

“ THE PRISMS FAMILY IS LIKE A NET THAT WILL CATCH YOU AND SPRING YOU BACK UP WHEN SMS ISSUES KNOCK YOU DOWN. THEY ARE A FAMILY THAT IS THERE WHEN YOU REACH OUT TO LISTEN, OFFER GUIDANCE OR SHARE THEIR EXPERIENCES FROM A COMMON PLACE. ”

SMS PARENT AND PRISMS MEMBER





OUR 2016 IMPACT

EMILY FIELDS, EXECUTIVE DIRECTOR



2016 was an incredible year for PRISMS and the SMS community. With your support, PRISMS has seen amazing achievements reflecting an investment of more than \$330,000 in programs and services dedicated to education, awareness and research.

In 2016, PRISMS awareness efforts and engagements reached more than 30,000 people around the world as it:



***Hosted the 8th
International SMS
Research Symposium
connecting the
world's leading
SMS experts and
researchers***



***Held its 9th
International
"Building Bridges of
Hope" Conference,
providing support and
engagement for more
than 300 families and
professionals from
around the world***



Published the latest resource on SMS, "A Smith-Magenis Guide: Exploring Adult Residential Living", free of charge to families



Launched an International Partnership Program, creating a network of SMS support organizations from around the world



Supported the hiring of a genetic counselor at Baylor College of Medicine to assist in advancing research initiatives and provide increased support to SMS families

There is much work to be done, but together I am confident we will move forward in education, awareness and research for the entire SMS community.

Onward!



President's Letter

JOHN MAYER, PRESIDENT

We had quite a year in 2016! Through the efforts of many dedicated people, PRISMS accomplished much, expanded its programs and provided more service to the SMS community. Included in this Annual Report are the details. You will read about our International Conference, Regional Representative Program, International Research Symposium, Family Fundraisers, International Partnership Program, Adult Residential Settings publication and more.

I couldn't be more proud of our organization, more grateful for the dedication of the many people who give their time to help us, or more appreciative of all of you for your support. We are what we are because of all of you. As it is said: Together we are strong.

As president, my duty is to coordinate the work of the Board of Directors. We bear responsibility for the stewardship of all that is PRISMS. For some, the status of PRISMS is easily seen in its financial statements—and when you look at the 2016 report you will see that we continue to grow. With a conference, a research symposium, a staff and new programs, our expenses were more than ever. And so was our revenue—through membership, special donations, sponsorship and other gifts.



Over the past two years, our growth has been remarkable.

While strong financial statements are essential, the value of our programs to you and to our community is the most important measurement of our work. In what ways do we make a difference to you? How do we have a positive impact on your family?

We want to know what you think. If PRISMS did not provide a benefit to you, it would not be doing its job.

Personally, the 2016 conference was the most fulfilling one I have experienced, with a healthy blend of interesting sessions, the chance to spend time with old friends and the opportunity to make new ones.

What was it like for you?

I hope you will share your stories. Send me a message, post your thoughts on our Facebook page or send us a letter. Tell us how we are doing. Our commitment is to you and your family.

In return, we hope you will remain committed to us. Your support fuels all that we do.



Financial Report

PHIL RUEDI, TREASURER

In 2016, PRISMS invested to deliver the 2016 International Conference, the 2016 Research Symposium, the Adult Living publication and support the costs of a genetic counselor—all to the benefit of the SMS community.

Specifically, International Conference expenses, including the teach scholarship program and expanded family scholarship program, exceeded fees and direct contributions by \$80,000. PRISMS invested an additional \$15,000 to support the Research Symposium. At the same time, PRISMS expanded its accounting controls and at the beginning of 2017 added additional administrative support for the Executive Director.

Another accomplishment in 2016 was the move to segment some of PRISMS cash balances to diversified, low-risk income investments. This resulted in an additional \$10,000 in combined dividend and unrealized investment gains to further support program services while honoring our fiduciary responsibility.

This year will bring another Research Symposium, and planning has already started for the 2018 International Conference. In addition, PRISMS will invest to identify new ways to support the SMS community, including an increased focus on specific research projects.

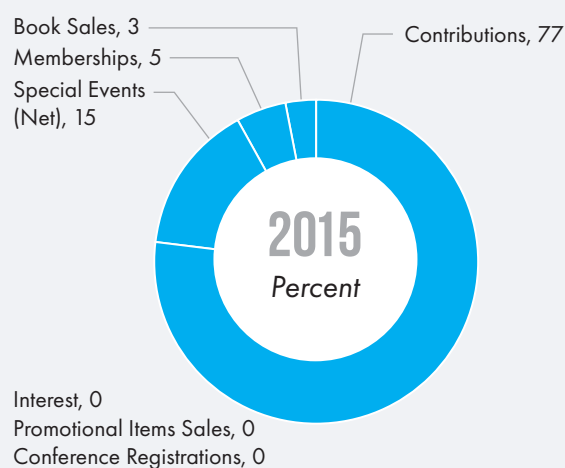
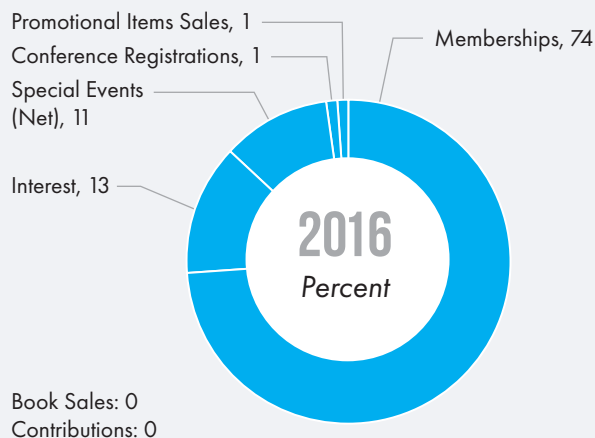
PRISMS is proud to highlight the financial strength of the organization that can be leveraged to support and expand our services to the SMS community. Cash and investments have reached an all-time high, at over \$500,000. Support from the membership and families of SMS persons resulted in net income of \$40,000 in 2016. This is a significant accomplishment in light of the investments made for the 2016 International Conference.

If PRISMS can execute its goals in 2017, these cash balances will likely come down. This would be a positive signal that PRISMS and the Professional Advisory Board have identified meaningful research projects to support. PRISMS is grateful for the support of its members and is committed to using such support to develop programs and support tools and identify impactful research projects that will benefit the entire SMS community.

