prisms
Parents and Researchers Interested in Smith-Magenis Syndrome

spectrum

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Residential School

Is It Right for My Child? Our Story with Zach

By Leah Baigell

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" Do I need to send my wonderful, challenging SMS child to a residential school?" If you get to this point, it will likely be one of the hardest decisions you will ever have to make. How can you send off your sweet, yet difficult child, who loves you, needs you, depends on you to get through every day and who, without question, is not understood by others. How did you get to this point? Such was the case for us. The end of our story is that Zach has been at a fabulous residential school for the past two years. He is happy, we are happy, his brother is happy and he is doing incredibly well. The beginning of the story wasn't so nice.

A brief history - Zach, now 17½ , was diagnosed with Smith-Magenis Syndrome on his 15th birthday. From birth we felt that something was not quite right. We put him into EI (Early Intervention) on his first birthday, and he has been on an IEP (Individualized Education Plan) since age three. You know the details . . . speech/ language, OT, PT, SI, Psych, not to mention medical doctors . . . oh, and did I mention he was diagnosed with Tourette Syndrome at age 6? (He really does have it!)

Zach's behaviors were always different from other kids. He is extraordinarily delightful, social, friendly, empathic and outgoing. He was exceptional at trashing things, not sleeping, banging his head now and then, ripping up books and punching holes in walls. When he was young we thought it was cute the way he had fun trashing things because usually he was smiling and singing. Destruction often took place somewhere between midnight and 3 a.m when there was no one awake to play with. Any of this sound familiar?!

Henry, Leah and Zach

Zach went from Early Intervention to an inclusion pre-school, and from there to an inclusion early education lab school. From there he went into the public school, repeating 2nd grade. We still had no diagnosis except what we began to call "Tourettes

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PRISMS, Inc.
21800 Town Center Plaza
Suite 266A-633
Sterling, VA 20164
972-231-0035
info@prisms.org
www.prisms.org

A Message from PRISMS President *Randy Beall*

Happy New Year!

In mid-Oct, the PRISMS Board of Directors met in Reston, VA for a 2-day planning session and board meeting. This was our second face-to-face board meeting in 2009. I thought I'd share just a few of our 2010 organizational goals.

Research surrounding SMS continues to get more and more exciting. There are multiple projects going on, studying many aspects of SMS: health, family and sibling support, behaviors, medication, and continued molecular studies to find out the exact regions/ramifications of the deletion that causes SMS. As you may know, our researchers have met before each PRISMS conference in a research roundtable, sharing discoveries and comparing findings. PRISMS plans to facilitate making these meetings more frequent, and expanding to more disciplines.

We would like to announce the 2010 SMS Research Alliance meeting to be held May 6, 2010 at the campus of the Elwyn Institute, in Elwyn, PA. You can find more information about that meeting in this newsletter.

The PRISMS board has set a goal to raise $100,000 during 2010 in part to help support this exciting meeting. I hope you will help us and consider hosting a local fundraiser. Every little bit counts!

PRISMS strives to efficiently use our financial resources. According to our last 2 years of Financial Statements (2007/2008), for each $1.00 of expenses:

$.90 goes directly to Programs (those include phone and email support, website, SMS Bulletin Board, database of registered families, information packets for newly diagnosed families, SMS brochures and bookmarks, our parent-to-parent program, our international conferences and our quarterly newsletter, Spectrum).
$.08 goes to Management & General
$.02 goes to Fundraising

We work hard to ensure income received goes directly to provide information and support to families of persons with Smith-Magenis Syndrome. Thank you for your generous donation.

We will soon be publishing our 2009 annual report. As always, this report will include our financials and be available on our website.

Jeri Gawlowski, our current Treasurer, has indicated that she will be resigning from the PRISMS BoD. I wish to thank Jeri for her many years of service. If you or someone you know would consider this position, please contact me via the email address below.

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Dr. James Lupski, M.D., Ph.D.

