

# SPECTRUM



## IT'S IN THE BOX

“An Educational Approach”

By Tina McGrevy

After failing to reach several milestones, our five year old son Garrett was diagnosed just before his second birthday. He began his first year of special education preschool at age three and was fortunate enough to receive an extra hour a week of in-home tutoring from Anne Conley. She introduced us to a "shoebox system" that has worked miracles for Garrett in his IEP and therapy goals.

Although this system is extremely easy to use and inexpensive to implement, it is difficult to describe. It involves a shelf that holds six plastic shoe boxes with a colored square velcroed on the outside of each box. The schedule is a strip of colored squares with velcroed backs that Garrett attaches next to the matching square and then removes the box.

These boxes each contain a separate activity. Every evening, we sit down at the dining room table and Garrett spends twenty minutes doing real work. In the photo, Garrett is matching bears. We have worked this summer on "same and different" and he finally understands! The shoe boxes keep Garrett focused because he knows that an activity has to be completed before moving on to the next box. We rotate the new things he is learning (like matching) in with goals he has already accomplished. If Garrett has a "victory" every other box, then he is less likely to meltdown on the tough ones. He loves them so much that we use them as a bribe on those SMS days!

For information on creating your own “Shoe Box” learning system, please see our article on page 11.



*Garrett enjoys his independence as he works his way through the boxes of tasks that his mother, Tina, has prepared for him.*

### INSIDE THIS ISSUE:

Teacher's Prospective	2
President's Message	4
Meet Sarah Poole	6
Membership Drive	7
Early Intervention	8
2005 Conference	9
Shoebox System	11

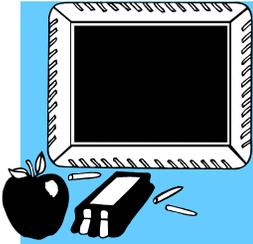
### What Is Smith-Magenis Syndrome?

*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.*



Questions?

**PRISMS, Inc.**  
**Randy Beall, President**  
 PO Box 741914  
 Dallas, TX 75374-1914  
 Phone: 972-231-0035  
 Fax: 413- 826-6539  
 E-mail: info@prisms.org  
 Website: www.prisms.org



# Educational Implications & Behavioral Concerns of SMS ...From the Teacher's Perspective

## Observations on the Behavioral and Personality Characteristics of Children with Smith-Magenis Syndrome

*by Barbara Haas-Givler, M.Ed.*

The primary focus of special education professionals is to provide a school environment that is designed to meet a student's full range of needs. Special educators are by nature a resourceful group who often rely on each other for assistance in designing appropriate educational and behavioral strategies for dealing with their students. By comparing notes about similar students, we draw on past experience in developing effective behavioral and learning approaches. One teacher often asks another, "Doesn't this boy's behavior remind you of another boy who used to be in the elementary program?" It was through such informal comparisons that several members of the education staff at Elwyn Inc., including both teachers in the classroom and the supervisory staff, recognized a group of children in our programs who shared strikingly similar behavioral features and learning styles. Through the efforts of the Genetics Service at Elwyn beginning in 1990, it was ultimately shown that the Elwyn students did in fact all have the same genetic syndrome, SMS.

The discovery of SMS in these children reinforced our observations about the similarity of their behaviors, but it did not help us with the overall problem of behavior management. A search of the professional literature was made for articles dealing with educational and behavior management approaches for children with SMS. We were not seeking a cookbook approach for dealing with SMS. After all, special education professionals are strong believers in fostering each child's individuality and unique differences! However, we were discouraged to find that there was not even one article that specifically discussed the educational needs of this unique group of children. The lack of written information motivated us to more carefully examine our classroom experiences over the years to gain insight and help us understand some of the strengths, weaknesses, and unique problems posed by students with SMS.

