



prisms

2024 ANNUAL REPORT

leading the way
together



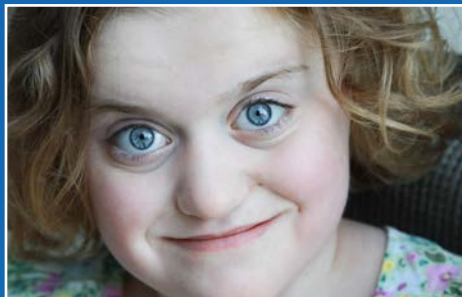
Smith-Magenis Syndrome

Parents and Researchers Interested in Smith-Magenis Syndrome

PRISMS 2024 ANNUAL REPORT

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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

We are a compassionate organization that cares deeply about the well-being and the needs of each and every individual within the SMS community.

EMPOWERING

We empower families with the knowledge they need to make the best decisions for their family's needs.

CONSCIENTIOUS

We are conscientious in ensuring that all of our actions and practices serve the needs of the SMS community.

INCLUSIVE

We encourage and seek participation from all those interested in advocating for and creating a positive impact for the SMS community.

EXCELLENCE

We focus on quality, conducting our work to the highest ethical and professional standards, and striving for excellence in all that we do.

MESSAGE FROM THE PRESIDENT

Percy Huston, President

As I reflect on my first year leading PRISMS, I am genuinely humbled by what an incredible organization it has become. Leadership is only as strong as the team behind it, and at PRISMS we are fortunate to have an extraordinary team. It all begins with our Board of Directors—a dedicated and passionate group of individuals who devote countless volunteer hours to ensuring our success. Our Executive Director, Michelle Larscheid, who transitioned permanently into this role in 2024, serves as the face of PRISMS, guiding our organization with commitment and vision.

Our Professional Advisory Board (PAB) continues to grow, bringing experience, expertise, and enthusiasm to our mission. Their contributions are invaluable to our success. Beyond that, we are supported by an incredible network of volunteers and staff, including our Regional Representatives, whose dedication is essential to achieving our mission.

Together, this remarkable team has truly led the way in 2024. Thanks to their hard work, we hosted our most successful international conference yet in Dallas this past July. In conjunction with the conference, we also held a pivotal Research Symposium, bringing together PAB members and other professionals.

This team's collective efforts have propelled PRISMS forward in many areas, from raising awareness and expanding fundraising efforts, to supporting Smith-Magenis syndrome (SMS) clinic development and so much more.

But the final, most vital part of this team is YOU—our SMS community. We are here for you, and we could not exist without your unwavering support. Whether through financial contributions or other means, your dedication fuels our mission.

For those who attended the 2024 conference, you may recall my opening remarks. My 34-year-old daughter, Jacqueline, who has SMS, is obsessed with The Wizard of Oz. Her room is filled with memorabilia—artifacts,



framed puzzles, posters—celebrating her love for the story. But what resonates with me the most is the poster on her bedroom door. It shows Dorothy, Toto, Scarecrow, Tin Man, and the Cowardly Lion walking down the yellow brick road, with an inscription that reads: "It's not where you go; it's who you meet along the way." As I continue this journey leading PRISMS into 2025, I look forward to meeting each of you along the way. We have much to accomplish together, and we will continue Leading the Way.

A handwritten signature in black ink that reads "Percy Huston". The signature is fluid and cursive, with a large, stylized "P" and "H".



MESSAGE FROM THE EXECUTIVE DIRECTOR

Michelle Larscheid, Executive Director

In my first full year as PRISMS Executive Director, I had the privilege of traveling across the country to represent PRISMS and advocate for the Smith-Magenis syndrome (SMS) community. From Dallas to Charlotte, Philadelphia to San Antonio, and Kansas City to Washington, D.C., and Minneapolis, I connected with leaders dedicated to making a difference in the world of rare diseases and fundraisers who are supporting our cause.

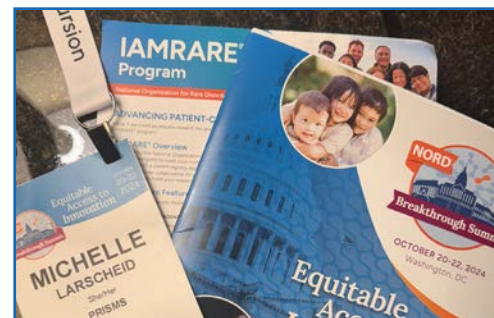
As you read this annual report, I invite you to reflect on our accomplishments. Every achievement highlighted in this report was made possible by a dedicated team of two staff members, 13 Board members, 14 Professional Advisory Board members, and countless volunteers who contributed over 7,000 hours of service. Their hard work and dedication have driven the creation of programs and services that enhance the lives of individuals with SMS and their families.

Looking ahead to 2025, we're not slowing down. We remain committed to our existing programs while launching new initiatives to expand our reach and impact. None of this would be possible without the unwavering support of our donors, volunteers, and community members. Your generosity fuels our mission of support, education, awareness, and research.

I am honored to lead PRISMS on this journey. Together, we are forging a brighter future for all those affected by Smith-Magenis syndrome. Thank you for your continued support, partnership, and belief in our mission. Let's continue leading the way—together!

With gratitude and optimism,

Michelle Larscheid





prisms BY THE NUMBERS



12

INTERNATIONAL
CONFERENCES

11



RESEARCH
SYMPOSIUMS



62

REGIONAL
REPRESENTATIVES



14

PROFESSIONAL
ADVISORY BOARD
MEMBERS



8

SMS
CLINICS



7,000+

VOLUNTEER HOURS THIS YEAR BY
DEDICATED PARENTS + PROFESSIONALS



4

SPECIALIZED
GUIDEBOOKS

31 YEARS

SERVING THE
SMITH-MAGENIS
SYNDROME
COMMUNITY

Prisms.org

2024 FINANCIAL REPORT

Phil Ruedi, Treasurer

PRISMS 2024 financial year was a success following another very successful year, 2023. The definition of success for 2024 is different. As we all know, 2024 was a conference year, and conference years are “investment” years for PRISMS.

Substantial financial support from our members combined with excellent cost controls allowed PRISMS to host a conference that was 10% larger than budgeted while incurring financial losses that were less than expected. This is significant as the per-attendee cost of the conference is well above attendee registration fees. Other highlights include the growth of the 17p11.2 Society by 17% in 2024, and we expect that growth to continue as the conference attracted new members. Individual, unrestricted donations increased by over 8% after a stellar 2023, and conference sponsorship and fundraising approached \$90,000.

As we entered 2024, the PRISMS board approved a budget that envisioned an operating loss of almost \$160,000, including a loss of \$143,000 for the conference. The conference delivered higher revenues and expenses driven by higher-than-expected attendance. Conference revenues were almost 50% higher than expected, combined with cost per attendee, which was 3% lower than expected, offset higher than expected attendance, and registration fees per attendee, which were 16% lower than expected. As a result, the conference investment was \$25,000 less while delivering an outstanding experience. The bottom line is that instead of a \$160,000 loss, PRISMS had an \$85,000 loss when investment income was included.

