

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Thursday, July 24, 2025

Time	Open Hours: Registration, Lounges, and Kids' Club
12:00 pm - 9:00 pm	Registration Desk
12:00 pm - 9:00 pm	The Social Hub: Adult Lounge Experience
12:00 pm - 4:00 pm 5:00 pm - 9:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)
12:00 pm - 4:00 pm 5:00 pm - 9:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)
Time	Event
5:00 pm - 9:00 pm	Happy Hour Starts Now: Bar Open (Cash Bar)
5:30 pm - 7:00 pm	Mix & Mingle: Welcome Cocktail Soirée
7:00 pm - 9:00 pm	Strength In Numbers: Welcome & Family Introductions

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Friday, July 25, 2025

Open Hours: Registration, Lounges, and Kids' Club

7:30 am - 5:30 pm	Registration Desk	
8:00 am - 5:00 pm	The Social Hub: Adult Lounge Experience Open	
9:00 am - 12:00 pm 1:00 pm - 5:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)	
9:00 am - 12:00 pm 1:00 pm - 5:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)	
Time	Event	Speaker
8:00 am - 9:00 am	Breakfast	
9:00 am - 9:30 am	Overview of RYR-1-Related Diseases (RYR-1-RD)	Carsten Bönnemann, MD, habil
9:30 am - 10:00 am	Genetics 101	Livija Medne, MS, LCGC
10:00 am - 10:30 am	Interpreting Genetic Test Results	Andrew McCarty, MS, CGC
10:30 am - 11:00 am	Mechanism and Functional Readouts of <i>RYR1</i> Variants	Robert Dirksen, PhD Filip Van Petegem, PhD
11:00 am - 11:30 am	Expert Panel: Sequela of RYR-1-RD	Moderator: Lindsay Goldberg, BSN, RN Panelists: Payam Mohassel, MD Nicol Voermans, MD, PhD Carsten Bönnemann, MD, habil
11:30 am - 12:00 pm	Q&A: RYR-1-RD Session	All of the Above
12:00 pm - 1:00 pm	Lunch & Group Photo	
1:00 pm - 1:45 pm	Psychosocial Insights: An Introductory Guide Breakout Groups	Julie Bowden, PsyD



## THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Friday, July 25, 2025

Time	Event	Speaker
1:45 pm - 2:15 pm	<b>Patient-Led Panels:</b> Accommodate & Thrive: A Patient-Led Panel on School Support Challenges & Triumphs: Living with Malignant Hyperthermia Phenotype Dating with Confidence: A Patient-Led Conversation  <b>Concurrent Session:</b> Psychosocial Breakout Groups	Amy Perrin, Lauren Heft, & Emily Pedersen Bob Hanich, Curt Keller, & Cody Hodgson Jeni Ryan  Julie Bowden, PsyD
2:15 pm - 2:30 pm	Break	
2:30 pm - 3:00 pm	Gene Therapy: Current Progress in Treating Neuromuscular Diseases and Future Hopes for RYR1-Related Myopathies	Isabelle Marty, PhD
3:00 pm - 3:30 pm	Expert Panel: Fueling Innovation: The RYR-1 Foundation's Research Grants	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Afrooz Rashnonejad, MSc, PhD Selene Ingusci, PhD Hichem Tasfaout, PhD, PharmD, MS Saverio Tedesco, MD, PhD
3:30 pm - 4:00 pm	Expert Panel: Exploring Current Treatment Options	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Payam Mohassel, MD Sheila Riazzi, MSc, MD, FRCPC Nicol Voermans, MD, PhD
4:00 pm - 4:30 pm	Expert Panel: The Road Ahead: Practical Perspectives on Future Treatments & Cure	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Susan Hamilton, PhD Robert Dirksen, PhD Carsten Bönnemann, MD, habil
4:30 pm - 5:00 pm	Q&A: Therapies & Treatment Options	All of the Above

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Friday, July 25, 2025

Time	Event	Speaker
One-on-One Consults		
9:00 am - 12:00 pm	Navigating Your Child's IEP: Personalized Help (15 minute consults)	Jeremy Armann, PhD
1:00 pm - 2:30 pm 3:30 pm - 5:00 pm	Personalized Genetic Interpretation (15 minute consults)	Livija Medne, MS, LCGC Carsten Bönnemann, MD, habil
1:00 pm - 5:00 pm	Personalized Variant Interpretation: Structural and Phenotypic (Symptoms) Analysis (15 minute consults)	Robert Dirksen, PhD Filip Van Petegem, PhD
Sessions		
9:00 am - 12:00 pm 2:00 pm - 5:00 pm	Strength in Movement: Ability-Based PT Groups (30 minute sessions)	Michael Brucker, PT, DPT, CSCS, CNC
1:00 pm - 1:45 pm	Accessible Yoga: Chair-Based Movement for Everyone (45 minutes)	Jennifer Orseck
Special Programming for Kids & Teens		
2:30 pm - 3:00 pm	Curiosity Corner: Q&A with Our Carnival Medical Experts	Livija Medne, MS, LCGC Carsten Bönnemann, MD, habil
3:00 pm - 3:30 pm	Inside Scoop: Teen Q&A with the Medical Experts	Livija Medne, MS, LCGC Carsten Bönnemann, MD, habil

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Saturday, July 26, 2025

Open Hours: Registration, Lounges, and Kids' Club

7:30 am - 5:30 pm	Registration Desk	
8:00 am - 5:00 pm	The Social Hub: Adult Lounge Experience Open	
9:00 am - 12:00 pm 1:00 pm - 4:00 pm 6:00 pm - 9:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)	
9:00 am - 12:00 pm 1:00 pm - 4:00 pm 6:00 pm - 9:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)	
Time	Event	Speaker
8:00 am - 9:00 am	Breakfast	
9:00 am - 10:00 am	Malignant Hyperthermia What You Need to Know Is it safe to have dental care in the office setting in the <i>RYR1</i> and MH patient?	Sheila Riaz, MSc, MD, FRCPC Andrew Herlich, DMD, MD, FAAP, FASA
10:00 am - 11:00 am	Concurrent with Q&A Sessions: Escalation & Then De-escalation of Respiratory Care During an Acute Illness (Pediatric) Bleeding Issues and Abnormalities Related to Menstruation and Pregnancy Understanding Your Options: Family Planning & Genetics Understanding Rhabdomyolysis and Malignant Hyperthermia in RYR-1-Related Diseases	Oscar Hank Mayer, MD Arti Mistry, PhD Livija Medne, MS, LCGC Nicol Voermans, MD, PhD & Sheila Riaz, MSc, MD, FRCPC
11:00 am - 12:00 pm	Concurrent with Q&A Sessions: Managing Heat Sensitivity: A Guide for Those with Malignant Hyperthermia Susceptibility Breathing Matters: Acute Adult Pulmonary Care RYR-1-RD: The Patient Perspective & Patient Participation (Clinical Trial Readiness Survey) Strength Within Limits: Exercise Options for RYR-1-RD	Susan Hamilton, PhD Jennifer Newitt, MD Lizan Stinnisen Nicol Voermans, MD, PhD, Sheila Riaz, MSc, MD, FRCPC, & Minal Jain, PT, DSc, FAPTA
12:00 pm - 1:00 pm	Lunch	

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Saturday, July 26, 2025

Time	Event	Speaker
1:00 pm - 2:00 pm	Legal Planning Tools for Holding and Transferring Wealth (Q&A included)	Megan Ingram, Esq
2:00 pm - 3:00 pm	Concurrent with Q&A Sessions: Hypoventilation Assessment and Management in RYR1 Myopathy (pediatric & adult) Schooling with RYR-1-RD: Survey Results & Key Considerations Understanding Your Rights Under the Americans with Disabilities Act	Oscar Hank Mayer, MD & Jennifer Newitt, MD Jeremy Armann, PhD & Tammy Hughes, PhD Jenee' Oliver, Esq (Disability Rights Pennsylvania)
3:00 pm - 3:15 pm	Break	
3:15 pm - 4:15 pm	Concurrent with Q&A Sessions: Comprehensive Pediatric to Adult Transition of Care - Process more than Event Movement Matters: PT, Exercise and Equipment Needs	Oscar Hank Mayer, MD & Jennifer Newitt, MD Minal Jain, PT, MS, DSc
4:15 pm - 4:45 pm	Patient-Led Panels: Stronger Together: A Patient-Led Discussion on Staying Active Navigating the World: Travel Insights from a Patient's Perspective From Patients, For Patients: Redefining Patient-Centered Care Fueling Our Lives: Patient Perspectives on Adult Nutrition	Andrew Huseh & Mairéad Ryan Marcie Epstein & Emily Pedersen Ilaria Salvatori Bob Hanich
6:00 pm - 9:00 pm	Game On & Dine: A Night of Food, Fun, and Family	

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Saturday, July 26, 2025

Time	Event	Speaker
One on One Consults		
TBD	Personalized Genetic Interpretation (15 minute consults)	Livija Medne, MS, LCGC TBD
9:00 am - 12:00 pm 1:00 pm - 5:00 pm	Personalized Variant Interpretation: Structural and Phenotypic (Symptoms) Analysis (15 minute consults)	Robert Dirksen, PhD Filip Van Petegem, PhD
10:00 am - 11:00 am 1:00 - 2:00 pm	Navigating Your Child's IEP: Personalized Help (IEP) (15 minute consults)	Jeremy Armann, PhD Tammy Hughes, PhD
2:00 - 5:00 pm	Financial Guidance for Individuals with Disabilities (15 minute consults)	Megan Ingram, Esq
Sessions		
9:00 am - 9:45 am	Accessible Yoga: Chair-Based Movement for Everyone (45 minutes)	Jennifer Orseck
10:00 am - 12:00 pm 1:00 - 5:00 pm	Strength in Movement: Ability-Based PT Groups (30 minute sessions)	Michael Brucker, PT, DPT, CSCS, CNC
Special Programs for Kids & Teens		
TBD	The Caring Carousel: Kids' Chat with Dr. Kristin	Kristin Lindquist, PsyD. ATR
TBD	Beyond the Surface: Teen Voices on Life & Feelings with Dr. Kristin	Kristin Lindquist, PsyD. ATR
TBD	Patient-Led Panel: Level Up: Career Talks for Teens & Young Adults	Andrew Huseeth & Mairead Ryan

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7:30 am - 2:00 pm	Registration Desk
8:00 am - 2:00 pm	The Social Hub: Adult Lounge Experience
9:00 am - 12:00 pm 1:00 pm - 2:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)
9:00 am - 12:00 pm 1:00 pm - 2:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)
Time	Event
10:00 am - 12:00 pm	Brunch Before Goodbye: A Warm Send-Off
12:00 pm - 2:00 pm	Closing Connections: Final Social Time