Susan Molloy, a life of activism

by Steen Hviid

Susan Molloy has been an advocate for people with environmental disabilities for forty years. Her focus areas include safe and affordable housing, where she has been able to get two housing projects built with government money. This is her story.

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The early years

Bob Molloy was a navigator on a big Navy patrol plane during World War II. They operated from bases in the United States, looking for submarines near the coasts. He met Sylvia May in high school and they got married during the war.

When the war ended they moved to Montana and then Oregon where Bob worked on logging crews.

Susan Molloy was born in 1949, while the family lived in the logging town of Myrtle Creek. The small family moved around a lot for work. She had moved more than twenty times before she started school.

By the time Susie started school her dad had moved into management at a lumber mill and that provided much more stability. They stayed in Arcata, California, almost all the years she grew up.

The years of freedom

Civil rights was the big issue in the 1960s, which fascinated Susie. She wanted to learn about how political systems worked so after finishing high school in 1967, she decided to study political science. She enrolled at Mills College in Oakland, across the bay from San Francisco.

There were a lot of demonstrations going on in San Francisco and Susie eagerly participated. But that was frowned upon at Mills College, so Susie had to sneak out to go across the Bay. After a year, she transferred to San Francisco State University, where she felt more welcome, and was surrounded by other politically active students.

She joined the campus activists that agitated for the university to hire faculty that were more diverse and not just white men. They also wanted the university to kick out the military, especially the Reserve Officers Training Corps (ROTC).

In the wider community, she participated in activism against the Vietnam war and the draft, etc. She joined the Students for Democratic Society. There were demonstrations nearly every week, and nearly every week demonstrators got arrested.

The following summer she traveled two weeks to Mexico to see how people lived there and how their society worked. This was the first time she ever went outside the United States and she went all on her own.

With all her political activities her studies languished and eventually she dropped out.

In 1973 she traveled abroad with her boyfriend. It was supposed to be a six-week trip to Europe, but it took a year before she returned to the United States.

They stayed a couple of weeks each in Ireland, Britain, and the Netherlands. In Amsterdam they borrowed an apartment in return for feeding the owner's cat.

They became more adventurous and after touring Greece they went to Turkey. Then they kept going east, into Iran, Pakistan, and Afghanistan.

In Kabul they broke up and parted ways. Susie headed south to India. In Delhi she was running low on money for her plane ticket home, so she instructed her bank in California to wire her money. The money never arrived.

After two months, she finally gave up waiting for the money. Fortunately, living in Asia was really cheap, where one could get by on a dollar a day.

From India she flew to Singapore and then on to Perth in Australia. Here she got a job as a waitress at the Sheraton Hotel, where she made good money.

After two months in Perth she moved to Melbourne, where she got a job in a bookstore. Once she had enough cash she started traveling again.

She hitchhiked around Australia. She even managed to hitch a ride on an airplane from Alice Springs to Uluru National Park.

From Australia she went to Indonesia, Laos, Thailand, and South Korea, with a brief visit to Tokyo before returning stateside.

She had seen a collection of ancient Chinese art in a museum in Melbourne that fascinated her, so when she was back home she decided to study art history at the University of California, Berkeley.

Unfortunately, people with a degree in art history do not have many job prospects, so when she graduated she became a taxi driver in San Francisco.

Then the travel-bug bit again and off she went for two months to Europe. She met a new boyfriend and they went off to southeast Asia. Altogether she was gone for another year.

With a boyfriend she then spent eight months in Mexico and Guatemala. This trip may have contributed to the health problems that started a year later, as pesticides were used excessively around them. Teams of young men with backpacks full of pesticides would walk around and spray everything. The stench was everywhere.

Genetic baggage

Susie was very healthy in her twenties, though there was some genetic baggage. Both her mother and aunt had milder versions of MCS. They had problems with cigarettes, food additives, and strong chemicals.

Her aunt worked in an office. She coped in various ways, such as secretly switching the covers on the typewriters, so hers had an old cover.

Nobody knew what it was and it was not taken seriously. Her mother liked to refinish old furniture and she kept doing it despite the symptoms it caused her.

Her dad's mother had severe allergies. They were so bad she went to the famous Mayo Clinic. There were other relatives with milder allergies too, and two had celiac disease (gluten intolerance). The people in the family didn't take that seriously either. It was treated as a joke. Susie grew up believing allergic people were overly fussy and self-indulgent.

