

## Summer 2016

### Engaging and Impacting the Community



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## President's Message

I was digging into our files to update a document about Charley's medical history. We have lots of files in various places: the attic, the office, the garage. Doctors' reports, IEPs, educational and behavioral assessments, daily notes from 1986. So much material ... (why, oh why, do we keep it all?).

I stumbled upon a report from our genetic doctor at Dartmouth Medical Center, dated February 1, 1996, which confirmed the deletion on Charley's 17<sup>th</sup> chromosome and gave us a diagnosis of Smith-Magenis Syndrome. Such a benign and simple computer printout. Little did we know how our world would change after receiving that report.

At the time, Charley was 11, coded with "pervasive developmental disability" and enrolled in the local middle school, where his team was mired in deep turmoil. Proven methods to support students with autism didn't work. There was so much frustration, mistrust and uncertainty.

While the diagnosis didn't help with the school, it dramatically helped our family. I remember connecting with PRISMS almost immediately. We started learning about SMS and realized there was a basis for much of what made Charley who he is. We learned about other families who had experienced much the same as we had.

That knowledge strengthened our belief in Charley. It gave us courage to seek a new school placement, and ultimately connected him with a school community which saw beyond his behaviors and embraced him as the person he is.

Also, we learned about plans for the first PRISMS conference that would be held in Bethesda, MD in March 1997. Debora and I both attended. It was such a powerful experience. One or both of us has been to every conference since then.

The PRISMS International Conference brings together speakers who provide insights about the latest

developments in fields related to SMS: sleep, behavior, genetic studies, and more. We have learned so much from this community of experts.

But the most important benefit for me is meeting families, making friends, sharing stories, and helping each other. These are the things that make up a community, and it is why I am so thankful to be part of PRISMS.

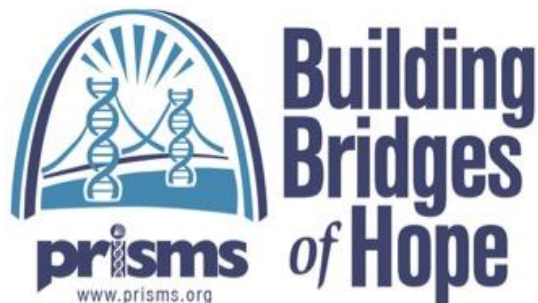
In just a short while, beginning July 28, the 9<sup>th</sup> PRISMS International Conference will be in St. Louis. I'll be there. I hope you will be too!

*John*

John Mayer, Board President

**To #joinmeinstlouis,  
register today!**

<http://www.prisms.org/us/2016-conference/registration-information>



9TH INTERNATIONAL CONFERENCE • ST. LOUIS 2016

## You're Invited to PRISMS Night at the 360-- An Evening of Celebration & Community

By Emily Fields, executive director



*Step out of your conference mode – and step into your evening mode!*

**When:** Thursday, July 28, 2016 8:00pm–10:00pm

**Where:** 360 Rooftop Bar™ at the *Hilton St. Louis at the Ballpark* hotel

The PRISMS board of directors invites you to come and join us for the first-ever fundraising social at the top of the *Hilton St. Louis at the Ballpark* hotel in the **Three Sixty™ Rooftop Bar!** (check it out [here](#))

This is an **adults only** (age 21+) event, and entry is \$100 per person.

Proceeds will offset some of the expenses that make the 2016 conference affordable for all families, including childcare costs and family scholarships.

This is a special and unique occasion for you to join your friends who are part of the PRISMS community and enjoy a social gathering. Your entry includes heavy hors d'oeuvres, an open bar, meeting old and new friends and an amazing view of the city. Entry is limited to 100 guests, so act quickly.

**To participate in this event**, please go to the [Night at the 360 Registration](#) page.

*If you are unable to attend this event, we hope that you will consider giving a donation to support the conference. To donate, please visit:*

<http://www.prisms.org/us/how-to-help/make-donation>

## Be a part of the 9<sup>th</sup> International Building Bridges of Hope Conference

**Join us on July 28-30 in St. Louis, MO at the Hilton Hotel at the Ballpark!**

**Conference registration is now open!**

To register for the conference:

<https://ww2.eventrebels.com/er/EventHomePage/CustomPage.jsp?ActivityID=16736&ItemID=62269>

To register for childcare:

<https://ww2.eventrebels.com/er/Registration/StepRegInfo.jsp?ActivityID=13931&StepNumber=1>

PRISMS biennial International “Building Bridges of Hope” Conference has been developed to educate and share information about Smith-Magenis Syndrome with families, educators, caregivers, physicians, researchers, and other stakeholders in this rare community.

Over the years, attendees have called this conference a life-changing event that anyone impacted by SMS should attend. Don't miss it in 2016!



