7th World Congress on Rett Syndrome

CLINICIAN MEDICAL EDUCATION SEMINAR

Exploring the Mysteries of Rett Syndrome—Providing an Understanding of Rett Syndrome for the Primary Clinician Care Giver

JUNE 23, 2012 | INTERCONTINENTAL HOTEL NEW ORLEANS, LA
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Dear Friends,

On behalf of the Host Committee of IRSF, it is our pleasure to welcome you to the 7th World Rett Syndrome Congress, “Charting the Course”.

As a resident of Louisiana myself, we are honored to host this prestigious event in New Orleans, a culturally rich, diverse city proud of its uniqueness and resiliency.

Throughout its long history, the people of New Orleans have demonstrated life lessons about the importance of perseverance and optimism. By sharing and blending cultures, secrets and novel practices, as well as ideas, we have shown what makes creativity and invention thrive. The people of New Orleans have taught the world that life is not measured by what you do, but how you do it.

In addition, this city practically invented the art of having fun and making memories that last a lifetime!

Our wish is that during your time here, you will indeed chart the course to a better tomorrow for those affected by Rett syndrome. We hope you will share your information and your ideas freely and forge relationships that will last a lifetime.

Your interactions with each other will allow meaningful solutions and concepts to be formed with the hope that they will lead to novel breakthroughs that can be translated into potential treatments and improved quality of life.

Hopefully, you will leave here happier than you arrived, with memories and friendships you will cherish.

Thank you for joining us on our quest to provide care today, and a cure tomorrow. We are optimistic about our common future.

Kathryn Schanen Kissam

Chairman, IRSF

Honorary Chair 7th World Rett Syndrome Congress

KATHRYN SCHANEN KISSAM

Chairman, IRSF Board of Directors

Kathryn Schanen Kissam, Chairman, IRSF Board of Directors, is a branding, public affairs and issues management consultant. Her clients include Fortune 500 companies, agencies, and law firms throughout the United States. Prior to forming her own consulting business, Kathryn was the Chief Marketing Officer and Founder of Evolve24, a technology-based issues management company. Kathryn also worked for Monsanto Company of St. Louis, Missouri for 13 years in various leadership capacities and served on the boards of the Monsanto Fund, The Pharmacia Foundation and The Missouri Historical Society. She is a graduate of Leadership Metro Richmond and a frequent speaker at branding and corporate citizenship conferences. Her connection to Rett syndrome began through her sister, RTT clinician and researcher, Dr. Carolyn Schanen, of DuPont Children’s Hospital and continues to grow through the meaningful relationships she has built with scientists, families, donors, board and staff.
About the International Rett Syndrome Foundation

IRSF is the world’s leading private funder of basic, translational and clinical Rett syndrome research, funding over $26M in high-quality, peer-reviewed research grants and programs to date. Annually, IRSF hosts the world’s largest gathering of global Rett researchers and clinicians to establish research direction and priorities while exchanging ideas and the most recent information. IRSF is the most comprehensive non-profit organization dedicated to providing thorough and accurate information about Rett syndrome, offering informational and emotional family support, and stimulating research aimed at accelerating treatments and a cure for Rett syndrome and related disorders. IRSF has earned Charity Navigator’s most prestigious 4 star rating. To learn more about IRSF and Rett syndrome, visit www.rettsyndrome.org or call IRSF at 1-800-818-RETT (7388).

MISSION STATEMENT

Core Mission
The core mission of the IRSF is to fund research for treatments and a cure for Rett syndrome while enhancing the overall quality of life for those living with Rett syndrome by providing information, programs, and services.

ELEMENTS OF MISSION

Research
The IRSF will coordinate, cultivate, accelerate, and fund research that will produce a cure for Rett syndrome and reveal and develop treatments that will make the lives of people living with Rett syndrome richer and free of pain and discomfort.

Family Support
The IRSF will assist families of individuals living with Rett syndrome by providing them with connections to critical and useful information, programs, services, and support from diagnosis to day-to-day life.

Advocacy & Awareness
The IRSF will advocate for and raise awareness about individuals with Rett syndrome so the scientific and medical community, policy makers, educators, care givers, and the general public can more thoroughly know, understand, and be motivated to help the research efforts and individuals dealing with Rett syndrome on a daily basis.
Dear participants in the World Rett Syndrome Congress,

I extend a personal welcome to Primary Care Givers—physicians, nurses, therapists, educators—attending this seminar, Exploring the Mysteries of Rett Syndrome. Four internationally recognized Rett syndrome experts will provide an understanding of Rett syndrome, including clinical diagnosis, genetics, and clinical management of common problems of Rett syndrome. There will be ample time for questions and answers so that you can discuss your Rett syndrome concerns and personally interact with the Rett experts. We hope that you will find this information useful as you care for the girls and women with Rett syndrome. On behalf of all the parents as well as the Rett specialists, I want to recognize and thank you for your dedication providing care for these individuals.

