

Speaker Headshots & Biographies

Alphabetical Order by Last Name

Name	Session	Headshot	Bio
Alan Abes	State Advocacy Explained: Creating Change at the State Level		Alan H. Abes is Vice President of the Board for Hamilton County Developmental Disabilities Services. He served previously on the Board of the Down Syndrome Association of Greater Cincinnati and its Governmental Affairs Committee. Alan and his wife have two sons, one of whom has Down syndrome and autism. Alan is a Partner with the law firm Dinsmore & Shohl, where he co-chairs the commercial litigation practice. He graduated from The Ohio State University and Northwestern University School of Law. His many volunteer efforts reflect his commitment to leadership, equity, and inclusion for all populations.
Jen Powers Alge, Esq.	State Advocacy Explained: Creating Change at the State Level		Jen Powers Alge, Esq., is the Regional Director of the Arc of Ohio, where she has made significant contributions to local and state policy. Notably, she played a pivotal role in advancing the OH organ transplant discrimination elimination bill, reflecting her dedication to equitable healthcare access. Currently, she is actively involved in legislative efforts to eliminate subminimum wage practices for individuals with disabilities in the state of Ohio. With her legal expertise and unwavering dedication, Ms. Alge continues to make a substantial impact on the lives of individuals with Down syndrome.



Britni Allen	Embrace Imperfection: Start Your Business Now	Britni Allen is an Apparel and Jewelry Designer. She is an entrepreneur and creator of Rosemerry Sparkle Designs. The name Rosemerry Sparkle means love, joy, and excitement. Britni makes all products by hand and chooses all colors and styles for her products. Rosemerry Sparkle was created in 2021 and launched in September 2022. One of every three offerings is donated to charity. Britni worked with the summer youth program from 2007-2011 in a daycare, restaurant, office, and a bookstore. She began taking various types of art classes as a hobby leading Britni to launch her own business. Britni continues to develop herself personally as well as professionally. She is a volunteer board member at eu2s.org. Britni has traveled to South Africa, Jerusalem, Greece, Italy, Florida, and Texas. Her favorite part of traveling is the hotel stay. Britni will launch her first book by January 2024.
Dr. Keri Allen	Embrace Imperfection: Start Your Business Now	Dr. Keri Allen, PhD is a Business, Engineering and Technology Professor. She is the President of EmpoweringU2SucSeed, Inc., a 501c3 not for profit organization that was formed in 2012. Dr. Allen began teaching business and technology in 2008 and is currently a former NYC certified teacher. She earned a master's degree from Teachers College, Columbia University and went on to pursue a Doctorate in Business Administration at Walden University. Dr. Allen understands the importance of professional development and remaining a "life-long learner". Therefore, she engages in weekly professional development virtual workshops. Additionally, Dr. Allen is Certified as a Minority Women-Owned Business Enterprise (M/WBE). M/WBE brings forth a value-added component to government contracts on behalf of minority groups. One of Dr. Allen's upcoming projects includes a new book as co-author with Britni Allen. Dr. Allen resides in the NYC metropolitan area.
Arik Ancelin	Keynote: Breaking Barriers through Beats: A Journey of Resilience, Music, and Love	Arik Ancelin is a singer/songwriter, activist and motivational speaker born and raised in Jacksonville, FL. In just a few years this young man with Down syndrome has made a huge impact taken the music industry by storm. Beginning in 2020, Arik channeled the difficulties of pandemic lockdown into the composition of positive, sincere lyrics and fresh musical beats. He has since released multiple singles, EPs and albums, amassing over 17 million streams across music platforms, and connecting with over 1.5 million followers on Tik Tok. He is thrilled to have had the opportunity to work with Grammy award winning producer, DJ Nitti Gritti, and perform live on stage with Andy Grammer.



Jennifer Ancelin	Keynote: Breaking Barriers through Beats: A Journey of Resilience, Music, and Love
Beau M. Ances MD, PhD, MSc	Down Syndrome and Alzheimer's Disease: Pathology, Diagnosis, and Early Intervention

Jennifer Ancelin is the mother of three wonderfully imperfect children, the youngest, Arik Ancelin, happens to have Down syndrome. Jennifer believes that all children will reach their potential through an outstanding and personal educational journey. As such, in support of Arik's development, she earned a master's degree in special education from the University of North Florida by the time Arik was 4 years old. Through the years, she has helped hundreds of families find optimal academic environments for their children with Down syndrome. Jennifer currently manages Arik's music and speaking engagements, is part of the Florida Developmental Disabilities Council's Transportation and Housing Cadre and is the Founder and EIC of Firty Fashion.



Dr. Beau Ances is the Daniel J Brennan MD Professor of Neurology and Vice Chair of Academic Affairs for the Department of Neurology at Washington University in Saint Louis. He is an author on over 250 peer reviewed publications and his work has been cited by numerous media outlets (including the Washington Post, Associated Press, Science, Time, etc.) and PBS documentaries (including Alzheimer's Disease: Every Minute Counts). Clinically, Dr. Ances sees both inpatients and outpatients with a variety of neurodegenerative diseases (especially Down syndrome) and has helped lead a COVID-19 vaccination clinic through the Greater Saint Louis Down Syndrome Association. He's funded by the National Institutes of Health (NIH) through multiple grants and is both site and project leader for the Alzheimer Biomarker Consortium for Down Syndrome to evaluate Alzheimer biomarkers in adults with Down syndrome. Additionally, he is the contact PI for the Aging Adult Brain Connectome (AABC).

Representative
Rachel Baker

Rachel Baker

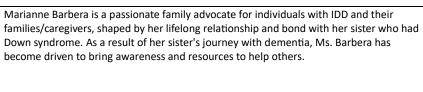
Creating Change
at the State Level



Rep Rachel Baker (Ohio) is a mom of three children, a pediatric nurse, a social worker, a court-appointed child advocate, a nurse researcher, and a State Representative. She has spent her career serving others and over the years developed a love of her community that led her to serve in the Ohio Statehouse.



