



## National Prion Disease Pathology Surveillance Center

Autopsy Consent, page 1

Main Telephone No.  
After Hours/Emergency No.  
Fax  
E-Mail  
Website

216-368-0587  
216-647-8148  
216-368-2546 / 216-368-4090  
[cjdsurveillance@UHhospitals.org](mailto:cjdsurveillance@UHhospitals.org)  
[www.cjdsurveillance.com](http://www.cjdsurveillance.com)

### CONSENT & AUTHORIZATION FOR POST-MORTEM BRAIN-ONLY EXAMINATION

I, \_\_\_\_\_, the \_\_\_\_\_, do hereby state  
*Authorized Representative Name* *Relationship with the Patient*  
that I am the Legal Next of Kin, Executor of Estate, or Durable Power of Attorney<sup>1</sup> (see below) as determined by my  
local jurisdiction for \_\_\_\_\_.  
*Name of the Patient*

I am legally entitled to authorize a post-mortem brain-only examination on this patient as arranged by the National Prion Disease Pathology Surveillance Center (NPDPC) and cooperating physicians and/or institutions (e.g., in the case of out-of-care brain removal). A copy of this advanced directive or legal documentation confirming my legal authority must and will be provided. I request that all tissue samples be sent to the NPDPC within 8 (eight) weeks after autopsy to facilitate a timely and accurate diagnosis.

I understand that:

\_\_\_\_\_ The examination may include the removal and study of tissues for diagnostic, scientific, research  
*Initials* and educational purposes as deemed appropriate by the physicians of the NPDPC.

\_\_\_\_\_ Testing at the NPDPC is limited to prion diseases, i.e., Creutzfeldt-Jakob Disease (CJD), Fatal  
*Initials* Familial Insomnia (FFI), Gerstmann-Sträussler-Scheinker (GSS), or Variably Protease-Sensitive  
Prionopathy (VPSPr), using neuropathological protocols only.

\_\_\_\_\_ If autopsy testing results are negative, I will have the opportunity to formally request the remaining  
*Initials* tissue be sent to another physician or institution for additional neuropathological consultation.  
This transfer is not covered by the NPDPC.

\_\_\_\_\_ The NPDPC conducts multiple tests on autopsy samples for CJD diagnosis and that I have the  
*Initials* option to receive either a full or partial diagnosis, including or excluding genetic analysis (more  
information on page 2).

\_\_\_\_\_ The NPDPC is usually able to arrange an autopsy within 1-3 days of patient's passing. However, if  
*Initials* passing should occur over a weekend or a holiday, a delay could be necessary due to staffing  
availability. The patient will need to remain in a refrigerated environment until autopsy  
arrangements are finalized.

\_\_\_\_\_ I have been given the opportunity to ask any questions that I may have regarding the scope or  
*Initials* purpose of the procedure.

\_\_\_\_\_  
*Authorized Representative Name*

\_\_\_\_\_  
*Relationship with the Patient*

\_\_\_\_\_  
*Authorized Representative Signature*

\_\_\_\_\_  
*Date*

<sup>1</sup> In accordance with state law, the following order of authority is generally recognized:

- |  |   |
|--|---|
| 1. Court-Appointed Guardian                                | 6. Parents                                  |
| 2. Durable Power of Attorney                               | 7. Adult siblings (eldest to youngest)      |
| 3. Executor of Estate                                      | 8. Adult grandchildren (eldest to youngest) |
| 4. Surviving Spouse or Legally recognized domestic partner | 9. Grandparents                             |
| 5. Adult children (eldest to youngest)                     | 10. Other adult relatives                   |



CONSENT FOR REPORTING OF GENETIC RESULTS

As part of our CJD Surveillance efforts, the National Prion Disease Pathology Surveillance Center (NPDpsc) conducts the listed tests on autopsy samples to obtain a full diagnosis, which includes:

- 1. Western Blot (on frozen tissue): This is the most sensitive test for prion disease, which detects the abnormal prion protein that causes CJD. A positive result indicates the presence of the disease.
2. Immunohistochemistry (on fixed tissue): Examines the distribution of abnormal prion protein in the brain tissue, helping determine the type of prion disease.
3. Genetic Analysis (on DNA extracted from frozen tissue): Identifies if the patient has a pathogenic mutation, and therefore a familial prion disease (occurs in ~10% of positive cases). In sporadic, iatrogenic or variant CJD, genetic analysis aids in identifying the specific subtype.

The NPDpsc understands that some families may prefer not to receive all the information, especially the genetic results, which affect not only the patient, but their biological relatives who may also have the mutation.

To ensure that we release only the information that the family wishes to receive, the Legal Next of Kin is encouraged to discuss any emotional, confidentiality and insurance concerns with a physician to help determine if they wish to receive the genetic test results of the patient.

Please check the appropriate box below.

- Partial Diagnosis - Please send only a partial report, which excludes genetic analysis results. The report will indicate only whether the case is positive or negative.
Full Diagnosis - please send a report with the full diagnosis, including the genetic analysis results (if frozen tissue is submitted). The report will indicate whether the case is positive or negative and specify the type of prion disease.
Undecided - I am not ready to decide at this time. Please follow up with me later.