Daniel G. Glaze, MD

Chair, Clinician Medical Education Seminar

7th World Rett Syndrome Congress

DANIEL G. GLAZE, MD FAASM
Professor, Pediatrics and Neurology
Baylor College of Medicine
Medical Director, The Children’s Sleep Center
Medical Director, The Blue Bird Circle Rett Center
Chairman, Bioethics Committee
Texas Children’s Hospital

Dr. Daniel Glaze has been the medical director of the Blue Bird Circle Rett Center for 25 years. In this capacity, he is responsible for diagnosis and clinical management of children and adults with Rett syndrome. Dr. Glaze participates in education concerning Rett syndrome for parents, educators, therapists, physicians and health care professionals. He participates in clinical research by serving as the site Principal Investigator for the Natural History study and the PI for the study of sleep in Rett syndrome and other rare diseases. Dr. Glaze’s special interests include the neurophysiology—seizures and sleep—of Rett syndrome.
7th World Rett Syndrome Congress
CLINICIAN MEDICAL EDUCATION SEMINAR
JUNE 23, 2012

SATURDAY, JUNE 23, 2012

1:30—4:30pm Opening Remarks / Meeting Overview
Chair: Daniel Glaze, MD
Our Presenting Sponsor: Katie’s Clinic for Rett Syndrome, Oakland Children’s Hospital
and Research Institute
Pontalba Room

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<tr>
<th>Time</th>
<th>Session Title</th>
<th>Presenter/Institution</th>
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<tbody>
<tr>
<td>1:30—2:10pm</td>
<td>The Diagnosis, Natural History and Common Clinical Problems of Rett Syndrome</td>
<td>Alan Percy, MD, The University of Alabama at Birmingham</td>
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<td>2:10—2:50pm</td>
<td>The Genetics of Rett Syndrome—How and When to Use Genetic Testing</td>
<td>Steve Skinner, MD, Greenwood Genetic Center</td>
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<td>2:50—3:10pm</td>
<td>Afternoon Break</td>
<td>Pontalba Reception Area</td>
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<td>3:10—3:50pm</td>
<td>The Motor Problems of Rett Syndrome—How to Manage and When to Make Referral</td>
<td>Meir Lotan, BPT, MScPT, PhD, Chaim Sheba Medical Center</td>
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<td>3:50—4:30pm</td>
<td>The GI/Nutrition Problems of Rett Syndrome—What the Primary Care Giver Can Do and When to Make Referral to the Specialist</td>
<td>Kathleen Motil, MD, PhD, Baylor College of Medicine</td>
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4:30pm Close program

GOALS and LEARNING OBJECTIVES

After completion of this seminar, participants should:

1. Be able to use current clinical criteria to diagnose typical and variant Rett syndrome

2. Understand how to use genetic testing in the management of Rett syndrome

3. Understand and recognize the common motor problems experienced by individuals with Rett syndrome and the management of these problems, including the use of therapy services and when referral to physical medicine and rehabilitation is indicated

4. Understand and recognize the common GI/nutrition problems of Rett syndrome and how to manage these problems, including appropriate referral to the GI specialist
Presenting Sponsor

We Thank Our Sponsors of the 7th World Rett Syndrome Congress
Speakers–Bios & Educational Goals
Alan Percy, MD

Professor of Child Neurology
Associate Director Civitan International Research Center
Director UAB IDDRC

Principal Investigator and PI of the Angelman, Rett, and Prader-Willi Syndrome Rare Disease Clinical Research Consortium

Alan Percy, MD is a pediatric neurologist at the University of Alabama. In 1983, Dr. Percy along with Dr. Vanja Holm and Dr. Mary Coleman were the first physicians to recognize Rett syndrome in the United States. In 1984, Dr. Hugo Moser, Dr. Holm, and Dr. Percy attended the Rett syndrome conference in Vienna organized by Dr. Rett. Since that time, Dr. Percy has actively pursued clinical and laboratory studies on this unique neurodevelopmental disorder, establishing Rett centers at Baylor College of Medicine and later at the University of Alabama at Birmingham where he is the principal investigator of the Angelman, Rett, and Prader-Willi Syndrome Rare Disease Clinical Research Consortium. He was responsible for recruiting Dr. Huda Zoghbi in these studies, leading to identification of mutations in $MECP2$. Since 1983, he has authored more than 120 scientific papers on Rett syndrome and is a co-author of The Rett Syndrome Handbook.

