

# PRISMS 2011



**ANNUAL  
REPORT**

# DRIVEN 2011



Our 2011 Board of Directors, volunteers with a drive for excellence!

Randy Beall, Ann Smith, Sarah Elsea, Maggie Miller, John Mayer, Tina McGrevy, Julia Hetherington, Mary Kate McCauley  
Not Pictured: Phil Reudl, Percy Huston

## 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.**

PRISMS was created to improve the lives of families affected with Smith-Magenis Syndrome. We provide much needed information and support; 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 that have sacrificed to make our mission a reality.

This past year we continued the planning for our 7th International Conference to be held this summer in Denver. Our conference co-committee chairs, Nina Kelly and Shannon Jantzi, and program committee, Amy Pereira, Maggie Miller, and Nancy Cordrey, along with parent volunteers, Kim and Eric Hoffman, Kellie Cooney, and Heather and Dan Wilde, have been hard at work. Our International Conference (held every 2-3 years) is a major undertaking – in effort as well as financially. I hope you will consider supporting our efforts and join us in Denver June 28 – July 1, 2012.

PRISMS wants to provide families, researchers, and care providers with the most accurate, up-to-date information available about Smith-Magenis Syndrome. And we want you to have it when you need it. On March 18, 2011, we launched our newly redesigned website. This huge project was carefully planned and implemented by Scott Miller, with contributions from many. Spanish translations were done by Maria Elena Carrancedo. The new website offers easy navigation, and takes advantage of the latest technology.





Be sure to check there often, as we update the information regularly. With articles, photos, and video available, the help you need may be only a click away.

We also want to keep our families connected to each other for advice and support. Please join us on Facebook and follow us on Twitter! You can also now shop for PRISMS merchandise online at The PRISMS Store.

We saw great support from our members this past year, with many of them hosting fundraising activities. These events continue to generate tremendous awareness, in addition to the much-needed funds that were raised. We hope you will consider helping us by hosting an event.

PRISMS was also a partner in Rare Disease Day in February 2011, and will also be a participant in 2012. PRISMS joined with the National Organization for Rare Disorders (NORD) and others around the world in observing Rare Disease Day on February 28, 2011. On this day, millions of patients and their families shared their stories to focus a spotlight on rare diseases as an important global public health concern. PRISMS represented all of our families worldwide with a display and representation at the National Institutes of Health to give a voice to those who cannot advocate for themselves, and to bring awareness to Smith-Magenis Syndrome.

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 with the same challenges that all of our parents face. In addition to all of the tasks it takes to keep an organization running, PRISMS board members spend many hours answering calls and emails from parents, doctors, support staff, teachers, researchers, and students. We try to give each one as much support and information as they need. Our children with SMS are our inspiration. Our board members and their children with SMS: Randy Beall (Laura, age 26), Margaret Miller (Deidre, age 21), John Mayer (Charley, age 27), Phil Ruedi, (Griffin, age 6), Julia Hetherington (Rachel, age 18), Mary Kate McCauley (Christi, age 34), Percy Huston (Jacqueline, age 21), and Tina McGrevy (Garrett, age 12). Sarah Elsea, Ph.D., our new Professional Advisory Board (PAB) Chair, while not a parent of a child with SMS, is a passionately-committed researcher who has 2 daughters. Also, Ann C.M. Smith, M.A., D.Sc. (Hon), our PAB Chair Emeritus, helps guide and direct our efforts. Our board members and other volunteers donate their time free of charge in order to make our programs successful.

Speaking of our board, this year, John Mayer and Mary Kate McCauley renewed their board terms for another 3 years. Both John and Mary Kate have great passion for our mission, and I'm thrilled they have renewed.

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!! Again, thank you for your continued support. I look forward to a great 2012 and seeing everyone at the conference.

Warm regards,

Randy Beall  
PRISMS, President

Behind the scenes work is on-going, with the Board of Directors meeting via teleconference monthly, and face-to-face two times a year.

## COMPASSIONATE



"PRISMS is like our home base. We check in with PRISMS quite a bit for new updates and events, and love to read the characteristics and help for teachers. It keeps me grounded and refreshes my mind when the behaviors get bad."

