ncdsa North Carolina Down Syndrome Alliance
empower · connect · support

North Carolina Down Syndrome Conference
Presented Virtually Saturday, November 13, 2021
Conference Session Participation Form

Name:	**Contact Info:**
Email:	
Organization:	

Attended	Session Title	Hours
Yes ☐ No ☐	The Groove in Individuals with Down Syndrome	1.5
Yes ☐ No ☐	Social Security Disability Insurance and Supplemental Security Income benefits: What you need to know	1.5
Yes ☐ No ☐	Sleepless Children and Exhausted Parents – Understanding Sleep Problems and Exploring Options	1.5
Yes ☐ No ☐	Is it Sensory or is it Behavior?	1.5
Yes ☐ No ☐	Ditching the Diapers: How to Move Forward with Toileting	1.5
Yes ☐ No ☐	Let’s Talk: Sexual Health Education	1.5
Yes ☐ No ☐	Ds & Autism: Recognizing the signs, understanding the process, and behavioral supports	1.5
Yes ☐ No ☐	The Down Syndrome Diet	1.5
Yes ☐ No ☐	Down Syndrome: The Early Years	1.5
Yes ☐ No ☐	Alzheimer’s and Dementia in Down Syndrome	1.5

North Carolina Down Syndrome Conference

Presented Virtually Saturday, November 13, 2021

Session Descriptions and Presenters

The Groove in Individuals with Down Syndrome

The groove is a common characteristic seen in individuals with Down syndrome of all ages. The groove is a preference for sameness, repetition, or routine. Drs. Chicoine and Frank will describe advantages and disadvantages of the groove, strategies to address problematic grooves, and methods to establish new grooves.

Katie Frank, PhD, OTR/L
Dr. Frank has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She earned her undergraduate degree in occupational therapy from Saint Louis University and her master's degree from University of Indianapolis. She earned her PhD in Disability Studies from the University of Illinois at Chicago. Dr. Frank's experience includes treatment and evaluation as well as conducting trainings and leading groups. In addition, she presents locally and nationally, does research, and shares her work in peer-reviewed journals.

Brian Chicoine, MD
Dr. Chicoine is the Medical Director and Co-Founder of the Adult Down Syndrome Center, which has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine graduated from Loyola University Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. Dr. Chicoine has provided medical care for adults with intellectual disabilities for over 30 years and has presented and written extensively on caring for adults with Down syndrome.

Social Security Disability Insurance and Supplemental Security Income benefits: What you need to know

The Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs both pay benefits to people with a disability. The two programs differ in fundamental ways and this session will discuss the distinctions, how both children and adults may qualify, how to file an application for benefits, and what you can do now or in the future to access these benefits.

David J. Melton began his career with the Social Security Administration in September 1976 as a Claims Representative. In 1979 he transferred to Louisiana and worked as a Claims Representative, Operations Analyst, and Operations Supervisor. In June 1990, he was selected as the Field Representative for a 14-county district in Virginia and West Virginia. He was responsible for the coordination of public information & education activities throughout the district. In 2005, Mr. Melton was selected as a Public Affairs Specialist for the Washington, D.C. Metropolitan Area. Through the establishment and maintenance of networks of working relationships, he consults with a wide variety of media outlets, governmental entities, special interest groups and key employers. He ensures the public is properly informed as to the solvency, direction, and purpose of Social Security Administration programs.

The Down Syndrome Diet

Discover how to eliminate or reduce the symptomatology of many of the health and developmental issues impacting children and adults with Down syndrome including autism, attention deficit disorder, diabetes, hypothyroidism and even Alzheimer's Dementia. A literature review implicating the high sugar and carbohydrate diet with many of the gastrointestinal, neurological, endocrine, and immune system dysfunctions associated with Down syndrome will be presented. A synthesis of recent research regarding dietary interventions will be discussed and recommendations from health care providers will be reviewed to see how we clinicians and caregivers can impact the course of some of the healthcare epidemics affecting individuals with Down syndrome.

