

## 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, leg rigidity, was misdiagnosed as arthritis in 2000. In 2003, his slurred speech, falls, and cognitive dysfunction

led to a misdiagnosis of stroke. Finally, a neurologist correctly 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.

Larry's brain autopsy confirmed PSP. Since then, BSN has coordinated over 1,500 brain donations.



August 2006

Larry's brain was first included in a landmark study published in Nature Genetics in June 2011 in which researchers identified three new genes linked to PSP.

## SUPPORTING OUR MISSION

Families that work with Brain Support Network for brain donation arrangements are part of a pay-it-forward program. Just as past families' contributions allow us to help your family, your family's charitable contribution makes possible brain donations for other families in the future. A \$750 gift allows us to help the next family who reaches out for help; a \$1,500 gift allows us to help the next two families.

Many families request memorial donations in lieu of flowers to support BSN's efforts to find cures for neurological disorders. We are grateful for these gifts and understand that the family has made possible this support.



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# Brain Donation



Brain autopsy is the only way to confirm the diagnosis of a neurological disease. Brain donations provide this autopsy **and** deliver the human tissue necessary for research to find a cure.

**Research programs for the following frontotemporal degeneration disorders need brain tissue:**

- **Progressive Supranuclear Palsy (PSP)**
- **Multiple System Atrophy (MSA) (PSP)**
- **Corticobasal Degeneration (CBD)**
- **Frontotemporal Dementia (FTD)**
- **ALS and Frontotemporal Degeneration**

Brain Support Network has helped over 1,500 families donate a loved one's brain since 2007. We can help your family, too.



Brain Support Network

## THE TWO BENEFITS OF BRAIN DONATION

When families first learn that their loved one is suffering from a neurodegenerative disease, they feel powerless. Brain donation benefits the family and others, letting the donor and family fight back against the disease.

The first benefit of brain donation is progress to find a cure. 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. **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. Brain autopsy is the only way to know what disease—or combination of diseases—was present.

Numerous research studies 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 (BSN) actively evaluates brain banks across the US. Based upon the donor's clinical diagnosis and history of neurological care, BSN will recommend a brain bank.

Next, BSN 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 recover 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 from the funeral home and pathology specialist are typically \$1,300. Grants up to \$1,000 are available to FTD families. Brain banks do not charge for their analysis and report. BSN charges no fee, but requests charitable contributions.

Once we know the costs and the process, the family decides if they would like to proceed.

BSN provides detailed step-by-step instructions to the family to accomplish the brain donation. For more info see [www.brainsupportnetwork.org/brain-donation](http://www.brainsupportnetwork.org/brain-donation)

### CONTACT US

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

- has received multiple, conflicting diagnoses, making the true diagnosis uncertain,
- was recently hospitalized or contracted aspiration pneumonia,
- has been placed on hospice, or
- wants to do whatever he/she can to support research to find a cure for frontotemporal degeneration or any neurological disorder.

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

