

Chapter 23

Postmortem Brain Donation and Autopsy

Purpose: Postmortem brain donation and autopsy are performed for definitive determination of the presence or absence of Alzheimer’s Disease, dementia and other neuropathologies as well as to make tissue available for various omics, including genomics, transcriptomics, proteomics, and metabolomics. Half of the brain will be flash frozen and the other half preserved in formalin for storage in the Columbia University Irving Medical Center / New York Brain Bank, so that these tissues can be made available for future research by qualified investigators.

Anticipated Sample Size: Based upon the current mortality rates, we anticipate that over the 5- year period of the grant, at least 250 older participants will pass away. Based upon the NECS experience, we anticipate that ~15% or ~40 participants (8 per year x 5 years) will donate their brains for study. All participants will be recruited for this effort.

The LLFS in-person consent form has the following language pertaining to brain donation:

“Some participants will be asked to participate in an additional study investigating the relationship between cognitive function and brain tissue. We will provide you with a letter and brochure explaining the opportunity to participate in a brain donation program after you have passed away. This portion of the study is completely optional and not necessary for participation in the Long Life Family Study.”

Procedure:

Step 1: During V3 Visit

- The research staff address the opportunity to participate in the optional brain donation program as part of the Visit 3 consent process, specifically during the section where participants can note whether they are interested in brain donation or not.
 - If the **participant expresses interest in enrolling in the brain donation program**, staff will:
 - Provide participant with the brain donation introductory letter and FAQs information sheet.
 - Fill out the top portion (**For RAs**) autopsy referral form.
 - If the **participant expresses interest in hearing more about** the brain donation during the visit, staff can provide the brain donation introductory letter and FAQs. RA should follow up at next annual follow-up and if interested, fill out the top portion (For RAs) autopsy referral form.

- If the **participant does not ask for additional information** about brain donation at the time of the visit, staff should mail the introductory letter and FAQs post-visit results. RA should follow up at next annual follow-up and if interested, fill out the top portion (For RAs) autopsy referral form.
- If the **participant directly says that they are NOT interested** in the brain donation program, staff should not mail the introductory letter and FAQs post-visit results nor fill out an autopsy referral form

Step 2: RedCap Entry

- After the visit is completed, RA should enter the date of referral (located on the bottom of the form) into REDCap Brain Donation Panel for all participants who expressed interest and have an autopsy referral form.

Step 3: WUSTL Box Upload to DMCC

- RA should upload the autopsy referral forms to WUSTL BOX within FC-specific Brain Donation Program folder, which is shared between the respective field center and the DMCC (e.g., NY-DMCC, BU-DMCC, PT-DMCC).

The remaining steps are completed by the DMCC and Brain Donation Center:

- The DMCC will consistently download and maintain copy of these referral forms from one local machine and move these over to a subsequent folder between the DMCC and the Brain Donation Center (e.g., DMCC-BDC).
- Once these files are downloaded by the Brain Donation Center, these files will be removed from BOX to ensure data security and participant safety.

The current contact person at the Brain Donation Center (as of September 2022) is:

Donovan Laing

- Clinical Research Manager, CUIMC
Phone: (212) 305-9086
Email: dal2190@cumc.columbia.edu

Step 4: Autopsy Consent Overview with the Brain Donation Center

Donovan will then call the participant to go over the autopsy consent form with them. This process is outlined below:

1. The participant designates a family member or other representative to contact Donovan Laing at the time of death or in the days leading up to death. When the LLFS participant passes away, it is important that Donovan Laing is contacted immediately, even if it is in the middle of the night.

2. The participant indicates their designated funeral home and if they are planning burial, open casket, cremation.
3. Donovan Laing will locate a local diener who will be willing, when the time comes, to go to the funeral home and remove the brain. Dieners generally charge about \$500-\$1000 for this service. The research staff should contact the funeral home Director about these future plans. The Director might be able to recommend the name of a diener or autopsy technician. Otherwise, contact local academic departments of pathology, hospital morgues or the local medical examiner for leads to finding a diener. It is helpful if a diener can be located, with contact information kept on file, in advance of death.
4. At the time of death, the family will contact Donovan, who will make all arrangements for the procedure and shipment to Columbia University Irving Medical Center (CUIMC).
5. The brain autopsy is performed, and the brain tissue is then stored in what is called a Brain Bank, at CUIMC. Brain tissue is available to qualified scientists across the country for aging-related research.
6. If the family wishes, the results of the autopsy will be made available to them. Completion of the report and disclosure of the results typically takes approximately six months; however, it is difficult to provide a definitive timeline. We encourage donor families to contact Donovan Laing periodically who can provide them with the latest information that is available. LLFS will also receive the results of the brain autopsy.

Enrollment Tracking:

In addition to being directly referred by LLFS staff, a number of LLFS participants may reach out directly to the Brain Donation Center based on information provided in the LLFS newsletter. There are therefore two ways in which LLFS will track enrollment into the brain donation program.

- 1) After filling out the referral form, staff will enter the date referred into REDCap.
- 2) On a quarterly basis, the Brain Donation Center will send a list of all enrolled LLFS participants to the DMCC. The DMCC will enter the date of brain donation enrollment into REDCap.

Neuropsychological-Neuropathology Consensus Conference: CUIMC pathologists will work with the LLFS dementia review panel in conducting clinical-anatomical correlations.

Attachments:

- Brain donation information letter
- FAQs sheet about brain donation and autopsy

- Brain donation and Autopsy referral form