

PRISMS ANNUAL REPORT₂₀₂₁

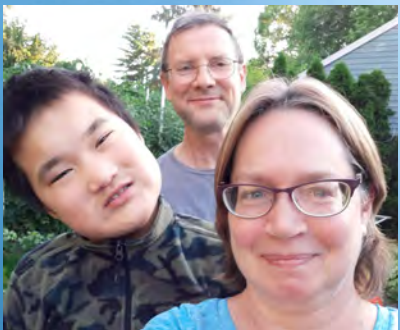


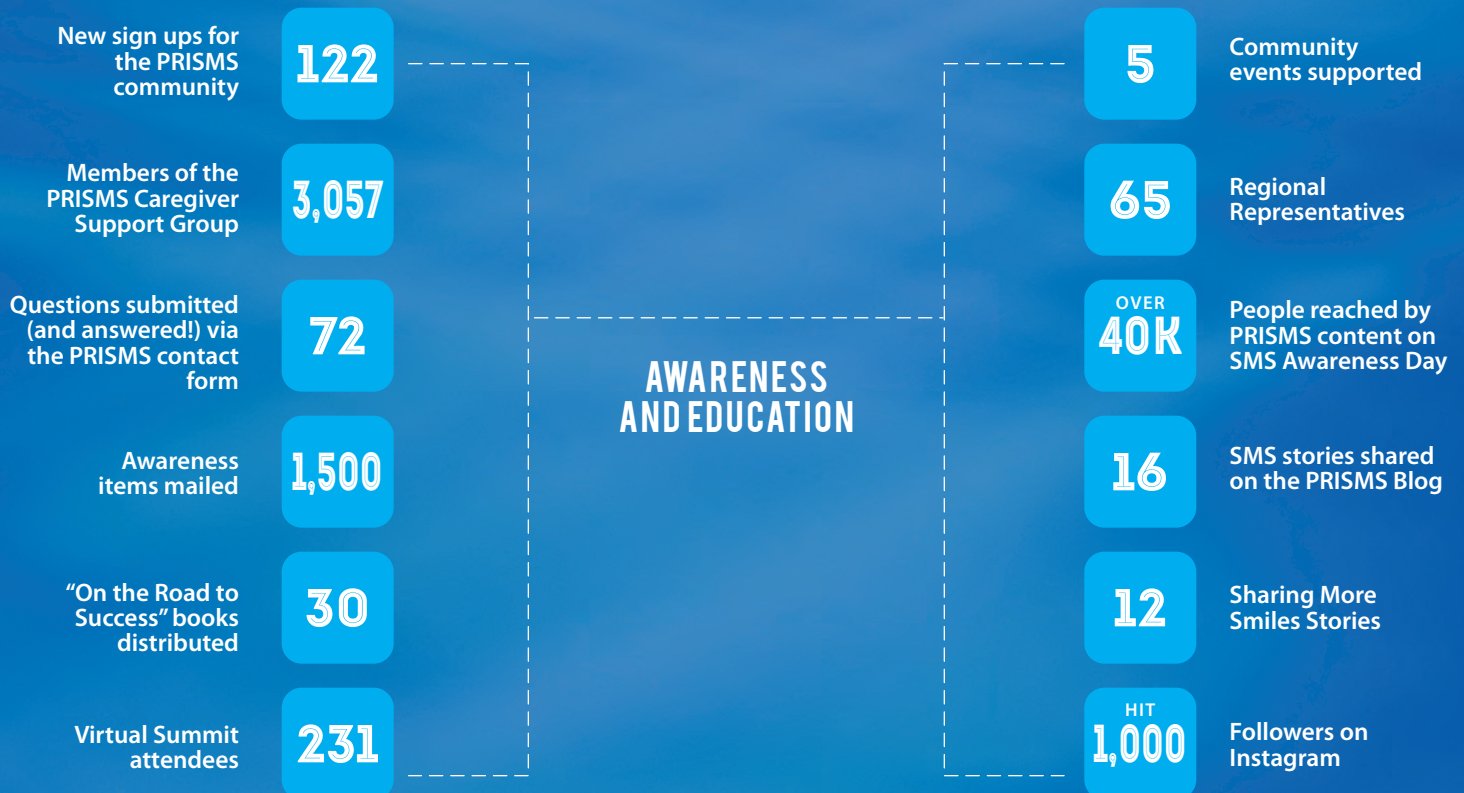


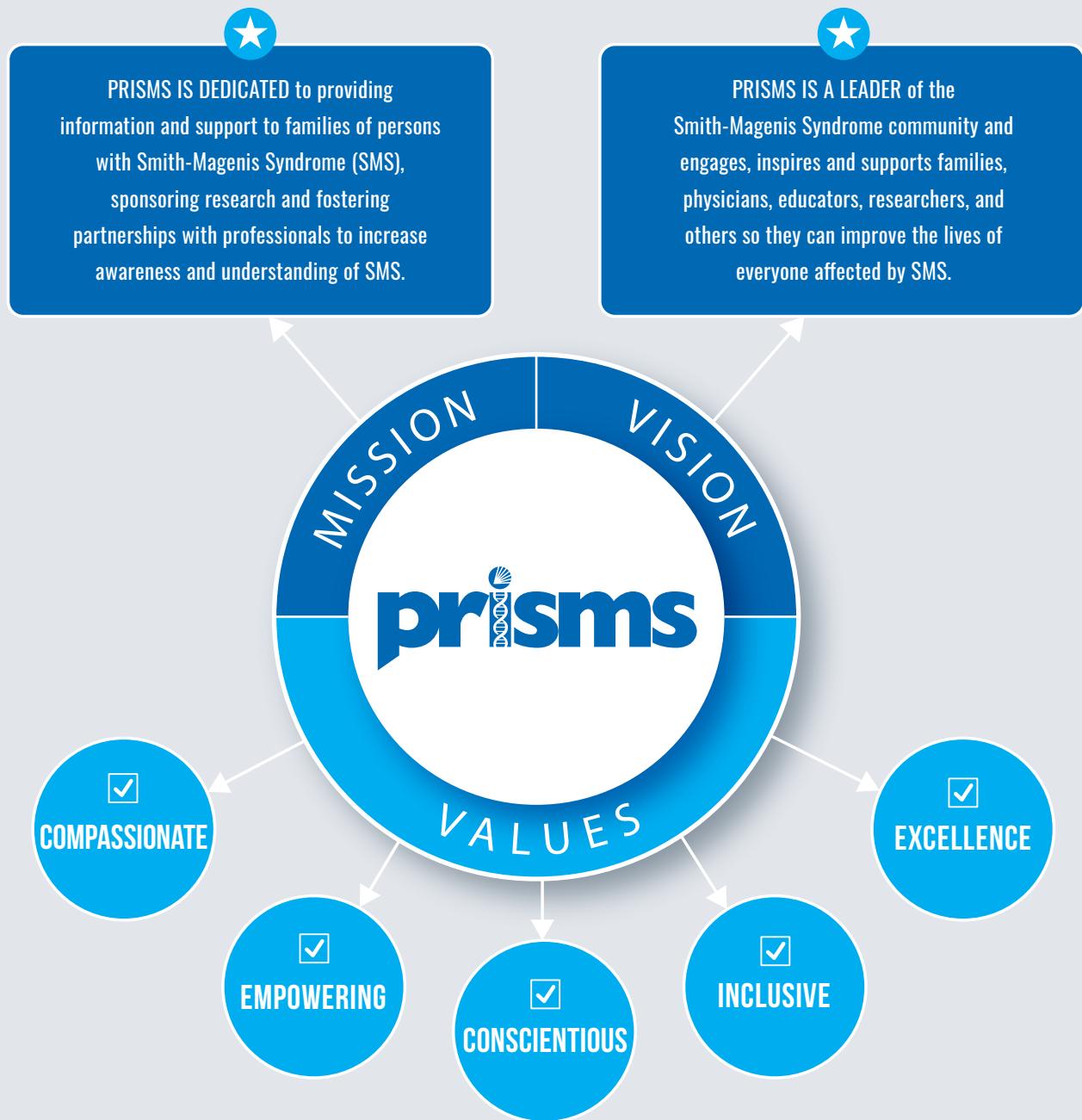
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Letter from the President

BRANDON DANIEL
PRESIDENT, PRISMS

AT THE END OF 2021, PRISMS COMPLETED its 28th year as an organization “dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS.” The PRISMS mission essentially remains the same as it did upon its initial creation 28 years ago. The impact that PRISMS is having today may be more evident now than at any time in the history of the organization. 2021 was a busy year for PRISMS and the SMS community. How many of you saw the Vanda commercial that mentioned Smith-Magenis Syndrome? I know that many of you and many others saw this commercial mentioning SMS. This highly visible commercial expanded the awareness of SMS to the general public in a much broader way than ever before. The increase in publicity and awareness will further generate interest in research and funding for future SMS awareness and research initiatives. That stated, we know that much work remains to be done to increase awareness and research of SMS.

With that in mind, the PRISMS board and Executive Director spent several months of the past year refining the PRISMS strategic plan. This plan will serve to guide the organization

through its next phase of growth in the next 3- 5 years. The goals within this plan are robust, with their aim to continue to further the PRISMS mission and vision well into the future. It will take all of us as an SMS “Team” to make these goals happen for our SMS community.