As we look forward, I am confident of PRISMS’ future financial performance. First, PRISMS has a strong balance sheet with over \$550,000 in cash and investments at the end of 2024 to fund future programs and conferences. Second, the financial operations are much tighter. The organization has developed strong cost control processes and is very focused on our spending.

For 2025, the PRISMS Board approved a budget that envisions growth in financial assets. One would have to go back over 10 years to find an approved budget forecasting positive net income. At that time, the organization did not have the costs associated with an Executive Director,



support staff, and a patient registry – all these resources are considered critical to our success. Finally, the support from our community has grown immensely over the last few years, and I expect it to continue to grow. Thank you!

It is an honor to return to the PRISMS Board and re-engage in my role as Treasurer, and I appreciate the confidence the Board and the PRISMS community have placed in me.

In addition to monetary donations, volunteer support is critical to ensuring PRISMS can carry out its mission. The PRISMS Board, Professional Advisory Board, and dozens of PRISMS community members contributed an amazing 7000+ hours of their time to PRISMS in 2024. We couldn't do this work without them! THANK YOU!



SPREADING AWARENESS BY SHOUTING IT OUT IN 2024

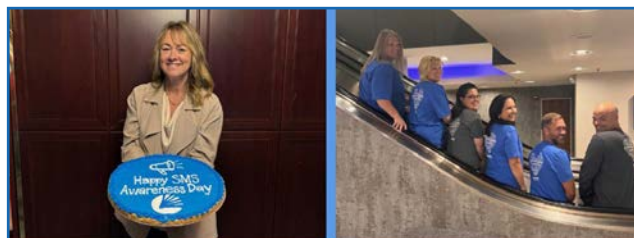
Michelle Lee, Awareness Chair

The year started with PRISMS celebrating its 31st anniversary as an organization. That same month, PRISMS joined the National Organization for Rare Disorders (NORD) and Baylor College of Medicine by attending their Rare Disease Day event at Texas Children's Hospital. Interacting with research teams, patient organizations, clinical groups, and patients and families with other rare diseases was a great opportunity.

PRISMS continued to raise awareness through various forms of social media, including Facebook, Instagram, and Twitter. These platforms were utilized to keep our Smith-Magenis syndrome families informed about research and events, such as our 12th International Conference as well as spreading the word about awareness days related to Smith-Magenis syndrome. This includes SMS Awareness Day in November when we shared facts, photos, research graphics, coloring sheets, and more. A few other national awareness days were also used to spread awareness. Some highlighted days were Sleep Awareness Day, National Sibling Day, and Grandparents Day. Blogs, personal stories, and amazing photos were used on these days to help raise awareness.

In July, PRISMS held its 12th International Conference. Our biennial conference provided an inspiring platform for families, researchers, and educators to come together to share information and ideas. Having our SMS community together in person allowed Rick Guidotti from Positive Exposure to take some great photos of our fabulous community. These pictures have been and will be used for posts and stories to help continue raising awareness throughout the years. We thank all of you who allowed your beautiful faces to be captured at this event. Be ready for the cameras to come out again in Minnesota in 2026!

This year's theme of "Shout Out for Smith-Magenis Syndrome Awareness Day" was a hit. *(cont.)*



(Awareness - cont.)

Everyone from the PRISMS Board to others from other rare disease organizations gave a shout out through social media. We focused on many positives and used that idea on our latest awareness day shirt. This was also our best year ever for shirt sales, which helped raise funds for PRISMS. During our awareness day, PRISMS was given the privilege by Rare Revolution Magazine to do a Takeover Tuesday in which we were able to share facts and research regarding Smith-Magenis syndrome on their organization's social media outlets. During our awareness day, PRISMS shared facts, personal stories, fun activities, and research through many sources, along with the awareness day alert texts.

As part of PRISMS' continued effort to raise awareness, we still have many Smith-Magenis syndrome resources available. Print materials are available for anyone needing information or help in our awareness campaign. You can also purchase PRISMS merchandise which can be accessed through the PRISMS website at www.prismsstore.org.

PRISMS is pleased to share that Smith-Magenis syndrome was highlighted nationally in an episode of Medical Stories docuseries on PBS. In this episode, a family shared their story of their child, Aaron, who was diagnosed with Smith-Magenis syndrome. They explained how the family is navigating the challenges of raising their son, including shedding light on the significant role played by his older sister, Abigail, in his progress. It can be seen across the country on local public television/ PBS stations, the Medical Stories website, and on YouTube channels.

We also continue to 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 to our rare community.



DEVELOPMENT UPDATE

Jackie Fallenstein Vice President, Development Chair

PRISMS' many programs and resources are only possible due to the generosity of our donors and sponsors. Here are some of this year's fundraising initiatives:

Silent Auctions

PRISMS held two silent auctions this year — one during the 2024 International Conference and one in recognition of Smith-Magenis Syndrome Awareness Day. With unique items and experiences, including Safety Sleepers, conversations with Ann C.M. Smith, and a one-of-a-kind guitar gifted by a friend of PRISMS, this was a new and unique way to support PRISMS and raised over \$15,000. Thank you to our auction donors and bidders!

We plan to hold another auction in 2025. If you have an experience, item, or service you would like to donate to an upcoming auction, please let us know at info@prisms.org.

Smith-Magenis Syndrome Awareness Day \$17,000 Match

In November, a group of committed donors offered a \$17,000 Match in recognition of Smith-Magenis Syndrome Awareness Day. The Match was a huge success, and our community blew past the \$17,000 match goal – for a total of over \$47,000 in giving! Thank you to our Match donors and Match participants.

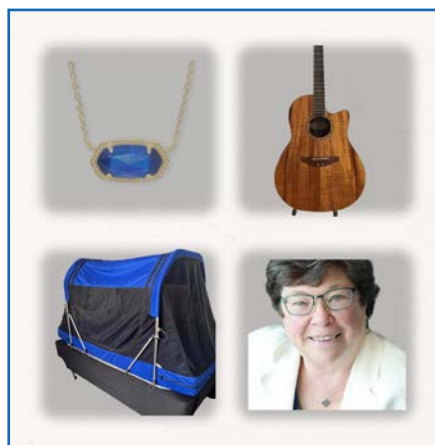
Social Media Fundraisers

In 2024, 65 members of our community held fundraisers on Facebook or Instagram, many of them in conjunction with a birthday or Smith-Magenis Syndrome Awareness Day. These fundraisers raised over \$15,000. Social media fundraisers can be set up in less than five minutes and can raise awareness of SMS while also raising important funding. Thank you to all our social media fundraisers.

Planned Giving

Would you like to make a lasting gift to PRISMS? Planned giving refers to the process of designating a major gift to a charitable organization, to be shared during your lifetime or as part of your estate plan. It could include cash, real estate, investments, or personal property. Careful planning with an attorney or financial planner is critical. To notify PRISMS of an intention to include PRISMS in your planned giving, email PRISMS' treasurer Phil Ruedi at pruedi@prisms.org.

