



Creutzfeldt-Jakob Disease
Foundation, Inc.

2017 CJD Foundation Family Conference
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Questionnaire Report

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CJD Foundation

Summary

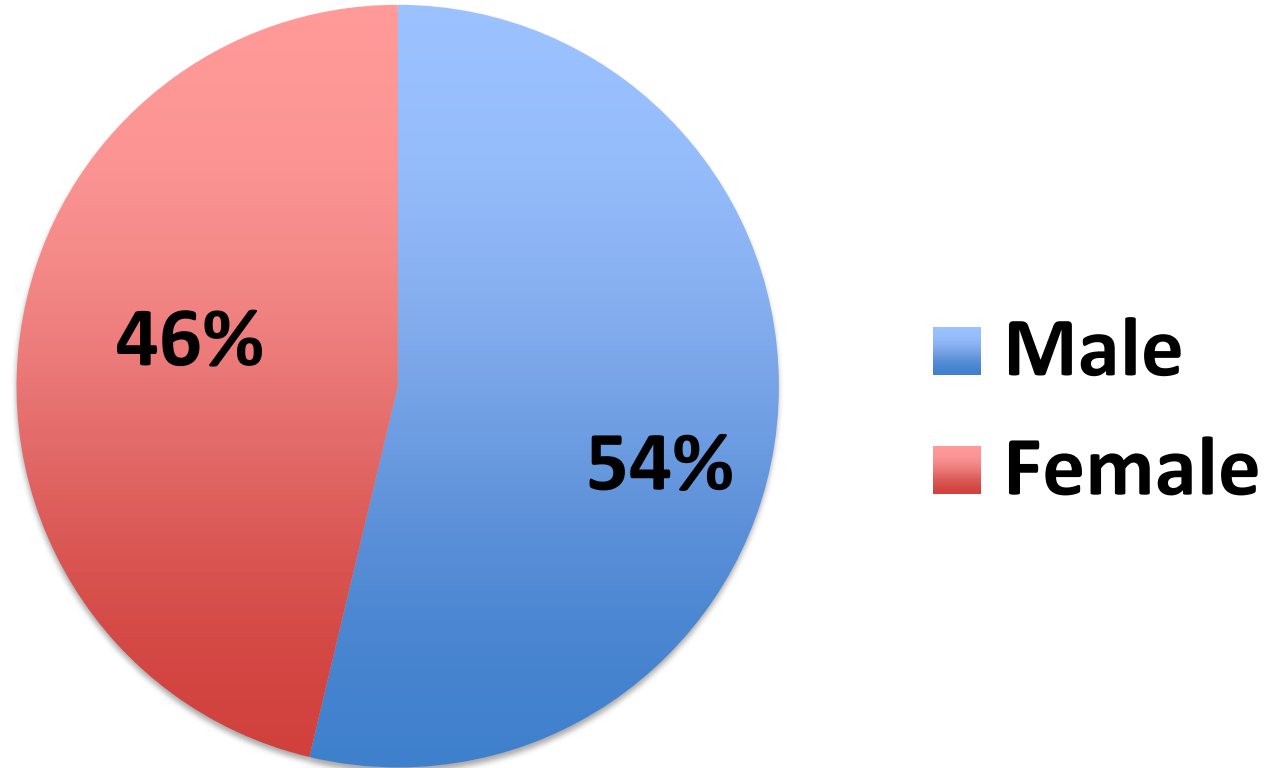
- **We have 3702 patients in our database**
- **Data has been collected since 2000**
- **The questionnaire underwent revisions in 2004, 2008 and 2011**

Summary (cont.)

- **Before 2004, questions were in narrative form**
- **Narratives are difficult to process for statistical analysis**
- **1304 patient questionnaires in total have been returned**

