

ANNUAL REPORT 2013

PRISMS



PRISMS Launches Regional Rep Program

PRISMS is proud to announce a new program that will underscore its outreach to families worldwide. Much work was put into this program and the planning of it during 2013. The Regional Rep Program is made up of parent volunteers from around the world who provide support and information to newly diagnosed families, and also responds to families in their region who may have questions and concerns about SMS. The regional rep is the central point-of-contact for families in their region and may be the very first PRISMS/SMS contact that families may encounter. The “reps” may also

be involved in planning family get-togethers and picnics, and encourage fellowship between all the families in their region. We are confident that this program will cultivate a close SMS community and also provide a network whereby families can share strategies and information about SMS.

The regional reps are divided into regions in the United States, as well as Canada, Mexico, Brazil, Australia, and Russia. We have a listing of our reps on the PRISMS website under the tab “Family Support” and “Contact Another SMS Parent.” We hope that this

program will encourage more dialogue and friendship between our families and provide a deeper level of support. Our reps are very dedicated to the families and have a heart for this endeavor. We are fortunate to have such dedicated volunteers and recognize their commitment.

We look forward to hearing about the regional gatherings and will share those stories with our members.

President's Message

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 some of our 2013 highlights:

- We began the development of a regional representative program that will roll out in 2014. It is our hope that this position will help us provide more local support and networking for our families.
- We continued to improve our website and also took steps to increase the security of our site.
- We continued our planning for the 2014 International Conference to be held in St Louis, MO in July 2014.
- We developed a new Awareness Committee. We also celebrated November 17th as SMS Awareness Day. Julia Hetherington is chair of this new committee.
- We updated our New Member Packet and redesigned the PRISMS brochure, a key tool to provide basic information about SMS and PRISMS. We also developed a new Compassion and Information card.
- We began work on an exciting new SMS Handbook publication which should be available at the 2014 conference.
- We provided new funding for SMS-related research at the National Institutes of Health (NIH).



- We began developing strategies to prompt professionals in the field to contribute articles related to various components of SMS. We also conducted a survey to assess the needs of our readers, (what articles they would like to see in future newsletters, ideas for columns, determine future authors for articles).
- We began development of a Spectrum database that collects information related to various topics, and provides information as to where we are producing most literature, where our needs are and where we may want to target in the future.
- We developed a fundraising strategy and a case statement for conference fundraising.
- We continued to work on our organizational structure and efficiency by updating our bylaws and job descriptions. We also improved our controls and reporting of fundraising events. We began to discuss hiring an Executive Director and succession planning for our executive leadership team.
- We recruited a new board member, Steve Corbett, to join our board as the Spectrum Journal Editor. And Percy Huston and Phil Ruedi were re-elected to another 3-year term.
- We created a Volunteer Coordinator position and recruited more volunteers to help us fulfill our mission. Percy Huston agreed to serve as our first Volunteer Coordinator.

Since 1993, PRISMS has served as the primary source of information and support helping affected families. Today, we serve not only those in the U.S., but families throughout the world. Together we are making a difference in the lives of so many!! Again, thank you for your continued support. I look forward to a great 2014 and seeing everyone at the conference.

Warm regards,

Randy Beall



Professional Advisory Board

Sarah H. Elsea, Ph.D., FACMG

As an internationally recognized group of basic scientists, educators and clinicians with expertise in SMS, PRISMS' ten-member Professional Advisory Board (PAB) serves to advise the PRISMS Board of Directors on medical, scientific, educational and therapeutic matters, and to assist in the education and research activities of the organization. Members include experts in genetics, healthcare, basic science, education, and policy who assist in the development of accurate and effective informational and promotional materials for Spectrum, the PRISMS website, and other publications. The PAB is focused on the dissemination of accurate medical information regarding diagnosis, management, education, and genetic counseling. Members of the PAB respond to inquiries directly from families, caregivers, educators, and healthcare providers, give presentations and provide consultations at the PRISMS conference, and provide comprehensive support to the broader community via the Smith-Magenis Syndrome GeneReviews.

The PAB reviews requests for research studies and any requests for access to our membership. We have a process of review that requires all studies have Institutional Review Board (IRB) approval in addition to critical review by members of the PAB for relevance to the membership. These procedures ensure that the studies are credible, safe, and appropriate for families. In 2013, published research improved our understanding of the molecular changes affecting sleep disturbance and circadian rhythm, studies explored social preferences and interactions among children with SMS, and animal model studies enhanced our knowledge of the metabolic disturbances observed in SMS. We also saw the development of improved, cost-effective techniques for diagnosis of SMS that will provide alternative means for diagnosis in regions of the world that may have fewer resources for diagnostic services.

