

## **A New Yorker with chemical sensitivities move to Arizona and finds a new calling as an activist**

**By Madeline Rivera**



**Madeline grew up in New York but had to move to the cleaner air in Arizona. Here she found her true calling as an MCS activist.**

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I spent my first 27 years in Brooklyn, New York, and grew up near the Brooklyn Navy Yard and downtown. Everything was within walking distance, so there were few cars. It was then a wonderfully diverse working-class neighborhood, with many European immigrants. My parents were born in Puerto Rico. My mother grew up in Arizona, and met and married my father in Brooklyn, where they had lots of family.

My mother had pre-eclampsia and almost died when both my brother and I were born, so we were Caesarean babies with compromised microbiomes. Mom read articles on health, shopped at a farmer's market, and fed us nutritious meals and cod liver oil. However, she cleaned every day with CN, a noxious disinfectant I hated, and she felt ill and had to lie down for a few hours every afternoon.

I was a picky eater, stopped eating red meat at age seven when I kept gagging on it, and suffered from rashes every winter and chronic sinus problems. Twice I had severe nosebleeds and was rushed to the ER, and in fourth grade I had bronchitis and missed school for two months.

I struggled in first grade until my teacher realized I already knew how to read but couldn't see a thing on the blackboard. She sent me to get my first pair of glasses, and from then on I did well in school. I was probably reacting somewhat, though, because I constantly bit my nails, and fresh paint and a certain perfume bothered me.

When I was 12, my father bought a car and a small grocery store several miles away. My parents worked in the store six days a week. Over the next few years, we moved three times, which meant fresh lead-based paint, new flooring, and pesticides. I hated the new neighborhoods but loved my new sixth-grade classmates. We planned to have a great time together in junior high, but my teacher had other plans. She had me take a test for Hunter College High School, a public school in Manhattan for grades 7-12 with many illustrious graduates. I was shocked when I was accepted and refused to go, but my mother insisted.

The education at Hunter was first-rate and my grades were good, but I had culture shock and a brutal three-hour round-trip commute, packed like a sardine in buses and trains. The best part of those years was seeing all the top Broadway shows for \$2.00 using our student passes and getting Paul Newman's autograph.

I binged on sodas and junk food, and wound up with 14 amalgam fillings. In grammar school I was often the emcee, but now I gradually became painfully shy and anxious. Years later I learned that these are symptoms of mercury poisoning, and I was a poor detoxifier. There was mercury in my amalgams, in the

thermometer that broke in my mouth, my tuna sandwiches, and the nose drops and contact lens solutions I used daily. More was to come.

In 1961, after six years at what was then an all-girls school, I was one of twelve girls among 3000 boys at Rensselaer Polytechnic Institute in Troy, New York. JFK was president and the race for space was on--we did calculations for getting to the moon on our slide rules. I was more interested in boys, playing bridge, and hanging out with friends every night, and rarely studied. In my defense, my brand-new dorm was filled with particle board. My major was chemistry, and the chemistry building, built around 1850, was probably moldy and toxic. I kept spilling things in lab, and my textbooks were slowly dissolving. Tobacco companies paid students to pass out free cigarettes, and I smoked on and off for the next 13 years. The drinking age in the State of New York was 18, so alcohol was free-flowing. Sophomore year I spent two weeks in the infirmary with a mystery virus, which I later learned was mono. In my junior year I withdrew rather than flunk out, which was not unusual, and moved back home.

For years I took college courses at night and worked during the day. I spent one year as a lab technician at International Flavors and Fragrances, making perfume samples from essential oils for companies that added fragrance to their products. One day my boss said casually, "You know, all these chemicals are carcinogenic." The air throughout the building was supersaturated with perfume, but I soon adapted to it and loved working there--until I sustained a head injury when a subway door violently closed on me as I was entering the train and passed out. I had never had a headache before, but now I was having severe headaches at work. My father had just died following surgery for a brain tumor, so I took a month off and visited family in Arizona. When I returned to work the headaches returned, so I had to quit. Thirty years later, former co-workers who were still on the job told me that one friend had also had to quit because of headaches due to a head injury. Another was a perfumer in Paris.