REVENUES AND EXPENSES AS PERCENT OF CONTRIBUTIONS

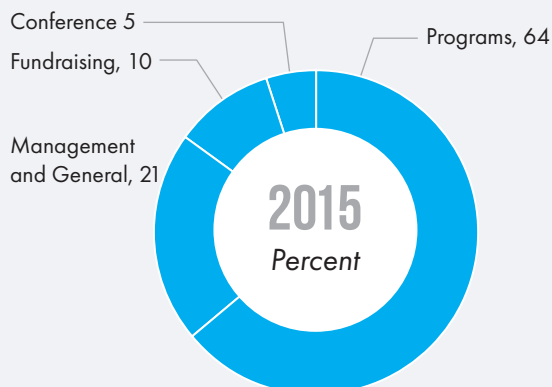
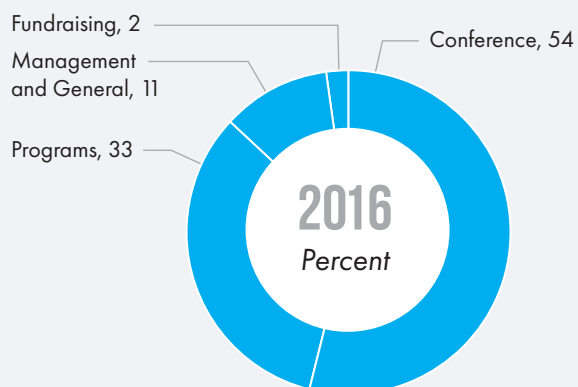
SUPPORT AND REVENUE

Audited



EXPENSES

Audited



	2016 ^a	2015 ^b
Support and Revenue		
Contributions	\$252,822	\$144,093
Conference Registrations	49,581	0
Memberships	10,185	9,992
Special Events (Net)	32,133	27,774
Promotional Items Sales	9,241	59
Book Sales	5,379	4,852
Interest and Investment Income	11,916	618
Total	371,257	187,388
Expenses		
Conference	172,462	6,850
Programs	107,015	85,154
Management and General	35,986	28,320
Fundraising	5,908	12,872
Total	321,371	133,196
Ending Cash and Investments	536,281	496,890
Ending Total Assets	703,438	661,513

^a Unaudited.

^b Audited.

Our Commitment to Research

DR. SARAH ELSEA, PH.D., PAB CHAIR & DIANNE SAMAD, GENETIC COUNSELOR

The 10-member PRISMS Professional Advisory Board (PAB) advises the Board of Directors on medical, scientific, educational and therapeutic matters, and assists in the education and research activities of the organization. The PAB 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.

As part of its mission, the PAB assists in the development of accurate and effective informational and promotional materials, and writes and edits articles for Spectrum, the PRISMS website and other publications. This dedicated group of experts responds to inquiries from families, caregivers, physicians, teachers and various other healthcare providers to support the SMS community and ensure the dissemination of current and accurate medical information.

In 2016, we were honored to welcome Dr. Santhosh Girirajan, MD, Ph.D. of Pennsylvania State University to the PAB.

8TH SMS RESEARCH SYMPOSIUM

On February 4-5, 2016, PRISMS held its 8th SMS Research Symposium at Baylor College of Medicine in Houston. Bringing together more than 40 of the world's leading SMS experts, researchers and professionals for the only event

of its kind focused on Smith-Magenis Syndrome, this investment of more than \$20,000 in advancing research for the SMS community was a great success.

As part of its commitment to supporting research and advancements for the SMS community and sharing that progress with our families, PRISMS funded the creation of abstract summaries to share the latest research findings with you. You can view those summaries on the PRISMS website at <http://prisms.org/us/smsresearch/2016-research-symposium>

SUPPORT OF GENETIC COUNSELOR

In 2016, PRISMS welcomed Dianne Samad, MS, CGC, as the newest member of its research team. Ms. Samad is a genetic counselor at the Baylor College of Medicine. As part of PRISMS commitment to research and education, the organization has partially funded the genetic counselor position.

Ms. Samad is working directly with Dr. 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. Ms. Samad also provides assistance and support to PRISMS in updating and maintaining the PRISMS website, and serves as a person of contact for questions regarding the genetics and inheritance of SMS.

"The symposium gave the perfect opportunity to gain so much in one place"

"I found [the symposium] to be a wonderful place to network and engage more about SMS"

"I liked the variety of presentations and demonstrations of commitment to SMS and related work"

"I felt privileged to participate [in the symposium]"

RESEARCH STUDIES AND PARTICIPATION OPPORTUNITIES

In 2016, PRISMS provided SMS experts and professionals opportunities to present on the latest research and findings at both its 8th SMS Research Symposium and its 9th International “Building Bridges of Hope” Conference (July 28-30 in St. Louis). Leading experts presented on a variety of innovative research with more than 20 presentations.

Along with highlighting the latest research, PRISMS also assisted in recruiting participants for current research opportunities across the country. Such opportunities include an SMS patient registry and clinical study investigating circadian rhythms and sleep disturbances in people with SMS through Vanda Pharmaceuticals; a research study at the University of Colorado in Boulder related to speech-language services and therapies provided to SMS children in schools; a study from the University of Tennessee Health Science Center on dental pulp in SMS individuals, and more.

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 quality of life for individuals with SMS.



Regional Representatives

PERCY HUSTON, REGIONAL REPRESENTATIVES CHAIR

The PRISMS Regional Representatives program continues to grow. It now has 31 regional reps, including nine internationally.

Our goal in North America is to have a representative in all 50 states, and we are constantly looking for volunteers who may be interested in serving. Our regional representatives are PRISMS Members who care and want to assist others who may be having similar needs or issues. Among other things, our regional representatives 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 to share the benefits of membership.

A series of support calls was established and held in 2016 to provide an avenue for our representatives to share thoughts, experiences, concerns, etc., to better facilitate their roles. Additionally, a Facebook group was established for regional representatives to remain connected and to share advice and insight from their experiences as a representative.

PRISMS held a session for regional representatives at the 2016 International "Building Bridges of Hope" conference in St. Louis to help promote and expand the program. There are plans to host a similar session at the 2018 conference in Pittsburgh.

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.

International Partnership Program

EMILY FIELDS, EXECUTIVE DIRECTOR

In early 2016, PRISMS launched an International Partnership Program in an effort to expand communication with and support of international organizations and associations dedicated to serving SMS families. Today, the International Partnership Program includes:

Smith-Magenis Syndrome Australia

Smith Magenis Mexico

Smith-Magenis Syndrome Foundation UK

Association Smith Magenis 17 France

Sirius e.V. Germany

PRISMS and the international partners agree to join forces to strengthen the common voice of people living with SMS; to promote SMS as an international public health priority; to enlarge outreach to SMS families, researchers, educators and physicians; and to expand networking and knowledge sharing.

