

2019
SWS
Child
Care



ANNUAL
REPORT

CARING 2009



Our 2009 Board of Directors, an enthusiastic group of dedicated volunteers.

John Mayer, Randy Beall, Julia Hetherington, Jeri Gawlowski, Ann C.M. Smith, MA, DSc (hon), Percy Huston, Margaret Miller

MISSION STATEMENT:

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), and fostering partnerships with professionals to increase awareness and understanding of SMS.

Dear Friends,

PRISMS seeks to improve the lives of families affected with Smith-Magenis Syndrome. Our mission is our passion.

To achieve our goal, every day a community of researchers, medical professionals, donors, and volunteers work tirelessly and passionately — no matter the economic climate.

The year 2009 was a very busy one for PRISMS. Although work actually started two years prior, we saw the fruits of our labors at the 6th International PRISMS Conference and

Research Roundtable held in Reston, VA in September. It is a major undertaking to host an international gathering, but worth it when we see the parents mingling with the researchers. Investigating the sleep disorders, genetics and behavioral strategies specific to SMS, our conferences allow researchers, professionals and SMS families to share significant new information. They also provide much needed social and emotional support for families with SMS children. The hugs, the tears, the “aha” moments, and the incredible information sharing are truly inspirational.



We also began the planning process for the 2012 conference. After reviewing many sites, the Board of Directors has signed a contract for the Renaissance Hotel in Denver, Colorado.

We saw great support from our members, with many of them hosting fundraising activities. These events continue to generate tremendous awareness in addition to the much needed funds that are raised.

In 2009, we began working with the Camp Breakaway organization and the process of investigating the development of a pilot U.S. camp for SMS individuals and their families. Camp Breakaway has successfully served many Australian SMS families for several years. It is our hope that this will help us foster family education, respite and research activities. Look for more information regarding this in the coming months.

We have made great strides in our "publications" area. Our new parent packet was revised and improved. A new bookmark was developed and distributed. Also, we created a large poster to be placed in various therapy clinics. This will help us find children with SMS who are yet to be diagnosed, and further raise awareness. We have seen expansion and significant improvement in our quarterly newsletter, Spectrum. All publications and our website are now adorned with our newly redesigned PRISMS logo.

Many hours were spent in the planning of the first Research Alliance Meeting recently held in Elwyn, PA. The PRISMS Advisory Board, select PRISMS board members, and parents met with prominent researchers to share information and prioritize future PRISMS research projects. The first project to come from this meeting is a scientifically designed questionnaire that you will be asked to complete. We hope to obtain significant

research data, including the similarities between Autism and SMS, and the medications, complementary alternative methods, and therapies that are working for families.

A Plan of Work document was written to help guide our Board in our 2010 efforts.

Of course, none of this work could be accomplished without our great group of volunteers. PRISMS is run solely by volunteers, most are parents of children with SMS, and all lead very busy lives.

I also want to acknowledge the dedication and tireless efforts of our board members. In 2009, both Charlene Liao and Lindsay Warman served out their board terms, and we appreciate their service and contributions. John Mayer joined the Board in March 2009 and has already shown us what a valuable asset he is, working initially as our secretary and most recently as the chair of our Membership committee. Finally, Ann C.M. Smith and Julia Hetherington renewed their board terms for another 3 years.

Since 1993, PRISMS has served as the primary source of information and support helping affected families. Today, we serve not only those in the US, but families throughout the world. Together we are making a difference in the lives of so many!! Thank you for your continued support.

Sincerely,

Randy

Randy Beall

PRISMS, President

BEAUTIFUL!



"It is amazing how wonderful our SMS children are. They are vibrant, inquisitive, and very wise. They greet you with such joy, and often remember details others forget. They can throw the biggest fits, but turn around and be the sweetest, most loving kids around."

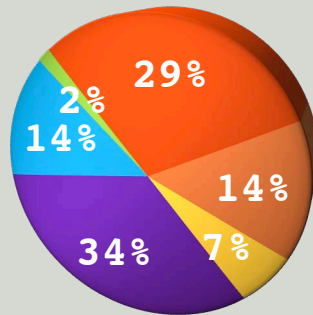
The PRISMS Board of Directors meets via teleconference monthly, and "face-to-face" two times a year.

