Smith-Magenis Syndrome Sibling Study: Results and Recommendations

Melanie Moshier, M.S.1, Timothy P. York, Ph.D.1, and Sarah H. Elsea, Ph.D.1,2
1 Dept. of Human and Molecular Genetics and 2 Dept. of Pediatrics
Virginia Commonwealth University, Richmond, VA

Part 1: As well siblings age, they experience significant changes in personality and express satisfaction with familial relationships as a result of having a sibling with SMS.

Well siblings have unique experiences, concerns, and familial relationships that directly result from having a sibling with a disability. The experiences of well siblings vary depending on the type of disability and its effects on the cognitive, physical, and emotional functioning of their sibling. It is important to note that living with a person with a disability has both positive and negative impacts on well siblings. Studies of families with children who have Down Syndrome and Rett Syndrome show that well siblings demonstrate increased tolerance, awareness of differences, and maturity when compared to peers (Dyke et al., 2009). These studies also found that well siblings typically have a caring and compassionate nature (Dyke et al., 2009).

Well siblings encounter many of the same emotional concerns as parents, including feelings of isolation and guilt, caregiving demands, a need for information, and concerns about the future of the person with a disability. In addition, well siblings experience unique issues not faced by their parents, such as resentment and embarrassment, peer issues, and a pressure to achieve (Conway & Meyer, 2008). These emotional concerns have a direct impact on the well sibling’s satisfaction with his or her relationship with the sibling with the disability. In addition to influencing the sibling relationship, the presence of an individual with a disability in the family affects the relationship between the well sibling and his or her parents. Differential parenting occurs when a parent’s expectations, treatment of, and quality of time spent with a child with a disability differ from that of other children. The greater the number and severity of maladaptive behaviors displayed by the sibling with a disability, the more time parents must spend addressing these behaviors. This results in less time available for the parent to spend with the well sibling. Research has found that families of children with disabilities tend to show greater rates of differential parenting than families of children without disabilities. In addition, studies have found that parents are likely to perceive their well child as being dissatisfied with differential parenting more than the well child reports him or herself feeling (Rivers & Stoneman, 2008; Taylor, Fuggle, and Charman, 2001).

To date, no research has been conducted on how the behaviors of individuals with Smith-Magenis Syndrome (SMS) influence the personalities of well siblings and their familial relationships. SMS is a rare condition characterized by unique behaviors, and as a result, the...
PRISMS is a community of volunteers who have been working with families and researchers for over 17 years providing information, support, and funding. There are many unique ways to help us spread SMS awareness. Did you know that PRISMS provides bookmarks, brochures, and presentations? You can refer your doctors, teachers, and therapists to our website for the latest information,...but what about families with an undiagnosed child? They often have no support, information or help until they find us. But we are constantly thinking of ways to do even more. For this reason one of the PRISMS board members, Julia Hetherington, has created a poster that will be used to send out to therapy centers in Mississippi with information about SMS and encouragement to "look for this child." This is a pilot program. According to our database, Mississippi, unlike all of the other 49 states, has no diagnosed individuals with SMS (although we know they probably do, they just don’t know it). If you would like one of these posters for your area, contact Julia at editor@prisms.org.

Speaking of SMS awareness, I would like to give a special recognition to Kiki Paladini (grandfather to Samantha, who has SMS, and father to Laura). Kiki has been faithfully helping PRISMS every year since he and Laura first attended our conference in Colorado. Kiki, a gourmet seafood sauce distributor based in the SF Bay area, redesigned the labels of his sauces to include information about SMS and PRISMS. Slide over Paul Newman!! People who bought these awesome sauces also learned about SMS. The more people who know, the better. His sauce line has recently been sold, but the new buyers agreed to keep information about SMS on the label. You can still find the sauces in Whole Foods stores and other specialty food stores. Kiki, thanks for all those years of faithful giving, advertising, and the thousands of people who learned about SMS through your efforts!

We also want to welcome two new board members - Phil Ruedi and Tina McGrevy- to the PRISMS board. We are thrilled to have both of these outstanding individuals!

Phil is our new Treasurer. He is a finance professional and is already making a significant contribution with his organizational skills and business acumen. He is a portfolio manager with Wellington Management, an institutional investment management company. Phil and his wife, Laura Staich, live in Boston with their four-year-old son, Griffin. Griffin was diagnosed with SMS as an infant.

Tina is an At-Large board member. Tina and her husband, Charlic, have raised funds for PRISMS for the last 4 years by hosting their annual 5k run/walk in Springfield, OH. Since she’s a fundraising pro, Tina plans to assist our families with fundraisers. Tina and Charlic have 3 sons, one of whom, Garrett, has SMS. Tina enjoys the lighter, funnier side of raising a child with SMS and contributed a story about it to Chicken Soup for the Soul. Welcome Phil and Tina!

As always, the PRISMS board is here to serve you, our members. We would love to hear from you.

Warm regards,

Randy

Join us on Facebook!
PRISMS Smith-Magenis
Dr. Ellen Magenis, M.D., has an extensive background in the fields of genetics and medicine. She graduated from Indiana University in 1946 with a Bachelor of Arts degree in Zoology, and received her M.D. at Indiana University Medical School in 1952. Her first medical internship was at University of Iowa Hospitals.

After taking some time off to raise her children, Dr. Magenis returned to the field of medicine in 1964, and interned at the Portland Sanitarium in Oregon. In 1966, Dr. Magenis began a Pediatric residency which was followed by a fellowship in Medical Genetics at the University of Oregon Medical School (now known as Oregon Health and Science University) where she helped start a clinical program in genetics and a Clinical Cytogenetics Laboratory.

