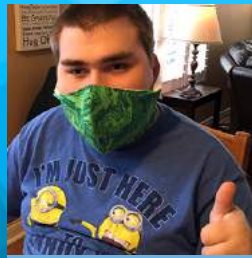


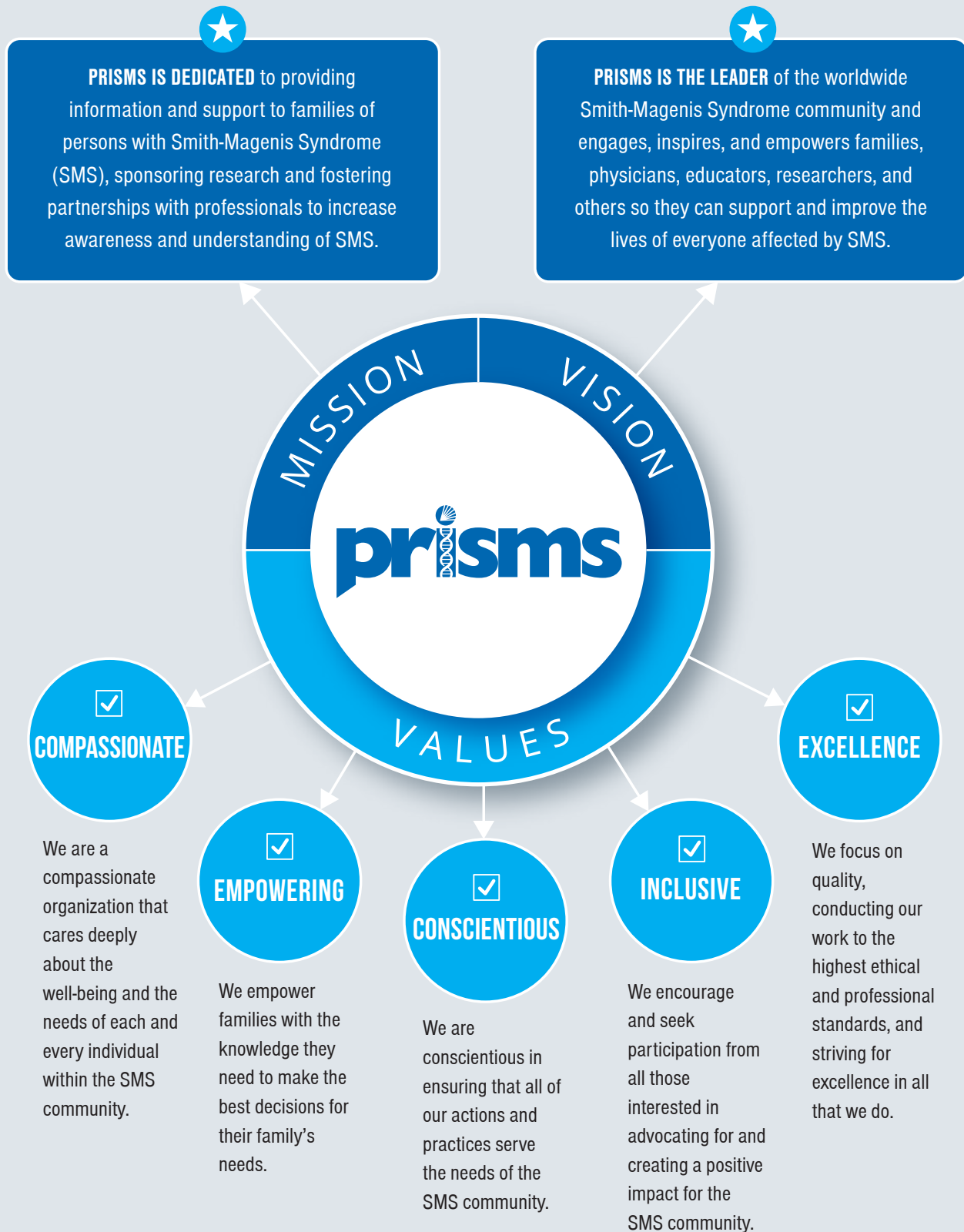


# 2020 PRISMS ANNUAL REPORT

## [ R E S I L I E N T ]



## PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME



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## Message From the President

BRANDON DANIEL



The word “Resilient” seems to summarize 2020 for many families and perhaps the entire SMS community. To say that it was (and is) challenging is an understatement of the impact the COVID-19 pandemic had on families and caregivers in the SMS community. We all had to work through alternative schedules with online learning, modified living arrangements and with caregivers and family. On top of that was the heightened concern and stress of understanding the COVID virus itself and its impact on family and friends, including loved ones with SMS. While life is still not back to normal, there is optimism on the horizon that the pandemic will be managed and that life as it we know it may start resembling something once considered normal before 2020. PRISMS, like every organization, also experienced challenges and change in 2020, but despite the circumstances PRISMS remained resilient in its mission to provide valuable resources to help those within the SMS community.

PRISMS had some transition on the Board in 2020. Long term board members John Mayer and Phil Ruedi departed. Both of these board members were instrumental in making PRISMS the organization that it is today. John Mayer was an officer on the board for several years, starting as Secretary, then President, and finally Immediate Past President. John was instrumental in providing structure to the governance procedures of board operations and he continues to be an active volunteer working with the Advocacy Workgroup today.

Phil was the Treasurer of PRISMS for the last several years. In that time, Phil established several vital financial processes to ensure the long-term financial health of the organization. Phil has been instrumental in guiding the finances of the organization into the position of strength it is in today, and he remains active as a volunteer on the finance committee. We are so thankful to John and Phil for their many years of dedicated service to the PRISMS community as Board members and are grateful that they are continuing their service with us as active volunteers.

With the departures of John and Phil, PRISMS had some big shoes to fill, so we welcomed a new Treasurer and added two board members in 2020. Percy Huston has volunteered and been approved by the Board as the new Treasurer moving forward. Amy Pereira joined the board in March 2020. Amy brings many years of volunteer experience with PRISMS to her Board role. She has been a member of the Conference Planning Committee since 2012 and is currently on the Conference Planning Committee, Education Committee and Awareness Committee. We are so thankful to have Amy as a member of our PRISMS Board.

