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Contact: Sheila Gibbons sgibbons@childrenscardiomyopathy.org 866-808-2873 x902

Children's Cardiomyopathy Foundation Nominates Consumer Advocates to Participate in the Scientific Review for the Peer Review Medical Research Program of the Department of Defense.

TENAFLY, N.J.—September 6, 2018— The Children's Cardiomyopathy Foundation (CCF) nominated four parents to serve as consumer advocates for the Department of Defense sponsored Peer Reviewed Medical Research Program (PRMRP). Wendy Borsari of Massachusetts, Sarah Foye of New Jersey, Joseph Hillenburg of Illinois, and Melissa McQueen of Arizona recently participated in the evaluation of research applications submitted to the PRMRP. As a consumer reviewer, Borsari, Foye, Hillenburg and McQueen were full voting members, alongside prominent scientists, at meetings to determine how the \$330 Million appropriated by Congress for Fiscal Year 2018 will be spent on PRMRP research.

The goal of the PRMRP is to fund studies that can improve the health and well-being of military personnel and their families with the potential to benefit all Americans. Consumer reviewers work together with scientists to evaluate the scientific merit of research applications. They are asked to represent the collective view of patients by preparing comments on the impact of the research on issues such as diagnosis, treatment, and quality of life. Borsari, Foye, Hillenburg, and McQueen were nominated for their commitment to research on pediatric cardiomyopathy. In 2017, cardiomyopathy was included in the PRMRP's fundable research area, a direct result of CCF's advocacy efforts to secure additional federal funding opportunities for pediatric cardiomyopathy research.

"It is such an honor to serve as a consumer reviewer and to be able to make an impact on health concerns that are dear to my heart," said Foye, who herself has a family history of cardiomyopathy. Borsari also has a family history of cardiomyopathy, and Hillenburg and McQueen both have children who were diagnosed with cardiomyopathy and then received a heart transplant.

Colonel Stephen J. Dalal, Director of the Congressionally Directed Medical Research Programs expressed his appreciation for consumer advocates during the scientific review sessions. "Consumer advocates are an integral part of the CDMRP's scientific review process. They provide a key ingredient to the review process, the patient's perspective, which is real and urgent. The collaboration of Consumer advocates alongside the scientists' subject matter expertise is a truly unique collaboration that is difficult to find in most medical research programs."

Scientists applying to the program propose to conduct innovative research focused on the development and implementation of medical devices, drugs, and clinical guidance that will enhance the precision and efficacy of prevention, diagnosis, and treatment across a wide range of disciplines. The PRMRP fills important gaps not addressed by other funding agencies by supporting groundbreaking, high-risk, high-gain research while encouraging out-of-the-box thinking.

More information about the PRMRP is available at <u>http://cdmrp.army.mil</u>, and background about the Children's Cardiomyopathy Foundation is available at childrenscardiomyopathy.org

About The Children's Cardiomyopathy Foundation

The Children's Cardiomyopathy Foundation (CCF) is a national organization focused on finding causes and cures for all forms of pediatric cardiomyopathy, the leading cause of heart transplants and sudden cardiac arrest in children. CCF started in 2002 with one family's determination to call attention to this poorly understood heart disease and to take action on the lack of medical progress and public awareness. Since then, CCF has grown into a global community of families, physicians, and scientists and has raised more than \$13 million for research and education initiatives, family support, and awareness and advocacy measures.