FTD Clinical Data Element Form

Principal Investigator Responsible for Accuracy of Data:	Name

Data entered by:	Name	Date Entered:	Date
Email:			

Subject Data

Subject ID Number:	
Visit:	Select Visit
Gender:	Select Biological Gender
Age at Sample Collection:	
Age at Sample Collection Units:	Select Age Units
Year of Birth:	
Country of Residence:	
Subject Zip Code (1st 3 digits):	

If subject is deceased, please enter one of the following:

Date of Death:	
Last Known Alive Date:	

Subject Affected Status

Subject Affected Status:	Select Affected Status

If subject is affected, please enter the following:

Subject Age at Onset:	
Subject Age at Onset Units:	
Subject Age at Diagnosis:	
Subject Age at Diagnosis Units:	

Ethnic and Racial Data

Ethnic Category (as reported by subject):	Select Ethnic Category
Racial Category (as reported by subject):	Select Racial Category
If other, please indicate race:	

Please indicate any additional ethnic/racial information:

Diagnosed By

Diagnosed By:	Select Diagnosed By
If other, please indicate diagnosed by:	

Data Collected By

Data Collected By:	Data Collected By
If other, please indicate data collected by:	

Family Member Samples in Repository

Family Member Samples in Repository?	Select

If yes, please list Subject ID(s) of Family Member Sample(s) in Repository:

FTD Medical History

Indicate current diagnosis of FTD:	Select Diagnosis

Signs Suggestive of FTD Diagnosis

Disinhibition:	Select	Limb weakness:	Select
Apathy or Inertia:	Select	Bulbar weakness:	Select
Loss of sympathy / empathy:	Select	Fasciculations:	Select
Ritualistic / compulsive behavior:	Select	Hyperreflexia:	Select
Hyperorality / dietary changes:	Select	Vertical gaze palsy:	Select
Neuropsychology c/w FTD:	Select	Falls:	Select
Imaging c/w FTD:	Select	Axial rigidity:	Select
Expressive aphasia:	Select	Asymmetric dystonia / rigidity:	Select
Impaired object naming:	Select	Apraxia:	Select
Poor sentence repetition:	Select	Myoclonus:	Select
Impaired word comprehension:	Select	Abnormal EMG:	Select

Genetic Characterization

Has Subject had Genetic Testing?	Select

If yes, please enter the following:

Mutation(s) Present in Subject:	

If yes, please enter the following:

Subject Mutation(s): Please indicate the gene(s) and mutation(s)	

Subject Genetic Characterization:	Select Genetic Characterization

Family History

Father Affected:	Select

If yes, please enter the following:

Affected Father Subject ID (if banked in Repository):	
Affected Father Age of Onset:	
Affected Father Diagnosis:	
Affected Father Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Mother Affected:	Select

If yes, please enter the following:

Affected Mother Subject ID (if banked in Repository):	
Affected Mother Age of Onset:	
Affected Mother Diagnosis:	
Affected Mother Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Sibling(s) Affected:	Select

If yes, please enter the following:

Affected Sibling 1:	
Affected Sibling 1 Subject ID (if banked in Repository):	
Affected Sibling 1 Age of Onset:	
Affected Sibling 1 Diagnosis:	
Affected Sibling 1 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Affected Sibling 2:	
Affected Sibling 2 Subject ID (if banked in Repository):	
Affected Sibling 2 Age of Onset:	
Affected Sibling 2 Diagnosis:	
Affected Sibling 2 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Affected Sibling 3:	
Affected Sibling 3 Subject ID (if banked in Repository):	
Affected Sibling 3 Age of Onset:	
Affected Sibling 3 Diagnosis:	
Affected Sibling 3 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Family History (cont.)

Affected Sibling 4:	
Affected Sibling 4 Subject ID (if banked in Repository):	
Affected Sibling 4 Age of Onset:	
Affected Sibling 4 Diagnosis:	
Affected Sibling 4 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Affected Sibling 5:	
Affected Sibling 5 Subject ID (if banked in Repository):	
Affected Sibling 5 Age of Onset:	
Affected Sibling 5 Diagnosis:	
Affected Sibling 5 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Affected Sibling 6:	
Affected Sibling 6 Subject ID (if banked in Repository):	
Affected Sibling 6 Age of Onset:	
Affected Sibling 6 Diagnosis:	
Affected Sibling 6 Confirmed Mutation(s): Please list gene(s) and mutation(s)	

Other Affected Family Members

List any other affected family members; include age of onset, diagnosis, subject ID, and known mutations:

Optional Data

UPDRS Total Motor Score:	
Standard Global CDR:	
FTD Supplemental CDR Sum of Boxes:	

Notes

Please list any additional information pertinent to this subject:
