November 5, 1987, I mailed a cover letter and lengthy 'treatise' to Dr. Weller at his home in Needham, Massachusetts.

One month later I received an answer letter from Dr. Weller that he had personally typed. Dr. Weller said he was well acquainted with Dr. Burgdorfer, having known him and admired his work over the years and especially his recent discovery of *Borrelia burgdorferi*. He appreciated my "… excellent summary of his scientific career." (To me, that was like receiving an "A" in his class at Harvard!)

He added that even though he and I might consider his *Borrelia burgdorferi* discovery worthy of Nobel recognition he did not feel his nomination would have any success because it had not received widespread press coverage.

He mentioned that other such nominations had failed such as Trager's cultivation of malaria parasites, which was a revolutionary boost for malaria researchers working on a disease that has killed hundreds of thousands yearly.

Dr. Weller agreed to "undertake the task" of finding an appropriate, distinguished award for Dr. Burgdorfer with my material at hand. He said he would obtain Dr. Burgdorfer's curriculum vitae (CV) as soon as he returned from a meeting out of the country and would begin his initiative after the holiday season.

A year and three months later, on February 9, 1989, he proved to be a man of his word when he sent out his well-prepared nomination for an appropriate award in America.

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By this time, I had received a letter from Dr. Burgdorfer. dated May 23, 1988, with an attached cable from Europe, sent to him three days earlier on May 19th: "WE ARE DELIGHTED TO INFORM YOU THAT THE VORSTAND AND WISSENSCHAFTLICHER BEIRAT OF THE ROBERT-KOCH-STIFTUNG HAVE DECIDED TO AWARD YOU THE 1988 ROBERT-KOCH-GOLD MEDAL IN RECOGNITION OF YOUR DISCOVERY OF THE PATHOGEN CAUSING LYME DISEASE (*BORRELIA BURGDORFERI*)."

In reference to the cable, Dr. Burgdorfer said in his letter that he wanted me, Dr. Paul Lavoie and Dr. Alan MacDonald to be among the first ones to learn of its message. He would travel to, Bonn, Germany for the award ceremony and he added, "Hopefully NIAID will sponsor my trip."

I was thrilled to receive this news, but I felt that our country had dropped the ball having never given him the kind of recognition he deserved. His *Borrelia burgdorferi* was the first new pathogenic bacterium to have been discovered in over half a century: a most remarkable, unprecedented, scientific discovery, a pathogen that had been repeatedly overlooked by countless other scientists and medical doctors in possession of less "prepared minds" (in the words of Dr. Louis Pasteur).

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Dr. Weller added in the last paragraph of his letter, that it was …"good to learn that Dr. Burgdorfer has been recognized in Europe by winning the Robert Koch Gold Medal"… and Dr. Weller agreed with me by writing that, "Recognition by his American colleagues is overdue".

It was wonderful news that finally someone as esteemed as Dr. Weller would attempt to place Dr. Burgdorfer's nomination before an appropriate awards committee in the United States, although my dreams of Dr. Burgdorfer's Nobel Prize were dashed.

Dr. Weller's efforts were successful. In 1989 Dr. Burgdorfer was named the Infectious Disease Society of America's (IDSA) honored recipient of the Bristol Award (now known as the Alexander Fleming Award), an award that Dr. Weller had also received nine years earlier in 1980. Dr. Weller personally presented the award to Dr. Burgdorfer, one great scientist honoring another, his role bringing a rare and preeminent distinction to the award.

105-113 pictures