Current research studies on neuronal stem cell creation and characterization, the cellular function of RAI1, and the complex relationship of RAI1 with other genes involved in neurodevelopmental disorders are underway by scientists around the world and will further enhance our understanding of this complex syndrome. Additional studies about speech and sibling concerns are also expected.

The PAB and the PRISMS Board of Directors together in 2013 took steps toward the creation of a patient registry and began discussions with pharmaceutical companies to enroll persons with SMS in clinical trials for medications to improve sleep and behavior. We continue to support the SMS Biobank in collaboration 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, providing much needed support for ongoing and future research studies to improve our understanding of SMS.

Funding of both novel and ongoing research endeavors is critical for improved support for families, caregivers, educators, and healthcare providers caring for anyone with Smith-Magenis Syndrome. Only through research can education, treatment, and management of SMS be improved. The PAB strives to bring the most current information and support to the members of PRISMS.

Professional Advisory Board 2013

Sarah H. Elsea, Ph.D., FACMG
PAB Chair
Baylor College of Medicine
Houston, TX

Kerry Boyd, M.D., FRCPC
Bethesda Services
Ontario, Canada

Gonzalo Laje, M.D.
Behavioral Health Associates, L.L.C.
Washington, D.C.

Ann C.M. Smith, M.A., D.Sc. (Hon), CGC
PAB Chair Emeritus
National Human Genome
Research Institute
Bethesda, MD

Brenda Finucane, M.S., CGC
Geisinger Health
Danville, PA

Ellen Magenis, M.D.
Oregon Health Sciences University
Portland, OR

Christine Brennan, M.A., CCC-SLP
Northwestern University
Chicago, IL

Andrea Gropman, M.D.
Children's National Medical Center
Washington, DC

Lorraine Potocki, M.D.
Baylor College of Medicine
Houston, TX

Barbara Hass-Givler, M.Ed., BCBA
Geisinger Health
Danville, PA

Membership Report

John Mayer

At the end of 2013 there were 323 individuals or families who were members of PRISMS. Our membership is strong and we added 40 new families as members throughout the year.

Our member list shows that PRISMS serves families from across the country and around the world - to members from 45 states and 13 foreign countries. (For your information states without members are Hawaii, Iowa, Mississippi, Tennessee, and West Virginia.)

There are many benefits from membership including receiving timely, helpful, and new information via the Spectrum journal, the monthly e-blast, the PRISMS web site, and the PRISMS facebook page; the opportunity to make or strengthen a connection with others at our international conferences; by receiving materials for family members, teachers, and advocates; and much, much more.

2014 will be an important and exciting year. The many volunteers and Board members are deep in our work to prepare for the 8th international conference that will be held in St. Louis beginning Thursday, July 31 and running through Sunday, August 3, 2014. All of us hope you will make plans to attend and “meet us in St. Louis!”

Your membership dues provide the financial resources PRISMS needs to operate – and this support enables us to help families. The organization is here for our members, and we are able to do our job because of your support.

Thanks to all of you who are part of PRISMS. We truly value your membership and support.

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

Please note: membership dues are for the calendar year – January through December, regardless of the month you have joined. If you have any questions about your membership, please do not hesitate to contact me.

John Mayer
PRISMS Membership Chair

2013 Members of PRISMS

An * after the name indicates a new member in 2013.

Alabama

Carol & Tom Braithwaite
Laura & Matt Markus
Josh & Jill Wood

Alaska

Robert Ermold*
Jennifer Schroeder*

Arizona

David & Elaine De Temple
Patty & Steve Loyer
Ines Oppenheim

Arkansas

Carolyn Bruister
Rosanne & Pace Hindsley

California

Gina & Steve Belden
Frank & Judy Carney
David Crumney

John & Priscilla Diamond
Paul & Susan Diamond
Diane & Joseph Erth
Jeanine & T.D. Hetherington
Mary Hetherington
Krista & David Karr
Charlene Liao & Liqun Luo
Frank & Adela Nevarez
Joan & Achille Paladini
Laura Paladini
Kim & Tom Pastore
Amy & Brian Pereira
David & Gail Reiner
Andrew Staich & Kelli Brasket*
Stephen & Arlene Marie Staich
Melissa & Rick Visosky*

Colorado

Barclay & Tony Daranyi

Kim & Eric Hoffman
Donna Hulse
Janie & Eric Peterson
Walter & Jeanette Praetorius

Connecticut

Marty & Jean Eichelman
Louise Tortora, D.P.M.
Stephen & Hoang Wood

Delaware

George & Anne Hobbs

District of Columbia

Gunther Birznicks
Jillian Nickel

Florida

Joan & John Bielunski
Dana & Robert Cohen*
Stan & Joan Hinden
Kathy Hofmann
Irene Karpowicz
Mike & Allison Leatzow*

