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Parents and Researchers Interested
in Smith-Magenis Syndrome

spectrum

Special Edition: PRISMS 10th International SMS Conference

PRISMS 10th International SMS Conference

Honoring the Past, Treasuring the Present, Shaping the Future

HONORING THE PAST / TREASURING THE PRESENT / SHAPING THE FUTURE

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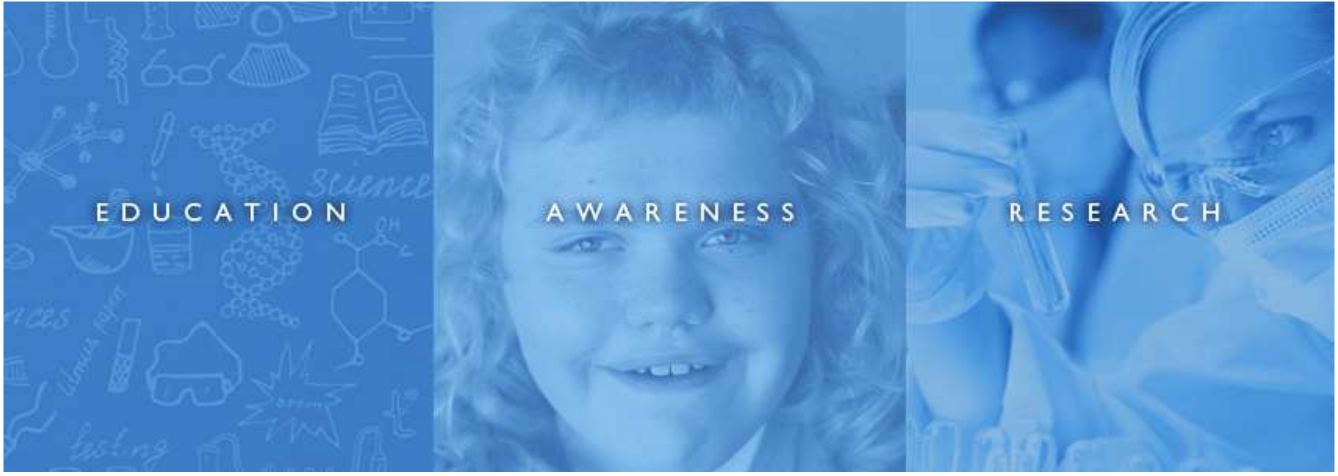
10TH INTERNATIONAL
CONFERENCE
PITTSBURGH 2018



Special Note to Our Community!

Whew! 2018 is proving to be one for the record books. PRISMS 10th International SMS Conference (July 19-21 in Pittsburgh, PA) has completely reached capacity with 370 registered attendees representing families and professionals from around the world. This will be the largest gathering of the SMS community as we come together in pursuit of education, awareness, and research. Due to our high number of registrations, PRISMS has had to close registration and will be unable to accept or accommodate onsite registrations.

In this special edition of the Spectrum Journal, we will focus on the conference, sharing information on session highlights as well as special events and onsite opportunities.

If you are unable to join us for our conference this year, please know PRISMS will provide session outlines and speaker handouts from all speakers who provide such information on the PRISSM website (www.prisms.org) following the conference. Stay connected with PRISMS on our social media to ensure you see the live updates from inside the conference.

Have questions? Please contact us at info@prisms.org.

President's Message

John Mayer, Board President

Pittsburgh, here we come.

It's the 25th year for PRISMS, and we will mark it with our 10th International Conference on Smith-Magenis Syndrome, July 19-21 in the Steel City. With a month to go, we were filled to capacity! We had exceeded registration of our largest conference by about 25 percent. We planned for growth in attendance, but we had no idea we would see this much interest from our community.

The international conference is the most important event we offer. It is where we share the latest information with our families and our network of educators, physicians, therapists and others. It is where we gather as a community.

