

Finding and Hiring Helpful Support Staff

By John Mayer

Charley is a 25-year-old young man with SMS who is supported with a community-based program in his town of Portsmouth, NH. This article is written by his father and offers personal suggestions for ways to find staff able to work with an SMS adult.

When young adults with SMS age-out of the school system, their parents (or guardians) face new challenges created by a new and less-structured environment. Developing a plan for adult life, building a successful program of activities, finding supports, even securing social services, involve associations with many new people, agencies, and governmental systems.

Beginning a process early to address these issues, well before graduating, can be critical in forming alliances and in establishing a successful process for transition to adult and perhaps community life. Needless to say, there are many factors to be considered involving resources available, the family's capacity to support the program, and knowing what works with the SMS adult. Taken all together, the choices to be considered and decisions to be made can be overwhelming.

And for those who are looking to develop activities in the community, unless they intend to provide the needed support

themselves, hiring staff to deliver and manage the program will be critical for success.

What do you want?

As you begin this process of program planning, establishing a vision and focus for your efforts is critical.

Ask yourself and any other members of your support team questions like, "What is possible?" "What is the right thing to do?" "Is it sustainable?" "What happens when we are no longer able to help?" The answer to these and many other questions will lead you in the planning process. It truly is a process and should involve at least an annual review of the situation – so these questions will never go away.

As part of the process, being open to learning from others is healthy and important. Over the years, as we developed our plans for Charley, Debora and I participated in a leadership program sponsored by the New Hampshire Institute on Disabilities*, interacted with local family support groups, attended conferences and workshops, and talked with specialists, families and others. It seems unending – but more than anything, reaching for a possible future and being able to describe it is important.

INSIDE THIS ISSUE	
President's Message	2
Sibling Article	6
SuperKid Coulter	9
Summer Camp	10
Sunny Side Up	15

(* similar Institutes on Disability exist in every state. Contact the Association of University Centers on Disability at www.aucd.org)

Charley's program is designed to reach for the greatest access to our community and to work with the least amount of restriction. We have been influenced by the concepts of community care and self-determination. Our experience has shown that he enjoys and thrives in situations where there are natural supports, and he can be part of the decision making process.

Currently, Charley is supported in a "community-based" program. He spends his days doing a variety of jobs for local businesses, running errands and completing chores that address his residential or daily-life needs, and enjoying social and recreational activities. The intent is that his day is meaningful to him, provides ways to be involved and connected in his community, and establishes a structure for routine and behaviors necessary for independent life.

...Continued on page 3



Parents and Researchers Interested
in Smith-Magenis Syndrome

Officers

President: **Randy Beall**
Richardson, TX

Vice President: **Margaret Miller**
Herndon, VA

Secretary: **John Mayer**
Portsmouth, NH

Treasurer: **Jeri Gawlowski**
South Lyon, MI

Board Members

Julia Hetherington Beaufort, SC
Percy Huston Port Girardeau, MO
Mary Kate McCauley Ardmore, PA
Ann Smith Bethesda, MD

Professional Advisory Board

Kerry Boyd, M.D.
Bethesda Services, Ontario, Canada

Sarah Elsea, Ph.D.
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

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
NIH, National Human Genome
Research Institute

Beth Solomon, M.S.
W.G. Magnuson Clinical Center
National Institutes of Health

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



A Message from PRISMS President *Randy Beall*

Our PRISMS 2010 membership drive is now in full swing!

As most of you already know, PRISMS is an all volunteer organization, dedicated to providing information and support to people with SMS and their families. We do all that we can with the dollars available -- maintaining a "home office," a terrific website, providing support information via phone and email, putting on conferences and collaborating with our outstanding researchers. (Not to mention most of us have day jobs!) However, we need your dues and donations to keep providing these services. When you receive your 2010 membership form, please send it in with your dues and an extra donation if you can. Also, please take note of the list of people who have donated to PRISMS this year. We all owe our donors (and volunteers) a BIG thanks for helping us help SMS families!

One of the best privileges of membership is receiving this newsletter, SPECTRUM. Our editor, Julia Hetherington, and her very small committee of volunteers, consistently provides us with articles on the latest research and information available about SMS, as well as touching and funny personal stories. We often hear from newly diagnosed families who say that it helps them so much to read these stories, see the pictures, and realize they "aren't all alone...others have the same difficult/wild/hilarious/exciting/inspiring experiences that they have...and that there are other people all over the world who are awake during the night with their SMS child." If you would like to contribute to the newsletter, you can send your articles and "superkid" stories and pictures to Julia (editor@prisms.org) for publication consideration.

This issue of SPECTRUM has the same quality mix of articles: information you can use, as well as stories you can relate to. If you will indulge me this chance to be a "PROUD DAD"....I have a favorite article in this issue. Our youngest daughter, Jenny (a soon to be college grad), writes about her experience as a sibling of a child with SMS. Although we often wished for a perfect, uneventful childhood for her, we love the resilient adult that she has become. Our girls have not had "Disneyland childhoods," but they are both princesses to me!

