### Living a Healthy Life! Five Ways to Promote Your Health

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

Katie Frank, PhD, OTR/L is an Occupational therapist at the Adult Down Syndrome Center in Park Ridge, IL. The majority of her work has been with individuals with Down syndrome (DS) of all ages. Dr. Frank has experience with treatment and evaluation, as well as facilitating groups for people with Down syndrome, conducting trainings for families and caregivers and offering a variety of other educational opportunities both locally and nationally. She earned her PhD in Disability Studies from the University of Illinois at Chicago, where her dissertation was “Parents as the Primary Sexuality Educators for their Adolescents with Down Syndrome.” Dr. Frank has been the primary investigator on multiple research studies including individuals with DS and/or their families and has had her work published in peer-reviewed journals.

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

Laura Chicoine is project manager for research and education at the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, IL. She manages the planning, implementation, and evaluation of projects related to research and education. Her responsibilities include overseeing the development and growth of an online database of resources, creating a library of health education videos featuring adults with Down syndrome, contributing to the planning and implementation of research studies, assisting with health and wellness groups for individuals with Down syndrome and planning events such as presentations, workshops and an annual run/walk. As part of her role, she collaborates with a variety of groups in the wider Down syndrome and intellectual disability community.
Mike Walther, II CPA/PFS, CFP®, CFA®, Oak Wealth Advisors

Mike Walther is a nationally recognized special needs financial planner who founded and heads one of the only fiduciary financial planning practices in the country that focuses on serving families with loved ones with special needs. Mike is an author, guest lecturer at multiple universities and has been frequently quoted in national publications about special needs planning topics. He was honored to be the first financial planner in Illinois admitted into the Academy of Special Needs Planners.

Unlike most financial advisors, neither Mike nor his firm, Oak Wealth Advisors, sell financial products or receive any compensation that creates a conflict of interest for them. They provide individualized and objective advice to families with special needs members. Oak Wealth Advisors only receives compensation from its clients. There are no fees paid to the company by any individual or company for recommending any other company or service to its clients.

Having a brother on the Autism spectrum, Mike founded Oak Wealth Advisors over 10 years ago specifically to provide families with special needs members with financial and special needs planning advice that was independent, objective, and otherwise unavailable in the market place.

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

Brian Chicoine, MD is the Medical Director of the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, IL. He is on the faculty of Family Medicine at Advocate Lutheran General Hospital. Dr. Chicoine is co-founder of the Adult Down Syndrome Center which has served and documented the health and psychosocial needs of over 6000 adolescents and adults with Down syndrome since its inception in 1992. Dr. Chicoine graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He co-authored two books Mental Wellness of Adults with Down Syndrome and The Guide to Good Health for Teens and Adults with Down Syndrome published by Woodbine House. Dr. Chicoine has provided medical care for adults with intellectual disabilities for over 30 years and has presented and written extensively on caring for adults with Down syndrome.
### Making Adult Learning Fun!

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<tr>
<th>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</th>
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Tavrick is currently an intern for Wichita State University's International Student Union and as a nature educator for Great Plains Nature Center. ([https://gpnc.org](https://gpnc.org)) both in Wichita, Kansas.

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<th>Anita Raghavan, Parent, PhD, Parent Trainer with Families Together Inc. in Wichita</th>
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Dr. Raghavan has a Ph.D in Communication Studies from the University of Florida and a MA and BA in Communication from the University of South Florida. Anita holds a Teacher's Training Certification. She works as a parent trainer with Families Together Inc. in Wichita which supports families and professionals involved in people with special needs and with the Independent Living Resource Center which has a similar goal.
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**Promoting Health and Wellness in Uncertain Times**

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<th>Sharon Milberger, Director, Michigan Developmental Disabilities Institute (MI-DDI), and MI-LEND, Wayne State University</th>
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Dr. Milberger received her ScD degree from the Harvard School of Public Health and her BSN degree from the University of Michigan. She has a deep commitment to the development of inclusive communities and quality of life for people with intellectual/developmental disabilities (I/DD) and their families. As the director of the Michigan Developmental Disabilities Institute (MI-DDI) – Michigan’s University Center for Excellence in Developmental Disabilities (UCEDD), she is responsible for statewide training, community services, research, and dissemination programs. She is also the director of Michigan’s Leadership Education in Neurodevelopmental Disabilities (LEND), an interdisciplinary, certificate program to prepare future leaders who will serve children with neurodevelopmental and related disabilities and their families. Dr. Milberger has over two decades of research and program experience in I/DD, health promotion and disease prevention.