### **BEHAVIORAL AND LEARNING STYLES OF CHILDREN WITH SMS**

The following observations were made by a group of Elwyn professionals led by fellow special educators, Debbie Ward and Patricia Stubbe, and me. Our group cumulatively represents over 100 years of experience in special education. This anecdotal information stems from ongoing discussions, which, although unpublished, can serve as the basis for future research into the educational needs of children and adults with SMS. Three major categories of behavior are described which can positively and/or negatively influence learning. None of the features listed is specific only to children with SMS, and there are certainly other children with different types of disabilities who share some of these characteristics. As expected in all children, we have also observed age-related differences in the behavior of children with SMS at various stages of childhood. In addition, some children with SMS pose relatively few behavioral difficulties, while others present ongoing and severe problems that greatly affect their classroom experience and that of their fellow students.

### **BEHAVIORAL ATTRIBUTES WHICH NEGATIVELY AFFECT LEARNING**

Children with SMS often present problems with attention-seeking, aggressive, and self-injurious behaviors. These are disruptive in the classroom setting, often requiring individual behavior management programs. Students with SMS tend to be very adult-oriented, demanding an inordinate amount of individualized attention from adults; when this is denied, aggressive and self-injurious outbursts are frequently the result. As one teacher put it, "If I could provide constant, unwavering, one-on-one attention to this child throughout the day, she might never have another tantrum." But what teacher or parent can do that?

## **POSITIVE ATTRIBUTES OF CHILDREN WITH SMS**

When a teacher or parent is working with a child who presents behavioral challenges, it is particularly important to emphasize the child's many positive attributes. Children with SMS are often among the more popular students in the classroom, despite the significant management problems they can present. A teacher can capitalize on these positive features in developing behavior management programs, both for the home and the school.

## **ATTRIBUTES WHICH CAN BE POSITIVE OR NEGATIVE**

Some behavioral characteristics of students with SMS complicate the picture because they can be perceived as either positive or negative, depending on the situation. Teachers are only human, and one may tend to reinforce the affectionate nature of a student, whereas another may feel that these behaviors are not appropriate (i.e. in an older child). The adult-seeking nature of children with SMS may interfere with the learning and teaching process in the classroom, if a child is demanding an excessive amount of teacher attention throughout the day.

## **CHARACTERISTICS OF STUDENTS WITH SMS**

### ***SMS ATTRIBUTES WHICH NEGATIVELY AFFECT LEARNING***

- **Attention seeking** - demanding an inordinate amount of one-on-one attention
- **Aggression toward others** - often in response to other students who want THEIR teacher's attention
- **Tantrums** - falling to the ground; refusing to walk; striking out at other children
- **Self-injurious behavior** - picking at nails and skin, inserting foreign objects into various body orifices (openings); putting hands under hot water or on hot objects; head banging
- **Poor impulse control** - child jumps out of seat; grabs things without asking
- **Negative reaction to changes in routine** - child needs a warning that an activity is about to change
- **Attention deficit disorder** - with or without hyperactivity
- **Perseveration** - repeatedly asking the same question, e.g., "What's your name?"; continuing to demand attention on a topic of interest while the class has moved on to another subject
- **Sleep Disturbance** - child may fall asleep in class

### ***POSITIVE ATTRIBUTES OF STUDENTS WITH SMS***

- **Engaging and endearing personality** - immature speech patterns, "cute" facial features, self-hugging; good eye contact and "impish" smile that animates the face
- **Appreciative of attention, excitable** - enjoy interaction with adults; learn and use names of teachers and students; use social expressions "please" and "thank you"; often demonstrate self-hugging or hand-squeezing motions.
- **Responsive to structure and routine** - react positively to consistency; follow classroom routine, especially with visual cues.
- **Motivated by a variety of reinforcers** - food, stickers, and attention
- **Eager to please** - show pleasure in voice, facial expressions, self-hugging.
- **Communicative** - verbal, gestural, sign language, picture board
- **Enjoy a variety of activities** - music, songs, water play and puzzles
- **Fascination with electronics** - toys, calculators, computers, etc.

*(Continued on page 5)*

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## A Message from PRISMS President...

