



RECORDED WORKSHOPS

Birth-5
 School Age
 Teen Adult
 All Ages
 DS-Autism Track
 Adult Sibs Track
 Delivered in Spanish
 Interpreted in Spanish

FRIDAY, JUNE 26, 3:30 – 5:00 PM

Feeding and Swallowing in Young Children With DS: Introduction to Structures and Function for Feeding and Swallowing and Difficulties That Can Occur

Jennifer Casteix, MS, CCC-SLP, Clinical Assistant Professor, The University of Arizona Department of Speech, Language, and Hearing Sciences, Tucson, AZ, and Keegan Gallagher, MS, CCC-SLP, Pediatric Speech-Language Pathologist and Feeding Specialist, Mealtime Connections, LLC, Tucson, AZ

How often do you think about your ability to eat? Eating for most of us is automatic. We take bites, chew, and swallow. We take sips, taste, and swallow. For many young children with DS, this is not the case. Low tone can lead to poor oral control, and significant medical issues can lead to difficulty swallowing. In this session, we will review the parts of the head and neck used for eating and swallowing, how these parts work together, and what can go wrong when they don't work smoothly. We will discuss how lack of experience with eating can lead to decreased skills. Finally, we will review how some medical conditions, including congenital heart disease and gastroesophageal reflux disease (GERD), can contribute to poor eating and swallowing.

Treadmill Training to Improve Walking in Children with Trisomy 21

Helen Milligan, MPT, Physical Therapist, The Children's Hospital of Philadelphia, son with DS, Philadelphia, PA

Current research has shown the treadmill training can help babies walk 3- 5 months sooner and more efficiently. Recently, there have been studies by Ulrich and colleagues which demonstrate that utilizing treadmill training with infants helps them walk earlier. A subsequent study by Wu, Ulrich and colleagues demonstrated how treadmill training can also improve children's gait by manipulating the intensity of training. This workshop will discuss the recent treadmill training studies and demonstrate with videos how therapists and families can implement the recent findings. The workshop presenter, Helen Milligan, MPT, is a mother of a 12 year old boy who has Down syndrome. She is a physical therapist at The Children's Hospital of Philadelphia and a therapist in Early Intervention. She has been utilizing treadmill training with many of the babies she sees in Early intervention and in the out patient clinic at CHOP. Videos will be a part of the presentation.



Making Private School a Reality for Children With DS

Beth Foraker, MS, *Teacher of Teachers, UC Davis School of Education, National Catholic Board for Full Inclusion, son with DS*, **Maggie Byrnes**, JD, *son with DS*, and **Erica Conway-Wahle**, DDS, *daughter with DS, all from Davis, CA*

Through their own experiences, the presenters have developed programs, models, and resources through *The National Catholic Board on Full Inclusion* to help parents, teachers, and administrators create successful learning environments for children with DS. This presentation will address the benefits of a private school education for children with disabilities, how these children add to the private school environment, how to find relief from the often adversarial relationship with the public school, and how to take control of your child's education. Most importantly, the presenters want to alleviate the fear many private schools have by showing examples of successful private school education across the country.



Fostering Adult Life-Long Learning Through Community Reading and Writing Clubs



Rachel Blackburn, *Program Assistant, Nisonger Center Social Programs, Columbus, OH*, **Alison Foose**, *Self-Advocate, NCBC Member, Dublin, OH*, and **Katherine Mahosky**, *Faculty Member, Northern Arizona University, Flagstaff, AZ*

This workshop will provide an overview of two highly successful community-based adult literacy programs for people with intellectual and developmental disabilities (IDD) - *Next Chapter Book Clubs* and *Jot It Down* writing clubs. These clubs are designed to promote literacy, community inclusion, and social friendships for adolescents and adults with IDD and meet weekly in community book stores, coffee shops, and cafes. Members and volunteer facilitators socialize and engage in wide variety of reading and writing activities. The presenters will provide an overview of the program models, discuss steps that can be taken to establish book and writing clubs at the local level, and provide various evaluation strategies. Additional ways to engage adolescents and adults with DS in activities that promote literacy and life-long learning will also be provided.



Bridging the Employment Gap for People With DS

Erica McFadden, PhD, *Policy Analyst, ASU Morrison Institute for Public Policy, Phoenix, AZ*, and **Kim Woloweic-Fisher**, PhD, *Assistant Professor of Special Education, Arizona State University, Tempe, AZ*

It is well-established that the great majority of people with DS are not in the labor market for a number of reasons including individuals' personal preferences; inadequate training and preparation; and/or the lowered expectations for this group among agencies, family members, and the overall community. Numerous studies have pointed to predictors that can change these outcomes beyond high school and lead to post-secondary education or employment. These predictors include interagency collaboration, greater opportunities for self-determination, paid work, independent living training, parental involvement, and social support and inclusion. This session highlights strategies that can be utilized in the person's daily life to promote opportunities for employment. Best practices and practical

recommendations are shared at the individual, family, systemic, and community-wide level to help individuals, families, and professional staff develop effective strategies to overcome persistent systemic barriers.