FINANCING 2009



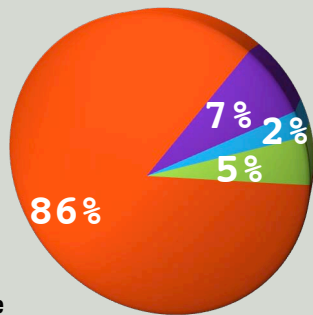
REVENUE

- Contributions
- Fundraising
- Interest income
- Conference and Research Roundtable
- Grants
- Membership fees



EXPENSES

- Programs
- Fundraising
- Management and General
- Conference and Research Roundtable



The financial results for 2009 were dominated by the 2009 PRISMS conference (\$137,008) and SMS Research Roundtable (\$19,096), which increased expenditures four-fold relative to 2008. These additional costs were only partially funded by direct conference fees and an NIH conference grant. Increases in membership contributions, product sales, and fundraising activities helped fund the balance of expenditures, but PRISMS also had to draw down some of the net assets of the organization. PRISMS remains committed to continuing its program services, supporting future research opportunities, and preparing for the next conference in July 2012. PRISMS financial goals for 2010 include the continued support of fundraisers, applying for grants, and specifically to fund \$100,000 for research focused on SMS. This will truly take a team of dedicated parents and professionals. If you are interested in helping with and/or hosting a fundraiser please contact us at info@prisms.org. We welcome your ideas.

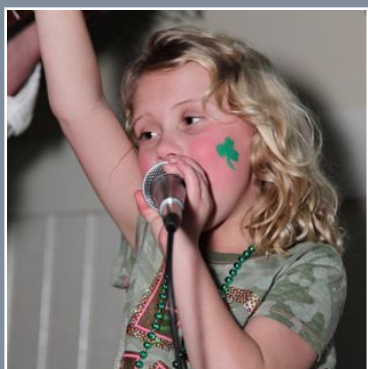
A copy of the 2009 audited financial report is available upon request.

SUPPORT AND REVENUE	2009	2008
Conference	44,335	----
Grants	21,700	----
Contributions	52,167	47,036
Membership fees	9,918	6,993
Interest income	2,384	4,843
Fundraising	20,764	8,106
Total	151,268	66,978

EXPENSES	2009	2008
Conference & Research Roundtable	156,004	----
Programs	12,251	47,020
Management & General	8,435	5,648
Fundraising	4,443	2,098
Total	181,133	54,766

TOTALS	2009	2008
Increase(decrease)in total assets	-29,865	12,212
Total assets, beginning of period	204,349	192,137
Total assets, end of period	174,484	204,349
Total assets consist of:		
Cash	173,634	203,499
Prepaid insurance	850	850

INTERACTIVE!



"You will never be bored around our children! They love, love, love to interact with people, especially adults. And they have such a great sense of humor!"

THANK You! 2009

Fundraising is so important to our organization. Every penny helps toward research and supporting our families!

We had many wonderful families give not only a donation, but their hearts and souls into educating others about our wonderful SMS family members. This is vital to our mission.

Fundraisers in 2009 came in a variety of venues and were organized by PRISMS members. John and Faith Stepic of Ohio held a golf tournament. Dawn Mock ran in marathon and raised funds for PRISMS, while Tina and Charley McGrevy, and Percy and Bernadette Huston sponsored road races in their respective states of Ohio and Missouri.

Achille and Joan Paladini generously donate a portion of their proceeds from their business to PRISMS (www.apaladini.com).

Julia Hetherington sold "Pottery for PRISMS" throughout the holiday season with all proceeds going to our organization.

Many of you contributed by supporting the above causes. Or maybe you participated in the Birdies for Charity, or the Silent Auction at the conference. You are so appreciated and your donations directly benefit our members!

If you need information on holding your own fundraiser, please don't hesitate to contact us at info@prisms.org.



**All of our
children are
winners!**



DONORS

2009



Our Donors Are Our Heros!

Donors: Jan 1 – Dec 31, 2009

\$1- \$500

Kawther & Monadhil Al-Hilali
 Harriet Arno
 Marsha & Gary Bach
 Lynne & Steve Baker
 Shirley Butler & Tom Barrett
 Carolyn & Bill Belcher
 Cheryl & Ned Berman
 Carla & Glenn Blaser
 Pat Boschetto
 Dr. Kerry Boyd
 Kristin & Carl Brown
 Stephen & Cindy Burns
 Dennis & Eleanor Bush
 Leslie & Christopher Calzaretta
 Patricio Chacana-Burchard
 Ilse & Randy Ciprich
 Rosemary & Roderick Clifford

