

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 (CoC) program was established in 2017 as a network of specialized 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 regional leaders and 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 optimize standards of care delivery for PSP, CBD and MSA and to create opportunities for multi-center research initiatives.

### **Center of Care designation/redesignation criteria**

**Note:** 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 PSP, CBD and MSA 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:

- Be dedicated to specialized care for PSP, CBD and MSA exceeding that available at most neurology centers
- See at least 50 unique patients with PSP and/or CBD in the last 12 months on EMR report for division and, if choosing CoC designation for all three diagnoses, at least 25 unique patients with MSA on EMR report for division
  - *Note:* Centers in low-population 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 or behavioral neurology involved in care of PSP, CBD and MSA.
  - *Note:* Exceptions may be made for a center with advanced practice providers with specialized training in PSP, CBD and MSA and/or location in a geographically rural area.

- Have access to advanced diagnostics and treatments for PSP, CBD and MSA including but not limited to neuroimaging, botulinum toxin, autonomic testing, neuropsychological testing, rehabilitation therapies, and objective swallowing evaluations
- Deliver coordinated, integrated, team-based 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, nurse, physician assistant, nurse practitioner, physical therapist, occupational therapist, speech therapist, palliative specialist, and/or other clinicians as appropriate (e.g., neuropsychologist, nutritionist, neuro-ophthalmologist, autonomic specialist, urologist)
    - *Note:* For those not available within the center, they be identified within the institution and/or community as referral sources
  - Training the center’s team in the diagnosis and care of PSP, CBD and MSA, consistent with their professional roles
  - Offering of a multidisciplinary clinic specifically for atypical parkinsonism is not required for designation/redesignation of CurePSP CoC but is encouraged.
- Deliver person-centered care for PSP, CBD and MSA, including:
  - 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, 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), and end of life.
  - Timely connection to mental health services and hospice services, when appropriate
- Organize and implement ongoing initiatives within your 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
  - Cherie Levien Quality-of-Life Respite Program
  - Brain Donation Assistance Program program/booklet (unless the CoC’s institution offers an internal brain donation program)
  - Peer support program
  - Family conferences and educational webinars
- Partner with CurePSP and other CoCs on CurePSP initiatives as feasible, including multi-center research initiatives, publications, working groups, advisory councils, educational programs, and awareness campaigns
- Send the CoC Site Director or designee to the biannual CurePSP CoC conference (virtual and/or in-person)
- Complete, within the appointed deadline, an annual report, including financial report on use of CoC award, due each spring

- Participate, when needed, in CurePSP marketing initiatives focused on CoC (e.g., newsletter articles, featured stories, press releases, CoC fundraising campaigns, social media posts)
- Organize and implement, to the extent feasible, local fundraisers to support local PSP/CBD/MSA care, 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
  - Examples include: Support groups, patient & care partner symposiums, newsletter, mentorship program, exercise and wellness programs
  - Newly applying centers that do not yet have this in place must describe plans to build this.
  - The programming offered by a CoC can largely be based on what is needed in the CoC's community (for example, if a strong PSP/CBD/MSA 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 allied health 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 of PSP, CBD and MSA among patients, families, healthcare professionals, local communities and/or 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)
  - Both within the institution and in surrounding community/in collaboration with other institutions
  - Examples include: Formal 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

## Research

CoCs must:

- Maintain awareness of current clinical trials and other translational research 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 research projects and/or writing projects in PSP/CBD/MSA
- *Note:* CurePSP recognizes that some centers may not be able to offer extensive research or clinical trials due to institutional barriers such as funding, support and capacity. When considered for CoC designation and redesignation, research and a record of publications in PSP/CBD/MSA (e.g., clinical trials, clinical care, observational research, epidemiological, genetic, basic/pre-clinic research) are encouraged and viewed favorably but are not required at this time.

