

Food-Related Problems with Smith-Magenis Syndrome

Authors: Laura Barton LV (1), Timothy York TP (1), Sarah Elsea SH (1, 2)

Affiliations: (1) Dept. of Human Genetics, Virginia Commonwealth University, Richmond, VA; (2) Dept. of Pediatrics, Virginia Commonwealth University, Richmond, VA

The physical characteristics of SMS are well-defined, and have not significantly changed since the initial description in 1986. However, the behaviors displayed by individuals with SMS are possibly more characteristic of the disorder than the physical manifestations, and while the behaviors seen in individuals with SMS are well-known (self-injurious, aggressive, and repetitive behaviors along with characteristic actions, such as self-hugging), detailed research to describe how those may change as the child ages has been lacking [1]. There has also been a lack of research into food-related concerns and how behaviors may influence the change from being underweight as a toddler and young child to being overweight or obese as a teen and adult, as is seen in so many people with SMS. An understanding of the problem behaviors, specific eating behaviors, and food-related concerns of individuals with SMS is important for the development of practice guidelines and specific interventions to prevent or help mitigate both the problem behaviors as well as obesity. In the fall of 2011, parents and guardians of children with SMS were given the opportunity to share information regarding the behaviors and food concerns they see in their children by completing an online survey, including three measures: the Behavior Problems Inventory, the Childhood Behavior Checklist, and the Food-Related Problems Questionnaire. This is the first report of the data collected from those surveys, and in this installment we will present the data from the Food-Related Problems Questionnaire (FRPQ) [2]. Future installments will include the data from the behavior measures and how those behaviors may correlate with food-related problems.

Methods and Analyses

Parents and guardians of children aged 18 months to 18 years

with SMS were recruited via Parents and Researchers Interested in SMS (PRISMS). PRISMS distributed links to the surveys which were hosted on

surveymonkey.com, a web-based survey hosting service (<http://www.surveymonkey.com>). From August 2011 to January 2012, two surveys were available for parents to complete, and the one selected corresponded to the age of the child: 18 months to 5 years, or 6 years to 18 years. Numerous inquiries from parents of adult children wanting to participate resulted in posting a third survey for children aged over 18 years in October 2011. The data from the survey for children aged over 18 are not included in this analysis, except for the responses describing three individuals who were 21 years old or younger and enrolled in high school. For analysis, the responses were separated into three age groups: 18 months to 5 years (18m-5y), 6 years to 11 years (6y-11y), and 12 years to 21 years (12y-21y). This was in order to do between-group comparisons with finer detail than two groups would allow.

Food-related concerns of parents were measured by the Food-Related Problems Questionnaire (FRPQ). The FRPQ was first published in 2003, and was designed to assess food-related problems seen in individuals with Prader-Willi Syndrome, a genetic condition with similar symptoms to SMS [2]. After obtaining the total scores for each participant, the average scores of each age group were compared.

Participants

Of a total of 40 respondents who were parents of children aged 18 months to 5 years, 17 completed the survey in its entirety. Due to the nature of the measures, only surveys entirely completed, including answers for all questions for each of the three scales, are included in this analysis. For the

-Continued on page 4

INSIDE THIS ISSUE	
President's Message	3
Gentle Teaching	8
Conference Update	10
Our Australian Holiday	12
Advocacy Corner	14
SuperKid—Frances	15



Officers

President: **Randy Beall**
Richardson, TX
 Vice President: **Margaret Miller**
Herndon, VA
 Secretary: **John Mayer**
Portsmouth, NH
 Treasurer: **Phil Ruedi**
Boston, MA

Board Members

Julia Hetherington Beaufort, SC
Percy Huston Port Girardeau, MO
Mary Kate McCauley Ardmore, PA
Tina McGrevy Springfield, OH
Sarah Elsea Richmond, VA

Professional Advisory Board

Kerry Boyd, M.D.
Bethesda Services, Ontario, Canada
 Sarah Elsea, Ph.D., Chair
Virginia Commonwealth University
 Brenda Finucane, M.S., CGC
Elwyn Training & Research Institute
 Barbara Haas-Givler, M.Ed., BCBA
Elwyn Training & Research Institute
 Andrea Gropman, M.D.
Children’s National Medical Center
 Gonzalo Laje, M.D.
NIH, National Institute of Mental Health
 Ellen Magenis, M.D.
Oregon Health & Sciences University
 Lorraine Potocki, M.D.
Baylor College of Medicine
 Ann C. M. Smith, M.A., D.Sc. (hon)
Chair Emeritus,
NIH, National Human Genome Research Institute
 Christine Brennan, M.A., CCC-SLP
Northwestern University

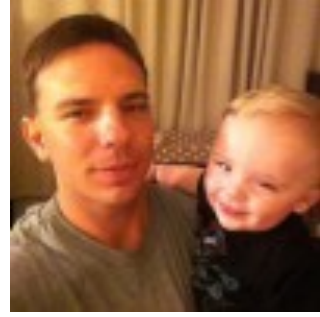
PRISMS, Inc.
21800 Town Center Plaza
Suite 266A-633
Sterling, VA 20164
972-231-0035
Fax: 972-499-1832
info@prisms.org

New Spectrum Editor-in-Chief and Editor

PRISMS is pleased to introduce you to our new newsletter editors! We are very grateful that these young men stepped forward when a request went out for volunteers. They come to us with excellent experience and an enthusiasm for the task.

Steve Corbett, Editor-in-Chief

Steve resides in New Orleans, LA with his wife Erin, their twenty-two-month-old son, Gavin, who was diagnosed with SMS at three months, and are expecting their second child in October. Steve is a school administrator at a Middle/High School and an Adjunct Professor at the University of New Orleans. He is currently finishing up his doctorate in education, with a focus on the educational experiences of students with Smith-Magenis Syndrome. Steve is excited to join the PRISMS team, and looks forward to working with the incredible community of parents, teachers, medical professionals, and researchers who support those with SMS. Steve hopes to build upon the tremendous work of Julia Hetherington, and anticipates the continued development of the newsletter in providing essential information to those interested in SMS.