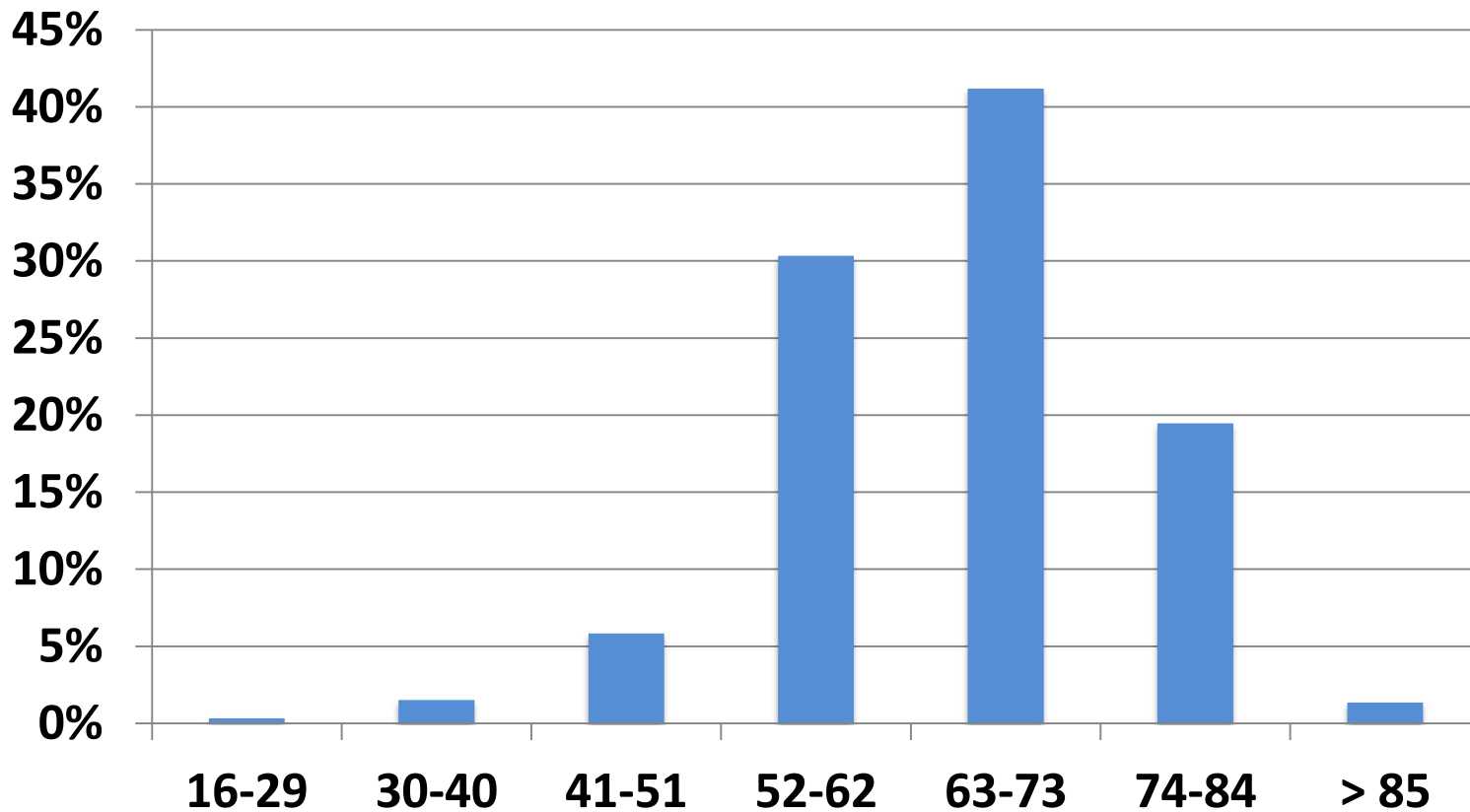
Demographics

Gender (1304 Patients)



