PARENTS AND RESEARCHERS INTERESTED IN SMITH-MAGENIS SYNDROME

SPECTRUM

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Psychotropic Medications in Smith-Magenis Syndrome (SMS): More Research Needed!

By Gonzalo Laje MD MHSc, Abbe Bosk BA, ACM Smith, MA, DSc(hon), Maryland Pao MD

The management of a wide range of behavioral issues in children and adolescents with SMS is particularly challenging. In addition to the genetic, clinical and neuropsychiatric manifestations of SMS, sleep disturbances associated with a reversal of melatonin secretion are a hallmark. Children with SMS have difficulty falling asleep, wakeup in the middle of night and very early in the morning and have increased daytime sleepiness often resulting in the need for naps. These sleep difficulties seem to aggravate behavioral issues such as impulsivity, aggression, hyperactivity and frequent temper tantrums. In addition, children with SMS frequently engage in self injurious behaviors such as head banging, hitting, pulling out hair, skin picking and scratching, as well as inserting foreign objects in their bodies. It is believed that these self injurious behaviors are caused by a decrease (or alteration) in sensitivity to pain and often serve as a way for children with SMS to express their frustration when they can not do something and or become over stimulated (Gropman, Duncan and Smith, 2006). Children and adolescents with SMS often have difficulty modulating body functions such as eating and sleeping as well integration of sensory stimulation; thus they are often hypersensitive to sound (Gropman, Duncan and Smith, 2006). While the physical features

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Smith-Magenis Syndrome Caregiver Study: Results and Recommendations Part 2: SMS Caregiver Well-Being

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Introduction

"Caring for my child with SMS [is the] most challenging experience thus far in life. I have seen aspects of myself that I've hated and other [aspects have] surprised me. [I've] felt anger and frustration…but I've also experienced love and compassion that is immeasurable."

Mother of 21-year-old with SMS

The preceding quote represents one of many comments from parents describing the numerous struggles and benefits of caring for a child diagnosed with Smith-Magenis syndrome (SMS). Generally speaking, little is known about family dynamics and caregiver adaptation among family systems coping with a SMS diagnosis. Studies have shown that families of individuals with SMS and other similar genetic syndromes may experience increased amounts of stress when caring for their children (Dyson, 1993; Fidler et al., 2000; Hodapp et al., 1998). Specifically, research shows that families of children with SMS are more likely to experience parent-child relational problems than families coping with

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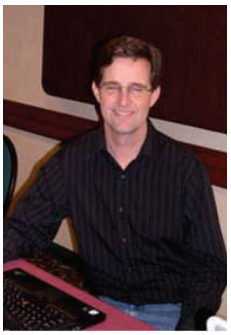

A Message from PRISMS President...

Randy Beall

Laura, our 23 year old daughter with SMS, sometimes calls me "the Money Man. " I don't know if that is because I work for a bank or because I never have any money. ☺

In addition to highlighting SuperKids Amanda Powers and Noy Gal, this edition of Spectrum has an article near and dear to my heart - the financial planning aspects of having a child with disabilities! Ok – before you fall asleep on this topic – know that a little planning now can make a huge difference in your child's financial future.

In our case, we don't think Laura will be able to support herself financially. And since she should outlive us, we need to do everything we can to provide for her after we are gone. Jenny, our 21 year old, will be a college graduate soon and should be able to take care of herself. On the other hand, Laura has…well…special needs. ☺

While the article enclosed is from the Grandparent's perspective, many of the points apply to parents as well. I hope you will read it and take action.

When Laura turned 18, she began to receive Supplemental Security Income (SSI) and Medicaid benefits. Those benefits have turned out to be substantial. We've had to work with our parents and other family members to change their wills (and ours) as well as life insurance, 401k and IRA beneficiary statements. As the article points out, a Special or Supplemental Needs trust is the only way to leave money without losing government benefits such as SSI or Medicaid. Many folks don't know that SNTs can be created at any time with a stand-alone trust agreement or at your death (as part of your will). Funds can be left to a Special Needs Trust (instead of the individual with SMS) and in so doing you won't be jeopardizing the long term government benefits such as SSI, Medicaid and housing assistance available to help your child over his or her lifetime.

How can we, as parents, be assured that our kids will lead as full and complete a life as possible after our death? We should all develop "life plans" for your kids so that we can be sure that their future is the best it can be. The financial piece is only one piece of the plan.

The PRISMS board is coming to Dallas soon (my hometown) for a weekend board meeting and planning session. We're working hard to provide you, our members, information and support.

On behalf of the PRISMS board, we are here to serve you. If you have any suggestions or concerns please feel free to can contact me at randy@prisms.org. My door is open!

Sincerely,

Randy Beall aka "the Money Man"

PRISMS, President

Grandparents: The Do's and Don'ts of Planning for Your Grandchild(ren) with Special Needs.

Grandparents want the best for their children and grandchildren. They often give gifts while alive, or make provisions for their loved ones after they are deceased. Grandparents who are in a position to leave money to grandchildren often want to do something for their grandchild(ren) with special needs. They often worry about a severely handicapped or disabled grandchild, who may need additional assets or assistance to lead a quality life. Grandparents are sometimes told not to leave their grandchild(ren) with special needs anything because the child(ren) may lose government benefits.

People are often confused as to what to do or not to do. Grandparents can leave money to their grandchild(ren) with special needs. There are very special ways to do it!

Money has to be left in such a way so that government benefits are not lost. Assets in excess of $2,000 will cause the loss of certain government benefits for the person with special needs.

Money should not be left to the grandchild directly, but should be left to a special needs trust. The special needs trust was developed to manage resources while maintaining the individual's eligibility for government benefits. The trust is maintained by a trustee on behalf of the person with special needs. The trustee has discretion to manage the money in the trust and decides how the money is used. The money must be used for supplemental purposes only. It should only supplement, or add to benefits (food, shelter or clothing) that the government already provides through Supplementary Security Income (SSI). It must not supplant or replace government benefits. If properly structured by a knowledgeable special needs attorney, the special needs trust assets will not count towards the $2,000 SSI limits for an individual.

Brief Summary of Do's and Don'ts!

Do's:

1) Make provisions for your grandchild(ren) with special needs. Leave money to the child's special needs trust. The special needs trust is the only way to leave money without losing government benefits.

2) Coordinate all planning with the child's parents or other relatives. Notify the parents when you plan for grandchild(ren). Plan with others.

3) Leave life insurance, survivorship whole life policies and annuities to the child's special needs trust. The special needs trust can be named as the policy beneficiary. When the insured or annuitant dies, the death benefit is paid to the special needs trust. The special needs trust then has a lump sum of money to be used in caring for the grandchild(ren) with special needs.

4) Consult with trained financial and legal professionals with specialties in special needs estate planning.

Don'ts:

1) Do not disinherit your grandchild(ren) with special needs. Money can be now left to a properly drawn special needs trust. It does not make sense to disinherit any of your grandchild(ren) with special needs.

2) Don't give money to your grandchild(ren) with special needs under UGMA or UTMA (Uniform Gift or Transfer To Minors Act). Money automatically belongs to the child(ren) upon reaching legal age. Government benefits can be lost!

3) Don't leave money to a grandchild with special needs through a will. Money left will be a countable asset of the child and may cause the loss of government benefits.

4) Don't leave money to a poorly set up trust. Money left in an improperly drafted trust can result in the loss of government benefits.

5) Do not leave money to relatives to "keep or hold" for the child with special needs. The money can be attached to a lawsuit, divorce, liability claim or other judgment against the relative.

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. ❋

For more information about this and other related topics, visit the MetDESK ® web site at www.metlife.com/desk or call 1-877-MetDESK

(1-877-638-3375).

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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.

Caregiver……..Continued from page 1

other genetic syndromes. In 2000, Fidler and colleagues reported that some of this increased family stress may be attributed to the heightened number of maladaptive behaviors (e.g., self-injury, sleep disturbance) displayed in individuals with SMS.

Regardless of the ups and downs of childrearing, one of the most important aspects of caregiving is taking care of oneself. Each year in the United States, thousands of families cope with the many caregiver responsibilities associated with raising a child diagnosed with SMS (Smith et al., 2006). Unfortunately, researchers have not formally investigated key aspects of caregiver well-being and salient psychosocial and physical health factors such as perceptions of child health vulnerability, perceptions of caregiver competence (caregiving satisfaction and self-efficacy/confidence), benefit finding, and symptoms of anxiety and depression that may facilitate caregiver outcomes. While no information is available on many of these variables as they relate to SMS caregivers, similar studies have suggested that stress has a direct effect on physical and psychological health (Lin & Ensel 1989); however, those reporting greater benefits and confidence in caregiving also report better caregiver adjustment (McCausland & Pakenham, 2003).

For this second installment of results from the SMS Caregiver Study, the primary aim was to determine demographic and psychosocial factors, such as perceptions of child health vulnerability, benefit finding, anxiety and depression symptomatology, and parental satisfaction and self-efficacy, which may contribute to overall caregiver well-being. The study also aimed to investigate interactions between symptoms of anxiety and depression and anxiety/depression counseling obtained after beginning the caregiving role on overall caregiver well-being. By better understanding the relationships between these variables, it may be possible to determine additional resources and interventions that will assist SMS caregivers in the future.

Methods

Caregivers were recruited between May 2007 and September 2007 via e-mails sent through the PRISMS (Parents and Researchers Interested in Smith-Magenis Syndrome) listserve and Yahoo SMS Listserve. Recruitment also took place at the PRISMS conference in May 2007 (Reston, VA). Those interested in participating completed an online survey, which included a variety of valid and highly reliable measures. The following measures were utilized for this installment of results:

1. *Caregiver Demographics* (gender, race/ethnicity, age, level of education achieved, income, utilization of health care and counseling services, etc.)
2. *Vulnerable Child Scale* (VCS, concerns about child's health and well-being; Perrin et al., 1989)
3. *Parental Sense of Competence Scale* (PSOC, parenting satisfaction and self-efficacy; Gibaud-Wallston & Wandersman, 1978)
4. *Benefit Finding* (perceptions of benefits among caregivers; Mohr, 1999)
5. *Center for Epidemiologic Studies - Depression scale* (CES-D, depressive symptomatology; Radloff, 1977)
6. *Beck Anxiety Inventory* (BAI, anxiety symptomatology; Beck, 1993)
7. *Caregiver Well-Being Scale* (Tebb, 1995).

Participants

Participants included 112 primary caregivers (i.e., mothers and fathers) of individuals diagnosed with SMS. Because initial analyses revealed that there were significant differences in caregiver well-being with mothers

	Mothers	**Fathers**
Number of Participants	97	15
Age	Average = 41.36 years; Range = 26 – 69 years	Average = 42.07 years; Range = 25 – 60 years
Race	93.8% White	100% White
Education Level	92.7% attended at least some college	84.6% attended at least some college
Household Income	62.8% over $60,000	73.3% over $60,000
Marital Status	77.3% married	100% married
Engagement in Depression/Anxiety Counseling	18.5% prior to caregiving role, 59.8% after caregiving role began	6.7% prior to caregiver role, 40% after caregiving role began
Stressfulness of having child with SMS (scale of 1 to 10 with 10 high)	8.02	8.86
Level of control or responsibility for child's SMS diagnosis (scale of 1 to 10 with 10	6.41	6.71
Percentage reporting perceiving benefits related to caregiving role	95.9%	86.7%

Table 1. Participant demographics. Gender comparison of caregiver information.

reporting higher levels of well-being than fathers, all analyses for this installment were conducted separately for mothers and fathers (see Table 1 for demographic information comparison).

For mothers. A total of 97 mothers participated (M_{age} = 41.36 years, SD_{age} = 9.60 years). Out of all mothers participating, 93.8% were White, 92.7% had attended at least some college, 62.8% had a household income of more than $60,000 per year, and 77.3% were married. Overall, only 18.5% had received counseling for anxiety or depressive symptoms prior to the birth of the child with SMS while 59.8% had engaged in counseling after beginning the caregiver role. On a scale from 1 to 10 with 10 being the most stressful experience of one's life, mothers rated having a child with SMS as 8.02. With respect to how much control or responsibility they feel for their child's genetic syndrome, mothers reported an average score of 6.41 out of 10. Despite challenges, 95.9% of mothers reported perceiving benefits related to their experience caring for a child with SMS.

For fathers. A total of 15 fathers participated (M_{age} = 42.07 years, SD_{age} = 9.85 years). Out of all fathers participating, 100% were White, 84.6% had attended at least some college, 73.3% had a household income of more than $60,000 per year, and 100% were married. Overall, only 6.7% had received counseling for anxiety or depressive symptoms prior to the birth of the child with SMS, while 40.0% had engaged in counseling after beginning the caregiver role. On a scale from 1 to 10 with 10 being the most stressful experience of one's life, fathers rated having a child with SMS as an 8.86. With respect to how much control or responsibility they feel for their child's genetic syndrome, fathers reported an average score of 6.71 out of 10. Despite challenges, 86.7% of fathers reported perceiving benefits related to their experience caring for a child with SMS.

Correlational Data Related to Caregiver Well-Being

For mothers. Among mothers participating in the study, those with higher levels of formal education indicated greater caregiver well-being. Mothers who reported having received counseling for depression or anxiety after beginning their caregiving role were more likely to show higher levels of caregiver well-being. Higher levels of caregiver well-being were also related to lower levels of perceived child health vulnerability, greater satisfaction with the caregiving role, higher caregiving self-efficacy, increased benefit finding, and lower endorsement of symptoms of anxiety and depression.

For fathers. Among fathers participating in the study, those who reported more benefits of having a child diagnosed with SMS were more likely to report higher levels of caregiver well-being. Those who indicated fewer symptoms of depression also reported higher levels of caregiver well-being.

Primary Results

For mothers. An analysis was utilized to assess the direct affects of perceived child health vulnerability, caregiver satisfaction, caregiver self-efficacy, and benefit finding on caregiver well-being. Based on significant correlations, the highest level of education achieved was investigated, as well. Results of the analysis showed that reports of caregiver well-being from mothers were directly and significantly influenced by all of these variables. Those with higher levels of education had significantly higher levels of well-being than those with fewer years of formal education. However, perceptions of child health vulnerability, caregiver satisfaction, caregiver self-efficacy, and benefit finding further impacted maternal reports of caregiver well-being beyond the influence of education. Overall, perceived child health vulnerability, caregiver satisfaction, and benefit finding seemed to be the most influential factors in determining caregiver well-being among mothers.

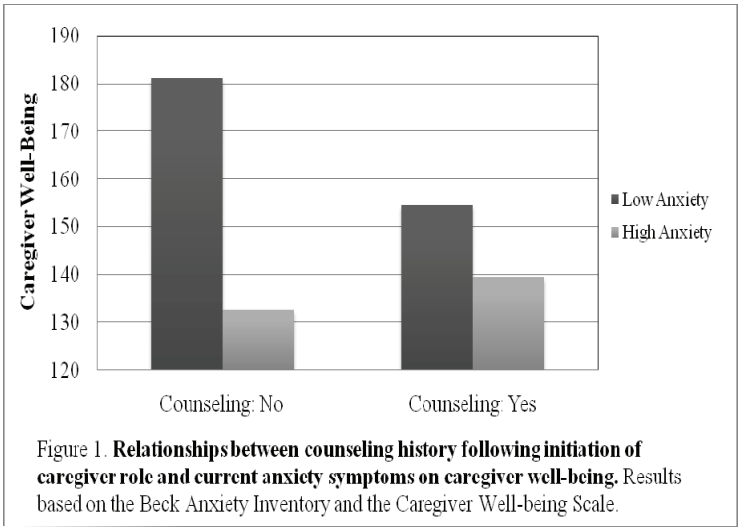

Figure 1. **Relationships between counseling history following initiation of caregiver role and current anxiety symptoms on caregiver well-being.** Results based on the Beck Anxiety Inventory and the Caregiver Well-being Scale.

In line with results presented in the first installment of this three part series on depression and anxiety symptomatology, two additional analyses were conducted to explore whether counseling for depression or anxiety after beginning the caregiving role could act to reduce symptoms of depression and anxiety in a way that promotes better caregiver well-being. Exploring anxiety symptoms first, results showed a significant interaction between anxiety symptomatology, having received counseling, and caregiver well-being. As shown in Figure 1, results show the highest level of well-being among mothers with low levels of anxiety who do not seek counseling. Those who show high levels of anxiety but do not seek counseling fair the worst in terms of well-being. As shown in Figure 2, results exploring the relationship between depression symptoms and counseling after the caregiving role began on caregiver well-being

were similar to those for anxiety symptoms. Those with low numbers of depressive symptoms and who did not seek counseling reported the highest levels of well-being, while those with many depression symptoms who did not seek counseling reported the worst outcomes in terms of well-being. Mothers who reported high levels of either depression or anxiety symptoms who sought counseling indicated higher levels of well-being than those who did not seek counseling.

