



Brain Support Network

MSA Brain Donation

Confirm diagnosis

Support research into a cure

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Three reasons for brain donation

1. Confirmation of a diagnosis is **ONLY** possible through post-mortem examination of brain tissue
2. Donated brain tissue enables research into the causes, treatments, and cure for MSA and other neurodegenerative diseases
3. Positive outcome for sad situation



Another MSA-specific reason

- Only way to know if diagnostic criteria should be changed!
 - 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?

- Diagnosis while someone is alive is **WRONG 40% of the time!**
 - Mayo study showed most common misdiagnoses were Dementia with Lewy Bodies and Parkinson's Disease. (Koga 2015)
- If autonomic symptoms appear "early," MSA-P diagnosis is accurate 88%.
 - Otherwise, accuracy is 54%! (O'Sullivan)



What is it if it's not MSA?

- Dementia with Lewy bodies (DLB)
- Parkinson's disease (PD)
- Progressive supranuclear palsy (PSP)
- Corticobasal degeneration (CBD)
- Vascular parkinsonism (VP)
- Something very rare



Features suggesting it's not MSA

1. One-sided parkinsonian features (PD, CBD)
2. Early cognitive dysfunction (DLB, PSP, VP, CBD)
3. Early hallucinations and delusions (DLB)
4. Cortical sensory loss or ideomotor apraxia (CBD)
5. Vertical gaze palsy, esp. downgaze (PSP)



Why does it matter when someone is alive?

- Medication management: what's appropriate or helpful, and what's not?
- Support for person with a neurological diagnosis and family
- Many say a diagnosis "gives a name"
- Enroll the right people in research studies



What's the value of brain donation?

- ONLY way to obtain a confirmed diagnosis
 - This may be helpful to children, grandchildren, and siblings.
 - 50% of BSN cases have had the wrong diagnosis!
- Tissue enables medical research
 - Development of diagnostic criteria
 - Proof of a biomarker in the future
 - What do we know from past brain donations?



We recommend Mayo Clinic Jax Brain Bank

- **Mayo Clinic:**
 - One of the top brain banks in the US.
 - Actively publish on MSA using brain tissue.
 - Deliver reports in 3-4 months (very fast!).
 - Family must order neurological records and provide a written family summary of symptoms and timeline.
- **Autopsy-only: different from brain donation**



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
- BSN
 - contacts everyone,
 - coordinates detailed arrangements, and
 - develops comprehensive instructions



Contact us if or when...

- Hospice begins such that death may be six months away
- Person is actively dying
- Even when death has already occurred and we'll try our best



Check out our website

- MSA brain donation case studies including
 - John Yanez-Pastor, (diagnosed accurately), and
 - Jack Campbell, (diagnosed inaccurately)
- Extensive list of frequently asked questions

www.brainsupportnetwork.org





Brain Support Network

**We've helped over 350 families
donate a loved one's brain.
We will help your family too.**

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