This annual report shows a culmination of the work PRISMS was able to complete in 2021 for the SMS community. Each of you needs to be commended for your ongoing support of PRISMS and its mission! Without you, none of this would be possible. I remain so grateful to work with this organization and the countless volunteers and donors who give their time and money to further the mission of PRISMS and public awareness of SMS. We look forward to being together again as an SMS family at the 2022 Annual Conference, “Envisioning the Possibilities.”

Thank you!
Brandon Daniel
President, PRISMS



PRISMS Rolls Out New Strategic Plan


BY AMY PEREIRA, STRATEGIC
PLANNING WORKGROUP MEMBER

IN MARCH 2022, THE PRISMS BOARD APPROVED A NEW PRISMS 2022-2024 Strategic Plan. This plan builds on our successful 2016 Strategic Plan and incorporates new goals and objectives to help guide PRISMS in its mission and programming. The Strategic Planning Committee began drafting the 2022-2024 Plan in May of 2021, with the help of Robert Miller. Robby has worked with PRISMS since 2014 on a number of efforts as a consultant, including the 2016 strategic plan, staff recruitment, and the Clinic Consortium.

With Robby's guidance, the Strategic Planning Committee reviewed the organization's Mission, Vision, and Values statements to ensure they are aligned with the SMS community's needs and allows for continued growth. As a result of this exercise, six new goals have been developed. Each goal provides strategies and measurable timelines to guide the PRISMS Board of Advisors as they make decisions about programming and funding allocations.

