BACK FROM THE EDGE

by Lisa Petrison, Ph.D.

How One Man's Discovery Brought Him From Desperately Sick With Chronic Fatigue Syndrome to the Top of Mt. Whitney in Six Months
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Foreword

This book tells the tale of one man’s ability to overcome chronic illness by the strength of his own meticulous observations. This book should inspire others with unexplained forms of chronic illness to trust their observations. I hope it will also inspire them to put those observations to the same kind of tests that Erik used to figure out that his symptoms were a function of his location.

A locations effect implies that an environmental exposure of some kind is triggering symptoms in one or more physical locations. It should follow that these very symptoms subside to a degree in the presence of cleaner, less toxic locations. The current peer-reviewed medical literature is lit up with evidence for both sudden onset and chronic symptoms caused by exposures to toxic air. Based on genetic studies, up to one in four people are susceptible to serious health problems caused by poor clearance of the toxins involved.

Research has shown that mold toxins can disrupt cell function in multiple ways, and that poor clearance of such toxins can lead to a form of inflammation that only gets worse until the sufferer is removed from ongoing exposure. Practice-based outcomes research by Ritchie Shoemaker, M.D., not only delineates the underlying problem but also a way to treat it with predictably positive results.

And the problem is not limited to toxin-producing molds. In addition to mold toxins, air found in water-damaged buildings has been shown to contain volatile organic compounds, fungal spores, bacteria, and fragments of the same. When this
kind of biotoxic mix repeatedly enters a genetically susceptible body, the inflammation won’t stop unless toxin egress steadily exceeds toxin ingress enough to quiet the internal chaos. Less is known about outside air hazards and how they trigger symptoms when inhaled by those vulnerable to poor toxin clearance. Erik’s story provides hints that a mix of molds, industrial chemicals, and nanoparticles play a role.

Estimates as to how many Americans are affected by what is variably known as chronic inflammatory response syndrome, mold toxicity, or biotoxin illness, range from four million to forty million people. Yet to the medical profession as a whole, it remains an invisible illness.

As a physician who treats patients with this condition, I can say with confidence that when mold remediation doesn’t work, it can be a real struggle to find a location with indoor air that is clean enough to support recovery. Those affected by toxic air plumes outdoors are hard-pressed to find places anywhere on the map that are clean enough to sponsor recovery.

That so many doctors would discount Erik’s observations over the years reflects sadly on the medical profession. As our healthcare system transitions to a model in which doctors and hospitals are no longer paid for what they do, but rather for how much less cash they burn, it will be interesting to see if they start paying closer attention to a condition that, if neglected, will cause them to hemorrhage cash.

Lisa has done a wonderful job of presenting Erik’s story. Together they are part of a vanguard of patients, clinicians, and other talented folks who are leading an insurgency against medical complacency when it comes to acknowledging a devastating yet treatable illness that is tied to the toxic byproducts of interactions between microbes and man-made chemicals.

Erik’s story is also a cautionary tale for our species. If we fail to recognize and respond to our toxic environment, and if we continue to inflame and perpetuate the problem, all of us will pay dearly in the end. We’d like history to record that in the 21st Century, humanity, acting upon reality-based observations, and accepting that it had but one location in which to survive, took up a global quest for health and sustainability and pulled itself back from the edge.

Keith Berndtson, M.D.
Park Ridge, Illinois
March 2014
Chapter 1

Introduction

In 1998, Erik Johnson had been ill with Chronic Fatigue Syndrome for 13 years and was on the verge of suicide.

Erik first acquired the illness in the mid 1980s during the Lake Tahoe epidemic, an outbreak in which the sufferers experienced very severe symptoms. The epidemic received widespread media attention and ultimately resulted in the Centers for Disease Control recognizing CFS as an official disease.

Erik experienced a partial recovery for a number of years but found himself sinking back into full-blown illness in the mid-1990’s.
“I was literally right back to crawling to the bathroom again,” he said. “I had one episode where I was just lying on the floor, unable to move. It was like my brain couldn’t move my muscles and nothing made sense.”

His doctor from the epidemic told him that he was at a level of illness that most people find intolerable, and that many individuals commit suicide as a result. The doctor stated that Ampligen, an experimental drug, was the only thing that would help.

The drug cost more than Erik could afford -- more than $50,000 a year. There was a free trial funded by the manufacturer, but because Erik was not wholly bedridden, he was not eligible for it.

“I did see some people improve on Ampligen, but for me it might as well have been on the moon,”” he said. “That was a real low point. I had nothing left to cling to. Possessions meant nothing to me. I was going to die. I had nothing left to lose anymore.”

So Erik decided to try an experiment that he’d been thinking about for a while.

Six months later, he climbed to the top of Mt. Whitney, the tallest mountain in the contiguous United States. The hike is 22 miles and has an elevation gain of 5000 feet, with a peak height of 14,500 feet. Half of the people who attempt the climb do not complete it.

Erik has maintained control over his illness -- including working full-time, exercising regularly and generally feeling good -- since that time.
Chapter 2

Early Life

Erik was born in 1956 and grew up with his brother and sister in the Lake Tahoe area of California. His parents divorced when he was young, and his mother remarried a dentist.

Erik wonders if he had a sensitivity to mold even when he was a child, living in an old hotel on Sonora Pass.

“There was a library that had the collected works of Mark Twain,” he recalls. “They were vintage and must have been worth a fortune. I remember being so drug-out while reading them that I had to sit on a couch next to an open door. I loved those stories, but I can remember getting to the point where I couldn’t read and had to go out for some fresh air. I would feel better and go, ‘Huh. Just a few minutes ago I could barely stand up for being so tired, and now I’ve got all the energy in the world. Is there something in there?’”
Erik attended Truckee High School in California in the early 1970’s. He states that the school was moldy and had a negative effect on him, making it difficult for him to focus on his schoolwork. The carpet in the front of the school was especially problematic, and he started using the side entrance to avoid it. The bus sheds also bothered him, and he was glad when he started driving so that he could avoid riding the bus and leave the school grounds at lunchtime.

Other students and teachers in the school also were affected by the mold, Erik said. Some accompanied him outside for breaks in the fresh air, while others who were experiencing the same symptoms (including pounding headaches, rashes, joint pain and cognitive problems) decided to stay indoors.

*Truckee High School. Erik says that this building was moldy when he was a student there in the early 1970’s and that it had gotten even worse by the early 1980’s. As described in the book “Osler’s Web,” it then became a cluster site for the “mystery disease” that later became known as CFS.*
The 1977 U.S. Army team for the Nijmegen March in Europe. Participating soldiers marched a total of 1000 miles with a 40-pound backpack during training and participation. Of the 150 soldiers who started training, only these 15 finished. Erik is in the back row, fourth from the left.

Chapter 3

Army Training

After graduating from high school, Erik joined the U.S. Army. He was trained as a nuclear missile launcher specialist and stationed in Germany.

In the army, Erik learned about how to deal with hazardous substances, such as chemical or biological warfare agents or nuclear radiation. The training was conducted with military tear gas, in order to make soldiers aware of how much of an effect even a small amount of cross-contamination could have on them.

“We were warned not to avoid washing fatigues simply because we didn't feel like the CS gas had been strong enough to worry about,” he said. “We were especially warned not to hang contaminated jackets in our locker where they could touch other garments. Field jackets were expensive to wash and starch, so there was always someone who thought, ‘This isn't so bad’ and would hang it in their locker. Then the inflammation would slowly sneak up on them. Suddenly they would start screaming and run for the barracks to take a shower. And once they were jacked
up, anything that the contaminated article had touched would slam them as well. So they had to wash their clothing anyway -- and everything it had touched.”

While in Europe, Erik served as part of the volunteer military contingent for the Nijmegen March, held in the Netherlands. His team trained for 1000 miles with 40-pound backpacks. Of 150 original volunteers, only 15 completed the event.

“I can remember the fatigue after each day’s march,” he said. “Sink down on your bunk with a cold German beer and soak up the rest and relaxation after a hard day’s trudging. It was glorious. The feeling of rest and recovery was enlivening and empowering, and one of the best times of my life.”

Even though Erik was in very good physical shape while in the army, he started experiencing some health issues there. The required vaccines seemed to have a permanent negative effect on him. He also reports getting a strange case of what seemed to be the flu while out on field maneuvers.

