

**ADC – NeuroBiobank Working
Group to Advance Brain
Donation and Utilization for
ADRD Research**

NIH Alzheimer's Disease Centers Panel Recommendations (2017)

- Improve autopsy consent processes for research broadly to help achieve diversity
- Maximize post-mortem rates
- Prioritize clinically well-characterized research participants and those of particular interest
- Expand opportunities for autopsies beyond UDS and clinical core participants when they facilitate AD and ADRD research
- Establish transparent guidelines for acceptance, retention, and sharing of tissue and data for research purposes to eliminate barriers and facilitate broad access to samples for research.
- Augment approaches to increase autopsy material from cognitively normal individuals

Working Group of ADC NP Cores and NBB

- Membership
 - Chaired by Dirk Keene (U Washington)
 - **NIA:** Nina Silverberg, Erika Tarver, Jennifer Watson, Grayson Donley
 - **NINDS:** Anna Taylor
 - **BDP:** Tish Hevel
 - **LBDA:** Angela Taylor
 - **NACC:** Walter Kukull, Maggie Dean, Merilee Teylan, Brian Stahly
 - **ADC:** Eileen Bigio (Northwestern), Anita Huttner (Yale), Julia Kofler (Pittsburgh), Andrew Lieberman (Michigan), Peter Nelson (Kentucky)
 - **NBB:** Sabina Berretta (Harvard McLean), Harry Haroutunian (Mt. Sinai), and Bill Scott (Miami)
- Monthly calls since July 2018

Pilot Project: Goals

- Demonstrate feasibility
 - Establish communication and coordination pipelines between donors, coordinators (TBDP, NBB, LBDA, etc.) and NP sites (NBB, NP Cores)
 - Build communication strategies for donors/families
 - To inform donors/families of benefits to science of donation (pretty much already done at TBDP)
 - To create harmonized strategies to relay neuropathologic findings to families of brain donors
 - Determine minimum and optimum clinical/other characterization criteria for brain donors (seen by a physician, psychometric data, imaging, genetics, etc.)
 - Develop program or site-specific inclusion/exclusion criteria
 - Develop central protocols to prioritize site selection for each donor
 - Geography
 - Prior participation in the Center
 - Site specific focus/emphasis (AD, TBI, etc.)
- Determine if donor coordination can improve frequency and utility of brain donation
- Identify areas of success and for improvement
- Extend to the broader research community

Inclusion/Exclusion Criteria (possibilities)

- AD/ADRD controls (aged, no dementia, low neuropathology)
- Young controls for aging studies
- Any non-caucasian donors
- Well-characterized local AD/ADRD subjects not in clinical core (formal psychometric testing)
- Subjects with specific neuroimaging (fMRI or PET imaging) or CSF biomarker studies
- Legacy cases (cases previously enrolled in a study at a particular center)
- Clinical trial participants
- Any familial AD/ADRD
- Any Down Syndrome, FTLD including PSP, CBD, Pick's, etc., MSA
- Cases with relatives including spouse in UW NP Core repository
- Any military service or college or professional contact sports

ADC-NBB Pilot:

- BDP or NBB refer cases to pilot Centers (Pitt, UW, Yale)
 - Inclusion Criteria:
 - Aged non-demented controls
 - Diagnosed with Alzheimer dementia by a neurologist
 - Anyone who has participated in a clinical trial for AD
 - Underrepresented minority
 - Subject resides within 100 mile radius of each Center
 - Outside this radius with approval and support from NBB for removal
- With referral, pilot Center obtains consent and makes arrangements as with other Center cohort subjects
- Upon death
 - Neuropathology workup (Center protocol adhering to minimum standard)
 - Demographic and neuropathologic data uploaded to NBB catalog
 - Center agrees to share tissue from that case if queried through NBB

Progress to date

- 3 referrals to UW from Seattle Metropolitan Area
 - F, age 95, vascular dementia with meningioma (consenting completed)
 - F, age 79, MCI (consenting in process)
 - F, age 65, non-demented (consenting in process)
- UW successfully uploaded a “test case” to NBB catalog
- No deaths to date

Potential Benefits of Program

- **Promotes collaboration** across NBB, ADCs, BDN to set the foundation for enhanced national access for brain donation and brain research in AD, ADRD
- Allows both NBB and ADCs ability to accept **greater number and greater diversity of community-based AD**, related dementia and control donations and make more biosamples and data available to the research community.
- Shared approaches/protocols can help **cross pollinate best practices** across programs
- **Improved and harmonized methods** to provide access to brain donors and scientists and for stakeholders to communicate with each other and donors/scientists.
- Increased ability for sites to retrieve registered cases outside of the pilot across programs (e.g. ADC can retrieve a case registered with NBB and be reimbursed for it)
- Shared costs allow for greater collection of cases of interest to all parties
- Small catchment area and specific expertise of ADCs **allows for rapid autopsy and tissue processing for next generation research approaches**

Comments/Questions