Marianne Barbera	If We Only Knew Then: Practical Insights on How to Support Aging Adults with Dow Syndrome







Ashley Barlow graduated from Miami University with a BS in German Education and received her JD from Chase College of Law. She was a German teacher and taught Law at Miami University. Her areas of practice now include special education and estate planning. Ashley serves on the State Advisory Board for Exceptional Children in Kentucky, the NDAC through NDSC, and the Education Advisory Board and the Government Affairs Committee at the DSAGC (past President). She participated in the Wrightslaw Institute of Special Education, serving as faculty twice. She also holds an Advanced Advocacy Certificate from COPAA. Ashley is also involved with many other federal and state advocacy groups. Ashley practices in Kentucky and operates a business to empower parents/advocates in special education, which can be found at www.ashleybarlowco.com. When not working, she is normally at the pool with her husband and two sons, one of whom has Down syndrome.



Allan
Bergman, CEO

Transition Law: Transition from School to Adult Life

Independence Panel



Allan I. Bergman is an accomplished nonprofit community agency and association executive and nationally recognized leader in influencing the development of federal and state policy relating to "best practice" services and supports for persons with disabilities. Bergman's career includes significant leadership positions within local, state and national non-profit agencies and associations. Most recently, he served as President and CEO of one of Chicago's largest community agencies, Anixter Center, supporting more than 5,000 individuals living with disabilities through 400 employees, 72 programs, and multiple sites. His earlier positions in Washington, D.C. included President and CEO of the Brain Injury Association of America, and significant leadership roles with United Cerebral Palsy Associations as Director of the Institute on Disability and Managed Care, Director of State-Federal Relations, and Director of Government Relations. After completing his undergraduate degree in Psychology at Cornell University, Allan's early career included responsibilities at the Texas State Commission for the Blind, as Executive Director for the Austin (TX) Cerebral Palsy Center, and Executive Director of three Arcs in Dallas, San Francisco, and Colorado.

Jane Boyle

If We Only Knew Then: Practical Insights on How to Support Aging Adults with Down Syndrome



Jane Boyle was primary caregiver, advocate, sidekick, and legal guardian for her sister who was born with Down syndrome in 1965 and died of Alzheimer's disease. She is an NTG-certified Dementia-Capable Caregiver Trainer, co-founded and facilitates a NJ Down Syndrome & Alzheimer's Family Support Group, and testified at the National Alzheimer's Project Act (NAPA) Council meeting.



Ruth Brown, PhD	Activating Happiness: A Parent's Guide to Behavioral Activation for Their Adult Child with Down Syndrome	Ruth Brown, PhD, is a Clinical Psychologist, an Assistant Professor at the Virginia Institute for Psychiatric and Behavioral Genetics at Virginia Commonwealth University. She is a member of the Down Syndrome Medical Interest Group Adult Regression and Mental Health Workgroup. She has partnered with families and individuals with Down syndrome since 2013. Her research is dedicated to improving the mental health care of people with Down syndrome and other intellectual and developmental disabilities. It is her hope that her research will lead to improved detection, prevention, and treatment of stress, anxiety, and depression in people with Down syndrome and intellectual and developmental disabilities.
Erin Burkey, BSN, RN	Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center	Erin Burkey, BSN, RN is the RN Care Coordinator for the Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities at UC Health. Erin worked as a bedside RN at University of Cincinnati Medical Center for 7 years before transitioning to care coordination. She now uses her nursing background to support individuals with intellectual and developmental disabilities in the outpatient setting. Erin assists patients and their families with managing complex medical conditions and navigating the healthcare system. She helps to foster coordination of care across multiple environments and systems. She is mindful that each patient has specific and individualized needs, and the focus is promoting high-quality care along with supporting and advocating for the individual.
Kenyatta Chandler	Financially Empowering People with Disabilities Through ABLE Accounts	Kenyatta Chandler serves as Director of the STABLE Account program, within the Office of Ohio Treasurer Robert Sprague. He is in his second stint with the office, having worked in the administrations of five Ohio treasurers. Prior to overseeing STABLE Account, he most recently served as the office's Director of Treasury Innovation. Before rejoining the Treasurer's office, Kenyatta held various positions overseeing financial strategy and business engagement with the Central Ohio Transit Authority, Ohio Department of Development, and Ohio Office of Budget and Management. His public sector service is well-complemented by private sector expertise, having worked for several private companies during his 30+ year career. Kenyatta is a two-time graduate of Franklin University (Ohio), where he earned a Bachelor of Science degree in Business Management and Organizational Leadership prior to receiving his MBA in Management Information Systems.



Dr. Brian Chicoine, MD	The Balancing Act: Health, Safety, and Independence Approaches to Mental Health Promotion and Treatment Addressing Bias in Health Care		Brian Chicoine, MD, is the medical director of the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, Illinois. He is on the faculty of the Family Medicine residency at Advocate Lutheran General Hospital. He received his medical degree from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. In 1992, Dr. Chicoine co-founded 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. 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.
Dr. Jensine' Clark, MD	Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center	Managed, 20 Showing of Concentry of Concentr	Jensine' Clark, MD, subspecializes in pediatric rehabilitation medicine and spasticity management. She enjoys helping patients and families tackle transition issues that include regaining independence and social integration within their communities. Specializing in spasticity management also allows her to help patients maintain and increase function in their daily lives. Her training in both physical medicine and rehabilitation and pediatric rehabilitation allows her the opportunity to see patients across their lifespan.
Phillip Clark	Not Your Father's Special Needs Planning Process: How to Plan for Peace & Security		Phillip Clark, the founder of ENABLE Special Needs Planning, helps families across the country plan for abundant futures. His younger sister, Sarah, has Down syndrome and is the catalyst for his unique approach to planning. He believes that planning should enable our loved ones to live happy, fulfilling, and purposeful lives today and in the future. Early in his career, he realized the industry's approach to special needs planning only prepared parents for when they could no longer care for their children. While having a plan for life's "What Ifs" is vital, as a proud big brother, he knew families needed better conversations about future planning centered around creating opportunities for success today. Phil is a Chartered Special Needs Consultant (ChSNC®). He enjoys volunteering with the special needs ministry at his church, Down Syndrome Indiana, Gigi's Playhouse Indianapolis, and recently served as a founding board member for Same As U.



