

# SMS Caregiver Education and Career Analysis

## Part 3 of the Smith-Magenis Syndrome Caregiver Study Results and Recommendations

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### Introduction

According to the U.S. Department of Health and Human Services (HHS, 2008), in 2005, 21.8% of U.S families were raising a child with special health care needs. Caring for a child with special health care needs requires many additional responsibilities and sacrifices. Such responsibilities and sacrifices have been reported by mothers of children diagnosed with Smith-Magenis syndrome (SMS):

*As her primary caregiver I have given up everything that I have known – my career, my dreams, my friends...the list goes on. I did this so that at some point in her life she hopefully can venture out on her own with support and have a fulfilling, happy, loving life. When (if) that happens that will mean more to me than any college degree I would have obtained if she wouldn't have come into my life.*

- Mother of a 14-year-old diagnosed with SMS

*I think all parents whose children have disabilities could tell the world an earful about this, and some*

*day I hope I can add their voices to the too-scarce literature available on this subject. Almost all of us feel INCREDIBLY ALONE. In our family, we originally planned to have my husband be the stay-at-home parent (I love my profession and have a better income; he loves children even more than I do), BUT he was unable to cope with being fulltime caregiver to our child with SMS. This has resulted in a reversal to more traditional roles (he works fulltime but makes too little to support the family; I work half-time and am also fulltime mom). It has been profoundly stressful to me, and our financial situation is a bit depressing considering our ages and levels of education. This is a common result of having a child with a disability.*

-Mother of a 16-year-old diagnosed with SMS

The preceding quotes coincide well with studies showing that working parents who are caring for a child with disabilities face numerous challenges when attempting to balance their work and family responsibilities (Rosenzweig, Brennan, & Ogilvie, 2002). Often the child's health care appointments must be scheduled during parent's workdays, the child's health crises can interrupt work and family life, and parents must make child-care and special education arrangements. Caregivers must find ways to cope as they try to integrate demands of employment and family life. Previous studies have shown that parents of individuals with developmental disabilities have decided not to pursue graduate school, forgo career development and advancement opportunities, or changed their career goals (Barnett & Boyce, 1995; Case-Smith, 2004; Freedman, Litchfield, &

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Warfield, 1995; Parish, 2006; Porterfield, 2002). However, little is known about the compromises caregivers of a child with SMS have made in their education and career plans, how satisfied caregivers are with their current careers, or how career satisfaction is related to caregiver well-being and satisfaction.

For this third installment of results from the SMS Caregiver Study, the first aim was to summarize the current educational attainment and occupations of mothers with a child with SMS and explore their educational and occupational goals. By exploring their goals, we can better understand the training needs of caregivers and determine additional resources that might aid them in obtaining their goals. The second aim of this installment was to determine how career satisfaction is related to demographic factors such as age and education level and psychosocial factors such as symptoms of depression and anxiety, quality of sleep, counseling services obtained, caregiver satisfaction, and caregiver well-being.

### Methods

Caregivers of a child with SMS were recruited between May 2007 and September 2007 via e-mails sent through the PRISMS (Parents and Researchers Interested in Smith-Magenis

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# A Message from PRISMS President...

## Randy Beall

Did you know that PRISMS is 15 years old this year! PRISMS was organized and incorporated in Virginia in 1993. According to the "history books," Margaret Miller and Ann Smith organized PRISMS at Ann's kitchen table. We are truly grateful for these women and their foresight.

As you may have noticed, this newsletter sports a new PRISMS logo (thanks to Margaret Miller and Mark Hernandez). This logo was designed to help us celebrate our 15<sup>th</sup> year. Our new logo is fresh and unique and reflects our vision to be the premier provider of information and support to families of persons with Smith-Magenis Syndrome (SMS). In addition, we want to continue to foster partnerships with professionals to increase awareness and understanding of SMS.

Our 2009 conference is right around the corner! It's hard to believe. I hope you are planning to attend. The conference will be packed with information and will provide everyone a chance to reconnect and share stories about our kids. We need corporate sponsors for this conference to help us make it more affordable for families. If you can help us in any way, please call me at 972-231-0035 or send me an email to [randy@prisms.org](mailto:randy@prisms.org)

If you are a member of PRISMS, I trust that you will take the time to renew your annual membership. Be on the look out for a membership renewal letter. As a member you'll continue to receive Spectrum, our terrific newsletter, plus you'll help us to maintain and update our website as well as provide our members email/ phone support. Membership dues also helps us host the professional roundtable and parent conferences. Families continue to tell us that we are an invaluable resource for them.

I hope you had a relaxed and blessed time during the holidays. Happy New Year, and I look forward to seeing you at the 2009 Conference.

Warm regards,

Randy



# Meet the PRISMS Professional Advisory Board

## Barbara Haas-Givler

Barbara Haas-Givler, MEd, BCBA, became a PRISMS Professional Advisory Board member in 2007, but has been a leading educator and behavior analyst in the study of SMS for many years. She is one of our most frequent Spectrum contributors/authors and long-time advocate and friend to many of our PRISMS families. She has been a part of the SMS journey, long before she ever knew it, and has dedicated her journey to teaching parents and educators about the challenges and strategies of behaviors associated with SMS. Barbara has tried to view the everyday world through the eyes of a person with SMS and begin always with knowledge and compassion, and move towards thoughtful and sensible solutions. “Barb” has presented at several of the PRISMS conferences, and is always available to parents to brainstorm and problem-solve. She remembers every SMS child she has ever worked with, (and they remember her!), and has a dedicated heart for our children. Barbara is a Board Certified Behavior Analyst and trained in the implementation of ABA, (Applied Behavior Analysis), working with children with SMS, Fragile X, Prader-Willi, Isodicentric 15 and 22q deletion syndromes.