Our new goals include:



This new Strategic Plan is a living document and we look forward to working towards meeting these new goals and ensuring PRISMS remains a leader in the SMS Community and beyond. For more information about the PRISMS 2022-2024 Strategic Plan, please visit our website at <https://www.prisms.org/who-we-are/the-mission/>. 

PRISMS Clinic and Research Consortium

MAGGIE MILLER, PROFESSIONAL ADVISORY BOARD (PAB) AND RESEARCH LIAISON

THE PRISMS CLINIC AND RESEARCH CONSORTIUM, (PCRC), continued to expand its services to our SMS community in 2021. New clinic sites were added including the Lurie Center for Autism at Massachusetts General Hospital, Rush University Medical Center in Chicago, and Children's National Medical Center in Washington, DC. We expect to include new PCRC sites in 2022 to increase the ability for families to meet with SMS professionals in their geographic region.

Members of the PCRC meet regularly to discuss specific patient needs and concerns and share optimal health strategies and recommendations. The PCRC is currently collaborating on treatment recommendations that will be shared with the SMS community to help promote appropriate care for all individuals with SMS, whether or not they can travel to a clinic location. These recommendations will be distributed to families through the PRISMS website and will inform the care of all families who visit the clinics.


The PCRC provides a solid foundation of care and surveillance for the person with SMS and another

nexus in a holistic approach to the management of Smith-Magenis syndrome. With the expansion of the clinic sites, we can bring in new professionals and researchers who join our list of SMS experts. These clinicians and doctors not only

provide comprehensive care but also expand awareness of this syndrome to their specific hospital or institute. We expect the PCRC program to have an impressive impact not only on patient care but on the recognition and awareness of SMS.

If families are interested in attending one of the clinics, PRISMS offers support for travel to the clinics. The PRISMS 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. This reimbursement is available to a family only one time.

For more information on the PCRC, please visit our website: <https://www.prisms.org/about-sms/living-with-sms/sms-clinics/>. 



PRISMS Clinic and Research Consortium

"The PRISMS Clinic and Research Consortium (PCRC) is designed to expand the availability of comprehensive, clinically appropriate care for the SMS community."

Thank you to VANDA Pharmaceuticals




VANDA PHARMACEUTICALS HAS CONTINUED its generous and strong support of PRISMS and its community. In 2021, VANDA was a top-level sponsor of the PRISMS Virtual Summit and also presented at the Virtual Summit. Christos Polymeropoulos, MD, and Frances Fritz, Associate Director of Health Education presented a panel discussion on the medication HETLIOZ®. HETLIOZ® was approved in December of 2020 for the treatment of adults and children with nighttime sleep disturbances associated with SMS. The panel addressed questions about the medication and also shared how families can work with their providers and insurance to obtain the new medication. VANDA also participated in a PRISMS Regional Rep meeting to directly answer any questions about Hetlioiz.

VANDA released a commercial for Hetlioiz in November of 2021 which highlighted the sleep challenges in SMS depicted by an animated sweet little boy. The animated commercial was very well-received by our community and many others. It was the first time SMS had a national presence on television and hopefully raised awareness of SMS!

We look forward to further collaboration with VANDA and are truly grateful for their generosity and support of our SMS community. 🌐

PRISMS Summer Scholar Update



PRISMS 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.

THE 2021 SUMMER SCHOLAR WAS AWARDED to Austin Burns. Austin is a 4th-year clinical psychology doctoral student at Saint Louis University, working on developing an intervention for adolescent siblings of individuals with SMS. Dr. Rebecca Foster, a pediatric psychologist at St. Louis Children's Hospital and PRISMS Professional Advisory Board Member, is serving as the mentor to Austin for this project. The program, entitled, "Connecting Siblings of Individuals with Smith-Magenis syndrome: A Sibling-to-Sibling Mentorship Program" launched in early 2022.

Austin is working to develop a research protocol for a sibling-to-sibling mentorship program for siblings of individuals with SMS. Adolescent siblings will be matched with young adult



Summer Scholar 2021 Austin Burns

mentors, all of whom have a sibling with SMS. Mentors will meet with mentees via telephone or virtual format throughout an 8-week program. During this program, mentees will gain support from mentors while discussing and processing topics unique to having a sibling with SMS, such as sibling relationships and caregiver roles, emotional needs, family dynamics, and communication, adaptive coping and personal growth, and self-care.

We look forward to the fruits of this program and are grateful that our amazing siblings will reap the benefits. PRISMS anticipates that this program may become a permanent resource for our siblings.

An Update on Our 2020 Summer Scholar


Anusha Gandhi, B.S. was the PRISMS Summer Scholar for 2020. Anusha is a graduate of Rice University and is 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



Summer Scholar 2020 Anusha Gandhi

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.

Anusha was a presenter at the PRISMS Virtual Summit last September and was a contributor to an abstract that was published in June 2021 in the Journal of Autism and Developmental Disorders. You can read the full paper at <https://pubmed.ncbi.nlm.nih.gov/32845423/> 



prisms

Virtual Summit

SEPTEMBER 9-11, 2021

Our First Ever SMS Virtual Summit

BY ALLISON STEPHANOUK,
CONFERENCE COMMITTEE MEMBER

IN SEPTEMBER 2021, AFTER TWO YEARS OF postponed in-person conferences, PRISMS brought the conference experience to the SMS community virtually. The last in-person conference hosted by PRISMS was in Pittsburgh in 2018. Keeping with the biennial rotation, the next PRISMS conference was scheduled for the summer of 2020, just as the pandemic was approaching its first peak. With everyone's health and safety in mind, the hard decision was made

to postpone the conference to the summer of 2021. Unfortunately, pandemic conditions did not allow for unrestricted travel and gathering in large groups in 2021, so the conference was once again postponed, and is now scheduled for August 2022.

