



Annual Report 2015

Reaching New Heights and Providing New Services







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ED U	JCATION AWARENESS RESEARCH

prisms.org

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2015—What a Success!



Emily Fields, Executive Director

PRISMS Friends,

It's difficult to imagine that 2015 is behind us already. How time flies when you're getting things done! I began my time with PRISMS in January 2015, and I have been stunned at the many successes we, as an organization, have been able to accomplish with your support over the last year.

Some of the organization's many accomplishments of 2015:

- Hiring and onboarding an Executive Director.
- Publishing four translations of "On the Road to Success with SMS" in Spanish, German, Danish, and French.
- Completing the organization's first Strategic Plan.
- Launching the creation of a new publication focused on adult residential settings for those with SMS and their families.
- Growing the Regional Representative program to offer more support to families and members.
- Refreshing the PRISMS brand through work with a professional designer.
- Expanding social media and awareness campaigns, including PRISMS Birthday, SMS Awareness Day and involvement in Rare Disease Day and GiveRare.

- Creating and releasing the organization's first promotional video to raise awareness and understanding of PRISMS' mission.
- Planning and promoting PRISMS' first SMS Research Symposium event separate from the International Conference.

Last year was one of great progress and transition. I am thankful to the PRISMS Board, a team of dedicated SMS families just like yours, who spend countless hours ensuring PRISMS is moving forward as an organization with the SMS community's best interests at heart. I am thankful to PRISMS Professional Advisory Board, a team of renowned experts who dedicate their time and knowledge to ensuring that PRISMS remains grounded in the best available knowledge. And I am thankful to each of you; your support is what makes all of the difference. Without dedicated members, volunteers, and donors in the community, PRISMS would be unable to effectively grow and enhance our programs and services to the Smith-Magenis Syndrome community.

There is much work to be done, but together I am confident we will move forward in education, awareness, and research for the entire SMS community.

Onward,

Emily

Emily Fields
Executive Director, PRISMS





2016 President's Message

John Mayer, President

Each year, in addition to our monthly teleconferences, PRISMS Board members meet in person to review our programs and to plan our activities for the coming year. When we met in October 2014, we boldly agreed that 2015 would be a year for "Reaching New Heights and Providing New Services." As you look through our Annual Report, I think you will agree: 2015 was transformative for PRISMS.

I became president of the board in January. Right around the same time, we hired Emily Fields as the first executive director for PRISMS. Organizing our resources, developing a plan for her work, and bringing Emily on board has dramatically changed how PRISMS works and what we can do for our families. Since Emily has been with us, she has effectively moved into the role of leading the organization and helping us build and strengthen the programs we offer.

During its search for a director, the Board became aware that it lacked a formal strategic plan.

Recognizing the need and importance of such a plan, in March we began the planning process with the help of consultant Robert Miller. We completed and approved the document at the end of 2015 and will soon share it with you. You will see there is much to the document. Most important, it focuses on building the scope, depth and quality of the services we provide our families. It is an inspiring roadmap for our future.

In 2015, I agreed to serve as the chair for a work group charged with developing a resource to assist families planning residential programs for their children with SMS. Over the years, I have heard families ask about this challenging process, and in response PRISMS has begun to put a publication together. I am proud to say we will have it ready in time for the 2016 conference.

You'll read in this Annual Report about our many other activities and accomplishments. None would be possible without the dedication and commitment of the Board, our staff and volunteers, and all those who have supported us. My thanks to all of you.

I am grateful to be part of such an important organization, and I am humbled to hear from our families who value and benefit from the support and services we provide.

There is much more to come, and 2016 will be another dynamic year of development and growth.

Thank you for your interest and your support.

See you in St. Louis!



Financial Report

Phil Ruedi, Treasurer

2015 marked a year of significant investment and growth for PRISMS. It welcomed its first paid executive director, Emily Fields; engaged an outside accounting firm to assist with financial reporting and controls; and invested in the development of a strategic plan for the organization.

PRISMS also started planning for the 2016 Research Symposium, which was held at Baylor College of Medicine in Houston in February, and for the 2016 International Conference, scheduled for July 28-30 in St. Louis.

Our program services continue to develop in an innovative fashion as PRISMS allocated money to support a genetic counselor at Baylor University and initiated the development of a publication focused on Adult Living for our SMS community. We consider this an exciting complement to our "On the Road to Success with SMS" publication for the school-age population.

Significant financial support from members allows PRISMS to make these investments while still improving our financial position. Donations in 2015 exceeded the 2014 total despite 2015 being a nonconference year. Cash balances increased again while the organization's cost base increased substantially.

PRISMS is in excellent condition to again subsidize the cost of the International Conference, including the expansion of the family scholarship program and the introduction of teacher scholarship program.

