

A TOWN FOR PEOPLE WITH CHRONIC FATIGUE

Patients diagnosed with chronic-fatigue syndrome moved from all over the country to Incline Village, Nevada, for an experimental drug. Then the drug disappeared.

By Mike Mariani 5:00 A.M.

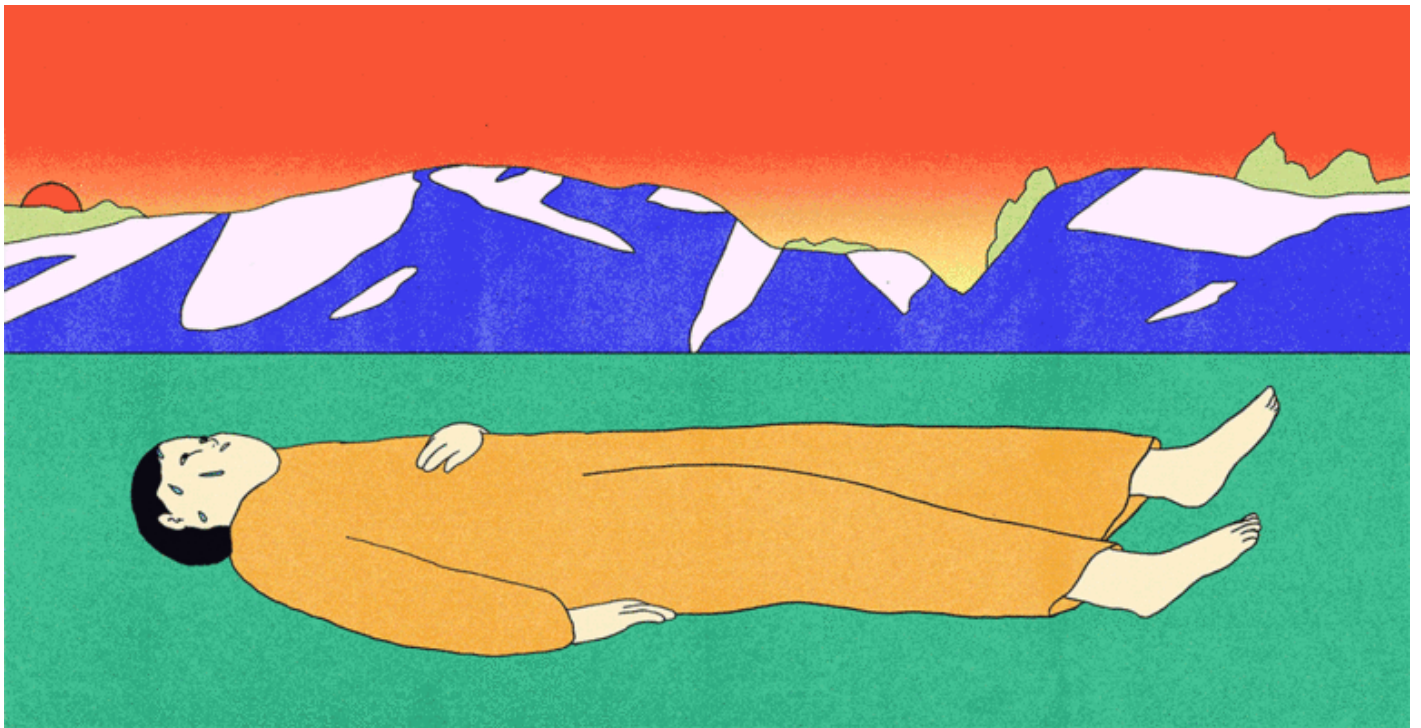


Illustration by María Medem

In December of 2012, I came down with what at first looked like a bad case of mononucleosis. I felt tired and had a sore throat, a cough, and a slight fever. At the time, I was twenty-six and working as an adjunct English professor at a small college in Westchester, New York. It was Christmas break, so I thought that I would sleep it off and feel better by the New Year. But over the next few months my symptoms grew to include muscle pain, migraines, and occasional vertigo. The cough went away but the tiredness got worse, and by the summer I was spending half my time resting in bed. I

was used to playing pickup basketball several times a week after work, but now a few pushups left me exhausted. I couldn't figure out what was happening. One afternoon, as an experiment, I went for a run near my apartment, in uptown Hoboken. I clipped my iPod Shuffle to my mesh shorts and jogged past Italian delis with dry-cured sausages in their windows and along a pier that hugged the Hudson. It felt amazing. But the next day, while grading papers with a few other teachers, suddenly, I became dizzy and weak. I left the office without explanation, and, for the next several days, I barely left my bedroom.