James Lupski, M.D., Ph.D., has served on the PRISMS Professional Advisory Board since its inception in 1993. Dr. Lupski was one of the primary researchers of Smith-Magenis Syndrome, partnering with Dr. Frank Greenburg at the Baylor College of Medicine in Houston, TX. Dr. Lupski came to be interested in the Smith-Magenis Syndrome during his study of Charcoat-Marie Tooth Syndrome and what would soon be discovered its close proximity to the deleted band in Smith-Magenis Syndrome. In the early 1990s, his team at Baylor characterized the novel sub-chromosomal duplication that gave rise to a common form of peripheral neuropathy called Charcot-Marie-Tooth (CMT) disease. (The discovery of copy number variation in genetic disease arose from that pursuit in 1991, when he discovered that people with CMT disease had an extra copy of the gene associated with the disease.) After a meeting with Ann Smith and Dr. Ellen Magenis, Dr. Lupski recognized the possibilities for the study of SMS and the significance to its link to other deletion syndromes. His collaboration with Dr. Frank Greenburg would prove to be the foundation for the protocol for the study of SMS at the Baylor College of Medicine. This protocol was the first to study the clinical and molecular aspects of SMS and was able to study many of the children of our PRISMS families. Dr. Lupski's laboratory was responsible for describing the mechanism that leads to the SMS interstitial deletion of the 17p11.2 region, which is now recognized to be a common genomic mechanism for other contiguous gene duplication and deletion syndromes. His pioneering work in molecular genetics/genomics laid the foundation by recognizing areas of low copy repeat gene sequences (or LCRs) that are prone to deletion or duplication. While studying the molecular basis of Smith-Magenis Syndrome, Dr. Lupski, alongside Dr. Lori Potocki, began to study the duplication of 17p11.2, and this investigation led to the discovery of *Potocki-Lupski Syndrome*.

Dr. James Lupski is Vice Chair and Cullen Professor of Molecular and Human Genetics and Pediatrics at Baylor College of Medicine in Houston. He is also the director of the Medical Scientist Training Program and American Editor of Neurogenetics. In 2002, Dr. Lupski received the Curt Stern Award from the American Society of Human Genetics for work in genetic disorders and the underlying mechanisms that explain many human diseases, and in 2004 received the Barbara Bowman Outstanding Texas Geneticist Award. He was also elected to the *Institute of Medicine* in 2002.

Dr. Lupski was recently interviewed for the inaugural edition of "On the Trail of Genomic Pioneers." This can be found at www.genomicpioneers.com. In the interview, Dr. Lupski details his research on using human genetics, genomics and molecular techniques to explain biological mechanisms for diseases. Dr. Lupski's laboratory at Baylor has also developed mouse models for genomic disorders, such as Smith-Magenis Syndrome. One of the original SMS mice was named "Jim," after Dr. Lupski! Dr. Lupski has co-authored over 450 scientific publications, is an inventor on more than 20 patents, co-author of the book Genomic Disorder, and has delivered over 325 lectures in 26 countries. Most importantly, to the study of SMS, Dr. Lupski has been a constant voice that propels the study of SMS forward and opens levels of investigation and research that examine the syndrome at a molecular level. Life all begins with a single cell, and Dr. Lupski has devoted his research to examining disorders from that one cell to another cell, looking for connections, rearrangements, order and disorder. We are thankful for Dr. Lupski's rare wisdom and commitment to the study of SMS, on behalf of the families, who have benefited from his research and the research of his lab. We loved having Dr. Lupski attend and present at the PRISMS conferences, keeping us all up-to-date on the research, the mice and what is on the horizon. Dr. Lupski's infectious, hearty laugh tempers the seriousness of his work and embraces the families who come to him with questions and concerns, and are reassured and comforted, knowing their children are not forgotten in the vast domain of research. Thank you, Dr. Lupski, for pressing on and for continuing to ask the questions and searching for the answers.

We thank Dr. Lupski for his many years of service on the Professional Advisory Board and wish him well in all of his many research endeavors, and will be awaiting his next discovery!✳

...Continued from page 2 - President's Message

The PRISMS board is here to serve you. If you have suggestions, concerns or comments, we would love to hear from you!! ✳
Warm regards,

Randy
randy@prisms.org

Baylor Obesity Study

If you have participated in a research protocol at Texas Children's Hospital/Baylor College of Medicine in Houston, Texas, or have ever been seen in the Genetics Clinic at Texas Children's Hospital by either Dr. Lori Potocki, Dr. Jim Lupski, or Dr. Frank Greenberg, and have not updated your mailing address, telephone number, and email address in the past 12 months, please send an update to:

Lorraine Potocki, M.D. at lpotocki@bcm.tmc.edu or call Dr. Potocki at 832-822-4292. The purpose of updating your contact information is to invite you to participate in a study about obesity in SMS. Once you update your information, a description of the study will be mailed to you.