For fathers. Based on significant correlations, an analysis was utilized to determine whether benefit finding and depressive symptomatology directly impacted caregiver well-being among fathers. Results indicated that, together, perceived benefits and depressive symptomatology did predict levels of caregiver well-being with those who reported more perceived benefits of the caregiver role and few depression symptoms fairing better when it comes to their well-being. Due to the small number of fathers participating in the study, no further analyses were conducted.

Additional thoughts on caregiver well-being from parents

When parents in the study were given the opportunity to provide additional thoughts on what it is like to care for a child diagnosed with SMS, many graciously offered a great deal of honest insight as to the daily challenges, blessings, accomplishments, and ongoing concerns of this caregiving role. Here are some of their thoughts:

"I know that he is a blessing and that God gave him to me for a reason. I also believe that God wouldn't give me anything I couldn't handle. However, at times I worry about my ability to handle whatever may lie ahead of us, i.e., behavior issues, health issues, school issues, etc."

Mother of 1-year-old child diagnosed with SMS

"I have often said I think I needed him much more than he has ever needed me. I have seen such tremendous growth in my other children. My son is amazing except when he's not. I tend to separate him from the disorder meaning [my child] is not SMS; he is a loving, productive, essential part of our family who happens to have this disorder called SMS. He had an unfortunate luck of the draw, but I believe we all have lessons to learn and in some way this disorder is our family's way of learning our lessons. I am a profoundly different person for having [him] in my life. It's certainly not to say that it hasn't been incredibly difficult at times; it has. But I believe there is no sense on losing yourself [for something] essentially you have no control over. We do the best we can each day. Some days we get through with a little more grace than others."

- Mother of 3-year-old child diagnosed with SMS

"My SMS daughter demands 100 percent of me. If I give her less she fails to thrive. It's exhausting, but the sweet SMS nature makes the sacrifice worth it."

- Mother of 8-year-old child diagnosed with SMS

"So far it has been a bit challenging but the unknown is what you never know about. I have learned to take life one day at a time and be very thankful!"

Mother of 3-year-old child diagnosed with SMS

"Terror of what would happen to her in the future motivated me to continue even when it seemed hopeless...which was often."

Mother of 12-year-old child diagnosed with SMS

"I love my daughter very much and she means the world to me. I was just amazed at the fact that many of the parents I met…seemed to have a different look on the whole situation than I do…But I personally just don't see how my daughter having a disorder is a blessing…I have also had a pretty stressful life and I always hear "it's a test of faith." Well how many tests can I possibly have? I know none of these children deserve this and don't know why it had to happen."

- Father of 3-year-old child diagnosed with SMS

"Not knowing your child has SMS is by far worse than knowing. You go thru so many years of finger pointing and terrible accusations by education professionals and receive a lot of criticism regarding your parenting skills. Your self-esteem really takes a beating and every answer you have for people gets reflected back at you as only an excuse or a cover up of some sort. It is very hurtful and demeaning to hear these things. I did every therapy available to my child and sacrificed a lot. When I found out the real diagnosis and became an overnight professional on SMS. My inner self was absolutely set free, and the Mom who knew her child was finally out and ready to rub some noses into it. I can now argue on his behalf and feel confident that I know who he is and what he needs and will fight till the end to get what he needs…It's very much been a life changing and positive in our lives as odd as that may sound."

Mother of 13-year-old child diagnosed with SMS

"Although there are moments when it is difficult to care for my son, I draw from his strength. He has been through so much in his short life yet he always has a smile for me."

Mother of 1-year-old child diagnosed with SMS

"This condition awakens the mind to GO BEYOND lateral thinking when anticipating SMS behavioural characteristics. Learning about SMS has been difficult, with little or no information readily available, and in my region there are not

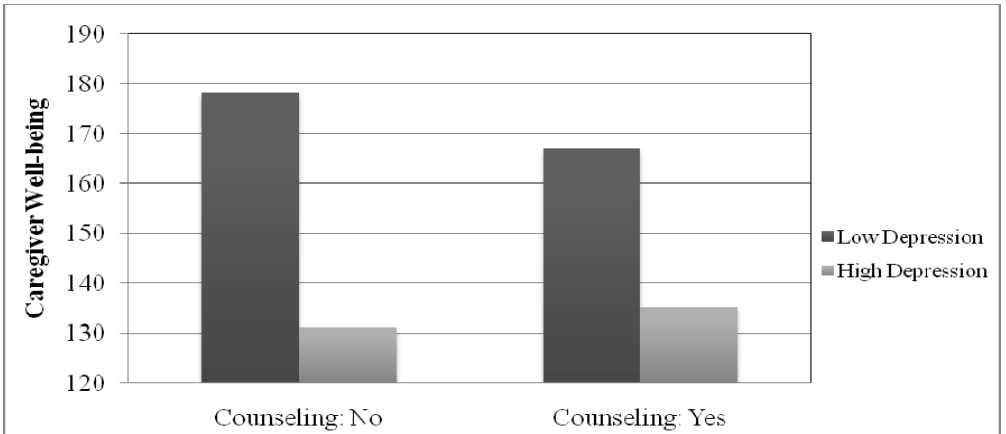

Figure 2. **Relationships between counseling history following initiation of caregiver role and current depression symptoms on caregiver well-being.** Results based on the Center for Epidemiological Studies Depression Scale and the Caregiver Well-being Scale.

real individual organizations or doctors with a vast knowledge of SMS. Although sites such as PRISMS are a godsend, my main difficulty or frustration is feeling helpless on occasions not being able to stop the self harm behaviour. My daughter means the world too me, and I worry about the future, what it holds for her. SMS children are most loving and wonderful. As a father of a beautiful little girl with SMS, I have experienced the highs and lows of this rare disorder."

