

A close-up, low-angle photograph of piano keys, showing the white and black keys receding into the distance. The keys are slightly curved, and the lighting creates a sense of depth and perspective. The background is a solid light blue.

# **NACC by the numbers: update and commentary**

New Orleans, LA

12 October 2013

ADC Directors' meeting

# NACC database

Clinical data available	Neuropathology data	Total subjects
MDS* only	10,784	66,111
UDS** (any)	2,645	29,004
<b>Total</b>	<b>13,429</b>	<b>95,115</b>

Numbers as of the September 1, 2013 data archive

\*MDS reflects ADC enrollment 1984 – 2005

\*\*UDS reflects ADC enrollment September 2005 – present

*Note: Some subjects who began in MDS were brought into the UDS if they were active and met the ADC's inclusion criteria. (Total MDS = 74,453)*

# UDS demographics

Characteristic		UDS (any)	Deaths	
			Milestone	NP data
<b>Sex</b>	Male	12,476	2,671	1,454
	Female	16,528	2,295	1,191
<b>Primary race</b>	White	23,434	4,370	2,494
	Black	4,033	447	99
	American Indian or Alaska Native	197	11	3
	Native Hawaiian or other Pacific Islander	17	5	3
	Asian	636	58	23
	Other	563	54	10
	Unknown	124	21	13
	Hispanic	2,241 (7.7%)	221 (4.5%)	100 (3.8%)
<b>Total</b>		<b>29,004</b>	<b>4,966</b>	<b>2,645</b>

Numbers as of the September 1, 2013 data archive

# Cognitive status

Clinical symptom		UDS (any)		Deaths	Neuropath data	
Not impaired		9,991	(34%)	613	284	(11%)
MCI or other impaired	Amnestic	3,938	(14%)	414	175	(7%)
	Non-amnestic	1,052	(4%)	113	59	(2%)
	Not MCI	1,274	(4%)	93	37	(1%)
Demented		12,749	(44%)	3,733	2,090	(79%)
<b>Total</b>		<b>29,004</b>		<b>4,966</b>	<b>2,645</b>	

Numbers as of the September 1, 2013 data archive

# Primary clinical diagnosis for dementia

Clinical diagnosis	UDS (any)	Deaths	Neuropathology
Alzheimer's disease*	9,656	2,554	1,377
Vascular dementia	310	99	49
Dementia with Lewy bodies	655	317	180
Parkinson's disease	183	72	38
FTLD**	1,440	518	340
Other dementia	505	173	106
<b>Total</b>	<b>12,749</b>	<b>3,733</b>	<b>2,090</b>

Numbers as of the September 1, 2013 data archive

\*Includes probable and possible Alzheimer's disease

\*\* FTLD includes bvFTD, SD, PPA, CBD, PSP, Picks, and other write-ins indicating a primary FTLD diagnosis

# Primary clinical diagnosis judged to be the cause of MCI

Clinical diagnosis	UDS (any)	Deaths	NP
Alzheimer's disease*	2,483	213	100
Vascular dementia	315	37	16
Dementia with Lewy bodies	82	10	5
Parkinson's disease	186	26	9
FTLD**	133	26	14
Other	960	77	28
<b>Missing</b>	<b>831</b>	<b>138</b>	<b>62</b>
<b>Total</b>	<b>4,990</b>	<b>527</b>	<b>234</b>

Numbers as of the September 1, 2013 data archive

\*includes probable and possible Alzheimer's disease

\*\* FTLD includes bvFTD, SD, PPA, CBD, PSP, Picks, and other write-ins  
indicating FTLD as suspected cause of MCI

# UDS enrollment and follow-up at currently funded ADCs

UDS visit	Eligible	Completed	Percent of eligible	Currently active**
Initial visit	n/a	25,777	n/a	13,274
Follow-up: 1	17,691	14,460	82%	9,037
2	13,341	10,819	81%	7,220
3	10,212	8,194	80%	5,845
4	7,662	6,221	81%	4,757
5	5,780	4,678	81%	3,849
6	3,748	2,907	78%	2,597

Numbers as of the September 1, 2013 data archive

**\*\*Defined as actively followed or followed for autopsy; not dead or discontinued.**

# LP Patient experience

Co-Investigators Drs Morris and Moulder of WUStL.

Visit type	Number completed	Number of participating Centers
Initial	442	18
Follow-up	341	

**Objective: to capture all subjects asked to have an LP and report their attitudes about LP and incidence of AEs**

Funded by Alzheimer's Association

Numbers as of the September 1, 2013 data archive



# FTLD Module Progress

Diagnosis	Number of subjects**
Any FTLD*	174
Not FTLD	87
<b>Total</b>	<b>261</b>

Numbers as of the October 1, 2013 data archive

\*Includes those with symptoms consistent with a diagnosis of ALS, PSP, CBD, bvFTD, or PPA, as noted on forms B3F and B9F.