Rescheduling for the second time would have caused four years between conferences. Recognizing how important conferences are

for the opportunities they provide to share information and experiences among SMS families, the PRISMS Conference Committee designed the concept of the Virtual Summit. Casey Gorman, PRISMS Executive Director noted, "It is critical that we share information with our community and provide the opportunity for SMS families to gather and connect."

PRISMS Virtual Summit was a successful three-day event, in September of 2021, that provided engaging content, education, and community connection. A considerable benefit of the Virtual Summit is that families who have not been able to attend an in-person conference, due to budget, time commitment, or distance, were able to attend the Virtual Summit from the comfort of their own homes. Attendees from all over the world were given the opportunity to listen and participate in 22 live and pre-recorded sessions offered by expert speakers, as well as virtually connect with panelists, the Board of Directors, and other SMS families. One attendee said, "It was just amazing being in a space where everybody gets SMS and with such a smorgasbord of presentations to choose from. It was fantastic! Thank you."

The first day of sessions was dedicated to sharing active research of Smith-Magenis Syndrome.



Caricatures of participants in our Virtual Summit Social.

Vanda presented on HETLIOZ® (tasimelteon), a drug that received FDA approval for nighttime sleep disturbances in SMS in 2020. Casey Gorman and Robby Miller discussed the new initiative, PRISMS Clinics and Research Consortium (PCRC), and how it will help serve our SMS community.

"I just really am glad to attend for the simple fact that I needed to hear from other parents to remind me that I am not alone."

There were also updates on the SMS Patient Registry by Theresa Wilson and the Summer Scholar program by Anusha Gandhi. Dr. Gianluca Pirozzi presented research updates on behalf of the Smith Magenis Research Foundation. Dr. Sarah Elsea, chair of PRISMS Professional Advisory Board, discussed

sleep's connection to metabolism and the consequences of chronic sleep deprivation.

Day two started with a keynote address by Ann C.M. Smith, MA, DSc (Hon), CGC, who presented on her more than 40-year journey with Smith-Magenis Syndrome. Ann is a founding member of PRISMS and chaired the PRISMS Professional Advisory Board (PAB) until 2011. She now serves



Ann C.M. Smith delivered the Virtual Summit keynote address.

as PAB Chair Emeritus, having dedicated over 3 decades of her professional career to the study of SMS, the syndrome she co-discovered in the early 1980s.

Also, on the second day of the conference, Allison Stephanouk and Dawnda Daniel, along with an outstanding group of Parent Ambassadors, hosted the "First Steps" session, which was designed to welcome, engage, encourage and support families with a recent diagnosis of SMS. Parent Ambassadors for this session were John and Brooke Widmer, John and Joanna Roseborough, and Jason and Charlene Michaud.

Additional sessions for day two included, "Managing Relational Stress," with speaker Eileen Devine, "Promoting Safety for SMS Persons Living Outside of the Home," by Dr. Rebecca Foster, and "Neurology Implications in SMS," with Dr. Andrea Gropman. There was even an evening social where attendees could meet the PRISMS Board of Directors.

On the third and final day of the Virtual Summit, the PRISMS Advocacy Workgroup hosted a wonderful panel presentation, "Building Resiliency; Developing a Caregiver's Behavioral Support Plan. We're Talking About YOU, not Your Kid!"

*"I loved that I could watch the recordings at my leisure.
We are new to the SMS community. So it was nice to
just get more information and advice from others."*

Speakers included Barclay Daranyi, Melissa Haley, Leah Baigell, John Mayer, Amanda Serio, and Tina McGrevy.


Additionally on the final day of the summit, Dr. Rebecca Foster presented another important session, "Promoting Well-Being for Siblings." Brenda Finucane and Dr. Santhosh Girirajan presented on Birt-Hogg-Dube and SMS. Barbara Haas-Givler presented, "Setting the Stage for Success: Effective Strategies to Support Behavior and Learning in Students with Smith-Magenis Syndrome from Early Years through High School." Then, the Virtual Summit came to a close with the "End of Summit Social," hosted by Diane Erth.

We sincerely appreciate our speakers for adjusting their materials and schedule to accommodate the virtual format. Thank you to our Virtual Summit sponsors, Vanda Pharmaceuticals, Rhythm Pharmaceuticals, Harmony Biosciences, Eleos Services, SMS Research Foundation, and Abram's Nation. We would like to also thank our conference committee members, Casey Gorman (chair), Maggie Miller, Amy Pereira, Allison

"It was just amazing being in a space where everybody 'gets' SMS and with such a smorgasbord of presentations to choose from. It was fantastic! Thank you."

Stephanouk, Michelle Larscheid, Pat Brown, and Athenna Harrison for making the shift to develop PRISMS first Virtual Summit.

Access to the Virtual Summit recorded presentations is now free. Go to: <https://www.prisms.org/education/2021-virtual-summit/> to watch these valuable presentations.

We are looking forward to gathering in-person after a four-year hiatus. Registration is now open for our conference at the Hyatt Regency Dallas, August 4-6: <https://www.prisms.org/education/sms-conference/> 





Regional Representative Program, Getting Stronger Every Year!

