



VALERIE OWEN, PH.D., began her career as a teacher of children with significant disabilities. Her current work is centered around access to the general education curriculum for students with the most significant disabilities.

Session 1: Typical Learning and the Student with RS

When given the necessary support and rich experiences, learning and development generally occur in similar, predictable sequences whether a person has a disability or not. In this session, Dr. Owen will describe some traditional theories of learning and development, give examples of significant milestones or age specific tasks that most children can do at certain ages, and explain how they look different for students with RS. The session will include some practical suggestions for parents about how and what to look for and what kind experiences they can provide, and how they can advocate for learning opportunities in school.

Session 2: IEP Development and Implementation

The Individualized Education Program or IEP is a legally binding document. It outlines the plan for meeting a child's unique educational needs. With the 1997 and 2004 reauthorization of the Individuals with Disability Education Act, or IDEA, the IEP guides the collaborative relationship between general and special education. Also, as a result of the linking of IDEA with the No Child Left Behind Act (NCLB), an IEP is to be aligned with the state testing system and educational standards as well as delineate the needed supports to enable access to the general education curriculum. This presentation will describe the parts of an IEP, including present level of performance, goals, characteristics of good short-term objectives/benchmarks, related services, and accommodations. Together, we will discuss what parents can do to prepare for the meeting, who should attend and other meeting tips.

ALAN PERCY, M.D., is an internationally known researcher on RS and has occupied prominent leadership positions in academic neurological societies. Dr. Percy is the Associate Director of the Civitan International Research Center, and Director of the Civitan-Sparks Clinic. He is currently the IRSA Scientific Director.

Session: RS101

Dr. Percy will present RS101, an introductory course for families who are new to the diagnosis. The session will cover the basic genetics, diagnostic criteria and clinical findings in RS. The session is a good overview for those new to RS and those who wish to take a refresher course.

Laura A. Riffel, Ph.D., is a behavior specialist who has trained thousands of teachers, parents, counselors, psychologists, administrators, and bus drivers how to make data based decisions as a way to change behavior. Her trainings are filled with humor and make data collection easy to understand and use in the classroom. Laura is the President of Behavior Doctor Seminars, a company dedicated to sharing the science behind changing behavior. She is also a consultant for the Bureau of Education Research. Most recently, Dr. Riffel has enjoyed teaching at the college level at Georgia State University. She has taught Applied Behavior Analysis and Managing Classroom Behavior. Dr. Riffel has also served as a district trainer for Technology, Developmentally Appropriate Science and Health (DASH), Hands on Math, Teacher Effectiveness-Student Achievement (TESA), McRel's Effective Teaching Model, and Madeline Hunter's Model.

Session: The Ins and Outs of Functional Behavioral Analysis and Behavior Analysis

Participants will learn critical features of writing a behavioral intervention plan based on function based data collection. Research indicates that data collection using descriptive observational methods are 80% reliable for determining the real function (reason) behind the target behavior. If interventions are based on the correct

function, the non-desired behaviors will decrease. If interventions are based on the wrong function, the targeted behaviors will significantly increase. Participants will be given two booklets that assist the parents and the school in implementing the principles of positive behavior support in the IEP.

DEBRA LYN SCOTT, ESQ., began working in the area of estate planning in 1995 and formerly was a relationship manager for the Private Bank of Bank of America, where she provided estate and trust management for larger estates, special needs trusts, private foundations and the Bank of America Donor Advised Fund. She now is the principal of her own firm called The Scott Practice, LLC, which specializes in estate planning, disability planning and elder law. Ms. Scott serves on the Board of the Elder Law Section of the Atlanta Bar Association. Ms. Scott is an active member of the State Bar of Georgia YLD Advocates for Special Needs Students.

Session: Special Needs Trusts For Children with Disabilities

In this session, Ms. Scott will provide information and guidance for selecting a trustee and administering a special needs trust.

CHERYL A. SINNER, M.ED., CCC-SLP, is a speech-language Pathologist and Assistive Technology Specialist. Her current assignment involves assisting local school systems with students with low incidence disabilities, including RS, to find appropriate assistive technology and augmentative communication (ACC) solutions.

Session 1: Communication in the Classroom

A brief overview of communication therapies, augmentative communication devices (AAC) and access methods for girls with RS will be reviewed. The focus of the session will be on ways to incorporate AAC into the classroom routine, with an emphasis on goals and strategies for using AAC to increase access to the curriculum (content standards). Suggestions for writing goals to ensure integration of AAC will be provided.

