

Fitness for Life

Thomas Hetherington, PT, OCS, FAAOMPT, CFMT

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We have all heard about the Smith-Magenis research mouse, the cute, overweight mouse with low muscle tone, which is similar to some of our SMS children. Many individuals with Smith-Magenis syndrome (SMS) will deal with issues of obesity, low muscle tone, delayed motor skills, and food-seeking behavioral issues.

If we, as parents, do not encourage healthy habits for our children, the chances of health-related problems increase. Obesity may play a role in heart disease, arthritis, diabetes, high blood pressure, and generally accelerates most diseases.

How, then, do we combat these problems associated with weight? The interventions discussed apply to the entire family, which in general will reap the benefits from a healthy lifestyle. Our SMS children will find it easier to adjust to changes if the entire family is involved. The key to family fitness includes regular exercise and healthy eating habits.

Regular exercise has been shown to improve physical, mental and emotional aspects of an individual's life. People feel better, sleep better, have more energy, and live longer with fewer physical problems if exercise is a regular part of their lives.

Leading by example is one way that parents can boost their family's activity level. The more our children see that exercise is a regular part of our lives, the easier it will be to incorporate exercise into his/her life. A family walk around the neighborhood after dinner each night will provide a chance to exercise together, and also a chance to spend quality time together. Regularly parking in the back of a parking lot and walking with your child into the store burns some calories. Using stairs instead of elevators, walking the dog with an adult, or allowing your children to help with yard work may initially

require extreme amounts of patience, but will pay off in the future.

Keeping our children motivated also requires planning. First, make the activities fun! Use a variety of activities to prevent boredom. Rewards, competition and games tap into our natural instincts to please and compete.

How do we keep activities fun? Inventory your child's natural likes and dislikes. One-on-one activities usually rank high on most SMS lists. Their likes may include music, animals, playgrounds, mountains, beaches, swimming, or specific sports. Incorporating a social support system of friends will give you respite and may fill your child's need for adult attention.

Surround your home with a variety of activities your child will enjoy. Examples might include a pool, sprinkler, slide, basketball hoop, sand box, or a soccer goal in the yard.

A Wii Fit provides many indoor fun-filled activities the whole family will enjoy. For individuals who enjoy music, dancing with a parent can be an option. Bowling, gardening, and yoga are also great activities.

Use of rewards builds self esteem and a sense of accomplishment, and can be a great motivator. Setting goals and using a token economy will help motivate children. For example: "If we walk every day, on Saturday we will go ____." Fill in the blank with a movie, playground trip, swimming, bowling, or anything that works for your family. Avoid using food as a reward, if possible. Don't forget, you can also reward

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PRISMS Smith-Magenis

PRISMS, Inc.
21800 Town Center Plaza
Suite 266A-633
Sterling, VA 20164
972-231-0035
Fax: 972-499-1832
info@prisms.org
www.prisms.org



A Message from PRISMS President *Randy Beall*

I hope you have had a chance to check out our great new website. We greatly appreciate all of the work Scott Miller put into this site. It is outstanding!! We are also proud to introduce The PRISMS Store, loaded with great merchandise to help increase awareness.

The PRISMS Board of Directors recently met in Richmond, VA for a 2-day planning session and board meeting. We had 2 days of intense work with an inspiring initial session at Dr. Sarah Elsea's lab at VCU. During a work break we had an emotion-packed presentation as we all shared with Ann Smith just how much she means to PRISMS, and that we fully support Ann as she moves into a new role as Chair Emeritus of our Professional Advisory Board. We also welcome Dr. Elsea as our new PAB Chair! Read more about both of these special events in this newsletter.

We are in the process of securing Ross W. Greene, Ph.D., as the keynote speaker for our 2012 Denver conference. Dr. Greene is the originator of the Collaborative Problem Solving (CPS) approach described in his first book *The Explosive Child* (now in its 4th edition), and most recently in his newest book *Lost at School*. He is an Associate Professor in the Department of Psychiatry at Harvard Medical School, and also founder of a nonprofit organization, *Lives in the Balance*, aimed at helping families that have challenging kids with support and resources.

Our volunteer grant writers (Ann Smith, Gail Kopp, and Mary Beall) have been hard at work to make PRISMS Camp Breakaway 2011 a reality. We are partnering with the Camp Breakaway organization (based in Australia) to develop a 4-day respite camp for individuals with SMS and their families. We hope to hold our first pilot camp in September 2011 at Covenant Harbor in Lake Geneva, WI, and another camp at Camp for All in Burton, TX. Camp Breakaway has successfully served many Australian SMS families for several years. It is our hope that this will help us foster family education, respite, and research activities.

