

CO-OCCURRING DOWN SYNDROME AND AUTISM SPECTRUM DISORDERS



Dallas, TX • July 12–15, 2018

The NDSC cares about serving the needs of all families, including those with loved ones with co-occurring autism (DS-ASD), or autism-like tendencies. As a result the NDSC is collaborating with the **Down Syndrome-Autism Connection**, a nonprofit that serves this population specifically, to offer a specially-designed DS-ASD track at the 2018 Convention in Dallas. Perhaps you have a loved one diagnosed with co-occurring DS-ASD, or you have wondered if your child may have “more than DS” due to behaviors or developmental issues, or perhaps you are a professional who works with individuals who seem to fit this profile...if so, then this track is for you!



The **Down Syndrome-Autism Connection** and **NDSC** together have developed this track, identifying experts in the field to speak on a variety of topics. In addition, professionals from the Connection will be on-site during each workshop to assist families and professionals with questions and concerns. Their warm, friendly staff has extensive training and personal experience and will be able to provide guidance, support and resources so you don't have to feel alone on this journey. Check out the learning opportunities we have secured below:

CONNECTIONS RECEPTION - THURSDAY, JULY 12, 7:00 - 9:00 PM

You Are Not Alone...When Your Loved One Has “More than DS”

This session will be facilitated by **Charlotte Gray**, Executive Director, and **Jeanne Wheeler Doherty**, Board President, of the Down Syndrome-Autism Connection. Both understand the joys AND challenges of raising a child with this complex, co-occurring condition.

It can be tremendously difficult and heartbreaking to learn that your child may be exhibiting some red flags for a second major diagnosis – Autism. This session is designed for parents who have a child with DS-ASD, or for those who suspect that their loved one with DS may have autism-like tendencies and behavioral challenges. The session is intended to give voice to the complexities of loving and caring for a person with this co-occurrence, as well as to foster a community of belonging for all on the DS-ASD journey.

PRE-CONFERENCE SESSION - FRIDAY, JULY 13, 8:00 AM - 12:00 PM *(separate registration required)*

DS-ASD 101: Understanding the BASICS of Co-Occurring DS-ASD



Charlotte Gray, Executive Director, Jeanne Doherty, President, DS-ASD Connection, both are parents of individuals who have co-occurring Down syndrome and autism spectrum disorder (DS-ASD) and both live in Massachusetts.

Down syndrome and autism can be challenging disabilities separately, however when combined the challenges can be quite complex and oftentimes are misunderstood by the family members and professionals in the individual's life. This workshop will take a look at what we know about DS-ASD, explore basic behavioral red flags from childhood through adulthood, learn more about the differences in thought processes and the strategies that can be used, and discuss the importance of building a support network and care team through the lifespan.

WORKSHOP OFFERINGS - FRIDAY, JULY 13 - SUNDAY, JULY 15



Will My Child Always Wear Diapers? Understanding Toileting Challenges and Exploring Solutions

Terry Katz, PhD, Senior Instructor, University of Colorado School of Medicine, Aurora, CO

Dr. Katz is a licensed psychologist who has worked with children with developmental disabilities for over 25 years. She co-founded a sleep behavior clinic and a toileting clinic for children with special needs at Children's Hospital Colorado. This presentation will cover issues related to toileting, including the challenges involved in toilet training children with special needs and useful, practical strategies to teach this important skill.



DS-ASD 101: Understanding the BASICS of Co-Occurring Down Syndrome and Autism Spectrum Disorder

Charlotte Gray and Jeanne Doherty, both are parents of individuals who have co-occurring Down syndrome and autism spectrum disorder (DS-ASD) and both live in Massachusetts. Charlotte serves as the Executive Director of the Down Syndrome-Autism Connection, and Jeanne serves as the President of the Board of Directors for the Connection.

Down syndrome and autism can be challenging disabilities separately, however when combined the challenges can be quite complex and oftentimes are misunderstood by the family members and professionals in the individual's life. This workshop will take a look at what we know about DS-ASD, discuss commonalities in family experiences, explore basic behavioral red flags, and discuss the need for a compassionate community that understands the joys and challenges of caring for children and adults with DS-ASD.



Autism Laws and Applied Behavior Analysis (ABA) Coverage

Terri Farrell, MBA, Project Director, Autism Insurance Resource Center, Worcester, MA

This workshop will provide information on how to help individuals with a dual diagnosis of autism and DS access behavioral supports through insurance. The presenter will explain the options available and provide guidance on how to access ABA/social skills through both commercial and public (Medicaid) insurers.



Medications and Problematic Behaviors and Psychiatric Illness in DS and ASD

Michelle L. Palumbo, MD, Pediatrician and Psychiatrist, The Lurie Center, Massachusetts General Hospital for Children, Lexington, MA

Autism spectrum disorder (ASD) is common in individuals with DS. ASD is associated with an increase in problematic behaviors and psychiatric illnesses, such as anxiety. Deciding on whether or not to take the medication route can be a difficult decision. During this workshop, we will discuss the common problematic behaviors and psychiatric illnesses that can be seen in DS and ASD, their treatment, and when medications may be a good option to consider as part of the treatment plan.



Characteristics of Co-Occurring DS and Autism

Lina Patel, PsyD, Director of Psychology, Anna & John J. Sie Center for Down Syndrome at Children's Hospital Colorado, Aurora, CO

This presentation will explore the characteristics of DS and Autism and when the two overlap. Participants will learn how behavioral characteristics intersect to create unique challenges for screening and evaluation, as well as implications for intervention. Dr. Patel will share her clinical expertise on the co-occurrence of these diagnoses and evidence-based intervention practices.



Common Behavior Issues in Children With DS-ASD (from a Medication Perspective)

George Capone, MD, Director, Down Syndrome Clinic and Research Center, Kennedy Krieger Institute, Associate Professor, Johns Hopkins University School of Medicine, Baltimore, MD

It is recognized that children with DS + ASD have especially complex needs because of the constellation of medical-developmental-behavioral challenges they face. This session will describe aspects of brain organization and function that may contribute to DS + ASD. Maladaptive behavior will be discussed, providing participants with new understanding and problem-solving strategies to manage internalizing (autism-like), externalizing (disruptive) or mixed behavior features. A comprehensive program usually involves combining strategies across several disciplines simultaneously. In situations where difficult behaviors have become entrenched, it may still be possible to discover what's missing from the program in order to make life better for you and your child.