An early pioneer in the field of cytogenetics, Dr. Magenis became the Director of the Clinical Cytogenetics Laboratory in 1977, and held that position for over 30 years! She is well-respected in her field, both by colleagues and patients. In 1999, she was named Professional of the Year by the ARC of Multnomah County in Oregon due to her work in the areas of genetic diseases and chromosome abnormalities, and her outstanding treatment of patients. Along with these achievements, Dr. Magenis has authored and co-authored over 150 articles, 120 abstracts, and 20 book chapters on various genetic and medical conditions and research.

The name Dr. Ellen Magenis is familiar to all SMS families. In a 1986 paper, Ann C.M. Smith, M.A., D.Sc.(hon) and Dr. Magenis described the chromosomal disorder associated with deletion 17p11.2, a disorder that had previously been misdiagnosed and misunderstood. During a Profiles and Perspectives interview for a genetic publication, Dr. Magenis described events leading to the paper on deletion 17p11.2 that she co-authored with Ann Smith. “One of the technologists in the laboratory...saw what he thought was a deletion on proximal 17p. I happened to see the patient in the clinic who had been thought to have Down Syndrome. Clearly, he didn’t have Down Syndrome, clinically or cytogenetically. It was only a few months later that we received another case, and then another case!”

Dr. Magenis goes on to say that she attended the 1982 meeting for the American Society of Human Genetics, where she met Ann Smith who presented two cases with the same 17p deletion. The two talked afterward and began collaborating to write the first paper on the syndrome. Along with other researchers, Ann Smith, M.A., D.Sc. (hon) and Dr. Magenis were able to describe the chromosome deletion and common physical, behavioral, and developmental features of nine patients who had the deletion of 17p11.2. The paper, published in The American Journal of Medical Genetics in 1986, is titled “Interstitial Deletion of (17)(p11.2p11.2) in Nine Patients” (Smith, AC, McGavran, L, Robinson, J, Waldstein, G, Macfarlane, J, Zonona, J, Reiss, J, Lahr, M, Allen, L, Magenis, E, Am J Med Genet. 1986 Jul;24(3):393-414). To honor the discoveries they made, the chromosomal disorder was officially named Smith-Magenis Syndrome in late 1980s.

Through more research, papers, and presentations, Dr. Magenis helped make medical professionals aware of SMS so that accurate diagnoses and effective treatment could be provided to SMS individuals and their families.

Thank you, Dr. Magenis, for your dedication to the field of genetics and for all the help and hope you’ve given SMS families! It is truly an honor to have you serving on the SMS Professional Advisory Board!
A patient advocate is someone who assists a patient or family to deal with factors that have a direct effect on the quality and cost of the patient’s health care and treatment. With each newsletter, we will try to review different programs or supports that might be helpful as we navigate the challenges of Smith-Magenis Syndrome.

Wrightslaw Yellow Pages for kids is a great start. Pete and Pam Wright are Adjunct Professors of Law at William and Mary Law School, and teach courses on Special Education. This website will help you find educational consultants, psychologists, educational diagnosticians, health care providers, academic therapists, tutors, speech-language therapists, occupational therapists, coaches, advocates, and attorneys for children. There are also training sessions for special education law and advocacy, educational books, and a blog where parents can network. There is even an easy to use map of the United States. Just click on your state, and it will give you many contacts, hopefully close enough to be of assistance to you. The website is: www.wrightslaw.com. The map page is: www.wrightsyellowpagesforkids.com.

PRISMS is seeking an Editor for Spectrum, our quarterly newsletter. This position requires typing and computer skills as well as organizational skills. If you have an interest in this position please contact Julia Hetherington at editor@prisms.org or call 843-521-0156 (EST).

Are you techno-savvy? PRISMS has developed a Website Committee and would like to add one to two members to this committee. This committee position requires interest and knowledge in website development/management. Please contact PRISMS at info@prisms.org.

The next Houston SMS picnic is planned for Saturday, Nov 13th at Bear Creek Park in Katy, TX. This has become an annual fun event, so please plan to attend. For more information please contact Ceci Poole at: foxwxgal@hotmail.com

Pat Boschetto of Utah was inadvertently left off our membership list in the annual report. Dawnda Daniels’ name was misspelled in the SuperKid article in the Spring 2010 issue.

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.

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.
experiences of siblings living with individuals with SMS may be greatly different from that of siblings of individuals with other types of disabilities. This study aimed to explore how having a sibling with SMS positively and negatively influences well siblings’ personalities and their familial relationships. The study further aimed to investigate how closely correlated parental perceptions of these influences are with well siblings reports of their experiences.

Methods and Analyses
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) listserver and Yahoo SMS listserve. 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 well 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 were 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 previous 3 months. The Sibling Inventory of Behavior assesses four positive (empathy/concern, leadership/involvement, kindness, acceptance), and four negative (avoiding, hurting, anger, embarrassment) personality traits. The second survey was the Satisfaction with Social Relationships (McHale and Gamble, 1989). On this scale participants were asked to rate (1 = very unhappy, to 5 = very happy) well siblings’ levels of satisfaction with certain components of their relationships with the sibling with SMS and their relationships with parents during the previous three months. This scale contained 8 questions that assessed 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 assessed 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, 6 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. For the first installment of results, primary analyses aimed to determine the impact of the age of the well sibling on well siblings’ personality traits and satisfaction with familial relationship, as well as the impact of well sibling age on parental perceptions of the aforementioned factors.