One of PRISMS' primary missions is to support families and provide information. We often talk to newly-diagnosed families who struggle to make sense of their diagnosis, and teachers and professionals who need help working with individuals. However, we also get involved in some tough situations which require intense Board and/or Advisory Board interaction. We have been called upon to provide expertise in SMS and it's characteristics in educational disagreements and legal matters. We do our best to represent SMS accurately to get the best help we can for all people with SMS. Our hearts break for families in crisis. We ask for your continued support of PRISMS but also ask you to keep struggling families in your thoughts and prayers.

As you all know, we are a member-supported organization. We depend upon our members to host our conferences and continue our many programs. Please don't forget to renew your PRISMS membership and get involved. You can find our 2011 membership form on our (new!) website. As always, the PRISMS board and volunteers are here to serve you. If you have suggestions, concerns, or comments, we would love to hear from you!!

Best regards,

Randy Beall
randy@prisms.org

Board Spotlight

Randy Beall, PRISMS President



Randy Beall has been the President of PRISMS for the last 8 years. He and his wife, Mary, live in Richardson, TX, a suburb of Dallas. They have two daughters: Laura, age 26, is currently living at home; Jenny, age 23, lives in Denver, CO (great place to visit). Randy works as a Treasury Management Sales Consultant for Wells Fargo Bank.

When asked how he got involved with PRISMS, he tells his story this way:

“I joined the PRISMS board shortly after our daughter, Laura, was diagnosed. She was 12. Maggie Miller put out a plea for a Treasurer, and I thought, I’m a banker, how hard can it be? Well, I can tell you, it was a lot harder than I thought. I quickly realized that I didn’t know anything about nonprofit accounting, or being on a nonprofit board. But I was willing to learn, and was enthusiastic about helping

the organization that helps our family so much.”

Randy became Treasurer, Vice-President, and then President. During his tenure, PRISMS has made many improvements, including creating an online database of PRISMS members, re-launching the website, adding more and better information, creating administrative/procedural efficiencies, and convening international PRISMS conferences in 2005, 2007 and 2009.

So what does the President do? Randy’s responsibility as President is to preside over conferences and board meetings: the board has monthly conference call meetings, and one or two face-to-face meetings per year. The PRISMS “office” is actually in his living room. He handles the many administrative tasks and signs all contracts.

He is also the frontline support for people in crisis: families, teachers and other professionals, who call about sleep and behavior problems, diagnosis issues, school issues, and even legal problems. He responds to all incoming emails and phone calls, prioritizing them and assigning them to volunteer leaders or quite often, returning the calls himself. He has a special concern for the families of children who are newly diagnosed, and tries to make sure to call them when he is going to have enough time for all of their questions. Another concern is parents who don’t speak English, and he works to find ways to communicate with them or to connect with someone who can. The most important pages on the website now have a button that will change English to Spanish.

When asked, why do you do it? He answered, “I love helping other parents. All of the work is worth it when we hear words like these from a parent, ‘ We are so glad that we are not alone. PRISMS has provided us such valuable information. Thank you a million times over!’ ”

The Advocacy Corner

It is often quite challenging to navigate federal or local programs when advocating for SMS individuals. Knowledge is key.

Children with disabilities are eligible for both Social Security Disabilities (SSDI) and Supplemental Security Income (SSI) under certain circumstances. According to Social Security definition a child must be the age of 18 (if over, under the age of 22), but must regularly attend school. Children may qualify for SSI if the disabling condition is severe enough, and they meet the income requirements. Children may qualify for SSDI if a parent or guardian is disabled. An individual disabled since childhood may receive disability benefits upon becoming an adult using the parent's social security number and work record. This is called a "child's benefit", even though it is derived using the parent's earning record.

Whether the conditions physical or mental, or a combination, the condition(s) must have lasted, or be expected to last, at least 12 months, or must be expected to result in death.

It usually takes the SSA three to five months to determine whether your child qualifies. To facilitate a smoother process, you should provide all relevant information to help the evaluation and expedite the process.

Discuss your situation with an experienced social security benefits attorney.

DREDF, Disability Rights Education and Defense Fund, has a good read about Idea Find Part 2: Assessment for Special Education. The IDEA "child find" requires every state to identify, locate, and evaluate all children with disabilities, from birth to the 22nd birthday, who may need early intervention or special education services.

Volunteer Opportunities

Newsletter editor still sought! PRISMS is seeking interested individuals who have organizational skills, computer skills, and an eye for design. There is a well-developed newsletter committee to support the editor. The current editor would like to work with someone for several issues during a transitional time. If you are interested and would like to talk to the editor, Julia Hetherington, please contact her at editor@prisms.org. Please give your contact information plus the best time to call, and Julia will gladly call you to answer all your questions.

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 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.

Dr. Sarah Elsea to Chair PRISMS Professional Advisory Board

After many years of distinguished service leading our Professional Advisory Board (PAB), Ann C.M. Smith, D.Sc. (hon), has decided to step down as chairperson. Ann will become the PAB Chair Emeritus and will continue to serve on the PRISMS Board of Directors in an *ex-officio* capacity. Effective immediately, Sarah Elsea, Ph.D., FACMG will become the new PAB chair.

Ann has made many significant contributions to PRISMS and our PAB. She has touched so many of us with her wit, dedication, and passion. Ann has not only been a devoted researcher in the study of SMS, but an advocate for persons with this syndrome. She has ensured that they receive the appropriate care, educational supports and necessary treatments vital to their well-being and quality of life. She continues to be a champion for persons with SMS and has challenged the research world to take notice and care of this rare syndrome. We will forever be grateful to Ann for all that she has done for our children. We appreciate her many years of commitment and service, and look forward to continuing to work with her.

Dr. Elsea is a distinguished researcher, and has served on the PAB since 2004. She has also been a friend of PRISMS for many years. She currently serves as an Associate Professor of Pediatrics and Human & Molecular Genetics at Virginia Commonwealth University (VCU) School of Medicine. She is board certified in biochemical genetics by the American Board of Medical Genetics. Dr. Elsea teaches introductory and advanced human genetics, trains graduate students in genetics/genetic counseling, provides clinical consultations, and focuses

on research efforts toward characterizing Smith-Magenis Syndrome and related genetic disorders. Dr. Elsea's lab identified the causative gene for SMS in 2003 (*RAI1*), and has focused research efforts toward characterization of *RAI1* using mouse and cell culture models, including the effects of *RAI1* on cellular pathways (particularly that involved obesity/behavior), and the identification of other possible genetic causes for SMS.

Please join me in welcoming Sarah, and wishing Ann continued success in her future endeavors.



Sarah Elsea, Ph.D., FACMG and Ann C.M. Smith, D.Sc. (hon)

We Were to Conquer the World

A Father's Perspective

David Moertl is the father of Jack. He and his wife, Lynn, also have a lovely daughter, Abigail.

A boy lives in his own world, venturing out into the greater world as he sees fit from time-to-time to try it out, only to return to his familiar surroundings after finding it bothersome or strange. He lives this way for many years, quietly observing his own world, getting to know it, cataloging it for his comfort. His venturing becomes more frequent as he ages, and his observations from the outside seem to collide with the comfortable world that he has made for himself. These observations challenge him; they bother him, disappoint him, excite him, and create deep questions within him which roil in the current of his emergent heart. Some questions make it to his surface and are asked by him, and though he lacks the vocabulary and experience necessary to nail them completely, he finds helping hands to lift him through the transition periods marked by the tumult of his unease. In this way, he grows into a man; choppy and by fits, begrudgingly and by bounds, all the while distancing himself from the world he once knew to be his own, and joining the collective world at large. His eyes slowly open, his soul slowly expands, his heart slowly burns, and he finds himself a man despite the multitude of scraped knees, bloody noses, and broken bones, both literal and metamorphic, through falling down solidly in the defeat of small failures that loomed large to him. He looks back on this and feels strength from the experience of getting up off the ground, dusting himself off, and eventually slaying the dragons of those small failures heroically to gain favor of and hold hands with his destiny on the road of life, and moves on.

This man marries and has a son. Never before had he known he had a new, hidden world within him so deeply rich with love, pride, excitement, and hope. This new world collides with his own, this time steamrolling over it, and replacing it as his primary world in a rush and a howl, and before he knows it he is transported to parenthood. The man has designs for his son. His son will be superior; he will throw, catch, and run well. He will shoot and ride well. He will fix things, and he will know, live, and love well. He will be a leader and a teacher, kind and strong, clearly winning the battles of youth with his peers, while retaining their respect and love. He will catch the eye and be the prize of all the ladies, and be included in and be a central component of all social aspects of his life. The man will play a vital role in all of this, being the boy's guide and mentor,



teacher and coach, walking with him every step of the way, while giving him everything he needs to succeed.

Then the boy is diagnosed with SMS, and everything changes. The man spends time in a temporary world of denial, defying anyone to prove his plans for his son as wrong, and is trapped in the confines of his rage. Slowly, the man tires of banging his head against the wall, and after seeing clearly for himself that the boy was correctly diagnosed, resignedly starts the acceptance process and feels failure at his weakness through the act of the letting go of his pride. Realization creeps in; realization of facts that preclude his son from being the model of “normalness” that he had assigned to him. His son would struggle: struggle to communicate, learn, grow, and behave. He will struggle to play sports, understand, and to keep up. He would be different. His peer group would separate from him, and he would see and know this and be left out, especially after puberty. The man's own last name might end with his son. Grief set in on the man; *the grief of what should have been.*

