

# The Adolescent Adventure: Puberty and Beyond

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The dreaded teenage years!! Parents of any child may look to adolescent years with trepidation as this time in life is often associated with “raging hormones”, behavioral shifts and, believe it or not, growth and maturity. Parents of children with Smith-Magenis Syndrome (SMS) can look forward to the same “adventure” with some additional considerations. Understanding what your adolescent is going through can help you not only be prepared for the journey, but get through it successfully with appreciation for the young adult your child will become. It is important for parents to understand some basic processes and changes occurring in their adolescence. Some parents fear that adolescence is a ticking time bomb, but it is best conceptualized as a ticking maturational clock. This article will examine puberty as it affects both males and females in terms of their biological clock, psychological development and the social transitions that are all a part of being a teenager.

Adolescence begins with a biological event, puberty, and ends in adulthood. This also pertains to youth with SMS. There are physical and physiological changes that result in the maturation of the body for both males and females. As the body matures physically, there are also psychological transformations. Their relationships begin to change with parents, peers and other adults. There are some important



biological, psychological and social transitions, challenges and opportunities.

## BIOLOGICAL CLOCK

The biological clock ticks for all youth and this is no different for adolescents with SMS. The sequence of biological changes is generally the same, but the age of onset and rate of development is variable. Girls generally reach puberty earlier than males.

### Bodily Changes:

Puberty begins with an adolescent growth spurt followed by changes in body composition. This is followed by the maturation of sex organs for both sexes and the development of secondary sex characteristics.

In males, there is gonadal/genital growth, increased sexual awareness and exploration, including masturbation . This

is an opportunity for parents and adult mentors to reinforce more adult social interactions, boundaries and "time and place" for self stimulation. Establishing good hygiene habits early in life will assist the adolescent to avoid off-putting body odor, and deter the development of pimples and acne. The importance of daily physical activity must be underscored for all adolescents, particularly those with

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## A Letter From the President of PRISMS



Greetings!!

If you haven't already renewed your membership for 2013, it's not too late. PRISMS depends on membership funds to sustain and grow our important programs. In 2013 the PRISMS board wants to focus our efforts on serving our members like never before. Renewing your membership online at [prisms.org](http://prisms.org) today can help.

This year we are working on a new and improved new member packet. We have new and exciting programs being developed to help with awareness. Also, a new PRISMS brochure is planned. Finally, we are working to improve and enhance our website and Facebook page.

Planning and fundraising for our 8<sup>th</sup> International Conference is underway. As many folks know, this is a huge undertaking. We are currently looking for session ideas and qualified speakers, and we also desperately need folks who can help with fundraising. If you can help or you know someone who can help, please email us at [conference2014@prisms.org](mailto:conference2014@prisms.org).

In addition to the PRISMS Board of Directors and Professional Advisory Board (PAB), PRISMS uses various committees to help us provide programs to our membership. Our committees are made up of board members and volunteers. Current committees include Newsletter, Membership, Fundraising, Finance, Conference Planning, Website, Research and Awareness.

In this edition of Spectrum, you'll read about our need for committee volunteers. Percy Huston, a long time board member, has recently agreed to serve as our Volunteer Coordinator. This is an important position. Percy will work to match the interests of volunteers with the needs of our various committees.

Finally, you'll notice in this issue that we have altered the name of our publication from *Spectrum Newsletter* to *Spectrum: The PRISMS Journal of Smith-Magenis Syndrome*. This change represents more accurately the research and professional articles that are published in each issue, and supports our efforts to continually engage the academic community.

I look forward to a great 2013. I appreciate my fellow board members and all of our wonderful volunteers. Together we are making a difference!

Warm regards,

Randy Beall  
PRISMS, President  
Father to Laura, age 28, with SMS

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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](http://www.facebook.com), join up, and get online to participate. It's free! Spread the word and "friend" us!

SMS for whom weight management can be an issue. Physical activity has been demonstrated to have benefits that extend beyond physical to mental health.

In females with SMS there is great variability in the timing of puberty with the most significant event being the onset of the menses. The start of the menstrual cycle may be associated with premenstrual syndrome/PMS (irritability, lability, behavioral challenges) and peri-menstrual cramping. It is important to work toward solid relationships among the adolescent, her parents and healthcare practitioners. Medical practitioners may be able to assist with issues of irregularity or discomfort during the menses, especially if cyclical issues can be documented on a calendar and brought to appointments.

