

Form A3: Participant Family History

In-person Remote

ADRC name: _____ Participant ID: _____ Form date: ____ / ____ / ____

Visit #: _____ Examiner's initials: _____ Language: English Spanish

INSTRUCTIONS: *This form is to be completed by a clinician with experience in evaluating participants with neurological and psychiatric diagnoses. Estimates are allowed if exact birth year or age at death is unknown. For additional clarification and examples, see the **UDS Coding Guidebook for Initial Visit Packet, Form A3.***

Section 1 – Biological parents

For any parent with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and *skip the subsequent questions in the row*. For a parent with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then *skip the subsequent questions in the row*. For a parent with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the Secondary diagnosis column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999= Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
..... SEE LIST OF CODES						
1a. Mother	_____	_____	_____	_____	_____	_____
1b. Father	_____	_____	_____	_____	_____	_____

Codes

*DIAGNOSES

- 00 No known neurological/psychiatric diagnosis
- 01 Alzheimer's Disease
- 02 Lewy Body dementia (includes DLB and PDD)
- 03 Vascular dementia
- 04 Stroke
- 05 FTLD* without motor neuron disease
- 06 FTLD* with motor neuron disease
- 07 Motor Neuron Disease
- 08 Parkinson's Disease
- 09 Prion pathology
- 10 Psychiatric condition
- 11 Dementia of unknown etiology
- 12 Other
- 88 No secondary diagnosis
- 99 Specific diagnosis unknown (*acceptable if method of evaluation is not by exam or autopsy*)

**METHOD OF EVALUATION

- 1 Participant /family report
- 2 Medical records
- 3 Exam
(co-enrolled family members)
- 4 Autopsy
(if autopsy report available)

**FTLD includes: bvFTD or FTD, PPA (any subtype), CBS or CBD, PSP*

Abbreviations: bvFTD = behavioral variant frontotemporal dementia, CBS = corticobasal syndrome, CBD = corticobasal degeneration, DLB = dementia with Lewy bodies, FTD = frontotemporal dementia, PDD = Parkinson's disease with dementia, PPA = primary progressive aphasia, PSP = progressive supranuclear palsy

YEAR OF BIRTH FOR FULL SIBLINGS & BIOLOGICAL CHILDREN: If birth year is unknown, please provide an approximate year on **UDS Initial Visit Form A3** and **UDS Follow-up Visit Form A3** so that the sibling or child with unknown birth year ends up in correct birth order relative to the other siblings/children.

Example: A participant is the oldest of three children. The participant was born in 1940 and the middle sibling in 1943; the youngest sibling's birth year is unknown. An approximate birth year of 1944 or later should be assigned to the youngest sibling.

Use that same birth year on **FTLD Module Form A3a**, if applicable, and across all UDS visits so that any new information on a particular sibling or child can be linked to previously submitted information. If it is impossible for the participant and co-participant to estimate the birth year, enter **9999=Unknown**.

Section 2 – Full siblings

3. How many full siblings does the participant have?

 If participant has no full siblings, **SKIP TO QUESTION 4**; otherwise, provide information on all full siblings.

For any full sibling with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and skip the subsequent questions in the row. For a full sibling with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then skip the subsequent questions in the row. For a full sibling with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the **Secondary diagnosis** column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
..... SEE LIST OF CODES						
2a. Sibling 1	_____	_____	_____	_____	_____	_____
2b. Sibling 2	_____	_____	_____	_____	_____	_____
2c. Sibling 3	_____	_____	_____	_____	_____	_____
2d. Sibling 4	_____	_____	_____	_____	_____	_____
2e. Sibling 5	_____	_____	_____	_____	_____	_____
2f. Sibling 6	_____	_____	_____	_____	_____	_____
2g. Sibling 7	_____	_____	_____	_____	_____	_____
2h. Sibling 8	_____	_____	_____	_____	_____	_____
2i. Sibling 9	_____	_____	_____	_____	_____	_____
2j. Sibling 10	_____	_____	_____	_____	_____	_____
2k. Sibling 11	_____	_____	_____	_____	_____	_____
2l. Sibling 12	_____	_____	_____	_____	_____	_____
2m. Sibling 13	_____	_____	_____	_____	_____	_____
2n. Sibling 14	_____	_____	_____	_____	_____	_____
2o. Sibling 15	_____	_____	_____	_____	_____	_____
2p. Sibling 16	_____	_____	_____	_____	_____	_____
2q. Sibling 17	_____	_____	_____	_____	_____	_____
2r. Sibling 18	_____	_____	_____	_____	_____	_____
2s. Sibling 19	_____	_____	_____	_____	_____	_____
2t. Sibling 20	_____	_____	_____	_____	_____	_____

Section 3 – Biological children

4. How many biological children does the participant have?

If participant has no biological siblings, **END FORM HERE**; otherwise, provide information on all biological children.

For any biological child with a neurological or psychiatric diagnosis, the entire row must be filled out.

If the clinician cannot determine the primary neurological/psychiatric diagnosis after reviewing all available evidence, enter **99 = Unknown** in the **Primary diagnosis** column, and skip the subsequent questions in the row. For a biological child with no neurological or psychiatric diagnosis, enter **00 = No known neurological/psychiatric diagnosis** in the **Primary diagnosis** column, and then skip the subsequent questions in the row. For a biological child with a primary diagnosis but no secondary diagnosis, enter **88 = No secondary diagnosis** in the Secondary diagnosis column.

	Birth year (9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary dx*	Secondary dx*	Method of evaluation**	Age of onset of primary dx (999=Unknown)
		 SEE LIST OF CODES			
3a. Child 1	-----	-----	---	---	---	-----
3b. Child 2	-----	-----	---	---	---	-----
3c. Child 3	-----	-----	---	---	---	-----
3d. Child 4	-----	-----	---	---	---	-----
3e. Child 5	-----	-----	---	---	---	-----
3f. Child 6	-----	-----	---	---	---	-----
3g. Child 7	-----	-----	---	---	---	-----
3h. Child 8	-----	-----	---	---	---	-----
3i. Child 9	-----	-----	---	---	---	-----
3j. Child 10	-----	-----	---	---	---	-----
3k. Child 11	-----	-----	---	---	---	-----
3l. Child 12	-----	-----	---	---	---	-----
3m. Child 13	-----	-----	---	---	---	-----
3n. Child 14	-----	-----	---	---	---	-----
3o. Child 15	-----	-----	---	---	---	-----

Not approved for