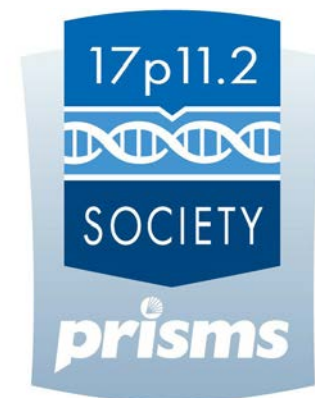
A sincere thank you to all donors. Your contributions are essential for PRISMS to continue its mission.



PRISMS 17p11.2 SOCIETY

The 17p11.2 Society is a group of donors committed to monthly giving at a minimum of \$17. This ongoing support helps PRISMS sustain income throughout the year. Thank you to all our 17p11.2 Society members.

To learn more or to join the 17p11.2 Society, go to www.prisms.org/get-involved/17p11-2-society/. Current members who would like to increase or adjust monthly giving can do so easily by emailing your request to: info@prisms.org.

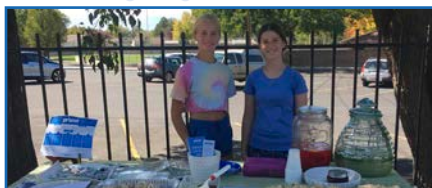


17p11.2 Society Members 2024

Leah Baigell	Dennis Dillon	Josephine Lawlor	Denien Rasmussen
Kayla Beecher	John Doherty	Allison & Mike Leatzow	Gail & David Reiner
Connie Bessette	Angela Eaton	Etienne Lecompte	Cherisse Rodriguez
Danielle Bier	Sarah Elsea	Michelle Lee	Jeremy Rude
Kristine & Glen Braden	Diane Erth	Patty Loyer	Philip Ruedi
Ellie Burnett	Jackie Fallenstein	Lisa & Michael Mariano	Leann Santiago
Lauren Carney	Sylvia Farber	Jessie McClintock	Eric Schaller
Maria Carrancedo	Manuel Faria	Tina & Charlie McGrevy	Caitlin Seldon
Daniel Cocilova	Alexander Hake	Jason Michaud	Allison Stephanouk
Sharon Cook	Tera Hickie	Alicia & Scott Miller	William Stephanouk
David Cordrey	Daniel Howell	Scott Miller	Jennifer Struck
Zachary D'Agostino	Cheryl Huber	Trinity & Mike Miodunski	Steven Tanenbaum
Kevin Daly	Percy Huston	Robyn Mogul	Stephanie & Mark Tonsoni
Barclay Daranyi	Jana Johns	Karin Monahan	Osman Umarji
Patty Davis	Paula Jump	Kevin O'Connor	Martina Vit
Alyssa Dickerson	Lynda Kilian	Charles Penn	Debi Waters
Brenda Dickerson	Bonnie Krautheimer	Amy Pereira	Mary Ann & Ron Zimmer
	Michelle Larscheid	Vanessa Plascencia	

COMMUNITY FUNDRAISERS

This year, generous PRISMS members held various fundraisers in their local communities to support PRISMS. Some of these fundraisers have been held annually for 10 years or more! We are so grateful for each of these unique, awareness-building fundraising events. Are you interested in creating a community fundraiser? Contact info@prisms.org for ideas and support.



Bardsley Lemonade Fundraiser

More than 80 neighbors and friends stopped by this lemonade stand, which was set up in Michelle Bardsley's neighborhood in Utah. They sold several sweet treats, homemade raspberry jam, two flavors of lemonade, and handcrafted glass magnets and raised \$1,847 for PRISMS.



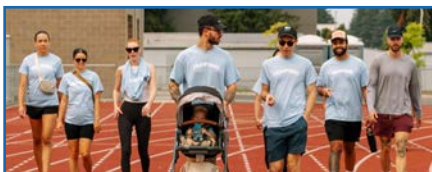
Nickles for Nico

Jean Bishop hosted the 13th Annual Nickles for Nico Cornhole Tournament in Kentucky. It was a huge success and raised over \$12,448 for PRISMS! The fundraiser had a record attendance with 235+ participants. There were also eight SMS individuals (including Nico) at the event, which is a huge record! They traveled from KY, TN, OH, IN, and IL to raise awareness of SMS.



Pickleball for PRISMS

Sylvia and Jeremy Farber held their 14th Annual Pickleball for PRISMS fundraising event in San Antonio on October 1. They had 150 attendees and raised over \$29,000! PRISMS Executive Director Michelle Larscheid and PRISMS Vice President Jackie Fallenstein were able to attend and help out. We appreciate the hard work and dedication that goes into an event of this magnitude.



SMS Champions

Thank you to Janet and Trent Standard for holding their SMS Champions run/walk fundraiser for PRISMS in honor of their daughter, Hazel. This was their very first fundraiser and they had over 200 attendees and raised over \$10,000!



The Mountain Goats Guitar and Concert Sales

The Mountain Goats band generously donated a signed guitar for our SMS Awareness Day Silent Auction, which brought in \$3,200. The Mountain Goats also donated a portion of ticket and catalog sales, which brought in over \$8,500 in 2024.

(cont.)

(2024 Community Fundraisers - cont.)



WWEX Corp North 5K

Luke Schumacher, dad to Will, worked with his company, GlobalTranz/WWEX Corp North in Minneapolis, MN, to designate PRISMS as the beneficiary for his company's 5K charity run/walk, which was held in honor of Will. The event and additional donations raised over \$9,000 and generated awareness for SMS in the local community.



SMS Bracelets

After attending the PRISMS Conference in Dallas, two SMS moms from Michigan, Michele Zdanowski and Eva Wludyka, were inspired to make bracelets for an SMS Awareness Day fundraiser to raise awareness and funds. They raised \$2,200 for PRISMS.



Hibbs Donut Fundraiser

Adrian Hibbs's family ran a fundraiser through Dunkin' Donuts in their neighborhood for SMS Awareness Day in honor of their son, Anderson. They raised \$1,200 with this fun, collaborative fundraiser.



PRISMS CLINIC AND RESEARCH CONSORTIUM (PCRC) UPDATE

Margaret Miller, Founding Board Member

This year, PRISMS made significant strides in expanding access to care by adding two Smith-Magenis syndrome (SMS) clinics, bringing the total to eight clinics. The PRISMS Clinic and Research Consortium (PCRC) is designed to expand the availability of comprehensive, clinically appropriate care for the SMS community.

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

The two new SMS Clinic sites are:

University of Florida Center for Autism and Neurodevelopment Smith-Magenis Syndrome Clinic

Clinic Directors: Kerri Peters, PhD, BCBA-D & Timothy Vollmer, PhD, BCBA-D

Medical Director: Takahiro Soda, MD, PhD, FAPA

Cincinnati Children's Hospital Neurobehavioral Psychiatry Clinic – Smith-Magenis Syndrome

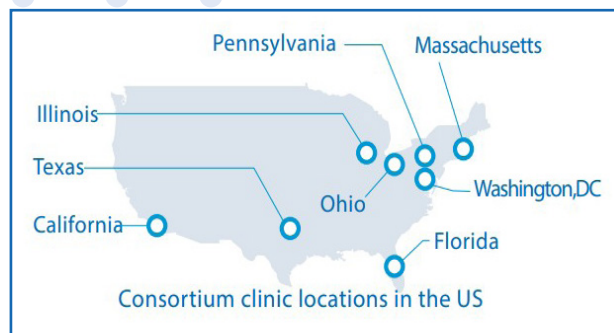
Medical Director: Katie Harris, MD

PRISMS will continue to investigate new opportunities for developing SMS clinics across the United States. To learn more about how to attend one of our eight clinics, click here:

www.prisms.org/wp-content/uploads/pdf/pcrc/PRISMS_PCRC_Clinics_Brochure.pdf



PRISMS Clinic and Research Consortium



PROFESSIONAL ADVISORY BOARD

Margaret Miller, Founding Board Member

PRISMS work would not be possible without the expertise of our outstanding Professional Advisory Board (PAB). In 2024, PRISMS welcomed four new members to the PAB, each of whom brings years of experience in SMS research and treats patients with Smith-Magenis syndrome.

Our new PAB members are:

Sinan Omer Turnacioglu, MD

Cora Taylor, PhD

John Berens, MD, FAAP, FACP

Christopher Vlangos, PhD, FACMG

<https://www.prisms.org/who-we-are/the-team/>

The PAB comprises highly regarded professionals who represent the diverse complexities of the SMS community. The board is an internationally recognized group of scientists, educators, and clinicians with expertise in SMS, genetics, molecular research, education, speech, development, caregiver/siblings, and medical management. PAB members are actively involved in research and/or clinical activities related to Smith-Magenis syndrome, and several members of the PAB are also involved in the SMS Clinics. The PRISMS PAB performs many roles that go beyond the extent of most scientific panels.

The PAB participates in a broad range of SMS research and authors and reviews all of the resources that PRISMS shares with the community. The PAB also offers stringent review over research funding requests and IRB-approved research projects and helps to expand our collaboration with academic and research institutes and industry partners. Their work outshines the limited scope of other such panels. We are truly indebted to the PAB and their dedication to the global SMS community.

The PAB also advises the PRISMS Board of Directors on medical, scientific, educational, and therapeutic matters, and assists in the organization's education and research activities. All of the resources we publish are authored and reviewed by these experts to ensure that these resources meet our standards of excellence. This is how you know you can trust information from PRISMS. (cont.)



(Professional Advisory Board - cont.)

Some of the key online resources our PAB has contributed to are:

Strategies to Address Emotional and Behavioral Challenges in Smith-Magenis Syndrome (SMS) (Published in 2024):
<https://www.prisms.org/education/publications-and-resources/>

Smith-Magenis Syndrome GeneReviews:
<https://www.ncbi.nlm.nih.gov/books/NBK1310/>

PRISMS Medical Management Guidelines & Treatment Recommendations:
<https://www.prisms.org/about-sms/living-with-sms/medical-management-guidelines/>

Our Living with SMS Articles:
<https://www.prisms.org/about-sms/living-with-sms/>

On the Road to Success with SMS:
<https://www.prismsstore.org/>

The PAB also provides input behind the scenes on PRISMS' programs, developing questionnaires for the SMS Patient Registry, reviewing grant applications, and reviewing potential research opportunities for the PRISMS community. The PRISMS Professional Advisory Board is a valuable asset to the Smith-Magenis syndrome community, and we are fortunate to have these professionals serving alongside the PRISMS Board of Directors. We look forward to having the PAB participate in the 2025 PRISMS Research Symposium.



PROFESSIONAL ADVISORY BOARD

- **Ann C.M. Smith, M.A., D.Sc. (Hon), CGC PAB Chair Emeritus**
- **Sarah Elsea, PhD, Chair**
- **Barbara Haas-Givler, MEd, BCBA**
- **Kerry Boyd, MD, FRCPC**
- **Andrea Gropman, MD, FAAP, FACMG, FANA**
- **Christine Brennan, PhD, CCC-SLP**
- **Rebecca Foster, PhD**
- **Santhosh Girirajan, MBBS, PhD**
- **Rachel Franciskovich, MS, CGC**
- **Nancy Raitano Lee, PhD**
- **John Berens, MD, FAAP, FACP, PhD**
- **Cora Taylor, PhD**
- **Christopher Vlangos, PhD, FACMG**
- **Sinan Turnacioglu, MD**

PRISMS' PATIENT REGISTRY DATA USED IN PUBLISHED PAPER

PRISMS PAB member Christine Brennan, PhD, CCC-SLP, published a paper that examined SMS Patient Registry data to compare two groups of individuals with SMS, those with a chromosome 17p11.2 deletion and those with an RAI1 variant.

The aim of the study was to determine if genetic differences influence the communication phenotype and to determine the importance of the RAI1 gene in hearing, speech, and language abilities in children. The results revealed small group differences for hearing status, otopathological findings, mode of communication, voice quality, intelligibility, speech-language abilities, and literacy. Overlap in the speech-language phenotype between groups confirms previous hypotheses that suggest haploinsufficiency (i.e., when the remaining functional copy of the gene is not adequate) of the RAI1 gene responsible for the SMS phenotype and that the RAI1 gene is critical for speech-language development.



The SMS Patient Registry provides a valuable resource for Smith-Magenis syndrome research. The collection of data describes the multiple and complex concerns for individuals with SMS and allows for investigation of the broad range of concerns impacting persons with SMS as well as their families.

These same data can lead to the identification of previously unknown concerns as well as approaches to treatment.

- Dr. Sarah Elsea, PhD, FACMG, Smith-Magenis syndrome researcher for over 25 years

This study has been published and for a limited time is available in full and for free by clicking on the link:

<https://www.sciencedirect.com/science/article/abs/pii/S0021992424000510?via%3Dihub>

SMITH-MAGENIS SYNDROME RESEARCH SYMPOSIUM

Margaret Miller, Founding Board Member

PRISMS 11th Smith-Magenis Syndrome Research Symposium brought together researchers from around the world to share and collaborate on research about Smith-Magenis syndrome (SMS) in Dallas, TX, on July 10-11.

The first ever hybrid symposium hosted researchers from around the globe and allowed for engagement from our in-person and virtual attendees. The symposium also adopted the theme of the PRISMS conference, “Leading the Way Together,” which dovetails with one of the symposium goals:

“Further research by building productive collaborations—including cross-disciplinary dialogue, partnerships, integration of researchers new to SMS, but with interest in specific facets of the syndrome.”

We want to thank Vanda Pharmaceuticals who sponsored the symposium. We are grateful for their continued support and generosity. After a “Call for Abstracts” (research summaries), researchers across many disciplines submitted abstracts which were defined by a strict criterion and then reviewed by the PRISMS Professional Advisory Board. Accepted abstracts were then presented at the symposium. Travel scholarships were granted to some attendees, facilitating attendance for new researchers.

Symposium presenters represented academia and institutes including University of Michigan, McGill University, Emory University, Baylor College of Medicine, NIH/NHGRI (National Institutes of Health/National Human Genome Research Institute), University of Texas, University of Rochester Center for Health + Technology, Rady Children’s Hospital, University of Colorado Boulder, St. Louis Children’s Hospital, University of Florida and Sirius e.V. The presenters were part of a diverse landscape of SMS research from basic science to clinical research and practice. A representative from Sirius e.V. (the SMS parent advocacy group in Germany) also presented. *(cont.)*



(cont.)

(SMS Research Symposium - cont.)

Abstract presentations included oral presentations as well as poster presentations. Valuable time was devoted to discussions and networking between the attendees. PRISMS also welcomed PTLS HOPE Research Foundation (Potocki-Lupski Syndrome), and researchers studying TCF20 syndrome; both also involve the key gene in Smith-Magenis syndrome – RAI1. We call ourselves the “RAI1 group,” and we commit to working together to pursue more research on the impact of RAI1 in these three disorders. We were very happy to include them, and look forward to future endeavors.

We anticipate new collaborations on the horizon as a result of the symposium. We are grateful to our dedicated researchers for their continued work and their commitment to the SMS community.

“I got great feedback on our research and really appreciated the chance to share our work with the SMS community. I especially enjoyed the many interactions with clinicians and SMS parents – this gave me an entirely new perspective on many facets of SMS I had not fully appreciated previously.

It also made clear how impressively strong and tight knit the SMS community is. The whole event was really informative and very well-balanced in terms of the talks and research presented. I feel very privileged to have been included.”

- Michael Sutton, PhD, University of Michigan Medical School



PRISMS' 12TH INTERNATIONAL SMS CONFERENCE



Member of PRISMS Board of Directors getting ready for the conference opening

The PRISMS community gathered for our biennial conference July 11-13 in Dallas, TX, at the Hyatt Regency hotel. The theme of the conference was "Leading The Way Together." It was amazing to see so many SMS families, teachers, researchers, and professionals gathered.

This year's conference included:

374 Conference Attendees

62 Sessions

45 Presenters

69 SMS Individuals

32 Siblings

22 Family Scholarship Recipients

11 Teacher and Support Staff Scholarship Recipients

Families attended from the US, Canada, France, Germany, Scotland, Switzerland, UK, and Mexico.

Our community gathered from across the country and from around the world to learn, share experiences, and support each other.

It was amazing to see so many conference attendees dancing to the music at the welcome reception, conversing between sessions, and sharing stories over ice cream at the end of the conference ice cream social. A special thank you to our sponsors Vanda Pharmaceuticals, Abram's Nation, and all of the other sponsors and donors whose generous donations made the conference possible.





CONFERENCE HIGHLIGHTS



Kevin Sperry speaking at the 2024 SMS Conference & signing autographs

KEVIN SPERRY SPEAKS

Kevin Sperry, a Florida State University quarterback recruit and PRISMS friend, was a keynote speaker at the PRISMS conference. He also played flag football with the siblings, signed autographs, and took pictures. Kevin has been a supporter of PRISMS since the very first day he met Coulter, his friend who has Smith-Magenis syndrome.

POSITIVE EXPOSURE

Rick Guidotti is an award-winning photographer who has spent more than twenty-five years collaborating internationally with nonprofit organizations, hospitals, medical schools, educational institutions, museums, galleries, advocacy groups, and communities to affect a sea-of-change in societal attitudes toward individuals living with genetic, physical, behavioral, or intellectual differences. Rick is the founder and director of Positive Exposure, a nonprofit organization that

promotes a more inclusive world through award-winning photography, film, and educational programs. He remains committed to collaborating with individuals, families, and communities around the world, celebrating the beauty and richness of our shared humanity. Rick has been attending the PRISMS conferences since 2001, and we were so happy he was back with us.



Rick Guidotti from Positive Exposure Gives Keynote Address



Past Presidents (image above) – L to R: Maggie Miller, Connie Bessette, Randy Beall, John Mayer, Brandon Daniel; Exec. Director Michelle Larscheid



Volunteer Award Recipients (image above) – L to R: Sylvia Farber, Exec. Director Michelle Larscheid, Jean Bishop

VOLUNTEER AWARDS

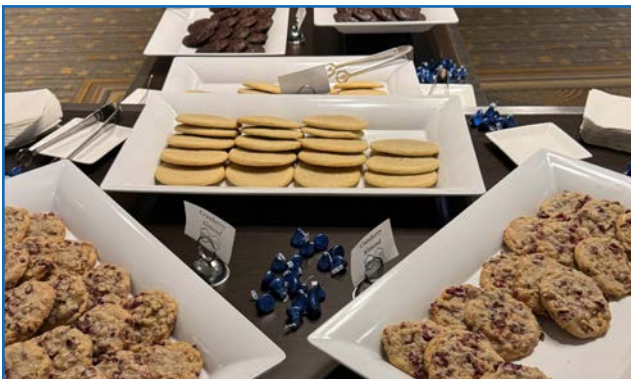
Leadership and Outstanding Volunteer Awards were presented to individuals who demonstrated exceptional dedication and commitment to PRISMS. Without the contribution of these volunteers, PRISMS would not have been able to achieve and sustain the level of

impact we have had in our community. These awards were in recognition of the tireless efforts of our volunteers in community leadership and fundraising.

SPONSORED COOKIE & ICE CREAM BREAKS

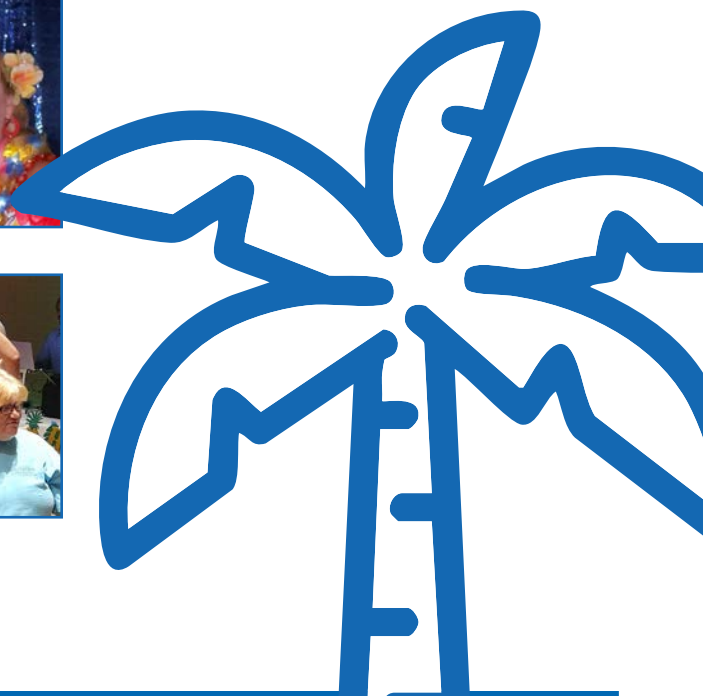
Alayna's Heart Foundation (<https://alaynasheart.com/>) donated money for family scholarships, a cookie break, and goodie bags for the siblings, childcare, and the den. Alayna was 3.5 months old when she was diagnosed with SMS and died shortly after of SIDS. Alayna's family started a foundation to improve the quality of life for children and adults with special needs and their families, with a special focus on those in the Smith-Magenis syndrome community. The Kevin O'Connor Family Fund donated money for family scholarships and also sponsored a cookie break in honor of Deane O'Connor.

The ice cream social was sponsored by the Percy Huston family in honor of their daughter, Jacqueline Huston. Conference attendees enjoyed a cool treat while socializing and recapping the three-day conference.



PRISMS HAWAIIAN FUNDRAISER

The Hyatt Regency ballroom was transformed into a Hawaiian Luau for the PRISMS Fundraiser. More than 100 people gathered for food, dancing, photo booth fun, and games. The fundraiser was sponsored by Vanda Pharmaceuticals and raised \$20,000 for PRISMS.



REGIONAL REPRESENTATIVES MEET UP AT THE CONFERENCE

15 PRISMS Regional Representatives attended the conference. They met in a session to discuss the upcoming year and how they can best help families in their region. Merlin, the therapy dog, even joined them.



PRISMS MERCHANDISE STORE

New merchandise was available for purchase throughout the conference. If you were not able to attend in person, you can purchase items from our online store at www.prismsstore.org.





PROFESSIONAL ADVISORY BOARD

PRISMS' Professional Advisory Board attended both the Research Symposium and the PRISMS Conference. Many of them gave presentations, consulted at the Curbside Consult sessions, participated in the fundraiser, and attended the PAB luncheon.

NEW! PRISMS PATHWAY

The PRISMS Pathway, an exhibit hall dedicated to PRISMS resources for our families and caregivers, was new at the conference this year.

We provided our families with a "Passport to PRISMS" card at registration. When families visited each of the 12 resource tables, they received a stamp for their visit. When the passports were completed, they were turned in at the merchandise table to receive a gift, and their completed passports were entered into a drawing for a grand prize.

The goal of the PRISMS Pathway was to be a place to ask questions, get more information, and make contacts. Information on our clinics, volunteering, the Board of Directors, research, and more was available.



FIRST STEPS SESSION

The First Steps session was created to welcome, engage, encourage, and support families attending the conference for the first (or second) time. The hope is that this session welcomes families into the

community, connects them with parents who have faced the same challenges, helps them navigate the conference, and allows them to discuss their experiences with Parent Ambassadors throughout the conference.



Parent Ambassadors: Carlton Bale, K. Nicole Harter-Bale, Kayla Beecher, Diane Erth, Lauren Mollerup, Denien Rasmussen and Natasha Schaller

First Steps Co-Chairs and Speakers: Allison Stephanouk, Charlene Michaud, Jason Michaud, and Dr. Ann Smith

TEACHER & FAMILY SCHOLARSHIPS

Part of PRISMS' mission is to be able to provide a conference that is cost-accessible for our community, as we believe in the importance of families and support staff being able to engage and learn together. Through the generosity of our donors and sponsors, we were able to continue our scholarship programs. PRISMS was able to provide some level of financial support to 24 families through our family scholarship program as well as 12 teacher and support staff members through our teacher and support staff scholarship program.

These grants help support staff receive training from SMS experts in the fields of education,

behavioral support, vocational training, job coaching, and genetics. This grant program was offered in conjunction with the Teacher Training Workshop that was presented by PRISMS Professional Advisory Board member Barbara Haas-Givler, MEd, BCBA, Geisinger Autism & Developmental Medicine Institute, and a panel of education professionals.

We extend our deep appreciation to all our donors and sponsors for your support of the 12th PRISMS International Conference. We look forward to continuing our family and teacher scholarship program at our 13th PRISMS International Conference in Minneapolis, MN, in July 2026.

I thoroughly enjoyed my time at the PRISMS conference in Dallas. The experience was overwhelming in the most positive way. As a professional, I have never attended a conference with such a family-focused agenda. The amount of support for families was very impressive. I loved the variety of sessions and discussions available. I hope more organizations can expand to what PRISMS is doing.

- Kelly Long, Teacher

SIBLING PROGRAM

In 2022, PRISMS launched a new conference program dedicated to our remarkable siblings. Ten siblings participated in that first year, and we offered nine sessions/activities to gauge interest in our new program. We received excellent feedback and spent the next two years improving and building upon the success of 2022.

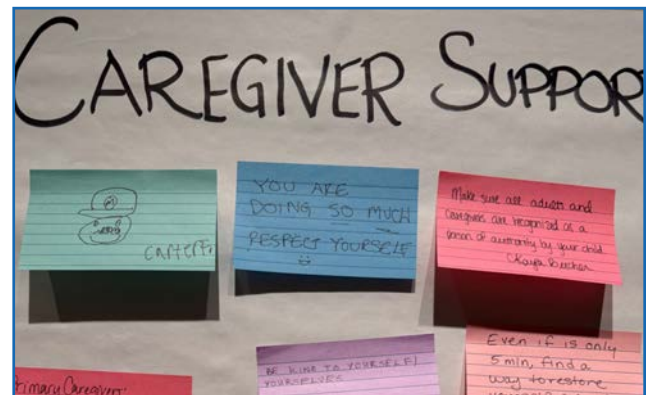
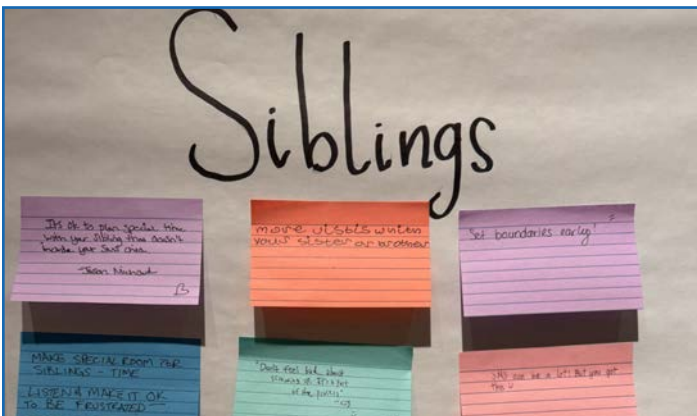
In 2024, over 30 siblings participated in an expanded program with sessions and activities specifically designed for our amazing siblings. We introduced a Siblings First Step session to welcome our siblings and set the tone for the conference. New sessions were added, including "The Sibling Experience," presented by Alyssa Dickerson, sibling to Colby. She shared her story with the group and facilitated an open dialogue to foster support and encouragement among the siblings.

In addition to new sessions, we added some fun new activities, including a flag football game with incoming Florida State quarterback Kevin Sperry and a poolside luau with ice cream and music. The expanded program was well received and we are excited to incorporate the feedback into our planning for the 2026 conference.



"WHAT WORKS" WALL

At the 2024 conference, we invited attendees to give us tips or tricks for the "What Works Wall." PRISMS has combined these tips to help loved ones navigate their surroundings, participate in activities, and enjoy life. These are meant to be helpful suggestions from your peers, not fact-based research. PRISMS has compiled the list to share with our SMS community here: <https://bit.ly/4guj3Og>



PRISMS WEBINARS

Allison Stephanouk, Education Chair

The PRISMS Webinar series is created by the PRISMS Education Committee, whose goal is to establish new platforms that more dynamically bring educational information and resources about Smith-Magenis syndrome to the community-at-large (via social media, technology and others), and encourage/activate engagement between families and professionals.

In 2024, PRISMS produced two webinars:

October 8th - Government Benefits 101 - Understanding SSI and Medicaid, SSDI and Medicare, and Childhood Disability Benefits.

Presenter: Allison Schaberg, Owner & Managing Partner of Consolidated Planning Group (CPG)

In this webinar, SSI & Medicaid, SSDI & Medicare, and Childhood Disability Benefits were reviewed. Also presented were when and how to apply, how to be prepared for your appointment, and how to maintain eligibility going forward. Attendees learned how to maximize benefits for their families. Many of our children with disabilities do not qualify for SSI & Medicaid as minors. The landscape changes when they turn 18. This webinar covered how to maximize your benefits, whether you are already receiving them or need guidance on how to get started.

December 9th - Building Bridges and Navigating Adult-Based Healthcare for Individuals with Developmental Disabilities

Presenter: John Berens, MD, FAAP, FACP

Assistant Professor, Center for Transition Medicine, Department of Medicine-Baylor College of Medicine

Numerous challenges make the transition from pediatric to adult-based healthcare difficult, particularly for individuals with intellectual and developmental disabilities. This webinar reviewed some of these barriers, discussed the lessons learned and experience of an adult primary care clinic caring for this population, and reviewed a framework that individuals and families can use to navigate the complex healthcare system.

If you'd like to view these and other webinar recordings, please visit:

<https://www.prisms.org/education/webinars/>



Building Bridges and Navigating Adult-Based Healthcare for Individuals with Developmental Disabilities

Monday, December 9
7:45 PM Eastern Time

Presenter: John Berens, MD, FAAP, FACP
Assistant Professor, Center for Transition Medicine, Department of Medicine-Baylor College of Medicine

REGIONAL REPRESENTATIVE PROGRAM

By Denien Rasmussen, Regional Representative Chair

The PRISMS Regional Representatives program is continually growing and evolving. Our Regional Representatives are PRISMS community members who volunteer their time and care deeply about our community. They want to assist others with similar needs or issues or just a safe space to vent to people who understand their lives.

We currently have over 48 Regional Representative Volunteers in our program. We also have 14 international regional reps, including Canada, Australia/New Zealand, Israel, Brazil, Italy, Mexico, Puerto Rico, Romania, Singapore, Russia, and the United Kingdom, to name a few.

PRISMS continues to have our quarterly Zoom meetings where we discuss many things, some of which are:

- **Newly diagnosed families and how to support them**
- **Hetlioz medication for sleep**
- **Topics for the upcoming 2026 PRISMS conferences**
- **New SMS clinics**
- **Social media**
- **Resources and state benefits; how to find them in your region**
- **Awareness materials**
- **Hosting fundraisers**
- **Ideas for regional get-togethers**
- **Upcoming webinar topics**

The quarterly Zoom meetings have been incredible, and we appreciate the reps' participation in the calls. They have been highly informative to PRISMS by providing an on-the-ground regional view of what families are dealing with and looking for from PRISMS.

In 2024, we had our 12th PRISMS International Conference in Dallas, Texas. The conference was a huge success. PRISMS tried something new at the conference called PRISMS Pathway. We had an exhibit hall dedicated to PRISMS resources, including the Regional Representative table, where Regional

(cont.)



(Regional Representative Program - cont.)

Representatives and I were stationed throughout the conference. This allowed families to stop by, meet us, learn more about our program, and find out who their Regional Representatives were for their area. We had over 100 people stop by the table.

I want to give a special thanks to Laurie Bellet & her therapy dog Merlin, Maria Carrancedo, Jean Bishop, and Michele Zdanowski for helping man the table.

Regional Representatives 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 log in to our fabulous webinars**
- **Encourage families to join our PRISMS community - which is free**
- **Encourage families to attend our conferences and local meet-ups**

I am so proud to work with this fantastic group of people. I look forward to every opportunity I have, whether it is 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 get in touch with us at info@prisms.org.

We currently need Regional Representatives in Oregon and Nevada. If you are interested or know someone who might be interested, please contact us at info@prisms.org.



REGIONAL REPRESENTATIVES

Delma & Alejandro Aguilar

Leah Baigell

Kara Bale

Eliane Barros

Cally Bauman

Mary Beall

Tracie Belcher

Abigail Bell

Laurie Bellet

Jean Bishop

Sabrina Bisiani

Heather Boney

Kristine & Glen Braden

Debbie Brooks

Maria Elena Carrancedo

Ashton Cheramie

Ilse Ciprich

Amanda Collins

Esteban Delgadillo

Brenda Dickerson

Amanda Downey

Roxana Dragan

Diane Erth

Maria Feagin

Rhonda Franklin

Noémie Grebler

Trevor Gritman

Mary Hards

Sheila Hernandez Vale

Kim & Eric Hoffman

Bernadette Huston

Linda Johnson

Jennifer Klump

Carissa Le

Allison Leatzow

Charlene Liao

Patty Loyer

Callihan Marshall

Lori Martin

Erin Morrison

Amy Myers

Kevin O'Connor

Mick Pearson

Sasha Piastro-Tedford

Denien Rasmussen

Marni Rolston

Laura Russell

Brianna Ryczek

Rao Sankar

Natasha Schaller

Theresa & Mark Smyth

Randi Tanenbaum

Bela and Alexander Tzetlin

Osman Umarji

Martina Vitt

Barbara Watson

Brooke Widmer

Brandi Wilson

Kim Wirth

Ana Witherspoon

Jill Wood

Bill Yates

Michele Zdanowski



MEET UPS

NORTH CAROLINA

In August, seven SMS families met in High Point, North Carolina, for fun at Q's Corner (a local play gym designed for people of all abilities). The kids had fun playing, and the adults got to catch up and enjoy a potluck lunch. Michelle Larscheid, PRISMS' Executive Director, got to join in the fun.



A group of North Carolina families also met in High Point, NC, on December 7 for some holiday fun at Q's Corner. Santa was the special guest of honor and was greeted with many holiday hugs. The kids enjoyed some snacks, gifts and fun play time while the adults took part in some adult conversation.



NORTHERN CALIFORNIA

Laurie Bellet hosted the annual Northern California (and beyond) SMS Family Gathering in Walnut Creek, California. There were about 40 SMS family members in attendance, most of whom have been getting together since the late 1990s. The event was held at Heather Farm Park, a beautiful space with a huge, all abilities playground.



SOUTHERN CALIFORNIA

PRISMS Board member Diane Erth organized a Southern California meetup at Mission Bay Park in San Diego. It was a hot day, but 11 families (including 11 SMS individuals) met for a potluck and to cool off with a swim. Total attendance was about 50 people who gathered to socialize and have fun with their local SMS community!



TEXAS

Cecilia Poole hosted an annual SMS Fun Day at Morgan's Wonderland in San Antonio, TX. Family members, as well as 8 SMS individuals, enjoyed the day. Everyone enjoyed the main park, including the new zipline.

After enjoying the main amusement park, everyone cooled off at the Inspiration Island waterpark, where they enjoyed the five colorful and varied splash pads. Afterward, families met up at Two Brothers Barbecue nearby and enjoyed visiting and eating the delicious food.



