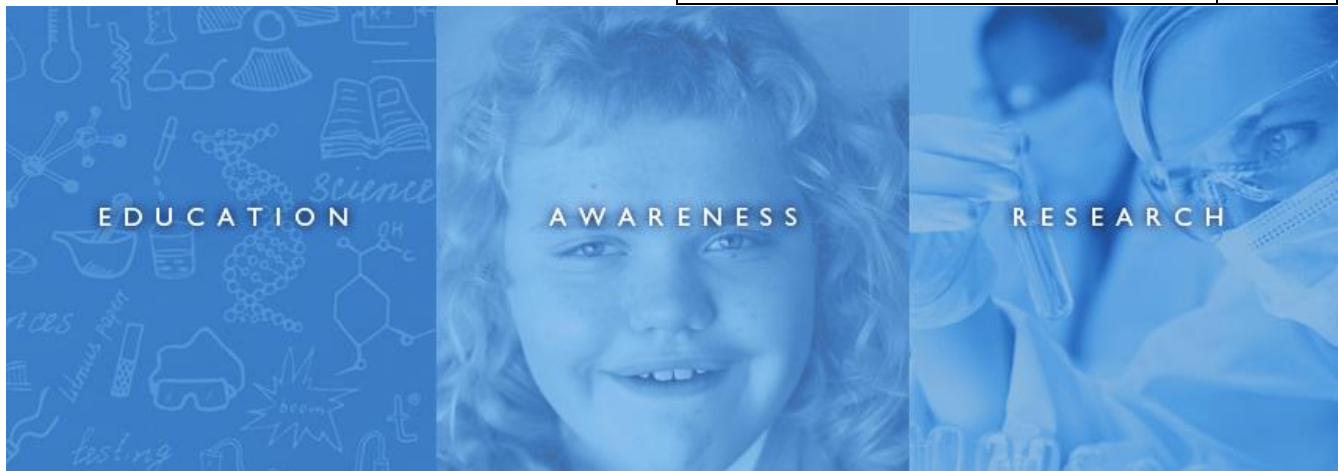


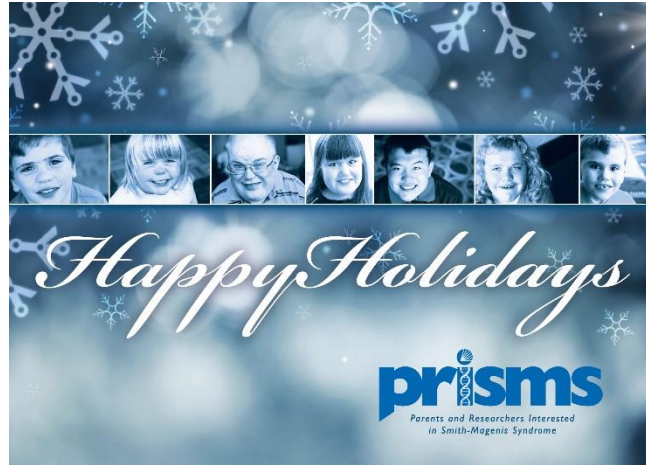
Reaching New Heights and Providing New Services



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Hope You Enjoyed Your Holidays!



PRISMS hopes you enjoyed your holidays and ringing in 2016 with family!

Thank you for being a part of this community, for taking part in PRISMS programs and services, and for supporting the organization's work through generous giving and engagement.

As we say goodbye to 2015, we look back at the work we were able to accomplish this past year and are amazed at how far we have come and where we are going. We have big plans for 2016 and beyond to further our mission while growing and improving our existing programs and services.

We look forward to continuing this work with you.

We wish you joy, peace, and happiness today and always.

Best Wishes,

Your PRISMS, Inc. Family



President's Message

2015 was a great year for PRISMS! As I look ahead to 2016, I have a feeling it too will be a great year—and most important—a significant year of service for all of our families. We will continue on a path of building a strong and capable organization dedicated to helping all of you.

