

## ABOUT BRAIN SUPPORT NETWORK

Brain Support Network (BSN) was formed 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 450 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

The work of the Brain Support Network is made possible by the generosity of our donors. Donations fund the work to organize brain donations, staff educational events, develop informational resources, and support local families. Many families that we have helped ask relatives and friends to make honorary or memorial donations.

A \$1,000 gift allows us to organize the brain donations for the next two families who reach out for help. A \$500 gift lets us staff a booth at an all-day educational symposium. A \$100 gift will host our web site for one month. A \$50 gift will print 50 copies of our educational brochures.



Brain Support Network™

PO Box 7264  
Menlo Park, California 94026

Phone 650-814-0848

Fax 650-233-9278

[info@brainsupportnetwork.org](mailto:info@brainsupportnetwork.org)

[www.brainsupportnetwork.org](http://www.brainsupportnetwork.org)

Registered 501(c)(3) charity

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Printed September 2017



# Brain Support Network™

The Brain Support Network (BSN) is a non-profit organization dedicated to the well-being of those afflicted with neurodegenerative disorders. While sharing many symptoms of—and often confused with—the more-common Parkinson's or Alzheimer's diseases, these disorders have distinct brain pathologies and virtually no treatments.

### The disorders include:

- **Corticobasal Degeneration (CBD)**
- **Lewy Body Dementia (LBD)**
- **Multiple System Atrophy (MSA)**
- **Progressive Supranuclear Palsy (PSP)**

### BSN focuses on three services:

- **Caregiver support group meetings**
- **Brain donation arrangements**
- **Information dissemination**

BSN was founded in 2004 and is based in the San Francisco Bay Area.

[brainsupportnetwork.org](http://brainsupportnetwork.org)

## CAREGIVER SUPPORT GROUP MEETINGS

Brain Support Network convenes semi-quarterly support group meetings for Northern California caregivers. These meetings are for family caregivers only. They allow caregivers to meet with others who have lived this experience and can provide information, practical insights, and empathy.

Typically, 20% of attendees are volunteers who have followed a loved-one through the inevitable decline and death that these disorders bring. These volunteers help caregivers in a way that medical practitioners cannot, sharing in-the-trenches experience and advice.

The goal of the meetings is to lighten the load on caregivers and to prepare them to manage the burden of caring for someone with these neurological disorders.

Meetings are convened late Sunday afternoons in an inexpensive restaurant on the San Francisco peninsula. Typically, 20-to-25 caregivers and 5 volunteers attend.

Caregiver seating at these meetings is grouped by disorder: CBD, LBD, MSA, and PSP. We strive to ensure that at least one experienced volunteer is present for each disorder represented by caregivers.

## BRAIN DONATION ARRANGEMENTS

Brain Support Network arranges for brain donations by persons diagnosed with neurological disorders. Each brain donation delivers two important benefits.

First, brain tissue is a prerequisite in the search for a cure to these disorders. Brain donation lets families contribute to the search for a cure so that medicine can work to end this blight on families.

Second, there is no blood test that can confirm the diagnoses for these neurological disorders. Only autopsy of the brain can deliver certain diagnosis.

Depending on the disease, the diagnostic error rate can exceed 50%. Half of the families we've helped have been surprised by the confirmed diagnosis of a loved one's neurological disorder.

BSN maintains relationships with brain banks and pathology resources across the United States. We make arrangements for the brain procurement and delivery to the brain bank.

The brain bank will perform an autopsy to deliver the definitive diagnosis. Most brains are delivered to the Mayo Clinic in Jacksonville, Florida, because it specializes in the research of many neurological disorders.

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.

## INFORMATION DISSEMINATION

Brain Support Network tracks research into these disorders and maintains relationships with most neurologists specializing in these disorders in Northern California.

We maintain a 400-name email list of caregivers and patients, organized by disorder. We send emails about upcoming events, research programs, relevant findings, and articles on caregiving. We never share our email list, even with affiliated groups.

We also use this list to put patients in contact with other patients with the same disorder. One goal is to pair up someone new to these disorders with others who are more experienced and in geographical proximity.

## WHO WE ARE

Brain Support Network is managed by an unpaid board of five directors—all former caregivers to someone with AD, LBD, PD, or PSP—in Northern California. Brain donation arrangements are managed by part-time employees selected for exceptional attention to detail.

Our medical advisor is Neng Huang, MD, PhD. Dr. Huang is a neurologist practicing in Los Gatos, California. **Visit us at [www.brainsupportnetwork.org](http://www.brainsupportnetwork.org).**