And it was real to him. Through this, a deep love for his son grew in him, and he loved him more for it, yet the grief remained and clarified and burnt at him, and it tired him. He chewed on the lost possibilities like rusty bolts, and felt the sick feeling that accompanies grief pool in his soul like a maddening flood. He mourned for his lost son, while loving his true son. With each outburst, with each phwap-phwap-phwap of his son hitting himself in the head, with each splat of his son's teeth biting through the skin of his hand and forearm spraying blood, the man's grief deepened. He grieved for his son, for his wife's grief over the pain of their daughter when the boy would bite her, and he grieved for the life-long burden placed on their

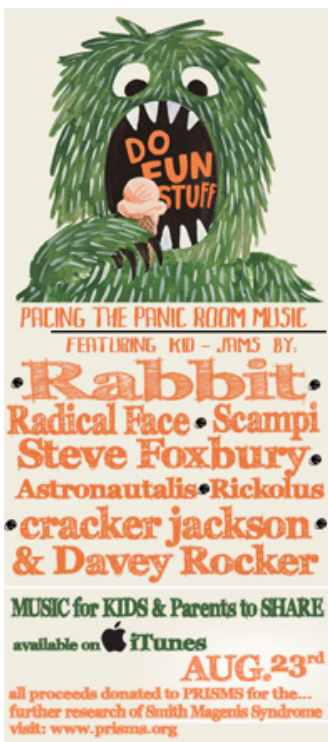
daughter. It seemed to the man that he lived in an *exit-less* world of grief and pain.

But the boy grew, and a funny thing happened; the man began to see the boy for who he was. He saw an incredibly sweet, generous, loving, funny, outgoing, and caring young soul, someone the man was proud of. The man was proud as the boy began to refute his offer of help in matters, preferring to do things on his own. Their relationship grew as father and son, and each relied on the other for the mutual need of returned love. They became a team, and created their own games and understandings, and outlooks and ways of doing things. The man's grief remained and reared its head at times when he saw the separation, inability, difference, or the meanness between his son and his peers, but it became apparent to the man that the grief was his own, not his son's. His son did not deserve the yoke of his grief. He realized that his grief was not for his son at all, but for himself and his hopes, designs, and ambitions. The man identified the difference between the pain of seeing his son

self-injure, fall short of others, or lack the capacity to complete a task, and the grief over the lost fact that he should be succeeding in all areas, separated them, and loved the boy all the more. His SMS son was happy living the life given to him; he was beautiful in and of himself, and really, the man should be so lucky to be half as happy as his son. The man came to realize that the grief of what should have been, though real, is not the real issue. The real issue is that everyone is who they are...no more, no less, and that love and happiness is the true measure of success, not the triumphant dreams of others. They did end up conquering the world, the man's expectant world, and the irony is that the son became the guide and mentor, teacher and coach, and not the other way around.

-Mertz-

"Do Fun Stuff" Album Support from Artist Ryan Marshall



"Do Fun Stuff" (Vol 1) is the first album (in a yearly release schedule) of original kids music that is for sale as a charity album benefiting the further study of Smith-Magenis Syndrome. The hope is that enough money is raised for PRISMS to establish an SMS Research Fellowship that funds a graduate student to study SMS, and support the SMS community. The album is a compilation of varying artists who all contributed their time and efforts to craft these kid tunes, all in an effort to drive awareness and funds toward Smith-Magenis Syndrome. This is a digital release via iTunes, and 100% of the proceeds goes into a charity trust set up by PRISMS. There are plans to eventually have a CD available, also.

The album is available online via iTunes Worldwide. The album itself is a great collection of kid and parent friendly tunes that makes "Do Fun Stuff" a kids record for parents. The album has mass appeal, and tunes are melodic, fun, sentimental, and hard to turn down. Contributors to this first volume are: Rabbit, Radical Face, Astronautalis, RickoLus, Scampi, Steve Burry, Cracker Jackson, and Davey Rocker. All of these artists were moved by the cause and happy to help.

-Ryan Marshall

The Grandparent's Turn... Of Events

By Joanne Seward

My name is Joanne Seward, grandmother of Cooper, an SMS child who was born into our family on March 29, 2010. Like all special needs children, we consider Cooper a gift and a blessing.

After an informational meeting in October 2010 with my daughter, Janet, her husband, Ronnie and his parents, Ann Smith, and Maggie Miller, the mother of Deirdre, an SMS young lady, I decided to get involved with PRISMS. I had several conversations with Maggie as to how to achieve that goal. We discussed numerous topics, and my idea of writing an article for the Spectrum newsletter from a grandparent's perspective evolved. It would be a forum and an opportunity to give voice to grandparents' concerns, suggest ideas, share stories, and have questions answered.

Here is the first article which is intended to help the grandparents, and subsequently the parents of SMS children. I feel grandparents have a unique viewpoint of their SMS grandchildren, watching their own children parenting an SMS child. Perhaps sharing our family's journey with Cooper may be a good way to begin The Grandparents' Turn....of Events.

