FOLLOW-UP VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form A3: Subject Family History

ADC name: _____ Subject ID: _ _ _ _ _ _ _ _ _ _ Form date: _ _ / _ _ / _ _ _ _

Visit #: _ _ _ Examiner's initials: _ _ _

INSTRUCTIONS: This form is to be completed by a clinician with experience in evaluating patients with neurological problems and psychiatric conditions. For additional clarification and examples, see UDS Coding Guidebook for Follow-up Visit Packet, Form A3.

SPECIAL INSTRUCTIONS for subjects who are receiving UDS Version 3 of Form A3 for the first time:

NOTE: A subject is receiving UDS v3 Form A3 for the first time if:

- *No A3 data has been submitted yet for this subject –OR–*
- *A3 data has been submitted for this subject, but it was collected using UDS v2*

For such subjects, you must fill out this form in its entirety, meaning:

1. You must answer **1=Yes** to Question 1 on genetic mutations and complete 2a – 4b.
2. You must answer **1=Yes** to Question 5 on parents and complete 5a – 5b.
3. You must answer **1=Yes** to Question 6a on siblings and complete 6aa – 6at, as appropriate.
4. You must answer **1=Yes** to Question 7a on children and complete 7aa – 7ao, as appropriate.

Corrections or new information on previously submitted family members — For family members who were denoted as being "affected" with a neurological or psychiatric condition or who were not affected at a previous UDS visit, any corrections to their data should be made to that previous A3 Form. Any newly obtained information (e.g., new mutation information, new diagnoses, new method of evaluation), including for family members previously reported as being affected at a past UDS visit, should be indicated on this form and should not be submitted as a correction to a previously submitted Form A3.

A summary of all previously submitted family history data can be found at: **https://www.alz.washington.edu/MEMBER/siteprint.html.**

1. Since the last visit, is new information available concerning genetic mutations addressed by Questions 2a through 4b, below?	☐ 0 No **(SKIP TO QUESTION 5)** ☐ 1 Yes ☐ 9 Unknown **(SKIP TO QUESTION 5)**
2a. In this family, is there evidence for an AD mutation? If Yes, select predominant mutation. NOTE: APOE should not be reported here.	☐ 0 No (**SKIP TO QUESTION 3a**) ☐ 1 Yes, APP ☐ 2 Yes, PS-1 (PSEN 1) ☐ 3 Yes, PS-2 (PSEN 2) ☐ 8 Yes, other (SPECIFY): _____ ☐ 9 Unknown whether mutation exists (**SKIP TO QUESTION 3a**)
2b. Source of evidence for AD mutation (check one):	☐ 1 Family report (no test documentation available) ☐ 2 Commercial test documentation ☐ 3 Research lab test documentation ☐ 8 Other (SPECIFY): _____ ☐ 9 Unknown

3a. In this family, is there evidence for an FTLD mutation? If Yes, select predominant mutation.	☐ 0 No (**SKIP TO QUESTION 4a**) ☐ 1 Yes, MAPT ☐ 2 Yes, PGRN ☐ 3 Yes, C9orf72 ☐ 4 Yes, FUS ☐ 8 Yes, other (SPECIFY): _____ ☐ 9 Unknown whether mutation exists (**SKIP TO QUESTION 4a**)
3b. Source of evidence for FTLD mutation (check one):	☐ 1 Family report (no test documentation available) ☐ 2 Commercial test documentation ☐ 3 Research lab test documentation ☐ 8 Other (SPECIFY): _____ ☐ 9 Unknown
4a. In this family, is there evidence for a mutation other than an AD or FTLD mutation? (If No or Unknown, **SKIP TO QUESTION 5**)	☐ 0 No (**SKIP TO QUESTION 5**) ☐ 1 Yes (SPECIFY): _____ ☐ 9 Unknown (**SKIP TO QUESTION 5**)
4b. Source of evidence for other mutation (check one):	☐ 1 Family report (no test documentation available) ☐ 2 Commercial test documentation ☐ 3 Research lab test documentation ☐ 8 Other (SPECIFY): _____ ☐ 9 Unknown

BIOLOGICAL PARENTS

5. Since the last UDS visit, is new information available concerning the status of the subject's biological mother or father?

