

## NIH NeuroBioBank: A Platform for Postmortem Brain Research

Interagency Autism Coordinating Committee

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# 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.

### NeuroBioBank Information

Please browse through the site to learn about the NeuroBioBank and the Donation process.

### WHY BRAIN DONATION?



[Contact Us](#) | [Accessibility](#) | [Privacy Policy](#) | [Links and Resources](#)

The NIH NeuroBioBank is comprised of:

[National Institute of Mental Health \(NIMH\)](#) | [Eunice Kennedy Shriver National Institute of Child Health and Human Development \(NICHD\)](#) | [National Institute of Neurological Diseases and Stroke \(NINDS\)](#)

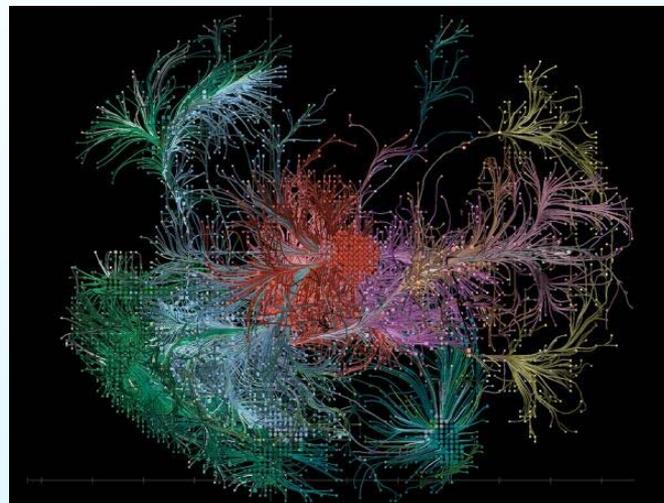
[U.S. Department of Health and Human Services](#) | [National Institutes of Health](#) | [USA.gov](#)