“I had raging sinus infections, neuro symptoms -- you know, the works,” he said. “But when I went on sick call, they wouldn’t let me go to the hospital because my temperature was below normal by a few degrees rather than elevated. So I spent the next week out in the back of a leaky five-ton truck in the pouring rain, so sick I couldn’t even get up to eat. After a few days, my own sergeant could tell I wasn’t faking and at least checked to see if I was still alive.”
Erik (leaning against the tank) with other soldiers from his unit in Germany.
Verdun Kaserne, Germany. Erik got sick from an exposure to toxic mold while serving here in the U.S. Army in the mid 1970’s. These photos show the buildings -- which were built as a bunker for Hitler -- as they looked in the 1940’s.

Chapter 4

Black Mold Bunker

In 1975, Erik was stationed at a bunker originally built for Adolph Hitler in Giessen, Germany. The bunker had five levels below ground that had been flooded at the end of World War Two. The soldiers used the buildings above ground.

Erik experienced health symptoms while helping to clean a basement that had become infested with black mold in one of the buildings.

“In 1976, we had some of the worst rain in Germany for over a hundred years, and the basement armory flooded,” Erik said. “I was part of a group detailed to go down weeks after and clean out the cardboard boxes that were covered in black mold. Within an hour or so, I could barely stand up. The others finally told me to
get lost, since I was just about useless and getting in the way. I looked like I was ready to collapse. I never recovered from that.”

Other soldiers got sick with the same sorts of symptoms that Erik had, and the supply sergeant who was in charge of the cleanup was evacuated to the U.S. with a brain tumor.

Erik started spending more time outside, going for long hikes to get away from the toxin that seemed to have enveloped the whole area. Usually this was helpful, but the outside was not always safe either, he said.

“I was doing my daily two-mile run around the base when I would run into what I believe to have been a spore plume and get knocked flat,” he said. “I would suddenly become unable to continue with a run that normally wouldn’t even raise a sweat.”

The problem seemed to be coming from vents that led to the underground bunker. Erik discussed the situation with the captain of his unit. Since the underground bunker had been used to store various chemicals such as organophosphate nerve gas and pesticides (which the Nazis had invented and produced in large quantities), Erik suggested that perhaps they were contributing the problem.

“I speculated that perhaps some chemical agent or pesticide left behind by the Nazis was leaching out of some hidden storage area and feeding the weird mold that was growing all over the place,” Erik said. “He actually listened to me. There were too many sick soldiers in my unit to be a coincidence. The chem/bio unit checked the premises but found nothing. So my captain said that all we could do was wait to see if more people became ill before deciding on further action. More soldiers did become ill, but the numbers were too few and the illness was too random to get any further investigation.”

One person who displayed an odd illness was the captain, who collapsed of a severe peanut allergy while disciplining Erik for an infraction.

“My first thought was that I had made him so enraged that he’d had a heart attack,” Erik said. “But he dropped just by inhaling a few peanut molecules from a sandwich I had just eaten. It was incredible. Peanuts were harmless to me, yet the slightest exposure could drop him in his tracks.”
Because the incident happened at the same time others were getting sick in various ways, Erik wondered whether the severity of his captain’s reaction might have been related to his system being stressed by the mold.

As Erik’s commitment to the service drew to a close, he was invited to attend officer training school. He decided that the experience with the mold had taken too much of a toll on his health and that he would be better off returning home.

*Erik (left) at work as a nuclear missile launcher specialist in Germany in 1976. The mold exposures he suffered during this time caused him to have a frequent bloody nose (explaining the presence of the tissue paper here).*
Chapter 5

Plumes and Spores

Back in Lake Tahoe, Erik started feeling much better -- until he came back into contact with his belongings from the moldy bunker in Germany.

“I had a great summer,” he said. “Then my stuff from Germany arrived. Stereo, records, tapes, clothes, etc. I was so happy. I unpacked everything, hooked up the stereo and listened to some music I hadn’t heard for a while. Then I passed out. I couldn’t believe it -- I went right back to feeling like crap. I was fresh out of the military in the best shape of my life, but suddenly I couldn’t keep up with my brother on a hiking trip, and he’d never backpacked or been a runner at all! It was just my stuff -- it was more than enough to do a number on me. I didn’t understand that at the time, but now I do.”

Erik decided to move to the San Francisco Bay Area, where he taught windsurfing and hang gliding. He also took up flying airplanes.
Things went well at first, but then he started running into the same environmental problem that he had in Germany.

“I got slammed while working on a construction project in Berkeley in 1980,” he said. “It was on the UC Berkeley campus, right next to the School of Law. While I was feeling so lousy, a guy that I was going to meet for lunch to hear his World War II stories walked in the front door, downstairs, apparently very chipper and feeling just fine. Poured himself a cup of coffee, sat down, had a massive heart attack and died on the spot. Since I felt bad and my heart was pounding after walking in the door, I didn’t think it was a coincidence, but nobody believed me.”

As he had in Germany, Erik felt affected outdoors as well as indoors.

“I was repeatedly knocked flat by something that went across Highway 80 just south of Gilman Street in Berkeley,” he said. “Two others on our crew became ill and started going to doctors. One suddenly acquired a reactivity to poison oak that he hadn’t had before. The other became so reactive to wheat that he had to give up all sources of it.”

Erik started to feel that same unpleasant sensation outdoors in various other places in the Bay Area, including in Richmond (a town located next to Berkeley), in Mountain View/Sunnyvale, and in San Anselmo. Much of the rest of the time, he felt pretty good.

At about this same time, Erik met a woman who he says was suffering from the illness that later would be named Chronic Fatigue Syndrome.

“This was in 1980, down in the South Bay Area, not too far from Silicon Valley,” he said. “One look at this person convinced me that absolutely no one would make this up. It was in an apartment complex that was full of people complaining of mysterious rashes, illness and sudden deaths. Doctors couldn’t find anything wrong and diagnosed her with ‘doctor-seeking behavior.’ I was visiting and the place just beat the crap out of me. When she told me how badly the doctor had treated her, it made me angry, because this place surely had the capacity to put me in the same position, given enough time.”
Berkeley, California, where Erik first encountered some “ferocious” outdoor plumes in 1980. “I went back a few years ago and they’re still there,” he said.
Chapter 6

A Sick Thermal

Erik also encountered the strange substance while hang gliding in Mt. Hull, near Ukiah in northern California. Bombers had previously treated the forested area below where he was flying with fire retardants.

“I had deliberately flown over a burned-out area from a forest fire because the bare ground absorbed more light and created the strongest thermals,” he said. “Suddenly I was so sick I could hardly keep my eyes open. I thought I was going to pass out. I bailed out of the thermal and made for the landing area, seven long miles away. I rested my head on the control bar and frantically shook myself awake a few times. Fortunately I recovered a bit before I got to the landing area. But I didn’t even take my harness off when I sat down and leaned against a log and didn’t move for several hours.”
After the run-in with what Erik now calls the “sick thermal,” he started experiencing even more frequent reactions to his environment.

“Buildings now had areas in corners of certain rooms that bothered me,” he said. “More highways had something rolling across the roadway that left me drenched and drained even after just momentarily passing through. Sections of some towns had a lingering effect that convinced me that I was better off for never going there, if at all possible.”

Because he usually felt better outdoors in the wilderness, Erik bought a small RV and began living in it at a hang gliding site on the coast a long way north of San Francisco. The only problem was that condensation caused mold to grow in the RV.

“It was an amazing lifestyle and seemed at first a perfect solution to my problems,” he said. “But eventually the headaches became blinding, the tiredness never completely left me, and my former endurance was ebbing away. This made teaching hang gliding, which involves a lot of running, very difficult and painful instead of the joy that it once was.”
Chapter 7

The Whole World Turned Sideways

In August 1984, Erik was knocked to the ground while working with a hang gliding student.

“I was out in some sand dunes on the coast and suddenly the whole world turned sideways,” he said. “That was the first utterly neurological sign that something was wrong. I just suddenly totally lost all perception of balance. It felt like I’d inhaled a blast of mold, but this was like nothing I had ever felt.”

Erik found himself recovering slowly from that event. He decided to go back to Lake Tahoe, where he had been spending winters shoveling snow to make money.

“By the time I arrived, I was grogged out and losing touch, and having a hard time making decisions,” Erik said. “My mom took a look at me and bundled me off to the nearest doctor, who happened to be right across the street in Carnelian Bay. That doctor was Paul Cheney.”
Dr. Cheney seemed to take Erik’s problems more seriously than the other doctors he had previously asked about his health symptoms back in the Bay Area.

