1.19.17 Senate Healthcare Forum - Testimony by Ann Serafin, MI

My name is Ann Serafin. I live in Ferndale Michigan, and I am 66 years old. I just want to say, I’m reading this statement, so it may not convey the real passion I feel about this issue. But please know how important this is to me.

I've had personal experience with Medicare since I was 40 years old, when I was diagnosed with multiple sclerosis. As you may know, MS is a neurological condition which varies in severity and is unpredictable.

My particular version resulted in functional quadriplegia, which means I can use my right arm with some help and a grab bar - but can barely move my left arm at all. Fortunately my vision, speech and cognitive abilities have been spared.

At the time I was diagnosed, I was a marketing professor at University of Detroit-Mercy. The University placed me on disability, and a year later my application for Social Security disability benefits and Medicare was approved. Thanks to strong union support, the University picked up my secondary health insurance until I turned 65.

Within a few years, new MS medications started coming onto the market, and my neurologist and I chose Copaxone. The price started out at about $8,000 a year but is now $84,000 a year.

After ten years, it became apparent that Copaxone was not working, so I tried several other medications, including Acthar Gel. In the ’70s, this cost $50 a month, but when the drug company realized it could benefit many people with MS, it shot up to $30,000 a month. Because it was off label, my insurance would not cover it. The National Organization for Rare Diseases helped for two months, but I could not afford to continue after that.

I am currently on Gilenya, with a co-pay of $38 per month. **Without Medicare or secondary insurance, this one drug would cost about $75,000 a year, which is nearly our total household income including our Social Security benefits.**

I have a handout here that can show you how prices have shot up for all MS drugs.

Disability is costly even beyond medications. Making our home accessible, purchasing an accessible vehicle, the scooter I drive, and hiring personal assistance … it gets expensive. This is why my 68-year old husband continues to work part time as a self-employed writer, while also serving as my primary caregiver. His monthly insurance costs were $900 before he turned 65. We rejoiced when he was able to get Medicare and have that number come down to $200 for supplemental insurance.

Without Medicare, I would have had to decide: do I eat, or do I get my meds?

Without Medicare, I would have to pay an astronomical cost for private insurance, if I could get covered at all.

While I was dealing with my own health issue, my aging parents needed increasing care and support. My father was a U.S. Army veteran who served as a paratrooper in World War II. He helped liberate Normandy with his D-Day combat jump. He was also an independent artist and relied on Medicare and the VA hospital for his health care. Even though my dad worked until his death at age 91, my husband and I needed to financially support my parents to keep them in their home. **This is what they wanted, to age with dignity. We're Greek, and Greeks take care of their own.**

I also have experience with Medicaid, which my my mother relied on for the last three years of her life. My husband and I took care of her financially before she passed away at age 98 this past October. Until my dad passed, my mother had Medicare with supplemental insurance. But my parents had no savings and no assets – we had bought them a condo and took over the mortgage payments. When my mother's dementia worsened to the point that she needed full-time care, we had to place her in a nursing home.

I could not care for her complex needs; I needed help for my own care.

Even a bare-bones nursing home would've been too much for us at $6,000 a month. She received $1,190 a month in Social Security and widow's VA pension benefits. **It was only because of Medicaid that she was able to get the help that she needed at the end of her life.**

Without Medicare and Medicaid, things would have been very different for my family. I don’t know how I could have cared for my mother on top of managing my own care. My family would have lost our home and all our savings trying to keep up with their bills.

So many families are squeezed like ours, having to afford care for their aging parents and their own care or childcare at the same time.

But with support, we don’t have to suffer just being alive. I can’t cook for myself, I can’t get myself out of bed... **but I can still contribute**. Because of these public programs, I can be productive and be involved in things that are important to me. This includes being here with you in Washington, talking with legislators, and volunteering as an advocate with Michigan United, Caring Across Generations, and the MS Society. **All because of the support I get from Medicare.**

If these programs are cut, people will face more catastrophes than ever before. People are panicking. If these services are cut, it will have a huge, huge, huge impact on the lives of so many people. Congress needs to know that. Thank you for letting me tell my story.