

PRISMS 2012



Annual
Report

PROGRESS

Parents and Researchers Interested in Smith-Magenis Syndrome



Our 2012 Board of
Directors, volunteers
with a drive for
excellence!

Mission Statement:

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), and fostering partnerships with professionals to increase awareness and understanding of SMS.



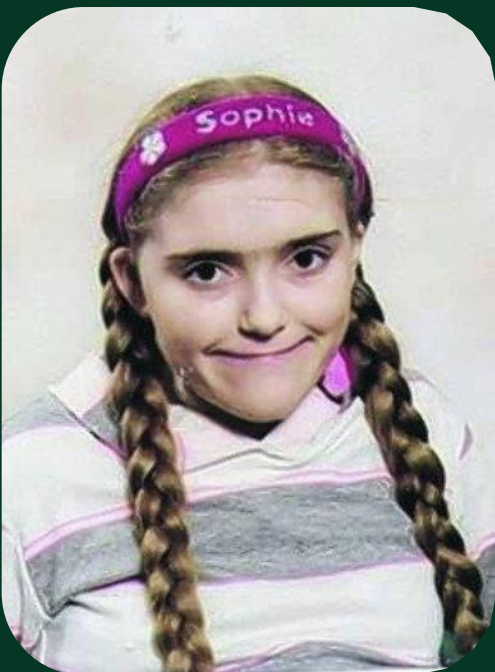
PRISMS is 20 years old. Happy Birthday to Us!!

This 20th birthday made me think of the many people whose efforts have improved the lives of people with SMS.

Everything we now know about Smith-Magenis Syndrome...the characteristics and the treatments...came from a huge amount of work by researchers with help and cooperation from our families and our children. For years, the PRISMS Professional Advisory Board (PAB) has served PRISMS without compensation for their time, sharing information with parents and each other to increase our understanding of this rare syndrome. Even before PRISMS existed, a small group of researchers was already collaborating and studying SMS. In those early days, a few researchers began to share information and ideas with each other. Those researchers included Ann C.M. Smith, Dr. Ellen Magenis, Brenda Finucane, Barbara Haas-Givler, Dr. Frank Greenberg, Dr. James Lupski and Dr. Lorraine Potocki. Then the next steps began towards making PRISMS a reality, with collaboration between researchers Ann Smith and Brenda Finucane, and Maggie and Scott Miller, parents of a child with SMS.

One of the worst things about coping with any rare diagnosis is feeling alone. If you're like me, no one in your family, actually no one you know, has ever even heard of SMS, and they sure don't know anything about it. That's why it's so important to be a part of PRISMS. Let us be your "SMS family." We can connect you to others who understand, and keep you informed with all of the latest and best information about Smith-Magenis Syndrome. And we can laugh together about the cute, funny things our kids say and do.

PRISMS can help you, and you can help PRISMS. Some of the most practical help available comes from other parents. Volunteer parents write articles, speak at our conferences, post on the PRISMS Facebook page,



“PRISMS is like our home base. We check in with PRISMS quite a bit for new updates and events, & love to read the characteristics & help for teachers. It keeps me grounded & refreshes my mind when the behaviors get bad.”

raise money, help plan events, participate in research and comfort other families.

Raising a child with SMS can be an overwhelming task. You may not have any energy left over to give, but please do what you can to support **your** organization. One thing that really helps to support PRISMS is to pay your membership dues each year. The dues are only \$35 per year and help to sustain a variety of programs. You can renew your membership online directly on the PRISMS website, or you can print out the form and send it in the mail. Working together, we can support each other, help the newly diagnosed families, and raise awareness of SMS.

We have a little group of families here in Dallas where we live. We met them when they joined PRISMS. We’ve shared many fun outings with the understanding that, as one of the invitations stated, “We’ll party until the first child melts down.” Now that’s my kind of party, one where everybody “gets it!”

PRISMS has been committed to supporting and connecting families, but also to providing the most accurate and up-to-date information on this syndrome. This year, many of you were sharing “SMS facts” on the Internet for SMS Awareness Day. Thank you. It’s so important to share correct information. Please continue to share; but we also have a request...point people back to the original source of the information. Our Professional Advisory Board and dedicated researchers have devoted a tremendous amount of their professional careers to the research of SMS so they may provide us with more tools to help our children. We update the PRISMS website regularly with the latest research papers, authored by these researchers. Keep spreading the news, and at the end of your facts, cite the author’s name or the website where it is published so the readers know where to go to learn more.

