

# SPECTRUM

## Giving SMS A Voice

As fellow parents and loved ones of children with SMS, we are often challenged by the fact that the majority of the population has never heard about this condition. How many times have we had to explain SMS to medical specialists and each new batch of teachers? We gather our materials and print off yet another stack to help educate more people. For our children, they also endure the looks of confusion from classmates at school who have never heard about SMS.

Our daughter, Sarah, was just diagnosed in May, 2004 at the age of 11. (Thank goodness for the new FISH technology that finally discovered the small deletion!) Despite normal DNA test results over the years, we as parents knew that Sarah had something more than ADHD. Without an official SMS label, we sought early intervention services to address her speech/motor delays and learning disabilities. When the mystery for her challenges finally became clear, we were actually relieved. As our family learned more about SMS, we decided it was



*Sarah Thoman*

time to share our story, to give Sarah her voice.

Sarah functions well academically in a mainstreamed environment, but her challenging behaviors and social skills can turn peers off. At last year's IEP meeting, I asked the team if we could somehow explain what we knew about SMS to Sarah's classmates. If they only realized the why's, maybe fellow pre-teens would better understand why she picked at pencil erasers, shredded paper into bits, liked telling silly jokes, and became bossy at times. We decided to wait until her 7<sup>th</sup>-grade year when students would be learning about genetics.

Taught in the context of the science genetic unit, Sarah and I developed a PowerPoint about SMS to add relevance to their discussions. My older son read the PowerPoint presentation and liked how it summarized some of the genetics basics, "SMS 101," in a concise, user-friendly way. By scanning in pictures of Sarah and the family into the presentation, we also added humanity along with the science.

The slide show began by helping students make comparisons and activate background knowledge about a more well-known chromosomal disorder, Down's Syndrome.

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### 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.

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.....Continued on page 8

## Who's Who in



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## A Message from PRISMS President...

**Randy Beall**

This past July was **Smith-Magenis Syndrome Awareness Month**. Together we celebrated all the wonderful attributes and talents of SMS'ers while educating our community, school, churches, medical professionals, families and friends. I hope you were able to join us and create some SMS awareness. As most of you know, researchers believe the incident rate for SMS is 1:25,000. However, only a small number of affected individuals have been identified.



Garrett and firemen

As you may or may not recall, PRISMS held a contest for the best awareness effort. I am pleased to announce that Charlie and Tina McGrey will receive one free night of lodging at the upcoming 2007 PRISMS conference in VA. They gave a SMS presentation at their church. Charlie is a fireman. Some of the fire station crew were able to attend and they've been wearing pink silicone bracelets ever since! Congratulations McGrey's on a great job!

We've had a number of PRISMS board changes since our last newsletter.

Connie Bessette, who served as PRISMS President for a number of years, and most recently on the board as past president and advisor, has decided to step down. Connie made a huge contribution to our organization. Connie brought tremendous enthusiasm and energy to PRISMS. She will be missed!!

In related news, Rochelle Wright has decided to step down as VP but continue to serve as Secretary. Margaret Miller, one of PRISMS co-founders, will now be serving as Vice President.

I would like to welcome Joe Zdanowski and Percy Huston as our newest PRISMS board members.

Joe and his wife, Michele, live in New Hudson, MI. They have a daughter, Krista, who is 13 years old with SMS, and also a son, Kurt, who is 16. Joe is an electrical contractor. Michele is a full time mom. Joe's sister is Jeri Gawlowski, who serves as the PRISMS Treasurer. Joe has agreed to manage our database and email blasts. Michele is working on fundraising and also coordinates our new parent package mailings. A big thank you to the Zdanowski's!!

Continued on page 3.....

# Pennies, Pickle Jar, PRISMS..... Pool

By Michele Zdanowski



“Pennies in the Pickle Jar for PRISMS” campaign was a big success at our house, and with the wonderfully warm summer we just added in the pool. Krista is not an accomplished swimmer or water-lover by any means. During this super hot summer Krista enjoyed many days just splashing around in her pool. To improve on her putting face in (never under) the water skills; we would throw the coins from the Pickle Jar into the pool and see how far she could reach with her hand or foot until she accidentally got her face wet.

