

Southern™
Illinois University
Carbondale



Our needs, our strengths: Families with children with rare trisomy syndromes

Shirley Lockwood, LVN
Deborah A. Bruns, Ph.D.
Michelle Evans-Hayden, B.I.S.
2006 DEC Conference
Little Rock, AK



Purpose of **TRIS** project

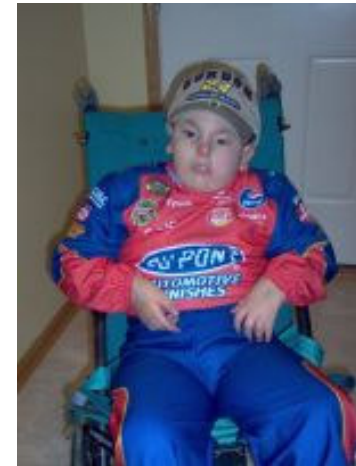
The **TRIS** project seeks to increase the knowledge base on rare incidence trisomy conditions and to make this information available to families and interested educational, medical and therapeutic professionals.

http://web.coehs.siu.edu/Grants/TRIS/pdfs/TRIS_informational_flyer_2005_May.pdf



TRIS PILOT SURVEY

- Development of pilot materials
 - Part I: Pregnancy and birth
 - Part II: Services and supports
 - Part III: Family issues
- Feedback from **TRIS** Advisory Committee on content and presentation
- Development of *Interested Parents Database*
- Distribute materials to parents in PDF format, fillable Word, and by snail mail



TRIS PILOT SURVEY continued

- Packets included:
 - Cover letter
 - Parts I, II and III and comment forms
 - Return envelope for snail mail
- Data collection: March – June 2006
 - Postal mailing (8) & electronic mailing (32)
 - Additional mailings (26)
 - Receive first surveys – snail mail & electronic
 - Closed survey in early June
- Total interested = 80; total sent = 66
- **Total TRIS Pilot Surveys received=27 (41%)**
3 excluded for analysis=24 (36%)



TRIS PILOT SURVEY

Part I RESULTS



- Complete data available for 19 respondents (79%)
 - 46% parents of children with Trisomy 18 (11 total: 9 full, 1 mosaic, 1 partial); 54% parents of children with Trisomy 13 (13 total: 10 full, 2 mosaic, 1 partial)
 - Education level: H.S. graduate (N = 5, 26%) to advanced degree (N = 5, 26%)
 - 19 (100%) reported being married and 16 (84%) earning \$50,000 or more in annual household income

TRIS PILOT SURVEY

Part I RESULTS continued

- Pregnancy data:
 - *Trisomy child was 1st child for 36% of parents (N = 8)*
 - *Pregnancy age = 22 to 43 years*
 - *9% of parents (N = 2) were aware of rare trisomy syndromes*
 - *8 of 22 children's trisomy condition was detected prenatally (36%) including ultrasound or sonogram (6; 75%), amniocentesis (7; 88%) or Alpha Fetal Protein test (4; 50%)*
 - *Seven mothers (88%) met with a geneticist*
 - *Trisomy condition confirmed between 19 – 36 weeks of pregnancy*



TRIS PILOT SURVEY

Part I RESULTS continued

- Gestational age: 29-41 weeks
(M = 37.7 weeks)
- Gestation weight: 1021-3629 grams
(M = 2610) [one ounce = 28 grams]
- Gestational length: 14-20.5 inches
(M = 18.3)
- Gender: 11 girls and 13 boys
- At time of survey completion:
11 living (46%) and 13 angels (54%)



TRIS PILOT SURVEY

Part I RESULTS continued

- Common physical characteristics
 - Low set ears (16 of 20; 80%)
 - Small jaw (8 of 20; 40%)
 - Microcephaly (9 of 20; 45%)
 - Extra finger or toe (10 of 20; 50%)
 - Cleft lip and/or palate
 - Hernia



TRIS PILOT SURVEY

Part I RESULTS continued

- Common medical issues
 - Respiratory distress (15 of 20; 75%)
 - Feeding difficulties (15 of 20; 75%)
 - Kidney problems (6 of 20; 30%)
 - Heart defect:
 - ASD = 30%
 - PDA = 25%
 - VSD = 40%



TRIS PILOT SURVEY

Part II RESULTS

- Services and supports
 - Early intervention including service coordination
 - Home & Center-based developmental therapy
 - Physical therapy
 - Occupational therapy
 - Speech & language therapy
 - Vision services
 - Audiology services
 - Respite
 - Specialized equipment including feeding pump, adapted stroller/wheelchair and nebulizer



TRIS PILOT SURVEY

Part II RESULTS continued

- Additional needs
 - Oxygen / Apnea monitor
 - Medication
 - Heart problems
 - Seizure disorder
 - Gastrointestinal difficulties
 - Hearing aids / Glasses
 - Splints / Orthotics



TRIS PILOT SURVEY

Part III RESULTS

- **Spouse identified as most supportive immediate family member:**

- “He walked the journey of carrying a dying baby to term and losing a much loved daughter.”
- “He's the most capable of helping.”
- “He is [name]'s father and we support each other.”

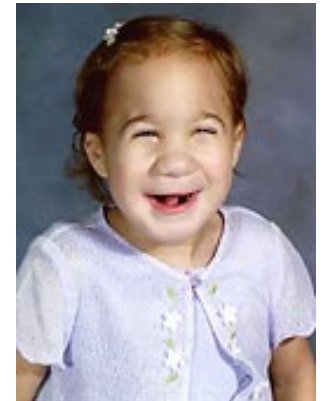


TRIS PILOT SURVEY

Part III RESULTS continued

- **Maternal grandmother identified as most supportive extended family member:**

- “She is always there to talk to.”
- “She was here for [her] birth, stayed to help, will keep her overnight. Has a way with her. She mourned the diagnosis with us and would be here in a flash if we needed her.”
- “She has come and stayed with us and helped with the care of the family and child. She also helps as a sounding board to issues that come up.”



TRIS PILOT SURVEY

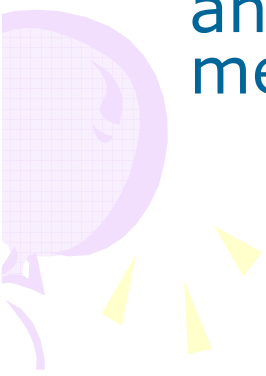
Part III RESULTS continued

- Friends and co-workers provided support but:
 - "...Since he died, they didn't know what to say so they said nothing. That was and is very painful."
 - "No one really knows what to say and although they tried they either tried to convince me that 'he'd be ok' or they offered prayers."
- Unmet needs include:
 - Emotional such as need for counseling
 - Financial such as funds for equipment
 - Sibling relationships
 - Spiritual needs





What's next for **TRIS**??

- Revision of **TRIS** Survey
 - Outreach efforts and continue to add names to database including other rare trisomy “flavors”
 - Upload revised **TRIS** Survey to website to collect and download data
 - **TRIS** interviews
 - Secure toll free phone number
 - Continue to submit conference proposals
 - Prepare informational materials including **TRIS** brochure, flyers, newsletter articles and manuscripts for education, family and medical related journals and publications
- 

For more information about the **TRIS** Project

Email: TRIS@siu.edu

Website:

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

Deborah Bruns,
Principal Investigator
Southern Illinois
University Carbondale
Shirley Lockwood,
Research Coordinator

