

Annual Report 2014



*Parents and Researchers Interested
in Smith-Magenis Syndrome*

**“A Year of Growth and
Excellence”**



2015 PRESIDENT'S MESSAGE

JOHN MAYER



I am honored to be appointed to the position of President of the PRISMS' Board of Directors. I have served as Board Secretary and Membership Committee Chair since February 2009, and I know our organization well. I have made important friendships with many of you who are part of PRISMS, and I have served with a dedicated group of hard-working board members.

I am fortunate to follow Randy Beall's lead. In his 10 years as President, Randy did amazing work for all of us, and PRISMS is a much stronger organization because of his leadership. As is evident in our 2014 Annual Report, we have a solid base of membership, our conferences are informative and rewarding, we have a world-wide network of experts, and a stable financial base.

My wife, Debora, and I have been involved with PRISMS since our son, Charley, now 30, was diagnosed with SMS in February 1996. Our family has been at every PRISMS conference; we have helped families with their diagnosis,

and we have been advocates for supports and services in both school and community settings.

I look forward to working with the entire SMS community and leading PRISMS to new stages of excellence – as a resource for you, as a clearing house of vital information, and as an open and well-run organization.

We're off to a great start in 2015 – especially with Emily Fields in place as our first Executive Director.

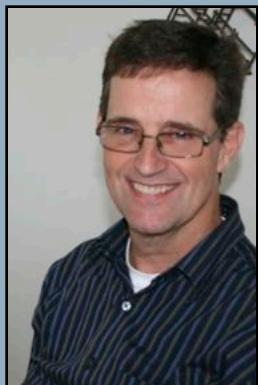
I look forward to meeting you all. In the meantime, please don't hesitate to contact me to share your thoughts about how PRISMS can serve you or how we can achieve great things together into our future.

Sincerely yours,
John Mayer

2014 PRISMS Board of Directors



John Mayer, Sarah Elsea, Ph.D., Phil Reudi, Maggie Miller, Percy Huston, Mary Kate McCauley, Randy Beall, Tina McGrevy, Jeremy Farber, Julia Hetherington



**MESSAGE
FROM
OUTGOING
PRESIDENT
RANDY
BEALL**

Dear Supporters:

PRISMS was created to improve the lives of families affected by Smith-Magenis Syndrome. We provide much-needed information and support, and we sponsor research and foster partnerships with professionals to increase awareness and understanding of SMS. To achieve this mission, our community of researchers, medical professionals and volunteers work tirelessly and passionately. We appreciate the support of our donors and the people who have sacrificed to make our mission a reality.

Here are just some of our many 2014 highlights:

- Hosted our largest gathering yet, with over 350 attendees at PRISMS' 8th International Conference, "Building Bridges of Hope" in St. Louis, MO.
- Rolled out PRISMS' Regional Representative program, providing our families increased local support and networking opportunities.
- Published PRISMS' SMS Handbook, "On the Road to Success with SMS – a Smith-Magenis Guidebook for Schools", written by Professional Advisory Board members Barbara Haas-Givler and Brenda Finucane.
- Welcomed 40 new members into the PRISMS' community.
- Initiated a logo redesign to emphasize our focus on three key areas: Education, Awareness and Research.
- Appointed John Mayer, former Board Secretary and Membership Chair, to serve as our new President beginning in January 2015.
- Appointed longtime board member and former Editor of the Spectrum, Julia Hetherington, to serve as our new Secretary.
- Recruited Jeremy Farber as a new board member to help with our fundraising efforts. Jeremy and his wife, Sylvia, live in San Antonio, TX and have two children, Austin and Ryan. Austin, their daughter, has SMS.
- Recruited Dennis Dillon as our new editor of the Spectrum journal. Dennis is a retired writer for The Sporting News. He and his wife, Tracey, live in Chesterfield, MO. They have three sons, Chris, Ryan, who has SMS, and Ben, and one daughter, Amy.
- Expanded our Professional Advisory Board (PAB) to 10 members by adding Rebecca Foster, Ph.D., a clinical psychologist at St. Louis Children's Hospital, and Jane Charles, M.D., a developmental pediatrician at the Medical University of South Carolina in Charleston, S.C.
- Entered into initial planning for PRISMS' 2015 SMS Research Symposium.
- Partnered with Baylor College of Medicine to support a genetic counselor position. This part-time position will report to board member and Professional Advisory Board Chair Dr. Sarah Elsea, and be a great new resource for SMS families.
- Worked with consultant Robert Miller, former Executive Director of the National Fragile X Foundation, to aid in the of hiring our first Executive Director.

Since 1993, PRISMS has served as the primary source of information and support helping SMS families. Today, we serve not only those in the U.S., but also families throughout the world.

I know the organization's future is in good hands with John Mayer. The year 2015 looks like it will be an amazing year!

It's been my pleasure and honor to serve this great community for many years. I'm looking forward to continuing to serve on the board and making a positive contribution.

Together we are making a difference!
Randy Beall

Professional Advisory Board

SARAH ELSEA, Ph.D., CHAIR

PRISMS was pleased to welcome two new members to its Professional Advisory Board (PAB) in 2014. Rebecca Foster, Ph.D., is a clinical psychologist at St. Louis Children's Hospital, with research interests focused on caregivers and siblings of individuals with developmental disorders. Jane Charles, M.D., is a pediatrician who cares for children with Smith-Magenis Syndrome and other developmental disabilities at the Medical University of South Carolina in Charleston, S.C.

