

PARKINSON'S. WE'RE IN THIS TOGETHER.™

Dr. **David Marsden** wrote the following **letter**, which was published in the United Parkinson's Foundation newsletter (#4, Part 2) in 1986. We thank UPF for permission to reprint the article.

Autopsies, Tissue Donations, and Brain Banks

It is not pleasant to contemplate one's own death, but it is one of life's two inevitabilities (the other being taxes!). Yet this final event is an opportunity to leave a priceless legacy to others. By donating our kidneys, livers, and hearts for transplantation, we can give the gift of life to those whose own organs need replacing. What about our brains? Allowing our brains to be used for research may one day contribute to discoveries that may lead to a cure for our family members or friends.

Diseases of the **brain** are the most difficult to study. We do not notice loss of a small part of our kidneys or liver. Doctors can remove the piece of kidney during life by a needle biopsy. The tiny core of tissue can be examined under the microscope or chemically. On the other hand, each part of the **brain** is unique. So we cannot remove pieces of the **brain** from the living, but must rely on the dead for tissue to study. This is why the gift of our brains after death is so crucial to research.

The discovery of Levodopa treatment for symptoms of Parkinson's disease (PD) came directly from chemical examination of the brains of patients after death. Demonstrations of the considerable loss of dopamine in the basal ganglia in patients with PD was the stimulus to use levodopa to try to replace the missing dopamine. Levodopa treatment has had a dramatic effect upon the quality of life in PD patients but it is not a cure. However, now there are real clues as to what might be the cause(s) of the illness, and the need for brains to study is all the more urgent.

Twins studies have shown that, in general, inheritance does not play a direct role in causing PD. So we must look to the environment. The remarkable MPTP story has shown that toxic substances are capable of producing parkinsonism, and the hunt is on for other such toxins. But we need to look for such agents and their effects within the brains of those with Parkinson's disease.

If you are persuaded by these arguments, then you need to take action now. Arrangements must be made in advance to ensure that the **brain** tissue is preserved as soon as possible after death. Your relatives, doctors, and attorneys must know of your wishes ahead of time so that there is no uncertainty. It is best to have all this settled, in writing.

At first sight, all this sounds as if it is directed only at the patients with Parkinson's disease, but there is an equally pressing need for **brain** tissue from normal subjects as well. We can only tell what is wrong in PD by comparing parkinsonian **brain** tissue to tissue from normal brains. So the normal spouses, relatives, and friends of those with Parkinson's disease can make a major gift of their own brains to help the study of this illness.

How can you get more information regarding the donation of brain tissue? The Parkinson's Institute Brain Donation Program is one of the largest of its kind in the country. We are happy to answer any questions you may have, and if interested, enroll you into the Program. For more information, please contact the Parkinson's Institute Brain Donation Program Coordinator.

By phone: 408.542.5627 Or By email: braindonation@theipi.org





Dear Friend,

Thank you for inquiring about donating your brain to medical research. We are deeply grateful that you and your family are considering this very personal decision.

If you are not already familiar with our work here at the Parkinson's Institute, let me emphasize that the primary mission of our researchers and clinicians is to unravel the cause of Parkinson's disease and related movement disorders and to find a cure for these diseases. In order to achieve these goals, the availability of tissue from both patients as well as control subjects without neurological disease represents a most critical resource. Only through neurochemical and neuropathological evaluation of these samples are we likely to fully understand the nature of the disease process.

Our tissue bank, which includes brain tissue as well as blood and spinal fluid samples, is a precious and rather unique tool. Unlike other brain banks, ours is focused on Parkinson's disease and related-disorders research, and for this reason each brain is examined by an experienced neuropathologist to confirm the clinical diagnosis. Brain donations from subjects who are not affected by Parkinson's disease or Parkinsonism are also important, since these brains allow us to compare the changes that occur in Parkinson's disease with non-parkinsonian tissues.

There are four forms for you to complete in order to enroll in the brain donation program. The **Information Form** begins the enrollment process and provides us with basic information to contact you, your family members, and your physicians as the need arises. The **Statement of Intentions Form** formally gives us permission to use your brain tissue for medical research. The **Medical Record Release Form** allows us to request your medical records from your physicians and hospital care givers. Medical records are essential to enable us to correlate neuropathology with clinical history. The **Autopsy Permission Form** must be signed by your next of kin to allow us to remove and examine the brain tissue after death.

Additional information, and copies of the forms can be obtained directly from our website at www.thepi.org under 'Support Us'. If you prefer, you can also contact our brain donation desk at (408) 542-5627, and we will be happy to mail you a set of forms and answer any further questions. If you are interested in participating in the program, please complete and return the forms to the following address:

The Parkinson's Institute
Attn: Birgitt Schuele, MD
675 Almanor Avenue
Sunnyvale, CA 94085

If you do choose to enroll, we ask that you make your attending physician(s) aware of your intent to donate your brain for research purposes, and also share this information with your

next of kin. It is important that at the time of a donor's death, the next of kin, another family member or the attending physician should notify us at the Parkinson's Institute as soon as possible, day or night, by dialing this 24-hour number: **(408) 656-1599**.

