

THE WOLF

Life Experiences With Lupus

By Bernard M. Collett, Ph.D.*

Life Pathways:

I grew up in the 50s in a small, rural town nestled in the mountains of Western Colorado. Some say it was a simpler time, and for the most part I agree. Then came marriage, college and family, the latter two simultaneously. Life got a little more complicated. Graduating in the mid-sixties with a Masters of Science led to employment with a large manufacturing company in the Northwest. I began to realize with that higher education came more responsibility, and life got a bit more complicated. I always wanted to teach and work with students on the graduate level, so in the late 60s I set out to work on a Ph.D. at the University of California at Berkeley. It took six long years because I couldn't afford such an undertaking with a young and growing family to support. Because of some fortuitous circumstances, I joined the staff at Berkeley as a lecturer and research scientist. It became very clear to me that with that Ph.D. came a good deal more responsibility, and even some stress. By the early 80's, I had left academia and gone into business for myself. I was also in my early 40's, thirty-five pounds overweight and a workaholic. My body began to send me a few signals that suggested, to my surprise, that I wasn't immortal! As with many who are of the ilk that defines the "upwardly mobile personality," I ignored these subtle warnings and, for the most part, continued life as usual.

The Wolf Circles:

By 1986 my ego had led me to the concept of trying to lose some weight. One day while jogging, I felt mildly disconcerting pain that seemed to run across my shoulder and along my upper back. I was pretty sure it wasn't a heart attack brewing because of the location and sharpness of the pain brought on by breathing a little more heavily during exercise. I forgot about it. Then one night I woke up with excruciating pain of the same nature but so much worse than before that I had to sit up and breathe shallowly in order to keep from screaming. The episode set off my scientific mind and in researching this malady, I concluded it was pleurisy. Pleurisy is an inflammation of the thin membrane sac surrounding the lungs (the pleura) and results in two surfaces moving over one another without lubrication. This is a layman's definition. I drank more water and tried to relax and manage my stress. I seemed to have

fewer attacks and thought I was winning. It never occurred to me to see a doctor.

During the next four years, I occasionally experienced reoccurring attacks of pleurisy and couldn't help but notice days when my knee would be painful, or my elbow or wrist would hurt. These joint pains seemed to move from area to area, and early on I found that with a good night's sleep and an aspirin, the pain would usually go away. I passed this all off as just part of getting older. By now I was commuting to work and traveling extensively as a business advisor for a large law firm dealing in the area of Chapter 11 bankruptcy reorganizations. There was a lot of stress related to this work along with the commuting and traveling. I was in New York on a case when, over the course of the day, my feet in the area of the ankle and the area over the top of the foot swelled and felt like they were on fire. I could hardly walk. I didn't know it, but I had just experienced an inflammation of the connective tissue in the area of a joint. A good night's sleep no longer abated the joint pain and swelling as it had earlier. In the somewhat typical male response, it didn't occur to me to see a doctor. Little did I know, the Wolf was moving in.

The Wolf Attacks:

In late 1991, I had made the decision to enter into a venture with my brother, a veterinarian, to determine if we could develop supplement products that would benefit both people and animals. During this time and into 1992, I continued to experience painful swelling in my joints and searing incidents of inflammation in the connective tissue surrounding joint areas. A new phenomenon now surfaced; small cuts or scrapes would routinely get infected and would not heal normally. Sometimes the peripheral area was dark blue/black . . . not a pretty sight.

I decided to get a physical examination before I began the new venture. My motivation was to do so while covered for medical under my current employment. In the back of my mind, I thought maybe the doctor could tell me something about the strange symptoms that I had been experiencing. The outcome was to set in motion a four-year journey in the wilderness of medical diagnosis. The doctor entered the room and said, "You have blood in your urine, and we have to find where it's coming from."