Participants
A total of 79 well siblings participated (Mage=20.3 years, SDage=10.6 years). Of the participating well siblings, 89.8% were Caucasian and 62% were female. 92.4% 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. 72.2% 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 (SDage=7.0 years). Parents reported that 86.7% of their well children were Caucasian and 70.8% 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. 84.7% of parents reported that their well child did not have any developmental, social, or emotional delays. 95% of the parents reported they were biologically related to the individual with SMS. The sibling and parent reports were mutually exclusive participants and could not be paired for analysis. 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 (89.9% of well siblings’ reports, 86.7% of parents’ reports).

Correlational Data
Correlations were examined to assess the relationship between age and the positive and negative personality traits experienced by well siblings exhibited towards their siblings with SMS. Correlations were also examined to assess the association between age on well siblings’ levels of satisfaction with their relationships with their parents and with their siblings with SMS. For correlation analysis of the Sibling Inventory of Behavior, positive correlation coefficients (r) signify that well siblings experience and display more...
of the given personality trait with age. The closer the correlation coefficient is to one, the greater the increase in the amount of the personality trait experienced and exhibited by well siblings with age. Negative correlation coefficients signify that well siblings experience and display less of the given personality trait with age. The closer the correlation coefficient is to negative one, the greater the decrease in the amount of the personality trait experienced and exhibited by well siblings with age. Likewise, for the Satisfaction with the Sibling Relationship Scale, positive correlations signify an increase in satisfaction with familial relationships with age, and negative correlations signify a decrease in satisfaction with familial relationships with age.

**Primary Results**

**Comparison of Well Sibling and Parent Perception of Well Sibling Personality Traits**

Comparisons of the mean well sibling responses and the mean parent ratings of well siblings showed no significant differences for empathy/concern, leadership/involvement, kindness, or acceptance (Figure 1). Furthermore, there was no significant difference between the mean well sibling responses and the mean parent ratings of the well siblings when the scores of these four traits were summed for an overall calculation of positive traits experienced and exhibited by well siblings. Comparisons of the mean well sibling responses and the mean parent ratings of well siblings showed no significant differences for hurting, anger, or embarrassment (Figure 2). Analysis of the mean ratings for avoiding showed that parents were significantly more likely to perceive well siblings as avoiding their siblings with SMS than the well siblings reported (p<.05). There was no significant difference between the mean well sibling responses and the mean parent ratings of the well siblings when the scores of hurting, anger, embarrassment, and avoiding were summed for an overall calculation of negative traits experienced and exhibited by well siblings.

**Correlational Data Related to Well Sibling Personality Traits**

For well sibling responses, the age of well siblings was significantly positively correlated with overall positive personality traits experienced and exhibited towards the sibling with (r=.300, p<.01); see Table 1. Kindness showed the highest positive correlation with well sibling age (r=.393, p<.001), followed by empathy/concern (r=.351,
Analysis of the parents’ responses of their perceptions of empathy/concern, leadership/involvement, kindness, and overall positive personality traits experienced and displayed by well siblings towards did not show significant correlations with well sibling age. Parents’ reported perceiving their well child as experiencing significantly decreased amounts of acceptance of their siblings with SMS with increasing age of the well child (r = -0.263, p < 0.01). Analysis of parents’ perception of avoiding, hurting, anger, embarrassment, and overall negative personality traits experienced by well siblings were not significantly correlated with well sibling ages.

**Comparison of Well Sibling and Parent Perception of Well Sibling Satisfaction with Familial Relationships**
For each of the ten questions assessed on the Satisfaction with the Sibling Relationship Scale, there were no significant differences in parent perception of well sibling satisfaction with familial relationships and well sibling responses (Figure 3). Parents reported perceiving their well child as wanting to spend significantly less time with their sibling with SMS than was reported by well siblings (p < 0.01); see Table 2. Additionally, parents reported perceiving their well child as wanting to spend significantly less time playing with their sibling with SMS than was reported by well siblings (p < 0.01). There were no significant differences in parent responses, and well sibling responses for changes well siblings would like to experience in the amount of time spent caring for the sibling with SMS, whether the well sibling would like to be more or less close with the sibling with SMS, whether the well sibling would like to be the boss of the sibling with SMS more or less often, or whether the well sibling would like to be more or less like the sibling with SMS.

**Correlational Data Related to Well Sibling Satisfaction with Familial Relationships**
Analysis of well sibling responses showed that well sibling age was significantly positively correlated with getting along with the sibling with SMS (p < 0.001); see Table 3. Increasing well sibling age was also significantly associated with an increasing desire amongst well siblings to spend more time with the sibling with SMS (p < 0.01), and to spend more time caring for the sibling with SMS (p < 0.05). Well sibling age was positively correlated with greater levels of satisfaction with parental treatment (p < 0.01), increased satisfaction in how often the well sibling could be the leader in the sibling relationship (p < 0.01), and a desire to spend less time being the boss of the sibling with SMS (p < 0.05). Additionally, well sibling age was positively correlated with well siblings wanting to be more alike with their sibling with SMS. Increasing well sibling age was significantly associated with an increase in overall well sibling happiness with their relationships with siblings with SMS (p < 0.01).

Analysis of the parents’ responses revealed a negative correlation of well sibling age with parent perception the well siblings’ satisfaction with the amount of time they spend with their siblings with SMS (p < 0.05). There were no additional correlations between well sibling age and parent perception of well sibling satisfaction with familial relationships. Furthermore, there were no correlations between well sibling age and parent perception of changes well siblings would like to experience in their relationship with their sibling with SMS.

**What do these results mean?**
The results of this study suggest that well siblings of individuals with Smith-Magenis syndrome experience significant changes with age in the positive and negative personality traits experienced and exhibited towards their siblings with SMS. Furthermore, well siblings experience significant changes with age in their satisfaction with their relationships between their SMS siblings and with their parents. The only personality trait for which well siblings did not demonstrate a significant change with age was acceptance of their siblings with SMS. As well siblings age, they experience greater levels of the other three positive personality traits of empathy, leadership, and kindness, and decreasing levels of all four negative personalities. These results suggest that having a sibling with SMS has an overall positive impact on the personality of well siblings, and this positive impact becomes more pronounced as the well sibling ages.