Our 2004/2005 membership drive has begun. I want to encourage everyone to fill out and return the enclosed membership form - today! We are a member-supported organization and your membership dues/contributions allow us to continue to provide information and support to SMS families. Plus, this allows us to update our database with your correct address and phone number. While the postal service might forward snail mail, the Internet does not forward emails and the phone company does not notify us of changes. So please keep us up to date - - we don't want to lose contact with you!

The PRISMS board is busy planning our 2005 conference. This conference is shaping up to be a great event. The 4th International PRISMS conference will be held at the Westin Hotel, Cincinnati, OH, April 28 - May 1, 2005. I hope you are planning to be a part of this event. As details are available they will be posted on our website. We'll start with a welcome reception from 5-8 pm on Thursday, April 28<sup>th</sup> (hors' d'oeuvres will be served) and conclude Sunday, May 1<sup>st</sup> at 11am. This year will offer online registration and online secure payment at [www.prisms.org](http://www.prisms.org). Please take advantage of this automated way to register.

I want to say a special "thank you" to the Cooney family and Van Nest family for hosting this year's OH golf tournament. This event raised \$15,000. Great job guys!! Not only do fundraising events like this raise money they also help to increase the awareness of SMS. Hosting an event is a very rewarding experience and a great way to make a difference! Please contact Mike Singleton (541) 212-3292 if you're interested in hosting a fundraising event such as a walk-a-thon or golf tournament. It's easier than you think to host something...and it's fun!

Finally, our new PRISMS website -- [www.prisms.org](http://www.prisms.org) -- is online! I know this new site has been a long time in coming. Take a peek and be sure to check back often. Hopefully it will be easy to remember and something you'll want to tell others about. We've made the site easier to navigate and added information on how to deal with SMS. We've also created sections for educators and medical professionals. Plus we've added language translation, photos and much more. A number of folks have worked hard to help us create our web site and make our new web site a reality. A special thanks goes out to our developers and content contributors -- Paul Severson, the crew at [m3style.com](http://m3style.com) (Duane Ronan, Peteris Bikis and Krisjanis Jukumsons-Jukumnieks), Ann C.M. Smith, D.Sc. (hon), Wally Duncan, Ph.D., Lynn Campbell, Margaret Miller and others. A huge "thanks" to Brenda Finucane who was instrumental in creating our first site and much of its content. Also, Tony Rocha at CrafTech Computer Solutions has provided web hosting pro bono for the past several years. They have provided a tremendous service to us all. Eventually the old site -- [www.smithmagenis.org](http://www.smithmagenis.org) -- will be phased out. Please update your favorites. However, for a period of time you'll still be able to use both URLs.

I look forward to seeing everyone in Cincy! Best regards, Randy Beall

## The SMS Advantage

### "At School"

By Laurie Bellet



Although many teachers do not recognize their good fortune, the teacher who has an SMStudent is truly blessed. Here are but a few of the advantages:

The SMSearcher can find any item a needy teacher requires whether within the classroom, in the school office or in another teacher's classroom!

Feel free to do away with that pesky Lost and Found Box. The class SMSleuth can identify each and every item.

The SMS volunteer is the first to offer assistance of every kind.

The student with SMS always has an answer (however tangential). Once the SMStudent has responded, all others are reassured that their answers will not be the most outlandish.

This fortunate teacher never has to make another photocopy. The SMSecretary is eager to fulfill all requisitions. (Single sided, black and white copies only. Please do not request anything to be collated or stapled).

Rules are meant to be upheld and, when the SMSentry yells "No running in the halls!" everyone can hear the warning. (\*Be advised that there will likely be little or no discrimination between teachers, students or administrators when applying the rules.)

Continued from page 3 -

- **Well-developed sense of humor** - generally enjoy joking, teasing; laugh at appropriate times
- **Identifiable causes of tantrums and aggression** - often due to changes in routine; parents and teachers can often predict triggers which might cause an outburst; child will often tell what's wrong
- **Tantrums and aggressive behaviors can often be redirected** - if the staff/parent can intervene before the child becomes too upset

#### POSITIVE FEATURES WHICH CAN BECOME NEGATIVE

- **Adult-oriented** - can become negative if student tries to monopolize teacher's attention, time; has little interest in interacting with peers
- **Affectionate** - can become negative if aggressive (rib- crushing!) hugging of others; indiscriminate hugging of strangers
- **Remorseful after acting out** - can become negative if student prolongs remorsefulness to gain or maintain attention
- **Visual learners** - can become negative if student becomes overstimulated by visual stimuli; student has visual impairment.