Joe Haroldsen, Editor

Joe and his wife, Jenn, live in Spanish Fork, UT. They have 5 children, 1 boy and 4 girls. Their fourth born child, Leah has SMS, and is 4 years old. Joseph has many years of experience in the business world of marketing and sales, where one of his responsibilities has been producing a company newsletter. He wishes to support PRISMS and it’s mission of bringing more attention to a relatively unknown Syndrome. He is committed to producing a good product that will bring attention to SMS and information to people who are caring for children and adults diagnosed with SMS.



If you would like to submit anything to the newsletter, or perhaps just help out on a committee, you can contact them at editor@prisms.org.



Join us on Facebook!
PRISMS Smith-Magenis



A Message from PRISMS President

Randy Beall

Dear PRISMS family,

Beginning with this edition of Spectrum, please welcome our next newsletter editor-in-chief, Steve Corbett, and our new editor, Joseph Haroldsen. We are delighted to have Steve and Joe on board.

I also want to say a huge THANK YOU to Julia Hetherington, our outgoing newsletter editor-in-chief. Julia has helped us produce one amazing edition of Spectrum after another plus some outstanding annual reports. Steve and Joe, you guys have BIG shoes to fill. Julia will continue to serve on the PRISMS board and will now focus on helping us raise awareness.

It's conference time again! Our international conference is a high priority for PRISMS, and the largest program we host. Planning for this conference began more than 3 years ago. The conference committee co-chairs, Nina Kelly and Shannon Jantzi, and program committee, Amy Pereira, Maggie Miller and Nancy Cordrey, along with parent volunteers, Kim and Eric Hoffman and Heather and Dan Wilde, have many duties, including arranging for all of the rooms, guest speakers, audiovisual equipment, t-shirts, nametags, conference notebooks, schedules, child care, and food. The list goes on and on.

I hope that many of you are coming to the conference. After this one, our next conference won't be until 2014 or 2015 - so don't miss this one! We want as many of our members as possible to benefit from this great opportunity to hear the speakers, meet the researchers and interact with other parents. If you are not coming this year, I hope you will make plans to come to our next one! Many folks have told me the information they learned at past conferences changed their lives. For my family, it's an event not to be missed.

The PRISMS conference benefits all members, even those who never get to come. How? Things that happen at a PRISMS conference:

- Researchers meet and present their research to each other, which leads to more ideas and more research.

- Speakers prepare and present information specific to Smith-Magenis Syndrome. Nationally known experts on behavior, autism, therapy, etc., learn much more about SMS, and raise awareness as they tell others. They bring us their new ideas to apply to our children. The presentations, new research, and ideas on behavior, sleep, and other SMS issues will be added to the PRISMS website where they will be available to everyone.
- Parents and teachers meet with other parents and teachers. The ideas they give each other often are later presented in articles in our newsletters.

There are lots of people with SMS and their families all in one place. Some of the defining characteristics of SMS have been first understood when several people with SMS were together, and/or several parents were discussing similarities.

So I hope you are excited that we are having a conference, whether you are coming or not. The PRISMS conference helps us all.

Please join me in saying a huge thank you to those who have donated and raised funds to make the conference happen. Without you guys this great event would not be possible!

Warm regards,

Randy Beall
PRISMS, President
Father to Laura, age 27, with SMS

Food-Related Problems with Smith-Magenis Syndrome - Barton

Continued from page 1

survey of parents of children aged 6 years to 18 years, there were a total of 83 respondents, and 61 completed the survey in its entirety. As stated above, data from three respondents who took the survey for parents of individuals over the age of 18 with SMS were included in this analysis because the individuals are still in a high school setting, giving a total of 64 respondents with children aged 6 years or greater: 36 in the 6y-11y group and 29 in the 12y-21y group.

As expected, the participants described their children as being overweight more frequently with each ascending age group (Figure 1). When responding to the question, "Do you have concerns regarding your child's eating behavior?", 65% in the 18m-5y and 6y-11y groups responded "Yes." This number rises to 89% in the 12y-21y group. When asked to

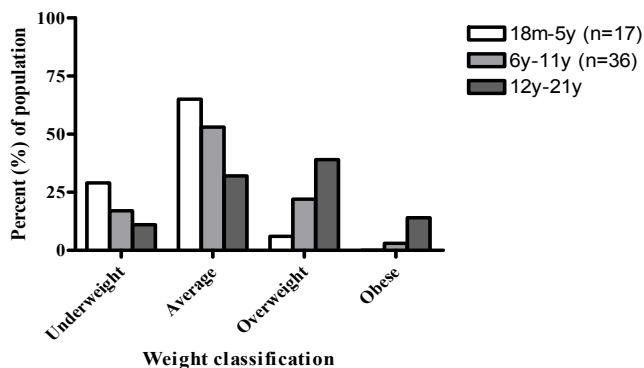


Figure 1 Weight classification responses of participants. Shown are the percent of respondents that selected each of the four classes of weight descriptors by age group.

describe those concerns, many respondents, across all three age groups, reported the child "stuffing" his or her mouth. In all three age groups, parents reported concerns such as "she over-stuffs her mouth," or "he stuffs his mouth full...." In the

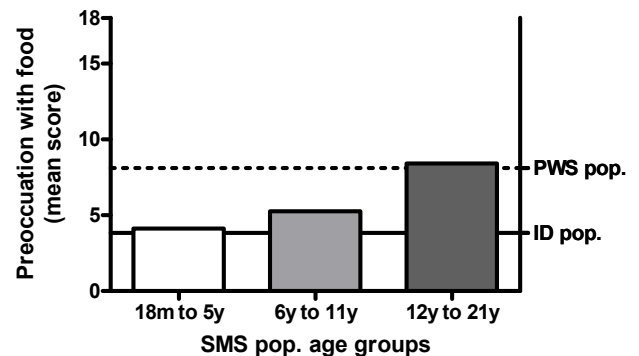


Figure 2 Children with SMS aged 18m-5y and 6y-11y exhibit significantly lower preoccupation with food mean scores than the 12y-21y SMS group on the FRPQ. Preoccupation with food mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop.; dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

older two groups, many children were described as not knowing when they are hungry or full. "I do not feel she has the understanding of ever feeling full," and "he can always eat, does not get full," are comments from two respondents who expressed a common view of concerns about their child's eating behavior.