On average, well siblings of individuals with SMS reported being between neither unhappy nor happy to somewhat happy with their familial relationships. With increasing age, well siblings reported experiencing greater levels of satisfaction with how well they get along with their siblings with SMS, how often they get to...
be in charge of their siblings with SMS, and overall happiness with the sibling relationship. Furthermore, well sibling age was correlated with greater levels of satisfaction with differential parenting. On average, well siblings reported not wanting to experience any changes in the sibling relationship. Further analysis revealed that well sibling age was correlated with a desire to spend more time with their SMS sibling, more time caring for their SMS sibling, and less time being in charge of their siblings with SMS. Well sibling age was also positively correlated with a desire of well siblings to be more like their sibling with SMS. These results imply that well siblings are satisfied with their familial relationships, and this level of satisfaction tends to intensify with age. Furthermore, as well siblings age they experience an increased desire to spend more time and to become closer with their sibling with SMS.

Comparisons of mean well siblings’ reports and mean parents’ reports of well siblings’ personality traits and levels of satisfaction with familial relationships did not reveal any differences, with the exception of avoiding. Parents reported their well children as demonstrating significantly higher levels of avoidance towards their siblings with SMS than was reported by well siblings. These results are not consistent with those found by other researchers who investigated the familial relationships of well siblings of individuals with autism. Prior studies concluded parents were significantly more likely to perceive their well children as having more negative attitudes towards their sibling with autism and as being dissatisfied with differential parenting than was reported by well siblings (Rivers & Stoneman, 2008; Taylor, Fuggle, and Charman, 2001).

When the responses of parents were analyzed in relation to the ages of the well siblings, results showed that parents did not perceive changes in the personalities of their well children, with the exception of acceptance. Well sibling age was negatively correlated with parents’ perceptions of the levels of acceptance felt displayed by their well children towards the siblings with SMS. Parents did not perceive changes with age in their well children’s levels of satisfaction with their relationships with familial relationships, with the exception of the level of satisfaction with the amount of time spent with the sibling with SMS. Analysis showed a negative correlation between parents perception of well siblings’ levels of satisfaction with the amount of time spent with their siblings with SMS and well sibling age. These results imply that, in general, parents’ perceptions of their well children’s personalities towards their siblings with SMS remain static as well children age. When parents did perceive a change in their well children with age, the trend tended to be decreasing in the amount of positive personality traits and positive attitudes of the well siblings. These findings are not consistent with those reported by well siblings, and the results imply there is a disconnect between parent perception and well sibling experience.

**Summary**
Understanding the unique family dynamics experienced by individuals living with a family member with a disability is limited due to the lack of prior research. Our research has shown that the experiences well siblings encounter as the result of having a sibling with SMS change as well siblings age. It is important for individuals within the family as well as individuals interacting with and providing care to the family of a person with SMS recognize and appreciate the evolving dynamics that occur between and within individual family members. Understanding familial dynamics is essential to providing adequate care to individuals with Smith-Magenis Syndrome as well as to their parents and siblings. Additionally, exploring the unique experiences of siblings of individuals with SMS will allow for parents to better understand the challenges faced by their well children as well as the benefits well children experience as the result of having a sibling with SMS. As our research has shown, parents and siblings have different perceptions regarding the positive and negative impacts of having a sibling with SMS on well siblings’ personality traits and satisfaction with familial relationship. This may add strain to the parent-child relationship, and may add unnecessary feelings of guilt on parents who perceive their well children as suffering more hardships and harboring more feelings of ill-will than they actually do. It is important for parents and their children to speak openly and honestly about their feelings related to family life. Additional resources for opening the lines of communication, including contact information for family therapists, may be found at the American Association for Marriage and Family Therapy website, http://www.aamft.org, or at the International Association of Marriage and Family Counselors website, www.iamfc.com.

**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. We thank Lauren Vanner-Nicely for helpful comments about this study and for reviewing the manuscript.
Table 1. Correlation between well sibling personality traits and well sibling age.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Well sibling response</th>
<th>Parent report on well sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy/concern</td>
<td>0.351**</td>
<td>0.137</td>
</tr>
<tr>
<td>Leadership/involvement</td>
<td>0.273*</td>
<td>-0.081</td>
</tr>
<tr>
<td>Kindness</td>
<td>0.393***</td>
<td>0.061</td>
</tr>
<tr>
<td>Acceptance</td>
<td>0.167</td>
<td>-0.265*</td>
</tr>
<tr>
<td>Total positive traits</td>
<td>0.300**</td>
<td>-0.026</td>
</tr>
<tr>
<td>Avoiding</td>
<td>-0.475***</td>
<td>0.180</td>
</tr>
<tr>
<td>Hurting</td>
<td>-0.485***</td>
<td>-0.127</td>
</tr>
<tr>
<td>Anger</td>
<td>-0.623***</td>
<td>-0.197</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>-0.332**</td>
<td>0.076</td>
</tr>
<tr>
<td>Total negative traits</td>
<td>-0.556***</td>
<td>-0.003</td>
</tr>
</tbody>
</table>