PRISMS is dedicated to strengthening the Smith-Magenis Syndrome community, creating a global network of resources and associations. PRISMS hopes to continue to develop partnerships with SMS associations around the world.

If you are a representative from an association or organization dedicated to Smith-Magenis Syndrome family support and are interested in learning more about the International Partnership Program, please contact Emily Fields, Executive Director, efields@prisms.org.

General questions about PRISMS and this new program? Contact us at info@prisms.org



Membership

ROCHELLE WRIGHT, MEMBERSHIP CHAIR

Membership in PRISMS continues to grow. At the end of 2016, there were 271 individuals or families from 46 states and 12 foreign countries across six continents who were members of PRISMS!

Membership dues are a critical part of funding PRISMS programs and services to support our community. As a nonprofit organization, we depend on the kind support of members and donors to continue to provide and improve all of the many valuable services and information to empower our community.

Membership is open to anyone interested in supporting and engaging with the SMS community. Our membership includes parents, siblings, grandparents, friends, educators, researchers, therapists and advocates. PRISMS membership is for the calendar year January-December.



6 REASONS WHY IT'S IMPORTANT TO BE A PRISMS MEMBER

1

MEET NEW FAMILIES JUST LIKE YOU

- Your regional representative will help you get in contact with other families in your area. He or she will also answer any questions you may have, and offer guidance and support.
- Many regions have informal family gatherings throughout the year. If we don't know who you are or how to contact you, you'll miss out on important opportunities to find support and meet others in your unique situation.

2

ACCESS TO THE INTERNATIONAL SMS CONFERENCE

- As a member, you'll receive regular updates on the PRISMS International SMS Conference directly to your email and a reduced registration fee for the event.

3

FOSTER RESEARCH AND SCIENTIFIC AWARENESS

- Becoming a member is critical to furthering research. Our membership list provides us with the latest number of cases of Smith-Magenis Syndrome. That number will give us an opportunity to accelerate research initiatives into SMS.
- As the go-to source of information about SMS for the scientific community, an updated membership list helps us to direct researchers to families interested in propelling research forward.
- With membership, you gain access to research updates sent directly to your email, including information on the latest in SMS research following each SMS Research Symposium.

4

MAKE AN IMPACT ON ISSUES IMPORTANT TO YOU

- Having a clear picture of how many families are affected by SMS will help us to raise awareness of SMS and its related conditions among national and local lawmakers, federal agencies and other non-profits in the special needs community.
- There's strength in numbers. It's important that we're able to show the impact of our community.
- An updated membership number will help us to gain support from additional donors and funders.

5

JOIN A GROWING INTERNATIONAL COMMUNITY

- We encourage families, researchers and educators around the world to become part of our organization. Membership is open to everyone.

6

STAY IN TOUCH WITH PRISMS

- As a member, you will receive quarterly Spectrum Journals via email with the latest news about families, research and the organization.
- You'll also get the latest news and information from PRISMS emailed to you about critical topics such as our international conference, research studies and updates on key developments that affect your family.

Questions about membership? Contact us at info@prisms.org

Our Members

Sarin & Eric Abati
Delma & Alejandro Aguilar
Betsy & Frank Andersen
Harriet & Martin Arno
Darla & Kevin Atherton
Leah Baigell & Henry Kon
Lynne & Steve Baker
Cally Bauman & Mathieu Lague
Mary & Randy Beall
Gina & Steve Belden
Sonia & Brian Bench
Jean-Mathieu Berger
Rachel & Daniel Berger
Cheryl & Ned Berman
Joan & Raymo Bishop
Carla & Glenn Blaser
Christine & Ken Bolt
Alice & Mark Bost
Janie Boyd
Dr. Kerry Boyd
Kristine & Glen Braden
Carol & Tom Braithwaite
Melissa & Steffen Brandt
Brigitte Braun
Diana & Paul Brice
Debbie & Niven Brooks
Carolyn Bruister
Stephanie & Timothy Buta
Jack Byrom
Denise & Stewart Caddy
Joan & Michael Campione
Lesslie & Blair Carnahan
Judy & Frank Carney
Maria Elena Carrancedo
Monique Caudill
Jane Charles
Ilse & Randy Ciprich
Rosemary & Rod Clifford
Dana & Robert Cohen
Jennifer & Joseph Comford
Cheri Connealy
Erin & Steve Corbett

Nancy & David Cordrey
Robin & Tim Coutu
Beverly Curtin
Robert Curtin
Diane & Thomas Daly
Dawnda & Brandon Daniel
Karen & Glen Daniel
Ashley & Tom Danis
Tony & Barclay Daranyi
Yolanda & Alfredo DaSilva
David & Sue Kuebler
David & Gail Reiner
Donna Davis
Patty Davis
Angela DeaMude
Shirley & Donald Dechainé
Jennifer & Esteban Delgadillo
Sharyn DeZelar
Dr. Lynn Diamond
Susan & Paul Diamond
Gwen & John Dill
Tracey & Dennis Dillon
June & Richard Dixon
Karen & Ronald Dixon
Lindsay & Christopher Doering
Kathleen McMonigal & John Doherty
Amanda & Brian Downey
Amanda Dunham
Jennifer Durham
Linda Duvall
Maryann & Paul Duzan
Angela Eaton
Sarah Elsea
Diane & Joseph Erth
Norma & Richard Erth
Ingunn Fagermoen
Allison Herman & William Faistenhammer
Jackie & John Fallenstein
Sylvia & Jeremy Farber
Rosa & Timothy Farrington
Ashley & Andrew Fazel
Ann & Dan Fields

Emily Fields
Rebecca Foster
Pernille & Sergio Fox
Beverly & Steven Frey
Karen & Chuck Friedman
Courtney Frist
Darlis & Tom Fuller
Carol & Howard Funnell
Sara & Tsvi Gal
Jennifer & Gene Gelfand
Nicole Gonzalez
Yira & Tino & Gonzalez
Amanda & Charlie Graham
Marilyn & Steve Groeteke
Terrie & Harry Grose
Christine & Joey Grzybowski
Sandy & Richard Hall
Rebecca & William Hallmark
Kristen & Michael Hamilton
Stephanie & Nicholas Hanson
Dennis Hartmann
Stacey Hayes
Tiffany Helling
Cheryl & Richard Herman
Jeanine Hetherington
Julia & Tom Hetherington
Mary Hetherington
Kecia & King Hickman
Rosanne & Pace Hindsley
Ann & George Hobbs
Kim & Eric Hoffman
Susan & Martin Holland
Kathy Hofmann
Cheryl & Eddie Huber
Jamie & Jim Humphreys II
Emily & Jim Humphreys
Sabrina & Bill Hurtgen
Bernadette & Percy Huston
Willard Hutton
Yukiko & Tetsuya Ichino
June & Todd Jacobson
Nancy C. Jacobus
Shannon & Darin Jantzi
Vidar Gunnarsson & Thuridur Jonsdottir
Paula & Arthur Jump
Irene Karpowicz
Krista & David Karr

