

General Information





About CurePSP

Founded in 1990, 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. The voices of those we serve guide our priorities and 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

Progressive Supranuclear Palsy (PSP)

PSP affects 30,000-40,000 people in the United States and it is currently estimated that, worldwide, roughly ten to twelve individuals have PSP per 100,000 people.* 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)

CBD affects 2,000-3,000 people in the United States and it is currently estimated that, worldwide, roughly one to two individuals have CBD per 100,000 people.* CBD is the most common phenotype of “corticobasal syndrome” (CBS) and can be quite difficult to diagnose during life. Due to this, neurologists sometimes use “CBS” for the clinical diagnosis. Primary symptoms include changes to balance and speech, stiffness, cognitive changes and difficulty with coordination.

Multiple System Atrophy (MSA)

MSA affects about 13,000 people in the United States and it is currently estimated that, worldwide, roughly three to five individuals have MSA per 100,000 people.* Symptoms include changes to movement, coordination and speech as well as to autonomic functioning, such as blood pressure regulation, breathing, urinary function and swallowing. Significant cognitive changes are not as common with MSA, although someone may have more difficulty with multitasking, organization, planning and attention.

What causes PSP, CBD and MSA?

PSP, CBD and MSA are neurodegenerative diseases, meaning they are caused by the progressive loss of brain cells over time due to many factors, including 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 many other neurodegenerative disorders, such as Alzheimer’s disease, frontotemporal dementia and chronic traumatic encephalopathy. In MSA, the protein causing neurodegeneration is called alpha synuclein which is also linked to Parkinson’s disease and Lewy body dementia.



“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 care partner, Martha



PSP, CBD and MSA are called sporadic diseases, meaning they rarely run in families and are not considered genetic diseases. Thousands of researchers around the world are working diligently to understand why people develop these diseases and to identify the biological mechanisms associated with all stages and types of neurodegeneration so that treatments and cures can be developed.

How are PSP, CBD and MSA diagnosed?

Arriving at the correct diagnosis of PSP, CBD or MSA can be a lengthy and confusing process, largely because these diseases are not well-known among healthcare professionals and the public. Early symptoms of the diseases, including stiffness, slowness, walking difficulty and tremor, can overlap with the more common Parkinson's disease, and PSP, CBD and MSA are often referred to as "atypical Parkinsonian syndromes." A clinical diagnosis is often made by neurological exam, a careful review of medical history and brain imaging.

How are they treated?

Symptoms of PSP, CBD and MSA are complex, in general progress faster than Parkinson's disease and require special considerations for care. There are different variants or sub-types of each of these diagnoses, although treatment should be tailored to an individual's unique symptoms and needs. While the progression of PSP, CBD and MSA cannot be slowed at this time, there are medications, rehabilitation therapies and lifestyle modifications available to manage symptoms. Connecting to resources and supporting the emotional and care needs of patients and families are also critical to maintaining and enhancing quality of life.

Learn more about the diseases

There are an estimated 1-1.5 million people living with PSP, CBD and MSA globally.* CurePSP recognizes the complex journeys experienced by people diagnosed and their family care partners and we are driven by the strength of this community and our unwavering dedication to care, consciousness and a cure. You can read more about PSP, CBD and MSA on our website (www.psp.org) or contacting us (800-457-4777, info@curepsp.org).

**Note: The prevalence of PSP, CBD or MSA may be higher than reported due to the frequency of misdiagnosis with other neurological conditions. Furthermore, obtaining accurate information on the incidence of these diseases is challenging due to the lack of definitive epidemiological studies.*



"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 Pillars

Care

We are 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.

- **Hope Line** – Our staff are available by phone and email to offer a listening ear, support, education and connection to resources.
- **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.
- **Collaborative Approaches to Resources, Education and Support (CARES) grants** – This program, launched in 2022, funds projects between two or more Centers of Care and supports clinical research focused on patient-centered care delivery and improvement of access to care.
- **Quality of life respite grant** – We offer 60 hours of professional, in-home respite care as a direct source of support for families caring for someone with PSP, CBD or MSA.
- **Online support groups** – From diagnosis-specific groups to care partner groups and more, we host a variety of virtual support groups open to anyone in our larger community.
- **Regional support** – Our growing network of peer supporters and locally-organized support groups offer connection for care partners and people living with PSP, CBD and MSA in their communities.
- **Bereavement support** – Our bereavement support group and journal were created to assist families as they navigate the complexity of the grief journey.

