

THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025

PRELIMINARY AGENDA

Topic/Session	Speaker
Lectures	
Overview of RYR-1-Related Diseases (RYR-1-RD)	TBD
Genetics & Family Planning	Livija Medne, MS, LCGC & TBD
Mechanisms of the RyR1 Receptor, <i>RYR1</i> Variants, & RyR1 Protein Structure in Relation to Clinical Phenotype	Robert Dirksen, PhD & Filip Van Petegem, PhD
Gene & Cell Therapies	Isabelle Marty, PhD
Heat Sensitivity in Malignant Hyperthermia Susceptibility & Lifestyle Changes	Susan Hamilton, PhD
Exercise Options, Rhabdomyolysis, & Heat Related Illnesses	Nicol Voermans, MD, PhD & Sheila Riaz, MSc, MD, FRCPC
Pulmonary Medicine	Oscar Hank Mayer, MD & Jennifer Newitt, MD
Malignant Hyperthermia	Sheila Riaz, MSc, MD, FRCPC & Andrew Herlich DMD, MD, FAAP, FASA
Physical Therapy	Minal Jain, PT, MS, DSc
Gynecologic Bleeding Complications	Arti Mistry, PhD
Psychosocial & Breakout Sessions	Julie Bowden, PsyD
MDA Resources	Marissa Lozano, MEd
School Considerations	Jeremy Armann, PhD
Financial Planning	Megan Ingram, Esquire
Expert Panels	
Sequela of RYR-1-RD	Nicol Voermans, MD, PhD & Payam Mohassel, MD
Current Treatment Options	Payam Mohassel, MD, Sheila Riaz, MSc, MD, FRCPC, & Nicol Voermans, MD, PhD
Therapeutic Pipeline & The RYR-1 Foundation's Research Grants	Michael Goldberg, MD, MPH & Research Grantees
Practicality of Future Treatments & a Cure	Susan Hamilton, PhD & TBD

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Topic/Session	Speaker
One-on-One Consultations	
Genetics	Livija Medne, MS, LCGC & TBD
<i>RYR1</i> Variants & RyR1 Protein Structure in Relation to Clinical Phenotype	Robert Dirksen, PhD & Filip Van Petegem, PhD
Individualized Education Plan (IEP)	Jeremy Armann, PhD
Financial Planning	Megan Ingram, Esquire
Patient-Led Panels	
Exercise	Drew Huseeth, AICP & Mairéad Ryan, BS, V27
Malignant Hyperthermia Phenotype	Robert Hanich, MD, FACC & Curt Keller, DMin
More to Come!	TBD
Interactive Sessions	
Physical Therapy Sessions	Michael Brucker, PT, DPT, CSCS, CNC
Chair Yoga Sessions	Jennifer Orseck
Kids' Club Talks	
Q & A on RYR-1-RD	Livija Medne, MS, LCGC & TBD
Psychosocial Discussions	Kristin Lindquist, PsyD, ATR
Teen Lounge Talks	
Q & A on RYR-1-RD	Livija Medne, MS, LCGC & TBD
Psychosocial Discussions	Kristin Lindquist, PsyD, ATR
Patient-Led Panel: Navigating High School/College	Mairéad Ryan, BS, V27 & Avi Orseck
Patient-Led Panel: Career Planning	Drew Huseeth, AICP & Mairéad Ryan, BS, V27