

TRIS project



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.



Sofia, full trisomy 13

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

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



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

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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.



Lillian, trisomy 13 mosaic

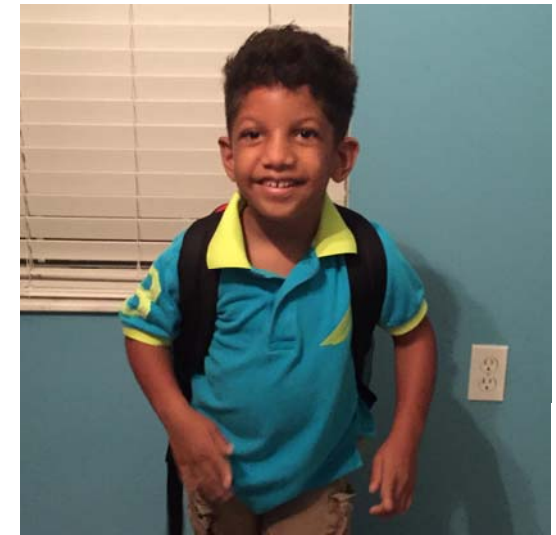
Mission Statement

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.



Jackson, trisomy 4p

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.



Ben, trisomy 9p

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