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

Warm regards,

Randy Beall
 PRISMS, President and one "Proud Dad"
randy@prisms.org

There is no center or workshop or other space that serves as a starting or ending place. His home, the businesses where he works, and the places in the community he enjoys provide a “natural” structure for him.

He is aided by a “staff” person, otherwise known as a “direct support professional” or “teacher” - as Charley calls them. To avoid burn-out, we divide the week between two people – one works with Charley two days, the other, three days of the week.

More than any other team member, his day-staff are crucial parts of his program and are vital for meeting program goals and developing long-term plans for Charley. Unfortunately, keeping these staff people has been difficult. Finding good helpers is a continuing challenge.

Here are some of the factors that make the staffing process difficult:

1. SMS is a difficult condition to support. Like others with SMS, Charley can be impulsive and aggressive, and his emotional needs are variable.
2. Working in the community means there is no central office. Staff needs to be able to vent, to share and get help. Building redundancy or being available for back up is important but challenging.
3. Providing training and orientation for new helpers takes a very long time. Keys to success includes orientation to SMS, behavior management and disability issues, as well as building a relationship with the person they will be supporting.
4. Finding candidates who are caring, interested in teamwork and respectful is rare. Yet these qualities are critical and make for the best helpers.

Compensation. It is important to pay people well. We pay nearly twice the starting hourly rate offered to workers by local agencies.

Program Management. There are many models and strategies for care – the design and choices made will reflect the interest and capacity of parents or providers, and also may reflect the unique resources available in your community.

To support Charley, we have tried two different systems: 1) contracting with a “vendor agency” that hires, trains and supervises staff, and 2) managing the program as a family and making those hiring decisions ourselves.

The vendor agency model is appealing largely because there is a management structure in place to handle much of the hiring process (at least that is the concept). Often an agency will provide back-up support and perhaps even “seamless” coverage. But there is a cost to this – generally a range of expenses involving management, training and overhead which take away from the resources that could be used for programming.

In our experience, this ideal, where hiring and backup coverage is effectively provided, rarely has been achieved. Instead, we have waited months for replacement staff, been presented with unqualified and uninterested options, experience frequent turn-over, and been expected to provide the necessary orientation for new staff.

The bottom line has always been that stability and consistency is important. Change and turmoil is hard for Charley, and the associated chaos carries over into the home environment.

For many of these reasons, we are currently working with a family-managed approach. The greatest downside to this scenario is that the responsibilities for all aspects of the program rest with the family. Not everyone is in a position to consider this type of program – the demands are significant. In our case, only one parent can work full-time. (The



associated pressures with this can be the subject of another essay.) But the reality has been that many of the duties have always rested with us anyway.

Finding Help. When seeking staff, we have increasingly relied on Craigslist for posting notices. There are few other alternatives – newspaper classified ads are virtually obsolete. We also try to tap into our network of community resources and broadcasting our need through word of mouth. But more than any other resource, Craigslist has become a vital tool to post our announcements.

Before posting, it is important to be prepared for the responses in a couple of ways – have information ready to share about the position, including a job description and overview of the program. Also, be ready to manage the replies by keeping a log and a file with the e-mails and supporting information received from each applicant.

Standards for managing these inquiries are really different than traditional job applications. In this new “on-line” environment people do not follow through, they don’t show up for meetings, they fail to formally withdraw, and you are exposed to all kinds of inquiries, some not legitimate. Use caution for spam and viruses.

Compared to job searches of even ten years ago, there truly is a different standard for communicating. We try very hard to keep people informed and to be considerate and polite with our communications. This means extra work in keeping track of the status of the

various applications. Unfortunately, more work is the last thing you need. But setting a standard of caring is appropriate and carries over in the way people work with you.

Interviews and Match-Making. When reviewing applications it is important to have a clear idea about the skills and qualifications you are seeking. An open-minded approach is good – you never know what will come your way – but you should have a firm idea of what qualities would make an ideal helper.

Finding a good match for Charley has never been easy. It is difficult to find people who accept the possibility of being hit. They also need to be able to see the benefit and importance of community involvement, they need to transcend his intense emotional moments with flexibility and humor, and they need to be caring and committed.

Once an application has been received, we review the applications and rank them in terms of appropriateness – good, possible, or not qualified. Any candidates who are not qualified are sent a note thanking them for their interest. Those candidates who are “possible” are placed in a holding pool. The “good” candidates are called on the phone.

For phone and in-person interviews, a standard list of questions further distinguish candidates and ensure important points have been covered. We ask questions like, “What are your experiences with disabilities?” “Why are you interested in this position?” “Have you worked in community settings?” “What are your greatest strengths and weaknesses?”

If the phone interview is positive, a direct interview is the next step and if others are involved in the program, they too should be part of the in-person meeting. These meetings often involve a repeat discussion of your standard questions as well as the job description and program goals. But most importantly, they provide

a time to interact with the candidate and to learn more about his/her personality.

And if all this seems to be going well, another meeting is set up so they can meet with Charley. Ultimately, his relationship with the helper is vital. A good relationship comes from mutual trust, respect and sincere enjoyment between one another. When this is in place the program works successfully and there can be stability and growth.