“At first glance, it seemed like I might have a brain tumor,” Erik said. “Like the other doctors, he didn’t attach much importance to the mold except as an effect of something deeper. This sounded reasonable enough since I didn’t exactly see lots of other people felled by mold the way I was, though a few did seem to be pretty uncomfortable.”

Dr. Cheney eventually told Erik that he had never seen any other patients like him before and wasn’t sure what to make of his case.

“He ordered a number of tests, including a brain scan, but finally in November 1984 he called me into his office to explain that he had run out of tests and ideas,” Erik said. “He recommended that I try the large medical centers down in Reno.”

Over the next year, Erik visited about 10 other doctors. Most gave him psychiatric diagnoses such as depression or hysterical hyperventilation, and none provided him with any help. Erik thus focused his attention on sanding away the mold growing in his camper, even though none of the doctors agreed with the idea that it might be a problem.
Dillon Beach in northern California, where Erik lived in his trailer as a hang gliding instructor in the early 1980’s.
Chapter 8

A Flu That Never Ended

Despite headaches and fatigue, Erik was able to earn a good living shoveling snow that winter. However, he was disturbed by stories of people in the community being felled by an even worse illness than the one he was experiencing.

“Word came from Truckee about a horrible flu that never ended,” he said. “It seemed that if someone got this flu and recovered within about four weeks, they were pretty much out of the woods, but if it went on for any longer than six weeks, they weren’t shaking it off at all and in some cases were getting worse.”

At first, Erik believed that because he was young and in pretty good shape other than the headaches and fatigue, he would be able to recover from the flu if he caught it. However, after one of the people on the snow shoveling team died of the flu, Erik became more concerned.
“We were working 10-12 hours a day, and you couldn’t do this unless you were in reasonably good shape,” Erik said. “The official report was that he died of heart failure. You’d think he would have died on the job if his heart was that weak. But no, he died at home, coughing his lungs out.”

Erik was able to work in his hang gliding job during the following summer. While in the Tahoe area visiting his family, he continued to be disturbed by stories of more people getting sick as a result of the “weird flu.” He spent most of his time outdoors in the hope of avoiding other people who might have the illness.

In August 1985, Erik went out one day with his brother to collect firewood.

“My brother ran the chainsaw while I loaded the logs in the truck,” Erik said. “Everything was going great until I picked up a log that was covered in fuzzy mold. It had a pale beige-green base and was white at the tips. A cloud of musty mold smell draped itself over me as I dropped the log and stepped back, but it was too late. I’d already taken a deep breath. Suddenly the world looked foggy to me. I sank to my knees, as my legs no longer seemed to work right.”

Within minutes, Erik felt the glands in his throat swelling and a sore throat starting. He felt feverish but didn’t have a temperature.

“Within two days, I had the worst sore throat I’d ever had in my life,” Erik said. “I had brain-crushing headaches and a constant hacking cough. I could barely stand up. I felt sick to the very core. There wasn’t one part of me that didn’t hurt, right down to the roots of my hair.”

As time passed, Erik continued to decline.

“By the end of six weeks, I couldn’t stand up at all,” he said. “Even crawling took so much out of me that I had to plan out my time frame for going toward the bathroom since I had to take plenty of breaks along the way. Every time I lay flat, I would experience wild vertigo, but if I tried to sit up, I’d pass out. At night, the dim light from a single clock would fill my eyes with blinding glare. Twenty hours a day were spent in a strange coma-like state that others would mistake for sleep, but it was like no sleep I’d ever felt before. It felt more like some kind of toxic poisoning than any kind of fatigue.”
Other symptoms included short-term memory loss, confusion, a sense of unreality, continued headaches and body-wide pain. Even scarier were periodic paralysis and loss of the ability to communicate.

“I can still remember the sense of panic the first time I told my arm to reach for something and nothing happened,” Erik said. “I remember saying things, and having everyone in the room tell me I was speaking in tongues. I could have sworn that I was speaking perfect English. Other times, I told people to speak clearly, because it seemed to me that they were talking Greek. This was not fatigue. It seemed to me more like a stroke victim who struggles, but cannot find the words to speak and cannot move.”

Erik continued seeing various physicians, none of whom took his illness very seriously or gave him any help.

“My mother drove me to doctor after doctor, while I lay flat as possible, with the passenger seat as low as it would go to keep me from passing out,” he said. “Most of these doctors didn’t even believe I was sick, despite the visible infection in my throat, visibly swollen glands and chronic cough.”

Eventually Erik made his way back to Dr. Cheney and his partner, Dr. Daniel Peterson, after reading an article in the local newspaper about how they had seen 20 patients with a “mysterious fatiguing illness” at their practice. By summer 1986, 160 cases of the illness in the Lake Tahoe area had been reported. Although specific symptoms varied a bit from person to person and across time, the presentation was remarkably similar across cases and in most was very severe, Erik said.

“Marathon runners, overnight, could not climb a flight of stairs,” he said. “People who set out in the morning for work had to be carried home. Those who could still drive got lost trying to find their way home. A math teacher could not do addition. An English teacher could not conjugate a sentence. Throats looked like people had gargled with battery acid. We could barely stand without leaning against something. Walking was more like lurching: aim for the door, and those with this illness only made it through fifty percent of the time. Those who closed their eyes dropped instantly. People suffered from malnutrition in the midst of a fully stocked kitchen because they couldn’t stand long enough or think well enough to prepare food. Reading was out of the question. If you tried, you’d find that you were reading the same paragraph over and over. TV caused seizures. Lights in the room burned our eyes. Music hurt our heads. We were like soldiers coming out of a war
zone. We lay comatose, but it wasn’t sleep. When we dragged ourselves back into consciousness, it was in groggy, toxic, Twilight Zone fashion.”

Erik said that it was striking to him that the “weird flu” seemed to mostly hit people who had previously been very healthy rather than those who he would have thought would have been immunocompromised.

“It didn’t hit the diabetics, the drug addicts, the heavy smokers, the alcoholics, the people in hospitals with broken limbs, or those with AIDS,” he said. “It just slammed teachers, kids who were out mountain biking or playing basketball, hikers, kayakers, tennis players, swimmers, skiers -- all the outdoorsy types.”

Erik found during this time that mold had more of an effect on him than ever before.

“I was reactive to mold before I got that weird flu, but afterward my reactivity was absolutely life threatening,” he said.

Eventually Erik realized that there were small amounts of mold in his house that were bothering him, and so he started spending more time away from the house.

“I found mold in the north wall of the house, and there was another bit under the sink,” he said. “If I went outside, then I could just about stand up, but if I tried to wash dishes at that sink, my eyes would go dim and I would collapse. I would have to hold my breath at that sink or suffer the consequences.”

Eventually he moved out of the house entirely, going back to living in his camper.

“I got sick and tired of feeling like crap in that house, so I’d go outside and sit in my camper for hours at a time,” Erik said. “The camper was just a basic shell and didn’t have a heater. Somehow sitting out there gave me a slight reserve of function that I could use for a short time. I used it to find and install a heater so I could spend even more time in the camper. That was the only thing that gave me any significant relief from this living hell of a weird illness.”
Lake Tahoe. Erik says that the year that the Mystery Malady struck their town, bright green cyanobacteria started growing all over the beach. He said that while this made him somewhat sick, it wasn’t the one that he learned to be especially cautious about.

Chapter 9

Bad Places

Similar to his experiences in Germany and the Bay Area, Erik experienced reactions to what he believed to be some kind of mold outdoors. The “effect” was much worse than what he had experienced in the past though, he said.

“There were these zones that did something by just momentarily passing through that would leave me wiped out and in distress for hours or days afterward,” he said. “For instance, in the ABC news story from 1985 about the mystery illness, it happens to show an intersection in Incline Village. The guy is flipping his coat over his shoulder and is about to step over a storm drain. There was something horrible coming out of that drain. My girlfriend worked in a 7-Eleven right in front of that drain, and when I walked in circles around her, I could tell she was drenched in it. I was amazed -- this ‘whatever’ was so bad that it could be carried from Point A to
Point B on people or objects and still knock me flat. And it was affecting her too, although not as much.”

As increasing numbers of people got sick, Erik observed that those individuals who were living or working in places that felt particularly problematic to him in terms of his mold reactions were more likely to get the “Tahoe Flu” and were much more likely to stay permanently sick if they did get it.