Nina & James Kelly
 Laura King
 Jessica & Mark Kirklin
 Jennifer & Lou Klump
 Irene & Dan Knoepfle
 Kristin Korinko
 Dana & Timothy Krimmel
 Kathy Krisko
 Beth & Paul Kurtz
 Catherine & Lincoln Lakoff
 Kathryn & Joe Larter
 Erin & James Lawlor
 Josephine Lawlor
 Robin & Miles Lawlor
 Carissa Le
 Mike & Allison Leatzow
 Michelle & Kerry Lee
 Karen & George Lemmert
 Judith & Matthew Livingston
 Melissa & Dan Longman
 Tammy Louviere
 Elaine Makinson
 Janet & Bill Manning
 Laura & Matt Markus
 Lily & Ronn Marriott
 Margaret & Paul Marshall
 Lisa & Matthew Martin
 Debora & John Mayer
 Mena & Tom Mazza
 Mary Kate & Joe McCauley
 Jim & Irene McCool
 Kipley & Ross McDaniel
 Olivia McGehee & Jim Schleicher
 Tina & Charlie McGrevy
 Heather & James Michalski
 Charlene & Jason Michaud
 Lorna Harris & Jennifer Miller
 Margaret & Scott Miller
 Mary & Paul Miller
 Anees & Ryan Miller
 Linda & David Mills
 Trinity & Mike Miodunski
 Yoko Mizutani
 Dawn & William Mock
 Maria & John Mosher
 Heidi Nag
 Natasha Neely Ray

Megan & Keith Nelson
 Aimee Nemeth
 Adela & Frank Nevarez
 Faith Nobilucci
 Kimerly & David Norman
 Shinji & Kaori Nozaki
 Stephany Nunez
 Dana Deane & Kevin O'Connor
 Jaye Orgera
 Amy Owens
 Joan & Achille Paladini
 Laura Paladini
 Kim & Tom Pastore
 Jean & Charles Patnode
 Benita & Paul Soper
 Celeste & Kemal Pegram
 Milissa & Michael Pelonero
 Lisa Peracki
 Michelle & Jay Perkins
 Linda & Van Peters
 Monica & Mark Peterson
 Tabitha & Dan Petkovich
 Diane & Michael Petrucci
 Mary Pinchiaroli
 Rolando Polanco
 Diane Powers
 Jeanette & Walter Praetorius
 Liz & Bob Pucci
 Debbie & Jim Rahfaldt
 Natalie & Patu Rangitoheriri
 Denien & Jim Rasmussen
 Kelly Rausch
 Ann & Lowry Reid
 Brenda & Tony Resha
 Zenaida Reyes
 Anne Riccardi
 Shannon & Darrell Richard
 Kelsey & Graham Roberge
 Janet & Dennis Roberts
 Johnna Robinson
 Jessica & Eric Rogers
 Aileen & Kyle Rohde
 Jan & Keith Rolston
 Marni Rolston & Jed Huseby
 Joanna & John Roseborough
 Suzanne & Charles Ruedi
 Judy Rupp

Renee Ryan
 Donna Santiago-Douglas & Michael Douglas
 Patty & Dan Saunders
 Jamie & Matthew Seward
 Sandra Seward
 Joan & Peter Sherman
 Jeanie & Michael Singleton
 Ann & Ron Smith
 Denise & David Smith
 Bonnie & Bill Spear
 Kelli Brasket & Andrew Staich
 Laura Staich & Philip Ruedi
 Jane Stanley
 Kristine Ahlgren & Espen Stavland
 Pauline Steinback
 Allison & Alex Stephanouk
 Elizabeth Sullivan
 Kathleen Macken & Kevin Swartz
 Dena Sweat
 Elanie & David De Temple
 Marika & Geoff Thomsett
 Sandy Tome
 Linda & Dan Tortorelli
 Margaret & Robert Tortorelli
 Katy & Frank Tra
 Gwen & John Turner
 Bela Kafengauz & Alexander Tzetlin
 Amina Hameed & Osman Umarji
 Ruth & Dennis Unglesbee
 Patricia van Nederveen
 Stacey & Scott Vandiver
 Denise & David Villani
 Celeste & Ronald Wacławik
 Catherine & Stuart Walker
 Madonna & Dan Walsh
 Isobel Watkinson
 Racheal Weaver
 Laura & Christopher Wells
 Ivy Wetherell
 John & Brooke Widmer
 Josh & Jill Wood
 Hazel Wotherspoon
 Rochelle & Paul Wright
 Claudia Zambrano
 Michele & Joe Zdanowski
 Annetta Zidzik

Supporting PRISMS Work

DENIEN RASMUSSEN, FUNDRAISING CHAIR

The PRISMS community raised more than \$40,000 through fundraising and awareness events in 2016. SMS families across the country used their creativity, resources and passion to hold events in their local areas to raise funds, increase understanding and garner support for the entire SMS community. Below are a few of the 2016 fundraisers you hosted in your communities:

- Cakes for a Cause. Organizer, Jill Wood
- Race for Patrick Toussaint. Organizer, Joseph Toussaint
- Nickels for Nico. Organizer, Jean Bishop
- Macken Family Fun Day. Organizer, Kathleen Macken
- The GodBox Performance and Benefit. Organizers, Mary Kate McCauley and Kate Hathaway
- Bowling for SMS. Organizers, the Farber family
- IL Support Group. Organizer, Denien Rasmussen





PRISMS is thankful for the generous donations to support its mission as well as the time and effort individuals, like you, put in to raising awareness for SMS through special events in your area. The work you do in your communities is immensely valuable. There are countless stories of connections made through these events which lead to increased understanding, valuable support and even diagnosis of a friend or family member.

The success of these events in 2016 is a driving force for PRISMS moving forward. In 2017, we look to providing resources to you and your family as we encourage you to continue to raise awareness and funds in your area to benefit our mission and programs.