I took drawing and painting classes at the Art Students League. The art chemicals were toxic, but if they were affecting me, I wasn't aware. I needed to earn money, and computer programmers were in high demand, so I also took a computer course. To my surprise I loved programming, and finally had a promising career.

In 1970 I was working in Yonkers helping to automate a 19th century sugar refinery that was sprayed every two weeks. We guzzled free sugary sodas all day, and a coworker told me about his friend Donald, who worked in real estate for his father Fred Trump and spent every conversation claiming that he could be president.

In order to shorten my commute, I moved to Greenwich Village. It was an exciting time. I went to the first Earth Day and Women's Equality rallies. My neighbors were great and got me interested in politics and travel. I took my first trip to Europe and loved it, despite getting sick from a typhoid vaccine and a stomach bug. I went back every year for the next eight years.

I was in a serious relationship, and my boyfriend ate a lot of red meat. For a while I became a heavy meat eater too, literally, gaining 15 pounds in no time, and feeling sluggish. I later learned that a plant-based diet was best for my blood type, A+. My childhood instincts were right.

My boyfriend's mother taught school and mysteriously got sick once a month (I'm sure now that's when her school was sprayed). She and her husband moved to a remote area in northern Maine with clean air, because the city's air made her sick, and she did much better. This was new and strange to us. Little did we suspect what was to come.

### **A perfect storm**

In 1972 I got a job close to home as a programmer/analyst for New York Telephone in a brand-new, airtight skyscraper built at the height of the energy crisis. New carpet fumes and pipe, cigar, and cigarette smoke were recirculating. My co-workers and I complained of various symptoms, some very serious. Within a few years, four men under 50 died of heart attacks: one was 27, one died at the lunch table. The term "sick building syndrome" was not coined until 1986.

My old fillings were crumbling, so my new dentist replaced them with a high-copper amalgam, which later was found to be the most problematic kind. He took no precautions to protect me from mercury. I was having some anxiety and depression; so was my neighbor, who went to the same dentist. Therapy was no help. It was very confusing, because we were both having fun. One day a therapy-group friend with the same symptoms called to say she'd had her amalgams removed and was now well, but I was preoccupied with new health problems.

In 1974 my building became heavily roach-infested, and our apartments were sprayed regularly. There were still bugs in the cat food, so I sprayed Raid daily. My neighbor had her apartment sprayed by an exterminator using a strong pesticide, and I did the same. Now, instead of going out every night, I went from my toxic apartment to my toxic office and back again, exhausted. I had several bouts of strep throat. Antibiotics were not working, and I didn't realize they were destroying my gut flora. I started having severe headaches daily and many food sensitivities.

My boyfriend and my neighbor both started complaining about bad air quality in our neighborhood. I was smoking again and had no idea what they were talking about. He threatened to wear a gas mask, and moved to Long Island; she moved to New Jersey. Were there toxic emissions in our area, or coming from industry across the river in New Jersey? Years later I learned that two other EIs had lived in my neighborhood and fallen ill about the same time I did.

By 1976 I was reacting to traffic fumes, formaldehyde, and my own lipstick. I obtained a transfer to an older building across town and moved to a nearby apartment. I disconnected the gas stove and never used pesticides, but still had a lot to learn. I quit smoking once and for all, and now no longer tolerated the tobacco smoke in the office. I was told to walk around the block when I felt ill, which was all day every day. Yet I felt better whenever I traveled.

I went from doctor to doctor, including a candida expert in Alabama, but nothing worked. One test indicated that my mercury levels were high, but the retest was normal. I began doing research on mercury. At one doctor's office I met a patient who had been to Dr. Randolph, the father of Clinical Ecology. She became my good friend and mentor. A clinical ecologist in Connecticut had me swallow dilute food and mold solutions and wait for reactions. This left me too ill to return for treatment and too ill to stay in New York.

