



The mission of CurePSP is to raise awareness, build community, improve care and find a cure for progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA).

Under this mission, the CurePSP Centers of Care program was established in 2017 as a network of medical centers with the goals to:

- Enhance access to accurate and early diagnosis, high-quality and state-of-the-art clinical care, and comprehensive support for PSP, CBD and MSA;
- Serve as international and regional leaders and vital resources for those affected by PSP, CBD and MSA and healthcare professionals;
- Increase awareness of PSP, CBD and MSA among patients, families, healthcare professionals, policymakers, and local and larger communities;
- Promote collaboration within the CoC network to establish and advance best practices in care delivery for PSP, CBD and MSA and to create opportunities for multi-center research initiatives.

Center of Care (CoC) designation/redesignation criteria

Notes:

We recognize that institutional or other barriers can preclude a center from achieving this full set of designation criteria. Diversity within our network and meeting the needs of the community are priorities for the CoC program. As such, both geographic need and a center's program offerings are taken into consideration with applications for designation and redesignation.

Centers have the option to choose CurePSP CoC designation for PSP, CBD and MSA or only for PSP/CBD.

Comprehensive care

CoCs must:

- Offer dedicated care for PSP, CBD and MSA exceeding the standard of care available at most neurology centers.
- See at least 50 unique patients with PSP and/or CBD (suspected or clinically diagnosed) in the last 12 months per EMR report for division, and if choosing CoC designation for all three diagnoses, at least 25 unique patients with suspected or diagnosed MSA on EMR report for division.
 - *Note:* Centers in lower populated areas that do not meet these thresholds will still be considered if other designation criteria are met.

- Have two or more neurologists with fellowship training in movement disorders, behavioral neurology or neuropalliative care involved in care of PSP, CBD and MSA patients.
 - *Note:* Exceptions may be made for a center with advanced practice providers with specialized training in atypical Parkinsonism and/or located in a geographically rural area.
- Have access to advanced diagnostics and treatments including but not limited to neuroimaging, botulinum toxin injections, autonomic testing, neuropsychological testing, rehabilitation therapies and objective swallowing evaluations.
- Stay up to date with and deliver best practices for assessment and management of symptoms.
 - E.g. regular and as-needed follow-up appointments, telemedicine, appropriate ambulatory equipment, swallow evaluation at baseline and every ~12 months, timely connection to mental health services and palliative care
- Deliver interprofessional care for PSP, CBD and MSA, specifically:
 - Close involvement and availability of the center's non-neurologists in patient care.
 - This may include a coordinator, clinical social worker, physician assistant, nursing professional, physical therapist, occupational therapist, speech-language pathologist, palliative care specialist, and/or other clinicians as appropriate (e.g., neuropsychologist, nutritionist, neuro-ophthalmologist, autonomic specialist, urologist)
 - Plan of care developed through the collaboration of healthcare professionals across multiple disciplines
 - *Note:* For disciplines not available within the center, they must be identified within the institution and/or community for referrals
 - *Note:* Offering of a specialty interdisciplinary clinic for atypical Parkinsonism is not required but is encouraged
- Deliver person- and family-centered care, including:
 - Assessing and addressing psychosocial needs of the patient and care partner(s) in a timely manner
 - Supporting hope, dignity and quality of life from diagnosis through end of life
 - Knowledge of and comfort with conversations around/education on/coordination of: mental health, care partner well-being, advance care planning, life-sustaining interventions, palliative and hospice care (including recognition of the differences between the two, when to refer and the benefits of both), advanced disease stages and end of life
- Aim to see new patients with suspected atypical Parkinsonism or diagnosed PSP, CBD or MSA within one month of referral, and to follow these patients for return appointments every 3-4 months.
- Organize and implement ongoing initiatives within the center dedicated to improvement of quality of and access to care (e.g., clinic workflow optimization, assessment of patient satisfaction, shortening wait times for clinic appointments).

Collaboration with CurePSP and CoC network

CoCs must:

- Connect patients, families and healthcare professionals with CurePSP resources, including:
 - Printed educational materials, which must be readily available in the clinic (e.g., *Some Answers* booklets, medical alert wallet cards)
 - Virtual national/international support groups
 - Quality of Life Respite Grants
 - Brain Donation Assistance Program program/booklet (unless the CoC's institution offers an internal brain donation program)
 - Peer support program and regional support groups
 - Family conferences and educational webinars
- Partner with CurePSP and other CoCs on CurePSP initiatives, such as working groups, CARES grants and other multi-center research initiatives, publications, advisory councils, educational programs or awareness/advocacy efforts.
- Attend the CurePSP-organized CoC meeting (virtual or in-person).
- Utilize the annual CoC award to support center's care and outreach services geared towards PSP, CBD and MSA.
- Submit, by the appointed deadline, the required annual report (or 3-year redesignation application) and annual financial report on use of CoC award.
- When able, participate in CurePSP educational activities geared towards healthcare professionals or researchers.
- Contribute, when needed, to CurePSP promotional initiatives focused on CoC (e.g., social media posts, newsletter articles, featured stories, press releases, CoC fundraising campaigns).
- Organize, to the extent feasible, local fundraisers with proceeds apportioned between the site and CurePSP according to a formula specified in the CoC bylaws.

Community education and outreach

CoCs must:

- Demonstrate regular effort to reach beyond the walls of the clinic through offering programs and initiatives available to the larger community specifically addressing PSP, CBD and MSA.
 - E.g., support groups, patient & care partner symposiums, newsletter, care partner mentorship program, exercise or wellness programs
 - Newly applying centers that do not yet have outreach programs in place must describe plans to develop.
 - Programming offered by a CoC can largely be based on what is needed in the CoC's community (for example, if a strong atypical Parkinsonism support group already exists nearby, the CoC does not need to start a redundant one).
 - Joint CoC programming, especially for those located in/serving the same communities, is acceptable.
- Act as a resource hub for patients, families and community members, maintaining an awareness of and relationship with PSP/CBD/MSA-knowledgeable resources in the surrounding community (e.g., regional atypical Parkinsonism support groups, Parkinson's

exercise classes, mental health resources, neuro/Parkinsonism-specialized rehabilitation professionals).

- Advocate for the improvement of care and life for PSP, CBD and MSA, including a commitment to:
 - Initiatives focused on earlier and accurate diagnosis
 - Increasing awareness among patients, families, healthcare professionals, local communities and policymakers
 - Addressing barriers to access to care and to outreach to/support for underserved communities

Professional education

CoCs must:

- Provide clinical education and training on PSP, CBD and MSA to healthcare professionals (e.g., neurologists, nurses, rehabilitation therapists, social workers, palliative care specialists).
 - Within the immediate team, division and wider institution
 - In the surrounding community, with a particular focus on general neurologists and other healthcare professionals/institutions in rural areas and underserved communities
 - e.g., clinic rotations, fellowships, in-services, grand rounds, continuing education programs
- Connect center's team members as well as healthcare professionals in the community with continuing education programs offered by CurePSP.

Commitment to research

CoCs must:

- Maintain awareness of current clinical trials and other research opportunities for PSP, CBD and MSA and refer patients to these offerings when appropriate.
- Demonstrate partnership with CurePSP and other CoCs on CurePSP-led research, multi-center investigator-initiated research projects and/or scientific writing projects.
- *Note:* CurePSP recognizes that some centers may not be able to offer clinical trials, translational research, investigator-initiated studies other research due to institutional barriers such as funding, support and capacity. When considered for CoC designation and redesignation, research and a record of publications on PSP, CBD and/or MSA are encouraged and viewed favorably but are not required at this time.

