What is the NeuroBioBank?

- A federated brain and tissue repository network integrated by an IT system (https://neurobiobank.nih.gov)
- Brain and tissue repositories are now being supported with contracts (NIMH, NINDS and NICHD)
- Focus on quality management, sharing, outreach
NIH NeuroBioBank

OUR MISSION

What is the National Institutes of Health (NIH) NeuroBioBank?

The NIH NeuroBioBank is a federated network of brain and tissue repositories in the United States that collects, evaluates, stores, and makes available to researchers, brain and other tissues in a way that is consistent with the highest ethical and research standards. The NeuroBioBank also ensures protection of the privacy and wishes of donors. Brain tissue is a precious resource that enables scientists to better understand disorders affecting the brain in order to develop treatments and cures.

The NIH NeuroBioBank also provides information to the public about the need for tissue donation and how to register as a donor.

PURPOSE/GOALS

To increase tissue donation by increasing awareness of the value of these gifts for understanding brain disorders.

https://neurobiobank.nih.gov
Why are we doing this?

• Increase the availability of tissue

• Standardize quality metrics

• Return data derived from banked tissues to public database

• Opportunities for discovery have never been greater (genetics, iPSCs, and –omics)
The NIH NeuroBioBank for tissue access

- Include specimen inventory and access information
- Set tissue quality and data standards
- Information/training for investigators
- Forum for collaboration among BTR Directors
The NIH NeuroBioBank for tissue access

Neurobiobank Web Portal

- Biospecimen inventory and Tissue Requests
- Information for the public
- Standards for tissue and data
- Standards for patient data, consent forms

Brain Bank A

Brain Bank B

Brain Bank C

Brain Bank D

Research Community

Advocacy Groups

Public & Patient Populations
NIH NeuroBioBank

NBB Brain and Tissue Repositories (BTRs)
- Donor recruitment
- Community outreach
- Specimen collection, processing, analysis, distribution

Provide current inventory of subjects / specimens

NBB Biological Specimen Inventory
- Database contains subject, specimen & clinical data from BTRs
  - BTRs update inventory monthly
  - Unifies data collection between BTRs
  - Standards for patient data, consent forms

Provide input on specimen availability

NBB Web Portal
- Publicly accessible NBB biospecimen inventory
- SOPs for tissue and data collection
- Standards for patient data, consent forms, MTA
- Requisition workflow management
* Coming soon

Populate web portal with available specimens

Public and Patient Populations
- Learn more about becoming a brain donor
- Explore how research advances have been accelerated through brain donation

Advocacy Groups
Access materials to help spread the message of the importance of brain donation

Research Community
- View / Query / Request specimens and associated data
- Consult with NBB BTRs
- Track progress of requested tissue

NBB Brain and Tissue Repositories (BTRs)

Public and Patient Populations

Advocacy Groups

Research Community

NBB Web Portal

Populate web portal with available specimens
# External Ethics and Scientific Panel

<table>
<thead>
<tr>
<th>Name</th>
<th>Role</th>
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<tbody>
<tr>
<td>Daniel Perl, MD USUHS</td>
<td>Neuropathologist/End-user, CTE</td>
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<tr>
<td>Samantha Wetzler, MD</td>
<td>Chair, Organ and Tissue Procurement Committee</td>
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<td>National Association of Medical Examiners (NAME)</td>
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<tr>
<td>Jeffrey Brosco, MD PhD</td>
<td>Bioethics/Autism and Child Health and Development</td>
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<td>University of Miami</td>
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<td>Carol Tamminga, MD UT Southwestern</td>
<td>End-user, ATP Advisor</td>
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<tr>
<td>Elliot Mufson, PhD Rush University</td>
<td>End-user, Translational Neuroscience</td>
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<tr>
<td>*Mary Giliberti, Esq</td>
<td>Advocacy/Executive Director NAMI (*will nominate member)</td>
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*Mary Giliberti, Esq* is a *will nominate member*.
Status of the NIH NeuroBioBank

• NeuroBioBank IT Portal is now live with information for the public, researcher site in development

• Contracts were awarded to five Brain and Tissue Repositories on September 1, 2013
  
  University of Miami, PI: Deborah Mash  
  Harvard University, PI: Francine Benes  
  Mt. Sinai, PI: Harry Haroutunian  
  Sepulveda Research Corporation, PI: Rashed Nagra  
  University of Pittsburgh, PI: David Lewis  

• Efforts to centralize/standardize toxicology testing are underway

• Proposals for FY14 sites will be reviewed at end of April.
• Neurobiobank implementation will focus on:
  - Quality Management (pH, PMI, RIN)
  - Increasing tissue and data access
  - Setting Standards (phenotype and tissue quality, neuropathology)
  - Outreach
Increase access to human tissues

- Geographically distributed brain and tissue repositories
- Increase public awareness/prospective donation
- Partner with disease advocacy communities and local medical examiners (ME) to increase donation
- Incentivize current bankers to increase diversity of donor pool
Deliverables/Requirements for NBTRs:

• Participation in PI teleconferences
• Quarterly Progress Reports
• Transition Plans
• IT Security Documents
• Procedures Manuals made available through the Portal
• PI Meeting—April 25th
Thank You

Why Brain Donation?
A Legacy of Hope

THE NIH NeuroBioBank
www.neurobiobank.nih.gov