

# Weekend Agenda

## 2022 RYR-1 Family Conference

Hyatt Regency Pittsburgh International Airport  
Pittsburgh, PA, USA • July 22 – July 24, 2022

### Friday, July 22

**9:00 am – 4:30 pm**

Registration

**4:00 pm – 6:00 pm**

**Meet & Greet**

Come Connect With Old Friends & Meet New Friends

*Refreshments will be Served*

**4:00 pm – 6:30 pm**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

Arts & Crafts, Activities & Games

**6:00 pm – 6:30 pm**

**Michael F. Goldberg, MD, MPH,  
President, The RYR-1 Foundation**

Welcome & Introduction to The RYR-1 Foundation

**6:30 pm – 7:30 pm**

**Hors D'oeuvres & Cash Bar**

**Kids & Teen Club**

Dinner

**7:30 pm – 9:30 pm**

**My RYR-1 Journey**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Kids ages 13 – 17**

Movie & Popcorn Night

### Saturday, July 23

**7:00 am – 10:00 am**

Registration

**7:00 am – 8:00 am**

**Continental Breakfast**

**Paul Sponseller, MD (Virtual)**

Keeping Your Bones Beautiful in RYR-1:

What to Look Out For & Q&A

Continental Breakfast with Dr. Sponseller

**8:00 am – 10:00 am**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

Arts & Crafts, Activities & Games

**8:00 am – 8:30 am**

**Carsten Bönnemann, MD**

Introduction to RYR-1-Related Diseases

**8:30 am – 9:00 am**

**Robert T. Dirksen, PhD**

The Role of Calcium and the Ryanodine

Receptor in RYR-1-Related Diseases

**9:00 am – 9:30 am**

**Livija Medne, MS, LCGC**

Genetics 101

**9:30 am – 10:00 am**

**Angela Gruber, PhD**

How to Interpret Your RYR-1 Genetic Testing

Results

**10:00 am – 10:45 am**

**Group Photo/Break!**

Wear your conference t-shirt!

**10:45 am – 12:15 pm**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

Arts & Crafts, Activities & Games

**10:45 am – 11:15 am**

**Carsten Bönnemann, MD**

**Robert T. Dirksen, PhD**

**Livija Medne, MS, LCGC**

**Angela Gruber, PhD**

Q&A Session - Overview of RYR-1-Related

Diseases

**11:15 am – 11:45 am**

**Nicol Voermans, MD, PhD**

Rhabdomyolysis, Heat/Exertional Related Disease, and Malignant Hyperthermia

**Livija Medne, MS, LCGC**

**Angela Gruber, PhD**

Family Planning

**11:45 am – 12:15 pm**

**Nicol Voermans, MD, PhD**

**Sheila Riazi, MSc, MD, FRCPC**

Q&A Session - Overview of Rhabdomyolysis

& MH

**Livija Medne, MS, LCGC**

**Angela Gruber, PhD**

Q&A Session - Overview of Family Planning

**12:15 pm – 1:30 pm**

**Lunch**

**1:00 pm – 1:30 pm (during lunch)**

**Susan Hamilton, PhD**

**Nicol Voermans, MD, PhD**

Roundtable Discussion on Menopause &

RYR-1-Related Diseases

**1:30 pm – 3:30 pm**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

Arts & Crafts, Activities & Games

**1:30 pm – 1:50 pm**

**Andrew Marks, MD**

Introduction to Rycals & the Ryanodine Receptor

**1:50 pm – 2:10 pm**

**Payam Mohassel, MD**

Update on Rycal Clinical Trial at NIH

**2:10 pm – 3:00 pm**

**Andrew Marks, MD**

**Payam Mohassel, MD**

Q&A Session - Rycals

**3:00 pm – 3:30 pm**

**Aviva Gaskill, PhD**

Psychological Concerns for Individuals with a Disability

**3:30 pm – 3:45 pm**

**Break**

**3:45 pm – 4:45 pm**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

**Mina Jain, PT, DSc, PCS**

**Michael Brucker, PT, DPT, CSCS**

Physical Therapy Session (Make a TikTok video)

**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

**4:45 pm – 6:00 pm**

**Break**

**6:00 pm – 7:30 pm**

**Dinner & Cash Bar**

**Kids & Teen Club**

Dinner

**7:30 pm – 8:00 pm**

**Award Ceremony**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Kids ages 13 – 17**

Movie & Ice Cream Sundae Bar

### Sunday, July 24

**7:00 am – 8:00 am**

**Continental Breakfast**

**8:00 am – 12:30 pm**

**Kids Club: Registered Kids ages 4 – 12**

**Teen Club: Registered Teens ages 13 – 17**

Arts & Crafts, Activities & Games

**8:00 am – 8:30 am**

**8:30 am – 9 am**

**9:00 am – 9:30 am**

**9:30 am – 10:00 am**

**11:30 am – 12:00 pm**

**12:00 pm – 12:30 pm**

**Michael Brucker, PT, DPT, CSCS**

PT Sessions (Groups of 10)

**8:00 am – 8:45 am**

**Oscar Hank Mayer, MD**

Pulmonary Complications of RYR-1-Related Diseases

**8:45 am – 9:30 am**

**Jennifer Newitt, MD**

Sleep-Related Breathing Issues in RYR-1-Related Diseases

**9:30 am – 10:00 am**

**Oscar Hank Mayer, MD**

**Jennifer Newitt, MD**

Q&A Session - Pulmonary Complications of RYR-1-Related Diseases

**10:00 am – 10:30 am**

**Break**

**10:30 am – 11:00 am**

**Mina Jain, PT, DSc, PCS**

Physical Therapy Services for Individuals with a Disability

**Heinz Jungbluth, MD, PhD**

RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle

**11:00 am – 11:30 am**

**Mina Jain, PT, DSc, PCS**

**Michael Brucker, PT, DPT, CSCS**

Q&A Session - PT

**Heinz Jungbluth, MD, PhD**

Q&A Session - RYR-1-Related Disorders – An Expanding Spectrum of Disease Throughout Life and Beyond Skeletal Muscle

**11:30 am – 12:00 pm**

**Tammy L. Hughes, PhD**

School Services for Individuals with a Disability

**12:00 pm – 12:30 pm**

**Tammy L. Hughes, PhD**

Q&A Session - IEPs

**12:30 pm – 1:30 pm**

**Lunch & Closing Remarks**

**1:30 pm – 2:30 pm**

**Final Socializing**