Getting sick

The good times ended in 1981. She had three incidents of anaphylaxis, each a month apart.

The first two times her eyes and the roof of her mouth swelled up. It was scary, but she didn't go to the emergency room. Instead, she toughed it out at home. She had no idea what caused it.

The third time was worse. It started while she was in the ladies' room. There was a big bucket of cleaning supplies, which may have been the cause.

She was part of a group of people on their way to a party in a nearby house. When they got there Susie dropped on a bed with her face swollen up. One of her friends got a doctor who was at the party to look at her, who said she had to go to the emergency room.

Two friends drove her there. The doctors administered the usual drugs for anaphylaxis and kept her overnight. The two friends stayed in the room all night and drove her home the next morning.

But all was not well. Something had changed, and it kept getting worse. She started to get reactive to all sorts of things: foods, cigarettes, her own clothes, laundry detergent, chlorinated tap water, mold, her apartment, even light.

She didn't know how to cope; nobody had heard about this before. She had to do a lot of trial and error to see what worked, always mindful that mistakes could result in another trip to the emergency room.

She found out that spring water in glass bottles worked best. The Calistoga brand came in glass in those days, though it was costly.

A friend lent her an ion generator, thinking it might improve the air in her apartment, but that made things worse.

She had several friends who tried to help. With her apartment causing so much trouble, she tried to sleep in other people's apartments and even some porches.

One friend also took advantage of the situation. Most washing machines were so contaminated with toxic laundry products that Susie couldn't tolerate her clothes after they were washed. But one "friend" had a safer machine and offered to wash for Susie, but at an exorbitant fee.

It was a scary situation with no good advice on how to cope. There wasn't even a name for it. The doctors were clueless and not helpful. A few were sympathetic, several were downright nasty.

She had about a dozen anaphylactic shocks over the first two years of her illness. Then she had the situation so much under control there were rarely any more episodes.

Susie became unable to work and sought financial help. But the Social Security office was full of people smoking cigarettes and the staff refused to help. They would not talk to her outside or on the phone. It took two years before she was able to apply.

After two years of not knowing what illness she had, not even knowing its name, not knowing if she was the only one with it, there was a breakthrough. A friend brought her the October 30, 1983, issue of the *Los Angeles Times.* It was the Sunday edition and right there on the front page was an article about a group of people just like her.

With that information she soon located a local support group called the Environmental Illness Association.

The support group held meetings at a local hospital in San Francisco, called French Hospital. They met in an ornate old ballroom with chandeliers. More importantly, it was bare with high ceilings, so there was a lot of airspace to dilute any fumes, and it had wooden floors, and windows that could open.

The people there were indeed much like Susie. Finding these people was a great help, as they understood more and had learned to cope in various ways. She now knew she was not the only one with this mysterious disease, which actually had a name.

Leaving the city

Susie didn't have a car at the time, so it was difficult to leave the city. A friend drove her up to the mountains in northern California to see if pristine air would help.

It became clear that she needed to leave the city, and that she needed help with a lot of things, so she moved back to her parents' house in Arcata. The house was located in a forest outside town, and her parents took care of shopping and everything.

The house wasn't wonderful, but it slowly got better. She initially had to sleep on the porch, then in a tiled bathroom with an open window. Finally she could use a bedroom.

The tap water made her sick, so they had to collect rainwater for her instead.

She didn't have her own car and she didn't tolerate the inside of her parents', but she could ride in the back of her dad's pickup truck. Many times her dad would drive to an area with trails, where they could hike in the woods.

Activism in Arcata

The County sometimes sprayed herbicides along the roads to control weeds (instead of mowing). The Molloy house was right next to a county road, so that was a real problem.

Susie discovered there was a local organization opposing road spraying, called the Humboldt Herbicide Task Force, which she joined. The activists had all sorts of reasons to oppose the spraying, but some were sickened by it just like Susie.

They were able to get a meeting with a County commissioner, who agreed to stop spraying in front of the houses of people who objected.

The success inspired Susie to create a new group, together with several Task Force members who also had chemical sensitivities. It was initially named the Environmental Allergies Organization (MCS was believed to be some sort of allergy in those days).

