



**International Rett Syndrome Foundation**  
**27<sup>th</sup> Annual Education and Awareness Conference**  
**May 27-30, 2011**  
**Boston Park Plaza Hotel**  
**Boston, MA**

**\*\* THIS VERSION INCLUDES IMPORTANT PROGRAM CHANGES AS OF WED, MAY 25 \*\***

DAY	TIME	SESSION	SPEAKER	SESSION TYPE/LOCATION
<b>Friday-Monday</b>	Fri: noon-8pm Sat: 7:30am-6pm Sun: 7:30am-5:30pm Mon: 8am-noon	Registration/Help Desk/Speaker and Volunteer Check-In	IRSF Staff and Volunteers	Mezzanine (2 <sup>nd</sup> Floor) Level
<b>Saturday-Sunday</b>	9am-5pm	Exhibitor and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics, IRSF regional representatives and more	Exhibitors and IRSF	Mezzanine (2 <sup>nd</sup> Floor) Level
<b>Saturday-Sunday</b>	8am-5pm	Bookstore: Awareness items, educational materials	IRSF Staff and Volunteers	Hancock
<b>Friday-Sunday</b>		Speaker Prep Room	IRSF	Fairfield

Friday May 27				
	Noon-8pm	Registration opens	IRSF Staff	Mezzanine (2 <sup>nd</sup> Floor) Level
	12:15pm-3:30pm	Lab tour: LIMITED SPACE. Pre-registration through IRSF required. Meet in hotel lobby near Concierge Desk at 12:15pm	Drs. Michela Fagiolini, Clifford Woolf, Scott Pomeroy, Omar Khwaja, and Chuck Nelson. Hosted by Children's Hospital Boston Trust and IRSF	Children's Hospital Boston: F.M. Kirby Neurobiology Center, Neurodevelopmental Behavioral Core, Clinical and Translational Study Unit (CTSU), Laboratory of Cognitive Neuroscience Boston
	6pm	<b>Welcome Reception</b>	Hosts: IRSF Board of Directors	Georgian Ballroom
	7pm	<b>Welcome and Orientation Address</b>	Paige Nues, IRSF	Georgian Ballroom
	8pm-9pm	<b>Crackerbarrel Breakout Sessions: Conference Hopes and Expectations</b>		
		3 yrs and under	Paige Nues, Dawn Conroy	Arlington, 2 <sup>nd</sup> floor
		4 - 7 yrs	Erica Robertson, Carole Cushman	Berkeley, 2 <sup>nd</sup> floor
		8 – 16 yrs	Cordelia Albanese	Clarendon, 2 <sup>nd</sup> floor
		17 yrs and over	Clifford and Judy Fry	Georgian, 2 <sup>nd</sup> floor
		Grandparents	Jennifer Endres	Statler, 2 <sup>nd</sup> floor
		Rettnetters and Facebookers	Shirley Hurlburt	Fairfield, 2 <sup>nd</sup> floor
		Spanish Speakers	Maggie Wurm	Stuart, 4 <sup>th</sup> floor
		Professionals	Evie Lynn Swan	White Hill, 4 <sup>th</sup> floor
		CDKL5	Katheryn Elibri-Frame	St. James, 4 <sup>th</sup> floor

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DAY	TIME		SESSION	SPEAKER	SESSION TYPE/LOCATION
<b>Saturday May 28</b>	7:15am-12:30pm		Respite Rooms Open		Lexington and Newbury, 4 <sup>th</sup> Floor
	7am-8:30am		<b>Breakfast</b>		<b>Plaza Ballroom</b>
	Morning 7:30am		<b>Understanding RTT and other MECP2 Disorders</b>	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	8:30am		<b>Parents' Experiences with Genetic Testing for Rett syndrome</b>	Christine Delaney, MS, Genetics Counselor	Imperial Ballroom <i>General Session and Live Webcast</i>
	8:45am		<b>IRSF Welcome Address</b>	Kathryn Kissam, <i>IRSF Board Chairman</i> , and Steve Bajardi, <i>IRSF Executive Director</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
<b>TIME CHANGE</b>	9:15am		<b>Keynote Motivational Address: "YES YOU CAN"</b>	Dick Hoyt of famed <i>Team Hoyt</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
<b>TIME CHANGE</b>	9:45am	Exhibitor Arena Open	<b>Refreshment Break and Exhibitor Arena</b>		
<b>TIME CHANGE</b>	10am		<b>Current State of Translational Research</b>	Tony Horton, PhD, <i>Chief Science Officer, IRSF</i> , Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i> , and Omar Khwaja, MD, PhD, <i>Director Rett Syndrome Program, Children's Hospital Boston</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
<b>NEW ADDITION</b>	11am		<b>The Enriched Environment and Moving Towards Best Therapeutic Practices</b>	Pamela Diener, PhD, MS, OT/L <i>Georgetown University</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	11:30am		<b>Communication at All Ages</b>	Susan Norwell, MS Ed	Imperial Ballroom <i>General Session and Live Webcast</i>
	12:15pm		<i>Lunch (on your own) and Exhibitor Arena. Respite rooms closed</i>		
	1:30pm-5:45pm		Respite Rooms Open		Lexington and Newbury, 4 <sup>th</sup> Floor
	Afternoon 1:45pm		<b>Sibling Panel</b>	Brian Skotko, MD, MPP, <i>Clinical fellow in genetics, Boston Children's Hospital</i>	Imperial Ballroom <i>General Session and Live</i>