Tim Hibbs joined the Board in late 2020. Tim and his wife Adrian bring energy, enthusiasm and a strong business acumen to the Board. Their son, Anderson, was diagnosed with SMS at 20 months old in December 2018. Tim is extremely excited and honored to be a part of helping as many families as possible experience the strength of PRISMS

*"We remain grateful for all those in the SMS community who volunteer their time, expertise and financial gifts to the organization to advance research and support for the SMS community."*

program support and resources. Tim will be assisting with fundraising and the finance committee on the Board during the coming year.

While the 2020 Conference was canceled, PRISMS continued meeting monthly via Zoom calls during the year. The capstone meeting of the year was completed with a full-day Zoom call this past October to establish goals and priorities for 2021. As you read through the 2020 Annual report, you will see a culmination of the work accomplished by PRISMS families, volunteers, staff, PAB members and Board members during the past year. As a Board, we are thankful for all the work that was accomplished in

2020. We remain grateful for all those in the SMS community who volunteer their time, expertise and financial gifts to the organization to advance research and support for the SMS community.

Despite the challenges of the past year, PRISMS remains financially and operationally strong to execute its mission into the future. As things across the globe start to open up, we look forward to meeting together with our SMS friends and family in person, not only through Zoom. That time is coming soon. I can't wait!

*Thank you!*  
*Brandon Daniel*



*The PRISMS Board gathering virtually via Zoom.*





## Message From the Executive Director

CASEY GORMAN

To our PRISMS Friends and Family,

2020 was a tough year for all of us. I am extremely grateful to the PRISMS community for your kindness and understanding towards each other (and us!) as we all figured out how to deal with the seemingly endless string of terrible happenings in the year that was 2020. I am sure I am not the only one who is happy to see that year disappearing into the rearview mirror.

Though we may not be “back to normal” yet, I can’t help but be excited at the prospect of better things to come for all of us in the SMS community. PRISMS is working on our end to make 2021 the best that it can be, and I feel privileged to be part of that effort. If you have any ideas, suggestions, or concerns, please don’t hesitate to drop me an email at [info@prisms.org](mailto:info@prisms.org).

I am (still) looking forward to meeting all of you in person at our conference in Dallas next year! Save that date!

*Best,  
Casey*



# PEOPLE



## PRISMS by the numbers 2020

# CLINICS &

# RESEARCH



# AWARENESS & EDUCATION

## A Salute to Our Former Board Members

TINA MCGREVVY



*Phil Ruedi and John Mayer*

The year was 2010. The Oscar winning movie, *The Hurt Locker*, was playing in the theaters, Train's "Hey Soul Sister" was playing on the radio and our TVs were tuned to Vancouver so we could cheer for our favorite Winter Olympic athletes. And in the early days of 2010, PRISMS welcomed Phil Ruedi as its newest board member. Phil came to the board with experience in the financial industry as a portfolio manager and was a natural fit as the PRISMS Treasurer.

When Phil joined the PRISMS Board, John Mayer was six months into his role as the new board Secretary. John came to the board with a history of non-profit work, even serving as an executive director for a history museum.

For the following ten years, John and Phil were a part of the team that lead PRISMS through much growth and many changes. Phil chaired the Finance Committee and updated the financial policies of PRISMS. John chaired the Membership Committee that transitioned to a free membership policy for our community, ensuring that PRISMS was truly inclusive for all families affected by SMS. After six years of serving as the PRISMS Secretary, John stepped up as PRISMS Board President. He chaired the Adult Living Workgroup, a team that presented a panel discussion and break out session at the PRISMS conference and published "A Smith-Magenis Guidebook: Exploring Adult Residential Living." This workgroup went on to publish "A Guidebook for Families Newly Diagnosed with Smith-Magenis Syndrome."

Under Phil's guidance as Treasurer, PRISMS grew and became stronger financially. This

meant that the PRISMS team was able to grow from an all-volunteer organization to one lead by a full-time executive director and four staff members. As staff members were able to manage the day-to-day operations, the PRISMS Board was able to focus its energy on ensuring that PRISMS remained a sustainable organization for families.

As board members, Phil and John would meet with the rest of the PRISMS Board for monthly teleconferences and twice a year for in person meetings. During this time, John and Phil's professional experiences were vital for the strategic planning of the board as we defined our goals, values and vision for the future of PRISMS. I cannot imagine accomplishing these lofty goals without them.

Their time spent was time away from their own families, and we should thank John's wife, Debora Mayer, and Phil's wife, Laura Staich, for lending their guys to us for an entire decade. John and Phil have both decided not to renew their terms as PRISMS Board Members. They continue to be volunteers, serving on the committees that they had led as board members.

So much has changed, for PRISMS and for the world. We have not been able to go to the movie theaters and the Olympics have been postponed. And the PRISMS Board has not been able to meet face-to-face to give John and Phil the sendoff that they deserve. We hope that they see their names here and know how much their fellow board members thank them for their years of service. We look forward to the day that we can give you the cheers (Hip, Hip, Hooray!!) that we are holding inside for now. 🌊



## PRISMS Goes Virtual

AMY PEREIRA

Unable to gather in-person and recognizing the desire to stay connected as a community, PRISMS offered new and exciting ways to interact in 2020!

In August 2020, the PRISMS Board and staff orchestrated a week-long virtual celebration on social media during our planned conference dates. We kicked the week off with a video featuring some of our PRISMS Board members and staff preparing for the conference, only to find out it had been postponed. The video, edited by Steve Brown, brother of PRISMS Board member Diane Erth, was a fun way to start the week! We concluded our week's activities with our first ever PRISMS Spirit Day! To celebrate, we hosted a virtual Ice Cream Social. Forty-five familiar faces joined the two-hour event, including Ann Smith, one of the founding members of PRISMS/PAB Chair Emeritus, Casey Gorman, PRISMS Executive Director, and many board members with their families.

In October 2020, the PRISMS team organized a virtual Halloween Parade on social media, feature our amazing community members in their favorite costumes. To continue our celebration of this fun holiday, PRISMS hosted a virtual Halloween Party for parents and families. We had a lot of fun showing off costumes and socializing virtually! 🌟



## Updates on Our Conference

AMY PEREIRA

The PRISMS Conference brings together families of persons with Smith-Magenis syndrome and professionals interested in “SMS” so that research information, medical, educational, and therapeutic treatment strategies may be shared throughout the community in order to improve the lives of persons with SMS.

Like the rest of the world, the pandemic has affected how PRISMS delivers its programs. Impacted most has been our International Conference. While we were hopeful we would be able to host our 11th International Conference in 2020, the Board of Directors made the tough decision last May to postpone our in-person conference.