- Connect with educators, researchers, therapists, clinicians, psychologists, and other SMS families
- Get the support you need through a network of professionals and parents
- Learn new techniques, behavioral interventions, and coping strategies
- Access the latest research by some of the world's leading SMS experts
- Start lifelong friendships and reconnect with old friends

In 2014, PRISMS 8<sup>th</sup> International “Building Bridges of Hope” Conference saw great success with:



- More than **350 registered attendees**
- More than **10%** of attendees were individuals **affected by SMS**
- Attendees representing **eight countries** from around the globe
- 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!
- Distribution of more than **25 scholarships** to assist families and caregivers in attending the conference

## 2016 9<sup>th</sup> International “Building Bridges of Hope” Conference Event Details

### *Conference Venue*

Hilton St. Louis at the Ballpark  
1 South Broadway  
St. Louis, MO 63102

Phone: 1-877-845-7354

**Room rate:** \$137.00 per night

Conference attendees are responsible for making their own hotel accommodations directly with the hotel. PRISMS has secured a special rate for rooms booked in PRISMS room block. To book adjoining rooms, or if you need other assistance with your reservation, please call the hotel at the number listed above.

Note: If you are planning to arrive on Thursday, July 28 please request early check-in. Early check-in is based upon availability but the hotel can store luggage if your room is not ready when you arrive.

To book your room(s) online, please visit:

[http://www.hilton.com/en/hi/groups/personalized/S/STL/BVHF-PRS-20160726/index.jhtml?WT.mc\\_id=POG](http://www.hilton.com/en/hi/groups/personalized/S/STL/BVHF-PRS-20160726/index.jhtml?WT.mc_id=POG)

# Conference Schedule

Notice the new start and stop days/times for this conference. \*\*\* Please note times may vary slightly. \*\*\*

- Sessions begin on **Thursday, July 28, 2016**
  - Childcare & the PRISMS Den open at 1:00pm
  - “First Steps” session: 1:15-2:45pm
  - Workshops: 1:30-4:30pm
  - Reception: 5:00–7:00pm
- Full-day sessions will be held on Friday and Saturday, July 29 and 30
- Sessions end on **Saturday, July 30, 2016 at 6:15pm**

The hospitality suite will be open on Saturday until 10:00pm. Please plan to stay late and celebrate!

PRISMS is proud to share a version of the agenda for the **2016 International “Building Bridges of Hope” Conference**. Please know that session times and speakers are subject to change. We hope you can join us for this three-day educational event filled with sessions covering topics such as sleep, behavior management, special needs planning, genetics 101, medication, sexual understanding and more! See the full agenda below:

## Thursday, July 28, 2016

|                       |   |
|-----------------------|---|
| <b>9:00am-12:00pm</b> | <b>Childcare check-in</b>                               |
| <b>12:00pm</b>        | <b>Conference registration opens</b>                    |
| <b>12:30-1:00pm</b>   | <b>Training for Parent Ambassadors (closed session)</b> |
| <b>1:00pm</b>         | <b>Childcare opens</b>                                  |
| <b>1:00-5:00pm</b>    | <b>PRISMS Den open</b>                                  |

**1:15-2:45pm** **First Steps: “Navigating the PRISMS Conference and Finding Support Along the Way.”**

**1:30-2:45pm** **Concurrent Sessions:**

**A) Teacher & Support Staff Training Session/Part 1**

**Speakers:** *Brenda Finucane, MS, CGC; Barbara Haas-Givler, BCBA*

**B) Exploring Adult Residential Housing: Panel Presentation/Part 1**

**Speakers:** *Deborah Wehrlen, moderator*  
**Panel:** *Leah Baigell, Mary Beall, Barclay Daranyi, John Mayer*

**2:45-3:00pm** **Break (coffee, tea, soft drinks)**

**3:00-4:30pm** **Concurrent Sessions:**

**A) Teacher & Support Staff Training Session/Part 2**

**Speakers:** *Brenda Finucane, MS, CGC; Barbara Haas-Givler, BCBA*

**B) Exploring Adult Residential Housing/Part 2**

**Speakers:** *Deborah Wehrlen, moderator*  
**Panel:** *Leah Baigell, Mary Beall, Barclay Daranyi, John Mayer*



|  |  |
|--|--|
| <p><b>4:00-7:00pm</b> Exhibitor Hall open</p> <p><b>4:30-7:00pm</b> Conference registration continues</p> <p><b>5:00pm</b> Childcare closes for the day. No evening childcare.</p> <p><b>5:00-7:00pm</b> Welcome Reception<br/><i>DJ, face painting for the kids, hors d'oeuvres, non-alcoholic drinks</i></p> <p><b>7:00-10:00pm</b> Hospitality Suite</p> <p><b>8:00-10:00pm</b> <i>PRISMS Night at 360</i></p> <p><b>Friday, July 29, 2016</b></p> <p><b>7:00am-5:00pm</b> Exhibitor Hall open</p> <p><b>7:00-8:00am</b> Continental Breakfast &amp; Registration</p> <p><b>7:45am</b> Childcare opens</p> <p><b>8:00-8:30am</b> General Session: Welcome &amp; Opening Remarks<br/><i>Speaker: Emily Fields, executive director of PRISMS</i></p> <p><b>8:30-8:45am</b> General Session:<br/><i>Speaker: Zach Kon</i></p> <p><b>8:45-9:00am</b> General Session: <i>Positive Exposure</i><br/><i>Speaker: Rick Guidotti</i></p> <p><b>9:00-9:30am</b> General Session: Keynote Address<br/><i>Speaker: Pat Furlong, Founding President and CEO of Parent Project Muscular Dystrophy (PPMD)</i></p> <p><b>9:30-9:45am</b> Break</p> | <p><b>9:45-11:00am</b></p> <p><b>CONCURRENT SESSIONS</b></p> <p><b>A) Breakout: Weight Management &amp; nutrition</b><br/><i>Speaker: Marsha Flowers, MS, RD</i></p> <p><b>B) Breakout: Teacher and Support Staff Training</b><br/><i>This is an abridged version of the Thursday workshop</i><br/><i>Speakers: Brenda Finucane, MS, CGC; Barbara Haas-Givler, BCBA</i></p> <p><b>C) Breakout: Special Needs Planning, Session #1</b> *session repeats<br/><i>Speaker: Salvatore Ferranto, CLU, ChFC, MetLife</i></p> <p><b>D) Breakout: Caring for the Caregiver</b><br/><i>Speaker: Rebecca Foster, PhD</i></p> <p><b>E) The Adolescent Adventure</b><br/><i>Speakers: Kerry Boyd, MD; Ann Smith, MA</i></p> <p><b>F) When feeding becomes a challenge: Facilitating improved mealtimes from a multidisciplinary perspective.</b><br/><i>Speakers: Laura Slosky, PhD; Brenda Sitzmann, SLP</i></p> |
| <p><b>11:00-11:15pm</b> Break</p> <p><b>11:15am-12:00pm</b> General Session: <i>Vanda Pharmaceuticals</i><br/><i>Speaker: Erica Schreffler, MS</i></p> <p><b>12:00pm-1:00pm</b> Lunch Buffet</p>   |  |



