Update of TRIS Survey results
September 2012

The Tracking Rare Incidence Syndromes (TRIS) project continues to grow!! At this time, approximately 500 families are enrolled in the project.

A combined total of 396 TRIS project surveys were completed during February 1, 2007 to September 1, 2012 including 238 Full Surveys (children living at least two months; collection of baseline data) and 158 Modified Surveys (infants living two months or less).

The largest trisomy group represented in the Full Survey was 64 children and adults with full trisomy 18 (27%). The next largest groups are full trisomy 13 (n=35, 15%) and trisomy 9 mosaic (n=19, 8%). Across all trisomy types, over 80% were living at the time of survey completion (n=197, 83%). The age range was two to 468 months (mean of 88 months). For the 41 children and adults who passed away (17%), age range was two to 290 months (mean of 58 months). Maternal age at child’s birth ranged from 17-45 years with a mean of 31.3 years.

Based on 158 completed Modified TRIS Survey, the largest group was comprised of 107 infants with full trisomy 13 (68%). The next largest group was full trisomy 18 (n=43, 27%). Approximately half of this group of infants were stillborn or passed away the day they were born (n=86, 54%) with a mean of nine days of survival. Maternal age at child’s birth ranged from 15-45 years with a mean of 31.4 years.

In addition, since February 1, 2008, 324 Follow-up Surveys were submitted (Year 1=137, Year 2=103, Year 3=58, Year 4=19, and Year 5=7). Follow-up Surveys are sent on the anniversary of initial completion of the Full TRIS Survey. Analyses are underway on overall health status, cardiac issues and sources of family support over time.

Please continue to spread the word and encourage parents, grandparents and guardians to share information about their child. This information is compiled, analyzed and prepared for presentations and publications that are disseminated to other families as well as medical professionals including nurses and clinical geneticists.

The TRIS project provides a means to change perceptions about children with rare trisomy conditions. The data shows long-term survival, positive surgical outcomes and achievement of developmental milestones such as using gestures and vocalizations to communicate, walking (with or without assistance) and interacting with family members.

Additional information from the TRIS Surveys is available by request: send an email to tris@siu.edu with your specific questions.