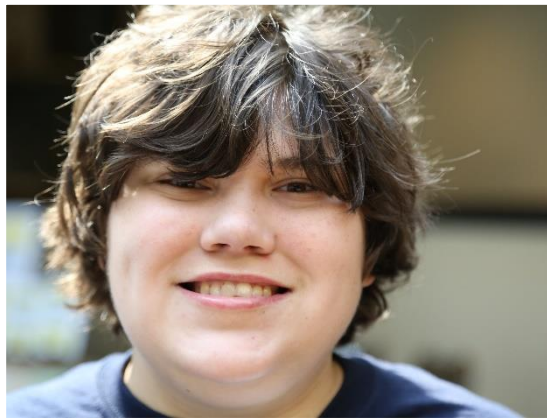


Reaching New Heights and Providing New Services



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President's Message



Greetings!

In less than a year we will be gathering in St. Louis for PRISMS' 9th International "Building Bridges of Hope" Conference (July 28-30, 2016). If you have never attended, or if you have been to our conferences before, I hope you can join us for these few days of education, empowerment, and community. Please mark your calendars and keep your eyes open for more details soon.

It's inspiring to see so many families and professionals come together to share their knowledge and experiences. The 2014 conference brought more than 350 attendees from eight countries! After each conference, I find myself renewed with energy and filled with new ideas—and I am supported by the new friendships I make and those I renew.

Organizing the conference is quite a process. All of us on the PRISMS Board are grateful for the leadership and hard work of Maggie Miller, chair of the Conference Committee. She and the committee members are responsible for organizing every aspect of the program. Their work begins almost immediately after the last conference, and is truly an all-consuming process. The results are remarkable.

PRISMS is committed to making the conference affordable and accessible for all. For families who might need help with travel or registration expenses, we will offer financial aid. Information will be available soon about this scholarship program.

Another important initiative you will read about is our 2016 Giving Campaign. Board members Jeremy Farber and Brandon Daniel are leading the effort to raise funds for the conference and for other PRISMS initiatives. It does "take a village", and you all are part of the PRISMS community. Your support makes a difference and is vital to our success. We welcome your contributions to meet our fundraising goals.

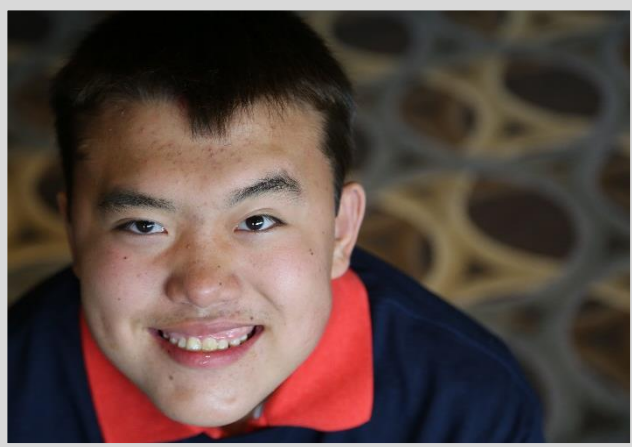
In October, the PRISMS Board will be holding its fall face-to-face meeting in St. Louis. The meeting will include a day-long retreat to complete our first-ever strategic plan, and a second day devoted to the budget and plan of work for 2016. These meetings are productive but exhausting. I am fortunate to be part of a Board that is completely dedicated to ensuring PRISMS moves forward with families' needs in mind.

As always, I thank you for your interest, participation, and support of PRISMS. We are here for you. Anytime you have an issue you would like to share with us, please let me know.

I look forward to hearing from you and seeing you in St. Louis!

Sincerely yours,

John Mayer
President, Board of Directors
jmayer@prisms.org



PRISMS 9th International “Building Bridges of Hope” Conference

July 28-30, 2016
Hilton Hotel at the Ballpark
St. Louis, Missouri

PRISMS biennial International “Building Bridges of Hope” Conference has been developed to educate and share information about Smith-Magenis Syndrome (SMS) with families, educators, caregivers, physicians, researchers, and other stakeholders in this rare community. PRISMS hosts this event every other year to create an educational environment where all can learn about SMS and the many facets of the syndrome, to share information and strategies for care and living, and to provide an area of support and understanding for families.

In 2014, PRISMS’ conference brought more than 350 registered attendees representing eight countries from around the globe! Attendees were given the opportunity to engage in more than 40 sessions covering topics ranging from *Nutrition Therapy, Sibling Support, and Behavior Strategies to Research Updates* from leading researchers in SMS, *Medical Management, Genetics 101* and more.