Dawnda & Brandon Daniel
 Shirley & Donald Dechaine
 Myrna & Donald DeFreise
 Ira & Betty Dyer
 Sylvia & Jeremy Farber
 Karen & Chuck Friedman
 Shirley & Ephraim Garber
 K.J. & Richard Hardegger
 Jeanine & T.D. Hetherington
 Julia & Tom Hetherington
 Mary Hetherington
 Douglas Hill
 Kim & Eric Hoffman
 Ian Howell
 Donna Hulse
 Jim & Emily Humphreys
 Janet Jacobs
 June & Todd Jacobson
 Ray & Rose Marie Johnson
 Delphine & Louis Kish

Vi & Jim Kowalski
 Josephine Lawlor
 Patrick Lawlor
 Charlene Liao & Liquin Luo
 Melissa & Dan Longman
 John & Jackie Maiher
 Debora & John Mayer
 Mary McArdle & Anne Green
 Jim & Irene McCool
 Sue McFee
 Mike & Audrey McQuhae
 Beverly & Marvin Melanson
 Margaret & Scott Miller
 Mary & Paul Miller
 David & Lynn Moertl
 Maria Mosher
 Patricia & Nicholas Murphy
 Frank & Adela Nevarez
 Shinji & Kaori Nozaki
 Carol & David Pacey

Diane & Michael Petrucci
 Katherine & Ned Porter
 Lorraine Potocki, M.D.
 H. Walter Praetorius
 Lowry Reid
 Andrea & Troy Robillard
 Harvey & Renee Rose
 Patty & Dan Saunders
 James Schleicher
 William & Laurel Sellyey
 Joan & Peter Sherman
 Ann & Ron Smith
 Denise & David Smith
 Bonnie & Bill Spear
 Laura Staich & Philip Ruedi
 Betty & Paul Sullivan
 Linda & Dan Tortorelli
 Carol & Stan Triantafellu
 Mary Unglesbee
 Ruth & Dennis Unglesbee
 Leanne VanDover
 Tom & Lee Varallo
 Adrienne Wampler
 Karin Weber
 Tina & Andrew Witkoff
 Carol & Glenn Wollschlager
 MaryAnn & Ron Zimmer

\$500+

Jessica & Mark Kirklin
 Mary Pinchiaroli

\$1000+

Carolyn Beall
 John Boschetto
 Kellie & John Cooney
 Kerry & Bob Fairweather
 Percy Huston
 Matt Koleske
 Dawn & William Mock
 Kevin O'Connor & Dana Deane
 Achille & Joan Paladini
 Amy Pereira
 Jeanne Shobert
 Faith & John Stepic

Please note: We have had trouble with our computerized database. If you feel you have been left off of this donor list, or the following membership list for 2009, please contact us as soon as possible so we can make appropriate corrections! We value each one of you!

PROGRESS!



"When I look back before 1993 and we had nothing, no information, no group, no website, nada...we have come a long way, especially for being such a rare disorder. And to see how PRISMS continues to grow, seeking to improve upon the support of research and families with SMS individuals, is truly heartwarming."



SUPPORTING

2009

RESEARCH AND FAMILIES



The 6th International PRISMS Conference



The 6th International PRISMS Conference, “Building Bridges of Hope,” took place September 17-20, 2009 in Reston, VA. Families and professionals from around the globe, (including Japan, Canada, Mexico, Iceland, the Philippines, Denmark, UK, France, Australia, and the US), came together to learn, share, advocate, support, and celebrate all that is SMS. This was our largest gathering thus far, with over 335 persons in attendance. Attendees participated in lectures and workshops, including research updates on Smith-Magenis Syndrome, effective behavioral strategies, genetics 101, sibling workshop, fitness for your SMS child, speech & communication strategies, estate planning, advocacy & awareness, puberty and adult issues, independent living, and “the inner toddler.” Many of our PRISMS parents presented these lectures, as their expertise is invaluable, and real and their strategies are “perfected.” The conference was energized by the presence of our SMS children (ranging in age from infants to adults) who were helping hands wherever they were needed. Rick Guidotti, Positive Exposure, was ever-present, photographing our SMS children and capturing their fabulous personalities! The conference also included a very successful silent

auction, (our fourth), with all proceeds benefitting PRISMS. We closed our conference on Sunday with a Parent Panel, where four families shared their stories and journeys while raising a child with SMS.