For those not able to attend, watch for information and content from conference sessions on the website (PRISMS.org). Keep in touch with your regional reps and, as we plan for the 2020 conference, keep us informed about your needs and interests.

For those able to attend, there are some activities intended to be fun and to strengthen your connection with our organization. On Thursday evening, we'll kick off the conference with The Night at the City Center, a parent-oriented social gathering where you can enjoy a cocktail, meet new friends and celebrate—knowing that the proceeds from your ticket supports conference expenses.

On Friday at 5:30 pm, during our Meet the Board session, you can get to know the PRISMS Board members. We want you to learn what we do and meet us in person; after all, we are all parents just like you. Most important, we will talk about ways you can get involved, perhaps by helping strengthen our Regional Rep program or serving on a committee.

I'll end my day on Friday by hosting a meet-up for people who have joined the 17p.11.2 Society. This is a newly formed group open to anyone who makes a monthly pledge to PRISMS of $17 or more. Now that membership is free and open to all, this is a way to cultivate financial support from interested people and build a foundation of dedicated patrons. And have some fun, too.

"A Guidebook for Families Newly Diagnosed with Smith-Magenis Syndrome" is a new PRISMS publication that will be available at the conference. This web-based resource is free to all. The handbook was written by the PRISMS Advocacy Workgroup and is designed to help families process and prioritize the broad range of information they receive upon getting the diagnosis of SMS.

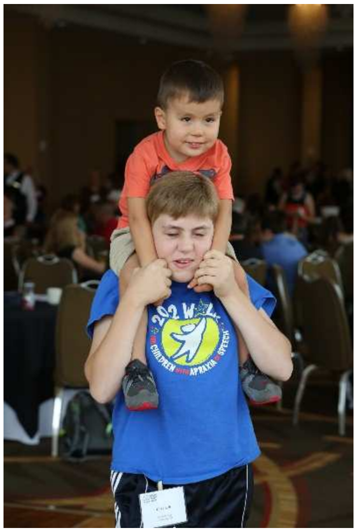
Since the first conference in 1997, my greatest pleasure is seeing old friends, meeting new people and hearing all the stories. I definitely gain insights from the sessions, but more than anything I look forward to connecting with our families. I can't wait.

Pittsburgh, here I come!

25 Years of Leadership…And A Future of Hope!

By Emily Fields
PRISMS Executive Director

PRISMS has been committed to education, awareness and research for 25 years! In that time, we have seen what began as a small group of incredibly dedicated parents and medical professionals grow into a strong community of families and supporters of Smith-Magenis Syndrome.



During our silver anniversary year we want to take the opportunity to reflect on our successes and reaffirm our commitment to the SMS community.

With your support, we have provided unparalleled opportunities to connect through resources for new families and support for all members of the SMS community. Our connection to the SMS scientific community ensures that all materials and programs are built on the current cutting-edge scientific knowledge. We are now building on this strong foundation to contribute additional evidence for research priorities, establish a global network and provide further assistance to patients and families as they navigate all aspects of living with SMS.

It is fitting that we have the opportunity to come together for our 10th international conference this year. It is an opportunity for engagement and community building for families and SMS professionals. This signature event highlights PRISMS commitment to science and community building.

As part of the celebration, we also intend to reflect on our values and how these are reflected in PRISMS current initiatives. We hope to reflect on how the organization and our community exemplify the following traits:

- Compassion
- Empowerment
- Conscientiousness
- Inclusion
- Excellence

Together, we hope to look toward the future as we engage as a global organization, ensure a comprehensive knowledge center for all things SMS, enhance the science of SMS and connect families with appropriate resources and opportunities to help all individuals with SMS meet their full potential!

#IAm Campaign

PRISMS believes *you* are your own storyteller. Our #IAm campaign is a positive awareness campaign for our SMS community to give a voice to our loved ones with SMS and to provide them with an opportunity to share who they are.

