Center for Human Brain Discovery

Where Knowledge is Created and Shared
Yale Pathology

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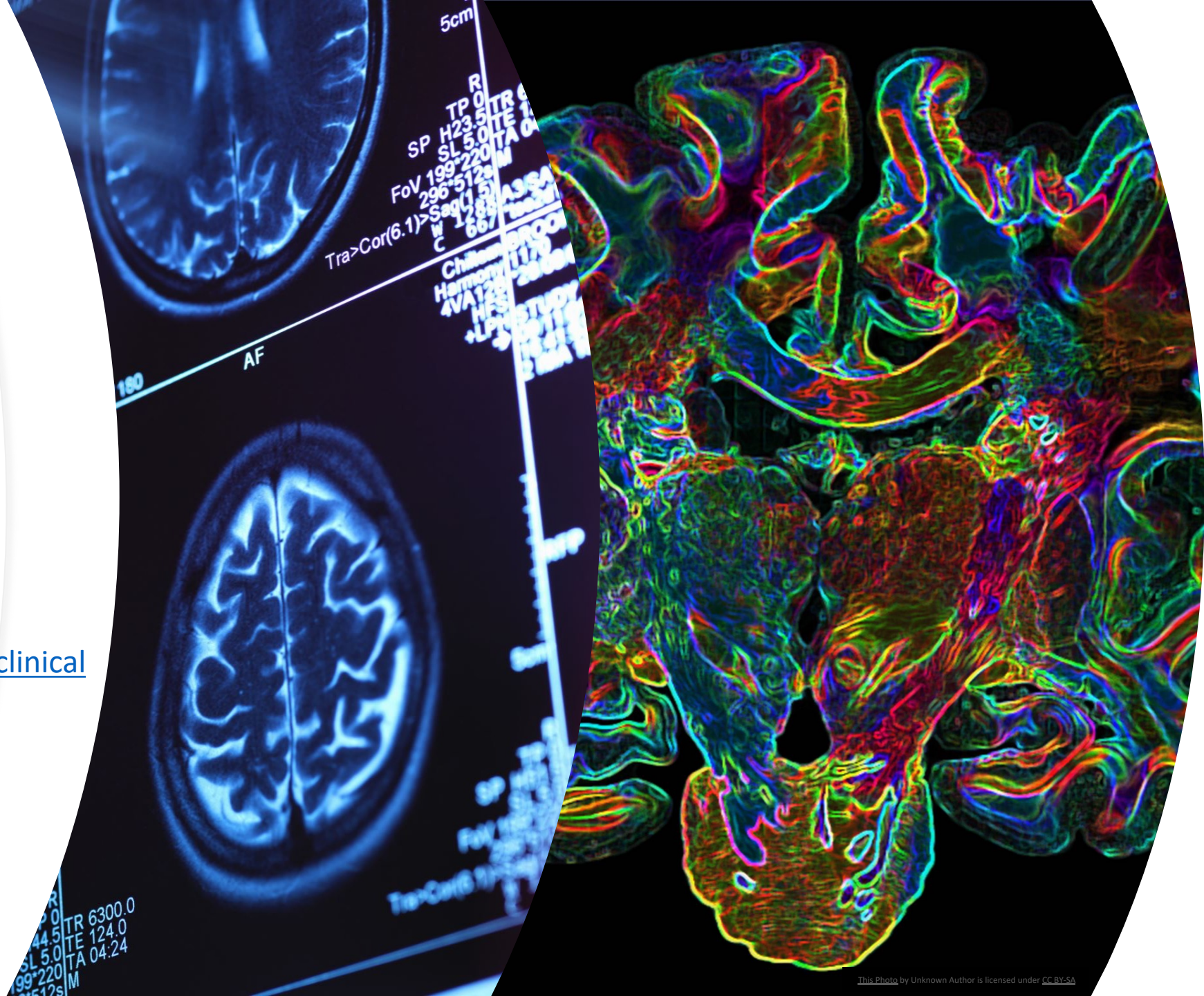
Center for Human Brain Discovery: overview

Vital, open-access resource in the Yale Pathology Dept. that supports research into the causes of and treatments for neurodegenerative diseases, as well as normal aging

https://medicine.yale.edu/pathology/clinical/brain/



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Center for Human Brain Discovery:
goals & objectives

