

# ***2015 CJD Foundation Family Conference***

***Washington, DC July 10th-12th, 2015***



## ***Questionnaire Report***

***Creutzfeldt-Jakob Disease  
Foundation, Inc.***

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***Associate Director***

***CJD Foundation***

***New York, NY***

# *Summary*

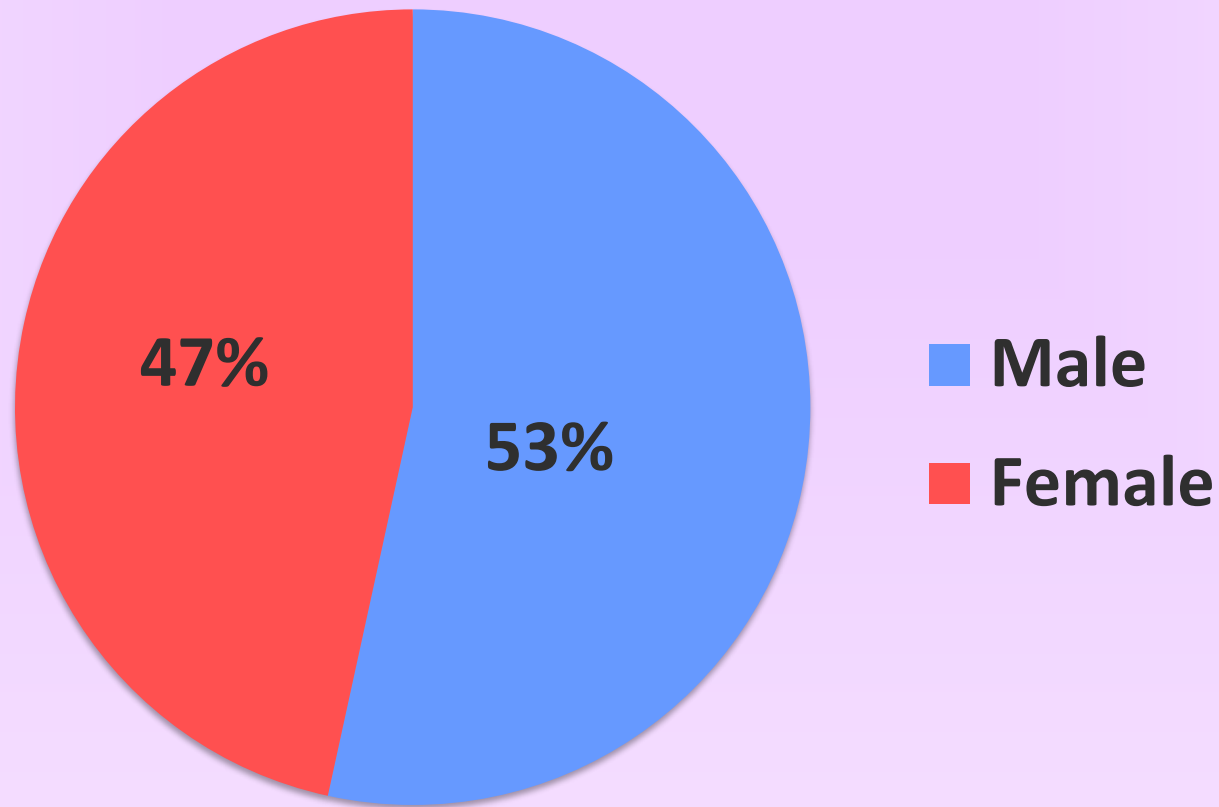
- **We have 3211 patients in our database**
- **Data have been collected since 2000**
- **The questionnaire underwent revisions in 2004, 2008 and 2011**

## ***Summary (cont.)***

- **Before 2004, questions were in narrative form**
- **Narratives are difficult to process for statistical analysis**
- **1226 patient questionnaires in total have been returned**

