

# Brain Donation Assistance Program



A diagnostic service for families.  
A contribution to science, leading  
a path toward a cure.

**National support for brain tissue donation  
for people diagnosed with:**

*Progressive supranuclear palsy (PSP)*

*Corticobasal degeneration/syndrome (CBD/CBS)*

*Multiple system atrophy (MSA)*

*Frontotemporal dementia with parkinsonism (FTDP)*

In partnership with the  
**Brain Bank at the Mayo Clinic,  
Jacksonville, Florida**

*“It felt like closing the loop on what we went through with the disease.  
It was a powerful part of his legacy and connected all of the dots, and  
that made my heart full.”*

*- Diane, whose husband chose to donate his brain*

# About the CurePSP Brain Donation Assistance Program

Thank you for considering a brain donation through the CurePSP Brain Donation Assistance Program.

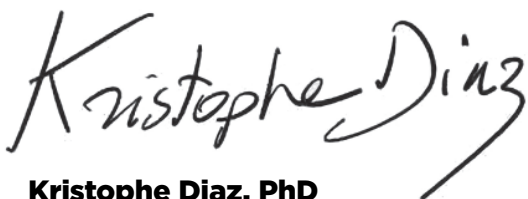
CurePSP is dedicated to our mission to raise awareness, build community, improve care, and find a cure for progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), multiple system atrophy (MSA), and related neurodegenerative diseases. The vision of CurePSP is a world free of neurodegeneration, so that future generations will not have to experience the complicated care and emotional journeys of these diseases. The study of brain tissue is critical in the path toward this goal. Since the founding of CurePSP's Brain Donation Assistance Program in 1998, we have proudly supported the donation of hundreds of brains. These donations have enabled leading scientists all over the world to advance important knowledge in prime of life neurodegenerative disorders.

Brain donations are a precious gift for science, establishing a long-term legacy of scientific progress that otherwise would not be possible. Brain tissue donated through this program is carefully studied by researchers working hard to understand human neurobiology and the causes of neurodegeneration. Brain donations have led, and will lead, to breakthroughs in science and the development of treatments and—ultimately—cures for PSP, CBD, MSA, and related diseases.

Importantly, after the donation, the next of kin will receive a comprehensive report that outlines the confirmed pathological diagnosis, as well as other possible contributing or coincidental pathologic processes. Many families who have participated in this program have shared with us that this report offered them answers and a step toward closure after many years of navigating a complicated disease journey and caring for their loved one.

By donating your brain, you build the most powerful legacy for yourself, your family, and science, as well as hope for others affected by neurodegenerative disorders. I want to share my sincere appreciation for your consideration of participating in the CurePSP Brain Donation Assistance Program. Please do not hesitate to reach out to the CurePSP team if we can be of any assistance or support as you navigate the process of brain donation.

Because hope matters,



**Kristophe Diaz, PhD**

Executive Director and Chief Science Officer  
CurePSP, Inc.



# Answers to Frequently Asked Questions

## **At what point after the diagnosis should the decision be made to pursue brain donation?**

Once a family has decided to move forward, it is important to set up a brain donation *as far in advance as possible*. Plans can be made months or even several years before someone is in more advanced stages of disease or approaching end of life. Sometimes, a family will choose brain donation as the person is in the final stages of the disease process when death is imminent, and this time frame can cause stress and logistical complications during an already emotional time. There are several reasons why it is best to plan brain donation as early as possible:

- It is ideal if the person with the neurodegenerative disorder is involved in the decision to donate their brain. Because of possible changes to cognition and speech, this can be more challenging as the disease progresses. Therefore, we recommend discussing brain donation with your partner or other family members to let them know of your interest and to participate in the decision and the process.
- An essential part of the donation process is identifying a person or agency to perform the procedure to collect the brain tissue, referred to as the “brain tissue procurement,” and shipment of the brain tissue to the brain bank. The neuropathology program coordinator at the Mayo Clinic Brain Bank can provide you with options for pathologists they have worked with in the past, but it is still important to confirm that the person is able and willing to do the procedure and to talk through the process, preparation, and possible cost ahead of time.
- There are several other steps to setting up a brain donation, including sending paperwork to the brain bank beforehand and arranging transportation and other services after the brain donation is complete (e.g., body donation, cremation, funeral service).
- Medical records are essential in interpreting brain findings by the brain bank neuropathologist. Therefore, as early as possible, the medical records release form (page 12) should be sent to the physicians who have evaluated the patient. This could include a neurologist, psychologist, or radiologist. Either hard copies or digital copies of the records are acceptable and should be sent to the brain bank.
- When someone passes away, there is a short time frame in which the brain tissue needs to be removed. Ideally, this time frame is 12–24 hours, but up to 48 hours is acceptable if a body has been kept in cold storage. This process takes coordination between the family, hospice (if hospice is involved), the mortuary service, and the pathologist and can be more complicated if someone passes away in the middle of the night or over a weekend or holiday.

These steps can take time and can bring up a number of questions; however, once they have been completed, patients and families have the peace of mind that the process is in place. The prearrangements are not legally binding, and the family can always change their mind at any point and for any reason. The family can then focus their time and energy on care, emotional health, relationships, and other needs. For these reasons, it is important to talk about, decide on, and set up brain donation early.

# Questions and Answers

## **Who may authorize a brain donation?**

Legally, the patient and/or healthcare power of attorney/next of kin can sign the Autopsy & Research Consent Form (page 13). If the patient does not have a spouse, the oldest child is considered next of kin, followed by the next closest blood relative. If there are no blood relatives, a witness can sign the form and must note the relationship. The patient or healthcare power of attorney/next of kin may sign the consent form prior to death, but in most circumstances, it is not legally binding and often requires confirmation (verbal or written) after death. You may wish to research your local state laws on these details. The person performing the brain tissue procurement may require their own additional consent/authorization documentation.

## **Can I donate other tissues?**

Currently, brain tissue is most important for the pathological study of neurodegenerative diseases and for providing a confirmed diagnosis to families. Still, some people who donate their brains also choose to donate other parts of the body (for example, spinal cord or even the entire body). This type of donation would need to be set up through a different program, as CurePSP and Mayo Clinic are only able to support brain donation. Local medical schools and teaching hospitals or a program like the Anatomy Gifts Registry ([www.anatomygifts.org](http://www.anatomygifts.org)) can often offer body donation programs and assist with the process. Some body donation programs will not take a body if a brain has been removed, and we recommend inquiring about program details, as well as other eligibility criteria and steps for body donation, if it is something you are considering.

Note that the donation of brains to science is different from organ donation, which is for the donation of healthy organs to be used in living people (organ transplants). You can be an organ donor, if you and your organs would be eligible for donation and use at the time, and then still donate your brain to science. The logistics for donating both your organs and your brain are more complicated, and we recommend discussing these plans with your family and healthcare team.

## **I do not have a known brain disease. Can I also donate my brain?**

Brain banks are also in need of healthy brains to serve as valuable control brains in research studies. It is very important to compare pathological changes in diseased brains with healthy brains. It 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. There are other programs that will take donations of healthy control brains, including the Brain Donor Project through the National Institutes of Health. *Please note that, at this time, CurePSP cannot provide financial assistance for the donation of healthy brains.*

## **Will it be visibly noticeable that brain donation has been performed?**

In most cases, only on very close inspection would anyone notice that a brain tissue donation has been performed. The exception would be if the person is bald, but most funeral directors have the skills to cosmetically conceal the incision in the scalp. In most cases, the family can have an open casket service and those viewing the body would not be able to see the scalp incision.

## **Where is the brain donation performed?**

If someone passes away in a hospital and if the attending physician has ordered the procedure, then the tissue collection will likely be performed in that hospital. Many people die in their home or in a hospice or long-term care facility. If that is the case, the person's body will need to be transported to the place where

the brain tissue removal will occur. This location depends on who you have set up to perform the tissue procurement and may be at a hospital, medical examiner office, funeral home, or other mortuary service. This means that you will also have to arrange for body transportation through a funeral home or mortuary transportation company.

