

Students with Smith-Magenis Syndrome: Education, Environment, and the Fallacy of Error

By Steve Corbett, Ed.D (ABD)

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In 1969, thirteen years prior to our first true understandings of Smith-Magenis Syndrome (SMS), psychologists, Jack and Carol Vale stated: "The way in which we regard individual differences may thus depend upon the way we consider them to have come about. If we think of them as error, their information value is nonexistent. On the other hand, if we understand their genetic as well as their environmental base and understand them to be integrated to the evolution that all behavior can be assumed to have undergone, individual differences become highly important in the search for behavioral determinants." [1]

An important aspect in understanding students with SMS, is understanding the individual as a product of both his/her own genetics as well as a product of their environment. Understanding the student and his/her behaviors as "error" would provide us with no value in understanding the context in which the behaviors were developed.[2] These observations create an avenue in which to evaluate individual and environmental factors, without viewing behavior as an isolated element related to human error. This is an incredibly significant concept when considering the behaviors of students with Smith-Magenis Syndrome. Students with SMS present a number of extremely challenging behaviors; however, these behaviors in many cases can be contributed to the genetic individuality of the student, making them not "error", but as unique human behaviors associated with their

individual genetic makeup. The only error would be in assuming that students with SMS should act as similarly and accordingly as other students within the same environmental context. For the context of this article, the term environment refers to conditions related to learning, which include, among other things, curriculum, instruction, physical design, programming, support structures, and interventions.

Students with SMS require additional environmental modifications to support them in becoming their best selves. Ignoring these environmental considerations would inherently limit the potential of students with SMS due to poor environmental design. The challenges they face are very different than those of their peers, and require both an understanding of their unique needs and appropriate



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A First-Timer’s View of the SMS Conference

By Joe and Jenn Haroldsen

In June of this year, we had the opportunity to attend our first SMS Global Conference in Denver, Colorado, USA. Our daughter, Leah, who is now five-years-old, was diagnosed almost three years ago with SMS. Like most parents, we struggled to find anyone in our local community who had heard of Smith-Magenis Syndrome, and we had to be the educators to Leah’s doctors, teachers, and therapists. There were two great things that we took from the conference: hope and a community.

Hope

As we listened to the amazing speakers and met SMS children and adults, we could project Leah into each of them and see the bright future that Leah has in front of her. At times the information overload felt like we were drinking from a fire hose and we were overwhelmed. But at the same time, we were given ideas as to how to help Leah achieve the highest quality of life physically, mentally and emotionally, which has always been our goal from day one.

Community

For our first conference, we decided not to bring Leah with us, but as we walked into the hotel, one of the first people we saw was a seven-year-old girl with SMS. She was the first person with SMS we had ever met, besides Leah. As the conference hall began to fill with more and more people, it was amazing to meet families from all over the U.S., and many from outside of the U.S. who could relate to us. Each conversation seemed to flow so easily, because we could all relate to each other’s circumstances. We had opportunities to both give and receive advice from the families that we met, and we created lasting friendships.

We know that it can be very difficult to make the trip and attend the conference, but for us and our family, we are extremely glad that we did and we look forward to attending many more.



Join us on Facebook!
PRISMS/Smith-Magenis



A Message from PRISMS President

Randy Beall

Greetings! This year has really flown by and the holiday season is here!! Be on the lookout for your PRISMS holiday card. There are lots of great gift ideas in our online store. In addition, one of our members, Michelle Lee, has created a wonderful 2013 PRISMS calendar with pictures of our special kids. It makes a great gift or stocking stuffer.

My family attended the annual Houston SMS Picnic a few weeks ago. It was great to catch up with our Texas friends and even meet a new family. If you would like to host a regional picnic or get together this spring, please let us know and we can help you get the word out.

We have so much to be thankful for this year. I appreciate our volunteers, researchers and wonderful donors. Without you, we would not be able to help the many families we reach. In this issue, we will have a parent's perspective on the 2012 International Conference, an educational article on the role the environment plays, an article on safe spaces, an advocacy piece on IDEA and much more.

I hope you are going to our website, www.prisms.org, often. There are many articles to help you with medical questions, behavior, sleep, and improving your family's ability to cope with SMS and enjoy your child. And now you can get all of the handouts from the presenters at the 2012 International Conference (thank you, Scott Miller!). There were sessions on behavior, sleep, genetics, speech and language, diet, and

therapy. We hope that you will access this great information to help you and the professionals who work with your child. Finally, a huge thank you to Julia Hetherington, our former editor, for your great work over the past few years. You've left big shoes to fill.

My family wishes you peace and joy during this holiday season.

Warm regards,

Randy Beall
PRISMS, President
Father to Laura, age 27, with SMS

educational programming to support them. Students with SMS have significantly higher levels of maladaptive behaviors, can be extraordinarily disruptive and hard to manage, and are often more demanding of attention than their counterparts with similar disabilities. [3] Additionally, children with SMS exhibit significant behavioral problems, “including temper tantrums, self-injurious behaviors, and physical aggression toward others.” [4] Evidence also suggests that the behavior problems associated with children with SMS are more severe than populations with similar genetic syndromes, including externalizing behaviors. [5]

Students with SMS are unique, and with that a unique set of understandings and environmental considerations must be made. Many theories, including Person-Environment Interaction theory (PEI), have been developed through a long existing analysis on the effects the environment has on the individual. The essential understanding is that environmental factors play a role in how an individual interacts with his/her surroundings,

and through environmental manipulations or understandings, the behaviors of individuals can be altered. [6] This theoretical understanding is important, because while research related to students with SMS in educational



settings cannot alter the genetic and biological differences these students present in comparison to their peers, it can support an understanding of environmental implications on these students, and offer solutions to support greater levels of learning and achievement.

Thompson, et al. (2010) contend that there are three significant reasons as to why educators focusing on special needs students should adopt the PEI framework. First, it focuses its energy on the strengths of students as well as the environmental contexts in which they exist. Whereas, other deficit models focus primarily on

weaknesses, the PEI framework “focuses on the gap between a person’s capacities and the environment” as well as the implications it has for teachers to close this gap. Secondly, the PEI approach supports already existing initiatives, including Positive Behavior Intervention Support (PBIS) and Universal Design for Learning (UDL) that work to implement interventions specifically designed to affect behavior. Not only do these types of interventions support students with disabilities, but they are the best practice approaches that support the academic achievement of all students. Finally, utilizing this approach allows students with disabilities to take control of their environments. By involving students in addressing their own needs, students begin to learn how to understand and navigate the gaps that exist between their own levels of ability and the environmental demands in which they exist. [7]

The authors argue that the PEI model, as well as other models relating to this framework, would have the potential to enhance the educational opportunities of students with disabilities. At the same time, the use of these models to understand and support students with disabilities would contrast existing deficit models that focus heavily on deficiencies and “fixing the student.” The American Association on Intellectual and Developmental Disabilities (AAIDD) first promoted the idea of utilizing the PEI framework to address the needs of those with intellectual disabilities in 1992, and uses the World Health Organizations functional definition of disability where disability is defined “not as a defect...but as a poor fit between the person’s capacities and the context in which a person functions.” [8]

Looking at the environment in how we support students with disabilities allows educators to focus on “providing supplementary aids and supports that result in enhanced opportunities to learn across multiple activities and settings.” [9] Adapting the environmental context in which students with disabilities learn, supports a process in which interventions can continually be adapted to meet the needs of students, rather than expecting the students themselves to adapt to their current environmental constructs.

Jensen (1968) states that “perhaps our greatest hope of achieving equality of educational opportunity lies in the possibility of finding significant patterns of individual differences in the development of abilities and in taking advantage of these differences.” [10] Thinking about these situations in a differential context will allow educators to meet the needs of diverse learners as individuals who respond differently to the environment than their peers.

A differential approach will enable an understanding, in particular for students with SMS, of how the environment can be utilized to support learners and enable positive learning outcomes.

As students with SMS attend school, it's important for us as parents, teachers, and advocates to understand that the difficulties they have are not, in fact, error on their part, but often error in how we expect them to perform in a school setting. If we see their actions solely as error, then their actions consequently may never be adequate for school. If, however, we view their actions as diverse, distinctive, and different, then we create the occasion to see them not as error, but as integral and inimitable contributions to our communities. As we continue to educate and support students with SMS, we must keep in mind the fallacy of error as it relates to genetic individuality, change the mindset of those who may see it differently, and build the environmental bridges necessary to help all of our students find success in school.