Melissa & Dan Longman
Georgia McClure*
Mark & Kelly Seaman*
Carol & Stan Triantafellu
Christopher & Laura Wells

Georgia

Ken & Christine Bolt
Lesslie & Blair Carnahan
James & Heather Michalski*
Michelle & Jay Perkins
Ann & Lowry Reid
Anne Ryder
Allison & Alex Stephanouk
Heather & Neil Whitaker
Rochelle & Paul Wright
Melissa Zbeeb*

Idaho

Monica & Mark Peterson
CecCee & Jesse Saxton
Jay Prakash Verma & Manju
Kaveri Kanakaraj*

Illinois

Joan & Michael Campione
Ashley & Tom Danis
Christine & Joey Grzybowski
Julianna & Jeremy LaPlant
Lori McKee*
Marissa McKee*
Robyn & Steve Mogul
Kevin O'Connor & Dana Deane
Helen & Michael O'Connell
Stacey & Larry Orleans*
Denien & Jim Rasmussen
Carol & Jeff Ross
Linda & Dan Tortorelli
Margaret & Robert Tortorelli
Dennis & Edee Norman Wiziecki
Carol & Glenn Wollschlager
Deann & Jeff Yerik

Indiana

Stan & Connie Sweeney
David & Jessica Vermeer

Kansas

Carol & David Pacey
Ryan & Jamie Peters
Van & Linda Peters
Katy & Frank Tra

Kentucky

William & Angela Bentley
Jean Bishop
Raymond & Joan Bishop

Louisiana

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

Maine

Susan & Daniel Longfellow
Jaye Orgera

Maryland

Christopher & Lisa Corbett
Mia Dudley*
Kerry & Bob Fairweather
Jim & Jamie Humphreys II
Yukiko & Tetsuya Ichino
Christian Lavedan*
Mary & Paul Miller
Amy Owens
Joanne Seward
Jane Stanley*
Ruth & Dennis Unglesbee

Massachusetts

Leah Baigell & Henry Kon
Cheryl & Ned Berman
Maryann & Paul Duzan
Rich & Julie Giurleo

David & Lynn Moertl
Diane & Michael Petrucci
Derek & Csilla Pickering
Joan & Peter Sherman
Laura Staich & Philip Ruedi

Michigan

Rod Allen
Herman & Lindy Hanko
Nichol & Jeff Hill
Jim & Irene McCool
Rajean Potter
Chad & Diane Ulrick
Jane Vit
Eva & Greg Wludyka
John & Terry Zdanowski

Minnesota

Jackie & John Fallenstein
Heidi Graf & Evan Steine
Melissa Haley & Tim Mulrooney
Cindy & Jeffrey Linert
Beverly & Marvin Melanson
Ian Severson & Cassie Meyer*
Carole Smith
Mary Kay & Dennis Vierling

Missouri

Lynne & Steve Baker
Thomas & Diane Daly
Dennis & Tracey Dillontes
Ashley & Andrew Fazel
Jim & Emily Humphreys
Sabrina & Bill Hurtgen
Percy & Bernadette Huston
Dennis & Sandra Raterman
Barbara Smith*
Madonna & Dan Walsh

Montana

Marni Rolston

Nebraska

Marilyn & Steve Groetke
Donna Stevens

Nevada

Patricia & Rafael Reynoso*
June Winkler-Teixeira

New Hampshire

Douglas & Jacquelyn Hill
James & Nina Kelly
Debora & John Mayer

New Jersey

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

New Mexico

Delma & Alejandro Aguilar
William & Laurel Sellyey

New York

Harriet & Martin Arno
Erin & Steve Corbett
Jan Corbett-Pittman
Dr. Lynn Diamond
Lisa Hutchinson
June & Todd Jacobson
Josephine Lawlor
Barbara Melamed

Kevin Murdock & Savitri Ramsingh
Mary Pinchiaroli
Liz & Bob Pucci
Ida & Richard Ruess
Renee Ryan*
Tracy & Linda Sundberg
Mary Ann & Ron Zimmer

North Carolina

Alice & Mark Bost
Linda Duvall
Robert & Shannon Duvall
Nancy C. Jacobus
George & Karen Lemmert
Susan Lenfestey
Alexis Lockhart*
Charles & Suzanne Ruedi*
Sam & Valerie Toke

