The Tracking Rare Incidence Syndromes (TRIS) Project

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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.

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:

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


Additional Info

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

Acknowledgements

Many thanks to Shirley Lockwood, John Carey, Bess Raulerson, Evelyn Barrientos-Perkins, Marissa Code, and the families participating in the TRIS project.