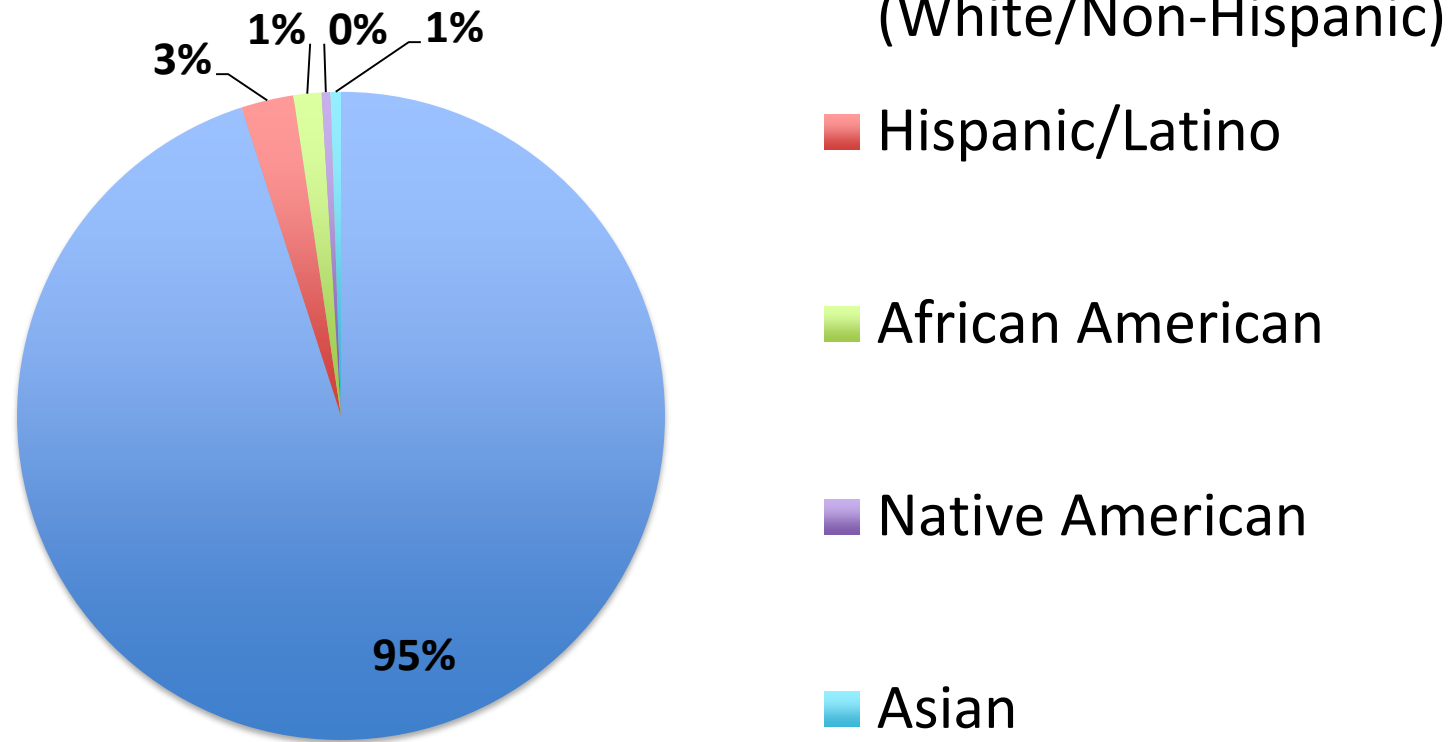
Age At Death

- Youngest person, age 16; oldest, age 96
- 65 is the average age at death



Ethnic Origin

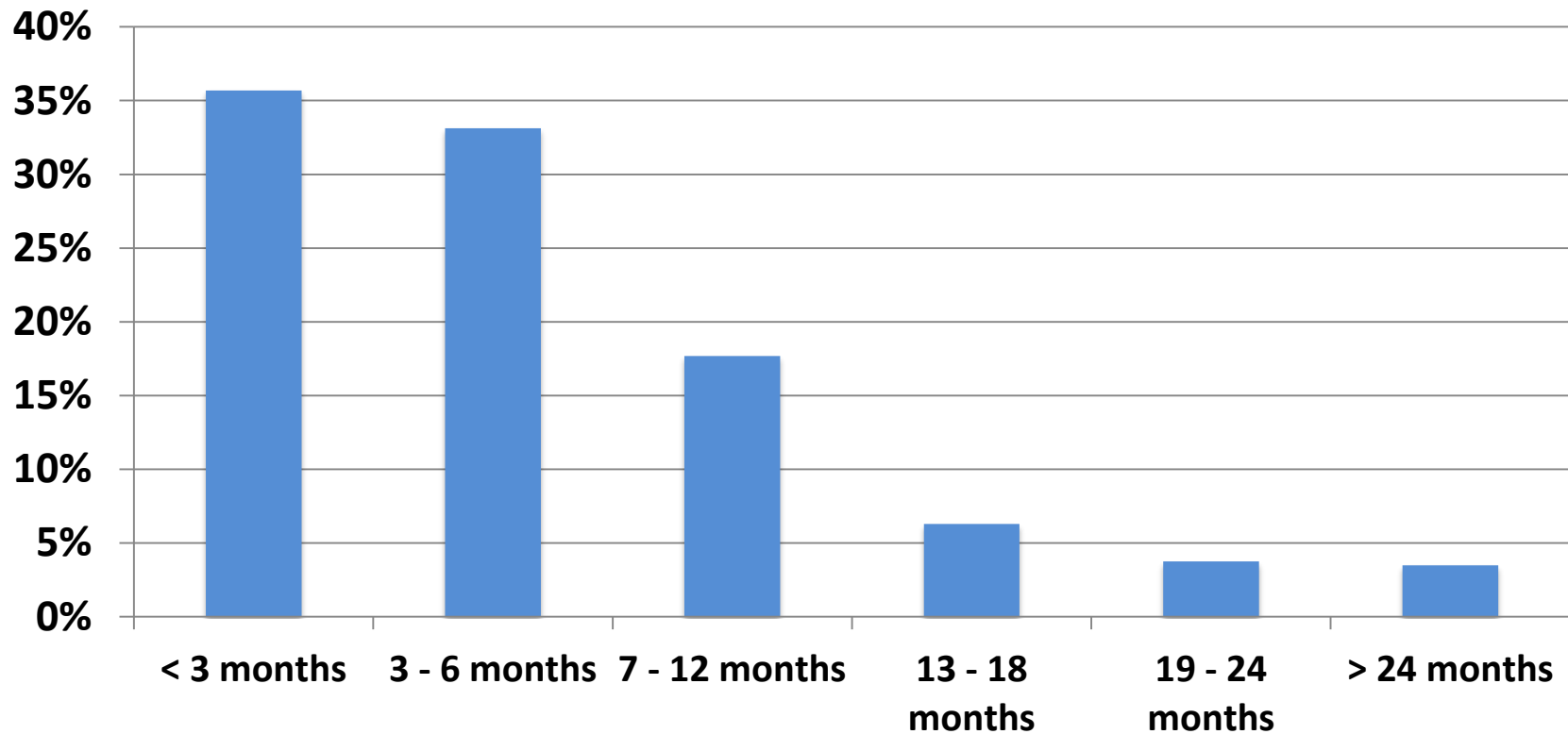
- **Of the 1304 patients**



- ***107 (8%) patient questionnaires with missing data.**

Duration of Illness

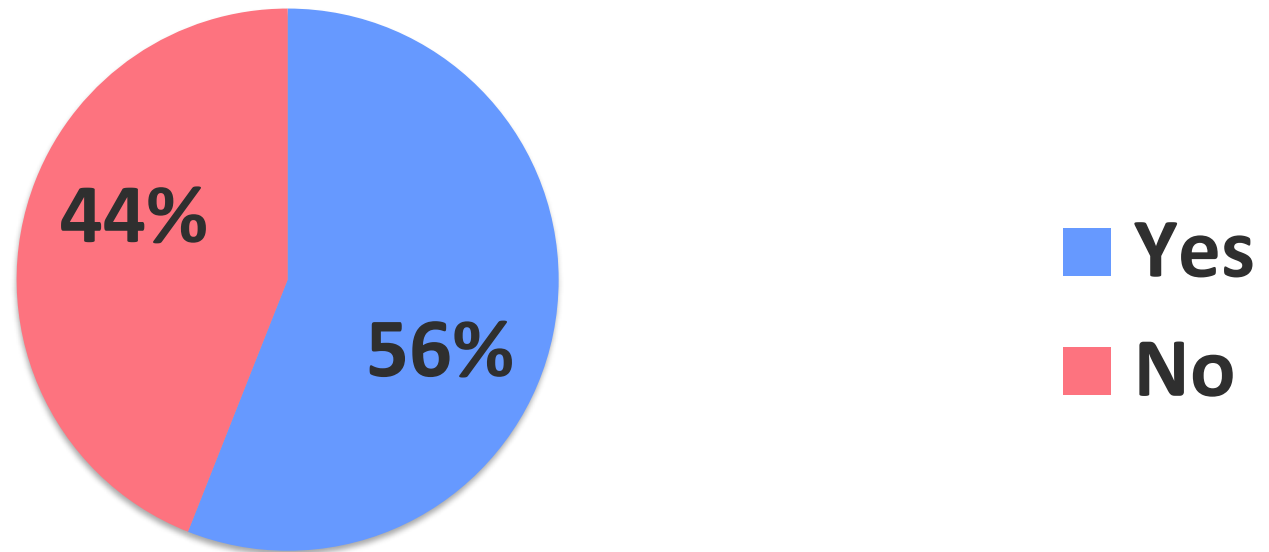
- Of the 1304 patients