Consideration may be given to the prescription of oral contraception which will increase predictability or eliminate menses altogether should this be medically or psychologically indicated. It can be a challenge to explain about menses, instill good hygienic practices and help young people anticipate this typically monthly event. Calendars and visuals with adult oversight, prompts and assistance can be helpful early on.

Parents who have youth on the brink of puberty are understandably apprehensive and have often reported the best advice comes from other parents of girls with SMS. There is, of course, variability in menstrual related issues; however there are some common concerns especially among mothers who take on most of the care in the earlier years. Healthcare practitioners and behavior therapists can provide input into a range of pubescent issues from how to manage cramps to perimenstrual behavior flareups. It's well understood by PRISMS affiliates that aiming for a decent night's sleep is also, at times, a more challenging part of "the adventure."

### Sleep Patterns:

It is well documented that individuals with SMS have significant sleep problems; adolescence brings with it a potentially new twist. Those who previously had no difficulty falling asleep can experience delayed onset of sleep during adolescence. This may be on top of or take

the place of the more typical childhood patterns of night awakenings, or an inability to get back to sleep once awake. Parents can assist their youth in optimizing sleep by considering the following: Adjust bedtime routines so that they are later, 'reasonable', and as consistent as possible. Daily physical activity to 'spend' excess energy is advisable but not right before bedtime. Ensure external cues that it's sleep time (e.g. darkened room /avoid screen time) and Melatonin help the SMS brain to 'turn in for the night.'

### Other Medical Considerations:

Throughout the lifespan, it is important to be current with medical and dental care. This is particularly true as it relates to the special medical predispositions for SMS.



SMS healthcare guidelines specify screenings and follow-up for dental, ENT (infections, hearing, voice changes), musculoskeletal conditions, peripheral neuropathy, endocrine, and metabolic issues (predisposition for excess weight gain). Medication reviews are important as adolescents may have outgrown dosages (e.g. ADHD medication). There may be new considerations or co-morbidities, such as anxiety or depression,

which will need to be understood and treated separately.

### PSYCHOLOGICAL DEVELOPMENT

Common tween/teen issues crop up with our teens, too. Many of the issues seem to be related to adolescent "drives." Most adolescents have a drive for independence. They may distance themselves from the adults they have been closest to and attach more to peers. They see their younger siblings begin to surpass them in many areas. There are common, classic mother/growing child dynamics that are tied to the drive for autonomy and accompanying, often negative, attitudes and behaviors. When parents have an understanding about the stages of adolescence, they can anticipate, accommodate and guide their teenager as they present more challenging behavior. Teenager's drive for independence can be tempered by offering choices wherever feasible to provide a sense of self-control. Unfortunately, a common complaint from most parents of teens is the diminished drive to complete typical

activities of daily living. This includes hygiene routines and participating in household and family routines. Parents' persistence with well-established, predictable routines may decrease some of the turbulence that accompanies this diminished drive to get undesirable things done. Some teens are more receptive to visual aids than parental prompting! Sex drive and the drive to drive can show up, so don't be dismayed. The sex drive may be tempered by daily physical activity and keeping busy with varied activities. The drive to drive may best be 'channeled.' One youth with SMS became proficient in cleaning cars and assisting a mechanic to perform regular car maintenance. While this did not completely replace the desire to learn to drive, it greatly reduced the perseverance and energy that was spent on the topic.

## SOCIAL TRANSITIONS

Adolescence is a time of social transitions. Relationships with family, peers and other adults change. Focusing on the adolescent's emerging strengths, growth and maturity as they develop (which does happen!) can assist parents to feel more positive about the "growing pains" that are felt by both the adolescent and those close to them. As maturity marches on, parents will see relationships evolving. Socially appropriate behavior can be shaped



and strengthened, especially when it is positively reinforced by parents and others close to the adolescent. There is power in the phrase "catch them being good" and that power increases with practice.

Positive social transitions may take work. It 'takes a village' to help broaden adolescent's social circles and

support networks. Community groups, hobbies, sports and other activities can be a good fit, even if for brief periods on a trial basis. Build on the positive attributes. Your adolescent will require on-going support to build a suitable repertoire of socially suitable behaviors. For example, while many individuals with SMS are very affectionate, demonstrations of this affection are less appropriate as they grow. Some displays of affection may become problematic, like that tight hug that is so characteristic. Socially appropriate alternatives can be taught through repetition and practice, practice, practice. Finding a mentor or peer to assist can be more acceptable to the teen than parental guidance and prompts.

