



FOR IMMEDIATE RELEASE

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Premiere of the RYR-1 Foundation Documentary

June 13, 2017 - The Premiere of the RYR-1 Foundation Documentary will occur on Wednesday, July 26, 6:00 pm, at **The Phoenix** (8480 W 3rd St., Los Angeles, CA 90048). The highlight of the event will be the first official screening of filmmakers Jason Kaminsky and Victor Ridaura's documentary about the RYR-1 Foundation. The event is being co-hosted by RYR-1 Trustee, Michael Legum, and Avi Swerdlow, of the Walt Disney Company. All proceeds will go to the RYR-1 Foundation to support its efforts in finding a cure for this debilitating disease.

To purchase a ticket or to make a donation to support the event, please visit:

<https://www.generosity.com/fundraising/ryr-1-foundation-documentary-premiere-fundraisers/x/16585672>

“Jason and Victor have made an incredibly moving documentary and we're so thrilled to be able to share it and raise awareness of RYR-1 and our amazing Foundation,” said Michael Legum.

“The RYR-1 Foundation is extremely fortunate to have a trustee like Michael Legum, who had the vision to host what I know will be an unforgettable event,” said Michael F. Goldberg, MD, MPH, President of the RYR-1 Foundation. “In addition, Avi, with his background in the film industry, played a critical role in the production and editing of this inspiring film.”

“We are honored to have had the opportunity make this film about the RYR1 Foundation,” said Jason Kaminsky. “Working with the Foundation founders and all the patients, families, doctors, and scientists who helped us tell this story was a rewarding and life-changing experience. We

are grateful for the opportunity to share it in a public screening, and hope it will bring further awareness and understanding about RYR-1, and support for the Foundation's work towards a cure.”

The RYR-1 Foundation hopes that this documentary helps educate the public, affected families, and physicians about the RYR-1 muscle disease, and explains how the RYR-1 Foundation is working to help find a cure.

About RYR-1 Muscle Disease and the RYR-1 Foundation

RYR-1 muscle disease is the most common form of “congenital myopathy” -- muscle weakness due to a genetic mutation. Symptoms can range in severity from severe weakness, including the inability to walk and breathe independently, to mild weakness (e.g., difficulty climbing stairs). In addition to these symptoms, RYR-1 has been linked to a potentially fatal reaction to anesthesia known as malignant hyperthermia. Yet, despite its prevalence and life altering/debilitating symptoms, the RYR-1 Foundation is the only organization that exists solely to address this disease and serve the needs of and advocate for RYR-1 individuals and their families. With the help of the Foundation, patients and their family members finally have a support system. More than that, however, the Foundation's work is giving affected individuals a new hope in the form of increased research, drug trials, treatments and perhaps even a cure. In fact, the RYR-1 Foundation has helped fund groundbreaking research which has the potential to lead to massive change for those living with RYR-1. To learn more about the RYR-1 Foundation, please go to: www.RYR1.org.