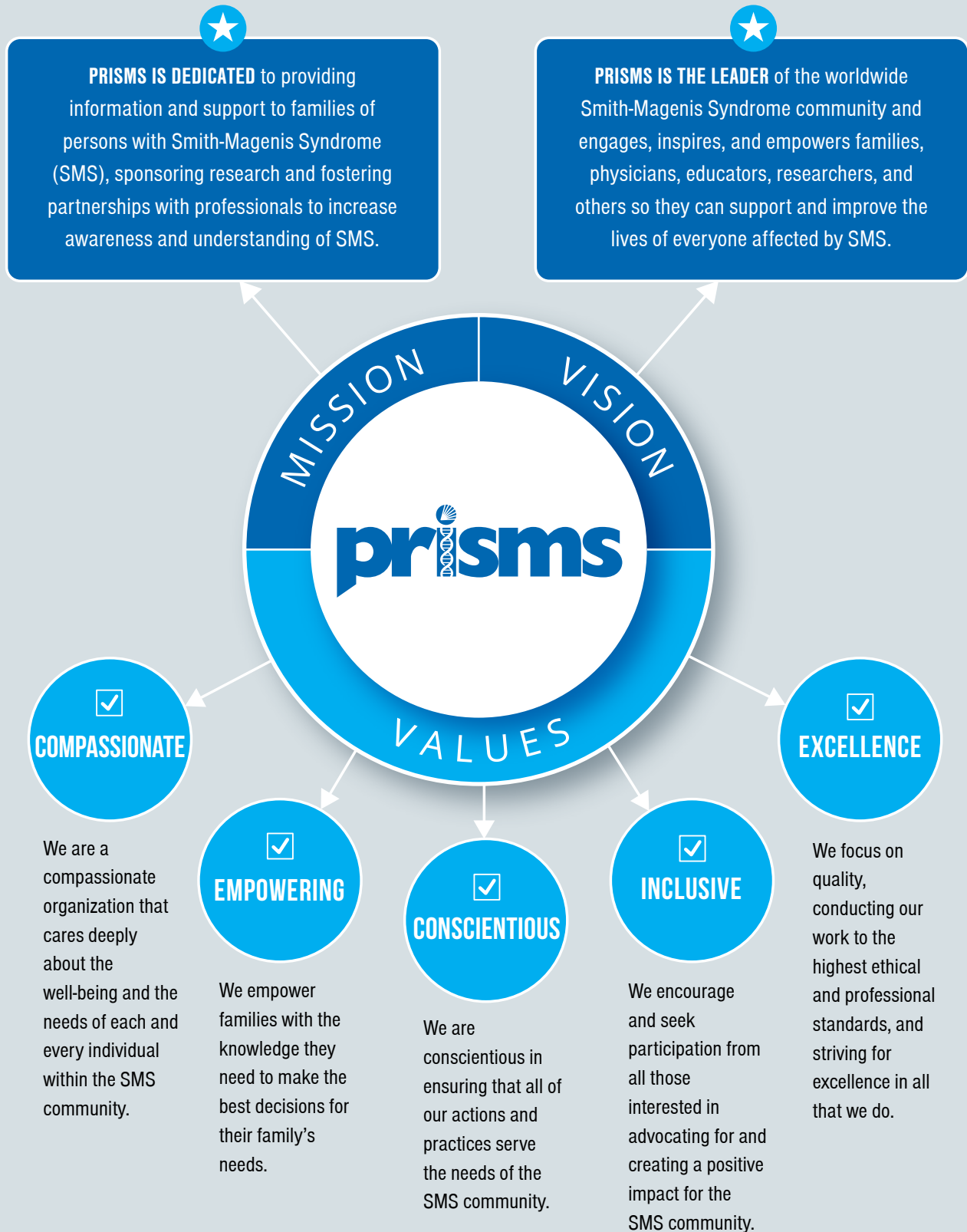




# 2019 PRISMS ANNUAL REPORT

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME



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The PRISMS  
board and staff.



## MESSAGE FROM THE PRESIDENT

*Brandon Daniel*

### WE ARE STRONGER TOGETHER! THAT STATEMENT MEANS EVEN MORE NOW THAN EVER TO OUR SMS COMMUNITY.

At this time (March 2020), I am challenged to gather my thoughts and summarize the activities of PRISMS in 2019. 2019 seems so long ago in light of the current situation that is confronting the entire world with the coronavirus. My well wishes and prayers are with each of you and your families as you cope with the new family dynamics of homeschooling, e-learning and reduced social interactions which are challenging to our SMS community.

As Eleanor Roosevelt once stated when explaining President Franklin Roosevelt's polio illness, "He had to think out the fundamentals of living and learn the greatest of all lessons – infinite patience and never-ending persistence." That statement . . . infinite patience and never-ending persistence resonates with our community now more than ever as we cope with the new dynamics of the world today. Most importantly, I am hoping you and your families remain healthy and safe as we live through this historic pandemic.

2019 marked PRISMS 26<sup>th</sup> year as an organization, and our mission remains to be a valued resource

to those living daily with SMS. 2019 was a year of transition as PRISMS hired its second Executive Director, Casey Gorman, in July. We look forward to the contributions Casey will make to PRISMS and the SMS community in the future.

PRISMS collaborated with SMSRF to host a successful Research Symposium in Houston in 2019. We all know the importance of research for our community, and plans are underway for the next Research Symposium in 2021! PRISMS remains committed to funding vital research, particularly the SMS patient registry, which provides a repository of valuable information for researchers to access to understand more about what SMS looks like and how it progresses throughout the lives of our SMS individuals.

PRISMS completed its first ever educational webinars in 2019. Board member Allison Stephanouk and the other volunteer members of the Education committee have pulled together great content for each of these webinar sessions. These public webinars were a first for PRISMS, and

something that the community indicated was needed. Webinars will continue to be an important resource for families into 2020 and beyond.

Today, PRISMS remains financially and operationally strong and committed to move forward with our mission into 2020 and beyond. The PRISMS Board is charged with ensuring the sustainability and growth of PRISMS for the next generation. As we move into a new decade and focus our energies on execution of programs for the year ahead, we also continue to build the groundwork for the long-term success of PRISMS.

On behalf of the PRISMS Board, we are thankful for all those who donate their time, energy and funding to increase awareness for SMS. Webinars, conferences, symposiums, the patient registry . . . all of this cannot happen without necessary financial support.

We are thankful for the families, volunteers and staff that makes PRISMS what it is today and look forward to the positive impact that PRISMS will continue to provide in the future.

*Thank you,  
Brandon Daniel*



## MESSAGE FROM THE EXECUTIVE DIRECTOR

*Casey Gorman*

Dear PRISMS Community,

Hello! For those of you I have not yet had the chance to meet, I am Casey Gorman, PRISMS newest Executive Director. I came on board in July of 2019 and spent the better part of the year getting to know this wonderful organization and the community we serve. Since PRISMS operates remotely, with a community all over the world, I have appreciated all the opportunities I have had so far to meet our inspiring board members, volunteers, and community members. Thank you all for the warm welcome I have received so far! I look forward to getting to know more of you this year and in the years to come.