*- This article was reprinted from Spectrum, Volume 1 (2), Summer 1994*



## Meet One of Our Kids....Sarah Poole

We adopted Sarah at 7 weeks. She is biologically my great-niece and was in need of a loving home. We felt we had a lot of love to give. What we never anticipated was how she would multiply our love many, many times over. This little ball of fire is a ray of sunshine to everyone she meets.

Sarah's biological parents had some problems, and we expected that Sarah would need some extra help. So when she continued to miss milestones, we consulted a pediatric specialist. I think he suspected a syndrome and immediately ordered chromosomal testing to, as he put it, "rule out syndromes like Prader-Willi". After submitting the blood work, we moved on with our busy lives and hardly thought about the testing. I figured the problem would be some kind of neurological damage. I got home to a message on our answering machine from Sarah's pediatrician. She sounded very concerned and said to contact her right away. Ironically, we found out, Sarah having SMS probably has nothing to do with her biological parents. I say probably because we have been unsuccessful in our attempts to get them to do testing for a mosaic distribution.



Sarah Poole, daughter of Cecilia Poole

As all SMS parents have experienced, the diagnosis was the beginning of a whirlwind of testing. We soon found out that at least so far, Sarah is one of the milder cases. Sometimes I feel guilty about that when I find out how many parents have so much more to deal with. For us, the biggest problem has been getting adequate rest. Both my husband and I work full time. We are trying to keep working so that we can keep our medical benefits, which fortunately, are very good. Unfortunately, Sarah has never slept well, even as an infant. Right now, we are giving her melatonin. Some nights are great...others are horrible. We've had to work hard to maintain a loving spousal relationship, because we have almost no time alone and no down time.

Sarah is awake until we all go to bed. And, she wakes us in the morning. Continuing to function and produce with very little sleep has been hands down, the hardest thing I have ever had to do. I've heard that sleep deprivation can be used as a form of torture. I believe it. As my husband puts it, having a child with SMS is like having a newborn forever. We try to help each other, taking turns sleeping. I've been sick more than ever in my life and I know it's because we are so run down. Still, we carry on, taking it one day at a time.

My stepdaughter Megan is now 16. We try hard not to shortchange her because we have to focus so much energy on Sarah. Because of Sarah, Megan has learned so much about the challenges of raising a child, especially one with special needs. Megan herself has some significant learning disabilities and we've often wondered what she will be able to do to make a living. Now, Megan has taken a keen interest in auditory therapy and is considering doing that for a living. And, its requirements match some of her stronger areas. We are so excited!

What are some of Sarah's health issues? She had a detached ureter and the resulting flow of urine was destroying her right kidney. Thanks to the screening guidelines however, we found out quickly and were able to get the problem fixed surgically. The doctors think her kidney will improve slowly. She has some hearing loss and wears hearing aids. She is far sighted and after a rough start, now happily wears her glasses...they help her see all the things she wants to do. She is walking and running, thanks to lots of physical therapy. She continues to have oral motor/speech, auditory, and occupational therapies.

Sarah likes to sign words and has a large vocabulary, both spoken and signed. She smiles a lot and loves to be chased. She often initiates a chase by saying "I get you!" and then runs away as she looks over her shoulder. She goes to preschool two mornings a week and always says "morning" loud and clear as she enters the building. She has a huge fascination with electronic objects and especially loves DVDs. If she sees anything closed and can't get into it, she'll take it to an adult and repeatedly say "Open. Open." She has such a zest for life...it's amazing.

What does the future hold? I'll be honest...I worry a lot. Yet, although I have never been more tired or worried, I have also never felt so alive. This little angel was heaven sent and I wouldn't trade her for anything. There's no going back...just going forward...dealing with the bad and rejoicing over all the good. Our eyes have been opened. Until Sarah, we never knew how much we were taking for granted. What a gift it is to get so much joy over even the smallest of successes!