BY DENIEN RASMUSSEN, REGIONAL
REPRESENTATIVE COMMITTEE CHAIR

PRISMS REGIONAL REPRESENTATIVE PROGRAM is continually growing. Our Regional Representatives are PRISMS community members who volunteer their time and care deeply about our community. They want to assist others who may be having similar needs or issues. 2021 continued to be a difficult year for some of our families, and we are extremely fortunate that our Regional Representatives are here to give support to many families during these times. We thank all our reps for taking time out of their stressful lives to help our families. We currently have over 65 Regional Representative Volunteers in our program. Most are in North America, but we also have reps in India, Africa, the United Kingdom, Italy, France, Brazil, Australia, and Russia to name a few.

This year, PRISMS instituted quarterly Zoom meetings with our reps. We discuss many things during these zoom meetings, some of which are:

- New SMS Clinics
- Hetliotz Medication
- Topics for the upcoming PRISMS conferences
- Resources and state benefits, how to find them in your region.
- Ideas for regional get-togethers.
- Upcoming Webinars

The calls have been incredible, and we appreciate the rep participation in the calls. They have also been highly informative to PRISMS by providing

an on-the-ground regional view of what families are dealing with and looking for from PRISMS.

Regional reps are there for you! Our Regional Reps are here to:

- Welcome new individuals and families into the PRISMS Community.
- Help families navigate through the PRISMS website for specific information.
- Guide families to local resources and state benefits.
- Encourage families to log in to our fabulous Webinars.
- Encourage families to join our PRISMS email list
- Encourage families to attend our conferences.

I am so proud to work with this amazing group of people and look forward to meeting them at the in-person PRISMS Conference this August.

To learn who your Regional Representative is, visit <https://www.prisms.org/get-involved/get-connected/>. If you have any questions about this program, please contact us at info@prisms.org.

We currently need Regional Representatives in the following states: Alaska, Georgia, Maryland, Mississippi, and Nevada. If you are interested or know someone who might be interested, please reach out to us at info@prisms.org. 🌐

2021 PRISMS Regional Representatives

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 2021!

Regional Representatives

Alejandro and Delma Aguilar	Diane Erth	Denien Rasmussen
Leah Baigell	Maria Feagin	Remi Robbins
Eliane Barros	Rhonda Franklin	Marni Rolston
Cally Bauman	Heidi Graf	John Roseborough
Mary Beall	Trevor Gritman	Brianna Ryczek
Tracie Belcher	Melissa Haley	Caitlin Seldon
Abigail Bell	Stephanie Hanquez	Mark and Theresa Smyth
Laurie Bellet	Mary Hards	Randi Tannenbaum
Jean Bishop	Sheila Hernandez Vale	Bela and Alexander Tzetlin
Sabrina Bisiani	Roberta Higgins	Osman Umarji
Heather Boney	Eric and Kim Hoffman	Brooke Widmer
Debbie Brooks	Bernadette Huston	Brandi Wilson
Maria Elena Carrancedo	Jennifer Klump	Jill Wood
Ashton Chermaine	Carissa Le	Bill and Liz Yates
Ilse Ciprich	Allison Leatzow	Michele Zdanowski
Jennifer Comfort	Charlene Liao	Annetta Zidzik
Kevin Daly	Rhonda Lowney	If you are interested in volunteering with PRISMS, please fill out our Volunteer Form. https://www.prisms.org/ get-involved/volunteering/ volunteer-form/
Barclay Daranyi	Patty Loyer	
Ana Delgadillo	Callihan Marshall	
Esteban Delgadillo	Kevin O'Connor	
Amanda Downey	Mick Pearson	

An Overview of SMS Awareness in 2021

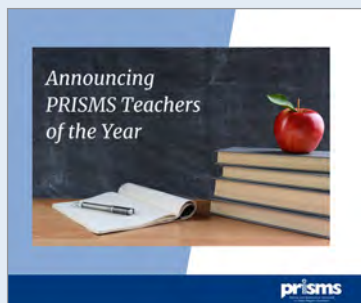
DIANE ERTH,
AWARENESS COMMITTEE CHAIR

Spreading Awareness on Social Media

It was a busy year spreading awareness about Smith-Magenis syndrome. We utilized our social media channels to harness the power of social networking. We continued our “Sharing More Smiles” monthly feature on Facebook and Instagram, posting 12 stories about some very special SMS individuals. We also shared 16 blog stories that have inspired us and helped to capture the spirit of our SMS community.

Our social media presence continues to grow. The Facebook support group, where members share stories, hope, and advice has grown from 2,892 to 3,200. The PRISMS Facebook page now has 2,384 followers and continues to post helpful resources and important information for the PRISMS community. The PRISMS Twitter account has more than 633 followers and the PRISMS Instagram account has over 1,072 followers. If you haven’t joined, followed or “liked” PRISMS, please do so! Liking, commenting, and sharing helps our pages get seen and is an easy way to help us spread awareness about Smith-Magenis Syndrome!

New Teacher of the Year Award Program



New this year was our Teacher Appreciation award program we instituted to thank some teachers for making a difference every day in the lives of our SMS families. We received

22 nominations and every nominated teacher certainly deserved to win. Reading all of the applications, one thing is clear – the nominated teachers went above and beyond their usual circle of support and resources to learn about SMS and create awareness in their schools.