In 2019, I was fortunate to oversee the rollout of our new webinar program, a successful research symposium co-hosted with the Smith-Magenis Syndrome Research Foundation, the expansion of the Bowling for SMS fundraiser, and the start of the new Clinic Travel Reimbursement Program. The Conference Committee has been hard at work preparing for the 11th International Conference since before I showed up, and I am truly thankful for their inexhaustible energy and dedication. 2020 may not turn out to be the year that we thought it would be, but know that PRISMS is still here for you. I will be doing my best to make sure that we continue to provide information and programs to support you, no matter what happens.

If you want to get in touch with me, please don't hesitate to drop me an email at [info@prisms.org](mailto:info@prisms.org). I am here for you!

With hope,

A handwritten signature in black ink, appearing to read 'Casey Gorman'.

Casey Gorman



*Casey and her husband with  
PRISMS community members  
Saori and Kaori Nozaki in  
Tokyo from earlier this year.*

# PRISMS BY THE NUMBERS, 2019



## PEOPLE

**1**

Full-time  
staff member

**2**

Part-time  
staff members

**9**

Board  
members

**10**

Professional  
Advisory Board  
members

**1,052**

Donors

**38**

17p11.2  
Society  
members



## CLINICS AND RESEARCH

**3**

SMS Clinics

**1**

Clinic travel  
request made  
(and funded)

**3**

Research  
Symposium  
Travel Scholar-  
ships awarded

**19**

Abstracts  
presented at  
the Research  
Symposium

**75**

SMS Patient  
Registry  
enrollees



## AWARENESS AND EDUCATION

**144**

New sign ups  
for the PRISMS  
community

**2,583**

Members of the  
PRISMS Parent  
Support Group, with  
809 posts in 2019

**72**

Questions submit-  
ted (and answered!)  
via the PRISMS  
contact form

**2,416**

Awareness  
items mailed

**30**

"On the Road  
to Success"  
books sold

**172**

Unique  
webinar views

**12**

Community  
events supported

**69**

Regional  
Representatives

**9**

Countries covered  
by PRISMS Regional  
Representatives

**6,746**

People reached by  
PRISMS content on  
SMS Awareness  
Day 2019



## SALUTE TO BRENDA FINUCANE, MS: GENETIC COUNSELOR AND SMS PIONEER

*by Ann C.M. Smith, MA, DSc (Hon)*

### LOOKING BACK TO 1990....

After relocating to northern VA (DC metro area) in 1990, I met Brenda Finucane, MS connecting with genetic colleagues in the Mid-Atlantic region. Attending the Mid-Atlantic Regional Human Genetics Network ("MARHGN") we often talked about genetics and Smith-Magenis syndrome (SMS). Brenda, after learning about the syndrome's features, worked to have several adults with DD/ID evaluated through her Genetics Clinic at Elwyn, leading to their diagnosis of SMS. Brenda's early role and dedicated work within the SMS community is part of the early PRISMS story.

The annual SMS Awareness Day picnic at Elwyn, organized by Brenda, laid the foundation for the

establishment of PRISMS in 1993; an event attended by the late Frank Greenberg, the Millers and me.

Within the genetics community we worked together to help raise awareness of SMS: while I secured a funding grant from MARHGN to cover PRISMS publication costs, Brenda produced the layout for the first SMS brochure (the "Red" one) and together we launched the PRISMS newsletter Spectrum with joint editorial input.

Brenda's work with Barbara Haas-Givler using the SMS "on-the-road" approach to visit teachers/school programs serving SMS students across the USA led to publication of their book, *On the Road to Success with SMS: A Smith-Magenis Guidebook for Schools*<sup>1</sup>, that has been translated and distributed worldwide.



Brenda served on the Professional Advisory Board since its founding and has been a regular speaker at the annual PRISMS conferences. She has written and contributed seminal publications about a variety of syndromes, including SMS!! It was Brenda who published article in 1994 that defining the “spasmodic upper-body squeeze” (i.e., SMS self-hug) as a characteristic behavior in Smith-Magenis syndrome.

Besides being a close colleague collaborator and fellow genetic counselor, Brenda has made considerable contributions to the field of genetic counseling: as a past President of National Society of Genetic Counselors (our professional organization) and serving on several genetics’ advocacy boards, including PRISMS and Fragile X Foundation. It has been truly been a privilege to know and work with Brenda for almost 40 years, both as colleague and friend.

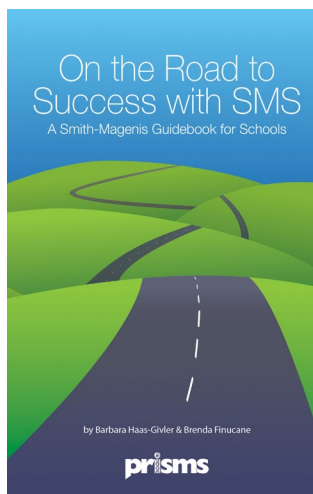
While her infectious spirit and enthusiasm for life, music, family, and longtime dedication to PRISMS and the Professional Advisory Board will be truly missed, we look forward to hearing about her next adventures. Prior to her genetics legacy of contributions, Brenda served in the Peace Corp -- yes, her adventurous spirit has deep roots! So, as we recognize Brenda’s retirement from her active Genetic Counselor role, we wish her well as she explores new horizons! 🌍



*Brenda Finucane, Ellen Mageniz, Ann CM Smith and Jim Lupski (ASHG genetics lunch).*



*Elwyn SMS Awareness Day at Elwyn (PA) Brenda Finucane, Frank Greenberg, Jim Lupski, and Scott Miller.*



*'Barbara Haas-Givler & Brenda Finucane (2014): On the Road to Success with SMS: A Smith-Magenis Guidebook for Schools. [Available in hard copy or digital form via Kindle; English & translated versions (French, German, Danish, Spanish, & Russian)]*



## 2019 SMS RESEARCH SYMPOSIUM

by Maggie Miller

September 30 – October 1, 2019, Houston, TX

The 2019 SMS Research Symposium was a joint collaboration between the SMSRF, (Smith-Magenis Syndrome Research Foundation) and PRISMS. This was the first partnership between the two organizations, who share the same goals of advancing SMS research and inspiring collaboration between researchers and research institutes. We were very proud to be standing with the SMSRF for this partnership, so that we may better serve the greater SMS community.

The 2019 symposium was the largest gathering of SMS researchers to date and we were

pleased to see that the interest in studying SMS is expanding and making inroads in new research disciplines. We welcomed almost sixty attendees to the symposium and a total of nineteen abstracts, were presented, (fifteen talks and four posters). Symposium presenters represented the Cerebra Centre in the United Kingdom, Baylor College of Medicine, National Human Genome Research Institute/The National Institutes of Health, University of Michigan, Rady Children's Hospital, Geisinger Smith-Magenis Clinic, Vanda Pharmaceuticals, St. Louis Children's Hospital, and The Children's Institute of Pittsburgh.