With COVID-19 safety concerns still present, PRISMS recently announced that our 2021 conference program would be offered in a virtual setting. We hope this allows our families and professionals the opportunity to connect with one another and gather important information and updates related to SMS, while keeping our community's safety a top priority. Our Virtual Summit will be held September 9th to 11th, 2021. Log on and join us!

We are very fortunate that our conference committee members have agreed to continue their service and have been working behind the scenes to ensure our conference program is educational, accessible and safe for our community. The committee members include Casey Gorman, Maggie Miller, Michelle Larscheid, Angela Williams, Tim Hibbs, Allison Stephanouk, Jackie Fallenstein, Amy Pereira, Pat Brown and Athenna Harrison.

We know our conferences are important events for our community and an opportunity for us to gather in-person and enjoy each other's company. With that in mind, PRISMS has worked with the hotel in Dallas to resume our bi-annual in-person conference schedule for 2022. We will see you August 4-6, 2022 in Dallas, Texas! 🌐



## Providing Virtual Education in 2020: PRISMS Webinars

ALLISON STEPHANOUK

**P**RISMS webinar series had a successful second year in 2020. We continued with our goal of sharing critical information with the SMS community directly from the experts, in an easily accessible and dynamic way. We expanded our library to include webinars on seven new topics for the year.

We began 2020 with a webinar from Ann C. M. Smith, M.A., DSc (Hon), discussing the history of Smith-Magenis Syndrome and the importance of what we have learned through research. In February, Dr. Amy McTighe, Director of Care Coordination at The Children's Institute in Pittsburgh, presented on the management of food seeking behavior for individuals with SMS. In March, Sylvia Farber, owner and founder of 101 Advocacy, discussed key education ideas so that planning for summer and the next school year can be more successful. Next, in an effort to support SMS families during the COVID-19 pandemic, we presented two behavioral webinars. Barbara Haas-Givler, MEd, BCBA, Director of the Smith-Magenis Syndrome Clinic at ADMI and PRISMS Professional Advisory Board member, presented Supporting Your Child with SMS in Special Times in March. Strategies to Increase Self-Engagement and Independent Play for Children with SMS was presented by Anissa Moore, M.Ed., BCBA, LBA in September. We closed out the year with Kelly Piacenti, MA, ChSNC®, Head of SpecialCare, MassMutual and Jerry L. Hulick, CLU, ChFC, ChSNC, CLTC, Gen-

eral Agent Emeritus, MassMutual Financial Group, presenting two very informative financial webinars in November and December, both with the goal of helping families prepare for the financial future of their dependent with special needs.

This past year we also began featuring a family from the SMS community during our webinars. Through these short personal videos we have been introduced to several incredible families. Thank you to Maggie, Scott, and Deirdre Miller; Sylvia and Austin Farber; Allison and Andy Leatzow; Betsy and Ezra Andersen; Dawn and Garrett Mock; and Brenda Dickerson and Colby Walter for taking the time to record and share your stories with all of us.

All of our webinars, as well as other PRISMS feature videos, can be found on PRISMS YouTube channel (PRISMS, Inc.). Please visit our channel and subscribe. A listing of upcoming webinars and a link to past recordings can be found on [prisms.org](https://prisms.org) under the education tab.

Our webinar series is brought to you by the PRISMS Education Committee. Education Committee members include Allison Stephanouk (Chair), Maggie Miller, Sylvia Farber, and Amy Pereira. We hope to see you at future PRISMS webinars! 🌟



## Regional Representatives Hold Strong in 2020

DENIEN RASMUSSEN

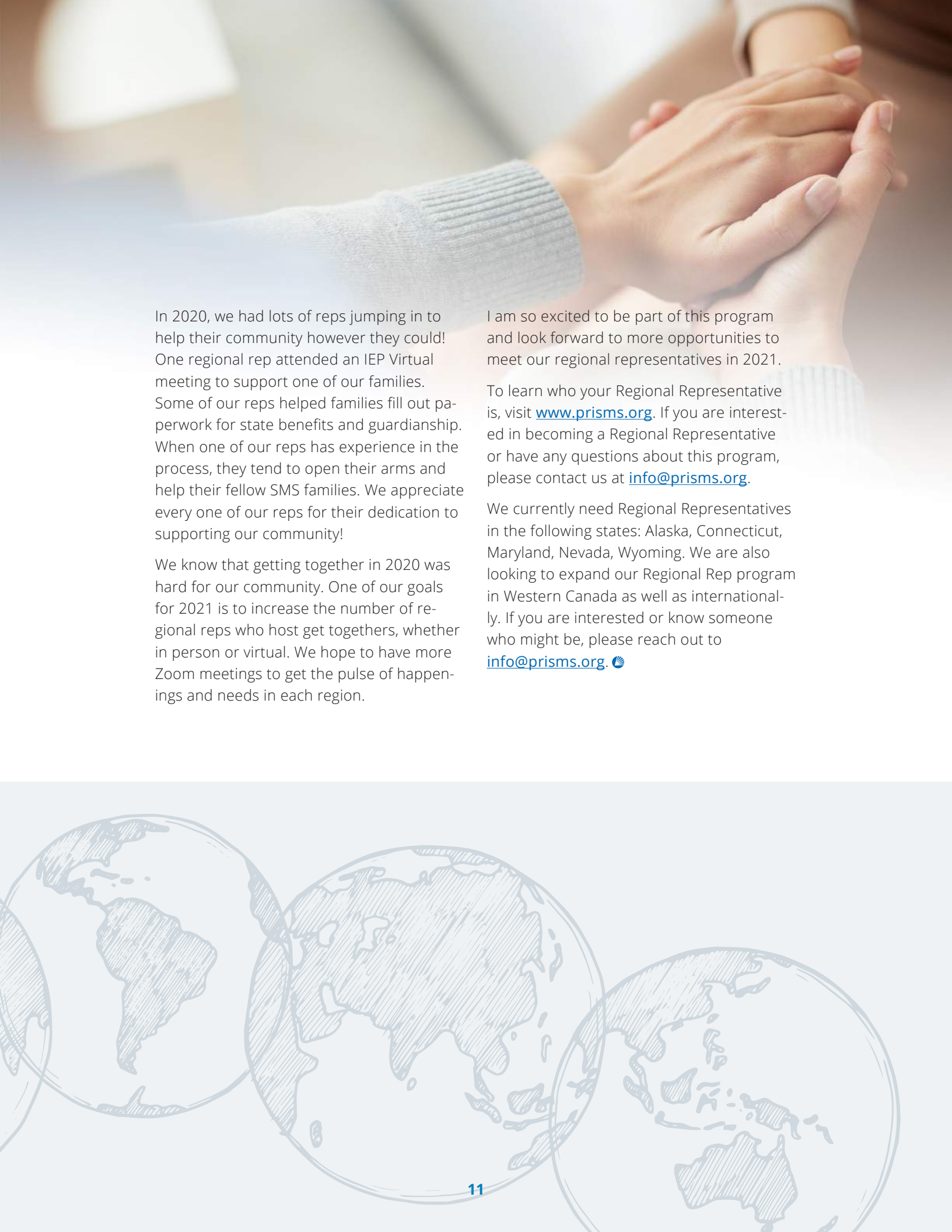
**P**RISMS continues to grow our Regional Representative program, with over 60 regional representative volunteers in the program. Most of our reps live in North America, but we also have reps in Russia, Australia, Brazil, France, Italy, Africa, and the UK. In some areas we have coverage from multiple volunteers, such as in Alabama, California, Colorado, Illinois, and Michigan!

