



**** PROGRAM SUBJECT TO CHANGE ****

DAY	TIME	SESSION	SPEAKER	SESSION TYPE/LOCATION
Friday-Monday	Fri: noon-9pm Sat: 7:30a-7:30p Sun: 7:30a-5:30p Mon: 8a-noon	Registration/Help Desk Bookstore: Awareness items, educational materials. (Silent Auction tables setup Friday through Saturday Tribute Reception only)	IRSF Staff and volunteers	
Saturday-Sunday	9am-5pm	Exhibitors and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics and more	Exhibitors and IRSF staff	
	Session hours only	Respite Program		
Friday May 28	9am-noon	Open House: Pikes Peak Therapeutic Riding Center		
	Noon-9p	Registration open	IRSF Staff	
	6pm-10pm	Dinner	At your leisure	Restaurant
	7:15pm	Welcome and Orientation	Paige Nues, Director, Family Support, <i>IRSF</i>	
		Welcome Address	Mickie McCool, Conference Planning Committee, <i>Parent</i>	
	8pm	Crackerbarrels: Hopes and Expectations	Session Facilitators	
		3 yrs and under		
		4 - 7 yrs		
		8 – 16 yrs		
		17 yrs and over		
		Grandparents		
		Rettnetters and Facebookers		
		CDKL5/Atypical Rett		
		Professionals		
Saturday May 29	6:30a-10:30a	Breakfast	At your leisure	Restaurant
	8a	Rett Syndrome 101	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Birmingham Civitan</i>	

			<i>International Research Center</i>	
	8:30a	Genetics 101	Steve Skinner, M.D., <i>Director Clinical Genetics Services, Greenwood Genetic Center</i>	
	9am	Keynote: The Power of the Powerless	Susan Zimmerman, author <i>Keeping Katherine</i>	
	9:45a	What's Going Right in the Brain	Aleksandra Djukic, M.D., Ph.D. <i>Director, Rett Syndrome Center, Albert Einstein College of Medicine at Montefiore</i>	
	10:10a	Apraxia and Communication	Linda Burkhart, <i>Simplified Technology</i>	
	10:55a	Enhancing Communication: Regulating Sensory Input and Supporting Ease of Access	Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>	
	11:40a	An Integrated Model of Communication and Literacy Instruction for Students with Rett Syndrome	Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>	
	1:15pm	General Health and Wellness	Jane Lane, RN, <i>University of Alabama Birmingham Rett Center and IRSF</i>	
	1:40pm	Neurology	Daniel G. Glaze, M.D. <i>Professor, Departments of Pediatrics and Neurology Baylor College of Medicine Medical Director, The Blue Bird Circle Rett Center Chief, The Rett Clinic, Texas Children's Hospital Chief, Texas Children's Hospital Sleep Clinic</i>	
	2:15pm	GI and Nutrition	Kathleen Motil, M.D., Ph.D. <i>Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH</i>	
	2:45pm	Orthopedics and Scoliosis	John Killian, MD, <i>Orthopedics for Kids</i>	
	3:15pm	Importance of Therapies	Aloysia Schwabe, M.D., <i>Physical Medicine and Rehabilitation, Blue Bird Rett Center, BCM, TCH</i>	
	4pm	Research and Clinical Trials	Tony Horton, PhD, <i>IRSF</i> and Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i>	
	5pm	Importance of Raising Awareness and Funds: Research to Reality Campaign and a \$1M Dollar Match	Steve Bajardi, Executive Director, <i>IRSF</i>	

	6p-10p	Dinner	At your leisure	Restaurant
	7:30p	Tribute Reception and Auction	Hosted by IRSF	
Sunday May 30	6:30am-10:30am	Breakfast	At your leisure	Restaurant
	8am - noon	Partner-Assisted Scanning with PODD Communication Books: Strategies for Children who have Rett Syndrome	Linda Burkhart, <i>Simplified Technology</i>	Workshop Ampitheater
	8am	PT/OT	Mike Binet, PT and Margaret Spring, OT, <i>Children's Hospital Denver</i>	
		The Maturing Woman with Rett Syndrome: From Puberty to Menopause	Jane Lane, BSN, RN, <i>University of Alabama Birmingham Rett Center and IRSF</i>	
		The Enriched Environment: A Model for Conversation with Schools and Others	Dr. Mary Jones, <i>Director, Katie's Clinic for Rett Syndrome, Oakland Children's Hospital & Research Institute</i>	
		Clinical Features and Current Research: CDKL5 and Atypical Rett Syndrome	Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i> and Dr. Katheryn Elibri Frame, <i>president of the International Foundation for CDKL5 Research (IFCR)</i>	
	9am	Getting Started Visual Supports and Book Reading. Who? What? How? and When?	Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>	
		Would Counseling Help?	Robert Furey, Ph.D.	
		Cognitive and IEP assessment tools 101	Dr. Terry Katz, <i>University of CO School of Medicine</i>	
		Nutritional Management of Children with Rett Syndrome	Marilyn Stevenson, RD, CSP and Margaret Spring, OT, <i>Children's Hospital Denver</i>	
		Crackerbarrel: School Bus Doesn't Come Anymore	<i>Facilitator</i>	
	10am	Climbing the "Eye Gaze Technology" Mountain: Steps for Conducting Successful Trials	Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital & Research Institute</i>	
		PT/OT	Mike Binet, PT and Margaret Spring, OT, <i>Children's Hospital Denver</i>	
		Adapting the Regular Education Curriculum	Mick Ross, MS and Diane Ross, MS, LCPC, <i>Educators and Parents</i>	
		Fundraising: A "How-To" Workshop	Jennifer Endres, <i>IRSF</i>	
		Nutritional Management of	Marilyn Stevenson, RD, CSP,	

		Children with Rett Syndrome	<i>Children's Hospital Denver</i>	
	11:10a	Sibling Panel	<i>Facilitated</i>	
	11:50a	Dad's Panel	<i>Facilitated</i>	
	<i>11am-2pm</i>	<i>Lunch</i>	<i>At your leisure</i>	<i>Restaurant</i>
	1:30pm	Creating Her Future Care Plan	Mary Ann Ehler, <i>Protected Tomorrows</i>	
		Communication Goals for the IEP	Linda Burkhart, <i>Simplified Technology</i>	
		Fundraising: A "How-To" Workshop	Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>	
		The Transition to Adulthood and Community Programs	Laura Marshall, M.A., <i>University of Colorado at Colorado Springs</i>	
		Implementing Effective Inclusive Practices	Robin Brewer, <i>University of Northern Colorado</i>	
	2:30p	Fostering Friendships	Diane Ross, MS, LCPC, <i>Educator, Therapist and Parent</i>	
		Hippotherapy	Nancy Beers, Program Director and Amanda Delizzio, OT, <i>Pikes Peak Therapeutic Riding Center</i>	
		Getting Started Visual Supports and Book Reading. Who? What? How? and When?	Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>	
		Climbing the "Eye Gaze Technology" Mountain: Steps for Conducting Successful Trials	Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>	
		Research Q&A	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Birmingham Civitan International Research Center</i> and Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i>	
	3:30pm	Break		
	4pm	Creating Her Future Care Plan	Mary Ann Ehler, <i>Protected Tomorrows</i>	
		Art Therapy	Karla Trapp, <i>Art Alchemy</i>	
		Becoming a Reader: Literacy Strategies from an Integrated Model of Communication Instruction.	Pati King-deBaun, M.S. CCC-SLP, <i>Creative Communicating</i>	
		Recreational Possibilities for Your Child with Rett Syndrome	Beth Fox, Operations Manager, <i>National Sports Center for the Disabled (NSCD)</i>	
		Writing SMART IEP Goals	Terry Wise, MA Special Education and Administration	
	5pm	Successful Integration of an	Judy Lariviere, M.Ed., OTR/L,	

		Eye-Controlled Communication Device into Conversations at Home, School, and in the Community	<i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>	
		Would Counseling Help?	Robert Furey, Ph.D.	
		Fundraising: A "How-To" Workshop	Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>	
		Writing SMART IEP Goals	Terry Wise, MA Special Education and Administration	
		Implementing Effective Inclusive Practices	Robin Brewer, <i>University of Northern Colorado</i>	
	6:15p	Closing Remarks	Paige Nues, Director, Family Support, <i>IRSF</i>	
	8pm	"Silent Angels" Movie Night		
Monday May 31	9am	Crackerbarrels: Learnings and Takeaways		
		Groupings by region: East, South, Midwest, Rocky Mountain, West	<i>Facilitated</i>	
	Noon	Registration/Help Desk Bookstore and close		