\*\*Includes 16 ADCs, plus 39 subjects from U Penn FTLD Center

# Research structural MRI

See in NACC session this afternoon

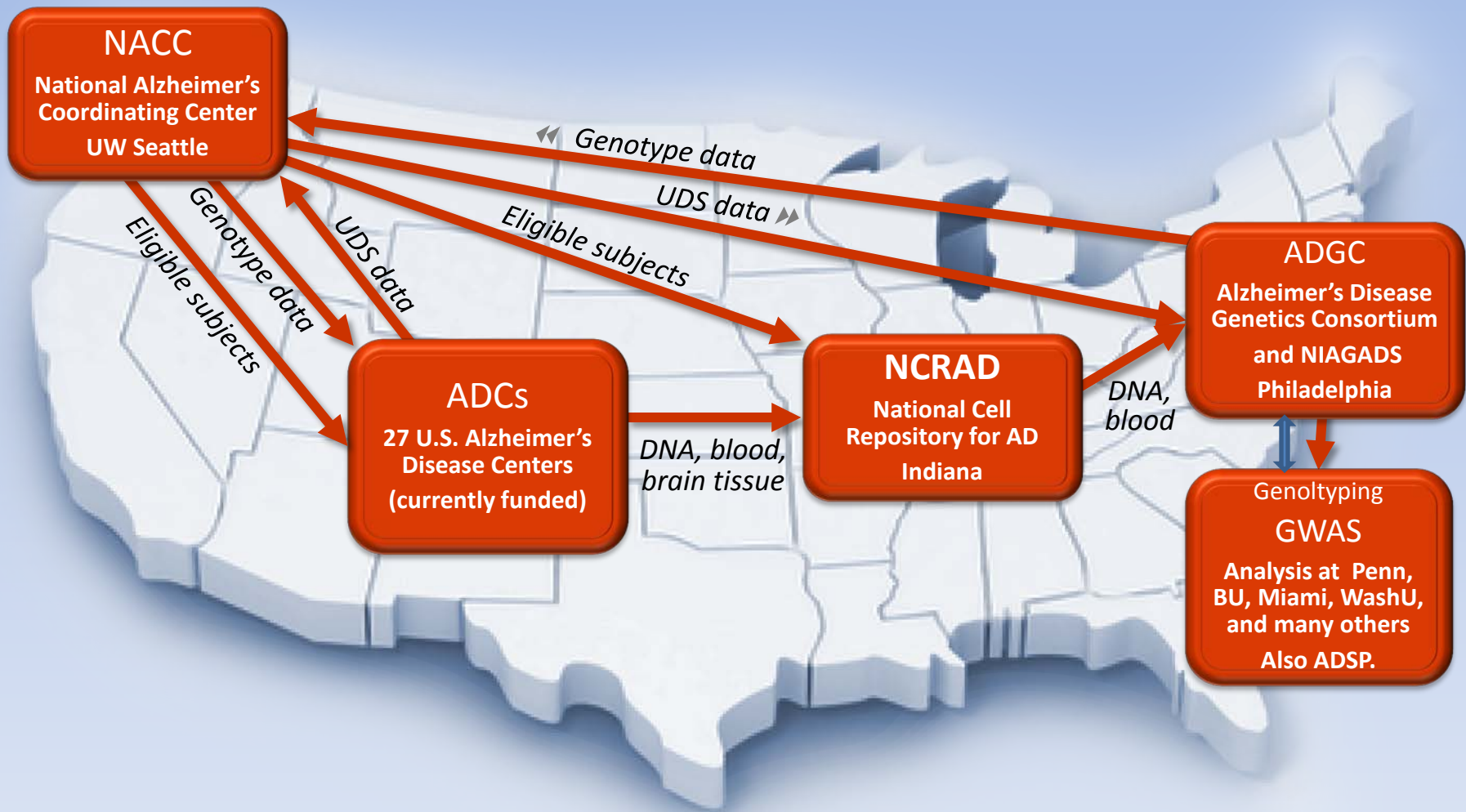
	Number of MRIs	Number of UDS subjects
Image files*	1,619	1,054
Total images**	4,778	

Numbers as of the October 1, 2013 data archive

\* .zip archives of scan sessions by ID and date (may contain multiple different scan types).

\*\* Including 3D T1, FLAIR, DTI, and other scan types.

# Genetic Collaboration!



# GWAS Phase II

Status at NCRAD	Number of subjects Dead/Discontinued	Number of active subjects	Total
Samples not received	7,726	6,874	14,600
Samples received	5,817	7,910	13,727
<b>Total on GWAS list</b>	<b>13,543</b>	<b>14,784</b>	<b>28,327</b>

	Clinical control	AD dementia	MCI	Non-AD	Total
Samples Received	5,034	3,801	1,348	3,544	13,727

Numbers as of October 8, 2013

\*At most recent UDS visit