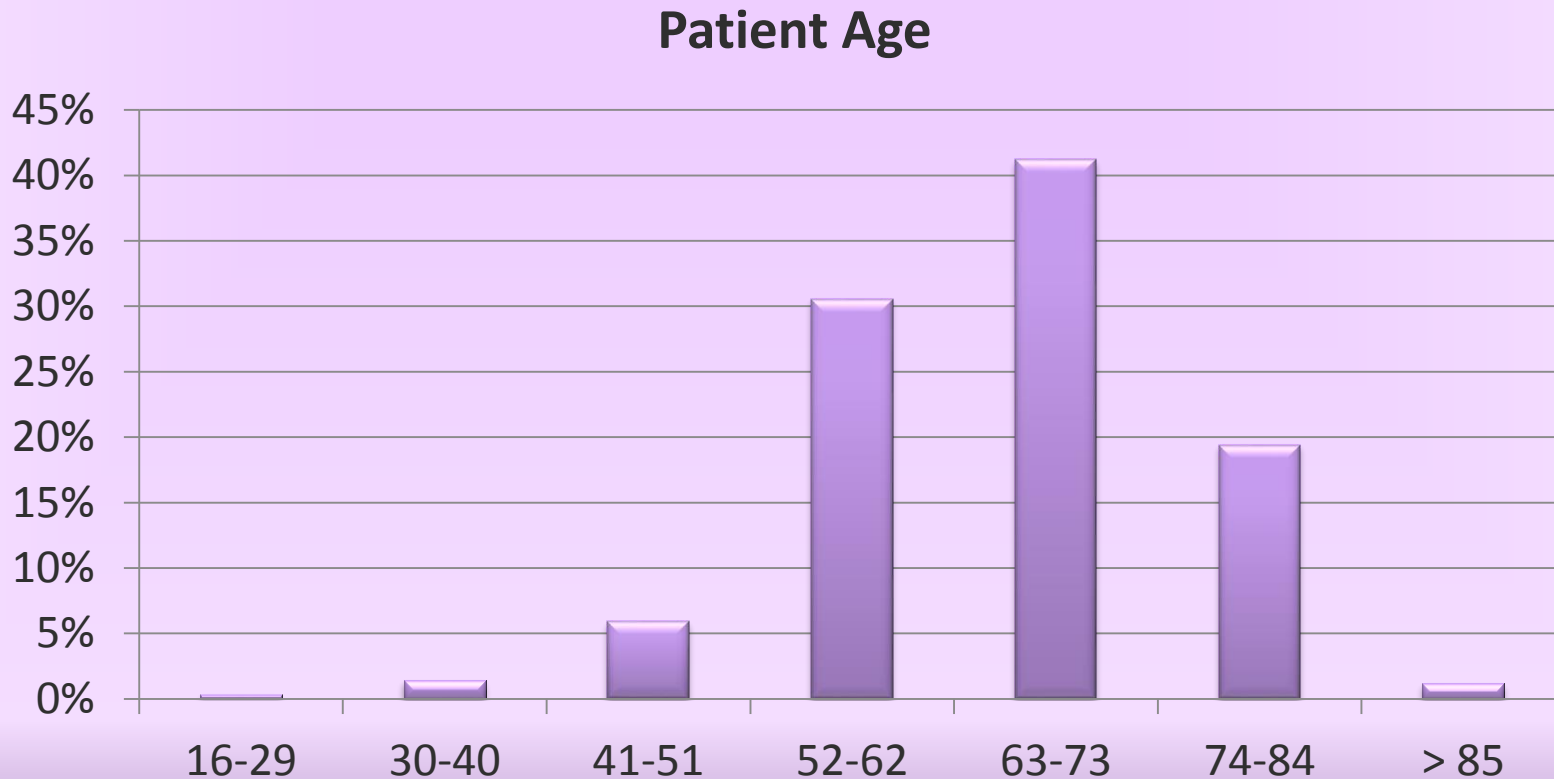
# ***Demographics***

## **Gender (1226 patients)**



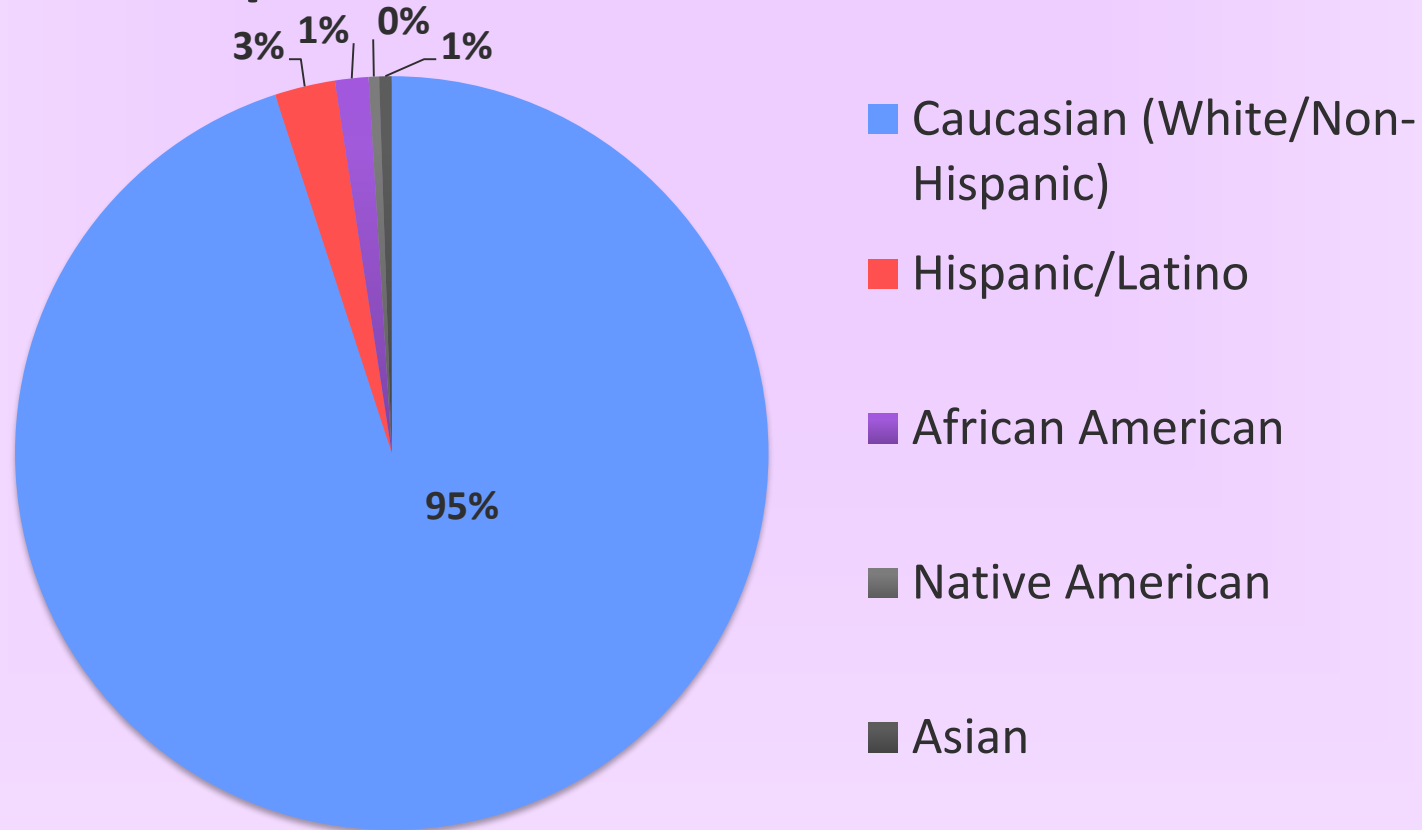
# *Age At Death*

- Youngest person, age 16; oldest, age 92
- 65 is the average age at death



