

The Bond Between Arkansas State Quarterback, Ryan Aplin, and His Younger Sister, Carlye

By Aaron Torres

Reprint of an article written on June 26, 2012 on the blog
“Crystal Ball Run”

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Entering the 2012 season, excitement is at an all-time high around the Arkansas State football program. Arkansas native, Gus Malzahn, has taken over as head coach. The team returns 12 starters off a team that won 10 games and a Sun Belt title last year. And most importantly three-year starter, Ryan Aplin, returns at quarterback, where the reigning conference Player of the Year already owns 16 school records, and is projected by some as a late round pick in the 2013 NFL Draft.

Yet, despite the numbers that Ryan has put up on the field, it’s actually another Aplin, Ryan’s sister Carlye, who might be more popular on the Arkansas State campus. The 15-year-old, who suffers from a rare disorder known as Smith-Magenis Syndrome, is at most home games and has become the unofficial “Team Sister” of many Red Wolves players.

According to Ryan, his mother knew something was wrong right away, with both parents spending long hours at the hospital immediately after her birth.

“Being a little kid, you just remember mom picking
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Advocacy Corner

By Mary Kate McCauley

On August 2, 2011, President Obama signed into law the Budget Control Act of 2011 (BCA), increasing our nation's debt limit and imposing a series of measures to limit spending and decreasing the nations debt.

The BCA calls for \$900 million in cuts to discretionary programs including education over the next decade. It also charged a Joint Select Committee with finding \$1.2 trillion more in cuts over the next decade. The Super committee failed and now sequestration and across the board cuts.

The Congressional Budget Office estimated that sequestration will mean a cut of approximately \$3.5 billion. The cut will be felt by every school in the nation and will impact education's ability to appropriately serve children and youth with disabilities. Other cuts have made it impossible to not reduce essential services.

The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving the educational success of individuals with disabilities and/or gifts and talents. CEC advocates for appropriate governmental policies, sets professional standards, and provides professional development and advocates for individuals with exceptionalities. They also help professionals obtain conditions and resources necessary for effective professional practice. The CEC is recognized as a leader in advocacy for special education.

Special Education Directors fear potential budget cuts, and the CEC, it's special interests division, the Council for Administrators of Special Education, has released a joint survey demonstrating that the pending sequestration, and across the board budget cut of 8% will further weaken districts' ability to serve students with exceptionalities at the local level.

If cuts go through as expected, the vast majority of special education administrators surveyed indicate that caseloads would increase further, funding for technology and other resources would decline and there would be greater strain on the availability of services for students. The impact on students would be dramatic because it would almost certainly lead to job cuts and fewer personnel in the classroom.

Want to help? Tell Congress that education matters. Avoid a sequester by passing a balanced deficit reduction measure. Send a letter to CEC's Legislative Action Center @<http://capwiz.com/cec/home> and get involved. Our children deserve all the help they can get.



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PRISMS/Smith-Magenis



A Message from PRISMS President

Randy Beall

Over 337 people attended our 7th International Conference this year – a record!! There was great information at the conference covering health, education, therapy, diet, and behavior. But many parents said that the very best part of being there was the support...being with people who understand what SMS is really like.

The conference would not have been possible without our wonderful planning committee, our many other volunteers and our donors. Thank you all.

We had many fine speakers at the recent 7th International Conference, but my personal favorite was Jonathan Kelly. Jonathan, who has SMS, opened the conference with a welcome speech.

Did you know what ranks as the top fear of most people? Fear of public speaking! I guess no one told our children with SMS. They never met a microphone they didn't like. Anytime a new speaker was called up to the podium, one of our children was right behind. A few stood right by during the whole presentation.

We also honored Ann Smith for her many years of work with our families. If you have any help from information about your child's syndrome, you can thank Ann and those who joined with her shortly thereafter.

Support is one of PRISMS's primary goals, and there are many ways to get support, even if you weren't able to come to the conference. Contact with others via our Facebook page (see FB link on our home page), or utilize our Parent-to-Parent network to find others in your area. My family gets together with our local Dallas parents, and also with all of the families in our state 1-2 times per year. We always feel better after being with them.

At our last Texas gathering we went to a "special" one-of-a-kind theme park in San Antonio called Morgan's Wonderland. As always, we had a wonderful time being with some of our favorite people. Our group met another family at the park who had a 16 year old son. He really seemed to fit with our group and one brave mom asked his parents if they had a diagnosis. She found out that they had been searching for answers for years. A few weeks later, due to our group's influence, this young man was diagnosed with SMS!! Pretty cool. His parents are relieved to have found a diagnosis and finally be part of a support group like PRISMS.

In closing, if you were able to attend the conference, I hope you take home some of the conference spirit and stay connected with others. Together we are making a difference!

Warm regards,

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

The Bond Between Arkansas State Quarterback, Ryan Aplin, and His Younger Sister, Carlye

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you up from school, dad picking you up, sometimes your grandparents,” Aplin said. “And you’d always go straight to the hospital.”

