



Children's Hospital of Philadelphia
Division of Neurology
 34th Street and Civic Center Boulevard
 Philadelphia, PA 19104
 Telephone: 215-590-1719



Cure CMD
www.curecmd.org
 PO Box 701
 Olathet, KS 66051
 Telephone: 866-400-3626

CMD Family and Affected Person Conference Agenda August 15 - 16, 2009

Saturday, August 15th

Time	Presentation			Presenter
8:00-8:30	Breakfast			
8:30-8:35	Welcome			Dr. Anne Rutkowski
8:35-8:45	Introduction			Dr. Carsten Bonnemann
8:45-9:15	Dystroglycanopathy & Merosin Deficient CMD			Dr. Kathy Mathews
9:15-9:45	Colalgen VI, LMNA, SEPN1 - CMD, Merosin Positive/undiagnosed CMD			Dr. Carsten Bonnemann
9:45-10:15am	Break			
10:20 – 12:00pm	Modarator: Carsten Bonnemann			
	Review of July conference: "Therapeutic Targets in CMD" Short and mid term targets for therapies in the various CMD			Dr. Anne Rutkowski Dr. Carsten Bonnemann
	Research in action: Recent research using Laminin 111			Dr. Dean Burkin
	Longterm targets: An outlook			Dr. Carsten Bonnemann
12:00- 1:15	Lunch			
1:15 – 2:00	What does it take to get CMDs to clinical trial readiness? The Role of Natural Disease Progression Studies			Dr. Anne Rutkowski Dr. Kathy Mathews
2:00-3:30	Pulmonary care Hank Mayer, MD	Cardiac care Beth Kaufman, MD	GI, Nutrition, Bone Health Johanthan Frick, MD Maria Hanna, MS, RD, LDN Robin Meyer, MS, RD	Orthopedic Care David Spiegel, MD
	Break			

Breakout Sessions

3:45-4:45	Siblings Childlife	Teens Alex Mejat Simon Cantos Margaret Mele	Meet the Doctor Dr. Bonnemann Dr. Mathews Dr. Sparks	Equipment Vendors Accessible Vans & Mobility Easy Walking Prospect Designs Permobile	OT/PT Alan Glanzman, PT, DPT, PCS, ATP Jean Flickinger, PT, PCS Tim Estilow, OTR/L, ATP Michelle Barr-Hsia, MS, OTR/L, ATP
	4:45-5:45	Dads Shawn Rudman Joe Pinkleman	Adults with CMD Mike Newton		
6:30-8:00		Dinner			



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Sunday, August 16

8:00-8:30	Breakfast	
8:30-8:45	Cure CMD Road Map and Advocacy	Rich Cloud
8:45-8:50	CMD Registry	Dr. Anne Rutkowski
8:50-9:05	Disability Advocacy	Margaret Mele
9:00-9:20	MDA: Advocacy and Research	Annie Kennedy
9:20-9:40	NIH: Advocacy and Research	Dr. John Porter
9:40-9:45	Myopathies.info	Dr. Alex Mejat
9:45 -10:00	Break	
10:00-10:45	Panel discussion: Advocacy, Research and Clinical Trials	Rich Cloud, Annie Kennedy, Dr. Porter, Dr. Bonnemann, Dr. Burkin, Dr. Mathews, Dr. Sparks, Margaret Mele

Breakout Sessions

10:45-12:15	Meet the Doctor Dr. Bonnemann Dr. Mathews Dr. Sparks	OT/PT: Alan Glanzman, PT, DPT, PCS, ATP Jean Flickinger, PT, PCS Tim Estilow, OTR/L, ATP Michelle Barr-Hsia, MS, OTR/L, ATP	Transition for Independent Living (auditorium) Annie Kennedy	Equipment Vendors Accessible Vans & Mobility Easy Walking Prospect Designs Permobile
12:15-12:30	Conference Summary			
12:30	Bag Lunch			
1:00-2:00	Informal Cure CMD Advocacy Meeting: What can you do?			