

ASCEND 2022 Agenda

Summit sessions are for registered attendees only except where indicated.
Session locations TBD and speakers subject to change.



WEDNESDAY, APRIL 27, 2022

- 3:00 - 7:00 pm** Registration Open
Location: Delta Island Bridge
- 5:00 - 7:00 pm** ASCEND Welcome Reception
Location: Water's Edge
**Registered attendees and guests*

THURSDAY, APRIL 28, 2022

- 7:00 - 8:00 am** Continental Breakfast
- 8:00 - 8:15 am** IRSF Welcome
Speakers: Co-Chairs Mr. Bill Babiarz & Ms. Mickie McCool
- 8:15 - 9:20 am** This is Rett
Speakers: Dr. Jeffrey Neul & Dr. Alan Percy
- 9:20 - 10:10 am** **Keynote: Neurophysiological Approaches to Understand and Modify the Course of Rett Syndrome**
Speakers: Dr. Huda Zoghbi with Dr. Dominique Pichard
- 10:20 - 11:10 am** **Option #1: Genetics 101 for Rett Syndrome**
Speakers: Dr. Steve Skinner & Dr. Margarita Saenz
- Option #2: Preparing for the Adulthood Medical Transition**
Speakers: Dr. Jessica Nickrand & Ms. Paige Nues
- 11:10 am - 12:00 pm** **Option #1: The Power of the Brain: Regression and Beyond (Possible for Child)**
Speakers: Dr. Rocco Gogliotti, Dr. Keerthi Krishnan & Dr. Sasha Djukic
- Option #2: What Hurts? Addressing and Treating Pain in Rett Syndrome**
Speaker: Dr. Scott Schwantes
- 12:00 - 12:40 pm** LUNCH (*Boxed Lunch Provided*)
- 12:40 - 1:00 pm** Taysha's Plans to Study Gene Therapy for Rett Syndrome
Dr. Suyash Prasad & Ms. Emily McGinnis
- 1:00 - 1:40 pm** **Keynote: The Power of Acceptance and Positivity**
Speaker: Mr. Chris Ulmer
- 1:50 - 2:50 pm** **Option #1: Understanding the Brain/Gut Connection & Managing Symptoms**
Speaker: Dr. Kathleen Motil
- Option #2: ABL Accounts vs. Special Needs Trusts: An In-Depth Discussion**
Speaker: Ms. Kacy Seitz
- 2:50 - 3:40 pm** **Option #1: "What was that?" - Seizures, Rett Episodes and Movement Disorders, Part 1**
Speakers: Dr. Robin Ryther, Dr. Bernhard Suter, & Dr. Dallas Armstrong
- Option #2: Building the Best Care Team for Your Child**
Speakers: Dr. Tim Benke & Dr. Art Beisang
- 3:45 - 4:30 pm** **Option #1: "What was that?" - Seizures, Rett Episodes and Movement Disorders, Part 2**
Speakers: Dr. Robin Ryther, Dr. Bernhard Suter, & Dr. Dallas Armstrong
- Option #2: Self-Care for Caregivers & Siblings**
Speakers: Dr. Sarika Peters & Family Panel
- 4:40 - 5:30 pm** **Option #1: Safe Alternative Medicines and Treatments - Finding What Works for Your Child**
Speaker: Dr. Tim Feyma
- Option #2: Managing Aggression, Self-Injury and Challenging Behaviors**
Speaker: Dr. David Lieberman

****DINNER ON YOUR OWN****

- 7:30 - 9:30 pm** **Rettworking**
**Registered attendees and guests*



FRIDAY, APRIL 29, 2022

- 7:00 - 8:00 am** Continental Breakfast
- 8:00 - 8:50 am** **Current Research and Curative Therapies**
Speakers: Dr. Kyle Fink, Dr. Julian Halmai & Dr. Dominique Pichard
- 9:00 - 9:50 am** **The Future of Clinical Trials**
Speaker: Dr. Eric Marsh
- 10:00 - 10:50 am** **Option #1: Physiatry Care in Rett Syndrome**
Speaker: Dr. Aloysia Schwabe
- Option #2: Respiratory Issues in Rett Syndrome**
Speaker: Dr. Girish Sharma
- 11:00 - 11:50 am** **Option #1: Avoiding Scoliosis – Stretching & Physical Therapy**
Speaker: Dr. Meir Lotan
- Option #2: Puberty & Womanhood**
Speaker: Ms. Jane Lane
- Option #3: Boys with Rett Syndrome**
Informal Discussion with Dr. Tim Benke
- 12:00 - 12:50 pm** LUNCH (Boxed Lunch Provided)
IRSF Vision & Presentation of Award to Dr. Alan Percy
- 1:15 - 2:15 pm** **Option #1: IEP: The Importance of Relationship Building and Parental Concerns**
Speaker: Ms. Mickie McCool
- Option #2: Parent to Parent – Let's Talk About Adulthood in Rett**
Informal Discussion
- 2:30 - 3:20 pm** **Nutrition in Rett Syndrome including Gastrostomy Tube Management and Troubleshooting**
Speakers: Dr. Art Beisang, Ms. Tristen Dinkel, & Ms. Suzie Geerts
- 3:30 - 4:20 pm** **Implementing the Rett Syndrome Communication Guidelines at Home, School, and in the Community**
Speaker: Dr. Theresa Bartolotta
- 4:30 - 5:30 pm** **The Beginning of the Conventional Literacy Journey in AAC**
Speakers: Dr. Karen Erickson & Dr. David Koppenhaver
- **DINNER ON YOUR OWN****
- 7:30 - 9:30 pm** **Purple Party & Mixer**
**Registered attendees and guests*

*For session descriptions, speaker bios,
and more, download the event app:*

Uthova





SATURDAY, APRIL 30, 2022

7:00 - 8:00 am Continental Breakfast

8:00 am - 12:00 pm Communications Fair

The Communications Fair features interactive and hands-on sessions based on the newly published Rett Syndrome Communication Guidelines because everyone with Rett syndrome deserves to be heard! Learn more about the advancement of the guidelines in the coordination of complex care from childhood through adulthood, and further your knowledge of communication in Rett syndrome. Choose from nine (9) repeating sessions or visit the Interactive Room featuring demonstrations from Tobii Dynavox, PRC-Salttillo, SmartBox, and more.

8:00 & 10:00 am **The Importance of “Yes” and “No” and Partner Assisted Scanning**
Speakers: Dr. Gill Townend & Ms. Madeline Caron

Getting Started with High-Tech Devices: From Trials to Conversations
Speakers: Ms. Judy Lariviere & Ms. Pati King-DeBaun

Start a Communication Profile
Speaker: Ms. Maggie Wurm

School-Based Services: Advocacy and the IEP
Speaker: Dr. Stephanie Meehan

Switch Adaption for Toys
Speakers: Mr. Lonnie Morrison & Ms. Sarah Morrison

9:00 & 11:00 am **Using High-Tech Devices for Fun and Engaging Activities for All Ages**
Speakers: Ms. Judy Lariviere & Ms. Pati King-DeBaun

Bill of Communication Rights and Regulation in Rett Syndrome
Speaker: Dr. Theresa Bartolotta

(Low-Tech) AAC for Friendship!
Speaker: Ms. Gerna Scholte

Using Shared Reading to Promote Communications
Speaker: Ms. Andrea Etkie

12:00 pm ASCEND Summit Ends



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