

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

# 2017 ANNUAL REPORT





*“We are a remarkable  
tapestry made up of a rich  
variety of personalities—  
all with a common goal to  
make the world a better  
place for people living  
with SMS.”*



# 2017 YEAR in REVIEW

1

Be a global organization

2

Be the "go to knowledge center" for all things SMS

## GOALS

3

Ensure that all actions taken by PRISMS are grounded in the best available knowledge

4

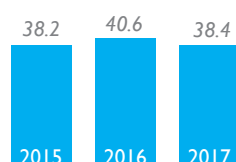
Ensure that those impacted by SMS have the resources and opportunities to achieve their fullest potential

5

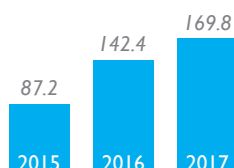
Be a sustainable organization

## FUNDRAISING & DONATIONS

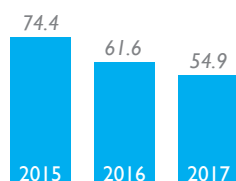
### MEMBER FUNDRAISING Thousand \$



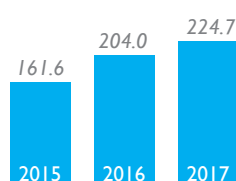
### UNRESTRICTED DONATIONS Thousand \$



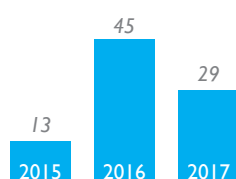
### RESTRICTED DONATIONS Thousand \$



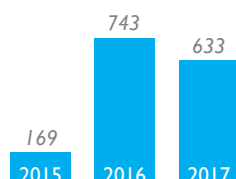
### TOTAL DONATIONS Thousand \$



### DONORS > \$1,000



### INDIVIDUAL DONORS



## PUBLICATIONS (2016 in parentheses)

### Adult Residential Setting (Digital)

40  
(60)

### On the Road to Success (Digital)

28  
(26)

### Adult Residential Setting (Hardcopy)

5

### On the Road to Success (Hardcopy)

87  
(174)

## COMMUNICATION

### PRISMS EBLASTS

20

### DIRECT MAILINGS

2

Released to more than

### CONFERENCES REPRESENTED AT

4

1,500

homes

## AWARENESS

PRISMS awareness  
campaigns reached

MORE THAN **300,000**

people across the  
world in 2017



TWITTER

**657**  
tweets

**503**  
followers

INSTAGRAM

**202**  
posts

**696**  
followers



### FACEBOOK GROUP

The Facebook Group  
has grown by

MORE THAN **300** members in 2017,  
reaching a total of **2,083** members



The community  
has posted

MORE THAN **1,200** original posts  
creating MORE THAN **15,000**  
COMMENTS

Members  
represent

MORE THAN **10** COUNTRIES

& **35,000**  
REACTIONS

### FACEBOOK PAGE

**1,517**  
LIKES

**35** | **7** | **1,200**

{ PRISMS receives an average of 35 reactions  
per post, posting an average of 7 times a  
week with an average post reach of 1200 }

**100%**

Reactions to PRISMS posts are 100% positive  
featuring affirming words in comments and  
inspiring solely the "Like" and "Love" reactions

## PROGRAMS & SERVICES

INFO@PRISMS.ORG  
REQUESTS

**62**

PRISMS OFFICE  
CALLS RECEIVED

**>40**

RESEARCH SYMPOSIUM

**41**

attendees

**9**

abstracts

SMS PATIENT REGISTRY

**17**

enrolled

REGIONAL REPRESENTATIVES

**28**

volunteers

MEET UPS

**7**

INTERNATIONAL PARTNERS

**5**

official partners

SPECTRUM JOURNAL

**4**

issues

with  
more  
than

**40**

articles

## Message from the President of the Board of Directors



I am feeling a little challenged with my task—how can I recognize all that has happened in 2017, acknowledge everyone for their support and good work, and celebrate the value of our work? This is the quandary of the Board president when we have done so much and involved so many.

**Attempt 1.** It is with much satisfaction that I look back on 2017—our Professional Advisory Board organized our 8th Research Symposium. We launched the PRISMS Patient Registry. We have funded a post-doc research initiative. And the groundwork was laid for 2018—our 25th year—with planning for a new website and our 10th international conference.

All true. But none of this would be possible with the many people who make up our organization. Members, volunteers, donors, our families, our kids, the staff. Our community is international—and at the same time we value the local, direct and individual connection.