Carlye was later diagnosed with Smith Magenis, but thankfully was able to return home from the hospital for good a few weeks after her birth. Only then, though did the true challenges begin. With their parents trying to balance work with a growing family and Carlye’s special needs, Ryan and his younger brother, Rhett, were tasked with significantly more responsibility than most kids are at their ages. Many days included picking up Carlye at the bus stop and taking care of her, helping to pass the hour or two between when school ended and when their parents returned home from work.

It wasn’t always easy, especially since individuals with SMS suffer from any number of irregular behavioral patterns. Many have strange sleep patterns (Carlye usually goes to bed around 7 p.m. and awakes around 4 a.m.), some have self-injurious behavior, and others have random and unprovoked mood swings. The last symptom is something Ryan knows quite well, after an especially painful incident when he was 16 years old.

“I have a memory of when I took my brother and sister to the mall,” Aplin began the story by saying. “She loved going on the playground and just getting out of the house.” Unfortunately, when it was time to leave, Carlye was none too happy. Apparently, neither was a bystander who witnessed what happened next. “I just remember her having a good time, but when it was time to go home she just threw herself down in the middle of the mall and threw a temper tantrum,” he said. “I had a lady walk by and look at me funny and tell us, ‘You need to get her under control.’ Finally I looked at her and said, ‘You have no idea what’s going on. You have no right to make a judgment like that.’ ”

Thankfully, as the years have gone on and as medication and understanding of the syndrome have improved, Carlye has grown to live a mostly normal

life. While she’ll never be able to live on her own or drive, she does go to high school with a strong special needs program, and just finished up middle school this spring. She communicates mostly through sign language, but according to her proud older brother is sharp with technology. “She works an iPhone better than I do,” he said, “and like many children her age, loves Nickelodeon.”



As a matter of fact, with Ryan now 12 hours away from home at Arkansas State, it’s actually Nickelodeon which can occasionally get in the way of some quality brother-sister time over the phone. “She’s a little wild thing,” Aplin said with a laugh. “Sometimes she’ll want to talk to me, and sometimes my mom will hand her the phone but she’ll stay with Hannah Montana, or whatever she’s watching.”

Still, even Hannah Montana can’t take away from Carlye’s trips to Jonesboro to watch her brother and his teammates play. Several Arkansas State players have spent one-on-one time with Carlye on trips to Ryan’s house over spring break, and others

have gotten to know her through visits to the school for games and practices. Carlye has taken an especially strong liking to senior defensive end, Tim Starson, whom she met when he visited the Aplin's house during spring break of the players' freshman year.



"We definitely built a relationship when I was down there," Starson said. "We played and swam in the pool, but she'll also get right into it with you. She'll yell, 'Jump on me', whatever." Aplin took it one step further. "She has a crush on Tim," he said.

As Aplin gets ready for his senior year, it's hard not to see how the maturity he gleaned from watching

Carlye all those years has helped him develop into the leader of the Red Wolves. He's on campus this summer leading voluntary workouts multiple times a week, as the Red Wolves get ready to try and defend their Sun Belt title. Starson calls his teammate "the ultimate leader," and it's easy to attribute Aplin's leadership capabilities to things he picked up along the way from his family. For starters, he's quick to credit his tireless work ethic to the parents who raised him.

"Parents of special needs kids don't get the credit they deserve," Aplin said repeatedly during a phone interview, praising them for balancing work, family life and Carlye's special needs.

As for Carlye herself, well, Aplin has learned from her not to take any single day for granted. His little sister has quietly become one of his biggest inspirations.

"It hasn't always been easy," Aplin said. "But I wouldn't change anything about her. I love her just the way she is."

Photos courtesy of Arkansas State Athletics and Lorile Aplin

<http://www.bloguin.com/crystalballrun/2012-articles/june/the-bond-between-arkansas-state-quarterback-ryan-aplin-and-his-younger-sister-carlye.html>



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!

Spectrum Spotlight - Q&A with Christine Brennan, MA CCC-SLP



We would like to welcome Christine Brennan as the newest member of the PRISMS Professional Advisory Board. Christine answered a few questions for us to get to know her better.

What are your professional affiliations?

Research:
Northwestern University, Evanston, IL
Doctoral Candidate (anticipated Ph.D. by Summer, 2013)
Developmental Cognitive Neuroscience Lab

Clinical Practice:
Brennan & Burns, LLC, Skokie, IL
Speech-Language Pathologist (Owner and clinician)

Member:
American Speech-Language Hearing Association (ASHA)
International Mind, Brain & Education Society (IMBES)
Cognitive Neuroscience Society (CNS)
Organization for Human Brain Mapping (OHBM)

What is your clinical background?

Most recently, I worked as a clinician, clinical supervisor, and

owner/partner at my private practice, Brennan & Burns, LLC, in Skokie, IL. I opened this practice with my mentor, Dr. Martha Burns, CCC-SLP in 2003, and it is currently being managed by a colleague, Nisha Malavia, MA CF-SLP.

Prior to starting the private practice, I worked as a speech-language pathologist for Niles Township Department of Special Education (NTDSE), District 807, IL (from 1999-2003). At NTDSE, I provided therapy and diagnostic services to children ages 3-21 years with a range of speech and language abilities and needs across a range of educational settings. I also had the opportunity to work collaboratively with OTs, PTs, Social Workers, Behavior Intervention Specialists, Psychologists, and Transition Counselors.