Now 10 members strong, the PRISMS PAB serves to advise the Board of Directors on medical, scientific, educational, and therapeutic matters, and to assist in the education and research activities of the organization. An internationally recognized group of basic scientists, educators, and clinicians with expertise in SMS, 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.

The PAB is focused on the dissemination of accurate medical information regarding diagnosis, management, and genetic counseling. Its members respond to inquiries directly from families, caregivers, educators, and healthcare providers, give presentations, and provide consultations at the PRISMS conferences, providing comprehensive support to the broader community.

In 2014, published research on SMS improved our understanding of the role of RAI1 in craniofacial development and in diet-induced obesity through the use of animal models of SMS. Additional studies described the molecular genetic relationships between SMS and other neurodevelopmental disorders, findings that will be a key toward understanding the impact of sleep disturbance in SMS and a variety of other genetic syndromes, and will provide additional data to support the development of therapeutic interventions.

Supporting efforts to enhance research in SMS, more than 30 researchers and key stakeholders attended the SMS Research Symposium on July 31, 2014, in St. Louis. This PRISMS-sponsored event provided an opportunity for social, behavioral, and basic scientists to come together to share their recent work on SMS. Presentations included work describing stem cell studies, molecular and phenotypic networks involving RAI1, sleep disturbance in SMS, and related disorders, and the identification of other genetic and environmental contributors to SMS.

Sibling and caregiver concerns in families continue to be a source of investigation, as well as prevention of obesity and other adult onset health conditions as individuals with SMS age. Ongoing studies on neuronal stem cell characterization, the cellular function of RAI1, and the immunological problems encountered in SMS are in process by scientists around the world, and will continue to enhance our knowledge and understanding of SMS.

The SMS Biobank is in its third year. In 2012, PRISMS joined with Coriell Cell Repositories, an NIH-funded entity that collects and stores DNA and cell lines for use in research of both rare and common disorders, creating a resource for researchers studying SMS. Once again in 2014, the PRISMS community came out in strong support of this endeavor at the PRISMS conference in St. Louis, contributing an additional 29 blood and skin samples for cell line generation, for a total of 71 SMS samples in the repository donated through PRISMS. These cell lines will provide much needed support for ongoing and future research



MEMBERS

Kerry Boyd, M.D.

Bethesda Services,
Ontario, Canada

Christine Brennan, M.A., CCC-SLP

Northwestern University

Jane Charles, M.D.

Medical University of
South Carolina

Sarah Elsea, Ph.D., Chair

Baylor College of Medicine

Brenda Finucane, M.S. LGC

Geisinger's Autism & Developmental
Medicine Institute

Rebecca Foster, Ph.D.

St. Louis Children's Hospital

Andrea Gropman, M.D.

Children's National Medical Center

Barbara Haas-Givler, M.Ed., BCBA

Geisinger's Autism & Developmental
Medicine Institute

Gonzalo Laje, M.D.

Washington Behavioral Medicine
Associates

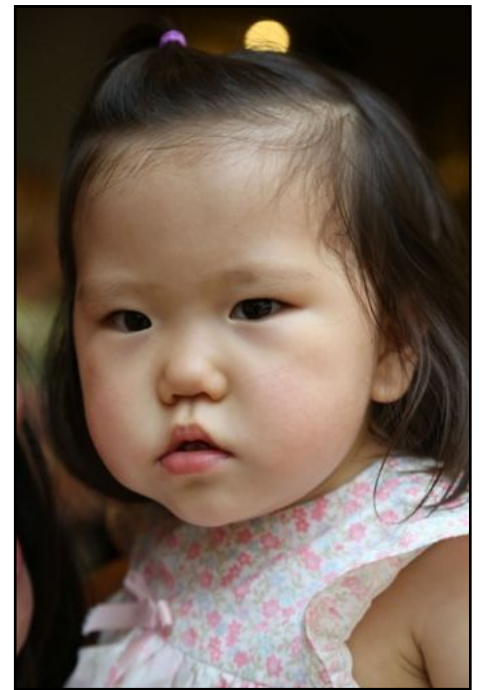
Ann C.M. Smith, M.A., D.Sc. (hon), Chair Emeritus

NIH, National Human Genome
Research Institute

studies to improve our understanding and potential treatment of SMS, including the development of induced pluripotent stem cells which have been used to create neuronal cell lines to better understand neuronal function in SMS.

Connecting interested families to research opportunities is a key for moving research forward in SMS. The Crossroads Patient Registry is a new program that PRISMS is sponsoring to develop a SMS registry that will allow families to easily participate in research studies and for researchers to access information about individuals with SMS. More information about this new project will be available in 2015.

Research funding for SMS and other disorders of intellectual disability is critical to our understanding of this complex disorder and to improve quality of life for individuals and families impacted by this syndrome. The key to improving research support is education of families, healthcare providers, and funding agencies about SMS and the potential outcomes of SMS research for the general population toward improved understanding of sleep, metabolism, and behavior that affects the broader community.



growth

excellence



FINANCIAL REPORT

PHIL RUEDI, TREASURER

Financially, PRISMS has never been stronger and the Board is excited that these resources will be deployed to support our families and SMS research in the coming years.

We strive for responsibility and excellence in all components of our work, especially our financials. We are proud to report the strength of PRISMS' financial position in 2014.