					Webcast
	2:30pm		Neurology: Epilepsy	Ann Marie Bergin, MB MD, BCH, BAO, Epilepsy Specialist, Rett Center, Children's Hospital Boston	Imperial Ballroom General Session and Live Webcast
	3:00pm		The Importance of Therapies	Donna L. Nimec, MD, Pediatric Physical Medicine & Rehabilitation Specialist, Children's Hospital Boston	Imperial Ballroom General Session and Live Webcast
	3:30p		Refreshment Break and Exhibitor Arena		
	3:45pm		Endocrinology	Ingrid A. Holm, MD, MPH, Director, Phenotyping Core, Program in Genomics, Divisions of Genetics and Endocrinology, Children's Hospital Boston	Imperial Ballroom General Session and Live Webcast
	4:20pm		Gastroenterology	Kathleen Motil, MD, PhD Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH	Imperial Ballroom General Session and Live Webcast
	5:00pm		Well Child and Adult Care Overview	Jane Lane, BSN, RN, University of Alabama and IRSF	Imperial Ballroom General Session and Live Webcast
	5:30pm		Sessions end for the day		
	5:45pm		Respite Rooms Close		Lexington and Newbury, 4th Floor
	5:45pm		Dinner (on your own)		
	7:30pm		Tribute Reception	Hosted by IRSF	Imperial Ballroom

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			RESEARCH	COMMUNICATION AND SCHOOL	MEDICAL ISSUES AND THERAPIES	FAMILY FOUNDATIONS	FUNDRAISING AND ADVOCACY
<b>Sunday May 29</b>	Respite 7:45am-12:30pm		Respite Rooms Open Lexington and Newbury, 4 <sup>th</sup> Floor				
	Continental Breakfast	7am-8:30am					Imperial Ballroom
	Morning 8am		<b>What is DNA?</b> (lab demo limited to a maximum 25 attendees) – Tony Horton, PhD, <i>Chief Science Officer, IRSF ARLINGTON</i>	<b>Emergent Literacy and Communication</b> – Susan Norwell, <i>MS Ed STATLER</i>	<b>Conductive Education: A Therapeutic Approach</b> - Eleonora Tamasne MA, QCS, QTS, ET BERKELEY	<b>Entender RTT y Otros Trastornos MECP2 – en español</b> – Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center, Maggie Wurm, IRSF Bilingual Representative interpreting (90 minutes) CLARENDON</i>	
<b>NOTE EXPANDED SESSION TIME</b>	9am	Exhibitor Arena Open	<b>What Happens in Rett Syndrome at a Molecular Level: Epigenetics and Assay Development</b> - Christopher Wynder PhD, <i>Schulich School of Medicine, University of Western Ontario ARLINGTON</i>	<b>“Mid Tech” Usage and the Literacy Assessment</b> – Susan Norwell, M.S. Ed. and Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children’s Hospital STATLER (2 hours)</i>	<b>Physical Therapy</b> – Barbara Deluca, <i>Physical Therapist, Cotting School, MA BERKELEY</i>		<b>Fundraising “How-To” Workshop</b> – Jennifer Endres, <i>IRSF and Jenni Grammer, IRSF PLAZA BALLROOM</i>
	10am		<i>Refreshment Break and Exhibitor Arena</i>				
	10:15am		<b>What Happens in Rett Syndrome at a Systems Level: Neurobiology of RTT</b> - Michela Fagiolini, PhD, <i>F.M. Kirby</i>	<b>“Mid Tech” Usage and the Literacy Assessment, continued</b> – Susan Norwell, M.S. Ed. and Judy Lariviere, M.Ed., OTR/L, <i>Communication</i>	<b>The Maturing Woman with Rett Syndrome: From Puberty to Menopause</b> - Jane Lane, BSN, RN, <i>University of</i>	<b>Expression and Movement Through Dance</b> – Prof. Carlinhos Faustini, <i>PEAMA, Brazil IMPERIAL BALLROOM</i>	<b>Advocacy 101</b> – Stephen Bajardi, Executive Director, <i>IRSF CLARENDON</i>

