



CONSENT & AUTHORIZATION FOR POST-MORTEM EXAMINATION (Brain-Only)

I do hereby state that I am the Legal Next of Kin* (**in order: spouse, adult child, parent, sibling**), Executor of Estate or Durable Power of Attorney as determined by my local jurisdiction for _____ (**PATIENT NAME**). I am legally entitled to authorize a postmortem examination on this patient as arranged by the National Prion Disease Pathology Surveillance Center (NPDPC) and cooperating physicians/institutions (e.g. in the case of out-of-area brain removal). I understand that the examination may include the removal and study of tissues for diagnostic, scientific, research, and educational purposes as deemed appropriate by the physicians of the NPDPC.

I request that all tissue samples be sent to the NPDPC within 8 weeks after autopsy in order to facilitate a timely and accurate diagnosis. I understand testing is limited to prion diseases, i.e. Creutzfeldt-Jakob Disease (CJD), Fatal Familial Insomnia (FFI), Gerstmann-Straussler-Scheinker Syndrome (GSS) or Variably Protease-Sensitive Prionopathy (VPSPr), using neuropathological diagnostic protocols only.

If negative, I will have the opportunity to formally request that remaining tissue be sent to another physician or institution for additional neuropathological consultation on the remaining tissues to search for any other diagnoses (the NPDPC does not cover the cost for this testing). I have been given the opportunity to ask any questions that I may have regarding the scope or purpose of the procedure.

**Power of Attorney, Health Care Proxy and /or Medical Power of Attorney signatures are not applicable as these advanced directives expire upon death.*

Date: _____

Name of Legal Next of Kin (please print): _____

Legal Next of Kin Signature: _____

Home Address: _____

Relationship to Patient: _____

Main Phone: _____

Alternate Phone: _____

ADDITIONAL CONTACT INFORMATION

Please list any additional persons who can be contacted if the LNOK is unavailable, incapacitated, or if additional information is needed? _____

What is their relationship to the patient? _____

Main Phone: _____

Alternate Phone: _____

PATIENT INFORMATION

Patient Name: _____ Date of Birth: _____

Race: _____ Male Female Married: Yes No

Residence (City, State): _____ Adult Child (18yrs +) Yes No

Where is the patient currently located? At home At a hospice or other medical care facility

Home or Facility address: _____

If at a facility, Name of contact person: _____ Phone#: _____

Please fill out the information in the box below, if applicable:

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

Are you willing to be contacted by the American Red Cross?

YES NO

PHYSICIAN CONTACT INFORMATION

The NPDPSA is only permitted to release results to a physician. Below, please list the names and contact information for physicians that you would like to receive copies of the autopsy results. **Please make sure that the physician(s) are aware that they will be receiving the results and are expected to disclose the results to the family.** Please be sure to include the physician's Fax number as this is the only way results are transmitted.

Physician Name: _____ Specialty: _____

Institution & Address: _____

Phone: _____ Fax: _____

Physician Name: _____ Specialty: _____

Institution & Address: _____

Phone: _____ Fax: _____

Physician Name: _____ Specialty: _____

Institution & Address: _____

Phone: _____ Fax: _____

CLINICAL HISTORY & FINDINGS

1. Symptoms concerning for Prion Disease (*Mark all that apply*):

<input type="checkbox"/> DEMENTIA Onset:	<input type="checkbox"/> ATAXIA Onset:	<input type="checkbox"/> MYOCLONUS Onset:	<input type="checkbox"/> VISUAL CHANGES Onset:
<input type="checkbox"/> EXTRAPYRAMIDAL Onset:	<input type="checkbox"/> PYRAMIDAL Onset:	<input type="checkbox"/> PSYCHIATRIC Onset:	<input type="checkbox"/> OTHER: Onset:

SOCIAL & FAMILY HISTORY (if “Yes” is circled, please provide additional details)

2. Has patient ever hunted? Yes / No Circle all that apply: Deer / Moose / Elk / Caribou / other State/Province: Year(s):	3. Has patient ever consumed wild game: Yes / No Circle all that apply: Deer / Moose / Elk / Caribou / other State/Province: Year(s):
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4. Is there a Family history of Prion Disease? Yes / No Type of Prion Disease: CJD / GSS / FFI / other Relationship to Patient:	5. Family history of Neurological Disease?: Yes / No Type of Disease (Alzheimers, etc.): Relationship to Patient:
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6. Has patient ever travelled to United Kingdom, Europe, or Saudi Arabia between the years of 1980-1996? Yes / No Countries: Year(s):
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MEDICAL & SURGICAL HISTORY

7. Has patient ever donated blood? Yes / No Facility: Date:	8. Has patient ever received blood? Yes / No Facility: Date:
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9. Has patient had any of these procedures? <i>Circle all that apply:</i> Neurosurgery Corneal transplant Dura mater graft None Facility: Date:	11. Has patient had any of these treatments? <i>Circle all that apply:</i> Human growth hormone Pituitary gonadotropin None Facility: Date:
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RADIOGRAPHIC FINDINGS

NPDPS offers MRI interpretation at no cost. For assessment, please send brain MRI on disc to our mailing address.

