

## 2021 Gatlinburg Conference Poster Submission

**Title:** School Supports and Educational Outcomes for Students with Sex Chromosome Aneuploidies

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**Introduction:** Sex chromosome aneuploidies (SCA) are the most common chromosomal abnormalities in children and are caused by the presence of an extra X or Y chromosome in the karyotype. Children with SCA conditions are at an increased risk for neurocognitive and behavioral disorders that may interfere with academic success, including early developmental delays, learning disabilities, executive function problems, and social communication deficits (Urbanus et al., 2020). Research on educational outcomes in SCA is limited in scope and was conducted prior to major changes in special education law and practices. With a sharp increase in prenatal identification of SCA through noninvasive prenatal testing (NIPT), educators will also see a dramatic rise in the number of students entering school with a diagnosed SCA and either a known risk for future learning disabilities or an established history of developmental delays and deficits in pre-academic and/or cognitive skills. It is critical to update our understanding of the way children with SCA are currently supported in their schools in order to guide educators and families and to inform educational systems and policy. This study aimed to examine parent reported school supports, educational outcomes in children and youth with SCA, as well as parent perceptions of educator knowledge of SCA conditions.

**Method:** Data for this study were collected from a larger international survey project (N=550) examining ecological supports for children with SCA conditions. Inclusion criteria for the larger survey were parents of children birth to 21 years with a diagnosis of SCA. The current subset of data (N=255) included those living in the U.S. with children ages 5-21 years who were currently enrolled in, or had recently completed, the K-12 education system. The electronic survey was created in the REDCap data management system by clinicians and researchers with expertise in SCA and education and pilot tested by parents of children with SCA. Participants were recruited through email listservs and social media websites associated with clinics and advocacy organizations. Questions focused on school support plans, academic accommodations, educational therapies, and school completion and took 5-20 minutes to complete.

**Results:** Overall, a vast majority of parent respondents reported their child received some type of formal educational support plan. For example, one quarter (26%) of all respondents reported their child received classroom accommodations through a 504 plan, and nearly three quarters (72%) received special education supports through an individualized education program (IEP). The most commonly reported accommodations were extended time (86%), preferential seating (57%), and breaks as needed (45%). Students with IEPs qualified under several educational disability categories including the two most frequent: Other Health Impaired (OHI, 24%) and Specific Learning Disability (SLD, 16%). Educational services provided through the IEP included academic interventions (78%), social/emotional/behavioral supports (65%), speech/language therapy (60%), and occupational therapy (34%). Some parents also reported they deferred their child's kindergarten start date by one year (19%) and/or their child repeated at least one grade level (18%). Additionally, well over half of respondents (71%) reported they believed their child's educators had little to no understanding of SCA conditions. A majority (78%) of respondents with children over the age of 18 (N=50) reported their child graduated from the K-12 system with a high school diploma or certificate and over 40% were currently attending some kind of post-secondary program/college.

**Discussion:** Results reveal the high rates of educational support services for children and youth with SCA. Educators, therapists, and medical providers should be aware of the frequent need for accommodations and individualized support plans in this population so that appropriate evaluations can be planned, and interventions implemented in a timely manner. Findings indicate that, despite a clear profile of educational need, with appropriate ecological supports, many students with SCA can successfully complete high school and pursue postsecondary education opportunities. Finally, parent perceptions that educators lack knowledge of SCA conditions justifies a need to train teachers and policy makers in the unique educational needs of children and adolescents with SCA.

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**References:** Urbanus, E., van Rijn, S., & Swaab, H. (2020). A review of neurocognitive functioning of children with sex chromosome trisomies: Identifying targets for early intervention. *Clinical genetics*, 97(1), 156-167.

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