



## **Mayo Clinic Jacksonville**

# **Parkinson's Disease & Related Disorders Brain Donation Program**

A Morris H. Udall National Institutes of Health  
Parkinson's Disease Center of Excellence

Mayo Clinic Jacksonville  
4500 San Pablo Road  
Jacksonville, FL 32224

The purpose of the Parkinson's Disease Brain Donation Program is:

1. To provide families with postmortem diagnostic evaluations for relatives suffering from Parkinson's disease and related disorders.
2. To provide tissue for Parkinson's disease research to scientists at Mayo Clinic Jacksonville and approved collaborating research centers.

The decision to obtain a brain autopsy and the formulation of plans for the autopsy should be done by the family members in advance. Preplanning minimizes additional upset at the time of death. If the patient dies in a hospital, the hospital pathologist, usually at no expense to the family, can perform an autopsy. Ask the physician responsible for the care of the patient to request an autopsy from the Pathology Department. Instruction for proper handling of tissue for research purposes is included on page 5. Hospital pathologists are often willing to perform brain harvests for research purposes from patients who do not die in their hospital, but they may then charge a fee for their services. It is best to check in advance; however, reasonable pathologist charges will be reimbursed by Mayo Clinic Jacksonville Parkinson's Disease & Related Disorders Brain Donation Program.

If the patient resides in a nursing home, it is important that you state your intentions for an autopsy to be done to the personnel at the nursing home or care center and to the attending physician. Make sure that a written statement or a copy of this form is placed in the nursing record along with phone numbers of the funeral director with whom you have made arrangements. It is advisable to plan with the funeral director in advance for the autopsy procedure. Inform the funeral director that the body is not to be embalmed before brain removal and that the body must be refrigerated if transportation is delayed. A copy of these instructions may also be given to the funeral director.

An original autopsy consent form signed in ink by the legal next-of-kin must be presented to the pathologist responsible for the brain autopsy. This is a legal requirement before an autopsy can be performed. If it is impossible to provide a written form at the time of death, it may be possible to give a witnessed phone consent for autopsy or a consent through a telegram. If the consent is signed before the death of the individual ("advance directive") it may not be legally binding. This depends upon local jurisdiction. It is not necessary for the signed consent to be notarized, but the signature should be witnessed and the date recorded. The pathologist will want to reconfirm the intent of the next-of-kin for these studies at the time of death and have the appropriate forms transported with the body to the hospital. The forms may be faxed, but the original must then be mailed.

If the family is willing and the patient resides in North Florida or South Georgia, the body can be transported from a local hospital to Jacksonville, Florida for the brain removal. There are no costs for a brain autopsy performed at the Mayo Clinic's St. Luke's Hospital in Jacksonville, but costs for transportation of the deceased to and from the hospital will usually have to be paid by the family. In some circumstances Mayo Clinic Jacksonville Parkinson's Disease & Related Disorders Brain Donation Program may be able to help offset this expense. It is best to call and make these arrangements in advance.

A written report of the diagnostic findings can be expected within 8 to 10 weeks, if requested by the next-of-kin. Proper evaluation of the tissue is aided by any medical information that may have been collected during the course of the disease. A medical records release form is included in

this packet (page 7) to facilitate release of this information to Mayo Clinic physicians. Extra copies of the medical record release can be made if more than one physician was responsible for the care or evaluation of the patient. Information from physicians who were involved in the evaluation and care of the patient in the earliest stages of the disease is as important as that from physicians who cared for the patient prior to his or her death.

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**NUMBER TO CALL AT TIME OF PATIENT'S DEATH:**

**Page Operator of Mayo Clinic Jacksonville                      (904) 953-2000**

Ask for the physician who works with you (Dr. Zbigniew Wszolek or Dr. Ryan Uitti), and if the appropriate doctor is not available, ask for the neurologist on-call for the Brain Bank.

## Questions and Answers About Autopsy

**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 in advance for an autopsy with a living will.

**Q. Is a complete autopsy performed?**

A. No. In most instances where Parkinson's disease 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. Where is the autopsy performed?**

A. If death occurs in a hospital, the autopsy may be performed in that facility. If death takes place in a nursing home, other arrangements will have to be made.

**Q. Can I have an open casket?**

A. Yes. Harvesting brain tissue for diagnosis and research leaves no disfigurement.

**Q. Will my relatives know the brain has been removed?**

A. Only on close inspection would anyone know that an autopsy had been performed.

**Q. Is it important for children of Parkinson's disease patients to have a confirmed diagnosis through autopsy?**

A. Yes. As our knowledge increases, it is clear that some cases of Parkinson's disease run in families. Other disorders are also occasionally mistaken for Parkinson's disease and a Parkinson's disease-like illness can sometimes be due to other diseases. If genetic tests or other tests eventually become available, it is important to know that Parkinson's disease is the actual diagnosis. If other family members might be prone to develop Parkinson's disease this information will be important for early diagnosis and treatment.