In February, the Professional Advisory Board (PAB) will meet for a Research Symposium in Houston, a two-day event that will include formal presentations and a planning meeting. The PAB is a valuable part of PRISMS. The 10-member, all-volunteer group of professionals represents a broad range of expertise, each related to different aspects of Smith-Magenis Syndrome. A critical focus of this meeting will be to strengthen the PAB and sharpen the focus on ways to guide research and better understand SMS.

In July, we will gather in St. Louis for our 9th international conference. From July 28-30, the PRISMS community will be together sharing knowledge and perspective, building relationships, and helping each other through this rich and wonderful exchange. The conference is our most important program. I am certain this will be an event not to miss.

There will be other new developments; some will be new projects and others will be improvements to existing programs. In July, we will present a new publication with information to assist families exploring residential settings for family members with SMS. Throughout the year, we will make the Regional Representative Program stronger and better able to connect and support families. There will be SMS events organized by families across the country (and around the world). You can learn about these and more by connecting to PRISMS through our social media sites on Facebook, Twitter, Instagram and Pinterest.

You will find in this Spectrum Issue some highlights from PRISMS' first-ever strategic plan, an initiative led by PRISMS Executive Director Emily Fields with support from our advisor, Robert Miller. We will soon share more details from this exciting plan for PRISMS' future.

This month marks the beginning of my second year as President of the PRISMS Board of Directors. Every day it seems I am involved in some PRISMS activity, and I continue to learn about our organization. Most important, I am regularly humbled and inspired by the dedication and commitment of our PRISMS community. It is an honor for me to serve as president.

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

5 Reasons to Give

More than 1.5 million nonprofit organizations registered in the United States solicited year-end gifts to support their programs and services. It's a new year, and it is never too late to make a gift to PRISMS, Inc. and support the future of an organization committed to serving the entire SMS community through programs dedicated to education, awareness, and research.

What makes PRISMS special?

1. **Mission.** PRISMS is the only organization of its kind working to provide comprehensive support to the SMS community. The organization's Board and staff work diligently each day to improve existing programs and services while creating new initiatives that can further progress for the community.
2. **History.** PRISMS was the first organization to begin serving the Smith-Magenis Syndrome community, more than 22 years ago. With just a few SMS families and some dedicated professionals, including Dr. Ann Smith, PRISMS was formed around a kitchen table. Today, PRISMS maintains a volunteer board of 11 individuals, all parents of children with SMS; 10 Professional Advisory Board members, including leading SMS researchers and professionals such as Dr. Sarah Elsea, Dr. Ann Smith, Brenda Finucane, Barbara Haas-Givler, Dr. Andrea Gropman, and more. In 2015, PRISMS hired its first full-time employee, Executive Director Emily Fields, to lead and grow the organization. There is no limit to what PRISMS can do with your support!
3. **Family Services.** PRISMS is in the business of serving SMS families. It maintains a comprehensive website filled with information on medical management guidelines, early intervention, financial planning, research, and more. The organization offers parent-to-parent support networks through the Regional Representative Program, encouraging families to connect and meet in their local areas. PRISMS provides a quarterly Spectrum Journal filled with articles and information submitted from families, researchers, educators, and other professionals to inform the SMS community. PRISMS hosts a biennial International Conference which brings together more than 400 members of the SMS community to engage with one another on topics ranging from research to behavior strategies. PRISMS published the only SMS resource guide of its kind, "On the Road to Success with SMS", a guidebook for families and educators with helpful tips and strategies for working with a person with SMS. PRISMS invests funding to create and provide each of these programs and services at low-to-no cost to families.
4. **Research Initiatives.** PRISMS supports research in many beneficial ways. It hosts a biennial SMS Research Symposium dedicated to creating open communication of early, unpublished scientific data to accelerate the pace of research and to further research through productive collaborations. PRISMS discovers and promotes verified research participation opportunities to the SMS community through our Spectrum Journal and website. PRISMS engages leading researchers and professionals through the Professional Advisory Board, chaired by Dr. Sarah Elsea. And PRISMS is committed to relaying and demystifying the latest research findings to the SMS community in family-friendly language.
5. **Any Amount Helps.** Just \$25 can provide a resource packet and telephone support to a newly diagnosed family. Whether your gift is big or small, it is put to use to support SMS families.

