

Weekend Agenda

2022 RYR-1 International Family Conference

Conference Categories

Overview of RYR-1-Related Diseases:

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

Family Planning:

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

Pulmonary Complications:

- Sunday 8:00 am – 10:00 am

School Services:

- Sunday 11:30 am – 12:30 pm

Rhabdomyolysis and Malignant Hyperthermia (MH):

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

Rycals:

- Saturday 1:30 pm – 3:00 pm
















Physical Therapy:

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



Friday, July 22, 2022


9:00 am – 4:30 pm	Registration Glenn Foyer		
4:00 pm – 6:00 pm	Meet & Greet Come Connect With Old Friends & Meet New Friends <i>Refreshments will be served</i> Allegheny ABC	4:00 pm – 6:30 pm	Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB
6:00 pm – 7:00 pm	Hors D'oeuvres & Cash Bar Regency Ballroom AB, Allegheny ABC, & Foyer		Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
7:00 pm – 7:30 pm	Welcome & Introduction to The RYR-1 Foundation Michael F. Goldberg, MD, MPH, President, The RYR-1 Foundation Regency Ballroom	6:00 pm – 7:00 pm	Kids Club & Teen Club: Dinner Regency Ballroom & Foyer
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) Regency Ballroom	7:00 pm – 9:00 pm	Kids Club: Movie & Popcorn Night Registered Kids ages 4 – 12 years old Lindbergh AB
			Teen Club: Movie & Popcorn Night Registered Teens ages 13 – 17 years old Wright AB

7:00 am – 10:00 am	Registration Glenn Foyer		
7:00 am – 8:00 am	Continental Breakfast Regency Ballroom & Foyer	Keeping Your Bones Beautiful in RYR-1: What to Look Out For & Q&A Continental Breakfast with Dr. Sponseller Paul Sponseller, MD (Virtual) Allegheny ABC	7:00 am – 8:00 am Kids Club & Teen Club: Continental Breakfast Regency Ballroom & Foyer
8:00 am – 8:30 am	Introduction to RYR-1-Related Diseases Carsten Bönnemann, MD, habil Regency Ballroom		8:00 am – 10:00 am Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
8:30 am – 9:00 am	The Role of Calcium and the Ryanodine Receptor in RYR-1-Related Diseases Robert T. Dirksen, PhD Regency Ballroom		
9:00 am – 9:30 am	Genetics 101 Livija Medne, MS, LCGC Regency Ballroom		
9:30 am – 10:00 am	How to Interpret Your RYR-1 Genetic Testing Results Angela Gruber, PhD Regency Ballroom		
10:00 am – 10:45 am	Group Photo/Break (wear your conference t-shirt!)               		
10:45 am – 11:15 am	Q&A Session - Overview of RYR-1-Related Diseases Carsten Bönnemann, MD, habil • Robert T. Dirksen, PhD • Livija Medne, MS, LCGC • Angela Gruber, PhD Regency Ballroom		10:45 am – 12:15 pm Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
11:15 am – 11:45 am	Rhabdomyolysis, Heat/Exertional Related Disease, and Malignant Hyperthermia Nicol Voermans, MD, PhD Regency Ballroom	Family Planning Livija Medne, MS, LCGC Angela Gruber, PhD Allegheny ABC	



11:45 am – 12:15 pm	Q&A Session - Rhabdomyolysis, Heat/Exertional Related Disease, and Malignant Hyperthermia Nicol Voermans, MD, PhD Sheila Riazi, MSc, MD, FRCPC Regency Ballroom	Q&A Session - Overview of Family Planning Livija Medne, MS, LCGC Angela Gruber, PhD Allegheny ABC	10:45 am – 12:15 pm	Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB	Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
12:15 pm – 1:00 pm	Lunch Regency Ballroom & Foyer		12:15 pm – 1:00pm	Kids Club & Teen Club: Lunch Regency Ballroom & Foyer	
1:00 pm – 1:30 pm	Break	Roundtable Discussion on Menopause & RYR-1-Related Diseases Susan Hamilton, PhD Nicol Voermans, MD, PhD Allegheny ABC	1:00 pm – 1:30 pm	Break	
1:30 pm – 1:50 pm	Introduction to Rycals & the Ryanodine Receptor Andrew Marks, MD Regency Ballroom		1:30 pm – 3:45 pm	Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB	Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
1:50 pm – 2:10 pm	Update on Rycal Clinical Trial at NIH Payam Mohassel, MD Regency Ballroom				
2:10 pm – 3:00 pm	Q&A Session: Rycals Andrew Marks, MD • Payam Mohassel, MD Regency Ballroom				
3:00 pm – 3:30 pm	Psychological Concerns for Individuals with a Disability Aviva Gaskill, PhD Regency Ballroom				
3:30 pm – 3:45 pm	Break		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 Lindbergh AB	Teen Club: Physical Therapy Session (Make a TikTok video) Mina Jain, PT, DSc, PCS Michael Brucker, PT, DPT, CSCS Wright AB
3:45 pm – 4:45 pm Group Sessions	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 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 Regency Ballroom				

4:45 pm – 6:00 pm	Break				
6:00 pm – 7:30 pm	Dinner & Cash Bar Regency Ballroom	6:30 pm – 7:30 pm	Kids Club & Teen Club: Dinner Regency Ballroom		
7:30 pm – 8:00 pm	Award Ceremony Regency Ballroom	7:30 pm – 8:00 pm	<table border="1"> <tr> <td data-bbox="1849 362 2486 628">Kids Club: Movie & Ice Cream Sundae Bar Registered Kids ages 4 – 12 years old Lindbergh AB</td> <td data-bbox="2486 362 3108 628">Teen Club: Movie & Ice Cream Sundae Bar Registered Teens ages 13 – 17 years old Wright AB</td> </tr> </table>	Kids Club: Movie & Ice Cream Sundae Bar Registered Kids ages 4 – 12 years old Lindbergh AB	Teen Club: Movie & Ice Cream Sundae Bar Registered Teens ages 13 – 17 years old Wright AB
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7:00 am – 8:00 am	Continental Breakfast Regency Ballroom & Foyer		7:00 am – 8:00 am	Kids Club & Teen Club: Continental Breakfast Regency Ballroom & Foyer	
8:00 am – 8:45 am	Pulmonary Complications of RYR-1-Related Diseases Oscar Hank Mayer, MD Regency Ballroom	<p>8:00 am – 8:30 am 8:30 am – 9:00 am 9:00 am – 9:30 am 9:30 am – 10:00 am</p> <p>PT Sessions (Groups of 10 people) Michael Brucker, PT, DPT, CSCS Brandon Karabinos <i>Pre-Registration Required</i> Allegheny ABC</p>  <p>Please scan the QR code to sign up or visit www.signupgenius.com/go/10c0e48aaa82da0f8c70-physical.</p>	8:00 am – 12:30 pm	Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB	Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB
8:45 am – 9:30 am	Sleep-Related Breathing Issues in RYR-1-Related Diseases Jennifer Newitt, MD Regency Ballroom				
9:30 am – 10:00 am	Q&A Session - Pulmonary Complications of RYR-1-Related Diseases Oscar Hank Mayer, MD Jennifer Newitt, MD Regency Ballroom				
10:00 am – 10:30 am	Break				
10:30 am – 11:00 am	Physical Therapy Services for Individuals with a Disability Mina Jain, PT, DSc, PCS Regency Ballroom	RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle Heinz Jungbluth, MD, PhD Allegheny ABC			



10:30 am – 11:00 am	Q&A Session - Physical Therapy Services for Individuals with a Disability Mina Jain, PT, DSc, PCS Michael Brucker, PT, DPT, CSCS Regency Ballroom	Q&A Session - RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle Heinz Jungbluth, MD, PhD Allegheny ABC	8:00 am – 12:30 pm	Kids Club: Arts & Crafts, Movies, Activities, & Games Registered Kids ages 4 – 12 years old Lindbergh AB	Teen Club: Arts & Crafts, Movies, Activities, & Games Registered Teens ages 13 – 17 years old Wright AB						
11:30 am – 12:00 pm	School Services for Individuals with a Disability Tammy L. Hughes, PhD Regency Ballroom	11:30 am – 12:00 pm 12:00 pm – 12:30 pm PT Sessions (Groups of 10 people) Michael Brucker, PT, DPT, CSCS Brandon Karabinos <i>Pre-Registration Required</i> Allegheny ABC  Please scan the QR code to sign up or visit www.signupgenius.com/go/10c0e48aaa82da0f8c70-physical .									
12:00 pm – 12:30 pm	Q&A Session - School Services for Individuals with a Disability Tammy L. Hughes, PhD Regency Ballroom										
12:30 pm – 1:30 pm						Lunch & Closing Remarks Regency Ballroom					
1:30 pm – 2:30 pm						Final Socializing					