

2015 Reaching New Heights and Providing New Services

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Basic Financial Guidance for Caregivers

10 Steps to Help You Start Preparing for the Financial Future of Your Dependent with Special Needs

1. **Plan for future medical, educational and housing needs for your dependent.** Start by thinking about what your dependent's needs will be – medical treatments, funds for college, living situation, etc., – and develop your financial strategy based on those projections.
2. **Review beneficiary designations.** To continue to receive federal aid, dependents with special needs cannot have any assets (cash, art, jewelry) in their name worth more than \$2,000.
3. **Have a family meeting.** With the thoughts that you have facilitated your dependent's special needs throughout their life, meet with your family members to discuss their concerns and options for future care.
4. **Speak with a special needs financial professional and create a team of professionals to assist you in planning.** It's important to form a support team that can help guide you through the options available to you and your family. It should include an attorney, and perhaps a health professional and a school guidance counselor, among others.
5. **Contact local nonprofit organizations for additional resource support.** They may be able to provide resources that can help with planning or that supplement the standard services provided by government agencies.
6. **Apply for government benefits.** Medicaid, Social Security, et al., may help provide for your dependent's needs in the form of medical treatments and supplies, equipment, financial assistance and more.
7. **Prepare your Last Will and Testament (review and update periodically).** It may be especially important to prevent automatic asset distributions directly to a person with special needs, and to be cognizant to not leave your dependent any assets in excess of \$2,000 (as discussed in No. 2 above).
8. **Consider setting up a special needs trust.** This allows caregivers to provide for their dependent's care and quality of life without disqualifying them for federal assistance. Trusts can be set up either funded or unfunded, and must be overseen by a trustee – often the dependent's caregiver and/or a bank trust officer. Funds can be contributed gradually over the years, or the trust can be designated as a beneficiary of an inheritance or life insurance policy. The money in the trust must be used to enhance the dependent with special needs' quality of life, and can help to supplement standard services and benefits provided by government agencies.
9. **Apply for guardianship and conservatorship, if applicable.** Caregivers must apply for a guardianship or conservatorship to maintain legal control over financial and healthcare decisions once a dependent turns 18. This can take up to a year in some states, so it's best to start this process early.
10. **Prepare a Letter of Intent.** Although not legally binding, this document is important for providing direction for the person or persons who will care for your dependent with special needs (it should be stored with other vital documents, such as your Will). Think of it as a "letter to the caregiver." It can cover day-to-day care routines, such as what medical assistance is needed, as well as quality of life guidance.

This is a summary of a presentation made by Salvatore Ferranto, CLU, ChFC, Met Life Representative, at the PRISMS Building Bridges of Hope: 8th International Conference last year in St. Louis.



A Message from PRISMS President *John Mayer*

Greetings! And welcome to the latest edition of Spectrum, the PRISMS journal. As you read the articles and updates in this issue, I hope that you will share in my excitement and appreciation for the projects we have started (or just completed). Behind these stories are many people who contribute to and support our work. I am grateful for their good ideas, their commitment, and their support of our SMS community.

I am beginning my fifth month as President and, even though it sounds like a cliché, it has been busy. Emily Fields, our Executive Director, has brought her enthusiasm, professional standards, and creative energy to our work. Together with my colleagues on the Board, we are building our capacity and developing new programs for you.

The PRISMS Board meets every month, mostly via teleconference. Twice a year we hold a face-to-face meeting, as we did in March, when we gathered in San Antonio where Sylvia and Jeremy Farber hosted our visit. Our in-person meetings are both exhausting and exhilarating as we focus our three days together on project planning and development. We always leave our meetings with a full list of actions to pursue and an updated plan of work for the year. I find this an effective and useful routine.

You will hear more about our initiatives, such as the 2016 international conference in St. Louis, the translation of the "On the Road to Success" book into several languages, new awareness projects, and a research symposium next spring.

To help families with children about to enter adult services, we have organized a work group to develop a publication and resource materials to support planning for adult life and community living. Also, we have started a strategic planning project and retained Robert Miller to lead us in the process. The plan will include vision and value statements, and goals to focus our work over the next three to five years.