Preceding the conference, on Thursday, September 17th, was the Fifth SMS Research Roundtable. The Research Roundtable gathered the Professional Advisory Board and other researchers and professionals from various research sites for a time of collaboration, discussion and planning, to further the research of SMS. The Research Roundtable works in tandem with the goals of the PRISMS conference, and the reinforces the partnership between parents and researchers.

“I can’t wait to go to the next one!”

The conference was supported by: National Human Genome Research Institute at the National Institutes of Health, Office of Rare Diseases, NIH, Gene Dx, Quest Diagnostics-Nichols Institute, and KIDS PLUS.

We look forward to the next conference which will be held June 28 – July 1, 2012, at the Renaissance Hotel in Denver, Colorado.

“One of PRISMS’ goals is to support and promote research into the causes, management, and treatment of Smith-Magenis Syndrome.”

MEMBERSHIP 2009

Our membership came from nearly every state and from fifteen countries around the world. We cherish each of our 328 family and individual members.



Alabama

Laura & Matt Markus

Arizona

Elaine & David DeTemple
Patty & Steve Loyer

Arkansas

Rosanne Hindsley

California

Gina & Steve Belden
Mark Brown
Austin Carney
Olivia Celis-Karim
Peter Cooper-Ellis & Sarah Weck
David Crummey
John & Priscilla Diamond
Paul & Susan Diamond
Mary Ellen Hesse
Jeanine & T.D. Hetherington
Mary Hetherington
Cheryl & Eddie Huber
Krista & David Karr
Jinsong Liao & Fengqiu Wu
Charlene Liao & Liquin Luo
Araceli Lonergan
Patricia Morgan
Gail & Bruce Napell
Frank & Adela Nevarez
Achille & Joan Paladini
Laura Paladini
Kim & Tom Pastore
Roberta Schannep
Elena Celis-Stout
Phyllis Strickland
Tom & Lee Varallo
Adrienne Wampler
Desiree Wessell

Colorado

Kim & Eric Hoffman
Donna Hulse
Robert & Jannie Morrison
H. Walter Praetorius

Connecticut

Lonnie Almeida
Jean Eichelman
Patricia & Frank Gonda
Linda & Henry Lyon
Louise Tortora
Stephen & Hoang Wood

District of Columbia

Barbara & Sam Dyer

Delaware

Carol & Gary Mears

Florida

Stan Hinden
Kathy Hofmann
Jeffrey & Christine Horn
Caroline & Thomas Irvine
Irene Karpowicz
Mary Kiupelis
Melissa & Dan Longman
Alicia Mangham
Patricia & Nicholas Murphy
Charles & Joan L. Ruedi Jr.
Carol & Stan Triantafellu

Georgia

Ken & Christine Bolt
Lesslie Carnahan
Amanda & Charlie Graham
Rosemary & David Hammond
Lowry Reid
Anne Ryder

Hawaii

Rhonda & Kevin Lowney

Idaho

Monica & Mark Peterson
CeeCee & Jesse Saxton

Illinois

Marsha & Gary Bach
Christine Brennan
Joan & Michael Campione
Ashley & Tom Danis
Christine & Joey Grzybowski
Kenneth & Mary Koppers
Shannon LaFave
Bill & Janet Manning
Nadia & Dan Marler
Kevin O'Connor & Dana Deane
Denien & Jim Rasmussen
Linda & Dan Tortorelli
Margaret & Robert Tortorelli
Dennis & Edee Norman Wiziecki
Carol & Glenn Wollschlager
Deann & Jeff Yerks

Indiana

Stan & Connie Sweeney

Iowa

Carla &
Glenn Blaser
Jim Rahfaldt & Debbie Fough
Karen & Chuck Friedman
Todd & Jennifer McQuown
Jan & Keith Rolston
Village Northwest Unlimited
Karin Weber

Kansas

Carol & David Pacey
Ryan Peters
Van & Linda Peters
Katy & Frank Tra
Todd & Shiloh Frese Walter

Kentucky

Janet & John Gothard
Jean Weil

Louisiana

Paul & Anna Hemker

Maine

Jaye Orgera
Jon R. Wiley

Maryland

Kerry & Bob Fairweather
John Goldsmith
Hanna Hildenbrand
Jim & Jamie Humphreys II
Yukiko & Tetsuya Ichino
Mary & Paul Miller
Dan & Susan Shannon
Jeanne Shobert
Doris Stiegman-Shina
Tina & David Thomen
Mary Unglesbee
Ruth & Dennis Unglesbee

