



spectrum

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME



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P R E S I D E N T ' S M E S S A G E

GOOD WISHES TO ALL. I HOPE YOUR HOLIDAYS WERE SAFE AND JOYFUL.

This time of year can be challenging just by itself. Add in the emotions, elevated energy, hidden expectations and more that our SMS family members can bring with them, and our holiday moments are likely to take an unexpected and surprising turn.

The way we all survive the season—hopefully with peace, joy and a sense of family—is what makes us special and binds us together. I appreciate all my friends in the PRISMS community. If nothing else, I know support and understanding is just a phone call away.

On behalf of the PRISMS Board, I am excited to say our plans for new programs in 2017 mean this will be a year of growth for PRISMS.

On October 14-16, board members gathered in Raleigh, NC for our fall face-to-face meeting. We had two critical goals: to establish the annual plan of work and to develop a budget for the coming year. We also identified some new programs to offer to our community.

Our new genetics counselor, Dianne Samad, will continue to be available for families and to support the work of our Professional Advisory Board. We will build upon this new program, and launch a patient registry to gather data and provide information for researchers and, ultimately, to help our families. In the fall, the PAB will gather for a research symposium to share new insights in a variety

of fields, and to update our list of research needs and opportunities.

We plan to launch several internal initiatives, including an update of the website so it is easier to use and up-to-date with useful information. We will coordinate our various social



media platforms so information is consistent and available in a variety of ways. And we will refresh our membership program so we attract and retain more families in our community.

The entire board was present at the meeting, including our two newest members—Denien Rasmussen, chair of the Fundraising Committee, and Rebecca Hallmark, chair of the Conference Committee. We covered a lot of material in our three days

together; by the end of the weekend we were exhausted albeit inspired by our plans for 2017.

As we look forward to 2017, there are some potential risks in the way schools and government agencies will support our children. Even without changes to existing programs or services, PRISMS recognizes the need to provide advocacy, support and access to information that can help you with a dispute or crisis.

During the year, a small workgroup will begin to identify ways to develop an advocacy program. As this new initiative takes form, we will share information about our goals and the services we can offer. In the meantime, please help us by sharing your thoughts about how to shape this program—and certainly let us know if you encounter a problem with your school or other programs.

Working together, we can do anything.

Best wishes to you all!

John Mayer
President, Board of Directors



2017 INITIATIVES

Growing resources and strengthening the SMS network





2017 PRISMS THEME

2016 was an incredible year for PRISMS. It hosted more than 40 attendees at its 8th International SMS Research Symposium and more than 350 attendees at its 9th International Building Bridges of Hope Conference.

It released the first residential living guide for adults with SMS, funded a genetic counselor position at Baylor College of Medicine to increase services to SMS families, launched an International Partnership Program, expanded its Regional Representative network, and funded SMS training for more than 15 educators and support staff.

With its awareness and educational materials, PRISMS has served more than 30,000 people around the world. That's 30,000 people who have now seen and can recognize the words "Smith-Magenis Syndrome." But we're not stopping here.

Our theme for 2017 is **"Growing resources and strengthening the SMS network."** With your support in 2017 PRISMS will:

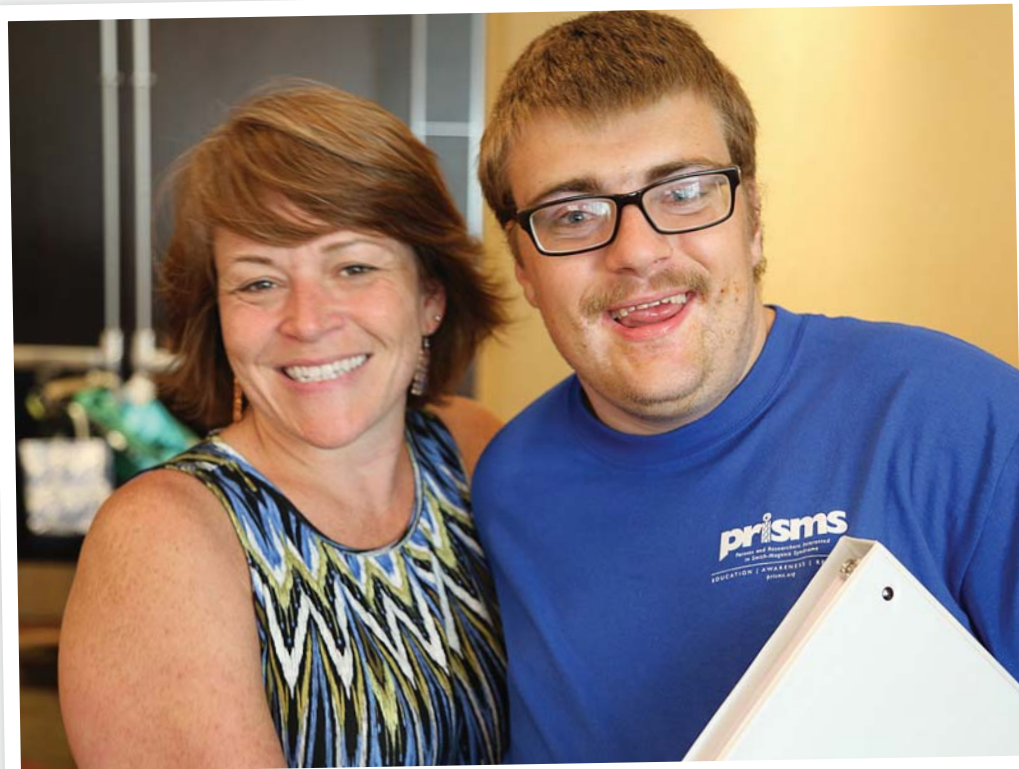
-  Host its 9th SMS Research Symposium—the only research event of its kind solely dedicated to Smith-Magenis Syndrome.
-  Launch the Smith-Magenis Syndrome Patient Registry with Redcap at Baylor College of Medicine. This international research project will allow SMS families to share their experiences with Smith-Magenis Syndrome by completing a series of surveys, centralizing information on SMS and expediting research potential for the condition.
-  Sponsor a multi-year, post-doctoral fellowship to support research in a discipline deemed critical by the PRISMS Professional Advisory Board, a multi-disciplinary panel of experts in SMS.
-  Strengthen the PRISMS Regional Representative program and International Partnership Program, allowing for increased communication and collaboration on SMS around the world.

- Enhance and grow SMS awareness campaigns with the support and expertise of a professional marketing team to allow for increased knowledge of SMS globally.
- Expand its services to members with enhanced new member packets, updated medical management guidelines, and improved awareness material.

Our exciting initiatives for 2017 are a **more than \$250,000 investment** in education, awareness and research for the entire SMS community. PRISMS is proud to work on behalf of you, your family, and your needs.

PLEASE CONSIDER GIVING BACK TODAY.

*Please consider supporting PRISMS work today!
Make a tax-deductible donation by going to
www.prisms.org and selecting “How to Help.”*





When an SMS Sibling Becomes a Guardian

By Stacey Collins

I always knew I would become responsible for my brother Craig's care when our mother died, yet I still felt overwhelmed when she passed away in 2007. I had so many unasked questions, so much to learn, and so many unresolved emotions to handle that I didn't know how I was going to proceed. But I was blessed that she had worked tirelessly for 47 years for Craig's well-being, and she had planned diligently for his future every step of the way.

Craig is now 55. I am two years younger, and I became his guardian and conservator shortly before our mother became terminally ill. When preparing to write this article, I asked myself what I wish I'd known at the time and what I think are the most important things to share based on my experiences. I'd like to start with a little background on how my mother handled having a child with Smith-Magenis Syndrome.

When Craig was born, there were no public services for anyone like him; there was no one to turn to for advice; no data or empirical information to reference. There wasn't even a name for what he had. But my mother refused to give in to the doctors' recommendation that he be institutionalized. Instead, she spent the next four decades fighting for and creating programs for him and others with developmental, mental, and physical challenges in our community. Thanks to her efforts, when the time came for me to become his guardian, Craig was already established in a government-run group home and had a team of people dedicated to his support and well-being.

Looking back, I realize that our family didn't have enough in-depth conversations about Craig's needs and how to manage them. Because our mother handled everything, my

“ I also wish that our entire family had discussed how we were going to work together to make sure Craig was taken care of, while also sharing our feelings and philosophies about his future. ”

two other brothers (who are older than Craig), our father, and I didn't fully understand how and why decisions were made and, at the time, we didn't appreciate the importance of everyone being informed and in agreement about his care.

