



FOR IMMEDIATE RELEASE

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"RYR-1-Related Diseases" is now an Entry on the NORD website

RYR-1-Related Diseases

NORD gratefully acknowledges Michael F. Goldberg, MD, MPH, Co-Founder and President, RYR-1 Foundation, for the preparation of this report.

Synonyms of RYR-1-Related Diseases

- RYR-1 myopathy
- RYR-1 muscle disease

The RYR-1 Foundation is excited to announce the publication of the first "Rare Disease Report" on RYR-1-Related Diseases on the website of the National Organization for Rare Disorders (NORD). Please click on the following link to explore more about 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 excited to have this association. The Foundation is also proud to be gaining further recognition by the medical community and to be expanding its ability to provide resources to and advocate for individuals affected by RYR-1.

Notably, this is the first time that NORD has recognized this spectrum of diseases by the unifying mutation in the RYR-1 gene, rather than by the various histopathologic (muscle biopsy) diagnoses (e.g. Central Core disease, Centronuclear myopathy, etc).

“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 an official report for RYR-1-related diseases on the NORD website will allow us to help an even greater number of people who may be affected by this condition.”

About the RYR-1 Foundation

The Pittsburgh, Pennsylvania-based 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. The RYR-1 Foundation is a public charity, designated as a 501(c)(3) by the IRS. To learn more about the RYR-1 Foundation, please go to: www.RYR1.org.