Father of 9-year-old child diagnosed with SMS

What do these results mean?

A number of factors plays roles in determining how well SMS caregivers are coping with and adjusting to daily caregiving demands. Among mothers, important factors in doing well seem to include being satisfied with the caregiving role, having confidence in one's caregiving abilities (i.e., caregiver self-efficacy), having a realistic view of her child's health vulnerabilities, and perceiving benefits related to the caregiving role. For those with high levels of anxiety or depression symptoms, counseling seems to be helping to alleviate these symptoms and to improve caregiver well-being. Interestingly, results also show that those with fewer symptoms of anxiety and depression may not benefit much in terms of caregiver well-being when counseling is sought. These findings suggest the need for additional screening procedures that would better identify which parents may be in need of counseling services and then offering the most appropriate services and resources based on the level of distress. Parents are strongly encouraged to seek counseling if experiencing a high number of anxiety or depression symptoms, especially if the symptoms are disrupting family and/or personal functioning.

Due to the small number of fathers who participated in this study, definitive results are difficult to address. Trends in the data seem to indicate that fathers who are able to perceive more gains and benefits of having a child with special needs also have improved well-being related to the caregiving role. Reduction of depressive symptoms also seems to improve well-being.

Overall, parents appear to vary in their perceptions of how they are coping with and embracing their caregiving roles. Quotes from parents overwhelmingly echo the results of the quantitative analyses with most parents reporting many benefits and advantages of coping with a child diagnosed with SMS despite the ongoing obstacles, frustrations, and daily worries. Being able to perceive benefits of having a child with SMS seems to be especially important among both mothers and fathers in terms of promoting caregiver well-being.

How can I learn more about caregiver/parent well-being and family coping strategies?

Further online resources are available online at:

www.parenting.com

www.nlm.nih.gov/medlineplus/parenting.html

www.parenting.org www.fathers.com

familyfun.go.com/

www.familyeducation.com

http://www.mindtools.com/pages/main/newMN_TCS.htm

Acknowledgements

We would like to thank all of the caregivers who took the time to complete our survey. Your time and efforts have provided a wealth of information that will allow us to inform other caregivers and healthcare providers of the unique needs of families coping with SMS and develop innovated approaches and interventions aimed at serving SMS families in the future.

In future issues of Spectrum . . .

Part III: SMS Caregiver effects on Social Support, Education, and Career

This study was supported, in part, by a generous funding from an anonymous donor who saw the difficulties faced by a friend whose child has SMS.

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Editors Note:

If you hosted any events to raise awareness of Smith-Magenis Syndrome during SMS month (September), we would love to hear from you!

editor@prisms.org

COLORADO

Rocky Mountain SMS Get-Together

The annual Rocky Mountain SMS Get-Together was held on Saturday, July 12th, 2008 at Heritage Square Amusement Park in Golden, Colorado.

Twenty six people attended and everyone seemed to enjoy themselves. The sun was shining and the temperature was just about right. There was a ferris wheel, merry-go-round, sizziler, tilt-a-whirl, go karts, bumper boats and magic show to be enjoyed.

As usual there was plenty of food and sharing of stories. We talked about starting down the road to Guardianship and Special Needs Trust for Nettie. We heard about Troy getting a job at a restaurant where he will work 3 hours a day. Some people got a chance to meet the Hollins family for the first time. We got to see Beas regaining her health.

There was a celebrity citing when Dwayne Chapman, aka Dog the Bounty Hunter, and his wife happened to be there at the same time. It was not a promotional event. They were just there to enjoy the park.

We were happy to see everyone who attended and wish all SMS families could have been there!❋

Submitted by Eric and Kim Hoffman

Photos by: Fred Jimenez

Web Search Highlight: Toys for special needs children

www.adaptivetoys.flaghouse.com
www.ableplay.org
www.adaptivechild.com
www.answers4families.org/family/special-needs
www.fisher-price.com/us/special_needs
www.toydirectory.com/specialneeds.htm
www.newhorizontoys.com
www.familyvillage.wisc.edu/at/adaptive-toys.html
www.enablingdevices.com

Charlie McGrevy made it back from Kuwait just in time to help his wife, Tina, and the Foster and Norman families, host a "5K Run and Family Carnival". The race and activities were held on Sunday, August 17, 2008 in Springfield, Ohio. Six SMS families were able to attend, so it was also a super networking opportunity, and all for a good cause in support of PRISMS!❋

Percy and Bernadette Huston hosted the "2nd Annual 5K run/1 mile walk for SMS" in Cape Girardeau, Missouri on June 21, 2008. They are the parents of 17 year old Jacqueline and active in PRISMS. They were able to raise $2,777.00. Approximately 125 people participated with fun had by all. If you would like to sponsor a race event and need more information, Percy can be contacted at 573-225-8308 or jphiv@charter.net.❋

A picnic is planned for the Houston area on Nov 8, 2008. It will be held at Bear Creek Park, 3535 War Memorial Drive, Houston, TX 77084. For more information contact Cecilia Poole at foxwxgal@hotmail.com or 713-823-4401.❋

Every year for the last 4 year's Texas area SMS families have met for dinner while their SMS kids and sibs attended Parents Night Out. Baylor College of Medicine Pediatric Student Association and the Department of Molecular and Human Genetics at BCM and Texas Children's Hospital are once again hosting their 4th Annual Parents Night Out on Friday, November 7th, from 6:00 - 10:00 p.m.