North Dakota

Shannon & Darin Jantzi

Ohio

Christina Craig
Gene & Jennifer Gelfand
Matt Haban*
Kristen & Michael Hamilton
Janet & Dennis Hartmann
Kathy Krisko
Kim Manix
Sue McFee
Tina & Charlie McGrevy
Faith Nobilucci
Chris & Kimberly Norman
Thomas & Susan Schmidt*
Cathy Witt

Oklahoma

Adam & Tara Carleton

Oregon

Shirley & Donald Dechaine
Jennifer & Lou Klump
Ellen Magenis
Jeanie & Michael Singleton

Pennsylvania

Lisa & John Bellopede
Nancy & David Cordrey
Beverly & Steven Frey
Suzanne & Harry Frost
Barbara Haas-Givler
Susan & Martin Holland
Jackie & Wayne Johnson
Paula & Arthur Jump
Mary Kelly
Dana Krimmel
Beth & Paul Kurtz
William & Monica Mason
Mary Kate & Joe McCauley
Mrs. Roberto Morrison*
Celeste & Kemal Pegram
Milissa & Michael Pelonero
Mark & Carol Divens Roth
Betty & Paul Sullivan
Katie McCauley Sullivan*
Sandy Tome
Ronald & Celeste Waclawik
Carol & Gary Zaiser

Rhode Island

John & Maria Mosher
South Carolina
Anesthesia Associates of Charleston
Sharon & Daryl French
Julia & Tom Hetherington

South Dakota

Kipley & Ross McDaniel

Tennessee

Jim & Peggy Laney
Tane & Dale Levin
Olivia McGehee & Jim Schleicher

Texas

Eric & Sarin Abati
Ruth Angol*
Carolyn Beall
Mary & Randy Beall
Jack Byrom
Dawnda & Brandon Daniel
Karen & Glen Daniel

Ronald & Karen Dixon
Meredeth Drummond-Cox
Sylvia & Jeremy Farber
Chantzee Harris*
Jessica & Mark Kirklin
David & Sue Kuebler
Tamara Michelle Lee
James Lupski, M.D., Ph.D.
Brenda Massey
Craig Massey
Cecilia & Gordy Poole
Ron & Chandra Powers
Johnna Robinson
Larry Sarver*
Paula & Joseph Toussaint
Leanne VanDover
Eva & Weldon Wamble

Utah

Pat Boschetto
Sandy & Richard Hall
Jennifer & Joseph Haroldsen
Margene & Jonathan Morris
Jennifer Large Seagrave*
Heather & Daniel Wilde

Vermont
Patty & Dan Saunders
Sally Scheindel & Jason Lewis*

Virginia

Sarah Elsea
Mark & Claudia Gibb
Amanda & Charlie Graham
Judith & Matthew Livingston
Margaret & Scott Miller
Alice & Troy Petty
Diane Powers
Shannon & Darrell Richard
Ann & Ron Smith
Jeff & Venessa Stevens

Washington

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

Wisconsin

Mary & Tim Kamp
 Linda & David Mills
 Kimberly & Charles Pechous
 Patti & Terry Schiller
 Bonnie & Bill Spear

Wyoming

Tiffany Helling
 Irene & Dan Knoepfle

PRISMS members from foreign countries:**Australia**

Kawther & Monadhil Al-Hilali
 Paul Alexander
 Cally Bauman*
 Angela Bonato
 Denise & Stewart Caddy
 Richard & June Dixon
 Stephanie & Nicholas Hanson
 Susan & Bryce Hoad
 Catherine & Stuart Walker
 Jennifer Tolhurst-White*

Brazil

Eliane Barros & Raul Santos

Canada

Sonia & Brian Bench
 Dr. Kerry Boyd
 Donna Santiago-Douglas & Michael
 Douglas*
 Brian & Amanda Downey*
 Trina & Justin Fillier
 Lorna Harris & Jennifer Miller
 Kelsey Roberge*

Justus & Jennifer Smith*
 Nathasa Sheets
 Andrea Tatarsk*
 Brandi Wilson

Denmark

Leslie & Christopher Calzaretta

Iceland

Vidar Gunnarsson & Thuridur
 Jonsdottir

Japan

Shinji & Kaori Nozaki

Mexico

Maria Elena Carracedo

Netherlands

Ronald & Carolina de Kimpe

Norway

Ingvild Arskog Kjeldsen
 Kristine Ahlgren & Espen Stavland

Russian Federation

Bela Kafengauz & Alexander Tsetlin

Scotland

Hazel Wotherspoon

Sweden

Stephanie & Jonas Waller*

United Kingdom

Kristine & Glen Braden
 Diana & Paul Brice
 Carol Funnell
 Emma Riddell
 Patricia van Nederveen

Fundraisers 2013

In 2013 SMS families from across the country held events in their local area to raise money for PRISMS.

