



**PRISMS Conference Program\***  
**Hyatt Regency Dallas**  
**Thursday, July 11, 2024 – Saturday, July 13, 2024**  
***(program, speakers and times subject to change)***

**Thursday, July 11, 2024**

**12:00pm**      *Childcare check-in*  
**11:00am-7:00pm**      *Conference Registration opens*

**12:15pm-1:15pm**      **Smith-Magenis Syndrome: Putting the Genetic Diagnosis in Context**  
**Speakers:** Barbara Haas-Givler, MEd, BCBA, and Cora Taylor, PhD

**1:15pm-2:45pm**      **Abram’s Nation First Steps Session: “Navigating the PRISMS Conference and finding support along the way.”**

**Facilitators:** Allison Stephanouk and Charlene Michaud

**Panel Members:** TBD

***This is a closed session for first- and second-time conference attendees. No children in the session please.***

**1:30pm-2:45pm CONCURRENT WORKSHOPS**

**A) Teacher and Support Staff Training/Part 1**

**Speakers:** Barbara Haas-Givler, MEd, BCBA, and Cora Taylor, PhD

**B) Adult Living: Residential and Vocational Options/Shared Living Collaborative**

**Speaker:** Daniela Morse, Executive Director

**3:00pm-4:15pm CONCURRENT WORKSHOPS & SESSIONS**

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

**Speakers:** Barbara Haas-Givler, MEd, BCBA, and Cora Taylor, PhD

**B) Adult Living: Engaging in a Self-Directed, Meaningful Life/Building Community**

**Speaker:** Daniela Morse, Executive Director

**C) Understanding the Genetics of SMS**

**Speaker:** Sarah Elsea, PhD

**D) Parent to Parent Series: An SMS Parent’s Perspective on Guardianship and Estate Planning**

**Speaker:** Randy Beall, Parent, Former PRISMS President

**5:00pm**      **Childcare & The PRISMS Den close for the day. No evening childcare.**

**5:00pm-6:30pm**      **Welcome Reception (DJ, hors d’oeuvres, non-alcoholic drinks)**

**8:00pm**      **17p11.2 Society meets in Monduel’s - all are welcome!**

## Friday, July 12, 2024

7:00am-8:00am      Registration check-in continues  
7:00am-8:15am      Continental breakfast  
7:45am-12:00pm    Childcare opens  
1:00pm-5:00pm      The PRISMS Den  
8:00pm -10:00pm    Evening Childcare

### 8:15am-9:45am GENERAL SESSION

8:15am-8:35am      **Welcome & Opening Remarks**  
*Speaker:* Michelle Larscheid, PRISMS Executive Director

8:35am-8:50am      **President's Address**  
*Speaker:* Percy Houston, PRISMS President

8:50am-9:15am      **Positive Exposure**  
*Featured Speaker:* Rick Guidotti

9:15am-9:30am      **Peer Friendship and Support**  
*Featured Speaker:* Kevin Sperry

9:30am-9:40am      **Be the Best You Can Be**  
*Featured Speaker:* Zach Kon

9:40am-9:45am      **Closing**  
*Speaker:* Michelle Larscheid

### 10:00am-11:30am PRISMS – Then, Now and Always

10:00am-10:05am    **Introduction**  
*Speaker:* Michelle Larscheid, PRISMS Executive Director

10:05am-10:15am    **PRISMS Professional Advisory Board (PAB)**  
*Speaker:* Sarah Elsea, PhD

10:15am-10:25am    **PRISMS SMS Patient Registry, (SMSPR)**  
*Speakers:* Theresa Wilson, MS, RD, and Jackie Fallenstein, PRISMS Vice President

10:25am-10:35am    **Recap of the 11<sup>th</sup> PRISMS Research Symposium**  
*Speaker:* Michelle Larscheid, PRISMS Executive Director

10:35am-10:45am    **PRISMS Clinic and Research Consortium, (PCRC)**  
*Speaker:* Ann C. M. Smith, MA, DSc, (Hon)

10:45am-10:55am    **PRISMS Alliances (Combined Brain Bio Repository, Rare Revolution, Patient Worthy, Brain Donor Project, VANDA Pharmaceuticals)**  
*Speaker:* Michelle Larscheid, PRISMS Executive Director

