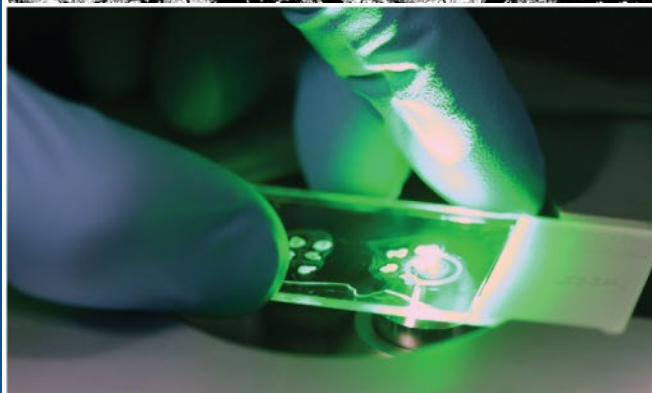
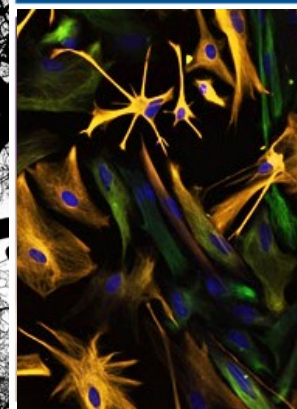
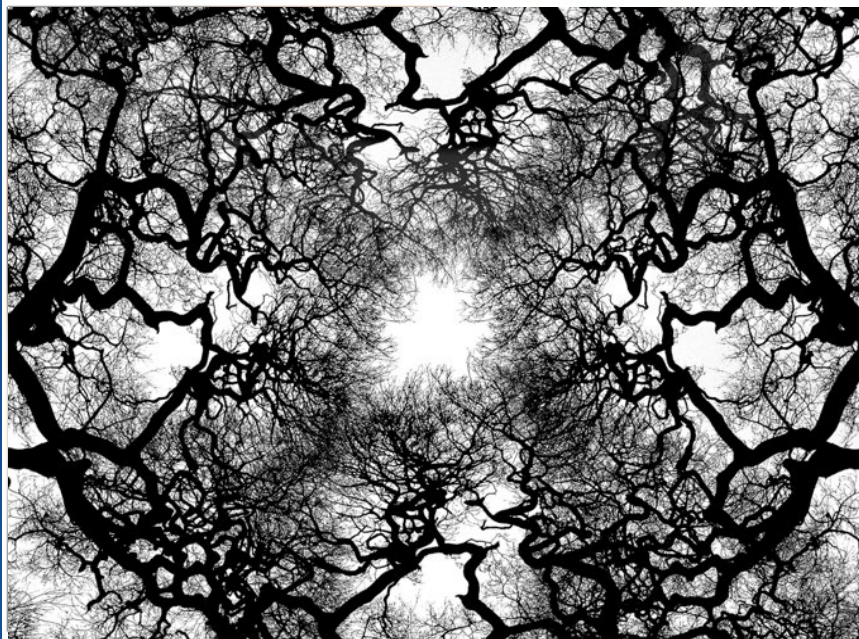
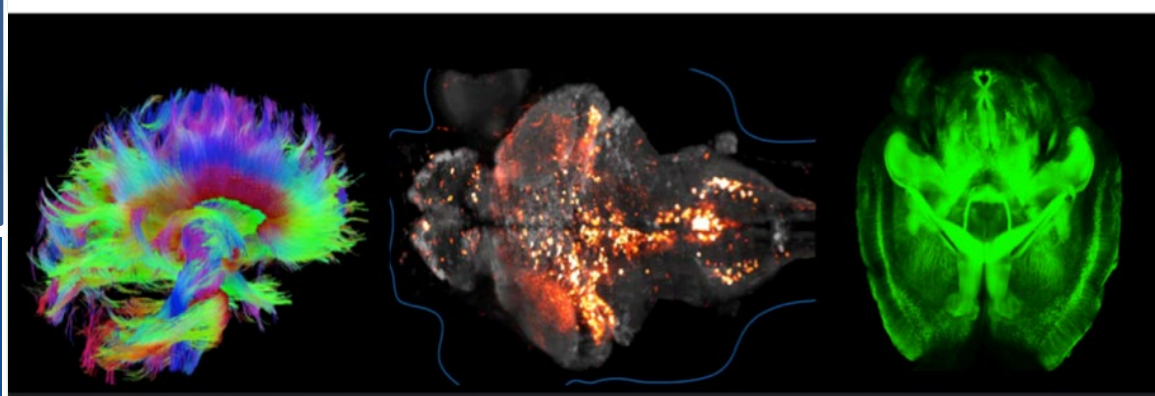