The Conference Planning Committee has already begun preparing for the 2016 PRISMS Conference. We hope that you will do the same and start planning your trip to attend this event next July. PRISMS Board and staff takes pride in creating a conference that is invaluable to families and professionals alike, and advances the SMS community forward. Each year, PRISMS makes every effort to ensure that the conference is as affordable as possible to all who wish to attend and benefit from the three-day education and support event.

To assist you in your planning, please consider the list of registration fees and our negotiated hotel rate. Each year, PRISMS offers a number of scholarships to families seeking financial aid to attend the conference. Limited financial aid will be available, and more details will be announced in the coming months. Childcare, at a cost still to be determined, will be available at the conference.

Registration Fees:

<i>Adult (16 & up)</i>	\$225
<i>Child (15 & under)</i>	\$100
<i>SMS Individual</i>	\$75
<i>Professional</i>	\$300
<i>Professional in training</i>	\$250

The guest room rate for the Hilton St. Louis at the Ballpark is \$137/night for a single or double room.

NOTE: Please don’t try to book your room 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 2016.

We hope you will join us next year for this unique opportunity for empowerment, support, and community!

Questions or comments about the upcoming conference? Contact Emily Fields, Executive Director, efields@prisms.org

Giving Campaign



PRISMS' Board and staff take pride in creating a conference that is invaluable to families and professionals alike, and advances the SMS community forward. Putting on such a large-scale event is no easy feat. Each year, PRISMS makes every effort to ensure that the International "Building Bridges of Hope" Conference is as affordable as possible to all who wish to attend and benefit from the three-day educational event.

PRISMS accomplishes this by providing scholarship opportunities to cover conference costs for families—ranging from registration, to hotel accommodations, to travel—heavily subsidizing the true cost to our attendees.

We believe that the conference should be accessible to all, and we are determined to keep costs of attendance for families and educators low. PRISMS is committed to organizing and hosting a high-quality conference full of content that is relevant and empowering for all attendees. We believe that together through education, awareness, and research for SMS, we are all stronger.

The true cost per person at our international conference is approximately \$700, with registration per attendee at just \$225. PRISMS subsidizes more than

\$500 of each registrant's cost of attendance, because we want this powerful opportunity to be accessible to as many families as possible.

You can help support our efforts to ensure that more families and educators have the opportunity to engage and learn at the 2016 International "Building Bridges of Hope" Conference by making a donation to our 2015 Giving Campaign. We accept charitable gifts of all sizes, and are actively searching for sponsors.

With a goal of \$110,000 by December 31, 2015, your support matters! To date, PRISMS has received generous contributions to the Giving Campaign totaling nearly \$31,000. We still have a long way to go. Help support PRISMS' work, and ensure that more families can benefit from the unique conference experience in 2016. Visit www.prisms.org to make your donation, or mail a check to 21800 Town Center Plaza, Suite 266A-633, Sterling, VA 20164.

You can also show your support by hosting a fundraiser in your area and contributing donations to PRISMS. Fundraisers don't have to be complicated and can be fun for the whole family! Let PRISMS know about an upcoming fundraiser, and we'll send you awareness materials, including PRISMS brochures, bookmarks, and SMS wristbands.

Here are some other ways to raise money and awareness for PRISMS:

- Ask a local restaurant or bar if they would be willing to host a fundraising night to benefit PRISMS and the SMS community. Many restaurants are willing to donate 10 to 25 percent of a night's earnings to a worthy 501(c)3, if you simply ask. Some participating restaurants include: [Applebee's](#), [Arby's](#), [Boston Market](#), [California Pizza Kitchen](#), [Chili's](#), [Chipotle](#), [Friendly's](#), [Fuddruckers](#), [Max and Erma's](#), [Outback Steakhouse](#), [Panda Express](#), [Panera](#), [Pizzeria Uno](#), [Ponderosa](#), [Red Robin](#), [T.G.I. Friday's](#), and [Wendy's](#).
- Host a BBQ at your house, inviting friends, family, and colleagues. Enjoy each other's

company, and share a bit about your SMS child and the challenges and successes you face. Share information about PRISMS and the support the organization offers to SMS families around the world. Ask your guests if they would be willing to share an email address or phone number with you to pass along to PRISMS. Share the list of contacts with PRISMS at info@prisms.org. PRISMS will reach out to your guests to explain more about the organization and let them know about opportunities to support the organization and our work.

- Clean out the attic, straighten up the garage, de-clutter the closets, and host a yard sale. Give patrons the option of making an additional donation to support PRISMS, Inc. Donate the proceeds.

