

The Importance of Brain Banking for PD

Beth Marten

Brain Bank Coordinator,

Mayo Clinic, Jacksonville, Florida

At the end of life for a PD patient, survivors are, at best, conflicted. Unless you have lost a loved one, it is very difficult to understand the frustration, the sense of loss and the enormous grief that is experienced.

Mayo Clinic in Jacksonville, Florida provides, under the auspices of Dennis W. Dickson, M.D., brain banking services for the State of Florida Alzheimer's Initiative, CurePSP, the Society for Progressive Supranuclear Palsy, the Einstein Aging Study and our own Department of Neurology's various clinical studies programs.

There are very good reasons to consider this tissue donation at the time of death for an PD patient.

- ✍✍ Tissue sent to a brain bank is generally used to provide a pathological diagnosis for the next of kin and then used in genetic and biological studies to someday determine the cause and hopefully, find the cure for PD.
- ✍✍ The only way to verify a clinical diagnosis is through pathology, and the only likely way that the cause and cure for PD will ever be discovered is through biological and genetic research.
- ✍✍ Because the disease is not understood, it can be misdiagnosed as Alzheimer's or a related neurological disease.
- ✍✍ Research, however, is how we hope to aid other families and individuals who live with PD.
- ✍✍ Our research has a significant genetic component for PD and other movement disorders, and the brain tissue contributes significantly in that work.

With the advent of the Human Genome Project, doors have been opened to the medical community that offer great new avenues toward discovering the cause and cure for many diseases, not just neurological ones. Because of the complexity of the human genome, genetic research is incredibly important right now, and it requires hundreds, perhaps thousands, of tissue samples to identify the features that are responsible just for PD. That is part of the reason why the need for brains is so great.

The tissue harvest is the first step in the process. All caregivers need to be aware of a loved one's plans at the time of death, including the nursing home or hospice, the funeral home, and a pathologist. We suggest making these arrangements in advance to

be sure that no issues arise, such as availability of a pathologist, and so the family will not have any unnecessary concerns at an already stressful time.

You can go to www.CurePSP.org and click on “Learn more about the Brain Donation Program” at the bottom of the home page. It will help you to understand the process, and answer some of your questions about what is needed. You will also see that the forms required for tissue donation are included.

There are two important parts of the tissue donation process that can “make or break” the family’s wishes.

First, it is necessary for the family to locate a pathologist or *diener* (pathologist’s assistant) in the area who will be able to harvest the tissue in a reasonable amount of time. That individual will only remove the tissue and prepare it for autopsy. Dennis W. Dickson, M.D., is the only one who performs the actual autopsy and analyzes the resulting data to determine the pathological diagnosis. Since the whole brain is removed in a standard procedure, it can be easily accomplished by a pathologist with no special training. Depending on where you live, it can sometimes be difficult to locate a pathologist. If there is a large hospital near you that has a pathology department or a hospital that the patient has used, someone there may be able to perform the procedure. The patient’s neurologist may be able to locate someone, or the medical examiner’s office may be able to help – they will sometimes do what they call a private autopsy, though this varies from state to state. If there is a university with a medical school, they may be able to help. If all else fails, we can try to help locate someone.

The second issue is the cost of the tissue harvest. Unfortunately, because we are funded by grants, that is the one piece that we are unable to help with. There are some agencies that do not charge for the procedure because they realize how valuable the tissue is to us. There are some who will request an unreasonable amount. We have found \$250 - \$500 to be a reasonable fee for the service.

Once the harvest has been accomplished, we take over at the Brain Bank. We ship containers and dry ice, as needed, to the pathologist to transport the tissue properly to our facility here in Florida. Dr. Dickson performs all autopsies once the tissue has been prepared for the procedure (normally after about two weeks). Then, slides are prepared, stains are completed and analysis of the tissue is completed by Dr. Dickson, who writes the autopsy report. A copy of that report is sent to the next of kin identifying anything neurological that had occurred in the brain. If there were other disease processes, or something such as strokes or hardening of the arteries, the report will reveal that. This process is normally completed within one month after the autopsy.

The tissue will continue to be used in support of our educational research and activities. We ask that families provide copies of the patient’s medical records tracking the progression of the disease. This provides relevant information for researchers as they work on specific experiments related to our research on PD

The bottom line for all of us: there will never be a cure for this especially nasty disease without tissue donation. The **PD community** is collaborating with world-renowned researchers who give hope that there will be a cure for PD, which has already destroyed the quality of life for too many patients and their loved ones.

Our thanks to you for considering donation.

Beth Marten
Brain Bank Coordinator
Mayo Clinic
4500 San Pablo Road
Jacksonville FL 32224
Phone: 904.953.2439
Marten.beth@mayo.edu