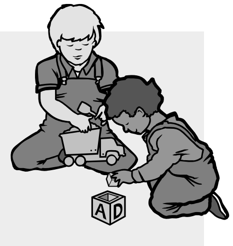
PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

SPECTRUM

PRISMS

VOLUME 11, ISSUE 2

SPRING 2007



# I'm Special Too! Siblings of Special Needs Children

By Judy Winter

Being the sibling of a child with special needs may be challenging. With the support of a loving family, this experience can result in rich life lessons that serve children well. So take time to let your children know they are all special.

It's not easy being the brother or sister of a child with special needs. These siblings may believe their parents' time and energy must go to meet the demands of their brother or sister with a disability, leaving little time for them. Research shows that siblings of children with special needs are at greater risk for depression. They also tend to be over-achievers to make up for the shortcomings of their brothers or sisters. Plus, they sometimes bury their needs to avoid adding conflict to already stressed-out families.

Many parents of children with special needs function on too little sleep, visit lots of hospital emergency rooms, and are primary caregivers 24/7. So it's easy to see how the needs of other children in the family may go unmet. That is especially true if these children appear to be doing well in other important areas of their lives, including school.

**It's not easy trying to be the perfect child.** Being the one without a disability can be a pretty heavy load to carry, too. Through no fault of their own, these kids are asked to cope with the loss of a simpler and more normal family life, and give up regular family outings.

They may be afraid their siblings will embarrass them in front of their peers. They may wonder how special needs in the family will affect their own social life, future plans and responsibilities. Add to this mix powerful emotions like anger, grief, fear, and the protectiveness siblings often feel toward the child with a disability, and it's easy to see why these kids need to understand where they fit in a challenged family.

**Seek a regular life in spite of special needs.** From the beginning of our special needs parenting adventure, we promised our oldest child, Jenna, that her brother's special needs would not shortchange her life dreams. During the past 12 years, it hasn't been easy to keep that promise. But now we are enjoying the

……..Continued on page 8

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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.*

☎ Questions?

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# A Message from PRISMS President…

## Randy Beall

The countdown to the next PRISMS conference has started. It will be held May 10-13 in Reston, VA (Washington, DC suburb).

Have you registered yet? Don't delay any longer, register today! A number of folks have been working countless hours to make this conference great and the best yet.

While PRISMS has a number of programs for our members, the conference is our "biggie" and it only comes around every 2-3 years. I hope you will make every effort to attend. Details are in this newsletter and on our website so check it out!

By now hopefully you've become aware that the PRISMS official address is now Sterling, VA and not Dallas, TX. In case you (ya'll) were wondering, my family still lives in Dallas but we are trying to be more efficient with the PRISMS mail. During the past few months, our transition period, some of our mail was not forwarded by the Dallas post office. So, if you've made a donation to PRISMS and we haven't cashed your check yet, please let us know by sending an email to info@prisms.org or calling us at 972-231-0035. Please accept my sincere apology for this inconvenience.

The PRISMS SMS Discussion Forum now has 56 registered users and over 91 "articles" have been posted. For those that have taken the time to join and post something - a big thank you!

You can check out this great new resource by clicking on the large Discussion Forum icon on the prisms.org home page. I encourage everyone to post something (anything!) but hopefully something you think others will find of value.

A discussion forum is really just a blank slate. This is our chance to get to know each other and share the insight and experience we've each gained from our children. Maybe you've discovered a medication or therapy technique that's really working for your child or perhaps you have something to share

Continued on page 3…...

# Challenger League

Luke loves to watch the Kansas City Royals on TV, yet it is hard to keep exercise and outside activities in the daily routine. Luke's parents were told, by a friend, about an organization forming in Kansas City called Challenger League. The league's mission is to take kids with all different types of delays, pair them up with a "buddy" (a child that can assist a special needs kid) and have them play baseball together. The Kansas City Challenger league teamed up with the Greater Kansas City YMCA and now has baseball, basketball and soccer. Football will be added next year. Luke now has activities all year round that get him out and exercising every week.

The Greater Kansas City YMCA's Challenger League has raised enough money in the city to develop their very own sports complex. The entire complex is designed with special needs kids in mind. Bases are level with the playing surface to make it easier on wheelchairs, kids with walkers, and other devises that make dirt fields challenging. Luke has been blessed to find an activity that is created for kids just like him.

*The Challenger Division of Little League is a program for mentally and physically challenged youth, helping them to enjoy the full benefits of Little League participation in an athletic environment structured to their abilities. More than the skills of baseball learned through the experience, the value of the Little League Challenger Division is found in the proven therapeutic and socialization benefits of participating in sports, the strengthening of participants' self-esteem, the opportunities to mainstream into other divisions of play, and the disciplines of teamwork, sportsmanship and fair play, which are hallmarks of the Little League program. The Little League Challenger Division provides the framework so Little League programs may offer a structured, athletic activity for all youth in their communities. Playing with the same equipment on the same fields, Challenger Division participants have the opportunity to experience the joys of pulling together as a team, being cheered, and earning awards for their achievements.*

**For more information on a Little League Challenger Division in your area or to order a starter kit for a Challenger program, please contact:**

**Jim Ferguson**
**Challenger Division Director**
**570-326-1921 ext. 212**
**jferguson@littleleague.org**
**www.littleleague.org**

**Luke with his younger brothers**

Randy's message continued from page 2

about past PRISMS conferences or maybe it's just how your child was diagnosed and your SMS journey. Whatever it is, we'd love to hear from you! If you have questions about joining or posting to the SMS Discussion Forum, please email prismsbb@prisms.org

I look forward to reading your post and seeing everyone in DC soon!