Consciousness

We empower 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.

- **Publications** – We are continually updating and growing our library of educational materials, including diagnosis-specific *Some Answers* booklets.
- **Community educational events** – Our Family Conferences, Wellness Workshops and regular Ask the Expert 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.
- **Education of the medical community** – Through the Centers of Care network and partnerships with other organizations, we build resources and programs designed to educate healthcare professionals, with the goals of leading to earlier diagnosis and access to high-quality care for people with PSP, CBD and MSA.
- **Advocacy** – As members of the Unified Parkinson's Advocacy Council (UPAC), led by the Michael J. Fox Foundation, CurePSP encourages policymakers to support legislation relevant to people diagnosed with parkinsonian and rare diseases and engages our community to participate in grassroots and larger scale advocacy.

Cure

Our goals are to identify the causes of PSP, CBD and MSA; to accelerate the development of diagnostic tests and useful biomarkers; and to be a catalyst in the discovery of new treatments and ultimately a cure. We strive to accomplish these goals through:

- **Funding critical research and looking to the future** – The CurePSP Pipeline and Pathway grant programs fund both early-career and well-established researchers dedicated to discovering the causes of PSP and CBD and how they can be prevented or treated. Our summer student research fellowships encourage young scientists and help nurture their interest in neurodegeneration under the close mentorship of faculty scientists.
- **Partnerships in grantmaking** – To leverage our funding capabilities and advocate for scientific advances for PSP, CBD and MSA, we establish grant partnerships with foundations and leading nonprofits working to solve neurodegeneration.
- **Research updates and opportunities** – In partnership with hundreds of key opinion leaders and industry experts, we follow current research and advances relevant to neurodegeneration in general and, specifically, PSP, CBD and MSA. This includes the evaluation and tracking of observational and interventional clinical trials as well as efforts advancing better biomarkers and translational research in neuroscience. We keep our community apprised of these developments and engage them to participate in research when possible.
- **Connecting the scientific community** – Our annual International Research Symposium brings together leading clinicians and scientists from around the world to share and discuss the latest breakthroughs. Starting in 2020, in partnership with the Alzheimer’s Association and the Rainwater Charitable Foundation, we organize the Global Tau meeting every 2 years.
- **Building alliances with industry** – We collaborate with pharmaceutical and biotechnology companies to facilitate the development of clinical trials for PSP, CBD, and MSA. We assist our industry partners in understanding and learning about our patient populations by producing surveys, patient focus groups, and other activities. Through these efforts, we aim to help industry better explore the possibility of developing new diagnostic and treatment approaches for these complex diseases.
- **Brain donation assistance program** – The study of brain tissue is essential to understanding PSP, CBD, MSA and other neurodegenerative diseases. CurePSP has proudly supported thousands of families with expenses related to brain donation. We work closely with leading brain banks, including the Mayo Clinic in Jacksonville, Florida, to make tissue samples available to qualified scientists worldwide.

Get Involved

As we work towards accelerating the understanding, treatment and cure of PSP, CBD and MSA, we are committed to fostering connection, resilience and improved care for individuals and families living with these diagnoses as well as increasing awareness of these diseases. Your participation is essential in supporting our efforts and expanding our programs. Whether through generously donating, volunteering or sharing your story with our community, there are a variety of ways you can advance CurePSP’s mission.

Contact Us

CurePSP is here for you. If we can offer support or assistance or if you would like to donate to our organization and cause, call our Hope Line at 800-457-4777 or email us at info@curepsp.org

For updates on research, events, resources and more, visit our website (www.psp.org) or follow us on social media.

CurePSP®

UNLOCKING THE SECRETS OF BRAIN DISEASE™

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