We encourage you to host a fundraiser in 2017. Please contact us at info@prisms.org. We will support you in making your event a success.

Didn't see your 2016 fundraiser listed above? Hoping to hold an event in 2017? Contact us at info@prisms.org. In 2017, we'll be improving our systems to better capture your fundraising and awareness efforts, but we need to hear from you. Reach out today!



Our Donors

\$25,000 +

Dyer, Betty
Staich, Laura

\$15,000-\$24,000

Vanda Pharmaceuticals

\$5,000-\$9,999

Bost Foundation, The

\$1,000-\$4,999

Allegis Group Foundation
Bazany, Frances A
Beall, Carolyn
Bishop, Jean
Bishop, Raymond & Joan
Campbell, Jamie & Kelly
Cape May Stage, Inc.
Clegg, Don
Daniel, Dawnda & Brandon
Daniel, Karen & Glen
Farber, Sylvia & Jeremy
Frances E Streit Foundation Trust
Glazer, Bruce
Huston, Percy & Bernadette
Kopp, Alan and Gail
Luo, Charlene Liao & Lique
Mayer, Bill & Sprung, Laurie
Mayer, Debora & John
Mayer, Elizabeth
McDaniel, Kipley and Ross
Northern Hills United Methodist Church
O'Connor & Dana Deane, Kevin
Rahfaldt, Jim & Debbie
Sarver, Lacey
Stone Oak Therapy Services
Wood, Josh & Jill

\$500-\$999

Anderson, Eric
Beall, Mary & Randy
Bielunski, Joan and John
Blanchette MD, Adam and Mrs. Karen
Blanchette,
Brooks, Niven & Debbie
Buckman, Andrew & Bettie
Cycle Bar
Dyer, Barbara & Sam

Elsea, Sarah
Fallenstein, Jackie and John
Hardegger, K.J. and Richard
Hartt, Linda & Jack
Layton, Samantha
Longman, Melissa & Dan
McDonough, William and Patricia
Mitchell, John and Alvina
Pinchiaroli, Mary
Pruett, Kay
Ross, Dominic & Paige
Rondon, Fernando & Kathy
Taylor, Betsy
Thomson, Harry & Janette
Toussaint, Paula & Joseph
Weber, Courtney
Williams, Ted
Wright, Rochelle & Paul

\$100-\$499

Abati, Sarin & Eric
Altsman, Bryan & Karen
Anderson, Telford and Kariann
Barron, David
Belcher, Billy
Belden, Gina & Steve
Belz, Jeffrey and Krishna
Bender, John & Mary Ann
Bending Branch Winery
Bennett, Robert
Berger, Rachel & Daniel
Birnbaum, Jason & Laura
Birsh, Joan
Bishop, Lisa
Bishop, Raymond
Boschetto, Pat
Braithwaite, Carol & Tom
Bristow, Brandon
Bush, Dennis and Eleanor
Byrom, Jack
Campioni, Joan & Michael
Carter, Miguel & Cecilia
Cassidy, Joseph
Cattie, Gerard F.
Chaumette, Inc.
Cheatwood, Kenneth & Patti
Clifford, Rosemary & Rod
Copeland, James and Michelle

Corbett, Christopher & Lisa
Costa, Kleber
Creel, Ronald and Carol
Crosland, Carl & Stacy
Daly, Kevin
Daly, Thomas and Diane
David & Sue Kuebler
Davis, Albert & Monica
Day, Robert & Anne
Delgadillo, Esteban and Jennifer
Dillon, Dennis & Tracey
Dixon, Ronald and Karen
Doering, Christopher & Lindsay
Doherty, Frank & Joyce
Downey, Brian and Amanda
Duvall, Linda
Elrod, George & O'Gatha
Elrod, Haley
Fech, Joseph
Finucane, MS, Brenda
Fuller, Matthew & Lynda
Fuller, Tom and Darlis
Gary, Daniel & Emily
Graham, Amanda & Charlie
Grose, Terrie & Harry
Haley, James
Hallmark, William and Rebecca
Hanna, Thomas and Marilyn
Haring, Frank and Michelle
Harrington, Daniel & Maria
Hindsley, Rosanne and Pace
Hobbs, George and Anne
Hoffman, Kim & Eric
Hogue, Steven & Sandra
Hunt, Michael & Lou Beth
Hunter, Kathryn and Peter
Huston, John & Donna
Huston, Matt and Charla
Ichino, Yukiko & Tetsuya
Jacobson, June & Todd
Jacobus, Nancy C.
Jantzi, Shannon & Darin
Johnson, Ray and Rose Marie
Jones, Roy & Renee
Jump, Paula & Arthur
Karr, David and Krista
Kemp, Jeremy & Sherri
Kirklin, Jessica & Mark

Klausing, Stephen
 Knights Of Columbus Robert H Jones
 Council #3078
 Koerner, Thomas and Kelly
 Krisko, Kathy
 L. N. Zimmermann, Inc.
 Lavedan, Christian
 Maggiano's
 Mason, H.W. & Linda
 Mathis, James & Joann
 Matoka, Angela
 Maynor, Gerald and Sarah
 Mays, Bryce & Kerry
 McCauley, Mary Kate & Joe
 McGrevy, Tina & Charlie
 Miller, Margaret & Scott
 Miller, Mary & Paul
 Miller, Pamela
 Mills, Linda & David
 Miodunski, Trinity and Mike
 Mock, Dawn & William
 Moya, Steven & Alissa
 Murphy, Gary & Mary
 Neely Ray, Natasha
 Nevarez, Frank & Adela
 Nuessle, William & Barbara
 Orgera, Jaye
 Parks, Richard
 Persyn, Anthony & Lori
 Petrucci, Diane & Michael
 Pettit, Scott & Lori
 Powell, Anthony & Laura
 Pruett, Stanley
 Pucci, Liz & Bob
 Quest Pumping
 Rasmussen, Denien & Jim
 Raterman, Dennis & Sandra
 Reid, Ann and Lowry
 Reyes, Zenaída
 Richardson, Joshua
 Roseborough, John & Joanna
 Roth, Mark and Carol Divens
 Rovner, Ronald & Stacy
 Ruder, Patrick & Bonnie
 Rule, Judy
 Ryan, Renee
 Sanchez, Thomas & Terri
 Saunders, Patty & Dan

