



Building Bridges 2009

The children were absolutely enthralled with magician, Dave Thomen and pianist, Jerry Roman. Alex Smith, singer, involved all ages with his wonderful music. It was quite a start for the 6th SMS conference in Reston, Virginia. A record number of parents were connecting as the welcome reception began. There were hugs all around as old friends reunited and new friendships began.



PRISMS president, Randy Beall, opened the conference on Friday morning, welcoming over 330 parents and researchers. Rick Guidotti, photographer from Positive Exposure,

spoke of challenging the stigma associated with difference by celebrating the beauty of human diversity. He is a delightful man who demonstrates, through his interactions with our SMS individuals, that he is true to his mission. His website www.positiveexposure.org is well worth a visit...plus, you can see pictures of our SMS children from the conference.

Our keynote speaker was Dr. William A. Gahl, MD, Ph.D. It was an honor to have the clinical director for the National Human Genome Research Insti-



tute provide us with information regarding rare disease patients. He brought the message of the importance of not just getting a disease named, but to move forward with a study of the disease. For researchers, this includes serving as consultants to the world, developing new treatments, and training others so research can occur. He left us with the following quote by Ernest Hemingway, "The world breaks everyone, and afterward, some are strong at the broken places."



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The wonderful SMSers "Ann" catcalls brought laughs and applause from the audience as Ann Smith, M.A., D.Sc. (hon) took the podium. Her presentation "My, how we've grown!", made everyone realize just how far such a small group has come.....from a kitchen table to a room filled with over 300 individuals. She acknowledged the important partnership between parents and researchers. SMS awareness is growing throughout the world, partly due to new and improved molecular diagnostic



Continued on page 6....



A Message from PRISMS President...

Randy Beall

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Recently, more than 335 PRISMS members and guests joined together at the Hyatt Regency Reston, September 17-20, for the 6th International Conference "Building Bridges of Hope", setting a new record for conference attendance. An SMS Research Roundtable was also held on Sept 16th. Families and researchers came from all parts of the globe, including Australia, Canada, Denmark, France, Iceland, Japan, Mexico, Philippines, U.K. and the U.S.

We met many new friends and re-acquainted ourselves with families that we had met at previous conferences. We learned...we laughed...and some of us even cried. I want to personally thank Margaret Miller, our conference chair, and her committee. Maggie spent countless hours working to make this conference a great success. Jeri Gawlowski is our "money gal" (aka Treasurer) and PRISMS-wear queen who made those great jewelry bracelets and hoodies. Thanks, Jeri! I want to also thank our great conference sponsors. It takes a lot of money (almost \$120,000) to help subsidize the conference and we depend on your generous support. Also, a big thank you to our speakers, volunteers and professionals!

This year our conference silent auction raised \$8590. Wow!! I want to extend a huge thanks to Kellie and John Cooney (and their volunteers) for an awesome job with such a fun event! Also, I would like to say "thank you" to all of our silent auction donors. Our first conference silent auction was held in 2002 at our Denver conference and now it's a conference tradition – and a terrific fundraiser!

This was my family's 5th conference and we've learned important information with each one. While some folks believe the conferences are primarily for newly diagnosed families, my family has always learned valuable information, met amazing people and felt re-charged after each conference.

Be sure to mark your calendars now for the 2012 Conference in Denver, June 28 – July 1, at the Renaissance Denver Hotel. This beautiful hotel offers a free airport shuttle and is conveniently located midway between Denver International Airport and Downtown Denver. A special thanks to Eric and Kim Hoffman for finding this great hotel.

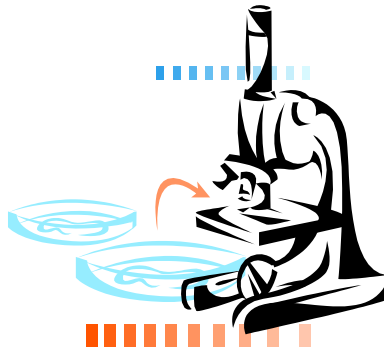
Finally, please think about ways you can get involved and support each other – post conference. SMS is a journey and we so desperately need to support each other and learn together. PRISMS can help you host a local fundraiser, host a picnic or just connect you with other local families. Or maybe you can help PRISMS in some way – for example, you could write an article for our newsletter or join our SMS discussion board and help answer questions folks have posted.