*SMS Research Foundation  
and PRISMS*

Travel scholarships were granted to three attendees reinforcing the goal of inclusiveness and access for new researchers.

The symposium was organized into five specific research specialties: Sleep, Clinical Care, Caregivers and Siblings, Basic Science and Clinical Research. A Poster Session was held during the symposium. Our Keynote speaker was Gianluca Pirozzi, MD, Ph.D, who is



*SMS Research Symposium Attendees*



(Left) PRISMS Professional Advisory Board (PAB) together at the symposium. (Below) SMSRF and PRISMS Board Members.



a member of the SMSRF Scientific Advisory Panel and parent of a daughter with SMS. Dr. Pirozzi's keynote address, "iHOPE in SMS Research," can be viewed here:

[https://www.facebook.com/SmithMagenisSyndromePRISMS/videos/626888334508650/?epa=SEARCH\\_BOX](https://www.facebook.com/SmithMagenisSyndromePRISMS/videos/626888334508650/?epa=SEARCH_BOX)

Dr. Pirozzi's unique perspective as both researcher and parent, allowed for a very impassioned keynote address.

The symposium was also a time for discussion and brainstorming between researchers and we look forward to new collaborations on the horizon. We are grateful to our dedicated researchers for their continued work and their commitment to the SMS community. We look forward to the 2021 SMS Research Symposium! 🌟

### Symposium Scholarship Attendee James Gordovez:

*"Thank you very much PRISMS and SMSRF for the invitation and the support to attend the 10th SMS Research Symposium.*

*I met experts devoted to studying SMS and exchanged ideas with other scientists coming from different disciplines. I was also able to share my findings regarding my research on cellular models for SMS. More importantly, I was able to learn more about people living with SMS and the experience of their caregivers.*

*Now, long hours in the laboratory is certainly more worthwhile knowing that in my own little way, I may be able to contribute to the growing knowledge which will someday improve the lives of people living with SMS.*

*May you continue enabling a collaborative research environment. I look forward to joining you again to future conferences!"*



## PAB SUMMARY, MEMBERS, AND RESEARCH OPPORTUNITIES

*Sarah Elsea, PhD, PAB Chair*

### Professional Advisory Board (PAB)

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

### The PAB is comprised of the following individuals:

Sarah H. Elsea, PhD, PAB Chair

Kerry Boyd, MD, FRCPC

Christine Brennan, MA CCC-SLP

Jane Charles, MD

Brenda Finucane, MS, LGC

Rebecca Foster, PhD

Santhosh Girirajan, MD, PhD

Andrea Gropman, MD

Barbara Haas-Givler, MEd, BCBA

Ann C.M. Smith, MA, DSc (Hon), CGC

Members of the PAB communicate directly with families, caregivers, physicians, teachers, and other healthcare providers to provide education to ensure the dissemination of current accurate medical information, including development and maintenance of the Smith-Magenis syndrome GeneReviews (<https://www.ncbi.nlm.nih.gov/books/NBK1310/>), the SMS Medical Management Guidelines (<https://www.prisms.org/about-sms/living-with-sms/medical-management-guidelines/>), the Spectrum Journal, the PRISMS website, and other publications.

The PAB also advises the PRISMS Board of Directors on medical, scientific, educational and therapeutic matters, and assists in the education and research activities of PRISMS. Members of the PAB review grant applications and potential research opportunities for the SMS and PRISMS community and are actively engaged in the development of questionnaires for the SMS Patient Registry.

Successful, productive research is a partnership among patients, families, clinicians, scientists, and funding agencies that are focused on advancing knowledge about SMS. As part of this collaborative approach, the PAB hosted the 10th SMS Research Symposium September 30 – October 1, 2019 Houston, Texas, where current research related to SMS was presented and research goals were discussed openly.



Ongoing financial support of research and collaborative and interactive programs is critical for increasing awareness and understanding of SMS so that therapies, treatments, education and other interventions can be identified, tested and/or designed to improve quality of life for individuals with SMS.

*A few of the PAB and board members enjoying the sunset in Houston (left to right: Christine Brennan, Diane Erth, Casey Gorman, Sarah Elsea, Jane Charles, and Allison Stephanouk).*



## **SMS Clinic Consortium**

SMS specialty clinics have been designed to provide comprehensive, complete, and holistic care for individuals with SMS. In addition to clinical care, these clinics have sought to provide individuals and families with opportunities to participate in ongoing research within the SMS community. By establishing these clinics, our goal has been to increase access to specialists within the SMS community, provide multi-disciplinary care, and encourage and advance research.

There are currently three SMS clinics across the United States: Texas Children's Hospital, Geisinger Health System-Autism and Developmental Medicine Institute (ADMI), and Rady Children's Hospital. Both Texas Children's Hospital and Geisinger Health System SMS clinics function as comprehensive, multi-disciplinary clinics and Rady Children's Hospital is a consultative clinic.

**Texas Children's Hospital** SMS clinic includes genetics, developmental-behavioral pediatrics, sleep medicine, and research coordination. Individuals with SMS can be scheduled quarterly to have a full evaluation targeted at adhering to the medical management guidelines, behavioral interventions, and sleep.

**Geisinger Health System's ADMI** SMS clinic includes genetics, neurodevelopmental pediatrics, neurology, psychology, behavior analysis, and speech pathology. Individuals with SMS can attend a quarterly clinic and receive care targeted at the specific needs for their child throughout the life span.

**Rady Children's Hospital** SMS clinic offers a quarterly, consultative clinic with a nurse practitioner, who holistically evaluates the individual with SMS and ensures that they have adhered to the published medical management guidelines and recommends referrals and evaluations that may be appropriate to prevent inadequate care.

## **SMS Patient Registry**

The Smith-Magenis Syndrome Patient Registry (SMSPR), housed at Baylor College of Medicine,

functions to support PRISMS long-standing aim to further collaboration between parents and researchers with the goal of improved understanding of SMS.

Individuals with SMS may enroll in the Registry at any time, sharing medical, genetics, educational, and developmental information that, taken together, can help to improve quality of life for persons with SMS and their families.

The patient registry collects and stores medically relevant information from individuals with SMS, enabling researchers to analyze these data and gain insight into the natural progression of SMS.

Enrollment in the SMS Patient Registry in 2019 rose to 75 individuals; however, for the SMS Patient Registry to be most productive and informative for research, we need more individuals with SMS—of all ages—to participate. In 2019, we launched a new online enrollment process to streamline enrollment and are working to expand the questionnaires available for participation. We will be collecting data over several years, across the lifespan of those with SMS, without a specific end-point at this time. Please consider enrolling in this opportunity to expand our understanding of SMS: (<https://www.prisms.org/research/sms-patient-registry/>)

## **Research Studies and Participation Opportunities**

Along with highlighting the latest research, In 2019, PRISMS assisted in recruiting participants for a variety of research opportunities, including the SMS patient registry, clinical trials relevant to the SMS population, including the Vanda Pharmaceuticals tasimelteon trial for circadian rhythm dysfunction (<https://vandapharmaceuticalsinc.gcs-web.com/node/8266/pdf>) and the Rhythm Pharmaceuticals (<https://www.rhythmtx.com>) setmelanotide trial for managing obesity in SMS, as well as several smaller studies focused on sleep, behavior management, and other concerns in SMS. 🌐



## INTRODUCING PRISMS WEBINARS

By Allison Stephanouk

**P**RISMS newest committee, the Education Committee, successfully launched PRISMS Webinar Series in 2019. As an extension of PRISMS biennial conferences, this program was designed to bring educational information and resources about Smith-Magenis Syndrome to the community at large in a more dynamic way and promote engagement between families and professionals. Committee members include Allison Stephanouk (Chair), Maggie Miller, Sylvia Farber, and Amy Pereira.

