

Community Spotlight:

Steve Monroe

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What is the biggest challenge of being diagnosed with MCS?

The biggest challenge of being diagnosed with MCS is access to health care providers with knowledge of the condition and getting a general practitioner, assuming you even have insurance, to refer you to a specialist, such as an environmental MD. But, we lack doctors in that field. Some states don't have any doctors listed with the American Academy of Environmental Medicine (AAEM). We also lack toxicologists, something I could have used years ago, but was unable to find or afford. Ten years ago this condition was mainly viewed as somatic or assumed to be "conventional allergies", but I'm seeing more and more providers take this seriously and several have told

me personally that they do believe it does exist and I do have it, but for either legal concerns, medical billing problems due to lack of a specific IDC-9 code, or political reasons, they prefer to use more established existing names due to insurance billing or the board that certified them has yet to accept the condition officially. Recently, I did obtain signed documents from licensed MD's saying I have chemical sensitivities and they are referring to multiple sensitivities in discussions at office visits. I'm also aware of providers in the past 3 years that have told me they themselves are having problems with fumes and scents affecting them now that didn't years ago. Some today have scent free policies at their clinics, with signs saying so, and that's been promising to see.

Why did you found MCS-Awareness?

It was started as a group of persons with MCS to discuss its awareness, offer support to those with MCS, share files and information related to MCS, and promotes its establishment in the medical field as a valid physical medical condition as other organizations are attempting also. A related web site with same name was set-up as an information site to promote the groups same goals. I hope to resume working on the web site with much more information and data links from my database collected over the years.



“CIIT's core research program on human health risks is funded by members of the American Chemistry Council.”

What do you think should be the primary focus of the MCS community in the next couple of years?

I would like to see the various environmental groups band together more, as there is power in numbers and there has been a lot of division with various advocates over the MCS "term" name. We need to either push to get the long standing 1999 abstract consensus accepted as is with the medical field or improve it with some minor rewording, as some propose, and stay on track. If I'd not been seeing gains with the medical field past 5 years, I'd say lets try a new name. But I'm concerned another "new term" would cause more delays. We have too many names now and that has compounded the problem. We all know chemicals are the likely cause of the problem, so lets settle on one name, define it, and focus our efforts on that. I know there's a committee working on this problem now in the US.

What do you think should be the primary focus of the MCS community in the next 5 years?

I would hope that in 5 years the CDC, AMA, or an existing medical board group will have finally accepted this condition so that existing and future victims can get better health care.

What do you know about the Chemical Industry Institute of Toxicology (CIIT)?

It's basically an industry trade group with heavy funding by many various chemical companies, and even the government, that claims to be doing the "proper science" of chemicals on human health via risk assessments. But that's been questioned by others, like the Union of Concerned Scientists. Even Consumer Reports magazine has been critical of their work or real purpose. Some believe they are behind the term "junk science" to dispute independent studies that point to the toxic chemicals behind most of today's health problems, such as ADD or Autism.

The CIIT funding from chemical companies is huge for their operating budget and they spend millions on lobby efforts to lawmakers and the public. The following info about CIIT comes from Source Watch; "The Chemical Industry Of Toxicology, also known as the CIIT Centers for Health Research or just CIIT, describes itself as "a private, not-for-profit research organization created by farsighted chemical industry leaders in 1974 to conduct independent research on the effects of chemicals. CIIT described its founding as being precipitated by: "alarming reports" about chemical pollution. CIIT's core research program on human health risks is funded by members of the American Chemistry Council. CIIT also receives research funding from federal grants and industry contracts".



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Where do we go from here?

I'd like to see a formal national foundation or association, like the chronic fatigue, fibromyalgia groups, and other groups established years ago, whose only mission is the research and promotion of MCS with the medical field and the public. The National Fibromyalgia Association is one example that exists today. Maybe it could be called the "Multiple Chemical Sensitivity Association". Other groups could be charter members or supporters. We do have national groups today, but I'm referring to something much bigger than exists today, with full time paid staff and scientists that go after grant research money, do the research, and have their own lobbyists working the lawmakers and medical associations.

Anything else you'd like to add?

I would like to see more advocates and groups that exist today work a little harder to get along with each other, which I've tried to do as best possible by being part of 3 MCS International Coalition of Allied Groups and Organizations (MICAGO) groups. I've been noticing less co-operation in the past 3 or 4 years compared to back 7 years

ago when everyone seemed to be focused on the same page. I really thought that around 2003 the movement was going well, until certain groups or persons split up and went in different directions and new terms were proposed that, in my humble opinion, slowed down progress. I believe a lot of the previously mentioned legal, medical, and political concerns would disappear once the condition is accepted and victims can get the legal and medical help they need. For many of us it's too late and our lives have been ruined medically and/or financially, but more and more people are developing this condition or are on disability related to it. The CDC recently accepted chronic fatigue syndrome (CFS) as a real physical condition after years of similar debate to what is going on in the MCS world today, even though the cause of CFS remains a mystery with unknown bio-markers. The CDC Chronic Fatigue Syndrome (CFS) guideline for doctors does mention multiple chemical sensitivity can co-exist with CFS. From my experience, MCS is the most common name in the medical field via published studies, not just in the USA, but worldwide and in the public via news media articles. So lets stick with it. It's likely always going to be the layman's term regardless.



Steve Monroe, a resident of Washington state, developed MCS after a pesticide exposure followed by heavy perfume exposure in the 1980's. After a divorce, partly due to his failing health, he was left homeless and lived in an office building with leaking Freon that compounded his illness. He finally closed a 22 year old business and went on Social Security Disability (SSDI). Steve now does volunteer work when he is able. He is charged with maintaining a database of local resources and agencies for assistance. He is also an active volunteer member of a 911 service that provides emergency medical services to the public. On the MCS forefront, Steve maintains membership in several environmental groups, subscribes to several environmental and medical newsletters, and runs the domain www.mcs-awareness.org.