The adolescent adventure will wind down and transitional considerations related to adulthood will be on the horizon. In most areas there are developmental service agencies and specialists who can play help with planning. The onset of puberty, surviving adolescence and entering adulthood are major milestones. The changes and challenges are opportunities for engaging others. Professionals such as educators, OTs, PTs, SLPs, psychiatrists, behavior specialists and psychologists may offer strategies and suggestions to help diffuse the ticking time bomb and get the maturational clock ticking as it is designed to do.

While adolescence can be very challenging, it is also a time of growth, development and memorable moments as the maturational clock continues to tick toward adulthood. □

*Linda Moroz has over 30 years of experience in the field of intellectual disabilities working with both children and adults. She has been Bethesda's Children's Behavior Therapist for the past 11 years working with families and their children in the Niagara Region.*

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## Nickels for Nico Cornhole Tournament

Join Nico Weil and his family in Louisville, Kentucky for the Annual Nickels for Nico Cornhole Tournament! Meet at the Thurman Hutchins Park on Saturday, August 10, 2013 at 4pm. Activities include food, drinks and cornhole games. Fees are \$10 per person or \$20 a team. All proceeds benefit PRISMS. Come and show your support!



## PRISMS 8th INTERNATIONAL CONFERENCE

### "BUILDING BRIDGES OF HOPE"

Thursday, July 31<sup>st</sup> – Sunday, August 3<sup>rd</sup>, 2014  
The Hilton St. Louis at the Ballpark, St. Louis,  
MO

**Keynote speaker: Brenda Finucane,  
M.S., CGC, PRISMS PAB Member**

### *“From Single Syndromes to Shared Pathways: The Evolution of Behavioral Research in Genetic Neurodevelopmental Disorders”*

Brenda Finucane is a certified genetic counselor who has had a long career at Elwyn, a large, nonprofit human services organization near Philadelphia. In 2013, she will be taking a position at Geisinger Health System's new Autism and Developmental Medicine Institute in Lewisburg, PA. Ms. Finucane is widely published and has gained international recognition for her expertise in the behavioral and cognitive manifestations of genetic syndromes. She serves on the scientific advisory committees of several genetics support organizations and was the 2012 president of the National Society of Genetic Counselors. She is a co-founder of PRISMS and has a particular interest in school and vocational issues for people with developmental disabilities.

The Conference Planning Committee has already begun preparing for the 2014 PRISMS Conference. We hope that you will do the same and start planning your trip to attend the conference. We realize that the conference is a large expense for families. To assist you in your planning, please consider the list of registration fees and our negotiated hotel rate. Please note that we have *not* raised the registration fees for the 2014 conference, so they will remain the same as the 2012 conference. In addition, we have been able to negotiate the same guest room rate as the 2012 conference.

Limited financial aid will be available and more details will be announced next year. Please do not try to book your guest room at the Hilton at this time. The Hilton is NOT ready to receive reservations for our conference yet; we will provide a link for the hotel reservations in early 2014. Childcare will be available at the conference, but the cost for childcare is to be determined.

#### **Conference fees:**

<b>Adult (15 &amp; up)</b>	<b>\$200</b>
<b>Child (14 &amp; under)</b>	<b>\$100</b>
<b>SMS Individual</b>	<b>\$75</b>
<b>Professional</b>	<b>\$275</b>
<b>Professional In training</b>	<b>\$225</b>

*The guest room rate for the Hilton St. Louis at the Ballpark is \$129/night for a single or double room.*



## Advocacy Corner

### Participating in Extracurricular Athletics

By: Mary Kate McCauley

An important component of an overall education program is extracurricular athletics, which includes club, intramural, or interscholastic athletics at all education levels. The United States Government Accountability Office (GAO) published a report that underscored that access to, and participation in, extracurricular athletic opportunities provide important health and social benefits to all students, particularly those with disabilities. These benefits can include socialization, improved teamwork and leadership skills, and fitness. Unfortunately, the GAO found that students with disabilities are not being afforded an equal opportunity to participate in extracurricular athletics in public elementary and secondary schools.