|                    |   |   |
|--------------------|---|---|
| <b>12:15pm</b>     | <b>Childcare closes for lunch.</b>  | <b>Speaker:</b> <i>Salvatore Ferranto, CLU, ChFC, MetLife</i>   |
| <b>12:45pm</b>     | <b>Childcare reopens</b>  |   |
| <b>1:00-5:00pm</b> | <b>PRISMS Den,</b> (ages 16 and up; must be preregistered)<br><br>Afternoon events and care for SMS adults ages 16 and up   | <b>E) Breakout: Genetics 101</b><br><b>Speaker:</b> <i>Sarah Elsea, PhD</i><br><br><b>F) Sibling Workshop for Kids Only,</b> (ages 7-12, Session #1)<br><b>Speaker:</b> <i>Ann Schad, LCSW</i>  |
| <b>1:00-2:00pm</b> | <b>General Session: Member Meeting</b><br><b>Speakers:</b> <i>Emily Fields, PRISMS executive director</i><br><i>John Mayer, president of PRISMS board of directors</i><br><i>Sarah Elsea, PRISMS professional advisory board chair</i>  | <b>3:30-3:45pm</b> <b>Break</b><br><br><b>3:45-5:00pm</b> <b>CONCURRENT SESSIONS</b><br><b>A) Breakout: Sibling info for Parents</b><br><b>Speaker:</b> <i>Leah Baigell</i><br><br><b>B) Sibling Workshop for Kids Only</b> (Ages 13-17, Session #2)<br><b>Speaker:</b> <i>Ann Schad, LCSW</i>              |
| <b>2:00-2:15pm</b> | <b>Break</b>  | <b>C) Breakout: Sexual Understanding and SMS: Session #1</b><br><i>To address the age group of teen years through adult years</i><br><b>Speaker:</b> <i>Sheila Warembourg</i>   |
| <b>2:15-3:30pm</b> | <b>CONCURRENT SESSIONS</b><br><b>A) Medication and SMS</b><br><br><b>Speaker:</b> <i>Thomas Challman, MD, TBD, (Session repeats, #1)</i><br><br><b>B) Sibling Session for Young Adult &amp; Adult Sibs</b><br><b>Speaker:</b> <i>Andrew Cordrey</i><br><br><b>C) Curbside Consults for Teacher/Support Staff Training</b><br><b>Speakers:</b> <i>Brenda Finucane, MS, CGC;</i><br><i>Barbara Haas-Givler, BCBA</i><br><br><b>D) Breakout: Special Needs Planning, Session #2</b> *session repeats | <b>D) Breakout: Positive Discipline</b><br><b>Speaker:</b> <i>Jackie Diver, MA</i><br><br><b>E) Breakout: Advocacy in the Schools</b><br><b>Speaker:</b> <i>Sylvia Farber, M.Ed., Special Education</i><br><br><b>F) Medication and SMS</b><br><b>Speaker:</b> <i>Thomas Challman, MD TBD, (session #2)</i> |
|                    | <b>5:00pm</b>   | <b>Friday day sessions conclude. Exhibitor Hall closes.</b>   |



