diagnosed, she said that her adult daughter who lived in Utah had been diagnosed as having probable MS.This diagnosis was later in doubt.

Leah soon moved from Arizona back to her childhood home state of Utah. She noted that brain tumors were quite common in and around Sandy, Utah, an area where she had lived as a young adult and where she and other family members first became ill with relapsing fevers. She had several miscarriages early on, and one baby was born with a heart problem, "septal defect".

(Tragically, in November of 2011, I received the sad news that Leah's heart ... "gave out"... she died at her home near Salt Lake City).

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When I called Ann, our former Tahoe neighbor who contracted MS after a 3-year history of handling her pet chipmunks during the 1970's she was still, after three decades, taking doxycycline with each of her MS exacerbations and doing extremely well. Her physician had noted how remarkably well the doxycycline worked for her therefore he continued to provide all she needed over the years. She had remarried, and still kept in touch with her ex-husband who was by now suffering from multiple health problems that eventually led to giving up his practice of medicine.

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Ann's second husband, John, was a Lake Tahoe native. After his mother died, he was raised by his aunt, Mabel Winter Whitney, in South Lake Tahoe, California, where she owned the exclusive Camp Chonokis, a girls' camp. The camp provided sessions for girls ranging from eight to eighteen both in the summer and during Christmas school vacations. John recalled that some of the campers became ill with high fevers, and that the father of one of the girls, Dr. Rodney Hadden, a doctor from Berkeley, determined that the campers were ill with, "recurrent fever", also known as Borrelia recurrentis and tick-borne relapsing fever (TBRF).

John said that during his childhood, his aunt often cautioned him to wear shoes and socks, and to be on the alert for ticks.

The camp hosted only twelve campers in 1928 and thirty-five campers attended the last session in 1952. The campers by then came from various parts of California as well as from the east coast. The camp was built in 1927, and featured tent cabins on the twenty acre location that had previously been a logging camp. Presently, there is a Raley's food market located directly in front of where the old forested campground existed. The United States Forest Service now owns the former camp property.

Because no one, other than our support group, has followed up on the later manifestations of TBRF, there has been no way of knowing how many of these girls suffered long term health issues, unless information might be found within the voluminous collection of photos, letters and files that are available within the Camp Chonokis archives located at the University of Nevada, Reno. (Special Collections at UNR).

Jacquelyn Sundstrand, Manuscripts & Archives librarian in the Special collections Department at the library was able to locate a letter dated June 22, 1937, that discusses relapsing fever at the camp. The letter was sent from Dr. K. F. Meyer at the UC Hooper Foundation Medical Center in San Francisco.

In part, the letter reads ... *"Returning to the question of relapsing fever, I have to say this: Occasionally it is very difficult indeed to see the spirochete in a blood smear taken during the first attack. Moreover, even if treatment is instituted early, relapses cannot be entirely excluded. Even with the best of treatment I have seen 4 or 5 relapses occur. However, I will write to Dr. Haddon and suggest that in the future these cases be treated more intensively and with larger doses of arsenicals."* (In 1937 arsenic based drugs were prescribed. This was during the pre-antibiotics years of the 1930's).

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In July of 2011, Dick and I visited Ann and John Whitney and Ann's ex-husband who was by chance visiting his and Ann's daughter, Courtney. Because Ann's ex-husband has remained on good terms with John and Ann over the years, the six of us all went to dinner together during our visit and had lengthy discussions about Borrelia.

John credited the intermittent courses of doxycycline since 1982 for keeping his wife Ann out of a wheel chair. Dick and I credit it for doing the same for our son Doug.

When we arrived at the Whitney's Lake Tahoe home at Zephyr Cove, Ann had just had back surgery for extensive disc problems (scoliosis and degenerative disc disease) that her surgeon had not attributed to her MS. Her physician ex-husband Todd, who was Ann and John's houseguest, attributed the multi-system health issues he suffered from over the last two decades as likely sequelae from Borrelia exposure in the late 1970's when Ann's pet chipmunks were much a part of their lives.

Todd was diagnosed with leukemia initially but when he learned of Ann's and Dick's Borrelia and that Dick's initial diagnosis was thought to be leukemia, he decided to be serologically tested for *Borrelia hermsii*. His titers were positive at extremely high levels for *B. hermsii*.

Todd's brother an airline pilot who visited Ann and Todd frequently in Tahoe, was later diagnosed and treated for leukemia. He remains in remission. The daughter of another physician who owned one of the four townhomes in our building is said to have died of leukemia. I could not confirm this last case and I was unsuccessful in contacting her physician father since he has retired from his former practice.

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In 1984 a woman from Fountain Valley, California wrote to me and told about her nineteen-year-old daughter Rosemary who had a history of tick bites within the past five years. She became increasingly exhausted physically and emotionally and at one time tested positive for lupus. It was later ruled out. After someone sent Charles Thornton's articles to her because lupus was mentioned in the list of tick-bite complications, she contacted me through the Arizona Republic newspaper.

The mother had been seeing a physician for herself regarding a thyroid problem that was also one of our support group's listed complications; several members had thyroid tumors, cysts and other things such as Hashimoto's and Grave's disease.

Of note, former President GW Bush was rumored to be diagnosed with Lyme disease and his mother and father, Barbara Bush and George Bush Senior have Grave's disease. It is extremely rare for two non-related family members to both develop Grave's disease without exposure to an environmental cause. Certainly, they resided in high-risk areas for Lyme disease.

When Rosemary gave her physician the Borrelia information he readily agreed to test her for it, the doctor having had experienced Borrelia cases during his years of service in the army.

Although Rosemary was likely infected with TBRF, not LD, tests were positive for both Lyme disease and tick-borne relapsing fever. She was treated appropriately with antibiotics. She was lucky to have a physician who was familiar with Borrelia treatment. He was cognizant of the Jarisch-Herxheimer reaction and warned that the treatment--even if given when fevers are at a low point--can sometimes make one feel worse initially. In his opinion, that kind of reaction confirmed the diagnosis.

