

# THE RYR-1 FOUNDATION INTERNATIONAL FAMILY CONFERENCE 2025

## PRELIMINARY AGENDA

| Topic/Session                                                                                                     | Speaker                                                                    |
|-------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------|
| <b>Lectures</b>                                                                                                   |                                                                            |
| 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                                                        |
| Psychosocial & Breakout Sessions                                                                                  | Julie Bowden, PsyD                                                         |
| 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           |
| MDA Resources                                                                                                     | Marissa Lozano, MEd                                                        |
| School Considerations                                                                                             | Jeremy Armann, PhD                                                         |
| Gynecologic Bleeding Complications                                                                                | Arti Mistry, PhD                                                           |
| Financial Planning                                                                                                | Megan Ingram, Esquire                                                      |
| <b>Expert Panels</b>                                                                                              |                                                                            |
| 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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| <b>One-on-One Consultations</b>                                                 |                                              |
| 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                           |
| <b>Patient-Led Panels</b>                                                       |                                              |
| Exercise                                                                        | Drew Huseeth, AICP & Mairéad Ryan, BS, V27   |
| Malignant Hyperthermia Phenotype                                                | Robert Hanich, MD, FACC & Curt Keller, DMin  |
| More to Come!                                                                   | TBD                                          |
| <b>Interactive Sessions</b>                                                     |                                              |
| Physical Therapy Sessions                                                       | Michael Brucker, PT, DPT, CSCS, CNC          |
| Chair Yoga Sessions                                                             | Jennifer Orseck                              |
| <b>Kids' Club Talks</b>                                                         |                                              |
| Q & A on RYR-1-RD                                                               | Livija Medne, MS, LCGC & TBD                 |
| Psychosocial Discussions                                                        | Kristin Lindquist, PsyD, ATR                 |
| <b>Teen Lounge Talks</b>                                                        |                                              |
| 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   |