Brain Donation

How it benefits MSA research. When to make arrangements.

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#1 of 2 Reasons for Brain Donation

Definitive diagnosis is ONLY possible through post-mortem exam

– Helpful to children, grandchildren, and siblings
– 50% of BSN cases have had the wrong diagnosis!
Enables research into causes, treatments, and cure for MSA

– Diagnostic criteria are based on confirmed cases of MSA. Criteria are only as good as support for brain donation.

– Brain tissue is required for
  • Genetic analysis
  • Biomarker research
  • Imaging studies
“When DLB, PD, and PSP masquerade as MSA” (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 provided 25% of the 134 brains used in study.
MSA Research Made Possible Through Brain Donation

- Is cognitive impairment part of MSA?
- Is dementia part of MSA?
- Are hallucinations/delusions part of MSA?
- ...and at what stage?
BSN Recommends the Mayo Clinic Brain Bank

• Led by Dr. Dennis Dickson, Mayo is a top US brain bank.
• Mayo actively publish on MSA using donated brain tissue.
• Autopsy reports delivered in 100 days.

Families must order neurological records and provide a written timeline of symptoms to Mayo.
Brain Donation Challenges

• Donation required within 24 hours of death
• Families generally bear cost of brain recovery (typically $1K)
  – CurePSP offers grants up to $750
• Arrangements with many organizations are required. That’s where BSN comes in!
  – Funeral home
  – Pathology service
  – Hospice or care facility
Donating a Brain Requires...

- Healthcare agent must consent
- Family must order medical records
- Pathology service must be available daily
- Many third parties must cooperate:
  - Funeral home
  - Hospice agency
  - Care facility

BSN coordinates all participants and prepares comprehensive instructions for each

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Start Arrangements When Donor...

- Is receiving hospice or palliative care,
- Is actively dying, or
- Has already died

For MSA, contact us early:
Many diagnosed with MSA pass away before entering hospice
Brain Support Network

- Founded in 2004
  - Registered as IRS 501(c)(3) non-profit in 2012
  - Five employees; all work from home
  - Dozens of volunteers
  - Based in Menlo Park (south of San Francisco)
- Has organized over 750 brain donations (neurological diagnoses)
- Currently averaging 100 monetary donations-$15,000/month
- 83% are in memory of a loved one
Check Out the BSN website

• Check out www.brainsupportnetwork.org/brain-donation

• Brain donation case studies, including:
  – John Yanez-Pastor (MSA)
  – Bob Thomas (MSA)
  – Jack Campbell (MSA → PD)
  – Joseph Nicolazzi (MSA → LBD)

• Extensive list of frequently asked questions

• Detailed description of brain donation process
We’ve helped over 750 families donate a loved one’s brain.

We want to help your family, too.

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