|                                       |  |                       |  |
|---------------------------------------|--|-----------------------|--|
|                                       | <i>Dinner on your own.</i>   |                       | <i>Girirajan, MD, PhD; Carole Le Coz, PhD.</i>   |
| <b>5:15pm</b>                         | <b>Childcare closes.</b>   |                       |  |
| <b>5:30– 6:30pm</b>                   | <b>Regional Reps Meeting</b><br><b>Speakers:</b> <i>Percy Huston, PRISMS board member; Emily Fields, executive director</i>  | <b>9:45–10:30am</b>   | <b>Breakout session: Healthy Relationships &amp; Understanding Emotions:</b><br><br><b>A Discussion Group for Women with SMS</b><br><b>Speaker:</b> <i>Sheila Warembourg</i> |
| <b>7:00-10:00pm</b>                   | <b>Hospitality Suite</b>   |                       |  |
| <b>7:00pm</b>                         | <b>Childcare opens, (for Sharing &amp; Caring attendees)</b>   | <b>10:15-10:30am</b>  | <b>Q&amp;A in General Session</b>  |
| <b>7:00-8:30pm</b>                    | <b>General Session &amp; breakouts</b><br><b>Sharing &amp; Caring Session</b><br><b>Speaker/Facilitator:</b><br><i>Rebecca Foster, PhD</i>   | <b>10:30-10:45am</b>  | <b>Break</b>   |
| <b>9:00pm</b>                         | <b>Childcare closes</b>  | <b>10:45-11:30am</b>  | <b>Breakout session: Healthy Relationships &amp; Understanding Emotions:</b><br><b>A Discussion Group for Men with SMS</b><br><b>Speaker:</b> <i>Sheila Warembourg</i>       |
| <b><u>Saturday, July 30, 2016</u></b> |  |                       |  |
| <b>7:00am-8:00am</b>                  | <b>Continental Breakfast</b>   | <b>10:45am-12:00p</b> | <b>CONCURRENT SESSIONS</b>   |
| <b>7:45am</b>                         | <b>Childcare opens</b>   |                       | <b>A) Breakout: “Good Grief: A Parent’s Journey” Session #1 (session will repeat)</b><br><b>Speaker:</b> <i>Jay Perkins</i>  |
| <b>7:50-8:00am</b>                    | <b>Housekeeping Remarks</b>  |                       |  |
| <b>8:00-8:15am</b>                    | <b>GENERAL SESSION: SMS Foundation UK</b><br><b>Speaker:</b> <i>Hazel Wotherspoon, chairperson</i>   |                       | <b>B) Breakout: Medical Management of SMS across the lifespan</b><br><b>Speakers:</b> <i>Ann Smith, MA; Gail Reiner, PhD</i>   |
| <b>8:15-10:15am</b>                   | <b>General Session: International Research Updates:</b><br>Panel will present on current research<br><b>Speakers:</b> <i>Sarah Elsea, PhD; Rebecca Foster, PhD; Joe Alaimo, PhD; Brenda Finucane, MS, CGC; Kosuke Izumi, PhD; Ann C.M. Smith, MA; Santhosh</i> |                       | <b>C) Breakout: Speech &amp; SMS: The Relationship Between Language &amp; Behavior</b><br><b>Speaker:</b> <i>Christine Brennan, MA, CCC-SLP</i>                              |
|                                       |  |                       | <b>D) Breakout: Sleep &amp; Smith-Magenis Syndrome</b><br><b>Speaker:</b> <i>Daniel Norman, MD</i>   |





|                      |   |                     |  |
|----------------------|---|---------------------|--|
|                      | <p><b>E) Genetics and YOU...for the sibs: A Hands-on Approach to Understanding Your Genes</b><br/>(Ages 12 &amp; up)<br/><b>Speaker: Joe Alaimo, PhD</b></p>  |                     | <p><i>To address age group of pre-adolescence to adolescence</i><br/><b>Speaker: Sheila Warembourg</b></p> |
| <b>12:00-1:30pm</b>  | <b>Lunch &amp; free time</b>  | <b>3:00-3:15pm</b>  | <b>Break</b>   |
| <b>12:15-12:45pm</b> | <b>Childcare closes for lunch.</b>  | <b>3:15-4:30pm</b>  | <b>Curbside Consults</b>   |
| <b>12:45</b>         | <b>Childcare reopens</b>  |                     | <b>Adolescent &amp; Adult Psychiatry</b>   |
| <b>1:00-5:00pm</b>   | <p><b>The PRISMS DEN</b><br/>Afternoon events and care for SMS adults ages 16 and up</p>  |                     | <b>Adult Living Behavior</b>   |
| <b>1:30-3:00pm</b>   | <p><b>CONCURRENT SESSIONS</b></p> <p><b>A) Breakout: "Good Grief: A Parent's Journey" Session #2 (session repeats)</b><br/><b>Speaker: Jay Perkins</b></p> <p><b>B) Breakout: Behavior</b><br/><b>Speaker: Mindy Scheithauer, BCBA</b></p> <p><b>C) Breakout: Exploring Adult Residential Settings Workshop</b><br/><b>Speakers: Deborah Wehrlen, moderator</b><br/><b>Panel: Leah Baigell, Mary Beall, Barclay Daranyi, John Mayer</b></p> <p><b>D) Breakout: Neuro-psych Testing</b><br/><b>Speaker: Jonathan Dodd, PsyD; Christopher Bosworth, PhD</b></p> <p><b>E) Breakout: Sexual Understanding and SMS: Session #2</b></p> |                     | <b>Developmental Medicine/Medication</b>   |
|                      |   |                     | <b>Feeding Issues</b>  |
|                      |   |                     | <b>Genetics</b>  |
|                      |   |                     | <b>Medical Management</b>  |
|                      |   |                     | <b>Neuro-psychological testing</b>   |
|                      |   |                     | <b>Sexuality</b>   |
|                      |   |                     | <b>Sibling &amp; Caregiver Care</b>  |
|                      |   |                     | <b>Sleep</b>   |
|                      |   |                     | <b>Speech &amp; Language</b>   |
|                      |   | <b>4:30-5:00pm</b>  | <b>General session: Closing remarks &amp; Slideshow &amp; video finale</b>                                 |
|                      |   |                     | <b>Speaker: Emily Fields, PRISMS executive director</b>  |
|                      |   | <b>5:00pm</b>       | <b>PRISMS Den closes promptly at 5pm!</b>  |
|                      |   | <b>5:15pm</b>       | <b>Childcare closes for the day. No evening childcare.</b>   |
|                      |   | <b>5:15-6:15pm</b>  | <b>Ice Cream Social</b>  |
|                      |   |                     | <i>Dinner on your own.</i>   |
|                      |   | <b>7:00-10:00pm</b> | <b>Hospitality Suite</b>   |