Thank you for your past (and hopefully future!) participation in our research!

SMS Sibling and Parent Study

You are invited to participate in a survey evaluating the effects on siblings from living with a brother or sister with Smith-Magenis syndrome. Siblings, ages 7 and older, of individuals diagnosed with Smith-Magenis Syndrome and their parents are eligible to fill out a survey. We are conducting research to investigate how living with a sibling with Smith-Magenis Syndrome positively and negatively influences the following:

- The sibling's personality
- The sibling's relationship with his or her sibling with Smith-Magenis syndrome
- The sibling's relationships with his or her parents

Parents are also invited to take the survey. Parents' responses will be compared to siblings' responses in order to examine how closely related parents' and siblings' perceptions are regarding the positive and negative impacts on the sibling from living with a brother or sister with Smith-Magenis Syndrome.

The following surveys are available on the internet:

Sibling Survey, siblings under 18 years of age
https://survey.vcu.edu/cgi-bin/qwebcorporate.dll?idx=E567FM

Sibling Survey, siblings ages 18 and older
https://survey.vcu.edu/cgi-bin/qwebcorporate.dll?idx=3G5YAC

Parent Survey
https://survey.vcu.edu/cgi-bin/qwebcorporate.dll?idx=MDQSEE

By choosing to participate in this survey you will help researchers to better understand both the rewards and challenges that families experience as a result of having a child with Smith-Magenis Syndrome. This research will also assist parents towards gaining insight into their well-child's experiences and feelings. Participants can register to be eligible for one of two $50 gift cards to www.amazon.com .

You may contact us directly if you would prefer a paper version. For additional information or to request a paper version of the survey, please contact Dr. Sarah Elsea at selsea@vcu.edu , or contact genetic counseling graduate student Melanie Moshier at moshierm@vcu.edu . You may also reach us at (804) 828-9632, ext. 123.

Thank you for your interest and support of Smith-Magenis Syndrome research.

Consider Supporting the ABLE Act

The Achieving a Better Life Experience Act (ABLE) of 2009 (S 493/HR 1205), which is supported by over 40 national disability organizations, has been introduced in both the Senate and House. The ABLE Act will give individuals with disabilities and their families the ability to save for their child's future just like every other American family, and help people with disabilities live full, productive lives in their communities.

The ABLE Act will allow individuals with disabilities to create a disability savings accounts or 'ABLE Accounts' that would accrue interest tax free resembling in many respects how IRAs work today. The account could fund a variety of essential expenses for the individual, including medical and dental care, education, community based supports, employment training, assistive technology, housing and transportation. The legislation prohibits amounts held by, or paid or distributed from any ABLE accounts from being treated as income or assets when determining eligibility for benefits provided by any Federal benefits program.

This bill would allow individual taxpayers a tax deduction, up to $2,000 per year, for contributions to an ABLE account. Asset development is one step toward improving economic self-sufficiency, and the legislation's focus on encouraging asset development will greatly encourage people with disabilities to live more productive lives through earning and saving resources for their future.

HR 1205 was sponsored by Rep. Ander Crenshaw (R-FL) and 137 other co-sponsors. It has now been referred to the House Ways and Means Committee and House Energy and Commerce Committee. Senate Bill 263 was sponsored by Sen. Robert Casey (D-PA) and 11 other co-sponsors. It has been referred to the Senate Finance Committee. The bill must pass both houses of Congress and be signed by the President to become law. If your member of Congress sits on one of these committees, it's very important for you to take action. For more information, visit http://www.govtrack.us

PRISMS encourages parents and professionals to contact their senators and representatives to support this Act. Please take a moment and send an email or letter to Congress today.

SMS Research Alliance Meeting

Announcing the 2010 SMS Research Alliance Meeting

The PRISMS Professional Advisory Board would like to continue the brainstorming that took place at the very successful 2009 Research Roundtable, held prior to the recent SMS conference. They will also reach out to other researchers who have complimentary areas of research, but may have never worked with SMS before. The first meeting, for invited researchers only, will be held May 6, 2010 at the campus of the Elwyn Institute, in Elwyn, PA. The hope is to educate other research disciplines about SMS, but to also welcome and incorporate their strategies, skills and ideas into the management of SMS. The PAB would like to include professionals who work in the autism community, alternative medicine, pharmacology, behavioral experts, etc. The Research Alliance will reach across the table to other experts, involve them in future research and SMS management and try to get them excited and involved in the study of SMS.