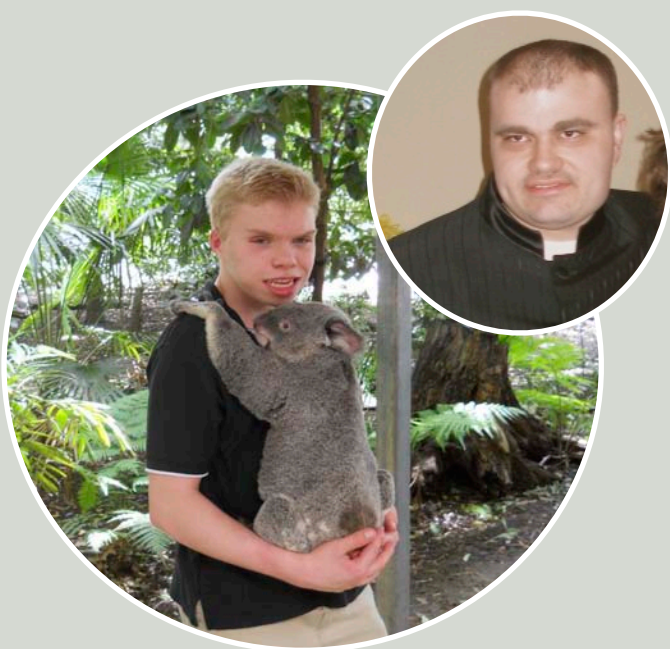
# Financing 2011



PRISMS financial goals include funding its continuing program services, supporting research opportunities, and preparing for the 2012 conference. Membership contributions, product sales, and fundraisers are all important components of our strategy to fulfill these goals. Total assets increased \$35,000 in 2011 after increasing by \$39,000 in 2010. This puts PRISMS in a strong financial position, as the significant costs of operating the 2012 conference are now being realized. It is anticipated that PRISMS will draw down its assets by almost \$100,000 in 2012 to fund an estimated \$170,000 in conference expenses. A portion of these expenses will be offset by conference fees and revenue, but a vast majority will be funded from financial reserves.

In 2011, but PRISMS received significant support from its members through individual donations and several fundraisers organized by its incredibly supportive members. Total contributions declined 5% in 2011 but were up 9% from 2009 levels. We view this as a strong reinforcement of the continuing commitment of the membership. Total membership fees were down in 2011 due to lapsed memberships and an extraordinary lifetime membership payment in 2010. Advance planning for the 2012 conference started in 2011 with almost \$17,000 spent to cover pre-paid conference services and planning for the event. Overall, 77% of total expenditures in 2011 were devoted to research, program expenses, and the 2012 conference.

PRISMS remains committed to supporting its membership through its program and supporting research. It is through the hard work of our dedicated membership that these goals are realized.



SUPPORT AND REVENUE	2010	2011
Conference	-	-
Grants	-	-
Contributions	72,228	68,762
Membership fees	9,244	6,914
Interest Income	1,407	1,241
Fundraising	4,642	5,380
Total	87,251	82,297

EXPENSES	2010	2011
Conference and Research	13,157	18,848
Programs	19,226	22,411
Management and general	14,982	10,837
Fundraising	840	1,283
Total	48,205	53,379

	2010	2011
Increase (Decrease) in Total Assets	39,046	34,643
Ending Cash	209,464	232,187
Ending Total Assets	216,240	250,703

## ACTIVE



"I want to be a part of this organization, learning from it, helping others, and supporting programs."

# Thank You! 2011

In 2011, SMS families from across the country spearheaded events in their local area to raise money for PRISMS, as well as awareness for Smith-Magenis Syndrome.

"Nickels for Nicco," a Corn Hole Tournament in Louisville, was held by Jean Weil and her friends. "Colin's Backyard Olympics," an event filled with backyard tournament games, food and raffles, was held by Chad and Diane Ulrick's family in Buffalo. On SMS Awareness Day, Sylvia and Jeremy Farber held a bowling fundraiser, and the "PRISMS Buck Creek 5K" was held in Ohio by Charlie and Tina McGrevy. Julia Hetherington sold "Pottery for PRISMS" in South Carolina and Nancy and David Cordrey held a jewelry party for PRISMS. Speaking of parties, the Dalys collected donations at a dinner party, the Fairweathers collected donations at a birthday party, and The Sweenys asked for donations at a the wedding. PRISMS was

chosen as a charity for Macy's annual "Shop for a Cause," and our members raised money by selling shopping passes.

