



**FOR IMMEDIATE RELEASE**

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***The 2018 RYR-1 International Family Conference***



*Group photo from the 2016 RYR-1 International Family Conference*

**October 23, 2017** - 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 second biennial RYR-1 International Family Conference in Pittsburgh, PA. The conference will take place on Friday, July 13 - Sunday, July 15, 2018. For more information and to register for the conference, please click [here](#).

The RYR-1 Foundation held their first conference in July 2016 with over 200 attendees, representing 75 RYR-1-affected families from 25 states and six countries. For many attendees, this event was the first opportunity to meet others with this rare muscle condition. What made this conference unique was the opportunity for so many affected individuals (ages 2 to 78!) and their families to meet, form friendships, learn about RYR-1-related diseases, and develop a true RYR-1 community. For these reasons, 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 the International Family Conference every two years.

RYR-1-related diseases include central core disease (CCD), centronuclear myopathy (CNM), multimincore disease (MMD), malignant hyperthermia susceptibility (MHS), congenital fiber-type disproportion (CFTD), and other forms of muscle disease. This forum has significant psychological benefits for these affected individuals and their families when they find someone else who understands what they have gone through.

“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.”

“The degree of physical impairment varies greatly in our community. 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!" said Jennifer Ryan, Trustee of the RYR-1 Foundation.

### **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](http://www.RYR1.org).