

NATIONAL PRION DISEASE PATHOLOGY SURVEILLANCE CENTER

*Brain Only Autopsy Informed Consent*

I do hereby state that I am the legal next of kin of, or the executor of the estate for, the patient and therefore am legally entitled to grant permission for the performance of a brain-only autopsy on this patient as arranged by the National Prion Disease Pathology Surveillance Center (NPDPS). The samples from this procedure are to be submitted to the NPDPS for diagnostic purposes and kept as part of research conducted by the Center. I respectfully request the pathologist performing the autopsy to submit all samples to NPDPS and that these samples be sent within a month of the autopsy to facilitate a timely and accurate diagnosis.

I further authorize NPDPS to obtain the patient's medical records from the physicians listed below. I understand that the results of this research will be released to the physicians listed on the consent, as the NPDPS is not authorized to release information directly to family members.

PRINTED NAME: \_\_\_\_\_

SIGNATURE: \_\_\_\_\_

TODAY'S DATE: \_\_\_\_\_

PHONE NUMBER: \_\_\_\_\_

RELATIONSHIP TO PATIENT: \_\_\_\_\_

PATIENT NAME: \_\_\_\_\_

*Informed Consent for Collection of Temporal Muscle and Pituitary*

We are now collecting muscle samples for cases of suspected CJD to be stored for future research studies. With your permission, we would like to collect a small sample of muscle and the pituitary as a part of the autopsy procedure. Both are located in the head and can be removed during the autopsy without any disfigurement or additional incisions. Because this is a research project, you will not receive any reports or diagnosis based on the muscle sample. Your decision to participate or not to participate in this research will not affect the diagnosis in any way.

If you would like more information on this project before making a decision, please contact our autopsy coordination team at 216-368-0587.

Please check the box below indicating whether you give consent for collection of muscle tissue as a part of the autopsy. Again, please remember that this is an independent research project and will not affect your ability to obtain a diagnosis.

- Yes, I give permission for the collection of temporal muscle and pituitary as a part of the brain only autopsy coordinated by NPDPS.
- No, I do not give permission for the collection of temporal muscle and pituitary.

PRINTED NAME: \_\_\_\_\_

SIGNATURE: \_\_\_\_\_

**PATIENT INFORMATION**

Patient Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Race: \_\_\_\_\_  Male  Female

City/State of residence: \_\_\_\_\_

In what month and year did the patient start showing signs of CJD? \_\_\_\_\_

Is the patient deceased?

- Yes – If YES, please fill out the information in the box below.
- No

Date of Death _____ Time of Death _____
City/State of Death _____

Is the patient married?

- Yes – What is his/her spouse’s name? \_\_\_\_\_
- No

What is the address of the patient’s current location? \_\_\_\_\_

What is the phone number? \_\_\_\_\_

At what hospital(s) was the patient seen? \_\_\_\_\_

Please list patient’s previous and/or current occupation:

\_\_\_\_\_

Does the patient have a known history of foreign travel?

- Yes: Where and when? \_\_\_\_\_
- No

Does the patient have a known history of hunting or eating wild game?

- Yes, hunting: In what state(s)? \_\_\_\_\_
- Yes, eating wild game: What kind and from where? \_\_\_\_\_
- No

Does the patient have a family history of CJD or early onset dementia?

- Yes – Please describe: \_\_\_\_\_
- No

Did the patient donate or receive blood? *(If yes, please specify which)*

- Yes – In what year(s) and city/state: \_\_\_\_\_
- No

**PHYSICIAN INFORMATION\*** (for additional physicians please submit on separate document)

\*we will contact these physicians for additional medical information as well as to report results

<b>Physician name</b>	<b>Specialty</b>	<b>Address</b>	<b>Phone</b>	<b>Fax</b>

**CONTACT INFORMATION**

Who is the primary family contact? \_\_\_\_\_

What is their relationship to the patient? \_\_\_\_\_

Main phone: \_\_\_\_\_ Alternate phone: \_\_\_\_\_

Has the family selected a funeral home/mortuary/crematory?

- Yes – If YES, please fill out the information in the box below.
- No

Name of facility: _____
Contact person: _____
Address: _____
Phone number: _____ Fax: _____

Name of the person who completed this form: \_\_\_\_\_

Phone number (if not noted above): \_\_\_\_\_