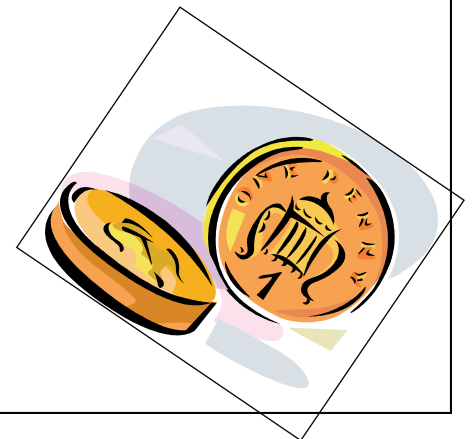
On any given day a jar full of coins could keep Krista busy for hours. (For me this is priceless!!) She would eagerly take anyone’s pocket full of loose change to add to her collection.

She enjoys sorting them into each different coin group, counting by ones, fives, tens and even twenty-fives, putting them in an automatic sorting machine and watching so they divide correctly, and rolling them into individual wrappers and then unrolling them too. She will even use a calculator and coin-u-lator so she can check and recheck her work. The coins are even great for pretend shopping trips! And at times that little SMS temper tantrum has occasionally sent the entire collection of pennies for PRISMS pickle jar scattered across the entire room!!

Thank goodness PRISMS has asked that we convert our entire summer collection into a check, because the thought of sending in

all our coins could send me into a meltdown!

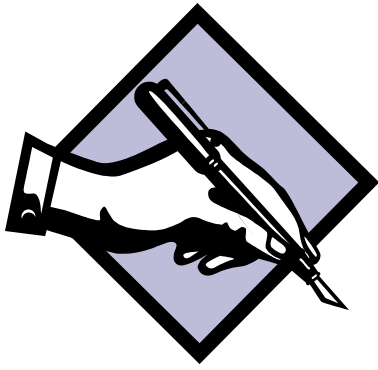
Donations received from the “Pennies in the Pickle Jar” campaign directly support food costs at Conference 2007. Please remember to send your check into PRISMS noted as “pickles”.



Randy’s message continued from page 2

Percy and his wife, Bernadette, a registered nurse, live in Cape Girardeau, MO. They have a daughter, Jacqueline, who is 15 years old with SMS, and also a son, JP, who is 13. Jacqueline was diagnosed 2 years ago. Percy is a bank-card sales representative. Percy has agreed to spearhead our fundraising efforts. We appreciate Percy and look forward to working together.

PRISMS depends on volunteers. I’m so grateful to have wonderful partners on the PRISMS board. All of these folks have made personal sacrifices to help our children. Please join me in welcoming Joe and Percy!



# ABC'S OF HANDWRITING

By Julia Hetherington, MHS, OTR, CHT

Have you ever sat in an IEP/school meeting and been told that your child can write “*just fine*” when he/she “*wants to*”? Our SMS children often have multi-faceted problems that affect their handwriting. Yet, if handwriting is the trigger that sends your child into a meltdown, what can be done?

As a parent, you can be versed in the basics of handwriting, what assessments are available, and what interventions are available. This helps you be a better prepared parent member of the team.

There are many factors that may come into play with handwriting and the SMS child. Issues with sensorimotor function, motor skills function, vision, fatigue level, and behavior all have a role in handwritten communication.

Several studies have suggested that instruction in handwriting be postponed until after the child is able to master the first 9 tasks on the Developmental Test of Visual-Motor Integration (VMI). The 9 figures are a vertical line, a horizontal line, a circle, a cross, a right-oblique line, a square, a left-oblique line, an oblique cross, and a triangle. Most typically developing children should be ready for handwriting instruction in the latter half of the kindergarten school year. Does this mean that you should hold off on handwriting until these skills are developed? No, I do not believe so. But be aware that the child may be pushed to accomplish something that they may not be developmentally ready for.

When a child has poor handwriting an individualized assessment is necessary. Data must be gathered from a variety of sources. Data might include written work samples, direct observation in the

natural setting (i.e. classroom), and discussion with the team members, including the parents, as well as other means.

Questions may be asked about comparison to peers, what handwriting method is being used, when does the child do the best written work, when does the performance break down, and are there other tasks (such as using scissors) that raise concerns. Parental input is needed on how the child performs in the home with homework, and with other writing tasks such as writing notes.

Measuring handwriting performance looks at four areas: 1) handwriting domains or tasks; 2) legibility; 3) writing speed; and 4) posture and motor control components.

