prisms
Parents and Researchers Interested
in Smith-Magenis Syndrome

spectrum

VOLUME 15 ISSUE 4 Fall 2011

A Conversation About Behavioral Medications

By Patricia Lowrimore, M.D.

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"If ya just eats yer spinach…"

What About Behavioral Medications?

Tons of patient encounters and all that education behind me and the image of Popeye with his can of spinach still come to mind every time I begin the discussion about medications with the family of a new patient. I suppose my early life exposure to Popeye cartoons has something to do with it. That, plus a quiet wish that it were as simple as eating a can of spinach to solve the complicated behavioral issues we encounter in neuropsychiatry. In my experience, it is far more difficult to get families to consider the use of behavioral medications than to get them to stop using them, or to use them less.

There are several factors I can think of that cause people to resist using medications for behavioral problems, though fear is at the top of the list. Many people fear that medications for behavioral problems imply negativity about their abilities as responsible, caring individuals. They fear that "psychiatric" is essentially the same as homeless or schizophrenic, strung out on drugs, weak, immoral, negligent in some way, worthy of blame, punishment, etc…

We can thank the media in large part for such an unfortunate misunderstanding, and I do include the internet. Despite its great value for propagating information, it often narrows our understanding; it does not always broaden it. But that is a topic for a different conversation.

The good news is that we have people who do a lot of the sorting for us, myself included. I like to think of us as "human macros." Some people prefer "physicians." Either way, if you "click" on us and input your information, we can push it through a series of information filters and hopefully spit out a reasonable answer to the problem you have queried, much like Google, but hopefully more realistic.

Another fear that many people express is that behavioral medications will somehow change the personalities of the people taking them.

Physicians and psychologists are greatly knowledgeable about medications and strategies for managing problem behaviors. Granted, there is plenty of room for variation in skill and approachability. We are just human, after all.

Which medications to use, how much, and to what end is a skill in understanding and grace that cannot be learned from a book. It is called experience. Medications in the right hands do not rob people of their personalities. Neither can they ensure the absence of side effects and adverse reactions.

It is true that the "first go" at a medication trial sometimes results in an unfavorable response, like a rash or sedation. The reality is that making use of medications for behavior, just as for epilepsy, hypertension, or any other medical condition, is a process and not an event; adjustments are almost always necessary. Done skillfully, the results should reflect an improvement in function with personality intact.

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A Message from PRISMS President

Randy Beall

I hope you've had a great summer. We just got home from a trip to Denver, Colorado, home of our youngest daughter, Jenny, and location of the PRISMS conference next June. Colorado is fabulous in the summer, so I hope you are making plans to attend. A few families are doing more than planning to come…they are raising money to make it possible! Read about "Collins Backyard Olympics" and the 5th Annual Buck Creek 5K on the PRISMS website, and please do what you can to support those events. Both events are donating the proceeds to PRISMS.

Interested in helping these families or conducting your own fundraiser? PRISMS can assist you. We've just launched a social media fundraising site called FirstGiving. FirstGiving has helped over 8,000 nonprofits raise over $1 billion. Please check it out at www.firstgiving.com/prisms and consider creating a page today. You can always contact Tina McGrevy, our fundraising chair, at fundraising@prisms.org for help.

Some of the professionals Mary and I have consulted in our quest to help our daughter, Laura, with her behaviors have been very helpful, while others knew so little that we had to educate them instead of the other way around. That's why we are so happy to have found a neuropsychiatrist (Dr. Patricia Lowrimore) who has experience with the type of behaviors that are typical of SMS. It's great to work with someone who " really gets it". In this issue she gives a framework for decisions about using medications.

Living with a person with SMS is never boring. When I arrived home from work yesterday, I found that my industrious nephew had painted our front door. There was even a sign on the door "wet paint" in Laura's unmistakable handwriting. Now, Laura gets very excited when I come home, and usually runs to greet me. A little thing like wet paint couldn't stop that. My best shirt now has green paint front and back. You just have to laugh.

