



# Ensuring a Good Learning Environment:

## A Guide for Parents of a Child with Cardiomyopathy



## **Pediatric Cardiomyopathy**

This guidebook was developed to guide parents of children with cardiomyopathy in working effectively with school personnel so that their children can enjoy a successful educational and social experience throughout their school years.

## Why This **Guidebook?**

---

This booklet accompanies a second guidebook, *A Cardiomyopathy Guide for School Personnel*, which is intended to help teachers and administrators learn about cardiomyopathy and the challenges that children with this disease face.

School personnel may be familiar with the legal requirements associated with having a disabled child in class, and they may have experience teaching other children with chronic conditions such as diabetes. Most, however, will be unfamiliar with the unique and potentially serious nature of pediatric cardiomyopathy. As a result, parents of children with this disease often find themselves in the position of having to act as educators and advocates for their children. This can be a positive experience if approached proactively, and the material in this guidebook is designed to help parents do this.

This guidebook will help parents understand their children's rights by federal law and will describe the legal documents available to help coordinate appropriate management within the school setting. It advises parents on effective ways of working with school personnel, including step-by-step suggestions for drafting letters, facilitating meetings, creating plans and more. Finally, it contains sample documents that parents may use in developing their own individual health, education and emergency plans for their children.

# **A Good Learning Environment: Your Child's Rights by Law**

According to federal law, school districts must provide a safe and supportive educational environment for students with chronic illnesses and ensure that such students have the same educational opportunities as do other students. This means that parents have the right to participate in the development of written plans that will ensure that their child's health and educational needs are being met.

The following laws protect children’s rights to a fair education and ensure that school districts will implement necessary accommodations.

## **Section 504**

This refers to Section 504 of the Rehabilitation Act of 1973. This civil rights law protects the rights of individuals with disabilities in programs and activities that receive federal funds from the U.S. Department of Education. Section 504 specifically requires school districts to provide a “free appropriate public education” (FAPE) to each qualified person with a disability. If medical accommodations or educational services are needed, a Section 504 education plan may be developed for a child with cardiomyopathy.

## **IDEA**

The Individuals with Disabilities Education Improvement Act of 2004 is a comprehensive civil rights law that protects those whose disability adversely affects their educational performance. It also provides special education services for eligible students between age 3 and 21.

## **ADA**

The Americans with Disabilities Act of 1990 and Amendment Act of 2008 guarantees equal opportunity to people with disabilities in employment, public accommodations, transportation, state and local government services, and telecommunications. It mandates that schools must make reasonable accommodations, such as making existing facilities accessible for people with disabilities.

## **FERPA**

The Family Educational Rights and Privacy Act protects the privacy of student education records.

# Asserting Your Child's Rights

Children with cardiomyopathy have the right to a “free appropriate public education.” By federal law, the school is required to make “reasonable accommodations” so that children with disabilities may access all facilities and participate in regular school activities, field trips and extracurricular activities.

It is the responsibility of the parents to inform the district of their child's medical condition and to request whatever accommodations may be necessary.

In order to advocate for your child's best interests, you will need to provide information to school personnel about cardiomyopathy and the modifications needed because of the disease. The following table lists common medical concerns among children with cardiomyopathy and provides examples of what may be considered “reasonable accommodations” in a school setting.

