

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Thursday, July 24, 2025

Time	Open Hours: Registration, Lounges, and Kids' Club	Room
12:00 pm - 9:00 pm	Registration Desk	Glenn Foyer
12:00 pm - 9:00 pm	The Social Hub: Adult Lounge Experience	Earhart A
12:00 pm - 4:00 pm (Meet & Greet Only) 5:00 pm - 9:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)	Lindberg AB
12:00 pm - 4:00 pm 5:00 pm - 9:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)	Wright B
Time	Event	Room
5:00 pm - 9:00 pm	Happy Hour Starts Now: Bar Open (Cash Bar)	Regency Foyer & Allegheny Foyer
5:30 pm - 7:00 pm	Mix & Mingle: Welcome Cocktail Soirée	Regency Foyer Allegheny Foyer Allegheny ABC
7:00 pm - 9:00 pm	Strength In Numbers: Welcome & Family Introductions	Regency Ballroom AB

# THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Friday, July 25, 2025

Time	Open Hours: Registration, Lounges, and Kids' Club		Room
7:30 am - 5:00 pm	Registration Desk		Glenn Foyer
8:00 am - 5:00 pm	The Social Hub: Adult Lounge Experience		Earhart A
9:00 am - 12:00 pm 1:00 pm - 5:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)		Lindberg AB
9:00 am - 12:00 pm 1:00 pm - 5:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)		Wright B
Time	Event	Speaker	Room
<b>8:00 am - 9:00 am</b>	<b>Breakfast</b> Natural History Study Opportunity - NIH		<b>Regency Ballroom</b>
9:00 am - 9:30 am	Overview of RYR-1-Related Diseases (RYR-1-RD)	Carsten G. Bönnemann, MD, habil	Regency Ballroom
9:30 am - 10:00 am	Genetics 101	Livija Medne, MS, LCGC	Regency Ballroom
10:00 am - 10:30 am	Interpreting Genetic Test Results	Andrew McCarty, MS, LCGC	Regency Ballroom
10:30 am - 11:00 am	Mechanism and Functional Readouts of <i>RYR1</i> Variants	Robert T. Dirksen, PhD Filip Van Petegem, PhD	Regency Ballroom
11:00 am - 11:30 am	<b>Expert Panel:</b> Sequela of RYR-1-RD	<b>Moderator:</b> Lindsay Goldberg, BSN, RN <b>Panelists:</b> Carsten G. Bönnemann, MD, habil Payam Mohassel, MD Nicol C. Voermans, MD, PhD	Regency Ballroom
11:30 am - 12:00 pm	<b>Q&amp;A:</b> RYR-1-RD Session	All of the Above	Regency Ballroom
<b>12:00 pm - 1:00 pm</b>	<b>Lunch &amp; Group Photo</b> Effective Fundraising: Tactics That Work - Emily Pedersen, Amy & Courtney Perrin, & Courtney Woomer		<b>Regency Ballroom</b>
1:00 pm - 1:45 pm	<b>Psychosocial Insights:</b> An Introductory Guide Breakout Groups	Julie Bowden, PsyD	Regency Ballroom
1:45 pm - 2:15 pm	<b>Patient-Led Panels:</b> Accommodate and Thrive: A Patient-Led Panel on School Support Challenges and Triumphs: Living with Malignant Hyperthermia Phenotype Dating with Confidence: A Patient-Led Conversation	Lauren Heft, Emily Pedersen, & Amy Perrin Bob Hanich, Cody Hodgson, & Curt D. Keller Jeni Ryan	Allegheny AB Yeager AB Earhart CD
	<b>Concurrent Session:</b> Psychosocial Breakout Groups	Julie Bowden, PsyD	Regency Ballroom
<b>2:15 pm - 2:30 pm</b>	<b>Break</b>		
2:30 pm - 3:00 pm	Gene Therapy: Current Progress in Treating Neuromuscular Diseases and Future Hopes for RYR1-Related Myopathies	Isabelle Marty, PhD	Regency Ballroom
3:00 pm - 3:30 pm	<b>Expert Panel:</b> Fueling Innovation: The RYR-1 Foundation's Research Grants	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Selene Ingusci, PhD Afrooz Rashnonejad, MSc, PhD Hichem Tasfaout, PhD, PharmD, MS	Regency Ballroom
3:30 pm - 4:00 pm	<b>Expert Panel:</b> Exploring Current Treatment Options	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Payam Mohassel, MD Sheila Riazi, MSc, MD, FRCPC Nicol C. Voermans, MD, PhD	Regency Ballroom
4:00 pm - 4:30 pm	<b>Expert Panel:</b> The Road Ahead: Practical Perspectives on Future Treatments and Cure	<b>Moderator:</b> Michael Goldberg, MD, MPH <b>Panelists:</b> Robert T. Dirksen, PhD Susan Hamilton, PhD	Regency Ballroom
4:30 pm - 5:00 pm	<b>Q&amp;A:</b> Therapies and Treatment Options Session	All of the Above	Regency Ballroom