Jean Weil and family hosted their Annual Nickels for Nicco Corn Hole Tournament in Kentucky and collected more than \$6,000. Jeremy and Sylvia Farber raised over \$8,000 during a bowling fundraiser in San Antonio. Heather Michalski ran a marathon in Georgia and collected over \$10,000 in donations. Jill Wood raised more than \$2,500 during a “cut-a-thon” where people donated money to PRISMS in exchange for a haircut.

Yolanda Dasilva participated in a community yard sale and donated her proceeds to PRISMS. In Canada, Lilly Wilson’s grade school paid \$2 to wear their PJs to school on SMS day. Bill and Monica Mason hosted a golf outing in Cochranville, Pennsylvania with a \$4,050 donation.

Other successful fundraisers were held by Valerie Toke, Julia Hetherington, and Amanda Kurtz. Each and every fundraiser is valued by PRISMS and helps us meet our goals. We are grateful for the support.

PRISMS continues to host an online giving page at www.firstgiving.com/prisms and Gail Kopp opened a page in honor of her daughter’s Sweet Sixteen Birthday. In the past two years \$23,000 has been collected for PRISMS through this site. Families can post a paragraph about their child, upload a picture and share with families and friends through email and social media. Consider hosting a “Virtual Fundraiser” as

PRISMS focuses on raising funds to support the 2014 International Conference.

With the help of PRISMS volunteer, Michelle Lee, the PRISMS online store continues to sell SMS awareness items while collecting a portion of the proceeds. Visit www.cafepress.com/smithmagenis and order your stylish SMS clothing for this summer’s conference in St. Louis.

Ideas for fundraisers can be found on the PRISMS website. If you would like more information on how to host a fundraising event in your area, send an email to fundraising@prisms.org. Thanks to those many volunteers who helped make the past year a success!

Submitted by Tina McGrevy, Board Member



Donor List – 2013

Up to \$100

Kawther & Monadhil Al-Hilali
 Paul Alexander
 Harriet & Martin Arno
 Marsha & Gary Bach
 Lynne & Steve Baker
 Gina & Steve Belden
 William & Angela Bentley
 Raymond & Joan Bishop
 Carla & Glenn Blaser
 Paul & Angela Bonato
 Andrew & Kathy Booker
 Alice & Mark Bost
 Carol & Tom Braithwaite
 Carolyn Bruister
 Jack Byrom
 Leslie & Christopher Calzaretta
 Holly & Pat Carmichael
 Lesslie & Blair Carnahan
 Frank & Judy Carney
 Maria Elena Carrancedo
 Ilse & Randy Ciprich
 Rosemary & Rod Clifford
 Erin & Steve Corbett
 Nancy & David Cordrey
 Thomas & Diane Daly
 Dawnda & Brandon Daniel
 Barclay & Tony Daranyi
 Yolanda & Alfredo DaSilva
 David & Elaine De Temple
 Esteban & Jennifer Delgadillo
 Marty & Jean Eichelman
 Robert Ermold
 Trina & Justin Fillier
 Sharon & Daryl French
 Karen & Chuck Friedman
 Rich & Julie Giurleo
 Amanda & Charlie Graham
 Dianne Griego
 Ryan & Alana Harris
 Douglas & Jacquelyn Hill
 Stan & Joan Hinden
 Rosanne & Pace Hindsley
 Susan & Bryce Hoad
 Susan & Martin Holland
 Jim & Emily Humphreys
 Sabrina & Bill Hurtgen
 Matt & Charla Huston
 Percy & Bernadette Huston
 Fern Jantzi
 Jamie Imber Jonas
 Mary & Tim Kamp
 Irene Karpowicz
 Krista & David Karr
 James & Nina Kelly
 Jennifer & Lou Klump
 Irene & Dan Knoepfle
 Kelly Koerner
 Jim & Peggy Laney
 Josephine Lawlor
 George & Karen Lemmert
 Melissa & Dan Longman
 Bill & Janet Manning
 Tina & Charlie McGrevy
 Barbara Melamed
 Mary & Paul Miller
 Linda & David Mills

Robyn & Steve Mogul
 John & Maria Mosher
 Kevin Murdock & Savitri Ramsingh
 Frank & Adela Nevarez
 Shinji & Kaori Nozaki
 Helen & Michael O'Connell
 Kim & Tom Pastore
 Cecilia & Gordy Poole
 Caroline Pope
 Rajean Potter
 Walter & Jeanette Praetorius
 Liz & Bob Pucci
 Jim & Debbie Rahfaldt
 Denien & Jim Rasmussen
 Ann & Lowry Reid
 Mark & Carol Divens Roth
 William & Laurel Sellyey
 Stephen & Michelle Smith
 Bonnie & Bill Spear
 Stephen & Arlene Marie Staich
 Tracy & Linda Sundberg