Her doctor went the extra mile with follow-up tests to compare with the first one. He contacted the Yale Lyme clinic for current Lyme treatments because there was no literature support for the long-term treatment of TBRF. He told Rosemary that her bacterial infection might require many years of repeated treatment.

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In the fall of 1984 I received a letter from a man named Leonard in Tennessee. He described his eleven-year-old daughter, who had contracted tick fever while living in Kenya, Africa, a highly endemic area for the soft tick, *Ornithodoros moubata*, a tick species that transmits the agent, *Borrelia duttoni*, a highly neurotropic type of Borrelia. Mr. Leonard, with his family, had served in Kenya as a missionary for three years. Although they had been back in the U.S. since 1983, His daughter continued to be chronically ill with intermittent relapsing fevers of up to 105 degrees.

Relapses of fevers are a hallmark nature of Borrelia and hence its name "relapsing fever". Somebody had given Leonard one of Charles Thornton's news stories and he contacted me via the newspaper to inquire about tests and treatments. He was unaware that tick fevers might require repeated treatments for many months to years if chronic relapses occur.

Tragically, the common dilemma for people who called or wrote to me was being unable to locate physicians who could knowledgeably answer their questions about Borrelia and its treatment. I answered Leonard's questions as well as I could and could only hope that his daughter would receive proper treatment.

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The most heartbreaking letter I received in 1984 was from a woman in Colorado who had contracted TBRF in a vacation cabin located in the mountains at Eagles Nest, New Mexico. Her stillborn, full-term baby was retrospectively diagnosed after she lost a second baby that was diagnosed with relapsing fever *Borrelia hermsii*.

Later, she realized that her parents and husband, a dentist, had been infected as well. No doubt, other families in her Eagles Nest neighborhood have been exposed but not likely diagnosed. Her physician agreed that this disease is under-diagnosed because physicians think of it as rare and almost never suspect it. Relapsing fever borreliosis is a common cause of pregnancy complications, miscarriage and neonatal death in sub-Saharan Africa." (Pathobiology of African relapsing fever Borrelia, Christer Larsson, Dept. of Molecular Biology, Umea University, Sweden, 2007)

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Another tragic account was from a world-famous former Olympic skier, Jimmy Huega, founder of the Vail Valley, Colorado based Huega Center for Multiple Sclerosis", now named "Can Do Multiple Sclerosis".

Jimmy called me after seeing my son Doug ski at the Jimmy Heuga Toyota Snow Express 13th annual international finals at Vail/Beaver Creek, Colorado, April 15-19, 1998, a charity ski meet to benefit MS. Doug had become active in these types of MS charitable events since his diagnosis of MS in 1995.

The preliminary events were held annually all over the United States and Canada. Doug was the captain of one team among dozens, at the Mount Bachelor, Oregon races. His team raised money totaling over $20,000.00, a targeted amount that qualified his team to attend an all-expense paid trip to Vail, Colorado for the finals.

The week-long Vail event included theme parties and a giant slalom race where twenty-six former Olympian and/or professional skiers competed among the approximately 200 skiers in the race. Jimmy was impressed that Doug, in spite of having MS, placed first out of the Bend skiers. He posted a better time than six of the former Olympian and professional skiers.

At this time, Jimmy was in a wheel chair, his MS in an advanced stage. He questioned Doug about his MS and wanted to know what treatment he was using.

Doug told Jimmy that he was skiing better than he had ever skied in his life despite the fact that just a couple of years prior he was having major problems with skiing, coordination, and balance. In the 1995/1996 ski season it was not unusual for Doug to fall five to ten times on what would normally be a very easy run. In 1998 he felt he was back to 100% balance and performance due to the doxycycline he was taking for his chronic TBRF, as well as his diet, exercise, eliminating caffeine, reducing stress and avoiding exposure to heat.

Jimmy agreed with Doug's regimen, especially the vigorous exercise. Jimmy, too, had found exercise to be beneficial although neurologists had warned him against it. Shortly after that day, Jimmy contacted me by telephone to inquire further, and learn more about what I could tell him about Borrelia. I asked Jimmy if he had ever lived in ponderosa-pine country or if he had been exposed to chipmunk and squirrel habitats. He laughed incredulously and said, "I was raised in Squaw Valley, California, in the Lake Tahoe basin where my brother and I trapped chipmunks as a hobby during our teens. We handled chipmunks every day!"

"Is your brother okay? I asked".

"No," he responded. "He has MS, too."

Jimmy and his brother had skinned and otherwise handled chipmunks during their teen years, getting blood and urine on their hands. Borrelia microbes can enter the skin directly through pores from body fluids of reservoir animals.

I told Jimmy that Dr. Burgdorfer confided to me that while working in his lab, during the 1980's he had contracted Borrelia from an infected, unruly, rabbit that urinated during his examination of it, splashing some urine in his eye. Jimmy and his brother were certainly at risk if they were exposed to the body fluids of chipmunks.

Jimmy said that the MS drugs he had tried were not helping him, and said he wanted to try taking doxycycline. He later told me that some of the influential members at his foundation talked him out of it, citing the fact that I was a mere housewife, so what could I possibly know? Besides, he thought it was too late for him to do so. He said that his income depended on the Jimmy Huega Center so he felt that he had to subordinate to his advisors' views or chance losing his income. Tragically, Jimmy Heuga was eventually confined to bed in a care facility. He died in February of 2010 at age sixty-six.

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In 2002 I received a phone call from a Bend, Oregon, resident Catherine McCoy who had MS. She had heard about my son Doug from a friend who urged her to call him regarding his successful MS treatment. Catherine had been injecting an MS drug under the care of her neurologist and her MS was getting worse not better. After contacting Doug, in 2002, she telephoned me at our home in Arizona to learn more. I agreed to share my information only if she promised to consider it under her physician's guidance.

