

Smith-Magenis Syndrome Sibling Study: Results and Recommendations Part II: Factors influencing well-sibling personality traits

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Introduction

"In my very early teens I remember feeling a little bit of resentment toward my sister because she would naturally get more of my parents' attention. But I quickly realized it was selfish and silly of me to feel resentment towards her because she needed that extra attention and I really didn't. Thinking back now I realize it only made me a stronger, more independent individual, and I have my sister to thank for that."
---Questionnaire response from a 20-year-old sister of an 18-year-old diagnosed with SMS

The preceding quote represents one of many comments from siblings describing the challenges and benefits of having a sibling with Smith-Magenis Syndrome (SMS). Despite the prevalence of individuals with disabilities, little is known about the impact that a person with a disability has on his or her sibling (J. L. Taylor, Greenberg, Seltzer & Floyd, 2008). Early research on siblings of children with disabilities focused almost exclusively on the negative effects on well siblings (Dyke, Mulroy & Leonard, 2009). However, it is important to note that having a sibling with a disability has both positive and negative effects on well



siblings. Studies on adolescents of a brother or sister with an intellectual disability reveal that well siblings generally demonstrate acceptance of their sibling, and feel that he or she brings pleasure to their own and their families' lives (Gralicker, Fishler & Kock, 1962; Caldwell & Guze, 1960). Additionally, studies on families with children with Down Syndrome and Rett Syndrome show that well siblings demonstrate increased tolerance, increased awareness of differences, and increased maturity when compared to peers.

The experiences of well siblings living with a sibling with a disability vary depending on the type of disability and its effects on cognitive, physical, and emotional functioning. To date there has been no research investigating how having a sibling with SMS influences the personality of the well sibling. For the second installment of results from the SMS Sibling Study, the primary aim was to determine demographic and psychosocial factors that contribute to the personality traits of well siblings, as well as parent perception of well sibling personality traits. The predictors examined in this study include well sibling age, well-sibling gender, SMS-sibling age, SMS-sibling gender, well-sibling education level, well-sibling marital status, housing situation of the siblings, and whether or not the well-sibling experienced benefits as a result of having a sibling with SMS. Four positive personality traits (empathy, leadership,

INSIDE THIS ISSUE

| | |
|-------------------------|----|
| President's Message | 2 |
| PAB Spotlight, A. Smith | 3 |
| Advocacy Corner | 4 |
| SMS Research | 9 |
| SuperKid, M. Hall | 10 |
| SMS Mouse | 12 |
| Where is the Life Vest? | 14 |
| Fundraising Support | 17 |
| SunnySide Up | 19 |

....Continued on page 5

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A Message from PRISMS President *Randy Beall*

In my last column I introduced Phil Ruedi as our new Treasurer. Phil replaced Jeri Gawlowski. Jeri is the aunt of Krista Zdanowski (SMS), and donated countless hours to PRISMS. Jeri served as our Treasurer from 2005-2010. In addition, Jeri made the great PRISMS merchandise that we've sold at the last several conferences. A HUGE thanks to Jeri for helping us with finances, with "PRISMS-wear" and in so many other ways— you will be missed!

While we work hard to provide information and support to families of persons with Smith-Magenis Syndrome, PRISMS proudly sponsors research, and fosters partnerships with professionals to increase awareness and understanding of SMS.

We recently helped fund a Virginia Commonwealth University research study on SMS siblings. The first part of the results and recommendations appeared in the Fall 2010 edition of *Spectrum*. The second part appears in this edition.

PRISMS also partially funded the research that resulted in an article published in the American Journal of Medical Genetics entitled "Autism Spectrum Features in Smith-Magenis Syndrome." This article was written by Gonzalo Laje, Rebecca Morse, William Richter, Jonathan Ball, Maryland Pao, and Ann C.M. Smith. A full copy should be available soon using NCBI's Entrez search engine or online in Wiley Online Library (wileyonlinelibrary.com). An abstract can be seen on page 13 of this newsletter.

By the time you read this, our PRISMS 2011 membership campaign will be in full swing! As most of you already know, PRISMS is an all-volunteer organization, dedicated to providing information and support to people with SMS and their families. We do all that we can with the dollars available – maintaining a "home office," a terrific website, providing support information via phone and email, putting on conferences, and collaborating with our outstanding researchers. (Not to mention most of us have day jobs!) However, we need your dues and donations to keep providing these services. When you receive your 2011 membership form, please send it in with your dues and an extra donation if you can. Also, please take note of the list of people who have donated to PRISMS this year. We all owe our donors (and volunteers) a BIG thanks for helping us help SMS families!

As always, the PRISMS board is here to serve you. We'd love to hear from you!

Warm regards,

Randy

PRISMS President and father to Laura, age 25, with SMS
randy@prisms.org

Professional Advisory Board Spotlight

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



Ann C. M. Smith, M.A., D.Sc. (hon), CGC, is a certified genetic counselor and internationally recognized leader in the field of medical genetics and genetic counseling. As one of the first graduates of the University of California, Irvine genetic counseling training program in 1975, she has worked and made significant contributions to the field of medical genetics, including over 100 published papers and reports in leading scientific journals and six book chapters. The most significant contribution that Ann Smith has made was the discovery of Smith-Magenis Syndrome, co-discovered with Ellen Magenis, M.D. in 1986. Ann had described the yet unnamed disorder in a paper in 1982, and by coincidence, met Dr. Ellen Magenis at a professional conference where the two women began to share notes on specific patients with the same unusual, yet striking, traits. This meeting of happenstance led to the collaboration between Ann Smith and Ellen Magenis, thus the naming of the disorder and the foundation for the steps of research of Smith-Magenis Syndrome.

Ann Smith joined the Division of Intramural Research of the National

Human Genome Research Institute in 1994. In 1997 she was awarded an honorary doctorate from her alma mater, Colorado College, in recognition of her national leadership in the field of genetic counseling and clinical research in genetics, and specifically Smith-Magenis Syndrome (SMS). In 2001 she assembled the interdisciplinary SMS Research Team of intramural investigators at the Hatfield Clinical Research Center, and serves as adjunct principal investigator of two National Institutes of Health (NIH) protocols studying Smith-Magenis Syndrome. Ann was awarded two NIH Bench-to-Bedside grants (totaling \$200,000) to study SMS, and also received three Office of Rare Diseases grants to fund the SMS Research Roundtables at the PRISMS conferences.

Ann Smith also co-founded PRISMS, and was the driving force to create an organization where parents and professionals would join forces to raise awareness of SMS, and also educate both families and professionals who care for a person with SMS. This awareness in the scientific, educational, and medical realms has propelled more research and study of SMS. For PRISMS she serves on the Board of Directors and is the Chair of the Professional Advisory Board of PRISMS. Ann's energy is infectious, and she is an advocate for persons with SMS and has worked with doctors, therapists, and teachers from around the globe ensuring that the proper care and interventions are put in place to support that SMS person. Her advocacy and research has taken her to Europe and Australia speaking at various professional conferences, and

she has directed research teams at Camp Breakaway (Australia) most recently in October 2010.