We can't do this work alone. We need you. Your gift will ensure that the Smith-Magenis Syndrome community continues to see progress in education, awareness, and research.

Visit us at www.prisms.org to make a gift.

PRISMS Strategic Plan

By Emily Fields
PRISMS Executive Director

At the end of each year, the PRISMS Board creates an annual plan of work, a document outlining the key activities to be accomplished over the next year. In 2014, the board concluded that the organization was growing to a point where more than an annual plan of work was needed and made plans to create a strategic plan in 2015.



A strategic plan provides an organization with a clear direction and focus, allowing it to understand the key goals and objectives it seeks to achieve in the coming years. It helps allow board members to provide good governance, ensure an organization's sustainability, solidify an organization's values, and continuously affirm community satisfaction. Since January 2015, PRISMS' Board and staff have worked hard to create the organization's first comprehensive strategic plan. It is a huge step forward for any organization.

PRISMS formed a Strategic Planning Workgroup, comprised of six Board members and the Executive Director, and led by Robert Miller, former executive director of the National Fragile X Foundation and a strategic planning consultant. For months, the Strategic Planning Workgroup surveyed members of

the Professional Advisory Board and SMS families on their perceptions of PRISMS and goals for the organization. The workgroup participated in email exchanges, conference calls, and various meetings, working together to create a plan which stood to solidify PRISMS' values, vision, and goals for the future in line with the community's needs.

In October 2015, the full PRISMS Board met in St. Louis for a regularly scheduled meeting as well as a full day committed to the strategic plan. During this meeting, led by Miller, the Board and staff discussed the values, vision, and goals drafted by the workgroup and worked to create the objectives and actions required over the next three years to achieve these goals and follow this vision.

PRISMS is now proud to present our mission, vision, values, and goals resulting from our strategic planning process.

Mission

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.

Vision

PRISMS is the leader of the worldwide Smith-Magenis Syndrome community and engages, inspires, and empowers families, physicians, educators, researchers, and others so they can support and improve the lives of everyone affected by SMS.

Values

Compassionate: We are a compassionate organization that cares deeply about the well-being and needs of every individual within the SMS community.

Empowering: We empower families with the knowledge they need to make the best decisions for their family's needs.

Conscientious: We are conscientious in ensuring that all of our actions and practices serve the needs of the SMS community.

Inclusive: We encourage and seek participation from all those interested in advocating for and creating a positive impact for the SMS community.

Excellence: We focus on quality, conducting our work to the highest ethical and professional standards, and striving for excellence in all that we do.

Goals

- I. Be a global organization
- II. Be the “go-to knowledge center” for all things SMS
- III. Ensure that all actions taken by PRISMS are grounded in the best available knowledge
- IV. Ensure that those impacted by SMS have the resources and opportunity to achieve their fullest potential
- V. Be a sustainable organization

If you have questions or are interested in discussing the organization's full strategic plan, with specific objectives and activities, please contact Emily Fields, Executive Director, at efields@prisms.org.

9th International Conference—Sneak Peek



July 28-30, 2016

**Hilton Hotel at the Ballpark
St. Louis, MO.**

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 strives to present new and relevant information at every conference while weaving in family time and downtime for attendees, so they may connect and forge new friendships.

PRISMS' 9th International Conference will be held July 28-30, 2016 at the *Hilton at the Ballpark Hotel*, in St. Louis, MO. In 2014, families enjoyed the local attractions in downtown St. Louis so we are back in St. Louis for another great conference! The conference planning committee has been busy planning the details of the conference, including the agenda. We are excited to announce two new workshops that will be presented at this conference. Beginning early Thursday afternoon, July 28, we will be offering a teacher training workshop and an adult living workshop.

The Teacher Training Workshop will consist of a two-part training session that will profile the PRISMS publication, *“On the Road to Success with SMS - A Smith-Magenis Guidebook for Schools”* by Barbara Haas-Givler and Brenda Finucane. Barbara Haas-

Givler, MEd, BCBA, and Brenda Finucane, MS, LGC, will present this workshop. It will be an engaging session directed towards educators, BCBAs, day-support providers, job coaches and school administrators and support staff. The workshop will present successful solutions to challenging situations that may occur when working with a person with Smith-Magenis Syndrome. This will also be an opportunity for attendees to brainstorm with one another and share effective approaches for classroom, vocational and residential situations. This workshop will provide effective instruction and strategies for those who will be teaching/working with a person with SMS and a forum for these professionals to share ideas. We encourage parents to invite their child's current teacher, or prospective teacher for the 2016-2017 school year, as well as behavior specialists and support staff.

We will offer a limited amount of funding to help support teachers and specialists to attend the conference. Information about the grant program will be announced in January 2016 and applications will be available in February. This grant program is being funded by one of our PRISMS families.

The Adult Living Workshop will also be offered on Thursday afternoon, July 28. It represents the work of a small group of parents who have collaborated to present different scenarios about residential living options for adult persons with SMS. The workshop will present a range of adult living situations that are being used by our SMS families. It will offer details about different residential settings, technical information associated with each program, and general notes about the process of putting the various programs in place. A publication that will complement the Adult Living Workshop will be available as a resource for families.

Besides these two workshops, conference sessions will include:

Caring for the Caregiver, The Adolescent Adventure, Special Needs Planning, SibShops, Adult Sibling Session, Advocacy, Research Updates, Medical Management, Medication, Genetics, Neuro-psych

testing, First Steps Session, Behavior Supports, Curbside Consults and more.

Please remember that the conference timetable has shifted compared to past conferences. We will begin sessions on Thursday, July 28 and conclude in the evening on Saturday, July 30.

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 and the *PRISMS Den*, (for our adult SMS attendees), will be available at the conference. Cost for childcare is still to be determined.

Registration Fees:

Adult (16 & up) \$225; Child (15 & under) \$100; SMS Individual \$75; Professional \$300; Professional in training \$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!

If you have questions about the upcoming conference, please contact us at: conference2016@prisms.org

PRISMS Conference Experience

By **Alejandro Aguilar**

We are proud parents of three beautiful girls: Delilah (our seven-year-old SMSer), Micaela (five), and Sarai (21 months). Delilah was diagnosed at 20 months. We were blessed to be told about PRISMS on the day Delilah was diagnosed.

If I had to describe the 2014 International PRISMS Conference in one word, it would have to be *community*. The single most important concept I learned is that my wife and I are not alone in this. This was my first time attending a PRISMS conference, and the sessions that were offered were wonderful and very useful because we were given the latest research and tools/methods that most of us will never be able to find on our own.

I remember my conversations very clearly from those few days, and we still stay in touch with those people that we met at the meet-and-greet. On occasion, we get to meet up in person too. As I write this, I was able to meet families in San Diego while I was there for a conference. The family I contacted was the first family we met at breakfast at the SMS conference.

My wife, Delma, and I agree that relationships are the key to survival. No one can go at it alone. Fortunately, from the conference, we developed a strong support network. Being a special needs parent is difficult, and many will try and sympathize with us. We try to educate and share with others what we do.

It is not that way with other SMS parents though; it is like a huge sigh of relief when we get together. I don't have to educate. I don't have to ask for sympathy. We all share the same look and we can see that "they know, they understand." I can let my guard down here. We can laugh more, and cry more too, because we have been there. We share the joys and trials that we go through.