Catherine's neurologist vehemently opposed her wish to discontinue the MS therapy she had been taking via injections. Instead, she wished to try what Doug had been doing; intermittent short ten-day to two-week courses of oral doxycycline, an option that her neurologist proclaimed as outrageously ludicrous. Catherine nevertheless persisted, and upon receiving my eight-page letter that detailed Doug's treatments with antibiotics, she informed her neurologist that her general practitioner had read my letter, and had agreed to give her the doxycycline.

Catherine's neurologist was alarmed by this and said, "Let me do an MRI scan, and then you come back in one year for another scan. I will then prove to you just how much more damage you can get by going off the MS drug injections.

One year later after her follow-up MRI scan, Catherine checked out perfectly. Her MRI scan results surprised the neurologist. He entered the examining room with the results saying, "I do not know what you are doing with that doxycycline, but keep it up. Your MS lesions have 'shrunk'. They have almost disappeared."

At that time Catherine had not recalled ever having been bitten by a tick. But when she told her mother about the possible link of her MS to earlier tick-bite exposure her mother reminded her that as a young child of age nine while vacationing at Cape Cod, Massachusetts, Catherine had a tick embedded in her scalp. Her mother removed it. Her mother also recalled that Catherine developed a distinctive circular, bull's-eye type rash that her physician did not recognize as something that had anything to do with her tick-bite in 1968. Over a decade or two later, in 1982, that rash became well known as the hallmark, *erythema chronic migrans* (ECM) a definitive diagnostic sign of Lyme disease. ECM was later changed to *erythema migrans* (EM).

Seven years after Catherine's tick bite at age sixteen, she became severely ill with exhaustion and other classic symptoms of infectious mononucleosis, a disease caused by the Epstein Barr virus (EBV). She also suffered from a strange, transient arthritis-like problem that was confined to the right side of her body, her right hand unexplainably being quite swollen. The right side of her body in later years became "numb" and very much a part of her MS neurological symptoms.

Blood tests for the EBV did not confirm mononucleosis initially when Catherine was sixteen, but at age twenty she again became severely ill, and this time her EBV convalescent blood work revealed elevated antibodies. Keep in mind that EBV and LD can cross-react on such tests as was noted by Dr. Louis Magnarelli during the mid-nineteen eighties serological studies of patients in New Haven Connecticut. These two disease agents could be co-infections acting in concert with each other as well during the waxing and waning of symptoms and signs.

I often have lunch with Catherine when we visit in Bend. When we met for lunch in 2008, I watched her as she left the restaurant. She walked confidently down the street, no sign of any compromise in her stride. She continues to occasionally use doxycycline as of this writing.

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In 2009, Tom Wilkes, a Grammy Award-winning art director, photographer, album cover designer, and Director of "Project Interspeak" an organization to benefit studies of whales, dolphins, and porpoises, tragically died at age 69 of a heart attack. Mr. Wilkes had telephoned me in 1996 after he experienced severe neurological problems following multiple tick bites that he suffered during a hiking trip in California. He said that he found several ticks in his sleeping bag.

Mr. Wilke's initial diagnosis was MS. He was enthusiastic about trying doxycycline for his MS as well as participating in a Mayo Clinic serology study that I instigated in 1996 on behalf of the MS patients in our support group. Even though his doctor at Scripps Clinic in La Jolla, California refused to provide him with doxycycline or a serum sample for my study, he obtained his blood serum from another doctor and purchased doxycycline over-the-counter in Mexico. He experienced several improvements, but was not cured.

By 1999 it was determined that he had amyotrophic lateral sclerosis (ALS) also known as Lou Gehrig' disease. Only about ten percent of ALS patients survive for 10 or more years. Tom was one of them.

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In 1996 while visiting the tiny town of Twisp, Washington, I learned from a local resident, Mickey Eiffert, that the numbers of neurological disease cases within blocks of her home were clearly indicative of a cluster. The cases included MS, and her husband's ALS, as well as his best friend, who had Parkinsonism, (the two friends had been lumberjacks several years earlier). I found this clustering to be true in other locations such as the Flagstaff and Pinetop areas of Arizona where the risk of ALS, MS, Parkinson's, dementia and brain tumors, was beyond coincidence. Scientist Dr. Lida Mattman, a 1998 Nobel nominee, did a study of seventy neurologically impaired patients and detected Borrelia bacteria in all eight of the Parkinson's patients, all forty-one of the MS cases and all twenty-one of her ALS cases. (See Breakthroughs in

Health & Medicine Online Newsletter "New Hope for Lyme Disease" August 2012.) Although, Borrelia may be found at the scene of the crime, co-infections, other toxins and genetics should be factored into that tip of the iceberg scientific, antigenic equation. (See also: Alan MacDonald, MD LD pathology studies regarding Alzheimer disease and dementia).

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By the spring of 2000, we sold our home in Gig Harbor, Washington, and moved to Arizona in order to assist our son Brad who had become the custodial single parent of his two and a half year-old daughter Sara.

Brad had a clinical history of TBRF since the winter of 1976/77. He was retrospectively diagnosed in 1984 with positive antibody tests to support his clinical diagnosis. We had assumed that his nearly one month course of antibiotic treatment, which he had received in 1984 had erased all traces of his chronic Borrelia infection. At the time the treatment had cleared up his persistent, recurring, epididymitis and other symptoms and signs that had become chronic.

Little did we suspect during all the intervening years, which since 1976, regardless of what we thought was adequate antibiotic treatment, an insidious Borrelia infection was slowly doing damage that would cause him multiple neurological symptoms and signs as well as heart problems that are closely related to the recently described Lyme disease symptoms of heart damage and neuroborrelioses. (Neurological Manifestations of Lyme disease, Brian Fallon, MD, Jennifer Nields et al.)

