



Dystroglycanopathy Patient and Family Conference 2021

Friday, July 16th: Welcome Reception

6:00 PM - 8:00 PM	Welcome Reception and Social Hour	Light Appetizers, Cash Bar, and Free Soda	Exhibit Hall (In-Person Only)
-------------------	-----------------------------------	---	-------------------------------

(Note: All times are in Central Daylight Time)

Virtual Talks (Available During and After the Conference)

All Talks Open for Viewing at 8:00 AM on Friday, July 16th	Pharmaceutical Industry Presentations	Various Industry Representatives	Online: Whova Video Gallery
	Advocacy Organization Videos	Various Advocacy Representatives	Online: Whova Video Gallery
	NIH Presentation	Glen Nuckolls, PhD	Online: Whova Video Gallery
	Caregiver Self-Care	Marcia Gilbert, LISW	Online: Whova Video Gallery
	Mental Health for Teens and Young Adults	Krista Kohl, PhD	Online: Whova Video Gallery
	Chair Yoga	Kim Blackwell, MPT, RYT	Online: Whova Video Gallery
	LGMD21/R9 Diagnostic Odyssey	Lauren Coffey	Online: Whova Video Gallery
	Introduction to Dystroglycanopathies	Kathy Mathews, MD	Online: Whova Video Gallery
	University of Iowa Foundation	Britt Bergquist	Online: Whova Video Gallery

We are grateful for the support we've received for the 2021 conference. Thank you!



National Institute of Neurological Disorders and Stroke





Dystroglycanopathy Patient and Family Conference 2021

Saturday, July 17th: Conference Sessions

8:30 AM	Registration and Light Breakfast	Fruit, Granola Bars, and Coffee/Tea	Exhibit Hall Foyer (In-Person Only)
9:30 AM	Welcome and Study Overview	Kathy Mathews, MD	Exhibit Hall and Streamed in Whova
10:00 AM	Dystroglycanopathy: Not Just a Muscle Disease	Steve Moore, MD, PhD	Exhibit Hall and Streamed in Whova
10:45 AM	BREAK		
11:00 AM	Cardiology Concerns in Dystroglycanopathy	Ferhaan Ahmad, MD, PhD	Exhibit Hall and Streamed in Whova
11:45	Non-FKRP: Ask the Doctor	Kathy Mathews, MD	Oakdale Room and Streamed in Whova
	FKRP: Ask the Scientist	Kevin Campbell, PhD and Steve Moore, MD, PhD	Exhibit Hall and Streamed in Whova
12:30	LUNCH		
1:30	FKRP: Ask the Doctor	Kathy Mathews, MD	Exhibit Hall and Streamed in Whova
	Non-FKRP: Ask the Scientist	Kevin Campbell, PhD and Steve Moore, MD, PhD	Oakdale Room and Streamed in Whova
2:15	Introduction to Clinical Trials and Therapeutics with Industry Q&A	Kathy Mathews, MD, and Industry Representatives	Exhibit Hall and Streamed in Whova
3:15	BREAK		
3:30	Pressure Makes Diamonds: Emerging Brilliantly from Life and Finding Joy	Melissa Grove, MS, LPC	Exhibit Hall and Streamed in Whova
4:15	Wrap-Up	Carrie Stephan, MA, BSN, RN	Exhibit Hall and Streamed in Whova
4:30	Group Photos	All In-Person Attendees	Exhibit Hall and Streamed in Whova
4:45	Social Hour for Teens and Tweens	Moderators: Christina Trout, MSN, RN and Krista Kohl, PhD	Whova (Online Only)
	In-Person Social Hour	Light Appetizers, Cash Bar, and Free Soda	Exhibit Hall (In-Person Only)

(Note: All times are in Central Daylight Time)