## **PRISMS Board of Directors – SMS Parents, just like you!**

Organized and incorporated in Sterling, Virginia on February 4, 1993, PRISMS, Inc, is governed by an 11-member board of directors. These individuals give of their time and talents to support and lead PRISMS every day to better support the SMS community. Most board members have children with Smith-Magenis Syndrome, and all have extensive understanding of and experience with the syndrome. Board members serve three-year terms and may serve additional consecutive terms. Several members of the board serve as corporate officers. These individuals are responsible for directing the organization's operations and serving the members.

### **John Mayer — President**

John joined the PRISMS board in 2009, serving for six years as secretary before being elected president in 2015. He has chaired the membership committee and led several fundraising campaigns to support the International Conference. Currently, he chairs the Adult Living Workgroup. John works professionally in the non-profit field for history museums, and has served as curator and executive director. He and his wife, Debora, live in Portsmouth NH. They are the parents of Charley, a 31-year old with SMS, and Owen, 25, who currently is working on a PhD in electrical engineering at Drexel University in Philadelphia.

### **Margaret Miller— Vice President**

Margaret Miller is the Founding President of PRISMS. She began PRISMS along with her husband Scott Miller, Ann Smith and Brenda Finucane. She was inspired to help develop this organization after receiving the diagnosis of SMS for her infant daughter. There were no SMS organizations at that time and very little information on the syndrome. She has served on the PRISMS Board as President, Past-President, Vice President, (currently), and Board Member and has helped to chair and plan nine

international conferences and eight research symposiums. She has been an invited speaker on SMS at educational conferences, college seminars, and the National Institutes of Health. Maggie is passionate about working closely with researchers and professionals and believes that we can only make greater strides in our mission when we work together. Maggie lives in a suburb of Washington DC, with her husband, daughter and son.

### **Phil Ruedi— Treasurer**

Phil has been a member of the PRISMS board since 2010. He joined as treasurer and continues to serve in that role as well as chair of the finance committee and a member of the executive committee. Phil is a portfolio manager at Wellington Management in Boston, MA. He and his wife, Laura Staich, live in Brookline, MA with their son, Griffin (10, SMS) and daughter, Arden (six).

### **Randy Beall — Immediate Past President**

Randy joined the PRISMS Board in 2001. He was the treasurer and vice president before serving 10 years as president, beginning in 2005. He currently serves as immediate past president and is on the executive committee, nominating committee and finance committee. Randy works professionally in banking. He and his wife, Mary, live in Garland, TX (a Dallas suburb). They are the parents of two daughters, Laura, a 30-year old with SMS, and Jenny.

### **Brandon Daniel — Secretary**

Brandon joined the PRISMS board in January 2015, assisting with fundraising, before assuming the role of secretary in January 2016. Brandon is the revenue administration manager at Ag-Power, Inc., a John Deere dealer with 17 locations throughout Texas, Arkansas and Missouri. He and his wife, Dawnda, live in Prosper, TX, a bedroom community north of Dallas. They have three boys, ages 11, nine and 22 months.

Their nine-year-old son, Coulter, was diagnosed with SMS in 2007.

### **Tina McGrevy — Awareness Chair**

Tina joined the PRISMS board in 2010, serving as the fundraising chair until 2014, when she became the awareness chair. Finding information on the PRISMS website to share with family, educators and healthcare professionals was a life-changing moment for the McGrevys, and Tina is excited to broaden this tradition in the social media era. She writes personal, informational and sometimes humorous stories about SMS that have been published on The Mighty, The Firefly Garden, and Chicken Soup for the Soul, and in various special needs magazines. She encourages PRISMS families to reach out to her with ideas for raising SMS awareness in the media, their local venues and within the healthcare system. Tina and her husband, Charlie, live in Springfield, OH with their three sons: Garrett, diagnosed with SMS in 2001, Patrick and Brennan.

### **Percy Huston— Regional Representative Chair**

Percy joined the PRISMS board in 2006, initially to spearhead fundraising efforts. As an at-large member, he has since served on the finance committee and strategic planning committee. In 2014, he was asked to initiate the regional representative program and coordinate volunteer efforts from those in the PRISMS community, a capacity he continues to serve in currently. Percy is involved in family banking in Missouri and also represents central payment in the credit card processing industry. He and his wife, Bernadette, live in Cape Girardeau, MO. They are the parents of Jacqueline, a 25-year-old daughter with SMS, and a son, J.P., who recently graduated from the University of Missouri. They also have two older sons, Shawn, 40, and Billy, 38.

