

# CurePSP Brain Tissue Donation Program

for Progressive Supranuclear Palsy (PSP)  
and Corticobasal Degeneration (CBD)

The Eloise H. Troxel Memorial PSP Brain Bank


Mayo Clinic

Jacksonville, Florida

**CurePSP**  
Society for Progressive Supranuclear Palsy



A Diagnostic Service for Families  
A Research Resource for Scientists



brain tissue research gives PSP and  
CBD patients and loved ones new hope

At the end of life for a patient with PSP or CBD, survivors may be conflicted and confused. One is losing someone who is near and dear to your heart, but please know that your loved one will no longer suffer from this dreadful disease. The frustration of dealing with this disease will soon end, but the loss will be enormous.

The vision of CurePSP is to cure and prevent progressive supranuclear palsy and corticobasal degeneration. Our mission is to increase awareness of PSP and CBD, fund research toward a cure and prevention, educate healthcare professionals, and provide support, information and hope for patients with PSP and CBD and their families.

CurePSP is committed to improving the quality of life for patients with PSP and CBD and their caregivers and to finding the cause and a cure for these diseases. Our goal is to prevent future generations from facing the devastation of PSP and CBD.

At the CurePSP Brain Bank, we ask you to consider brain tissue donation prior to the time of death.

By making this very generous gift, you improve the chances of finding a cure for these devastating diseases. Diagnosis by direct examination of brain tissue through the microscope is the only way to verify the clinical diagnosis of PSP or CBD. That report will also provide information about other brain conditions that may exist, including those that may have caused 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 PSP or CBD. Research is a tangible process that will provide patients and loved ones with the answers they deserve.

## why make your decision in advance

CurePSP urges you to make advanced arrangements for brain donation for several reasons:

- Family members, other loved ones, and most often the patient should be involved in the decision. It may take time for the involved parties to come to an agreement. The CurePSP Brain Bank staff 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 available to make sure this is accomplished within 24 hours after death.
- In addition to the tissue donation, research efforts are aided by getting copies of the patient's medical records relating to the progression of the disease. Since the analysis of the tissue is generally performed two weeks after the patient's death, it is more efficient for everyone involved if copies of the medical records are requested in advance so that the records are on file in the Brain Bank offices to assist the pathologist's examination.
- It can be helpful to ensure that all caregivers as well as the funeral home are aware of these arrangements so you will not have to think about them during a time of grieving.

## after your decision has been made

Registration is accomplished by completing the Donor Registration Form and mailing or faxing it to the CurePSP Brain Bank at the Mayo Clinic in Jacksonville, Florida. CurePSP or Brain Bank staff will provide copies of the Brain Bank donation packet, 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 on the next page.

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, that location may be 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. In any of these circumstances, it will be necessary to locate a pathologist or diener (a pathologist's assistant) who will travel to the location to collect the tissue.

If the patient dies in the hospital, the hospital's attending physician may be requested to collect and send the brain tissue 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. This is another reason why it is important to make these arrangements in advance for your own peace of mind at the time of death.

Locating a pathologist can be a difficult task. The CurePSP 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'—or 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 agent.

## a word about the cost of brain tissue donation

The cost of tissue collection is the responsibility of the family. The CurePSP 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 that the cost of the tissue collection can be prohibitive for some families. A generous donor has recently contributed funds to create the CurePSP Brain Tissue Donation Fund. This has allowed CurePSP to provide financial assistance 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 Dr. Richard Gordon Zyne, President-CEO, CurePSP, Executive Plaza III, 11350 McCormick Road, Suite 906, Hunt Valley, Maryland 21031, phone: (800) 457-4777.

## arrangements in advance

For questions about making advanced arrangements for tissue collection, contact the CurePSP Brain Bank:

Brain Bank Coordinator:	Beth Marten
Phone:	(904) 953-2439, Monday–Friday, 8 am to 5 pm (Eastern time)
Fax:	(904) 953-7117, available 24/7
Email:	marten.beth@mayo.edu

## once you have located a pathologist...

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

Some paperwork is required to perform a legal tissue collection. Please see the “Consent for Donation of Postmortem Brain Tissue” form in this packet. This document can be signed only by the following individuals in this order: Spouse, oldest adult child, parent, adult sibling, guardian or power-of-attorney. This document must accompany the deceased along with the “For the Pathologist” form when the tissue collection takes place.

