

CCF-ACCREDITED CENTER OF CARE FORM INSTRUCTIONS

To be considered as a CCF-Accredited Center of Care, please complete this form so that we may evaluate your center's information against CCF's accreditation requirements. If approved, your center's information will be made available to parents of children with cardiomyopathy.

The deadline for submission is the second Friday of July every year. CCF will announce new designated Accredited Centers of Care in September. Listed below are instructions for completing certain sections of the form.

HOSPITAL INFORMATION

- List the heart center or pediatric cardiomyopathy program or clinic if there is a specific name.
- Provide the physical address of the pediatric cardiomyopathy (PCM) clinic, heart center, or pediatric cardiology department where patients go to see their doctor.
- Provide the general phone number for patient inquiries and appointments for the pediatric cardiomyopathy program (PCM) or pediatric cardiology department if there is no specific PCM program.
- Provide website address for the pediatric cardiology department or the pediatric cardiomyopathy program.

PEDIATRIC CARDIOMYOPATHY PROGRAM

- A center with a pediatric cardiomyopathy (PCM) program utilizes a multi-disciplinary approach to evaluation, treatment, and long-term management. If your center has a special day and time during the week to see cardiomyopathy patients, please provide clinic hours for each day.
- If your center has a hypertrophic cardiomyopathy (HCM) program that caters to both adults and children, please complete the sections that are applicable to your HCM program.

PEDIATRIC CARDIOMYOPATHY PATIENT POPULATION

- Provide both the total number of diagnosed pediatric cardiomyopathy (PCM) patients managed at your center in the past 12 months and the total number of visits by patients with pediatric cardiomyopathy at your center in the past 12 months. Please do not include patients seen outside your center in satellite locations.
- Include pediatric patients with any form of pediatric cardiomyopathy: dilated cardiomyopathy (DCM), hypertrophic cardiomyopathy (HCM), restrictive cardiomyopathy (RCM), left ventricular non-compaction cardiomyopathy (LVNC) or arrhythmogenic right ventricular cardiomyopathy (ARVC).
- Include both primary and secondary forms of cardiomyopathy when calculating the number of pediatric cardiomyopathy patients. Also, include both new patients and past patients being monitored in the last 12 months.

RESEARCH PARTICIPATION

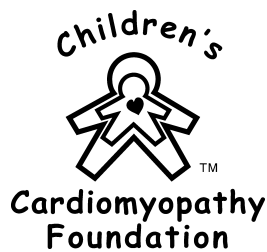
- Check the appropriate box if your center has submitted or submits patient data to the North America Pediatric Cardiomyopathy Registry (PCMR) or blood or tissues samples to the Pediatric Cardiomyopathy Repository.

CCF RESOURCES

- CCF provides patient educational materials to medical centers free of charge. Visit www.childrenscardiomyopathy.org (click on Support Services/Educational Materials) to view. All materials are written for a lay audience and have been reviewed by a physician.
- Indicate if you are interested in educating families about cardiomyopathy by participating in a CCF webinar or Expert Q&A session as a featured guest. Past topics have included pediatric heart failure and transplantation, diagnostic testing, medications, device therapy, transition to adult care, genetics and genetic testing, and psychosocial issues.

CCF CONTACT

Janine Burke, Medical Outreach Manager
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ACCREDITED CENTER OF CARE FORM

Please return form by fax to 201.227.7016 or by email to gpeattie@childrenscardiomyopathy.org.
For questions about the application process, please call Gina Peattie at 866.808.CURE, ext. 905.

GENERAL INFORMATION

Date	
Name	
Title	
Email	
Phone	

HOSPITAL INFORMATION

Hospital Name	
Heart Center or PCM Clinic Name	
Street Address	
City/State/Zip Code	
Mailing Address (if different)	
City/State/Zip Code	
Phone	
Website	
Medical School Affiliation	

PEDIATRIC CARDIOMYOPATHY PROGRAM

Does your hospital have a pediatric cardiomyopathy <u>or</u> hypertrophic cardiomyopathy program? <i>(If neither, please skip to "Pediatric Cardiology Services" on pg. 2)</i>	PCM Clinic <input type="checkbox"/> HCM Clinic <input type="checkbox"/> Neither <input type="checkbox"/> Both Clinics <input type="checkbox"/>
Medical Director of Pediatric Cardiomyopathy Program	
PCM Program Coordinator	
Coordinator Email	
Coordinator Phone	
Are there specific clinic hours for pediatric cardiomyopathy patients?	Yes <input type="checkbox"/> No <input type="checkbox"/>
PCM Clinic Days	M <input type="checkbox"/> T <input type="checkbox"/> W <input type="checkbox"/> TH <input type="checkbox"/> F <input type="checkbox"/> SA <input type="checkbox"/> SU <input type="checkbox"/>
PCM Clinic Hours <i>(specify if different each day)</i>	

PEDIATRIC CARDIOLOGY SERVICES

What pediatric cardiomyopathy related services are available at your hospital? *(check all that apply)*

High Quality Imaging (echocardiogram, cardiac magnetic resonance imaging)

Interventional Cardiology (catheterization, endomyocardial biopsy)

Cardiac Surgical Services (septal myectomy, cardiac device implantation)

Heart Failure Management and Heart Transplantation

Prenatal or Fetal Echocardiography Pediatric Cardiac Electrophysiology

Genetic Testing and Counseling Pediatric Neurology

Social Work Child Life

Nutritionist Cardiac Rehabilitation Service

Other *(please specify)*

PEDIATRIC CARDIOMYOPATHY PATIENT POPULATION

Total # of PCM related surgical operations (myectomy, ICD implantation) performed at your hospital in the past 12 months?		
Data Source	Database <input type="checkbox"/> Estimate <input type="checkbox"/> Business Office <input type="checkbox"/> Other <input type="checkbox"/>	
Total # of VAD support procedures at your hospital in the past 12 months?		
Data Source	Database <input type="checkbox"/> Estimate <input type="checkbox"/> Business Office <input type="checkbox"/> Other <input type="checkbox"/>	
Total # of pediatric cardiac transplants performed at your hospital in the past 12 months?		
Data Source	Database <input type="checkbox"/> Estimate <input type="checkbox"/> Business Office <input type="checkbox"/> Other <input type="checkbox"/>	

PEDIATRIC CARDIOLOGY STAFF

Chief of Pediatric Cardiology	
Medical Director of Heart Center <i>(if different)</i>	
Medical Director of Pediatric Cardiac Transplant Program	
Cardiologist Name	
Cardiologist Name	
Cardiologist Name	
Cardiologist Name	
Cardiologist Name	
Cardiologist Name	

HEALTHCARE STAFF

Social Worker Name	
Child Life Specialist Name	
Genetic Counselor Name	
Cardiac Nurse Name	
Cardiac Nurse Name	
Cardiac Nurse Name	

PEDIATRIC CARDIOMYOPATHY PATIENT POPULATION

How many pediatric cardiomyopathy patients (DCM, HCM, RCM, LVNC, ARVC) were seen at your hospital in the past 12 months? (Include both primary and secondary forms of CM in children under age 18)			
Total # of PCM Patients Managed		Total # of PCM Patient Visits	
Date Source	Database <input type="checkbox"/>	Estimate <input type="checkbox"/>	Business Office <input type="checkbox"/> Other <input type="checkbox"/>
PCM Patients by Type <i>(if known)</i>	DCM:	Data Based on: (check one): Number of Patients <input type="checkbox"/> % of Patients <input type="checkbox"/>	
	HCM:		
	RCM:		
	LVNC:		
	ARVC:		
Data Source	Database <input type="checkbox"/>	Estimate <input type="checkbox"/>	Business Office <input type="checkbox"/> Other <input type="checkbox"/>

RESEARCH PARTICIPATION

Does your hospital participate in pediatric cardiomyopathy research studies?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Does your hospital participate in any of these research groups/efforts? (check all that apply)	
Pediatric Cardiomyopathy Registry <input type="checkbox"/>	Pediatric Cardiomyopathy Repository <input type="checkbox"/>
Pediatric Heart Transplant Study Group <input type="checkbox"/>	Pediatric Heart Network <input type="checkbox"/>

CCF RESOURCES

Do you have any CCF patient education materials?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Would you like to receive CCF educational materials?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Would you consider being a featured guest for a CCF webinar or Expert Q&A session?	Yes <input type="checkbox"/> No <input type="checkbox"/>
Would you like to schedule a phone call to learn more about CCF's family resources and services?	Yes <input type="checkbox"/> No <input type="checkbox"/>

ADDITIONAL COMMENTS