- Support and Revenue in 2014 was the highest in the history of PRISMS, over \$330,000, far exceeding the \$210,000 generated in 2012.
- The PRISMS 2014 conference was a success as measured by registrations, which grew 10% over 2012.
- Member and corporate support for the conference exceeded \$60,000, a 50% increase versus 2012.
- Financial reserves and conference support allowed PRISMS to offer over \$10,000 in scholarships to our member families.
- Between 2013 and 2014, PRISMS reduced spending expectations by \$25,000 as related to the conference.
- During 2014, PRISMS funded the publication: "On the Road to Success with SMS - A Smith-Magenis Guidebook for Schools", providing necessary resources and information to the SMS community. The financial result is reflected in higher product sales and program costs. As with other programs, financial reserves subsidized a portion of the costs to make the book affordable to our members.

The financial strength of PRISMS in 2014 gives the Board confidence to proceed with exciting new commitments in 2015.

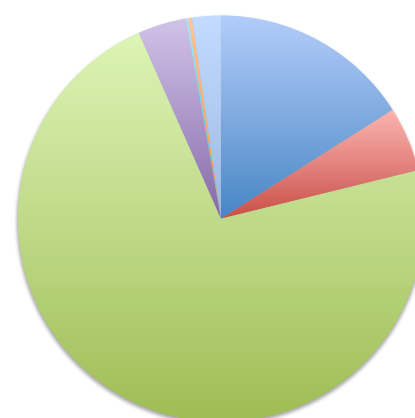
In late December, PRISMS received a substantial unrestricted donation from one of our families and also received a commitment from another family that would specifically fund 90% of an Executive Director's salary each year for up to four years. PRISMS was thrilled to bring on Emily Fields to fill this role in January 2015.

PRISMS' financial goals include funding its continuing program services, supporting research opportunities and preparing for the 2016 Conference. The organization looks forward to moving ahead with funding family support and research at levels that will be higher than in previous years.

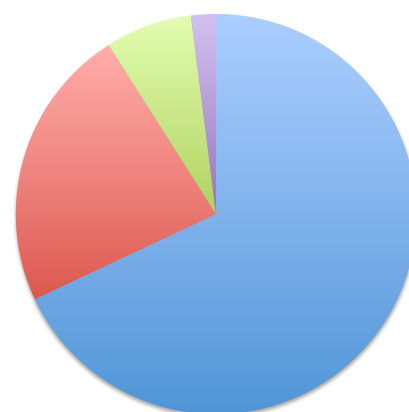
Support and Revenue	2013**	2014**
Conference Registration	\$0	\$53,241
Product Sales	\$1,204	\$17,153
Contributions	\$75,676	\$240,179
Membership Fees	\$11,197	\$12,825
Interest Income	\$620	\$615
In-Kind Services	\$858	\$1,000
Assets Released from Restrictions	\$13,130	\$7,598
Total	\$102,685	\$332,611
Expenses	2013**	2014**
Conference	\$0	\$157,530
Programs	\$38,166	\$53,601
Management and General	\$9,660	\$15,691
Fundraising	\$4,118	\$5,324
Total	\$51,944	\$232,146
	2013**	2014**
Increase (Decrease) in Total Assets	\$44,551	\$88,972
Ending Cash	\$308,842	\$399,387
Ending Total Assets	\$335,415	\$424,227
Support and Revenue Sources	2013*	2014**
Conference Registration	0%	16%
Product Sales	1%	5%
Contributions	74%	72%
Membership Fees	11%	4%
Interest Income	1%	0%
In-Kind Services	0%	0%
Assets Released from Restrictions	13%	3%
Total	100%	100%
Expenses (% of Total Year)	2013*	2014**
Conference	0%	68%
Programs	74%	23%
Management and General	19%	7%
Fundraising	7%	2%
Total	100%	100%

* Audited

**Unaudited

2014 Support and Revenue (\$)

- Conference Registrations
- Product Sales
- Contributions
- Membership Fees
- Interest Income
- In-Kind Services
- Assets Released from Restrictions

2014 Expenses (%)

- Conference
- Programs
- Management and General
- Fundraising

MEMBERSHIP REPORT

JOHN MAYER



PRISMS is, first and foremost, a community of support for individuals and families affected by Smith-Magenis Syndrome. This community is built upon a base of our members, which in 2014 grew to 323 individuals and families. Last year, we welcomed 40 new faces to our membership family!

Our membership list shows that PRISMS serves families from across the country and around the world - with members from 42 states and 13 foreign countries on six continents. (Note: states currently without members are Alaska, Delaware, Hawaii, Indiana, Louisiana, Mississippi, Oklahoma, and West Virginia. You can help us fill this gap and encourage SMS families from these states to join us.)

There are many benefits to being a member of PRISMS, including receiving timely, helpful, and new information via the Spectrum journal, our monthly e-Blasts, the PRISMS website, and the PRISMS Facebook page; using the opportunity to make or strengthen a connection with others at our international conferences; gaining access to materials for family members, teachers, and advocates; and much more.

PRISMS is excited to begin 2015 with a solid membership and our first Executive Director, Emily Fields. A critical task for Emily

will be to strengthen the many programs we have in place, while at the same time building a foundation for new services to our community. Our membership program is a core aspect of these efforts. Membership dues provide the funds PRISMS needs to operate, and our members are at the center of our mission to connect SMS families with the resources and support they need.

We truly value your membership. Please know that PRISMS is your organization, and your voice matters. As we move forward into 2015, we invite you to let us know about your needs and interests. Please contact our offices with questions, suggestions, and feedback at any time by sending a message to info@prisms.org. We look forward to hearing from you.

