Reference Center for Prion Diseases in Poland

https://www.neurodegenerationresearch.eu/survey/reference-center-for-prion-diseases-in-poland/

Title of the register

Reference Center for Prion Diseases in Poland

Name of Principal Investigator

Title	Dr
First name	Beata
Last name	Sikorska

Address of institution where award is held

Institution	Medical University of Lodz
Street Address	Czechoslowacka 8/10
City	Lodz
Postcode	92-216

Country

Poland

Website

http://www.umed.pl/pl/index1.php?dir=inf&mn=jednostka&cc=20730600

Contact email

1. Conditions included, or expected to be included, in the disease register

Prion disease

2a. Stated aim of the cohort

Surveillance of human prion diseases in Poland

2b. Features distinguishing this register from other disease registers

This is the only center for prion diseases in Poland

3a. i) Number of publications that involve use of register to date

0

3c. Information (i.e. research findings) expected to be gained from the register

The number of cases is still low and the conclusions need to be verified on a higher number of cases

4a. Study criteria: age range of participants

Age in years from:	50
To (‘until death’ is applicable):	until death

4b. Study criteria: inclusion criteria

Cases fulfilling criteria for probable or possible prion disease

4c. Study criteria: exclusion criteria

No clinical evidence for CJD

5. Size of the register (i.e. number of patients enrolled)
0 – 500 clinical cases
6a. Measures used to characterise participants

Age, sex, clinical symptoms at onset, MRI if available

6b. Are there defined primary and secondary endpoints (e.g. defined health parameters)
No
7a. i) Is the register of fixed duration

1

7a. ii) Data collection start date

02-01-2003

7b. Stage of data collection/analysis for the register
Data collection ongoing
Data analysis ongoing
8. Funding of the register

How the register is funded	No dedicated funding. Some means from governmental grants for research projects on prion diseases

9. Data sweeping

Number of data sweeps that have taken place 0

10.The clinical (phenotypic) information held in the register from patients and other participants such as family members is
Routinely collected as medical records
11. Limit on the number of studies that can be based on this set of patients
No
12a. Data stored in a database

Yes/No	% available
No	
No	
Yes	100
Yes	100
No	

12b. Data held as individual records

Yes/No	% available
Yes	100
No	

Yes 50
No
No

13a. Are data available to other groups

2

13b. Access policy/mechanisms for access if data are available to other groups
Apply to PI or co-ordinator at resource
Applicant needs to provide separate external ethics approval
14. Data sharing policy specified as a condition of use
No policy exists
15a. Are tissues/samples/DNA available to other groups

2

15b. i) Description of available tissues/samples/DNA
Living donors:blood
Living donors: cerebro-spinal fluid
Post-mortem donors: brain
15b. ii) Form available tissues/samples/DNA are supplied in
Primary Samples: Stabilised samples (frozen or fixed)
15b iii) Is the access policy/mechanism for obtaining samples the same as that for obtaining data

2

16a. Is information on biological characteristics available to other group
No
16b. Is the access policy/mechanism for obtaining details of the characteristics the same as that for obtaining other data

2