G71 Forensic Pathologists and the NICHD Brain and Tissue Bank for Developmental Disorders

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After attending this presentation, attendees will be able to recognize the significant contribution of forensic pathologists to medical research by support of the activities of the NICHD Brain and Tissue Bank for Developmental Disorders.

This presentation will impact the forensic community and/or humanity by showing the significant contribution of forensic pathologists to medical research involving the use of postmortem human tissues.

Medical developments have increased the use of human tissues, especially for research purposes. The National Institute of Child Health and Human Development (NICHD), in 1991, established a Brain and Tissue Bank at the University of Maryland with a collaborating retrieval site at the University of Miami. Establishment of the Bank was in response to requests by family support groups for increased research on developmental disorders affecting children and young adults.

The Bank obtains donors through efforts by support groups and forensic pathologists. Through a coordinated outreach effort to support groups the Bank has registered over 2400 potential donors. The efforts have resulted in donation of autopsy tissue from nearly 1000 donors with over 100 different developmental disorders.

The legal and ethical issues regarding the use of human tissues donated for medical research have received great public attention. To protect the deceased's body from being used for postmortem research that is incompatible with the deceased or their families' wishes and values, informed consent is obtained for all tissue donations. The Bank provides the means for tissue donors to leave a legacy that will benefit future generations. A partial list of disorders includes adrenoleukodystrophy, autism, chromosomal disorders, metabolic disorders, Prader-Willi syndrome, sudden infant death syndrome, and tuberous sclerosis. Tissue from an additional 2000 donors has been obtained from local hospitals and the Office of the Chief Medical Examiner in Maryland. Tissue is stored formalin fixed and frozen at –80°C. The Bank has collected over 55,000 tissue samples.

The availability of normal control tissue is critical to studying developmental disorders. The ONLY source of control tissue is from accident victims who come under the jurisdiction of medical examiners. Support by the Office of the Chief Medical Examiner of Maryland has enabled donation of tissue from normal individuals as well as individuals with autism, chromosomal disorders, PraderWilli syndrome, etc. In fact, disorders that are not inherently life threatening, such as autism, rarely come to autopsy unless death is accidental. The participation of medical examiners throughout the United States has enhanced the collection of tissues from normal donors (especially under 17 years of age) and donors with rare disorders.

The Bank serves an additional role: making the tissue available to qualified researchers. To date the Bank has distributed 12,000 tissue samples to 360 researchers in 11 countries. These researchers have published 150 full-length publications and an equal number of abstracts based on studies utilizing tissue from the Bank.

This report focuses on the role of forensic pathologists in medical research by support of activities of the Brain and Tissue Bank for developmental disorders. The mechanisms of how to obtain informed consent from the families of the newly dead is also addressed.

Forensic Pathologists, Tissue Donation, Medical Research

 ** Presenting Author*