Table 1 Demographic information for SMS population

Characteristic	18m-5y (n=17)	6y-11y (n=35)	12y-21y (n=29)
Average age of child	3.35 ± 1.32 years	8.23 ± 1.92 years	15.34 ± 2.46 years
Gender of child	53% Male (9) 47% Female (8)	49% Male (17) 51% Female (18)	34% Male (10) 62% Female (18) 1 No response
Gender of respondent	12% Male (2) 88% Female (15)	11% Male (4) 89% Female (31)	18% Male (5) 79% Female (22) 1 No response
Ethnicity of child			
White, not of Latino background	10	29	26
Latino	1	0	0
African American	0	0	0
Asian American	0	1	1
Native American	1	1	1

Results

For the three principle subscales measured by the FRPQ, preoccupation with food (Figure 2), impaired satiety (Figure 3), and composite negative behavior (Figure 4), the 18m-5y group and 6y-11y group had significantly lower average

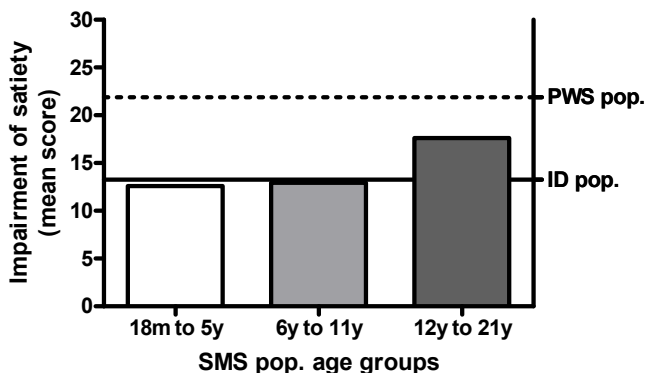


Figure 3 Children with SMS aged 18m-5y and 6y-11y exhibit significantly lower impaired satiety mean scores than the 12y-21y SMS group on the FRPQ. Impaired satiety mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop., dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

scores than the 12y-21y group, and no significant differences were noted between the two younger groups. When the FRPQ was published, reference scores were included from two adult populations: one with Prader-Willi Syndrome (PWS) and one with individuals with various degrees of general intellectual disability (ID). Prader-Willi Syndrome is a genetic condition that has similar features to SMS, including

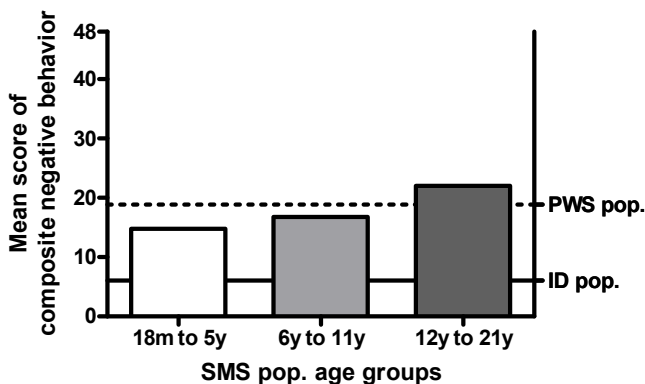


Figure 4 Children with SMS aged 18m-5y and 6y-11y exhibit significantly lower composite negative behavior mean scores than the 12y-21y SMS group on the FRPQ. Composite negative behavior mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop., dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

short stature, intellectual disability, aggressive and stereotypic behaviors, failure to thrive in early life, and obesity seen as the child ages, with nearly 100% of individuals overweight by age 10 [3, 4]. Prader-Willi Syndrome provides a model where researchers have been able to design an effective intervention to prevent and reverse obesity seen in Prader-Willi Syndrome by understanding the behaviors leading to the weight gain [5].

The average scores of the SMS groups and these reference groups were not compared statistically, but these values are noted in the figures to provide some comparison. The 18m-5y and 6y-11y groups' average scores on all three subscales were generally more consistent with the general intellectual disability population, while the 12y-21y SMS group's average scores for the three subscales were more consistent with the average scores of the Prader-Willi

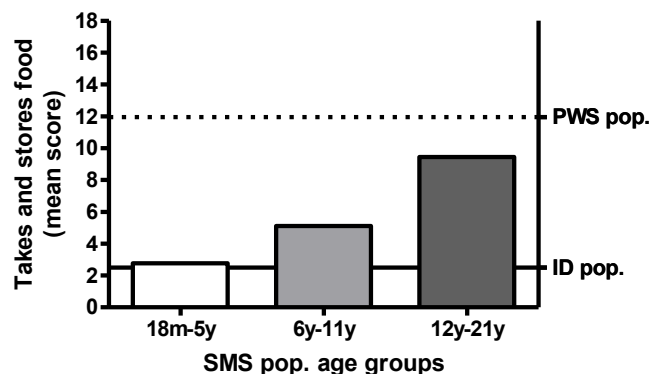


Figure 5 Children with SMS exhibit significantly increased takes and stores food mean scores with increasing SMS age group on the FRPQ. Takes and stores food mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop., dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

Syndrome population.

Differences among the three SMS groups were also examined in the subcategories that comprise the composite negative behavior score. For takes and stores food, both the 6y-11y SMS group and the 18m-5y SMS group had average scores that were significantly lower than the 12y-21y group. Further, the 18m-5y group scored significantly lower than the 6y-11y group (Figure 5). There was no significant difference in the SMS age groups for the subcategories of eats inedibles or inappropriate response. When comparing the SMS groups to the Prader-Willi Syndrome and general intellectual disability groups, the 12y-21y group is most similar to the Prader-Willi Syndrome population, and the 18m-5y and 6y-11y groups were more similar to the general intellectual disability population for takes and stores food.

Average scores for the total FRPQ (Figure 6) maintain the pattern seen in the three principle subscales and the subcategory of takes and stores food. The two youngest SMS

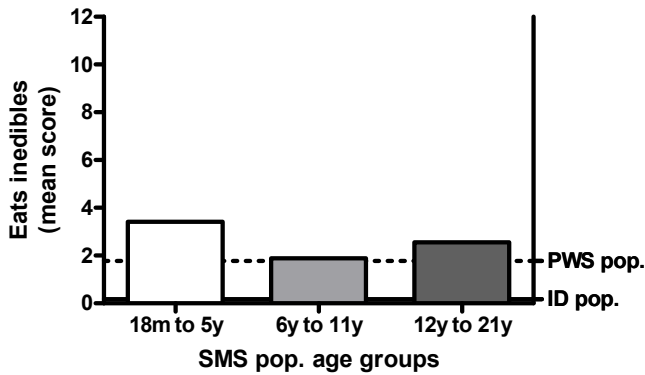


Figure 6 Children with SMS exhibit no significant differences based on age groups for eats inedibles mean scores. Eats inedibles mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop.; dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

groups had a significantly lower average score than the 12y-21y SMS group. Again, the 18m-5y group and the 6y-11y group had average scores similar to the general intellectual disability group, and the 12y-21y SMS group had a very similar average score as the Prader-Willi Syndrome group.