They distributed flyers and put up tables at outdoor fairs to educate the public and recruit new members. The organization slowly grew and in January 1985 they published their first newsletter. Called *The Reactor,* it was edited by Susan Molloy, with a lot of help from another woman who owned a computer (they were expensive in 1985 and Susie was sickened by them anyway).

Humboldt State University had a community outreach program that was willing to help print and mail the newsletters at a bulk rate. Susie was the editor of *The Reactor* for the next ten years.

Soon after, the organization changed its name to the Environmental Health Association (EHA) and became part of a network of California groups with that name. The wider organization was spearheaded by Sheldon Dunn in Sacramento, who used to be a hospital administrator and had a lot of organizational experience.

Sheldon coached Susie in how to grow the organization and she traveled around the state to help set up new chapters.

The EHA became a part of the nationwide organization Human Ecology Action League (HEAL), but that organization did not allow local affiliates to do activist work. They apparently thought it to be undignified. Instead, HEAL focused on social activities and how to get along with the toxic world as it is.

Susie wanted to do activism to get civil rights for the environmentally ill, so she created a new organization named the Environmental Health Network (EHN).

Getting married

Susie got married in 1986 and moved in with her new husband, who lived in Corte Madera a few miles north of the Golden Gate. Moving back to the Bay Area suited Susie well as she could do more activist work there than in Arcata.

The house was not so great, so it took a real toll on her. She had to spend a lot of time in bed with symptoms and exhaustion.

Her husband did not have chemical sensitivities, but had extreme allergies, so he understood what feeling sick from the environment meant. He was very considerate of Susie's disability.

They both wanted children, but Susie had trouble getting pregnant, and when it happened she miscarried. Having children was essential to her husband, so when it became clear that was not possible, that ended their marriage. It lasted 3½ years.

In hindsight it was probably a blessing Susie had no children, as they would likely be sickly, since both parents were.

Back to school

While married, Susie went back to school to get her Masters, so she could be an even more effective advocate for people with environmental disabilities.

She decided on San Francisco State University, but getting accepted was not easy. She first tried their Department of Rehabilitation, but they refused. They said chemical sensitivity was not a disability, in their view. She tried various health departments, but they too refused her.

Finally, she had to create her own major, and was able to find a sympathetic faculty advisor.

The advisor was very helpful, and even willing to stand in line in toxic buildings Susie could not enter, when she needed to register for a class.

She took classes in industrial safety, epidemiology, sociology, urban planning, and other areas. It often came down to which professor was willing to work with her. Some were downright nasty when she asked to open a window. Some were prejudiced against her as the exposures affected her gait and made her speech slurred (symptoms that went away once outdoors for a while).

The professors slowly came around when they could see that the homework she handed in was not made by an imbecile.

She was only able to take one or two classes each semester, but it still took a toll, so in her first year there Susie had to start using a wheelchair on campus.

For one school project she interviewed fifty environmentally ill people about their lack of access to medical services. For a second project she, and two helpers, interviewed 103 people with environmental illness about their need for safe housing.

The second project was later used to show the federal agency Housing and Urban Development (HUD) that there was a documented need for non-toxic housing for disabled people on a low income.

These projects taught Susie the value of documentation with numbers demonstrating a need. At this time there were no studies at all documenting how common this disability really was.

Besides studying, Susie continued her activist work. She published her bi-monthly newsletter and was a member of the Mayor's Council, a disability policy group advising the San Francisco mayor. She was also on the program committee for the San Francisco branch of the Independent Living Centers.

In May 1992, Susie was handed her diploma at an outdoor commencement ceremony at San Francisco State. It had taken her five years.

Activism in the Bay Area

Susie got involved in all sorts of activist work while living in Corte Madera.

When the nearby Marin General Hospital was building a new wing, she joined with others to demand it be accessible to people with MCS. Eventually the hospital management agreed to some measures, such as no carpeting in the patient rooms and an extensive bake-out to quickly outgas the whole wing.

A pushback against the rising acceptance of MCS as a legitimate disease was rising in the early 1990s. When the American College of Allergy & Immunology held their annual meeting in 1990, it was held at the San Francisco Hilton. The topic for one whole day was MCS. All the presentations were by doctors dismissive of MCS as legitimate.