**Attempt 2.** I couldn't be more grateful for the efforts of the many people who give their time to help us, or more appreciative of all of you for your support. PRISMS has a wonderful leadership team—including Emily Fields



“ PRISMS is all of you—each of us doing ”  
what we can to support our community.

our Executive Director, my colleagues on the Board of Directors, the members of the Professional Advisory Board chaired by Dr. Sarah Elsea, our regional reps, our international affiliates, our committee members, workgroups and volunteers. We are a remarkable tapestry made up with a rich variety of personalities—all with a common goal to make the world a better place for people living with SMS.

That seems pretty close. But our work is really about you—I am wondering why any of this matters to you or your family.

**Attempt 3.** Charley, our son, is 33. He was diagnosed with SMS when he was 11, which means Debora and I have been involved with PRISMS for 22 years. We’ve been to every conference (well...I missed one to take care of Charley), we have Ann Smith’s, Brenda Finucane’s and many other numbers in our phone in case of emergency,

we’ve learned from and we helped many families in all kinds of ways, and it wouldn’t be possible to add up the meetings and phone calls we’ve been part of for all kinds of projects. And we are just one family. There are many others doing this and more. PRISMS is all of you—each of us doing what we can to support our community.

I am proud of our work in 2017—but honestly the best accomplishment is preparing for what comes next. And here it comes—PRISMS is changing. We want everyone to be involved and help us make our organization a resource for you. Let’s see how we do. I have a feeling great things are on the horizon with all of us working together.

With appreciation,

John Mayer  
*President, Board of Directors*



YEARS OF  
LEADERSHIP  
A FUTURE  
OF HOPE





# RESEARCH

SARAH ELSEA

## 9<sup>th</sup> SMS Research Symposium

PRISMS held its 9th SMS Research Symposium in Houston on May 18-19, 2017. Bringing together more than 40 of the world's leading SMS experts, researchers and professionals for the only event of its kind focused on Smith-Magenis Syndrome, this investment of more than \$20,000 in advancing research for the SMS community was a great success.

As part of PRISMS commitment to supporting research and advancements for the SMS community and sharing that progress with our families, PRISMS funded the creation of abstract summaries to share the latest research findings with you. You can view those summaries on the PRISMS website ([www.prisms.org](http://www.prisms.org)).

### Support of Innovative SMS Research at the University of Michigan

PRISMS was honored to announce the award of \$150,000 to Dr. Shigeki Iwase and Dr. Michael Sutton at the University of Michigan to support their research into the "Roles of RAI1 in Translating the Histone Methylation Code into Synaptic Plasticity."

In 2017, PRISMS opened up an application process to research institutions around the world to apply for funding to support a post-doctoral fellowship for a research project related to SMS at \$75,000 per year for two years. PRISMS received several applications, all of which were reviewed and scored by PRISMS Professional Advisory Board, taking into account the significance of the proposed research, the innovation of

the proposed research, the methodologies, timeline, cost feasibility and the opportunity the proposed research presented for future SMS research. Upon review, the workgroup was delighted to fund Dr. Iwase and Dr. Sutton's innovative project.

RAI1 mutations are responsible for two distinct neurodevelopmental disorders: Smith-Magenis and Potocki-Lupski syndromes (SMS and PTLs). Individuals with SMS and PTLs are characterized by abnormal adaptive behavior, which requires synaptic rewiring by experiences. The molecular and cellular roles of RAI1 in the brain remain unclear, which makes it difficult to design rational therapeutics for these conditions.

"With the support of this funding from PRISMS, we aim to uncover what RAI1 does in neuronal cells at molecular and cellular levels," Drs. Iwase and Sutton say. "More specifically, we will test our prediction that RAI1 'reads' specific chemical marks that are placed on chromatin, DNA-containing materials, in neurons and by doing so, RAI1 controls gene expression and rewiring of neuronal connectivity. Our hope is to pinpoint molecular and cellular roles of RAI1, thereby generating a solid ground for the future therapeutic design. Since this is an early phase, exploratory project, it would be challenging to





obtain federal funding. PRISMS fund is highly instructive for our collaborative team to jump-start this exciting and important project."

This research initiative will involve the co-mentoring of a post-doctoral fellow in the Sutton and Iwase labs, which will enable this individual to become an independent scientist focused on RAI1 biology and related brain disorders.

"PRISMS could not be more proud at the opportunity to fund this research on behalf of the SMS community," Executive Director Emily Fields says. "Investing in this project is an investment in building future researchers with an interest in and commitment to SMS research. Additionally, we are excited about the opportunity this research presents to guide future therapeutic developments for SMS."

