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For NPDPSC use only

Zip Code:

Ordering Provider (required)

Ordering Provider Name:

Hospital/Institution:						
Phone:				Fax*:		
Street Address:						
City:	Sta	te:			Zip	Code:
NPI Number :	ICD		ICD-	D-10 Diagnosis Code:		
Note: Results will be transmi	tted to	o Or	dering	Provi	der <u>vi</u>	ia fax only.
Referring Laboratory						
Contact Person:						
Laboratory/Institution:						
Phone:			Fax*:			
Street Address:						
City:	State:				Zip	Code:
NPI Number :			100	10.0		and Caralan
NET NUMBER.				וט טו	lagni	osis Code:
Note: Results will be transmi	tted to	o the	e Refer	ring L	ab <u>vi</u>	a fax only.
Patient Information (re	equire	ed)				
Patient ID (MRN#):						
Last Name:	t Name:		First Name:			
Sex:		Do	ate of	Birth	(mm-	dd-yyyy):
☐ Male ☐ Female						
Race (select from the drop-dov	lown list):			Hisp	oanic	:/Latino Ethnicity:
Patient Address:						
City:	Sta	te:				Zip Code:
Is patient deceased?	1				est in	the Autopsy
☐ Yes ☐ No		Program?				
Date of Death (mm-dd-yyyy	,)·	Tir	ne of	Y 🗆 Deat		□ No
Date of Death (min-ad-yyyy	7.	111	110 01	Deal		□ am
		1				□ nm

Note: If we are to bill the patient directly for CSF, Blood or Biopsy testing, please fill out the information below.

Please include a copy of the front and back of the insurance card.

State:

Fax*:

Accounts Payable/Billing Information (if applicable)

☐ Check here if AP/Billing information is the same as Referring Laboratory. Otherwise, please fill out the

information below.

Laboratory/Institution:

Name:

Phone:

City:

Street Address:

Primary Insurance Information (if applicable)

Subscriber Name (if different than patient):			
Subscriber Name (ii dineren man panerii).			
Insurance Name:		Effective Date (mm-dd-yyyy):	
Policy Number:	Gr	Group Number:	
Relationship to Patient:			
☐ Self ☐ Spouse ☐ Other:		□ Dependent	
Insurance Company Address:			
City:	Stc	ite:	Zip Code:

Secondary Insurance Information (if applicable)

Subscriber Name (if different than patient):			
Insurance Name:		Effective Date (mm-dd-yyyy):	
Policy Number:	Group Number:		
Relationship to Patient:			
☐ Self ☐ Spouse ☐ Other:		□ Dependent	
Insurance Company Address:			
City:	Sto	ite:	Zip Code:

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Patient Information (required)

Patient ID (MRN#):	Date of Birth (mm-dd-yyyy):
Last Name:	First Name:

Samples Enclosed (required)

Sumples Enclosed (required)
Cerebrospinal Fluid
☐ Cerebrospinal Fluid Panel (RT-QuIC, 14-3-3y (ELISA), Total TAU (ELISA)
Collection Date (mm-dd-yyyy):
Volume (enter number): ml.
Whole Blood
☐ Blood (PRNP Genetic Testing) Note: Testing & Reporting Policies Form must be completed and submitted with this form.
Collection Date (mm-dd-yyyy):
Volume (enter number): ml
Biopsy Tissue
☐ Frozen Brain (Western Blot)
Collection Date (mm-dd-yyyy):
Amount:
☐ Fixed Brain (Immunohistochemistry (IHC), Hematoxylin & Eosin staining (H&E))
Collection Date (mm-dd-yyyy):
Amount:
□ No

For shipping and contact information on CSF, Blood, and Biopsy Tissue, please scan the QR code below, or click the following link:

CSF, Blood, and Biopsy Tissue Shipping Instructions



Autopsy Tissue				
☐ Frozen Brain (Western Blot)				
Collection Date (mm-dd-yyyy):				
Amount: Whole Brain Half Brain Other: gr				
☐ Fixed Brain (Immunohistochemistry (IHC), Hematoxylin & Eosin staining (H&E))				
Collection Date (mm-dd-yyyy):				
Amount:				
Formic Acid Treated: ☐ Yes ☐ No				
Skin, Lymphoreticular				
☐ Skin Sample				
Collection Date (mm-dd-yyyy):				
☐ Apex ☐ Posterior to ear ☐ Lumbar spine				
☐ Lymphoreticular Tissue				
Collection Date (mm-dd-yyyy):				
□ Appendix□ Visceral Lymph Nodes□ Spleen				

