

## **WIEN CENTER, Mount Sinai Medical Center STATE OF FLORIDA BRAIN BANK**

The State of Florida through its Alzheimer's Disease Initiative, has formed a Brain Bank to study the brain of Individuals with dementing illness and to provide tissue for research to find some of the answers about these devastating diseases.

Only by your participation in this program will your family have a definitive diagnosis. Perhaps even more than that, we need your help in our fight against Alzheimer's. At the present, only a brain autopsy at the time of death can confirm that an individual definitively suffered from Alzheimer's disease.

### **How to Become a Donor**

Families will receive a packet of information with forms to be completed and signed. Written consent must be obtained by one of the following persons: spouse, adult children, brothers or sisters or legal guardian (witness needed).

### **Will it cost to donate?**

There will be no additional cost over the usual expenses associated with a funeral. You can change your mind at any time. You have the right to withdraw at any time. The autopsy will not interfere with funeral arrangements or open casket viewing.

### **What will happen to my brain tissue?**

It will be stored and used for research purposes by authorized personnel only. Collaborations between scientists are very important in research studies. Scientists from various centers in the United States and elsewhere may request samples of brain tissue from this Brain Bank. Such requests will be honored and samples of tissue that are unidentified by name or birth date will be provided for legitimate requests by credentialed researchers.

### **Procedure for Autopsy**

At the time of death:

- The Brain Bank coordinator can be contacted through a 24-hour paging system
- The Brain Bank will make all arrangements pertaining to the donation procedures (gather information, arrange transportations for autopsy etc.)
- The brain will be shipped to the Mayo Clinic in Jacksonville for pathological study and will be used for future research
- The family will be provided with the neuropathological diagnostic report within three months, along with a letter explaining the findings.

For more information, please call Yirah Ochoa or Lidia Perrotta at 305-674-2018.

# WIEN CENTER, MOUNT SINAI MEDICAL CENTER THE STATE OF FLORIDA BRAIN BANK

## FACTSHEET:

1. Verification of the diagnosis in individuals with dementia is helpful to researchers conducting genetic research in Alzheimer's disease and related disorders.
2. Legally the autopsy must be requested by the next-of-kin or guardian. Legal order of standing's spouse, adult son or daughter, parent, sibling.
3. An autopsy will rarely delay or complicate the family's plans for funeral, cremation, or burial and will not interfere with a family's desire for an open casket funeral.
4. An autopsy is the only method by which Alzheimer's disease and other related memory disorders can accurately be diagnosed.
5. The autopsy should be performed within 12 hours of the time of death to assure maximum research value. It is essential to notify the Local Brain Bank Coordinator immediately following death.
6. The State of Florida Brain Bank will pay for the autopsy procedure. In addition, transportation from the site of death to the site of the autopsy will also be the financial responsibility of the Brain Bank. The family will be financially responsible for all other funeral arrangements and expenses.

If the family does not have a funeral home at the time the paperwork is does not have a funeral home at the time the paperwork is submitted, it is their responsibility to notify the Local Coordinator in writing when the funeral home had been selected.

7. Due to budgetary shortfalls in the State of Florida, we continually need support for the State of Florida Brian Bank. Your contribution may be made to the State Trust Fund. Checks are to be sent to:

Yirah Ochoa Brain Bank Coordinator  
Mount Sinai Medical Center  
The Wien Center for Alzheimer's Disease and  
Memory Disorder Center  
4300 Alton Road  
Mimi Beach, FL 33140