



MEDICAL MANAGEMENT OF SMS ACROSS THE LIFESPAN - JULY 12, 2024

Ann C. M. Smith, MA, DSc (Hon) & Gail Reiner, DNP, FNP-C

Newborn to Early Adolescence – 1:00 PM – 2:15 PM • Reunion B
Transition to Adulthood – 2:30 PM – 3:45 PM • Reunion C

Natural history studies are an important tool for understanding the etiology, range of manifestations and progression of rare diseases like Smith-Magenis syndrome (SMS). This workshop examines the guidelines for medical management and treatment for individuals with SMS developed by PRISMS Professional Advisory Board that were updated in 2018. Management involves evaluation for manifestations of SMS and treatment to mitigate associated symptoms and conditions. Ongoing surveillance recommendations as well as health promotion strategies will also be discussed. Each session will address general and age-related issues.

I. Medical management recommendations for SMS

- A. At Diagnosis
- B. Infancy to Early Adolescence
- C. Across the lifespan – surveillance and transition from late adolescence to adulthood: caveats from SMS Natural History study that warrant attention and management intervention.

II. Problem Identification in SMS - Personalized problem management

- A. Health promotions strategies & transition to adulthood
- B. Hands-on approach/practical tips that work for the child/adult with SMS and entire family

III. Added Resources/Links:

SMS Medical Management Guidelines and Checklist (v1.2018), available at <https://www.prisms.org/about-sms/living-with-sms/medical-management-guidelines/>

Bright Futures/AAP Recommendations for Preventive Pediatric care (2024): <https://www.aap.org/en/practice-management/care-delivery-approaches/periodicity-schedule/>

Apps for individuals with developmental disabilities that can be customized to the needs of the individual <https://www.trend-able.com/25-life-changing-apps-for-people-with-disabilities/>

2024 Adult Preventive Health Guidelines: Ages 19 through 64 Years <https://www.uspreventiveservicestaskforce.org/uspstf/recommendation-topics/uspstf-a-and-b-recommendations>

Medical Passport application (CamRare) fillable pdf: <https://www.camraredisease.org/rare-patient-passport/>

PRISMS Clinic & Research Consortium (PCRC): Multidisciplinary SMS clinics are designed to expand the availability of comprehensive, clinically appropriate care for the SMS community (6 sites across USA). <https://www.prisms.org/about-sms/living-with-sms/sms-clinics/>

2022 PCRC Treatment Recommendation: Constipation in Individuals with Smith-Magenis Syndrome: Recognition and Recommendations for Treatment (AU: Gail Reiner, DNP, FNP-C, Myra Woolery, PhD, RN, APRN-CNS, CPON, and Ann C.M. Smith, MA, DSc (Hon.), CGC) <https://www.prisms.org/constipation-treatment-recommendations-for-sms/>

2024 PCRC Treatment Recommendation: Strategies to Address Emotional and Behavioral Challenges in Smith-Magenis Syndrome (SMS) (AU: Barbara Haas-Givler, BCBA; Kerry Boyd, MD; Christine Brennan, PhD; Mary Beall, Med; Hanna Hildebrand, MSOTR/L; Cora Taylor, PhD; and Rebecca H Foster, PhD.) <https://www.prisms.org/education/publications-and-resources/prisms-behavior-guidelines/>

Medical Management of SMS Across the Lifespan (Smith, Reiner)

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