page 105 - 113 are pictures. These are scanned seperately

PART II

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THE LYME FOUNDATION

In March of 1988, at the suggestion of Dr. W. Burgdorfer, Karen Vanderhoof Forschner telephoned me in Germantown, TN to ask if I would fly to New York City to become a member of the board of directors of the new foundation that she and her husband were forming.

She planned to assemble a diverse group of strangers in the boardroom of Cigna Re insurance company on the 52nd floor of the One Liberty Plaza building located directly across from the World Trade Center. Karen explained during our conversation that her purpose was to create a Lyme Borreliosis Foundation *(LBF) that name later being changed to Lyme Disease Foundation (LDF)* that would advance the knowledge, research and understanding of tick-borne disease by the sponsoring and hosting educational conferences for not only the research and medical communities, but to include the general public. I was skeptical as she described her goals, but I knew that I was talking with one of the most intelligent and determined human beings I had ever met.

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The next day, Dick and I went to New York where I attended the first meeting of the board candidates.

We took a taxi from the airport to "One Liberty Plaza" and upon arrival Dick took a photo of me in front of the building. This fifty-four-story structure was impressive. Each floor was nearly as large as an acre. Leaving Dick to tour the World Trade Center across the street, I proceeded on into the Liberty Plaza building alone and headed for the elevator. It sped upward on a seemingly endless journey to the fifty-second floor. Meanwhile, Dick was rising even higher exploring the wonders of the World Trade Center. He is grateful to have seen it at that time.

The elevator doors opened onto the largest reception room imaginable, with towering high ceilings to match. The silence within was deafening and I forced myself to walk across the broad expanse to the reception desk and inquire as to where I should go from here. The receptionist directed me to a corridor that led to a conference room. The meeting had just begun previous to my arrival.

Karen was already speaking when I arrived just seconds after the meeting started. She graciously introduced me to the attendees before proceeding, explaining the purpose of the new foundation.

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The esteemed Paul Duray, MD (Yale, Harvard, Fox Chase, National Cancer Institute) followed Karen's talk and he presented a slide show as part of his prepared lecture. I was delighted to be able to hear his views in person because although I had never met him, I knew who he was. He was well known as being an esteemed Lyme disease expert. I had read some of his published papers and he had worked in close collaboration with Drs. Burgdorfer, Lavoie et al.

I was fascinated with Dr. Duray's extensive knowledge of Borrelia; I listened intently. At one point, he stated that, "To our knowledge. Borrelia spirochete infections do not cause cancer."

I raised my hand and offered, "It is in the literature that the spirochetes of syphilis can imitate or cause certain cancers, especially mycosis fungoides type lymphomas."

("Secondary syphilis can imitate many diseases such as lymphoma, including mycosis fungoides." (New Eng. J. of Med., April 12, 1984, p. 980)

Dr. Duray raised his eyebrows expressing surprise and then he said, good-naturedly, "That shows you what we doctors know!"

Over the next twenty years Dr. Duray and I shared information regarding our borreliae/lymphoma discussions via letters and phone calls. I have known him to be a very compassionate man, one who goes the extra mile for anyone who requests his expertise and help. His contributions to medicine have been remarkable, especially within the realm of Lyme disease.

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That day Karen and Tom, her supportive husband, selectively chose board members who were: patient advocates (myself included at Dr. Burgdorfer's request) private business executives, government scientists, physicians, academic university professors, state health officials, and a veterinarian.

Having started all of this in the middle of March, they wasted no time. Less than three months later, on June 9th, miraculously, they were

to host the first annual international conference. But this was only the beginning, because in future years, Karen and Tom were to go on to educate the world about Borrelia like no one else ever had, appearing on talk shows, including Geraldo and *20/20*; in magazine articles; in two books authored by Karen, lobbying and speaking to Congress, in Washington, DC; producing and airing two award-winning TV shows; and obtaining precious, much needed federal grants for research.

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Their driving motivation came from the tragic circumstances that transpired following the birth of their son Jamie.

The LDF was started two and a half years after their infant son Jamie was insidiously ravaged with an undiagnosed case of LD. There was nowhere to turn for meaningful help. As a mother, Karen felt the hopeless desperation of not being able to stop the advance of a strange disease that afflicted her son, because physicians failed to recognize it as Borrelia. Unknown to her or her doctors at the time, her baby had been infected with Borrelia during her pregnancy when she was bitten by a tick.

After her tick bite, Karen was diagnosed with crippling arthritis, but her physician did not recognize her multi-system symptoms as caused by Borrelia; nor did the doctor consider that the baby she was carrying could be affected in any way by this sudden appearance of her ill health and arthritis.

Karen and Tom had been elated when she delivered what appeared to be a beautiful healthy baby boy who looked just like Tom.

Karen added, "Well, except that the doctors declared he was born with some type of infection, which was definitely not syphilis."

Karen was especially happy for Tom because he had been raised in orphanages and now he was blessed by having Jamie, a real blood relative! This happy young couple was now a family. After an extra week in the hospital they finally brought Jamie home to their lovely upscale home located in Stamford, CT with a nursery fully prepared for him.

When Jamie was a month old the vomiting started, and his other insidiously mounting problems such as eye tremors began to manifest. It was determined that he was deaf, lacked muscle tone, and his eyes were showing signs of permanent damage. At about age 1, he underwent surgery that was supposed to "realign" his stomach and stop the vomiting. Nothing worked.

Desperate for answers to Jamie's ever-worsening condition and after many months of consulting doctor after doctor without any positive results for her baby, Karen opted to search for her own answers from medical books and literature at a state medical library.

On the very day Karen discerned at the library that her son had an infection called "*Borrelia burgdorferi*", her husband Tom was at an opthalmologist's office for an appointment to examine Jamie. The doctor told Tom that he thought his son Jamie had an infection caused by a spirochete. As a young doctor who was aware of the infamous Tuskegee, Alabama, syphilis study, he knew about this kind of infection. He noted that neither Karen nor Jamie had syphilis because of recent blood work at the hospital. He concluded that the eye damage to the back of Jamie's retina implicated a different species of spirochete.

So this one lone physician of the many who had been consulted suggested that Karen and Jamie be tested for the Lyme disease spirochete, *"Borrelia burgdorferi."* Both of them were positive for it.

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Karen required repeated courses of antibiotics that eventually returned her to good health. For Jamie, the antibiotics seemed to be remarkably effective at first but over time it was apparent that much of the damage already done was permanent. His nervous system and eyesight were severely compromised, as was his muscle coordination. Since the surgery he required feeding through a tube in his stomach since the surgery to stop his vomiting.

Karen's resolve to do something to help her son grew. In a broader sense she resolved to do something to guarantee that other families would not have to endure similar tragedies.

Jamie's condition was entirely preventable, but because most people in the medical and local community were not yet aware of Borrelia bacteria, he was not diagnosed in time for curative treatment. In fact, even today there is great uncertainty of how to even prove "curative" treatment.

By this time, Karen learned that Borrelia was well described in "old" turn of the century literature, but such literature had long since been forgotten. It was virtually ignored by modern day medicine. Her frustration was harnessed into positive action and her devoted husband threw his complete support behind her resolve to educate professionals and laypeople alike about Borrelia. The idea of having professional

medical doctors, scientists and lay people join in a cooperative effort with the Forschners at the helm was an excellent goal. They could combine patient groups with professionals, and collectively they might make a positive difference.

The Forschners gave up lucrative careers in the banking and insurance fields to start their foundation. They planned to put Borrelia on the map, by making it known to everyone. They would speed up new discoveries about the diagnostics and treatments by bringing science, laypeople and physicians together in a consortium to share information and to learn from one another during conferences sponsored by the foundation.

Surely this was an ambitious dream and very noble, but could this little mom and pop organization actually accomplish much? It didn't take long to demonstrate the remarkable power of this young couple, a power that would move mountains in this field of science and medicine.