Thanks to these many volunteers, PRISMS is able to continue our mission of supporting families of persons with SMS by "sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS." Please contact Tina McGrevy at [fundraising@prisms.org](mailto:fundraising@prisms.org) if you would like more information on how to host a fundraising event in your area. Don't forget, The PRISMS Store is now open on Cafepress! Visit [www.cafepress.com/smithmagenis](http://www.cafepress.com/smithmagenis) to get your SMS awareness items, and PRISMS will receive a portion of the proceeds.





# SUPPORTING PRISMS

PRISMS mission is *dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.* But how does PRISMS go about fulfilling this mission? This newsletter you are reading is one example. And, hopefully, by now you have had a chance to visit our updated website ([www.prisms.org](http://www.prisms.org)). Maybe you have given the PRISMS pamphlets or bookmarkers to family and friends, as well as that new medical professional who has “never heard of SMS.” Or, like my husband, Charlie, and me, you have been counting down the weeks until the next PRISMS conference since you checked out of the Reston Hyatt Hotel in 2009.

All of these things come at a cost. As a non-profit organization, PRISMS relies solely on membership fees and donations to continue our purpose to provide support to families affected by SMS.

2012 will be an exciting year! Another conference, this one held in Denver, Colorado. But, that also means that the PRISMS 2012 budget will be very high. And we need your help.

Please consider hosting a PRISMS fundraiser. It is not as daunting as it sounds. A fundraiser can be as big, or as small, as you feel comfortable organizing. Every dollar raised for PRISMS will help.

There are two types of Fundraising Models outlined in the PRISMS Policy and

Procedure Manual. The first type is when PRISMS is the beneficiary. This is essentially when someone would host an event and donate all, or a portion, of the proceeds to PRISMS. A couple of examples of this type of event could be a bake sale, garage sale, a “Donation Jar” placed at a family reunion or local gathering of your friends.

The second model is known as an event where PRISMS is the sponsor. This is the method Charlie and I have been using for our annual 5K in Springfield, Ohio. At first, this model can seem a little intimidating, but if two people that had never operated a lemonade stand can do it, anyone can!

Because PRISMS is a 501(c)3 non-profit, there are a few rules we must follow. For this reason, a budget of the event must be approved by the PRISMS Board. When PRISMS is the sponsor, 100% of all proceeds go to PRISMS. Because PRISMS was our sponsor, we were permitted to use the PRISMS logo and name. This added legitimacy to our event (especially the first year) when we approached local businesses with our donation request letter on PRISMS letterhead.

In this type of fundraiser, PRISMS reimburses the event organizers for the expenses. We found that companies were willing to bill PRISMS, which left little



upfront cost on our end. Also, PRISMS provides liability insurance in this kind of event. Our race is held in a state park and proof of insurance is required.

We want to encourage everyone to raise money for PRISMS! Regardless of which type of fundraiser you choose to follow, PRISMS can provide awareness items such as our bookmarkers and bracelets. We can include information about your event in the newsletter or e-blast to families in your area. And remember, donations to PRISMS are tax deductible.

As the fundraising chairperson for PRISMS, I would be happy to talk to anyone about doing a fundraising event. You can send me an e-mail at [fundraising@prisms.org](mailto:fundraising@prisms.org) or call me at 937-327-9354. I hope to hear from you soon!

*Tina McGrevy*

## FirstGiving: a powerful new tool to help us raise funds

PRISMS needs to raise close to \$100,000 to host the upcoming Denver conference. To help our members, we are utilizing a powerful new online fundraising tool called FirstGiving. FirstGiving allows you to create a personal fundraising page with your child's story complete with pictures and video. Your fundraising page might be for a special birthday, a sporting event, or a fundraising event you are hosting such as a walk or 5k run. You can even create a page to honor your child. After your personal page is created, you use the FirstGiving site to email your contacts – family, friends and colleagues-asking them to support your efforts. You'll be amazed at how easy this is to set up. And with a simple click, your supporters can contribute online and can post comments to your page in support of your efforts.

