

SPECTRUM

Behavior Management In SMS

By Mary Beall, SMS Parent, M.Ed

This article is from a series of articles to be published in Spectrum, based on workshops at the PRISMS 2005 conference by the author.

What are the common behavior problems for Smith-Magenis Syndrome?

- Attention Deficit With or Without Hyperactivity
- Frequent Outbursts/Temper Tantrums
- Seeking Attention
- Impulsivity
- Distractibility
- Disobedience/defiance
- Aggression and Destruction
- Self-Injury: biting or hitting self , head-banging, and skin picking
- Nail-Yanking and Insertion of foreign objects into body
- SMS Stereotypic behaviors: self-hugging in excitement, hand clapping, page turning

There are also other problems commonly mentioned by parents, but not yet documented.

These may be a result of other symptoms, for example, children with sensory integration problems may cut the tags out of all of their clothes, or refuse to wear sweaters.

Some behaviors relate to modulation. They don't know when enough is enough, or else they don't have the skills to use just enough. They squeeze way too much toothpaste, pour way too much drink, spread way too much butter, use too much toilet paper, squeeze way too hard when they hug a person or an animal, and run instead of walking.

They can keep a household in upheaval when they take the batteries out of everything, get into the toothpaste and shampoo (sometimes smearing it all over), raid the refrigerator and dump the food, or rip up the film in your camera bag. And they are loud! They enjoy yelling or singing loudly, which is particularly annoying at 4:00 a.m.

While it is possible that a person with SMS could never show significant behavioral problems, some degree of self-injurious behavior and sleep disturbance occurs in most SMS individuals. Despite their very difficult behaviors, children and adults with SMS are very affectionate and have engaging personalities and much untapped potential.

Why do they behave this way?

.....Continued on page 8

INSIDE THIS ISSUE:

President's Message	2
Exercise for Everyone	4
Silent Auction Info	7
Special Needs Trust	10

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.

Randy Beall, President

21800 Town Center Plaza

Suite 266A-633

Sterling, VA 20164

Phone: 972-231-0035

E-mail: info@prisms.org

Website: <http://www.prisms.org>

Who's Who in



Officers

President: **Randy Beall**
Richardson, TX

Vice-President: **Margaret Miller**
Herndon, VA

Secretary: **Rochelle Wright**
Springboro, OH

Treasurer: **Jeri Gawlowski**
South Lyon, MI

Board Members :

Ann Smith Bethesda, MD
Charlene Liao Palo Alto, CA
Joe Zdanowski New Hudson, MI
Percy Huston Cape Girardeau, MO

Professional Advisory Board

Ann C.M. Smith, M.A., D.Sc. (hon), Chair
NIH, National Human Genome Research Institute

Judith Allanson, M.D.
Children's Hosp. of Eastern Ontario

Sarah Elsea, Ph.D.
Virginia Commonwealth University

Brenda Finucane, M.S.
Elwyn Training & Research Institute

Andrea Gropman, M.D.
Children's National Medical Center

Barbara Haas-Givler, M.Ed.
Elwyn Training & Research Institute

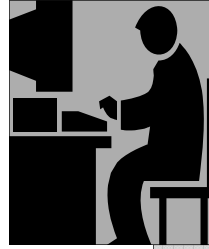
Kyle P. Johnson, M.D.
Oregon Health & Science University

James Lupski, M.D., Ph.D.
Baylor College of Medicine

R. Ellen Magenis, M.D.
Oregon Health & Sciences University

Lorraine Potocki, M.D.
Baylor College of Medicine

Beth Solomon, M.S.
W.G. Magnuson Clinical Ctr.
National Institutes of Health (NIH)



A Message from PRISMS President...

Randy Beall

The new PRISMS sponsored bulletin board is now officially online! But this great new program will only reach it's full potential if everyone starts using it. It's designed to be a well organized "knowledge base" for SMS – created by parents, professionals and people affected with SMS. Folders exist for you to post your questions, comments or concerns. Or for you to offer your advice to others. Want to talk about the upcoming conference? Well, consider making a post! Because of the structure, good posts with valuable information should be easy to find. A special thanks to Joe Zdanowski for all of his hard work to make this new program a reality.

Please go to the PRISMS website (www.prisms.org) today and click on the SMS Discussion icon on the right hand side of our home page. There is also more information on page 6 of this newsletter.

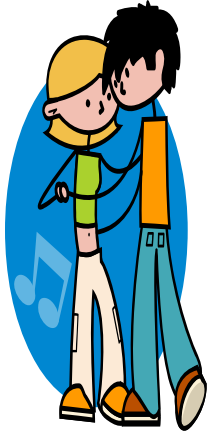
Our 2007 Building Bridges of Hope conference is only a few months away in beautiful Reston, VA (a Washington, DC suburb). The hotel is located in Reston Town Center – with shops, over 20 restaurants plus entertainment venues – all within easy walking distance. Many folks have been working hard to make this conference the best ever. My family has

attended 3 conferences now. I guarantee that you will meet the most amazing people at this conference - parents, researchers, educators, childcare givers, board members, medical professionals, siblings, family members, foster parents, adoptive parents, and so on. I hope you'll make every effort to attend.

Most folks don't realized how much money it takes to hold a conference. The biggest cost is hotel food. Our conference committee works hard to make our conferences affordable. However, we are dependent on our members, family and friends to raise money through the year to help us subsidize the cost to each family. This year PRISMS will once again pay a significant portion of the cost, so that the registration fee can remain reasonable. While we've chosen to offer childcare, I want to encourage you to leave your children at home if possible. As much as you love your child, you probably need a break. Plus, this is an educational conference and it's hard to juggle the conference and your child. Some families will utilize the childcare to attend this conference because they don't have a caregiver available at home. While the childcare we offer at the conference seems expensive, it's also heavily subsidized by our generous donors and past supporters.

Continued on page 3.....

Nettie's Big Day



Our 15 year old daughter, Nettie, has Smith-Magenis Syndrome. She was diagnosed with SMS at 13 months of age.

She started at a brand new high school this year. The school sent home a notice that there was going to be a football game and a homecoming dance. We were not sure that either event would be a good idea for Nettie. She has never shown any interest in sporting events and has never danced in her life. But when her Personal Assistant, Melinda, offered to take her we decided to let her give it a try. We figured they would be back home after an hour or so.

Nettie enjoyed the football game and cheered her school's team on to a 49-13 win. At the game Nettie tried to talk to a girl she saw there. When she started to talk to her the girl turned around and shouted "Shut Up Nerd!" Melinda, who looks more like she is in her late teens than the twenties, asked the girl what she

said. The girl had no problems with repeating what she said. Melinda asked the girl how she would like it if she said that to her. The girl responded she wouldn't like it. Melinda asked the girl why she thought it was okay to say it to Nettie. The girl responded with a dismissive response and the matter was dropped.

Nettie then came home, had dinner and got ready for the homecoming dance. Once again we figured they would be back home after an hour or so.

Nettie enjoyed herself at the dance. She and Melinda went on a hayride. Melinda told us she had special needs requirements when she was in school. She said she tried not to hover around Nettie so the other kids would not pick on her for having an adult watching over her. At the dance Nettie told Melinda to stay where she was while she talked to her friends. Melinda said that was fine as long as she could see her. But a little while later Nettie returned and pulled Melinda over to introduce her to her friends. It was a girl on the student council that saw Nettie and found a boy being a "wall flower" and told him he should ask Nettie to dance. The boy then came over and asked her to dance. We don't know how much dancing was done but it was great to hear she had a good time.

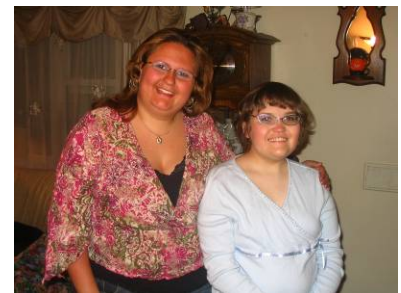
Melinda said she worked hard to overcome her own special needs and

says she knows some of what Nettie goes through. The nice thing about Nettie is that even if someone calls her the worst names, Nettie can go over and give that person a hug a hour later.

We are glad Nettie got to try both events and enjoyed them. We are thankful Melinda was willing to take her. If we had tried to take Nettie she would have most likely misbehaved and argued with us.

We try to let Nettie experience new things and if she shows an interest give her the opportunities to do them. She may not have the response we hope she would have but unless she is given the chance we will never know.

Proud parents of Nettie,
Eric and Kim Hoffman
Denver, CO



Melinda and Nettie

Randy's message continued from page 2

If money is an issue for your family, please consider contacting local or state social services groups, your state developmental disability council, local churches, local synagogues, special ed services, Knights of Columbus (www.kofc.org), The Shriners (www.shriners.com), Lions Clubs International (www.lionsclubs.org), Salvation Army, Angel Flight www.angelflight.org or 1-888-4-AN-ANGEL and National Patient Air Transport (www.npath.org). Be creative and start now! Finally, a very limited amount of financial assistance is available directly from PRISMS. Please send an email to Jeri Gawlowski using this special email account - financialaid@prisms.org

I hope to see you in Reston!

Outside the Box: Exercise for Everyone



Michaele R. Smith, PT, Med

The trend towards obesity has risen in the last few years in the adult population as well as the pediatric population. Data from the National Center for Health Care Statistics report that 30% of adults and 16% of children/teens are considered obese. Obesity is often accompanied with health problems, specifically those of high blood pressure, diabetes, and high cholesterol. For these reasons, many grassroots organizations have launched nation wide effort to educate adults and children about the consequences obesity.

The public has begun to realize that it's not just typical children that may benefit from physical activity but children with disabilities also need physical activity. Children with disabilities are generally eligible to receive therapy and related services when there is documentation of a specific diagnosis or delay of skills. These services received in the school are educationally relevant for the child. This means that the child receives therapy services if the disability interferes with the learning process. Often as the child matures, and achieves the identified school goals for therapy, these services are discontinued. Parents may want to know how to advance the skills of the child once therapy services have stopped. At this point, parents may ask, how can I as a parent continue to enhance the physical activity of my child once therapy services are discontinued?

We know the benefits of physical activity are numerous. Physical activity may assist in improving stamina, improving muscle strength, promoting feelings of well being, improving social interaction, and also reducing the potential for health related illness such as diabetes, high blood pressure, or heart disease. In children with Smith Magenis Syndrome, physical activity would certainly have similar benefits and allow for the family to participate in activities as well.

Before participating in any physical activity, the persons involved should obtain a physician consult. After receiving clearance from the physician, the family may schedule activities involving short intervals of activity (5-10

minutes) and gradually increasing the amount of time the family is participating in the activity each day. Two to three times a week is a recommended frequency for participation in any physical activity. The key point to keep in mind is that physical activity does not need to be strenuous to achieve health benefits!!!! The idea is to provide opportunities for physical activity that are motivating to the child. With support and motivation, the child is more likely to participate and succeed in regular physical activity.

Some examples of physical activities for children with disabilities are walking, hiking, dancing, basketball hoops, Frisbee throwing, stationary bikes, swimming, lawn bowling, or soccer. Existing family activities can be modified to include parking the car further from your primary destination. The family can be engaged in participating in chores, raking the leaves, shoveling snow, or folding laundry. Utilization of area recreation and parks for a low or no fee cost, can also provide an action packed day for the entire family.

Organized opportunities can be found in the way of challenger league baseball/softball, or soccer, local YMCA/YWCA's, local schools, or para-olympic programs. But remember the activity doesn't always have to be organized for the family to achieve the goal of physical activity. Sometimes may be best to arrange the child and activities within the family unit. This may decrease anxiety your child may experience while trying a new event.

