



Envisioning the Possibilities

11TH INTERNATIONAL CONFERENCE | DALLAS, TX

PRISMS CONFERENCE PROGRAM*: “Envisioning the Possibilities”

Hyatt Regency Dallas

Thursday August 4, 2022 – Saturday, August 6, 2022

**Program and times subject to change*

Thursday, August 4, 2022

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

Speaker: Maddie Williamson, LGC

Facilitator: Barbara Haas-Givler, MEd, BCBA

1:15pm – 2:45pm **First Steps: “Navigating the PRISMS Conference and finding support along the way.”**

Speakers/Facilitators: Dawnda Daniel, Diane Erth, Allison Stephanouk, parents

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

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

A) Teacher and Support Staff Training /Part 1

Speaker: Barbara Haas-Givler, MEd, BCBA,

Facilitator: Maddie Williamson, LGC

B) Adult Living: Residential and Vocational Options/Shared Living Collaborative/Part 1

Speaker: Daniela Morse, Executive Director

C) Patient Registry enrollment

Speaker: Theresa Wilson, MS, RD

3:00pm – 4:30pm **CONCURRENT WORKSHOPS**

A) Teacher and Support Staff Training Session/Part 2

Speaker: Barbara Haas-Givler, MEd, BCBA,

Facilitators: Bernadette Damiano, MA, BCBA, LBS, Taylor Ochsenreither, Maddie Williamson, LGC, Al Mitton

B) Adult Living: Residential and Vocational Options/Shared Living Collaborative/Part 2

Speaker: Daniela Morse, Executive Director

C) The Importance of Building Leisure Skills

Speakers/Facilitators: Sylvia Farber, M.Ed., Dawnda Daniel, parent Sibshop facilitator

D) PRISMS Patient Registry enrollment

Facilitator: Theresa Wilson, MS, RD

4:00pm – 7:00pm Exhibitor Hall is Open
 5:00pm Childcare & The Den closes for the day. No evening childcare.
 5:00pm – 6:30pm Welcome Reception
 8:00pm 17p11.2 Society meets in Monduel's, All are welcome!

Friday, August 5, 2022

7:00am – 8:00am Continental breakfast
 7:45am – 12:15pm Childcare opens
 1:00pm – 5:00pm The PRISMS Den
 8:00pm – 10:00pm Evening Childcare

8:00am – 9:30am **GENERAL SESSION**

8:00am – 8:15am **Welcome & Opening Remarks**

Speaker: Casey Gorman, PRISMS Executive Director

8:15am – 8:30am **#SMSPossibilities**

Speaker: Brandon Daniel, PRISMS President

8:30am – 9:00am **Keynote Address**

Speaker: Mike Porath, Founder of *The Mighty*

9:00am – 9:15am **SMS Patient Registry**

Speaker: Theresa Wilson, MS, RD, Sarah Elsea, PhD, Baylor College of Medicine

9:15am – 9:30am **Positive Exposure**

Speaker: Rick Guidotti

9:45am – 11:00am **CONCURRENT SESSIONS**

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

Speakers: Barbara Haas-Givler, MEd, BCBA, Mary Beall, MEd

B) Medical Management of SMS Across the Lifespan

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

C) Managing Food Seeking Behaviors with Help from Prader-Willi Syndrome

Speaker: Amy L. McTighe, PhD

D) Special needs financial and estate planning

Speaker: Randy Beall

E) It Takes a Village: A discussion on building a support network and the role of a professional and peer support team.

Speaker: Landre Kingdon, LCSW

F) Sibling Workshop for Kids Only (For ages 7-12)

Facilitators: Dawnda Daniel, Ardis Lo, MS, LPC-S

11:15am – 12:00pm

Breakout session: Pub Trivia for Teens and Adults with SMS

This session is for teens and adults with SMS, ONLY, (ages 12 and up)

Speaker: Christine Brennan, PhD, SLP

11:15am – 12:00pm

Birt-Hogg Dube´: Clarification of diagnosis and concerns in relationship to SMS

Speaker: Laura Schmidt, PhD, Ann C. M. Smith, MA, DSc, (Hon)

11:00am – 12:00 pm

Reunion Tower Tour for Siblings

12:00pm – 1:30pm Lunch

1:30pm – 2:45pm CONCURRENT SESSIONS

A) Speech & Assistive Technology

Speaker: Heera Chandani, SLP

B) Severe Challenging Behavior: Celebrating Success when Supports are in Place

Moderators: Barbara Haas-Givler, MEd, BCBA, Thomas Challman, MD

Panel Presenters: Taylor Ochsenreither, Bernadette Damiano, MA, BCBA, LBS, Al Mitton

C) An Update from Vanda Pharmaceuticals

Speakers: Panel presentation

D) The Adolescent Adventure

Speakers: Kerry Boyd, MD, FRCPC, Ann C.M. Smith, MA, DSc, (hon)

E) Neurological Implications in SMS, (autism dx and seizures, etc)