My daughter, Janet, had a normal pregnancy and anxiously awaited the birth of her third child. The results of her first trimester screening were slightly above normal. She and Ronnie decided to have a CVS (chorionic villus sampling) to rule out any genetic disorders. These test results proved to be normal. In the wee hours of the morning on March 29, little Cooper was born. His parents' excitement of his arrival was tempered, however, when he did not appear "quite right." The pediatrician on call in the hospital was summoned, and upon examination of Cooper, she stated that he has the characteristics of a Down Syndrome baby. Needless to say, Janet and Ronnie were stunned to hear the tentative diagnosis. They felt that their expectations for Cooper were shattered, and that their lives would be changed forever.

During his stay in the hospital, his blood was drawn to secure a more definitive diagnosis. Two days after returning home with him, the results were completed and proved negative for Down Syndrome.

However, as the days went by and Cooper approached two months of age, they felt something was "just not right." He did not



smile very much, exhibited a blank stare, weak muscle tone, and seemed too small. Janet and Ronnie decided to schedule appointments with a genetic doctor and Cooper's pediatrician. The genetic doctor noticed Cooper's heavy, labored breathing, a reduction to less than the 5th percentile for weight gain, and a gasping for breath in addition to nasal snorting while drinking his bottle. Her recommendation was that a swallow study be scheduled. In addition, a microarray blood test would be done to detect any genetic disorders. After three weeks of waiting and worrying, an evening phone call was received at home that Cooper tested positive for Smith-Magenis Syndrome.

Janet called me with the diagnosis on June 16, 2010. I was stunned, yet relieved to finally have a name to match with the symptoms. I had never heard of SMS, let alone know much about chromosomal deletions. The only knowledge I had was related to Down Syndrome. As more information came to light, and the more educated we became through physician meetings and research on our own, we knew as a family we were facing a formidable diagnosis.

Now that the diagnosis was confirmed, from a grandparent's perspective my heart ached. I was concerned about the well-being and future of my youngest grandchild. How disadvantaged would he be, what about his education, his siblings' reactions, how were his parents to cope (especially my daughter, who is his mother)? What role could I play in assisting and where do I fit in?

Since then I have tried to be present as much as I can, accompanying my daughter to doctors' visits and meetings. I also began participating in a fun music class with Cooper and his older brother, Mitchell. I feel, like Janet, that any kind of early exposure to the sounds and rhythms that music can provide, or any sensory stimulation is most beneficial. I am hopeful that whatever supplemental therapy or assistance I can provide will help him in the long run. We were fortunate that he was diagnosed as early as he was, as we have been told that it is a positive benefit. From an emotional standpoint, I have watched my daughter and her husband from the sidelines. The road has not been easy, and the sadness and grief prevails at times. They ask, "Why us? How could this happen? What went wrong?" Honest questions, no easy answers, if any.

However, there is always the hope that research provides, and a myriad of ways to fund that endeavor. As a family, it is our goal to heighten awareness of SMS and raise funds for PRISMS. Just by wearing the SMS bracelet people take notice and ask about it. Also, Janet and Ronnie have consented to a natural history study and entry into a clinical research trial.

As for support from grandparents, various possibilities would be babysitting, having your grandchild over to spend the night, observing at therapy appointments (and even assisting in therapy), paying special attention to siblings, and providing transportation and running errands. Being creative with any assistance you could give would help immeasurably.

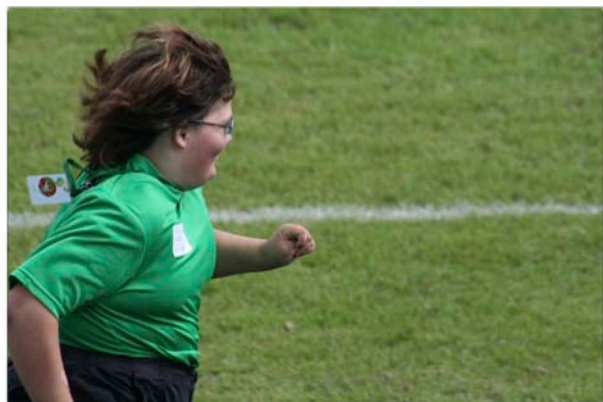
I have learned as I have gotten older that life keeps throwing those unexpected curve balls. Being able to catch them and knowing how to deal with them once they hit your glove is another matter. In the circumstance of having a grandchild with a disability, acceptance, loving support both for the SMS child and your own children is paramount. These grandchildren are a part of us and inhabit the nucleus of the family and beyond. The SMS child can certainly open our eyes to

the possibilities of living a life filled with joy, blessings and wonder.

So, grandparents, please feel free to submit your thoughts, special events and share your stories. This column is dedicated to you. It is now The Grandparents' Turn!

