



UNLOCKING THE SECRETS OF BRAIN DISEASE®

## **Community Advisory and Advocacy Committee**

### **Our mission:**

The Community Advisory and Advocacy Committee (former names: Programs & Education Committee; Patient and Carepartner Advocacy Committee) ensures that the perspectives and expertise of the larger community served by CurePSP are incorporated into CurePSP's program development and strategic priorities.

### **Who we are:**

The CurePSP Community Advisory and Advocacy Committee is a diverse cross-section of people personally impacted by progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA), healthcare professionals, volunteers, and staff who serve as advisors to and collaborators with CurePSP leadership.

Co-chairs: Ileen McFarland, CurePSP Board of Directors, and Kelsey Woods, CurePSP Community and Resource Manager

### **What we do:**

- Offer guidance to CurePSP on the development of educational resources that are created to advance the mission of the foundation and improve quality of life for people diagnosed with PSP, CBD, and MSA, and their families.
- Advocate on behalf of, and alongside, people diagnosed with PSP, CBD, and MSA and their family care partners through working with CurePSP to assess and address unmet needs of the community.
- Advise CurePSP on initiatives related to support, education, and advocacy, and reinforce the work of CurePSP's staff, Board of Directors, and peer volunteer and support group network to accomplish related goals.
- Serve as CurePSP's ambassadors in the community by identifying opportunities to raise awareness and to share CurePSP's resources & mission with patients and families, healthcare professionals, policy makers, and the public.

### **How we do this:**

- Listen to the experiences, challenges, strengths, and needs of CurePSP's community members and represent the voice of people diagnosed with PSP, CBD, and MSA, and the families and healthcare professionals who care for them, in resource and program development.
- Work together to carry out the strategic plan of the foundation, in collaboration with CurePSP staff and Board of Directors.
- This a standing committee with sub-committees created as needed to pursue specific initiatives and tasks.
- Members must commit to regular attendance of virtual meetings of the committee and respective sub-committees.