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<th>Mary Borman</th>
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Mary Borman is a 21-year-old woman with Down syndrome. The first person with Down syndrome to attend the University of Arkansas in Fayetteville, she is also the first person with Down syndrome to model in NWA Fashion Week. She is an ambassador for Down syndrome for the National Down Syndrome Society (NDSS) and in 2018 was named their Self-Advocate of the Year. She has been to Washington, D.C. on a number of occasions to lobby for disability rights and was instrumental in helping pass the national ABLE Act that allowed people with disabilities to save money for education. Mary swims competitively, both nationally and internationally, with Special Olympics and the Down Syndrome International Swimming Organization. She speaks to organizations all over the country concerning health, fitness, and nutrition for individuals with Down syndrome as well as helping others understand what it is like to have Down syndrome.
| 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  
| Specializes in working with families; individuals with Down syndrome infancy to adulthood; language disorders in infants, toddlers, and children; speech and language development; articulation and phonology; speech intelligibility; childhood apraxia of speech  |

| Research Update: Down Syndrome & Alzheimer’s Disease  
| James Hendrix, Chief Scientific Officer, LuMind IDSC Foundation  
| As the Chief Scientific Officer, Dr. Hendrix directs scientific initiatives for LuMind IDSC. A critical element of his role is to establish the nationwide Down Syndrome – Clinical Trial Network (DS-CTN) and to oversee the first clinical trial in the DS-CTN, the Longitudinal Investigation for Enhancing Down Syndrome Research (LIFE-DSR) Study. The LIFE-DSR study is a natural history study focused on adults 25 years of age and older at high risk for Alzheimer’s disease. Dr. Hendrix is also focused on building potential collaborations with industry, academic and government scientists focused on Down syndrome research to maximize LuMind IDSC’s scientific impact.  
| Prior to joining LuMind IDSC, Dr. Hendrix was Director of Global Science Initiatives at the Alzheimer’s Association. In this role Dr. Hendrix managed industry consortia such as the Alzheimer’s Association Research Roundtable (AARR), lead the Global Biomarker Standardization Consortium and assisted with the coordination of the $100 m.  |
## Planning for the Future

**Jerry L. Hulick, CLU, ChFC, ChSNC, CLTC, Principal, Caring Consulting Group**

Jerry has been active in the financial services industry for over 40 years and was one of the first people in the country to receive the Chartered Special Needs Consultant (ChSNC) designation from The American College. He is the Principal of The Washington Group Special Care Planning Team which has specialized in planning for special needs families for over 15 years. In 2014, he started Caring Consulting Group (CCG). CCG offers consulting in education and technical advisory on special needs planning for non-profit organizations, businesses, corporations and educational institutions with the mission of understanding and enhancing the quality of life issues of caregivers and individuals with disabilities. Jerry is also an expert witness on financial and insurance matters for families with special needs situations.

A pioneer and advocate for the special needs community, Jerry has spoken across the country at various conferences, forums and panels dealing with issues and planning for the special needs community (World Congress on Disabilities, Academy of Special Needs Planners Conference, National Down Syndrome Congress, etc.). He has also been a guest on numerous radio talk programs (Hugh Hewitt Show, Sirius XM’s Dr Radio Show, etc.).

## A Life of My Own

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

Jan is a retired business owner and currently serves as Director of The Each and Everyone Foundation, a non-profit created for the purpose of assisting with vocational training and opportunities for adults with intellectual differences. Jan has never shied away from a challenge. Continuing to advocate for employment for those in the IDD community, Jan is creating a unique vocational on-the-job training setting through her non-profit and family trust for those with IDD.