Steve Corbett is the father of Gavin, a beautiful boy with Smith-Magenis Syndrome. He is currently conducting research on the educational experiences of students with SMS, and will serve as the Founding Principal of East Harlem Scholars Academy II, a K-5 public charter school opening in the fall of 2013.

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Are you online? Check out the PRISMS Facebook page.

Our numbers are growing quickly. Our page is being organized by volunteers, David and Denise Smith. Facebook looks like it will become a new and popular way for families and others to share information and learn about Smith-Magenis Syndrome.



If you have a Facebook account, search for "PRISMS/Smith-Magenis" and become a "friend." If you are new to social media, log onto www.facebook.com, join up, and get online to participate. It's free!

Safe Spaces

By Brandi Wilson

As our daughter, Lilli, learned to stand and walk holding on to furniture, it became obvious that her bedroom was not working. She woke in the night and opened her baby gated door yelling, “Mom, Mom. Hi”. So the quest began. I called every charity under the sun in Ontario, getting the same response from all: “I’m sorry, but this is not something we can assist you with.” I was looking for help to get Lilli, a much needed Safe Space bedroom. A tent bed would not cut it for Lilli as she was used to having her whole room, and the idea of her being confined to her bed didn’t seem like a good option for her.

In my desperation, I typed an email outlining Lilli, SMS and what we needed, unsure of where I would send it. Then I remembered my favorite websites had previously helped raise



funds for a volunteer rescue squad. My email had a destination -- theChive -- an entertainment website. I began, “I know this is not what you guys are all about, but I didn’t know what else to do.” I hit send and forgot about it, feeling better to have just gotten it off my chest. I never expected an answer. A few weeks later I got a response; they were very interested in Lilli, SMS & helping us. My heart was overflowing! After many months of planning, emails back & forth, phone calls and much excitement, we were ready.

The big day came and Lilli’s story was posted; we were asking for the chivers (people who frequent the website) to donate \$17,000. That’s about how much Lilli’s Safe Space would cost, after the exchange rate, shipping fees, and having to pay for an installer to come to Canada from England and install Lilli’s room. John (co-creator of theChive), called giving me

updates regularly. After 30 minutes \$5,000 had been raised and at one hour it was \$10,000. In less than two hours, people I would never know and would never be able to thank had opened their hearts and wallets to us and had donated the \$17,000. John let the chivers know and then something amazing happened -- the donations kept coming! When it was all said and done, in 24 hours those amazing people had donated \$34,000.

Then we were ready. We had the money to get my girl what we needed so badly and could never have given her. We ordered her room, then had to wait what felt like forever. It was about 3 months from when we ordered it until we finally got it. The room had been stuck in customs for a very long time. So we had her room, but then there was more waiting: a weekend for the installer to arrive. He was so awesome; he taught Sid how to put it together so that if we move he knows how to take it down and put it back together. There ended up being money left over, so I made John a list of sensory toys for Lilli, and still there was extra money. John came here to Sault Ste Marie Ontario, all the way from Venice Beach, CA. He took me out shopping for toys for the kids; he paid a friend of mine to dress up as Santa and he gave my kids a Christmas they will never forget.



Now, nearly a year into having Lilli's Safe Space, it is the best thing I've been able to do for her and the rest of my family. Lilli is safe, she's quiet in the night, she can't get out, and my family can sleep at night.

Manna Gift Cards for the Holidays.

Do you like to give gift cards as holiday gifts? Don't forget about the PRISMS fundraising program through The Manna Group Scrip Program. Manna offers the same gift cards available in stores for all of the major retailers, restaurants and much more.

To get started, just send me an e-mail requesting to be set up on Manna and include your mailing address and phone number. Once this is done, you will receive an e-mail from me with instructions on how to order gift cards at www.mannaorders.net. Please keep this program in mind over the holiday season and throughout the year to help support PRISMS.

Thanks,

I denienr@comcast.net.
Manna Coordinator

Nickels for Nico 2nd Annual Cornhole Tournament

By Jean Weil (Nico's Mom)

The second annual "Nickels for Nico Cornhole Tournament", held in Louisville, KY was a great success for PRISMS, Inc., raising over \$4,500 this year.



Although Dayton High School is over an hour away from Louisville, the students in their ACTS (Assisting Community Through Service) group have chosen our Smith-Magenis family as their philanthropy for the past two years. A group of young people, who themselves are often in need of assistance through public funds, choose to help us by sponsoring this event, making signs and sending out letters to promote the event and solicit donations. They found out about Smith-Magenis and PRISMS through their social worker, Sherri Chan, who is a personal friend of the mother of Nico, a 5-year-old with SMS.

