



FOR IMMEDIATE RELEASE

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RYR-1 Foundation Announces Over \$500,000 in Research Grant Funding

April 4, 2017 - The RYR-1 Foundation is proud to announce the recipients of the RYR-1 Foundation's most recent round of research grants. This represents a commitment of over \$500,000 of research funding. The Foundation is very excited to fund this quantity and quality of research, as it is a vital part of the RYR-1 Foundation's mission: *To support research leading to an effective treatment or a cure for RYR-1-related diseases*

"As President of the RYR-1 Foundation, I am grateful for the opportunity to award our second round of grants to such an impressive group of world renowned researchers. This quality and quantity of research funding will advance our understanding of RYR-1 myopathy and, hopefully, identify potential new therapies," said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation.

Dr. Goldberg also expressed gratitude to all of the donors who made this level of grant support possible. In particular, the matching grant from the Schooner Foundation of Boston led to a very successful fundraising campaign in late 2016. Grant Recipients include:

Angela Dulhunty, MD, PhD, Australian National University (Australia): *"Developing Animal Models with an RYR-1 Mutation and Clinical Phenotype for the Purpose of Evaluating Cell and Molecular Mechanisms of RYR-1 Disease"*

Alexander Kushnir, MD, PhD, Columbia University: *“RyR1 Myopathy Database”*

William R. Lagor, PhD, Baylor College of Medicine: *“Targeted Removal of Pathogenic RYR1 Alleles”*

Filip Van Petegem, PhD, University of British Columbia (Canada): *“Structural Investigation of Disease-Associated Mutations in the Ryanodine Receptor Pore and EF Hand Region”*

Kang Zhang, MD, PhD, University of California, San Diego and Robert Dirksen, PhD, University of Rochester: *“HITI-Mediated Gene Editing for RYR1 Myopathy”*

These applications were selected after a rigorous evaluation process, with each application receiving at least two expert reviewers. To avoid potential conflicts of interest, members of our Scientific Advisory Board who submitted grant applications did not participate in the review process.

For more detail on each grant, please [click here](#).

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.