The Children’s Cardiomyopathy Foundation’s (CCF) Second International Scientific Conference Keeps Cardiomyopathy at the Forefront of Pediatric Medicine and Research

By Renee Thekkakara

CCF’s Second International Conference on Cardiomyopathy in Children, co-sponsored by the National Heart, Lung and Blood Institute (NHLBI), the University of Miami Miller School of Medicine, the Myocarditis Foundation, and GeneDX was held May 13-14 in Bethesda, MD. The scientific workshop called attention to the critical issues related to cardiomyopathy in children. Manuscripts from the conference will be featured in three issues of Progress in Pediatric Cardiology. Plans are also in place for additional working group sessions that will focus on finalizing a research agenda and developing action plans for collaborative studies aimed at improving diagnostic methods and optimizing care for children with cardiomyopathy.

Sixty of the top clinicians and researchers from the US, UK, Canada and Australia convened to identify key research areas, share best practices and review new research data and findings on pediatric cardiomyopathy. A wide range of medical disciplines was present, including cardiologists, geneticists, molecular biologists and epidemiologists. Representatives from the NHLBI, the National Cancer Institute, and the National Institute of Child Health and Development also participated in the exchange of ideas and information.

“Cardiomyopathies result in some of the worst pediatric cardiology outcomes, as nearly 40% of the children who present with symptomatic cardiomyopathy receive a heart transplant or die within the first 2 years after diagnosis,” said Conference Chair & CCF Medical Advisor Steven Lipshultz, MD. “This conference is a critical step in bringing together the best in the field to understand the molecular and genetic issues in cardiomyopathy and to identify the most critical and promising areas for clinical research efforts for this disease,” continued Dr. Lipshultz.

CCF was the first to organize a conference dedicated specifically to pediatric cardiomyopathy. The first conference took place in January 2007 with conference proceedings featured in three dedicated issues of Progress in Pediatric Cardiology. Due to the general lack of information on the disease, these three issues became the most downloaded articles in the 20-year history of the scientific journal. Following the first conference, an additional $1 million was committed to pediatric cardiomyopathy research by the Foundation.

The two-day conference was organized into six moderated sessions centered on topics of various interests. Panel moderators included: Jeffrey Towbin, MD; Wendy Chung, MD, PhD (Genetic Issues); Steve Webber, MBChB; Daniel Bernstein, MD (Molecular Mechanisms); Steve Lipshultz, MD; Michael Burch, MBChB (Biomarkers); Steve Colan, MD; Robert Weintraub, MBBS (Hypertrophic & Restrictive Cardiomyopathy, Left Ventricular Noncompaction); Leslie Cooper, MD; Charles Canter, MD (Myocarditis); Daphne Hsu, MD; and Robert Shaddy, MD (Medical & Transplant Therapy). The conference also included five young investigators who are at the start of their medical careers and represent the future of cardiomyopathy research. These investigators outlined the findings of their work to date.

“An important part of CCF’s mission is to provide accessible educational materials that are current, easy-to-understand, and offer practical guidelines for living with the disease for patients, parents/caregivers and medical practitioners. CCF works with various healthcare organizations and medical societies to develop these materials in print and electronic formats. All materials have been carefully reviewed by CCF’s medical advisors, and in most cases are offered free-of-charge.”

A new family panel was introduced this year in which attendees had the opportunity to hear from parents of affected children. Five parents from the Bethesda area shared their experiences of navigating the medical system and discussed the challenges of raising a child with a chronic illness. They also offered suggestions on which patient
resources and support services are most helpful and what physicians could do to further assist parents after a child’s diagnosis.

CCF plans to organize another Scientific Conference within the next two years.

The Children’s Cardiomyopathy Foundation (CCF) is a national, non-profit organization focused on pediatric cardiomyopathy, a chronic disease of the heart muscle. CCF is dedicated to accelerating the search for a cure by stimulating and supporting promising research on pediatric cardiomyopathy, by educating and assisting physicians and patients on the complexities of the disease, and by increasing awareness and advocacy on behalf of affected children and their families.

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For more information or to order these and other materials please visit CCF at www.childrenscardiomyopathy.org/site/pamphlets.php

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