CONFERENCE AT-A-GLANCE

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7:30-9:00am	Registration
9:00-10:30am	Breakout Session I
10:30-11:00am	Break
11:00am-12:30pm	Breakout Session II
12:45-2:15pm	Awards Luncheon
2:15-2:45pm	Break
2:45-4:15pm	Breakout Session III
4:15-5:30pm	Networking Reception

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EARLY MORNING BREAKOUT SESSION 9:00-10:30AM

Topic	Speaker(s)
New Parents: Sharing Our Stories	Sarah Cullen, Family Support Director, Massachusetts Down Syndrome Congress; Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Angela Lombardo, MSW, Program Manager, Down Syndrome Program, Boston Children's Hospital; Tatiana Salinas, Bilingual (Spanish) Family Support Specialist, Massachusetts Down Syndrome Congress; Brian Young, Facilitator, MDSC Dads Program
Behavior News You Can Use	Dr. Stacy Taylor, BCBA-D, President/Clinical Director, Advance Behavior & Learning
Current State of Health Equity in Down Syndrome and Alzheimer's Disease (DS-AD) Therapies and Beyond	Anna Fedewa, Senior Manager of Government Relations, National Down Syndrome Society; Hampus Hillerstrom, President & CEO, LuMind IDSC Foundation; Matthew P. Janicki, Co-President of the National Task Group on Dementia and Intellectual Disabilities
Supporting Individuals and Families During Transition Planning	Victor Hernandez, EdM, Deputy Assistant Commissioner, Massachusetts Department of Developmental Services
Belonging Is The New Inclusion: Understanding the Dimensions of Authentic Belonging In Community Groups	Lisa Drennan, Founder, MERGE Inclusion Consulting

SELF ADVOCATE WORKSHOP: On My Way to Make Music!

BROTHERS & SISTERS WORKSHOP: Sibling Meet & Greet

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MID-MORNING BREAKOUT SESSION 11:00AM-12:30PM

Topic	Speaker(s)
Navigating the Down Syndrome-Autism Spectrum Disorder (DS-ASD) Journey	Jeanne Doherty, President, Down Syndrome-Autism Connection; Charlotte Gray, Executive Director, Down Syndrome-Autism Connection
Toilet Training Tips and Tricks	Dr. Stacy Taylor, BCBA-D, President/Clinical Director, Advance Behavior & Learning
Toddlerhood to Transition: Top 10 Tips for an Amazing Future	Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Angela Lombardo, MSW, Program Manager, Down Syndrome Program, Boston Children's Hospital
Women's Health and Down Syndrome: What You Should Know	Hannah Graham, MD, Physican, Advocate Medical Group Adult Down Syndrome Center; Charlotte Woodward, Program Associate, National Down Syndrome Society
Understanding the Current Landscape of Clinical Trials in Down Syndrome and Alzheimer's Disease	Regan Fong, Executive Director, Clinical Development - Neurology, Ionis Pharmaceuticals; Hampus Hillerstrom, President & CEO, LuMind IDSC Foundation; Lois Kelly, RN, MS, Vice President, Clinical Operations, LuMind IDSC Foundation; Dr. Anke Post, Chief Medical Officer, AC Immune; H. Diana Rosas, MD, Neurology, Massachusetts General Hospital; Brian Skotko, MD, MPP, Director of MGH Down Syndrome Program & Professor at Harvard Medical School
Grandparents: Sharing and Caring	Sue Laing, Co-Leader, MDSC Grandparents Support Group

SELF ADVOCATE WORKSHOP: On My Way to Perform!

BROTHERS & SISTERS WORKSHOP: Alike & Different

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AFTERNOON BREAKOUT SESSION 2:45-4:15PM

Topic	Speaker(s)
Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know	Brian Skotko, MD, MPP, Director of MGH Down Syndrome Program & Professor at Harvard Medical School
"What If?" & "Now What?": Navigating Aging and Dementia Care Needs for Adults with Down Syndrome	Clorinda "Clo" Cottrell, LICSW, CDCP, Social Worker, Care Manager, Certified Dementia Care Partner; Julie A Moran, DO, Geriatrician, Intellectual and Developmental Disabilities Consultant, Tewksbury Hospital, Clinical Instructor of Medicine, Harvard Medical School
Pathways to Employment Through Self Direction	Paula Collins, Assistant Vice President, WORK Inc.; Cindy Thomas, MS, CRC, Director, Institute for Community Inclusion, University of Massachusetts Boston
Make It Visual: A Hands-On Workshop for Creating Choice Boards, Visual Schedules, and Personalized Books.	Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Jessica Handler, MS, CCC-SLP, Feeding and Swallowing Team, Boston Children's Hospital
The Time is NOW: Your Guide to Powerful Advocacy!	Kate Bartlett, Program Specialist Intern, Massachusetts Down Syndrome Congress; Genevieve Thompson, Manager of Advocacy, National Down Syndrome Society; Charlotte Woodward, Program Associate, National Down Syndrome Society

SELF ADVOCATE WORKSHOP: On My Way to Create a Masterpiece!

BROTHERS & SISTERS WORKSHOP: Finding "My Way"

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EARLY MORNING BREAKOUT SESSIONS

(registrants will select ONE workshop to attend)

New Parents: Sharing Our Stories

Sarah Cullen, Family Support Director, Massachusetts Down Syndrome Congress; Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Angela Lombardo, MSW, Program Manager, Down Syndrome Program, Boston Children's Hospital; Tatiana Salinas, Bilingual (Spanish) Family Support Specialist, Massachusetts Down Syndrome Congress; Brian Young, Facilitator, MDSC Dads Program

We invite new parents to come and hear the stories from experienced parents and share their own stories, meet other new parents, learn about helpful resources and/or just listen and relax in the warm community of other new families.

