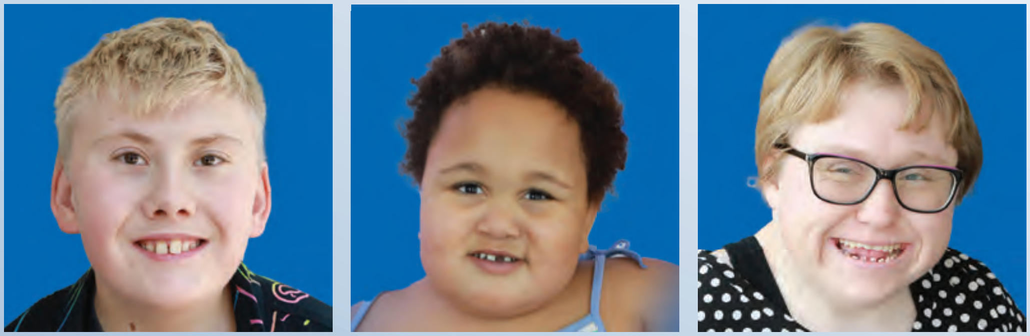
PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

prisms

PRISMS ANNUAL REPORT

2022



> *PRISMS has been dedicated to providing information and support to families of persons with SMS, sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS. Our mission has not changed since 1993. PRISMS ensures the organization continues to grow and remain sustainable to serve families within the SMS community.*

BRANDON DANIEL
PRESIDENT, PRISMS BOARD OF DIRECTORS




PRISMS
ANNUAL
REPORT
2022

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A Note from PRISMS Executive Director, Casey Gorman

As we celebrate our 30th anniversary this year, I think about our 2022 conference theme, "Envision the Possibilities" and what lies ahead for the future of PRISMS. With the support of our amazing SMS community and the hard work and expertise of our Board, Professional Advisory Board, staff and volunteers, I believe we truly can accomplish anything we envision!

It was great to meet so many of you in person at the conference in Dallas. I loved hearing what the conference meant to our SMS community. Here are just a few of the sentiments I heard throughout the weekend:

> *"It felt like we found where we belong."*

> *"There aren't enough pictures or words to describe how much these last few days at the PRISMS Conference have meant to us."*

> *"We are going home with a renewed strength and hope as we continue with our journey with SMS."*

This is why we do what we do at PRISMS.

We are here for you, to help every person affected by Smith-Magenis syndrome on their journey with SMS. Our staff and volunteers are already hard at work putting together our next International Conference, and we hope you will join us back in Dallas in 2024!

Until then, know that PRISMS is always here for you. Even in a non-conference year, we will continue to provide educational content through our webinar series and focus on fostering community with the help of our Regional Representatives.

As I read through this annual report, I can't help but be proud of what we have achieved as an organization this past year. I hope you will join us as we continue to provide programming, research, and events to support this amazing SMS community.

With hope,
Casey Gorman

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

MISSION

PRISMS IS 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.

VISION

PRISMS IS A LEADER of the Smith-Magenis Syndrome community and engages, inspires and supports families, physicians, educators, researchers, and others so they can improve the lives of everyone affected by SMS.

VALUES

- ☑ COMPASSIONATE
- ☑ EMPOWERING
- ☑ CONSCIENTIOUS
- ☑ INCLUSIVE
- ☑ EXCELLENCE

2022

PRISMS BY THE NUMBERS

OPERATIONS

2	FULL-TIME STAFF
1	PART-TIME STAFF
11	BOARD MEMBERS
11	PROFESSIONAL ADVISORY MEMBERS
53	17P11.2 SOCIETY MEMBERS
6	SMS CLINICS

AWARENESS

3,500	PRISMS SUPPORT GROUP MEMBERS
2,142	AWARENESS ITEMS MAILED
100	NEW COMMUNITY MEMBERS
126	“ON THE ROAD TO SUCCESS WITH SMS” BOOKS SOLD
30,755	UNIQUE WEBSITE VISITORS
64	REGIONAL REPS
3,800	CONTENT REACH ON SMS AWARENESS DAY
115	SMS FAMILIES PARTICIPATING IN PATIENT REGISTRY
15	BLOG STORIES
12	SHARING MORE SMILES STORIES

CONFERENCE

301	CONFERENCE REGISTRANTS
167	FIRST-TIME ATTENDEES
51	SMS INDIVIDUALS LIVING WITH SMS IN ATTENDANCE
62	SPEAKERS
12	TEACHER SCHOLARSHIPS AWARDED
34	FAMILY SCHOLARSHIPS AWARDED

Where Would We Be Without PRISMS?

BY BRANDON DANIEL, BOARD PRESIDENT

When I think of PRISMS, I think about my first connection to this organization which now has become a valuable resource to our family and so many others as we continue our journey with Smith-Magenis syndrome (SMS).

It was 16 years ago, we were grasping to determine what condition our newborn son was dealing with. Several doctor's appointments and visits to genetic counselors yielded very little success in determining our son's diagnosis. We had no answers. My wife's motherly intuition and persistent research of our son's symptoms led her to find the PRISMS website during the summer of 2007. Based upon the information found on the PRISMS website, my wife knew instantly our son's diagnosis. All that was left was officially verifying this diagnosis (which we did) and we have been a part of the SMS community and PRISMS ever since. Our family and so many others owe a debt of gratitude to the founding trailblazers of PRISMS that created this wonderful organization some 14 years prior to our diagnosis.

The PRISMS founders' selfless work to create something greater than themselves has benefited so many families since 1993. I sometimes think, what if PRISMS had not been established? Where would our SMS community be today? How would families live with SMS without this valuable resource and organization to bring our community together? I also think about all those families that were living with SMS prior to 1993 and coping daily with the challenges of SMS without an organization and community to support them. My heart goes out to those families as I can only imagine the struggles they faced without the support and knowledge of an entire community.

The PRISMS journey is ongoing as new families receive their diagnosis and join our community each year. Since day one in February 1993, PRISMS has been 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. Our mission has not changed since 1993. PRISMS ensures the organization continues to grow and remain sustainable to serve families within the SMS community.