Handwriting tasks or domains include:

- Writing the alphabet and numerals from memory.
- Copying. Near-point – copying from the same horizontal surface. Far-point – copying from a distant vertical surface (i.e. chalkboard).
- Manuscript-to-cursivetransition. More advanced with the child copying from a book to cursive writing.
- Dictation. A higher level function which combines auditory directions and a motor response.
- Composition. The generation of sentences or paragraphs. This requires sensorimotor, cognitive, and organizational skills as well as language abilities.

Legibility is readability. Components include letter formation, alignment,

spacing, size, and slant.

Writing speed, combined with legibility is the baseline need for functional handwriting. Speed typically decreases as the handwriting demands increase. This could lead to frustration, discouragement, and some of those full-blown SMS episodes that we are so familiar with.

Ergonomic factors are some of the easiest factors in handwriting to address, however, are often overlooked. Writing posture, upper-extremity stability and mobility, and pencil grasp are all ergonomic factors that need to be assessed. How does the child sit at his desk? Are the desktop and chair the appropriate heights? Does the child write with the whole arm moving? Does the other hand stabilize the paper? Is there excessive pressure to the writing tool?

Often too much attention is paid to the pencil grasp. A variety of pencil grasp patterns exist among typical adults and children. An atypical grasp pattern by itself does not necessarily result in handwriting difficulties. Traditionally the dynamic-tripod pencil grasp is stressed by teachers and Occupational Therapists. This is when the writing utensil is resting against the far part of the middle finger, while the pads of the thumb and index finger control it. The lateral tripod grasp may be considered as an alternative to the dynamic-tripod grasp. In this grasp, the thumb is held against the side of the index finger rather than against the pencil, thereby trapping the pencil in place.

Data gathering, as shown above is multi-faceted. Data gathering should also include formal, or standardized testing.

This is important because they provide objective measures and quantitative scores. In addition, formal tests aid in monitoring a child's progress, and assist professionals to communicate more clearly. Objective measures are a must in goal setting!

Numerous standardized handwriting instruments are available and need to be chosen with consideration given to the matching of areas of concern regarding the child's handwriting issues. Assessment tools commonly used in the United States include:

- The *Children's Handwriting Evaluation Scale* (Phelps, Stempel, & Speck, 1984)
- The *Children's Handwriting Evaluation Scale-Manuscript* (Phelps & Stempel, 1987)
- The *Denver Handwriting Analysis* (Anderson, 1983)
- The *Diagnosis and Remediation of Handwriting Problems* (Stott, Moyes, & Henderson, 1985)
- The *Evaluation Tool of Children's Handwriting* (Amundson, 1995)
- The *Minnesota Handwriting Assessment* (Reisman, 2000)
- The *Test of Handwriting Skills* (Gardner, 1998)

Each of these assessments looks at various aspects of handwriting. They typically test legibility and speed, as well as near and far point copying. The child's age and the type of script required are also important in choosing a standardized or formal test. Your school should provide you with a list of which tests they have available.

Once handwriting performance has been measured, and other components such as sensory, motor, and visual needs have been addressed, an intervention plan must be developed by the team. This may include classroom adaptation, extended time allowances, sensory integration techniques, and behavioral planning.

Several handwriting intervention pro-

grams exist. The most commonly used are:

**Callirobics** This utilizes children's songs and workbooks. More information available from Therapro, Inc., 1-800-257-5376

#### Big Strokes for Little Folks

Designed for children who already recognize most letters, ages 5-9.

Available from  
Therapy Skill Builders,  
1-800-211-8378

#### Handwriting Without Tears

A comprehensive set of manuals addressing remediation.

Available from Handwriting Without Tears,  
1-301-983-8409

#### Loops and Other Groups: a Kinesthetic Writing System

A 6 week program aimed at second grade students to teach cursive through movement patterns.

Available from Therapy Skill Builders,  
1-800-211-8378

#### TRICS for Written Communication: Techniques for Rebuilding and Improving Children's School Skills

Provides over 400 remedial and compensatory strategies for improving student's handwriting in the classroom.