We look forward to reporting more on this in future issues of Spectrum. A big thanks to all who have supported this through our holiday card fundraiser.

SMS SuperKid!

Marcus Triantafellu

Smith-Magenis Syndrome has touched all the lives of the people who read SPECTRUM. But I wonder if we truly realize how much it touches the lives of our families, friends and the communities in which we live.

Marcus Wade Triantafellu was born on June 18, 1994, in Colorado Springs, CO. We moved to New Smyrna Beach, FL in May 2000. He passed away on October 3, 2009, from complications from an illness.

We got Marcus' diagnosis of SMS when he was 2 1/2 yrs old and at that time we were told that he was the youngest child diagnosed with SMS. That of course has changed now and children are being diagnosed in-utero so that parents can prepare for their special gift.

Marcus had a huge impact on people's lives, not just on his family but on his community. He loved his school families and they loved him. That's not to say that school was easy because as he got older it was increasingly difficult with some things, but people always overlooked the difficult and focused on the positive things in his life. He was always asking "What name?" and then would tell you his name "Marcus T." He would always say "When I grow up" and then he would look to Mom or Dad to fill in the blanks... "He wants to do your job when he grows up." He always wanted to do everything, he had no limitations set for himself. In high school now, he'd been able to choose his own lunch and sit where he wanted, and as a typical 15 year old boy, he chose to sit with the girls, many of whom he didn't know, but he was teenager enough to realize that was a cool thing. The girls often had to remind him to come back and eat his lunch as he would be ready to go off and socialize whenever the idea hit him. But the girls didn't care. He'd come back and give hugs to all after lunch was over.

He loved the people in the stores of our community. He loved to grocery shop with his dad and the folks in Walmart, and he'd be grown up enough to go into Blockbuster Video and pick out a movie, always with Dad in sight. I'm sure the people at our Home Depot wondered who arranged their shelves so well, as he would do that while Dad was looking for whatever part was needed. He would always ask names and remember them. Something I still can't do!!

Marcus was one of the 30% or so children with an immune deficiency, so we were always fighting some illness- usually ears or sinus. He was no stranger to the doctors and actually loved them, often helping the lab techs with the blood drawing and the x-ray techs wanting to help push the buttons for this or that. He loved his doctors and they knew him well and took good care of him.

As Marcus grew older, he would sit on the front porch in the rocking chair and watch our neighbors go about their lives. He'd welcome them home with a "Hi, Jill" or a big wave as they drove by. They would always see him with his headphones on and music playing on his MP3.

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SuperKid continued from page 9.....Marcus Triantafellu

Country Music was his favorite and he would be singing along to most of them and rocking away.

He also loved to dress up in costumes- Spiderman and the ROCK guy from Fantastic Four. He'd walk circles in the yard with his costumes on, shooting webs or being the tough guy. So our neighbors knew him well and always waved back with a smile.

Another favorite thing for Marcus was to talk on the phone. He knew the speed dial numbers on our phones and would call his big brother just to talk or to be cheered up, that's what brothers are for, after all. He'd call his grandmother and aunt as often as I'd let him. They live in different time zones, so I'm sure they didn't always appreciate that early morning wake up, but no one ever complained. They'd just talk and he'd love it, walking around while talking and showing them things.

It was not always so easy to take drives or go out to eat with Marcus when he was younger, but as he got older, he liked to help Dad look at the map or choose where to go out to eat. He liked making the choices and it was no longer a difficult thing for him but something he really looked forward to doing.

As we look back on Marcus' life, we are so proud of him and can truly give thanks for the young man he turned out to be. We'd had our issues with meltdowns, self abuse, speech delay issues, escaping from the house in the dead of night, and on...but he was such a gift to us. He grew up to love life, he loved to be outdoors, to go kayaking, camping, bike riding, walking and hiking, he loved music, people, and in general he was so happy with who he was. I am envious of the fact that he could read people and emotions and help in ways I'll never be able to do, such was that 6th sense that our children have.

Marcus was one of the unfortunate people to succumb to pneumonia and H1N1. We are so blessed to have had 15 wonderful years to share with him. He gave us much more in life that we ever gave to him. And I think our family and our community would say the same thing.