The PRISMS board is here to serve you. If you have suggestions or concerns, I would love to hear from you!

Randy

Research Roundtable

Thirty-eight invited researchers and clinicians attended Thursday's 5th SMS Research Roundtable convened & co-sponsored by PRISMS Professional Advisory Board and NIH SMS Research Team. The invited scientific symposium was funded in part by a conference grant from the Office of Rare Diseases Research, NIH, and administrative support from Office of the Clinical Director, National Human Genome Research Institute's Intramural program at the NIH. Research presentations on both clinical and basic science research topics related to SMS were presented and updated summaries of this research were later shared with the PRISMS conference attendees at the Research Update on Saturday or as part of workshops presented during the conference.



What Is Smith-Magenis Syndrome?



Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann CM Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

Ann
with
some
of
our
conference
stars



Conference Sponsors:

The following institutions and companies generously supported the conference:

- **The Office of Rare Diseases Research at the National Institutes of Health**
- **The Office of the Clinical Director, National Human Genome Research Institute at the National Institutes of Health**
- **Gene DX**
- **Quest Diagnostics– Nichols Institute**
- **Kids Plus**

The conference was also supported by generous contributions from PRISMS families.

- **Deane O'Connor and family**
- **Pat Boschetto**
- **Carolyn Beall**

Parent to Parent

Did you know that PRISMS sponsors a parent-to-parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another SMS parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps a list of parents willing to be contacted. We'll send you addresses and phone numbers and then you can talk all you want. Contact:

Mary Beall

Phone: 972-231-0035

mary.beall@tx.rr.com

Important note:

PRISMS parent-to-parent program will only give out information on parents who have agreed to be contacted. If you would like to be added to the list of contact parents, please email Mary at the above address.

Silent Auction Summary

By Kellie Cooney

The conference is over. The auction is closed. My daughter, Julia, and I want to thank everyone who donated items. We had set a goal of 200 items. Due to everyone's generosity, we not only met our goal, we surpassed it! We had 241 items! As we were setting up, the items just kept flowing in!

The Boss (Julia) and I want to thank all the people at the conference, including our SMSers, for making our silent auction successful. We all had a lot of fun bidding against one another! Alan Kopp and I have battled the last three auctions! This auction he out-bid me on most of the items. Next auction..... Look out Alan!

I want to thank some people for their help. Without all the help I have received, it would have been impossible for me to do what we did. I would like to thank my Aunt Gretta, who has helped me with 4 silent auctions for PRISMS. I want to thank my friends, Maggie Miller, Bob and Cathy Hunt, Kristy Hamilton, David and Denise Smith, the Hetheringtons, Lynn Diamond and Jeri Gawlowski. A huge thank you to my family, John, Julia, Blythe and my mom, Kathy. Julia wants to thank her friends, as well, for helping with our auction: Laura Beall, Tyler Gothard, Tyler Boman and Deane O'Connor. OK, now for all of you who helped me, and I am forgetting to list your names, *please* remember I have a 10-year-old with SMS who has *the* memory! She's not

here right now and for the last 10 years my brain power has been rapidly diminishing! PLEASE know I appreciate all the help everyone gave us.

In three years we will be in Colorado. Guess what, Julia has already signed a contract with



PRISMS to run the silent auction! Have any of you ever used a monthly calendar to help the obsession of an upcoming event settle your SMSer? Do you know what it is like to have Julia doing the count down for Colorado already?! UUUUGGGGGHHHHH

In three years I will be Julia's assistant again. We will contact you closer to the time of the conference. Until then, if you find something that would be great for the silent auction, just put it in the closet until 2012. And if you have any suggestions, please contact me at silentauction@prisms.org.

Once again, thank you to everyone. We look forward to seeing you in 2012! Until then, have a safe and healthy year.