CA law and the Individuals with Disabilities Education Act (IDEA) both provide for appropriate, individual instruction in physical education for students with disabilities. For the student with mobility disabilities or orthopedic impairment this includes instructions in motor skills and motor development. All students should get exposure to physical sports, team sports and “lifetime” sports like running and swimming. PT and OT are separate and distinct services. PT and OT help students work towards IEP goals. Some students with disabilities may require one-on-one.

To ensure that students with disabilities consistently have opportunities to participate in extracurricular athletics equal to those of other students, the GAO recommended that the United States Department of Education clarify and communicate schools’ responsibilities under Section 504 of the Rehabilitation Act of 1973 (Section 504) regarding the provision of extracurricular athletics. The Department’s Office for Civil Rights (OCR) is responsible for enforcing Section 504, which is a Federal law designed to protect the rights of individuals with disabilities in programs and activities (including traditional public schools) that receive Federal financial assistance.

Simple adaptations to physical games can allow students to play together. Adaptive mitts or racquets can assist athletes with motor coordination disabilities. Athletes with attention difficulties or executive functioning limitations can benefit from well-defined boundaries (delineated with cones or chalk lines) and playing equipment in bright or contrasting colors.

Students with disabilities who cannot participate in the school district’s existing extracurricular athletic program - even with reasonable modifications or aids and services - should still have an equal opportunity to receive the benefits of extracurricular athletics. When the interests and abilities of some students with disabilities cannot be as fully and effectively met by the school district’s existing extracurricular athletic program, the school district should create additional opportunities for those students with disabilities.

OCR is committed to working with schools, students, families, community and advocacy organizations, athletic associations, and other interested parties to ensure that students with disabilities are provided an equal opportunity to participate in extracurricular athletics. Individuals who believe they have been subjected to discrimination may also file a complaint with OCR or in court. □



#### PRISMS Mission Statement:

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS.





DEVELOPMENTAL FX  
The Developmental & Fragile X Resource Centre  
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## Sensory Diet Concept for Use with Individuals with Smith-Magenis Syndrome (SMS) and Use of the Sensory Diet Template

By: Tracy Stackhouse, M.A., OTRCo-Executive  
Director Developmental FX

### SMS and Sensory Diet

Children and adults with SMS often struggle with challenging behaviors, which may include self-injury, and this can disrupt their daily functioning. Due to sleep disturbance, peripheral neuropathy and an intense need for increased sensory input (for example, intense self-hug behavior and frequent teeth grinding), there are phenotypic aspects of having SMS that require sensory-based intervention. Additionally, those with SMS can struggle with coping skills affecting both emotion regulation as well as attention and behavior management. All of these areas may be well supported with the use of a sensory diet approach. The sensory diet is a treatment strategy, devised and monitored by a clinical occupational therapist, that structures sensory-based supports into the individual's day in a way that matches their sensory-based needs and supports coping and self-regulation.

### Issues in SMS that Suggest the Need for a Sensory Diet

#### Challenging Behaviors in Children with SMS

- Stereotypic behaviors bruxism (teeth grinding)
- Hands and/or object mouthing
- Covers eyes or ears
- Repetitive page turning or "lick and flip"
- Walks on tip toes
- Flaps, waves or claps hands
- Purposefully drops or throws objects
- Taps or rubs objects or body
- Rocks or sways back and forth
- Stares closely at objects or hands

- Spasmodic upper body squeeze or self-hug
- Self-injurious behaviors (SIB), self-biting, self-hitting, hits self against surface or object

All of these behaviors seem to be associated with SMS; in other words, they are phenotypic behaviors, as they have been reported to occur at least 50% of the time (Dykens & Smith, 1998; Martin, et al., 2006; Smith, et al., 2010), up to 80% of the time (Martin, et al., 2006) in individuals with the syndrome.

Dykens and Smith suggest that the degree of sleep disturbance appears to be the strongest predictor of these challenging behaviors (Dykens & Smith, 1998). Likewise, from a neuroscience perspective, the degree of the sensory-based problems should predict more behavioral involvement as well. In a study published in 2012 by Hildenbrand & Smith, several specific sensory processing issues were found to be common in individuals with SMS. This study utilized a parent report measure, The Sensory Profile, and revealed that individuals with SMS tend to have difficulties with:

- Basic sensory processing impairments in vestibular, touch and multisensory processing areas
- Endurance/tone, body position and movement
- Modulation of sensory input affecting emotional responses
- Behavioral/adaptive outcomes related to sensory processing
- Generally more likely to manifest sensory seeking, sensitivity, avoidance and registration problems compared to typical sample

### What Is a Sensory Diet?

A **sensory diet** is a treatment strategy used within the framework of occupational therapy to address two particular problems: sensory defensiveness and difficulties maintaining appropriate states of arousal. Sensory defensiveness is the tendency to respond in a negative or avoidant manner to sensory input; even normal sensations such as the feeling of clothing on the skin, water at bath time or lights in a gymnasium can be sources of negative overstimulation. When this presents in a pattern of over-responsivity coupled with behavioral response of avoidance or agitation, it is called sensory defensiveness.