Sarah Cullen is the Family Support Director for Massachusetts Down Syndrome Congress. She oversees the National Parents First Call Center, including the Parents First Call Program, which supports both new and expectant parents and has been replicated in over 30 Down syndrome organizations across the country. Sarah and her husband, Dan, have three children, including Matthew who is 28 and has Down syndrome.

Angela Lombardo, MSW is the Program Manager for the Down Syndrome Program at Boston Children's Hospital. She is also the Training Director for the Boston Leadership Education in Neurodevelopmental and Related Disabilities Program (LEND). Angela's biggest and most important job is being the single mom of a 29 year old son, Isaiah, who has Down syndrome.

Emily Jean Davidson, MD, MPH, RYT is a developmental pediatrician with a passion for working for children with Down syndrome and other complex medical and developmental issues. She is a graduate of Harvard College and Yale Medical School and has a Master of Public Health degree from Harvard. She completed her residency training and developmental behavioral pediatrics fellowship at Boston Children's Hospital where she works as an attending physician seeing children with Down syndrome from the time of diagnosis to age 22. She also works in the Boston Children's Hospital Complex Care Service with children with medical complexity. In addition, Dr. Davidson is a Registered Yoga Teacher and level 2 Reiki practitioner and teaches inclusive yoga at Boston Children's Hospital. Her research interests include exercise for children with Down syndrome and respite for families of children with complex needs.

Tatiana Salinas is the Bilingual (Spanish) Family Support Specialist for the Massachusetts Down Syndrome Congress and connects with Spanish-speaking families. She also supports new and expectant parents through the Parents First Call program. Tatiana has three children and was connected to the MDSC since early pregnancy. Her first born who has Down syndrome is now 11 years old.

Brian Young (42) and his wife Jess have two children. Their son, Connor, who has Down syndrome is 13, and their daughter Liana is 8. They live in Rutland, and Brian is a retired carpenter, now a stay-at-home dad. Brian and Jess created and have led the Central MA Family Group for many years, hosting Parents Nights Out, playground meet-ups, and more. Brian is also the Facilitator for the MDSC Dads Program!

Behavior News You Can Use

Dr. Stacy Taylor, BCBA-D, President/Clinical Director, Advance Behavior & Learning

Behavior can be frustrating and confusing, but the good news is that there is a science of learning and behavior that can help..no matter what age or stage your child is in. It is important to understand the basics of behavior because once you do, you can apply them to a variety of situations. Participants will learn some behavior basics and effective strategies they can use to prevent, teach and respond to behavior at home, at school or in the community.

Dr. Stacy Taylor received her Doctorate in Special Education at Nova Southeastern University. She is also a doctoral level Board Certified Behavior Analyst. For over 20 years, she has provided support to people with developmental disabilities, learning differences, and behavioral challenges. She has served as director for 3 clinical programs and currently owns and operates an ABA program, Advance Behavior & Learning, and a fully inclusive private school, Advance Learning Academy in Central Florida. Dr. Taylor has worked in a variety of settings including clinics, schools, and homes. In addition to providing 1:1 treatment to children, she also provides training and consultation around the country. She speaks at conferences, presenting information on early intervention, education, and behavioral treatment. She has taught many college level courses to help students learn more about inclusion, learning, child development, and behavior. Her programs function as an internship and practicum site for students just starting in the field. Dr. Taylor is married and has 4 amazing children, including Addison, who is almost 18 years old and has Down syndrome.

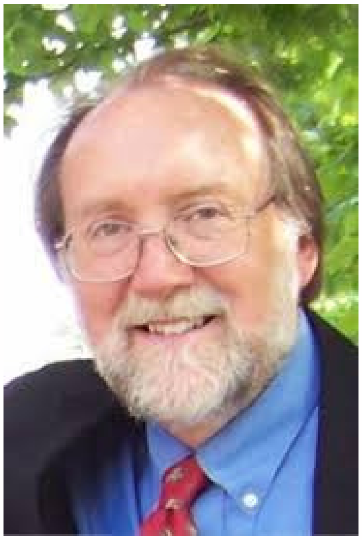
Current State of Health Equity in Down Syndrome and Alzheimer's Disease (DS-AD) Therapies and Beyond

Anna Fedewa, Senior Manager of Government Relations, National Down Syndrome Society; Hampus Hillerstrom, President & CEO, LuMind IDSC Foundation; Matthew P. Janicki, Co-President of the National Task Group on Dementia and Intellectual Disabilities

What will it take for the Down syndrome community to see inclusive and equitable health policy? This moderated discussion will center on the Down syndrome community's fight for inclusion in Alzheimer's research/clinical trials and how those battles fit into the context of a greater health equity conversation. The panel will address the need for changes in federal policies on key topics: blood biomarker diagnostics, treatment outcomes, general trial participation, FDA considerations, NAPA Council changes, and CMS's federal GUIDE program.

Anna Fedewa is the Senior Manager of Government Relations for the National Down Syndrome Society. In this role, she leads and directs the organization's work to influence federal, state, and local policies and regulations that impact people with Down syndrome. 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 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.