Have you checked out the PRISMS store? Some of them are hilarious…in a SMS kind of way. Be sure to visit the store, and also to enter the contest for a new t-shirt slogan. First prize is awesome!

Warm regards,

Randy

Professional Advisory Board Spotlight
Beth Solomon, SLP

Beth Solomon, SLP, has been a member of the PRISMS Professional Advisory Board since 2001. She is a Speech Language Pathologist and is currently the Chief of the Speech Language Pathology Section of the Rehabilitation Medicine Department at the NIH Clinical Center. Beth is also part of the Clinical Team at the National Institutes of Health researching Smith-Magenis Syndrome, and she has seen many patients worldwide with SMS. Beth brings a very comprehensive and extensive knowledge of not only SMS, but of the natural history study of speech, swallowing, and voice production in various pediatric genetic and metabolic conditions. She was also part of the NIH SMS Research Team that traveled to Australia to participate in the SMS Research Clinics at Camp Breakaway. She was part of the team that partnered with families and other researchers in Australia, collecting vital baseline research data. Ms. Solomon is also one of the contributors to the GeneReview of SMS, which includes the Medical Management Guidelines for Smith-Magenis Syndrome. She has also presented scientific posters and papers on SMS at national and international professional conferences, as well as presenting at several PRISMS conferences.

She is currently involved in a host of research protocols investigating phenotypic expressions of Niemen Pick Disease, Neurofibromatosis Type I, Smith Lemli Opitz Syndrome, Smith-Magenis Syndrome, Neonatal Onset Multisystem Inflammatory Disease and Kennedy's Disease. Ms. Solomon has been recognized as an Infant and Toddler Specialist by the Governor's Office for Children, Youth and Families in the State of Maryland. She has been appointed the Speech Language Pathology Liaison to the Public Health Service and United States Surgeon General's Office for five consecutive terms of office.

We thank Beth Solomon for her continued dedication to her ongoing study of SMS and the challenges that is proposes in regard to early feeding issues and speech delays. Families have truly benefitted from her guidance and expertise in medical and therapeutic interventions in the areas of speech and language.
Publications include:

Solomon, B., McCullah, L., Krasenwich, D., Smith. ACM.: Oral Sensory Motor, Swallowing and Speech Findings in Smith-Magenis Syndrome: A Research Update. American Society of Human Genetic Research 71 (4) Supplement Oct 2002 p. 271.

Zalewski, Christopher K., Solomon, Beth, McCullagh, Linda, Smith, Ann C.M.: Audiologic Phenotype of Smith-Magenis Syndrome, Brewer, Carmen C. ASHA Leader 2003 Vol. 8 p. 77.

The Advocacy Corner

As the parent of a special needs child, you are probably already aware of the importance of an Individual Educational Plan (IEP) and 504 plan. But are you also aware of the benefits of the addition of a Medical Management Plan (MMP), also known as a Health Care Plan?

MMPs and Health Care Plans are additional ways you can secure your child's health and well-being while he or she is at school. Children with special health care needs are often under the care and supervision of a doctor. This might include a pediatrician, psychologist, psychiatrist, gastro-enterologist or other specialist. To be sure the school has the necessary information to address your child's needs, you can work with your child's physician to develop one of these plans.

Your child may have epilepsy, diabetes, asthma, AD/HD, or severe allergies that require medication, health care support, or nursing care at school. A Medical Management Plan can help identify these needs and outline how they will be met in the school setting. If your child doesn't have an IEP, you may still submit an MMP. If they do have an IEP or 504 plan already, the MMP should be attached. Both options can provide your child's team with the important information they need to address their specific health care needs at school.

The school staff may want to contact the specialist directly. Before they do this, you will need to sign a release of information form to consent to this exchange of information. Another option is to have the district staff person put his or her questions in writing, and then you can bring these concerns to the specialist. This way you remain in the communication loop and know first-hand the exchange of information between the two agencies.

