



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 ****

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	Mezzanine (2 nd Floor) Level
Saturday-Sunday	9am-5pm	Exhibitor and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics, IRSF regional representatives and more	Exhibitors and IRSF	Mezzanine (2 nd Floor) Level
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	Mezzanine (2 nd Floor) Level
	12:15pm-4pm	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	Welcome Reception	Hosts: IRSF Board of Directors	Georgian Ballroom
	7pm	Welcome and Orientation Address	Paige Nues, IRSF	Georgian Ballroom
	8pm-9pm	Crackerbarrel Breakout Sessions: Conference Hopes and Expectations		
		3 yrs and under	Paige Nues	Arlington, 2 nd floor
		4 - 7 yrs	Erica Robertson, Carole Cushman	Berkeley, 2 nd floor
		8 – 16 yrs	Cordelia Albanese	Clarendon, 2 nd floor
		17 yrs and over	Clifford and Judy Fry	Georgian, 2 nd floor
		Grandparents	Jennifer Endres	Statler, 2 nd floor
		Rettnetters and Facebookers	Shirley Hurlburt, Cathy Merrill	Fairfield, 2 nd floor
		Spanish Speakers	Maggie Wurm	Stuart, 4 th floor
		Professionals	Evie Lynn Swan	Cambridge, 4 th floor
		CDKL5	Katheryn Elibri-Frame	St. James, 4 th floor

DAY	TIME		SESSION	SPEAKER	SESSION TYPE/LOCATION
Saturday May 28	7:15am-12:30pm		Respite Rooms Open		Lexington and Newbury, 4 th Floor
	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>
	8:30am		Parents' Experiences with Genetic Testing for Rett syndrome	Christine Delaney, MS, Genetics Counselor	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	Exhibitor Arena Open	Current State of Translational Research	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>
	10:00am		Keynote Motivational Address: "YES YOU CAN"	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, MD, PhD, <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, 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, 4th Floor
	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	Ann 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		The Importance of Therapies	Donna L. Nimec, MD, <i>Pediatric Physical Medicine & Rehabilitation Specialist, Children's Hospital Boston</i>	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</i> ,	Imperial Ballroom

				<i>Phenotyping Core, Program in Genomics, Divisions of Genetics and Endocrinology, Children's Hospital Boston</i>	<i>General Session and Live Webcast</i>
	4:20pm		Gastroenterology	Kathleen Motil, MD, PhD <i>Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	5:00pm		Well Child and Adult Care Overview	Jane Lane, BSN, RN, <i>University of Alabama and IRSF</i>	Imperial Ballroom <i>General Session and Live Webcast</i>
	5:45pm		Respite Rooms Close		Lexington and Newbury, 4th Floor
	5:45pm		<i>Dinner (on your own)</i>		
	7:30pm		Tribute Reception and Silent Auction	Hosted by IRSF	Georgian Ballroom

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

		<i>School</i>				
		ARLINGTON				
	11:15am	Researcher Panel Q&A – Drs. Horton, Percy, Neul, Wynder, and Fagiolini ARLINGTON	Making Eye Gaze Technology a Reality: The Road from Trials to Conversations - Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i> (90 minutes) STATLER	In Common: Music (Therapy) – Donna Chadwick, <i>Music Therapist, MA</i> BERKELEY	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> PLAZA BALLROOM	
	Lunch 12:30pm – 1:30pm	<i>Lunch served in IMPERIAL BALLROOM and Exhibitor Arena open (Respite Rooms closed during lunch)</i>				
		<i>Regional Representative Meeting 12:40pm – 1:30pm with Jennifer Endres and Lisa Hayden</i> PLAZA BALLROOM				
	Respite 1:30pm-6pm	Respite Rooms Open Lexington and Newbury, 4th Floor				
	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	IEP Panel Discussion: Your Real-Life IEPs (90 min) STATLER	Nutritional Management of Children with Rett Syndrome – Gail Seche, MMSc, RD, CSP, <i>Rett Syndrome Clinic, Oakland Children's Hospital, CA</i> BERKELEY	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> PLAZA BALLROOM	

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

			Boston GEORGIAN BALLROOM			
	5:30pm		Farewell and Closing Remarks – Paige Nues, <i>IRSF</i> GEORGIAN BALLROOM			
	Respite Closes 6pm		Respite Rooms Close Lexington and Newbury, 4th Floor			

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