## **Searching**

I obtained a transfer to the Phoenix office, near my brother, but couldn't tolerate it and turned it down. I was told I could get well living by the ocean, so I took a trip down the west coast from Vancouver, Canada, to Seattle, Portland, and San Francisco, and decided on La Jolla, California.

In 1981 I gave notice at work, sold my apartment in two days, and was on my way, convinced I'd be well enough to get a new job in one month, or at most two. I loved the area and rented an apartment in Pacific Beach, right on the beach, but there were bonfires and thick black smoke every night. Within five days I was coughing up blood and reacting everywhere. Santa Fe was a little better, but the altitude didn't agree with me. My favorite aunt and uncle had retired to Tucson and invited me to visit, so I did.

I rented a series of apartments near a bus line and shopping. All were problematic. I got sicker and sicker and was bedridden for a couple of months, feeling as though a truck had run over me. My mother moved from Phoenix to help, and did my shopping. A very kind man at the EPA sent me air quality reports for the entire country, and we decided that the only place with clean air was some uninhabited land between Wyoming and Idaho. So I stayed.

Sulfur dioxide emissions from smelters miles away were polluting the air. Greenpeace activists occupied the San Manuel smokestacks in protest, and in 1987 that smelter was shut down. However, there was still considerable pollution coming from two smelters in Mexico.

One day on TV I saw Liliás' yoga program. I followed along every day, then added Jack LaLanne's program. I was still hypersensitive, but my fibromyalgia disappeared as long as I kept moving: exercising, walking, or swimming, I visualized myself being strong and healthy, made healthy meals, got vitamin injections, and was feeling good outdoors, though not indoors. Every couple of weeks I had severe reactions for days. Why?? It turned out that maintenance dusted the apartment vents with pesticides for scorpions every two weeks. I moved once again.

Smoking was prohibited in grocery stores, yet people were lighting up as I shopped. I joined Nonsmokers Incorporated, a local group working to ban smoking in more public places. Each of us found tobacco smoke highly offensive. Ironically one member was highly offended that her perfume was also a big problem for me.

In 1983 I bought a car, learned how to drive, and, thanks to a loan from my mother, bought a house with an assumable mortgage in northwest Tucson. My mother's house-warming gift was one of her dogs, two-year-old Sammy, the perfect companion. Sammy loved people, was always happy, and went everywhere with me. He refused to eat dog food and loved whatever I ate, plus the steak I cooked him twice a day even though I was a vegetarian.

My house was four years old, as recommended by the clinical ecologist to allow for outgassing, yet I was getting worse! I couldn't go walking in the neighborhood because all the neighbors sprayed Roundup. There were noxious fumes several times a day from a malfunctioning sewage treatment plant a mile away and a dairy three miles away, and pungent fumes at 3 AM. More insidious was the chlordane I later learned was used to termite-treat the house when it was built. Chlordane was banned for use as a termiticide in 1988 and was later found to last for 30 years.

I discovered a park 14 miles away with good air quality, so Sammy and I would spend hours there every day. We were very happy there, and Sammy made us many friends. I learned that any time I was having a bad reaction, I could go to a park and soon feel better.

One day a friend who knew how chemically sensitive I was called me with exciting news: she had seen a notice in a health food store about a new support group being started for chemically sensitive people!

I called the phone number posted on the bulletin board and a young woman named Carole Jenkins answered. She had become acutely sensitive while working in a lab as a graduate student at the University of Arizona, trying to prove that the paradichlorobenzene in mothballs was toxic. We became good friends, and she introduced me to other EIs, the pendulum, and **HEAL**, the **Human Ecology Action League**, a national non-profit established in 1977 “to provide information to those concerned about health effects of chemicals and alert the general public about the potential dangers of chemicals.” Dr. William Rea was encouraging his patients from all over the country to start local HEAL chapters, so Carole, along with Sol Blackman and Bea Kitter, started **HEAL of Southern Arizona**. When MTBE was added to fuel in Arizona in 1992, several of our members, including Carole, moved out of state.