If you would like more information about this year's event, or to reserve the night for your children, please contact the lead medical student—Clara Lin at BaylorBPSA@gmail.com

or the project coordinator, Valerie Price, at 832-822-4292. Reservations must be made by October 18th to assure that all children have a medical student "buddy." ❋

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PRISMS sincerely appreciates all donations. If you feel like you have made a donation that is not noted here, please contact us as soon as possible at info@prisms.org

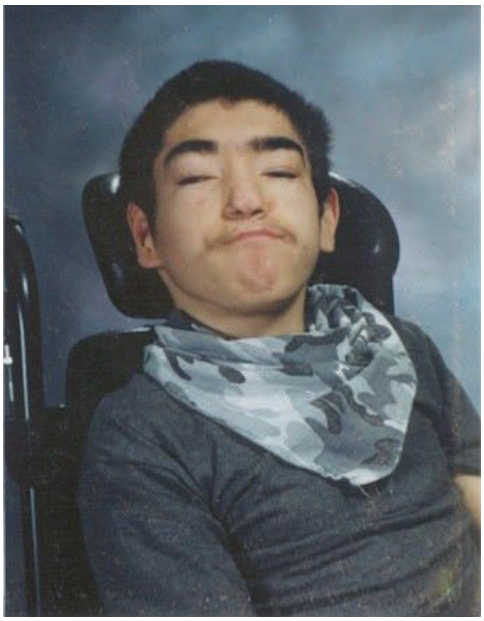
In Celebration of the Life of

Edwin Jimenez

September 25, 1981—August 23, 2008

Edwin Jimenez, a very dear member of our PRISMS family passed away quietly in his sleep on August 23, 2008; born on September 25, 1981, Edwin was almost 27 years old. Edwin will forever remain a true SMS "pioneer" in the journey to understand Smith-Magenis syndrome. The stories of the discovery of SMS and my early genetics career have deep roots in Colorado and Edwin and his family played a big role in the story.

I first met Edwin over 26 years ago in Fall of 1981 when I was a much younger Genetic Counselor; Edwin was only 2 months old when his caring & loving parents, Fred and Stella and his sister Dawn were seen for genetic consultation & counseling at Denver Children's Hospital. Born with cleft lip and a congenital heart defect, Edwin also had a history of failure to thrive, and I recommended chromosome analysis as part of the evaluation. About 2-3 weeks later the result revealed a visible interstitial deletion of chromosome 17 within the p11.2 band. While the diagnosis of deletion 17p11.2 was made when Edwin was 3 months old, the deletion had not been reported in the literature before, but coincidentally we had seen a very similar deletion earlier in 1981 in another infant who was also born with congenital heart disease and cleft palate. However, there was no information about what the deletion meant for Edwin and his future.



I often use a picture of a rutted, rocky road in the Colorado Rocky Mountains as an analogy to what was known about SMS in 1980's – not much! Today, over quarter of a century later, SMS is a clinically recognized syndrome; yet it still remains underdiagnosed. So the road may be paved, but still is not a super highway! Together, Edwin and his family laid the foundation for the SMS journey in Colorado, later to be joined by other families working in partnership with a small group of professionals and researchers to map out the "journey" to understand the deletion 17p11.2 that became known as Smith-Magenis syndrome or SMS in 1989.

PRISMS is built on the strong partnership between parents and families of individuals with SMS, professionals and researchers - a partnership that is essential to expanding knowledge about this rare syndrome and identifying management strategies and/or therapies likely to benefit these children. Much of what is known about SMS was not learned from a medical textbook, but rather from the families - the true experts about the syndrome – through their observations, questions and shared stories.

No one could have predicted that the first chapter of the book about SMS would begin in 1981, after meeting Edwin and his family – but it did! Edwin's role in the legacy of SMS discovery follows my presentation of his case at the 1982 scientific meeting of the American Society of Human Genetics, where, serendipitously Ellen Magenis was in the audience. Edwin and his family also met the late Dr. Frank Greenberg and Dr. Jim Lupski during their travels to Colorado and on to Oregon in the 1989; both physicians played a major role in further expanding the phenotype of SMS. The Jimenez's shared Edwin's story with others at past PRISMS conferences and they will always be part of the PRISMS family.

I was truly very fortunate to have had the opportunity to know Edwin since he was a baby. He and his family taught and inspired me to begin a "journey" that has played a major role in my professional career. While we/I know more today about SMS than was known in 1981, the SMS story continues to be written, chapter-by-chapter. Yet, today, as we celebrate his life, we remember that the story of SMS began with a boy named Edwin; a young man who was dearly loved as a son, a brother, and a dear & courageous friend to all whose lives he touched – especially for those of us privileged to know him and receive one of his strong SMS hugs. Edwin was challenged only by the limitations the world put upon him. His young life became the cornerstone for others to learn and observe and teach and help. His family was brave enough to share Edwin with all of us, and help to enlighten and guide the research that followed in his path. Edwin represented all that is perfect with our children; their courage, and humor, inner strength and most of all, unyielding love. Thank you Edwin for softening the "rocky road," and leaving us with a portrait of your enduring spirit.❋

Ann C.M. Smith, M.A., D.Sc. (hon), Chair

PRISMS Professional Advisory Board

SMS SuperKid!