Cecilia Poole

Mom to Sarah (Age 3 with SMS)



## 2004-2005 MEMBERSHIP FORM

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS) and fostering partnerships with professionals to increase awareness and understanding of SMS. PRISMS is a 501(c)(3) non profit organization. Donations made to PRISMS are tax deductible to the extent allowed by law. Your membership and/or gift is greatly appreciated.

**Please provide the following information (PLEASE PRINT):**

Today's Date (mm/dd/yyyy): \_\_\_\_\_

Membership Type: (Check One)  New  Renewal

Your Name(s): \_\_\_\_\_

Name of Person with SMS (First And Last Name):  
\_\_\_\_\_

Address Line 1: \_\_\_\_\_

Address Line 2 (optional): \_\_\_\_\_

City: \_\_\_\_\_ State/Province: \_\_\_\_\_

ZIP/Postal Code: \_\_\_\_\_ Country: \_\_\_\_\_

Telephone with Area Code (Home): \_\_\_\_\_

Telephone with Area Code (Work): \_\_\_\_\_

Telephone with Area Code (Cell): \_\_\_\_\_

Email: \_\_\_\_\_

Alternate Email: \_\_\_\_\_

Occupation(s): \_\_\_\_\_

Gender of Person with SMS: (Check One)  Male  Female

Date of Birth of Person with SMS (mm/dd/yyyy): \_\_\_\_\_

Your Relationship to Person with SMS:

- Parent(s)
- Grandparent(s)
- Other Relative / Friend
- Geneticist / Genetic Counselor
- Physician / Health Professional
- Teacher / Therapist
- Other : \_\_\_\_\_

**Parent-to-Parent Program**

PRISMS occasionally receives calls from parents of SMS children who want to speak to another SMS parent. Some of these folks have newly diagnosed children; some have children that have diagnosed for awhile but just want to talk to someone that lives close by or has a child the same age. For confidentiality reasons, PRISMS does not provide a list of our membership. Hence, we can only connect you with other interested parents or visa versa through our "Parent-to-Parent" program. We strongly urge you to consider allowing us to release your name as a possible contact person for PRISMS Parent-to-Parent program.

**YES** - PRISMS may release my name, address, email and phone number as a possible contact person for another SMS parent or PRISMS member.

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**2004/2005 MEMBERSHIP DUES (in U.S. Dollars):**

SMS Parent(s)/Immediate Family - \$30	\$ _____
SMS Parent(s) but cannot afford dues - \$0	\$ _____
SMS Relative or Friend - \$30	\$ _____
Teacher - \$30	\$ _____
Physician/ Health Professional - \$50	\$ _____
Geneticist/Genetic Counselor - \$50	\$ _____
Additional Donation - \$10, \$25, \$50, \$100, other	\$ _____
International members - \$5 additional*	\$ _____
<b>TOTAL</b>	\$ _____

\* Note: Due to the high cost of mailing, please add \$5.00 USD for international memberships.

**International members**: We prefer to receive international money orders or cashier's checks denominated in US Dollars. However, if you are unable to send us a US dollar payment, we can accept a personal check or draft in your local currency. Please ask your local bank about the current foreign exchange rate or for help converting your foreign currency. If you would like us to charge your credit card, please email or fax us your authorization (be sure to send us both pages of this application).

Card type (Visa or MasterCard): \_\_\_\_\_ Card number: \_\_\_\_\_

Signature: \_\_\_\_\_ Expiration date: \_\_\_\_\_

<p><i>Please return form along with your check to:</i></p> <p><b>PRISMS, Inc., P.O. Box 741914, Dallas, TX 75374-1914 USA</b>  <b>Fax: 413.826.6539 Email: info@prisms.org</b></p>
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**PRISMS 2004/2005  
MEMBERSHIP DRIVE  
HAS BEGUN!**

As many of you know, PRISMS has annual membership dues. However, this year we forgot to send out a letter in early 2004. Thus, membership dues paid now will cover the remainder of 2004 and all of 2005. Our annual membership fee is \$30-\$35 per year for SMS parents and slightly more for professionals. Please complete and return the enclosed membership form – today!