The Cornhole Tournament itself is 100% profit for PRISMS. An area of a city park near downtown Louisville was reserved with a large playground and picnic tables, and an area was set up with six cornhole sets.

Hamburgers, side dishes and desserts were all provided by Nico's family. Drinks were donated by Planning for Life, Inc, a residential provider for disabled adults.

Prizes were donated by Churchill Downs, The Kentucky Derby Museum, Joe Huber's Restaurant, and White Castle.

TEKsystems, an IT staffing and services company, offered a matching donation to all of their employees who contributed to the tournament. Nico's uncle, Brian Bishop, and his co-workers at TEK systems contributed \$1,000 and were matched 100% by the corporation for a total of \$2,000 from TEKsystems.

Nico and his family want to thank everyone who helped to make this event a wonderful day of fun: Sherri Chan and the students of Dayton High School's ACTS, the companies who donated prizes and drinks, family members for the donation and preparation of the food, and a special thanks to TEKsystems for their very generous donation.



Prisms Online Store: Holiday Gifts

Visit the PRISMS online store for all your holiday needs!

Select from several original PRISMS designs that can be printed on the items of your choice. We have apparel for men, women and children. Find unique gifts such as a keepsake box, apron and mugs.

We have many other items available: ball caps, bumper stickers, even a shirt for the family dog!

Visit our site at www.cafepress.com/smithmagenis or follow the link on the PRISMS website www.prisms.org.

Proceeds from the sale benefit PRISMS, so shop till you drop! It's for a good cause!



There's an App for That!!

Many parents are discovering the many uses that iPads, iPhones and iPod touches can have as tools and resources for people diagnosed with SMS. Although there are a multitude of apps in the app store that many people diagnosed with SMS use and enjoy, they can be difficult to find. Because the SMS community is small and relatively unknown, we depend on some of the larger special needs communities for advancement in technology.

Touch Autism has created *Autism Apps* which is a comprehensive list of apps that are being used with and by people diagnosed with Autism, Down Syndrome and other special needs.



SMS Superkid!

Freddy Schiller

Freddy Schiller is a true SuperKid with lots of wonderful stories. Freddy turned 25-years-old on June 10. We have had many adventures throughout his years! He is very comical.

At Christmas parties Freddy helps us hand out gifts by recognizing letters in names to know who the gift belongs to. Freddy also loves to shop. He is “down to earth.” Once I was debating if I should buy a vase and he asked if I liked it. I said yes, so he said, “Then get it.”

He loves looking at books and movie boxes in the stores. Last fall, however, we found him pushing a shopping cart filled with all kinds of things. He said, “I’m Christmas shopping.” Indeed, he had found gifts that various family members would like.

Freddy lives in a group home in a small town (less than 1,000 people) and works in that town filling pop machines and helping deliver supplies and mail to other group homes. He loves working with the guys and sitting in the shop with a can of pop after work. He has many friends and enjoys stopping in the local gas station to check on his friends and to buy a lottery ticket. (He often wins a dollar or two. He gets really excited about that.)

He graduated from the local high school in 2005. That was a proud day as he wore a cap and gown and sat among the other grads and friends of his.



When he was in school he loved going to the office to say hello and stop in to visit some of his teachers. He also took shop classes. There were always one or two classmates who gave Freddy some extra assistance.



Freddy loves books and puzzles and playing computer games. He has his own laptop and connects to the Internet and uses the favorites icon to find his games. His all-time favorite movie star is Pee Wee Herman, with Disney characters and Jay Leno close behind.

Freddy used to enjoy swimming and participated in Special Olympics bowling, but as he got older he switched to climbing and riding on the 4-wheeler. He also likes climbing (gulp!) such as climbing into the deer stand or climbing a ladder that might be nearby. He is very, very careful doing that but his parents are always right behind him (a bit nervously I might add!).

Freddy always asks how his relatives are, picking out small gifts for people. He likes letting someone else have a turn. That works well when doing activities that he is not interested in – he will go on a walk, knowing he will then have a turn to go to a store. He keeps track of people’s schedules and reminds everyone of what they need to be doing. We went on vacation every summer to Wisconsin

Dells, which is a huge water park area, and Freddy always enjoyed the water slides and the wave pool. One time he got lost there and after a heart-wrenching half hour he was found at the wave pool. He said, "I know my way around!"