We are special parents of special children. We have gifts and knowledge gained by experience through trial and error. Just know that our children - with whatever issues they come with- also touch the lives of all those around them. We are so richly blessed to have been given the opportunity to share their lives and they are lucky to have been given us as parents. Consider yourselves hugged by Marcus.✳

Carol and Stan Triantafellu
Parents to Marcus Wade Triantafellu
(15 SMS)

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 contact the editor at editor@prisms.org.

...Continued from page 1 - Residential Care

Plus." Public school was okay, but not great, for 3rd and 4th grades. In 5th grade we began to experience some of the force that was taking over our pre-pubescent boy. Fifth grade is where Zach began to show us what he was made of. The rough behaviors started to move out of our house and into school . . . furniture being thrown and other safety issues. At this point we decided to go the "medication route." We had been down that road unsuccessfully when Zach was six, but now he was 11 and we had to try something.

In 6th grade, Zach went to a special education day school, where for two years he vacillated between doing very well and being restrained day after day after day. I was called to pick him up countless times, moments after the bus dropped him at school, or if I drove him I'd get the call before getting back home. Over this two-year period things were brewing, percolating and exploding on a daily, sometimes hourly, basis. His behaviors were out of control. It was at this point we began to ask: Is what we are providing in Zach's best interest? Is it working for the family? Is he experiencing success? Zach's behavior was so out of control – out of his control – and there was little we could do about it. He started exhibiting self-injurious behaviors, as well as becoming injurious towards others - always with remorse, never with malice, and never, ever understanding the consequences of his actions. At this point, the story moved from the school into the psych ward. While he was in the hospital, we had to do some soul searching to decide what the next step would be. We wanted to keep him home, but his behavior was too unpredictable. Would he be safe? Would we be safe? Could he learn to be safe? For over three months he could not take a step outside the hospital without flipping out. So we made the difficult decision to begin the hunt for a residential school.

There are some important things to do and to think about as you start the process of finding a school. Contact the out-of-district liaison in your town; review the DOE (Department of Education) website for residential schools in your area; contact your DDS (Department of Developmental Services, formerly DMR – Department of Mental Retardation) liaison for advice. Call the schools you think could work for you, ask your liaison to send out whatever paperwork is necessary for you to set up appointments. Plan initially to visit without your child. You have to be okay with the school before you consider it for your child. We learned that many of these schools take children straight from hospital settings. If your child cannot get to the school for a visit, the school can come to whatever setting they are in. If it doesn't go well, that's okay. The school I wanted Zach to go to came to the hospital to meet him and he hit the interviewer in the face. They left, but returned one week later and accepted him. Remember, these folks run schools for children with behavioral difficulties and cognitive deficits. There is nothing your child is doing that they haven't seen before. What is critical is how they respond to our children.

You have to ask yourself many questions while on this journey. How far from home do you want your child? How often do you want to visit your child or have him come home? What does the physical setting look like? Will it work for your child? Do the kids attending this program look happy? How are they treated? What is the "timeout" system like? What is the restraint policy and training for staff? If they have them, what do the restraint or break areas look like? If there are no safe areas, how does the staff respond to children who, in another setting, would need to be restrained? Do the teachers and staff look happy? Is the school open for the children 365 - 24/7? What is the staff/child ratio? What is staff turnover? Are they asking questions about your child? Have they ever worked with an SMS child? Who makes medication decisions? How involved do they want the parents to be? How responsive is the staff to parental concerns? How involved do you want to be? What is the make-up of the population? Are there kids functioning at your child's level? Are there medically involved children? Do they have a vocational program (if appropriate for your child's age)? How open is the school to working with you, the parent, on training to work with your SMS child? This last question is very important. Most schools have never heard of SMS, never worked with children with SMS, and they try to fit our children into the closest program available. You have to guide the staff, but more importantly, the staff has to be willing to work with you. Zach tanked out of one wonderful day school because the staff was convinced they had more experience with kids with behavior issues than we did. They had never seen an SMS'er before us!

You will not find a perfect match, since there are so few of our kids out there. It seems to me that the best schools for SMS kids have programs that include PDD-NOS/spectrum kids. These kids, like ours, tend to lack impulse control, want to learn, are not street smart, are not mean with

intent, understand limits and they want to please.

While searching for a school, if not sooner, you need to find out if your district is on board in terms of financial support, as these schools are extraordinarily costly. If your district is not behind you, you might need to find an advocate, consultant, or lawyer who specializes in children with special needs to help you in this endeavor. Many of these specialists have special needs children themselves so they have an understanding of what you are going through. We were fortunate in that our district has always financially supported Zach. We were running an ICU in our house 24/7. This is no way to live.

