



MCS-Aware
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Rome Resolutions: Consensus on MCS Treatment
Understanding Electro-Hypersensitivity
Formaldehyde
Lupin Allergy
Buteyko Breathing



PLUS: HOMESICK
*The new documentary
about living with Chemical
Sensitivity*

Homesick

A film about MCS by Susan Abod

"Making a film is hard work. Making a good film is almost impossible. Making a good film about MCS when you also *have* MCS – much less two films – is, well, virtually unimaginable."



In the early 1980s, Susan Abod was doing administrative work at Massachusetts Institute of Technology (MIT) by day and moonlighting as an up-and-coming jazz singer on the Boston club scene at night. Reviews, as both singer and songwriter, were excellent; the Boston Herald pronounced her songs "...infused with an intimacy and a zest for living." Then in 1986, after recurring bouts of what seemed "a really bad flu," it all crashed down around her. She was diagnosed with CFIDS (chronic fatigue immune deficiency

syndrome) and a year later with MCS.

Life changed and Susan's dreams of a promising singing career came to an abrupt halt: "I realized I had to learn to love my life as it is," and out of that came the gift of an epiphany and a remarkable change of career. Considering things she could manage from home or a safe office, Susan went back to school to study for a Master's degree in counselling. She got through the course work okay, and even thought she had found a building she could tolerate to do her practical. The

problem was the clients she had to see to fulfil her degree requirement all wore fragrance. She could not work with them without getting "brain fog" and, hence, could not complete her degree, a distinct setback to her plans.

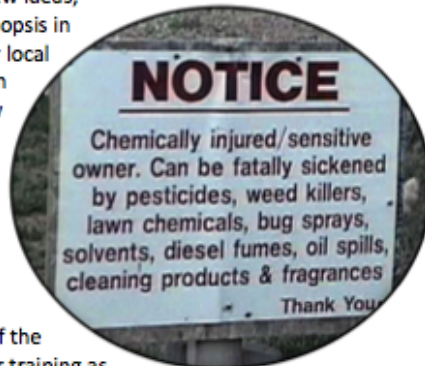
In July, 1993, she saw an Academy Award-nominated HBO documentary feature, 'Broadcast Tapes of Dr. Peter', a two-year video diary delivered by a physician dying of AIDS. Watching it changed Susan's life. "He was just so out there with his condition and the way he talked

about it. He was fighting stereotypes, breaking down social taboos, and helping viewers to better understand the disease. People supported him so much for that. He kept recording his pieces as his health visibly declined. It was really powerful. I wanted to do something like that for MCS."

Motivated by these new ideas, Susan wrote a film synopsis in 25 minutes, talked her local cable-access TV station into letting her borrow some cable equipment, hired one of the station's editors, and got to work! "I learned the ropes from a former Boston TV editor who became the director of the film," she recalled. Her training as a musician was an asset to her as a filmmaker, helping her understand timing, which gives her films a unique style. Her debut film 'Funny, You Don't Look Sick' was born. When it was finished and presented to the public. The Chicago Tribune hailed it as "A fine documentary on an important theme." The reviewer for the Boston Herald wrote that it "...invites the healthy and the disabled to recognize a common will to endure and prevail. This autobiographical video is not the product of a victim. It is the self-discovery of a survivor."

"This intimate documentary self-portrait is told with humour and compassion. Susan Abod is a woman living with Chronic Fatigue Immune Dysfunction Syndrome (CFIDS) and Multiple Chemical Sensitivities (MCS) or

Environmental Illness. Filmed over a period of 18 months in 1994-95, Susan describes in detail the nature of her illness, illustrates her daily routine, and gives us a guided tour of her environmentally "safe" apartment. 2005 Merit Award Winner Superfest International Disability Film Festival."