Our Regional Representatives are PRISMS community members who care deeply and want to assist others who may be having similar needs or issues. 2020 has been a difficult year to say the least. We are fortunate that our Regional Representatives were here to give support to many families during this time. We thank all our reps for taking time out of their stressful lives to help our families!

Among other things, our Regional Reps are here to:

- Respond in a timely manner to email request from families in their regions.
- Welcome new individual and families into the PRISMS community.
- Listen to individual needs, help families navigate through the PRISMS website for specific information.
- Encourage regional get togethers for PRISMS families.
- Encourage families to join our free PRISMS membership.
- Encourage families to log in to our fabulous Webinars





In 2020, we had lots of reps jumping in to help their community however they could! One regional rep attended an IEP Virtual meeting to support one of our families. Some of our reps helped families fill out paperwork for state benefits and guardianship. When one of our reps has experience in the process, they tend to open their arms and help their fellow SMS families. We appreciate every one of our reps for their dedication to supporting our community!

We know that getting together in 2020 was hard for our community. One of our goals for 2021 is to increase the number of regional reps who host get togethers, whether in person or virtual. We hope to have more Zoom meetings to get the pulse of happenings and needs in each region.

I am so excited to be part of this program and look forward to more opportunities to meet our regional representatives in 2021.

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).

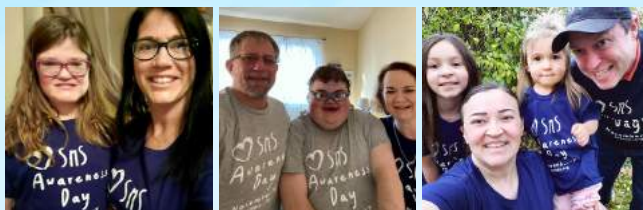
We currently need Regional Representatives in the following states: Alaska, Connecticut, Maryland, Nevada, Wyoming. We are also looking to expand our Regional Rep program in Western Canada as well as internationally. If you are interested or know someone who might be, please reach out to [info@prisms.org](mailto:info@prisms.org). 🌐





## Raising SMS Awareness No Matter What

DIANE ERTH



In April of 2020, PRISMS launched the new “Sharing More Smiles” monthly feature on Facebook and Instagram. Each month on the 17th, we featured a person diagnosed with Smith-Magenis Syndrome. The stories varied from sharing artwork, to working on first words, to winning a photo contest, but each story was guaranteed to make you smile. Our “Sharing More Smiles” posts were shared 45 times and “liked” 12,170 times.

Our social media presence continues to grow. The Facebook support group now has 2,892 members who share stories, hope and advice. The PRISMS Facebook page now has 2,326 followers and continues to post helpful resources and important information for the PRISMS community. The PRISMS Twitter account has more than 924 followers and the PRISMS Instagram account has over 993 followers. If you haven’t joined, followed or “liked” PRISMS, please do so! Liking, commenting and sharing help our pages get seen.



Every November, PRISMS encourages the community to take action, raise awareness, and get involved in honor of SMS Awareness Day! Here’s a glimpse at all the ways our SMS community helped spread awareness:

We kicked off the month inviting the community to order newly designed SMS Awareness Day t-shirts. More than 52 orders were placed. It was great to see so many smiling faces with their new shirts on our social media channels.

New this year was an Awareness Calendar on the PRISMS website with action steps and prompts for our community members to get involved and spread awareness. The calendar included a thank you card for our Professional Advisory Board, a sibling story, a coloring page activity, an inspirational blog post, and many ideas for our community to spread awareness with their family and friends. A new PRISMS webinar was presented and we teamed up with SMS Australia to help spread awareness around the world!

Many members of our community jumped in to run online fundraisers to spread awareness of SMS and raise funds for PRISMS in November! This year’s Bowling for SMS fundraiser raised \$5,485 in much-needed funds for PRISMS programs, education and research. In addition, lots of you jumped on Facebook to raise funds for PRISMS! We had 8 different Facebook fundraisers this year and raised \$7500 through your efforts! Special shout out to Monica Vedvig, who committed to biking 17 miles for SMS Awareness on November 17th and exceeded her fundraising goal of \$1700 for PRISMS with her Pedaling for PRISMS fundraiser!

On November 17th, SMS Awareness Day, we posted a graphic made up of the PRISMS letters with images submitted by our





Smith-Magenis Syndrome community. This graphic represents the heart of our community and was well received with almost 8,200 engagements through Facebook!

PRISMS continues to provide awareness tools to the SMS community, including brochures, books, wristbands, book-marks, and awareness/compassion cards. PRISMS has mailed 698 awareness items to our members!



The PRISMS online store ([prismsstore.org](https://prismsstore.org)) continues to sell awareness merchandise, including the SMS Superhero items. This year a new item was available for purchase through Abrams's Nation—a PRISMS face mask. Almost 100 masks were sold. It was heartwarming to see photos of our community wearing their PRISMS masks during the pandemic reminding us that we were all in this together.

