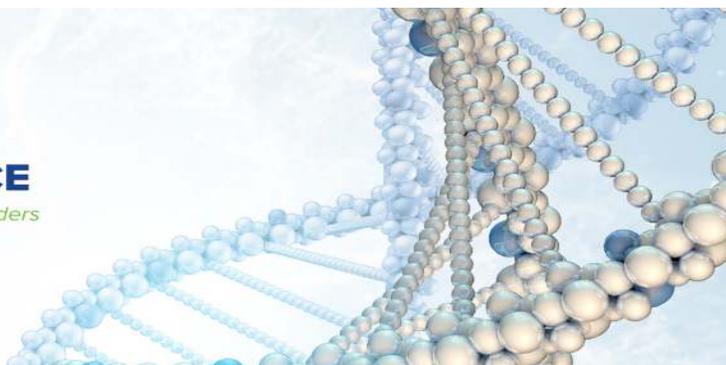


2022 INTERNATIONAL METABOLIC CONFERENCE

For Families Affected by Fatty Acid Oxidation Disorders



July 22, 2022

	Presentation	Speaker(s)	Teen Time	Children Activities
4:00 PM	Welcome / Opening	Kira Mann, CEO MitoAction	Teen Room Open	Children Room Open
4:15 PM	Community Update: "Fatty Acid Oxidation Treatments: Growing Options"	Dr. Jerry Vockley, UPMC	Introduction: Tasia and Alex: Icebreaker games Hear Your Song Intro Share story	Introduction: Silly Songs w/ Mr. Harry on guitar "Get to know you" Activities "My Special Body" storytime Hear Your Song Intro
5:15 PM	The Journey of a Study	Beth & Luke Folcher, FAOD Family		
5:30 PM	Ultragenyx Community Updates	Laura Pisani-Betancourt, MD	*Teen Room open	*Free time activities
6:00 PM	Meet and Greet Reception		*Teen Room open	

July 23, 2022

	Presentation	Speakers	Teen Time	Children Activities
7:00 AM	Breakfast	*****		
7:45 AM	Morning Welcome	Kira Mann, CEO MitoAction		Play Room Opens (Children Drop Off)
8:00 AM	Caregiver/Young Adult Panel Discussion	Caregivers/Young Adults		Morning Activity: Scavenger Hunt / Lego Challenges / Hear Your Song Sessions
8:45 AM	Understanding the Effect of FAODs on the Liver and Immune System	Dr. Eric Goetzman, UPMC	Let's Talk about Food- Creatively!: Dr. Melanie Gillingham and Marie Norris	"Everybody has something" and Understanding G-tubes
9:30 AM	When it is Not Your FAOD: getting medical support when there is a dual diagnosis or complex care	Dr. Michael Decker, UPMC	Let's Talk about Food- Cont.	*Free time activities/ Hear Your Song
10:15 AM	Morning Break	*****		FAOD BINGO
10:30 AM	How to Approach Sports and Exercise with an FAOD	Dr. Melanie Gillingham, OHSU		*Free time activities/Hear Your Song Sessions

11:15 AM	Roundtable Discussions: *Disease Specific *Ultragenyx Questions *Reneo Questions	*Disease Specific: Family Led Moderators *Ultragenyx (teen room) *Reneo	Teen Roundtable (Located: Main Session space with Dr. Vockley)	Minute to Win it!/ Hear Your Song Sessions
12:00 PM	Lunch	*****	Teen Room Closed for Lunch	Play Room Closed for Lunch
1:00 PM	HITT Exercises and Stretching for all FAODs	Dr. Pamela Tucker, PT, DPT Institute of Human Performance	*Join the main session!	*Join the main session!
1:45 PM	"How to Talk the Talk while You Walk the Walk": How to explain FAODs to people/professionals who don't know about FAODs.	Dr. Mark Korson, VMP Genetics	*Teens meet in the children's room to help with cell activity!	"Inside the Human Body" with Ms. Frizzle and Learning about our Cells!
3:00 PM	Inborn Errors of Metabolism and Puberty	Dr. Jerry Vockley, UPMC		Afternoon Celebration/Movie Time
3:45 PM	Afternoon Break	*****	Teen room open	(Celebration Continued...)
4:00 PM	Clinicians' Panel Discussion	Dr. Melanie Gillingham, UPMC Dr. Eric Goetzman, UPMC Dr. Pamela Tucker, IHP Dr. Michael Decker, UPMC		(Celebration Continued...)
6:00 PM	Group Photo/ Dinner Break	*****	Teen room open	
8:00 PM	Social Hour	*****		

July 24, 2022

		Speakers	Teen Time	Children Activities
7:00 AM	Breakfast			
7:45 AM	Morning Welcome	Kira Mann, CEO MitoAction		Play Room Opens (Children Drop Off)
8:00 AM	Introducing Food and Mealtime & How to Watch Fasting without Making it Weird	Marie Norris, U of U	Teen Room Open	Coloring Time/Make your Own Puzzle/Board game fun/ "Hear Your Song Sessions"
8:45 AM	Pandemic Lessons Learned from the Mitochondrial Disease Community	Dr. Peter McGuire, NIH	Game room open for Teens/ Hear Your Song	Create Your Own Pillowcase!
9:30 AM	Transitioning from Pediatric to Adult Care	Dr. Georgianne Arnold, UPMC		Make New Friends but Keep the Old: friendship bracelets/ freetime activities/ "Hear Your Song Sessions"

10:15 AM	Round Table Discussions: Navigating School:504/IEPs Sibling Support Traveling/Nutrition Tips Dad's Table	Moderators: Beth Folcher Pamela Lane, MSW, LSW, CHOA Stephanie Harry Nate Mudd and Mike Folcher	*Teens please meet in Children's room to play games and participate in Panel Discussion	Little Big Conversations: Game time with the teams, followed by a "circle time" panel discussion
11:15 AM	Checkout / Lunch	*****	Teen room closed	Playroom Closed
12:15 PM	Roadmap to Self-Care: Supporting Families and Caregivers of Children with Chronic Illnesses	Pamela Lane, MSW, LCSW, CHOA		FAOD Bingo
1:00 PM	Clinicians' Panel Discussion	Dr. Jerry Vockley, UPM Marie Norris, U of U Dr. Peter McGuire, NIH Dr. Georgianne Arnold, UPMC Pamela Lane, MSW, LCSW, CHOA		*Free time activities
2:00 PM	Closing	Kira Mann, CEO MitoAction		