One group included a dozen teachers at Erik’s old high school. Another was at a local casino that Erik found to be especially moldy. Employees at both of these places expressed suspicions that the buildings were having a negative impact on their health, but were unsure what the cause might be. At the time, there was nothing in the medical literature that suggested that mold could create negative health effects except as a result of allergies or of toxins in grain. They thus dismissed the mustiness of the buildings as not being relevant.

A number of individuals working in Incline Village near what Erik started calling the “killer plume” coming from the storm drain also got very sick. Some individuals living in buildings that Erik found to be especially moldy became permanently ill as well.

Erik observed that the other people who were sick with his illness had the same kinds of reactions to the environment that he did.

“I led people in and out of mold exposures, and they would fall apart,” he said. “I would ask them, ‘What do you think that was?’ They would either say, ‘It’s just me’ or ‘It’s just a reaction to chemicals,’ even though the places I would take them had visible mold and little potential for containing chemicals.”

The outdoor toxins that were problematic to him were particularly strong just prior to and during the epidemic in 1984 and 1985, Erik said.

“It was like an asteroid strike,” he said. “I don’t know why it got so bad for a while.”

During this period of time, the entire Lake Tahoe area seemed to be changed in a variety of ways, Erik states.

“When the mystery malady hit Lake Tahoe, people got cancers of all types,” he said. “Others lit up with viral infections. Some were diagnosed with Lyme disease. Sick Building Syndrome became rampant. Mold grew where it had never grown
before. Workers in offices that acquired this mold began complaining of severe fatigue, regardless of what diagnosis they had. A strange bright-green algae appeared that was so unfamiliar that people thought it was grass, ignoring cursory examination which showed that it was not. Children showed up in dental offices with hypoperfused oral tissue that looked like they had diabetes or alcoholism, or were long-time smokers.”

Animals also were affected, Erik said.

“Veterinarians wondered what went wrong for so many dogs to suddenly start sprouting tumors and dying,” he said. “A mile up the dirt road from Dr. Cheney’s old office, there is a small meadow that used to vibrate with the sound of frogs. The frogs dwindled from vast ground-shaking numbers down to one or two solitary holdouts.”

Erik told Dr. Cheney and Dr. Peterson about his own reactivities to the mold.

“My complaint from the first time I walked into Dr. Cheney’s office in 1984 was that I had an inexorably increasing reactivity to mold that grows progressively worse no matter where I live or how well I take care of myself,” Erik said. “Many people caught that strange flu-like illness at the same time, but not all of them went on to become chronically ill. I proposed that if not all people succumbed to perpetual illness, one might consider a more primary cause of the illness to be whatever differences existed between those who recovered and those who did not.”

The doctors told Erik that the patients were reacting to all kinds of ordinary substances, and that the mold was no different.

“They said that the mold didn’t matter, because this reactivity was just the result of something else,” Erik said. “They were talking about a possible virus, so I asked why a virus would care about mold. When they said it wouldn’t, I said, ‘Well, it must be a bacteria then, because whatever’s got a hold of me seems to care a great deal about mold.’ Finally I just said, ‘Fine. While you figure out what the something else is that’s causing this illness, I’m going to stay away from the mold.’”

Like the other patients in the epidemic, Erik tried a wide variety of treatments to attempt to feel better. Nothing other than the mold avoidance made more than a little bit of difference, he said.
For instance, in 1986, Erik’s stepfather introduced him to a biochemist specializing in vitamin development, in the hope of getting specific suggestions for Erik’s condition.

“He told me about CoQ10 and L-carnitine,” Erik said. “I couldn’t tell if the CoQ10 was doing anything, but the L-carnitine did seem to help a bit. Not a lot by most people’s standards, but I guessed that I was crawling to the bathroom at least 10% faster than usual and that meant a lot to me. I told everyone that I had a small but significant improvement. Years later, Dr. Peterson released an abstract describing an acetyl L-carnitine deficiency in CFS.”

Another acquaintance of his stepfather’s, a local physician, encouraged Erik to try vitamin C that same year. “I started taking sodium ascorbate to bowel tolerance and got some benefit, most notably with digestion,” he said.

Erik’s stepfather, practicing as a mercury-free dentist, removed Erik’s amalgams safely in 1987. “It didn’t make any difference at the time, but who knows?” he said. “Perhaps it was a factor in improvement later on.”

Donner Lake, where the teacher who recovered from the drop-dead flu went in his camper during breaks to drink coffee and grade papers.
Truckee High School, just outside the room used as a makeshift teachers’ lounge during the mid-1980’s. All twelve of the teachers who used the room became ill with the drop-dead flu. One teacher who spent most of his preparation time in his camper rather than in the lounge recovered; the rest remained ill. The teachers were suspicious that a toxin was responsible for their illness and knew that the room was especially moldy, but the idea that environmental molds could make dangerous toxins had not yet become part of the medical literature.
Truckee, California, where many of the sickest patients during the Lake Tahoe epidemic lived or worked.

**Chapter 10**

**An Officially Recognized Disease**

Because the people in the epidemic were so severely sick, the outbreak received nationwide publicity. The Centers for Disease Control did an investigation, and a number of prestigious doctors and scientists became involved in working on the outbreak.

They found that Erik and the other particularly sick members of his cohort had a variety of laboratory abnormalities.

“One of the weirdnesses that caused Dr. Peterson to call the CDC was a zero erythrocyte sedimentation rate in many patients,” Erik said. “Not one, two or three, but zero. We had activated RNase-L/RNA ribosomal destruction unlike anything that anyone had ever seen before. Unbelievably high Interleukin-2, only seen in things like hairy T cell lymphoma. Blown up B cells by a huge herpes virus that nobody had ever seen before, which was called HBLV, then HHV6, then HHV6a. There was low Natural Killer Cell function, low red cell mass and morphology, swollen spleens and lymph nodes, a skewed suppressor/helper T cell ratio that was the mirror image of AIDS, and unidentified bright objects on our MRI’s. And we
lost our fingerprints. That really blew people away, that we could do a blank ink blot.”

Several doctors knowledgeable about Myalgic Encephalomyelitis (ME), including Byron Hyde, eventually visited the town and agreed that the patients there were suffering from a particularly severe outbreak of ME. This was a disease that previously had been recognized by the World Health Organization and that had been discussed in the academic literature (including in the leading British medical journal, *The Lancet*), but that had not been recognized in the U.S.

Eventually the CDC said that they were going to establish an official disease based on the people in the Tahoe epidemic. Erik said that he was surprised to be asked by Dr. Cheney to be one of the prototypes.

“Initially I tried to refuse because I had already told him that mold was making me sick and that I was feeling somewhat better as a result of avoiding it,” Erik said. “But he particularly wanted my cooperation, because I was negative for Epstein-Barr Virus and he wanted to show that our illness was not caused by chronic EBV. He told me that my case would receive special attention, and it then occurred to me that as a prototypical case of illness, the CDC authorities would be forced to examine my abnormal mold complaints in particular. I wanted them to look into this substance that had been having such an effect on me and others, so I decided to do it.”

However, the CDC ended up giving the illness a trivializing name (Chronic Fatigue Syndrome) and a broad definition, and did not study the original cohort at all, Erik said. Instead, the research that was done into the disease was on people who were much less ill (like Erik was before coming down with the “weird flu”).

“They created what was supposed to be a loose working definition of the illness for research purposes,” Erik said. “We thought it was going to be used in the way that they said it would be, to research those abnormalities. But that’s not what they did. They just found some tired people who had little or nothing to do with our illness, snuck them in under the loose research definition, started studying them, and completely abandoned the people the CFS definition was ostensibly created to study.”
The experimental airplane that Erik built in the early 1990s. He said, “When I began to recover by spending time in the desert, I killed two birds by building this there. It was originally an ultralight trainer that was sold to me in pieces. I built new wings, lengthened the empennage, enlarged the horizontal stabilizer, and put on a bigger engine and a giant 72-inch prop. Then I added the floats. It had an incredible rate of climb and went straight up.”

Chapter 11

Rural Avoidance

Meanwhile, Erik continued to do his best to avoid the environmental exposures that he found particularly problematic and continued to improve.

“At first, every time I tried to do so much as walk, I would fall apart,” he said. “I couldn’t even walk up my driveway. But when I went out of my way to avoid ‘the stuff,’ I noticed a shift. My crashes were a bit less. It wasn’t much, but it was a direction to push in when nothing else was doing anything. So I pushed. Slowly it began to pay off.”