Susie and other activists arranged a demonstration outside and inside the hotel, and shut down the meeting. The event was filmed by a local TV station and used in the program *Bad Chemistry,* which featured Susie in the middle of it. Due to the chemical exposures she had to use a wheelchair. The program was aired locally and the following year it was shown on the PBS network.

Another demonstration she participated in was when the movie star Elizabeth Taylor unveiled her new signature fragrance at a hotel in San Francisco. The demonstrators were outside and not allowed to send a delegation inside. Susie was able to go inside in her wheelchair and deliver a protest letter to one of Elizabeth Taylor's staffers. The guards didn't think to stop someone in a wheelchair.

The federal agency entrusted with providing guidelines on how to accommodate people with disabilities is the Access Board. Their politically appointed commissioners meet regularly in Washington, DC. Once a year they meet in some other city.

When they met in San Francisco, Susie and other activists showed up asking them to help people disabled by environmental illness. When they gave her the usual runaround she stormed out of the room, ran into several rest rooms and collected a stack of fragrancing devices in a plastic bag. She then went back and dumped the stinky mess on the table in front of the commissioners. Alas, they kept ignoring the issue, and largely still do, despite several more attempts over the years.

United Airlines

In 1990 Susie was invited to speak at the annual American Academy of Environmental Medicine conference in Idaho. In the airport she was barred from boarding the plane. The local flight surgeon had seen Susie on the local TV channel and put her on a medical no-fly list because she had MCS. With the help of her physician and a lawyer, who were both going to the same conference, she convinced the staff to let her on anyway.

On the way back, she was again denied access, this time by two security guards. Again, she was able to convince them to let her onboard, with the help of the same physician and lawyer.

Around the same time another woman with MCS was also barred access to a United Airlines flight, and was not able to get onboard, despite that she was going to visit her dying father.

The two women sued the airline. It was a long battle and they had to settle out of court, but people with MCS have since been allowed on airplanes.

Ecology House

Susie's trouble finding a safe place to live really got her focused on trying to do something about the housing crises many people with environmental illnesses face. It is especially difficult for those who have to live on a low income, such as Social Security, as safe houses command premium prices and rents.

The U.S. government does fund housing for people who are disabled, but they are not environmentally safe. They are built of toxic materials, and the other renters often smoke and use toxic products, which can pass right through the walls between apartments.

It was clear to Susie that there was a need for an apartment building just for the EIs, and with government funding so the rent was low. Nobody in the whole world had done such a thing before. (Later in the 1990s there were similar housing projects in Dallas, Canada, and Sweden, but they had different types of financing. The Swedish project faltered altogether.)

The timing was right. In the early 1990s the newspapers were full of articles describing people with MCS, and the articles were very sympathetic towards them. The federal agency Housing and Urban Development (HUD) had their local department circulate an internal memo stating that MCS was a legitimate disability which they should accommodate.

When Susie approached HUD to fund a housing project, bringing her study documenting the need, they agreed if she could present them with one that met their criteria.

Finding a suitable place to build turned out to be very difficult. She found a large wonderful property near Forestville, which was a former Buddhist retreat. It was ideal, located on a hill with clean air, and in an area zoned for low density housing. But it didn’t meet HUDs strict criteria for wheelchair access. The road was too steep and there was no bus stop nearby. The hill and the lack of stinky diesel buses were great features for people with MCS, but HUD would not compromise.

In 1992 she met with the Sebastopol city council about building on a lot there. But they gave it only a lukewarm welcome, so Susie didn’t dare spend the money for an architect to draw up a full proposal, which might be rejected.

Susan Molloy in 2017, holding a newspaper from 1992 about her Ecology House meeting in Sebastopol.

In the end, she had to compromise. The project ended up on a city lot in San Raphael, with a bus stop outside and a big powerline next door so Susie couldn't live there herself.

The building opened in 1994 and was designed very well. There were eleven apartments, which all faced a courtyard to protect the tenants against the diesel buses. There was a community room, laundry, and off-gassing room.

The building materials were chosen carefully, but there was a screwup with the kitchen cabinets which caused the new renters problems the first months. This screwup made national news, and by this time the media had become hostile towards the sick people. The house was portrayed as a failure, and that it was not possible to ever please these people. Never mind Ecology House became a success (and still is) with a long waiting list.

Moving to the desert

The polluted air in California was always a problem, and often causing Susie to have to use her wheelchair. When she heard about a guy who had moved to the high desert of northern Arizona to find relief, she went to check it out.