We can now accept Visa or MasterCard for your membership dues, simply click on the Network for Good icon on the left side of the <http://www.prisms.org/> home page. If you pay online, don't forget to mail in your membership form so that we can update our database. Also, please indicate that you've paid online.



**ENTERTAINMENT BOOKS**

PRI SMS is once again raising funds by selling Entertainment® books! In 2004, we raised over \$500 for our kids by selling these great books.

Even though this is a 2005 book, the coupons are valid immediately and do not expire until 11/1/05. The Entertainment® book is available for 150 cities throughout the United States and Canada. The coupon books are packed with Buy-One-Get-One-Free and 50% off discounts on restaurants, theatres, video rentals, dry cleaners, sporting events, and more. The savings also continue nationwide with great offers like 50% off hotels and discounts on airlines and car rentals. The easiest way to preview and purchase your own local book is to visit [www.entertainment.com](http://www.entertainment.com). The PRI SMS Group Account Number is 742332. PRI SMS will automatically receive 20% profit of each book purchased. For more information, contact Michele Zdanowski, (248) 437-7251, [jzdanowski@comcast.net](mailto:jzdanowski@comcast.net). Also, please consider ordering 5+ books to sell in your office or neighborhood. For 5+ orders, please order books from Michele to get your shipping waived.

*"These Books Make Great Gifts for the Holidays"*

***MOVING RIGHT ALONG.....DR. SARAH ELSEA IN NEW LOCATION***

As some of you already know, Dr. Elsea accepted a new position at Virginia Commonwealth University at the Medical College of Virginia in Richmond. This is a really great move for her and for the lab, and we are excited about the new opportunities. Dr. Elsea's new position will allow her to devote more time to research and will require less teaching. It will be good to have her back in a medical school full-time with all of the support necessary to do her research.

Dr. Elsea assures everyone that the research on SMS is continuing and will be better supported in this move to the Medical College of Virginia. Although she will have some down-time in the process of moving, she is excited about this move and looks forward to the changes ahead.

Feel free to contact her with any questions.

New address (office):

Sarah H. Elsea, Ph.D.

Dept of Pediatrics

Virginia Commonwealth University

P.O. Box 980441

12-018A Sanger Hall

1101 E. Marshall

Richmond, VA 23298-0441

804-628-0987 (office)

[selsea@vcu.edu](mailto:selsea@vcu.edu)





# Early Intervention

"HELP YOUR TODDLER GET OFF TO A GOOD START"

By Mary Beall, M. Ed.

Knowing the cause of your child's developmental delays can facilitate a family's access to critical early childhood intervention services such as speech and language therapy, occupational therapy (OT) and/or physical therapy (PT). Early intervention has proven to be effective in many disabilities including SMS. In addition, early intervention may help program staff identify areas of specific need or risk. For example, some SMS families have benefited from using sign language with their child before his or her speech developed. Additionally, a diagnosis of SMS opens the doors to a network of information and support from professionals and other families dealing with the syndrome. By law, U.S. public school districts that receive federal funds under the Individuals with Disabilities Education Act of 1997 (IDEA'97) must provide early intervention programs for children under the age of 3. "The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is a federal grant program that assists states in operating a comprehensive statewide program of early intervention services for infants and toddlers with disabilities, ages birth through age 2 years, and their families. In order for a state to participate in the program it must assure that early intervention will be available to every eligible child and its family." Check with your public school district to see what programs are available in your area. Your physician can help you determine the need for therapy or you can have your child evaluated by a therapeutic service provider. For most school-aged children, therapy services will be provided by your school district if included in your child's Individual Education Plan (IEP). Services may be provided as direct or consultation services, depending on school policy. It is important to note that schools will provide therapies only if your child's delays are seen as "affects their ability to learn." For some delays, private services are the only answer.