For more ideas, check out this fun [A-Z Fundraising Guide](#) developed by the National Organization for Rare Disorders to help individuals come up with clever ways to raise funds to support patient organizations, like PRISMS. Whether you raise \$10 or \$10,000, your donation matters and goes a long way to ensuring that PRISMS is able to reach and engage all SMS families.

Questions? Interested in starting a fundraiser but not sure how to begin? Contact Emily Fields, Executive Director, efields@prisms.org or 972-231-0035

Infections vs. Autoimmune Diseases in SMS Patients

By Dr. Neil Romberg

People with Smith-Magenis Syndrome experience a significant number of typical and atypical infections. Dr. Neil Romberg is studying the immune system of people with SMS to determine the biological explanation for this phenomenon. A key objective of his work is to catalogue the types of infections and other immunological problems that people with SMS experience.

The immune system has two major functions: first to protect us from getting infections, and second to prevent us from developing autoimmune diseases. Most patients with genetic diseases of the immune system have difficulty performing both of these tasks.

In an upcoming issue of "The Journal of Allergy and Clinical Immunology", Dr. Romberg and colleagues investigate why SMS patients experience an increased susceptibility to infections but not autoimmune diseases. At the heart of the puzzle is the gene *TAC1*, located on chromosome 17p11.2 near the SMS gene *RAI1*.

In the article, Romberg shows that *TAC1* is essential for both protection from microbes and removal of self-reactive white blood cells that cause autoimmune diseases. Using blood samples from SMS patients with one *TAC1* gene deleted, the researchers demonstrated that while one *TAC1* gene is sufficient to prevent autoimmune disease, two are required to prevent infections.

At PRISMS' 2014 International Conference in St. Louis, more than 60 families described the immunological issues experienced by their SMS-affected family member by completing Dr. Romberg's "SMS Immunological Diseases Survey." The survey responses were rich and compelling.

"We could not have completed this work without PRISMS, who helped us to partner with SMS patients and families interested in participating in our research," said Dr. Romberg, who recently moved his laboratory from Yale University to the Children's Hospital of Philadelphia. Families interested in participating with Dr. Romberg's ongoing work on the immunology of SMS are encouraged to visit the "Research Participation Opportunities" section of the PRISMS website.

(The full article and findings will be published through [Pub-med](#) at the end of 2015.)

Advocacy Resources

PRISMS is always ready to support SMS families through its Regional Representative Program, Professional Advisory Board, and network of more than 300 members. However, we realize that sometimes you need to step outside of our community to find an advocate for your SMS family member. Below is a list (with descriptions) of some of the national, and international advocacy resources available.

NORD's Rare Action Network

National Organization for Rare Disorders' (NORD)'s Rare Action Network mobilizes grassroots supporters across the country to advocate for policies that benefit patients with rare diseases. The network operates primarily at the state level to complement NORD's already robust Federal policy work.

The network is composed of stakeholders across the community, including NORD members, other patient advocacy groups, state-based health coalitions, state health departments, state health insurers, healthcare providers, and professional medical societies.

To learn more about the Rare Action Network, visit <http://rarediseases.org/for-patient-organizations/ways-partner/advocacy/>

Rare Disease Legislative Advocates (RDLA)

RDLA is a collaborative organization designed to support the advocacy of all rare disease groups. By growing the patient advocacy community and working collectively, we can amplify our many voices to ensure rare disease patients are heard in state and federal government.

For more information on policies and regulations, and how RDLA impacts the SMS community and the rare disease community as a whole, please visit <http://rareadvocates.org/>

National Disabilities Rights Network (NDRN)

www.ndrn.org

The National Disability Rights Network advocates for disability rights on a large scale.

Council of Parents, Attorneys and Advocates

www.copaa.org

COPAA is a national American advocacy association of parents of children with disabilities, their attorneys, advocates, and others who support the educational and civil rights of children with disabilities.

Wrightslaw (www.wrightslaw.com)

Wrightslaw is a leading website about special education law and advocacy, with thousands of articles, cases, and resources.

Canadian Organization for Rare Disorders (CORD)

www.raredisorders.ca

CORD is Canada's national network representing all those with rare disorders. It provides a strong common voice to advocate for health policy and a healthcare system that works for those with rare disorders. CORD works with governments, researchers, clinicians, and industry to promote research, diagnosis, treatment and services for all rare disorders in Canada.

EURORDIS (www.eurordis.org)

EURORDIS is a non-governmental, patient-driven alliance of patient organizations representing 687 rare disease organizations covering more than 4,000 diseases in 63 countries. EURORDIS' mission is to build a strong pan-European community of patient organizations and people living with rare diseases, to be their voice at the European level, and, directly or indirectly, fight against the impact of rare diseases on their lives.