You will need to bring all forms to the doctor so she/he can sign an authorization form for your child to receive appropriate care at school. Consider providing a three-day supply of medications and other supplies to be kept in a safe place for use in emergency situations.

Finally, bring the physician's letter, MMP, or Health Care Plan, and any relevant documents to the IEP/504 meeting to share with the team. The MMP or Health Care Plan will provide the school district with the information it needs to provide training and supervision to the staff that cares for your child.

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 under-diagnosed, but as awareness of it increases, the number of people identified grows every year.

Tips to Maximize Your Child's School Progress

By Sylvia Farber
Special Education Advocate and SMS Mom

Being a parent of a child with specials needs and working as an advocate has given me a unique perspective. Unfortunately, many of my clients come to me when they are unhappy with their child's special education services. I would like to offer some tips so that families can avoid reaching this point of despair.

First, it is essential to monitor your child's progress more frequently than at the annual ARD. Schools are required to provide a report of IEP Progress at least as often as report cards are given. Depending on your school, this will be every 6 or 9 weeks. It is imperative that data be reflected on these reports. A parent should be able to read the report and know how close the student is to reaching the objective and/or goal. General comments like "doing great", "I'm so proud of your child", or "student is expected to achieve by annual ARD" are not sufficient as stand-alone comments. These comments are appropriate when supported by data. Following are examples of data driven progress reports.

> **Goal:** Student will answer 2 step word problems involving addition and subtraction with 80% accuracy in 7 of 10 assignments. **Data:** in 5 of 10 assignments student had 80% or higher accuracy; scores were 55%, 40%, 65%, 75%, 85%, 75%, 80%, 85%, 80%, 85%.
>
> **Goal:** Student will comply with directions with no more than 2 incidences of non-compliance per day for 3 consecutive weeks. **Data:** Student is 66% toward goal; week 4 of the 6 weeks there were 2 days with more than 2 incidences; week 5 of the 6 weeks no days had more than 2 incidences; week 6 of the 6 weeks no days had more than 2 incidences; week 6 had 4 days with 1 incidence and 1 day with 0 incidences.

The second aspect I feel is critical to maximizing your child's progress is to become an active participant at the ARD. Prior to each ARD, write a list of questions and/or concerns that you would like to address. It is appropriate to provide this list to the ARD committee prior to the ARD to ensure the school will be prepared to address your questions and/or concerns. I fully realize how intimidating an ARD can be even with the best intentions of a school to put a parent a ease. A written list will help ensure your questions and concerns are addressed. Unintentionally, schools often run an ARD like a assembly line. When a parent is an active member of the ARD, the "I-individual" is put back into the IEP.

Lastly, I feel maintaining good relationships with your child's teacher and other staff members working with your child is vital for your child's progress. As a former special education teacher, I know the countless hours your child's teacher spends planning, teaching, assessing, and completing what seems to be limitless paperwork for your child. Little gifts, words of appreciation, and/or affirmations provide teachers and staff some additional vigor that will spill over positively to your child.

These small steps can make giant strides in maximizing your child's progress. Monitor, participate, and compliment. I hope these pointers have empowered you to become a stronger advocate for your child.

A Father’s Perspective
“The Power That Is”

By David Moertl

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

You know you don’t stand a chance when the negotiating begins. The negotiating power of SMS children, at least the one I know and love best, is at the same time both breathtaking to behold and a big pain in the rear to square off against. It is designed to completely wear down any instance of a parental stance on any random issue and, is frighteningly efficient at doing so. I think there may be a Secret SMS Negotiating Society operating somewhere that instructs young SMS children in the martial-like art of barreling over their parents and installing their will on them in any given situation.