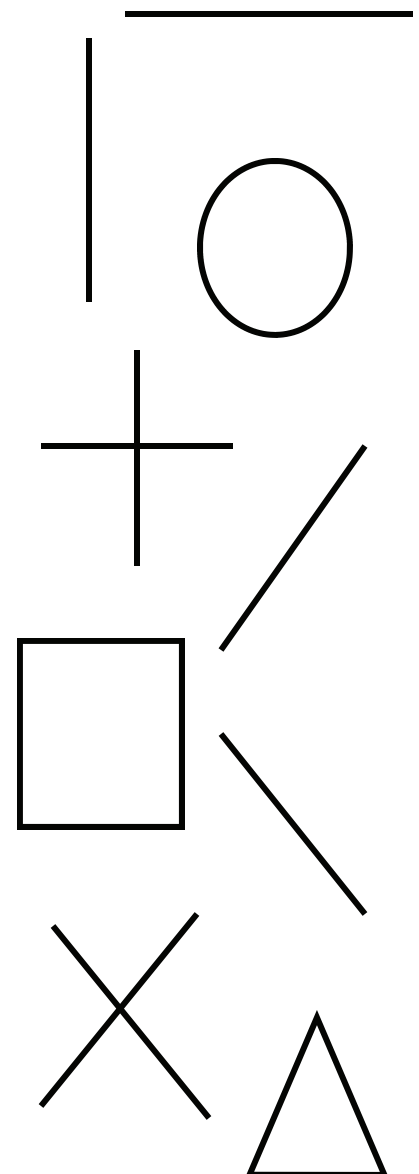
Available from O.T. Kids, Inc. 1-907-235-0688

Handwriting is an important task to master if at all possible. It has great academic importance and carries over into our children's everyday lives, both today and as they become adults. Having the knowledge of the basics and what is available is invaluable to the

parent as they play an ever important role on the team.

*Julia is an Occupational Therapist, Certified Hand Therapist, and the mother of 12 year old Rachel, SMS.*

*The 9 figures are a vertical line, a horizontal line, a circle, a cross, a right-oblique line, a square, a left-oblique line, an oblique cross, and a triangle.*





PRISMS - Parents and Researchers Interested in Smith Magenis Syndrome can now use GoodSearch! GoodSearch is a Yahoo-powered search engine with a unique mission – 50% of its advertising revenue, about a penny per search, is shared with the nonprofit organizations selected by its users. The more people who use GoodSearch, the more money will be directed towards PRISMS cause. The sky is the limit!

**Just think .....**



**What if PRISMS earned a penny every time you searched the Internet? Well, now we can!**

**Just go to [www.goodsearch.com](http://www.goodsearch.com) and be sure to enter PRISMS as the charity you want to support. With just 500 of us searching four times a day would raise about \$7300 in a year without anyone spending a dime!**

**Be sure to spread the word!**



***"An Authentic Taste of San Francisco"***  
**Paladini Quality Seafood Sauces**



Kiki with his granddaughter, Samantha

Mr. Achille "Kiki" Paladini of San Mateo, CA owns a Seafood Sauce business. He has dedicated the [Paladini Seafood Sauces](http://www.paladini.com) to include information about SMS. In addition to the SMS awareness, Mr. Paladini also donates profits from the sales to PRISMS. Please ask your local [grocer](http://www.grocer.com) for these sauces, or locate a store near you at [www.apaladini.com](http://www.apaladini.com).



# A Sister's Story

By Lindsay Warman

From the moment my mother brought my baby brother home, we were inseparable. He was so small and fragile. He would need a protector to look out for him, that role could only be filled by me, his big sister, Lindsay. As he grew older, much like other families in our situation, we noticed certain behaviors and manners that were not "right." When Christopher was very young we took him to have extensive testing. This was back in the early 1980's so the technology and the knowledge wasn't as advanced as it is today. The doctors tried very hard, but really could not define what was going on with him. As a young child my parents would try to explain the situation to me, I just stared at them blankly and said "Chris is just Chris and that is okay with me." That has been our family motto. As Chris and I grew older, our bond strengthened. For a long time I was the only one that could understand what he was saying. Now he stays a night with me whenever he is in town.

Chris has been lucky enough to be involved with some magnificent programs in Kentucky, the most current one being the KHAKI program. The staff in this program is so wonderful. They felt it was time to run up-to-date genetic testing on Chris. My brother, at the ripe age of 23, was diagnosed with SMS. Finding out the official term for his condition did not change much within our family. Chris is still "just

Chris." We have had many years to accept and work with Chris's behavior problems. As a sibling there were times I felt like I was getting slighted for all the attention needed for Chris. But then when I was around Chris, it didn't seem to matter. He is a wonderful person with a huge heart. I am lucky enough to be his favorite person (but don't tell the rest of the family, we try not to play favorites).

