

The Trials and Tribulations Of Raising a Teenager With Smith-Magenis Syndrome

By: Bernadette Samson Huston, Mother of
Jacqueline Priscilla Huston, a SMS teenager

When I was asked to write about the perils of having a SMS teenager, I thought how could I ever describe all of my thoughts, worries, joy, and aggravation in less than 1200 words? There are so many challenges that our SMS teenage daughter has presented to her father and me that I suddenly was hit with thousands of these images that were flying at me. Since her birth, we knew that there was something different about Jacqueline, but her physicians could never understand what it was exactly.

When Jacqueline was 13, a neurologist who was treating her for epilepsy, referred her again for genetic testing. This time the special lab revealed that she had Smith-Magenis Syndrome (SMS), caused by the 17th chromosome abnormalities. Our counselor referred us to the SMS website (www.prisms.org) for more information. She added that she was not familiar with the syndrome, but we could call her if we needed counseling. Jacqueline's father, Percy, and I had mixed emotions when we finally had a diagnosis of her "abnormal" behavior, developmental delays, and health problems, but we were overwhelmed with all of the characteristics of the syndrome. Wow, it was uncanny how the SMS matched our daughter's bizarre behavior, temper tantrums, sleep disturbances, and multiple health problems. Instantly, I called her pediatrician, teachers, parents, family, and

friends exclaiming our "good news" and directing them to the website to better understand our daughter's "special" needs too.

Her teachers had helped us from Kindergarten to High School with different behavior modifying techniques to deal with Jacqueline's temper tantrums at school and home. Jacqueline had received Individualized Education Program (IEPs) since 1st grade, so we continued this process throughout her upper grades. With the new diagnosis, Jacqueline's IEPs were tailored more for her learning ability with activity plans for school and home. They even included mid morning naps in the school's nurse station because her two anti-seizure medications made her sleepy. In high school, we tried mainstreaming her into general education classes, such as reading and government, but she was unable to keep up with the reading or memorize facts. A quick IEP was done at that time to place her back in the special education classes where more assistants could help in a more structured environment. Our plans are to keep Jacqueline in the extended school years which will involve half days working in a profession with an assistant until she is past her 22nd birthday.

On the medical side, we made all of Jacqueline's physicians aware of SMS and encouraged them to review our daughter's complicating health issues such as frequent ear infections, scoliosis, seizure disorder, kidney anomaly, hypothyroidism, and impaired immune function. Every physician or nurse

INSIDE THIS ISSUE:	
President's message	2
Meet Sarah Elsea	3
Youth finds satisfying work	6
SuperKid	10
Conference Info	11

who was involved in her care was given the quick overview sheet on SMS copied on bright colored paper, so that it would stand out in her chart. The various physicians involved in Jacqueline's care included an Internal Medicine Physician, Pediatricians, Neurologists, Immunologists, Ear, Nose and Throat (ENT) Specialists, Renal Specialist, Gastroenterologist, Infectious Disease, and Orthopedic surgeons. In addition, as a 20-year veteran as an Intensive Care registered nurse and 10-year veteran in Nursing Education, I knew the medical language, lab values, and diagnostic tests to interpret and recommend. I also felt comfortable educating people involved in her care since I knew more about this rare syndrome than they did.

When Jacqueline was 14 ½ years old, she had surgery to correct her scoliosis, and she developed a postoperative infection that required surgery to cleanse out the infection with subsequent months of Intravenous (IV) antibiotic therapy. At first, the medicine was administered by the home health nurse during the day while Jacqueline received public educational home schooling for a month. When she went back to school, we continued to administer her IV medications for another 5 months. This was particularly hard for Jacqueline to keep up with the homework after missing a few months of her freshman year at a new

Continued on page 4....



A Message from PRISMS President...

Randy Beall

Greetings!

I hope you had a wonderful Holiday Season. My family certainly did.

Our 2009 membership drive is now in full swing. Recently you should have received a membership mailing. If you didn't receive our membership form or have misplaced it, we have provided another form as an insert in this newsletter. It's also posted on our website – prisms.org

The online form allows you to complete the form online and then you can print your completed form (and we can read it ☺) and mail it along with your check.

