



**** PROGRAM SUBJECT TO CHANGE ****
ALL SESSION TIMES ARE MOUNTAIN TIME ZONE

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	IRSF Staff and volunteers	Promenade Level Foyer
Friday-Monday	Fri: 5p-9p Sat: 7:30a-7:30p Sun: 7:30a-5:30p Mon: 8a-noon	Bookstore: Awareness items, educational materials	IRSF Staff and volunteers	Boardroom
Saturday-Sunday	9am-5pm	Exhibitors and Information Booths: Assistive technology, adaptive equipment, fundraising, clinics and more	Exhibitors and IRSF staff	Promenade Level Foyer area
	Session hours only	Respite Program		Shoshoni and Manitou
Friday May 28	9am-noon	Barn Tour: Pikes Peak Therapeutic Riding Center	See Concierge desk for map and details	
	Noon-9p	Registration open	IRSF Staff	
	6pm-10pm	<i>Dinner</i>	<i>At your leisure</i>	<i>Mountain View Restaurant</i>
	7pm	Welcome and Orientation	Paige Nues, Director, Family Support, <i>IRSF</i>	Colorado Ballroom
		Welcome Address	Mickie McCool, Conference Planning Committee, <i>Parent</i>	Colorado Ballroom
	8pm	Crackerbarrels: Hopes and Expectations		
		3 yrs and under	Katie Guernsey and Joey Razzano	White River I
		4 - 7 yrs	Emilie Rabke and Deberah Patterson	White River II
		8 – 16 yrs	Cordelia Albanese and Shannon Stoiber	Cheyenne I
		17 yrs and over	Clifford and Judy Fry	Cheyenne II
		Grandparents	Diane Ross and Jennifer	Executive Press

26th Annual Conference Program - IRSF
 "Ain't No Mountain High Enough"
 May 28-31, 2010

Cheyenne Mountain Resort, Colorado Springs, Colorado
www.rett syndrome.org

			Endres	Room/Amphitheatre
		Rettnetters and Facebookers	Shirley Hurlburt	Comanche
		CDKL5/Atypical Rett	Katheryn Elibri Frame	Ute
		Professionals	Will Rabke	Kiowa
Saturday May 29	6:30a- 10:00a	<i>Breakfast</i>	<i>At your leisure</i>	<i>Mountain View Restaurant</i>
	8a	Rett Syndrome 101	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Birmingham Civitan International Research Center</i>	Colorado Ballroom
	8:30a	Genetics 101	Steve Skinner, MD, <i>Director Clinical Genetics Services, Greenwood Genetic Center</i>	Colorado Ballroom
	9am	Keynote: The Power of the Powerless	Susan Zimmermann, author <i>Keeping Katherine</i>	Colorado Ballroom
	9:30a	<i>Break</i>		<i>Foyers</i>
	9:45a	What's Going Right in the Brain	Aleksandra Djukic, MD, PhD <i>Director, Rett Syndrome Center, Albert Einstein College of Medicine at Montefiore</i>	Colorado Ballroom
	10:10a	Apraxia and Communication	Linda Burkhart, <i>Simplified Technology</i>	Colorado Ballroom
	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>	Colorado Ballroom
	11:40a	An Integrated Model of Communication and Literacy Instruction for Students with Rett Syndrome	Pati King-deBaun, MS CCC- SLP, <i>Creative Communicating</i>	Colorado Ballroom
	12:15pm	<i>Lunch</i>	<i>Mountain View Restaurant Hours 11am – 2pm</i>	<i>Mountain View Restaurant</i>
	1:15pm	Well Child and Adult Care Overview	Jane Lane, RN, <i>University of Alabama Birmingham Rett Center and IRSF</i>	Colorado Ballroom
	1:40pm	Neurology for Rett Syndrome	Daniel G. Glaze, MD <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>	Colorado Ballroom
	2:15pm	Gastroenterology for Rett Syndrome	Kathleen Motil, MD, PhD <i>Pediatrician and Gastroenterologist, Blue Bird Rett Center BCM, TCH</i>	Colorado Ballroom
	2:45pm	Orthopedics and Scoliosis	John Killian, MD, <i>Orthopedics</i>	Colorado Ballroom

			<i>for Kids</i>	
	3:15pm	Rehabilitation Therapeutic Interventions in Rett Syndrome	Aloysia Schwabe, MD, <i>Physical Medicine and Rehabilitation, Blue Bird Rett Center, BCM, TCH</i>	Colorado Ballroom
	3:45pm	<i>Break</i>		<i>Foyers</i>
	4pm	Research and Clinical Trials	Tony Horton, PhD, <i>IRSF</i> and Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i>	Colorado Ballroom
	5pm	Importance of Raising Awareness and Funds: <i>Research to Reality</i> Campaign and a \$1M Dollar Match	Steve Bajardi, Executive Director, <i>IRSF</i>	Colorado Ballroom
	6p-10p	<i>Dinner</i>	<i>At your leisure</i>	<i>Mountain View Restaurant</i>
	7:30p	Tribute Reception and Auction	Hosted by IRSF	Centennial Ballroom (Main Lodge Entry Level)
Sunday May 30	6:30am-10:00am	<i>Breakfast</i>	<i>At your leisure</i>	<i>Mountain View Restaurant</i>
	8am - noon	<i>Partner-Assisted Scanning with PODD Communication Books: Strategies for Children who have Rett Syndrome</i>	Linda Burkhart, <i>Simplified Technology</i>	<i>Workshop Executive Press Room/Amphitheatre</i>
	8am	The Enriched Environment: A Model for Conversation with Schools and Others	Mary Jones, MD, <i>Director, Katie's Clinic for Rett Syndrome, Oakland Children's Hospital & Research Institute</i>	White River I
		PT/OT	Mike Binet, PT and Margaret Spring, OT, <i>Children's Hospital Denver</i>	Cheyenne II
		The Maturing Woman with Rett Syndrome: From Puberty to Menopause	Jane Lane, BSN, RN, <i>University of Alabama Birmingham Rett Center and IRSF</i>	Cheyenne I
		Clinical Features and Current Research: CDKL5 and Atypical Rett Syndrome	Jeffrey Neul, MD, PhD, <i>Baylor College of Medicine</i> and Dr. Kathryn Elibri Frame, <i>president of the International Foundation for CDKL5 Research (IFCR)</i>	Colorado Ballroom I
	9am	Getting Started Visual Supports and Book Reading. Who? What? How? and When?	Pati King-deBaun, MS CCC-SLP, <i>Creative Communicating</i>	White River II
		Would Counseling Help?	Robert Furey, PhD	Cheyenne II
		Cognitive and IEP	Dr. Terry Katz, <i>University of CO</i>	White River I

		assessment tools 101	<i>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>	Colorado Ballroom I
		Roundtable Discussion: Once She's Grown Up and Out of School	Clifford and Judy Fry	Cheyenne II
	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>	White River I
		PT/OT	Mike Binet, PT and Margaret Spring, OT, <i>Children's Hospital Denver</i>	Cheyenne II
		Accessing the General Education Curriculum	Mick Ross, MS and Diane Ross, MS, LCPC, <i>Educators and Parents</i>	Cheyenne I
		Fundraising: A "How-To" Workshop	Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>	Colorado Ballroom I
		Nutritional Management of Children with Rett Syndrome	Marilyn Stevenson, RD, CSP, <i>Children's Hospital Denver</i>	White River II
	11:10a	Sibling Panel	Nakisha Whittington	Colorado Ballroom I
	11:50a	Dads' Panel	Jeff Huisinigh	Colorado Ballroom I
	12:30pm	<i>Lunch</i>	<i>Mountain View Restaurant Hours 11am – 2pm</i>	<i>Mountain View Restaurant</i>
	1:30pm	Your Journey Through an Eight Step Special Needs Planning Program	Mary Anne Ehlert, <i>Protected Tomorrows</i>	White River II
		Writing Goals and Objectives for Authentic Communication	Linda Burkhart, <i>Simplified Technology</i>	Executive Press Room/Amphitheatre
		Fundraising: A "How-To" Workshop	Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>	Colorado Ballroom I
		The Transition to Adulthood and Community Programs	Laura Marshall, MA, <i>University of Colorado at Colorado Springs</i>	Cheyenne II
		Implementing Effective Inclusive Practices	Robin Brewer, <i>University of Northern Colorado</i>	White River II
	2:30p	Fostering Friendships: Toddlers to Teens	Diane Ross, MS, LCPC, <i>Educator, Therapist and Parent</i>	Cheyenne I
		Hippotherapy	Nancy Beers, Program Director and Amanda Delizzio, OT, <i>Pikes Peak Therapeutic Riding Center</i>	Cheyenne II
		Getting Started Visual Supports and Book Reading. Who? What? How? and When?	Pati King-deBaun, MS CCC-SLP, <i>Creative Communicating</i>	White River II
		Climbing the "Eye Gaze Technology" Mountain: Steps	Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett</i>	White River I

		for Conducting Successful Trials	<i>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>	Colorado Ballroom I
	3:30pm	Break		
	4pm	Your Journey Through an Eight Step Special Needs Planning Program	Mary Anne Ehlert, <i>Protected Tomorrows</i>	White River I
		Art Therapy and Rett Syndrome	Karla Trapp, <i>Art Alchemy</i>	Colorado Ballroom I
		Becoming a Reader: Literacy Strategies from an Integrated Model of Communication Instruction.	Pati King-deBaun, MS CCC-SLP, <i>Creative Communicating</i>	White River II
		Recreational Possibilities for Your Child with Rett Syndrome	Beth Fox, Operations Manager, <i>National Sports Center for the Disabled (NSCD)</i>	Cheyenne I
		Writing SMART IEP Goals	Terry Wise, MA Special Education and Administration	Cheyenne II
	5pm	Successful Integration of an Eye-Controlled Communication Device into Conversations at Home, School, and in the Community	Judy Lariviere, M.Ed., OTR/L, <i>Communication Specialist, Rett Clinic, Oakland Children's Hospital</i>	White River I
		Would Counseling Help?	Robert Furey, PhD	Cheyenne I
		1:1 Consults with the IRSF Fundraising Team (<i>signups taken at the IRSF Fundraising Exhibitor booth</i>)	Jennifer Endres, Family Resource Manager, <i>IRSF</i> and Jenni Grammer, Special Events Program Manager, <i>IRSF</i>	Colorado Ballroom I
		Writing SMART IEP Goals	Terry Wise, MA Special Education and Administration	Cheyenne II
		Implementing Effective Inclusive Practices	Robin Brewer, <i>University of Northern Colorado</i>	White River II
	6:15p	Closing Remarks	Paige Nues, Director, Family Support, <i>IRSF</i>	Colorado Ballroom I
	8pm	"Silent Angels" Movie Night		Executive Press Room/Amphitheatre
Monday May 31	9am	Crackerbarrels: Learnings and Takeaways		
		Groupings by region: East, South, Midwest, Rocky Mountain, West	Leslie Greenfield, Deborah Jennings, Shannon Stoiber, Heidi and Rhett Burnham, David and Melissa Luntz	White River

	Noon	Registration/Help Desk Bookstore and close		Foyer and Boardroom
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