Since the start of the program in June 2019, six webinars have been successfully broadcast. Webinars are moderated by Allison Stephanouk, who is a board member, the Regional Representative for the state of Georgia, and mom to Natalie who is nine years old with SMS.

PRISMS first webinar was exclusively for PRISMS Regional Representatives and was broadcast on June 12, 2019. Presenters included Percy Huston, the founder and coordinator of PRISMS's Regional Representative Program, as well as board members Denien Rasmussen, Diane Erth, and Tina McGrevy. Some of the topics covered in this webinar were regional representative responsibilities, tips for hosting fundraisers

and meetups, and resources for regional representative to share.

The second webinar on June 22, 2019, was the ***SMS Patient Registry Webinar***. Theresa Wilson MS, RD, PRISMS Research Coordinator, presented information on what the SMS Patient Registry is, how the information provided is used, and how families can enroll using the new electronic consent form.

On August 6, 2019, PRISMS third webinar, ***Understanding the Genetics of Smith-Magenis Syndrome*** was broadcast. Rachel Francis-kovich, MS, CGC, PRISMS Genetic Counselor, was the speaker for this webinar. She began with a basic lesson on genetics and shared specifics on the genetics behind Smith-Magenis Syndrome.

PRISMS began 2020 with the webinar, ***The History of Smith-Magenis Syndrome***. This webinar was broadcast on January 22, 2020 and was presented by Ann C. M. Smith, M.A., DSc (Hon). Ann discussed the history of Smith-Magenis Syndrome and the importance of what we have learned through research. Ann is a founding member of PRISMS and chaired the Professional Advisory Board (PAB) until 2011. She now serves as PAB Emeritus Chair, and has dedicated over 3 decades of her professional career to the

study of SMS, the syndrome she co-discovered in early 1980's.

The fifth webinar from PRISMS was ***Food Seeking Behavior Management*** on February 6, 2020. Dr. Amy McTighe, Director of Care Coordination at The Children's Institute in Pittsburgh, presented strategies for managing food seeking behavior for individuals with Smith-Magenis Syndrome. She also discussed the SMS Model for Care Coordination at The Children's Institute in Pittsburgh, which will begin seeing SMS patients in 2020.

On March 24, 2020 Sylvia Farber presented a webinar on Special Education. In this session, participants learned key education ideas so that planning for summer and the next school year can be more successful!

PRISMS has received overwhelming positive feedback from participants about this new program and is excited to offer this important resource to the SMS community. Plans for upcoming webinar topics include sleep, medication, behavior, new research, and many more. A listing of upcoming webinars as well as recordings of all past webinars can be found on [prisms.org](https://prisms.org) under the education tab. 🌐

## REGIONAL REPRESENTATIVE PROGRAM CONTINUES STEADY GROWTH IN 2019

*By Percy Huston*

**T**he PRISMS Regional Representative program finished 2019 with a record number of 69 active regional representatives – an increase of 21 reps from 2018! This marks the largest single year increase since the program's inception just a few short years ago. Most reps live in North America (including Canada and Mexico), but there are also worldwide reps in Russia, Australia, Brazil, France, Puerto Rico, Italy and the UK.

Our goal in North America continues to be to have at least one rep in all 50 states. Based on geography we are continuing the trend of having multiple reps in some of our larger states to better serve our families. We are truly blessed with the number of volunteers who have stepped forward over this past year to volunteer their time in this capacity. Our regional reps are PRISMS members who care deeply 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 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 and utilize funds available to accomplish these meet ups.
- Encourage families to join PRISMS and share the benefits of membership
- Promote the PRISMS Patient Registry and assist families in registering their SMS relative to help ensure success of the program
- Promoting the newly established webinar program implemented by PRISMS in 2019 to ensure families have access to topics of interest





Our PRISMS website continues to sport a wonderful new look with complete information on our Regional Representative program including bios and photos of most of our reps.

As our number of reps continues to grow we hope we are able to grow a regional list of shared resources for families to use for services and doctors and educators that members are currently using successfully.

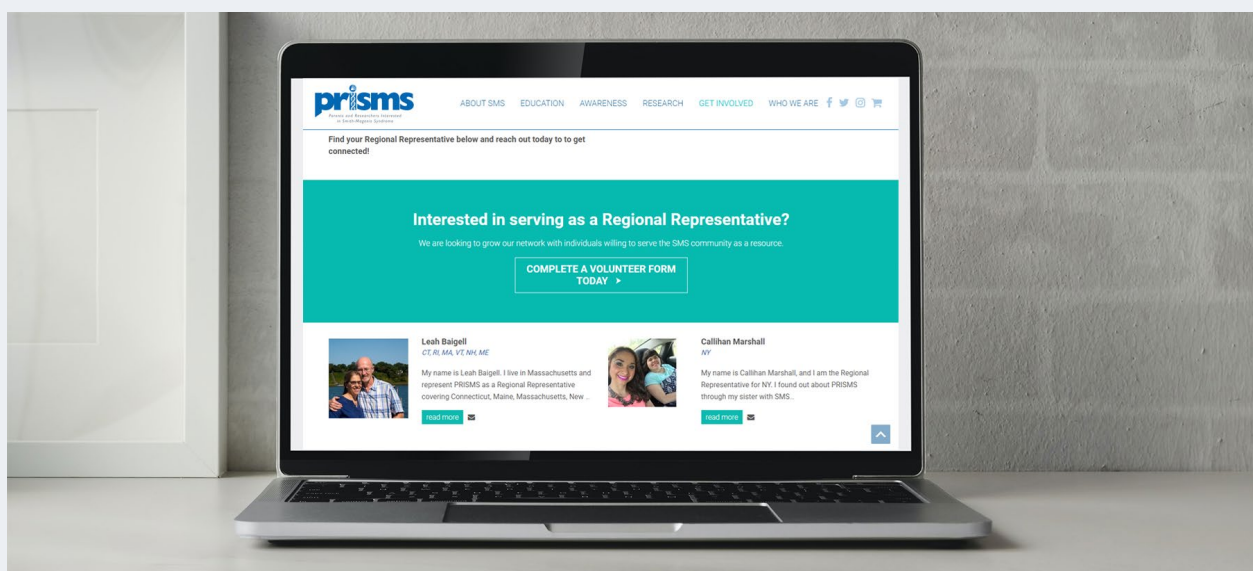
As our newly implemented webinar series grows we want to continue to emphasize its use and importance in providing much needed access to important topics for our families.