### **Who performs the brain tissue procurement, and how do I locate them?**

A pathologist or diener (someone who works with or assists pathologists) will collect the brain tissue and ship it. Please contact the Mayo Clinic neuropathology program coordinator, Rachel LaPaille-Harwood, at 904-953-2439 or [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu). The Brain Bank maintains a list of pathologists and dieners in the U.S. and parts of Canada with whom they have worked in the past. You can also ask a funeral director or the patient's neurologist if they can recommend someone, or directly contact the pathology department at your nearby hospital or the medical examiner/coroner to see if they would be able and willing to perform the tissue procurement. Currently, CurePSP is unable to assist in this step of the process.

### **Is there a cost associated with brain donation?**

The Mayo Clinic Brain Bank does not charge for neuropathologic evaluation, including generating a neuropathology report. However, it is possible that the pathologist or diener will charge for their services in removing, preparing, and shipping the brain tissue. This cost typically ranges from \$500 to \$2,000 and is the responsibility of the family. Additionally, a funeral home or mortuary service may impose a fee for transportation of the deceased and/or for the provision of cold storage (in addition to other services you may choose to hire them for, such as embalming, cremation, or burial).

At CurePSP, we recognize that the expenses of brain donation can be prohibitive for some families. Because of this, and thanks to the generosity of many individual supporters, CurePSP is able to offer reimbursement up to \$1,000 for expenses incurred related to brain donation (e.g., pathologist/diener fee, fees for cold storage/facility/transportation for the purposes of brain donation). If you have questions related to reimbursement of brain donation expenses, please contact Joanna Teters at 347-294-2871 or [teters@curepsp.org](mailto:teters@curepsp.org).

### **How long does it take for my family to receive the neuropathology report?**

Please allow two to four months from the time the Mayo Clinic Brain Bank has received the tissue and the patient's medical records. The final report is sent to the person who did the brain tissue procurement, and a copy is mailed to the person who had legal authority to grant the brain donation, most often the next of kin. This information, including mailing address, should be provided on the CurePSP brain bank questionnaire.

### **How will the brain tissue be used? And will my identity be kept confidential?**

The Mayo Clinic Brain Bank collaborates with many national and international scientists who use human brain tissue as part of their research. The brain bank does not require payment from researchers to whom it supplies brain tissue. Researchers use brain tissue to understand the pathology of neurodegenerative disorders and their relationship to clinical features. Sometimes brain tissue is accompanied by clinical information in which the patient's identity has been withheld. The clinical information that researchers receive is from notes sent from the neurologist as well as from information you supply in the brain donation form. The name of the donor and any other identifying information is not shared outside of the brain bank or in any resulting publications.

# Steps for Brain Donation

## **I have decided to donate my (or my family member's) brain. What are the next steps?**

### **1. Enroll in the CurePSP Brain Donation Assistance Program as far in advance as possible by completing the attached documents and follow the directions outlined at the top of each page.**

- Mail, email, or fax pages 9-14 (page 15 is optional) to the Mayo Clinic Brain Bank:

Rachel LaPaille-Harwood, Neuropathology Program Coordinator  
Mayo Clinic  
4500 San Pablo Road  
Birdsall Building, Room 310  
Jacksonville, FL 32224  
Email: [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu)  
Phone: 904-953-2439  
Fax: 904-953-7117

- Additionally, you should share page 12 (the Medical Release form) with the patient's neurologist or physician of record so that they may send relevant medical notes to the Mayo Clinic. It is preferred that this step is done in advance while the patient is still alive. Please be aware that if you are requesting records after the patient has passed, facilities may require additional documentation, such as a copy of the death certificate or court documents showing who is the legal executor of the estate.
- Keep all copies in a safe and easily accessible location.