What do these results mean?

All areas measured by the FRPQ showed relative stability until the group including teens, when these problems become more common. This finding may be a result of increased availability of and autonomy in food choices with age more than a change in the disease. An increase in the problems

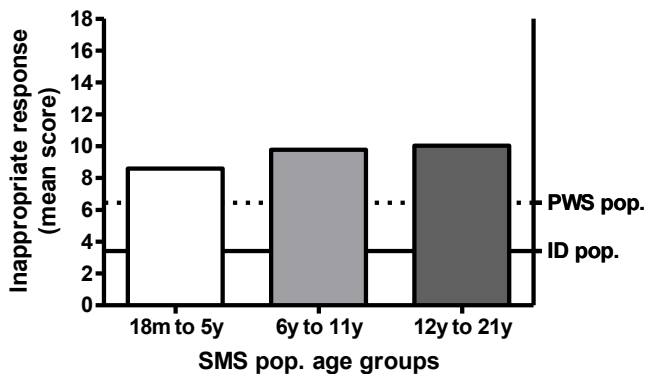


Figure 7 Children with SMS exhibit no significant differences based on age groups for inappropriate response mean scores, but are elevated relative to the PWS pop. mean score. Inappropriate response mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop.; dotted line indicates mean score of PWS pop.

related to food in ascending age groups is not surprising considering the increase in individuals who were reported to be overweight or obese in ascending age groups in our population.

The two youngest groups scored similarly as the group with general ID, and the 12y-21y group scored more similarly to the group with PWS, which may suggest the SMS population of older children may have similar food-related problems as individuals with PWS, and so they may benefit in the weight control measures designed for treatment in PWS. It has been shown that a strictly-controlled diet that is low in fat and carbohydrates is effective in preventing and reversing

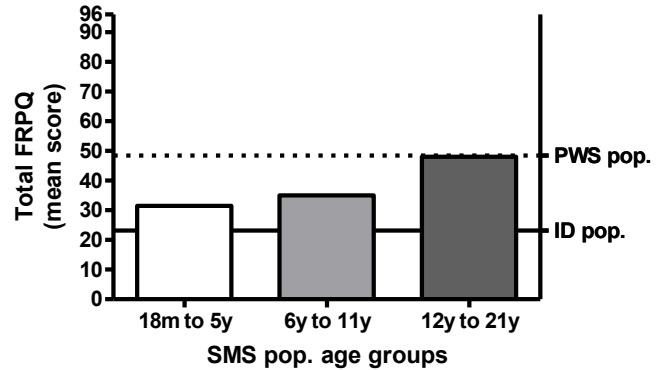


Figure 8 Children with SMS aged 18m-5y and 6y-11y exhibit significantly lower total FRPQ mean scores than the 12y-21y SMS group. Total FRPQ mean scores are shown for each SMS group. Solid line indicates mean score of general ID pop., dotted line indicates mean score of PWS pop. (Russell & Oliver, 2003). Data shown are mean score.

the obesity seen in PWS [6]. Since the controlled diet has shown to mitigate weight gain in individuals with PWS who would be expected to be overweight with food-related behaviors similar to those seen in SMS, it is possible that beginning a similar, carefully controlled diet with close food intake monitoring at an early age can prevent the obesity so often seen in individuals with SMS.

While it is possible the use of a diet effective in PWS will be effective in SMS, one should consider the two groups may not be equal in their caloric needs. Children with PWS have been shown to require a lower daily calorie intake than typically developing children to maintain the same weight, suggesting an underlying metabolic problem may be present in addition to, or possibly instigating, the food-related behavior problems [7]. This has not yet been evaluated in children with SMS, but it is important for the clinician to take this possibility into account when prescribing a diet. While there is no data in a human population, a mouse study showed *Rail* haploinsufficiency resulted in obesity with no evidence of metabolic Syndrome [8]. There could be a difference in the underlying metabolism of individuals with PWS and individuals with SMS, and so any dietary change should be monitored by a physician.

While our knowledge of SMS is growing, it will be important in the future to further examine the effect of puberty on these behaviors as well as study genotype/phenotype correlations and the data from the surveys taken by parents of adults with SMS. A study in which individuals are followed over a long period of time may be best suited to give the most detailed description of the changing behavioral phenotype over time, and how that phenotype may interact with and be affected by the child's environment.

Acknowledgements

We'd like to thank PRISMS for providing a portion of the funding for this project as well as facilitating the distribution of the links to the surveys. We'd also like to thank all the parents and guardians who took the time to complete our surveys. Thanks to your efforts, we have been able to collect a vast amount of data regarding the behaviors seen in people of all ages with SMS. With this work, and other analyses to come, we can be on the road to developing more effective therapies and treatments for those affected by SMS. The authors would also like to thank Lauren Vanner-Nicely, MS, CGC and Va-LEND for providing helpful feedback and support during the writing of the article.

Works Cited

1. Smith, A.C., E. Dykens, and F. Greenberg, *Behavioral phenotype of Smith-Magenis Syndrome (del 17p11.2)*. Am J Med Genet, 1998. **81**(2): p. 179-85.
2. Russell, H. and C. Oliver, *The assessment of food-related problems in individuals with Prader-Willi Syndrome*. Br J Clin Psychol, 2003. **42**(Pt 4): p. 379-92.
3. Holm, V.A., et al., *Prader-Willi Syndrome: consensus diagnostic criteria*. Pediatrics, 1993. **91**(2): p. 398-402.

4. Wollmann, H.A., et al., *Reference values for height and weight in Prader-Willi Syndrome based on 315 patients*. Eur J. Pediatr, 1998. **157**(8): p. 634-42.

5. Schmidt, H., et al., *Successful early dietary intervention avoids obesity in patients with Prader-Willi Syndrome: a ten-year follow-up*. Eur J. Pediatr Endocrinol Metab, 2008. **21**(7): p. 651-5.