### **Funding of a Genetic Counselor**

As part of its commitment to research and education, PRISMS has partially funded a genetic counselor position at the Baylor College of Medicine. The genetic counselor works directly with Dr. Sarah Elsea on establishing and maintaining a patient registry for individuals with SMS, the overall aim being to improve patient care through a better understanding of the nature of the disorder. The counselor also provides assistance and support to PRISMS in updating and maintaining the PRISMS website and serves as a person of contact for questions regarding the genetics and inheritance of SMS.




### Launch of SMS Patient Registry

The Smith-Magenis Syndrome Patient Registry (SMSPR) is one of PRISMS most recent initiatives toward its long-standing aim of supporting research for SMS. The Smith-Magenis Syndrome Patient Registry is a collaboration between families and researchers that will work together to improve our understanding of SMS.

We are collecting medically relevant information. This information is important in helping us understand, more clearly, the natural history of Smith-Magenis Syndrome.

Listed below are some of the records we are collecting:

- Genetic test results
- Sleep studies
- Magnetic Resonance Imaging (MRI) or Computerized Tomography (CT) scans
- Hearing tests
- Spine X-rays
- Photographs, videotapes and audiotapes
- Questionnaires regarding medical history, daily activities, sleep habits and quality of life, among others

We expect to collect data over several years, without a specific end-point at this time. SMS families can consider enrolling as for long as this study is active. 

### PRISMS Professional Advisory Board

*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 the Spectrum Journal, the PRISMS website and other publications. This dedicated group of experts responds to inquiries from families, caregivers, physicians, teachers and various other healthcare providers to support the SMS community and to ensure the dissemination of current, accurate medical information.*

*The PAB is comprised of the following individuals:*

**Sarah Elsea**, PhD, PAB Chair

**Ann C.M. Smith**, MA, DSc (Hon), CGC, PAB Chair Emeritus

**Brenda Finucane**, MS, LGC

**Barbara Haas-Givler**, MEd, BCBA

**Kerry Boyd**, MD, FRCPC

**Andrea Gropman**, MD

**Christine Brennan**, MA CCC-SLP

**Jane Charles**, MD

**Rebecca Foster**, PhD

**Santhosh Girirajan**, MD, PhD



## REGIONAL REPRESENTATIVES

PERCY HUSTON


**T**he PRISMS Regional Representatives program continues to grow and evolve. Our goal in North America continues to be to have a representative in all 50 states and we are constantly looking for volunteers who may be interested in serving. Recently we have 21 new regional rep volunteers who are in the process of receiving their initial volunteer packets and awaiting regional assignments. These, to go along with our 31 established regional reps, will hopefully lead us closer to our ultimate goal. States we currently have no representative presence in include CT, RI, VT, NH, DE, VA, SC, AL, IA, WV, MI, OK, AR, KS, ND, SD, TN, MS, LA, ID, NV, WY, UT, NE, Hawaii and Alaska. Please let us know if you have an interest and are from any of these states.

Our regional representatives are PRISMS members who care and want to assist others who may be having similar needs or issues. Among other things, our regional representatives 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 to answer questions as needed.
- Listen to individual needs, reference the PRISMS website for specific information and develop a supportive rapport.
- Participate and cultivate a “regional” community through get-togethers when possible.
- Encourage families to join PRISMS and to share the benefits of membership.
- Promote our newly released patient registry and assist families in registering their SMS relative to help ensure success of this program.

As we move forward in 2018 our new website will be updated to include photos and bios of all our regional reps. We will continue to promote and encourage use of our regional representative Facebook group so that reps can stay connected and share advice and insight from their own personal experiences. As we continue to add reps we will proactively reorganize regions based on new volunteer interest to assure reps manageable regions to deal with in order to help insure their success.

With our next international conference scheduled in July 2018 in Pittsburgh we hope to have our largest regional rep attendance ever and planned meetings to support and clarify their work and importance. We encourage everyone to register early and plan on attending this very exciting conference.

To learn who your regional representative is, visit [www.prisms.org](http://www.prisms.org). If you are interested in becoming a representative or have any questions about this program, please contact us at [info@prisms.org](mailto:info@prisms.org). 



# FUNDRAISING

DENIEN RASMUSSEN

**T**he PRISMS community raised more than \$38,000 through fundraising and awareness events in 2017. More families participated in outings and picnics, and more people donated than in previous years. Many SMS families, extended families and friends across the country used creative ways to raise money and awareness for PRISMS.