All personality traits were assessed using the Sibling Inventory of Behavior. Well siblings of individuals with SMS display significant increases in empathy/concern, leadership/involvement, kindness, and overall positive personality traits with age. Well siblings display significant decreases in avoiding, hurting, anger, embarrassment, and overall negative personality traits with age. Parents perceive well siblings as showing significantly decreasing amounts of acceptance of their siblings with SMS with age. \( n_{\text{well-siblings}} = 79; \ n_{\text{parents}} = 60; \ * \ p<.05; \ ** \ p<.01; \ *** \ p<.001 \)
Table 3. Correlation between well sibling age and well sibling satisfaction with familial relationships.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Age of well sibling</th>
<th>Parent report of age of well sibling</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amount of time</td>
<td>0.199</td>
<td>-0.326*</td>
</tr>
<tr>
<td>Getting along</td>
<td>0.515***</td>
<td>-0.089</td>
</tr>
<tr>
<td>Care giving</td>
<td>0.144</td>
<td>-0.146</td>
</tr>
<tr>
<td>Closeness</td>
<td>0.127</td>
<td>0.001</td>
</tr>
<tr>
<td>Play</td>
<td>0.160</td>
<td>-0.086</td>
</tr>
<tr>
<td>Treatment</td>
<td>0.318**</td>
<td>0.163</td>
</tr>
<tr>
<td>Boss</td>
<td>0.356**</td>
<td>-0.129</td>
</tr>
<tr>
<td>Alike</td>
<td>0.072</td>
<td>0.145</td>
</tr>
<tr>
<td>Attention</td>
<td>-0.014</td>
<td>-0.181</td>
</tr>
<tr>
<td>Happy</td>
<td>0.308**</td>
<td>-0.122</td>
</tr>
</tbody>
</table>

Well sibling satisfaction with familial relationships was assessed using the Satisfaction with the Sibling Relationship Scale. As well siblings age they experience increased levels of satisfaction with how well they get along with their sibling with SMS, how often they are able to be the boss of their sibling with SMS, how happy they are with the sibling relationship, and the treatment they receive from their parents as compared to the treatment the sibling with SMS receive. Parents report that their well children are less satisfied with the amount of time spent with the sibling with SMS as well children age; whereas the siblings report satisfaction with time spent. \( n_{well-siblings} = 79; n_{parents} = 60; * \ p < .05; ** \ p < .01; *** \ p < .001.\)
Our daughter was diagnosed with Smith-Magenis Syndrome shortly after birth. Caroline fits most of the typical SMS characteristics and more! Caroline is now 12-years-old and in a special sixth grade class in middle school in Henderson, NV. She is a very happy, healthy, social young lady, participating in the school’s Stomp Club as a dancer/performer and even helping with the choreography. She is also an active member of the Girl Scouts. Caroline is well-known in her community, at school, at the grocery stores, rec centers, libraries, restaurants; you name it, someone there knows her name! She is very lucky to have a wonderful teenage brother, Charlie, who is popular in his own right, and helps to pave the way for Caroline’s reception by people who might otherwise not understand her personality.

”Liney” loves horseback riding and her weekly visits to Spirit Therapies of Las Vegas—therapeutic horseback riding. She loves to be with animals & people. Her communication & confidence skills are further developed by caring for the horses, walking and grooming ”Gracie”, the mini horse, interacting with the Director, Laurie, and all of the great ”human” volunteers, and even the dogs and cats. Caroline likes the diversity of riding different horses every week; she gets to know their personalities and they get to know hers. She benefits physically from riding; by nature a toe-walker, Caroline walks flat-footed or ”normal” and has a more relaxed disposition after her sessions. Caroline is the exhibition rider for many of Spirit Therapies fund raising functions. As you can see in the photo, she is very comfortable riding a horse.

Footnote by brother Charlie:
I think that since Caroline has been going to Spirit Therapies her behavior has definitely matured. Sometimes she will get upset at the littlest thing and she will go into a tantrum or ”fit” which, for some reason, gives her super human strength so neither I nor my mom can control her or talk her through the situation. When Caroline does this, it’s hard on the whole family, and when it gets really bad my mom will break down into tears of frustration and I pray to God that some day the ”fits” will stop. Now, after almost 2 years of going to Spirit Therapies, Caroline behaves and is able to talk out many of her issues. Sometimes I will go and watch her ride, and all she does on the way home is talk about how fun it was and what she did that was exciting. Spirit Therapies has become an answer to my prayers.

Caroline’s dream would be to someday have her own ”Spirit Therapies” ranch. And our dream would be for her dream to come true :)
The first SMS Research Alliance, convened and sponsored by PRISMS, was held at Elwyn’s campus in Media, PA, on May 6th, 2010. The goal of the SMS Research Alliance meeting was to build collaborative ties among researchers who share interests and expertise in specific priority research areas. For the first Research Alliance, PRISMS invited top experts working in the areas of behavior intervention, complementary and alternative medicine, and targeted pharmaceuticals in order to explore strategies, skills and research ideas that may benefit persons affected by Smith-Magenis Syndrome (SMS). The group also included the PRISMS Board of Directors, members of the Professional Advisory Board (PAB) and parent representatives interested in promoting SMS research. PRISMS’ goal in supporting this meeting is to identify specific research priorities on which to focus fundraising efforts.

The one-day meeting, co-moderated by PRISMS PAB members Ann C.M. Smith, M.A, D.Sc. (Hon) and Brenda Finucane, M.S., led off with presentations by invited experts in three priority areas:

1. Overview of ABA and Behavioral Interventions (Barbara Haas-Givler, PRISMS PAB/Elwyn, PA)
2. Complementary and Alternative Medical Treatments (CAM) for Autism Spectrum Disorder (ASD) (Dr. Susan Levy, MD, Children’s Hospital of Philadelphia, PA)
3. Targeted Pharmaceuticals for Genetic Disorders (Dr. Paul Wang, Seaside Therapeutics, Cambridge, MA).

