

Good morning, Chairman Guthrie, Ranking Member Eshoo, and members of the Subcommittee on Health.

My name is George Manahan. I am testifying today as a patient and advocate in support of H.R. 2365 or better known as The National Plan to End Parkinson's Act.

I'm not a policy expert. I am a small business owner from West Virginia trying to navigate the world of Parkinson's while providing jobs to 12-full time employees.

Mr. Chairman, can I ask for a show of hands? I am interested to know ... how many people on the committee know personally someone with Parkinson's disease?

I ask that question because when I was diagnosed 13 years ago, at age 49, I didn't know anyone with the disease.

For those of you who don't know someone with Parkinson's disease, I humbly say ... you do now.

Everyone's Parkinson's journey is different.

Mine started with the tightening of muscles in my right arm and leg and followed with tremors. The tremors became so bad that I would hide my shaking arm in a pocket, the couch cushions, or anything that would keep my disease from becoming public and to relieve the pain that I experienced from the tremors in my arms.

I was persuaded to try brain surgery known as Deep Brain Stimulation or DBS.

The result was incredible. My tremors were mostly gone.

I remember crying with my wife, Susan, in the doctor's parking lot after my Parkinson's specialist turned on my brain stimulator and I watched my tremors fade away.

But DBS is not a cure. It's an effective therapy for some people with movement issues. Over the years, my brain has slowed significantly, making it difficult for me to manage more than one task at a time.

They call it loss of executive function. I call it forced retirement.

Some nights I act out in my dreams, another byproduct of my Parkinson's, and I fear that I will someday injure my wife or myself.

My speech has been impacted and I am having some difficulty swallowing. One of the leading causes of death in Parkinson's is choking on food.

One of these symptoms by themselves wouldn't be a problem, but Parkinson's has a way of piling on.

When I was diagnosed, I craved to find other people who had this disease, like me. But, in my hometown, they were nowhere to be found. I found out later that they were home, suffering alone.

So, we started a 5k walk and run that blossomed into support groups and free exercise classes and caregiver forums and more. Soon, we had over 200 people or more showing up to raise money, advocate and learn from each other.

A 2022 report, *The Economic Burden of Parkinson's*, calculates the cost of PD at \$52 billion. Half of that cost is paid by the federal government and half is paid by patients and their families.

I don't believe that those figures calculate the tremendous loss of income and jobs that families experience when someone has to stay home to care for their loved one.

I often worry about the burden just ahead for my wife.

I am here today to speak in support of H.R. 2365, which is an important first step to relieve the economic and emotional burden of Parkinson's disease.

The National Plan is a bipartisan, no cost legislation, that is being championed by Rep. Bilirakis and Rep. Tonko here in the House and my Senator, Shelley Moore Capito in the Senate. It's patterned after highly successful legislation that passed ten years ago for Alzheimer's disease.

What I particularly like about this bill is that patients, caregivers, healthcare providers – people on the front line of this disease – will have a seat at the table.

This legislation will bring together the public and private sector to develop a National Plan.

The title of the bill may seem a little ambitious.

You might ask ... is this possible? To end Parkinson's? I believe it is.

Through research, all things are possible.

We now have a biomarker that can detect Parkinson's disease with a high degree of accuracy.

Imagine: we will soon be able to detect Parkinson's disease long before we see the first symptoms. This will open research and treatment opportunities that haven't previously been available.

Mr. Chairman, Parkinson's patients throughout the country support H.R. 2365. Let's take this first step together to find a cure for this disease.

Thank you.