PRISMS is a member supported organization. We depend on member dues to provide programs such as our newsletter, our website, telephone and database support and our conference. And only members receive our fantastic newsletter and receive discounted rates for our international conference. Last year only a small number of folks in our database paid their dues. Ugh! I know these are tough economic times but PLEASE...PLEASE...PLEASE consider paying your dues.

The membership form allows us to make sure our information is up-to-date. Unlike some snail mail, email does not get forwarded so if your family moves and you're not a member, we could easily lose track of you. We also try to use e-mails to save money.

Our 2009 conference is right around the corner! It's hard to believe. I hope you are planning to attend. The conference will be packed with information and will provide everyone a chance to reconnect and share stories about our kids. We still need corporate sponsors and local fundraisers for this conference to help us make it more affordable for families. If you can help us in any way, please call me at 972-231-0035 or send me an email.

I'd like to say a special thank you to our board and our volunteers for their tireless efforts. Without their contributions, we would not be able to accomplish our on-going goals.

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

Warm regards,

Randy

randy@prisms.org

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Sarah Elsea, Ph.D. FACMG

Dr. Sarah Elsea, PhD has worked with SMS for 14 years and has been a significant contributor to PRISMS, and has served on our Professional Advisory Board since 1998. She has many interests regarding SMS with the main focus of her research being to understand the function of RAI1 and how it works within the cells in our body to affect the many different systems involved in SMS.

She has a keen interest in the families and the effects of living with a person with SMS. She is one of the author's of the three part series regarding the "*SMS Caregiver*" published in *Spectrum*, volume 12, issues 3 & 4, and volume 13, issue 1.

Dr. Elsea expresses that she is constantly amazed at how well all of the families function, even with the chronic sleep disturbance that certainly affects all family members. She feels it is important to remember that the health and well-being of the primary caregiver is key to the success of the child and the family. She has found that educating families to be aware of potential issues for themselves, as well as informing and educating health and educational professionals, is truly key to well-being for the entire family.

Dr. Elsea relates her feelings of professional satisfaction with her research efforts. She specifically recalls a mother's feelings of validation when her daughter was diagnosed with SMS through the sequencing of RAI1 mutation. Years of social difficulties and blame vanished for this mother, and the daughter now knew why she was different.

Affiliated with Virginia Commonwealth University School of Medicine, Dr. Elsea is an Associate Professor with the primary departmental program area in genetics.

She has been honored twice by the American College of Medical Genetics with the March of Dimes Travel Award. She is a NIH Individual National Research Service award recipient, and listed among the Who's Who in the World, Who's Who in Science and Engineering, and Who's Who in American Women.

Expert services include being a reviewer of manuscripts for multiple scientific journals, including the *American Journal of Human*

Genetics, *Genetics in Medicine*, and *Journal of Clinical Investigation*, to name a few.

She currently serves on the Virginia Department of Health Genetics Advisory Committee and has made multiple presentations on a local, regional, and national level regarding SMS. She has been an invited speaker at each of our PRISMS conferences since 2000.

Her resume is most impressive, with a long list of service to the profession and the community. Not only does she excel as a scientist, but she has a very creative side also, winning a pie baking contest as well as a cookie contest! And, as if she weren't busy enough, she has been an active volunteer in Girl Scouts USA since 2001.

Families of Smith-Magenis children are truly fortunate to have Dr. Elsea on their side. She has published multiple times on SMS in professional peer reviewed journals. She is part of the PRISMS Professional Advisory Board which wrote the GeneClinics Clinical Profile on SMS (www.geneclinics.org). She has published articles in *Spectrum* many times including: Winter 1997, Spring 2002, Fall 2003, Summer 2007, Winter 2008, Summer 2008, Fall 2008, and Winter 2009.

We are proud to have Dr. Sarah Elsea as an expert on our Professional Advisory Board.



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, MA, a genetic counselor, and Ellen Magenis, MD, 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.

school with new teachers too.

