

How opponents of MCS and EHS created the term Idiopathic Environmental Intolerance



In the 1990s major industries realized that if MCS became accepted it would cause them major financial hardship. One way to ward off the threat was to attack the legitimacy of MCS by changing its name. Later it was also applied to electrical sensitivities (EHS).

Keywords: chemical sensitivity, MCS, electrical sensitivity, opposition, history, Idiopathic Environmental Intolerance, Environmental Sensitivities Research Institute, ESRI

A scientific workshop was held over three days in Berlin in February 1996. The purpose was to discuss MCS, including whether it was an organic (i.e. "legitimate") or a psychosomatic illness.

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Most of this article is based on the draft report, which provides a narrative of the meeting, its conclusion and appendixes listing the participants, etc. (IPCS, 1996).

The workshop was convened by the International Programme on Chemical Safety (IPCS) together with three German government agencies. The IPCS is associated with the World Health Organization, though some accuse it of serving the interests of the chemical industry (Abrams, 1996).

It was an invitation-only meeting with 17 MCS experts and two officials. The host country, Germany, was represented by seven experts, the United States also by seven. The countries of Britain, Canada and Sweden each by one person.

One invited expert, Dr. Ronald Gots, was representing the Environmental Sensitivities Research Institute (ESRI) in the United States. ESRI was an industry-funded organization that actively worked to undermine the legitimacy of MCS through speeches and articles. The year before, ESRI had paid for an article that was brought in many newspapers and made to look like a regular news story. It stated that MCS "exists only because a patient believes it does and because a doctor validates that belief" (McCampbell, 2001; Donnay, 1997; Ashford, 1998).

Dr. Gots was also director of the National Medical Advisory Service, which provided medical experts to assist corporations sued by people with MCS (Ashford, 1998; Wilson, 1996).

Another invited expert was Dr. Herman Staudenmayer who was a psychologist and professor at the University of Colorado. He was also an outspoken opponent against accepting MCS. During a 1990 medical conference at the San Francisco Hilton his anti-MCS speech was shut down by demonstrators (Hileman, 1991; El Wellspring, 2018).

Besides the 17 experts and two officials, there were 18 "representatives and observers." Twelve of them were from various German ministries and agencies. Then there were six people from three "non-government organizations" (IPCS, 1996).

There were thus a total of four non-government organizations (including Dr. Gots' ESRI), and all were closely aligned with industry interests, despite their bland names. In fact, some of their representatives were full-time employees of the chemical industry, including BASF, Bayer, Monsanto and Coca Cola (Ashford, 1998: ch 9; Abrams, 1996).

MCS patient groups, environmental, consumer or labor organizations were not represented at all at this invitation-only meeting (Ashford, 1998).

The only person present at this workshop that is known to be fully accepting of MCS was professor Claudia Miller from the University of Texas.

Absent were prominent physicians who actually treated people with MCS, such as Drs. William Rea and Grace Ziem, or university types such as Iris Bell, Nicholas Ashford and Mark Cullen.

The presentations

The first day of the workshop there were 18 short presentations by the experts. The speeches are briefly summarized in the draft workshop report (IPCS, 1996).

Many of the presenters stressed that the lack of an accepted definition of MCS was a major hindrance to conducting research on MCS, and there was much about it that was not understood and was at odds with current understanding of toxicology. Also, there didn't seem to be diagnosable organ damages.

Some also pointed out the similarities with chronic fatigue syndrome, Gulf War Syndrome, and a German phenomenon called "wood preservative syndrome." (The wood preservative was pentachlorophenol, trade name Lindane; Ashford, 1998: ch 7 & 8). Two presenters also noted a possible similarity with electrical sensitivities.

Four of the speakers strongly promoted a psychological explanation of MCS, while the majority seemed to straddle the fence whether MCS is a psychological or a "legitimate" illness, or a combination.

Professor Staudenmayer focused on his small study that found women with MCS had a higher likelihood of childhood sexual abuse, which he used to promote the psychosomatic explanation of MCS. (This finding was later disproved by a larger study: Bailer, 2007.)

Professor Altenkirch of Spandau Hospital in Germany made two presentations, including a video with three MCS patients. One showed signs of paranoia and drug abuse, another had severe epilepsy while the third was severely bipolar (manio-depressive). They were hardly representative of the MCS population.

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Dr. C. J. Gothe was a corporate physician in Sweden. He lumped MCS together with electrical sensitivity and people who had problems with dental amalgams. He called them Environmental Somatization Syndrome.

Getting to work

The second and third day of the workshop were dedicated to discussions and reporting. The major objectives were:

- to review information on MCS
- to determine whether or not MCS constitutes a syndrome
- to examine relationships with other environmental illnesses (EI)
- to identify possible causes
- to discuss diagnostics and treatments

Renaming MCS

A number of the participants wanted a different name instead of MCS. This was especially promoted by Dr. Gots and Dr. Gothe, two of the promoters of labeling MCS as psychosomatic.

Dr. Gots wanted a "less categorical" name, that was "less suggestive of causation" (i.e. to distance MCS from "chemicals"). (IPCS, 1996).

The group identified no less than 26 names that had been used in the popular press or elsewhere, such as "Chemical AIDS," "Universal Allergy," "Cerebral Allergy" and "Total Allergy Syndrome."

A number of alternative names were suggested, including:

Environmentally Associated Symptoms
Environmental Somatization Syndrome
Multiple Chemical Intolerances

The name that was acceptable to the most was Idiopathic Environmental Intolerances, IEI, with the understanding that "idiopathic" means "unknown cause" (though many interpret it as synonymous with psychosomatic).

Since the discoverer of MCS, Dr. Theron Randolph, had died the year before it would be natural to name it after him (i.e. "Randolph's disease"). That would also

be a neutral name, though perhaps not acceptable to those who promoted the "psych" model, and thus wanted the "idiopathic" name.

The conclusion of the workshop report states that "MCS should be discontinued because it makes an unsupported judgment on causation" (Anonymous, 1996; IPCS, 1996).

Other work

The group also worked on a better definition of MCS and suggestions for further research. None of this work appears to be of real consequence.

The protests

In 1991, a major magazine serving the chemical industry stated:

Clearly, the economic stakes in this issue are very high. If MCS is eventually verified as a definite medical illness ... the chemical industry could be faced with many more thousands of very costly lawsuits. (Hileman, 1991).

An internal document created by the Chemical Manufacturers Association also spelled out the problems MCS could create for its members. One of the suggested remedies was to work closely with physicians opposing MCS (CMA, 1990).

The group assembled in Berlin was not impartial. Using a "stacked" group of people is a well-known method to produce reports and statements that serves special interests, while appearing to be impartial (Ladou, 2007; McGarity, 2008).

The chair of the meeting, Dr. Howard Kipen, with another participant, Claudia Miller, and 58 other physicians, who were not invited, sent an official protest to the World Health Organization (Abrams, 1996).

They complained about "improper influence by business interests" at the meeting, and that the meeting sponsor, IPCS, had in the past shown itself to be under "excessive influence by business interests," where they have repeatedly seated "full-time employees of chemical corporations at the table as NGO representatives," as they did here.

They also stated that: "There was little distinction made between participants and observers at this meeting: observers were allowed to actively participate in

discussions, and votes were unrecorded" (i.e. the observers might have participated in the voting).

Howard Kipen and Claudia Miller also separately sent protest letters to the IPCS (Ashford, 1998: ch 9).

The protests achieved very little, except that the draft version of the report was up front labeled with a statement that it does "not necessarily represent the decisions or the stated policy of the United Nations Environment Programme, the International Labour Organization or the World Health Organization." (IPCS, 1996; Anonymous, 1996).

The publication coup

In the scientific world, publication in a medical journal is essential. If the workshop's recommendation of changing the name of MCS did not get into a journal, the effort would be nearly worthless.

Since the whole workshop and its report was strongly contested, the normal procedure was to either not publish a report or work on a compromise.

The IPCS gave up on publishing a report. Only an "unedited" version is available on the web (IPCS, 1996).

But someone else then produced a very brief "conclusions and recommendations" article that was published with no author name (Anonymous, 1996).

It was published in a special supplement of *Regulatory Toxicology and Pharmacology*, which contained other anti-MCS articles, such as one about how NOT to accommodate people with MCS in the workplace (Dolin, 1996) and one by Dr. Gots (Gots, 1996).

The journal acknowledged that this supplement was "made possible" through a grant from Dr. Gots' organization ESRI (Ashford, 1998: ch 9; Reg Tox Phar, 1996).

The journal *Regulatory Toxicology and Pharmacology* that made this coup possible has later been singled out by several scientists as being willing to bend the rules to support industry interests (Ladou, 2007; Michaels, 2020).

Promoting the new name

Despite the protests, some of the MCS opponents actively promoted the new term and the disputed report's conclusions (Staudenmayer, 1997; Baird, 1997; Wilson, 1996; Carruthers, 1996). The "idiopathic" term was from then on used in some scientific papers, especially those that promoted the belief that MCS was purely a psychological problem. Much later it started to appear in more neutral publications.

Two years later the controversy continued, so the World Health Organization issued a brief statement to the workshop participants (WHO 1998). It stated that the meeting was a "workshop" and not a "conference" or "panel" (which must meet a higher standard). And then stated:

With respect to "MCS", WHO has neither adopted nor endorsed a policy or scientific opinion.

Despite all this, the MCS opponents continued to list the "Anonymous" workshop report as published by the World Health Organization (Fung, 2000).

IEI and electrical sensitivity

The World Health Organization convened a workshop in Prague, the Czech Republic, in 2004 to discuss electrical hypersensitivity (WHO, 2004).

There were 31 participants from twelve countries. 21 were affiliated with a university or national institution. The Swedish EHS community sent one representative. The affiliations of the remaining nine people are murky; they probably had some sort of industry connection.

One participant from the 1996 Berlin workshop was present again in Prague: Herman Staudenmayer from the USA.

The report is only eight pages, so we don't know much about what happened during the meeting. There were three work groups, which each reported separately in the report.

The "Characterization, Diagnosis and Treatment" group was headed by Lena Hillert from Sweden, who was a prominent opponent of EHS.

Like at the Berlin conference, the group decided to distance EHS from its cause and call it "idiopathic."

The term Idiopathic environmental intolerance (Electromagnetic field attributed symptoms), or IEI-EMF, is proposed to replace terms that imply an established causal relationship between symptoms and electromagnetic fields...

To further delegitimize EHS, they also stated:

...IEI is not to be used as a diagnostic classification ... diagnosis should be based on the most pronounced symptoms (e.g. headache)...

And, indeed, the World Health Organization has continued to refuse issuing a specific diagnostic code for EHS.

The "Research Needs" group also supported using IEI as the new term, though one participant, Olle Johansson from Sweden, did not join the consensus.

The "Policy Options..." group stated that WHO should produce a fact sheet about EHS, which does not "attribute causality to EMF," does not include prevalence data and should "discourage measurements in homes."

This group also advised governments to not use EHS as a basis for disability, and not lower any radiation limits.

Comments on WHO

The World Health Organization prefers to use such panels of experts to guide their actions, rather than using other methods such as systematic reviews, etc. (Oxman, 2007).

This of course means WHO can be manipulated by "stacking" the panels with one-sided opinion, which is sometimes done by special interests (Ladou, 2007; McGarity, 2008). Another example of a stacked panel associated with WHO is ICNIRP, which advises on radiation limits for mobile phones (Hardell, 2017). This was clearly the case with the Berlin meeting. The objections filed by so many scientists in the field may be the reason WHO did not adopt the term Idiopathic Environmental Intolerance, though some people have falsely claimed it did.

The 2004 Prague meeting seems to have guided the WHO, since it continues to refuse accepting EHS and it shortly after published a "fact sheet" that closely followed the report's recommendations.

More information

For more environmental illness history, see:

<http://www.eiwellspring.org/history.html>.

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