

Weekend Agenda

2022 RYR-1 Family Conference

Hyatt Regency Pittsburgh International Airport
Pittsburgh, PA, USA • July 22 – July 24 2022



FRIDAY, July 22

Registration: 9:00 am – 4:00 pm

	Topic	Kids Club	Teen Club
4:00 pm	4:00 pm – 6:00 pm Meet & Greet Come Connect With Old Friends & Meet New Friends <i>Refreshments will be Served</i>	4:00 pm – 6:30 pm Kids Club: Arts & Crafts, Activities & Games Registered Kids ages 4 –12	4:00 pm – 6:30 pm Teen Club: Arts & Crafts, Activities & Games Registered Teens ages 13 – 17
4:15 pm			
4:30 pm			
4:45 pm			
5:00 pm			
5:15 pm	6:00 pm – 6:30 pm Welcome & Introduction to The RYR-1 Foundation Michael F. Goldberg, MD, MPH, President, The RYR-1 Foundation		
5:30 pm			
5:45 pm			
6:00 pm			
6:15 pm			
6:30 pm	6:30 pm – 7:30 pm Hors D'oeuvres & Cash Bar	6:30 pm – 7:30 pm Kids Club: Dinner	6:30 pm – 7:30 pm Teen Club: Dinner
6:45 pm			
7:00 pm			
7:15 pm			
7:30 pm			
7:45 pm	7:30 pm – 9:30 pm My RYR-1 Journey Share Your Experiences with RYR-1 with Other Members of the RYR-1 Community (Open Mic)	7:30 pm – 9:30 pm Kids Club: Movie & Popcorn Night Registered Kids ages 4 – 12	7:30 pm – 9:30 pm Kids Club: Movie & Popcorn Night Registered Teens ages 13 – 17
8:00 pm			
8:15 pm			
8:30 pm			
8:45 pm			
9:00 pm			
9:15 pm			
9:30 pm			

Conference Categories

Overview of RYR-1-Related Diseases:

- Saturday 8:00 am – 10:00 am
- Saturday 10:45 am – 11:15 am

Rhabdomyolysis and Malignant Hyperthermia (MH):

- Saturday 11:15 am – 12:15 pm
(Voermans and Riazi talk and Q&A)

Family Planning:

- Saturday 11:15 am – 12:15 pm
(Medne and Gruber talk and Q&A)

Rycals:

- Saturday 1:30 pm – 3:00 pm

Pulmonary Complications:

- Sunday 8:00 am – 10:00 am

Physical Therapy:

- Sunday 8:00 am – 12:30 pm (group sessions)
- Sunday 10:30 am – 11:30 am

School Services:

- Sunday 11:30 am – 12:30 pm





SATURDAY, July 23

Registration: 7:00 am – 10:00 am

	Topic	Concurrent Topic	Kids Club	Teen Club
7:00 am	7:00 am – 8:00 am Continental Breakfast	7:00 am – 8:00 am Keeping Your Bones Beautiful in RYR-1: What to Look Out For & Q&A Continental Breakfast with Dr. Sponseller Paul Sponseller, MD (Virtual)	7:00 am – 8:00 am Kids Club: Continental Breakfast	7:00 am – 8:00 am Teen Club: Continental Breakfast
7:15 am				
7:30 am				
7:45 am				
8:00 am	8:00 am – 8:30 am Introduction to RYR-1-Related Diseases Carsten Bönnemann, MD		8:00 am – 10:00 am Kids Club: Arts & Crafts, Activities & Games Registered Kids ages 4 –12	8:00 am – 10:00 pm Teen Club: Arts & Crafts, Activities & Games Registered Teens ages 13 – 17
8:15 am				
8:30 am				
8:45 am				
9:00 am	8:30 am – 9:00 am The Role of Calcium and the Ryanodine Receptor in RYR-1-Related Diseases Robert T. Dirksen, PhD			
9:15 am				
9:30 am				
9:45 am				
10:00 am	9:30 am – 10:00 am How to Interpret Your RYR-1 Genetic Testing Results Angela Gruber, PhD			
10:30 am				
10:45 am				
11:00 am				
11:15 am	10:45 am – 11:15 am Q&A Session - Overview of RYR-1-Related Diseases Carsten Bönnemann, MD • Robert T. Dirksen, PhD Livija Medne, MS, LCGC • Angela Gruber, PhD		10:45 am – 12:15 pm Kids Club: Arts & Crafts, Activities & Games Registered Kids ages 4 –12	10:45 am – 12:15 pm Teen Club: Arts & Crafts, Activities & Games Registered Teens ages 13 – 17
11:30 am				
11:45 am				
12:00 pm				
12:15 pm	11:15 am – 11:45 am Rhabdomyolysis, Heat/Exertional Related Disease, and Malignant Hyperthermia Nicol Voermans, MD, PhD			
12:30 pm				
12:45 pm				
1:00 pm				
1:15 pm	11:45 am – 12:15 pm Q&A Session - Overview of Rhabdomyolysis & MH Nicol Voermans, MD, PhD • Sheila Riazzi, MSc, MD, FRCPC			
1:30 pm				
1:45 pm				
2:00 pm				
2:15 pm	1:00 pm – 1:30 pm Lunch		1:30 pm – 3:45 pm Kids Club: Arts & Crafts, Activities & Games Registered Kids ages 4 –12	1:30 pm – 3:45 pm Teen Club: Arts & Crafts, Activities & Games Registered Teens ages 13 – 17
2:30 pm				
2:45 pm				
3:00 pm				
3:15 pm	1:30 pm – 1:50 pm Introduction to Rycals & the Ryanodine Receptor Andrew Marks, MD			
3:30 pm				
3:45 pm				
4:00 pm				
4:15 pm	1:50 pm – 2:10 pm Update on Rycal Clinical Trial at NIH Payam Mohassel, MD			
4:30 pm				
4:45 pm				
5:00 pm				
5:15 pm	2:10 pm – 3:00 pm Q&A Session: Rycals Andrew Marks, MD • Payam Mohassel, MD			
5:30 pm				
5:45 pm				
6:00 pm				
6:15 pm	3:00 pm – 3:30 pm Psychological Concerns for Individuals with a Disability Aviva Gaskill, PhD			
6:30 pm				
6:45 pm				
7:00 pm				
7:30 pm	3:30 pm – 3:45 pm Break			
7:45 pm				
8:00 pm				
	3:45 pm – 4:45 pm Discussing and Sharing Strategies for Dealing with the Challenges of Living with an RYR-1-Related Disease or Living with an Individual Affected by an RYR-1-Related Disease Group Sessions		3:45 pm – 4:45 pm Kids Club: Physical Therapy Session (Make a TikTok video) Mina Jain, PT, DSc, PCS • Michael Brucker, PT, DPT, CSCS	3:45 pm – 4:45 pm Teen Club: Physical Therapy Session (Make a TikTok video) Mina Jain, PT, DSc, PCS • Michael Brucker, PT, DPT, CSCS
	Group A: Individuals Affected by RYR-1-Related Diseases			
	Group B: Parents/Grandparents of Individuals Affected by RYR-1-Related Diseases			
	Group C: Spouses and Partners of Individuals Affected by RYR-1-Related Diseases			
	4:45 pm – 6:00 pm Break			



SUNDAY, July 24

	Topic	Concurrent Topic	Kids Club	Teen Club			
7:00 am	<div>7:00 am – 8:00 am</div> <div>Continental Breakfast</div>						
7:15 am							
7:30 am							
7:45 am							
8:00 am	<div>8:00 am – 8:45 am</div> <div>Pulmonary Complications of RYR-1-Related Diseases</div> <div>Oscar Hank Mayer, MD</div>	<div>8:00 am – 8:30 am</div> <div>8:30 am – 9:00 am</div> <div>9:00 am – 9:30 am</div> <div>9:30 am – 10:00 am</div> <div>Physical Therapy Sessions</div> <div>(maximum capacity: 10 people per group)</div> <div>Pre-Registration Required</div> <div>Michael Brucker, PT, DPT, CSCS</div>	<div>8:00 am – 12:30 pm</div> <div>Kids Club: Arts & Crafts, Activities & Games</div> <div>Registered Kids ages 4 –12</div>	<div>8:00 am – 12:30 pm</div> <div>Teen Club: Arts & Crafts, Activities & Games</div> <div>Registered Teens ages 13 – 17</div>			
8:15 am							
8:30 am							
8:45 am	<div>8:45 am – 9:30 am</div> <div>Sleep-Related Breathing Issues in RYR-1-Related Diseases</div> <div>Jennifer Newitt, MD</div>						
9:00 am							
9:15 am							
9:30 am	<div>9:30 am – 10:00 am</div> <div>Q&A Session - Pulmonary Complications of RYR-1-Related Diseases</div> <div>Oscar Hank Mayer, MD • Jennifer Newitt, MD</div>						
9:45 am							
10:00 am							
10:15 am	<div>10:00 am – 10:30 am</div> <div>Break</div>						
10:30 am							
10:45 am	<div>10:30 am – 11:00 am</div> <div>Physical Therapy Services for Individuals with a Disability</div> <div>Mina Jain, PT, DSc, PCS</div>	<div>10:30 am – 11:00 am</div> <div>RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle</div> <div>Heinz Jungbluth, MD, PhD</div>					
11:00 am	<div>11:00 am – 11:30 am</div> <div>Q&A Session - PT</div> <div>Mina Jain, PT, DSc, PCS • Michael Brucker, PT, DPT, CSCS</div>	<div>11:00 am – 11:30 am</div> <div>Q&A Session - RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle</div> <div>Heinz Jungbluth, MD, PhD</div>					
11:15 am							
11:30 am	<div>11:30 am – 12:00 pm</div> <div>School Services for Individuals with a Disability</div> <div>Tammy L. Hughes, PhD</div>	<div>11:30 am – 12:00 pm</div> <div>12:00 pm – 12:30 pm</div> <div>Physical Therapy Sessions</div> <div>(maximum capacity: 10 people per group)</div> <div>Pre-Registration Required</div> <div>Michael Brucker, PT, DPT, CSCS</div>					
11:45 pm							
12:00 pm	<div>12:00 pm – 12:30 pm</div> <div>Q&A Session - IEPs</div> <div>Tammy L. Hughes, PhD</div>						
12:15 pm							
12:30 pm	<div>12:30 pm – 1:30 pm</div> <div>Lunch & Closing Remarks</div>						
12:45 pm							
1:00 pm							
1:15 pm							
1:30 pm	<div>1:30 pm – 2:30 pm</div> <div>Final Socializing</div>						
1:45 pm							
2:00 pm							
2:15 pm							
2:30 pm							