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On June 9, 1988 a packed auditorium at a hospital in Newington, CT., was hushed of conversation, coughs and paper shuffling as Karen and Tom introduced their first speaker. The Forschners had accomplished an amazing feat in a matter of weeks. A film crew from the TV news program *20/20* had cameras set up all around and rolling, in order to capture what these medical and research scientist pioneers had thus far learned about the newly discovered species *Borrelia burgdorferi.*

The film crew had been at the Forschner's home in Tolland the previous day to conduct an interview with Karen and the world famous Dr. W. Burgdorfer, the man of the hour who seven years earlier had discovered the pathogen causal to Lyme disease. Karen had appeared very much at ease in gardening shorts and a tee shirt, chatting with Dr. Burgdorfer and passing out lemonade to the film crew and scientists, while seeing to Jamie's needs between takes. Crew members pitched in to assist her with Jamie's care and they fell in love with her child.

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Now, one day later, center stage and dressed to the nines, Karen stood cool and collected at the podium, opening the first annual Lyme Borreliosis Foundation medical conference to a packed audience of lay-people, scientists, pharmaceutical representatives, and physicians. In less

than three months, Karen and Tom had delivered exactly what they promised. They were on their way. The crew of 20/20 was filming the historical event.

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Dr. Burgdorfer was introduced by Karen as "... the scientist who discovered the bacterium of Lyme disease, *Borrelia burgdorferi.*" His topic was, "Complexity of Arthropod-borne Spirochetes (Borrelia spp.) With Reference to the Lyme Disease Agent, *Borrelia burgdorferi.*"

I didn't know that Dr. Burgdorfer had been investigating Borrelia and multiple sclerosis on his own time since my earliest correspondence with him about that subject in 1983.

The title of his speech didn't give away the content, so I was surprised that a portion of his program included the discussion of an MS/Borrelia cause and effect possibility. His opinion regarding such a possibility was based upon his thorough investigation of older research that esteemed scientists had performed in the past, scientists who early in this century had described "proof" of what they claimed was a Borrelia/MS cause and effect.

These researchers were now dead and forgotten. Their scientific papers describing laborious works of proof that spirochetes cause MS were destroyed during the holocaust in Germany or left to gather dust in the archives of science and medicine.

The last two of the MS/Borrelia researchers in the United States were microbiologist Rose Ichelson, Ph.D., and neurologist Gabriel Steiner, M.D.

In 1950 Steiner found spirochetes that he described as looking like "Borrelia type spirochetes" in and around the brain plaques of MS patients at autopsy. Of course Steiner did not know about Lyme disease in the 1940's and 1950's because it was not yet recognized.. Tick-borne Borrelia was thought to be rare, and louse-borne Borrelia was rarely discussed in high-brow science.

Microbiologist Rose Ichelson cultivated spirochetes from large numbers of MS patients, and saw with her own eyes, under her microscope, "Borrelia-like spirochetes" that appeared to be the same as those Dr. Steiner had observed.

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There was no hint at the beginning of Dr. Burgdorfer's presentation that his talk would be about multiple sclerosis or Dr. Gabriel Steiner's Borrelia spirochete *granules.*

He began his speech by giving credit to all the early doctors and scientists who had discovered various species of spirochetes that cause human disease. These early discoveries took place over the last century beginning in 1868 with Otto Obermeier, Ehrenberg in 1835, Flugge in 1891, Dutton and Todd as well as Sergent, Foley and Koch during 1903 to 1905.

Suddenly, my eyes and ears were riveted to the stage as Dr. Burdorfer mentioned "granules." I had been interested in the controversy over spirochete granules since reading Oscar Felsenfeld's book about Borrelia in 1983. It made me think of comparing how seeds can lay dormant for long periods of time only to grow into full-blown plants and trees when conditions are favorable.

Dr. Burgdorfer went on to say Dutton and Todd noticed that the spirochetes could seemingly disappear. A phenomenon labeled "a negative phase" when the spiral shaped organisms were not visible, but "granules" were observed that seemed to be associated with the reappearance of spirochetes and could cause another relapse of infection. Hindle, in 1911, described his experiments that were similar to Dutton and Todd's. Spirochetes in ticks "disappeared" only to reappear as full-grown spirochetes when ground-up tick particles were injected into mice.

In 1950 Dr. Edward Hampp of the National Institute of Dental Research claimed that his laboratory cultures containing only these granules, after sitting dormant for over two and a half years, grew to be typical, spiral-shaped, full-grown spirochetes when he transferred the granules to fresh medium.

DeLamater and co-workers at the University of Pennsylvania Medical School observed similar findings that supported a conclusion of spirochetes multiplying by not only one, but two different methods: One way is by means of "transverse or binary fission" (asexual cell division), this being the more popular and, for the most part, the only long established view. A second way, observed by DeLamater and other earlier researchers, is the transformation of granules that can be dormant but later emerge as a new generation of spirochetes.

Many fine researchers, including Dr. Burgdorfer, in 1951 could not endorse the granule view, because their own studies did not support it. They believed that these granules were just "degeneration products" of the dead spirochetes.

Experiments conducted earlier in the century by Wittrock, Kleine, and Eckard, Kleine and Krause, Feng and Chung, likewise found no evidence of a negative phase of development in the species they studied. So based upon this as well as his laboratory studies, Dr. Burgdorfer, in 1951, could not scientifically support the findings of such researchers who claimed to observe a negative granule phase. However, he kept an open mind with respect to the possibility.

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Now here he was on stage, thirty-seven years later, telling how scientists working at his own Rocky Mountain Laboratories, a National Institutes of Health and National Institute of Allergy and Infectious Disease laboratory of pathobiology, were finally finding, with new deoxyribonucleic acid (DNA) techniques, evidence that his newly discovered Borrelia burgdorferi might very well possess the controversial "complex life cycle of blebs, spherules or gemmae and granules" that were first described by Dutton and Todd way back at the beginning of the 20th century.

This talk was a fine example of how Dr. Burgdorfer has based his entire career on establishing scientific proof before making a statement of fact. He doesn't rule out theories or label someone wrong simply because he, as a scientist, hasn't reproduced the work of other scientists. He had respected the works of Dutton, Todd and other heroes whose experiments were painstakingly conducted and conclusions extracted amid deplorable conditions in Africa and elsewhere.

Dr. Burgdorfer had not always agreed with their findings but he believes that the foundation of true biomedical science is, and was, laid brick on brick by the published works of these early pioneers. The keen firsthand observations and historical, century-old, findings of these early microbe hunters are now emerging as critical issues of today's world within the complexity of Borrelia biomedical research.

A major point of Dr. Burgdorfer's speech was evident when he described "new discoveries" made possible by methods using state of the art equipment for the testing of Borrelia burgdorferi's deoxyribonucleic acid (DNA). DNA is an acid found in all living cells and it provides genetic information about all organisms except for certain viruses. These newer tests are exacting and species specific in identifying differences in closely related microorganisms. Surprisingly, in many cases these sophisticated new methods confirmed what turn of the century

scientists had already suggested about the many facets of Borrelia and its life cycle. These new studies indicated that those old guys, and a couple ladies, way back when, were right all along about many issues regarding Borrelia.

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Most significant to Dr. Burgdorfer's talk that day was that in 1954, Dr. Gabriel Steiner had observed... "Enormous masses of granular bodies"... inside cells as well as outside cells in recent plaques of MS patients.

Dr. Steiner thought the granules were the breakdown of spirochetes outside the cells, which were then "ingested" inside cells. In 1954 Dr. Burgdorfer would not have given much scientific credit to the observations of such granules by Steiner. During some of our discussions about these granules during the early 1980's, he had told me that he did not know quite what to think about... "those guys who advanced the granule theory".

But now, in light of recent discoveries by workers at his own government laboratory proving that such granules do indeed exist, he was compelled to look back at research material left by Steiner and others during the first half of our century and admit that Steiner's work appears to have been quite valid after all.

Steiner's claims that he found "Borrelia-like spirochetes" in and around MS patients' plaques at autopsy were scorned by the medical community of his day and literally drummed out of existence merely because a handful of researchers could not (or would not) reproduce his work. Dr. Burgdorfer remarked, *"Despite his* (Steiner's) *convincing observations and excellent photographic illustrations, Steiner's hypothesis attracted few supporters."*

He went on to say: *"Even though these points of criticism could readily be refuted, funds and clinical support for spirochetal research were withdrawn and directed towards still ongoing studies of viruses as the causative agent of MS."*

"Indeed, after almost 40 years of intensive research, there seems to be no reason to believe that MS is caused by a viral agent and perhaps the time has come to reevaluate the 'spirochtete hypothesis' using the sophisticate immunochemical, molecular and even genetic methodologies now available."

