

NATIONAL PRION DISEASE PATHOLOGY SURVEILLANCE CENTER

Brain Only Autopsy Informed Consent

I do hereby state that I am the nearest relative of, or I have power of attorney 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 further scientific study and diagnostic purposes. 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.

SIGNED: _____

PRINTED NAME: _____

TODAY'S DATE: _____

PHONE NUMBER: _____

RELATIONSHIP TO PATIENT: _____

PATIENT NAME: _____

NATIONAL PRION DISEASE PATHOLOGY SURVEILLANCE CENTER

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.

SIGNED: _____

PRINTED NAME: _____

TODAY'S DATE: _____

PHONE NUMBER: _____

RELATIONSHIP TO PATIENT: _____

PATIENT NAME: _____

PATIENT INFORMATION

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

Where is the patient currently located? _____

What is the phone number? _____

What hospitals was the patient seen at? _____

Does the patient have a known history of foreign travel?

- Yes: Where? _____
- No

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

- Yes: In what state? _____
- No

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

- Yes – Please describe: _____
- No

Did the patient donate blood?

- Yes – In what year and city: _____
- No

PHYSICIAN INFORMATION

| Physician name | Specialty | Phone | Fax (if available) |
|-----------------------|------------------|--------------|---------------------------|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

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: _____ |
| City and state: _____ |
| Phone number: _____ |

Name of the person who completed this form: _____

Phone number (if not noted above): _____