Dr. Jennifer Kimes is the Executive Director of Educational and Clinical Services at Down Syndrome of Louisville where she has served in a variety of roles for over 14 years. She provides direct early intervention services, as well as behavioral supports and family support services. Dr. Kimes also provides diagnostic clarification for co-occurring issues in her role as a licensed psychologist. She holds Bachelor's Degrees in Early Childhood and Elementary Education and a Doctoral Degree in Clinical Psychology. However, her favorite role is as mother of four children, one of whom happens to have Down syndrome and Autism.

Is it Sensory or is it Behavior?

Has anyone ever suggested your loved one with Down syndrome has sensory processing deficits? Can transitioning between activities or places be challenging? Are certain medical procedures difficult to complete? Do you find that your loved one seeks out sensory input or maybe even tries to avoid it all together? Sensory processing impacts all of us, but for many individuals with Down syndrome, the inability to control their sensory needs can impact their independence and community participation. This workshop will describe sensory processing and the different ways sensory processing can impact individuals with DS as they age. Tips for deciding if it is truly a sensory need or actually a behavior will be shared. Practical sensory activities that can be incorporated daily as well as affordable equipment suggestions will be provided.

Dr. Katie Frank has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She earned her undergraduate degree in occupational therapy from Saint Louis University and her master's degree from University of Indianapolis. She earned her PhD in Disability Studies from the University of Illinois at Chicago. Dr. Frank's experience includes treatment and evaluation as well as conducting trainings and leading groups. In addition, she presents locally and nationally, does research, and shares her work in peer-reviewed journals.

Ditching the Diapers: How to Move Forward with Toileting

This presentation will cover issues related to toileting including the challenges involved in toilet training children with special needs and useful and practical strategies to teach this important skill.

Objectives:
1. Understand the challenges involved in toilet training individuals with special needs
2. Discuss key components of a successful toileting program
3. Review materials and resources for families

Terry Katz is a licensed psychologist and Senior Instructor with Distinction who has been privileged to work with children with developmental disabilities and their families for over 30 years. She co-founded a sleep behavior clinic in 2009 and a toileting clinic in 2011 for children with special needs at Children's Hospital Colorado. She has worked in both clinics since they were first established. Dr. Katz has helped develop a number of educational materials for caregivers. These include sleep and toileting toolkits for Autism Speaks and a book on sleep, Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families. She also wrote a chapter on sleep in the book When Down Syndrome and Autism Intersect: A Guide for Parents and Professionals (edited by M Froehlke and R.S. Zaborek.) She just recently published a book on toileting: Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience.

Let's Talk: Sexual Health Education

Sexuality and relationship education is *more* than teaching about sexual activity. It should be an ongoing process starting early and encompassing basic body awareness, health information, communication skills, decision making, and social skills. However, discussing sexuality with children (and adult children!) is challenging for many parents and caregivers. To overcome this barrier and gain comfort and confidence in addressing uncomfortable topics, this session will provide parents and caregivers support and resources to help them begin to talk to their tweens and teens about sexual development and health. Specific topics addressed in this session will include how bodies change during puberty, how hormones affect one both physically and emotionally, and the importance of hygiene.

Margaret DeRamus (duh-RAY-muhs) is a licensed speech-language pathologist at the Carolina Institute for Developmental Disabilities (CIDD) at the University of North Carolina at Chapel Hill. She has over two decades of experience working with individuals with intellectual and developmental disabilities (IDD). In addition to providing direct clinical services, she has been involved with research focusing on individuals with a range of developmental disabilities. Ms. DeRamus co-facilitates a modified/accessible sexual health education (SHE) group for youth and adults with IDD and their families/caregivers. In addition, she co-leads a community partners workgroup to address the sexual violence epidemic in the IDD community. Ms. DeRamus is a member of the Association of University Centers on Disabilities (AUCD) Sexual Health special interest group.