"In its latency period, pathogenesis, clinical symptoms, histopathology, and chronic central nervous system involvements, MS is similar to Lyme disease, relapsing fever, and neurosyphilis, and it is safe to state that the complexities of these disorders are reflected by the complexity of their causative agents."

"Although less than seven years have passed since the detection of microfilarieae in the hemolymph of two Ixodes dammini ticks from Shelter Island, New York led to the discovery of the Lyme disease agent, B. burgdorferi, hundreds of papers have been published on various biological aspects of this organism. Still lacking however, is the information concerning the spirochete's development in and its interactions with the host. These data are crucial for our understanding of Lyme disease and related disorders. They also may lead to the characterization of disease processes of other neurospirochetoses (such as relapsing fever, neurosyphilis) and of certain closely related diseases of the central nervous systems (such as MS)."

Complexity of Arthropod-borne Spirochetes (Borrelia spp.) With Reference to the Lyme Disease Agent, Borrelia burgdorferi. Presented June 9, 1988, at Newington CT, Lyme Borreliosis Foundation Seminar.

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The applause was deafening as Dr. Burgdorfer exited the stage. I was stunned and elated all at once. In 1984 I had sent copies of Dr. Vincent Marshall's letters and Steiner's as well as Rose Ichelson's publications to Dr. Burgdorfer. At that time Dr. Burgdorfer had not dismissed the compelling evidence that Dr. Marshall presented regarding the works of Rose Ichelson and Gabriel Steiner demonstrating scientifically that Borrelia could cause MS. Instead of snubbing Ichelson and Steiner's work, he personally looked into many more scientific papers published in previous years and found the work to be valid.

He also looked into the long forgotten experiments of other early researchers in Europe who had done animal studies, injecting animals with spinal fluid taken from MS patients that unequivocally confirmed that spirochete infections subsequently developed in the test animals.

Until this day no one in the scientific community gave Steiner's work any lasting credit that I knew about with the exception of microbiologist Julia Rawlings and a virologist, Dr. Vincent Marshall, DVM from Iowa.

Julie had performed Borrelia serology tests on MS patients' sera in cooperation with neurologists statewide in Texas during the middle 1980's. Dr. Marshall had tried in vain over a period of many years during and after the 1980's to bring spirochetes into legitimate MS research circles.

Julie Rawlings was sitting next to me in the audience, she being one of the guest speakers invited by Karen to this first LBF conference. We

were both thrilled that this important scientist, the famous Dr. W. Burgdorfer, was, before our very eyes, the first scientist in the United States to publicly revive credible support for the works of Steiner and other historical researchers who linked Borrelia as a causae of MS. It was this kind of endorsement that I had worked toward.

Surely, from this day forward, respect for the 'old spirochete theory' would be a given, and funds would become available to researchers like Julie who had already demonstrated an interest in pursuing this with her extensive serological studies of MS patients who were antibody- positive for previous Borrelia exposures. Scientists would no doubt conduct definitive studies proving cause, and cures for MS would swiftly follow. (How naïve I was in those days!)

At the intermission, Dr. Burgdorfer approached me and handed the podium copy of his speech to me. "Here," he said smiling modestly, "I thought you might like to have this.

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NIH – DR. ROBERT QUACKENBUSH

That June of 1988 meeting was just one of several symposiums I attended over the next two years. From that time on, Karen and Tom like no one else would bring Lyme disease from relative obscurity to an international stage, melding the cooperative efforts of patients, physicians and science alike.

In the fall of 1988 they hosted a meeting at White Plains New York and another that they co-hosted with Pfizer Pharmaceutical at nearby Groton, Connecticut. Karen assigned Julie Rawlings and me to welcome an NIH representative who would attend, Dr. Robert Quackenbush. She asked that we usher him throughout the conference activities and explain the goals of the foundation.

Dr. Quackenbush was in charge of research grants at NIH. As a microbiologist he readily understood what Lyme disease is all about.

I seized the opportunity to tell him about TBRF and its similarity to Lyme disease. He was fascinated to learn of the MS cases that our Arizona support group had linked to TBRF as well as those that I had linked to it at Lake Tahoe. I had hopes that he would consider a research grant for Julie and Dr. Bob Lane at UC Berkeley. Julie was already very much involved with MS/Borrelia studies in Texas and at Berkley. She took over the task of moonlighting serology for our Arizona group at Dr.

Ron Johns' rabies laboratory in Austin Texas. A grant would give her the funds to expand her work and complete her doctoral degree.

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Dr. Quackenbush said that he was in charge of organizing a scientific workshop that would be hosted by the National Institutes of Health in December. He hoped to bring together a select group of pioneering medical experts to congregate under the umbrella of two branches of NIH public health agencies, National Institute of Allergy and Infectious Diseases (NIAID) and National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMSD).

The meeting would take place December 13-15, 1988, at the Hyatt Regency Hotel in Bethesda, Maryland. It would be restricted to an 'invitation only' list of leaders in the field. EIS officer, Dr. Allen Steere, the rheumatologist who was put in charge of Polly Murray's appointments at Yale Univ. in the mid 1970's was slated to receive an award of some sort for his role in the initial and continuous investigation of Lyme arthritis. (Later called Lyme disease).

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Julie and I suggested that Polly Murray and Judith Mensch receive awards because they were the ones who told Dr. Steere about it in the first place. And, definitely, Dr. Burgdorfer deserved an award as well since it was his discovery that revealed the multi-system spectrum of disease and its treatment.

Dr. Quackenbush was open to those ideas and he, Julie, and I went to visit Polly at her home in Lyme, Conecticut, for him to learn more.

Karen was one of the already selected people invited to speak about the "Priorities of the Lyme Borreliosis Foundation" (LBF).

After Julie and I talked to Dr. Quackenbush about TBRF for two days we convinced him that Borrelia had been lurking under our noses, undetected for ages. Julie had evidenced this two years earlier having uncovered over 500 cases in Texas in 1986 alone. Tick-borne Borrelia clearly has existed under the radar for at least a century. We convinced him that it yet remains to be determined whether Lyme disease is new or merely another newly discovered type of the very old relapsing fevers Borrelia.

Dr. Quackenbush decided to put us both on the invitation list. He

wanted us to meet with his boss, Dr. John La Montagne, Deputy Director of NIAID, and tell him what we had learned.

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Dr. Quackenbush called me on November 22nd to personally confirm my invitation to the December meeting. He said that as Julie and I had suggested, Dr. Burgdorfer, Judith Mensch, and Polly Murray would receive awards in addition to the award for Dr. Steere. I gave him Polly's phone number. Julie and I felt that recognition by our government was long overdue for all three of them. Dr Quackenbush agreed.

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In Europe Dr. Burgdorfer was being treated like a king, having won the distinguished Robert Koch Gold medal as well as the Schaudin-Hoffman award. His namesake, *Borrelia burgdorferi*, was the first new microbe to have been discovered in over fifty years. European researchers recognized this remarkable find, yet our government had failed to give him his due even though in the tradition of science his discovery was worthy of the highest honors. *Borrelia burgdorferi* is now the most common vector-borne disease agent infectious to humans in the United States.

Dr. Burgdorfer was to be a moderator for part of the program. Now that Dr. Quackenbush and his boss, Dr. La Montagne had decided that he was to be honored with an award, Dr. Quackenbush needed some background information about him for his introduction. I mailed him a five-paged copy of the biographical letter that I had written to Dr. Thomas Weller as well as a copy of his curriculum vitae (CV).

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In December, when I arrived at the registration desk for the meeting, I was greeted warmly by Dr. Quackenbush. He introduced me to Dr. John R. La Montagne, who was the co-chairman of the meeting, along with Dr. Lawrence E. Shulman, National Institute of Arthritis and Musculoskeletal and Skin Diseases. Dr. La Montagne was intrigued at what little I was able to tell him about our Arizona TBRF group during our brief introductory discussion.