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. 🌐

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

## PAB and Research Overview

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**, PhD, CCC-SLP

**Jane Charles**, MD

**Rebecca Foster**, PhD

**Rachel Franciskovich**, MS, CGC

**Santhosh Girirajan**, MBBS, PhD

**Andrea Gropman**, MD

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

**Nancy Raitano-Lee**, PhD

**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 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. 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. 🌐

## PRISMS Summer Scholar Expands Patient Registry Research

MAGGIE MILLER

**P**RISMS Summer Scholar Program seeks to fund emerging researchers and medical professionals who have an interest in Smith-Magenis Syndrome. The recipient of this program must have the capability to focus on a specific project that enriches ongoing SMS research. The scholar is supervised by a senior professional(s) and supported by adjunct staff. The project is established with a specific focus of study and a well-defined timeline.



Anusha Gandhi, B.S. was the PRISMS Summer Scholar for 2020. Anusha is a graduate of Rice University and currently a medical student at Baylor College of Medicine. PRISMS


Professional Advisory Board members Dr. Rebecca Foster and Dr. Sarah Elsea served as mentors to Anusha for this Student Intern Project. Anusha analyzed data from the Smith-Magenis Syndrome Patient Registry, (SMSPR) to assess eating and food-related behaviors and sleep concerns in the SMS patient registry to identify associations between sleep, eating behaviors, and weight status, in the context of medications and cultural implications.

We appreciate Ms. Gandhi's contributions to ongoing SMS research and look forward to the opportunity for her to present her findings at the PRISMS Virtual Summit this year.

### 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 2020 rose to 85 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.

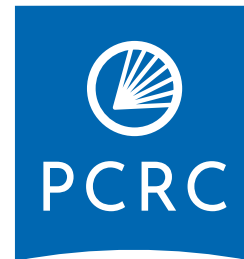
In 2020, we made the patient registry consents and surveys available in four new languages: Spanish, French, Italian, and German. We also added several new surveys, focusing on general behavioral concerns, as well as food-related behaviors, sleep, speech and language development, and body type. We are excited about this new avenue of research and hope that our SMS community will consider signing up for the registry to help us expand our knowledge of SMS. 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/>. 



## PRISMS Clinic and Research Consortium

MAGGIE MILLER


The PRISMS Clinic and Research Consortium, (PCRC) was formally launched in 2020. Smith-Magenis syndrome clinics were already established prior to 2020, including Geisinger, Rady Children's Hospital, and Texas Children's Hospital. Now, the organization of a formal consortium threads these clinics (and newly added clinic sites) together in order to provide consistent and targeted care for persons with SMS across the clinic sites. The consortium was founded so that clinic providers can collaborate and share best practices and also advance research of SMS and lend research participation opportunities to families.



PRISMS Clinic  
and Research  
Consortium

Clinics within the PCRC provide multi-specialty, comprehensive and compassionate care for patients with SMS. The clinics provide families an opportunity to receive medical and clinical care and/or treatment and address the challenges and health concerns associated with SMS. The clinics' approach to care includes consultation with other treatment specialists as needed while developing a plan of care for each patient that strives for health and well-being.

The PCRC meets monthly to discuss patient-specific challenges and share any updates from each clinic. The PCRC is developing consensus documents which will be shared with clinics and families and provide treatment recommendations. These consensus documents originate from the Medical Management Guidelines, (written by the PRISMS Professional Advisory Board), and real-life experience in treating patients with SMS. The Professional Advisory Board works with the PCRC in reviewing the consensus documents.

PRISMS hopes to grow the consortium across the U.S. in order to provide greater access for all of our families. If families are interested in attending one of the clinics, PRISMS offers support for travel to the clinics. The SMS Clinic Travel Fund Reimbursement Program supports families who need to travel to one of the clinics within the PCRC. This fund will help defray costs for travel, (airline or mileage support), lodging costs or other miscellaneous costs attributed to traveling to a clinic. For more information on the PCRC, please visit our website: <https://www.prisms.org/about-sms/living-with-sms/sms-clinics/>. 

## Moving Care of Smith-Magenis Syndrome Forward

MAGGIE MILLER

**O**n December 1, 2020, the Food and Drug Administration (FDA) approved the use of HETLIOZ® (tasimelteon) capsule and liquid formulations for the treatment of adults and children, respectively, with nighttime sleep disturbances associated with Smith-Magenis Syndrome (SMS). This is the first medication ever approved for use in persons with Smith-Magenis syndrome. VANDA has worked closely with the SMS community over several years to develop a clinical trial of the medication, tasimelteon, which progressed from an observational/interventional study to a PK (pharmacokinetic) study, to enrollment in the clinical trial of the medication.

PRISMS was first invited to a face-to-face meeting with VANDA Pharmaceuticals in May of 2013 where parents were allowed to share the everyday challenges that families face in regard to sleep issues for persons with SMS. Parents were also invited to provide helpful guidance in the design of the study to make the experience a bit easier for the participants and their caregivers.

The study continued with the expansion of trial sites across the U.S and the extension of the trial to include in-home visits from a nurse to reduce the number of travel requirements for families and the stress related to travel. A few families were also able to speak directly to an FDA panel about the impact of the sleep challenges on their SMS child and the impact on the entire family.

VANDA understood the tremendous sacrifices that families would undertake in participating in these trials and thus, VANDA's willingness to allow input and access from PRISMS, the Professional Advisory Board (PAB) and families projected that understanding. We are grateful for the ability to have been a small voice in the design and implementation of the study and hope this medication can make a difference in the lives of our SMS individuals and families. 🌱

*The first medication approved specifically for use in Smith-Magenis Syndrome*

### **HETLIOZSolutions**

"The FDA approval of HETLIOZ® for the treatment of nighttime sleep disturbances in SMS would not have been accomplished without the heroic efforts of SMS patients and the efforts of their families and advocates supporting the recruitment, design, and conduct of the study," said Mihael H. Polymeropoulos M.D., Vanda's President and CEO. "We remain committed to providing this much needed therapy to patients with SMS."

For more information: HETLIOZSolutions™ was created to support people who have been diagnosed with nighttime sleep disturbances in SMS. The program can assist with coordinating care to help answer insurance questions, as well as provide financial support and educational resources. <https://hetlioz.com/abouthetlioz>.



## Our Community Gets Creative During the Pandemic

CASEY GORMAN

None of us were sure what would be possible during a pandemic, but you, our amazing community, were able to pull through in 2020 to raise funds and make a difference for PRISMS and the SMS community! Thanks to the creative efforts of our #HugOrBeHugged community, you raised more than \$50,000 through fundraising and awareness events!

