

PART I

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There are three stages in the history of every medical discovery. When it is first announced, people say that it is not true. Then, a little later, when its truth has been borne in on them, so that it no longer can be denied, they say it is not important. After that, if its importance becomes sufficiently obvious, they say that anyhow it is not new.
-----Sir James Mackenzie, 1853 - 1925

MYSTERY ILLNESS

In 1976, my family purchased a newly built four-level vacation townhome on a mountainside at Lake Tahoe. My brother, Dale, who resided nearby and several local neighbors warned us that newcomers to the area often got sick with fevers within the first year; and rumor had it that two people had even died.

Once these people became ill, many of them remained ill intermittently for many months and some for years. One such person was our next-door neighbor, Ann. Her husband, a physician, was baffled by her illness. Ann had previously been robustly healthy and suddenly his young wife was exhausted, weak, and suffered a variety of symptoms that recurred over time. Three years after repeatedly experiencing intermittent fevers, and neurological symptoms and signs, she was diagnosed as having MS.

It struck me as quite a coincidence that Kirt Boeckstiegle, a carpenter who built our spa room, also had MS. He, too, had experienced the same kind of relapsing/remitting fevers shortly after moving to the Tahoe Keys area. He was a close friend to Ann and her husband and had frequently visited them as well as done carpentry work for them and other neighbors.

My brother Dale explained that local physicians had been unable to diagnose the unusual patterns of illness and for lack of anything better some surmised it could be *bubonic plague* but we didn't hear of anyone who was diagnosed conclusively; besides, the specific rashes and symptoms and signs of plague other than the high fevers were not evident in people with whom we talked so plague didn't seem to fit. Nevertheless we remained on the lookout for fleas that might transmit bubonic plague.

We found a dead chipmunk near our foundation during the time our spa room was being constructed; so, being cautious, we picked it up with a shovel and buried it. Little did we know then how close we were to the

actual source of the fevers, although we suspected at the time that this healthy looking but dead chipmunk might offer a clue to the neighborhood's illness puzzle. We decided to take my brother's concerns seriously, and we were careful to stay away from rodents and dogs that might carry bubonic plague fleas.

During that first early winter of 1976 we took frequent trips from our desert home in Scottsdale, Arizona to our mountain retreat at Tahoe for our sons' school vacation days. Our oldest son Brad became extremely ill about a week after our return to Scottsdale from a ski trip to Tahoe but we didn't suspect that his fevers had anything to do with the ski trip because he was almost immediately diagnosed as having infectious mononucleosis caused by the Epstein Barr virus (EBV) a fairly common illness among teenagers everywhere. We did not know *then* that certain EBV tests can cross-react with tick-borne disease agents' tests and one can be mistakenly diagnosed as the other.

Brad developed double vision problems and had nightmares initially. Later on he suffered hypnagogic hallucinations (a type of hallucination that occurs at certain stages of sleep). Most troubling was his chronic case of testicular inflammation, *epididymitis* that did not respond to antibiotics. He had mood swings and depression that he had never experienced before, along with other personality changes.

During the Christmas holiday season of 1976 I was struck suddenly with high, malaria-like fevers. I was confined to bed, missing out on our usual extended family's Christmas Eve gathering in Scottsdale. I thought I had a very bad flu but failed to relate it to our trip to our Tahoe vacation home the week before. I took some sample tetracycline antibiotics that a pharmaceutical salesman friend had given us and the drug dramatically arrested the fevers.

I later learned that by taking that antibiotic during certain kinds of bacterial-caused high fevers I could have died from what is known as a "Jarisch-Herxheimer" (JH) reaction, a dangerous type of shock. Fortunately, my fevers resolved without any ill effects from the drug and I quickly recovered.

Within a week I noticed on my chest an unusual, dime-sized, oval shaped skin lesion that didn't heal. After two months, I had a biopsy performed on the lesion. That evening when the Novocain wore off from my shaved biopsy, the remaining lesion became extremely painful. The pain radiated to my underarm in an area where I could feel swollen lymph nodes. Every major joint in my body became excruciatingly painful. I had never had anything like it in my entire life.

My husband Dick rushed out to purchase four hot water bottles and two heating pads. We placed them as hot as my skin could stand, on my elbows, knees, and wrists throughout the night. The hotter the water bottles the better it helped to ease the pain. I finally fell into an exhausted sleep. By morning all the pains were completely gone.

My dermatologist called later in the day to say that our local Arizona lab was unable to determine what the lesion was, so the tissue was being sent on to a world expert dermatopathologist, A. B. Ackerman, MD., in Pennsylvania.

When the biopsy report finally came back, it was diagnosed as a probable cutaneous T-cell lymphoma (CTCL). (In those days this category of CTCL had been misnamed as "mycosis fungoides lymphoma" because the skin lesions resemble fungus infections)

Alarmed by possibly facing an incurable disease, I sought a second opinion from a California lymphoma expert, Peter Sacks, an MD who was a hematologist/oncologist at Scripps Clinic in La Jolla. After performing some tests, and much to my relief, he changed the probable lymphoma diagnosis to "pseudo-lymphoma," which in plain language means that it looks like lymphoma under the microscope but it isn't. By this time, the lesion was almost healed. I have since wondered if the antibiotics that I took after Christmas that year had anything to do with its healing and this welcome change in the diagnosis.

In the following months I felt exhausted at times and my pulse was extremely slow. At other times, unexpectedly my pulse became irregular and rapid. We didn't know at the time that our "Tahoe disease" had anything to do with that either and blamed it on change of life hormones.

MY HUSBAND'S FEVERS

In 1982, my husband Dick and I traveled from Tahoe to Minnesota to Texas. While in Texas, Dick became severely ill with extremely high fevers. He had drenching malaria-like sweats between bouts of fevers that waxed and waned over a period of five days. He refused to go to a hospital and insisted on flying home to Scottsdale. We arrived home on the fifth night of his illness.

Dick still refused to go to a hospital and he collapsed in bed, exhausted from the trip home. I kept checking him by placing the fever thermometer strips on his forehead. His temperature began to rise rapidly again and reached 105.5 degrees, at which time he awoke in a foggy, delirious state of confusion. His face was ashen grey with a yellow tinge. I feared he was dying and literally dragged him from the bed to our car rushing him to the hospital in a severely weakened condition.

The emergency room physician at our local Scottsdale hospital first suspected pneumonia or lung cancer after viewing admitting X-rays. Then several different possibilities were discussed in an effort to make sense of the results of blood tests and X-rays that were performed during the long night spent in the emergency room.

Dick was finally admitted by early morning with a diagnosis of *acute leukemia*. Our family physician later told us that, had he died that night, leukemia would have been listed as cause of death on his death certificate. Bone marrow studies later proved this diagnosis incorrect, but we did not know what had caused his devastating illness. His fevers abated. He was still weak but otherwise felt reasonably well.

A parade of specialists visited his bedside, probing, prodding and testing samples of bone marrow, blood and body fluids along with a series of kidney and gastrointestinal tests. Each specialist in turn suggested a diagnosis within his or her own field of expertise, and it seemed to be true that his illness had affected numerous organ systems.

Each specialized diagnosis was eventually discarded and no one could offer proof of anything. Dick was discharged from the hospital within a few days, exhausted from the illness and countless tests. The final diagnosis was "fever of unknown origin," (FUO).

One week later the fevers returned and he was readmitted. This time we were lucky to have a doctor on call that was fairly well trained in infectious disease. I brought up the possibility that my husband might have been exposed to something in our Tahoe vacation neighborhood.

The physician asked if we had mice in the area and suggested a number of infectious disease possibilities, including bubonic plague. Food poisoning was also possible because he had eaten clams the night he became ill and clams have their own set of infectious agents that can cause severe illness.

The doctor noted our travel history and I recalled my husband noticing a bruise-like bug bite and suggested it might have been a tick bite. Maybe "Rocky Mountain spotted fever" I conjectured? The ER physician said that we should tell our family physician about that possibility.

Our family physician, Dr. Harold Deal thought I might be on the right track and called in an infectious disease specialist to investigate my tick-bite idea. Meanwhile, I feared that Dick would become as sick as he was during his first bout of fevers, although this time he clearly wasn't as ill. Yet, we remained in limbo without a diagnosis, so I gathered up all available medical reports and headed to our public library.

The librarian handed over a stack of medical books that were kept behind the reference desk. Among these was a dilapidated tome of "Principles and Practices of Internal Medicine," a book I randomly opened first. Extraordinarily, the first page I opened was entitled – Borrelia-- and it caught my eye enough to read a little about it. It was also called "relapsing fever" and could be transmitted by ticks.

The second emergency room physician had mentioned that lice could cause relapsing fevers, but we knew my husband didn't have lice. He had not mentioned, however, that ticks could cause relapsing fevers.

I decided to keep that "Borrelia" name in mind but was in a hurry to find Rocky Mountain spotted fever (RMSF) my primary suspect. RMSF symptoms were similar to my husband's, but he had not had the rashes on his extremities like those described in the book. I read on through; tick fever, Salmonella, Q fever, typhus, typhoid fever, and others that seemed plausible. One of Dick's tests had shown slightly elevated antibodies to "typhoid A" but nothing I was reading completely matched his profile although he had some symptoms in common with all of the above.

After two hours of study I turned back to Borrelia. This time I read it carefully as I gradually realized that this disease description matched my

husband's symptoms, clinical course, as well as his many test results. The relapse pattern also fit his case precisely. Most importantly, the tick that transmitted this disease was called, *Ornithodoros hermsi* (O hermsi) a chipmunk tick!