During the editing of 'Funny, You Don't Look Sick', Susan began to ask herself how many others were going through the same nightmare she was. How were others coping with the problem? Were they having as much trouble as she was in finding a safe place to live? Did finding safe housing improve their health? Was one part of the country safer than another? In 1996 another film beckoned as Susan decided to go on a road trip to try to find answers to her questions. She managed to get a funding from an ADA (Americans with Disabilities Act) Mini Grant. It paid for a camerawoman who drove the van they travelled in. Sometimes Susan stayed in the homes of people with MCS. Other times she slept in the van. She travelled across the Southwest to find out what

housing might be available to individuals who had become hypersensitive to chemicals and mould, as she has. She interviewed numerous people with chemical intolerances who've landed on their feet and now live in stable homes that

"Susan's videos are one-of-a-kind. Why haven't we seen any other videos with such insight into the challenges of living with MCS? Because only someone suffering from MCS can provide deep insight into the ways in which we can cope and adapt. Yet until this spring, everyone I know stricken with the illness was far too sick to be able to marshal all the resources and dedicated time to writing, developing, filming and producing professional quality video. This spring I met Susan Abod and discovered that somehow, through all her own suffering with MCS, she had managed to get these videos written, filmed with her in the leading role, produced, and distributed! It is an extraordinary personal achievement, a triumph of the spirit and of her irrepressibly creative, artistic temperament. In each video, she brings viewers into her daily life and shows them how she has met challenge after challenge of living with our extreme reactivity to the everyday chemicals we experience. Along the way she provides a well thought-out explanation of what is happening to our bodies that accounts for our symptoms. There are so many extraordinary qualities to these productions..." Craig Barth



meet their individual specs for safety. She also interviewed people who are still living as 'runners', searching night by night for a safe enough place to sleep, who are crying out for a way to slow the progression of what has become a downward spiral. She met chemically sensitive architects, teachers, housewives, social workers, nurses, doctors, lawyers and students. There was no email back then so Susan found people through phone connections which led to contacts through local MCS newsletters. She visited their homes— homes that included a stilt house, several tents, a straw bale house, a teepee, retrofitted trailers, retrofitted houses, and a few new homes made of wood, glass and steel. She witnessed their occupants' daily struggles. In total, she interviewed some 40 people, including MCS specialist Dr. Erica Elliott; architect Paula Baker (co-author of the book *Prescriptions for a Healthy House*); Linda Reinhardt, an ordained minister who established a spiritual community for people with MCS (one of the people the film is dedicated to as she died before its release), and a man living in an airstream trailer where two previous occupants with MCS had taken their own lives. Most of Susan's subjects are female, which reflects the pattern of the illness: For reasons not yet adequately scientifically explained, it strikes women far more frequently than men. The similarities in all her subjects' stories were staggering. Finding safe housing was invariably their biggest challenge. "I was overwhelmed by what I saw. We shot 24 hours of film and condensed it into a final cut 56 minutes long. A house is only as "safe" as the neighbourhood it's in. Time and again, individuals who finally moved into a safe enough place were effectively evicted, with no notice, (maybe ½ hour to pack a few things and get out), and no legal recourse, by a neighbour using dryer sheets, a computer router, lawn care chemicals, or other superficial commercial products. This kind of eviction, that has possibly lethal effects, is illegal to do to anyone else in the United States.

Housebound or Bedbound?

The 25% M.E. Group is a unique nationwide community based voluntary group. They provide a range of services to people affected by severe M.E. (Myalgic Encephalomyelitis).

"Because of the intensity of the symptoms and disabilities experienced by severe M.E. sufferers we seek to alleviate the isolation which having this illness can cause. The 25% M.E. Group encourages: communication between members; participation in the Group at a number of levels; assistance with articles and information for the newsletter etc. These are just some of the initiatives employed by the group. If you feel you would like to help, or if you wish to join and become a member (a small annual membership fee is required) or a group supporter then please contact us: **25% M.E. Group**, 21 Church Street, Troon, Ayrshire, KA10 6HT"

**MEMBERS' ADVOCACY
HELPLINE**
0141 570 2938

See our Website at:
www.25megroup.org

Or e-mail
enquiry@25megroup.org

- Twice Yearly Newsletter
- Group Library
- Practical and Emotional Support
- Advocacy
- Welfare Advice and Assistance
- Listening Ear Helpline
- Raising Funds to Promote & Support Medical Research into this Condition
- Various Fund Raising Initiatives
- Special Interest Groups organised by members themselves

During the filming, Susan had her own housing crisis and for two years had to stay with a chemically sensitive friend while she looked for her own safe place. In video-diary style, she filmed herself when the house she finally rented and believed would work for her made her too sick to stay in it. (She is the only person shown in the film when their symptoms flared, an artistic decision she made out of respect for her interview subjects.) At one point she broke down and cried, "I'm going to be one of those people with MCS who are homeless." I really didn't want to go there." After six more months of additional labour and time, she was finally able to tolerate and live in the house she had chosen.

