

**John Czwartacki**  
**Multiple Sclerosis Survivor and Founder Chairman Survivors for Solutions**

**Written Testimony**  
**United States House Committee on Energy and Commerce, Oversight and Investigations**  
**Subcommittee Hearing on “At What Cost: Oversight of How the IRA’s Price Setting**  
**Scheme Means Fewer Cures for Patients.”**

**September 20, 2023**

**Testimony Summary:**

- John Czwartacki was diagnosed with Multiple Sclerosis (MS) in 1993. At the time, he was a press secretary for a member of the US House of Representatives.
- When he was first diagnosed, there wasn’t a single disease-modifying treatment, or DMT, to slow his disease’s progression, but thanks to a decade-earlier bipartisan congressional compromise, the medical innovation ecosystem was thriving and would afford him multiple MS treatments to consider years to come.
- Czwartacki credits medical innovation and science for giving him his family, an extensive career in public policy, and independence.
- The Inflation Reduction Act (IRA), however, ends four decades of bipartisan agreement that supported innovation and saved lives. This partisan bill will ration care.
- Lawmakers need to understand that their policies have serious implications for patients downstream. By desensitizing scientific discovery, price controls will make Americans sicker, take away hope, and lead to fewer medical breakthroughs for current and future patients.
- Czwartacki’s health journey is a testament to the importance of protecting innovation but is one of many patient stories that lawmakers need to consider before doubling down on harmful policies.

Thank you, Chairman Griffith, Ranking Member Castor, and members of the committee. I am pleased to testify today and share my story, health journey, and what innovation means to me and so many other patients.

First, I want to say how much personal respect I have for this committee, including for the US Congress, which I served as a young person, barely a sick day in my life. I wasn't a patient; I was impatient for my life to unfold.

In fact, it was in the building next door when I had my first MS symptom. I lost my sight in my left eye, gone to this day. I was 23 when I was diagnosed with Multiple Sclerosis in the spring of 1993.

Later that year, the very first disease-modifying treatment, or DMT, was approved for the treatment of MS. After decades and decades of scientific research and generations of patients who suffered without a way to control the disease, an interferon was isolated and was found to slow progression for most patients. Most, but not all.

A flywheel of medical innovation that unleashed patient hope was set in motion ten years earlier. It was 1984 and a hard-fought compromise reached by ideological opposites—liberal Democrat Congressman Henry Waxman and conservative Republican Orin Hatch. The results were an unending pipeline of life-saving treatments, catapulting the US from a laggard in medical discovery to the undisputed global leader.

No doubt a noteworthy achievement, but for me, opening the floodgates of innovation would mean everything.

Soon, I was put on the DMT available once additional symptoms presented: numbness in my face and hands, pins and needles, minor stuff but increasing in frequency. My life continued. The problem was that despite being proven effective for most MS patients, the one approved DMT didn't work for me.

And just as I was starting a new job over in 1998 in the Senate, the attacks got so severe they became impossible to ignore.

I was treated in a hospital for two weeks and then moved to a nursing home. I was suffering from unpredictable seizures, couldn't walk, or even safely swallow food or water. I was 28. No mortgage. No steady girlfriend. I was on my life's launchpad. My parents could see how counterproductive having me in such a facility and offered their help; they rented a hospital bed for the basement of my childhood home and moved me back in with them.

However, the second DMT for MS had been approved the year earlier, and on May 1, 1998, I began my first dose. The daily injections took a few weeks to work, but once they did, my life began again. My body was given a respite from a haywire autoimmune system. Combined with intense physical therapy, rest, and prayer, I was able to move out of my parent's basement, rejoin a meaningful career, and meet the woman with whom I would soon marry and start a family. Four healthy and active sons. In short, the drug saved my life in every way possible.

It was baseball games, hockey practice, and homemade hoverboards for almost twenty years. After two decades, the treatment began to lose effectiveness. I would come to need two more breakthrough drugs – both discovered since my diagnosis – to keep me upright (mostly) and productive.

But it's safe to say that while you all debate and make policy choices, there are patients, real patients, downstream of those choices. You need to understand the lives you change with the policies you create.

I owe my life to your former colleagues who chose to let medical innovation flourish and discover life-changing medicines. Hatch-Waxman was comprehensive bipartisan legislation that unleashed the scientists and researchers who gave a life to the dad of Sam, Nick, CJ, and Henry. I can barely get out the words, let alone put a price tag on the results.

Being a government nerd, as I read the 300 relevant pages in the IRA – mind you, that was pushed through by only one party with little public debate – I became enraged. At best, this partisan price control experiment would end four decades of bipartisan agreement in support of innovation and saving lives.

Most patients would never believe that their elected representatives would purposefully take steps to impede scientific discovery.

It's already way too costly to be sick in America, but the IRA makes it harder to get well.

The cures being prayed for at Mt. Sinai, St. Jude's, or any hospital chapel across the globe are further away because of this signature bill. Kids with rare disease, women with cervical cancer get no relief from EV tax credits.

Instead of spreading hope, the government is now rationing out doses of despair.

You can fix this. “First, do no harm” wasn’t your thing last year. But while you’re in a hole, you can stop digging. Stop doubling down on a policy that is directly ending hope for the most vulnerable.

I can never repay those who are responsible for allowing me to live my wonderful life, but what I can do is stand up for the people you ignored. I can remind my good friends that this policy is sentencing real people to needless suffering, mental anguish, and the potential of early death.

Here’s a little secret: It’s not just for me and my kids, the kids at St. Jude’s, or even your constituents. It’s for you and those young staff behind you. Because I learned the hard way: we’re all patients were, are, or will be.

I am honored to speak with your committee today, share my story, and speak up for patients and hope because, ultimately, hope matters most, and we all deserve a chance at being a survivor. Thank you.