Testimony of Nancy Dargan before the Committee on Energy and Commerce Subcommittee on Health United States House of Representatives January 30, 2018

Good morning, and thank you for allowing me to be here today to provide testimony regarding the Drug Quality Safety Act (DQSA). My name is Nancy Dargan, and I live in Brighton, Michigan. I am going to tell you about how a contaminated compounded medication permanently harmed my health, putting a premature end to my career and ruining my family's finances and plans for the future.

To begin my story, I have to travel back to early 2012. I was experiencing pain from arthritis in my back and my hip, and my primary physician referred me to a pain clinic, for periodic injections of a steroid called Methylprednisolone. The shots gave me some relief, and I continued my busy life as a grant writer and business consultant, until everything changed that August.

I had driven from my home in Michigan to West Virginia to meet with a new client and help them set up a nonprofit organization. During my stay, I began to feel sick, though I didn't think much of it at first. But the symptoms steadily worsened, and I realized I had to cut my trip short. As I drove home, an excruciating burning sensation developed in my right hip and spread down to my knee. The pain became so unbearable that I had to use my left foot for the gas and brake pedals. I arrived in Michigan, completely unable to bear weight on my leg, and my husband Mike took me to the hospital, to try to figure what was going on.

The doctors ordered x-rays, a spinal tap, a biopsy, and other tests, and expressed that my condition was something they had not seen before. They worked to treat my pain but initially had no clear diagnosis and sent me home. It was there that I got a call from the pain clinic that had administered my steroid injections. They said I'd potentially received contaminated drugs and should go to the emergency room immediately. By this time, the

hospital staff were realizing that my case was not an isolated one. Other patients were showing up at the hospital with infections and pain similar to mine, and like several of them, I was ultimately diagnosed with a fungal infection.

I underwent surgery and spent two weeks in the hospital. I was placed on the maximum dose of Voriconazole – a powerful antifungal medicine with side effects that seemed nearly as bad as death itself. I took it 4 times a day for 14 months, even waking in the middle of the night to receive a dose.

After I was discharged, my husband, Mike, became my caretaker at great personal expense to him, both mentally and physically. His job was one of the worst a care partner can experience – dealing with the unknown effects of a major medical event. I can't tell you how many times Mike would come into a room and I would be carrying on a conversation with my daughter who died in 1979 – the result of hallucinations caused by the antifungal medication. I would call out for our pet, Deuce, and would get frustrated when he wouldn't respond. We had put him down the year before due to cancer.

Throughout this nightmare, Mike made sure I made it to every doctor's appointment—often 3 or 4 per week—on top of other tests including blood draws every Friday. If something needed to be done, including all of our household chores, he did it. For 14 months, he never left my side unless I was napping and he could get errands run. He was not only my caregiver but my constant advocate.

Of course, all of this has had a devastating impact on our lives and plans for the future. Financially, we lost everything to this event. The hospital and doctor bills were astronomical. I lost my ability to maintain self-employment and regrettably had to close my business and refer my clients to others. We had partial ownership in a cabin left to my husband and his sister by his father, but had to sell our interest in this treasured family property, which we enjoyed so much and which held wonderful memories for my husband. I saw the grief in Mike's eyes every

time we had to sell something he loved. The financial toll has threatened our retirement and our independence as we grow older together.

Today, 5 years after this tragedy began, I still have recurring symptoms and numerous side effects. I walk with a limp and cannot get an orthopedic surgeon to consider replacing my right hip because there are still fungal pockets on my bones. My pain levels are always elevated. My disease and treatment have made me vulnerable to opportunistic infections that have attacked my kidneys and sinuses. I continue to suffer from short term memory loss, and it is getting worse year after year.

Before this happened to me, I had never heard of drug compounding, and I never would have imagined coming to Washington to speak about it. But I feel obligated to do so because sadly, there are many others who have endured as much suffering or more. I weep for the 79 families who lost their loved ones to this deadly and preventable outbreak, and for the hundreds of patients who live every day with the lasting consequences of illnesses caused by contaminated compounded drugs. Many of these people are friends and neighbors who live in our community, and I am here to speak up for them, too.

I don't want another soul to experience what we have. As a result of contaminated drugs, and a failure to oversee them, I am now a person who will spend the rest of my days dealing with a complex illness. It was not easy for Mike and I to get here today. We hope that by sharing our story, we can help prevent this from happening to anyone else.

Thank you for allowing me to take some of your time today to allow me to share my story.