

Annual Family Conference

IRSF carefully and thoughtfully plans an annual conference for families, caregivers, and allied health professionals. It is the only one of its kind where the parents and professionals of those with Rett syndrome and Related Disorders come together from all over the world, under one roof, to learn the most current recommended care and advocacy strategies for every stage of life, and hear first-hand the latest in research and clinical trials. Even though so many resources today can be accessed online, nothing can replace the face-to-face experience of meeting with experts; hands-on interactions with carefully selected Exhibitors; spending time developing lasting relationships with other parents, attendees and all of us at IRSF. In addition to being a critical continuing education opportunity for you, it is also a chance for caregivers to relax, recharge your batteries, and have a little fun. We hold our conference in a different, easily accessible part of the U.S. each year to reduce the travel distances for attendees.

ANNOUNCING:

29th Annual Education and Awareness Conference

June 27 – 29, 2013

Zermatt Resort & Spa

Midway, Utah

Check back late January 2013 for Program Details and Online Registration.

Registration Fees will remain approximately \$280/per person which includes all sessions and meals, and does not include hotel rooms or transportation to/from the resort. Negotiated room rates and reservation codes will also be posted late January.

We look forward to seeing you in beautiful, relaxing Midway, Utah. Just steps away from the world-class resort town of Park City, and a short drive from the international Salt Lake City airport.

In June 2012, over 500 people from over 20 countries convened in New Orleans to face the future and Chart the Course forward for Rett Syndrome research and care. IRSF was pleased to host this exceptional event with the support of worldwide partners, organizers, sponsors, speakers, and exhibitors. It was quite magical to have such incredible and transformative discussions and debates happening under one roof and at every turn amongst the scientists, researchers, families, and clinicians who care so much about Rett syndrome, MECP2 and CDKL5 disorders. Friendships were made, personal and professional relationships advanced, and the course forward has been fueled thanks to everyone's concerted efforts. Please visit the World Congress website for materials, Photo Gallery, and recordings.

"Cheers to Research to Reality"

May 27 – 30, 2011

Boston, MA

IRSF 2011 Rett Syndrome Education and Awareness Conference

The 2011 IRSF conference provided families and caregivers with hope, inspiration, and the power of accurate information needed to dare to dream of reversing Rett syndrome in our loved ones; to be empowered to keep her healthy today and how to have endurance along the way. Beyond the actual learning of information, valuable contacts and relationships were made face to face that attendees carried back to their personal and online communities and support networks.

[Click here to view the 2011 IRSF Conference Program Photo Gallery](#)

2011 Conference Video

{mp4}2011-conference-1{/mp4}

IRSF Conference Program Final 2011 125.71 Kb

Featured this past year:

Motivational keynote by Massachusetts's own Dick Hoyt of Team Hoyt. Leading Research experts from Boston Children's, Harvard and MIT, including IGF-1 Clinical Trial Investigator Dr Omar Khwaja. Communication experts Susan Norwell and Judy Lariviere. World-renowned treatment experts and centers such as the Boston Children's Hospital Rett Center, Baylor College of Medicine Blue Bird Rett Center in Houston, University of Alabama Rett Clinic in Birmingham, and more. Sessions on therapies, education, family foundations, financial and legal life planning and a first-ever track of sessions on the direction of research from leaders who have been with us from the time the syndrome was named, to finding the gene, to reversing symptoms in the lab, to keeping Rett syndrome in the forefront of neuroscience discoveries.

Over 300 people joined IRSF over Memorial Day weekend to meet and learn from top Rett syndrome experts at our 27th annual Education and Awareness conference in Boston, MA. Of special interest to attendees this year was the first-ever dedicated session track on research. Especially well received were the early results reported by Omar Khwaja, MD, PhD, director of the Rett Syndrome Program in the Department of Neurology at Children's Hospital Boston, on his newly begun IGF-1 clinical trial. The conference began on Friday afternoon with a private Children's Hospital Boston lab tour, where many parents for the first time ever toured labs and saw a full 360 degree bench-to-bedside approach to Rett syndrome Basic to Translational and Clinical Research Studies in action.

