A project to raise awareness and provide support for families and professionals involved in the care of children and adults with rare trisomy conditions

Email: TRIS@siu.edu
Website: tris.siu.edu/
Facebook: www.facebook.com/TRIS.Trisomy.project

An online version of this document is available at tris.siu.edu/

November 2015

Sofia, full trisomy 13

Philina, partial trisomy 6p and Faren, full trisomy 18

Madison, full trisomy 18

Partial funding for the TRIS project is provided by the Support Organization for Trisomy 18, 13 and related disorders (SOFT) (http://trisomy.org/) and Southern Illinois University Carbondale.

Our hope is that the data collected by the TRIS project surveys will assist families and professionals worldwide to facilitate optimal outcomes for children and adults with rare trisomy conditions.

Project Contacts

Deborah A. Bruns, Ph.D.
Principal Investigator
Southern Illinois University
Carbondale, Illinois
USA

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

Sofia, full trisomy 13

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TRIS
The Tracking Rare Incidence Syndrome (TRIS) project began with a small group of parents expressing their need for more information about care for their children with rare trisomy conditions. This group, along with key medical professionals interested in the topic, formed the foundation for the TRIS project.

The TRIS project aims to increase and improve available information concerning the medical, health, educational and support needs of children and their families, and sharing the resulting information with interested professionals, including medical specialists, educators and therapists.

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.

Efforts are also underway to develop a database highlighting hospitals, supportive programs and medical professionals able to assist families receiving a trisomy diagnosis, as well as providing care for a member with a rare trisomy condition. Recruitment of additional families to participate in the TRIS project is a related outcome of development of this database.

TRIS Survey
A critical part of the project is the TRIS Surveys. The surveys collect data focusing on medical conditions, educational and therapy needs, developmental milestones, family support, and demographic information for families with a living or deceased member with a rare trisomy condition. TRIS Survey results have been shared at international conferences and published in leading medical journals.

The survey is available on our website at: tris.siu.edu/
If you would like more information, please visit the TRIS project website or email us:
TRIS@siu.edu