Session 2: Using Augmentative Communication in the Classroom: Practical Applications

This session will focus on reviewing many of the augmentative communication systems (AAC) and/or devices that are effective for girls with RS, and presenting practical ideas of how AAC can be integrated into an educational environment. Suggestions will be given for selecting the best AAC to meet varying educational needs, and tips will be provided for how to include AAC into different classroom situations.

RO VARGO is the mother of three daughters, the oldest of which has RS. She is President of JOENRO, Inc. and works as a Special Education and Parent consultant, as well as a community advocate. She has been a tireless leader and champion on behalf of systems change that supports the full inclusion of students and adults with disabilities into the mainstream. She currently serves on Syracuse University's Center on Human Policy and is co-founder and a steering committee member for the ONCAMPUS Program at Syracuse University. Ms. Vargo and her husband, Joe, have authored numerous articles, book chapters and produced two videos on the subjects of inclusive education and advocating for the rights of parents and children with disabilities. Currently, Ms. Vargo works in the Adult Education Programs at OCM BOCES as an Instructor.

Session: Still Me: Creating Adult Opportunities

This session will provide a framework with which to individualize, normalize and implement adult services for individuals with RS. "Reach me and teach me" can be realized through activities such as book clubs, church folk groups, volunteering, college, fitness clubs, symphony performances and much more.



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Speakers/Sessions

HEIDI BRITZ, MA, CCC/SLP AND JAIME URIBE, MS, CCC/SLP are speech language pathologists at New Prospect Elementary School in Alpharetta, Georgia. New Prospect serves both general education and special education students and is a center-based school for students with autism. Ms. Britz has practiced as a SLP at Arnold Palmer Hospital for Women and Children in Orlando, Florida, Providence Speech and Hearing in Orange, California and Scottish Rite Children's Hospital in Atlanta, Georgia. Ms. Uribe's background experience is comprised of Early Intervention (Birth to Three), Easter Seals Rehabilitation Center, St. Vincent's Special Needs School for children with severe disabilities and elementary school practice. She is trained in Neuro-Developmental Treatment, Hannon, and PROMPT.

Session: Creating Social Stories: Tools to Navigate the World

This session will provide an overview to help you understand what social stories are, how to write them, who they are appropriate for and the materials you need to create them. Social stories will be presented reflecting pragmatic situations that can present obstacles to success as we navigate our world.

PATI KING DEBAUN is a speech language pathologist who has specialized in communication for children with severe disabilities. She has worked extensively with infant/toddlers and their parents, the preschool special needs population in the classroom setting and school-age children with a wide range of physical and cognitive disabilities. She has written and continues to write and publish numerous articles,

books and software (Storytime Series). Ms. DeBaun speaks throughout the world on the topics of interactive communication, augmentative communication, emergent literacy and creativity for children with disabilities. She consults in a variety of classrooms with children who have a wide range of physical and cognitive disabilities. Pati is an adjunct professor in the University of Utah's Special Education Department.

Session 1: Early Communication: Strategies for Success

This session will demonstrate successful strategies for building early communication in the home and preschool programs. Emphasis will be placed on developing engagement skills, recognizing early modes of communication, early conversational skills, and making language visible in routine activities, as well as providing strategies for building early motor skills using computer interactions and ultimately, communication success.

Session 2: Supported Book Reading Strategies for Promoting Language and Emergent Literacy

This presentation will focus on strategies to promote language/communication and early literacy skills through story-supported readings. Emphasis will be placed on book selection, adaptations and presentation techniques for students struggling to communicate. This session is appropriate for students in preschool or early elementary programs who are at early literacy levels.



REGISTRATION We try our best to keep conference costs as low as possible while still providing you with a weekend to remember. Full conference fee includes the welcome reception, two breakfasts and two lunches, all registration and all conference materials. Space is limited and early registration is encouraged. **Please note that hotel costs are not included and room reservations must be made with the hotel.**

FULL CONFERENCE FEE

Before April 15	Member \$250	Non-Member \$325
After April 15	Member \$265	Non-Member \$340

ONE DAY REGISTRATION FEE (Per day - meals and entertainment not included)

Saturday or Sunday

Before April 15	Member \$120	Non-Member \$150
After April 15	Member \$150	Non-Member \$175

Friday or Monday

Before April 15	Member \$60	Non-Member \$75
After April 15	Member \$75	Non-Member \$87.50

FINANCIAL ASSISTANCE Scholarships are available from IRSA to those in need (to cover the cost of registration fees only). Scholarships are open to current IRSA parent members, one per family, on a one time basis. Please write, call or visit the website for information and application forms.

HOTEL The conference will be held at the Atlanta Downtown Sheraton, which has 760 stunning guest rooms and 22 suites. All rooms feature: The Sheraton Sweet Sleeper® bed, high-speed wireless internet access, on-demand video, iron and ironing board, coffee maker, hair dryer, complimentary weekday newspaper, complimentary fitness center and 24 hour room service.

