

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 at the Mayo Clinic
Jacksonville, Florida

A Diagnostic Service for Families
A Research Resource for Scientists
2017 Edition



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 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.

Preparing for Your Brain Donation

Thank you for considering a brain donation to the Eloise H. Troxel Memorial Brain Bank hosted by the Mayo Clinic in Jacksonville, Florida. CurePSP's Brain Tissue Donation Program started in 1998 and has been with the Mayo Clinic ever since. At the Mayo Clinic, Dr. Dennis Dickson oversees the operations of the brain bank. Dr. Dickson is a



world-renowned scientist and pathologist who is very experienced in the field of prime of life brain diseases and diagnosing PSP, CBD, MSA, FTD, ALS, and CTE as well as many other neurodegenerative diseases.

Brain donations are an extremely valuable resource for science and for developing future therapeutic interventions for all neurodegenerative disorders including Alzheimer's and Parkinson's disease. Researchers from all over the world benefit from brain donations to the Mayo Clinic as Dr. Dickson collaborates with many national and international scientists. By donating a brain to the Brain Bank, you create your own legacy in science that could be part of a future therapy. After the tissue collection, the next-of-kin will receive a comprehensive autopsy report that often offers closure after many years of suffering and caring for a loved one.

Once again, I would like to thank you for considering a brain donation. If you have any further questions, please do not hesitate to contact me or the brain bank coordinator, Rachel R. LaPaille-Harwood (see contact details below).

Dr. Alex Klein

Vice President - Scientific Affairs

Phone: +1 (347) 294-2872

Email: klein@curepsp.org

For questions about making advance arrangements for a brain donation, please contact the Brain Bank at the Mayo Clinic:

Rachel R. LaPaille-Harwood

Brain Bank Coordinator at the Mayo Clinic, Jacksonville, FL

Phone: +1 (904) 953-2439, Monday-Friday, 8 am to 4:30 pm (Eastern time)

E-Mail: LaPaille-Harwood.Rachel@mayo.edu Fax: +1 (904) 953-7117

Questions and Answers

Q. Why Make Your Decision in Advance?

A. For several reasons, CurePSP urges you to prepare all arrangements for a brain donation in advance. Your loved one can die suddenly, which is extremely stressful. A decision may have been made to donate the brain; however, without making prior arrangements, it is possible that the donation will not occur. The 24-hour window to perform the brain donation after death 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 brain donation, research efforts are aided by getting copies of your loved one's medical records showing the progression of the disease. These records will be correlated with the autopsy results; hence 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.*

Q. Who may authorize a brain donation?

A. Legally, the patient and/or next-of-kin are the persons to sign the Autopsy & 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 or organ donation?

A. No. In most instances where these diseases are suspected, only brain tissue will need to be examined for diagnosis.

Q. Where is the brain donation performed?

A. If death occurs in a hospital, the 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.

Questions and Answers

Q. Will it be visibly noticeable that the brain has been removed?

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

Q. How do I find a pathologist who will perform the brain donation?

A. Please contact the Brain Bank Coordinator, Rachel R. LaPaille-Harwood, at LaPaille-Harwood.Rachel@mayo.edu or at +1 (904) 953-2439. The Brain Bank has a list of pathologists in the U.S. and Canada and is available to help you locate a professional in your area. You can also ask a funeral director or the patient's neurologists.

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

A. While clinical diagnosis has been greatly advanced, there is no way to confirm a diagnosis for most of these diseases other than by examining brain tissue. That is why your brain donation provides invaluable material for developing less invasive diagnostic tests in the future, such as blood tests or brain scans that can be carried out during the lifetime of a patient.

Q. How long does it take for the autopsy report to be released?

A. Please allow up to 90 days for receiving the results of the autopsy. The report will be sent to the person who is listed as next-of-kin.

Q. I don't have any known brain disease; can I still donate my brain?

A. Yes, the Mayo Clinic Brain Bank actively searches for healthy brains that serve as valuable control brains in research studies. It is very important to compare pathological changes in diseased brains with healthy brains; this helps the scientists to better understand disease processes and consequently to develop novel therapeutic strategies. Please contact the Mayo Clinic Brain Bank for more information on healthy brain donation. Please note that CurePSP cannot provide financial assistance for the donation of healthy brains. If you have any questions, please do not hesitate to contact Dr. Alex Klein, Vice President - Scientific Affairs at CurePSP, at klein@curepsp.org or +1 (347) 294-2872.