## **Speech and language therapy**

Onset of speech is often delayed in children with Smith-Magenis Syndrome and articulation can be affected by muscle tone issues. Once speech has been acquired children often experience difficulties with processing information. A licensed speech/language pathologist can address all speech/language related issues.

## **Occupational therapy**

Children with Smith-Magenis Syndrome often have visual-spatial deficits and difficulty with fine muscle control, such as picking up small objects. Occupational therapy primarily addresses fine motor skill development in children with SMS, but is also your source for help with feeding issues and sensitivity to textures. Occupational therapy should be provided by a licensed Occupational Therapist. You can obtain more information about Occupational therapy by visiting the website of the American Occupational Therapy Association.

## **Physical therapy**

Children with Smith-Magenis Syndrome can have balance problems and weak muscle tone. Physical therapy will address gross motor skill development in children with SMS. Physical therapy should be provided by a licensed Physical Therapist. You can obtain more information about Physical therapy by visiting the website of the American Physical Therapy Association.

## BUILDING BRIDGES OF HOPE SMS CONFERENCE 2005

PRI SMS is proud to sponsor international conferences where families and professionals can come together to learn and support each other. Our conferences are typically held every 2-3 years. Please make every effort to attend these important events.

- **Dates:**
  - Research Roundtable: April 28, 2005
  - Parent Conference: April 28 - May 1, 2005
- **Place:** Westin Hotel, Cincinnati, OH

The 4th International PRI SMS conference will be held at the Westin Hotel, Cincinnati, OH, April 28 - May 1, 2005. The objectives of the conference are to: 1) learn about SMS, past, present and future and 2) share information and tips with other families. Please note that this conference is intended for parents and professionals. If possible, please try to make local arrangements for your children. Limited child care will be available and additional costs will apply. We hope to have online conference registration and more details soon. If you're interested in volunteering to help with this event, please contact Rochelle Wright at [rochelle.wright@ncr.com](mailto:rochelle.wright@ncr.com)

### PRELIMINARY PROGRAM

- Research/Medication Updates
- Behavior Management
- Positive Exposure
- Parenting "sibs"
- Total Communication
- Family Networking (look to the experienced for ideas!)
- Mother's Tea
- Silent Auction
- Sleep Issues Panel
- Residential Options (for children and adults)
- Parent Expo
- Curbside consults with professionals
- Overview of SMS for newly diagnosed families
- Father's Coffee

### CONFERENCE SCHEDULE Thursday, April 28th

4:00 - 8:00 pm - Registration

5:00 - 8:00 pm - Welcome Reception

### Friday, April 29th

7:00 - 8:30 am - Registration & Continental Breakfast

8:30 am - Conference Begins

### Saturday, April 30th

7:00 - 8:00 am - Continental Breakfast

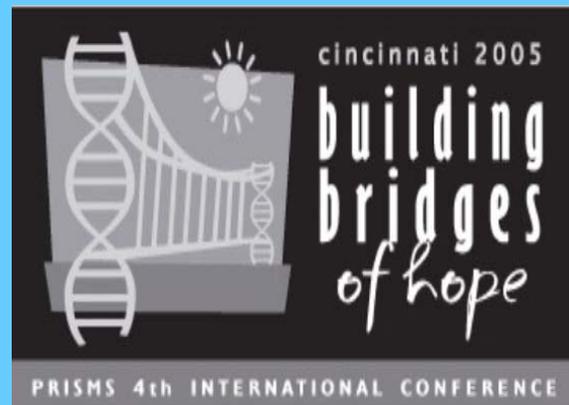
8:30 am - Conference Continuation

### Sunday, May 1st

8:00 - 11:00 am - Continental Breakfast and Conference continuation.

**Note** - The conference will conclude promptly at 11:00 am.

The Westin Cincinnati is a beautiful downtown hotel located across the street from historic Fountain Square. Our hotel room rate is \$89 single, \$109 double plus tax.