I recalled that the week before my husband first got sick, we sat viewing Lake Tahoe at sunset on a big granite rock where we often sat, and where we fed nuts to a very tame chipmunk as it scampered playfully all around us. We called the rock, "Chipmunk rock." Now I suddenly remembered the dead chipmunk we found at the base of our spa room. That chipmunk could have had *Borrelia*! "That's it," I thought, chipmunk ticks. I remembered further that our next door neighbor, Ann, had tamed two wild chipmunks after moving into the neighborhood. They habitually crawled all over her, waking her almost every morning, having entered an opened window off the porch roof. It finally made sense.

I was sure of it. My husband has *Borrelia*! I ran to the nearest telephone and excitedly called him at the hospital.

By this time, the infectious disease expert that our family doctor had consulted about Dick having had a possible tick bite had just finished his examination and decided that Dick had "a classic case of Colorado tick fever." (CTF)

I strongly disagreed. I had already eliminated that from my list of possibilities during my library research because it did not fit the total picture as *Borrelia* did. However, after much discussion, I was overruled when my husband sided with the physician's diagnosis.

A few days later I was berated by both of them with my husband's reminder of "he's the doctor" and the doctor's condescending "a little knowledge is a dangerous thing."

Because CTF is a viral rather than bacterial disease, no treatment was given to Dick. Very much against my wishes, he was soon pronounced well enough to return to his job as a commercial airline pilot. I disagreed and feared that, if the doctor was wrong and I was right, Dick would likely suffer more flu-like relapses of further damaging infection unless he was given appropriate antibiotic therapy.

He began to feel feverish again on the last leg of his first flight back at work. He called me from the Phoenix airport after he landed and complained that, in addition to feeling very feverish again, he was having

difficulty with vision in one eye.

I called the specialist physician's office immediately but the receptionist said he was too busy to talk to me. He eventually came to the phone when I persisted. He let me know in no uncertain terms that I was interrupting his busy schedule. I pleaded with him to give us a prescription for some antibiotics, because I was now convinced that Dick had *Borrelia* and he could be at risk for permanent eye and organ damage without this treatment. He became increasingly irate and informed me that body lice cause *Borrelia*, not ticks!

"Does your husband have body lice?" he asked, sarcastically.

"No," I said desperately. "*Borrelia* can be from ticks."

"What kind of ticks are you talking about, girl," he demanded, impatiently. (Lyme disease *borrelia* was as yet unknown to physicians and TBRF was not known by most, even by infectious disease specialists).

I stumbled phonetically through the genus name of the chipmunk ticks... "*Orn-ith-o-do-ros berm-si*."

"I read it in a book at the library, and it transmits *Borrelia hermsii* (*B. hermsii*) infection which is treated with tetracycline." I quickly added, "We can't wait any longer, we must have antibiotics!"

"Your husband has CTF, and as soon as his blood test for that comes back, I'll prove it to you! It's a virus and I will not give him antibiotics."

I nonetheless continued to press my point of needing the antibiotic and he continued to refuse until he finally said in an exasperated tone, "I suggest you get yourself another doctor", and he hung up the phone abruptly. I was devastated but we later decided that that was the best advice he gave us.

Many of our concerned friends offered valuable advice. One friend was a rancher in Blythe, California, who knew of a well-respected *Borrelia* expert in Irvine, California. I quickly telephoned the infectious disease specialist, Dr. Thomas Cesario, at his office at the University of California, Irvine (UCI). I was grateful that he personally came to the phone immediately. I rapidly blurted out Dick's illness history. Before I had the chance to mention *Borrelia* to him, he said, "I think your husband has a disease you have never heard of. It's called *Borrelia*."

"That's what I have been suspecting, because I read about it at the library. But what can we do? My husband is on his way home from the

airport, and he is running another fever, his head aches and he is having trouble seeing out of one eye!"

"Good, if he's running another fever right now you must get some blood smears immediately, and then you will have positive proof of the infection if *Borrelia* can be demonstrated on the smears."

He cautioned, "If his fever breaks it will be too late to prove anything, because the bacteria are only present in the blood during the fever."

"Okay," I said, "Dick is on his way home, so I'll give you the number of our hospital's blood lab and you can order the tests while I meet Dick in our driveway and rush him to the hospital before his fever breaks."

"Wait a minute," he said, "I can't order these tests, because I am out of state, so your local physician will have to do it for you."

"But I can't call him. He just hung up on me and told me to get another doctor. That's why I called you!"

"I wish I could help, but I just can't as an out of state doctor, so try to get those tests any way you can before his fever breaks! I didn't feel confident about being able to do it. I sat in stunned silence wondering what to do next just as Dick came through the bedroom door and, without even saying hello he collapsed in a heap on our bed. He was exhausted, weak and feverish."

I pleaded, "Come on, don't go to sleep, we have to go to the hospital immediately to get some more blood tests."

"Forget it," he said, sluggishly, "I'm not going back to that damned hospital, I've already had two admissions there and all I got was torturous tests and no answers!" He ignored my pleas and then fell into a fitful sleep.

My mind was racing. We needed someone to help us get the tests ordered at a different hospital or I knew for sure that Dick would not cooperate. I left him alone so he could get a few minutes of some much-needed sleep while I contacted a local physician, Dr. Jeffery Schwimmer, who was filling in for our regular family doctor. I briefed him on our dilemma and asked for his help. He was upset upon hearing that Dick's doctor had hung up on me.

I told him the urgency of obtaining the *Borrelia* tests before Dick's fever broke but that Dick refused to go back to the hospital. Dr. Schwimmer, who happened to be Johns Hopkins-trained in infectious disease, arranged for a friend of his, Dr. Jerome Targovnik, who was on the board of another hospital to order the tests. His friend said he was glad to help and that the blood test orders would be waiting for us at the

front desk of the new hospital. Dr. Schwimmer quickly arranged for a prescription of tetracycline antibiotics to be delivered to our house because he was by now convinced that Dick indeed had *Borrelia*.

The phone rang as soon as we finished our conversation. It was the pathology doctor, Dr. Sid Guber, calling from the first hospital's laboratory. It appeared that Dick's doctor had torn himself away from his busy schedule after he hung up on me and headed straight to the hospital's lab to check on the Colorado tick fever test results in person.

Dr. Guber nervously asked if I would please bring Dick in for more blood work because they had lost his other samples and it was extremely important to him to obtain more blood. He said that Dick's doctor had just left his lab after leaving his office during a busy day to check on the CTF tests. Once he learned that the test had not yet been done, he furiously lit into the pathologist, creating quite a scene at the lab about the mistake. Dick's doctor demanded that the pathologist call us for "more blood."

I said, "Dick refuses to go back to your hospital, and since his doctor hung up on me an hour ago, we consider him off the case!" But after he continued to plead, almost pathetically, apparently blaming himself I said we would request another CTF test at the new hospital where we were headed even though I was sure he did not have that. Before we left our house, I made another quick call to my doctor friend and asked for the additional test.

I then coaxed Dick from the bed to the car with the promise that he would only have to get blood drawn and then he could come home and finally begin taking the antibiotics. I quickly drove him to the emergency room.

In the blood laboratory Dick slumped, exhausted and weak, into a chair, leaning back against the wall in a stuporous and still feverish state. I gave the lab nurse the orders for the *Borrelia* and Colorado tick fever tests that we had picked up at the front desk.

She studied the paper and with a puzzled look she walked over and consulted her supervisor, who also gave the orders a quizzical look. Finally the supervisor said, "This must be a mistake in handwriting, it

must be for 'malaria' and 'Rocky Mountain spotted fever'."

Alarmed, I interrupted. "No, there's no mistake! It's for Borrelia and Colorado tick fever!" The supervisor reached for a voluminous textbook on her desk. She opened it and with raised eyebrows shook her head, and again said, "This has to be a mistake, so I'm going to call your doctor to see if this is really what he ordered."

"No," I pleaded, "there isn't time! We must get the blood drawn before my husband's fever breaks; and besides, we don't even know the doctor who put in the order. He did so at my request via another doctor who is a friend of ours but not on the board here."

She eyed me suspiciously but slowly placed the phone back down in its cradle. "Just who is your 'doctor friend' and why is he doing this?"

I related the story to them both as quickly as I could, one eye on Dick who was now sleeping and still very obviously running a fever.

"I'll check this out first before we can proceed," she said in a professional tone. "I'll put in a call for the doctor on our staff for confirmation of your story." She did so and found out he was gone "for the week."

Again, I pleaded with her, saying, "Please, hurry and draw the blood before his fever breaks. We don't need tests for anything but Borrelia right now, but if you still think that this written order is a mistake, I'll pay for all four tests, anything! Just do what you want, but please do it now! The Borrelia test has to be done now!"

She seemed to consider this, and I thought she would accommodate my request, but she was the one who was ultimately responsible for any mistakes made in this laboratory so it was understandably a difficult situation for her as well as for us. However, at that crisis moment I was in no mood to be understanding about her cautious position for this.

"Why don't you get your doctor friend on the phone and let me talk to him," she offered. I frantically fumbled in my purse for his home phone number, all the while watching Dick for signs that his fever would break before the blood was drawn. This delay was an agonizing eternity.

The doctor confirmed my story and urged her to quickly draw blood for the Borrelia tests. She did so, promptly after hanging up the phone. Dick sat stoically through the procedure while she drew more blood for "all four" diseases... just in case there was a mistake.

Keep in mind that this was 1982. At that time Borrelia and CTF were unfamiliar to medical professionals, whereas malaria and RMSF were well known. It was understandable for her to think the Borrelia order was a mistake. She had never heard of it before.