A **sensory diet** can help maintain an age-appropriate level of attention for optimal function as well as be



used to reduce sensory defensiveness. Like a diet designed to meet an individual's nutritional needs, a sensory diet consists of specific elements designed to meet the child's sensory integration needs. The sensory diet is based on the notion that controlled sensory input can affect one's functional abilities. Martin (1991) states in *Principles of Neuroscience*:

A **sensory diet** is best designed by the family and therapist together. The therapist utilizes direct treatment time to learn the individual child's "formula" for attaining and maintaining appropriate sensory reactivity and arousal modulation. The therapist takes this information, and together with what she or he knows about the family's schedule and resources, designs a schedule of sensory supports that comprises the sensory diet.

A **sensory diet** typically contains the following elements:

A schedule of the key events in the individual's day (e.g., wake up, eat breakfast, get ready for day, bus to school, etc.). These serve as the guide for scheduling the specific sensory diet activities that follow.

*Routines and Activities to add to the Sensory Diet*

### **Select Appropriate Sensory-Based Activities to Build the Sensory Diet**

Sensory diet activities are adapted for each individual, but are based on sound neuroscience principles about how the brain takes in and makes use of sensory input to create optimal states of arousal and performance. An occupational therapist trained in sensory integration has the expertise to know how to use neural principles (such as "adaptive response"—how each sensation is processed and what it produces neurally) to design an appropriate sensory diet.

The sensory diet allows you to anticipate the events of the day (transitions) that need extra sensory support. Typically, these supports are set up in routines to ease transitions. For example, if a child is hyperaroused going to music class, the transition routine could include carrying a weighted basket of musical instruments to the class. This visual of the musical instruments helps the child to prepare for what is coming next, which can ease anxiety. In addition, the proprioceptive activity of carrying the weight should support lower arousal, easing the difficulty. The types of sensory input used in

transition routines are similar to those generally used in a sensory diet.

Putting all of these components into a set weekly schedule produces a structured sensory diet. A template example of a sensory diet is provided below.

Difficulties with sensory integration can have a profound effect on a child's participation in everyday childhood "occupations"—play, school and family activities. Collaboration between the therapist, teacher and parents is the most efficient way to understand the child's behavior and unique sensory needs. The "therapist-teacher-parent team" must work together to successfully implement a sensory diet and support the child's performance in roles and occupations across multiple environments.

### **Sleep Routines Important for SMS**

Because sleep disturbance is common in those with SMS, planning the sensory diet to target this challenging issue will be a pivotal part of the sensory diet. The sleep disturbance in SMS is described as frequent night awakenings with accompanying sleepiness during the day. The individual typically has reduced REM sleep with early morning waking (4:30-5:30 a.m.). There appears to be a characteristic inverted circadian rhythm.

To build the sensory diet around the sleep issue, the following considerations should be used as a guide for the therapist:

### **Sleep Intervention**

#### **Environmental Variables**

- After examining the child's sleep environment more closely, there may be some adaptations and modifications needed to assist the child's ability to relax at bedtime.

#### **Bedtime Routines**

- Bedtime routines and rituals are very important for most children in establishing positive sleep patterns, but are extremely critical for children with SMS.

#### **Enhancing Routines with Sensory Supports**

- Use of weighted blankets, rhythmic generators for movement input, hammock or other adapted beds, etc. This is determined individually by the OT.

## Schedule to Accommodate

- Ensure parents are getting enough sleep.
- Ensure safety in morning hours with routines and environmental changes.
- Day schedule should allow for appropriate, structured, scheduled naps and minimize frequent dozing.

## Sleep Training

- Specific behavioral interventions may be needed to augment the sensory diet intervention

## Use of the Sensory Diet Template

The sensory diet typically is comprised of a schedule of the key events in the individual's day.