6. Bonfig, W., K. Dokoupil, and H. Schmidt, *A special, strict, fat-reduced, and carbohydrate-modified diet leads to marked weight reduction even in overweight adolescents with Prader-Willi Syndrome (PWS)*. ScientificWorldJournal, 2009. (9): p. 934-9.

7. Hoffman, C.J., D. Aultman, and P. Pipes, *A nutrition survey of and recommendations for individuals with Prader-Willi Syndrome who live in group homes*. J. Am Diet Assoc, 1992. **92**(7): p. 823-30, 833.

8. Burns, B., et al., *Rai1 haploinsufficiency causes reduced Bdnf expression resulting in hyperphagia, obesity and altered fat distribution in mice and humans with no evidence of metabolic Syndrome*. Hum Mol Genet, 2010. **19**(20): p. 4026-42.

Annual Report - Correction

The following members of PRISMS were left off of the Spectrum 2012 Annual Report:

Pat Boschetto
Barbara Melamed

We apologize for the error and thank you for your membership.



Are you online? Check out the 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!

The Power of Gentle Teaching

by Jan Holland, MA

**“May I live this day, Compassionate of heart,
Gentle in word, Gracious in awareness, Courageous
in thought, Generous in love.”**

-Eternal Echoes By John O'Donohue

Importance of Relationships in Gentle Teaching

Who in your life helps you feel safe and confident? Who shares the things you love, and understands your challenges? The one who hangs in there even when you're tired or out-of-sorts? We all need relationships of unconditional love.

How can we express such love in the life style we create, and sustain this posture even in the midst of what feels like “disaster moments”? What is needed in order to do more than just survive? What are the conditions necessary for growth and challenge in a person's life?

Parents of children with Smith-Magenis Syndrome learn quickly that their child needs help to overcome heightened sensitivities of anxiety and frustration, communication problems, sleep difficulties and delayed development associated with the Syndrome to take part in the ordinary events of life.

Creating a safe and loving home for the child with SMS requires parents to become more intentional and organized with daily routines and with their parenting. Life may seem unpredictable to their child with even the smallest changes, switching to a new activity or the differing approach or expectation of those supporting him/her.

Gentle Teaching provides a basis for building healthy interpersonal relationships in both its values and methods. When there are personal connections, people often grow in exciting and unexpected ways.

What is Gentle Teaching?

Gentle Teaching is a unique relational approach centered on building safe, loving and engaged relationships.

Gentle Teaching creates pathways to develop these safe and caring relationships through providing leadership, invitation and example rather than trying to impose control. Shared activities and moments are used to teach and build relationships of reciprocity and fairness. Developing the capacity to offer warmth and understanding in challenging moments is foundational for establishing an authentic relationship of trust. Video review helps us identify the places we need to change and be transformed.

Four Elements of Successful Teaching/Parenting

Gentle Teaching espouses: “We change for those we care about and trust.” It provides a framework for learning and growth by having clear goals, creating a plan, and setting up an organized environment without losing the relationship focus. Within this context, challenging moments are better anticipated, prevented and refocused.

Consistently integrating the following elements can experientially establish trust:

- Environmental arrangement—safety, minimize distraction, learning style
- Flow of activity—balance routine activities & introducing change
- Adequate information/communication—visual, verbal, gestural, physical
- Sustaining the relationship in personalized ways—value & encouragement

Organizing the four elements begins with the reflective practice of asking:

“What is this person communicating and how does he interpret information?”

This creates a dialogue where the individual feels listened to, and is more willing to communicate in ways that are less hurtful, disruptive, controlling and obsessive.

Case Study Using the Four Elements

I have used the principles and practice of Gentle Teaching in my professional and personal life for more than 30 years. The reflective aspect of this philosophy continues to challenge me to become a safer, more loving and engaged person in all my relationships. Over the last 3 years, I've had the pleasure of working with a family and support team for a 26-year-old man with SMS. The focus of this work has been assisting Bryan and his team to develop caring, predictable relationships that support Bryan and his household to live happy and engaged lives at home and in the community. Let's examine how the four elements were considered to facilitate a successful transition from his parent's home to a shared living arrangement (home with live-in, paid companions). Bryan had tried on several occasions to make this transition achieving only limited periods of success. His impulsivity, over-eating, explosive moments and periodic physical aggression made sharing life stressful for all involved. What did we learn from the failed attempts at shared living in this house previously?

Organizing the environment began with these changes as our starting point:

- Bedroom in rear of the house selected to minimize his anxious looking out the front window to track the neighbors coming and going, avoid uncomfortable neighbor relations when Bryan was naked without drawing the curtains
- Decorations of the bedroom and furniture arrangement designed to reduce distraction, compulsive habits, and improve sleep patterns
- Location of the game room – accessed by passing through the center of the house and the kitchen, helping him engage with the people in the house

Flow of activity in the house and community made safer and healthier:

- Use of multiple live-in companions (instead of one) helped establish relationships of trust more easily for all in the household, and interrupted out of balance dependency.
- Home and community support came from the live-in companions to create smoother and safer transitions.
- Home routines were established for all members of the household.
- Varied menus and meals at the table were planned as part of the new lifestyle.

Adequate information and communication was explored through:

- Developing task analysis for home and work tasks
- Providing calendars for events and people, use of lists
- Use of texting when phone calls created anxiety

Sustaining the relationship in personalized ways evaluated through:

- Effective organization of the day and week sequencing challenging tasks prior to preferred activities
- Determining the important people to include daily, weekly, holidays
- Ensuring adequate time with those individuals
- Creating a fun, interesting and meaningful rhythm of life

Successful Results

Addressing these questions based on Bryan's previous experience has provided a good foundation for a successful year of shared living. His family and team have been amazed by Bryan's ability to relate in fairer and more caring ways. He adapted relatively well to the initial changes in his bedroom, game room location, new routines, and flow to the week. His team struggled more than he did as they

anticipated his response to the changes. Bryan has lost 40 pounds and assumes leadership for eating a greater variety of healthy foods. There have been several changes of people within the house and the disruption has been much milder than in the past. The "just right" combination of the four elements within the context of these caring and trusting relationships has allowed Bryan to grow and mature in wonderful ways.

His monthly progress notes have comments such as these:

- Bryan is truly enjoying life these days. He has enjoyed the company of his new friends. They have met for meals, bowling, movies and game night. Bryan is really proud to be telling his companions or family that he can't do something because he "has plans."
- Bryan is practicing being a gentleman. He will ask visitors if they would like a drink or snack. He will walk friends out to their cars when they leave.
- Bryan is making healthier choices. He can accept reminders to limit his choices as he will sometimes try and order multiple items from the menu.
- Bryan continues to do well at his job sites. Companions are currently helping him update his resume and business cards. He has applied to two businesses and had one interview. Bryan was very mature when he went to the interview, and said he would like to work there.
- Bryan has made amazing gains in being able to express his concerns. He is more flexible with his expectations and has been able to handle changes in schedule and staff in a much calmer manner.

Characteristics of the team – household members, parents & management

- Vested in a commitment to creating a culture of gentleness and inclusion with each other, with the household and within the broader community
- Vested in a process of continual change and growth through self-reflection using videos and creating a no-blame culture, allowing for mistakes with openness and sense of humor

More information and resources with GT consultants or these websites:

Jan.Holland@crotchedmountain.org; Gentle Teaching International, HOMES Society, Globe Star

danhobbs@wildblue.net, ironwyuk@googlemail.com, Gentle Teaching UK and Ireland, Bradstow School UK

Conference News



Building
Bridges of Hope
prisms 7TH INTERNATIONAL
CONFERENCE | DENVER 2012

June 28 – July 1, 2012 Denver Renaissance Hotel, Denver, CO *Final Call for Registration*

The **7th International PRISMS Conference** in Denver, CO is fast approaching, yet there is still time to register and attend. This is the largest gathering worldwide for families and professionals who care for a child with SMS. We will welcome families from several countries as well as the United States, and we want to see you there, too! The information presented at the conference will be valuable and practical, and SMS research updates will also be presented. We have an array of highly respected and knowledgeable speakers, including many of our PRISMS parents. There is something for everyone, no matter the age of your child. The greatest event that happens at the PRISMS conference is the unending support that you will receive, and the life-long friendships that you will make. Please plan to attend!

Full conference details as well as a link to conference registration is available on the PRISMS website, (www.prisms.org). Onsite registration will also be available for last minute attendees.

Schedule of Events

You can see the complete schedule of events and biographies of the speakers on the PRISMS website and registration page as the agenda is finalized.

Renaissance Hotel Information

The conference will be held at the *Renaissance Denver Hotel in Denver, CO.*

* Please use the website link below to reserve a room at the PRISMS discounted rate of **\$129.00 single/double**, plus applicable taxes.

* Make your reservations prior to **June 5, 2012** to receive the discounted rate.

* After **June 5, 2012**, the discounted rate may not be available.

* Please visit the PRISMS homepage for the link to the hotel or call 1-800-468-3571 or 303-399-7500.

Annual 5k Run/Walk for PRISMS

Come join us in **Springfield, Ohio** on **Friday, September 21, 2012** for the **6th Annual 5K Run/Walk for PRISMS** at beautiful Buck Creek State Park. Sign in begins at 5pm with the race starting at 6pm.

On **Saturday, September 22**, we are hosting a picnic at the Springfield Firefighter Clubhouse from noon-4pm. It is located at 703 N. Bird Road and has a large playground area for the kids. We will be serving hot dogs, sloppy joes, chips and drinks. Bring something sweet to share and backyard games to play.

There is a block of rooms at the Hampton Inn for Friday and Saturday nights. Call the hotel directly at 937-325-8480 to get the PRISMS rate of \$94+tax per room.

Visit their website at:
www.springfieldoh.hamptoninn.com for directions.

For the more adventurous ones, campsites are available at Buck Creek State Park. Call 1-866-OHIOPARKS for reservations.

We hope to see you in the fall!

Charlie and Tina McGrevy
1347 Bowman Road
Springfield, Ohio 45502
cmcgrevy@yahoo.com
937-327-9354

Cooking with the SMS Family



Thank you PRISMS families for the overwhelming response for our recipe callout! The book has been sent to the publisher and will include more than 200 of our best dishes. If we choose your photo to be in the book, you will be contacted to fill out a consent form. We received so many wonderful pictures; unfortunately, we could only use eight.

Books will be available for purchase at the conference for \$15.00. For those who pre-ordered and will not be attending the conference, we will be mailing them to you during the second week of July.

Thanks to everyone who helped make this project such a success!

Tina McGrevy and Mary Kate McCauley

Our Australian Holiday, 2011

The Adventures of Tyler Boman and (Grandma) Pat Boschetto

What a great idea, I thought, spending Christmas and New Year's in Australia. Tyler will have so many new experiences, and it will probably be his only opportunity to travel outside the United States.

I completed the passport application and had his photo taken. Ok, the picture wasn't exactly the most flattering, but it would do. Tyler's excitement when his brand new passport arrived was over the top.



To me, planning is half the fun of traveling. I spend time learning the geography of the destination, calculating the approximate driving time to cities and attractions so as not to "over-plan." The internet is loaded with information and colorful pictures of far away places, beckoning visitors to come and discover the many sights and activities on offer. Since this trip was to be for Tyler, who's 14, I searched all the kid-friendly places I could find. There were plenty. But with an SMSer, I had to decide which activities would be suitable.

December 20 came and we were off. Two hours' drive to Las Vegas to catch a flight to Los Angeles. So far, so good. Then it was time for the 14-hour flight to Brisbane. Ohhhhh, I was nervous about how Tyler would handle this part. His doctor had suggested a medication to "make him sleep the whole way." But I said I wanted him to enjoy the flight: food, movies, snacks, music. Still, so far, so good. After about six hours, he got restless and was up looking for more food and soda. He discovered the galley and that was it; couldn't get him out of there. Upon boarding, I had informed the flight attendants of their "special" passenger, that he won't listen to me, and please be firm if he gets in the way. Mostly, the flight went well. We had a third person in our row who was very helpful and kind to Tyler, in spite of the numerous times he had to get out of his seat to let Tyler out and back in. One of my favorite parts of international travel is watching the flight path progression on the monitor as we cross geographic markers. From the

U.S. to Australia, it's the equator and the international dateline, as well as various tropical islands.