They hit it off great. She moved into his large house that was located in the open country east of the small town of Snowflake (named after Mr. Snow and Mr. Flake). It was a great place for Susie and she felt so well there she no longer needed her wheelchair.

Two other MCS households had moved there, so there was already a small community.

When the relationship ended, her now-former boyfriend gave her a twenty-acre (eight hectare) lot next to his, and a neighbor built her a little house that she still lives in.

She became the booster for the area, and people kept coming. By year 2020 there were about thirty five EI households in the area, including a dozen clustered together around Susie's house.

The Snowflake housing project

Susie worked for several years to also build housing in Arizona. She identified which part of the Arizona state apparatus that provided housing for people with disabilities and began convincing them to do something.

One example of her efforts was when the agency did a "listening tour" in 2003, where they held open meetings in several towns around the state. For each meeting, Susie asked local people to show up and tell about the EI housing crisis. Late in the tour, they quipped "I wondered who of you would show up this time."

They eventually gave in and built a four-unit development in Susie's neighborhood. A variance was needed, since the lot was only zoned for two houses. A local realtor objected on principle, but didn't prevail (developers get zoning variances all the time, then they can do it to help disabled people too).

Another problem was to find a local non-profit organization to manage the houses. There was only one that met the state criteria, it provided housing for recovering alcoholics. They were used to a very different kind of clientele, so it was not an easy fit.

There were other compromises that had to be made, but the end result turned out very well anyway. The houses opened in 2008.

Susie’s timing was again lucky. Once the four houses were built, the state cut the budget and all the state people Susie had worked with were laid off. A second phase, with four additional houses, never happened.

Susan Molloy: the movie

The documentary filmmaker Drew Xanthopoulos visited Snowflake several times over three years to film Susie. He even went on a trip to Washington, DC, where Susie attended a disability conference. The film came out in 2017 and features two other families, one in Kansas and another in Arizona. Susie is clearly the hero in the film.

Continuing activism

Susie had to wind down her activities in California, and living in a remote area made it difficult to have an impact. Nonetheless, she has been active in many projects both regionally and nationally.

Her phone constantly rings with sick and desperate people who are looking for a safe place to crash, or to hear the voice of experience telling them that their lives are not over now they have severe environmental illness.

Many a person have camped overnight in Susie’s driveway, while they travel around looking for some place to live now they had to flee the polluted city.

Another ongoing effort is to reach out to other disability groups, which she does by conference calls and annual trips to big disability conferences. Unfortunately, people with EI have a low status within the disability civil rights movement, so they are leery of lending any support, or even mention the existence in a footnote.

Susie has been a part-time staffer at the Centers for Independent Living, both in California and in Arizona. They are federally-funded organizations that provide assistance to disabled people so they can live in their own homes instead of in an institution.

One of her long term goals was to get a local center in her area, which could both help regular disabled people as well as those with EI disabilities. This becomes increasingly important as many of the Snowflake EI community people are aging, and the presently available services are very limited and not inclined to accommodate people with EI (think home health care workers with cell phones, reeking of fragrance and fabric softener).

Honors

Susan Molloy has received awards for her activist work from the American Academy of Environmental Medicine (AAEM) and the Chemical Injury Information Network (CIIN). The community room at Ecology House is named after her.

The key to her success

Susan Molloy was able to get two housing projects built with public funding. Nobody else in the United States have ever done that.

When asked what her secret is, she replied it was her willingness to compromise and not get discouraged by criticism.

She was able to work through tough compromises as she realized the people in power simply would not do what the EIs really needed, for their own reasons. It was better to get usable housing rather than holding out for pie-in-the-sky projects that would never happen.

As the polical winds changed at HUD at the time Ecology House was finished, in retrospect it is likely the whole project had been cancelled if she had not compromised and gone forward in San Rafael.

Susie was able to live with the negativity she faced from the EI community. People blamed her for not delivering the perfect project. There are lots of armchair activists out there.

Over the years she invested a lot of effort talking to all sorts of politicians and bureaucrats, hoping if she just got the facts in front of people, they would do the right thing. It took her a long time to realize that is not how it works.

About

This article is based on several conversations with Susan Molloy, as well as some newspaper articles.

More information

Other personal stories are available on www.eiwellspring.org/facesandstories.html.

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