Together, we can ignite a deeper understanding of the array of unique qualities, passions and talents of our SMS family.

We have received dozens of videos from families around the world showcasing just who their child with SMS is. From #IAm a Hip Hop Dancer to #IAm a Black Belt, from #IAm Finding My Voice to #IAm a Pianist, it is clear we have a vibrant and incredible community. We'll be showcasing this campaign at the conference in a session led by master of ceremonies Brandon Daniel and his assistant master of ceremonies, Zach Kon.

PRISMS Conference By The Numbers

This year, we celebrate ***25 years*** of PRISMS leadership and a future of hope we are building with *YOU* for the global SMS community. For PRISMS ***10th*** International Smith-Magenis Syndrome Conference, we are welcoming our largest group of families and professionals.

An unprecedented ***370 attendees*** from around the world, including Australia, Canada, Mexico, the United Kingdom and Norway, and more than ***30 states*** from the United States.

More than ***125 attendees*** will attend their first PRISMS conference.

More than ***35 sessions,*** led by more than ***60 experts,*** with such topics as weight management and nutrition, special needs planning, caring for the caregiver, medication and SMS, sibling sessions, genetics 101, speech and SMS, sleep and more.

PRISMS has provided more than ***$40,000*** in speaker honorariums and fees, family support scholarships and teacher/support staff grants to ensure that the information and event is accessible to as many families and professionals as possible.

As a whole, the conference is a ***more than a $200,000 investment*** from PRISMS to the SMS community to ensure that opportunities for education, awareness and research continue to build confidence and hope across the community.

The three days that attendees will spend at the conference will be filled with opportunities to connect, share information and create lasting memories.

Follow along on social media by connecting with PRISMS via Facebook and Twitter. We will post updates, photos and video from the conference in real time. Be sure to look on the PRISMS Blog for stories following the conference from various attendee perspectives and more.

Conference Sessions – Sneak Peek!

Take a sneak peek at some of the more than 35 sessions attendees can experience at the conference!

"First Steps: "Navigating the PRISMS Conference and Finding Support Along the Way."
For first- and second-year attendees. This session will welcome you into the PRISMS community and give you tips on how best to navigate the conference and connect with other SMS families.

"Understanding the Genetics of SMS."
This session is geared toward families with a new SMS diagnosis and those wanting a refresher course on the basics of genetics behind SMS.

"Let's Talk SMS Research: The Need for a Diversified Approach to the Research of SMS."
A panel will discuss specific areas of SMS research and the need for research of such a rare disorder to be diversified. SMS research requires a collaborative and comprehensive approach that builds relationships between basic science, clinical and social research.

"Coping with a Sibling with SMS: Relations with Gratitude, Benefit Finding and Internalizing and Externalizing Behaviors."
Qualitative information provided during sibling interviews will be presented with quantitative results to discuss possible interventions such as sibling support groups and/or individualized strategies emphasizing adaptive coping specific to SMS and implementation of positive and cognitive strategies such as recognizing benefits of having a sibling with SMS and adopting gracious attitudes.

"Approaching Acute Behavior Changes in Individuals with SMS."
This presentation will discuss more severe behaviors sometimes found in persons with SMS and offer strategies and interventions to consider.

"What to Expect at Your Child's Appointment with a Developmental Pediatrician or Neurologist."
An introduction to what to expect from the visit and the testing that may be performed.

"Siblings Timeout with Coach Dave."
All SMS siblings are invited to participate in an active and engaging session filled with fun activities.

"Neurological Implications in SMS; What We Have Learned."
This presentation will focus on the neurological and cognitive features of persons from SMS, from infancy to adulthood.

"SMS Organizations Across the Globe: SMS Puerto Rico."
A presentation on SMS Puerto Rico.