### **2. As detailed in the "Questions and Answers" section, contact Rachel LaPaille-Harwood of the Mayo Clinic Brain Bank at [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu) or 904-953-2439, to confirm receipt of documents and to obtain information on pathologists/dieners in your area.**

### **3. Once you have been provided information of pathologists/dieners, reach out to them to discuss the following:**

- Explain the brain donation program/process and inquire if they would be able and willing to perform the brain tissue procurement and shipment.
  - If they have questions regarding the tissue procurement and shipment, or the protocol for these steps, direct them to page 14 of this packet (which they will also receive at the time of brain donation) and suggest they speak directly with the Mayo Clinic Brain Bank.
- Inquire about:
  - Their fee, as well as their payment process. Ask if there are hours they do not work or if their fee will change depending on the time of day or day of the week.
  - Direct contact information for who to call at the time of death.
  - The location of where they are able to perform the brain tissue procurement.

- If they need anything from you at this time. For example, they may just want the patient’s name and date of birth to save in a file for future cases, or they may want copies of pages 9-14 in this packet. They may have their own paperwork for you to complete.
- Anything else you need to be aware of regarding their process now and at time of death.

#### **4. If you have arranged for mortuary service (e.g., funeral home, crematorium), inform them of the brain donation process.**

- If the pathologist needs a space to perform the brain tissue procurement, you can inquire with the funeral service if there is the possibility of using their space. If so, inquire if they would charge an additional fee for utilization of their space. If necessary, put the funeral service and the pathologist in touch to discuss this process further.
- Explain that the brain tissue procurement must occur within 12–48 hours of death and that up until the procedure, the body must be kept in cold storage. Cold storage before brain tissue procurement may be needed if the pathologist is not available immediately. Inquire if there is a cost associated with this service.
- Additionally, explain that the person’s body will need to be transported from the place of death to the place of the procedure (unless it is out of the mortuary service’s space) and then to the mortuary service. Inquire if there is a cost associated with this transportation service.
- If you have prearranged for body donation, make sure to inform them as well.

#### **5. Inform involved partners, family members, and healthcare professionals of your wish to donate your brain and the process.**

- If the person resides in a long-term care facility or is under hospice care, these teams should be informed of your decision and the process to coordinate brain donation.
- Confirm that involved family members and/or healthcare professionals have a copy or are aware of the location of the brain donation paperwork. This information is especially important for pages 13 and 14, which must travel with the body to be completed by the pathologist and shipped with the brain tissue.
- Confirm that everyone is aware of who needs to be contacted at the time of death.

#### **6. At the time of death:**

- Contact the prearranged person who will be performing the brain tissue procurement, and contact the funeral home/mortuary service or body donation program, if applicable. Put the two entities in touch with one another to coordinate transportation and services.
- 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.
- *Important:* Page 13 (Consent Form for Autopsy & Donation) and page 14 (Autopsy Information Form) must travel with the body. The Autopsy Information Form will be completed by the pathologist. Both documents will be shipped with the brain tissue.

# Steps for Brain Donation

**7. Within two weeks after death, inform the person's neurologist and ask to send medical records to the Mayo Clinic Brain Bank if they had not been requested already and sent in advance.**

**8. After brain donation has occurred, if you wish to submit a request for reimbursement up to \$1,000 for expenses incurred related to brain donation (e.g., pathologist fee, fees for cold storage/facility/transportation for the purposes of brain donation), please contact Joanna Teters at 347-294-2871 or [teters@curepsp.org](mailto:teters@curepsp.org).**

**You are welcome to reach out to us with questions related to the CurePSP Brain Donation Assistance Program.**

We recognize that this multi-step process can seem daunting. Families frequently share with us that they gain peace of mind once the brain donation setup is behind them. Please know that you do not need to be alone in this process. Your family or healthcare team may be able to assist you, and the staff at CurePSP and the Mayo Clinic Brain Bank are here to offer support as much as possible.