Hampus Hillerstrom is President and CEO of LuMind RDS Foundation since September 2017, after serving on the board of directors for three years, including one year as Vice-Chair. 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, and he served as EVP and CFO prior to joining LuMind RDS as CEO. Previously, he was an associate at leading European biotech venture capital firm HealthCap. Hampus also spearheaded a project at AstraZeneca to evaluate decision-making leading to Phase III clinical trials and worked on the pharmaceutical industry at investment bank Lazard. Hampus holds a Masters in Economics from the University of St. Gallen, an MBA from Harvard Business School, and an MSc in Health Sciences and Technology from MIT/Harvard Medical School. Hampus has two sons, including 11 year old Oskar who has Down syndrome.



Matthew P. Janicki, Ph.D., the co-chair of the US National Task Group on Intellectual Disabilities and Dementia Practices, is also a member of the US Federal Advisory Council on Alzheimer's Research, Care, and Services (under the National Alzheimer's Project Act). He also holds an appointment at the Department of Disability and Human Development at the University of Illinois at Chicago. Formerly, he was director for aging and special populations for the New York State Office for People with Developmental Disabilities. Currently, he is leading a study of specialized group homes designed for dementia related care of adult with intellectual disabilities, and previously was the principal investigator of studies examining how community agencies provide community supports to adults with intellectual disabilities affected by Alzheimer's disease and how families are aided by community agencies in supporting adults with Down syndrome affected by Alzheimer's disease. He is the author of numerous books and articles in the area of aging, dementia, public policy, and rehabilitation with regard to people with intellectual and developmental disabilities (including: Dementia, Aging, and Intellectual Disabilities: A Handbook) and has lectured and provided training in aging and intellectual disabilities across the world. He was also the project director of an effort that provided the World Health Organization with a series of background reports on promoting longevity among adults with intellectual disabilities throughout the world. He is the founding editor of the Journal of Policy and Practice in Intellectual Disabilities.

Supporting Individuals and Families During Transition Planning

Victor Hernandez, EdM, Deputy Assistant Commissioner, Massachusetts Department of Developmental Services

In this workshop, we will review the Turning 22 transition process and DDS supports available to help youth and families develop a vision, understand service options, and plan for the future. We will discuss the role of the DDS Transition Coordinators, the support services available through the DDS Family Support system, and the array of DDS services offered to the youth and their families during this time.

Victor currently holds the position of Deputy Assistant Commissioner for the Department of Developmental Services (DDS), the largest state agency in the Commonwealth of Massachusetts. He has held key leadership positions including Chief of Staff, Legislative/Constituent Laison, Statewide Transition Coordinator for Ch 688, Asst Area Director and Commissioner's liaison for special projects with the Governor, Secretariat and stakeholder interests. Victor holds degrees from University of California, Davis and Harvard University. He has also held administrative roles in schools and agencies for multi-handicapped individuals in California and Massachusetts.

Belonging Is The New Inclusion: Understanding the Dimensions of Authentic Belonging In Community Groups

Lisa Drennan, Founder, MERGE Inclusion Consulting

Inclusion isn't enough, time to move the goal post! Learn how authentic belonging for individuals with disabilities involves meaningful participation into existing activities rather than creating separate specialized programs or experiences. This session will explore the key dimensions of belonging such as presence, invitation, being welcome, acceptance, support, and friendship. Understand how these factors contribute to meaningful participation and true inclusion in community groups. Ideal for advocacy of all age ranges.

Lisa’s career is defined by her dedication to fostering inclusion for individuals with intellectual and developmental disabilities. Her journey began at New England Village in Pembroke, Massachusetts, where she progressed from a direct support professional to designing the Sollar Wellness Center, which offers aquatics, fitness, music, art, and education tailored for those with disabilities. In 2014, Lisa became the Association Director of Inclusion at the South Shore YMCA, where she developed innovative programs and focused on staff training to enhance social and recreational inclusion. Her leadership earned her national recognition, culminating in her role as Co-Chairperson of Y-USA’s Diverse Abilities Working Group. In 2018, Lisa founded MERGE Inclusion Consulting, expanding her impact by offering consultation, training, and systems implementation to various community organizations committed to disability inclusion. This initiative reflects her passion for sharing best practices and creating inclusive communities.

MID-MORNING BREAKOUT SESSIONS

(registrants will select ONE workshop to attend)

Navigating the Down Syndrome-Autism Spectrum Disorder (DS-ASD) Journey

Jeanne Doherty, President, Down Syndrome-Autism Connection; Charlotte Gray, Executive Director, Down Syndrome-Autism Connection

Down syndrome and autism can be challenging disabilities separately, however when combined the challenges can be quite complex and oftentimes are misunderstood by the family members and professionals in the individual’s life. If you suspect that your child may also have autism, or are new on this journey, then this presentation is for you. This workshop will take a look at what we know about DS-ASD, discuss commonalities in family experiences, explore basic behavioral red flags, discuss treatment recommendations, where to get a diagnosis, how parents feel about an autism diagnosis, and what they can do if their child has DS-ASD.

Jeanne Doherty serves as board president for the Down Syndrome Autism Connection. Having been in this role since 2016, she provides leadership and direction and. oversee operations for the oganization . Jeanne brings with her a wealth of knowledge and experience in providing care for individuals with complex needs. in the past, jeanneserved as the Family Support Specialist for the Massachusetts Down Syndrome Congress's well as past Board President for a regional provider of residential group homes for adults with IDD. She is owner operator of 21 Reasons LLC. and is a Certified Nurses Assistant. Jeanne resides in Denver with her husband and three daughters, including Jessica , the inspiration for Jeanne's passion and dedication to this community.