I am pleased to serve as President of PRISMS, to have a chance to work with our Board, volunteers, members of the Professional Advisory Board, and others—all in service of you and our SMS community. As always, do not hesitate to reach out to me with your thoughts, ideas and suggestions. We are here for you!



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Meet our Newest Board Members!

Brandon Daniel

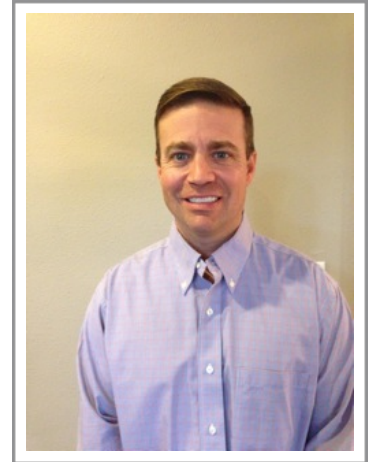
As a first-time member of the PRISMS Board, my role will be to serve as co-chair for fundraising activities. Along with Jeremy Farber, I will work with PRISMS volunteers to expand and grow fundraising events, grants, and donations.

My wife, Dawnda, and I have three boys ages 10, 8 and 11 months, and we live in Prosper, Texas, a suburb north of Dallas. I am the Revenue Administration Manager at Ag-Power, Inc., a John Deere dealer with 17 locations throughout Texas, Arkansas and Missouri.

We received an SMS diagnosis for our 8-year-old son, Coulter, in 2007. PRISMS was instrumental in helping us to determine Coulter's diagnosis at an early stage. If not for the PRISMS website, his diagnosis would have taken much longer.

I look forward to working with the other board members and the PRISMS community in helping PRISMS expand its opportunities both nationally and internationally.

—Brandon Daniel



Rochelle Wright

After approximately a 10-year absence—I previously served as Secretary and later Vice President. I am excited to be back on the PRISMS Board and to support the SMS community as the new Membership Chairperson.

My husband, Paul, and I live in Peachtree City, GA where we moved five years ago from Springboro, OH. We have two sons: Luke, who graduated from high school in May, and Zachary (SMS), who just finished eighth grade and will transition to high school in the fall. Zachary is looking forward to his first time being away from home, when he spends five nights at summer camp in June.

I work for Siemens in the Digital Factory Division, and I am the Director of U.S. Repair Center Operations. I am responsible for nine centers across the U.S. that repair the many Siemens products used in industrial applications including motors, gears, power drives, and controls.

—Rochelle Wright



PRISMS Off to the Races!

Every year, PRISMS is honored to have parents, advocates, friends, and family work together to host awareness and fundraising events across the country to support PRISMS' mission to the SMS community through awareness, education, and research. Each donation is used to advance our programs and services, and to improve our ability to serve SMS families around the world. No idea is too small or impossible.

Joe Toussaint of Houston, TX took initiative this spring to raise awareness and funds in support of PRISMS' work through racing! This is his story.

By Joe Toussaint

As my wife so aptly puts it, we are members of a club we did not seek to join. In fact, all of our families are in the same club: We have children/loved ones with Smith-Magenis Syndrome. That said, I know we are fortunate to have an accurate diagnosis and the resources and support of PRISMS to better understand the issues and how we might seek to address them.

My wife and I are blessed to have an 18-year-old son, Patrick, and a 10-year-old daughter, Megan. We knew from birth that there were issues with Patrick, but it wasn't until we moved to Houston in 2005 that he was diagnosed with SMS.

I have been passionate about automobiles and racing for a long time. I have been active in amateur racing since 2002, and I have raced in a handful of professional races, too. I decided that I would race in a select number of professional races in 2015 in a series known as the Pirelli World Challenge (www.world-challenge.com). This series receives TV exposure, so I thought it would be a good forum to raise awareness for two organizations that have been especially helpful to us and to Patrick: PRISMS and The National Ability Center in Park City, UT. The team I race with, Autometrics Motorsports, also graciously put the logos on their other cars.

In addition to placing the logos on the race cars, I emailed a group of friends in support of the effort. My thought was that even a \$1 contribution would be more than would have otherwise been raised. I know that a meaningful amount of donations were made to both PRISMS and the NAC, so the outcome was terrific!

The first race was in March in Austin, TX at the Formula 1 track known as the Circuit of the Americas. I soon realized I was in the very deep end of the talent pool; some of the world's best sports car drivers race in this series. Needless to say, I was intimidated! I had a self-inflicted issue in the first race, and the second race was held in a torrential rain. I finished—and not in last place—so I can say that was a little victory. Both of the Autometrics cars finished on the podium (first and third) in their races, with the PRISMS logo proudly displayed!

The real victory was for PRISMS and The National Ability Center!

Contact us at info@prisms.org to find out how PRISMS can support your efforts!



Support the PRISMS 2015 Giving Campaign

We are excited to announce our PRISMS 2015 Giving Campaign, which we hope will become an annual fundraising initiative to advance PRISMS' mission and ability to support SMS families around the world through education, awareness and research. **Our PRISMS 2015 Giving Campaign goal is to raise \$110,000 by the end of the year.**

The funds we raise together will be utilized to support PRISMS' general fund, with special emphasis on the 2016 Building Bridges of Hope Conference to be held July 28-30, 2016 in St. Louis. Through this campaign, PRISMS can ensure that more families, educators, and researchers can attend and benefit from this unique, three-day experience and gain access to the support they need.

We can't meet our goal without you! Consider hosting a fundraising event in your area this summer. There is no better time than now to organize a fundraising event in your community as PRISMS looks to grow and expand its reach both nationally and internationally to provide needed resources to the entire PRISMS family.

Along with supporting our 2016 International Conference, this campaign will allow further

research on SMS through PRISMS' Professional Advisory Board and the pursuit of additional publications that will assist the PRISMS community with the challenges and opportunities of caring for those with SMS. An example of a future publication your efforts can help make possible would be a resource on "Adult Living and Residential Settings for those with SMS."

Interested in organizing a fundraising event in your community? Want to help but aren't sure where to start? Contact us at info@prisms.org and resources will be provided to assist your efforts.

Fundraising proceeds and donations will be tracked on our website throughout the campaign as we work toward the goal.

PRISMS is thankful for your kind and generous support!

We are stronger together.

Brandon Daniel & Jeremy Farber
PRISMS Fundraising Co-Chairs



Pennies for PRISMS

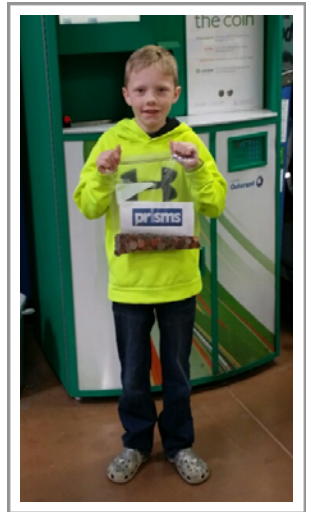
There is no age limit when it comes to supporting the SMS community. 10-year-old Ridge Daniel, brother to Coulter (SMS), decided he wanted to do his part by collecting loose change from around his house to donate to PRISMS' mission. We could not be more thankful or proud of Ridge's initiative! Read more in Ridge's own words below.

Not many people know about the PRISMS organization for helping families with siblings with SMS (Smith-Magenis Syndrome). Which is when you don't have a 17th chromosome which affects your mind in oral motor skills and sensory integration.

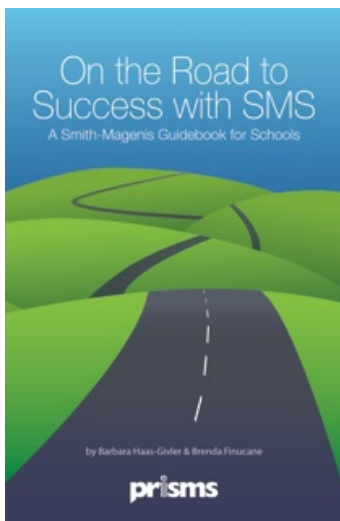
So what we have done is collected change and put it in a jar for a few months and then cash it in and we had \$25.00 for PRISMS and we encourage you to do it too!

Just get any spare change you have and keep collecting for a while and cash it to PRISMS. And there you have it!

--Ridge Daniel, age 10, brother to Coulter (with SMS)



International SMS Resource



SMS is a condition that affects families around the world and across many languages. PRISMS recognizes this fact and the important role our organization must play in education, awareness, and research internationally. Our SMS community knows no boundaries, which is why PRISMS is thrilled to announce a translation initiative for "On the Road to Success—A Smith-Magenis Guidebook for Schools" by Barbara Haas-Givler and Brenda Finucane.

We currently are working with our international community members to bring this resource to five other languages: Italian, German, Danish, Spanish, and French. In the future, these languages will be available in digital form via Kindle.

First introduced at the 2014 International Conference in St. Louis, "On the Road to Success" is comprised of practical tips, strategies, and accumulated wisdom from professionals who have spent years working with the SMS community. Resources like this are imperative to our community, as the journey to raise and care for our SMS loved ones is not an easy one.

The book includes features such as:

- Common Behavioral Challenges in the School Setting: Tips for Successful Inclusion
- Challenges for Siblings
- Finding Support for the Whole Family

English Version: Please go to the online order form to order your copy today! Please use the following link to purchase the PRISMS book in digital form from Amazon - http://www.amazon.com/dp/B00R0G4AMQ/ref=r_soa_s_b.

Interested in learning more about our initiative to make this resource available in other languages? Questions? Comments? Please contact Emily Fields, Executive Director, at efields@prisms.org

“Top 10 Clues”



By Tina McGrevy, PRISMS Board Member

*Tina McGrevy is a PRISMS Board Member and Awareness Chair with three sons, Garrett (SMS), Patrick, and Brennan. She blogs regularly at tinamcgrevy.blogspot.com and her stories about SMS life have appeared in *Chicken Soup for the Soul*, on the *Firefly Garden*, and *The Mighty*. Tina’s “**10 Signs That You Are a Special Needs Parent**” has most recently been featured on *The Mighty* and *Yahoo.com*.*

When our son was diagnosed with Smith-Magenis Syndrome, family and friends reminded me that he hadn’t really changed. Although he may have been the same baby I had fallen in love with, I was the one who had endured a major transformation: I was now a special needs mom. How did I know I was different from my fellow “Mommy and Me” acquaintances?

The reasons are listed below.

The Top 10 Clues that You Are a Special Needs Parent

10. You have watched three generations of Barney’s Backyard Gang grow up.

9. Your conversations contain more acronyms than a military SOP (standard operating procedure).

8. You know that white vinegar gets “the smell” out of clothes, bleach gets “the stain” out of clothes; and bad things happen if you accidentally mix vinegar and bleach.

7. Most of your phone contacts are your child’s teachers, aides, school secretary, bus drivers, doctors and therapists.

6. You know it always comes down to two choices: laugh or cry.

5. You never leave home without a Plan B. Sometimes, even a Plan C!

4. Your house has more locks and alarms than Fort Knox.

3. You find yourself using sign language without even realizing it.

3. You kick yourself for not having the foresight to have invented Clorox bleach wipes.

3. You are so exhausted that your Top 10 List actually has 12 items because you wrote No. 3 three times.

2. Your retirement plans include three people, not two.

1. And the No. 1 clue that lets you know that you are a special needs parent is when your absolute, very BEST friends are those parents who have a child with the same syndrome, disability or condition as yours—and you cannot imagine your life without them!



PRISMS 8th SMS Research Symposium

PRISMS is honored to announce that our 8th SMS Research Symposium will be held on February 4-5, 2016 at Baylor College of Medicine, Houston, TX.

The two-day PRISMS' event will include:

- A formal meeting of PRISMS' Professional Advisory Board
- Evening reception for all symposium attendees
- Full day of presentations on current research related to SMS

This research meeting seeks contributors from around the globe who are actively participating in research related to SMS with recently published or ongoing studies with interim results.