After a year of these symptoms, I visited an internist in Manhattan, who gave me a diagnosis: I had chronic-fatigue syndrome. According to the National Academies of Sciences, C.F.S. (sometimes referred to as myalgic encephalomyelitis) affects between eight hundred thousand and two and a half million Americans and is characterized by extreme exhaustion. Patients with severe cases are bedridden for years and rarely move or speak. Doctors are still not sure what causes it. For decades, many thought that it was psychosomatic. (My symptoms were so odd that, over the preceding year, I, too, had wondered if I was going crazy.) This sense lingers in popular culture. In the pilot episode of "House," from 2004, a patient comes to the clinic complaining of C.F.S., and Dr. House successfully treats him with mints from the vending machine. In a standup set in 2007, Ricky Gervais joked about people who say they have C.F.S. because they "don't feel like going to work." Today, though, most doctors who study C.F.S. think that its symptoms are caused by a dysfunction of the immune system, which is typically triggered by an infection, such as the Epstein-Barr virus (which causes mono) or viral encephalitis. Still, they don't understand why, even as most people bounce back from these ailments, a small percentage of them never recover. Because there's no clear biological cause, doctors recognize the disease by gauging symptoms subjectively, which makes diagnosis, in the eyes of skeptics, unreliable, and has kept away funding for research. There are currently no F.D.A.-approved medications to treat C.F.S.

Over the following three years, I saw a dozen doctors, who prescribed a range of treatments. The internist in Manhattan put me on injections of an amino acid derived from the livers of Argentine cows. On a few occasions, leaving his office, I experienced an energizing high that was either a temporary response to the cow liver or a marvellous placebo effect; it always wore off within a day, and I was later taken off the drug. An endocrinologist gave me a medication that stimulated my thyroid. Some

patients resort to folk remedies, like kombucha tea or licorice, or riskier treatments, such as amphetamines or shots of hydrogen peroxide. I tried testosterone creams, antiviral pills, blood-plasma infusions, and so, so many nutritional supplements. Nothing stuck, except the medical bills, and I was running out of specialists in the area who could help.

In 2016, I heard about an internist named Daniel Peterson, who was treating patients in Incline Village, Nevada, with an experimental medication called Ampligen. Few outside the isolated network of C.F.S. patients, caregivers, and specialists have heard of Ampligen, but, within the illness's sphere, the drug has developed a fabled reputation. In 2012, the F.D.A. provisionally rejected Ampligen's application for approval, because trial results had not conclusively proved that it was effective; Peterson is gathering more evidence to re-apply. Because data is limited, the drug's reputation hinges on anecdotal evidence, which should, of course, be considered with caution. But C.F.S. patients are very active in online message boards, and, when I Googled Ampligen, I came across powerful stories about the drug's effects. In a patient testimony from 1998 that was posted online, a woman named Karen, who was functionally disabled by C.F.S., wrote that, after three months on Ampligen, she was well enough to do her taxes again and go skiing with her son. A blogger named Kelvin wrote on a Web site called *The New Ampligen Diaries* that, after getting on the drug, he "started to experience a taste of 'normal' life—a *free* life—for the first time in a very long time!" The Web site for the American Myalgic Encephalomyelitis and Chronic Fatigue Syndrome Society quoted Kenny De Meirleir, a doctor based in Belgium, as saying that eighty per cent of his patients reported "complete clinical recovery" on Ampligen. (De Meirleir later told me that, in fact, only a small subset of his patients had fully recovered.)

Peterson first discovered Ampligen's potential for treating C.F.S. in the late nineteen-eighties, and, since then, patients have moved to Incline Village from all over the country to get on the drug. Ampligen is administered as a twice-weekly infusion, and it suppresses symptoms but doesn't cure them, meaning that treatment needs to be continuous in order to remain effective. Some patients have stayed in Incline for only a few months of temporary treatment, but many have settled there permanently, hoping to take the drug for the rest of their lives. In all, Peterson treats some fifty C.F.S. patients who live in the area full time, and periodically sees around eight hundred more. I had no idea whether it would work for me, but I had little to lose. In the summer of

2016, I quit my job, packed up whatever would fit in my car, and drove across the country in the hopes of getting on Ampligen.