There were eight of us at my first HEAL meeting. Sol, a retired teacher, had been elected president. The meeting location seemed ok to most of us, but one woman passed out and had to be carried out to her car. Sol had assigned everyone a job and had me take minutes. It was the start of my HEAL career. Soon I was scouting out meeting places and lining up speakers. Sol motivated all of us to do whatever it took to make our fledgling group succeed. EIs were being referred to us by Dr. Rea and National HEAL, and we were growing. I now had all these terrific friends who were chemically sensitive like me. In those pre-internet days we taught each other how to cope with what was later called MCS, and I needed all the help I could get.

I was still active in Nonsmokers Incorporated. They had gotten smoking banned in Tucson grocery stores and movie theaters. Now some wanted to ban smoking in restaurants, but I was passionate about protecting people in the workplace, and won that debate. We demonstrated downtown, and it was a good sign when newspaper and TV reporters featured my story about having had to quit my job in New York because of tobacco smoke in the office. With help from a lawyer, a top activist in California, and Canyon Ranch, we placed Proposition 201 banning smoking in enclosed Tucson workspaces on the 1985 ballot. We barraged the newspapers with letters to the editor when the tobacco companies came to town. I wrote, “You’ve come a long way, baby, to try to stop the passage of Prop 201.” We won, by less than 1%, the first successful citizen-sponsored tobacco legislation in the U.S., we defeated Big Tobacco, and it was exhilarating! I was hooked on activism and wanted similar progress for MCS. But first I had to get better. I was down to three foods and going downhill fast.

**Healings**--*we are all different; what follows is strictly fyi.* I read a book about insecticide and heavy metal poisoning called *How to Avoid the New Health Catastrophes* by H.R. Alsleben, M.D., D.O. A friend knew him and said he'd be visiting Tucson soon, so I called and invited him to speak at a HEAL meeting. I liked his approach to healing but first wanted to try doing a sauna detox at a health club, along with an EI family. Within one year the mother and daughter were well and leading normal lives, but the father developed Parkinson's. Within one week I was jaundiced.

In exchange for computer work I spent ten days at Dr. Alsleben's clinic in Kansas City. Every patient received EDTA chelation, osteopathic adjustments, digestive supplements, and live thymus hormone to restore the immune system, a treatment used in Sweden. The results were incredible. I felt normal for about a year and was able to eat almost anything I wanted and tolerate vehicle exhaust. Elaine Hall described her healing by Dr. Alsleben in our Winter 2020 issue. I had one follow-up treatment and would have had more if the feds had not been chasing him around the country until he moved to a clinic in Mexico.

Back home I was developing a diagnostic program for the doctor on a borrowed computer, added Chapter Contact to my HEAL responsibilities, and kept records for over 600 Nonsmokers members. I was far too busy and reluctantly gave up Nonsmokers. They had many more victories, and we had a wonderful reunion party 25 years later.

I got a small grant to educate schools about least-toxic pest control but soon had a major setback: my hatchback door came crashing down on my head, and a chiropractic adjustment made matters even worse. I had severe head and neck pain, was mostly bedridden for months, and was reacting to everything, including my dog Sammy. I had to give him back to my mother. Eventually I discovered that a neighbor across the street was filling his huge dump truck with fresh asphalt every night and parking it in his driveway. Asphalt fumes were infiltrating my house. Thankfully Planning and Zoning made him park the truck elsewhere, and I felt better.

I sold my house and moved to an apartment in the Catalina Foothills, where the air quality was good. A friend and I had our amalgams removed safely by a dentist in California who was an amateur magician with nimble fingers and replaced them with temporaries in no time. Now I no longer swallowed mercury, but it took several years to find replacement materials I could tolerate. The Clifford test showed how extremely hypersensitive I was, but the materials it recommended made me sick. My very patient dentist had to muscle-test every product before

using it on me, and I would double-check using pulse testing and various other methods.

