

# 2023 NDSS Adult Summit

# Self-Advocate Schedule

All scheduled times are Eastern Time

Thursday, November 9, 2023 1:30 -2:30 PM ET

<u>Opening Keynote: Fostering Independence and Positive Relationships to Increase Community</u> 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 - 3:45 PM ET

# <u>Self-Advocate Room 1: Live a Healthy Life! Five Ways to Promote Your Health for Individuals with Down Syndrome</u>

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

Laura Krohn, Project Manager, Advocate Medical Group Adult Down Syndrome Center

Living longer and healthier lives is an active process. Adults with Down syndrome can and should be encouraged to participate in their own health promotion. But where should we start? This presentation will share five areas to focus on when making healthy lifestyle choices. The presenters 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. This presentation is intended for individuals with Down syndrome.

Location: Floor 3, Breakout Room F

Self-Advocate Room 2: Authentic and Successful Aging: Let's Get Old Together!

**Ley Linder,** Board Certified Behavioral Analyst, Owner and Operator, Crescent Behavioral Health Services



Authentic and successful aging should be a goal for every person, but how do we personalize our aging experience? How do we sustain existing, as well develop new, leisure skills as we progress through adulthood? This self-advocacy-focused session will be an audience led discussion promoting successful aging in daily life through facilitated conversations focusing on global well-being and quality of life. The open dialogue approach will be promoted through audience member anecdotes and presenter experience, which are then guided through evidenced-based domains which promote successful aging, including physical, social, emotional, cognitive, and material well-being, as well as obtaining personal life goals. Key takeaways for all audience members will be clearly identifiable areas that define successful aging, as well as how to enact plans for personalized and authentic aging.

Location: Floor 3, Breakout Room G

# Friday, November 10, 2023 8:15 AM – 9:15 AM ET

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

**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' J 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 Care Coordinator, 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.

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.

Floor 3, Regency Ballroom A-C

#### 9:30 AM - 10:30 AM ET

#### <u>Self-Advocate Room 1: Real Talk with your Doctor!</u>

Jamie Valis, PhD, Director of Training and Education, Kramer Davis Health

Do you feel like sometimes your doctor does not listen to you? Or that sometimes you do not understand your doctor? Well, now is the time to change that! It is time to make the most out of every medical appointment. Join us to learn about ways that you can be a strong self-advocate for YOUR health. During this presentation, you will hear from health professionals and fellow self-advocates about how you can make an action plan for your next appointment.

Location: Floor 3, Breakout Room F

# Self-Advocate Room 2: What Does it Mean to Participate in Down Syndrome Research?

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

Research in the Down syndrome community comes in many shapes and sizes. In this session we will explore, along with research professionals, the research experience. First, we will discuss how a research study is different from a typical doctors visit. 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. 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 all any and all questions about participating in research and if it may or may not be right for you!

Location: Floor 3, Breakout Room G

10:30 AM - 10:45 AM ET

Self-Advocate Room 1: Guided Activity

**Self-Advocate Room 2:** Guided Activity



# 11:00 AM - 12:00 PM ET

# Self-Advocate Room 1: Authentic and Successful Aging: Let's Get Old Together!

**Ley Linder,** Board Certified Behavioral Analyst, Owner and Operator, Crescent Behavioral Health Services

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Location: Floor 3, Breakout Room F

Self-Advocate Room 2: Staying Happy and Healthy with 321go!

Monica Forquer, Author, 321go! Program

The 321*go!* program was developed by NDSS to help you to stay active, eat a healthy diet, and manage your emotions every day. The program includes daily goals and fun challenges to make health fun. In this session, Monica Forquer, author of the 321*go!* program, will teach you the basics of the 321*go!* program through four main activities. You'll start by learning about physical activity with a short workout using the 321*go!* exercise cards. Next, you'll build a healthy snack in person to learn about food groups. Then, you'll practice some positive thinking techniques to support your emotional wellness. Finally, you'll wrap up the session by learning to track your health on the 321*go!* Tracker.

Location: Floor 3, Breakout Room G

12:00 PM - 12:15 PM ET

**Self-Advocate Room 1:** Guided Activity

Self-Advocate Room 2: Guided Activity

12:15 PM - 1:15 PM ET: LUNCH

Location: Floor 2, Sungarden



## 1:15 PM - 2:15 PM ET

#### Self-Advocate Room 1: #Adulting

**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

Are you tired of people not treating you like an adult even though you are over the age of 18? This interactive workshop will share the benefits and expectations of being an adult to encourage independence.

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Jamie Valis, PhD, Director of Training and Education, Kramer Davis Health

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Location: Floor 3, Breakout Room G

# 2:30 PM - 3:30 PM ET

# <u>Self-Advocate Room 1: I Want to Date! A Session for Self-Advocates on Skills Needed for Successful Romantic Relationships</u>

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

Do you have an interest in dating? Do you have questions on how to meet someone to date or how to maintain a healthy relationship? This presentation will focus on what skills individuals with Down syndrome need in order to enter into and maintain dating relationships as well as activities to develop these skills.

Location: Floor 3, Breakout Room F

**Self-Advocate Room 2:** Guided Emotional Wellness Activity

Location: Floor 3, Breakout Room G



### 3:45 PM - 4:45 PM ET

<u>Self-Advocate Room 1: Guided Activity: Reflection</u>

Location: Floor 3, Breakout Room F

<u>Self-Advocate Room 2: Live a Healthy Life! Five Ways to Promote Your Health for Individuals with</u>

Down Syndrome

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Laura Krohn, Project Manager, Advocate Medical Group Adult Down Syndrome Center

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# 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 - 10:30 AM ET

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# <u>Self-Advocate Room 2: I Want to Date! A Session for Self-Advocates on Skills Needed for Successful</u> Romantic Relationships

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10:30 AM - 10:45 AM ET

**Self-Advocate Room 1:** Guided Activity

Self-Advocate Room 2: Guided Activity



# 11:00 AM - 12:00 PM ET

# <u>Self-Advocate Room 1: Starting your Own Business: Create, Design, and Snack Outside the Box!</u>

Will Sanborn, Adult Employment Coordinator, Down Syndrome Association of Northeast Ohio

Have you ever thought of starting your own business? Do you want to learn how? Join us for this interactive session, where you will practice essential skills for the workplace. By creating and selling an original snack box, you will learn about design, marketing, customer service, and more. The skills you acquire in this session can lead to success in a wide variety of jobs. Get ready to snack outside the box!

Location: Floor 3, Breakout Room F

# Self-Advocate Room 2: #Adulting

**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

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Location: Floor 3, Breakout Room G

12:00 PM - 12:15 PM ET

**Self-Advocate Room 1:** Guided Activity

**Self-Advocate Room 2:** Guided Activity

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.