# ***Ethnic Origin***

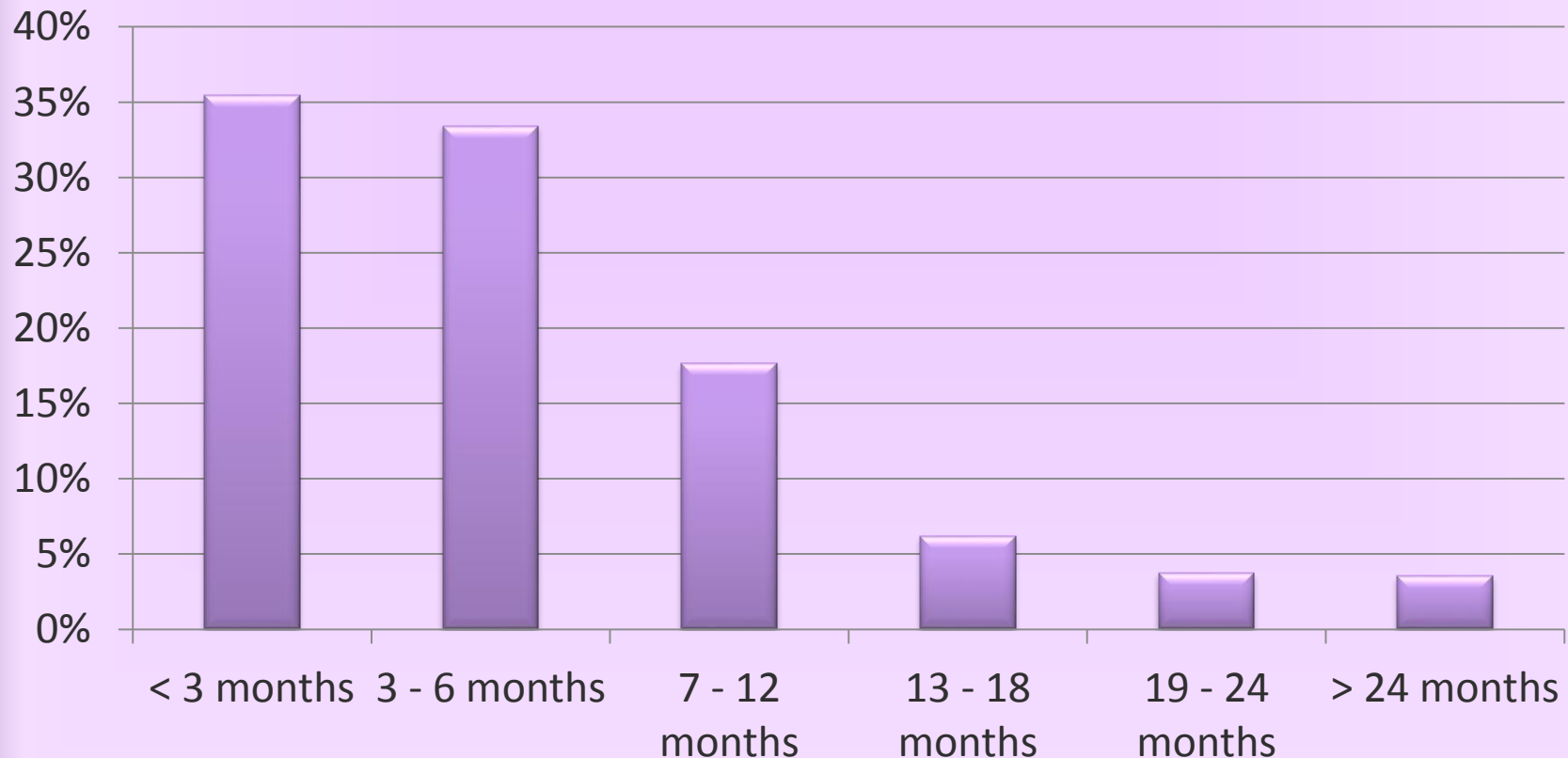
- **Of the 1226 patients**



- **\*108 (9%) patient questionnaires with missing data.**

# *Duration of Illness*

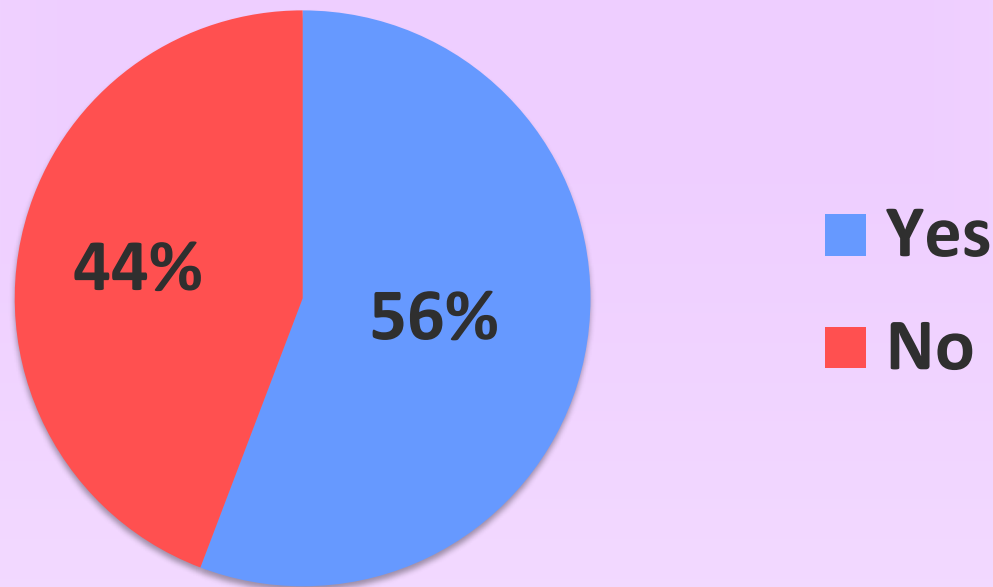
- Of the 1226 patients