Barbara Haas-Givler, first worked with an SMS pre-school child in 1974, (undiagnosed at that time), several years before the first paper describing SMS would even be written! Barbara was working at Elwyn Institute in Elwyn, PA, as an educator, when she met this young child. Barbara still works at Elwyn as an Education Specialist and Behavior Analyst, providing consultation and training for successful classroom settings for children with varying developmental delays. In 1994, she wrote her first paper on Smith-Magenis Syndrome, “*Observations on the Behavioral and Personality Characteristics of Children with Smith-Magenis Syndrome*,” which appeared in *Spectrum*, and in 1995 was followed with “*What’s a Teacher to Do? Classroom Strategies that Enhance Learning for Children with Smith-Magenis Syndrome*,” also appearing in *Spectrum*, written with Brenda Finucane, MS. The latter paper became a benchmark and stepping point from where teachers and parents could begin to understand the behavioral aspects of SMS, specifically within the challenges of a classroom setting. This paper became a “must” at IEP meetings,

finally promoting dialogue between educators, therapists and parents. Barbara was determined to further study and document the behavioral aspects of SMS, the challenges they bring on any given school day, and advise successful strategies to promote a more positive classroom experience for that student. Barbara’s recent paper, “*Prevention versus Intervention: Effective Behavioral Strategies for Children with Smith Magenis Syndrome*,” appeared in *Spectrum* this past spring. Barb has collaborated with Brenda Finucane, MS, an Elwyn colleague and a founding PRISMS PAB Member, on additional SMS research and publications.

Since the journey still needs to move forward, Barbara envisions a plan to implement collaboration and communication between professionals who work with or teach a child with SMS. The collaboration would take place in a forum that could provide the interaction between behavior specialists, psychologists, and special education teachers who have had experience with more than one student with SMS or experience over several years, resulting in successful programming (day or residential setting) for a student with SMS. The result of this group effort could provide pathways to success for our children in their school and even vocational settings.

Barbara continues to work in varied professions in the field of special education: from teacher to trainer, to advocate and ally. We are truly honored to have Ms. Givler as part of the PRISMS Professional Advisory Board and look forward to many years of partnership and alliance with her and anticipate the strides we will make together!

Finucane BM, Konar D, Haas-Givler B, Kurtz MB and Scott CI (1994) “The spasmodic upper body squeeze: A characteristic behavior in Smith-Magenis syndrome.” *Developmental Medicine and Child Neurology*, 36:78-83.

Finucane B, Haas-Givler B, and Simon E (2003): Genetics, Mental Retardation, and the Forging of New Alliances. *American Journal of Medical Genetics* (Part C, Seminar in Medical Genetics), 117C, 66-72), in press.

Finucane, B. and Haas-Givler, B. (2009): Smith-Magenis syndrome: Genetic basis and clinical Implications. *Journal of Mental Health Research in Intellectual Disabilities* (in press).



### 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.

Syndrome) listserve and Yahoo SMS Listserve. Recruitment also took place at the PRISMS conference in May 2007 (Reston, VA). Caregivers interested in participating in the study 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, income, level of education achieved, educational goal, current occupation, and occupational goal, etc.).
2. *Parental Sense of Competence Scale* (PSOC, parenting satisfaction and self-efficacy; Gibaud-Wallston & Wandersman, 1978).
3. *Center for Epidemiologic Studies—Depression scale* (CES-D, depressive symptomatology; Radloff, 1977).
4. *Beck Anxiety Inventory* (BAI, anxiety symptomatology; Beck, 1993).
5. *Caregiver Well-Being Scale* (Tebb, 1995).
6. *Career Satisfaction Scale* (Greenhaus, Parasuraman, & Wormley, 1990).

**Participants**

Among families raising a child with special needs, mothers and fathers both play essential roles; however, research indicates that mothers are more likely to adapt their schedules and educational/career goals as compared to fathers (Lewis, Kagan, & Heaton, 2000). With this in mind, this installment focuses on the education and career factors of mothers only. A total of 97 mothers participated ( $M_{age} = 41.31$  years,  $SD_{age} = 9.60$  years). Out of all mothers participating, 94% were Caucasian, 77% were married, 93% had attended at least some college, and 63% had a household income of more than \$60,000 per year. Detailed demographics are listed in Table 1.

