



NDSS Virtual Adult Summit

All scheduled times are Eastern Daylight Time

Monday, May 4, 2020

12:00 – 1:15 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.



Tuesday, May 5, 2020

10:00 – 11:15 AM

The Essential Elements of a Special Needs Plan

Mike Walther, II CPA/PFS, CFP®, CFA®, Oak Wealth Advisors

If you have ever thought about the financial needs your loved one might have in the future, been overwhelmed, or confused by what you should do, you are not alone. Join Mike as he shares what we need to know to optimize financial planning opportunities. ABLE Accounts and Supplemental Needs Trusts allow families to provide as much support as possible for their loved ones with special needs without losing access to government benefits. Mike will share the importance of developing a plan for future care and share the Ultimate Guide which assists families in organizing their future planning. The importance of family-wide coordinated communication will be discussed as will the significance of reviewing and updating all beneficiary designations. His presentation will include common financial planning mistakes and how they can either be avoided or overcome.

12:00 – 1:15 PM

Decline in Skills and Regression in Adolescents and Adults with Down Syndrome

Brian Chicoine, MD, Co-founder and Medical Director, Advocate Medical Group Adult Down Syndrome Center, Parkridge, IL, Author: *Mental Wellness of Adults with Down Syndrome*, and *The Guide to Good Health for Teens and Adults with Down Syndrome*

There is a growing number of clinical case reports of adolescents and adults with Down syndrome who have shown regression in cognitive and adaptive functioning, motor function, communication skills, and behavior. As reported by their families, this regression occurs following a period of stable functional skill acquisition in adolescents or adults. There are many physical, psychological, and social reasons individuals with Down syndrome may show a decline in skills. While there have been several articles published about regression in adolescents and adults with Down syndrome, there remains a great deal that is still unknown. In this presentation, this will be referred as “regression syndrome.” The discussion will focus on causes other than autism in younger children and Alzheimer’s disease in older adults. Clinical features, evaluation, differential diagnoses, treatment, and prognosis will be discussed. Emphasis will be given to some of the most challenging patients who manifest catatonia, autoimmunity, sleep apnea, and severe mental health symptoms. Case studies will be shared and time for discussion will be provided.



3:00 – 4:15 PM

Making Adult Learning Fun!

Anita Raghavan, Parent, PhD, Parent Trainer with Families Together Inc. in Wichita

Tavrick Lawless, Self-Advocate, Intern for Wichita State University's International Student Union, Nature Educator for Great Plains Nature Center, Wichita, Kansas, NDSS Self-Advocate Board member

As adults, we continue to be curious about the world around us. People with Down syndrome are no exception. Join Anita and Tavrick as they share practical tips for education and socialization, as well as explore successes and failures. Discover how the use of catchy, colorful, humorous and accessible methods encourage learning in adults with Down syndrome.

3:00 – 4:15 PM

Promoting Health and Wellness in Uncertain Times

**** Self-Advocate Friendly**

Mary Borman, Self-Advocate, Student

Sharon Milberger, Director, Michigan Developmental Disabilities Institute (MI-DDI), and MI-LEND, Wayne State University

This interactive session will focus on evidence-based holistic approaches to health and wellness which are especially important in uncertain times such as the current pandemic. Topics will include physical health (physical activity, healthy eating, and sleep), emotional health, and self-care strategies. Stress reduction techniques will be demonstrated.

Wednesday, May 6, 2020

11:00 AM – 12:15 PM

Communication Skills for Adult Life & Employment

Libby Kumin, PhD, CCC-SLP, Professor of Speech-Language Pathology and Audiology, Loyola University, Maryland

Communication skills have an impact on adult life, including employment and independent living. Libby will identify and discuss a variety of speech and language skills including intelligibility, receptive language, expressive language, pragmatics, and social language, as well as electronic communication skills. Sharing research and clinical experience she will present practical suggestions for working on the skills in daily living. A checklist of speech, language, and communication skills in adults with Down syndrome will be included.

11:00 AM – 12:15 PM

Research Update: Down Syndrome & Alzheimer’s Disease

James Hendrix, *Chief Scientific Officer, LuMind IDSC Foundation*

People with Down syndrome (DS) are at a much higher risk for Alzheimer’s disease (AD) than the general population. In addition, people with DS will experience symptoms of AD in their 40’s and 50’s, decades earlier than in the general population. With this serious health care crisis, new research efforts have been launched in AD in DS with the hope that a better understanding of the disease will lead to new and better treatments. Several new research studies will be highlighted including the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) study led and sponsored by LuMind IDSC.

1:00 – 2:15 PM

Planning for the Future

Jerry Hulick, *Senior Planner, The Washington Group Special Care Planning Team Caring Consulting Group – Virginia Tech*

For every life chapter there is a financial backdrop, this workshop will explore some of those chapters and how to best prepare. This session will explore the financial needs of a person with Down syndrome across their adult life including transitioning issues (employment & residential), legal issues (Special Needs Trusts), and Government programs and benefits. This workshop will also explore ABLE account and other financial tools.