Including Charley in the interview can be very interesting – often we use the card game, UNO, as a way to create a social opportunity. And Charley will understand we are looking for someone to help him – so he can ask a few questions as well.

As a final step in the process, we set up times for candidates to shadow during the day so they can see the type of situation we have developed. This provides a chance to observe a potential staff person in on-the-job situations.



Closing the Deal. If all of these steps have worked well and a decision to hire a candidate has been made, there is a final step in the selection process that includes a check of references and a background search. Our area agency will help with the background search that includes a check of driving and criminal record. Phone calls to references also involve a standard set of questions to ensure a complete and consistent understanding is developed.

Hopefully, these final steps will yield positive results, and you can move

forward with hiring a great helper for your program.

Then the work begins to provide orientation, one-on-one training and creating opportunities to build a relationship with Charley. All of this will take time. The goal is to establish a successful routine and then fade from the daily program. Best not to rush any of this – ultimately, you want there to be a good and healthy relationship for the program to build upon and to last a long time.

Summary Thoughts

For families with a young adult with SMS and who are looking to develop a community-based program, finding help is a critical need. If they are taking on these duties themselves, the responsibility can be overwhelming. Developing a thoughtful structure and establishing a plan to find staff will greatly assist in these efforts.

Our greatest dream is to have access to a pool of many qualified and capable helpers. But this is never the case. That said, with a deliberate and thorough process, we have been fortunate in finding dedicated and thoughtful helpers who have been involved in Charley's life.

Take courage and be positive. It can be done and it is possible to develop a meaningful and successful program that will provide support and growth.❁

Volunteers Needed

WANTED – A few interested **Volunteers**. Could it be YOU?!

PRISMS is currently seeking a Treasurer to join the Board of Directors.

This person would be responsible for managing the accounts of PRISMS, keeping financial records in order, and presenting financial reports at the Board's monthly meeting. He or she would be involved in the decision-making processes of the board, and may participate in other committees and initiatives, if desired. Candidates should have knowledge of accounting practices, preferably as they regard non-profit organizations, but do not need to have experience as a Treasurer. The ideal candidate would be a PA or CPA, perhaps a CFO with another business or organization.

Perhaps you aren't sure about joining the Board but you have some time, interest and skills and want to help the organization. Volunteers are needed to manage the PRISMS website, assist with Membership Committee, and to join our committee for the 2012 conference in Denver. Writing opportunities are also available on the Newsletter Committee.

These opportunities are part of a 2010 initiative to improve the organization by including new people and expanding our capacity to support our membership.

All Board of Directors positions, including officers such as the Treasurer, are voluntary and without compensation. Typically, one serves on our Board because they are committed to supporting people with Smith-Magenis Syndrome, want to help families, or are interested in improving the programs and effectiveness of PRISMS. It's a great opportunity to learn something new and to be part of this important and dynamic organization.

Interested? Let us know today! For more information, to suggest a potential candidate, or to apply – please contact Randy Beall, President of PRISMS at randy@prisms.org

Cute Pictures Needed!

Our annual report is almost ready to go out and we need a few good pictures of our SMS stars. If you have one of your child that you would like to share, please consider sending it to us! It can be emailed to:

editor@prisms.org

Many Thanks!!



Look for 2010 Membership Renewal information in your mailbox soon!

Please renew! Membership support is the foundation for our operations and we need you, your friends and family to be part of the organization now more than ever. Thank you!



Make sure we have your correct Email address. If you have not received an "eblast" lately, then we probably have an incorrect address!

On Being “The Normal One”

By Jenny Beall



My name is Jenny Beall. I am the daughter of Mary and Randy Beall, but most of all I am the sister of Laura, who has SMS. My whole life I've been labeled as Jenny, Laura's sister, as if the two words are eternally attached. My experience as a sibling is unique to most people, but to our SMS family it is all too familiar. My hope is that each of you can empathize, gain insight, hope and most of all laugh at my experiences with SMS.

For those of you who don't know, I spoke at the 2009 PRISMS conference during the Sibling Workshop with Dr. Wanda VanSyke. During our session, we covered many of the emotions that siblings feel, both positive and negative. I understand that a dilemma faced by parents of both an SMS child and a 'normal' child is that the 'normal' child does not express his or her emotions quite as boldly as the SMS child, making it hard to understand what he or she is feeling. In my 22 years as a sibling, I think I've experienced every possible emotion, from anger and grief to times of laughter and happiness.

From as early as I can remember, Laura has made herself the center of attention. It does not matter if we are at home, at church, at the grocery store, or even at the PRISMS conference, Laura finds a

way to make herself noticed. Growing up, I began to resent my sister for always drawing attention to our family. Not because I personally wanted the attention, I was never the attention-seeking type, but because sometimes I simply wanted to blend in.

I remember one time specifically - I was in 4th grade and my elementary school was having a Halloween carnival. I had been looking forward to the Halloween carnival all year and could not wait until I got to go. My family was invited too, which meant (unfortunately for me) Laura was coming. Before we left my mom gave Laura this whole talk about how this was my event and how she was not going to make a scene (but if you ask me, I think that just spurs her on). Things were going somewhat ok; I mean, she was still loud and cutting everyone in line but no big fits or anything, until I heard her unmistakable screaming from across the way. Turns out, somewhere in the midst of the carnival Laura had lost her hearing aid. To make a long story short, the entire school spent the rest of the carnival searching everywhere for my sister's hearing aid. Talk about not blending in.