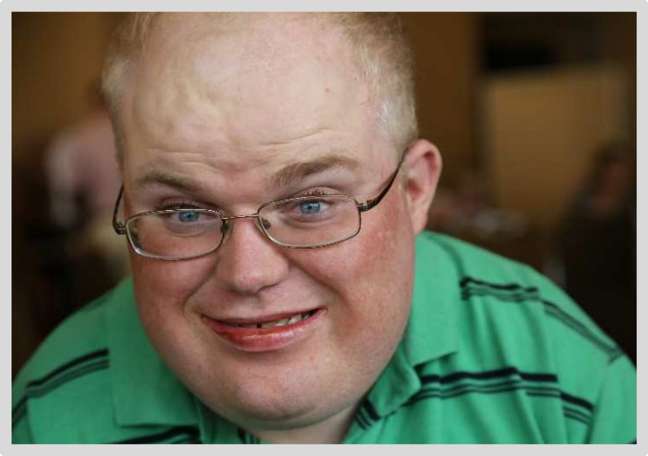
"The Regulation and Timing of Sleep and Wakefulness: Sleep Disturbance Associated with SMS."
A discussion on the sleep disorder associated with SMS, how it compares to other sleep disorders and what might be the underlying cause.
Speaker: Joseph T. Hull, Ph.D.

"Managing Ourselves While Managing SMS."
Facilitated conversation about managing anxiety, fear and other emotional challenges parents of SMS children face.

“Approaching Acute Behavior Changes in Individuals with SMS.”
A discussion on the more severe behaviors sometimes found in persons with SMS, along with strategies and interventions to consider.
Speaker: Jaimie Purdy, M.Ed.

“Medical Management of SMS Across the Lifespan.”
A workshop examining the guidelines for medical management, educational and behavioral planning for individuals with SMS developed by the PRISMS Professional Advisory Board and updates in 2018.
Speaker: Ann C.M. Smith, M.A., D.Sc. (Hon).

“The Adolescent Adventure.”
Real-life stories of transition through adolescence into adulthood will highlight a discussion on the challenges, opportunities and triumphs of people with SMS.



Special Conference Events

PRISMS is thrilled to host a number of special events throughout the jam-packed three days of conference sessions. Here is a sneak peek:

First Steps: “Navigating the PRISMS Conference and Finding Support Along the Way” (1:15-2:45pm in Marquis A). First- and second-time conference attendees will have the opportunity to meet with veteran families, who will offer guidance and answer questions. This session will be repeated from 1-2pm Saturday in Salon 1.

Welcome Reception (5:00-6:30pm Thursday in the Grand Ballroom 3-5). Make sure to drop by and enjoy the celebration, which will include a live DJ, hors d’oeuvres, non-alcoholic drinks and temporary tattoos.

PRISMS Night at the City Center (8:00-11:00pm Thursday in City Center A&B). Step out of your conference mode and step into your evening mode. PRISMS Board of Directors invites you to join us for a fundraiser celebrating 25 years of PRISMS and a future of hope for the SMS community. This is an “adults only” (21 and over) event and entry is $100 per person. Proceeds will be used to offset some of the expenses that make the 2018 conference affordable for families. This will be a special and unique occasion for you to join your friends who are part of the PRISMS community. Your entry includes heavy hors d’oeuvres and a cash bar. Tickets will be sold in the registration area. Tickets are limited so act quickly.

Session for SMS Teens and Adults (11:00am-noon Friday in Salon 1). This special session will be led by Christine Brennan, PhD, SLP.

Coffee and Tea with the PRISMS Board (5:15-6:30pm Friday in Grand Ballrooms 3-5). Don’t miss this opportunity to meet with the remarkable team responsible for overseeing and guiding PRISMS activities and operations.

17p11.2 Society Gathering (9:00pm Friday in the hotel’s Steelhead Brasserie and Wine Bar). Join PRISMS President John Mayer and Membership Chair Diane Erth to meet and mingle, and to share a toast in celebration of PRISMS 25th anniversary. This gathering is reserved for PRISMS donors who generously contribute $17 or more a month to ensure that PRISMS programs and services continue growing. You can register to be a member of the 17p11.2 Society at the registration and merchandise table any time during the conference.

