



FOR IMMEDIATE RELEASE

Contact: Nicole Wallace
Program Director, RYR-1 Foundation
nicole@ryr1.org
(412) 529-1482

**THE 2020 RYR-1 INTERNATIONAL FAMILY CONFERENCE IS
CANCELLED**

March 24, 2020 - Due to the ongoing Covid-19 pandemic, the RYR-1 Foundation Board of Trustees held an emergency meeting on Sunday, March 15, 2020 to discuss the feasibility of hosting the 2020 RYR-1 International Family Conference scheduled for July 31-August 2, 2020 in Orlando. Many members of the RYR-1 community are considered to be at risk for complications of Covid-19 due to impaired respiratory function.¹ In addition, as non-essential travel is strongly discouraged, none of the scheduled speakers would be allowed to attend the Conference. Therefore, the RYR-1 Foundation's Board of Trustees has cancelled the 2020 RYR-1 International Family Conference. We hope to reschedule this conference for the Summer of 2021. A date and location have yet to be determined.

"The RYR-1 Foundation regrettably made the tough decision to cancel the 2020 RYR-1 International Family Conference. While patient outreach is one of the most important missions of the RYR-1 Foundation, the wellbeing and safety of the entire RYR-1 community are our top priorities," said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. *"The RYR-1 International Family Conference is our signature event for individuals and families to meet each other and learn more about their condition. We hope to take this opportunity to*

1

www.cdc.gov/coronavirus/2019-ncov/specific-groups/high-risk-complications.html?fbclid=IwAR1UMtYKDMPxwURBdBFBhdAbEBkNyaRbSQ290jLhk6_GYqIYZWyxohkFKGM

improve our online resources and increase the ways that members of the RYR-1 community can connect online.”

All registered attendees will have the option to receive a full refund. These individuals have all received an email with further instructions. For questions, please contact Nicole Wallace, Program Director, at nicole@ryr1.org.

For more information on the implications of the Covid-19 outbreak for individuals with RYR-1-related diseases, please check out: <https://youtu.be/ARXFhnJJj-w>.

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-related diseases, the most common cause of congenital myopathy. The mission of the RYR-1 Foundation is to support research leading to an 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.