Throughout the rest of the weekend, families and professionals chose from over 40 unique sessions focused on Research, Communication and School, Medical Issues and Therapies, Family Foundations, Fundraising and Advocacy. Also joining us were over 15 interactive Exhibitors, demonstrating products and services of specific interest and benefit to our children living with Rett syndrome.

The Tribute Reception was an incredibly special highlight event hosted in the grand historic Imperial Ballroom at the Boston Park Plaza Hotel. The program opened with a unique and lovely Boston cultural Irish Step Dance performance, followed by the annual award ceremony, viewing of the 2011 Tribute video, and an amazing live concert performance featuring Ayme (Sanchez) Loren, singing her hit song "Silent Angels" with guitarist Eduardo Toledo Guimaraes.

2011 AWARD RECIPIENTS

Art of Caring Award recipient Dr Omar Khwaja, Director

Rett Syndrome Program, Children's Hospital Boston

Each year at the Tribute Reception, IRSF recognizes individuals who have made significant contributions towards IRSF's mission to advance research for treatments and a cure for Rett syndrome while improving the overall quality of life for those living with Rett syndrome today. The following awards were presented by IRSF's Board of Directors to:

- Omar Khwaja MD, PhD, Director Rett Syndrome Program, Children's Hospital Boston - Art of Caring Award, IRSF's most prestigious award for exceptional devotion to Rett syndrome

- Jeffrey Neul, MD, PhD, Assistant Director Blue Bird Circle Rett Center, Baylor College of Medicine - Circle of Angels Award, for his enduring commitment to Rett syndrome biomedical and clinical research

- Donna Wright, grandmother to Naomi - Giving Hope a Hand Award, for her inspiration acts of advocacy and awareness

- Henry Perez, father to Lily - Volunteer of the Year Award, for his overall outstanding dedication to IRSF's mission

IRSF congratulates and thanks our award recipients for going above and beyond every day for our children.

We hope you enjoyed the 27th Annual IRSF Family Conference. We look forward to seeing you next year as IRSF hosts the World Congress on Rett Syndrome in New Orleans, June 22nd-26th, 2012. The family sessions will be held June 22nd-24th, and the researcher meeting will be June 24th – 26th !

Here are important links and downloads:

- Information for Conference Attendees 2011

- 2011 Conference Program
- 2011 Tribute Reception Program
- 2011 Helping Hands Keepsake Journal
- Session handouts and downloads:

Select conference sessions are available as DVDs or Audio MP3s. Please [click here](#) to visit the IRSF Store to purchase these valuable resources, or scroll through this table to download the speaker slides at no charge.

SATURDAY, MAY 28

SESSION

SPEAKER

Understanding RTT and other MECP2 Disorders 4.43 Mb

Alan Percy, MD, Director UAB Rett Center at the University of Alabama Civitan International Research Center

Entender RTT y Otros Trastornos MECP2 – en español

Alan Percy, MD,

Maggie Wurm, IRSF Rep

Parents' Experiences with Genetic Testing for Rett syndrome

Christine Delaney, MS, Genetics Counselor

IRSF Welcome Address 16.13 Mb

Kathryn Kissam, IRSF Board Chairman, and Steve Bajardi, IRSF Executive Director

Current State of Translational Research 6.25 Mb

Tony Horton, PhD

Jeffrey Neul, MD, PhD

Omar Khwaja, MD, PhD

Enriched Environments and Best Practices 10.39 Mb

Pamela Diener, PhD, MS, OT/L

Georgetown University

Marymount University

Communication at All Ages

Susan Norwell, MS Ed

Neurology: Epilepsy

Ann Marie Bergin, MB MD, BCH, BAO, Epilepsy Specialist, Rett Center, Children's Hospital Boston

