

“Canaries in a Coal Mine”

Testimony by Rev. Dr. Sharon Kiesel of Medina, Ohio

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Chairwoman Jones, Ranking Member Tavares, and members of the Senate Health and Human Services Committee, I thank you and your staffs for listening to the concerns of people in need. I represent millions of victims of Multiple Chemical Sensitivity (MCS). According to disability rights activist, Darrell Lynn Jones, sixteen percent of the U.S. population (51 million) are unusually sensitive to chemicals. Six percent of the population (19 million) are chronically ill and disabled by exposures. Three percent (9.5 million) have electrical sensitivities.¹ I am blessed today to be a voice for those who cannot be here, because they are imprisoned in their homes and beds, sickened by what has happened to our environment. One of them is my friend, Toni Temple, founder of The Ohio Network for the Chemically Injured, who is dying of cancer. For years we, who have MCS, have been known as “canaries in a coal mine.” Like the caged canaries who were brought into coal mines to detect poisonous gases, we are early warners of the effects of the uncontrolled use of toxic chemicals.

Imagine leaving behind ten years as a pastor because you react to fragrances, chemicals and mold in buildings. You cannot hug people because of the smells of dryer sheets on their clothes or their shampoo, deodorant or hand cream. Imagine fleeing your house, a store, the movie theatre, or a restaurant because your throat is closing up. Imagine being a retired Army officer who has to sleep in your car with an electric heater during the winter. You move to a camper because you react to the construction materials and paint off-gassing in your house. Imagine fleeing a friend’s home because your lungs burn from the lawn maintenance company spraying next door. Imagine loved ones and colleagues backing out of their relationships with you because you are strange and overwhelming to them. Imagine a family doctor laughing you and your spouse out of his office and telling you that you need to be on tranquilizers. Finally, a natural gas compressor station for the Nexus pipeline is planned for within five miles of your home. Scientific research is showing that tons of hazardous air emissions (some of which are carcinogenic), minute-sized particulates, and volatile organic compounds will be emitted annually in the normal operation of said facility.² This is a small taste of my new reality, because I have a broken immune system. I carry an arsenal of Epi-pens, a bronchodilator, and face masks, as I am literally fighting for my life each day...

After years of worsening symptoms and countless doctor visits, an expert medical doctor from New Mexico diagnosed me in 2015 as having Chronic Inflammatory Response Syndrome (CIRS). This was triggered by a genetic susceptibility to mold and years of exposures to water-damaged buildings. Biotoxin researcher, Dr. Ritchie

¹ During her presentation at the American Disabilities Association Conference in December of 2014 and based on a U.S. population of 319 million people.

² see Wilma Subra’s report at <https://www.docdroid.net/EiPsa5C/comments-on-wadsworth-compressor-station-air-permit.pdf.html> viewed on April 18, 2106.

Shoemaker reports that the overuse of fungicides, like benomyl, introduced in 1968, has allowed “resistant strains of fungi” to emerge,³ just like the overuse of antibiotics has caused antibiotic resistant bacteria to flourish. As is common for those of us with environmentally-derived illnesses, I developed Multiple Chemical Sensitivity.

According to Dr. Ann McCampbell, one of the founders of the Chemical Sensitivity Foundation,⁴ MCS is a chronic medical condition that is characterized by a heightened sensitivity to chemicals. Substances that frequently cause symptoms in chemically sensitive people include pesticides, fertilizers, scented products, fresh paint, new carpets, many building materials, solvents, fresh ink, smoke, vehicle exhaust, fuels, industrial fumes, and many cleaning products. Scented products include air fresheners, fragrance-emitting devices, potpourri, incense, essential oils, many beauty and laundry products. Synthetic chemicals and petrochemicals, extracted from crude oil or coal tar most often trigger symptoms in those with MCS. Exposures to common outdoor pollutants like nitrogen dioxide, carbon monoxide, and hydrogen sulfide can also be problematic, as are heavy metals like lead and mercury. Finally, I know three people who developed MCS after taking prescription drugs for the first time.