ROOM RATES \$99 single/\$119 double

RESERVATIONS Sheraton Downtown Atlanta Hotel
165 Courtland Street NE, Atlanta, Georgia 30303
404-659-6500 or 1-800-325-3535 or
www.rettsyndrome.org/conference

RECREATION Located in the courtyard, the heated indoor pool is open year round. The area flourishes with tall trees, flowing fountains and beautiful flowers. The Jacuzzi and a large, 24 hour fitness center are located adjacent.

LOCATION AND TRANSPORTATION The Atlanta Downtown Sheraton Hotel is located in the heart of Atlanta's convention, sports, and entertainment district, only minutes from the city's most exciting attractions. Premier shopping, dining, and entertainment options are nearby, including Hard Rock Cafe, Underground Atlanta, CNN Center, Centennial Olympic Park, and Peachtree Center Mall. The Hotel is within walking distance of the Georgia World Congress Center.

- The Hotel is located 10 miles north of Hartsfield-Jackson Int'l Airport.
- Easy access is available via Interstates 75/85 (off exits 248C, 249A)
- Atlanta's economical rapid transit system, MARTA, available from the airport to Peachtree Center station, just two blocks from the Hotel. MARTA costs \$1.75 each way. (www.itsmarta.com)
- Atlanta Link provides shuttle service two times an hour and costs \$16.00 each way or \$28.00 round trip. (www.theatlantalink.com or 404-524-3400)
- Taxi cost is approximately \$25.00 each way.
- On-site car rental. Prices vary. (404-589-8071)

ONLY \$250*
Before April 15th
*IRSA Member Discount

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ONLINE:

www.rettsyndrome.org/conference

OR CALL

1-800-818-RETT

SPECIAL THOUGHTS

The IRSA annual conference is for adults only. Children under 12 are not permitted in the sessions nor the meals.



TRAVEL AGENT Call Maryann at Sato Travel, 1-800-872-7286 or 703-931-4290. She is available via email at msabo@satotravel.com.

DRESS Dress is casual for the weekend and you should dress for comfort. Don't forget a swimsuit for the pool and hot tub, and some comfortable shoes for getting around outdoors during free time.

PARKING IRSA has negotiated a special \$10 per day rate.

QUESTIONS? Call the IRSA office at 1-800-818-RETT, 301-856-3334 or fax us at 301-856-3336. Email us at admin@rettsyndrome.org. For up-to-date information, visit our website at www.rettsyndrome.org/conference.

SPECIAL EVENT A special evening together is planned for Sunday night. Details will follow soon. Tickets must be purchased in advance.

MUSICAL TRIBUTE Each year we do a touching musical tribute to our daughters. To be included, please send a color photograph and/or a few minutes of video on Mini-DV, short for Mini Digital Video (no DVDs, no VHS, no Hi-8, no 8mm). Be sure to include your daughter's name. Please email photos to jwhite@rettsyndrome.org or send videos/photos to the IRSA office NO LATER THAN MAY 10.

SILENT AUCTION The Silent Auction promises fun for all, and everyone wins! Send your contributions to IRSA or bring them with you and turn them in at Registration. Have a ball looking over the variety of great merchandise, which will be displayed in the Bookstore.

BOOKSTORE The IRSA Bookstore is a lively place. Here you will find pamphlets, books, videotapes, tee shirts and a host of other items that will attract your interest. Stop by to find that special something to take back home as a souvenir or a special purchase. Credit cards are welcome.

Conference Events

“Education is not filling a bucket,
but lighting a fire.”

-WILLIAM YEATS



Friday, May 25

- 12:00 - 6:00 Registration
- 5:30 - 6:30 Welcome Reception
- 6:30 - 7:15 The Light is On and She's Home — Kathy Hunter
- 7:30 - 8:30 Crackerbarrels — Kids 7 and Under • Kids 8-16 Years • Kids 17 and Over • Kids in Placement • Teachers/Therapists • Single Parents • Siblings • Rettnetters • Grandparents • Dads Only

