



# Brain Support Network

## PSP and CBD Brain Donation

*How does it help families?*

*How does it help researchers?*

*How is it arranged?*

Robin Riddle, [robin.riddle@brainsupportnetwork.org](mailto:robin.riddle@brainsupportnetwork.org), 650-814-0848  
June 29, 2024 - PSP/CBD Symposium (Co-hosted by BSN and Stanford)

# 1<sup>st</sup> Key Reason for Brain Donation

**ONLY way to confirm a diagnosis!**

- Closure and peace-of-mind
- Explanation for what caused symptoms



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# Brain Bank Study - Accuracy of Clinical Diagnosis

## “Clinical Outcomes of PSP and MSA”

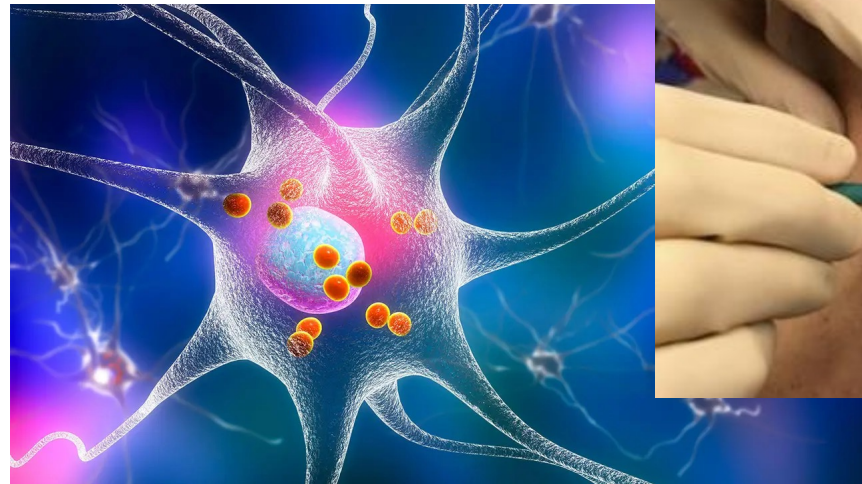
- RS: 86% of cases had a correct clinical diagnosis
- PSP-P: Only 41%. Commonly masquerades as Parkinson’s Disease



# 2<sup>nd</sup> Key Reason for Brain Donation

Enables research into the accurate diagnosis, treatments, causes, and cures

- Brain tissue is required to validate biomarkers, such as skin biopsies or tau imaging



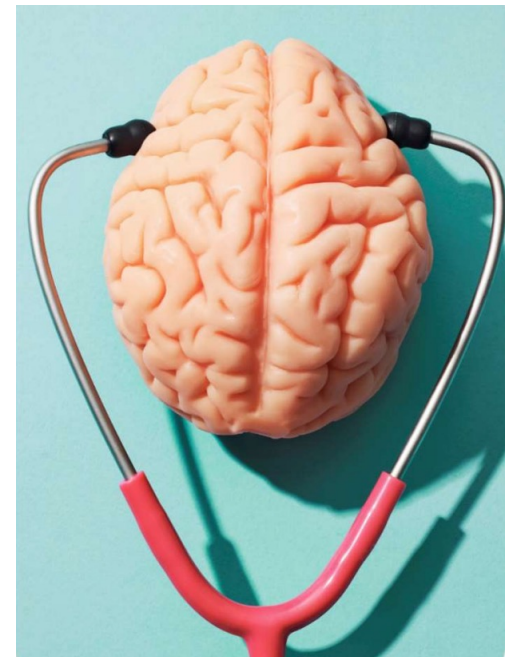
# Brain Bank Studies - Clarify Types of PSP and CBD

“Characteristics of two distinct clinical phenotypes” of PSP:

- RS and PSP-P are very different!

“Criteria for the diagnosis of CBD”

- CBS, FBS (frontal behavioral spatial), PPA, and PSP syndrome



# Genetics Discoveries

Starting in 2011: genome-wide association studies in PSP

- Over 1,000 PSP brain donation cases, mostly in the US and UK
- Found three new genes associated with PSP



# Donating a Brain Requires...

- Family consent
- Neurological records
- Pathology service must be available daily
- Cooperative funeral home (and available daily)
- Advance arrangements:  
24-hour deadline
- Brain bank expert in PSP/CBD



# BSN Recommends the Mayo Clinic Brain Bank

- + Large numbers of PSP (1800) and CBD (200)
- + While records are required in advance, there's no minimum time since diagnosis
- + Actively publish on confirmed PSP and CBD
- + 100 days for report





# Challenges with the Mayo Clinic Brain Bank

- Families must make their own arrangements
  - This is where BSN comes in!
- Families bear cost of brain recovery
  - CurePSP offers grants up to \$1K





# Pay-it-Forward

BSN requests a \$750 or greater pay-it-forward charitable contribution from every family we help.

Memorial contributions are welcome.



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# Check Out the BSN Website - [www.brainsupportnetwork.org](http://www.brainsupportnetwork.org)

- Fill out form - “Advance Planning” “Immediate Need” “Urgent”
- Case studies
- Process document
- FAQs

## The Process for Brain Donation



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# Brain Support Network

**We've helped 1,400 families  
donate a loved one's brain.  
We are honored to help  
your family, too.**



Robin Riddle, Brain Support Network (non-profit)  
Phone 650-814-0848; Email [robin.riddle@brainsupportnetwork.org](mailto:robin.riddle@brainsupportnetwork.org)