In a slight glimpse of normalcy in a topsy-turvy year, Sylvia and Jeremy Farber were able to host their 11th Annual Farber Bowling event! Although attendance had to be scaled back to allow for social distancing at the venue, they were still able to raise over \$20,000 with their in-person event! To accompany the Farber's heroic efforts, PRISMS hosted the 2nd annual Bowling for SMS event.

For the rest of us, the theme of this year was virtual. Our annual Bowling for SMS campaign raised over \$5,000, with our bowlers getting creative and bowling at home leading up to SMS Awareness Day.



Many of you took to Facebook to get the word out about PRISMS among your friends and family. You raised over \$15,000 on Facebook alone, between Facebook birthday fundraisers, SMS Awareness Day fundraisers, and fundraisers just because you felt like it!

We want to give a huge



*Kaitlyn's  
Cookie  
Fundraiser*

shout out to our regular event fundraisers who went out of their way to still raise some funds for PRISMS this year, even without their regular in-person events!

- Jean Bishop, regular host of Nickels for Nico, who hosted a Facebook fundraiser!
- Denien Rasmussen, regular host of the ABC Fundraiser, who ran a birthday parade fundraiser and 50/50 Raffle!
- Kathleen Macken, co-organizer of Family Fun Day, who ran a OneHope Wines Fundraiser!

A big thank you also to our first-time event hosts!

- Pedaling for SMS, from Monica Vedvig: Monica committed to riding her bike 17 miles on SMS Awareness Day in honor of her daughter and others who are facing SMS. Her goal was to raise \$1700, and she blew past it with a total of \$2300!
- Kaitlyn's Kookies Bake Sale, from Kaitlyn and Amy Pereira: Kaitlyn got her friends together to bake boxes of holiday cookies. Her goal was to sell 40 boxes of cookies—she ended selling 140! That's a lot of dough!
- Acreations T-Shirt Fundraiser, from Arti Mahendra Sharma: Arti created custom shirts to benefit the SMS community! She



# 2020 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!*

## **Raised \$10,000 +**

Jeremy & Sylvia Farber

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

Jean Marie Bishop

Diane Erth

Bonnie Krautheimer

Allison Leatzow

Amy & Joey Pereira

Kaitlyn Pereira

Denien Rasmussen

Mark Roth

Jennifer Sauer

Allison & Natalie Stephanouk

Monica Vedvig

## **Raised \$500-\$999**

David Clarkson

Brandon, Dawnda &  
Coulter Daniel

Jennifer Klump

Tina McGrevy

Kay Pruett

Katie Sullivan

## **Raised \$250-\$499**

Heather Andrews

Rachel Marie Lawrence

## **Raised \$100-\$249**

Alejandro Aguilar

Randy Beall

Heather Boney

Ilse Ciprich

Courtney Hallmark

Dan Harhausen

Kristin Korinko

Susan Longfellow

Michelle Larscheid

MaryKate McCauley

Tabitha Petkovich

Connie Semmelroth



recognized that our SMS individuals have diverse interests and wanted to make sure everyone could get a shirt that fit them perfectly.

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 2020! Your dedication and support in such a difficult year is even more meaningful than ever. We're looking forward to more (in-person) events with our SMS community in 2021! 🌊

## 17p11.2 Society: Key Supporters of PRISMS Programs and Services

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 2020, the 17p11.2 Society has 43 dedicated members who have pledged to donate a minimum of \$17 a month. The Society has donated a total of \$11,042 to help support PRISMS in 2020, 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.

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

*Cally Bauman*

*Danielle & Damian Bier*

*Robin & Tim Coutu*

*Dawnda & Brandon Daniel*

*Barclay & Tony Daranyi*

*Patty Davis*

*Dennis & Tracey Dillon*

*John Doherty &*

*Kathleen McMonigal*

*Robert & Shannon Duvall*

*Angela Eaton*

*Sarah Elsea*

*Diane & Joseph Erth*

*Jackie & John Fallenstein*

*Sylvia & Jeremy Farber*

*Beverly & Steven Frey*

*Jennifer Groeteke*

*Rebecca & William Hallmark*

*Julia & Tom Hetherington*

*Percy & Bernadette Huston*

*Paula & Arthur Jump*

*Krista & David Karr*

*Bonnie & Jeff Krautheimer*

*Josephine Lawlor*

*Allison & Mike Leatzow*

*Lisa & Michael Mariano*

*Tina & Charlie McGrevy*

*Donald Michaud*

*Jason & Charlene Michaud*

*Scott & Maggie Miller*

*Mike & Trinity Miodunski*

*Faith Nobilucci*

*Kevin O'Connor*

*Amy & Brian Pereira*

*Denien & Jim Rasmussen*

*Wendy & Jack Schaller*

*Caitlin & William Seldon*

*Ann & Ron Smith*

*Allison & Alex Stephanouk*

*Stan & Connie Sweeney*

*Derek Waldeck*

*Adrienne Wampler*

*Christopher Weber*

*Mary & Ron Zimmer*



## FINANCIAL REPORT

PERCY HUSTON

While 2020 was a year many of us would like to forget, it is all the more reason I am grateful for our PRISMS family and supporters. In a year of curtailed activities, never-before seen mandates and virtually no social activities across the country, most notably our PRISMS International conference in Dallas, PRISMS was able to grow its financial strength.

In 2020, PRISMS' assets grew over 40% to almost \$824,000! This growth was fueled by strong earnings that resulted from a net income increase of almost 150% over 2019 levels. This can be attributed to 2 main factors: 1) less than expected expenses resulting from our International conference being postponed and 2) some incredibly unexpected generosity in the way of donations from our PRISMS community.

While member fundraising was down over 30% in 2020 due to COVID gathering restrictions, our Individual Unrestricted donations were up 123% over 2019 levels to over

\$365,000! This was unprecedented in our 25+ year history and a tremendous credit to our individual donors who made this possible. We are so appreciative of these generous donors.