After the blood was finally drawn and being distributed on slides and in tubes, my hyper-emotions calmed and she gradually became interested in our plight and sympathetic to our needs as we talked.

As she finished her labeling of the samples, we both glanced over at Dick, who had fallen asleep. He was suddenly drenched in sweat, his fever broken! We had beaten the clock by mere seconds, drawing the blood just before the Borrelia organisms could disappear completely from the blood and hide undetected in the tissues which they are known to do once the fever breaks.

As soon as we arrived home, Dick began his first double dose of the antibiotics that had been delivered for us. He went to bed and slept most of the day. It was a good thing that by this time his fever had broken because the California doctor told us that it can be dangerous to administer antibiotics to Borrelia-infected patients during high fevers because of the potential for the Jarisch-Herxheimer (JH) shock-like reaction which can shoot fever levels even higher and then cause low blood pressure.

I watched him carefully and took his blood pressure frequently to be sure he was okay. The doctor had also warned that if his blood pressure dropped "suddenly", it could herald the start of a JH reaction, so if it got below 80/50, "Call the paramedics!" Fortunately it didn't.

I called the California physician again and told him that the blood had been drawn.

"That is terrific," he said. "Bring it with you and drop it off at our lab when you arrive tomorrow night so we can read the slides before your appointment in the morning."

"I can't do that," I said. "The ER nurse said they have to send it out to their own labs."

He said, "Those slides are very difficult to read unless you are an expert and know what to look for. Try to stop them before they are sent to the lab... I really need the 'thick and thin smears'.... There must be some way you can get them."

"Now what can we do?" I wailed in despair at my mother who had just stopped by to see how Dick was feeling. "That doctor, who we don't even know, who ordered the tests, is out of town for the week!"

"Why not call the lab on his behalf?" my mother suggested.

When I reached the lab the shift had changed and a man's voice answered.

Hoping to sound official, I said, "I'm calling for Dr. Targovnik, and I understand that you have some blood work that was drawn today for Richard Bennett?"

"Just a minute I'll check the fridge." My heart was in my throat as I waited.

"Yeah, part of it is here. It looks like some of it has been picked up and sent to Northampton labs."

"Oh, no!" I said with what I hoped was the proper indignation for such a grievous error. "That blood was supposed to be hand-carried by the patient to his UC Irvine appointment in California on Monday."

"Oh, Oh..." he sighed sheepishly.

"Can you tell me what was sent, and what's left?"

"Sure just a minute... Rocky Mountain spotted fever and Colorado tick fever were both sent out, but we still have the *Borrelia* and malaria here."

"Good," I said, hoping my relief wasn't too obvious.

"Do me a favor, please, so there is no more room for mistakes, and put a large note on the samples with an order to release them *only* to Bonnie Bennett to hand carry to the UC Irvine hospital in California." I made sure he did so before hanging up.

My mother spent the night with us, and provided much needed moral support by driving us to the airport after we made a quick stop at the hospital lab to pick up the blood samples.

As I entered the lab reception desk area and plopped my small ice chest down on the window ledge near the receptionist, I was grateful that the desk attendant was someone I had not seen before.

"Hi, I'm Bonnie Bennett, and I understand that you have some blood work for me to pick up here?"

"I'll check," she said cheerfully, disappearing for a few moments. She returned, still reading "the note", then tore it off and deftly placed the precious cargo in my opened ice chest. "There you go Bonnie, have a nice day!"

Finally, after all these weeks, I felt a momentary sense of guarded relief, because after we picked up the blood work we went directly to the airport, and I was fairly certain that we would get our answers at our appointment in California the next morning. It was our last hope. We had run out of any other options.

Dick was weak and exhausted. He had relapsed two times in the past two months, had been shuffled through a parade of 11 consulting physicians during two hospital stays and three emergency room visits,

and in each instance he received incorrect diagnoses, suffered exhausting and painful diagnostic tests costing thousands of dollars, and was still so weak he could hardly walk. Worse yet we still didn't know anything for sure except that one thing had helped him dramatically, the antibiotic he was finally given the day before had arrested his fever. But by now, he looked 10 years older in only two months' time, and so did I.

At our appointment Dr. Cesario greeted us smiling broadly. "I microscopically viewed those blood slides that you dropped off last night, and saw nothing." My heart skipped a beat and Dick shifted uncomfortably in his chair.

"But," he continued, "I decided to take another good look this morning and spotted-- no mistaking it-- the faintly stained, coiled strands of five beautiful *Borrelia hermsii* spirochetes!" Dick had tick-borne relapsing fever (TBRF) no doubt about it now. It is *rarely* diagnosed! The doctor cautioned Dick not to return to flying for at least eight weeks, to stay on his antibiotics and to get lots of rest.

The following week we got a call from Dr. Jerome Targovnik, the physician who had ordered the blood work for us. He introduced himself and asked, "What happened to the blood-work I ordered at Dr Schwimmer's request for your husband?"

I explained the whole story, including the part about my impersonating his office staff in order to get possession of the *Borrelia* blood smears for the California specialist to view. I was a little nervous that he would be angry with that but he just laughed good-naturedly and said he was glad to have been of help and was proud of me for proving my case. He said, in an amused tone, that the Colorado tick fever and Rocky Mountain spotted fever tests proved negative but the hospital personnel were "still looking for the rest of those blood slides!"

Dr. Targovnik soon recognized and treated one of his patients who he discovered had *Borrelia*.

The next week we got a call from Dr. Guber, the laboratory doctor at the first hospital who had "lost" Dick's CTF blood work. He said, "Mrs. Bennett, we finally found your husband's blood samples and the results are back from his Colorado tick fever test!"

Before he had a chance to tell me I said, "And let me guess. It was completely negative!"

"How did you know?" he asked with astonishment.

COUSINS

Two months later in December of 1982, our cousin and her Yale University trained physician fiancé, John, visited us at Tahoe. We had a wonderful time eating out at area restaurants, many of which feature outdoor deck tables. I noticed how the local chipmunks loved being fed by patrons and watched them scamper eagerly across the snow toward anyone who fed them table scraps. We had always thought this was so cute, but now knowing what we did about Dick's illness we decided that our contact with them needed to be handled with care. Maybe if we didn't share our food, they wouldn't come so close and share their diseases.

John, as a physician, was fascinated with the details of Dick's clinical pattern of disease and eventual diagnosis. We talked about it at length, including that I was a little concerned that Dick had been getting some unusual symptoms many weeks after his assumed cure. He complained of exhaustion, slept too much, had headaches, felt numbness and tingling in his legs, had difficulty with vision in one eye, was often losing his balance, and more. I said that our family doctor had joked with us that he had a hard time getting Dick's knee reflexes to react properly to his little hammer taps and that, lately, Dick seemed to get very teary-eyed and even choke up over corny old movies on TV. His personality had changed and he slept a lot. He was depressed, not his usual self. John agreed with our family physician, "It takes time to recover from such an illness."

John and Barbara came for another visit a month later to celebrate their honeymoon. Then they continued their trip on to Mexico. John became ill with fevers within a week of departing Tahoe. While vacationing in Mexico John became so ill with fevers he became delirious. Not suspecting *Borrelia*, and forgetting everything we had

warned him about, he decided to treat himself with a broad-spectrum antibiotic which he kept on hand in his physician's bag.

He had not only forgotten our warnings of tick-borne relapsing fever *Borrelia* occurring within a week or two of visiting Tahoe, but also our warnings about antibiotics that can cause "Jarisch-Herxheimer" reactions if administered during high fevers of 103 degrees and above. JH reactions can cause fevers to escalate upwards and blood pressure can drop to shock levels.

He did indeed collapse in shock shortly after he gave himself the antibiotics. His frantic new bride had to transport him during the night to a hospital in San Diego, California, necessitating the border guards to open the border after midnight. He was rushed to a San Diego hospital where he lay in extremely critical condition.

Barbara was allowed a cot in his room so she could remain at his side. During his hospitalization neither he nor his doctors suspected tick-borne relapsing fever. Although he was a highly intelligent physician, he had failed to relate Dick's identical illness with his own, even though it had only been a month since he had heard Dick's story in great detail.

He was discharged a few days later as having a viral disease, but like Dick, he relapsed with drenching sweats and high fevers a week later. His pajamas and bedding required changing from the malaria-like, drenching sweats.

When his wife brought the possibility of *Borrelia* to the attention of John's physician, he was retrospectively diagnosed as having TBRF.

The physician upon hearing about *Borrelia* immediately said, "Of course that is what you had, it was a classic case I should have recognized!" His convalescent serology test was positive for *B. hermsii*.

John's personality changes were alarming following his recovery from the fevers. He exhibited severe, bizarre and erratic psychiatric behavioral problems in the following year, including sexual deviance, psychosis, and pyromania. Their brief marriage soon ended in divorce.

Because his illness occurred in December, we wondered if we had brought ticks into the house on firewood or possibly on the Christmas tree.

ANN

In late 1982 I began trying to locate our previous next-door Tahoe neighbors, a physician and his wife Ann, who had moved out of state. Upon finally reaching them I told them about Dick and our cousin getting the fevers.

I said I was concerned because I had heard that Ann had been sick with unexplained fevers before leaving Tahoe. I thought that she might have contracted Borrelia directly from the two chipmunks she had tamed as pets when they lived in our neighborhood, especially because she handled them on a regular basis and let them crawl on her arms, in her hair and all over her body.

"No, Bonnie," said Ann. "I finally did get diagnosed. Unfortunately, I have MS."

My brother and other neighbors had already told me that Ann had MS. I said, "Dick has been having MS symptoms, too. I think you both may have complications from Borrelia." I added, "I think it is possible that Borrelia is the cause of these symptoms of MS". I reminded her that our mutual friend, the carpenter who had worked in our neighborhood, also had MS. He, too, was sick with fevers previous to his diagnosis. Ann admitted that was quite a coincidence.

Then she recalled something and said, "You could be right, now that I think of it. My husband worked for a short while as an emergency room physician in Tonopah (Nevada) where he saw several workers from the mines coming into the emergency room night after night running high fevers. The doctors there could not figure it out until one night one of them showed up with a tick on his back".

"This makes sense to me as connected to my MS because I have regularly noticed that every time I take antibiotics my MS seems to go into remission."

MEGAN SEES A TICK

In August of 1983, a young bride, Megan Methvin became ill shortly after arriving in Phoenix, Arizona, just one week following her honeymoon at Lake Tahoe. She experienced a series of relapsing, extremely high fevers, drenching sweats and shaking chills that had been

diagnosed as a virus. Her grandfather, a friend of our family, called me because Megan thought she might have Borrelia. She was very familiar with Dick's history of TBRF. Besides, she recalled having seen an "ugly" bug that looked like a potato bug with eight legs that she found in her bed while honeymooning at Tahoe. She squashed it and noted it was filled with blood. She flushed it down the toilet. Megan is one of few people who have ever seen this type of reclusive, soft-bodied tick.

Megan's grandfather continued, "We're having a little problem convincing Megan's doctor that she might have Borrelia. Would you mind going with us to her appointment?"

It was 110° in the parking lot when we arrived at St. Joseph's hospital clinic. Despite the stifling August heat, Megan was so cold she had wrapped herself in a large, down quilt but she was still shaking uncontrollably with chills.

Her fever was, like Dick's and our doctor cousin John's, extremely high. I escorted her to the examining room. As soon as I requested that she be tested for Borrelia, her doctor asked me to leave.

As I sat nervously in the waiting room, I spotted Megan dejectedly walking down the hall accompanied by the physician. She tearfully told me that the Dr. had handed her a prescription for honeymoon cystitis.

Before the doctor could reach the end of the hall, I caught up with him. "Excuse me," I said, "are you treating her for Borrelia?"

"Of course not," he smiled, "She has a virus and maybe a little honeymoon cystitis!"

I knew with that response that he had not taken my request seriously about testing her for Borrelia. I also knew that this was my only chance to have Megan's blood drawn at the perfect time to demonstrate borreliae (plural form of Borrelia) on blood slides. The reason being that she still had a fever! I had to hurry, to convince him quickly, before her fever broke.

With no time for polite discussion, I rudely began blurting out every medical term I could remember from the medical book at the library, such as, "thrombocytopenia, leukopenia and a rebound leukocytosis." Somewhat taken aback, he stood wide-eyed and motionless. He looked as if he was trying to distance himself from my onslaught as best he could, but I thought he seemed to finally be paying attention to what I was telling him.

I insisted that he test her for Borrelia and assured him that he would find Borrelia in the blood from "one drop" if the blood was drawn immediately while she was still running a high fever. I told him to stain her blood smears with acradine orange or Giemsa stain and be sure to have

everyone at the lab, including him, look for the *Borrelia* spirochetes until they spotted them, because they are difficult to spot by the untrained eye.

"You'll find hematuria (the presence of blood in her urine) and, if you give her antibiotics while she's running this high fever it could cause it to rise even higher, from a possible Jerisch-Herxheimer reaction that could kill her if her blood pressure drops to shock levels."

Looking a little askance at me, he said, "Tell Megan to come back to the examination room, please." He was obviously trying to assimilate all that I had just explained to him.

An hour later, Megan was resting in her sick bed when the phone rang. It was Megan's doctor telling Megan's grandfather that he had found everything I had described in the blood, urine, and stained slide smears, "including the *Borrelia*!" He then good-naturedly asked what medical school I had attended.

Megan enjoyed a quick recovery without any major problems except for feeling weak during her antibiotic treatment. Much later we tried to obtain her blood slides at the request of another doctor but by then her "*Borrelia*" doctor had transferred to the Nalle Clinic in North Carolina and his receptionist could not find the slide that we requested. (Interestingly enough, in later years, two other *Borrelia* experts I knew about, one from Denver and another from Lake Tahoe, were also transferred to the Nalle Clinic.)

I cautioned Megan that although the medical books I had read didn't say so, I thought that *Borrelia* spirochetes, like syphilis spirochetes, might possibly be transmitted through body fluids during the initial febrile infections. I suggested that to be on the safe side she should refrain from intimate relations with her new husband, at least until she finished the antibiotics. Megan's cheeks flushed, "Too late, Bonnie, we're honeymooners you know!"

The incubation period had been exactly seven days for my husband, our cousin, and now Megan. The medical books listed anywhere from three to eighteen days. Surely it was too late for her husband to get it now.

Just in case, I wrote a lengthy description of the symptoms, tests and treatment for them to carry with him in his wallet as they traveled to his military base in Georgia.

When they arrived in Georgia, Megan's husband was ill. He immediately went to the infirmary with a high fever and malaria-like sweats. The lab technician found blood in his urine (*hematuria*) a hallmark sign of borreliosis that I had described in the letter so he gave my *Borrelia* letter to his physician. The doctor treated him with tetracycline immediately and he quickly recovered although at his next appointment he had an abnormal cardiogram.

I suspected that this incident could be an example of sexual transmission of *borreliae* during fevers. Years later I was convinced by other couples that this certainly can be the case. Several Phoenix support group members reported relapsing fevers related to sexual contact.

UNIVERSITY OF NEVADA AT RENO

Dick and I decided that we had better learn all that we could about *Borrelia*, so during our next trip to Tahoe we consulted an expert entomologist (insect specialist) at the University of Nevada at Reno.

Dr. Harry Smith showed us around his department and explained in depth why he thought that TBRF was "epidemic" in the Tahoe/Reno area. He explained how difficult it is to get physicians to consider a disease that they think of as being "rare".

"Actually, most physicians have never even heard of *B. hermsii*." And, "Almost no one ever actually sees this soft-bodied tick because they are very reclusive, feed at night and drop off their victims without being detected. So when victims of bites experience malaria-like fevers and drenching sweats a week later, their doctors are unaware of any tick-bite history and usually dismiss it as a virus or some sort of encephalitis."

Dr. Smith had many years earlier recognized the disease in his own son, but he said he had an extremely difficult time getting his son's physician to consider it. Once he convinced him of the possibility Dr. Smith had to explain how to test for it because the physician didn't know. The tests were positive for *Borrelia*.

Dr. Smith tried to do his part in educating and alerting the public and physicians by giving talks to various groups and appearing on local news

media shows. He stated that eighty-five to ninety percent of all human disease is incited by "bug bites" as vectors of infectious and toxic agents between animals to humans.

He believed *Borrelia* to be quite common but very rarely recognized, so it was usually diagnosed as something else. We were shocked to learn that in spite of his efforts, local physicians identified an epidemic outbreak of what he knew to be *Borrelia* as caused by recluse spider bites, even though he emphasized that: "There are many species of ticks but *no* recluse spiders in this area of Nevada."

He gave me a little box containing nine dead *Coreaceus* ticks explaining that these soft-bodied ticks closely resemble *Borrelia hermsi* soft ticks, so I could compare them in the unlikely event that I found any of these very reclusive ticks in our neighborhood. He said that these particular *Ornithodoros coriaceus* soft bodied ticks (AKA *Pajaroella*) had been collected after they had bitten a group of phone line workers up on the mountain who developed "tick-paralysis". We learned that tick paralysis is caused by toxins, which several species of ticks can transmit. Dr. Smith said that *Coriaceus* ticks also "could" transmit *Borrelia*.

He told us a great deal about exterminating techniques for the ticks as well as trying to control, and protect ourselves from their host animals such as mice, squirrels and chipmunks that might be in our woodpile, cellar etc. He didn't think it would do much good though because, "All you need is one chipmunk or squirrel to run across your porch again." He cautioned us not to sit out on our decks at night because the ticks were usually night feeders that could detect victims from 50 feet away, crawl up on the deck, feed and drop off in 10 or 15 minutes.

Dr. Smith said that this kind of tick is rarely seen by victims because of its painless bites and speedy feeding. He explained that, unlike the "hard-bodied dog, bear, or deer ticks known to transmit other diseases, this genus of soft-bodied tick is associated with chipmunks, mice, squirrels and other small animals and rodents."

1982-1983

All through the winter of 1982 and 1983, I studied details about *Borrelia*. Dick was exhibiting chronic symptoms of fatigue and paresthesias as well as a variety of other symptoms common to MS. I by now realized that my husband wasn't the only one in our Lake Tahoe

neighborhood to suffer from a variety of the infection's lingering complications. Several people had developed all sorts of autoimmune-type disease complications, including MS as well as such things as epilepsy, dementia, and certain cancers. I wondered if these later events were related to the Tahoe mystery fevers that I now knew were tick-borne infections.

I believed that tick-bite infections, especially *Borrelia* infections, were actually the cause of what had been thought to be a "virus" disease that we were warned about before we moved into our Tahoe vacation town home. But *Borrelia* is not a virus. It is a bacterial disease, meaning that people can be treated with antibiotics if it is diagnosed.

The rumors of bubonic plague were plausible because fleas usually transmit the microbial agent of plague, *Yersinia pestis*. I wondered if ticks could transmit *Y. pestis* as well, or if those who were ill were exposed to both ticks and fleas and could have both infections. It was certainly possible. Both plague and TBRF are, unlike a virus, treatable with antibiotics. Ticks could also transmit *Rickettsia* as well as many viruses and other microbes so the possibilities were endless. However, I focused primarily on *Borrelia* at the time. That was the only infection we had been able to identify on blood smears in my husband's case.

It was puzzling as to why local physicians had not discovered any of this, and more puzzling as to why Dr. Harry Smith's *Borrelia* talks around the Reno area were not enough to sound an alarm. He was an esteemed professor of entomology at the University and if he was unable to convince local physicians that there was a problem, then who could?

In addition to Dr. Smith, I continued to get in touch with physicians, veterinarians, and local, county, state and national level health authorities. No one did anything to help beyond listening sympathetically. After a token nod I was always referred on to someone else, who again offered nothing more other than advice about how to get our building professionally exterminated. But, even after we did that, we remained concerned because, as Dr. Smith had warned, "All you need is to have another chipmunk carrying ticks run across your deck."

LIBRARY RESEARCH

After calling several local public health agencies, in Nevada and Arizona without having any luck of getting any substantive information, it became clear that if anything at all was to be learned from our

devastating experience that nearly killed my husband and affected so many others, I had no option but to seek more information and inform myself about it.

I needed to know what was causing our family and others so many lingering symptoms and what could be done to heal them. Our family physician, Dr. Harold Deal, and I were both worried that Dick might have early MS. Dr. Deal encouraged me to look into the later complications of Borrelia to see if there was any long-term neurological damage described in the medical literature.

I was determined to research Borrelia but in the early 1980's there was no Internet research available to me. So, once we returned from Tahoe to our primary home in Scottsdale, Arizona I began to seek information from libraries and old medical books that I found at auctions and garage sales. It didn't take long to cover the tick-borne relapsing fever Borrelia information in medical books at Phoenix's public library since there was very little written about it.

After little luck at the library science desk, the librarian suggested that I go to a medical library for more information, especially if I wanted to pursue the idea that Borrelia could cause serious problems like MS.

The next week, armed with my notebook and pens, I ventured into the intimidating world of medical literature at the Phoenix Veteran's Hospital library to see what I could find. Before Dick's illness I had not been in a library since finishing high school, twenty-six years prior.

I was unsure that I could remember the Dewey decimal system or how to use the card catalog. Yes, card catalogues were still in use in the early 1980s. And any computer assistance was way out of my league in those days. I wandered around the stacks trying to decide how to approach my research and what to look at first.

I tried to appear aloof and focused because the librarian kept glancing in my direction and I did not want her to think I didn't know what I was doing. It was a lot easier at the public library where all the medical books were behind the science desk. All that was required was to ask the attendant for a stack of them. Now I was faced with rows and rows of medical and technical journals. I decided to stroll through the aisles and see what I could find at random on the shelves.

There was not much more about tick-borne Borrelia in the books I examined than what I'd seen already, so I moved on to researching

bacteria. I had so far learned that Borrelia bacteria were from a large family of bacteria generally referred to as "spirochetes" (order, *Spirochaetales*, genus, *Spirochaeta*). Various types of these closely related spiral shaped spirochetes could cause many different diseases such as yaws, pinta, trench mouth, relapsing fever (tick and louse-borne RF) and syphilis. Spirochetes were older than Methuselah, and some were among the first anaerobic (growing without oxygen) bacteria on earth. But the only spirochetes that seemed to get significant research attention over the last century were those that caused syphilis, *Treponema pallidum*, and the louse-borne relapsing fever spirochete, *Treponema recurrentis*. The latter received attention during wars because of its association with war fevers that were epidemic.

Unfortunately, tick-borne Borrelia received only token descriptions. Worse yet, there was not much literature available about post-Borrelia infection causing many complications. In fact, there was virtually nothing about any long term or chronic complications in the years following initial exposures.

Syphilis, on the other hand, was researched for decades and the long-term manifestations were well documented. I decided to learn all I could about this first cousin of Borrelia and see if the latter's symptoms resembled those that I was observing. It didn't take long to learn that these first cousins are almost identical in their mirror-image nature and I realized that both could cause chronic, multi-system complications.

By my second visit to the medical library, I was ready to research my suspicion of Borrelia causing MS. I looked through the card catalog but wasn't coming up with anything. I must have looked frustrated because the librarian approached me and asked, "Are you having trouble finding something?" She was a very pretty, bright-looking woman with thick, natural-curly, strawberry-blond, hair. The glasses she propped on her nose, below her green eyes, gave her a studious air. Her name was Jean Crosier.

"Yes, I'm trying to look up a connection of spirochetes causing MS, and there's nothing here on MS" I said dejectedly. "I can't find anything at all about MS."

"There must be something... what are you looking under?" she inquired.

"Muscular sclerosis," I responded.

She cleared her throat, and looking amused, she said, "Why don't you try *multiple sclerosis*; muscular, as in *muscular dystrophy*, is a different disease."

I was so embarrassed I nearly left the library. In retrospect, it illustrates how little I knew about MS then. But it wasn't long before I began to learn about MS and found enough evidence in the literature to lend support to my inquiry into spirochetes as possible causes of MS.

On my third visit Jean recognized me and offered a cup of ice water. She asked, "Just what is it that you are trying to do?"

I took a deep breath and told her about Dick's illness, the eleven doctors, the chipmunks, our neighbors in Tahoe getting sick, later MS symptoms in some of them, and how I was now interested in finding more information about spirochetes that would support a connection between spirochete infections and MS. I ended with, "The bacterium can cause neurological symptoms in some people, and the ticks that carry *Borrelia* are located in the exact same geographic areas where MS is most prevalent. I think tick-bite infections may actually be the cause of MS."

Jean paused, studied my face a few seconds then put her glass down and turned abruptly, leaving the room saying evenly, "I'll be right back."

A minute later, she returned with a physician in tow. "This is Dr. Don Dahl. Tell him exactly what you just told me."

He said, "Interesting... hmmm... interesting (nod, nod) ...interesting", all the way through my recitation. Then they both disappeared to the back room again.

A few minutes later Jean returned with a pen and pad. "I'm going to help you find whatever you need from now on. First I had to ask Dr. Dahl whether you were crazy or knew what you were talking about."

"What did he say?"

"He said, 'you're not crazy, you do know,' and he thinks you might be right."

THE EXPERTS

Among the many public health officials that I had contacted early on was a Ph.D. microbiologist, Dr. John Doll. Now I knew two physicians with phonetically the same name, Dr. Dahl from the medical library, and

Dr. John Doll, the manager of vector-borne and zoonotic diseases at the Arizona Department of Public Health Services in Phoenix, Arizona (ADHS). After making several calls to county and state officials in 1982, I eventually was referred to him as the top public health professional in Arizona to consult about the subject of tick-borne *Borrelia*.

Dr. Doll was a highly intelligent, patient and compassionate man who spent much time on the telephone with me, discussing my MS/*Borrelia* connection. He, like Dr. Dahl, thought I might be "on to something" but he warned, "Bonnie, you could research this full-time for twenty years and ultimately have your theory collapse in a heap around you as incorrect." Despite this warning I felt encouraged by both doctors' comments.

Dr. Doll was a good mentor in that during our discussions, he patiently taught me the rudiments of *Borrelia* bacteria, the family, genus, species and strains and made the information easy to understand.

In the spring of 1983 Dr. Doll encouraged me to call Dr. Byron Waksman at the New York headquarters of the National MS Society. Dr. Waksman, MD was "the man" to talk with regarding my theoretical ideas. Because research is always dependent upon funding, his influence counted heavily.

I was unaware at the time of my first call to him that Dr. Waksman's father, Russian born Selman Waksman, had received a Nobel Prize in 1952 for his discovery of streptomycin, an antibiotic effective against tuberculosis and other infections. Dr. Waksman never mentioned this fact throughout any of our numerous verbal and written contacts we were to exchange over the next ten year period. He was a very modest man, and one who did his best to help and guide me over many years.

Dr. Waksman's first response to my idea was to tell me that I wasn't the first person in the world to think of a spirochete cause of MS. It had been a popular 'theory' in the early 1940's, especially in Germany.

It had never been funded by his society as it had fallen out of favor when viruses became the popular theory. He sent me several historical

published papers regarding spirochetes as well as some copies of letters from a virologist, Dr. Vincent Marshall, DVM, who had more recently tried to revive interest in the spirochete theory for which he was seeking grant money. He warned me not to try to contact Dr. Marshall but he did not say why.

1982 - 1984 CASES

Between the late winter of 1982 and the early spring of 1984, more cases of *Borrelia* emerged through stories I was told by people who had heard of Dick's illness. One case was a man who had been on a ski trip to Colorado. A mutual friend put him in touch with me after the friend recognized a similar illness pattern closely resembling Dick's ordeal. The skier who called me also had been vacationing in the mountains, and began to suffer fevers one week later. As in Dick's case, his doctors were unable to give him a definitive diagnosis after many weeks of recurring fevers, after which he suddenly developed painful arthritis in his knees and wrists.

One physician thought he should have intestinal surgery. That had also been something suggested in Dick's case, until I read at the library that with TBRF the ileum section of the small intestine can be temporarily paralyzed. Dick had declined the recommendation of surgery and so did the Colorado man, choosing instead to send a blood serum sample to Dr. Burgdorfer at the Rocky Mountain Laboratory in Montana. His serology was positive for *Borrelia*. The man was treated with the proper antibiotics. His arthritis, along with his exhaustion and other symptoms, promptly disappeared.