Before negotiations begin, you see the telltale signs in your child and instantly, but futilely, try to suppress your panic: that slight reddening of the cheeks; the light-switch-like change in demeanor from sweet to stuck-in-the SMS-loop where something seems to be smoldering just under the surface in him or her; that almost imperceptible shrinking to the wall, falling back from the moment to the rut-ridden road of obstinacy; body language changing from bright and springy to crumpled and dissatisfied, all signaling the impending storm on the horizon. You cringe at this but gather all your bravery for Custard’s Last Stand (until the next stand, that is) and try to quickly cut off your child at the pass before it is too late. Too late it normally is; perpetually, it seems. Your child has retreated into the dark, dank cave guarded by scary dragons where he or she cannot be reached.

This scenario usually occurs right about the time that you are already five minutes late for a meeting or event that is fifteen minutes away, adding a time pressure to unlocking your child and weakening your bargaining power immensely...masterfully done, son! Tempers fueled by anxiety rise on both sides of the aisle, elevating the moment to time bomb status and threatening the yard with wood, metal, and glass shards from the impending housing blowout that is sure to happen. But you take a deep breath, and armed with being well-versed in this scenario, you try to move your child along through distraction, or plea, or command, or humor, or threat of abandonment...to no avail, of course. Your child digs spur-like heals into the ground, rendering an immovable object whose psyche could fly further south at any moment, if you are not careful, creating a disaster. Staring into the brooding, foreign-yet-familiar eyes of your child in the standoff, you feel like you are trying to disarm volatile, alarm clock-strapped sticks of dynamite tucked in the ceiling of a fuel depot.

Sweating, you carefully reach for any bargaining chip that will work for you, careful not to bump the wrong wire: “No ice cream if you act this way”;“I will take away your DS if you don’t get in the car/get to your room/get ready for bed, etc”; “What happened to my beautiful son, where did he go?”; “Well, now, you are acting silly. C’mon, I need my ten year old back,”; and on and on. Nothing works.

Soon you are forced into negotiation; soon you will lose said negotiation. The negotiation terms are your child’s terms, not yours. They could be over wearing shorts in forty degree weather or a parka and hat in summer. They could be over bringing along some ridiculous item for no other reason than it was in your child’s field of vision, or not bringing along a key item like a change of clothes (which usually are hidden and brought, anyway). They could be about a parade of items all at once, each taking the place of the former in a machine gun-rapid fire-grand stall-act. Frustration mounts, frustrating the frustration from the last frustrating negotiation stand-off, multiplying your current frustration exponentially.

So what do you do? If you are like me, compromise (aka: lose.) The shorts can be worn in the car but pants will need to be put on before the event (may or may not happen). You can wear the silly parka and hat. What do I care if you are smoking hot (and look absolutely ridiculous to our neighbors, friends, family, and coworkers....fret). You can bring your friend the giant lamp so you are not lonely on the ride. (What? Errr.) I am not going to bring a change of clothes for you even if you have an accident (I really need to learn to keep a change in the trunk!) Yes, you can. Yes, you can. Yes, you can on the items in your parade (Let's go, we are now a half an hour late.).

Just like that, you have been worn down, polished to perfection by your SMS child in the blink of an eye. And this happens at all times, not just when you are trying to leave or to go somewhere. You negotiate at dinner, negotiate at bed time, negotiate where to walk outside or how, negotiate which shoes to wear, negotiate how to play a game; really, you negotiate for EVERYTHING as SMS children need things to be on their own terms at all times, it seems. That need becomes obsessive many times, further strangulating the ability for reason to emerge in the matter by anyone. Sometimes the negotiating is so outrageous, that it becomes quite funny in a Monte Python way - just plain silly.

So, just what are the alternatives to all this compromising/losing to get things done? Are there any alternatives? I honestly do not believe there are any if you want any semblance of normal life. Like a man worn down by facing middle age, I have finally accepted this ever-present, subservient compromise as life. And I am happy and content for this; really, I am. I just wish I could get my hands on that darn Secret SMS Negotiating Society....

