



Frequently Asked Questions

Q: I don't want to get involved in politics. Why should I care about this?

A: There are many ways to advocate for the progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA) community. Legislative advocacy is one way to bring awareness at the highest level and to the larger population as well as to create a path for increased research, treatments, support and, ultimately, a cure. While there are overlaps in symptoms and treatments with Parkinson's disease and there is power in uniting with the larger Parkinsonian community, we also want to ensure that we highlight the unique needs of people with PSP, CBD and MSA through this legislation. Recent breakthroughs in other neurodegenerative diseases came on the heels of big legislative investments and supports, and we hope this bill will follow that path.

Q: Why is CurePSP getting involved in advocacy for this specific bill?

A: This is the first time that the three atypical Parkinsonian diseases are specifically named and have been included in a bill of this magnitude. CurePSP wants elevate the voices of those living with these three diseases and to raise awareness among Congress and the public about the impact they have on patients, care partners, and medical professionals across the country.

Q: Why are there 2 bills - HR 2365 and SB 1064?

A: HR stands for House Resolution, which means this is a piece of legislation that is filed in the House of Representatives. SB stands for Senate Bill, which means this is a piece of legislation that is filed in the United States Senate. Filing the bill in both chambers gives the bill two chances to go through the legislative process instead of just one shot in one branch. The language is identical so the result of either bill passing would be the same.

Q: What else can I do other than send an email or call my elected officials?

A: We are so glad you asked! There are many ways to continue your advocacy and we will be sharing more with you in the coming months. We are hoping to support our community in hosting in person/virtual meetings with their own members of Congress and continuing to learn more about the bill. This is a long process that has many points where we will call upon you mobilize and advocate, so persistence is key. We will be providing updates on this so stay tuned!

For additional questions, please contact advocacy@curepsp.org