| <b>Common Medical Concerns</b>   | <b>Suggested School Modifications &amp; Accommodations</b>  |
|--|---|
| <b>Medications needed during school hours</b>  | <ul style="list-style-type: none"> <li>• Understand intake schedule and administration procedure.</li> <li>• Provide hall passes and allow time for scheduled nursing visits.</li> </ul>  |
| <b>Side effects from medication such as diminished concentration or increased need to use the restroom</b> | <ul style="list-style-type: none"> <li>• Understand the child's health plan, including potential effects of medications and how they may affect school performance.</li> <li>• Schedule extra time for certain tests.</li> <li>• Allow restroom privileges as needed.</li> </ul>  |
| <b>Physical activity restrictions due to the risk of sudden cardiac arrest</b>                             | <ul style="list-style-type: none"> <li>• Modify physical education class as recommended by the child's physician.</li> <li>• Work with the child to select alternative activities.</li> </ul>   |
| <b>Dietary monitoring, increased food and fluid intake</b>   | <ul style="list-style-type: none"> <li>• Allow child to have water or snacks in the classroom if recommended.</li> <li>• Work with school on meal plans and inform lunch supervisor of any special food needs.</li> </ul>   |
| <b>Fatigue due to medications or diagnosis</b>   | <ul style="list-style-type: none"> <li>• Allow two sets of textbooks (one for home and one for classrooms) if needed.</li> <li>• Permit access to elevators if stairs are problematic.</li> <li>• Schedule classes closer together or allow extra time to travel within buildings.</li> <li>• Schedule breaks for the child during the day if needed.</li> <li>• Arrange for a peer buddy to accompany the child and help carry books if needed.</li> </ul>                       |
| <b>Frequent absences due to illness, hospital treatments and doctor visits</b>                             | <ul style="list-style-type: none"> <li>• Meet with the parents to determine ways to meet the academic needs of the student.</li> <li>• Allow the child to reschedule tests or make up assignments without penalty.</li> <li>• Allow time to make up work while recovering from illness or surgery.</li> <li>• Make arrangements for home education if extended absences occur.</li> <li>• Have a buddy provide copies of class notes if absent due to medical reasons.</li> </ul> |
| <b>Possibility of symptoms occurring at any time</b>   | <ul style="list-style-type: none"> <li>• If a child develops symptoms, accompany the child to the nurse or office for evaluation and notify the parent or guardian.</li> <li>• Special events, extracurricular activities and field trips may require advance planning.</li> </ul>  |
| <b>Use of a pacemaker or an implantable cardioverter defibrillator (ICD)</b>                               | <ul style="list-style-type: none"> <li>• Avoid contact sports that could cause impact to the device site.</li> <li>• Avoid strong electrical or magnetic fields, including strong magnets, security wands, high power lines, anti-theft devices at libraries and battery-powered cordless power tools.</li> </ul>   |
| <b>Greater intolerance to illnesses</b>  | <ul style="list-style-type: none"> <li>• Inform nurse and parents if the child develops signs of an illness.</li> <li>• Inform parents of any school outbreaks of communicable illnesses such as chicken pox or influenza.</li> <li>• Promote frequent hand washing or use of hand sanitizing gel.</li> </ul>   |

# Managing Physical Activity Restrictions

Many children with cardiomyopathy need to adhere to physical activity restrictions, as recommended by their cardiologist. The degree and type of restriction will vary depending on the type of cardiomyopathy that your child has, how severe his or her disease is, current medical treatment, and family history.

Despite these restrictions, it is nevertheless important for your child to participate in as many normal daily activities as possible to maintain both physical and mental health.

Based on guidelines set by your child's physician, the gym instructor and teacher should design a physical activity program based on your child's needs, abilities and limitations. Teachers should include you and your child in selecting safe activities that allow him or her to enjoy physical activities with classmates to as great a degree as possible. Modifications should address issues of intensity, endurance and fatigue.

## General Guidelines for Activity Modifications

- ✓ Exercise or recreational sports should not be pushed to the point of exhaustion.
- ✓ Permit participation at the child's own rate, with freedom to rest as necessary.
- ✓ Instruct the child in self-monitoring techniques so he or she understands how to keep from becoming overly tired.
- ✓ Provide adequate time for gradual warm-up and cool-down and teach relaxation techniques, safety and proper breathing mechanics.
- ✓ Monitor the child's level of exertion more closely under extreme weather conditions.
- ✓ Ensure that the child is well hydrated during prolonged exercising or exercising in increased heat.
- ✓ Maintain a heart rate during exertion in an acceptable range as recommended by the child's physician.



## Written Plans for the School Team

It is advisable for parents to work with school staff to develop three written plans: a health plan, emergency plan and education plan. The purpose of these plans is to explain the child's medical condition, inform school personnel how to prevent and respond to a disease-related emergency, and guide the implementation of necessary modifications.