NIH NeuroBioBank: Overview and opportunities for collaboration with ADC NP cores

Anna Taylor, PhD

Division of Extramural Activities,
NINDS, NIH

October 19, 2018



Brain Banking at NIH

- **Pre 2010**
 - Brain banks funded primarily on Rs
 - Collections focused on PI's area of research interest
 - No central coordination, no accountability for access
- **2010 - 2012**
 - NIMH-led working group established to explore shared needs for brain banking across NIH
 - Solicited community input via RFI and workshop
 - NIMH, NINDS, and NICHD released notice announcing the change in funding from grants to contracts and plans for a federated system

Notice of Change in Funding Mechanism for Brain Banks

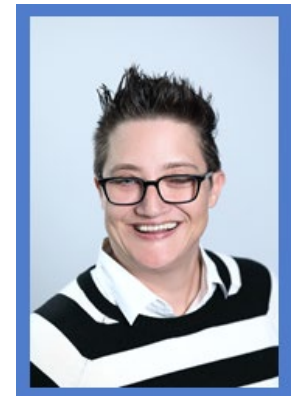
Notice Number: NOT-MH-12-020

- **2013 to present**
 - **NIH NeuroBioBank formed**
 - Initial participation from NIMH and NINDS
 - NICHD joined in 2014
 - **NIA joined in 2018**
 - Current investment ~\$9 M