Freddy loves parties for any reason and enjoys the many people he meets by living at the group home. We have always had him come home every month for several days and for holidays and to take him to many of his appointments. His favorite foods are onion rings, chocolate shakes, cookies and milk. He is the person to ask to peel hard boiled eggs and onions and open packages that have a wrapper – he relishes those jobs. He enjoys animals and likes to observe bees. Freddy is indeed fun to be around. He is blessed with a very sociable nature; after all – he has Smith-Magenis Syndrome! Freddy is a real SuperKid!

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.

Do you have an SMS SuperKid? We know what amazing things our kids can accomplish, and those big and small moments of success need to be celebrated for all to see. Please consider sharing your moments with us. If you have questions or need help with the story, please contact the editor at: editor@prisms.org.

In 1997, Congress amended the Individuals with Disabilities Education Act (IDEA). Since then, Positive Behavioral Supports has held a unique place in special education law. PBIS, referred to as Positive Behavioral Intervention and Supports in IDEA, is the only approach in addressing behaviors that is specifically mentioned in the law. This emphasis on using functional assessment and positive approaches to encourage good behavior remains in the current version of the law as amended in 2004.

In 1972, a court in District of Columbia found that students with disabilities were being excluded from educational opportunities for issues related to behaviors. Congress in 1988 very much wanted to strip schools of the unilateral authority they had traditionally employed to exclude disabled students, particularly emotionally disturbed students, from school. Congress recognized the need for schools to use evidence-based approaches to proactively address the behavioral needs of students with disabilities. Congress explicitly recognized the potential of PBIS to prevent exclusion and improve educational results by providing incentives for whole school approaches. Some of these approaches include; scientifically based early reading programs, positive behavioral interventions and supports, and early intervening services. These programs have been established to reduce the need to label these children as disabled, and to address their learning and behavioral needs.

School-Wide Positive Behavioral Interventions and Supports (SWPBIS) is a universal prevention strategy currently implemented in 16,000 schools across the United States. SWPBIS intends to reduce students' behavioral problems by altering staff behaviors and developing systems. The first of its kind study looking at a widely-used program designed to improve behavior finds that the strategy is proving effective for students with or without disabilities. A study by Catherine P. Bradshaw, PhD, Med, showed multilevel results indicating significant effects of SWPBIS on children's behavior and

concentration problems, social-emotional functioning, and pro-social behavior. Children in SWPBIS schools also were 33% less likely to receive office discipline referral than those in the comparison schools. The effects tended to be strongest among children who were first exposed to SWPBIS in kindergarten.

These findings provide support for the hypothesized reduction in behavior problems and improvements in pro-social behavior and effective emotion regulation after training in SWPBIS. The SWPBIS framework appears to be a promising approach for reducing problems and promoting adjustments among elementary school children.

For years, SWPBIS has been touted in special education circles as a means to reduce behavior problems among children with disabilities. More recently, as concerns have been raised about the use of restraints and seclusion in schools, everyone from U.S. Secretary of Education, Arne Duncan, to disability advocates have cited SWPBIS as a preventive measure that schools can implement. For more information and a video on how SWPBIS works go to www.pbis.org.

6th Annual Buck Creek 5K

On September 21, 2012, thirteen PRISMS families met in Springfield, Ohio for the 6th Annual Buck Creek 5K. Runners ran, walkers walked and our kids charmed the crowd. The following day, we gathered for a family picnic and a relaxing visit. As always, we just appreciate being with those who “get” our unique situation.



Thanks to everyone who helped raise extra funds on our FirstGiving website, brought their own fundraising donations, gave to the raffle and walked for a great cause. All together, we raised \$2,500 for PRISMS!

Charlie and Tina McGrevy

PRISMS Cookbook on Sale Now!

Over 200 delicious recipes from PRISMS families! Appetizers, soups & salads, desserts, gluten-free, main dishes, and more!

The PRISMS cookbook also makes an outstanding awareness tool for SMS. Besides tasty recipes, the cookbook has pages describing Smith-Magenis Syndrome, PRISMS' mission and history, and photos of very distinguished chefs.

It makes a great holiday gift for family, friends, teachers and co-workers. The cookbook is dedicated to the parents of children with SMS, so don't forget to purchase a copy for yourself.