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Friday, July 25, 2025

Time	Event	Speaker	Room
One-on-One Consults			
9:00 am – 12:00 pm	Navigating Your Child’s Individualized Education Program: Personalized Help (15 minute consults)	Jeremy G. Armann, PhD, NCSP	Foerster
1:00 pm – 2:15 pm 3:45 pm – 5:30 pm	Personalized Genetic Interpretation (15 minute consults)	Carsten G. Bönnemann, MD, habil (1 <sup>st</sup> Timeframe) Livija Medne, MS, LCGC (1 <sup>st</sup> & 2 <sup>nd</sup> Timeframe)	Foerster
1:00 pm – 2:15 pm	Personalized Variant Interpretation: Structural and Phenotypic (Symptoms) Analysis (15 minute consults)	Robert T. Dirksen, PhD Filip Van Petegem, PhD	Allegheny C
Sessions			
9:00 am – 12:00 pm 2:00 pm – 5:00 pm	Strength in Movement: Ability-Based Physical Therapy Groups (30 minute sessions)	Michael Brucker, PT, DPT, CSCS, CNC	Earhart B
1:00 pm – 1:45 pm	Accessible Yoga: Chair-Based Movement for Everyone (45 minutes)	Jennifer Orseck	Earhart B
Special Programming for Kids & Teens			
2:30 pm – 3:00 pm	Curiosity Corner: Q&A with Our Carnival Medical Experts	Carsten G. Bönnemann, MD, habil Livija Medne, MS, LCGC	Lindbergh AB
3:00 pm – 3:30 pm	Inside Scoop: Teen Q&A with the Medical Experts	Carsten G. Bönnemann, MD, habil Livija Medne, MS, LCGC	Wright B