Goal of procuring, archiving, and distributing high-quality brain tissue specimens, paired with blood, cerebrospinal fluid, and non-CNS tissues, such as muscle, fibroblasts, etc., & patient health records data

- Neuropathologically annotated brain tissue (+ paired non-CNS) samples (de-identified) and biological information available to qualified researchers
  - Accessed via a secure, purpose-built bidirectional data portal that integrates a full range of patient data from electronic health records and other sources

- Bidirectional data portal also incorporates experimental information from researchers, thus facilitating data sharing and collaborations between internal and external investigators

Long-term: Center for Human Brain Discovery enables cross-cutting and impactful investigation across the neurosciences at Yale and nationwide

Center for Human Brain Discovery: Brain Bank Initiative (April 2022 to present)

Vision / Mission statement

Regulatory

- ✓ Consent
- ✓ Permit for biorepository IRB, HIC input

Critical infrastructure / Personnel

- ✓ Physical space (-80 C freezers, long-term storage)
- ✓ Neuropathology + molecular
- ✓ Technical support
- ❑ Informatics/Bioinformatics database (Pathology ITS, Dr. Peter Gershkovich) in progress
- ❑ Collaborators in neurology and neuroscience
- \- Admin support in progress

Procurement

- ✓ Standardized biobanking protocol and tissue sampling (per NIH NeuroBioBank best practices)
- ✓ Rapid autopsy / minimize PMI to ensure highest quality of specimens

Histologic / IHC neuropath annotation and genetics (WES)

- ✓ Neuropath workup (per NIH NeuroBioBank best practices)
- ✓ Neuropathologic report will be provided to clinician and family

Tissue access / retrieval

- ✓ Tissue distributed to multiple Yale labs
- ✓ Requirements: acknowledge in publications, data sharing

Communications / Outreach

- ✓ Website with FAQs for families
- ❑ Outreach to local nursing homes, local organizations supporting caregivers

https://medicine.yale.edu/pathology/clinical/brain/donors-family-information/

Information for Donors and Families

We are asking you to take part in a research program becausedonating your or your loved one's brain tissue will provide one of the most meaningful resources to help us advance our knowledge of neurological diseases and aging and aid biomedical research. Brain donation helps researchers better understand the causes of and treatment options for Alzheimer's disease and related dementias. A single donated brain can provide resources for hundreds of research studies. In this way, it provides a gift of hope to future generations at risk of developing dementia.

All research projects seeking to use your loved one's brain tissue will undergo ethical review by the Yale Institutional Review Board (IRB) committee. Only qualified researchers and scientists receiving an IRB approval will be allowed to use your loved one's brain tissue for research. No personal/identifying information but will ever be shared.

Families who request will receive a full report on the type and levels of pathology in their loved one's brain and gain insights into how these brain changes may have contributed to dementia. Researchers will gain a better understanding of the relationship between clinical test results, fluid and imaging biomarkers, and the brain changes detected in the donated tissue. These insights enable scientists to constantly test new ideas and advance discovery that may one day result in effective therapies.

Deciding to donate your brain can be difficult. Start thinking about brain donation early so that you have plenty of time to consider whether it's right for you. Your decision might require more than one conversation with your family and/or doctor. You may want to consider:

- **Conclusive diagnosis —** Some lab and imaging tests can help your doctor/neurologist see biological signs of the disease in a living person. However, by examining the brain after death under a microscope, signs of Alzheimer's disease, such as amyloid plaque and tau tangles, or other brain diseases can be identified. Many families find that a confirmed diagnosis provides closure and resolution.
- **Advancing science, offering hope** — Your donated brain will help researchers better understand normal aging as well as the causes of and treatment options for Alzheimer's disease and related dementias.

Removal of the brain and other tissue will NOT interfere with funeral arrangements. The Center for Human Brain Discovery will pay for all expenses involved with the brain autopsy and donation, including transportation to and from the donation site.

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Pathology MENU

To learn more about brain tissue donation, please fill out this form and we will get back to you.

Frequently Asked Questions

Why is tissue needed for scientific research?

Donation of your or your loved one's brain tissue will provide one of the most meaningful resources to help us advance our knowledge of neurological diseases and aging. Brain donation helps researchers better understand the causes of and treatment options for Alzheimer's disease and related dementias. One donated brain can provide resources for hundreds of research studies. In this way, it provides a gift of hope to future generations at risk of developing dementia.