Beginning Our Journey

By Faith and John Stepic

A few months ago, our baby, Kaitlyn, was diagnosed with Smith Magenis Syndrome. Kaitlyn was 8-months-old; however, she was not sleeping or eating like an 8-month-old. She was no longer meeting the major milestones for her age.

We suggested that she have a general chromosome test done. We just wanted to rule out anything medical.

To our surprise, things didn't come back as expected. The doctor gave us the PRISMS website, which was our link to finding out about what Kaitlyn has. We went through all the emotions and called people from around the country for answers.

Our lives from that moment on have been changed forever. Our days are now filled with doctor and therapy appointments. We now know what is causing Kaitlyn's lack of sleep.

We have tried to keep some normalcy and have planned fun days with the family: no doctor appointments. We started to sign with her in hopes that she will be able to communicate with us so it won't be so frustrating for her.

We are proud to say that her brothers, Stephen and Anson, are becoming very good at signing. It is a different way of life for us now.

Kaitlyn is a true joy and our little blessing. She already has a sense of humor. She cracks herself up which, in turn, gets us laughing.

We have also received words of encouragement, hope and support from families we have met through PRISMS. We are very blessed to be able to talk to these families to find



Faith, John, and Kaitlyn

out more about what the future has in store for us. Thank you so much for helping us to have hope when we thought there was none. We feel so blessed to have met so many wonderful people.

Through all of this, we decided to do something that would make us feel like we had some control of what is going on in a life that now feels so out of control. We had a golf outing 3 months after finding out that Kaitlyn was diagnosed with SMS. We were new at this but it was a success and raised awareness, which is what we wanted the most. We donated all of the proceeds, \$1944.00, to PRISMS.

We had so much fun and got such a positive response, we are planning

another golf outing in Columbia Station, Ohio, June 2010. We were overwhelmed with the generosity of those around us and believe our next outing will be an even bigger success. We hope to see you there. More details to come.

The Stepic Family

PRISMS Support

techniques as well as the work of PRISMS. The mean age at diagnosis is now 4.5 years, with the majority of cases being diagnosed in the last 5 years.

Attorney Robert Bullock brought his unique style and extensive knowledge of special needs trusts to our morning. This could be an all day seminar (or more), but he was able to give a picture of what needs to be done. It is, as he states, "The federal and state Medicaid statutes have been described as the regulatory equivalent of the Serbonian Bog!" So many things to remember! We hope to have him write an article on this subject for our newsletter! He brings personal experience to the table, as he has successfully advocated for his daughter with Down Syndrome throughout her life. He is so right when he says that we are our child's advocate, and although it is not a joyride at times, it is necessary to know this information. We really hope to be able to provide more about this for those who were unable to attend this year's conference.

"It Doesn't Have to be This Hard" was presented by Suzanne Mintz from the National Caregiver Association. She discussed family caregiver wellbeing, sending the message



of ... believe in yourself, protect your health, reach out for help and speak up for your rights. She recommended the following websites: www.nfca.lotsahelpinghands.com, www.sharethecare.org, and www.thefamilycaregiver.org.

Friday afternoon brought four concurrent sessions which were REALLY hard to choose just one from. The newly diagnosed had a special session just for them, led by Dr. Smith and Dr. Introne. Dr. Laje spoke on pharmacologic strategies for behavior management. He specifically noted that data retrieval is crucial to learning the best "set" of medica-

tions for SMS individuals. He encouraged each of us to keep a medication log. The ABC's of behavior strategy was addressed by Barbara Haas-Givler, BCBA. Christine Brennan, SLP, shared her speech therapy expertise by reviewing early communication needs...giving concrete suggestions and activities. All of these provided wonderful take-home strategies.



Wow, you would think the day would be over by now! But the information just kept coming! A break was given and then it was time for more informal education and sharing. The experts were available for "curbside" consults. This was such a wonderful opportunity for the parents. It is something that is pretty unique for our group researchers and parents truly working together! Time was also given to browse the silent auction and just sit and talk if you wanted.