In an effort to give me credibility, Dr. Quackenbush said, "Lay

people like Bonnie know more about this than we do." Dr. La Montagne nodded resignedly and said, "Isn't that always the case?"

It was true, lay people were accumulating knowledge at a pace that was remarkable. The LDF had already spurred action among the public and professionals. Support groups were springing up all over and their members devoured any literature they could access. Their newsletters began to rival medical journals.

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Many of the attendees that I already knew or had corresponded with since 1982 were present at this meeting. The night of the banquet dinner, Dr. Paul Lavoie was seated next to me at our table. He and I were caught by surprise when Dr. Burgdorfer singled us out, sharing his "Lyme-light" by thanking Dr. Jorge Benach, Dr. Lavoie, and me during his talk.

Dr. Ken Liegner, who was investigating high numbers of Lyme patients who developed MS or MS-like symptoms within his private medical practice, requested a seat at our table because he wanted to question me about the MS/Borrelia patients from our Arizona and Tahoe TBRF groups that Polly Murray had told him about. After the conference I mailed him several pages of the anecdotal evidence I had documented from the previous five years since 1982.

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Dick had bid his airline schedule with overnights in Washington DC, so when the meeting was over I flew back on his flight to Memphis where we learned that he was offered the position to become an instructor in the new A-320. I wanted to accompany him while he trained in Florida and when he later became an instructor in England and elsewhere. We planned to move to Gig Harbor, Washington within a year, so in March of 1989 I resigned from the LDF board thinking once again that my days with TBRF and LD were over.

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I kept in touch with the LDF and our Phoenix support group. When I resigned in March of 1988, Karen gave me the token title of "Advisor to the Board." Although I was technically no longer connected to the Foundation, I remained interested and attended meetings on a less active,

occasional basis. Congressman Berkley Bedell became my replacement on the board of directors.

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BORRELIA IN TENNESSEE

In 1989, our Germantown, Tennessee, neighbors had a block party. Our newly built neighborhood consisted of a very long block with one cul-de-sac midway and another cul-de-sac on the end. Dick and I lived on the end cul-de-sac, and that was where we met with all our neighbors for block parties. The neighborhood had been carved out of the woods, so we had encroached on nature when our homes were built.

Knowing what I did about Borrelia sprouting up in newly constructed neighborhoods that disturbed animal habitats, I was very conscious of creepy crawler bugs that might seek out human blood meals as substitutes if their natural animal sources had been crowded out of the area by humans.

Only two of my neighbors knew that I had been involved with Lyme disease and tick-borne relapsing fever, Borrelia, infections. By this time I had moved on to playing golf, having done all I could do. So, it was with reluctance that I became involved that night with the "mysterious illness" of an eighteen-month old baby, Daniel, on our block.

It was a beautiful summer night. Children and adults of all ages were milling about, eating and drinking from the tables heaped with pot-luck favorites. One of the neighborhood families was missing that night because their baby (Daniel) lay critically ill in the hospital. Doctors had been unable to diagnose his fevers that had been occurring over a period of weeks. I tried to tell myself, "No, this can't be Borrelia; it doesn't exist here in Tennessee".

But the more I listened, the more familiar the story sounded. I had heard it over a hundred times before. Rarely does anything other than relapsing fever cause this repeated pattern of illness.

I didn't say anything that evening because these neighbors were a family I did not know well. They lived on the other cul-de-sac. The next day my next-door neighbor, Vicki Monize, caught me in the yard to say that the baby was thought to have a rare disease similar to leukemia that would be fatal.

The doctors had asked that the parents sign a release to allow them to treat the baby with "experimental" chemotherapy. They explained how

the therapy would not save his life, but because he was "... going to die, anyway ..." the parents might be helping other children by allowing this experiment.

The grief-stricken father refused. He thought his baby had been through enough suffering. He wished to protect him from any more.

I told Vicki that I thought that the baby quite possibly had Borrelia, but I didn't want to stick my nose in their business because I barely knew these people.

Vicki was shocked, and took me to task, "You absolutely have to stick your nose in their business! Their baby is dying and this could be the last chance to save his life if you are right about it."

She quickly called the parents' answering service and told them what I thought.

An hour later, the baby's father (Bob) called to learn more. I said that I was quite sure that Dr. Burgdorfer would agree to test the baby's blood sera for Borrelia if the doctors were willing to send some. Bob said he would *insist* that they send it.

He said that the doctors thought the baby only had about 4 more days to live. His voice was racked with grief and desperation. The doctors had diagnosed his precious baby with a potentially fatal syndrome, "Hemophagocytic lymphohistiocytosis" (HLH). The serum sample was sent by express mail to Dr. Burgdorfer's government laboratory (NIH/NIAID)

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My friend Vicki came over four days later and said, "It is too late to test his blood". The doctors have told the family that the baby only has a few more hours to live, and he will probably die within four hours."

It was evening in Tennessee, so I rushed to phone Dr. Burgdorfer, hoping he would still be in his laboratory in Montana. He was.

"Dr. Burgdorfer," I began, "Never mind doing the tests for the baby, the doctors say he won't live through the night."

"That baby has relapsing fever! He has Borrelia!" His voice boomed over the phone. "Give me the number of that hospital and the doctors' names!"

Dr. Burgdorfer said he would give the test results to the physicians and tell them "the drug of choice" but that he could not advise medical treatment because he is a scientist, not a medical practitioner.

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I quickly telephoned Dr. Alan McDonald, M.D. in New York, waking him at night, New York time. He compassionately agreed to immediately contact the hospital personnel to advise definitive treatment. Appropriate intravenous (IV) antibiotics were started promptly following his call, even though the doctors were skeptical of the Borrelia diagnosis.

The physician in charge agreed with the baby's parents when they let it be known that they wanted their baby to have this antibiotic treatment: "What could it hurt to try antibiotic treatment specific for Borrelia at this point?"

The next day, miraculously, baby Daniel, jaundiced but smiling, weakly sat up in the bed where he had lain almost comatose and looked hopefully at his worried parents. He took nourishment by mouth for the first time in many days.

His sister, Faith, came skipping down the sidewalk by my house one day a few weeks later, and smiling brightly she said, "Mrs. Bennett, Daniel isn't yellow anymore, and he is learning to walk again, he is almost completely well!"

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THE GERMANTOWN STUDY

After Daniel Wharton's recovery from his nearly fatal illness I was reminded more than once by our Germantown neighbors that two other children at the end of our street had become ill with unexplained fevers. They went into shock, requiring emergency ambulance transportation to a hospital. They were Daniel's playmates.

The neighbors began to wonder if those two children may have had TBRF and suggested that some of us should get tested to see if there was relapsing fever or Lyme disease present even if local and national health authorities denied Borrelia was a problem in Tennessee.

I spoke with a local physician who was willing to draw blood at a nominal fee, and further found that three of my microbiology friends would test sera at no charge.

My three friends were in charge of the country's top labs for Lyme disease; Dr. W. Burgdorfer, MT., RML (NIAID), Dr. John Anderson, CT (State Dept. of Health) and Dr. Robert Lane, CA. (UC Berkeley). I was acquainted with Dr. Anderson from my Lyme Disease Foundation days as a fellow director on the board. He was the first to get back to me and report that six of our neighbors were reactive on the serology. He was surprised by the positive reactions from this area of the country. Lyme

disease was not thought to occur there, and he was especially surprised by one man's high titer. However, because that man was from New Jersey, we both agreed his exposure was perhaps from there, not Tennessee.

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I anxiously awaited the serology reports still pending from Drs. Burgdorfer and Lane. When I finally heard from Dr. Lane, I was disappointed.

Dr. Lane said he showed the same number of "reactives" as Dr. Anderson's tests but, he concluded that the titers were "too low" to be of any significance. I disagreed because I noted that none of the titers in question were any lower than my husband's and his titer level should have been the standard for positive levels; His case had been confirmed quite beyond doubt in 1982 with five *Borrelia hermsii* spirochetes clearly demonstrated on a blood smear.

