

TRIS Project: Parent completed surveys on a growing population

Deborah A. Bruns
Southern Illinois University, USA

The Tracking Rare Incidence Syndrome (TRIS) project developed to increase awareness and knowledge about children and adults with rare trisomy conditions such as trisomy 18 (t18) and trisomy 13 (t13). The project aims to facilitate improved decision making and optimal services and supports for affected children and their families. The TRIS project collects data in several ways. The primary method is the online TRIS Full Survey which, to date, has been completed on behalf of approximately 250 children and adults. The survey examines topics such as presenting and chronic medical conditions, developmental milestones, therapeutic needs, and family support. Demographic data is also collected. Completion of the TRIS Full Survey provides baseline data. Project participants also complete an annual TRIS Follow-up Survey to document their child's progress, medical interventions and related service needs.

Findings have indicated longer survival rates for children with full t18 and full t13 which contradict the "incompatible with life" claims evident in the literature and often discussed in clinical practice. Data also indicate achievement of a range of developmental milestones including walking, self-feeding and using gestures, sign language and verbalizations to indicate wants and needs. Data from TRIS project surveys offers a new perspective on long-term survivors with rare trisomy conditions. It is hoped that TRIS project data will add to the existing knowledge base and be utilized to assist professionals who work with this population.

Biography

Deborah A. Bruns is an Associate Professor and Coordinator of the Special Education program in the Department of Educational Psychology and Special Education at Southern Illinois University Carbondale. She teaches undergraduate and graduate level coursework in Early Childhood Special Education. Dr. Bruns is the Principal Investigator of the Tracking Rare Incidence Syndromes (TRIS) project. She has presented at national and international conferences on TRIS project related topics to nurses, clinical geneticists and early intervention professionals. Dr. Bruns has also published project findings in leading medical journals such as the *American Journal of Medical Genetics*.

dabrun@sium.edu