



NDSS Virtual Adult Summit Week Three

All scheduled times are Eastern Daylight Time

Monday, May 18, 2020

11:00 AM – 12:15 PM

Self-Advocacy in Your Community: Providing Tools and Resources

John Seely, Parent, Founder, Empowering Lives Foundation

Join John as he shares ways you can use your smartphone or tablet to create a one-page profile for self-advocacy. In this hands-on session, you will learn about resources available to support and empower you in your community, to set goals, and to plan for the things you want to do. Don't forget to bring your smartphone or tablet.

1:00 – 2:15 PM

"If the Shoe Fits," The History, Science, and Future of Shoe Gear for those with Atypical Foot Types

Marc Colaluce, DPM, All Florida Podiatry, St. Petersburg, Florida, Special Olympics Fit Feet Clinical Director

Dr. C, as a leader in the Special Olympics Healthy Athlete program is very aware of the unique foot needs of adults with Down syndrome. Join his session to learn about shoe gear - it's origin and early development, and the style, function, and sizing of shoe gear, as well as specific sizing and fit for those with atypical feet. He will also share some exciting news about new horizons in measuring and data collection, and the future technology of shoe gear fit and sizing. If someone you know with Down syndrome has difficulty finding shoes that fit or are uncomfortable you won't want to miss this session.

2:00 – 3:15 PM

How to Bring Your Business and Brand Online

Martin Guerrero, Community Affairs Associate, eCommerce and Online Specialist, Square

As soon as people hear about a brand they'll typically hop online and search for your business or brand. Do you have the presence you're hoping they will find? Join Square eCommerce specialist, Martin Guerrero to walk you through the basics of claiming your online presence and what you need to build your website. In our time together we will cover claiming your domain, creating a first impression, and focusing on the right website elements for your business or brand.



3:30 – 4:45 PM

LuMind Focus Group

Marly Chevrette, Marketing Director, LuMind IDSC

3:30 – 4:45 PM

How to Ace Your Next Interview

– Limited Space Available

** Self-Advocate Friendly

Matteo Lieb, NDSS Employment Policy and Program Manager

Have you ever felt nervous going into an interview? Did an interview ever get in the way between you and your dream job? If so, this workshop will be a great resource! This session will take an interactive approach to building interview skills. We will cover a selection of commonly asked interview questions as well discussing additional ones from the audience. Whether you have not yet been through an interview process or are looking to build on previous experience, this workshop will provide valuable insight on how to close the deal and land that next job!

Tuesday, May 19, 2020

10:00 –11:15 AM

Pathways to Inclusive Employment

****Self-Advocate Friendly**

David Egan, Self-Advocate, Community Relations Coordinator, SourceAmerica, Sargent Shriver International Global Messenger, Joseph P. Kennedy Jr. Public Policy Fellow

Matteo Lieb, NDSS Employment Policy and Program Manager

Employment is a defining aspect of adult life. It connects us to full participation and inclusion in our communities. As a person with Down syndrome who has over 20 years of experience in competitive employment and a career of advocacy, David will share his perspectives and Pathways to Inclusive Employment. We want employers to hire us and we want to be useful members of our society. Because we are citizens that matter, David will also challenge you to believe in yourself and reach for the stars to show the world that individuals with Down syndrome are valued, able and ready to work.



12:00 – 1:15 PM

Plenary Session: Improv Domination! How the Improvaneer Method is Blowing Up Job Opportunities and Blowing Away Perceptions in the Down Syndrome Community!

Rob Snow, Parent, Motivational Speaker, Founder, Stand Up of Downs, Creator, The Improvaneer Method

Rob Snow's non-profit Stand Up For Downs has always had a mission of enhancing the lives of those with Down syndrome through humor. In 2018, that mission took on a new twist. The humor would be found in improvisation, and improvisation would prove to provide so much more than laughs for those with Down syndrome. Rob and his team created The Improvaneer Method, by first casting and studying the world's first all Down syndrome improvisation troupe. Two years and countless national media pieces later, they have proven how improvisation can build and develop skills that will greatly increase social and workplace opportunities for those with Down syndrome. This is absolutely a can't miss session for those interested in finding new and necessary opportunities for their loved ones with Down syndrome to achieve their dreams!

3:00 – 4:15 PM

Hospital-Based Special Needs Program/Inclusive Health

Doreen Bestolarides, R.N. Developmental Disabilities Nurse, Dignity Health, St. Joseph's Medical Center, Stockton, California

People with intellectual/developmental disabilities (IDD) experience high rates of hospitalization, compared to the general population. Patient diversity requires progressive services that link to the needs of the community, deliver timely procedures, utilize best practice, improve communication and accessibility to supports. Join Doreen as she provides information about the "Special Needs Caregiver Program" — care coordination in the hospital setting focused on nursing care that is based on the knowledge of chronic or developmental health issues. Participants will explore the value of individualized care planning and tools to establish baseline information to create a relationship-based approach to care.