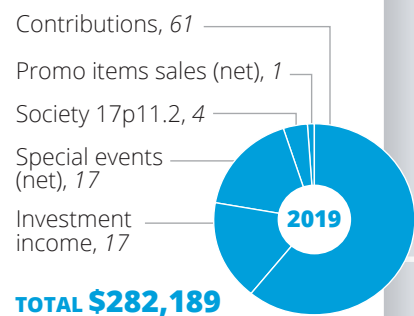
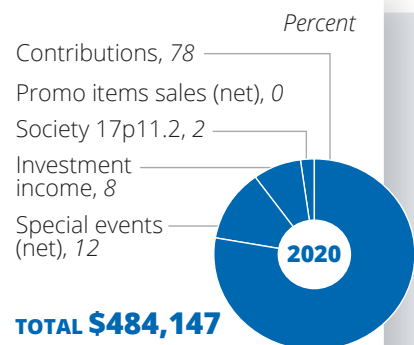
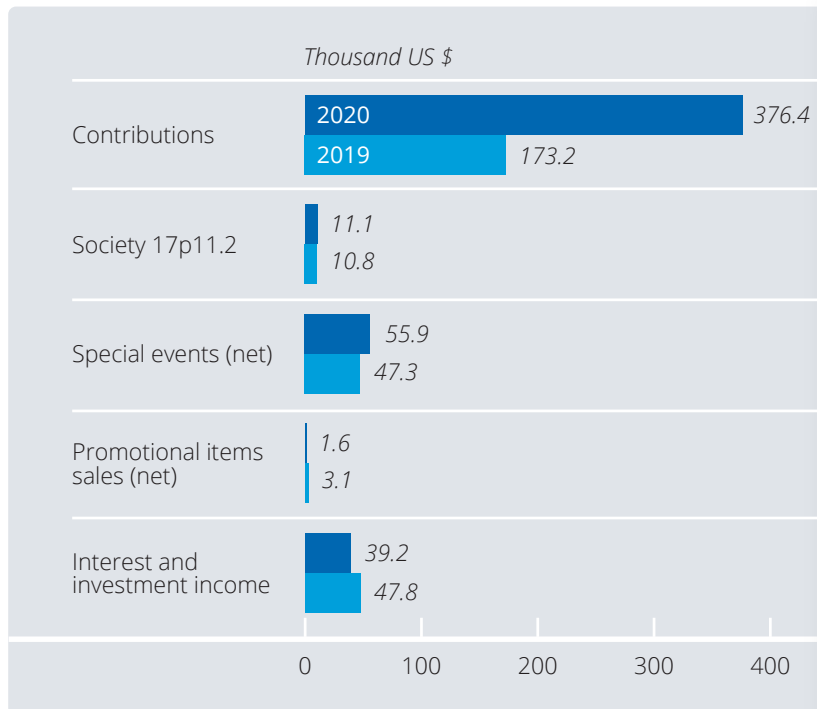
As we regroup and look forward to 2021 we are reevaluating our research initiatives with the help of our PAB in hopes of allocating our resources to the most beneficial needs of our community. We know the 2021 virtual conference will look different and we are extremely excited about the prospects of finally getting our generous community together in person for an all-out conference in Dallas in 2022.

Speaking of generosity, we will forever be grateful for the services of Phil Ruedi as our Treasurer. Phil's term ended in December after 11 years of tireless service and we are thankful for his leadership and many contributions. Both he and his wife Laura have been tremendous supporters of PRISMS for many years. Under Phil's guidance our finances have grown to unprecedented heights, along with the professional level with which the financial operations of our organization are run.

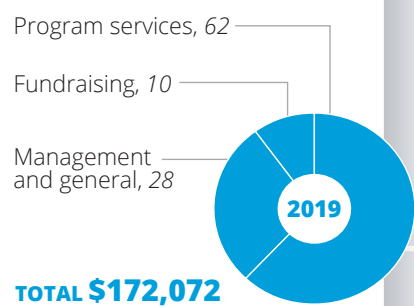
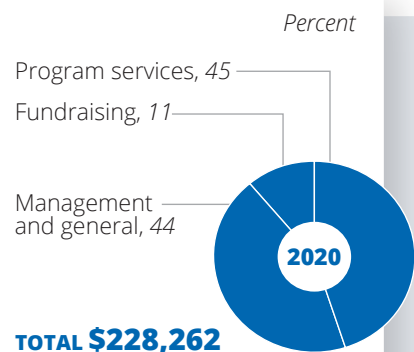
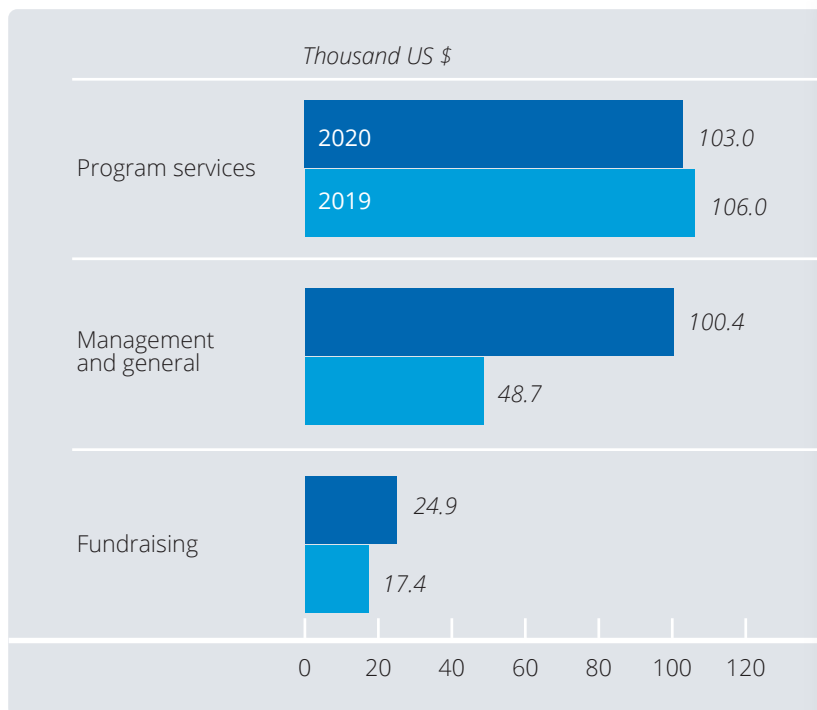
I am honored to follow in Phil's footsteps and can only hope the organization is as strong when my time comes to step down. Realizing I have big shoes to fill, I will be eternally grateful to have served with Phil for his guidance and leadership, but even more importantly to call him my friend. 🌊



## Support and Revenue, 2019<sup>a</sup> and 2020<sup>b</sup>



## Expenses, 2019<sup>a</sup> and 2020<sup>b</sup>



	2020	2019
Ending Cash and Investments	<b>\$790,068</b>	<b>\$561,104</b>
Ending Total Assets	<b>\$823,747</b>	<b>\$587,333</b>