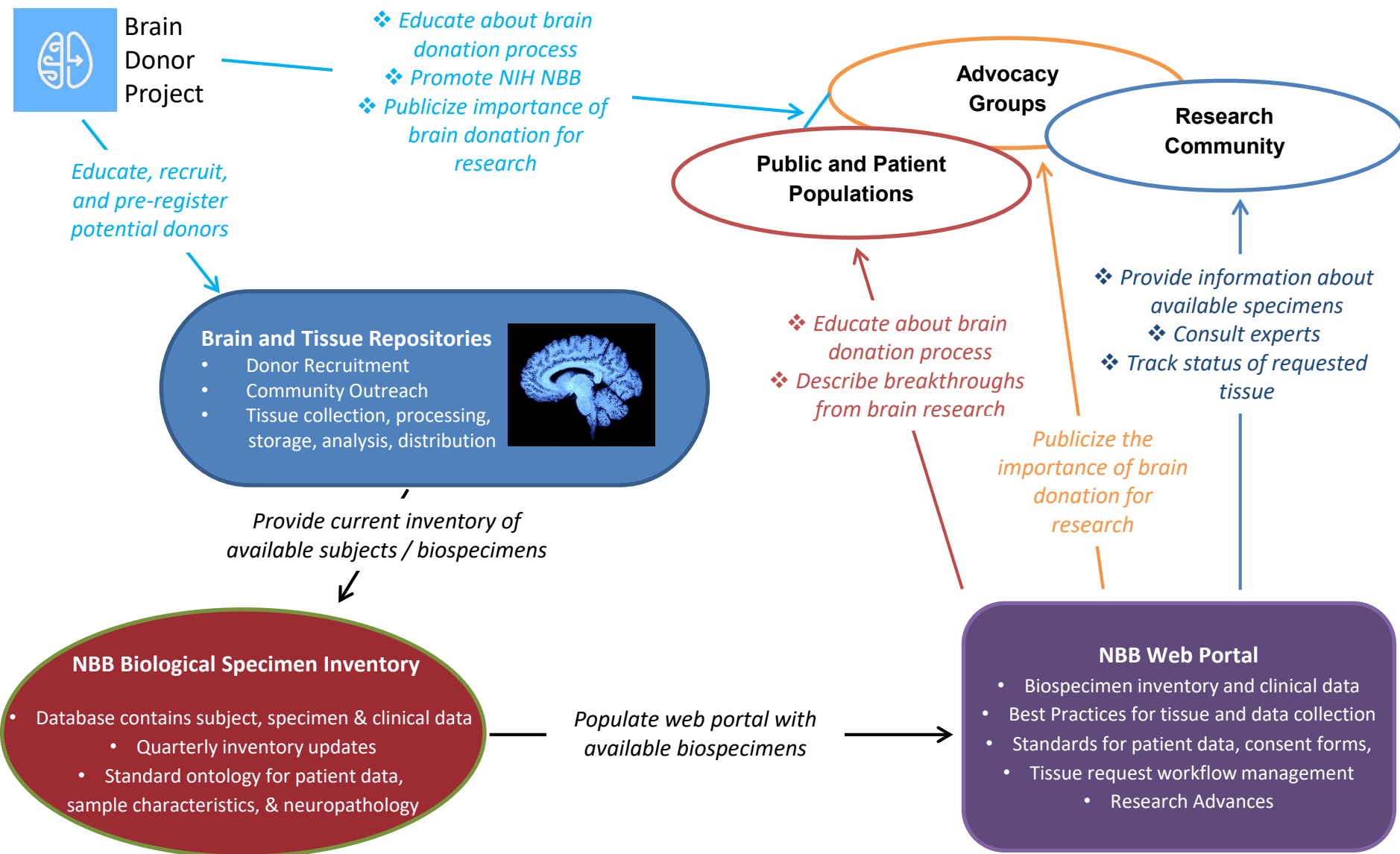
The NIH NeuroBioBank Team

- NIMH
 - Michelle Freund (COR)
 - Olivia Spicer
 - Mike Loewe
- NINDS
 - Anna Taylor (Co-Lead)
 - Alisa Schaefer
- NICHD
 - Melissa Parisi
 - Alice Kau
- NIA
 - Nina Silverberg



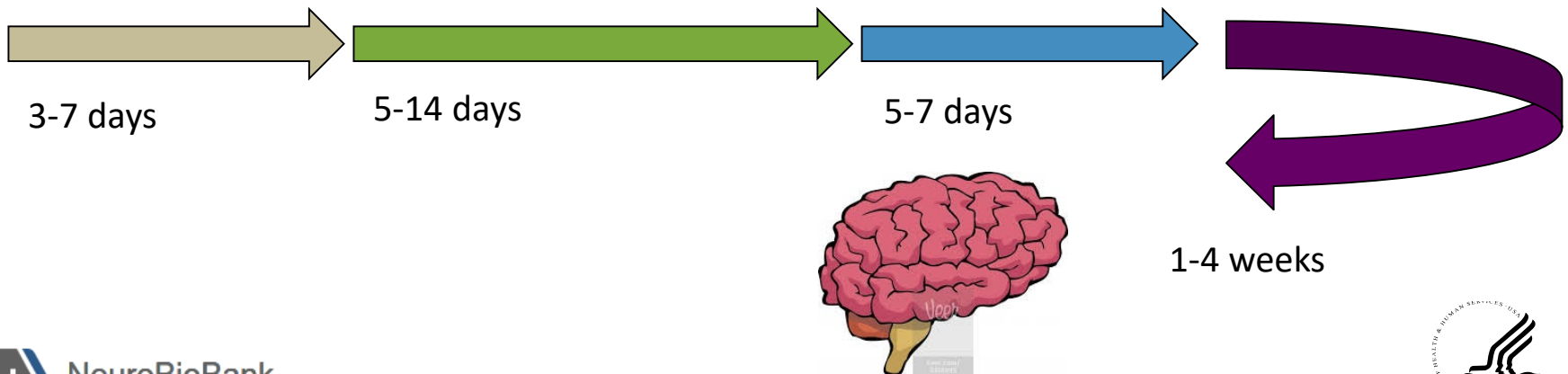
Who we are and What we do

- A federated brain and tissue repository network integrated by a centralized IT platform
 - 6 contracted Brain and Tissue Repositories
 - University of Maryland [PI: Tom Blanchard – formerly Ron Zielke, retired 2017]
 - University of Miami [PI: Bill Scott – formerly Deborah Mash, resigned 2017]
 - UCLA/Sepulveda [PI: Rashed Nagra]
 - Mt. Sinai [PI: Harry Haroutunian]
 - University of Pittsburgh [PI: David Lewis]
 - McLean [PIs: Sabina Berretta, Wilson Woo – formerly Francene Benes, retired 2013]
 - Contracted centralized Toxicology and IT services
 - National Medical Services [Toxicology]
 - Information Management Solutions [IT – database, website]
- Focus on
 - **Transparency:** Making complete inventories of BTRs available to all users
 - **Quality:** BTRs share common best practices, protocols
 - **Access:** Tissue made broadly available to research community
 - **Outreach:** Working with NGOs to increase awareness of need for brain donation