☐ 0 No **(SKIP TO QUESTION 6)** ☐ 1 Yes **(COMPLETE QUESTIONS 5A–5B, AS APPLICABLE)**

If birth year is unknown, please provide an approximate year on the Initial Visit Form A3 and ensure that it is consistently reported on all Forms A3 submitted (Initial Visit and Follow-up). If it is impossible for the subject and co-participant to estimate year of birth, enter *9999=Unknown.* For any biological parent with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter *9=Unknown* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the parent has no neurological or psychiatric problem, enter *8=N/A — no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=Unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
			See CODES below this table			
5a. Mother	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___
5b. Father	___ ___ / ___ ___ ___ ___	___ ___ ___	___	___ ___ ___	___	___ ___ ___

***CODES for neurological problems and psychiatric conditions**

1 Cognitive impairment/behavior change
2 Parkinsonism
3 ALS
4 Other neurologic condition such as multiple sclerosis or stroke
5 Psychiatric condition such as schizophrenia, bipolar disorder, alcoholism, or depression
8 N/A — no neurological problem or psychiatric condition
9 Unknown

****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

*****CODES for method of evaluation**

1 Autopsy
2 Examination
3 Medical record review from formal dementia evaluation
4 Review of general medical records AND co-participant and/or subject telephone interview
5 Review of general medical records only
6 Subject and/or co-participant telephone interview
7 Family report

Year of birth for full siblings and 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/child with unknown birth year ends up in correct birth order relative to the other siblings/children.

Example: A subject is the oldest of three children. The subject 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 subject and co-participant to estimate year of birth, enter *9999=Unknown.*

FULL SIBLINGS

6. How many full siblings does the subject have? ⎵⎵ If subject has no full siblings, **SKIP TO QUESTION 7.**

6a. Since the last UDS visit, is new information available concerning the status of the subject's siblings?

☐ 0 No **(SKIP TO QUESTION 7)** ☐ 1 Yes **(COMPLETE QUESTIONS 6aa–6at, AS APPLICABLE)**

For any full sibling with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter *9=Unknown* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the sibling has no neurological or psychiatric problem, enter *8=N/A — no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=unknown)	Primary neurological problem/psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
			See CODES on page 4			
6aa. Sibling 1	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ab. Sibling 2	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ac. Sibling 3	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ad. Sibling 4	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ae. Sibling 5	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6af. Sibling 6	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ag. Sibling 7	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ah. Sibling 8	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ai. Sibling 9	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6aj. Sibling 10	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ak. Sibling 11	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6al. Sibling 12	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6am. Sibling 13	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6an. Sibling 14	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ao. Sibling 15	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ap. Sibling 16	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6aq. Sibling 17	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6ar. Sibling 18	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6as. Sibling 19	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵
6at. Sibling 20	⎵⎵/⎵⎵⎵⎵	⎵⎵⎵	⎵	⎵⎵⎵	⎵	⎵⎵⎵

BIOLOGICAL CHILDREN

7. How many biological children does the subject have? ⌊_⌊_ If subject has no biological children, **END FORM HERE**.

7a. Since the last UDS visit, is new information available concerning the status of the subject's biological children?

☐ 0 No **(END FORM HERE)** ☐ 1 Yes **(COMPLETE QUESTIONS 7aa–7ao, AS APPLICABLE)**

For any biological child with a neurological or psychiatric problem, the entire row must be filled out. If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence, enter *9=Unknown* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row. If the child has no neurological or psychiatric problem, enter *8=N/A — no neurological problem or psychiatric condition* in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

	Birth month/year (99/9999=Unknown)	Age at death (888=N/A, 999=unknown)	Primary neurological problem/ psychiatric condition*	Primary Dx**	Method of evaluation***	Age of onset (999=unknown)
			See CODES below this table			
7aa. Child 1	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ab. Child 2	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ac. Child 3	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ad. Child 4	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ae. Child 5	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7af. Child 6	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ag. Child 7	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ah. Child 8	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ai. Child 9	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7aj. Child 10	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ak. Child 11	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7al. Child 12	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7am. Child 13	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7an. Child 14	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_
7ao. Child 15	⌊_⌊_/⌊_⌊_⌊_⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_	⌊_	⌊_⌊_⌊_

***CODES for neurological problems and psychiatric conditions**

1 Cognitive impairment/behavior change
2 Parkinsonism
3 ALS
4 Other neurologic condition such as multiple sclerosis or stroke
5 Psychiatric condition such as schizophrenia, bipolar disorder, alcoholism, or depression
8 N/A — no neurological problem or psychiatric condition
9 Unknown

****CODES for primary diagnosis**

See Appendix 1 on page 5 of this form.