Amanda Powers

My SuperKid
By Diane Powers

"*Go Blue-Tailed Lizards*"! That is often what you will hear coming from the sidelines of the soccer field near our home each Saturday morning. Amanda is 6 years old and is the un-official "Team Manager" of the Northern VA Blue-Tailed Lizards Soccer Team (of which her big brother Andrew is a member). Amanda's involvement in the team has been a wonderful experience for her, her brother and his teammates & coaches alike.

Some of her duties include field preparation, getting equipment in place for drills and helping with water breaks. During practice, she paces the field with a ball under her arm along side the coaches and often participates in the conditioning drills!

Amanda is quick to greet EVERY player, parent and sibling by name and uniform number with a very enthusiastic hug (tackle) or pat on the back (the boys have gotten used to her "love taps"). The coaches and teammates have embraced her as a member of the team. She has a jersey and loves to let everyone know that she is "double zero"—her jersey number is "00".

When Amanda is not on the soccer field, she rides horses as part of the Northern Virginia Therapeutic Horseback Riding Program (NVTRP). We are entering our third year of horseback riding and this is truly the best outlet for her. She receives her physical therapy on the horse while having the undivided attention of 3 sidewalkers and an instructor—it doesn't get any better than that! Amanda was recently asked to participate in a real horse show, representing NVTRP. The show included riders of all ages and they asked her to participate in the under 8 age bracket. Amanda rode like a pro and came away with the 1st Place Blue Ribbon! We are so proud of her and her accomplishments. She is our SMS Blue Ribbon wearing SuperKid!

Amanda (on the left) with the Blue-Tailed Lizards

Do you have an SMS SuperKid? We would love to publish a picture and a story about your child. As we all know, even small accomplishments are encouraging for our SMS families. Please consider sharing your good moments with us. If you have questions or need help with the story, please call the PRISMS editor, Julia Hetherington, at 843-521-0156, or contact through email at

editor@prisms.org

Noy Goes to Camp

By Josie Weightman, Camp Lee Mar

Noy bounces out of the car with a contagious smile spread across her face. "Oh, hello *Jose*!" she exclaims, recalling the Spanish nickname she had created for me last summer. It is clear that Noy is thrilled to be back at camp. Her face is bright as she pulls her mother down the hill to her former cabin. "I can't wait to see all of my friends again!"

I follow along, chatting with Noy's mother about the year that has gone by, when Noy looks over and politely says: "Excuse me Josie? This year, I would like a job. I want my job to be a counselor-in-training. I just turned sixteen, and when you turn sixteen, you get to be a counselor."

Sure enough, when it came time to filling out job applications for the Camper Worker Program, Noy had her heart set on being a counselor assistant, and was disappointed when she did not see it listed on the application form. The position was not listed because it had never been offered before. Yet Noy was determined, and spoke maturely with the job coordinator about the position she had envisioned. Being her former Resident Assistant (RA), I was responsible for creating a job description for Noy and monitoring whether or not she performed her duties. While I brainstormed possible duties for Noy, I couldn't help but reflect on how far she has come since she first came to camp.

Noy experiences at Camp Lee Mar began in 2006, and that first summer was one filled with many challenges faced by both Noy and her counselors. Camp Lee Mar is a seven-week residential program for children and adolescents with mild to moderate learning and developmental challenges. Campers enjoy traditional camp and recreation activities PLUS academics, speech and language therapy, music and art therapy, and daily living skills. Noy had never been away from home for such a long period of time, and had to learn how to cope with the structure of the schedule, the responsibility of being part of a group, as well as all the feelings that come along with being away from home.

That summer, Noy had great difficulty transitioning between activities and to mealtimes. Most mornings an administrator was paged to her cabin to wait outside until Noy was ready to go to the dining hall for breakfast. Noy had been used to doing things her way; however, at Lee Mar, she needed to learn how to be part of a group. Applying for a job that first summer was out of the question. In order to have a job at camp, a child must be able to travel around camp independently, show up on time, and be able to take instructions from a supervisor.

Since that first summer, Noy has simply flourished. She has progressed from being one of six campers in a group to one of fourteen. She has gone from not walking with her group to a single meal to leading the line down the hill to breakfast. She has gone from hitting herself during tantrums several times a day to learning how to walk away and say "I feel frustrated."

Noy has made an impact on the lives and touched the hearts of many who have come to Lee Mar. Her endearing personality and clever humor make all who meet her fall madly in love. Noy recently attended the Camper Worker party for maintaining her job all summer. She volunteered to give a speech to express her appreciation for her job.

After her speech, I look over at Noy and say: "So what do you think Noy? Will you be back next summer for another year of counselor-in-training?" She pauses for a moment before flashing that charming smile. "No, Josie. I think next year I want to be an RA-in-training." I laugh. It is clear that Noy is a young lady who knows what she wants. And if she has learned anything from Lee Mar, it is that the possibilities of what she is capable of are endless. ❋

A Parent's Perspective

This summer was Noy's third year at camp. This camp has done wonders for her behavior, her independence, and her social skills. The first time Noy attended camp they had to struggle with her behaviors, and we had to work on quite few skills before they accepted her the following summer. The second year she was on probation, which means that depending on her behavior she was to leave camp at the mid point of the 7 weeks session. Fortunately, she did well and has attended the complete session for two consecutive years with no problems.

Both the family and the school felt the improvement in Noy's behavior after attending the camp. The camp is highly structured, has great counselors, and keeps the kids busy morning to night.