When should plans be made for possible brain and tissue donation?

Coping with care for a loved one nearing the end of life is not easy. Making plans in advance as much as possible is still painful, but is easier than waiting until the last-minute. Our goal is to make the brain donation proceed smoothly. Contacting us through this form will allow us to help you through the planning steps

Will my (donor's) family receive a diagnostic autopsy report?

Yes, families who request will receive a brain autopsy report (typically within three months) on the type and levels of pathology in their loved one's brain and gain insights into how these brain changes may have contributed to his/her clinical decline.

Who is paying for the study?

Center for Human Brain Discovery and Department of Pathology. There will be no cost to you.

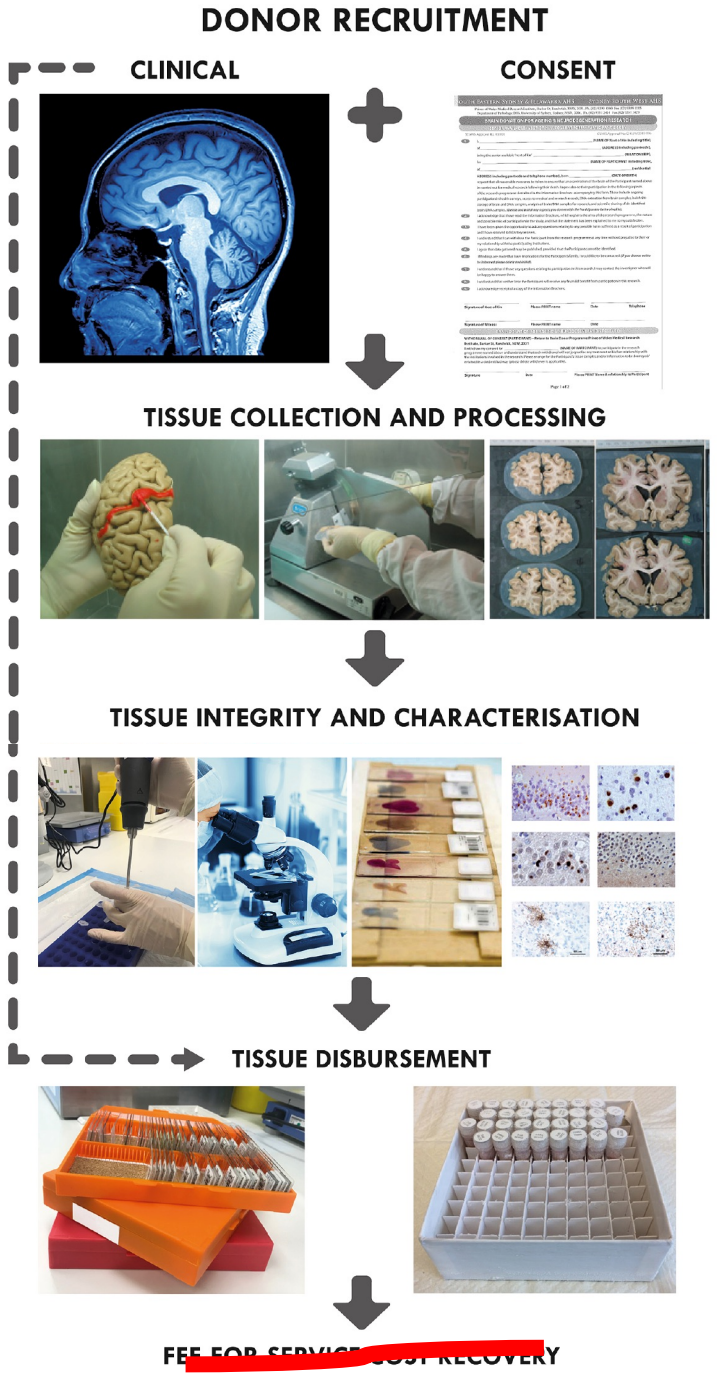
Has the Center for Human Brain Discovery received approval from Yale's Institutional Review Board?

Yes, this research study has been approved by Yale's Institutional Review Board.

Donor recruitment, outreach, and collaboration

We need you, our clinical neurology colleagues!