*NIH... Turning Discovery Into Health®*

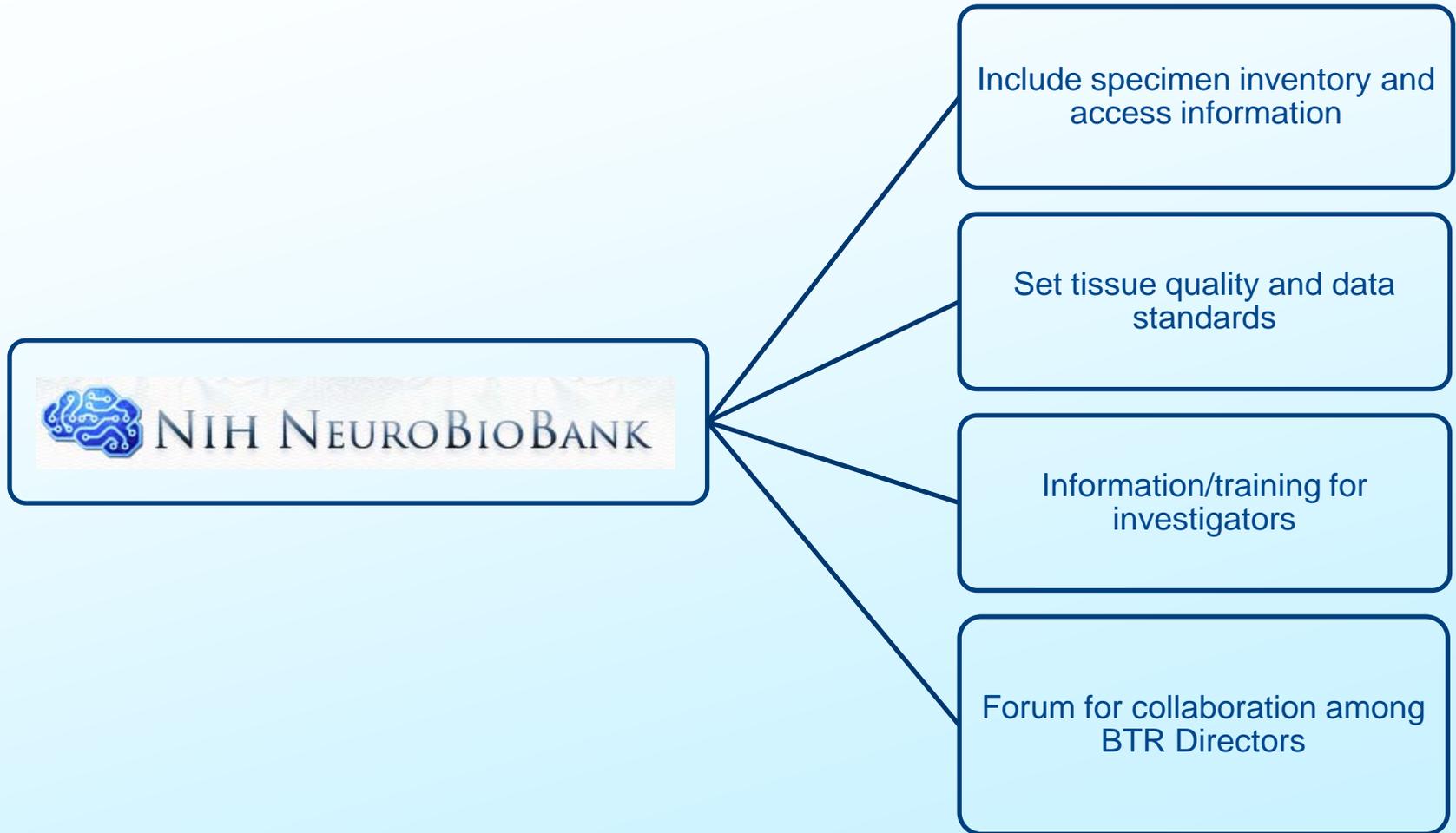
<https://neurobiobank.nih.gov>

# Why are we doing this?

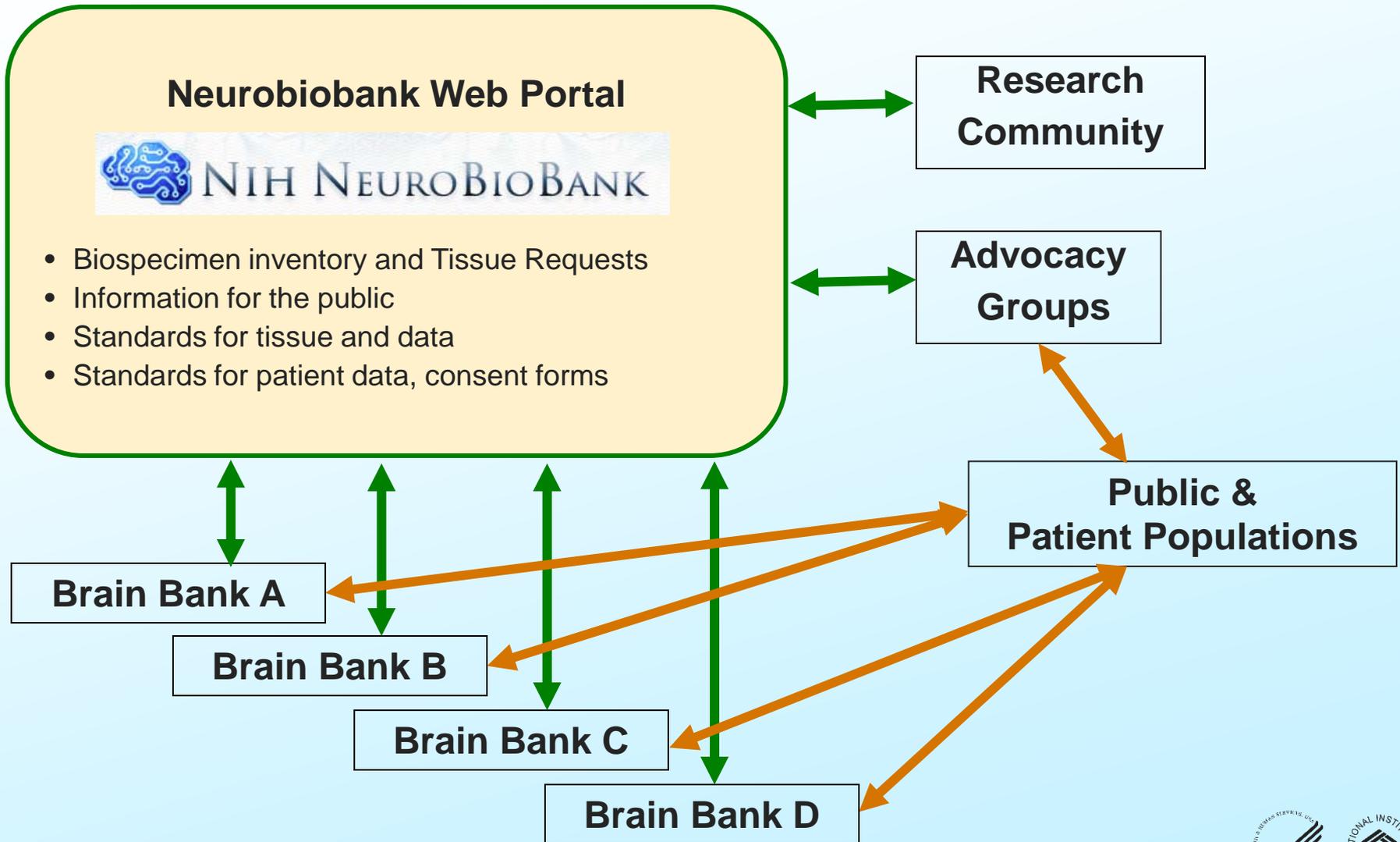
- Increase the availability of tissue
- Standardize quality metrics
- Return data derived from banked tissues to public database
- Opportunities for discovery have never been greater (genetics, iPSCs, and –omics,)