Many found a quick dinner and then came back for more with sessions from 7-8:30 pm. Concurrent sessions were again available for all SMS age ranges. John and Debora Mayer gave so much hope to the parents approaching SMS adulthood. They spoke of their pioneering approach to the concept for independent living for their son, Charley, and also of their development of a self-employment work option for Charley. They have found that the options for our SMS adult individuals often don't "fit" our children. It is hard work to find meaningful options, but the audience came away with courage to take that often rocky road to find a better

alternative for our children. Attendees also had the session on Genetics 101 presented by Dr. Elsea and Dr. Smith, or the session for newly diagnosed families led by Dr. DeLeersnyder, Dr. Potocki, Brenda Finucane and Barbara Haas-Givler to choose from. Both of these provided a non-intimidating environment to further understanding of SMS. Many questions were answered.

And all this was just on the first day of presentations! Go ahead...make arrangements for the 2012 conference!

Saturday saw continued energy from the parents, the researchers, and of course, from all of the SMSers present! A note here: There were many comments about how wonderful it was as a parent NOT to be looked at oddly when your child had "a moment". Where else does everyone "get it"???!!!

Developmental Asynchrony: Embracing the Inner Toddler in SMS. What an interesting topic, brought forth from years of observation by Brenda Finucane, M.S., CGC. Ongoing research is being done on this unevenness in the intellectual and socio-emotional development of SMS children. The take-home message was that the emotional side should be addressed in educational and work settings. This does not mean that you treat older individuals with SMS as a young child, but that you use many of the successful strategies in a "grown up" manner. A full article is available on the PRISMS website in the Summer 2008 edition of Spectrum. We hope to have a follow-up on this as research continues.





Concurrent sessions fully filled the rest of Saturday morning, interspersed with visits to the silent auction, and loads of personal sharing. An amazing story was heard from Tina McGrevy and Kim Norman on how they came together and how they are spreading the word of SMS. Sibling impact was discussed by school psychologist and sibling, Jenny Beall. In other areas of the building, communication with your physician was addressed. Mary Beall presented on behavior strategies, always a popular topic. We heard from SMS parent, Tom Hetherington, P.T., on fitness for life. Dr Boyd, Dr. Merideth, and Linda Moroz, Behavior Therapist, provided a session on puberty and SMS implications. Dr. Elsea and Rebecca Foster, M.S., presented their research on Caregivers (Spectrum Summer '08, Fall '08, Winter '09). The Behavior Brainstorming session was filled as parents met with age specific groups to problem-solve.

More followed with a general session of International SMS Research updates, moderated by Dr. Smith and Dr. Elsea (we are so lucky!). The following research was reviewed:

National Institutes of Health, (Bethesda, MD):

Ann C. M. Smith, M.A., D.Sc. (hon):
Natural History Study Update

Hanna Hildenbrand, OT: A Comparative Study of Sensory Processing in Children with Smith-Magenis Syndrome and Children with Autism.

Myra Woolery, RN, MN, CPON: What Goes in Must Come Out: Constipation in Smith-Magenis Syndrome.

Baylor College of Medicine, Houston, TX:

Wenli Gu, Ph.D., Melanie Heney, M.Sc :
What's new on the mouse front. Updates on the mouse study of Smith-Magenis Syndrome.

Virginia Commonwealth University:

Sarah Elsea, Ph.D.: Updates on research at VCU and the SMS Sibling Survey Project.

France:

Helene DeLeersnyder, MD, Didier Rosch, MD, Psychiatrist

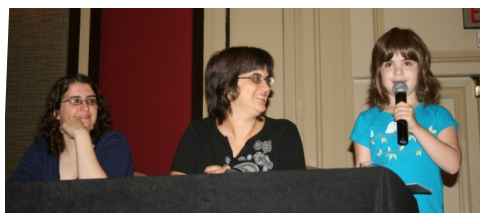
United Kingdom:

Peter Hammond, Professor of Computational Biology, UCL Institute of Child Health, (University College London)

All researchers thanked the parents for participating in this vital research. Please take the time to answer the surveys, and otherwise participate in research. It is critical for Smith-Magenis Syndrome knowledge to progress!