The PRISMS Board is excited by the financial strength of the organization as it opens up many opportunities to invest to help improve the lives of our member families and SMS individuals.





	<u>2015**</u>	<u>2014*</u>
Support and Revenue		
Conference Registrations	\$0	\$52,271
Product Sales	4,656	17,104
Contributions	237,705	228,601
Membership Fees	9,995	11,825
Interest Income	618	615
In-Kind Services	100	750
Assets Released from Restrictions	<u>0</u>	22,383
Total	253,074	332,611
Expenses		
Conference	9,575	167,156
Programs	55,570	82,678
Management and General	84,509	20,243
Fundraising	<u>8,672</u>	<u>7,137</u>
Total	158,326	277,214
Ending Cash	496,891	402,580
Ending Total Assets	721,794	528,876
Revenues and Expenses as Percentage of Contr	ributions 2015*	2014*
Support and Revenue		
Conference Registrations	0%	16%
Product Sales	1%	5%
Contributions	74%	69%
Membership Fees	11%	4%
Interest Income	1%	0%
In-Kind Services	0%	0%
Assets Released From Restrictions	<u>13%</u>	<u>6%</u>
Total	100%	100%
Expenses		
Conference	6%	60%
Programs	35%	30%
Management and General	54%	7%
Fundraising	<u>5%</u>	<u>3%</u>
Total	100%	100%

^{*} Audited

^{**} Unaudited



Professional Advisory Board

Sarah Elsea, Ph.D., PAB Chair



The 10-member PRISMS Professional Advisory Board (PAB) advises the Board of Directors on medical, scientific, educational and therapeutic matters, and assists in the education and research activities of the organization. The PAB is an internationally recognized group of basic scientists, educators and clinicians with expertise in SMS, genetics, molecular research, education, speech, development, and caregiver and sibling concerns.

As part of its mission, the PAB assists in the development of accurate and effective informational and promotional materials, and writes and edits articles for Spectrum, the PRISMS website and other publications. This dedicated group of experts responds to inquiries from families, caregivers, physicians, teachers and a variety of other healthcare providers to support the SMS community and ensure the dissemination of current and accurate medical information.

2015 was a busy year for SMS research with publications describing *RAI1* gene regulation and

concerns about sleep and developmental concerns, illustrating the complex web of interactions underlying sleep disturbance and growth and development in SMS. Additional studies describing the identification of clinical overlap between SMS and other disorders of childhood obesity may provide avenues to investigate concerns related to obesity, satiety and growth in SMS.

The SMS Biobank at the Coriell Cell Repositories now has more than 100 blood and skin fibroblast samples from individuals with SMS. These samples are provided with ready access for researchers anywhere in the world. This biobank provides a research infrastructure to facilitate studies of SMS, and will provide an unprecedented resource going forward to support SMS research. Thank you to those families who have donated samples to support this cause.

Members of our PAB have been engaged in SMS-related research and clinical activities throughout the year. Dr. Kerry Boyd was awarded a Phoenix Fellowship to create a "Curriculum of Caring" for people with developmental delays. Curriculum of Caring videos have been developed to allow people who might not otherwise have a voice to express their opinions, concerns and hopes to healthcare professionals, and one of these videos features an individual with SMS. These videos have become powerful vehicles to stir compassion and motivate students to engage in person-centered care.

Successful research is a partnership among families,



clinicians, scientists and funding agencies focused on improving research and knowledge about SMS. Continued support of research programs is critical for increasing awareness and understanding of Smith-Magenis Syndrome so that better therapies, treatments, education and other interventions can be identified or designed to improve quality of life for individuals with SMS.

Regional Representatives

Percy Huston, Regional Representatives Chair

The PRISMS Regional Representatives program continues to grow. By the end of 2015, there were 25 regional reps, including nine internationally.

Our goal in North America is to have a rep in all 50 states, and we are constantly looking for volunteers who may be interested in serving. Our regional reps are simply individuals who care and want to assist others who may be having similar needs or issues. Among other things, our regional reps are here to:

- Respond in a timely manner to email requests from families in their regions.
- Welcome new individuals and families into the PRISMS community, and try and answer questions as needed.
- Listen to individual needs, reference the PRISMS website for specific info and develop a supportive rapport.

- Participate and cultivate a "regional" community through get-togethers, if possible.
- Encourage families to join PRISMS and share the benefits of a membership.

A series of support calls were established and held in late 2015 to provide an avenue for our reps to share thoughts, experiences, concerns, etc., to better facilitate their roles. The plan is that these calls will continue going forward on a periodic basis to support the needs of both new and existing reps.

There also will be a time (session) for regional reps to gather at our upcoming international conference in St. Louis in July to further promote and expand this program.