<u>Dr.</u> Dennis Cleary, PhD	Ensuring Community Engagement Across the Lifespan Through Employment	Dr. Dennis Cleary is a Senior Researcher at Cincinnati Children's Hospital. He has over 25 years of experience as an occupational therapist. Dennis's clinical practice has been primarily with children and adults with intellectual disabilities to encourage their full participation in all aspects of life at home, and work, and in the community. He has had faculty positions at The Ohio State University and Indiana University. He has numerous publications and national and international presentations.
Dr. Ann Cohen	The Research Experience in Adults with Down Syndrome: Facts and Fiction What Does It Mean to Participate in Down Syndrome Research?	Dr. Ann Cohen is an Associate Professor of Psychiatry at the University of Pittsburgh School of Medicine. She is also the Director of the Neuroimaging Core of the University of Pittsburgh Alzheimer's Disease Research Center and the co-Director of the Molecular Biomarkers in Psychiatry Program. Dr. Cohen is also the lead of the recruitment team on the Alzheimer's disease Biomarker Consortium-Down Syndrome (ABC-DS) and is the PI of multiple NIA funded studies. She earned her PhD in Neuroscience from the University of Pittsburgh and completed a postdoctoral fellowship at Western Psychiatric Institute and Clinic at UPMC in 2011. Her primary research interests focus on PET imaging to explore early detection of amyloid in Alzheimer's disease using the amyloid imaging agent Pittsburgh-compound B and the relationship of lifestyle factors to Alzheimer's disease pathology.
Carol Cronin	Critical Crossroads: Down syndrome and Alzheimer's Disease Research	B2B Sales/Donations/Mama Bear at John's Crazy Socks. John's Crazy Socks was started by Carol Cronin's son, John, a young man with Down syndrome who loves colorful crazy socks. They are on a mission to Spread Happiness. She hopes to share John's passion for socks with the world! More than half of the employees at John's Crazy Socks have differing abilities and they strive to show what's possible when a person with a differing ability is given a chance. They partner with the Special Olympics, the National Down syndrome Society, and the Autism Society of America.



John and Mark Cronin	Embrace Imperfection: Start Your Business Now	John and Mark X. Cronin are the father-son team that created John's Crazy Socks, a social enterprise with a mission to spread happiness. They are fierce advocates for people with differing abilities focusing on employment and entrepreneurship. They bootstrapped their business into the world's largest sock store. John is not only an entrepreneur, but he has Down syndrome. Every day, John and Mark show what people with differing abilities can do — more than half their colleagues have a differing ability. And they show their gratitude through their Giving Back program that has raised over \$650,000 for their charity partners. Most of all, they are spreading happiness one pair of socks at a time.
Andrea DeRossett, LISW-S	Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center	Andrea DeRossett, LISW-S (Licensed Independent Social Worker with Supervision privileges) is the Behavioral Health Care Manager/Therapist at UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities (Freeman Center). At the Freeman Center, Andrea assists with care management roles for patients with psychiatric needs and provides behavioral health therapy for patients. Andrea has a passion for helping patients and families understand their mental health and how to cope with the many struggles' life brings.
Dr. Lindsay DuBois, PhD	Ensuring Community Engagement Across the Lifespan Through Employment	Dr. Lindsay DuBois is a research associate at the Human Services Research Institute (HSRI). Her work is driven by a passion for collaborative, inclusive research to promote equity and support people to thrive in their communities. She is particularly dedicated to working with disability service systems staff to identify opportunities for improving the quality of services. She is highly skilled in communicating research findings in accessible and meaningful ways to different audiences. Prior to joining HSRI, Lindsay was a project manager at the Shirley Ryan AbilityLab, where her work addressed improving personcentered supports for people who use home and community-based services. Prior to that, Lindsay worked as Director of Research and Evaluation on health programming at Special Olympics. When not at work, Lindsay enjoys crochet, baking, and getting active outdoors with her husband and three children.



education with a minor in psychology from Texas A&M University and a graduate certificate in nonprofit management from the Bush School of Government and Public Service.

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David Egan	State Advocacy Explained: Creating Change at the State Level	MY LIFE WITH DOWN SYNLHOME More Alike Than hifterent DAVID EGAN at 16 filled 15 miles	David Egan is a well-known champion of the rights of people with intellectual disabilities. Born with Down syndrome, he has served as a Special Olympics Sargent Shriver International Global Messenger. He was the first person with an intellectual disability to serve as a Joseph P. Kennedy Jr. Public Policy Fellow. In that role, he worked for the Ways and Means Social Security Subcommittee on Capitol Hill and with the National Down Syndrome Society. He also represents self-advocates on various nonprofit advocacy boards and with the National Institutes of Health Down Syndrome Consortium and has delivered his message to audiences around the world.
Lisa Eicher	Keynote: Fostering Independence and Positive Relationships to Increase Community Integration		Lisa Eicher is a single mother of four from Houston. Her oldest two, Archie and Sevy, both have Down syndrome and were adopted from Bulgaria at ages 7 and 13. She also has two biological kids, Radko 9 and Ace 15. She is the Executive Director and Founder of Sandal Gap Studio - an art studio for adults with intellectual disabilities.
Anna Fedewa	Turning Your Passion into Policy Change		Anna Fedewa is the Manager of Federal Government Relations for the National Down Syndrome Society (NDSS) where she works with members of Congress and their staff, federal agencies, and grassroots advocates to improve policies and pass legislation that is beneficial to the Down syndrome community. Anna's passion for advocacy and disability rights grew from the friendships she made with individuals with Down syndrome and other disabilities as a young child and was further cultivated during her time teaching high school special education and working with her alma mater's inclusive post-secondary program. Originally from Houston, TX, Anna holds a bachelor's degree in early childhood-12 special



Monica Forquer	Supporting Daily Health Habits through the 321go! Program Staying Happy and Healthy with 321go!	
Forrest Foster, MD	Critical Crossroads: Down syndrome and Alzheimer's	

Monica Forquer is a consultant for the National Down Syndrome Society (NDSS) and author of the 321go! wellness program launched in 2022. Monica has over 17 years' experience supporting wellness at the individual, community, national, and international levels. Monica has a strong passion for supporting people with intellectual disabilities to adopt a healthy lifestyle. Prior to her work with NDSS, Monica was the Senior Manager of Fitness for Special Olympics where she oversaw the development and dissemination of exercise and nutrition programming and resources for athletes of all ages. Monica has a master's degree in Exercise Science from George Washington University and is currently a doctoral candidate in the George Washington University School of Public Health.



