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

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Thank You
Due to the generous support of the Support Organization for Trisomy 18, 13 and related disorders (SOFT), Trisomy 18 Support Foundation, Inc. and Noah’s Never Ending Rainbow, the TRIS project began in 2004.

Our hope is that the information collected from the TRIS Survey and the resources on the TRIS website assist families and professionals worldwide.

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Claire, full trisomy 18
Natalia, full trisomy 13
Philina, partial trisomy 6p
and Faren, full trisomy 18

An online version of this document is available at: www.coehs.siu.edu/tris
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. Through discussion and outreach, this group grew in size and the foundation for the TRIS project was developed.

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

TRIS Survey

A critical part of the project is the dissemination of the TRIS Survey. The purpose of the survey is to collect and analyze data focusing on medical conditions, educational and therapy needs, developmental milestones, family issues and demographic information for families with a member with a rare trisomy condition (living as well as deceased). The resulting information will be shared with interested groups through presentations and publications.

The survey is available on our website at: www.coehs.siu.edu/tris

If you would like more information, please visit the TRIS website or email us:

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