Erik found that if he got outside of towns into more rural areas, he usually would start to feel much better.

“I eventually recovered enough to start driving again, and it was a tradition for us Bay Area hang glider pilots to congregate and celebrate Thanksgiving,” he said. “I really wanted to go, even though there was no way I could think about flying and felt so ill that I wasn’t sure if I could make it. But I had been sick for so long that it
felt like if I dropped dead it would be a relief, so I went. Much to my amazement, I had more energy and less pain than I had experienced in two years.”

Eventually, by spending time in pristine areas, he recovered to the point of being able to resume athletic activities.

“I had to spend several hours outside every day, and I had to stay away from certain buildings and certain areas in town,” he said. “People thought I either was a slacker for spending so much time out in the woods instead of building a career, or must be some kind of athlete survivalist. But I had no choice. This is what I had to do to stay functional.”

Although Erik was doing better, he did not feel well enough to resume his former jobs of teaching hang gliding and shoveling snow. His stepfather suggested that he become a dental technician, making gold crowns. Erik completed the training and started his own business.

Because Erik missed hang gliding and wanted to get back into the sky, he decided to try building an experimental airplane. While working on it, he encountered another CFS patient who seemed to be pursuing the same route toward wellness that he was.

“I built my airplane out in the Godforsaken desert,” he said. “The entire time was spent outside of Incline Village and in a feel-good place. So I combined my hobby and therapy. I remember my stunned amazement when I met a guy out raking a dirt airstrip for no reason. ‘The doctors say that I have CFS, and I’m out here because this is the only thing that makes me feel better,’ he told me.”

Recalling that he had felt particularly good while in Crete, Erik decided to visit the island again for a bicycle trip.

“I rode all around the island and hiked the Samarian Gorge with no problem,” he recalls. “I felt good for a fair amount of the trip, but then stayed in a moldy hotel in Hania and completely lost it. People were amazed since I had been such a dynamo over the course of the tour but then suddenly, overnight, could scarcely stand up.”
Erik’s experimental airplane in flight. He said, “I could fly rings around a normal terratorn. Ground roll of a hundred feet, then straight up. The manufacturer thought I was crazy. He said, ‘You’ll kill yourself. It won’t work.’ Within a year, they copied my design and released it themselves.”

Near Highway 50 in Silver Springs, Nevada, in the early 1990’s. Erik said, “This was a pretty neat little bush plane. I landed it on dirt roads, beaches and dry lake beds. Unfortunately, it wasn't very fast. Maximum speed of 85, cruise at 65. If I had any headwind at all, the cars would be passing me.”
After partially recovering from his illness, Erik visited Crete on a bicycle trip in the early 1990’s. He says it was one of the very best places he ever has been.
Chapter 12

Relapse

In 1994, Erik purchased a house just outside Incline Village in Kings Beach to use for his residence and his business. He had sold the first aircraft he had built and planned to use the house to build a second one.

“At the time, I just wanted to move and didn’t know how to judge a place,” he said. “I could feel that it was bad when I moved in, but it had been bad where I had come from too, so I felt like I was caught in my own personal problems more than attributing it to the environment.”

Soon after moving into the house, Erik started having periodic severe symptoms.

“My symptoms were somewhat different when I relapsed than they were in the beginning, but nothing about this illness has ever stayed the same for more than a
few months,” he said. “It was as if the disease was determined to hit every major organ system. It just kept jumping around until it hit all of them. I remember lying on the floor one day, unable to move and realizing that if anyone found me, I would be taken to a hospital and pumped full of drugs, and not one person would believe me about the mold. I managed to crawl out to my camper, where I felt somewhat better.”

Erik supported his health with various supplements and continued doing outdoor activities in the wilderness as much as possible. Over a period of a few years, his health continued to deteriorate. His reactions to chemicals were especially problematic at this time.

“I remember having problems with trees, diesel, new cars, paint, carpet, outgassing plastics, perfume, stores and EMF’s,” he said. “I also was reacting to all kinds of foods. I had to give up drinking wine, eating cheese, bread, nuts. It was overwhelming. It seemed like everything was out to kill me and closing in on me.”

By 1997, Erik was more ill than he had ever been.

“I would crawl into a shower and lie on the floor, curled up fetal, and just let the water run over me,” he said. “Sometimes I was too sick to get out of the shower and would stay there for hours.”

After Erik relapsed, he started seeing Dr. Peterson again. (By then, Dr. Cheney had moved to another state.) Dr. Peterson stated that Erik was still negative for EBV and was still a perfect case of CFS. He suggested that Erik try Ampligen, an experimental drug with an effect on the immune system that seemed to help some CFS patients.

“The problem was that because of the mold avoidance I was already doing, I didn’t qualify for the funded study because I was still capable of walking,” Erik said. “They wanted patients who were bedridden. Dr. Peterson told me that I could have the drug, but that it would have to be on a cost recovery basis. The cost would have been more than $50,000 a year, and I couldn’t afford it.”
Fort Churchill State Historic Park in Nevada. Erik spent a great deal of time in remote areas of the Nevada desert during the early stages of his recovery.

Chapter 13

A Last-Ditch Experiment

Discouraged, Erik went on a camping trip to the desert with his family. He said his goal was to spend some time with them before shooting himself.

“I was planning to go out to the desert to die like an old coyote,” Erik said. “Instead, I said, this feels pretty good!”

Erik said that while he didn’t feel totally well in the desert, it was enough of an improvement to make him consider how much better he might be if he stayed there all the time.

Erik wondered what it was about the rural desert that made so much of a difference for him. He thought about his experiences with controlling for cross-contamination in the military, and about his captain’s severe reaction to the peanut
butter on his breath. He wondered if the toxins that he knew bothered him -- the mold in buildings and the substance that came out of the storm vents in Incline Village -- might be harmful enough to him in very tiny quantities to keep him totally sick.

He decided to make one last try at getting better, by applying the techniques he had learned to deal with hazardous substances in the military to his current situation. He went to Dr. Peterson and asked him to help devise a strategy.

“He said that he didn’t think it would work,” Erik remembers.

Erik started out by spending extended periods of time in the “Godforsaken desert,” staying mostly in campgrounds within easy driving distance of Lake Tahoe. For these expeditions, he purchased new clothing and camping gear from stores that felt good to him and then washed it all in the wilderness. He bagged it all carefully before going back to civilization.

After spending several days in the wilderness with clean possessions, Erik would start to feel better. However, when he returned to problematic places, they felt worse to him than ever. Even his car -- which he had previously thought of as a refuge -- started to bother him.

“I was pretty confused about this at first at first,” Erik said. “Imagine being out in the wilderness and finding that I couldn’t get close to my vehicle. Not even stand next to it! Eventually my ability to perceive became so great that I wound up pointing at the most unbelievable things -- objects, people, places, air currents, sunshine on an area of carpet.”

As Erik spent more time in the wilderness, he could tell that his house was problematic. At first he hoped that he could remediate it, and hired a mycologist to help him look for and identify the molds that were present. They first found colonies that tested as *Aspergillus* and *Penicillium*, but these had only a small effect on Erik. Then they disrupted a colony of green-black mold.

“As I collapsed on the floor, I said, ‘That’s the one!’” Erik said. “It turned out to be *Stachybotrys* -- and that was the first time I had heard the name. If I hadn’t been really pushy on this, we might have stopped at the *Aspergillus* and not found it.”
Erik sets up his camp for a getaway in Evolution Basin in the Kings Canyon backcountry in the eastern California Sierra Nevadas. When he was first doing extreme avoidance, he spent a great deal of time tent camping.

Chapter 14

Infinitesimal Amounts

In order to better understand the effect that this mold had on him, Erik used techniques he had learned for dealing with hazardous materials to take a small sample of it out to the desert with him.

“After getting myself as clear as possible, I did proximity testing to see at what distance a tiny amount would have a discernible effect,” he said. “It was astounding, just like the peanut allergy in my commanding officer. Infinitesimal amounts were creating sensations that were only discernible by the fact that there was a shift in symptoms.”

When exposures were small, the first symptoms that Erik felt were related to emotional issues and sleep. If he continued to be exposed at the same levels, eventually physical symptoms would kick in as well.
“If I was slightly depressed, it would get worse,” he said. “If I had difficulty sleeping, the problem would turn into full-on insomnia. If I felt slightly anxious, it would turn into a sense of desperation. So I started using my ‘depression response’ as an indicator of low-level toxic exposures.”