***96 (8%) patient questionnaires with missing data.**

Unusual Stress Prior to the Onset of Symptoms

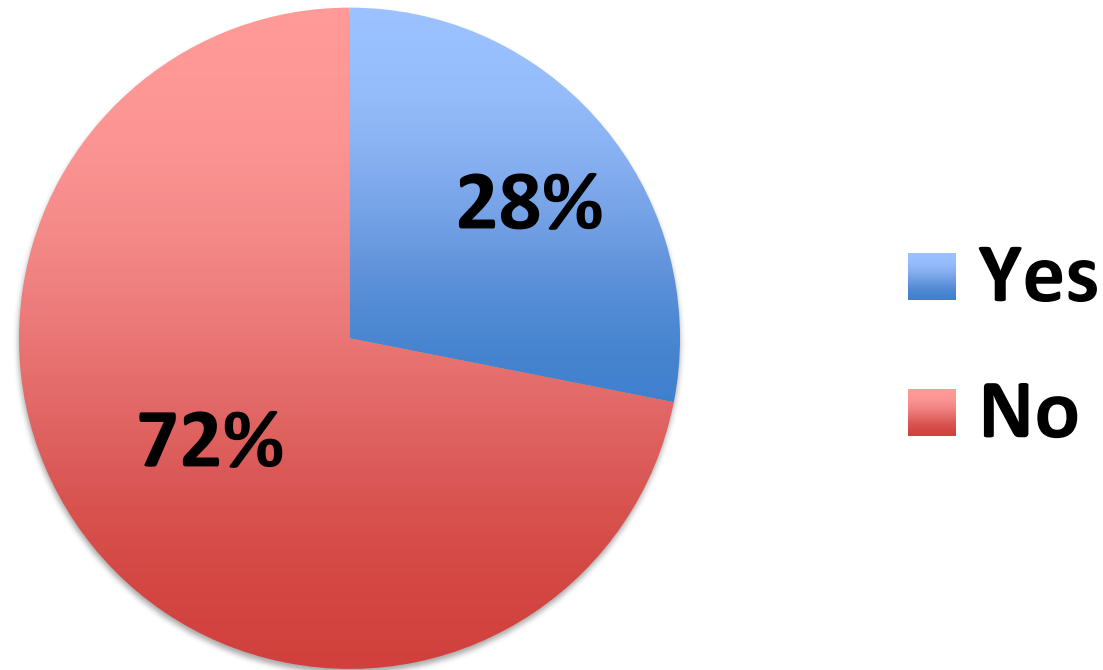
- Of the 1304 patients



- *295 (23%) patient questionnaires with missing data.

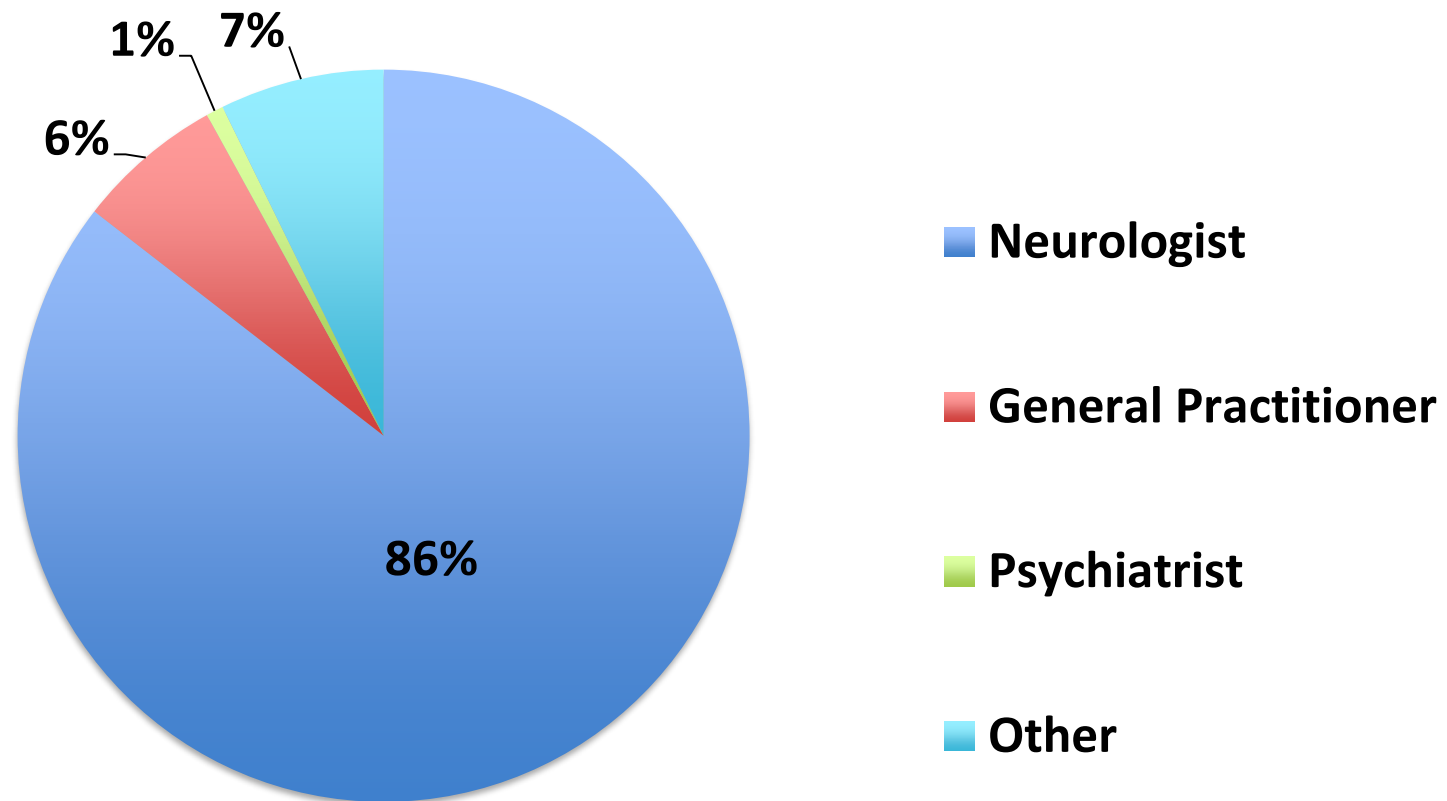
Did Patient Develop Dry Cough

- Of the 1304 patients



- *367 (28%) patient questionnaires with missing data.