**\*98 (8%) patient questionnaires with missing data.**

# *Unusual Stress Prior to the Onset of Symptoms*

- Of the 1226 patients

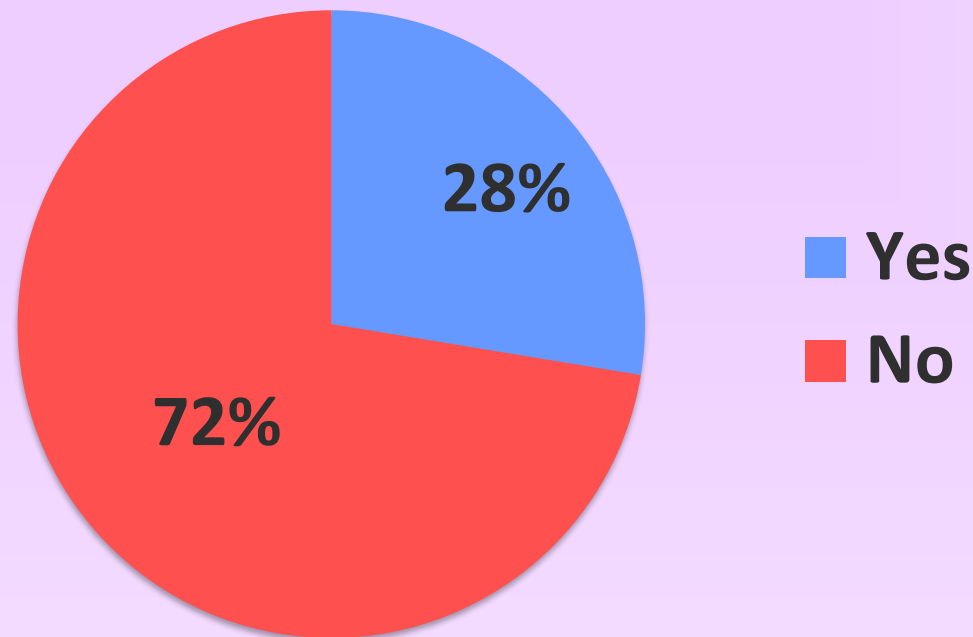


- \*292 (24%) patient questionnaires with missing data.



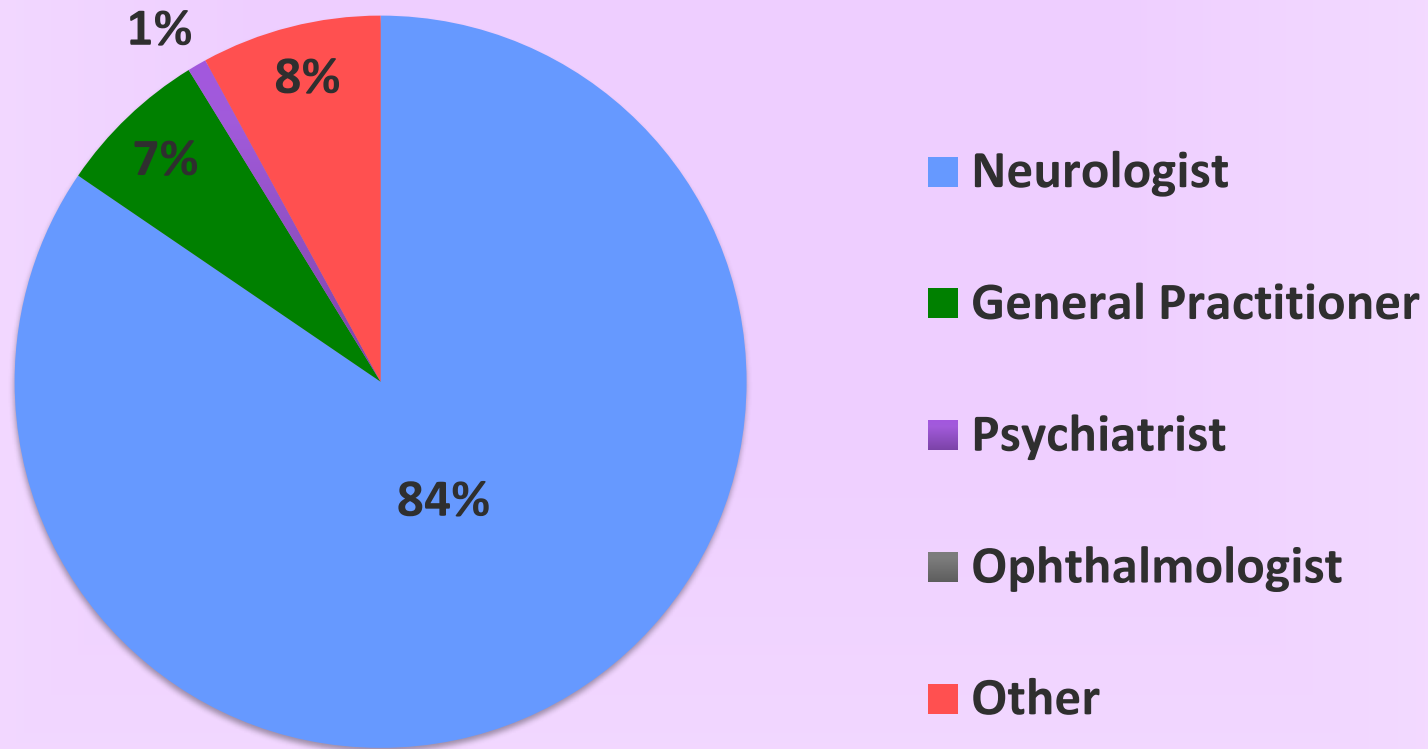
# ***Did Patient Develop Dry Cough***

- Of the 1226 patients



- \*360 (29%) patient questionnaires with missing data.

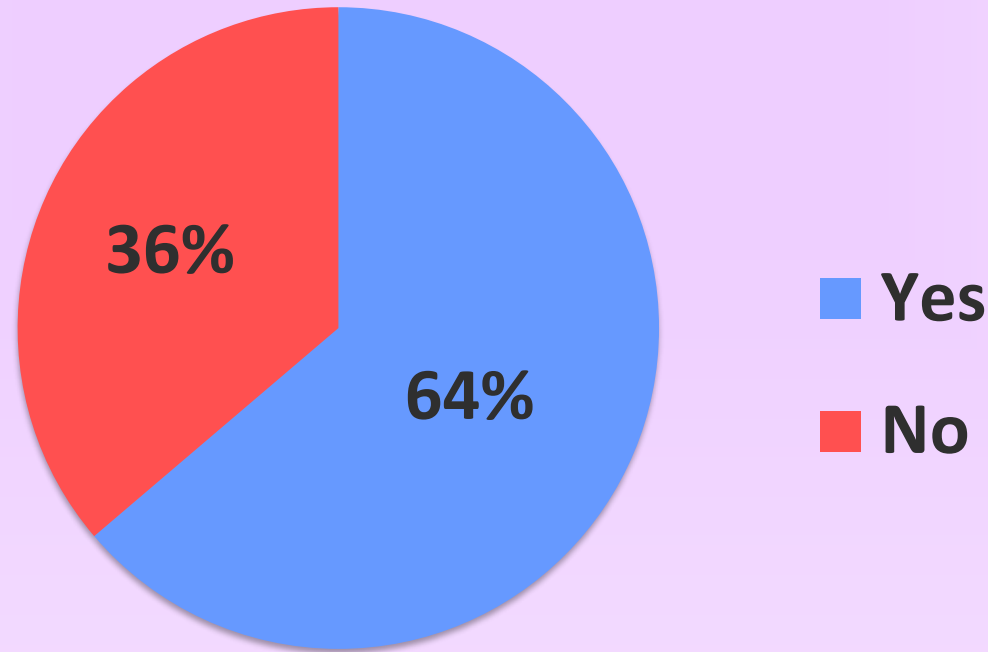
# *Diagnosing Physician*



- **748\* (61%) patient questionnaires with missing data.**

# ***Autopsy Information***

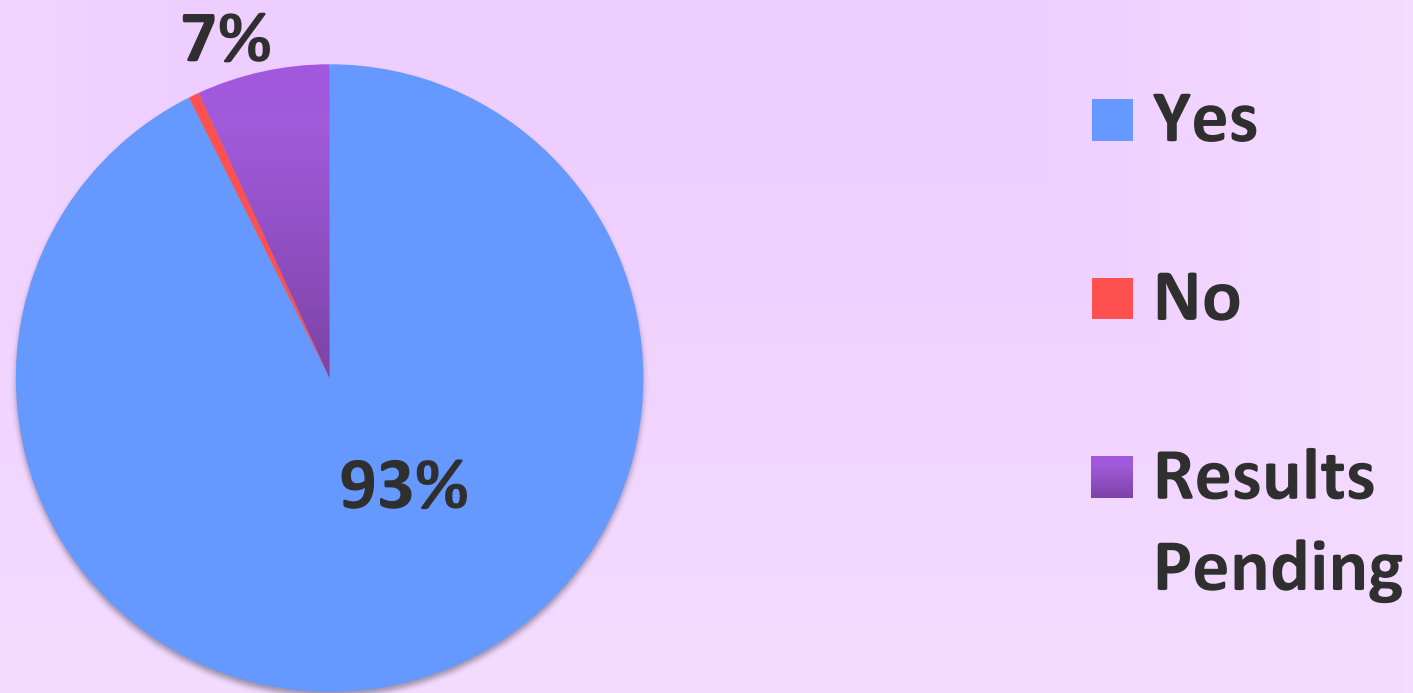
- **Was an Autopsy performed?**



- **28\* (2%) patient questionnaires with missing data.**

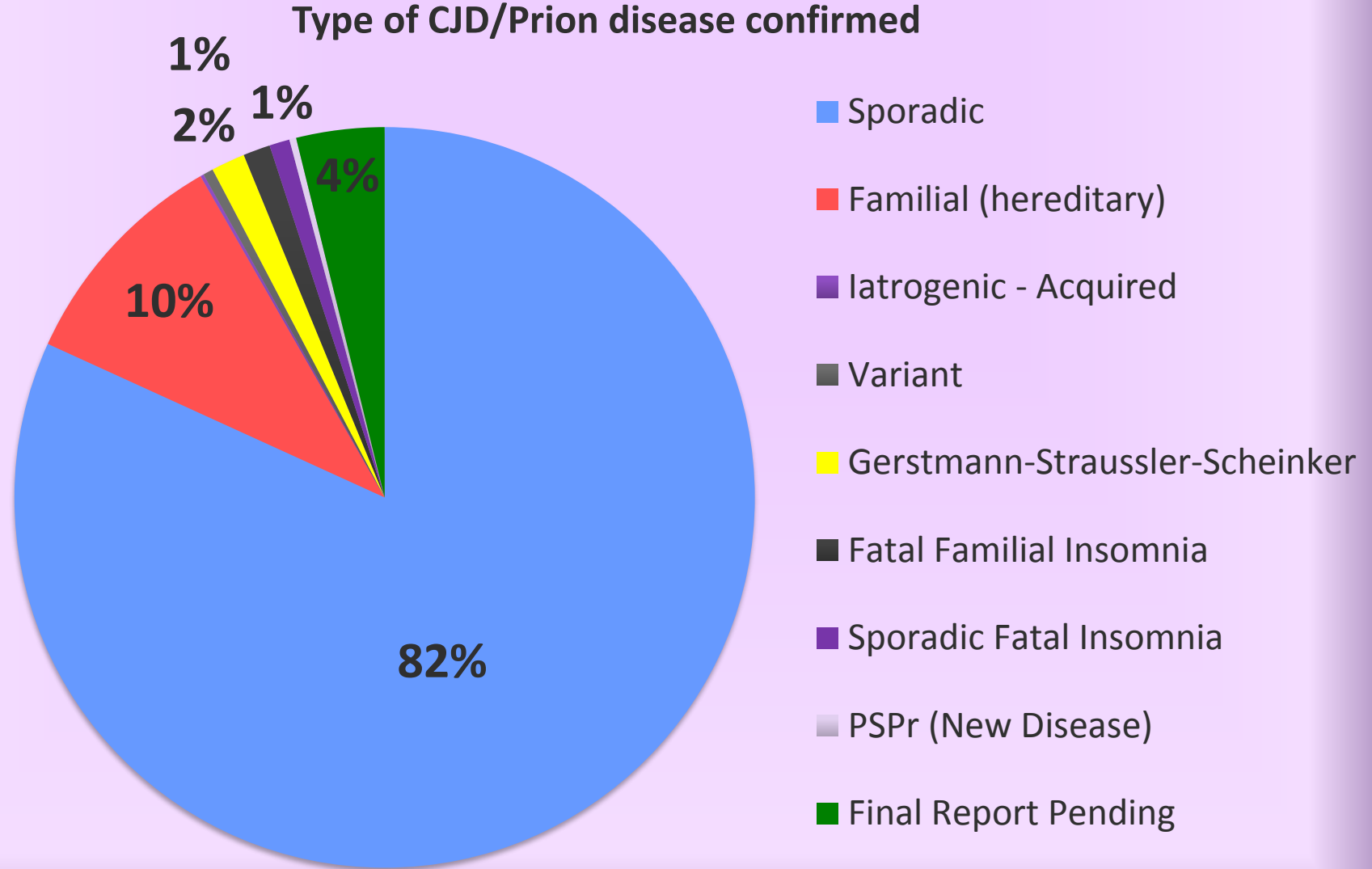
# ***CJD/Prion Disease Confirmed***

- From Autopsy (764 Patients), was CJD or Other Prion Disease Confirmed?



- 34\* (4%) patient questionnaires with missing data

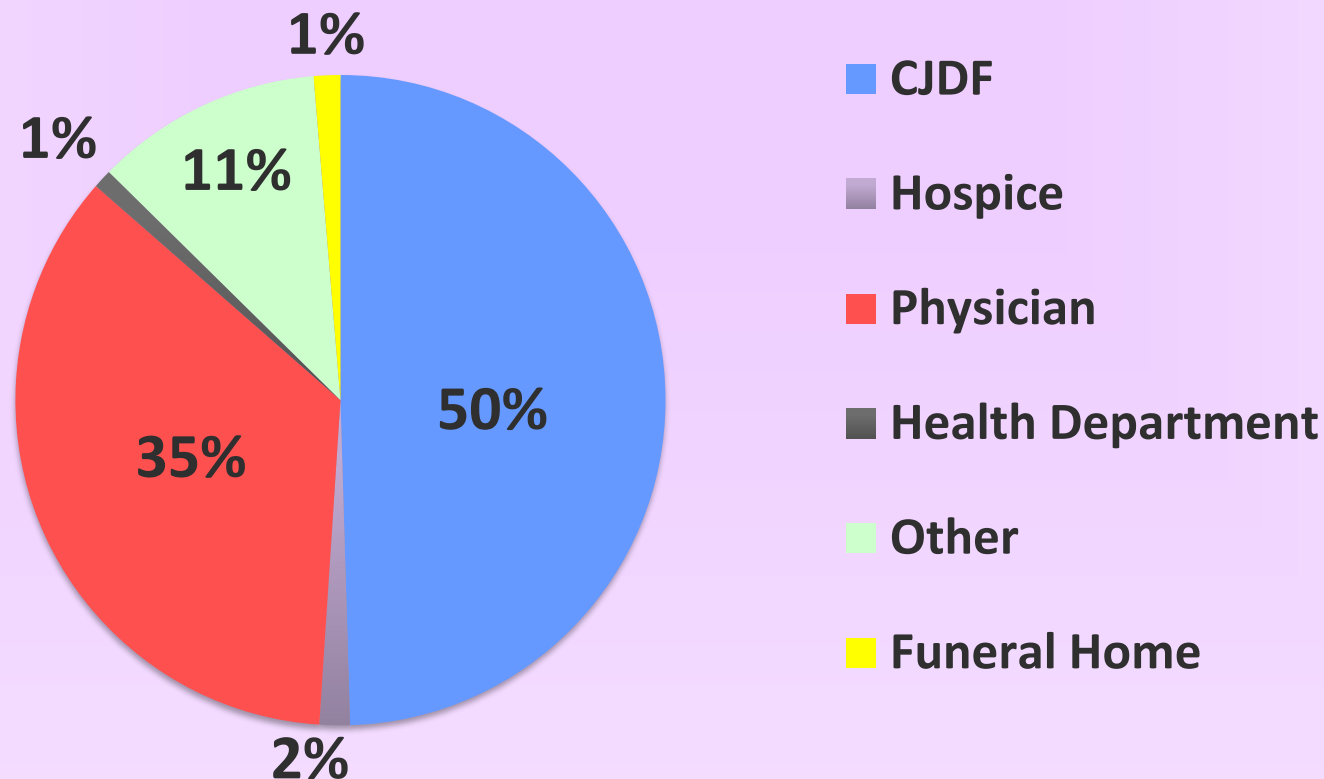
# *Type of CJD/Prion disease confirmed (Out of 676)*



# *Autopsy Referral to NPDPSC*

- Of the 764 patients

Who referred autopsy to NPDPSC



- 233\* (30%) patient questionnaires with missing data.

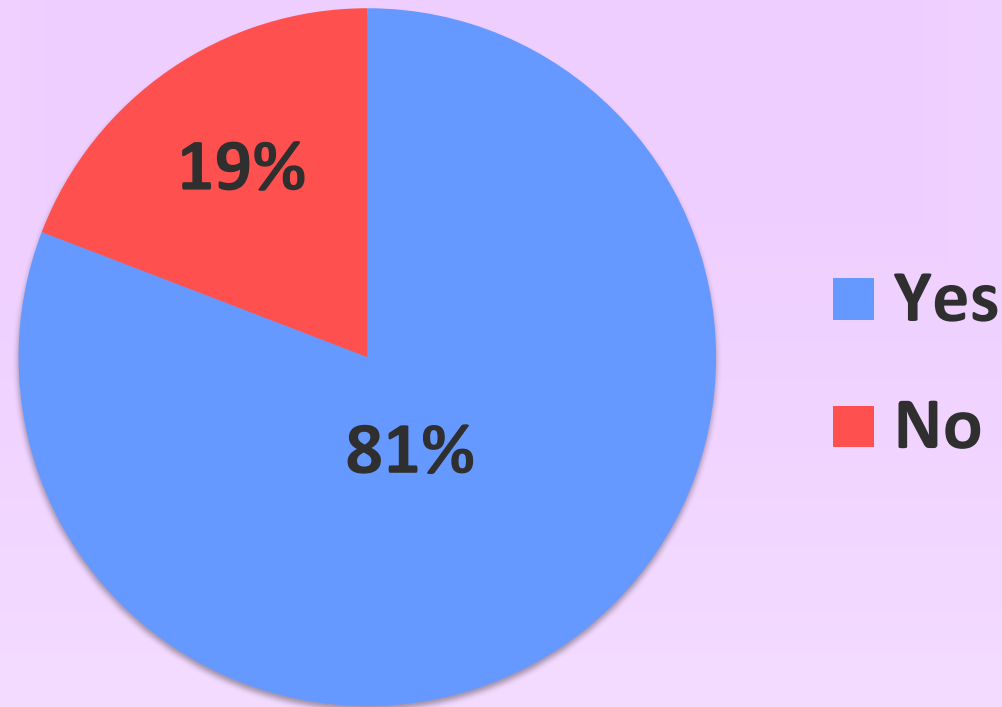
# ***Physician Information***

- **Was the Physician ....**

<b>Informed about CJD</b>	<b>643 (52%)</b>
<b>Informed about CJDF</b>	<b>262 (21%)</b>
<b>Informed about NPDPSC</b>	<b>290 (24%)</b>
<b>Compassionate</b>	<b>692 (56%)</b>
<b>Recommended</b>	<b>840 (69%)</b>

# ***CJD Listed On The Death Certificate***

- Of 1226 patients



- \*485 (40%) patient questionnaires with missing data.



# ***Food Consumption and Animal Exposure (1226)***

- **Patients who consumed beef**

Yes	1094 (99%)
No	13 (1%)

**\* 119 (10%) patient questionnaires with missing data**

- **Patients who consumed deer/elk**

Yes	574 (56%)
No	459 (44%)

**\* 193 (16%) patient questionnaires with missing data**

# ***Travel Outside the US***

<b>Yes</b>	<b>670 (62%)</b>
<b>No</b>	<b>414 (38%)</b>

**\* 142 (12%) patient questionnaires with missing data**

<b>Travel to:</b>	<b>No. (%)</b>
<b>United Kingdom</b>	<b>226 (18%)</b>
<b>Japan</b>	<b>46 (4%)</b>
<b>Eastern Europe</b>	<b>104 (8%)</b>
<b>France</b>	<b>131 (11%)</b>
<b>Canada</b>	<b>204 (17%)</b>

# ***Surgery and Tissue/Organ Transplant History***

- **Type of Organ Transplant**

	<b>No.</b>
<b>Liver</b>	<b>1</b>
<b>Corneal</b>	<b>1</b>

# ***Medical procedures***

- Medical Procedures of Interest**

<b>Gastric (Upper GI)</b>	<b>42 (3%)</b>
<b>Endoscopy</b>	<b>147 (12%)</b>
<b>Colonoscopy</b>	<b>384 (31%)</b>
<b>Other</b>	<b>65 (5%)</b>

# ***Other Medical Procedures***

<b>Spinal tap (other than for CJD diagnosis)</b>	<b>131 (11%)</b>
<b>Conditions associated with the thyroid</b>	<b>157 (13%)</b>
<b>Blood donor</b>	<b>357 (29%)</b>
<b>Blood recipient</b>	<b>101 (8%)</b>
<b>Transfusion of albumin or Immunoglobulin</b>	<b>22 (2%)</b>

# ***Of Possible Interest***

<b>Dental surgery</b>	<b>730 (60%)</b>
<b>Eye surgery</b>	<b>247 (20%)</b>
<b>Contact lenses</b>	<b>176 (14%)</b>
<b>Eye drops</b>	<b>386 (31%)</b>
<b>HGH treatment</b>	<b>13 (1%)</b>

# ***Of Possible Interest***

<b>Hormone replacement therapy Females (out of 569 )</b>	<b>111 (20%)</b>
<b>Unknown</b>	<b>57 (10%)</b>
<b>Blank/No</b>	<b>401 (70%)</b>
<b>Homeopathic/herbal therapy</b>	<b>63 (5%)</b>
<b>IV drug use</b>	<b>33 (3%)</b>
<b>Acupuncture</b>	<b>63 (5%)</b>

# ***Of Possible Interest***

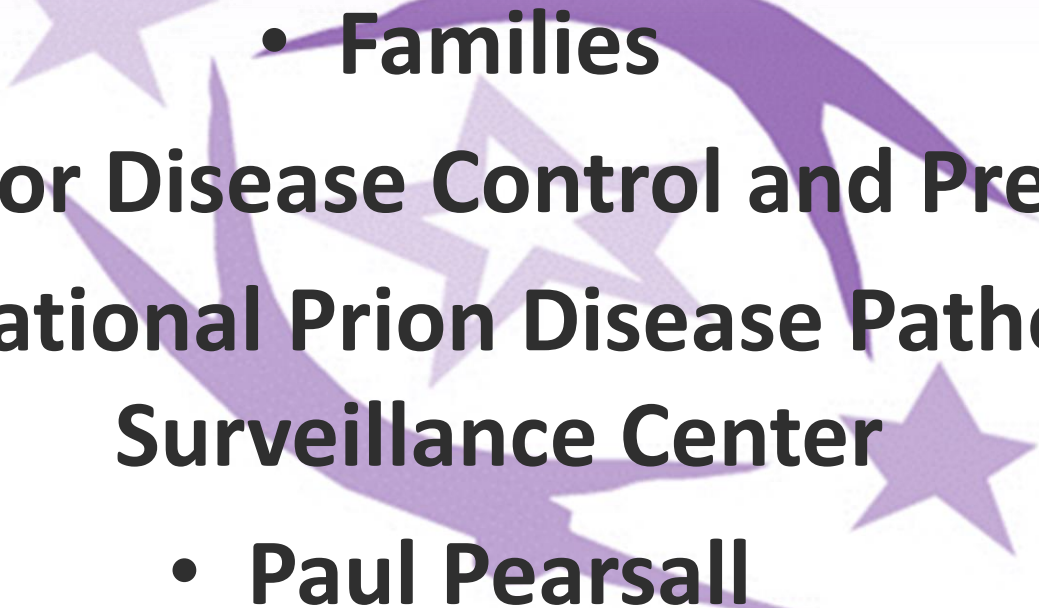
<b>Vaccinations/ Injections</b>	<b>381 (31%)</b>
<b>Tattoos</b>	<b>64 (5%)</b>
<b>Piercings</b>	<b>340 (28%)</b>



# Pin Map



# **The CJD Foundation Gratefully Acknowledges**

- 
- **Families**
  - **Centers for Disease Control and Prevention**
    - **The National Prion Disease Pathology  
Surveillance Center**
  - **Paul Pearsall**

**Creutzfeldt-Jakob Disease**  
*Foundation, Inc.*