Q. How do I contact the Brain Bank?

A. For all inquiries with regard to the brain donation, please contact

Rachel R. LaPaille-Harwood

Brain Bank Coordinator at the Mayo Clinic in Jacksonville, FL

Phone: +1 (904) 953-2439, Monday-Friday, 8 am to 4:30 pm (Eastern time)

E-Mail: LaPaille-Harwood.Rachel@mayo.edu

Fax: +1 (904) 953-7117

Weekend and after-office-hours voicemail messages will be returned the next business day.

Next Steps

After Your Decision to Donate Has Been Made

Important paperwork is required to perform a legal tissue collection. Please follow the guidelines below and complete all four forms that are contained within this brochure. You can also download the forms and this brochure at www.psp.org/brain-donation.

STEP 1: Please contact the Brain Bank Coordinator, Rachel R. LaPaille-Harwood. She will help you understand the next steps and procedures.

Phone: +1 (904) 953-2439, Monday-Friday, 8 am to 4:30 pm (Eastern time)

E-Mail: LaPaille-Harwood.Rachel@mayo.edu

STEP 2: Enroll in the Brain Bank by completing the **Brain Bank Questionnaire** and mailing, faxing or e-mailing it to the Brain Bank ahead of time. It is important to have this information on record once the brain arrives at the Mayo Clinic. It also helps to facilitate the process of the autopsy.

STEP 3: The **Medical Release Form** authorizes physicians who diagnosed and/or treated the patient's neurological disease to send copies of their clinical notes to the Mayo Clinic. Only the patient or the next-of-kin can authorize the release of these records, which are important to the Mayo Clinic's researchers. Please send copies of this form to all physicians and neurologists (1) who are listed on the **Autopsy & Research Consent Form**, (2) who have treated the patient for a neurodegenerative disease, and (3) whose clinical records could provide assistance to the researchers at the Brain Bank.

STEP 4: Complete the **Autopsy Information Form**. *Make sure to have it placed in the patient's chart or medical files.* The pathologist will sign and send the form along with brain tissue to the Mayo Clinic Brain Bank.

STEP 5: Complete the **Autopsy & Research Consent Form**, signed by the patient and/or next-of-kin. *Make sure to have it placed in the patient's chart or medical files.* This is the actual consent for donation of a post-mortem brain. This form can be signed only by the following individuals in this order: the patient, spouse, oldest adult child, parent, adult sibling, guardian or power-of-attorney. **The Autopsy & Research Consent Form**, with original signature(s), must accompany the deceased along with the Autopsy Information Form for the tissue collection to take place. **Without a fully signed Autopsy & Research Consent Form, no brain donation is possible.**

STEP 6: At the time of death, all family members and healthcare professionals need to know of the patient's wish to donate his or her brain. Please make sure that you have the pathologist's contact details available, so that he or she can be contacted immediately.

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. 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. Please note that extra costs might occur in case transportation of the body is necessary.

Next Steps

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 Mayo Clinic Brain Bank.

Please note that it is required to have a pathologist or diener (a pathologist's assistant) in place to collect the tissue. Please remember that the brain tissue can only be harvested within 24 hours after death.

Locating a Pathologist

Locating a pathologist can be a difficult task. Please contact Rachel R. LaPaille-Harwood, who is the Brain Bank Coordinator, at +1 (904) 953-2439 (Monday-Friday, 8 am to 4:30 pm Eastern time) or at *LaPaille-Harwood.Rachel@mayo.edu*. The Brain Bank has a list of autopsy resources around the country and is available to help you locate a professional in your area. Please note, CurePSP does not provide a pathologist finder service.

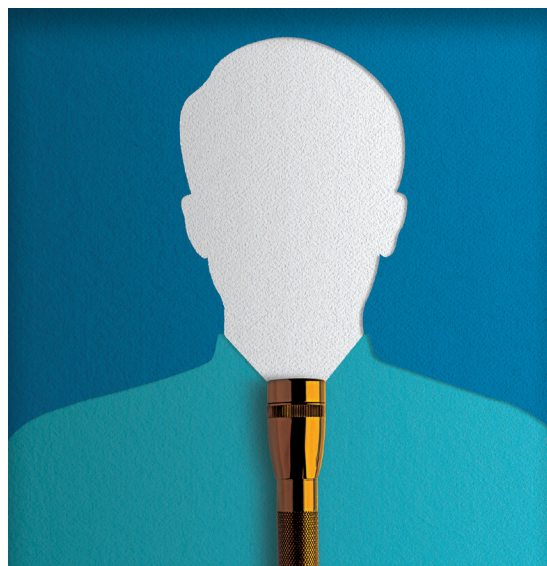
The Brain Bank Coordinator is available to answer any questions you or the pathologist may have. The Coordinator will also work directly with the pathologist to ensure that the tissue arrives at the Mayo Clinic in a timely and safe manner.