When I later called Dr. Lane with my concerns, his tone was polite but noncommittal and flat, completely unlike his usual friendly, enthusiastic self. Still later, when I talked with Dr. Burgdorfer, he too was unusually cool, and he didn't offer to tell me about any of the serology he had tested regarding this study. Worse yet, he said, he could ... "no longer do any serology for you (meaning me) at all."

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Something was definitely wrong, but I could not put a finger on any good reason. Finally, I was told by a top scientist friend (who asks that I not disclose his name in this book) that an official at CDC had sent a written complaint to the head of the Department of Health and Human Services, Dr. Louis Sullivan, telling him that Bonnie Bennett was making fools of government scientists. Dr. Sullivan then issued a directive... *"No more serology tests for Bonnie Bennett"* ... and further remarked ... *"She is making fools of government scientists."*

I was surprised that Dr. Sullivan knew who I was. I did not know whether I should take that as an insult or a complement.

In spite of my disappointment, I realized that at least we had some attention from a prominent public health official even if it was negative.

That negativity became more apparent in later years when we had moved out of Tennessee to Gig Harbor, Washington. It became clear to me from that point on that our public health representatives were under

strict directives to not communicate freely with the lay public. Letters that I sent were rarely answered after that, phone calls were put on speakerphone, and officials (other than Drs. Burgdorfer and Dr. Duray) sounded like robots speaking in monotones.

In those early days, letters were the main communication. After the Internet became available, things changed dramatically and information became available to patients, scientists and physicians alike. Our new age of Internet information had arrived just in time for many desperate patients of tick-borne illnesses.

One of our former Tennessee neighbors, Mary Ellen Urbanowicz, wrote a note on her Christmas card to us that the Centers for Disease Control had conducted a neighborhood investigation on our street in Germantown, shortly after we had moved to Gig Harbor. Another former neighbor, Sue Massey, called us in 1995 when she and her husband visited friends near us in Gig Harbor. She told me she thought that her husband had had relapsing fever and said that CDC investigators had investigated their family as well.

Reminiscent of my initial correspondence with our Arizona group's dilemma, CDC (again) never contacted me for an interview about our Tennessee neighborhood, and my inquiries to them as to results of their investigation went unanswered.

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Shortly before we moved from Tennessee to Washington State in early spring of 1989, I had received a call from the Memphis physician who had partnered with me for our Germantown neighbors' Borrelia study. Now, he was in charge of the annual "Memphis in May" medical conference. He called to personally invite me to attend the conference. The study we did sparked his interest, and it inspired him to invite Dr. Burgdorfer and Julia Rawlings to speak at the conference. They both agreed to attend and give presentations about Borrelia.

Their participation proved to be the highlight of the conference. It alerted local physicians to the fact that Borrelia was very much present in Tennessee.

At the close of the conference Julie told Dr. Burgdorfer that she planned to attend an upcoming meeting of my old Phoenix support group. I was invited to attend the same meeting.

The meeting had been organized by James Bunch and his wife, who had become leaders within the group since I had moved to Tennessee.

They were doing a terrific job by getting the word out to patients and doctors. They invited Dr. John Doll (ADPHS) as well as Julie to speak and take questions in an attempt to bring peace between patients, public and local health authorities.

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After talking with Dr. Burgdorfer, Julie told me that she had changed her mind about going to Phoenix to speak at the meeting. She said that while discussing it with Dr. Burgdorfer he advised her not to go because... "That group and Bonnie were too militant"... and such an association could hurt Julie's career in public health, especially with CDC.

Dr. Burgdorfer told Julie that I should have more respect for the officials at CDC because I might have to sit down and work with them one day. I was incensed by this news and later told him that I would never sit down and work with CDC in light of their treatment of me and our group. I listed my reasons in no uncertain terms in a letter and said that I was quite offended by his labeling our support group and me as 'militant'. He promptly apologized profusely and agreed with me that I had been doing the work of our government by default since 1982, and I certainly had good reasons to be angry about it.

In spite of Dr. Burgdorfer's and Julie's views, I flew from Memphis to Phoenix to attend the support group meeting held at the Phoenix Women's Club. Dr. John Doll, from the Arizona Department of Public Health Services, was invited to speak. As he spoke, it was obvious to me that he was under some kind of pressure to defend the bureaucratic, i.e., CDC, stance that "Lyme disease is not a problem in Arizona."

Rather than helping to resolve the divisive issues in a spirit of mutual cooperation, he was dismissive and he actually stonewalled our members when they asked for specific answers regarding tests and treatment questions. He did not offer anything to help our members' plight. This was not the same Dr. John Doll I knew, the one who had kindly encouraged and helped me over the years. The audience was becoming an angry, disappointed group.

Dr. Doll was bombarded with questions and accusations to the point that I felt sorry for him. Jean Crosier, Jim Bunch, his wife Donna, and I met with him after the meeting broke up. Dr. Doll and his wife were visibly shaken by the angry, confrontational session. We tried to smooth things over.

I sensed that he was sympathetic to us on an emotional level but his

loyalty to his career had obviously dictated his public stance. We parted friends in spite of the chasm between our group and his official position. It was a sad day for all of us. Julie was not in attendance.

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Jim and Donna Bunch proved to be dynamic in their leadership role of the support group. Among many other efforts Jim took it upon himself to have copies of Oscar Felsenfeld's Borrelia monograph made up at his own expense to distribute to physicians at the next Lyme foundation meeting in Austin, Texas.

Felsenfeld's monograph is one of the best sources of documented research about human and animal borrelioses ever written; yet I had never seen it cited or referenced by any of the Ivy League Lyme experts. No wonder patients knew more about Borrelia than what their physicians could find in their literature.

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The Arizona meeting and the later Austin Texas meeting would be the last meetings I attended. By then we had moved to the state of Washington. It was hard to say goodbye to all my Phoenix area friends, especially Jean Crosier. Without her I never would have been able to access the kinds of medical papers she was able to provide. We spent hours at her library poring over medical literature. She had retrieved hundreds of medical publications for me, our support group members, physicians, and others who requested them. She was also a founding member of our Arizona support group and had become my good friend.

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By 1990 our original list of symptoms and signs of TBRF had grown significantly from the original list that was compiled at our first meeting, in 1984. We knew that Borrelia did not cause *everything*, but by now Lyme disease, like syphilis, was considered the "Great Imitator" of all disease because of its many long-term complications. TBRF, being a first cousin to LD (and to syphilis) was nearly identical in its course of later complications according to our list.

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DOUG'S STORY

The insidious onset of our son Doug's multiple sclerosis (MS) did not become obvious to us until 1994 even though in retrospect we should have recognized it much earlier. In 1994, at the age of thirty-three Doug began having serious eye problems. He had experienced a history of unusual eye problems since 1972 at age eleven when he first complained that he could not read road signs with his left eye. This was one year after we spent our first month-long vacation at Lake Tahoe.

Now his symptoms were worse, after twenty-two years of intermittent problems. His vision had dimmed down and was blurry at times. He saw double images and, the pupil in his left eye dilated. I didn't connect his eye symptoms to Borrelia because they had begun during his childhood long before I knew anything about Borrelia. Besides, as a child he had experienced an injury to the left eye when he was hit by a baseball and we assumed that eye was severely damaged. Many years later, when I became well acquainted with the habits of Borrelia spirochetes, I began to realize that spirochetes by their nature are innately saprophytic (scavengers of dead tissue) and that they could quite naturally have an appetite for damaged or dead tissue in his eye.

A definitive diagnosis was never forthcoming during his childhood, because every time he saw a doctor his vision had changed, sometimes better and sometimes worse.

The first doctor we consulted thought the baseball injury might have caused the problem but said it was more likely "amblyopia," what is more commonly known as "lazy eye." Each ophthalmologist that he consulted suggested a different diagnosis.

One doctor wanted to perform surgery for cosmetic reasons, even though there was nothing cosmetically wrong that we could see. After seeking a second and third opinion, two other doctors agreed with us; he did not need surgery.

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It wasn't until 1994 that Doug experienced his first signs of balance and coordination problems when he was water skiing in a slalom course over the period of a few weeks at Firebird Lake in Arizona. He later told me that he was experiencing stiff necks, headaches, exhaustion, night sweats, and numbness and tingling in his extremities along with worsening eye symptoms.