Noy's stay at camp helps the whole family rest and recover. At home, she does have tantrums, hit her head and scratch her legs but the camp tells me they see very little of these behaviors at camp. They mostly work on her attending activities (she is a "couch potato"), doing things in a timely manner, and being organized and neat. She is well loved as she does have a great sense of humor, and she loves the fact that there are so many nice counselors that give her tons of attention. ❋

Sara Gal

Medication…..Continued from page 1

and molecular genetic causes of Smith-Magenis Syndrome have been well characterized, there is little research on the efficacy of psychotropic medications in the treatment of the many behavioral comorbidities (including cognitive impairment, learning disabilities, obsessive compulsive symptoms, anxiety, and depressive symptoms) associated with this complex genetic disorder.

There are no published clinical trials on the use and effectiveness of psychotropic medications such as psychostimulants, antipsychotics, antiepileptics and antidepressants in children with SMS. There is one reported case study of a 12 year old male patient with SMS with psychomotor agitation, Attention Deficit Disorder, aggression and depression who was treated with psychotropic medication (Niederhofer, 2007). This patient was first treated with paroxetine without improvement. Carbamazepine was added to the paroxetine for eight weeks, again without symptom improvement. After these medications were washed out of the boy's system, he was treated with risperidone (first week 1 mg daily, second week 2 mg and then 3mg for the following two weeks). His psychiatric symptoms diminished significantly with risperidone treatment after which he was able to attend school regularly. While this case study provided useful information on the use of psychotropic medications in one adolescent, larger scale studies are needed to make accurate generalizations about the effectiveness of psychotropic medications in children and adolescents with SMS.

The largest collection of unpublished data on psychotropic medication use in SMS was obtained during the course of a longitudinal protocol (01-HG-0109) studying the natural history of SMS at NIH. However, this data is retrospective and based on parental recall of medications their child had taken. Parents reported on how useful the medications were, what (if any) side effects occurred and reasons for discontinuing the medication. From this longitudinal study no significant results on medication effectiveness were found (Laje et al., 2007). The current lack of reliable information on psychotropic medication use in children and adolescents with SMS has led researchers to recommend prospective data collection with multiple data points, a large number of participants and standardized responses on psychotropic medication usage in this population (Laje et al., 2007). This information is greatly needed for a number of reasons. First of all, given the increasing number and combinations of psychotropic medications available, without standardized (and organized) data collection, it is impossible to establish the efficacy and tolerability of the medications in this population. Additionally, the many children and adolescents with SMS need to be treated with psychotropic medications to control the many behavioral manifestations of this disorder. However due to the severe sleep disturbances and propensity for weight gain among these patients, it can be difficult to balance the effectiveness of these medications in reducing behavioral issues with their side effects. To further compound the complicated issues surrounding the effective use of psychotropic medications, poly-pharmacy is typically necessary in order to treat the wide array of psychiatric symptoms associated with this disease further increasing the need for an understanding of the usefulness and side effects of specific classes of medication (Gropman, Duncan and Smith, 2006; Laje et al., 2007).

The paucity of information on psychotropic medication use in SMS children, adolescents and adults makes it nearly impossible to adequately treat the numerous behaviors that severely impair the functioning of individuals with SMS. To carefully and effectively assess psychotropic medication use in children and adolescents with SMS, we are developing a web-based system to monitor individual medication use. The proposed project is a collaborative effort between PRISMS and the NIH SMS Research Team (See side box). In essence, parents would provide a monthly report on medications stopped or started, dose adjustments and any adverse reactions that occurred. Over time and with the concerted effort of SMS -parents around the world, this database would result in a large collection of experiences that will help us determine which medications work best for which behaviors and which adverse effects are more common in SMS. (Laje et al., 2007). Overall, there is a great need to gain information in this area and determine effective treatments for the psychiatric manifestations of SMS as soon as possible to improve the quality of life for these children and their families.❋

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The PRISMS Board of Directors has appointed an Advisory Committee tasked with developing and overseeing the SMS Medication Tracking Database Project (SMS-RX –Tracker) to track medication use in Smith-Magenis syndrome. The web-based application is being developed by the Clinical Trials Data Base (CTDB) team at the National Institute of Child Health and Human Development (NICHD), NIH working in collaboration with members of the NIH SMS Research Team (Ann C.M. Smith MA, DSc(hon), NHGRI/NIH, Maryland Pao, MD, NIMH/NIH and Gonzalo Laje, MD, NIMH/NIH) and PRISMS Advisory Committee members Charlene Liao, PhD, PRISMS Liaison/SMS Parent and consulting pediatric psychiatrist Carl Feinstein, MD, Stanford University. Pilot testing is planned for late Fall, 2008.

Save the Date

PRISMS 6th International Conference

"BUILDING BRIDGES OF HOPE"

Sept. 17-20, 2009
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*This is the same site as the 2007 conference. Our families loved the location and were able to easily enjoy the shops and restaurants with-in walking distance. We hope to see you all return AND we welcome new families and faces to the 2009 conference. Start planning and saving now! Be a part of the celebration!!

Parent to Parent

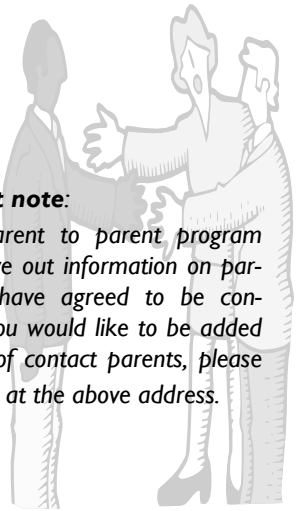
Did you know that PRISMS sponsors a parent to parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another SMS parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps 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 Mary at the above address.

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