December 22 and we were there. Wait! Where did December 21 go? Oh, yes; the international dateline. After customs, we picked up the rental car. We sat in the car for several minutes, while I reminded myself that everything would be backwards from U.S. driving. During the entire two weeks we were "down under", I only turned on the wipers three times instead of the turn signals. Tyler got a kick out of that. It was a beautiful morning, but very soon we drove into rainy weather. I worried that we'd have a lot of rain on this trip, and sure enough, there was rain every day for the first four days. But it turned out not to be much of a problem, other than frizzing up my hair!

After arriving in Brisbane, we drove north to Caloundra to visit Top Shot Fun Park for mini golf and arcade games. The next day we went to The Ginger Factory in Yandina. It's a small place where ginger is processed and bees make honey. We ate and souvenir shopped and rode a couple of rides. Beautiful grounds; tropical. Next day we drove back to Brisbane. On the way, we noticed a road sign to "BURpengary." BURPengary. Well, boys love burping, so that entertained us for hours. BURPengary. Being from the U.S., we have Disneyland and Disney World. We've been to both and are spoiled by how wonderful they are. So going to Warner Bros. Movie World in Oxenford was somewhat disappointing. While standing in line for a children's-sized roller coaster (we don't like roller coasters), two young brothers were curious about Tyler. So I told them a little about SMS. They wondered if he'd ever get "better", and I told them regrettably no. The boys were very kind to Tyler, and I felt like we had just made two new friends in that 10-minute period. It makes me smile to think about the boys.

Then, on Christmas day, came my absolutely favorite part of the trip. We visited the Lone Pine Koala Sanctuary in Fig Tree Pocket. We were able to hold a koala, Jaffa, for picture taking; then we fed and petted kangaroos. They were all so sweet. Jaffa was very cuddly, and the roos were happy to see all the visitors, as we had small bags of pellet treats for them. They gently ate right out of our hands, and we were able to stroke them like you would a dog or cat. I was in heaven with all those little buddies. Sorry to say,



SMS reared its head while petting the kangaroos. I tried all the “tricks” to minimize Tyler’s meltdown, but nothing worked – not until Tyler himself was ready to behave. He yelled and stomped at the roos to scare them. People stared. I cringed. Tyler didn’t care. Sound familiar?

The next day we drove south to the famous Gold Coast where we spent a short time at the beach, rode an Aquaduck bus/boat around town and then into the water, and played a few rounds of mini golf.

I had seen Aussie Waterballs on the internet and decided we had to give it a try. They are big, heavy-duty plastic balls that you climb into. Then the attendants close you up



inside and give you a shove into the water. It’s almost impossible to stand up inside when you’re on the water. All we could do was crawl and fall against the ball to get it to move. We went on a quad bike safari one afternoon out in the mountains; beautiful scenery. The Gold Coast is a bustling tourist town, with sidewalk cafes on every block. Tyler is a good eater, but I’m not too keen on trying new foods, so I always ordered “safe” items, keeping away from strange meats, strong cheeses, raw and weird seafood, etc. I encouraged Tyler to try different things since he didn’t know they were “different.”

We took two days driving south to Sydney. As usual, I got lost everywhere we went, so driving took longer than necessary. But it enabled us to see more of Australia (and to meet more Aussies as I stopped to ask for directions; they’re so nice). I had pre-arranged to stop in San Remo to visit Camp Breakaway. Michelle Price, Jodie Davis and a few others were there to greet us and show us around the camp. We had met them at the last PRISMS conference in Virginia, and I was eager to see them again and tour their wonderful camp. They do extraordinary work there, providing respite for all members of the family of special



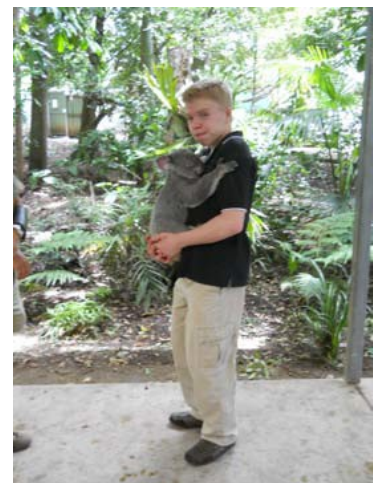
needs people. The grounds are beautiful, as are the people who work and volunteer there. It was another highlight of the trip for me.

In Sydney, we took a harbor cruise under the Sydney Harbor Bridge, past the Opera House, and around the interior harbor, viewing many neighborhoods that border the harbor. It was a huge thrill for me; I was in Sydney seven years earlier, and on my first day there, I climbed the Sydney Harbor Bridge. It was exhilarating! We walked around the Sydney Harbor area, visiting the Sydney Aquarium where they had a giant Lego display, made a 360 degree tour of the Opera House, dodged the many other tourists, and souvenir shopped. As usual, on this trip Tyler didn’t listen to me AT ALL. He was always walking way ahead of me. I would stop and wait for him to realize that I wasn’t with him; he’d turn around and come back as though nothing was wrong. Our hotel in Sydney was in the Sydney Olympic Park. We walked across the street to the aquatic center where Tyler had a blast in the Splasher’s Pool, and down a block to the Olympic Golf Center– more mini golf. Tyler loves mini golf, arcades, and bowling, so we did a lot of that.

New Year’s Eve day was spent sightseeing and enjoying lunch and the beach at famous Bondi Beach. Back at our hotel, we were able to watch the fireworks at midnight on the Sydney Harbor Bridge, avoiding the enormous crowds in town. The next morning, January 1, 2012, we flew back to Brisbane for a couple of days. We took a water-taxi ride on the Brisbane River, souvenir shopped, and Tyler bowled and played arcade games.

On January 3, we were at the Brisbane Airport preparing to return to the U.S. Tyler seems to have an addiction to soda, and when he dropped one, he had a huge meltdown. It got so bad, the Federal Police, airport security, and Qantas supervisors came to check it out. Ultimately, they wouldn’t let us board because of Tyler’s erratic SMS behavior. We had to spend another day until we could get a doctor’s release for him to fly. It was a difficult trip home. SMS impulses were in control, and I worried the entire time that Tyler would melt down again. It all worked out in the end.

I knew it would be a huge risk taking an SMS person on such an ambitious trip, but the desire to give Tyler the Aussie experience outweighed the risk. And I’m very glad I took the risk.



