SUID Tissue Consortium to Help Solve the Dilemma: Asphyxia or Brain Abnormality

Larissa M. Gregorin, MPH¹,Bruce A. Hyma, MD², and Betty L. McEntire, PhD¹
¹American SIDS Institute, ²Miami-Dade Medical Examiner Department

Abstract

Sudden unexpected deaths of infants and toddlers are tragic to families while challenging the forensic and scientific communities. Often the only forensic finding is an unsafe sleep environment. Medical examiners across the country differ in whether to classify them as asphyxia, SUID, SIDS or undetermined. Disagreement exists as to the extent, if any, underlying pathology such as a brain abnormality is responsible. This dilemma will not be resolved without the availability of research tissue along with thorough scene data on large numbers of cases and controls.

The purpose of the SUID Tissue Consortium is to systematically obtain tissue and data from children < 4 years of age (SUIDs and controls) and bank it for current and future researchers. The Consortium has 7 ME offices collecting tissue and data which is being banked at the University of Baltimore Brain and Tissue Bank (UMD BTB). Typically research tissue donation is explained to families by local donor services, with final consent obtained by UMD BTB. When consent is obtained, the tissue is collected at autopsy and samples are either fixed or frozen to be shipped later to the UMD BTB.

The consortium is managed by the American SIDS Institute. Lab equipment and dry ice are provided by them, and tissue kits and overnight shipping are provided by UMD BTB so that ME offices do not have additional costs. Cases are filtered through local donor services so that donations for live recipients take precedence over research donation.

The biggest challenge to banking research tissue is obtaining consent from next of kin before the autopsy begins. Parents are difficult to reach and they often require more time to decide than is available. Other issues involve cases being missed by donor services, cases ruled out for donation by the ME and lack of viability of tissue. The consent rate is currently 12% for infants and 3% for toddlers.

The consortium began collecting data in August of 2011. Participants include 5 ME districts in Florida (Miami, West Palm Beach, Naples, Tampa and Lakeland), the Minneapolis ME and the GBI (GA Bureau of Investigation). Tissue and data have been banked on 35 infants and 3 toddlers.

In addition to efforts aimed at increasing the consent rate, the consortium is seeking to add additional ME offices within the next year.