By February of 2007 an MRI scan revealed white matter damage to his brain, and sub-cortical small vessel involvement. In 2008 a SPECT scan described by the consulting physician … "lit up his brain like a Christmas tree!"

Brad had damage in several areas of his brain. Some areas indicated earlier skull injuries, but most significantly the scan revealed ongoing encephalitis; his neurologist thought it was most likely Borrelia-caused. (Spirochetes by their very nature are scavengers of dead or damaged organic matter).

My husband and I were shocked to learn that the areas of his brain that were damaged demonstrated a physical cause of nearly all his health issues such as; slurred speech, depression, cognitive difficulties, MS-like neuropathy in his hands and feet, exhaustion, sensitivity to light and noise. Psychiatrists rarely rule out neuroborreliosis before jumping to the conclusion that a patient has a psychosomatic condition. Therefore, patients are usually treated with psychiatric drugs instead of the antibiotics they desperately need for a brain infection.

Brad has dramatically improved over the past three years, with short, repeated courses of antibiotic therapy, although much of the damage is irreversible.

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DR. BURGDORFER HAS HIS NAMESAKE DISEASE

During a phone conversation with Dr. Burgdorfer on February 21, 2007, he told me that he had been having mini-strokes, known as trans-ischemic attacks (TIA's). He also had been experiencing other disturbing neurological physical symptoms and signs. These things were in addition to his already health-compromising diabetes. His speech was noticeably slower and his Swiss accent made it more difficult than ever to understand him because he slurred words. It entered my mind almost immediately as he talked that he might have neuroborreliosis.

He said that he had fallen down on more than one occasion when his leg no longer supported him. An ambulance was called after a recent episode of what was thought to be a full-blown stroke. I knew of at least one study that linked intracranial aneurysms and strokes to Lyme borreliosis, the researchers comparing it with the later manifestations of syphilis vasculitis. (J. Oksi, M K Viljanen, J.Neuro Psychiatry, 1998)

Dr. Burgdorfer's physicians were puzzled over his MRI scans and not sure of his diagnosis.

He was resigned to thinking that his "mind was going" because he felt confused at times. He explained that during his presentations at recent conference meetings in Germany and San Francisco, he found himself involuntarily alternating from English to German and at one point losing his concentration completely to the point of collapse. I was shocked to hear this but I thought that his confused condition could be a latent neurological encephalopathy complication caused by his years earlier exposure to Borrelia in his laboratory.

As previously mentioned, a Borrelia-infected rabbit had urinated during his examination of it in his laboratory during the mid-nineteen eighties. The Borrelia-contaminated urine had splashed in his eye. Tests that he performed on himself later confirmed his fear and the predictable febrile illness that manifested within a week.

I said, "Willy, you have your own disease! You have classic late neurological Lyme disease!

"Oh, my God, Bonnie, I never thought of that!"

I said, "Well, why don't you look into the literature by Dr. Brian Fallon and see what you think. He and his wife, psychiatrist Jennifer Nields Branson, MD, and a few others have published some excellent data about neuro-borreliosis".

Dr. Burgdorfer was well aware that, like syphilis, Borrelia spirochetes can cause brain and spinal disease complications twenty to thirty years after the initial infection. Dementia, strokes and a shuffling gait and even paralysis are part of the sequelae. It was disturbing that he had failed to recognize this possibility in himself. I added, "You need to seriously consider taking antibiotics."

"You are right about that" he said excitedly, "Bonnie, excuse me please, I have to get off the phone now and call my doctor right away!"

"Let me know what you find out."

"Okay, I will call you back"!

"Oh, one more thing Bonnie, is it okay that I give my doctor your phone number and if he has any questions he can call you?

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By this time it had been twelve years since Dr. Burgdorfer had first discussed my son Doug's MS diagnosis with me. At that time we both speculated that the cause of Doug's MS was his Borrelia infection that he had suffered over a decade earlier.

I was not sure after today's phone conversation that in his present state of health Dr. Burgdorfer would recall the details of that earlier discussion about my son over a decade ago. I had never forgotten the advice that he gave to me on that day those many years ago.

As a friend who believed that I could be right about Doug's MS being caused from his tick-bite history, he had suggested that if I was convinced of it, "Why not just treat the Borrelia and, see what happens to his MS?"

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Oddly enough, during that same period of time when I called Dr. Byron Waksman about Doug's diagnosis he said the same thing; "*Treat your son. Just remember, Bonnie, you cannot save the world.*"

Dr. Waksman did not believe that Doug had true MS. He said that most neurologists in the U.S. do not know how to diagnose it definitively. When I defended the diagnosis by explaining that he was diagnosed at a world famous facility, Barrow Neurological Institute, by an Arizona "Top Doc" he said dismissively, *'What do they know?"*

***

After that phone conversation with Dr. Burgdorfer, I wrote a letter to confirm what we had discussed as well as to remind him of the events years earlier in 1995 when he had supported my theory of MS being a chronic form of relapsing fever borreliosis. I wanted to make sure he recalled what we talked about because if he thought his mind was going, a letter would help refresh his memory. I had also reminded him that Dr. Paul Lavoie had suspected strongly that the autoimmune disease, diabetes, was caused by Borrelia in genetically predisposed people.

Several weeks later we spoke again; he had been taking the antibiotics and except for his diabetes problems, he was feeling remarkably better. I noticed that his speech had improved, and his memory seemed to be excellent once more. It was amazing. I credited the positive improvements to the antibiotics he had taken. He agreed.

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In the interim period of time, only one week after our conversation of February 28, 2007, a film crew gathered at Dr. Burgdorfer's home to conduct an interview with him regarding Lyme disease for an upcoming documentary, "Under Our Skin".

According to the published accounts of that particular day, one of Dr. Burgdorfer's fellow scientists from the nearby bio-level-four Rocky Mountain Laboratory pounded on the door and asked to be admitted in order to "supervise" Dr. Burgdorfer's interview.