Incline Village is an affluent town of nine thousand people, perched on the north shore of Lake Tahoe and shrouded in ponderosa pines. Its stunning natural beauty and proximity to beaches and ski slopes have made it a vacationers' paradise. Peterson's treatment center, Sierra Internal Medicine, is situated in a brown-stucco building near one of the lake's bays. Inside, patients sit for doses of Ampligen in the infusion room, largely in silence, while nurses tend to their I.V. bags and researchers pore over blue binders. Peterson, who is sixty-eight, with broad shoulders and a mustache, shuffles through the office quietly. He has become a kind of folk hero among his patients. Anita Patton, a fifty-seven-year-old mother of three who recovered from C.F.S. on Ampligen, told me that Peterson "was directly responsible for giving me the health to raise my children." Anthony Komaroff, an internist at Harvard who studies C.F.S., said that Peterson had doggedly researched the disease for decades, "against a lot of negative feelings among some of his colleagues." On the wall of the infusion room at Sierra Internal hangs a cartoon of Peterson and his former partner, Paul Cheney, amid a clutter of beakers and textbooks, captioned "Cheney & Peterson Turned into the Woodward & Bernstein of Clinical Medicine!"

Peterson moved to Incline in 1981, fresh out of his residency, and established Sierra Internal. There were only a handful of doctors in town, mostly general practitioners, so the practice flourished. In the fall of 1984, Peterson and Cheney began to receive patients who described a strange set of symptoms. Hillary Johnson details these visits and their fallout in her book "Osler's Web," a groundbreaking account of the early days of C.F.S. First, a wealthy woman in her sixties, who summered in Tahoe, came in, complaining of overwhelming exhaustion. Peterson initially suspected that she had cancer, but her blood tests came back normal. Next, a motorcycle enthusiast, who was six feet three and two hundred and sixty pounds, grew weak after returning from a Harley-Davidson rally in South Dakota; a friend had to drive him to his appointment, which he found humiliating. A woman in her early forties, who had completed the San Francisco marathon five times, told Peterson that she could no longer eke out a mile at a light jog.

In December of that year, around half of the Incline High School girls' basketball team came down with a similar illness, causing the team to forfeit the season. By the end of the school year, a handful of teachers from nearby Truckee, California, got sick. "They were hit really hard with whatever this was," Peterson told me. By the fall of 1985, Peterson and Cheney had seen more than two hundred patients who described the same symptoms. "In the beginning, it looked like mono," Cheney told me. "They had sore throats, they had swollen glands, they had low-grade fevers, they had severe fatigue." Some patients recovered, but many didn't, and the doctors couldn't explain why. "It's almost like the Great Plague came through," Cheney said.

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Peterson and Cheney reached out to colleagues all over the country and sent blood samples to distant laboratories, hoping to identify some physiological abnormality. "Cheney and I were very inquisitive, very forceful," Peterson said. "We can't just sit by and watch this." The closest they came to a working theory was an article in the *Annals of Internal Medicine*, in January, 1985, which described a possible connection between the Epstein-Barr virus and persistent fatigue in adults. "My original hypothesis was

that they got some other virus that reactivated E.B.V.,” Peterson said. Desperate for answers, he reached out to a friend at the Centers for Disease Control to ask for help. In September, 1985, two C.D.C. epidemiologists, Jon Kaplan and Gary Holmes, were dispatched from Atlanta to investigate the so-called Tahoe malady.

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The C.D.C. investigation in Incline lasted nearly a month. The epidemiologists, who were trained to be skeptical—part of their protocol for such inquiries involves ruling out “pseudoepidemics,” in which misleading laboratory tests or other red herrings falsely suggest the spread of a disease—took a wary tack. When they examined the patients, their apprehensions were deepened by the varied symptoms they encountered: most reported fatigue and muscle or joint pain, but some also experienced light sensitivity, hair loss, and anomic aphasia—difficulty recalling words and phrases. “The whole situation was bizarre,” Kaplan told Johnson, years later. “I mean, here you have this exceptionally beautiful place with weird people and weird doctors and a weird medical problem—the whole thing was weird.” Holmes described the situation to Johnson as “two doctors isolated in a mountainous area who had worked themselves into a frenzy.”

When the doctors set up interviews with Kaplan and Holmes and their sickest patients, the conversations only reinforced the investigators’ skepticism. Peterson and Cheney were ebullient to finally have the chance to show this flummoxing condition to highly trained epidemiologists; to Kaplan and Holmes, it felt as though they were being aggressively lobbied to believe in a strange new disease. Kaplan later confessed to Johnson that he suspected a kind of “collusion” between the doctors and patients. The pair left Incline with a sense that the epidemic was exaggerated. They believed that, at most, it was a set of disparate symptoms haphazardly lumped together. At times, they seemed to imply that it was a sort of mass folie à deux—a shared delusion. (There are documented cases of group psychogenic illness. In 2011, some twenty girls at a high school in Le Roy, New York, simultaneously developed a condition that caused them to

stutter and twitch uncontrollably, and which seemed to have no biological cause. In the past few years, hundreds of refugee children in Sweden have fallen into coma-like states after being informed that their families would be deported.) Peterson had considered the possibility of psychosomatic illness but felt it improbable, because many of the patients were otherwise well-adjusted, with no history of mental instability or trauma. “I’d seen almost all these people for three years when they were well,” he told me. Any psychological theory just “wasn’t right.”

