

The Tracking Rare Incidence Syndromes (TRIS) Project began in 2004 with a focus to raise awareness and increase the knowledge base about individuals with low incidence trisomy conditions including trisomy 18, trisomy 13 and trisomy 9 mosaicism by offering information to families and interested professionals such as educators, medical professionals and therapists. The project also focuses on encouraging appropriate services, treatment options and supports for children with rare trisomy conditions and their families.

Data collection with the TRIS Survey (Full, Modified and Follow-up versions) began in 2007. The surveys request information relating to medical conditions, education and therapy needs, developmental milestones, family issues and demographic information about the child and his/her family. The Follow-up survey collects information once a year (tracking aspect of project).

The project continues to recruit participants, analyze data and prepare results for dissemination on the TRIS website, at national and international conferences and publications in medical journals as well as newsletters of trisomy support organizations. There are also case studies and online modules with project results. TRIS project also shares information on the project's Facebook page.

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