**We need your help. Please go to <http://www.firstgiving.com/prisms> and get started with your own fundraising page today!**

### **A few things we have learned after hosting five 5K runs...by Tina McGrevy**

1. We have an annual excuse to visit with our SMS friends! And each year we have more families attending our event.
2. Be a copy cat! We attended other races in our area and “borrowed” their ideas. The Red Cross had their 5K at our state park. We thought the low traffic and large amount of parking would work well for people with children. We used the location and the route from that Red Cross 5K.
3. When should we have it? Our main concern is that our event did not overlap with the other annual fundraisers in our county. Avoid the weekend of established fundraisers and find your “spot” on the calendar.
4. Who is going to come? First, of course, were our friends, family, and classmates of our son. But we were surprised to find our biggest partners have been other organizations (VFW, Red Cross, local foundations, churches, etc.). So be sure and ask those groups if they would be willing to volunteer, make donations, or spread the details of your event to their members.
5. Contacting media. At first, we did not have any luck when we attempted to reach the editors or station managers.
  - Newspaper - We read a human interest story and contacted that reporter about our race and SMS. She wrote a story about us that raised more awareness than the radio and TV combined.
  - Radio - Just like the newspaper, we had better luck contacting a specific DJ. We emailed the DJ who covered charity-type events, and she interviewed us for her weekly show.
  - Television - Again, we did not have any luck until we contacted a specific reporter. That contact info is on the stations’ websites.
6. Having a fundraiser was an opportunity for friends to “do something” for us. We learned that people have wanted to help our family, but were at a loss on how to do that. Also, after our race, people seemed more comfortable asking us questions about SMS.



### **Some Fundraising Ideas:**

**Bake Sale** - Maybe you can set up a table at the school’s next game, or a neighborhood festival, or club/church/organization event. The commitment is only a few hours, but what a great chance to raise funds for PRISMS and SMS Awareness. (And while you’re baking the goodies, send those fantastic recipes in for the PRISMS Cookbook! See insert for details.)

**Garage Sale** - Raise money for PRISMS and clean your basement/garage/whole house at the same time! It’s a WIN-WIN!!

**Craft Sale** - Got a special talent? Sell your treasures at a craft show and donate the proceeds to PRISMS. Our own Julia Hetherington raised enough money at her Pottery for PRISMS sale this fall to pay for our keynote speaker, Dr. Ross Greene.

**Corn Hole Tournament** - Enjoy tossing the corn bags with your friends? Make it a competition and charge an entry fee. Jean Weil and her family held a successful Corn Hole event in Kentucky this year.

**Bowling Tournament** - Maybe bowling is more your game. See if your bowling alley will donate some lanes for a bowling fundraiser. Sylvia and Jeremy Farber from

San Antonio, Texas held this kind of event on SMS Awareness Day.

**Olympic Events**-too many fun games to decide? Family and friends of Chad and Diane Ulrich held an Olympic-style fundraiser near Buffalo.

**Campaign Letter** - Write a letter about your child, the SMS diagnosis, and the PRISMS organization...and mail to your family and friends (you still have that list from the holidays, right?). Ask them to send a donation directly to PRISMS and we will send them a Thank You and a Tax Receipt.

**Make it a Birthday Party**...use your child’s birthday as a chance to write your campaign letter.

**Make it a Virtual Tea Party**...include a tea bag and ask your friends to join you for a “tea party.”

**Fun Runs/Walk-a-Thons/Marathons/5K** - Whatever you choose to call it, there are many ways to move your feet and make money for PRISMS at the same time.





# DONORS

## 2011



## Our Donors Make It Possible!

### Over \$1000

Carolyn Beall  
Mary & Randy Beall  
Kerry & Bob Fairweather  
Sylvia & Jeremy Farber  
Julia & Tom Hetherington  
Charlene Liao & Liquin Luo  
Debra Libby  
Ryan Marshall  
Joan & Achille Paladini  
Roberta Schanep

### \$500 - \$1000

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Nancy & David Cordrey  
Laura Duncan  
Vi & Jim Kowalski  
G. Patrick Lester  
William & Patricia McDonough  
Mary Pinchiaroli  
Jeanne Shobert  
Stan & Connie Sweeney  
Jean Weil

### \$1 to \$499

Dave & Linda Abati  
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Thank you to our in-kind donors:  
 Bank of America Print Center  
 Scott Miller



# LOVING



"It keeps me up-to-date on what is happening in the SMS world. I love to be able to meet other families; maybe I can help them or they can help me."

