

1. Welcome to the CurePSP Centers of Care

Welcome

Thank you for applying to become a **CurePSP Center of Care**. We hope that this initiative will raise the standard of care for patients with PSP and CBD and allow you to be recognized for your dedication to this cause.

The deadlines for completing this application survey are May 30 and November 30 each year. Your application will be reviewed by CurePSP's Center of Care Steering Committee within three months after submission.

We do not require documentation of the facts that you enter into this application, but you should be prepared to provide that on CurePSP's request at some future date.

For more details on the **procedures, upcoming deadlines, and the general concept** of the CurePSP Centers of Care, please visit www.psp.org/centers-of-care.

For any further **questions or technical issues** while completing this survey, please contact **Dr. Lawrence Golbe from our Steering Committee at +1 347-294-2871 or golbe@curepsp.org**. If you don't receive a separate and personalized confirmation email from CurePSP within one week after submission, please contact Dr. Golbe at golbe@curepsp.org. Keep an electronic copy of all (free text) responses in a Word or other text file in case something goes wrong during the electronic submission process.

Mission of the CurePSP Centers of Care Program:

- Help patients with PSP and CBD to find the best possible local/regional care they need
- Increase awareness of PSP and CBD spectrum disorders
Provide local/regional resources for physicians seeking more information about PSP and CBD
- Form a network of centers that can serve a base for more intense collaboration improving clinical care, optimizing standards of patient care, and establishing hubs for PSP/CBD clinical and preclinical research.
- Provide educational material to patients, caregivers, and healthcare professionals

2. Uploads

1. Upload of **Letter of Intent** (free style; max. 2 pages including letter head etc.; signed by applicant)

The Letter of Intent should describe the PI's reasons for applying, qualifications, experience, ambitions for the Center, and special circumstances that might justify the presence of a CurePSP Center of Care at this institution. It should not unnecessarily duplicate other material in this questionnaire, but should highlight whatever the applicant feels is important and should add any additional information that CurePSP should take into account.

No file
chosen

2. Upload of **Letter of Support** from the Dept. Chair or equivalent confirming that adequate space, time and other resources for the CurePSP Center of Care will be available to the applicant

The Letter of Support should discuss any special resources that the department or division would be able to devote to supporting the CurePSP Center of Care. It should also describe in general terms the space and personnel available as well as any other information that may assist CurePSP in evaluating the application.

No file
chosen

3. Contact Details

3. Name of applying Center of Care Director, typically a neurologist. This contact information is for CurePSP office use only and will not be provided to patients, families or anyone else. Please provide only a direct phone line or cell phone (not a number to an office phone tree) and individual email contact (not "info@___").

First Name	<input type="text"/>
Middle Name (Optional)	<input type="text"/>
Last Name	<input type="text"/>
Relevant Degree	<input type="text"/>
Institution	<input type="text"/>
Department	<input type="text"/>
Address	<input type="text"/>
Address 2	<input type="text"/>
City/Town	<input type="text"/>
State/Province	<input type="text"/>
ZIP/Postal Code	<input type="text"/>
Country	<input type="text"/>
Email Address	<input type="text"/>
Phone	<input type="text"/>
Fax	<input type="text"/>

4. Name of the center coordinator or patient education coordinator

First Name

Middle Name (Optional)

Last Name

Relevant Degree

Institution

Department

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

Phone

Fax

4. Staff

*** 5. Center Director's publication record:**

- Neurologist without peer-reviewed publication in PSP spectrum disorders in the past 5 years
- Neurologist with peer-reviewed publication in PSP spectrum disorders in the last 5 years
- Neurologist with peer-reviewed publication in PSP spectrum disorders and current grant funding for PSP research

Comments

*** 6. Center's experience:**

- No experience in coordinating clinical care or research projects in neurodegenerative disease
- Experience in coordinating clinical care or research projects in a neurodegenerative disease (please specify below)
- Experience in coordinating a dedicated center in a neurodegenerative disease (please specify below)

Comments

*** 7. Will your CurePSP Center of Care professional team include at least one neurologist subspecializing in movement disorders?**

- No
- Yes, but without previous focus on PSP/CBD disorders
- Yes, with previous focus on PSP/CBD disorders

Comments

*** 8. Will your CurePSP Center of Care professional team include at least one neurologist subspecializing in behavioral neurology or psychiatrist subspecializing in neuropsychiatry?**

- None
- Yes, but without previous focus on PSP/CBD disorders
- Yes, with previous focus on PSP/CBD disorders

Comments

*** 9. Would (neurology) trainees have access to the CurePSP Centers of Care?**

- Neurology residents
- Movement disorders or behavioral neurology fellows
- All trainees
- None

Comments

10. Will your CurePSP Center of Care medical team include other specialists who focus on the treatment of PSP and CBD patients?

- No
- Yes

If yes, please specify.