### **Rochelle Wright – Membership Chair**

After a 10-year absence, Rochelle rejoined the PRISMS board in 2015 as the new membership chairperson. She previously served on the board as secretary and vice president. Rochelle works for Siemens in the digital factory division, where she is responsible for managing U.S. Repair Operations. The Siemens products repaired are used in industrial applications, including motors, gears, power drives and controls. She and her husband, Paul, live in Peachtree City, GA with their two sons, Luke and Zachary (SMS).

### **Rebecca Hallmark – Conference Chair, 2018**

Rebecca recently joined the board of directors as conference chair. Her duties include overseeing the planning and execution of the PRISMS International Conference, advancing the mission and vision of PRISMS, and supporting and engaging members of the PRISMS community. Rebecca has served in the U.S. Air Force as a senior linguist, and has spent the last 20 years serving the intelligence community in many capacities, including forensics specialist, senior analyst/researcher, commercial manager, and cyber security expert. Rebecca is also a member of the Hearing Loss Association of America, the Association for Positive Behavior Support, the National Organization for Rare Disorders (NORD) and the NORD Rare Action Network, and The Arc of Greater Prince William. Rebecca resides in Northern Virginia with her husband, Will, and their three children: Ahja, Naia, and Eva, eight, who has SMS. Their son, William, is enlisted in the Army and stationed at Fort Campbell, KY.

### **Denien Rasmussen – Fundraising Chair**

Denien became a member of PRISMS in 2008, when her son, Matthew, (then four), was diagnosed with SMS. She attended her first PRISMS conference that year in Virginia, and has been to every conference since then. In 2010, she and Matthew joined Ann Smith at the NIH for the Bright Light Sleep Study. Denien organized the “PRISMS Manna Script Gift Card Program” and created the “It worked for me” section in the Prisms’ newsletters. She was invited to

speak at the Northwest Special Recreation Association (NWSRA) to educate the staff about SMS. She is an active participant and resource for Palatine School District 15 Multiple Needs Program. Professionally, Denien is the chief operating officer of R.W. Smith & Associates, LLC, where she has worked for more than 30 years. She and her husband, Jim, live in Palatine, IL and are the parents of 11-year-old twin boys, Matthew (SMS) and Michael.

### **Sarah Elsea – Professional Advisory Board Chair**

Dr. Sarah Elsea is an associate professor of Molecular and Human Genetics, and director of the Biochemical Genetics Laboratory at Baylor College of Medicine in Houston, TX. She is a board-certified biochemical geneticist by the American Board of Medical Genetics. Dr. Elsea is an educator, training students at all levels, including high school, college, graduate, medical, and postgraduate. She also provides clinical consultations and focuses her research efforts toward characterizing Smith-Magenis Syndrome and related genetic disorders. Dr. Elsea's lab identified RAI1 as the causative gene for SMS, and has targeted research efforts toward understanding the function of RAI1, particularly in the role of RAI1 in circadian rhythm and obesity. Her more recent work assesses caregiver and sibling concerns in families of children with developmental disabilities.

## **Coming Soon! The New PRISMS Guidebook of Residential Options for Adults with SMS**

By John Mayer, board president

We are excited to announce the upcoming publication of "***A Smith-Magenis Guidebook: Exploring Adult Residential Living***". This guidebook will soon be available at no charge on the PRISMS website as a downloadable PDF file, with hard copies available from PRISMS for a nominal fee. The launch date of this publication will be around the time of the PRISMS 9<sup>th</sup> International Conference, in St. Louis, MO on July 28.

Recognizing the need to support those with SMS beyond school-age years, PRISMS formed a workgroup chartered to explore residential life post "high school" and to create a publication for the SMS community. This group included parents of adults with SMS and professionals skilled in developing residential services.

The guidebook includes information about a variety of residential programs, both in the home and in the community; helpful how-to suggestions for finding support and funding; and case studies contributed by families from across the country. These case studies provide personal insights about the benefits and challenges of different living situations. Also touched on are how these young adults spend their days.

Identifying the residential setting that best meets the needs of an individual with SMS is a personal decision for each family to explore and settle on. The easy-to-read guidebook is organized to help families navigate this difficult and time-consuming process.

The publication of this guidebook is a major accomplishment for PRISMS, one that will serve our families as a useful tool as their children with SMS transition to adulthood. Members of the residential living workgroup will be at the conference in St. Louis, offering details about their experiences with adult living programs in panel discussions and at breakout sessions.

We want to recognize and thank Betty and Ira Dyer, grandparents of Charley Mayer, who made a generous gift to PRISMS allowing for the development of this guidebook. It would not have been possible without their generosity.

## **Welcome, Dr. Santhosh Girirajan to the PRISMS Professional Advisory Board!**

PRISMS is delighted to welcome Dr. Santhosh Girirajan as the newest member of its professional advisory board. Now 11 members strong, the PAB advises the PRISMS board of directors on medical, scientific, educational and therapeutic matters, and

assists in the education and research activities of the organization. The PAB is an internationally recognized group of basic scientists, educators and clinicians with expertise in SMS, genetics, molecular research, education, speech, development, and caregiver and sibling concerns.

