



NDSS Virtual Adult Summit

All scheduled times are Eastern Daylight Time

Monday, April 19, 2021

12:00 -1:15 PM ET

Staying Fit for Life: A Special Olympics Approach

Monica Forquer, MS, Fitness Senior Manager, Special Olympics International

There are many benefits of maintaining an active and healthy lifestyle. Special Olympics offers programs and resources that help athletes stay fit. The good news—you don't have to be an athlete to improve your health and everyday performance!

Join us for this interactive session in which Sr. Manager of Fitness for Special Olympics Monica Forquer will discuss the benefits of fitness, share considerations for people with Down syndrome and give advice on easy ways to stay active. Monica will also lead the group in a quick Fit 5 workout and teach you how to stay fit using the Fit 5 goals.

4:30 – 5:45 PM ET

Lifestyle Interventions and Obesity

Dr. Stamatis Agiovlasitis, Associate Professor, Mississippi State University

Dr. Nicolas Oreskovic, Assistant Professor, Harvard Medical School/Massachusetts General Hospital

Moderator: James Hendrix, Chief Scientific Officer, LuMind IDSC

Individuals of all ages with Down syndrome are at higher risk to be overweight and obese compared to the general population. Possible reasons for the increased weight in individuals with Down syndrome include a low metabolism, sedentary behaviors and unhealthy food choices. Research on the relationships between physical activity, physical fitness and health in Down syndrome will be discussed. This session is intended to empower families with evidence-based research as they consider their lifestyle choices.



Tuesday, April 20, 2021

12:00 – 1:00 PM ET

Futures Planning for Families Supporting Those with Lifelong Disabilities: Exploring Decision-Making Options

Christina Smith, Director, Astrive Advocacy

This session will explore multiple decision-making options by providing information on guardianship and alternatives to guardianship, including supported decision-making, that will enable individuals with intellectual and developmental disabilities, their families and others in their lives to make informed decisions when choosing the appropriate level of planning and protection. An overview of various planning options that exist to meet the health, financial, legal and quality-of-life needs of individuals with disabilities will be provided, with further discussion on which options allow for the achievement of maximum independence and self-determination of the individual.

2:00 – 3:15 PM ET

Alzheimer's Disease and Down Syndrome

Dr. Michael Rafi, Associate Professor of Neurology, Keck School of Medicine, University of Southern California

There have been great advances in our understanding of the natural history of Alzheimer's disease in people with Down syndrome through the work of the Down Syndrome Biomarker Initiative and the Alzheimer's Biomarker Consortium for Down Syndrome (ABC-DS), among others. We are now embarking on developing clinical trials to bring the latest AD therapeutics to the DS community through the NIH-funded Alzheimer's Clinical Trial Consortium - Down Syndrome (www.actc-ds.org). In this session, some of the latest findings on our understanding of AD in DS will be presented.

4:00 – 5:15 PM ET

Health Promotion Panel: How to Practically Approach the Aging Process

Lucille Esralew, PhD, Senior Psychologist for the California Department of Developmental Services, Office of Statewide Clinical Services

Dr. Beth Marks, Co-Director of the HealthMatters Program in the Department of Disability and Human Development, University of Illinois at Chicago, Principal Investigator of the CDC's Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (IDD), and Past President, National Organization of Nurses with Disabilities

Jasmina Sisirak, PhD, MPH is Co-Director of the HealthMatters Program in the Department of Disability and Human Development at University of Illinois at Chicago (UIC) and Co-Investigator of the CDC's Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (IDD)

Moderator: Seth M. Keller, MD, Neurologist

Getting older holds many promises as well as challenges and uncertainties. A considerable body of research has shown that caring for oneself throughout life does matter and can have an impact on the aging process. This panel will bring together national experts on wellness and health promotion as well as advocates who will discuss the current research and provide a practical approach that everyone should follow. This session will also describe how a team approach is best to ensure that living well as one ages can lead to a positive and productive future.



Wednesday, April 21, 2021

12:00 – 1:15 PM ET

So You Want to Start A Business?

Martin Guerrero, Small Business & Community Advocate at Square Inc.

Zoie Abrams, Founder of Zoie's ART 21

Collette Divitto, Founder of Colletthey's Cookies

Moderator: Matteo Lieb, Employment Policy and Program Manager, NDSS

There are many components to starting a successful business - branding, logistics, product development and more! Hear from two businesses led by entrepreneurs with Down syndrome, Zoie's Art and Colletthey's Cookies, as they share their own business journey. We will talk about the inspiration for their businesses, as well as how they were able to get started. This session will also feature a technical expert from Square who will address resources and tools aspiring entrepreneurs can use to launch their business. If you are thinking about starting a business, or are early in your journey, this session is for you!