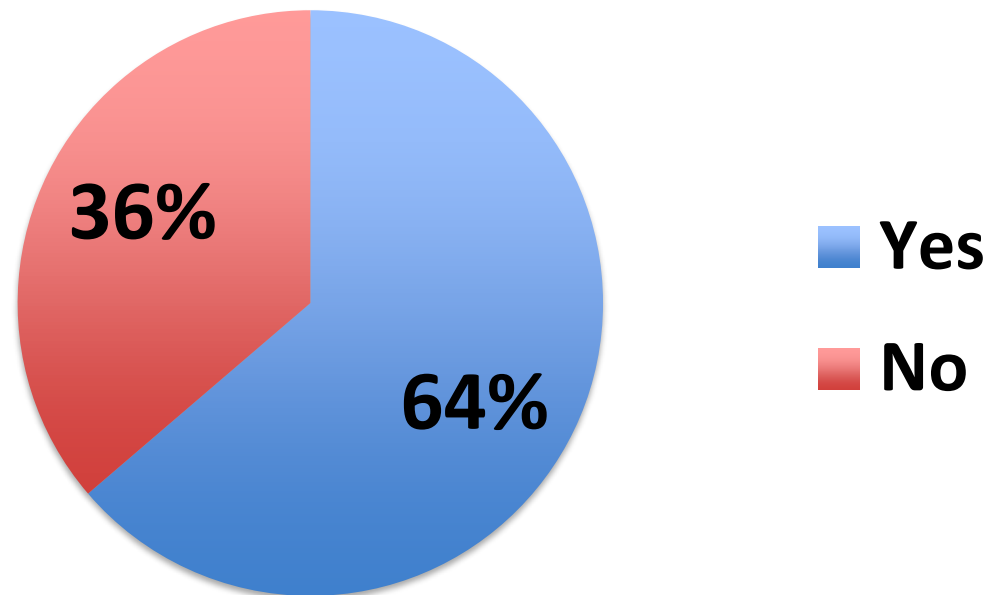
Diagnosing Physician



- **753* (58%) patient questionnaires with missing data.**

Autopsy Information

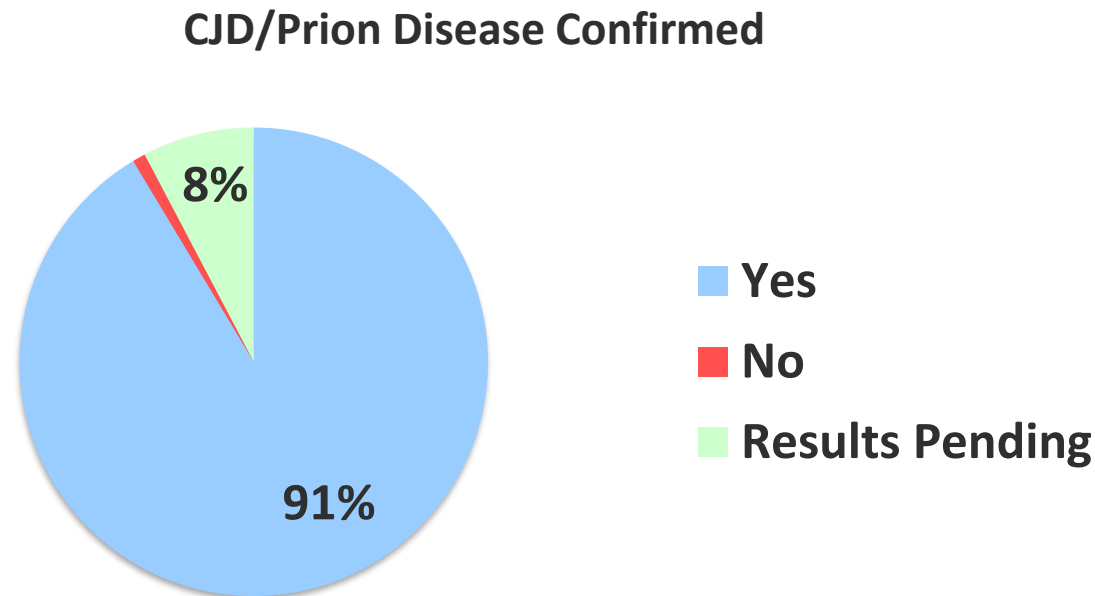
- Was an Autopsy performed?



- 30* (2%) patient questionnaires with missing data.