The two winners of our PRISMS Teacher of the Year prize pack were Jeri-Lynne Jones and Bernadette Damian. The winner of the 2021 PRISMS Teacher of the Year was Rhonda Barbieri. Rhonda was the winner of a \$50 Amazon Gift card and a copy of *On the Road to Success with SMS* book.

Awareness Day

This year, we pulled out all the stops to raise awareness for Smith-Magenis Syndrome for SMS Awareness Day. We kicked off the month by unveiling new SMS Awareness Day t-shirts. The “Get Ready to Be Hugged” themed shirts were very popular and were available in both white and blue. It was great to see so many smiling faces with their new shirts on our social media channels as November 17th approached.



An Awareness Calendar was posted on the PRISMS website with action steps and prompts for our community members to get involved and spread awareness. The calendar included a PRISMS Facebook frame, a sibling story, a coloring page activity, a creative fundraising blog post, and many ideas for our community to spread awareness with their family and friends. We also posted Ann Smith's Keynote Address from the Virtual Summit "Smith-Magenis Syndrome – Decades of Discovery."



PRISMS was on the news! PRISMS Regional Representative Callihan Marshall is a local news anchor at WSYR-TV in New York. Her 31-year-old

sister Briahna Marshall has SMS. Callihan produced a feature story on Smith-Magenis Syndrome and shared it in honor of SMS Awareness Day.

This year we had 15 members of our community run online fundraisers and 4 members run in-person fundraising events which raised close to \$40,000! These much-needed funds will go towards PRISMS programs, education, and research. It was truly amazing to see so many take part in raising money for PRISMS.

On November 17th, SMS Awareness Day – we shared a united voice with several international SMS organizations (PRISMS, Smith-Magenis Syndrome Foundation UK, Sirius, SMS Australia, SMSRF) in a special video produced by Smith-Magenis Foundation UK which highlighted the spirit of celebrating SMS around the globe.

And let's not forget the first-ever Smith-Magenis syndrome television commercial! We worked together with our partners at Vanda

Pharmaceuticals to make sure that SMS was portrayed as accurately as possible in a 30-second time slot. It premiered on networks across the United States just in time for SMS Awareness Day.

It was wonderful to be able to scroll through social media and see so many joyful and supportive posts from our SMS community. We saw so many messages from the SMS community across social media—it was truly heartwarming to see our community at work. Looking at our analytics, we reached over 10,000 people with our social media content on Facebook and hit 30,000 impressions on Twitter on SMS Awareness Day! We also mailed over 1,000 pieces of awareness materials.

PRISMS continues to provide awareness tools to the SMS community, including brochures, behavior cards, wristbands, bookmarks, and awareness/compassion cards. The PRISMS online store prismsstore.org continues to sell apparel and awareness items. PRISMS also continues its work with major national organizations, including the National Organization of Rare Disorders (NORD) and Global Genes, to help celebrate Rare Disease Day and raise awareness of rare disorders.

The energy and enthusiasm from our SMS community will propel us into the new year with a renewed excitement for making our voices heard. Remember, you don't have to wait until November to raise awareness about SMS – we can do it together all year long! 🌐



A Community Back Together

BY MICHELLE LARSCHEID,
PROGRAM COORDINATOR

THIS YEAR WE WERE ABLE TO GET BACK

together to socialize, catch up, find support, raise money, and most importantly, hug each other! The summer was the perfect opportunity to gather outside with our SMS community. Here are some of the great meet-ups and fundraisers that were held this summer.

FAMILY MEET-UPS

Morgan's Wonderland

Cecilia Poole organized a meet-up for families with SMS at San Antonio's Morgan's Wonderland (Inspiration Island) on Saturday, June 5th. It had been 2 years since the last get-together and everyone was so happy to be back together for this annual event. There were 29 people (8 with SMS) who enjoyed the all-access splash pads and park (complete with a Ferris wheel, merry-go-round, and train).

Northern California Family Meet-Up

PRISMS Regional Representative Laurie Bellet hosted a San Francisco Bay Area SMS picnic in August in Walnut Creek, California. The meet-up event was held at the Heather Farms All Abilities Playground from 11 a.m. to 4:00 p.m. Laurie's daughter, Ariel, was able to show her mini horse to all the attendees at the picnic.

Laurie says of the long-awaited get-together: "SMS parents are hungry for connection and

truly incredible connections were made and older relationships revived. Families drove hours to come. One family booked a hotel room. A previously local family who now lives in Germany was able to attend. Folks brought more food than you can imagine. The youngest child with SMS was James at 18 months. Adults with SMS were represented by Ariel at 36 and Angelica at 29."

Did you know PRISMS offers up to \$350 in reimbursement for qualified meet-up expenses? If you are interested in hosting an in-person meet-up and need some help getting started, please reach out to your Regional Representative or email info@prisms.org for assistance.

FUNDRAISERS

Thank you to our Hug or Be Hugged Fundraisers for their in-person fundraising efforts this year!

Money raised from fund-raising events is critical for our organization to keep moving forward. The funds can help us spread awareness to the world about Smith-Magenis Syndrome and keep people informed and educated about SMS. Fundraising efforts help PRISMS to improve our programs, keep conference costs more affordable for families, support innovative SMS research, and more! A big PRISMS thank you to all the in-person event organizers as well as to those that were able to attend.



San Antonio meet-up at Morgan's Wonderland.



Missouri meet-up for Corvettes, Camaros & Collectibles.