In conjunction with Dr. Wang’s presentation, Dr. Sarah Elsea provided an update on role of RAI1 and other genetic contributions to the SMS phenotype.

Discussion followed each presentation to identify potential research areas and key steps necessary to promote future collaborative research efforts, and address possible barriers and funding requirements. A full summary of the meeting proceedings is in progress; however, the SMS-CAM study highlighted in this issue is a direct outgrowth of the PRISMS

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

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 1 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, PhD, NIMH, Wendy Introne, M.D., NHGRI Medical Responsible physician, and William Gahl, MD, PhD, NHGRI principal investigator. Five children with SMS have completed the bright light part of the trial; recruitment of an additional 10 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 4 weeks, followed by a 4-day (3 nights) NIH inpatient admission with serial blood sampling and EEG-monitoring conducted during the trial period.

Children’s Hospital of Philadelphia, PA)
Complementary and Alternative Medical Treatments for ASD
Presented at PRISMS Research Alliance Meeting by Dr. Susan Levy

Dr. Susan Levy (See bio inset) shared her extensive experience working with families of children with autism spectrum disorders (ASD), including a special focus on the efficacy of use of Complementary and Alternative Medical (CAM) treatments with this population. ASD has an estimated prevalence of 1/110, occurring more often in males (1/70 males) than females (1/315 females). ASD is a behavioral construct that is defined by three core features that include deficits in socialization skills, communication, and presence of repetitive/stereotypic behaviors. Unlike SMS where the genetic etiology (cause) is recognized (del 17p11.2), the cause of ASD is unknown in the majority (approx 90%) of cases. However, several genetic disorders including SMS overlap with ASD suggesting avenues for potential treatment strategies. Given the rarity of SMS, treatment approaches are often based on anecdotal evidence or single case reports of efficacy, lacking formal, controlled treatment trials. Thus, knowledge about treatments that may/may not work for persons with ASD may provide a useful “window” to identify potential treatments to target core or common symptoms that occur in SMS. Such treatments are not limited to medications (pharmacological), but also include optimal educational programs and developmental therapies (speech/language therapy, physical and occupational therapies) across the lifespan. Dr. Levy and colleagues conducted a survey of parents of children with ASD to determine the use of CAM treatments in ASD. CAM is defined by the NIH National Center for Complementary and Alternative Medicine as “a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine.”

All research trials involving human subjects (children or adults) require a rigorous review of risks/benefits by an Investigational Research Board (IRB) to ensure protection of human subjects. The gold standard in the research of treatment approaches is the Randomized Control Trial (RCT), which is based on strict research methodology that begins with a testable hypothesis. Conducting a controlled treatment trial requires prior knowledge of the natural history of a disorder to identify measurable parameter(s) that can be used as objective outcome measure(s) to document the positive/negative benefits of the controlled trial. Controlled studies all involve use of a placebo or “sham” treatment and follow a study designed to resemble the actual experimental drug or treatment as closely as possible. Uncontrolled studies do not include control or placebo group, and therefore, are not as scientifically “rigorous” in documenting the full efficacy of a treatment. In children with ASD, a number of CAM treatments have been studied to determine the efficacy of these approaches (i.e., the positive vs. negative results) leading to a CAM treatment report card for ASD based on the strength of the evidence. See table on next page.


Susan E. Levy, M.D. is a developmental pediatrician who directs the Regional Autism Center (RAC) at Children’s Hospital of Philadelphia (CHOP). Working in the area of neurodevelopmental disabilities, her clinical and research interests focus on autism spectrum disorders (ASD), specifically related to the early identification, diagnosis, and surveillance and treatment of children with ASD. The prevalence of autism depends on the populations studied, ranging from 3.3 to 10.6 of every 1000 children.

Dr. Levy’s unique experience and research in use of complementary and alternative medical treatments (or CAM) in ASD was presented and discussed at PRISMS’ Research Alliance meeting in May. Based on a web-based CAM-ASD survey to identify novel treatments used for autism spectrum disorder, Dr. Levy found/reported that more than 30% young children recently diagnosed with ASD were using some type of CAM at the time of their initial evaluation by RAC. Although anecdotal reports of CAM use in SMS is known, the prevalence of CAM use remains unstudied. In collaboration with Dr. Levy, Rio Friday, a master’s genetic counseling student at University of Maryland who attended the Research Alliance, has adapted the ASD-CAM survey for use with the SMS population as part of her graduate thesis project. Serving as a baseline, the SMS-CAM study is a direct outgrowth of collaborative ties between PRISMS and Dr. Levy that was forged at the Research Alliance. Dr. Levy is excited to extend the CAM survey to other groups of children with known genetic disorders associated with clinical manifestations of autism like SMS. Such collaborations help promote better understanding of the prevalence of CAM use in children with neurodevelopmental disabilities and their effectiveness as a treatment intervention approach.
<table>
<thead>
<tr>
<th>CAM Treatment for ASD</th>
<th>Evidence Grade (type of study)</th>
<th>Evidence Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yoga</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Music therapy</td>
<td>B</td>
<td>1-2</td>
</tr>
<tr>
<td>Chiropractic</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Craniosacral massage</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Massage therapy</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Auditory integration</td>
<td>B</td>
<td>2</td>
</tr>
<tr>
<td>Transcranial magnetic stimulation</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Nutritional supplements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>B6/Mg++</td>
<td>B</td>
<td>2</td>
</tr>
<tr>
<td>DMG</td>
<td>B</td>
<td>2</td>
</tr>
<tr>
<td>Vitamin C</td>
<td>B</td>
<td>1-2</td>
</tr>
<tr>
<td>Melatonin</td>
<td>A</td>
<td>1</td>
</tr>
<tr>
<td>Carnosine</td>
<td>B</td>
<td>2</td>
</tr>
<tr>
<td>Omega 3 fatty acids</td>
<td>B</td>
<td>1-2</td>
</tr>
<tr>
<td>Folate and oxidative stress</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Hyperbararametric therapy</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Chelation</td>
<td>C</td>
<td>2(-)</td>
</tr>
<tr>
<td>Immune therapies</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Antifungal agents</td>
<td>C</td>
<td>2</td>
</tr>
<tr>
<td>Secretin</td>
<td>A</td>
<td>1(-)</td>
</tr>
<tr>
<td>Gluten-free/Casein-free diet</td>
<td>B</td>
<td>1*</td>
</tr>
</tbody>
</table>