Wednesday, May 20, 2020

11:00 AM – 12:15 PM

A Map to Medical Insurance Coverage For Reconstructive Procedures

Sarah Briggs, Medical Insurance Advocate, Ozark Prosthodontics (OP)

Throughout this presentation I will touch on a few treatment plans that are common with patients with Down syndrome, specialties that are typically involved, and how commercial medical insurance can alleviate the financial burden associated with them. I will also explain different parts of medical insurance plans, and legislations that help get this treatment covered.



1:00 – 3:00 PM

Increasing Self-Advocates' Civic Engagement

****Self-Advocate Friendly**

Adrian Forsythe, *Self-Advocate, NDSS Advocacy Program Specialist, NDSS Registered Lobbyist, NDSS Self-Advocacy Board Liaison*

Mitchell Levitz, *Self-Advocate; Self-Advocacy Coordinator, Westchester Institute for Human Development/University Center of Excellence in Developmental Disabilities, Valhalla, New York; Contributing Faculty, LEND Interdisciplinary Graduate Training, New York Medical College; Coordinator, Hear Our Voices Self-Advocacy Group; Staff Liaison, WIHD Community Advisory Board; Author; Member NIH/NICHHD National Down Syndrome Research Consortium; Chairperson, NDSS Self-Advocacy Board; Review Board Member, National Center for Prenatal and Postnatal Down Syndrome Resources/Lettercase Project, University of Kentucky*

Ester Lee “Essie” Pederson, *Sibling, Teacher, SABE GoVoter Project*

Julianna Huereña, *National Advisor, Self-Advocates Becoming Empowered (SABE); Administrative Assistant, SABE GoVoter Project*

Teresa Moore, *Director, Self-Advocates Becoming Empowered (SABE) GoVoter Project; Director, Self-Advocates Resource & Technical Assistance Center Projects*

Nicole Patton, *Manager, NDSS Grassroots Advocacy; Manager, NDSS DS-AMBASSADOR® program; Manager, NDSS Buddy Walk® on Washington*

Civic engagement is open to everyone but not everyone participates. Learn how civic engagement can be a part of your life. In this session we will focus on one aspect of civic engagement, voting. We will talk about the importance of voting, knowing our rights and responsibilities when voting, training opportunities to learn about voting, being prepared to cast our ballot, choosing how we want to cast our ballot (early voting, Vote at Home or Election Day Voting), and knowing how to learn about candidates and issues.

3:30 – 4:45 PM

Plenary Session: The Long and Winding Road: Down Syndrome, Alzheimer’s Disease and Advanced Care Planning

Jane Boyle, *Sibling*

In recent years, we have learned that individuals aging with Down syndrome (DS) may be at risk for Alzheimer’s disease (AD). While researchers stress that AD is not a foregone conclusion, many self-advocates, their families and care partners seek a greater understanding of changes that may occur, strategies to adapt, and models of care. This session will explore the actual experience of a woman with DS and AZ from early warning signs and diagnosis to advanced stages. Most importantly, it will address the critical role of Advanced Care Planning to ensure quality of life.



Thursday, May 21, 2020

10:00 – 11:15 PM

Promoting Healthy Aging While You Are Stuck at Home

Adel Herge, OT, Thomas Jefferson University

Mary Stephens, MD, Thomas Jefferson University Hospitals

Mary and Adele, two members of the interprofessional team (a primary care physician and an occupational therapist) will provide practical advice for families and care providers who support individuals with Down syndrome in maintaining a healthy lifestyle, avoiding disease and staying engaged in activities while at home.

12:00 PM – 1:15 PM

Interview Prep

– Limited Space Available

** Self-Advocate Friendly

Matteo Lieb, NDSS Employment Policy and Program Manager

Have you ever felt nervous going into an interview? Did an interview ever get in the way between you and your dream job? If so, this workshop will be a great resource! This session will take an interactive approach to building interview skills. We will cover a selection of commonly asked interview questions as well discussing additional ones from the audience. Whether you have not yet been through an interview process or are looking to build on previous experience, this workshop will provide valuable insight on how to close the deal and land that next job!



12:00 – 1:15 PM

Stop Hiding Your Money: Save, Invest, & Keep Your Public Benefits

Douglas Jackson, *Deputy Director of STABLE Accounts from the Office of the Ohio Treasurer*

Eric Ochmanek, *Deputy Chief of Staff for the Office of the State Treasurer of Ohio*

Many people with disabilities and their families are concerned about financial matters, especially the ability to save without impacting the needed supports provided through public benefit programs like Medicaid and SSI. STABLE account is a tool that can be used to help achieve financial independence. However, individuals and families remain unfamiliar with ABLA accounts, are not sure how to use them, and may not be using them to their full potential. STABLE Account offers a unique opportunity for a person with a disability to save and control money like never before without risking eligibility for government benefits. STABLE Account offers saving and spending opportunities that can enhance the independence of individuals with disabilities.