We are blessed to have several SMS families continue, year after year, to help raise money and awareness for PRISMS—and we are very thankful for them. Below are a few:

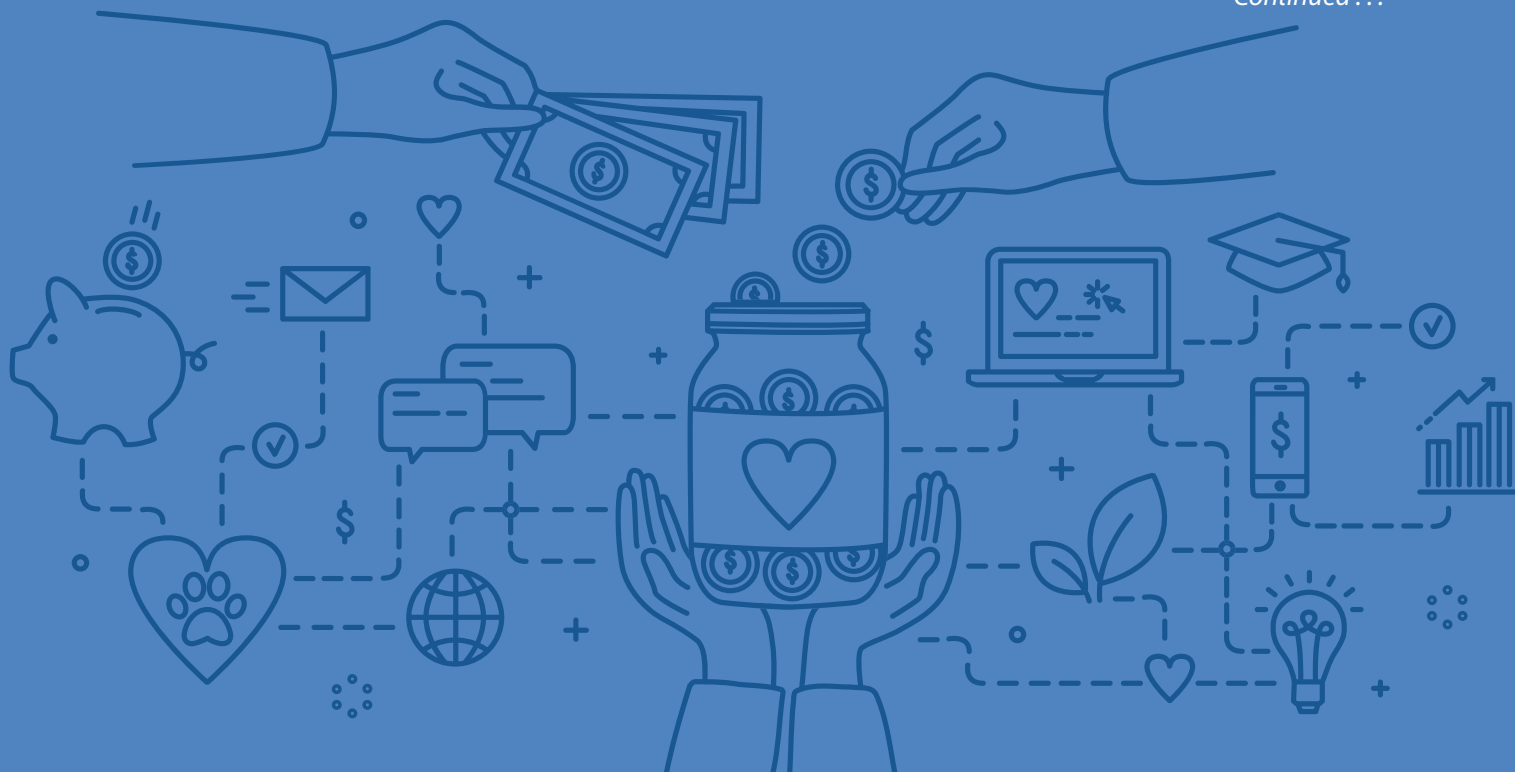
- Race for Patrick Toussaint. Organizer, Joseph Toussaint.
- Nickels for Nico. Organizer, Jean Bishop.

- Cuts for a cause. Organizer, Jill Wood.
- Farber Bowling for SMS. Organizer, the Farber Family.

First-time SMS families and friends jumped in and ran fundraising events in 2017, including:

- The 1st PRISMS ABC fundraiser. Organizer, Denien Rasmussen.
- PRISMS Parachutist-Freefalling for Families. Organizer, Andrew Staich.
- SMS See Me Shine. Organizer, the Comfort Family.
- Encinitas Makers Market Sale. Organizer, Kathleen Macken.

*Continued...*





What a fun and exciting year 2017 was on Facebook for PRISMS. Many of you joined the Facebook fundraiser bandwagon, and PRISMS is so appreciative to you all. Among the events:

- Donate my Birthday fundraisers. Organizers, Tram Nguyen, Jessica Christopher, Jaimi Brown, Larry Lehman, Chava McClenahan, Emily Fields, Denien Rasmussen, Maureen Monroe, Shannon Pollard Duvall, Jamie Jagearsand Allie Herman.
- FilmRaiser Movie fundraisers: My Little Pony, Wonder. Organizer, Denien Rasmussen.
- Giving Tuesday Facebook Fundraiser. Organizers, Emily Fields, Denien Rasmussen, Dawnda Daniel and Tina McGrevy
- Facebook Fundraisers for PRISMS. Organizers, Christian Hope, Kathleen Macken, Allison Stephanouk, Randy Beall, Diane Erth and John Mayer
- Phantom Tea & Wine Celebration. Organizer, Emily Fields.

Several new families planned fundraisers for the first quarter of 2018, along with several Facebook fundraisers. This is PRISMS 25th anniversary and its 10th international conference will be held July 26-28 in Pittsburgh. We will have another great fundraiser, "Night at the City Center," at the conference (more details to come). This will be a fun event and we hope you will attend and support PRISMS.

PRISMS needs your energy and enthusiasm to ensure that this founding organization will continue to grow and serve the SMS community through programs of education, awareness and research. Your fundraising efforts help PRISMS to improve its programs, keep conference costs more affordable for families, support SMS research and more.

Please consider hosting a special event. Not only will the funds you raise play a huge role in PRISMS ability to serve more SMS families, but you also could earn free conference fees! Fundraising events help bring together SMS families and broader communities in a fun and supportive environment, helping to raise awareness of SMS around the world.

Check out our website for more details on the ideas below:

50/50 Raffle
5K Walk or Run
Bake Sale
Spaghetti Dinner
Movie Night
Bingo Event: Bingo flyer / Bingo tickets
Book Sale
Pancake Breakfast
Restaurant Event
Painting Event
Yard Sale

We've created a few easy guides to get you started. And we are here to help support you in your fundraising efforts. Send us an email ([fundraising@prisms.org](mailto:fundraising@prisms.org)) or give us a call (972-231-0035), and we'll gladly assist you with planning your event.

Don't see a fundraiser that's right for you? Feel free to get creative! The sky's the limit and every little bit helps.

Some other ways to raise funds and support PRISMS:

Visit the PRISMS Firstgiving website ([www.firstgiving.com](http://www.firstgiving.com)) and set up your own page. Write a short paragraph about your family's journey with Smith-Magenis Syndrome, add a photo and attach a video. Then email, Facebook and Tweet this page to your friends and host a virtual PRISMS fundraiser from the comfort of your home. It really is that easy!

Or, get your children involved and set up a bake sale table at a local event. Hold a rummage sale with your

family and donate all proceeds to PRISMS. Maybe you would prefer writing a letter to family and friends about your experiences with Smith-Magenis Syndrome. Ask them to consider making a tax deductible donation to PRISMS in honor of your child.

I have enjoyed speaking with many of you about your ideas for fundraising. The SMS community is so compassionate and has creative, out-of-the-box ideas. After all, we have to always be a step ahead of our SMSers, so being creative is our thing.

Your fundraising endeavor, no matter how big or small, will help to support the mission of PRISMS and its programs. For more information, please contact Denien Rasmussen at [fundraising@prisms.org](mailto:fundraising@prisms.org) or [drasmussen@prisms.org](mailto:drasmussen@prisms.org)

Thank you for your support! 🌀





**I**N 2017, PRISMS DECIDED TO MOVE  
TO FREE MEMBERSHIP FOR ALL.  
MEMBERSHIP IS NOW OPEN TO ANYONE  
INTERESTED IN SUPPORTING AND  
ENGAGING WITH THE SMS COMMUNITY.  
OUR MEMBERSHIP INCLUDES  
PARENTS, SIBLINGS, GRANDPARENTS,  
FRIENDS, EDUCATORS, RESEARCHERS,  
THERAPISTS, AND ADVOCATES.



## 6 REASONS WHY IT'S IMPORTANT TO BECOME 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 Conference directly to your email.

### 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.

# R S H I P

- 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 eight 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. 🌐



# MEMBERS



Rod Allen  
 Frank & Betsy Andersen  
 Harriet and Martin Arno  
 Kevin & Darla Atherton  
 Lynne & Steve Baker  
 Nicole Harter Bale  
 Eliane Barros and Tiago Madruga  
 Mary & Randy Beall  
 Gina & Steve Belden  
 Sonia & Brian Bench  
 Ann Berger  
 Rachel & Daniel Berger  
 Cheryl & Ned Berman  
 Joan and John Bielunski  
 Raymond & Joan Bishop  
 Carla & Glenn Blaser  
 Ken & Christine Bolt  
 Angela Bonato  
 Dr. Kerry Boyd  
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 Steffen & Melissa Brandt  
 Brigitte Braun  
 Niven & Debbie Brooks  
 Carolyn Bruister  
 Jack Byrom  
 Denise & Stewart Caddy  
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 Frank and Judy Carney  
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 Ashton & Lynn Cheramie  
 Ilse & Randy Ciprich  
 Rosemary & Rod Clifford  
 Cheri Connealy  
 Blythe Cooney  
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 Patty Davis  
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 Dr. Lynn Diamond  
 Paul & Susan Diamond  
 Gwen & John Dill  
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 Kathy & Deanna Hofmann  
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 Jennifer and Lou Klump  
 Irene & Dan Knoepfle  
 Alan and Gail Kopp  
 Kenneth and Mary Koppers  
 Bonnie Krauthimer  
 Timothy and Dana Krimmel  
 Kathy Krisko  
 Beth & Paul Kurtz

Lincoln and Catherine Lakoff  
 Josephine Lawlor  
 Miles & Robin Lawlor  
 Carissa Le  
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 Michelle and Kerry Lee  
 Michael & Michele LeMasney  
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 Stephen & Hoang Wood  
 Deann & Jeff Yerk  
 Michele & Joe Zdanowski  
 Annetta Zidzik



# DONORS



## **\$25,000+**

Laura Staich & Philip Ruedi  
Betty Dyer

## **\$10,000-\$24,999**

Percy & Bernadette Huston

## **\$5,000-\$9,999**

Janet Manning  
The Bost Foundation

## **\$1,000-\$4,999**

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Karen & Glen Daniel  
Sara & Tsvi Gal  
Alan and Gail Kopp  
Susan Ambrose  
Denien & Jim Rasmussen  
Jeanne Shobert  
Jean Bishop  
Raymond & Joan Bishop  
Bryan & Karen Altzman  
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# AWARENESS REPORT

TINA MCGREVY



In 2017, PRISMS awareness campaigns regarding Smith-Magenis Syndrome reached more than 300,000 people around the world. PRISMS is honored to play a role in spreading understanding and awareness of SMS to communities globally through print messaging, public speaking engagements, and social media campaigns.

- Our Facebook Group (Smith-Magenis Syndrome Support-PRISMS, Inc.) grew by more than 300 members in 2017, reaching a total of 2,083 members with members representing more than a dozen countries.
- Our Facebook Page (PRISMS, Inc.) reached more than 1,500 followers by the end of 2017 with each post receiving an average of 35 reactions.
- Our Twitter account (@PRISMS\_SMS) reached a total of just over 500 followers, having tweeted over 650 messages about SMS.
- Our Instagram account (@smsprisms) reached a total of nearly 700 followers.





- We released three direct mailings over the course of 2017 to more than 2,000 homes and offices with information about SMS and the work of the organization.
- We spread awareness materials including brochures, wristbands, informational bookmarks, and awareness/compassion cards to families and professionals around the world to disseminate in their own local communities.
- We sold more than 150 PRISMS publications to individuals globally looking for more information on SMS with regards to residential settings and school success.
- We promoted knowledge of SMS through national and international channels including National Organization for Rare Disorders, Global Genes, and Eurordis.
- And More!

PRISMS believes awareness leads to understanding. We are honored to continue to build and share awareness materials and campaigns to bring greater understanding to our SMS families. 🌐



# FINANCIAL REPORT

PHIL RUEDI, TREASURER

**2**017 represented another strong year of investment in the PRISMS organization and community. In previous non-conference years, PRISMS built its cash balances in preparation for investing in the next conference. In 2017, PRISMS took a different approach and elected to incur a slight operating loss in order to fund our programs and research.

Last year, PRISMS began the funding of a post-doctorate research program at the University of Michigan, sponsored the 2017 Research Symposium and continued our funding of genetic counselling services at Baylor University. In aggregate, more than \$67,000 was spent on these programs. The University of Michigan project is a commitment of \$150,000 over two years, of which \$37,500 was paid in 2017, \$75,000 to be paid in 2018, and the balance to be paid in 2019.

PRISMS incurred a loss of approximately \$10,000 in 2017 before interest and investment income. Interest and investment income more than doubled in 2017—to more than \$25,000—due to strong financial markets. As a result, net income in 2017 was more than \$15,000 despite the significant investments highlighted above. We are grateful to the SMS community for all its support.

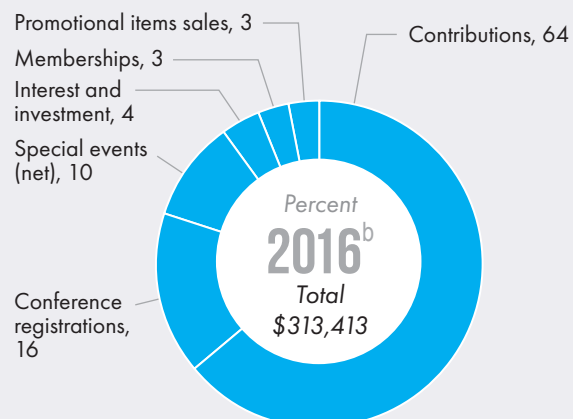
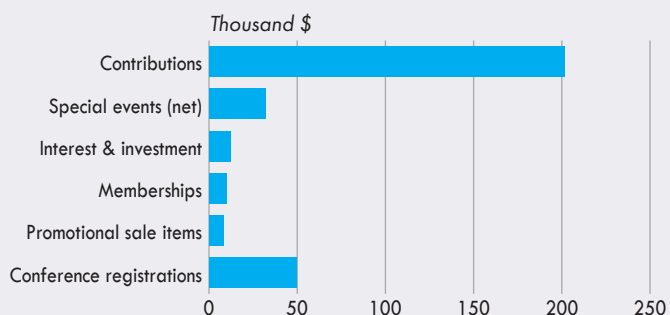
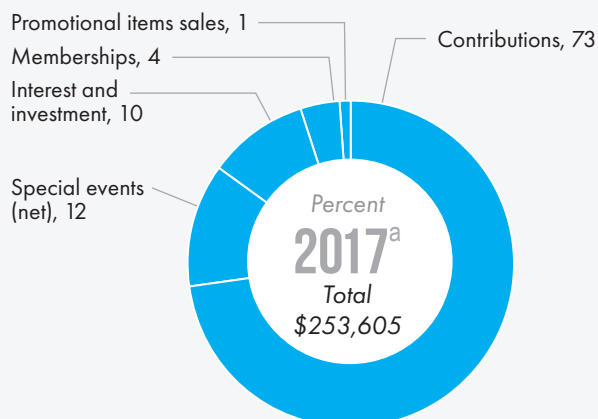
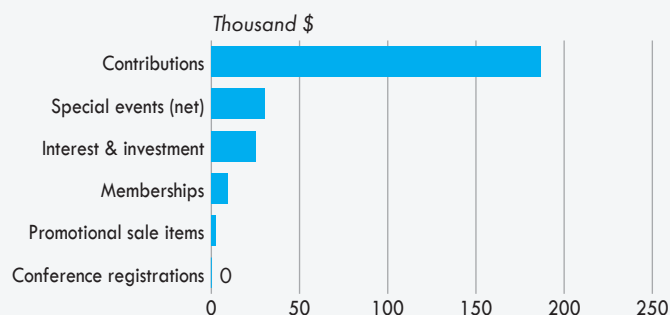
In last year's annual report, PRISMS highlighted that it would expect its cash balances to decline due to those investments, but strong community support and investment returns allowed PRISMS to maintain its strong financial position with more than \$500,000 in cash and investments at the end of the year.

With the 2018 International Conference and a full year of research support, 2018 should be a year where PRISMS will draw on its financial reserves. In addition, the elimination of membership fees and changes in the U.S. tax code may weigh on revenues.

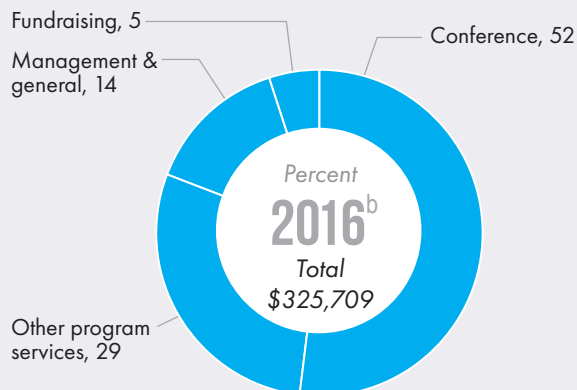
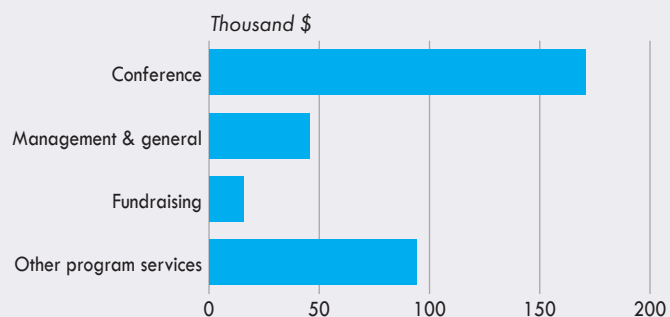
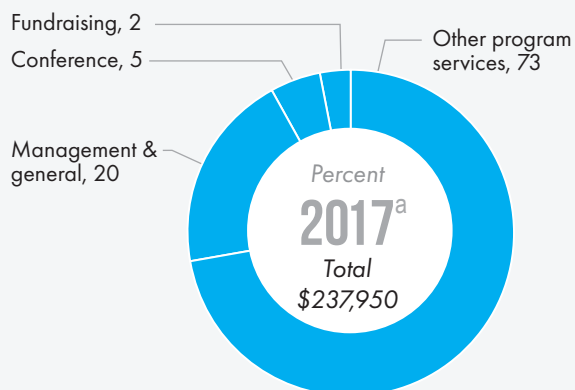
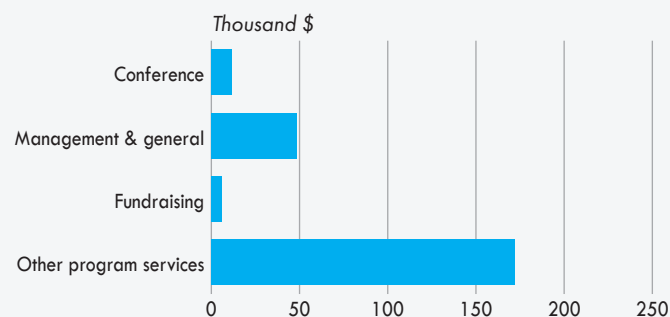
PRISMS continues to seek out new sources of funds to support its work and organization. Fortunately, strong support from the membership and families of SMS persons has put the organization in a position of strength. PRISMS is grateful for all the hard work of the executive director, staff and volunteers to identify, develop and fund new programs and research that will provide lasting benefits to our community. 

<sup>a</sup>Unaudited  
<sup>b</sup>Audited

## SUPPORT AND REVENUE



## EXPENSES



ENDING CASH AND INVESTMENTS **\$535,541**

**\$535,873**

ENDING TOTAL ASSETS **\$664,318**

**\$649,620**



## SUPER SMSers

**S**pectrum is proud to recognize the following SMSers for their accomplishments.

**Kaylor McDaniel, 10, Sioux Falls, SD.** An early riser, like so many SMS kids, Kaylor has started accompanying her father, Dr. Ross McDaniel,



to his 5 a.m. Wednesday weightlifting workouts. Dr. McDaniel, a chiropractor, works out with a group of fellow weight lifters that call themselves “Macho Madness.” Kaylor waits at each weightlifting station, and when it’s time for the group to move on, she blows a whistle. Sometimes, Kaylor will point to her eyes and then point to a

weight lifter—just to let him know she’s watching him. “Wednesday mornings have become her favorite,” says Kipley McDaniel, her mother. “The members of Macho Madness and other people working out at the gym are so kind to her and inviting.” Kaylor, who participates in adaptive aquatics and adaptive cheerleading, also helps her dad coach a Special Olympics basketball team on Friday nights.

**John Brissey, 28, Medical Lake, WA.** After a 3 ½-year process, John recently was placed in a residential building called Lakeland Village. “There’s been a few bumps in the road ... but it’s going really well,” said his mother, Tina Brissey, who originally was denied the placement but

won on an appeal. Among the 250 residents are several others with SMS, including one lady who has been there for 25 years. John works at a Goodwill store and enjoys Special Olympics bowling and surfing on his iPad.

**Amelie Lague, 12, Melbourne, Victoria, Australia.** Two years after making her first full green runs with the assistance of a harness, Amelie recently made multiple ski runs harness free. Amelie, who began skiing at age 4, is continuing to develop her skills, and plans to participate in Victoria’s state Interschools Disabled Wintersport competition in August.

**Austin Lawrence, 4, Marion, OH.** Austin enjoyed a big day out recently when he went to COSI, a hands-on science museum in Columbus, OH; watched “Snow White and the Seven Dwarfs;” and ate dinner at a restaurant—and his behavior was exemplary. “It was like a day with a typical kid,” says Rachel Lawrence, Austin’s mother. “It was exciting.” The Lawrences adopted Austin from Bulgaria in July 2016.

**Nihael Mannukadan, 9, Melbourne, Australia.** Nihael and his sister, Nissel, 6, danced in two Indian community stage shows, one last October and another at Christmas time. They teamed up again for another performance in early April.

*If you have an SMSer who deserves recognition for his or her achievement, email [ddillon923@gmail.com](mailto:ddillon923@gmail.com). 🌐*





