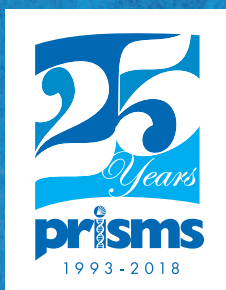
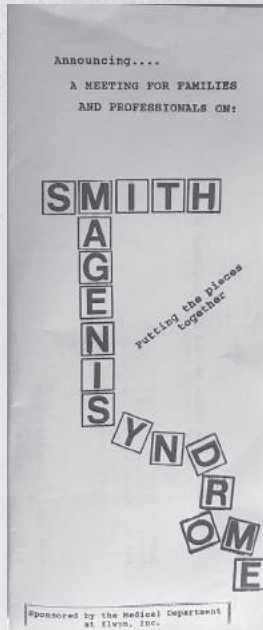


PRISMS ANNUAL REPORT 2018



PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

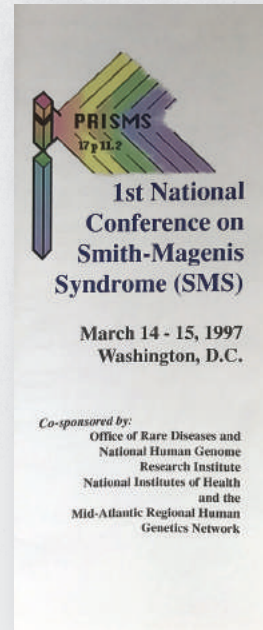
2018 marked the 25-year anniversary of PRISMS. Here's a look back at some early PRISMS promotional and informational products . . .



First PRISMS meeting.



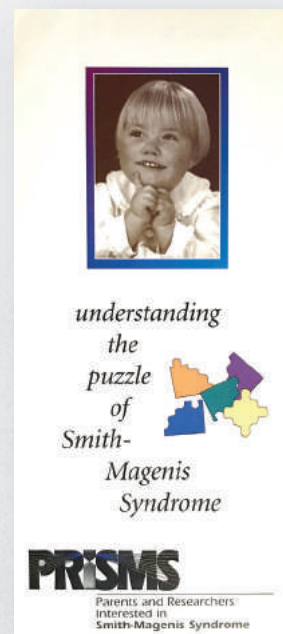
First PRISMS brochure.



First PRISMS conference.



First PRISMS Spectrum newsletter.



Second PRISMS brochure.

PRISMS ANNUAL REPORT 2018

TABLE OF CONTENTS

2	<i>Message from the President of the Board of Directors</i>
4	<i>Remarkable People, Milestone Events Mark PRISMS 25-Year Evolution</i>
6	<i>Our 10th International Conference on SMS Highlighted PRISMS 25th Anniversary</i>
8	<i>Join the 17p11.2 Society and Help PRISMS Continue To Thrive</i>
10	<i>Conference Revenue Reached \$92,000 in 2018—A New High for PRISMS</i>
12	<i>PRISMS PAB Ensures the Dissemination of Current, Accurate Information on SMS</i>
14	<i>Regional Representative Program Reached Record Number</i>
16	<i>“I Am” Campaign Highlighted PRISMS Awareness Mission</i>
18	<i>Fundraisers, Awareness Events Raised More Than \$68,000</i>
20	<i>PRISMS 2018 Donor List</i>
23	<i>2018 Year in Review by the Numbers</i>





MESSAGE FROM THE PRESIDENT OF THE BOARD OF DIRECTORS

BRANDON DANIEL

It's hard to believe that 2018 is officially in the history books. It was a busy and productive year for PRISMS. Not only did the organization celebrate its 25-year anniversary, it also hosted its 10th International SMS Conference—with record attendance in Pittsburgh.

Other highlights for 2018 included:

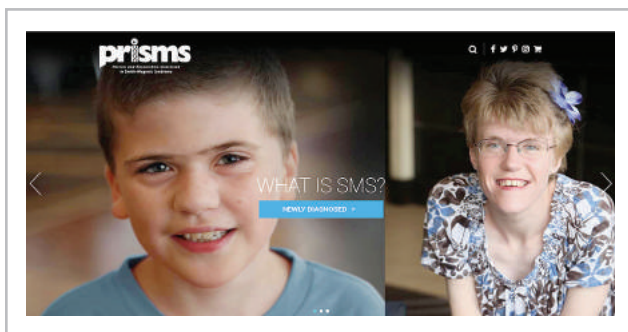
- Launching a new PRISMS website (www.prisms.org).
- Creating and distributing “A Guidebook for Families Newly Diagnosed with Smith-Magenis Syndrome.”
- Revising and launching Medical Management Guidelines
- Completing and operationalizing the organization's first marketing/communications audit.

- Funding the SMS Patient Registry.

As 2018 concluded, changes were taking place in the organization. Emily Fields, PRISMS first executive director, moved on to other challenging opportunities. In addition, I was humbled and honored to be appointed to the position of president of the PRISMS Board of Directors. I have served on the board since January 2015, initially as a co-chair for fundraising and then as the secretary.

I am fortunate to follow John Mayer as president. John led the organization during the past five years and provided sound structure and stability as PRISMS experienced continued growth in both membership and awareness of SMS. PRISMS is

“ I simply can't imagine my SMS journey without PRISMS ”



New PRISMS Web Site.

stronger because of the leadership of John, who will continue on the board as immediate past president. I am also fortunate to have a strong group of dedicated SMS parents and volunteer board members to work alongside in this new role.

As an organization, we remain strong and committed to moving forward with our mission in 2019. Work continues on key initiatives, such as the planning for the International Conference in 2020 and for the Research Symposium later this year.

Our volunteer families, regional representatives and committees will continue their critical work of helping fulfill our mission. PRISMS

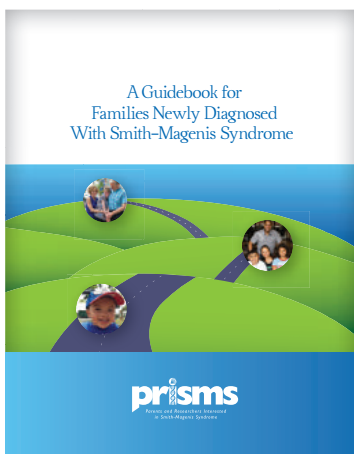
is a resource for you and exists to provide value, support and assistance to all those dealing with SMS.

Herb Kelleher, founder of Southwest Airlines, once said, "It is my practice to try to understand how valuable something is by trying to imagine myself without it." I simply can't imagine my SMS journey without PRISMS, which has been a valuable resource for my family since the day our son, Coulter, received his diagnosis.

As we move into 2019, know that PRISMS "gets it" and exists to help you along your SMS journey.

Thank you.

Brandon Daniel
President, Board of Directors



Guidebook for families newly diagnosed with SMS.

2019 PRISMS BOARD OF DIRECTORS

Brandon Daniel
President

Margaret Miller
Vice President

Phil Ruedi
Treasurer

Tina McGrevy
Secretary

John Mayer
Immediate Past President

Sarah Elsea
Chair, Professional Advisory Committee

Diane Erth
Chair, Membership / Fundraising Committee

Percy Huston
Chair, Regional Representatives Committee

Denien Rasmussen
Chair, Membership / Fundraising Committee Staff

Julie Bernatz
Interim Director

Angela Williams
Office Assistant

REMARKABLE PEOPLE, MILESTONE EVENTS MARK PRISMS 25-YEAR EVOLUTION

JOHN MAYER

PRISMS celebrated its silver anniversary in 2018. During these 25 years of service, many remarkable people have helped make PRISMS the extraordinary organization it is today. Along the way, there have been many milestones and important events organized to provide support or deepen our knowledge about Smith-Magenis Syndrome.

- The discovery begins in 1981 when genetic counselor Ann C.M. Smith, MA, then working as clinical director of genetic services for Denver Children's Hospital, identifies two children with similar clinical characteristics. Ann discovers a common deletion on the 17th chromosome and, with help from her colleagues, presents a paper entitled, "Deletion of the 17 Short Arm in Two Patients with Facial Clefts and Congenital Heart Disease."
- Ann Smith's paper is presented at the 1982 meeting of the American Society of Human Genetics. Among those in the audience is Dr. Ellen Magenis, who realizes Ann is describing a new microdeletion syndrome that a patient in her care may also have. Genetic testing confirms the condition. That's when Ann and Ellen begin their collaboration that leads to the 1986 publication and initial delineation of the clinical spectrum associated with deletion 17p11.2.
- In the late 1980's, geneticists at the Baylor College of Medicine, including Dr. Frank Greenberg, Dr. Jim Lupski and others, share their investigations relating to deletions on the 17th chromosome. They identify additional patients and systematically expand the phenotype for patients with a deletion of 17p11.2.
- In 1989, the syndrome is named Smith-Magenis Syndrome. By 1991, 65 patients, ranging in age from one month to 72 years, have been identified and described in reports to the medical community.
- In May 1990, Margaret and Scott Miller receive a diagnosis of SMS for their daughter, Deirdre. They establish a connection and begin working in partnership with Ann Smith, now a researcher at the National Institute of Health in Bethesda, MD. They work to gather researchers and families with children who have SMS.
- As a result of many discussions and much planning, the first gathering of the SMS community is held on October 5, 1991 at Elwyn Institute, near Media,



***Ann Smith (L) and
Ellen Magenis***

PA. The gathering is hosted by Brenda Finucane, MS, a genetic counselor and one of the founders of PRISMS. This alliance builds and more families are identified.

- On February 4, 1993, Parents and Researchers Interested in Smith-Magenis Syndrome (PRISMS) is formed and officially recognized as a non-profit organization. As PRISMS continues to develop, it offers a parent-to-parent network, telephone support line, an awareness brochure and a newsletter.
- The first PRISMS conference is organized and held March 14-15, 1997 in Bethesda, MD. The conference includes researchers, clinicians and families. This mix of medical experts and families establishes a powerful partnership.
- Soon, a professional advisory board is established and the first SMS Research Roundtable is held on September 21, 2000.
- In 2003, Dr. Sarah Elsea and her team of researchers identify the RAI1 gene as a major aspect of the SMS syndrome.

In the 15 years since then, PRISMS has continued with this important program, added new initiatives and worked to broaden its service to families around the world. Today, it operates with more than 2,000 members and international affiliates in five countries.

It has been a humbling experience attempting to acknowledge the many ways people have contributed to PRISMS. Thanks to the many volunteers, board members, staff, researchers, clinicians, families and persons with SMS who have made PRISMS what it is today.

Here's to the next 25 years of service to our community! 🌐

PRISMS International Conferences

- | | |
|------------------------|---|
| 1st | March 14-15, 1997
Bethesda, MD |
| 2nd | September 21-24, 2000
Arlington, VA |
| 3rd | July 4-7, 2002
Westminster, CO |
| 4th | April 28-May 1, 2005
Cincinnati, OH |
| 5th | May 10-13, 2007
Reston, VA |
| 6th | September 17-20, 2009
Reston, VA |
| 7th | July 28-Aug. 1, 2012
Denver, CO |
| 8th | July 31-Aug. 3, 2014
St. Louis, MO |
| 9th | July 28-30, 2016
St. Louis, MO |
| 10th | July 19-July 21, 2018
Pittsburgh, PA |



OUR 10TH INTERNATIONAL CONFERENCE ON SMS HIGHLIGHTED PRISMS 25TH ANNIVERSARY

MAGGIE MILLER

PRISMS presented its 10th International Conference on Smith-Magenis Syndrome, July 19-July 21, 2018, at the Marriott City Center in Pittsburgh. The conference theme was *"Honoring the Past, Treasuring the Present and Shaping the Future."* The conference was the highlight of PRISMS 25th anniversary celebration, and it capped off a year of milestones and memories for families across the globe.

It was PRISMS largest conference gathering, with 376 attendees from Australia, Canada, Mexico, the United Kingdom, Norway and the United States. Despite the growth in attendee numbers, it felt like a close-knit family gathering.

We welcomed new exhibitors to our conference, including the SMSRF (Smith-Magenis Syndrome Research

Foundation), and welcomed back our friends from Abram's Nation (The Safety Sleeper Bed.) New alliances were formed and new friendships were made as we came together to support and encourage each other for three special days.

The conference began on Thursday with two workshops, both offering a two-part series: "Teacher and Support Staff Training" and "Adult Living: Residential and Vocational Options." The workshops consisted of panel sessions comprised of professional and parent experts. The "First Steps Session" also was held on Thursday. It served as a conference guide for first-time attendees while also offering support and building connections between families.

Our welcome reception was a time for attendees to celebrate



PRISMS families and friends celebrate our wonderful community at the 10th International SMS Conference in Pittsburgh.

Conference
by the
Numbers

376

Registered
attendees

155

First-time
attendees

42

Individuals
with SMS

21

Siblings under
the age of 16

our wonderful community and engage in dancing, eating ... and more dancing. Our SMS individuals were the stars of the reception and filled the air with joy and energy! Later that evening, the "Night at City Center" celebration and fundraiser took place. It was a beautiful event that kept the festive mood continuing.

On Friday, the conference's keynote speakers included a panel of parents and SMS individuals who shared their proudest moments as part of the PRISMS "I Am" campaign. We were all moved by their heartfelt stories, and we celebrated the accomplishments of all of the SMS individuals. The "I Am" campaign resonated throughout the conference, underscoring the feeling of community, family and support.

The conference offered sessions regarding key challenges and aspects of Smith-Magenis Syndrome. Physicians, researchers, therapist, clinicians, educators and other leading experts in the SMS

field presented relevant and focused information in varying disciplines of SMS. Presentations included research updates, therapeutic approaches addressing a variety of challenges, (including sleep, speech and language, and medication); behavior and educational supports; medical management of SMS; adult concerns; and family supports.

New sessions included information on legal considerations, traditional medicine and alternative approaches, psychiatric admissions, adult healthcare, managing ourselves while managing SMS, and managing food-seeking behaviors.

Siblings attended sessions that allowed them to openly share their concerns and challenges of being an SMS sib. They were able to have some fun time with Coach Dave, who led them through a variety of games and activities. Our dear friend, Rick Guidotti, of Positive

Exposure, captured the faces of our children and families and made all of them feel like rock stars! We finished the conference with an ice cream social and more time for making memories and connections.

We are grateful for all of our presenters, including the PRISMS Professional Advisory Board, educators, clinicians and researchers and parents. Their dedication to this rare community has tremendous impact, and PRISMS is honored to be the liaison between our dear families and devoted professionals.

PRISMS 11th international conference will be in Dallas in 2020. See you there! 🌊



PRISMS families come together at the conference for support and encouragement.

10

Grandparents

35

*Attendees through
the Family Support
Scholarship*

12

*Teachers funded
through the Teacher/
Support Staff
Scholarship*

108

*Attendees at the
"Night at City
Center" event*

JOIN THE 17p11.2 SOCIETY AND HELP PRISMS CONTINUE TO THRIVE

DIANE EARTH

When PRISMS moved to free membership in 2018, it created the 17p11.2 Society to help continue to receive funds. It was named after the specific genetic material missing from chromosome 17, which leads to the Smith-Magenis Syndrome diagnosis.

The generous 17p11.2 Society members ensure that PRISMS continues with its programs and services dedicated to education, awareness and research. The 17p11.2 Society currently consists of 45 dedicated members who have pledged to donate a minimum of \$17 a month through an automatic pay system.

To join the 17p11.2 Society, simply go to PRISMS.org.

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

Each member will receive a custom color premium quality pin to signify their commitment to PRISMS and the SMS Community—and the knowledge that you are an active participant in helping PRISMS continue. 🌈



Cally Bauman	Lisa Mariano
Danielle Bier	John Mayer
Brandon Daniel	Tina McGrevy
Barclay Daranyi	Donald Michaud
Dennis Dillon	Jason Michaud
Robert Duvall	Scott Miller
Angela Eaton	Michael Miodunski
Sarah Elsea	Robyn Mogul
Diane Erth	Faith Nobilucci
Jacklyn Fallenstein	Kevin O'Connor
Sylvia Farber	Leibnitz Denisse Pirozzi
Emily Fields	Gianluca Pirozzi
Beverly Frey	Denien Rasmussen
Jennifer Groeteke	Teresa Roberts
Rebecca Hallmark	Aileen Rohde
Julia Hetherington	Caitlin Seldon
Percy Huston	Ann Smith
Paula Jump	Allison Stephanouk
Krista Karr	Derek Waldeck
Michael Kingston	Adrienne Wampler
Bonnie Krautheimer	Chris Weber
Josephine Lawlor	Mary Ann Zimmer
Allison Leatzow	

(Full-time and partial year 2018 members)

CONFERENCE REVENUE REACHED \$92,000 IN 2018—A NEW HIGH FOR PRISMS

PHIL RUEDI

Demand for the 2018 International Conference in Pittsburgh was overwhelming and this is reflected in \$92,000 in conference revenue, a new high for the organization. The strong level of support from the PRISMS membership and outside organizations offered PRISMS the chance to invest \$180,000 to organize and present the event.

The annual loss of \$50,000 was a little larger than prior conference years reflecting a higher level of fixed salary and support staff expense offset by the deferral of some expenses for the University of Michigan post-doctorate and the Baylor genetic counselor from 2018 into 2019.

PRISMS expects to continue to its support for research and program services at a higher level in the coming year including continued investment in the patient registry, genetic counselling for our members and research programs.

Of note is that in prior conference years, the conference would account for 65-70% of total expenses. In 2018, this metric declined to 46% and reflects the increasing focus on other program services and research on the part of PRISMS. One positive of note was the higher contribution to income of fundraisers held by members on behalf of PRISMS. This contribution grew by over 150% year over year. We are greatly appreciative of everyone's efforts.

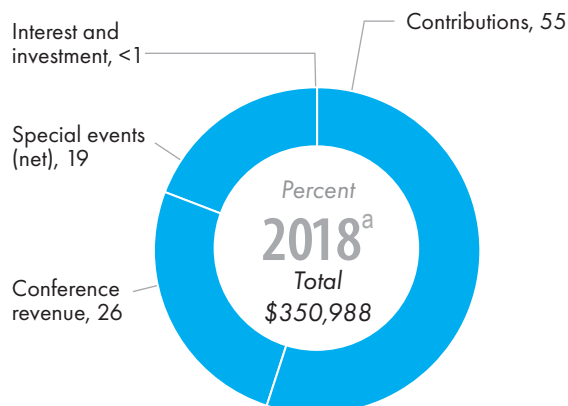
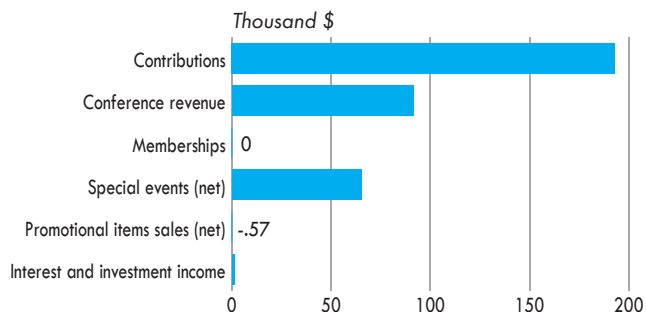
As PRISMS continues to grow and increases its investment in research we encourage all our members to find ways to contribute. One last note is that in 2018 membership fees were eliminated. We believe the lost income was easily replaced by greater levels of membership engagement and enthusiasm.

PRISMS 2019 budget call for continued drawdowns of our cash balances. Funding for the Research Symposium, the genetic counselor, the patient registry and the balance of the Michigan post-doctorate work may exceed \$150,000. Fortunately, the organization maintains financial assets upon which we can draw to fund these investments along with our other program services.

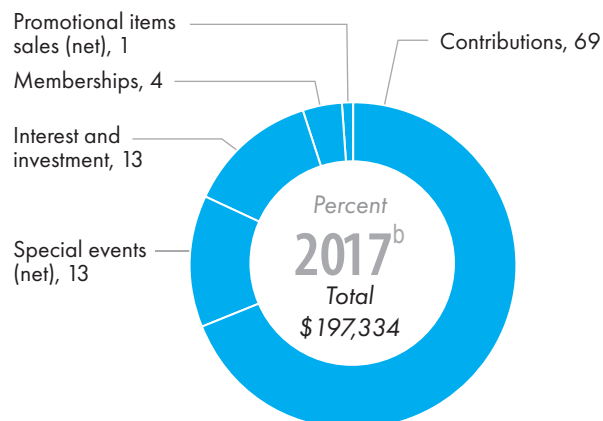
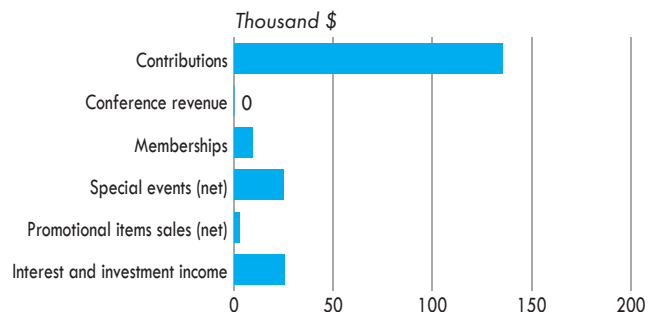
PRISMS continues to seek out new sources of funds to support its work and organization. 2019 should prove to be an exciting year as the organization works to develop a coordinated fundraising plan to support our future growth. PRISMS is grateful for all the hard work of its Executive Director, staff and volunteers to identify, develop and fund new programs and research that will provide lasting benefits to our community. 🌊

SUPPORT AND REVENUE

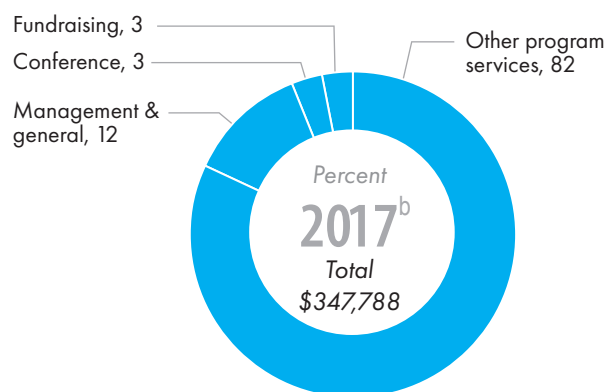
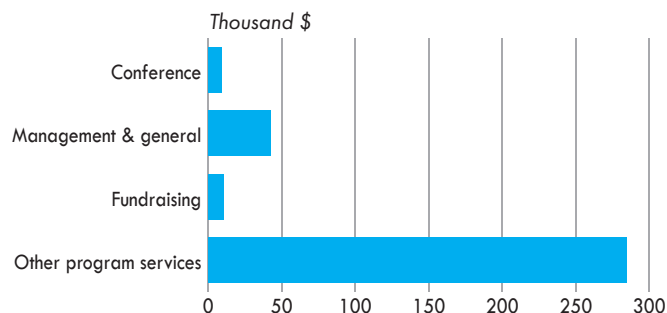
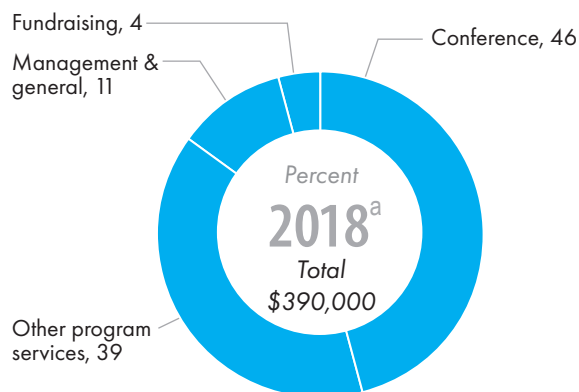
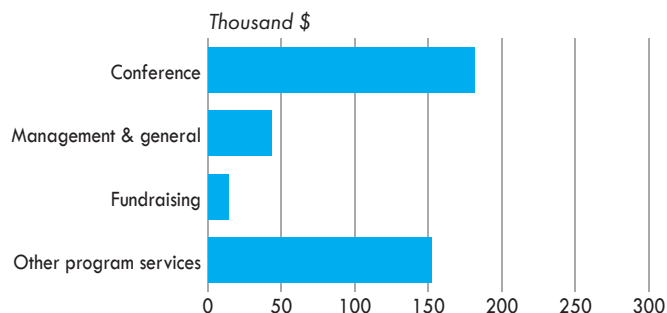
2018



2017



EXPENSES



ENDING CASH AND INVESTMENTS

\$491,000

\$540,184

ENDING TOTAL ASSETS

\$558,941

\$607,631

^aUnaudited; ^bAudited

PRISMS PAB ENSURES THE DISSEMINATION OF CURRENT, ACCURATE INFORMATION ON SMS

SARAH ELSEA

PRISMS Professional Advisory Board

Sarah H. Elsea, PhD, PAB Chair

Kerry Boyd, MD, FRCPC

Christine Brennan, MA CCC-SLP

Jane Charles, MD

Brenda Finucane, MS, LGC

Rebecca Foster, PhD

Santhosh Girirajan, MD, PhD

Andrea Gropman, MD

Barbara Haas-Givler, MEd, BCBA

Ann C.M. Smith, MA, DSc (Hon), CGC,
PAB Chair Emeritus

The PRISMS Professional Advisory Board (PAB) consists of 10 individuals representing the diverse needs of the SMS community. It is an internationally recognized group of basic scientists, educators and clinicians with expertise in SMS, genetics, molecular research, education, speech, development, and caregiver and sibling concerns. Most PAB members are actively involved in research and/or clinical activities related to Smith-Magenis Syndrome.

The PAB advises the PRISMS Board of Directors on medical, scientific, educational and therapeutic matters, and assists in the education and research activities of the organization. Members also communicate directly with families, caregivers, physicians, teachers and other healthcare providers to provide education to ensure the dissemination of current accurate medical information, including development and maintenance of the Smith-Magenis Syndrome GeneReviews (<https://www.ncbi.nlm.nih.gov/books/NBK1310/>), the SMS Medical Management Guidelines (<https://www.prisms.org/about-sms/living-with-sms/medical-management-guidelines/>), the PRISMS website, the Spectrum Journal and other publications.

PAB members are actively engaged in the development of questionnaires for the SMS Patient Registry, review grant applications and review potential research opportunities for the SMS and PRISMS community. The PAB looks forward to the 10th SMS Research Symposium to be held in 2019 in Houston, where current research related to SMS will be presented and research goals for the community discussed in an open format.

Successful research is a partnership among families, clinicians, scientists and funding agencies focused on improving research and knowledge about SMS. Continued support of research programs is critical for increasing awareness and understanding of SMS so that better therapies, treatments, education and other interventions can be identified or designed to improve the quality of life for individuals with SMS.

Supporting Research and Education

As part of its commitment to research and education, PRISMS has partially funded a genetic counselor and research coordinator at Baylor College of Medicine. The genetic counselor works directly with Dr. Sarah Elsea on establishing and maintaining a patient registry for individuals with SMS, the overall aim being to improve patient care through a better understanding of the nature of the disorder. These research and counseling services also provide assistance and support to PRISMS in updating and maintaining the PRISMS website, and serve as contacts for questions regarding the genetics and inheritance of SMS.

SMS Patient Registry

In 2017, the Smith-Magenis Syndrome Patient Registry (SMSPR) was launched in support of our long-standing aim to further collaboration between parents and researchers, with the goal of improved understanding of SMS. The patient registry collects and stores

medically relevant information from individuals with SMS, enabling researchers to analyze this data and gain insight into the natural progression of SMS. Enrollment in the SMS Patient Registry in 2018 rose to 58 individuals, with more inquiries every month. Future goals for the patient registry include a streamlined enrollment process that can be completed online, as well as to expand the questionnaires available for participation. We expect to collect data over several years, without a specific endpoint at this time. Please consider enrolling in this opportunity to expand our understanding of SMS: <https://www.prisms.org/research/sms-patient-registry/>

Research Studies and Participation Opportunities

Along with highlighting the latest research, PRISMS also assisted in recruiting participants for current research opportunities across the country. Such opportunities include the SMS Patient Registry and clinical trials relevant to the SMS population, including the Vanda Pharmaceuticals tasimelteon trial for circadian rhythm dysfunction (<https://finance.yahoo.com/news/vanda-announces-positive-pivotal-study-120000053.html>). 🌐

REGIONAL REPRESENTATIVE PROGRAM REACHED RECORD NUMBER IN 2018

PERCY HUSTON

The PRISMS Regional Representative program finished 2018 with a record number of 48 active regional representatives—an increase of 17 reps from 2017. Most reps live in North America (including Canada), but there also are worldwide reps in Russia, Australia, Brazil, France, Puerto Rico, Mexico, Italy and the UK.

Our goal in North America continues to be to have at least one rep in all 50 states. Based on geography, it would not be unusual to have multiple reps in a given state to better serve our families. This trend has already started in some of our larger states.

Our regional reps are PRISMS members who care and want to assist others who may be having similar needs or issues. Among other things, our regional reps are here to:

- Respond in a timely manner to email requests from families in their regions.

- Welcome new individuals and families into the PRISMS community and try to answer questions as needed.
- Listen to individual needs, reference the PRISMS website for specific information and develop a supportive rapport.
- Participate and cultivate a “regional” community through get-togethers when possible.
- Encourage families to join PRISMS and share the benefits of membership.
- Promote the PRISMS Patient Registry and assist families in registering their SMS relative to help ensure success of the program.

Our PRISMS website was overhauled in 2018 and has a wonderful, new look, including photos and bios of our regional reps. This is helpful for our families who strive to put a face to a name when interacting with their individual representatives.




PRISMS held a session for regional reps at the 2018 International Conference in Pittsburgh to help promote and expand the program. This session provided a meaningful venue for regional reps to share ideas as well as the opportunity to meet and bond with each other.

As we move forward in 2019, a Regional Representative committee has been formed and will meet at least quarterly in an effort to further expand and improve on the program. This committee will be comprised of the following regional reps, who have graciously volunteered even more of their time for the betterment of the program: Brandi Wilson, Kevin O'Connor, Allison Leatzow and Denien Rasmussen. This committee will report directly to the PRISMS board. Among other things, the committee hopes to move forward the following initiatives:

- Creating smaller "regional zones" with committee members serving as zone mentors.

- Providing additional shared resources to families for services and doctors that members are currently using.
- Creating webinars for regional reps to keep everyone up to date on issues important to the families in their regions.
- Adding additional reps to the committee as necessary.

To learn who your regional representative is, visit www.prisms.org. If you are interested in becoming a representative or have any questions about this program, please contact us at info@prisms.org. We currently need regional reps in the following states: Alabama, Alaska, Arkansas, Connecticut, Delaware, Hawaii, Idaho, Iowa, Maine, Maryland, Mississippi, Montana, Nebraska, Nevada, New Hampshire, North Dakota, Oklahoma, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Virginia, West Virginia and Wyoming. 

“I AM” CAMPAIGN HIGHLIGHTED PRISMS AWARENESS MISSION

TINA MCGREVY

Awareness. PRISMS believes that “increasing awareness and understanding of SMS” is so important to our community that awareness is one of the three cornerstones of our mission.

In 2018, PRISMS created the “I Am” campaign, a year-long, positive awareness initiative that gave a voice to our loved ones with Smith-Magenis Syndrome. This platform allowed individuals with SMS to share who they are and included: “I am a dancer,” “I am a singer,” “I am a chef,” “I am a graduate” and “I am a friend.” These photos and videos were shared across social media and were highlighted at the PRISMS International Conference in Pittsburgh and again on SMS Awareness Day, November 17, 2018.

Other PRISMS awareness accomplishments in 2018 included:

- A year-long celebration highlighting the 25th anniversary of PRISMS; establishing a 501©3 non-profit that is “dedicated to providing information and support to families of persons with SMS; sponsoring research; and fostering partnerships with professionals to increase awareness and understanding of SMS.
- The Facebook support group increased by 300 members for a total of 2,347 members who shared stories, hope and advice daily online. The PRISMS Facebook page has more than 2,000 followers.




- The PRISMS Twitter account has more than 550 followers and has tweeted more than 750 messages.
- The PRISMS Instagram account has 770 followers and has shared 245 posts.

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

PRISMS expanded the list of SMS publications to include a guidebook for newly diagnosed families. This book joins the PRISMS library of publications to help guide families throughout the lifespan of their individual with SMS.

PRISMS joined international organizations, including the National Organization of Rare Disorders (NORD) and Global Genes, to help raise awareness of rare disorders.

The PRISMS online store (prismsstore.org) continues to sell awareness merchandise, including SMS Superhero items.

The updated PRISMS website now includes a link for newly diagnosed families and a blog for shared stories to inspire and educate the worldwide community. 



FUNDRAISERS, AWARENESS EVENTS RAISED MORE THAN \$68,000

DENIEN RASMUSSEN

In 2018, the PRISMS community raised more than \$68,000 through fundraising and awareness events, with many families participating in outings, picnics and other events. A growing number of families also organized Facebook fundraisers.

PRISMS biggest event of the year was the “Night at the City Center,” held during the 10th International Conference in Pittsburgh. Hosted by Denien Rasmussen, Diane Erth and Brandon Daniel, this event raised more than \$22,000!

We appreciate the generous support of all who participated in these events, and we hope this fundraising growth continues in 2019. Financial support generated through fundraising events is essential and helps PRISMS continue its programming. We appreciate the hard work and generous support of everyone who organized and contributed to a fundraising event in 2018.

Here is an overview of the fundraising events:

Continuing Annual Events:

- The Farber Bowling Fundraiser, hosted by Sylvia and Jeremy Farber
- Nickels for Nico, hosted by Jean Bishop
- ABC Fundraiser, hosted by Denien Rasmussen and Kyle Rohde

First-time Events:

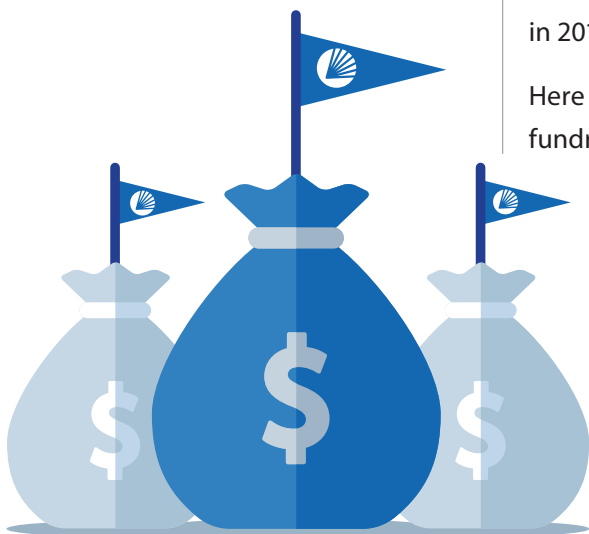
- Fundraiser at C.P. Coolers, hosted by Stephanie Billhardt
- Smith Magenis Syndrome Fundraiser, hosted by Trevor and Kasey Deamude
- T-Shirt Campaign, hosted by Robert and Shannon Duvall
- Vettes in the Vineyard, hosted by Percy and Bernadette Huston
- Family Fun Day, hosted by Diane Erth and Kathleen Macken

Film-Raiser Movie Fundraiser:

- Hosted by Denien Rasmussen

Yankee Candle Fundraiser:

- Hosted by Denien Rasmussen



Facebook Fundraisers:

- Dana's Fundraiser, hosted by Dana Benson Krimmel
- Kerry's Fundraiser, hosted by Kerry Lee
- Michelle's Fundraiser, hosted by Michelle Freeman Lee
- Kathleen's Fundraiser, hosted by Kathleen Macken
- PRISMS Fight for Hope, hosted by Kathleen Macken
- PRISMS Future of Hope, hosted by PRISMS
- Gail's Fundraiser, hosted by Gail Reiner
- Shannon's Fundraiser, hosted by Shannon Richard
- John's Fundraiser, hosted by John Roseborough
- Christian's Fundraiser, hosted by Christian Taylor

Facebook Birthday Fundraisers:

Davey Andersen
Lori Lynn Arthur
Michelle Bills
Jaimi Brown
Tracey Bunde
Jessica Christopher
Brooke Collins
L. Robyn Fell
Steve Flores
Jeff and Bonnie Schneider
Frautheimer
Cassie Jones
Heather Kay
Brandi King
Amanda Lamb
Allison Emrick Leatzow
Lando Livingston
Maureen Monroe
Riana Owens
Tabitha Petkovich
Marcio Pinto
Danielle Breaux Ramagos
Libby Robinson
Denien Rasmussen
Kandi Sykes
Joe Toussaint
Jose Ruben Vargas
Ashley Walker

Facebook Giving Tuesday Fundraisers:

Randy Beal
Danielle Cocilova Bier
Judy Carney
Diane Erth
Denien Rasmussen

Your fundraising endeavor, no matter how big or small, will help support the mission of PRISMS and its programs. It will be my pleasure to assist you in your fundraising needs. For more information, please contact Denien Rasmussen at fundraising@prisms.org or drasmussen@prisms.org. 🌐



Fundraisers help support PRISMS' mission and programs and our community.

PRISMS 2018 DONOR LIST

**COMPILED BY JULIE BERNATZ
AND ANGELA WILLIAMS**



*PRISMS donors are making a
difference in lives and families
touched by SMS. Thank you!*

\$25,000 and above

Laura Staich and Philip Ruedi

\$10,000-\$24,999

Betty Dyer

Vanda Pharmaceuticals

\$5,000-\$9,999

David and Holly Berger

The Bost Foundation

Karen and Glen Daniel

Pat Brown

\$1,000-\$4,999

Abram's Nation

Kevin and Darla Atherton

Raymond and Joan Bishop

Dawnda and Brandon Daniel

Christopher and Lindsay Doering

Barbara and Sam Dyer

Trevor and Kasey Gritman

Richard and Kate Hardegger

Tammie Henson

Alan and Gail Kopp

Mark and Brittany Lemmons

Debora and John Mayer

Margaret and Scott Miller

Kevin O'Connor

Denien and Jim Rasmussen

Jeanne Shobert

Denise and David Smith

Stone Oak Therapy Services

\$100-\$999

Sarin and Eric Abati

Ancient Order of Hibernians

Leah Baigell and Henry Kon

Lynne and Steve Baker

Michael and Kara Bale

Carolyn Beall

Peter Beavan

Billy Belcher

Gina and Steve Belden

Jeffrey and Krisha Belz

Rachel and Daniel Berger

Scott and Julia Beu

Joan and John Bielunski

Jason and Laura Birnbaum

Raymond Bishop, Jr.

Adam Blanchette, M.D. and Karen Blanchette

Pat Boschetto

Brandon Bristow

Ronald and Lynn Brown

Andrew and Bettie Buckman

Dennis and Eleanor Bush

Denise and Stewart Caddy

Joseph Caldas

Joan and Michael Campione

Paula Canham

Lesslie and Blair Carnahan

Causality

Robin and Tim Coutu

CP's Cooler

Peggy Craig

Tobin and Stacy Crosland

Kevin Daly

David and Sue Kuebler

David and Gail Reiner

Patty Davis

Robert and Anne Day

Dana Deane

Dennis and Tracey Dillon

John Doherty and Kathleen McMonigal

Linda Duvall

Robert and Shannon Duvall

Diane and Joseph Erth

Jackie and John Fallenstein

Sylvia and Jeremy Farber

Joseph and Desiree Fech

Christopher Ferreri

Brenda Finucane, MS

Jessica Florey

Timothy and Candace Ford

Frances E Streit Foundation Trust

Beverly and Steven Frey

Tom and Darlis Fuller

Austin Garrison, D.D.S.

Gene and Jennifer Gelfand

GeneDx

Jennifer Groeteke

Terrie and Harry Grose

Richard and Sarah Gunderson

William and Rebecca Hallmark

Daniel Hard

Frank and Michelle Haring

Linda and Jack Hartt

Julia and Tom Hetherington

King and Kecia Hickman

Douglas Hill

Kim and Eric Hoffman

Steven and Sandra Hogue

Stephen and Ceena Holzer

The Hom Family Fund

Cheryl and Eddie Huber

Jim and Emily Humphreys

Kathryn and Peter Hunter

Sabrina and Bill Hurtgen

H.J. and Gabrielle Huston

Jacqueline Huston

John and Donna Huston

Matt and Charla Huston

Nick and Leslie Huston

Percy and Bernadette Huston
 Nancy C. Jacobus
 Pamela Jaderlund
 Johnny's Rainbow Foundation
 Stephanie Jordan
 Todd and Debra Jordan
 Mary and Tim Kamp
 Gavin Kane
 Krista and David Karr
 Tyrone and Natalie King
 Lorna Kingston
 Jessica and Mark Kirklin
 Wes and Tiffany Kleckley
 Knights of Columbus Robert H Jones Council #3078
 Karen Krause
 Jeff and Bonnie Krautheimer
 Joseph and Kathy Krisko
 Ladies Ancient Order of Hibernians - Div. 3
 John Latas
 Miles and Robin Lawlor
 Samantha Layton
 Mike and Allison Leatzow
 Christine Loh
 Melissa and Dan Longman
 Lawrence Lordi
 Patty and Steve Loyer
 Theresa Luebcke
 Charlene Liao and Liqun Luo
 Janet Manning
 Michael and Lisa Mariano
 Mary Frazer Vaughn Legacy Fund
 Catherine McCann
 Mary Kate and Joe McCauley
 William and Patricia McDonough
 Olivia McGehee and Jim Schleicher
 Tina and Charlie McGrevy
 Janet Mendoza
 Timothy and Bonnie Menz
 Sean and Julie Metcalf
 Donald Michaud
 Jason and Charlene Michaud
 Ryan and Anees Miller
 Linda and David Mills
 Trinity and Mike Miodunski
 John and Alvina Mitchell
 Jason and Katherine Mull
 Marilyn Murray
 Sarah Neathery
 Kyleen Newlander-Jones
 Chau Nguyen
 Shinji and Kaori Nozaki
 Richard Parks
 Pediatric Therapy Associates
 Emil and Mary Helen Peter
 Monica and Mark Peterson

Diane and Michael Petrucci
 Scott and Lori Pettit
 Mary Pinchiaroli
 Lorraine Potocki, M.D.
 Pradeep Malhotra
 Walter and Jeanette Praetorius
 Ronald Purpora
 Quest Pumping
 Steven Ramirez
 Dennis and Sandra Raterman
 Alan and Elizabeth Rohde
 Kyle and Aileen Rohde
 Mark and Carol Divens Roth
 San Diego Remodel Works, Inc.
 Patty and Dan Saunders
 George Jr. and Janet Scherzer
 Ronald and Wanda Schuckmann
 Jordan Schultz
 Jason and Wendy Schwartz
 David and Linda Sedlar
 William and Caitlin Seldon
 Joan and Peter Sherman
 Kenneth and Frances Shipman
 Donald and Catherine Shoemaker
 Keka Sircar and Mark Lucas
 Shirley Skadan-Smith
 James and Amber Slater
 Holly Slaughter
 Ann and Ron Smith
 Debby Snyder
 Spectrum Communications and Consulting, Inc.
 David and Kathryn Stanush
 Thomas and Leah Starr
 Jonathan and Michelle Stehling
 Allison and Alex Stephanouk
 Elena and Anthony Stout
 Keefe Sullivan
 Brian and Linda Swierc
 Stacey Symonds
 Paul Taylor
 The Hills Local Pub
 Linda and Dan Tortorelli
 Carol and Stan Triantafellu
 Philip Turturro
 J. Marie Tuthill
 Denise and David Villani
 Cynthia Villaplana
 Ronnie and Janet Wagoner
 Derek Waldeck
 Patricia Walsh
 Eva and Weldon Wamble
 James Warman
 Larry and Judy Watters
 Christopher Weber
 Stephen and Cyndi Weinstein

Mark Whitaker
 Jennifer Wiedmar and Kenneth Brown
 Luke and Jamie Wilburn
 Josh and Stephanie Williams
 Ted Williams
 Jason and Mandy Williamson
 Jeffrey and Denise Wolf
 Rochelle and Paul Wright

\$1-\$99

Patricia Albert-Ross
 Kathleen Anderson
 Harriet and Martin Arno
 Marsha and Gary Bach
 Stephen and Mary Bale
 Brandon and Lindsey Ballschmiede
 Richard and Ruth Ballschmiede
 Robert and Christina Barfield
 Cally Bauman and Mathieu Lague
 Jason and Heather Benjamin
 William and Angela Bentley
 Jean-Mathieu Berger
 Julie Bernatz
 Damian and Danielle Bier
 Joseph and Ann Bishop
 William and Clari Bohannon
 John and Majorie Bolly
 Angela Bonato
 Cheryl Brand
 Michael and Rebecca Brown
 Michele Brumleve
 Deidra Busbee
 Yoo Chung Chang
 Gregory and Beverly Cherry
 Ilse and Randy Ciprich
 Dana and Robert Cohen
 Erin and Steve Corbett
 Mark and Lindy Cordell
 Sarah Costa
 Thomas and Diane Daly
 Ashley and Tom Danis
 Barclay and Tony Daranyi
 Christopher and Becky Davenport
 De Treville
 Timothy Dement
 Bryan and Janis Denman
 Robert and Terese Densmore
 Michael and Cher Doherty
 Leonard and Robin Dufkis
 Angela Eaton
 Marty and Jean Eichelman
 MariLou Elizondo
 Allison Elmore
 Sarah Elsea
 Caroline Embry

Judith Emmert
 Michael and Karmella Everhart
 Andrea Eyring
 Bruce and Linda Fech
 Linda Fernandez
 Anthony Fessina
 Ann Fields
 Emily Fields
 Karen and Chuck Friedman
 Stephen and Jenifer Fuson
 Tamra George
 Steven and Dorislee Gilbert
 Deborah Gonzalez
 Tino and Yira Gonzalez
 Anne Griffin
 Marilyn and Steve Groeteke
 Steven and Valerie Gruenwald
 Christine and Joey Grzybowski
 Mary Ann Gschwind
 Steven and Yvonne Hagan
 Sandy and Richard Hall
 Bruce and Murna Hansemann
 Heather Hansen
 Michelle Harter
 Heather Hartlage
 Jared and Abigail Heckendorn
 Maricela Hernandez Garcia
 Raymond and Shawn Herrick
 Erkia Heyer
 Steven and Elaine Hoff
 Kathy Hofmann
 Susan and Martin Holland
 Donald and Deborah Humphrey
 Christoffer Jacobsen
 Thomas and Kyla Jacobsen
 Patricia Jeremiah
 Craig Johnson
 Talia Judy
 Paula and Arthur Jump
 Scott and Marcia Kalina
 Jacqueline Kallenbach
 Edward and Joanne Kelly
 Nickolas and Leonor Kennaly
 Bryan Kettring and Diane Sears
 Saejit Kim
 Jennifer Koeser
 Beth and Paul Kurtz
 April Langston
 William and Roxanna Lauderdale
 Josephine Lawlor
 Donald and Rachael Lawson
 April Lefurgey
 Karen Lemcke
 George and Karen Lemmert
 Lance and Eleni Levitan
 Jason and Apryl Lowe

Jimmie and Katherine Loy
 Rose Lucchese
 William and Monica Mason
 James and Joann Mathis
 Joseph and Jane McCade
 Jim and Irene McCool
 Bruce and Kathleen Medaugh
 Mary and Paul Miller
 Darlene K Moore
 John and Maria Mosher
 Laurel Murray
 Mary Nees
 Colin and Sarah Neumann
 Frank and Adela Nevarez
 Quang and Diane Nguyen
 Faith Nobilucci
 Roger Ohlman
 On Small Feet
 Jaye Orgera
 Tom and Heidi Owen
 Laura Paladini
 Hector Paredes
 Kim and Tom Pastore
 Paul and Benita Soper
 Katrina Place
 Cecilia and Gordy Poole
 Rajean Potter
 Trina and Don Pulver
 Lonnie Raimond
 John and Audra Rankin
 Richard Rasmussen
 Douglas Read
 Ronald and Sandra Reigel
 Rock and Metal Systems, Inc.
 Eric and Jessica Rogers
 Carolyn Rohde
 Jan and Keith Rolston
 Anthony and Stacy Rukas
 Kevin and Stephanie Sanders
 George and Anna May Scherzer, Sr.
 Mabel Scherzer
 Scott and Jamie Shallcross
 Joseph Sicilian
 Kenneth and Mary Smith
 Kimberly Smith
 Stephen and Michelle Smith
 Nancy Snyder
 Larry and Mareen Stanley
 Paul Steele
 Robert and Patricia Steffan
 Steven Stith
 Vick Strong
 Kathleen Macken and Kevin Swartz
 Tracy Tempest
 David and Elaine De Temple
 Kathy Theis

Margaret and Robert Tortorelli
 Aaron and Michaela Towne
 Katy and Frank Tra
 Floyd Trujillo
 Anne Vincent
 Ellen Vogel
 Adrienne Wampler
 Brian Ward
 Angela Williams
 June Winkler-Teixeira
 Dennis and Edee Norman Wiziecki
 Carol and Glenn Wolschlager
 Robert and Jane Zbeeb
 Mary Ann and Ron Zimmer
 Gayle and Lawrence Zucker



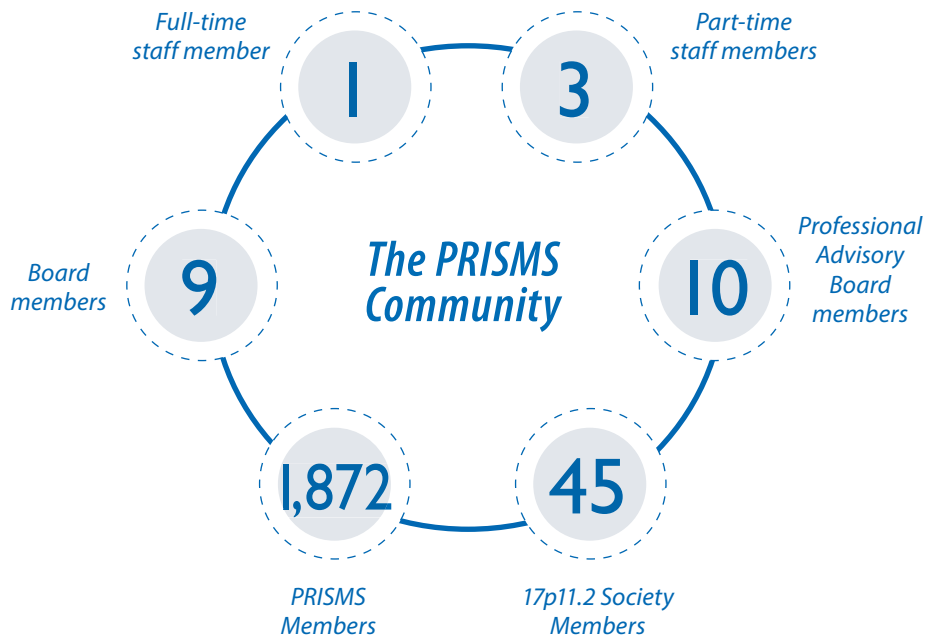
Donors share in the progress being made on behalf of those diagnosed with SMS.



2018 YEAR IN REVIEW

by the numbers

JULIE BERNATZ



Conference Social Media

PRISMS post engagement

was up **122%**

with **15,508** posts

Increased PRISMS page followers

by **371%**

with **170** new followers

PRISMS videos were viewed

more than **10,000** times

PRISMS posts reached

more than **17,000** people

Programs and Services

48

Regional Representatives

9

Regional Representative meet-ups

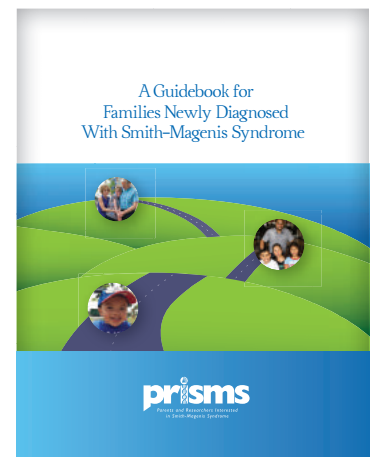
5

International Affiliate Organizations

58

SMS Patient Registry enrollees

Publications



Available to download on our website: www.prisms.org

65

"On the Road to Success" (hard copies)

3

Spectrum Journals

Awareness and Social Media



The **FACEBOOK GROUP** grew by more than

300
in 2018

reaching a total of

2,347
members



The **FACEBOOK PAGE** posted

2,007
likes

and had more than

2,000
followers



TWITTER

750
tweets

550
followers



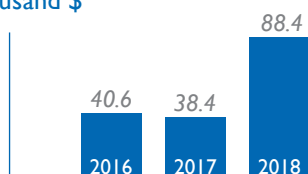
INSTAGRAM

245
posts

770
followers

Fundraising and Donations

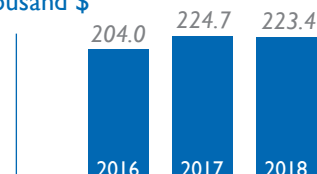
Member Fundraising
Thousand \$



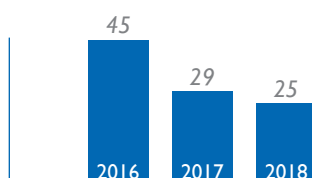
Unrestricted Donations
Thousand \$



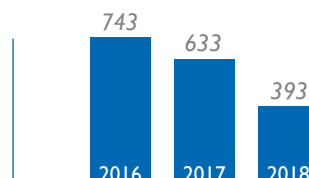
Total Donations
Thousand \$



Donors >\$1,000



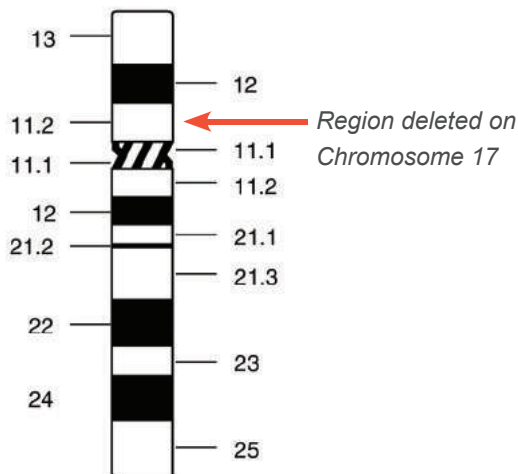
Individual Donors



What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2.

The first group of children with SMS was described in the 1980s by Ann C.M. Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is under-diagnosed, but as awareness of it increases, the number of people identified grows every year.



VOLUNTEER OPPORTUNITIES

PRISMS is always looking for helping hands from the community to serve as members of one of our various committees, assist in a program, or coordinate an event. Interested in sharing your time and talents with the SMS community? Contact us at info@prisms.org.

Editor-in-Chief: Dennis Dillon

Interim Director: Julie Bernatz

Office Assistant: Angela Williams

Designer: Mark Hernandez

Newsletter Committee Member: Pat Boschetto



EDUCATION | AWARENESS | RESEARCH

prisms.org