3:00 – 4:15 PM

Siblings: What We Need to Know

Embry Burrus, *Sibling and Caregiver to Margaret, SLP*

Mary Merriman, *Sibling to Pete*

Heidi Metcalf, *Sibling to Darin*

Michelle Sagan, *Sibling to Marie*

Hank Unnerstall, *Sibling to Nick*

Each of the panelists have a brother or sister with Down syndrome. They will share some of the joys and challenges they have had as they support the changing needs of their brothers and sisters. The panel has siblings ranging from a teen through the early 60s and each has varying skills and needs for support. The panel will share tips that they believe are important for all siblings to know and that parents can think about as their loved ones with Down syndrome grow up and age with Down syndrome. Resources that the siblings have found helpful will also be shared.

Friday, May 22, 2020

12:00 – 1:30 PM

BYO Virtual Lunch and Learn with NDSS and LuMind IDSC!

Join us for the first NDSS Adult Summit Virtual Lunch and Learn, hosted and moderated by LuMind IDSC, where you get to decide what you want to hear from a panel of speakers with over four decades of experience as caregivers, healthcare providers, and Alzheimer’s research for adults with Down syndrome. Register and submit any questions you have for the panelists below about the journey of adults with Down syndrome through their senior years. Then, bring your lunch on May 22 at 12:00 ET and join the panelists live for the answers to your questions and more.



Brian Chicoine
 Co-founder and Medical Director of the Advocate Medical Group Adult Down Syndrome Center

Author:
Mental Wellness of Adults with Down Syndrome

The Guide to Good Health for Teens and Adults with Down Syndrome



Anne Burke
 Geriatric Psychiatrist and the Director of Neuropsychiatry at Barrow Neurological Institute

Principal Investigator for the LIFE-DSR study site at Barrow.



Matt Janicki
 Co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG)

Department of Disability and Human Development at the University of Illinois at Chicago and Research Professor at UMaineCenter on Aging



Phyllis Ferrell
 Caregiver - myteresajourney.wordpress.com
 Head External Engagement, Alzheimer's and Neurodegeneration at Eli Lilly and Company

Founder Women Against Alzheimer's

Dr. James Hendrix, the Chief Scientific Officer of LuMind IDSC will present your questions to the panelists who will answer as many as they can that day. A couple of weeks later, all who attend will be notified when all of the submitted questions have been posted along with the panelist’s answers on <https://www.lumindidsc.org/research-faq-panel/>.



2:00 – 3:15 PM

Essential Tips for Supporting Individuals with Down Syndrome and Alzheimer's: Lessons Learned from Two State-Wide Efforts

David Coon, Ph.D., Associate Dean, Research Initiatives, Support, & Engagement and Professor, Edson College of Nursing & Health Innovation at Arizona State University

Melissa Kushner, Senior Program Coordinator for Sonoran University Center for Excellence in Disabilities at University of Arizona

Yumi Shirai, Assistant professor for the Sonoran Center for Excellence in Developmental Disabilities in the Department of Family & Community Medicine at the University of Arizona

This panel will discuss the efforts of two statewide projects: Implementation of the Dementia Capable Care Training, and the Arizona Dementia Capable System Expansion. The focus of the panel presentation will be related to 1) Health Care Advocacy, 2) Positive Behavioral Support across Different Stages of Alzheimer's Disease and the Lifespan, 3) Caregiver Self Care, and 4) Networking and Communication.

3:00 – 4:15 PM

Living a Healthy Life! Five Ways to Promote Your Health – Limited Space Available

***** Self-Advocate Friendly***

Laura Chicoine, Project Manager, Research and Education, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, Illinois

Katie Frank, PhD, OTR/L, Occupational Therapist III, Advocate Medical Group Adult Down Syndrome Center, Park Ridge, Illinois

Living longer and healthier lives is an active process. Adults with Down syndrome are encouraged to participate in their own health promotion. But where do we start? Laura and Katie will share five areas to focus on when making healthy lifestyle choices. They will discuss why these five areas are important, facilitate activities to reinforce the information, and share strategies that can be incorporated at home and in the community.

We request that a family member or caregiver “attend” with the participant with Down syndrome so that they can hear the information and help reinforce it later.

We recommend that the participants join on a computer or tablet (rather than a phone) so that they can see the words and pictures on the slides. This will help them be able to participate in the interactive portions of the workshop.

This session will not be recorded.