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Speech before the CFS Advisory Committee

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Good afternoon. My name is Kathleen Manganaro, and I have had ME/CFS since 1984. I have traveled from Pittsburgh today to discuss the role that biotoxins/molds have played in my illness. If doctors had only known about the mold connection to my Chronic Fatigue Syndrome, there is no question that a great part of my suffering and pain could have been prevented.

In January 1983, I was 29 years old, married and the mother of a 3 year old son. I jogged regularly, was very energetic and had always been in excellent health. Then I went back to work as a school speech/language pathologist, working in four different schools ranging from kindergarten to high school.

In one of my buildings, I had an office that had a roof leak, water damage and mold. I felt especially sick there and convinced the administrators to let me see students in an abandoned bathroom that didn't make me feel quite as bad. I felt sick in that building from the start, with a variety of classic CFS symptoms that got worse over time.

In 1985 I saw an integrative physician who helped me regain some of my health with an anti mold protocol, after having spent two years seeing many doctors and specialists with no improvement. Others in that building had similar symptoms and one eventually had to quit working due to extreme fatigue. Six young teachers developed different cancers and died within a short time of diagnosis.

In 1991 I had a twin transfusion pregnancy which I attribute to working in that building – I nearly died and my twin daughters died shortly after birth.

Fortunately in 1992, I was transferred from that building. My health got much better, though I never had the energy that I did before working in the building.

From 1992 until 2003, my health was stable. Then in 2003, I was reassigned rooms and worked in an office in one of my school's basements. I saw water marks and peeling paint on the wall, but no visible signs of mold. My symptoms returned and got worse over time. Another person working in that office after me also got sick, but she improved once she was assigned to a different part of the building.

By May 2007, I had to stop working because I couldn't function. Then I went to a specialty CFS clinic, the Fibro and Fatigue Center in November 2007. Despite normal thyroid levels, the doctor gave me a large dose of T3 thyroid hormone without ramping it up slowly, as part of their CFS treatment. Within a month I had a major heart attack. The doctors I talked to afterward said that there was no other reason that I should have had a heart attack at all, and felt it was the thyroid medication. Lack of research monies and acceptance of this illness are contributory factors to my heart attack. Life is a test and making a difference to help others is what brings me here today.

My brother was an excellent physician, and before his death in a bicycle accident last summer, he looked into the medical literature and felt it was plausible that mold/biotoxins had made me sick.

I was diagnosed as having CFS by Paul Cheney, one of the most knowledgeable doctors in the field. If mold is a part of my CFS, then it's possibly a factor for a segment of other patients as well. I've encountered others with classic ME/CFS who got sick as a result of mold exposures, but have recovered much of their health after getting away from it. I am fortunate that the biotoxins/molds were in my workplace and not in my home, because I have been able to regain some of my health, but I must pace! But visit a moldy building for even 10 minutes and I will be back in bed for days.

As a speech pathologist, I saw the importance of early intervention in preventing dysfunctions from becoming permanent. My own health history suggests that if I'd just gotten away from that first moldy school, I might be totally well today.

Not everyone in the buildings where I worked got sick. I've been told that some people are more genetically predisposed to the effects of biotoxins and molds. Some people say that the retrovirus XMRV can make people more susceptible. Regardless, I was never sick prior to the first mold exposure in the 80's and not sick again until the second exposure in the mid 2000's.

The Hippocratic Oath includes the line, "I will prevent disease whenever I can, for prevention is preferable to cure." I urge doctors to carefully consider whether their CFS patients might also be getting exposures to toxic mold, and to encourage them to reduce those exposures, if so. Today, I am in congestive heart failure, got SSDI on the first try, without the assistance of a lawyer, and am on permanent retirement disability from work. My life could have been very different.