My thanks to all of you who are part of PRISMS.

And thanks to colleagues in the PRISMS office and on the Membership Committee for their efforts: Mary Kate McCauley, Scott and Maggie Miller, and Angela Williams.

Our Members

(* New member in 2014.)

Alabama

Carol & Tom Braithwaite
*Millie Gannon
Laura & Matt Markus
Jill & Josh Wood

Arizona

Rhonda & Kevin Lowney

Arkansas

Carolyn Bruister
Rosanne & Pace Hindsley

California

Gina & Steve Belden
*Melissa Brandt
Susan & Paul Diamond
Diane & Joseph Erth
Maricela Hernandez Garcia
Jeanine Hetherington
Mary Hetherington
Krista & David Karr
Charlene Liao & Liqun Luo
Patricia Morgan
Gail & Bruce Napell
Adela & Frank Nevarez
Joan & Achille Paladini
Laura Paladini
Kim & Tom Pastore
Amy & Brian Pereira
Arlene Marie & Stephen Staich
Elena & Anthony Stout
Melissa & Rick Visosky
Adrienne Wampler

Colorado

Kim & Eric Hoffman
Terry Katz
Lori & Matt Martin
Jeanette & Walter Praetorius
Jennifer & Jeff Wittenauer

Connecticut

Jean & Marty Eichelman
Jennifer & Chris Iannuzzi

District of Columbia

Barbara & Sam Dyer

Florida

Joan & John Bielunski
*Deanna Damiano
*Angela Eaton

*Rosa & Timothy Farrington
Kathy Hofmann
Irene Karpowicz
Allison & Mike Leatzow
Melissa & Dan Longman
Alicia Mangham
Carol & Stan Triantafellu
Laura & Christopher Wells

Georgia

Christine & Ken Bolt
Blair & Lesslie Carnahan
Heather & James Michalski
Michelle & Jay Perkins
Ann & Lowry Reid
Anne Riccardi
Allison & Alex Stephanouk
Rochelle & Paul Wright

Idaho

*Megan Everett-Anderson
*Sharon Cook
Monica & Mark Peterson
CeeCee & Jesse Saxton

Illinois

Marsha & Gary Bach
Joan & Michael Campione
Ashley & Tom Danis
Christine & Joey Grzybowski
Julianna & Jeremy LaPlant
Marissa McKee
Robyn & Steve Mogul
*Jessica & Chad Mosley
Dana Deane & Kevin O'Connor
Denien & Jim Rasmussen
Margaret & Robert Tortorelli
Kathy Whitehall
Edee Norman & Dennis Wizecki
Carol & Glenn Wollschlager
Deann & Jeff Yerk

Iowa

Carla & Glenn Blaser
Karen & Chuck Friedman
Kecia & King Hickman
Debbie & Jim Rahfaldt
Jan & Keith Rolston

Kansas

Lynda Deane & Don Frey
Carol & David Pacey
Linda & Van Peters
Katy & Frank Tra
Shiloh Frese & Todd Walter

Kara Walters

Kentucky

Angela & William Bentley
*Brian Bishop
Jean Bishop
Joan & Raymond Bishop
*Nicklas Vincent Weil

Maine

Susan & Daniel Longfellow
Jaye Orgera

Maryland

Lisa & Christopher Corbett
Kerry & Bob Fairweather
Jamie & Jim Humphreys II
Tetsuya & Yukiko Ichino
Christian Lavedan
Mary & Paul Miller
Amy Owens
Joanne Seward
Mary Unglesbee
Ruth & Dennis Unglesbee
Janet & Ronnie Wagoner

Massachusetts

Leah Baigell & Henry Kon
Cheryl & Ned Berman
*Debra Coghill
Maryann & Paul Duzan
Diane & Michael Petrucci
Joan & Peter Sherman
Laura Staich & Philip Ruedi
Wendy & Michael Tyman



Michigan

Rod Allen
Heidi & Todd Carpenter
*Anna Hesson
Nichol Hill
Irene & Jim McCool
Rajeon Potter
*Lisa Wiltrakis
Michele & Joe Zdanowski

Minnesota

Jackie & John Fallenstein
*Carissa Le
Cindy & Jeffrey Linert
Carole Smith
Mary Kay & Dennis Vierling

Missouri

Lynne & Steve Baker
Diane & Thomas Daly
Tracey & Dennis Dillon
Rebecca Foster
Wei Zheng & Jian Ping Huang
Emily & Jim Humphreys
Sabrina & Bill Hurtgen
Bernadette & Percy Huston
Trinity & Mike Miodunski
Barbara Smith
Madonna & Dan Walsh

Montana

Marni Rolston & Jed Huseby

Nebraska

Cheri Connealy
Marilyn & Steve Groeteke
Donna & Zechariah Stevens

Nevada

Patricia & Rafael Reynoso
June Winkler-Teixeira

New Hampshire

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Nina & James Kelly
Debora & John Mayer

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Dorit Berlin
*Rebecca Burt
Ilse & Randy Ciprich
Rosemary & Rod Clifford
Yolanda & Alfredo DaSilva
Sara & Tsvi Gal
Marie Gallo
Caroline Pope

New Mexico

Delma & Alejandro Aguilar

New York

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Jan Corbett-Pittman
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Barbara Melamed

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Mary Pinchiaroli
Liz & Bob Pucci
Ida & Richard Ruess
Renee Ryan
Linda & Tracy Sundberg
Mary Ann & Ron Zimmer