CJD/Prion Disease Confirmed

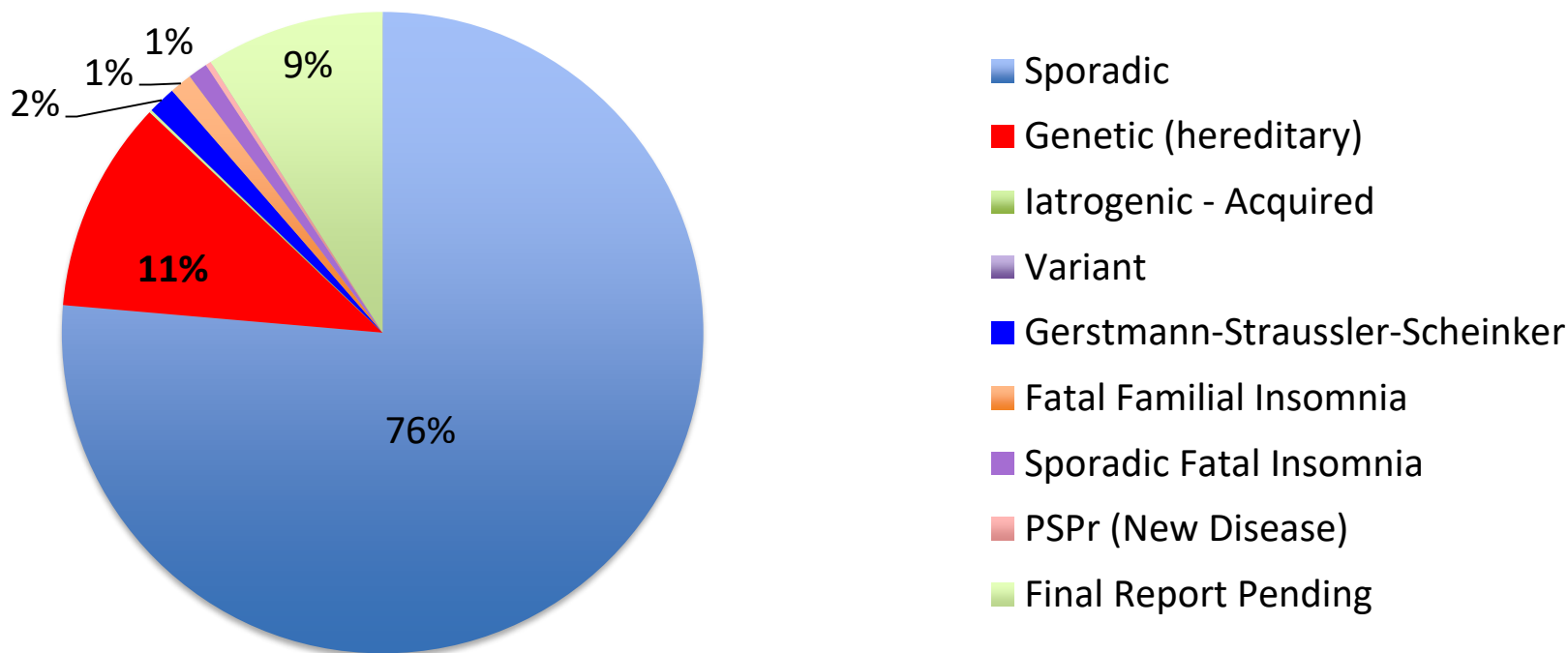
- From Autopsy (813 Patients), was CJD or Other Prion Disease Confirmed?



- 35* (4%) patient questionnaires with missing data

Type of CJD/Prion disease confirmed (Out of 711)

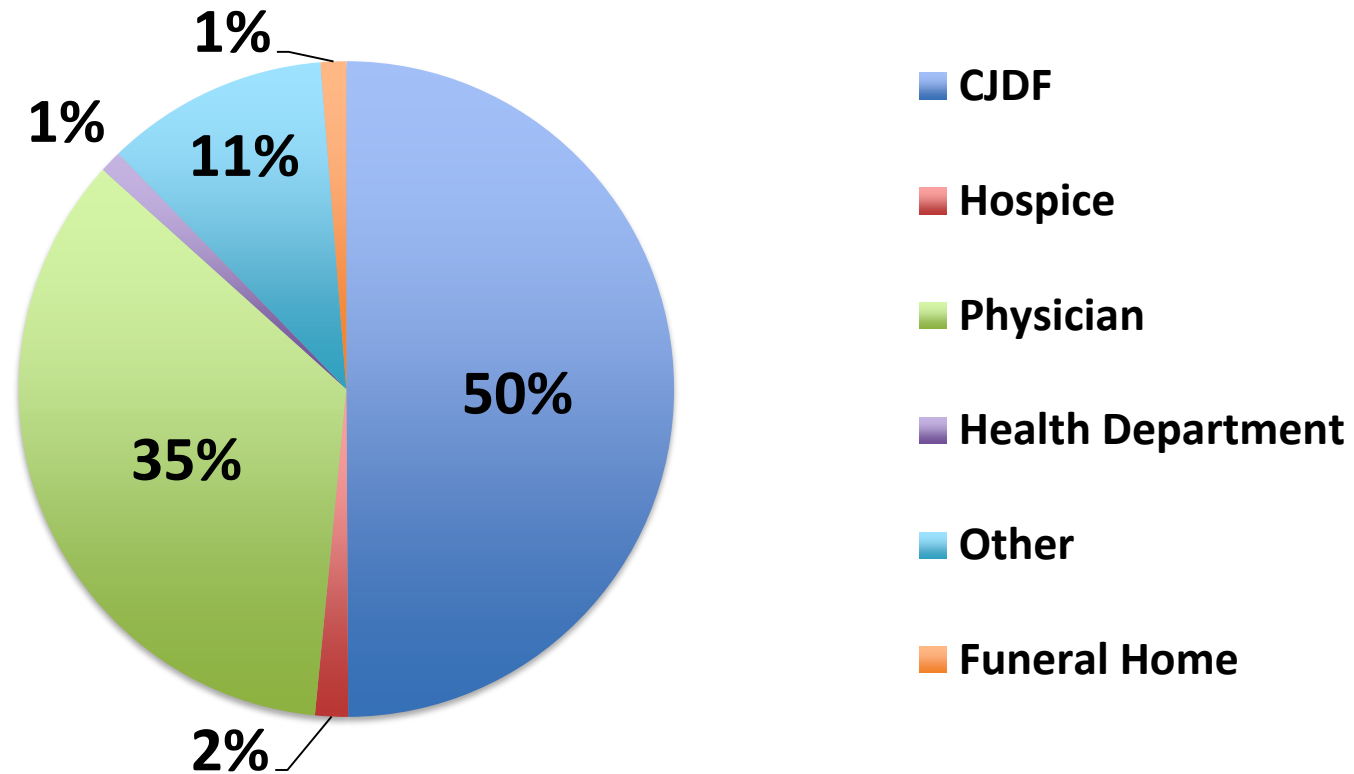
Type of CJD/Prion disease confirmed



Fatal Familial Insomnia	1.1%
Gerstmann-Straussler-Scheinker	1.14%
Iatrogenic (Acquired)	0.1%
PsPr	0.3%
Sporadic Fatal Insomnia	1.0%
Variant	0.6%

Autopsy Referral to NPDPSC

- Of the 813 patients



- 241* (30%) patient questionnaires with missing data.

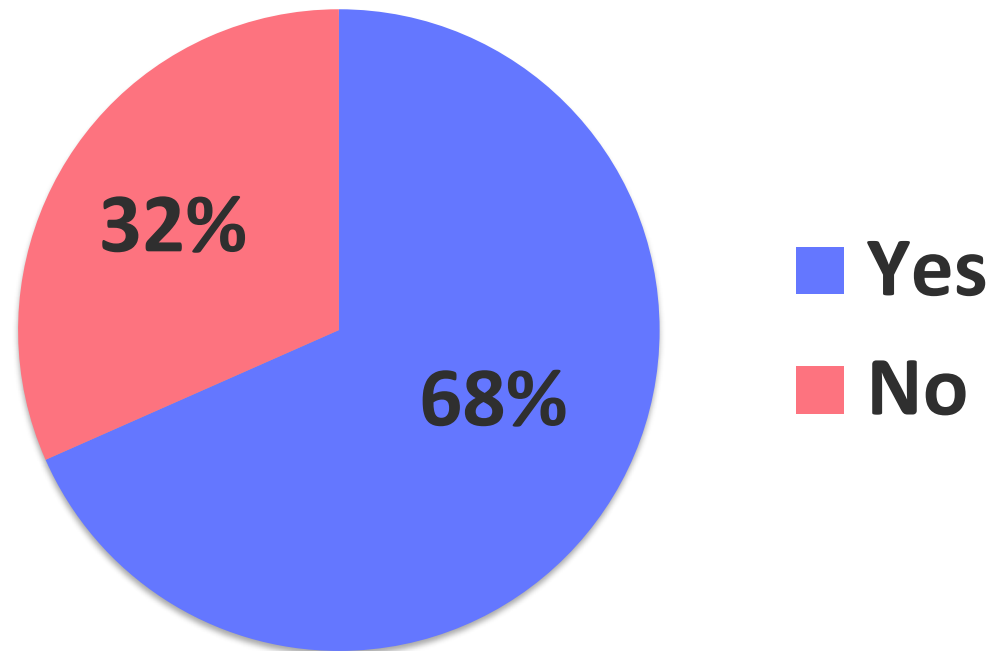
Physician Information

- **Was the Physician**

Informed about CJD	707 (54%)
Informed about CJD Foundation	289 (22%)
Informed about NPDPSC	323 (25%)
Compassionate	754 (58%)
Recommended	907 (70%)