12. Has patient had an MRI suggestive of prion disease?	YES	NO	MRI not performed
13. Has patient had EEG with periodic sharp wave complexes?	YES	NO	EEG not perform

RELEASE OF MEDICAL INFORMATION

Patient Name: _____ Date of Birth: _____

Address: _____

**Please fax medical records to: NPDPS / Attn: Autopsy Team
Cleveland, OH 44106
Fax A: 216-368-2546 or Fax B: 216-368-4090**

I, the undersigned and authorize the release of the medical records listed below for diagnostic testing to ensure that the autopsy diagnosis is as accurate as possible and to identify atypical cases for further study.

<input type="checkbox"/> Neurology Notes	<input type="checkbox"/> Physician Transcribed Notes	<input type="checkbox"/> Surgery Reports
<input type="checkbox"/> EEG / Brain MRI Reports	<input type="checkbox"/> History and Physicals	<input type="checkbox"/> Discharge Summaries
<input type="checkbox"/> CD Copies of Brain MRI		

Name of Legal Next of Kin (please print): _____

Legal Next of Kin Signature: _____

Relationship to the patient: _____ Date: _____

The Surveillance Center is fully compliant with HIPAA Regulations: See 45 CFR 164.506 (as further explained on the United States Department of Health & Human Services website at <http://www.hhs.gov/ocr/privacy/hipaa/understanding/coveredentities/usesanddisclosuresfortpo.html>). The NPDPS, as a covered entity, is authorized to receive health information for the purpose of examination and analysis of tissues and specimens. It is understood that the NPDPS will adhere to privacy and confidentiality guidelines as set forth by HIPAA.

CONSENT FOR REPORTING GENETIC RESULTS

As a part of our surveillance efforts for CJD, the National Prion Disease Pathology Surveillance Center (NPDPS) conducts four different tests on the autopsy samples we receive

- 1) **Western Blot:** This test demonstrates the presence of the abnormal prion protein, which is believed to cause CJD and other prion diseases. If the abnormal protein is present, the case is positive. The Western Blot is the most sensitive test for prion disease. **This test is performed on frozen tissue.**
- 2) **Immunohistochemistry (IHC/Histology):** In these tests, the neuropathologist examines slides of specially prepared brain tissue to see where the abnormal prion protein appears in order to help determine the type of prion disease. Different types of CJD have different distribution patterns of the abnormal protein. These tests are performed on fixed tissue.
- 3) **Genetic Analysis:** This test determines if the patient has a genetic mutation, and therefore a familial prion disease. The genetic analysis can only determine if a case is familial (which occurs in about 10% of positive cases); in all other forms of prion disease such as sporadic, iatrogenic, or variant CJD, the genetic analysis may help to identify the specific type. This test is performed on frozen tissue or blood. If we receive sufficient amounts of frozen tissue, blood is not required.

All four of these tests must be performed in order to provide a full diagnosis. The NPDPS realizes that some families may not want to receive all of the information our testing provides. In particular, some families do not wish to know results of genetic testing. Genetic mutations not only affect the patient, but other blood relatives who could also have the mutation. It is important for the Legal Next of Kin to discuss any psychological implications, confidentiality and insurance concerns with a physician to help determine if they wish to receive this information.

In order to ensure that the family receives only the information they would like, we are asking clinicians to consult with families to determine if they would like to receive a full or partial diagnosis. Please indicate their choice below. **The NPDPS will not release the final autopsy report until this form is returned with legal next of kin signature.**

For questions, please contact us at 216-368-0587 or cjdsurveillance@uhhospitals.org.

✓ **Please check the appropriate box listed below:**

- Please send only a partial diagnosis, including the Western blot (if frozen tissue is available) and IHC/Histology (if fixed tissue is available), without the genetic analysis. The partial diagnosis will only indicate if the case is positive or negative.
- Please send the full diagnosis, including the genetic analysis (only available if blood/frozen tissue is submitted). The full diagnosis will indicate if the case is positive or negative and provide the type (sporadic and the subtype of sporadic, familial, or variant) of prion disease if the case is positive.
- I cannot make this decision at this time. Please follow-up with me at a later date.

Date:	Patient Name & Date of Birth:
LNOK Name (print):	LNOK Signature:

RELEASE OF DECEASED PATIENT

*I hereby request and authorize to release the body of _____ (PATIENT NAME) to the funeral home listed below or its representatives for the purpose of a limited brain-only autopsy as arranged for by the NPDPSC.

*I also certify that I have the right to issue this authorization, and in so doing, I hereby release the NPDPSC, Case Western Reserve University, its' officers and representatives from any liabilities which might be incurred in releasing this body to my instructions.

