SCHOOL OF MEDICINE
CASE WESTERN RESERVE UNIVERSITY

National Prion Disease Pathology Surveillance Center
Case Western Reserve University
Institute of Pathology
2085 Adelbert Road, Room 419
Cleveland, OH 44106
MAIN PH#: 216-368-0587 AFTER HOURS/EMERGENCY PH#: 216-647-8148
FAX A: 216-368-2546 FAX B: 216-368-4090
www.cjdsurveillance.com Email: cjdsurveillance@uhhospitals.org

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 post mortem examination on this patient as arranged by the National Prion Disease Pathology Surveillance Center (NPDPSC) 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 NPDPSC.

I request that all tissue samples be sent to the NPDPSC 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 and/or request physicians from the NPDPSC perform an additional neuropathological consultation on the remaining tissues to search for any other diagnoses (**for a fee**). 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 NPDPSC 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)*:

❒ DEMENTIA Onset:	❒ ATAXIA Onset:	❒ MYOCLONUS Onset:	❒ VISUAL CHANGES Onset:
❒ EXTRAPYRAMIDAL Onset:	❒ PYRAMIDAL Onset:	❑ PSYCHIATRIC Onset:	❒ 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):

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:

6. Has patient ever travelled to United Kingdom, Europe, or Saudi Arabia between the years of 1980-1996? **Yes / No** Countries: Year(s):

MEDICAL & SURGICAL HISTORY

7. Has patient ever donated blood? **Yes / No** Facility: Date:	8. Has patient ever received blood? **Yes / No** Facility: Date:

9. Has patient had any of these procedures? *Circle all that apply*: **Neurosurgery** **Corneal transplant** **Dura mater graft** **None** Facility: Date:	11. Has patient had any of these treatments? *Circle all that apply*: **Human growth hormone** **Pituitary gonadotropin** **None** Facility: Date:

RADIOGRAPHIC FINDINGS

NPDPSC 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: **NPDPSC / 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.

❒ Neurology Notes	❒ Physician Transcribed Notes	❒ Surgery Reports
❒ EEG / Brain MRI Reports	❒ History and Physicals	❒ Discharge Summaries
❒ CD Copies of Brian 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 NPDPSC, 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 NPDPSC 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 (NPDPSC) conducts four different test 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 NPDPSC 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 NPDPSC 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. <u>The patient will need to remain in a refrigerated environment until autopsy arrangements can be made</u>. 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.**