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Correspondence
Tracking Rare Incidence Syndromes (TRIS) Project

Deborah A. Bruns*
Educational Psychology and Special Education, Southern Illinois University—Carbondale, Carbondale, Illinois

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To the Editor:

It is with great excitement that I read the articles about trisomy 18 in a recent issue of the American Journal of Medical Genetics Part A. It is encouraging to see clinical information about this under-studied population.

The Tracking Rare Incidence Syndromes project (TRIS) (http://web.coehs.siu.edu/Grants/TRIS/) intends to further the research agenda in this area through development of a database with information from parents of living and deceased children with trisomy 18 and related chromosomal disorders (http://web.coehs.siu.edu/Grants/TRIS/survey.html). At the present time, pilot data has been collected on similar types of clinical characteristics as those provided by Kosho et al. [2006], Lin et al. [2006], and Niedrist et al. [2006]. An additional study published in this series [Pont et al., 2006] describes the common congenital malformations in infants with trisomy 18. These authors emphasize the utility of this information in clinical decision-making and to assist families with understanding treatment options. The TRIS project also focuses on increasing the knowledge base related to medical, therapeutic and educational interventions with an added emphasis on family resources and support. In fact, the one of the project's sponsors is the support organization for trisomy 18, 13, and related disorders (SOFT) (www.trisomy.org).

The TRIS project is aimed at both families and professionals in the hopes of increasing and expanding information related to daily care, medical interventions and developmental accomplishments as a means toward greater understanding in decision-making in children and adults with rare trisomy syndromes. We will begin by examining families with a child or adult with trisomy 18 or 13 and then expand to include rarer trisomies.

The TRIS survey is currently in revision and will be available in print and electronic formats by the end of the year. The project will begin in the United States and expand to other English-speaking countries and, ultimately, be launched on a worldwide scale.

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*Correspondence to: Deborah A. Bruns, Ph.D., TRIS Principal Investigator, Educational Psychology and Special Education, Southern Illinois University Carbondale, MC 4618, Carbondale, IL 62901.
E-mail: dabruns@siu.edu
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