In May, 1986, Kaplan and Holmes published their findings in a weekly C.D.C. digest. (Holmes declined to be interviewed for this story, and Kaplan couldn’t be reached for comment.) The brief article, titled “Chronic Fatigue Possibly Related to Epstein-Barr Virus - Nevada,” advised doctors to make a diagnosis of chronic Epstein-Barr virus—the C.D.C. didn’t adopt the name “chronic-fatigue syndrome” for another two years—only at the exclusion of all other possible diseases. The article acknowledged that the patients had unusually high Epstein-Barr antibodies in their blood but noted that these proteins could sometimes be found at similar levels in the general population. “Currently available data neither prove nor disprove the hypothesis that E.B.V. activity is responsible for chronic illness,” Kaplan and Holmes concluded. Municipal officials and local media outlets, eager to end a saga that they worried was damaging the tourism industry, seized on the report’s skepticism. The Reno *Gazette-Journal* ran a piece titled “Health Officials Dismiss Mystery Disease at Incline.”

Despite the report’s ambivalence, people all over the country with similar symptoms to those detailed in it began to contact Sierra Internal. “It materialized instantaneously that we had hit a very big chord,” Cheney said. The doctors told Johnson that, in the three days following a press conference about the illness, they received two hundred calls from patients and doctors. Letters flooded the office; in one, a magazine editor wrote that she is “sick to the point where sometimes brushing my teeth is all I have the energy for in a day.” In the years that followed, Peterson and Cheney—who started his own clinic, in Charlotte, North Carolina, in 1990—saw more than seven thousand patients with C.F.S. But, in the absence of a drug to treat the disease, the doctors were forced to troubleshoot by administering antiviral medication, to beat back Epstein-Barr, and treating symptoms like chronic pain and insomnia with additional prescriptions. “It was a steep learning curve,” Cheney said. “None of us knew what the hell to do.”

The theory that the condition was psychological predated the Tahoe malady by more than a century. During the eighteen-sixties, doctors in America diagnosed an illness called “neurasthenia,” which was characterized by tiredness, headaches, and insomnia, and was thought to be brought on by the anxieties of urbanization. In 1881, the neurologist George Miller Beard wrote that neurasthenia was caused by “*modern civilization*, which is distinguished from the ancient by these five characteristics: steampower, the periodical press, the telegraph, the sciences, and the mental activity of women.” Many contemporary experts believe that this was an early description of C.F.S. Freud, who studied neurasthenia at the end of the nineteenth century, believed that it stemmed from “non-completed coitus.” Treatments included bed rest and electroshock therapy. In the nineteen-thirties and forties, epidemics of what was referred to at the time as neuromyasthenia or atypical poliomyelitis—but which may have been C.F.S.—were reported in Southern California and eastern Switzerland, and were attributed by some doctors to mass hysteria. So many of these cases were reported in a fishing village in northern Iceland that, for a time, the condition was known as “Iceland disease.”

The 1986 C.D.C. report did little to clear the confusion. In the nineteen-eighties and nineties, C.F.S. was derisively nicknamed “yuppie flu” and “the Hollywood blahs.” Young scientists were afraid that researching C.F.S. would lead them to be shunned by the medical community. The term for the disease, meanwhile, led to further misunderstanding. A report by the Institute of Medicine (which is now part of the National Academies of Sciences), in 2015, found that “the name ‘chronic fatigue syndrome’ leads others, including clinicians, to think that patients are malingering.” The report suggested calling it “systemic exercise intolerance disease,” but that term never caught on.

In the two-thousands, hundreds of studies demonstrated biological abnormalities in C.F.S. patients—impairments in the way cells metabolize energy, inflammation in the central nervous system, and a slew of immunological irregularities—but none found a clear pathological cause. “It made everyone uncomfortable to define an illness just by subjective symptoms,” Komaroff, the Harvard internist, said. This lack of clarity formed a decades-long tension: patients aggressively sought treatment for a diagnosis that many of their clinicians didn’t believe in. The more frantic and indignant that patients became, the more clinicians grew convinced that the issue was psychiatric. There are

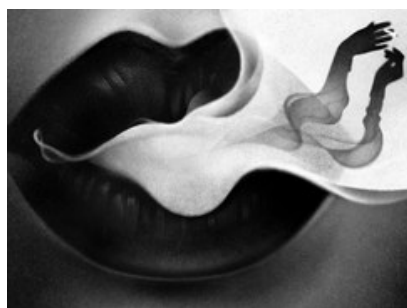
still some doctors who hold this view. In 2015, Suzanne O'Sullivan, a neurologist at the National Hospital for Neurology and Neurosurgery, in London, published a book called "It's All in Your Head," which includes a chapter about a young woman with C.F.S. symptoms that O'Sullivan determines to be psychosomatic. "Psychological factors and behavioral issues, if they are not the entire cause, at the very least contribute in a significant way to prolonging the disability that occurs in chronic fatigue syndrome," she writes. Her reasoning, she says, rests on the "lack of evidence for an organic disease."