Sam & Valerie Toke
 Linda & Dan Tortorelli
 Paula & Joseph Toussaint
 Ruth & Dennis Unglesbee
 Patricia van Nederveen
 Melissa & Rick Visosky
 Ronnie & Janet Wagoner
 Catherine & Stuart Walker
 Christopher & Laura Wells
 Cathy Witt
 Dennis & Edee Norman Wiziecki
 Gary Zaiser

\$100-\$1,000

Eric & Sarin Abati
 Lynda & Richard Algea
 Don & Stephanie Allison
 Karen Altsman
 Todd Amann & Kristina Bush
 Michelle Baudean
 Mary & Randy Beall
 Carolyn & Billy Belcher
 Jeffrey & Krisha Belz
 Joan & John Bielunski
 Lisa Bishop
 Adam Blanchette, M.D.
 David Blanton
 Pat Boschetto
 Tony & Sue Braddock
 Brian & Christie Busenlehner
 Dennis & Eleanor Bush
 Kathleen & Douglas Campbell
 Joan & Michael Campione
 John Cassapo
 Christiana Beer Outlet
 David Clarkson
 Margaret Clarkson
 James & Michelle Copeland
 Jan Corbett-Pittman
 Kathleen Costa
 Michael & Dionne Coston
 Stephen & Susan Cunningham
 Kevin & Mary Daly
 Ashley & Tom Danis
 Christopher & Becky Davenport
 Robert DayJohn & Priscilla Diamond

Paul & Susan Diamond
 Theresa Dicks
 Dennis & Tracey Dillon
 Ronald & Karen Dixon
 John Doherty & Kathleen McMonigal
 Sharon Durham
 Linda Duvall
 Barbara & Sam Dyer
 Elisabeth M. Dykens, Ph.D.
 Pamela Ferraro
 Shai & Hector Fietze
 Susan Garrett
 Joanne Garty
 George Gleghorn
 Scott & Paige Gorman
 Greer Chesco Dance Center
 Alice Hamby
 Thomas & Marilyn Hanna
 K.J. & Richard Hardegger
 Brooke Hardy
 Jeanine Hetherington
 Andrea Hilliard
 Kim & Eric Hoffman
 Kelly & Erik Hougen
 Ian Howell
 Casey & Tina Hudson
 Tammi Hughes
 Kathryn & Peter Hunter
 Yukiko & Tetsuya Ichino
 June & Todd Jacobson
 Nancy C. Jacobus
 Fred & Stella Jimenez
 Paula & Arthur Jump
 Judy & Dan Kearney
 Stephen Klausing
 Christina Knox
 Matt & Sharon Koleske
 Alan & Gail Kopp
 Kathy Krisko
 David & Sue Kuebler
 Beth & Paul Kurtz
 Tane & Dale Levin
 Cindy & Jeffrey Linert
 Debora & John Mayer
 Gerald & Sarah Maynor
 Mary Kate & Joe McCauley
 Kipley & Ross McDaniel
 William & Patricia McDonough
 Christine Meyer
 Margaret & Scott Miller
 John & Alvina Mitchell
 Katrina Munteanu
 Kerri R. Newlander
 Chris & Kimberly Norman
 Lisa Nunes
 Kevin O'Connor & Dana Deane
 John & Janet O'Reilly
 Ines Oppenheim
 Jaye Orgera
 Stephen Owens
 Jill Parrino
 Laura Pelaia
 Amy & Brian Pereira
 Diane & Michael Petrucci
 Sarah Pierce
 Kathy Platzman
 Lorraine Potocki, M.D.
 C. Ray Rathman
 Michelle & Timothy Reilly
 David & Gail Reiner
 Shannon & Darrell Richard

Fernando & Veronica Rizo
 Katherine Rundall
 Patty & Dan Saunders
 Betsy Schaffer
 Patti & Terry Schiller
 DeAnn Schleussler
 Terri Searcy
 Ann & John Sherman
 Joan & Peter Sherman
 Kenneth & Frances Shipman
 Jeanne Shobert
 Donald & Catherine Shoemaker
 Robert Simmermon
 Charles & Marcia Smallwood
 Ann & Ron Smith
 Denise & David Smith
 Jason & Jill Smith
 Angela & Kenneth Sparks
 Andrew Staich & Kelli Brasket
 Ann Stallard
 Danielle Stephenson
 Patricia Strawther
 David & Rhonda Stuart
 Stan & Connie Sweeney
 Cristine Thorp
 Ann Tidwell
 Sandy Tome
 Carol & Stan Triantafellu
 Rebecca & Richard Trout
 Coleen & James VanOsten
 Mary Vaughan

