

## **Lost Opportunity: the Harvard University Hoffman Chemical Sensitivity Research Program**



**Harvard University was given five million dollars for research and education about multiple chemical sensitivity and chemical exposures. Very little actually happened. Most of the money apparently disappeared.**

*Keywords: MCS research funding, Harvard University MCS, chemical sensitivity research funding, Marilyn Hoffman*

Multiple chemical sensitivity (MCS) is a global problem. It is found in countries from the United States to Indonesia, from Japan to Uruguay and all over Europe. It affects about 15 percent of the population. Most people have the mild version. For the severe cases, the illness is completely life-altering, and can cause chronic disability, loss of income, disruption of family, social isolation, and poor quality of life.

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Despite the obviously urgent need to help these people, very little research has ever been carried out. Almost none has been done in the United States in the past two decades, while some has happened in Europe and Japan.

A 2018 study found that much fewer research papers have been published about MCS than either fibromyalgia or chronic fatigue syndrome, which are also “newer” diseases that are poorly understood and controversial (Hu, 2018).

Scientists who want to do MCS research are routinely turned down by funding agencies (Meggs, 2017).

### **The Hoffman bequest**

Marilyn Brachman Hoffman had MCS for more than fifty years. She was affected by paints, fragrances, and much else, and had problems finding places she could live safely (Yoder, 2006).

She was also regularly disbelieved. As she stated to the *Boston Globe* in 2006:

*What the eye doesn't see, the mind often doesn't believe (Yoder, 2006).*

Upon her death in 2013, she bequeathed five million dollars to Harvard University to do research. This became the Marilyn Brachman Hoffman Program on Chemicals and Health (HPH, 2015).

The *Harvard Public Health* magazine called it a “research and education program to explore multiple chemical sensitivities.” One of the two leaders stated, “We want to uncover the biologic mechanisms that lead to these chemical sensitivities” (HPH, 2015).

The leaders held out hope for scientific studies that were not based on dogma, and with the possibility of breakthroughs:

*This bequest is transformative.*

And:

*Some of the research we're interested in is not considered mainstream, and wouldn't win traditional funding. But with this gift, we now have the ability to support novel research – to take risks (HPH 2015).*

In the scientific world, “taking risks” means pursuing science that is more avant garde, further beyond what is established, and thus has trouble getting funding

from risk-adverse funding agencies. It can also mean a risk to the reputation of the scientist.

The program's website stated:

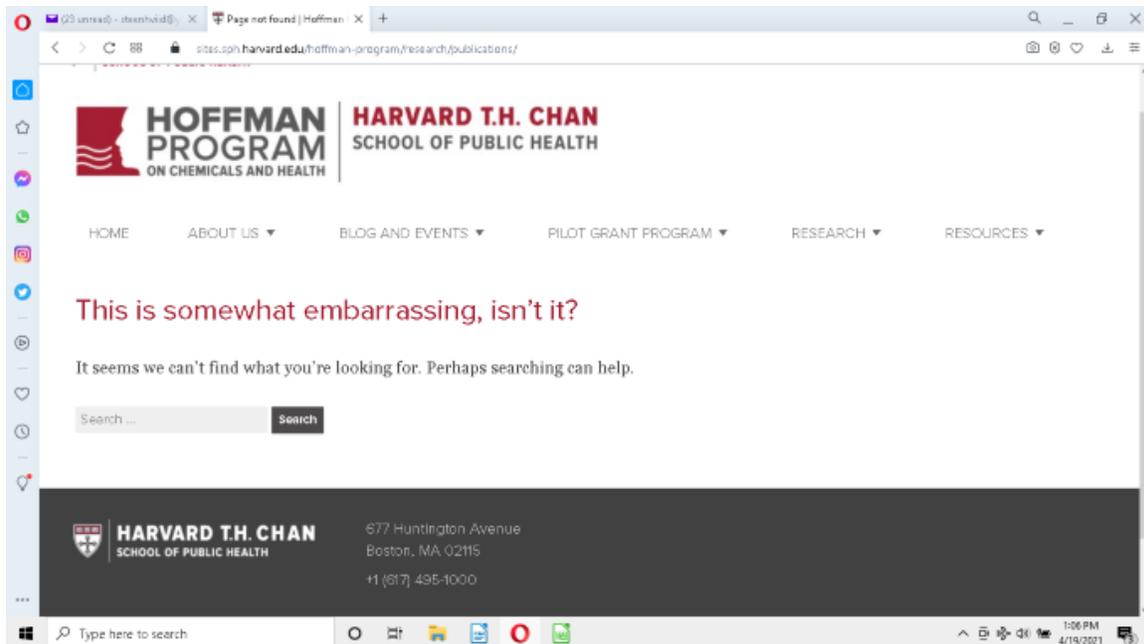
*The mission of the Hoffman Program on Chemicals and Health is to advance the understanding of environmental and chemical intolerance in people and to reduce the risk of contaminant exposures (Mission, 2021).*