*****CODES for method of evaluation**

1 Autopsy
2 Examination
3 Medical record review from formal dementia evaluation
4 Review of general medical records AND co-participant and/or subject telephone interview
5 Review of general medical records only
6 Subject and/or co-participant telephone interview
7 Family report

**APPENDIX 1: PRIMARY DIAGNOSIS CODES

040	Mild cognitive impairment (MCI), not otherwise specified
041	MCI — single domain amnestic
042	MCI — multiple domain with amnesia
043	MCI — single domain nonamnestic
044	MCI — multiple domain nonamnestic
045	Impaired, but not MCI
050	Alzheimer's disease dementia
070	Dementia with Lewy bodies
080	Vascular cognitive impairment or dementia
100	Impairment due to alcohol abuse
110	Dementia of undetermined etiology
120	Behavioral variant frontotemporal dementia
130	Primary progressive aphasia, semantic variant
131	Primary progressive aphasia, nonfluent/agrammatic variant
132	Primary progressive aphasia, logopenic variant
133	Primary progressive aphasia, not otherwise specified
140	Clinical progressive supranuclear palsy
150	Clinical corticobasal syndrome/corticobasal degeneration
160	Huntington's disease
170	Clinical prion disease
180	Cognitive dysfunction from medications
190	Cognitive dysfunction from medical illness
200	Depression
210	Other major psychiatric illness
220	Down syndrome
230	Parkinson's disease
240	Stroke
250	Hydrocephalus
260	Traumatic brain injury
270	CNS neoplasm
280	Other
310	Amyotrophic lateral sclerosis
320	Multiple sclerosis
999	Specific diagnosis unknown *(acceptable if method of evaluation is not by autopsy, examination, or dementia evaluation)*

Neuropathology diagnosis from autopsy	
400	Alzheimer's disease neuropathology
410	Lewy body disease — neuropathology
420	Gross infarct(s) neuropathology
421	Hemorrhage(s) neuropathology
422	Other cerebrovascular disease neuropathology
430	ALS/MND
431	FTLD with Tau pathology — Pick's disease
432	FTLD with Tau pathology — CBD
433	FTLD with Tau pathology — PSP
434	FTLD with Tau pathology — argyrophyllic grains
435	FTLD with Tau pathology — other
436	FTLD with TDP-43
439	FTLD other (FTLD-FUS, FTLD-UPS, FTLD NOS)
440	Hippocampal sclerosis
450	Prion disease neuropathology
490	Other neuropathologic diagnosis not listed above

***APPENDIX 2: METHOD OF EVALUATION

1. **Autopsy**

   If the autopsy was performed at an outside institution, **you must have the report** to code as diagnosis by autopsy.

2. **Examination**

   The subject must have been examined in person at your ADC/ institution or by genetic studies staff associated with your ADC/ institution to code as diagnosis by examination. Medical records may or may not have been used when assigning diagnosis.

3. **Medical record review from formal dementia evaluation**

   Medical records should be from an examination that focused specifically on dementia; that was performed by a neurologist, geriatrician, or psychiatrist; and that includes a neurologic examination, an imaging study, and cognitive testing (e.g., MMSE, Blessed, or more formal tests). A telephone interview may also be used to collect additional information.

4. **Review of general medical records AND co-participant and/or subject telephone interview**

   General medical records can be of various types, including those from a primary-care physician's office, hospitalization records, nursing home records, etc. They may include a neurologic exam and a cognitive test such as the MMSE along with a medical history. **The telephone interview** with the subject and/or the co-participant should include a medical history to capture the nature and presentation of cognitive deficits, if present, and age of onset if symptomatic. If the subject is normal or is in the early stages of cognitive impairment, brief formal cognitive testing should be included in the interview.

5. **Review of general medical records ONLY**

   See definition No. 4 above. If general medical records are used to diagnose a subject as demented or not demented, they should include a medical history, neurologic exam, and a cognitive test such as an MMSE. In most cases, general medical records alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTLD spectrum subtypes, or of parkinsonian disorders other than Parkinson's disease.

6. **Subject and/or co-participant telephone interview**

   See definition No. 4 above.

7. **Family report**

   Family report should be coded when the co-participant for the family reports a subject as having been diagnosed with a particular disorder. In most cases, family report alone should not be used to assign a diagnosis of mild cognitive impairment, or of any of the FTLD spectrum subtypes, or of parkinsonian disorders other than Parkinson's disease.