North Carolina

Linda Duvall
Shannon & Robert Duvall
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*Renee & Sherman Fullard
Terrie & Harry Grose
Cheryl & Richard Herman
Nancy C. Jacobus
Karen & George Lemmert
Susan Lenfestey
Dawn & William Mock
Monica Moreira & Marcio Pinto
*Ana Narvaez
Suzanne & Charles Ruedi

North Dakota

Shannon & Darin Jantzi

Ohio

Kellie & John Cooney
Christina & Billy Craig
*Patty Davis
Jennifer & Gene Gelfand
Kristen & Michael Hamilton
Mary & Greg Hards
Dennis Hartmann
Kathy Krisko
Kimberly & Jamison Manix
Tina & Charlie McGrevy
Faith Nobilucci
Kimberly & David Norman
Faith & John Stopic
Cathy Witt

Oregon

Shirley & Donald Dechaine
Jennifer & Lou Klump
*Dale Schwartz
Jeanie & Michael Singleton

Pennsylvania

Lisa & John Bellopede
Nancy & David Cordrey
Brenda Finucane, MS
Beverly & Steven Frey
Suzanne & Harry Frost
Barbara Haas-Givler
Susan & Martin Holland
Paula & Arthur Jump
Dana & Timothy Krimmel
Beth & Paul Kurtz
*Margaret & Paul Marshall
Lisa & Matthew Martin
Mary Kate & Joe McCauley
Celeste & Kemal Pegram
Milissa & Michael Pelonero
Mark & Carol Divens Roth
Michelle & Stephen Smith
Sandy Tome

Celeste & Ronald Waclawik
Cheryl & Chad Worden

Rhode Island

Maria & John Mosher

South Carolina

Sharon & Daryl French
Julia & Tom Hetherington

South Dakota

Kipley & Ross McDaniel

Tennessee

*Catherine & Lincoln Lakoff
Peggy & Jim Laney
Olivia McGehee & Jim Schleicher
Amy & Tim Myers
*Brenda Resha
*Paige Resha
*Jessica & Eric Rogers

Texas

Sarin & Eric Abati
Cindy & Danny Abbott
Carolyn Beall
Mary & Randy Beall
Christine Beck
Jack Byrom
*Wu-Lin Charng
Dawnda & Brandon Daniel
Karen & Glen Daniel
Karen & Ronald Dixon
Meredeth Drummond-Cox
Sarah Elsea
Sylvia & Jeremy Farber
*Lynda & Matthew Fuller
*Darlis & Tom Fuller
Jessica & Mark Kirklin
Sue & David Kuebler
Michelle & Kerry Lee
James Lupski, M.D., Ph.D.
Brenda Massey
Cecilia & Gordy Poole
Johnna Robinson
*Gilbert Salgado
*Leann Santiago
Larry Sarver
Paula & Joseph Toussaint
Eva & Weldon Wamble
*Janson White

Utah

Pat Boschetto
Sandy & Richard Hall
Jennifer Large Seagrave
Heather & Daniel Wilde

Vermont

Patty & Dan Saunders

Virginia

*Rachel & Daniel Berger
Claudia & Mark Gibb
Amanda & Charlie Graham
Judith & Matthew Livingston
Margaret & Scott Miller

*Megan Nelson
Diane Powers
Shannon & Darrell Richard
Ann & Ron Smith
Venessa & Jeff Stevens

Washington

Kathy & Andrew Booker
Jennifer & Esteban Delgadillo
Heather & Lance Eberlein
Kathleen McMonigal & John Doherty
Maureen & Robert Monroe

Wisconsin

Mary & Tim Kamp
Gail & Alan Kopp
Linda & David Mills
Bonnie & Bill Spear

Wyoming

Tiffany Helling
Irene & Dan Knoepfle

International Members

Australia

Angela & Paul Bonato
Denise & Stewart Caddy
June & Richard Dixon
*Julie Gligora
Stephanie & Nicholas Hanson
Susan & Bryce Hoad
Cally Bauman & Mathieu Lague
*Natalie Rangitoheriri
Jennifer Tolhurst-White
Catherine & Stuart Walker

Brazil

Eliane Barros & Raul Santos

Canada

Sonia & Brian Bench
Dr. Kerry Boyd
Donna Santiago-Douglas & Michael Douglas
Amanda & Brian Downey

Lorna Harris & Jennifer Miller
Justus & Jennifer Smith
Kelsey & Graham Roberge
*Karyn Thompson
Brandi Wilson

