

Dear Congresswoman Lee,

I am contacting you to ask that you please co-sponsor and support the passage of S.1064 - The National Plan to End Parkinson's Act. The quicker this is done, the quicker we can start working on real solutions for people with and affected by Parkinson's.

This is my story:

I am a PWP which means a Person with Parkinson's Disease or PD. I am a 60-year-old Mom with two adult kids who live with me because they are on the Autism spectrum and cannot live on their own without close oversight. They also have chronic illnesses that make it very difficult, if not impossible for them to work.

I started to notice my PD symptoms when I was about 54 years old. My kids were 15 and 20 and needed me to be very proactively involved in overseeing their health care and education. I was good at this. I was always a very organized and determined person. This served me well when I worked as a stage manager, producer, and event coordinator. I was unflappable. My calmness and eye for detail also served me well when I worked in practical film effects as a pyrotechnician.

Now, I cannot do any of these things because of Parkinson's Disease. It has taken away my ability to do fine motor work because of my shaking. It has taken away my calmness and replaced it with constant physical and emotional anxiety. Medications do not fully work to quiet the internal tremble I have. Medications do not restore the confidence and organizational skills I once had and so desperately need to run the business of my life, especially for my kids who don't have these skills. As a result, they are not getting the care they need.

I can no longer parent. This devastates me.

One of the most prevalent changes in my life is the great difficulty in socializing. Due to my nerves constantly feeling frayed, I cannot manage anything remotely exciting. I can no longer attend plays or see most films. Gatherings with friends or colleagues are nearly impossible. I can barely leave my house for routine outings. I get overwhelmed very easily. If I don't take my PD meds every 3-4 hours, I hit a low, I get twitchy and irritable, I can't think and I shut down. This is a daily occurrence. The way I respond to the meds changes daily depending on my sleep and other factors. This is no way to live.

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Signing this bill is an easy thing to do and support. It is cheap - the funding is inexpensive for the results that will be gained. The reduction of money wasted by ineffective actions and programs will easily pay for the committee. It is bi-partisan. It would put the PD community on par with the government so we can be heard.

Again, please co-sponsor and support S.1064 - The National Plan to End Parkinson's Act.

I am available to be contacted if you need further information.

Thank you for your time and consideration.

Amy