Erik says that if it weren’t for his depression response, he would be unable to practice mold avoidance effectively. Antidepressants to blunt this response are the last thing he would want, he said.

“I believe that depression is a warning, not an illness,” he said. “Depression is to toxic exposures as pain is to a hot stove -- just the signal that tells the brain about the inflammatory response. So you can see why I’m a kind of crusader against psychologizers. Their view is that these emotional responses are responsible for the illness of CFS, while my view is that the sudden shift in an emotional response that has no intellectual stimulus is a sign of your immune system trying to warn you of an inflammatory upregulation. Psychologizers have cause and effect completely reversed, and we ignore the depression response at our peril.”

Further experimentation gave Erik more insights into the properties of the mold as well as how to best avoid it.

“I noticed that some contaminated places gave me a huge hit but that I could recover without decontamination,” he said. “Other places might hit me less, but I would carry the reaction with me. This led me to believe that the neurotoxic reaction was to aerosolized mycotoxins and not necessarily inhalation of spores. I tested this by placing a contaminated article in HEPA filters and taking it to my clean place. I put it under six layers of blankets and slept on it. I got the usual reaction and removed the article but went back to sleep on the same blankets. The reaction was gone. This convinced me that that spores had not penetrated the filter or blankets and that the toxic gas was truly my primary irritant.”
Most of the time since 1998, Erik has lived and worked in Reno, which bills itself as “the biggest little city in the world.”

Chapter 15

Living In Civilization

After Erik spent time in the wilderness and then returned to civilization (or, as he had taken to calling it, “civilidevastation”), it gave him a different perspective on how to manage his problem.

“At first, I went nuts trying to remediate my house,” he said. “We found one small colony in it, but getting rid of it did nothing. Then I started going to the woods to get clear, then back to the property without going inside, and I still got slammed. I checked the wind direction, and it was coming from the sewer. It finally sunk in that nothing I did inside the house was ever going to make that area safe for me. I could have burned the house to the ground and built another, and it wouldn’t have made any difference in my illness.”

Erik eventually sold the house and bought an RV with a shower. He said that while he considered leasing an apartment, having a mobile residence worked better for him because it allowed him to stay more easily in pristine places and to have a
shower more readily available. Another problem with apartments was that many did not accept cats, he said.

“My cat went everywhere with me through this experience,” he said. “When we were stuck in a moldy place and the weather was making the plumes go wild, she would act frantic and desperate. The RV was a good home for both of us.”

He decided to call his RV a “Mobile Environmental Containment Unit” or “MECU,” since its purpose was to provide a safe space with regard to environmental influences.

When in town, Erik used the depression response and other symptoms (such as heart palpitations and deep skin dents) to know when he was being hit by the substances that were particularly problematic for him. Regardless of whether the hit took place inside a building or outdoors, he immediately decontaminated.

“Every time I felt a mold hit, even if it were slight, I’d run to my rig and take a shower, change clothes, and bag the clothes in a separate compartment for washing later,” he said. “It seemed crazy to people that sometimes I was taking up to ten showers a day and changing my clothes every time, but that’s what I did. Preemptive, preemptive, preemptive! Catch the response before it has a chance to go ballistic.”

Erik also soon realized that it was important not to let the RV sit for too long in bad places, because then it would bother him even in good areas. He ended up moving his RV frequently when in town, due to changes in wind direction and barometric pressure that caused the toxins that were problematic to him to be present in different places at different times.

Especially during winter months, outdoor plumes tended to be much worse during times of approaching storms, Erik said. In order to prevent his RV and possessions from being contaminated, he often fled to less populated locations during those times.

“When I’m out in a good place, the barometric pressure can do what it wants and I don’t feel a thing,” he said.
Castle Peak near Donner Pass, outside of Truckee, California. Erik took this picture while hiking well above the environmental problems in the town.

Chapter 16

Sweating and Altitude

Erik said that detoxification appears to have been essential in allowing him to move toward wellness. Although he owned an infrared sauna (stored at his mother’s house), he found sweating through exercise to be more effective in allowing him to detox. The toxins also came out automatically through sweating and breathing when he was sleeping in a really good place, he said.

“I feel fairly sure that if it weren’t for exercise, I would still be a semi-invalid,” he said. “The peculiar difference between good and bad locations was that the post-exertional malaise and immune paralysis didn’t seem to happen in good locations. I never really got out of shape. All I had to do was stay really clear, and I soon started doing better.”
Erik found that gradually increasing elevation while hiking was particularly restorative, since it seemed to decrease the inflammation that he experienced when being hit with mold.

“It had to be a steady increase in altitude or it didn’t work,” he said. “I tried this at various elevations, and going to a lower one ruined the effect. It had to be a steady increase from whatever altitude I was accustomed to. It was really weird. I had to breathe at the exact threshold of just barely starting to push the aerobic threshold, but not go beyond. Definitely not go beyond, or pay for it with a crash. If I could maintain precisely this balance for about 30 minutes a day, the effect was near miraculous. It made a difference in ‘push-crash’ when nothing else made a dent.”

*On Devils Oven Lake on the Pacific Crest Trail, near Truckee, California.*
Summer 1999. Six months after being accepted for the CFS drug Ampligen but not being able to afford it, Erik (far right) climbed to the top of Mt. Whitney with friends. The hike is 22 miles and has an elevation gain of 5000 feet, with a peak height of 14,500. Half the people who attempt the hike do not make it to the top.

Chapter 17

Back from the Dead

Gradually, Erik’s overall health improved.

“I had to look backwards over month-long periods and try to compare to see if I was really getting better or just imagining it,” he said. “And then after maybe four months, something shifted and my improvement just took off. When my inability to withstand temperature ranges corrected itself, it was sudden. It literally happened overnight. I was so amazed that I went out and threw snowballs. I hadn’t been able to do that for ten years without Raynaud’s like symptoms.”

Six months after starting avoidance, Erik was able to climb the tallest mountain in the contiguous U.S., Mt. Whitney.
“I was shocked to get clear and find that respiratory problems and altitude sickness gradually disappeared,” Erik said. “I suffered from altitude sickness my whole life until I started controlling for cross-contamination of my clothing. Now I feel awesome on top of Mt. Whitney -- like a superman! No altitude sickness at all.”

Also at about the six-month point of what he started calling “extreme mold avoidance,” Erik’s food and chemical sensitivities dissipated.

“I had become reactive to many substances, more and more as time went on,” he said. “This is a process well known to people with MCS, called spreading. When I remembered that my problems had started with mold and started treating that as my primary reactivity, everything got better. No amount of chemical or food avoidance ever decreased my reactivity to mold, but mold avoidance alone reduced my reactivity to everything else.”

Erik found that with sufficient continued avoidance, most of his symptoms went away. A few (including specific cognitive issues such as having more difficulty doing math than before he got sick) remained.

A few years after starting extreme mold avoidance, Erik decided to try a pulsed course of doxycycline, which addresses pathogens such as mycoplasma and borrelia. His reactivity to toxic mold decreased a bit during this time, but after about a year he decided that he was not getting any further benefit and stopped the drug.

Erik also tried a brief course of the drug cholestyramine while temporarily living in a somewhat problematic environment but didn’t feel that it was helpful to him. He has taken no drugs or supplements of any sort since 2001. As he has his whole life, he eats a balanced diet consisting of mostly produce and meats, including moderate amounts of white flour and sugar. He is able to tolerate all foods (including coffee and alcohol) as long as he is not getting too much exposure, he says.

“One mold doctor gives his patients a handout on mycotoxin laden foods to avoid,” he said. “Wine, cheese, nuts, a bunch more. I told him that although I had become reactive to some of those things and had to give up eating them while in a moldy apartment, once I started actively avoiding inhaled mold, I had no further problems with them. I can eat all of them I want now, with zilcho reaction. Giving them up while in the mold zone had done almost nothing to reduce my illness. So I consider the edible factor to be paltry compared to the inhaled one.”
A glimpse of the top of Mt. Whitney through the Whitney Arch.

At the top of Mt. Rose (altitude 9600 feet) near Lake Tahoe in 2006.
Erik kayaking near Lake Tahoe.

Erik at the top of Mt. Judah near Tahoe.
Hiking in Round Valley on the Pacific Crest Trail near the Donner summit outside of Truckee, California.
Moab, Utah. Erik’s RV (which he calls a Mobile Environmental Containment Unit) allows him to spend more time breathing the good air in areas far away from cities.