That's when I realized Doug had classic symptoms of a neurological Borrelia infection. By early 1995, he noticed while riding his bike that if he lowered his neck downward to stretch it his leg would go numb. When he brought his head back up his leg returned to normal.

He was losing his balance on occasion and had trouble finding the right words when talking. Sometimes a totally unrelated word would come out when he meant to say another. He had headaches at the base of his skull and excruciating neck pain at times.

Some of these symptoms had gone on for several years but Doug, a non-complainer, had ignored them and blamed each symptom on such things as chronic unfixable eye problems, neck strain from sports, not enough sleep, etc. Up to now we had blamed his eye problems on injuries, but when the vision in his good eye started acting up, such as blurring with mild exertion, he told me about it. Upon questioning him in detail, he confessed to a long list of symptoms and signs.

"Doug", I said incredulously, "You have chronic, neurologic borreliosis, and you need to get on some antibiotics right away."

Yet Doug did not get on antibiotics right away. Instead, he began a year long, nerve-wracking, journey through a step-by-step wait and see series of physicians. Each step required a wait of several weeks or months for an appointment with a different specialist, and each suggested a different opinion. By now he was waking up at night with all four limbs numb temporarily. He had great difficulty climbing stairs, and experienced a strange sensation of coldness on various areas of his skin. Despite increasing balance and coordination problems he was able to ride a bike and continue to water and snow ski but he was falling up to ten times per ski run.

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Doug asked every doctor in turn if Borrelia could be causing his symptoms. Not one of them knew what *Borrelia hermsii* was.

One neurologist agreed to test Doug for Lyme disease *Borrelia burgdorferi*, apparently not realizing that those tests are not designed to test for *Borrelia hermsii*. In addition, the only LD test available to that neurologist at the time was an antibody test. Antibody tests are not diagnostic by themselves, especially for most people after months or years following the initial infection when the body stops producing them, particularly if borreliae are sequestered safely in the brain. Then, he would not likely be producing detectable antibodies at this late date for

any type of Borrelia.

Nevertheless, the doctor erroneously interpreted the results of his negative Lyme disease antibody test as proof that he did not have any type of Borrelia.

This doctor clearly did not understand antibody tests. His interpretation was wrong in more ways than one.

Although MS was suspected as "possible" because of Doug's many neurologic symptoms, no definitive diagnosis of it was yet determined. I sent a letter explaining why negative Borrelia antibody titer tests do not rule out Borrelia and since Doug already had a history of TBRF I asked if Doug could be treated empirically for Borrelia with appropriate antibiotics under this neurologist physician's supervision, just to see if he improved.

Doug decided to try having the neurologist read the letter I had written and he handed it to him during his appointment. The doctor asked, "Who is your mother?"

Doug said, "What do you mean?"

"I am going to have to get out my medical reference books to understand her letter. I am not familiar with some of the terminology."

The doctor explained the findings of Doug's brain and spine scans that revealed some plaque in his brain but they were not definitive enough to be of great concern. There was an MS type lesion about the size of an almond in his cervical spine (C3).

The doctor further explained, "Technically MS means multiple lesions, and you have one definitive MS type lesion located in your neck at C3 with some other questionable plaque and demyelination in your brain so I would say you are in the early stage of MS."

Then Doug asked what could he do, and the physician said he wouldn't do anything until it gets worse.

In an attempt to obtain the antibiotics Doug said, "I'd just like to try doxycycline to see if it makes any difference; after all, if I had pimples you could treat them with doxycycline." The doctor refused, saying, "You do not have Borrelia."

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Doug's doctors constantly assumed that *Borrelia hermsii* was the cause of Lyme disease; the confusion between *Borrelia hermsii* and *Borrelia burgdorferi* was often revealed by their comments. One neurologist said, "We don't have Borrelia in Arizona, Lyme disease is only diagnosed in

people who move here from New England." Little did he know that the largest epidemic of "relapsing fever" (caused by *Borrelia hermsii*) ever recorded in the United States had occurred at the Grand Canyon in the 1970's. And it is true that these two diseases are first cousins and can be compared but, they have never scientifically been proven to be identical in the initial or long-term effects.

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In March of 1995 Doug moved from Phoenix to Bend, Oregon. He didn't change his insurance because he was afraid to risk not being covered for all preexisting conditions, especially when he didn't have a diagnosis for his problems. Dick and I urged him to consult a neuro-opthalmologist in Portland because we were extremely concerned about his worsening eye problems.

Doug agreed and was able to make an appointment for July. The doctor gave Doug the most thorough exam of any he had had since his long trek began. Besides being thorough, the doctor seemed genuinely compassionate. He found things that had not been noted by previous physicians and he suggested in a kind way that Doug had a neurological condition that resembled MS. He talked with Doug at length in a way that made him feel that this physician really cared about what happened to him.

A week later I wrote to the Portland neuro-ophthalmologist and thanked him for at least being able to establish that Doug had a neurological condition. He was the first specialist of five who even ventured a guess that it was suggestive of, but not typical of, MS.

In my letter to him I explained in detail why I thought neuro-borreliosis should be considered in his diagnosis, and asked if he would allow Doug to try a course of doxycycline. After reading my letter he did not find my request unreasonable under the circumstances, and agreed to give Doug a prescription for doxycycline. Doug got the prescription filled, but he did not start taking it because he was still wondering if it was the right thing to do.

***

By August, Doug's symptoms continued to get worse. He fell down on one occasion when he lost feeling in his legs. He decided, at Dick's and my insistence, to fly back to Phoenix where his insurance was

still based, and to see the neurologist at Barrow Neurological Institute who had examined him the year before, in order to rule out MS.

He couldn't get in right away, because the neurologist was booked solid for three months. He set up an appointment for Thanksgiving weekend and decided to wait until after his appointment to try the antibiotics, just in case taking them before hand would interfere with a definitive diagnosis.

When he arrived for his appointment the doctor ordered tests, which included a magnetic resonance imaging (MRI) scan of the spinal column. Because Doug's airline ticketed return flight was for just the weekend, the test was scheduled for that evening. One of Doug's former girlfriends, Tina, a nurse he ran into at the hospital, accompanied him to radiology. The scan revealed some areas of demyelination of the cervical spine.

The doctor told Doug over the telephone when he called for his test results, "You have MS".

Doug was shocked. It was his worst fear, and now the doctor had confirmed it.

Doug was stunned upon finally hearing the definitive diagnosis. He later told us that instead of feeling devastated by this diagnosis, he was actually relieved to know that he did not have a brain tumor or something worse than MS. Later that night our phone rang, in Washington. "Mom and Dad, I have MS."

Dick and I were devastated. Now it was an established fact. We tried to sound optimistic, but everything we said seemed to come out flat and our anxiety was obvious, it didn't fool him. Then Doug said, "I want to try the antibiotics that the doctor in Portland gave me."

"But, what if I am wrong and it does you harm? Maybe you really have MS and not Borrelia," I said.

"No, I've thought about it for months, now, and I've made a decision. I've been carrying the antibiotic around in my shaving kit, and I have decided to start taking it tonight."

***

I was scared. What if my son did this under my influence and it turned out to be wrong? His MS had already robbed him of his energy, sight, his balance, the way he walked, talked and much more. He had fallen down on one occasion when his leg was completely numb, he couldn't climb stairs without extreme difficulty, and he had to give up

sports for his lack of strength and balance. He almost constantly felt numbness or loss of feeling in his limbs and trunk. We now knew that his longstanding visual problems had actually been early hallmark signs of MS. The eye problems had begun a few months after spending our first summer at Tahoe shortly after his eleventh birthday in December.

It frightened us to think Doug was in such bad shape. He was going to try what I believed was right but an antibiotic was totally against conventional medical treatment for MS. Then again, he had said it himself, "There was no viable alternative."

The Phoenix doctor had said MS drugs have never been proven to cure MS. And, after all, Doug did have the history of a tick bite and his symptoms were classic for neuroborreliosis. Dr. Burgdorfer had said, "Forget about the MS diagnosis, if you think he has neuroborreliosis just treat him as though he has Borrelia, then see what happens."