Our final morning, Sunday, was much more informal, but no less valuable! A wonderful Australian contingency presented their dreams of bringing Camp Breakaway to the US (Spectrum, Winter '09). Everyone there was ready to sign up on the spot! Talk of a camp for respite, adult time, programs for sibs, and



SMSers, all made you feel like someone with really big, warm arms was giving you a hug. It is a viable dream which you will hear more about in the coming year. And most would be happy to come all the way to Reston just to hear our fantastic SMS families of David and Nancy Cordrey, Sara and Tsvi Gal, Jessica Kirklin, and Pala and Arthur Jump. They were great! All spoke of their trials



and tribulations, bringing a message of hope. The presentations were filled with humor, real-life experiences, and an unexplainable sharing of emotions. What a wonderful, wonderful end to a successful conference.

None of this would be possible without the tireless efforts of Margaret (Maggie) Miller and her conference committee. Years were spent in the planning of this conference. But, we can definitely congratulate Maggie on a job well done. We hope to see everyone, plus more, at the next conference!



Deane's Grandma

By Dana Deane

Deane's grandma talks to Deane on the phone everyday. It's magic.

Deane's grandma, he calls her Lyn, also happens to be my mother. To provide some context for my story about Deane's grandma, I want to tell you a little about my mother, about some of the qualities my mother did not have when I was a kid. But, because it is Mothers' Day and out of guilt, I will first tell you a couple of her great qualities as my mother.

First, I know that she is always on my side, absolute unconditional love. As an adult, I recognize how rare that is and how lucky I was (and still am) to have it. My mom never forgot that she was the adult and I was the child, so she forgave all my childish transgressions, even when I committed them at age 25. But she never talked down to me or patronized; she addressed me as an equal (or at least a potential equal). And she purposefully instilled in me the confidence to live as a strong, independent woman. So, I think all of those positive qualities, and more, are a part of me.

However, to understand her as Deane's grandma, I need to tell you some of the qualities she did not have as a mother. (In fairness, neither do I.) My mom was never a *talk baby talk to your baby* kind of mother. She was not a *get on the floor and play with the kids* kind of mother. She was not a *take the kids to Disneyland because even though you will hate it they will love it* kind of mother. And, although she is and was an avid reader herself, she was not a *read to your kids* kind of mother. In fact, she thought kids' books were poorly written and gen-

erally pretty bad. And she certainly did not need to read them more than once. (Maybe the upshot of that was further independence. "If you like this story, you might want to learn how to read it yourself.")

Finally, and most important to my point, my mother does not suffer fools. She is impatient with both systems and people who are slow or inefficient or otherwise waste her time. (I got a lot of that quality, too.)

Then, along comes Deane. Deane is our oldest child. And he was my parents' first grandchild. Before the second was to come along, Deane was diagnosed with a chromosomal deletion labeled Smith-Magenis Syndrome. He's missing a piece of a chromosome. There are lots of characteristics associated with this deletion, including an unusual sleep cycle, impulse control issues, and intellectual disability, which in Deane's case is pretty serious. Those of you who know Deane know that his most obvious deficiency is probably his speech—he doesn't speak well. But I need to tell you that he talks much better than he used to.

For many years, Deane's primary communication medium was using sign language. Kevin, Ellis (and to a lesser extent, I) can sign with many a proficient two-year-old. But don't ask us to sign with any of you who sign. You see, when you are learning to sign with and for a two-year-old, you learn farm and zoo animals, colors, and basic needs (eat, bathroom, stuff like that)—basically, baby talk—not much that's useful to most conversations with people older than toddler-age. Ironically, one of Deane's greatest strengths has always

been communication. He loves to communicate. He has what they call "high communicative intent"—he will work very hard to communicate. When he was younger, he would pull on people and point to what he wanted; he would use some speech, some sign, and some pantomime to get people to understand what he wanted to say. And because our sign language vocabulary was pretty limited, and because he hears, Deane would use sign language homonyms. (For those of you trying to remember which ones are homonyms, those are the words that sound alike but mean different things.) So, for example, Deane would use the sign for car to ask "Who's going to car the turkey?"

Over the years, as Deane's speech has improved, the signing and pantomiming have diminished and his speech has increased. But once in a while you may notice that he will not know how to say something or will not be understood; then he will fall back on sign language.

Deane has always liked to talk on the telephone. It didn't work very well at first because he couldn't use signing and pantomimes to communicate on the phone. (It was fun watching him try, though.) So, eventually,



Deane would be on one phone and either Kevin or I would be on another trying to translate where we could. Although inconvenient for us, Deane didn't mind—he wanted to stay connected. You might say that talking on the telephone was (and is) Deane's favorite hobby. And beginning very early on, Deane's favorite phone buddy was my mother. That's right—my generally impatient, intolerant mother. She has talked to Deane on the phone nearly every day, for 10 to 20 minutes a day, for more than 10 years.

No matter what she is doing, no matter what else is going on for her, when Deane calls, my mother usually stops what she is doing, and talks to Deane. Now, these are not always the most stimulating or engaging discussions, at least not from what I hear of them. Some of you may have talked to Deane frequently enough to know that he will often ask a series of concrete questions on the same topic each time he talks to you. So, he asks the same questions every time he talks to you. And the same is true with his conversations with my mother—same questions every call. And, in the case of Deane's grandma, the result is almost comical. You see, Deane's grandma pretty much does the same things, eats the same things, and goes to the same places everyday. So, day after day, the conversation is basically the same conversation. At least, that's what it sounds like to me.

But, here's the magic part. When I ask my mother if she minds talking to Deane everyday, which I do occasionally ("After all, Mom, don't you get bored?"), she exclaims, "Oh no, not at all!" My mom, who wouldn't read *Cat in the Hat* to me even a second time (and probably never did read it to my younger brother), loves talking to Deane everyday. My mom

sees her conversations with Deane, not in bite-sized daily occurrences, but in a continuum. She gains insights into how his mind works; she recognizes incremental improvements in his speech; she identifies increased complexity in his use of language; she notices improvement in his ability to engage as a talker as well as an interrogator; and she gets a kick out of the colloquial expressions that enter his lexicon ("Hey, guess what?" and "So, what's the scoop for today?" being a few of the recent additions).

Deane's grandma loves him in a way I will never understand but very much admire. She may know him in a way that no one else does. And I think he knows her in a way I don't, and in a way I don't understand. In fact, when I step back and look at it, I cannot understand their relationship on any rational level. So over the years, with input from my Uncle Fritz (my mother's brother), I have put together a back-story for this. My mother would probably deny the connection; she talks to Deane because she loves him. She enjoys it. I believe that is true. But I think there is something else going on here.

Here is what I believe. I believe this is all connected to my parents' siblings. You see, my parents are each the oldest child of their parents. They each have a living younger brother. But they each had another sibling, and both of those siblings died at or shortly after birth. In my dad's case, evidently immediately. In my mom's case, her brother, Stephen, lived for a while. Stephen was identified at birth, in 1941, as Mongoloid—meaning he probably had Down Syndrome. I understand that the doctors convinced my grandmother that "it would be better" if she never saw him and that he should be placed in a residential facil-

ity immediately—so he was. Stephen died shortly after that.

My mother says that she believes that the guilt for sending Stephen away never left her family. My Uncle Fritz says that Deane is our family's opportunity for redemption. We're doing it better this time, as a society and as a family. My mom, Deane's grandma, talks to Deane on the phone everyday. Lovingly. Patiently. Everyday.

Texas!

Annual SMS Picnic - Houston, TX

Date: **Nov 7, 2009**, 10:30am. Place: Bear Creek Park, 3535 War Memorial Drive, Houston, TX. Contact Information: Cecilia Poole. Email: foxwxgal@hotmail.com, phone: 713-823-4401

Baylor College of Medicine Annual Parents' Night Out - Houston, TX

Date: **Nov 6, 2009** (sign-up deadline **Oct 23, 2009**), 6PM-10PM. Place: Texas Children's Hospital Clinical Care Center, 6701 Fannin St, 3rd Fl., Houston, TX. Contact Information: Valerie Price, Tara Banaszek or Holly Hodges. Email: baylorbpsa@gmail.com Phone: Valerie 832-822-4292, Tara 314-920-5636 or Holly 662-312-9427

SMS Parents plan to meet for a relaxing dinner (minus kids) at a nearby restaurant (D'Amico Italian Market Cafe, 5510 Morningside Dr, Houston)

SMS SuperKid!

