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CELEBRATING
THE TORCH
WITHIN

May
22-25

IRSF 25TH ANNUAL RETT SYNDROME
EDUCATION & AWARENESS CONFERENCE

Lansdowne Resort & Spa
Leesburg, Virginia

PROGRAM WILL BE UPDATED WEEKLY

DAY	TIME	SESSION	SPEAKER
Friday-Monday		Registration/Help Desk	IRSF Staff
Friday-Monday		Bookstore: Educational materials and awareness items (DVDs, tshirts, etc)	IRSF Staff
Saturday-Sunday		Exhibitors and Information Booths: Assistive technology, adapted equipment, Aurora Recording, fundraising, clinics and more	
Friday May 22	Noon	Registration opens	
		Welcome orientation	Paige Nues
		<i>Dinner – Riverside Hearth</i>	
		Crackerbarrels: Hopes and Expectations – breakouts by child's age group; Grandparents; Siblings; Rettnet	Session facilitators
		Evening entertainment	
Saturday May 23		Rett Syndrome 101	Alan Percy, MD, Director Sparks Clinic Rett Center, UAB
		Keynote Address	
		Communication sessions: Importance of, How-to's, Partner Assisted Communication and PODD, In High School and Adulthood, Literacy	Susan Norwell, MS Ed Linda Burkhart, Simplified Technology and more!
		Education planning sessions: IEP and the law; Integration/Mainstreaming: "How to" case study	Jennifer Ethridge-Integration, Educator with Mickie and Dave McCool – parent case study
		Life Planning: Special Needs Trusts, Powers of Attorney, Guardianship,	

		Placement, Estate Planning, Adult Day Programs	
		Family Issues: Dad's and Sibling panels	
		Tribute Reception and Auction	Coffee and Dessert
Sunday May 24		Genetics of Rett Syndrome	Carolyn Schanen, MD, PhD, <i>Nemours Biomedical Research, Alfred DuPont Hospital for Children</i>
		Medical Management: Understanding the Signs and Symptoms of Rett Syndrome in Your Child, Epilepsy, Orthopedics, Gastroenterology, Endocrinology: Bone Health, Pulmonary, Psychiatry, Womanhood, Sleep	<i>Specialists from the Kennedy Krieger Institute at Johns Hopkins University School of Medicine:</i> SakkuBai Naidu, MD, <i>Director Rett Syndrome Research Project and Dept of Neurology</i> Paul Sponseller, MD, <i>Orthopedics</i> C Cuffari, MD, <i>Gastroenterology</i> Jay Shapiro, MD, <i>Endocrinology</i> Elaine Tierney, MD, <i>Psychiatry</i> Cynthia Salorio, MD, <i>Neuropsychiatry</i> Jane Lane, RN, <i>UAB and IRSF</i> and more
		Therapies: PT, OT, Music, Therapeutic Riding	Jennifer Swain, PT, <i>KKI</i> And more
		Research: Biomedical, Clinical, World Congress highlights – lectures and panel discussions	Tony Horton, PhD, <i>IRSF</i> Carolyn Schanen, MD, PhD, <i>Nemours</i> Walter Kaufmann, MD, <i>RettSearch and KKI</i> Alan Percy, MD, <i>UAB</i> and more
		Closing Remarks	
Monday May 25		Crackerbarrels: Learnings and Takeaways– breakouts by child's age group; Grandparents; Siblings; Rettnet	Session facilitators
	Noon	Bookstore and Registration/Help Desk close	IRSF Staff