*Information for the Hospital Pathologist:*

**Parkinson's Disease & Related Disorders  
Brain Donation Program  
Mayo Clinic Jacksonville**

**4500 San Pablo Road ? Jacksonville ? Florida 32224**

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Dear Doctor:

Thank you for agreeing to perform an autopsy to establish a diagnosis of neurological disease and to obtain tissue for special studies and research in neurological diseases. Please perform the harvest as soon as possible after death, preferably within 12 hours (up to 24 hours is still acceptable). The time lapse between death and autopsy should be noted as well as the fresh brain weight when drained of CSF. Split the brain down the middle through the corpus callosum, cerebellar vermis and brainstem. Put the right hemisphere in a plastic bag into the coldest possible freezer (preferably at -70°C). In order not to distort the specimen, put the medial aspect of the brain down flat, so that it will freeze in its normal shape. The left hemibrain is simply immersed in formalin, buffered to neutrality.

When ready to ship, the frozen specimen is packed in a Styrofoam shipping container with enough dry ice to last for 48 hours. The formalin fixed-specimen is put into a leak-proof plastic bag in a separate shipping container. Both boxes (do not ship in one container) are to be sent overnight by Federal Express, Priority One Delivery. We can provide shipping containers and dry ice if needed, and will be happy to provide you with our FedEx number to cover the cost of shipping the tissue.

Both packages should be addressed to:

Dennis Dickson, M.D.  
Mayo Clinic Jacksonville  
Birdsall 347  
4500 San Pablo Road  
Jacksonville, FL 32224  
(904) 953-2439 or  
(904) 953-7137

Please send the tissue early in the week so as to avoid delivery during the weekend when no one is available to receive and process the packages. Do not ship on Thursday or Friday.

Any clinical history emphasizing mental, neurological, occupational and familial aspects of the patient is very helpful in completing the autopsy. A copy of the autopsy report will be sent to the pathologist, and to the next of kin if requested. We can also provide a set of slides if requested by the pathologist. Please call Dr. Dickson at one of the numbers given above if you have any questions.

*Information from the Hospital Pathologist:*

**Parkinson's Disease & Related Disorders  
Brain Donation Program  
Mayo Clinic Jacksonville**

**4500 San Pablo Road ? Jacksonville ? Florida 32224**

**Autopsy Information:**

Patient's Name: \_\_\_\_\_ Sex: M F  
Pathologist: \_\_\_\_\_ Phone # \_\_\_\_\_  
Date of Death: \_\_\_\_\_ Time of Death: \_\_\_\_\_ Age at Death: \_\_\_\_\_  
Postmortem Interval: \_\_\_\_\_ Fresh Brain Weight: \_\_\_\_\_  
Body Refrigerated: Yes No Temperature of stored tissue before shipment: \_\_\_\_\_

**Contact Persons for Further Information on the Patient:**

**Primary Physician:** \_\_\_\_\_ **Phone:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_

**Next of Kin:** \_\_\_\_\_ **Phone:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_

**Nursing Home:** \_\_\_\_\_ **Phone:** \_\_\_\_\_  
**Address:** \_\_\_\_\_  
\_\_\_\_\_

**MAYO CLINIC  
MEDICAL RECORDS RELEASE FORM**

*(Copies of this consent should be sent to the doctor(s) who evaluated or treated the patient for clinical and pathologic correlation.)*

I/we, \_\_\_\_\_, \_\_\_\_\_ and next of  
Name Relationship

kin of \_\_\_\_\_, give permission to \_\_\_\_\_  
Name of Patient Name of Doctor

to release a copy of the medical reports and/or records of \_\_\_\_\_  
Name of Patient

to Mayo Clinic. Please include history, medical and neurological evaluation, diagnosis, CT or MRI scans, other x-ray reports, electroencephalogram report, medication history, electrocardiogram report and any other pertinent data. All information will be held in the strictest confidence and should be sent to the Mayo Clinic Brain Bank to the attention of Dr. Dennis Dickson:

Dr. Dennis Dickson  
Neuropathology Laboratory  
Mayo Clinic  
4500 San Pablo Road  
Jacksonville, FL 32224

\_\_\_\_\_  
Signature of Patient

Or

\_\_\_\_\_  
Signature of Person Authorized to  
Consent for Patient, & Relationship to  
Patient

\_\_\_\_\_  
Witnessed by (Name and Title)

\_\_\_\_\_  
Date

