## INITIAL VISIT PACKET UNIFORM DATA SET (UDS) VERSION 4.0



## Form A3: Participant Family History

ADRC name: Participant ID:				nte:	_ / /				
	Examiner's initials	:	_						
ions. Estimates are	allowed if exact bir	th year or age at de	ath is unkn	-					
or biological children)?					□ □ 0 No				
ogical Parent	S								
For any parent with a neurological or psychiatric condition, the entire row <u>must be filled out</u> .  If the clinician cannot determine the primary neurological problem/psychiatric condition after reviewing all available evidence enter <b>9 = Unknown</b> in the <b>Primary neurological problem/psychiatric condition</b> column, and <i>skip the subsequent questions in the row</i> . For a parent with no neurological or psychiatric problem, enter <b>0 = No known neurological illness</b> in the <b>Primary neurological problem/psychiatric condition</b> column, and then <i>skip the subsequent questions in the row</i> .						questions			
Birth year (9999=Unknown)	Age at death (888=N/A, 999 = Unknown)	problem/psyc condition	hiatric *	Dx**	Method of evaluation***	Age of onset (999 = Unknown)			
		_	-	———	_				
		_	-		_	———			
*NEUROLOGICAL PROBLEMS & PSYCHIATRIC CONDITIONS  0 No known neurological illness  1 Dementia syndrome typical of Alzheimer Disease (AD)  2 Dementia syndrome typical of non-AD disease (ex. LBD, FTLD, Vascular dementia)  3 Dementia syndrome of uncertain etiology or not typical of AD, LBD, FTLD, etc.  4 Other neurologic disorder including Parkinsonism, ALS  5 Psychiatric condition			THOD OF articipant / ledical reco xam o-enrolled fa	evaluat EVALUAT (family reports	<b>FION</b> port				
	s form is to be compions. Estimates are at UDS Coding Guice affected first-degrical children)?  "= having demential, Page 4)  Degical Parents  neurological or ps  the Primary neurological or ps  the Primary neurological with no neurological mysychiatric concompsychiatric concompsyc	Examiner's initials:  s form is to be completed by a clinician ions. Estimates are allowed if exact bird:  e UDS Coding Guidebook for Initial V.  affected first-degree relatives (biological children)?  "= having dementia or one of the no 1, Page 4)  Digical Parents  neurological or psychiatric condition of the Primary neurological problem in the Primary neurological or psychiatric condition column, and the With no neurological or psychiatric condition column, and (888=N/A, 999=Unknown)  Birth year (9999=Unknown)  Age at death (888=N/A, 999=Unknown)  PROBLEMS CONDITIONS  Brological illness  drome typical of Alzheimer Disease drome typical of non-AD disease ascular dementia)  drome of uncertain etiology or not LBD, FTLD, etc.	Examiner's initials:  Is form is to be completed by a clinician with experience in ions. Estimates are allowed if exact birth year or age at dee UDS Coding Guidebook for Initial Visit Packet, Form affected first-degree relatives (biological parents, full stical children)?  If a having dementia or one of the non-normal diagnos 1, Page 4)  Degical Parents  In eurological or psychiatric condition, the entire row management of the Primary neurological problem/psychiatric condition the Primary neurological problem/psychiatric condition that with no neurological or psychiatric problem, enter 0 (a)  In the Primary neurological or psychiatric problem, enter 0 (a)  In the Primary neurological or psychiatric problem, enter 0 (a)  In the Primary neurological or psychiatric problem, enter 0 (a)  In the Primary neurological problem/psychiatric condition column, and then skip the substitution of the problem	Examiner's initials:  Is form is to be completed by a clinician with experience in evaluating ions. Estimates are allowed if exact birth year or age at death is unknown in the primary neurological parents, full siblings, ical children)?  If a having dementia or one of the non-normal diagnoses 1, Page 4)  Degical Parents  In eurological or psychiatric condition, the entire row must be filled at determine the primary neurological problem/psychiatric condition columnt with no neurological or psychiatric problem, enter 0 = No known/psychiatric condition column, and then skip the subsequent querely psychiatric condition column, and then skip the subsequent querely psychiatric condition column, and then skip the subsequent querely psychiatric condition with the primary neurological problem/psychiatric condition with primary neurological problem/psychiatric with primary neurological primary neurological primary neurological	Examiner's initials:	Examiner's initials:  strom is to be completed by a clinician with experience in evaluating patients with neurological planes. Estimates are allowed if exact birth year or age at death is unknown. For additional clarification of the planes of the planes of the planes of the planes of the planes.  affected first-degree relatives (biological parents, full siblings, ical children)?  "= having dementia or one of the non-normal diagnoses			

Participant ID:	Form date:	/	/	Visit #:	
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**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*.