Ds & Autism: Recognizing the signs, understanding the process, and behavioral supports

About 20% of children with Down syndrome meet criteria for a co-occurring diagnosis of autism spectrum disorder (ASD). However, less is known about this group than children with either condition in isolation. This session will describe the signs and symptoms of ASD in children with Down syndrome as well as the diagnostic process. During the session, research on the learning and behavior challenges that may be experienced by children Down syndrome and co-occurring ASD will be discussed. Suggestions for the types of behavioral supports that may benefit children with Down syndrome and co-occurring ASD will be provided. Additionally, information about empirically-supported interventions for ASD will be described in order to introduce attendees to the types of approaches that may be helpful for children with Down syndrome and co-occurring ASD.

Nancy Raitano Lee, PhD, is a licensed psychologist and associate professor in the Department of Psychological and Brain Sciences at Drexel University. She received her Bachelor of Science Degree in Human Development and Family Studies from Cornell University and her doctorate in Child Clinical Psychology from the University of Denver. Her clinical training includes the completion of a pre-doctoral internship at the Children's Hospital of

Colorado and a post-doctoral fellowship at the University of Colorado School of Medicine's Center for Excellence in Developmental Disabilities. As a postdoctoral fellow, she received specialized clinical training in the diagnosis and treatment of neurodevelopmental disorders, with a particular emphasis on diagnosing autism spectrum disorder (ASD) in young children with genetic disorders associated with intellectual disability, such as Down syndrome. Following her training in psychology, Dr. Lee completed a fellowship at the National Institute of Mental Health focused on the use of structural neuroimaging to study the developing brain in youth with Down syndrome and other genetic disorders as well as children with typical development. Dr. Lee currently leads the LADDER (Learning And Developmental Disabilities Educational Neuropsychology Research) Lab at Drexel where she conducts both clinical and translational research on neurodevelopmental disorders, with a particular emphasis on neurogenetic syndromes. She has published on executive function, language, and ASD symptoms in youth with Down syndrome and those with sex chromosome disorders. She has also published research on the developing brain in these groups. Dr. Lee's research has been funded by the Lejeune Foundation and the National Institutes of Health. The long-term goal of her research is to identify novel targets of treatment to ameliorate the cognitive weaknesses that characterize different neurodevelopmental disorders in order to optimize outcomes and quality of life for these groups.

Taralee Hamner, PhD, is a postdoctoral fellow in pediatric neuropsychology at Nationwide Children's Hospital. She received her bachelor's in Psychology at Georgia State University. After working at the Marcus Autism Center in Atlanta, Georgia, she obtained her masters and doctorate degrees in Clinical Psychology at Drexel University in Philadelphia, Pennsylvania, under mentorship of Dr. Nancy Raitano Lee. She completed a doctoral internship at the Kennedy Krieger Institute / Johns Hopkins Hospital in Baltimore, Maryland. Taralee has expertise in neurodevelopmental disorders with a particular passion for working with those who have special healthcare needs or co-occurring conditions. She has published on brain development as well as cognitive and autism profiles for children with Down syndrome. Clinically, she has provided early intervention to children with co-occurring Down syndrome and ASD. Her research focuses on early social learning across conditions in order to inform interventions and promote quality of life for children and their families.

Sleepless Children and Exhausted Parents – Understanding Sleep Problems and Exploring Options

This talk is designed for parents and providers who want to learn more about sleep, why children with special needs may have difficulty sleeping, and what they can do to help everyone in the family sleep better. The session will be informative and practical, providing families with ideas that they can use at home.

Objectives:

1. Review information about the basics of sleep
2. Discuss reasons why children with special needs have difficulty with sleep
3. Identify treatment strategies that will help children (and their families!) sleep better

Terry Katz is a licensed psychologist and Senior Instructor with Distinction who has been privileged to work with children with developmental disabilities and their families for over 30 years. She co-founded a sleep behavior clinic in 2009 and a toileting clinic in 2011 for children with special needs at Children's Hospital Colorado. She has worked in both clinics since they were first established. Dr. Katz has helped develop a number of educational materials for caregivers. These include sleep and toileting toolkits for Autism Speaks and a book on sleep, Solving Sleep Problems in Children with Autism Spectrum Disorders: A Guide for Frazzled Families. She also wrote a chapter on sleep in the book When Down Syndrome and Autism Intersect: A Guide for Parents and Professionals (edited by M Froehlke and R.S. Zaborek.) She just recently published a book on toileting: Potty Time for Kids with Down Syndrome: Lose the Diapers, Not Your Patience.