Tissue Access Process

- Requests are pre-screened by NIH
- Reviewed by NBTR Directors. Availability of tissues is coordinated and Directors have opportunity to recommend or reject the request
- Programmatic input can be sought from expertise within NIH.
- Final approval comes from NIH COR
- Tissue is prepared and distributed
- Average request takes 4-8 weeks from initiation to fulfillment



Search the NeuroBioBank for Tissue Samples/Subjects

Filter the list of available brain bank resources using the search interface below. The NIH NeuroBioBank contains an inventory of specimens that are available through its brain and tissue repository network, as well as some that are offered by external repositories. To select a specimen that is part of the NeuroBioBank network, simply mark the checkbox in the "Request" column. External specimens are marked with a  and can only be obtained by going through the request process of the external repository. Clicking the  will prompt you to visit the specimen request page of the associated external repository. When you have selected all desired NIH NeuroBioBank network specimens, click on the "Create Request" button and your checked selections will be automatically added to your request.



Disclaimer

Sample Accuracy and RNA Integrity Number (RIN)

Subject and Specimen Search

[View Subject/Sample Counts](#)

Text Search

Alzheimer's

Demographics

Race

Ethnicity

Sex

Age Group

Data Last Updated: Oct. 3, 2018

[Add Columns](#)

[Clear Selections](#)

[Create Request](#)