If you have any questions with regard to the process of a brain donation, please call or contact Rachel R. LaPaille-Harwood, Brain Bank Coordinator at the Mayo Clinic. Her full contact details can be found on page 3.

Cost of Brain Tissue Donation

The cost of a brain donation (i.e., the cost for the pathologist and – if necessary – for transportation) is the responsibility of the family. The Brain Bank covers all other charges, including shipping the brain 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 brain donation 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 or e-mail our Vice President - Scientific Affairs, Dr. Alex Klein, at +1 (347) 294 2872 or klein@curepsp.org.



Brain Bank Questionnaire

This form must be completed by the family and sent to the Brain Bank ahead of time.

Please mail, e-mail, or fax this form to:

Rachel R. LaPaille-Harwood

Brain Bank Coordinator at the Mayo Clinic Jacksonville, FL
Neuropathology Lab; Mayo Clinic Jacksonville

4500 San Pablo Road; Jacksonville, FL 32224

E-mail: LaPaille-Harwood.Rachel@mayo.edu; Fax: (904) 953-7117

Name of patient: _____ Date of birth: _____

Name of next-of-kin: _____

Relationship to patient: _____

Address (of next-of-kin): _____

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.

1. Current diagnosis: _____

2. Age at onset of symptoms: _____

3. Is there a family history of PSP, CBD, MSA, FTD, ALS, CTE, Parkinson's or Alzheimer's disease, or any other form of movement disorder or dementia? _____

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. For how many years? _____

___ Disorientation

___ Tremors

___ Wandering

___ Visual problems

___ Agitation

___ Stiffness

___ Violent outbursts

___ Weight loss

___ Delusions

___ Hallucinations

___ Difficulty walking

___ Eating disorder

___ Sleep disorder

___ Falls

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? If yes, when, how often and where was it performed?

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? _____

Medical Release Form

Copies of this form should be sent to the doctor(s) who diagnosed or treated the patient and who are listed on the Autopsy Information Form

I _____ (name of patient), _____ (date of birth)
and/or the patient's next-of-kin _____
Relationship to patient _____ give permission to release a copy of the medical reports
and/or records of the patient to Mayo Clinic Jacksonville. Please include history, medical and neurologi-
cal 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

Date

Signature of next-of-kin/witness
(if no next-of-kin was chosen, a witness can sign this release form)

Date

For further information and support, please contact the Brain Bank Coordinator:

Rachel R. LaPaille-Harwood

Phone: +1 (904) 953-2439, Monday-Friday, 8 am to 4:30 pm (Eastern time)

E-Mail: LaPaille-Harwood.Rachel@mayo.edu

Fax: +1 (904) 953-7117

Contact information of next-of-kin/witness

Full name of next-of-kin/witness: _____

Relationship to patient: _____

Address: _____

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

Phone: _____ Email address: _____

Autopsy Information Form

This form must be completed by the family and should go with the body to the pathologist who will sign and finalize it.

Patient's name: _____ Date of birth: _____

Your accession number: _____

Name of pathologist: _____

Phone: _____ Email: _____

Date of death: _____ Time of death: _____

Postmortem interval: _____ Fresh brain weight: _____

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

Signature of pathologist:

Date

Clinical information

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: _____

Information for the 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

Phone: +1 (904) 953-7137

Please send this material early in the week to avoid delivery during the weekend. 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. The Autopsy Information Form and the Autopsy & Research Consent 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 & 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.*

Name of Patient: _____

Next-of-kin information

Name of next-of-kin: _____

Relationship to patient: _____

Address: _____

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

Phone: _____ Email: _____

Pathologist Information

Full name: _____

Facility/Company: _____

Address: _____

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

Phone: _____ Email: _____

Autopsy Permit

I _____ (name of patient), _____ (date of birth)
and (optionally) the patient's next-of-kin _____ (name of next-of-kin),
_____ (relationship to patient) and in that capacity and as signer of this autopsy permit, I/we 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.

Signature of patient *Date*

Signature of next-of-kin *Date*

*To obtain medical records, please provide the following (as applicable; please list all healthcare professionals
who hold medical records of the patient and who have received the Medical Release Form.
Please add pages if necessary).*

Name of most recent physician/neurologist

Full name: _____ Facility/Hospital: _____

Address: _____

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

Phone: _____ Email: _____

Nursing home

Full name: _____ Facility/Company: _____

Address: _____

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

Phone: _____ Email: _____

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UNLOCKING THE SECRETS OF BRAIN DISEASE™

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Secrets of Brain Disease, and Because Hope
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