## Sensory Diet Activities

The sensory diet activities are designed for the individual, but are based on sound neuroscience principles about how the brain takes in and makes use of sensory input to create optimal states of arousal and performance. The neuroscience evidence suggests that several key types of sensory input have the qualities required to produce these effects. The key types of sensory input include input to the touch, pressure, muscle and joint receptors (tactile and proprioceptors), movement input, oral tactile/proprioceptive input, respiration and auditory/rhythm input. An occupational therapist trained in sensory integration has the expertise to know how to use these neural principles to design an appropriate sensory diet.

## Transition Strategy/Routines for Success

The sensory diet allows you to anticipate the events of the day (transitions) that need extra sensory support. Typically, these sensory supports are set up in routines to ease the transition. The types of sensory input are similar to those in the sensory diet activities. □

*Tracy Stackhouse is the Co-Executive Director of Development FX, and was a presenter at the PRISMS Building Bridges of Hope Conference in 2012. For additional information, please visit [www.developmentalfx.org](http://www.developmentalfx.org).*

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### **Spectrum Articles**

Have you worked with a doctor or specialist who has been particularly knowledgeable or has a great understanding as to how to work with people diagnosed with Smith-Magenis Syndrome? Or have you had a particular experience that has been very successful to help your SMS child? Our SMS community could use your help. Spectrum Newsletter is always looking for articles to publish in our upcoming newsletters.

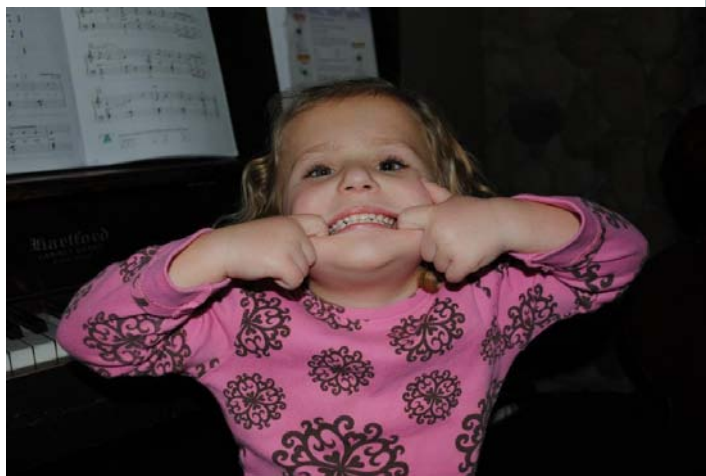
If you have an article that you think would be interesting or helpful for others to read, please send it along. We are currently looking for SuperKid, Parent Perspective, It Worked for Me, Professional, Sunnyside Up, and other articles related to SMS.

Please send an email to [editor@prisms.org](mailto:editor@prisms.org) for more information.



# Sunnyside Up

Our daughter, Leah, has coined a new phrase in our house. On Mother's Day as she helped to bring breakfast in to her mom, Leah yelled, "Happy Hoonie!!" We have no idea who or what a Hoonie is, but since then multiple times a day we hear "Happy Hoonie!" yelled by one of our other four children. We are excited for the day that the word Hoonie is added to the dictionary and we can finally find out what it is.

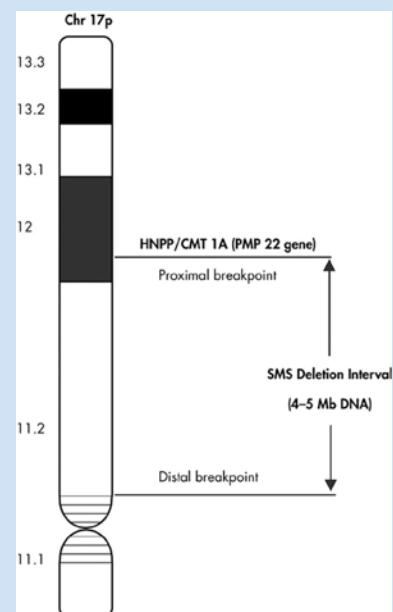


## What is Smith-Magenis Syndrome?

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.



Join us on Facebook!  
PRISMS/Smith-Magenis

# SMS SuperKid

## Lucas



Lucas is our adorable son. He is four-years-old. When he was a baby he presented low muscle tone, developmental delay, lethargy and complacency...And cute rosy cheeks.

As he was growing up, we realized that the delays were persisting. He started to have nighttime awakenings and daytime naps, as well as maladaptive behaviors. Many times we had to return home because of his tantrums and outbursts.