"This comes from the highest authority," he said. He added, "There are things Willy can't talk about."

The producer, Andy Abrahams Wilson, successfully turned this National Institutes of Health official away and proceeded with his planned interview.

During the interview Dr. Burgdorfer was asked if he had Lyme disease. He said, "No."

In a later phone conversation I asked him why he said "no" when he knew very well that he had been infected in his lab. He said that officials at NIH had been exerting pressure on him to deny his illness. They had repeatedly tried to convince him not to tell anyone that he had Lyme disease because they did not believe that was the case.

That is ridiculous, I thought. Why would the officials from NIH and NIAID insist that Dr. Burgdorfer, the world expert and namesake of *Borrelia burgdorferi* was unable to correctly assess his own disease, especially when they knew far less about it than he did?

I said, "Do you now believe that those officials are correct?" He paused only slightly and answered firmly, "No!"

After the end of the filmed interview of "Under Our Skin" when the film crew was preparing to leave, Dr. Burgdorfer was quoted as saying, "I didn't tell you everything."

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LYMPHOMAS AND CHRONIC CASES

In August of 2009 my husband's stepfather, Alan, was diagnosed as having cutaneous T-cell lymphoma (CTCL). Dick's mother had died 19 years earlier of natural causes. She had suffered from arthritic knees and Parkinson's disease since the mid 1980's, shortly after a Lake Tahoe vacation. (She could have had tick exposures at Tahoe, and possibly from the many exposures she had while living at Big Bear and Lake Arrowhead, Calif. decades earlier) Dick's biological father was diagnosed as having pancreatic cancer and re-evaluated as having lymphoma two years later in 1994.

Most recently both my husband and Dr. Burgdorfer who were each infected with Borrelia nearly three decades ago have had squamous cell carcinomas removed. In a web search I found it interesting that squamous cell carcinoma patients have a "double" risk of lymphomas. Their profiles of neurological sequelae are very similar as well.

I tried to reach Dr. Paul Duray about our now having three cases of non-Hodgkin's lymphomas within our *unrelated* family members to include, mine, later diagnosed in 1977 to be pseudo-lymphoma, my husband's father, and now in 2009 my husband's stepfather. All three of us had spent vacations in Tahoe. Three in one family is off the charts with statistical numbers of occurrence, three per million in those years.

Dr. Duray had retired from the National Cancer Institute by now and after serving for a while at a Veterans Administration hospital closer to his home in Massachusetts I had lost touch with him but I knew that he

would be interested in knowing about this third lymphoma case in our family.

He had remained a believer that Borrelia could cause lymphomas since we first met in 1988. He urged me to call him whenever I had any new ideas because he was in a position to test specimens in his pathology laboratory.

When I first met Dr. Duray in 1988, he was in charge of an entire pathology floor at Fox Chase Cancer Institute. After that he served several years at the National Cancer Institute, next he became a staff pathologist at the New England Veterans Administration during which time he was called up to serve for ninety days as a flight surgeon in Iraq on three occasions, 2004, 2006, and in 2007 at age seventy he served his last assignment in Iraq to my knowledge. He had previously been a professor of medicine at Yale and also at Harvard. His expertise was well established.

Recently, it is rumored by a credible source (whom I don't have permission to quote and cannot confirm its validity) that Dr. Duray had served on the advisory board of the Infectious Disease Society of America, (IDSA). He also became an EIS officer. Then, he published a paper that denied his finding of borreliae in pathology specimens of treated patients. This was in opposition to his earlier scientific views and is highly unusual. The last rumor I heard about him in January of 2012 was that he was extremely ill. My unnamed source stated, "They did something to him!"

Coincidentally, the same source told me that Dr. Duray's long-time friend, fellow pathologist Dr. Alan MacDonald had developed debilitating, sudden dementia and he did not recall researching *anything*. More recently I discovered that Dr. MacDonald has fully recovered. Although he is retired, he is actively volunteering his time to the "Paul Duray Foundation" working with pathology laboratory studies and teaching his techniques to other pathologists. He is currently proving with laboratory demonstration of spirochetes that neuroborrelioses can, like syphilis be chronic with many long-term manifestations. Much of what he discovered in the early 1980's has lately been confirmed by other scientists as being correct.

Besides trying to contact Dr. Duray about our family's lymphomas, I had E-mailed some photos of my niece's bull's eye rash to him when she contracted neuroborreliosis shortly after moving to Albuquerque, New Mexico in 2007. It was after these two contact attempts when I felt that something was not right. It was as though Dr. Duray wanted to help, but his hands were tied, his demeanor not unlike that flat, almost robotic tone I had heard from others such as Dr. Eva Asbrink, Dr. James Webb, Dr. Derek Gay, Dr. Jacob Pinnas, and Dr. Alan MacDonald.

I had asked Dr. Duray a year or two earlier if he, like other experts I consulted, would be under any type of threat because of my calls and emails to him. He laughed and responded confidently, "Bonnie, you may call or email me anytime you want!" I do not know what happened since then to have changed that, but something following that conversation prevented him from ever calling me again.

My niece was finally diagnosed by her dermatologist who immediately identified her hallmark bull's eye rash as "Lyme disease". Following antibiotic treatment her cutaneous and neurological symptoms remarkably resolved. When I called to pass this news on to Dr. Duray, although he had been unsure of her bull's eye rash diagnosis earlier, he now said that he agreed with the diagnosis. It was the last time I heard from him. It would be five more years (October of 2012) when I learned of his sudden decline in health and early death at age 74 from a dementia–like disease and pneumonia. I also learned that his wife, Estelle, had been hospitalized and suffered "seizures" and memory problems. She is presently living in Colorado with son, Paul Jr. and family.

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If Dr. Duray were still alive today, I am certain that he would be interested to learn about several families from our Tahoe townhouse that have suffered long term health problems after tick exposures. Their problems included 3 non-Hodgkin's lymphomas and one Hodgkin's lymphoma, one of which I linked retrospectively to Borrelia hermsii TBRF in 1977. In the 1980's lymphomas were extremely rare but, in the years since then their numbers have sky-rocketed to be more common now.