The Advocacy Corner

All children have a right to a safe and enjoyable education. Bullying children with special educational needs and disabilities has to be the cruelest expression of cowardice. Singling out a child because they are different is unacceptable and terribly wrong. Yet 1 in 5 case affects a child with disabilities. Children with special educational needs are often more isolated and have difficulty understanding the social context of bullying.

Bullying of students with disabilities represents both a civil rights and public health challenge. Amongst the possible effects of bullying, the U. S. Department of Education (DOE, 2000) include lowering academic achievement and aspirations, increased anxiety, loss of self-esteem and confidence, depression and post traumatic stress, deterioration in physical health, self-harm and suicidal thinking, suicide, feelings of alienation, absenteeism, and other negative impacts, both educational and health related.

The DOE (2000) letter defines disability harassment as “intimidation or abusive behavior toward a student based on a disability that creates a hostile environment by interfering with or denying a student’s participation in or receipt of benefits, services, or opportunities in the institution’s program... When harassing conduct is sufficiently severe, persistent, or pervasive that it creates a hostile environment, it can violate a student’s rights under Section 504 and the Title II regulations... even if there are no tangible effects on the student. (DOE, 2000, p.3) The letter also notes that failure to address disability harassment may constitute a violation of the individuals with Disabilities Education Act’s

(IDEA) guarantee of a Free and Appropriate Public Education (FAPE) for students with disabilities, when harassment prevents or diminished the ability of a student to benefit from his or her education (DOE, 2000, p.4).

The U.K. website, www.parentlineplus.org.uk has an excellent guide to dealing with bullying for parents of disabled children. It contains information about spotting the signs of bullying, the action you take, your child’s rights, and stories and tips from other parents. It lists several ways to identify signs and symptoms of bullying:

- Becoming withdrawn
- Reluctant to go to school or to a youth club
- Change in mood, becoming depressed, angry, unhappy
- Bedwetting
- Showing aggression at home

They also list several ways to approach the school:

- Have a named person your child can tell about the bullying.
- Have a safe place your child can go to during breaks or lunchtimes.
- Provide training for school and local authority staff in special education
- Encourage communication between teaching staff and lunchtime supervisors so they’re aware of what could be happening in the playground and classrooms

For many more suggestions, visit the website noted above.

It Worked for Me ...

Shoe Tying Trick

To help my daughter learn to tie her shoes, I threaded a sneaker with two different colored laces. It was much easier for her to understand what was happening (and to do it herself) when practicing with contrasting laces.

Jessica James, Mullica Hill, New Jersey



Better Sensory Ball Pit

Instead of having a pricey ball pit, I made one for my son using an inexpensive inflatable kiddie pool and plastic balls that I found at the toy store. Ours is much bigger, which means all of the kids can play in it at the same time.

Denien Rasmussen, Palatine, Illinois

If you have a solution that worked for you and would like to share it, please send it to editor@prisms.org



SMS Superkid!



In September 2011, Frances, her sister, Olivia, and their dance school travelled from Cairns, Australia to the USA. They danced at Disneyland, California Land and Universal Studios.



Frances and the others had a fantastic time performing, and were very proud to represent their country overseas. The organiser at Universal Studios proclaimed that it was the best representation of a country they had witnessed to date.

It wasn't all hard work and dancing for Frances and her sister. They also enjoyed some sightseeing fun with their parents and grandparents. In San Francisco they toured around on a double-decker bus and visited Alcatraz. Frances and her grandmother were given a lift up the hill while the others had to walk at

Alcatraz. Frances sat right up in the front with the pilot of the helicopter when they flew into the Grand Canyon. It was a truly amazing experience that the family will always treasure. The holiday highlight for Frances was meeting her favourite characters at Disneyland. She had her photo taken with so many characters and also has many autographs! Special characters included Pluto, Goofy, Cinderella, Dora, Sponge Bob, Chip and Dale, and Mickey and Minnie Mouse.

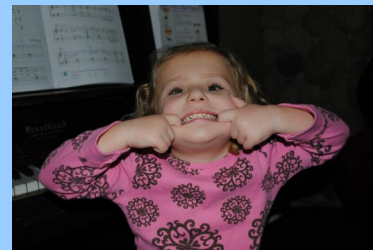


Frances started dancing just before she turned 5 years old. She describes her dance teacher, Miss Louise, as "one of the best teachers in the world." She had a fantastic time with her family and dance mates in the USA. She is already asking her family when they can go back to Disneyland.

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.

Sunny
Side

UP ↑



Julia Cooney is 13 and in the 6th grade. We are working on several bathroom/living skill issues with Julia.

One day, about a month ago, Julia was in our bathroom taking care of business. She yelled for her dad. He didn't answer. She yelled for me. I didn't answer. She yelled again for her dad. This time John said, "Julia, you need to wipe yourself. I am busy." So Julia yelled for me again. I said, "Julia, you need to wipe yourself. I am in the middle of something." This time.....silence.

I thought to myself, "Oh, thank goodness; it worked this time,"

only to look up from the kitchen table to see Julia standing there with her pants and underwear around her ankles wobbling towards me.

I said, "Julia,"

Julia interrupted me and said, "Really, mom, what does it take for a girl to get a wipe around here?"

Needless to say, she won again. This time I was laughing, trying to explain the lessons!!

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

Return Service Requested

The information contained herein reflects only the opinion of the authors or associates. Spectrum content is for informational purposes only. It is not intended to be used as a substitute for obtaining professional medical, health, therapeutic advice or treatment, or otherwise supplanting examination, diagnosis, and treatment by a qualified professional. This newsletter may contain links to websites that are created and maintained by other organizations. PRISMS does not necessarily endorse the views expressed on those websites, nor does it guarantee the accuracy or completeness of any information presented there. Spectrum is the official newsletter of PRISMS. Readers are free to duplicate all or part of its contents for your personal, non-commercial use with proper attribution to PRISMS. In accordance with accepted publication standards, PRISMS must be acknowledged in print of any article reproduced in another publication. Letters to the editor, comments on articles, and suggestions for future articles are always welcome.

Editor in Chief:


Steve Corbett editor@prisms.org

Editors:

Randy Beall Ann C.M. Smith, M.S., D.Sc. (hon)
Joe Haroldsen

Newsletter Committee Members:

Julia Hetherington Pat Boschetto



Join us on Facebook!
PRISMS Smith-Magenis



Our SMS SuperKid Frances and her sister, Olivia, in China Town - San Francisco.