My experience working with children and adults with disabilities spans over 23 years. I first began working with individuals who have disabilities as a volunteer at a summer recreation program on Long Island, NY, called the ANCHOR Program. I worked at ANCHOR for nine consecutive summers before starting the graduate speech pathology program at Northwestern in 1997. I believe this prepared me for a career focused on providing assessments and intervention for individuals with disabilities.

How many years working with SMS?

I began working with my first client with SMS in 2004. The client was 13 years old at the time. I worked with him twice weekly until 2008, when I returned to Northwestern to begin the doctoral program. I continue to meet with this client approximately once per week for coffee and we work on social conversation skills and communication for community-based activities. In 2009, I began working with another young man with SMS who was 8 years old. I continue to work with both of these clients on a weekly basis. Additionally, I attended the three most recent PRISMS conferences and presented on speech and language intervention at the conferences in 2009 and 2012.

Current research focus

At Northwestern University my research focuses on phonology, specifically, how speech is processed and how phonological grain size plays a role in reading development.

Grain size refers to the size of the speech units (e.g., a single speech sound, like /a/ is a small grain size; a word like /cat/ has three sounds and is a larger grain size). I conducted one study in which I compared different forms of reading instruction on accuracy and processing speed for different grain sizes. This is critical because reading (at least in English) requires flexibility with attention to different phonological grain sizes. For example, irregular words require recognition at the largest grain size, the whole word (e.g., “yacht”), whereas regular words can be sounded out at their smallest grain size, letters (e.g., “cats”). The results of this study showed that when instruction focused on the largest grain size, accuracy for larger grain sizes and reaction time for all grain sizes was faster. This is a critical finding for clinicians and educators who provide reading instruction, since at different points in the training program, emphasis may be placed either on larger or smaller grain sizes. This study provides efficacy data that supports the use of different instruction to achieve this goal. Future investigations can consider if these instruction methods have similar or different results for typical children, as well as those with reading difficulty.

My dissertation project expands on the findings of my previous study by examining how phonological grain size is processed by the brain. I plan to use functional magnetic resonance imaging (fMRI) to determine if different regions in the auditory cortex show sensitivity to different phonological grain sizes. In the visual cortex, the part of the brain that processes visual information, a gradient has been found that shows different sensitivity to letters and whole words. So far, a similar gradient has not been shown in the auditory cortex, although there is reason to believe that this may be the case. If a gradient can be identified in a typical population, future studies could consider clinical populations. For instance, children with language delays and disorders may show a weaker gradient. Additionally, if individuals with deficits in phonological awareness lack this gradient, perhaps intervention focused on phonological grain size can improve speech processing and language comprehension abilities.

Research interests related to SMS

I conducted a case study on language skills in SMS which was presented as a poster at the Symposium for Research in Child Language Disorders in 2006. This preliminary investigation demonstrated that the language skills in children with SMS may be very different from other types of syndromes that impact language and cognitive development. In fact, this study revealed that basic level language skills such as vocabulary, grammar use and comprehension were significantly delayed, whereas the ability to comprehend more complex stories was largely

intact. This means that despite difficulties using accurate grammar in spoken sentences, or having vocabulary that falls behind age expectations, the ability to listen to a story and answer higher-level questions about inferences, main ideas, and predictions was good. This is a very surprising finding and may suggest that individuals with SMS may be able to compensate for limitations in language skills using other cognitive abilities. Since my current research involves brain imaging (using fMRI), I am very interested in conducting a study that compares brain activation in individuals with SMS to age-matched peers, as well as individuals with other learning disabilities to see if engagement of the brain differs in individuals with SMS. I suspect that there are unique differences associated with SMS. Further, these unique differences may align with the finding that higher level language comprehension is a relative strength while basic level language skills are more impaired. If this is true, this finding would ultimately provide improvements to the treatment and intervention methods provided to children and adults with SMS. I hope to pursue this line of investigation after completing my Ph.D.

Any incidental thoughts, perspectives, or observations?

Attempting to help an individual improve his/her communication skills can take time and be challenging, especially when there are additional variables that impact cooperation and participation (such as amount of sleep, attention, behavior regulation, impulsivity, etc.). An important thought to keep in mind, whether you are a parent, educator, or clinician, is that everyone communicates when motivated. Motivating factors can include things we want or don't want, such as attention of others, opportunities, physical needs (like food, drinks, sensory input or avoidance), and escape from undesired situations. You cannot force an individual to communicate when they are not self-motivated, so in order to improve communication ability, you should capitalize on what is motivating. Create situations in which the individual with SMS is motivated to communicate wants, needs, and requests for attention or escape. Be sure to reinforce attempts at communication even when you cannot give in fully to the requests. While this approach may be a starting point for some, you can expand this method to include higher level language-based activities, such as for conversations and daily life skills (like shopping or meal preparation).