Her passion for this work comes from her love for all of the families who have a child with SMS. That is most apparent at our conferences where Ann can be found usually surrounded by at least three or four of the kids. They all know her by her full "first" name, "Ann Smith", and see her as a friend, and nothing less. Ann makes herself accessible to the families, and is always willing to answer any questions of the families, tempered with compassion and concern.

Today Ann works fulltime as a senior genetic counselor under contract to the National Human Genome Research Institute (NHGRI) in the Office of the Clinical Director, dividing her time between clinical and research activities. As adjunct principal investigator of both the natural history study (01-HG-0076) and phase I sleep treatment trial (07-HG-0076) of SMS, she heads the multidisciplinary team of basic science clinical researchers who work collaboratively on SMS at the NIH.

Married for 36 years to Ron Smith, Ann has lived in the Washington, D.C. area since 1990. The couple has two adult children, Alex and McKenzie. Thank you, Ann, for your continued dedication to the research and study of SMS, and thank you for your boundless support of our families. We look forward to the steps ahead, parents and professionals both paving a better way for persons with Smith-Magenis Syndrome.

The Advocacy Corner

DREDF is the acronym for Disability Rights Education and Defense Fund. Their website at <http://dredf.org/mail-se2010/> will allow you to sign up for their email updates. I recently started receiving them, and found them full of useful information.

In August there were some great tips for starting the school year, including having a "Quick Tips Sheet" for your child's teacher that would include your child's strengths and challenges, and the successful strategies that you and past teachers and others have found to work for your child.

DREDF's most recent email was loaded with information on FTA, the Federal Transportation Authority. Access to transportation is a key to independence and full community participation for people with disabilities. The ADA, Americans with Disabilities Act, sets forth specific requirements for transit systems, including fixed routes. DREDF advocates for the development and implementation of strong, comprehensive ADA transportation requirements, works toward additional accessible transportation services, and provides in-depth training for people with disabilities and others on ADA transportation that includes current policy developments and best practices. Did you know you can apply for ADA Paratransit Eligibility, and at least one companion (also termed an associate) may ride with an eligible recipient of Paratransit services? There is a travel-training course in November. They also have online courses.

Submitted by Mary Kate McCauley
Board of Directors
Membership Committee

NE SMS Group Picnic

The first annual NE SMS Group picnic was held in August. It was great fun for those who were able to attend. Twelve families from CT, NY, NJ and PA drove many miles to enjoy lots of food, good company and a beautiful, sunny day. There was enough food to feed an army...although, the more than 75 people who attended were not near enough army to finish the food. Siblings enjoyed the playground equipment, and running and playing with other siblings. There was a large picnic area for grilling and eating. There was also ample space for family members to roam freely, but still be able to be seen by watchful parents. As a finishing touch, the entertainer, a professional clown-magician, competed for attention and laughs with the antics, natural wit, and stage presence of many SMS entertainers, age 2 to 23. We are already looking forward to the next NE SMS Group event!

Submitted by Gretchen Hannoush

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 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.

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 1980s by Ann C.M. Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

kindness, and acceptance) and four negative personality traits (avoiding, hurting, anger, and embarrassment) were examined in this study.

Methods

Parents and well siblings of persons with SMS were recruited between September 2009 and March 2010 via e-mails sent through the PRISMS (Parents and Researchers Interested in Smith-Magenis Syndrome) listserv and Yahoo SMS listserv. Recruitment also took place at the PRISMS conference in September 2009 (Reston, VA). The e-mails were sent primarily to parents who were provided with the option of allowing their child(ren) to participate. Those interested in participating completed an online survey which was composed of two previously validated surveys. The first survey utilized was the Sibling Inventory of Behavior (Schaeffer & Edgerton, 1979). On this scale participants are asked to rate (1 = *never* to 5 = *always*) the frequency with which the well siblings directed specific positive and negative behaviors toward their sibling with SMS during the past 3 months. The Sibling Inventory of Behavior assesses four positive (empathy, leadership, kindness, acceptance) and four negative (avoiding, hurting, anger, embarrassment) personality traits.

The second survey utilized was the Satisfaction with the Sibling Relationship Scale (McHale and Gamble, 1989). On this scale participants are asked to rate (1 = *very unhappy* to 5 = *very happy*) well siblings' levels of satisfaction with certain components of the relationships with the siblings with SMS, and the relationships with the parents during the past three months. This scale contains 8 questions that assess the well sibling's level of satisfaction with the amount of time spent with the sibling



with SMS, how well the siblings get along, time spent caring for the sibling with SMS, how close the siblings are, the amount of time spent playing with the sibling with SMS, how often the well sibling gets to be the boss, how alike the siblings are, and overall

happiness the well sibling feels as a result of having a sibling with SMS. Two questions assess the well sibling's level of satisfaction with parental treatment, and the amount of attention received from parents as compared to the sibling with SMS. Additionally, six questions were posed that asked participants to rate (1 = *less*, 2 = *no change*, 3 = *more*) changes the well siblings would like to experience in their relationships with the siblings with SMS.

Participants

A total of 79 well siblings participated ($M_{age}=20.3$ years, $SD_{age}=10.6$ years). Of the participating well siblings, 89.8% were Caucasian and 62% were female. Ninety-two point one percent reported the individual with SMS was their biological sibling, 46.8% reported that they live full-time with their sibling with SMS, and 51.9% reported having additional siblings.

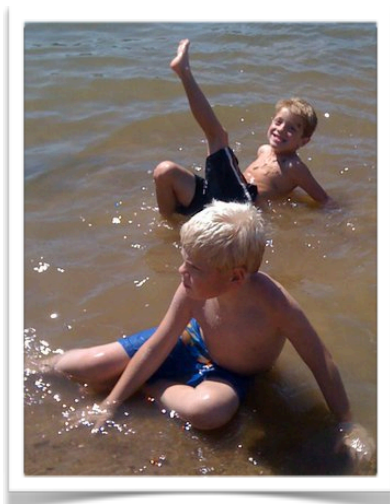
Seventy-two point two percent of well sibling participants were single.

A total of 60 parents of well-siblings of individuals with SMS participated. Parents reported a mean well sibling age of 14.5 years ($SD_{age}=7.0$ years). Parents reported that 86.7% of their well children were Caucasian and 50.8% were male. Parents reported that 86.2% of well siblings had additional siblings; 93.3% were single, and 70% lived full-time with their sibling with SMS. Eighty-four point seven percent of parents reported that their well child did not have any developmental, social, or emotional delays. Ninety-five percent of the parents reported they were biologically related to the individual with SMS.

Well siblings and parents provided demographic information on the individual diagnosed with SMS. Well siblings reported an average SMS sibling age of 18.7 years ($SD=8.9$ years). Parents reported an average SMS sibling age of 13.8 years ($SD=7.1$ years). Well siblings reported their siblings diagnosed with SMS were predominately male (53.2%). Parents reported their children diagnosed with SMS were predominantly female (55%). Participants reported that the individuals diagnosed with SMS were predominantly Caucasian /white (89.9% of well siblings' reports, 86.7% of parents' reports).

Multiple Regression Analysis

This study aimed to explore the positive and negative behaviors and feelings exhibited by well siblings of individuals with Smith-Magenis syndrome and the parental perception of these behaviors and feelings. For each of the positive personality traits assessed in the Sibling Inventory of Behavior, four different questions were asked to assess the level of the positive traits demonstrated by the well sibling. The scoring system was based on a Likert-like scale of 1-never to 5-always. The scores of each of the four questions for a positive personality trait were summed, thereby resulting in a range of 4 to 20 for any given



positive personality trait, with higher scores indicating that the well sibling displays more of that personality trait towards the sibling with SMS. Additionally, the scores for each of the four positive personality traits were then summed for an overall positive personality trait score, thereby resulting in a range of 16 to 80. For each of the negative personality traits assessed in the Sibling Inventory of Behavior, three different questions were posed to assess the level of negative traits demonstrated by the well sibling. The scores of each of the three questions for a negative personality trait were summed, thereby resulting in a range of 3 to 15, with higher scores indicating the well sibling displays more of the negative trait towards the sibling with SMS. The scores for each of the four negative personality traits were summed for an overall positive personality trait score, thereby resulting in a range of 12 to 60.

Multiple regression was conducted to determine which of the predictors tested significantly influenced the outcomes for positive and negative well-sibling personality traits (data not shown). The following predictors were tested: the well-sibling age, well-sibling gender, SMS-sibling age, SMS-sibling gender, well-sibling education level, well-sibling marital status, housing situation of the siblings, and whether or not the well-sibling experienced benefits as a result of having a sibling with SMS.

Results

Well-sibling positive personality traits are primarily influenced by the ages of the well-sibling and the sibling with SMS.

For well-sibling responses, the most significant predictors of positive personality traits were the age of the well sibling, the age of the sibling with Smith-Magenis Syndrome, and whether the sibling reported experiencing benefits from having a sibling with SMS (Figure 1).



Increase in well-sibling age was associated with a significant increase in empathy, acceptance, leadership, kindness, and overall positive traits, while an increase in SMS-sibling age was associated with a significant decrease in

leadership, kindness, and overall positive traits. Well siblings who reported experiencing benefits as a result of having a sibling with SMS reported significantly greater levels of overall positive traits compared to siblings who have not experienced benefits. The ages of the well sibling and of the sibling with SMS and whether or not the parent perceived the well child as having experienced benefits were also the most significant determinants of parent perception of well-sibling positive traits. While parents' perceptions of positive traits demonstrated by

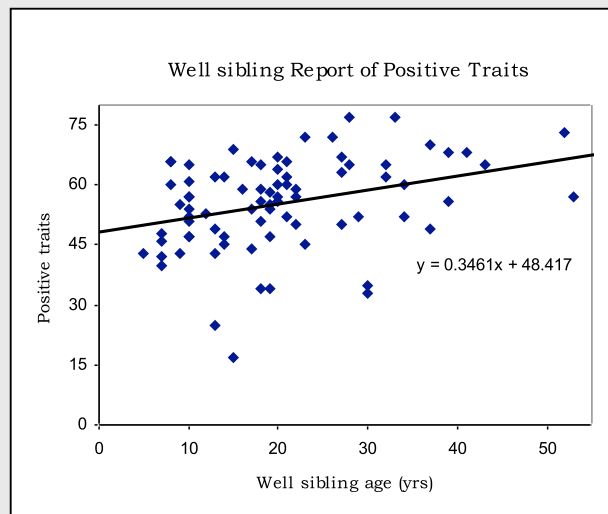


Figure 1. Changes in the overall positive personality traits exhibited and experienced by well siblings. Positive personality traits were assessed by the Sibling Inventory of Behavior. Scores for overall positive personality traits were calculated by summing the individual scores for empathy, acceptance, kindness, and leadership. The potential range of scores was from 16 to 80, with higher scores indicating that the well sibling exhibited greater levels of positive personality traits. Results show an increase in the amount of positive personality traits experienced and exhibited by well siblings with age.

well-siblings were generally influenced by the same predictors, parents tended to report lower levels of well-sibling positive personality traits than was reported by the well-sibling (Figure 2). These results indicate that, overall, parents are able to accurately assess the factors that influence well-siblings positive personality traits, but they tend to under-appreciate the degree to which well siblings' personalities are positively influenced as a result of having a sibling with SMS.

Well-sibling negative personality traits are primarily influenced by well sibling age

For well-sibling responses, the most significant predictor of negative personality traits was the age of the well sibling (Figure 3). Increase in well-sibling age was associated with a significant decrease in anger, avoiding, embarrassment, hurting, and overall negative traits. For parent responses, the most significant predictors of negative traits were the age of the SMS sibling, whether or not the siblings live together, and whether or not the parents perceive the well sibling as having experienced benefits as a result of having a sibling with SMS. For parent report, increase in SMS, sibling age was associated with a significant increase in well-sibling negative traits (Figure 4). Parents reported significantly greater levels of negative traits for siblings who lived apart than for siblings who lived together. Parents who perceived the well sibling as having experienced

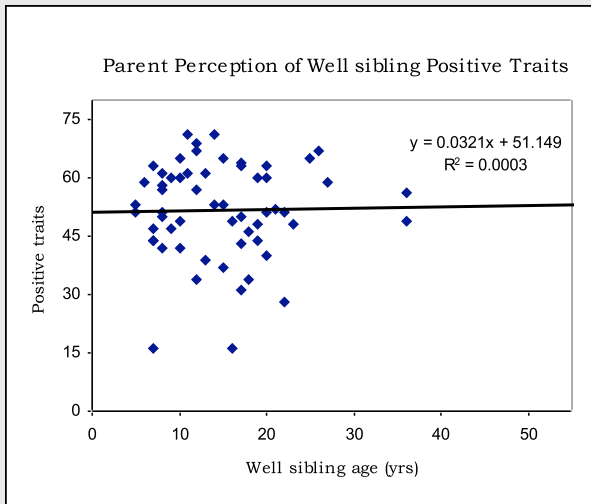


Figure 2. Changes in the overall positive personality traits exhibited and experienced by well siblings as perceived by parents. Positive personality traits were assessed by the Sibling Inventory of Behavior. Scores for overall positive personality traits were calculated by summing the individual scores for empathy, acceptance, kindness, and leadership. The potential range of scores was from 16 to 80, with higher scores indicating that the parent perceived the well sibling as exhibiting greater levels of positive personality traits. Results show that parents perceive well siblings as exhibiting greater levels of positive personality traits with age; however the increase in parent perception is not as great compared to well-sibling report.

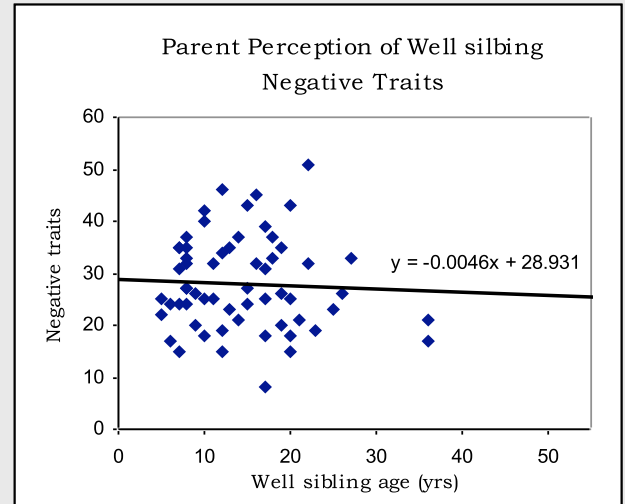


Figure 4. Changes in the overall negative personality traits exhibited and experienced by well siblings, as perceived by parents. Negative personality traits were assessed by the Sibling Inventory of Behavior. Scores for overall negative personality traits were calculated by summing the individual scores for anger, avoiding, hurting, and embarrassment. The potential score range of negative traits was from 12 to 60, with higher scores indicating greater levels of negative personality traits, and were exhibited by the well sibling. Results show that parents perceive a slight decrease in the amount of overall negative traits exhibited by well siblings; however, parents do not perceive the change as being as great as reported by well siblings.

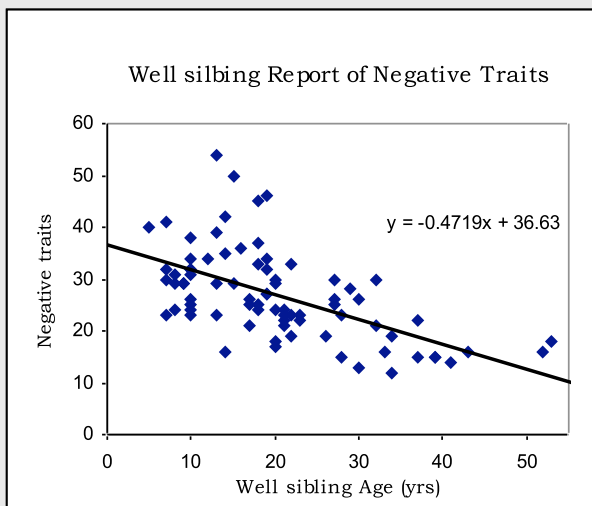


Figure 3. Changes in the overall negative personality traits exhibited and experienced by well siblings. Negative personality traits were assessed by the Sibling Inventory of Behavior. Scores for overall negative personality traits and were calculated by summing the individual scores for anger, avoiding, hurting, and embarrassment. The potential score range of negative traits was from 12 to 60, with higher scores indicating greater levels of negative personality traits exhibited by the well sibling. Results show that well siblings experience decreasing levels of negative personality traits with age.

benefits reported significantly lower levels of negative traits. Overall, parents reported greater levels of negative personality traits compared to well-sibling responses. These results indicate that parents are not able to accurately assess the factors that influence well-sibling negative traits, or the degree to which well-siblings' personalities are negatively affected as a result of having a sibling with SMS.

Summary

Understanding the positive and negative impacts on well siblings of individuals with neurodevelopmental disabilities is essential to providing adequate care to families of individuals with Smith-Magenis Syndrome, as well as to their parents and siblings. Prior research on the experiences on well-siblings of individuals with disabilities is limited. Thus, understanding of the unique family dynamics experienced by individuals living with a family member with a disability is restricted. Our research has shown that the positive effects of having a sibling with SMS on well-siblings' personalities are primarily influenced by the age of the well-sibling, the age of the SMS sibling, and whether or not the sibling has experienced benefits as a result of having a sibling with SMS. These predictors are also the most influential factors on parent perception of well-sibling positive traits. For negative traits,

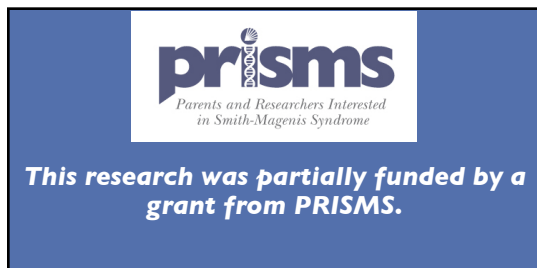
the age of the well-sibling is the most significant predictor of how having a sibling with SMS negatively impacts the personality of the well-sibling. This predictor does not factor into parent perception, indicating that parents are not able to accurately assess the factors that influence how having a sibling with SMS negatively impacts the well-sibling's personality. Furthermore, parents tend to overestimate the negative impacts and under-estimate the positive impacts on well-siblings' personalities as a result of having a sibling with SMS. For parents, having a better understanding of how well-siblings are influenced by the presence of a sibling with SMS in a family, and being able to realize that, overall, well-siblings experience more positive effects and less negative effects may lead to improvement in family relationships and the well-being of the family as a whole.

Acknowledgments

We would like to thank all of the siblings and their parents who took the time to complete our survey. Your time and efforts have provided a wealth of information that will allow us to inform healthcare providers of the unique needs of families coping with SMS, and to develop novel approaches to serve SMS families in the future.

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Current SMS Research

One of the core values of PRISMS' mission is to "foster partnerships with professionals" through collaboration between parents and professionals. PRISMS supports the following new research studies, and would like to extend these opportunities to families and teachers to participate in this research. We hope that you will consider being a part of this valuable research, and thus contribute to its results.

ACTIVE RESEARCH STUDIES

Conducted by: Dr. Sarah Elsea, VCU, and Meghan MacNeal, genetic counseling graduate student, University of Pennsylvania

Dr. Sarah Elsea at Virginia Commonwealth University is currently investigating sleep habits in children with RAI disorders and their parents. These disorders include Smith-Magenis Syndrome and Potocki-Lupski Syndrome. The study is open to parents and teachers of children with RAI disorders. The purpose of the study is to collect information about how RAI disorders affect sleep habits and behaviors of children with these disorders and their parents, with the goal of finding interventions or tools to improve sleep and behavior for the family. To participate in the survey, please follow these links:

For Parents:

<http://www.surveymonkey.com/s/TZLQJB7>

For Teachers:

<http://www.surveymonkey.com/s/GCKX9ZZ>

Please check www.prisms.org frequently for opportunities to participate in current research. If you are interested in fundraising for research, please contact Tina McGrey at fundraising@prisms.org.

Conducted by: Rio Friday, Genetic Counseling Intern, Masters in Genetic Counseling Program, University of Maryland - Baltimore, School of Medicine, in association with: Ann C. M. Smith, NIH

The following survey is being conducted to learn about complementary and alternative therapies (such as melatonin, vitamins, music therapy, etc.) that have been tried by families who have children with SMS. As of now, most of the knowledge of the types of therapies that families have tried is anecdotal. This study intends to find out not only what kinds of therapies have been tried, but also what therapies have been successful or unsuccessful for individuals with SMS. Once this is complete, the results of the study will be published for the PRISMS community with the hope that it will provide some insight as to what may be helpful or not helpful to try with the SMS individual in your care. Identifying potential therapies that may benefit persons with SMS helps to lay the foundation for future proposed research studies. Participation in this study is completely voluntary, anonymous, and will not influence your relationship with PRISMS in any way. Participants should NOT include any identifying information in their survey responses. Should you chose to participate in the survey, at any time you can stop, delete your answers to the questions, or decline to answer a question that you are uncomfortable answering. Your responses will be kept confidential, and the researchers will not collect any identifying information.