A Rare Syndrome, a Brother's Love

By Susan Seligson

By Cydney Scott for Boston University Photography



When Zach Kon was an infant, his mother suspected something wasn't right. He had a protruding jaw, a prominent forehead, and flattened features. As Zach grew, his speech was delayed, his facial muscle tone slackened, and when he did speak, his words were slurred and often

unintelligible. Despite his exuberance toward strangers, he had aggressive outbursts at home and at school. And he constantly hugged himself. After years of misdiagnoses of Tourette syndrome or autism, DNA testing revealed that Zach had a rare disorder called Smith-Magenis syndrome (SMS), the result of a mutation in his DNA.

The family's struggle to identify and treat Zach's disorder inspired his older brother, Max Kon, to become a linguist and speech pathologist and devote his research to better understanding the disorder his family once called "Tourette's Plus."

Because SMS is not widely understood, there is no specific treatment for it, says Kon. He hopes that studying how children with SMS learn to speak and why they interpret written and spoken words differently than typically developing learners will lead to a targeted approach to treatment.

From the delayed speech and language skills to the irrepressible bonding with strangers—"He has way more friends than I do," his brother says—Zach fits the textbook profile of SMS, a condition that affects an estimated one in 25,000 people worldwide.

The disorder is not typically inherited and is caused by a mutation, or permanent alteration, in a DNA sequence during the formation of reproductive cells in the early development of the fetus. The mutation's cause is unknown, Kon says, and the precise genetics of SMS are for scientists in another field to decipher.

As of now, the disorder, identified in 1986 by geneticists Ann Smith and Ellen Magenis, remains poorly understood, says Kon's mentor, Sudha Arunachalam, a Sargent College assistant professor of speech, language, and hearing sciences, and director of the Boston University Child Language Lab, where master's student Kon trained to do his research. Study sample sizes have been small, not only because the disorder is rare, but because it often goes undiagnosed.

Individuals diagnosed with SMS are often treated with applied behavior analysis (ABA), which targets skills related to attention span, language comprehension,

and reading and math. (Other practitioners address SMS children's sleep disturbances and behavior issues.) Designed for children and teens, the tasks used in ABA involve clear instructions, positive reinforcement, and repeated trials.

For Zach, who wasn't diagnosed with SMS until his teens, intervention with ABA had mixed results, Kon says. Zach's treatment involved modifying inappropriate behavior by focusing on the "antecedent"—the conditions leading up to the behavior—rather than on the outcome. For children with SMS, "this tilts the balance toward maintaining a positive, helpful environment rather than setting expectations," his brother says. This treatment is frequently used to treat children with autism, but tends to be less reliable for those with SMS, he says, who require more individualized intervention.

Kon has been working with Arunachalam to establish the first comprehensive picture of what the SMS population looks like in terms of language expression and understanding: their strengths and weaknesses, how their abilities grow over time, and whether this growth is dependent on the kinds of intervention they experience, she says.

Arunachalam advised Kon as he prepared the study, helping him to "formulate questions and look at the disorder from a broader research perspective," he says. Since Kon's graduate education has been largely focused on clinical practice as a speech pathologist, Arunachalam helped him integrate the more clinical aspects, such as language testing and

behavior management, with the rigorous standards of research. She helped Kon ensure his documentation and testing met the standards of the University's Institutional Review Board (IRB), which must approve all research involving human subjects.

In July 2014, Kon attended PRISMS' 8th International "Building Bridges of Hope" Conference in St. Louis, where those with SMS and their families gathered to share experiences and learn about research and treatment updates. Kon emailed families on the participant list before the conference and recruited eight children to his study. "While autism is a more common disorder and we can recruit participants to come to the lab, SMS is far less common, so I need to go to them," he explains. At the four-day conference, he tested the children, one-on-one, whose parents had agreed to participate.

The children, who ranged in age from 5 to 10, took part in a series of tests to probe their levels of language ability and comprehension. In one test, Kon held up a board with four pictures and asked his young participants to point to the objects—shovel, tree, hat—as he named them. While some were capable of following directions, others responded to something close, pointing, for example, to "cat" instead of "hat," which indicates difficulty listening, hearing, or comprehending the command, says Kon. One child pointed to a dog when asked to point to a cat, indicating difficulty associating meanings and sounds. "And some children, while social and happy enough to spend time with me," he says, "did not respond at all,

indicating poor comprehension or an inability to recognize my intent.”