Reaching a Child in the Junior High Setting with Smith-Magenis Syndrome by Penny Kotas, Intervention Specialist

For three years, I had the privilege of teaching a female student with Smith-Magenis Syndrome. For purposes of this article, I will refer to my past student as simply "T." Teaching in a multi-ability and multi-age multiple disabilities unit (grades six through eight) requires great flexibility and a willingness on the part of the teacher to accept the diverse needs of each of her students. A thorough review of past school records along with a review of any academic research available is a key prerequisite to serving the diverse needs of each child. Recognizing and taking a proactive approach to instruction that often necessitates the total restructuring of the classroom environment is often mandatory. My students typically have disabilities requiring both remedial and compensatory measures to take place in order for them to succeed in school. The fall of 2008 introduced five new students to my unit within the third week of school which did not provide precious time needed to customarily do a thorough review of the research. It was that September that T joined my classroom, and I was introduced to her very rare but fascinating disorder known as Smith-Magenis Syndrome (SMS). Prior to the fall of 2008, I had never heard of Smith-Magenis Syndrome and was intrigued with the prospects of learning about this very rare and complex disorder.

Although research appeared to be lacking in the area of instruction and inclusion of school-aged children with SMS (in the public school spectrum), I felt I was able to draw upon the literature that was available in order to gain some perspective as to how to teach and integrate her educational program with the entire school community.

To complicate matters, I was stunned by a recent television news report about a female student in a city within our county who suffered the ill-effects of SMS children placed in public school settings. The news report stated that an elementary student with SMS was at the center of an abuse scandal involving a paraprofessional (one-on-one educational assistant), a special education teacher, an occupational therapist and a physical therapist. Apparently, the one-on-one assistant used excessive force when trying to restrain the little girl with SMS and the school had failed to contact Child Protective Services until eight days after the incident. A teacher, two classroom assistants, an

occupational therapist as well as a physical therapist were in the classroom when the incident occurred. The television news cast claimed that the SMS child had thrown herself to the ground when she did not get her way and one of the assistants used her foot to shove the child away from her. In the end, all staff present at the time of the incident were dismissed, licenses to teach and/or to service children were stripped and the little girl was withdrawn from public school and placed in a private setting. I was stunned and appalled with what I had read and seen on television. The next morning I met with my principal and discussed the incident at length. I shared with him all the research I had found on SMS and vowed to remain steadfast in my quest for ongoing research into an area that few educators seemed to understand. My goal quickly became to create an environment conducive to learning and to present the types of lessons that minimized the escalation of behaviors associated with children with SMS.

Reading over my student's past school records and then consulting the literature and a child psychiatrist (who by the way had never heard of Smith-Magenis Syndrome), I became consumed and determined to create lessons that offered T the greatest chance for success. I asked myself, how would I begin to prepare for such a task that demanded I (somehow) create a classroom environment that could lessen the impulse for a child to try and gain control or attention when trying to manage eight students? The more I read, the more empowered I became. I quickly began planning and organizing the types of activities and computer programs that had worked countless times before with other students who displayed similar behavioral outbursts and challenges. I integrated technology as much as possible with the goals and objectives on T's Individualized Educational Program (IEP) and was careful to give single-step directions to T instead of more complex ones. I had read how important this one simple factor could be to her overall behavior patterns. Having worked with other students who shared similar behavior types as well as having had the profound experience of raising my own child with Autism, I quickly determined that the educational implications were not so different.

Throughout the early days with T, I continually reminded myself what a professor had once said in class; as long as I was willing to work tirelessly to search for better

strategies and materials to reach each of my students, everything would somehow work out in the end. In addition to what appeared at the time to be an enormous task, I also was determined to make T's transition as smooth as possible for her, her family and for my other students. Instead of focusing only on the individual behaviors explained within her past school records, I decided it was imperative to create the conditions necessary in class that lessened the likelihood that meltdowns or outbursts would arise. Providing T with picture schedules, a quieter environment, highly structured routines, single-step and not multi-step instructions (which frequently could transform confusion into frustration in the SMS child), and by utilizing the types of strategies and positive behavioral supports (response costs and other token economies/behavior contracts and incentives) that have worked in the past, the transition period would surely be easier for T and the entire class.

T's first week of school was a bit challenging to say the least, but manageable. Three years after the fact, few behaviors exhibited during those first few weeks surfaced again in that severity. T was enjoying attending general art, music and accompanying her classmates on community trips. T quickly adapted to her new environment at junior high school. Central to teaching a student with SMS is involving the parent(s) at every step of the process. Meeting frequently and assuring parents that they are a principle member of the team and that their input is welcomed and appreciated is also a necessary step. Accepting the realization that a student's first teacher is always the parent(s) and that the information they provide affords the teacher greater insight into the child's unique learning style can simplify the research process for the teacher. What I found was that my student with SMS was very intelligent, had a great sight vocabulary and enjoyed interactions with staff, peers and people she met in the community. Each year, she added more and more words to her evolving vocabulary bank and enjoyed reading stories regarding a wide range of topics (weather-related phenomena, animals, different cultures, music, etc.).

