

# CELEBRATING THE TORCH WITHIN

IRSF 25<sup>TH</sup> ANNUAL EDUCATION  
& AWARENESS CONFERENCE

**PROGRAM SUBJECT TO CHANGE**

DAY	TIME	SESSION	SPEAKER	SESSION TYPE
<b>Friday-Monday</b>	Fri: noon-9pm Sat: 7:30a-7:30p Sun: 7:30a-6p Mon: 8a-noon	Registration/Help Desk  Bookstore: Educational materials and awareness items (tshirts, etc)	IRSF Staff and volunteers	
<b>Saturday-Sunday</b>	9am-5pm	Exhibitors and Information Booths: Assistive technology, adapted equipment, Aurora Recording, fundraising, clinics and more	Exhibitors and IRSF staff	
<b>Friday May 22</b>	Noon-9p	Registration open	IRSF Staff	
	6p	Dinner	Riverside Hearth Restaurant open 6pm-10pm	
	7:15pm	Welcome orientation and IRSF Update	Paige Nues, <i>IRSF</i>	General
	8pm	Crackerbarrels: Hopes and Expectations	Session Facilitators	Concurrent
<b>Saturday May 23</b>	6:30a	Breakfast	Riverside Hearth Restaurant open 6:30a-10:30a	
	7:45a-8:30a	Rett Syndrome 101	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center</i>	General
	9am	Keynote Address	Martha Slay, <i>Fighter Mom</i>	General
	9:30am	Principals of Communication and Dynamic Assessments	Linda Burkhart, <i>Simplified Technology</i>	General
	10:30am	Break		
	10:45am	Importance of Communication and Some Practical How-To's	Susan Norwell, MS Ed	General
	11:30am	Literacy	Judy Lariviere	General
	noon	Lunch	Riverside Hearth Restaurant	

25<sup>th</sup> Annual Conference Program - IRSF  
"Celebrating the Torch Within"

May 22-25, 2009

Lansdowne Resort and Spa in Leesburg, Virginia

[www.rettsyndrome.org](http://www.rettsyndrome.org)

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			open 11am–2pm	
	1:30p-2:30p	Communication: In High School and Adulthood	Susan Norwell, MS Ed	Concurrent A
		Communication: Advanced technology, specifically eye-gaze	Judy Lariviere	Concurrent A
		Measurable IEP Goals	Irene Moore	Concurrent A
		Integration: A Case Study	Jennifer Ethridge and Mickie McCool	Concurrent A
	1:30p – 4p	<i>Communication: Pragmatically Organized Dynamic Displays (PODD)</i>	<i>Linda Burkhart, Simplified Technology</i>	<i>Workshop</i>
	2:40p	Measurable IEP Goals	Irene Moore, <i>PEATC</i>	Concurrent B
		Creating Her Future Care Plan	Mary Anne Ehlert, <i>Protected Tomorrows</i>	Concurrent B
		Integration: A Case Study	Jennifer Ethridge, <i>Educator</i> Mickie McCool, <i>Parent</i>	Concurrent B
		Fundraising and Advocacy How To's	Jennifer Endres, <i>IRSF</i>	Concurrent B
	3:40p	Break		
	4pm-5pm	How to Talk to Schools So Schools Will Listen (and Listen So Schools Will Talk)	Irene Moore, <i>PEATC</i>	Concurrent C
		Communication: In High School and Adulthood	Susan Norwell, MS Ed	Concurrent C
		Communication: Advanced technology, specifically eye-gaze	Judy Lariviere	Concurrent C
		Creating Her Future Care Plan	Mary Anne Ehlert, <i>Protected Tomorrows</i>	Concurrent C
	5pm	Dads Panel	Panelists	General
	5:30pm	Siblings Panel	Panelists	General
	6p	Dinner	Riverside Hearth Restaurant open for dinner 6p-10p	
	7:30p	Tribute Reception and Auction		Ballroom A/B
<b>Sunday May 24</b>	6:30a	Breakfast	Riverside Hearth Restaurant open breakfast 6:30a-10:30a	
	7:45a-8:15a	Genetics of Rett Syndrome	Carolyn Schanen, MD, PhD <i>Nemours</i>	General
	8:30a	Understanding the Signs and Symptoms of Rett Syndrome in Your Child	Sakku Bai Naidu, MD, and Dr Genila Bibat <i>Rett Syndrome Research Project and Dept of Neurology at the Kennedy Krieger Institute (KKI) at Johns Hopkins University</i>	General

	9:15am	Epilepsy and Seizure Management	tba	General
	9:35am	Orthopedics	Paul Sponseller, MD, <i>KKI</i>	General
	10a	Break		
	10:15am	Gastroenterology	Carmen Cuffari, MD, <i>KKI</i>	General
	10:35am	Endocrinology: Bone Health	Jay Shapiro, MD, <i>KKI</i>	General
	10:50am	General Health: Flu, Colds, and Immunizations	Jane Lane, RN, <i>UAB and IRSF</i>	General
	11am	Neuropsychology	Cynthia Salorio, MD, <i>KKI</i>	General
	11:15am	Behaviors in Rett syndrome	Elaine Tierney, MD, <i>KKI</i>	General
	11:40a	Physician Q&As	All – Breakout Meeting Rooms	Concurrent
	12:30p	Lunch	Riverside Hearth Restaurant open for lunch 11am – 2pm	
	1:30p	Physical Therapy	Jennifer Swain, PT, <i>KKI</i>	Concurrent A
		Sleep	Judy Barrish, RN, <i>Blue Bird Rett Center Baylor College of Medicine</i>	Concurrent A
		Adolescence and Womanhood	Jane Lane, RN, <i>UAB and IRSF</i>	Concurrent A
		Therapeutic Riding (Hippotherapy) and Aquatherapy	Jill Wagner, <i>Progressive Peds</i>	Concurrent A
		Music Therapy	Sara Jourdan, <i>Simple Changes</i>	Concurrent A
	2:30p	Physical Therapy	Jennifer Swain, PT, <i>KKI</i>	Concurrent B
		Sleep	Judy Barrish, RN, <i>Blue Bird Rett Center Baylor College of Medicine</i>	Concurrent B
		Adolescence and Womanhood	Jane Lane, RN, <i>UAB and IRSF</i>	Concurrent B
		Therapeutic Riding (Hippotherapy) and Aquatherapy	Jill Wagner, <i>Progressive Peds</i>	Concurrent B
		Music Therapy	Sara Jourdan, <i>Simple Changes</i>	Concurrent B
	3:30p	Break		
	3:45p	<i>Science and Research Presentations and Discussion</i>		General
		World Congress on Rett syndrome: Biomedical and Clinical Research overview	Carolyn Schanen, MD, PhD <i>Nemours</i>	General
		What is Stem Cell Research?	Tony Horton, PhD, <i>IRSF</i>	General
		NIH RDCRN Natural History Study	Alan Percy, MD, <i>Director UAB Rett Center at the University of Alabama Civitan International Research Center</i>	General
		Rett Syndrome Classification: ICD-10 and RettSearch	Walter Kaufmann, MD, <i>RettSearch and KKI</i>	General

	4:15p	Research Panel Q&A	All	General
	4:45p	Closing Remarks	Paige Nues, <i>IRSF</i>	General
	5:15p	Fundraising and Advocacy How To Workshop	Jennifer Endres, <i>IRSF</i>	Breakout Room
	7:30p	"Silent Angels" Movie Night	All are welcome	Amphitheater
<b>Monday May 25</b>	9am	Crackerbarrels: Learnings and Takeaways		
	Noon	Bookstore and Registration/Help Desk close		