

“Together We Are Better”

Chicago 2008

Conference Schedule

Day	Time	Topic	Speaker	Session
Friday May 23	Opens at noon	Registration		
	5:30p – 7:45p	Evening Welcome Reception and Keynote		
	8p – 9p	Crackerbarrels	Kids under 7 yrs	Concurrent
			Kids 8-16 yrs	Concurrent
			Kids 17+ yrs	Concurrent
			Professionals (Teachers, therapists, etc)	Concurrent
			Rettnetters	Concurrent
Saturday May 24	7a-8:30a	Continental Breakfast		
	7:30a – 8:15a	Rett Syndrome 101	Alan Percy, M.D.	General
	8:30a-9a	Motivational Keynote	Bill Keegan, Author <b><u>Closure: The Untold Story of the Ground Zero Recovery Mission</u></b> and Parent	General
	9:15a-9:45a	Neurology	Daniel Glaze, M.D.	General
	9:45a-10:15a	Nutrition/GI	Kathleen Motil, M.D., Ph.D.	General
	10:15a-10:30a	Break		
	10:30a – 11a	Importance of Therapies	Alan Percy, M.D.	General
	11a – noon	“Let’s Get Together and Communicate!”	Susan Norwell, M.S. Ed	General
	Noon -1:30p	Lunch and IRSF Updates	Kathryn Kissam/Chuck Curley	Food/bev
	1:45p – 2:45p	Neurology Q&A	Daniel Glaze, M.D.	Concurrent A
		GI Q&A	Kathleen Motil, M.D., Ph.D.	Concurrent A
		Issues of Womanhood	Jane Lane, RN, BSN	Concurrent A
		Day-to-Day Care	Judy Barrish, B.S.N., RN	Concurrent A
		Simple How To’s + Q&A of Communication	Susan Norwell, M.S. Ed	Concurrent A
	3p-4p	How Should We Spend Our Time? A functional approach to effective physical therapy goals, treatment and integration of tools and techniques at home.	Marybeth Finch, M.S., PT	Concurrent B
		Issues of Womanhood	Jane Lane, RN, BSN	Concurrent B
		Access to Communication:	Judy Lariviere, M.Ed., OTR/L	Concurrent B

		Working together makes it better!		
		Communication Devices	Susan Norwell, M.S. Ed.	Concurrent B
	4:15p – 5:15p	How Should We Spend Our Time? A functional approach to effective physical therapy goals, treatment and integration of tools and techniques at home.	Marybeth Finch, M.S., PT	Concurrent C
		Day-to-Day Care	Judy Barrish, B.S.N., RN	Concurrent C
		Literacy	Susan Norwell, M.S. Ed.	Concurrent C
		Access to Communication: Working together makes it better!	Judy Lariviere, M.Ed., OTR/L	Concurrent C
	5:15p – 6:30p	Fundraising and Media Outreach 101	Barry Rinehart/Chuck Curley/Kathryn Kissam	
	7:30p – 11pm	Socializing and Networking	Hospitality suite open – evening hours	
Sunday May 25	7:15a-8:30a	Continental Breakfast		
	8a-8:30a	Genetics101	Carolyn Schanen, M.D., Ph.D.	General
	8:45a-9:45a	Direction of Research: Translational, Therapeutic, Gene, Stem cell, etc	Carolyn Schanen, M.D., Ph.D.	General
	9:45a-10a	Break		
	10a–10:20a	Research update: Osteopenia	Kathleen Motil, M.D., Ph.D.	General
	10:20a-10:40a	Research Update: RDCRN Natural History Study	Alan Percy, M.D.	General
	10:40a-11:15a	Research review	Jeffrey Neul, M.D., Ph.D.	General
	11:15p –noon	Research Q&A panel	All researchers	general
	noon-1:30p	Lunch - sitdown		Food/bev
	1:45p – 3p	The continuum of services and the continuum of supports: The process and options for determining the best classroom placement for your daughter	Valerie Owen, Ph.D.	Concurrent A

		Adult program options: jobs, programs, sheltered workshops	Professional panel discussion	Concurrent A
		New Opportunities for Obtaining a Free Appropriate Public Education in the Least Restrictive Environment	Matt Cohen, J.D.	Concurrent A
		Planning for the Future: Gov't Benefits, Financial Planning	Steve Medlin, Financial planner and parent	Concurrent A
		Planning for the Future: Legal Issues	Sherri Schneider, founder Family Benefit Solutions	Concurrent A
	3p-3:15p	Break		
	3:15p – 4:30p	The continuum of services and the continuum of supports: The process and options for determining the best classroom placement for your daughter	Valerie Owen, Ph.D.	Concurrent B
		Adult program options: jobs, programs, sheltered workshops	Professional panel discussion	Concurrent B
		New Opportunities for Obtaining a Free Appropriate Public Education in the Least Restrictive Environment	Matt Cohen, J.D.	Concurrent B
		Planning for the Future: Govt Benefits, Guardianship, Financial Planning	Steve Medlin, Financial planner and parent	Concurrent B
		Planning for the Future: Legal Issues	Sherri Schneider, founder Family Benefit Solutions	Concurrent B
	6:30p – 11:30p	Tribute Dinner		
Monday May 26	8a – 9:30a	Continental Breakfast		General
	9a – 9:45a	Sibling Panel		General
	9:45a–10:30a	Dad's Panel		General
	10:30a	Farewell/Closing		General

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