Insight into the distinct behavioral patterns of my student with SMS was provided initially by her mother who stated that her daughter "craved" and "demanded" the attention of adults. She warned us that her daughter often chewed her fingernails until they bled or fell off, and that it was imperative to stay calm when this occurred; an "alarmed" expression would only serve as negative reinforcement and the behavior would surely continue. That was difficult to do initially but we learned how to calmly turn her attention away from biting her nails with frequent cues. During those first few weeks

with our student, we also learned from her mother that her daughter would strive (at any cost) to gain control of the classroom. She recommended that we do not engage T in needless dialogue regarding the "why" or "why not" of a typical behavior. It was clear to us that T was very intelligent and knew exactly what her goals were. Probably the most vital piece of information shared by my student's mother was that it was necessary to let her child know early on that "she does not control the classroom – in other words, she is not the boss!" In addition, she suggested that it is best to not stand too close to T - she often misinterprets this as an invitation to try and hug, touch or poke the person. I learned in those early weeks the importance of staying calm absent of alarm for even the most outrageous behaviors witnessed in class (swimming on the floor, her acting as if she is about to eat a chicken bone, or trying to eat crab apples on a walk) extinguishes the likelihood that these events will surface again.

I'll never forget the first moment my student with SMS arrived in my classroom: she looked around the room and something in her eyes told me that she recognized the fact that we welcomed and planned for her. We had created an engaging work station, as well as a peaceful library area complete with books and a cot for her to sleep. Within the first few moments, she ran towards the cot, fell onto it and sat there for the first few minutes. In her own way, I sensed she was saying "thank you" for recognizing her needs in advance.

For any junior high multiple disabilities program, it is essential to incorporate some community-based instructional activities within the functional curriculum in order for students to practice skills in real settings; meaningful learning trials allow for transference and generalization to take place. An obstacle to planning these trips around T's need for sleep at inopportune times of the day was challenging but doable. We took day trips each month to a Decorative Arts Center, local stores, restaurants, the library, as well as the local bowling alley. My students routinely called and made reservations with a local transit system in order to take our weekly community trips each Friday. We were limited to the morning and early afternoon times when our student with SMS was at her peak wakefulness. My educational assistant and I learned early on that waking our student with minimal time to sleep or trying to simply keep her awake caused more erratic and disruptive behavior overall. Like clockwork for three years, T fell asleep each day somewhere between 11:30 and 1:00 pm. Once, we were eating a holiday meal at a local restaurant and although she was excited and enjoying herself eating with her friends, she suddenly fell asleep. As a matter of fact, I saw that she was clenching

a French fry in her right hand as I cradled her to a bench nearby to lie down. It broke my heart when I had to wake her for a fire drill to evacuate all the children out of the building as quickly as possible. I would quickly grab her coat and cover her with a blanket and lead her to the area where we needed to stand outside. There were times each year that required the fire marshal to actually come into the building and pull a fire alarm without warning to staff or administration. My principal always tried to plan fire drills around T's sleep schedule. She was difficult to wake at times and a plan was in place to assist us in getting her outside in the event of a drill.

It was clear that our student had excellent computer skills and quickly became immersed with the developmentally appropriate text provided by the online reading series, Raz-Kids/Learning A-Z. In addition, she quickly learned to navigate through various other software programs used in class (Cambium Learning/Intellimathics, Intellitools, PCI Reading Series, and the Edmark Real-Word Vocabulary Series). These materials were critical in those initial weeks when teacher attention needed to be turned away to other students. Positioning our student out of arms reach from other students kept her from trying to poke, touch or agitate other kids. Instruction and assessment forms with this individual student included interactive types of performance-based learning trials, adjunct aids (synchronized speaking text, computer generated highlighted materials, graphic organizers, etc.), one-on-one direct/explicit instruction, as well as peer mentors and tutors to review skills more effectively. My student enjoyed the interaction of various peer mentors each year, and this in turn gave her the opportunity to discuss her learning in social settings. Reminders were given in advance of activities with peers to ask "appropriate questions" or to not cross into others' "personal space" – these were only two of many cues used which signaled her to not repeat questions over and over or to not lean into or bear hug another student or staff member without warning.

I cherish the time I shared with T over the three-year-period she attended junior high. She has had a profound impact on me as a teacher and as an individual. I miss her cheerful greeting each morning: "Hi, Mrs. Kotas! Did you sleep okay?" Everything was about sleep! I also miss the challenge of finding better strategies and ways to teach and assess her skills. In the time we were together, I saw real progress in all areas of her learning and only hope she continues to succeed in school and throughout adulthood. Maybe this sounds a little arrogant but I fear her teachers in the future may not realize just how smart, kind and funny she really is and somehow limit access for her to participate in real-world

learning experiences and settings. The behaviors that accompany children with SMS in public school can be overwhelming at times; the key is to create the conditions necessary within each particular setting that do not trigger the onset of troubling behaviors. "I never teach my pupils; I only attempt to provide the conditions in which they can learn." Albert Einstein.