Counterattack (Firing Blindly):

My doctor referred me to an urologist. The urologist, after many tests, pronounced me to be the victim of kidney disease. To be precise, the diagnosis was glomerulonephritis. The urologist then referred me to a nephrologist. The nephrologist conducted more tests and found not only blood in the urine but abnormal amounts of protein. At the urging of my

brother, I sought a second opinion from doctors at the University of Southern California. Their tests showed that the urinalysis indicated the presence of blood, abnormal protein and "casts," which, in lay terms, are a "picture" or "shadow" of the nephrons of the kidney. They concluded that I had an "IgA kidney." This describes a kidney that is failing due to inflammation caused by a malfunctioning immune system. They recommended a kidney biopsy. I returned home to contemplate what to do next. I stalled. I was losing weight and found that, given the chance, I could sleep for 10 or 12 hours and still feel like sleeping more. I had no energy and had developed a sore on my right ankle that would not heal. Instead, it was black and expanding as if the flesh surrounding was dead. I didn't know it, but this was a vasculitic ulcer or lesion, often seen in diabetics with poor circulation and diseased vessels in the legs. I decided to fight at home. We had relocated and I had a new doctor. I transferred my medical records to him and the process started over. During the next year, and without my actually realizing it, my new doctor was running various tests to attempt to pin down a diagnosis. He was concerned about my worsening kidney function and suspected an autoimmune disease. He referred me to a nephrologist in a nearby city with an excellent hospital. It was early 1996. I was tired, sick and discouraged from spending nearly four years in the "wilderness" of medical diagnosis, being passed from one specialist to another.

Putting the Wolf at Bay:

The new nephrologist looked at my medical records, conducted numerous blood and urine tests, and told me I must have a kidney biopsy to assess the damage to the kidney. Twenty-four hour urinalysis confirmed the previous findings. In addition, however, this doctor spotted and knew the signs of autoimmune disease, low blood "complement", presence of anti-nuclear-antibodies (ANA), elevated creatinine, elevated blood pressure and anemia, just to name a few. The latter answered the question as to why I wanted to sleep all the time. He scheduled the kidney biopsy and I went into the hospital. Strangely, the results of the biopsy indicated that the kidneys had sustained relatively minor damage when compared to the results of the urine and blood test indicators. He immediately referred me to a rheumatologist.

At this point, I must digress and explain that during the last two years before referral to the rheumatologist, I had been busy with the new venture in supplementation of people and animals with my brother. We had come up with what we believed to be a new approach in which we would produce a supplement based on whole foods and food concentrates with special emphasis on the essential fatty acids (EFAs), particularly the omega 3s. The concept, now patented as to formulation and process, was to combine minimally processed "superfood" (nutrient dense) ingredients with specially grown flaxseed as a major ingredient to deliver the EFAs

and superior fiber. The supplements were to be produced with, as nearly as possible, the elimination of heat, light and oxygen. These are the factors that cause degradation of precious food molecules due to the action of free radical attack and oxidation (which are accelerated by heat). In a nutshell, the supplementation concept featured EFAs in an optimum ratio, both soluble and insoluble fiber of the highest quality, and phyto (plant) nutrients known to have health-benefiting properties. We were, by unique formulation, innovative processing and protective packaging, bridging the "gap" between what Mother Nature intended us to eat and the heated, processed and preserved foods that characterize our modern "Western" diet. I was studying the scientific literature^{1,2,3,6} in these areas, particularly how the body "handles" the essential fatty acids. And, I had been taking the yet-to-be-marketed product as a staple in my own diet. **

Defeating the Wolf:

The diagnosis by the rheumatologist was immediate and frightening: systemic lupus erythematosus (SLE) manifest as positive ANA, renal involvement, arthralgias (joint pain), pleurisy and anemia with the accompanying "flags" of depressed serum complement C3 and C4 levels, elevated serum creatinine (renal insufficiency), hypertension and low serum albumin. There's an old saying that you can't play until you understand the game. My doctor understood the game. He immediately put me on the corticosteroid prednesone, 40 mg per day. The plan was to hit "the wolf" hard and see if we could stabilize the inflammatory process that was causing, of most concern, progressive renal failure. I swelled up like a balloon, particularly in the face. Sleep was difficult because I would suddenly wake up gasping for breath. The prednisone seemed to cause my breathing rhythm to stop for sufficiently long periods of time that I would awake out of a dead sleep. Prednisone has two faces; it's powerful, fast acting and inexpensive, but high doses can trigger significant side effects.