2:00 – 3:15 PM ET

Women's Health: What You Need To Know!

Kate Nolan, MSN, WHNP, NP-C

With all the health topics those with Down syndrome face, sometimes we needed to be reminded about the health topics just for women: menstruation, feminine hygiene and more. Please join us in the session as we will talk about what to expect during these changes in life, along with how to prepare for a pelvic exam (yes, they should be done), Pap smear guidelines, HPV vaccine, etc.

4:00 – 5:30 PM ET

Employer/Employee Relationships: Showcasing Success

Eden Rapp, Employee at MOD Pizza

Garylee Dreiske, General Manager, MOD Pizza, Rolling Hills Estates

Miles Evans, Employee at BlackBerry Market

Kathy Stolp, Manager at Blackberry Market in Glen Ellyn

Moderator: Matteo Lieb, Employment Policy and Program Manager, NDSS

People with Down syndrome are valuable members of the workforce. Hear from two employees with Down syndrome who are currently working in the community. Additionally, we will feature each of their supervisors who will share their experiences managing employees with Down syndrome.



Thursday, April 22, 2021

12:00 – 1:15 PM ET

Down Syndrome & Keratoconus: A Parent's Perspective

Mitch Ibach, Optometrist at Vance Thompson Vision

Mary Prudden, Director of the National Keratoconus Foundation

Sylvia Moran, parent of Sarah – a member of the Down syndrome community

Doctors estimate that 5-30% of children with Down syndrome have an irregular cornea or keratoconus. This panel will feature Mitch Ibach, an Optometrist at Vance Thompson Vision; Mary Prudden, Director of the National Keratoconus Foundation and Sylvia Moran, parent of Sarah – a member of the Down syndrome community who was diagnosed with keratoconus in high school. Together, they will discuss Sarah's journey living with keratoconus – from diagnosis to treatment and beyond.

2:00 – 3:15 PM ET

HOW TO: Create a Special Needs Plan that Allows Your Child to Live a Purposeful and Impactful Life

Phillip Clark, Founder and President, ENABLE

Planning should enable you to confidently answer the following questions: "What does a happy and fulfilling life look like for my child today—and every day in the future?" and "How do I make sure my child is able to live this GREAT life that I envision?"

In this interactive workshop, we will educate you on the essential areas of Special Needs Planning (Vision, Financial, Legal, Resource, Government Benefits, Life, Transitions) and show you how you can create a Special Needs Plan that enables your loved one to live a purposeful life that aligns with your vision and allows you to successfully navigate the years ahead.

You will leave this session with the tips and tools you need to create a flexible plan that can adjust in a rapidly advancing world. We'll also give you access to our team's "Quick Start Guide" to help you continue making progress. The true benefit of planning is the peace of mind you'll gain from knowing that your family is well prepared for today—and the future!



Friday, April 23, 2021

12:00 – 1:15 PM ET

Eye Health 101: Common Conditions Associated with Down Syndrome - What Every Parent Should Know

Ann Ostrovsky MD, NYU Langone Health

Children born with Down syndrome face a multitude of health issues, among them eye and vision disorders. Ann Ostrovsky MD, of NYU Langone Health will discuss what every parent should know about the most common vision conditions, the symptoms you should look out for, how often to schedule your child's vision screenings and more. Early diagnosis and intervention in many of these diseases are important to improve your child's quality of life.

2:00 – 3:15 PM ET

Remote Support Service – SafeinHome's Person-Centered Solutions

Ann Eubank, LMSW, OTR/L, ATP- Director of Marketing and Business Development, SafeinHome

Learn how consistent, encouraging Remote Support Service provides an environment of safety and learning where people have the opportunity for increased independence. SafeinHome meets people where they are by safely supporting their next step towards what independence means to them. SafeinHome's intelligent system integrates multiple technologies and sensors for superior accuracy and real-time 24-hour response. Learn how SafeinHome's Remote Support Service – from its core processes to supporting people in their homes and communities - is fundamentally person-centered. To see a quick video of how SafeinHome supports Chris' independence click on this link: https://www.youtube.com/watch?v=Wm4xZI_GNgl.