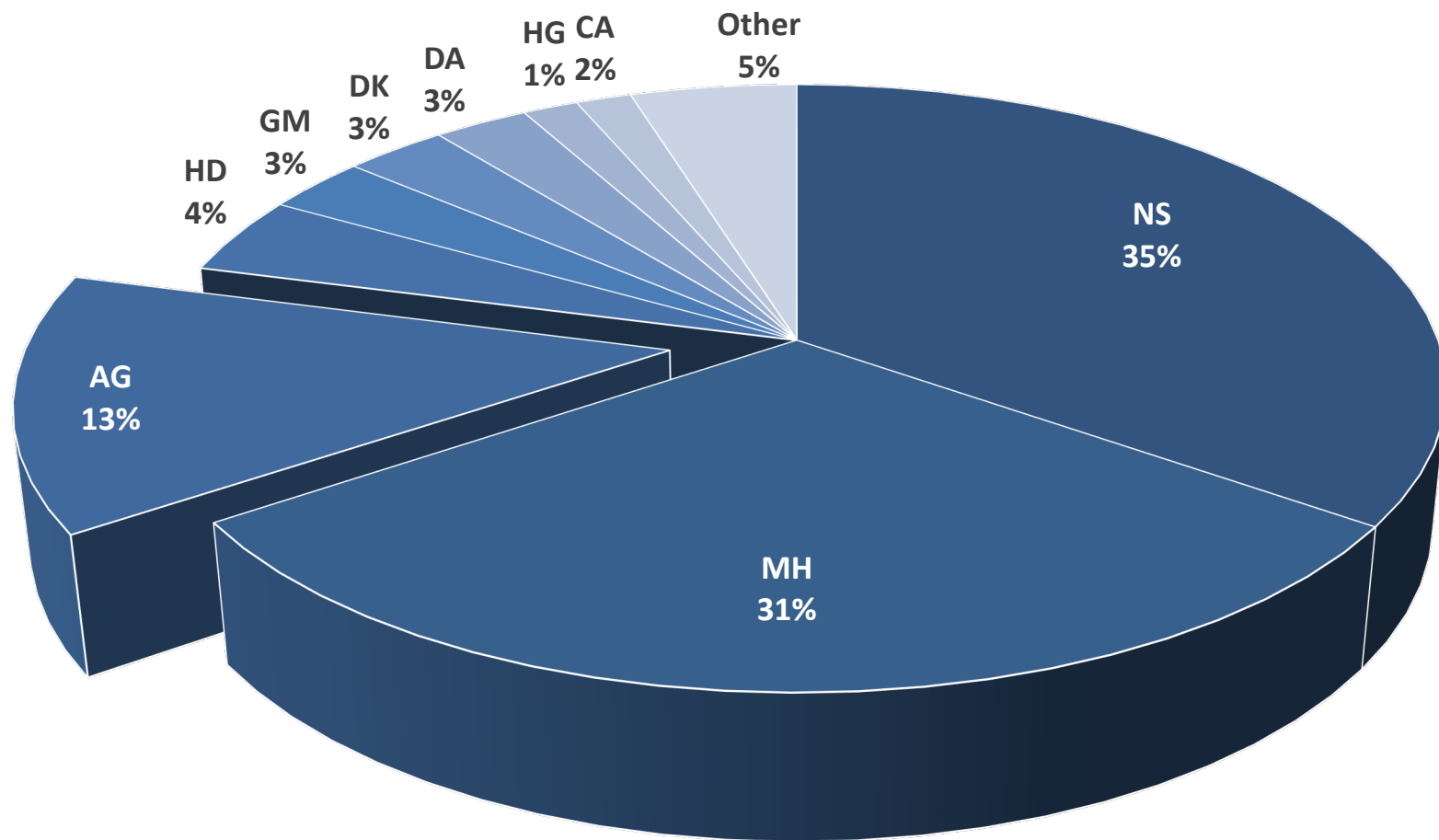
☐ Only Show Current Selections

♦ Repository	♦ Subject Id	♦ Clinical Brain Diagnosis	♦ Age	♦ Sex	Request (0)
Sepulveda	4023	Alzheimer's Disease	72	Male	<input type="checkbox"/>
Sepulveda	3949	Alzheimer's Disease	81	Female	<input type="checkbox"/>
Sepulveda	1967	Alzheimer's Disease	82	Female	<input type="checkbox"/>
Sepulveda	3925	Alzheimer's Disease	61	Male	<input type="checkbox"/>
Sepulveda	2261	Alzheimer's Disease	77	Female	<input type="checkbox"/>
Sepulveda	2331	Alzheimer's Disease	82	Female	<input type="checkbox"/>
Sepulveda	4376	Alzheimer's Disease	85	Male	<input type="checkbox"/>

NBB by the numbers (since 2014)

- ❑ **12,600** cases in the inventory (includes pre-contract legacy cases)
- ❑ **2,111** Donors Banked
- ❑ **>400** Disorders Represented
- ❑ **871** Requests Submitted / **784** Requests Fulfilled
- ❑ **565** Investigators Served

NIH Institute support for NBB Requestors (Extramural and Intramural)



Most Requested Disorders *(not in alphabetical order)*

Alzheimer's disease	Alexander's disease
Autism Spectrum Disorder	Ataxias
Huntington's disease	Cockayne syndrome
Parkinson's disease	Diabetes
Schizophrenia	Lysosomal Storage Disorder
ALS	Prader-Willi
Major Depressive Disorder	Dystonia
Down's syndrome	TBI
Multiple Sclerosis	Williams syndrome
Rett syndrome	Angelman

AD in the NBB (since 2014)

❑ **>1,800** AD cases in the inventory (includes pre-contract legacy cases)

- Range of onset and severity
- **140** cases with co-morbid diagnoses
 - Parkinson's disease
 - Lewy Body Dementia
 - Down Syndrome
 - Bipolar

❑ **~200** AD Donors Banked

❑ **161** AD Requests Submitted / **140** AD Requests Fulfilled

❑ **119** Investigators Served

➤ Most studies supported are basic research focused on understanding AD

ADC/NBB Opportunities for synergy and collaboration

- Working Group of NBB and ADC NP core leaders
 - Chaired by Dirk Keene
 - **NIH:** Nina Silverberg, Anna Taylor, and Michelle Freund
 - **ADC:** Eileen Bigio, Dennis Dickson, Matt Frosch, Anita Huttner, Andrew Lieberman, Peter Nelson
 - **NACC:** Walter Kukull, Maggie Dean, Merilee Teylan
 - **NBB:** Sabina Berretta, Harry Haroutunian, and Bill Scott
- Monthly calls since July 2018
- Focus to date on understanding program operations

ADC/NBB Opportunities for synergy and collaboration

– Donation / Referrals

- Share list of all sites and POCs across programs
- Identification of high-value cases for both programs
- Develop decision tree for donation referrals
- Coordinate messaging for potential donors and families

– Tissue and Data sharing

- Cross promotion of resources and catalogs
- Explore central location for displaying comprehensive catalogs

– Training

- Trainee rotations
- Centralized training resources

ADC/NBB Opportunities for synergy and collaboration

– Brain Retrieval / Neuropathology

- Develop a shared contact list of dieners across US
- Provide cross-site brain removal / neuropathology services in low coverage areas
- Develop shared minimum NP workup for specific disorders / aging controls
- Develop shared list of site-specific expertise

Discussion / Questions?

Neuropathology in the NBB