CREMATORIUM / FUNERAL HOME / MORTUARY INFORMATION

Has the family selected a crematorium / funeral home / mortuary (e.g. prearrangements in place)?

- Yes – If yes, please fill-in the information below.
- No

Name of Facility: _____ Contact Person: _____

Address: _____

Phone: _____ Fax: _____

Name of Legal Next of Kin (please print): _____

Legal Next of Kin Signature: _____

Relationship to the patient: _____ Date: _____

Please fax or email this completed form to our office as soon as possible as our goal is to have the autopsy arrangements in place prior to the patients passing.

***The NPDPSC is usually able to make brain-only autopsy arrangements within 1-3 days of passing. However, if passing should occur over a weekend or holiday, a delay could be necessary depending on staffing availability. The patient will need to remain in a refrigerated environment until autopsy arrangements can be made. Depending on the autopsy location additional forms may be required. We understand that this can be a very difficult time for the family and our team members are available any time to assist as needed at 216-368-0587 or 216-647-8148.**

<p style="text-align: center;">National Prion Disease Pathology Surveillance Center Autopsy Q & A</p>

Are we required to have an autopsy conducted in cases of suspected CJD?

Currently, we are not aware of any state that requires autopsy in cases of suspected CJD. However, several states require that the case be reported to the State Department of Health, and they strongly recommend that an autopsy be performed if CJD is suspected by a medical doctor. Your doctor should be able to tell you what is required in your state.

Why should we have an autopsy conducted?

- An autopsy is the only way to confirm the clinical diagnosis of CJD.
- It also is the only way to determine the type of CJD. Most CJD cases are sporadic. Other types of CJD are genetic, iatrogenic, or new variant.
- It helps to further our understanding of CJD. Some day, we hope to be able to successfully treat this disease. In order to reach that goal, we must first understand how the disease works. Tissue acquired at autopsy by the Center is made available to laboratories qualified to do research on prions, helping to reach that goal.

What does the autopsy entail?

We perform brain only autopsies. This means that we will remove the entire brain for analysis. If for some reason you would like to have a full autopsy conducted, please let us know. We will try to make arrangements with the Institution where the autopsy is to be performed.

Will we still be able to have an open casket if we want one?

Only your funeral home can make that decision. However, many of the families who have an autopsy done have been able to have open casket funerals. Our autopsy coordinators are available to address any concerns that your funeral home might have.

How long will it take to have an autopsy performed?

The Center will make every effort to have the procedure completed within a day. However, please note that weekends and holidays can slow the process down. However, the autopsy can be performed with up to a few days delay without jeopardizing the diagnostic examinations.

Can the autopsy be performed locally?

Whenever possible, the Center brings a pathologist to the autopsy location in order to make the process as easy and quick as possible. However, the Center occasionally has to use an out-of-town provider. The Center will make all of the transportation arrangements and cover costs if they are necessary, and works to complete the entire process as soon as possible. The Center will keep you posted if delays are expected so that you can adjust your plans accordingly.

How do we make arrangements for an autopsy if you decide that to have the autopsy done?

Some hospitals will provide autopsy services for their patients. If they do not, the Center will make all of the arrangements. If you would like the Center to make autopsy arrangements for your loved one, call our Autopsy Coordinators at 216-368-0587. All you will need to do is provide some basic information about your loved one and send written consent to perform the autopsy. The Center will take care of everything else.

How much will an autopsy cost?

If the Center arranges the autopsy for you, it will be provided free of charge, including transportation if necessary. Please note that we cannot cover funeral or embalming charges.

Will the Center send us the results?

Our Internal Review Board requires the Center to send the results to a medical doctor only. Often, the Center sends the results to the patient's neurologist or family doctor. You will be asked which doctor you would like to receive the results, and you can change this list at any time. These doctors can discuss the results with you, answer any questions you might have, and consult with you on the next steps. Please note that the Center cannot release the information directly to family members.

How long will it take to get results?

The samples must be treated before they can be safely sent to our facility. On average, most samples arrive to us in about two weeks from the autopsy date. The Center's first test results will be available two weeks from the date of receipt. These preliminary results will tell you if the findings are consistent with prion disease or not, but they will not provide a full or complete diagnosis. The final diagnosis is provided in 1½ to 2 months on average. On rare occasions, the process can take longer, since some cases are challenging. At any time, you can contact the Autopsy Coordinator to learn the status of your case.

What if my loved one turns out not to have CJD?

The Center is willing to send the tissue samples to another facility for analysis. The Center will do everything possible to support your family in your search for answers. Unfortunately, the family must cover these expenses (if any) for the diagnosis made at other institutions.

What if I have more questions?

If you have any additional questions or would like to discuss your situation with someone at our Center, please call our Autopsy Coordinators at 216-368-0587.