Randy

# Special Needs Planning Beyond the IEP and Age 22

For more information about this and other related topics, visit the Met**DESK** website at www.metlife.com/desk
or call 1-877-Met**DESK** (1-877-638-3375).

Parents of disabled persons over age 22, who want to plan for the financial future of their child with special needs, often have different issues to consider than those of younger children. For many parents with younger children receiving special education services, the nature of the disability, interventions, ultimate prognosis and outcomes may still be uncertain and unknown. Parents may try different therapies, educational and treatment modalities, and be very proactive in trying to positively impact their child's special needs. Whereas parents of older children may have a clearer sense of their child's capabilities, limitations, and what the future may hold for them.

Parents of both younger and older children may have need to calculate just how much money is needed to supplement educational, medical, social, recreational, housing, or vocational services. Government benefits may need to be supplemented through additional planning efforts. Some of these issues will be explored that are directly related to calculating how much money is actually needed when special education services end at age twenty-two.

After a student's twenty-second birthday, mandated education services are generally no longer provided. The Individuals with Disabilities Education Act (IDEA) requires that children with disabilities receive:

1. Free appropriate public education for children ages 3-21.
2. Education as close as home as possible with children who do not have disabilities.
3. Supplemental services (such as speech therapy, occupational therapy, or a classroom aide) to complete their education.
4. An assessment to determine the child's needs.

Parents of children with disabilities, who turn age 22 and transition from IEP and special education services, are faced with many new issues and obstacles. Hopefully, well-designed transition plans were put in place years ago by the educational team and the disabled person successfully transitions to further education or the world of work. The nature, scope, and severity of the disability will determine whether additional transition, rehabilitation, day programming, medical, or vocational services are needed. Some disabled persons will continue to receive government benefits such as SSI and Medicaid, while others will not.

Many privately held health insurance policies do not cover students or disabled persons past the age of 22. Parents need to carefully review their health policies to determine coverage for disabled dependent persons over the age of 22. Coverage varies from plan to plan. Some policies do provide extended coverage past age twenty-two, while others do not . Parents should contact their benefits department to determine extended health coverage for a disabled dependent person over age twenty-two.

For those persons who do not receive government health insurance benefits, the cost of medical care is staggering. Many states provide supplemental health care coverage for disabled persons over age 22, which may not be tied to SSI eligibility. These supplemental policies may require either an extra premium or larger co-insurance deductible. However, many states do not provide supplemental health care policies for the disabled. Parents need to check with their state welfare or Medicaid office to determine the level of coverage and services provided in their state. Levels of coverage and the scope of medical services provided vary from state to state!

Parents of an uninsured disabled person often experience "sticker shock" and large medical bills if their child is not receiving government health insurance benefits or if they are not covered under a parent's individual or group health policy. Parents of the disabled should seek out knowledgeable professionals and advocates to help secure needed health care benefits and services for their children. There are advocacy organizations in most states that can advise parents on health insurance related issues.

Special needs planning is sometimes very different for parents of younger children than for parents of older children. Parents of younger children often do not know what type of long-term care of support that their children will need and whether or not that they will be able to function independently. They do not know whether all their hard work, therapy and doctors' visits, and advocacy efforts will pay off for their children in the long run. Parents of younger children are very hopeful for positive outcomes, adaptations, and results.

By age 22, most parents have a solid understanding of their child's skill levels and future potential. Parents usually know whether they will go onto college, job market potential, ADL skill level, and interpersonal skills and competencies. They know whether or not that their children will be self-sufficient, need government benefits, can live alone, or will need supplemental assistance and support to be provided by parents or loved ones through special needs planning efforts.

Special needs planning, when coordinated with a properly funded special needs trust, can help parents plan for the financial future of their child (ren) with special needs. If structured by knowledgeable special needs professionals, assets can pass to a special needs trust and not count towards the $2,000 SSI limits for an individual which means that government benefit eligibility will be maintained and money can be used to supplement the lifestyle of the special needs individual. The trustee needs to make certain that the money is used for supplemental purposes only.

*Continued on page 5*………..

*Continued from page 4………..*

An important part of special needs planning is to make certain that a mechanism is set up to provide "enough" money to meet long-term needs. Parents with children under age 22, whose multiple needs are being met through local school systems, may find themselves with additional bills after their children "graduate" from the educational system. Parents may find that they now have to pay out of pocket for additional speech therapy, occupational therapy, counseling, physical therapy or other services previously provided under the terms of the IEP. When planning for a disabled person under age 22, parents cannot forget to incorporate important benefits and services provided by the local school system. Replacement services and costs need to be carefully planned for. They will become the responsibility of the parent or the disabled person themselves after their 22nd birthday.

Due to the complexity of federal and state laws, you may require specially trained professionals to help you plan for the future of your child(ren) with special needs.

### Transition Planning

A Few Websites

http://www.metlife.com/desk
http://www.wrightslaw.com
http://ici2.umn.edu
http://www.ericdigests.org
http://www.schwablearning.org
http://www.ncset.org/publications
http://www.nichcy.org
http://www.taalliance.org

Note: search "iep and transition planning"

## PRISMS Support

Help us raise awareness of SMS, and money for PRISMS **Saturday, August 25, 2007** in Springfield, Ohio! Grab your running shoes for a **5K Race** at beautiful Buck Creek State Park starting at 8am. Or, let the runners pass you by and join us in a leisurely one mile walk!

