

## 1. Welcome to the CurePSP Centers of Care

### Welcome

Thank you for applying to become a **CurePSP Center of Care**. We are excited to launch this new project helping PSP and CBD patients and healthcare professional to provide better care.

**The next deadline for completing this application survey is 2:00pm Eastern Standard Time (New York) on November 30, 2018.** Your application will be reviewed by CurePSP's Medical Steering Committee within three months after submission. We expect to have two calls for applications per year.

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](http://www.psp.org/centers-of-care).

For any further **questions or technical issues** while completing this survey, please contact **Dr. Alex Klein, VP of Scientific Affairs, at +1 347-294-2871 or [klein@curepsp.org](mailto:klein@curepsp.org)**. If you don't receive a separate and personalized confirmation email from CurePSP within one week after submission, please contact Dr. Alex Klein at [klein@curepsp.org](mailto:klein@curepsp.org). It is advised to keep a electronic copy of all (free text) responses in a word file, in case something went wrong during the electronic submission process.

### Mission

- Help PSP and CBD patients 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 (the Center Director or Center Coordinator should serve as the primary contact for internal use by CurePSP; only direct e-mail addresses and phone lines are acceptable - no switch board phone numbers or info@.... e-mail addresses)**

First Name	<input type="text"/>
Middle Name	<input type="text"/>
Last Name	<input type="text"/>
Title (MD, MD PhD, etc.)	<input type="text"/>
Position	<input type="text"/>
Hospital	<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. If applicable, name of the center coordinator**

First Name

Middle Name

Last Name

Title (MD, MD PhD, etc.)

Position

Hospital

Department

Address

Address 2

City/Town

State/Province

ZIP/Postal Code

Country

Email Address

Phone

Fax

## 4. Staff

**5. Please describe the Center Director's background:**

- 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
- Other (please specify)

**6. Please describe the 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)

Please specify your experience.

**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 spectrum disorders
- Yes, with previous focus on PSP/CBD spectrum 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?**

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

Comments

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

- Neurology residents
- Movement disorders or behavioral neurology fellows
- Neither

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 come to your medical center/practice per year? (number of total patients, not number of visits)**

**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)**

PSP spectrum disorder

CBS spectrum disorder



## 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?**

- Yes, attended by professionals in 2 areas
- Yes, attended by professionals in 3 or more areas
- No

Comments

## 7. Treatment and Services

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

- None
- Yes, but not for blepharospasm
- Yes, including for blepharospasm

Comments

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

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

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

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

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

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

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

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

**19. Do you offer speech-language therapy for PSP and CBD Patients?**

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

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

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

**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 and CBD patients

Other telemedicine efforts:

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

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

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

- No
- Yes

If yes, please list your national and international collaborators over the past five 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.**

## 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?**

Comments

**27. How many IRB-approved interventional treatment trials for 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?**

Comments

**28. How many original, full-length, peer-reviewed publications in clinical aspects of movement disorders have you had in the past 5 years? (Include both interventional and non-interventional studies, PSP/CBD and non-PSP/CBD movement disorders. Exclude editorials, review articles and publications without data or samples from patients with PSP/CBD.**

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

PSP

CBD

Other diseases

## 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 Dr. Alex Klein at [klein@curepsp.org](mailto:klein@curepsp.org). It is advised to keep a electronic copy of all (free text) responses in a word file, in case something went wrong during the electronic submission process.**

### CurePSP

