

**7<sup>TH</sup> WORLD CONGRESS ON RETT SYNDROME**  
**FAMILY EDUCATION AND AWARENESS SESSIONS**  
**JUNE 22-24, 2012**

**\*\* PROGRAM SUBJECT TO CHANGE \*\***  
**CHECK REGISTRATION/HELP DESK FOR CONFIRMED SESSION TIMES AND ROOM ASSIGNMENTS**  
**ALL SESSION TIMES ARE CENTRAL TIME ZONE**

SPECIAL EVENTS, FRIDAY - SUNDAY, JUNE 22-23, 2012				
DAY	TIME	SESSION	SPEAKER	SESSION TYPE/LOCATION
Friday-Sunday	Fri: 10am – 7pm Sat: 7am-5pm Sun: 7:30am-2pm	<b>Registration</b> and Help Desk Speaker, Exhibitor and Volunteer Check-In	IRSF Staff and Volunteers	La Salle foyer, 3 <sup>rd</sup> floor
Friday-Sunday	9am-4pm (close mid-afternoon Sunday)	<b>Exhibitor and Information Booths:</b> Assistive technology, adaptive equipment and more	Exhibitors and Sponsors	Le Salon foyer, 3 <sup>rd</sup> floor
Friday-Sunday	9am-4pm (approximately)	<b>Bookstore:</b> Awareness items and educational materials	IRSF Staff and Volunteers	La Salle foyer (near elevator bank), 3 <sup>rd</sup> floor
Friday-Sunday	Fri: 12:30p-6:30p Sat: 7:30a-12:30p, 1:30p-5p Sun: 8a-12:30p	<b>Respite:</b> pre-register and pre-pay Contact Lisa Hayden by June 15 ( <a href="mailto:lhayden@rettsyndrome.org">lhayden@rettsyndrome.org</a> )	KPH Pediatric Staffing and Volunteers	Poydras and Fulton Rooms, 3 <sup>rd</sup> floor
Friday - Saturday	To Be Announced – see Registration Desk	<b>Gene Machine :</b> Greenwood Genetics Traveling Classroom Bus	Hosted by: Greenwood Genetics	St. Charles Street, front of hotel
Saturday	9am-11am	Attendee <i>Technical Support/Readiness Setups</i> table for Sunday iPad workshop	Volunteers	Exhibitor arena
Saturday	7:30pm – 10pm	<b>Tribute Reception</b>	IRSF and Volunteers	La Salle A, B, and C, 3 <sup>rd</sup> floor
Friday	9am – 7pm	<b>Speaker Prep Room</b>	IRSF	Acadian II, 3 <sup>rd</sup> floor

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FRIDAY, JUNE 22, 2012			
TIME	SESSION	SPEAKER	ROOM AND MEETING TYPE, 3 <sup>RD</sup> FLOOR
8am-9am	<b>Yoga for the Caregiver “Find Serenity”</b> ( <i>pre-register by June 20, no fee, to <a href="mailto:vhberlitz@aol.com">vhberlitz@aol.com</a></i> )	Violaine Herlitz	Acadian I
10am-11am	<b>Yoga for the Caregiver “Find Serenity”</b> (repeat) ( <i>pre-register by June 20, no fee, to <a href="mailto:vhberlitz@aol.com">vhberlitz@aol.com</a></i> )	Violaine Herlitz	Acadian I
10am - 7pm	<b>Registration Desk</b>	IRSF Staff	La Salle foyer
10am-4pm	<b>Exhibitors and Bookstore</b>		Le Salon foyer
12:30pm-6:30pm	<b>Respite</b> (pre-register, pre-pay by June 15 <a href="mailto:lhayden@rettsyndrome.org">lhayden@rettsyndrome.org</a> )	KPH Pediatric Staffing and Volunteers	Poydras and Fulton Rooms
1pm	<b>World Congress Opening and Family Keynote</b>	Kathryn Kissam, <i>World Congress Chairperson</i> Paige Nues, <i>IRSF</i> Mickie McCool, <i>Parent</i>	La Salle Ballroom A and B General Session
1:30pm	<b>“Charting the Course” for Those Living with Rett Syndrome</b> <b>The Natural History of Rett Syndrome: An Update on Recent Progress</b>	Alan Percy, MD, Professor of Pediatrics, Neurology, Neurobiology, and Genetics, University of Alabama at Birmingham and World Congress Co-Chair	La Salle Ballroom A and B General Session
2:30pm	<b>What Goes Right In Her Brain</b>	Aleksandra Djukic, MD, PhD	La Salle Ballroom A and B General Session
3:00pm	<b>Apraxia and Communication</b>	Linda J. Burkhart	La Salle Ballroom A and B General Session
3:30pm	<i>Refreshment Break</i>		<i>3<sup>rd</sup> floor foyers</i>
3:45pm	<b>Interventions and Therapies in Rett syndrome. Early Not Late: By One and All</b>	Sarojini Budden MD ,FRCP C ,FAAP	La Salle Ballroom A and B General Session
4:15pm	<b>Databases: Importance of Family and Patient Contributions to Our Collective Understanding of Rett Syndrome</b>	Helen Leonard, M.D	La Salle Ballroom A and B General Session
4:30pm	<b>Therapies for Rett Syndrome: Past and Current Clinical Trials, and Future Prospects</b>	John Christodoulou, AM MB BS PhD FRACP FFS Sc FRCPA	La Salle Ballroom A and B General Session
5:30pm-6:30pm	<i>(NIH RDCRN NHS coordinator meeting)</i>	<i>Investigators, IRSF</i>	<i>Meeting by invitation – Room 502</i>
5:30pm-6:30pm	<b>Crackerbarrel Breakout Sessions: Conference Hopes and Expectations</b>	Facilitated Discussion Groups	