In another, slightly more difficult test, Kon used two pictures, one of a boy kicking a ball and one of a boy hugging a girl, and asked the participants to identify the picture of the boy hugging the girl. This test examines a child’s understanding of syntax. “Think of how complicated English can be,” Kon says. Sentences as similar as “The boy hugged the girl” and “The boy was hugged by the girl” require what speech pathologists call “syntactic comprehension. Testing this comprehension can reflect whether children show patterns in their syntax—passive versus active sentences, for example,” he says, “or whether they understand relatively complicated sentences, but can’t respond verbally with the same level of complexity. Tests like these also measure verbal memory.”

Kon hopes his work will eventually help improve diagnosis of SMS, which now is diagnosed only through genetic testing. He plans to apply to a PhD program to continue his research for the next three to four years and get a better sense of the range of abilities among those diagnosed with the disorder. He also aims to show the key differences between autism spectrum disorder and SMS, and find ways that treatment that has been effective for autism might be tailored to children with SMS. Ultimately, he hopes that his research will enable doctors to diagnose SMS more quickly and that it will lead to a targeted treatment that can be applied as consistently at home as it is at school.

“I’m still in the preliminary phase of analysis,” says Kon, who is in the process of renewing his IRB certification, which will enable him to continue collecting data to increase the sample size as well as track the same participants over time. In the meantime, the more kids with SMS Kon meets, the more he understands the challenges his brother Zach has faced. Now 22, Zach is a high-functioning extrovert living in a group home. A fan of the *Guinness Book of World Records* who is emphatic about people spelling his name right, he is on medications that have largely calmed his aggression.

At the PRISMS Conference in 2014, Zach gave a speech to children with SMS and their families. “My family is the rock of my life and I love them dearly,” he said. “My older brother is really helpful,” and has been “right there from the start. When I am going through a rough patch he says things like, ‘Zach, calm down, take a deep breath,’ and these words will never leave my brain.”

This article is reprinted from BU Today with permission by the author.

Tweets and Pins and Hashtags...Oh My!

By Tina McGrevy

There are a lot of exciting things going on in the PRISMS social media accounts.

For me, checking in with the PRISMS community is a daily ritual. Families are telling stories and posting photos and personal videos from all over the world. Social media is *almost* as great as sharing a cup of coffee across from another SMS family. (Is it time for the 2016 PRISMS Conference yet?)

Below are some highlights of the accounts the PRISMS Awareness Committee currently maintains:

FACEBOOK: PRISMS has a public group on Facebook. “Public” means anything posted in this group can be read by anyone on Facebook. There are more than 1,300 members in the group, which includes parents, siblings, teachers, medical professionals, friends and people born with SMS. The conversations that occur in this group are my favorite part of being the group administrator. Families share photos of milestones—and the whole community cheers! Parents can ask questions about anything from behaviors to gift-giving ideas. More personal questions can be posted anonymously by sending them directly to me (awareness@prisms.org).

TWITTER: The PRISMS Twitter account, also public, is maintained by PRISMS Executive Director Emily Fields. The more than 300 followers include many other rare syndrome organizations, and live conversations happen where exciting information is shared. By following PRISMS on Twitter you’ll gain access to the latest information from a variety of

disabilities organizations, patient advocacy organizations, and healthcare professionals. You can find PRISMS on Twitter @PRISMS_SMS.

INSTAGRAM: Imagine a world-wide photo album. That is the PRISMS Instagram account. PRISMS volunteer Tabitha Petkovich, an SMS sibling, started this account and it has quickly grown to 422 followers. Scrolling down the PRISMS Instagram wall reminds me of the conference photo slide show and brings a lump to my throat every time.



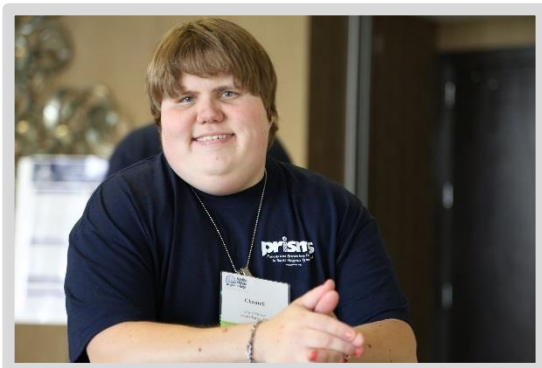
PINTEREST: This fairly new account is a great visual way to store information. Folks can create a “board” that is like a bulletin board hanging in the kitchen. Each board can be labeled, for example, “SMS Articles, News, and Blogs” or “SMS Facts” and related photos, links to newspaper articles or charts of SMS Symptoms can be “pinned” to the appropriate board. I am the administrator for this group and I can’t tell you how much I love this account. Now I can quickly find that great story from a Virginia news channel because the link is pinned to my board. It’s always there! Followers of the PRISMS Pinterest account can visit that board and pin the story to their boards as well.