The editorial staff of Spectrum would like to have grandparents contribute articles for "The Grandparent's Turn." If you would like to submit an article or just talk to someone about an idea you may have, please contact the Spectrum editor at editor@prisms.org.

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your other children for helping your SMS child with regular exercise.

Most of us are motivated by friendly competition. Challenge your child to race around the block, or to swimming games. "Who can jump the highest?" or "Who has the best dance move?" may challenge your child. Organizations such as Special Olympics incorporate wonderful, friendly competition with recognition and fun. The Wii Fit software keeps scores and sets goals, as well as giving verbal praise for a job well done.

Finding community based organizations which can help our children become fit, sometimes requires a bit of detective work. Special Olympics for sports (www.specialolympics.org), Ambucs for adaptive tricycles (www.Ambucs.com), and therapeutic horseback riding for increasing core strength (www.americanequestrian.com/therapy) are some examples. Most states provide camps or sporting leagues. These can be found with an internet search of your area's disability organizations. The ARC in larger communities is another source (www.thearc.org).

Healthy family eating habits are part of a general fitness program. Americans too often turn to high fat, preservative-filled convenience food or fast food restaurants to ease our time constraints. With planning, we can eat healthy.

Basic guidelines for healthy eating include eating more fruits and vegetables, and whole grain foods. Additional good choices include fat free milk, poultry, fish, and lean meat. Check labels for foods low in saturated fats and avoid foods with trans fats. Also check that foods have low sodium content and limited sugars.

A great source of information on healthy eating habits and exercise can be found at www.mypyramid.gov. You will find tips for better eating habits and a resource for low fat recipes.

Lifestyle change takes a commitment from everyone involved. Have a family meeting to discuss any changes you wish to make. Talk about the benefits of exercise and healthier eating to bring the whole family on board. It takes the whole family to make this work when an SMS individual is involved!

Thomas is the father of a 17-year-old daughter with SMS.

Tips to help achieve a healthier lifestyle:

- Buy fewer candies, cookies, ice cream, and chips. Instead, use fruit and carrots/celery for snacks.
- Eat at regular times each day.
- Ask school personnel not to use sweets for snacks or rewards.
- Pack a healthy lunch box for your child. Schools often have unhealthy choices.
- Drink a full glass of water before each meal.
- Reduce portion sizes by using smaller dinner plates and limit second helpings.
- When eating out, discuss healthy menu choices before you get to the restaurant.
- Locks on the refrigerator and pantry will reduce temptation.
- Discuss increasing the amount of physical activity at school with teachers.
- Plan to exercise daily and use rewards to motivate.



Erica!

Celebrating World SMS Day – Glow for SMS

Erica, our 36-year-old daughter with SMS, has worked in a sheltered workshop for 9 years. Her “effervescent” personality and her “wanting to please” have often led to challenging and difficult interactions with peers and staff members at her workshop. My husband and I decided that World SMS – Glow for SMS Day would provide a good opportunity for increasing the workshop staff’s understanding of our daughter and what SMS is all about.

Erica’s new behavior therapist was willing to conduct an SMS in-service for her workshop staff. Erica lives with 2 other special needs girls in a community-based apartment operated by her residential care agency. Her residential site coordinator and a new member of her residential site staff also were invited to attend the in-service workshop.

In recognition of “Glow for SMS”, we provided glow sticks and attendance certificates to all who attended. Due to staff turnover, a follow-up in-service is planned for Erica’s residential site staff.

As SMS parents, PRISMS and the Spectrum newsletter have been most helpful to us since Erica’s diagnosis of SMS at age 29. Now, at age 36, Erica continues to mature, learn, show improved speech patterns, and evolve as a loving and enthusiastic purveyor of life. Erica is our SMS SuperKid!

Submitted by Erica’s Mom, Emily



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.

Parents and Researchers

Connecting. That was the overwhelming feeling as the PRISMS Board of Directors met with Sarah Elsea, Ph.D., FACMG, and her research team. Meeting together were the researchers and the board members. The researchers were able to put a face on the SMS families that they have huge potential to impact. The Board members were able to express their utmost appreciation to the “real” people who are studying many aspects of SMS.

Presentations were made by genetic and genetic counseling students, health care policy students, biostatistics, and bioinformatics students. The board heard reports of fascinating studies being done regarding sleep issues, siblings, early childhood onset obesity, hyperphagia, and the circadian rhythm as they relate to SMS. Dr. Elsea shared her continued study of the RAI1 gene. A genetics student shared his research into pediatrician perceptions of the patient-centered medical



home. The board learned about zebrafish being established as a model for RAI1 gene analysis. A Ph.D. student in genetics reported on her research into a shared network between neurodevelopmental disorders.

This was very rewarding to the board members. It really put all of the hard work into perspective as we once again saw that we truly are Parents and Researchers Interested in Smith-Magenis Syndrome! The students were encouraged to attend the PRISMS conference and Research Roundtable. We hope to see all of them continue along the SMS research road.