Forrest Foster, MD focuses on Behavioral Neurology and Neuropsychiatry at the University of Cincinnati College of Medicine/UC Physicians. Dr. Foster subspecializes in all aspects of cognition and treating diseases such as Alzheimer's disease, Lewy body dementia and frontotemporal dementia. He also has a focus on cognition in Down syndrome and intellectual disabilities. Dr. Foster recognizes that working with patients who have deficits in their memory, thinking or behavior is complex and requires attention to all aspects of a person's life and health. Not only does he work closely with his patients, but their family members and caregivers as well, providing them with the necessary tools to help the patient focus on what is important to them.



Katie Frank, PhD, OTR/L Live a Healthy Life! Five Ways to Promote Your Health for Individuals with Down Syndrome

I Want to Date! A Session for Self-Advocates on Skills Needed for Successful Romantic Relationships

#Adulting

Mastering Social Skills for Success in the Workplace

Supporting Your Loved One with Down Syndrome to Learn Skills Necessary for Developing Healthy Relationships

The Balancing Act: Health, Safety, and Independence



Dr. Frank has worked as an occupational therapist at the Adult Down Syndrome Center since 2016 and in the field of occupational therapy since 2001. She also serves as the president of the Down Syndrome Medical Interest Group-USA. Dr. Frank earned her degree in occupational therapy from Saint Louis University and her PhD in Disability Studies from the University of Illinois at Chicago. Most of her work has been with individuals with Down syndrome of all ages. Dr. Frank's experience includes treatment and evaluation as well as facilitating groups for people with Down syndrome, conducting trainings for staff, families, and caregivers, and offering a variety of other educational opportunities across the United States. Her research has been published in peer-reviewed journals.



Steve Friedman	Independence Panel	Steve Friedman is a proud parent, award-winning author, and advocate for the Dow syndrome community. He lives with his wife and their three cats in Austin, Texas. The daughter Gwendolyn (29), who has been on her own wonderful independence journey for years, now lives nearby at the Marbridge residential living community. Friedman has captured their lessons of discovery and added inspiring stories from a variety of other families who love someone with Down syndrome, as well as the expertise of medical financial, and housing professionals, to present 'The Essential Guide for Families with Down Syndrome: Plans and Actions for Independence at Every Stage of Life.'
Courtney Gaines	Turning Your Passion Into Policy Change	Courtney Gaines is a 19-year-old from Midwest City, Oklahoma. Courtney has Dow syndrome and currently participates 100% in the general education setting. She is involve in her school and community including the Choctaw High School AFJROTC, student council varsity soccer team, and has appeared in many school plays and performing arts. Courtnet is also an Ambassador for African American Girls and Women with Disabilities via GirlTresince 2018 and the first African American with Down syndrome to walk the runaway in the history of the Miss Teen USA, Miss USA, Miss Universe franchise. She is the reigning Mis Amazing Oklahoma Jr. Miss. Courtney is also an active advocate for the Down syndrom community. In 2022, Courtney and her mom, DeAnna, led efforts to pass Courtney's Lav

19-year-old from Midwest City, Oklahoma. Courtney has Down y participates 100% in the general education setting. She is involved nunity including the Choctaw High School AFJROTC, student council, d has appeared in many school plays and performing arts. Courtney for African American Girls and Women with Disabilities via GirlTrek : African American with Down syndrome to walk the runaway in the en USA, Miss USA, Miss Universe franchise. She is the reigning Miss Miss. Courtney is also an active advocate for the Down syndrome ourtney and her mom, DeAnna, led efforts to pass Courtney's Law, a Down syndrome informational law, in Oklahoma. Courtney is an NDSS DS-Ambassador, the 2023 DS-Ambassador of the year and involved with the Down Syndrome Association of Central Oklahoma, the Global Down Syndrome Foundation, and a member of the National Down Syndrome Congress National Down Syndrome Advocacy Coalition (NDAC). Courtney plans to attend college and is committed to walking the path that allows her to help individuals who face challenges and adversity.



Dr. Carly B. Gilson, PHD	Using Everyday Technology to Increase Employment and Social Skills for Individuals with IDD	Dr. Carly B. Gilson is an Associate Professor of Special Education at The Ohio State University. Her research interests center on equipping adolescents and young adults with IDD for integrated employment and inclusive higher education, supporting individuals and families through the school-to-work transition, and equipping strong educational team collaborations among secondary special education teachers and paraprofessionals.
Benjamin Golden	Mental Health in Adults with Down Syndrome	Benjamin Golden is 29 years old and was born in Waterville, Maine. His favorite hobbies are building and traveling. He enjoys traveling with his family and riding the bus around the town. He has been building Lego architectures since 2017. His interests are art and music. Benjamin likes to sketch, color, and listen to music including dance, classical, classic rock, rap, rock, and pop. He met Dr. Eric Rubenstein at a T21RS conference before joining his research team in 2022.
Christy Gregg	Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center Supporting Siblings	Christy Gregg, CTRS (Certified Therapeutic Recreational Specialist) is the Program Manager at UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities (Freeman Center). Christy has over 22 years of experience of working in non-profit, services and support for individuals with intellectual and developmental disabilities and their families. She has an adult brother with Down syndrome and brings both a professional and personal lens to her work. In 2022 she graduated from the University of Cincinnati's LEND (Leadership Education in Neurodevelopmental and related Disabilities) program as the first adult services representation and was the Adult Matters Coordinator at the Down Syndrome Association of Greater Cincinnati for over 9 years prior to starting this position. She is a trainer for NTG (National Task Group on Intellectual and Developmental Disabilities). She is passionate about breaking down the silos and barriers that have been experienced by patients and families in the past, especially as it relates to healthcare and well-being.



Stacey Gruber

Supporting Siblings



Stacey Gruber grew up in rural Midwest Ohio as the third of four siblings. Her oldest sibling has cerebral palsy. She was struck by the lack of support for siblings of people with disabilities throughout the lifespan. She has been working alongside others in the sibling support space through organizations like OhioSIBS, Siblings with a Mission, the Siblings Leadership Project, the Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program, and others. Since 2016, Stacey has been formally involved in advocating for siblings to professionals, government agencies, and families through organizing presentations, symposiums, and panels at Cincinnati Children's Hospital Medical Center, the University of Cincinnati, and local, state, and national meetings and conferences. Stacey has a doctoral degree in biomedical engineering and works professionally in the pharmaceutical industry.

Hampus Hillerstrom Critical Crossroads: Down syndrome and Alzheimer's Disease Research



Hampus Hillerstrom became president and CEO of LuMind IDSC Foundation in 2017 after serving on the board of directors for three years. Previously, he co-founded Proclara Biosciences in 2007, a company developing a novel approach for treating Alzheimer's, Parkinson's, and other protein misfolding diseases. Early in his career, he spearheaded a project on clinical trials conduct at AstraZeneca. Hampus holds degrees from University of St. Gallen (Switzerland), an MBA from Harvard Business School, and an MSc in Health Sciences and Technology from MIT/Harvard Medical School. Hampus lives in the Boston area with his wife and children. Their oldest son, Oskar, has Down syndrome.



Lucinda Hurst

Turning Your Passion into Policy Change



Lucinda Hurst has been advocating for the disability community since her son, Andy, was born with Down syndrome 21 years ago. She served on the board of the Down Syndrome Association of Greater Cincinnati for over nine years, three of those as Board Chair. Lucinda also completed the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program at Cincinnati Children's Hospital in 2011. She currently serves as the Secretary of the Board of Directors of the Ken Anderson Alliance (KAA). In response to the national Direct Support Professional (DSP) shortage, Lucinda completed her DSP certification in late 2022 to better serve those who are employed at one of KAA's micro enterprises, o2 Urban Farms. The Farm employs people with disabilities and also offers job development opportunities for those looking for integrated employment, all while growing an assortment of high-quality lettuces, herbs, and micro greens indoors.

Maura Iorio

Create Your Own Path: Transition Planning through Learning, Indepen dent Living, Working, and Self-Advocacy

Supporting Daily Health Habits through the 321go! Program



Maura lorio is the Senior Director of Education at Pathfinder Village. She oversees programming at Pathfinder School as well as Otsego Academy. With over 10 years of experience in the fields of special education and human services, she brings with her a wealth of knowledge about transition planning and assisting individuals with developmental disabilities as they exit high school and journey into adult life.



Stacy Jackson	Independence Panel		Stacy Jackson is a Regional Director for GiGi's Playhouse National Office. A graduate of Kent State University and the University of Akron, Stacy resides with her family in Canton, Ohio and serves on the board at the GiGi's location there. Stacy and her husband, Rick, have seven children, including a daughter with Down syndrome, Maleah, who was born in July 2016.
Kayla Jones	Create Your Own Path: Transition Planning through Learning, Indepen dent Living, Working, and Self- Advocacy	Low multe	Kayla is in her second year at Otsego Academy. She has a passion for working with animals and volunteers frequently at our local animal shelter. Kayla loves pop music and knows all the words to every New Kids on the Block song. She is also a huge fan of hockey and attends Utica Comets games with her family.
Emily Kendall	Independence Panel		Emily Kendall is an omni-mom: stepmom, mom of three, and dog mom. Her four-year-old son Luke has Down syndrome. Emily spent her 20+ year career in marketing and sales primarily commercial real estate with a focus on equity capital fundraising. Inspired by Luke, Emily and her husband Mark are leveraging their professional expertise and personal passion to change the landscape of housing options for adults with IDD. Emily is also a writer and recently published "Let it Flow", a journal designed to help moms navigate their breastfeeding journeys. Learn more about Emily at www.empowermeliving.com and www.emilyLkendall.com.



Leigh Ann	Developing
Kingsbury	Advance
	Directives:
	Another Tool for
	Self-
	Determination,
	Autonomy,
	Empowerment,
	and Self-Advoca



Leigh Ann Kingsbury is the owner and Principal Consultant of InLeadS Consulting, a small disability- and aging-services focused consultancy. For more than 30 years she has worked to use best practices in supporting people who live with disabilities, including people with physical disabilities, people who live with intellectual and developmental disabilities, older adults, and people living with Alzheimer's disease and other dementias. One of her passions is helping people with disabilities remain in charge of their lives and be self-determined by naming their healthcare power of attorney and developing advance directives. Advance care planning is not just about end of life. It is about empowerment, self-determination, autonomy, relationships, and trust. Leigh Ann, along with colleague Mary Beth Lepkowsky, developed and co-leads the facilitator course "Person Centered Approaches to Healthcare Decision Making" and is the author of "People Planning Ahead: A Guide to Communicating Healthcare and End of Life Wishes."

Laura Krohn

Live a Healthy

Life! Five Ways to

Promote Your

Health for

Individuals with

Down Syndrome



Laura Krohn 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.



Eliza	beth
"Boo"	Krucky

Supporting Daily Health Habits through the 321go! Program



Elizabeth "Boo" Krucky, Program Coordinator of Teen and Adult Services, joined the DSACO team in March 2022. Boo graduated from Quincy University in 1989 with a bachelor's degree in computer science. She moved from Missouri to Columbus to be a computer programmer. After two and a half years, she decided to change careers so she would feel "more alive" in her job by working with adults with developmental disabilities. Prior to her start with DSACO, for over 30 years she held a handful of different roles at Goodwill Columbus in their Adult Day Services. As DSACO's Program Coordinator of Teen and Adult Services, Boo's main responsibilities are the coordination of Virtual Cooking Classes, Stamping Club, the Adult Conference, and other teen and adult initiatives throughout the year.