# The NIH NeuroBioBank for tissue access

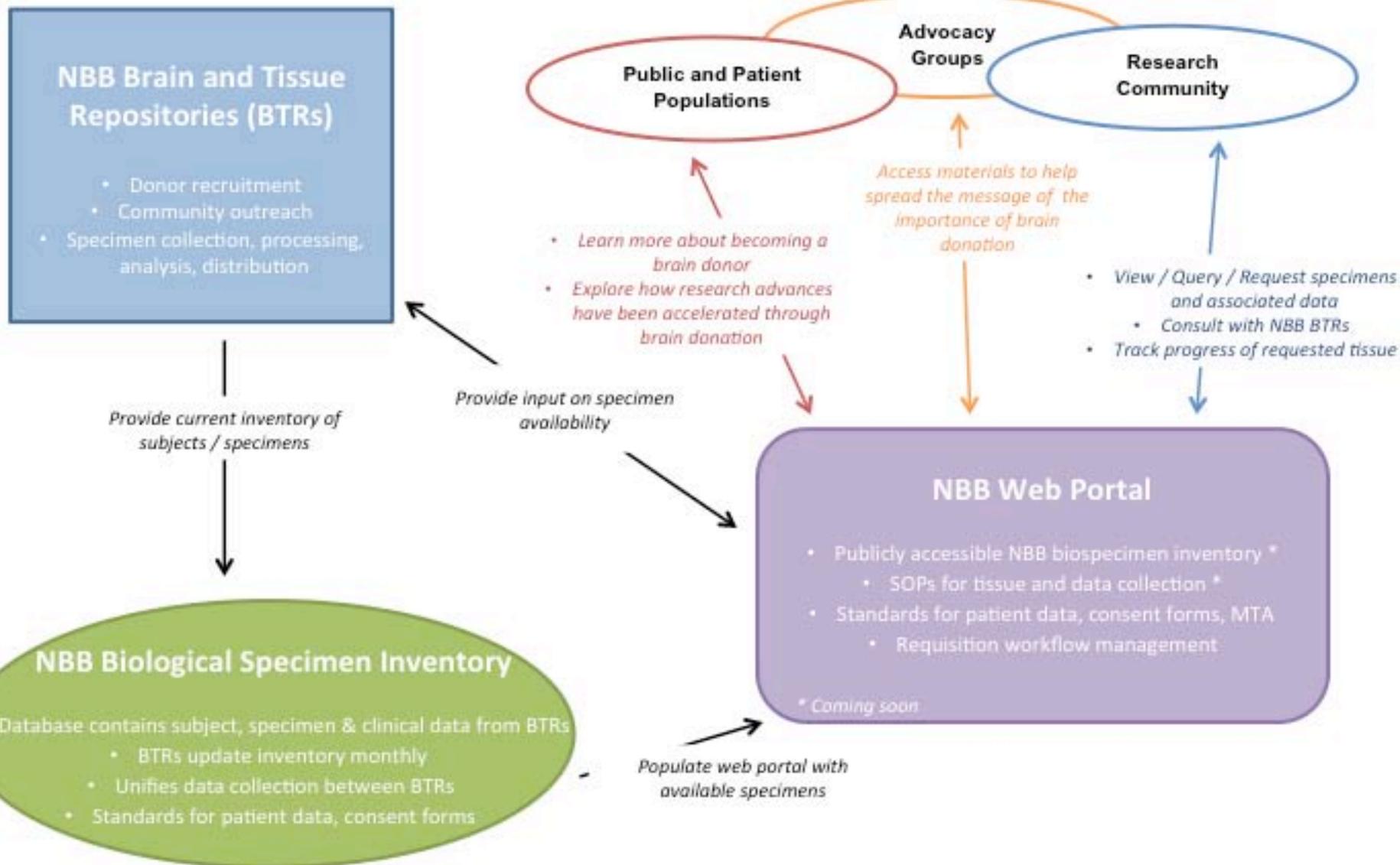


# The NIH NeuroBioBank for tissue access

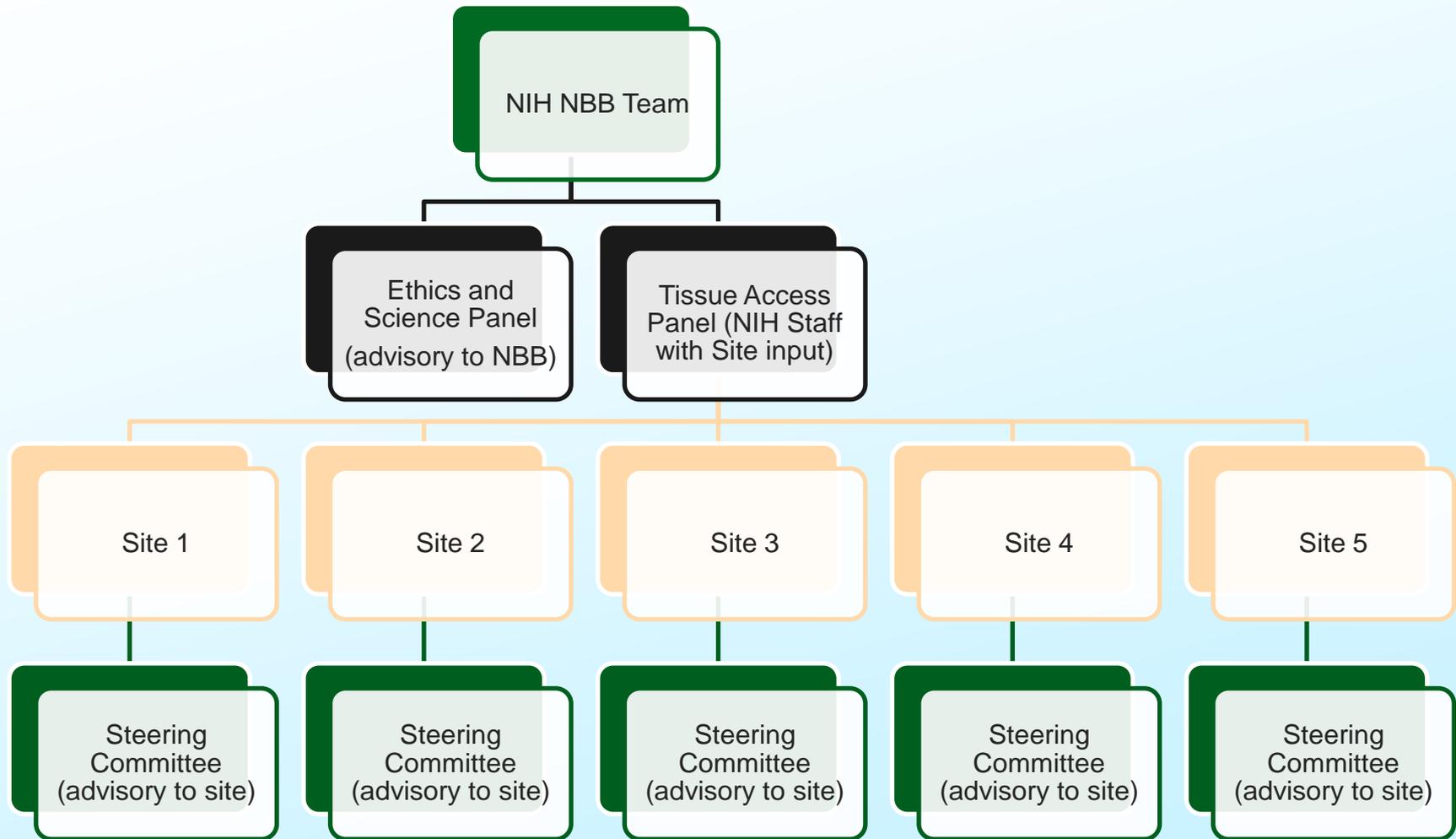




# NIH NEUROBIOBANK



# Governance



# External Ethics and Scientific Panel

Name	Role
Daniel Perl, MD USUHS	Neuropathologist/End-user, CTE
Samantha Wetzler, MD National Association of Medical Examiners (NAME)	Chair, Organ and Tissue Procurement Committee
Jeffrey Brosco, MD, PhD University of Miami	Bioethics/Autism and Child Health and Development
Carol Tamminga, MD UT Southwestern	End-user, ATP Advisor
Elliot Mufson, PhD Rush University	End-user, Translational Neuroscience
*Mary Giliberti, Esq	Advocacy/Executive Director NAMI (*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](http://www.neurobiobank.nih.gov)