Special thanks to Sarah Elsea, Ph.D., FACMG, for sharing her lab studies with us. The presenters were Mandy Hebert, Lauren Bierema, Callie Langworthy, Catie McConnell, Chris Ray, Daniel Lee, Danielle Bartholomew, Stephen Williams, Ph.D., Laura Meyer, and Sureni Mullegama.



The PRISMS Store!!

The PRISMS Store is open for business!

Visit our online store and select from several original designs that can be printed on the items of your choice. Want to be stylin' while raising awareness for Smith-Magenis Syndrome? We have apparel for men, women, and children, as well as several gift items.

Need a present for a special occasion? Find unique gifts such as a keepsake box, apron, mug, and a tote bag. 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 find a link on PRISMS website, www.prisms.org.

A portion of the proceeds from the sales benefit PRISMS, so shop till you drop! It's for a good cause!



PRISMS Survey

Take the 2011 PRISMS Survey!

Included in this newsletter and available on the web is the 2011 PRISMS Survey. We hope that everyone involved with and interested in PRISMS will take a few minutes to complete the survey and share their thoughts about our programs, membership, and more. The survey is open to everyone interested in our organization.



The survey has just a few questions. It is designed to gather comments about the services offered by PRISMS, and to assess how useful they are to you and other SMS families. We'll be collecting information from the survey up until July 31, 2011.

There are several ways you can be part of the survey. You can fill out the paper copy enclosed in the newsletter and mail it back to us. Or you can find an electronic version of the survey

online through our website, www.prisms.org, and the PRISMS facebook page, www.facebook.com/prisms.smithmagenis. Or, it is available by typing this address in your web browser – <https://www.surveymonkey.com/s/2011SurveyPRISMS>

Whichever way you choose, we look forward to hearing from you.

PRISMS was organized in February 1993. Since that time, the organization has steadily grown. Today, our members live in nearly every state and in several countries around the world. Among other services, PRISMS offers a bi-annual conference, assistance to families through a parent-to-parent network, and publications. Board members are actively involved in the research and medical communities as well.

The survey is part of our planning process, and will help us learn from you about the programs you value, where we can improve, and new ways we might be able to assist families. After the survey period closes, we will be tabulating the information and preparing a report for the Board and membership. Based on what we learn, we will evaluate new initiatives to develop and further serve the SMS community.

The survey has been organized by John Mayer, board secretary and chair of the membership committee. For further information or any questions about the survey please contact us at info@prisms.org. We look forward to hearing from you.



Are you online? Check out the new 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!

PRISMS Launches Its New Website

Have you seen our “new look?”



PRISMS has launched its new website, and we invite you to take a look at our updated and vibrant new look. The new website has beautiful photos of our SMS persons scattered throughout, adding to the warmth and inviting vibe of the new website. Photographer, Rick Guidotti, of “Positive Exposure”, took many of the photos that appear on the website.

The new website has several new features, including:

- * The PRISMS Store and Awareness items
- * Online membership
- * Spanish translation on certain pages
- * Online donation via PayPal
- * Links to our Facebook page and Twitter account
- * Search capability and print/text-only option

The website also has new and updated content, including:

- * The SMS Toolkit
- * New videos
- * New and updated research publications
- * Updated Superkids
- * New articles written by parents and siblings

Please visit our website at

www.prisms.org.

Colin’s Backyard Olympics

Colin’s Backyard Olympics is a tournament of games fundraiser named after, and in honor of, an adorable six-year old boy named Colin Ulrick. Colin was born with Smith-Magenis Syndrome.

This will be held September 17, 2011 in Island Park, Williamsville, NY.

The Backyard Olympics will consist of a tournament of outdoor lawn games. Every team must complete a series of games, and points will be given and determined by the position in which the team has placed in each game. The teams that acquire the highest points will compete in a

championship game. The top three winners will receive a gold, silver, or bronze medal along with a little gift. In addition to the tournament of games, we will have side events occurring simultaneously. These include face painting and animal balloons for the children, a clown, a caricature artist, 50/50 split club raffle, and individual drawings for other donated items with all proceeds benefiting PRISMS.

For more information, please email jbog7@yahoo.com or call 716-838-9027.



International Conference — Save the Date!!

PRISMS Presents the 7th International Conference on Smith-Magenis Syndrome

When: June 28 – July 1, 2012

Where: Denver Renaissance Hotel, Denver, CO

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

More details will follow in the coming months, including hotel costs, room reservation information, and prospective speakers.

Please visit our website, (www.prisms.org), our Facebook page, and look for upcoming details in the newsletter and in emails from PRISMS.

