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The 2020 RYR-1 International Family Conference



Group photo from the 2018 RYR-1 International Family Conference

November 8, 2019 - The RYR-1 Foundation, the only organization in the world that exists exclusively to serve the needs of and advocate for individuals with RYR-1 muscle diseases, will be hosting the third biennial *RYR-1 International Family Conference* in Orlando, FL, USA at the Hilton Orlando Bonnet Creek. The conference will take place on Friday, July 31, 2020 - Sunday, August 2, 2020. For more information and **to register for the conference, please click [here](#)**.

The theme of this year's Family Conference is: "Where Dreams Come True".

The RYR-1 Foundation held the first ever RYR-1 International Family Conference in July 2016 in Baltimore, MD and the second RYR-1 International Family Conference in July 2018 in Pittsburgh, PA. Combined, these events have hosted 388 attendees, representing 75 RYR-1-affected families from 31 states and eight countries. These conferences are unique opportunities for affected individuals and families to meet, learn from world-renowned experts, form friendships, and develop a genuine RYR-1 community. To learn more about the family conferences, please visit: www.ryr1.org/conferences.

For a rare condition like RYR-1-related diseases, providing a forum for affected individuals and families to meet others like them has a significant psychological value. When affected individuals or their family members seek others who understand what they are experiencing, a Family Conference becomes an invaluable and necessary resource. It is a goal of the RYR-1 Foundation to enhance and enrich these relationships within the RYR-1 community by hosting international family conferences every other year.

RYR-1-related diseases include central core disease (CCD), centronuclear myopathy (CNM), multiminicore disease (MMD), malignant hyperthermia susceptibility (MHS), congenital fiber-type disproportion (CFTD), and other forms of muscle disease. To learn more about RYR-1-related diseases, please go to: www.ryr1.org/diseases.

“Patient outreach is one of the most important missions of the RYR-1 Foundation,” said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. *“This can be done in a variety of ways, including social media, but the RYR-1 International Family Conference is our signature event for individuals and families to meet each other and learn more about their condition. It also provides a forum for RYR-1 clinicians and scientists to network with each other, share the latest research, and meet affected individuals.”*

Jennifer Ryan, Trustee of the RYR-1 Foundation, is the organizer of the family conferences. *“The degree of physical impairment varies greatly in our community,”* said Ms. Ryan. *“Looking at me or my child, you would never know that we have CCD unless you watched us walk up*

stairs or asked us to run or jump. Many members of our community are mildly affected physically, but still have fatigue and physical challenges that affect our daily lives. But we all struggle to address varying social and emotional challenges dealing with a rare physical disability. And so do our family members! The chance to meet and become better informed on RYR-1 diseases and offer one another support and practical advice related to parenting a child with this disability, supporting a spouse with it, or finding ways to overcome the challenges we live with each day- is an invaluable opportunity- don't miss it!"

In addition to the world-renowned speakers and invited guests, **there will be special perks to attending this year's Family Conference and staying at the Hilton Orlando Bonnet Creek.** These include¹:

- 1) **Continuous free shuttle service to all four Disney® Theme Parks & Disney Springs® throughout the duration of your stay (including before and after the Family Conference).**
- 2) High-Speed Wi-Fi access throughout the resort and public areas (excluding meeting space).
- 3) Kids Meal Deals in Harvest Bistro: Kids 12 and under eat dinner free when ordering from the Kid's Menu and accompanied by an adult purchasing a full-priced entrée. Kids ages 6-12 enjoy a 50% discount on our breakfast buffet when accompanied by an adult purchasing a full-priced entrée or buffet. Breakfast buffet is complimentary for children under 5 years of age.
- 4) Access to Fitness Center.
- 5) Access to the Waldorf Astoria Golf Club practice facilities.
- 6) Free golf club rental after 2:00 pm.
- 7) 20% discount off Spa Treatments at the Waldorf Astoria Spa.
- 8) Use of Lazy River Tubes & 10% off Cabana Rentals (advanced reservations required).

¹ Based upon the RYR-1 Foundation achieving 80% group hotel room pick up.

About the RYR-1 Foundation

The Pittsburgh, Pennsylvania-based 501(c)(3) public charity was launched in October 2014 by members of the Goldberg family, who have been affected by RYR-1 muscle disease. It is currently the only organization that exists solely to advocate for and serve the needs of patients with RYR-1 myopathy, the most common cause of congenital myopathy. The mission of the RYR-1 Foundation is to support research leading to effective treatment or a cure for RYR-1 related diseases, to educate physicians about these diseases, and to provide patient/family support and advocacy. To learn more about the RYR-1 Foundation, please go to: www.RYR1.org.