

PARKINSON'S POLICY FORUM

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HOW TO TELL YOUR STORY

Your voice matters.

When meeting with your members of Congress and their staff, it's important to talk about your experience with Parkinson's disease (PD) and how it relates to your everyday life — that's what we mean when we say "tell your story." Sharing your story puts a very real face on the issues that are important to our community, and it helps legislators understand how their actions impact their constituents living with Parkinson's disease.

Below, three advocates share examples of how they've told their story in meetings with lawmakers. Feel free to use these as a starting point to begin crafting your own narrative.

Dan Kinel, New York: "I was diagnosed with Parkinson's disease five years ago at 43, when my sons were six and eight. It hit me like a ton of bricks. What would my future and the future of my family be like? When I finally got up and dusted myself off, I realized that the most effective way to help myself, pursue a PD-free future for my children and reduce the ever-growing societal impact of the disease was to engage in research. I do this both as a clinical trial participant and as an advocate of research funding. I know my lawmakers are looking out for the best interests of our citizens. Congress has the power to devote government resources to finding a cure and improving people's lives. Allocating resources to fight PD is an investment in our collective futures that is urgently needed."

Leslie Peters, Colorado: "My name is Leslie Peters and this is my fourth time coming to Washington to advocate for the Parkinson's community. My mother-in-law had PD and my husband has young-onset Parkinson's disease. My husband and his mom grew up in Allentown, Pennsylvania, which is highly industrial. I feel there is a possible genetic component and environmental component to their PD. Recently, my oldest daughter developed a tremor. Coming to Capitol Hill and doing all that I can to push research forward is the most important thing in the world to me. New research helps us know if others in my family will be at risk for Parkinson's. In the past few years, scientists have made significant progress understanding the genetic aspects of PD, but there's still work to do. This is not the time to slow or stop this critical work."

Israel Robledo, Texas: "I was diagnosed with Parkinson's disease 11 years ago when I was 42. With no family history, it came as quite a shock and it took me a while to come to terms with the diagnosis. I knew that I had to do something to help and decided to use my voice to advocate for health-related issues and increased research funding at the federal level. My medications, which were developed thanks to investments in research, do a good job of meeting my needs and helping me maintain a good quality of life. But that's not the case for every person with PD because this disease affects each individual differently. The need for continued federal research funding is of the utmost importance because many patients need improved treatments to adequately manage their PD."