About CurePSP

CurePSP is the leading nonprofit organization dedicated to the awareness, care and cure for three neurodegenerative diseases: progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA). As a catalyst for new treatments and a cure, we establish important partnerships and fund critical research. Through our advocacy and support efforts, we enhance education, care delivery and quality of life for people living with PSP, CBD and MSA and their families. Science, community and hope are at the heart of CurePSP’s mission and all of our services.

CurePSP is a registered 501(c)(3) charity within the United States (Federal Employer ID Number: 52-1704978). Our work is possible thanks to the generosity and support of those in our community and beyond.

Mission
To raise awareness, build community, improve care and find a cure for PSP, CBD and MSA.

Vision
A world free of neurodegenerative disease.

Hope is a driver, a touchstone, a source of meaning. This is what our community has shared with us and why hope takes shape and is instilled at every level of CurePSP.
The Diseases We Support

CurePSP recognizes the complex journeys experienced by people diagnosed with PSP, CBD and MSA and their families. We are driven by the strength of this community and our unwavering dedication to care, consciousness and cure.

PSP, CBD and MSA are neurodegenerative diseases, meaning that they are caused by the progressive loss of brain cells over time and by the abnormal folding and accumulation of proteins inside of brain cells. In PSP and CBD, this protein is called tau, which is also associated with Alzheimer’s disease. Alpha synuclein is the protein involved in MSA, as well as Parkinson’s disease. It is not yet known why people develop these diseases.

Arriving at the correct diagnosis of PSP, CBD or MSA can be a lengthy and confusing process. Symptoms, which may include stiffness, slowness, imbalance and tremor, can be complex and require special considerations for care. While treatment cannot slow the progression of these diseases at this time, there are options to manage symptoms and support the needs of patients and families. Healthcare professionals and researchers are working diligently to understand, prevent and treat PSP, CBD, MSA and other neurodegenerative diseases.

**Progressive Supranuclear Palsy (PSP)**
Affects 30,000-40,000 people in the United States. Symptoms include loss of balance, changes in personality and cognition (particularly with impulsivity and judgment), weakened downward eye movements and other vision changes, slurred speech and difficulty with swallowing.

**Corticobasal Degeneration (CBD)**
Affects 2,000-3,000 people in the United States. Primary symptoms include changes to balance and speech, stiffness, cognitive changes and difficulty with coordination.

**Multiple System Atrophy (MSA)**
Affects roughly 13,000 people in the United States. Symptoms include changes to movement, coordination and speech as well as to autonomic functioning, such as blood pressure regulation, breathing, urinary function and swallowing.
“Any diagnosis is a big change to anyone’s life. But we try to face each day as an opportunity to do exactly what we want and are still able to do.”

- Ben, diagnosed with PSP, and his wife and carepartner, Martha

“A dragonfly means change, transformation, adaptability and self-realization. And I think these describe what MSA patients go through.”

- Jeaninne, diagnosed with MSA

“Through the love of family and laughter, we are trying to be the treatment for the incurable. These days are extraordinary. I cherish and approach them all with gratitude.”

- Sanjay, grandson of person diagnosed with CBD
Our Three Pillars

Care

CurePSP is here for our community of people diagnosed with PSP, CBD and MSA and their families through a commitment to enhancing the delivery of care, building community and providing direct support.

- **CurePSP Centers of Care** – This network of specialized medical centers across the United States and Canada is dedicated to the comprehensive care of PSP, CBD and MSA. Research and collaborations within this network will lead to improved diagnosis, options for treatment and symptom management, and resources.

- **Support groups** – From diagnosis-specific groups to care partner groups and more, CurePSP hosts a variety of virtual support groups open to anyone in our larger community. We also assist over 40 locally-organized support groups across the U.S.

- **Quality of life respite program** – We offer grants for 60 hours of professional, in-home respite care as a direct source of support for families caring for someone with PSP, CBD or MSA.

- **Peer support network** – Our growing network of peer supporters offers assistance and connection for care partners and people living with PSP, CBD and MSA in their local communities.

- **Bereavement support** – Our bereavement support group and bereavement journal were created to assist PSP, CBD and MSA families as they navigate the complexity of the grief journey.

Consciousness

CurePSP empowers people diagnosed with PSP, CBD and MSA and their families with tools to understand their diagnosis and advocate for themselves. Additionally, raising awareness of PSP, CBD and MSA among healthcare professionals and the public is a top priority.

- **Printed resources** – We are continually updating and growing our catalog of educational materials on PSP, CBD and MSA, including diagnosis-specific Some Answers booklets, the Care Partner Guidebook and medical alert wallet cards.

- **Community educational events** – Our biannual Family Conferences and regular Ask the Expert and Community Conversation webinars are opportunities for individuals and families to gather useful information for their care journey.

- **PSP/CBD/MSA 101** – Receiving a diagnosis of PSP, CBD or MSA can bring up many emotions and questions. This educational support series offers information and connection for people who are newly diagnosed.

- **Advocacy** – We are actively implementing new and expanded programs aimed at increasing awareness of PSP, CBD and MSA. We are growing our volunteer programming, as well as funding programs and research grants within our Centers of Care network and in collaboration with other organizations aimed at access to care, outreach to underserved communities and education of the medical community. CurePSP is also working to advocate for legislation that would result in improved quality of care and life for people with PSP, CBD and MSA.
CurePSP is devoted to our goals to identify the causes of PSP, CBD and MSA; accelerate the development of diagnostic tests; and be a catalyst in treatments to prevent, slow, halt or even reverse disease progression. We strive to accomplish these goals through:

- **Funding critical research** – We offer grant programs for both early-career and well-established researchers dedicated to discovering the causes of the diseases and how they can be prevented or treated.

- **Looking to the future** – Our summer student research fellowships encourage young scientists and help nurture their interest in neurodegeneration under the close mentorship of faculty scientists.

- **Harnessing industry** – CurePSP partners with pharmaceutical and biotechnology companies interested in designing and implementing clinical trials aimed at new ways to diagnose and treat PSP, CBD and MSA.

- **Supporting brain donations** – The study of brain tissue is essential to understanding PSP, CBD, MSA and other neurodegenerative diseases. CurePSP has proudly assisted hundreds of families with the expenses related to brain donation. We work closely with the Brain Bank at the Mayo Clinic to make tissue samples available to qualified scientists worldwide.

Get Involved

As we support researchers and clinicians working to understand, treat and cure PSP, CBD and MSA, we are also driving connection, resilience, awareness and improved care for people living with these diseases now. Your involvement makes a difference in strengthening and expanding our offerings. Whether through generously donating, volunteering or sharing your story with our community, there are a variety of ways to advance CurePSP’s mission.

Contact Us

CurePSP is here for you. If we can answer any questions, connect you to resources or offer support, or if you would like to donate to our organization and cause, please reach out to us at 800-457-4777 or info@curepsp.org