Strength of Evidence by grade (type of study):
A=High quality: randomized controlled trial (RCT)
B=Moderate quality: Observation study/case controlled
C=Low or very low quality: Case reports or theories

Evidence Rating to support or refute use of intervention:
1= strong, 2= weak, (-)=against use

*Caveats related to study of CAM dietary treatment approach in ASD based on Dr. Levy’s experience: While use of gluten-free and/or casein-free diet has been tried by many ASD and several SMS families, such diet studies are complex and costly to conduct given the many variables that need to be tracked and/or controlled.
Dear PRISMS Members,

I am writing to tell you about an upcoming survey regarding complementary and alternative therapies, or CAMs (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 completed, 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 or may not be helpful to try with your children. Identifying potential therapies that may benefit persons with SMS helps to lay the foundation for future proposed research studies.

I am a graduate student in the Master’s in Genetic Counseling program at the University of Maryland. I took an interest in Smith-Magenis Syndrome, and I was fortunate enough to meet some of you at the PRISMS sponsored Smith-Magenis Syndrome Research Alliance meeting in May 2010. The conference inspired this study.

Participation in this study is completely voluntary, anonymous, and will not influence your relationship with PRISMS in any way. Your responses will be kept confidential, and the researchers will not collect identifying information. For more information about this study, please contact Rio Friday at rfridoot@umaryland.edu, or call 412-491-3614.

I know that your lives are extremely busy and you get many survey requests. If you can find the time to complete the SMS-CAM survey, it would be exceedingly helpful in understanding the use and effectiveness of CAM in SMS, which will in turn benefit your fellow PRISMS members. With your participation, we will be able to provide you with a more complete resource when we release the results of the study in August 2011. The survey will be posted online sometime in August or early September, at which point a notification will be sent out to the PRISMS membership.

All the best,
Rio Friday
Master’s in Genetic Counseling Program, University of Maryland

An Opportunity to Participate!
“Do Fun Stuff” album release scheduled!
Support from artist Ryan Marshall

"Do Fun Stuff" (Vol 1) is the first album (in a yearly release schedule) of original kids music that will be for sale as a charity album benefitting the further study of Smith-Magenis Syndrome. The hope is that enough money is raised for PRISMS to establish a 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 only release via iTunes and 100% of the proceeds goes into a charity trust set up by PRISMS.

I reached out to Ann Smith almost one year ago about this project as it was first being realized, and with her guidance and care, she led me to John Mayer, who has been a huge ally in both confidence and information, and a strong dose of enthusiasm to boot, for me to get this album finished and ready for release.

The album will be available online after Aug 30th via iTunes Worldwide. It is being promoted and pushed through my personal blog “Pacing The Panic Room” where I launched a call for help, a recruitment of bloggers from all over the web to unite on Aug 23rd to announce the release of this album. On Aug 30th over 300 bloggers, all with varying readerships, will post links to the album to buy, and links to PRISMS to educate. The hope is that the posts will create a buzz and a web storm, and this album will do some real good on raising cash for the research front, and at the same time just get more people aware that SMS exists.

The album itself is a great collection of kid 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

Are you on-line? 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 on-line to participate. It’s free!

Spread the word and “friend” us!
United Way Donations

The United Way begins its annual fundraising drive each fall in nearly every community in the United States, Canada and many other countries. It provides a way for many charities to obtain funds by individuals contributing a portion of their paycheck through payroll deduction. Each United Way chapter lists a variety of organizations that may be chosen for payroll deductions, most of which are locally based. Many of the United Way’s 1,400 chapters or member organizations also allow individuals to write in the charity of their choice. The 501(c)(3) non-profit status of PRISMS qualifies us for the write-in option (assuming the local chapter accepts write-ins). Here’s all of the information you’ll need: PRISMS, Inc., 21800 Town Center Plaza, Suite #266A-633, Sterling, VA 20164, Tax ID 54-1652029.

To obtain a write-in campaign in your workplace, contact your company’s United Way chairperson or your local United Way agency (national.unitedway.org) to ask if there is a write-in or designation option. Most co-workers are eager to donate to a cause that is personally tied to a colleague. Posting a public letter or a poster asking your fellow employees to join you in supporting SMS through PRISMS might be one way to reach all the employees and increase our funding.

Fundraising Support

PRISMS is always appreciative of member support through fundraising. We have had donations from the Longman family of Florida, and the Stepic family of Ohio. Melissa and Dan Longman held a road race to support SMS research with a portion of their proceeds being donated to PRISMS. Faith and John Stepic held their 2nd golf tournament to benefit PRISMS. We recognize the amount of work these young parents put into these functions, all to support our SMS community.