The bottom line is that we all want inclusion for our children, but you must look at each child individually. Inclusion will work for some but sometimes tough decisions need to be made, then you have to ask: "What is my child getting from this? Is there a setting in which his academic education and navigation skills can be maximized? Are best practices in place? What will happen when my child turns 18 or 22? Is he ready for what's out there? Are we, as parents, prepared for his impending adulthood? Residential (and many day) schools can help you prepare for the future. On one hand, it's hard to plan out beyond six months with our children; on the other, we always have to have a flexible long term goal in place. We plan for Zach in the short term –– make sure he is in a safe controlled environment, we talk to him everyday, we talk to or e-mail staff, nurses and his clinician several times a week. We also think about the long term for Zach - changing schools, thinking about guardianship, wondering how will he function in the world as a learner, an employee, a friend -- and what are the things we have to do to facilitate that.

Residential school isn't for everyone, but in some cases it is necessary for the sanity of all involved. There are things your child can learn best from others, provided the setting is appropriate. Sending your child to a residential school does not mean you are giving up your rights as a parent. It does not mean you are losing your child to the system. And by no means does it mean that you do not love your child. Think of a residential placement as a home for your child to be the best he can be with 24-hour support. Zach is thriving at his school. His day is routinized and structured, most of his needs are being met, and best of all, we see the positive changes that allow him to function (always with support!) as a successful and happy young adult. ✳

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.

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.

A Perfect Match

Baylor's Parents' Night Out and the Houston Picnic

On Friday night, November 6th, for the 5th year in a row, Dr. Lorraine Potocki of the Baylor College of Medicine at Texas Children's Hospital and the Baylor Medical Students took care of Smith-Magenis Syndrome and Down Syndrome children and their siblings, so that their parents could have a night out. Each child was paired with at least one medical student partner.

Tara Banaszek, BPSA Parents' Night Out Coordinator 2009, provided the following description of the event. "We started off and had dinner donated by Chick-Fil-A! (while our volunteers enjoyed burritos donated by Freebirds and fajitas donated by Fajita Petes!).

Then Gymboree did a fun sing-a-long time and we played with the giant parachute. We had face painting, balloon animals, sugar cookie decorating, crafts, coloring, board games, dress up clothes and wagons to play with as well!

Additionally, we had special visitors: Spiderman, Cinderella and Bert and Ernie (med students in disguise!). We also had our favorite: 'Tiny', our 6'2'' rodeo cowboy clown med student that fiddles WHILE unicycling! It was a fun and busy night!

Cecilia Poole, who plans and hosts the picnic along with her husband, Gordy, provided an excerpt from her blog about what the SMS parents did during their evening out. "That night, our group of parents of children with Smith-Magenis Syndrome headed to D'Amico's Italian Restaurant in Rice Village. It is crazy, busy around there on a Friday night, but they cleared a space for us. The food was fantastic and the wait staff excellent."

Cecilia continues as she describes what took place after the dinner. "This year, in our home, we hosted Randy and Mary Beall (president and wife of the president of PRISMS). They brought along their 24 year old daughter, Laura, who has SMS. They also brought another little girl, Rachel, with SMS whose family was busy at a tournament for her sister. We had a great, albeit intense, time. You see, people with SMS have a huge zest for life and a persistence to get what they need, which I would venture to guess is second to none. Saturday morning before the picnic I am making breakfast in the kitchen, and at times I had my SMSer, Sarah, and the other two girls right on top of me. They were all wonderful, of course. But I must say, it was quite comical at times. We enjoyed seeing the similarities and differences. Such an experience sheds a lot of light on what we deal with day-to-day, because you see behaviors that they all have in common."