I was amazed at looking at all the other SMSers, both young and old. It warmed my heart to see them all and realize how all of them are so alike yet with their

own distinct personalities. It's great to know Delilah has many siblings. The old adage, it takes a village to raise a child rings so true for PRISMS.

We cannot wait to take Delilah with us to the 2016 conference. See you there!

Regional Representatives

When Eric and Kim Hoffman's daughter, Nettie, was diagnosed with Smith-Magenis Syndrome at 13 months, their pediatrician immediately put them in touch with geneticist Ann Smith and Maggie Miller, another SMS parent, who were just starting up the support group that would become PRISMS (Parents and Researchers Interested in Smith-Magenis Syndrome).

After talking with Smith and Miller for several hours, the Hoffmans realized there were other people out there who knew what they were going through and could provide much-needed support. Nettie participated in SMS studies at Baylor University when she was three, and in the first SMS study at the National Institute of Health in Bethesda, Md., when she was six. The Hoffmans attended the first PRISMS "Building Bridges of Hope" Conference in 1997—and they have been to every conference since then. They also helped present two conferences in Denver.

Recently, Eric Hoffman talked about his and Kim's roles as PRISMS regional representatives.

Why did you decide to become a regional rep?

My wife and I wanted to give back the support that Ann and Maggie gave us that first night with the SMS diagnosis. When the program started, we became the regional reps for Colorado, Wyoming—and now we have added Kansas and Utah.

Why is this a good program for PRISMS?

Support for SMS families is very important. SMS families can offer support to each other that non-SMS

families would find more difficult. SMS families better understand what SMS families are going through. Being able to talk with someone, and maybe get suggestions on how to handle certain situations is invaluable. Having multiple points of contact for support helps the support system work more efficiently.

What are the most important duties of being a regional rep?

Being there to offer support to SMS families. Keeping up on the latest SMS information. Passing along information to SMS families.

What are the most common kind of questions you get as a regional rep?

Since we started the local SMS support group in 1997, most of the common questions have already been addressed. It has been a couple of years since a new SMS family has contacted us.

What kind of support can you provide SMS families?

Being there to offer support to SMS families. Keeping up on the latest SMS information. Passing along information to SMS families. Organizing opportunities for SMS families to participate in supporting each other. We look forward to expanding the support to SMS families in Kansas and Utah.

Specifically, how have you helped other SMS families in your region?

We have organized several gatherings at amusement parks, restaurants, parks, music concerts, dinner theaters, each other's homes, etc., where SMS families can enjoy each other's company and give each other support. Some SMS families collected food for a family that needed help. Other SMS families were pallbearers at an SMS individual's funeral, offered support for an SMS family that had to address a court regarding SMS issues, and supervised SMS individuals from other SMS families.

Eric and Kim Hoffman are PRISMS representatives for the Central West Region (Colorado, Kansas, Wyoming and Utah).



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.

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



SMS Awareness Day Success!

On November 17, the Smith-Magenis Syndrome community came together for SMS Awareness Day, a day dedicated to spreading education and understanding of Smith-Magenis Syndrome around the world. Posts were “shared”, “liked”, “followed”, “retweeted”, and commented on from social media users around the world, including the United States, Mexico, France, Italy, Canada, Brazil, Australia, Germany, and the United Kingdom.

Across PRISMS’ social media platforms, posts were seen by over 31,000 people with thousands of people joining the conversation through hashtags: #hugorbehugged, #prismsorg, #smsawarenessday.

Thank you to everyone who participated in ensuring that SMS Awareness Day 2015 was a global

success. We look forward to planning activities for SMS Awareness Day 2016!