Scherzer, George & Janet
 Schwartz, Jason & Wendy
 Sherman, Ann and John
 Shipman, Kenneth and Frances
 Shirley, Rhett & Molly
 Shobert, Jeanne
 Shoemaker, Donald and Catherine
 Sircar & Lucas, Keka & Mark
 Slaughter, Holly
 Smith, Ann & Ron
 Smith, Denise & David
 Smith, Kimberly
 Smith, Robert
 Smith, Stanley
 Snead Auto Parts
 Spear, Bonnie & Bill
 Staich, Andrew & Brasket, Kelli
 Staich, Stephen & Arlene Marie
 Stanush, David and Kathryn
 Starr, Thomas and Leah
 Steele, Richard & Gayle
 Steinback, Pauline
 Stone Oak Aesthetic Dentistry
 Stout, Elena & Anthony
 Stuart, David and Rhonda
 Stuffings, Jeffrey
 Swangler, Valerie
 Swierc, Brian & Linda
 Taylor, Tony and Ruth
 Thompson, Sue
 Tidwell, Ann
 Tilley, Chris & Andrea
 Tome, Sandy
 Tortorelli, Linda & Dan
 Triantafellu, Carol & Stan
 Trucksess, William & Janice
 Tuuri, Timothy & Janet
 Unglesbee, Ruth & Dennis
 Vonsavage, David & Claudia
 Warman, James
 Wash Tub, The
 Watters, Larry & Judy
 Wells, Christopher and Laura
 West Ohio Chapter DDNA
 Wetherell, Ivy
 Whitaker, Mark
 Wiedmar, Jennifer
 Williams, Josh & Stephanie

Williamson, Jason & Mandy
 Wilson, Stacy
 Wolf, Jeffrey & Denise
 Woodland, William and Rebecca
 Young, Aaron and Megan
 Zachar, Mike & Kathy
 Zimmer, Mary Ann & Ron

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Abati, Dave and Linda
 Alder, April
 Alexander, Charles & Carla
 Alldredge, Larry and Sherri
 Allison, Lee & Kelli
 Altilio, Gerald
 Arno, Harriet and Martin
 Arthur, Cecil & Lori
 Baigell, Leah
 Bailey, Joseph & Karen
 Baker, Lynne & Steve
 Barrett, Michele
 Barsby, George & Pamela
 Benjamin, Jason & Heather
 Bentley, William and Angela
 Blackmon, Myra
 Blaser, Carla & Glenn
 Bohannon, William & Clari
 Bolly, John & Majorie
 Bonato, Angela
 Brooks, Marlin & Patsy
 Bruister, Carolyn
 Brumleve, Michele
 Burgess, James and Amy
 Canham, Paula
 Cardwell, Sara
 Carnahan, Lesslie and Blair
 Church, Joby & Carol
 Cleveland, Jack and Sonya
 Cohen, Dana and Robert
 Criswell, James and Nancy
 Criswell, Michael & Lori
 Cullen, Barbara
 Cummings, Diana
 Cutler, Thomas & Deborah
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 Davis, Sandra
 Decker Farms
 Decker, Terry & Joyce

Diamond, Paul & Susan
 Dill, Gwen & John
 Dilullo, Lisa
 Duffy, William & Pamela
 Durham, Jennifer
 Dyer, Morris & Becky
 Erth, Diane & Joseph
 Erth, Norma and Richard
 Everhart, Michael
 Fain, Stuart
 Farris, Gina
 Feetterer, Robert & Catherine
 Fields, Dan & Ann
 Fitzgibbons, Julia
 Fountain, Timmy and Sherri
 France, Gerald & Connie
 Frey, Beverly & Steven
 Friedman, Karen & Chuck
 Frist, Courtney
 Fuson, Stephen & Jenifer
 Grant, Nancy
 Grzybowski, Christine & Joey
 Gschwind, Mary Ann
 Guinan, Thomas and Judith
 Hammond, Dennis
 Hansen, Sandy
 Hartmann, Dennis
 Hathaway, Gerald & Kathleen
 Haynes, Billy & Carolyn
 Herrera, Melissa
 Hetherington, Jeanine
 Hetherington, Julia & Tom
 Huber, Cheryl & Eddie
 Hudson, Ruby
 Huffstutler, Sharon
 Humphreys, Jim and Emily
 Hunt, Bridgette
 Husk, Rodney
 Jeremiah, Patricia
 Jones, Mark & Lori
 Kamp, Mary and Tim
 Karpowicz, Irene
 Kelly, Edward and Joanne
 Kelly, James and Nina
 Kempf, Timothy & Chelsea
 Krakauer, Molly
 Langley, Alexander & Boyer, Nicole
 Laughlin, Edward and Mary Ann

Law, Mary
 Lawlor, Josephine
 Lawlor, Miles & Robin
 Lee, Cecile
 Lemmons, Mark & Brittany
 Levitan, Lance & Eleni
 Liberty Bank
 Light, James & Joanne
 Lipscomb, Warren
 Lowney, Rhonda and Kevin
 Loy, Andrew
 Loy, Kester
 Lucchese, Rose
 Lyles, Cynthia
 Lyles, Gordon & Bonnie
 Mangham, Alicia
 Mansfield, Joseph
 Martin, Lisa & Matthew
 Martinez, Caesar
 Massey, Tiffany
 Maurer, Terri
 McAfee, Michael & Sara
 McDermott, J.
 McGuinn, Tricia
 Middlebrooks, Michael and Vanessa
 Moreira, Monica and Pinto, Marcio
 Morrison, Grant
 Mosher, John & Maria
 Mull, Jason & Katherine
 Murphree, Charles & Martha
 Murray, Laurel
 Newlander, Kerri R
 Noel, Deborah
 Noel-Mozer, Carol
 Norman, David & Kimberly
 Nozaki, Shinji & Kaori
 Ogle, Bryan & Marie
 Ohlman, Roger
 Overhand, Leah
 Painter, Brenda
 Patnode, Jean & Charles
 Paugh, Angela
 Paul & Benita Soper
 Paulose, Betsy
 Payne, Greg & Donna
 Perez, David
 Perkins, Michelle and Jay
 Peterson, Monica & Mark