Accessible equipment to get started with physical activity are stationary bicycles, simple pulleys, theraband, a home exercise program, or a local pool. You can challenge balance skills by looking for or simulating uneven terrains, finding moderately steep hills, or local play areas where there may be a chute, tunnels, or a pit of balls. Additional activity resources for children with disabilities can be found on these web sites: The President's Council on Physical Fitness and Sports, The Department of Health and Human Services, Office of Disability, Year of

the Healthy Child, and Healthy People 2010 to name a few.

The benefits of physical activity are numerous. Physical activity can be performed for short periods of time, in different settings, varying times, and can be organized or recreational. It is important, however, that whatever activities you choose as the family physical activity program, it should be fun for all, and be performed with consistency.

Resources

Presidents Council on Physical Fitness and Sports

(www.fitness.gov)

DHHS/Office on Disability

I Can Do it, You can do it

www.hhs.gov/od/physicalfitness.html

Surgeon General: Improving Health and Wellness of Persons with Disabilities

(www.surgeongeneral.gov/library/disabilities)

Year of the Healthy Child

(www.surgeongeneral.gov/healthychild)

Healthy People 2010

(www.healthy-people.gov)

KEEN USA

(www.keenusa.org)

References

Bloom B, Dey AN. Summary of Health Statistics for U.S. Children: National Health Interview Survey, 2004. National Center for Health Statistics. Vital Health Stat 10(227). 2006.

Culver L. Physical Therapy for Special Populations. *PT Magazine of Physical Therapy*. 2006 Oct pp 70-72.

CDC, Healthy People 2010: Objectives for Improving Health Disability and Secondary Conditions, Nov 2000, pp6-5.

Michaele Smith, PT, MEd

SMS Research Team

National Institutes of Health

Bethesda, MD 20892

Web Resources for Youth and Young Adults with Disabilities

*Adaptive Equipment for Sailing

<http://www.ussailing.org/swsn/technical-adapt.htm>

*Adaptive Mobility Equipment

<http://www.amemobility.com>

*American Alliance for Health Physical Education Recreation and Dance

1900 Association Drive

Reston, VA 20191

Telephone: (703) 476-3400

1-800-213-7193

<http://www.aahperd.org/aahperd/template.cfm>

*Cerebral Palsy International Sports & Recreation Association

<http://www.cpisra.org/>

*Consortium for Citizens with Disabilities

The Consortium for Citizens with Disabilities

1331 H Street, NW, Suite 301

Washington, DC 20005 Telephone: (202) 785-3388

<http://www.c-c-d.org>

*Disabled Dealer

<http://www.disableddealer.com>

*Disabled Dealer

www.teamamsvans.com

*Disabled Sports USA

<http://www.sdusa.org>

*Dynamic Directory

<http://www.maximumedge.com/cgi/dir/index.cgi/sports/disabled>

*National Center on Physical Activity and Disabilities

116 Albert Street, Suite 400

Ottawa, Ontario K1P 5G3

Telephone: (613) 231-SIRC

1-800-665-6413

<http://www.ncpad.org/>

Compiled by Michael Smith, PT, MEd

Successful Fund Raiser In California

Cheryl and Ed Huber, parents of 13 year old Smith-Magenis teenager David Huber, chose a park near their hometown of Victorville, CA to host a gathering for the SMS families in Southern California.

What started as a small family gathering became a large fundraising picnic that netted over \$4600 for

the PRISMS organization!

Attendees included one other SMS family, relatives, friends, neighbors, and co-workers. Activities included a silent auction, continuous raffles, cakewalks, volley ball, face and nail painting, as well as games for the children.

Raffle items were donated by businesses and private individuals. Food and

drink, all donated by local businesses was available for purchase. In addition, several people who were unable to attend sent cash donations.

Many friends and family members worked together to make this event a huge success!

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).



David Huber

**Are you a 2007 PRISMS member?
Membership forms are available at
www.prisms.org**

Join PRISMS to be a part of and support for all who are affected by Smith-Magenis Syndrome; help families through various stages of life faced by both children and adults with SMS by providing information, increasing public awareness, and understanding through education.



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 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!



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 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



GOING ONCE, GOING TWICE, GONE!

Shhhhh... it's a SILENT AUCTION!

It is conference time in May and that means you have another opportunity to help out PRISMS. Once again, the popular SILENT AUCTION will raise money for OUR organization and you can be a big part of that. Here is what we need from you...

1. Talk to your employer and see what kind of items they are willing to donate for the auction. This could be something they produce, something they've received, something they can obtain. Just ask. Do they deal with other businesses that would offer something? Gift certificates, personal items, tickets, etc.? Just ask!
2. Do you have a friend that is in some kind of creative business? An artist? Someone that owns a business that would be willing to donate a gift certificate or something electronic or a painting or anything that would raise money for PRISMS.
3. Did you receive **another** IPOD for Christmas and don't know what to do with it? Let us put it up for auction to help PRISMS. Anything lying around your house that might be a great auction item? A PICASSO, a signed basketball from Michael Jordan, a \$100 gift certificate from McDonalds? (that would last about a week with my SMS daughter Melissa) Do you have a vacation home you would let us bid on? Look around your house and let us know so we can put it on the list.
4. What kind of items would you be interested in bidding on? Send your list to bazzar@nc.rr.com and we can look for something you want.
5. Be creative! If you have an idea about obtaining items but don't have the time to make the contact, let us do it for you. Just send your suggestions to bazzar@nc.rr.com and we will do the legwork.

We have a donation receipt letter that we will be glad to send to anyone that donates to the auction. Please let us know what you've obtained or can obtain for the auction so we can put it on our list. We have a lot of storage space to accommodate just about anything, so help us fill it up! You can reach us through the information below. Thanks for your help and let's make this a great SILENT AUCTION!

Barry Woodhouse
103 Lake Meadow Dr.
Apex, NC 27502
919 303-0429 (h)
919 306-7019 (c)
bazzar@nc.rr.com





It is unclear exactly what causes these behaviors, however past research in the study of behavioral aspects of the syndrome (Dykens and Smith, 1998) show that sleep (or lack thereof) is the most significant factor predicting the difficult behaviors that occur in SMS.

Other factors are probably multi-faceted. There may be an internal drive to do these things, sort of a “short-circuit” that makes them react without a filter to stop them. They seem to have an immediate “fight or flight”, adrenaline-driven response to many situations.

Other possible causes include:

- Anxiety: Young adults who have SMS (finally at an age where they can talk about their emotions) mention that they worry and feel anxious a lot.
- Frustration: At themselves, others, their lack of skills, their communication problems, (and because they don't get to be in charge!)
- Speech/Language Problems: their speech is delayed, and when/if they can speak, it is difficult to understand them. They also have delays in understanding what others say to them, and in the ability to follow verbal directions.
- Delayed Development: they can't do things others their age can do, and if they are in a situation with others their age, they are often expected to be right on target.
- Delayed Emotional Development: their ability to control and understand their own emotions is similar to that of a child much younger than they are.
- Sensory-integration problems
- Sleep-deprivation: their sleep disorder and inverted circadian rhythm makes them “up and at ‘em” at a time when the rest of the family is asleep, and very sleepy and sometimes irritable when others are wide awake.
- Medical Problems: ear infections, frequent colds, toilet-training issues, and constipation are common, some have hearing impairment, seizures, scoliosis, and renal abnormalities.



So What's a Parent to Do?

You have an extremely difficult job. You have to cope with all of the problems that SMS brings while slowly working for positive change. This job is constant. There are times when all you can do is take each problem as it comes, and do the best that you can.

Here are some common misunderstandings :

- Our children are choosing to act badly.
- Inconsistent or poor parenting causes the behaviors.
- More consistent applications of rewards and punishments would cure them.
- They are misbehaving to get back at you for something.
- We should be able to control our child's behaviors.
- The child needs to understand “who is boss” and then they will comply.



