



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

**** THIS IS A PROGRAM PREVIEW ****

The formal program with additional sessions and speaker details will be published shortly

DAY	TIME	SESSION	SPEAKER	SESSION TYPE/LOCATION
Friday-Monday	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	Atrium Lobby
Saturday-Sunday	9am-5pm	Exhibitor and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics, IRSF regional representatives and more	Exhibitors and IRSF	Atrium Lobby
Saturday-Sunday	8am-5pm	Bookstore: Awareness items, educational materials. (Silent Auction and Raffle tables setup Saturday only)	IRSF Staff and Volunteers	Hancock
Friday-Sunday		Speaker Prep Room	IRSF	Fairfield

Friday May 27				
	Noon-8pm	Registration opens	IRSF Staff	Lobby Atrium
	12pm-4pm	Lab tour: LIMITED SPACE. Call IRSF at 1.800.818.7388 to pre-register and for details.	Drs. Michaela 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	Welcome Reception	Hosts: IRSF Board of Directors	Georgian Room
	7pm	Welcome and Orientation Address	Paige Nues, IRSF	Imperial Ballroom
	8pm-9pm	Crackerbarrel Breakout Sessions: Conference Hopes and Expectations		
		3 yrs and under	Paige Nues	TBA
		4 - 7 yrs	Erica Robertson, Carole Cushman	TBA
		8 – 16 yrs	Cordelia Albanese	TBA
		17 yrs and over	Clifford and Judy Fry	TBA
		Grandparents	Jennifer Endres	TBA
		Rettnetters and Facebookers	Shirley Hurlburt, Cathy Merrill	TBA
		Spanish Speakers	Maggie Wurm	TBA
		Professionals	Evie Lynn Swan	TBA
		CDKL5	Katheryn Elibri-Frame	TBA

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Saturday May 28	Morning 7:30am		Understanding RTT and other MECP2 Disorders	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>
	8:45am		IRSF Welcome Address	Kathryn Kissam, <i>IRSF Board Chairman</i> , and Steve Bajardi, <i>IRSF Executive Director</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	9:15am	<i>Exhibitor Arena Open</i>	Current State of Translational Research	Tony Horton, PhD, <i>Chief Science Officer, IRSF</i> and John McCall, PhD, <i>President and Founder, PharMac LLC</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	10:00am		Keynote Motivational Address	Dick Hoyt of famed <i>Team Hoyt</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	10:30am		<i>Refreshment Break and Exhibitor Arena</i>		
	10:45am		What Goes Right with Her Brain	Aleksandra Djukic, M.D., Ph.D. <i>Director, Rett Syndrome Center, Albert Einstein College of Medicine at Montefiore</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	11:30am		Communication at All Ages	Susan Norwell, M.S. Ed.	Imperial Ballroom <i>General Session and Live Webcast</i>
	12:15pm		<i>Lunch (on your own) and Exhibitor Arena</i>		
	Afternoon 1:45pm		Sibling Panel	Brian Skotko, MD, MPP, <i>Clinical fellow in genetics, Boston Children's Hospital</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	2:30pm		Neurology: Epilepsy and Sleep	Anne Marie Bergin, MB MD, BCH, BAO, <i>Epilepsy Specialist, Rett Center, Children's Hospital Boston</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	3:00pm		Orthopedics		Imperial Ballroom <i>General Session and Live Webcast</i>
	3:30p		<i>Refreshment Break and Exhibitor Arena</i>		
	3:45pm		Endocrinology	Ingrid A. Holm, MD, MPH, <i>Director, Phenotyping Core, Program in</i>	Imperial Ballroom <i>General Session and Live</i>

				<i>Genomics, Divisions of Genetics and Endocrinology, Children's Hospital Boston</i>	<i>Webcast</i>
	4:20pm		Gastroenterology	Kathleen Motil, M.D., Ph.D. <i>Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	5:00pm		Steps to Good Health	Jane Lane, BSN, RN, <i>University of Alabama and IRSF</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	5:45pm		<i>Dinner (on your own)</i>		
	7:30pm		Tribute Reception and Silent Auction	Hosted by IRSF	Plaza Ballroom

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The order and time slots of the Sunday concurrent sessions will be finalized closer to May