Have ideas for SMS Awareness Day 2016? We would love to hear them! Contact Emily Fields, Executive Director, efields@prisms.org

‘Curriculum of Caring’

Submitted by Dr. Kerry Boyd



Associated Medical Services (AMS) Phoenix Project issued a Call to Caring for Ontario’s Health Education institutions to resurrect compassion and person-centered practices in healthcare. People with developmental disabilities (DD) both need and inspire compassionate care. PRISMS Professional Advisory Board member Dr. Kerry Boyd was awarded a 2013-2015 Phoenix Fellowship grant that has been used to create a *Curriculum of Caring for People with DD*.

McMaster University Medical School’s Niagara Regional Campus and Bethesda Services have partnered to provide opportunities for medical and nursing students to learn from people with DD. *Curriculum of Caring* videos have been developed to allow people who might not otherwise have a voice to express their opinions, concerns and hopes to healthcare professionals.

A variety of video segments feature a cross section of capable spokespersons providing unscripted personal narratives and advice. Personality, vitality, and valuable insights are expressed through a

growing number of videos featuring people and families whose lives are touched by disability and healthcare needs.

The vision for the Curriculum of Caring videos has been to raise people with DD up as “champion educators” and let them share in ways that work for them. The process is invariably creative. The videos have become powerful vehicles to stir compassion and motivate students to engage in person-centered care.

A champion educator with Smith-Magenis Syndrome is featured in one of the *Curriculum of Caring* clinical skills interview videos that model how to communicate CARE in simulated scenarios. Shane lives with SMS and has become a favorite among students! Although he does not currently have serious medical problems, he has been seen by many healthcare providers over his 30 plus years of life.

Shane made his video debut in “Shane: Up at Night with Smith-Magenis Syndrome.” He displays supreme charm and wit as he engages medical student Jessica Graham (now a family medicine resident). In the video, Shane’s clinical team meets with him and his mom to discuss ways to promote health and sleep. Shane’s mom shares what she sees as important with Shane’s clinicians.

Shane’s video and other *Curriculum of Caring* resources can be found on our website: CommunicateCARE.MacHealth.ca. Shane’s case is linked to the Surrey Place Center HealthWatch guidelines for Smith-Magenis Syndrome.

The Curriculum of Caring has provided opportunities for people such as Shane and his mother to share their experiences and insights. Their input is recognized as important to influence attitudes, current practices and systems. Many have volunteered to participate in various parts of the project. Feedback about their *Curriculum of Caring* experience has been very positive. After participating, many have reported increased confidence when they encounter healthcare providers.

Similarly, medical and nursing students report positive experiences with increased comfort, confidence and competence working with people who have some special needs. Among their responses:

- *“I would love the future experience of working with this population.”*
- *“The resilience of the people that come to us for their healthcare is moving and inspiring. It is and will continue to be a privilege to serve them.”*
- *“The stories that families share with us are truly amazing and enriching.” They open themselves up to us, in the spirit of education, to learn about all of the hardships and successes they’ve faced over the years. They let us know where experiences with the healthcare system fit in, both positively and negatively. They are excited to contribute to the future of medicine by sharing these stories with us. It is amazing how this has an effect on a learner. The privilege of this opportunity is not lost on us.”*

This has the potential to positively impact the care people with DD receive from these future professionals and others we anticipate they will influence. With the web-based resources, there are far-reaching benefits for people with DD/ID who desire/require respectful and responsive healthcare.

The Curriculum of Caring continues to encourage collaboration. There is an expanding network of people who share the vision of compassionate care for people living with a developmental disability.

The positive energy is palpable. Person-centered care is catching on with a “ripple effect.” Healthcare recipients, learners and providers are making a difference.

New viewers are welcome. Check out our music video section for more examples of champion educator talent.

Curriculum of Caring website link:
CommunicateCARE.MacHealth.ca

From Russia with Love

By **Bela Kafengauz**

Our family lives in Moscow, Russia. Our eldest daughter, Sophia (usually called Sonia), now 31, has Smith-Magenis Syndrome (SMS). When Sonia began to develop non-typically, we sought help from numerous specialists. At that time, however, nobody in Russia was aware of SMS. Our daughter was diagnosed only in 1997, by which time she was 13 years old, in Canada. Soon afterwards, with the growing availability of the Internet in Russia, we found out about PRISMS. As far as we know, Sophia was the first person in Russia to be diagnosed with SMS. This was a very hard road for our family, since we were the first to take it.

