

**The Stanley Medical Research Institute
Statement about the Stanley Brain Collection**

January 2007

The following is to provide correct and relevant information to the public about the Stanley Brain Collection and our research.

- The Stanley Medical Research Institute (SMRI) is a nonprofit organization that is funded specifically to improve research on severe brain diseases, in particular, schizophrenia, bipolar disorder, and severe depression. Research on these severe brain diseases has severely lagged behind other areas of medical research, in part because brain tissue for these diseases cannot be obtained from living individuals, adequate animal research models do not exist for these diseases, and very little postmortem brain tissue has been available for study. Thus, in 1995 the decision was made to begin the Stanley Brain Collection to make brain tissue available worldwide without charge to researchers.
- The Stanley Brain Collection was modeled after other brain collections in the United States, including the National Institute of Mental Health's brain collection, and uses a scientific protocol for collecting brains that has proven to be invaluable for research. See Torrey EF, Webster MJ, Knable MB, Johnston N, and Yolken RH, The Stanley Foundation Brain Collection and Neuropathology Consortium, *Schizophrenia Research* 2000;44:151–155. Single copies of this article can be downloaded and printed for personal research and study by linking to www.stanleyresearch.org/publications/documents/brain-collection.pdf.
- In the past ten years, SMRI has provided postmortem tissue to over 240 researchers in 20 countries. This has involved the collection, processing, and shipping of over 200,000 sections (pieces) of tissue. Over the past decade, SMRI has provided at least half of all postmortem brain tissue used for research on these diseases in the world. More than 180 research papers deriving directly from this research have been generated and published in peer-reviewed journals. SMRI has never profited financially from this program, while the financial cost of this program to SMRI has been considerable.
- In order to research these severe brain diseases, it is necessary to collect the whole brain because it is not yet known specifically where the abnormalities for these diseases are located. Many brain diseases, such as Parkinson's disease, cerebral palsy, and herpes virus encephalitis, affect only a very small brain area. One of the purposes of the Stanley Brain Collection was to learn more about the location of brain abnormalities in these severe psychiatric brain diseases. SMRI has stated in publications, on our website, and elsewhere that we collect brains. SMRI's former Executive Director and current Associate Director for Laboratory Research, Dr. E. Fuller Torrey, has appeared many times in the national media (*Life* magazine, *American Medical News*, the *Washington Post*, *60 Minutes*, *A&E*, etc.) holding a whole brain and explaining the importance of such research to the public.
- To our knowledge, the person obtaining consent explains the donation of the brain to the next of kin, and the consent forms have stated that the donation includes brain tissue, without limitation on the amount or size of the donated tissue. Information on SMRI and its research is offered to the next of kin at the time of the donation and is provided afterwards upon request. This information is also publicly available on our website at www.stanleyresearch.org. In addition, when the family receives an autopsy report, the report may state that the brain has been sent to SMRI. Finally, SMRI often directly contacts family members after the donation.

- Tragically, high incidences of sudden, unexpected deaths occur among those who suffer from schizophrenia, bipolar disorder, and severe depression. SMRI works with medical examiner offices because these offices receive cases of sudden death for investigation. In addition, the medical examiner offices have the personnel and facilities for proper tissue recovery.
- Unlike some organ and tissue donations, prior consent from the decedent is not practical because of the process that must be followed to qualify the tissue for the Stanley Brain Collection. SMRI's brain research requires rigorous prescreening of donations, preparation of the tissue in exactly the same way so that there is no variation in technique from case to case, and data collection at the time of the donation. It also requires extensive follow-up to obtain medical histories for each case.
- SMRI has never knowingly obtained any donation of brain or other tissue without the full consent of available next of kin. Like many other organ and tissue donations, this typically is done by telephone because time is critical and next of kin generally are not present at the medical examiner's office. Generally, tissue is not useful for brain research purposes if obtained more than 72 hours after death. The shorter the time between death and preparing the brain, the more useful the tissue is likely to be for research.
- These time constraints mean that families must be approached for donations of tissue shortly after the death of their family member, as is also the case for many other types of organ and tissue donations. This is a very stressful, traumatic period for family members, especially when the death is unexpected.
- Medical examiners offices normally remove the brain and other organs at the time of autopsy to check for possible causes of death, e.g., stroke, meningitis, and renal failure. Thus, it is not the collection of tissue for research purposes that necessitates the removal of the brain and other organs, because this usually occurs as part of the autopsy. What tissue donation additionally requires is that the brain and other tissues be prepared in a specific manner to make them usable for medical research. This preparation is a complicated process that can take several hours of detailed work. As seemingly simple a task as providing adequate dry ice for each shipment can involve extensive time and effort to obtain the ice due to limitations on sources and delivery. The more complicated process of preparing and preserving the tissue for research is especially critical, requiring a detailed knowledge of neuroanatomy so that significant parts of the brain are not destroyed in the process.
- Obtaining brain and tissue donations is complex, labor-intensive work, requiring particular sensitivity to bereaved family members. It can involve public education outreach efforts and contacting several families before one actual donor is found, because some families decline to give consent, and, in other cases, facts come to light that make the tissue unusable for our research, e.g., too long a period following death, severe brain trauma, or other disease. In addition to obtaining the consent and processing the tissue, developmental, demographic, and medical history information from the family and health care providers is obtained.
- SMRI confirms the psychiatric or normal diagnosis and the usefulness of the tissue for research after record collection, neuropathological examination, testing, and professional review. SMRI often directly contacts family members to obtain and confirm medical histories; the collection of medical histories on normal control cases is less extensive and time-consuming than for cases involving psychiatric diseases. Altogether, this is laborious, painstaking work that requires sensitivity to the bereaved family and persistence in obtaining medical records that can extend for weeks and months after the

donation. Without specific information that usually can be obtained only with the cooperation of family members, the donated tissues cannot be used for research.

- SMRI has paid a reasonable amount of compensation for the services of those who have helped obtain donations of brain and other tissue for the Stanley Brain Collection, comparable to that paid to medical and tissue bank personnel elsewhere in the United States. To compensate for this work is legal and ethical.
- States have passed standardized legislation under the Uniform Anatomical Gift Act to encourage families to donate postmortem tissue for transplantation and research. Families who make such donations are to be commended; in SMRI's case, such families are making a major contribution to research on schizophrenia, bipolar disorder, and severe depression that would not occur without their donation.
- Distorting and sensationalizing this process ultimately discourages the donation of tissue for medical research. All who have these diseases, all families who have relatives afflicted with these brain diseases, and all who do research on these diseases lose when this happens. The general public also loses because it has a vested interest in the health and welfare of all our citizens, including the severely mentally ill.
- SMRI will continue undaunted, focusing on our mission to find the causes, cures, and better treatments for severe brain diseases. SMRI is thankful to all those who have contributed so selflessly to our mission.