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.*

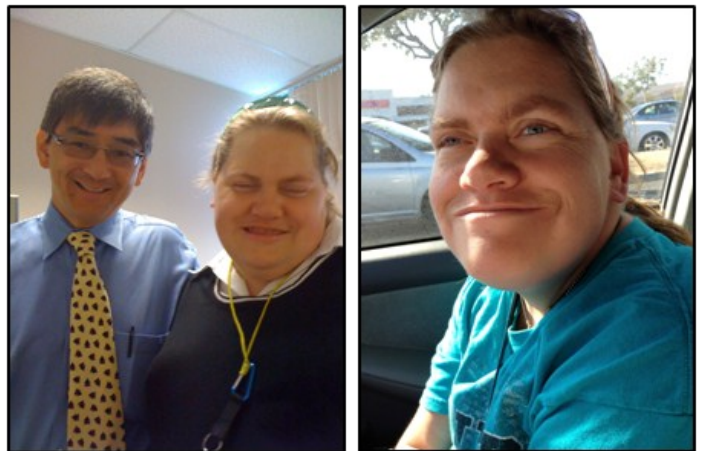
Choosing Life - Sonja's Weight Loss

By Gail Reiner

Sonja Jane, now 35 years old, was born at home in the summer of 1977 when her father was just finishing graduate school. Although I was working as a registered nurse, my pregnancy was not covered under insurance and so a sympathetic physician friend who had delivered many babies in Africa “with a pen knife and a blade of grass” agreed to deliver her at home. Three days after she was born I weighed her at the grocery store on the vegetable scale. She measured an even 7 pounds. Early in her life she had feeding difficulties so common in children with Smith-Magenis Syndrome. She would pull away when breastfeeding seeming to struggle to eat and breathe at the same time and her weight gain was very slow. Through her early years she remained slender despite squirreling food and bingeing during one of her many night awakenings. At age 6 she once ate an entire tray of brownies during the night. Her tantrums and hyperactivity seemed to burn enough calories to keep up with her intake until the teen years when her weight began to creep upwards. During physical illness crises she would retain a lot of fluid, and her blood sugars would spike high enough to require insulin during hospitalizations for surgery and pneumonia.

Sonja was 32 years old when she was finally diagnosed with Smith-Magenis Syndrome after the 4th genetic testing of her life. The much-welcomed diagnosis came just a few weeks before she was diagnosed with a Schwannoma tumor in her spine which required emergency neurosurgery on Valentine's day in 2010. Her weight had just hit an all-time high of 242 pounds. She was living in a group home that loved her through sweets and noodles and she had continued nighttime food raids sometimes downing a whole jar of peanut butter. With a 5'3" frame her blood sugar skyrocketed and she ended up on medication for blood pressure and diabetes. After surgery we really had a talk about weight and whether or not Sonja wanted to choose life. Her primary care doctor sent her to a counselor who talked with Sonja about using food as a self-comforting measure. Fortunately, the counselor had experience in working with intellectually disabled clients and Sonja had a powerful bond with her during the 6 occasions they met. Sonja was also referred to a dietitian who had food models and who talked about positive food choices. She respected Sonja and spoke directly with her in a truly encouraging manner. Our pastor encouraged Sonja to use the phrase “shedding weight” advising that if she

spoke about losing weight she might go looking for it again. I took her to a cooking class and we also had one in our home for all the clients and staff in her group home. It was a vegan-based cooking class and the teacher involved all of the audience in helping to prepare a delicious salad, a spritzer of sparkling water and juice, and delicious vegetarian roll-ups.



From Left to Right: Sonja with her neurosurgeon in Feb. 2010 at 242 lbs. Sonja feeling proud and pretty July of 2012, 72 pounds lighter.

Today Sonja is maintaining a weight of 170 pounds, 72 pounds lighter than her weight 2 years ago, which she decided to tackle a year and a half ago. She exercises daily by walking in her day program and doing arm weights a minimum of one hour each morning except on Tuesdays when she attends a dance class. She quit drinking soda except on rare occasions, she reads labels and makes the very best choices she can 80% of the time. When we go to Starbucks we split a dessert and have non-sugary drinks, and we shop at Farmer's Market together for fresh fruits and veggies. She says she never feels full but she has learned to eat slowly, enjoy her food until it's gone and raiding the cupboard at night has become a rare event, not a nightly one. She is in a new group home which promotes her responsible choices but which does not send her to day program with 3 donuts in her lunch. If Sonja, with all the challenges of SMS can shed weight and exercise daily, it's an inspiration for us all. She has chosen to live and I am so glad.

Sonja's words: "The best way to lose weight is to exercise, not drink soda and drink lots of water."

Parents Perspective - Reflection on the Water

By David Moertl

My son moves through time in the “here and now” while simultaneously living in his SMS world with its own realities. Sayings such as “Really, Mom, you have to bail on me?” while she walks out the door to the bus stop with our daughter, leaving our perennially late son inside to put on his own boots, and “dude, have to get that,” when he sees something he likes sometimes catches me by surprise. Because I have been so focused on him as an SMS Child, the “here and now” son of mine often feels the need to stand up and yell, “Here I am, right here. Enough already. I do exist, you know...”