It was too bizarre to be coincidental for us to have three people develop MS within our four-unit townhouse at Lake Tahoe. At a rate of ten percent, that is overwhelmingly the largest epidemic per square foot area ever recorded for MS in the entire world. Other MS epidemics such as the Sitka Alaska "3" cases are measured by towns and countries, not square feet.

Add to these from our building alone: four lymphomas and two leukemia cases, one brain tumor, thyroid problems including Grave's

disease, four early dementia cases, arthritis, and several cases of spinal disc disease, heart irregularities, and most recently my husband's irregular or ulcerated carotid artery, brain aneurysm, vertebral artery stenosis and inner ear vestibular neuronitis causing severe dizziness, nausea, loss of balance and more. The above-mentioned health issues mirror the sequelae of advanced syphilis and Lyme disease, first cousins of TBRF. A John's Hopkins paper lists "Borrelia and *Chlamydia pneumonia*" in addition to viruses as causes of vestibular neuronitis. If my husband's vestibular neuronitis was actually caused by his earlier (1982) exposure to *B. hermsii,* his would be the first known case to be linked to "chronic" tick-borne relapsing fever in the world.

All of the above in addition to all the other aforementioned sequelae described in this book calls to question; why are studies and education for physicians, non-existent for this important disease complex! Relapsing fever is an ancient disease… doctors don't know it.

It could be legitimately argued that the clustering of chronic diseases and cancers are commonplace and they cannot necessarily be linked to any specific environmental source. But … "*glioblastoma multiforme (GBM)* brain tumors are the most common and most aggressive brain tumors in humans, involving 52% of all functional tissue brain tumor cases and 20% of all intracranial tumors. GBM tumors are extremely rare with an incidence of 2-3 cases per 100,000 in Europe and North America." Our support group members reported six brain tumors, including two of unknown type, two GBM's, one nasopharyngeal carcinoma, and one meningioma. Meningiomas are common but only about 3% are malignant. (Glioblastoma multiforme, Wikipedia).Two GBM's in our support group of 200 represented odds of 100,000 to 1.

My former neighbors Jim and Lou Richards died of brain tumors. They taught school for ten years at the north rim of the Grand Canyon, an area that is extremely high risk for *Borrelia hermsii.*(Tick-borne relapsing fever: an interstate outbreak originating at Grand Canyon National Park., AM J Epidemiol., 1977 May; 105(5):469-79., Boyer KM, et.al.) The odds of this couple dying of brain tumors are incalculable.

The TBRF outbreak at the Grand Canyon was the largest ever indentified in North America and established the area as an endemic source of TBRF. TBRF could very well be suspected as the environmental exposure risk for these extremely rare brain tumors, especially when both husband and wife lived for ten years in that endemic high-risk area. Arizona's Mogollon Rim, Payson and Pinetop areas are just as high risk but physicians in that area rarely recognize it.

Oscar Felsenfeld and others who were cited in his monograph book "Borrelia" were puzzled about the "neurotropism" of borreliae and speculated that it may be strain specific. "Borreliae were found in the C.S.F. (cerebral spinal fluid) in the brain, as well as in *brain tumors.*"

In 1990 the National Cancer Institute's epidemiologist Paul Levine investigated Tahoe physician Dan Peterson's practice for an increase in cancers during the 1984-1985 local chronic fatigue syndrome (CFS) epidemic. He found five cases of lymphomas and three brain cancers. (See Hillary Johnson's book, "Osler's Web", p.424). Peterson's practice was located at "north" Lake Tahoe whereas, within 25 miles, the three cases of lymphomas plus my cousin Larry (making four) and, one case of brain cancer were all counted among our *family members alone* who were exposed to ticks at our "south" Lake Tahoe residence. In addition to lymphomas and my nephew's adenoid cystic carcinoma brain cancer, an added "coincidence" of GBM brain cancer occurred in a resident within two miles of our townhouse.

Lymphomas have become more common in recent years and have been linked to Borrelia worldwide. (See, "Lymphoma Rate Rise Continues to Baffle Researchers," J Natl. Cancer Inst.) Ken Garber, describes the 81% increase in lymphomas between 1973 and 1997 in the U.S. Recently, many researchers are linking lymphomas to Borrelia and some report positive results after antibiotic therapies.

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ARIZONA DOCTORS TREAT LYMPHOMA WITH ANTIBIOTICS

In August of 2009 I wrote to two physicians who were caring for my husband's stepfather who had been diagnosed with multiple infections and "Cutaneous T-cell lymphoma." See letter in "Addenda" at the end of this book. Following my letter, his doctors agreed to try treating his cutaneous T-cell lymphoma with doxycycline once daily. His caregiver reported that his skin rash faded within one week. Unfortunately he did not remain on any medications after that week. He was in very poor health and just decided to stop all treatments. He died within two months at age ninety-five.

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LAKE TAHOE CEBV-CFS-ME

In 1984 through the early 1990's the multi-system disease syndrome that was recognized in and around the areas of Lake Tahoe, Nevada and California, was investigated by great numbers of physicians, and scientists.The syndrome was thought to be caused by the *Epstein-Barr virus* (EBV) and later associated with *chronic fatigue syndrome* (CFS). One of the lead investigators was Anthony Komaroff, MD, director of internal medicine at Harvard's Brigham and Women's Hospital. I briefly discussed Dr. Komaroff and the Lake Tahoe chronic Epstein Barr (CEBV) earlier in this book.Although the cause of CEBV and CFS were thought to be viruses or a retrovirus, nothing was definitively proven.

The EBV has been implicated as causal to a number of serious diseases. Most recently, a report in Science Weekly describes the discovery of EBV within plaques of MS patients.