After reflecting on my past, growing up with a special needs sibling, and seeing all the struggles that our family went through, I wanted to help others out in our situation.

I am fortunate enough to work for Patrick Thompson, the owner of the Aveda Institute Columbus. We are a training institute for inspiring cosmetologists and esthetologists. "Our mission at Aveda is to care for the world we live in, from the products we make to the way in which we give back to society. At Aveda, we strive to set an example for environmental leadership and responsibility, not just in the world of beauty, but the world around us". Because the students are not licensed professionals, they may not receive compensation. In lieu of tips we donate to a charity every

month. I asked the student council if PRISMS could be put on the calendar for a charity. When I told the students about my brother, they were all too eager to help. We had station stalkers printed with a picture of Chris and I. The students are the shining stars that raised \$2,511.69 in one month. The students at our Institute believe in the Aveda mission. When they saw an opportunity to help families with special needs as well as personally reach out for something I believe in, there was not a moments hesitation.

I know the struggle for new families is a very hard road to travel. I hope this story helps SMS siblings out there. I have always felt that I am blessed to have Chris in my life and I hope it inspires others to help the world. Also a deep heart felt thank you to the wonderful students and staff at the Aveda Institute Columbus, as well as the clients who gave so generously to a wonderful cause.



Chris and Lindsay

**Giving SMS a Voice.....continued from page 1.....**

(Down's involves an extra chromosome 21 and SMS involves a missing piece of the 17<sup>th</sup> chromosome.) Using prisms.org as our reference, we included pictures of FISH-detected chromosomes and listed some physical and behavioral characteristics. For the presentation, I mostly explained the content and Sarah shared what she was doing in the pictures: dancing, playing her clarinet, and exploring her world. We ended the show with an emphasis about how kids with disabilities exhibit resilience, achieve success, and interact actively with others.

During the presentation, the teacher encouraged me to share my feelings and frustrations as a parent. Even though I was apprehensive and fearful about not controlling my emotions, the teachers and kids were surprisingly very engaged and supportive-they were awesome! A side benefit was that others siblings could share their stories about living with various other disabilities. During ques-

tions and answers, several peers told their stories: a brother had Down's, a younger sister wasn't talking yet and the Mom was really worried, many wished people would stop making jokes about their medication – ADHD was real!

By helping Sarah share

of the students and teachers at Shiloh Middle School in Hampstead, MD. Many faculty members popped in to see the presentation as well. Ms. Clayton, the science teacher, deserves special recognition for creating an accepting classroom environment where kids learn to

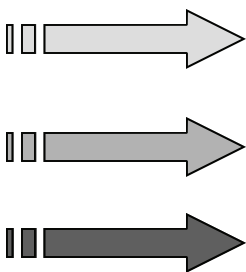
*How many times have we had to explain SMS to medical specialists and each new batch of teachers?*

her voice, we gave others a voice as well. Non-disabled peers can be huge advocates for our kids, as long as we communicate openly and educate them. Several children actually came to the front and shook Sarah's hand, praising her for her courage. Many classmates enjoyed the slide showing Sarah taking a catnap and commented how she always used to sleep at school – now they knew why! Sarah also received a large Thank You card from the five classes that we presented to throughout the day. In turn, I greatly appreciated the support

respect and value diversity in each other.

Please feel free to adapt the PowerPoint presentation which is available at the PRISMS website. Scan in pictures of your child and share his or her story with classmates. The rewards are immense – knowledge empowers and creates acceptance.

*Written by Tina Thomen, mother of Sarah, a young teenager with Smith-Magenis Syndrome.*



**Watch for these in your mailbox!!**

Annual Fundraising Letter Drive November 2006  
Membership Dues Renewal January 2007  
Conference Registration February 2007  
Next Issue of Spectrum January 2007





building bridges  
of hope

PRISMS 5th INTERNATIONAL CONFERENCE  
reston 2007

**SAVE THE DATE FOR THE NEXT PRISMS CONFERENCE!**

## “BUILDING BRIDGES OF HOPE”

**WHEN:** MAY 10-13<sup>TH</sup>, 2007

**WHERE:** THE RESTON HYATT HOTEL, RESTON, VA\*

*WHO SHOULD ATTEND:* PARENTS, PHYSICIANS, RESEARCHERS, TEACHERS, THERAPISTS\*\*

*Please mark your calendars and plan to attend our Fifth International Conference. Sessions will include: Research updates, Intervention strategies, SMS across the lifespan, The Parent Expo, Estate planning/Special needs trusts, Creative recreational activities, Educational issues and “How to’s,” and The Parent Connect session. Most of all, come and meet new and old friends and celebrate all that is “SMS!”*