Dr. Burgdorfer was not giving medical advice, something that as a scientist, he never does; he merely encouraged us to do what we thought was best.

I tried to convince myself that this would work and secretly applauded Doug's decision to try the antibiotic. After all, his doctor had offered him no real hope of any kind, and the antibiotics were far less dangerous than any MS drug. At this point antibiotic therapy was his best choice of all the available options.

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Doug experienced a severe night-sweat the first night he took the drug. But within three days he reported that his "brain fog" seemed to have cleared. (Many members of our Arizona group reported this same strange occurrence within just a few days of taking antibiotics). His MS symptoms remained unchanged.

On December 1st, Doug spoke with the neuro-ophthalmologist in Portland to see if he could get more antibiotics, to insure taking them long enough to make a difference. The doctor agreed to provide a prescription, but urged Doug to establish himself with a neurologist in Bend. Upon his recommendation, Doug got an appointment within a week. The Portland doctor sent a letter to the neurologist explaining my views as well as a lengthy history on Doug.

Doug assured the Portland physician that he would refrain from taking the antibiotic until after his neurology appointment in Bend in case it would interfere with any new tests the specialist might want to perform.

Doug's history included a brain scan report that described "signal alteration in cerebral white matter" (His scan showed that an area of his brain had some unidentified bright objects (UBO's).

Such UBO findings do not usually appear in young people unless they are caused by a disease such as MS. It is more commonly observed in old age. UBO's are compatible with MS but not necessarily diagnostic of it. When present at Doug's young age of thirty-three, and in which case MS is highly suspected, the findings are significant in the diagnostics.

The Bend, Oregon based neurologist gave Doug a thorough examination and read his history carefully. He also read my letters. His conclusion was that Doug had ... "definite MS" ... and he should waste no time getting on an MS drug. In fact, he should ... "get on Betaseron right away." He didn't think much of my theory or the doxycycline therapy. Doug said he would think about it.

My resolve faltered again after hearing this. I said, "Doug, what if this is really MS and Borrelia has nothing to do with it? You could be making a terrible mistake by not doing what the doctor says. You should at least try the MS drug."

"Mom, those MS drugs are still experimental. I'll try the doxycycline antibiotic again. If it doesn't work I'll think about it."

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He remained on the doxycycline for nearly a month (28 days) and took acidophilus pills along with it to protect his intestinal flora. After he was off the drug about two weeks, he said he thought he noticed improvements in his handwriting and speech. He began to feel generally quite well, over the following weeks. He wasn't as tired, he got his balance back, he walked better, he talked better and his numbness and tingling was not as severe, although he still had many MS symptoms. Our hopes began to soar.

Three months later, he relapsed, and his symptoms got worse. Dick and I were shaken to hear this. Undeterred, Doug went right back on the doxycycline. This time he took it for only two weeks. Again, he noticed some changes in two or three days, but gradually bigger changes began to manifest several weeks after he quit taking the drug. Some of his symptoms were gone.

This cycle continued for four years. Each time the relapses occurred at more distant intervals and his symptoms continued to diminish: After

a year, he went long intervals without any, or with very few, symptoms and rarely needing to take the antibiotic.

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Three and a half years after Doug's definitive diagnosis of MS, he returned to the Phoenix neurologist at Barrow Neurological Institute at my urging because I wanted him to have another MRI exam to see if there were any evident changes.

He was so much better than he was at the time of his earlier diagnosis, we wondered if he had actually remyelinated some of the damaged areas.

His doctor, neurologist Robert Shapiro, MD, seemed amazed at what good condition Doug was in. He checked his reflexes and with a puzzled, almost incredulous, look on his face he said, "Did I tell you that you had MS three years ago"?

The doctor said that there was no need to run any tests because Doug checked out perfectly.

He then looked at Doug as if remembering something, and said; "Didn't you say something about taking doxycycline three years ago"?

"Yeah, every time I get an MS exacerbation, I go on doxycycline for a couple of weeks, and my symptoms go away." Doug continued to successfully control his symptoms and signs for the next several years with doxycycline.

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Doug's update

A decade later, By May of 2011, Doug experienced an exacerbation of several MS symptoms and signs that were worse than usual. He had suffered some physical traumas to his neck, injuries incurred while skiing in Bend over the past couple of years. The worst injury occurred when he was hit in the head by a snow-boarder who was traveling at uncontrollably high speed. It was believed by ski patrolmen that Doug suffered a serious concussion. He also noticed that his left leg was weaker after that and his gait was affected similar to the weakness in that leg at the time of his MS diagnosis in 1995. His daily episodes of sudden exhaustion and heat intolerance have become more pronounced of late.

He has had similar MS-like exacerbations following other head concussions and neck injuries, such as when he slipped off a rocky cliff

and landed on his head during a mountain bike ride, and following illnesses such as the flu. He was severely compromised following a tetanus booster shot.

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At my urging, in May of 2011, he made an appointment and returned to Barrow Neurological Institute to consult with the director of their Multiple Sclerosis Center. We needed to know whether or not his worsening symptoms were the result of the injuries and/or MS, and if he had any surgical options. As stated earlier in this book, I have long held the view that if you have a spirochete infection, the microbes will target injured area of one's body, their nature being scavenger-like saprophytes. Could his injuries to his head and neck have caused another relapse of TBRF infection and consequently more MS symptoms? "Yes," I thought.

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The neurologist in charge of Doug's appointment reviewed his history since Doug's original evaluation at BNI sixteen years earlier in 1995. He was visibly shocked to learn that Doug had not seen any neurologists over the interim sixteen years. Worse yet, he was not pleased to hear that Doug was taking short courses of doxycycline that Doug thought had been remarkably successful at arresting each exacerbation episode until lately. He ignored the fact that the antibiotic had worked well for Doug. After all, Doug did not have any obvious signs of MS and had remained active, skiing powder and "diamond" difficult ski trails as well as mountain biking and other sports. He was better now than when first diagnosed in 1995 by simply intermittently treating his symptoms with doxycycline whenever they occurred.

Doug firmly believes that his MS was incited by his TBRF. He is convinced that intermittent courses of minocycline and doxycycline have dramatically arrested his exacerbations of MS symptoms and signs until now. For sixteen years he has periodically taken courses lasting ten days to two weeks, three or four times per year without any noticeable ill effects other than sunburn and mild indigestion.

The neurologist said dismissively that MS is not caused by Borrelia. His rationale was entirely summed up for Doug up by his pronouncement; "The geographical areas for high risk Lyme disease are

not the same as for the high risk areas for MS." Obviously, he did not differentiate between LD and TBRF. And, he did not know geography.

There is a difference in the geographical areas of the specific species and strains of borreliae that are more apt to cause the neurological complications than arthritis for example. The TBRF borreliae in the northern U.S. and Canada, and certain species and strains of Borrelia in Europe and TBRF in Africa are more apt to target the central nervous system than do certain Lyme-arthritis prone strains.

For instance, according to C. Larrson et al, Borrelia *duttonii causes a persistent, residual brain infection in mice ... "which remains long time after the bacteria are cleared from the blood.*

(Larrson, C., Bergstrom, S. (2006) Persistent brain infection and disease reactivation in relapsing fever borreliosis. Microbes Infect. 8, 2213-2219.

***

Doug knew that the neurologist's pat-answer geographic profile was in opposition to the facts. I repeat here, that MS has occurred in direct proportion to high-risk, U.S. and Canada forested tick habitat areas and military camps, as well as in Great Britain, Russia, and certain countries of Europe during the war years where louse-borne as well as tick-borne disease has been well documented to precede MS epidemics. MS was more prevalent among men than women during the WW-1 and WW-2 periods of history.

The high-risk areas were not the only parallels between Borrelia and MS. There is a great deal of legitimate support as has been demonstrated in this book alone. Other contemporary research is convincing and can be found on the web especially the research done by lecturer Tom Grier, of Duluth MN whose LD was initially diagnosed as MS. His meticulous research can be accessed online; "Lyme on the Brain," "Why Aren't We Talking about Relapsing Fever?" and much more. Mr. Grier is one of few researchers who can discern the complexity of all species and strains of Borrelia. For that reason, I chose to include his expertise in both the Foreword and Afterword of this book.