Huston family host meet-up in Missouri.

Nickels for Nico

Jean Bishop and the Bishop family hosted the Nickels for Nico 10th Annual Cornhole Tournament in Louisville, KY on August 14 at Thurman Hutchins Park. In addition to the tournament, there was a dinner, raffle, and t-shirts for sale.

Corvettes, Camaros & Collectibles in the Vineyard

On August 14, the Huston family hosted Corvettes, Camaros & Collectibles in the Vineyard to benefit PRISMS at the Chaumette Vineyards & Winery in Genevieve, MO. Families from across Missouri joined together with the local community for a fun day celebrating SMS families and PRISMS work. There was a car show, silent auction, drawings, door prizes and food, cake, and beverages.

Roll in for Rare

Kalin Roberts teamed up with car enthusiasts to host her first PRISMS fundraiser in honor of her daughter, Kennedy Williams, who was diagnosed with SMS in February of 2020. Her Roll in for Rare event was held on August 21st and she raised over \$5,000. They had a car show, snow cones, face paintings, a photo booth, food trucks, an auction, and live music at her event!

A big thank you also to everyone who fundraised through Facebook. You raised over \$12,000 for PRISMS by creating birthday fundraisers and SMS Awareness Day fundraisers throughout the year! You can start a fundraiser on Facebook at any time by visiting: <https://www.facebook.com/fund/SmithMagenisSyndromePRISMS/>

Thank you to all of our amazing volunteers, donors, and fundraisers! You are the center of our SMS community. PRISMS wouldn't be what it is today without you! 🌟

Events

Over \$10,000

Jeremy & Sylvia Farber	2021 Pickleball for PRISMS
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\$5,000 - \$9,999

Jean Marie Bishop	Nickels for Nico
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\$1,000 - \$4,999

Percy & Bernadette Huston	Vettes in the Vineyard
Tim & Adrian Hibbs	Anderson's Donut Fundraiser

\$500 - \$999

Kalin Williams	Roll in for Rare
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\$100 - \$499

Kathleen Macken	One Hope Wine
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San Francisco meet-up at Heather Farms All-Abilities Playground.



Louisville, Kentucky meet-up for Nickels for Nico Cornhole Tournament.



Anderson's Donut Fundraiser.

Thank You to Our 17p11.2 Society

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 2021, 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 \$12,993 to help support PRISMS in 2021, and we are extremely grateful to them for their continuous support.

To join the 17p11.2 Society, simply go to 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. For more, go to: <https://www.prisms.org/get-involved/17p11-2-society/>.



17p11.2 Donors

Alex & Allison Stephanouk

Allison & Mike Leatzow

Angela Eaton

Arthur & Paula Jump

Bernadette & Percy Huston

Bonnie & Jeff Krautheimer

Brandon & Dawnda Daniel

Brian & Amy Pereira

Caitlin & William Seldon

Cally Bauman

Charlene & Jason Michaud

Charlie & Tina McGrevy

Connie & Stan Sweeney

Damian & Danielle Bier

David & Krista Karr

Donald Michaud

Faith Collins

Jennifer Struck

Jeremy & Sylvia Farber

Jim & Denien Rasmussen

Jackie & John Fallenstein

John Doherty

Joseph & Diane Erth

Josephine Lawlor

Kathleen McMonigal

Kevin O'Connor

Levi Schaller

Lisa & Michael Mariano

Margaret & Scott Miller

Mathieu & Cally Lague

Mike & Trinity Miodunski

Patty Davis

Ron & Mary Zimmer

Shannon & Robert Duvall

Steve & Robyn Mogul

Steven & Beverly Frey

Tim & Robin Coutu

Timothy & Adrian Hibbs

Tom & Julia Hetherington

Tony & Barclay Daranyi

Tracey & Dennis Dillon

Wendy Sawyer & Jack Schaller

Financial Overview

PERCY HUSTON, TREASURER

PRISMS' 2021 FINANCIAL YEAR COULD BE best defined as one of stability. Asset growth was a modest 3% ending up at almost \$850,000 in total assets, a new high-water mark for the organization.

Fundraising efforts from special events continued to be hampered by lingering COVID restrictions in some areas of the country. However, this anomaly was offset by the receipt of two PPP loans which were ultimately forgiven resulting in a \$34,000 windfall for the organization. To go along with this, we had a 17% overall growth in our Society 17p11.2 contributions, which is so important because it provides a dependable operational revenue stream. We are so thankful to these ongoing committed donors and look forward to expanding this program further as we move ahead in 2022.

