



## FOR IMMEDIATE RELEASE

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### *"RYR1-Related Diseases"*

*RYR-1 Foundation Announces the Publication of Updated Entry in the National Organization for Rare Disorders (NORD) Rare Disease Database*

#### **RYR1-Related Diseases**

NORD gratefully acknowledges Joshua J. Todd, PhD, CCRP, National Institutes of Health, Michael F. Goldberg, MD, MPH, Co-Founder and President, RYR-1 Foundation, Robert T. Dirksen, PhD, University of Rochester, and Nicol C. Voermans, MD, PhD, Radboud University (The Netherlands), for the preparation of this report.

#### **Synonyms of RYR1-Related Diseases**

- RYR1 myopathy
- RYR1 muscle disease
- RYR1-related disorders

**March 17, 2021** - The RYR-1 Foundation is excited to announce the publication of the second "Rare Disease Report" on RYR1-Related Diseases on the website of the National Organization for Rare Disorders (NORD). Please click on the image above or the following link to read this report: [rarediseases.org/rare-diseases/ryr-1-related-diseases/](https://rarediseases.org/rare-diseases/ryr-1-related-diseases/).

NORD is the leading advocacy organization for individuals affected by "rare" diseases, and the RYR-1 Foundation is a proud member of this leading organization. Patients, families, caregivers, physicians, researchers, and advocacy organizations look to NORD for assistance, and the updated report on RYR1-related diseases in the NORD database will be an invaluable resource.

“We are grateful to be associated with a highly respected organization such as NORD,” said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. “Having this updated official report for RYR1-related diseases on the NORD website will allow us to help an even greater number of people who are affected by this condition.”

Updating this report was a collaborative effort by:

- **Joshua J. Todd, PhD, CCRP**, National Institutes of Health
- **Michael F. Goldberg, MD, MPH**, Co-Founder and President, RYR-1 Foundation
- **Robert T. Dirksen, PhD**, University of Rochester
- **Nicol C. Voermans, MD, PhD**, Radboud University (The Netherlands)

Drs. Dirksen and Voermans are members of the RYR-1 Foundation’s Scientific Advisory Board ([www.ryr1.org/scientificadvisoryboard](http://www.ryr1.org/scientificadvisoryboard)).

### **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 an RYR1-related 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 RYR1-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).