Full Inclusion Works! One Family’s Journey Toward Full Inclusion

Rob Billerbeck, MS and Sarah Billerbeck, MA, ECSE, parents of a son with DS, Lakewood, CO

Full inclusion in the neighborhood school is achievable! One family will present their story of how they have achieved full inclusion in their neighborhood elementary school for their son. Rob and Sarah will share their vision for their son’s education, examine barriers to inclusion, and present strategies they have used for overcoming them. They will share ideas for working successfully with school personnel and ways to stay inspired during the tough times. In this interactive session there will be opportunities to ask questions, and share ideas, experiences and strategies.



iTalk: Using Technology as a Transitional Communication Tool



Katie Maddox, OTR/L, Occupational Therapist & Co-Owner, and Katie Dames, MS, CCC-SLP, both from Fusion Therapy & Learning Center, Palmyra, MO

Will my child ever start talking? What is keeping you from exploring the use of transitional speech technology? Can’t afford it? Afraid it will deter your child from ever using their own voice? Join us as we bust through the communication myth that the use of alternate communication strategies hamper speech production in children who can talk. Explore “off the shelf” technology tools that make transitional communication with your child less scary and more successful. Support your child’s innate desire to communicate using a system that can be both affordable and efficient. We believe that technology can promote your child’s ability to talk, regardless of their speech diagnosis.



Prenatal Testing – Getting the Facts to Pregnant Women and Medical Professionals

Michelle Sie Whitten, MA, Executive Director, Global DS Foundation, daughter with DS, Denver, CO, David Tolleson, Executive Director, NDSC, son with autism, and David Charmatz, Senior Vice President, Global DS Foundation, Denver, CO

This workshop will examine the 2nd edition of the DS Prenatal Testing Pamphlet developed by the National DS Congress and the Global DS Foundation. Special attention will be given to the first national survey of pregnant women and medical professionals that informed the second edition. Why many pregnant women are given inaccurate information at the point of prenatal or postnatal diagnosis and lack of education in this area will be examined. An update on “Non-Invasive Prenatal Tests” will also be provided. The workshop will provide families and individuals important tools to help get current, accurate information about DS to pregnant women, and how to educate medical professionals in their area.



My Brother and I: Independent Living is Possible



Edgardo Pezzettoni, self-advocate, and **Georgina Pezzettoni**, brother with DS, both live in Buenos Aires, Argentina



Presented in Spanish with simultaneous interpretation into English available.

Parents and other family members are vital to the development of individuals with Down syndrome from birth to adulthood. The pillars that support a person with DS throughout his/her life are: family, social integration, school and workplace inclusion. Siblings will be the ones who continue to provide guidance and support when the parents are no longer able or are no longer there. Georgina and Edgardo will share their experience of growing up in a very close family, and living independently as adults now that both of their parents have passed away. They have worked hard to allow Edgardo to continue his life as usual, with the goal of achieving independence. Georgina is the manager of a tourism portal and Edgardo works at a Mercedes Benz industrial plant.

SATURDAY, JUNE 27, 8:30 – 10:00 AM



Developing Communication Skills: Birth to Early Sentences

Libby Kumin, PhD, CCC-SLP, Professor of Speech-Language Pathology and author, Loyola University, Baltimore, MD

The session will focus on building strong foundations for the development of communication skills in children with DS from birth to early sentences. What are the differences between communication, language, and speech? What contributes to your child’s ability to use language? What prepares your child to speak? How does your child progress from sounds to words to early sentences? Dr. Kumin will describe and demonstrate examples of home activities to help children master necessary communication, language, and speech skills.



Preparing for Puberty: A Session for Parents of Girls with DS

Terri Couwenhoven, MS, AASECT Certified Sex Educator, TC Services, daughter with DS, Port Washington, WI

Families often experience anxiety when their daughter with DS begins exhibiting the physical and emotional changes that occur during puberty. In this workshop, parents will learn about the most common issues and concerns that arise. Practical ideas and resources to address these issues will be shared.



Building a Better Reader Through Use of Active Comprehension Strategies

Dana L. Halle, JD, Executive Director, DS Foundation of Orange County, Vice President, Education and Outreach, DS Education USA, NDSC Board Member, son with DS, Orange County, CA

Students with DS may be able to accurately read words and sentences they do not understand. In such cases, a student's decoding or sight reading skills are said to be ahead of their comprehension skills. In this session intended for parents and educators of students who are working on sentence or text level comprehension, the presenter will discuss a hierarchy of reading skills and specific active comprehension strategies helpful in building an effective reader.



Strategies for Supporting Positive Behaviors in the Inclusive Classroom

Michael L. Remus, MS, Director Student Support Services, Deer Valley Unified School District, Phoenix, AZ

Behavior is caused for several reasons. Kids do not come to school to misbehave. We must approach behavior differently. This session will explore the reasons children misbehave and will look at strategies in the classroom to avoid these behaviors.



Turning 18 – What to Expect and How You Can Prepare

Maureen A. Mills, Communications Coordinator, Raising Special Kids, Phoenix, AZ

Turning 18? It will be here before you know it! Once you finally get the hang of this parenting thing, your child is about to become an adult. New questions with regard to education and self-determination arise and new opportunities for learning present themselves. This presentation explains the IEP transition planning process, and how parents can remain involved in decision-making with schools, doctors and other professionals.



The Language of Business: How to Use Business Language to Successfully Include Individuals With DS in the Workforce

Debra Ruh, Global Disability Inclusion Strategist, G3ict Employability & Technology Chair, Ruh Global Communications, daughter with DS, Rockville, VA

Case managers and family members often forget to speak the language of business with an employer. This session will cover strategies to use when approaching employers about positions for individuals with DS. By not only understanding the needs of a particular business, but by also helping the employer understand the benefits of hiring people with DS, meaningful employment can be achieved.



Latest Legislative Developments: How They Impact You

Susan Goodman, JD, Governmental Affairs Director, NDSC, son with autism, Olney, MD

Federal legislation directly impacts education, community living, housing, support services and employment for individuals with DS and their families every day. This session will offer parents the opportunity to learn how these laws affect their family and the future and how what is happening in Congress directly impacts their lives. The budget crisis and the threat to services for people with disabilities will be discussed, as well as the latest developments in the education laws, prospects for improving employment outcomes for individuals with disabilities, and health care updates. We will also talk about what families and advocates can do to make sure their voices are heard!