Ashlea Lantz

Embrace Imperfection: Start Your Business Now



Ashlea Lantz is the Senior Policy Advisor on Disability Employment at The Harkin Institute (THI) for Public Policy and Citizen Engagement at Drake University. At THI Ashlea supports efforts in advancing disability employment specializing in business consulting. Ashlea's insightful thinking and background in rehabilitation counseling, supported employment, and accessibility help her support businesses in accessing a hidden talent pool. Ashlea delivers high-level, boutique consultation to corporations on increasing disability hiring initiatives. Ashlea has worked as a Senior Consultant with Griffin-Hammis Associates and as a Subject Matter Expert on various federal grant projects. Ashlea started her career at Candeo, a community-based organization where she was the Director of Employment services. Ashlea is a certified benefits planner through Virginia Commonwealth University and completed her master's degree in Rehabilitation Counseling at Drake University.



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Marin Melone	Create Your Own
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Path: Transition
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Living, Working,
and SelfAdvocacy



Marin is in her third year at Otsego Academy. Originally from Georgia, she has loved getting to experience New York winters while at school! Marin is currently employed at a local bakery which she very much enjoys but hopes one day to have a career that focuses on helping others. Marin loves country music, Dancing with the Stars, and staying active by jogging!

Kristin Mendez, MS, CSCS

Better Together: Promoting Physical Activity and Exercise within the Down Syndrome Community



Kristin Mendez, MS, CSCS is an exercise physiologist in Athens, GA. She holds a B.S. and M.S. in Exercise Physiology and is a doctoral candidate in Kinesiology at the University of Georgia. Kristin is currently studying physical activity and skeletal muscle function in individuals with Down syndrome. She is a Certified Strength and Conditioning Specialist through the National Strength and Conditioning Association and has been a head powerlifting coach with Special Olympics Florida and Georgia for the past 6 years. Kristin has also worked professionally as a neuro-exercise physiologist, prescribing and implementing exercise programs for individuals with spinal cord injuries and neurological disorders, as well as older adults. Her research and professional interests focus on improving muscle physiology and quality of life through physical activity and exercise, specifically in historically marginalized populations. She is also interested in the effects of physical activity and exercise on one's epigenome. Kristin hopes to bridge the gap between scientific discovery and practical application to better health outcomes in our underserved communities.



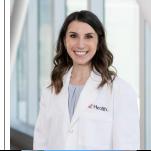
Luis Morissette	Using Everyday Technology to Increase Employment an Social Skills for Individuals with IDD
Kelsie Newton, MS. RD. LD	Keynote: <i>The</i> Value of an



Luis Morissette is a doctoral student majoring in Special Education with a research focus in transition to employment for individuals with IDD. He is in his third year at Texas A&M University, where he has also served as a job coach for Aggie ACHIEVE, which is an inclusive postsecondary education program at Texas A&M University.

Kelsie Newton,
MS, RD, LD

Walue of an
Interdisciplinary
Healthcare Team:
Q&A with Team
Members of the
Freeman Center



Kelsie Newton, MS, RD, LD is the RD Care Coordinator for the Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities at UC Health. Kelsie has a background in clinical nutrition, providing medical nutrition therapy to hospitalized patients on various topics including oncology, diabetes, gastrointestinal concerns, and nutrition support. She has a passion for working with individuals with intellectual and developmental disabilities. Kelsie is excited to now work in the outpatient setting and follow with patients over a more extended period to help them improve quality of life and meet their nutrition-related goals.

Alexis Padula

Path: Transition
Planning through
Learning, Indepen
dent
Living, Working,
and SelfAdvocacy



Alexis is in her second year at Otsego Academy. She has a talent for fashion and organization and loves to be on the go! Fun fact, Alexis has a twin brother! She is very close with her family, and they have been a huge support to her throughout her post-secondary education journey. This year, she is hoping to land an internship at our local animal shelter so that she can give back to the community.



Humberto Pena Jr., PhD	Using Everyday Technology to Increase Employment and Social Skills for Individuals with IDD	
Kandi Pickard	Addressing Bias in Health Care	



Dr. Humberto Pena Jr is Assistant Professor of Research in Educational Psychology in the Applied Behavior Analysis Program at the University of Texas at San Antonio. Dr. Pena's work centers on closing the employment gap for young adults with autism, intellectual disabilities, and other developmental disabilities. Specifically, he examines ways of teaching social skills often seen in competitive integrated employment with the end goal to promote inclusion and employment. Dr. Pena's work also looks at Applied Behavior Analytic interventions aimed at decreasing maladaptive behaviors and improving social-communication skills in children with autism.



Kandi Pickard is the President & CEO of the National Down Syndrome Society (NDSS) where she provides vision and leadership, working collaboratively with individuals and organizations to support the entire Down syndrome community. Kandi holds a degree in business administration and brings two decades of experience in operations and effective administration management to her role at NDSS. Kandi's involvement in the Down syndrome community first began as a local volunteer and advocate after her youngest son, Mason, was born with Down syndrome. Ten years later, she leads NDSS with a focus on building community and keeping people with Down syndrome at the center of everything the organization does. Kandi's vision for the future of NDSS includes resources, programs, and support for individuals with Down syndrome and their families from birth to adulthood, with a special focus on caregiving, public health, and supporting aging adults.



Sophia Porter	Create Your Own Path: Transition Planning through Learning, Indepen dent Living, Working, and Self- Advocacy	And the second s	Sophia is in her second year at Otsego Academy. Originally from Georgia, she considers herself the University of Georgia's Bulldogs football team's #1 fan! Sophia is outgoing and competitive. She loves exploring the community and learning more about career options through her internships. Sophia especially loved working in the retail and animal care fields.
Neva Ricardo	Create Your Own Path: Transition Planning through Learning, Indepen dent Living, Working, and Self- Advocacy		Neva is in her second year at Otsego Academy. She has big dreams of being a star one day! Neva loves to sing, dance, and act. She also loves working in the kitchen creating new recipes! Her current career goal is to work in an office setting or in a school where she could help young children have fun and gain confidence in themselves.
Dr. Aurora Rivendale, MD	Keynote: The Value of an Interdisciplinary Healthcare Team: Q&A with Team Members of the Freeman Center		Aurora Rivendale, MD is a dual trained physician in Family Medicine and Psychiatry. She has a passion for working with individuals with intellectual and developmental disabilities. She currently spends part of her time working within the Freeman Center for Intellectual and Developmental Disabilities at the University of Cincinnati. Her focus is on working in a collaborative care model as a psychiatrist to further aid individuals in their personal journey towards a healthy and full life as they define it.