YOUTUBE: Coming Soon! PRISMS will soon be unveiling a YouTube channel to showcase SMS videos. Stay tuned!

HASHTAGS: Did you know that you can easily search for items shared in a PRISMS account? The trick is in the Hashtag. You know, the pound sign. The Tic-Tac-Toe board. This guy, right here: #.

That is why we ask folks to post to the PRISMS accounts with the hashtag #hugorbehugged, #smithmagenissyndrome and #prismsorg. This works in any of the social media accounts. Go to any search engine and type in these hashtags (no spaces and no periods). When a member posted online and included a hashtag, they made it “searchable” by putting a sort of label on it.

The PRISMS Awareness Committee has some exciting plans coming up for our most favorite of the hashtags: #hugorbehugged. “Hug or Be Hugged” describes life with our unique family members to a “T”; in fact, PRISMS volunteer Dawnda Daniel has created a T-shirt with this hashtag. Wear the Hashtag offline and raise some SMS awareness! Proceeds from the sale benefit PRISMS. Visit the PRISMS Facebook group to learn how to order your shirt today, or contact info@prisms.org.





Regional Representatives

PRISMS routinely receives calls and requests from families of persons with SMS from around the world and at various stages—from newly diagnosed to teens to adults. Often, these families seek to speak to other parents of children with SMS who reside in their geographic region, or have an SMS child in a similar age range.

Last year, PRISMS began work to establish a world-wide regional representative network of parents and families ready to provide support to those families seeking guidance, comfort, and answers. We firmly believe in supporting family connection and the sharing of experiences.

The Regional Representative Program continues to grow and evolve as PRISMS establishes the program to best meet the needs of SMS families. Today, the program is comprised of more than 25 dedicated volunteers committed to sharing lessons learned, providing resources, facilitating meet-ups, and supporting SMS loved ones and their families. PRISMS is thankful to each of these volunteers!

Please know, regional representatives are volunteers, dealing with their own professional and personal lives outside of their volunteer-support efforts with PRISMS. If you need more immediate assistance answering a question, are interested in connecting with other SMS families, or are planning a meet-up of your own, feel free to reach out to PRISMS directly at info@prisms.org.

(Please see the following list for a regional representative nearest to your location.)

North America/US Regions:

New England Region (CT, RI, MA, VT, NH, ME):	Leah Baigell lbaigell@prisms.org
Northeast Region (PA, NY):	Judy Bogdan jbogdan@prisms.org
East Region (NJ, DE, MD):	Ilse Ciprich iciprich@prisms.org
Mid-Atlantic Region (OH, WV, VA):	Mary Hards mhards@prisms.org
Southeast Region (NC, SC, GA, FL):	Mary Daly mdaly@prisms.org
Great Lakes Region (WI, MI, IL, IN):	Brianna Collins bcollins@prisms.org
North Region (MT, ND, SD, MN):	Heidi Graf hgraf@prisms.org
Great Plains Region (IA, NE, MO, OK):	Annetta Zidzik azidzik@prisms.org
South Region (KY, TN, AL, AR, MS, LA):	Jean Bishop jbishop@prisms.org
Northwest Region (OR, ID, NV):	Jennifer Klump jklump@prisms.org
Central West Region (CO, KS, WY, UT):	Eric & Kim Hoffman ehoffman@prisms.org
Southwest Region (NM, AZ):	Alejandro & Delma Aguilar adaquilar@prisms.org

West Region (WA, HI): [Heather Eberlein
heberlein@prisms.org](mailto:heberlein@prisms.org)

Texas Region: [Mary Beall
mbeall@prisms.org](mailto:mbeall@prisms.org)

California Region: [Charlene Liao
cliao@prisms.org](mailto:cliao@prisms.org)

Alaska Region: [Jennifer Schroeder
jschroeder@prisms.org](mailto:jschroeder@prisms.org)

North America/Canada Regions:

Eastern Canada: [Brandi Wilson
bwilson@prisms.org](mailto:bwilson@prisms.org)

Western Canada: [Amanda Downey
adowney@prisms.org](mailto:adowney@prisms.org)

North America/Mexico Region:

Mexico: [Maria Elena Carrancedo
mcarrancedo@prisms.org](mailto:mcarrancedo@prisms.org)

South America Region:

Brazil: [Elaine Barros
ebarros@prisms.org](mailto:ebarros@prisms.org)

France Region:

France: [Stephanie Hanquez
shanquez@prisms.org](mailto:shanquez@prisms.org)
[Virginie Sergent
vsergent@prisms.org](mailto:vsergent@prisms.org)