Behavior and DS: A Brain-Based Perspective for Identification and Treatment



David Stein, PsyD, Co-Director, The DS Program at Boston Children's Hospital & Harvard Medical School, sister with DS, and Nicole Baumer, MD, MEd, Co-Director, The DS Program at Boston Children's Hospital, Boston, MA

Behavior problems impact 30% of children with DS. Left untreated, these same children often exhibit behavior problems as adults, limiting work and independent living opportunities. Many typical behavioral management tools are less effective for children with DS. In order to address behavior problems in DS effectively, one must understand the brain-based reasons for these challenges, and direct treatment appropriately. This workshop will present the basic neuroscience of DS and how this informs effective behavior management and will review behavioral and medical approaches to behavior management.



Medical Issues in DS - What Families Need to Know!

Kishore Vellody, MD, Medical Director, Associate Professor of Pediatrics, DS Center of Western Pennsylvania, brother with DS, Pittsburgh, PA

People with DS are at increased risk for several medical conditions, yet many families and doctors are not familiar with the most important issues that can occur. This presentation will cover the common medical, developmental, and behavioral conditions that occur at a higher frequency in people with DS. The American Academy of Pediatrics Healthcare Guidelines, which are intended to screen for and hopefully prevent these issues, will be discussed.



Alzheimer's Disease and DS

Huntington Potter, MD, Director of Alzheimer's Research, Linda Crnic Institute for DS Department of Neurology, University of Colorado, Denver, CO

People with DS invariably develop the pathology of Alzheimer's disease by age 30-40 and about half develop dementia by age 50-60. In addition, people with Alzheimer's disease develop cells with trisomy 21 throughout their bodies. This workshop will consider the reasons why AD develops in people with DS

and in typical people, and how this information is being used to develop new diagnostics and therapies for both populations.

Esp

El niño con Síndrome de Down: Evolución, Problemas y Soluciones

Dr. Jesús Flórez, Catedrático de Farmacología y Presidente de la Fundación Iberoamericana Canal Down21

Cada niño nace con sus propias características. El síndrome de Down añade peculiaridades derivadas de la presencia de una trisomía del cromosoma 21, que cada vez conocemos mejor. Estas peculiaridades condicionan el desarrollo del niño en sus diversas dimensiones: salud, cognición, comunicación y lenguaje, conducta, etc. Explicaremos los principales problemas que pueden aparecer y las soluciones que actualmente podemos aplicar a lo largo de su infancia, su niñez y su adolescencia. La adecuada atención durante estas etapas consiga que la vida del adulto sea madura y plenamente integrada en la sociedad.

SATURDAY, JUNE 27, 10:30 AM – 12:00 PM



Sing Me a Story: Using Music to Enhance Language Development in Young Children

Sarah Billerbeck, MA, ECSE, Music Educator, Certified Early Childhood Special Education Specialist, Stanley British Primary School, son with DS, Lakewood, CO

Music can be a powerful tool to help young children develop speech and language skills. Join this fun, interactive session to learn and practice musical strategies designed to help infants, toddlers, and preschoolers increase expressive and receptive language skills. Come away with new ways to incorporate music into everyday routines that will make learning language fun for children and their parents.



Speech and Language Preparation for Adult Life: Elementary School, Middle School and Beyond

Libby Kumin, PhD, CCC-SLP, Professor of Speech-Language Pathology, Loyola University, Baltimore, MD

This presentation will focus on speech and language planning with the future in mind. We know a great deal about areas of communication that are important for adult employment and a good quality of life. We also know how professionals and parents can work as a coordinated team to help children and adolescents maximize their communication skills. Information in this workshop will address how to support these future needs at the elementary school level, including auditory comprehension, pragmatics, social skills, conversational skills, and narrative discourse. We will look at three young adults with DS and the paths they have followed to become communicative, caring, productive adults. Dr. Kumin will present a lifelong planning model for communication skills and teach you how to use the model to help develop school and home evidenced-based treatment programs that can positively impact the future.



Students With DS Can Learn Grade-Level Aligned Content: Using NCSC's Free Instructional Resources for a Standards-Based Education in Grades K-12

*Ricki Sabia, JD, edCount Senior Associate, National Center and State Collaborative Technical Assistance and Parent Training Specialist and NDSC Consultant, son with DS, Silver Spring, MD, and **Audra Ahumada, MEd, Director of Alternate Assessment, Arizona State Department of Education, Phoenix, AZ***

This session will inform participants about free publicly available curriculum and instructional resources created by the National Center and State Collaborative (NCSC) to provide a grade level-aligned, standards-based education to students in grades k-12 who take (or will likely take) an alternate assessment. During the session, the presenters will take participants on a guided tour through the resources available to support their child's or students' education. Participants will also learn about other documents and PowerPoints designed to help them share information about the curriculum and instructional resources with parents, educators, and/or administrators. The Director of Assessment for the Arizona State Department of Education will share that state's experience using the NCSC curriculum and instructional resources.



Creating and Supporting Dating Relationships: Advice From Self-Advocates



*Terri Couwenhoven, MS, AASECT Sex Educator, TC Services, daughter with DS, Port Washington, WI, and **Katie Frank, MHS, OTR/L, University of Illinois, Chicago, IL***

Many parents struggle with how to support their son or daughter as he or she becomes involved in a dating relationship. In this workshop, parents will have an opportunity to hear from couples with DS at various stages of their dating relationships. Resources for teaching about dating and supporting healthy relationships will be shared.



The Future of Postsecondary Education: Advocating for a Better Future

Stephanie Smith Lee, Chair, Accreditation Workgroup, Think College, daughter with DS, Oakton, VA.