Dr. Gabriel Steiner discovered spirochetes in and around MS patients' plaques during the 1950's. It appears that if his Borrelia-like spirochetes, "*spirocheta myelopthera,*" represent a probable cause of MS.It indicates that more than one pathogen including EBV and at least two other viruses have now been demonstrated to be at the scene of the crime. (*Chlamydia pneumoniae* is another bacterium that is linked not only to MS but to Lyme disease as well).

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In my view, the Lake Tahoe CEBV epidemic was caused by tick-bites, whether it is Borrelia alone or there is more than one cause such as a combination of multiple tick-borne pathogens to include viruses and retroviruses. These *combined* pathogens have never been scientifically ruled in or out. Research generally implicates single causes, not multiple.

After working for two and a half years in search of a virus during the Lake Tahoe epidemic, esteemed MS researcher, Elaine DeFreitas, PhD., isolated a retrovirus that offered the first real proof of a source. Dr. DeFreitas worked directly under her boss, the famous Nobel Prize nominee Hillary Koprowski. Dr. Koprowski served as chief of the distinguished Wistar Institute in Philadelphia. He supported and encouraged her because he had long held the view that neurological diseases such as MS, Parkinsonism, and many more related neurological diseases were caused by brain-sequestered viruses.

In September of 1990 Dr. Koprowski chaired the retrovirus portion of a large international neuropathology conference held in Kyoto, Japan. It was at this meeting and with his encouragement that Dr. Elaine DeFreitas announced her findings.

Her retrovirus was not recognized as the final proof of cause after CDC claimed that their scientists could not reproduce her findings.

I disagree and think she was the closest of any other scientist to discovering a highly unusual retrovirus source that could possibly interact with borreliae and other tick-borne pathogens to cause many diverse chronic disease patterns. Her findings remain a mystery. Dr. DeFreitas was unable to complete her work. She was under-funded and working with less than state of the art equipment. After suffering severe injuries in a car accident, she retired.

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The mystery illness that was investigated at Lake Tahoe during the middle 1980's was eventually called Chronic Fatigue Syndrome (CFS). CFS, like TBRF and LD, is a syndrome that manifests symptoms following specific flu-like illnesses and includes autoimmune diseases as later manifestations. Over time all three of these above-named have evolved to encompass a plethora of symptoms, signs, and chronic disease states in common with each other, some of which are fatal.

There are those among the TBRF and LD communities, including myself, who believe that fibromyalgia and this trio; CFS, TBRF and LD are caused by a common source of multiple pathogens. Tick-bites should be the number one suspected cause.

When genetic profiles as well as multiple inflammatory disease pathogens, injuries, and toxins are acting in concert in a competitive and/or symbiotic fashion over a period of weeks, months and years, immunological chaos can be the result. Microbes such as the malaria microbe and Borrelia spirochetes are known to sequentially create a variety of immune up-regulating, dysregulating, and down-regulating events, becoming long-term partners in crime.

Moreover, "Suppressive serum factors have been identified with anergy accompanying syphilis and infectious mononucleosis." (Infections in the Abnormal Host, Michael H. Grieco, MD, ed., Yorke Medical Books, Inc. N.Y., p. 272, 1980.

A microbial flurry of activity can precipitate quiescent viruses to opportunistically emerge as part of the complex.

Often, a single virus or retrovirus is thought to cause a specific disease when in fact that virus may be merely one component among many. It may be at the scene of the crime but that does not prove it to be the only causative culprit. A variety of outcomes can evolve in each individual case when multiple pathogens, rather than single pathogens are involved in genetically predisposed people.

An excellent example of this is Burkitt's lymphoma; a type of lymphoma that is thought to be caused by the Epstein Barr virus (EBV). In recent years it appears that more than one cause is evident in the endemic form that includes certain genetic profiles, such as the C-myc gene; environmental exposure to malaria; and more. In one African study, Burkitt's lymphoma occurred only when both malaria and EBV were present. Another suggests that C-myc translocation occurs in all cases of Burkitt's lymphoma.

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There are likely many competing as well as symbiotic pathogenic agents that can create havoc within infected host immune processes. In Africa at least one published account states that a secondary malaria infection could reactivate a quiescent relapsing fever brain infection. The authors also stress the importance of co-infection effects … "medical personnel are generally not aware of the existence or RF borreliosis, even though the incidence of that condition in countries such as Senegal is the highest described in Africa for any bacterial disease" (Vial,L.,G. Diatta, A. Tall, et al.,2006.Incidence of tick-borne relapsing fever in west Africa: longitudinal study. Lancet 368:37-43). [PubMed]. As quoted from: *Concomitant Infection Decreases the Malaria Burden but Escalates Relapsing Fever Borreliosis.*(Jenny Lunqvist, Christer Larsson, Maaria Nelson, Mane Andersson, Sven Bergstrom and Cathrine Persson). Infection and Immunity, 2010 May: 78(5): 1924-1930.

A further observation is that "… normal human lymphocytes can produce auto-antibodies as a response to malarial antigens". (Holland-Frei, Cancer Medicine – NCBI Bookshelf, Chapter 22 Parasites, Piero Mustacchi, MD.)

Auto-antibodies are present in autoimmune diseases such as MS, lupus, arthritis and more, and these chronic, inflammatory diseases are among the sequelae of TBRF and LD. It appears logical that in addition to malaria, more than one infectious agent, especially paired with other tick-borne agents, could precipitate lymphocytic auto-antibodies and be a root cause of an endless variety of autoimmune diseases as well as lymphomas and other antigen-driven cancers such as prostate and breast cancers in genetically predisposed people.

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THE FORSCHNER FAMILY - 2010

In February of 2010 the Forschner family, Karen, Tom and their fifteen-year-old daughter visited us at our home in Saddle Brooke, Arizona. It had been several years since I had seen Karen. It was interesting but proved disappointing to hear about the latest Lyme disease news. Nothing much had happened to improve the plight of patients with chronic LD since I served on the foundation's board in 1988. Tests and treatments were even more controversial than they had been in the mid-eighties, a controversy that has pushed researchers to accept the notion that "easy cures" are not available to everyone.