By this time I was already aware of fourteen cases from our Tahoe neighborhood alone. Other cases were from Pinetop, Arizona, and involved two families who owned a cabin that harbored chipmunks in the crawl space. One man later died from a glioblastoma brain tumor. His partner's wife developed crippling arthritis, her sister died in her twenties of melanoma, her brother developed MS, and her daughter developed breast cancer.

I heard that a physician from our Lake Tahoe townhouse was so ill he gave up his medical practice. He developed seizures and was diagnosed as having epilepsy.

A friend of this physician, also a medical doctor, became ill with undiagnosed fevers that relapsed repeatedly after leaving Lake Tahoe. He was given a warning letter that I had passed around among residents in the neighborhood. He treated himself with the drugs of choice and recovered.

Another physician ex-neighbor called me in March of 1984. He said he had been getting repeated attacks of fevers. He remembered Dick's illness and called us to discuss the possibility of his having *Borrelia* seven years after leaving our neighborhood at Lake Tahoe. He complained of symptoms that matched those of others I knew of by now such as diplopia, epididymitis, exhaustion and depression. I gave him information about Dick's blood work findings and suggested possible tests. He called me back within a few days and said his blood work was "off the charts" and he wanted to know how the doctors had treated Dick.

THE CENTERS FOR DISEASE CONTROL

In the early spring of 1984 during a conversation with Dr. Doll at ADPHS, he suggested to me that I write a letter to Centers for Disease Control (CDC) in Atlanta.

I took his advice and in April I sent a letter and enclosed an eight-page treatise.

When no answer arrived after two weeks, I called CDC. The doctor in charge was flippant and uncaring. "Oh, yeah, 'that' letter. To tell you the truth, I barely glanced at it and didn't really have time to read it. I wouldn't have answered it anyway because I don't have a secretary."

It was quite obvious that this man was not planning to do anything to help our group, and he never did help.

"Why don't you call your local health department, since we don't have *Borrelia* in Atlanta."

"I explained that I had already called the local agency. They told me to call you.... and one of the cases described in my letter that you just 'glanced at' was diagnosed in your state of Georgia."

He sighed, ignoring that fact, and replied, "I suggest you start at a grass roots level."

I assured him I would, and added; "And, I guarantee you will hear about it in the future." By May 20th he apparently did hear more.

I called Dr. Doll back and told him what happened, lamenting, "I don't know what to do. Maybe if I took his advice and started at a grass roots level, it would at least help *some* people. I've already called and written to experts all over the U.S. and can't see anything much being done about this."

"Why don't you call the newspaper and see if they will run an article about *Borrelia* and see what happens?" Dr. Doll offered. That sounded like a good idea to me. I would think about it.

ORANGE COUNTY, CALIFORNIA

In the summer of 1983, I got a call from an entomologist, Dr. James P. Webb, Orange County Vector Control District in California. (In this realm "vector" is a bug or insect that carries and transmits microbial and/or parasitic disease agents from one host to another.)

Dr. Webb's field of interest included other arthropods as well as insects that vector disease agents, toxins, and parasites to mammalian hosts from their original animal or mammal reservoirs: diseases pathogenic to humans such as relapsing fever, malaria, bubonic plague, and other exotic sounding diseases of nature that survive and reproduce in the tissues and body fluids of live human and animal hosts.

Dr. Webb had learned of Dick's illness through the Orange County reporting system and out of curiosity called us to inquire about his recovery. His tone was one of interest and respect as he listened to more about Dick and the other people I now knew about; their tick-bite experiences as well as their later complicated symptoms and signs of disease. I related a growing list of symptoms such as: exhaustion, muscle and joint pains, rashes, depression, loss of balance, and what I thought might be MS.

"Do you think this causes arthritis?" Dr. Webb asked.

"Well, a couple of these people have developed joint pain within the weeks following their fevers, and Dick is having pain and movement trouble with his knees and thumb joints," I told him.

I answered "no" when he asked if I had ever heard of 'Lyme arthritis.'

Dr. Webb explained that it was a newly recognized juvenile arthritis clustered around the town of Lyme, Connecticut. It was associated with tick-bites.

"We had an article in one of our newsletters recently," he said. "I'll send you a copy."

This was the first time I had ever heard of Lyme arthritis, a name that was later changed to "Lyme disease" when it became apparent that it was not just confined to or associated exclusively with it causing juvenile arthritis but to all age groups, and many more symptoms and signs beyond arthritis could develop in afflicted patients.

"Maybe you should call Dr. Willy Burgdorfer. He is probably the world's best tick-borne disease expert, and I think he recently discovered a bacterial cause of Lyme arthritis. It seems to me it might have been a *Borrelia spirochete*."

We discussed at length the difficulty of getting a diagnosis in individual cases. Dr. Webb agreed that although *Borrelia* is a common disease, physicians haven't been trained in how to recognize it, so it is rarely diagnosed.

"Most people accept that they 'just had a virus' and never know the difference when they later get complications," he remarked.

"I can well understand the ordeal that you and your husband suffered in trying to get a correct diagnosis without dying first," he said, wryly. "My wife and I had a similar nightmare when I got so sick I lost forty pounds and nearly died before getting diagnosed, correctly."

Dr. Webb began reciting a number of his symptoms, which sounded familiar to me from my recently acquired medical education at the library.

"What was it? It sounds like it might have been 'histoplasmosis'."

"What made you think of that?"

"I read about it at the library, and it sounds very much like that is what you are describing."

"I don't believe this," he said. "I went from doctor to doctor all over the country before I was diagnosed. It took months! Now, you tell me this after merely hearing a few symptoms!"

"Am I right?"

"No," came his answer. "But, you are very close! I had 'blastomycosis', which is very similar to histoplasmosis. They are both systemic fungal infections. If I ever get sick again," he laughed, "I'll call you!"

When our long conversation came to a close, he said, "If you find any ticks at your Tahoe place, I'd really like to have them. By the way, I think you should consider joining our 'Society of Vector Ecologists' organization. I'll send the application forms to you."

In October I received a letter from Dr. Webb with the Society of

Vector Ecology (SOVE) application form enclosed along with a request for me to send a report of my findings for the SOVE newsletter.

I was startled to read the "requirements" for membership into the society; e.g. a Ph.D., a Bachelor's Degree from an accredited college or university and a minimum of three years of experience in the field of vector ecology or related fields of education or research, or an undergraduate student with a letter from a major professor or department head, etc. I picked up the phone and called Dr. Webb.

"Thanks, but I can't join your group. I can't qualify with only a high school diploma."

There was a long pause.

"Just fill in the application, and send it to me, I'll see what I can do." Not long after, I received an official looking certificate in the mail "*THE SOCIETY OF VECTOR ECOLOGISTS, recognizes Bonnie Bennett as a member who has fulfilled the Society's qualifications in the field of Vector Ecology.*" I felt a sense of pride to get this official-looking certificate, not unlike how I felt in third grade when I won the Spelling Bee.

I sent my contribution in to their newsletter. They published my story. Two more articles were printed in later publications. I was truly surprised that I was invited to present my observations and self-taught knowledge to some very learned specialists in the field of vector ecology. Some of them in later years became very vocal supporters of my views.

DR. WILLY BURGDORFER

After talking with Dr. Webb, I decided to call Dr. Burgdorfer. His name had been mentioned by Drs. Webb and Doll, both of whom thought he was "the" world expert regarding tick infections.

I was nervous when I picked up the phone to call Dr. Burgdorfer at his National Institutes of Health (NIH), National Institutes of Allergy and Infectious Diseases (NIAID) Laboratory of Pathobiology, at Rocky Mountain Laboratory in Hamilton, Montana. Dr. Webb and Dr. Doll were important scientists in my opinion and, if they were in awe of Dr. Burgdorfer's expertise, how was I going to talk to such an accomplished scientist? I felt like Dorothy about to meet The Wizard.

I almost hung up the phone receiver as soon as the secretary put me through the switchboard... "Too late!"

A kindly, very polite-sounding voice heavily laced with a Swiss-German accent spoke, "Good afternoon, this is Dr. Burgdorfer speaking."

His dignified tone made me more nervous, he was Dr. Louis Pasteur himself as far as I was concerned. How was I to know then that this highly esteemed, world famous scientist would one day honor me with the gift of his original doctoral thesis, published in 1951.

From the beginning Dr. Burgdorfer shared his knowledge with me as though I were his peer. He respected my opinions and answered my questions, no matter how trivial. When I got up nerve enough to tell him that I thought *Borrelia* caused MS, he didn't laugh or call it wrong. He in fact sounded quite interested.

"What makes you think that?" he prodded. "Tell me more about what you think ... But, 'what' is the antigen?" (I quickly wrote "a-n-t-i-g-e-n" in my notes to look up later) "How are you going to 'prroooove' that?" he boomed, the "r" sound in prove almost rolling.

He told me about the links between ticks and *Borrelia* and I told him what I was observing in the people who had been sick with tick-borne relapsing fever. He agreed with all the other experts I had consulted that the disease was common but that it was seldom diagnosed.

He offered to do serologic tests for our family and friends, free of charge, if I could find a physician willing to draw the blood samples. Fortunately our family doctor, Harold Deal, MD, was willing to do this.