Parents and students have been the driving force behind the development of new inclusive postsecondary education opportunities for students with intellectual disabilities over the past decade. While over 200 postsecondary programs exist, demand outstrips availability, and federal funding is at risk. In this interactive presentation, the most up-to-date information on inclusive postsecondary education from Think College will be shared. Successful state-wide coalitions resulting in new postsecondary opportunities will be highlighted, as well as strategies for developing and expanding high-quality inclusive opportunities in your locality. Urgent advocacy needs at the national level to continue appropriations and model demonstration programs and how to successfully advocate for a better future will be outlined.



DS and Cancer Research

Tom Blumenthal, PhD, Director, Linda Crnic Institute for DS, Aurora, CO, and **Joaquin Espinosa**, PhD, Associate Director for Science, Assistant Professor, Department of Molecular, Cellular, and Developmental Biology, University of Colorado at Boulder

This talk will summarize recent findings from research into DS with special emphasis on the relationship between the extra chromosome in DS, leukemia, and solid tumors. People with DS have higher than normal rates of childhood leukemia, yet seem to be protected from many kinds of solid tumors. The DS community is in a strong position to make a huge contribution to the general public if the mechanism behind the protective effect of the extra chromosome 21 on solid tumors can be determined.



Oh, The Things You Can Think: Understanding Behaviors

Lina Patel, PsyD, Director of Psychology, Sie Center for DS at Children's Hospital Colorado, Aurora, CO

This presentation will review the neuropsychological factors contributing to common behaviors observed in children with DS. Information will then be utilized as a framework to discuss general strategies that can help children with DS navigate their environment more effectively. Audience members will be taught how to assess a problematic behavior in order to determine what targeted strategies can be used to address that behavior.



Apps Smackdown

Sean Smith, PhD, Associate Professor, Department of Special Education, University of Kansas, Lawrence, KS

Apps, apps, and more apps. This presentation will be an interactive experience where the presenter and participants will share their favorite apps and why, demonstrate some of the best, and leave with an interactive list to share, build upon, and/or apply to the needs of those with DS. Participants should be interested in learning about the coolest apps, want to leave with more apps for their toolbox, and be ready to be dazzled by peers on the apps that are applicable to the needs of those with DS. Come ready to learn, share, and have fun. Don't forget your iPad, tablet, or mobile device!



Tips for Getting the Most Out of Your Adult Sibling Toolkit: A Primer on Post-Parental Care

Moderated by Jennifer Carroll, Affiliate Relations Director, daughter with DS and **Tamara Pursley**, Resource Specialist, son with DS, both from NDSC, Roswell, GA

This workshop will be presented by members of the NDSC Sibling Task Force and will break down each section of the Adult Sibling Toolkit. Task force members will provide examples of how to begin the conversation with aging parents on planning for the future for their brother or sister with DS. Strategies will be shared for keeping everyone in your family working towards the same goal as well as how to meaningfully include your sibling with DS in the process. Don't have an Adult Sibling Toolkit? Don't worry, kits will be provided to each family at the workshop.



What Autism Looks Like in a Child With DS

Susan Hepburn, PhD, Associate Professor, University of Colorado School of Medicine, Director of Research for JFK Partners, Aurora, CO

This presentation will explore the connection between DS and autism and provide a variety of resources to help navigate this complex diagnosis. Participants will learn how behavioral characteristics intersect to create unique challenges for screening and evaluation, as well as implications for intervention. Dr. Hepburn will provide an overview of the differences in behaviors presented with a co-occurring diagnosis and, most importantly, allow time for questions from participants.



Síndrome de Down: Sexualidad y Estrategias Educativas

Dra. Teresa Aguilascho, Médico Gineco-Obstetra, Presidenta de la Fundación Síndrome de Down de Nuevo León, A.C., Monterrey, Nuevo León, México

Tema que emerge a lo largo de la vida de las personas con trisomía 21. Los comportamientos en diversos ámbitos, se refieren a las acciones que desarrolla una persona frente a los estímulos que recibe y a los vínculos que establece con su entorno. Las estrategias educativas serán el conjunto de habilidades conceptuales, sociales y prácticas que se espera aprendan para funcionar en sus vidas cotidianas. La educación sexual es un tema que no espera, esta presente en todas las etapas del ser humano. La historia negativa que nos antecede de siglos pasados es una realidad muy diferente en el siglo XXI, las personas con trisomía 21 son criados y educados por padres generosos, amorosos y dedicados que necesitan una guía y un conocimiento de las etapas evolutivas de sus hijos en las cuales las conductas apropiadas y esperadas por la sociedad crean un impacto importante en su desarrollo. Las personas encargadas de una atención encaminada a la adquisición de un desempeño adecuado a la situación y lugar son los padres en primera instancia y secundariamente a los profesionales que impactan en su desarrollo y para ello es necesario conocer, adquirir, informarse y formarse en las habilidades necesarias para que las personas con síndrome de Down se puedan desempeñar en contextos cotidianos, adecuada y oportunamente, con un impacto de aceptación personal y social por lo que en este taller esperamos proporcionar estrategias que den seguridad a la hora de educar y así llegar a un bienestar.