Symptoms occur after inhaling, touching, or ingesting these or other substances. **What is important to note is that chemically sensitive people can be harmed by exposures to minute amounts, even levels considered safe for the general public.** They also experience different symptoms from differing toxins and levels of exposure. This individual variability and sensitivity at minute amounts can be so pronounced, that many scientists and doctors do not accept it. The full range of toxicity of most chemicals is not known; nor are the accumulating effects of chemical exposures and the effects of being exposed to more than one chemical at a time. Despite this lack of research, workers and the public are often falsely reassured about the safety of their chemical exposures.

MCS frequently creates imbalances in a person’s nervous, immune, and hormonal systems, as well as the body’s impaired ability to remove toxins. Food and medication intolerance are common. Brain reactions, characterized by difficulty in thinking, speaking, or remembering often occur. Some people with MCS are sensitive to electromagnetic fields (known as Electronic Illness). They are sickened by exposures to cell phones and towers, computers, wireless and electrical devices, fluorescent lights, microwave ovens, security and scanning equipment. Many also have Chronic Fatigue Syndrome or Fibromyalgia. Many researchers believe there are related environmental causes for the epidemic of asthma, allergies, autism, ADHD (Attention Deficit Hyperactivity Disorder), diabetes, Parkinson’s, Alzheimers and other chronic illnesses.

³ Shoemaker, Ritchie C. *Surviving Mold: Life in the Era of Dangerous Buildings*. (Baltimore: Otter Bay Books), 2010, 256.

⁴ This description of MCS is summarized from <http://www.chemicalsensitivityfoundation.org/pdf/What-Is-MCS-by-Ann-McCampbell.pdf> viewed on March 24, 2016.

How can elected officials help those of us with environmental illnesses like MCS?

1. I ask you to declare May as Multiple Chemical Sensitivity Awareness Month.
2. The uncontrolled and untested release of toxic chemicals into our world is raising the incidence of chronic diseases like MCS. According to the Environmental Working Group, “the EPA (Environmental Protection Agency) has only reviewed a few hundred chemicals for safety. There are nearly 85,000 chemicals currently approved for use that the federal government and consumers know little to nothing about.”⁵ And more toxic chemicals are being introduced every year with inadequate testing. For the latest research on the shale gas industry, which is contributing more pollutants and public health effects, see *Shale Gas Extraction and Public Health: A Resource Guide* published by The League of Women Voters of Pennsylvania.⁶
Toxic chemical reform is badly needed. The inadequate regulation of chemical industries continues to threaten our rights to a clean and healthy environment and the quality of life for future generations.
3. Years of scientific research (to include modern and alternative / functional medicine) on environmental illnesses has been ignored, causing grave harm to the sufferers. Modern and functional medicine, government, insurance, all facets of the chemical industry, and the building construction sectors need to be united around the realities of environmental illnesses and must be responsive to its many sufferers. Funding is needed for continued research on diagnosis, treatment and prevention.
4. Immediately enforce the American Disabilities Act for those disabled by their environments. MCS and other environmental illness victims desperately need understanding, safe shelter, proper diet, and effective medical treatment. Ensure that they are accommodated in their homes, workplaces, public and medical settings according to their levels and types of disability. This includes timely processing of legal and Workman’s Compensation cases.

We all play a role in polluting our environment and we all are responsible for making our world safe for us and for future generations. **Environmental illness is not a political issue, but a public health crisis.** We must set aside our territorial nature and work together for the measurable reduction of toxic chemicals to safe levels for all people, including: children, elderly, those with environmentally-compromised immune systems, and those living in poverty.

As “canaries in a coal mine,” MCS survivors like myself are teetering on our perches. Many of our friends have already died needlessly at the bottom of the cage. We wonder if anyone is really paying attention...

⁵see <http://www.ewg.org/key-issues/toxics/chemical-policy> viewed on September 30, 2015.

⁶ <https://www.docdroid.net/lqBCnA7/pa-league-of-women-voters-shale-health-.pdf.html> viewed on April 18, 2016.