

SPECTRUM

Planning for the Future: It's Not Just About Money!

By Tracie L. Belcher



Having just entered into another decade of my life on the climb up to being "Over the Hill", my mind has been more and more on the thought of "What will happen to my child when I'm gone"? At first, as with anyone, I began to wonder if I had enough insurance and/or savings set aside for someone to provide care for my daughter should something happen to me. After attending an Estate Planning class at the local YMCA, I can answer that question with a big "NO", no I don't. Since my husband and I are both civil servants, unless we win the lottery, the odds are we will not have the financial resources to leave behind to provide care for our daughter in the manner in which she has become accustomed. She has been raised a "Princess" and it will be hard to financially maintain the "Queen" in our absences, that I'm sure of.

After attending this Estate Planning workshop, I began to feel somewhat limited on what I could do financially in preparation for my daughter's future without me. I can tell you, I lost many a full night's sleep thinking about it.....no, wait.....that's right.....I never get a full night's sleep. Seriously, what I did come away with from the workshop was the idea and sample guideline for a "Letter of Intent", a document which helps prepare any future caregiver for my daughter's other needs. What other needs you might ask? Well, in my opinion, the most important of all needs: Her likes and dislikes, her does and don'ts, her wills and won'ts and everything else we encounter on a daily basis. For example, no one in our family probably knows that my daughter hates tags in her clothes. Oh, I'm sure she would tell them if they handed her a new shirt with a tag in it...or would she? She loves to rip things and pulling a tag out of clothing is a favorite. That is why, when I purchase a new article of clothing for her, my first task is to cut the tag out before she has the opportunity to rip it out, ensuring an additional arm, neck or leg hole isn't created. Another example, as with most teenagers, my daughter can turn the volume up on her stereo until the windows rattle and the dogs begin to bark. Oh yeah, my daughter freaks out at the sound of loud barking dogs! Can you imagine? I wonder if anyone in my family knows this? Loud music, okay...loud barking dogs, a sure meltdown. Go figure!

Although I am taking an active approach at the financial planning part of her future, I have taken an even more active approach at preparing for the morning that I don't see the sun come up, and you know as a parent of a child with SMS, we're usually awake to see the sun coming up. What I've done is purchase a journal...a pretty little book, with a cute saying on it by Mary Engelbreit about "Walking toward the sun and the shadows will fall behind you" to begin this task. Although it is called a "Letter of Intent", mine, as I said, has become a book, a big book...not only am I including the things necessary to help my daughter make a smooth transition to someone else's care, but I have also included those little stories about the important things in her life that she loves for me to tell her over and over again, like the day she was born or her first day at school and how bad I, not she, cried. Although she has the memory of an elephant and probably could recite these stories as well as I, they are still something that connects us and if written for prosperity, can connect us long after I'm not here to reminisce.

Some examples of information you could include in your "Letter of Intent", or my case "Book of Intent": Favorite foods, comfort items, fears, things that make your child happy or sad, current physical and mental abilities religious ideas, people who have a calming affect on your child, friends, favorite teachers, favorite healthcare professionals, future housing plans, future education plans, burial arrangements, etc.

These are only examples and should not be used to limit you from putting whatever your heart desires into this. You are the expert when it comes to what you may think any future caregiver would need to know about your child.

Although the subject of life for your child without you is one of sadness, it is my hope by offering you this information that you can be more at ease knowing that you have left behind the most precious gift you could for your child, knowledge, knowledge that will assure that their life is just as you would have it to be.

"Now back to the "Big Book of Emily"...April 8, 2005: *Dear Caregiver, you won't believe how great my daughter is at finding things...you'll never lose another thing with my Emily around.*

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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.



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A Message from PRISMS President...

Randy Beall

Dear SMS families and friends:

The next PRISMS conference is almost here!! Are you excited?? I am. The conference will be held April 28-May 1, 2005 at the beautiful, downtown Westin Hotel in Cincinnati, OH. This conference is a major PRISMS program held every 2-3 years. Some of our board members, as well as many others, have been working very hard to make this conference the best ever. Please make every effort to attend. As Laura, my 20 year old daughter with SMS says – “It should be awesome, man!”

If you've paid your 2004/2005 membership dues already – thank you! If you haven't done so, please remember to pay. We need your money ☺ but we also need your email address, updates on your phone number, address, etc. You can mail a check to the PRISMS office or visit us at www.prisms.org. If you're registering for the conference, you can pay your membership dues during the online registration process. We depend on the support and generosity of our families/members to continue to provide our programs.

PRISMS SMS silicone bands are coming soon! Jay Maiher, one of our board members, has been working on silicone bands similar to the popular yellow Lance Armstrong Live Strong bands. Purple PRISMS bands will be available at the conference. These bands are a great way to spread awareness about SMS and help PRISMS raise money. Thanks Jay and please buy bands!

