Frequently Asked Questions (FAQs)

Q. How do I make a decision?
A. Make your decision freely. First, learn as much as you need to know. Discuss the options with the people you trust will follow your wishes. Make your own personal decision and explain that decision to the people you trust.

Q. Who may request an autopsy?
A. Legally, the next-of-kin or guardian is the person who makes the decision. If the spouse is deceased, the oldest child is considered next-of-kin. In some states the deceased may arrange for an autopsy with a living will.

Q. Is a complete autopsy performed?
A. No. In most instances where a degenerative brain disorder is suspected, only brain tissue need be examined for diagnosis; however, a complete autopsy is often recommended for atypical cases, where examination of the spinal cord, muscle and nerves may be informative.

Q. Can I have an open casket?
A. Yes. Harvesting brain tissue for diagnosis and research leaves no disfigurement. Only on close inspection would anyone know that an autopsy had been performed.

Q. Are there any religious considerations I need to think about?
A. The majority of world religions support autopsy if there is a hope that the knowledge gained will improve the lives of others in the future. Many world religions recognize the mandate to heal and the call to compassion. This gift of hope may provide relief for those who have symptoms now and may also provide a healthier future for generations to come. Please consult your religious leader to learn how your religion interprets brain donation.
What is the Brain Donation Program?
Dr. Irene Litvan, Director of the Movement Disorder Center, has created a partnership between UC San Diego and the Mayo Clinic in Jacksonville, FL. This partnership allows patient's suffering from neurodegenerative disorders the opportunity to receive a post-mortem brain autopsy and final diagnosis at no charge.

Who can donate?
Anyone suffering with a degenerative, neurological disorder can donate.

Commonly accepted diagnoses are: Parkinson’s disease (PD), Progressive Supranuclear Palsy (PSP), Corticobasal Degeneration (CBD), Multiple System Atrophy (MSA or Shy-Drager Syndrome), Vascular Dementia (VaD), Frontotemporal Dementia (FTD), and Creutzfeldt-Jakob Disease (CJD)

Why should I donate?

Definitive Diagnosis
Currently, the only way to obtain a definitive diagnosis of a degenerative brain disorder is through direct examination of brain tissue.

Family Medical History
This valuable information may be important for disorders with a genetic component.

Scientific Advancement
By making this very generous donation to science, you improve the chances of finding a cure and treatment options.

How to enroll
Enrolling in the Brain Bank Donation Program is easy. Follow the steps below or contact your UCSD Movement Disorder Specialist for help enrolling.

1. Request a Brain Donation Packet. This packet contains all the necessary information and paperwork you will need to help in making this important decision. Contact your UCSD Movement Disorder Specialist for this information or download it at: http://www.psp.org/research/bank.html
   *Click on the Download Our Brochure link

2. Enroll. The first step is to register with the Brain Bank by completing the questionnaire (pg. 4) and mailing or faxing it to the Brain Bank Coordinator at the CurePSP Brain Bank at Mayo Clinic in Jacksonville, FL.

Mailing Address
CurePSP Brain Donation Program for Diagnosis & Research on PSP
Eloise H. Troxel Memorial PSP Brain Bank
4500 San Pablo Road
Jacksonville, Florida 32224

Brain Bank Coordinator
Phone: (904) 953-2439, M-F, 8am-5pm EST
Fax: (904) 953-7117, available 24/7

3. Find a local pathologist. The UCSD Movement Disorder Center will help local individuals locate a pathologist. Dennis Dickson, M.D. at the Mayo Clinic in Jacksonville will help facilitate locating a pathologist for individuals residing outside the Greater San Diego area. Dr. Dickson can be contacted at (904) 953-7137.

How soon should the services be done?
To preserve the integrity of the tissue, brain tissue must be harvested and shipped within 24 hours of passing away. When the time comes, a local pathologist will perform this procedure and take care of preparing and shipping the brain to the Mayo Clinic in Jacksonville.

How much will this cost?
Financial Obligation. The cost associated with brain donation is minimal, if any. Once you are enrolled in the Brain Bank Donation Program, all expenses related to shipping and performing the brain autopsy are covered. Minimal expenses may be incurred from the harvesting of the brain tissue.

Individuals should contact the pathology department at the hospital or facility where death occurs. Typically these services should be performed free of charge. Local individuals passing away at home or at a private facility can contact Craig Gibson at Autopsy Pathology Services in San Diego, CA. The phone number is (800) 350-5908.

Need more information?
If you are interested in learning more about the Brain Donation Program, please contact:

Robin Ellam, BA, CCRC
UC San Diego, Movement Disorder Center
La Jolla, California

(858) 822-5751
rellam@ucsd.edu

(800) 350-5908

The UCSD Movement Disorder Center’s goal is to create a movement disorder neurological brain bank in partnership with the Mayo Clinic in Jacksonville, Florida. The brain bank will be called the CurePSP Brain Bank at Mayo Clinic, Jacksonville.

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