Ice Cream Social (5:15-6:15pm Saturday in the Grand Ballroom Foyer). This will be held following the final remarks session.

Corporate Kids Childcare: (for children ages 4-18; advance registration is required). The programs will be held in Salons 1 & 2 on Thursday and City Center A&B on Friday and Saturday. The Corporate Kids staff will be available on Thursday from 9am-noon for check-in and ID photos in the Grand Ballroom Foyer B. Please see the Corporate Kids Program Information page for more information in Section 4. ***Note: Children must be picked up promptly at the end of each session. A fee will be added if you are late.***

Sessions for Siblings. Check out our special offerings throughout the conference just for siblings. There will be a workshop offered for SMS siblings ages 7-12 from 9:30-10:45am Friday and a session for SMS siblings 13 years and older from 2:15-3:30pm Friday. Both will be held in Marquis A. On Saturday, siblings will have an opportunity to learn about genetics, DNA and what makes each person unique in a Genetics of You! Session, 10:30-11:45am in Marquis A. Finally, siblings will have a chance to engage and get active with Coach Dave Gray from 2:15-3:30pm Saturday in Marquis A. More details about these sessions can be found in the program agenda.

The PRISMS Den Event (1:00-5:00 pm, Thursday, Friday and Saturday in the Three Rivers Conference Center, lobby level). Advance registration is required for this session for SMS adult attendees and siblings ages 16 and up. Attendees must be picked up promptly at 5:00pm ***Note: A fee will be added if you are late.***

PRISMS Hospitality Suite: (7:00-10:00 pm Thursday in Salon 2; 7:00-10:00 pm Friday and Saturday in Marquis C). Families can sit down, relax and enjoy the company of old friends and new ones alike.

Exhibitor's Hall: (open 4:00-7:00pm Thursday and 7:00am-5:00pm Friday in Grand Ballroom Foyer A). Come visit and see what products, opportunities and important resources are available to the SMS community

Curbside Consults: (3:45-4:45pm Saturday in Grand Ballroom 2-5). A multidisciplinary group of professionals will be available to answer questions from attendees in one-on-one settings. This session will provide attendees an opportunity to have brief consult questions answered by professionals from a wide variety of disciplines and sub-specialties

PRISMS 17p11.2 Society

The PRISMS 17p11.2 Society is comprised of the most dedicated supporters of the SMS community: our monthly donors.

Those who seek to build a future of hope for the entire SMS community contribute monthly in the amount of $17 or more. These regular and generous contributions ensure that PRISMS continues to grow and serve SMS families and professionals with programs and services dedicated to education, awareness and research.

17p11.2 is significant to our SMS families because it refers to the specific piece of genetic material missing from the 17th chromosome that leads to the SMS diagnosis.

To join the PRISMS 17p11.2 Society and make an impact with us, simply visit our **Donate** page on the PRISMS.org website and check the box to "Make this donation monthly". Be sure to make your monthly donation a gift of $17 or more.

Thanks to all for supporting us in creating a future of hope for our SMS community!

(Members of the PRISMS 17p11.2 Society are invited to wear their society pin throughout the conference. A special gathering for the 17p11.2 Society will be held at the Steelhead Brasserie and Wine Bar in the hotel lobby at the Pittsburgh Marriott City Center. Details will be available in the conference program. Attendees of the conference will have an opportunity to join the society on site.

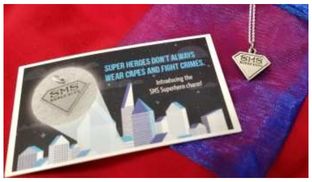
#SMSSwag at the Conference

PRISMS is excited to offer all kinds of new merchandise and opportunities for you to raise awareness of Smith-Magenis Syndrome in your community. Take a look at some of the items we'll be offering to conference attendees for purchase. All proceeds from sales go directly back to PRISMS and supporting our mission to education, awareness and research on behalf of the entire SMS community. Products that are not sold on site at the conference will be available on the PRISMS website after the conference.

PRISMS Superhero Line

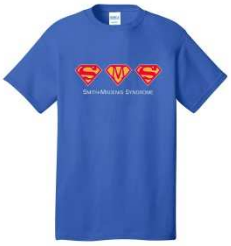
Calling all SMS Superheroes! PRISMS believes its community is filled with many heroes: individuals with Smith-Magenis Syndrome, parents, siblings, grandparents, researchers, teachers, therapists, caregivers and all those who support our mission. Check out our new line of superhero-inspired products available to promote PRISMS and showcase all of our amazing SMS superheroes!

Superhero Necklace



Our new necklace celebrates the superhero in all of us and symbolizes not only the strength we have as individuals navigating SMS but also the power we have as a community to spread awareness, support each other and affect change in the lives of those with SMS and their families.

Superhero Shirt



Celebrate your amazing strength, power and courage with your own SMS Superhero T-shirt! This shirt is inspired by Superman's emblem and our community of amazing heroes who fight the battle of SMS every day.

Superhero Cape:

What is a superhero without a cape? Our new SMS superhero cape is the perfect way to bring out the SMS superhero in you! Featuring the SMS Superhero logo, our capes are the perfect complement to our SMS superhero T-shirts. Our capes are 24 inches long, are made from 100 percent polyester satin and have a Velcro fastening on the collar.

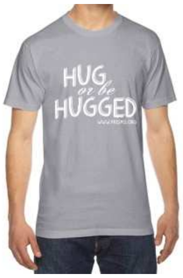
Clothing

Conference Shirt

Featuring our 25th anniversary logo on the front and all 10 international conferences on the back, this shirt is the perfect way to celebrate PRISMS past, present and future. Get yours and proudly promote PRISMS and raise awareness for the SMS community. Child and adult sizes are available.

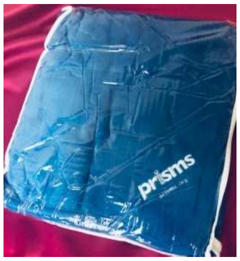
Hug or Be Hugged Shirt

There is nothing better than getting a hug from someone with SMS! Their love and compassion shine through each time they embrace someone. Get your shirt now and join *#hugorbehugged* on social media.



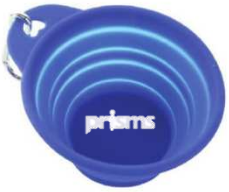
Blanket

For the first time, you could own a PRISMS chenille throw blanket. This new product is perfect for traveling, sitting on the sideline at a game or cuddling up with a book. You can stay cozy while promoting PRISMS and raising awareness.



Pet Accessory

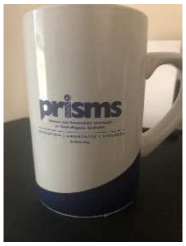
PRISMS is now offering something for our furry friends: a collapsible pet bowl perfect to take with you to the park or on a walk. This soft, flexible silicone bowl has an 8-ounce capacity that works great for water or pet food when you're on the go.



Drinkware

Coffee Mug

Drink your coffee or tea in a new PRISMS mug—and show off your support for the SMS community!

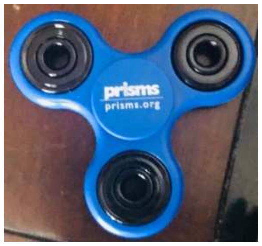


Tumbler

You can promote PRISMS and SMS each time you walk out the door with your coffee with this stylish new tumbler. It has a slide lock to help prevent spills and a non-skid base to keep it upright.

