



ZNM - Zusammen Stark! e.V.
Verein für Zentronukleäre Myopathien

FOR IMMEDIATE RELEASE

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RYR-1 Foundation Announces Collaboration with German Muscle Disease Organization

#StrengthInNumbersRYR1 #TogetherWeAreStrong

February 6, 2018 - The RYR-1 Foundation (Pittsburgh, PA) and ZNM-Zusammen Stark e. V. (Stuttgart, Germany) are excited to announce a collaboration to further their shared interest in helping those with certain forms of congenital muscle disease. ZNM recently donated 8,000 Euros to the RYR-1 Foundation, with those funds earmarked for RYR-1-related research. ZNM is an association for all centronuclear myopathies, which can be caused by mutations in several genes, including RYR-1, MTM-1, DNM-2, SEPN-1, BIN-1 and other genes. Approximately 25% of the families associated with ZNM are affected by RYR-1-related myopathy. It is hoped that this will be one of many future collaborations between the two organizations, as the RYR-1 Foundation's goal is to serve affected individuals in not only the United States, but also in Europe and around the world.

“The slogan of the RYR-1 Foundation is ‘*Strength In Numbers*’, and the slogan of ZNM is ‘*Together We Are Strong*,’” said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. “For rare conditions like RYR-1-related myopathy and CNM/MTM-1, it is absolutely critical that organizations work together to accelerate the pace of research funding and,

hopefully, expedite the discovery of a cure for rare muscle diseases.”

"In ultra rare diseases like centronuclear myopathies, it is crucial for patient organizations to cooperate with others internationally and also beyond the very specific diagnosis -to see bridges and gates instead of borders and walls," said Dr. Holger Fischer, President of ZNM. "In this spirit, we, as an association for all centronuclear myopathies, are very happy to extend our cooperation with the RYR-1 Foundation. Together we are strong!"

Historically, congenital muscle diseases have been diagnosed via muscle biopsy, yielding diagnoses based on the appearance of the muscle cell; these include, centronuclear myopathy (CNM), central core disease (CCD), multi-minicore disease (MMD), etc. More recently, genetic testing has become a more prevalent strategy in diagnosing congenital muscle disease, with diagnoses based on the which gene demonstrates a mutation; these include the RYR-1 and MTM1 genes. For a more in-depth discussion of these terms, please go to www.ryr1.org and the National Organization of Rare Disorders (NORD) (<https://rarediseases.org/rare-diseases/ryr-1-related-diseases/>).

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.

About the ZNM - zusammen stark e. V.

The German-Dutch-based is the German association of myotubular myopathy (MTM) and other centronuclear myopathies (CNM). The goals of ZNM - Zusammen Stark e. V. are to give families a voice, share information about CNM, and support research to find a treatment or a

cure for CNM. To learn more about the ZNM, please go to:
<http://www.znm-zusammenstark.org/en/our-association/>.