To learn who your regional representative is, visit www.prisms.org. If you are interested in becoming a rep or have any questions about this program, please contact us at info@prisms.org.

Membership

Rochelle Wright, Membership Chair

At the end of 2015, there were 274 individuals or families who were members of PRISMS. We added 35 new families as members during the year.





Our member list shows that PRISMS serves families from across the country and around the world with members from 48 states and 19 foreign countries on six continents.

There are many reasons to be a PRISMS member, below are six to name a few:

6 Reasons to Be a PRISMS Member

1—Meet new families that are just like you

- Your Regional Representative will help you get in contact with other families in your area. He or she will also answer any questions you may have, and offer guidance and support.
- Many regions have informal family gatherings throughout the year. If we don't know who you are or how to contact you, you'll miss out on an important opportunity to find support and meet others in your unique situation.

2—Access to the International SMS Conference

 As a member you'll receive regular updates on the PRISMS International "Building Bridges of Hope" Conference directly to your email and a decreased registration fee for the event.

3—Foster research and scientific awareness

- Becoming a member is critical to furthering research. Our membership list provides us with the latest number of cases of Smith-Magenis Syndrome. That number will give us an opportunity to accelerate research initiatives into Smith-Magenis Syndrome.
- As the go-to source of information about SMS for the scientific community, an updated membership list helps us to direct researchers to families interested in propelling research forward.
- With membership you gain access to research updates sent directly to your email, including information on the latest in SMS research following each SMS Research Symposium.

4—Make an impact on issues important to you

- Having a clear picture of how many families are affected by SMS will help us to raise awareness of SMS and its related conditions among national and local lawmakers, federal agencies, and other non-profits in the special needs community.
- There's strength in numbers. It's important that we're able to show the impact of our community.
- An updated membership number will help us to gain support from additional donors and funders.



5—Join a growing international community

- We encourage families, researchers, and educators around the world to become part of our organization. Membership is open to everyone.
- PRISMS has members from more than 8 countries.

6—Stay in touch with PRISMS

- As a member you will receive quarterly Spectrum Journals via email with the latest news about families, research, and the organization.
- You'll also get the latest news and information from PRISMS emailed to you about critical topics such as our international conference, research studies or updates on key developments that affect your family.

Your membership dues provide the financial resources PRISMS needs to operate and this support enables us to help families. Remember, PRISMS is your organization, and we are able to do our job because of your support.

Thanks to all of you who are part of PRISMS. We truly value your membership and support.

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, info@prisms.org.

Our Members

PRISMS is grateful to our members for joining the SMS community and supporting PRISMS work through annual membership.

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Fundraising

Emily Fields, Executive Director

The PRISMS community raised more than \$45,000 through fundraising and awareness events in 2015. SMS families across the country used their creativity, resources and passion to hold events in their local areas to raise funds, increase understanding and garner support for the entire SMS community. Below are a few of the 2015 fundraisers you hosted in your communities:

- Cuts for a Cure. Organizer, Jill Wood
- Vineyard-to-Vineyard Fun Walk. Organizers, Percy and Bernadette Huston
- Emily Mason Golf Tournament. Organizers, Bill and Monica Mason
- Race for PRISMS Awareness. Organizer, Joseph Toussaint
- Kassidy's Ohana-Rock 'n' Roll Marathon.
 Organizer, Kathleen Macken
- Nickels for Nico. Organizer, Jean Bishop
- #HugorBeHugged Awareness T-shirts. Organizer, Dawnda Daniel
- Bowling for SMS. Organizers, the Farber Family

PRISMS is thankful for the generous donations to support its mission as well as the time and effort individuals, like you, put in to raising awareness for SMS through special events in your area. The work you do in your communities is immensely valuable. There are countless stories of connections made through these events which lead to increased understanding, valuable support, and even diagnosis of a friend or family member.

The success of these events in 2015 is a driving force for PRISMS moving forward. In 2016, we look to providing resources to you and your family as we encourage you to continue to raise awareness and funds in your area to benefit our mission and programs. Should you be interested in holding a



fundraiser in 2016, please contact us at info@prisms.org. We will support you in making your event as successful as possible.

Didn't see your 2015 fundraiser listed above? Hoping to hold an event in 2016? Contact us at info@prisms.org. In 2016 we'll be improving our systems to better capture your fundraising and awareness efforts, but we need to hear from you. Reach out today.

Our Donors



PRISMS is grateful for our generous donors! What we are able to accomplish each year with these gifts is immense, and we are thankful for the generosity and trust in the organization's work. We are achieving great things, and it's thanks to you.

Donors \$10,000 +

Ira and Betty Dyer New 38th Floor Productions, Inc. Laura Staich and Philip Ruedi

Donors \$5,000-\$9,999

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Michelle Iafigliola Nancy C. Jacobus Patricia Jeremiah Marissa Johnson

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Paula and Arthur Jump Mary and Tim Kamp Irene Karpowicz

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Timothy Kempf

Patricia and Ronald Kendrick

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Div. 3

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Awareness

Tina McGrevy, Awareness Chair



PRISMS is committed to raising awareness of Smith-Magenis Syndrome around the world. In 2015

PRISMS launched several initiatives and participated in a number of campaigns to increase knowledge of SMS in the rare disease community and beyond.

In 2015 PRISMS:

- Continued and grew our partnership with the National Organization for Rare Disorders (NORD), raising awareness of SMS through a national platform
- Published multiple articles with the Firefly Garden, increasing knowledge of SMS in the special needs community
- Launched a partnership with The Mighty, bringing information about SMS to an audience of more than 800,000
- Created PRISMS Instagram account with more than 500 followers
- Participated in national tweetchats with ABC, NORD, Global Genes, and other national organizations and media sponsors
- Took part in Rare Disease Day, promoting global education of rare diseases
- Held an SMS Awareness Day campaign engaging over 5,000 people with posts seen by over 80,000 individuals around the world
- Celebrated 22 years of PRISMS serving the SMS community on PRISMS birthday

Shared PRISMS first promotional video, educating the community on PRISMS mission and programs for families and professionals

And more! PRISMS has big plans for 2016 to increase education and awareness of SMS globally.

Thank you to each of you who raised your voices with us in 2015! You can take part in our awareness efforts by joining us on one of our social media pages. You can find PRISMS on Facebook, Twitter, Instagram, and Pinterest. To connect, visit us at www.prisms.org to find our social media handles.

Find Us on Social Media

Host a fundraiser or awareness event in vour area

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

Join the PRISMS community by becoming a member for 2016

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













SAVE THE DATE for the PRISMS CONFERENCE
PRISMS 9th INTERNATIONAL CONFERENCE
"BUILDING BRIDGES OF HOPE"

When: Thursday, July 28, 2016—Saturday, July 30, 2016
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 attend, and we will spend a few days together learning about new research and interventions regarding Smith-Magenis Syndrome. Attendees also will have the opportunity to spend time in a caring and supportive environment, and sharing special time together. 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.

The conference committee has been busy planning for many months, (since the 2014 conference finale), to ensure we present a quality conference that is educational and welcoming for our families and professionals. Many volunteer hours are dedicated to the planning and execution of the conference, and *PRISMS subsidizes almost 70% of the conference costs*. This combination of generous volunteerism and fundraising translates to much lower conference fees for the attendees. PRISMS also offers scholarships for families to attend the conference and grants for professionals to attend the Teacher and Staff Training Workshop and conference.

PRISMS regards the conference as its foremost program and encapsulates its mission within the framework of the conference, which includes

Education | Awareness | Research

The conference also underscores our commitment to providing viable services and information to our community *in an immediate way*, and sets our sights on improving each conference and including more first-time attendees. We use the evaluations from the previous conference to define the agenda and include the community in the planning. PRISMS offers the largest event dedicated to SMS, and this venue provides outreach to our community across the world.



We will offer two new workshops this year in addition to the First Steps session, all of which will be held on Thursday, July 28, 2016:

- Adult Living Workshop, (open to all)
- Teacher and Support Staff Training Workshop, (open to all)
- The First Steps Session, (for first- or secondtime attendees only)

Notice the new start and stop days/times for this conference!

- Sessions begin: Thursday, July 28, 2016
 - Childcare and the PRISMS Den open at 1:00pm, Thu.
 - o First Steps session: 1:15–2:45 p.m., Thu.
 - o Workshops: 1:30-4:30 p.m., Thu.
 - o Reception: 5-7 p.m., Thu.
- Full-day sessions will be held on Friday and Saturday, July 29–30.
- Sessions end at 6:15 p.m. on <u>Saturday</u>, July 30.

The Hospitality suite will be open on Saturday until 10 pm. So, please plan to stay late and celebrate!

*** Please note: Some times may vary slightly. ***

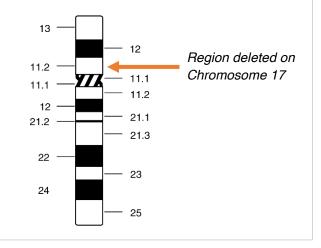
Watch for more details to follow in the months ahead through PRISMS website, emails, Facebook and Twitter. More detailed conference information is available on the PRISMS website. Registration is now open. We hope to see you there!

For questions: conference2016@prisms.org

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 underdiagnosed, but as awareness of it increases, the number of people identified grows every year.





Thank you for making
2015
PRISMS most successful year yet!