

ADULT SUMMIT CINCINNATI • 2023

2023 NDSS Adult Summit

All scheduled times are Eastern Time
More sessions will be added over the coming weeks.

Thursday, November 9, 2023

1:30 PM - 2:30 PM ET

Opening Keynote: Fostering Independence and Positive Relationships to Increase Community Integration

Lisa Eicher, Owner of Sandal Gap Studios

Lisa's keynote will touch on the work done at Sandal Gap Studio as well as her experience with fostering independence, positive sibling relationships, and creativity and its collective application in entrepreneurship. Through both Sandal Gap Studio and her work as a parent, Lisa is creating a world where people with Down syndrome and IDD are fully welcomed into the community.

Location: Floor 3, Regency Ballroom A-C

2:45 PM - 4:00 PM ET

Create Your Own Path: Transition Planning through Learning, Independent Living, Working, and Self-Advocacy

Maura Iorio, Senior Director of Education, Pathfinder Village

Marin Melone, Third Year Student, Otsego Academy

Kayla Jones, Second Year Student, Otsego Academy

Alexis Padula, Second Year Student, Otsego Academy

Sophia Porter, Second Year Student, Otsego Academy

Neva Ricardo, Second Year Student, Otsego Academy

Creating a seamless transition plan can be difficult. Otsego Academy is a two-year post-secondary program designed to support young adults as they navigate the path to employment and independent living. Our program blends on-campus dorm living, academic and enrichment courses, vocational internship opportunities, and important partnerships with local universities to assist young adults with developmental disabilities in gaining the knowledge, skills, and confidence needed to bridge the gap between high school and adult life. This presentation will offer information about Otsego Academy, as well as the key components that should be included in any successful transition plan. Featuring past and current students, we will discuss how the right post-secondary program can instill individuals with the self-advocacy skills needed to reach their goals!

Location: Floor 3, Regency Ballroom A-C

Supporting Your Loved One with Down Syndrome to Learn Skills Necessary for Developing Healthy Relationships

Katie Frank, PhD, OTR/L, President, Down Syndrome Medical Interest Group-USA, Occupational Therapist, Advocate Medical Group Adult Down Syndrome Center

Does your loved one with Down syndrome have an interest in dating? Do you feel like you need more information in order to better support them on this journey? This presentation will focus on what skills individuals need in order to enter into and maintain dating relationships as well as how to help them develop these skills.

Location: Floor 3, Buckeye

At a Critical Crossroads: Down Syndrome and Alzheimer's Disease Research

Hampus Hillerstrom, President & CEO, LuMind IDSC

Dr. Forrest Foster, MD, Behavioral Neurology and Neuropsychiatry, University of Cincinnati College of Medicine/UC Physicians

Dr. Stephanie L. Santoro, M.D., Dir. of Quality Improvement Research, MassGeneral Hospital Down Syndrome Program; Clinical Geneticist, Massachusetts General Hospital and Assistant Professor, Harvard Medical School

Carol Cronin, B2B Sales/Donations/Mama Bear at John's Crazy Socks

Join LuMind IDSC for a comprehensive look at the latest developments in Alzheimer's disease research, the pathways of drug development, and how related policies impact the Down syndrome community. This session will provide meaningful insight into our community's fight for equitable access to new Alzheimer's drugs and incorporates key perspectives on research participation from both the researcher and participant viewpoint.

Location: Floor 3, Regency E

Activating Happiness: A Parent's Guide to Behavioral Activation for Their Adult Child with Down Syndrome

Ruth Brown, PhD, Assistant Professor at Virginia Institute for Psychiatric and Behavioral Genetics at Virginia Commonwealth University

Join us for an informative parent workshop designed to help parents of adults with Down syndrome improve the mood and engagement of their loved ones using Behavioral Activation. Behavioral Activation is an evidence-based approach that involves identifying and engaging in activities that are rewarding and meaningful, with the goal of increasing positive experiences and improving overall well-being. This workshop will equip you with practical strategies and tools that you can use to support your loved one with Down syndrome. You'll learn how to apply Behavioral Activation effectively, understand when it's most helpful, and tackle common challenges that can arise.

Location: Floor 4, Wolverine

Changing Perspectives One Shirt at a Time!

Nate Simon, CEO, 21 Pineapples

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Holly Simon, Executive Director, 21 Pineapples

Since the day Nate was born, Holly and Nate Simon have been on a remarkable journey to challenge and reshape societal perceptions of individuals with Down syndrome. From the very beginning, they knew they had a mission to fulfill, a mission fueled by love, determination, and a belief in the limitless potential of every individual. Through their Hawaiian shirt business, they became champions of inclusivity, showing that everyone, regardless of their abilities, could make a positive impact on the world. In this session, they'll share lessons from their journey and inspire attendees to believe that with determination, love, and a touch of moxie, anyone can change the world.

Location: Floor 4, Hoosier

Self-advocate Networking Event: 6:30-7:30 PM

Location: Floor 3, Regency E

Networking Event: 6:30-7:30 PM

Friday, November 10, 2023

8:15 AM - 9:15 AM ET

Opening Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center

Dr. Lauren Wang, MD, Medical Director, UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities

Dr. Aurora Rivendale, MD, Family Medicine and Psychiatry Provider, Freeman Center

Dr. Jensine' Clark, MD, Assistant Professor of Clinical Neurology & Rehabilitation Medicine, University of Cincinnati College of Medicine

Christine Gregg, CTRS, Program Manager, Freeman Center

Andrea DeRossett, MSW, LISW, Behavioral Health Care Manager/Therapist, Freeman Center

Erin Burkey, BSN, RN, Registered Nurse Care Coordinator, Freeman Center

Kelsie Newton, MS, RD, LD, Registered Dietician, Freeman Center

Join a panel of staff from UC Health's Timothy Freeman, MD, Center for Intellectual Developmental and Developmental Disabilities (Freeman Center) located in downtown Cincinnati. The Freeman Center's mission is to provide specialized, coordinated, patient-centered healthcare for adults with intellectual and developmental disabilities and to train and empower future physicians to care for this population in their communities. We will review concepts of positions that have been developed at the center and will learn about some of the "Whys" to our work. Attendees will learn about our strategic focuses and about the current services offered, along with what we aspire to offer in the future.

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The panel will represent our interdisciplinary team which currently includes primary care, psychiatry, dietitian, social work, community navigation, RN care management, behavior support, and more. Attendees will have a chance to ask questions of those directly involved in the healthcare at the Freeman Center.

Location: Floor 3, Regency Ballroom A-C

9:30 AM - 10:45 AM ET

Independence Panel

Stacy Jackson, Regional Director, Gigi's Playhouse National Office

Emily Kendall, Co-Founder, Empower Me Living

Steve Friedman, Author, The Essential Guide for Families with Down Syndrome, Beyond Down Syndrome

Allan Bergman, CEO, High Impact Mission-based Consulting and Training

Moderator: Ryan Rotundo, Director of Programs, National Down Syndrome Society

What does independence really look like? This panel will reframe our conception of independence, allowing self-advocates and loved ones to envision a possibility where individuals with Down syndrome and IDD are functioning to the best of their ability, with or without supports. Families and caregivers will gain a roadmap toward increased independence, and professionals will gain insight on how to serve their clients in a more impactful way. This panel will focus on how an individual functions in the areas of residential living, self-care, employment, clinical independence, as well as independence within the community.

Location: Floor 3, Regency Ballroom A-C

Mastering Social Skills for Success in the Workplace

Katie Frank, PhD, OTR/L, President, Down Syndrome Medical Interest Group, Occupational Therapist, Advocate Medical Group Adult Down Syndrome Center

Abby Rowley, LCSW, Clinical Therapist, Advocate Medical Group Adult Down Syndrome Center

Although people with Down syndrome can be excellent employees, research and experience have demonstrated that inadequate social skills is one of the main reasons that people with Down syndrome lose their jobs. Social skills are not inherent. They are an abstract concept that most individuals with Down syndrome need to be taught and learn. In this interactive workshop, Katie and Abby will identify common workplace dilemmas and offer strategies to teach skills to facilitate socially appropriate behavior. They will also provide resources developed from social skills groups offered at the Adult Down Syndrome Center in Park Ridge, Illinois.

Location: Floor 3, Buckeye

A Silent Triad of Need: Down Syndrome, Aging, and Dementia

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Ley Linder, Owner and Operator, Crescent Behavioral Health Services

What are the differences between normal age-related changes in adults with an intellectual disability (e.g., Down syndrome) and dementia? The “Early Detection and Screen for Dementia (NTG-EDSD)” has been developed to provide direction to all people who are involved in supporting people aging with intellectual disabilities, answering this question. The NTG-EDSD is the foundation of a larger discussion of aging and Down syndrome, centering on changes in behavior and cognition, medical comorbidities, and global education.

Location: Floor 3, Regency E

Using Everyday Technology to Increase Employment and Social Skills for Individuals with IDD Panel

Humberto Pena Jr., PhD Psychology, Texas A&M

Dr. Carly B. Gilson, Associate Professor of Special Education, The Ohio State University

Luis Morissette, Associate Professor of Special Education, The Ohio State University

Adults with intellectual and developmental disabilities (IDD) continue to be employed at disproportionately lower rates than their counterparts without disabilities. Naturalistic support via portable electronic assistive technology can help to fill this employment gap to promote sustained employment for adults with IDD. Adults with IDD can use portable electronic devices (e.g., smartphones, tablets) to support them with social skills in the workplace. In this presentation, we will discuss how to use everyday technology (e.g., smartphones, tablets) to support adults with IDD in the workplace and how to promote self-determination and independence for adults with IDD.

Location: Floor 4, Wolverine

State Advocacy Explained: Creating Change at the State Level

State Representative Rachel Baker (Ohio)

Ashley Meier Barlow, JD, Special Education Attorney, Special Education Advocate

Jen Powers Alge, Esq., Regional Director of the Arc of Ohio

Alan H. Abes, Vice President of the Board for Hamilton County Developmental Disabilities Services

David Egan, Author

Moderator: Nick Leto, Manager of State Government Relations, NDSS

Join us for a dynamic session that delves into the crucial role of state advocacy and equips you with the tools to transform your voice into a catalyst for change. Our expert panel, comprising a diverse range of perspectives, including a seasoned self-advocate, a statehouse insider, a local leader, and a dedicated member of the NDSS staff, will illuminate the multifaceted impact of advocacy on the state legislative process. Walk away from this presentation empowered to build enduring connections with elected officials, poised to drive meaningful change in your community.

Location: Floor 4, Hoosier

11:00 AM – 12:15 PM ET

Mental Health in Adults with Down Syndrome

Eric Rubenstein, PhD, ScM, Assistant Professor, Department of Epidemiology, Boston University's School of Public Health

Ashley Scott, MPH, Project Coordinator, Department of Epidemiology, Boston University's School of Public Health

Kaethe Sigelko, Self-Advocate and Co-Researcher with the Rubenstein Lab, Boston University School of Public Health

Benjamin Golden, Self-Advocate and Co-Researcher with the Rubenstein Lab, Boston University School of Public Health

To live their best lives, people with Down syndrome need to care for their physical and mental health. There is a lot of focus on physical health but not as much on mental health. We will present three talks on mental health in adults with Down syndrome. First, we will describe what mental health conditions people with Down syndrome are diagnosed with and what kind of mental health care they receive, according to more than 120,000 adults with Down syndrome enrolled in Medicaid and Medicare. Then, we will discuss our process and present findings from a survey on mental health in adults with Down syndrome, led by researchers with Down syndrome. Lastly, we will discuss structural barriers to mental health care, or things in society that prevent people from getting the help they need, and what we can do to overcome them.

Location: Floor 3, Regency Ballroom A-C

The Balancing Act: Health, Safety, and Independence

Dr. Brian Chicoine, MD, Medical Director and Co-Founder, Advocate Medical Group Adult Down Syndrome Center

Katie Frank, PhD, OTR/L, Occupational Therapist, Advocate Medical Group Adult Down Syndrome Center, President, Down Syndrome Medical Interest Group-USA

Abby Rowley, LCSW, Clinical Therapist, Advocate Medical Group Adult Down Syndrome Center

This presentation will be a facilitated discussion about the challenges of providing support while also respecting the autonomy and independence of an individual with Down syndrome. The panelists will be Brian Chicoine, MD, Katie Frank, PhD, OTR/L, and Abby Rowley, LCSW, from the Adult Down Syndrome Center in Park Ridge, Illinois. This presentation will address topics such as dignity of risk, safety, decision-making abilities, and rights. Case examples related to health and community participation will be presented and discussed.

Location: Floor 3, Buckeye

Everybody Deserves to Work

Jed Seifert, Co-Founder, Stakes Manufacturing

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This session will help and hopefully inspire individuals with disabilities and their families to find meaningful employment to attain financial independence, purpose, and happiness while in-turn helping employers solve labor shortages and improve company culture by inclusive hiring. This session will present how employment has changed the lives of Jed's brother, family, company, and employees. We will discuss the benefits and ROI to organizations through a clear business case for disability inclusion in the workplace, as well as highlighting the supported employment model and incredible resources available to support employers hiring disabled job seekers.

Location: Floor 3, Regency E

If We Only Knew Then: Practical Insights on How to Support Aging Adults with Down Syndrome

Jane Boyle, NTG-certified Dementia-Capable Caregiver Trainer, Co-Founder and Facilitator, NJ Down Syndrome & Alzheimer's Support Group

Kathy Service, RN, MS, FNP-BC, CDDN, Board Officer, National Task Group on Dementia and Intellectual Disabilities

Marianne Barbera, Family Advocate, Board Member, National Task Group on Dementia and Intellectual Disabilities

The purpose of this presentation is to provide information and practical insights into the health, social, and support needs of aging adults with Down syndrome specific to dementia. The focus for the presentation will be to help families plan for their loved one's future to help support quality of life. Planning should include establishing a written baseline of function for future caregivers and health care providers, assuring a differential diagnosis is conducted to rule out treatable causes for decline and changes, making sure any dementia related diagnosis is accurate, seeking out organizations and services for support at home or in group residential settings, managing day-to-day responsibilities and caregiving when there are increased care needs, and navigating the health care system. Respite, support groups, and end-of-life planning resources will also be suggested.

Location: Floor 4, Wolverine

Supporting Siblings Panel

Christy Gregg, CTRS, Program Manager, UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities

Stacey Gruber, PhD, Sibling

Diana Temple, Executive Director, Ohio SIBS

The relationship between siblings is the longest-lasting relationship, and many siblings of people with disabilities eventually become primary caregivers for their loved ones. Despite this, most siblings of people with disabilities do not feel prepared for this role and/or do not have formal plans for the transition, leading to unnecessarily difficult and sometimes traumatic care transitions. Even with planning, siblings often experience a steep learning curve related to the complicated systems in place that are meant to help. Siblings can feel isolated from their peers, not only in this process, but throughout their lifespan. Please join us in this session to learn about tools and initiatives available to siblings and to have a conversation about how we can all support and recognize siblings as valuable parts of the disability community.

Location: Floor 4, Hoosier

12:15 PM – 1:45 PM ET: Lunch

Location: Floor 2, Sungarden

1:45 PM – 3:00 PM ET

Ensuring Community Engagement Across the Lifespan Through Employment

Dennis Cleary, OTD, Senior Researcher, Cincinnati Children's Hospital

Nancy Raitano Lee, PhD, Leader, Project Aspire, Associate Professor, Department of Psychological and Brain Sciences, Drexel University

Gregory Wallace, PhD, Leader, Project Aspire, Associate Professor, Department of Speech, Language and Hearing Sciences, The George Washington University

Dr. Lindsay DuBois, PhD, Research Associate, Human Services Research Institute

Community engagement, including employment, is important across the lifespan. This panel will delve into the vital connection between employment, daytime activities, and the long-term well-being of adults with Down syndrome. Also discussed will be the importance of studying employment for people with Down syndrome, recent findings, and remaining knowledge gaps that still need to be addressed. Preliminary findings from an NIH-funded online study involving caregivers of young adults with Down syndrome called Project ASPIRE will be summarized. Among the information provided will be rates and types of employment, engagement in other daytime activities, and cognitive and mental health factors that are associated with employment outcomes for individuals with Down syndrome. This panel will also discuss VocFit, a reliable 15-minute skills-based employment assessment and job-matching tool developed for adults with Down syndrome and other intellectual and developmental disabilities by Occupational Therapists at Cincinnati Children's Hospital and Colorado State University. Practical takeaways will be shared such as ways to support cognition and mental health to optimize community engagement among adults with Down syndrome and IDD.

Location: Floor 3, Regency Ballroom A-C

Addressing Bias in Health Care

Dr. Brian Chicoine, MD, Medical Director and Co-Founder, Advocate Medical Group Adult Down Syndrome Center

Kandi Pickard, President and CEO, National Down Syndrome Society

Progress has been made in reducing bias against people with Down syndrome. However, significant bias persists in health care as evidenced by the experiences of many people with intellectual disabilities during the COVID-19 pandemic. In this session, Brian Chicoine, MD will describe bias in health care, define ableism, share clinical examples, and facilitate a discussion of strategies to address bias in health care and the role individuals with Down syndrome and their families can play in the process. Kandi Pickard, President and CEO of the National Down Syndrome Society, will explain how to address bias through legislative advocacy.

Location: Floor 3, Buckeye

The History and Rights of Research Participation

Nicole White, PhD, Director of Operations for Research, Cincinnati Children's Hospital

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The landscape of research participation has changed and evolved since the inception of the 1979 Belmont Report. While the Belmont report addresses ethical principles of respect for people, beneficence, and justice in the framework of how research should be conducted. Many misconceptions about research participant rights, ethics, and how research is conducted remain. This presentation will share information about the history of research participation, explain what the Belmont Report is, and allow the audience to understand more about their rights to participation in research and how to protect the dignity, rights, and welfare of themselves, and their loved ones when deciding to participate in a research study.

Location: Floor 3, Regency E

Transition and Law

Allan Bergman, CEO, High Impact Mission-based Consulting and Training

In this session you will learn the language, meaning, and goals of the federal IDEA and Vocational Rehabilitation laws and regulations. You'll also learn about the rights all students with disabilities have to be included in their IEPs and to have the tools needed for a successful transition from high school to an active and meaningful adult life.

Location: 4 Floor, Wolverine

Developing Advance Directives: Another Tool for Self-Determination, Autonomy, Empowerment, and Self-Advocacy

Leigh Ann Kingsbury, Owner and Principal Consultant, InLeadS Consulting

Advance Care Planning is not just an end-of-life process. It is about empowerment, self-advocacy and self-determination, autonomy, relationships, and trust. We ALL need to know we can rely on someone we trust to honor our wishes if we're unable to advocate for ourselves. Having Down syndrome or other intellectual disabilities does not mean one is incapacitated in all decision making. People with Down syndrome can be supported to develop advance directives, including identifying their clear wishes and values for self-identified quality of life, choosing their health care preferences, and choosing someone to act on their behalf if needed. This session will review concrete practices, strategies, and resources for supporting people with Down syndrome and their families in developing advance directives.

Location: Floor 4, Hoosier

3:15 PM – 4:30 PM ET

Embrace Imperfection: Start Your Business Now

John Cronin, Co-Founder, John's Crazy Socks

Mark Cronin, Co-Founder, John's Crazy Socks

Angad Sahgal, Co-Founder, Let ME Do it

Amit Sahgal, Co-Founder, Let ME Do it

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Britni Allen, Co-Founder Rosemerry Sparkle Design

Dr. Keri Allen, PhD, Co-Founder, Rosemerry Sparkle Design

Co-Moderator: Charlotte Woodward, Education Programs Associate, National Down Syndrome Society

Co-Moderator: Ashlea Lantz, Senior Policy Advisor, Harkin Institute

Are you waiting for the perfect moment to start your own business or looking to explore an alternative to traditional employment? Join us for an enlightening panel discussion with entrepreneurs on embracing imperfection and adopting the lean startup approach. In this session, we will delve into the concept of the minimally viable product (MVP) and how it can help you get your business off the ground swiftly. Our experienced speakers will share valuable insights gained from their own entrepreneurial journeys, as well as lessons from other successful ventures. Don't delay your dreams any longer; take the leap and start your business now!

Location: Floor 3, Regency Ballroom A-C

Approaches to Mental Health Promotion and Treatment

Dr. Brian Chicoine, MD, Medical Director and Co-Founder, Advocate Medical Group Adult Down Syndrome Center

Abby Rowley, LCSW, Clinical Therapist, Advocate Medical Group Adult Down Syndrome Center

There is not a one-size-fits-all approach to mental health promotion. How we work towards optimal mental health can vary not only from person to person but also from one phase of life to another phase. In this presentation, Abby Rowley, LCSW, and Brian Chicoine, MD, will describe mental health and mental illness in adults with Down syndrome. They will discuss a variety of ways to support adults with Down syndrome throughout the different phases of adulthood and present case examples to demonstrate how mental health promotion strategies can be used.

Location: Floor 3, Buckeye

Guardianship and Supported Decision Making

Ashley Meier Barlow, JD, Special Education Attorney, Special Education Advocate

Guardianship and Supported Decision Making are often confusing and intimidating to families, yet the need to establish plans is so important. In this session, caregivers and self-advocates will learn the difference between the two formats and will understand next steps in facilitating either a guardianship or a supported decision-making plan.

Location: Floor 3, Regency E

Better Together: Promoting Physical Activity and Exercise Within the Down Syndrome Community

Kristin Mendez, MS, CSCS, Exercising Physiologist

The benefits of physical activity (PA) and exercise (EX) are well-documented scientifically and supported anecdotally. By incorporating healthy and appropriate activity-based behavior, individuals with Down syndrome can reap these same rewards. During this presentation, we will learn how PA/EX positively impacts overall health in people with Down

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syndrome. Through lecture, discussion, and activity integration, we can better understand expected physiological and psycho-social improvements associated with PA/EX. Facilitation of an audience dialogue will provide valuable insight into potential barriers and limitations of PA/EX in our community. "Participatory research," as sampled here, increases community involvement in the experimental process, making research more significant and impactful. Through community research, education, and service, we aim to combat identified obstacles and encourage increased participation in PA and EX in people with Down syndrome.

Location: Floor 4, Wolverine

Not Your Father's...Special Needs Planning Process: How to Plan for Peace & Security

Phillip Clark, Founder, ENABLE Special Needs Planning

At ENABLE, we believe that your child was made on purpose, for a purpose. Special Needs Planning should enable you to confidently answer the following: "What does a happy, fulfilling life for my child look like today and in the future?" and "How do I ensure my child is able to live this GREAT life?" In our interactive workshop, we discuss many components of Special Needs Planning (e.g., SSI, SSDI, Medicaid waivers, ABLE accounts, special needs trusts, guardianship, trustees) and show you how you can create a Special Needs Plan that enables your child to live a purposeful life aligned with your vision of success. You will leave this session with the tips and tools you need to create a flexible plan that can adjust in a rapidly changing world. The true benefit of planning is peace of mind from knowing your family is prepared for today and the future!

Location: Floor 4, Hoosier

Saturday, November 11, 2023

8:15 AM –9:15 AM ET

Opening Keynote: Breaking Barriers through Beats: A Journey of Resilience, Music, and Love

Arik Ancelin, singer/songwriter, activist, motivational speaker

Jennifer Ancelin, MSpEd, Arik's' Mother and Manager

Step into the world of Arik Ancelin, a remarkable rapper with Down syndrome, as he takes center stage in an inspiring keynote speech. Arik's story is a testament to the power of determination, creativity, and the universal language of music. In this captivating keynote, Arik and his mother, Jenn, share about his incredible journey of breaking down barriers, defying stereotypes, and finding his voice through hip-hop and music. Arik's message goes beyond music, emphasizing the importance of inclusion, acceptance, and embracing one's unique abilities. Join us for an unforgettable experience as Arik Ancelin delivers a heartfelt and empowering message that will leave you inspired to overcome any obstacle and celebrate the beauty of diversity. Don't miss this opportunity to witness the transformative impact of Arik's talent and resilience.

Location: Floor 3, Regency Ballroom A-C

9:30 AM - 10:45 AM ET

Down Syndrome Clinics: Value, Purpose, and Benefit

Nicole White, PhD, Director of Operations for Research, Cincinnati Children's Hospital

Dr. Stephanie L. Santoro, M.D., Dir. of Quality Improvement Research, MassGeneral Hospital Down Syndrome Program; Clinical Geneticist, Massachusetts General Hospital and Assistant Professor, Harvard Medical School

Dr. Lauren Wang, MD, Medical Director, UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities

Down syndrome clinics (DSC) are uniquely positioned specialized care clinics that focus on facilitating care for individuals with Down syndrome. This session will discuss the value of care facilitation from the perspectives of an adult intellectual and developmental disabilities clinic, a pediatric medical provider, and a parent. This session aims to leverage families with information on the value and benefits of attending a DSC and how they may begin to advocate for the establishment of one within their community.

Location: Floor 3, Regency Ballroom A-C

Financially Empowering People with Disabilities Through ABLE Accounts

Kenyatta Chandler, Director of STABLE Account

1 in 6 Americans live with a disability, yet these individuals are not well represented in the workforce or the financial system. This presentation, led by the National Association of State Treasurers (NAST) through its ABLE Today initiative, will provide a comprehensive overview of ABLE Accounts. The Stephen Beck Jr., Achieving a Better Life Experience (ABLE) Act of 2014 established tax advantaged saving, investment, and spending accounts specifically for people with disabilities. Despite the benefits of ABLE accounts, they remain a little-known secret in the disability community. Approximately 8 million people are eligible to open an ABLE account however only a little more than 131,000 accounts have been opened so far. Program providers, including 46 states and the District of Columbia, cite lack of awareness as the greatest obstacle to assisting eligible people with disabilities to benefit from these tax-advantaged accounts. This session will discuss how these ABLE financial tools can help people with disabilities build wealth without jeopardizing their disability benefits and pay for disability-related expenses, including education, housing, transportation, employment training and support, assistive technology, personal support services, health prevention and wellness, financial management, administrative services, and legal fees.

Location: Floor 3, Buckeye

The Research Experience in Adults with Down Syndrome: Facts and Fiction

Dr. Ann Cohen, Director, Neuroimaging Core, University of Pittsburgh Alzheimer's Disease Research Center

Dr. Benjamin Handen, Professor of Psychiatry, Pediatrics, Psychology and Instruction and Learning (Education

Arthur Johnson

Lauren Kubic, Research Specialist

Research in the Down syndrome community can differ in a variety of ways. In this session we will explore, along with research professionals, the research experience. First, we will discuss how a research study is different from typical medical care. We will also discuss what to expect when participating in a research study, frequently asked questions about research studies and participation, and what you can expect when completing the study related to disclosure or results and other information. Additionally, we will focus on what happens to samples provided by participants in a research study, like blood, brain, and other tissues. Next, we will discuss some of the benefits of participating in different kinds of research and how it might help the Down syndrome community. There will also be time to ask questions about research and if it may or may not be right for you, your family, and friends!

Location: Floor 3, Regency E

Financial Wellness and Special Needs Planning

Phillip Clark, Founder, ENABLE Special Needs Planning

At ENABLE, we believe that your child was made on purpose, for a purpose. Special Needs Planning should enable you to confidently answer the following: "What does a happy, fulfilling life for my child look like today and in the future?" and "How do I ensure my child is able to live this GREAT life?" In our interactive workshop, we discuss many components of Special Needs Planning (e.g., SSI, SSDI, Medicaid waivers, ABLE accounts, special needs trusts, guardianship, trustees) and show you how you can create a Special Needs Plan that enables your child to live a purposeful life aligned with your vision of success. You will leave this session with the tips and tools you need to create a flexible plan that can adjust in a rapidly changing world. The true benefit of planning is peace of mind from knowing your family is prepared for today and the future!

Location: Floor 4, Wolverine

11:00 AM - 12:15 PM ET

Down Syndrome and Alzheimer's Disease: Pathology, Diagnosis, and Early Intervention

Dr. Beau Ances, MD, PhD, Daniel J Brennan MD Professor of Neurology and Vice Chair of Academic Affairs, Department of Neurology, Washington University in Saint Louis

Down syndrome results from having three full or partial copies of chromosome 21 instead of two. It is this 21st chromosome that is responsible for the production of a protein called amyloid. Too much amyloid in the brain is a hallmark of Alzheimer's disease, so individuals with Down syndrome are at greater risk of developing Alzheimer's disease at an earlier age (30-60 years). This session will include important insights into the early origins of Alzheimer's disease in people with Down syndrome, as well as explain why individuals with Down syndrome could greatly benefit from early intervention and inclusion in clinical trials.

Location: Floor 2, Regency Ballroom A-C

Down Syndrome Regression Disorder: Updates and Latest Research

Dr. Stephanie Santoro, MD, Director of Quality Improvement Research, Massachusetts General Hospital Down Syndrome Program

In this session, Dr. Stephanie Santoro will review the results of the research she has participated in, describing the clinical phenotype and management of individuals with Down syndrome regression disorder. She will also focus on the latest research from others in the field and summarize ongoing research efforts to learn more about Down syndrome regression disorder.

Location: Floor 3, Buckeye

Turning Your Passion into Policy Change

Lucinda Hurst, Direct Support Professional at o2 Urban Farms,

Pepper Stetler, Professor at Miami University

Courtney Gaines, Student, Member of NDSS Board of Directors

Moderator: Anna Fedewa, Manager of Federal Government Relations, National Down Syndrome Society

Are you passionate about issues that impact the Down syndrome community? Do you wish you could use your voice to create change that positively impacts people with Down syndrome and other disabilities? Join NDSS Manager of Federal Government Relations and seasoned grassroots advocates as we discuss tangible ways you can turn your passion into policy change and use your voice for good!

Location: Floor 3, Regency E

Supporting Daily Health Habits through the 321go! Program

Monica Forquer, Author, 321go! Program

Maura Iorio, Senior Director of Education, Pathfinder Village

Boo Krucky, Program Coordinator of Teen and Adult Services, Down Syndrome Association of Central Ohio

People with Down syndrome are at a higher risk for many chronic conditions including obesity, depression, anxiety, diabetes, and Alzheimer's disease. While predispositions to hypothyroidism and low metabolic rate contribute to this increased risk, lifestyle factors also play a major role. The NDSS 321go! program was developed to support adults with Down syndrome to adopt a healthy lifestyle. The program includes resources for individuals with Down syndrome, families, caregivers, and other supporters. Monica Forquer, author of 321go!, will provide an overview of the program and share how you can get involved. Using the materials, Monica will provide tips for family members and caregivers looking for ways to support their loved ones to make healthy choices. Monica will also share how clinicians and affiliate groups can encourage regular practice of 321go! goals and challenges. Finally, Monica will share a preview of upcoming 321go! resources.

Location: Floor 4, Wolverine

Note: The respite room will be available throughout the NDSS Adult Summit for anyone who needs a break. This room is located on Floor 4, in the Board of Directors room.

national down syndrome society

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