Now there were powerful groups able to exert political pressure on legitimate scientists who were obliged to comply with agendas that did not necessarily have patients' welfare as a top priority. Instead, it appeared that Lyme disease had become a tangled web of questionable science versus honest science; power and greed versus altruistic goals amid the maze of funding and career security. Instead of the cooperative spirit that existed between patients, physicians and scientists early on, the atmosphere had changed to one of ridicule, derision and division. Not much had been accomplished to give patients the help needed. The literature was now full of inaccuracies.

Karen said that she and her family had been harassed by an employee of NIH, a controversial microbiologist, Dr. Ed McSweegan. He had been hired by Dr. Bob Quackenbush who she thought at the time was unaware of Dr. Mc Sweegan's distain for the public advocates of LD. Karen said that Mc Sweegan had sent threatening emails to her via Russia, but the sender had forgotten to delete his name on the original, so his name and his instructions to his accomplice remained on the Email posting. He seemed to be bent on the destruction of the Lyme Disease Foundation. The story of this battle was published in great detail in the national press, and NIH put Dr. McSweegan on two weeks leave. (The Washington Post, Monday April 21, 1997, page A-15.)

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By now, Karen had gone back to college, received her law degree in health law and an advanced doctorate in law degree. She was the recipient of an honorary doctorate degree as well. Tom had taken a new position and the two of them were unable to devote full attention to the foundation they had started in 1988.

Although these two as a young couple, had on behalf of their Lyme disease-stricken son Jamie spearheaded a foundation that served over many years to do more to put Lyme diseaseon the map worldwide than any other single source, they had reasons to move on with their lives. Several other foundations had sprung up over the years affording Lyme patients access to information.

Tom was offered a new career option that he wanted to pursue. And Karen's focus had to be diverted because her mother had recently died and she was required to handle a complicated estate. Moreover, she was personally suffering through a long convalescence following multiple orthopedic surgeries on her badly broken leg and knee. Karen and Tom's remarkable foundation was winding down.

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Karen suggested that we plan a visit to see Dr. Burgdorfer in Montana. We both agreed that there were questions we wanted to ask him in person, especially because we had both heard rumors about Lyme disease being a bio-warfare issue. We already knew that the insurance and pharmaceutical industries as well as other special interest groups who funded studies could influence the direction of research either directly or indirectly. Rumors of monetary payoffs and diverted funds to key officials at CDC and elsewhere were no secret. But, the bio-warfare issue could explain why our public health officials, especially CDC, seemed to be at constant odds with patients' diagnoses and treatments. Their tactics were not to argue the science but to employ belittling ridicule, even slanderous labels and threats to suppress anyone who disagreed with their criteria.

If the government was indeed involved in clandestine activities, the bio-warfare rumors might have some truth to them and it would explain a lot. Karen was intrigued by Dr. Burgdorfer's statement, "I didn't tell you everything" following his interview for the documentary, "Under Our Skin". She wanted to ask him in person about that.

After discussing the progress of Lyme disease (and the lack of progress for TBRF patients) since the late 1980's, Karen and I went ahead with our plans for a trip to see Dr. Burgdorfer. I would meet her and her daughter Christy in Missoula the middle of September, then drive to Dr. Burgdorfer's home near Rocky Mountain Laboratory in Hamilton. "Willy," as we now called him, was delighted to hear that we were planning to visit him.

In addition to our wanting to see Willy after all these years, Karen planned to ask him point blank about the controversial bio-warfare issue surrounding Lyme disease and his "I didn't tell you everything" statement. We both agreed that he would be honest with us. He had never lied to us that either of us ever knew. We decided that our prospective visit would answer some very puzzling questions.

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VISITING DR. BURGDORFER

Karen, (with a brace on her broken leg, aided by crutches and a wheel chair) her 15-year-old daughter, Christy, and I visited Dr. Burgdorfer at his home in Hamilton, MT., in Sept. of 2010. He looked well in spite of his ongoing physical problems that in addition to diabetes included a diagnosis of Parkinson's disease. We talked non-stop throughout the entire day but when Karen finally got to the point of questioning him about Plumb Island and Borrelia, he hesitated... Then, he slowly responded, "You know I worked at Fort Detrick... Sometimes research has accidental releases."

(Karen said later, "After he said that, "Everyone got silent.")

For fear that he might reveal something that was of a top secret nature, I interrupted her further questions of whether Borrelia was a bio-weapon that escaped on purpose or by accident from Plum Island by saying, "Willy, are these things that you are not supposed to talk about?" He became silent again, nodded slightly, and as all of us became silent again, the momentum was lost.

Karen could have killed me, she admitted later. "Now, we will never know if he would have told us everything",,she said resignedly. I felt that I had betrayed her on our mission for the truth, but I realized that Willy could have been in serious trouble if he were to reveal top secret or classified information.

Many mysterious puzzles had cropped up over the years regarding the origins of Lyme disease. Conspiracy speculations began first to circulate among local Lyme, Connecticut, and Long Island, New York, residents; speculations that linked Plum Island scientific experiments with bio-warfare agents and Lyme disease. Given Plum Island's bio-warfare history, and its being in close proximity to both Lyme and Long Island, it did not take long for such rumors to take root and spread distrust throughout patient groups. The rumors were not entirely unfounded.

Patients wanted answers as to why Lyme disease was being suppressed in so many areas of science and medicine. Many thought it was a government bio-warfare issue, others thought it was a... "Follow the money" scenario regarding insurance companies, pharmaceutical companies, universities grant money and, foundations and government institutions that fund studies. Each, of the above mentioned could cooperate for the sake of their own ends. Karen and I wanted to know what we could find out from Dr. Burgdorfer if possible.

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