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Charlotte has served as the executive director of the Down Syndrome-Autism Connection since 2015. In addition to managing the daily operations and fiscal reporting, Charlotte provides direct support to families across multiple channels. Charlotte presents workshops on DS-ASD both in person and via webinars for audiences which include the NDSC, MDSC and DSAIA conferences. Charlotte also co-founded Morning Travelers, a play group for families who have a child with Down syndrome, which now has three other locations in Massachusetts. Charlotte worked for a child psychologist as a Floortime Therapy Consultant for children with ASD for four years providing homebased support and therapy for children with emotional and social developmental challenges, and currently works as an accounting manager for a property management company. Charlotte has her Master’s in Business Administration and lives in the Denver area with her husband Bill and their son Jacob who has DS-ASD.

Toilet Training Tips and Tricks

Dr. Stacy Taylor, BCBA-D , President/Clinical Director, Advance Behavior & Learning

Behavior can be frustrating and confusing, but the good news is that there is a science of learning and behavior that can help... no matter what age or stage your child is in. It is important to understand the basics of behavior because once you do, you can apply them to a variety of situations. Participants will learn some behavior basics and effective strategies they can use to prevent, teach and respond to behavior at home, at school or in the community.

Dr. Stacy Taylor received her Doctorate in Special Education at Nova Southeastern University. She is also a doctoral level Board Certified Behavior Analyst. For over 20 years, she has provided support to people with developmental disabilities, learning differences, and behavioral challenges. She has served as director for 3 clinical programs and currently owns and operates an ABA program, Advance Behavior & Learning, and a fully inclusive private school, Advance Learning Academy in Central Florida. Dr. Taylor has worked in a variety of settings including clinics, schools, and homes. In addition to providing 1:1 treatment to children, she also provides training and consultation around the country. She speaks at conferences, presenting information on early intervention, education, and behavioral treatment. She has taught many college level courses to help students learn more about inclusion, learning, child development, and behavior. Her programs function as an internship and practicum site for students just starting in the field. Dr. Taylor is married and has 4 amazing children, including Addison, who is almost 18 years old and has Down syndrome.

Toddlerhood to Transition: Top 10 Tips for an Amazing Future

Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Angela Lombardo, MSW, Program Manager, Down Syndrome Program, Boston Children's Hospital

This workshop presents our top 10 building blocks to thrive in adulthood. We will take a lifespan approach to developing competence in: 1) communication 2) behavior 3) skills 4) literacy 5) healthy habits 6) community building 7) friendships 8) advocacy/self-determination 9) work and volunteering 10) mental health and wellbeing for parents and children. We will start by exploring your vision for the future and then present strategies and practical tips in each of these 10 key areas.

Emily Jean Davidson, MD, MPH, RYT is a developmental pediatrician with a passion for working for children with Down syndrome and other complex medical and developmental issues. She is a graduate of Harvard College and Yale Medical School and has a Master of Public Health degree from Harvard. She completed her residency training and developmental behavioral pediatrics fellowship at Boston Children's Hospital where she works as an attending physician seeing children with Down syndrome from the time of diagnosis to age 22. She also works in the Boston Children's Hospital Complex Care Service with children with medical complexity. In addition, Dr. Davidson is a Registered Yoga Teacher and level 2 Reiki practitioner and teaches inclusive yoga at Boston Children's Hospital. Her research interests include exercise for children with Down syndrome and respite for families of children with complex needs.

Angela Lombardo, MSW is the Program Manager for the Down Syndrome Program at Boston Children's Hospital. She is also the Training Director for the Boston Leadership Education in Neurodevelopmental and Related Disabilities Program (LEND). Angela's biggest and most important job is being the single mom of a 29 year old son, Isaiah, who has Down syndrome.

Women's Health and Down Syndrome: What You Should Know

Hannah Graham, MD, Physican, Advocate Medical Group Adult Down Syndrome Center; Charlotte Woodward, Program Associate, National Down Syndrome Society

Women with Down syndrome and their caregivers can often find it difficult to navigate some of the nuances of women's health and how what they experience may or may not be different than their typical peers. In this session, we will focus on similarities and differences for women with Down syndrome when it comes to their health and share resources available and strategies to help understand and learn about women's health topics that span adulthood.

Hannah Graham, MD is a physician at the Advocate Health Care Adult Down Syndrome Center in Park Ridge, IL. The Center serves people aged 12 + with Down syndrome. Dr. Graham graduated from Loyola University Chicago Stritch School of Medicine. She completed her residency in Family Medicine at Advocate Aurora Lutheran General Hospital. Prior to working at the Adult Down Syndrome Center. Dr. Graham practiced general family medicine. She is currently a faculty member with the Family Medicine Residency Program at Lutheran General Hospital and the Assistant Education Director of Family Medicine at Rosalind Franklin University Chicago Medical School. She is also a mom to a young child with Down syndrome.

Charlotte Woodward is the 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 Suma Cum Laude from George Mason University with a bachelor's degree in sociology with a concentration in inequality and social change.

Understanding the Current Landscape of Clinical Trials in Down Syndrome and Alzheimer’s Disease

Regan Fong, Executive Director, Clinical Development - Neurology, Ionis Pharmaceuticals; Hampus Hillerstrom, President & CEO, LuMind IDSC Foundation; Lois Kelly, RN, MS, Vice President, Clinical Operations, LuMind IDSC Foundation; Dr. Anke Post, Chief Medical Officer, AC Immune; H. Diana Rosas, MD, Neurology, Massachusetts General Hospital; Brian Skotko, MD, MPP, Director of MGH Down Syndrome Program & Professor at Harvard Medical School

This workshop will provide an overview of the current and upcoming clinical trials in Down syndrome-associated Alzheimer’s disease followed by a panel discussion. After a landscape summary by LuMind IDSC, representatives from each study will share information about their respective clinical trials. A moderated Q&A will follow. The workshop will focus on the distinctions of the proposed therapies, the potential benefits and risks of these proposed therapies, and the important role of the family in successful trial participation.

Regan Fong works at Ionis as an Executive Director in the Neurology Clinical Development group and serves as the Project Team Lead for the HERO study. He is originally from Canada and moved to the US more than 30 years ago to complete his PhD in Neuropsychology. During his graduate training, he worked in various memory clinics with patients who had Alzheimer’s disease. It was this work that spurred a personal interest and goal to help bring potential treatments to patients and their families who are impacted by this disease and other neurological disorders. He has over 25 years of experience in central nervous system drug development.

Hampus Hillerstrom is President and CEO of LuMind RDS Foundation since September 2017, after serving on the board of directors for three years, including one year as Vice-Chair. 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, and he served as EVP and CFO prior to joining LuMind RDS as CEO. Previously, he was an associate at leading European biotech venture capital firm HealthCap. Hampus also spearheaded a project at AstraZeneca to evaluate decision-making leading to Phase III clinical trials and worked on the pharmaceutical industry at investment bank Lazard. Hampus holds a Masters in Economics from the University of St. Gallen, an MBA from Harvard Business School, and an MSc in Health Sciences and Technology from MIT/Harvard Medical School. Hampus has two sons, including 11 year old Oskar who has Down syndrome.

Lois Kelly, RN, MS, is the Vice President of Clinical Operations at LuMind IDSC, where she leads initiatives at the intersection of Down syndrome research and clinical operations. Since joining LuMind IDSC in 2023, Lois has played a pivotal role in advancing the organization's research efforts. She initially led the suite of studies within LIFE-DSR, LuMind IDSC's natural history study. Currently, she oversees post-study activities, collaborating with researchers to analyze LIFE-DSR data and translate findings into meaningful advancements in Down syndrome research, and working to prepare more clinical study site teams to be able to welcome individuals with Down syndrome and their families to their sites to participate in clinical studies. With 18 years of experience in clinical research within the pharmaceutical industry, Lois has held leadership roles in Clinical Operations, overseeing international clinical trials in many disease areas. Most recently, she served for six years as a Senior Director in Clinical Operations, managing global studies focused on chronic kidney disease, advanced kidney failure, and potential anti-rejection therapies for kidney transplant recipients. Early in her career, she worked for many years as a Registered Nurse providing direct care to patients, then pursued advanced education and training as she transitioned to the pharmaceutical and biotechnical industry running clinical studies, and where she held leadership positions in clinical operations across various therapeutic areas.

Dr. Post joined AC Immune in September 2024 as Chief Medical Officer. She brings with her extensive experience in leading neuroscience drug development programs in the pharmaceutical industry. She started her career at Novartis in Basel, and subsequently moved to Eli Lilly & Co., where she was responsible for a global medical group in early clinical development, located initially in the USA, and then in the United Kingdom. Then she became Head of Translational Medicine in Neurology at Roche in Basel. Following this extensive experience in both early and late-stage development in psychiatry and neurology-related indications, she moved into Biotech and Medtech companies from 2020 onwards. Here she held senior management and CMO responsibilities. Anke studied medicine at Universities in Berlin, Vienna and Muenster, earning her M.D. from the University in Muenster, Germany. She completed her residency and fellowship training in Psychiatry, Psychotherapy and Neurology at the Max Planck Institute of Psychiatry in Munich where she obtained her specialization degree in 2002. Her habilitation degree was awarded by the Ludwig Maximilian University in Munich in 2004.

Dr. H. Diana Rosas is an adult neurologist at Massachusetts General Hospital (MGH), Harvard Medical School (HMS). She has been on the faculty since 1997 and is currently Professor in the Departments of Neurology and Radiology/Athinoula Martinos Center at MGH/HMS.
She is the Director of the MGH MIND Clinic, a multi-disciplinary clinic that supports patients with neurodegenerative disorders and Co-Director of the Aging & Developmental Disabilities Clinic, which assesses and supports adults with Down syndrome, based at McLean Hospital.
For the past 18 years, Dr. Rosas has been the Director of the Center for Neuroimaging of Aging and Neurodegeneration, a translational clinical research program funded by the National Institutes of Health. She is an active member of the Alzheimer’s Biomarker Consortium-Down Syndrome and is involved with several other initiatives focusing on issues related to aging in Down Syndrome.

A Board-certified medical geneticist, Dr. Skotko is the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital. As the Director of the hospital's Down Syndrome Program, he has dedicated his professional energies toward children with cognitive and development disabilities. He co-authored the national award-winning books, Common Threads: Celebrating Life with Down Syndrome and Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters. He is a graduate of Duke University, Harvard Medical School, and Harvard Kennedy School, and he is currently a Professor of Pediatrics at Harvard Medical School. Dr. Skotko is a leader on clinical and translational research about Down syndrome. He has been featured in The Wall Street Journal, The New York Times, The Washington Post, The L.A. Times, NPR's "On Point," and ABC's "Good Morning America." Dr. Skotko has a sister with Down syndrome and serves on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress.

Grandparents: Sharing and Caring

Sue Laing, Co-Leader, MDSC Grandparents Support Group

Being an active and supportive grandparent is a way to help everyone thrive, grandparent included. Sometimes the road is rough, and being part of a team makes the journey easier. Sometimes the road is joyful, and it is wonderful to share that. Regardless of distance or difficulty, finding our own way to be an active and supportive grandparent is the key. Come and share with other grandparents!

Sue Laing is the proud grandmother of Chloe Laing, age 14 and a highly active teenager who was born with Down syndrome. After more than 30 years of teaching in the field of Health and Physical Education and Adapted Physical Education, Sue is very involved as the Co-Leader of the MDSC Grandparents Support Group and hosts a monthly Zoom for Grandparents. Many years ago, she conducted swimming programs both at her family's swimming school and the local collaborative for children with Down syndrome. Now, she is so happy to be a part of this wonderful and loving community of those with children and grandchildren with Down syndrome and the many passionate professionals that devote their careers to our incredibly special children and young adults.

AWARDS LUNCHEON

At the Awards Luncheon portion of our Annual Conference, MDSC will bring our 2025 theme — ON MY WAY — to life in the DCU Grand Ballroom. We will do this by highlighting the individuality and determination of our MDSC self-advocates, who will take center stage for special performances and our 2025 Self Advocate Keynote speech. Plus, we will unveil our On My Way Video Montage, featuring MDSC member-submitted photos.

Of course, our Awards Luncheon is also when we present MDSC's Annual Awards to honor those individuals who have made a significant impact on the Down syndrome community. We hope you will join us at our 41st Annual Conference for a day of learning and celebrating!

Nicole Volpe ©2025 United Dance

United Dance will be performing a ballet choreographed by Gianni Di Marco, a powerful piece that embodies the essence of their repertoire-celebrating the unique differences that unite us all. The United Dance Company brings together professional dancers with Down syndrome and classical ballet artists, making inclusion an integral part of the art form. The company is dedicated to vibrant storytelling, exceptional artistry, and the celebration of diversity, offering performances for audiences of all ages. United Dance also provides high-quality dance education for children and young adults with Down syndrome across three continents, fostering creativity and self-expression through movement. Discover more about their performances and dance courses here.

Keynote Speaker: Carey Daly

Carey Daly is a 36-year-old from Cape Cod. Always on the go, he is active in his local community. Carey enjoys music, movies, and holidays. In his spare time, you can find Carey spending time with friends, leading group exercise classes, participating in Special Olympics basketball and track and field events, and cheering for the Boston sports teams.

Through the years, Carey has been a mainstay at MDSC events, running the Falmouth Road Race for Team MDSC, attending the Annual Conference, and being a Self Advocate Ambassador at the Buddy Walk by the Sea.

Carey developed a love for long-distance road bike riding during his decade-long stretch working at Bike Zone. In this role, he became involved in the Best Buddies Challenge, initially fixing tires for the riders until he decided to participate. For three years, he's been riding a tandem bike with his "buddy." Together, they have reached the 55-mile mark and are working their way up to the full 100-mile ride.

Carey also has experience working at West Marine, Men's Warehouse, and Hearth & Kettle. He is hardworking, dedicated, and reliable!

Emcee: Lauren Beckham Falcone

Co-Host, The ROR Morning Show Emcee

Lauren Beckham Falcone (LBF) is the co-host of the ROR Morning Show with Bob Bronson, LBF and Brian on 1057 FM in Boston. Formerly an award-winning reporter and columnist for the Boston Herald, she credits her current success as a pop culture commentator to watching too much TV as a kid and scouring the internet too much as an adult. LBF has been a regular contributor to NECN and Boston 25, as well as numerous publications in the Boston area. She is a graduate of the MA Families Organizing for Change Family Leadership series and an Honorary Board Member at the Massachusetts Down Syndrome Congress. Lauren lives in Canton with her husband Dave and her daughter Lucy.

Sarah Peterson

Acting Commissioner, Massachusetts Department of Developmental Services (DDS)

Sarah Peterson, Acting Commissioner of the Massachusetts Department of Developmental Services (DDS), is leading the implementation of her department's mission to provide supports for individuals with intellectual and developmental disabilities, including those with Down syndrome. Commissioner Peterson served as DDS General Counsel from June 2022 to August 2024, when she was named Acting Commissioner. She previously served as Deputy General Counsel from 2017 to 2022. We look forward to hearing Commissioner Peterson's insights and vision for the future.

State Senator Michael Rodrigues

Chair, Senate Committee on Ways and Means

State Senator Michael J. Rodrigues, Chair of the Senate Committee on Ways and Means and a 25-year champion for disability rights, has been instrumental in passing landmark legislation that has transformed lives in our community. His leadership was crucial in the passage of both the Higher Education Bill in 2022, which opened doors for individuals with intellectual disabilities to attend state colleges, and the recent A.B.A. Therapy Bill, ensuring insurance coverage for vital therapy services. Senator Rodrigues, who received MDSC's 2022 Legislator of the Year Award, continues to demonstrate an unwavering commitment to creating opportunities for people with Down syndrome to live full, rich lives. Don't miss this opportunity to hear from one of our community's most dedicated advocates.

Welcome Remarks

Maureen Gallagher, Executive Director, Massachusetts Down Syndrome Congress

AFTERNOON BREAKOUT SESSIONS

(registrants will select ONE workshop to attend)

Keeping Children and Adolescents with Down Syndrome Healthy: All the Medical Updates that Parents Need to Know

Brian Skotko, MD, MPP, Director of MGH Down Syndrome Program & Professor at Harvard Medical School

In this presentation, Dr. Brian Skotko reviews all of the questions and concerns that parents most often have about their sons and daughters with Down syndrome. He provides the answers and action steps, stemming from the latest clinical research on people with Down syndrome. Based on his clinical experience in the Down Syndrome Program at Massachusetts General Hospital, Dr. Skotko makes sure that every parent can anticipate medical conditions so that the potentials of all people with Down syndrome are maximized.

A Board-certified medical geneticist, Dr. Skotko is the Emma Campbell Endowed Chair on Down Syndrome at Massachusetts General Hospital. As the Director of the hospital's Down Syndrome Program, he has dedicated his professional energies toward children with cognitive and development disabilities. He co-authored the national award-winning books, Common Threads: Celebrating Life with Down Syndrome and Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters. He is a graduate of Duke University, Harvard Medical School, and Harvard Kennedy School, and he is currently a Professor of Pediatrics at Harvard Medical School. Dr. Skotko is a leader on clinical and translational research about Down syndrome. He has been featured in The Wall Street Journal, The New York Times, The Washington Post, The L.A. Times, NPR's "On Point," and ABC's "Good Morning America." Dr. Skotko has a sister with Down syndrome and serves on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress.

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"What If?" & “Now What?": Navigating Aging and Dementia Care Needs for Adults with Down Syndrome

Clorinda "Clo" Cottrell, LICSW, CDCP, Social Worker, Care Manager, Certified Dementia Care Partner; Julie A Moran, DO, Geriatrician, Intellectual and Developmental Disabilities Consultant, Tewksbury Hospital, Clinical Instructor of Medicine, Harvard Medical School

Adults with Down syndrome are now routinely reaching old age and are encountering a variety of age-related challenges, including an elevated risk of developing dementia due to Alzheimer’s disease. This workshop will focus on general principles of planning for the lifespan proactively, to help families and caregivers support individuals with Down syndrome from adulthood into old age. Special emphasis will be on caregiving, supports, and future planning after a diagnosis of dementia due to Alzheimer’s disease.

Clorinda "Clo" Cottrell, LICSW, is a social worker with extensive experience supporting individuals with Down syndrome, autism, and intellectual and developmental disabilities. For eight and a half years, she worked at the MGH Down Syndrome Program, where she provided care across the lifespan, including for adults with Down syndrome who are aging or living with Alzheimer’s disease. Currently, Clo works at Clear Guidance, where she partners with individuals and families to navigate the challenges of cognitive impairment, dementia, disability care, and mental health. She has also completed specialized training with the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the Dementia Capable Care Curriculum and serves as an NTG Affiliated Trainer.

Dr. Julie Moran is a board-certified geriatrician/internist specializing in older adults with intellectual and developmental disability (I/DD). Dr. Moran is an attending physician for the specialty inpatient unit at Tewksbury Hospital serving adults with I/DD and also runs a busy statewide outpatient consultation service for older adults with I/DD through the support of the Massachusetts Department of Developmental Services (DDS). Dr. Moran is a Clinical Instructor of Medicine at Harvard Medical School and participates in the teaching and training of geriatric medicine fellows, residents, and students.

Pathways to Employment Through Self Direction

Paula Collins, Assistant Vice President, WORK Inc.; Cindy Thomas, MS, CRC, Director, Institute for Community Inclusion, University of Massachusetts Boston

People who receive DDS funding and their families are increasingly choosing to self-direct their services and often employment is one of their goals. Join us as we talk about what quality employment supports look like and how those can be integrated into a plan for self-direction. We will share resources and will include plenty of time for questions and discussion.

Paula Collins is an Assistant Vice President at WORK Inc. in Fitchburg, MA where she leads a team of job developers and community inclusion specialists. She made a career change after a successful business career to turn her passion for an inclusive workplace into a full-time career about 9 years ago. She has been advocating for people with disabilities for over 20 years, including her work as the Co-Chair of the Shrewsbury SPED PAC, a Special Olympics Coach in both basketball and soccer, and member of the Shrewsbury DEI Task Force. Paila is a current board member of both the Stepping Stone Community Theater and MA APSE as well as a member of the ICI Community Advisory Council and DDS Statewide Quality Council. She holds her CESP certification as well as Marc Gold & Associates Customized Employment Certificate. She is an active member of the Fitchburg Community where she is also a graduate of the Fitchburg Leadership Institute at Fitchburg State University and Disability Steward. You may know her as “Tucker’s Mom” due to her advocacy on behalf of Tucker and others with Down syndrome.

Cindy Thomas is the Director of the Institute for Community Inclusion, UMass Boston. She has over 25 years' experience providing technical assistance, training and employment services. She has worked with state agencies serving individuals with intellectual and developmental disabilities, the vocational rehabilitation system and community organizations. Currently, in addition to leading ICI, Cindy is working on projects designed to expand opportunities for employment and community life engagement. In her community, she has served on the Board of Directors for several non-profit organizations, served two terms as an elected member of her town's school board, as an appointed member of her town's finance committee and was recently appoint to the disability commission. She holds a master's degree in Rehabilitation Counseling and is a Certified Rehabilitation Counselor. Cindy shares her household with her brother-in-law who receives supports from DDS and has taught her much about the role of family caregivers.

Make It Visual: A Hands-On Workshop for Creating Choice Boards, Visual Schedules, and Personalized Books

Emily Jean Davidson, MD, MPH, RYT, Developmental Pediatrician, Boston Children's Hospital; Jessica Handler, MS, CCC-SLP, Feeding and Swallowing Team, Boston Children's Hospital

Visual supports can help children, teens, and young adults with Down syndrome make choices, indicate needs, prepare for unfamiliar situations, and build independence. This hands-on workshop will briefly review some of the uses of visuals and online supports, and then you will make your own visuals to take home for immediate use. Bring your photos on your phone or a USB stick. We will have printers, laminators, scissors, Velcro and everything you need to make visual supports for your child(ren).

Emily Jean Davidson, MD, MPH, RYT is a developmental pediatrician with a passion for working for children with Down syndrome and other complex medical and developmental issues. She is a graduate of Harvard College and Yale Medical School and has a Master of Public Health degree from Harvard. She completed her residency training and developmental behavioral pediatrics fellowship at Boston Children's Hospital where she works as an attending physician seeing children with Down syndrome from the time of diagnosis to age 22. She also works in the Boston Children's Hospital Complex Care Service with children with medical complexity. In addition, Dr. Davidson is a Registered Yoga Teacher and level 2 Reiki practitioner and teaches inclusive yoga at Boston Children's Hospital. Her research interests include exercise for children with Down syndrome and respite for families of children with complex needs.

Jessica "Jessie" Handler is a Massachusetts-certified Speech-Language Pathologist and Lactation Counselor. Though she has been working on the Feeding and Swallowing Team at Boston Children's Hospital for 7 years, her clinical fellowship and early training was completed in Early Intervention. Along with her role through the Down Syndrome Program, she onducts Modified Barium Swallow (MBS) studies and clinical feeding evaluations and works within the Growth and Nutrition Program (GNP) at BCH. She is passionate about weaving her knowledge of feeding/swallowing into communication/language development, especially in the toddler population.

The Time is NOW: Your Guide to Powerful Advocacy!

Kate Bartlett, Program Specialist Intern, Massachusetts Down Syndrome Congress; Genevieve Thompson, Manager of Advocacy, National Down Syndrome Society; Charlotte Woodward, Program Associate, National Down Syndrome Society

"The Time is NOW: Your Guide to Powerful Advocacy!" empowers parents and caregivers to become effective advocates at community, state, and federal levels. Learn practical tools for sharing your family's story, engaging with policymakers, and making your voice heard on critical disability issues. This interactive workshop, led by NDSS Advocacy Manager Genevieve Thompson, NDSS Program Associate Charlotte Woodward, and MDSC Program Specialist Intern Kate Bartlett, combines real-world examples with hands-on training for creating positive change.

Kate Bartlett works part-time at AQUENT, a staffing company in Boston. She is also the Program Specialist Intern for the MDSC and a member of the MDSC's Self Advocate Advisory Council. She lives in an apartment by herself and enjoys musical theater, movies, shopping, and traveling. Kate has friends, a fiancé, and a busy social life. She graduated from high school with her diploma at age 18 and then went on to attend Middlesex Community College. Kate is passionate about public speaking because it allows her to advocate for people with Down syndrome. She has spoken at various conferences and events both in Massachusetts and around the country. Kate also testified at a US Senate hearing in Washington, DC as well as at the Massachusetts State House on two bills, the Higher Education Bill and a Housing bill. She is a recipient of the NDSS' Voices Award and Champion of Change Award.

Genevieve engages with advocates' passion and energy nationwide to advance state-level advocacy priorities. Before moving to D.C., Genevieve served as a Community Access Disability Inclusion (CADI) Manager with the Deaf and Blind Services of Minnesota and served the disability community through her work as a Direct Service Provider. Genevieve holds a bachelor's degree in Justice and Peace Studies from the University of St. Thomas in St. Paul, Minnesota, and a master's degree in public policy from George Mason University.

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Charlotte Woodward is the 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 Suma Cum Laude from George Mason University with a bachelor's degree in sociology with a concentration in inequality and social change.

SELF ADVOCATE WORKSHOPS

For teens and adults with Down syndrome ages 13+

On My Way to Make Music!

Nicole Craven, MA MT-BC, CEO & Founder of Sing Explore Create, LLC; Natalie Condon, MT-BC, Clinical Director and Music Therapist at Sing Explore Create, LLC

We'll make music and try other creative exercises and games while learning how music, rhythm, and the arts affect our minds and bodies! This interactive and educational workshop will provide a supportive space where everyone can feel comfortable making music and getting creative.

On My Way to Perform!

Eric Butler, Director and Producer, Broadway in Worcester; Cait Lubelczyk, Director and Choreographer, Broadway in Worcester

Discover the magic of theater and movement! We'll tap into our our creativity and build confidence while exploring the key elements of theater performance, including improvisation, movement, choreography, and storytelling. Through engaging exercises and group activities, we'll learn to express ourselves authentically and connect with others on stage. Whether you're a seasoned performer or stepping into the spotlight for the first time, this workshop offers a supportive environment to grow your skills and unleash your inner artist!

On My Way to Create a Masterpiece!

Design a piece of art that represents you! We are all unique and that's what makes us incredible. As a group, we'll talk about what makes us each shine and play a fun game to see what we have in common. Then, we'll use different materials, textures, and colors to create a masterpiece to show off our interests, feelings, and dreams for the future! We'll end the day with a dance party!

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BROTHERS & SISTERS WORKSHOPS

For brothers and sisters ages 12-18 who have a sibling with Down syndrome

Sibling Meet & Greet

Come meet others who have a sibling with Down syndrome, and get to know each other through games, activities, and conversation.

Alike & Different

How do sibling relationships and family dynamics change (or stay the same) when you have a family member with Down syndrome? Talk with other siblings who can relate to the unique joys and challenges of having a brother or sister with Down syndrome.

Finding "My Way"

Break into small groups to discuss having a positive sibling relationship while still being your own advocate and staying true to what you want in life. What are the different paths for the future for both you and your sibling, and what might your role look like?

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