Eleven years after her road trip, sick and out of money, she confessed to a friend that she feared the film would never be completed. Her friend introduced her to a Seattle producer, Basil Shadid, who had worked as post-production coordinator on the Academy Award-nominated documentary "Iraq in Fragments." He agreed to help Susan complete the film. The finished product is touching, informative, and affecting—and thoroughly professional.

"Homesick' is aimed at the population as a whole: MCS can strike anyone; all it requires is that they be in the wrong place at the wrong

time. The message Susan wants most to get out is that we should all be aware of this and live accordingly. She explains: "By the time you realize that your new carpet is making you sick, or the chemicals you're exposed to at work, it's too late."

Susan has lived in a safe housing in New Mexico now for six years. When her health allows, she sings again. And despite what she's been through, her talents are none the less. The reviews have not changed, an entertainment newspaper reviewed her performance as: "Blessed with a



clear, expressive voice, daring playfulness and an empathetic heart, Abod filled the songs with a lively presence that was irresistibly unpredictable." She's now hard at work recording a CD of her own music. Four of the songs are featured in Homesick. She's also looking for a safe community space in her neighbourhood where people with MCS can gather. As for a new creative project? She laughs, "I might try writing."

A trailer for the 57-minute video, Homesick: Living with Multiple Chemical Sensitivities, is available free online at homesick-video.com/. The video can be rented for \$8.99 at the same website or purchased for \$19.99 plus shipping.



To Purchase Susan's first film: "Funny You don't Look Sick" on DVD go to :
<http://susanabod.com/funny-you-dont-look-sick-an-autobiography-of-an-illness/>
 Produced by Susan Abod and Lisa Pontoppidan, (1995). Color, 64 mins

Excerpts from this story were first published in an article by Diane Thomas in The Human Ecologist, Summer 2014.

First biological proof that ME is real found by scientists

Columbia University has found that changes to the immune system represent 'the first robust physical evidence' that ME is a biological illness rather than a psychological disorder. Scientists have shown for the first time that patients suffering from chronic fatigue syndrome show distinct changes in their immune system: Columbia University has found that there are specific patterns in 51 immune biomarkers for people with ME. The test also shows differences for short and long term sufferers.

Researchers looked for differences in immune system signalling chemicals (cytokines) between people with CFS/ME and healthy controls. Comparing all CFS/ME participants with controls found few differences. However, differences were found when the CFS/ME group was divided into those with short- (three years or less) and long-term (more than three years) disease. These results suggest that people with CFS/ME may have higher levels of some cytokines until around the three-year mark, at which point the differences disappear.

Researchers are hopeful that an immune test could help improve diagnosis. Dr Mady Hornig, director of translational research at the Center for Infection and Immunity at Columbia University said: "Our results should accelerate the process of establishing the diagnosis after individuals first fall ill as well as discovery of new treatment strategies focusing on these early blood markers."

Crucially there are already drugs on the market which can dampen levels of cytokines and potentially help sufferers, although researchers said their findings would need to be replicated before clinical trials could take place. The study supports previous suggestions that the condition may be triggered by viruses. It is thought that the immune system may simply fail to switch off. "It appears that ME/CFS patients are flush with cytokines until around the three-year mark, at which point the immune system shows evidence of exhaustion and cytokine levels drop," says Dr. Hornig.

Professor Michael Sharpe, professor of psychological medicine at the University of Oxford, said: "Whilst this finding that some patients with CFS/ME have an immune abnormality is potentially interesting, we should treat it with great caution ... This type of study [a case-control study] is notorious for producing findings that other researchers subsequently fail to replicate." He added: "Everyone who has worked clinically with patients with CFS/ME knows this is a real illness; this study neither proves nor disproves that observation." The UK NHS website commented: "The study is not reliable enough on its own to prove that the disease has distinct stages, and it doesn't give us any more clues as to how or why these particular cytokines might be involved in the condition. Other studies, and study types, are needed to build on these initial findings."

Sources: www.nhs.uk, www.telegraph.co.uk