Secti	on 2 -	- Full	Sibl	inas
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If participant has no full siblings, SKIP TO QUESTION 7; otherwise, provide information on all full siblings.

For any full sibling with a neurological or psychiatric condition, 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. For a sibling with no neurological or psychiatric problem, enter **0 = No known neurological illness** in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

See list of codes (below):	Birth year (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 LIST	r of codes	•••••	
<b>3a</b> . Sibling 1			_		_	
<b>3b</b> . Sibling 2			_		_	
<b>3c.</b> Sibling 3			_		_	
<b>3d</b> . Sibling 4		———	_		_	
<b>3e.</b> Sibling 5			_		_	
<b>3f.</b> Sibling 6			_		_	
<b>3g</b> . Sibling 7			_		_	
<b>3h</b> . Sibling 8			_		_	
<b>3i</b> . Sibling 9			_		_	
<b>3j</b> . Sibling 10			_		_	
<b>3k</b> . Sibling 11			_		_	

Participant ID:	Form date:	/ /	Visit #:
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## **Section 2 – Full Siblings**

continued...

See list of codes (below):	Birth year (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 LIST	r of codes	•••••	
<b>3l</b> . Sibling 12			_		_	
<b>3m</b> . Sibling 13			_		_	
<b>3n</b> . Sibling 14			_		_	
<b>3o</b> . Sibling 15			_		_	
<b>3p</b> . Sibling 16			_		_	
<b>3q</b> . Sibling 17			_		_	
<b>3r</b> . Sibling 18			_		_	
<b>3s.</b> Sibling 19			_		_	
<b>3t</b> . Sibling 20			_		_	

## **Section 3 – Biological Children**

4.	How many biological children does the participant have?

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

For any biological child with a neurological or psychiatric condition, 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. For a biological child with no neurological or psychiatric problem, enter **0** = **No known neurological illness** in the **Primary neurological problem/psychiatric condition** column, and then skip the subsequent questions in the row.

See list of codes (below):	Birth year (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)
<b>4a</b> . Child 1					<u></u>	
<b>4b</b> . Child 2			_		_	
<b>4c</b> . Child 3		———	_		_	———
<b>4d</b> . Child 4			_		_	

Participant ID:	Form date:	/	Visit #:

# Section 3 – Biological Children Age at death Primary neurological Primary Method of Birth year Age of onset

See list of codes (below):	(9999=Unknown)	(888=N/A, 999=Unknown)	problem/psychiatric condition*	Dx**	evaluation***	(999 = Unknown)
, ,			······ SEE LIS	······ SEE LIST OF CODES ······		
<b>4e</b> . Child 5			_		_	
<b>4f</b> . Child 6			_		_	
<b>4g</b> . Child 7			_		_	
<b>4h</b> . Child 8			_		_	
<b>4i</b> . Child 9			_		_	
<b>4j</b> . Child 10		———	_		_	
<b>4k</b> . Child 11			_		_	
<b>4l</b> . Child 12			_		_	
<b>4m</b> . Child 13			_		_	
<b>4n</b> . Child 14			_		_	
<b>4o</b> . Child 15			_		_	

#### \*\* Appendix 1: Diagnosis Codes 01 Alzheimer's Disease Lewy Body dementia (includes DLB and PDD) 02 03 Vascular dementia FTLD\* without motor neuron disease 04 05 FTLD\* with motor neuron disease Motor Neuron Disease 06 07 Parkinson's Disease 80 Prion pathology 09 Other 99 Specific diagnosis unknown (acceptable if method of evaluation is not by exam or autopsy)

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

continued...

<sup>\*</sup>FTLD includes: bvFTD or FTD, PPA (any subtype), CBS or CBD, PSP