1:00 – 2:15 PM

A Life of My Own

Austin Underwood, *Self-Advocate, Founder & Owner, Austin’s Underdawgs, Fort Worth, Texas*

Jan Underwood, *Parent, Founder, Director, Each and Everyone Foundation, Fort Worth, Texas, and the Mingus Job Accelerator, Mingus, Texas*

Austin had always dreamt of being a chef, but it was not an easy journey. After a tireless search for a vocational school that would accommodate his needs, Austin was able to learn the skills to become a certified prep chef and has successfully held a variety of positions in the restaurant industry. With help from his family (aka his Mom, Jan), Austin’s Underdawgs launched in April 2016 selling “Dawgs” – hot dogs – and became an overnight success! Now four years later, Austin has sold more than 34,000 Underdawgs from his 32-foot Dawgmobile. Come learn how one dream has led to a successful business venture and is guiding the expansion of other programs to support adults as they explore their passions and create exciting futures. Austin wants to show people that with a little support and training, anyone can grow to be a successful member of their community



3:30 – 4:45 PM

Mindfulness for Caregivers: Cultivating Lifestyle Practices to Support Optimal Health and Well-Being

Reita Clanton, *Coordinator of Performance and Health Optimization in the School of Kinesiology at Auburn University, Author, Professional Speaker, Olympic Athlete, Coach, and Alabama Sports Hall of Fame Inductee*

During this session, you will be introduced to the 5 Pillars of Health (Breathing, Hydration, Nutrition, Movement, and Sleep), and how these affect your overall quality of life. You will be given practical strategies for improving your health and managing stress, and learn how to cultivate a daily mindfulness practice that will enhance your self-awareness and lifestyle choices.

Thursday, May 7, 2020

12:00 – 1:15 PM

Medical Home Care: Family-Centered Care, Shared Decision-Making, and Supported Decision-Making

Robin Blitz, MD, *Developmental-Behavioral Pediatrician, Medical Director, Special Needs Initiative/Complex Health Solutions, UnitedHealthcare*

Join Dr. Blitz as she discusses medical home care, a way of delivering comprehensive, quality, compassionate care. Discover how she helps patients in the Special Needs Initiative transition to adult care and incorporates family-centered care, shared decision-making and, the use of supported decision making. This approach has helped adults with a disability make life decisions related to medical care, living arrangements, the supports desired, and vocational options.

12:00 – 1:15 PM

Understanding ABLE Accounts

Gabriella (Gabby) Barnes, *Marketing Associate for ABLEnow*

The ABLE Act offers more than eight million Americans with disabilities and their families the ability to establish a tax-advantaged ABLE savings account without fear of losing eligibility for certain public benefits, including health care, Supplemental Security Income payments, housing and food assistance. Many consider the ABLE Act the most significant federal legislation addressing the needs of people with disabilities since passage of the Americans with Disabilities Act. Unfortunately, less than one percent of eligible individuals and families have opened an ABLE account. Join this session to separate fact from fiction and understand how ABLE accounts work. We'll talk about ABLE in easy-to-understand language using the national ABLEnow program as an example.

Friday, May 8, 2020

11:00 AM – 12:15 PM

The Story of Fionnathan Productions: A Social Enterprise Run by a Son and Father

Fionn Crombie Angus, *Irish Social Entrepreneur with Down syndrome*

Jonathan Angus, *School Teacher, Fionn's Father and Business Partner*

This is the story of Fionnathan Productions, a social enterprise in Ireland run by a son (Fionn) and father (Jonathan). You can pronounce it Fear nothin' – close enough.

The seed capital came from a hard-won government grant for self-directed supports, the first of its kind in Ireland. Fionn, who has Down syndrome, hired Jonathan as his assistant. The next major innovation was using a disability hiring grant to employ Fionn with a person-centered job description.

They have followed Fionn's core passions to build an amazing career.

- He is a regular fixture of the Galway arts scene: a film maker, visual artist, and traditional musician
- His deep love of nature won him a place on the Heritage Council's Experts Panel, teaching children in schools nationwide
- To help clarify Fionn's goals, he has conducted over 600 video interviews, asking "What do you love about your life?"

Working with numerous organizations in seven countries, they have led advocacy courses and family consultations; published works; served on government committees; and presented at conferences worldwide. This story will be of use to anyone interested in unique approaches to self-directed funding and/or person-centered employment. Fionnathan shows that supported entrepreneurship, with a creative approach to financing, is a robust and adaptable way to a sustainable and meaningful career.

11:00 AM – 12:15 PM

Non-Medicinal Strategies to Promote Health and Mental Wellness

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

Katie will discuss three different non-medicinal strategies that can be used to promote health and mental wellness. Discover how sensory techniques can help with transitions and behavior (especially during medical procedures and self-care tasks), visual supports can be used to teach new skills or improve task performance, and socially appropriate behavior helps to promote healthy social interactions at home and in the community. Resources will be shared.



2:00 – 3:15 PM

Fathers and Sons: Raising a Successful Self-Advocate

**** Self-Advocate Friendly**

Bill DeSanctis, Father

David DeSanctis, Self-Advocate, NDSS Public Relations & Outreach Associate

Brandon Gruber, Self-Advocate, Artist

Tim Gruber, Father

Raising a strong self-advocate is sometimes an exercise of trial and error. Brandon, David, and their dads, Tim and Bill will share how they discovered their sons' gifts and talents that make them strong self-advocates now. Along the way, the dads learned when it was time to pass the baton and let their sons speak for themselves. Tips on communications and the power of technology, as well as working with organizations will be shared. Walk out of this session with the confidence needed to share your gifts and knowledge.