



FOR IMMEDIATE RELEASE

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RYR-1 Foundation Adds New Members to Its Scientific Advisory Board

May 1, 2018 - The RYR-1 Foundation is honored to announce the newest members of its Scientific Advisory Board (SAB). The SAB is responsible for setting the research priorities of the RYR-1 Foundation and determining which research grant applications receive funding. Under the leadership of its chair, Dr. Andrew Marks, the SAB is comprised of a group of world-renowned researchers and clinicians who have dedicated their careers to helping those affected by RYR-1-related diseases. With these latest additions, the SAB will continue to be an invaluable resource to not only the RYR-1 Foundation, but also to individuals and families affected by RYR-1.

The newest members of the SAB are listed below. For detailed biographical sketches, please go to: <http://www.ryr1.org/scientific-advisory-board>.

Livija Medne, MS, LCGC

*Co-Director Individualized Medical Genetics Center, Senior Genetic Counselor
The Children's Hospital of Philadelphia (United States)*

Sheila Riazi, MSc, MD, FRCPC

*Director of The Malignant Hyperthermia Investigation Unit
Toronto General Hospital (Canada)*

Susan Treves, PhD

*Professor: Departments of Anesthesia and Biomedicine
University of Basel (Switzerland)*

Nicol Voermans, MD, PhD

*Neurologist
Radboud University Medical Centre (Netherlands)*

Drs. Riazi, Treves, and Voermans as well as Mrs. Medne will join the current members of the RYR-1 Foundation SAB, listed below:

Andrew R. Marks, MD (Chair)

*Chairman of the Department of Physiology and Cellular Biophysics
Columbia University (United States)*

Carsten G. Bönnemann, MD

*Pediatric Neurologist and Senior Investigator
National Institutes of Health (United States)*

Robert T. Dirksen, PhD

*Chair of Pharmacology and Physiology
University of Rochester Medical Center (United States)*

James Dowling, MD, PhD

*Neurologist
Hospital for Sick Children (Canada)*

Susan Hamilton, PhD

*Chair of the Department of Molecular Physiology and Biophysics
Baylor College of Medicine (United States)*

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.