Form fields for Patient Name, Patient's Date of Birth, Authorized Representative Signature, and Date.

Please list the names and contact information for the medical provider(s) you authorize to receive the autopsy results. Please note that we are not permitted to send results directly to family members, but can only submit reports to Doctors of Medicine (MD), Nurse Practitioners (NP), Doctors of Osteopathic Medicine (DO), or Physician Assistants (PA).

Form for listing medical providers, including fields for Provider Name, Organization/Facility Name, Department, Street Address, City, State, Zip Code, Phone Number, Fax Number (Required), and E-Mail Address.



Part I: Authorized Representative Information

- Please enter your information as accurately as possible.

Form with columns: Prefix, First Name, Middle Initial, Last Name, Relationship to Patient

Form with columns: Street Address, City, State or Province, Zip Code

- Will the documentation confirming your legal authority (e.g., Advanced Directive, Living Will, Last Will and Testament, etc.) be submitted with this consent form?

Yes, I am including it with the consent form.

Not yet, I will submit it separately. - Please Note: this documentation is required to help us confirm that the person signing is legally authorized to provide consent. The autopsy will not be coordinated and performed by the NPDPSC without the appropriate signatures and documentation.

- Please enter your contact information and preferred method of contact.

Form with columns: Phone No., Alternative Phone No., E-mail Address, Preferred method of contact (Phone, E-mail)

What is the best time to reach you?

Time Zone (select one or write in):

Part II: Secondary Contact Information

- Please list any additional people who can be contacted in case the primary authorized representative is unavailable, incapacitated, or additional information is needed.

Form with columns: Prefix, First Name, Middle Initial, Last Name, Relationship to Patient

Form with columns: Phone No., Alternative Phone No., E-mail Address



PART III: Patient Information

First Name Middle Initial Last Name Sex Date of Birth
M or F (mm/dd/yyyy)

Race Hispanic/Latino Married? Do They Have Adult Children?
Yes No Yes No Yes No

City of Residence State of Residence Patient's Current Location
Home Hospice/Medical Facility

if applicable

Hospice/Facility Name Hospice/Facility Contact Person Phone no.

Street Address City State Zip Code

Is Patient Deceased? Date of Death Time of Death City of Death State of Death
Yes No (mm/dd/yyyy)

Are you willing to be contacted by the American Red Cross? Yes No

PART IV: Crematorium, Funeral Home or Mortuary Information

Are there pre-arrangements in place with a crematorium, funeral home or mortuary regarding the patient?

Yes - please fill in the information below.

Facility Name Facility Contact Person Phone no. Fax no.

Street Address City State Zip Code

No - If no, please be advised that having these arrangements in place before the patient's passing is necessary to ensure timely autopsy coordination.

By signing below, you authorize the release of the patient's body to the facility (or its representatives) listed above for the purpose of a limited brain-only autopsy, as arranged by the NPDPC.

Authorized Representative Signature Relationship with patient Date

Patient Full Name:	Date of Birth (mm-dd-yyyy):
--------------------	-----------------------------