- ❑ Recruit and consent potential donors, including patients and unaffected family members
- ❑ Education and community outreach
- ❑ Research collaborations
  - investigators, including all of you, can access the tissue and data at no cost (funding provided by anonymous donor)



FAQs

- What is the process for patients/families?
  - ❑ Make initial inquiry through the Qualtrics form on our website
  - ❑ We will review clinical presentation and provide general information to patient/family about brain donation requirements and process; if interested, consent is provided for patient and family to review
  - ❑ Questions answered and consent signed and returned if wish to proceed
  - ❑ When death imminent (days), family should alert Yale autopsy service, logistical arrangements made with care facility, funeral home
  - ❑ Once patient passes, NOK must provide consent for brain autopsy
- Is there a cost for potential donors? **no**
- What is the process for clinicians?
- Are reports generated and provided to the clinician? **Yes and to the family**
- How do researchers request access to tissue? **See website – in process of updating this section**
  - Is there a fee? **all costs are covered by anonymous donor**; no cost recovery fees at this time

Questions?

To learn more, email Dr. Chen Liu (PI and Dept. Chair) chen.liu@yale.edu

Pallavi Gopal pallavi.gopal@yale.edu

Check out our website:

https://medicine.yale.edu/pathology/clinical/brain/

WHY US ?

The Center for Human Brain Discovery at Yale School of Medicine is a vital and open resource that supports research into the causes of and treatments for neurodegenerative diseases, as well as normal aging, with the goal of procuring and archiving high-quality brain tissue specimens, paired with blood, cerebrospinal fluid, and non-central nervous system tissues, such as muscle, fibroblasts, etc., as well as deep patient health records data.

INFORMATION FOR DONORS AND FAMILIES

We are asking you to take part in a research program because donating your or your loved one's brain tissue will provide one of the most meaningful resources to help us advance our knowledge of neurological diseases and aging and aid biomedical research. Brain donation helps researchers better understand the causes of and treatment options for Alzheimer's disease and related dementias as well as Parkinson's disease and other neurodegenerative diseases. A single donated brain can provide resources for hundreds of research studies. In this way, it provides a gift of hope to future generations at risk of developing dementia and other age-related neurologic disorders.

Frequently asked Questions

WHY IS TISSUE NEEDED FOR SCIENTIFIC RESEARCH?

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Why is it imporatant for diverse populations to participate in brain donation?

African American and Latino/a/x individuals are more likely than Caucasians to have dementia. Yet, African Americans and Latino/a/x are less likely to participate in clinical trials and are underrepresented in research. Including diverse participants in research helps scientists to identify unique factors that may contribute to Alzheimer's disease and related dementias in these populations.

If I don't have memory problems or a neurodegenerative disease , can I still participate in brain donation?

People without memory or other neurologic problems play a vital role in research on neurodegenerative disorders. They help us to identify the age-related processes and changes that occur in a healthy brain. This knowledge helps researchers determine which changes in the brain are specifically related to neurological disease and which are normal parts of aging.

FAQ continued

WHEN SHOULD PLANS BE MADE FOR POSSIBLE BRAIN AND TISSUE DONATION?

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WHO IS PAYING FOR THE STUDY?

Center for Human Brain Discovery and Department of Pathology. There will be no cost to you.

WILL MY LOVED ONE'S HEALTH DATA BE SHARED?

Never. Your loved one's confidentiality will be respected at all time. De-identified information about the donor's clinical and neurologic history will be associated with his/her brain tissue, but no information that discloses his/her identity will be released or published.

WHAT IF I CHANGE MY MIND AND NO LONGER WISH TO DONATE MY BRAIN?

You can cancel your donation at any time. Please contact center for Human Brain Discovery Coordinator as soon as possible should you want to change your decision.

From start to finish, what is involved in the brain donation process?

1. Enroll in the brain donation program and complete a consent form (contact us through our website).

2. Talk to your family about your decision and designate a family member or other representative to contact the Yale morgue and Center for Human Brain Discovery coordinator at the time of death.

3. At time of death, your representative should contact the center immediately, ideally within two hours of death. The next of kin will re-affirm wish to donate and provide autopsy consent.

4. The Center for Human Brain Discovery coordinator will assist your loved ones in making arrangements for transportation to and from the donation site.

5. The brain removal and autopsy is performed, and the brain tissue stored in our carefully controlled brain bank.

6. The body is returned to the family for burial or cremation and related ceremonies.

7. Your family and doctor will be notified of the brain autopsy results (~ 3 months).

8. Donated brain tissue, blood, and CSF is available to qualified scientists for critical research.