



Brain Support Network

Brain Donation

How has it benefited MSA research?

When to make arrangements?

Robin Riddle, robin.riddle@brainsupportnetwork.org, 650-814-0848
September 28, 2018, MSA Coalition Conference, San Francisco Bay Area

2 key reasons for brain donation

#1 - Confirmation of a diagnosis is **ONLY** possible through post-mortem exam of brain tissue

- This may be helpful to children, grandchildren, and siblings.
- 50% of BSN cases have had the wrong diagnosis! About half of all supposed MSA cases are not confirmed as MSA!



2 key reasons for brain donation

#2 - Donated brain tissue enables research into the causes, treatments, and cure for MSA and other disorders

- Diagnostic criteria are based on confirmed cases of MSA. The criteria are only as good as support for brain donation within the community.



What do we know from brain bank studies of MSA?

“When DLB, PD, and PSP masquerade as MSA: An autopsy study of 134 patients.”
(Mayo study, Koga, 2015)

- Diagnosis while someone is alive is WRONG 40% of the time!
- Most common misdiagnoses were Dementia with Lewy Bodies and Parkinson’s Disease.
- BSN responsible for 25% of 134 brains.



What MSA research are we making possible through brain donation?

- Can cognitive impairment be part of MSA? What stage?
- Can dementia be part of MSA? What stage?
- Can hallucinations/delusions be part of MSA?



We recommend Mayo Clinic Jacksonville (FL) Brain Bank

- One of the top brain banks in the US.
- Actively publish on MSA using donated brain tissue. (“Masquerade” article)
- 100 days for a report.
- Family must order neurological records and provide a written family summary of symptoms and timeline.



Key challenges with Mayo Clinic

- Family must pay about \$1K to donate a brain. CurePSP offers MSA families a grant up to \$750.
- Family must make the comprehensive arrangements with the funeral home, pathology service, hospice, and care facility. That's where Brain Support Network comes in!



Donating a loved one's brain or your brain requires...

- Healthcare agent gives consent and will order neurological medical records
- Funeral home is cooperative
- Pathology service is available daily
- Hospice agency is cooperative
- Care facility is cooperative
- We contact everyone, coordinating comprehensive instructions



Contact us if or when...

- Receiving hospice or palliative care
- Person is actively dying
- Even when death has already occurred and we'll try our best
- And....for MSA, contact us any time since so many with MSA pass away when not on hospice



Check out our website

- Check out our website -
www.brainsupportnetwork.org/brain-donation
- Brain donation case studies, including:
 - John Yanez-Pastor (MSA)
 - Bob Thomas (MSA)
 - Jack Campbell (PD)
- Extensive list of frequently asked questions and process document





Brain Support Network

**We've helped over 500 families
donate a loved one's brain.**

We will help your family too.

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