Stay until the afternoon for a "SMS Family Friendly" **Carnival** just one mile away at the Springfield Firefighters Lodge. There will be food, rides, games and prizes, raffles, a silent auction and a live auction. What is more important, there *will not* be loud Disc Jockeys or Bands, scary stuffed characters trying to hug you, or helium filled balloons flying away, or air filled balloons dragging on the ground, or even water filled balloons bursting!

For more information, contact Charlie and Tina McGrevy at 937-327-9354 or cmcgrevy@yahoo.com. Stop by our table at the conference. *Please bring a snapshot of your child and share a story about his or her accomplishments.* We plan to make flyers for the race participants so that they can better understand our kids and why they are so special. **If you would like more info on how Charlie and Tina set up this fundraiser, please contact them at the above number.**

*If you have hosted a fund raiser for PRISMS and wish to share your success please contact the newsletter editor with information. If you would like ideas on how to organize a fund raiser, please contact Percy Huston (jphiv@charter.net or 573-278-6763).*

## Have you updated your address book?

PRISMS, Inc.
21800 Town Center Plaza
Suite #266A-633
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If you have sent mail, i.e. SMileS donation or membership renewal, to the old Texas P.O. Box in the last six months, please verify by checking to see if your check has cleared your bank. Any questions, contact info@prisms.org.

## Sibling Support

A few websites for
additional information.
(see article page 1)

http://www.judywinter.com

http://www.partnershipforlearning.org

http://www.med.umich.edu

http://www.parentingpress.com

http://www.siblingsupport.org

http://www.aboutourkids.org

http:/www.kidsource.com

Note: search "siblings of special needs children"

## Monthly Emails

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

Please add 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 or prismsnews@prisms.org .

PRISMS - Parents and Researchers Interested in Smith Magenis Sydrome 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 go to 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 we could raise about $7300 in a year without anyone spending a dime!**

## PRISMS 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 – and check out the link to this important new resource. If you have questions, please email prismsbb@prisms.org

# SILENT AUCTION

If you haven't been paying attention to the last few articles we've sent then I want to tell you about the upcoming SILENT AUCTION to benefit PRISMS. If you don't know a reason to help with this auction, I'll give you 10...

## TOP TEN REASONS TO DONATE TO THE UPCOMING PRISMS CONFERENCE SILENT AUCTION

NUMBER 10 – You don't know what to do with that antique vase you inherited from your relatives in England since it doesn't match your bright chartreuse paisley couch. - DONATE IT! (the vase, not the couch)

NUMBER 9 – You received the latest Beatles CD compilation for your birthday but you'd rather listen to your “Best of Contemporary Elevator Music, vol. 12” CD. DONATE THE BEATLES – Keep the vol.12!

NUMBER 8 – That bottle of '01 Sine Qua Non On Your Toes Syrah wine is collecting a lot of dust on your table. Instead of getting a Swiffer to clean it, DONATE IT!

NUMBER 7 - “My new, unopened KitchenAid mixer has way too many gadgets! I'd rather use a fork. I think I'll DONATE IT to the PRISMS Silent Auction!”

NUMBER 6 - “Hey, honey, I received a $100 gift certificate from work to Outback Steakhouse but since we are both vegetarians, what should we do with it?” - DONATE IT!

NUMBER 5 – Your husband went to the local bar and bought a round for the house... a house of 50+. Get him back by donating a round of sessions at a day spa.

NUMBER 4 – Your wife went over the limit on her VISA but you really can't say anything since you just bought a round for the house but you can send a gift certificate to TGI Friday's. Then you can bid on it and buy another round.

NUMBER 3 - “Who is Honus Wagner anyway?” Might as well get rid of that baseball card since you need to make room for all those Ichiro cards you bought. - DONATE IT!

NUMBER 2 - You stayed an extended day at that really expensive hotel during a “business” trip. You are now feeling guilty that your spouse was dealing with the multitude of characteristics your SMS child exhibits, all in that one day. while you were lounging at the pool with an umbrella drink in your hand, listening to KC and the Sunshine Band sing “That's the Way, uh-huh, uh-huh I Like It!”. And to top it off, you earned enough hotel points because of that pleasure filled day, to get a free weekend hotel stay. FEEL BAD? Then DONATE IT!

AND THE NUMBER 1 REASON TO DONATE TO THE UPCOMING PRISMS SPECIAL AUCTION – My wife has threatened to put me on Melissa (our sweet SMS child) duty for a solid month if we don't come close to the money raised during the last PRISMS Conference. And if you don't want me calling you at 3 in the morning as I “rewind Barney for the 18th time” to quote a popular song, to let you in on the latest item she has jammed down her ear canal, then you will help out. DONATE!!!!!!!!!!!!!

The best reason to donate is to support our wonderful organization, PRISMS! That helps all our great SMS families. We have space to store what you have or you can bring your items to the conference. We need a lot more, so DONATE!

Thanks so much to those who have already contributed. Please contact us if you have any questions.