10:55am-11:05am    **PRISMS Development Committee**  
*Speaker:* Jackie Fallenstein, PRISMS Vice President

11:05am-11:15am    **PRISMS Parent Advisory Group**  
*Speaker:* Barclay Daranyi

11:15-11:30am      **Q&A**

11:45am-12:45pm    **Lunch Buffet**

## 1:00pm-2:15pm CONCURRENT SESSIONS

**A) Setting the Stage for Effective strategies to support behavior and learning in students with Smith-Magenis syndrome from early years through high school**

**Speaker:** Barbara Haas-Givler, MEd, BCBA

**B) Building Bridges and Navigating Adult-based Healthcare for Individuals with Developmental Disabilities**

**Speaker:** John C. Berens, MD, Associate Professor, Department of Medicine, Transition Medicine, Baylor College of Medicine

**C) Medical Management of SMS (From newborn to early adolescence)**

**Speakers:** Ann C. M. Smith, MA, DSc, (Hon), and Gail Reiner, D.N.P., FNP-C

**D) Inclusive Recreation Starter Kit: Participation Tools**

**Speaker:** Erin Fogarty, MS, CTRS

## 2:30pm-3:45pm CONCURRENT SESSIONS

**A) Interventions for Severe Behavior**

**Speakers:** Dr. Timothy Vollmer, PhD, and Kerri Peters, PhD, BCBA-D

**B) Government Benefits**

**Speaker:** Allison Schaberg, President, Consolidated Planning Group

**C) Medical Management of SMS (Transition to Adulthood)**

**Speakers:** Ann C. M. Smith, MA, DSc, (Hon), and Gail Reiner, D.N.P., FNP-C

**D) Practical Applications of Stress Management for Caregivers**

**Speakers:** Karen Canada, LCMHCS, MS, and Shannon Duval, parent

## 4:00pm-5:15pm CONCURRENT SESSIONS

**A) Parent to Parent Series - What are the Keys to a Meaningful Life for Your Adult Child with SMS**

**Facilitators:** Barclay Daranyi and Leah Baigell

**Panel Members:** TBD

**B) Approaching Acute Behavior Changes in individuals with SMS: Behavior Concerns for SMS Individuals with Severe SMS Behaviors**

**Speakers:** Kerry Boyd, MD, Barbara Haas-Givler, MEd, BCBA, and Mary Beall, MEd

**C) How to Navigate Puberty for Girls**

**Speaker:** Cora Taylor, PhD

**D) Speech and Language Development/Production and Social Communication**

**Speaker:** Christine Brennan, PhD, CCC-SLP

**5:15pm – 6:00pm Curbside Consults**

**Dinner on Your Own**

**5:00pm Childcare & The PRISMS Den closes**

**8:00pm – 10:00pm Evening Childcare**

**8:00pm – 11:00pm PRISMS Hawaiian Paradise Fundraiser at The Courtyard Rooftop**

## Saturday, July 13, 2024

7:00am-8:00am      Continental breakfast  
7:45am-12:00pm    Childcare opens  
1:00pm-5:00pm     The PRISMS Den

### 8:00am - 9:45am GENERAL SESSION

**Research Updates:** Panel will present SMS research updates from around the globe  
**Moderators:** Sarah Elsea, PhD, and Santhosh Girirajan, MBBS, PhD