SATURDAY, JUNE 27, 3:30 – 5:00 PM



Supporting Parents and Educators as Allies for Inclusion in Kindergarten and Beyond

Angela Jarvis-Holland, MA, Executive Director, and **Pamela Dye**, New Parent/Early Childhood Outreach Coordinator, both parents of daughters with DS and both from Northwest DS Association, Portland, OR

A successful transition into kindergarten is a critical determinate of a child's trajectory of access to inclusive education. Join parent engagement leaders from the Northwest DS Association/All Born (In) as they discuss the Kindergarten Inclusion Cohort, a unique program supporting parents to be empowered partners in advocating for their children, achieving inclusive school placements, and working collaboratively with educators to support children in the least restrictive environment. The KIC is part of

NWDSA's All Born (In) work, a cross-disability movement in pursuit of an inclusive civil society. Since 2010, KIC has supported dozens of families with a 90% success rate in accessing inclusive kindergarten.



Oral Placement Therapy to Improve Speech Clarity

Whitney Pimentel, MA, CCC-SLP, TalkTools®, Charleston, SC

This course is designed to address the oral placement skills and movements that are critical for the development of muscles needed for safe and effective feeding and speech clarity. Participants will learn how to watch for specific movements that are necessary for speech clarity and determine when a tactile cue is needed to stimulate the movement. Participants will also learn techniques to facilitate lip closure, lip rounding, tongue retraction, tongue tip elevation, abdominal grading, and jaw stability and grading. In addition, the medical, environmental, and sensory experiences that can affect development will be addressed.



Technology Today and Tomorrow

Sean Smith, PhD, Associate Professor, Department of Special Education, University of Kansas, Lawrence, KS

This session provides interactive, innovative, and practical technology-based solutions for the student with DS. Participants will engage in activities to further expand their understanding of apps, technology-based solutions, and innovative tools applicable to challenges in the area of academic, functional, and social growth and development. Parents and educators will walk away with practical tips for students and children of all ages.



Promoting Self-Esteem, Competence, and Independence in Teens and Adults With DS

Dennis McGuire, PhD, Senior Consultant, Global DS Foundation, Denver, CO



This workshop will provide information on the tried and true ways to promote self esteem, competence, and independence in people with DS. Participants will learn how to understand and take advantage of unique behavioral characteristics such as self talk, social sensitivity, grooves, visual memory, and receptivity to visual cues to build competence and independence. In addition, participants will learn how to avoid failure and dependence by specifically targeting key areas of weakness; why good social skills, sex education and safety training are so important; and how to identify and promote unique talents and skills.



Tapping Into Hidden Human Capital: The Global Journey of Successful Employment of Persons With DS

Debra Ruh, *Global Disability Inclusion Strategist, G3ict Employability & Technology Chair, Ruh Global Communications, daughter with DS, Rockville, VA*

This session will cover best practices in the employment of persons with DS including accommodations, accessibility, and market opportunities. Ms. Ruh will explore ways corporations have employed and empowered individuals with DS in their workforce and look at programs in the United States that are models for other countries. While helping employers understand the value of inclusion, we tap into people's abilities instead of only focusing on their disabilities. Ms. Ruh will also review the latest findings from her book, *Uncovering Hidden Human Capital: How Leading Corporations Leverage Multiple Abilities in Their Workforce*.



Advances in DS Cognition Research – “Seizing the Momentum”

Michael Harpold, PhD, *Chief Scientific Officer and Chair, Scientific Advisory Board, LuMind Foundation, Marlborough, MA*, **Jamie Edgin**, PhD, *Assistant Professor of Psychology, Sonoran UCEDD Faculty, Director, Memory Development and Disorders Lab at the University of Arizona, Tucson, AZ*, and **Carolyn Cronin**, *Executive Director, LuMind Foundation, Marlborough, MA*

The presentation and interactive research panel discussion will provide the latest updates on advances in DS cognition biomedical research, clinical trials, and additional research initiatives. Researchers have made rapid and dramatic progress in understanding the cognitive mechanisms and differences associated with both the developmental intellectual disability and Alzheimer's disease in DS, together with the identification of multiple new therapeutic targets which have led to clinical trials for potential treatments to improve cognitive function and prevent cognitive decline. What are the latest research advances and what do they reveal? What could be the significance of this new DS cognition research for the daily lives of individuals with DS? How might sleep problems impact cognition? Could individuals with DS and this research be a unique key to successfully developing effective new therapies for Alzheimer's disease?



Why Research and NIH Funding is Important for People With DS

Michelle Livingston, *Director of Operations and Government Affairs, Global DS Foundation, Denver, CO*

This workshop will describe how basic and clinical research could have short-term as well as long-term benefits for people with DS. Health care issues such as sleep, behavior, and speech will be highlighted. Participants will learn how the NIH funding has dramatically declined in the last decade and what the DS community can do to ensure increased funding levels for people with DS, while having some control of funding priorities.



What to do When Behaviors Challenge Us: Identifying Meaning and Teaching Alternatives

Scott Shepard, Director of Avenues Supported Living Services, Professor at CSU Northridge, Cal-TASH Board Member, Valencia, CA

What do we do when behaviors challenge us, jeopardize the safety of self or others, or when they simply bring unwanted attention or embarrassment? This workshop will review tools that help to identify why the behaviors are occurring and what the person may be communicating through their behaviors. Participants will learn how to develop a comprehensive support plan to teach replacement behaviors and skills as a positive alternative to the challenging behavior(s). Behavior motivations and natural ways to provide reinforcement will also be shared.



Have Questions? Ask the Doctors! (Pediatrics)

Kishore Vellody, MD, Medical Director, Associate Professor of Pediatrics, DS Center of Western Pennsylvania, brother with DS, Pittsburgh, PA

Specific guideline-directed care for people with DS is relatively new, and specialized DS centers with access to specialists in DS are available in only some areas. So, this session provides an opportunity to ask questions about the care of your loved one with DS. Dr. Vellody and Dr. Bulova direct the Pediatric and Adult DS Centers of Western Pennsylvania. Ms. Cannon is a developmental specialist who coordinates both centers. Questions will be asked and answered anonymously so that the privacy of the person with DS is maintained.