			RESEARCH	COMMUNICATION AND SCHOOL	MEDICAL ISSUES AND THERAPIES	FAMILY FOUNDATIONS	FUNDRAISING AND ADVOCACY
Sunday May 29	Morning 8am		What is DNA? Extract It Yourself From a Strawberry (lab demo limited to 25 attendees, please signup at the Registration Desk) – Tony Horton, PhD, <i>Chief Science Officer, IRSF</i>	Emergent Literacy and Communication – Susan Norwell, M.S. Ed.	Conductive Education: A Therapeutic Approach - Eleonora Tamasne MA, QCS, QTS, ET	Understanding RTT and other MECP2 Disorders – en espanol – Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center</i> , Maggie Wurm, <i>IRSF Bilingual Representative interpreting (90 minutes)</i>	
	9am	Exhibitor Arena Open	What Happens in Rett Syndrome at a Molecular Level: Epigenetics and Assay Development - Christopher Wynder Ph.D, <i>Schulich School of Medicine, University of Western Ontario</i>	“Low Tech” Communication Solutions Workshop – Karen Patterson, <i>Special Educator, Biloxi, MS</i>	Physical Therapy – Barbara Deluca, <i>Physical Therapist, Cotting School, MA</i>		Fundraising 101 – Jennifer Endres, <i>IRSF</i> and Jenni Grammer, <i>IRSF</i>
	10am		Refreshment Break and Exhibitor Arena				
	10:15am		What Happens in Rett Syndrome at a Systems Level: Neurobiology of RTT - Michela Fagiolini, Ph.D., <i>F.M. Kirby Neurobiology Center, Children's Hospital and Harvard Medical School</i>	“Mid Tech” Usage and the Literacy Assessment – Susan Norwell, M.S. Ed. and Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic,</i>	The Maturing Woman with Rett Syndrome: From Puberty to Menopause - Jane Lane, BSN, RN, <i>University of Alabama and</i>	Fostering Friendships – Diane Ross, MS, LCPC, <i>Educator, Therapist and Parent</i>	

			<i>Oakland Children's Hospital</i>	<i>IRSF</i>		
	11:15am		Eye-Gaze/"High Tech" Usage At Home, School and in the Community - Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>	In Common: Music (Therapy) – Donna Chadwick, <i>Music Therapist, MA</i>	Special Needs Wills and Trusts – Donald Freedman, <i>Rosenberg, Freedman & Goldstein LLP</i> and John W. Nadworny, CFP(r), <i>Bay Financial Associates LLC</i>	
	Lunch		<i>Lunch (Imperial Ballroom) and Exhibitor Arena</i>			
			<i>Regional Representative Meeting with Jennifer Endres and Lisa Hayden (Room TBD)</i>			
	Afternoon 1:45pm		Ways to Make it Go Right: A Look at IGF-1 and other Small Molecules – Mriganka Sur, PhD, <i>Paul E. Newton Professor of Neuroscience Head, Dept of Brain and Cognitive Science, MIT</i> and Omar Khwaja, MD, PhD, <i>Director Rett Syndrome Program, Children's Hospital Boston</i>	IEP Professional panel discussion: Your Real-Life IEPs (90 min)	Nutrition and Growth – Gail Seche, <i>Nutritionist, Rett Syndrome Clinic, Oakland Children's Hospital, CA</i>	Transition to Adulthood and Community Programs (90 min) - Donald Freedman, <i>Rosenberg, Freedman & Goldstein LLP</i> and Alan K. White <i>Director of Residential Alternatives TILL, Inc.</i>
	2:45pm		How to Search Out and Critically Read Research Articles - Kate Barnes, BSc, and Heather O'Leary, BSc, <i>Research Coordinators, Rett Syndrome Program, Department of Neurology, Children's Hospital Boston</i>		To Sleep, Perchance to Dream: Sleep Disorders in Rett Syndrome - Judy Barrish, RN, <i>Blue Bird Rett Center Baylor College of</i>	Clinical Features and Current Research: CDKL5 and Atypical Rett Syndrome – David Frame, PharmD, <i>IFCR</i>
						Strollathon: the IRSF signature fundraiser

					<i>Medicine</i>		
	3:30p		<i>Refreshment Break and Exhibitor Arena</i>				
	3:45pm			Inclusion Strategies and Adapting Curriculum	Applied Behavior Analysis and the Consultation Process – <i>May Institute</i>	Dad's Panel	
	4:45pm		<i>How Do Clinical Trials Happen? An Inside Look at the IGF-1 Clinical Trial - Omar Khwaja, MD, PhD, Director Rett Syndrome Program, Children's Hospital Boston</i>				
	5:30pm		Farewell and Closing Address				

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