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
2020 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. A brain bank at the Mayo Clinic in Jacksonville, Florida, one of the leading such facilities in the world, is supported in part by CurePSP, which provided the initial impetus for the brain bank’s founding in 1998.

The final autopsy report from the brain bank provides the authoritative diagnosis as well as information about other brain changes that may exist, including those that may have contributed to a clinical misdiagnosis. The Brain Bank provides tissue samples to reputable scientists worldwide for investigation into the genetics and other aspects of the causes of neurodegeneration. Of course, the donor’s name or other identifying information is removed before the tissue is shared outside of the Mayo Clinic. After a few weeks, 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. The Brain Bank does not charge the family for its services. Neither does it require payment from researchers to whom it supplies brain tissue.
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 and his team oversee the operations of the brain bank.

Dr. Dickson is a world-renowned neuroscientist. He’s a thought leader and experienced researcher in the field of prime of life brain diseases. He’s an expert neuropathologist and has advanced the field in diagnosing PSP, CBD, MSA, FTD, ALS, and CTE as well as many other neurodegenerative diseases.

Brain donations are an extremely valuable resource and represent the ultimate gift for science and the development of future cures and treatments 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 hundreds of national and international scientists. By donating a brain to the Brain Bank, you create your own legacy in science. By donating a brain to the Brain Bank, you enable studies that would otherwise be impossible to conduct. Ultimately, you bring to life possible breakthroughs. Importantly, after the donation, the next-of-kin will receive a comprehensive autopsy report that can offer closure and a path to heal after many years of suffering and caring for a loved one.

A sincere 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, Ms. Rachel LaPaille-Harwood (see contact details below).

Dr. Kristophe Diaz
Vice President - Scientific Affairs
Phone: +1 (347)-394-1652
Email: diaz@curepsp.org

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

Rachel LaPaille-Harwood
Brain Bank Coordinator at the Mayo Clinic, Jacksonville, FL
Phone: 904-953-2439, Monday-Friday, 8:00 a.m. to 3:00 p.m. (U.S. Eastern Time).
Email: lapaille-harwood.rachel@mayo.edu
**Q. Why Make Your Decision in Advance?**

A. For several reasons: 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. Ideally, there’s a 24-hour window to perform the brain donation after death (48 hours is also acceptable). This 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 (48 hours is not recommended but acceptable). 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?**

Legally, the patient and/or next-of-kin are the people who sign the Autopsy & Research Consent Form (available in our brochure).

If the patient’s spouse is deceased, the oldest child is considered next-of-kin. In some states, the patient or next-of-kin may sign the consent form prior to death. In other states, consent 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, and if the attending physician has ordered the procedure, the tissue collection will likely be performed in that hospital.

If death takes place in a nursing home, hospice, or at home, then 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, the funeral home may charge for transport.

**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 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 Mayo Clinic Brain Bank coordinator, Rachel LaPaille-Harwood, at lapaille-harwood.rachel@mayo.edu or 904-953-2439. The Brain Bank has a list of pathologists in the U.S. and Canada to help you locate a professional in your area. You can also ask a funeral director or the patient’s neurologist.

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.

Q. How long does it take for the autopsy report to be released?
A. Please allow 90-120 days from the time we have both the tissue and the patient’s medical records on site. The final 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. These serve as valuable control brains in research studies. It is very important to compare pathological changes in diseased brains with healthy brains. This helps scientists to better understand disease processes and 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, you may contact Kristophe Diaz, PhD at CurePSP, at diaz@curepsp.org or (347)-394-1652.

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. You can download the forms from www.psp.org/meedsupport/braindonation, Or you may contact Joanna Teters at teters@curepsp.org or 347-294-2871, and we will send you a printed copy of the forms.