Power, Alice
 Priest, Jennifer
 Rein, Allison
 Ridgeway, Bonnie
 Rolston, Jan & Keith
 Ruess, Ida & Richard
 Rukas, Anthony
 Said, Denise
 Schaller, Susan
 Scherzer, George & Anna May
 Senft, William & Louise
 Shaaber, Christopher & Kelly
 Sherman, Joan & Peter
 Singleton, Jeanie & Michael
 Sipe, Nicolette
 Smith, Glen & Darlene
 Smith, Lonnie & Joan
 Smith, Stephen and Michelle
 Southeast Church of Christ
 Special Needs Law Group of
 Massachusetts, PC
 Stavland, Kristine Ahlgren and Espen
 Stith, Charlotte
 Stith, Steven
 Stone, Bartley and Donna
 Stuartt, Sean & Oliverer, Jennifer
 Sullivan, Elizabeth
 Susanin, Helene
 Swain, Robert and Ashley
 Swartz, Kevin & Macken, Kathleen
 Teitelman, Steven & Susan
 Thomas, Shelly
 Tirey, Jason and Vanessa
 Toussaint, Joseph & Gail
 Turner, Melissa
 Underwood, Cinda
 Vanbogaert, Raegen
 Vaughan, Mary
 Vales, James and Diana
 Walker, Catherine and Stuart
 Walsh, Madonna and Dan
 Wetherill, Marjorie
 Williams, Henry & Kimberly
 Winkler, Lois
 Wolf, Judith



Making the SMS Voice Heard

TINA MCGREVY, AWARENESS CHAIR

Raising awareness of Smith-Magenis Syndrome is part of the PRISMS mission statement. In 2016, PRISMS participated in many activities to help increase awareness and understanding of SMS. It maintained multiple social media accounts that reached thousands of people on Facebook (1,265 likes), Instagram (643 followers), Twitter (453 followers) and Pinterest (138 followers).

In addition, PRISMS:

- Celebrated its 23rd birthday.
- Took part in Rare Disease Day, promoting global education of rare diseases.
- Joined the worldwide SMS community during SMS Awareness Day for the See My Specialness Campaign.
- Created SMS Superhero Shirts to celebrate the SMS superpowers.
- Distributed PRISMS awareness games and coloring pages at the PRISMS International Conference in St. Louis.
- Hosted the popular PRISMS photo booth at the Conference for parents, researchers, friends, family, teachers, professionals and people with Smith-Magenis Syndrome.
- Held its first video contest (winner Diane Erth was awarded two adult registrations to the PRISMS International Conference).

PRISMS has big plans for 2017 as it approaches its 25th anniversary of being the global organization and “go to center” for all things related to Smith-Magenis Syndrome. Follow our social media accounts to see how you can get involved. Together, we can make our voices loud and help bring awareness to our unique syndrome.





International Conference 2016

MAGGIE MILLER, CONFERENCE CHAIR 2016 & REBECCA HALLMARK, CONFERENCE CHAIR 2018

P RISMMS presented its 9th International Conference on Smith-Magenis Syndrome July 28-30, 2016 in St. Louis. The "Building Bridges of Hope" conference brought together families and professionals from all across the globe for a time of sharing, friendship, support and education.

This was the largest gathering for families and professionals, who came together to exchange information about SMS and celebrate all persons with SMS. They were the stars of the conference and they infused their exuberance and love into every aspect of the event. We welcomed back our alumni attendees, who gracefully welcomed our new families and created new friendships.

PRISMMS held two workshops on Thursday afternoon before the official commencement of the conference. Brenda Finucane and Barbara-Haas Givler, PRISMMS Professional Advisory Board Members and co-authors of "On the Road to Success with SMS - A Smith-Magenis Guidebook for

Schools", presented a two-part series, **"Teacher and Support Staff Training Sessions."** This workshop served as a forum for teachers and support staff to learn and share strategies and successful classroom supports, and to ask questions in an environment that encouraged solutions and positive results. PRISMMS provided funding for teachers to attend the conference and take advantage of this training so they could incorporate what they learned into their classrooms or day programs.

The second workshop, **"Exploring Residential Housing Programs for Adults with SMS"**, provided an overview of adult services and residential programs, and explained types of public support available to families of adult persons with SMS. This workshop was designed to highlight a recent PRISMMS publication, *A Smith-Magenis Guidebook: Exploring Adult Residential Living*.

Attendees came together for three days to hear presentations from leading researchers, clinicians,





therapists and parents about a variety of issues concerning SMS. Presentations included research updates, therapeutic approaches addressing a variety of challenges, (sleep, speech and language, medication), behavior and educational supports, medical management of SMS, adult concerns and family supports. Siblings had the opportunity to attend several sessions dedicated to their unique challenges while having fun and meeting new friends. The Keynote Speaker was Pat Furlong, Founding President and CEO of Parent Project Muscular Dystrophy, and Zach Kon kicked off the opening day with a heartfelt and personal speech, "The Dignity of Risk."

Rick Guidotti of Positive Exposure captured the best smiles of our SMS kids and their families. *Night at the 360*, an evening reception and fundraiser, was a huge success and a time for attendees to visit and spend time together in a warm and cozy setting. The Ice Cream Social was a sweet way to wind down after the conference, and the down times became the opportunities for acquaintances to become friends.

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

See you in Pittsburgh in 2018!

Thank you very much for inviting me to attend the PRISMS meeting. It was a very precious experience for me, and I had a very good time in St. Louis. I greatly appreciate your role in organizing the group, since I deeply understand the meaning of this type of organization for the families. I plan to continue working on SMS, so I hope to have a chance to attend the PRISMS meeting again in the future.

—Dr. Kosuke Iumi, MD, Ph.D., The Children's Hospital of Philadelphia



I want to thank you and PRSIMS for the amazing conference. I was truly honored to be a part of this wonderful event. The educational information along with the rest of the sessions were extremely helpful. Each different session I attended, I learned several valuable pieces about SMS. I can't thank you enough for this experience.

—Julie Stephens, Teacher-Support Staff grant recipient

CONFERENCE BY THE NUMBERS



With the great attendance and huge success of the PRISMS 2016 International Conference, I realize what a grand undertaking I am faced with as the new Conference Chair. I am extremely thankful for Maggie Miller's guidance and support as we have transitioned over and I'd like to express how very grateful I am to have such a grand challenge facing me in the planning and implementing of our 2018 International Conference.

I make this promise to you all, our amazing PRISMS community: I will not let you down! I am especially excited for our upcoming conference, as we will not only be celebrating our 10th PRISMS International Conference but also PRISMS 25th Anniversary! I look forward to working with you all and I ask that you help me by sending in your thoughts and suggestions so that I may incorporate them into the planning with the Conference Committee.

In the meantime, know that your Conference Committee is already hard at work and we will be reaching out to you with updates as time gets closer. Can't wait to see you in Pittsburgh, July 2018!

Rebecca Hallmark, Conference Committee Chair 2018



Adult Residential Living Guide

JOHN MAYER, PRESIDENT

As chair of a volunteer workgroup focused on adult living environments, I am proud to provide a report about a special project to develop a guidebook for families and others seeking residential situations for adults with Smith-Magenis Syndrome.