As we move forward in 2020, I have some exciting news to announce regarding the Regional Representative Program. It has been my pleasure, over the past few years, to be able to launch and grow the program as it exists today.

Effective February of 2020, I will be passing the baton to fellow board member Denien Rasmussen who will be taking over for me. Denien is currently a Regional Rep in the state of Illinois and she is passionate about the program. She has no doubt been one of our most active and involved Regional Reps and I know you will all appreciate her passion and ideas moving forward.

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

We currently need regional reps in the following states: Alaska, Connecticut, Delaware, Hawaii, Maine, Maryland, Nebraska, Nevada, New Hampshire, North Dakota, Pennsylvania, Oklahoma, Rhode Island, South Dakota, Tennessee, Utah, Vermont and Wyoming. 🌐



*PRISMS Regional Representatives page on the PRISMS website.*

## BRINGING AWARENESS TO SMS IN 2019

*by Tina McGrevy*

**A**wareness. PRISMS believes that “increasing awareness and understanding of SMS” is so important to our community that awareness is one of the three cornerstones of our mission

Other PRISMS awareness accomplishments in 2019 included:

PRISMS partnered with SMSRF in the month of November to promote #StrongerTogether for SMS Awareness Day

Bowling for SMS, held October to November, allowed members of our community from across the country to bowl with friends and family in celebration of SMS Awareness Day. We had 10 participants and raised \$10,000 for PRISMS. Special thanks to Sylvia Farber, who inspired the effort with her successful annual bowling fundraiser and helped spearhead the event.

Our social media presence keeps growing: the Facebook support group increased to a total of 2,583 members who share stories, hope and advice daily online. The PRISMS Facebook page has more than 2,000 followers. The PRISMS Twitter account has more than 550 followers and the PRISMS Instagram account has over 900 followers and has shared over 300 posts.

PRISMS continues to provide awareness tools to the SMS community, including brochures, wristbands, bookmarks and awareness/compassion cards.

PRISMS continues to work with major national organizations, including the National Organization of Rare Disorders (NORD) and Global Genes, to help raise awareness of rare disorders.

The PRISMS online store ([prismsstore.org](http://prismsstore.org)) continues to sell awareness merchandise, including SMS Superhero items.



## FUNDRAISERS, AWARENESS EVENTS RAISED MORE THAN \$72,000

by Denien Rasmussen

In 2019, the PRISMS community raised more than \$68,000 through fundraising and awareness events, with many families participating in outings, picnics and other events. Financial support generated through fundraising events is essential and helps PRISMS continue its programming. We are very appreciative of the hard work and generous support of everyone who organized and contributed to a fundraising event in 2019.

PRISMS biggest event of the year was the 10th Annual Farber Bowling event, hosted by Sylvia and Jeremy Farber. This year, in conjunction with the Farber Bowling event and inspiration from Sylva, PRISMS hosted its first Bowling for SMS Bowl-a-Thon. Many of us participated and we all had a fun time. We thank the Farbers and all the bowlers again for their support of PRISMS.

We also want to give a huge shout out and thank you to our other wonderful families who have also held events for PRISMS several years in a row:

- **Nickels for Nico**, hosted by Jean Bishop
- **ABC Fundraiser**, hosted by Denien & Jim Rasmussen and Kyle & Aileen Rohde
- **Vettes in the Vineyard**, hosted by Percy and Bernadette Huston
- **Family Fun Day**, hosted by Diane Erth and Kathleen Macken.

Thank you also to our First Time Events hosts:

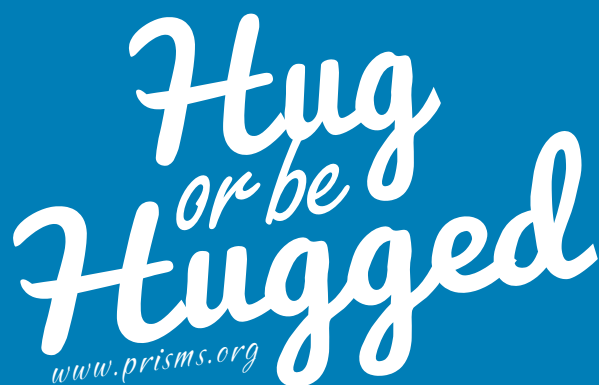
- **Dress Down**, hosted by Carol Gritman
- **Lemonade Stand**, hosted by Jason & Charlene Michaud
- **Bowling for SMS Columbus**, hosted by Allison Stephanouk

A growing number of families also organized Facebook fundraisers. Our Facebook fundraisers continue to be instrumental for PRISMS. In 2019, our community ran Facebook fundraisers for birthdays, Giving Tuesday, SMS Awareness day, and fundraising event support. All in all, these Facebook fundraisers raised over \$15,500! Thank you to all of you who hosted a fundraiser to support PRISMS on Facebook in 2019 and we hope you do it again in 2020!



(Left) Cooper and his parents helped raise \$400 for PRISMS. (Middle) Rasmussen family at ABC Fundraiser. (Right) The Michaud lemonade stand.





### 2019 Hug or Be Hugged Community Fundraisers

Our generous Hug or Be Hugged Community includes those people who ran fundraisers, either in-person or online, in support of PRISMS.

We greatly appreciate your hard work in support of PRISMS!

<p>► <b>Raised \$10,000 +</b></p> <p>Jeremy &amp; Sylvia Farber</p> <p>The Rasmussen &amp; Rohde Families</p>		<p>► <b>Raised \$5,000-\$9,999</b></p> <p>Jean Marie Bishop</p> <p>Allison Stephanouk</p>
<p>► <b>Raised \$1,000-\$4,999</b></p> <p>Lindsay Doering</p> <p>Diane Erth</p> <p>Percy &amp; Bernadette Huston</p> <p>Kathleen Macken</p>	<p>► <b>Raised \$500-\$999</b></p> <p>Carol Gritman</p> <p>Bonnie Krautheimer</p> <p>Allison Leatzow</p> <p>Tamara Sutherland</p>	<p>► <b>Raised \$250-\$499</b></p> <p>Holly Collins</p> <p>Ryan &amp; Nikolas Michaud</p> <p>Gail Reiner</p> <p>Mark Roth</p> <p>Anna Sewell</p>
<p>► <b>Raised \$100-\$249</b></p> <p>Debbie Billington</p> <p>Tracey Bundle</p> <p>Joan Cole</p>	<p>Jason Doscher</p> <p>Maricela Garcia</p> <p>Brenna Hartman</p> <p>Tabitha Petkovich</p>	<p>Deana Slatton</p> <p>Tyrell Swafford</p> <p>Liz Yates</p>

## THE 17p11.2 SOCIETY

*by Diane Erth*



When PRISMS moved to free membership in 2018, it created a monthly giving program to help continue to receive a steady stream of funds to support our daily operations. We named it the 17p11.2 Society after the specific genetic material missing from chromosome 17, which leads to the Smith-Magenis Syndrome diagnosis.

The generosity of our 17p11.2 Society members ensures that PRISMS can sustain its programs and services dedicated to education, awareness and research.