This is not to say that I dismiss my son; nothing could be further from the truth. But I must admit to narrowing my focus on his limitations at times, thereby missing the “him” in him when I do. Perhaps the reason could be that he is a master of sympathy-manipulation, skillfully playing me to obtain his goal of being waited on hand and foot, coupled with my soft spot for doing so. By playing the son-in-distress, he garners appreciable attention and he gets a lot of mileage out of doing so. A perfect example of this is zippers. When he was younger he really struggled with zippers, and I, naturally, helped him zip up (many times to simply keep the show moving out the door!). As he grew his dexterity improved, but so did his cunning. He figured out that if he pretended to not be able to zip up that he could keep his personal attendant at hand, and it worked for zippers as well as for other things: reading, writing, dressing, yard work, cleaning, dishes, putting seat belts on, washing hair...you name it, he had me do it. After a while, you just fall into the limitation trap, I guess.

Now eleven, an expert at electronic gadgets, he has adopted the local teen vernacular (like, totally—remember?), and the associated aloof coolness that goes along with it. He is both a boy of the world and an SMS kid rolled into one complex package. I sometimes wonder where my zipper boy went, but I am amazed at the growth and maturity that I see from him (most of the time, anyway). He is part of a Green-Machine gang in the neighborhood, rides his bike and scooter everywhere, is known by all, and often prefers to do his own thing without interruption from his family, thank you. He

dresses like you see on TV, has his own rules of interaction (break them and talk to the hand!), has posted a “Keep Out” sign on his bedroom door, cranks tunes at all hours (he is SMS, you know), and never has a clean face or shirt after eating, which he does continually (mostly ketchup.) Total eleven-year-old, he is.

Headed on a collision course with my pre-teen, dude-son is my SMS son. My SMS son does not really have an age, per se, and is hard to decipher when things are going smoothly. But he is there, lurking, standing in the shadows, smoldering, waiting, hanging, and holding his alter ego back a bit...you get the picture. He is not malicious, harmful, hateful, or mean in and of himself, but when he is overcome by his SMS limitations, he can be all of the above...and remain innocent. When the storm hits suddenly, I am reminded instantly that this boy needs love, support, structure, and time to gather himself. He does not speak or act as himself during tantrums and his words and actions are devoid of true meaning during them. The dichotomy of my “here and now” son to my “SMS episode” son is striking, to say the least. No common ground exists between them with the exception of physical form and function.

Thinking about this, maybe I cannot separate the two. Perhaps this is the reason that SMS is so insidious, because SMS children (and teenagers and adults) are both “here and now” and “SMS” all at once, and it just depends on the time and circumstance as to which side is winning. Like the ebb and flow of the ocean and the ups and downs of teeter-totters, my SMS son is both liberated from and confined by SMS...it’s in his genes, as they say. As a father, I want to rip the SMS out of my child and plunge it down the disposal, obliterate it, which of course, I cannot. All I can do is love my son and provide a comfort zone for him that he can return to after his senses become overloaded and he cannot cope for a time. And then wait. And when the “him” in him returns to me and I hear him say something like “No way, dude, that is sick,” I will simply smile and enjoy the moment as the reverse will be sure to come again. And then go...

6th Annual Buck Creek 5K

6th Annual Buck Creek 5K for PRISMS
Friday, September 21, 2012. Sign-in starting
at 5:00 p.m. Race starts at 6:00 p.m.

Buck Creek State Park in Springfield, Ohio.
Join Charlie and Tina McGrevy for a 5K
run/walk in Buck Creek State Park.

Register online through PRISMS FirstGiving
site: <http://www.firstgiving.com/prisms/6th-annual-buck-creek-state-park-5k-runwalk>
or find the link on the PRISMS homepage.

We have a block of rooms at the Hampton
Inn for Friday and Saturday nights. Call the
hotel before September 6 at 937-325-8480
to get the PRISMS rate of \$94 + tax per
room. Visit their website at
www.springfieldoh.hamptoninn.com for
directions.

Campsites are available at Buck Creek
State Park. Call 1-866-OHIOPARKS for
reservations.

Prisms Family Picnic

PRISMS Family Picnic
Saturday, September 22, 2012 from noon-
4 p.m.

Firefighter Club House at 703 North Bird
Road, Springfield, Ohio

Come for lunch at noon and stay for games
and fun. We will be serving hot dogs, sloppy
joes, chips and drinks. Bring something sweet
to share and backyard games to play.

We hope to see you at one or both events.
This is a great chance for families to get
together and share our common joys and
struggles with SMS. Last year, we had eleven
SMS families attend...don't miss out! Contact
Tina and Charlie McGrevy for more info at
cmcgrevy@yahoo.com or call 937-327-9354.



What is Smith-Magenis Syndrome?

Smith-Magenis Syndrome (SMS) is a chromosomal disorder characterized by a specific pattern of physical, behavioral and developmental features. It is caused by a missing piece of genetic material from chromosome 17, referred to as deletion 17p11.2. The first group of children with SMS was described in the 1980s by Ann C.M. Smith, M.A., a genetic counselor, and Ellen Magenis, M.D., a physician and cytogeneticist. Although the exact incidence is not known, it is estimated that SMS occurs in 1 out of 15,000 births. SMS is underdiagnosed, but as awareness of it increases, the number of people identified grows every year.