**Results**

**Education:** The education achieved by the participants and their educational goals were compared to determine how many mothers wanted to further their education. At each level of education achieved by the participants, with the exception of those obtaining graduate or professional degrees, 50% or more of the mothers desire to further their education (Figure 1). For example, among mothers whose highest level of education was a high school diploma or GED, 57% reported a desire to advance their formal

| Participants                                   | n  | %  |
|--|----|----|
| <b>Ethnicity (n = 97)</b>                      |    |    |
| Caucasian                                      | 91 | 94 |
| Latino   | 3  | 3  |
| African-American                               | 2  | 2  |
| Biracial or multiracial                        | 1  | 1  |
| <b>Current age (n = 95)</b>                    |    |    |
| 26 – 35  | 27 | 28 |
| 36 – 45  | 35 | 37 |
| 46 - 55  | 28 | 30 |
| 56 - 65  | 3  | 3  |
| 66 - 75  | 2  | 2  |
| <b>Marital status (n = 97)</b>                 |    |    |
| Married  | 75 | 77 |
| Single   | 5  | 5  |
| Divorced                                       | 12 | 13 |
| Separated                                      | 1  | 1  |
| Living with parent of child diagnosed with SMS | 3  | 3  |
| In contact with child’s other parent           | 1  | 1  |
| <b>Education (n = 96)</b>                      |    |    |
| High school diploma or GED                     | 7  | 7  |
| Some college                                   | 29 | 30 |
| Associate degree                               | 14 | 15 |
| Bachelor degree                                | 25 | 26 |
| Some graduate school                           | 6  | 6  |
| Graduate or professional degree                | 15 | 16 |
| <b>Household income (n = 94)</b>               |    |    |
| Less than \$15,000                             | 2  | 2  |
| \$15,000 - \$24,999                            | 3  | 3  |
| \$25,000 - \$34,999                            | 6  | 6  |
| \$35,000 - \$44,999                            | 11 | 12 |
| \$45,000 - \$59,999                            | 13 | 14 |
| \$60,000 or above                              | 59 | 63 |

**Table 1: Maternal demographics.**

educations. For those who had obtained an associate degree, 64% stated that they would like additional education.

The age at which mothers had their first child was assessed to explore relations between having a child and educational attainment. For the mothers who had their first child while in high school, 100% have obtained some college credits. For the mothers who were in the traditional college-aged group (i.e., ~19–22-years-old) when they had their first child, 79% attained at least a high school education or some college credits, while 21% have obtained a degree (associate, bachelor, or graduate degree). Data showed that of the mothers who were past traditional college age (i.e., > 23-years-

old) when they had their first child, 18.8% attained at least a high school education or some college credits, while 81.1% obtained a degree. The data clearly indicate that mothers who had their first child after age 23, were more likely to obtain a degree than the mothers who had a child in high school or while they were of college age.

**Occupations:** Participants were asked to indicate their current occupation and their occupational goals. Table 2 represents a comparison of the 74 out of 97 mothers participating in the study who reported their current occupation as well as their desired occupation. The occupations reported by the participants comprised fifteen occupational categories based on the U.S. Department of Labor’s Standard Occupational Classification (SOC)

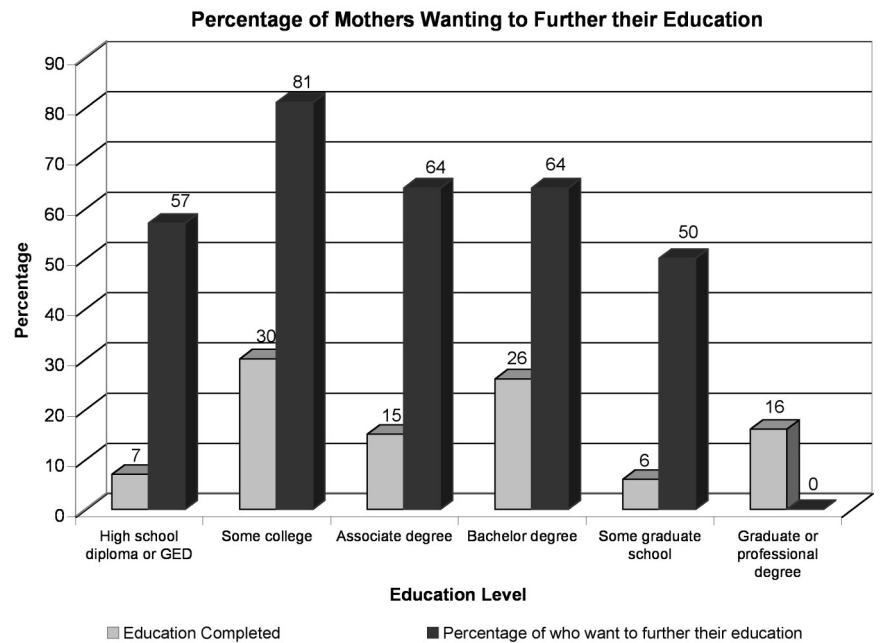
system. The categories with the highest representation included Personal Care and Related Occupations (31.1%), Education, Training, and Library Occupations (9.5%), Office and Administrative Support Occupations (10.8%), Management Occupations (13.5%), and Healthcare Practitioners and Technical Occupations (10.8%).

Of the 74 mothers who reported their occupational goal, 45% of the mothers indicated that they desired an occupation outside of their current profession. Within the Personal Care & Related Occupations category, 87% of the participants indicated that their current occupation is Homemaker, and 13% stated they are Daycare Providers. Interestingly, this category was noted to have the largest decrease from the current occupation to the occupational goal. Of these participants, 56.5% indicated that their occupational goal was outside of the Personal Care Occupations category (53.8% Healthcare Practitioners or Support Occupations, 23.1% Education, Training, and Library Occupations, 15.4% Arts, Design, Entertainment, Sports and Media Occupations, and 7.7% Community and Social Services Occupations). See Table 2.