Chapter 18

Living Arrangements

A few years after starting extreme avoidance, Erik started dating a woman who he observed was being made ill by mold.

“She had a particularly severe case of mononucleosis, but described it mostly as being fatigued,” he said. “The illness that hit my cohort in Incline Village was not like that. We didn’t wonder why we were so tired, we wondered why we weren’t already dead, which would have been a relief. But her reaction to mold was strikingly similar to mine.”

Erik taught his girlfriend his avoidance protocols, and they spent a great deal of time going on camping and backpacking trips. Her reactivity went down substantially over the course of their four-year relationship. The relationship ended when their RV and their truck camper went moldy at the same time and she moved into an apartment.
Erik decided he was not going to take chances on having another RV go moldy on him, and so built a new truck camper out of only inorganic materials. The commercial RV’s all had buried wood in them, such as plywood roof caps, and thus were not safe, he said.

“I had had four commercial RV’s go bad on me since 1984, and I got really sick of getting kicked around by this stuff,” he said. “Rather than trying to minimize condensation, I built it in such a way that no amount of condensation is a problem. There’s nothing in it except metal and plastic, with four inches of styrofoam in the walls and eight inches in the floor and roof. Not only that, but I put a titanium wood stove in it. It’s one of the warmest and best-insulated RV’s around. The stove puts out so much heat in the winter that I can keep the windows and door open all the time.”

However, a number of years later, Erik again began to be affected by his RV. After a great deal of search, he found that there was mold growing inside the lining of his commercial RV refrigerator.

“I tore my rig apart and still couldn’t find it,” he said. “Finally, when I had eliminated everything else that it could be, I opened up the refrigerator. Mold was hidden inside the junction of the plastic and the foam. It was just a little colony, but that’s all it takes. It turned out that the foam is injected into a foil-lined cardboard form, not visible from the outside. So I built my own refrigerator box out of styrofoam and plugged the cooling unit onto the back of the box.”

Erik also has started to treat all the water that he uses for any purpose, to control for contamination with toxic cyanobacteria. Microcystis that periodically grows in Boca Reservoir results in contamination of the water supplies of both Reno and Lake Tahoe, he said.

“Once the contaminated water hit my tanks, I was unable to clean them,” he said. “It actually seems as if drinking the water is less harmful than inhaling the air from areas where the water has evaporated. Filtering doesn’t adequately get rid of this contamination. Boiling does. All water now hits a rolling boil before I use it or allow it to stay in my rig. Washing, showers, laundry, toilet flushing, everything! Showers with boiled water are unexpectedly refreshing. I should have done this years ago. I never felt so good at this time of year before now.”

Although Erik still has to be careful with regard to exposures, his own reactivity has decreased substantially since he started doing extreme avoidance in 1998.
“I don’t get all freaked out about bad buildings any more,” he said. “I worked full-time for years in a place that I wouldn’t have been able to stand for 15 minutes when I was first starting out with this.”

Erik made up for the moldiness of his workplace (a dental lab in Reno) by taking particular care with his sleeping space. In 2010, he purchased a cargo trailer to use as a workspace and went into business on his own again.

“I said to myself that I’m always telling people that this could be a perfect ‘poor man’s MECU,’ and figured I’d put my own words to the test,” he said. “I moved in some camping gear and an electric heater, and within half an hour had a functional space that could be used by someone as an escape route.”

Toxic cyanobacteria growing on Boca Reservoir, source of drinking water for the Reno-Tahoe area.
Erik and his best friend, Kitty, sleep in a truck camper that Erik built from all mold-resistant materials.

Erik’s truck camper in the process of being built in 2005.
A mostly housebound CFS patient follows Erik’s instructions with regard to getting clear in Death Valley. She was able to hike all day every day without post-exertional malaise, was freed from her daily headaches, and lost her alcohol and sugar intolerance. After the two-week sabbatical, she went back to her home and made changes that have allowed her to not become ill again.

Chapter 19

Teaching Avoidance

During the past several years, several dozen severely ill CFS patients have attempted to duplicate at least some of Erik’s avoidance tactics. All who have followed his instructions have achieved significant benefit, he said.

“One problem is that people often think that they are doing avoidance, but are misled by odors and allergies,” he said. “This reactivity is nothing like an allergy. It is so difficult to describe that I literally have to haul people in and out of exposures asking, ‘Do you feel it now?’ It really saves a lot of time -- as in, years of trying!”
The key to moving toward wellness through mold avoidance is unmasking, Erik says. He encourages people to spend an extended period of time in a place that is known to be clear, such as a few weeks in the proverbial “tent in the Godforsaken desert.” After doing this, they will be much better able to identify problematic toxins and thus to avoid them effectively, he said.

“People in the midst of chronic damaging exposures are almost universally unaware of it,” Erik said. “People can get carried out on a stretcher, and they still don’t know what happened to them. Everyone I’ve seen who has returned from getting clear is surprised that sources of exposure that they thought to be negligible were far more significant than they had previously perceived.”

Molds in areas that have not been touched by manmade chemicals invariably feel fine to Erik and to others who have used his approach to move toward wellness, he says. He thus suggests that mold in itself -- regardless of the species -- is not the real problem. Instead, he thinks it’s the interaction of molds with chemicals.

“Molds utilize the principles of biological conservation of energy to metabolize complex molecules available from chemicals into potentiated ‘supertoxins,’” he posits. “Mold still looks like mold, but what we are feeding it has turned it into a killer.”

Erik points out that mold has been shown to have the ability to transform silver into its nanoparticle form. Insofar as mold has the ability to do this with other substances present in the environment, it might end up creating particularly damaging toxins that humans are not adapted to tolerate, he suggests. While a wide variety of metals and chemicals might conceivably be used by molds in this way, he suspects that the most problematic ones are fire retardants (especially PBDE’s); silver iodide used legally or illegally for cloud seeding; industrial solvents such as TCE; and certain pesticides.

Erik said that he believes that, like the nuclear radiation that he learned about in the army, the biotoxins that have an effect on him exert much of their damage by altering the immune system and allowing various pathogens to reactivate. His observations have been that this is especially likely to happen with herpes family viruses.

“For instance, at one point I was working in a restaurant and we were getting spore plumed,” Erik said. “Thanks to being hypersensitive, I was aware of this while people of lesser reactivity were clueless regarding this variable. Much to my
amazement, every employee who had herpes broke out simultaneously. I don’t have herpes simplex, but I felt horrible all the same. When the weather changed and the plume died down, so did people’s herpes infections.”

*Erik at the sand dunes near Stovepipe Wells at Death Valley National Park, California. Death Valley is one of Erik’s favorite feel-good places.*

Chapter 20

A Particularly Bad Toxin

The environmental biotoxins that are problems for him have become much more prevalent during the past 30 years, Erik said. There are more moldy buildings than in the past, and the outdoor problem has gotten much worse. Although the Tahoe-Truckee and the San Francisco Bay areas remain particularly problematic with regard to this outdoor toxin, it is present in an increasing number of other places as well, he says.

“I’ve been aware of my reactivity to bad zones for enough years to see that many, many places that used to be good have now turned bad,” he said. “The plumes don’t necessarily feel more potent to me than ones I have encountered in the past. They are mostly just larger. Much larger. It’s not my sensitivity that is changing. This stuff is spreading.”
Erik believes this outdoor toxin to be associated (at least in the Reno/Tahoe area) primarily with sewers, sewer ponds, and areas that have been subjected to certain fire retardants.

“There is a killer compost farm located right next to the air tanker base south of Carson City,” he said. “Everyone who is downwind of it for half a mile is showing signs. Some of the most fierce mold I found around that tanker base was in decomposing weeds in a drainage ditch leading away from the fire retardant loading station. I wondered if my reaction was to the chemicals themselves, so to check, I wandered around the base and made sure to inhale fuel fumes and step in piles of spilled retardant. No reaction. But that drainage ditch was pure murder.”

On occasion, Erik has found this particularly problematic toxin (which he can recognize as a result of his specific reactions to it) to be present inside buildings. Those buildings tend to be ones that are associated with particularly severe human illness, he says.

“Some buildings, like Truckee High School, have a few hot spots of this really bad stuff along with the normal bad mold,” he said. “When it is inside, it usually seems to be coming up from underneath, from below foundations, from sewers, or the darndest depths of the darkest basement.”