Ronald & Celeste Waclawik
 Alden & Kelley Weg
 Janice Wilder
 Ted Williams
 Brandi Wilson
 A. Thomas & Patricia Winters
 Tina & Andrew Witkoff
 Carol & Glenn Wollschlager
 Josh & Jill Wood
 Rochelle & Paul Wright
 Andrew Zbeeb
 Jane Zbeeb
 Box Top Advertising
 Hill Country Electric Supply
 Kauffman Gas
 Kirkwood Pharmacy
 McComsey Builders
 Meadowood Behavioral Health
 Mid Atlantic Behavioral Health
 Octorara Security Professionals
 Rock & Metal Systems, Inc.
 SmartSource Corporation
 Stoltzfus Fence, Inc.
 Stone Oak Pharmacy
 Stone Oak Therapy
 Two Alpha Management
 Umble Fence, Inc.
 Walton Farms, LLC

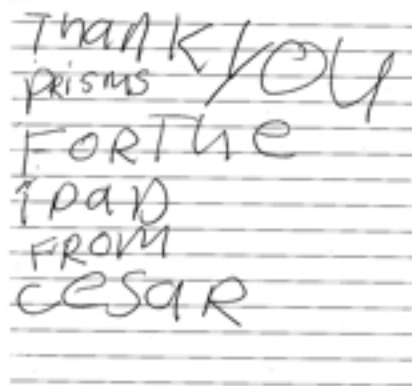
\$1,000-\$5,000
 Carolyn Beall
 Kerry & Bob Fairweather
 Sylvia & Jeremy Farber
 Julia & Tom Hetherington
 Charlene Liao & Liqun Luo
 William & Monica Mason
 James & Heather Michalski
 Joan & Achille Paladini
 Mary Pinchiaroli
 Zhenhai Shen
 American Endowment Foundation
 Constantinides Family Foundation
 TEK Systems

 Over \$5,000
 Fairfield Police Officers Assoc.

 Donation in Kind
 Bank of America
 Cibolo Liquor
 The Wash Tub
 John Mayer

Awareness Day 2013

PRISMS sponsored Smith-Magenis Syndrome Awareness Day, November 17, 2013. Any individual hosting a PRISMS awareness activity during the month of November could enter into a contest to win an iPad Mini. Many activities were held with wonderful success stories. Our winner was Yolanda DaSilva.



I'm always eager to share awareness of Smith-Magenis Syndrome. I found out that a local supermarket was hosting a yard sale. I inquired as to distributing information regarding SMS and they said it would be OK. I had a wonderful time selling items to raise funds for PRISMS and sharing information with area residents about my son, Cesar, and SMS.

When I was told that I could enter in a drawing to win an iPad, I prayed that I would win it so Cesar and I would be able to use it. I am very thankful to PRISMS for allowing Cesar and I to enjoy the iPad and also be active in sharing information about SMS.

Yolanda

Conference Report Maggie Miller



The PRISMS Conference brings together families of persons with Smith-Magenis Syndrome and professionals interested in “SMS” so that research information, medical, educational and therapeutic treatment strategies may be shared throughout the community in order to improve the lives of persons with SMS.

PRISMS 8th International Conference will take place this summer, July 31, 2014 - August 3, 2014 in St. Louis, MO. The PRISMS conferences are a powerful expression of the mission of PRISMS where parents and researchers come together every two years in a collaborative effort to share further research and promote awareness of SMS.

Planning for this conference began immediately after the 2012 conference ended and the committee has been busy ever since organizing the conference. We are very fortunate to have the same committee members planning the 2014 conference and are grateful for their ongoing dedication and commitment to planning another successful conference. The committee members include Nancy Cordrey, Shannon Jantzi, Nina Kelly, Margaret Miller and Amy Pereira. The Silent Auction will also take place at the conference and Lynne and Steve Baker are chairing the auction along with help from Heather and Dan

Wilde who organized the 2012 auction. Our local St. Louis help comes from Tracey and Dennis Dillon. Tracey and Dennis have been busy securing local speakers, volunteers and helping out in a variety of jobs. We are so appreciative of all of our volunteers who help to plan and execute the conference. The conference is the foremost program of PRISMS and requires tremendous effort and support. Many volunteers come together to share in this endeavor to provide a positive and educational experience for the attendees. We also applaud all of our conference sponsors and donors whose contributions support the financial costs of the conference.

The keynote speaker for this year’s conference is Brenda Finucane, M.S., CGC, PRISMS PAB Member. Brenda’s presentation is titled “From Single Syndromes to Shared Pathways: The Evolution of Behavioral Research in Genetic Neurodevelopmental Disorders.”