I look forward to seeing everyone at our 2014 conference in St. Louis. Together we are making a difference!

Warm regards,

Randy Beall

PRISMS, President

Father to Laura, age 27, with SMS

Behind the scenes work is on-going, with the Board of Directors meeting via teleconference monthly, and face-to-face two times a year.

PRISMS Professional Advisory Board (PAB)

PRISMS' ten-member Professional Advisory Board (PAB) serves to advise the Board of Directors on medical, scientific, educational and therapeutic matters and to assist in the education and research activities of the organization. An internationally recognized group of basic scientists, educators and clinicians with expertise in SMS, the PAB assists in the development of accurate and effective informational and promotional materials, and writes and edits articles for the Spectrum newsletter, the PRISMS website and other publications. The PAB is focused toward the dissemination of accurate medical information regarding diagnosis, management and genetic counseling. Members of the PAB respond to inquiries directly from families, caregivers, educators and healthcare providers, give presentations and provide consultations at the PRISMS conference, and provide comprehensive support to the broader community via the Smith-Magenis Syndrome GeneReviews. In 2012, the PAB collaborated to update the SMS GeneReviews:

<http://www.ncbi.nlm.nih.gov/books/NBK1310/>

During 2012, SMS research enhanced our knowledge and understanding of the molecular changes affecting sleep disturbance, detailed the breadth of neurosensory issues in children with SMS, investigated the sibling relationships in

families with typically developing children and children with SMS, and contributed to our understanding of the function of *RAI1*, the critical gene in Smith-Magenis Syndrome. Current studies on eating behaviors, neuronal stem cell characterization, and the cellular function of *RAI1* are in process by scientists around the world and will further enhance our understanding of this complex disorder.

The PAB and the PRISMS Board of Directors also came together in 2012 to support the creation of an SMS Biobank in collaboration with Coriell Cell Repositories, an NIH funded entity that collects and stores DNA and cell lines for use in research of both rare and common disorders. The PRISMS community came out in strong support of this endeavor at the PRISMS conference in Denver, CO, contributing more than 45 blood and skin samples for cell lines generation. These cell lines will provide much needed support for ongoing and future research studies to improve our understanding of SMS.

Funding of both novel and ongoing research endeavors is critical for improved support for families, caregivers, educators and healthcare providers caring with anyone with Smith-Magenis Syndrome. Only through research can education, treatment and management of SMS be improved. The PAB strives to bring the most current information to the members of PRISMS.



SAVE THE DATE for the 8th INTERNATIONAL PRISMS CONFERENCE

"BUILDING BRIDGES OF HOPE"

When: Thursday, July 31, 2014 – Sunday, August 3, 2014

Where: The Hilton St. Louis at the Ballpark, St. Louis, MO

Please start making your plans to attend the conference. Families and researchers from around the globe will be in attendance and we will spend a few days together learning about new research and interventions regarding Smith-Magenis Syndrome. Attendees will also have the opportunity to spend time in a caring and supportive environment, and sharing special time together. The city of St. Louis has many historical and family-friendly sights within walking distance, and the conference hotel is set amidst the backdrop of the famous Gateway Arch.



Financing 2012



PRISMS financial goals include funding its continuing program services, supporting research opportunities and preparing for the 2014 conference. Membership contributions, product sales and fundraisers are all important components of our strategy to fulfill these goals. Thanks to the substantial support of our members, 2012 can be described as a resounding financial success for PRISMS and its members. Membership support for the conference in the form of over \$31,000 in conference sponsorships and several fundraisers initiated by members combined with tight management of expenses resulted in PRISMS realizing an increase in assets in 2012. This is a reversal of prior conference years where the organization would run a deficit. In last year's Annual Report the Board noted it was expected that PRISMS would draw down its assets by \$100,000 to fund the conference but when the year was over assets actually increased by over \$40,000. With the next conference less than two years away instead of three (as was the case with the 2012 conference) PRISMS is in an outstanding financial position to fund our next event and expand its support of SMS research.

In 2012, PRISMS total contributions including conference sponsorships increased by over 250% versus 2011 to over \$120,000. Total membership fees increased in 2012 by over 150% which is consistent with a conference year as members re-engaged with the organization. Advance planning for the 2014 conference has already started and PRISMS expects to start to incur conference costs in 2013. Overall, 89% of total expenditures in 2012 were devoted to program expenses and the 2012 conference.

