

Pediatric Cardiomyopathy Registry (PCMR)

National Institutes of Health-National Heart, Lung, and Blood Institute (R01-HL053392)

The Pediatric Cardiomyopathy Registry (PCMR) was established to describe the epidemiologic features and clinical course of selected cardiomyopathies in children (aged 18 years or younger) and to promote the development of specific treatment for this disease, which has significant morbidity and mortality.

The Administrative Coordinating Center for the PCMR is at the University of Miami, Miller School of Medicine and is led by Principal Investigator, Dr. Steven Lipshultz, Professor and Chairman of Pediatrics, with the assistance of Dr. James Wilkinson, Professor of Pediatrics and Epidemiology and Public Health.

The PCMR has been funded since 1994 by the National Institutes of Health-National Heart, Lung, and Blood Institute (R01-HL053392). The local clinical site investigator is Dr. Paolo Rusconi, Associate Professor and Medical Director for the Heart Transplant and Heart Failure Clinic.

Previously published results include the first population-based estimates for cardiomyopathy in North America and a description of outcomes for children with dilated and hypertrophic cardiomyopathy. As part of its current research aims, the PCMR, through its affiliated academic medical centers, has enrolled a cohort of 400 children looking simultaneously at clinical, genetic, and functional assessment data.

The PCMR has also collaborated with the Pediatric Heart Transplant Study group to provide the first multi-institutional review of outcomes after transplantation taking into account factors at time of diagnosis of cardiomyopathy. The PCMR is instrumental in advancing the research strategy for pediatric cardiomyopathy by holding the first International conference “Idiopathic and Primary Cardiomyopathy in Children: Research Directions and Strategies” in January, 2007, in association with the Children’s Cardiomyopathy Foundation, NHLBI, and Genzyme (<http://www.pediatrics.med.miami.edu/x431.xml>). For additional information, please visit the PCMR website at www.pcmregsitry.org.