Today, though, most of the major health agencies, including the C.D.C. and the National Institutes of Health, have concluded that C.F.S. likely has a biological origin. Since the epidemic in Tahoe, there have been outbreaks in upstate New York, Northern California, and North Carolina, and many researchers believe that these outbreaks are caused by clusters of other infections, such as mono or Ross River fever, which leave commensurately large populations—as many as one in ten people who contract the viruses, according to the C.D.C.—with C.F.S. (The largest outbreaks may be caused by an as yet unidentified virus that leaves an even greater proportion of patients with C.F.S.) Experts think that these viruses can send the body's defenses into overdrive. "There is a lot of evidence that says the symptoms of the illness reflect a state of chronic activation of the immune system," Komaroff said. Dendritic cells, which warn the body of foreign substances, and white blood cells, which kill pathogens, are put on high alert, wearing the body out. Komaroff believes that the process also produces large quantities of immune cells called cytokines, which cause fatigue, muscle pain, and even cognitive impairment when released at high levels. Other doctors think that mitochondria, the energy generators in cells, are impaired, which would help explain the chief symptom of the disease.

The dominant theory holds that C.F.S. may not have a single etiology but may instead be a dysfunctional state of the immune system triggered by one of several ailments. Another asserts that C.F.S. is actually an umbrella term for several immune conditions with similar presentations. Ongoing research at Stanford and Columbia focusses on pinpointing the causes of the illness and on developing laboratory tests to diagnose it. But progress remains slow because, though the N.I.H. has now determined that the disease is biological, funding has yet to catch up. Between 2015 and 2018, the agency allocated a yearly average of a little less than eleven million dollars to C.F.S., which is a

tiny sum for medical research. The agency gave more funding to tuberous sclerosis, a rare genetic disorder that affects fewer than forty thousand Americans, and to osteogenesis imperfecta, a brittle-bone disease, which affects some twenty thousand.

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When Peterson was treating his first patients, in the eighties, there was no research funding for C.F.S. at all. He conducted his investigations alone, looking for patterns in the lab work. In 1988, he was reviewing a blood test for a woman who had become so sick that she needed to be transported to his office on a stretcher, and he noticed unusually high levels of the HHV-6 strain of the Herpes virus. Many people carry HHV-6, but its strength in the patient suggested that her immune system was in disarray. He asked his colleagues if they knew of any medications that could both fight viral infections and modulate the immune system. A biochemist named Robert Suhadolnik told him that he was doing some work for Hemispherx Biopharma, a pharmaceutical-research company in Philadelphia, which was developing Ampligen and hoped to get approved to fight immune-system disorders. It sounded promising.

Later that year, Peterson flew to Philadelphia and met with William Carter, who was then the C.E.O. of the company, and David Strayer, its medical director, to see if they

would be willing to let him test the drug as a C.F.S. treatment. The AIDS epidemic had made the F.D.A. more open to small, improvisatory trials, and Peterson hoped that this environment would work in his favor. “I just want to try it on this one patient and see what happens,” he told them. The executives agreed, and, after a year on Ampligen, the woman improved dramatically. Ampligen appeared to rehabilitate some of her immunological deficiencies by restoring her dendritic and white blood cells to normal functioning. Peterson then ran a pilot study with ten more patients. After twelve months, seven reported moderate or significant improvement of their symptoms. Among the early patients were “super responders,” Peterson said—“people who went back to work, back to skiing.”

A drug goes through three trial phases, of increasing size and rigor, before the F.D.A. considers it for approval. In 1990, Hemispherx began a Phase 2 trial of Ampligen. The study, which lasted twenty-four weeks and included ninety-two participants, from Peterson’s clinic and three other sites, used the Karnofsky Performance Scale to assess patients. A perfectly healthy person gets a hundred on the scale, and a dead person gets a zero. The scores of patients with C.F.S. fell as low as thirty, indicating severe disability. After six months, patients receiving Ampligen improved by an average of ten points, and the control group experienced no change. It was, quietly, a major breakthrough. “Ampligen is the only drug that’s ever made it through Phase 2 trials in all these years,” Peterson told me, proudly. An early patient described herself on Ampligen as “like Lazarus rising from the dead.”