The MCS community was elated. Finally there was a research program to look into some of the many issues that have been ignored for so long. The hope was that the research could help MCS become accepted as a “legitimate” disease, instead of one mired in disbelief and false myths. Hope that such research could make studying MCS a field considered worthy of more funding, so the many urgent research questions could be answered, and that the people stricken with MCS would no longer be treated with suspicion and disbelief by all parts of the health care system in America.

## What came out of it?

The Hoffman Program started in 2014. Seven years later, in 2021, we looked into what was actually produced. What did Harvard University do with the five million dollars?

We got a very symbolic indication when we visited the Hoffman Program website and clicked on their listing of research publications. The server's response was:



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Looking further, it appeared the website had not been updated since 2017, i.e. four years before.

A fancy-looking report of 2015 - 2016 activities was listed, but when we clicked on it the server refused to display it. There were other broken links here and there. It was unfinished and unprofessional.

The activities listed on the pages were all low budget “pilot projects” (max funding: \$25,000 each) and some seminars.

Clearly, that could not be all! So we contacted the Program and were assured that much had happened and they would get the website cleaned up. Our other questions went unanswered.

#### **The second checkup**

We waited a year to come back and see what information was now available. Not much had changed. There was a page listing “peer-reviewed publications funded by our program.” There were only five such articles listed. Confusingly, the page listed several other articles as well, which a casual reader might think were also part of the Hoffman Program.

Five articles is not much, especially since they all appear to be low-budget. More importantly, *none* of the five research papers were about MCS!

Two were about autism, the others were about chemical exposures from flame retardants, nail polish, and flight attendant uniforms.

The most MCS-relevant study surveyed airline flight attendants regarding their symptoms from their new uniforms that were heavily treated with chemicals (especially flame retardants).

All worthy topics to study, but they don’t really tell us anything about MCS. None of these can remotely be seen as “novel” or “transformative” or “taking risks.”

They are all unremarkable small projects, presumably all within the max \$25,000 budgeted pilot projects.

The program hosted seven one-day seminars on the Harvard University campus and a three-day meeting in Dallas. They flew in speakers from Europe. The Dallas event was co-hosted with the separate MBH Foundation and gathered 26 people, including two from Europe (both from Denmark). The Dallas event was all about

MCS and discussions about future research. The campus seminars were on a variety of related topics.

There are no reports from any of the seminars or the meeting in Dallas. One object of the Dallas meeting was to discuss future research recommendations, which would naturally result in a report. When we asked the Harvard people, we were given an excuse referring to the Covid-19 epidemic.

It is important for scientists in the field to meet and talk, and the campus seminars might attract researchers who are considering entering the field. If no scientists are willing to study MCS, then having funding doesn't help.

That can be a problem, since the Hoffman Program will only fund researchers working for Harvard, and not even their own Ph.D. students (About, 2021). This makes the pool of talent very small.

The announcement in *Harvard Public Health* magazine said they wanted to build a website that would be a “clearinghouse for scientific articles” and “address the rights of individuals with [MCS] in relation to health care, restaurants, hotels, transportation, and other public environments” (HPH 2015).