# SUPPORTING

2011

RESEARCH AND FAMILIES



Building  
Bridges of Hope

**prisms** 7TH INTERNATIONAL  
CONFERENCE | DENVER 2012

## The 7th International PRISMS Conference

June 28 – July 1, 2012

Denver Renaissance Hotel, Denver, CO

We hope you have all marked your 2012 calendars for the conference and are planning to attend. The conference is a unique opportunity to meet other families who have a child with Smith-Magenis Syndrome, and share stories and strategies. You will also attend presentations from our Professional Advisory Board and invited speakers regarding the latest research on SMS, and pertinent information for your child and family. We will again have daycare available for a limited group of SMS children, provided by Corporate Kids. We hope to see many returning families, as well as first-time attendees. There is so much to gain from attending the conferences, and you will leave with as much support and encouragement as our families and professionals can share!

The conference details, including hotel costs, room reservation information and prospective speakers, are also available on our website. Please visit our website ([www.prisms.org](http://www.prisms.org)), our Facebook page, and look for upcoming details in emails from PRISMS.

Your conference committee is made up of volunteers, all who are parents of a child with Smith-Magenis Syndrome. They have dedicated many months to all the planning and execution of the numerous conference details, including the silent auction. We truly thank our dear parents who are the most extraordinary volunteers! The conference is the largest and most expensive program that PRISMS supports, and we rely on our dedicated members to help organize and host the conferences. Our PRISMS members are also some of our speakers at the conference, and they generously share their time and expertise. As soon as the 2012 conference ends, planning begins for the next one! This is your conference and we need your support! PRISMS subsidizes most of the conference costs and keeps the cost of registration fees low by funding the conference. We need your help with fundraising, sponsorship, and financial donations in order to keep those costs down. Please consider becoming a conference sponsor or seeking conference sponsorships to keep these costs affordable. There is still time, and every donation counts and supports the mission of the conference. If you would like to help with fundraising and sponsorship, please contact the conference committee at: [Conference2012@prisms.org](mailto:Conference2012@prisms.org)  
We hope to see you at the conference!

*“They, (the conferences), are extremely helpful in providing education on SMS, parent support, and information exchange. The conferences are always very well run with excellent accommodations.”*

# MEMBERSHIP 2011

At the end of 2011, there were 238 individuals or families who were members of PRISMS. Our membership came from 42 states and from ten countries around the world. States currently without members are Alaska, Hawaii, Idaho, Mississippi, Montana, South Dakota, Vermont, and West Virginia – who do you know in those states that might benefit from a membership with PRISMS? Please help us reach out to those families and invite them to join us!

There are many benefits from membership, including receiving helpful information via newsletter, e-blast, the web site, or Facebook page; making or keeping a connection to others; having access to materials for family members and supporters; and more. Most importantly, your membership dues provide the financial resources for PRISMS to continue to operate – and that support enables us to continue to help families. The organization is here for our members, and we are able to do our jobs because of your support.



2012 will be an exciting year with our conference in Denver. In addition, we will work to increase our membership by reaching out to new families, and working to capture the interest of those who have let their memberships lapse. The results from the 2011 PRISMS survey supports our goal of improving communication with our members.

Thanks to all of you who are part of PRISMS – and to my colleagues on the Membership Committee for their efforts: David and Denise Smith, Tara Carlton, and Mary Kate McCauley.

*John Mayer, Chair*  
PRISMS Membership Committee

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# PROFESSIONAL ADVISORY BOARD

## Driving Research

PRISMS' ten-member Professional Advisory Board (PAB) serves to advise the Board of Directors on medical and scientific matters and to assist in the educational 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. The board writes and edits articles for Spectrum newsletter, PRISMS website, and other publications. Dissemination of accurate medical information about diagnosis, management, and genetic counseling is provided by PAB members to individuals and to the broader community through direct consultation, and via the Smith-Magenis Syndrome GeneReviews.

<http://www.ncbi.nlm.nih.gov/books/NBK1310/>

Members of the PAB individually respond to ongoing inquiries about clinical, educational, research, and management issues received via [info@PRISMS.org](mailto:info@PRISMS.org) from families of persons with SMS, as well as lay, educational, and professional service providers.



