

May 27, 2019

Dear Physician,

RE: Recommended Health Care Guidelines for Children and Adults with Down syndrome

Treating primary health conditions and related comorbidities lead to a better quality of life for all of us, but this is especially true for people with neurodevelopmental disabilities such as Down syndrome. My name is George T. Capone, MD and I am the Director of the Down Syndrome Clinic and Research Center at the Kennedy Krieger Institute in Baltimore, Maryland. Over the past three decades I have been committed to research that explores the co-morbid sleep, neurobehavior, and psychiatric disorders associated with Down syndrome. Since 1990 I have seen over 3000 families/patients with Down syndrome for evaluation and management from across the United States. This includes many patients with complex neurodevelopmental and behavioral concerns and adolescents and adults with complex medical (sleep disturbance, gastrointestinal disorders, thyroid disease, and obesity) and co-occurring mental health conditions.

My experience evaluating individuals with complex presentations underscores the importance that for some conditions screening medically asymptomatic individuals is warranted, rather than dealing with issues once symptoms have surfaced. It is important to look beyond observed behaviour for physiological factors that can benefit from proper diagnosis and treatment.

Comprehensive primary care health management should consider neurocognitive and behavioural development, mental health, weight management and metabolism, physical activity, healthy nutrition and restorative sleep. It is important to note that obstructive sleep apnea is very common in Down syndrome and that airway factors likely present a greater risk factor for sleep apnea than obesity for these patients.

I recommend the following tools to assist in the health care management of people with Down syndrome:

The American Academy of Pediatrics Health Care Guidelines (2011)
<http://www.healthychildren.org/English/health-issues/conditions/developmental-disabilities/Pages/Children-with-Down-Syndrome-Health-Care-Information-for-Families.aspx>

The Canadian Health Watch Table for Down Syndrome (2011)
<http://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/>


Expected release by 2020: Medical Care Guidelines for Adults with Down Syndrome
<https://www.globaldownsyndrome.org/medical-care-guidelines/>

The Down Syndrome Medical Interest Group (DSMIG-USA) is a group of health professionals committed to promoting the optimal health care and wellness of individuals with Down syndrome across the lifespan. DSMIG-USA seeks to educate professionals on the latest research and comprehensive care regarding Down syndrome, facilitate networking among health professionals caring for individuals with Down syndrome, support the development of Down syndrome clinics, and identify and disseminate best practices of care. DSMIG-USA maintains a website and hosts an annual symposium.

www.dsmig-usa.org

These tools aim to improve access to evidence-based medical care for people with Down syndrome and equip primary care physicians with the knowledge to provide this care with confidence. By following the health care guidelines, we can effectively raise the bar for quality of life for people with Down syndrome and their families.

Sincerely,



George T. Capone, MD
Director, Down Syndrome Clinic and Research Center
Kennedy Krieger Institute
Associate Professor of Pediatrics
Johns Hopkins University
Baltimore