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

Austin is an adult living independently with Down syndrome in Fort Worth, Texas. Austin owns and operates his own business, Austin’s Underdawgs, a food truck hot dawg caterer, serving the Fort Worth-Dallas Metroplex since 2016. As one of the first and oldest people with Down Syndrome to own and operate their own business, Austin shows us all how far one can go if opportunity is available. Not only does Austin manage his business, he also works as a host for an Italian restaurant located near his home.
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| 3:30-4:45 PM    | Mindfulness for Caregivers                                                                | Reita Clanton, Coordinator of Performance and Health Optimization in the School of Kinesiology at Auburn University  
Reita Clanton is the Coordinator of Performance and Health Optimization in the School of Kinesiology at Auburn University. She teaches Performance-Based Stress Reduction to undergraduate students and conducts seminars on Mindful Optimal Health and Well-Being. She was a three sport athlete at Auburn University, 1984 Olympian, member of the Tiger Trail of Auburn and a 2010 inductee to the Alabama Sports Hall of Fame. |
| Thursday, May 7, 2020 | Medical Homecare, Family-Centered Care, Shared Decision-Making, and Supported Decision-Making | Robin Blitz, M.D., Medical Director, United Healthcare Special Needs Initiative  
Robin Blitz, M.D. is a board-certified developmental pediatrician. Her clinical interests include medical home care, shared and supported decision-making, transition to adult care, Down syndrome, foster and adopted children, prenatal alcohol and drug exposure, ACEs, ASD, Fragile X Syndrome, ADHD, learning disabilities, premature infants and children with multiple developmental disabilities. For 30 years, Dr. Blitz has provided care for children with special health care needs, educated providers, students and families, and directed patient-centered programs such as the Down syndrome clinic at Phoenix Children’s Hospital, prior to joining UHC. She is a fellow of the American Academy of Pediatrics and Society for Developmental and Behavioral Pediatrics. Dr. Blitz has served on multiple committees, including the Down Syndrome Medical Interest Group, AAP’s Council on Children with Disabilities, Make-A-Wish, Governor’s Autism Committee, First Things First, and AZ Telemedicine Council. |
| 12:00-1:15 PM   | Understanding ABLE Accounts                                                               | Gabriella (Gabby) Barnes, Marketing Associate for ABLEnow  
Gabriella (Gabby) Barnes serves as Marketing Associate for ABLEnow, the national tax-advantaged disability savings program administered by Virginia529. With accounts in all 50 states, ABLEnow is one of the fastest-growing ABLE programs in the country. Gabby is honored to help build this entirely new financial product that can empower millions of Americans with disabilities to save for their future – just like everyone else. Gabby holds a Bachelor’s Degree from Hampton University and lives in in Richmond, Va. |
### 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**

We share our stories of audacious creativity and abiding optimism with the masses, opening one heart at a time. Through music, live presentations, videos and visual arts, we seek to collaborate with diverse people who are passionate about what they do. We playfully engage with the world of celebrity and pop culture. And we are seriously into social justice and conserving natural habitats. With this project, we hope to achieve three primary goals:

1. to win for Fionn an excellent life, while documenting and sharing the journey
2. to inspire and support other people in achieving their own dreams
3. to shift the societal paradigm, so that unique and alternately-gifted people are celebrated

Through example, we show that the best way to support one another is in loving interest: that’s how each one of us shines.

### 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, IL**

Katie Frank, PhD, OTR/L is an Occupational therapist at the Adult Down Syndrome Center in Park Ridge, IL. The majority of her work has been with individuals with Down syndrome (DS) of all ages. Dr. Frank has experience with treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for families and caregivers, and offering a variety of other educational opportunities both locally and nationally. She earned her PhD in Disability Studies from the University of Illinois at Chicago, where her dissertation was “Parents as the Primary Sexuality Educators for their Adolescents with Down Syndrome.” Dr. Frank has been the primary investigator on multiple research studies including individuals with DS and/or their families and has had her work published in peer-reviewed journals.
Fathers and Sons: Raising a Successful Self-Advocate

**Self-Advocate Friendly**

**Bill DeSanctis, Father**

I have lived in Louisville Kentucky all my life and I am a husband and father of five children, David being the youngest. I was an educator for 40 years and taught Elementary School for 13, Middle School for 8 and was a Technology Resource Teacher for the rest. I was member of the Board for Down Syndrome of Louisville for 6 years and a member of The Foundation for Down Syndrome of Louisville for 5 years. I am presently on the Board of the Zoom Group in Louisville Kentucky. I have been involved with coaching Special Olympics for 10 years. Now my main job is trying to stay up with David and all his activities, jobs and hobbies. I love to travel, play tennis, golf and have time with my family.

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

David is the Public Relations Outreach Associate for The National Down Syndrome Society (NDSS). In his role, he serves as a face for NDSS at various functions and events. David is an inspirational speaker and an actor, and he is thrilled to be able to use his talents to raise awareness for NDSS and Down syndrome!

**Brandon Gruber, Self-Advocate**

Brandon loves modeling, art, traveling and networking. He is a recipient of The Diana Award, in memory of Diana, Princess of Wales for 2019, Founder of 321life+1 Project and proud to represent the National Down Syndrome Society (NDSS) as a member of the NDSS Board of Directors.

**Tim Gruber, Father**

Tim Gruber is a published author, speaker, workshop leade, and currently works as Vice President of Human Resources with Granite Construction Company. He is father to Brandon Gruber, NDSS Board Member, and has been married to his wife Teresa for 37+ years.