



The Tracking Rare Incidence Syndromes (TRIS) Project

Deborah A. Bruns, Ph.D.

Southern Illinois University Carbondale

Mission

The Tracking Rare Incidence Syndromes (TRIS) project seeks to increase awareness and knowledge for families and professionals touched by rare trisomy conditions and aims to facilitate improved decision making for optimal services and supports for affected children and their families

Contextual Background

Literature indicates poor prognosis, common physical markers, medical conditions and provision of interventions such as resuscitation and surgery (e.g., cardiac, gastrostomy placement) (e.g., Brewer et al., 2002; Chen, 2004; Niedrist et al., 2006)

Majority of families offered limited hope for their child's survival or social support for day-to-day care, medical decision making, etc.



Data collection instrument: TRIS Survey

Effectiveness of a parent registry to collect data and inform families, professionals and policy makers (Glicklick & Dreyer, 2007). Supplies information similar to hospital and population-based registries.

Completion of TRIS Survey open to parents with children representing all varieties of rare trisomy syndromes (e.g., full, mosaic, partial, deletions). Majority of participants have a child with a trisomy 18 or 13 variant.

The TRIS project utilizes the Full (children surviving longer than two months), Modified (infants surviving 60 days or less after birth) and Follow-up (longitudinal data on long term survivors) versions of the survey

Launch in February 2007, 110 completions (45 Full; 65 Modified) in first 12 months. Survey completed online or mailed in paper and pencil format if requested.

TRIS Database continues to grow through parent and professional contacts and focused outreach efforts. Ongoing outreach through parent-to-parent contact, professional groups and online sources.

Additional Info

For more information about the project, contact:
Deborah A. Bruns, Ph.D. at
dabruns@siu.edu or tris@siu.edu

Implications

Contrary to the literature, more than 10% of infants surviving at one year of age; need for professionals to be knowledgeable of medical and developmental needs and advocate for their provision

TRIS parent registry data confirms previous literature regarding common medical conditions (e.g., Kosho et al., 2006; Pont et al., 2006; Shaw, 2008)

Need for longitudinal research with "survivors" to update the literature about long term needs and outcomes

TRIS Website

- Faces of trisomy photos
- Family Resources
- Overview of TRIS Survey
- Request for TRIS account activation
- TRIS Brochure
- TRIS Flyer
- TRIS In the News

<http://web.coehs.siu.edu/Grants/TRIS/>

Dissemination

Continued outreach to families, perinatal hospice professionals, genetic counselors, early intervention professionals and other interested individuals and organizations

Pilot study results:
Bruns, D. A. (2008). Pregnancy and birth history of newborns with Trisomy 18 or 13: A pilot study. *American Journal of Medical Genetics Part A*, 146(3):321-326.

Publication venues in associated disciplines including *Journal of Early Intervention* and *Neonatal Network*

Selected presentation venues: *Advanced Practice Neonatal Nurses*, *Division for Early Childhood of the Council for Exceptional Children* and the *Support Organization for trisomy 18, 13 and Similar Disorders*



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