- For questions related to the donation process, assistance in getting copies of the patient's medical records for use in ongoing research projects, and help locating a pathologist in your area to collect the tissue, please contact:

Rachel LaPaille-Harwood  
Mayo Clinic Neuropathology Program Coordinator  
Phone: 904-953-2439  
Email: [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu)

- For questions related to CurePSP, including this brain donation program, the diagnoses, or other support or educational resources:

Jessica Shurer, MSW, LCSW  
Director, Clinical Affairs and Advocacy, CurePSP  
Phone: 919-525-8355  
Email: [shurer@curepsp.org](mailto:shurer@curepsp.org)

## **Please note:**

*CurePSP offers the Brain Donation Assistance Program as a source of support; as a diagnostic tool for patients and families; and as a contribution to science, understanding, and cure of neurodegenerative disease. CurePSP is proud to be able to offer reimbursement, when requested, up to \$1,000 for incurred related expenses. At this time, CurePSP is not able to assist in the coordination of brain donation, nor is CurePSP responsible for the quality or the experience of the process itself, including working with a pathologist, the coordination and steps at time of death, the cost of services that are not reimbursed, or the resulting neuropathology report. By completing this paperwork and participating in this program, you are acknowledging that you are aware of and in agreement with the process and the role of CurePSP as described above.*



# Brain Tissue Donation Questionnaire

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

**Please mail, email, or fax this form to:** Rachel LaPaille-Harwood  
Mayo Clinic Neuropathology Program Coordinator  
4500 San Pablo Road  
Birdsall Building, Room 310  
Jacksonville, FL 32224  
Email: [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu)  
Phone: 904-953-2439  
Fax: 904-953-7117

Date of completion: \_\_\_\_\_

Name of patient: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Name of next of kin: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

Address of next of kin: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

Patient's date of birth: \_\_\_\_\_

Sex assigned at birth:  Female  Male Preferred gender pronoun(s) to use: \_\_\_\_\_

Race:  Asian  Black or African American  Hawaiian or Other Pacific Islander

Native American, Indigenous, or Alaska Native  White  Other

Ethnicity:  Of Hispanic, Latino, or Spanish Origin  Not of Hispanic, Latino, or Spanish Origin

## Current neurological diagnosis:

Progressive supranuclear palsy (PSP)

Corticobasal degeneration/syndrome (CBD/CBS)

Multiple system atrophy (MSA)

Frontotemporal dementia with parkinsonism (FTDP)

Other: \_\_\_\_\_

Year of diagnosis: \_\_\_\_\_

Year of symptoms onset: \_\_\_\_\_

What were the patient's early symptoms, in the first year before/of diagnosis?

\_\_\_\_\_  
\_\_\_\_\_

# Brain Tissue Donation Questionnaire

What symptoms has the patient experienced since the initial onset (check all that apply):

**Movement symptoms:**

- Tremors
- Imbalance/frequent falls
- Difficulty with walking
- Difficulty with general coordination
- Difficulty moving/using hands
- Stiffness/rigidity of muscles
- Painful muscle contractions (“dystonia”)

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Cognitive changes:**

- Short-term memory loss
- Long-term memory loss
- Loss of orientation (e.g., not knowing the year, familiar locations, familiar people)
- Difficulty with word finding
- Poor judgment
- Disinhibited behavior
- Impulsivity
- Delusions (e.g., paranoia)
- Hallucinations
- Uncontrolled laughing or crying
- Personality changes

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Autonomic symptoms:**

- Dizziness
- Difficulty with blood pressure regulation/fainting
- Excessive sweating
- Changes to breathing (e.g., shortness of breath, labored breathing, sudden large breaths)
- Changes to bladder or bowel function
- Sexual dysfunction
- Changes to circulation (e.g., discoloration in hands or feet)

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Vision changes:**

- Double vision
- Blurry vision
- Dry eyes
- Difficulty moving eyes
- Difficulty opening and/or closing eyelids

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Sleep changes:**

- Development of sleep apnea
- Acting out dreams
- Restless leg syndrome
- Difficulty falling or staying asleep at night
- Daytime fatigue/sleepiness

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Other symptoms:**

- Changes to speech/voice
- Difficulty with swallowing
- Weight loss
- Anxiety
- Depression
- Apathy

Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Does the patient have a known history of:**

Alcoholism:  Yes  No

Drug use:  Yes  No

High blood pressure:  Yes  No

Other known medical conditions or primary symptoms: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Is the patient  left- or  right-handed?