Fidget Spinner

Everyone loves this toy. Now while you're showing off your cool tricks, you can also be raising awareness for PRISMS. (You might want to buy two—just in case someone "borrows" your first one).

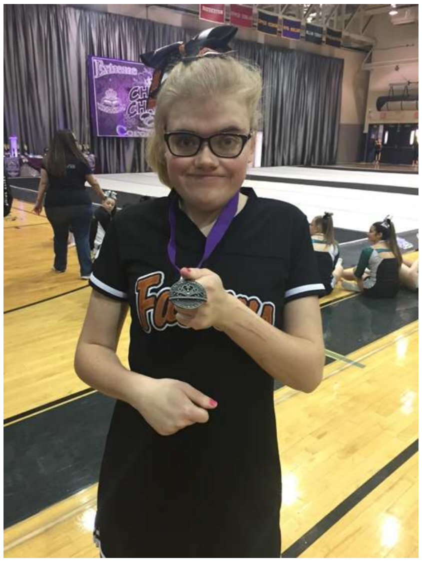


Super SMSers

By Dennis Dillon, Journal Editor

Spectrum is proud to recognize the following SMSers for their accomplishments.

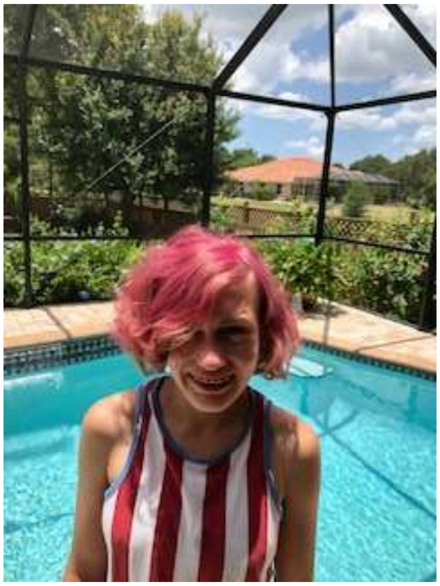
Lauren Kurtz, 21, Langhorne, PA.



Lauren belongs to the "Fireflies", a special needs cheerleading group in the Pennsbury Falcon Cheerleading Association. Buddied up with a junior coach, Lauren practices once a week from September through March and participates in four competitions during that time. "She likes to be the ham," says Beth Ann Kurtz, Lauren's mother. "She usually runs out with her arms up in the air, trying to get everybody to clap." Lauren, whose best move is her "famous somersault", recently graduated from a Life Skills vocational training program.

Lilli Wilson, 10, Sault Ste. Marie, Ontario. Lilli recently competed in two swimming pool contests—filling a bucket with water from a sponge and pushing a flutter board across the pool. She won a second place ribbon for the bucket competition and received "Best Attitude" honors overall for females. Lilli is integrated into a general classroom in school with one-on-one support. One of her duties is to count out milks and snacks and help deliver them to the classrooms.

Austin Farber, 15, San Antonio, TX. Austin has flown three times, by herself, to visit her grandmother in Arcadia, Fla. She always flies direct on Southwest Airlines. On her last trip, Austin had a Group C boarding pass so her mom, Sylvia Farber, warned her that she probably would end up in a middle seat. But just before takeoff, Austin texted her mom to say, "Don't worry, I got an aisle seat. I negotiated with a man." On a previous trip, which was near Austin's birthday, the flight attendants constructed a birthday cake out of peanuts, toilet paper rolls and swizzle sticks, and everyone on board sang "Happy Birthday" to her. Another time, Austin departed the plane with a huge bag of peanuts. When not traveling, Austin participates in a special gymnastics program called "Kinetic Kids."



If you have an SMSer who deserves recognition for his or her achievement, email Dennis Dillon at ddillon923@gmail.com.

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 FREE
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 efields@prisms.org

Editor in Chief: Dennis Dillon editor@prisms.org

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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.
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