When she was almost 16 years old, Jacqueline required more back surgery to remove the recurring infection and old hardware, and she was placed in traction with halo tongs and weights attached to her head for a month. She was hospitalized at Shriner's Hospital in St. Louis which is 2 hours from our home. Fortunately, there are parent's apartments there where we lived when it was our turn to stay with her. We made a point not to leave her alone at the hospital, except when she was sleeping or in therapy. We bought her a cell phone, so that she could call her friends and family, especially her three brothers. The staff was educated about her SMS and special needs, and they were very accommodating. She was a hit with the therapists, nursing staff, security guards, and housekeepers who loved her quick wit, humor, and ability to memorize names and details of their lives. Although Jacqueline was always pleasant to them, she took all of her aggravation out on us.

After the month of traction, a new surgery placed stabilizing hardware from her lower thoracic back region to her mid-neck region, and she was placed in a halo jacket for 6 months. Her teachers, friends, family, and even strangers showered her with many gifts, cards, and phone calls during this time which cheered her up immensely. During her recovery, she developed another infection which required three more surgeries to clean out the incision when she was placed on IV and oral antibiotics. We are now 2 years post surgery and still on antibiotics, but her X-rays and lab values are looking better. During this time, we dealt with tons of outbursts and temper tantrums that were corrected very gradually over the years by



Jacqueline and St. Louis Blues Players

limiting TV time or by grounding her from her phone—her prized possession. During many outbursts, observers would just smile with that sorry look in their eyes which is better than most of the glares that we encountered over the years when Jacqueline acted out in public. Surprisingly, she did not require a lot of pain medications, which is a blessing because her behavior was worse on pain medications since they caused severe itching. During this time, we continued to ensure that we did daily walks together which she enjoyed more because of the attention.

Now that Jacqueline is quickly approaching 18, we are dealing with obtaining guardianship for her and pondering about future sterilization issues. She is not able to take birth control pills (BCP) because of her already elevated liver enzymes from seizure medications and the possible interference with other medications. She already requires two different anti-seizure medications because of the interaction with antibiotics that she has been on for 2 years now. Dealing with her "periods" has been a big issue too with extreme mood changes, discomfort, as well as personal hygiene. Her IEP this year included teaching Jacqueline how to be more independent with her hygiene, so she is gaining this experience with weekly showers at school. We send extra clothes, shampoo, and a swimsuit that she can wear while showering. They are also working on her nail and dental care. We still have to prompt her through this at home, but she is starting to show more independence. We also set her medications out, and she keeps on track with this as they are spaced out during the day. At night, we always tuck her into bed and say prayers with her because she loves this routine. If we accidentally fall asleep before we say prayers, she'll text us from her phone all night long until we wake up. She has no concept of time, but she knows when routine has been broken, and she doesn't like it!

Jacqueline and her younger brother J.P. have attended the same high school for the past 2 years. We are rarely on time with Jacqueline as she "ALWAYS" forgets something in the house and she has to run back in the house after we are loaded and ready to pull out of the driveway. I resigned myself not to worry about the clock and arrive safely instead of fuming and screaming inside; however, J.P. figured out that if he rides with the neighbor, he is always on time for school.



Jacqueline with her father, Percy, her mother, Bernadette, and Dr. Magenis and Dr. Smith.

This lessens his frustration and has also given him some independence. Siblings of special education children learn to be more nurturing and have more patience than other children, and they are also more likely to choose professions that are more socially giving or nurturing. Jacqueline's older two brothers are great fathers who exhibit so much patience with their children. They were 11 and 13 when Jacqueline was born, so they helped us immensely with her. When they were young, we took Jacqueline to all of their school events and church outings despite her outbreaks, and the boys would help us if she needed to be taken outside for her "meltdown".

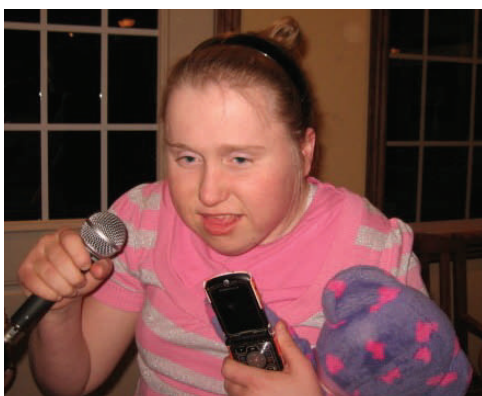
On a social level, Jacqueline still loves to watch Barney, Doodlebops, and Blues Clues. She also loves to watch movies over and over, such as *Annie*, *Home Alone 1, 2, & 3*, *Wizard of Oz*, *Freaky Friday*, and any movie with Jim Carey in it. In fact, she would sit in front of the TV all day if we didn't make her get up and exercise or do something different. At least, she can multi-task while watching TV as she also works on her Word Search books. She participates in Special Olympics in their swimming, basketball, and bowling activities, and we even traveled to the State games in May so that she could participate in the swimming events. It works out better that we travel with her on outings or take her ourselves because of her medication schedule. She also enjoys playing dominos, *Uno*, *Skipbo*, checkers, and some board games with anyone who will play, including grandparents, aunts, friends, and brothers. In fact, her younger brother J.P. has figured out how to keep Jacqueline from attending his soccer games and embarrassing him when she talks and hugs all of his friends. He promises her that he'll play so many games of *Skipbo* or *Uno* if she doesn't go to his game, and she thinks that is a fantastic trade. I always tease him that if he ever starts dating someone that adores Jacqueline too, then that girl will be a good wife someday. Jacqueline's older brothers are married, and

she has 5 nephews, all under the age of 7. She enjoys watching TV or playing games with them, and they all love playing games with her too.

Another social thing that Jacqueline loves to do is to go to the movies. Every time we attend, Jacqueline always remarks how she is considered an adult because we pay adult prices for her. Subsequently, she uses this same line to try to invite herself to “Adult-only” gatherings with her comments, “But mom, I’m an adult! They always say that I am an adult at the movies.” I have to remind her that “She is considered an adult, so they can make more money from her,” but I’ll have to change that phrase after she turns 18. At church, she loves to help collect the offertory and take up gifts during mass. She usually walks up and down the aisle appropriately, but she has this frown on her face, so I always try to get her attention to have her smile. However, she knows what I’m up to and avoids looking at me.

We travel a lot visiting grandparents, family, and friends, and when we pass a potato chip, soda, cupcake, or beer truck on the highway, Jacqueline usually comments, “I love Bud light,” or “I love Doritos and I need to have some right now!” Hopefully, no one other than her family is listening, so they don’t think we allow these indulgences. At home, we have to hide cupcakes, chips and soda from her; otherwise, she would eat a whole bag in one sitting.

When you ask Jacqueline what she wants to do when she grows up, she’ll comment sometimes that she wants to be a Veterinarian until she finds out all of the things that they have to perform. Other times, she comments that she



“Jackie” with two of her favorite things...the microphone and the telephone!

Web site searches for “transition” and “special education” brings up many sites. Here are a few helpful results:

Transition planning

<http://www.family-friendly-fun.com/special-needs/transition-planning.htm>

Articles about transition

<http://www.wrightslaw.com/info/trans.index.htm>

Free publications

http://www.wrightslaw.com/links/free_pubs.htm

Students with Disabilities Preparing for Postsecondary Education: Know Your Rights and Responsibilities

<http://www.ed.gov/about/offices/list/ocr/transition.html>

wishes to be married someday and be housewife, but that she doesn’t want any children or clean the house, just have a dog and a husband. She does chores at home like unloading the dishwasher, folding towels, and wiping counters, but she needs a lot of assistance and reminders, so I wonder how she could ever be a housewife.

Besides school every day, Jacqueline has a regular exercise routine. This consists of light weight-bearing program, walking 1-2 miles on the track, and using the exercise bike at the fitness center about 6 days/week. All of the staff and most of the patrons there know her, and she calls them all by name. She loves to treat the staff with bottles of water or soda, so we have to monitor this and allow it only on special occasions. One week, she spent over ten dollars on them. Last winter, a child aggravated her in the pool, and Jacqueline bit her finger. Since that time, her freedom was limited and she has to stay in the same area as her parents when she exercises. The parents of the other child pressed assault charges that were dismissed by the prosecuting attorney based on the juvenile officer’s personal interview with Jacqueline. Knowing Jacqueline’s condition and usually happy affect, he was in disbelief that the parents even considered pressing assault charges.