Q. How do I contact the Brain Bank?
A. For all inquiries with regard to the brain donation, please contact

Rachel LaPaille-Harwood
Brain Bank Coordinator at the Mayo Clinic, Jacksonville, FL,
Phone: 904-953-2439, Monday-Friday, 8:00 a.m. to 3:00 p.m. (U.S. Eastern Time).
Email: lapaille-harwood.rachel@mayo.edu

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

After Your Decision to Donate Has Been Made

1. Contact the Brain Bank coordinator, Rachel LaPaille-Harwood, who will help you understand the next steps and procedures. Phone: 904-953-2439, Monday–Friday, 8:00 a.m. to 3:00 p.m. (U.S. Eastern Time). Email: lapaille-harwood.rachel@mayo.edu

2. Enroll in the Brain Bank by completing the Brain Bank Questionnaire (in the above-mentioned brochure) and mailing, faxing, or emailing it to the Brain Bank ahead of time. It is important that this information be on record once the brain arrives at the Mayo Clinic.

3. Please send copies of the Medical Release Form to all of the following physicians and neurologists:
   a. Those who are listed on the Autopsy & Research Consent Form
   b. Those who have treated the patient for a neurodegenerative disease
   c. Those whose clinical records could assist the researchers at the Brain Bank

4. 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.

5. 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 the brain tissue, to the Mayo Clinic Brain Bank.

6. 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 postmortem brain. This form can be signed only by the following individuals, and in this order of preference: patient, spouse, oldest adult child, parent, adult sibling, guardian, or power-of-attorney. For tissue collection to occur, the Autopsy & Research Consent Form, with original signature(s), and the Autopsy Information Form must accompany the deceased. Without a fully signed Autopsy & Research Consent Form, no brain donation is possible.

7. At the time of death, all family members and healthcare professionals need to know of the patient’s wish to donate their brain. Please make sure that you have the pathologist’s contact details available, so that they 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.

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. 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. We emphasize that the most difficult step in this process is to identify someone nearby who is willing and able to remove, prepare, and ship the brain quickly after death. This is the most important reason to make arrangements in advance.
Next Steps

**Locating a Pathologist**

Locating a pathologist can be a difficult task. Please contact Rachel LaPaille-Harwood, Brain Bank Coordinator at the Mayo Clinic, Jacksonville, FL, Phone: 904-953-2439, Monday-Friday, 8:00 a.m. to 3:00 p.m. (U.S. Eastern Time). Email: 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 LaPaille-Harwood, Brain Bank Coordinator at the Mayo Clinic. Her full contact details can be found on page 3.

**Cost of Brain Tissue Donation**

Neither CurePSP nor the Mayo Clinic imposes a charge for any part of the brain donation process. However, charges are typically imposed by the technician removing, preparing, and shipping the brain, and the funeral home that transports the deceased and provides a facility for brain removal. This cost typically ranges from $500 to $2,000 and is the responsibility of the family.

At CurePSP, we recognize that the expenses 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 contact Joanna Teters at 347-294-2871 or teters@curepsp.org. We emphasize that this program has limited resources and is intended only for families whose financial situation would not otherwise allow brain donation to occur.
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  
Mayo Clinic Brain Bank Coordinator  
4500 San Pablo Road  
Birdsall Building, Room 310  
Jacksonville, FL 32224  
Email: lapaille-harwood.rachel@mayo.edu  
Phone: 904-953-2439

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  ____ Weight loss
____ Tremors  ____ Delusions
____ Wandering  ____ Hallucinations
____ Visual problems  ____ Difficulty walking
____ Agitation  ____ Eating disorder
____ Stiffness  ____ Sleep disorder
____ Violent outbursts  ____ Falls

7. Personality changes (describe): _____________________________________________________________________

___________________________________________________________________________________________________

8. Other noteworthy symptoms (please list): __________________________________________________________________

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


11. Was a CT scan or MRI performed? If yes, when, how often and where was it performed?  
What did the report show? ___________________________________________________________________

12. _______________________________

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 ____________________________ 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 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
c/o Rachel R LaPaille-Harwood
Mayo Clinic Brain Bank Program
4500 San Pablo Road
Birdsall Building, Room 310
Jacksonville, FL 32224

_________________________________________________  __________________________
Signature of patient                                                                                                         Date

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

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

Rachel LaPaille-Harwood
Phone: 904-953-2439, Monday-Friday, 8:00 a.m. to 3:00 p.m. (Eastern time)
Email: 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 48 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:
Dickson Lab
4500 San Pablo Road
Birdsall Building, Room 347
Jacksonville, FL 32224
Phone: +1 (904) 953-2439

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.
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: _____________________________________________