This annual report shows a culmination of the work PRISMS was able to complete in 2022 for the SMS community. 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. This work was evidenced by our successful 11th International Conference that was held in Dallas in July.

On behalf of the PRISMS Board of Directors, thank you for your ongoing commitment and financial support of PRISMS!

Brandon Daniel

PRISMS Professional Advisory Board and Research Update

BY SARAH ELSEA, CHAIR, PROFESSIONAL ADVISORY BOARD

The PRISMS Professional Advisory Board (PAB) continues its work of service and dedication to the SMS community and we thank them for their tireless work.

The all-volunteer PAB is responsible for providing the most comprehensive, evidence-based information to PRISMS, including composing management and treatment guidelines across several disciplines to provide the most current information for individuals with SMS and their families. As part of this effort, the PAB updates the Smith-Magenis syndrome GeneReviews, a comprehensive resource for families and clinicians, https://www.ncbi.nlm.nih.gov/books/NBK1310/. GeneReviews is an international online database for inheritable diseases that undergoes rigorous editing and is peer reviewed.

The PAB is responsible for overseeing the review of proposed research studies and to steer the development of SMS research, encouraging scientists and clinicians in other disciplines to bring their expertise to SMS. As part of this effort, the PRISMS PAB also oversees the addition of survey questions for the PRISMS SMS Patient Registry (SMSPR). Their oversight maintains the integrity of questions that are included in the registry, assuring that information included in the registry is relevant and appropriate.

Recent publications and new and ongoing studies support the importance of the SMSPR and demonstrate PRISMS' foresight and support of research through a variety of mechanisms over the past year.

A publication from the work of **Anusha Gandhi**, 2020 PRISMS Summer Scholar and medical student at Baylor College of Medicine, in collaboration with Drs. Foster and Elsea from the PAB and Ms. Theresa Wilson, describes associations between behavior, medication use, and obesity in SMS.

> ***Relationships between food-related behaviors, obesity, and medication use in individuals with Smith-Magenis syndrome.***[a]

Christine Brennan, Ph.D. CCC-SLP, a member of the PAB, presented the results of her research at the 2022 PRISMS Conference entitled, ***SMS Patient Registry Results: Speech-Language Development and Hearing Health***. Dr. Brennan's research was based on data derived from the PRISMS SMS Patient Registry, which underscores the importance of having the registry data available to researchers and the collaborative nature of the SMSPR. Relevant and abundant data can lead to better outcomes in research of SMS.

Sarah Elsea, Ph.D. (Chair of the PAB) and Stephanie Sisley, M.D. at Baylor College of Medicine received an R21 grant award from the National Institutes of Health (NIH) to develop better outcomes measures for persons with SMS with regard to eating behaviors and the development of obesity. The SMSPR was an integral part of their application and several participants in the SMSPR have already participated in focus groups, both at the PRISMS 2022 Conference and virtually, to provide input regarding the most important concerns related to eating behaviors facing individuals with SMS and their families. The SMSPR was an excellent resource to identify potential participants within the required age ranges and will be a resource for testing new outcomes measures and for collection of longitudinal data.

Rebecca Foster, PhD, a pediatric psychologist and member of the PAB, completed a pilot of a sibling mentorship program. The project entitled, ***Connecting Siblings of Individuals with Smith-Magenis syndrome: A Sibling-to-Sibling Mentorship Program***, aimed to improve emotional well-being, family and sibling relationships, and coping among adolescents growing up with a sibling with SMS. The program was well-received by our siblings, caregivers, and mentors and highlighted the need and desire for this type of program within our community.

A study by **Ann Smith, M.S., C.G.C.** (PAB member, Chair Emeritus) and colleagues describes individuals with SMS also with a diagnosis of Birt-Hogg-Dubé syndrome, supporting the medical management guidelines recommended by PRISMS (https://www.prisms.org/birt-hogg-dube-and-smith-magenis-syndromes-separate-disorders-linked-through-17p11-2/)

> ***A diagnosis of Birt-Hogg-Dubé syndrome in individuals with Smith-Magenis syndrome: Recommendation for cancer screening.***[b]

Exciting new SMS research was recently funded by the NIH to support Shigeki Iwase, Ph.D. at the University of Michigan to study RAI1 and sleep in a diurnal rat model of SMS. Laboratory mice do not show the same sleep disturbances as people with SMS because they are nocturnal (awake during the night, asleep during the day), so this new model provides an opportunity to better understand RAI1 and its role in sleep in SMS. This project developed out of a PRISMS postdoctoral award to Takao Tsukahara, Ph.D. in Dr. Iwase's research group.

Dr. Elsea and colleagues, along with PRISMS, coordinated the collection of biological samples for biomarker studies at the PRISMS 2022 Conference. The willingness of attendees to participate in this research opportunity was tremendous! We look forward to seeing results of this new investigation into non-invasive biomarkers for SMS.

Taken together, these studies underscore PRISMS' commitment to SMS research and highlight the success of our grant programs to drive research forward. Continuing support of research efforts is a key part of the mission of PRISMS.

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[a] Gandhi AA, Wilson TA, Sisley S, Elsea SH, Foster RH. *Res Dev Disabil. 2022 Aug;127:104257. Doi: 10.1016/j.ridd.2022.104257. PMID: 35597045*

[b] Vocke CD, Fleming LR, Piskorski AM, Amin A, Phornphutkul C, de la Monte S, Vilboux T, Duncan F, Pellegrino J, Braddock B, Middelton LA, Schmidt LS, Merino MJ, Cowen EW, Introne WJ, Linehan WM, Smith ACM. *Am J Med Genet A. 2023 Feb;191(2):490-497. doi: 10.1002/ajmg.a.63049. PMID: 36513625*

PCRC

PRISMS Clinic
and Research
Consortium

PRISMS Clinic and Research Consortium Expands

BY MAGGIE MILLER, BOARD VICE PRESIDENT

The PRISMS Clinic and Research Consortium (PCRC) continued to expand its services to the SMS community in 2022. The PCRC provides a solid foundation of care and surveillance for the person with SMS and another nexus in a wholistic approach to management of Smith-Magenis syndrome. With the expansion of the clinic sites, we are able to 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. The PCRC program has had an impressive impact not only on patient care but in the recognition and awareness of SMS.

Members of the PCRC meet on a regular basis to discuss specific patient needs and concerns and share optimal health strategies and recommendations. The PCRC has recently collaborated on treatment guidelines for constipation: ***"Constipation in Individuals with Smith-Magenis syndrome: Recognition and Recommendations for Treatment."*** https://www.prisms.org/wp-content/uploads/pdf/respub/PCRC_Constipation_in_Individuals_with_SMS.pdf

These guidelines are shared across the clinic sites to ensure appropriate and mutual care and are available to families that visit the clinics who in turn may share the guidelines with their child's local doctors.

Besides the regular meetings between the PCRC, members also provided in-depth presentations on specific matters related to the care and management of Smith-Magenis syndrome.

- Kristen Wigby , MD, of Rady Children's Hospital presented on tethered chord.
- Sarah Elsea, PhD and Theresa Ann Wilson, MS, RDN from the Baylor College of Medicine presented on the PRISMS SMS Patient Registry, (SMSPR), describing the role and goals of the SMSPR, from a clinician's perspective, and how clinicians might be able to utilize the contribute to the data generated in the registry.
- Barbara Haas-Givler, BCBA, Geisinger Autism & Developmental Medicine Institute, presented and led a discussion on the behavioral challenges in SMS.

The PRISMS Clinic and Research Consortium looks forward to the continued expansion of SMS clinics and widening its reach to provide optimal care for individuals with Smith-Magenis syndrome.

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/.





Envisioning the Possibilities

PRISMS 11th International Conference Highlights

BY JASON MICHAUD, BOARD MEMBER-AT-LARGE

The PRISMS community gathered on August 4-6, 2022, in Dallas, Texas for the 11th PRISMS International Conference. Titled "Envisioning the Possibilities," the energy and excitement were palpable after a 4-year hiatus to the bi-annual conference due to the COVID pandemic.

Attendees and presenters came from all over the world to teach, listen and learn all about Smith-Magenis syndrome. With a record 51 individuals living with SMS and 167 first time attendees the conference space was filled with a community creating awareness and gaining a greater understanding of SMS.

There were 62 presenters who spoke about topics which supported parents and caregivers at all ends of their SMS journey. The presentations also included SMS research updates from around the world. Several members of the PRISMS Professional Advisory Board gave presentations and also spent time meeting with families one-on-one during the Curbside Consults.

A highlight of all PRISMS conferences is the ability for families to connect with other families and once again these opportunities were provided. Siblings could be seen laughing and sharing in conversation with other siblings during the sibling workshops or in the PRISMS den and parents and caregivers engaged in networking at the parent connect sessions and the socials.

The success of the conference can be attributed to our generous donors and sponsors that made the conference possible. It has always been part of the mission for PRISMS to be able to provide a conference that is cost accessible for our community as we believe in the importance of families being able to engage and learn together. The generosity of our donors and sponsors was extended to our scholarship programs. PRISMS was able to provide some level of financial support to 34 families through our family scholarship program as well as 12 teacher and support staff members through our teacher and support staff scholarship program. Special thank you to all our donors and sponsors for your support of the 11th PRISMS International Conference.

While our stories are not all the same, our journeys are quite similar. One SMS mom said "Look at all these beautiful people. All the similarities and knowing so many is incredibly inspiring. How wonderful it is to see so many who are just like my child." This is the power of the PRISMS community and the International Conference. Make sure to mark your calendar for PRISMS 12th International Conference in Dallas, Texas at the Hyatt Regency July 11-13, 2024!

Conference Fundraiser: Night at the Courtyard Rooftop

BY DENIEN RASMUSSEN, CONFERENCE FUNDRAISER CO-CHAIR

At our 2022 PRISMS Conference in Dallas, Texas, we held the Night at the Courtyard Rooftop Fundraiser which was sponsored by Vanda Pharmaceuticals. Thank you, Vanda!

This adults-only event raised over $14,000 to continue our support of our families, conferences, programs, education, and research. More than 125 people bought tickets to attend the fundraiser and attendees came dressed in their best country attire. We saw lots of boots, cowboy hats and fringe! The venue was absolutely stunning with a cool indoor lounge, bar and two outdoor terraces where views of the Dallas skyline could be seen for miles. It was a beautiful night to hang out on the rooftop.

The night began with butler-passed hors d'oeuvres and a champagne welcome drink. There was a photo booth with props to capture memories of the evening. Planned games like the heads or tails and a 50/50 raffle were played and winners won gift cards and over $750 dollars.

Overall, it was a very fun and successful evening where families were able to socialize, commiserate, and, most importantly, have fun. A big thank you to all those who came out to support PRISMS. You contributed to a very fun night. We look forward to our next PRISMS conference fundraiser. We hope to see you at the next one!

17p11.2 Society Continues to Grow

BY JASON MICHAUD, BOARD MEMBER-AT-LARGE

The PRISMS 17p11.2 Society is comprised of the most dedicated supporters of the SMS community—our monthly donors. 17p11.2 is significant to our SMS families as it refers to the specific piece of genetic material missing from chromosome 17 that leads to SMS. This past year the 17p.11.2 Society grew by 10 members. Recurring contributions build a strong foundation of support for PRISMS and ensures that PRISMS continues to grow and serve SMS families and professionals with programs and services dedicated to education, awareness, and research. Each new monthly donor enrolled received a 17p11.2 custom pin that signifies their commitment to PRISMS and the SMS community. In addition to growing in size in 2022, a highlight for the 17p11.2 Society was the social gathering for this group at the 11th PRISMS International Conference where attendees learned about the 17p.11.2 Society and its value to PRISMS.

Interested in joining the 17p11.2 Society? Simply go to PRISMS.org:

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

17p11.2 SOCIETY MEMBERS

Our monthly donors are helping to make progress happen for the SMS community every month as their generous contributions are used to advance programming and services for all families seeking support from PRISMS. Thank you to ALL of our 17p11.2 Society Members.

Danielle Bier
Glen & Kristine Braden
Lauren Carney
Faith A. Collins
Sharon Cook
Robin Coutu
Kevin Daly
Barclay Daranyi
Patty Davis
Dennis Dillon
John Doherty
Robert Duvall
Angela Eaton
Diane Erth
Jackie Fallenstein
Manuel Faria
Cheryl Huber
Percy & Bernadette Huston
Paula & Arthur Jump
David & Krista Karr
Bonnie Krautheimer
Michelle Larscheid
Josephine Lawlor
Allison & Mike Leatzow
Etienne Lecompte
Michelle Lee
Patty & Steve Loyer
Lisa & Michael Mariano
Tina McGrevy
Chris Meemken
Donald Michaud
Jason Michaud
Alicia & Scott Miller
Karen & Keith Miller
Maggie & Scott Miller
Mike Miodunski
Robyn Mogul
Kevin O'Connor
Amy Pereira
Denien Rasmussen
Gail & David Reiner
Jeremy Rude
Wendy Sawyer
Caitlin Seldon
Allison Stephanouk
Jennifer Struck
Connie & Stan Sweeney
Steven Tanenbaum
Todd Tanenbaum
Stephanie & Mark Tonsoni
Osman Umarji
Derek Waldeck
Mary & Ron Zimmer

Q&A With Three of PRISMS Community Fundraisers

BY JACKIE FALLENSTEIN – BOARD MEMBER-AT-LARGE

One of the ways PRISMS members and friends support our mission is by holding fundraisers in their local communities. **In 2022, these fundraisers raised over $60,000 for PRISMS programs!** Fundraisers can take many formats and may be inspired by the organizer's interests or connections. PRISMS is always willing to help support these community fundraising efforts.

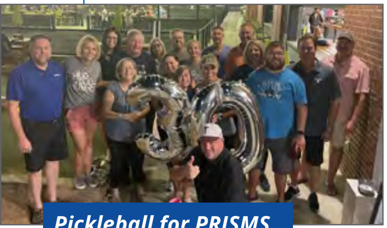
Three of PRISMS' 2022 community fundraisers, Sylvia Farber, Jason Michaud, and Jean Marie Bishop shared information and thoughts about their respective events:

Saves for SMS

Carmen Parsons/Cormack Photography

Q: What is the name of your fundraiser, and how would you describe it?

SF: **Pickleball for PRISMS** is a fun, family-friendly event for every level of play. The event includes a tournament, free play on pickle ball courts, bocce ball, and yard games. Dinner and drinks are also included.



Pickleball for PRISMS

JM: **Saves for SMS** is a hockey-themed fundraiser. Our sons Ryan and Nikolas combined their love of their sister Jillian (who has SMS) with their love of ice hockey. Nikolas is a hockey goalie, and the boys sought pledges for every save Nikolas made in February 2022. The boys created a video about their fundraiser and posted it on Facebook. With the help of media attention, they had over 200 donors!

JB: **Nickels for Nico** is a cornhole tournament that also includes a raffle and dinner (Nico is my fifteen-year-old son with SMS). Funds are raised through entry fees, donations, and a 50/50 raffle.

Nickels for Nico

Q: Is this year the first time you held this fundraiser? If not, what year did you start it and have you repeated it annually?

SF: 2022 was our second year with the pickleball format. Previously we held a similar bowling event called Bowling for SMS, which we created around 2010.

JM: This was the first year the boys did this fundraiser. The hope is that it becomes a bi-annual event. We are hoping for a bigger and better Saves for SMS in 2024!

JB: We have held Nickels for Nico annually except for a year or two during COVID. 2022 was the 11th year we have held the fundraiser.

Q: What prompted you to start a fundraiser for PRISMS?

SF: Shortly after our daughter Austin's diagnosis, we attended our first PRISMS conference. The education and support PRISMS provides is not available anywhere else. It took us 5 ½ years of searching for answers to finally get an SMS diagnosis. We wanted to support PRISMS so greater awareness can be generated, and other families can access the support and education PRISMS offers sooner!

JM: In the spring of 2019 the boys did a bake sale fundraiser for PRISMS. They decided they

Saves for SMS

Carmen Parsons/ Cormack Photography

wanted to create another fundraiser to support PRISMS. As a family we brainstormed several ideas and Saves for SMS was the idea the boys decided on.

JB: I wanted to support more conferences! PRISMS has helped our family on our journey in multiple ways, and the most important to me are the conferences.

Q: Why did you pick this specific fundraiser?

SF: We wanted a family-friendly event that allowed for socializing.

JM: The idea came from watching the World's Longest Hockey Game, a massive cancer fundraiser in our local community. Nikolas said we should do a "world's longest game for PRISMS." This was the beginning of the discussion to do a fundraiser for PRISMS using hockey as the vessel. A "world's longest" game was not feasible, but the idea of Saves for SMS was born.

JB: A cornhole tournament is easy to organize. We rent a park, and it doesn't require logistics like closing streets or hiring police. There's a playground for families to use, too. The cornhole bracket is quite easy to create the day of the event. My siblings take care of the food and drink each year, which is a big help.

Q: Beyond fundraising, what else do you think was achieved with the event? Were there any unexpected outcomes or surprises?

SF: Awareness is also a great outcome! There are always new attendees at our fundraisers, so we get the opportunity to educate new people each year.

JM: The boys also wanted to raise awareness of SMS. After every game Ryan wrote an email to all donors. Each update contained a fact about SMS and something the boys loved about Jillian. The amount of feedback he received from his updates was heartwarming – people loved learning about SMS and Jillian. A big surprise from the event was that through the media attention the fundraiser garnered, we ended up learning there were four families in our community with children with SMS that we didn't know beforehand!

JB: Celebrating Nico and his unique personality! Raising awareness. Reconnecting with other SMS families. I invite other SMS families to stay and enjoy a cookout and pool party the following day. It's a great way to connect in a more low-key setting.

Q: What advice would you give another PRISMS member considering creating a fundraiser?

SF: Just do it! Come up with an idea where your friends are inviting their friends. It becomes way less overwhelming when you invite a few with the expectation that those few then invite a few more.

JM: Just go for it! We had a crazy idea with modest expectations and were overwhelmed with love and support from people all over the country. You will never know unless you try, and even the smallest fundraiser still has huge impact for PRISMS and our SMS families.

JB: Anything is better than nothing! The community loves our kids!!!

Q: Anything else you would like to share?

SF: I would be happy to share any materials and insights from our fundraising experience and walk alongside anyone that desires to fundraise for PRISMS.

PRISMS is deeply grateful for Sylvia, Jason, Jean and their families, and every community member who organized or participated in a fundraiser in 2022. Your efforts support PRISMS and increase awareness of SMS. THANK YOU!

If you would like more information or ideas for fundraising for PRISMS, please contact Michelle Larscheid, PRISMS' Event & Community Engagement Manager at info@prisms.org.

Pickleball for PRISMS

prisms Meet-Ups

Cecilia Poole Hosts Event at Morgan's Wonderland

Cecilia Poole organized a meet-up for SMS families to enjoy a fun day at Morgan's Wonderland and Inspiration Island in San Antonio. Six families with their children, including their SMS kiddos, enjoyed seeing each other and playing at the all-access parks. It was a hot day so the five splash pads at Inspiration Island were a favorite place to hang out. Afterward, everyone reconnected at nearby Two Brothers Barbecue and enjoyed the barbecue, conversation, and especially the air conditioning.

Laurie Bellet Hosts Bay Area Picnic

17th Annual Houston Picnic

Laurie Bellet, hosted a San Francisco Bay Area SMS picnic in Walnut Creek, California. The meet-up event was held at the Heather Farms All Abilities Playground. Laurie's daughter, Ariel, was able to show her mini horse to all the attendees at the picnic.

The 17th Annual Houston SMS picnic was held at Bear Creek Park in Houston. Nineteen families joined the fun with their SMS individuals, for a total of 36 attendees. Dr. Sarah Elsea also made a welcome appearance.

Financial Overview

BY PERCY HUSTON, TREASURER

The 2022 fiscal year for PRISMS will go down as one of the more financially challenging in our 30-year existence. PRISMS' resources took an overall hit of over 25% due to a number of factors. In addition to increased planned internal overhead as we continue to make our organization as professional as possible, the two major contributors were higher-than-expected conference expenses and a severe market downturn that greatly impacted our investment resources.

The good news is that we finally had our long-awaited conference in Dallas after two consecutive postponements due to COVID concerns. PRISMS is always committed to executing successful conferences, and costs ended up being exponentially higher than expected, far higher than any we had ever experienced in hosting previous conferences.

However high the costs were, it is hard to say they weren't worth the effort. Our community was revitalized by the meeting in Dallas after being away for so long due to COVID and pandemic restrictions. Much-needed camaraderie, bonding, healing and learning took place in Dallas, and it is impossible to put a price tag on the impact that this has on our families. We are, and always will be, better for the time spent together and the learning and relationship building that the PRISMS conference brings about.

On the investment side, like most of the country, market conditions greatly declined last year, and some of our investments have lost value.

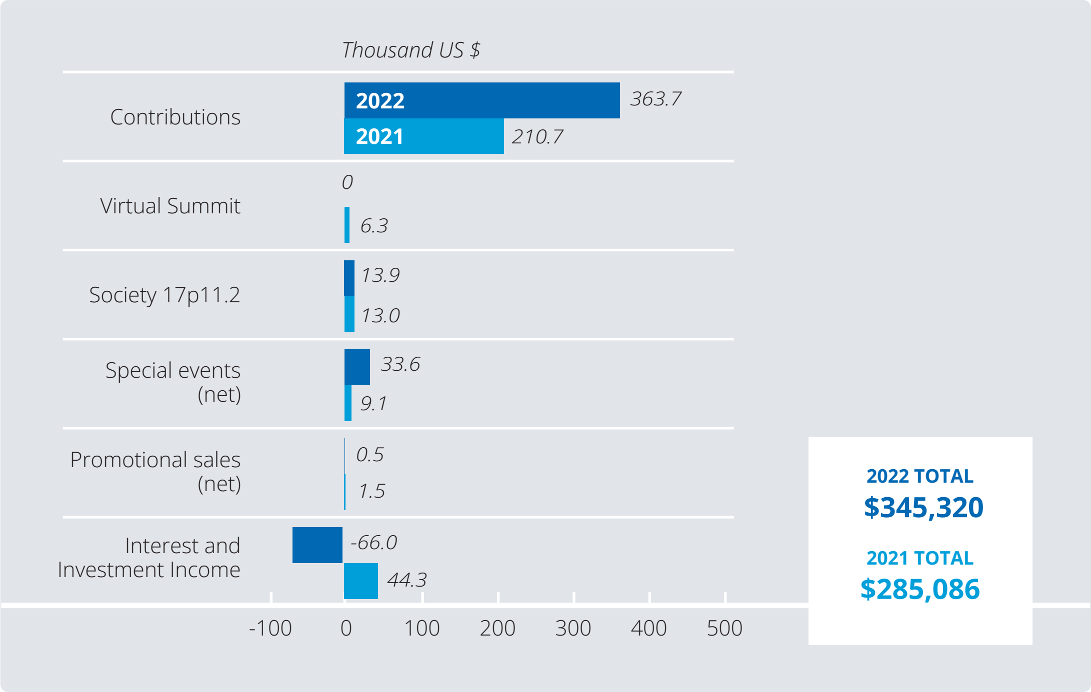
Moving forward, we continue to be extremely grateful to our many supporters and cannot thank them enough. Our 17p11.2 Society of monthly donors continues to grow along with our donor base and our dedicated community members who continue to host fundraisers in support of PRISMS. All of this work takes a lot of time and commitment. My wife and I were privileged to travel to San Antonio last fall to participate in Jeremy and Sylvia Farber's annual pickleball fundraiser. It was an honor to be there and a super fun event. I highly recommend anyone having a chance to attend to do so!

In closing, PRISMS remains committed to our community. If you have not yet become part of our Patient Registry please do so, as every participant counts to help support vital advances in SMS research. PRISMS will be hosting our next conference in Dallas in July of 2024. Please consider attending, especially if you did not come in 2022. It is a wonderful venue and planning is well underway for this event.

WE CONTINUE TO BE EXTREMELY GRATEFUL TO OUR MANY SUPPORTERS AND CANNOT THANK THEM ENOUGH.

OUR 17P11.2 SOCIETY OF MONTHLY DONORS CONTINUES TO GROW ALONG WITH OUR DONOR BASE AND OUR DEDICATED COMMUNITY MEMBERS WHO CONTINUE TO HOST FUNDRAISERS IN SUPPORT OF PRISMS.

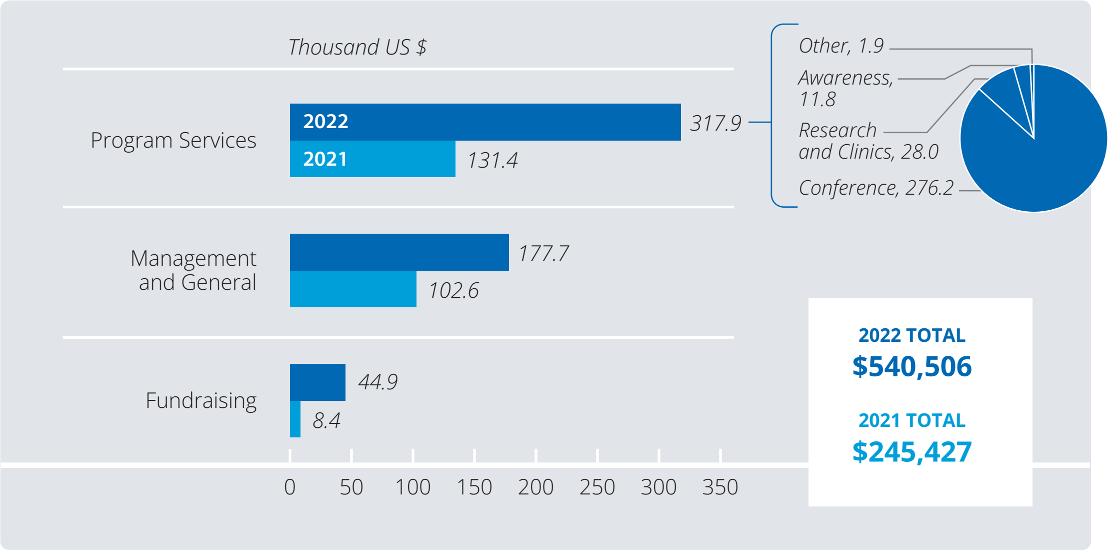
Support and Revenue, 2021-22



2022 TOTAL
$345,320

2021 TOTAL
$285,086

Expenses, 2021-22



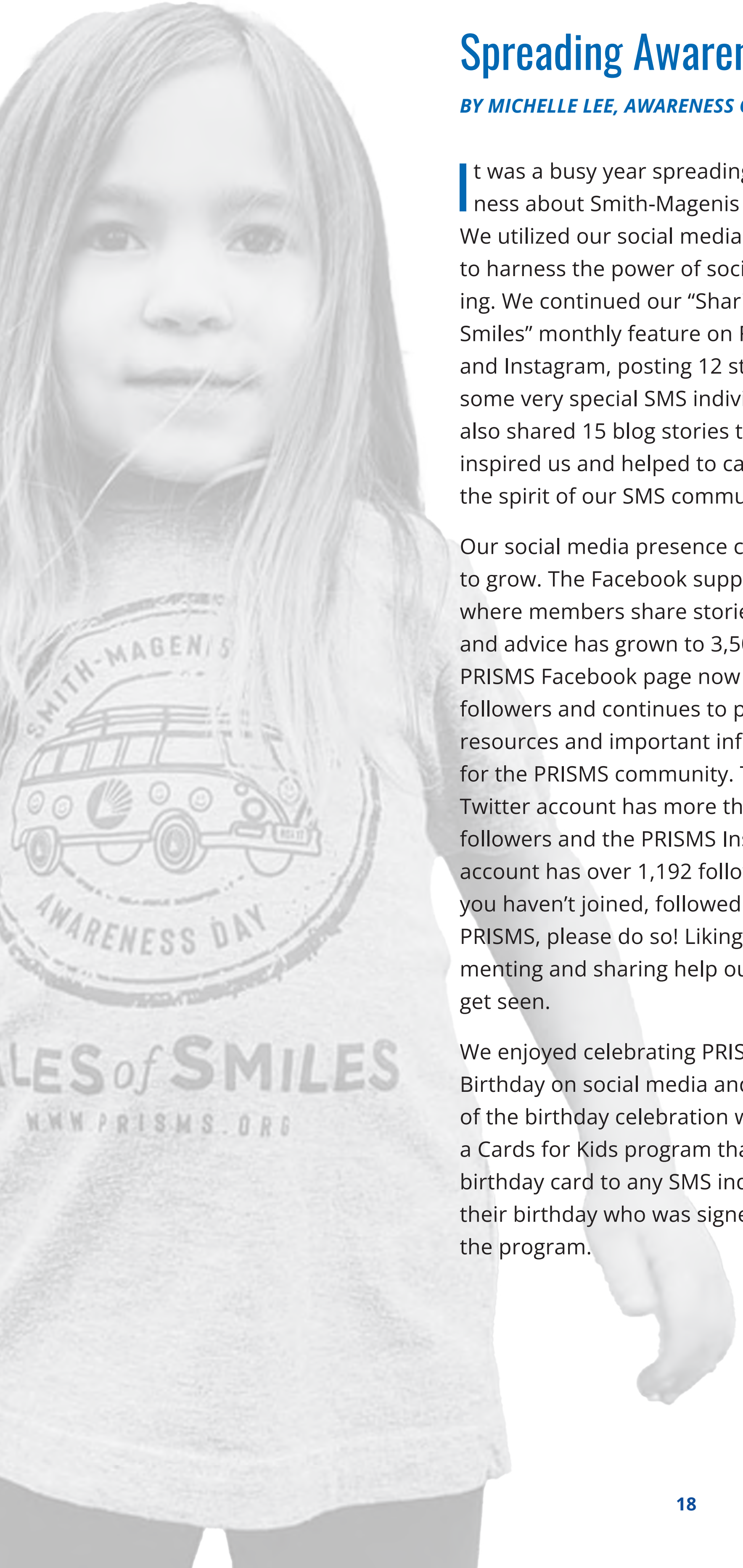
2022 TOTAL
$540,506

2021 TOTAL
$245,427

	2022	2021
Ending Cash and Investments	**$569,292**	**$809,282**
Ending Total Assets	**$594,963**	**$849,598**

One of the ways you can help make sure PRISMS is around for the next 30 years is by making a planned gift by naming PRISMS in your will or life insurance.

All you need to do is give this information to your attorney: Our legal name **PRISMS Inc.** and common name for reference **PRISMS**, our **EIN: 54-1652029**, and our mailing address: **PRISMS, Inc., 205 Van Buren Street, Suite 120 #1027, Herndon, VA 20170**



Spreading Awareness

BY MICHELLE LEE, AWARENESS COMMITTEE CHAIR

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 15 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 to 3,500. The PRISMS Facebook page now has 2,568 followers and continues to post helpful resources and important information for the PRISMS community. The PRISMS Twitter account has more than 654 followers and the PRISMS Instagram account has over 1,192 followers. If you haven't joined, followed or "liked" PRISMS, please do so! Liking, commenting and sharing help our pages get seen.

We enjoyed celebrating PRISMS 29th Birthday on social media and as part of the birthday celebration we started a Cards for Kids program that sent a birthday card to any SMS individual on their birthday who was signed up for the program.

SMS Awareness Day

Our community stepped up in a big way to spread SMS awareness through Miles of Smiles on social media! Thanks for showing off your shirts and sharing other content about Smith-Magenis syndrome to spread the word. With your help, we've reached over 3,800 people on Facebook, Twitter, and Instagram in one day! You also helped us reach over 1,000 views on our new SMS Awareness video. Thank you for sharing it! If you missed it, you can find it here on YouTube.

Special Awareness Day Activities and Fundraisers

PRISMS Board member Denien Rasmussen ran an SMS Squares fundraiser at her corporate office and sold130 squares, raising $650 from her efforts.

Joan Cole is a pre-engineering teacher at Life Ready Center- LPS in Lawton, Oklahoma. Her son, Austin, was diagnosed with SMS when he was just 18 months old. He is now 31 years old.

This year, Joan stepped out of her comfort zone to encourage her students to use the design, research and interview process along with printing equipment to have her students create a poster campaign to celebrate Smith-Magenis syndrome for SMS Awareness Day. The students interviewed Ms. Cole about her son, who was one of the first people to be identified with SMS in Oklahoma. The kids were also encouraged to wear pink (Austin's favorite color) or wear PRISMS blue and they also made a video project. By learning more about Austin and the care he needs, the students not only practiced skills but also expressed empathy.

Charlene Jostes was successful in her quest to have Kansas Governor Laura Kelly sign a proclamation to declare November 17th SMS Awareness Day in the state of Kansas. What a huge accomplishment for helping to bring awareness to her home state!

We had 12 people run fundraisers for SMS Awareness Day on Facebook that raised $5000 for PRISMS!

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 Facebook frame, a coloring page activity, and many ideas for our community to spread awareness with their family and friends. We also posted 17 days of SMS facts each day leading up to SMS Awareness Day and a new infographic for the community to share.

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 sells apparel and other awareness items. You can now purchase the ***On the Road to Success with SMS*** book though the PRISMS store.

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.

Thank you for your tireless efforts to help us raise awareness about Smith-Magenis syndrome. Educating your community of friends, neighbors, family, physicians, educators, and more is exactly how we bring understanding and support for our rare community.

PRISMS Regional Representative Program Continues to Evolve and Grow

BY DENIEN RASMUSSEN, REGIONAL REPRESENTATIVE CHAIR

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, or just provide a safe space to vent to people who understand our lives.

In 2022 we had our bi-annual conference in Dallas, Texas. We were excited to see so many of our Regional Representatives attend our Regional Rep meeting. We thank all our reps for taking time out of their stressful lives to help our families.

We currently have over **64** Regional Representative Volunteers in our program. Most are in North America, but we also have reps in Canada, Australia, France, Brazil, Italy, Mexico, Puerto Rico, Russia and the United Kingdom.

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

1. Newly diagnosed families and how to support them
2. Topics for the upcoming 2024 PRISMS conferences
3. New SMS Clinics—which we continue to open
4. Social Media
5. Resources and state benefits, how to find them in your region
6. Awareness Materials
7. Hosting Fundraisers
8. Ideas for regional get-togethers
9. Upcoming webinar topics

The quarterly Zoom meetings 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! They have been at the beginning of your journey, through your journey and will be for the remainder of your journey. #ThenNowAlways.

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 join our PRISMS email list to stay up to date on PRISMS programming
- Encourage families to attend our conferences, webinars and meet-ups

I am so proud to work with this amazing group of people and look forward to every opportunity I have in either speaking with them through Zoom or meeting them in person. 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, Delaware, Georgia, Maryland. If you are interested or know someone who might be interested, please reach out to us at info@prisms.org.

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 2022!

Alejandro and Delma Aguilar

Leah Baigell

Eliane Barros

Cally Bauman

Mary Beall

Tracie Belcher

Abigail Bell

Laurie Bellet

Jean Bishop

Sabrina Bisiani

Heather Boney

Debbie Brooks

Maria Elena Carrancedo

Ashton Cheramie

Jennifer Comford

Kevin Daly

Ana Delgadillo

Amanda Downey

Diane Erth

Maria Feagin

Rhonda Franklin

Heidi Graf

Trevor Gritman

Melissa Haley

Stephanie Hanquez

Mary Hards

Sheila Hernandez Vale

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

Denien Rasmussen

Remi Robbins

Marni Rolston

John Roseborough

Brianna Ryczek

Virginie Sargent

Natasha Schaller

Caitlin Seldon

Randi Tanenbaum

Mark and Theresa Smyth

Bela and Alexander Tzetlin

Osman Umarji

Brooke Widmer

Brandi Wilson

Kim Wirth

Jill Wood

Bill and Liz Yates

Michele Zdanowski

Annetta Zidzik

Regional Representatives Debbie Brooks and Patty Loyer at the PRISMS Conference.

KEY PRISMS VOLUNTEERS AND CONFERENCE LEADERSHIP

VOLUNTEERS

- Leah Baigell
- Randy Beall
- Barclay Daranyi
- Sylvia Farber
- Melissa Haley
- John Mayer
- Scott Miller
- Erik Murdock
- William Stephanouk
- Steve Tannenbaum

CONFERENCE COMMITTEE

- Pat Brown
- Casey Gorman
- Athenna Harrison
- Michelle Larscheid
- Michelle Lee
- Jason Michaud
- Maggie Miller
- Amy Pereira
- Allison Stephanouk
- Angela Williams

CONFERENCE VOLUNTEERS

- Baylor Research Students
- Mary Beall
- Randy Beall
- Dawnda Daniel
- Alyssa Dickerson
- Brenda Dickerson
- Kaitlyn Pereira
- Dalton Lee
- Alex Stephanouk
- Catherine Stephanouk
- William Stephanouk

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Maggie Miller
Vice President
Percy Huston
Treasurer
Diane Erth
Secretary

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Denien Rasmussen
Regional Rep Committee Chair
Michelle Lee
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Amy Pereira
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Jackie Fallenstein
Board Member at Large
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Board Member at Large

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Rebecca Foster, PhD
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Rachel Franciskovich, MS,CGC
Nancy Raitano Lee, PhD

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Casey Gorman, Executive Director
Michelle Larscheid, Events and Community Engagement Manager
Lynda Kilian, Administrative Assistant

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#1027,Herndon, VA 20170
972-231-0035 (phone)

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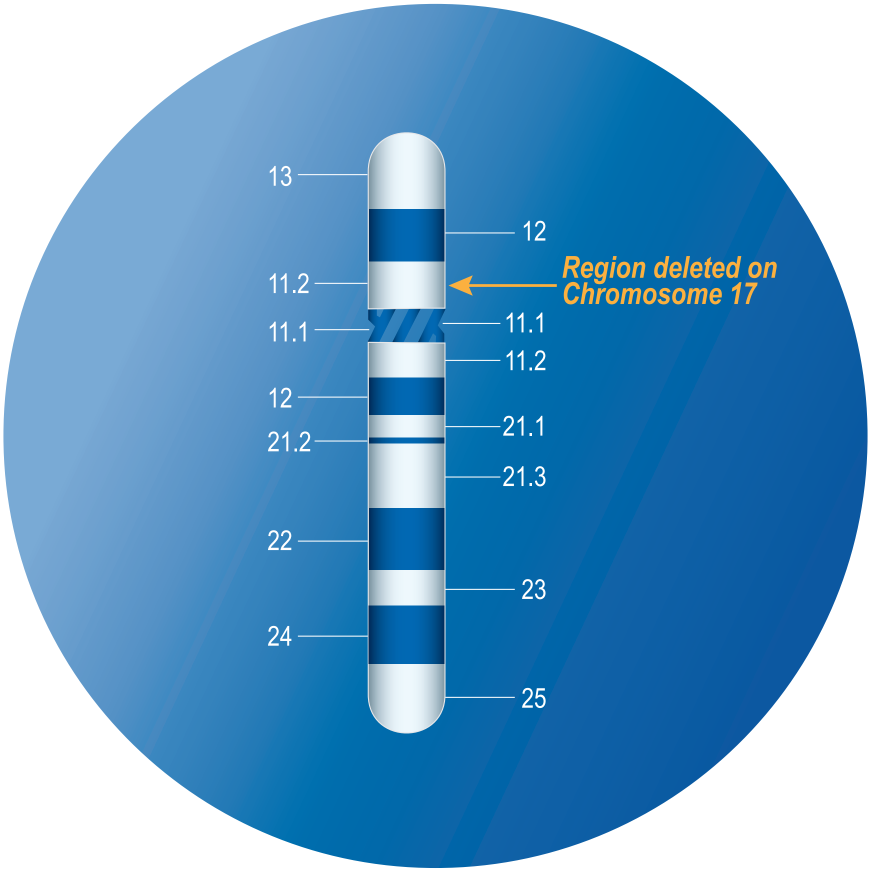
c/o Wood & Huston Bank
PO Box 724
Cape Girardeau, MO 63702-0724

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 most commonly 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.



Thank You

PRISMS work is made possible through the generous contributions of our donors. As a non-profit organization, PRISMS strives to build education, awareness, and research opportunities for all those affected by SMS. All of our programs, including our webinar series, are fully funded by our generous donors.

If you are interested in supporting PRISMS and the programs it provides families impacted by Smith-Magenis syndrome, please visit our website and make a contribution at www.prisms.org/donate.

On behalf of everyone impacted by SMS, thank you for supporting our community!

This report made possible by contributions from:

Casey Gorman
Executive Director

Michelle Larscheid
Events and Community Engagement Manager

PRISMS Board of Directors

Many photos throughout this annual report are
courtesy of **Rick Giudotti, Positive Exposure**

Designer: **Mark Hernandez**

prisms

PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME