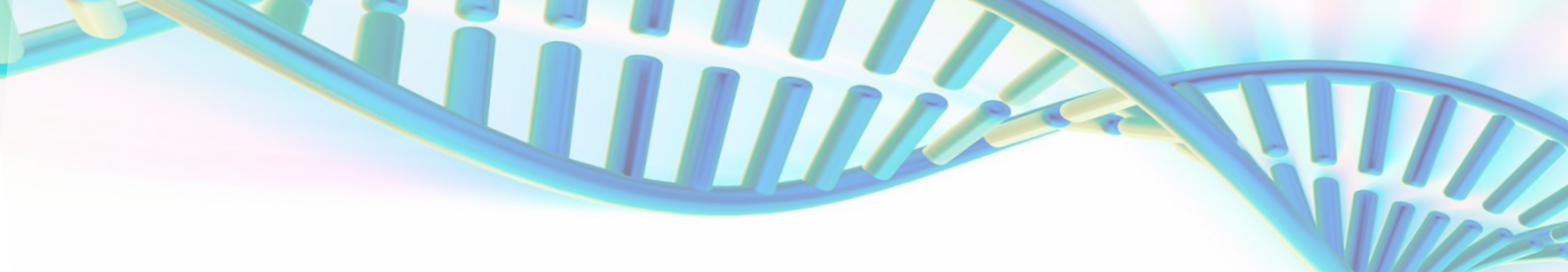




PROGRAM AGENDA

	Auditorium	Lounge	
All times are EST		Roundtable/Panel Discussions	Kids' Activities
Friday, July 24			
1:00 PM	Welcome Speaker: Kira Mann		
1:10 PM	Inform & FAOD Community Update Speaker: Dr. Jerry Vockley		Ice Breaker - Connections
2:00 PM	Infection, Immunity and FAOD Speaker: Dr. Peter McGuire		
3:00 PM	Preparing for a New Normal in Covid-19 and Being Your Best Advocate Speaker: Annette Hines, Esq.		FAOD Bingo
4:00 PM	Ultragenyx's Commitment to the LC-FAOD Patient Community Speaker: Tobin Chettiath, PharmD, MBA		
5:00 PM	MitoAction Mobile - Taking Control of Your Care Speaker: David Williams, CEO, Karen		
6:00 PM		Virtual Cocktail Hour LCHAD/VLCAD Group Discussion MCAD Group Discussion CPT 1/2 Group Discussion Other Diagnosis Group Discussion	
Saturday, July 25			
9:00 AM	Sick Day & Emergency Protocols: Helpful and Potentially Harmful Speaker: Dr. Mark Korson		Ice Breaker - Connections
10:00 AM	Newborn Screening in FAOD Speaker: Dr. Georgianne Arnold	I Have a Rare Disease: Teens & Young Adults Discussion Speaker: Dr. Jerry Vockley	
11:00 AM	Pre-Clinical Treatment Studies in FAOD Speaker: Dr. Jerry Vockley	Preparing for College: Young Adult Panel Discussion Speakers: Ali Hamadeh, Jordan Kaylic, Kylie Newman, Alex Salser, Tasia Rechisky, John Sullivan	Word Find
12:00 PM	Break	Q&A With Reneo Pharmaceuticals Speaker: Wendy Johnson, COO Q&A with Dr. Jerry Vockley Speaker: Dr. Jerry Vockley MitoAction Mobile: Get Started Speaker: Dave Williams LCHAD/VLCAD Group Discussion MCAD Group Discussion CPT 1/2 Group Discussion Other Diagnosis Group Discussion	



	Auditorium	Lounge	
All times are EST		Roundtable/Panel Discussions	Kids' Activities
1:00 PM	Acylcarnitines: What are They and What Do They Mean Speaker: Dr. Melanie Gillingham	My Sibling Has a Rare Disease: Teens & Young Adult Discussion Speaker: Mary Summers	Cape Decorating
2:00 PM	Life Transitions from Pediatric to Adult Patients with Rare Disorders Speaker: Brittany Holmes, MSN, APRN, FNP-BC		
2:30 PM	Patient Panel: Transitioning to Young Adult Speakers: Ali Hamadeh, Jordan Kaylic, Kylie Newman, Alex Salser, Tasia Rechisky, John Sullivan		Wikki Sticks Crafting
3:00 PM	Practical Tips from the VLCAD Nutrition Guidelines and Toolkit Speakers: Mary Sowa, MS, RD, CSP, Dr. Sandy Van Calcar, PhD, RD, LD		Bookmark Craft
4:00 PM	Break	MitoAction Mobile: Get Started Speaker: Dave Williams A Conversation with Ultragenyx's Chief Medical Officer: Insight into Future LC-FAOD Research Speaker: Camille Bedrosian A Conversation with Ultragenyx's Global Metabolic Dietitian: How to Use the Newly FDA Approved Medicine Speaker: Bridget Reineking LCHAD/VLCAD Group Discussion MCAD Group Discussion CPT 1/2 Group Discussion Other Diagnosis Group Discussion	
6:00:00 PM	Magic Bracelet Screening Speakers: Stacy Goldberg, Ari Goldberg, Dr. Mark Korson, Tamika Lamison (Make a Film Foundation), Diablo Cody (Oscar Winning Writer), Jon Poll (Director)		
Sunday, July 26			
9:00 AM	Caregiver Panel Discussion Speakers: Eileen Sullivan, Sharickah Rogers, Evelyn Romano, Christy Abrams, Stephanie Harry, Jessica Gowans		
10:00 AM	Disability Benefits & Planning Speakers: Annette Hines, Esq. and Mark Worthington, Esq.		Puzzle Decorating
11:00 AM	Research & Clinical Trials Update Speakers: Dr. Jerry Vockley and Dr. Melanie Gillingham		FAOD Bingo



	Auditorium	Lounge	
All times are EST		Roundtable/Panel Discussions	Kids' Activities
12:00 PM	Break	Q&A With Dr. Jerry Vockley Speaker: Dr. Jerry Vockley Advocacy & Planning Q&A Speaker: Annette Hines, Esq., Mark Worthington, Esq. LCHAD/VLCAD Group Discussion MCAD Group Discussion CPT 1/2 Group Discussion Other Diagnosis Group Discussion	
1:00 PM	Cardiac Issues & FAOD Speaker: Kathryn Chatfield, MD, PhD		
2:00 PM	Closing Remarks Speaker: Kira Mann		