-Mertz-

Research Survey Regarding Eating Behaviors

You are invited to participate in a survey evaluating the eating behaviors and other behavioral concerns of children with Smith-Magenis Syndrome. Parents of children age 18 months to 18 years of age are eligible to participate.

The following surveys are available on the internet, based on the age of your child with Smith- Magenis Syndrome:

For parents of children older than 18 months and younger than 6 years old: http://www.surveymonkey.com/s/SMS18m_5

For parents of children between 6 years old and younger than 19 years old: http://www.surveymonkey.com/s/SMS6_18

By choosing to participate in this survey, you will help researchers to better understand the eating behaviors unique to Smith-Magenis Syndrome. This research can help develop targeted treatments and/or therapies for children with Smith-Magenis Syndrome in the future. Participants can register to be eligible for one of two $50 gift cards to www.amazon.com.
For additional information on this survey, or to request a copy of the survey to be mailed to you to complete by hand, please contact **Dr. Sarah Elsea** at selsea@vcu.edu , or contact genetic counseling graduate student, Laura Meyer, at meyerlv@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.

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!

Slogan Contest!

SMS Awareness Day is November 17, 2011! Submit your slogan in the PRISMS SMS Awareness Day contest, and your idea could be on the merchandise (t-shirts, mugs, bags, etc.) sold in the PRISMS store.

First place winner will receive one free night at the beautiful Denver Renaissance Hotel during the 7th Prisms International conference next summer AND a $50 credit to the PRISMS store.

Runner's up will also win credit to the PRISMS store:

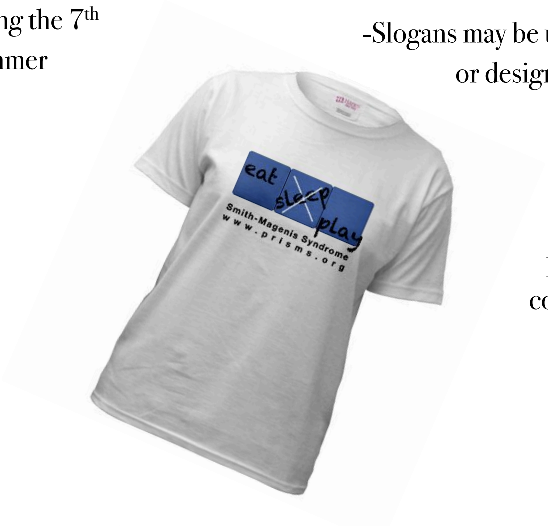
1st runner-up $50

2nd runner-up $25

3rd runner-up $25

The rules:

- Include your name, address and phone number with the entry (if under 18, include parent's name and address).



- Submit as many slogans as you would like.

- Deadline for submissions is September 17, 2011

- Submit your slogan(s) by email to fundraising@prisms.org, or message PRISMS Facebook account.

-Slogans may be used in conjunction with PRISMS logos or designs.

-All entries/submissions may be used by PRISMS for future SMS awareness (presentations, merchandise, website, publications, etc.) without compensation to the entrant.

Cooking with the SMS Family

Calling all cooks and their helpers! We would like to put together a cookbook of favorite recipes including helpful hints on how to get a meal on the table with our Smith-Magenis darlings underfoot. We would like to include favorite pictures of your child, preferably helping you to cook or eating their favorite foods. Any comical anecdotes would also be appreciated. For example: Christy loves French onion dip with her pepperoni. Some of you may also have special diets or unique recipes you would like to include. Once we set this up, we will send out an e-blast telling you how to submit your recipes on-line. Each contributor can submit as many as three recipes in seven different categories.

Our goal is to have the cookbook ready by conference time. Preorders will be sold at a discount. Recipes or hints can be submitted by email or snail mail. Simply send them to me, and I will make sure they are included.