Participants were asked to indicate their career satisfaction to date. Of the respondents, 34.1% reported low career satisfaction, 29.4% reported moderate career satisfaction, and 36.5% reported high career satisfaction. In terms of demographic factors, those with higher household incomes were more likely to report greater levels of career satisfaction; current age, educational attainment, and age of the child diagnosed with SMS were not significantly related to career satisfaction. Mothers who had received counseling for anxiety or depression after beginning the caregiving role were more likely to endorse higher career satisfaction. Data also showed that career satisfaction was higher among mothers reporting fewer symptoms of anxiety and depression and better quality sleep. Further, mothers who reported higher levels of career satisfaction also reported greater caregiver well-being and satisfaction with the caregiver role. In a follow-up analysis, symptoms of anxiety and depression, quality of sleep, caregiver well-being, and caregiver satisfaction predicted self-perceptions of career satisfaction beyond the influence of household income. Independently, caregiver well-being and caregiver satisfaction each directly predicted ratings of career satisfaction.

#### What do these results mean?

These data indicate that the majority of mothers who had their first child prior to the age of 23 were able to obtain a high school education



**Figure 1. Education advancement.** This figure illustrates the level of education attained by mothers of children with Smith-Magenis syndrome (light grey). The percentage of women in those categories who would like to further their education is shown in dark grey.

| Occupational Code  | Current Occupation n = 74 (%) | Occupational Goal n = 74 (%) |
|--|-------------------------------|------------------------------|
| Architecture and Engineering Occupations                   | 5.4                           | 1.4                          |
| Arts, Design, Entertainment, Sports, and Media Occupations | 2.7                           | 5.4                          |
| Business and Financial Operations Occupations              | 1.4                           | 1.4                          |
| Community and Social Services Occupations                  | 1.4                           | 6.8                          |
| Computer and Mathematical Occupations                      | 1.4                           | 1.4                          |
| Education, Training, and Library Occupations               | 9.5                           | 16.2                         |
| Food Preparation and Serving Related Occupations           | 2.7                           | 1.4                          |
| Healthcare Practitioners and Technical Occupations         | 10.8                          | 17.6                         |
| Healthcare Support Occupations                             | 1.4                           | 4.1                          |
| Legal Occupations  | 2.7                           | 1.4                          |
| Life, Physical, and Social Science Occupations             | 0                             | 1.4                          |
| Management Occupations                                     | 13.5                          | 16.2                         |
| Military Specific Occupations                              | 1.4                           | 0                            |
| Office and Administrative Support Occupations              | 10.8                          | 4.1                          |
| Personal Care & Related Occupations                        | 31.1                          | 17.6                         |
| Sales and Related Occupations                              | 4.1                           | 4.1                          |

**Table 2. Current occupations and occupational goals of mothers of a child with SMS.**

and some college credits. On the other hand, a majority of mothers who had their child after they were college-aged were able to obtain an associate, bachelor, or graduate degree. The data also show that a large percentage of mothers are interested in furthering their education. A large portion of mothers who are currently in the Personal Care occupations indicated that they wanted to change occupations, with nearly half expressing interest in Healthcare Practitioners or Support occupations. In terms of career satisfaction, mothers with higher household income reported higher career satisfaction. Additionally, mothers reporting better quality of sleep and fewer symptoms of depression and anxiety also endorsed higher career satisfaction. The data also suggest that career satisfaction is an important factor for the caregiver, such that higher career satisfaction relates closely to higher caregiver well-being and higher caregiver satisfaction.

### 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. 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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### How can I learn more about educational/career development and balancing family and career demands?

Further online resources are available online at:

- [http://online.onetcenter.org/\(O\\*NET Online, career exploration\)](http://online.onetcenter.org/(O*NET Online, career exploration))
- [http://www.bls.gov/oco/\(Occupational Outlook Handbook\)](http://www.bls.gov/oco/(Occupational Outlook Handbook))
- [http://www.careers.org/\(Career Information\)](http://www.careers.org/(Career Information))
- [http://www.umext.maine.edu/onlinepubs/htmpubs/4186.htm\(Family Issues Facts\)](http://www.umext.maine.edu/onlinepubs/htmpubs/4186.htm(Family Issues Facts))
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- [http://www.sharedprosperity.org/topics-work-and-family.html\(Reports addressing work and family issues\)](http://www.sharedprosperity.org/topics-work-and-family.html(Reports addressing work and family issues))

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PRISMS believes that philanthropy is based on voluntary action for the common good. It is a tradition of giving and sharing that is primary to the quality of life. As a result, we have adopted the Donor Bill of Rights as developed by the American Association of Fund-Raising Counsel (AAFRC), Association for Healthcare Philanthropy (AHP), Council for Advancement and Support of Education (CASE) and National Society of Fund-Raising Executives (NSFRE).

Also, PRISMS had an official receipt and public acknowledgement policy. While we encourage online giving through our partnership with Network for Good, it is our policy for donors who pay via check will have their cancelled check serve as their receipt for donations \$100 or less. PRISMS will send all donors a receipt for donations over \$100 or more, or upon request. We will print the names of all contributors annually in our newsletter, unless otherwise requested. However, the amounts of donations will not be disclosed. However, those who contribute more than \$500 will be listed as major contributors. Memorial gifts will also be printed in the newsletter with no gift amounts given and acknowledgement notices will be sent to the family that a tribute gift has been made.

Thank you for your continued support. Together we are making a difference in the lives of our families!!

# SMS "Down Under"

By Mary Beall

On Nov. 4, Ann Smith, Gail Kopp (SMS parent and nurse), and I (Mary Beall (SMS parent and teacher), set out for Australia. When we arrived, it was Nov. 6! Armed with our Melatonin tablets, and Dr. Wally Duncan's sleep instructions, we tried our best to adjust to the very big change in time zones. Our destination was Camp Breakaway in San Remo, NSW (just north of Sydney!), where we were dubbed "Team USA."

Camp Breakaway is a non-profit charity that is dedicated to enhancing the lives of people with disabilities, and at the same time providing respite for the families and caregivers. They invited families to an amazing 4 day retreat at their beautiful facility. Parents had their own private room for two, relaxing activities, and entertainment. They were treated to elegant meals in a "Parents Only" dining room. Siblings had their own bunkhouse and activities. But, best of all...if you can believe it,...the children with SMS all spent the nights together in one big room. Each child with SMS had their own trained volunteer to work with them during the day, providing them with the one-on-one attention that they thrive on. They did some of the activities with their siblings, but for



Jay and Sophie help out.

those who had their own ideas, there were other activities available. The night shift volunteers never complained, although it was rumored that at 3:30 everyone was awake!

So what is it like to deal with SMS in Australia? The setting is different,

the seasons are different, and the TIME ZONE is different...but the children are the same. When someone said "MUM (for mom)!" in that gravelly little voice, every mother in the room turned. At the camp, meltdowns and SIBs were seen. Their sleep is disruptive to them and the family, and many had vision and hearing problems.

But they share the same strengths too. They are outgoing and friendly, and they speak to people by name by reading those nametags!

On the first day, Josef, who I hadn't yet met, walked by me and said "G'day, Team USA-Mary!" I didn't even see him look at me, but he managed to have time to read my nametag. They are "helpful" too. Nineteen year old Emma Rae skipped the activities in favor of working in the office, answering the phone and taking messages beautifully!

Ann Smith set up the SMS Research Clinic and spent three days seeing each family individually, performing physical examinations, reviewing medical history and collecting completed questionnaires that will further research about SMS (See RETURN TO CAMP BREAKAWAY sidebar). Children (age 3-20 years) who participated in the clinic had their vital signs (height/weight and blood pressure) measured and pictures taken by nurse Gail at her "Height Station." Gail and Ann also collected daytime saliva samples with lots of help from the volunteers and parents. These samples will be used to measure melatonin, and will help in the research on sleep. Two teenagers, Jay and Sophie, were reluctant to come to Gail's Height station (part of Ann's research) until they were allowed to help. Then they proceeded to become able "assistants" to measure heights and weights and take the pictures we needed. They did an accurate job, too, better than I did when I was trying to help.

I had a powerpoint available on a laptop for individuals to watch. I looked over, and tiny Abby, was working it!

Just like at PRISMS conferences, huddles of parents could be seen discussing symptoms and strategies..."your child bites herself too?" as well as proudly sharing those cute and funny SMS stories. Gail, Ann and I answered lots of questions about SMS and PRISMS.



Emma-Rae provides office help.



Abby running the powerpoint presentation.

Since I joined PRISMS, I have met many extraordinary families. The Aussies are no exception. Just like the USA families, they have big hearts, developed by hard days, harder nights, and love.

## RETURN TO CAMP BREAKAWAY 2008 – RESPITE AND RESEARCH

Ann C.M. Smith, M.A., D.Sc.(hon),  
NHGRI, NIH, Bethesda, MD

In collaboration with Camp Breakaway, the SMS Research Team from the National Institutes of Health led by Ann C.M. Smith, M.A., D.Sc.(hon), principal investigator and co-discoverer of the syndrome, organizes and conducts the SMS Research Clinic at Camp Breakaway (CB). Thanks to the tremendous organizational skills of Gae Miller and Jodie Davis who coordinated the camp, and the dedicated CB staff and team of volunteers, we have forged a model partnership that began in 2003. Camp Breakaway not only provides families and children with SMS with vitally needed support and respite, but it also offers them the opportunity to participate in the SMS Research Clinic conducted by researchers from National Institutes of Health (Team USA).

The 2008 SMS Research Clinic is the third at CB, following two prior clinics in February 2003 (Aussie Summer) and July 2006 (Aussie Winter). Two members of the NIH SMS Research Team, Beth Solomon, MS, a speech pathologist, and Wallace Duncan, PhD, a circadian biologist, joined Ann in 2003 and 2006. However, government travel funds in 2008 limited the NIH team to a solo Ann, who was excited to welcome PRISMS SMS parents/liaison's Mary Beall and Gail Kopp to join TEAM USA. Seven new and thirteen returning SMS families participated in the research clinic. Gail's nursing skills were tapped to assist in the collection of growth measures and help Ann spearhead the saliva collection using salivettes. Gail had extensive experience in

Continued from page 7...

saliva collection thanks to her daughter's, Elizabeth's past "help" in perfecting the SMS quick and easy collection approach. Mary also assisted with pictures and both she and Gail shared their personal experience and SMS "tips" on behavior management strategies, including Mary's excellent powerpoint talk on the topic. In addition to evaluating 20 children with SMS over the course of the 3-day clinic, Ann also presented a research update for parents and professionals attending the camp.

