

2021 DSAIA – Enhancing Medical Outreach Possibilities: Adding the GLOBAL Medical Care Guidelines for Adults with Down Syndrome to your Organization’s Toolkit

Presenters: Dr Brian Chicoine, Medical Director, Adult Down Syndrome Center
Bryn Gelaro, Senior Director of Adult Initiatives and Special Projects, Global Down Syndrome Foundation
Dr. Moya Peterson, Medical Director, University of Kansas Adult Down Syndrome Clinic
Michelle Sie Whitten, President & CEO, Global Down Syndrome Foundation

Length: 75 minutes
Date: Friday, February 19, 2021
Time: 2:30pm-3:45pm ET

Description

The Global Medical Care Guidelines for Adults with Down Syndrome have been published in the Journal of American Medicine and are now available to share! These Guidelines provide the first evidence-based, medical recommendations covering nine important health topics for adults with Down syndrome. This presentation will cover the creation process, the feedback from family focus groups, and the toolkits available. We will discuss how local Down syndrome organizations can best use the Guidelines and answer your questions.

Presenter Bios

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.

Dr. Brian Chicoine is Medical Director and co-founder of the Adult Down Syndrome Center in Park Ridge, IL, serving the health and psychosocial needs of more than 6,000 adolescents and adults with Down syndrome since its inception in 1992. He graduated from Loyola University of Chicago Stritch School of Medicine and completed his Family Medicine residency at Lutheran General Hospital. He co-authored two books, *Mental Wellness of Adults with Down Syndrome*, and *The Guide to Good Health for Teens and Adults with Down Syndrome*. Dr. Chicoine has provided care for adults with intellectual disabilities for over 30 years and has presented/written extensively on caring for adults with Down syndrome. He is a board member of the Down Syndrome Medical Interest Group, and an author on the GLOBAL Guidelines.

Dr. Moya Peterson has been involved in the care of people with Down syndrome for most of her professional career, starting with children with Down syndrome at Children’s Mercy Hospital in Kansas City, Missouri, as a staff nurse. Her work with adults with Down syndrome eventually progressed to start a clinic. In 2009, Peterson started a clinic for adults with Down syndrome at the University of Kansas. It is a unique model in that it has a nurse practitioner as the sole provider. She is a member of the Down Syndrome Medical Interest Group, and an author on the GLOBAL Guidelines.

Presentation Outline:

- 1) Self-advocate's perspective on why the GLOBAL Guideline is important
- 2) Impact of the Guideline nationally for medical practitioners
 1. University of Kansas Adult Down Syndrome Clinic, Kansas City, KS
 2. Adult Down Syndrome Center, Park Ridge, IL
 3. Important and crucial role of JAMA publication
- 3) Overview of 14 recommendations covering 9 medical areas
 1. With special attention to:
 - I. Diabetes
 - II. Behavior
 - III. Cardiovascular Disease
- 4) Important next steps: The five-year plan
 1. Continuing to adhere to highest level of rigor through PICOT & Grade framework
 2. Sleep apnea & cancer
 3. Caregiver friendly & self-advocate friendly materials
 4. Research needs
- 5) Challenges and how local Down syndrome organizations can help
- 6) Q&A