

Past IRSF Annual Conference

26th Annual Conference - 2010

The IRSF annual education conference is the only one of its kind where parents and professionals of girls and women with Rett syndrome 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.

ON-DEMAND Webcast registration includes:

- (1) "virtual seat" to continuous on-demand web access to the 14 sessions presented on Saturday, May 29, 2010. These sessions will be accessible online starting mid-June 2010, and will continue through mid-September 2010. [Click here to register.](#)
- PDF copies of Conference materials and the Helping Hands Keepsake Journal
- IRSF will email access information as soon as the on-demand sessions are available * Technical requirements: a relatively new MAC or PC that can handle audio/video play, with high-speed internet connection (**dial-up will not deliver a satisfactory viewing experience**), and connected, powered audio speakers.

* See www.rettsyndrome.org/conference for the Saturday session program and speakers. The May 28-31, 2010 conference held in Colorado Springs, CO was one of the best attended conferences in years. The evaluations rated the conference tops, especially for newly added programs such as onsite Respite, and the live streaming webcast package that enabled virtual attendance from around the world. IRSF thanks our internationally recognized panel of speakers, planning committee members, professional exhibitors, regional representatives, board of directors, Cheyenne Mountain Resort staff, Tribute Reception award recipients, entertainers, auction donors and bidders, our design friends at Paradowski Creative, and most of all, the hundreds of families and attendees, for making this an incredible, powerful conference.

All materials will be available shortly! For those unable to attend, or for the attendee wishing to take home the information learned, the video-recorded sessions (Saturday) and audio-recorded sessions (Sunday) will be available for purchase shortly through the IRSF Store. And the majority of speaker slides and handouts will be posted at no charge to this webpage in coming weeks (these pair especially well with the audio recordings).

Check back regularly for updated information on session recordings, and future conference planning. For now, please read through the program posted here to anticipate which session recordings you are interested in, and enjoy reading the incredibly heartwarming Helping Hands Keepsake Journal – thank you again to all who contributed to this inspiring journal of Hopes and Dreams.

IRSF Conference Program 2010 2.48 Mb

IRSF Helping Hands Keepsake Journal 2010 13.20 Mb

The IRSF conference provides families and caregivers with hope, inspiration, and the power of accurate information needed to achieve our dream of reversing Rett syndrome in our loved ones, how to keep her healthy and how to have endurance along the way. Beyond the actual learning of information, it is the contacts and relationships made face to face which you will carry back to your personal and online communities and support networks.

Featured this year:

- Motivational keynote by Colorado's own Susan Zimmerman, author of "Keeping Katherine"
- Leading Communication trio Linda Burkhart, Pati King-deBaun and Judy Lariviere
- World-renowned treatment experts and centers such as the Baylor College of Medicine Blue Bird Rett Center in Houston, University of Alabama Rett Clinic in Birmingham, Albert Einstein College of Medicine Rett Center at Montefiore, and more
- Sessions on therapies, recreational activities, marriage and family strengthening, financial and legal life planning
- 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, hosted by IRSF's own Chief Science Officer Dr. Tony Horton
- 2010 Conference Program 2.48 Mb
- Can't attend in person? NEW this year - SATURDAY sessions broadcast via LIVE webcast. To register for live streaming Saturday sessions [click here!](#) Early Bird Rates available NOW through May 9th. This conference offers the information, materials, and inspiration necessary to blaze our trails forward. Because there "Ain't No Mountain High Enough" when you are well-informed and well-equipped. Be a part of our 26th conference. We look forward to seeing you there.

Financial Planning for Onsite Attendance or Webcast Package

- Always check with your child's Case Manager first as she may have info for financial resources to attend conference
- If your child has a DD Medicaid Waiver you may stipulate some waiver funds for "Family and Caregiver" travel

will pay for conference fee

- Check with local "First Steps", Early Intervention, Mental Health Assoc. to see if funds are available
- Contact the Governor's Planning Council- Family Consumer Involvement funds on the website to apply for
- Check with INsource to see if funds are available (can Google or search)
- Always check with the local clubs to see if assistance is available such as Elks Club, Lions Club, and Knights of Columbus

Columbus

- Ask family members to help financially with your IRSF conference costs in lieu of birthday, holiday, anniversary gifts