Denmark

Leslie & Christopher Calzaretta
Pernille & Sergio Fox

Ireland

*Cecilia O'Neill

Japan

Shinji & Kaori Nozaki

Mexico

Maria Elena Carrancedo
* Cecilia Medellin Alarcón & Gonzalo Sevilla

Netherlands

Carolina & Ronald de Kimpe
Yolanda Van der Schoot

Norway

Kristine Ahlgren & Espen Stavland
*Heidi Nag

Russian Federation

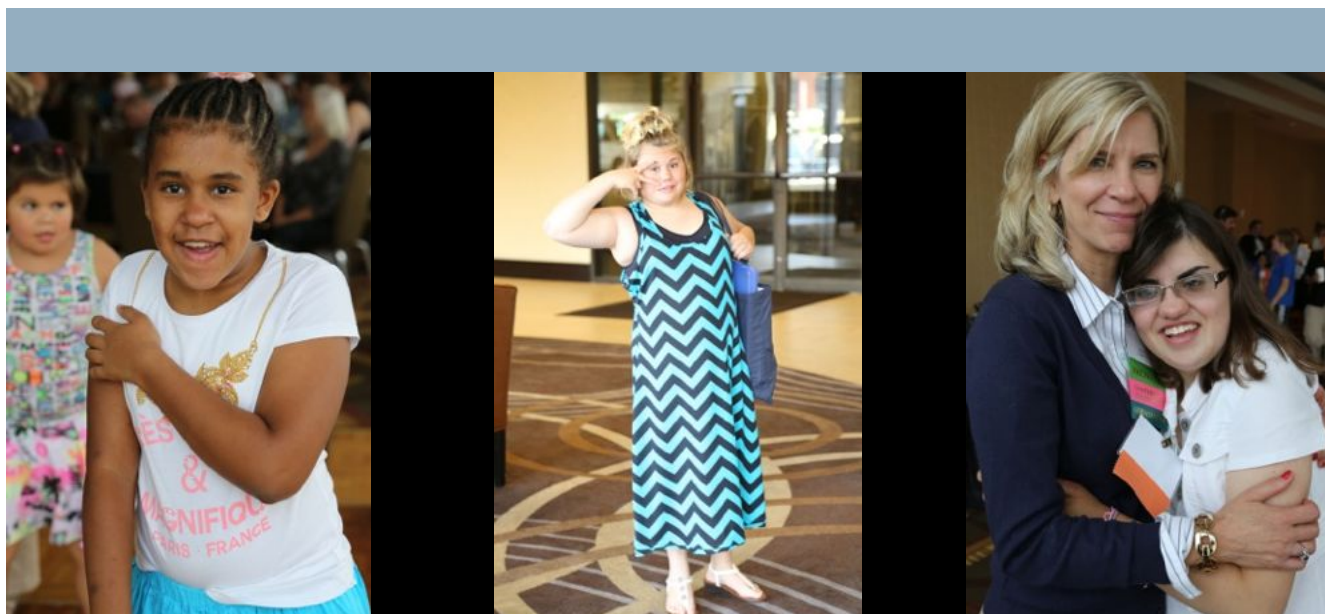
Bela Kafengauz & Alexander Tsetlin

South Africa

*Paulin Kamuangu Kamizelo

United Kingdom

Kristine & Glen Braden
Diana & Paul Brice
Carol & Howard Funnell
Susan Herring
Nick & Salli Hunt
Emma Riddell
Patricia van Nederveen
*E. Ann Whitworth



FUNDRAISING REPORT

JEREMY FARBER



The PRISMS community raised more than \$37,000 through fundraising and awareness events in 2014! 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 just a few of the 2014 fundraisers you hosted in your communities:

- **Cuts for a Cure.** Organizer, Jill Wood
- **Vineyard-to-Vineyard Fun Walk.** Organizers, Percy and Bernadette Huston
- **Emily Mason Golf Tournament.** Organizers, Bill and Monica Mason
- **Family Fun Day.** Organizers, Macken/Swartz and the Deamude Families
- **Nickels for Nico.** Organizer, Jean Bishop
- **T-Shirts for Awareness.** Organizer, Jessica Lockhart
- **Bowling for SMS.** Organizers, the Farber Family

PRISMS is thankful for the generous donations to support our 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 2014 is a driving force for PRISMS moving forward. In 2015, we look to provide

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. Should you be interested in holding a fundraiser in 2015, please contact us at info@prisms.org. We will support you in making your event as successful as possible!

Didn't see your 2014 fundraiser listed above? Hoping to hold an event in 2015? Contact us at info@prisms.org. In 2015 we'll be improving our systems to better capture your fundraising and awareness efforts, but we need to hear from you. Reach out today.



Join us on Facebook!
PRISMS Smith-Magenis

PRISMS Donors - THANK YOU!

\$1-\$99

Laura Beth & Bob Akers
 Darlene & Edward Alarcon
 Maria Gomez Alarcon
 Mary Alberici
 April Alder
 Sherri & Larry Alldredge
 Mary & Scott Armstrong
 Harriet & Martin Arno
 Leah Baigell & Henry Kon
 Cindy & Robert Bailey
 Lynne & Steve Baker
 Linda & Albert Barrera
 Stephanie & Paula Baumgart
 Stephen Beck
 Gina & Steve Belden
 Angela & William Bentley
 Rachel & Daniel Berger
 Cheryl & Ned Berman
 Jatin Bhai
 Brian Bishop
 Myra Blackmon
 Carla & Glenn Blaser
 Clari & William Bohannon
 Angela & Paul Bonato
 Kristine & Glen Braden
 Carol & Tom Braithwaite
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 Nancy Clemons
 Charles Cleveland
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 Stephanie Crotty
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 Susan & Paul Diamond
 Peggy Dillon
 Amanda & Brian Downey
 Jean & Marty Eichelman
 Danielle & Joshua Elmore
 Kim & Trent Eubanks
 Rosa & Timothy Farrington
 Lisa & James Finn
 Chris FitzGerald
 Sherri & Timmy Fountain
 Marlene & James Frachiseur
 Karen & Chuck Friedman