			Neurobiology Center, Children's Hospital and Harvard Medical School	Specialist, Rett Clinic, Oakland Children's Hospital STATLER	Alabama and IRSF BERKELEY		
	11:15am		ARLINGTON				
			<b>Researcher Panel Q&amp;A</b> – Drs. Horton, Percy, Neul, Wynder, and Fagiolini ARLINGTON	<b>Making Eye Gaze Technology a Reality: The Road from Trials to Conversations</b> - Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i> (90 minutes) STATLER	<b>In Common: Music (Therapy)</b> – Donna Chadwick, <i>Music Therapist, MA</i> BERKELEY	<b>Special Needs Wills and Trusts</b> – Donald Freedman, <i>Rosenberg, Freedman &amp; Goldstein LLP</i> and John W. Nadworny, CFP(r), <i>Bay Financial Associates LLC</i>  PLAZA BALLROOM	
	Lunch 12:30pm – 1:30pm		Lunch served in IMPERIAL BALLROOM and Exhibitor Arena open (Respite Rooms closed during lunch)				
			Regional Representative Meeting 12:40pm – 1:30pm with Jennifer Endres and Lisa Hayden PLAZA BALLROOM				
	Respite 1:30pm-6pm		Respite Rooms Open Lexington and Newbury, 4th Floor				
	Afternoon 1:45pm		<b>Ways to Make it Go Right: A Look at IGF-1 and other Small Molecules</b> – Mriganka Sur, PhD, <i>Paul E. Newton Professor of</i>	<b>IEP Panel Discussion: Your Real-Life IEPs</b> (90 min) STATLER	<b>Nutritional Management of Children with Rett Syndrome</b> – Gail Seche, MMSc, RD, CSP, <i>Rett Syndrome Clinic, Oakland Children's Hospital, CA</i>	<b>Transition to Adulthood and Community Programs (90 min)</b> - Donald Freedman, <i>Rosenberg, Freedman &amp; Goldstein LLP</i> and Alan K. White <i>Director of Residential Alternatives TILL, Inc.</i> PLAZA BALLROOM	

			Neuroscience Head, Dept of Brain and Cognitive Science, MIT and Omar Khwaja, MD, PhD, Director Rett Syndrome Program, Children's Hospital Boston ARLINGTON		BERKELEY			
	2:45pm		How to Search Out and Critically Read Research Articles - Kate Barnes, BSc, Research Coordinator and Heather O'Leary, BSc, Biomedical Engineering Research Scientist, Rett Syndrome Program, Department of Neurology, Children's Hospital Boston  ARLINGTON		To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome - Judy Barrish, RN, Blue Bird Rett Center Baylor College of Medicine BERKELEY	Fostering Friendships – Diane Ross, MS, LCPC, Educator, Therapist and Parent CLARENDON	Clinical Features and Current Research: CDKL5 and Atypical Rett Syndrome – David Frame, PharmD, IFCR GEORGIAN	Strollathon: the IRSF signature fundraiser - Jennifer Endres, IRSF and Jenni Grammer, IRSF EXETER
	3:30p		Refreshment Break and Exhibitor Arena					
	3:45pm			Accessing the General Education Curriculum - Mick Ross, MS and Diane Ross, MS, LCPC, Educators and Parents STATLER	Creating a Vision – Elaine Rabbitt, Federation for Children with Special Needs ARLINGTON	Dad's Panel GEORGIAN BALLROOM		
	4:45pm		How Do Clinical Trials Happen? An Inside Look at the IGF-1 Clinical					

			<b>Trial - Omar Khwaja, MD, PhD,</b> <i>Director Rett Syndrome Program,</i> <i>Children's Hospital Boston</i> GEORGIAN BALLROOM
	5:30pm		<b>Farewell and Closing Remarks</b> – Paige Nues, <i>IRSF</i> GEORGIAN BALLROOM
	Respite Closes 6pm		<b>Respite Rooms Close</b> Lexington and Newbury, 4th Floor

<b>Monday May 30</b>	9am	<b>Crackerbarrel Breakout Sessions: Conference Learnings and Takeaways</b> STATLER
	Noon	<b>Help Desk and Bookstore Close</b> – <i>See You at World Rett Syndrome Congress, New Orleans, June 2012!</i>