Independent Living: Independence into Adulthood

Steve Freeman, Program Coordinator, daughter with DS, and Shannon Bergman, Self-Determination Coach, both from DIRECT Center for Independence, Tucson, AZ

Independent living is part of the civil rights movement for people with disabilities. Instead of agencies deciding what is best for a person, independent living means the person is their own expert! Come learn about the Independent Living model and how to encourage, equip, and empower individuals with disabilities to lead active and independent lives to the fullest extent possible.



When DS and Autism Intersect: Gaining a Better Understanding of DS-ASD

REPEATED Sunday, 8:30 – 10:00 am

Margaret Froehlke, RN, BSN, Sarah Hartway, RN, MS and Robin Zaborek, all representatives of the DS-Autism Connection, including two seasoned parents of children with DS-ASD, Denver, CO

Could it be more than DS? This presentation will provide an overview of DS-ASD for family members who suspect that a person in their life may have autism, or for those who have already received an autism diagnosis. This presentation is also valuable for professionals who want to learn more about the co-occurrence and how to understand and help the families in their care. Come and learn about

research findings, recognizing autism behaviors, barriers to receiving a proper evaluation and diagnosis, parents' emotional journey, and finding support and inspiration for the journey.

Esp

El desarrollo de habilidades cognitivas desde edades tempranas a través del uso de gestos

Fabiana Sevilla Godoy, *Fonoaudióloga, Magister Desarrollo Cognitivo, Programa de Atención Temprana. Laboratorio de Neurorehabilitación Pediátrica. Pontificia Universidad Católica de Chile y Centro de Desarrollo Cognitivo. Universidad Diego Portales. Santiago, Chile*

Existe una interrelación entre las habilidades cognitivas y las lingüísticas, por lo cual en todo tratamiento fonoaudiológico de personas con síndrome de Down, es necesario estimular de manera sistemática, ambas habilidades desde edades tempranas. En esta charla, se hablará sobre la importancia de estimular las habilidades cognitivas a edades tempranas, mediante el uso de los gestos. Se destacarán los beneficios de esta herramienta, tales como: el desarrollo del lenguaje, la estimulación de la atención, de la memoria de trabajo y de largo plazo, el desarrollo de la planificación y la organización, así como de los factores afectivo-motivacionales y el vínculo de comunicación y afectividad entre padres e hijos. Se discutirá el fundamento teórico de la propuesta de Feuerstein; se identificarán las funciones cognitivas emergentes de cada fase del acto mental y las estrategias de estimulación de cada una de ellas, desde el contexto terapéutico y familiar. Los gestos son una herramienta que puede servir en un primer momento como comunicación aumentativa, pero en el caso de que el desarrollo del lenguaje se retrase o no se produzca, se puede transformar en una herramienta de comunicación alternativa, pero en cualquiera de los casos, produce desarrollo cognitivo.

SUNDAY, JUNE 28, 8:30 – 10:00 AM



Bridging the Communication Gap With Sign Language

Angie Willey, *Advanced Signing Time Instructor, ABC Signing Kids, son with DS, Elmwood, NE*

This session provides an overview of the research-based benefits of using sign language with children of all abilities and hearing levels, the impact of sign language on early literacy, strategies for jump-starting sign language, basic sign language instruction, and a number of "super signs" for getting started.



Can Count, Now What? Using Numbers to Add and Subtract

Dana Halle, *JD, Executive Director DSF/Developer of The Learning Program™, Down Syndrome Foundation of Orange County, son with DS, Newport Beach, CA*

Understanding early number concepts can provide a solid foundation for upper level math skills, but there are so many other concepts to master for independence. By developing a math plan for your learner, you can keep focused and track progress. This session walks through the components of a basic math plan and demonstrates strategies for teaching addition and subtraction. Instruction for working with double digit equations and word problems is included.



Microboards and Cooperatives: Creating Inclusive Community Lives



***Vicki Niswander**, MA, Executive Director and Parent, Illinois Association of Microboards and Cooperatives, daughter with DS, and **Annie Niswander**, Self-Advocate, both from Mahomet, IL*

By thinking outside the box, caregivers can help to create an enviable life for an individual with DS by developing a microboard and/or a human services cooperative. Learn about the applications of person-centered planning and how to build personal networks and natural supports. Hear real-life examples of an adult with DS who is supported to live in her own apartment, has a real job, connects with friends, and volunteers in the community.



Have Questions? Ask the Doctors! (Teen & Adult)



***Kishore Vellody**, MD, Medical Director, Associate Professor of Pediatrics, DS Center of Western Pennsylvania, brother with DS, **Peter Bulova**, MD, Medical Director, UPMC Adult DS Center, and **Sheila Cannon**, MEd, Program Director, DS Center UMPC, daughter with DS, all from Pittsburgh, PA*

Specific guideline-directed care for people with DS is relatively new, and specialized DS centers with access to specialists in DS are available in only some areas. So, this session provides an opportunity to ask questions about the care of your loved one with DS. Dr. Vellody and Dr. Bulova direct the Pediatric and Adult DS Centers of Western Pennsylvania. Ms. Cannon is a developmental specialist who coordinates both centers. Questions will be asked and answered anonymously so that the privacy of the person with DS is maintained.



Health Promotion for the Child With DS: How Parents Can Help Their Child

***Marilyn Bull**, MD, FAAP, Morris Green Professor of Pediatrics, Developmental Pediatrics, Riley Hospital for Children at Indiana University, Indianapolis, IN*

Health care supervision recommendations have undergone several significant changes, and it is important that family, caregivers, and health care professionals understand how they can participate in ensuring a child with DS gets the best possible care. An explanation of the reasons for the most up-to-date recommendations will be discussed and specific resources will be given including the parent guidelines released in 2013. Patient examples illustrating some of the critical issues will be presented, as well as tools and techniques to help families navigate the medical system.



i M-RURAL Living 101

***Kate Dougherty**, Founder & President, Down Country, son with DS, Taylor, MO*

This workshop will explore positive ways to encourage, educate, empower, and enrich your rural community for individuals who are "outside the box" learners, while exploring the differences between the rural versus metropolitan dynamic. Down Country was founded in 2011 and, in three years time, has grown to be a positive rural outreach and advocacy group for not only individuals with DS, but for all

those who learn differently. This workshop is designed to provide individuals or groups with concrete, take home ideas that can work in their rural communities.



Introduction to Dads Appreciating DS (D.A.D.S.)

REPEATED Sunday, 10:30 am – 12:00 pm

Joe Meares, President, D.A.D.S. National, daughter with DS, Indianapolis, IN

Over the past 10 years, Dads Appreciating DS has connected thousands of fathers with the DS movement, their local DS community, and each other. D.A.D.S. National offers an online community and provides a template for local DS organizations to implement a local D.A.D.S. program. This interactive workshop is for fathers to learn about D.A.D.S. and the value of support, fellowship, and action in becoming a more engaged and effective advocate for your child. All fathers are invited to join us, share your story (if you choose), and become a part of D.A.D.S. in a comfortable environment with other fathers.



The Neurodevelopmental Complexity of DS: Implications for Learning

Mary Pipan, MD, Program Director, Trisomy 21 Program of the Children's Hospital of Philadelphia, PA

Individuals with DS vary greatly in their development and learning. Understanding basic strengths and weaknesses is important in optimizing their capacity to understand and interact with the world around them.



Letter of Intent



Dana Young, Parent, Consultant, daughter with DS, Monrovia, CA

A Letter of Intent is simply a document that provides information about your loved one to others. No one knows your child or loved one with DS as well as you do, but what would happen if you were unable to care for him or her? Without you, your loved one would become dependent on other caregivers who do not possess all of your personal knowledge and insight. A Letter of Intent provides that knowledge so that the transition to a new caregiver can go as smoothly as possible, resulting in your loved one receiving the best possible care. Writing such a document can seem like a daunting task, but Ms. Young gives a step-by-step guide to creating your own individualized Letter of Intent.



When DS and Autism Intersect: Gaining a Better Understanding of DS-ASD

REPEATED Saturday 3:30 – 5:00 pm

Margaret Froehlke, RN, BSN, Sarah Hartway, RN, MS and Robin Zaborek, all representatives of the DS-Autism Connection, including two seasoned parents of children with DS-ASD, Denver, CO

Could it be more than DS? This presentation will provide an overview of DS-ASD for family members who suspect that a person in their life may have autism, or for those who have already received an

autism diagnosis. This presentation is also valuable for professionals who want to learn more about the co-occurrence and how to understand and help the families in their care. Come and learn about research findings, recognizing autism behaviors, barriers to receiving a proper evaluation and diagnosis, parents' emotional journey, and finding support and inspiration for the journey.

Esp

El Adulto con Síndrome de Down: Perspectivas, Logros, Problemas

Dr. Jesús Flórez, *Catedrático de Farmacología y Presidente de la Fundación Iberoamericana Canal Down21*

La llegada de nuestro hijo con síndrome de Down a la edad adulta es una realidad gozosa pero, al mismo tiempo, nos supone a él y a nosotros nuevos retos. En esta pre-conferencia abordaremos los más importantes, que versarán sobre: la salud, la educación, la vida activa y bien ocupada, la búsqueda de empleo, la utilización del tiempo libre, el desarrollo de actividades comunitarias, el envejecimiento precoz (¿Alzheimer, sí o no?)... Pero habrá que insistir en dos premisas previas indispensables: 1) cada persona y su entorno son únicos y distintos; 2) la vida del adulto se prepara desde la niñez y la adolescencia.

SUNDAY, JUNE 28, 10:30 AM – 12:00 PM



Effective Strategies for Improved Communication and Speech Clarity for Children With DS

Jennifer Gray, *MS, CCC-SLP, Speech-Language Pathologist, Grays Peak Speech Services, LLC, Westminster, CO*

This presentation will focus on factors that impact appropriate communication and strategies that foster speech and language and prevent communication difficulties in children with DS from birth to school-age. Sensory, motor, and oral-placement skills will be discussed in the framework of a comprehensive language learning system, providing parents and educators with a better understanding of how multiple strategies can be implemented to address speech clarity and overall communication.



Teaching Children with DS to Read

Dana L. Halle, *JD, Executive Director, DS Foundation of Orange County, Vice President, Education and Outreach, DS Education USA, NDSC Board Member, son with DS, Orange County, CA*

This session provides participants with evidence-based methods, activities, and tools for effective home and classroom literacy instruction. Intended for children 2 through 5 years (or any child who is not yet reading), topics include vocabulary development, sight word acquisition, sentence building, basic comprehension support, and the creation of personalized books. Illustrated with video examples from students in The Learning Program™, this session equips parents and professionals with the skills to work

effectively with children with DS and other visual learners. Guides and sample materials will be provided.



Preparing for Puberty: A Session for Parents of Boys With DS

Terri Couwenhoven, MS, AASECT Certified Sex Educator, TC Services, daughter with DS, Port Washington, WI

Families often experience anxiety when their son with DS begins exhibiting the physical and emotional changes that occur during puberty. In this workshop, parents will learn about the most common issues and concerns that arise. Practical ideas and resources to address these issues will be shared.