Dr. Burgdorfer told me that very little had been published about tick-borne *Borrelia* since 1953, when government funds for studies were cut off. At that time someone in authority at the National Microbiological Institute had decided that relapsing fever was a disease of the past. Others, like the Pasteur Institute of Iran and the London and Hamburg School/s of Tropical Medicine, followed that premise. As a result, there had been fewer than ten scientific papers per year published since 1950. And literally no one had studied any long-term effects. (Our *Borrelia* group members felt that long-term effects were our biggest concern).

Dr. Burgdorfer had stoically continued his *Borrelia* research, unfunded, by keeping and studying his tick colonies on a moonlighting basis, putting in laboriously long hours without pay. He is rare among scientists.

"Are you saying, then," I asked incredulously, "that I am the only one in the world that has observed long-term symptoms of relapsing fever?"

"Unfortunately, yes." He answered, "However, if you can find them, there are some very good published studies that were done in the first

half of the century that list a few later manifestations. Oscar Felsenfeld wrote a book called "Borrelia" which is one of the best publications." (I wrote that in my notes as well and found it at a used bookstore, then read it in one sitting, cover to cover). I added this extremely informative monograph book to my meager collection of early 1900's published relapsing fever medical journal papers.

Felsenfeld's book did indeed document some post fevers, describing more immediate complications to include brain tumors and other multi-systemic symptoms and signs. Yet the long-term complications had not been followed up on patients over the ensuing months and years. The complications consequential to syphilis have been well documented over periods of entire lifetimes. Syphilis involved so many disease complications that syphilis spirochete infections became known as the great imitators of all disease.

Dr. Burgdorfer was right. I was the only one in the world thus far to have observed and linked a connection between TBRF and later complications, especially MS.

Dr. Burgdorfer told me about Lyme disease and its similarity to tick-borne relapsing fever as well as louse-borne relapsing fever. But he cautioned on more than one occasion, "They are three *different* diseases caused by *Borrelia*."

I strongly disagreed with him once I had read and cited Dr. Felsenfeld's book that, on page 118, presents the concept that... "There is only one species of *Borrelia* and, all *Borrelia* types we are speaking and writing about are mere variants of only one single microbial entity."

"They are the same," I'd argue.

"No, they are not. They are different," he would emphasize, patiently but firmly. However, he would add politely, "You and Dr. Felsenfeld are of course, entitled to your own opinions."

My admiration and respect for him grew as he became my mentor during our frequent subsequent telephone talks.

About this time, the Lyme disease bacterium was named after him (*Borrelia burgdorferi*) in honor of his discovery of the bacterium. This was the first new bacterium to have been discovered in over half a century and it was a highly esteemed scientific honor to have it named for him. Yet, in all our conversations this modest man never boasted about this achievement nor even mentioned it. When I finally learned of it from

someone else and congratulated him, he just quietly said, "Thank you." Then, without any further discussion, he sent me a copy of "Science" magazine, a journal that contained the first published account of his discovery in 1982. It revolutionized the studies of Lyme disease.

THE PRESS

By spring of 1984 I decided to take Dr. Doll's advice and contact the local newspaper. Charles Thornton was the medical writer for the Arizona Republic newspaper in Phoenix to whom I sent a brief synopsis about TBRF suggesting a possible article about the dangers of tick-bite infections such as *Borrelia hermsii* that was endemic in Arizona, but which most people have never heard of before. He called me to do a brief telephone interview of why I was interested in this topic.

Then, as we talked, he seemed increasingly interested. He said he would very much like to do the story. I said, "We don't want our names in the paper, so don't mention us if you tell Dick's story."

"Of course not, I understand completely. Is it possible that I could just come to your home right now and talk to you and your husband to get the feel of this story?" Mr. Thornton had a charming southern accent.

"No, we don't want the story about us, just the disease. I'm trying to pass on information to large numbers of people and physicians with an article that will save me writing a lot of letters. Your paper could reach thousands."

"I agree, but if I don't make this a human interest story, no one will read it. I'll just drop by this afternoon to interview you and Dick."

"We don't want our names used!" I reiterated.

Ignoring my protests, Mr. Thornton continued on. "I once did a story in Memphis on Rocky Mountain spotted fever and there was not a single death from that terrible tick infection in the entire following year! I'll see you, soon!"

Mr. Thornton arrived at our house flanked by a photographer carrying two cameras.

"What is he doing here?" I asked defensively.

"Oh, he and I work together and we just happened to be going in the same direction, that's all," was his breezy reply.

Dick gave me an "I don't trust this guy" look.

Mr. Thornton looked and talked like Rhett Butler from the movie "Gone with the Wind." His speech was charmingly Mississippi/Memphis southern.

By the time he and the photographer left hours later, we were on a first names basis and we had learned a great deal about his southern roots. Charles assured us as he walked out the door that we were doing a fine, humanitarian thing by sharing our story. Our names would barely be mentioned, they probably would not even use the pictures the photographer took for their files, and the story would most likely be on the back page of the Sunday "Travel Section," where hardly anyone would read it anyway.

Sunday morning I was startled out of a sound sleep as Dick burst into the bedroom fuming, and practically threw the newspaper across the bed at me.

There we were. Our picture was as big as life on the front page. The headline read "WIFE SOLVES BAFFLING ILLNESS." Underneath was printed, "Tracks disease trail of tick ... she may unwittingly have discovered the cause of several serious diseases, including multiple sclerosis-like ailments, lupus and some forms of arthritis." (AZ Republic, pp 1 and 11, May 20, 1984).

I was insulted that after all my research Charles Thornton wrote that I had "unwittingly" linked *Borrelia* to MS. I had explained to him the convincing evidence to connect the two. Many months later I learned that by mentioning the MS, lupus and arthritis in his lead paragraph he had infuriated government scientists. Government officials were angry that Charles had publicized in the lay press convincing but anecdotal observations discovered by a housewife.

Our phone started ringing before 6:00 a.m. and didn't stop for two weeks. We left home for the next two weeks and went on a cruise to Alaska to celebrate our twenty-fifth wedding anniversary.

After we arrived home again we continued to get calls. I was able to respond to only some of them. The story had hit the news wires and I got calls from as far away as New York and Pennsylvania. Phoenix health officials were also inundated with calls, as was the newspaper's office. The editor, Ed Foster, later told me that our story had generated more calls and letters than any other story since he began working at The Arizona Republic and Gazette.

Everyone who called or wrote letters to the newspaper had their own tale to tell of illness developing after tick bites or camping out or handling sick animals. After their fevers, many had developed arthritis or MS-like symptoms, had miscarriages, as well as developing lupus and other autoimmune type diseases. Virtually all had doctor-shopped for a diagnosis, and most had finally just given up when their doctors couldn't seem to help them.

In addition to all the calls, many letters were forwarded to me from the newspaper office, among them one from the District Health Department of "Reno Washoe County Sparks, Nevada". It was written by the District Health Officer, Michael Ford, M.P.H., who said that my April 7th letter to CDC regarding relapsing fever had "found its way to" his office, and my efforts had certainly made his department more cognizant of the occurrence of relapsing fever.

At the bottom of the page I noticed a copy had been sent to the same doctor who had snubbed me at CDC in Atlanta. Maybe he had something to do with forwarding my April letter to Nevada within two days following the Phoenix, May 20th, news story, although I couldn't be sure. Nevertheless, I wondered if the CDC doctor had hired a secretary since we last talked.

Michael Ford enclosed a copy of the March-April 1984 Washoe County District Health Department EPI-NEWS, which described relapsing fever within the county. A case reported in April of that year described a 6-year-old Reno, Nevada, a girl who was diagnosed with *Borrelia* when the bacteria were observed on a blood smear during her second relapse of fevers. Staff members of the District Health Department had identified a tick found on her bedroom wall as the soft tick that normally is associated with relapsing fever *Borrelia*. The determined risk factors in this case were a woodpile at a caretaker's home and a pine cone collection in the girl's home. The pine cones had been collected in the Sierra Nevada mountain range stretching from Lake Tahoe to Susanville, California.

The newsletter included a one sentence description of four "allegedly" confirmed cases and one other possible case contracted at Tahoe between 1982 and 1984, which Mr. Ford had evidently described based on information contained in my eight page treatise to CDC sent April 7, 1984.

The two-paged newsletter along with a thorough one-page detailed description of tick-borne relapsing fever was mailed out to local physicians. I thought his newsletter relapsing fever report was excellent. Charles Thornton was not impressed. He said, "They are just covering their bureaucratic asses."

I was so naïve at the time, having never dealt with bureaucrats, that I really didn't know what Charles Thornton's remark meant. I was soon to get educated, because from this point on, it was a bureaucratic shuffle for me and other people who looked to public health officials for help. If we contacted local health authorities, we were referred to CDC. If we contacted CDC, we were ignored and referred back to local agencies or to NIH.

Instead of the news article accomplishing something good, it appeared to have been the first shot fired in an endless, no-win battle among various public health agencies, patients, and physicians. And, instead of the article allowing me to walk away, having done all I could to alert people to what I knew about *Borrelia*, it only made things worse. Because even though now more people knew that they had the disease, there was still no one who knew what to do about it.

ALICE HOLMGAARD

Dr. Deal called me one day in the summer of 1984, shortly after Charles Thornton's article was published, and asked if I would mind talking to one of his patients who had come in to see him, sick with fevers shortly after returning from a trip to the *rim country*, an area of high desert and mountains north and northeast of Arizona's lowland desert. Dr. Deal said, "Her case sounds so similar to Dick's I took the liberty of mentioning his story. She would very much like to talk with you about it." Dr. Deal was planning to send her blood work to Dr. Burgdorfer for tests. "Her name is Alice Holmgard."