**Barry Woodhouse 103 Lake Meadow Dr. Apex, NC 27502 bazzer@nc.rr.com**
**919 306-7019**

……..continued from page 1…….

fruits of our commitment and spending time with two well-adjusted and happy children. Jenna, now 18, is following her long-held dreams of becoming a photojournalist. She has high self esteem and a wisdom beyond her years. And she's a wonderful big sister and role model for others.

**Here are six tips to meeting the needs of siblings without disabilities.**

1. Make one-on-one time with the child without a disability a priority. If that means getting a sitter, do it. Siblings deserve time away so they can have your full attention. Such efforts may also help your child make it through those days when special needs demands more of your time and attention.
2. Encourage your child to express honest feelings about having a brother or sister with special needs. Siblings may hold back emotions to avoid adding stress to the family, or because they feel guilty about having negative feelings. Let them know these feelings are normal.
3. If despite your best efforts, your child still has a hard time coping with her role, seek professional help. This can challenge even the most well adjusted child. It's OK, and sometime necessary, to ask for help.
4. See your family's special challenges as a chance to model positive problem-solving behavior for your children. Kids with brothers and sisters with special needs often display a maturity and sensitivity beyond their years, which can serve them well in other challenging situations.
5. Encourage your children to keep journals, then honor their privacy.
6. Try hard to avoid using siblings as caregivers. There are community agencies designed to help with these needs. Access them.

Judy Winter is an award-winning writer, national speaker, and the author of **Breakthrough Parenting for Children with Special Needs: Raising the Bar of Expectations**. For more information, visit www.JudyWinter.com. This article is reprinted with the author's permission.

# What could you do with $30?

*You could*

Have dinner at a restaurant?
Fill your car with a tank of gas?
Buy a few lattes at Starbucks?
Pay a parking ticket?
Renew a magazine subscription

*OR*

**RENEW YOUR PRISMS MEMBERSHIP!!**

Our **Annual Renewal of Membership Drive** is already in full swing. We thank all those that have sent in their dues and especially thank those members who have included an "extra" donation with theirs. But, in order to stay current and remain on the **PRISMS Newsletter** mailing list, we need you to fill out the 2007 Membership form and send in your dues.

**PRISMS** relies solely on donations and membership dues to support its programs. All of the worker-bees involved in **PRISMS** are all volunteers, so much time and energy and talent is also donated. We need members to help support those programs through the yearly dues. Your membership fee goes a very long way and in the end, helps to raise awareness and educate families and professionals all over the world. Please continue to support **PRISMS** through your yearly dues, as well as keep your mailing information current and your name on the mailing list.

We appreciate all your support!
The membership form can be found at www.prisms.org.

Parents and Researchers Interested in Smith-Magenis Syndrome

**PRISMS, Inc.**
**21800 Town Center Plaza**
**Suite #266A-633**
**Sterling, VA 20164**
Tel: 972.231.0035
info@prisms.org
www.prisms.org

**Please complete this Membership Form.** Please print**.**

**NEW** **RENEWAL**

LAST NAME: ______________________________________________
FIRST NAMES (MR., MRS., MS.): ______________________________________
ADDRESS: ______________________________________________
CITY: ____________________STATE/PROVINCE: __________ZIP: __________
COUNTRY: ______________EMAIL: ______________________
HOME PHONE: ______________CELL PHONE: ____________________

I am willing to have newly diagnosed families contact me (Parent to Parent Program).
I am interested in being a PRISMS volunteer.
I would like to receive the Spectrum Newsletter via email only.

| | | | | | |
|---|---|---|---|---|---|
| SMS PERSON'S FULL NAME:______________________________ | | | | | |
| DATE OF BIRTH (mm/dd/yyyy) :__________ | | | GENDER (M/F):__________ | | |
| RELATION- | Parent | Relative | Professional | Grandparent | Other |

**Annual Membership Contribution Information in U.S. Dollars**

$30 SMS Parent/Caregiver/Relative/Friend

$35 International SMS Parent. Payment by credit card or international money order/cashier's check obtained at your local bank denominated in U.S. dollars. Payment by check or draft in your local currency. Please contact your bank for the current foreign exchange rate or obtain a rate using www.xe.com/ucc/.

$50 Physician/Health Professional

$50 Other Organization (please specify)________________

If you would like to join PRISMS but cannot afford membership, please make as generous a contribution as you can afford at this time.

Enclosed is my contribution of $_______.

Basic Membership contributions do not cover all PRISMS annual operating costs.

Please consider making an additional contribution.

**Payment Information.** Please return this Form with your Membership Contribution to above address.

Membership Contribution: $______ Enclosed is my __Check Check #________ Date:________
Additional Contribution: $______ __VISA __ Mastercard

Card #:________________________ Exp:_______

Name on Card (please print):____________________

Total $ Signature:______________________________

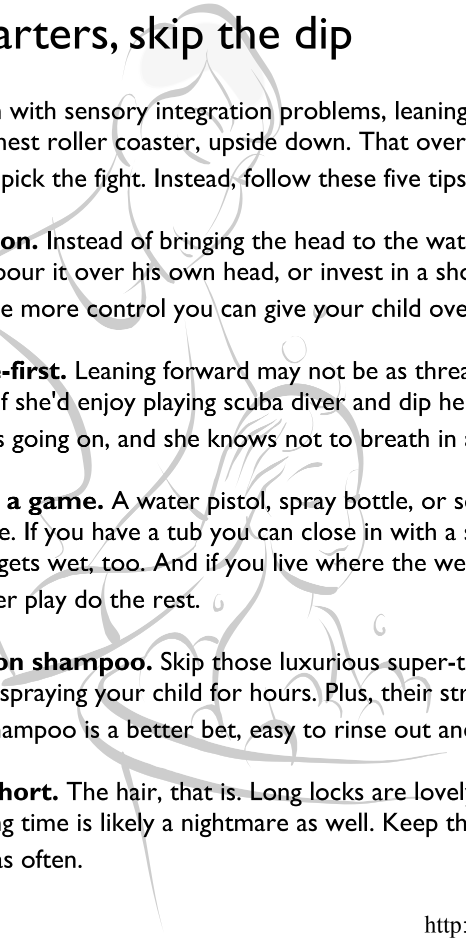
*We appreciate your support and participation.*