- Conference Scholarship Application

- Conference Widget {mosloadposition widget2}Conference Sessions and PDF Files

File

RET

Alan Percy, MD
 Steve Skinner, MD
 Susan Zimmermann
 Aleksandra Djukic, MD, PhD

sensory input & Supporting Ease of Access

Judy Lariviere, M.Ed., OTR/L

Mb

Well

Jane Lane, BSN, RN
 Daniel Glaze, MD
 Kathleen Motil, MD, PhD

Scoliosis

John Killian, MD
 Jeffrey Neul, MD, PhD, and Tony Horton, PhD

PhD 1.08 Mb

Kathryn Kissam and Stephen Bajardi

Kissam and S. Bajardi 1.59 Mb

Jane Lane, BSN, RN

Assessment Tools 101

Terry Katz, PhD

Syndrome

Marilyn Stevenson, RD, CSP and Margaret Spring, OT

Stevenson, RD, CSP and M. Spring, OT 96.92 Kb

for Conducting Successful Trials

Judy Lariviere, M.Ed., OTR/L

Successful Trials 2.54 Mb

Jennifer Endres, IRSF and Jenni Grammer, IRSF

Special Needs Planning Program

Mary Anne Ehlert, Protected Tomorrows

Eights Steps to Protected Tomorrows Handout 152.44 Kb

Robin Brewer

Nancy Beers

Home, School and in the Community

Judy Lariviere, M.Ed., OTR/L

Mick Ross, MS and Diane Ross, MS LCPC

Toddlers to Teens

Diane Ross, MS, LCPC

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

25th Annual Conference - 2009 Over 250 parents, caregivers, and professional attendees from all over the world came together to meet with over 50 Rett syndrome experts and exhibitors for learnings and celebrations at the very special IRSF 25th annual education and awareness conference in Leesburg, Virginia over Memorial Day weekend May 23-26, 2009.

If you missed this fantastic conference, want to revisit a session, or need to catch one you missed, you can experience it just like being there by purchasing the session audio CDs or MP3s from Aurora Recording. Listen while you read through the speaker handouts, many of which are posted below. Slides are listed in order of the program sessions.

IRSF 2009 Conference Audio Recording Form 2009-06-23 05:15:55 131.87 Kb

Revisit Conference & View our Photo Album

See table below to download and treasure the Helping Hands Keepsake Ad Journal. This was a first of its kind & now that you see what it's about, start planning your ad for next year's conference journal

Save the Date: 26th annual conference Colorado, Memorial Day Weekend, May 28 & 31, 2010

& Celebrating the Torch Within session downloads:

of the material.	SESSION	SPEAKER	Celebrating
Mb	IRSF	Helping Hands Keepsake Ad Journal	IRSF
29 13:06:37 68.01 Kb	Hostess Paige Nues	Family & Friends, How Miracles Are Created - Families	
06-23 05:12:53 2.85 Mb	Dr. Carolyn Schanen and Maureen Woodcock	25th Conference Congratula	
Commentary {flv}IRSF_25TH_ANNIVERSARY_8{/flv}	Baylor Rett Center team	Huda Zoghbi &	
Research Award” Acceptance			
{youtube}iiQVslI3DxQ{/youtube}	Dr. Huda Zoghbi	Rett Syndrome 101	2009-06-24 10:50:44 3.28
Symndrome After 25 Years Handout	2009-06-23 09:23:04 44.50 Kb	Dr. Alan Percy	Keynote Address
”Fighter Mom: For Mothers and Others”		Martha Slay, FightSMA	Catching a GL
Flames of the Hidden Torch Within	Linda Burkhart	Let's Get Together and Communicate!	
4.41 Mb	Susan Norwell, M.S. Ed.	Communication: In High School and Adulthood (Discussion session	
presented)	Susan Norwell, M.S. Ed.	”Jumpstarting” Literacy Learning: It's n	
Judy Lariviere, M.Ed., OTR/L		Partner-Assisted Scanning with PODD Communication Books: St	
who have Rett Syndrome	Linda Burkhart	Successful Use of ”Eye-Gaze” Technol	
Assessment to Conversation	Judy Lariviere, M.Ed., OTR/L	Measurable IEP Goals	Ir
Schools So Schools Will Listen (and Listen So Schools Will Talk)	Irene Moore	Integration in th	
Environment & A Success Story	Jennifer Ethridge and Mickie McCool	Creating Her Future	
Anne Ehler	Carrying the Fundraising Torch: A ”How-To” Workshop	2009-06-22 11:23:24 3.16	
Mb	Jennifer Endres	Lighting Your Path to the Transition to Adulthood and Community Programs	
Genetics 101	2009-06-23 06:32:18 736.99 Kb	Carolyn Schanen, MD, PhD	Carolyn's Geneti
06-23 08:40:20 112.01 Kb	Carolyn Schanen, MD, PhD	Top 5 Reasons to Have MECP2 Testing &	
06-23 06:21:02 48.45 Kb	Jane Lane, BSN, RN	Understanding the Signs and Symptoms of Rett Syndr	
2009-06-24 11:40:38 4.52 Mb	Dr. SakkuBai Naidu	Epilepsy and Seizure Management	2009-06-24
Dewi Depositario-Cabacar	Growing Straight and Tall with Rett: Bone and Muscle Orthopaedic Issues	2009-06-24	
07:37:09 939.63 Kb	Dr. Paul Sponseller	Gastroenterology	2009-06-22 12:15:04 2.40 Mb
Darbari	Endocrinology: Bone Issues and their Treatment in Rett Syndrome	2009-06-29 06:57:35 939.63 Kb	
Shapiro	Cognitive assessment and intervention	2009-06-29 06:51:49 969.92 Kb	Dr. Cynthia Salo
Syndrome & Handout	2009-06-23 08:49:33 71.67 Kb	Dr. Elaine Tierney	Well Child and Adult
2009-06-29 09:51:25 513.69 Kb	Jane Lane, BSN, RN	Physical Therapy	2009-06-23 08:35:05 36.99
PT	PT Handout	2009-06-23 08:29:29 830.32 Kb	Jennifer Swain, PT
Puberty to Menopause	2009-06-29 08:52:40 1.70 Mb	Jane Lane, BSN, RN	To Sleep, Perchance to
Disorders in Rett Syndrome	2009-11-18 11:59:58 169.96 Kb	Judy Barrish, RN	Making a Differenc
Music Therapy	2009-07-16 10:19:08 1.07 Mb		

