



# Brain Support Network

## Brain Donation

*How it benefits MSA research. When to make arrangements.*

Steven Russell, Director, Brain Support Network

[steven.russell@brainsupportnetwork.org](mailto:steven.russell@brainsupportnetwork.org)

+1 650-995-6379

MSA Coalition Conference, Orlando, Florida

September 27, 2019

# #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!



Brain Support Network

# #2 of 2 Reasons for Brain Donation

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



Brain Support Network

# Example of a Brain Bank Study

“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.



Brain Support Network

# 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?



Brain Support Network

# 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 Support Network

# 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



Brain Support Network

# 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



Brain Support Network



# 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

# 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



Brain Support Network

# Check Out the BSN website

- Check out [www.brainsupportnetwork.org/brain-donation](http://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



Brain Support Network

We've helped over 750 families donate a  
loved one's brain.

We want to help your family, too.

Steven Russell, Director, Brain Support Network  
steven.russell@brainsupportnetwork.org  
+1 650-995-6379

MSA Coalition Conference, Orlando, Florida  
September 27, 2019



Brain Support Network