

# 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**

- Bruns, D.A. (in revision). Neonatal experiences for infants with full trisomy 18. Neonatal Network.
- 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, 146A*(3), 321-326. (Research Letter)
- Bruns, D. A. (2006). Tracking rare incidence syndromes (TRIS) project. American Journal of Medical Genetics Part A, 140A(22), 2510. (Letter to the Editor)

# Recent and Upcoming Presentations

- Bruns, D. A. & Blair, D. (2008, September). An overview of the tracking Rare Incidence
   Syndromes (TRIS) project. American Academy for Cerebral Palsy and Developmental Medicine, Atlanta, GA.
- Bruns, D. A. & Raulerson, B. (2008, April). NICU findings of the Tracking Rare Incidence Syndromes (TRIS) project. Presented at 5th National Advanced Practice Neonatal Nurses Conference, Miami, FL.
- Lockwood, S., Bruns, D. A., & Evans-Hayden, M. (2006, October). Our needs, our strengths: Families with children with rare trisomy syndromes. Poster presented at the International Division for Early Childhood Conference on Children with Special Needs, Little Rock, AR.

#### 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





funding research. promoting education. raising awareness. changing lives.

- 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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