I wish I had asked her more specific questions about working with government officials, about his medical issues, and about how to handle his behavioral outbursts. I also wish that our entire family had discussed how we were going to work together to make sure Craig was taken care of, while also sharing our feelings and philosophies about his future.

Conversation and idea sharing have been particularly essential in the process of creating and implementing Craig's behavior plan. All of us who care for or about someone with SMS know the syndrome entails complicated behavioral challenges. I can look back on a lifetime of successes and

failures when coping with Craig's behaviors, from charts at home to countless hours with multi-disciplinary specialists trying to figure out the best ways to anticipate, avoid, and manage negative behaviors.


We tried so many different things, including state-of-the-art therapies, medications, in-patient psychiatric care, and even police and community input on how to respond to public outbursts. Some strategies worked well for a time, while others failed right away. Our current behavior plan has been in place since 2013, and it has made an incredible difference in Craig's life. It took more than a year to develop and it incorporates input from every person who has a role in Craig's care, from residential staff and administrators to day program providers, family members, and Craig himself.

The key to the plan's success is that we all stick to it diligently. If a negative behavior escalates now, it is usually because there was some inconsistency in how we acted or reacted. Craig also tracks his behaviors every day and enjoys and takes pride in following the plan.

In closing, I'd like to emphasize the following points:

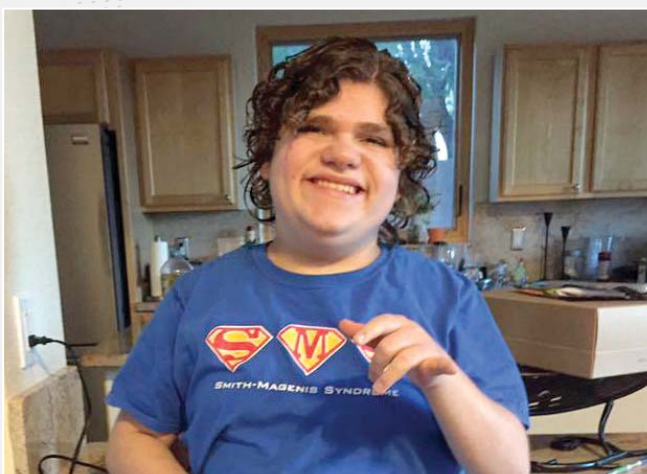
The greatest gift my mother gave me was planning for my brother's future. She never shied away from making difficult decisions she knew would help me care for Craig.

Open communication among family members and caregivers about expectations and responsibilities is essential.

Helping an SMSer manage his or her behavior requires a plan they can understand and follow, and that is implemented consistently by everyone involved in their lives. 

ON NOVEMBER 17 WE CELEBRATED SMS AWARENESS DAY!

This is a day dedicated to spreading education and understanding of Smith-Magenis Syndrome around the world. PRISMS, Inc., encouraged you to take action throughout the month of November and you did! Throughout the month of November, PRISMS photos, posts, awareness materials, blogs, and educational resources were shared with more than 30,000 people around the world, thanks to you!





IEP PROGRESS REPORTS SHOULD BE DATA DRIVEN

By Sylvia Farber

Parents, the next IEP progress report (issued concurrent with report cards) should be arriving soon. The IEP progress report is crucial for monitoring student progress, and it should be given close attention. It is imperative that data-driven information be reported.

Following are some points to make sure the IEP progress report is an accurate measure of your child's progress.

1. Make sure you receive an IEP report *every* time a report card is given.
2. The report should tell you how close the student is to reaching the goal; it should reflect language similar to the goal. If the goal is about double-digit addition, the report should reflect progress on double-digit addition. If the goal is about maintaining social interactions, the report should reflect progress on the student's social interactions. If the goal is about physical aggression, the report should reflect progress on physical aggression.
3. Make sure the report reflects data-driven information.

Examples:

- Average of 60% on last three trials of double-digit addition
- Of the last 4/5 opportunities, the student maintained an interaction for at least five minutes and had at least three verbal exchanges
- There has been one incident of biting and zero incidents of hitting in the last two weeks

Generic, non-specific information *does not* provide a good measure of student progress. Examples:

- Student is making good progress
- Student is working really hard
- Student is expected to meet goal by annual meeting

If you receive an IEP progress report that does not reflect data-driven information, send it back and request it to be resubmitted. Make sure the staff understands moving forward that the expectation is to receive a report that reflects data-driven information.

Additionally, if you would like to see work samples or the data used to complete the progress report,

ask for it. Remember, this report is valuable for you to understand your child's progress throughout the year. Accurate progress reports will help you know if your child's progress is adequate. If progress is not adequate, a meeting should be held to evaluate/discuss why progress is not as expected. If the rate of progress is better than expected, a meeting should be held to revise/create new goals.

By expecting data-driven information and using the progress report to monitor student progress, there should be no surprises at the annual meeting. 🌀

Sylvia Farber is an advocate in Texas. She and her husband, Jeremy, are the parents of Ryne, 12, and Austin, 13, who has SMS.



Welcoming Individuals and Families into the SMS Community

The PRISMS Regional Representatives network is composed of volunteer SMS families around the world who are dedicated to welcoming individuals and families into the SMS community, sharing information and providing support to other SMS families, and participating in cultivating their local and regional SMS community through meet-ups.

PRISMS invites you to complete this survey <https://www.surveymonkey.com/r/PRISMSRegionalReps> if you are interested in connecting with other SMS families through an organized local, state or regional SMS meet-up. Your feedback is valuable and greatly appreciated.

Questions? Email Emily Fields, Executive Director, efields@prisms.org

TAKE THE
SURVEY



SMS BOWLING



PRISMS is grateful to the Farber Family (San Antonio, TX) for, once again, hosting their Bowling for SMS fundraising event on November 17 in support of PRISMS mission and the entire SMS community. This year, the Farber Family raised more than \$16,000 for PRISMS and our programs dedicated to education, awareness, and research. Thank you Farbers and all who came out to support your fun and fantastic event!





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FIND US ON SOCIAL MEDIA

Host a fundraiser or awareness event in your area

Contact info@prisms.org for support and ideas to make your event a success

Join the PRISMS community by becoming a member for 2017

Learn more about membership by visiting our website at www.prisms.org

Make a donation

Support PRISMS mission to increase awareness, education, and research for the SMS community by visiting our website and making a donation today at www.prisms.org

Share your story with us

We want to hear from you. Reach out to PRISMS Executive Director at efields@prisms.org



EASY SUPPORT FOR PRISMS

Support PRISMS while you shop. Amazon will donate 0.5% of the price of eligible AmazonSmile purchases to PRISMS.

AmazonSmile is the same Amazon you know—same products, same prices, same service. Follow these simple steps to support PRISMS while you shop!

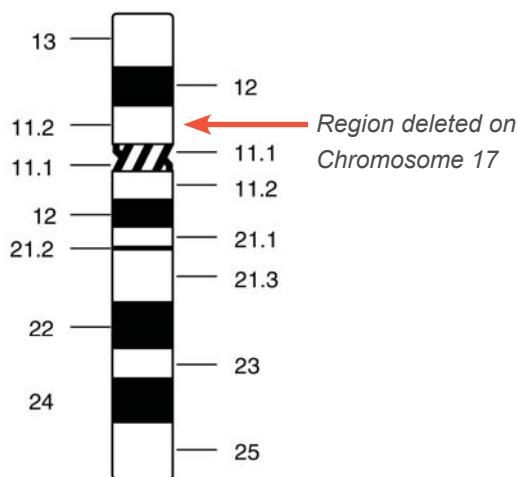
1. Go to www.smile.amazon.com
2. Type “PRISMS, Inc” in the pick your charitable organization text box. Click Search. (Note: type PRISMS in capital letters.)
3. Select “Prisms, Inc.” There are a few organizations with the same name. Choose the PRISMS in Sterling, VA founded in 1993. Click “about” if you want to confirm you have chosen the correct PRISMS.
4. Save smile.amazon.com to your bookmarks or favorites bar to make it easy to return to AmazonSmile. In order for PRISMS to receive a percentage, you must shop through smile.amazon.com.
5. Share with friends and family.
6. Enjoy shopping knowing you are supporting PRISMS!



What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2.

The first group of children with SMS was described in the 1980s by Ann C.M. Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is under-diagnosed, but as awareness of it increases, the number of people identified grows every year.



VOLUNTEER OPPORTUNITIES

PRISMS is always looking for helping hands from the community to serve as members of one of our various committees, assist in a program, or coordinate an event. Interested in sharing your time and talents with the SMS community? Contact us at info@prisms.org.

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