5. Patient Volume

*** 11. How many patients with PSP and CBD received care at your department/practice in the most recent calendar or academic year? (number of total patients, not number of visits)**

1-10

11-30

>30

Please include the entire range of the PSP spectrum disorders: PSP-RS (PSP with Richardson's syndrome), PSP-P (PSP with predominant parkinsonism), PSP-PGF (PSP with progressive gait freezing), PSP-CBS (PSP with predominant CBS), PSP-SL (PSP with predominant speech/language disorder), PSP-F (PSP with predominant frontal presentation), PSP-OM (PSP with predominant ocular motor dysfunction), PSP-PI (PSP with predominant postural instability)

6. Diagnostics

12. Do you have a standard diagnostic and therapy protocol and disease management plan for PSP and CBD patients? None Yes

If yes, please provide a brief summary of your standard procedures:

*** 13. Do you offer a regularly-scheduled multidisciplinary clinic or patient management conference to coordinate provision of care for patients with PSP/CBD?** No Yes, from 2 specialties Yes, from 3 or more specialties

Comments

7. Treatment and Services

*** 14. Do you offer botulinum toxin therapy for PSP/CBD patients?**

- No
- Yes, but not for blepharospasm
- Yes, including for blepharospasm

Comments

*** 15. Are services of a social worker available for PSP and CBD Patients?**

- None
- Available only by referral at a different time and site
- Available on-site, but requires a separate visit
- Available on-site, same day

Comments

*** 16. Are services of a neuropsychologist available for PSP and CBD Patients?**

- None
- Available only by referral at a different time and site
- Available on-site, but requires a separate visit
- Available on-site, same day

Comments

*** 17. Do you offer physical therapy for PSP and CBD patients?**

- None
- Available only by referral at a different time and site
- Available on-site, but requires a separate visit
- Available on-site, same day

Comments

*** 18. Do you offer occupational therapy for PSP and CBD patients?**

- None
- Available only by referral at a different time and site
- Available on-site, but requires a separate visit
- Available on-site, same day

Comments

*** 19. Do you offer speech-language/dyshagia therapy for PSP and CBD patients?**

- None
- Available only by referral at a different time and site
- Available on-site, but requires a separate visit
- Available on-site, same day

Comments

*** 20. Do you have a neuro-rehab facility?**

- No
- Yes, different site within an hour's drive
- Yes, on-site

Comments

*** 21. Does your center offer telemedicine?**

- Not for neurological disorders
- Established telemedicine program not (yet) in use for PSP/CBD patients
- Established telemedicine program currently seeing PSP-CBD disorder patients

Comments

*** 22. Are there local hotels or other accommodations (overnight lodging) available for caregivers and/or family members of patients?**

- No
- Yes, within a 10-minute drive
- Yes, in the same building complex

Comments

*** 23. Do you collaborate in research or in development of clinical services with other centers specializing in PSP/CBD?**

- Yes
- No

If yes, please list you national and international partners over the past 5 years

24. Would your CurePSP Center of Care provide PSP/CBD patients with a standard printed or electronic set of care instructions for use at home?

- No
- Yes

If yes, please provide a short summary of such procedures.

25. Please use this section to list anything else that you think needs to be mentioned as part of your CurePSP Center of Care application.

A large, empty rectangular box with a thin black border, intended for the applicant to provide additional information or details for their CurePSP Center of Care application.

8. Clinical Research

*** 26. How many IRB-approved interventional treatment trials for movement disorders other than PSP or CBD have been under way at your institution at some point in the past 5 years where you were the PI or site PI?**

- None
- 1 or 2
- >2

Comments

*** 27. How many IRB-approved interventional treatment trials for PSP or CBD where you were the site-PI have been under way at your institution at some point in the past 5 years where you were the PI or site PI?**

- None
- 1 or 2
- >2

Comments

*** 28. In the past 5 years, how many publications have you had that were original, full-length, peer-reviewed and used data or samples from patients with PSP/CBD? Exclude editorials, chapters and review articles.**

- None
- 1 - 10
- >10

Comments

*** 29. How many IRB-approved clinical research projects in PSP and CBD (other than clinical trials) have been conducted in your center in the past 5 years (count all studies including the ones where you were not the lead PI)?**

- None
- 1 or 2
- >2

Comments

*** 30. Are there other CurePSP Centers of Care near you?**

- Other CurePSP Centers of Care available in metro area / region
- Other CurePSP Centers of Care available within a one-day round-trip by car
- Other CurePSP Centers of Care not available within a one-day round-trip by car

Please check our center finder on www.psp.org/centers-of-care.

9. Thank you!

Thank you for your interest in the CurePSP Centers of Care. Please finish this survey by clicking the "Done" button below. If you don't receive a separate confirmation email from CurePSP within one week after submission, please contact CurePSP at info@curepsp.org. Keep an electronic copy of your free text responses in a Word or other text file in case something goes wrong during the electronic submission process.