For that reason, when our daughter was somewhat older, my husband and I decided that we could and should help other families of children with SMS. As a step in that direction, I wrote a book about our daughter's infancy and her preschool and school years, and the difficulties our family had confronted. My book, *A Child with a Hereditary Syndrome: the Story of Her Upbringing, or Faith, Hope, Love, and Sophia*, was published in 2008. The print run of 2,000 copies sold out.

In 2010, we established a Russian-language informational website about SMS: <http://smsru.ucoz.ru/>. Over the past five years, 42 users have registered on our site, including 11 parents of children with SMS. These children include four boys and seven girls, all of them a good deal younger than our Sonia. Their ages range from three to 15 years. They are from Russian-speaking families, some of whom reside in Russia, Ukraine, or Belarus, while others are émigrés, currently living in Canada or the United States. Thus, our initiative has resulted in the formation of a small Russian SMS community, made up of parents. Our group is not officially registered and has no financial resources.

Our site provides a link to PRISMS, and a full Russian translation (http://smsru.ucoz.ru/index/o_sindrome/0-4) of the overview “Smith-Magenis Syndrome” (Ann Smith et al.: October 22, 2001; Last Update: June 28, 2012) from *Gene Reviews* (<http://www.ncbi.nlm.nih.gov/books/NBK1310/>), as well as other literature we have found useful. We have a forum for parents to exchange experiences, and archives of photos and other materials. I correspond privately with many parents. I try to help them on issues related to rearing and educating their children, as well as addressing the medical problems typical of our syndrome: sleep disturbances, distractibility, tantrums, chronic runny nose, ear infections, constipation, bedwetting, and so forth.

The educational mission of our site is an urgent one. In the past few years, cytogeneticists and clinical geneticists have established the ability to diagnose SMS in Russia. Consequently, children have begun to be diagnosed with SMS. Other specialists, however, including general practitioners, specialist MDs, preschool staff, and school teachers and psychologists, with rare exceptions, remain completely in the dark about SMS. The availability of “Smith-Magenis Syndrome” in Russian translation on our site is a step toward solving this problem. Parents can give any doctor or teacher the link or a printed-out copy of that overview.

We realize that developmental disturbances manifest themselves differently in various children with SMS. Nonetheless, it is useful for parents who need to choose the right type of education, map out an educational program, and evaluate the developmental prospects of a child with SMS, to have access to the example of a child and parents who have gone through this experience. In any event, when we were bringing up Sonia we always missed having precisely this — the example and experience of people who had already been there. Therefore, on our site I tell about the life and activities of our daughter. We are happy to share our experience with PRISMS. I have previously written in *Spectrum* about our family, Sonia, and her problems and pursuits

(http://www.prisms.org/pdf/Newsletter/Spectrum_winter2012.pdf).

This is my second report.

For the past eight years, our daughter's life and that of our entire family have incorporated a close relationship with Technological College № 21, a state-run vocational institution (<http://tk21.mskobr.ru/>) in the eastern part of Moscow. An organizational unit called the Center for Social Adaptation and Professional Training, serving young people with mental and behavioral development challenges, opened there in 2006. This school is unique in Moscow and in Russia as a whole. It was founded on the initiative and with the support of a regional charitable public organization called the Center for Therapeutic Pedagogy, which focuses on special education projects (<http://www.ccp.org.ru/>). It is essentially a rehabilitation center, where young people with mental disturbances, intellectual disabilities, genetic diseases, or combined disabilities can learn a trade in creative craft workshops for ceramics, woodworking, textiles (sewing and weaving), artistic printing, and flower-growing. The Center for Social Adaptation and Professional Training is often called "the special workshops" (<http://om21.ru>).