Link to the survey: www.surveymonkey.com/s/smscam

If you have any problems or concerns about the survey, please contact Rio Friday at rfridoor@umaryland.edu, or you may call 410-706-4713. You can also contact Ann Smith at acmsmith@mail.nih.gov. We appreciate your time and effort in completing this survey.



Matt Hall



Matt Hall loves to read. This 26-year-old young man with SMS spends several days a month reading, playing games, and assisting with show-and-tell with preschool children at St. James Catholic Church.

Sandy Hall, Matt's mom, knew something was "not right" shortly after Matt was born. But like many, it took 17 years before the doctors put a name to what was causing the developmental delays. "When they finally told us the name, we had never heard of it, but when I went home and looked it up on the internet I knew for sure that's what he had," Sandy said. "I ran upstairs and told my husband that we finally had the right diagnosis."

Matt has always wanted to help little children. After graduating from high school, he asked St. James preschool teacher Terry Ward if he could read to her class. She agreed and says "The kids just love "Mr. Matt." It's good for him and good for the kids. He sits in a chair and the kids all gather around him while he reads to them." Matt spends hours and hours over several days, making decisions on books, treats, and even makes the children little trinkets sometimes.

Matt says that seeing the children smile makes it all worth his time. "I love all of their smiley faces, and they say thank you," he said. "They are adorable. I like kids. They are all so cute."

Matt likes to read stories about the Teenage Mutant Ninja Turtles, Superman and Spiderman, as well as stories about Christmas, Easter, and Thanksgiving.

Ward says, "He is just the neatest kid. He talks about everyone else and is so interested in other people. He's really been an asset to our classroom."

Matt is a member of Knights of Columbus, a Catholic Fraternal Service Organization that focuses on charity. He recently earned the fourth degree which is the highest degree of the order. He also enjoys working on daily living skills such as laundry, cooking, grocery shopping, and learning how to handle money.

Parts of this article excerpted from the Standard Examiner of Utah.



Do you have an SMS SuperKid? We know what amazing things our kids can accomplish, and those big and small moments of success need to be celebrated for all to see. Please consider sharing your moments with us. If you have questions or need help with the story, please contact the editor at: editor@prisms.org.

A Letter to the Doctor

This letter was written by Matt's Mom, Sandy Hall. It was written as a thank you note to Matt's physician. She wanted to share it with all SMS families. It has been edited for length, but is a wonderful story of her journey.

Dear Dr. Pfeffer,

I am not sure why I feel an overwhelming desire to write this letter. I very much want to tell you how much we enjoyed our office visit with you and your staff. Our visit prompted me to reflect back on my Smith-Magenis Syndrome journey, which started 17 years before I ever knew the term Smith-Magenis Syndrome. It was often a painful journey.

It made me realize "I DID IT!" My husband did it, Matt's brother did it, YOU DID IT!, many professionals did it, our community did it, and most of all MATT DID IT! There were many days I did not think I could deal with it any longer. There were not answers to the behaviors, medical issues, or developmental delays. No one knew what to do and no one knew what we were going through. As tantrums occur, you learn to put up walls with the onlookers, and close your ears to their words. You survive. Are the answers to these extreme behaviors with psychiatry and drugs, residential treatment centers, psych wards, behaviorists and locked time-out rooms, placement of these children in state custody in a home? I don't know. Our journey has been long, exhausting, time consuming, and life changing. We took a syndrome with unbelievable behaviors, medical issues, and challenges, and nurtured a very kind, sensitive, loving, humorous, and unique individual. Matt brings much happiness to the people surrounding him. He is a delight to be around and makes everyone laugh.

He has turned into a productive adult. He goes to a day program where he has learned to do his own laundry, prepare simple meals, and shop for necessary food items. He volunteers at a nursing home. He has a goal to volunteer at a pre-school, reading stories to the children. He has touched the hearts of many.

We no longer have out of control episodes at home. We choose outings carefully to avoid over-stimulation and sensory overload. We do our best to keep Matt as medically well as we can. He is happy. We are happy. It is not to say that the challenges of SMS don't continue, because they do, on a day to day basis, but life is so much easier now.

When Matt was younger, if someone had told me that things would be okay when he was an adult, I would not have believed them. It took the efforts of many specialists, countless hours, days, years of teaching, and an enormous amount of patience to get us where we are today. I am glad we did not give up on Matt. Look what we would be missing out on now. I am glad I did not always follow the advice of the specialists as Matt may not be home with us today. I received advice from a Doctor at the University when Matt was only 10 months old that got me through many a dark day. He examined Matt and said, "My advice to you is to take Matt home, grow him, no one will know and love him the way you do." So I did. We did get a diagnosis as you know, at age 17, but by that time I had already grown him. I am proud of our accomplishments. I am proud of Matt with the enormous challenges he was given. But I could not have done it without the help of family and professionals, even though none of us knew what to do! We made mistakes along the way. We did the best we could with the tools we had at the time. Our visit made me realize I did not fail, I succeeded! You Succeeded! Matt succeeded! It calls for celebration! WE DID IT!

Please know, Dr. Pfeffer, as you share Matt with your family, I share you with mine. You are remarkable. Thank you for your genuine heart-felt love and caring for children and their families. We hold a special spot in our hearts for you. Best of luck with your SMS patients and their parents and if I can be of assistance let me know. I have no advice for these parents. I cast no judgements for their decisions. I only have my story of life with SMS.

Sincerely,
Sandy Hall

A Day in the Life of an SMS Mouse in the Lupski Lab... By Vincent the Mouse!



Let me introduce myself. I am Alan the mouse, and I have SMS. I've got plenty of relatives and friends with SMS too, but not all of us have the same SMS deletion – some of us have mutations in the gene *RAI1*. We all live in Houston at Baylor College of Medicine where we are taken care of by the researchers in the Lupski lab. I am so excited to be writing this article, and to finally get all the credit I (and my fellow mice) deserve! My friends and I have been very, very busy doing all sorts of tests, including tests for learning and memory, sleep/wake cycles, motor skills, anxiety, and social behavior. I don't know where these researchers get their ideas – they have me

walking on dowels, running in wheels, hanging from wires, crawling in tubes, investigating open fields, and even swimming in a pool – this often feels great with the Houston hot and muggy weather!

As it turns out, I tend to have some trouble learning as quickly as some of my brothers, and I'm not as quick on my feet. I'm also not quite as social with my fellow mice, and I tend to be more anxious in some situations. My trainers are hoping that enriching my home-cage environment with stimulating objects (like toys) might help me improve on some of these tests. I will keep you posted on the results in the upcoming months! As for my sleep cycle, it turns out that I have trouble falling (and staying) asleep when I should. We will be testing the effects of light intensity on my sleep cycle to see if that helps. Understanding the specific areas where I need help is useful in order to identify what types of therapies might be needed to help treat these symptoms. As potential treatments are developed, I will be first in line to test them out!

In other news, these researchers have also been monitoring my weight, blood cholesterol levels, and body fat. I've been told that I'm a touch overweight; this might be due in part to my lack of exercise. However, a strict, low-fat diet has been able to help keep my weight under control, which is good news. In other good news, with a low-fat diet, my body fat, blood cholesterol, and blood sugar levels all seem to be reduced. My buddies with the *RAI1* mutation seem to have more trouble with their weight and cholesterol, so they are starting a low-fat diet as well. We hope that this can help them to reduce their weight gain just like it helped me.

