

2021 DSAIA – Collaborative Leadership During a Crisis: Creation of the Down Syndrome and COVID-19 Resource

Presenters: Dr. Nicole Baumer, Co-Director, The Down Syndrome Program at Boston Children's Hospital
Bryn Gelaro, Senior Director of Adult Initiatives and Special Projects, Global Down Syndrome Foundation
Dr. Hampus Hillerstrom, President & CEO, LuMind IDSC Foundation
Dr. Seth Keller, Co-chair, National Task Group on Intellectual Disabilities and Dementia Practices
Kandi Pickard, President & CEO, National Down Syndrome Society
David Tolleson, Executive Director, National Down Syndrome Congress
Michelle Sie Whitten, President & CEO, Global Down Syndrome Foundation

Length: 75 minutes
Date: Friday, February 19, 2021
Time: 12:15pm- 1:30pm ET

Description

Leaders of a consortium of six national Down syndrome organizations who created the Q&A on COVID-19 and Down Syndrome will present on this critical resource. The information will help local organizations understand current updates on Down syndrome and COVID-19, including treatments and vaccines. The session demonstrates a model for collaborative leadership during period of crisis. Bring your questions!

Presenter Bios

Dr. Nicole Baumer is a neurodevelopmental disabilities pediatrician/ child neurologist at Boston Children's Hospital and instructor at Harvard Medical School. Dr. Baumer completed her undergraduate studies in biology and psychology at Skidmore College. She received her Medical Degree cum laude from Harvard Medical School. She trained in pediatrics at Massachusetts General Hospital and completed a fellowship in Neurodevelopmental Disabilities at Boston Children's Hospital. Dr. Baumer also has a Master's in education from Harvard Graduate School of Education. In January 2015, Dr. Baumer became Co-Director of the Down Syndrome Program at Boston Children's, where she has been seeing patients since 2011. She is a member of the Down Syndrome Medical Interest Group-USA.

Michelle Sie Whitten is Co-Founder, President and CEO of the Global Down Syndrome Foundation. Global's focus is research and medical care benefiting people with Down syndrome. Global provides excellent medical care to 2,000 patients and supports 200 scientists through its affiliates at the Sie Center and the Crnic Institute. Michelle has been the architect for Global's work including the Global Guidelines. She holds a Master of Arts degree in International Studies and a Graduate Certificate in Business Administration, from Harvard University. She's first generation Chinese-Italian, married to a Brit. They have two kids, Sophia and Patrick, and Sophia has Down syndrome.

Bryn Gelaro joined the Global Down Syndrome Foundation in 2015 and serves as the Senior Director of Adult Initiatives and Special Projects. She is a Licensed Social Worker with a background in behavioral health for adults with Down syndrome. Her work includes furthering Global's adult care initiatives, serving as an executive committee member and co-author of Global Guidelines, and managing the development and operations of Global's efforts to open a World Class Medical Clinic for adults with Down syndrome. Her role oversees many of Global's exciting international projects, including Uganda, Iceland and Albania.

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. Hillerstrom's experience

includes time with a leading European biotech venture capital firm HealthCap where he participated in a large number of investment transactions including several IPOs. Hampus also spearheaded a project on clinical trials conduct at AstraZeneca and worked on the pharmaceutical industry at investment bank Lazard. Hampus holds a Masters in Economics and Finance from the University of St. Gallen (Switzerland), an MBA from Harvard Business School, and an MSc from MIT/Harvard Medical School (HST). Hampus' oldest son Oskar has Down Syndrome.

David Tolleson, has served as Executive Director of the National Down Syndrome Congress (NDSC) since 2003. During his tenure, NDSC's Annual Convention has grown to be the world's largest gathering of people with Down syndrome, their families, and the professionals who work with them. Additionally, the organization is the recognized leader in Federal Down syndrome policy and advocacy, as well as engagement of traditionally underserved communities. He and his wife have two adult children, one of whom has autism.

Kandi Pickard is 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'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. Eight 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.

Dr. Seth Keller is a board-certified neurologist in private practice with Neurology Associates of South Jersey. Dr Keller is on the Executive Board of the Arc of Burlington County as well as on the board for The Arc of New Jersey Mainstreaming Medical Care Board. Dr Keller is the Past President of the American Academy of Developmental Medicine and Dentistry (AADMD). Dr Keller is the co-chair of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG). Dr. Keller is also the chair of the Adult IDD Section with the American Academy of Neurology. He received his bachelor's degree from Temple University, earned his medical degree from The George Washington University School of Medicine in 1989, and completed his neurology internship and residency at Bethesda Naval Hospital.

Presentation Outline:

- 1) Self-Advocate's perspective on COVID-19 and why this resource is important
- 2) Why this collaboration is important to each organization and their constituents
- 3) What local organizations need to know to use this resource to use the information to support families
 1. Prioritization of topics and focus areas
 2. The timeline of updates and what's different in the various versions
 3. Example communication efforts and social media planning
- 4) How local organizations can apply the "collaborative consensus" model
- 5) Sneak Peak: What to expect in the soon to be published newest version
 1. Latest research updates on COVID-19 and DS
 2. Vaccines and testing
- 6) Q&A