PRISMS remains committed to supporting its membership through its programs and supporting research. It is through the hard work of our dedicated membership that this goal is realized.

Support and Revenue	<u>2011</u>	<u>2012</u>
Conference	\$ -	\$ 48,760
Grants	-	\$ 4,000
Contributions	\$ 48,252	\$ 122,252
Membership Fees	\$ 6,914	\$ 10,895
Interest Income	\$ 1,241	\$ 733
Fundraising	\$ 3,714	\$ 16,081
Total	\$ 60,121	\$ 202,721

Expenses	<u>2011</u>	<u>2012</u>
Conference and Research	\$ 12,492	\$ 120,561
Programs	\$ 20,573	\$ 18,450
Management and General	\$ 11,749	\$ 12,405
Fundraising	\$ 2,615	\$ 4,059
Total	\$ 47,429	\$ 155,475

	<u>2011</u>	<u>2012</u>
Increase (Decrease) in Total Assets	\$ 31,448	\$ 40,711
Ending Cash	\$ 232,180	\$ 277,252
Ending Total Assets	\$ 247,376	\$ 288,087



Supporting PRISMS

2012 was a successful year for PRISMS fundraising! SMS families from across the country held events in their local areas to raise money for PRISMS as well as awareness for Smith-Magenis Syndrome.

Students from Dayton High School in Kentucky assisted Jean Weil and Sherri Chan with the 3rd Annual Nickels for Nicco Corn Hole Tournament. Jeremy and Sylvia Farber went "Bowling for SMS" at their Texas bowling alley...on SMS Awareness Day. Todd and Heidi Carpenter held a successful fundraiser in Michigan with the Moose Lodge. Bill and Monica Mason hosted a golf outing in Cochranville, Pennsylvania. Charlie and Tina McGrevy hosted the 6th Annual Buck Creek 5K in Ohio. Hetherington Pottery in South Carolina donated profits from their holiday office sales.

In Wisconsin, Patti Schiller wrote a campaign letter and mailed it out to her family and friends. Denien Rasmussen is selling gift cards through the Manna Group Scrip Program from Illinois. Diane Erth sold Scentsy products during the PRISMS conference and donated her commission to PRISMS.

PRISMS continues to host an online giving page at www.firstgiving.com/prisms. The families of Nolan Jantzi, Jacqueline Huston, Laura Beall and Christy McCauley held virtual birthday parties in their honor. "Bowling for SMS" and "Buck Creek 5K" created an event page so that participants (and those who could not attend the actual event) could donate to the fundraiser.

PRISMS volunteer, Michelle Lee, updated the PRISMS online store, "PRISMS 2.0." Michelle also compiled the first PRISMS calendar, our most successful product! Plans are in the works



for the 2014 PRISMS calendar, so start capturing those SMS moments now. It's not too late to order the 2013 calendar. Visit www.cafepress.com/smithmagenis.

PRISMS cookbooks were a huge success. Place your order on the PRISMS website at www.prisms.org before they are gone.

Please contact me at fundraising@prisms.org if you would like more information on how to host a fundraising event in your area. Thanks to these many volunteers who help make the past year a huge success!

Tina McGrevy, Board Member

Our PRISMS store has been updated!

Visit www.cafepress.com/smithmagenis and check out the new SMS awareness items. PRISMS volunteer, Michelle Lee, has been working hard to add new ways to spread SMS awareness. Find more clothes for women, men, kids...even the family dog! We have stationary and phone cases, buttons for your coat and a magnet for your car. At the end of the day, relax in your PRISMS pajamas. (Sorry, sleep NOT included!)

Order the 2013 PRISMS calendar! Filled with photos submitted by PRISMS families, it is a great way to spread awareness every day of the year. Remember PRISMS gifts for birthdays, graduations and special occasions. PRISMS receives a portion of the profits from every sale.

The 2012 PRISMS “Building Bridges of Hope” Conference Summary



Building
Bridges of Hope

prisms 7TH INTERNATIONAL
CONFERENCE | DENVER 2012

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome, sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.

The above mission statement for Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) was seen alive and in action in Denver, Colorado at PRISMS 7th International Conference, “Building Bridges of Hope.” This was our largest conference yet! Common sights that were observed were parents gathering to decide which sessions to go to, professionals deep in conversation with families and lots of hugs and happy greetings all around. Of course, the total acceptance of SMS individuals and the support given those during meltdowns was incredible.

Families and professionals came from across the globe. The United States, Canada, Philippines, United Kingdom, Finland, Norway, Sweden, France, Denmark and Mexico were all represented. There was record attendance by parents, siblings and individuals with SMS.

The speakers were diverse, with presentations on subjects such as genetics, research, siblings, behavior, education, alternative therapies and nutrition, medications and life experiences. Our families had overwhelmingly requested presentations on behavior to be available at the conference, so behavior supports was an overriding theme throughout the conference. Many of our speaker handouts are on our website, so if you

didn't have the opportunity to attend the conference you may still get a glimpse of some of the materials presented.

There were also many special events planned, including an opening reception, several parent connect sessions, a hospitality suite, meals, movie night and a silent auction. There was so much enthusiasm at all of these events! At times, it was like a large family reunion!

SMS researchers convened the Thursday prior to the conference start for The 6th SMS Research Symposium. Researchers from various research sites and institutions came together to share their research of SMS. This meeting unites those on the research fronts in areas of molecular genetics, clinical genetics, special education, speech, occupational and physical therapies, and sleep disorders. The Research Symposium works in tandem with the goals of the PRISMS conference, and the partnership between “parents and researchers” stays rooted and cohesive. Many of our symposium attendees were also presenters at the conference. We are very grateful that we have such dedicated researchers and professionals who not only bring their expertise to the conference, but also become a valued part of **our** community.

A new addition to our conference was the presence of The Coriell Institute for Medical Research. Coriell was onsite to obtain blood and/or tissue samples for the PRISMS Biobank from volunteer parents and SMS individuals. In the study of human genetic disorders, samples from patients and their families are a critical resource for researchers; however, it is often a major hurdle to



identify families with specific chromosome abnormalities like SMS. Many of our families stepped up and aided us in developing a repository of cell lines. For more information on the PRISMS Biobank, please visit our website at www.prisms.org.

PRISMS was fortunate to have a wonderful conference planning committee. It was composed of Nina Kelly, Nancy Cordrey, Maggie Miller, Shannon Jantzi and Amy Pereira. These ladies worked tirelessly for over two years to bring this conference to fruition. The feedback was fabulous! The committee followed up the conference with a questionnaire and went right to work with the feedback and suggestions. They began immediately putting together the next conference.

Of course, none of this could have happened without a multitude of

volunteers and financial support from individuals and corporations. PRISMS is grateful for each contributor, whether it be in a large or small way through time, money and/or donations of materials.

We hope that all who attended took away valuable information and perhaps made new friendships along the way. See you in 2014!



2012 Conference Donors

Donors (organized by level)

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Thomas and Julia Hetherington
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Up to \$100

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Contributions for Speakers' expenses

Smith-Magenis Research Foundation (expenses of Dr. Gi)
Nancy Cordrey (expenses of Jackie Diver)

In-kind gifts and donated services for the conference

Dance Trax Entertainment
Frederic Printing

*We are grateful to the
many donors who made
special and generous
gifts in support of the
conference!!*

**Thank
you!!**



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Membership 2012

At the end of 2012 there were 328 individuals or families who were members of PRISMS. This is a significant increase from our 2011 total of 272. We added members throughout the year, and several individuals and families joined at the conference in Denver. Our member list shows that PRISMS serves families across the country and around the world, with members from 45 states and 15 foreign countries. For your information, states without members are Alaska, Hawaii, Louisiana, Mississippi and West Virginia.

There are many benefits from membership including receiving helpful information via the *Spectrum* newsletter, the monthly e-blast, the PRISMS website, and the PRISMS Facebook page;. Other advantages are making or strengthening a connection with others at our international conferences; by receiving materials for family members, teachers, and advocates and more.

Most importantly, your membership dues provide the financial resources PRISMS needs to operate – and this support enables us to help families. The organization is here for our members, and we are able to do our job because of your support.

2013 will be an important year as the Board focuses on ways to improve our support for families, and as we begin to prepare for the 2014 conference in St. Louis.

Thanks to all of you who are part of PRISMS – and to my colleagues in the PRISMS office and on the Membership Committee for their efforts: David and Denise Smith, Mary Kate McCauley, and Angela Williams.

Please note - Membership dues are for the calendar year, January through December, regardless of the month you have joined. If you have any questions about your membership, please do not hesitate to contact us.

John Mayer
PRISMS Membership Chair



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