Then there was the time when I was in 7th grade and Laura and I were at the same junior high. She had this horrible teacher and one time when she'd run out of options for how to control Laura, her teacher came to get me out of my 7th grade Biology class. To make matters worse, when she came to get me she announced to my entire class that my sister was out of control and that she needed my help to contain her. Ouch.

Finally, there was the time when I was a freshman in college moving into the dorms. My family was there to help me move in, as were the other 600 girls' parents. There were people everywhere

moving in boxes, carpets, dressers, etc., which is always the type of scenario where I'd like to be embarrassed the least, and Laura tends to embarrass me the most. My Dad and I were sitting in my room with my roommate and her family, whom we have just met, and as if on cue, we hear screaming and stomping from down the hall. I dragged myself to the door to see what was going on and sure enough my sister was mad about not getting her soda, or whatever it is she gets mad about, and throwing everything that she could find down the hall at my mom. I cannot even begin to describe the looks people gave us, or the countless explanations I had to make throughout the following year.

Although I never wanted the kind of attention that she got, I couldn't help but feel like everything was all about her. Even now, when I come home from school for breaks, I can hardly have a conversation with my parents without Laura feeling so attention deprived that she throws a fit. Through the years, I often felt a deep loneliness because I didn't think anyone would ever understand. Many of my friends have experienced traumatic events in their lives and I am lucky to have people in my life who try to be empathetic, but it is an entirely different experience to grieve over something that you're born into. Don't get me wrong, I love my sister, but I've gone through many periods in my life where I have needed to grieve over not having what I considered a "normal" home life. Whether it was not having siblings that I could play with, or my parents not being able to attend certain events with me, or one of the aforementioned episodes, I had to come to terms with the fact that my life is not like everyone else's, as I think we all have.

Yet, despite all of the hard times, I know without a doubt that I would not be the

person that I am today if I did not have Laura for a sister. My mom always tells me that all of these hard things are “developing my character,” until one day I told her, “Enough already! I don’t want any more character!” But seriously, having someone with SMS in our families gives us resilience unlike any other. I learned at a very early age what really matters in life, and how to not let a little bit of wind blow me over. But what I think I’ve learned the most, is how to laugh. My family can testify that more than anything else, even at inopportune times, Laura makes me laugh. Just last night my family attended the wedding of an old friend of mine and as we walked into the reception, with Laura just a couple of steps in front of us, she lifted up her dress that my mom had carefully picked out, stuck her hand down the back of her hose, and started scratching an itch that apparently could not wait until she got into the restroom. Instead of being embarrassed, all I could do was laugh out loud.

Laura is so famous for her embarrassing yet funny moments that my friends have coined them “Laura stories,” and I am encouraged to tell them at any occasion where people need a good laugh. Whether it’s Laura being scantily dressed in front of my boyfriend, stealing food from Kroger because she thought it was free, flopping through a fancy restaurant in scuba gear, learning foul language, or any of the other ridiculous, impulsive things that she does, it never fails to give me and those around me a good laugh, as well as remind me of why I love my sister.

I know that being a parent to any child isn’t easy, but parenting a child with SMS is 10 times harder (or maybe I should say 100!). Then, when you have a ‘normal’ child on top of that, I’m sure it sometimes seems impossible to balance. My parents worked so hard at being good parents to both Laura and myself. I always struggled between being frustrated at the things they weren’t able to do for me, and empathizing with them because I knew parenting Laura was so hard and that they were doing the best they could. There

were many things that my parents did right when it came to parenting both my sister and me. First of all, I was always thankful that they were so open. They never tried to pretend like they had it all together, or that I shouldn’t feel anything that I was feeling. I remember specific times when Laura was being really difficult and my Mom would turn to me and say, “This is hard, isn’t it?” Knowing that a) my parents thought this was hard too and b) I was allowed to feel however I wanted to feel, made the situation so much better because I didn’t feel guilty about my feelings. Furthermore, by my parents labeling my emotions it helped me to understand how I was feeling and it let me know they wanted me to communicate with them.

They also never made me be Laura’s third parent. Yes, there were times when I was sent to retrieve her, such as at church and school, and yes, sometimes I took it upon myself to try and make her behave, but my parents never put me in that role. They never required me to physically take care of her and they never expected me to try to control her, which freed me up to just be her sister. There were many times where Laura and I were able to play together like any sisters would, and there were times where we fought just like sisters would. I remember one time specifically that actually happened just last year. We were having Christmas at my cousin’s house in Austin and it was time for my family to leave. We were packing up the car and Laura, trying to be helpful, gathered all of my things in her hands, but of course tried to gather too much at once. On the way out the door, my purse opened and my new Blackberry fell out onto the cement. I immediately screamed and ran to my phone but it wouldn’t turn on and I knew that it was broken. We got in the car and started heading home, but I was so angry that an hour later I still wouldn’t speak to her. When we stopped to eat dinner my mom leaned over to me and said, “You know she can’t help it,” and I said, “I know. But she’s also my sister and right now I just want to be mad at my sister.” And my

mom said, “Of course, and that’s ok.” This is a perfect example of how my parents never expected me to be anything other than Laura’s sister.