After many comings and goings, we discovered he had Smith-Magenis Syndrome. He was three-years-old at that time.

We felt sad and lost. We began to study, to read all the papers and articles that we could. Finally, we found out about PRISMS and became members. We have read the many parent statements and have seen so many cute pictures on the website.

We always encourage our Lucas. We noticed that the irritability decreased. Today, he has multiple therapies: music therapy, art therapy, speech therapy, and occupational therapy in a special school. He studies at this same school in the afternoon. He has enjoyed school a lot

and his temper is getting better.

He is very cute. He speaks his own way and we understand him. A few months ago, he said he loved me. I'm so proud of him.

Lucas loves Mickey Mouse and his friends! He loves playing Angry Birds.

He has a 13-year-old sister. He loves when she hides him under the pillows so that I can try and find him.

He loves very much to stay in my arms inside the swimming pool.

His smile is delightful!!!!

Nowadays, when I realize that a tantrum is coming, I ask about Mickey Mouse or Goofy and his happy smile comes back

Lucas is our adorable SMS SuperKid!!! - Mom, Eliane



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](mailto:editor@prisms.org).

## The World of Head Banging

From someone with  
Smith-Magenis Syndrome to you

by Evelyn Popper

I want to act right,  
Really I do.  
But sometimes inside  
I boil like a stew.

Like a bubbling pot  
It all overflows,  
And then I feel bad  
From my head to my toes.

If I'm tired or nervous  
Or think that I failed,  
If *you* act too jumpy,  
Then I get de-railed.

If noises surprise me  
Or it's stressful too long,  
If I'm bored or in conflict,  
Things start to go wrong.

I can't say how I feel.  
I can't tell you what's wrong.  
So the angries build up.  
The frustrations get strong.

'Til the feelings push out  
And explode out of me,  
It is scary to feel,  
It is scary to see.

My brain starts to make  
Strong electrical sparks  
That fill up my insides  
And thrash me like sharks.

Though I try so, so hard  
To be calm and OK,  
It is tough when my heart  
Keeps on pounding this way.

My muscles take over  
By quivering and tightening.  
I start hitting myself.  
I'm embarrassed. It's frightening.

My neck gets rock hard,  
I start banging my head,  
Punch my face with my fists  
'Til my cheeks turn bright red.

SMS takes control,  
Don't know how, don't know why.  
I can't stop it at first,  
Though I want to, and try.

Please help me by being  
Relaxed as can be.  
Don't hold me or scold me.  
That's not right for me.

Please notice I'm working  
So hard to calm down.  
Praise me for trying,  
Don't threaten, don't frown.

Let me borrow your calm,  
Cheer me on, coach me through.  
Say encouraging words,  
Those are things you can do.

Be easy and soft,  
Or you'll just make things worse,  
You will add to my woes  
If you're angry or terse.

I will get back to me,  
We both know that's true.  
Then we'll start things afresh  
And continue like new.

Credit for the idea of letting an SMSer "borrow your calm"  
goes to Mary Beall.

## 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.*



## It Worked For Me!!



### **Book Rehab**

My daughter tends to get rough with her board books and often ends up tearing off the cover and the spine. I don't like tossing out the books, so I turn them into flip books by cutting the pages away from the spine, hole-punching them and keeping them all together with a loose binder ring.

### **Picture Shop**

Before we go on grocery trips, I use clip-art images to make my daughter her own shopping list of items she's responsible for finding in the store. It's a great learning experience, and I love watching her act so grown-up and she is so proud to help!



### **Screen Saver**

After we installed a screen door, my two-year-old son would push on the screen to open it. To stop him from punching through the mesh, I traced his hand on construction paper, laminated the paper and taped it to the area where he should push. It worked instantly.

## **Volunteers Welcomed**

Volunteers have always had an important place at PRISMS. Our volunteers have supported efforts at conferences, edited articles for Spectrum, raised awareness, held fundraising events, served on the Board, and contributed in dozens of other ways. As we continue to support more and more families, we are expanding our volunteer opportunities. We are asking members who would like to support PRISMS to send an email to [info@prisms.org](mailto:info@prisms.org).

Percy Huston will coordinate these efforts moving forward. We look forward to hearing from you.



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PRISMS/Smith-Magenis



Lucas, our SuperKid enjoying some time in his hammock.