



NACC update

ADC Directors Meeting

Baltimore, MD

15 October 2016



Nobel Prize Winner Bob Dylan

*“...Yes, to dance beneath the diamond sky
With one hand waving free...”*



Announcements

- NACC Session this afternoon
 - DLB Module update
 - Spanish UDS 3 test battery and forms update
 - Database News from Duane
 - And some wonderful science from exiting investigators!
- Pre-meeting Statistical Conference (Dr. Zhou)
 - It was Thursday... so maybe next time?
 - Collaboration between NACC and IALSA
- Unfounded rumors
 - ADGC is *really* “23 and me”
 - “a protein found in jellyfish improves cognition”
 - The “A-jellyfish-4-U” Trial recruitment

The NACC database: total subjects

...UDS longitudinal clinical data and Neuropathology data really make this database unique and most valuable

Clinical data available	NP data records	Total subjects
Subjects in MDS* only	11,029	66,042
Subjects in UDS**	4,287	34,326
Total	15,316	100,368

FTLD module data available	NP data records	Total subjects
Number of Subjects	68	1,299 (22 centers)

Numbers as of the September 1, 2016 data freeze

*MDS reflects ADC enrollment 1984 – 2005

**UDS reflects ADC enrollment September 2005 – present



UDS SUBJECTS

Clinical etiologic diagnosis by cognitive level

Clinical diagnosis	MCI	Dementia	Impaired, not MCI
Alzheimer's disease	2,852	11,348	308
Lewy body disease	327	971	42
Vascular brain injury	433	384	91
FTLD - with bvFTD	44	947	15
FTLD – with PPA	41	617	7
Other FTLD	84	338	9
Other/Unknown	1,897	602	993
Total	5,678	15,207	1,465

Special initiatives – MRI

	Number	Centers participating
Unique Subjects with a scan session	3,263	15
Number of MRI scan sessions	4,638	
MRI scan types		
T1	4,024	
T2	1,750	
Flair	3,078	
DTI	590	
Other scan types (DWI, other)	1,255	
Longitudinal MRIs (unique subjects)	857	
Scans with calculated volume data	1,971	

Numbers as of September 19, 2016

Special initiatives – Amyloid PET scans

...well, it is voluntary, of course...and it's early yet.

	Number	Centers participating
Unique Subjects with a scan	117	1
Number of scan sessions	137	
Longitudinal PET scans (unique subjects)	20	

Numbers as of September 19, 2016

Special initiative – CSF assay data

...well, it is voluntary, of course...and it's early yet...and the assays differ somewhat...and there may be within and between site/subject variation...and....

	ELISA	Luminex	Total	Centers participating
CSF data values				
CSF A β	287	978	1,265	4
CSF P-tau	272	978	1,250	
CSF T-tau	283	978	1,261	

Numbers as of September 19, 2016 data freeze

UDS 3 summary

*reminder: March deadline for use of C1 (UDS 2) test battery
proprietary tests; NACC agreement expires*

	Initial	Follow-up *
Number of subjects . . .		
. . . in Working Database (as of 9/19/2016)	228	967
. . . in Current Database (as of 9/19/2016)	1,659	7,797
. . . in September Frozen Database	1,640	7,741
Neuropsychological battery		
. . . Using Form C1* (September data freeze)	<i>30</i>	1,527
. . . Using Form C2 (September data freeze)	1,610	5,195

* Form C1 completed at the initial visit is **the Spanish C1 form**