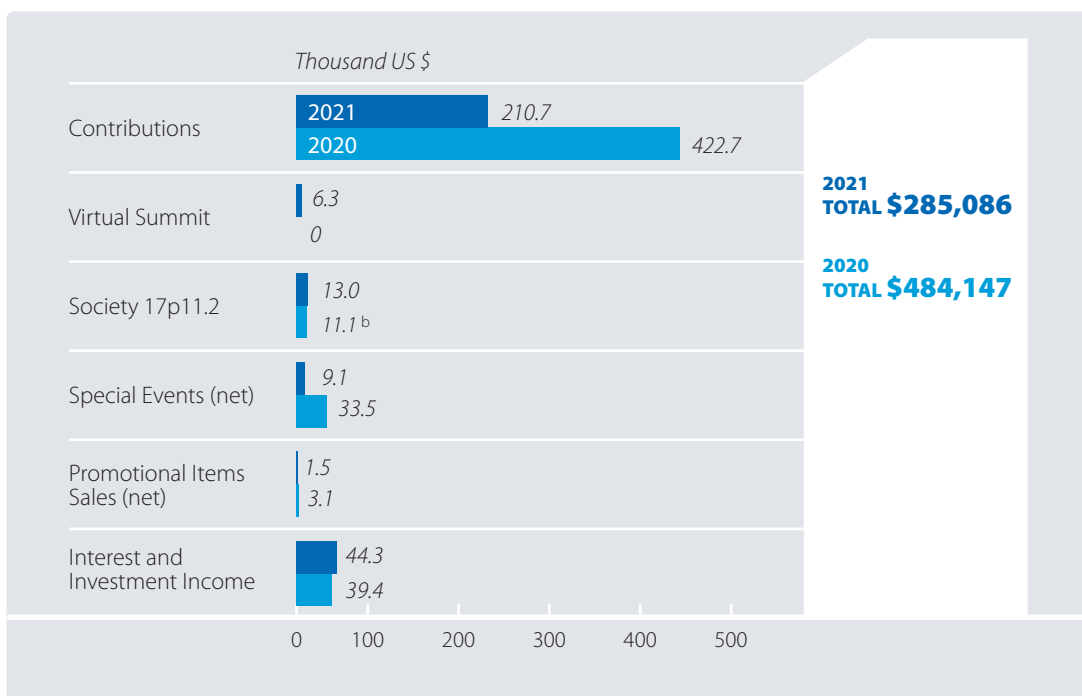
Another positive in 2021 was continued support from our corporate sponsors for the Virtual Summit and other ongoing operational needs. While we were indeed disappointed to once again postpone our in-person conference in Dallas we felt blessed to host our first ever Virtual Summit to provide much needed resources and information to our ever-growing community.

As we move forward to 2022 we are committed to our August face to face conference in Dallas and are comfortable in knowing we have the resources to hold such an event thanks to the generosity of all of our supporters. We also look forward to exploring new research opportunities with guidance from our PAB and what those might bring in the way of results for our community.

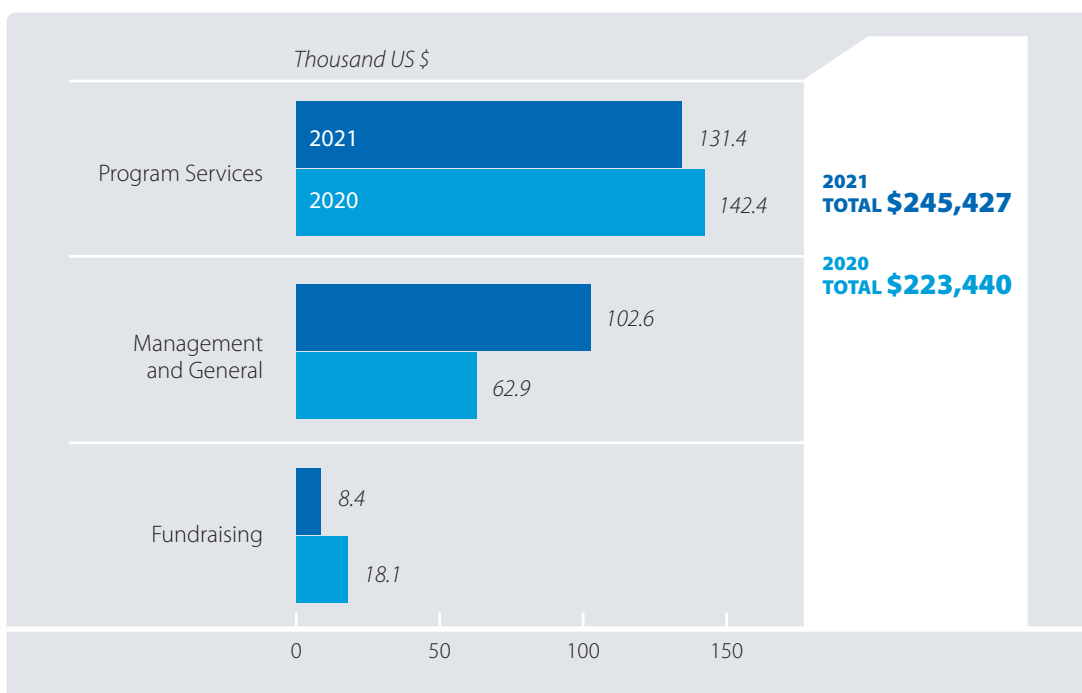
Having just completed my first year as Treasurer for this wonderful organization I look forward to both the challenges and opportunities 2022 will bring. I am also excited about reuniting with many friends and families in Dallas in August as it has been far too long since we have been together as a community to celebrate our successes and plan our future. I sincerely hope that all of you will seriously consider joining me there for what I think will be one of our best conferences ever! 🌐



Support and Revenue, 2020^a and 2021^b



Expenses, 2020^a and 2021^b



	2021	2020
Ending Cash and Investments	\$809,282	\$796,772
Ending Total Assets	\$849,598	\$829,935

^a Audited. ^b Unaudited.

2021 BOARD

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2021 COMMITTEE VOLUNTEERS

Leah Baigell

Randy Beall

Barclay Daranyi

Sylvia Farber

Jackie Fallenstein

Melissa Haley

John Mayer

Scott Miller

Tabitha Petkovich

Amanda Serio



STAFF

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PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME