Parents and Researchers Interested in Smith-Magenis Syndrome

# ANNUAL REPORT 2025

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# PRISMS 2025 ANNUAL REPORT

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# MISSION

Parents and Researchers Interested in Smith-Magenis syndrome (PRISMS) is dedicated to providing information and support to families of individuals with Smith-Magenis syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness, understanding, and treatment 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 we turn the corner of yet another year at PRISMS, I can't help but marvel at the generosity of our community. 2025 was a benchmark year for PRISMS in continuing to raise funds to support all of our important initiatives. I cannot say enough about our generous families, especially those who take on individual fundraising initiatives to support our organization. Along with all our "grass root" efforts, we cannot reach our fundraising initiatives without our generous sponsors, led by Vanda Pharmaceuticals, who continue to support our efforts year after year.

Organizationally, fundraising does not happen without good leadership, and we are blessed to have two of the best in Jackie Fallenstein and Michelle Larscheid. Jackie serves as our V.P. and Director of Development, while I'm sure many of you know Michelle is our Executive Director and the face of our organization. I cannot thank them both enough for all they have done in the area of development and relationship building for PRISMS.

As an organization with an all-volunteer board, I can never thank or recognize them enough for all their behind-the-scenes hard work. As 2025 draws to an end, so do the terms of two of our board members, Brandon Daniel and Michelle Lee. I want to take this opportunity to thank them both for their years of service to our organization and for their continued support. They both will be missed, but certainly not forgotten. It has been my privilege to serve PRISMS for yet another year as President, and I look forward to 2026.

I want to send a special thank-you for the dedication and hard work of both our Regional Representatives and our PAB (Professional Advisory Board). These groups are essential to our continued growth and success. But even more importantly, we need all of YOU. Get involved, participate, join our Patient Registry, organize a fundraiser, or join one of our committees. The possibilities are endless, and we would love to have you all involved in some capacity. In closing, 2026 will give us the opportunity to host yet another international conference. It will be held in Minneapolis, which should be very convenient for many of our families, and if you have not attended one of these, I cannot stress enough the importance of coming or the impact it can have on your SMS journey through life. Come and join us as we hope to be "Shining a Light and Igniting Hope" for all of you!





# MESSAGE FROM THE EXECUTIVE DIRECTOR



***Michelle Larscheid, Executive Director***

This past year has been one of remarkable growth — growth in our reach, our impact, and our vision for the future.

In October, the PRISMS Board of Directors had a productive meeting in Boulder, Colorado, immediately following the successful Research Symposium. Plans were developed to guide the organization's strategic direction for 2026 and beyond. Our goals are clearly mapped out: Financial Excellence, Programming Excellence, Governance Excellence, and Leverage Research and Related Opportunities.



This plan will guide the organization through its next phase of growth over the next 3 years. The goals within this plan are robust, with the aim of continuing to advance PRISMS' mission and vision well into the future. Sustainable growth requires both vision and stewardship, and we remain committed to both. We look forward to working towards meeting these goals and ensuring PRISMS remains a leader in the SMS Community and beyond.

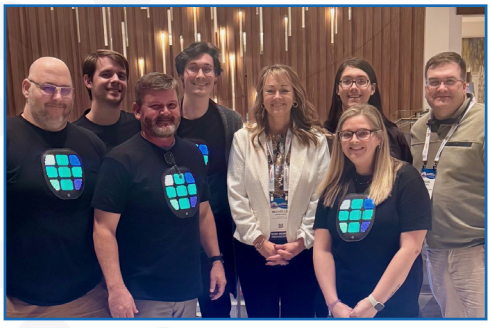



The momentum we are experiencing is only possible because of you — our families, donors, volunteers, and advocates. Your belief in our mission fuels our progress, and we want to ensure that every family feels seen, supported, and empowered.

I look forward to being together again as an SMS family at the 13th International Smith-Magenis Syndrome Conference in Minneapolis, July 30 - August 1, 2026.

With gratitude and optimism,

Michelle Larscheid



# FINANCIAL REPORT

***Phil Ruedi, Treasurer***



2025 was a strong year for PRISMS from a financial perspective. Generous donations plus financial support dedicated to the upcoming 2026 conference drove revenues to a level not seen before in a non-conference year. The resulting positive net income puts PRISMS in an excellent position to fund the conference while also dedicating more resources to support SMS research.

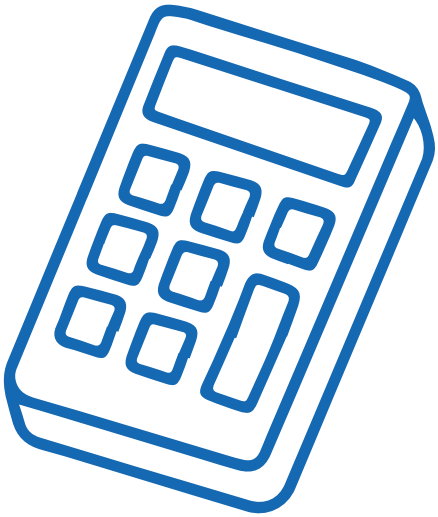
Revenues in 2025 slightly exceeded $400,000 and were 15% above our original budget. Individual donations were down slightly year over year, which is to be expected when comparing a non-conference year to a conference year. One area that is particularly exciting is the growth of the 17p11.2 Society. Revenues increased by 24% in 2025 on the back of a 17% increase in 2024. The society now provides almost $30,000 in revenue to fund programs and operations. Revenues also benefited from over $50,000 in donations in 2025, specifically restricted to support the 2026 conference.

As a fiduciary of the funds provided by you, our donors, PRISMS has also made a strong commitment to monitor and control expenses. In 2025, PRISMS invested funds in support programs, the patient registry, and an enhanced website. We are proud that total expenses in 2025 were just $120 above the $340,000 budget, while revenues were over $60,000 higher! Thank you to our Executive Director, Michelle Larscheid, for her focus and discretion.

Entering 2026, PRISMS is budgeting for an operating loss of $113,000 after generating income of $66,000 in 2025. We have a goal of achieving a financial cadence that generates enough income in non-conference years to fund our "investment" in the conference. Our 2025-2026 performance would be the closest that we will get to this goal in this post-COVID era, where the cost of the conference has gone up substantially due to higher hotel costs, especially around food and beverage. PRISMS also expects to make a substantial investment in the patient registry in 2026, and these expenses are already included in the budget.

PRISMS finished 2025 in a strong financial position with $650,000 in liquid assets, which will support operations and fund the conference. Budgeted expenses in 2026 are $663,000. These funds also offer PRISMS the ability to be opportunistic in investing in research and new programs to benefit our families. Returning to the importance of being a fiduciary of the assets you have provided, PRISMS has implemented further budget controls in 2026. Recognizing that a conference year is a year of investment but also understanding the need for financial discipline, the PRISMS Board has approved a guideline in no year will a budgeted operating loss exceed 20% of the prior year's ending liquid assets. This will help ensure the organization can fund its fixed costs and maintain its future financial viability.

PRISMS greatly appreciates the support from our community and its growth over the past few years. It is an honor to be a member of the PRISMS Board and serve our community in the position of Treasurer.



# prisms BY THE NUMBERS

**12** INTERNATIONAL CONFERENCES

**12** RESEARCH SYMPOSIUMS

**15** PROFESSIONAL ADVISORY BOARD MEMBERS

**57** REGIONAL REPRESENTATIVES

**9** SMS CLINICS

**5,000+** VOLUNTEER HOURS THIS YEAR BY DEDICATED PARENTS + PROFESSIONALS

**4** SPECIALIZED GUIDEBOOKS

**4** SUMMER SCHOLARS

**32** YEARS SERVING THE SMITH-MAGENIS SYNDROME COMMUNITY

# SPREADING AWARENESS

***Michelle Lee, Awareness Chair***



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

The year started with a celebration of National Hug Day. Our SMS individuals give the very best hugs! In February, PRISMS celebrated its 32nd birthday. PRISMS is proud of the legacy our founders and families have created, and we are honored to have their continued involvement today.



On February 27, PRISMS participated in an event in support of Rare Disease Day at Texas Children's Hospital. Information about SMS was handed out, and a table was shared with our PTLS Hope Research Foundation friends.

Throughout the year, PRISMS continued to raise awareness through various forms of social media, including Facebook, Instagram, and blog stories. These platforms were utilized to keep our Smith-Magenis syndrome families informed about research and events.






The month of November saw us gear up for Smith-Magenis syndrome Awareness Day on November 17. PRISMS shared facts, personal stories, and fun activities in support of SMS.

For this year's theme, we flashed back to an old favorite, "Hug or Be Hugged". It was our best year ever for shirt sales, which helped raise funds for PRISMS. The PRISMS Board could be seen wearing their SMS Awareness Day shirts when they gathered to take photos during the in-person Board meeting in Colorado.

(Cont.)

*(Awareness - cont.)*

During our awareness month, PRISMS was given the privilege by Rare Revolution Magazine of hosting a Takeover Tuesday, during which we shared facts and research on Smith-Magenis syndrome on their organization's social media outlets.

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

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 to our SMS community for hosting events, launching fundraising, and amplifying our message. You help play an important role in building understanding, promoting advocacy, and encouraging collective action on SMS awareness day.

Global Genes®
Allies in Rare Disease

NORD®
National Organization for Rare Disorders









# BRIAN PEREIRA MEMORIAL FUND

Those privileged to know Brian Pereira recall him as a gentle giant—someone whose presence brought comfort, whose actions inspired trust, and whose unwavering kindness left an indelible mark. His journey through life was defined by a steadfast dedication to his family, friends, and, in particular, the PRISMS community.

In memory of Brian's remarkable life, the Brian Periera Memorial Fund was established to recognize and support a unique group: siblings of those affected by Smith-Magenis syndrome. These individuals walk a path shaped by both challenge and love. The fund seeks to honor siblings who, like Brian, demonstrate empathy, resilience, and a profound sense of responsibility—not just within their families, but within the wider SMS and PRISMS communities.

In 2025, PRISMS awarded two recipients with an inaugural Brian Pereira Memorial Grant. Each recipient received $1,500 to be applied toward tuition at their chosen post-secondary institution.

**Avery Zemlack**
My name is Avery from Pacific Palisades, CA. I'm 18 years old and in the fall, I will be starting as a freshman at the University of Colorado at Boulder! I love to cook, spend time with friends and family, dance, shop, listen to music, and more! When I was 3 years old, my younger brother, Logan, was born, and when I was 5 years old, he was diagnosed with Smith-Magenis Syndrome. Anyone living with someone who has SMS knows that it inevitably changes your life. Over the past 15 years, I have chosen to find out how Logan and his diagnosis can change my life for the better.

Being a sibling to someone with special needs is no small feat, but the lessons I have learned, the communities I have supported and been supported by, and the person I am because of it makes every challenge worth it. Throughout the course of my life, I have held many titles from daughter to friend to student, yet my favorite and proudest will forever and always be "Logan's sister." I am truly filled with gratitude for receiving the Brian Pereira Memorial Fund Grant and I would like to greatly thank PRISMS for honoring me and for all the work they do for the SMS community. You are all so important to our community.

(cont.)





*(Brian Pereira Memorial Scholarship- cont.)*

**Sophia Gerberg**

My name is Sophia Gerberg. At six weeks old, my sister, Abby, who has Smith-Magenis syndrome, underwent open-heart surgery, an experience that became a defining moment not just in her life, but in mine. I was young, but I remember the hospital visits, the fear in my parents' eyes, and the strength it took for our family to move through each uncertain day. From that moment forward, I began to see the world through a different lens: one shaped by love, advocacy, and the deep desire to make things better for her.



Growing up as her older sister, and one of her primary caregivers, taught me more than any textbook ever could. I learned how to interpret her needs when she couldn't express them. I learned to celebrate small victories, to practice patience even on the hardest days, and to stand up for her when the world didn't understand her. These lessons shaped the core of who I am: someone who leads with empathy, finds strength in service, and believes that care must extend far beyond clinical knowledge. Everything I do, I do with her in mind. She is my why. She is the reason I don't give up, even when the road is hard. I want to build a life where I honor her, every single day, not just in memory, but in action. And one day, I hope to care for children like her, with the same tenderness and hope that my family always fought for her to receive.



*The Brian Pereira Memorial Fund stands as a living tribute, not only to the man for whom it is named, but to the enduring spirit of compassion, integrity, and perseverance that he embodied. If you would like to contribute to this fund in honor of Brian, you can make a donation here: [www.prisms.org/donate](www.prisms.org/donate)*

# DEVELOPMENT UPDATE

*Jackie Fallenstein, Vice President, Development Chair*



**Smith-Magenis Syndrome Awareness Day Match**

In November, in recognition of Smith-Magenis Syndrome Awareness Day, a dedicated group of community members generously offered a $25,000 matching gift challenge. Their leadership inspired an outpouring of support from PRISMS donors, who responded with great enthusiasm. Together, our community not only met the match but far exceeded it—raising more than $81,551 to support research, resources, education, and direct support for families impacted by Smith-Magenis syndrome. Thank you to our matching-gift donors for leading the way, and to everyone who gave and helped make this campaign a meaningful success.




**17p11.2 Society**
The 17p11.2 Society is a dedicated community of donors who have chosen to support PRISMS through monthly gifts of $17 or more. These steady contributions provide a predictable income throughout the year. We are deeply grateful to each member of the 17p11.2 Society for your commitment, generosity, and belief in our mission. You are truly helping strengthen our community month after month. To join the 17p11.2 Society, go to https://www.prisms.org/get-involved/17p11-2-society/

**Memorials and Bequests**
PRISMS is deeply honored to have received many memorial gifts in tribute to loved ones within our community who have passed this year. We extend our deepest condolences to their families and friends, and we are sincerely grateful they chose to honor their loved ones by supporting PRISMS and its mission.

A number of community members have also chosen to remember PRISMS in their wills or estate plans. A planned gift is a meaningful way to ensure individuals and families impacted by Smith-Magenis syndrome continue to receive support, information, and resources into the future. For information on including PRISMS in your plans, email info@prisms.org.

**Donor Advised Funds**
The use of Donor Advised Funds (DAF) has greatly increased in popularity among donors in recent years. We extend a sincere thank you to the many donors who have designated PRISMS as a recipient this year. We appreciate your dedication to our mission.

If you choose to designate PRISMS as a beneficiary for your DAF, please inform PRISMS so that we can ensure personal acknowledgement. If you would like to learn more about using a DAF for the benefit of PRISMS, contact your financial advisor.

# PRISMS 17p11.2 SOCIETY

The 17p 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. Society donations grew 24% in 2025, with contributions from over 70 community members. Thank you to all our 17p Society members.

Current members who would like to increase or adjust their monthly giving can do so easily by emailing their request to: info@prisms.org.

## 17p11.2 Society Members

Leah Baigell
Kayla Beecher
Connie Bessette
Danielle Bier
Pat Boschetto
Kristine & Glen Braden
Ellie Burnett
Lauren Carney
Maria Carrancedo
Daniel Cocilova
Sharon Cook
David & Nancy Cordrey
David Crummey
Kevin Daly
Barclay Daranyi
Patty Davis
Alyssa Dickerson
Brenda Dickerson
Dennis Dillon
John Doherty
Angela Eaton
Sarah Elsea
Jana Epperly
Diane Erth
Jackie Fallenstein
Sylvia Farber
Manuel Faria
Alexander Hake
Tera Hickle
Daniel Howell
Percy Huston
Paula Jump
Lynda Kilian
Bonnie Krautheimer
Michelle Larscheid
Josephine Lawlor
Allison & Mike Leatzow
Michelle Lee
Patty Loyer
Lisa & Michael Mariano
Jessie McClintock
Charlie & Tina McGrevy
Alicia & Scott Miller
Scott Miller
Mike & Trinity Miodunski
Robyn Mogul
Michele Narveson
Kevin O'Connor
Bonni Pellicciotti
Charles Penn
Vanessa Plascencia
Denien Rasmussen
Gail & David Reiner
Cherisse Rodriguez
Rhonda Roos
Victor Roos
Mr. & Mrs. Jeremy Rude
Philip Ruedi
Leann Santiago
Carmela Saunders
Eric Schaller
Caitlin Seldon
Brian Settle
Allison Stephanouk
William Stephanouk
Steven Tanenbaum
Stephanie & Mark Tonsoni
Osman Umarji
Martina Vit
Debi Waters
Mary Ann Zimmer

# 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 15 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.












**Heather Sievers Birthday Fundraiser**
Thank you to Heather Sievers for hosting a birthday fundraiser for PRISMS in honor of her daughter, Rowan. She raised almost $800 with her efforts.

**Bardsley Lemonade Fundraiser**
Michelle Bardsley's family hosted their 2nd annual neighborhood bake sale in Utah. The weather was beautiful, and they had a steady stream of donations. They raised almost $1000.

**Deleo Lemonade Stand**
Alana DeLeo held a lemonade stand fundraiser for PRISMS in honor of her niece, Angelina Ulwick, in August. This was the 2nd year the lemonade stand has been part of an annual "Family Day" event at Wingaersheek Beach in Gloucester, MA. At least 20 people attended to enjoy races, an egg toss, a pie-eating contest, and, of course, lemonade! They raised almost $1,200!

**Putting for PRISMS**
Jackie Fallenstein, PRISMS Board Vice President, and Michele Narveson co-hosted Putting for PRISMS at the Links at Dred Scott in Bloomington, MN. Guests enjoyed a beautiful morning of mini-golf, coffee, juice, donuts, and great conversation. Thanks to the generosity of local sponsors who supported all 18 holes, the welcome table, and the 19th hole, the event was a success. With more than 50 attendees, this fun-filled fundraiser brought in over $4,700 to support PRISMS' mission—raising both critical funds and awareness for individuals and families living with Smith-Magenis syndrome.

**Nickels for Niko**
The Jean Bishop family hosted the 14th Annual Nickels for Nico Cornhole Tournament in Kentucky. There were over 200 attendees and eight SMS families represented. The event raised $13,000 for PRISMS!

*(cont.)*

*(2024 Community Fundraisers - cont.)*



**Pickleball for PRISMS**
For 15 years, Jeremy and Sylvia Farber have turned their family's journey with Smith-Magenis syndrome into a mission to give back. From bowling alleys to pickleball courts, their annual fundraiser aims to provide support for PRISMS. This year marked their most successful event to date, with a total of $31,400 raised. You can read how the Farber family has built a community of hope and awareness for SMS on the PRISMS blog: https://www.prisms.org/from-bowling-to-pickleball-one.../




**Michigan Fundraiser and Meetup**
One of our newest Regional Representatives, Sherry Kay Thompson, hosted a meet-up and fundraiser at Verhage Fruit Farms & Cider Mill. The event brought together families affected by Smith-Magenis syndrome to connect and share experiences. It was a day filled with laughter, tears, and new friendships — and thanks to everyone's generosity, $320 was raised for PRISMS. Kids enjoyed hayrides, the giant pillow jump, slides, and cider and donuts — but the best part was the joy of being together.



**The Mountain Goats Concert**
John Darnielle performed a sold-out concert at Pinhook in Durham, NC, to benefit PRISMS. The standing-room-only acoustic show drew more than 225 fans and raised $10,682 for PRISMS. A table was set up for concertgoers to learn more about Smith-Magenis syndrome and PRISMS.



# PRISMS CLINIC AND RESEARCH CONSORTIUM (PCRC) UPDATE



***Maggie Miller, Founding Board Member***

PRISMS Clinic and Research Consortium, (PCRC) continues to deliver specialized care to SMS families. The PCRC is a network of Smith-Magenis Syndrome Clinics across the United States that provide coordinated multi-disciplinary care to address the challenges of SMS.

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

The PCRC meets regularly to discuss and author critical guidelines that are used across the clinics to maintain a collaborative, consistent, and evidence-based standard of care for individuals with Smith-Magenis syndrome. In 2025, Growth Standards for Children with Smith-Magenis Syndrome (SMS) was published (Coordinated by Ann C.M. Smith and included authors from the PCRC) and distributed across the clinic network, enabling providers to incorporate this important tool into their clinical assessments. https://pubmed.ncbi.nlm.nih.gov/41117131/

Since June 2025, the PCRC has collectively evaluated 53 individuals with Smith-Magenis syndrome (SMS) from across the United States and internationally. Fifty-three families accessed the specialized expertise and coordinated care provided by clinicians within the PCRC. Several families benefited from support through The PRISMS SMS Clinic Travel Fund Reimbursement Program. This program supports families who need to travel to one of the clinics within the PCRC. This fund helps to 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. Please email info@prisms.org to request information and an application. Currently, there are nine SMS Clinics in the US, with the expectation to grow the clinic network.

PCRC

PRISMS Clinic and Research Consortium

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 nine clinics, click here: www.prisms.org/wp-content/uploads/pdf/pcrc/PRISMS_PCRC_Clinics_Brochure.pdf

# PROFESSIONAL ADVISORY BOARD



***Maggie Miller, Founding Board Member***

The PRISMS Professional Advisory Board (PAB) continues to serve the SMS community as leaders in research, clinical outreach, family support, and the development of key publications and care guidelines related to Smith-Magenis syndrome. The PAB is composed of a diverse group of professionals across multiple specialties who not only care for individuals with SMS but also collaborate on research to advance understanding and explore potential treatments. Their leadership within the research community has produced impactful publications, evidence-based clinical guidelines, and meaningful advancements that continue to shape the future of SMS care and therapeutic developments. The PAB meets regularly to review research priorities, discuss treatment updates, and determine next steps to advance care and research for SMS.



One of the publications authored by the PAB in 2025, was the updated version of GeneReviews. GeneReviews is an international point-of-care resource for clinicians, providing clinically relevant and medically actionable information for inherited genetic conditions, covering diagnosis, management, and genetic counseling for patients and their families.



Each chapter in GeneReviews is written by one or more experts on the specific condition and goes through a rigorous editing and peer review process before being published online. Each GeneReviews chapter is updated regularly in a formal and comprehensive process. Ann C.M. Smith, PAB, Chair Emeritus, with the assistance of PRISMS Professional Advisory Board, has completed the 2025 update of the Smith-Magenis syndrome entry for GeneReviews. You can find the updated entry here: https://www.ncbi.nlm.nih.gov/books/NBK1310/



The PRISMS PAB was also an integral part of the PRISMS Research Symposium in 2025. Their guidance and support in planning and carrying out the symposium were key to making it a meaningful, well-organized event that brought researchers and clinicians together to move Smith-Magenis syndrome research forward.

(Cont.)

*(Professional Advisory Board - cont.)*

The PRISMS PAB reviews all research project requests that are submitted to PRISMS as well as any new requests to access the PRISMS SMS Patient Registry, (SMSPR). All research submissions require a strict criterion (outlined by the PAB) and stringent oversight by the PAB to ensure scientific rigor, ethical integrity, and alignment with the mission and priorities of PRISMS.

We look forward to presentations from the PAB at the PRISMS International Conference in MN in July 2026. The PAB generously donates their time to serve on the PAB and we greatly appreciate their dedication to the SMS community.

**PROFESSIONAL ADVISORY BOARD**

**Ann C.M. Smith, MA, D.Sc. (Hon), CGC PAB Chair Emeritus**

**Sarah Elsea, Ph.D. Chair**

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

**Kerry Boyd, MD, FRCPC**

**Andrea Gropman, MD, FAAP, FACMG, FANA**

**Christine Brennan, Ph.D. CCC-SLP**

**Rebecca Foster, Ph.D**

**Santhosh Girirajan, MBBS, Ph.D.**

**Rachel Franciskovich, MS,CGC**

**Nancy Raitano Lee, Ph.D.**

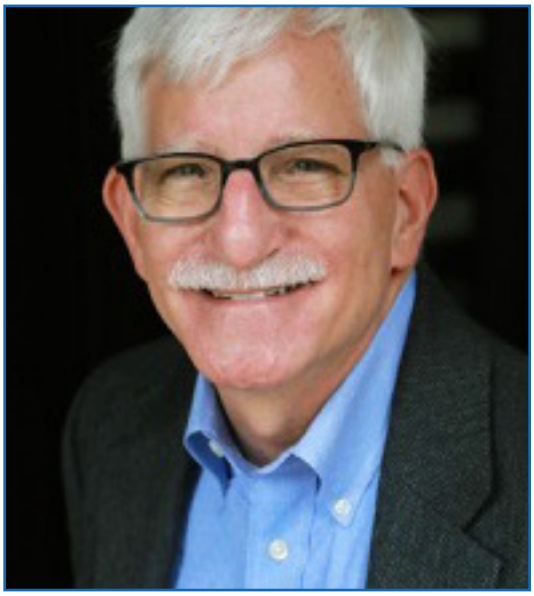
**John Berens, MD, FAAP, FACP**

**Cora Taylor, Ph.D.**

**Christopher Vlangos, Ph.D., FACMG**

**Sinan Turnacioglu, MD**

**Seth M. Keller, MD**



*Dr. Seth Keller, the newest member of the PRISMS Professional Advisory Board*

# PRISMS PATIENT REGISTRY



***Margaret Miller, Founding Board Member***

The Smith-Magenis Syndrome Patient Registry, (SMSPR) is a catalyst for scientific discovery in the research of Smith-Magenis syndrome. The SMSPR is an essential tool that provides the building blocks for the study of SMS and the basis for research endeavors. The registry provides a blueprint for data-driven research, enabling investigators to identify patterns, define meaningful outcomes and accelerate discoveries that will lead to therapeutic interventions.

The SMSPR is an IRB approved program supported by PRISMS and requires the oversight of a Principal Investigator, staff to manage the registry and review of the registry surveys, and research requests by the PRISMS Professional Advisory Board. IRB approval means the registry's design, data collection methods, consent process, and privacy protections have been reviewed and authorized by an Institutional Review Board (IRB) to ensure the protection of human participants. PRISMS is required to follow all regulations of the IRB to protect health data of all participants.

**Registry Function:**

The SMSPR was created as a comprehensive tool to capture the SMS profile of each participant in the registry. The registry allows for the collection of longitudinal data across the lifespan providing key insights into the natural history of Smith-Magenis syndrome. As new discoveries are elucidated from this data, new surveys are added to the registry in response to these discoveries. The registry is like a window into the many complexities of SMS helping researchers to advance the development of targeted therapies and care strategies.

**Registry Outcomes:**

The SMSPR provides real-world data to researchers through a collection of surveys (instruments) that are completed by registry participants. These surveys target medical history (including developmental milestones), genetic reports, and questionnaires assessing multiple body systems, such as sleep, neurological, behavioral, gastrointestinal, speech and language, and quality of life. The registry data guides researchers toward defining research priorities, uncovering the natural history of SMS and the disease progression, and most importantly, accelerating therapeutic development. Basic science researchers and clinicians rely on this valuable data to develop new therapeutics and improved clinical care management.

**Registry Participation:**

Every participant in the SMSPR contributes to the greater understanding of SMS. Your participation will help grow the landscape of SMS data across the lifespan and help to accelerate research, including clinical trials. The SMSPR offers insight to researchers and helps to attract pharmaceutical companies that may be interested in SMS and impact research funding. https://www.prisms.org/research/sms-patient-registry/

# SUMMER RESEARCH SCHOLARS



***Maggie Miller, Founding Board Member***

PRISMS Summer Research Project Grant funds research opportunities for junior researchers studying specific issues related to Smith-Magenis syndrome, under the mentorship of members of PRISMS Professional Advisory Board and PRISMS Clinic and Research Consortium institutions. In 2025, PRISMS awarded scholarships to four students to support their research during the summer.

**2025 Summer Research Projects:**

- Evaluating existing research and utilizing PRISMS Patient Registry to investigate how feeding concerns evolve over time for individuals with SMS
- Understanding the communication, social-emotional, and executive functioning skills in adults with SMS and their relationship to meaningful daily activities and vocational success
- Using the PRISMS Patient Registry and other sources to analyze the use of pharmacological interventions in addressing neurobehavioral issues in SMS in order to identify prescribing patterns and trends
- Implementing a feasibility study using remote tracking devices to evaluate sleep and activity in individuals with SMS to enhance understanding of sleep disturbance, activity level, and weight gain







The scholars also had the opportunity to present their findings to SMS researchers at PRISMS' 12th Research Symposium in September, fostering new collaborations and advancing future research opportunities.

(Cont.)



*(Summer Scholars - cont.)*

# SUMMER RESEARCH SCHOLARS



## BEN LITVAK-HINENZON

Ben is an undergraduate student at Williams College. Ben will be working with Dr. Samantha Vanderslice and Dr. Ann Neumeyer at the Lurie Center for Autism at Massachusetts General Hospital. The title of their project is “Pharmacological Review of Neurobehavioral Issues in Smith-Magenis Syndrome.”



## NICOLE PERRINO

Nicole is a doctoral student in the University of Florida/Behavioral Analysis Doctoral Program. Nicole is working with Dr. Vivian Ibañez on a project titled “Understanding Feeding Concerns for Individuals with Smith-Magenis Syndrome.”

Given that feeding challenges are heterogeneous and affect multiple domains including growth, nutritional status, and social interactions, Nicole will work with Dr. Ibañez to better understand the unique needs of individuals with Smith-Magenis syndrome (SMS) and examine whether individuals with SMS are represented in published behavioral feeding research.



## HAILA JIDDOU

Haila is a psychology master’s student at Drexel University’s Department of Psychological and Brain Sciences. Haila is working with Dr. Nancy Raitano Lee and Dr. Christine Brennan on a project titled “Vocational Activities and their Cognitive-Behavioral Correlates in Adults with Smith-Magenis Syndrome.”

This project aims to understand cognitive and behavioral factors that are associated with greater independence in everyday activities among people with SMS.



## HSING-YI CHEN

Hsing-Yi is an undergraduate at Rice University. Hsing-Yi is working with Dr. Sarah Elsea at the Elsea Lab at Baylor College of Medicine. Her project is “Remote Assessment of Activity and Sleep in Smith-Magenis syndrome (ReAActS-SMS)”.

This study aims to explore sleep patterns and physical activity in individuals with SMS using wearable devices. They hope to better understand the daily routines of individuals with SMS and explore ways to support better sleep and encourage physical activity in the future.

# PRISMS 12TH SMITH-MAGENIS SYNDROME RESEARCH SYMPOSIUM



***Michelle Larscheid, Executive Director***

PRISMS convened the 12th Smith-Magenis Syndrome Research Symposium in Boulder, CO, on September 25th- 26th, 2025. The backdrop of the Rocky Mountains provided an inspirational landscape for thought-provoking discussions and the exchange of new ideas in Smith-Magenis syndrome research. The PRISMS symposium was a hybrid event which hosted researchers from around the globe and enabled engagement from both in-person and virtual attendees.

One of the symposium's goals is to further research by building productive collaborations—including cross-disciplinary dialogue, partnerships, and the integration of researchers new to SMS who have an interest in specific facets of the syndrome. Many successful SMS research collaborations have originated from past research symposiums, and PRISMS' investment in junior researchers has helped cultivate the next generation of scientific leaders in the field. Our investment in the next generation of researchers and clinicians supports the PRISMS' mission of "fostering and sponsoring research."

In response to a "Call for Abstracts" (research summaries), researchers from multiple disciplines submitted abstracts that were evaluated according to stringent criteria and reviewed by the PRISMS Professional Advisory Board. Accepted abstracts were presented at the PRISMS Research Symposium. Travel scholarships were awarded to selected attendees to support participation by emerging researchers.

**Symposium presenters represented academia and institutes from:**

- **Ann and Robert Lurie Children's Hospital of Chicago**
- **Baylor College of Medicine**
- **Children's National Medical Center**
- **Cincinnati Children's Hospital**
- **Fondazione IRCCS Casa Sollievo Della Sofferenza, San Giovanni Rotondo, Italy**
- **Geisinger ADMI**
- **Governor Kremers Centre, Maastricht University, the Netherlands**

prisms Research Symposium




*(cont.)*

*(SMS Research Symposium - cont.)*





- **Lurie Center for Autism, Massachusetts General Hospital**
- **McGill University**
- **Michigan State University**
- **National Institutes of Health**
- **Northwestern University, Feinberg School of Medicine**
- **Office of the Clinical Director, National Human Genome Research Institute, Rice University**
- **St. Jude's Children's Research Hospital**
- **St. Louis Children's Hospital & Washington University School of Medicine**
- **Texas Children's Hospital**
- **University of Colorado - Boulder**
- **University of Florida**
- **University of North Carolina, Chapel Hill**
- **University of Michigan Medical School**
- **University of Minnesota**
- **Williams College**

***I found the symposium immensely valuable. Next time, I will be pushing my grad students and postdocs to attend as well. Thank you for organizing this very inspiring meeting!***

***- Mike Sutton, Ph.D. University of Michigan***

The presenters represented a diverse landscape of SMS research from basic science to clinical research and practice. Abstract presentations included both oral and poster presentations. Three of our four PRISMS Summer Scholars were in attendance to present their final results of their summer project. Attendees devoted meaningful time to engaging in scientific discussions and building connections with fellow participants.

We look forward to the emergence of new research collaborations inspired by the PRISMS Research Symposium, and we are grateful to our dedicated researchers for their continued work and their commitment to the SMS community.

We extend our heartfelt thanks to Vanda Pharmaceuticals for sponsoring the Research Symposium and for their many years of steadfast partnership and support of PRISMS. We are grateful for their continued support and generosity.






*(SMS Research Symposium - cont.)*

> ***My head is exploding with ideas & to see/hear about progress being made. The collaborative ties stemming from the meeting will be exciting to watch!***
>
> *- Ann C.M. Smith*
>
> *MA, DSc (Hon), CGC, PAB Chair Emeritus*

## PRISMS Research Symposium Abstract Titles:

- Self-Injurious Behavior in Individuals with Intellectual and Developmental Disabilities: An Interdisciplinary Family Systems Review
- Developing a Diurnal Rodent Model of Smith-Magenis Syndrome
- Smith Magenis Syndrome and Behavior Analysis: A Review of Previous Literature and Future Directions
- In-Depth Language Profiling of an Adult with Smith-Magenis Syndrome: Insights from Standardized Testing and Narrative Sampling
- Understanding the Communication Phenotype of Smith-Magenis Syndrome: Findings from Patient Registry Research
- Making a Case for the Single Case: Implications of Single Case Designs in SMS Research, Assessment, and Intervention
- Quantitative EEG Biomarker Development for Angelman Syndrome and Applications for Smith-Magenis Syndrome
- Melatonin Levels in 89 Individuals with Smith-Magenis Syndrome
- Implementation of Screening Guidelines for Birt-Hogg-Dubé Syndrome Among Smith-Magenis Syndrome Registry Participants: A Caregiver Survey
- Remote Assessment of Activity and Sleep in Smith-Magenis Syndrome (ReAActS – SMS)
- Neurogenesis in Smith-Magenis Syndrome: When Brain Development and Lipid Metabolism Go Awry
- The Roles of RAI1 in the Neoteny of Human Neurodevelopmental Gene Expression Program
- Understanding and Supporting Siblings of Individuals with Smith-Magenis Syndrome: Insights for Healthcare Professionals
- Distinct Phenotypic Signatures in RAI1-Related Disorders: A Comparative Retrospective Study of Smith-Magenis and Potocki-Lupski Syndromes
- Pharmacological Review of Neurobehavioral Issues in Smith-Magenis Syndrome
- Empowering Through Structured Boundaries: An Integral Model for Fostering Balanced Eating and Nutritional Well-Being
- Investigating Food-Related Behaviors in Smith-Magenis Syndrome: The Development and Validation of Tailored Questionnaire

# 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 2025, PRISMS teamed up with The SMS Foundation UK, in collaboration with CVI Now, to host a vital and informative webinar focused on Cerebral/Cortical Visual Impairment (CVI) — a condition that affects how the brain processes visual information.

Presented by experts Ali Mahady and Lacey Smith from CVI Now at the Perkins School for the Blind, the webinar was designed especially for parents and caregivers in the SMS community.

If you'd like to view all the recordings in our webinar library, please visit: https://www.prisms.org/education/webinars/ . If you have an idea for a webinar, please email info@prisms.org.








# 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 57 Regional Representative volunteers in our program. We also have international regional reps from Canada, Australia, Israel, Brazil, Italy, Mexico, Puerto Rico, Romania, Singapore, Russia, and the United Kingdom.

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

- **Newly diagnosed families and how to support them**
- **Medications for sleep**
- **Medications for weight management**
- **Topics for upcoming PRISMS conference**
- **SMS clinics**
- **Hosting fundraisers**




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

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, or are interested in being a rep, please get in touch with us at info@prisms.org.

*(cont.)*

# REGIONAL REPRESENTATIVES

Alejandro & Delma Aguilar
Leah Baigell
Kara Bale
Eliane Barros
Cally Bauman
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
Eric & Kim Hoffman
Bernadette Huston
Linda Johnson
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
Mark and Theresa 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

## MINNESOTA

PRISMS Executive Director, Michelle Larscheid, traveled to Minneapolis, MN, to work on the 2026 International Conference. While there, she had the opportunity to meet up with a group of local SMS families for some much-needed summer fun and connection.



## NORTH CAROLINA

Heather King organized a meet-up for several North Carolina families in High Point, NC, in August at Q's Corner (A local play gym specifically designed for people of all abilities).



## NORTHERN CALIFORNIA

In August, Laurie Bellet hosted her annual Northern California SMS meet-up, a tradition she has carried on for more than 20 years as one of PRISMS dedicated Regional Representatives. Nearly 30 attendees gathered for a day of connection and community—joined by a special guest, Merlin the therapy dog. Laurie also helped raise over $100 in donations to support PRISMS mission.




## SOUTHERN CALIFORNIA

PRISMS Board Member, Diane Erth, hosted her annual San Diego SMS Family Picnic in September, bringing together 12 amazing SMS families for a day filled with connection, laughter, and sunshine. From the youngest attendee at just 20 months old to the eldest at 48 years, it was a beautiful reminder of the strength and spirit of our SMS community.



## TEXAS

One of our SMS parents, Cecilia Poole, once again hosted the annual SMS Family Fun Day on Saturday, June 21st, at Morgan's Wonderland, which is an all-access park in San Antonio, TX. Ten families attended (36 people total, with 10 individuals with SMS ages 2 to 35). Later, many of the families met up at nearby Two Brothers Barbecue. Three of the families were joining the annual event for the first time.



## UTAH

The Bardsley family hosted a regional SMS picnic in Pleasant Grove, Utah, on Saturday, September 6th. There were about 30 in attendance, including eight SMS individuals, a family from western Colorado, several siblings, and extended family members. It was such a great success, the Bardsleys are planning to host another meet-up next year.



# CONTINUED WORK WITH ADVOCACY PARTNERS

In 2025 PRISMS continued its goal to expand our circle of 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 to advance the mission of PRISMS.

## 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 more than 20,000 articles on rare disease and shared them across all the primary social media platforms.

They reach over 50,000 people every day on their website and more that 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 join as partners in teaching and reaching other families, researchers, physicians, and industry.

Patient Worthy partnered with us for SMS Awareness Day, significantly amplifying our social media reach and sharing our website and resources with new families and professionals. Their efforts strengthened PRISMS outreach and broadened our community of advocates. We look forward to continued collaboration with Patient Worthy.

patient worthy®

## 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 of 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 to donate. 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 the advancement of 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/

## RARE REVOLUTION

PRISMS is proud to be a charity partner of RARE REVOLUTION, an international not-for-profit media company dedicated to rare disease storytelling and awareness. Through its dynamic digital platform—including online articles, social media, video content, and RARE REVOLUTION Magazine—RARE REVOLUTION provides rare disease organizations with a powerful space to share information and amplify their voices.

Our partnership with RARE REVOLUTION enables PRISMS to extend our global reach and share trusted resources about Smith-Magenis syndrome (SMS) with families, professionals, and advocates around the world. In November 2025, RARE REVOLUTION Magazine featured PRISMS in recognition of SMS Awareness Day, complemented by a series of coordinated social media posts that helped raise awareness and celebrate our community.

We look forward to continuing our collaboration with RARE REVOLUTION and are grateful for their ongoing support.

RARE™ REVOLUTION MAGAZINE

## RAI1 & TCF20 Group

In 2025, PRISMS continued its partnership with members of PTLS Hope Research Foundation (Potocki-Lupski syndrome), https://www.ptlshope.org, and TCF20 syndrome, Project TCF20, https://projecttcf20.org.

All three syndromes share either a common factor with the RAI1 gene, which is the causative gene for SMS and PTLS and is paralogous to the TCF20 gene. All three syndromes share common challenges, and elucidation of one of the syndromes may provide critical insights into the others, accelerating understanding and informing potential therapeutic strategies across all three conditions. 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. Some members of PTLS Hope Research Foundation and TCF20, including researchers, attended the PRISMS 2025 symposium. We are enthusiastic about emerging research opportunities that will strengthen this collaboration and pave the way for meaningful new discoveries.



# VOLUNTEERS

**General Volunteers:**
Kristine Braden
Pat Boschetto
Heather King
Michele Narveson
Natasha Schaller
Kerrie Slattery

**Tech Work Group:**
Carlton Bale
Robert Duvall
Margaret Miller
Allison Stephanouk

**Advocacy Workgroup:**
Leah Baigell
Barclay Daranyi
Melissa Haley
Percy Huston
John Mayer

**Conference Committee:**
Kayla Beecher
Diane Erth
Lynda Kilian
Michelle Larscheid
Michelle Lee
Jason Michaud
Amy Pereira
Maggie Miller
Michele Narveson
Jackie Fallenstein

# BOARD

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Jackie Fallenstein, Vice President, Development Chair
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Eric Rogers, Secretary
Maggie Miller, Founding Member
Brandon Daniel, Immediate Past President

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Denien Rasmussen, Regional Rep. Committee Chair
Michelle Lee, Awareness Committee Chair
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Amy Pereira, Board Member at Large
Jason Michaud, Board Member at Large
Diane Erth, Board Member at Large



# STAFF

Michelle Larscheid, Executive Director
Lynda Kilian, Office & Communications Manager
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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 diagnosed with SMS and our organization continues to grow, we must 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.

**DONATION MAILING ADDRESS:**
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**This report was made possible by contributions from:**

Michelle Larscheid, Executive Director

Melissa Denman, Office Manager

Pat Boschetto, Proofreader

PRISMS Board of Directors

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2025

# 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.**

