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Patient Information (re	equired)			Accounts Paya	ble/Billing	Inf	<b>ormation</b> (if c	ipplicable)
Patient ID (MRN#):				☐ Check here if Referring Labo	_			
Last Name:	Firs	t Name:		information be	elow.		•	
				Name:				
Sex:	Do	ite of Birth	(mm-dd-yyyy):					
☐ Male ☐ Female		1		Laboratory/Institu	tion:			
Race (select from the drop-dow	n list):	His	panic/Latino Ethnicity:	81				
Patient Address:			□ 162 □ 140	Phone:		Fax	K*:	
railetti Addiess.				Charach Aslabasas				
City:	State:		Zip Code:	Street Address:				
City.			Zip Code.	Cit. "	C+~+		7in (	20 do:
Is patient deceased?	ls t	here inter	est in the Autopsy	City:	Stat	e.	ZIP	Code:
☐ Yes ☐ No		gram?	csi iii iiic 7.010psy					
□ 1e3 □ 140		Y	′es □ No	Note: If we are t				
Date of Death (mm-dd-yyyy)	: Tim	ne of Dea	th: □ am		Biopsy testing, please fill out the information below.  Please include a copy of the front and back of the			
			□ pm	insurance o				<del></del>
Note: CDC-sponsored brain exclude prion disease. Call				Primary Insuran				le)
Ordering Provider (	equired)			Subscriber Name	(if different th	nan	patient):	
Ordering Provider Name:								
11 11 11 11				Insurance Name:			Effective Date	(mm-dd-yyyy):
Hospital/Institution:								
Discourse		ale.		Policy Number:		Gr	oup Number:	
Phone:		ax*:						
Street Address:				Relationship to Po				
Sileer Address.				☐ Self☐ Other:	□ Spouse		⊔ Dep	pendent
City:	State: Zip Code:		Zip Code:	Insurance Compo	Insurance Company Address:			
		1						
NPI Number :		ICD-10	Diagnosis Code:	City:		Stc	ite:	Zip Code:
Note: Results will be transmit	tted to Ord	l dering Prov	ider via fax only.					
				Secondary Insu	rance Info	rm	<b>ation</b> (if appli	cable)
Referring Laborator	У			Subscriber Name				,
Contact Person:								
				Insurance Name:			Effective Date	(mm-dd-yyyy):
Laboratory/Institution:								
				Policy Number:		Gr	oup Number:	
Phone:	F	ax*:						
				Relationship to Po				
Street Address:				□ Self	☐ Spouse		□ Dep	pendent
				☐ Other:				
City:	State:		Zip Code:	Insurance Compo	any Address:			
NPI Number :	1	ICD-10	Diagnosis Code:	City:		Stc	ite:	Zip Code:
INTERNATION .		1 100-10	Diagnosis Code.	1 1				1

Note: Results will be transmitted to the Referring Lab via fax only.

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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
☐ <b>Blood</b> (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:   Whole Brain  Half Brain  Other:   gr
Fixed Brain (Immunohistochemistry (IHC), Hematoxylin & Eosin staining (H&E))
Collection Date (mm-dd-yyyy):
Amount:

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:   Whole Brain  Half Brain  Unstained Slides: #  Cassettes: #  Paraffin #  Embedded Blocks				
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</u>, Skin, Lymphoreticular Tissue Shipping Instructions



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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:

<b>Clinical History and Findings (required)</b> To be completed by the requesting physician. A	lso, please attach a clinician's assessment from th	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:	☐ Myoclonus, onset: ☐ Visual Changes, onset:	⊔ No Hunted game: □ Deer
1-2-3-4-5-6-7-8-9-10	□ Extrapyramidal, onset: □ Pyramidal, onset: □ Psychiatric, onset:	□ Elk □ Moose □ Caribou
Medical & Surgical History Blood Donations	☐ Other:	□ Other
Has patient ever <u>donated</u> blood? ☐ Yes	Radiographic Findings	State/Province:
☐ No If yes, donation institution:	NPDPSC offers MRI interpretation at no cost. For assessment, please send brain MRI on disc to our mailing address.	Hunting Year(s):
Donation year:	Has patient had MRI suggestive of CJD?	Consumption
Do you agree to be contacted by the American Red Cross?	☐ Yes ☐ No ☐ Not performed	Has patient ever consumed venison?  ☐ Yes ☐ No
Blood Transfusions	Has patient had EEG with periodic sharp wave complexes?	Consumed game:  Deer Elk
Has patient ever <u>received</u> blood? ☐ Yes ☐ No  If yes, transfusion institution:	☐ Yes ☐ No	☐ Moose ☐ Caribou ☐ Other
II yes, Iransiosion institution.	□ Not performed  Family History	State/Province:
Transfusion year:  Surgical Procedures	Prion Disease in Family	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 <b>yes</b> , what type of Prion Disease?	Saudi Arabia between years 1980-1996?   Yes  No  Countries:
Procedure facility:	Name:	Year(s):
Date (mm-dd-yyyy):	Relationship to patient:  Neurological Diseases in Family	Teur(s).
Medical Treatment	Is there a Family History of Neurological	
Has the patient had any of these treatments? Check all that apply:	Disease?  Yes  No	Contact and Mailing Address:  NPDPSC Institute of Pathology, CWRU
☐ Pituitary gonadotropin (cadaveric) ☐ Human growth hormone (cadaveric) ☐ None	If <b>yes</b> , 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.**
- 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.

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.			
Pati	ent Name:	_ Date:		
Phy	vsician Name (print):	Signature:		
Phy	vsician Phone:	Physician Fax:		