All PRISMS contributions are tax deductible under 501(c)3 of the IRS Code, to the extent allowable by law.

PRISMS keeps all information confidential and will not share or distribute personal information to anyone else without authorization.

# Ways to Handle Hairwashing Hassles

## For starters, skip the dip



To children with sensory integration problems, leaning backward to dip hair into water may feel like being stuck on the world's highest roller coaster, upside down. That overwhelming resistance that seems like stubbornness may in fact be real fear. Don't pick the fight. Instead, follow these five tips for making hair-washing fun and fast.

**1. Pour it on.** Instead of bringing the head to the water, bring the water to the head. Let your child fill a cup or a pail with water and pour it over his own head, or invest in a showerhead that can be pulled away from the wall and used as a sprayer. The more control you can give your child over the process, the better.

**2. Go face-first.** Leaning forward may not be as threatening to your child as leaning backward, since she can see where she's going. Ask if she'd enjoy playing scuba diver and dip her head all the way down face first. Make sure you're in the bathroom when this is going on, and she knows not to breath in a nose-full of bathwater.

**3. Make it a game.** A water pistol, spray bottle, or squirt bottle can do the trick of wetting and rinsing, and bring a little fun to bath time. If you have a tub you can close in with a shower door or curtain, let your child go wild with the spraying, as long as the hair gets wet, too. And if you live where the weather's warm and your child loves running in sprinklers, lather up and let the water play do the rest.

**4. Skimp on shampoo.** Skip those luxurious super-thick potions -- they take forever to rinse out, and you don't want to be dousing or spraying your child for hours. Plus, their strong scent may be a turn-off for kids with sensory sensitivities. A thinner baby shampoo is a better bet, easy to rinse out and working up a fluffy head of bubbles with just a little actual product.

**5. Cut it short.** The hair, that is. Long locks are lovely, but they take more washing time than your child may be able to give, and combing time is likely a nightmare as well. Keep that hair as short as you can stand -- as an extra bonus, you won't have to wash it as often.

http://specialchildren.about.com

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Book Review:

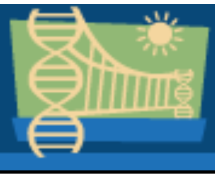
# The Explosive Child

There was a time for a while there when every new behavior book seemed to be about "The _____ Child." The Challenging Child. The Out-of-Sync Child. Transforming the Difficult Child. Skeptics, especially those who thought "The Child Who Gets His Butt Spanked Once in a While" would pretty much take care of the problem, made jokes about all this child-tagging, and nothing made eyes roll more than The Explosive Child, which seemed from its title to imply that you should back slowly away from your child and never dare to challenge him.

But if you have a child who is chronically inflexible, or who seems to get locked into behaviors he's powerless to stop, parenting may feel quite a bit like being one of those bomb squad guys in an action movie, trying, as the digital clock of doom ticks down, to figure out which wire to cut, knowing that one defuses the situation and the other brings mass destruction. The Explosive Child can be enormously helpful in suggesting parenting methods that will dampen burning fuses or keep them from being lit in the first place.

Book by Ross W. Greene, Ph.D.; 334 pages. "*A new approach for understanding and parenting easily frustrated, chronically inflexible children.*"

http://specialchildren.about.com



**building bridges** *of hope* PRISMS 5th INTERNATIONAL CONFERENCE reston 2007

# The Conference is coming! The Conference is coming!

# Are you ready?

**When:** May 10-13th, 2007

**Where:** Reston Hyatt Hotel, Reston, VA

**Why:** To learn about SMS, past, present and future and to share information and strategies with other families.

**What will be offered:** Sessions on sleep, behavior, therapeutic interventions, medications, school issues, estate planning, stress and the family, Parent Expo and the Silent Auction.

| **CONFERENCE COSTS:** | **Up to 4/18/07** | **After 4/18/07** |
|---|---|---|
| *Adult (15+) | $175 | $225 |
| *Child (14 & under) | $75 | $100 |
| *SMS Individual | $75 | $100 |
| *Professional | $250 | $300 |
| Professional In-training | $200 | $250 |

## CONFERENCE SCHEDULE OVERVIEW:

**Thursday, May 10**

2:00 – 4:00 pm – Parent Connect

4:00 – 7:30 pm - Registration

5:00 – 7:30 pm - Welcome Reception

**Friday, May 11**

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

8:00am-5:15pm - Conference Sessions

**Saturday, May 12th**

7:00 – 8:00 am – Continental Breakfast

8:00 am – 5:00pm - Conference continuation

**Sunday, May 13st**

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

***Note** – conference ends promptly at 11:00 am.

## HOTEL COSTS:

At the Reston Hyatt Hotel, PRISMS has a special room block rate available at: **$119** single/double per night, **(Thurs-Sat, only),** plus applicable tax. This special rate is available only until 4/18/2007. Please reserve your room early by calling 1-800-233-1234 or by going to: http://reston.hyatt.com/groupbooking/restosmss2007

## CHILDCARE:

**KiddieCorp** will provide childcare on site for SMS children only. **KiddieCorp** has provided high quality children's programs and youth services for 21 years. Activities are appropriate for each age group, and include arts and crafts, music and movement, videogames, karaoke, movies, story time and dramas.