The Importance of Therapies

Donna L. Nimec, MD, Pediatric Physical Medicine & Rehabilitation Specialist, Children's Hospital Boston

Endocrinology 10.90 Mb

Ingrid A. Holm, MD, MPH, Director, Phenotyping Core, Program in Genomics, Divisions of Genetics and Endocrinology, Children's Hospital Boston

Gastroenterology 7.07 Mb

Kathleen Motil, MD, PhD Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH

Well Child and Adult Care Overview 1.31 Mb

Jane Lane, BSN, RN, University of Alabama and IRSF

SUNDAY, MAY 29

SESSION

SPEAKER

RESEARCH TRACK

Clinical Features and Current Research: CDKL5 and Atypical Rett Syndrome

David Frame, PharmD, IFCR

How to Search Out and Critically Read Research Articles

Kate Barnes, BSc

Heather O'Leary, BSc

What Happens in Rett Syndrome at a Molecular Level: Epigenetics and Assay Development 6.96 Mb

Christopher Wynder PhD

What Happens in Rett Syndrome at a Systems Level: Neurobiology of RTT

Coming Soon!

Michela Fagiolini, PhD

Ways to Make it Go Right: A Look at IGF-1 and other Small Molecules

Coming Soon!

Mriganka Sur, PhD

COMMUNICATION AND SCHOOL

Creating a Vision 2.55 Mb

Elaine Rabbitt, Federation for Children with Special Needs

IEP Panel Discussion: Your Real-Life IEPs 243.12 Kb

Dr Mary Jones

Susan Norwell, M.S. Ed.

Judy Lariviere, AT

Mickie McCool, parent,
Barbara DeLuca, PT
Stacey Salter, OT

Emergent Literacy and Communication

Susan Norwell, MS Ed

Making Eye Gaze Technology a Reality: The Road from Trials to Conversations 759.80 Kb

Judy Lariviere, M.Ed., OTR/L, Communication Specialist, Rett Clinic, Oakland Children's Hospital

"Mid Tech" Usage and the Literacy Assessment, Part 1 of 2

Susan Norwell, M.S. Ed.

"Mid Tech" Usage and the Literacy Assessment, Part 2 of 2

Judy Lariviere, M.Ed., OTR/L, Communication Specialist, Rett Clinic, Oakland Children's Hospital

MEDICAL ISSUES AND THERAPIES

Conductive Education: A Therapeutic Approach

Coming Soon!

Eleonora Tamasne MA, QCS, QTS, ET

Expression and Movement Through Dance

Coming Soon!

Prof. Carlinhos Faustini, PEAMA, Brazil

In Common: Music (Therapy)

Coming Soon!

Donna Chadwick, Music Therapist, MA

Nutritional Management of Children with Rett Syndrome

Coming Soon!

Gail Seche, MMSc, RD, CSP

Physical Therapy

Coming Soon!

Barbara Deluca, Physical Therapist

The Maturing Woman with Rett Syndrome: From Puberty to Menopause

Coming Soon!

Jane Lane, BSN, RN

To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome

Coming Soon!

Judy Barrish, RN

FAMILY FOUNDATIONS

Fostering Friendships

Coming Soon!

Diane Ross, MS, LCPC

Special Needs Wills and Trusts

Coming Soon!

Donald Freedman,

John W. Nadworny

Transition to Adulthood and Community Programs

Coming Soon!

Donald Freedman,

Alan K.

If you are seeking additional information from any of our wonderful 2011 Exhibitors, please visit their websites or contact us at admin@rettsyndrome.org.

- Armbraces for Kids
- BC Campus School
- Boston Brace
- Canines for Kids
- Eyes Please
- Giving Greetings
- MyTobii
- Otto Bock Healthcare
- Perkins Braille and Talking Book
- Pine Tree Society
- Proxtalker.com
- SleepSafe Beds
- Special Need Creations

[Click here to access complete information including videos from last year's conference.](#)