At the end of 2019, the 17p11.2 Society has 38 dedicated members who have pledged to donate a minimum of \$17 a month. The Society has donated a total of \$10,754 to help support PRISMS, and we are extremely grateful to them for their continuous support.

To join the 17p11.2 Society, simply go to [PRISMS.org](https://PRISMS.org).

- Click “Who we are.”
- Click “Get Involved.”
- Click “17p11.2 Society” and follow the prompts.

Each member will receive a custom color premium quality pin to signify their commitment to PRISMS and the SMS Community—and the knowledge that you are an active participant in helping PRISMS continue.

## M E M B E R S

---

*Cally Bauman  
Danielle Bier  
Brandon and Dawnda Daniel  
Barclay Daryani  
Dennis Dillon  
Robert and Shannon Duvall  
Angela Eaton  
Sarah Elsea  
Diane and Joseph Erth  
Jackie and John Fallenstein  
Sylvia and Jeremy Farber  
Steven and Beverly Frey  
Jennifer Groetke  
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Scott Miller  
Scott and Maggie Miller  
Mike and Trinity Miodunski  
Faith Nobilucci  
Kevin O'Connor  
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William and Caitlin Seldon  
Ann and Ron Smith  
Allison and Alexander Stephanouk  
Derek Waldeck  
Adrienne Wampler  
Christopher Weber  
Ron and Mary Ann Zimmer*

## 2019 FINANCIAL NARRATIVES

*by Phil Ruedi*

**P**RISMS' investment focus in 2019 centered on research. The highlight of the year was certainly the 2019 Research Symposium presented jointly with the Smith Magenis Research Foundation. The Symposium was considered a success from a scientific perspective and the financial support of the two leading organizations focused on Smith Magenis Syndrome helped to preserve your organization's financial strength.

PRISMS also continued the funding of the University of Michigan Post-Doctorate work and we are excited to see the results of that research program in the near future. In total, research spending represented 22% of total operating costs in 2019 and would have been higher if the grant for the genetic counselor and support at Baylor University was included. Payments to support that program were made in the first quarter of 2020.

PRISMS is excited that Casey Gorman joined as Executive Director in the middle of 2019! The timing

of finding a new Executive Director was 3 months later than budgeted and so your organization absorbed the employment costs for 6 months of the year, so we expect those expenses to ramp through 2020.

As 2019 was a non-conference year, conference related expenses were small and make year to year comparisons less relevant. Administrative expenses remain fairly low for an organization of our size, averaging less than 20% across 2018/2019 combined, and we are happy that they remained relatively flat in 2019 despite our continued growth. We continue to expect program expenses, including research, to remain in the 65 percent range of total expenses in non-conference years.

In terms of revenues (excluding investment income), contributions and sales were up 40% in 2019 versus 2017, due to continued expansion of the 17p11.2 Society and strong performance of member sponsored fundraisers. This is an appropriate comparison given both are non-conference years.

We are excited by the continued support of the members of PRISMS for the operations of the organization and are honored to be entrusted with these funds such that we can continue to develop programs and provide support for the SMS community. The growth of the 17p11.2 Society has provided a stable source of donations that exceeds our prior Membership Dues program, validating our decision to move away from the membership model.

Combined, all of these factors resulted in an operating income of \$28,000 to be used to fund future conferences, research and support programs. The performance of our investment portfolio and dividends added an additional \$48,000 in income in 2019 and put PRISMS in a very strong financial position with almost \$560,000 of assets against \$87,500 in future commitments for research at Baylor and the University of Michigan.

On a final note, this is the last financial summary I will be writing as your Treasurer. I have served you in this capacity for about 10





years now and the organization has changed dramatically over that time. When I started, PRISMS survived year to year on a small checking account balance and had no support staff.

Now the organization is financially strong, supported by excellent and caring staff and has taken on commitments that would have not even been discussed a decade ago.

I elected to extend my final Board term for one year to help with the transition to a new Treasurer. Percy Huston will be stepping into my role and I could not be more excited. He is energetic, inquisitive and very sharp and has been my partner in managing the financial operations of PRISMS for the last 10 years. He will do an outstanding job and help take PRISMS to a new level.

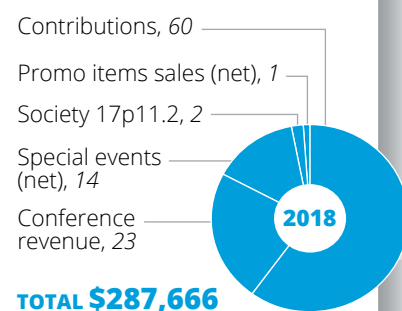
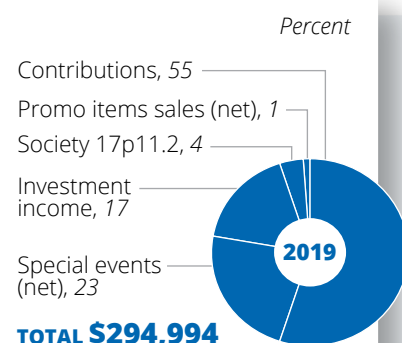
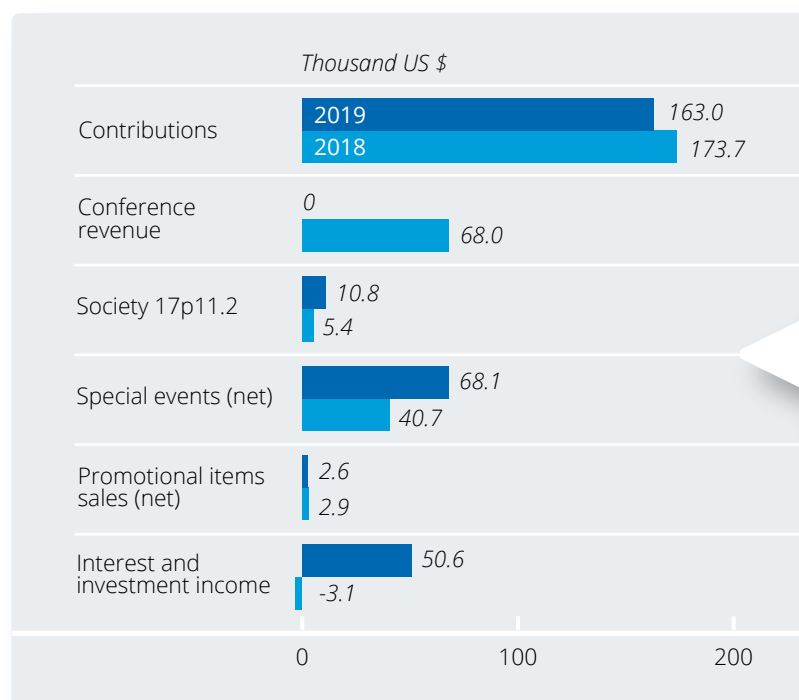
I will miss this role but feel that many things in my life were taking away from giving PRISMS my all. I know that you understand this, given that we are all caretakers of someone with SMS. I will still be

around as a volunteer and member of the Finance Committee so that I can continue to support the mission.

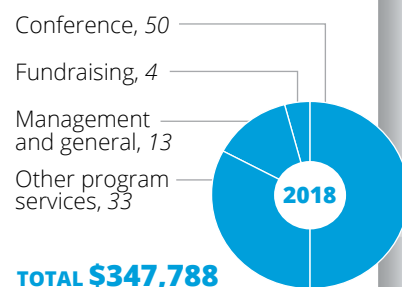
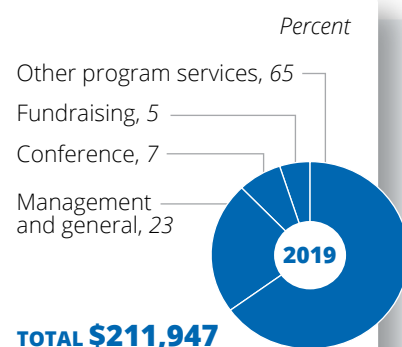
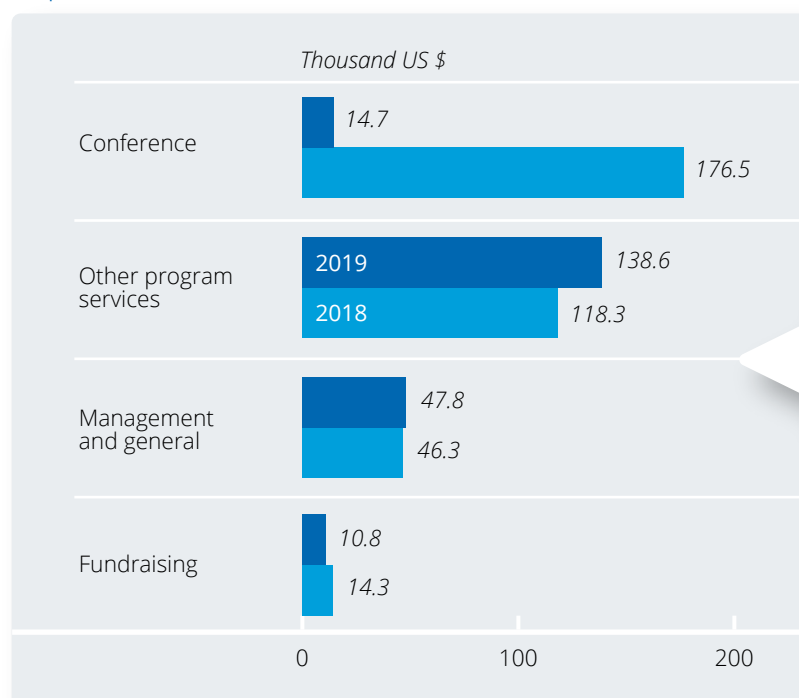
Finally, I write this sitting across from my SMS son as in addition to my day job I am also now serving, with my wife, as his teacher and the teacher of our 10-year-old daughter. These times are challenging, particularly for families like our own, but SMS I think has trained us to deal with adversity, to adapt and to overcome. I pray for the health, safety and sanity of our community and all of the world. 🌍

***We are excited by the continued support of the members of PRISMS for the operations of the organization and are honored to be entrusted with these funds such that we can continue to develop programs and provide support for the SMS community.***

## Support and Revenue, 2018<sup>a</sup> and 2019<sup>b</sup>



## Expenses, 2018<sup>a</sup> and 2019<sup>b</sup>



	2019	2018
Ending Cash and Investments	<b>\$559,674</b>	<b>\$487,617</b>
Ending Total Assets	<b>\$583,309</b>	<b>\$504,027</b>

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

## 2019 DONOR LIST

### **\$10,000 and above**

Anonymous Donors

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

Mary & Randy Beall  
Rosalind & Alfred Berger  
Foundation  
The Bost Foundation  
Rhythm Pharmaceuticals

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Sylvia & Jeremy Farber  
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Josephine Lawlor  
Miles & Robin Lawlor  
Patrick Lawlor  
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Mike & Allison Leatzow  
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Michael & Lisa Mariano  
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Linda & David Mills  
Trinity & Mike Miodunski  
Barbara Moser  
Marilyn Murray

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 Faith Nobilucci  
 David & Kimberly Norman  
 Lisa Nunes  
 Kevin O'Connor  
 Aaron Patrick  
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 Jerrica Rodriguez  
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 Linda & Dan Tortorelli  
 Paula & Joseph Toussaint  
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 Mary Frazer Vaughn Legacy Fund  
 Mary Kay & Dennis Vierling  
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 Eva & Weldon Wamble  
 Adrienne Wampler  
 Larry & Judy Watters  
 Mark Whitaker  
 Thornton Wright  
 Anthony & Virginia Yoho  
 Michele & Joe Zdanowski  
 Mary Ann & Ron Zimmer

### **\$1-\$99**

Deborrah Almaguer  
 Mary Anderwald  
 Harriet & Martin Arno  
 Marsha & Gary Bach  
 Leah Baigell & Henry Kon  
 Carlton & Nicole Bale  
 Cheryl & Ned Berman  
 William & Clari Bohannon  
 Ilse & Randy Ciprich  
 David & Amanda Clark  
 Robin & Tim Coutu  
 Joe & Monica Crouch  
 Yolanda & Alfredo DaSilva  
 Frederick Dittrich  
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 Richard & Catherine Morrill  
 Melissa Munn  
 Shinji & Kaori Nozaki  
 Jaye Orgera  
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 Shannon and Darrell Richard  
 Jan & Keith Rolston  
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 Joan & Peter Sherman  
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 Stephen & Michelle Smith  
 Jenn Sporcich  
 James & Marsha Stepic  
 John & Cheryl Stevens  
 Elizabeth Sullivan  
 Steve Swann  
 Brian & Brenda Templeton  
 John & Gwen Turner  
 Olivia Waschczyn  
 Gordon & Mary Whitehead

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*These donation totals reflect the amount given through the PRISMS website or directly to PRISMS via Facebook. Donations given through event fundraisers and non-PRISMS Facebook fundraisers are reflected in the fundraiser's total on the Hug or Be Hugged Community Fundraiser page (see page 16).*



## 2019 NEW MEMBERS

Cindy & Danny Abbott	Lisa Fox	Amanda Klages	Sandra Sassoon
Lana Anderson-Phelps	Michele Fryman	Kristel Kok	Natasha Schaller
Laura Armentano	Patricia Garay	Rebekah Laffoon	Amanda Schroeder
Deborah Bagocius	Eloina Garcia	Ashley Lane	Amy Scott
Deshanae Baker	Richell Gardiner	Diane Leland	Lori Semprevio
Dylan & Annabelle Baron	Marina Georgieva	Macey Leo	Solange Serena Paz
Amy Bartos	Marjorie Goldberg	Michelle Lewis	Josh & Jennifer Sewell
Cally Bauman & Mathieu	Michelle Greenhagen	Cathelijne Linders	Nikunj & Charmi Shah
Lague	Richard Gritman	Thomas Londen	Samuel & Elizabeth
Anne Bishop	Sarah Gross	Tabitha MacKay	Smith
Leslie Bishop	Carolyn Harrison	Laura Maddocks	Mark Smyth
Louise Blanchard	Michael Harrison	Clement Marie Pierre	R. Isabel Sotelo
Lauren Brothers	Tara Haye	Heather Marks	Barbara Spodniakova
Megan Brown	Richard & Ann	Callihan Marshall	Dylan Stanco
Lisa Bryant	Henderson	Brenda Massey	Amanda Starr
Claire Burney	Maricela Hernandez	Mindy McCoy	James Stephen
Sheridan Cain	Garcia	Lacey Medious	Leeann Stevenson
Tammy Calderon	Gabrielle Hernandez	Colleen Mielke	Bashier Surve
Claudia Canizales	Dorene Hibbs	Lauren Mollerup	Liz Tesone
Michelle Carr	Angela Hicks	Bill & Vivienne Monos	Holly Thomson
Jamie Castillo	Amy Holdge	Ray Monts	Ebru Tursin
Laurent Chemartin	Rebekah Holland	Lee Morrison	Ellen Valentine
Jessica Cherry	Linda Hoover	Samantha Newman	Tina Watkins
Leah Cohen	Corey Jackson	Isabel O'Rourke	Haley Watson
Clare Collins	Peter Jakobsen	Miguel Oliveira	Paul & Denise Wilkins
Beverly Combs	Phthessa Jansen van	Sandra Palmer	Suzie Wilkinson
Desarae Crispin	Vuuren	Mick Pearson	Ashley Williams
Petrina Cross	Cyndi Jennings	Lisa Peracki	Derek & Holly Winstanley
Jack Croyle	Kristie Jensen	Sonia Perez	Amy Woods
Michelle Cunningham	Paula Jimmieson	Victoria Perko	Candace Wooten
Kathie Davis	Alliyah Johnson	Kyle Perry	Maycee Zhao
Esteban & Jennifer	Evan & Michelle Johnson	Gaia Pontarelli	
Delgadillo	Jennifer Johnson	Neelam Rawat	
Theresa Dixon	Maria Johnson	Samantha Rayle	
Amber Doiron	Cynthia Jules-Miller	Morgan Razon	
Nadine Doran	Gudrun Kaminski	Alivia Reno	
Lauren Fallin	Swapnil Kendre	Zech & Shelby	
Karen Farrar	Steve & Heather Khraiss	Rothermund	
Dale & Robyn Fell	Sian Kinoshi	Darren Salisbury	
John Fisher	Angie Kirk	Marty Sanchez	



## PRISMS BOARD AND STAFF

### BOARD

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**MARGARET MILLER**, *Vice-President*

**TINA MCGREVVY**, *Secretary*

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**JOHN MAYER**, *Immediate Past President*

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**CASEY GORMAN**, *Executive Director*

**ANGELA WILLIAMS**, *Office Manager*

**JULIE BERNATZ**, *Executive Assistant*

### CONTACT US!

Email: [info@prisms.org](mailto:info@prisms.org)

#### Office Information

21800 Town Center Plaza

Suite #266A-633

Sterling, VA 20164

972-231-0035 (phone)

#### Donation Mailing Address:

PRISMS, Inc.

PO Box 206528

Dallas, TX 75320-6528

## 2019 PRISMS VOLUNTEERS

PRISMS would not be able to support our SMS community without the help of our wonderful volunteers. Thank you to everyone who worked with us in 2019!

### Committee Volunteers

Leah Baigell

Randy Beall

Barclay Daranyi

Jackie Fallenstein

Sylvia Farber

Melissa Haley

Scott Miller

Amy Pereira

Tabitha Petkovich

Trevor Gritman

Melissa Haley

Stephanie Hanquez

Mary Hards

Sheila Hernandez Vale

Julia Hetherington

Roberta Higgins

Eric and Kim Hoffman

Bernadette Huston

Jennifer Klump

Carissa Le

Allison Leatzow

Charlene Liao

Rhonda Lowney

Patty Loyer

Callihan Marshall

Maureen Monroe

Kevin O'Connor

Mick Pearson

Milissa Pelonero

Kyle Perry

Denien Rasmussen

Marni Rolston

John Roseborough

Brianna Ryczek

Virginie Sargent

Caitlin Seldon

Mark and Theresa Smyth

Wanda Stahlman

Allison Stephanouk

Bela and Alexander Tzetlin

Osman Umarji

Brooke Widmer

Brandi Wilson

Jill Wood

Bill and Liz Yates

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Abigail Bell

Laurie Bellet

Jean Bishop

Sabrina Bisiani

Heather Boney

Debbie Brooks

Maria Elena Carrancedo

Ashton Chermaine

Ilse Ciprich

Jennifer Comford

Kevin Daly

Mary Daly

Barclay Daranyi

Esteban Delgadillo

Ron Dixon

Amanda Downey

Heather Eberlein

Diane Erth

Maria Feagin

Rhonda Franklin

Heidi Graf

If you are interested in volunteering with PRISMS, please fill out our Volunteer Form. (<https://www.prisms.org/get-involved/volunteering/volunteer-form/>)

## ANNUAL REPORT: KEY RESOURCE LINKS

Gianluca Pirozzi, MD, Ph.D, keynote address, "iHOPE in SMS Research,"

[https://www.facebook.com/SmithMagenisSyndromePRISMS/videos/626888334508650/?epa=SEARCH\\_BOX](https://www.facebook.com/SmithMagenisSyndromePRISMS/videos/626888334508650/?epa=SEARCH_BOX)

SMS GeneReviews

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

SMS Medical Management Guidelines

<https://www.prisms.org/about-sms/living-with-sms/medical-management-guidelines/>

SMS Patient Registry

<https://www.prisms.org/research/sms-patient-registry/>

Vanda Pharmaceuticals tasimelteon trial for circadian rhythm dysfunction

<https://vandapharmaceuticalsinc.gcs-web.com/node/8266/pdf>

Rhythm Pharmaceuticals setmelanotide trial for managing obesity in SMS

<https://www.rhythmtx.com>

PRISMS Volunteer Form

<https://www.prisms.org/get-involved/volunteering/volunteer-form/>



***This report made possible by contributions from:***

*Casey Gorman, Executive Director*

*Angela Williams, Office Manager*

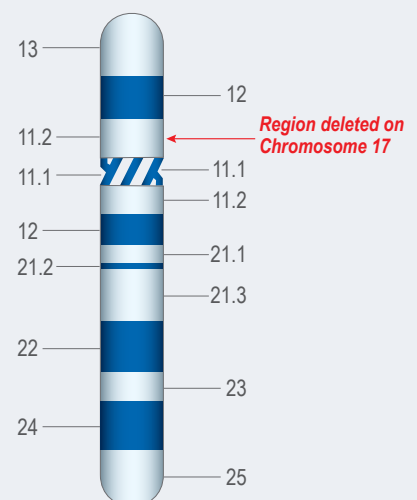
*Michelle Larscheid, Program Assistant*

*Designer: Mark Hernandez*

## 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.







Parents and Researchers Interested  
in Smith-Magenis Syndrome