Brief Report: The Role of National Brain and Tissue Banks in Research on Autism and Developmental Disorders

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Donated organs and tissues give life and sight, teach researchers how the brain works, provide drugs for fighting cancer, and allow us to master the very genes that define us as human. (Swerdlow, 1989)

Multiple approaches are required to solve the mystery of autism. Some answers will be found in psychological testing, some in new scanning procedures of the living functioning brain, and others in new educational techniques, but others are hidden deep in the brain. Only through careful evaluation of tissue from individuals with autism will the underlying mechanism causing autism be discovered. When an individual with autism dies due to an accident or other disease, the opportunity exists to make a significant contribution to solving the frustrating tragedy of autism.

As one approach to overcoming autism and other developmental disorders, the National Institute of Child Health and Human Development has established two closely interacting Brain and Tissue Banks to meet the needs of families and medical researchers. Both banks, one at the University of Maryland School of Medicine and one at the University of Miami, work with families facing difficult decisions as death approaches for a loved one and with researchers who require human tissue for research.

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Some researchers are working diligently to obtain tissue donation either at surgery or time of death for specific disorders in addition to performing medical research. The purpose of centralized Brain and Tissue Banks is to supplement these efforts rather than to supplant them. Many researchers cannot invest the time, money, and emotional energy it requires to deal with families at such stressful times. For tissue recovery to be successful, full cooperation has to be obtained from the family, the physician, nursing staff, genetic counselors, hospice workers, funeral director, pathologist, and hospital administrative personnel. This is a daunting undertaking if done infrequently. The staff of the two banks have experience with all aspects of tissue recovery. In addition, the banks will work together with researchers who have special protocol requirements. Tissue is also available from unaffected individuals to serve as a comparison group.

The two banks are sensitive to the concerns of grieving families. It has to be recognized that some families are troubled by the concept of tissue donation. It is appropriate that these individuals decline to donate tissue. However, a significant number of individuals have concluded that when this life ends, it is only right that organs which no longer function be donated to benefit generations to come. A third group of individuals have not reached a conclusion because the necessary information has not been provided to them. Once families are informed about tissue donation and the existence of Brain Banks for research on autism and related disorders, they will make a decision that is appropriate for them.

One of the most important issues is advance planning. Tissue recovery has to be completed within 24 hours, and preferably 8 hours, after death. After that time the tissue is no longer useful for research purposes. Due to these time constraints it becomes very difficult to complete tissue recovery without prior planning. Individuals and families are often uncomfortable planning in advance for the death of themselves or a loved one. Since many developmental disorders, including autism, are not immediately life threatening, uncertainty exists about the time that death may occur. This leads to the conclusion that planning can be postponed. However, death may occur unexpectedly due to an accident or other illness and the tissue recovery may not be feasible. Considering the depth of thought and commitment that goes into a decision to donate, and the unique and irreplaceable nature of donated tissue, each lost donation is a blow to research and humanity that is difficult to measure.

In the case of any prolonged illness resulting in death, the most common rationalization for refusing an autopsy is that the loved one has “suffered enough.” This feeling may extend to both the lay public and the medical community who have had close and caring contact with the patient. Families have to be reassured that once a person has passed out