Lisa and Jack Bellopede, longtime PRISMS members and advocacy champions from Pennsylvania, have raised funds through their foundation, Johnny’s Rainbow Foundation. Many of you remember the slideshow at our 2007 conference which honored their son Johnny’s life. Johnny had Smith-Magenis Syndrome and autism. He passed away in 2006 at the age of nine. Lisa and Jack Bellopede are very active members of their local advocacy community and Jack has served on the PTO Board at Johnny’s school, Devereux CARES, and Lisa served on the board of Delco Family P.A.S.S., (Delaware County Family PDD/Autism Spectrum Support). Lisa and Jack established a scholarship fund for the Delco Family P.A.S.S community, where family members and caregivers can apply for scholarships to attend conferences and trainings. Their financial support reaches far out into the community and supports various needs for all children with special needs, including the SMS community. Johnny’s Rainbow Foundation provides funding for therapy, parent education, and family counseling services. Johnny’s Foundation has also provided playground equipment specifically designed for children with special needs, a safety car vest, a specialty bike for a child, and sponsored the Challenger Baseball league (Johnny’s team). These funds are called “Rainbow Grants.” The Bellopedes have raised funds through golf tournaments and donations to benefit many individuals and organizations. PRISMS was the recipient of funds that will be used to directly support the research efforts at Dr. Sarah Elsea’s lab at Virginia Commonwealth University. They truly brighten the lives of many through their “Rainbow Grants.”

Charlie and Tina McGrevy are hosting the 4th Annual 5K Run/Walk for PRISMS on Sept 17th, 2010. This includes a family picnic. For more information, contact cmcgrevy@yahoo.com.

On October 15, 2010, the Fairfield Police Officers Association (Fairfield, California) is sponsoring their ninth annual charity golf tournament. This year’s tournament will raise money to support PRISMS. This is to honor Joey Pereira, the son of FPD Officer Brian Pereira and his wife Amy. For more information, contact Kevin Carella at: kcarella@ci.fairfield.ca.us or call 707-580-0051.
November 17, 2010

Celebrate World Smith-Magenis Day
Light up the world!

Where: Anywhere you are in the world!

Why: Because persons with SMS should be celebrated and we want you to let their light glow!

November 17, 2010, is a day of collective celebration for the person with SMS in our lives. This is a day to not only share in the jubilation, but to use the day as a platform to spread awareness of Smith-Magenis Syndrome. November 17th is THE day where SMS is at the head of the table and we have the floor! So shout it from the rooftops…we want to hear you. It’s our day to be heard!

We would love to have everyone share the celebration in a unique fashion that sets SMS apart from other disorders. Since our SMSers embrace the night, we are suggesting a “Glow” event. To match their “glowing” personalities, we are encouraging everyone to purchase glow necklaces and glow sticks, and have a nighttime celebration; maybe a walk in the neighborhood, glow parties with friends and families, or glow bowling, skiing or a round of glow ball golf! The glow necklaces are very inexpensive and can be bought in bulk. Maybe drop a basket of glow necklaces along with information about SMS at your child’s doctor’s or therapist’s office, or local disability advocacy office, (ARC). Let’s light up the nighttime sky while raising awareness of SMS. Remember to take pictures of the ways that you celebrate November 17th, and please send them to PRISMS so we can capture them in our next newsletter and on our website. Also, please post the pictures on our Facebook page. If you would like to have PRISMS bookmarks to share on this day, please contact PRISMS at info@prisms.org.

So ready, set, GLOW, and celebrate World SMS Day!!

PRISMS CONFERENCE 2012
Denver, CO,
June 28 - July 1, 2012
Renaissance Denver Hotel

The Conference planning committee for the upcoming 2012 still needs a conference chairperson. We have the start of an excellent committee, but a chairperson(s), is needed to organize and direct the committee and steer the conference planning. The chair of the committee could be easily co-chaired, if that is an interest of two people.

The conference chair:

* should have attended at least one of the past PRISMS conferences to understand the mission and the flow of the conference

* will be asked to work closely with the PRISMS board and the Professional Advisory Board in the planning of the conference agenda, working closely with the hotel, obtaining speakers and staying on budget

* the chair can live in any location, as the planning can be done remotely and you do not have to live in Denver to consider this task. (The chair is expected to communicate through emails, with his/her committee, speakers and hotel staff.)

The chair and conference committee will have lots of support from local PRISMS families and the support of veteran PRISMS conference planners, and a professional planner who will work alongside the chair and committee.

We need your help, so please consider taking on this very rewarding job and be a part of the most wonderful group of families you will ever meet!

For more information, please contact: info@prisms.org or call 972-231-0035.
**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.

---

**A Bear By Any Other Name**

My husband was helping Rachel clean up a few items in her room before putting her to bed. A stuffed teddy bear was lying on the floor. Mark told Rachel that she needed to pick the bear up from off the floor. Insulted by his impersonal reference to her bear, Rachel replied, “Daddy, her name is Pinky, not ‘The Bear’. You don’t call me ‘The Human Being’.” Mark abruptly apologized and asked her if she would please pick up Pinky. Naturally, Rachel was happy to comply.

Submitted by Jessica Kirklin

---

**Buckaroo!**

After many unsuccessful attempts at potty training our son, Garrett, we thought it might be a good idea to get him more involved in the process. My husband, Charlie, decided to let Garrett pick out his own “big boy underwear” in the hopes that Garrett would be more interested this time around.

Since Garrett’s most favorite place in the whole wide world is Wal-Mart, this is where the big shopping trip took place.

Charlie was busy showing Garrett the fine selection of underwear choices, and he did not notice another customer come up beside them. We live in a rural area, and this man was wearing the typical farmer’s uniform: jeans, boots, a button up flannel shirt, and a cowboy hat. Garrett, who never speaks clearly unless he is about to say something embarrassing, turns to the man and says, “Howdy Buckaroo!”

Submitted by Tina McGrevy