I arrived in Incline Village on the Fourth of July in 2016, amid fireworks and star-spangled bathing suits, and rented a one-story home on Lake Tahoe’s western shore. At the time, Peterson’s practice was the only place in the country where I could get on Ampligen. (A doctor in Raleigh, North Carolina, and another in Salt Lake City, Utah, were receiving supplies for people whom they had been treating for years, but neither was admitting new patients.) Peterson receives the drug through a “compassionate-care open-label cost-recovery trial,” which is a long way of saying that patients can be sure they are receiving the drug, rather than a placebo (unlike in double-blind experiments, such as the Phase 2 and 3 trials), but they pay for it themselves. This is not an uncommon practice, but it places a burden on patients: a year’s supply of Ampligen costs almost thirty-seven thousand dollars and is not covered by insurance. It was a

huge sum, but, between my savings and some help from my dad, I scraped together enough money for a year on the trial.

Before I could start on Ampligen, Sierra Internal administered a battery of tests intended to capture my body's "baselines." I sat in padded blue blood-drawing chairs while nurses felt for raised veins, and I ran on a treadmill with a plastic mask strapped to my face and a snarl of wires dangling from my chest. Peterson was seeing some thirty-five patients a day, and the atmosphere at the practice was hectic. It occurred to me that, for him, the Tahoe epidemic never really ended; his panel of C.F.S. patients has only grown. After my tests, I had several appointments in the exam room with Peterson. He chooses his words carefully and seems to focus best without the distraction of conversation, so our sessions were largely silent. At the end of one appointment, he told me that, because of my age, my lab tests, and the recent onset of my illness, I was a "very good candidate" to respond to Ampligen.

While I waited to get on the drug, I tried to distract myself by exploring the area. I took cautious walks through the Sierra Nevadas, which were still covered in snow. I didn't tell people why I'd moved to Incline, preferring vague pretenses; I'd learned that when I mentioned C.F.S., they either became skeptical or joked that they probably had it, too. But over time I began to discern two groups living side by side in the town: the well-to-do Californians, who took rumbling powerboats out onto the lake, and an almost invisible group of C.F.S. patients, some of whom were too sick to leave their beds but many of whom lived quiet, normal lives in recovery. Patients ride scooters through the aisles of the grocery store, because it's easier than walking, and wear surgical masks to prevent infection. Those who are too tired to drive take local cab services around town and rent condos close to Sierra Internal to keep the trips short. Some of Peterson's first patients still live in Incline, and they form a tight-knit group of old-timers who give each other rides to appointments and travel together to C.F.S. conferences. Living in Incline affords them a sense of community and legitimacy that doesn't exist anywhere else.

One of the patients I met in Incline was Mary Schweitzer, a former professor of history at Villanova University, in Pennsylvania. Now, at sixty-nine, Schweitzer has sharp eyes and the sarcasm of someone who's had to wring laughs out of difficult circumstances. In 1990, Villanova had an outbreak of mono, and Schweitzer, despite contracting it earlier

in life, came down with a reactivated case. She recovered somewhat, and resumed teaching, but continued to feel off. Then, in October, 1994, she sat down in her office to grade a stack of papers and found that she couldn't read them. She struggled to comprehend passages of books, couldn't decipher her teaching notes, and failed to recall details from her research—she specializes in the American Colonial period, and, during a lecture, she couldn't remember George Washington's name. "One after another, different students from my class"—who had family members with C.F.S.—"came up to me and said, 'I know what you have, and it's not good news,'" she said.

Schweitzer took a leave of absence from her job, spent most days in bed, and only left the house in a wheelchair. She told me that her doctors were dismissive, believing C.F.S. to primarily afflict "upper-middle-class professional women trying to have it all, and their bodies were saying, 'You can't.'" After an infectious-disease specialist gave Schweitzer the official diagnosis, he asked if she wanted to see a marriage counsellor. She asked him why. "Well," he replied, "most husbands abandon their wives when they get sick like this."

In early 1999, Schweitzer joined an Ampligen trial in Pennsylvania. Within two months, she was able to walk again. Three months later, her teen-age daughter recommended the novel "Memoirs of a Geisha," and she devoured it in a single night. "All through that year I got presents," Schweitzer said. "One day I couldn't do something, and the next day I could." Before starting Ampligen, she set three goals for herself: to read a book, to walk on the beach, and to dance at her son's wedding. By the fall, she'd done all three.