Other buildings in Truckee that have some of this toxin are the CALfire firefighting station (closed due to mold growth) and the Henness Flats apartment complex, he said.

“The immunological meltdowns of people at Henness Flats were so diverse that they made it appear to others that they must be unconnected,” Erik said. “It is only us sensitives who say, ‘Well, no wonder! The place feels like it could kill almost anyone if given enough time.’ To really get the full sense, you have to hit it right when a storm is coming. It’s like a World War One battlefield, with clouds of ‘brain fog gas’ wafting through.”

In some cases, this toxin appears to be brought inside buildings on people’s shoes or clothing, Erik said.

“In my last house, there was a little bit in the neighborhood,” he said. “I think it was from the sewer. It got on my cat, and my cat nearly killed me by jumping up in my lap. I wound up in the ER.”
Even healthy people who do not seem bothered by moldy buildings can be affected by this substance, Erik said.

“I took my mom to the storm drain at Lakeshore and Village Boulevards in Incline Village during the epidemic,” Erik said. “I thought she was immune to everything and so did she, but it knocked her out.”

Erik poses in his old Army uniform in one the most problematic outdoor locations he’s encountered, just north of Carson City, NV. A compost farm is behind him on the left and a fire retardant loading station is on the right.
Mold illness specialist Dr. Ritchie Shoemaker and Erik at a CFS conference in 2009. Chapters about Erik’s experiences are included in two of Dr. Shoemaker’s books, “Mold Warriors” and “Surviving Mold.”

Chapter 21

Not Just Genetic Susceptibility

Dr. Ritchie Shoemaker, who has published a number of peer-reviewed articles on biotoxin illness in humans, says that Erik’s HLA DR genotype (4-3-53 and 7-2-53) makes him especially susceptible to biotoxin poisoning. Erik said that he does suspect that some of his other family members have been affected by mold. Included are his father and his paternal grandmother, who coincidentally was from the small town of Molde, Norway.

“I come from a farming family which used to supply hay for the U.S. calvary,” he said. “My grandmother complained bitterly about living right next to the hay barn and forced my grandfather to build her a new house less than a mile away. I had my father take me to both places a couple of years ago, and the old one was surrounded by the sensation that I recognize as the bad mold. The new one felt pretty good to me.”
However, the phenomenon that he observed during the Lake Tahoe epidemic seemed to go way beyond individual genetic predispositions, he said.

“The illness just plain raced through groups in a manner unlike anything an individual problem could do,” he said. “When you have half a girls’ basketball team get sick, genetics seem almost inconsequential in comparison to the thing that unveiled the susceptibility.”
Chapter 22

Contacting Researchers

Erik said that ever since he started running into this particularly problematic outdoor toxin in the Bay Area in 1980, his primary goal in life has been to draw attention to its presence in order to get it studied. His hope was that by climbing to the top of Mt. Whitney for 10 years in a row -- thus proving that his having overcome the post-exertional malaise that is the hallmark symptom of CFS was not a fluke -- he would get doctors and researchers to ask him how he did it. Unfortunately, things did not work out the way he thought they would, he said.

Erik has written letters to hundreds of CFS and biotoxin researchers. He says that until 2011, the only person to respond in any sort of substantive way was Dr.
Shoemaker, who included chapters written by Erik in his books “Mold Warriors” (2005) and “Surviving Mold” (2010).

“I was so concerned about this specific phenomenon that I even went to famous CFS doctors and paid them to listen to my story about the mold clues,” he said. “There is a virtual brick wall of medical denial created by the fundamental philosophy that ‘If we don’t already know it, then it cannot be worth investigating.’”

More recently, Erik has been working with a team of scientific investigators from the World Health Organization who are devoting their attention toward understanding why certain kinds of biotoxins have become so much more deadly.

“They just told me that their preliminary work is consistent with my hypothesis about the nanoparticles,” Erik said. “They went so far as to say, ‘You are right.’ So we will see what happens.”

In addition, Erik has spent substantial amounts of time over the past three decades attending CFS support group meetings and posting on online CFS forums with the goal of making patients aware of the connection between CFS and biotoxins.

“When I went to CFS groups to tell my story, I could feel mold hits consistently on almost everyone’s clothing,” he said. “They were virtually all bringing up the same clues that led me to my conclusions, yet they would consistently discard my story and reject my proposal. I led people in and out of mold exposures, and they would fall apart. Some even told me later, ‘You almost had me convinced because I could feel it for myself, but then I went to my doctor and he told me that this is impossible.’ Unless people are willing to try and get clear with full knowledge of what the goal is, they just cannot believe that this effect might really exist.”

The fact that virtually no research has ever been done into the connection between biotoxins and CFS remains a source of frustration for Erik.

“I would have thought that a story like mine would have been something that no one could ignore,” Erik said. “I was present at the different illness clusters that scared Dr. Peterson into calling the CDC and that led to this CFS phenomenon. I felt this effect at all of them. I wanted help finding out what’s going on. I never got that help with learning more. What I know, I had to learn on my own, the hard way.”
The consequences of the ignorance about the phenomenon for those people who knowingly or unknowingly share his reactivity to these toxins are horrifying, Erik said.

“If they have no Plan B or means of escape from these toxins, they will not survive,” he said. “They will beg for a merciful death. They will commit suicide, and I cannot blame them for doing it. In my environmental bubble, I am quite comfortable. I can have adventures, but it is a false life. I wanted to make my way back to a real life, but instead of getting medical attention for this problem, all I see is people getting no meaningful help and winding up in my situation, except that they have no lifeboat to swim to. It feels like I am sitting in a lifeboat watching everybody drown, and there is nothing I can do about it.”

To demonstrate his continued recovery, Erik climbed to the top of Mt. Whitney every summer for ten years in a row. This photo is from Summer 2000 (Climb #2).
Additional photos from Mt. Whitney: Summer 2007 (Climb #9) and Summer 2008 (Climb #10).
About the Publisher

For more information about Chronic Fatigue Syndrome and Mold/Biotoxin Illness, or to make a donation to fund research into the relationship between CFS and biotoxins, please visit the Paradigm Change website.

Paradigm Change is a not-for-profit organization with the goal of producing and disseminating quality information about Chronic Fatigue Syndrome, Myalgic Encephalomyelitis, Mold/Biotoxin Illness, Chronic Lyme Disease, Fibromyalgia, Gulf War Illness, Autism Spectrum Disorders, and Environmental/Food Sensitivities.

The Paradigm Change website includes summaries of peer-reviewed medical studies and links to media coverage, and is designed to be of use to physicians, healers, medical researchers, journalists, courts, employers, schools, advocates, patients and the general public.

Paradigm Change also has the goal of fostering research into whether environmental toxins (especially ones produced by microorganisms such as molds and cyanobacteria) may be playing a role in these neuroimmune illnesses.

The website address is:

www.paradigmchange.me
About the Author

Lisa Petrison completed her doctorate in marketing and social psychology from the Kellogg School of Management at Northwestern University in 1998, a few years after first acquiring Chronic Fatigue Syndrome. She was a tenure-track professor in business at Loyola University Chicago until becoming disabled with the disease in 2001 and then near-bedridden with it in 2007.

Prior to getting her Ph.D., Lisa worked in marketing/PR for the Chicago Association for Retarded Citizens and in the banking and video game industries, and was a reporter for Adweek magazine. She has a B.S. in journalism and an M.S. in marketing communications from the Medill School of Journalism at Northwestern University.

Since 2008, Lisa has been focusing her attention on the topic of the role of toxins in ME/CFS and similar diseases. She is based in Chicago but has spent most of the past five years traveling around the U.S. in a non-moldy RV, visiting 23 states and spending time in hundreds of different locations. She now is mostly recovered (including with return to pre-illness levels of cognitive capacity, resolution of chemical sensitivities and greatly decreased reactivity to mycotoxins/biotoxins), and credits extreme mold avoidance and detoxification for her return to functionality.
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Giles Meehan (producer of the outstanding video series “Get Well from ME”) long has been a role model for me with regard to the credible, factual way in which he has gone about communicating information about this illness paradigm. I thus have felt very fortunate that he has been willing to act as a resource for the development of this book and for the Paradigm Change endeavor as a whole. I am grateful for his unfailingly calm and wise counsel; for his consistent ability to redirect my attention to the inherent meaning of the work during those times when I felt frustrated or overwhelmed; and for his repeated insistence that this endeavor is important enough to justify the effort that others and I have put into it.

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Lisa Petrison, Ph.D.
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