## ABOUT BRAIN SUPPORT NETWORK

Brain Support Network (BSN) was formed in the San Francisco Bay Area in 2004 by Robin Riddle after her father, Larry Riddle, was diagnosed with Progressive Supranuclear Palsy (PSP).



July 2002

One of Larry's early symptoms was leg rigidity and he was diagnosed with arthritis in 2000. In 2003, his slurred speech, falls, and

cognitive dysfunction led to a diagnosis of stroke. Finally, a neurologist diagnosed PSP in February 2004.

Robin formed a Northern California support group for caregivers in June 2004 and arranged for the donation of Larry's brain

upon his death in October 2007. Since then, BSN has coordinated over 170 brain donations.

Larry's brain was first included in a landmark

August 2006

study published in *Nature Genetics* in June 2011 in which researchers identified three new genes linked to PSP.

## SUPPORTING OUR MISSION

Many families make charitable contributions to Brain Support Network to make future brain donations possible for other families. Many ask family and friends to make memorial donations in lieu of flowers. A \$500 gift allows us to help the next family who reaches out for help.



### **Brain Support Network**

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Registered 501(c)(3) charity

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# Brain Donation

Brain donation is the only way to confirm the diagnosis of a neurological disease. Donations also make possible the research necessary to find a cure.

Research programs for the following neurological disorders need brain tissue:

- Alzheimer's Disease (AD)
- Corticobasal Degeneration (CBD)
- Frontotemporal Dementia (FTD)
- Lewy Body Dementia (LBD)
- Parkinson's Disease Dementia
- Progressive Supranuclear Palsy (PSP)
- Vascular Dementia

Brain Support Network has helped over 170 families donate a loved one's brain since 2007. We can help your family, too.



brainsupportnetwork.org

# THE TWO BENEFITS OF BRAIN DONATION

When families first learn about brain donation, many are motivated to fight back against neurodegenerative disease. Brain research benefits us all, making brain donation an ideal way to achieve a positive outcome despite a difficult situation.

The second benefit of brain donation is a confirmed diagnosis. Brain donation is the only way to confirm the diagnosis of a neurological disease.

Half of the families we've helped have been surprised by the confirmed diagnosis of a loved one's neurological disorder. There is no blood test that can confirm the diagnoses for these neurological disorders.

Numerous research studies of Alzheimer's and other dementia types demonstrate the inaccuracy of during-life diagnostics. Depending on the disease, the error rate can exceed 50%. Only autopsy can deliver certain diagnosis.

# THE PROCESS OF BRAIN DONATION

Brain Support Network actively evaluates brain banks across the US and Canada. Based upon the donor's clinical diagnosis and history of neurological care, Brain Support Network will recommend a brain bank.

Next, Brain Support Network contacts the funeral home or cremation center to learn if it accommodates brain donation, its requirements, and its fee, if any.

Then we find the best pathology specialist for the donor. The specialist may be the least expensive, the closest geographically to the funeral home, or the one available 24x7.

Research protocols require that the pathology specialist procure the brain within 24 hours of death. Brain donation does not interfere with viewing of the body during funeral ceremonies.

The costs to the family of services by the funeral home and the pathology specialist are typically \$1,000. Brain banks do not charge for their neuropathological analysis and report. Brain Support Network charges no fee.

Once we know the costs and the process, the family decides if they would like to proceed. Brain Support Network provides detailed step-by-step instructions to the family to accomplish the brain donation.

#### **CONTACT US**

It is never too soon to contact us.

We encourage you to contact us when the family member...

- · has been placed on hospice,
- was recently hospitalized or has contracted aspiration pneumonia,
- has received multiple, conflicting diagnoses, making the diagnosis uncertain, or
- wants to do whatever he/she can to support research for a cure of Alzheimer's, Lewy Body Dementia, or any neurological disorder.

Please contact us before death is imminent. However, whenever you contact us, we will do our best to help.

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