Each workshop is organized according to the same scheme. The shop is headed by a professional artist. This is extremely important for developing the students' artistic sensibilities, thus guaranteeing that their products will be beautiful and of artistic value. The artist attempts to develop simple, easy-to-do processes for making the items, selecting them to match each student's interests and abilities. In each workshop several assistant teachers work with the artist. These staff members have had prior training in the main processes used in that shop. Many of these teachers are also professionally trained psychologists.

Because of their special individual needs, these students cannot work independently, but need helpers and other people to be with them. The teachers are the ones who provide this guidance. They help the youngsters master basic, simple tasks

for their particular technology, trying not simply to instruct, but to suggest making something beautiful together. Thus, creating objects is not the purpose or the main educational result here, but rather a method for developing each individual. Working in fellowship with their teachers, the students gradually become more independent and self-confident, and require less assistance from their helpers.

For example, those working in the textiles shop, and their teachers, work with fabric, thread, wool, and dyes. They weave on looms (of which there are several in the shop), make felt out of wool, and decorate cloth using special dyes. Combining various materials into a coherent whole, the students sew items by hand or stitch them on a sewing machine. Their creations include personal ornaments, decorative batik, scarves, napkins, amazing cushions, fashionable handbags for young people, skirts, and even dresses.

These brightly colored, extraordinarily expressive, and naively touching products, made by students at the College, are regularly exhibited at shows and sell well at charitable fairs. Twice a year the College holds a fair, one in winter (just before Christmas) and the other in spring (at the end of the school year).



Our daughter began to attend the Center in 2007, shortly after it opened. For the first few years of its existence, few people knew about the Center. That was lucky for our Sonia, who was accepted into two

training programs: she first completed a three-year program, then was accepted for a six-year program. At first Sonia worked in the ceramics shop, later switching to textiles. This school year is Sonia's last in the textiles shop's six-year program.

The number of people applying to study at the "special workshops" of Technological College №21 has greatly increased. Parents have to get in line to place their child at the College. Despite this growth of demand, the economic crisis in our country has brought cuts in government funding for educational programs, as well as the limitation of training programs in the "special workshops" to shorter periods of time. As of September 1, 2015, 130 young people are studying at the Center. The age range is 18 to 35, with training courses of three years.

Sonia is the only person studying at the College who has SMS. We are very pleased with the Center, its wonderful teaching staff, and its creative atmosphere! During her years of study, Sonia has gotten used to working as part of her team and has made friends. She has mastered several methods of processing fabric and has learned to work with a helper and to stay with a project until it is finished. She understands that other people like the things she makes with her own hands, that they make people happy, and that there is demand for these items.



Included in the article above are some of Sonia's most interesting works, in order to show how many different skills are within reach for people with SMS.



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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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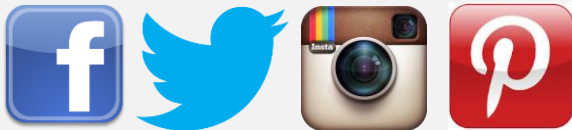
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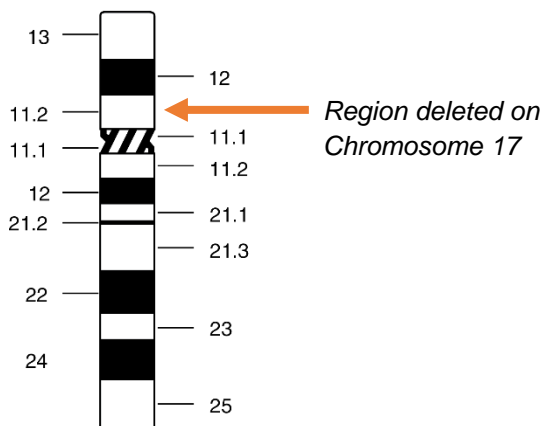
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What is Smith-Magenis Syndrome?

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 requires 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.

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