Italy Region:

Italy: [Sabrina Bisiani
sbisiani@prisms.org](mailto:sbisiani@prisms.org)

Australia Region:

Australia: [Cally Bauman
cbauman@prisms.org](mailto:cbauman@prisms.org)

Russia Region:

Russia: [Alexander & Bela Tzetlin
abtzetlin@prisms.org](mailto:abtzetlin@prisms.org)

For families whose primary language is Spanish, we've identified several contact families that are bilingual:

- [Maria Elena Carrancedo, Mexico City, Mexico
mcarrancedo@prisms.org](mailto:mcarrancedo@prisms.org)
- [Claudia Gomez, Haverstraw, NY
cgoomez@prisms.org](mailto:cgoomez@prisms.org)
- [Ines Oppenheim, Sierra Vista, AZ
ioppenheim@prisms.org](mailto:ioppenheim@prisms.org)
- [Maria Groenewold, Delta, BC Canada
mgroenewold@prisms.org](mailto:mgroenewold@prisms.org)

For families whose primary language is Chinese, we've identified the following contact family:

- [Charlene Liao and Liqun Luo, CA
cliao@prisms.org](mailto:cliao@prisms.org)

Questions regarding the Regional Representative program? Feedback to help strengthen the service to families? Contact Emily Fields, Executive Director, efields@prisms.org



8th SMS Research Symposium



PRISMS will host its 8th Smith-Magenis Syndrome Research Symposium on February 4-5, 2016 at Baylor College of Medicine in Houston, TX.

The two-day event will include:

- A formal meeting of PRISMS' Professional Advisory Board.
- An evening reception for all attendees.
- A 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 outwardly 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 on the symposium will be shared with the entire PRISMS community in the 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 along in the planning process.

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



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Andrea Gropman, M.D. Children's National Medical Center
Gonzalo Laje, M.D. NIH, National Institute of Mental Health
Ann C. M. Smith, M.A., D.Sc. (hon) Chair Emeritus, NIH, National Human Genome Research Institute
Christine Brennan, M.A., CCC-SLP Northwestern University
Jane Charles, M.D. Medical University of SC
Rebecca Foster, Ph.D. St. Louis (MO) Children's Hospital

Music Therapy: Effective in Smith-Magenis Syndrome?

Catherine M. Alexander, MT-BC

Music therapy is the use of musical interventions by a music therapist to address therapeutic goals. The client does not need to possess musical talent to benefit from music therapy, only the ability to enjoy music.

The developmental and behavioral features of Smith-Magenis Syndrome can be addressed through music therapy. Learning to play a musical instrument requires focus and attention. Learning to sing involves breathing skills, ear-tuning skills and rhythmic abilities which can help improve speech and articulation. It can even help reduce impulsivity and repetitive activities.

Music therapy also can benefit SMS features through interactive activities, learning to play an instrument, and music listening. The Listening Program, by Advanced Brain Technologies (ABT), is a documented tool that impacts SMS. It is an at-home listening program conducted five days a week for 30 minutes each day. The Listening Program is documented to impact changes in executive function, communication, auditory processing, social-emotional function, stress response, motor coordination and creativity. It is comprised of specifically chosen classical music altered in gentle, yet effective ways to address these areas.

ABT also has developed the inTime program, which utilizes solely percussive instruments. The percussive nature of the inTime program is more energetic and musically aggressive than The Listening Program, but they complement each other well.

I recently performed a case study using the inTime program on an 11-year-old boy diagnosed with SMS and experienced great results. When he was diagnosed with SMS as a small child, his parents intervened which allowed him to develop strong coping skills. He exhibits difficulty processing information, can be out of sync with his environment, has difficulty with physical coordination, and lacks organization and focus.

The subject was put through two cycles of the inTime program adhering to a basic listening schedule. He was subjected to testing and evaluation to help monitor his progress over the course of the trial. I met with the subject once a week for 30 minutes using Therapeutic Instrumental Music Performance (TIMP) and Musical Executive Function Training (MEFT) to observe and document changes in his behavior. Weekly videos of the subject playing a drum were taken to help document progress.

Changes were observed throughout the course of the 16-week program. Weekly notes and videos taken during each session confirmed that the subject demonstrated more focus, organization, coordination and processing abilities than he had previously demonstrated. No other change occurred in the subject's environment during the trial period. All changes were attributed to the inTime program. The results support the theory that the inTime program is an effective intervention to influence change in behavior of a subject with SMS.

Please contact Catherine M Alexander, MT-BC, at www.harmonylanestudios.com for additional information regarding Music Therapy, the Listening Program, or the case study referenced in this article.

