#### UNLOCKING THE SECRETS OF BRAIN DISEASE®

The CurePSP Quality of Life Respite Grant was established to provide support for hiring in-home respite care services for those living with or caring for someone diagnosed with progressive supranuclear palsy, corticobasal degeneration or multiple system atrophy. The fund provides a one-time grant for 60 hours of in-home care services (up to \$35/hr) by a home care agency chosen by the awardee. You will not need to pay directly; the home care agency will be paid directly by CurePSP.

Eligibility:

- Individuals and care partners living with a clinical diagnosis of PSP, CBD or MSA anywhere in the United States
- The person with PSP, CBD or MSA is cared for at home (not in a long-term care facility)
- Has not been a recipient of a CurePSP Quality of Life Respite Grant in the past
- Is not receiving more than 15 hours per week of professional respite care services (i.e. adult day care, in-home care)
- Has a combined annual income of less than \$90K and does not have long-term care insurance

Grants are awarded on a quarterly basis and the deadlines are as follows: January 31, April 30, July 31 and October 31. Due to ongoing updates to the grant program, please make sure that the application you are submitting corresponds with the correct quarter.

You may mail, fax or email questions or completed applications to Joanna Teters at:

CurePSP ATTN: Joanna Teters 325 Hudson Street, Floor 4 New York, NY 10013

Office: 347-294-2871 Fax: 410-785-7009 E-mail: teters@curepsp.org

UNLOCKING THE SECRETS OF BRAIN DISEASE®

### Patient and Care Partner Information

\* 1. Name of person living with PSP/CBD/MSA

Name	
Address	
Address 2	
City	
State	
ZIP	
Email Address (if applicable)	
Phone Number	

\* 2. Date of birth of person living with PSP/CBD/MSA (MM/DD/YYYY)

\* 3. Gender of person living with PSP/CBD/MSA

🔘 Male

 $\bigcirc$  Female

○ Non-binary

 $\bigcirc$  Prefer not to respond

* 4. Race/ethnicity of person living with PSP/CBD/MSA
Asian
Black or African American
Hawaiian or Other Pacific Islander
🗌 Native American, Indigenous, or Alaska Native
White
Prefer not to respond
Other (please specify)
* 5. Is the person living with PSP/CBD/MSA of Hispanic or Latino origin?
Yes
No
Prefer not to respond
* 6. Marital status of person living with PSP/CBD/MSA
⊖ Single
◯ Married
○ In a relationship
◯ Widowed

#### UNLOCKING THE SECRETS OF BRAIN DISEASE®

\* 7. What is the relationship of the primary family care partner to the individual with PSP/CBD/MSA?

Note: if the person applying does <u>not</u> have a primary family care partner and/or is currently only receiving care from a home care professional, please select "none of the above"

○ Spouse/partner

O Adult child

◯ Friend

Other (please specify)

O None of the above (this individual lives alone and does not have a clearly identified primary family care partner)

\* 8. Approximately how many hours <u>per day</u> is the person living with PSP/CBD/MSA receiving direct care from their primary family care partner?

\* 9. Does the primary family care partner live with the person diagnosed?

○ Yes, the primary family care partner lives with the patient

 $\bigcirc$  No, the primary family care partner does not live with the patient

* 10. Primary family care partner's contact information:		
Name		
Address		
Address 2		
City		
State	•	
ZIP		
Email Address		
Phone Number		

\* 11. Primary family care partner date of birth (MM/DD/YYY)

\* 12. Gender of primary family care partner:

🔿 Male

◯ Female

○ Non-binary

 $\bigcirc$  Prefer not to respond

\* 13. Is the primary family care partner currently working?

○ Part-time

○ Full-time

○ No, not currently working

\* 14. Is there anybody else who is involved in the care or support of the person living with PSP/CBD/MSA?

* 15. Relationsh	ip of applicant to person living with PSP/CBD/MSA?
○ I am the pa	tient
◯ Spouse/Par	tner
🔿 Child	
○ Friend	
◯ Healthcare	Professional
🔿 Other (plea	se specify)
	nation of the applicant (if different from the contact information of the y family care partner listed earlier in this application)
Name	
Organization/medic al institution (if applicable)	
Address	
Address 2	
City	
State	<b></b>
ZIP	
Email Address	
Phone Number	

UNLOCKING THE SECRETS OF BRAIN DISEASE®

#### Finances & Insurance

\* 17. Which of these best describes the combined household income for the person living with PSP/CBD/MSA from the past year?