Dr. Percy has occupied prominent leadership positions in numerous academic neurological societies, including Past President of the Child Neurology Society and the Child Neurology Foundation, and Director of the American Board of Psychiatry and Neurology. He is a Fellow in both the American Academy of Pediatrics and American Academy of Neurology. He currently serves as Professor of Pediatrics, Neurology, Neurobiology, and Genetics at UAB, and is Associate Director of the Civitan International Research Center and UAB Intellectual and Developmental Disability Research Center Principal Investigator.

The Diagnosis, Natural History and Common Clinical Problems of Rett Syndrome

RETT SYNDROME 101 FOR THE PRIMARY CARE PROVIDER

Educational Goals:

- Understand the diagnosis of Rett syndrome (RTT), both classic and variant, using the 2010 criteria
- Understand the clinical profile and natural history of RTT in young children, teenagers, and adults
- Understand the clinical profile of individuals with $MECP2$ mutations not meeting clinical criteria for RTT
- Understand current understanding of medical management
The Genetics of Rett Syndrome—How and When to Use Genetic Testing

Educational Goals:

• Review the basics of the genetics of Rett syndrome
• Discuss which genetic tests are helpful in the diagnosis of Rett syndrome
• Discuss the limitations of certain genetic tests in regards to Rett syndrome
• Discuss how genetic tests results may be helpful in management and treatment of Rett syndrome
The Motor Problems of Rett Syndrome—
How to Manage and When to Make Referral

RETTE SYNDROME: A HOLISTIC PARAPROFESSIONAL APPROACH TO INDIVIDUALS PRESENTING COMPLEX MEDICAL CHALLENGES

Educational goals:
• Understand the importance of team work when intervening with individuals with Rett syndrome
• Understand the challenging medical, educational and habilitational issues typical of individuals with Rett syndrome
• Be able to advise families of individuals with Rett syndrome on appropriate paraprofessional interventions in regards to issues, typical of individuals diagnosed with this syndrome
KATHLEEN J. MOTIL, MD, PHD
Associate Professor of Pediatrics
Section of Gastroenterology, Hepatology and Nutrition
Baylor College of Medicine

Kathleen J. Motil, MD, PhD is an Associate Professor of Pediatrics and research scientist at the USDA/ARS Children’s Nutrition Research Center, Baylor College of Medicine, and serves as a pediatric gastroenterologist in the Section of Pediatric Gastroenterology and Nutrition, Texas Children’s Hospital, Houston, TX. Dr. Motil earned her MD degree at The Medical College of Pennsylvania and her PhD in nutritional biochemistry and metabolism at The Massachusetts Institute of Technology. She completed her pediatric residency at Montreal Children’s Hospital and her fellowship in pediatric gastroenterology and nutrition at Boston Children’s Hospital Medical Center. At Baylor College of Medicine, Dr. Motil’s research interests focus on growth and nutrition in children with rare genetic disorders, including Rett syndrome. She has conducted studies on the dietary energy and protein needs, oral motor and upper gastrointestinal dysfunction, and the clinical outcomes of gastrostomy placement in girls with Rett syndrome. Her current projects examine the natural history of osteopenia and the role of dietary calcium in reversing low bone mineral density in girls and women with Rett syndrome. Dr. Motil has served on the Scientific Advisory Boards of the International Rett Syndrome Foundation and the National Foundation for Ectodermal Dysplasias. She has published more than 120 articles in her field.

The GI/Nutrition Problems of Rett Syndrome—What the Primary Care Giver Can Do and When to Make Referral to the Specialist

NUTRITIONAL AND GASTROINTESTINAL TWEETS IN RETT SYNDROME

Educational Goals:
• Recognize the nutritional aspects of growth disturbances, oral motor dysfunction, and bone health in Rett syndrome
• Initiate appropriate nutritional therapy to manage growth disturbances, oral motor dysfunction, and bone health in Rett syndrome
• Recognize the clinical features of gastrointestinal dysmotility in Rett syndrome
• Initiate appropriate medication therapy to manage the gastrointestinal problems of Rett syndrome
Third Floor

Meeting Rooms
- Acadian Rooms I & II
- Fulton Room
- La Salle Ballrooms A, B & C
- La Salle Pre-Function Area
- Le Salon Pre-Function Area
- Pelican Rooms I & II
- Pelican Pre-Function Area
- Poydras Room

Advantage Office

Second Floor

Meeting Rooms
- Audubon Boardroom
- Les Continents
- Cypress Room
- Lobby Conference Room
- Magnolia Room
- Oak Room

Lobby Bar
Concierge & Business Center
Guest Registration
Guest Relations
Veranda Restaurant
Zachary Taylor Room

Ground Floor

Meeting Rooms
- Cabildo Room
- Orleans Room
- Pontalba Room
- Vieux Carré Rooms A & B

Advantage Office
Baggage Check-In
Gift Shop
Pete’s Bar & Grill
Sweet Car

444 St. Charles Avenue New Orleans, LA 70130
Notes