Although we all have SMS, it seems like my friends with the *RAI1* mutation have different symptoms than those of us with the deletion. *RAI1* mice may have more symptoms relating to their weight, but they seem to have fewer behavioral symptoms than we deletion mice have. Our researchers plan to investigate the underlying differences between these two “groups” of mice, but we all look the same to me!



Life as a lab mouse isn't so bad, and it is rewarding to know that the results of these tests might help explain the causes behind some of the symptoms of Smith-Magenis Syndrome. Of course, I couldn't do it all on my own – it takes many of us mice (including the deletion, *RAI1* mutation, and control siblings) to perform each test. Oh, and I guess the researchers help too. I look forward to updating you periodically on my new and exciting activities!

Sincerely,

Vincent

PS: Check me out on Facebook (Lupski Lab Facebook site)

Here I am learning to find a platform in a HUGE pool. How do I get myself into these situations? Don't they know I don't always like getting my paws wet?!



Melanie Heney and Wenli Gu of the Lupski Lab.

Bios: Lupski lab

Melanie Heney is working towards her Ph.D. in Molecular and Human Genetics at Baylor College of Medicine. Her project involves the study of the mouse models for Smith-Magenis Syndrome and Potocki-Lupski Syndrome in Dr. Jim Lupski's lab. Born and raised in Canada, Melanie completed her undergraduate degree in genetics from the University of Western Ontario in London, Ontario. She then went on to complete a Master's degree from Lakehead University in Thunder Bay, Ontario where she studied chemotherapies and cancer cells. Melanie hopes to continue research on genetic disorders once she completes her degree. She currently lives in Houston with her fiancé, Dave and puppy, Nala.

Wenli Gu is a postdoctoral researcher in Dr. Jim Lupski's lab at Baylor. Wenli obtained her Ph.D. in genetics in Germany and worked in the field of neurogenetics in Bonn, Cologne, and Munich. She is currently working with Melanie to use the mouse models to study SMS and PTLs, as well as to resolve the biological function of the RAI1 protein.

The Lupski Lab would love to hear from you. Please feel free to contact us by email (jlupski@bcm.edu, heney@bcm.edu, or wgu@bcm.edu), phone, (713)-798-6873, or now on Facebook (search for the BCM Lupski lab page)!

For more info, feel free to visit the official Lupski Lab website: <http://www.bcm.edu/genetics>

Abstract

Autism Spectrum Features in Smith-Magenis Syndrome

GONZALO LAJE, REBECCA MORSE, WILLIAM RICHTER, JONATHAN BALL, MARYLAND PAO, AND ANN C.M. SMITH - American Journal of Medical Genetics, Part C (Seminars in Medical Genetics) 154C: 456462 (2010).

Smith-Magenis Syndrome (SMS; OMIM 182290) is a neurodevelopmental disorder characterized by a well-defined pattern of anomalies. The majority of cases are due to a common deletion in chromosome 17p11.2 that includes the RAI1 gene. In children with SMS, autistic-like behaviors and symptoms start to emerge around 18 months of age. This study included 26 individuals (15 females and 11 males), with a confirmed deletion (del 17p11.2). Parents/caregivers were asked to complete the Social Responsiveness Scale (SRS) and the Social Communication Questionnaire (SCQ), both current and lifetime versions. The results suggest that 90% of the sample had SRS scores consistent with autism spectrum disorders. Moreover, females showed more impairment in total T-scores ($P_{1/40.02}$) and in the social cognition ($P_{1/40.01}$) and autistic mannerisms ($P_{1/40.002}$) subscales. The SCQ scores are consistent to show that a majority of individuals may meet criteria for autism spectrum disorders at some point in their lifetime. These results suggest that SMS needs to be considered in the differential diagnosis of autism spectrum disorders, but also that therapeutic interventions for autism are likely to benefit individuals with SMS. The mechanisms by which the deletion of RAI1 and contiguous genes cause psychopathology remain unknown, but they provide a solid starting point for further studies of gene-brain-behavior interactions in SMS and autism spectrum disorders. 2010 Wiley-Liss, Inc.

Where is the Life Vest?

Is the Life Line Attached? An Aunt's Experience.

Visiting family and playing games with the kids takes on a slightly different perspective when one of the kids you love has Smith-Magenis Syndrome (SMS). Families who live day in and day out with a child with SMS learn to cope with daily activities in a variety of ways, but when you are visiting, there is no learning curve. Sharing my recent experience with you is a way to thank the writers and readers of the Spectrum, and share how important you are.

My 16-year-old niece, Rachel, has SMS. She lives with her parents and three brothers. I had the opportunity to visit for an extended period of time so her parents could go on their first vacation in 16 years – WITHOUT THE CHILDREN. I was looking forward to spending time with the kids. The best part of having a brother with four kids is the ability to spoil them, as any proper “auntie” would.

After being loaded up with nine-plus pages of notes from the parents, I was feeling very capable and confident, and thus the children and I began this 12-day adventure. I memorized codes and combinations for the pantry, the refrigerator and lunch box. I learned the daily schedule and “taxi” routes for the family’s daily activities, and tried my utmost to stay awake in order to keep up with these activities until they were done. By the time Rachel went to sleep at night, I was usually exhausted, but this was my

time to spend with her brothers, to talk and do things together, although it was

probably less in quantity and quality due to my exhaustion. There is a



lot of work and needed endurance that comes from having a child with SMS. You learn to not take things personally, and to redirect with a smile and soft coaxing attitude. There is no heavy-handed control happening, because that would lead to World War III in an instant. Rachel is smart, so you have to be one step ahead of her at all times. It is an endurance race most of the time, with constant vigilance day and night!

On the 7th day of my stay, Rachel woke up at 5:00 a.m. and had two meltdowns before 9:00 a.m. This meant the activities for the day had to be canceled, because there was no way to circumvent the emotional roller coaster. It was a hard day and took 120% of my attention **and** the boys’ help to keep Rachel calm and working with the family. We made it through the day, and Rachel had a good day at school the next day. However, that was the last “easy” day. The following day Rachel decided not to go to school because her stomach hurt, and she wanted to visit the doctor. Rachel had many special outings with church friends and family over the week to help with the schedule, and was eating everything she is not supposed to eat. She also has a fascination of the medical world, and talks about becoming a doctor; she loves doctor visits. Rachel had no fever and was probably just reacting to the increased amount of sweets she had consumed, so I let her stay home. Mistake number one. After the boys left for school, she got dressed and was a happy kid ready for a day of adventure with her aunt. But, not wanting to reward her behavior, I stated that since she was sick and could not go to school, then she was too sick to go out to breakfast, make cookies or go to the library, all of which were her suggestions. Rachel sat down and said that she wanted to go to school. Now comes my next

mistake.....I took her to school expecting her to go into the class room, because she had said she would. Those with SMS kids know the push/pull circle of reasoning, “I want it; I don’t want it.” Unfortunately, “I” was not prepared and now, as you can imagine, once we were stopped outside of her school, she decided that she no longer wanted to go to school. We returned home and had a terrible day. I was fraught with insecurity. Had I done the wrong thing? What should I have done instead? Needless to say, Rachel’s behavior began deteriorating over the next few days.