Which side of the body have the movement symptoms mainly affected? \_\_\_\_\_

What medications has the patient taken to manage the symptoms since the neurological diagnosis?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

What kind of professional work did/does the patient do? \_\_\_\_\_

Does the patient have a history of brain injury or possible brain injury?  Yes  No

*For example, a history of trauma or repeated concussions related to combat, work activities, or sports.*

Please provide details here: \_\_\_\_\_

\_\_\_\_\_

Is there a family history of movement or memory disorders or other neurological diseases?  Yes  No

Please list diagnoses and the relationship of the person to the patient (*e.g., Alzheimer's disease – father*)

\_\_\_\_\_  
\_\_\_\_\_

**Most recent physician who managed the patient's neurological diagnosis and care:**

Name of physician: \_\_\_\_\_

Specialty (*neurology, primary care, etc.*): \_\_\_\_\_

Facility/Hospital: \_\_\_\_\_

Facility address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Email (*if available*): \_\_\_\_\_

**If patient is under care of hospice:**

Name of hospice agency: \_\_\_\_\_

Facility address (*if person is residing in inpatient hospice*): \_\_\_\_\_

\_\_\_\_\_

Contact person: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**If patient resides in a skilled nursing or assisted living facility:**

Name of facility: \_\_\_\_\_

Facility address: \_\_\_\_\_

Contact person: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

# Medical Release to Send Notes to Mayo Clinic

› In addition to sending a copy to the Mayo Clinic Brain Bank, this form should be sent to the doctor who diagnosed or primarily managed the patient's neurological diagnosis and who is listed on the questionnaire. Please ask that they send all current and previous records to the Mayo Clinic Brain Bank as soon as they can.

› Please ask them to keep this form on file in the patient's medical records to refer to if needed.

› At the time of the patient's passing and brain donation, please contact the provider's office and ask them to send any new recent visits since the original request was made with relevant neurology notes to the contact information below.

By completing and signing this document, I give permission to \_\_\_\_\_  
(name of doctor and institution/hospital) to release a copy of the medical reports and/or records of  
\_\_\_\_\_ (name of patient), \_\_\_\_\_ (date of birth),  
to the Mayo Clinic Brain Bank in Jacksonville, Florida.

## Signature of patient or authorized patient representative:

Circle one: patient, healthcare power of attorney, next of kin, or witness

\_\_\_\_\_  
Date: \_\_\_\_\_

## Contact information of patient's healthcare power of attorney/next of kin:

Name: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Note to medical center:** 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 data pertinent to the neurodegenerative diagnosis. These notes are used with the results of the brain tissue analysis and diagnosis. All information will be held in the strictest confidence.

## Please have all neurology records sent to:

Rachel LaPaille-Harwood  
Mayo Clinic Neuropathology Program Coordinator  
4500 San Pablo Road  
Birdsall Building, Room 310  
Jacksonville, FL 32224  
Email: [lapaille-harwood.rachel@mayo.edu](mailto:lapaille-harwood.rachel@mayo.edu)  
Phone: 904-953-2439 Fax: 904-953-7117

# Consent for Autopsy and Donation of Brain Tissue

› This form acts as your consent for donation of postmortem brain tissue for research purposes. This form must be completed by the patient/family and must travel with the body for use by the pathologist and for their records. The pathologist will ship this form along with the brain tissue and the autopsy information form they complete (next page).

› Please note that it is likely that the pathologist will also have their own consent or other paperwork for you to complete in advance or at the time of brain donation.

**Name of patient:** \_\_\_\_\_ **Date of birth:** \_\_\_\_\_

Name of healthcare power of attorney/next of kin: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Pathologist information:**

Name: \_\_\_\_\_ Facility/Company: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

**Funeral/mortuary/body donation service:**

Name of Company: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Name of primary contact person: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

In capacity and as signer of this autopsy permit, I/we do hereby direct that postmortem brain tissue from the autopsy of \_\_\_\_\_ (name of patient), \_\_\_\_\_ (date of birth), be procured by the agreed upon pathologist (as listed above and on page 14), out of the agreed upon location and, if applicable, in collaboration with the above-listed mortuary service, and shipped and donated to the Mayo Clinic Brain Bank for special studies and research on neurodegeneration diseases through the CurePSP Brain Donation Assistance Program.