**Clinical History and Findings**

<p><b>Clinical Symptoms</b></p> <p><i>*Please mark all that apply, and indicate the symptom onset (mm/yyyy)</i></p> <p><input type="checkbox"/> Dementia: _____</p> <p><input type="checkbox"/> Ataxia: _____</p> <p><input type="checkbox"/> Myoclonus: _____</p> <p><input type="checkbox"/> Visual Changes: _____</p> <p><input type="checkbox"/> Extrapyramidal: _____</p> <p><input type="checkbox"/> Pyramidal: _____</p> <p><input type="checkbox"/> Psychiatric: _____</p> <p><input type="checkbox"/> Other: _____</p>	<p><b>Social History</b></p> <p><b>Hunting</b></p> <p>Has patient ever <b>hunted</b> venison?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>Venison Type: <i>(check all that apply)</i></p> <p><input type="checkbox"/> Deer <input type="checkbox"/> Elk <input type="checkbox"/> Moose <input type="checkbox"/> Caribou</p> <p>Hunting State/Province: _____</p> <p>Hunting Year(s): _____</p>	<p><b>Medical &amp; Surgical History</b></p> <p><b>Medical Treatment</b></p> <p>Has the patient had any of these treatments? <i>Check all that apply:</i></p> <p><input type="checkbox"/> Pituitary gonadotropin <input type="checkbox"/> Human growth hormone <input type="checkbox"/> None</p> <p>Treatment Facility: _____</p> <p>Date (mm-dd-yyyy): _____</p>
<p><b>Family History</b></p> <p><b>CJD in Family</b></p> <p>Is there a Family history of <b>prion disease</b>?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>If <b>yes</b>, what type of <b>prion disease</b>?</p> <p><input type="checkbox"/> CJD <input type="checkbox"/> GSS <input type="checkbox"/> FFI <input type="checkbox"/> Other: _____</p> <p>Relationship to patient: _____</p>	<p><b>Consumption</b></p> <p>Has patient ever <b>consumed</b> venison?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>Venison Type: <i>(check all that apply)</i></p> <p><input type="checkbox"/> Deer <input type="checkbox"/> Elk <input type="checkbox"/> Moose <input type="checkbox"/> Caribou</p> <p>Hunting State/Province: _____</p> <p>Hunting Year(s): _____</p>	<p><b>Surgical Procedures</b></p> <p>Has the patient had any of these procedures? <i>Check all that apply:</i></p> <p><input type="checkbox"/> Neurosurgery <input type="checkbox"/> Corneal transplant <input type="checkbox"/> Dura mater graph <input type="checkbox"/> None</p> <p>Procedure Facility: _____</p> <p>Date (mm-dd-yyyy): _____</p>
<p><b>Neurological Diseases in Family</b></p> <p>Family history of <b>neurological disease</b>?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>If <b>yes</b>, what type of disease?</p> <p><input type="checkbox"/> Alzheimer's <input type="checkbox"/> Other: _____</p> <p>Relationship to patient: _____</p>	<p><b>Travel</b></p> <p>Has patient ever travelled to UK, Europe, or Saudi Arabia between years 1980-1996?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>Countries: _____</p> <p>Year(s): _____</p>	<p><b>Blood Transfusions</b></p> <p>Has patient ever <u>received</u> blood?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>Facility: _____</p> <p>Year: _____</p>
<p><b>Radiographic Findings</b></p> <p><i>NPDPC offers MRI interpretation at no cost. For assessment, please visit our website for instructions on how to submit a brain MRI to our center.</i></p> <p>Has patient had MRI suggestive of CJD?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not performed</p> <p>Has patient had EEG with periodic sharp wave complexes?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not performed</p>	<p><b>RT-QuIC Testing</b></p> <p><b>RT-QuIC Results</b></p> <p>Patient's RT-QuIC Results:</p> <p><input type="checkbox"/> Positive <input type="checkbox"/> Negative <input type="checkbox"/> Indeterminate <input type="checkbox"/> Not Performed</p>	<p><b>Blood Donation</b></p> <p>Has patient ever <u>donated</u> blood?</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unknown</p> <p>Facility: _____</p> <p>Year: _____</p>



AUTHORIZATION FOR RELEASE OF MEDICAL RECORDS

Patient Name: Patient DOB:

Patient Address:

To whom it may concern,

I, as the

and authorized representative of the listed patient, authorize the release of the medical records indicated below to the National Disease Pathology Surveillance Center for diagnostic testing to ensure that the autopsy diagnosis is as accurate as possible, and to identify atypical cases for further study.

(Please check all that apply)

- History and Physicals
Discharge Summaries
Surgery Reports
Neurology Notes
Physician Transcribed Notes
EEG / Brain MRI Reports
CD Copies of Brain MRI

Sincerely,

Authorized Representative Signature Date

Please fax or email the medical records to:

Address: NPDPC/ Attn: Autopsy Team
2085 Adelbert Rd, Pathology 419
Cleveland, OH 44106
Fax: 216-368-2546 (primary) / 216-368-4090 (secondary)
E-mail: cjdsurveillance@uhhospitals.org

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. The NPDPC, 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 NPDPC will adhere to privacy and confidentiality guidelines as set forth by HIPAA.



## **NPDPSC AUTOPSY COORDINATION PROGRAM – FAQ**

### **➤ Autopsy Requirements & Recommendations**

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

A: 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.

**Q: Why should we have an autopsy conducted?**

A:

- 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 variant.
- It helps to further our understanding of CJD. Someday, we hope to be able to successfully treat this disease. 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.

### **➤ Autopsy Procedure & Logistics**

**Q: What does the autopsy entail?**

A: 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.

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

A: Only your funeral home can make that decision. However, many 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. Ultimately, institutional policy changes are at the discretion of the funeral homes, and we cannot directly impact their internal policy-making or operational policies.

**Q: How long will it take to have an autopsy performed?**

A: 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

**Q: Can the autopsy be performed locally?**

A: 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 may have to use an out-of-town provider. The Center will make all 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.



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

A: Some hospitals will provide autopsy services for their patients. If they do not, the Center will make all 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.

➤ **Costs & Payments**

**Q: How much will an autopsy cost?**

A: 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.

➤ **Autopsy Results & Reporting**

**Q: Will the Center send us the results?**

A: The NPDPSA cannot release results directly to family members. Our Internal Review Board (IRB) 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.

**Q: How long will it take to get results?**

A: Once the tissue is received, the NPDPSA typically performs up to four different tests on the submitted tissue. Final reports are released approximately three months from the date of autopsy. Turnaround times may vary due to several factors, including circumstances outside of our control or the complexity of a case.

At any time, you can contact the NPDPSA by calling 216-368-0587 or by emailing [cjdsurveillance@uhhospitals.org](mailto:cjdsurveillance@uhhospitals.org) to learn about the status of your case.

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

A: 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.

➤ **Additional Support & Contact**

**Q: What if I have more questions?**

A: 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.