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

# [ 2020 Donor List



*These donation totals reflect the amount given through the PRISMS website or directly to PRISMS via Facebook fundraiser. Donations given through event fundraisers are reflected in the fundraiser's total on the Hug or Be Hugged Community Fundraiser page (see page 19).*

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

Anonymous donors

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

The Bost Foundation  
Glen & Karen Daniel  
Tom & Julia Hetherington  
Kevin O'Connor  
Rhythm Pharmaceuticals

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

Alexion Pharmaceuticals  
Kevin & Darla Atherton  
Randy & Mary Beall  
Berger Family  
Foundation, Inc.  
Joan & Raymond Bishop  
Don & Patty Clegg  
Ashley & Tom Danis  
Joe & Julie Day  
Betty Dyer  
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Sarah Elsea  
Diane & Joseph Erth

Jackie & John Fallenstein  
Sylvia & Jeremy Farber  
Richard & Kate Hardeggar  
Ian Howell  
Jacqueline Huston  
Percy & Bernadette Huston  
Janssen Cares  
Contributions Fund  
Bonnie & Jeff Krautheimer  
Mark Lemmons Group  
Lincoln Investment  
John & Debora Mayer  
Scott & Maggie Miller  
Navy Federal Credit Union  
Denien & Jim Rasmussen  
Joseph Sicilian  
Allison & Alex Stephanouk  
Martha Whitehead

## **\$500-\$999**

Sarin & Eric Abati  
MayBeth Bruckmann  
Andrew & Bettie Buckman  
Dawnda & Brandon Daniel  
Christopher &  
Lindsay Doering  
Robert & Shannon Duvall  
Sara & Tsvi Gal  
Google, LLC  
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Richard Parks  
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Quest Plumbing  
David & Gail Reiner  
Elena & Anthony Stout  
Transnet Communications  
Christopher Weber

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Gina & Steve Belden  
Danielle & Damian Bier  
Brandon Bristow  
Ben Carnahan  
Ilse & Randy Ciprich  
David Clarkson  
The Corporation of  
the Episcopal Diocese  
Robin & Tim Coutu  
Betty & Mark Freemer  
Austin Garrison DDS, Inc.  
Genesis Behavioral Health  
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Faith Nobilucci  
Barbara Pereira  
Monica & Mark Peterson  
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Jennifer Sauer  
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Angela & Kenneth Sparks  
David & Kathryn Stanush  
Kristin Taliaferro  
Linda & Dan Tortorelli  
Stan & Carol Triantafellu  
Mary Frazer Vaughn  
Legacy Fund  
MaryAnn & Ron Zimmer

## **\$100-\$249**

Anthony & Christy Ackley  
Delma & Alejandro Aguilar  
Anonymous  
Marsha & Gary Bach  
Cally Bauman &  
Matthew Lague  
Jeanine Bedel  
Dee Bedrich  
Billy Belcher  
Karen & Gregory Bellos  
Krisha Belz  
Rachel & Daniel Berger  
Cheryl & Ned Berman  
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Amelia Cabato  
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Maria Cleary  
James & Michelle Copeland  
Mary Crougham  
Stephen & Susan  
Cunningham  
Barclay & Tony Daranyi  
Yolanda & Alfredo DaSilva  
Patty Davis  
Robert & Anne Day



Dennis Devine	Michelle & Craig Larscheid	Andrew Staich & Kelli Brasket	Elizabeth Boykin
Dennis & Tracey Dillon	Josephine Lawlor	Anna Stone	Lori Brennan
Elizabeth Doering	Miles & Robin Lawlor	Temple Isaiah Sisterhood	Jillian Bricher
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Todd & Jennifer Finch	Sue McFee	Ruth & Dennis Unglesbee	William Busk
Brenda Finucane	Tina & Charlie McGrevy	United Way Delaware	Joan & Michael Campione
Miriam & David Foster	Kelly McKenna	Shereen Venning	Eve Camuso
Beverly & Steven Frey	Chris Meemken	Veteran's Drug Club	Denise Carlini & Steve Pinge
Tom & Darlis Fuller	Donald Michaud	Derek Waldeck	The CarMax Foundation
Leslee Galluzzi	Jason & Charlene Michaud	Adrienne Wampler	Gayle Carnahan
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Gretchen Hannoush	Patrick & Patricia Pollio	Michele & Joe Zdanowski	Glenn & Karen Doering
Janice & James Herrity	Pati & Ron Radish		Thomas & Zahal Doolittle
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 William & Elizabeth Yates  
 Annie York  
 Michael Zawistowski

## 2020 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 2020!*

### Committee Volunteers

Leah Baigell  
Randy Beall  
Barclay Daranyi  
Sylvia Farber  
Jackie Fallenstein  
Melissa Haley  
John Mayer  
Scott Miller  
Tabitha Petkovich  
Amanda Serio

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Cally Bauman  
Mary Beall  
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Abigail Bell  
Laurie Bellet  
Jean Bishop  
Sabrina Bisiani  
Heather Boney  
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Rhonda Lowney  
Patty Loyer  
Callihan Marshall  
Maureen Monroe  
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Allison Stephanouk  
Bela and Alexander Tzetzlin  
Osman Umarji  
Brooke Widmer  
Brandi Wilson  
Jill Wood  
Bill and Liz Yates  
Michele Zdanowski  
Annetta Zidzik

If you are interested in volunteering with PRISMS, please fill out our Volunteer Form.

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

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MARGARET MILLER  
*Vice-President*

TINA MCGREY  
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*Executive Director*

ANGELA WILLIAMS  
*Office Manager*

MICHELLE LARSCHIED  
*Program Assistant*

ROBERT M. MILLER  
*Advisor on Clinic Relations*

---

### 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

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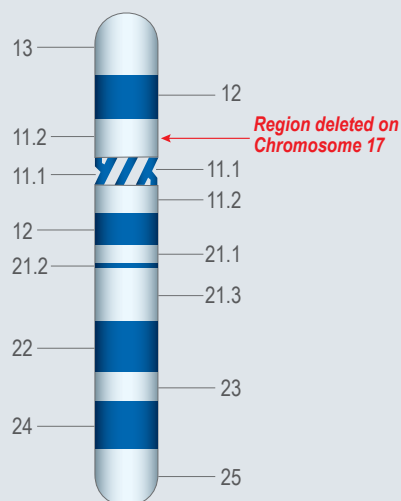
Casey Gorman, *Executive Director*  
Angela Williams, *Office Manager*  
Michelle Larscheid, *Program Assistant*  
Designer: Mark Hernandez



## 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