Massachusetts

Leah Baigell & Henry Kon
Cheryl & Ned Berman

Caregivers RTR

Maryann & Paul Duzan
Debra Orgera & George Kohout
Diane & Michael Petrucci
Joan & Peter Sherman
Laura Staich & Philip Ruedi
Sean Stuart & Jennifer Oliver
Wendy & Michael Tyman

Michigan

Rod Allen
Heidi & Todd Carpenter
Jeri & Bill Gawlowski
Dolores Guy
Nicole & Jeff Hill
Vi & Jim Kowalski
Lindsay LaRocca
Jim & Irene McCool
Rajean Potter
Margaret Troon
Chad & Diane Ulrick
Jane Vit
Brenda Wagner
Eva & Greg Wludyka
Ed Zdanowski
John & Terry Zdanowski

Minnesota

Betsy Bruvold
Melissa Haley & Tim Mulrooney
Janet Jacobs
Cindy & Jeffrey Linert
Jean & Charles Patnode
C. Ford & Susan Runge
Carol Smith

Missouri

Lynne & Steve Baker
Dennis & Tracey Dillon
Jim & Emily Humphreys
Sabrina & Bill Hurtgen
Percy Huston

Montana

Marni Rolston
Rikki & Mark Saali

Nebraska

Marilyn & Steve Groeteke

Nevada

June Winkler-Teixeira

New Hampshire

Paul & Verna Brooks
Douglas Hill
James & Nina Kelly
Debora & John Mayer

New Jersey

Chana & Laurent Bensimon
Ilse & Randy Ciprich
Rosemary & Roderick Clifford
Yolanda & Alfredo DaSilva
Marie Flitcraft
Sara & Tsvi Gal
Gretchen Hannoush
Caroline Pope

New Mexico

William & Laurel Sellyey
Denise & David Smith

New York

Harriet Arno
Marcy Bulger
Dr. Lynn Diamond
Josephine Lawlor
Patrick Lawlor
Mary McArdle & Anne Green
Barbara Melamed
Kevin Murdock & Savitri Ramsingh
Leslie & William Perski
Mary Pinchiaroli
Evelyn Popper
Liz & Bob Pucci
MaryAnn & Ron Zimmer

North Carolina

Alice Bost
Nicholas & Kendra Caruso
Kevin & Mary Daly
Terrie & Harry Grose
Nancy C. Jacobus
Dawn & William Mock
Monica Moreira

North Dakota

Shannon & Darin Jantzi

Ohio

Kellie & John Cooney
Joan Currey
Lynda & Peter Deane
Kristen & Michael Hamilton
Mary Hards
Janet & Dennis Hartmann
Matt Koleske
Kathy Krisko

Kim Manix
Sue McFee
Charlie & Tina McGrevy
Faith Nobilucci
John & Janet O'Reilly
Faith & John Stepic
James Warman
Rochelle & Paul Wright

Oklahoma

Tara Carleton

Oregon

Shirley & Donald Dechaine

Pennsylvania

Talitacumi Acevedo
Kristin & Carl Brown
Dennis & Eleanor Bush
Leslie & Christopher Calzaretta
Nancy & David Cordrey
Gwen & John Dill
Milissa Ferry-Pelonero
Brenda Finucane, MS
Beverly & Steven Frey
Suzanne & Harry Frost
Marjorie Goldberg
Pat & Ed Gowland
Susan & Martin Holland
Cathy & Robert Hunt
Jackie & Wayne Johnson
Paula & Arthur Jump
Dana Krimmel
Beth & Paul Kurtz
Lisa & Matthew Martin
William & Monica Mason
Gina & Gary Masters
Mary Kate & Joe McCauley
Margaret & James Misewich
Celeste & Kemal Pegram
Mark & Carol Bivens Roth
Betty & Paul Sullivan
Sandy & John Tome
Carol & Gary Zaiser

Rhode Island

Maria Mosher

South Carolina

Carolyn & Billy Belcher
Jennifer & Joseph Comfort
Sharon & Daryl French
Julia & Tom Hetherington
Lisa & Teddy Johnson
Coye Riley
Trevor & Sharon Strever

Tennessee

Elisabeth M. Dykens, Ph.D.
Katherine & Ned Porter
Tane & Dale Levin
Olivia McGehee & Jim Scheicher
Tyrell & Carrie Swafford

