The Tracking Rare Incidence Syndromes (TRIS) project: Update and family support data

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TRIS project
Mission statement

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. (http://web.coehs.siu.edu/Grants/TRIS/)
An overview of how the TRIS project began

- Experience with young children with full trisomy 18 in the early 1990’s
- Parent/family concerns on Tri-family and Tri-med lists including family needs, interactions with professionals and medical / health concerns
- Formation of planning group
- TRIS was “born” in 2003; pilot data collected in 2005-06; online survey launched February 1, 2007
TRIS Survey

- Full and Modified Surveys
- Follow-up Survey
Completed surveys

- 321 parents in TRIS database
  - Contact and child information
  - Survey access number
- As of July 11, 2008, the number of completed TRIS Surveys:
  - Total received = 173 (54%)
    - Full Survey = 83; largest group - full t13 (18)
    - Modified Survey = 90; full t13 (67)
  - Follow-up Survey = 45 eligible with 23 returned; reminder is sent 12 months after completion of Full TRIS Survey
Data analyses

- Survival rates
- NICU experiences of newborns with full trisomy 18
- Sources of support (immediate and extended family)
- Attainment of developmental milestones
Publications


Recent and Upcoming Presentations


TRIS Website

- Homepage – News, access to TRIS Survey and links to project supporters
- Project staff
- TRIS Flyer and Brochure (can download)
- Overview of TRIS Survey
- Family Resources
- In the News
- Photo Gallery
- Give to TRIS
TRIS Supporters

- **Organizations**
  - Support Organization for Trisomy 18, 13 and related disorders (SOFT)
  - Hope for Trisomy 13 and 18
  - Noah's Never Ending Rainbow

- **Online communities**
  - tri listservs (tri-med, tri-family)
  - livingwithtrisomy13.org

- Southern Illinois University Carbondale
Next steps continued

- **What are your areas of interest?**
  - Data analysis – what types of results?
  - Outreach – who and where?

- **How can we continue to raise awareness of the TRIS project?**
  - With families
  - With professionals

- **Other suggestions!!**
TRIS Project
Core Staff

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