Another thing I appreciated about them was how they allowed me to be independent. They always did the best they could to let me have a life outside of being Laura’s sister. Growing up I was a gymnast, played sports, danced, was in the choir - all things that gave me an identity of my own. My parents weren’t always able to attend my performances, or sometimes Laura came and was very loud, but my parents never made me feel guilty for being able to do things that Laura couldn’t. This was important because it gave me areas of my life where I could simply be ‘normal’ and blend in, and it also gave me confidence in myself and my abilities. Finally, my parents tried hard to spend separate time with me when they could. Usually it was only one of them at a time, but a special dinner with Dad or a shopping trip with Mom made all the difference in the world because it reminded me that they did see and care about my individual needs.

As wonderful as my parents are, there are some things I wish had been different that can hopefully help all of you be better parents to your children. At the PRISMS conference, I received a lot of questions about how I felt about having two sets of rules. I’m not going to lie, sometimes it was really frustrating. Especially when I was younger, I hated how I could get in trouble for something but if Laura did it she would just get a warning, or they wouldn’t even notice, because there were such bigger issues with her. The best advice I can give is to have as many rules as possible apply to all children, and for the few that don’t, communicate with your children and explain why. I always felt better when at least my parents acknowledged the double standard. However, as great as communication is, parents also need to be aware that children don’t always want to communicate. When I was a teenager, my parents constantly wanted me to talk

about how I was feeling but they couldn't seem to get me to open up. I know that it worried them, as I'm sure it worries many of you with teenagers, but sometimes I just wanted to blend. I realized that my experience was different than most of my friends, but I just didn't want to talk about how I was different all the time because to me, that just made it worse. Sometimes I just wanted to be a normal teenager, even when things were hard.

My life has been one big rollercoaster, but I wouldn't trade it for anything. Yes, there have been hard times, and yes, I sometimes still struggle with having a family that is different, but overall I am a

happy, well-adjusted 22-year-old with a sister I adore more than anything. I will graduate from Baylor University this coming May and I plan on attending graduate school for Professional Counseling in the fall so that I can help people just like you and me. So in conclusion, in the words of Laura when she quotes her favorite cartoon, "That's All Folks!" ❀

A Special Way to Honor a Loved One

by Randy Beall

My dad, William Beall, had 7 grandchildren that called him "Big Pa." And he had a special relationship with Laura, his granddaughter with SMS. In lieu of flowers, when dad passed away a few years ago, we put some language in his obituary that honored his memory and helped families that have children with SMS. Here's what we wrote:

If desired, a donation in memory of (name of deceased) may be made to P.R.I.S.M.S. to support families with Smith-Magenis Syndrome in honor of (name of individual with SMS). Memorials may be mailed to PRISMS, 21800 Town Center Plaza, Ste. 266A-633, Sterling, VA 20164. PRISMS is a 501c3 nonprofit organization. All memorial gifts are tax-deductible.



Coulter Daniel



Our son, Coulter, began Therapeutic Riding at Mane Gait in September 2008. The focus of the lessons is skill development and progression while improving the rider's physical, cognitive, emotional and/or social skills. At that time, Coulter was almost two and still not walking, so we felt it would be a good addition to our regular physical therapy sessions and hoped he would share his mom's love for horses.

Coulter did well and was always happy to begin his sessions, but he was completely exhausted by the end. During this time he started walking and showing more independence, so we continued the sessions in the spring and then decided to sign him up for his first horse show in May. All participants competed in a Western Pleasure class and a Trail Riding class.

The classes were scored on rider posture and attention to the horse. Coulter was the youngest participant and rode with two side

walkers and a leader. Instead of holding the reins and paying attention to the horse, Coulter smiled and waved at the crowd on each pass in true SMS fashion.

We were worried he wouldn't be able to endure the entire length of the show since his sessions were usually only 45 minutes and the show would be over 2 hours. Instead, he was the one who kept his team entertained during breaks by doing the motions to the Itsy Bitsy Spider, dancing to the music that was being played and giving high fives. Despite getting fifth and sixth place in his division, he looked so cute and enjoyed getting so much attention!

Coulter is our SuperKid!
Dwanda and Brandon Daniel

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.

Summer Camp for Your SMS Child

By Leah Baigell

Summer camp is a place to have fun. It's a place to have great experiences, meet new people and take a break from everyday life. When you have a special needs child, you have to carefully select where to send your child so as to maximize his or her experience, and you want to make sure the experience is as positive as can be. There are questions to ask yourself and camp staff as you make summer plans for your child. Sometimes your town has summer programming to offer that might be just right. In addition, there is always the question of how to fund summer programming. The bottom line is that you want your child to have an amazing experience, and you want to minimize the chance that you are going to get that phone call we've all gotten . . . "please come pick up your son/daughter . . . NOW." How do you set about doing this?

When thinking about summer camps for your SMSer, there are so many things you have to consider. Before hitting the road to look at camps, ask yourself the following questions: are you looking for day or overnight camp; mainstream (with inclusion) or strictly special needs camp; educational, recreational, or a combo camp. Think about location – is it far from home? In the case of a day camp, how much traveling is required each day? If overnight, is it too far for the emergency visit you might have to make? Think about the size of the camp, if it is co-ed, who is the staff comprised of – teens or adults, are they trained to work with special needs kids? Does your child have a medical need? If so, are there trained personnel to deal with daily and emergency medical needs? How do they handle a child who is raging out of control? What is their restraint policy? Are the providers trained in proper restraint procedures?

It is helpful if you can see the camp in operation prior to sending your child there. That is not easy to do. It means thinking about camp well in advance. Maybe this is the summer you can explore some options in order to plan for next summer. It is helpful to see how counselors work with kids, and it is nice to see how your child might fit in. It is immensely helpful to get a sense of the physical layout to see if it can work for your child. In lieu of visiting a camp, you can explore websites, and you can ask the camp for a list of local families you can contact who have attended their camp. Do not forget the importance of talking to friends who have sent their children to camps – they can offer a wealth of information.

One place to start is your town. Does your district offer a summer program? According to the Individuals with Disabilities Education Act (IDEA), each state is required to provide a Free and Appropriate Public Education (FAPE). This can carry over to the summer if it can be demonstrated that without support there will be regression. In order for your district to support summer services, it has to be written into the Individualized Education Plan (IEP). The IEP must specify the need for extended school year services (ESY). Some districts have their own summer programs, others might be connected to private programs, and of course, many districts offer nothing.

Maybe you can piecemeal a summer together. Think about the activities your child loves to do. Does your local Special Olympics offer a program? Is there a week long art camp? Drama camp? Sports camp? Are there adaptive sports programs? Are there special educational programs that run weekly sessions? Is there a children's museum, aquarium or science museum in your area that might



have summer programs? Does your local recreation center offer something? Could your child attend any of these alone, with an aide, a friend, a sibling? Does your local Parent Advisory Council (PAC) offer a list of summer camps and programs? Usually around January/February there are camp expos that have information on all kinds of camps.

Communication is probably the most important advantage you can give your child to ensure a successful experience. If you are looking at a public camp (not school run where they likely know your child), it is very important to be forthcoming about your child's syndrome, and what support they will need. Little anecdote: One summer I signed my son, Zach, up for an inclusion summer day camp not far from home. He was familiar with it as his older brother had been a CIT there the previous summer. I had many conversations with the owners prior to signing up, describing all the parts that made up my child. The camp was willing to set things up so that Zach could attend camp. I signed him up and paid the non-refundable fee in full. That spring, Zach had a major meltdown, the likes of which precluded him from being involved with any summer activity. I called the camp to let them know what happened, and that we were going to have to withdraw. Because I had honest up-front conversations with camp staff prior to

signing up, I was able to get a full refund. They told me had I not explained my child, they would not have given me a refunded thinking I just found a better alternative and was bailing on them. That said, if Zach had been able to attend camp that summer, I have no doubt that he would have had an amazing experience. The staff knew all about him and what to expect. They were willing to hear what I had to say about my child, and in turn, they could be honest about whether or not they could handle him. It's all about being open and honest.

One thing I find helpful is to provide a one page (no longer) cheat sheet about my child. This gives providers, who likely will not read an entire IEP, some quick important information about my child. Included might be things like a definition of SMS, things your child loves to do, things likely to cause an outburst, what can help when there is an outburst,

emergency phone contacts, anything you think is important for providers to know in a nutshell.

How are you going to pay for all of this? All too often we empty our bank accounts providing for our special needs children, especially with all the therapies, tutoring, doctors, medications and supplies they need. Often we have to just pony up. You can look for scholarship money to help with summer camp. If your child's IEP indicates the need for extended year schooling (schooling can be loosely defined as academic, social, recreational), then you can petition your district to cover the cost of an outside camp for the amount they would have to spend on an inside program (or go for the whole thing – can't hurt to try!). Some other places to look for additional funding might be your local chamber of commerce, fraternal organizations and other charitable organizations.

Summer camp is a place to have fun and create wonderful lifelong memories. Help your child do that by doing your research, being honest and communicating with anyone who might potentially provide service for them. Our children are the most wonderful and the most difficult to work with. Their unpredictability makes them challenging, their wonderful love and concern for everyone makes them the best. If we do our job well, then we have the best chance for a successful summer. Good luck!❖



A Letter to the Camp

By Mary Beall

Sample Letter I Give to Camp Counselors and Caregivers
(Feel free to use it to write one to fit your child's needs)

Notes on helping Laura Beall control her behavior:

Laura has a syndrome called Smith-Magenis Syndrome. It is rare, and you have probably never met someone who has it. She is extremely personable, cute and outgoing. She can do a lot for herself and is pretty easy to care for until she gets frustrated or loses her temper. She is a helpful, loving, sweet child, and most people who know her love her. But...

Behavior problems are a hallmark of Smith-Magenis Syndrome. Laura has to work very hard to control her outbursts, hyperactivity, mood changes, etc. You probably will see things she does that make you wonder why none of us ever worked on it....that's a common response the families of these children get. Most likely we/the school/the therapists/the doctors have worked on it a lot, and Laura is doing the best she can. Her IQ, her general knowledge and her sweet demeanor are very much more developed than her emotional self-control. This is not her fault, it is a trait she shares with everyone with her syndrome. So here are some suggestions on the best way to help her control her behavior

Best Approach to Discipline Issues (like if she is refusing to do what you ask):

Try to keep your voice neutral. Harsh tones and force can escalate a situation with Laura. She gets most angry when anyone tries to be really strict and authoritative with her. When possible, wait a minute and let her decide to cooperate, she loves to please others. An example would be, you say " we're going to the playroom" and she says "no!" You wait a few seconds and then start walking without saying anything, assuming she will comply.

A little freedom (or perceived freedom) is very important to her. It seems to help her to have control of things...maybe where to sit in a group, or whether or not she needs a jacket, or whether she wants to participate in something or just watch. She acts offended if

she is micro-managed. Exaggerated praise works wonders with her. You sometimes can change her bad mood by telling her excitedly what you do like that she is doing.

Acknowledge/accept her fears and anxieties and give her a way to cope - even if it means she skips an activity or just watches.

If she needs to be given a consequence for something, make it pretty low-key and try not to show a forceful attitude. Say something like, "Ok, why don't you sit out for awhile," but make it short.

If possible, find a way to give her a "choice". (eg., "Ok, I know you don't want to go now, but I have a problem. I can't leave the other kids, and they want to go....so can you think of a compromise? Could you come and help me watch them?"). You may have to get creative.

If you can tell she is beginning to be upset, try to distract her...that is successful most of the time.

She may be more moody in the afternoon, because her sleep disorder affects her most then.

Self-abuse

She is very anxious on the inside and will often show it on the outside by biting her palm and/or hitting herself. It won't last, and she seems to need to do it. She even sometimes does it when she is very happy about something. Just let it happen. Don't worry about trying to stop her, she'll stop quickly, and doesn't usually hurt herself badly (she may need a Band-Aid). It's not helpful to interfere or to try to make her stop or even to talk to her about what she's doing. It's best to either say/do nothing, and just wait quietly by, or to comment on the situation she is facing, "You seem kind of worried about the slide. Is that right?" It's fine to try to distract her by changing the subject or giving her a job to do or something if she just seems anxious but isn't acting out.

She carries a small teddy bear in her purse; it is very soothing for her to touch it, and it calms her when she starts to feel anxious.

If Laura becomes very upset and starts a tantrum: (this is rare)

Although these tantrums appear to be "spoiled brat behavior," they are actually caused by this genetic syndrome. Typical discipline techniques (punishment/reward) don't help them through these "fits" because they lose control of themselves and actually CAN'T get themselves to stop. Parents and teachers have to work together to come up with a way to help her get control again.

During a tantrum she will seem quite defiant. It will remind you of a fierce two-year-old with no control over herself. She may threaten you and/or throw some things, but she has no history of hurting other kids, or even adults, unless they are trying to hold her down (generally makes her worse). Your goal should be to keep the environment and yourself calm enough that she can calm herself down.

Don't get into a power struggle with her, she gets wrapped up in it and then can't get herself out. A good analogy would be that of a cornered animal; they aren't reasonable and logical, they just become panicked and reactionary. Stay calm and quiet. Waiting and not reacting at first usually works great. Give her some physical space. Ignore what she is saying; think of it as garbage that really means, "I'm frustrated and scared". You can try talking to someone else in the room about something that might interest her, but don't say it to her - sometimes she gets busy listening to your conversation and forgets she is angry. She may seem really mad and defiant, and even may be threatening you verbally, but if you give her time to get back control of herself she will be ok and remorseful. If you need to tell her something after she is already in a meltdown, write a note; often that gets less problem reaction than saying something. Sometimes she will need some time alone with her bear, or a chance to nap.

Special note to caregivers: having a tantrum does not mean she doesn't like you or that you did something wrong...it usually means that she feels overwhelmed in some way and can't contain herself.

Getting Laura involved if she doesn't want to be:

Ask her to help you with something. She will gladly run any errand or do whatever, she loves that. She also loves having a "buddy" with her. She's bribe-able, particularly with soda. Best to reserve this for emergency use.

Fears:

Loud noises like fireworks

Balloons popping

Having her picture taken (this is getting a little better, but if she refuses and starts to act agitated, it's best to give up or she will get really upset)

Surprises, or the kind of excitement that typical kids like...crazy loud skits, wild costumes...

