



2017 global summit & gala schedule of events



Thursday, November 30, 2017

10^{AM} – 6^{PM}

Angelman Biomarkers and Outcome Measures Meeting (A-BOM)*

Hyatt, Randolph IAB

Complimentary lunch

Cocktail reception following

**private meeting by invitation from the director of A-BOM*

Friday, December 1, 2017

9^{AM} - 5:30^{PM} FAST Science Summit

Swissôtel, Zurich Ballroom

NEW LOCATION. Directions to the Zurich Ballroom from the Hyatt: Take the Hyatt escalator, or elevator, to the Bronze Level of the East Tower. After passing the Randolph meeting rooms, turn left through the glass doors and follow the signage to the Swissôtel.

9^{AM} - 5:30^{PM} AAC Carnival

Visit our exhibitors and sponsors!

- 9^{AM} - 10:20^{AM} Session I — Just for Parents: Research, Studies & Data Collection**
As we move ever closer to bringing effective treatments to our children, we need our community caregivers' assistance to ensure we are designing the best possible clinical trials and outcome measures. This entails everything from participating in online surveys to enrolling in clinical research studies. Every parent plays a critical role in making sure we are successful. Listen to speakers from Boston Children's Hospital, Roche, RTI International, the Angelman Biomarkers and Outcome Measures Alliance and more. They will explain how you can help move us forward in our mission to cure Angelman syndrome.
- 9^{AM} - 9:20^{AM} Terry Jo Bichell, Ph.D., director, Angelman Biomarkers and Outcome Measures Alliance**
- 9:20^{AM} - 9:40^{AM} Meagan Cross, chairwoman, FAST Australia**
- 9:40^{AM} - 10^{AM} Anjali Sadhwani, Ph.D., clinical psychologist, Boston Children's Hospital**
Anne Wheeler, Ph.D., public health researcher, RTI International
- 10^{AM} - 10:20^{AM} Meghan Miller, Ph.D., discovery project leader, Roche**
- 10:20^{AM} - 10:30^{AM} Break**
- 10:30^{AM} - 12:30^{PM} Session II — In the Clinic**
Exciting clinical trial updates from Ovid Therapeutics and Disruptive Nutrition
- 10:30^{AM} - 11:30^{AM} Jeremy Levin, D.Phil., MB BChir, chairman and chief executive officer, Ovid Therapeutics Inc.**
Amit Rakhit, M.D., MBA, chief medical and portfolio officer, Ovid Therapeutics Inc.
- 11:30^{AM} - 12:30^{PM} Mike McCandless, founder, Disruptive Nutrition**
Donna Herber, Ph.D., chief science officer, Disruptive Nutrition
Jessica Duis, assistant professor of pediatrics, Vanderbilt University Medical Center
- 12:30^{PM} - 1:30^{PM} Complimentary Lunch for Summit Attendees**
- 1:30^{PM} - 4:15^{PM} Session III — Towards a Cure: Gene Therapy for the Treatment of AS**
Currently, there are multiple gene therapy strategies in development to treat Angelman syndrome. These strategies will be discussed in detail.
- 1:30^{PM} - 1:50^{PM} FAST Research Agenda Overview**
Allyson Berent, D.V.M., chief science officer, FAST
- 2^{PM} - 3^{PM} Keynote: James M. Wilson, M.D., Ph.D., Rose H. Weiss professor and director, Orphan Disease Center; director, Gene Therapy Program, Perelman School of Medicine, University of Pennsylvania**
- 3^{PM} - 3:15^{PM} Break**
- 3:15^{PM} - 4:15^{PM} Jodi Cook, Ph.D., chief operating officer, Agilis Biotherapeutics**
Edwin Weeber, Ph.D., professor, University of South Florida
Jennifer Daily, Ph.D., director of research, Agilis Biotherapeutics
- 4:30^{PM} - 5:30^{PM} Session IV — Gene Therapy Round Table: Ask the Experts**
Not sure what a viral vector is? Can't pronounce antisense oligonucleotide? Not sure how treating a genetic disorder is even possible? Come ask the experts! Dr. Jim Wilson, University of Pennsylvania; Dr. Arthur Beaudet, Baylor College of Medicine; Dr. Scott Dindot, Texas A&M University; Dr. Kevin Nash, University of South Florida; Dr. David Segal, University of California, Davis; and Dr. Edwin Weeber, University of South Florida.

Saturday, December 2, 2017

9^{AM} - 5:30^{PM} FAST Educational Workshops

Hyatt Regency Hotel, Ballroom

9^{AM} - 5:30^{PM} AAC Carnival

Visit our exhibitors and sponsors!

Session A

9^{AM} - 10^{AM} Introduction to Augmentative and Alternative Communication (AAC)

Kelly Fonner, *M.S., educational assistive technology trainer and consultant*

10:15^{AM} - 11:15^{AM} Reading and Writing in Angelman Syndrome

Kelly Fonner, *M.S., educational assistive technology trainer and consultant*

11:15^{AM} - 12^{PM} Lunch Break

12:15^{AM} - 1:15^{PM} Beginning Communication is Just a Tool Away - Accessing Multiple Environments through Assistive Technology

Nancy Robinson, *Ph.D., Communicative Disorders Program, San Francisco State University*

Kathleen Sadao, *Ed.D., educational consultant*

1:30^{AM} - 2:30^{PM} Ask the Experts Panel

Kate Ahern, *M.S.Ed.*
Kelly Fonner, *M.S.*
Nancy Robinson, *Ph.D.*
Kathleen Sadao, *Ed.D.*

Session B

9^{AM} - 10^{AM} AAC Vendor Presentations
Prentke Romich Company (PRC), Salttillo, and Tobii-Dynavox

10:15^{AM} - 11:15^{AM} Understanding Anxiety and Challenging Behaviors in Angelman Syndrome

Kate Ahern, *M.S.Ed., assistive technology specialist*

11:15^{AM} - 12^{PM} Lunch Break

12:15^{PM} - 1:15^{PM} Augmentative and Alternative Communication (AAC) as an Intervention to Anxiety and Challenging Behaviors

Kate Ahern, *M.S.Ed.*
Shibvon Sargent, *parent*

1:30^{PM} - 2:30^{PM} Implementing Strategies in the School Placement Panel

Amy Girouard, *parent*
Shari Holt, *MHS, CCC-SLP*
Danielle Williams, *B.A., LBS I*
Trish Brawley, *B.A., LBS I*

6^{PM} - Midnight FAST Gala

Hyatt Grand Ballroom

ALL GUESTS MUST CHECK IN AT REGISTRATION

Celebrity Meet & Greet ticket holders must arrive by 5:15^{PM}

6^{PM} - 7^{PM} Cocktail Hour

Entertainment by Swinging the Standards
Raffle and Silent Auction

7^{PM} - 9^{PM} Dinner and Program

Entertainment by The Shannon Rovers
Three-Course Dinner
Celebrity Heads & Tails Game
Guest Speaker: Colin Farrell
Keynote Speaker: Dr. Edwin Weeber
Paddle Raise

9^{PM} - Midnight Entertainment by 7th heaven Band

Midnight ALL GUESTS MUST CHECK OUT AT REGISTRATION