Solving The Mystery of the Individualized Education Plan (IEP) Process

Julie Harmon, Director of Parent Services, PEAK Parent Center, NDSC Board Member, two sons with DS, Colorado Springs, CO

Have you ever felt like the IEP for your child or student was decided “behind closed doors?” This practical, hands-on session will de-mystify the IEP process, teach ways of becoming an effective communicator, and explore communication skills that can open doors to total IEP team membership. Participants will be guided through three main stages of the IEP: preparing for the IEP meeting, content of the IEP, and implementation and follow up of the IEP. If you are interested in learning about the basics of IDEA specifically related to IEPs, evaluation and consent for services, eligibility, SMART goals, accommodations and modifications, progress monitoring, and much more, then this is the session for you!



Promoting Adolescent and Adult Health and Wellness

Brian Chicoine, MD, Medical Director, Advocate Medical Group Adult DS Center, nephew with DS, Park Ridge, IL

Adolescents and adults with DS are participating in a wider variety of opportunities than in the past and are having a great deal of success. Optimizing their participation and success in these opportunities is more likely with good health. Health optimization for adolescents and adults with DS is more successful if the individual is able to participate in their own health care and health promotion. This workshop will focus on the more than 23 years of experience of the Advocate Medical Group Adult DS Center in promoting health for adolescents and adults with DS with an emphasis on fitness, good nutrition, appropriate medical care, self-promotion of health, screening for illnesses, and some of the health problems experienced by adolescents and adults with DS.



Microenterprise as an Employment Option: The KK Glass Experience



Kailin Kelderman, *Self-Advocate, KK Glass Co-Owner, Kelderman Klassy Glass*, and **Mary Bryant**, *daughter with DS, Reno, NV*

Kelderman Klassy Glass is a microenterprise co-owned by 20-year-old Kailin Kelderman. With the assistance of her family, she makes fused glass jewelry which is sold on her website, at conferences, and in stores. Kailin and her family will talk about how they decided on a business, the process for starting a microenterprise, resources available, and the benefits and drawbacks of a microenterprise.



Evaluating the iPad as a Communication Device; a Journey not for the Faint-Hearted

Laurel Buell, *MAEd, OTR/L, Occupational Therapist, Assistive Technology Specialist, Southwest Human Development, Phoenix, AZ*, **Marilyn Willcoxon**, *MS/CCC-SLP*, and **Sarah Hales**, *MA, CCC-SLP*

This presentation provides an overview of variables to take into account when considering using the iPad as a communication device. Topics reviewed will include apps (pros and cons of different communication apps), and why you might choose to use one over another. Access method accessories and cases (with and without amplification) will be reviewed, as well as durability, support, and emotional buy-in. Finally, networking resources accessible following the conference will be shared.



The ABLE Act – Another Tool in the Tool Chest



Stephen W. Dale, *JD, LLM, niece with DS, Pacheco, CA*, and **Susan Goodman**, *JD, Governmental Affairs Director, NDSC, son with autism, Olney, MD*

This presentation will review the ABLE Act with a focus on when this tool is appropriate in saving for long-term needs and when other tools may be more appropriate. This piece of legislation has gone through many changes over the past year, and the final version is very different from when it was originally introduced.



Quit the Food Police! Strategies to Create and Support Healthy Eating for All Ages and Stages

Joan Medlen, *MEd, RDN, LD, JEM Consulting, son with DS, Portland, OR*

It begins with a vision. A vision of health for your family. We all have a different vision of what it means to be healthy. Including a person with DS in your family doesn't change that vision, but it may alter the path. Together, we'll explore sensory and oral motor challenges, discuss nutrition-related concerns specific to children and adults with DS, and see the power of universal design for learning (including visual cues, early literacy techniques, and more) in creating successful, healthy lives for everyone in your family.



Soul Sisters

Tanya & Michelle Ponich, sisters with DS

Sisters Tanya and Michelle Ponich will take attendees on a journey through their life together as they find their place in the world. They will speak candidly about their views on life, family, and DS. Through their life experiences, their message is abundantly clear...unconditional love, hope, fearlessness, and a big dash of humor are the keys to living an extraordinary life.



Herramientas que Pueden usar los Padres para Favorecer la Construcción de la Autoestima desde las Etapas Tempranas del Desarrollo

Dra Macarena Lizama y Fabiana Sevilla Godoy, Fonoaudióloga, Centro UC Síndrome de Down, Universidad Pontificia Católica de Chile. Programa de Atención Temprana, Laboratorio de Neuro-rehabilitación Pediátrica UC, Santiago, Chile

Taller destinado a padres y a cuidadores de personas con síndrome de Down. Por medio de palabras simples, conoceremos qué es la autoestima y cómo se construye. Conversaremos de qué manera la autoestima influye en el desarrollo de las distintas áreas de la persona y la relevancia del auto-reconocimiento e identificación que tiene una persona con síndrome de Down sobre sí mismo. Revisaremos el efecto de los mensajes verbales y no verbales de las personas que nos rodean y sus efectos positivos y negativos en la construcción de la autoestima y aprenderemos a reconocer las situaciones que los potencian, y cómo se pone en práctica la propuesta del Dr. Reuven Feuerstein sobre la modificación de los entornos. Por medio de ejemplos, entregaremos estrategias que favorezcan un adecuado desarrollo de la autoestima desde el contexto familiar. Se pondrá énfasis en los aspectos más importantes que hay que tener en cuenta en las etapas tempranas del desarrollo, priorizando algunos de ellos. Finalmente reforzaremos distintas herramientas a utilizar, dependiendo de la edad de la persona con síndrome de Down y de las distintas conformaciones familiares.