Abby Rowley,	Approaches to
LCSW	Mental Health
	Promotion and
	Treatment
	#Adulting
	Mastering Social
	Skills for Success
	in the Workplace
	The Balancing
	Act: Health,
1	Act. Health,



Abby Rowley, LCSW, is a clinical therapist at the Advocate Medical Group Adult Down Syndrome Center in Park Ridge, Illinois. She completed her Bachelor of Science degree in Rehabilitation and Disability Studies and her Master of Social Work degree from the University of Illinois at Urbana-Champaign. She is a licensed clinical social worker who previously worked as a case manager in a residential community for children and adults with intellectual and developmental disabilities, as well as in the school system as a social worker.

Safety, and Independence

Eric Mental Health in Rubenstein, Adults with Down

Syndrome

PhD, ScM



Eric Rubenstein, PhD, ScM, is an Assistant Professor in the Department of Epidemiology at the Boston University School of Public Health. His research focuses on improving health and well-being in people with intellectual and developmental disabilities. Dr. Rubenstein's research is motivated and inspired by his friends, Special Olympic athletes, and fellow advocates in the intellectual and developmental disability community.



Angad<mark>and</mark> Amit Sahgal Embrace Imperfection: Start Your Business Now



Angad Sahgal is an individual with Down syndrome who is a student at Georgia State University. Angad knows firsthand the soft bigotry of low expectations, and many people think that a disability means that someone is broken or "less than". Anged is determined, hardworking, and is Georgia's ambassador for Supported Decision Making (SDM). Alongside his father, Amit, Angad is the founder of Chai Ho Teas, a gourmet tea company, and Let Me Do It (LMDI), an accessible decision-making application for persons with disabilities. This app helps people to stay in control of their own life and make their own decisions. It is a solution to the problem of unnecessary guardianship. Angad and Amit started this with the purpose of building an inclusive and welcoming world for people of all abilities.



Will Sanborn

Starting your Own Business: Create, Design, and Snack Outside the Box!



Will Sanborn is the Adult Employment Coordinator for the Down Syndrome Association of Northeast Ohio (DSANEO) and the manager of Sunburst Snacks, a training program that prepares adults with Down syndrome for community employment through the operation of a small snack business. Since its launch in 2022, Sunburst Snacks has employed nine individuals with Down syndrome, partnered with dozens of organizations, and sold over 5,000 snack boxes. Will began his career in the performing arts as a professional actor, teacher, and director. He is most proud of his work with Stagecrafters' Broadway Buddies, an adaptive theater program for teens and adults with special needs. Will holds a BFA in Theatre Arts (Acting) from Elon University and will graduate in December with a Masters of Nonprofit Organizations (MNO) from Case Western Reserve University. He is the brother of Julie and Allison, who are identical twins with Down syndrome.

Commented [RG1]: add photo of Amit



Dr. Stephanie	Down Syndrome
Santoro	Regression
	Disorder: Updates
	and Latest
	Research
	Down Syndrome
	Clinics: Value,
	Purpose, and
	Benefit



As a pediatrician-trained clinical geneticist, Dr. Stephanie Santoro has devoted her career to the health of individuals with genetic syndromes. Down syndrome is her primary genetic syndrome of focus and area of clinical expertise to which she is passionately dedicated. She was the co-director of the Adult Down Syndrome Clinic at the Ohio State University previously and currently is the Director of Quality Improvement Research at the Massachusetts General Hospital Down Syndrome Program. Within the field of Down syndrome, Dr. Santoro has specialized in quality improvement approaches and increasing adherence to guidelines for medical care. She is a K23 awardee and is funded to develop a novel instrument to measure health in Down syndrome. She is a graduate of the University of Cincinnati, the University of Cincinnati College of Medicine and completed residency at Cincinnati Children's Hospital Medical Center. Dr. Santoro is currently an Assistant Professor in Pediatrics at Harvard Medical School. Dr. Santoro serves on the Health Advisory Board of the Medical and Scientific Advisory Committee of the Massachusetts Down Syndrome Congress, the Board of Directors of the Down Syndrome Medical Interest Group (DSMIG-USA), and the Executive Committee of the American Academy of Pediatrics Council on Genetics.

Ashley Scott, MPH Mental Health in Adults with Down Syndrome



Ashley Scott, MPH is a project coordinator in the Department of Epidemiology at Boston University's School of Public Health where she supports research on intellectual and developmental disability and health disparities in preterm birth, as well as severe maternal morbidity.



Jed Seifert	Disability Inclusion in the Workforce	STAKES

Kathy Service If We Only Knew
Then: Practical
Insights on How
to Support Aging
Adults with Down

Syndrome



Jed Seifert is the co-founder of Stakes Manufacturing, a print-on-demand apparel company out of Cleveland, OH where they are passionate about inclusion and currently employ a number of individuals with different disabilities. Stakes was recently awarded the APSE 2022 National Employer of the Year recognizing their hard work building an inclusive workforce employing people with disabilities. Jed is the proud younger brother of Darren, who has Fragile X and has always been Jed's inspiration. Jed has been working with the disability community since he started coaching Special Olympics as a young teenager. Jed is a board member for the National Fragile X Foundation and proudly serves on the CEO Commission for Disability Employment founded by Voya Financial, SHRM, and NDSS. He's also on the Board of Directors and Business Advisory Council for SEEC, an organization dedicated to helping individuals with disabilities attain meaningful employment opportunities and supports his brother.

Kathy Service, RN, MS, FNP-BC, CDDN has continually worked in the field of intellectual disabilities since 1976 and since 1979 as a nurse practitioner. She has served on the National Task Group on Dementia and Intellectual Disabilities since its inception and contributed to both NDSS guidebooks on aging and dementia.