### Health Plan:

Parents and their child's physician may develop a medical management or individual health plan to address the health needs of the child. This includes contact information, medication administration, physical restrictions and emergency care. Although this plan is not usually required by law, it does help the nurse and other school personnel to clearly understand the medical needs of the child with cardiomyopathy.

### Emergency Plan:

The emergency care plan provides easy-to-read, step-by-step instructions about how to handle a cardiac emergency. The plan will include information about the child's medical condition, treatment, warning signs that require medical attention, appropriate interventions and emergency contact information. The plan must be available to all staff, including substitute personnel, who have daily contact with the affected child.

### Education Plan:

Depending on the child's condition, he or she may require a range of school modifications or accommodations to help function at his/her maximum potential. An education plan clearly states what special educational services the child will receive and why. There are two primary education plans used by schools and parents: an Individualized Education Plan (IEP) or a Section 504 plan.

Samples of these plans, which may be adapted as needed, are included with this school resource kit.

# Section 504 or IEP: Which Education Plan is Right for My Child?

An **Individualized Education Plan (IEP)** is a special education document that identifies and outlines what special services a child needs and why. IEPs include the current health status of the child, academic and behavioral goals, and description of the accommodations and services that may be needed. An IEP is usually considered when the child's condition impedes a major life activity such as seeing, walking, talking or learning. IEPs require testing of the student, identification of measurable goals and annual evaluations.

Most children under consideration for special education and an IEP will need to undergo a series of multidisciplinary evaluations completed by the school system. These are done at no cost to the family. Parents also have the right to have evaluations done by an independent qualified professional of their choice, at their own expense. Private evaluations can be done in place of or in addition to the school assessment, and the school team must consider the information from independent evaluations when making decisions about a child's program.

A **Section 504 plan** is also a written education plan that outlines specific medical accommodations, educational aids and services that a student needs in order to function within the school setting. The plan's name refers to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act, which prohibits

discrimination on the basis of disability. This plan is appropriate for children who may not have learning problems, but who do require some accommodations such as needing an extra set of textbooks, using an elevator rather than stairs, or other modifications related to activity restrictions. Section 504 plans are usually developed jointly by the school team and the child's parents.

**Determining which plan to use depends on the severity of a child's condition, what services may be needed, and how individual states interpret the laws.**

Children with cardiomyopathy may be more likely to require a Section 504 plan, although some may have educational needs that render them eligible for an IEP. If a child is eligible for an IEP, the school may receive extra federal funding and services to meet the child's needs, whereas Section 504 plans do not involve additional funding for the school.

If you are not sure which plan to use, talk with your child's school to determine which plan is appropriate.

# Working with Your School

The health, safety and educational progress of a child with cardiomyopathy depends on the cooperation and collaboration of the child's family and school personnel.

With careful planning and follow-up, it is possible to educate school personnel about cardiomyopathy and ensure your child's safety and well-being in school.

The following are suggested steps for effectively working with the school:

- 1. Inform the school principal that your child has cardiomyopathy** at the time of enrollment or when your child is newly diagnosed with the disease. An example of a letter to the school is included in this school resource kit.
- 2. Request a meeting with the principal and other appropriate personnel** as determined by the principal. Other school personnel may include the child's teachers, school nurse, physical education teacher, school counselor and special education coordinator.
- 3. Provide emergency contact information** through your child's individual health plan and emergency care plans.
- 4. Be prepared to educate participants at the meeting** about your child's disease. Offer the school team the information you have gathered, including *A Cardiomyopathy Guide for School Personnel* and publications from the Children's Cardiomyopathy Foundation.
- 5. Work together to develop an education plan** with which you are satisfied. Explain the kinds of accommodations your child will need and ensure that activity restrictions are described in the education or health plan. It may be easier to get the full scope of accommodations written into the plan initially, even if not all of them are needed, than to amend it later.
- 6. Provide an adequate supply of your child's medications** and any other medical supplies to the designated school staff.
- 7. Confirm which school personnel will be involved** in overseeing your child's modifications and accommodations. Confirm placement, proper functioning of AEDs, and training of staff in the use of AEDs if needed. Also, discuss the process by which other school personnel will be notified about your child's condition.
- 8. After the initial meeting, inform school staff of any changes** in your child's health status. Request another meeting if there are new things to address.
- 9. Keep a record of meetings** that you have with school personnel, including notes of who participated, assessments, recommendations, decisions and agreements for future meetings.

