Written testimony of George Manahan
Parkinson's Advocate and Patient
Subcommittee on Health
House Committee on Energy and Commerce
Regarding the Hearing: *"Examining Proposals that Provide Access to Care for Patients and*
Support Research for Rare Diseases."
June 14, 2023

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 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. I didn't have a family connection, although about 15

percent of people with PD have a family connection.

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 movement aspects of PD.

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 executive function. I call it forced retirement.

Some nights I act out in my dreams, and I fear that I may 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.

More than 1.2 million people in the U.S. struggle with Parkinson's disease. That number is expected to double by 2040. West Virginia has the third highest prevalence rate of Parkinson's.

After finding out that West Virginia had very little services for people with Parkinson's, I, along with our team of volunteers, took on the challenge to establish support groups, exercise classes, statewide symposiums, caregiver forums and more.

According to a recent report, The Economic Burden of Parkinson's is $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, the National Plan to End Parkinson's Act, which will establish an Advisory Council, chaired by the Secretary of Health and Human Services, that will meet quarterly throughout the year.

The National Plan is a bipartisan, no cost legislation, that is being championed by Representative Gus Bilirakis here in the House and my Senator, Senator Shelley Moore Capito. 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. Long before the cells that produce dopamine are killed off in the brain. This will open research opportunities that haven't previously been available.

I will conclude by saying: H.R. 2365 is the boldest, most comprehensive PD-focused legislation considered by Congress. Let's take this first step together to find a cure for this disease.

Thank you, Mr. Chairman.

One-Page Summary of the Written testimony of George Manahan, Parkinson's Advocate and Patient

- I am a Parkinson's patient and advocate from Charleston, West Virginia.

- I was diagnosed 13-years ago at 49-years of age.

- I am testifying today in support of H.R. 2365, The National Plan to End Parkinson's Act. The legislation is patterned after the highly successful Alzheimer's Disease bill passed 10 years ago.

- Every Parkinson's journey is different. Mine started with tightening of muscles, followed by tremors. I've had two brain surgeries to calm my tremors.

- Over the years, my brain functions have slowed. Some nights I act out in my dreams, putting my wife and myself at risk of injury.

- I struggle with Parkinson's disease while running a small business with 12 full-time employees.

- H.R. 2365 will create an advisory board of federal and non-federal members. The legislation will allow for patients, caregivers, and Parkinson's doctors a seat at the table.

- We now have a biomarker that can detect Parkinson's disease with a high degree of accuracy long before we see the first symptoms. This will open new research opportunities that could lead to a cure.

- The National Plan to End Parkinson's Act is a bipartisan, no cost legislation that is being championed by Rep. Gus Bilirakis and Sen. Shelley Moore Capito. The legislation has 68 co-sponsors in the House.

- H.R. 2365 is the boldest, most comprehensive PD-legislation considered by Congress. Let's take this first step together.