The days immediately following the death of a loved one are inevitably filled with grief. In order to avoid additional stress to the family, staff from the Parkinson's Institute will coordinate the procedure for brain autopsy. We travel to the location, whether it be a mortuary, nursing home or hospital, remove the brain and transport it to our facility, within 24 hours of death. Removal must occur before the body has undergone the embalming process. If a patient dies in the hospital, hospital personnel may perform the brain removal if requested by the patient's family or the attending physician. Unfortunately, due to very limited funding we are currently not able to cover all costs, and donors who are not patients of the Parkinson's Institute will be responsible for organ recovery fees and associated costs charged by the hospital, mortuary or funeral home. The neuropathological analysis and detailed report are complimentary.

Neuropathology results typically take several months to obtain. We will contact your family to personally discuss the results with them, should they desire. Most families find this a very positive experience that helps to bring closure.

We appreciate the generous spirit that prompted your inquiry about our brain donation program and pledge to treat the donated tissue with respect and in accordance with the highest standards of ethical medical research practices. We strongly feel this is a critical program not only for researchers in the field of movement disorders, but perhaps more importantly, for patients and their families who will benefit from the outcome of this research.

Warmest personal regards.

Sincerely,



J. William Langston, M.D.
Founder, CEO



**The
Parkinson's Institute
and Clinical Center**

Donor Information Form

Date: _____

Donor Name: _____ Sex: M F

Date of Birth: _____ Home Phone: (____) _____

Address: _____

E-Mail: _____

Medical Record Number (if applicable): _____

Next of Kin 1/Relationship: _____

Address: _____

Home Phone: (____) _____ Preferred Phone: (____) _____

Next of Kin 2/Relationship: _____

Address: _____

Home Phone: (____) _____ Preferred Phone: (____) _____

Family Physician: _____

Office Address: _____

Office Phone: (____) _____

Neurologist: _____

Office Address: _____

Office Phone: (____) _____

Nursing Home: _____

Contact: _____ Phone: (____) _____

Address: _____

Mortuary: _____

Contact: _____ Phone: (____) _____

Address: _____



**The
Parkinson's Institute
and Clinical Center**

**BRAIN DONATION PROGRAM
STATEMENT OF INTENTIONS FORM**

It is my intention that, in the event of my death, my brain be donated for research purposes to the Parkinson's Institute:

The Parkinson's Institute
675 Almanor Avenue
Sunnyvale, CA 94085
408-734-2800 (phone)
408-734-8788 (fax)

Signature of donor/representative

Date

Donor's Name - please print

Date of Birth

Witness Signature

Date

I _____, _____, give permission to the Parkinson's Institute and
(name of donor/representative) *(relationship)*
Clinical Center to release a copy of the medical records for _____ to: Dr. Dennis
(name of donor)
Dickson at the MAYO Clinic Neuropathology Lab, 4500 San Pablo Rd, Jacksonville, Florida in connection
with this Brain Donation program.

Signature of patient or person authorized to consent _____

Date _____

If you have any questions please do not hesitate to call the Brain Donation Program at: (408) 542-5627.



**The
Parkinson's Institute
and Clinical Center**

AUTOPSY PERMISSION FORM

This section to be completed by next of kin:

Donor's Name

Date of Birth

I, _____ certify that I am:

Spouse Child (age: _____) Parent Other _____

of the above named donor. I am the closest reasonably available next of kin and have the legal right to authorize the removal and retention of such specimens, organs and tissues as the examining physician deems proper for diagnostic, therapeutic, transplantation, education, research or scientific purposes.

I hereby authorize a post-mortem examination of the above named donor with the following exclusions or limitations (if none, so state):

I further authorize the release of tissue samples recovered from this post-mortem examination to representatives of the Parkinson's Institute for research purposes, without limitation, but in accordance with all laws and regulations.

Signature of Next of Kin

Signature of Witness

Printed name - Next of Kin

Printed name - Witness

Date

Date



**The
Parkinson's Institute
and Clinical Center**

REQUEST FOR MEDICAL RECORDS

To: _____

Please release my medical records to:

**Brain Donation Program, The Parkinson's Institute
675 Almanor Avenue, Sunnyvale, CA 94085
Phone: (408) 542-5627 Fax: (408) 734-8788**

Any and all records pertaining to:

- Original History & Physical
- MRI reports and films
- Consultation reports
- Doctors' notes (including muscle testing & UPDRS)
- Recent History & Physical
- Laboratory reports

Purpose of Disclosure:

Research Continuity of care Other _____

Date of Expiration: This authorization shall remain in effect until _____ or for one year from the date of my death.

Revocation of Request: This authorization is also subject to written revocation by the undersigned at any time between now and disclosure of information by the disclosing party. My written revocation will be effective upon receipt, but will not be effective to the extent that the requestor or others have acted in reliance upon this authorization.

Redisclosure: I understand that the recipient may not lawfully further use or disclose the health information unless another authorization is obtained from me or unless such use or disclosure is specifically required or permitted by law.

Minimum Necessary Standard: The Protected Health Information requested is the minimum necessary to accomplish the specified purpose.

Patient's Name

Date of Birth

Medical Record Number

Social Security Number

Patient's Signature (or legal representative)

Date