Since 2003, thirty-two Australian families (SMS-AUS group) have participated in the SMS Research clinic at CB (NIH protocol 01-HG-0109) providing vital and important research data about a group of Australian children/adults diagnosed with SMS. More importantly, twenty-one individuals with SMS have been seen for follow-up at a 2<sup>nd</sup> and/or 3<sup>rd</sup> CB SMS clinic, providing critical longitudinal data for analysis. This has led to several new insights and provided data that contributes to the knowledge about natural history of SMS across different ages. When similar findings are found in children with SMS (SMS-USA) and different countries (e.g., SMS-AUS), it supports the syndrome specific nature of the findings; when differences are noted, it raises new questions about other factors in the environment or management approaches that require further research. For example, longitudinal growth data (height, weight, head circumference) gathered for American (NIH and PRISMS), Australian, and French SMS groups will be used to develop and compare growth curves. Comparison between the different SMS groups offers a strong argument that validates syndrome specific growth findings versus the potential for recognition of other factors that contribute to the increased obesity that appears to occur with adolescence/adulthood. Australian families have also par-

ticipated in the SMS home Assessment of Sleep (under NIH protocol 01-HG-0109) using actigraphy, a non-invasive approach that serves as a surrogate measure of sleep (tracks rest & activity patterns). Not unexpectedly, SMS-AUS results show the same sleep issues as SMS-USA; collectively they provided the critical background data used to design the current sleep treatment trial that began in April at NIH (See Spectrum Volume 12, Issue 1 ). The frequency of hyperacusis in SMS-USA and SMS-AUS was also the same (~78%), supporting further expansion of features specific to SMS (See Spectrum Volume 11, Issue 4, BREWER et al).

All three members of TEAM USA got to experience jet-lag and the effects of their own melatonin shift (nighttime in USA = daytime in Australia) – but it was all worth it! Special thanks to the Camp Breakaway staff and volunteers for making the Camp Breakaway experience such a success and to the many families in USA and elsewhere who have participated in our ongoing SMS research and who continue to extend our knowledge about this rare syndrome. Perhaps one day, funding might be found to "transport" the CB-experience (Respite and Research) from Australia down-under (OZ) to the USA.



Camp Breakaway coordinators, Gae Miller (left) and Jodie Davis (middle) and TEAM USA (Ann Smith, Gail Kopp and Mary Beall).

## 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.

## Support PRISMS

Now, it's easier than ever to show your support for PRISMS. eScrip is a hassle-free way to raise money for PRISMS through your everyday purchases made at eScrip merchants. It's easy...it's free...and it's powerful!! There are no receipts to collect, no voucher or certificates to buy, no hassles for you - and every purchase counts! And unlike similar programs, you don't have to make your purchases through a specific website. Simply register your various cards - grocery club cards, credit cards and ATM/debit cards with eScrip and watch your everyday purchases add up! For every purchase made, PRISMS receives a portion of the sale price. eScrip's rebate percentages vary by merchant but most are in the 2-10% range. You can sign up online at <http://www.escrip.com>. Our group ID number is 150239751.

If you've signed up in the past, now is a good time to check to make sure that all of your credit cards are listed and eScrip has current information. Thank you for participating in this great program.



# A Letter of Understanding

The following is a letter written as a guide for people working with our 10 year old daughter (she is now 12). I am sure many of you can relate to these same issues. My advice to parents about writing their own quick reference guide is to keep it simple, real to life and not too clinical. Not many people have the time or attention span to leaf through pages and pages of difficult to read information. Start with whatever information is most important to you and then provide brief details. Sharing information like this not only helps your child and her teachers begin their relationship in a more positive manner, but it also lets teachers know that you are a willing partner in your child's education .

## RACHEL 101

By Jessica and Mark Kirklin

We need to clear up the biggest misconception about Rachel. Rachel often appears bright and mature in casual conversations with adults. The problem is that because of this, it is easy to assume that Rachel can handle herself in all situations and environments. But, that simply isn't true. Rachel requires specific support to be able to cope in what appear to be simple situations.

Try to imagine beginning your day without your cup of coffee. It would make for a challenging day. Now put yourself in Rachel's shoes. She begins everyday with the following challenges:

- Rachel always feels like she is missing her cup of coffee. Because of her inverted circadian rhythm, her body wants her to sleep during the day instead of at night.
- She has depth perception difficulties with her eyes. It is difficult for her to manage tracking from left to right on a worksheet, and nearly impossible to copy from a distant board.
- She has sensory integration issues. Something as simple as an unfamiliar staircase terrifies her and makes her feel as if she is falling. Playground equipment is often more frightening than fun. Noisy, crowded places are also difficult to handle.
- She has motor skill difficulties. Handwriting, arts or crafts, and P.E. always pose a challenge and are a source of frustration.
- She has difficulty processing sequential information, and her brainwaves occur in a disorganized pattern. She needs someone to organize her time so she knows what to do when.
- Her attention span is short. She is only capable of staying on task for a limited amount of time, even for things that she loves to do. She makes strange noises (Ehhhh sounds) as a way to help her focus, but they are bothersome to everyone else.