Favorites/Interests:

Her bear, board games like Monopoly and checkers, card games, math activities, music, U.S. geography (where each state is), license plates, Dallas Cowboys (especially Troy Aikman #8, and Tony Romo #9)

Strengths:

Her endearing, bubbly, personality

Her reading skills

Her observational skills—she learns very complicated skills by watching, and she will know what everyone has on, and if you have lost something, ask her, she may have seen it

Willing and able to help others

Sleep problems:

All kids with Smith-Magenis Syndrome have a major sleep disorder. Their natural body clock tells them to be awake at night and asleep during the day. (It's a melatonin thing). Laura takes a medication at night to sleep, and it is usually very effective for her, but it wouldn't be unusual for her to wake up in the wee hours.

Soda obsession:

She is crazy about soda. Tell her ahead of time how many and when she can have them. Of course, we would like her to drink diet soda, but don't let that cause problems for you. You can use this obsession for a bribe if you are having a behavior problem.

Summary

*Keep yourself calm, non-reactive and positive with her.

*If she starts to get agitated, it's best to stay quiet yourself and wait a minute for her to calm down.

*Acknowledge/accept her fears and anxieties and give her a way to cope, even if it means she skips an activity or just watches.

*Accept that she is trying hard, and try to stay on her side.

*Give her freedom and choice when you can. Don't micro-manage her because it will add to her frustration. Remember that she is a young adult. ❀

Golf Fundraiser in Ohio

We are so excited. It is almost time for another golf outing. We are busy making plans, big and small. The fundraiser will be on Saturday, June 19th at Emerald Woods Golf Course in Columbia Station, Ohio. Tee time is at 10:00 a.m. We are hoping to have enough people for a shot gun start this year. Silent Auction and Dinner activities begin at 2 p.m. Kelly Cooney has graciously accepted the challenge with us of taking on a silent auction. We are hoping that this will make our event an even bigger success. To RSVP and for ticket information you can contact Faith and John Stepic at (440)554-4257 or e-mail us at faithann1000@verizon.net. We are anticipating having a good outcome this year. The number of people attending will decide where at Emerald Woods our event will be held, so please sign up before June 8th so we can plan our event accordingly. We would truly be grateful for any auction items donated. They can be mailed directly to us at 3992 Ganyard Ave, Brunswick, Ohio 44212. Hope to see you there.



Parent to Parent

Did you know that PRISMS sponsors a parent-to-parent program? If you need someone to talk to who REALLY UNDERSTANDS what your life is like, try another SMS parent. You may want to find another parent in your area, or perhaps one who has a child the same age as yours. Tell us what you need. PRISMS keeps a list of parents willing to be contacted. We'll send you addresses and phone numbers and then you can talk all you want.

Contact:

Mary Beall
Phone: 972-231-0035
mary.beall@tx.rr.com

Important note:

PRISMS parent-to-parent program will only give out information on parents who have agreed to be contacted. If you would like to be added to the list of contact parents, please email Mary at the above address.

Special Note to Membership

Dear Membership,

It has come to the Board of Director's attention that much of our data has not been processed over the previous 3 months. This would mean many of you have not received proper thank you notes or other mailings. We are working hard to correct this error. Please do not hesitate to contact us if you have concerns. Thank you for all your wonderful support!

Sincerely,
PRISMS Board

Correction

The last issue of Spectrum was wrongly listed as Fall 2009, Volume 13, Issue 4. Correct labeling would be Winter 2010, Volume 14, Issue 1.

What is Smith Magenis Syndrome?



Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980's by Ann 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.

Sunny Side Up

One time in sixth grade, I had to check Rachel out of school for an orthodontist appointment. Rachel must have been pretty excited that I was coming. When I was signing her out, her teacher told me how cute she was while she was waiting for me to come. She was whispering in confidence to her Coke while smiling from ear to ear, “Shhhhhh, Coke, my mommy’s coming.”

She’s had a few really funny, although unintentional, one liners:

We were over at a friend’s house when the phone rang. The Caller ID read *Out of Area*. Rachel piped up and said, “Hey! They call my house, too.”

Rachel constantly asks how to spell things that she is looking up on Google. She rarely thinks before she speaks and often asks us how to spell words that she already knows. But the best one so far was when she asked us how to spell S.P.C.A.

Our most recent endearing moment happened when I hosted a baby shower for a friend’s baby at my house. My husband was upstairs with our dogs trying to remain scarce. I was planning to include him in anything that was being served. We were having mimosas and hors d’oeuvres at the beginning of the party and cake and punch at the end. My youngest daughter, Olivia, took him a plate of food. Later, Rachel took him some cake and some punch. Since I had forgotten to bring Mark a mimosa, he asked Rachel what the drink was. She told him it was punch. He explained that he thought someone was supposed to bring him a mimosa. To that Rachel replied, “No Daddy, those are just for the adults.”

Submitted by Jessica Kirklin



Note from the Editor

SPECTRUM is pleased to announce the initiation of the “Sunny Side Up” column. This 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.

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

Return Service Requested

Spectrum is the official newsletter of PRISMS. Readers are free to duplicate all or part of its contents. In accordance with accepted publication standards, we request acknowledgment 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:

Julia Hetherington editor@prisms.org

Editors:

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

Newsletter Committee Members:

Margaret Miller Tina Thomen
Jessica Kirklín Pat Boschetto

SMS SuperKid!

