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The RYR-1 Foundation Adds New Members to its Board of Directors, Board of Advisors, and Scientific Advisory Board

December 7, 2021 - The RYR-1 Foundation is honored to announce the newest members of its **Board of Directors**, **Board of Advisors**, and **Scientific Advisory Board**. Mr. Drew Huseth will join as a director, Drs. Jessica Nance and Matthew Tompkins will join as advisors, and Dr. Johanna Lanner will join as a member of the Scientific Advisory Board. Below are detailed biographies of each individual. Members of the Board of Directors, Board of Advisors, and Scientific Advisory Board play critical roles in advancing the mission of The RYR-1 Foundation and ensuring its continued success.

“Drew as well as Drs. Lanner, Nance, and Tompkins will be tremendous additions to The RYR-1 Foundation’s leadership,” says Michael F. Goldberg, MD, MPH, President of The RYR-1 Foundation. “The RYR-1 community and The RYR-1 Foundation are lucky to have them on our team.”

Drew Huseth, AICP, Director: Drew is a Land Entitlement Manager for Woodside Homes of Arizona, a single-family residential development and homebuilding company. Prior to Woodside Homes, he spent 12 years working as a Land Entitlement Planner for a privately held consulting firm. Drew has a bachelor’s degree in Housing and Urban Development from Arizona State University. He is a member of the American Institute of Certified Planners (AICP), the Arizona Chapter of the American Planning Association (APA), and also the Arizona Chapter of the Urban Land Institute (ULI). Drew has a recessive form of RYR-1 caused by mutations in the *RYR1* gene.

Johanna Lanner, PhD, SAB Member: Johanna Lanner, PhD, is a preclinical expert in muscle pathophysiology, and her interdisciplinary and translational research program is

focused on understanding mechanisms and identifying novel therapeutic interventions to combat muscle dysfunction and weakness. She is an Associate Professor at The Department of Physiology & Pharmacology, Karolinska Institutet, Stockholm, Sweden. Her background includes a master's degree in chemistry from Stockholm University, Sweden, and a PhD in medical sciences from Karolinska Institutet. She did her postdoc training in Professor Susan Hamilton's laboratory at Baylor College of Medicine in Houston, Texas, focusing on muscle dysfunction in RYR-1-related disease.

Johanna has conducted research on different signaling pathways in muscles for over a decade and has made significant advances in this field by characterizing novel mechanisms of muscle weakness and linking oxidative stress and altered muscle metabolism to the impaired contractile function of muscle. She has published over 50 original articles and reviews in leading scientific journals and is frequently invited to present her research at acknowledged scientific conferences and congresses. Dr. Lanner is the recipient of national and European grants, and her research team recently identified a mitochondrial protein that potentially can be targeted to improve muscle function in genetic diseases and non-communicable disorders.

Jessica Nance, MD, Advisor: Dr. Nance is a pediatric neurologist with specialized training in pediatric neuromuscular disorders. She is an Assistant Professor of Neurology and the Director of the Johns Hopkins Pediatric Neuromuscular Clinical Trials Group. Dr. Nance cares for children and families affected by genetic nerve and muscle diseases in her clinics at The Johns Hopkins Hospital and the Kennedy Krieger Institute in Baltimore, Maryland. She is an investigator in several multi-center, industry-sponsored clinical trials evaluating neuromuscular therapies. Dr. Nance's research focuses on the development and validation of measurements of motor function in patients with neuromuscular disorders.

Matthew Tompkins, PhD, Advisor: Matthew L. Tompkins, PhD, is the Chief Operating Officer for TC Defense in Arlington, VA where he works as a Consultant for Naval Weapon Systems. Matthew has spent more than 20 years in the field of Science and Technology for Naval Systems. He is an Editorial Board Member for IEEE Transactions on Engineering Management and enjoys conducting research and doing peer reviews for research. Matthew is also an Adjunct Professor at The George Washington University School of Engineering and Applied Science. Matthew has several family members who are affected by RYR-1 and is passionate about finding solutions that provide support for those suffering from RYR-1 disease.

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 RYR-1-related 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 causes 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.