After taking Ampligen for twenty months, "I was pretty damn normal," she said. "I thought I was cured." She stopped taking the drug and started making plans to go back to teaching. A year later, she relapsed. In 2002, she joined a trial at a hospital in Philadelphia, and again her condition improved. But, six years later, the physician running the trial died, the trial ended, and she relapsed again. Though many doctors were shuttering their clinics—the staffing, equipment, and paperwork required to administer Ampligen make it time-consuming and unprofitable—Schweitzer heard that Sierra Internal was still taking patients. In 2010, she moved to Lake Tahoe and got back on the drug. She found it comforting to be close to Peterson and to others with the illness. "Everywhere I'd been, I've had to be the expert on the disease," she said. "I'm

not the expert here. I can just be a patient.” Within six months, she was walking several miles a day and working on a memoir about her experience with C.F.S. She met her brother in Point Reyes, and they hiked along moss-covered cliffs and windy beaches. Assessing the last twenty-five years, Schweitzer told me, “I didn’t feel like a normal person for one minute of one hour of one day until I got on Ampligen.”

In 2012, Peterson and Strayer, from Hemispherx, published the results of Ampligen’s Phase 3 trial in the scientific journal *PLOS One*. The experiments had begun in 1998, at twelve sites throughout the country. In addition to the K.P.S. scale, researchers had used an exercise-tolerance test, which assesses a person’s physiological responses to walking on a treadmill. The findings of the trial were mixed. Patients who received the drug showed a net improvement of twenty-one per cent on the stamina test. But the trial was not able to replicate the same results on the K.P.S. measurement as the earlier study; there was no statistically significant difference between the results of the patients getting Ampligen and those who weren’t.

A few months later, Ampligen went up for approval. A team of scientists at the F.D.A. put together a comprehensive review of the drug using data from both the Phase 2 and Phase 3 trials. They found several points of concern. Although they agreed that the Phase 2 trial demonstrated improvement among patients on Ampligen, they reported several “conduct issues” with the study. There were data discrepancies, including inconsistent baseline testing. Hemispherx had made several modifications to the trial months after it had begun, including shortening it from forty weeks to twenty-four, which the F.D.A. found troubling. (Strayer says that he felt that the trial could be shortened without compromising the data’s validity.) They worried that the Phase 3 trial, meanwhile, was too small to give an adequate sample. (Most Phase 3 trials include between three hundred and three thousand patients; the Ampligen trial included two hundred and thirty-four.) When they analyzed the data, they found negligible differences between the study and placebo groups for both the K.P.S. and the exercise-tolerance test—a finding that differed from the company’s conclusions.

That December, the F.D.A. convened an advisory panel to vote on approving Ampligen. The transcript of the meeting speaks to a panel split not so much on the drug’s potential—most members agreed that it appeared to work well for some patients—but on whether the trials’ small sizes and mixed results made it unwise, at that stage,

to put the drug on the market. Larry Borish, an immunologist who supported the drug's approval, told the committee that he "wanted to send a message that I really think there's a signal here that this drug works." But Lenore Buckley, the committee chair, said that, "as excited as we all are" at the prospect of a treatment for C.F.S., "I can't imagine rolling out and approving a drug based on placebo-controlled trials in only a couple of hundred people." Komaroff, who sat on the panel and argued against Ampligen, told me that he was worried that the data was not yet decisive. The scientists voted eight to five against the drug, and the F.D.A. rejected it.

The fact that we still understand so little about C.F.S. may have helped to foil the trial. There are likely a variety of causes for the disease, so it affects patients differently, creating "subsets." About seventy per cent of patients have a clear viral onset, according to Cheney, and thirty per cent develop the disease over several years. Patients are further demarcated by the levels of viruses like HHV-6 in their systems, the functioning of their white blood cells, and the length of time they've been sick. According to Charles Lapp, an internist who ran a C.F.S. clinic in North Carolina, Ampligen appears to generate a "very favorable response" in only around forty per cent of his patients and likely affects some but not all subsets. Because there's still no consensus on which patients will respond to Ampligen, the trial admitted a wide range of patients, which may have masked the drug's effect on some of them. "A study that did not parse M.E./C.F.S. by subtype might miss a bona fide treatment response," Ian Lipkin, a virologist at Columbia who studies C.F.S., said. Cheney stopped administering Ampligen in the late nineties because of the mixed results. "It helps save some people, but I don't think it helped most of the patients," he said. "C.F.S. is a much more complicated illness than Ampligen can solve."