The cost is \$18 per book, which includes all shipping costs.

Visit www.prisms.org to order online, or download the mail-in order form. Hurry before they are all sold out!



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 1980s by Ann C.M. 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 15,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

Articles and Contributions for the Newsletter

Have you worked with a doctor or specialist who has been particularly knowledgeable or has a great understanding as to how to work with people diagnosed with Smith-Magenis Syndrome? Or have you had a particular experience that has been very successful to help your SMS child? Our SMS community could use your help.

Spectrum Newsletter is always looking for articles to publish in our upcoming newsletters.

If you have an article that you think would be interesting or helpful for others to read,

please send it along. We are currently looking for SuperKid, Parent Perspective, It Worked for Me, Professional, Sunnyside Up, and other articles related to SMS.

Please send an email to editor@prisms.org for more information.

It Worked for Me ...



Turn That Down!

To keep my son from playing with the volume control on the remote, watching bad channels and to keep the batteries in the remote we found the Weemote control for kids. Parents can program the volume level, channels and the batteries only come out with a screw driver. It is also durable. www.weemote.com
Denien Rasmussen, Palatine, IL

Wild Oats!

I turned my one-year-old daughter's sand table into a safe place to play by filling it with dry oatmeal. It's really easy to clean up, and I don't have to worry about her putting sand in her mouth.

Holly Weese, Medford, MN.



Food for Thought

My three-year-old son, Alex, has a severe allergy to nuts, so I created a personalized sippy cup with photos of Alex, his allergy information, and what to do in case of an emergency. Now everyone who takes care of him has an on-hand reminder of his condition.

Rachel Laey, Bon Aqua, TN

If you have a solution that worked for you and would like to share it, please send it to editor@prisms.org

SMS Around the World

Perth, Australia – Approximately 1,200 children with disabilities will benefit from new expansion that supports early intervention services for those with Prader-Willi, Williams, Smith-Magenis and Angelman Syndromes. This new legislative expansion will take place on January 1, 2013.

The program will allow all eligible children under the age of seven to receive up to \$12,000 in funding, with up to \$6,000 in any one financial year.

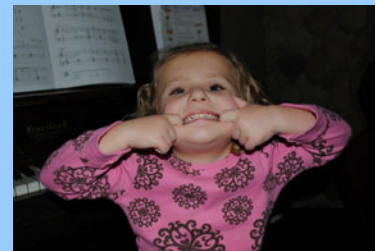
Burgundy, France – In Burgundy, an SMS association hopes to shed more light on Smith-Magenis Syndrome, as three people in the area are affected by it. Quentin, Nico, and Leo all have Smith-Magenis Syndrome, but Quentin's mother notes that "there are probably more that have not been detected", and the association hopes to help more families cope with their situations.



San Remo, Australia – BREAKAWAY at San Remo hosted a camp for children with Smith-Magenis Syndrome and their families. The camp lasted three days, and families from all over Australia and different parts of the world joined in. There are an estimated 48 people in Australia with SMS. Professor Ann Smith of the National Institute of Health also attended the camp.

Sunny
Side

UP ↑



On November 3rd, we attended the SMS picnic in Houston. A surprising but humorous discussion with my children preceded this event.

Once he recalled attending last year's picnic, Dalton (nine - who has SMS) was very excited about going. Since the news of the picnic broke, he had started asking questions about SMS. We had purposely waited for him to start asking questions instead of just trying to explain it. Previous to this, he actually thought that I had SMS and quickly told one SMS child who asked him if he had SMS that "no, he did not have it." The slightly confused young lady asked who did. He bluntly told her that his mom did. We assume it was because I was the one who attended the conference.

The upcoming picnic and inquiring questions from

Dalton have made his brother more aware of SMS, as well. The night before the picnic, after calming Dalton down about "HIS" picnic, his younger brother, Xander, and my husband had this discussion. Xander is 5:

Xander: Do I have SMS?

Dad: No, you do not.

Xander: Why not?

Dad: It is just something that happened to Dalton. (He avoided the "happen at conception" part.)

Xander: Will I get it when I'm older?

Dad: No.

Xander: (a large, disappointed) Aaahhh man!!!

I could not help but laugh. After all, if you have SMS you get to go to a conference and a picnic. Right!



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Lilli and her brother in her safe space.

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