Fundraising Made Simple - Manna

Dear SMS Parents, Families and Friends:

We have exciting news to share about a new fundraising program for PRISMS. It's called The Manna Group Scrip Program. This scrip program will allow PRISMS to fundraise while we shop.

"Scrip" is the name given to gift cards and certificates which are provided by local and national retailers.

They are the same gift cards available in stores.

Nationally known retailers include Sam's Club/ Walmart, Target, Albertsons/Jewel, Safeway/ Dominick's, Walgreens, JC Penney, Kohl's, Best Buy, Shell, Speedway, Starbucks, Home Depot, Subway and Cheesecake Factory, to name a few. These companies participate in the scrip program along with hundreds of others.

How can these retailers help us raise money? It's simple. Partnered vendors agree to sell gift cards to our organization at a discount. Families like yours buy the gift cards at full face value and PRISMS keeps the difference as profit. **NO SELLING INVOLVED!**

Put your everyday shopping dollars to work. Earn money for our organization without spending

anything additional. All you need to do is send me an e-mail requesting to be set up on Manna and include your mailing address and phone number. Once that is done you will receive an e-mail from me with the PRISMS organization #, your participation code#, password and a list of vendors showing the percentage going to PRISMS. Then you can start ordering online at:

www.mannaorders.net

You will need to pay through Mannapay. They don't accept credit cards; if they did it, the charge from the credit card company would wipe out the percentage going to PRISMS.

Ideniern@comcast.net.
Manna Coordinator

It Worked for Me ...

Swallow that pill, please!

Limited on medications because my son won't swallow pills was very frustrating. How can I train him to swallow without being scared to do so. I found the perfect cup: The Pill Swallowing Cup by Oralflo. I ordered the cup and we practiced with white tic tacs. He did it! It took about three tries each night for a swallow, but he did it. One week later he swallows on the first try. Check it out! www.oralflo.com

Denien Rasmussen, Palatine, Illinois



Make a Splash!!

My son hates having his sticky hands cleaned after eating, so once I wipe down his tray I pour a little water on it. He has a blast splashing around, and his hands get clean without the fuss.

Tara Brown, Davie, Florida

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



SMS Superkid!



Molly is 25 years old and a graduate of the Austine School in Brattleboro, Vermont. She grew up in Vermont and has a big family there. Molly has loved all animals, and especially horses, since early childhood. Her mother owns a horse stable and Molly rides and helps take care of the horses every day.

Molly has a dog named Lacey, and two brothers and two younger sisters in her family, as well as many aunts and uncles and cousins and grandparents who live in her town and who visit. Molly is very important to her family. She remembers everyone-where they live, who they live with, what kind of car they drive, who their pets are. She loves to give gifts and takes good care of her family.

For the last six months, Molly has been working at her family's maple syrup farm store. Molly's dad, step-mom, younger sisters, brothers, aunts and uncles all work at Hidden Springs Maple in Putney, Vermont, making the syrup, canning it, selling it in the store, and shipping it to customers who order on the internet.

At Hidden Springs Maple, Molly has a lot of friends and knows how to do many different jobs. Molly's aunt is the store manager and gives her jobs to do when she comes into the store to work. Usually her cousin drives her to work and helps her with her jobs. She likes to pick up the mail from the mailbox out in front of the store. She likes to open packages and she is good at putting new store displays together. She uses the price "gun" to put prices on the maple sugar candy, helps pack up the



syrup that gets shipped all around the country, and can operate the cash register. Her aunt says that Molly notices things that need to be done that no one else notices. She is learning to make change by taking out the quarters and dimes and bills to add up to the right amount.

Many of the customers know Molly from the horse barn or from around the village. Everyone likes to see Molly doing her job. She introduces herself to customers and has great customer relations skills.

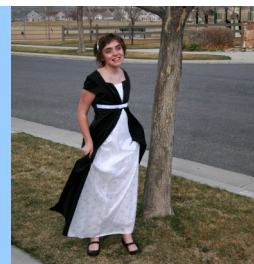
At the end of her hours of work in the store, Molly likes to shop. She often chooses a maple soda from the cooler and tries one of the new products such as maple shortbread. Sometimes she takes something home for her mom.

For more information on where Molly works, Hidden Springs Maple, please visit www.hiddenspringsmaple.com.

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 ↑



Our beautiful daughter, Madison (above), was able to go to a dance sponsored by Best Buddies, Utah. She was so excited to get all fancy with a formal dress and some make-up. When we arrived at the dance, there was a red carpet laid out for all of the special guests to walk in on, complete with paparazzi taking pictures. Madison danced all night with one of the many volunteers (he was a good sport!). She had a fabulous time at her "prom!"

- Dan & Heather Wilde

One day I was fussing at my daughter, who is 18 and has SMS. It was all about cleaning her room, picking up her dirty clothes, etc. I guess I was on a roll. She stopped me dead in my tracks and asked me, with a silly grin, "Mom, are you missing a piece of chromosome too?" We looked at each other and burst out laughing. The things they say!!

-Julia Heatherington



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PRISMS Smith-Magenis



Sonja, mom and sister, Julie at their brother, Jeremy's, wedding in 2011.

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