**Signature of patient or authorized patient representative:**

Circle one: patient, healthcare power of attorney, next-of-kin, or witness

\_\_\_\_\_ Date: \_\_\_\_\_

# Autopsy Information Form

› In addition to the Consent for Autopsy and Donation of Brain Tissue form, this form must travel with the body. It will need to be completed by the pathologist and shipped along with the brain tissue.

## To be completed by the patient/family:

Name of patient: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Name of healthcare power of attorney/next of kin: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

## To be completed by the pathologist/diener:

Name: \_\_\_\_\_ Your accession number: \_\_\_\_\_

Direct phone: \_\_\_\_\_ Email: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Date of death: \_\_\_\_\_ Time of death: \_\_\_\_\_

Postmortem interval: \_\_\_\_\_ Fresh brain weight: \_\_\_\_\_

Signature of pathologist: \_\_\_\_\_

Date: \_\_\_\_\_

## Information/Protocol 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 if the body has been kept in cold storage).

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 available deep freezer (preferably  $-70^{\circ}\text{C}$ ). To prevent distortion of the specimen, put the medial aspect of the brain down flat so that it will freeze in its normal shape. Immerse the left hemibrain in formalin so that it is buffered to neutrality.

### Shipping instructions:

When ready to ship, pack the frozen specimen in 48 hours' worth of dry ice in a Styrofoam shipping container. If you need dry ice provided, please reach out to the Mayo Clinic to coordinate having dry ice provided. Separately from the frozen specimen, wrap the formalin-fixed specimen in paper towels that are damp with formalin and put into a leakproof plastic bag in a separate shipping container. Do not tie the boxes together. Ship both boxes separately using an agency that will deliver overnight, such as FedEx or UPS. FedEx will not accept Collect on Delivery (COD) packages, so it must be prepaid, but we can reimburse you for this expense. Please call the Mayo Clinic Brain Bank directly for the FedEx account number. Please send this material early in the week to avoid delivery during the weekend. Do not ship on Thursdays or Fridays.

### Ship both packages to:

Neuropathology, Mayo Clinic • 4500 San Pablo Road • Birdsall Building, Room 347 • Jacksonville, FL 32224

Both the "Consent for Autopsy and Donation of Brain Tissue" and the "Autopsy Information Form" must be sent along with the tissue.

We will mail the report of our findings to you. We will provide a letter and a copy of the report to the next of kin regarding our findings. We are interested in other types of parkinsonism and neurodegenerative diseases 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.

Please contact the Mayo Clinic Brain Bank at 904-953-2439 with any questions related to brain tissue procurement or shipment.

# Medical Release to Send Report to Physician

› *OPTIONAL: If you wish for Mayo Clinic Brain Bank to send a copy of the neuropathology report to the patient's neurologist or a different healthcare provider, complete this release and send it to the Mayo Clinic Brain Bank. Please note that the family will be receiving this report via mail and can choose to provide a copy of it to any provider as well as follow up with that provider to review the report.*

› *Please note that the Mayo Clinic Brain Bank is able to send the neuropathology report to only one medical provider. Additionally, Mayo Clinic is not responsible in the event that the provider's contact information is not correct or the provider is no longer at the listed institution.*

**By completing and signing this document, I give permission to the Mayo Clinic Brain Bank to release a copy of the neuropathology report of \_\_\_\_\_ (name of patient), \_\_\_\_\_ (date of birth), to:**

Name of doctor: \_\_\_\_\_

Name of institution/hospital: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

**Signature of patient or authorized patient representative:**

Circle one: patient, healthcare power of attorney, next of kin, or witness

\_\_\_\_\_  
Date: \_\_\_\_\_

**Contact information for healthcare power of attorney/next of kin:**

Name: \_\_\_\_\_

Relationship to patient: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_ ZIP code: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

# CUREPSP®

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