Kaethe Sigelko	Mental Health in Adults with Down Syndrome	Kaethe Sigelko is 28 years old and living independently in an apartment with another young adult. She has been working in the healthcare field at a well-known hospital for 8 years. She graduated from the Cutting-Edge program at Edgewood College in 2019 with a certificate of completion. She likes to spend time with family, friends, & her roommate, and the many hobbies she enjoys doing. She is a proud owner of her own public speaking business and an author of inspiring quotes. She hopes to educate and tell others about how the research process is going as well as what it means to be part of the team.
Nate and Holly Simon	Changing Perspec tives One Shirt at a Time!	Holly and Nate Simon are a mother and son duo that are changing the way others perceive those with Down syndrome one funky shirt at a time. Nate is the CEO of 21 Pineapples, a Hawaiian shirt company. Nate is also a model and actor, with his first movie premiering on World Down Syndrome Day. He is a gold medalist in golf, bowling, basketball, you name it. Holly designed 21 Pineapples to employ as many people with disabilities as possible. Together, they travel the country speaking about the endless possibilities that people with Down syndrome can achieve. Their mission is to start a conversation. They believe that love and kindness will always win, and showcasing everyone's talents will help to change the world.
Pepper Stetler	Turning Your Passion Into Policy Change	Pepper Stetler is a professor at Miami University in Oxford, Ohio. Her book, A Measure of Intelligence: One Mother's Reckoning with the IQ Test, will be published in the fall of 2024. Her essays calling for disability justice have appeared in The New York Times, The Atlantic, Slate, and The Progressive. She is the mother of Louisa, an amazing sixth grader who has Down syndrome.



Diana Temple	Supporting Siblings	Dianna Temple is the Ohio SIBS Executive Director. She is pictured here with her older SIB Jackie. She also has a younger SIB, Emily, a practicing OB Labor and Delivery nurse at Ohio Health in Mansfield. Dianna has a bachelor's degree in fine arts, a master's degree in visual studies from the University of Missouri, and an Occupational Therapy Doctorate from the University of Toledo. Throughout her studies, she has completed academic research involving teenage siblings of people with disabilities using the Photovoice method, published research on the impact of creating digital stories for caregivers of those with dementia, developed a self-advocacy program and researched how the history of photography impacts the way we view disability.
Jamie Valis, PhD	Real Talk with Your Doctor!	Jamie Valis, PhD is a learning and development specialist focused on using training as a mechanism for improving the health status of people with disabilities. As the Vice President of Training, Development, and Engagement for Kramer Davis, she leads design, development, and implementation of training and education initiatives with the focus on improving quality of healthcare service delivery and health outcomes of individuals with intellectual and developmental disabilities. Before joining the team at Kramer Davis Health, Dr. Valis spent 5 years at Special Olympics International contributing to inclusive health for people with IDD through training, health screenings, and self-advocate leadership development.
Dr. Gregory Wallace, PhD	Ensuring Community Engagement Across the Lifespan Through Employment	Gregory Wallace, PhD, is an applied developmental psychologist and an Associate Professor at The George Washington University in the Department of Speech, Language and Hearing Sciences. Together, Dr. Raitano Lee and Dr. Wallace lead Project ASPIRE, a study focused on vocational outcomes among young adults with Down syndrome. This is an online study funded by the National Institutes of Health. The immediate goal of the project is to describe the daily activities of 200 young adults with Down syndrome as well as cognitive and mental health factors that predict greater engagement in the community, including employment. The long-term goal of this study is to provide the foundation necessary to develop more effective approaches to support and optimize vocational outcomes for adults with Down syndrome.



Dr. Lauren	Keynote: <i>The</i>
Wang, MD	Value of an Interdisciplinary Healthcare Team:
	Interdisciplinary
	Healthcare Team:
	Q&A with Team

Down Syndrome Clinics: Value, Purpose, and Benefit

Members of the

Freeman Center

The History and Rights of Research Participation



Dr. Lauren Wang is an Adjunct Assistant Professor in the Department of Family and Community Medicine at the University of Cincinnati and a Fellow of the American Academy of Developmental Medicine who is the Medical Director of UC Health's Timothy Freeman, MD, Center for Intellectual and Developmental Disabilities. Dr Wang spearheaded the creation of the Freeman Center in January 2021 in response to the significant health inequity both locally and nationally for adults with IDD who have aged out of the pediatric health system. The Freeman Center is an interdisciplinary primary care clinic that strives to become a national leader in a) providing specialized, coordinated, patient-centered healthcare to adults with IDD and b) training future physicians to care for this underserved population in their own communities. The Freeman Center is developing a model for other academic health centers to improve healthcare delivery and access for adults with IDD.

Dr Wang was recently appointed to serve on the Board of Directors for the National Down Syndrome Society. She also served on the Board of Directors for the Down Syndrome Association of Greater Cincinnati for three years and is a member of their Health Advisory Board. She has presented locally and nationally on topics of transition from the pediatric to adult healthcare system, collaborative care models, and the Freeman Center. She lives in Cincinnati with her husband and three children.

Nicole White, PhD

Down Syndrome Clinics: Value, Purpose, and Benefit

The History and Rights of Research Participation



Nicole White, PhD, is a researcher interested in improving the facilitation of care for people with Down syndrome. She is also the parent of a loved one with Down syndrome. Currently she works at Cincinnati Children's as the Director of Operations for Research. She also supports and advocates with many Down syndrome non-profit organizations on building community support and developing resources for families and healthcare providers. In her free time, she enjoys running and has been a member of the NDSS Athlete Ambassador Team for three years.



Charlotte Woodward Embrace Imperfection: Start Your Business Now



Charlotte is the Education Program Associate for the National Down Syndrome Society (NDSS) where she supports the development of education-related resources and educational policy initiatives. Charlotte was born with Down syndrome, as well as a heart condition, and had four open-heart surgeries when she was young. She is one of the very few people born with Down syndrome to receive a life-saving heart transplant, and she regularly shares her story to educate and advocate for others. Charlotte holds an associate degree from Northern Virginia Community College and recently graduated Summa Cum Laude from George Mason University with a bachelor's degree in sociology with a concentration in inequality and social change.