9:45am-10:30am    Research Symposium Poster Session

### 10:45am-12:00pm CONCURRENT SESSIONS

#### A) Sleep & SMS

**Speaker:** Kevin Kaplan, MD

#### B) Neurological implication in SMS, (autism dx and seizures, etc)

**Speaker:** Andrea Gropman, MD, CNMC, Division Chief, Neurodevelopmental Pediatrics and Neurogenetics

#### C) What a Parent Must Know about Special Education

**Speaker:** Sylvia Farber, MEd

#### D) How to Navigate Puberty for Boys

**Speaker:** Cora Taylor, PhD

12:00pm-1:30pm Lunch Buffet

### 1:45-3:00pm CONCURRENT SESSIONS

#### A) Food Related Behaviors/Obesity in Smith-Magenis: Causes and Strategies for Treatment

**Speaker:** Stephanie Sisley MD, Endocrinologist

#### B) Parent to Parent Series: Resilience: What can you, the caregiver, do to stay strong and keep on going?

**Moderator:** Barclay Daranyi, parent, Member of the PRISMS Parent Advisory Group

**Panel Members:** TBD

#### C) The role of pain and discomfort in aggressive and self-injurious behaviors.

**Speakers:** Timothy Vollmer, PhD, and Kerrie Peters, PhD, BCBA-D

### 3:15pm-4:30pm CONCURRENT SESSIONS

#### A) Parent to Parent Series: Prioritizing Your Relationship

**Speakers:** Nancy Cordrey and David Cordrey

#### B) Introduction to AAC and Successful use of AAC

**Speaker:** Christine Brennan, PhD, CCC-SLP

#### C) From a Maze of Communication to Amazing Communication: Practical Steps to Advocating for Yourself and Others.

**Speaker:** Karen Canada, LCMHCS, MS,

#### D) Sleep and SMS (This is a repeat session)

**Speaker:** Kevin Kaplan, MD

## **GENERAL SESSION**

**4:45pm-5:15pm**      **Final Words, Slideshow & Celebration of SMS Community!**

**Speakers:** Michelle Larscheid, PRISMS Executive Director, and Percy Houston, PRISMS President

**5:00pm**              **PRISMS Den and Childcare closes promptly at 5:15pm!**

**5:30pm-6:15pm**      **Ice Cream Social**

**CONFERENCE CONCLUDES**

**PRISMS Conference Program for Siblings**  
**Thursday, July 11, 2024 – Saturday, July 13, 2024**  
*(program, speakers, activities and times subject to change)*

**Thursday, July 11, 2024**

**3:30pm – 4:15pm**    **First Steps: Siblings** (For Siblings 7-17)

**Facilitators:** Amy Pereira, Kaitlyn Pereira

**5:00pm-6:30pm**    **Welcome Reception** (DJ, hors d'oeuvres, non-alcoholic drinks)

**7:00pm-7:45pm**    **Retro Video Game Tournament** – *sign up required*

**8:00pm-8:30pm**    **Pub Trivia for Siblings** (ages 13-17)

**Facilitator:** Christine Brennan, PhD, CCC-SLP

**8:15pm-10:00pm**    **Sibling Hangout Room Open** (no supervision)

**Friday, July 12, 2024**

**7:00am-8:15am**    **Continental Breakfast**

**9:00am-10:00pm**    **Sibling Hangout Room Open** (no supervision)

**8:30am-9:30am**    **Minute to Win It – Stress Management Style** (For ages 13-17)

**Facilitator:** Karen Canada, LCMHCS, MS

**9:45am-10:45am**    **Football Fun with Kevin Sperry**

**10:45am-11:45am**    **FREE Reunion Tower and Observation Deck Tour**

**11:45am-12:45pm**    **Lunch Buffet** (Sibling Scavenger Hunt during lunch)

**1:30pm-2:15pm**    **Heredity and YOU: *for the sibs*: Understanding Genetic Traits** (For Ages 7-17)

**Speaker:** TBD

**2:30pm-3:15pm**    **“The Sibling Experience”**

**Speaker:** Alyssa Dickerson

**4:00pm-5:15p**    **Poolside Luau – All Siblings are Welcome** (No lifeguard on duty)

## Saturday, July 13, 2024

**7:00am-8:00am**      **Continental Breakfast**  
**9:00am-5:00pm**      **Sibling Hangout Room Open (no supervision)**

**9:15-10:15am**      **Healing Art for Siblings (For ages 13-17)**  
**Facilitator:** Karen Canada, LCMHCS, MS

**9:45am-10:30am**      **Sibling Workshop for Kids Only (For ages 7-12)**  
**Facilitator:** Dawnda Daniel

**10:45am-11:15am**      **Merlin, the Therapy Dog**  
**Facilitator:** Laurie Bellet

**12:00am-1:30pm**      **Lunch Buffet**

**1:30pm-2:30pm**      **Healing Art for Siblings (For Ages 7-12)**  
**Facilitator:** Karen Canada, LCMHCS, MS

**3:15pm-4:30pm**      **Sibling Workshop for Kids Only, (For ages 13-17)**  
**Facilitator:** Dawnda Daniel

**5:30pm-6:15pm**      **Ice Cream Social**

**CONFERENCE CONCLUDES**