Down Syndrome: The Early Years

Are you new to the journey of parenting a child with Down syndrome? It can often feel overwhelming and confusing to know where to begin or gain a clear understanding of certain needs. This session is ideal for expectant parents, new parents, and caregivers with children up to the age of 3 years old. We will cover some basic Down syndrome facts, but attendees will learn more about:

- Specific healthcare needs of children with Down syndrome
- What therapies to focus on as part of early intervention
- Benefits your child may qualify to receive
- How to become your child's best advocate
- Family life and how to support yourself and your loved ones
- The process of transitioning from early intervention to Pre-k services

We will also look ahead to the future. Attendees will be able to prioritize next steps for the overall care of their loved one with Down syndrome. Time will be allotted for Q&A so bring your questions and concerns.

Mahala Turner holds a bachelor's and master's degree in Special Education. Additionally, she received a certification in School Psychometry that allows her to administer and interpret educational assessments. Mahala has twelve years of experience as an educator in a variety of settings, grade levels, and educational environments. Currently, Mahala is the Family Support Specialist for the North Carolina Down Syndrome Alliance (NCDSA) providing assistance to families of children with Down syndrome across the lifespan. Through her work at the NCDSA, she is the facilitator of the North Carolina First Call Program. The First Call Program provides support to families when they receive a diagnosis of Down syndrome and welcomes new families with resources and information, connects new families with trained parent mentors, and nurtures an online space and social events for families to connect and communicate with one another. She is the teacher and facilitator of The Learning Program, a program that uses effective teaching strategies and customized materials to support families in the educational process of teaching their child reading and math. Mahala also plans medical outreach efforts by providing accurate and up to date information to medical providers ensuring they are prepared to deliver a diagnosis of Down syndrome and the best care possible for patients with Down syndrome. Mahala is also the parent to eight year old twins and three year Beau. Beau just happens to have Down syndrome.

Alzheimer's and Dementia in Down Syndrome

This presentation will cover the current understanding of Down syndrome associated Alzheimer's disease and will explore the common dementia symptoms. The presentation will also cover the current state of research including the development of potential new treatments. General advice for caregivers will also be included.

As the Chief Scientific Officer, Dr. Hendrix directs scientific initiatives for LuMind IDSC. A critical element of his role is to establish the nationwide Down Syndrome – Clinical Trial Network (DS-CTN) and to oversee the first clinical trial in the DS-CTN, the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) Study. The LIFE-DSR study is a natural history study focused on adults 25 years of age and older at high risk for Alzheimer's disease. Dr. Hendrix is also focused on building potential collaborations with industry, academic and government scientists focused on Down syndrome research to maximize LuMind IDSC's scientific impact.

Prior to joining LuMind, Dr. Hendrix was Director of Global Science Initiatives, at the Alzheimer's Association. A critical element of his role was the management of industry consortia such as the Alzheimer's Association

Research Roundtable (AARR); lead the Global Biomarker Standardization Consortium; and assist with the coordination of the $100 million dollar Imaging Dementia—Evidence for Amyloid Scanning (IDEAS) Study on the clinical usefulness of amyloid PET imaging.

Before joining the Alzheimer's Association, Dr. Hendrix worked as a medicinal chemist with a focus on drug discovery for CNS diseases. Dr. Hendrix spent 18 years working at Sanofi-Aventis and predecessor companies, where he rose to level of senior director, U.S. site head for CNS research. He also spent two years working in the biotech industry with various companies, including companies focused on the treatment of Alzheimer's disease.

Dr. Hendrix received his Ph.D. and a postdoctoral fellowship in organic chemistry from Colorado State University.