I prayed and got out the latest copy of Spectrum, Volume 14, Issue 2, and found two articles that were my rescue. First I read the article by Jenny Beall, “On Being ‘The Normal One’.” She told of how she loved her sister, AND how the unexpected meltdowns affected her life. This was the life vest I was thrown. As I read Jenny’s story and visualized Rachel’s behavior, I thought, “Yes, all of this is just a part of SMS. I was not missing something; it was just the way it is.” Jenny’s article helped me realize that I was not alone. Others were frustrated with outbursts in public, and disappointed by frequently having to change plans and activities midstream. The seven days of good behavior had lulled me into a false sense of security.

The next article I read was a “[Letter to the Camp](#)” written by Mary Beall who, I assume, is Jenny’s mother. This letter



was the life line that was attached to the vest. Mary had written pages of specific ideas and helpful hints. I had combed the nine pages of notes from Rachel's parents, desperate to find the one cue I had missed. The truth was, there was no cue; this is the life of a family with a child of SMS. Calm settled over me, and we got through the day. Then we got through the next day. The best advice I received was from a friend I had called and asked to pray for us. He said, "Love her, just love her."

In the end, the time was full and sprinkled with so much love that I can't wait to visit again! Not just because we are family,

but because the moments of joy are so evident with an SMS child. Rachel's ability to share, care and love others is precious. Watching her smile and win another board game is worth the lack of sleep or the interrupted movie. Plus her brothers are VERY special people. Yes, I also love their mother and father too! OK, I admit I may be a bit biased.

I praise all parents of SMS kids and the families that love them! I am grateful for the contribution of all who write and share stories, edit and create the Spectrum! Your publication educates and supports those who live in the SMS world daily. Hope is the reminder that

you are not alone with this child, as others know what you are going through, and can understand the frustration and the joy. Thank you and keep up the great work!

Rachel's Aunt Mary

Phase I Treatment Trial of Circadian Sleep Disturbance in Smith-Magenis Syndrome at NIH



In 2008, researchers at the National Institutes of Health (NIH) began active enrollment for the first controlled treatment trial to determine if bright light alone, or in combination with a melatonin tablet preparation, is effective in treating the sleep disturbance in children with Smith-Magenis Syndrome (SMS). Sponsored by the National Human Genome Research Institute's Division of Intramural Research (NHGRI-DIR) at NIH, the phase I treatment trial (protocol 07-HG-0076) is conducted by the interdisciplinary SMS Research Team led by adjunct principal investigator, Ann C.M. Smith, MA, D.Sc.(Hon), NHGRI and co-investigators, Wallace Duncan, Ph.D., NIMH, Wendy Introne, M.D., NHGRI Medical Responsible physician, and William Gahl, MD, Ph.D., NHGRI principal investigator. Five children with SMS have completed the bright light part of the trial; recruitment of an additional ten children with SMS are sought to complete this portion of the trial. [See www.clinicaltrials.gov NCT00506259.]

Children with a confirmed SMS diagnosis (del 17p11.2) who are between 5-16 years of age, have not reached puberty, and are seizure free may be eligible to participate in the study. Since certain medications may exclude individuals

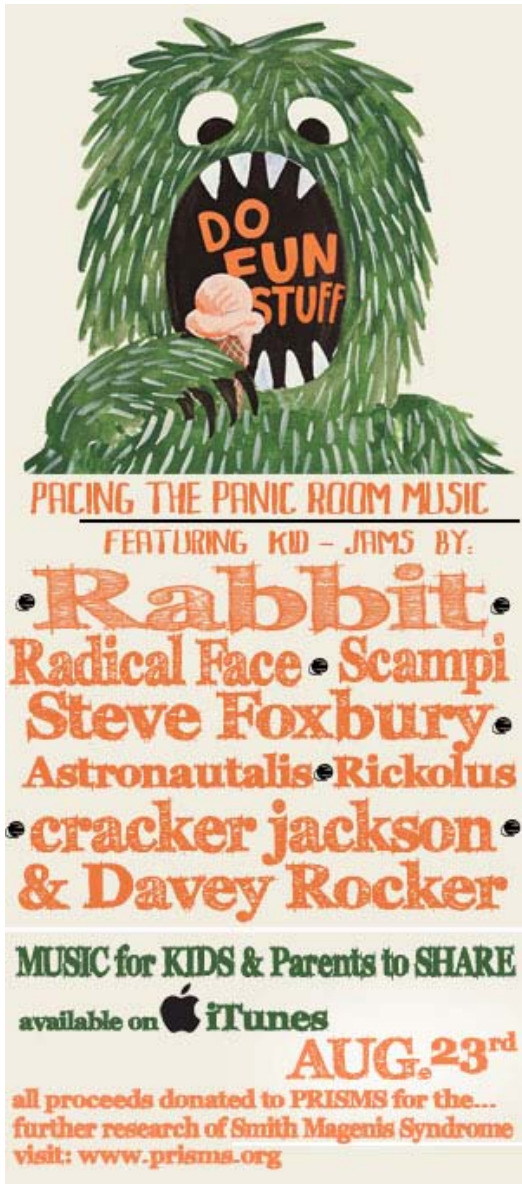
from participation, a telephone screen to review your child's medications (both prescribed and over-the-counter) will be conducted as part of the eligibility review. Partial funding is available to offset travel costs to/from NIH (based on standard government rates).

The bright light trial includes the pre-trial Home Assessment of Sleep (HAS) with actigraphy for four weeks, followed by a 4-day (3 nights) NIH inpatient admission with serial blood sampling and EEG monitoring conducted during the trial period.

Parents interested in learning more about this treatment study should contact:

Ann C.M. Smith, MA, D.Sc(Hon), Adjunct Principal Investigator
Office of Clinical Director, National Human Genome Research Institute, NIH
Bldg 10, Room 10C103, 10 Center Drive, MSC 1851
Bethesda, MD 20892-1851
Tel 301-435-5475
Email: acmsmith@mail.nih.gov

“Do Fun Stuff” Album Released! Support from Artist Ryan Marshall



"Do Fun Stuff" (Vol 1) is the first album (in a yearly release schedule) of original kids music that is for sale as a charity album benefiting the further study of Smith-Magenis Syndrome. The hope is that enough money is raised for PRISMS to establish an SMS Research Fellowship that funds a graduate student to study SMS and support the SMS community. The album is a compilation of varying artists who all contributed their time and efforts to craft these kid tunes, all in an effort to drive awareness and funds towards Smith-Magenis Syndrome. This is a digital release via iTunes, and 100% of the proceeds goes into a charity trust set up by PRISMS. There are plans to eventually have a CD available also.

The album is available online via iTunes Worldwide. The album itself is a great collection of kid and parent friendly tunes that makes *Do Fun Stuff*, a kids record for parents. The album has mass appeal, and tunes are melodic, fun, sentimental, and hard to turn down. Contributors to this first volume are: Rabbit, Radical Face, Astronautalis, RickoLus, Scampi, Steve Burry, Cracker Jackson, and Davey Rocker. All of these artists were moved by the cause and happy to help.