Wendy Fulenwider
 Darlis & Tom Fuller
 Jenifer & Stephen Fuson
 Haylee Gani
 Dorislee & Steven Gilbert
 Deborah & Henry Gonzales
 Annette & Stewart Goodson
 Amanda & Charlie Graham
 Sandra & Troy Green
 Angela & Heath Grona
 Christine & Joey Grzybowski
 Mary Ann Gschwind
 Randy Guzman
 James Haley
 Dennis Hammond
 Beverly Handwerk
 Michelle & Frank Haring
 Melissa Herrera
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 Emily & Jim Humphreys
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 Megan Jacobs
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 Alicia & Randy Jeffries
 Patricia Jeremiah
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 Mary & Tim Kamp
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 Jennifer & Christopher Kester
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 Beth & Paul Kurtz
 Bric Latham
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 Patrick Lawlor
 Gilbert Ledun
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 Peggy & Calvin Lindsay
 Warren Lipscomb
 Judith & Matthew Livingston
 Rose Lucchese
 June & Thomas Madison
 Janet & Bill Manning
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 Savitri Ramsingh & Kevin Murdock
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 Caroline Pope
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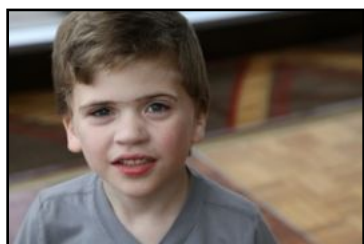
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Building Bridges of Hope

MAGGIE MILLER

PRISMS' 8th International Conference, "Building Bridges of Hope", (July 31-August 3, 2014 at The Hilton St. Louis at the Ballpark in St. Louis, MO) was our largest gathering yet. We welcomed families and professionals from all over the world. Attendees came together for three days to engage in presentations from leading researchers, clinicians, therapists and parents about a variety of issues concerning Smith-Magenis Syndrome.

Presentations included research updates, therapeutic approaches addressing a variety of challenges (nutrition, speech and language, medication), behavior and educational supports, medical management of SMS, adult issues, and family supports. Brenda Finucane, MS, CGC, a PRISMS Professional Advisory Board member, delivered the keynote address.

PRISMS also presented a session uniquely devoted to addressing the concerns and questions of first-time conference attendees. "FIRST STEPS: Navigating the PRISMS Conference & Finding Support Along the Way", welcomed new families to our community and offered these attendees an opportunity to meet with parent ambassadors and ask questions in a private and supportive environment.

Rick Guidotti of Positive Exposure captured the best smiles of our SMS kids and their families. His presence infused the conference with much joy and delight! We finished our Saturday sessions with the conclusion of the Silent Auction, which raised \$6,400 for PRISMS.

The 7th International Research Symposium preceded the conference. This symposium brought together the most respected researchers from around the world, who shared their research on SMS and prompted dialogue and collaborations.

We deeply thank the conference committee (Nancy Cordrey, Shannon Jantzi, Nina Kelly, Margaret Miller, and Amy Pereira) whose members planned and executed every detail of the conference and gave generously of their time over the past two years. We also thank all of the volunteers who assisted with a variety of conference tasks. We are grateful for your help! It is an extraordinary undertaking, and we are very fortunate to have dedicated volunteers who have been so committed to putting on the very finest conference.

www.prisms.org

2014 Conference:

Success in Numbers

Number of attendees: **352**

Number of countries represented: **8**

Number of persons in attendance with SMS: **39**

Number of presenters: **35**

Number of Research Symposium experts: **25**

Number of Research Symposium presenters: **14**

Number of sessions: **42**

Number of "On the Road to Success—A Smith-Magenis Guidebook for School" sold: **200**

Amount raised by silent auction:

\$6,400

Amount awarded in conference scholarships: **\$10,000**

Number of hugs given and received:

10,000++



2016 PRISMS International Conference

PRISMS 9th INTERNATIONAL CONFERENCE
 "Building Bridges of Hope"
 When: July 28 - July 30, 2016
 The Hilton St. Louis at the Ballpark, St. Louis, MO


We hope to see you there!



PRISMS PUBLISHES BOOK

On the Road to Success with SMS

A Smith-Magenis Guidebook for Schools



PRISMS launched the publication of its first book: “On the Road to Success with SMS: A Smith-Magenis Guidebook for Schools” by Barbara Haas-Givler and Brenda Finucane, PRISMS Professional Advisory Board Members. This book is a compilation of many years of experiences and travels by Brenda and Barbara. The book is an invaluable tool that will provide step-by-step guidance and practical assistance for maneuvering through the school years and beyond. The Guidebook will foster success for all involved, (teachers, therapists, families and SMS individuals), and provide a road map for positive achievements and small victories.

PRISMS introduced the book at the 2014 conference in St. Louis and our authors, Brenda and Barb, were on hand to sign copies and meet families. This book will be the first in a series of resource books that PRISMS will publish in the future.

In December 2014, "On the Road to Success with SMS - A Smith-Magenis Guidebook for Schools" went digital and is available on the Kindle. If you do not own a Kindle, there is a free Kindle Reading app that will allow you to purchase and download the book for other mobile devices and computers.

Please use the following link to purchase the PRISMS book in digital form from Amazon - http://www.amazon.com/dp/B00R0G4AMQ/ref=r_soa_s_b

We are working on making the book available in other languages in digital form. We ask for your patience as we navigate this process to ensure accurate translations. Stay tuned for more information.

If you would like to order a hard copy version of the book, (\$28.00 for US mailing and \$40 for International mailing), please visit the homepage on the [PRISMS website](http://www.prisms.org).