Other conference sessions will include information on:

- Navigating the conference and finding support along the way (for first- and second-time attendees)
- Transitioning to adulthood
- Nutrition to manage symptoms of SMS
- Education supports and strategies
- Special needs planning
- Behavior supports and interventions
- Research updates
- Technology in the classroom
- Speech and communication
- Sibling workshops
- Opening communication channels that encourage healthy relationships
- Sleep
- Advocacy in the educational system
- Siblings spotlight
- Medical management across the lifespan

We hope you will plan to attend and meet with families from across the globe. It is not just an educational conference, but also a celebration of our children! For more information on the conference, please visit the PRISMS website.

Committee members:
Shannon Jantzi, Nina Kelly, Margaret Miller, Amy Pereira, and Nancy Cordrey



Ryan Marshall Grant Update

The Ryan Marshall grant fund represents the personal efforts of Ryan Marshall to raise money for PRISMS to promote research of Smith Magenis Syndrome. In March 2013, PRISMS awarded \$13,130 to Ann C.M. Smith, M.A., D.Sc.(Hon), who leads the interdisciplinary SMS Research Team in the Division of Intramural Research of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health, Bethesda, MD. The majority of the Ryan Marshall award is allocated toward partial support of the NIH post-baccalaureate intramural research training award (Postbac IRTA); these funds support 40% of a fulltime position to work on major SMS research initiatives as a research assistant under the supervision of Ann C.M. Smith, M.A., D.Sc.(Hon).

In July 2013, Folami Duncan, B.S. began a one year Postbac IRTA fulltime position with NHGRI, joining the interdisciplinary SMS Research Team (SMS-RT) to work with Dr. Smith on ongoing SMS research initiatives stemming from the two active

SMS protocols at NIH (01-HG-0109; and 07-HG-0076). Ms. Duncan's early experience with families and children with Smith-Magenis syndrome began after high school when she spent several summers with NHGRI under the NIH's 8-week Summer Internship Program (NIH-SIP). After completing a B.S. degree from Temple University in Philadelphia, Folami accepted the full-time position as Postbac IRTA to spend a year with Dr. Smith in NHGRI-NIH before pursuing further graduate training. Very quickly she assumed the role as research assistant and has been integrally involved in management and analysis of clinical data collected by SMS-RT investigators at NIH Clinical Center under the SMS natural history protocol (01-HG-0109) that will lead to future publications. As a pre-med major at Temple University, Ms. Duncan plans to pursue a career in medicine and begins medical school in summer 2014 at Meharry Medical College in Nashville, TN.



PRISMS Booklet

On the Road to Success with SMS: A Smith-Magenis Guidebook for Schools

By Barbara Haas-Givler and Brenda Finucane

PRISMS is happy to announce the first in a series of SMS resource booklets. The first booklet will be available for purchase this summer at the conference and available online.

Brenda Finucane and Barbara Haas-Givler, PRISMS Professional Advisory Board members, are the authors of the booklet. Brenda and Barb have vast knowledge and experience with the education challenges facing SMS individuals. They have spent many years traveling around the world advising parents and school systems on the positive supports needed for children with SMS and outlining best outcomes and interventions that support their success. Brenda and Barb have also consulted on residential placements and training of staff to ensure the successful transition and placement of the individual.

Brenda and Barb have detailed their experiences in this booklet and provide practical hands-on strategies that can be applied to diverse school settings. This booklet will be a valuable resource for both families and professionals who are caring for an SMS individual of any age.

PRISMS is proud to sponsor this new resource as an additional service to our members.

PRISMS Updated Brochure

New in 2013!

PRISMS released a new brochure in the fall of 2013. The new brochure includes updated and expanded information on Smith-Magenis Syndrome, as well as updated information on PRISMS and its programs. The PRISMS brochure also includes photos of our beautiful SMS individuals and it represents the PRISMS trademark and is cohesive with the PRISMS website.

The new brochure can be downloaded from the website. Go to the home page and click on SMS Awareness Tools. You may request brochures at info@prisms.org and we will also have brochures at the conference. The PRISMS brochure is a resource tool, for parents to share with doctors, teachers and family. It provides a snapshot of the aspects of the syndrome, as well as information on PRISMS and how we serve our members.

PRISMS Board of Directors 2013

John Mayer
 Julia Hetherington
 Steve Corbett
 Mary Kate McCauley
 Philip Reudi
 Tina McGrevy
 Percy Houston
 Sarah Elsea, PhD
 Randy Beall.
 Not pictured:
 Maggie Miller

