



Brain Support Network

MSA Brain Donation

How does it help MSA families?

How does it help researchers?

How is it arranged?

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May 4, 2024 - MSA Symposium (Co-hosted by BSN and Stanford)

#1 Key Reason for Brain Donation

ONLY way to confirm a diagnosis!

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

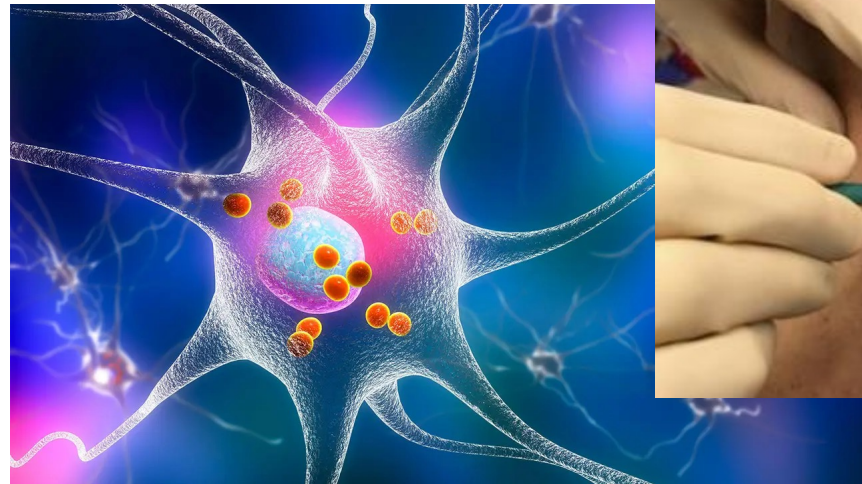


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#2 Key Reason for Brain Donation

Enables research into the accurate diagnosis, treatments, causes, and cure for MSA

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



Brain Bank Study - Poor Accuracy with Diagnosis

“When DLB, PD, and PSP masquerade as MSA”
(Mayo study, Koga, 2015)

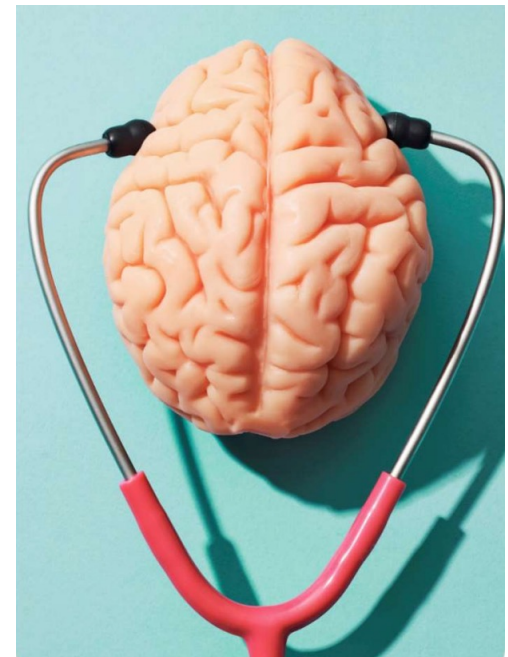
- A clinical diagnosis is only correct 60% of the time!
- Most common misdiagnoses
 - Dementia with Lewy Bodies
 - Parkinson’s Disease



Brain Bank Study - Typical MSA Symptoms

“Clinical features of autopsy-confirmed MSA” (Mayo study, Koga, July 2021)

- 23 people (13%) were NOT clinically diagnosed with MSA but instead with PSP, PD, and DLB
- Those with MSA pathology alone rarely develop dementia early on



Improving MSA Diagnostic Criteria

New criteria published in April 2022

- Incorporates what we've learned through brain donation



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Improving Clinical Trials

Since only 60% of the people diagnosed with MSA actually have MSA, what good is enrolling people with “MSA” in drug trials? In other research studies?



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
- MSA expert brain bank



BSN Recommends the Mayo Clinic Brain Bank

- + Largest number of confirmed MSA cases (400)
- + While records are required in advance, there's no minimum time since diagnosis
- + Actively publish on confirmed MSA
- + 100 days for report



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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



Brain Support Network's Role

Coordinating advance arrangements with many parties

- family
- funeral home or body donation program
- pathology service
- hospice and care facility, if any
- clinics (for medical records)



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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

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

The Process for Brain Donation



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



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