PRISMS REGIONAL REPRESENTATIVES

In 2014, PRISMS laid the foundation for a Regional Representative program. Comprised of 31 individuals, the Regional Representative program allows for increased communication and engagement within SMS communities around the world. Regional Representatives were charged with responding to inquiries from families in their region, listening to and advising individuals and families as they encounter unique issues with their SMS loved one, distributing PRISMS resources when helpful, and encouraging families to join the PRISMS community of support. We are thankful to those who have volunteered their time to serving as a Regional Representative in 2014 and look forward to growing and enhancing the program in years to come.

North America/US Regions:

New England Region (CT, RI, MA, VT, NH, ME):
Leah Baigell - lbaigell@prisms.org

East Region (PA, NY, NJ, DE, MD):
TBA

Mid-Atlantic Region (OH, WV, VA):
Mary Hards - mhards@prisms.org

Southeast Region (NC, SC, GA, FL):
Mary Daly - mdaly@prisms.org

Great Lakes Region (WI, MI, IL, IN):
Brianna Collins - bcollins@prisms.org

North Region (MT, ND, SD, MN):
Heidi Graf - hgraf@prisms.org

Great Plains Region (IA, NE, MO, OK):
Cindy Linert - clinert@prisms.org

South Region (KY, TN, AL, AR, MS, LA):
Jean Bishop - jbishop@prisms.org

Northwest Region (OR, ID, NV):
Jennifer Klump - jklump@prisms.org

Central West Region (CO, KS, WY, UT):
Eric & Kim Hoffman - ehoffman@prisms.org

Southwest Region (NM, AZ):
Alejandro & Delma Aguilar - adaguilar@prisms.org

West Region (WA, HI):
Heather Eberlein - heberlein@prisms.org

Texas Region:
Mary Beall - mbeall@prisms.org

California Region:
Charlene Liao - cliao@prisms.org

Alaska Region:
Jennifer Schroeder - jschroeder@prisms.org

North America/Canada Regions:

Eastern Canada:
Brandi Wilson - bwilson@prisms.org

Western Canada:
Amanda Downey - adowney@prisms.org

North America/Mexico Region:

Mexico:
Maria Elena Carrancedo - mcarrancedo@prisms.org

South America Region:

Brazil:
Elaine Barros - ebarros@prisms.org

France Region:

France:
Stephanie Hanquez - shanquez@prisms.org
Virginie Sergent - vsergent@prisms.org

Australia Region:

Australia:
Cally Bauman - cbauman@prisms.org

Russia Region:

Russia:
Alexander & Bela Tzetlin - abtzetlin@prisms.org

For families whose primary language is Spanish, we've identified several contact families that are bilingual:

Maria Elena Carrancedo, Mexico City, Mexico -
mcarrancedo@prisms.org

Claudia Gomez, Haverstraw, NY - cgomez@prisms.org

Ines Oppenheim, Sierra Vista, AZ - ioppenheim@prisms.org

Maria Groenewold, Delta, BC Canada -
mgroenewold@prisms.org

For families whose primary language is Chinese, we've identified the following contact family:

Charlene Liao and Liqun Luo, CA - cliao@prisms.org

EMILY FIELDS

EXECUTIVE DIRECTOR



Friends of PRISMS,

I'm honored to join this rare and beautiful community of passionate families, researchers and physicians dedicated to meeting the needs and challenges of Smith-Magenis Syndrome. As an aunt to a loving and hilarious 12-year-old nephew with a rare genetic condition, I know what it is like to seek support and understanding from a school system, physician, and community that have never heard of SMS. And as a former employee of the National Organization for Rare Disorders, I know how important dedicated organizations such as PRISMS are to advocating for and meeting the needs of rare communities.

The road to this point has taken dedication, commitment, and support from the member community, the Board of Directors, the Professional Advisory Board, and others. The work and progress is evident in this 2014 annual report. PRISMS has never been stronger than it is today.

I'm confident in the work that has been done, and I'm looking forward to working together to continue to grow and improve the organization. As we move forward into 2015, this is a time in which we will reassess the community's needs and renew our commitment to working toward a world in which every life is lived to the fullest as we pursue advancements in research, increased early diagnosis, enhanced resources and services, a growing network of members, acknowledgment from the broader community, and more.

I could not be more excited to take this journey with you. It will take work and there will be challenges, but I am inspired by you, your families, and the opportunities ahead. Know that PRISMS is dedicated to working with and for this community, so I encourage you to reach out and engage with us. Your voices are the ones that count. I'm looking forward to hearing from you! Contact me anytime at efields@prisms.org

Thank you for your continued commitment to PRISMS' mission. The board and I are thrilled to see what we can accomplish with you in 2015 as we strive to reach new heights and provide new services for the SMS community.

Onward,

Emily Fields

growth

How You Can Get Involved in 2015!

Find us on Social Media



Host a Fundraiser or Awareness event in your area

Contact info@prisms.org for support and ideas to make your event a success

Join the PRISMS community by becoming a member for 2015

Learn more about membership by visiting our website at www.prisms.org

Make a Donation

Support PRISMS' mission to increased awareness, education, and research for the SMS community by visiting our website and making a donation today at www.prisms.org

Share your story with us

We want to hear from you. Reach out to PRISMS' Executive Director at cfields@prisms.org

*"2015 -
Reaching
New
Heights
and
Providing
New
Services"*

All photos courtesy of Rick Giudotti, professional photographer and founder of Positive Exposure. Positive Exposure utilizes photography and video to transform public perceptions of people living with genetic, physical and behavioral differences. Rick is a true friend of PRISMS and has graciously allowed us to use his beautiful photos taken at our most recent conference. Please visit his website: positiveexposure.org to learn more.



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