CJD Listed On The Death Certificate

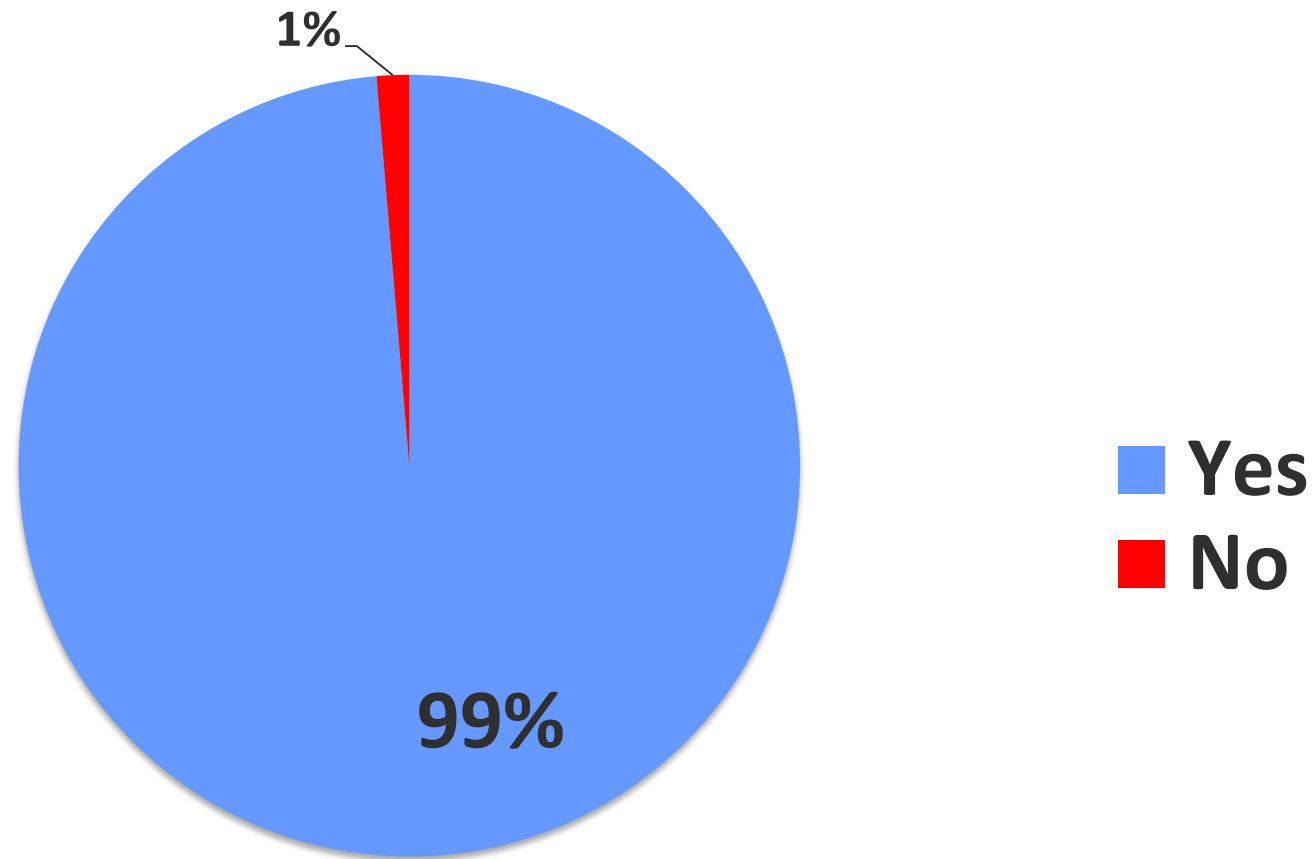
- **Of 1304 patients**



- ***349 (27%) patient questionnaires with missing data.**

Food Consumption and Animal Exposure (1304)

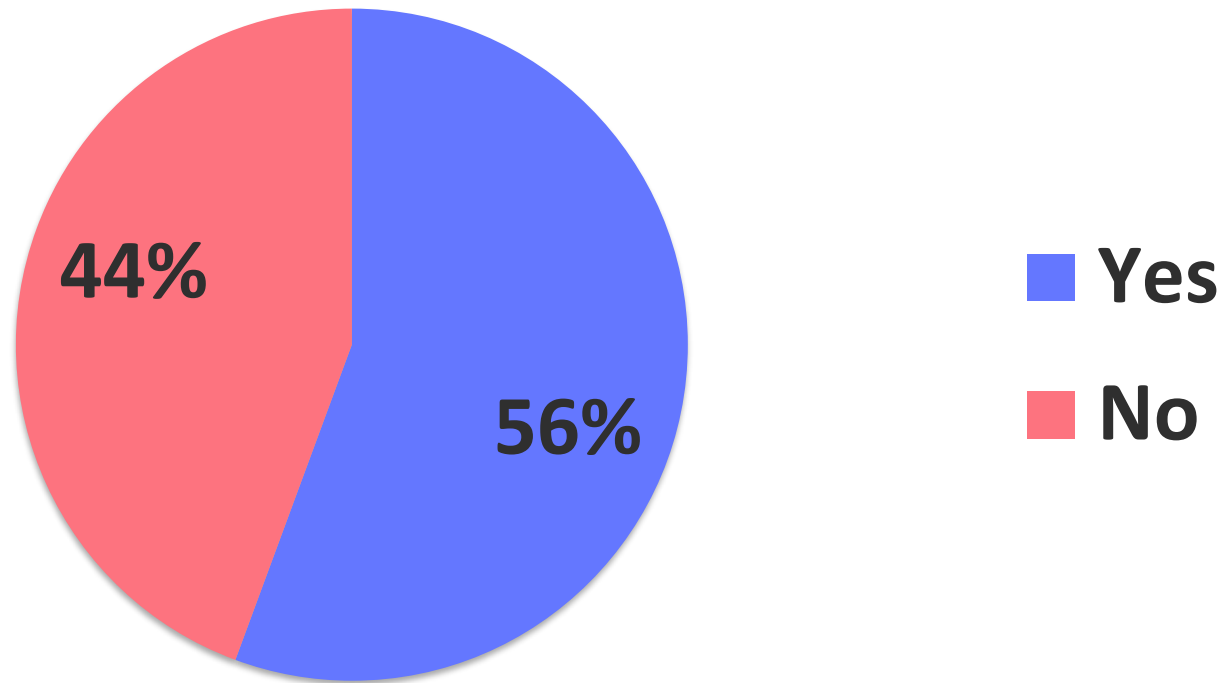
Patients Who Consumed Beef



* 112 (9%) patient questionnaires with missing data

Food Consumption and Animal Exposure (1304)

Patients who consumed deer/elk



- *** 195 (15%) patient questionnaires with missing data**

Travel Outside the US

Yes	715 (61%)
No	450 (39%)

*** 139 (11%) patient questionnaires with missing data**

Travel to:	No. (%)
United Kingdom	241 (18%)
Japan	49 (4%)
Eastern Europe	112 (9%)
France	143 (11%)
Canada	219 (17%)

Surgery and Tissue/Organ Transplant History

- **Type of Organ Transplant**

	No.
Liver	1
Corneal	1

Medical procedures

- **Medical Procedures of Interest**

Gastric (Upper GI)	45 (3%)
Endoscopy	165 (13%)
Colonoscopy	435 (33%)
Other	69 (5%)

Other Medical Procedures

Spinal tap (other than for CJD diagnosis)	141 (11%)
Conditions associated with the thyroid	180 (14%)
Blood donor	383 (29%)
Blood recipient	106 (8%)
Transfusion of albumin or Immunoglobulin	27 (2%)

Of Possible Interest

Dental surgery	783 (60%)
Eye surgery	265 (20%)
Contact lenses	192 (15%)
Eye drops	424 (33%)
HGH treatment	13 (1%)

Of Possible Interest

Hormone replacement therapy Females (out of 603)	116 (19%)
Unknown	63 (10%)
Blank/No	424 (70%)
Homeopathic/herbal therapy	67 (5%)
IV drug use	35 (3%)
Acupuncture	72 (6%)

Of Possible Interest

Vaccinations/ Injections	405 (31%)
Tattoos	72 (6%)
Piercings	367 (28%)

The CJD Foundation Gratefully Acknowledges

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

www.cjdfoundation.org * 800-659-1991



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