

CurePSP Brain Tissue Donation Program

Progressive Supranuclear Palsy (PSP)
Corticobasal Degeneration (CBD)
Multiple System Atrophy (MSA)
Frontotemporal Dementia (FTD)
Amyotrophic Lateral Sclerosis (ALS)
Chronic Traumatic Encephalopathy (CTE)

Supported by the
Eloise H. Troxel
Memorial Brain Bank Mayo Clinic
Jacksonville, Florida



A Diagnostic Service for Families
A Research Resource for Scientists

CurePSP[®]
UNLOCKING THE SECRETS OF BRAIN DISEASE[™]

www.curepsp.org



Brain tissue research gives patients and loved ones new hope.

The vision of CurePSP is a world free of neurodegeneration. Our mission is to provide awareness, education, care and cure for prime of life brain diseases. CurePSP is committed to improving the quality of life for patients and families.

CurePSP asks you to consider brain tissue donation when the clinical diagnosis is made. Pathologic diagnosis by direct examination of the brain tissue through the microscope is the only way to verify a clinical diagnosis. By making this very generous donation, you improve the chances of finding a cure and treatment options for these diseases.

The final autopsy report that you will receive provides information about other brain changes that may exist, including those that may have contributed to a clinical misdiagnosis. The Brain Bank will provide tissue samples to reputable scientists worldwide for investigation into the genetics and other aspects of the causes of neurodegeneration. Research is a tangible process that will provide loved ones with the answers they deserve and better serve patients currently suffering with these diseases.

Arrangements in Advance

For questions about making advance arrangements for tissue collection, please contact the Brain Bank:

Brain Bank Coordinator, Mayo Clinic

Phone: (904) 953-2439, Monday-Friday, 8am to 5pm (Eastern time)

Fax: (904) 953-7117

Why Make Your Decision in Advance?

For several reasons, CurePSP urges you to prepare all arrangements for brain donation in advance.

Your loved one can die suddenly, which is extremely stressful. A decision may have been made to donate tissue, but without making prior arrangements, it is possible that the donation will not occur. The 24-hour window to collect the tissue cannot always be met on short notice, especially on weekends and holidays.

- The patient, family members and other loved ones should be involved in the decision. It may take time for everyone to come to an agreement. The Brain Bank Coordinator is available to answer any questions and assist in making the arrangements.
- It can be difficult to locate a pathologist to perform the tissue collection. It is most important to have someone lined up in advance to make sure this procedure is accomplished within 24 hours after death. The Brain Bank Coordinator can assist with finding a pathologist in your area.
- It is helpful to talk with family and friends, as well as the funeral home, about the planned arrangements. Planning in advance and the support of others will help during the time of grief.
- In addition to the tissue donation, research efforts are aided by getting copies of your loved one's medical records showing the progression of the disease. Since the analysis of the tissue is generally performed two weeks after death, securing medical records in advance is a significant help to the pathologist conducting the examination. The Brain Bank Coordinator can advise and guide you through this process.

Questions and Answers

About Autopsy and Tissue Collection

Q. Who may request a tissue collection?

A. Legally, the patient and/or next-of-kin are the persons to sign the Research Consent Form. If the patient's spouse is deceased, the oldest child will be considered next-of-kin. In some states, the patient or next-of-kin may sign this form prior to death. In other states such as Texas, this is not legally binding unless signed after death.

Q. Will there be a need for any other tissue collection?

A. No. In most instances where these diseases are suspected, only brain tissue will need to be examined for diagnosis. However, a more complete autopsy is sometimes recommended for atypical cases where examination of the spinal cord, muscle and nerve may be informative.

Q. Where is the tissue collection performed?

A. If death occurs in a hospital, the autopsy and tissue collection will likely be performed in that facility if the procedure has been ordered by the attending physician. If death takes place in a nursing home, with hospice, or at home, the body will have to be transported to the funeral home, crematorium, hospital or medical examiner's office for the collection to take place. In that case, there may be additional costs for transport by the funeral home.

Q. Can there be an open casket?

A. Yes. Collecting brain tissue for diagnosis and research leaves no disfigurement to the body, but be sure to inform the pathologist or diener (pathologist's assistant) that there will be an open casket.