Saturday, May 26

- 8:00 - 9:00 Breakfast
- 8:00 - 9:00 RS101— Alan Percy, M.D.
- 9:00 - 10:00 Early Communication: Strategies for Success — Pati King DeBaun
- 10:00 - 11:00 Speech/Communication Therapy — Cheryl Sinner, CCC-SLP
- 11:00 - 11:15 Break
- 11:15 - 12:00 Questions and Answers
- 12:00 - 1:30 Lunch and Annual General Meeting
- 1:30 - 2:30 Concurrent Sessions
 - A. Supported Book Reading Strategies for Promoting Language/Emergent Literacy
 - B. Augmentative Communication in the Classroom: Practical Applications
 - C. Creating Social Stories: Tools to Navigate the World
 - D. Creating Special Needs Trusts
- 2:30 - 3:00 Break
- 3:00 - 4:00 Concurrent Sessions
 - A. Supported Book Reading Strategies for Promoting Language/Emergent Literacy
 - B. Augmentative Communication in the Classroom: Practical Applications
 - C. Title TBA - Subject: Transitioning to Adult Programs
 - D. The Ins and Outs of functional Behavior Analysis and Behavior InterventionPlans

Sunday, May 27

- 7:15 - 8:00 Breakfast
- 8:00 - 9:00 Typical Learning and the Student with RS — Valerie Owen, Ph.D.
- 9:00 - 10:00 Reach Me...and Teach Me to Read — David Koppenhaver, Ph.D.
- 10:00 - 10:15 Break
- 10:15 - 11:15 Reach to Teach: Communication — Susan Norwell, M.S., Ed.
- 11:15 - 12:00 Questions and Answers Panel
- 12:00 - 1:30 Lunch
- 1:30 - 2:30 Concurrent Sessions
 - A. IEP Development and Implementation
 - B. From Emergent to Conventional Literacy in Girls with RS
 - C. Hands on Communication and Literacy
 - D. Still Me: Creating Adult Opportunities
- 2:30 - 3:00 Break
- 3:00 - 4:00
 - A. Title: TBA - Subject: Applied Behavior Analysis
 - B. From Emergent to Conventional Literacy in Girls with RS
 - C. Hands on Communication and Literacy
 - D. End of Life Decisions
- 7:00 Tribute Dinner

Monday, May 28

- 7:00 - 8:00 Breakfast
- 8:00 - 10:30 Research Review
- 10:30 - 10:45 Break
- 10:45 - 11:30 Parents Panel
- 11:30 - 12:15 Closing Remarks

Speakers/Sessions cont.

KATHY HUNTER founded IRSA and has worked as a leader for the past twenty-three years. Her life's work with RS is inspired by her daughter, Stacie, 33.

Session: The Light is On and She is Home

We have come a long way since the first published medical reports on RS classified it as a degenerative disease resulting in dementia and profound mental retardation. Today, we are in the process of re-writing the natural history of RS. Years of study and follow-up have shown us that early intervention and treatment can make a difference.

DAVID KOPPENHAVER, PH.D., is an Associate Professor in the Department of Language, Reading, and Exceptionalities at Appalachian State University. Dr. Koppenhaver has worked for the past twenty years with preschool- and school-aged children who have a wide variety of literacy learning difficulties.

Session 1: Reach Me and Teach Me to Read

Individuals with RS have significant difficulties in learning how to read and write conventionally. In this talk, Dr. Koppenhaver will give an overview of basic issues and strategies in literacy acquisition and explore how to make them accessible to girls with RS. This talk is aimed at a mixed audience of parents, educators, and related services personnel.

Session 2: From Emergent to Conventional Literacy in Girls with RS

The existing literacy research involving girls with RS and many of the recommendations found in print and on websites focus on what is characterized as "emergent literacy." Emergent literacy is a set of understandings and unconventional ways of using print and interacting with others about those experiences. It includes activities like listening to stories, pointing to pictures, scribbling (with pencils or computer keyboards), and generally becoming increasingly aware of the forms, content, and uses of literacy. It is a very important starting place, but it is not the end goal of literacy instruction. In this presentation, Dr. Koppenhaver will talk about organizing instruction and teaching individuals with RS in ways that move them into conventional literacy (i.e., independent reading and writing, that, while not perfect, follows enough convention to enable written communication with a wider audience of others who are literate).

SUSAN NORWELL, M.S., ED, has worked with a wide array of students, primarily those with an autistic spectrum, for more than twenty years. She has spent the last thirteen years in private practice working primarily with children on the autistic spectrum and girls who have RS.

Session 1: Reach to Teach: Communication

Girls with RS are dependent upon our ability to "reach in" and grab every bit of communication intent and make it more robust - more powerful! This session will demonstrate, through video clips, the art of communicating and teaching a girl with RS. Learn the importance of being a meaning maker, reading eye gaze, building reciprocity, the fun and importance of play and how to support and challenge thinking skills.

Session 2: Hands on Communication and Literacy

This workshop will give participants the opportunity to see various communication and literacy tools that have proven successful for girls with RS. Each tool will be modeled through the use of video clips and a handout will be provided that describes each tool and its use. You will have a chance to interact with others and ask questions about the resources that may help your child to "Reach to Learn."