CONTINUED WORK WITH ADVOCACY PARTNERS

In 2024, PRISMS continued its collaborations with global advocacy partners. PRISMS continues to strengthen these alliances and seeks to expand its circle of researchers, advocates, and adjacent rare disorders. PRISMS envisions a society of like-minded thinkers who have similar goals of advancing the research of not only SMS but other rare disorders. These partnerships help drive awareness and research of Smith-Magenis syndrome and thus help advance PRISMS' mission.

COMBINEDBrain

PRISMS continues to work with COMBINEDBrain as a Patient Advocacy Organization. As a member of COMBINEDBrain, we join forces with other rare neurodevelopmental disorder organizations to advance research by engaging with pharmaceutical companies, research institutes, and industry representatives. When we collaborate with other neurodevelopmental disorders, we accelerate research by widening the scope and reach of new researchers and unlocking undiscovered data. It is imperative that SMS is not studied in a vacuum or only



in isolation. Valuable research requires many tools (basic science, clinical, and longitudinal data), and today's research is better served when studied in a consortium and in collaboration with other disorders.



Brain Donor Project

The Brain Donor Project

In 2018, PRISMS partnered with The Brain Donor Project to raise awareness about the critical need for this type of donation to research neurological disorders and brain disease. While this is a very difficult topic to consider and discuss, it is important that brain donation be included as a part of the research on Smith-Magenis syndrome. The Brain Donor Project is working with PRISMS to further the science of brain disease. "BDP" works as a conduit for potential brain donors by raising

awareness of the urgent need for this precious resource and by simplifying the process of donating. The Brain Donor Project was developed exclusively to support the NeuroBioBank of the National Institutes of Health (NIH) in making available high-quality, well-characterized donated post-mortem brain tissue to neuroscientists.

Since 2018, the Brain Donor Project has been widely recognized as an advocate partner with many organizations like PRISMS and is dedicated to advancing research in neurodevelopmental disorders. The Brain Donor Project has made the process as easy as possible, and all arrangements can be made years and years in advance. PRISMS recognizes that it can be distressing to even consider such a donation, but PRISMS is dedicated to sponsoring all research, and the research landscape should include this type of donation. For more information: <https://www.prisms.org/research/active-research/brain-donor-project/>



PATIENT WORTHY

PRISMS continues to be an advocacy partner with Patient Worthy. Patient Worthy's mission "is to amplify the voices of rare disease families and the advocacy groups which serve them." Patient Worthy has published over 20,000 articles on rare diseases and shared them across all the primary social media platforms. This includes sharing patient stories, publicizing new developments in treatments, genetic testing, or other advances, and advertising your webinars, patient meetings, and scientific conferences. They reach over 50,000 people every day on their website and more than 2.2 million every

week on social media. Approximately 42% of their readers are from the global community, as rare disease knows no boundaries. Patient Worthy has over a hundred patient advocacy groups who partner in teaching and reaching other families, researchers, physicians, and industry.

Patient Worthy partnered with us for SMS Awareness Day and increased our social media presence in volumes, and shared our website and resources with new families and professionals. The impact of their work has increased PRISMS outreach and has expanded our circle of advocates. We look forward to more endeavors with Patient Worthy.



RARE REVOLUTION

PRISMS is a charity partner with RARE REVOLUTION. RARE REVOLUTION is an international not-for-profit media company specializing in rare disease content. RARE REVOLUTION has a digital platform that allows rare disease organizations to share information about the disorder via online content, social media, video, and the online magazine RARE REVOLUTION Magazine. PRISMS' partnership with RARE REVOLUTION allows us to expand our reach across the globe and share valuable SMS resources with every corner of our community. In November of 2024, RARE REVOLUTION Magazine featured PRISMS on SMS Awareness Day, and through a series of social media posts throughout the day, PRISMS was able to raise awareness and celebrate our community. We have more social media events planned with RARE REVOLUTION and are grateful for their support.



RAI1

In 2024, PRISMS embarked on a new partnership with members of PTLs Hope Research Foundation (Potocki-Lupski syndrome) and TCF20 syndrome. All three syndromes share a common factor with the RAI1 gene, which is the causative gene for SMS and PTLs and is paralogous to the TCF20 gene. We invited the founders of PTLs Hope, along with researchers of PTLs and TCF20, to form an alliance. The common thread of advancing research of all three disorders is our shared goal, and we were aligned in creating new opportunities to work with each other and expand our circle of experts. Members of PTLs Hope Research Foundation and TCF20, including researchers, attended the PRISMS 2024 symposium and conference in Dallas, TX. We are excited about new research opportunities that will elevate the RAI1 Group and lead us all to a path of new discoveries.

VOLUNTEERS

General Volunteers:

Kristine Braden
 Pat Boschetto
 Tabitha Dostal
 Kerrie Slattery
 Steve Tanenbaum

Michelle Larscheid
 Jason Michaud
 Margaret Miller
 Amy Pereira

Tech Work Group:

Carlton Bale
 Robert Duvall
 Margaret Miller
 Scott Miller
 Allison Stephanouk

Conference Volunteers:

Mary and Randy Beall
 Dawnda Daniel
 Ridge Daniel
 Alyssa Dickerson
 Brenda Dickerson
 Sandra Edward
 Ryne Farber
 Doris Fuller

Advocacy Workgroup:

Leah Baigell
 Barclay Daranyi
 Melissa Haley
 Percy Huston
 John Mayer

Fred Henninghausen
 Mary Henninghausen
 Jessica Kirklin
 Rachel Kirklin
 Dalton Lee
 Michelle Lee
 Charlene Michaud

Conference Committee:

Kayla Beecher
 Pat Brown
 Athenna Harrison
 Lynda Kilian

Brian Pereira
 Kaitlyn Pereira
 Alex Stephanouk
 Catherine Stephanouk
 William Stephanouk



BOARD

EXECUTIVE COMMITTEE:

Percy Huston, President
Jackie Fallenstein, Vice President
Phil Ruedi, Treasurer
Diane Erth, Secretary
Maggie Miller, Founding Member
Brandon Daniel, Immediate Past President

BOARD MEMBERS:

Allison Stephanouk, Education Committee Chair
Denien Rasmussen, Regional Representative Committee Chair
Michelle Lee, Awareness Committee Chair
Sarah Elsea, PhD., Professional Advisory Board Chair
Amy Pereira, Board Member at Large
Jason Michaud, Board Member at Large
Eric Rogers, Board Member at Large

STAFF

Michelle Larscheid, Executive Director
Lynda Kilian, Office & Communications Manager

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GuideStar Listing:

<https://www.guidestar.org/profile/shared/2b650bf5-20dc-4129-b436-c853de7ed0d5>

Thanks to the generosity of our supporters, we have accomplished many things this year, but our work is far from over. As more families are being diagnosed with SMS and our organization continues to grow, we must continue to expand our efforts. You can make a lasting difference today. Please consider donating to support our mission and help us reach even more people in the coming year. Visit www.prisms.org/donate to make a donation. Together, we can continue to lead the way. Thank you for your support.

DONATION MAILING ADDRESS:

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

This report was made possible by contributions from:

Michelle Larscheid, Executive Director
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PRISMS Board of Directors
Mike Sorenson, Graphic Designer
Pat Boschetto, Proofreader
Many photos throughout this annual report are courtesy of Rick Guidotti, Positive Exposure

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, MD, 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.