Childcare is available for **SMS** children ages 4-18 years. Program dates are May 11-12, 2007. **Fee**: $150 per child for both days. Space is strictly limited. Register via the link at www.prisms.org or directly at www.kiddiecorp.com/prismskids.htm. Or you can call 858-455-1718 (FAX 858-455-5841).

## CONFERENCE REGISTRATION:

You can register online for the conference by going to the link below. If you need a registration form mailed to you, please call the PRISMS office at 972-231-0035.

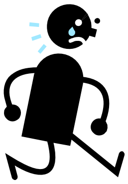
http://ww2.eventrebels.com/er/EventHomePage/CustomPage.jsp?ActivityID=1394&ItemID=5163

All of the details of the conference are available on the PRISMS website at www.prisms.org. We hope you will attend, whether it is your first conference or your fifth. Come meet new friends and visit with old friends. You will also have the opportunity to meet with the researchers and professionals who are spearheading the latest research on SMS. Where else can you go and have immediate access to our Professional Advisory Board and dedicated professionals!

Be a part of the dynamic partnership with our professionals and our families as we ALL "build the bridge" to a better understanding, acceptance, and quality of life for persons with SMS.

**COME CELEBRATE ALL THAT IS SMS!! SEE YOU THERE!**

# Behavior Management In SMS



### *By Mary Beall, SMS Parent, M.Ed*

This article is the second in a series published in Spectrum, based on workshops at the PRISMS 2005 conference by the author. The first part of this article can be found in the Winter 2007 issue of Spectrum. Available on the web at www.prisms.org.

***So What Can We Do?***

Do What Works! Don't worry about what someone else says, or what the current parent magazines say, or whether your methods are "fair" to other children. ( is it fair to expect your child with SMS to behave exactly like typical children when she has so many more problems?) You may have to try several methods, and you may have to use them in conjunction with each other. There is no perfect answer, and no program that will give 100 % compliance, or that will guarantee that the child won't explode. The good news , however, is that there are some SMS parent-tested strategies that can make it *more likely* that your child can control himself and improve his behavior.

### Thoughts to consider

**Try to get some sleep.** Work on finding a sleep solution first-because sleep deprivation increases their behaviors, and decreases our ability to cope.

**Children with SMS shouldn't be expected to be to able control their own behavior without assistance.** The behaviors are a documented symptom of SMS, in other words, you could say they have a "behavioral control" disability. If a child has vision impairment, people don't just expect them to work out a way to see, and then punish them if they don't. They are given tools and instruction and encouragement to overcome their disability. In the same way, our children need our help, our coaching, our encouragement to accomplish what is for them a very difficult task.

**If you want them to control and change their behavior, you may first have to control and change your own behavior ( as explained by Dr. Ross Greene, in The Explosive Child).** We can't expect them to conform to our methods and our standards. We have to find ways to change our approach to make it more likely for them to succeed.

**Use of force and authoritative commands as your primary discipline technique can make it more likely that the undesirable behaviors will increase.** These children react strongly to a strident tone of voice and lots of authoritative commands. They get into power struggles and get "locked in." At that point, no threat of punishment or offer of reward is big enough to stop them. You can actually see a change in their demeanor, and from that point on, they will be acting controlling, menacing, and threatening. This looks very much like defiance, but you can tell the difference because they only do it when they get locked into a power struggle.

**Many behaviors can be minimized by creating a relaxed, supportive, flexible atmosphere.** When you can, let them control something,…anything. Try not to be rigid or demanding. That doesn't mean you don't set boundaries, just that you try to keep from having to constantly say NO! or overpower them. Try to stay calm, or at least act calm when they are "losing it." They need to "borrow your calm."

### Set Up An "SMS-Friendly" Environment

**Caregivers are kind, and flexible.** When a child begins to get defiant, the adult makes sure that their own tone of voice and body language are very neutral-not negative, you don't want to set them off worse!

**Lots of the "house rules" are handled by the environment so the adults aren't always having to say no.** SMS-proof similarly to baby-proofing. Try locks on cabinets and refrigerators, locking up remote controls…

**Plan rules/expectations around the child's developmental and emotional age.** For example, if their developmental age is 4, then you can can't expect them to be able to stay on task much longer than a 4 year old would.

**Respect their attention span.** Don't expect them to sit still for very long. Many of them can't even sit still to watch more than a few minutes of their very favorite video, how can we expect them to sit and be quiet for long periods of time?