So don your chef's cap, break out Aunt Bell's famous cheesecake recipe, and let's see if we can create the world's most interesting cookbook.
Watch for our e-blast with instructions on how to submit recipes on-line
You may also mail them to me at:

Mary Kate McCauley
24 E. Golfview Rd.
Ardmore, Pa. 19003

Continued from page 1

In a perfect world, there are relatively simple guidelines for defining the role of medications for the management of behavior. If a person is dangerous to themselves or to others, and the behavioral disturbance is not linked to an underlying medical emergency, then a trial of behavioral medications may make sense after a trial of talk therapy.

If a person does not have language or has limited psychological mindedness, what then?

What if it is a medical condition like a developmental disability that underlies the behavioral disturbance, but is not itself an emergency?

How about when a person's tantrums and intrusive behaviors become so unmanageable that the caregivers are ready to blow, and the family is starting to fall apart?

You can see that it gets complicated pretty fast once the obvious issues have been addressed. Are all problem circumstances potentially appropriate for the use of behavioral medications? Of course not, but behavioral medications should not be automatically ruled out either.

If there is a truth implied by the Popeye/spinach metaphor, it is that sometimes it is necessary and right to take the "outside in" approach. Popeye pops the top of a can and pours thirty-six tons of spinach down his throat when he's in trouble. Here, we consider the possibility of using medication to help shape a person's behavior. Not exactly the same thing, but you get the picture.

The use of medication to shape behavior is a concept that is greatly debated. Clearly, medication alone is almost never the solution. However, there are certain circumstances under which medications can make all the difference in terms of the qualities of life that we want for the people we know and care about, and for ourselves.

Yes, I did say for ourselves. If you are questioning whether or not you as a caregiver have any right to contemplate using medication to stabilize the behavior of your child or family member in the interest of the rest of your family, you do. It is difficult to balance the needs of one individual with those of all the others in a given family. I think it is fair to say that most families I have encountered have done and will do just about anything for the sake of their impaired child, except use behavioral medications, of course.

Some argue that it is not right to subject a person who cannot make decisions on their own to the potential side effects of medications just for the comfort of others. Absolutely correct. But what about the impaired family member? We sometimes forget that even people with cognitive impairment have awareness of the level of stress and strain in their surroundings, and this is often reflected in the form of behavioral upset.

If a person is crying or screaming a good bit of the time, or generally unhappy and uncomfortable, it probably warrants a good medical "looking over" to rule out fever, pain, digestion problems, and so on. If no obvious physical explanation for their distress is found, then perhaps an evaluation for depression or anxiety makes sense.

Aggression and self injury are obvious circumstances under which behavioral medications may be necessary. Sometimes they may be necessary even before a medical work-up for physiologic illness can be undertaken.

Some argue that it is every person's right to have access to all forms of medical treatment, including those in the behavioral domain. If access could ensure a good outcome, there would be no point in writing this narrative. But in general, I have to agree with this. It is often difficult, if not impossible, to proceed with behavioral therapies until the extremes of behavior and upset are stabilized. Medications are often invaluable for this kind of thing, but both undoubtedly work best when used together.

Comfort, safety, function- -these are all reasons for wearing eye glasses, using wheelchairs, and taking blood pressure medications. They improve the qualities of our lives. Behavioral medications can be just as necessary and helpful. Be open, not afraid.
And eats yer spinach. It's good for you.

SMS SuperKid!

