

# SPECTRUM

## Teaching SMS Children in the Residential Setting

A Teacher's Perspective

By Jane Burnett



*Ms. Burnett teaches middle and high school age children in a residential setting.*

“What can I do?” “How can I help?” What is the key I need to open the door to a positive future for this child?” These, and questions like them, are asked by special education teachers in the residential setting every day, as they struggle to provide what each child in their class requires to succeed in life. Special concerns come with children who have Smith-Magenis Syndrome (SMS); unrelenting craving for adult attention, aggressive behavior, and self-injurious behaviors appear to heighten the need for highly individualized treatment. I have found that while individualized treatment is a necessity for all special needs children there are some methods that can be used in a broader manner that have proven successful, at least in my small corner of the world, with children who have SMS and are members of a classroom of special needs students who do not suffer from their particular disability, yet have needs that require a residential setting.

First, allow me to introduce myself. I am a special education teacher who specializes in instructing students who have a dual diagnosis, and are placed outside of their home. My students have both behavioral issues, either as the result of severe abuse or from an organic basis, as well as various levels of mental retardation. In general my students

have IQs in the 40-65 range. I also had two students with SMS who had these issues as well. Students with both behavioral problems and mental retardation present unique issues when trying to maintain order in the classroom. During my years of teaching this group of students I have come across certain instructional methods that have proven to be successful in maintaining order in the classroom and adjusting the behavior of the students in the class. While a calm classroom is a blessing, actually imparting a change in behavior in a student is exciting and what we special education teachers live to see happen in our students. Allow me to share what has worked for my students and perhaps you will find a little nugget that will be golden for your situation.

The first and most important action any teacher or care giver can pursue with students with SMS is ***CONSISTENCY***. This may seem like a simple enough idea, but implementation in a special education classroom is not as easy as one might think. There is a constant demand for the teacher's attention. The demand goes from needing help with class work, to wanting to go to the bathroom, to wanting to know what is for lunch, to complaining that “Someone is looking at me!” and so on and so on. It never

*Continued on page 6*

INSIDE THIS ISSUE:

President's message	2
Differences in SMS	3
Speech Therapy Ideas	4
Picnic information	10
SMS SuperKid	13
“Funraising”	14

*What Is Smith-Magenis Syndrome?*

*Smith-Magenis syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann CM Smith, MA, a genetic counselor, and Ellen Magenis, MD, a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 25,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.*



PRISMS, Inc.  
21800 Town Center Plaza  
Suite #266A-633  
Sterling, VA 20164  
1-972-231-0035  
E-mail: [info@prisms.org](mailto:info@prisms.org)  
Website: <http://www.prisms.org>

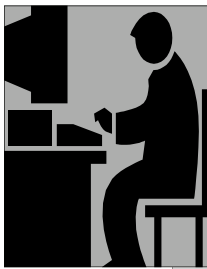
## Who's Who in

### Officers

President:	<b>Randy Beall</b> Richardson, TX
Vice-President:	<b>Margaret Miller</b> Herndon, VA
Secretary:	<b>Lindsay Warman</b> Loveland, OH
Treasurer:	<b>Jeri Gawlowski</b> South Lyon, MI
Board Members :	
	<b>Percy Huston</b> Cape Girardeau, MO
	<b>Charlene Liao</b> Palo Alto, CA
	<b>Ann Smith</b> Bethesda, MD

### Professional Advisory Board

Sarah Elsea, Ph.D.	Virginia Commonwealth University
Brenda Finucane, M.S.	Elwyn Training & Research Institute
Barbara Haas-Givler, M.Ed., BCBA	Elwyn Training & Research Institute
Andrea Gropman, M.D.	Children's National Medical Center
Kyle P. Johnson, M.D.	Oregon Health & Science University
James Lupski, M.D., Ph.D	Baylor College of Medicine
R. Ellen Magenis, M.D.	Oregon Health & Sciences University
Lorraine Potocki, M.D.	Baylor College of Medicine
Ann C.M. Smith, M.A., D.Sc. (hon), Chair	NIH, National Human Genome Research Institute
Beth Solomon, M.S.	W.G. Magnuson Clinical Ctr. National Institutes of Health (NIH)



## A Message from PRISMS President...

Randy Beall



I'm writing this column from my living room, and there are enticing scents coming from the kitchen. My daughter, Laura (SMS, 22) has been baking cookies...all right! I love the holidays!

By the time you receive this the holidays will be over. I hope your holidays were happy and not too exhausting. I also hope you received your Holiday card from us. Our children on the front are so cute! BTW, the holiday picture was taken at a 5K Ohio fundraiser for PRISMS, organized by Charlie and Tina McGrevy.

Joe Zdanowski has resigned from the PRISMS board. Joe was had a hand in a number of PRISMS activities – our member database, website, email communications and discussion list. Joe made a huge contribution to our group in so many ways. He will be missed.

I would like to welcome Lindsay Warman as the newest PRISMS board member. Lindsay lives in a Cincinnati, OH suburb. Her brother, Christopher, has SMS.

I recently read an article about how “efficient” some nonprofits were and I thought I'd brag about us! (Plus folks in Texas like to brag!) Because we are an all-volunteer organization, we are able to spend 90% of our money on our “mission” (to provide information and support to caregivers and families of children with SMS). Many of you may not know that we have an outside auditor review our records every year. I'm pleased to say that we receive “clean” audits every year (no easy task). We also file an IRS form 990 every year and produce Annual Reports which we post to the website. We strive to be a “transparent” organization and make the most of every dollar raised. Many thanks to Jeri Gawlowski, our Treasurer, for the great job she does.

Last but not least it's time to renew your PRISMS membership. These dues are really just a small contribution that helps us provide programs for our members. Please send us your form soon . and maybe send me some cookies?! Laura just announced that the ones she made are for her friends and I'm not getting any...oh well, maybe I can sneak one...\*



# Genetic, Clinical, and Gender Differences in SMS



By Emily Edelman, MS, CGC

This project focused on the medical, behavioral, genetic, and gender differences in 105 SMS subjects. The study was initiated by Emily Edelman in Dr. Elsea's group and published in *Clinical Genetics* 71(6):540-50 (2007) as a collaborative effort between the following authors: Emily Edelman, Santhosh Girirajan, Brenda Finucane, Dr. Pragna Patel, Dr. James R. Lupski, Ann C. M. Smith, and Dr. Sarah Elsea.

We collected clinical and genetic information on subjects enrolled in research at Virginia Commonwealth University and Michigan State University from medical records, parent surveys, educational evaluations, and laboratory reports. We also referenced cases from the medical literature since there are many published reports about individuals with SMS. We collected information about participants' medical and developmental history, behaviors, sleep patterns, appetite and eating habits, and physical characteristics. For each of the 105 participants, we noted the genetic cause of SMS, including 17p11.2 deletions of different sizes or *RAI1* mutations.

Common features in our study population include developmental delay (100%), stereotypical and self-injurious behavior (90%), sleep disturbance (88%), eye abnormalities (87%), hoarse voice (86%), oral/motor dysfunction (85%), hyperactivity (74%), short stature (67%),

hearing loss (60%), and dental anomalies (54%). This population included 44 males and 61 females.

We compared the clinical features between those with *RAI1* mutations and participants with 17p11.2 deletions. Some features were seen more often in individuals with *RAI1* mutations, including muscle cramping, dry skin, some self-injurious behaviors, obesity, and over-eating issues. Other features were seen more often in persons with 17p11.2 deletions, including short stature, hearing loss, heart birth defects, and frequent ear infections.

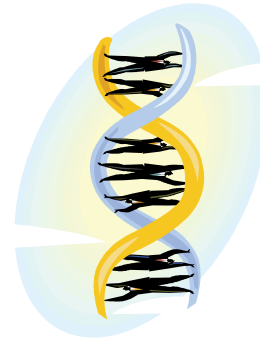
We also compared individuals with different sized 17p11.2 deletions. Some cases had a very small chromosome deletion of this region and other participants had a larger deletion. Most individuals with SMS have an average-size or "common" deletion. The larger the deletion, the more chromosome material is missing. Depending on the size of deletion, individuals may be more or less likely to have certain features, including seizures, oral/motor dysfunction (for example, swallowing and breathing complications), dental anomalies, and challenging behaviors. Some of these differences are likely due to the fact that participants with larger deletions have more genetic material deleted and therefore, may have more health complications and more sig-

nificant delays.

Individuals with small deletions have features similar to those with *RAI1* mutations, while those with common or larger deletions have more significant delays and medical problems. *RAI1* cases exhibit more severe behavioral problems and have less severe developmental delays. Larger deletion (larger than common) cases have more significant motor and cognitive delays and often have fewer behavioral problems likely associated with decreased motor skills.

Finally, we looked at the clinical features seen in males and females. We found that females were more likely to have eating/appetite problems, difficulty finding shoes that fit, cold hands and feet, and frustration with communication and were more likely to wear glasses. These gender differences may represent a discrepancy in referrals and perceptions based on a child's sex. Children with SMS often have sensory aversion, and it is possible that females have more sensory integration issues. It is also possible that these reported behavior differences actually reflect a bias in parental or health provider perceptions toward boys and girls, rather than a biological basis for gender differences.

Additional studies will be required to understand more fully any significant



Continued on page 13....



# Speech Therapy Ideas For Children With SMS

By Christine Brennan, MA. CCC-SLP/L

School-based speech therapy services can address multiple speech, language and communication needs in children with SMS. School-based speech therapy can address communication issues that impact educational progress and overall functionality. It is important that parents, speech pathologists, and educational teams work together to identify clearly defined communication goals that are measurable, achievable, and can be incorporated into daily school routines. Also, as the needs of children with SMS can vary, awareness and use of multiple strategies can lead to improved development of communication abilities.

Four important issues related to addressing communication needs of school-age children with SMS are (1) writing measurable goals, (2) incorporating sign language into daily routines, (3) using alternative and augmentative communication (AAC), and (4) addressing communication needs of adolescents with SMS.

IEP goals selected for speech/communication should target abilities that will have the greatest impact on social, academic, and functional success. While it may seem critical to address every need and deficit, it is unfortunately not practical nor efficient. Children with multiple needs in communication make optimal progress when only a few goals/objectives are addressed at a time. It is better to have 2-3 goals with 1-3

benchmarks or short-term objectives per goal. Having too many goals and objectives can result in diluted therapy and limited overall progress.

Long-term goals, such as improving receptive language abilities for academic and social activities, target broader aspects of communication. Short-term objectives are highly specific and measurable. An example of a well written objective for receptive language is: Child will follow novel 2-step directions during group activities given visual picture cues and up to one reminder with 80% accuracy.

***It is important that parents, speech pathologists, and educational teams work together to identify clearly defined communication goals that are measurable, achievable, and can be incorporated into daily school routines.***

Well written objectives will state the exact communication behavior being targeted (“increase accuracy for following directions”), state the setting or activity (“during group activities”), state supports if needed (“given visual pictures cues and up to one reminder”), and state the target accuracy (“80%”). An objective that includes these parameters will tell anyone reviewing the IEP, assessing progress, or implementing intervention, what the child is expected to do. Accuracy a well written goal/objective can be measured and reported on regularly.

Selecting objectives should be based

on the child’s needs regarding functionality and past progress. While articulation may be a need, for example, a child who can be understood but can not answer questions may benefit more from working on expressive language, than on articulation. Functional objectives can be formulated by identifying the aspects of communication that have the greatest impact on behavior, frustration, learning, and socialization at school, at home, and in the community.

One important goal for children with SMS is to increase success of receptive and expressive language. For many children with delayed but emerging language skills, use of sign language can enhance both expressive skills and receptive comprehension.

Receptively, use of sign can serve as visual cues that supplement verbal communication. Anytime multiple modalities are employed, the likelihood that messages will be understood increases. Typical children as young as one year of age can begin to discriminate sign when paired with verbal communication. Use of sign to support comprehension can also be used with children with SMS from infancy.

Expressively, young children with SMS who also have deficits in speech production/articulation may experience frustration when they are unable to make themselves understood. Teaching and reinforcing the use of verbal speech in addition to sign language can give these children multiple ways to

.....Continued on page 5

communicate with others. One limitation of sign is that there may be people the child encounters who are unfamiliar with sign and can not benefit from the child's use of that communication tool; however, there is no danger when using sign paired with verbal communication that this will prevent a child from learning to talk. Use of sign can only enhance communication and language development and will not cause a child to become non-verbal or reduce his/her verbal communication. Use of sign and/or AAC will result in improved communication, reduced frustration, increased vocabulary, better language skills and improved behavior.

When verbal communication and sign is still insufficient, an alternative/augmentative communication (AAC) system may be considered. Use of AAC at home and at school can include low or high-tech systems. AAC systems can vary in size, complexity, and cost. Low-tech systems are cheaper and more durable. High-tech systems are more expensive and generally, more prone to damage. Low-tech systems include sign, pictures, communication books, and Picture Exchange Communication. High tech systems include devices with recorded or synthesized voice output that generally hold more vocabulary. The more messages in a system, the more the user must understand how to use the device and remember the locations of the various messages. Some devices have computer-based software with dynamic LCD displays, while others have buttons that can play recorded messages.

Some companies that make and sell devices include: Dynavox ([dynavoxtech.com](http://dynavoxtech.com)), Prentke Romich Company ([prentrom.com](http://prentrom.com)), Enabling Devices ([enablingdevices.com/](http://enablingdevices.com/)

[catalog](http://catalog)), Ablenet ([ablenetinc.com](http://ablenetinc.com)), Adaptation ([adaptation.com](http://adaptation.com)), Adamlab ([adamlab.com](http://adamlab.com)) AMDI ([amdi.net](http://amdi.net)), Attainment ([attainmentcompany.com](http://attainmentcompany.com)), Great Talking Box ([greattalkingbox.com](http://greattalkingbox.com)), Words ± ([words-plus.com](http://words-plus.com)), and ZYGO ([zygo-usa.com](http://zygo-usa.com)).

Selection of an appropriate communication system requires an evaluation of communication abilities and needs to include (1) what a child wants and needs to communicate, (2) how many messages a child can generate, (3) accuracy for identification within given fields of various sizes, (4) visual processing abilities, (5) visual memory, and (5) level of independence. The process of evaluating and selecting an appropriate AAC system can and should take several months and will mostly likely be continuously re-evaluated and updated, especially as the child's communication needs change over time.



As the school-age child begins to reach adolescence demands and expectations will begin to shift from basic functional communication and focus more on increasing independent living skills, leisure skills, and vocational skills. Communication goals may include comprehension of directions for job-based activities and daily living tasks, communication with peers and less familiar adults (such as people encountered in work places), and appropriate and safe communication within the community. Communication skills for adolescents should help develop and sustain peer relationships and friendships. Communication skills including negotiation skills, initiation

of appropriate communicative exchanges, self-monitoring during social encounters, predicting outcomes, and decision-making should also be addressed. Adolescents with SMS seek control and independence and are often motivated to earn opportunities to demonstrate their skills. Rewarding these interests with opportunities to practice and use appropriate communication strategies during vocational tasks may be an effective way to channel these interests; instead of trying to engage the adolescent in more controlled structured and adult-directed activities.

While intervention planning is important, it is also important to remember that the best or worst written goals are unimportant when compared to the quality of educational and therapeutic intervention. When school teams (parents, therapists and educators) work together, listen, and collaborate, so our children will be in the best position to learn and make progress. While team members may disagree on aspects of a program or IEP, there is always a way to merge ideas and incorporate various concepts into one child's educational program. To optimize the educational process, focus on overall goals and objectives and work to incorporate the targeted behaviors into the daily routine. Practice, reinforcement, and redundancy will result in the greatest changes. Persistence and cooperation will ease and expedite the process. ✨

Christine Brennan, M.A. CCC-SLP/L is a speech-language pathologist working in Skokie, IL. Christine has over 18 years experience working with children and adults with developmental disabilities in public schools, private practice, and special recreation programs. She lectures at Northern Illinois University as well as at national and state speech pathology conventions. Comments & questions can be sent to [christine@brennanandburns.com](mailto:christine@brennanandburns.com)

stops, but it can be dealt with in a positive manner. All responses must be the same whenever possible. There will always be those rare times when stepping away from the normal course is appropriate, but those times should be very rare. Consistency provides the student with a sense of control. They know what to expect; no one is getting special treatment and thus the demand for attention becomes less. The demand does not go away, but if an SMS child perceives that someone else is getting special attention they will immediately want it for themselves. Since “perception is reality” it is important to significantly limit any actions which would inherently cause them to demand even more attention.

The second method with which I have found a great deal of success is in making sure that all authority in the classroom comes from and through the teacher. This is not an ego trip for the teacher, but a necessary form of continuing the vital link of consistency in the classroom. In my residential classroom environment there is the teacher (me) and 1-2 direct care professionals (DCPs) or classroom behavior assistants whose responsibility is to follow and enforce the behavior program for each child in the classroom. The problem evolves when the DCPs are not the same everyday. While that would be the optimum plan, it is clearly unavailable in a residential program in which the students/clients have DCPs monitoring them 24/7. This means that I can have several different DCPs in my classroom during the week and often during just one day. The main problem with this scenario is that each person is an individual and has their own

way of dealing with disruptions in the classroom. Some come down hard, immediately, some try to be the student’s friend and make deals with the students to evoke good behavior, and some just try to make it through the day. They are all doing the best they can and I admire their efforts for working at a very difficult job. However, it is exactly these differences that make it so very important that the authority in the classroom flows through the teacher. If the teacher is not the ultimate authority

*...the inherent feeling of safety, as well as the accompanying reductions in distractions the students are able to more fully focus their attention on the work at hand.....*

in the classroom the students will negotiate with the DCPs to get what they want, and are often very good at this.

I have a saying when explaining to adults how my classroom is run: “No one has the freedom to do anything in my classroom but breathe, without my permission.” That may seem harsh, but it really isn’t. Students must raise their hands and ask permission to speak, or leave their chair, or get a piece a paper, or get crayons, or get coloring paper, unless it is part of the lesson. I do this because it is my firm belief that due to this level of control, through me – the teacher, the students enjoy a feeling of safety that is hard to come by in a residential program populated with children suffering behavioral disorders. The students in my classroom do not need to worry about another student harming them while they are doing their class work as no student is allowed to move from their seat without my permission and even when they do it is one student at a time that is allowed to move and when they do at least two sets of eyes are on them at all times. As a result of the inherent feeling of safety, as well as the accompanying reductions in distractions the students are able to

more fully focus their attention on the work at hand and less on what is going on around them. This method also allows the teacher to give individual attention to the students who need it and the SMS students do not feel slighted.

The method of dealing with students learning the classroom procedures as described above must also be consistent. As an example, if a student leaves their desk without permission I immediately ask them; “Do you have permission to leave your desk?” and instruct them to return to their desk and ask permission to get out of their chair. Generally the student starts to explain why they are away from their desk. I immediately repeat the question just asked, without the addition of the instruction to return to their seat and will continue to ask the question every time they attempt to explain why they are up without permission. This clearly demonstrates to the student that they must adhere to the classroom procedures. It will not take long before that student will either follow the classroom procedures on their own or self-correct by starting to get up and then stopping themselves and raising their hands. If this method is generally followed concerning all classroom procedures the students quickly adjust and the classroom becomes calmer and the students more focused. This method, at first, does take a lot of effort and constant monitoring on the part of the teacher, but the outcome is clearly worth the effort.

As a balance to the students being made to follow classroom



Continued on page 7

procedures so closely is to have a highly reinforcing classroom atmosphere. It is vital that the students are highly rewarded for “getting it right”. Make it as rich as you can. I use a variety of reinforcement programs. It is important that they are of varying lengths of attainment. One program combines an immediate reinforcement with a long term goal. We call it “The Race To Success”. It works like this:

There is a racetrack on one of the bulletin boards in the classroom. Each student gets to select the picture of the race car of their

choice. Their name is put on it and it is stapled onto the track. Their race car will move forward one space every time they earned 10 race points. The first three students whose car crosses the finish line first will be treated to a lunch from any local fast food restaurant of their choice. The race takes about 3 months to complete – this is the long term goal. The awarding of race points comes immediately after the completion of a class. Each student earns one race point for every class in which they are in attendance for the entire class and are participating fully in the lesson – this is the immediate reinforcement goal. High grades are not the goal here, attendance and participation is.

Another program is known as “Earning the Blue Star”

There is a “Class Stars” board. For each full school day in which they have no behavioral problems they earn a star. There are five stars they need to earn and each has a color assigned to it. Star 1 = red; Star 2 = orange; Star 3 = green; Star 4 = yellow and Star 5 = blue. It is not necessary that the stars be earned con-

secutively. If a student has a bad day they do not lose the star they have earned previously, they just do not get one for today. When the student earns the blue Star 5 they get to choose a snack from a bag I keep in my filing cabinet. The treats might be a small bag of chips, a bag of animal crackers, maybe a lollipop or whatever small edible item that they like. This is a reinforcement program that is immediate in that the student earns a star in one day, but also is a middle length goal in that it takes at least 5 days to reach the goal of the program. In this program we are emphasizing good behavior which means this goal is very much in the control of the student. It is very popular with my class.

The third program involves help from the community; specifically Pizza Hut. The final program includes a wonderful program which encourages reading that is offered by Pizza Hut and I strongly endorse it. The program is called “Book It”. Each student has the opportunity to earn a personal pan pizza of their choice (cheese, pepperoni or cheese) once a month. The method used to

determine what reading goal must be met to earn the pizza is left entirely to the classroom teacher. Once the monthly goal is met the student earns a coupon which can be exchanged at Pizza Hut restaurants for one personal pan pizza. In my reading class we count how many school days there are in the month. The class, carefully guided by the teacher, discusses how many days a student must be in reading class AND participating to earn the pizza. We usually end up at a number that allows a student 2-3 off task days. If a month has 22 school days, then the student must attend 100% of the reading

class and participate for 19 days in order to earn the pizza. This is a medium length long term goal that focuses on both behavior and academics. It is also extremely popular with the students.

It should be noted that failure to meet the goals for the above reinforcement goals can and should be very expensive to the unresponsive student. The point is to make reaching the goals a real achievement for the student who is responding to desired changes in their behaviors and academic work, while choosing to not follow the rules and procedures of the classroom, both academically and behaviorally, very expensive. Most students, and in particular SMS students do not want to be “left out” and will, in time, adjust their behavior so that they also can earn everything there is to earn.

A few final points, I am a strong believer in non-verbal signals that project that the teacher is an authority figure and not a buddy. I strongly recommend that teachers always dress professionally, not use the latest slang, and insist upon being addressed by an appropriate title. We need to express our authority in many ways.

The residential setting has many different factors that effect how my program works. All of this may not be appropriate for your setting or individual student, yet, I hope that you have found a golden nugget that will work for your student and/or your classroom\*



See  
**A Parent’s Perspective**  
Continued on page 8.....

...continued from page 7

### A Parent's Perspective

My daughter was in 4 different schools in her 6 years of elementary school, and many different classrooms. Things would get tough, behaviorally, and she would be transferred to a new school, new class, or new team. My daughter is very wise, and can outlast, outsmart, and outwit the best! Until she met Ms. Burnett!

I had tears in my eyes the first time I observed my daughter through the one-way glass...being truly **taught**. My daughter and all the other "very difficult" children were sitting calmly in their seats, raising their hands, and excitedly answering questions about the Antarctic explorer Sir Edmund Hillary. They were looking at the globe, discussing snow, and adventure. I was amazed!

Ms. Burnett's methods may sound harsh as you read them in the written

form. Yet, they aren't. I saw an organized, learning environment. The use of "authority flows through me" really worked for this classroom. And for my daughter! I have seen her totally control situations to her advantage through her interactions with her behavioral assistant. In her current setting, the assistant is there to help with behavior, as directed by the teacher. The teacher is calm, and confident. The students look to one source for direction.

I truly believe that our SMS children are some of the hardest to move to their educational potential....because of difficult behaviors. There are many approaches to educating SMS children, this being one that worked for my child.\*

Julia Hetherington  
Mother of Rachel, 13, SMS

# Save the Date

**PRISMS Sixth International Conference**

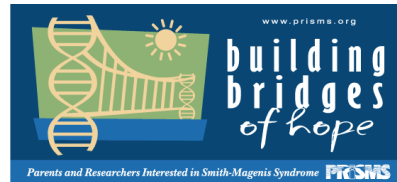
**"BUILDING BRIDGES OF HOPE"**

**Sept. 17-20, 2009**

**Reston Hyatt Hotel**

**Reston, VA**

\*This is the same site as the 2007 conference. Our families loved the location and were able to easily enjoy the shops and restaurants in immediate walking distance. We hope to see you all return AND we welcome new families and faces to the 2009 conference. Start planning and saving now! Be a part of the celebration!!

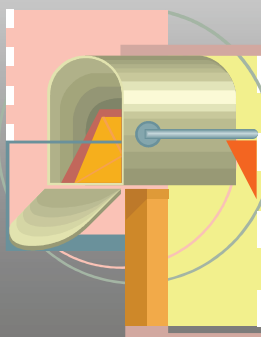


## PRISMS 2008

### MEMBERSHIP DUES DRIVE

**is right around the corner...**

Look for 2008 membership forms and information in your mailbox soon. Remember, if you would like to continue to receive this newsletter in your mailbox, we need your support! PRISMS exists solely on volunteers and donations. Stay up-to-date with your membership and stay connected!



In the next issue of Spectrum.....

*"Prevention versus Intervention: Effective Behavioral Strategies for Children with Smith Magenis Syndrome"*

*By Barbara Haas-Givler*



# The Question Box

**“What can I do to keep my child safely buckled up in the car?”**

*We have used the E-Z-On Vest. It has worked great. It keeps Arthur secure and safe. He is currently using the Zip up the back style. He is now 13 and 135 lbs. He wears a medium so you can see they fit small children to large adults. The website is located at [www.ezonpro.com](http://www.ezonpro.com) if you want more information. Medicaid paid for Arthur's vest. This is the second one that Arthur has received just because he is growing. He donated his first one to his school because it was still in good condition. They use them on the school busses. We hope this helps.*

*Jonny and Margene Morris  
Parents to Arthur 13*



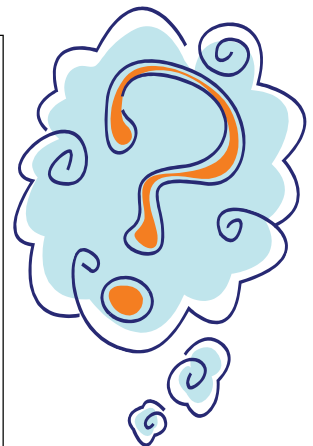
The Question Box is a new feature of Spectrum. Please email your questions/suggestions/answers to [notfar@earthlink.net](mailto:notfar@earthlink.net)

Fax: 843-986-9369

**Question:**

***"How do I deter my SMS child's "food-seeking" behavior? We have tried various locks on pantry and refrigerator doors with little success. The locks become inconvenient or my son breaks the locks."***

***Rochelle Wright,  
Parent of Zach***



# Tomestead SMS Picnic

On Sunday, October 14th, at 11 A.M we hosted The Tomestead SMS picnic and welcomed other families who came to share the day with us. The Tome family has played hosts to this picnic for about five years now.

Tomestead is the name we took for our organization when we incorporated in 1997. We then began to provide services and supports for our daughter, Kimberly, who was diagnosed with Smith-Magenis Syndrome in 1998. Our hope is that our other children will continue our efforts when we are no longer willing or able to do this.



For five years now, we have succeeded in encouraging others to come to take part in our SMS festivities. All who attend learn more of what bridging the distance means to families whose kids have a harder time than most and whose parents struggle even harder to do whatever it takes to make life matter in spite of it all. We always try to plan on having as much a fun time as possible and to make the day a memorable one for all the kids of all ages. Kim

is fifty years old now.

This year we had local authentic Native American Indian dancers and singers to entertain us. Twelve or so Indians came and they were very receptive to our kids and helped a lot to make the day especially nice. The food is always plentiful and good, and everyone contributed. We even had a doggie roast later in the day, with s'mores. Even later we had popcorn made the old fashioned way in one of the glass covered kettles like they use in movie theaters.

There is a macadam driveway here for the kids who wanted to ride their bikes or skate, or do whatever they wanted to do to burn off their energy. If anyone needed a nap, we could even accommodate him or her in the house or in the camper right here on our property. We wanted everyone to feel comfortable and at home. Thanks to everyone who came, the picnic was a huge success.

Our next SMS picnic is scheduled for Saturday, July 12, 2008. Do plan on coming.\*

Sandy Tome

Here is a nice letter from attendee Dana Krimmel, from Lancaster, Pa. My first SMS picnic is one that I will never forget. I had the pleasure of meeting Kim and her family a few days before so I had some idea of what to expect. My parents joined my 3½-year old SMS son Cole, and I, for emotional support as well as to

satisfy their own curiosity. My husband spent the day with our five-year old son, Hunter, at home.

To meet other children as well as to be able to talk to parents who could understand what I was talking about was truly remarkable. The similarities are outstanding but yet each child is completely different. We are forever bonded by SMS.

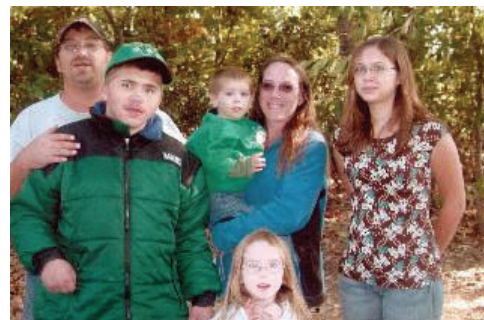


Before being formally introduced to each one I could look around and almost hand pick which child was SMS. Each child stood out in their own special way, as both my knowledge and heart were able to recognize.

Meeting the parents was equally special, because finally I was with others who knew SMS, understood SMS, and lived with SMS, and I could learn how other families coped, and at last, to be able to have others give my curiosity a bit of closure. I have since that day related to and thought about all those families with whom I spent the day.

I hope this gives you some insight of the picnic through my eyes. Again, a special day was had for all. The Indians were amazing and it truly was a day I will never forget!\*

Dana



# The 4th Annual Houston SMS Picnic



The 4th Annual Houston SMS Picnic was held at Bear Creek Park on November 10, 2007. With more than 50 people in attendance, it was the biggest picnic yet. There were several new families in attendance this year. There was plenty of fun to go around with a moon bounce, cotton candy machine, cookie walk, scavenger hunt, sensory, and craft/book corner and more! The lunch was carefully prepared by several skillfull chefs including our own PRISMs president Randy Beall!

---

---

.....Funraising from pg 14

receive a t-shirt you can have these produced and incorporate the cost of the shirt into the entry fee. This is a nice touch but just a little more work. You may want to solicit more sponsors to cover the costs of the t-shirt and add monies to your fundraising efforts. If you have a local hospital, you can spread the word for the event throughout the workplace. If the hospital has an Air Evac helicopter, they may make it available for your event for the kids to see. You can contact your local fire dept. and they may bring a truck out to the finish line for the same purpose. The possibilities are endless and there is really no right or wrong way to do things.

One final thing that is necessary

for this event is drinks and snacks. They must be available at the finish line. Contact your local grocers, beverage distributors, etc. and they will be glad to donate bottled water and possibly other samples of energy drinks, energy bars, or fruit, that can be used at the finish line for the benefit of the participants.

The most important goal at all of these fundraising events is to keep it fun while incorporating hobbies that



we all like to do! These same concepts can be applied to planning a bake sale at a local church, or having a miniature golf outing at your local

miniature golf course. The possibilities are endless! When organizing events, spread the word and be sure to include everyone that comes in contact with your SMS child. They will be interested and very likely to participate for the benefit of that child. Lets all do our part in raising awareness and funds for the benefit of that special SMS person in our lives!\*

For more information regarding fundraising, or if you would like to be part of the fundraising committee, please contact Percy Huston.

[jphiv@charter.net](mailto:jphiv@charter.net)



## Sara Cardinal “Olympic Champion” Special Olympics Summer Games June 2007

This summer, our very own Sara Cardinal, qualified to participate in the Special Olympics Summer Games. Many of our PRISMS families know Sara, as she has attended several PRISMS conferences, and was our “mistress of ceremonies,” and all-around goodwill ambassador. Sara has been a “celebrity” of sorts at our conferences, and now has another jewel to add to her crown! Sara participated in three different track events and earned three gold medals! Wow! Sara won a gold medal for running the 400K, 800K, and the mile. We knew Sara was a fast learner, with an excellent memory, but who knew she was also a track star!

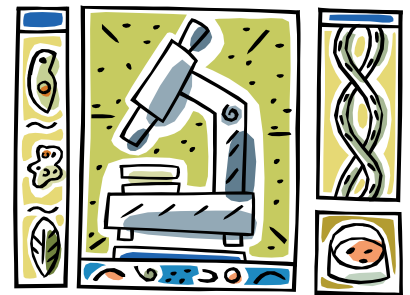
Sara qualified for the state Olympic events by attending the local meet where she ran the 5K, mile, 800K, and 400K. Sara also qualified because she attended all of her practices and because of her positive sportsmanship that she exhibits when she is at the track. Way to go Sara! You will always be a champion to all of your friends at PRISMS!



Sara, with arms raised in victory, receives her gold medal.

*Genetic.....Continued from pg 3....*

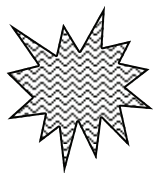
differences between males and females with SMS. Specific studies focusing on the basis for phenotypic differences in males and females and exploration of parental and health providers’ attitudes towards a child’s behavior may explain the observed differences between sexes found in this study. Further research is also needed to confirm the effects of deletion size or *RAI1* mutation on clinical presentation and the potential differences between males and females.



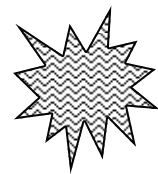
*Acknowledgements:*

We would like to thank Lori Potocki, MD and the late Frank Greenberg, MD for their dedication and significant contribution to our knowledge of SMS, Kim Hoffman, MS (Elwyn, Inc.) for assistance with data ascertainment, the Va-LEND (Leadership Excellence in Neurodevelopmental Disabilities) program, and the individuals and families with SMS for their participation and advocacy. This work was funded by a grant from U.S. National Institutes of Health (R01 HD38534) to S.H.E. and resources from the Virginia Commonwealth University (to S.H.E.).

Do you have a SMS SuperKid? Send a story with pictures to Julia Hetherington at [notfar@earthlink.net](mailto:notfar@earthlink.net) Fax: 843-986-9369



# Fundraising Should Be



## Funraising

By Percy Huston

Dad to Jackie, age 16

Fundraising is very important to PRISMS, and directly supports those diagnosed with SMS and their families. Fundraising should not have to be work, but rather, FUN! Start with a "fun" activity you may already be participating in, and make it a positive activity for the future of PRISMS. Being involved in some sort of activity that aids SMS families gives us pride and ownership in PRISMS and is something that we can **all** do at some level.

No matter how big or small the undertaking may be, the cumulative financial effect, is potentially awesome. Consider what would happen if families across the country participated in fundraising for PRISMS!

Over this past year I have undertaken several activities to raise money for PRISMS that each and every one of you can also do right in your own "backyard". Not all activities will apply to everyone, but there are other activities that can be substituted in their place. The objective is that these are activities that we like or enjoy doing already, and we somehow make them into a small (or big) fundraiser for that SMS person who is close to us!

Some examples of fundraising activities include bowling, exercising (running or jogging), playing cards, baking, and playing golf. I will take a few of these examples and explain how they work, but remember there are endless possibilities. Just use your imagination!

### Card Extravaganzas:

This is a catchall phrase for any type of card game that can be incorporated into a tournament format.

In my example, the card game is "Texas Hold 'Em", which is a form of poker that has taken the sports world by storm in recent years. It is played privately all the time in many circles.



The idea here is that games are already being played routinely in your community, so why not organize an event to benefit your SMS child! Because it is in a tournament format, everyone will pay an entry fee to play. It is from this entry fee that your fundraising dollars will be derived. Typically, entry fees run between \$50 and \$100. This is not an unusual fee for people who play in these tournaments, and at the end of the evening the tournament winner will receive a predetermined percentage of the gate, with the rest of the proceeds going to PRISMS. The predetermined percentages should not exceed fifty percent of the gate. It is very important to keep overhead expenses at or near zero when hosting these types of functions. Where should you host these tournaments? This is a frequently ask question. Your residence is a possibility, but not one I recommend. Start inquiring at your local or nearest beer distributorship. They are generally glad to donate the use of their hospitality room, which will be already set up

with tables and chairs and possibly other amenities, such as beverages and big screens televisions. If this is not a possibility, try your local Elks, KC Hall, Eagles, etc. These organizations, many of which we already belong to, are glad to help out a needy cause by donating space. If you feel you need food or snacks, ask family members or friends to send a crock-pot of chili, bag of chips, etc. to make the evening more enjoyable. To enhance attendance, get the word out to whatever groups of people you know who like to play the type of game you choose for the tournament. Do not forget to provide whatever is needed to play the game including cards, poker chips, scoring pads, and whatever else might be needed. Those who play the games routinely will have these supplies and you will not need to go out and buy anything. These types of events can be held as often as you feel you can get an audience to play, and you do not have to be limited to once/year. Two to four times a year is a more realistic number.

### Bowling Events

Many people love to bowl and if you are a "bowler," you know what I



Continued on pg 15.....

mean. However, many more novice bowlers just do not go to bowling events, but when they do, they have a ball (no pun intended). The idea here is to get people to rally behind your SMS child and a great cause, and to raise money while having a good time. Start by working with your local bowling lanes and pick a date and time that is typically not as busy for them. Do this in order to get as good a deal as possible, rate wise, for your event. They will be glad to work with you and hopefully give you a very good deal. Whether it is a two or three game event, compute what your cost to the bowling alley will be, per entrant. You will still charge a tournament fee on top of this amount. Participants understand that you are charging this fee to support the fundraiser, and this overage will be the fundraising portion that goes to PRISMS. In order for the event to be successful, it must be well attended. In this case, it's not just bowlers you are seeking, but anyone looking for a fun time, that may also know your SMS child and would like to help. In reality, there is no bad turnout for an event like this. It is fun for everyone, and in most cases, people are participating in hobbies or sports they enjoy anyway. Most importantly, the fundraising event will educate people about SMS and PRISMS. As a result of the event, they will be encouraged to simply make a donation to a great cause!

### Running Events

Running events take a little more planning and will certainly be done less often, but can involve many par-

ticipants. Exercise, running, and jogging, has become a considerable part of many people's daily lives. I'm sure there have been various running events in your area, depending on your community's size, but not so many that **you** cannot have a very successful event.

First of all, determine how far the "race" is going to be. I recommend a 5K/1 mile run/walk. For those who like to run, the 5K, (approx. 3 miles), is appropriate, and for those who wish to walk, the mile is a reasonable distance. These choices will greatly enhance participation and more importantly keep your event time to less than an hour (max). Any person no matter what their age or physical condition can participate in an event like this. The goal, again, is to raise awareness through participation.

Next, where to have the running event? Because it is a short race, huge amounts of space are not needed. Inquire with your local parks to see if they can accommodate the event, or if your community has



walking or biking paths, as these make perfect venues for such an event. There should be no charges for using these parks or biking paths, because there is no need to close roads or streets for the

short distance. Just be sure to notify your parks dept. and or city hall as to your plans from a courtesy standpoint. You will need to lay out a start and finish line based on your selected distances. You will need volunteers at both places, especially at the finish area to assist with drinks and snacks when participants have completed the race.

If possible, enlist the assistance of your local runners club. Many communities have these clubs and they are often glad to help in many ways. The clubs can assist in laying out and



recommending a course, providing volunteers, advertising for your event, and most importantly lending a timing device that can be situated at the finish line so times can be recorded.

There needs to be a fee charged to enter the event. The 5K will be somewhat competitive and the fee can be higher for these participants. You will want to give awards for the 5K in various age groups for those with the best times. (I would suggest medals for 1<sup>st</sup>, 2<sup>nd</sup> and 3<sup>rd</sup> places in each age group.) Generally, participants in the 1-mile walk are just there to participate and are not expecting awards. Age groups may be determined at your discretion, but generally range in ten-year age intervals. Your local running "gurus" will have valuable input on this. Approach local athletic stores for their support of the medals or awards. They will either donate or greatly discount medals, thus keeping your expense to a minimum.

Beyond this, these types of events can be as big or as small as you want them to be. If you want everyone to



Parents and Researchers  
Interested in  
**Smith-Magenis Syndrome**

NONPROFIT ORG  
U.S. POSTAGE PAID  
DALLAS, TX  
PERMIT NO. 2024

PRISMS, Inc.  
21800 Town Center Plaza  
Suite #266A-633  
Sterling, VA 20164

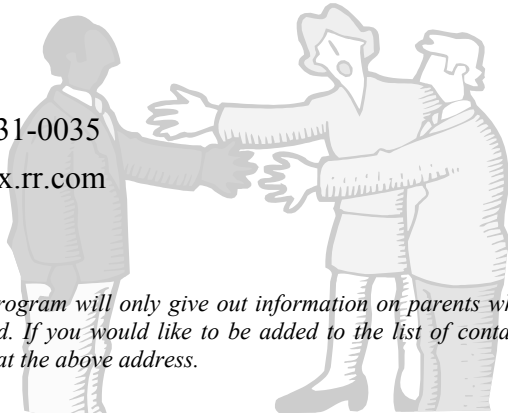
## Parent to Parent

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 that 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.*



## THANKS!

*Spectrum* is the official newsletter of PRISMS. Readers are free to duplicate all or part of its contents. In accordance with accepted publication standards, we request acknowledgment in print of any article reproduced in another publication. Letters to the editor, comments on articles, and suggestions for future articles are always welcome.

**Editor in Chief:**

Julia Hetherington  
notfar@earthlink.net

**Editors:**

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

**Newsletter Committee Members:**

Margaret Miller  
Michele Zdanowski