As part of its mission, the PAB assists in the development of accurate and effective informational and promotional materials, and writes and edits articles for Spectrum, the PRISMS website and other publications. This dedicated group of experts responds to inquiries from families, caregivers, physicians, teachers and a variety of other healthcare providers to support the SMS community and ensure the dissemination of current and accurate medical information.

**Dr. Santhosh Girirajan, MBBS, PhD**



Santhosh Girirajan, MBBS, PhD, is an assistant professor in the Department of Biochemistry and Molecular Biology and Anthropology at Penn State. A physician by training, Dr. Girirajan obtained his medical degree from Bangalore University and a PhD in human genetics from the Medical College of Virginia, Virginia Commonwealth

University, Richmond, VA. During his graduate studies in the lab of Dr. Sarah Elsea, Dr. Girirajan performed human genetics research to identify and characterize genes responsible for Smith-Magenis Syndrome. He performed postdoctoral training in the lab of Dr. Evan Eichler in the Department of Genome Sciences at the University of Washington, studying the mechanisms and consequences of large genomic changes with particular relevance to human neurodevelopmental disorders. Dr. Girirajan joined Penn State as a faculty member in the summer of 2012. The primary focus of his current research is to understand the clinical and genetic heterogeneity of neurodevelopment disorders with a specific focus on autism.

## Lessons I Learned from an SMS Friend

By Georgie Finney

I first learned about Smith-Magenis Syndrome two years ago, when a family moved into a house up the street from mine. When I went up to meet them for the first time, an energetic little boy named Cooper came to the door. I could tell from his distinctive facial features that he must have been affected by some sort of condition.

When his mother invited me inside, I introduced myself, saying I lived down the street. Cooper continued to stare at me with a blank expression on his face. His mother explained his condition and said that even though he has his challenges, he's very spontaneous. Then, she told me she was looking for babysitters in the neighborhood and asked if I would be willing to watch Cooper sometime.

At first, I was a little apprehensive because it sounded like babysitting Cooper could be challenging for me, given his special needs. But then I reconsidered and told her I would be more than happy to babysit. Cooper's mother was thrilled to hear this, and told me that she would explain everything when I came to babysit for the first time.

Months passed before I got asked to babysit Cooper. Before his mother left, she gave me her laptop, opened to a website called prisms.org (PRISMS is an acronym for Parents and Researchers interested in Smith-Magenis Syndrome). She told me that I could read more about Cooper's condition while he was napping and hopefully gain a better understanding of SMS. As I explored the website, I learned more than I expected. PRISMS outlined all of the details of the disorder, from general information to symptoms. After reading through this information, I felt like I had gained a significant amount of insight that would be useful the next time I babysat Cooper.

Last August, I was asked to watch Cooper for a couple of days while his parents were at work. This was the first time that I would be babysitting Cooper for an entire day, but I knew with my past experiences and

knowledge I would be able to handle it. I was also babysitting Cooper's brother, who is a couple years older than him. They got along great for most of the day, but when his brother wanted alone time to play by himself and Cooper tried to interfere, he got angry and kept moving to different spots in the room to get away from him. I tried my best to distract him with his toys, and I even put on an episode of Elmo, which is his favorite show. As soon as Elmo showed up on the TV screen, Cooper stopped what he was doing and raced to the living room. I have never seen anyone move that fast in my life.

I thought I distracted him for good, but one thing I learned over the course of those two days is that people with SMS get distracted very easily. One minute, Cooper was in the family room with his eyes glued to the TV; the next minute, he was back to the laptop, watching his brother play his games. For 20 minutes I just sat there and observed how he frantically switched from the TV to the laptop. I knew then what Cooper's mother meant when she told me that there is never a dull moment in her household.

As Cooper gets older, he is teaching me more things in life that I might never have realized had I not met him. He has taught me the importance of what it means to interact with new people you encounter. When I took him to the pool on the second day I babysat him, he approached dozens of people sitting in lounge chairs, and they all seemed to know him fairly well. I was really surprised, especially when he went up to one lady who appeared to be sleeping while listening to music with headphones on. As I tried to stop him from going up to her, I was also interested to see if this woman knew him. To get her attention, he grabbed her sandwich, climbed on her lounge chair and held it in front of her face. At first, she was startled. As I began to apologize, her face immediately lit up as she said, "Cooper! I haven't seen you in a while!"

While I found these experiences profoundly moving, I also found it really interesting that he only approached certain people that he must have remembered from past encounters instead of complete strangers. While babysitting Cooper is without a doubt filled with much humor, there are also some challenges presented that we have to work through together. Whenever it is time

for him to take his nap, he will sometimes have a tantrum. My first instinct is to respond to this behavior by letting him get his way because I don't like seeing him upset. However, I continually have to remind myself that I am not doing anything wrong, but rather I am doing the right thing because I am helping him to learn, as hard as it may be sometimes.

Cooper has also made me appreciate the different aspects I value in my life, and he is the main reason why I love being a babysitter. The satisfaction that I get from babysitting him is indescribable. Joy fills my heart as I think of the impact I am having on his growth and development. Seeing him smile and laugh when I read to him is just one of the many examples where I truly feel so much happiness and a sense of accomplishment. Cooper is an amazing boy who has had an immense effect on my life, and I know I would not be where I am today if it wasn't for him.