Doug was fast losing confidence in his neurologist with his every new assertion. The doctor apparently assumed that TBRF is Lyme disease. It is no wonder that his geographical link of MS/Borrelia dismissal was way off base. He could not be more mistaken.

Doug did not argue or attempt to correct the doctor thinking that it would do no good in the face of his dogmatic arrogance. Doug decided that if nothing else, this appointment would at least give him a chance for some answers if the doctor ordered MRI scans.

The physician proceeded to order magnetic resonance imaging of Doug's brain and spine, but he forewarned Doug that he has MS, not neuroborreliosis, and to "Be prepared, that you will be going on an MS drug, giving yourself injections.

The neurologist repeated his stern admonition several times to Doug, to prepare himself to start taking the MS drug as soon as possible following his next appointment, that being the appointment where he would get the results of his MRIs.

The physician did not tell Doug the name of the drug he wanted him to take, but in advance of his next appointment I guessed (correctly) that it would be Copaxone.

I knew that this drug was rated high among all the MS drugs. I agree that it offers some very favorable effects, but I have never seen any study that supports it or any other MS drug that can demonstrably arrest the progression of MS nearly as well as minocycline or doxycycline long term. I was not familiar at that time with the oral drugs being offered.

A small study of ten MS patients that were treated for nine months with minocycline by mouth twice daily was reported at the American Academy of Neurology (ANN) during its annual meeting on April 11, 2003. The overwhelming success of the study was described as being one out of three of the top most exciting new approaches to therapy.

At the meeting that included a total of 250 scientific papers three therapies were selected from seventy-five novel therapeutic approaches. (See "Emerging Therapies for MS", April 11, 2003, McGill University and the Montreal Neurological Institute).

There have been other studies that combine MS drugs with minocycline and doxycycline such as the one in Canada where minocycline was an add-on to improve the efficacy of glatiramer acetate (Copaxone) at the University of Calgary. (Metz, L.M., et. al).

In March of 2013 a pharmaceutical company announced the availability of their new MS pill at a cost of *only* $54,900.00 per patient, per year... less than the first pill already on the market from another company that costs patients $60,000.00 per year if they do not have insurance or qualify for assistance from the companies. The recent sudden, increase in the price of doxycycline and minocycline is miniscule by comparison.

A study at Louisiana State University Health Sciences Center (Minagar A. et al) used a combination therapy with interferon beta-1a and doxycycline. The two drugs were tested in an open-label trial.

The conclusions in the Canada study were that the risk of relapse was lower in the minocycline/Copaxone combination group than in the Copaxone group alone. "The dual treatment was safe and well tolerated."

The Louisiana study found that the combination of intramuscular interferon beta-1a and oral doxycycline treatment was "effective, safe, and well tolerated".

In both of the above studies the MS drugs were used in combination with either minocycline or doxycycline and compared with the MS drugs alone. Except for the excellent results of the minocycline ten-patient study mentioned above, the question remains as to why doxycycline and minocycline have not been compared as *alternative* therapies to all the MS drugs on the market. Why study it *only* when the antibiotics are *combined* with MS drugs? Could it possibly be that the minimal cost of doxycycline alone would ruin the multibillion-dollar treatments currently in place for MS? (Recently, doxycycline prices have dramatically increased).

Since these tetracycline type drugs evidently have proven to work extremely well and they are well tolerated and far less expensive than current MS drugs, why not test each of them, alone, against a placebo as well as against all MS drugs to prove it? The extremely minimal cost of tetracycline type drugs compared to the billions of dollars spent on the top four MS drugs should be reason enough to provide them as an option to MS patients.

"Meanwhile," said one researcher, "In the face of all this, I do not know of any neurologists who are willing to prescribe the antibiotics", (See "Overcoming Multiple Sclerosis, Minocycline likely to be highly effective in MS despite poor study design").

The summarized results of Doug's tests regarding the MRI images of his cervical spine as well as his thoracic spine were that, "No enhancing cord lesions are identified to suggest acute or active demyelination." And his brain scan result was, "No enhancing lesions are identified to suggest acute or active demyelinating plaques."

As already mentioned in this book, there are controversial opinions among scientists about persistent, chronic, Borrelia infections, especially so for persistence in the brain. One study that supports ongoing infection discovered that "To investigate if the residual infection is in a quiescent state or if the borrelia bacteria are actively dividing, mice with residual brain infection were treated with the cell-wall disrupting antibiotic

ceftriaxone, which is only active against dividing bacteria. Since ceftriaxone cured all the mice it was concluded that the bacteria were actively growing rather than in a latent, dormant state. (Larsson, C., Lundqvist, J & Bergstrom, S. Residual brain infection in murine relapsing fever can be successfully treated with ceftriaxone. Microbial Pathogenesis In press.)

Doug had taken a short, ten-day, course of doxycycline in the weeks preceding this appointment. If he had any active *plaques* in his brain or active spine demyelination before taking the antibiotic, the areas are no longer active.

This is identical to what was observed in MS patients in Canada where, during and after taking minocycline, no new brain plaques were manifested in patients who had MRI confirmed, active MS (MRI monitored) activity going into the study. (See Emerging Therapies, L. Metz, et al, Univ. Calgary, 2003). Other Canada-wide studies are more recently confirming similar results; however, the more recent studies pair up the antibiotic with MS drugs such as Copaxone.

At his next appointment Doug received the MRI scan reports. The reports described that there was ... "No evidence of ongoing activity". Doug asked the physician about the size of one of the "inactive" cervical cord lesions. The doctor said it was very small, "insignificant," and "less than the size of a dime."

Compared to what was observed originally in 1995, this was good news, because the doctor in 1995 had described that same lesion as the size of an almond. It had apparently shrunk! How long his lesions have been inactive and his MS lesions have been in remission is impossible for us to know for sure because he is lacking interim MRI scans 1995 for comparison. Doug is most concerned about the sudden neck pain that he experiences at night sometimes when turning over in bed. The pain is excruciating when it occurs and may be due to bone spurs.

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In view of his MR image reports of "inactive lesions" he has decided that injecting Copaxone and possibly going on the oral pill treatment in a year is not his choice of action. His next move will be to consult with an expert orthopedic surgeon to see if there is any possibility for a reasonably safe surgical solution or other therapeutic approach to his neck issues and left leg weakness.

As long as the doxycycline continues to arrest Doug's exacerbations he will continue to use it. We know that it is not a cure, only an effective

way of putting the brakes on his chronic condition with each insidious attack. Hopefully, someone will find a "cure" for MS in the near future so patients like Doug can be restored to full health.

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NOTE – Since this update of Doug's health was written a year ago, and described in the first printing of this book, he has developed severe back pain. A recent MRI still shows "inactive" MS spinal lesions. As of this date, April of 2014, and during the editing and second printing of this book, Doug has also had difficulty walking. His recent MRI scans, one month ago, did not show any "active MS lesions." He has been diagnosed as having arthritis of the spine. He recently began another course of doxycycline after experiencing the drenching night sweats that have always heralded the onset of each MS exacerbation, although there is controversy over night sweats being or not being a part of the MS complex of symptoms. It is possible that Doug was exposed to Babesia as well as Borrelia in 1985. One of our former Tahoe neighbors tested serologically-positive for Babesia so it is likely that Doug was exposed to it as well. He will seek a diagnosis and treatment of that if it is another option at this late date.

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ANECDOTAL STORIES

In the following pages, I will try to briefly tell a select few of the many patient stories.

At the time of Doug's MS diagnosis in 1995, we had already been living in Gig Harbor, Washington for five years. I had long since given up any active involvement with our Arizona group, although I still kept in touch with some of the members. Once Doug was diagnosed, I contacted some of the people to tell them about Doug.

Leah King was one of those people. She had kept in touch with me since her diagnosis of tick-borne relapsing fever while living in Arizona in 1984. Over many years she struggled with complex, multi-system, relapsing symptoms and signs. Each time she was treated with doxycycline, she improved. She said that several members of her family had been exposed to ticks in Utah. Not long after our son Doug was