An SMS mom has written about her experiences raising a son with SMS. The book is called *It's All About Me! One Family's Experiences with SMS* by Shirley Dechaine with Ann C.M. Smith, M.A., D.Sc. (Hon) and Ellen Magenis, M.D. The book will be available for sale at the conference. It's also available on the PRISMS website. Please order your book today.

I look forward to working with all of you as we continue to solve the puzzle of SMS together!

Best regards,

Randy Beall
President

**THIRD ANNUAL GREAT LAKES REGION
SMITH-MAGENIS SYNDROME GOLF OUTING**

Saturday, June 25, 2005

VALLEYWOOD GOLF CLUB
13501 Airport Hwy.
Swanton, Ohio 419-826-3991

12:30 SHOTGUN START
18 HOLES OF GOLF AND CART
4 PERSON SCRAMBLE

LUNCH, DRINK TICKETS, STEAK DINNER,
RAFFLES, PRIZES AND CONTESTS INCLUDING HOLE-
IN-ONE
LIVE AND SILENT AUCTION

COST PER GOLFER: \$80.00

LIMITED TO 144 GOLFERS *RAIN OR SHINE*

Soft spikes, collared shirts and proper golf attire required

DON'T PLAY GOLF?? ATTEND DINNER WITH AUCTIONS AND PRIZES
\$30.00 PER PERSON

BLOCK OF ROOMS AVAILABLE AT COURTYARD BY MARRIOTT
LISTED UNDER PRISMS/SMS GOLF OUTING 419-866-1001

REGISTRATION DUE BY JUNE 15, 2005

For more information, please call Julie and Lin Van Nest at (419) 836-4505

Or contact them via email at JVanNest@hotmail.com

THANK YOU FOR YOUR SUPPORT!!



SMS Awareness Bracelets

Order Your SMS Silicone Band today!

These purple bands are a great way to build awareness about SMS. Bands will be available at the PRISMS conference and also on the PRISMS website (<http://www.prisms.org>) soon.

- * 1 band - \$3.00
- 5 bands - \$12.00
- 10 bands - \$20.00
- 20 bands - \$35.00

*singles are only available at the conference.

All prices are US Dollar and do not include shipping.

4th Annual "Tome" Smith-Magenis Picnic

Place: 929 Hill View Road, York, PA 17406

Date: July 30, 2005

Time: 9:00 A.M. until whenever (all day)

Contact Info: Sandra Tome or Jeanne Mitchell

email: tomestead@blazenet.net

phone: 717-757-6600



THANKING YOU FOR YOUR GENEROSITY!

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A special thank you to the Xerox Reproduction Center at Bank of America for their generous donation of paper and printing for this newsletter.

If you are interested in making a donation in memory or honor of that special someone in your life, please consider making a donation to PRISMS.

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CENTRAL MICHIGAN UNIVERSITY FUND-RAISER FOR PRISMS “CMU for SMS”



By: Joanna Harris

My name is Joanna and I am a sophomore at Central Michigan University. I decided to do a charity dance to support Smith-Magenis Syndrome (SMS) because I know Krista Zdanowski from South Lyon, Michigan. She is a sweet, young girl who has SMS and I felt that I should help out. I never knew about SMS until meeting Krista and her family, so I felt it was time to educate and spread the word about SMS. I wanted to make it known around campus and have students take back information to their professors, families and friends. The best way to educate on a college campus is by putting on a program, which made me look into doing a dance. I put together a university-wide dance and sold “CMU for SMS” rubber bracelets for the cause which were so generously donated by Jeri and Bill Gawlowski, aunt and uncle to Krista, and Rosemary and Dennis Harris, my parents. ALL ticket money raised and wristband money will be donated to PRI SMS. My dormitory, Robinson Hall, and Central Michigan University covered all the costs of the dance, which was held February 19, 2005, including a DJ from the local radio station. Wristband sales and ticket sales were very successful, all together we raised \$450.00. With a \$50.00 donation from another university organization, Child Abuse and Neglect Awareness (C.A.N.A.), it brought us to a total of **\$500.00 for PRISMS**. I set up a table in the University Center for four weeks prior to the dance to sell wristbands and promote the dance. I also had a booth in the Robinson Hall lobby every other night. Many students took information and were going to pass it on to their professors, families and friends. This is why it was so successful. My main goal was to educate more people about SMS and that is what was accomplished.

I want to thank everyone who helped with the dance and working the booths with me. I could not have done it without you. I also want to say thank you to all parents, guardians, friends and families of children and adults inflicted with this syndrome, for supporting and making more people aware of SMS.

Central Michigan University
SMS Fundraiser Dance



Krista Zandowski

CMU
4
SMS



Joann Harris & Scott



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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



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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