The Tracking Rare Incidence Syndromes (TRIS) Project began in 2004. We seek to increase the knowledge base about individuals with these conditions and make it available to families and interested professionals such as educators, medical professionals and therapists. The TRIS Survey (Full, Modified and Follow-up versions) is the primary vehicle of the project. Each version requests information relating to children’s medical conditions, education and therapy needs, developmental milestones, family issues and demographic information about the child and his/her family.

At the present time, the project is recruiting participants, collecting data and analyzing the information. The results will be shared on the TRIS website, at conferences and publications in medical and educational journals as well as newsletters of trisomy support organizations. Work is also underway to secure funding to expand the scope and activities of the project.

The TRIS project intends to use survey results to raise awareness as well as encourage appropriate services, treatment options and supports for children with rare trisomy syndromes and their families.

For further information, contact:
Deborah A. Bruns, Ph.D. 
Principal Investigator
Southern Illinois University Carbondale
Carbondale, IL

Shirley Lockwood, L.V.N.
Research Coordinator
Parent of an adult with partial trisomy 6p
Escondido, CA

Email: tris@siu.edu
Website: http://www.coehs.siu.edu/TRIS/