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

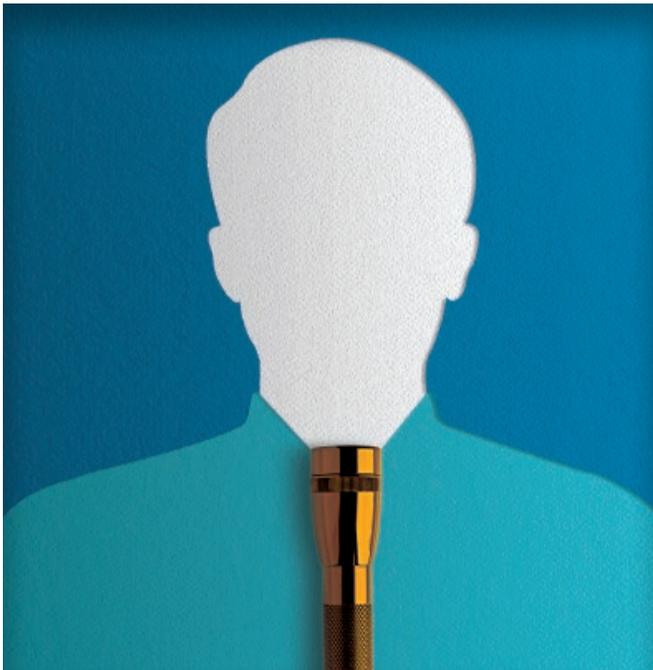
A. Only on close inspection would anyone discover that a brain tissue collection has been performed.

Q. Is it important for children of patients to have a confirmed diagnosis of the diseases through autopsy?

A. Yes. From our current research studies, it is clear that some diseases run in families. Other disorders are also occasionally mistaken for prime of life neurodegeneration or may sometimes be masked by other medical conditions. If genetic tests or other tests eventually become available, it is important to confirm the actual diagnosis. If other family members might be predisposed to the diseases, this information will be important for early diagnosis and treatment.

Q. Are there other ways to definitely confirm a diagnosis of neurodegenerative disease?

A. While clinical diagnosis has been greatly advanced, at this time there is no way to confirm a diagnosis for most of these diseases other than by examining brain tissue. However, autopsy tissue provides invaluable material for developing less invasive diagnostic tests in the future, such as blood tests or brain scans.



After Your Decision Has Been Made

Enroll in the Brain Bank by completing the *Brain Bank Questionnaire* and mailing or faxing it to the Brain Bank at the Mayo Clinic in Jacksonville, Florida. For the most efficient processing, please include the *Medical Release Form* with the *Questionnaire*.

Next, complete the additional forms contained in this brochure. The *Research Consent Form* should be completed, signed by the legal next-of-kin, and placed in the patient's chart or medical files. This form must go with the body for the tissue harvest. The *Autopsy Information Form* should also be completed as much as possible by the family and will also go with the body. The pathologist will complete the *Autopsy Information Form* and should send it to the Mayo Clinic along with the tissue. The *Medical Release Form* should be completed by the family. This form will authorize physicians who diagnosed and/or treated the patient's neurological disease to send copies of their clinical notes to the Mayo Clinic. Only the next-of-kin can authorize the release of these records, which are important to the Mayo Clinic's researchers as they design their research protocols.

The Brain Bank Coordinator can answer any questions about the donation process, assist in getting copies of the patient's medical records for use in ongoing research projects, and help locate a pathologist in your area to collect the tissue. Contact information for the Brain Bank is included in this brochure.

If the patient dies at home, in a nursing home or with hospice, the funeral home or crematorium will be involved in arrangements for the tissue donation. They are responsible for transporting the body to the location where the tissue will be collected.

At times the procedure can be performed at the funeral home or crematorium. In other cases, it may be necessary to transport the body to a hospital or medical examiner's office for the procedure.

If the patient dies in the hospital, be sure that the physician has placed an order in the patient's chart to have the tissue collected and sent to the Brain Bank. Generally, there is no charge for the collection in this situation. However, a small hospital may not be able to provide this service, which is another reason it is important to make these arrangements in advance. No matter what the circumstances at the time of death, it is necessary to have a pathologist or diener (a pathologist's assistant) in place to collect the tissue.