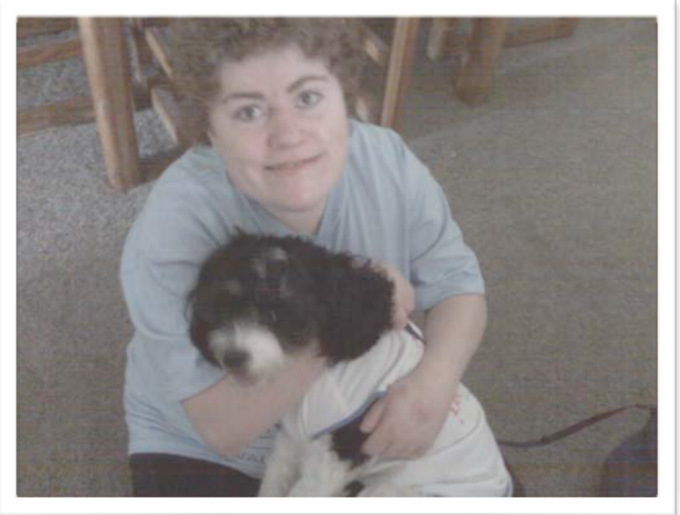
Christy

Christy McCauley is the fourth of five children of Mary Kate and Joe McCauley of Ardmore, Pa. She has been at Bancroft Neuro Health in New Jersey since she was 16. She calls it her handicapped college. Her sisters were all going off to college at the time she joined Bancroft. She seemed to understand that this would help her with her skills and future employment. After finishing school, she entered their vocational program. She has various duties, including mail sorting, working the copier, and delivering Meals on Wheels. Her latest job has been learning to prepare and bake dog treats that are sold within the community.

Recently, she was featured in a photo and bio display on a golf cart at a Bancroft Golf Fundraiser. She was very excited. She got to greet the golfers, and her picture was displayed on the golf cart for Team five. Christy is very social, and this suited her to a TEE. Bancroft's flyer is shown below.

Bancroft
One world. For everyone.

Captain Team #5:
Christine McCauley



Christine is a vibrant young woman who lives in Marlton and has a job preparing, baking, packaging and selling homemade dog biscuits. She came to Bancroft when she was 16 years old. She is absolutely among the funniest and smartest people one could ever meet. She is a social butterfly who enjoys spending time with family and friends doing anything and everything. She loves the shore, bowling in Special Olympics, talking on the phone, dancing and listening to music, and of course shopping.

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.

JOHNNY'S RAINBOW FOUNDATION

Johnny's Rainbow Foundation was founded by Lisa and John Bellopede in honor of their son, Johnny, who died in his sleep in 2006, at the age of nine. Johnny had Smith-Magenis Syndrome and Autism.

It is the foundation's mission to help families with special needs children by providing them with financial support called a Rainbow Grant. The Rainbow Grant is intended to make a significant difference in the life of the special needs child by funding equipment, experiences, parent education, family counseling, therapy, or any other of the child's needs. "JRF" has also been a generous supporter of PRISMS and research of SMS.

Johnny's Rainbow Foundation also assists special needs children through Johnny's Scholarship Fund, which provides special educational grants to parents of Delco Family P.A.S.S. (a Delaware County Autism Support Group serving over 250 families), as well as to the research of Smith-Magenis Syndrome. Johnny's Rainbow Foundation would especially like to reach out to Pennsylvania families who have a child with Smith-Magenis Syndrome. If you have a need that might be supported by the mission and generosity of "JRF", please visit their website at:
www.johnnysrainbowfoundation.org

Building Bridges of Hope
prisms 7TH INTERNATIONAL CONFERENCE | DENVER 2012

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

When: June 28 – July 1, 2012
Where: Denver Renaissance Hotel, Denver, CO

Fundraising Help Needed

The 7th International PRISMS Conference, "Building Bridges of Hope," is less than a year away. Planning is underway, but we need your help with fundraising to help defray conference registration fees. To keep costs affordable for our families, PRISMS subsidizes much of the conference costs. So, in order to keep your cost down, we need help with fundraising. Our planning committee and conference helpers are all volunteers and parents of an SMS child, so we need everyone to share the load and assist in various ways.

There are many ways to hosts a fundraiser or to help organize fundraising events. We also need help with obtaining sponsors for the conference. This is your conference, so please consider helping with a fundraiser in order to keep your costs affordable! If you would like to volunteer or host an event, please contact the fundraising chair: fundraising@prisms.org.

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!

Parents and Researchers Interested in Smith-Magenis Syndrome

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