The problem behaviors are a documented symptom of SMS. Of course, some of the behaviors they display are just naughty, just as the behaviors of any child can be. It can be really hard to tell what is caused by the SMS, and what is not. It is better to err on the side of assuming that the SMS is causing, or contributing to it, because the symptoms of SMS have such an overwhelming affect on their lives. And how can it hurt if you first think about how the SMS may be contributing before you decide they are just “choosing to be bad”.

There is a difference between annoying behaviors and behaviors that are dangerous and destructive. They aren't going to be cured of SMS, and so will probably always act somewhat differently than you would expect. Decide what you can live with.

Choose your worst or most irritating problems and make a plan. What needs to change? It may be the space they are in, or the way people deal with them, or even the time of day that you try to do something. You can arrange your house, yard, and car so that some things won't be a behavioral issue at all. If you can solve the problem with an environmental change, do it.

The next article in this series has concrete ideas for behavior management- can't wait? You can find the full article now at www.prisms.org under “Living With SMS” and “Behavior”.



Calling all Dads



Mother's Day Picture Contest

PRISMS is having a Mother's Day Picture Contest! As you may know, our conference, "Building Bridges of Hope," will be held May 10-13, 2007, which is over Mother's Day weekend. We would like to have a "Happy Mother's Day Picture" insert in the conference binder and we would like your SMS child to design it!

We ask that the picture be able to fit on **8 1/2" x 11"** white paper and may be done in color. **The picture design should be vertical, not landscape.** Dad's you may want to be in charge of this project and help your child design and color the best Mother's Day picture ever. The winning picture will be displayed in the conference binder.

Please make sure that your child's name appears on the lower right hand corner of the front of the picture. All submissions must be sent in by April 10th, 2007. Please send the picture, **unfolded, and ready to print!**

Send pictures to:

Maggie Miller

1237 Cooper Station Road

Herndon, VA 20170

Send email questions to:

trellims@aol.com



Moms too!



building bridges
of hope

PRISMS 5th INTERNATIONAL CONFERENCE
reston 2007

SAVE THE DATE FOR THE NEXT PRISMS CONFERENCE!

“BUILDING BRIDGES OF HOPE”

WHEN: MAY 10-13TH, 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!”

Conference registration is available at www.prisms.org. Conference information is sent out via postal mail and e-mail also. Please be sure we have up to date information on you!

The conference hotel is the Hyatt Regency Reston Hotel.

We hope to see you there! It is a wonderful time to connect with other parents and professionals who KNOW Smith-Magenis Syndrome!

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

Ways to Fund Special Needs Trusts

While many parents of children with special needs have done some basic estate planning, few have done very comprehensive special needs planning. Some parents have wills or living trusts while others have special needs trusts. Legal documents alone will not guarantee that money will be available, or that there will be enough of it to meet the long-term care needs of a child or other dependent with special needs.

Although a simple will is better than no will at all, it is not the solution for most special needs planning situations. A living trust or a special needs trust, even when correctly drafted, may not be adequate. If not coordinated and integrated with other legal documents and with all the financial assets, a child or other dependent with special needs will not be provided for properly.

Parents never want their child to be a financial burden on a guardian or caretaker. A well designed estate plan, when coordinated with a properly funded special needs trust, can help parents plan for the financial future of a child 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. This means that government benefit eligibility will be maintained and the trust assets can be used to supplement the lifestyle of the individual with special needs. The trustee needs to assure that the money is used for supplemental purposes only. An important part of special needs planning is to make certain that a mechanism is set up to provide sufficient assets to meet long-term needs and provide quality of life.

Different Ways to Finance

Real estate- Properties are not liquid assets and due to market fluctuations, there is no guarantee that the money will be available when needed. Real estate is frequently left to meet residential needs, however, upkeep, maintenance, and staffing issues often not addressed or planned for. Real estate is rarely the primary funding vehicle for a special needs trust.

