

PPMD's 2016 Connect Conference – DRAFT AGENDA

(SUBJECT TO CHANGE)

Saturday, June 25th

11:00 AM	Registration Opens
12:00-5:00	CDCC Coordinator's Meeting
12:00-5:00	PAAC Meeting
6:00-9:00	Teens and Adults living with Duchenne Poolside Social (hosted by PPMD's Adult Advisory Committee)

Sunday, June 26th

7:45 AM	Registration Opens
8:30-9:30	Breakfast
9:00-10:30	Newly Diagnosed families (private meeting)
9:00-12:00	Teens and Adults with Duchenne
10:00-5:30	Vendor Resource Fair is open in the Atrium
10:30-12:15	Panel: Navigating Duchenne A Parent to Parent panel discussion for Newly Diagnosed families and all who want to attend regarding putting the pieces in place to navigate the world of Duchenne (finding care, school, family balance, etc.)
12:00	Lunch available in the atrium
1:00-1:30	Conference Welcome Address
1:30-1:40	Interpreting Duchenne: Session Introduction
1:40-2:00	Genetics: complicated, complex and critical to understand
2:00-2:20	Modifiers: what changes Duchenne
2:20-2:50	Data makes a difference <ul style="list-style-type: none"> • DuchenneConnect • PCORI
2:50-3:00	Q&A and break
3:00-5:00	Kids Track Kids Track kicks off
3:00	New Tools for Clinical Trials pt. 1
3:00-4:00	Panel Discussion
4:00-4:10	Break
4:10-5:15	New Tools for Clinical Trials pt. 2
4:10-4:30	Learning from Placebo Data
4:30-5:15	Collecting and Interpreting Data
5:20-6:00	Keynote Address
6:00-8:00	Welcome Reception

Monday, June 27th

7:30 AM	Registration Opens
8:00	Connect Conference .1K to end Duchenne <ul style="list-style-type: none"> • Registration and Bib pick up • Mimosas and training tips • Invited Speakers
8:00-3:00	Vendor Resource Fair open
8:30-9:30	Breakfast

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9:30-12:30	Kids Track Today's kids track activities will be broken up into 3 age groups and will include lunch. Meet at the Coral room for drop off and pick up.
9:15	Trials in Duchenne: Session Introduction
9:20-9:40	Sarepta
9:40-10:00	BMS
10:00-10:20	Pfizer
10:20-10:40	Santhera
10:40-11:00	Capricor
11:00-11:20	Summit
11:20-11:40	Q&A / Break
11:45-12:45	Panel: Clinical Trials – next steps
12:45	Lunch
12:45-2:40	Duchenne Poster Session Please enjoy lunch while visiting the numerous poster presenters. Posters will explore various new research and clinical programs occurring in the Duchenne space.
2:30-4:30	Kids Track
2:40	More Current Clinical Trials in Duchenne: Session Introduction
2:40-3:00	Marathon
3:00-3:20	Reveragen
3:20-3:40	Catabasis
3:40-4:00	Q&A / Break
4:00-4:20	Cardero
4:20-4:40	Mitobridge
4:40-5:00	Fibrogen
5:00-5:15	Q&A
5:15-6:30	Panel: the PAAC men

Tuesday, June 28th

8:00	Breakfast		
8:00	Intro to Session		
8:05-8:25	Summary of In-Depth Care meetings hosted and convened by PPMD <ul style="list-style-type: none">- Pulmonary Meeting- Cardiac Meeting- Bone Health		
8:30-8:45	Platform Presentation from Winning Poster – Clinical		
8:45-9:00	Platform Presentation from Winning Poster – Research		
9:00-12:00	Care Breakouts		
9:00-12:00	<u>Care Breakout Early Childhood/Childhood Room- Crystal A</u>	<u>Care Breakout Tween and Teens Room-Crystal CDE</u>	<u>Care Breakout Young Adults Room- Crystal B</u>
	9:00 - 9:25 Steroids: doses, schedules, considerations	9:00-9:25 Steroids: doses, schedules, considerations	9:00-9:25 Steroids: doses, schedules, considerations
	9:25 - 9:50 Keeping Lungs Healthy	9:25-9:50 Staying out of the Hospital	9:25-9:50 Breathing: What are my Options?

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9:50 - 10:15 Everybody poops (but what if they don't?)	9:50-10:15 GI, GU and Nutrition	9:50-10:15 GI and GU and Nutrition
10:15 - 10:40 Caring for Little Hearts	10:15-10:40 Caring for Medium Sized Hearts	10:15-10:40 Caring for Adult Hearts
10:40 - 11:05 Managing Behaviors and Learning	10:40-11:05 Almost Grown Up!	10:40-11:05 Living Independently with Duchenne
11:05 - 11:30 Living with Duchenne	11:05-11:30 Keeping Bones Healthy	11:05-11:30 Managing Bone Health
11:30 -12:00 Nutrition and Supplements	11:30-12:00 Living With Duchenne	11:30-12:00 Making an Emergency Plan

9:00-12:00	Kids Track
12:00-12:45	Lunch
12:45-2:00	Panel: Gene Therapy and CRISPR Cas9 - Similarities and differences
2:00-2:15	Break
2:15-2:20	Robotics: Session Introduction
2:20-2:40	Solid Suit
2:40-3:00	X-Ar arm
3:00-3:20	Flexextension
3:20-3:35	Q&A
3:00-5:00	Kids Poolside Meet-Up Please note a parent or guardian must be present, this is NOT part of Kids Track.
3:35-3:40	Emerging Research and Trials: Session Introduction
3:40-4:00	Epicatechin
4:00-4:20	GSK
4:20-4:40	TBD
4:40-5:00	Q & A
5:00-6:00	Panel: Hope vs. Hype, a parent and patient discussion What it is like to be in a clinical trial, how to decide which trial is right for you, and other questions related trial participation
6:45	Cocktails
7:15	Connect Celebration

Wednesday, June 29th

8:30-10:00	Every Single One breakfast Join us for this conference wrap up and action planning seminar
10:00-12:30	Physical Therapy Workshop Exploring the benefits of PT and other interventions