Locating a pathologist can be a difficult task. The Brain Bank has a list of autopsy resources around the country and is available to help you locate a professional in your area. A funeral director or the patient's neurologist may also be able to assist with this task. Occasionally, the medical examiner or coroner in your area will be able to do what is called a "private autopsy," one that is requested but not required by the circumstances of an unnatural or unexpected death. There are also autopsy services around the country that will travel to your location to perform the tissue collection. Prices for these services generally start around \$1,000 plus travel expenses, as opposed to the \$500 average when the procedure is performed by a local medical professional.

Once You Have Located a Pathologist...

The Brain Bank Coordinator is available to answer any questions you or the pathologist may have. The Coordinator will also work directly with the pathologist to ensure that the tissue arrives at the Mayo Clinic in a timely and safe manner.

Important paperwork is required to perform a legal tissue collection.

These forms are contained within this brochure.

Research Consent Form - Consent for Donation of Postmortem Brain. This document can be signed only by one of the following individuals, in this order: spouse, oldest adult child, parent, adult sibling, guardian or power-of-attorney. This document, with original signature, must accompany the deceased along with the *Autopsy Information Form* for the tissue collection to take place. The “Clinical Information” section should be completed by the family along with the “Sources for Further Information” section before the form is sent to the pathologist who will complete it.

The Medical Release Form may need to be copied because this form, with the next-of-kin’s original signature, must be sent to each doctor who has treated the patient for a neurodegenerative disease, and whose clinical records could provide assistance to the researchers at the Brain Bank. Call the Brain Bank at (904) 953-2439 if you have any questions.

Please make every effort to fill out all the forms in the brochure completely.

More About the Cost of Brain Tissue Donation

The cost of tissue collection is the responsibility of the family. The Brain Bank covers all other charges, including transporting the tissue to the Mayo Clinic, as well as all costs associated with performing the autopsy and any research projects using the tissue.

At CurePSP, we recognize the fact that the cost of the tissue collection can be prohibitive for some families. A generous donor has contributed funds to create the CurePSP Brain Tissue Donation Fund. This has allowed CurePSP to provide financial assistance of up to \$750 to families who wish to donate brain tissue but may have financial constraints. If your family needs assistance with the tissue collection costs, please call 800-457-4777, and ask to speak with a CurePSP staff person regarding the need for financial help.

Research Consent Form

*Consent for Donation of Postmortem Brain Tissue For Special Studies and Research Purposes.
This form must be completed by the family and should go with the body.*

Next-of-kin information

Full name: _____ Phone: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

Information on the facility from which body or brain is being sent

Organization name: _____

Name of contact person: _____ Phone: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

I, _____, am the _____ (list relationship to patient), and legal next-of-kin of _____ (patient's name) and in that capacity and as signer of this autopsy permit, I do hereby direct that postmortem brain tissue from the autopsy of the above-named patient be donated for special studies and research on PSP and related diseases.

Signed: _____ Date: _____

Signed: _____ Date: _____

Information for the Hospital Pathologist

Thank you for agreeing to perform an autopsy to establish a diagnosis and to obtain tissue for special studies and research. Please perform the autopsy as soon as possible after death, preferably within 12 hours (up to 24 hours is still acceptable). Split the brain right down the middle through the corpus callosum, cerebellar vermis and brainstem. Put the right hemisphere in a plastic bag into the coldest available deep freezer (preferably -70 C). In order to prevent distortion of 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 48 hours worth of dry ice in a Styrofoam shipping container. The formalin fixed specimen is wrapped in paper towels that are damp with formalin, put into a leak-proof plastic bag in a separate shipping container, wrapped separately from the frozen one. Both boxes (do not tie together) are sent by an agency that will deliver overnight, such as Federal Express or UPS. Federal Express will not accept COD packages so it must be prepaid, but we can reimburse you for this expense (call the Brain Bank directly for the FedEx account number). Both packages are sent to:

Dr. Dennis Dickson
Neuropathology Laboratory, Mayo Clinic Jacksonville
4500 San Pablo Road, Jacksonville, FL 32224
(904) 953-7137

Please send this material early in the week so as to avoid delivery during the weekend when no one will be here. Do not ship on Thursdays or Fridays. We will need a clinical history or a contact person from whom we can obtain clinical history. The time lapse between death and autopsy should be noted. This form and the Autopsy Information Form should be filled out and sent along with the tissue. We will send the report of our findings to you. We can also provide an extra set of slides, if desired. We are interested in other types of Parkinsonism and, of course, control brains as well, if they have been reasonably well worked up by the clinicians, especially where good psychometric studies have also been done. We will provide a letter and a copy of the report to next-of-kin regarding our findings.

