



JOUBERT SYNDROME &
RELATED DISORDERS FOUNDATION

The faith to believe, the hope to dream, the love to see it through

Exploring Options

2011 Joubert Syndrome & Related Disorders Foundation Conference
July 13 – 16, 2011

Tuesday, July 12, 2011

6:30 -8:30pm	Registration open	JSRDF Office Biscayne Bay
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Wednesday, July 13, 2011

8:00-10:00am	Registration and Sales Table open	Tampa Bay Lobby
9:00 am – 12:00am	Playroom open *	Pensacola Bay
9:00am – 9:40 am	<u>Scientific Keynote</u>: History of Joubert syndrome Dr. Eugen Boltshauser	Tampa Bay Ballroom
9:40am-10:10 am	Genotype-phenotype correlations in JS Dr. Dan Doherty	Tampa Bay Ballroom
10:10am-10:40 am	<i>BREAK</i>	
10:40am-11:20 am	Brain imaging findings in JS Dr. Andrea Poretti	Tampa Bay Ballroom
11:20am-noon	Central Respiratory Control Abnormalities in JS Dr. Maida Chen	Tampa Bay Ballroom
noon -1:15pm	<i>LUNCH: On your own</i>	
1:15pm-2:15 pm	Abnormal Brain Development in JS Dr. Russell Ferland	Tampa Bay Ballroom
2:15pm-3:15 pm	Clinical kidney and liver disease Dr. Meral Gunay-Aygun Dr. Theo Heller	Tampa Bay Ballroom
3:15 pm– 3:45 pm	A New Gene for JS Dr. Ji Eun Lee	Tampa Bay Ballroom
4:00pm -5:30pm	Registration and Sales Table Open	Tampa Bay Lobby
5:30pm -7:00pm	Opening Dinner Buffet Keynote: Mr. Rick Guidotti	Oceans Ballroom (main building)
7:30pm-8:00pm	Remembrance Ceremony ALL ARE WELCOME ☺	Tampa Bay Ballroom

Thursday, July 14, 2011

12:00 am – 9:00 pm	Playroom open*	Pensacola Bay
7:00am – 9:00 am	<i>BREAKFAST: Buffet</i>	Oceans Ballroom (main building)
8:00am--2:00pm	JSRDF BioBank	JSRDF Office Biscayne Bay
9:00am-2:00pm	Family-Investigator Meetings (check personal schedule)	Coral A & B
9:00am-11:15am	<u>WORKSHOP: Stress Management</u> Ms. Kim Walton, MSN, APRN	Tampa Bay Ballroom
10:00am-10:15am	<i>BREAK</i>	
11:30am-1:00pm	<i>LUNCH: Buffet</i>	Oceans Ballroom (main building)
1:00pm-3:00pm	<u>WORKSHOP: Anat Baniel Method</u> Ms. Jenna Stewart	Tampa Bay Ballroom
3:00- 3:15pm	<i>BREAK</i>	
3:15- 4:00pm	Eye Disease in JS Dr. Avery Weiss	Tampa Bay Ballroom
3:30pm-??	<i>Ms Stewart and Dr. Holway are available for private sessions (at your expense)</i>	Building 2 Room #205
4:00- 4:50pm	Kidney Disease Biology Dr. Friedhelm Hildebrandt	Tampa Bay Ballroom
5:00pm-6:30pm	Generating a Research Agenda for the Future Scientific Panel: Invited Participants only	Boardroom 17 th Floor
5:00pm-8:00pm	<i>DINNER: On your own</i> Consider joining us at Sweet Tomatoes for a JSRDF fundraiser!!	
8:30pm - ???	Guys Night Out – location TBA	Meet in lobby

Friday, July 15, 2011

12:00 am – 9:00 pm	Playroom open*	Pensacola Bay
7:00am – 9:00 am	<i>BREAKFAST: Buffet</i>	Oceans Ballroom
9:00am – 4:00 pm	<u>NIH Research Study: Measurements of JSRD-affected Individuals</u>	Mediterranean A (main building)
9:00am-9:55am	<u>WORKSHOP: AAC- Building Communication Through the Lifespan</u> Ms. Erin Lozott and Ms. Summer Perkins	Tampa Bay Ballroom
9:00am-10:00am	<u>SibShop: You Are Special, Too</u> (AGES 6-10years) Ms. Kim Walton, MSN, APRN	Mediterranean B (main building)
9:55am-10:05am	<i>BREAK</i>	
10:05am- 11:00am	<u>WORKSHOP: Reading and Writing with Technology</u> Tami Folks	Tampa Bay Ballroom
10:15am-11:15am	Grandparent's Social	Mediterranean C (main building)
11:00am-1:00pm	Augmentative Communication Displays and Samples Vendors available	Tampa Bay Lobby
11:30am-1:00pm	<i>LUNCH: Buffet</i>	Oceans Ballroom
1:00pm-3:30pm	<u>WORKSHOP: Cranial Sacral Therapy and Behaviour</u> Dr. Cathy Holway	Tampa Bay Ballroom
2:00pm-2:15pm	<i>BREAK</i>	
3:45pm-4:30pm	JSRDF Membership: General Meeting ALL WELCOME ☺	Tampa Bay Ballroom
4:30pm-??	<i>Ms Stewart and Dr. Holway are available for private sessions (at your expense)</i>	Florida Bay 3
4:40pm-???	<i>DINNER: On your own</i>	

Saturday, July 16, 2011

12:00 am – 7:00 pm	Playroom open*	Pensacola Bay
7:00am – 9:00 am	BREAKFAST: <i>Buffet</i>	Oceans Ballroom (main building)
9:00am-11:00am	<u>WORKSHOP: Genetic Research Update</u> Dana Knutzen, Genetic Counselor	Tampa Bay Ballroom
10:00am-10:15am	<i>BREAK</i>	
	<u>WORKSHOP: Genetic Research Update (continued)</u> Dana Knutzen, Genetic Counselor	Tampa Bay Ballroom
11:30am-1:00pm	LUNCH: <i>On your own</i>	
1:00pm-3:30pm	<u>WORKSHOP: Neurofeedback</u> Mike Cohen, Centre for Brain Training	Tampa Bay Ballroom
2:00pm-2:15pm	<i>BREAK</i>	
	<u>WORKSHOP: Neurofeedback (continued)</u> Mike Cohen, Centre for Brain Training	Tampa Bay Ballroom
3:30pm – 7:00 pm	Silent Auction open	Oceans Ballroom (main building)
4:30 – 9:00 pm	Closing Gala & Silent Auction <i>Don't forget to wear your Crazy Hat!</i>	Oceans Ballroom (main building)

*Children are welcome to use the playroom at any time of the day or night, under adequate adult supervision.
The JSRDF cannot be held responsible for any child(ren) left unattended.