*Georgie Finney is a high school senior. She presented this article as a speech to her fellow students as part of an academic requirement.*

## PRISMS: The Road Ahead

By Emily Fields, Executive Director

Since January 2015, the 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. In the past several Spectrum Journals, PRISMS has been proud to release its mission, vision, values, and goals resulting from its strategic planning process. You can revisit those on the PRISMS website: <http://www.prisms.org/us/about-us/mission-vision-values-a-goals>

In an effort to achieve the organization's five key goals and live up to its expressed values, PRISMS board of directors, executive director and volunteers are working hard on leading new activities and growing current programs to ensure we continue to move forward in service of the entire SMS community.

As a reminder, **PRISMS goals are:**

- 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.

Some activities PRISMS will work on over the next several years to accomplish these goals include:

**GOAL: Be a global organization**

- Create a registry to capture and store information on SMS individuals worldwide.
- Create a network of international partner organizations.
- Expand international representation on PRISMS professional advisory board.
- Expand and modify programs and materials to better serve an international community of families.
- Create a directory of research and treatment professionals.
- Develop a global feedback mechanism for the board of directors from international communities.

**GOAL: Be the “go-to knowledge center” for all things SMS**

- Expand the regional representative program so as to assist with the awareness and accessing of local resources.
- Communicate information about the latest research to families in understandable language.
- Share information about SMS with physicians and other professionals (e.g. special needs educators,

trust planners, attorneys, genetic counselors, et al) and their offices.

- Create a network of known educators and therapists who work with SMS individuals to connect them with each other as a means of support.
- Provide guidance to parents in advocating for their child.

**GOAL: Ensure that all actions taken by PRISMS are grounded in the best available knowledge**

- Ensure regular communication between PRISMS and its professional advisory board.
- Establish a review process to ensure content and materials are up-to-date and are based on consensus and evidence-based research.
- Establish a procedure with the PAB for identifying, soliciting, and evaluating research opportunities.
- Grow basic science, clinical and educational research funding.

**GOAL: Ensure those impacted by SMS have the resources and opportunity to achieve their fullest potential**

- Develop and improve PRISMS informational content for all stages of life, from infancy to old age.

**GOAL: Be a sustainable organization**

- Develop a comprehensive and detailed annual funding plan to provide regular updates at board meetings.
- Develop an internal succession and recruitment plan for board members and committees.
- Ensure PRISMS continues to identify and implement the best practices in all of its programs and operations.

We have much to accomplish as we move towards our goals. We appreciate the support and confidence of the community, and look forward to accomplishing these goals with you!



**Officers**

|                |                                       |
|----------------|---------------------------------------|
| President      | <b>John Mayer</b><br>Portsmouth, NH   |
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| Secretary      | <b>Brandon Daniel</b><br>Prosper, TX  |
| Treasurer      | <b>Phil Ruedi</b><br>Boston, MA       |

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|  |  |
|--|--|
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St. Louis (MO) Children's Hospital



## Connect with PRISMS

### Host a fundraiser or awareness event in your area

Contact [info@prisms.org](mailto:info@prisms.org) for support and ideas to make your event a success

### Join the PRISMS community by becoming a member for 2016

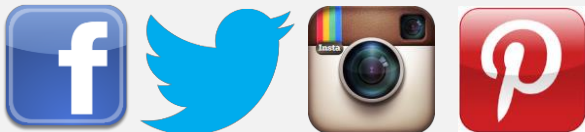
Learn more about membership by visiting our website at [www.prisms.org](http://www.prisms.org)

### 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](http://www.prisms.org)

### Share your story with us

We want to hear from you. Reach out to PRISMS' executive director at [efields@prisms.org](mailto:efields@prisms.org)



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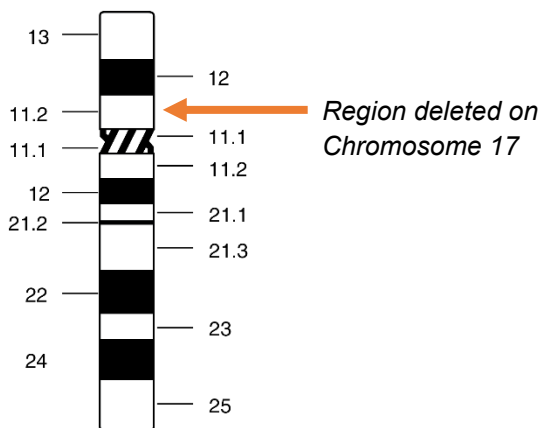
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2. Type "PRISMS, Inc" in the pick your charitable organization text box. Click Search. (Note: type PRISMS in capital letters.)
3. Select "Prisms, Inc." There are a few organizations with the same name. Choose the PRISMS in Sterling, VA founded in 1993. Click "about" if you want to confirm you have chosen the correct PRISMS.
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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. SMS is under-diagnosed, but as awareness of it increases, the number of people identified grows every year.



## Volunteer Opportunities

**PRISMS is always looking for helping hands from the community to serve as members of one of our various committees, assist in a program, or coordinate an event. Interested in sharing your time and talents with the SMS community?**

**Contact us at [info@prisms.org](mailto:info@prisms.org)**

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