For shipping and contact information on Autopsy, Skin and/or Lymphoreticular Tissue, please scan the QR code below, or click the following link:

<u>Autopsy, Skin, Lymphoreticular Tissue Shipping Instructions</u>



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Patient Information (required)

Procedure facility: _

Date (mm-dd-yyyy): ___

Patient ID (MRN#):	Date of Birth (mm-dd-yyyy):
Last Name:	First Name:

Clinical History and Findings (required) To be completed by the requesting physician. A	olso, please attach a clinician's assessment from t	he EMR.
Clinical Suspicion of Prion Disease	Clinical Symptoms	Social History
On a scale 1-10, with 1 being <u>LOW</u> and 10 being <u>HIGH</u> , what is the clinical suspicion of prion disease?	Illness Onset (mm/yyyy): Dementia, onset: Ataxia, onset:	Hunting Has patient ever hunted? ☐ Yes ☐ No
Please check one of the boxes: 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 □ □ □ □ □ □ □ □ □ □	□ Myoclonus, onset: □ Visual Changes, onset: □ Extrapyramidal, onset: □ Pyramidal, onset: □ Psychiatric, onset:	Hunted game: Deer Elk Moose Caribou
Medical & Surgical History Blood Donations Has patient ever donated blood? □ Yes	Radiographic Findings NPDPSC offers MRI interpretation at no cost. For	☐ Other State/Province:
☐ No If yes, donation institution:	assessment, please send brain MRI on disc to our mailing address. Has patient had MRI suggestive of CJD?	Hunting Year(s): Consumption
Donation year: Do you agree to be contacted by the American Red Cross? ☐ Yes	☐ Yes ☐ No ☐ Not performed	Has patient ever consumed venison? ☐ Yes ☐ No
□ No Blood Transfusions Has patient ever received blood? □ Yes □ No	Has patient had EEG with periodic sharp wave complexes? ☐ Yes ☐ No	Consumed game: Deer Elk Moose Caribou Other
If yes, transfusion institution: Transfusion year: Surgical Procedures	□ Not performed Family History Prion Disease in Family	State/Province: Consumption Year(s):
Has the patient had any of these procedures? Check all that apply:	Is there a Family History of Prion Disease? ☐ Yes ☐ No	Travel Has patient ever travelled to UK, Europe, or
□ Neurosurgery □ Corneal transplant □ Dura mater graft □ None	If yes , what type of Prion Disease? CJD GSS FFI Other:	Saudi Arabia between years 1980-1996? Yes No Countries:
Procedure facility: Date (mm-dd-yyyy):	Name: Relationship to patient: Neurological Diseases in Family	Year(s):
Medical Treatment Has the patient had any of these treatments? Check all that apply:	Is there a Family History of Neurological Disease? Yes No	Contact and Mailing Address: NPDPSC Institute of Pathology, CWRU
☐ Pituitary gonadotropin (cadaveric) ☐ Human growth hormone (cadaveric) ☐ None	If yes , what type of Disease? □ Alzheimer's □ Other:	2085 Adelbert Rd, Room 414 Cleveland, Ohio, 44106-4907 Phone: 216-368-0587

Relationship to patient:

Phone: 216-368-0587 Fax: 216-368-4090

Email: cjdsurveillance@uhhospitals.org

National Prion Disease Pathology Surveillance Center Testing and Reporting Policies

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

- <u>Western blot</u>: 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.**
- <u>Immunohistochemistry (IHC)/Histology:</u> 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.**
- <u>Genetic analysis:</u> 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.

A full diagnosis can be provided as long as the above appropriate samples are available. If one of the samples is not available, a partial diagnosis can be created.

Although we perform all of the above tests for our important research efforts on prion disease, we realize that some families may not want all of the information we collect. In particular, some families do not want to receive genetic information. Genetic mutations not only affect the patient, but also other blood relatives who could also have the mutation. It is important to discuss the psychological implications, confidentiality and insurance with them to determine if they wish to receive this information.

In order to insure that the family receives only the information they want, 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 and fax it to us at 216-368-4090. The NPDPSC will not release genetic information until this form is returned.

Please note for blood only cases where the family wishes to receive the genetic information, please check the "full diagnosis" box to release the genetic analysis.

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 IHC/Histology (if fixed tissue is available), without tonly tell if the case is positive or negative.	,			
	Please send the full diagnosis, including the genetic analysis (only available if blood/frozen tissue i submitted). The full diagnosis will tell 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.				
Pat	ient Name:	_ Date:			
Ph	ysician Name (print):	_Signature:			
Phy	ysician Phone:	Physician Fax:			