SMS children require a lot of patience and energy, so I run marathons to replenish myself. Sometimes, Jacqueline travels with me on my trips if her father comes along to watch

her while I race. Her father hunts wildlife and goes fishing to replenish his energy, and we enjoy all family vacations together. Jacqueline loves adventure and traveling even though she has to pack 3 bags of personal things, including her portable DVD player and word search books wherever she goes. While on vacation, she always calls her friends to tell them where she is and what’s going on, even later recalling events that I had forgotten. I encourage other parents with special education children to refuel their brains and energy stores, so that they’ll come back refreshed. Life with any teenager is difficult, but one thing for sure, with a SMS teenager, the adventure is never dull! ✨

Charley Mayer Lights Up People's Lives

By Karen Dandurant

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Special needs adult finds work, friendship

This article was originally published on Jan 13, 2009 in the Portsmouth Herald, NH. It is reprinted with permission from the author.

Charley Mayer is a man of few words, but the people he works for say he is priceless.

Charley, 24, has a developmental disorder known as Smith-Magenis syndrome, but has not let that get in the way of doing what he can to live as normal a life as possible. In fact, he has developed lasting relationships with several Portsmouth business owners for whom he does chores as part of his business, Charley's Lightbulb Connection.

The choice of the "light bulb" is no accident. Charley checks all of the businesses to make sure their light bulbs are working.

"We call him 'Light Bulb Charlie,'" said Betsy Scott, owner of The Flower Kiosk on Market Street. "He tells all of us when we need to replace a light bulb. Here, he also takes out the trash and he greets people when they come in."

Smith-Magenis syndrome affects many parts of the body. Major symptoms are mild to moderate mental retardation, delayed speech and language skills, distinctive facial features, sleep disturbances and behavioral problems. It is not considered hereditary.

"It's technically a deletion of DNA on the 17th chromosome," said John Mayer, Charley's dad. "He had been coded in the autism spectrum, but we were not comfortable with that. He didn't display the typical signs of autism."

Mayer said Charley was diagnosed at age 12.

"His biggest issues are cognitive delays," Mayer said. "He didn't speak until he was 5, and communication is still an issue. Also, when he has an idea and is not being understood and supported, he gets frustrated."

Among businesses Charley works for are The

Flower Kiosk, the Portsmouth Athenaeum, Coastal Pediatrics on Greenland Road, Eye Look Optical and Bailey Works, both on Congress Street, and he volunteers at Strawberry Banke Museum. He also delivers The Wire, a local newspaper.

"I just like it," Charley said of his work. "I like to work and I like to visit my friends downtown."

John Mayer said he and his wife, Debora, worked with school officials while Charley was in high school to find a vocation that would help make him more self-sufficient as he became an adult.

"We had to start planning for his future, to find him a work opportunity that would be meaningful," John Mayer said. "He works in each place about a half-hour to 45 minutes. A regular job with a company would be really hard for him, so we came up with shorter visits here and there."

John and Debora Mayer said they found people willing to give Charley a chance.

"Eye Look Optical and Coastal Pediatrics are his longest relationships," John Mayer said.

"Word of mouth has opened up others, and we are always looking for more. The goal for him is to have these businesses he can work with on a regular schedule that Charley takes ownership of. The structure is important for him."

John Mayer said his work makes Charley feel that he's giving back to the community. And, he said, Charley walks all the time, getting exercise he needs.

"He gets money and has his own bank account," Mayer said. "He has a credit card he uses to buy lunch. On weekends, he goes downtown and visits regular places like Run-



Charley Mayer, 24, poses shyly with The Flower Kiosk owner, Betsy Scott, left, and employee, Trisha Siudut. Mayer has developed some unique relationships with some businesses downtown who hire him to do small chores. Deb Cram photo

ner's Alley and Bull Moose (Music). People look forward to seeing him. If we were a social economy, Charley would be a millionaire. He wants to do it on his own terms, to be his own man. It's challenging."

Patty Donovan, owner of Eye Look Optical, said she's known Charley since he was 15. Charley's done work for her for about four years.

"He comes in two to three days a week," Donovan said. "He takes care of our recycling and takes out the trash. He has forms he can print out. He restocks toilet paper, fills the candy bowls and the dog bowls. We have dogs here, and we keep a bowl outside for people walking by with their dogs."

"Sometimes he wants us to help him just because he wants it, but he can do it all himself very quickly."

And Donovan said Charley always asks if there's anything else she needs once he's done with his list.

"He's very sweet," she said. "Monday after-

A perspective from Charley's parents, John and Debora Mayer

The article profiling Charley and the work he does for local businesses was initiated by one of the owners because she wanted to develop public awareness about Charley, his disability, and the work he can do.

When Charley turned 21 his educational supports ended and he started to receive services through the NH Medicaid system. Medicaid provides funds for a family managed program geared to building his independence. We have used these funds to build a unique program centered on vocational skills and Charley's abilities with the goal towards increasing his independence. Charley has a support person to assist him throughout the day.

It has been extremely difficult to find a successful setting or program for Charley. He has been kicked out of almost every day care, school, and traditional employment setting we have tried. To succeed, we knew we would need to explore less traditional vocational situations and thought self-employment might be a good fit for Charley.

He has been "self employed" for at least five years. Over this period we have steadily added new work places and Charley has embraced a weekly schedule and routine with seven different worksites.

The self-employment model works for Charley because:

- We cultivated independently owned businesses, ones that Charley and we know. We asked if they were willing to work with us on this project.
- We designed his job so it would be helpful to each business and within Charley's capability.
- Charley is paid by the task, so it doesn't matter how long he takes to finish his work.
- Although Charley has a schedule, the businesses are flexible on arrival time. There is no problem if Charley is not ready on time or having a melt down and unable to make it to work that day.
- Most of Charley's jobs take half hour-1 hr to complete. Traditional employment require a 2 hr minimum- which only got Charley into trouble as he has a hard time staying focused for that long a period of time.
- We started slow and added more places gradually. The first employer was a neighbor who wanted to help get Charley started. She paid him to carry the trash and recycling out of the house to the curb. At first, he was no help at all, but she stuck with it and now he looks forward to Wednesday afternoon trash.
- The small amount of money Charley receives for his work goes into his bank account. He uses the account to pay for some of his recreational activities and many of his lunches downtown.

This has been years in the making. There have been set backs, frustrations, as well as successes.

Some of these ideas came from a presentation given by Joe and Marilyn Henn at the PRISMS Conference in 2005, and a book they recommended *Making Self Employment Work for People with Disabilities* by David Hammis and Cary Griffin. ✱

noons, he comes with me to do errands for the store. We've gotten close to his parents through him."

Jon Bailey, owner of Bailey Works, said he and Charley's father are dear friends. Both are members of the Leftist Marching Band. Charley's work at the shop includes trash removal and taking recyclables to the transfer station. But, it's more than that.

"We love Charley Mayer," Bailey said. "He comes in and does his light bulb inspections. How it all fits into the real world of Charley is only something Charley can understand."

Bailey said he encourages anyone who could use Charley's services to take him on.

Tom Hardiman, keeper of the Portsmouth Athenaeum, said Charley conducts a scan of every light bulb in the building when he visits.

"He's been here for three years. Robert Dunn was our custodian, and he retired in 2005," Hardiman said. "We limped along and Charley discovered we had a need and offered us his services. We all like him, and we've watched him grow up."

Janice Wooldridge, office manager for Coastal Pediatrics, said Charley takes care of the office's trash and does some cleaning.

"He interacts socially with the staff as they are working," she said. "We love Charley. He always makes sure to ask the doctor what time he is going home and makes sure to remind him when it's time to go. He checks the message lights, and he lets the staff know they have a phone call to return."

Mayer said Portsmouth is a perfect place for Charley. It's hard to imagine another place so supportive, he said.

"The world is changing and the resources out there, the options, are becoming fewer and fewer," Mayer said. "We worry a lot because we won't be here forever. We worry about what kind of world can people with special needs find themselves in."

But for now, Charley is happy to have found his place. ✱

PRISMS Donor Policy

PRISMS believes that philanthropy is based on voluntary action for the common good. It is a tradition of giving and sharing that is primary to the quality of life. As a result, we have adopted the Donor Bill of Rights as developed by the American Association of Fund-Raising Counsel (AAFRC), Association for Healthcare Philanthropy (AHP), Council for Advancement and Support of Education (CASE) and National Society of Fund-Raising Executives (NSFRE).

Also, PRISMS had an official receipt and public acknowledgement policy. While we encourage online giving through our partnership with Network for Good, it is our policy

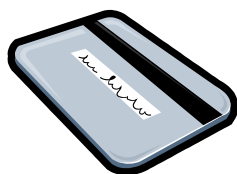
for donors who pay via check to have their cancelled checks serve as their receipt for donations \$100 or less. PRISMS will send all donors a receipt for donations over \$100 or more, or upon request. We will print the names of all contributors annually in our newsletter, unless otherwise requested. Although we will not disclose the amounts of most donations, we will recognize major contributors of \$500.00 or more. Memorial gifts will also be printed in the newsletter with no gift amounts given. Acknowledgement notices will be sent to the family that a tribute gift has been made.

Thank you for your continued support. To-

gether we are making a difference in the lives of our families!!*



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Our group ID number is **150239751**.

If you've signed up in the past, now is a good time to check to make sure that all of your credit cards are listed and eScrip has current information. Thank you for participating in this great program. *

Silent Auction Donations

It is conference time in September and that means you have another opportunity to help out PRISMS. Once again, the popular silent auction will raise money for OUR organization and you can be a big part of that. Here is what we need from you.....

Talk to your employer and see what kind of items they are willing to donate for the auction. This could be something they produce, something they've received, something they can obtain. Just ask. Do they deal with other businesses that would offer something? Gift certificates, personal items, tickets, etc.? Just ask!

Do you have a friend that is in some kind of creative business? An artist? Someone that owns a business that would be willing to donate a gift certificate or something electronic or a painting or anything that would raise money for PRISMS.

Did you receive *another* IPOD for Christmas and don't know what to do with it? Let us put it up for auction to help PRISMS. Anything lying around your house that might be a great auction item? Do you have a vacation home you would let us bid on?

Be Creative!

Thanks for your help and let's make this a great SILENT AUCTION!

You will hear more about this in the next newsletter but if you want more information or have questions please email silentauction@prisms.org



Volunteer!

Please consider checking the volunteer box on your membership form! PRISMS needs a database of ready and willing volunteers. Do you have experience with websites, advertising, internet searches, grant writing, typing, proof-reading, databases, fundraising, publishing, organizing get-togethers, or are you just a great errand runner? There are many opportunities to help PRISMS. It could be for just a day, or in a more long term endeavor. All of the Board Members are volunteers and put in many hours for YOU. Please consider "giving back." Sign up and just maybe the perfect fit will be found! Need more info...email editor@prisms.org



Picnic
Fun In



The 5th Annual Houston SMS picnic was held on November 7th at Bear Creek Park. Nearly 50 people, representing 12 families, participated in the fun. One of the big hits was the cotton candy machine. There was also a moonwalk, scavenger hunt, Cookie Walk, and several rounds of Bingo. The picnic was held the day after Parents Nights Out, hosted by Baylor Genetics. Parents enjoyed an evening out while their children (SMS and siblings) were entertained with a variety of activities provided by the Baylor medical students. Chick-Fil-A and The Children's Museum of Houston provided goodies and giveaways. Everyone is looking forward to next year's get-togethers. *



Birdies For Charity



PRISMS is proud to announce that it will be participating in the "Birdies for Charity Fundraising Program," at the John Deere Classic. Birdies for Charity is the official fundraiser of the PGA John Deere Classic. It enables non-profit groups, like PRISMS, to capitalize on this PGA TOUR event by raising money from individual and corporate donors. The 2008 John Deere Classic Birdies for Charity Program raised over 2 million dollars in pledges. The John Deere Classic will be held **July 6-12, 2009**, at TPC at Deere Run in Silvis, IL. Birdies for Charity is an easy and great way to raise individual donations based on how well the professional golfers score during the John Deere Classic. You do not have to be present to donate ☺!

Look for details and pledge cards to come in your mail late spring and on the PRISMS website! Make a pledge "FORE" PRISMS!! For more information contact Percy@prisms.org.