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# CREATING YOUR OWN "SHOEBOX" LEARNING SYSTEM AT HOME

By Ms. Anne Conley, Garrett McGrevy's Itinerant Preschool Teacher

I learned about the "shoebox system" at several TEACCH (Treatment and Education of Autistic and Related Communication Handicapped children) workshops presented by folks from the University of North Carolina at Chapel Hill, NC., and from Troy City Schools, Troy, Ohio, where they have used TEACCH for years. One can become familiar with TEACCH by accessing their website: <http://www.teacch.com/>

TEACCH stresses the importance of structure, consistency, predictability and visual cuing when teaching people with autism and related communication handicaps. The shoebox system is a "slice" of the "TEACCH pizza."

Garrett, who was 3 when I first met him, had difficulty sitting at a small table for more than 2-3 minutes; transitioning from one activity or place to another without protest (or meltdown), was unable to focus on developmentally appropriate activities for more than about a minute; did not speak, but used about 25 signs with his mom and gradually with me; LOVED books and would sit with Mom or Dad to be read to; LOVED Barney.

All of the above gave me reason to suggest using the shoeboxes at home with Garrett.....to increase his in-seat time, to transition from one shoebox to the next smoothly, to focus on each activity to completion and to increase his expressive communication skills...both in signing and vocalizations.....all with activities he enjoyed, especially books and Barney!

## Shoebox System Requirements

- 1 fiberboard shoe shelf, approx. 12" x 23" (typically found in discount stores in "household-closet" dept. They come unassembled. When assembled, you have 3 "shelves" for shoes (in our case, shoeboxes). They cost about \$10. This shelf unit will fit on a card table, on a kitchen table or possibly on a child's table.
- 6 plastic shoeboxes with lids.....found in those same discount stores as well as in the dollar stores.....about \$1 each.
- 1 rectangular laundry basket, empty cardboard box or plastic lidded tote, to use as the "finished" basket/box.
- 1 file folder, which you'll be cutting.
- 1 roll of Velcro "coins".....precut round pieces, available at Staples or Office Max. I usually shop Staples on-line.

You use a lot of Velcro with the activities.

6 pieces of colored paper.....copying paper doesn't fade like construction paper does. With preschoolers I used the basic colors. Make sure the colors are obviously different. (As your child matures, you can use shapes, letters, numbers, etc. etc. instead of colors.)

You will need 2 1 1/2" X 2" rectangles, covered with clear plastic covering to preserve.

1 roll of clear plastic covering or laminate to preserve paper items for activities.

1 piece of cloth, towel or baby blanket to cover shoe shelf when not in use. (outa sight, outa mind!)

## Activities to put into the Shoeboxes

Activities and the number of shoeboxes you use at each sitting are arbitrary. You create activities that are simple, have a defined beginning and end, and, most important, that interest your child. They could also be pre-academic and consistent with your child's IEP goals and objectives. Seek ideas from teachers, PT's, OT's and ST's.....but all activities must fit into a shoebox and require your child to do something functional with their hands to complete each activity.

Many of the activities are home-made, using items like colored chips (Wal-Mart or Staples), beads for stringing (toy stores, educ. supply stores, Wal-Mart and Staples), poker chips, margarine containers with lids, snack zip bags, decks of matching picture cards (Wal-Mart or Staples), matching items from any dollar store. Once you decide what skills you want to teach or reinforce with your child, when you go shopping, things will pop out at you to accomplish this. It really happens!!!

The shoebox system has worked with a variety of children with autism, syndromes and associated delays.....in their classroom and at home. Parents have reported years later to me, that their children are STILL finding the systems to be calming to them to use at home. The way to use the system never changes. The activities and number of shoeboxes do. Children have learned to do their shoebox "routine" independently, after 1 on 1 training.

Another website given to me by a mom is: <http://www.discountschoolsupply.com/> They have great manipulatives, matching and counting items, books and story puppets and art supplies.

# THANKS!

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## Editors

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## 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 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. Here's how, contact:

Mary Beall  
Phone: 972-231-0035  
[mary.beall@comcast.net](mailto:mary.beall@comcast.net)



### 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 me at the above address.

# PRISMS

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