During 2011, Ann C.M. Smith, M.A.,D.Sc. (Hon), stepped down as Chair of the PAB after 18 years. Ann was critical to the formation of the PAB and has been Chair since its inception. PRISMS and the PAB are indebted to Ann for her dedication, passion, and many years of service. We look forward to continuing to work with her as she continues her role as a member of the PAB providing expert support to PRISMS.

The new Chair of the PAB is Dr. Sarah Elsea, member of the PAB since 1998, and an Associate Professor of Pediatrics and Human & Molecular Genetics at Virginia Commonwealth University (VCU) School of Medicine. Her research is focused toward characterizing Smith-Magenis Syndrome and related genetic disorders. Dr. Elsea's lab identified RAI1 as the causative gene for SMS in 2003, and has focused research efforts toward characterization of RAI1 using mouse and cell culture models, including the effects of RAI1 on pathways involved in obesity, sleep, and behavior, and the identification of other possible genetic causes for SMS-like disorders.

During 2011, research enhanced our knowledge and understanding of the behavioral aspects of SMS, including self-injurious behaviors, autism spectrum disorder, and sleep disturbance, provided additional evidence for the molecular mechanisms leading to chromosomal deletion, and described the impact on career choices for mothers caring for a child with SMS. Continued support of research endeavors is critical, and is the primary means by which treatment and therapies move forward. Current studies on sibling relationships, eating behaviors, stem cell analysis, and investigating the cellular function of RAI1 are underway, and will further enhance our understanding of this complex disorder.







"I have been blessed by conversing with and finding help from the PRISMS staff and the other members I have had the opportunity to meet. I am also thankful for the cafe store which is spreading the word to SMS families and others. I am very thankful to be part of the PRISMS family."



## The 2011 PRISMS Survey

This past June, PRISMS distributed the first-ever survey of our constituents both through the *Spectrum* newsletter and on-line using the web-based program **Survey Monkey**. By the time the survey period closed on July 31, there were 114 completed responses – 65 through the web and 49 through the mail.

While the survey was open to anyone interested in PRISMS, only 6 non-members submitted a response– the balance of the 108 surveys received were from members. Considering the PRISMS membership stands at just over 260 – nearly 40% of the PRISMS membership responded – a remarkable indication of the interest and dedication of the membership.

### Why the survey?

PRISMS is a volunteer run organization with a small board of directors, and a mission to provide meaningful and helpful service to our members and the SMS community. Conducting a survey is one method to understand the needs and interests of our audience, and a direct way to evaluate which programs are useful, and those that could improve.

"I always refer doctors, teachers, and therapist to the PRISMS website for information."

The information gathered through the survey will help the board develop plans for future efforts. During the November face-to-face meeting of the board, we will be reviewing the data from the survey and use that information to develop our annual plan of work.

There were two types of questions in the survey – questions to measure the quality of PRISMS programs offered, and open-ended questions to learn about needs and interests of our constituents.

### Questions evaluating PRISMS programs

Several questions asked for a ranking of the usefulness of programs, while others asked about the membership program. The responses were strongly positive about the work of PRISMS. "PRISMS is our lifeline..." "Great to be connected to other families..." "You are doing a good job keeping parents informed..." The conference, newsletter and website stood out with very strong and positive rankings.

Areas of concern which will be reviewed by the board are the annual report, questions about membership status, the Parent-to-Parent program, and the New Parent Packet.



### Open-ended questions about new programs or initiatives

Question 5, regarding new areas for research and study, and Question 10, regarding important challenges and how PRISMS can help, generated a diverse list of important responses. "Sleep disorders," "handling behaviors," "what to do when my child becomes an adult" were frequently mentioned. But more specific questions about use or abuse of medications, communications, and genetic features of the syndrome were posed.

One issue that was frequently mentioned was an interest in and the value of regional gatherings, and the need to interact and share information with other families. Clearly, a mechanism for connecting families would be valued.

As above, these data will be discussed by the board and the research advisory council.

### Interested in learning more?

This is a brief and preliminary report about the survey. There will be more information and actions that follow. The 2011 PRISMS Survey is just one mechanism we will use to communicate with our members and other constituents, and to learn about needs and opportunities for the future. In the meantime, do not hesitate to contact PRISMS if you have additional comments or questions, or if you want to learn more about the survey. Our thanks to everyone who participated in this important effort.

-- John Mayer, Secretary



# 2011

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