The picnic always takes place on the day that follows the Parents' Night Out event. Cecilia describes the event. "The picnic was wonderful. First of all, it was on Saturday when the weather was gorgeous! We had a scavenger hunt, played fall bingo, did a cookie walk, played a new game called sticker attack, bounced in the moonwalk and enjoyed favorite songs. Thanks to SMS big sister, Megan Poole, for providing the outstanding selection of music. We had a sensory nook with a big tub of bird seed which the kids enjoyed shoveling and digging in (and sometimes sitting in). And there was a reading nook with all kinds of kids books. We also were treated to a wonderful hamburger/hot dog lunch with Gordy Poole and Keith Miller doing the cooking. Everyone brought something and we thank them all for that. Our most distant family came all the way from Mexico City. And we had several families from the San Antonio area. We look forward to seeing everyone again next year."✳

Sunny Side up

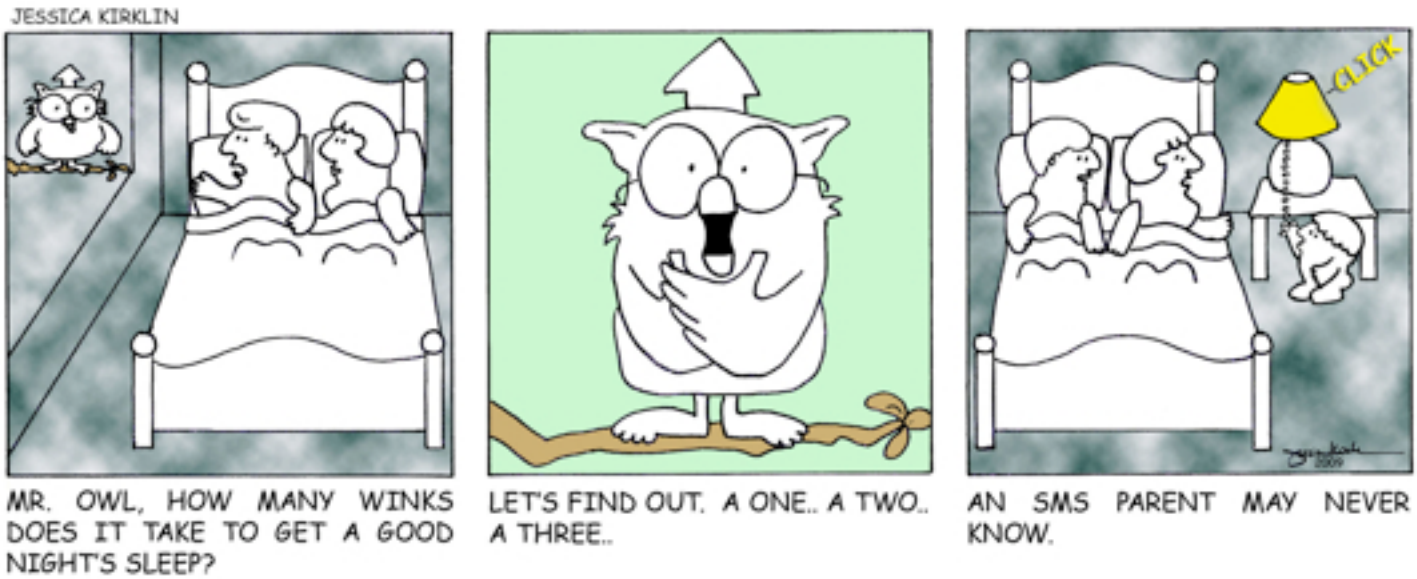
Rachel, our 13 year-old daughter with SMS, has provided us with some truly endearing moments in our lives. I remember the time that Rachel and I were taking breakfast to her teachers during Teacher Appreciation Week. Naturally, Rachel wanted to go with me to pick up the breakfast, so she did not ride the bus that morning. When we arrived in her classroom, we found out that all the boys were in trouble for using bad language on the bus. Even though Rachel was 11 at the time, her entire vocabulary of inappropriate words consisted only of the word *stupid*, so it was fortunate that she was not exposed to other inappropriate words. Rachel must have heard the term *bad language* throughout the day and equated it with being naughty. That evening around bedtime when a meltdown occurred, she wanted to be her very nastiest, so she screamed at me, "Bad language! Bad language!" She thought she was really telling me off with the latest curse word. I knew exactly what she thought she was doing and it was all I could do not to burst with laughter. I managed to hold it together and did not spoil her moment. She thinks she really got me good that night and she did.. in the funny bone.

Submitted by Jessica Kirklin

Julia Cooney in an "uh-oh" moment

Note from the Editor

SPECTRUM is pleased to announce the initiation of the "Sunny Side Up" column. This is intended as a spot where parents, siblings or others with SMS connections can share their funny and heartwarming stories. Please send your stories and pictures to editor@prisms.org, or call (843) 521-0156 if you have any questions.



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Parents and Researchers Interested in Smith-Magenis Syndrome

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

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