Conference Wish List:

This is **your** conference and we need **your** support! PRISMS subsidizes most of the conference costs, and keeps the cost of registration fees low by funding the conference. We need your help with fundraising, sponsorship, and financial donations in order to keep those costs down. Please consider becoming a conference sponsor, or seeking conference sponsorships to keep these costs affordable. Every donation counts and supports the mission of the conference. If you would like to help with fundraising and sponsorship, please contact the conference committee at: Conference2012@prisms.org

We need your support in order to present the best and most dynamic conference, and remember to “SAVE THE DATE!”

Walk for PRISMS - Ohio

Come join us in **Springfield, Ohio** on **Friday, September 23, 2011** for the **5th Annual 5K Run/ Walk for PRISMS** at beautiful Buck Creek State Park. Sign in begins at 6pm with the race starting at 7pm. See the PRISMS website (www.prisms.org) for online registration or return the enclosed form.

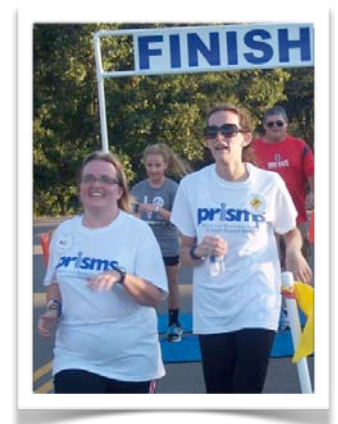
On **Saturday, September 24**, we are inviting families to our home for a cookout. Our house is right across from the high school with plenty of parking, a baseball field, and a large playground. Come for lunch at noon, and stay for games and fun. We will be serving hot dogs, sloppy joes, chips, and drinks. Bring something sweet to share, and backyard games to play.

We have a block of rooms at the Hampton Inn for Friday and Saturday nights. Call the hotel directly at 937-325-8480 to get the PRISMS rate of \$94 plus tax per room. Visit their website at www.springfieldoh.hamptoninn.com for directions. For the more adventurous ones, campsites are available at Buck Creek State Park. Call 1-866-OHIOPARKS for reservations.

We hope to see you in the fall!

Charlie and Tina McGrevy
cmcgrevy@yahoo.com

937-327-9354



Sunny Side Up



Mr. Busybody

By Grandma Pat (Boschetto)

It was the night of Tyler's Christmas choir program. He was looking so good all dressed in his clean white dress shirt, black tie, and black pants. Grandma was so proud.

When I delivered him to the rehearsal, he ran straight up to his teacher and crush-hugged her. She's very receptive to him, which encourages his over-zealous behavior. She was trying to get all the 8th and 9th graders on stage and in place to warm up — like trying to gather up waves on the beach! Tyler "helped" by shadowing her every step.

Then it was time to begin the concert. Tyler, of course, found his place next to the teacher rather than on stage. As she conducted the choir, Tyler waved his arms, but hardly in rhythm. It was apparent the students were following her, not her protégé. Evidently, a more important matter came up, because suddenly Tyler bolted off, running up the aisle, and out the back door of the auditorium. A few minutes later he strolled back down to the front of the room, taking his seat next to Miss G. as poems were being recited on stage. After several minutes, up popped Mr. Busybody. He saw me sitting over on the side of the room, and thought he should borrow my camera to take pictures of the performers. Of course, he went back to the front of the audience to snap the photos. Then back to grandma to return the camera.

It was time for several more songs, so Miss G. and Tyler were again leading the troupe, but Tyler had another call out of the room, so off he went. Back again. As "they" were conducting, Tyler started looking over Miss G's sheet music. She didn't miss a beat as she gently took the pages out of his hand and placed them back onto the stand. Not having the music to look at, he pulled on the banner that was draped across the front of the music stand, moving it "off center." Teacher again made the adjustment without losing her place.

The group Tyler was to perform with was on bleachers down in front of the stage. My boy is quite the social one at times. While they were singing, he decided to give a high-five to a row of five

boys and two girls. Then he made another pass by each one, tousling their hair as he went. Like teacher, none of them missed a beat; at the end of the song they checked each other's hair. All this activity must have been tiring for Tyler, because he made frequent trips back to his seat, but only for a moment, as he had "things to do."

Back up the aisle and out the door one more time, returning a few minutes later to his place next to Miss G. at the conductor's stand. Another trip up to the group for a poke in their bellies. Back to his seat. Up again to turn around and have a look at the audience. Sits back down. Stands up to just look around. Back to that one row of kids on the bleachers; gives each one a kiss on the cheek, then a low-five.

I was almost glad when the concert was over, because my face and belly were aching from laughter. It was the best laugh I've had in a long time.



Tyler Boman, age 13, 8th grade

Note from the Editor

This column 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.

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

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Editor in Chief:

Julia Hetherington editor@prisms.org

Editors:

Randy Beall Ann C.M. Smith, M.S., D.Sc. (hon)

Newsletter Committee Members:

Margaret Miller Tina Thomen
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