Over the years, PRISMS has heard from many families asking for guidance and information as they transitioned from a school setting into an adult situation. To address this need, I led a workgroup to develop a resource for our community.

Deborah Wehren, an expert in supports for people with disabilities, served as the project consultant and lead writer. The project team was comprised of parents of adults with SMS, including Mary Beall, Leah Baigell, Barclay Daranyi and myself; Brandon Daniels, a parent of an adolescent with SMS; and PRISMS Executive Director Emily Fields. I'm thankful to all of them for their dedication to the project. We worked for more than 18 months exploring the topic and then writing the guidebook, which was made available just before the 9th International "Building Bridges of Hope" Conference last July in St. Louis.

The guidebook includes information about a variety of residential programs, both in the home and in the community; helpful how-to suggestions for finding support and funding, and case studies contributed by families from across the country. These case studies provide personal insights about the benefits and challenges of different living situations.

Funding to support the project was donated by Ira and Betty Dyer, grandparents of Charley Mayer, my son, and a 32-year-old who lives in a community home.

This guidebook is available at no charge on the PRISMS website as a downloadable PDF file <http://www.prisms.org/us/whats-new/sms-guidebook-exploring-adult-residential-living> with hard copies available from PRISMS for a nominal fee.

A Smith-Magenis Guidebook

JUNE 2016

Exploring Adult Residential Living



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PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

Looking Ahead

EMILY FIELDS, EXECUTIVE DIRECTOR

While we accomplished a lot in 2016, we have even more in store for 2017. We need your support to ensure that we continue to grow and improve the programs and services we provide for the SMS community. Some of our projects for 2017 include:

- Launching a Smith-Magenis Syndrome patient registry to collect information on the SMS patient community, expedite research and provide increased understanding of this rare condition.
- Hosting the 9th International SMS Research Symposium, ensuring that leading SMS researchers and professionals have an opportunity to present the latest SMS research and network with one another to advance SMS understanding.
- Expanding the Regional Representative program to allow for increased SMS family meet-ups and support around the world.
- Sponsoring a post-doctoral fellowship for two years in support of further research into SMS.
- Creating a global awareness plan to increase awareness and understanding of SMS with newly diagnosed families, researchers, physicians, clinicians, therapists, educators and more.

PRISMS exists to provide hope, support and resources for families and professionals providing love and care for individuals with Smith-Magenis Syndrome. We will be investing **more than \$340,000 this year** in programs and services dedicated to the entire SMS community.

**24
YEARS**

serving the
SMS community

START

Started by
PARENTS & PROFESSIONALS

SMS
PARENTS

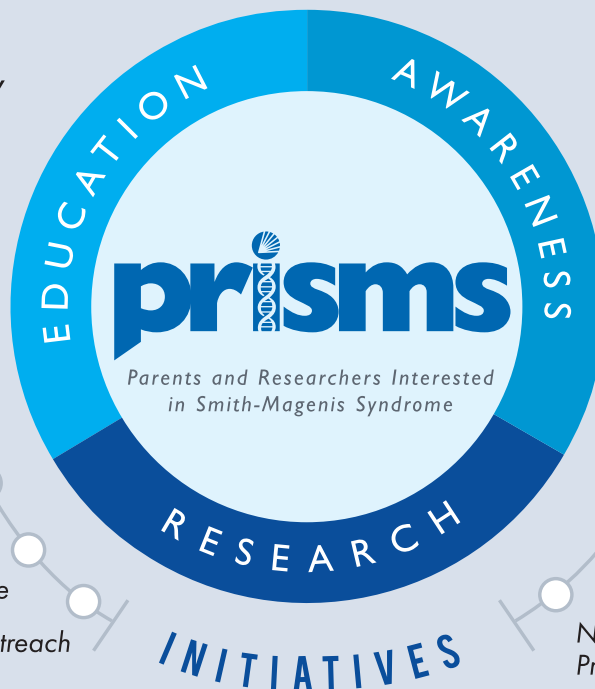
Led by a
**VOLUNTEER
BOARD**



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of leading experts
in the SMS community

Spectrum Journal
Regional
Representatives
Research Symposium
Multi-Year
Postdoctoral Grant
Internationally translated
SMS publications/
resources
International SMS Conference
Global SMS Awareness Outreach



Genetic
Counselor Services
Family
Membership
Professional
Membership
International
Partnership Program
Newly Diagnosed
Program

THE SMS ORGANIZATION

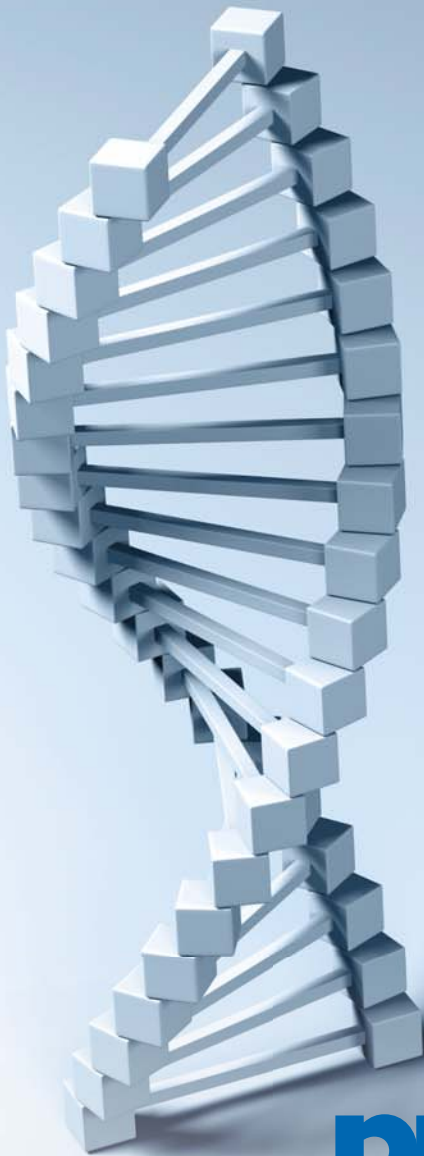
providing comprehensive family and professional support



SPECIAL THANKS

To Dennis Dillon, Pat Boschetto, Julie Bernatz, and Mark Hernandez who gave of their time and talents to create the PRISMS 2016 Annual Report.

Thank you for helping us to share the PRISMS mission!



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*Parents and Researchers Interested
in Smith-Magenis Syndrome*

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