We invite members of the research community who are involved in current research of SMS or who may be interested in learning more about SMS for future research and collaborations. The intent of this meeting is not only to share research information within the established SMS research community, but also to reach outward to engage prospective researchers and broaden the current research landscape of SMS. The Research Symposium is a closed event for members of the research professional community. A report of the symposium will be shared with the entire PRISMS community in the PRISMS Spectrum following the meeting in 2016, as well as at the 2016 International "Building Bridges of Hope" Conference in St. Louis, MO.

More information regarding PRISMS' 8th SMS Research Symposium will follow in the months to come as we move further in the planning process.

Questions? Please contact Emily Fields, Executive Director, at efields@prisms.org.

PRISMS 9th International "Building Bridges of Hope" Conference

Work for the 2016 PRISMS Conference in St. Louis is underway! Our goal is to put together a conference that meets the needs of our families as determined by the feedback from the 2014 PRISMS Conference.

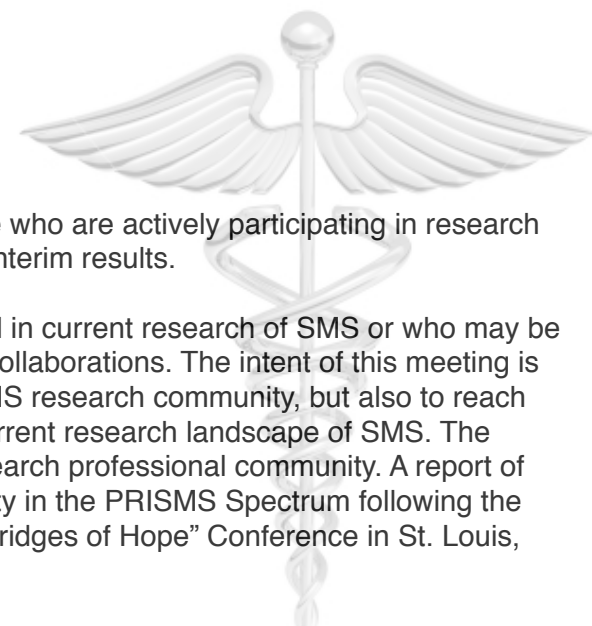
PRISMS 9th International Conference will be held July 28- 30, 2016 in St. Louis at the Hilton Hotel. The conference will begin with pre-conference sessions on Thursday afternoon and Friday with full day and evening sessions. The conference will conclude on Saturday afternoon with a closing reception.

We are currently seeking your conference session ideas and suggestions for speakers. The conference planning committee is busy planning the agenda for the conference and PRISMS would like your input. If you have an idea for a specific session topic or speaker, please let us know. All suggestions will be reviewed and decided upon by the planning committee and the PRISMS Professional Advisory Board.

Thank you for your support!

You can share your suggestions by sending an email to conference2016@prisms.org

Save the Date! 2016 PRISMS Conference will be held July 28-30, 2016 at the Hilton St. Louis at the Ballpark, St. Louis, MO.





Neal turned eight last October and is in second grade. He remains enthusiastic about school (we'll see if that passion lasts through high school!). We are glad that he spends much of the day with his second grade classmates but can still go to the Life Skills classroom for down time. He is learning to read many sight words, and he excitedly goes to the library and loads up a basket full of every book he can find about airplanes. And he checks out the books by himself. Now we just need to work on getting them back on time!

Neal also is growing socially, and he's learning to share, take turns, and deal with emotions. He receives guidance from such TV shows as "Daniel Tiger's Neighborhood" and "Ni Hao, Kai Lan." He is an "Ask this Old House" enthusiast and tells us that he wants to paint our house a different color—yellow. This was after he helped paint our house

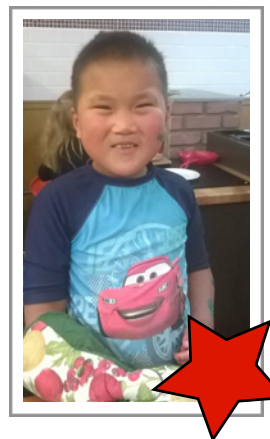
green. He is more than willing to take up a brush and apply paint to all vertical surfaces—no matter what they are. The minute we get a tape measure out, Neal takes one end and we start measuring all sorts of wooden things, such as doors and floor pieces.