- She is easily distracted. Just try to do anything without her noticing.
- She has major anxiety, mood swings, heightened emotions, and developmental delays. In most ways, she is like a much younger child, only with a large vocabulary.
- She has the self-injurious behaviors of picking sores and beating her chest.

All of these issues play a role in her daily life and make it very difficult for her do something as simple as play with her peers or watch a movie.

In a nutshell, Rachel has Smith-Magenis Syndrome, or SMS. Every one of her challenges is caused by SMS. She is missing a chunk of genetic material, and it completely affects how she processes the world and how she functions within it. These issues will be lifelong challenges. They cannot be fixed with a cup of coffee, an IEP, or a BIP. They cannot be fixed at all, but they can be managed.

We know that Rachel's behavior is managed best..

- ..in a calm, consistent classroom.
- ..with a small student/teacher ratio.
- ..with re-enforcers and motivators.
- ..with teachers who view situations with a sympathetic attitude.
- ..with teachers who look for ways to intervene before a situation escalates, i.e.- redirection, distraction, humor, allowing a break, emotional support, flexibility.
- ..with teachers who seek to help her calm down without overreacting when Rachel has lost control. Once composure is regained, Rachel can be a very different child in a matter of minutes. We have to understand that once she is calm, in her mind, she has moved on. We have to move on as well and not dwell in the past (even if it was only 15 minutes ago). She doesn't enjoy being out of control, and to a large degree she cannot control it. The majority of the time she tries to please rather than displease.
- ..when time-outs are kept short. If a time-out

or separation from others is warranted, that she is not forced to stay separated for a period longer than it takes for her to calm down. Otherwise, it will escalate her distress as well as her undesirable behavior.

..with teachers who keep in mind that we are managing Rachel's behavior. Her behavior is due to her disability and cannot be disciplined out of her. You can't take the tantrum out of Rachel, but you can take Rachel out of the tantrum.

Strategies that don't work well for Rachel are...

- ..overreactions to situations.
- ..discussing consequences before Rachel is calm. If given the proper support so that Rachel can calm down, a serious consequence may not even be warranted.
- ..choosing consequences that Rachel cannot handle, i.e. - detention.
- ..giving consequences that are too lengthy or too far in the future.
- ..focusing too much on consequences in the first place. It is more important to redirect her and let her get back on track. Rachel usually has very specific reasons and circumstances that cause her to lose control. Every time she is placed in those circumstances without the support she needs, she will lose control regardless of any previous consequences.

Note: Most of Rachel's behavior issues occur when she is away from people who understand the type of support that she needs. When someone learns to recognize Rachel's signs of tiredness or frustration, they can quickly intervene. In unstructured situations such as lunch and recess, her behavior greatly improved when we structured her time and allowed her close proximity to adults.

For more information on SMS see [www.prisms.org](http://www.prisms.org)

# Garrett Mock

Drastic improvements in self-esteem, discipline, physical strength, stamina and concentration. Balancing on one foot, breaking a ¼ inch board with his hand, a “side kick”, and a “round house kick”. Counting to 10 in English, Spanish, and Korean, using “yes sir” and “no sir” consistently, understanding body, eye, and mind focus, running sideways and backwards, performing push ups, jumping over another child (without landing on them), crab walking across a room, and remembering a 10 step sequence using both feet and hands... I could go on and on. These sound like wonderful accomplishments for any six-year-old to achieve within six months. However, for a child with Smith-Magenis Syndrome, it is even more special. Garrett, who turned six in March, began taking Tae Kwon Do last February. He could not do many of the things mentioned at the beginning of this article and can now perform them all.

Tae Kwon Do (pronounced tay-kwon-doe) is a martial art that was developed in Korea. This total art form encompasses the mind, body and spirit. Tae Kwon Do (TKD) not only helps one achieve flexibility, strength, endurance and balance, but provides a foundation for self-confidence, respect and discipline that carries over into school and home.

I could never have imagined that TKD would have as many benefits for Garrett as it has. It is so much more than I thought. The physical development and improved stamina is better than any kind of physical therapy. It is very physical, so it helps kids stay in shape while having fun! I worried about Garrett being able to speak the commands. When he started, he had to be prompted to say almost everything – now his “Yes Sirs” and “Kee-yahs” and counting are the loudest in the class. TKD meets so many of Garrett’s needs. Garrett loves structure, adult attention and pleasing adults. He gets all of this at TKD. Because of the improvements and his love for it – he now attends 3-4 days a week. He participates in a “Tiny Kicker” program for 4-6 yr olds and periodically attends the 6-8 yr class. He has earned his high white, yellow, orange and purple belts. Each belt test is a test in the philosophy of TKD, and the proper sequencing of steps and punches. Garrett is now working on his 20 step sequence. He is very much a visual learner, so seeing and then doing is how he is learning.

Unlike other team sports, (falling asleep in the

outfield, getting run over by the bigger more coordinated kids with the soccer ball) TKD is individual, but with the benefits of participating and following directions with others. They participate with others who are more advanced to give them something to strive for and those that are newer, allowing them to be the demonstrator. Everyone moves at their own pace, and they learn to always do their best, and more importantly to never quit. Many of the kids are intimidated at the thought of breaking a board with their hand or foot. However, the instructors are very encouraging and will not let the kids give up. The look of pride and excitement on their faces when they break the board is priceless. They learn that they can accomplish anything with hard work and perseverance.