	Under 3 years old		La Salle C
	3 - 5 years old		La Salle B
	6 – 10 years old		La Salle A
	11 – 18 years old		La Salle A
	19 - 22 years and over		Pelican I
	22+ years old		Pelican I
	Grandparents		Acadian I
	CDKL5		Pelican II
	MECP2 mutations/duplication – males		Pelican II
	Professionals		Acadian II

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SATURDAY, JUNE 22, 2012			
TIME	SESSION	SPEAKER	SESSION AND MEETING TYPE, 3 <sup>RD</sup> FLOOR
7:30am-12:30pm	<b>Respite</b> (pre-register, pre-pay by June 15 to <a href="mailto:lhayden@rettsyndrome.org">lhayden@rettsyndrome.org</a> )	KPH Pediatric Staffing and Volunteers	Poydras and Fulton Rooms
7am-9am	<b>Continental Breakfast</b>		<i>3<sup>rd</sup> floor foyers</i>
9am-4pm	<b>Exhibitors</b>		Le Salon foyer
8am-10am	<b>Nutrition and GI Tweets for Rett Syndrome</b>	Kathleen Motil, MD, PhD Suzanne Geerts, MS, RD, LD	Pelican Rooms Concurrent Session
	<b>Scoliosis and Orthopedic Issues</b>	Jenny Downs, BAAppSci, MSc, PhD John Killian, MD Ms. Drew Long	La Salle C Concurrent Session
	<b>Taking the Mystery Out of Seizures</b>	Daniel Glaze, MD	Acadian I and II Concurrent session
	<b>Partnerships in Care of Individuals with Rett Syndrome. Integrating Medical, Therapeutic and Educational Interventions</b>	Sarojini Budden, MD ,FRCP C ,FAAP Theresa Bartolotta, PhD, CCC-SLP Cochavit Elefant, RMT, MEd, PhD Meir Lotan, BPT, MScPT, PhD Carrie Luse, MSR, OT/L, ATP	La Salle A Concurrent session
10am	<i>Refreshment Break</i>		<i>3<sup>rd</sup> floor foyers</i>
10:30am	<b>The Importance of Autonomic Problems in Rett syndrome</b>	Jeffrey Neul, MD, PhD	Pelican I Concurrent Session
	<b>Diagnosis and Classification of Rett Syndrome: DSM-5 and Other Systems</b>	Walter Kaufmann, MD	Pelican II Concurrent Session
	<b>Genetics: Beyond the Basics</b>	Steve Skinner, MD	La Salle C Concurrent Session
	<b>A Good Night's Sleep for the Whole Family: Managing Sleep Problems in Rett Syndrome</b>	Daniel Glaze, MD	Acadian I and II Concurrent Session
	<b>Speech-Language Pathology: Partnering with Families, Teachers and Therapists to Maximize Communication</b>	Theresa Bartolotta, PhD, CCC-SLP	La Salle B Concurrent Session
11:30am	<b>Emotion and Behaviors In Rett Syndrome</b>	Sarojini Budden, MD ,FRCP C ,FAAP	Acadian I and II Concurrent Session