For a few terrifying months in that apartment, I had *severe* electrohypersensitivity (EHS) and was having trouble walking. The clinic I went to was useless. My potassium levels were borderline low and electrolytes helped a bit. Luckily a friend in Phoenix took me to his electroacupuncture practitioner. The computer said I had malathion in my kidneys. Aha! My neighbors had their apartment sprayed monthly with malathion. I got a homeopathic remedy for malathion, homeopathic corn silk to cleanse the kidneys, lost the EHS (but not the MCS) in two weeks, and bought my second house.

### **National HEAL, the ADA, and the Medfly**

In 1990 I accepted National HEAL's invitation to join the Board and coordinate the chapters. By that time there were chapters in nearly every state, some very large and active. Louise Kosta, head writer for HEAL's quarterly publication *The Human Ecologist*, was an excellent mentor and I enjoyed the many hours we spent on the phone. I was surprised to learn that the Board had decided early on not to label HEAL an EI organization in order to have credibility with government officials and work behind the scenes.

The Americans with Disabilities Act (ADA) had recently been enacted to provide protection against discrimination in employment and access to workplaces, public buildings, public places, and public transportation. I invited City ADA Coordinator John Thomas to our next HEAL meeting. Seeing one of our members nearly pass out in that stuffy room, and two others have a screaming tug of war with a door because one wanted to let outside air in and the other didn't, made quite an impression on him.

John Thomas was totally on our side. He helped me write *MCS and the ADA: A Guide to Accommodation*, (which Louise edited and HEAL published but never promoted, fearing that it would be misused). He introduced me to City maintenance staff, who agreed to use less-toxic products. Finally, he had the Mayor appoint me to the Tucson Commission on Disability Issues.

At meetings I was moved by how hard life was for people with other disabilities. One commissioner described crawling up the steps to board an airplane and feeling humiliated. The accommodations they needed often involved costly structural changes, unlike those I described in my presentation on MCS. From then on no one wore scented products to meetings, but now there was body odor to contend with, which became so unbearable for me I had to resign. Thankfully

Susan Molloy and Mary Lamielle have been working on MCS disability issues for many years. We are honored to have them as members of our chapter.

In 1994 Louise got word that the federal government was issuing an Environmental Impact Statement (EIS) in preparation for aerial spraying to combat the Medfly, or Mediterranean fruit fly, in several states including Arizona. It was my worst nightmare. I sent our chapter members a letter telling them where to send polite letters describing the adverse impact spraying would have on their health. The completed EIS contained more letters from our members than from all the other states combined. Unfortunately, Louise's worst nightmare was realized when an unknown EI called the official in charge of the program, went ballistic, and threatened to get him fired. The official blamed Louise, and she blamed me. She was obviously still very angry by the next Board meeting, so I thought it was best to resign from National HEAL. Massive spraying for the Medfly went on for years, sickening many people. But not in Arizona.

## **Moving On**

I was in yet another toxic housing situation and getting sicker. When I bought my house two years earlier, I would walk to Sabino Canyon past pristine desert, and the air quality was excellent. Now construction was everywhere, termites infested my subdivision, and all my neighbors were termite-treating. I wasn't, so the termites moved to my house. Miriam Finkel, then president of our chapter, was a lifesaver, letting me stay at her EI-safe house when things got too bad.

At the same time my savings were running out. I had quit my job 14 years ago, and in order to get disability I would have to prove I was sick then as well as now. I was sure I couldn't. I am so grateful to everyone who kept after me until I applied and gave me the help I needed. Over the next three years I got corroborating testing and rounded up my old doctors, employers, co-workers, and a terrific lawyer who dug up records that won my case. My judge was over 90, and I prayed for him every night. He ruled in my favor and then overruled those who tried to overturn his decision. It was a very close call.

I had gotten a bit better by using the pendulum to test foods and supplements as Carole had taught me, and by taking glutathione. Now I had Medicare, and my new doctors helped resolve some longstanding health issues.