Tae Kwon Do allows individuals to set goals and to take responsibility for their own actions. It improves mental development and develops self-strength, self-knowledge, self-confidence, and self-control. Tae Kwon Do cultivates the positive aspects of an individual's personality: Respect, Courtesy,

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](mailto:editor@prisms.org)



★ Garrett with his instructor.



Goodness, Trustworthiness, Loyalty, Humility, Courage, Patience, Integrity, Perseverance, Self-control, an Indomitable Spirit and a sense of responsibility to help and respect all forms of life. More importantly, Tae Kwon Do strives for this unification of diversity whether through race, creed, nationality or individual ability. They are all one in the same. Tae Kwon Do reaches toward the total development of the individual.

I know this may feel like an advertisement for TKD, I just can not say enough good things about the comprehensive development and positive impact it has made for Garrett. I never would have imagined he would have accomplished all that he has in such a short time. Garrett did not walk until almost two. This just shows us that all of our kids have strengths and given the right support, they can be very successful. I hope this sends encouragement to new SMS parents.

Some of Garrett's other hobbies include the Presidents. He knows them all and some "quirky" trivia about them. For instance, he thinks it is funny that John Quincy Adams named his son George Washington. He knows them by full name and then nick name - James Earl Carter AKA Jimmy Carter, William Jefferson Clinton AKA - Bill Clinton. On a recent visit to the NIH (understanding it was near DC) Garrett asked if we could meet George Washington, I told him he was president along time ago and that he had died. His response was "Oh- we missed him?" He then asked about Teddy "Bear" Roosevelt, Abe Lincoln and now knows which presidents are living. He knows every teacher at school (and they know him) and what bus every kid in his class rides (both morning and afternoon). He loves classical composers and can identify movements by Mozart, Beethoven, Bach, Chopin and others. We are now into knock-knock jokes. Every sentence is a knock-knock joke....Here is a recent one - "Knock-Knock", "Who's there", "Merry", "Merry Who?" "Merry Christmas!" - or... "Christmas", "Christmas Who?" "Christmas Lights!", ...."Banana", "Banana Who?", "Banana Split with cherries on top!". Garrett is our super kid.



## "BUILDING BRIDGES OF HOPE"

Sept. 17-20, 2009

Reston Hyatt Hotel  
Reston, VA

The next PRISMS conference is just around the corner. We hope you have all marked your 2009 calendars for the conference and are planning to attend. The conference is a unique opportunity to meet other families who have a child with Smith-Magenis Syndrome and share stories and strategies. You will also attend presentations from our Professional Advisory Board and invited speakers regarding the latest research on SMS and pertinent information for your child and family. We will again have daycare available for a limited group of SMS children, provided by Corporate Kids. We hope to see many returning families as well as first-time attendees. There is so much to gain from attending the conferences, and you will leave with as much support and encouragement as our families and professionals can share!

**Transportation:** Accessible from Dulles Airport, IAD (6 miles)

**\*Hotel Costs:** \$125/single/double occupancy, (Thurs., Fri., and Sat. rates)  
\$ 169 (Wed., Sept. 16<sup>th</sup> rate only)

**Registration Fee:** To be determined (Fundraising will help determine cost. We will try to keep registration costs as low as possible).

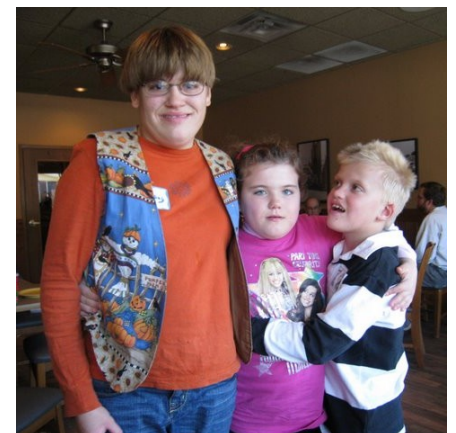
Scholarships for the conference are very limited, so we encourage families to seek local agencies for monetary assistance.

\*You may reserve rooms at the Hyatt now. Please mention PRISMS when you are making reservations. (1-800-233-1234) There will be more information to follow next year and plenty of time to make reservations next spring and summer.

**Look for more conference information next year on the PRISMS website as well as a conference mailing that will be sent next spring.**



Many members of the SMS community in Minnesota and Iowa gathered at a Saint Paul pizza joint in early October to see each other's children, share stories and to get to know one another a bit more. It was a wonderful success. Nine families were able to come. The highlight of course was the children - Ariel, Annie, Kelsey, Liam and Garrett were the life of the party and an inspiration to the adults. As Annie's mom, Jean Patnode put it, seeing everyone and getting the bear hugs from the kids was the "shot in the arm" many needed to "keep on keeping on." Another highlight was meeting and hearing from Shirley and John, parents of a thriving 40-something son, Tom, with SMS. It was heartwarming and reassuring to hear how Tom, who is now living with his sister, is doing so well -- happy, healthy, and caretaking his extensive collection of LP records. Everyone at the party was grateful to hear from the others "in the same boat," to be around people living the same exciting, stressful, blessed existence as an SMS family, and to make connections that with luck and a little persistence will endure. The families intend to stay in touch via email and plans are already hatching for a summer, 2009 picnic, where hopefully even more families will be able to attend.



Kelsey, Ariel, and Liam

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