Please make every effort to fill out all the forms in this packet completely. The “Authorization for Release of Medical Records” may need to be copied because the form, with the next-of-kin’s original signature, must be sent to each doctor who has treated the patient for PSP or CBD, and whose clinical records could provide assistance to the researchers at the Brain Bank. Call Beth Marten at (904) 953-2439 if you have any questions.

## 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 “Consent for Donation of Postmortem Brain Tissue” form, though there is no reason why the entire family and loved ones should not be involved in the decision. If the patient’s spouse is deceased, the oldest child will be considered next-of-kin. In some states, the deceased may arrange in advance for an autopsy with a living will. In other states this is not legally binding.

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

A. No. In most instances where PSP or CBD is suspected, only brain tissue will need to be examined for diagnosis. However, a 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 when requested 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 (the 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 PSP/CBD patients to have a confirmed diagnosis of the diseases through autopsy?**

A. Yes. From our current research studies, it is clear that some cases of PSP or CBD run in families. Other disorders are also occasionally mistaken for PSP or CBD and a PSP-like disease may sometimes be due to other medical conditions. If genetic tests or other tests eventually become available, it is important to know that PSP or CBD is the actual diagnosis. If other family members might be predisposed to develop PSP or CBD, this information will be important for early diagnosis and treatment.

### **Q. Are there other ways to definitely establish a diagnosis of PSP and CBD?**

A. At this time there is no way to diagnose PSP or CBD 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.

CurePSP  
Executive Plaza III  
11350 McCormick Road, Suite 906  
Hunt Valley, Maryland, 21031

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

[curepsp.org](http://curepsp.org)



**“My father never fully understood  
the disease that was slowly taking  
his life—and neither did we at first.”**

My father, Laurence was an intelligent, proud, funny, robust, active, and athletic man with many types of arthritic injuries and health problems that disguised the onslaught of PSP. Still, he was a tiger. In fact, he was the one taking care of my mom when she was in declining health.

At one point, we noticed that dad was falling a lot. We thought it was mom pulling him down, but it was the other way around. The areas of the brain that were affected most caused increasing damage to his motor skills.

My dad’s disease was gradual, but it progressed steadily toward the end. I found this so sad and wondered why dad deserved this kind of suffering. It was only after he died that his disease was confirmed. It was progressive supranuclear palsy, PSP. So few people have ever heard of PSP and now I want to do everything I can to prevent others from undue suffering.

Since its founding in 1990, CurePSP has provided thousands of patients, caregivers, and healthcare professionals with support and education on PSP. Its mission has always been to raise awareness, advance research toward a prevention or cure, educate healthcare professionals, and provide support, education, and hope for persons with PSP or CBD and their families. CurePSP is a lifeline to people who would otherwise be alone and without support.

Your support of the CurePSP Genetics Program is essential to achieving our vision of a world free from PSP and CBD.

**Patricia Richardson**

Actress and National Spokesperson for CurePSP

# Research Consent Form - Hospital Pathologist

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## Consent for Donation of Postmortem Brain Tissue for Special Studies and Research Purposes

Name, address and phone number of next of kin:

Name, address and phone number of facility from  
which body or brain is being sent:

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I, \_\_\_\_\_, am \_\_\_\_\_  
(Relationship to Patient)

and legal next-of-kin to \_\_\_\_\_

In that capacity and as signer of the accompanying autopsy permit, I do hereby permit and direct that post-mortem brain tissue from the autopsy of the above-named patient be donated for special studies and research on PSP and related diseases.