Lakes and ocean beaches are Neal's favorite places. He collects just about everything—leaves, nuts, shells, feathers, sticks, rocks—for his sand castles. He loves swimming and has enough lung capacity to swim almost an entire width of the pool underwater. Neal also loves gymnastics, especially hanging upside down from the monkey bars and jumping headfirst into the foam pit. Mini-golf is his new passion. He now has his own putter and handily makes holes-in-one ("Easy peasy," he says).

Neal also is learning about the "birds, bats and the bees." When asked about the difference between a bat and a bird, he said it is the feathers. When we viewed a full-scale skeleton of an elephant at the zoo, he noted that the baby elephant grows in the tummy, and then he found an example of a small "baby" elephant close by on exhibit to emphasize his point. Speaking of babies, he once told his mother that he wished he could have a baby in his tummy. When she told him that only women could have babies in tummies he said, "Oh, bummer!"

Well, that is the news about Neal. His parents are doing well—we are a bit tired but grateful to have Neal and our family surrounding us with love. We sing to Neal these lyrics from a special song:
 "You are our ray of sunshine.
 "You are our shining star.
 "You are our dearest treasure.
 "We love you for who you are."

--Lou and Jennifer (parents)

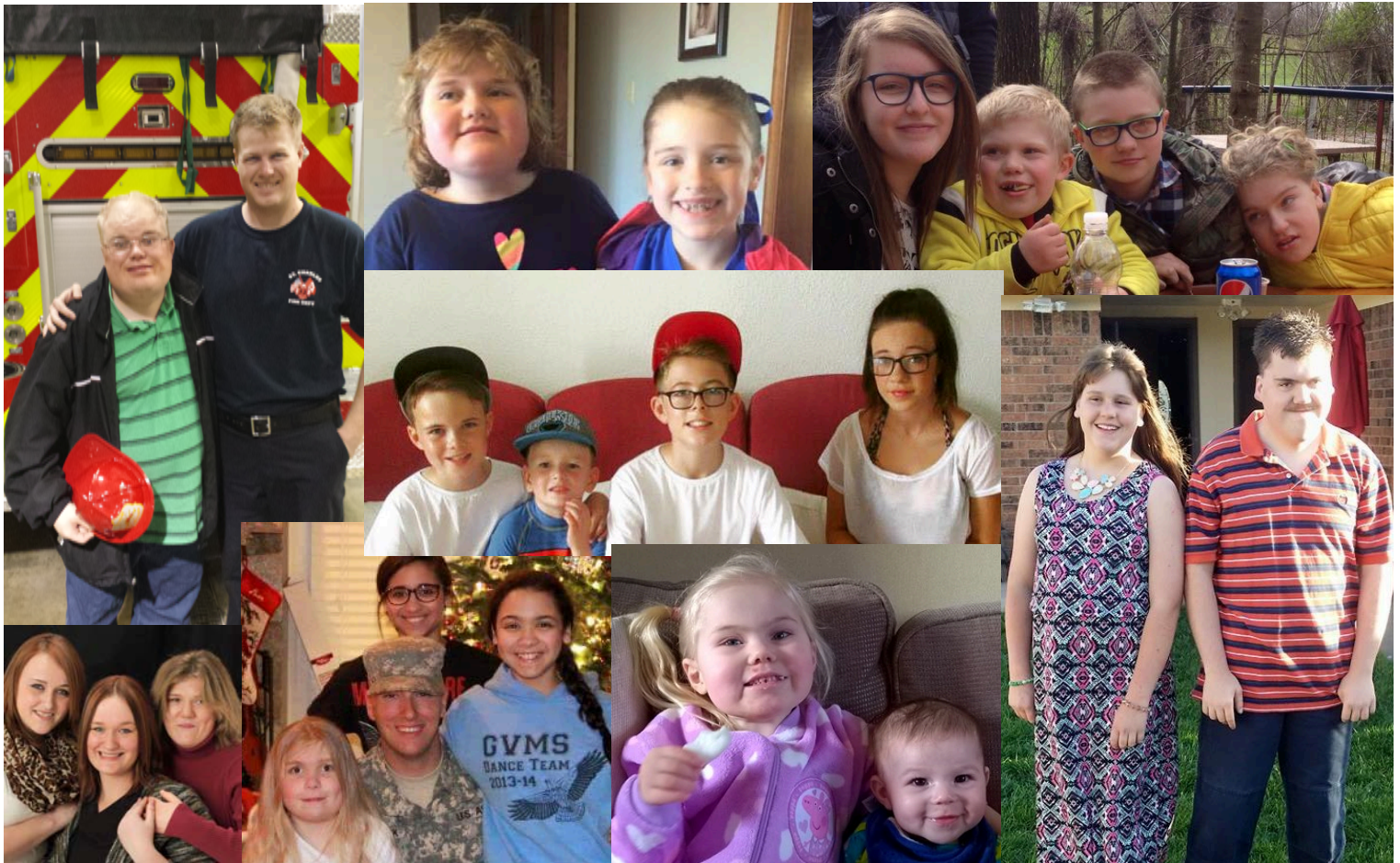


Siblings



The bond between siblings is special and lifelong, and on April 10, 2015 PRISMS' families joined in celebrating that bond by sharing photos across social media for National Siblings Day. Take a look at some of these special sibling moments.





Thank you to all of our siblings for their love, strength, and support!



Find us on Social Media



Host a fundraiser or awareness event in your area

Contact info@prisms.org for support and ideas to make your event a success

Join the PRISMS community by becoming a member for 2015

Learn more about membership by visiting our website at www.prisms.org

Make a donation