But working on projects I'm excited about is what really energizes me, and now there was a lot to get excited about. Contacting the newspaper reporter who wrote the series on the man with MCS that we ran in our last few issues led to local articles and TV coverage over the years featuring various chapter members. I created a handout about MCS, *Are Chemicals Affecting Your Health?*, and enlisted

advisors for our chapter listed on the back; we give the handouts to our members to educate family and the public, and also distribute them throughout the Pima County library system every year. Diane Ensign and I set up seminars at Nanini Library to educate the public about MCS. Starting in 2003, the Governor issued an annual proclamation recognizing MCS Awareness Week. We had a party to celebrate, and added holiday parties too.

In 2000 I sold my house and moved into my mother's mobile while I house hunted--for the next 16 years. The one I bought and fixed up made me so sick I had to sell. My mother had dementia and was wandering far from home, not knowing where she lived. When I broke my ankle and was in a cast for six weeks, I had to put her in a nearby care home. I visited her every day until she died at 83 following a stroke. I was devastated. She was incredibly supportive to me all my life and never lost her sense of humor. My brother was a great help at this time.

What also helped was getting a donated used computer from the Rural Disabled Assistance Foundation, getting connected to the internet, and getting busy. Cheryl Stewart created our website, [healsoaz.org](http://healsoaz.org), I did the design, and Shay Cardell got us online. Pima County Health Department officials spoke at one of our library meetings about West Nile virus, which is transmitted by mosquitoes and was spreading throughout the US. Then in 2005, Dr. Kristi Mattson assisted by HEAL members organized the West Nile Virus Workshop to educate county officials, the Arizona State Health Department, and other municipalities about the dangers of West Nile Virus versus those of adulticide pesticide spray exposure to humans, animals, plants, and insects. Experts were brought in, and it helped convince Pima County that larvicide and local residential education was a better approach to mosquito control.

Unlike other HEAL chapters that were once going strong but have since folded, as has national HEAL, ours has had continuity. When Miriam Finkel stepped down, Ariel Barfield took over as President and Treasurer, along with all Miriam's other duties. Then Alan Simms stepped up as President while Ariel kept doing everything else. Likewise, the newsletter has been published without a break. When I became publisher in 2003, I had to learn by trial and error how to do formatting, layout, and photos. We were very lucky that Dianne Timbers and Jeanie Marion agreed to be co-editors in 2011..

### **Today [Year 2020, Ed.]**

I hope you all stay well during this pandemic. One of my friends had a bad case of covid-19 but managed to stay out of the hospital and recover at home, thanks to home health care, her naturopath, and an oxygen supplement. My life hasn't changed much, except that not long ago I learned about histamine sensitivity

online, adopted a low histamine, low-tyramine diet, and the migraines that plagued me for 45 years are gone! I enjoy staying at home, social distancing at the park, and keeping in touch by phone, but do miss having meetings.

I still enjoy doing the newsletter, getting involved in new projects, and getting calls from EIs around the country, doing my best to help. I feel very lucky to be a member of our chapter, to have had fun, learned so much, and helped make the world a little less toxic, all while making so many wonderful friends.

For the past 3½ years I've been living in an apartment where I do pretty well; however, I'm at the mercy of my neighbors so am still house hunting. Someday I hope to find a safe house and have a Hound Dog party for my sniffers. Hope you can come--keep your fingers crossed!

### **About**

This story ran as a two-part series in the spring and summer 2020 issues of *Ecologic News*, the newsletter of the Tucson MCS support group. She joined the group when it started in 1983. The story is reprinted with Madeline's permission.

The picture is courtesy of Diane Ensign.

### **More information**

More stories on [www.eiwellspring.org/facesandstories.html](http://www.eiwellspring.org/facesandstories.html).

For more information about environmental illness, go to [www.eiwellspring.org/intromenu.html](http://www.eiwellspring.org/intromenu.html).