Many with C.F.S. were devastated by the rejection. When the decision came out, Bob Miller, a sixty-year-old patient at Sierra Internal who had read about the brash, unapologetic methods of AIDS activists, went on a hunger strike for eleven days. "I just thought it was completely unfair and unjust," he said. His wife, Courtney, a researcher for a labor union, showed me binders of letters that she had collected from more than seven hundred people, urging the F.D.A. to approve the drug. A father in Colorado who had scaled several of the Rockies' highest peaks writes that he can no longer leave his house; a working mom in Michigan describes her life as a "Lifetime movie" of days whiled away in bed. Patients recount being labelled dishonest, lazy, and mentally

unstable by their doctors. “It is criminal that this medication is not available,” Courtney said. Bob had received his first supply of Ampligen, which had significantly improved his condition, through the same Phase 3 trial that the F.D.A. had found unconvincing.

After the rejection, Ampligen sites dwindled, but Peterson continued treating patients, trying to discern which subsets were most likely to respond to the drug. (Slow progress is being made; in 2016, Hemispherx released an analysis of the data showing a higher rate of efficacy among patients who have had the disease between two and eight years.) To win approval, Peterson and Hemispherx will have to gather data for the next few years, and then mount another Phase 3 trial. “The bottom line for Ampligen . . . is it’s the most effective thing in assuring recovery,” Peterson said. “Which is why I always stuck with it.”

In April, 2017—nine months after I moved to Tahoe—I was approved for Ampligen. I sat for my first infusion, which takes about an hour. After the butterfly was inserted into my forearm and a saline flush was administered, I felt a cold rush surge up my arm as the drug entered my body. If I was a “responder,” the nurse told me, I would feel the effects in a few months. Two weeks later—a few days after my third infusion—Hemispherx put the trial on hold. The company said that it had identified issues with the clinic’s drug accountability and record-keeping, which would need to be addressed before the trial resumed. (The hold was then extended because Hemispherx ran low on supplies.) In the meantime, everyone in Incline was pulled off Ampligen, and patients who had relied on the drug for years to lead normal lives relapsed. Some declined quickly. By May, Bob Miller, who was well enough in the fall to attend all of his son’s home football games, couldn’t go to any of his other son’s baseball games. Others deteriorated over months, losing the ability to bathe themselves, and then to get dressed. Family members scrambled to fly to Tahoe to care for their relatives.

That winter, I visited Mary Schweitzer at her wood-frame home on the outer edge of Incline. When I arrived, she was letting her Irish setter, Duke, out into the back yard. She now relied on a wheelchair when she left the house. Reading had again become arduous, and she could barely make it through short news briefs. She settled into a reclining chair opposite her fireplace and told me that the most difficult aspect of the experience was the uncertainty. “There’s something that works that I might not be able to get back,” she said.

The same week, Sierra Internal held an informational meeting at a community center in Incline. I sat on a folding chair in a room full of other patients—some of whom hobbled in on canes—and the family members of those who were too sick to leave home. Gunnar Gottschalk, the trial’s research coordinator, said, “It’s not lost on me that people have uprooted their entire lives and moved up here.” He noted that he thought the trial would resume in as little as two weeks, but people didn’t seem heartened by the news. “We’d all be looking a lot happier if we trusted it,” one said. Peterson urged them to be patient and emphasized the long-term research implications that the trial would have when it resumed. They were not comforted. “My husband can’t get out of bed,” Courtney Miller said.

I stayed in Incline for eight more months, waiting to get back on Ampligen. My first three infusions had no effect, and I still had muscle pain and trouble concentrating. The exhaustion came in waves when I pushed myself too hard; at one point, on my way to visit a friend in San Francisco, while driving eighty miles per hour on the interstate, I suddenly felt dizzy and had to pull off and find a gas station to rest. In the winter, my car’s tire was gashed open by craggy ice, and I walked home in a blizzard, which wiped me out. I spent my afternoons pacing around my kitchen, making furious calls to Sierra Internal, to no effect. In November, 2017, after a year and a half in Tahoe, I gave up, packed my things, and left for D.C., exasperated at how close I had come to getting the treatment. I was lucky that I could drive across the country: most patients who made the pilgrimage to Tahoe literally didn’t have the strength to leave.

In July, 2018, eight months after I left, I got word that the trial had finally resumed. Hemispherx—which this week changed its name to AIM ImmunoTech, as part of a rebranding effort—is now actively recruiting new participants. Longtime patients are once again recuperating. After a year back on Ampligen, Schweitzer is reading and writing again, and taking short walks. I’m almost exactly where I started three years ago, trying to decide whether to pick up my life and move back to Incline. It’s the only place where I can receive a drug that could change my life, but access remains precarious. For Schweitzer, this is her fourth time recuperating on Ampligen. “I can be normal on this drug,” she said. “I’m terrified of losing it.”

Mike Mariani is a writer based in northern California. [Read more »](#)