A Ram Sam Sam

{flv}A_Ram_Sam_Sam{/flv}

Allee Galloo

{flv}Allee_Galloo{/flv}

Clap Your Hands Together

{flv}Clap_Your_Hands_Together{/flv}

Family Song

{flv}Family_Song{/flv}

Goodbye Song

{flv}Goodbye_Song{/flv}

Hello Song

{flv}Hello_Song{/flv}

I've Got the Rhythm in My Drum

{flv}I've_Got_the_Rhythm_in_My_Drum{/flv}

Jingle Your Bells

{flv}Jingle_Your_Bells{/flv}

Round and Round the Circle
{flv}Round_and_Round_the_Circle{/flv}

Tap Your Head
{flv}Tap_Your_Head{/flv}

Tap Your Sticks
{flv}Tap_Your_Sticks{/flv}

Where Oh Where is the Tambourine
{flv}Where_Oh_Where_is_the_Tambourine{/flv}

Wind Chimes
{flv}Wind_Chimes{/flv}

Sara Jourdan, MA, BM, MT-BC World Congress Update on Therapies: Those Mice are Working
23 09:21:11 663.17 Kb Carolyn Schanen, MD, PhD NIH RDCRN Natural History Study 2009-06-2
Kb Dr. Alan Percy Rett Syndrome Classification and DSM-V 2009-06-22 11:41:03 330.97 Kb

2009 – “Celebrating the Torch Within” – Leesburg, VA

2008 – “Together We Are Better” – Chicago, IL

2007 – “Reach Me, Teach Me” – Atlanta, GA

2006 – “Bridges of Hope” – San Francisco, CA

2005 – “Trails to Discovery” – San Antonio, TX

2004 – “Believe in Better Days” – Baltimore, MD

2003 – “Ship Shape for Caregivers” – Bahamas

2002 – “Empowerment” – Chicago, IL

2001 – “Possibilities” – Washington, DC

2000 – “Hitting the Jackpot” – Las Vegas, NV

1999 – “Meet Me in St. Louis” – St Louis, MO

1998 – “Grass Roots” – Charleston, SC

1997 – “Keeping Afloat” – Bahamas

1996 – “Spirit of ‘96” – Boston, MA

1995 – “A Road Less Traveled” – Minneapolis, MN

1994 – “A Decade of Caring” – Chicago, IL

1993 – “Stepping Stones” – San Diego, CA

1992 – “New Horizons” – San Diego, CA

1991 – “Up, Up and Away” – Denver, CO

1990 – “Family Ties” – Washington, DC

1989 – “Hope for Tomorrow” – Washington, DC

1988 – “Rett Families Conference” – Houston, TX

1987 – “RS Diagnosis & Management” - Houston, TX

1985 (November) – “Rett: A New Syndrome” - Baltimore, MD

1985 (January) – “No Longer Alone” - Baltimore, MD