Autopsy Information Form

The lower portion of this form must be completed by the family and should go with the body.

Patient's name: _____ Date of birth: _____

Your accession number: _____

Name of pathologist: _____ Phone: _____

Date of death: _____ Time of death: _____

Postmortem interval: _____ Fresh brain weight: _____

Body refrigerated? Yes No Temperature of freezer storing tissue: _____

Clinical information (optional)

Age of patient at onset: _____

Major signs and symptoms, neurological and other, with date when first noticed: _____

Drug therapy during last year: _____

Family medical history: _____

Sources for further information

Physician/neurologist

Name : _____ Phone: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

Nursing home

Name of contact person: _____ Phone: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

Next-of-kin

Name : _____ Phone: _____

Relationship to patient: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

Medical Release Form

Copies of this form should be sent to the doctor(s) who diagnosed or treated the patient.

I/we, _____
(name and relationship to patient)

and next-of-kin to _____, whose date of birth is _____

give permission to release a copy of the medical reports and/or records of above mentioned patient to Mayo Clinic Jacksonville. 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:

Dr. Dennis W. Dickson

Neuropathology Laboratory

Mayo Clinic Jacksonville

4500 San Pablo Road Jacksonville, FL 32224

Signature of patient or person authorized to consent for patient

Relationship to patient

Witnessed by (name and title)

Relationship to patient

CurePSP Brain Bank Questionnaire

This form must be completed by the family and sent to the CurePSP Brain Bank.

Name of PSP, CBD or MSA patient: _____ Date of birth: _____

Name of person(s) providing the information below: _____

Relationship to patient: _____

Address: _____

City: _____ State/Province: _____ ZIP/postal code: _____ Country: _____

Phone: _____ Email address: _____

It is necessary to have certain information to advance our research. We need to know in detail the following, as best as you can provide it. It may be helpful for the entire family to participate in piecing together this important summary. The information should be as complete as possible. Use extra pages if necessary.

Please fax or mail the completed form to us at: **Eloise H. Troxel Memorial Brain Bank**

Mayo Clinic Jacksonville
4500 San Pablo Road
Jacksonville, Florida 32224
Fax: (904) 953-7117

1. Current Diagnosis: _____

2. Age at onset of symptoms: _____

3. Is there a family history of PSP, CBD, MSA, FTD, ALS, CTE or Parkinson's disease? _____

4. What were the symptoms in the early stages? _____

5. Was the progression of the illness rapid? _____

6. Check any of the following that were present: How many years? _____

- | | |
|---|---|
| <input type="checkbox"/> Disorientation | <input type="checkbox"/> Weight Loss |
| <input type="checkbox"/> Tremors | <input type="checkbox"/> Delusions |
| <input type="checkbox"/> Fluctuating Course | <input type="checkbox"/> Hallucinations |
| <input type="checkbox"/> Wandering | <input type="checkbox"/> Difficulty Walking |
| <input type="checkbox"/> Visual Problems | <input type="checkbox"/> Eating Disorder |
| <input type="checkbox"/> Agitation | <input type="checkbox"/> Sleep Disorder |
| <input type="checkbox"/> Stiffness | <input type="checkbox"/> Falls |
| <input type="checkbox"/> Violent Outbursts | |

7. Personality changes (describe): _____

8. Other Noteworthy Symptoms (please list): _____

9. Was the patient right or left handed? Right Left

10. Did a neurologist evaluate the patient? A psychologist? A psychiatrist? _____

11. Was a CT scan or MRI performed? _____

12. If yes, what did the report show? _____

13. What kind of work did the patient do? _____

14. Did the patient have any other medical issues? _____

15. What medications did the patient take? _____

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curePSP[®]

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30 E. Padonia Road
Suite 201
Timonium, MD 21093

Tel: 410-785-7004
Toll-Free: 800-457-4777
Canada: 866-457-4777
Fax: 410-785-7009