Support PRISMS' mission to increase awareness, education, and research for the SMS community by visiting our website and making a donation today at www.prisms.org

Share your story with us

We want to hear from you. Reach out to PRISMS' Executive Director at cfields@prisms.org

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Support PRISMS while you shop. Amazon will donate 0.5% of the price of eligible AmazonSmile purchases to PRISMS.

AmazonSmile is the same Amazon you know--same products, same prices, same service. Follow these simple steps to support PRISMS while you shop!

1. Go to www.smile.amazon.com
2. Type "PRISMS, Inc" in the pick your charitable organization text box. Click Search. (Note: type PRISMS in capital letters.)
3. Select "Prisms, Inc." There are a few organizations with the same name. Choose the PRISMS in Sterling, VA founded in 1993. Click "about" if you want to confirm you have chosen the correct PRISMS.
4. Save smile.amazon.com to your bookmarks or favorites bar to make it easy to return to AmazonSmile. In order for PRISMS to receive a percentage, you must shop through smile.amazon.com.
5. Share with friends and family.
6. Enjoy shopping knowing you are supporting PRISMS!



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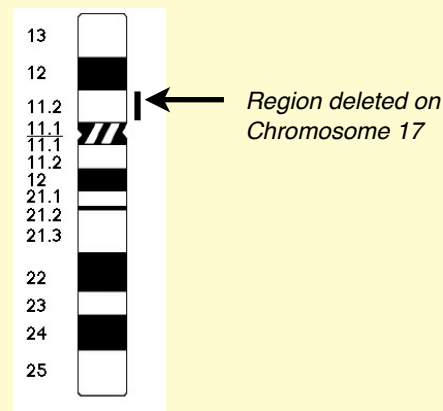
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What is Smith-Magenis Syndrome?



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 under-diagnosed, but as awareness of it increases, the number of people identified grows every year.

Volunteer Opportunities

Journal assistant editor sought! PRISMS is seeking a volunteer with organizational skills, computer skills, and an eye for design. We are specifically seeking an individual with experience in publishing software. We need someone to get the data from the editor of Spectrum and place it into the right format for electronic distribution. This position does require computer experience and good communication skills. There is a well-developed newsletter committee to support the editor and assistant editor. For more information on how you can help PRISMS please contact editor@prisms.org.