

Agenda CMD Family Conference 2011: July 22nd-24th

Friday, July 22nd 6-10 PM	Welcome Dinner		Cleanup Crew signups	
Saturday, July 23rd 8-8:30 AM	Breakfast and Registration			
8:30-8:40 AM	Welcome and Logistics		Joey Bower 2011 CMD Family Conference Lead	
8:40-9:10 AM	CMD Therapeutic Targets		Carsten Bonnemann, MD NINDS Cure CMD SMAB Chairman	
9:10-9:40 AM	Key Note Speaker: Developing Therapies for the CMDs- Perspectives from the Lab Bench		Sweta Girgenrath, PhD Boston University	
9:40-10:10 AM	CMD Clinical Trials		Anne Rutkowski, MD Cure CMD Chairman	
10:10-10:45 AM	Q &A: CMD Therapy Panel Rutkowski, Bonnemann, Girgenrath		Moderator: Eunice Kim, MBA Cure CMD Vice Chair	
10:45-11:00 AM	Break			
11:00-11:30 AM	Key Note Speaker: Developing Therapies in CMD- The BioTech Sector and Rare Disease		Jas Seehra, PhD	
11:30-12:00 AM	Getting to Clinical Trials: A Family and an Individual's Commitment		Eunice Kim Cure CMD Vice Chair	
12:00-1:00	Lunch, Group Photo			
1:00-1:15 PM	CMD Clinical Best Practices		Meganne Leach, MSN CRNP Children's National Medical Center	
1:15-1:20 PM*	Breathing in CMD: Luke Hoban's BiPAP Video		Introduction by Jim Hoban	
1:20-1:40 PM	How do we breathe and what goes wrong in CMD? Lungs, Diaphragm, Spine, Chest wall muscles		Hemant Sawnani, MD Cincinnati Childrens Hospital Medical Center	
1:40-2:15PM	Individual CMD Experiences: Tracheostomy, BiPAP, Cough Assist Panel		Moderated by Hank Mayer, MD	
2:15-2:20PM	Nutrition in CMD: The Gold Family Takes on Gtube Video		Introduction Eunice Kim	
2:20-2:45PM	Nutrition Support and Bone Health		Donna DiVito, RD, CNSD, LDN Neuromuscular Clinic Dietitian	
2:45-3:00	Break			
3:00-3:30 Breakout Session #1	Perspectives for Newly Diagnosed Families Moderator: Rutkowski/Bonnemann/ Hoban-Smith/Sklaroff- Van Hook	Nutrition and CMD: Tubes, Supplements, Dehydration and Constipation Presenter: DiVito	CMD BioBank: Purpose, Function and Link to CMDIR Presenter: Berlin	Breathing and CMD: How do we track how the lungs are doing? Presenter: Mayer, Sawnani

3:30-3:45 PM	Break			
3:45-4:15 Breakout Session #2	CMD Care Guidelines- What questions do you have that are not answered? Moderator:Bonnemann/Hoban-Smith/Sklaroff-Van Hook/Leach	Cognitively Disabled CMD Experiences: Presenter: Abby Huntington	CMD BioBank: Purpose, Function and Link to CMDIR Moderated: Berlin	Transition to Adulthood in Pulmonary Care: Presenter: Mayer, Sawnani
4:15-4:30	Break			
4:30-4:45	Mental Health: Coping with CMD Abby Huntington, OTR, LMFT			
4:45-5:45	Teen Breakout Session Matt Purinton	Coping with CMD: Caregivers Abby Huntington		
6:00-7:30	Dinner Cleanup Crew Sign Ups			
	<p>*1:15-3:00 PM Special Session for Clinicians:</p> <ul style="list-style-type: none"> • 1:15-2:00 PM Diagnostic Overview for Clinicians, Bonnemann • 2:00-3:00 PM Using the Ultrasound to Diagnose CMD, Bonnemann 			
Sunday, July 24th				
8-10AM	CMD Family Breakfast: Hilton Buffet Style			
9-9:15 AM	Prevention Genetics: Paving the Way to Genetic Diagnosis in CMD Tom Winder, PhD,			
9:15-9:30AM	Connecting the Community to the Cause Jackie Nelson, Cure CMD Advocacy Lead			