Stocks, bonds, and mutual funds - Like real estate, they are also subject to market fluctuations, jeopardizing the assurance of providing cash when it is needed. While the stock market has historically enjoyed large returns, there are no guarantees that this trend will continue or that a market downturn will not occur when the money is required. Stocks, bonds, and mutual funds are often used when funding a special needs trust although they are rarely the primary funding vehicle.

Pensions and retirement funds- Plans such as IRAs, Roth IRAs, 401(K) Plans, and 403(b) tax deferred annuities are designed for retirement. Using these plans to fund a special needs trust may compromise that retirement, unless death occurs beforehand. Therefore, this strategy is not generally recommended as a primary funding source. One other consideration associated with the use of retirement funds is that the proceeds cannot be deferred or rolled over into another qualified pension plan, resulting in fully taxable income and larger tax bills.

Various forms of life insurance - Life insurance is an excellent funding source for a special needs trust because it

makes certain that the money will be there when it's needed the most. Premiums can be budgeted and insurance amounts can be selected to meet the needs of each specific situation. Death benefits are usually probate and income tax free. Various types of life insurance are used in different situations and for different purposes. The parent of the child with special needs will want to consider not only how much life insurance to buy but whether individual, joint (first to die) or second to die coverage will best meet the needs of the child as well as those of the other family members. How much insurance do you need? What kind of policy is best for you and your family? What additional needs arise if both parents were to die? Each family has unique needs, by working a trained specialist we can help determine what's right for you and your family.

Due to the complexity of federal and state laws, you may require specially trained professionals to help you prepare for your child or other dependent with special needs. By adequately planning now, you will insure their future happiness.

For more information about this and other related topics, visit the MetDESK website at www.metlife.com/desk . This article was provided by MetLife.



More on this subject with a special preview from Randy Beall's lecture to be presented at the 2007 PRISMS Conference in Reston!!!

A Special Needs Trust is a special kind of trust that holds title to property for the benefit of a child or adult who has a disability. Since a person with a disability who has assets over a certain dollar amount won't qualify for various governmental assistance programs such as Supplemental Security Income (SSI) or Medicaid, a Special Needs Trust can be used to provide for their "supplemental" benefits. Supplemental benefits might include things such as medical care, dental care, medical insurance, the purchase of computers and/or electronic equipment, the purchase of goods and services that add pleasure and quality to life including videos, furniture, televisions, and the providing of a personal care attendant or escort. A trust can hold cash, personal property, or real property, or can be the beneficiary of life insurance proceeds. A Special Needs Trust can be created by an attorney while you are still living or as part of your will. You'll need to find an attorney with special needs trust experience. And you or your attorney will need to apply for a tax id number with the IRS for the trust. Once you have a trust agreement and a tax ID you'll be able to open a trust account at a bank or brokerage firm and begin to fund the account. That's the fun part!

Be sure that people in your family don't will money to your child directly since this would defeat the purpose of a Special Needs Trust and possibly disqualify them from governmental assistance. Also, you may want to consider changing the beneficiaries on your IRAs and 401k accounts so that your child with disabilities is not listed. However, a Special Needs Trust can be listed as a beneficiary on most tax deferred accounts but you'll probably need the tax ID and signed trust agreement or will.



Parents and Researchers
Interested in
Smith-Magenis Syndrome

NONPROFIT ORG
U.S. POSTAGE PAID
GARLAND, TX
PERMIT NO. 151

**21800 Town Center Plaza
Suite #266A-633
Sterling, VA 20164**

PARENT TO PARENT

Did you know that PRISMS sponsors a parent to parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another SMS parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps a list of parents willing to be contacted. We'll send you addresses and phone numbers and then you can talk all that you want. Contact:



Mary Beall
Phone: 972-231-0035
mary.beall@tx.rr.com

Important note:

PRISMS parent to parent program will only give out information on parents who have agreed to be contacted. If you would like to be added to the list of contact parents, please email me at the above address.

THANKS!

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

Editor in chief: Julia Hetherington
notfar@earthlink.net

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

Newsletter Committee Members:

Margaret Miller
Michele Zdanowski