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025 AGENDA

Saturday, July 26, 2025

Time	Open Hours: Registration, Lounges, and Kids' Club		Room
7:30 am - 9:00 pm	Registration Desk		Glenn Foyer
8:00 am - 9:00 pm	The Social Hub: Adult Lounge Experience		Earhart A
9:00 am - 12:00 pm 1:00 pm - 5:00 pm 6:00 pm - 9:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)		Lindberg AB
9:00 am - 12:00 pm 1:00 pm - 5:00 pm 6:00 pm - 9:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)		Wright B
Time	Event	Speaker	Room
8:00 am - 9:00 am	Breakfast		Regency Ballroom
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 RYR1 and MH Patient?	Sheila Riaz, MSc, MD, FRCPC Andrew Herlich, DMD, MD, FAAP, FASA, FAAOMS(H)	Regency Ballroom
10:00 am - 11:00 am	<b>Concurrent with Q&amp;A Sessions:</b> Escalation and 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 and Genetics Understanding Rhabdomyolysis and Malignant Hyperthermia in RYR-1-Related Diseases	Oscar Henry Mayer, MD Arti Mistry, PhD Livija Medne, MS, LCGC Sheila Riaz, MSc, MD, FRCPC & Nicol C. Voermans, MD, PhD	Allegheny AB Yeager AB Earhart CD Regency Ballroom
11:00 am - 12:00 pm	<b>Concurrent with Q&amp;A Sessions:</b> Managing Heat Sensitivity: A Guide for Those with Malignant Hyperthermia Susceptibility Breathing Matters: Acute Adult Pulmonary Care RYR-1-RD: The Patient Perspective and Patient Participation (Clinical Trial Readiness Survey) Strength Within Limits: Exercise Options for RYR-1-RD	Susan Hamilton, PhD  Jennifer Newitt, MD Lizan Stinnisen, MSc  Minal S. Jain, PT, DSc, FAPTA; Sheila Riaz, MSc, MD, FRCPC; Nicol C. Voermans, MD, PhD	Allegheny AB  Yeager AB Earhart CD  Regency Ballroom
12:00 pm - 1:00 pm	Lunch Congressional Advocacy: Making Your Voice Heard - Amy Perrin & Courtney Woomer		Regency Ballroom
1:00 pm - 2:00 pm	Legal Planning Tools for Holding and Transferring Wealth (Q&A included)	Megan Ingram, Esq	Regency Ballroom
2:00 pm - 3:00 pm	<b>Concurrent with Q&amp;A Sessions:</b> Hypoventilation Assessment and Management in RYR1 Myopathy (Pediatric & Adult)  Understanding Your Rights Under the Americans with Disabilities Act Schooling with RYR-1-RD: Survey Results & Key Considerations	Oscar Henry Mayer, MD & Jennifer Newitt, MD Jenee' Oliver, Esq Jeremy G. Armann, PhD, NCSP; Tammy L. Hughes, PhD, ABPP; Christine Porter, MA, JD	Allegheny AB  Yeager AB Earhart CD
3:00 pm - 3:15 pm	Break		
3:15 pm - 4:15 pm	<b>Concurrent with Q&amp;A Sessions:</b> Comprehensive Pediatric to Adult Transition of Care - Process More Than Event  Movement Matters: PT, Exercise and Equipment Needs	Oscar Henry Mayer, MD & Jennifer Newitt, MD Minal S. Jain, PT, DSc, FAPTA	Allegheny AB  Yeager AB
4:15 pm - 4:45 pm	<b>Patient-Led Panels:</b> 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	Mairéad Ryan Marcie Epstein & Emily Pedersen Ilaria Salvatori Bob Hanich	Allegheny AB Yeager AB Earhart CD Regency Ballroom
6:00 pm - 9:00 pm	Game On & Dine: A Night of Food, Fun, and Family		Regency Ballroom

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One on One Consults			
8:30 am - 9:45 am 11:15 am - 12:00 pm	Personalized Genetic Interpretation (15 minute consults)	Livija Medne, MS, LCGC Payam Mohassel, MD	Foerster
9:00 am - 12:00 pm 1:00 pm - 3:00 pm	Personalized Variant Interpretation: Structural and Phenotypic (Symptoms) Analysis (15 minute consults)	Robert T. Dirksen, PhD Filip Van Petegem, PhD	Allegheny C
10:00 am - 11:00 am 1:00 pm - 2:00 pm	Navigating Your Child's Individualized Education Program: Personalized Help (15 minute consults)	Jeremy G. Armann, PhD, NCSP Tammy L. Hughes, PhD, ABPP	Foerster
2:00 pm - 5:00 pm	Financial Guidance for Individuals with Disabilities (15 minute consults)	Megan Ingram, Esq	Foerster
Sessions			
9:00 am - 9:45 am	Accessible Yoga: Chair-Based Movement for Everyone (45 minutes)	Jennifer Orseck	Earhart B
10:00 am - 12:00 pm 1:00 pm - 5:00 pm	Strength in Movement: Ability-Based Physical Therapy Groups (30 minute sessions)	Michael Brucker, PT, DPT, CSCS, CNC	Earhart B
Special Programs for Kids & Teens			
11:00 am - 12:00 pm	Beyond the Surface: Teen Voices on Life and Feelings with Dr. Kristin	Kristin Lindquist, PsyD	Wright B
1:00 pm - 2:00 pm	The Caring Carousel: Kids' Chat with Dr. Kristin	Kristin Lindquist, PsyD	Lindbergh AB
2:00 pm - 3:00 pm	<b>Patient-Led Panel:</b> Level Up: Career Talks for Teens and Young Adults	Mairéad Ryan	Wright B

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7:30 am - 2:00 pm	Registration Desk	Glenn Foyer
9:00 am - 2:00 pm	The Funhouse Clubhouse (Kids' Club for Ages 5 - 12)	Lindberg AB
9:00 am - 2:00 pm	The Teen Spot (Teen Lounge for Ages 13 - 17)	Wright B
Time	Event	Room
10:00 am - 12:00 pm	Brunch Before Goodbye: A Warm Send-Off	Regency Ballroom
12:00 pm - 2:00 pm	Closing Connections: Final Social Time	Regency Ballroom