## **Privacy: Balancing Desire for Privacy with Safety Concerns**

While discussing your child's cardiomyopathy with school personnel, it is important to clearly state your preferences regarding privacy about your child's medical condition. Parents have the right to maintain privacy regarding personal information.

The decision about what information to share with school personnel, classmates and others lies entirely with the parents. Even so, it can be challenging to balance the desire for privacy with the need for people to be informed so that they can appropriately supervise your child or respond to problems that may occur. When meeting with school personnel, parents should consider the following recommendations:

**1. Give your medical team permission to discuss your child's medical needs with school personnel** and facilitate their communication by phone or email. Additional information from your medical team will help school staff become more confident and observant in the education of your child, and may make medical appointments more effective.

**2. Determine how your child's information will be made available to various school personnel.** This includes regular teachers, substitutes and anyone taking the class on field trips or extracurricular activities. Remember that

other personnel, such as cafeteria workers, bus drivers, librarians and others may be supervising your child during parts of the day and that they need to be kept informed.

**3. Explain how your child feels about classmates knowing about the condition.** Explain how teachers should handle questions from other children, so that they are able to respect your desired level of privacy.

**4. If your child has had a heart transplant, you may want the school to notify other parents that there is an immune-suppressed child at school.** Specify whether such communications should name your child and whether it should include any details about your child's condition.

# Tips for Working with the School Team

Cardiomyopathy in children is rare, and therefore it is important for parents to become experts on the disease so that they can be in the best position to teach others and to advocate for their children. The challenge for a parent is to be assertive without being hostile when negotiating for their child's needs.

## **Tips for effectively working with your child's school include:**

- 1.** Avoid using the words 'best for my child' because schools might do what is 'appropriate,' but not always what is best for a single child.
- 2.** Acknowledge that having a student with a heart condition can be frightening to a teacher. Arrange to educate the school staff about the disease and establish a plan to help ease their fears.
- 3.** Ask the principal to assign your child to a teacher who will be less intimidated by your child's diagnosis.
- 4.** If your child is shy or uncomfortable talking about his or her heart condition, consider coming into the classroom or inviting the school nurse to teach the class about cardiomyopathy and answer their questions.
- 5.** Consider hiring an advocate who is well-versed in education law and the accommodations and modifications that school systems are required to make. Occasionally, laws related to special education may be revised, and an informed advocate will be in a better position to communicate your child's educational needs to the school.

# Roles and Responsibilities

A school team is formed to carry out the provisions of the child's written plans and provide the necessary assistance in the school environment. Understanding the roles and responsibilities of everyone on the child's team will make the process clearer and easier for all parties involved.

## Responsibilities of School Personnel

- Identify students with chronic health conditions.
- Review their health records.
- Meet with the child's parents to discuss health accommodations and educational needs, as described in the child's health, education and emergency plan.
- Develop protocols for school staff to coordinate efforts related to the health and educational needs of the child.
- Implement strategies to ensure the student's safety and ability to participate in school, after school programs, off-site events, extracurricular activities and field trips.
- Ensure that the student receives medications as directed.
- Ensure training of staff to handle health needs and emergency situations.
- Develop a protocol to maintain records and share information among school staff as needed, while protecting confidentiality.

### **Responsibilities of the Parents**

- Inform the school that your child has pediatric cardiomyopathy.
- Provide current emergency contact information.
- Understand federal, state and local laws pertaining to the school's responsibilities to children with cardiomyopathy.
- Request and participate in the initial and annual meetings of the school team to review medical accommodations and educational services your child may need. Together with this team, develop an appropriate educational plan.
- Authorize communication between the school and your child's medical team.
- Provide and maintain any medications or supplies needed for your child.
- Inform school personnel of any changes in your child's health status.