SuperKid! SMS

Joel Hanson

My name is Nick and I am the father of 18 year old Joel Hanson, born with Smith-Magenis Syndrome (SMS) caused by a deletion on the 17th chromosome.

Joel is pretty unique with about 40 brothers and sisters diagnosed with the same syndrome in Australia. One thing they all share is a reversed circadian rhythm (sleep in the day, party at night), developmental delay, autism-like characteristics and a few peculiar SMS behaviours as well.

Joel's main love "read obsession" is cars and we can often be seen casing them out. Joel will peer into every car in the car park while I stand back slightly apologetic. Have no fears this is not a Fagan/Oliver relationship, we are law abiding. His knowledge of cars and incidentally geography is outstanding. Joel will approach strangers in the street and within minutes the bonnet* is popped and a blokey conversation ensues.

Joel is a child of the dot.com generation. I am not. I go into a cold sweat when the telly needs to be re-tuned or the computer things need rethingamaggingg. Who is there to fix it? Joel. I deliberately do not ask myself how things get stuffed in the first place.

Joel's place is in the community. Many people are out there to give him a life scouts, special nippers**, respite carers and friends.

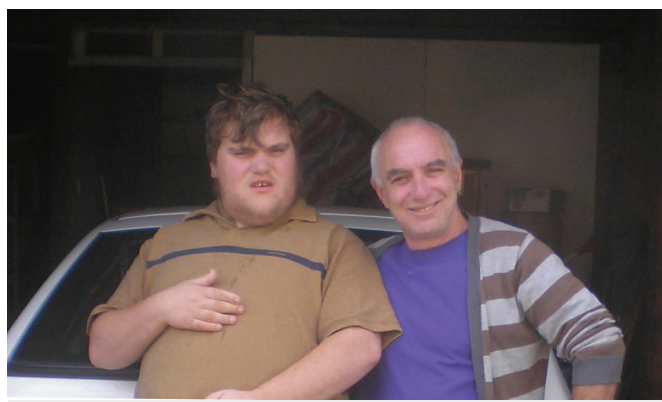
Having a disabled child limits one's choices in life, but having said that, he has added a dimension that few people would dream of. He can be

infuriating, frustrating, funny and above all loving "that's our Joel-e-bear."

*Joel informs me that in the U.S. you refer to this as the hood. He's usually right about things like that.

** Putting in a plug for special nippers here. In Australia we have surf life saving clubs all of which have a junior section known as nippers. The aim is to teaching ocean swimming skills, beach safety, life saving and general fitness. A few of the clubs (not enough) have established "special nippers." It is wonderful as we parents sit on the beach while our children (and young adults) are entertained and kept safe in the surf by trained life-savers (who incidentally love doing it, all volunteers). This programme is so good I try to spread the word. I don't know if you have a similar thing in the U.S., but if not, it would be a great thing to get happening. *

Do you have an 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



Joel with his father, Nick



PRISMS Conference

Sept. 17-20, 2009

Reston Hyatt Hotel

Reston, VA



A great group of siblings of SMS children discuss their trials, tribulations, and thoughts during the 2007 conference.

We hope you have all marked your calendars for the conference. 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 expert Professional Advisory Board, researchers, and invited speakers regarding the latest research on SMS and pertinent information for your child and family. We will again have day-care 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 conference, and you will leave with as much support and encouragement as our families and professionals can share!

Transportation: Accessible from Dulles Airport, IAD (6 miles)

***Hotel Costs:** \$125/single/double occupancy, (Thurs., Fri., and Sat. rates)
\$ 169 (Wed., Sept. 16th rate only)

Registration Fee:

	Up to 9/04/09	After 9/04/09
Adult (18+)	\$175	\$225
Child (17 & under)	\$75	\$100
SMS individual	\$75	\$100
Professional	\$250	\$300
Professional In-training	\$200	\$250

Scholarships for the conference are very limited, so we encourage families to seek local agencies for monetary assistance.

*You may reserve rooms at the Hyatt now. Please mention PRISMS when you are making reservations. (1-800-233-1234)

Look for more conference information on the PRISMS website, in the next issue of Spectrum, as well as a conference mailing that will be sent soon.

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