Alice called me that very afternoon and we compared notes. She, like Dick, had experienced fevers followed by recovery, more fevers, recovery etc. Then she noticed a general feeling of ill health and exhaustion as though she couldn't quite shake off the illness. She developed a sudden onset of arthritis, especially painful in her knees, and found that she would burst into tears at the drop of a hat. Alice's husband, Don, a strapping, six-foot-four successful businessman, was so

concerned about the abrupt changes in his wife that he was taking valuable time away from his development office to accompany her to her numerous doctor appointments. He, too, had noticed problems in himself since their trip to the rim country, but brushed them off and was more concerned for Alice.

I told Alice that I had been inundated with calls and letters from people who thought they had *Borrelia* after reading the newspaper article about Dick's illness. She suggested that we have a meeting as soon as possible to compare notes and perhaps form an organized support group. It appeared to us that since local physicians knew very little about relapsing fever, we would have to seek out our own answers.

Dr. Deal encouraged us to pursue this in an organized way. I had been having frequent discussions with him since Dick's illness. He knew I was very worried that Dick was developing MS, particularly since the day he was unable to get proper reflex responses with his hammer-taps while examining him. I told Dr. Deal about the two cases of MS in our Tahoe neighborhood. But I didn't know if I wanted to get involved anymore than I already was with this strange disease. It was beginning to take a lot of time from our lives.

Dr. Deal cautioned, "You may be observing, first hand, how and why MS develops, and if you don't do something about it, who will?"

I was feeling helpless because, even after discovering that I was not the first person to think MS was caused by spirochetes, e.g., the observations of researchers from Germany, a country where MS patients were thought to have their disease caused by the syphilis spirochetes, spirochetes and *Borrelia*/MS studies have never been seriously considered in the United States. Dr. Deal was right. If I didn't start making a lot of noise about this, who else would?

When Alice's blood tests came back positive for *Borrelia*, Dr. Deal put her on a tetracycline antibiotic, which was the drug of choice for *Borrelia* at that time. Her arthritis was seemingly cured almost overnight! She was elated. All her symptoms went away. But, two months later, all her symptoms returned. She resumed taking the antibiotics. This pattern continued repeatedly because as soon as she was off the drug for a period of time, her symptoms returned.

Alice said, "If I could just stay on the tetracycline my whole life, maybe I could stay well!" Dr. Deal did not agree and was worried about

continuing the antibiotic because there was nothing in the medical literature about tick-borne relapsing fever to support this kind of continuous therapy. The available literature of the day suggested that it was easily cured during one course of tetracycline. We knew from experience that the literature and medical books were wrong; that it is not easily cured at all!

TAKING ACTION

Dr. Deal did not know what to do. He suggested that Alice and I pursue it on our own by going to Yale University in Connecticut where we could talk with Lyme disease experts about how they were treating their fairly recently discovered type of *Borrelia*-caused arthritis. Lyme disease certainly sounded similar to our western states' relapsing fever *Borrelia*. Dr. Deal arranged for an appointment for Alice to consult a rheumatologist expert in Connecticut within a few weeks time.

Meanwhile, we spent what was left of the summer organizing a support group and trying to enlist help from The Centers for Disease Control in Atlanta, Georgia, as well as from local authorities and physicians, universities, and whoever else we could think of to contact about the subject. Alice and two of her best friends, Noreen Nagle and Barbara Spack, possessed good organizational skills, and by late summer word had spread about *Borrelia* through media sources and word of mouth. Thanks to their hard work and skills and we were able to schedule our first "official" meeting at a Methodist church in Scottsdale.

Unfortunately, only 38 people of nearly 100 contacts were able to attend; many of the others were too exhausted and ill to make the effort. Others were discouraged by the negative stance of our public health department, or lived out of the city.

A local infectious disease specialist physician was invited to speak about *Borrelia*. He brought a nurse along to draw blood samples, which he intended to use for a blind study. Sadly, he never completed the study, and a year later his physician partner requested that I pick up the blood sera samples that were "only taking up room in their freezer."

We drew up a petition to be signed by members of our group to be sent to the Centers for Disease Control (CDC) to try once again to generate their interest in our health problems. We knew that CDC had already exerted internal pressure and had issued directives to Dr. Burgdorfer, and other local health officials to stop any further testing of Arizona people for *borreliac*. But, like it or not, we thought we might have to deal directly with CDC.

Copies of the petition were sent to President Ronald Reagan, The Surgeon General of the United States, and Arizona lawmakers Senator Barry Goldwater, Senator Dennis De Concini, Rep. John McCain, Rep. Morris Udall, Rep. Bob Stump, Rep. Eldon Rudd, and Rep. Jim McNulty. No one gave us any real help, with the exception of Senator Goldwater who compassionately intervened on our behalf at one point when Alice's husband, Don Holmgard, asked him for assistance in pressuring the government to allow Dr. Burgdorfer to continue doing blood tests for anyone who needed them. Goldwater got the "okay" immediately via political channels. And within two days of his request on our behalf, Dr. Burgdorfer called me and said he would be happy to offer tests to our group once again on "an occasional basis." We did not hear from CDC.

People were interested in comparing symptoms with one another to see if there was a pattern following tick-bite infections. We decided to make that the major topic of our next meeting, which was held at the Scottsdale Senior Citizens Center. Our list of members was growing and eventually would number over 200 people. I brought the list that I had already begun to keep since Dick's illness two years earlier. But when people started documenting their many symptoms, we were in a quandary. There were so many diverse symptoms that it sounded as if hypochondriacs had compiled the list of complaints. Still, we didn't know which symptoms and signs to leave out, so we listed everything anyone mentioned as long as two or more people had any symptoms and signs in common.

Three years later, a Lyme disease expert whom I did not meet until 1985, Paul E. Lavoie, M.D., of San Francisco said, "It's amazing, that the list you drew up in 1984 is now known to be 95% correct for all the implicated complications of *Borrelia*."

Of course, none of us believed that every symptom was a result of

previous *Borrelia* exposure. Yet, historically, spirochete bacteria have been known to cause almost anything, because they can invade virtually every part of the body. Spirochetes are notoriously labeled, "The great imitators of all disease." Therefore, we decided to not rule out anything just because it sounded like hypochondria. After all, it is quite possible that hypochondriacs actually have undiagnosed organic disease.

Most people were able to determine how many of their symptoms and signs were related to infection by how many symptoms and signs cleared up after taking antibiotics.

Symptoms seemed to occur in groups, following a pattern of exhaustion, muscle and body pains, eye problems, fuzzy thinking, and much more. Some people had arthritic-type problems while others suffered neurological problems as well as a wide variety of other multi-system disease symptoms. The most skeptical physicians were becoming impressed by how dramatically their patients responded to antibiotic treatments. They agreed that certainly not all improvements could be dismissed as placebo effects.

The emerging problem became that the antibiotics did not always appear to be a permanent solution. In fact, some of the people who went untreated seemed in the long term to do almost as well as those that were treated. We did not understand the reason for this.

Our biggest hurdle was finding doctors who were willing to treat those patients who wanted to be treated. Most medical books described the disease as self-limiting or easily cured with one course of antibiotics. It was rare that a doctor was willing to believe the disease could relapse and need repeated treatments.

We needed specialists who were willing to consider that the nature of this disease might be worse than the current medical books described.

ARIZONA DOCTORS

Dr. Deal suggested that we talk to as many infectious disease specialists as we could find to see if they were willing to consider our dilemma. The problem was that you could count the number of infectious disease specialists in our area on the fingers of one hand.

Worse yet, one of the most respected ones in the area had been Dick's former doctor, the one who I got crosswise with and who told us to find another doctor.

"Oh," I said indignantly, "I suppose you think I should just march right into Dr. Yerger's office and ask him to kindly do us a favor after all we went through with him?"

Amused, Dr. Deal said, "That's not a bad idea." Then he added, "He admitted to me one day that he was in a very bad mood the day you called and locked horns with him, and he was sorry about the whole thing in retrospect."

"Well, sorry or not, there is no way I will ever consider talking to him about anything! And, I'm certainly not going to ask him for any favors."

Alice and I talked with two other infectious disease physicians who both seemed receptive to learning more about *Borrelia*. They accepted our entire group as patients, and they agreed to treat them appropriately with antibiotics. A few group members chose to go to them, but others lived too far away to drive to their offices for appointments.

A few family physicians had already referred some of our group's patients to Dick's former doctor, Dr. Yerger and his partner. Despite knowing how I felt about Dr. Yerger, our groups' members urged me to go with Alice to talk with these two specialists about our problems.

Jessica was one of the patients being treated by Dr. Yerger's partner and she was a very sick little girl, suffering from kidney problems and multiple other symptoms and signs. Her mother, Jackie Brennan, didn't feel confident enough to insist on *Borrelia* treatment because her daughter's symptoms did not fit the clinical picture precisely. The doctor suggested some grueling kidney and bladder tests which frightened Jackie. Tick-bite infections often result in serious kidney problems yet rarely do physicians recognize or diagnose the tick-related pathogens as the source.

Jackie and Jessica had both had *Borrelia* histories confirmed by tick-bite histories and positive serology after they were exposed to ticks on Jackie's father's farm in Arkansas. They couldn't find a doctor willing to treat them. Jackie, as a young working single parent, was financially strapped. She wanted to be sure she wouldn't be paying for unnecessary urological tests if her daughter's problem was actually *Borrelia*.

Another patient, Sharon Kurtz, said that she had been started on treatment but the antibiotics were discontinued prematurely by the doctor because she broke out in a rash which he said was a fungus infection. She relapsed with all of her symptoms returning when the