Texas

Carolyn Beall

Mary & Randy Beall
Jack & Bobbie Byrom
Brenda Clemons
Dawnda & Brandon Daniel
Karen & Glen Daniel
David & Sue Kuebler
Meredeth Drummond-Cox
Sylvia & Jeremy Farber
Jessica & Mark Kirklin
Gloria Lopez
James Lupski, M.D., Ph.D.
Rick & Susan Moore
Ines Oppenheim
Cecilia & Gordy Poole
Lorraine Potocki, M.D.
Ron & Chandra Powers
Johnna Robinson
Paula & Joseph Toussaint
Leanne VanDover
Eva & Weldon Wamble

Utah

Sandy & Richard Hall
Margene & Jonathan Morris
Heather & Daniel Wilde

Vermont

Patty & Dan Saunders

Virginia

Sarah Elsea, Ph.D.
Mark & Claudia Gibb
Brian Gillions
Judith & Matthew Livingston
Margaret & Scott Miller
Diane Powers
Shannon Richard
Ann Smith, M.A., D.Sc (Hon)
Ron Smith
Venessa Stevens
Vicky King

Washington

Scott & Charlene Hamilton
Beth Seely
Michael & Bethany Shadder
Karla & Daniel Willson

West Virginia

Daniel Bryan

Wisconsin

Elaine G. Bennett
Alan & Gail Kopp
Linda & David Mills
David & Lynn Moertl
Amanda & Michael Ruff
Patti & Terry Schiller
Bonnie & Bill Spear

Wyoming

Irene & Dan Knoepfle

International Members**Argentina**

Julio Alberto Novo & Clarisa Marchetti

Australia

Kawther & Monadhil Al-Hilali
A & P Bonato
Camp Breakaway
Denise Caddy
Stephanie & Nicholas Hanson
Susan & Bryce Hoad
Kirrily McMahon
Mary Storch

Canada

Brian & Sonia Bench
Kerry Boyd, M.D.
Emely & John Coultis
Eric & Lorna Harris
Jill & Douglas McComb
Denis Mercier
Teegatha'oh Zheh

Chile

Patricio Chacana-Burchard

Denmark

Sergio & Pernille Fox
Mette Frederiksen
Joakim Lundstrom
Charlotte Thaasti

France

Helene De Leersnyder, M.D.

Iceland

Thuridur Jonsdottir & Vidar Gunnarsson

Ireland

Shirley Butler & Tom Barrett

Japan

Shinji & Kaori Nozaki

Mexico

Maria Elena Carrancedo

Netherlands

Ronald & Carolina de Kimpe

Norway

Kristine Benedichte Fyhn-Roevik

Philippines

Kristine & Glen Braden

Slovenia

Tanja Persolja

United Kingdom

Diana & Paul Brice
Carol Funnell
Sonya Lowe
Patricia van Nederveen

LOOKING FORWARD TO 2010 AND BEYOND

There is great excitement among our board members for PRISMS' future. With our "Plan of Work," we are driven to move forward with many new initiatives.

We have already met one of our goals for 2010 by bringing together many researchers at our first Research Alliance Meeting held at Elwyn, Inc. PRISMS sponsored this research forum and Elwyn donated the meeting space. The excitement among the invited guests was palpable. Even with many budget cuts for research grants in today's economy, we have hope that through the work of PRISMS and our membership we can continue to promote and provide funding for SMS research.

We are developing expanded committees to include more members in our organizational work. Committees include: Membership, Finance, Fundraising, Newsletter, Conferences/Programs, and Technology/Website.

If you would like to explore your own role in one of these committees, please contact us at info@prisms.org.

Look for a membership survey to come in the mail. And be sure to pay your 2010 dues. We are cleaning up our database, and don't want you to miss any of our information or the quarterly issues of Spectrum.

Remember, we are a volunteer run organization and we need everyone's help and input. If you see a way to make PRISMS even better, please let us know. We value and appreciate input from all of our families and professionals. And of course, donations to PRISMS are tax deductible.



Loving our
beautiful SMS
individuals!

Please note: We have had trouble with our computerized database. If you feel you have been left off of the donor list or the membership list for 2009, please contact us as soon as possible so we can make appropriate corrections! We care that we get it right!

PRISMS, INC.
21800 Town Center Plaza
Suite 266A-633
Sterling, VA 20164

972-231-0035

www.prisms.org
Info@prisms.org

**Great things
happen when you
have great
volunteers!**



2009 Annual Report



21800 Town Center Plaza
Suite 266A-633
Sterling, VA 20164

Address Service Requested

NONPROFIT ORG
US POSTAGE
PAID
DALLAS, TX
PERMIT NO. 2024