UNDERSTANDING

PEDIATRIC CARDIOMYOPATHY

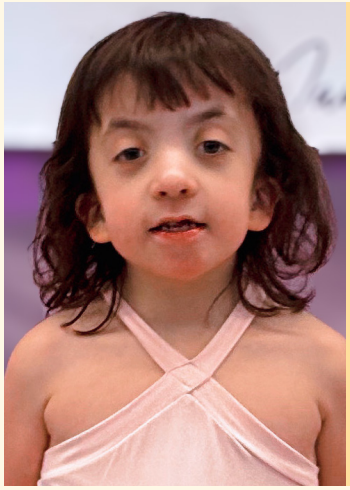
Children's Cardiomyopathy Foundation

What is pediatric cardiomyopathy?

Cardiomyopathy means “a disease of the heart muscle.” It is a chronic and sometimes progressive disease in which the heart muscle (myocardium) becomes abnormally enlarged, thickened, and/or stiffened such that the heart can no longer contract or relax normally. Eventually, the heart loses its ability to pump blood effectively, and irregular heartbeats (arrhythmias) and heart failure may occur.

Cardiomyopathy can affect anyone regardless of age, race, sex, or socioeconomic background. Cardiomyopathy predominantly affects adults. However, in rare instances, it does affect infants and children, in which case it is called **pediatric cardiomyopathy**.

According to the CCF-supported Pediatric Cardiomyopathy Registry (PCMR), 1 in every 100,000 children in the U.S. under the age of 18 is diagnosed with cardiomyopathy. This conservative estimate does not include children that are undiagnosed or have secondary cardiomyopathy, where the heart condition is caused by infection, metabolic irregularities, or another systemic disease.



Saoirse, who was diagnosed with HCM and Noonan syndrome, has a fighting spirit that shines through her sweet smile even amid her challenging diagnosis.

There are five types of cardiomyopathy

Arrhythmogenic Cardiomyopathy (ACM)

ACM is the least common form and extremely rare in young children. Instead, it usually presents in teens or young adults. ACM is caused by the death of healthy heart muscle and its replacement with scar tissue and fat. This results in a disorganized structure of heart muscle tissues causing abnormal electrical activities (arrhythmias) and problems with the heart’s contraction.

Dilated Cardiomyopathy (DCM)

DCM is the most common form, which occurs when the muscle fibers of one or both pumping chambers are weak and unable to contract normally. As the heart pumps less strongly, it enlarges to help deliver more blood with each beat. Eventually, the weakened heart fails, causing fluid to build up in other organs.

Hypertrophic Cardiomyopathy (HCM)

The second most common form, HCM, is characterized by the abnormal growth and arrangement of muscle fibers in the heart. The thickened and stiffer heart muscle reduces the capacity of the heart to fill and contract properly. This may lead to arrhythmia or obstruction of blood outflow from the heart. In advanced HCM, the heart muscle may thin and stretch to compensate for the poor pumping action.

Noncompaction Cardiomyopathy (NCCM)

NCCM is a rare form of cardiomyopathy that can manifest as DCM, HCM, or RCM. With this condition, the developing heart muscle fails to become compacted, resulting in a spongiform appearance of the chamber wall, increased muscle thickness, and weak pumping action.

Restrictive Cardiomyopathy (RCM)

RCM is a less common condition, and it accounts for 3 to 5 percent of patients with cardiomyopathy. With this form of cardiomyopathy, the heart has normal contraction, but abnormal relaxation. The walls of the ventricles become stiff, preventing the heart from filling with blood. The low amount of blood in the heart leads to exercise intolerance and heart failure.

Each type of cardiomyopathy is characterized by a slightly different disease process and set of symptoms. For specific information on the different forms of cardiomyopathy, please refer to the inserts available for this booklet.

What causes cardiomyopathy?

Currently, the cause of cardiomyopathy in children is poorly understood. Approximately two-thirds of reported cases do not have a known cause. Of those cases where a cause is identified, myocarditis (27 percent) and familial inheritance (25 percent) are the leading reasons according to the PCMR. This is followed by neuromuscular disorders (22 percent), metabolic disorders (16 percent), and genetic malformation syndromes (10 percent).

Cardiomyopathy can be inherited or acquired. Some cardiomyopathies (primary cardiomyopathies) are isolated and affect only the heart, while other cardiomyopathies (secondary cardiomyopathies) are associated with medical problems unrelated to the heart. Both can be caused by genetic or unknown (idiopathic) reasons. Genetic conditions are usually caused by changes in specific genes (mutations) that are inherited from one or both parents. In some instances, cardiomyopathy can occur for the first time in a family due to a sporadic genetic mutation in the child that is not inherited from either parent. This happens when changes in the DNA of a gene occur spontaneously during fetal development for unknown reasons.

When the disease is inherited, there are several ways that cardiomyopathy can be passed on to the child. In autosomal dominant genetic conditions, one parent carries a genetic mutation for cardiomyopathy and has a 50 percent chance of passing the mutation on to their child. Usually, this parent also has cardiomyopathy, and may or may not show symptoms of the disease. In autosomal recessive genetic conditions, such as fatty acid oxidation defects or glycogen storage diseases, both parents are unaffected carriers and have a 25 percent chance of having an affected child. Some forms of cardiomyopathy caused by Barth syndrome or Duchenne muscular dystrophy can occur sporadically in boys or may be passed on from mother to son (X-linked transmission). In these cases, sons will be at a 50 percent risk of having the condition while daughters will not have the condition, but may be carriers like their mothers.

Pedro, who was diagnosed with DCM, is a joyful and delightful boy who loves to walk, paint, and play with water.

Some cardiomyopathies are acquired due to exposure to infection, toxins, or medications that can weaken the heart muscle. The most common cause of acquired cardiomyopathy is myocarditis, a viral infection that causes inflammation of the heart. Viruses that can affect the heart include coxsackie A & B, echovirus, adenovirus, HIV, and mumps. Less common causes of acquired cardiomyopathy include nutritional deficiencies and exposure to excessive alcohol, radiation, heavy metals, and cancer chemotherapy drugs.

Cardiomyopathy can also develop in response to an underlying medical condition that affects other organs or the entire body system. These include metabolic and mitochondrial abnormalities, buildup of proteins in the heart (amyloidosis), excess iron in the heart (hemochromatosis), thyroid disorders, severe anemia, complications from other cardiovascular conditions (congenital heart defect, hypertension, or surgery), autoimmune disease (lupus), and pregnancy-related complications.

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There are more than 100 specific causes of cardiomyopathy in children that can be classified into one of five forms (ACM, DCM, HCM, NCCM, and RCM). Determining the root cause of the disease can be a complex and involved process. Most of the rare disorders associated with cardiomyopathy can only be confirmed by diagnostic testing and evaluation from other medical specialists. Your child's cardiologist and team of specialists (geneticists, neurologists) will work together to determine the cause of the disease in your child.

How is cardiomyopathy diagnosed?

Since pediatric cardiomyopathy is rare, it can be missed or misdiagnosed. Many times, the disease goes undetected in young children because there is no family history of cardiomyopathy or the child shows no symptoms (asymptomatic). Many children with cardiomyopathy are active, appear healthy, and meet their developmental milestones.

An accurate and thorough diagnosis involves determining the type of cardiomyopathy, its severity, and cause. The more specific the diagnosis, the more tailored and effective the treatment can be. If a child is suspected of having cardiomyopathy, an evaluation will begin with a visit to a pediatric cardiologist for a complete history review and physical examination. During the evaluation, the cardiologist will ask about the child's and family's medical history, symptoms, and prior medical tests. The physician will also examine the child and listen to the heart through a stethoscope. Specific cardiac tests will follow to determine the heart's size and whether there is thickening, blood flow obstruction, or valve leakage.

Diagnosis is confirmed by an electrocardiogram (ECG/EKG) and two-dimensional echocardiogram with Doppler ultrasound. An ECG/EKG records the heart's electrical activity (rate and rhythm) using electrodes placed on the child's arms, legs, and chest. An echocardiogram uses ultrasound waves to produce moving pictures of the beating heart on a video screen. These cross-sectional views of the heart allow the cardiologist to measure the heart's size, muscle thickness, pumping ability, degree of obstruction and potential leakage (regurgitation).

Other noninvasive procedures may be performed, including magnetic resonance imaging (MRI), a Holter monitor, and an exercise stress test for older children. In some cases, an invasive procedure under anesthesia may be necessary for further investigation of the heart's function or to determine possible causes. This includes cardiac catheterization, radionuclide ventriculogram, heart (endomyocardial) biopsy, skeletal muscle biopsy, or an electrophysiology (EP) study. These procedures are explained in more detail on CCF's website.

If necessary, the diagnostic visit also may involve blood or urine testing,

assessment of a child's neurological development and muscle tone, review of any unusual physical features associated with other syndromes, and evaluation of any organs that might be affected. Some forms of cardiomyopathy are further defined by genetic testing.

During the evaluation process, you may work with a pediatric cardiologist, geneticist, heart surgeon, and possibly specialists from neurology, immunology, nutrition, endocrinology, and infectious disease. Whenever possible, it is best to work with a team of experts at a medical center that treats many children with cardiomyopathy and engages in research on the disease. These are usually large teaching hospitals with a pediatric cardiomyopathy clinic and a heart failure or heart transplant program. CCF's Centers of Care Program recognizes medical centers with expertise in pediatric cardiomyopathy. These hospitals provide high-quality cardiac care and specialized disease management to children with cardiomyopathy.

What are the common symptoms?

Cardiomyopathy is an extremely variable disease which can manifest differently in adults and children. Symptoms can vary with different forms of cardiomyopathy and even among family members with the same form of cardiomyopathy. Symptoms can be absent, mild or severe.

Children may be diagnosed following the detection of a heart murmur or evidence of heart enlargement during a routine visit to the pediatrician. However, the signs of cardiomyopathy are not always so obvious in children. Symptoms may be mistaken for being a common cold, flu, asthma, or stomachache. In babies and young children, it is more difficult to assess the severity of the disease because they are not able to clearly communicate how they feel.

Many children are only referred to a heart specialist once more serious symptoms appear. These symptoms include shortness of breath, rapid breathing, fainting spells (syncope), irregular or rapid heart rate (palpitations), chest pain, and extreme fatigue. In infants, symptoms include poor weight gain, difficulty feeding, excessive sweating (diaphoresis), and unusual fussiness or lethargy. For information about symptoms associated with a particular form of cardiomyopathy, please refer to the ACM, DCM, HCM, NCCM, and RCM inserts available with this booklet.

What are available treatment options?

Cardiomyopathy is a chronic disease of the heart muscle. Unfortunately, there is no treatment that can repair the structural damage of the heart. If detected in the early stages, cardiomyopathy can be controlled with medications and certain surgical procedures. In general, the goal is to restore a child to the best possible health with the least amount of intervention.

A child's treatment plan should be done in consultation with a pediatric cardiologist, and if necessary, a cardiothoracic surgeon, electrophysiologist, and geneticist. Treating cardiomyopathy in a standardized manner is difficult because of its variability in manifestation and outcome. Each type of cardiomyopathy has slightly different symptoms, and therefore requires an individualized treatment plan to address varying short- and long-term medical issues. Several factors, such as the child's age, overall health, medical history, underlying cause, disease severity, tolerance for certain medications and procedures, and the expected outcome for the disease will determine the appropriate therapy. The risk of arrhythmia, sudden cardiac arrest, and progressive heart failure will also determine how aggressive treatment should be.

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Medication or medical therapy is used for various reasons: to help the heart pump more effectively, control symptoms related to heart failure or blood flow obstruction, prevent the formation of blood clots, reduce inflammation, and regulate abnormal heart rhythms. Medications commonly prescribed include angiotensin-converting enzyme (ACE) inhibitors, beta-blockers, calcium channel blockers, digoxin, diuretics, antiarrhythmics, antibiotics, and anticoagulants. These medications require careful monitoring for possible side effects and changes in heart function. The medications and dosages will depend on each child's heart condition and may change as the child grows and responds to therapy.

If a child has an irregular heartbeat, a pacemaker or automatic implantable cardioverter-defibrillator (AICD) may be recommended. This is a small mechanical device surgically placed under the skin of the chest or abdomen with wire leads attached to the surface of the heart. In older children, this can be done without surgery in the catheterization laboratory, with the device placed under the skin of the chest and the wire leads threaded through the veins into the heart. This is a self-regulating sensing device that activates when a patient's heartbeat reaches dangerously high or low levels. In some DCM cases, a biventricular pacemaker may be used to synchronize the contraction of the left and right chambers of the heart, even without the presence of arrhythmia.

Surgery may be an additional treatment option for HCM patients. A septal myectomy involves removing a part of the thickened heart muscle. When there is mitral regurgitation, a valve repair or replacement is performed to stop leakage of blood from the left ventricle into the left atrium (mitral regurgitation). These surgical procedures help to control symptoms of heart failure, but they do not stop the progression of the disease. For DCM and RCM, there are no surgical options for improving symptoms.

When a child no longer responds to treatment and experiences end-stage heart failure, a heart transplant may be necessary. While waiting for a donor heart, intravenous medications and cardiac assist devices may be used to extend the life of a child's heart.

Maëlys, diagnosed with NCCM, enjoys the outdoors and attending church with her family. She loves butterflies, books, and dinosaurs, as well as singing and playing musical instruments.

What is the likely prognosis for my child?

The long-term outlook of pediatric cardiomyopathy continues to be unpredictable because of its multiple causes and wide spectrum of disease presentation and outcomes. It is not unusual for one child to have a more severe form of the disease and another sibling or parent to have a mild or asymptomatic form of the same disease. The overall prognosis for a child will depend on the type of cardiomyopathy, cause of the disease, family history, and the severity of cardiac dysfunction when diagnosed.

Although there is no cure for the disease, symptoms and complications can be managed and controlled with regular monitoring. Some children will stabilize with treatment and lead a relatively normal life with few physical activity restrictions. Other children, with a more serious form of cardiomyopathy, may face more limitations, need specialized care, and encounter minor developmental delays. Occasionally, children with certain types of cardiomyopathy do improve, but the majority do not show any recovery in heart function.

For the most severe cases, a heart transplant may be necessary. Children diagnosed with DCM or RCM are more likely to require a transplant. This is less common with HCM. Post-transplant survival continues to improve with two-year survival rates greater than 80 percent, and ten-year survival rates near 70 percent. Survival outcomes continue to improve with more medical progress and research.

Should my family undergo screening or genetic testing?

Since cardiomyopathy can be inherited, other family members may be at risk, even if they do not have symptoms. Therefore, it is recommended that parents and siblings of a diagnosed child undergo an echocardiogram and ECG/EKG screening. This is especially important for at-risk individuals where there is a family history of sudden infant death, sudden cardiac arrest, or heart attack under the age of 40. Even if the initial exam results are normal, family members may need periodic re-screening. Screening frequency will depend on the type of cardiomyopathy, its cause, and the age of the individual. Your cardiologist and geneticist will advise what is appropriate for your family's medical situation.

Clinical genetic testing may also be an option for certain types of cardiomyopathies. These diagnostic tests can determine whether an individual has a known genetic mutation that may cause the disease. Early detection can lead to treatments that can control or limit the damage caused by the disease. If a child is known to have a genetic mutation associated with cardiomyopathy, testing immediate family members may be useful in determining whether the parents or siblings are also at risk for developing cardiomyopathy. Additionally, parents discovered to carry a gene mutation associated with cardiomyopathy should seek genetic counseling to determine who else in the extended family may be at risk, and to discuss the possibility of recurrence in future pregnancies.

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How will the disease impact my child and family?

While pediatric cardiomyopathy is a serious heart condition, many children can lead a normal life with proper medical management. The degree of impact on lifestyle will depend on whether a child improves, stabilizes, or progresses to an advanced stage of heart failure. A diagnosis will mean more frequent visits to the cardiologist to monitor changes in heart function, evaluate treatment effectiveness, and discuss any new complications. It may also mean daily intake of various medications and some activity restrictions. If surgical procedures are required and there is prolonged hospitalization, a child may temporarily fall behind developmentally or academically.

Daily challenges that might arise include dealing with the psychological issues of living with a chronic disease and adjusting to modified routines related to medication intake, diet, and restrictions on activity level. As a child gets older, other issues such as handling school and social situations, obtaining special child services, ensuring medication compliance, and securing health and life insurance may arise.

Poor appetite and slow weight gain are common in children with cardiomyopathy. This is due to a child's inability to take in sufficient calories while the body tries to compensate for the heart's increased workload. Symptoms such as rapid breathing, fatigue, respiratory infections, and abnormal absorption of nutrients may also contribute to poor appetite. In this situation, a nutritionist may recommend smaller, more frequent feedings, a higher calorie diet, or supplements to encourage weight gain. With metabolic-based cardiomyopathies, a low-fat diet, special formulas, or supplements may be prescribed to help regulate body function. In addition, children taking certain types of medication may require higher levels of magnesium or potassium in their diet, whereas children with DCM and those in heart failure may need a low-sodium diet to prevent fluid retention.

How will cardiomyopathy impact school?

Some children do have physical activity restrictions, and they are unable to participate in gym activities that involve vigorous exertion. For children at risk of sudden cardiac arrest (SCA), they may be advised to refrain from weightlifting, competitive team sports, and strenuous activities that could put strain on the heart. Excessive sweating or exposure to extreme temperatures may also aggravate existing symptoms. Moderate exercises, walking, and less intense recreational sports are acceptable as long as they do not lead to dehydration or exhaustion.

Lena, diagnosed with NCCM after surviving a sudden cardiac arrest, is now a budding artist who loves drawing, painting, and crafting. At the young age of 2, she served as a CCF *Walk for a Cure* Ambassador.

KATELYN

Guidelines for physical activity restrictions should be set by your child's physician based on your child's type of cardiomyopathy, family medical history, disease severity, and medical management.

All school personnel, including the principal, school counselor, nurse, classroom teachers, gym instructor, and special education coordinator should be made aware of your child's diagnosis. Depending on your child's condition, school modifications and accommodations may be necessary. It is advisable to schedule a meeting at the beginning of the school year to discuss academic or social issues that might arise. Practical issues such as common symptoms, medication side effects, special dietary needs, precautions related to implantable devices, and exercise and sports restrictions should be discussed. The need for automated external defibrillators (AEDs) and CPR-trained personnel on school premises should also be covered.

Parents can work with school staff to develop three essential plans: an education plan, a health plan, and an emergency plan. An individualized education plan (IEP) states what special educational services or modifications a child needs to function at their greatest potential in school. This plan may detail a place and time to take medication, request special test-taking or homework modifications, require adaptive physical education, and specify special arrangements to reduce fatigue during the school day. The health needs of your child are addressed by the health plan, which includes basic information about


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the disease, contact information, medication administration and possible side effects, physical activity restrictions, and emergency care. The emergency care plan provides details about how to recognize and respond to a cardiac emergency. This may include information about your child's treatment, warning signs, appropriate interventions, and emergency contact information. More information about these plans and how to best work with your child's school system can be found in CCF's Ensuring a Good Learning Environment: A Cardiomyopathy Resource Kit for Parents and School Personnel.

Aside from diet and school concerns, other decisions will need to be made. This includes whether your child should wear a medical alert bracelet, whether to purchase an AED for home and travel use, and whether to schedule annual flu shots to protect your child's heart from influenza. Your child's doctor should be consulted on whether antibiotics are needed before dental or surgical procedures, and which over-the-counter decongestants or herbal remedies should be avoided.

Consideration should be given to how the disease is explained to your child, their siblings, and others close to them. A parent can help siblings, friends, and classmates understand and accept their child's condition by talking about the disease in simple terms, using age-appropriate books, and through role-play. Child life professionals and child psychiatrists can help you address any further concerns that you or your child may have. More information about explaining a cardiomyopathy diagnosis to children and adolescents can be found in the *Cardio What?* guidebook developed by CCF in partnership with the National Society of Genetic Counselors, Inc. (NSGC).

How do I cope with a chronic disease?

As with any chronic and potentially life-threatening disease, the entire family is affected. The possibility of deterioration or premature death creates unique social and emotional issues for families. The anxiety of an uncertain future, combined with the isolation of dealing with a rare disorder can, at times, make raising a child with cardiomyopathy stressful. Some families feel responsible for passing the disease on to their child, while others mourn the lost dream of raising a healthy child. As a parent, it is natural to feel a mixture of intense emotions such as fear, anger, guilt, shame, and sadness. Keeping a journal, maintaining open communication with family members, and developing a support network — whether it is relatives, friends, a faith-based group, or other cardiomyopathy families — will help you accept the challenges of living with the disease.

Being knowledgeable about the disease can also alleviate feelings of anxiety and helplessness. Educate yourself and your family about pediatric cardiomyopathy, and be prepared for a cardiac emergency should it occur. Some parents may become more protective of their child's safety, but it is important to try to maintain a "normal" lifestyle and allow your child to interact with other children and engage in routine play. As long as your child is being monitored regularly and receiving appropriate treatment, the likelihood of a sudden cardiac event is low. As your child gets older, they may face different social and emotional issues related to the disease. While your child passes through these stages, you should try to manage your own feelings so that your fears and disappointments do not interfere with your child's coping process or outlook on life. With many children, restrictions in activities can make them feel different or left out. Therefore, it is important to introduce your child to new activities that are less physically demanding, yet are rewarding and enjoyable. Be positive about what your child can do rather than focus on what they cannot do. Work together to find special-interest clubs and activities that provide a sense of inclusion, as well as self-assurance.

You can help your child adjust by educating them about the disease and about what to expect. Encourage your child to become involved in their own care, to recognize their physical limitations, and to be aware of certain warning signs that require immediate medical attention. Your child should also feel comfortable talking about their condition with others. With this approach, your child will more likely be confident and positive about living with cardiomyopathy.


MYLES

Where do I go for more information and support?

Cardiomyopathy is a complex disease, and it can be difficult to understand completely. Healthcare professionals, support groups, and other resources can provide you with medical information, practical advice, and emotional support.

The Children's Cardiomyopathy Foundation (CCF) (childrenscardiomyopathy.org) provides detailed information on pediatric cardiomyopathy as well as helpful resources. Additional resources include the American Heart Association (heart.org), the National Organization for Rare Disorders (rarediseases.org), and the National Heart, Lung and Blood Institute (nhlbi.nih.gov). For more specific answers to your child's treatment or care, you should contact your child's pediatric cardiologist or nurse.

Talking to families with similar circumstances can also be comforting. Group support can be especially helpful at the beginning stages and on a long-term basis. The Children's Cardiomyopathy Foundation (CCF) can help put you in touch with other affected families who understand the issues that you are facing through CCF's Ambassador Program. Additionally, CCF's private online **community**, *CCF Connect,* serves as a safe space for registered families of children with cardiomyopathy to connect, ask questions, and support one another.

Kenna was diagnosed with DCM and had open-heart surgery at 4 weeks old. She has improved on medication and is now a spunky kid who loves playing outside, singing, and riding her scooter.

What research is underway?

Most research to date has been focused on identifying the genes that cause cardiomyopathy and on understanding how these genetic abnormalities contribute to the disease. Some studies use mouse or other animal models to mimic the disease found in humans. Others are genetic studies of extended families with a strong history of the disease. CCF has supported various research initiatives to collect DNA and tissue samples to better understand the genetic basis of cardiomyopathy.

While new genetic causes are being identified, researchers are also studying why the disease manifests and progresses so differently among individuals affected by the same genetic mutation. Molecular-based research helps in the development of genetic tests that are specific to pediatric cardiomyopathy. These diagnostic tests, performed in a clinical lab, are used to identify or rule out cardiomyopathy, guide family planning, and aid asymptomatic family members in making informed medical care decisions.

In addition to basic research, epidemiological and clinical research are also being conducted. The National Institutes of Health (NIH)-funded North American Pediatric Cardiomyopathy Registry (PCMR) is tracking and analyzing clinical data on the features and outcomes of children with various forms of cardiomyopathy. Other multi-center studies focusing on factors affecting disease progression and long-term health outcomes have been initiated by the Pediatric Heart Network (PHN) and Pediatric Heart Transplant Study (PHTS) Group.

Getting more families involved in research is important for advancing medical knowledge of the disease. Currently, studies are looking at how heart function changes over time and how new therapies can improve symptoms and heart function in children with cardiomyopathy. If your child or another family member is interested in participating in clinical research, a cardiologist or geneticist can guide you in selecting the right study. ClinicalTrials.gov is a commonly used resource for identifying federal and privately-supported clinical studies.

What else should I keep in mind?


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It is important to remember that cardiomyopathy in children is rare. Information on the disease is limited, and knowledge in the field is still evolving. When reviewing published medical literature on the disease, parents should keep in mind that there is a wide spectrum of outcomes, and studies may be based on the most serious cases or on a small sample group.

With any rare condition such as pediatric cardiomyopathy, parents and caregivers need to take an active role in their child's disease management. Try to learn as much as possible about your child's disease so that you can make informed decisions. Prior to any appointment, prepare a list of questions to discuss all relevant concerns. Remember that no question is too simple or unimportant to ask. Also, work closely with your child's medical team to provide feedback that might assist in their evaluation and treatment.

When necessary, do not be afraid to seek a second opinion or to ask your physician to consult with a cardiomyopathy and heart failure center. Specialists at these medical centers will likely have more experience managing children with cardiomyopathy and be aware of the latest treatment developments. These specialty centers will also have expertise in arrhythmia, heart failure, cardiac assist devices, and transplantation. CCF's Centers of Care program recognizes medical centers with expertise in pediatric cardiomyopathy. These hospitals provide high-quality cardiac care and specialized disease management to children with cardiomyopathy. Educating yourself about the disease, taking a proactive approach, and consulting with the top specialists will ensure that your child gets the best possible medical care.

About the Children's Cardiomyopathy Foundation (CCF)

The Children's Cardiomyopathy Foundation (CCF) is a national non-profit organization dedicated to finding causes and cures for pediatric cardiomyopathy. CCF was established in 2002 with one family's determination to call attention to this chronic 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 focused on improving diagnosis, treatment, and quality of life for children with cardiomyopathy.

CCF is involved in all aspects of the disease ranging from research and education to patient support, awareness, and advocacy.

To date, more than 20 million dollars has been raised to support cardiomyopathy-related programs in research, education, and family support. CCF has led the way in funding multi-center studies, developing educational materials, planning scientific conferences, and getting the first cardiomyopathy-focused legislation passed in Congress and signed into law.

CCF continues to be an invaluable lifeline to thousands of affected families worldwide by providing information, resources, and guidance. Currently, CCF's educational materials are distributed to more than 45 hospitals in the U.S. and Canada. CCF's hope for the future is that more lives will be saved, and every child with cardiomyopathy will have a chance to live a full and active life.

This booklet, featuring real children with cardiomyopathy, was created to provide families and caregivers with a broad overview of cardiomyopathy and is for general information only. The material presented is not intended to be complete or serve as medical advice. The information should not be a substitute for consultation with a qualified health care professional who is more familiar with individual medical conditions and needs. For additional questions, please contact your child's physician.

Register with CCF for additional resources: childrenscardiomyopathy.org

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Children's Cardiomyopathy Foundation

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