*Please watch for updates on the website. Conference information will be mailed in **future months**. Information will also be emailed. (Please make sure that we have your current mail information.)*

*If you are interested in contacting potential sponsors for the conference, or sponsoring any part of the conference yourself, please contact Maggie Miller, ([trellims@aol.com](mailto:trellims@aol.com)), or Percy Huston, ([jphiv@charter.net](mailto:jphiv@charter.net)), for details.*

*We hope to see you there!*

*\*Dulles Airport, (IAD), is 15 minutes from the Hyatt and has a free shuttle service to the airport. Reagan National is approximately 40 minutes away. BWI airport is 60 minutes away.*

*\*\*This is an educational conference. Childcare will be provided again by KiddeCorp, but space is limited.*



## Workshop of interest in Maryland

### **Genetics in the Classroom: Behavior and Interventions for Students with Genetic Syndromes**

**WHEN:** December 14-15, 2006 (12/14: 8:00 - 5:00; 12/15: 8:00 - 12:30)

**WHERE:** Baltimore Marriott waterfront Hotel, Baltimore, MD 21202

**DESCRIPTION:** This conference for special education professionals, educators, behavior specialists, nurses, social workers, parents and others will focus on the practical applications of genetic information in the school setting. Conference sessions will describe advances in genetic diagnosis and key research in behavioral, psychiatric, and cognitive genetics in specific genetic conditions, including fragile X, 22q11.2 deletion, Smith-Magenis, and Angelman syndromes.

**COST:** Cost is \$120 per person, including meals.

**FOR MORE INFORMATION:** For more information, contact Brenda Finucane, MS, CGC at [brenda\\_finucane@elwyn.org](mailto:brenda_finucane@elwyn.org) or visit <http://www.elwyngenetics.org>.

# Camp Days

Suzanne is a 13 year old with SMS. The past two summers she has attended camp with typical children entering 6th, 7th, & 8th grades from our church. This year we had 7 buses taking the kids to a camp in a neighboring state for 4 nights. The camp provided a one-on-one aide for Suzanne.

It was a great experience for Suzanne. Of course, she loved the attention. They did not make her walk everywhere - they had a golf cart for her to ride in. She made friends fast with the children who wanted to hitch a ride. Some of the activities she participated in included: crafts, swimming, kayaking, horseback riding, climbing wall, and camp group games. Other activities available at the camp which she either did not have time for, or chose not to do, include: zip line, high ropes course, bmx dirt biking, skateboarding, canoeing, paintball, archery, riflery, pole climbing, water slide.

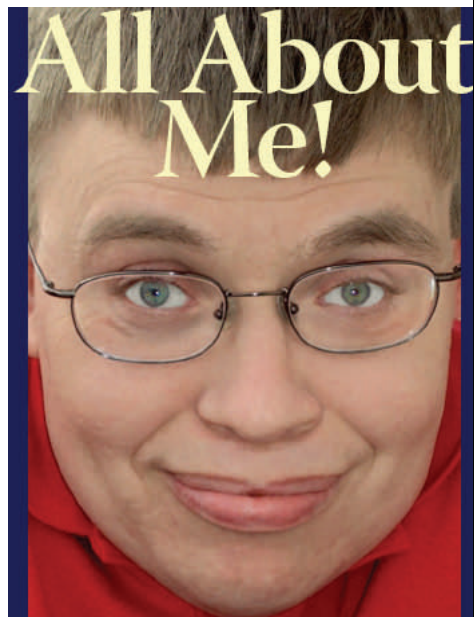
I'm thankful for our church and this camp for including children with special needs. You can check it out at [www.springhillcamps.com](http://www.springhillcamps.com) (They do say in their brochure that they accept special needs children.)

Carol Wollschlager



Suzanne

BOOK BOOK BOOK



## One Family's Experiences with Smith-Magenis Syndrome

By Shirley Dechaine

With

Ann C.M. Smith, M.A., D.Sc.(Hon.) Genetic Counselor, National Institutes of Health, Bethesda, MD

And

R. Ellen Magenis, M.D., Clinical Geneticist/Cytogeneticist, Oregon Health & Science University, Portland, OR

Number of copies of <i>All About Me!</i> @ \$11.95 each: _____		Subtotal: _____	
U.S. orders add \$2.50.			
International orders inquire at <a href="mailto:don.dechaine@verizon.net">don.dechaine@verizon.net</a>		Shipping/handling: _____	
Send to:	Mountain Creek Publications		
	5775 SW Sequoia Dr., Tualatin, OR 97062	Total enclosed:	_____

## DINE, SHOP, TRAVEL, SAVE.

### With the new 2007 Entertainment Books!!

The coupons are valid immediately and do not expire until 11/1/07. These 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 2007 books are available for nearly 160 Metro Cities throughout the United States and Canada. Would you consider helping?



Here are some selling ideas:

1. Could you sell 10 books to family and friends?
2. Do you have a business or a workplace that could display a sample book and take orders?
3. Books make a great holiday gift for business' to give their employees—all you have to do is ask?
4. Host a telethon or send out 20+ emails?

The ideas are endless.

The easiest way to preview and purchase your own local book is at [www.PRISMS.org](http://www.PRISMS.org) and click on the Entertainment Book link. As you go through the purchasing process you will receive the discounted group price and PRISMS will automatically receive 20% profit off each book purchased.

Thank you,

Michele Zdanowski

SMS Parent and Fundraising Volunteer

[mzdanowski@comcast.net](mailto:mzdanowski@comcast.net)

(248) 437-7251

## PRISMS New SMS Discussion Forum

The new PRISMS SMS Discussion Forum or Bulletin Board is online! This great new resource is designed to build a "knowledge base" for SMS - created by parents, professionals and people affected with SMS - to help and support each other. Because of the structure, good posts with valuable information should be easy to find and won't get automatically archived because of age. It's easy to search the various forums - either by category and forum and topic, or just by using the search function to find entries.

Other features:

- \* Information is well-organized to help newly diagnosed parents and persons find what they need
- \* It's easy to begin new discussion topics
- \* It's easy to post daily updates
- \* Registered users can easily access all posts which have been made since their last visit
- \* You can edit your own postings - if you make a typo or need to explain something
- \* If you post a question, you can click "watch this topic" and you get email notification when someone responds to you
- \* Private messaging (PM) allows you to contact others privately
- \* Anyone can view most areas of the forums; to post you must register
- \* Personal information (real name, location, personal website) may be made public or kept private - it's up to you

We hope you will go to the PRISMS website – [www.prisms.org](http://www.prisms.org) – and check out the link to this important new resource. If you have questions, please email [prismsbb@prisms.org](mailto:prismsbb@prisms.org)



### Monthly Emails

We have started sending out monthly informational emails to keep everyone up to date on fundraising, reminders, conference information, etc.... Please add

[prismsnews@prisms.org](mailto:prismsnews@prisms.org) to your address book and spam exception list to insure you keep receiving your infomails. If you have not received these emails and would like to, send your name and email address to [info@prisms.org](mailto:info@prisms.org) or [prismsnews@prisms.org](mailto:prismsnews@prisms.org).

This past July, PRISMS participated in the Birdies for Charity Fundraiser. This "Birdies" fundraiser was held during the "John Deere PGA Golf Tournament" in East Moline, IL. This was our first endeavor with this fundraising campaign. The object was to pledge a small coin amount, (one cent, five cents, etc.), per each birdie scored throughout the four day tournament. When the total number of birdies were tallied for the tournament, you paid the total birdie amount pledged. PRISMS received a total of \$710 in pledges. **Fore!**

PRISMS receives 100% of the profits from Birdies for Charity. The fundraiser was also very easy. Birdies for Charity takes care of all the paperwork, notifies pledges of their amount due, and best of all, the "pros" have to do all the hard work. No golf skills required! We hope to participate in future Birdies for Charity tournaments next spring and have an even greater response from our PRISMS members and friends. Look for more Birdies for Charity information at our conference in May. Let's get you signed up and cheering for the pros and cheering for PRISMS!





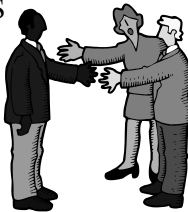
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## PARENT TO PARENT

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 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@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.

## THANKS!

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