Speaker: Andrea Gropman, MD

F) Sibling Workshop for Kids Only (ages 13 and up)

Facilitators: Dawnda Daniel, Ardis Lo, MS, LPC-S

3:00pm – 4:15pm CONCURRENT SESSIONS

A) Curbside Consults for Speech & Language concerns

Speakers: Christine Brennan, PhD, SLP, Heera Chandani, MA, SLP

B) Understanding the Genetics of SMS

Speaker: Sarah Elsea, PhD

C) Strategies for Adult Living

Speakers: Nancy Cordrey, David Cordrey

D) What to Expect at Your Child's Appointment with a Developmental Pediatrician or Neurologist

Panel Speakers: Thomas Challman, MD, Anne Marie Morse, DO

E) Behavioral phenotypes of Smith-Magenis syndrome. Individual and characteristics and parental and school staff's experiences.

Speaker: Heidi Nag, PhD

F) Managing Food Seeking Behaviors with Help from Prader-Willi Syndrome

Speaker: Amy L. McTighe, PhD

4:25pm – 5:00pm GENERAL SESSION

SMS Organizations across the Globe

Moderator: Casey Gorman, PRISMS Executive Director

Smith-Magenis Syndrome Research Foundation:

Speakers: Missy Longman, Founder, Immediate Past President, Dan Longman, Founder, Treasurer

SMS Mexico

Speaker: Marilena Carrencedo

Sirius eV, Germany

Speakers: Astrid Diederichs, Detlef Diederichs

SMS UK

Speaker: Nigel Over

ASM 17 France

Speaker: Jean-Mathieu Berger

5:15pm – 6:00pm Curbside Consults

Dinner on your own & Night at The Courtyard Rooftop at 8:00pm

EVENING SESSIONS

8:00pm – 10:00pm Childcare

7:00pm – 7:45pm Teacher & Support Staff Meet-up

Facilitators: Sylvia Farber, MEd, Mary Beall, MEd

7:00pm – 7:30pm SMS International Partnership Program Meet-up

Facilitator: Casey Gorman, PRISMS Executive Director

8:00pm – 11:00pm PRISMS Night at the Courtyard Rooftop

Saturday, August 6, 2022

7:00am – 8:00am Continental Breakfast

7:45am – 12:15pm Childcare opens

1:00pm – 5:00pm The PRISMS DEN

8:15am – 10:00am GENERAL SESSION

8:15am – 8:30am Brain Donor Project

Speaker: Tish Hevel, CEO, Founder

8:30am – 10:15am International Research Updates: Panel Presentation

Moderators: Sarah Elsea, PhD, Santhosh Girirajan, MBBS, PhD

10:30am – 11:45am CONCURRENT SESSIONS

A) Sleep & SMS

Speakers: Lorraine Potocki, MD, Kevin Kaplan, MD

B) Endocrine Issues & SMS

Speaker: Stephanie Sisley MD

C) Understanding how SMS behaviors “fit” into a complex syndrome.

Speaker: Mary Beall, MEd

D) Resilience: "What do you do to keep on going?"

Moderators: Barclay Daranyi, Tony Daranyi

Panel presentation

E) Heredity and YOU: *for the sibs: Understanding Genetic Traits For siblings only! (Ages 7-14 years)*

Speakers: TBD

12:00pm – 2:00pm Lunch & free time

1:00pm – 2:00pm First Steps regroup

Speakers/Facilitators: Dawnda Daniel, Diane Erth, Allison Stephanouk

1:00pm – 2:00pm Regional Rep Meeting

Speaker: Denien Rasmussen, PRISMS Board Member

2:15pm – 3:30pm CONCURRENT SESSIONS

A) SMS Research breakout discussion

Speakers: Sarah Elsea, PhD, Santhosh Girirajan, MBBS, PhD

B) Adults with Developmental Disorders and Complex Health Care Issues - Building Capacity in the Adult Healthcare System

Speaker: John C. Berens, MD

C) What a Parent Must Know about Special Education

Speaker: Sylvia Farber, M.Ed., Special Education

D) Hitting a Bump in the Road; Thinking about psychiatric admissions

When you need it, what it looks like, and how to go about doing it: considerations for assessing admission to a psychiatric facility.

Speaker: Landre Kingdon, LCSW

E) Pub Trivia for Siblings, (ages 8 and older)

Facilitator: Christine Brennan, PhD, SLP

3:30pm – 4:30pm

Heart of Texas Therapy Dogs visit – for siblings

GENERAL SESSION

3:45pm – 4:30pm Curbside Consults

4:30pm – 5:00pm Final Words, Slideshow & Celebration of SMS Community!

Speakers: Casey Gorman, PRISMS Executive Director, Brandon Daniel, PRISMS President

5:00pm PRISMS Den and childcare closes promptly at 5pm!

5:15pm – 6:15pm Ice Cream Social

CONFERENCE CONCLUDES