O Under \$30,000

O Between \$31,000-\$60,000

O Between \$61,000- \$90,000

Over \$91,000

\* 18. What type of health insurance does the person living with PSP/CBD/MSA have?

	Yes	No
Medicare (original + supplemental plan or Medicare advantage plan)	0	0
Medicaid	$\bigcirc$	$\bigcirc$
Veteran's Benefits	0	$\bigcirc$
Private Insurance	$\bigcirc$	$\bigcirc$
Other (please specify)		

\* 19. Does the person living with PSP/CBD/MSA have long-term care insurance?

◯ Yes

🔘 No

\* 20. If the person living with PSP/CBD/MSA <u>does</u> have long-term care insurance, are they currently using it to pay for professional care services?

◯ Yes

() No

 $\bigcirc$  N/A - patient does not have long-term care insurance

UNLOCKING THE SECRETS OF BRAIN DISEASE*
Patient History and Current Care Needs
* 21. What is the person's diagnosis?
Progressive supranuclear palsy (PSP)
Corticobasal degeneration or corticobasal syndrome (CBD/CBS)
Multiple system atrophy (MSA)
Other (please specify)
* 22. What year did the person begin exhibiting symptoms?

\* 23. What year was the person diagnosed with PSP/CBD/MSA?

 $^{\ast}$  24. If the person living with PSP/CBD/MSA has any other medical conditions, please list here:

* 25. What areas of daily living does the person living with PSP/CBD/MSA need assistance with?
Please check all that apply:
Showering/bathing
Toileting
Dressing
Eating
Ambulation/mobility
Other (please specify)
* 26. Which activities or tasks could the person living with PSP/CBD/MSA and/or their family/care partner benefit from assistance with? Please check all that apply:
Cooking/preparing meals
Household tasks/cleaning
Grocery shopping/errands
Medication reminders
Transportation (to appointments, etc.)
Companionship/activity engagement/socialization
Supervision/monitoring due to cognitive decline and/or falls risk
Care partner respite
Other (please specify)

UNLOCKING THE SECRETS OF BRAIN DISEASE®
Network of Care
* 27. Is the person living with PSP/CBD/MSA currently receiving professional care services? (This does not include PT/OT/SLP)
Please check all that apply:
In-home care
Adult day care
Skilled nursing care
Other (please specify)
None of the above
* 28. If the person living with PSP/CBD/MSA is currently receiving professional care services, how many hours per week? (adult day care, in-home care, etc.) Please be specific.
* 29. Is the person living with PSP/CBD/MSA currently receiving hospice services?
⊖ Yes
◯ No

\* 30. In the past, has the person living with PSP/CBD/MSA received this CurePSP respite grant?

 $\bigcirc$  No

○ Yes (please note month/year the grant was received)

\* 31. Has the person living with PSP/CBD/MSA ever received any other respite grants or vouchers?

O No

○ Yes (please specify)

\* 32. How did you hear about this grant program?

 $\bigcirc$  Friend or family

 $\bigcirc$  CurePSP website

○ CurePSP peer supporter or volunteer

 $\bigcirc$  Local support group

O Physician or healthcare professional

🔘 Social media

○ Other (please specify)

- \* 33. Narrative In a few sentences or a short paragraph, please tell us:
  - 1. how the person living with PSP/CBD/MSA and/or their family plans to use this grant
  - 2. how the person living with PSP/CBD/MSA and/or their primary family care partner (e.g. emotional/physical health, stress) has been impacted by the PSP/CBD/MSA diagnosis and journey
  - 3. and how receiving this grant would positively impact daily quality of life and care.

Please also use this space to share anything else you would like us to consider while reviewing your grant application.

UNLOCKING THE SECRETS OF BRAIN DISEASE®

### **Proof of Diagnosis**

34. Please <u>download a copy of the physician diagnosis verification form</u> and upload completed and signed version here

### PLEASE NOTE THAT YOUR APPLICATION WILL NOT BE REVIEWED AT THE QUARTER DEADLINE IF YOU DO NOT SUBMIT THIS FORM.

Choose File

Choose File No file chosen