### **Responsibilities of the Student**

- If appropriate, participate in meetings with the school team to discuss the educational plan and medical plan.
- Work with the physical education teacher on modifying gym activities as recommended by the physician.
- Wear a medical alert identification.
- Inform teachers or other school personnel of any symptoms.



## Parents Share their Insights:

*"Be sure that your child's medical information accompanies the child on any field trips."*

*"We have our daughter's photo in the front office with a note about her condition, so that more staff will be able to recognize her and look out for symptoms."*

*"We placed a large medical card in each of our child's classrooms."*

*"Understand that teachers may feel afraid and ask for their help at the beginning of the year. Show that you think they can do it."*

*"Parents or school nurses should notify the emergency medical services (EMS) in the area that a cardiac emergency could happen at the school. This way, they will be better prepared to treat a child. Often when the EMS is called for a heart issue, they assume it will be for an adult."*

*"Use a medical ID product. Although it costs a little bit, it is worth it. Use one that will allow you to update all health information. If your child is on a field trip and has to go to a hospital, one call to the ID company will make sure all medical information is provided."*

*"Talk to other parents about your child's condition. We all want our children to live as 'normal' lives as they can, so we hope there will be after-school play-dates, kids working together on projects, and doing homework with a friend. Other parents need to be aware of the situation, so that we can feel safe and secure when they are in the care of other families."*



## Addressing problems:

### What if the school does not cooperate or comply?

If a resolution does not follow, parents may consider the following:

- ✓ Schedule a meeting with the school principal.
- ✓ Speak with the state Department of Education.
- ✓ Seek information on special education and Individualized Education Plans from the National Disability Rights Network. Find your state's protection and advocacy office at [www.napas.org](http://www.napas.org).
- ✓ Hire an advocate who is well-versed in the modifications that schools must make to comply with Section 504, IDEA, and ADA. To find a special education advocate in your state, as well as other legal and advocacy resources, visit Wrightslaw's Yellow Pages for Kids ([www.yellowpagesforkids.com](http://www.yellowpagesforkids.com)).

If the school district does not comply with needed accommodations or modifications, parents should try to resolve the issue in a personal meeting with the principal.

Parents might also write a letter to the school team to document the problem and request a change.

# Additional Resources

## Resources on federal and state education laws

- National Institutes of Health: Students with Chronic Illnesses – Guidance for Families, Schools and Students ([www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.pdf](http://www.nhlbi.nih.gov/health/public/lung/asthma/guidfam.pdf))
- Families and Advocates Partnership for Education ([www.fape.org](http://www.fape.org))
- Individuals with Disabilities Education Act (<http://idea.ed.gov>)
- U.S. Department of Education: Frequently asked questions about Section 504 and the education of children with disabilities (<http://www2.ed.gov/about/offices/list/ocr/504faq.html>)
- U.S. Department of Education: State Listings and Education Information ([www.ed.gov/about/contacts/state/index.html](http://www.ed.gov/about/contacts/state/index.html))
- Wrightslaw: Information about education law, IEP/504 plans and advocacy for children with disabilities ([www.wrightslaw.com](http://www.wrightslaw.com))

## Resources for learning more about pediatric cardiomyopathy

- Children’s Cardiomyopathy Foundation ([www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org))
- American Heart Association ([www.americanheart.org](http://www.americanheart.org))
- National Heart, Lung & Blood Institute ([www.nhlbi.nih.gov](http://www.nhlbi.nih.gov))
- National Organization for Rare Diseases ([www.rarediseases.org](http://www.rarediseases.org))

## Sample forms included in school resource kit

- Letter to School
- Individual Health Plan
- Section 504 Education Plan
- Emergency Care Plan



**The goal is to develop a cooperative relationship with school officials and teachers so that they can help your child continue to learn using the most appropriate programs.**



[www.childrenscardiomyopathy.org](http://www.childrenscardiomyopathy.org)



P.O. Box 547  
Tenafly, New Jersey 07670  
866.808.CURE  
[info@childrenscardiomyopathy.org](mailto:info@childrenscardiomyopathy.org)

Funded in part by a grant from:

*Charles Tillman*  
**CORNERSTONE**  
**33**  
FOUNDATION