	<b>Meaningful Access: An Occupational Approach to Increasing Independence for Children with Rett Syndrome</b>	Carrie Luse, MSR, OT/L, ATP	La Salle C Concurrent Session
	<b>Womanhood in Rett Syndrome 2012: From Puberty to Menopause</b>	Jane Lane, BSN, RN	Pelican I Concurrent Session
	<b>Physical Therapy for Rett Syndrome: A 24/7 Activity Program</b>	Meir Lotan, BPT, MScPT, PhD	La Salle B Concurrent Session
12:30pm	<i>Boxed Lunches</i>		To be announced, 3 <sup>rd</sup> floor
1:30pm-5pm	<b>Respite</b> (pre-register, pre-pay by June 15 to <a href="mailto:lhayden@rettsyndrome.org">lhayden@rettsyndrome.org</a> )	KPH Pediatric Staffing and Volunteers	Poydras and Fulton Rooms
1:30pm	<b>Care Concerns for the Adult with RTT: A Family Panel and Discussion</b>	Clifford Fry, PhD	Pelican I Concurrent Session
	<b>“Light Tech” Communication, part 1</b>	Linda J. Burkhart	La Salle C Concurrent Session
	<b>Music and Music Therapy – What Can it Afford Individuals with Rett Syndrome?</b>	Cochavit Elefant, RMT, MEd, PhD	Pelican II Concurrent Session
	<b>Integration in the Elementary and Middle School Environment: A Success Story!</b>	Jennifer Ethridge, Educator Mickie McCool, Parent	La Salle B Concurrent Session
2:30pm	<b>“Ramping up” Eye Gaze Technology: Enhancing Communication and Literacy Learning for Girls with Rett Syndrome</b>	Judy Lariviere, MEd, OTR/L	Pelican I and II Concurrent Session
	<b>“Light Tech” Communication, part 2</b>	Linda J. Burkhart	La Salle C Concurrent Session
	<b>Beyond Emergent Literacy – Let’s Teach Them To Read!</b>	Susan Norwell, M.A. Spec. Ed.	Acadian I and II Concurrent Session
3:30p	<i>Refreshment Break</i>		<i>3<sup>rd</sup> floor foyers</i>
4pm	<b>Dads Only</b>	Mick Ross, MS	Pelican I Concurrent Session
	<b>Grandparents Only</b>	Facilitated Panel	Pelican II Concurrent Session
	<b>Sibling Panel (open to all attendees)</b>	Diane Ross, MS, LCPC	La Salle C Concurrent Session
5pm	<i>Dinner (on your own)</i>		
5pm	Respite Rooms Close	KPH Pediatric Staffing and Volunteers	Poydras and Fulton Rooms
7:30pm-10pm	<b>Tribute Reception</b>	Dessert, coffee, cash bar	La Salle Ballrooms

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SUNDAY, JUNE 24, 2012			
TIME	SESSION	SPEAKER	SESSION AND MEETING TYPE, 3 <sup>RD</sup> FLOOR
8am-12:30pm	<b>Respite</b> (pre-register, pre-pay by June 15 to <a href="mailto:lhayden@rettsyndrome.org">lhayden@rettsyndrome.org</a> )	KPH Pediatric Staffing and Volunteers	Poydras Room, 3 <sup>rd</sup> floor
7:30am-9:30am	<b>Continental Breakfast</b>		3 <sup>rd</sup> floor foyers
9am-4pm	<b>Exhibitors</b>		Le Salon foyer, 3 <sup>rd</sup> floor
8:30am-11am	<b>iPad Workshop: “APPy Tyme” - APPsolutely APPropriate APPs</b>	Linda Burkhart Judy Lariviere, MEd, OTR/L Susan Norwell, M.A. Spec. Ed. Joy Rosen	La Salle A and B Concurrent Session
	<b>Science Workshop: Understanding Chromatin, Epigenetics and the MeCP2 protein</b> <b>From Mind to Molecules: the Neurobiology of Rett Syndrome</b>	Anna Kalashnikova, PhD Jennifer L. Larimore, PhD	Pelican I and II Concurrent Session
	<b>Bringing You Protected Tomorrows: Your Journey Through an Eight Step Special Needs Planning Process</b>	Mary Anne Ehlert, CFP	La Salle C Concurrent Session
10am	<i>Refreshment Break</i>		3 <sup>rd</sup> floor foyers
11:30a–12:30pm	<b>Keynote: “Charting the Course”</b>	Huda Y. Zoghbi, MD	La Salle A and B General Session
	<b>Closing of Family Education and Awareness Conference</b>	IRSF: Steve Kaminsky, PhD, Paige Nues, and Kathryn Kissam	La Salle A and B General Session
12:30pm	<i>Boxed Lunches</i>		To be announced, 3 <sup>rd</sup> floor
1:30pm-3:30pm	CDKL5 Family Meeting	Katheryn and David Frame, International Foundation for CDKL5 Research (ICR)	Acadian II
	World Association Executive Meeting	<i>By invitation</i>	Pelican I
	IRSF Regional Representatives	<i>By invitation</i>	Pelican II