**Consider their Language Level.** If they have auditory processing problems, they will have trouble following directions, and long conversations. They have a hard time "holding their thoughts in their head", and so may be constantly interrupting before they forget what they wanted to say. They don't know "turn-taking" in conversation. They may be at a language stage where they can only talk about something happening right now, that they can see. At this stage they can't talk about what happened at school, or particularly "why" it happened. They will be very literal. They may not be able to use "self-talk" inside their head to help them control themselves. **And remember that language levels decrease when we are upset, resulting in even more communication problems and behaviors…think of times you have been very angry and couldn't be rational.**

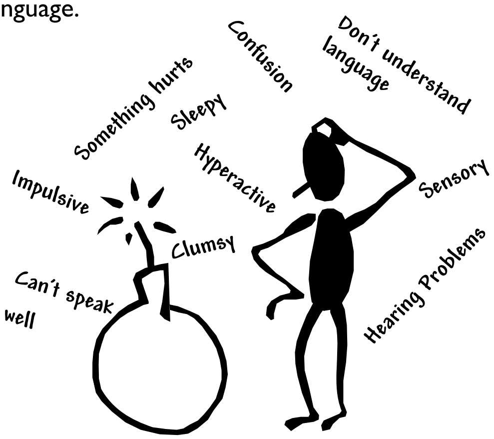
**Use Visuals.** Use notes, drawings, photos, gestures, and even your facial expressions to help them get more information. A daily

*Continued on page 11…….*

*….continued from page 8*

schedule with photos can reduce anxiety about transitions. Since many can read, written reminders and lists can help them take care of themselves.

**Act as a narrator for their feelings and teach them words to use for emotions. "**Your face is scrunched up and your legs are kicking, You are so MAD!" At first, the emotions may have to shown in sign language.



***But what can we do to make him behave?***

- When you can, use the same good parenting skills you would use on any child.
- Speak at the child's level, one command at a time.
- Have a plan, and a backup plan, especially for high risk situations.
- Be as consistent as you can ( no one is 100%!).
- Help the child understand that you are the authority ( not harshly).
- Give reasonable choices.
- Distract them.

**But**…

*Sometimes, particularly in the early years, all you can do for most of the behaviors is :*

**Keep a Lid on It ! Preventing the SMS Explosion**

Children with SMS have so many problems, that they are often keyed up or "boiling" on the inside.

Sometimes they boil over just from their own internal struggles. Things that happen to stress them are just added flames . Each thing that happens makes the flames higher, and makes the child that much closer to boiling over into an explosion.

| Examples of Flames: | Biggest flames: |
|---|---|
| Someone tells them "No", or "Hurry" | Being forced to do something |
| Someone yells | Power struggles |
| Teasing | A parent/teacher's attitude that they have to "win" |
| Change/Transition | |
| Attention is on someone else | |
| They are hurried | |
| Asked to sit still for a long time | |

We can't change their SMS, and their tendency to "boil." Our job is to keep the flames as controlled as we can. It's a balancing act, trying to recognize their mood and ability to stay in control. We don't want to add "fuel to the flame."

**Fire Prevention: "Only You Can Prevent Forest Fires, Your Child Can't!"**

***Three ways to control the "flames" .***

1. *Put them out*. Change what is bothering them, or reduce the stressors.
2. *Stop, Breathe, Get Control.* If you can control your own reactions, and keep your own adrenaline from flowing, they have a better chance to control theirs.
3. *Do something to slow down or eliminate the "fight or flight" adrenaline .*

They are stressed already, just by the problems that come with SMS. Then they get extra stressors, or "triggers" that set them off. At this point, their natural reaction is to "lose it" and explode or self-abuse. Their own reaction ( and our reactions to theirs) then stresses them more, and the cycle starts all over again. We have to find some Cycle Interrupters, or some Flame Reducers.

**Vicious Cycle Interruption (Flame Reducers)**

Definition: Anything that you can do to interrupt the cycle-also called "Redirection" or "Distractors"

Whisper.
Surprise them in some way-blow a bubble, laugh, pull out a flashlight.
Sing your instructions instead of saying them in a demanding way.
Use an excited voice and change the subject.
Request their help with something totally unrelated to the problem causing the stress.
Provide coaching, a second person ( whoever they are not angry with at the time) can sometimes give advice on what to do, or get them to go for a walk.
Send them on an errand.

Appeal to their natural sense of empathy-show them a cut on your finger.

*Continued on page 12…….*

Ignore or "pretend" not to notice a behavior they are doing just to engage you.

Physically moving them, or better yet, enticing them to go somewhere else.

Changing the person they are dealing with-move them away from who they are mad at.

Think about the positive. If you are thinking , "What a brat!" it will show up in your tone of voice and body language.

Point at something out the window.

Use routines for bedtime, morning, etc, always doing things in the same order.

Write or draw whatever you want to communicate to them.

Use humor or drama, i.e., they say "No!" and you say in a southern drawl, "Well I declare, Miss Scarlet, you do say that well!"

Find a way to give them some freedom and a sense of control.

Make them think something is their idea.

Refuse to react to their provocations.

Keep yourself as calm as you can.

Use exaggerated, excited praise for any tiny step your child makes towards controlling himself, i.e., "You are really furious, but you only hit me once!" See book by Glasser.

Wait-sometimes just waiting a moment and being silent can calm them down.

*(Note: There are many more suggestions in the behavior management article by Bev Frey, 1999. It can be read on www.prisms.org under managing behavior. )*

**Special note about being forceful with them: Sometimes it works, but watch out!**

Yelling at them and being forceful ( this is more than assertive) sometimes controls them very well. I believe that the reason is because it is just another one of the distractors/vicious cycle interruptors. Using a threatening tone of voice, or yelling can surprise or shock them enough to break the cycle. This is particularly true if they are "revving themselves up" by perseverating on something.