None of that ever happened. The website says they created a library about MCS – a surprisingly small one. The website listed 4 books, 2 news articles, and 27 research papers.

These are quite underwhelming results for such a well-funded program at a major Ivy League university.

### **Why did the Hoffman Program falter?**

We can only guess why the Hoffman Program was such a failure. Were they not able to attract any researchers that could do important research? That the Hoffman Program limited itself to only fund Harvard staff may be a big reason, as that is a limited pool of research talent.

The controversies around MCS could deter some researchers, who might be afraid that it could taint their all-important reputations if they seriously studied something that is (falsely) considered illegitimate by too many.

There can be many other possible reasons, such as personalities, inertia, bureaucracy, and how the Hoffman Program was promoted.

We sent an email with these questions to the leader of the program, but received no reply.

Poorly managed research programs do happen. An important example was the National Institutes of Health's AIDS research programs in the early 1990's. Despite generous funding, virtually nothing happened for two years, while thousands of people were dying. The apparent problems were inertia, personalities, and conflicts of interest. The scientists also refused to involve the patient community. It took a major effort by AIDS activists, and an act of Congress to throw out the bad leadership. That helped tremendously (France, 2016).

### **What happened to the money?**

The bequest was for \$5 million, according to Harvard's own magazine (HPH, 2015).

If we assume that each of the ten listed pilot projects were funded at the stated maximum of \$25,000, that the seven on-campus seminars cost \$10,000 each, and their part of the shared cost for the meeting in Dallas was \$50,000, that tallies up to roughly \$375,000. Then there are salaries and various overhead expenses. That may bring us to a total of one million dollars, if we are very generous.

What happened to the other four million dollars? Are they still waiting for good projects to fund? Did they get "redirected" or "absorbed" elsewhere? We asked by e-mail, but received no response.

### **This has happened before**

In the 1980s, MCS activists in California worked very hard to get funding for MCS research. In 1984 a bill passed both the State Assembly and Senate, but was vetoed by the governor.

The following year a new bill was introduced in the California State Assembly, but it never passed.

Then the MCS activists campaigned to get help from Assemblywoman Sally Tanner. This involved writing letters and meeting with her staff – which had to be done outdoors, as her office was too toxic. This time there was success. Tanner was able to get some money. It was earmarked for research into health effects from indoor air problems, with the understanding it was to study MCS.

The money was given to scientists at the California Department of Health Services. But they opted to study something less controversial. Instead of MCS, they studied asbestos and mold (Molloy, 2022).

Harvard recently had another scandal with donated research funds, as reported by Harvard professor Naomi Oreskes in *Scientific American*, though the circumstances were quite different (Oreskes, 2020).

### **The lost opportunity**

Harvard University had an opportunity here to really help people who are struggling with a debilitating illness, an illness that is being ignored by funding agencies and thus by the research community. It was an opportunity to help people who are routinely met with suspicion, derision, and inappropriate treatment by the medical system, and dogmatic disbelief everywhere, because there is a lack of science to demonstrate that MCS is indeed a “legitimate” medical problem.

There is an urgent need for balanced funding of MCS research, and not just for those who promote the “all in their head” paradigm and related echo chambers. Identifying biomarkers should be a top priority.

The Hoffman Program has done nothing to help. It was a lost opportunity.

Bequeathing money for MCS research seems like an obvious way to help, but how to make sure it actually does any good? There needs to be oversight by people committed to helping the MCS sufferers, without compromising scientific integrity. Such oversight was not evident for the Harvard Hoffman Program.

### **Make it right, Harvard**

Harvard is enormously rich. They should take \$5 million dollars out of their endowment and make up for their egregious failure by creating a real MCS research program. It must be open to researchers everywhere, and there must be oversight that includes the MCS patient community, so the money does not get siphoned away again and the scientists do not repeat the same mistakes we’ve seen in so many studies (especially provocation studies).

### **More information**

Articles about all aspects of living with MCS are available on [www.eiwellspring.org](http://www.eiwellspring.org)

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