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17 Essential Resources for PRISMS Families

1 **Website – www.prisms.org**
PRISMS is dedicated to providing information and support to families of SMs individuals, sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMs.

2 **Patient Registry**
The SMSPR is a collaboration between PRISMS and researchers. With a minimal time commitment and by providing extremely valuable information, families can help move SMS research forward by participating in the registry.

3 **Conference**
Join families, researchers, and professionals from around the world as we come together to learn, connect, and advance our understanding of Smith-Magenis syndrome (SMS). This conference is a unique opportunity to gain valuable insights, share experiences, and build lasting connections within the SMS community.

4 **International Partners**
PRISMS is dedicated to strengthening the SMS community by creating a global network of advocacy partners. Together, we strengthen the voice of SMS individuals and expand outreach, networking, and knowledge sharing.

5 **On the Road to Success Book and other publications**
PRISMS serves as a central clearinghouse for information about Smith-Magenis Syndrome (SMS). PRISMS publishes guidebooks and provides access to an array of external resources to best meet the needs of the community we serve. Among these is the On The Road to Success Book available in six different languages.

6 **Facebook Support Group Page**
You're not alone— join the Facebook Support Group page and connect with other parents and caregivers of SMs individuals.

7 **Webinars**
The PRISMS Education Committee has developed an extensive webinar library that contains educational information and resources about the SMS community at large.

8 **Professional Advisory Board**
The PAB consists of 14 individuals representing the diverse needs of the Smith-Magenis syndrome (SMS) community. It is an internationally recognized group of scientists, educators, and clinicians with expertise in SMS, genetics, molecular research, education, speech, development, and caregiver and sibling concerns. Most PAB members are actively involved in research and/or clinical activities related to Smith-Magenis syndrome.

9 **SMS Clinics/Clinic Visit Reimbursement Funds**
Clinics provide multi-specialty, comprehensive and compassionate care for patients with SMS. The clinics provide families an opportunity to receive medical and clinical care and/or treatment recommendations that they can share with their local providers. The PRISMS SMS Clinic Travel Fund Reimbursement Program supports families by helping to defray some travel costs associated with visiting a clinic.

10 **Medical Management Guidelines**
PRISMS Professional Advisory Board has created a set of Medical Management Guidelines and associated Checklist for SMS to best inform families and the physicians who serve them on evaluations to be conducted following initial SMS diagnosis, treatment of manifestations, and ongoing surveillance of the syndrome.

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11 **Awareness Materials/Awareness Toolbox**
PRISMS is dedicated to helping you spread the word about SMS. Educating your friends, neighbors, family, physicians, educators, and more is exactly how to bring understanding and support for our rare community. PRISMS has SMS Awareness tools available, at no charge.

12 **PRISMS Store**
The PRISMS store is the perfect place to find PRISMS accessories, apparel and gifts for everyone. It also carries our On The Road To Success book in a paperback version.

13 **Summer Research Scholars**
Through our Summer Scholars Program, PRISMS supports emerging scientists and researchers as they pursue impactful projects that offer valuable early-career experience while advancing progress in SMS research.

14 **Research Symposium**
PRISMS proudly hosts the biennial Smith-Magenis Syndrome Research Symposium. This unique event brings together researchers focused on Smith-Magenis syndrome to share the latest findings, collaborate on ongoing studies, and expand the overall understanding of this syndrome.

15 **Advocacy Partners**
One of the most significant drivers of progress in rare disease research is the formation of strong, collaborative partnerships. Collaborative partnerships allow stakeholders from various fields – including researchers, clinicians, pharmaceutical companies, patient advocacy groups, and government agencies – to pool their resources and expertise. At PRISMS, we recognize the importance of partnerships in supporting our SMS community and have strived to build these partnerships over the years.

16 **Regional Representatives**
PRISMS' Regional Representatives are dedicated individuals who support individuals and families affected by Smith-Magenis syndrome (SMS). Each representative is a family member of someone with SMS who volunteers to support the community by helping families access information and stay connected to PRISMS' programs and services. They also organize local gatherings that create meaningful opportunities for families to connect, share experiences, and build lasting relationships.

17 **We can't do all this without the support of our donors: Donate Here**

Your donation directly supports the programs, resources, and services that PRISMS provides to families and professionals seeking guidance and connection. Because PRISMS receives no government funding, our work depends entirely on the generosity of donors like you. With your help, we can make a lasting difference in the lives of those affected by SMS, their families, and the professionals who serve them—raising awareness, expanding knowledge, and advancing vital research on this rare and life-changing syndrome.

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