However, use it very cautiously and as seldom as you can because:

1. You are their model, and you will probably hear whatever you said come out of their mouths later.
2. They learn that "force" is the way to get what you want and you may see them try to become more forceful.
3. A pattern of force can send them into a pattern of rages, and can increase the problems you are hoping to decrease.

Trying to control them with force brings out our own "fight or flight," adrenaline-driven responses. That just makes things worse, plus there is a danger of hurting them if we let our anger take control of us. In The Explosive Child, Dr. Greene presents this formula:

**(Inflexible Child +Inflexible Adult = Meltdown!)**

**Tips For a full-blown melt-down**

-child is now shouting, hitting, threatening

-child taunts and defies authority

-may be injuring herself

-destroying property

-strength seems superhuman

Goal: stop the tantrum, or give child tools to get himself out

Goal is not: trying to teach a lesson, trying to show who is boss

( That enhances a power struggle, and these children get locked into their own power struggles and will not/cannot give in!)

- **Give them physical space if they are aggressive**. Don't crowd them in a threatening manner.
- **Active ignoring**. You are close by, preventing as much danger and destruction as you can, but you don't give them eye contact, even if you have to pick them up. You just act like they are a "sack of potatoes"
- **Move them**. If you can, safely, the goal is to help them calm down by getting them away from the place where they were "set off", ( their visual trigger) ; try to choose a place that has few things they can destroy ( this is most effective when they are really small, and of course gets much harder later).
- **Control yourself**. Voice and body language awareness. Show no emotion except possibly boredom.
- **Don't react!** To their words or deeds trying to "get to you."
- **Don't interact**. Don't argue back, don't answer questions, don't repeat instructions.
- **If you have to overpower them** to help them get control, ( watch out, sometimes this one backfires!), then try to find a

neutral way, one that doesn't involve excessive force by an adult. Put them in an empty room, use a therapeutic hold ( but you must get trained first!) *A therapist taught us how to roll our daughter up in a sheet like a hot dog-head out of course, it seemed to really help her.*

- **Don't expect them to be able to talk about it or make restitution yet. Some can't do that for many years!**

They get control of themselves in stages. As they begin to calm down, their ability to stay that way is still very precarious. If something happens to stress them, they escalate quickly back to the tantrum.

- **Provide recovery time.** Let them eat something, or rest, or play on the computer.

**Forgive, and make each day new.**

**Think of Yourself as Their Behavior Coach**

How to Be a Behavior Coach

*This technique is very powerful and is much better explained in Transforming the Difficult Child by Howard Glasser.

**-Set the bar low to ensure success**. Set your expectations for how he should behave not by what a "typical child" is doing, but by his own abilities, by what he is showing you right now. The first goal should be to do a little bit better, which probably won't be anywhere near what you really want.

**-Celebrate and praise even the most basic good behavior**. They should get more attention from us for the things they do right, than for the things they do wrong.

**-Prioritize and work on only a few skills at a time.** A good coach knows that you can't learn it all in a day.

**-A good coach teaches skills, and doesn't expect them to already have them.** Explain, draw, and demonstrate what you want, and help him to practice.

**-Reward effort, not just success.** The coach knows that the hardest work may be in the beginning, while the most learning is happening. "You look very angry right now, but so far you are staying in control, keep it up!" or "That must have been hard, I can see you were trying your best"

**-Encourage the discouraged**. "You almost did it!"

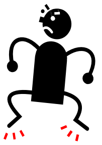
**Tools that may make it easier for them to learn control**

- Occupational and Physical therapy to help them with motor skills and sensory integration issues.
- Sign language-to help them communicate while speech is developing.
- Medication-can give them enough control of themselves that they can then respond to behavioral techniques.
- Some people have had luck with special diets and vitamins.

***Final thoughts…***

When my daughter, Laura ( age 20, has SMS) saw that I was writing about how to manage children with SMS, she said, " Well, Mom, just tell them Matthew 7:12, from the Bible! " Knowing Bible verses is one of her quirky strengths. When I went to look it up, I realized it said, " Do unto others as you would have them do unto you!" I guess in that short sentence, she said most of what I have been trying to say.

Start each day new. They do…they need a new clean slate. Don't keep score…on them or on yourself. You WILL make mistakes. Some days you'll be too exhausted to do anything but survive. I've been watching March Madness, because for once in a lifetime, my college team made the playoffs. These players are good…amazing even, but the funny thing is, they only get it in the basket about 50 % of the time…and they keep on shooting. They have been facing that free throw line all of their basketball careers, you would think they would be able to do it blindfolded by now. But they can't, because it is such a hard task, and so is parenting the child with SMS.



***If you feel like you have to walk on eggshells…***

Well, maybe you do…

The eggshell protects the chick until it is developed enough to be ok on it's own. If the egg is cracked too early, and the chick is exposed before it is ready for the pressure, it will not survive.

In the same way, our SMS children need us to protect them and give them time to develop. Their emotional/behavioral control is very slow to develop. They need coaching, patience, encouragement, acceptance, and flexible boundaries until they can develop enough control on their own to begin to break free of their frustrations and let their sweet natures dominate.

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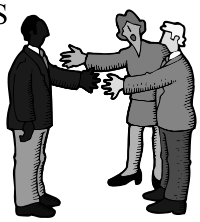
## PARENT TO PARENT

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@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 me at the above address.

## THANKS!

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