SMS SuperKid

Our son, Cooper, is affectionately known as “Super Duper” Cooper. So when asked to write the SuperKid article for Spectrum, we were excited for the opportunity to share what we think is Super Duper about Cooper!

When Cooper was born, he was examined by a doctor who thought he might have Down syndrome, but tests proved negative. At his two-month well visit, we had several concerns about Cooper’s low muscle tone, growth, and inability to swallow properly. Cooper’s blood was tested a second time and the chromosome SNP (single-nucleotide polymorphism) microarray test was performed, resulting in his diagnosis of Smith-Magenis Syndrome.

To this day, we remember the call we received on June 12, 2010 from our pediatrician providing us with Cooper’s diagnosis. Dr. Jim Fragetta was unfamiliar with SMS but was willing to educate himself, and he promised to provide Cooper the best care. *We will treat Cooper as any other typically developing child until he proves us otherwise*, promised Dr. Fragetta, who has been a source of strength for Cooper—and for us! Dr. Jim has provided thoughtful recommendations for Cooper’s care and is one of Cooper’s biggest cheerleaders in all of his accomplishments.

We find that many people in the medical community are unfamiliar with SMS. Maybe because it’s such a rare genetic disorder. This is what makes our children and adults with SMS so SUPER! They are truly special people with such amazing and endearing qualities.

Something we find amazing about Cooper is his interest and fascination with letters. He absolutely loves to form letters, trace letters, recognize letters in his environment, sign letters, sing the ABC song, and watch YouTube videos of letter tracing. (He’s also a big fan of Playdoh Egg Surprise on YouTube!)

Cooper’s attraction to letters began around his fifth birthday when we gave him the LeapFrog Scribble & Write toy. He uses the child-sized stylus to trace upper- and lowercase letters, as well as numbers, by following the lights on the retraceable surface. The toy pronounces each letter or number after it is completed, and this has also helped Cooper learn letter sounds and numbers. Once he forms a letter he clears the surface and chooses another letter or number to trace. Cooper has been known to play with this interactive toy for hours at a time.



Once Cooper discovered how amazing letters can be, he started recognizing letters more frequently in his environment and in people's names. He points out the name and sound of letters on a sign, in a book, and at the beginning of a person's name. For example, when he meets someone whose name begins with a "B" he will then explain to us how a "B" is formed: "A line straight down, a curved line to here ..." His description is *exactly* how the LeapFrog toy explains how to trace the letter he's describing.



In addition to having excitement for letters at home, Cooper also has demonstrated his "super" ability to recognize and form letters in school. Cooper is

currently in kindergarten at our public school, and his teachers and therapists have commented on the progress he has made with letters. They have showed him how to use a dark marker to trace over letters they have written with a yellow marker. This has helped him tremendously in writing his name, following dotted lines, and forming other shapes. He's also able to form letters when someone gives him the "starting dot," which he then uses as a beginning point in writing letters.

All of this is leading to Cooper's love for books as he starts to learn to put letters together to make words. We are all so proud of "Super Duper" Cooper and his super letter fascination!

Cooper is our SMS Superkid!

Footnote by brother Keefe:

As Cooper's brother, I have noticed his love for letters and for reading. His ability to "read" familiar books to himself really helps him monitor his behavior. It's cool to walk into his room and hear his voice attempting to read Dr. Seuss or Curious George books. I think his interest in letters also has made him smarter and more enthusiastic about learning how to read.

--Janet and Ronnie Wagoner, and brothers Keefe and Mitchell

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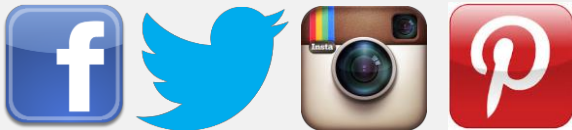
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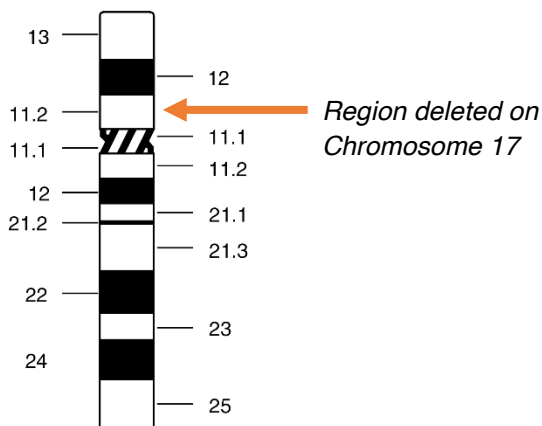
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What is Smith-Magenis Syndrome?

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.



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