Over the next few months, the doctor reduced my prednisone to 30 mg a day and added the antimalarial drug hydroxychloroquine at 200 mg per day. He also put me on blood pressure medication. The hydroxychloroquine caused me to have headaches, nausea and tremulousness. He had read that the over-the-counter androgen dehydroepiandrosterone (DHEA), which is a natural steroid that the body manufactures, had modest benefit in patients with SLE in early clinical trials. He ceased treatment with hydroxychloroquine and substituted DHEA at 50 mg per day. Gradually over the next two years the prednisone was reduced and the DHEA was increased to 100 mg per day. Things began to improve. The anemia was corrected, the sore on my ankle healed, the urinalysis showed the protein decreasing to a more

normal range and the creatinine improved slightly, indicating kidney function was stabilized.

The Wolf's Still Out There:

They say lupus is incurable. Looking at my medical tests over the years I guess I'd have to agree. A few of the telltale "flags," such as slightly low blood serum complement, are still there . . . diagnosis, "active SLE, but stable and in remission".

This "story" was not meant to be a comprehensive treatise of lupus as a disease. The disease takes several forms varying from skin rashes to deadly attack of vital organs including kidneys, lungs, and the cardiovascular system. Various drugs are used depending on the severity of the disease. Those that I have mentioned are but a few. Most have serious side effects depending on duration of use. In lupus, the body's immune system begins to make auto-antibodies (antibodies which attack the "self"). When the immune system loses the ability to distinguish between self and non-self, it starts to attack the body's own cells and tissues. During periods of disease activity, the auto-antibodies react with "self" antigens, which deceive these antibodies into identifying the antigens as "foreign." Such "immune complexes" build up and cause inflammation that results in injury and pain in tissues throughout the body (systemic). Lupus affects men, women and children of all ages. However, eight out of nine people with lupus are women, and the average age of onset is around 30 years of age.

Reflections:

Lupus means wolf and lupine means wolf-like. Wolves can be cunning, unpredictable, deceptive and vicious. So it is with the disease named for this animal. They don't really know what causes this autoimmune disease. I recall being asked if I had been exposed to any toxic chemicals, pesticides, or undue exposure to pollution. I was not, at least not to a degree any worse than other Americans.

What have I learned? First, don't spend a lot of time in the "wilderness" of medical diagnosis. If you have reoccurring symptoms such as described herein, insist that your primary care physician refer you to a rheumatologist. They deal with inflammatory diseases that include arthritis and a host of autoimmune disease types. Second, be proactive in managing the disease. I must insert a "caveat" here, because your doctor will probably not be of much help outside of medical and drug treatment regimes.

Your body will need all the help you can give it. I wrote about my "life pathways" because I believe long years of stress from our modern 21st

century lifestyle was one of the "triggers" in my own lupus. I believe diet is very important. As with many Americans, the years between 25 and 45 can result in significant weight gain. Obviously, this results from eating too much of the wrong kinds of foods. Refined, heated, preserved and over-processed foods are all around us; junk foods, food with "empty" calories, soft drinks, refined white sugar, saturated fat from too much red meat, transfatty acids from oils, deep fried foods and margarines, diets devoid of the omega 3 essential fatty acids, too much meat and not enough whole, raw and fresh foods in our diets . . . the list goes on. Combine this with lifestyles that preclude exercise and you have a formula almost guaranteed to promote degenerative diseases.

I believe had I not been proactive in changing my lifestyle in these ways, I would be an invalid or dead. I believe that in 1993, had I not been involved in learning about the omega 3 essential fatty acids which lead to my taking the supplement we had developed (The Missing Link® Master Nutrient Formula™**), kidney failure could have been my destiny. The scientific literature 4,5,6 shows that the anti-inflammatory action of the omega 3 EFAs is powerful. When used in combination with drug therapy prescribed by a physician, the omega 3 EFA acts as an "adjunct", helping to moderate the amount and time one may have to be on powerful drugs with severe side effects.5,6

If the "wolf" begins to circle in your life, the message is clear. Get to the right doctor and be proactive in managing the disease. Live with the hope and knowledge that new research is leading to more effective treatment, and someday, even the cure of this strange and mysterious disease called "lupus."

*Dr. Collett received his Ph.D. from the University of California at Berkeley. He has spent many years studying, writing and in research and development in the field of preventative natural health care.

**The supplement referred to here is The Missing Link® Master Nutrient Formula™, Original formulation by Designing Health, Inc. (www.designinghealth.com). Please email for references for this article.