Signed \_\_\_\_\_  
(Next-of-Kin)

Date \_\_\_\_\_

Witness \_\_\_\_\_

Date \_\_\_\_\_

## Information - For the Hospital Pathologist

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Dear Doctor:

Thank you for agreeing to perform an autopsy to establish a diagnosis of Progressive Supranuclear Palsy (PSP) and to obtain tissue for special studies and research in PSP. Please, do the autopsy as soon as possible after death, if possible 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 possible deep freezer (preferably at -700C). In order not to distort 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 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 some agency that will deliver overnight, such as Federal Express. Federal Express will not accept COD packages, so it must be prepaid. However, we can reimburse you for this expense. (Please call for our Federal Express 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. Please see the attached forms, which 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 so 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

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Patient's Name \_\_\_\_\_

Your Accession Number \_\_\_\_\_

Pathologist \_\_\_\_\_ Phone Number \_\_\_\_\_

Date of Death \_\_\_\_\_ Time of Death \_\_\_\_\_ Age at Death \_\_\_\_\_

Postmortem Interval \_\_\_\_\_ Fresh Brain Weight \_\_\_\_\_

Body refrigerated?  Yes  No

Temperature of refrigerator used to store tissue before shipment \_\_\_\_\_

## **Clinical Information (Optional)**

Age of Patient at Onset \_\_\_\_\_

Major signs and symptoms, neurological & other, with date when first noticed \_\_\_\_\_

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

Drug therapy during last year \_\_\_\_\_

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

Agonal circumstances \_\_\_\_\_

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

Family history \_\_\_\_\_

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

## **Sources for Further Information**

PHYSICIAN \_\_\_\_\_ Phone # \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

NURSING HOME \_\_\_\_\_ Phone # \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

NEXT OF KIN \_\_\_\_\_ Phone # \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

# Medical Release Form

- DO NOT SEND THIS ORIGINAL FORM.

Copies to be sent to the doctor(s) who diagnosed or treated the patient.

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I/We, \_\_\_\_\_, \_\_\_\_\_  
Name Relationship

and next of kin of \_\_\_\_\_  
Name of Patient

give permission to \_\_\_\_\_

to release a copy of the medical reports and/or records of \_\_\_\_\_  
Name of 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 Subject or \_\_\_\_\_  
Signature of Person Authorized to Consent for Subject

\_\_\_\_\_  
Witnessed By (Name and Title) \_\_\_\_\_  
Relation to Subject

# Questionnaire - To be filled out by the family and sent to the PSP Brain Bank.

Dear Family Member:

It is necessary to have certain information to expedite our research on PSP. 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 summary should be filled out as completely as possible, use extra sheets of paper if necessary. Please send the information to us at:

**CurePSP Brain Donation Program For Diagnosis & Research on PSP**  
**Eloise H. Troxel Memorial PSP Brain Bank at Mayo Clinic Jacksonville**  
**4500 San Pablo Road • Jacksonville, Florida 32224**

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

Name of the person with PSP: \_\_\_\_\_

Name of the person(s) providing the information below: \_\_\_\_\_

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

Phone: \_\_\_\_\_ E-mail: \_\_\_\_\_

Name and phone numbers of all physicians who may have evaluated this patient including neurologists, psychologists or psychiatrists:

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

1. Date of birth: \_\_\_\_\_ 2. Age at onset of symptoms: \_\_\_\_\_

3. Is there a family history of PSP or Parkinson's disease?  Yes  No

4. What were the symptoms in the early stages: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. Was the progression of the illness rapid \_\_\_\_\_ How many years? \_\_\_\_\_

6. Check any of the following that were present:

- Visual Problems  Delusions  Falls  Fluctuating Course  Wandering  Sleep Disorder  
 Disorientation  Agitation  Hallucinations  Violent Outbursts  Weight Loss  Eating Disorder  
 Tremors  Stiffness  Difficulty Walking  
 Personality Changes (Describe) \_\_\_\_\_  
\_\_\_\_\_

Other Noteworthy Symptoms (Please List) \_\_\_\_\_  
\_\_\_\_\_

7. Was the patient  right or  left handed?

8. Did a neurologist evaluate the patient? A psychologist? A psychiatrist? \_\_\_\_\_  
\_\_\_\_\_

9. Was a CT scan or MRI performed? What did the report show? \_\_\_\_\_  
\_\_\_\_\_

10. What kind of work did the patient do? \_\_\_\_\_

11. Did the patient have any medical illness? \_\_\_\_\_  
\_\_\_\_\_

12. What medications did the patient take? \_\_\_\_\_  
\_\_\_\_\_