Rachel Hetherington

We've told all our family and friends that they would be put on the "naughty list" if they ever gave Rachel money. At 15, she will bug you and bother you until that money is spent! And we all know how persistent our SMS children can be! So when her school sent home a fund raising project for the American Heart Association, we were very hesitant to let her participate. Would she turn over the money? Would she understand that it wasn't her money?

Well, our fears were totally misplaced. With only a parent walking along (and having to stay at the road), Rachel went to the neighbors and raised \$170.00. No one could say no. She wouldn't let them! We have found a new strength in Rachel. Maybe we can put her to work for PRISMS. ©

She was so proud. She was the 3rd highest fund raiser at her school. The fundraiser was called Hoops for Heart. She won several prizes, including a prized basketball. She then got to play in a basketball game, with typical peers, and against the teachers. She loved all the attention and really did well.

Rachel is our SuperKid! She is sweet, funny, and has a heart of gold. She is passionate about life, so quick to forgive and forget, wise in many ways, and a friend to all. We laugh sometimes because we can't go many places in our small town that someone doesn't call out "Hey Rachel!"

Do you have a SMS SuperKid? We would love to publish a picture and a story about your child. As we all know, even small accomplishments are encouraging for our SMS families. Please consider sharing your good moments with us. If you have questions or need help with the story, please call the PRISMS editor, Julia Hetherington, at 843-521-0156, or contact through email at editor@prisms.org



United Way Donations

As you may know, the United Way begins its annual fundraising drive each fall in nearly every community in the United States, Canada and many other countries. It provides a way for many charities to obtain funds by individuals contributing a portion of their paycheck through payroll deduction. Each United Way chapter lists a variety of organizations that may be chosen for payroll deductions, most of which are locally based. Many of the United Way's 1,400 chapters or member organizations also allow individuals to **write in the charity of their choice**. The 501(c)(3) non-profit status of PRISMS should qualify us for the write-in option (assuming the local chapter accepts write-ins). Here's all of the information you'll probably need: PRISMS, Inc., 21800 Town Center Plaza, Suite #266A-633, Sterling, VA 20164, Tax ID 54-1652029.

To obtain a write-in campaign in your workplace, contact your company's United Way chairperson or your local United Way agency (national.unitedway.org) to ask if there is a write-in or designation option. Most co-workers are eager to donate to a cause that is personally tied to a colleague. Posting a public letter or a poster asking your fellow employees to join you in our fight against SMS might be one way to reach all the employees and increase our funding.

Annual Rocky Mountain SMS Get Together 2009

It was time to organize our annual Rocky Mountain SMS Get Together for 2009. Many people helped choose a site and get things organized. We gathered at noon on August 15th. The day started off with a light rain, but soon the sun was shining on us as we all enjoyed the miniature golf and go-karts. The temperature was not too hot and not too cold, just right.

There were 34 people from Colorado and Wyoming at the Get Together. Logon's family joined us for the first time. It was nice to meet them and observe the "SMS connection" as Logon gave Amy a great big hug.

Many people gathered under the tent area to talk and share stories, while others enjoyed the golf and go-karts. There was the typical parent-swapping among the kids (isn't it great to know your child is understood?!) The grills were started and soon we were all enjoying hamburgers, hot dogs, grilled chicken, potato salad, potato chips, brownies, soda and ice water.

Families flowed in and out of the Get Together. It was a wonderful day of laughter and sharing. We are grateful for Fred Jimenez for suggesting this venue and look forward to getting together again next year.

Eric, Kim and Nettie Hoffman
Northglenn, CO





*Parents and Researchers Interested
in Smith-Magenis Syndrome*

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