-Ryan Marshall

Check it out at: www.pacingthepanicroom.com

Fundraising Support

Buck Creek 5K Run/Walk

On the third weekend in September, 14 SMS families met in Springfield, Ohio for the Fourth Annual Buck Creek 5K Run/Walk for PRISMS. The race was held Friday night where runners, walkers, and even a couple bike riders donned their PRISMS t-shirts and supported our favorite cause. We raised almost two thousand dollars, and received a great surprise from the McQuown family (see Todd's article, page 18, for more on that story).

On Saturday afternoon, 11 SMS individuals and their extended family and friends met for a picnic at the McGrevy house. Kite flying, bubble blowing, and lawn games kept the kids busy while the adults shared stories and SMS strategies with each other. A camaraderie, which included seven states and even Mexico and Canada, that only families of our special kids can understand. We cannot wait until next year!



Mark your calendars for **FRIDAY, September 23, 2011** for the Fifth Annual PRISMS 5K. Once again, our race will be held at the Buck Creek State Park. Camping and cabin reservations can be made at www.dnr.state.oh.us. We will be checking into group room rates at one of the local hotels. Stay overnight and attend the picnic on **SATURDAY, September 24, 2011**. We hope to see you there!

Charlie and Tina McGrevy

.....

California Golf Outing A HUGE SUCCESS!



The Fairfield Police Officers Association (FPOA) recently sponsored its 9th annual charity golf outing at the Paradise Valley golf course in Fairfield, CA. This year's proceeds were donated to PRISMS to benefit Joey Pereira and others with SMS. Joey is the youngest son of Brian Pereira, a police officer in Fairfield, and his wife Amy. Joey was diagnosed earlier this year with SMS.

The outing was held on October 15, 2010 with 85 golfers participating. A dinner and raffle were held afterwards with 120 people in attendance. In addition to entry fees, monies were raised through hole sponsors and raffle sales. A total of \$9,885.17 was raised as a result of the tournament. The FPOA decided to donate an additional \$3,114.83 bringing the total donation to PRISMS to \$13,000!

Congratulations and "thank you" to all those involved in making this event

a huge success, with special thanks to Bob Wilkie, Brian and Amy Pereira, and the Fairfield Police Officers Association.

.....

"A Night for a Cure"

On November 19, 2009, "A Night for a Cure," fundraising event was held at Oheka Castle in Huntington, NY. Nicole and Bruce Gerberg, parents of an SMS child, helped to organize the event, whereby Smith-Magenis Syndrome would be one of the diseases recognized and supported by the fundraiser. The event was sponsored by Angela's House. Angela's House is a 501 C3 non-profit organization that sponsored this fundraiser to support the research of many different childhood diseases and disorders. This event raised \$4,784 which will go toward research in SMS.



“Mc” Support! McQuown Supports McGrevy Event for PRISMS

This past summer, the day after committing to visit Ohio the weekend of Sept 18th, I found out about the PRISMS 5k walk/run at Buck Creek State Park in Springfield, Ohio. After missing the past couple of SMS conferences, I could not pass up the opportunity to meet with other SMS families. Since this event was put together to raise the awareness of SMS, I wanted to do my part by soliciting my friends, neighbors, and co-workers in Forest City, IA to sponsor my walk. I started this endeavor three days before we left for Ohio. I had the notion that if I could visit 100 people and get a \$5 sponsorship from each one, then I would be able to raise \$500 for PRISMS. This campaign turned out to be very therapeutic for me. Not only was I able to share with others about how SMS impacts three separate families within my work place of around 1700 employees, but I was able to be pleasantly surprised by the generosity and support that I received. I don't know the exact total of how much money that I was able to bring in, but I do know that it was over the \$500 goal. (Some individuals preferred donating online through PRISMS.org.)



Callie and Tod McQuown, Ashley Hodge, Pam McQuown, and Shannon Hodge



Carly and her sisters, Kelsey and Callie

Friday night at Buck Creek turned out to be a very special evening. Not only did we get some good exercise, but we were able to develop new friendships as well. Also, my mother, sister, and niece from Bellefontaine, Ohio were able to join my youngest daughter Callie and me in our walk for SMS. Thanks again to Tina and Charles McGrevy for organizing the event and hopefully we will be able to participate again in the future.

Submitted by Todd McQuown, father of Carly McQuown, age 13, diagnosed with SMS at the age of 2, residing in a community of 4,500 people in Northern Iowa that has 2 residents with SMS.



Are you online? Check out the new PRISMS Facebook page. Our numbers are growing quickly. Our page is being organized by volunteers, David and Denise Smith. Facebook looks like it will become a new and popular way for families and others to share information and learn about Smith-Magenis Syndrome.

If you have a Facebook account, search for “PRISMS/Smith-Magenis” and become a “friend.” If you are new to social media, log onto www.facebook.com, join up, and get online to participate. It's free!



Spread the word and “friend” us!

Sunny Side Up



“HEY, I KNOW THAT GUY....!” ADVENTURES IN WASHINGTON, D.C.

My name is Diane Powers and I am the mother of three children, one of whom is my 8-year-old daughter, Amanda who has SMS. We live in the Washington, D.C. Metro area, so when family and friends visit, we often venture into the city to do some sight-seeing. On a recent fall weekend while my sister and her family were in town visiting, we decided to tour several of the Smithsonian Museums.

We started at the newly-renovated American History Museum (which, as a side note, has a great hands-on area for children) and then proceeded to the Natural History Museum. The day was going quite well—no SMS meltdowns to speak of!

Since things were going so smoothly, we decided to pop our heads into the Museum of Art for the benefit of the older kids and grown-ups in our group. Amanda literally ran into the first gallery room hollering, “I know this guy.” Before anyone could get to her, she walked up to a self portrait of the Spanish painter, Goya, and put her open hand squarely on the center of the painting and says again, “Hey, I know this guy. This is Goya.” I thought we were both going to be arrested, or at the very least, escorted out of the museum! On a positive note, she clearly learned and retained something from the art program at our local elementary school! Her teachers were very happy to hear about her successful visit to the Museum of Art in Washington, D.C.



RIDING THE BUS WITH MOM

Griffin goes to a school 45 minutes away, and every morning I drive him to school. One day he was crying when we got in the car and I asked him “Why are you crying?” He told me that he was upset that the other kids get to ride in special buses (since there is quite a commute for everyone), and he wanted a “bus” of his own, to take him to school. I told him that he gets a special “bus” of his own and that his “bus driver” is also his mom -- how special is that! I then proceeded to talk in a low voice and say “Hello, Griffin, welcome to your bus.” Now, no matter what, everyday, when we get in the car, and during our morning commute for 45 minutes, I have to talk to him in a low voice. When I don’t, he says, “Mommy, you’re my bus driver, not my Mommy. Use the low voice, bus driver!”



Submitted by Griffin’s mom, Laura Staich

Note from the Editor

This column is intended as a spot where parents, siblings, or others with SMS connections can share their funny and heartwarming stories. Please send your stories and pictures to editor@prisms.org, or call (843) 521-0156 if you have any questions.

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