



CCF School Presentation Guidelines

Arranging a school presentation is an excellent way to raise awareness of cardiomyopathy in your community during National Heart Month (February) and Children's Cardiomyopathy Awareness Month (September). The Children's Cardiomyopathy Foundation (CCF) has developed a simple school presentation that can be customized by any child or parent to educate classmates and school personnel on cardiomyopathy.

Scheduling the Presentation

To start planning, contact the classroom teacher, physical education teacher, health teacher, school nurse, school counselor or principal to discuss your purpose and plan. The school presentation can be delivered to an individual classroom or to a larger group at a school assembly. When meeting with school personnel you will want to discuss 1) where the presentation should be given, 2) how long the presentation should be, 3) what topics should be covered, 4) how to notify others about the presentation, and 5) what materials can be distributed to students and parents.

Preparing for the Presentation

Once the presentation has been scheduled, a copy of CCF's presentation can be requested from Gina Peattie, at gpeattie@childrenscardiomyopathy.org. Students can customize the length and content of the presentation and include information about their experience with the disease. Videos and personal photos also can be added. It is recommended that you show a school staff member the presentation for feedback on content and length.

It is a good idea to practice your presentation at home with other family members and in front of the mirror to become comfortable with the material and to have an understanding of the flow and length of the presentation. If you would like to distribute any materials about cardiomyopathy, please contact CCF at least two weeks in advance of the presentation.

Materials Needed

- Your outline and talking points
- Power Point presentation (optional)
- CCF pamphlets, fact sheets and/or patient educational materials
- Cardiomyopathy quiz
- Laptop computer and necessary cords
- School to provide screen, projector, podium, microphone and sound system if needed

Tips for Presenting

- Prepare your notes ahead of time
- Test your power point presentation on your computer
- Practice your delivery
- Smile and make eye contact with the audience
- Speak clearly and loud enough to be heard
- Be confident and personable in your delivery

After the Presentation

We are interested in hearing how your presentation went. Please send us your presentation and any photos or video clips that we can share with other CCF families. It would be helpful if you could include information on how many people were in attendance, the date of the presentation, age group/grade of audience, and school name and location.



CCF School Presentation Outline

To develop your school presentation, please refer to CCF's sample power point presentation on cardiomyopathy. A copy can be requested from Gina Peattie: gpeattie@childrenscardiomyopathy.org

Introduction

- Let class know the reason for your presentation – to share your story and educate others about the disease
- Briefly explain what you will cover in your presentation

Give Overview of Cardiomyopathy

Ask for a show of hands – who knows what cardiomyopathy is? Who has heard of it before?

- What is cardiomyopathy
- How many children are affected
- Leading cause for heart transplants in children and top cause of sudden cardiac arrests among young people
- What causes cardiomyopathy
- Who can have cardiomyopathy
- Cardiomyopathy is a variable disease
- Common symptoms of cardiomyopathy
- How is cardiomyopathy detected
- How is cardiomyopathy treated
- No cure for cardiomyopathy
- More research is needed to understand the disease

Share Personal Experience

Customize your presentation to share as much or as little as you are comfortable with.

- Type of cardiomyopathy you are diagnosed with
- Symptoms you experienced/experience
- Diagnosis
 - How did you find out you had cardiomyopathy
 - What age were you diagnosed
 - How you felt when you were diagnosed
 - Cause of your cardiomyopathy (if known)
- Lifestyle changes – how has cardiomyopathy changed your life
 - Activity restrictions
 - Medications, treatment, surgery
 - Additional lifestyle changes

- How others (teachers, classmates) can support you
 - Reduce chances of illness
 - Raise awareness about cardiomyopathy
 - Recognize signs of heart failure or cardiac arrest
 - Understand gym and sports restrictions

Suggest Educational Resources

- Children's Cardiomyopathy Foundation (CCF) is a national organization focused on all forms of cardiomyopathies affecting children.
 - Dedicated to supporting research and education, providing family support and increasing awareness and advocacy on behalf of children with cardiomyopathy and their families all over the world
 - Raised more than \$8 million for research and education initiatives, family support, and advocacy and awareness measures
 - Works with patients/their families and medical professionals (researchers, pediatric cardiologists, geneticists)
 - Offers a wide range of educational materials on pediatric cardiomyopathy

Wrap Up Presentation

- Ask for any questions
- Distribute cardiomyopathy quiz to each audience member
- Ask class what they can do to help raise awareness about cardiomyopathy
 - Host a bake sale or organize another community fundraising event
 - Pass out educational materials
 - AED hunt and post photo on social media
 - Give presentation to community organizations
 - Sell CCF curebands or merchandise
- Distribute CCF educational materials
- Thank everyone for their interest in learning more about pediatric cardiomyopathy



Cardiomyopathy Quiz: True or False?

Test your knowledge of cardiomyopathy

1. Cardiomyopathy is a disease of the heart muscle that affects how the heart pumps blood to the body. True or False?
2. About 10,000 children in the U.S. are affected by cardiomyopathy. True or False?
3. Recessive cardiomyopathy is one type of cardiomyopathy. True or False?
4. Children with cardiomyopathy are born with the heart disease. True or False?
5. An endocrinologist is a doctor who specializes in taking care of hearts. True or False?
6. Cardiomyopathy is a leading cause of heart transplants in children and sudden cardiac arrest among young people. True or False?
7. Surgery can repair the heart of a child with cardiomyopathy and restore it to normal function. True or False?
8. Some symptoms for cardiomyopathy include difficulty breathing, extreme tiredness, dizziness, chest pain and fainting. True or False?
9. Children with cardiomyopathy typically look sick and miss a lot of school. True or False?
10. Reviewing your family heart history is not always necessary. True or False?

To learn more about pediatric cardiomyopathy, visit the Children's Cardiomyopathy Foundation website, www.childrenscardiomyopathy.org

ANSWER SHEET

Cardiomyopathy Quiz: True or False?

Test your knowledge about pediatric cardiomyopathy:

1. Cardiomyopathy is a disease of the heart muscle that affects how the heart pumps blood to the body.
True or False?
2. About 10,000 children in the U.S. are affected by cardiomyopathy. True or False?
It has been estimated that 30,000 children are living with some form of cardiomyopathy. This is comparable to the number of adults and children in the U.S. with cystic fibrosis.
3. Recessive cardiomyopathy is one type of cardiomyopathy. True or False?
The five types of cardiomyopathy are dilated, hypertrophic, restrictive, left ventricular non-compaction and arrhythmogenic right ventricular cardiomyopathy
4. Children with cardiomyopathy are born with the heart disease. True or False?
Not all children are born with cardiomyopathy. Although it can be inherited, it can also be acquired later in life through a viral infection or as a result of cancer chemotherapy.
5. An endocrinologist is a doctor who specializes in taking care of hearts. True or False?
A cardiologist is a doctor who specializes in taking care of hearts.
6. Cardiomyopathy is a leading cause of heart transplants in children and sudden cardiac arrest among young people. True or False?
7. Surgery can repair the heart of a child with cardiomyopathy and restore it to normal function. True or False? While surgery may prolong survival and improve the quality of life, it is not a cure for cardiomyopathy.
8. Some symptoms for cardiomyopathy include difficulty breathing, extreme tiredness, dizziness, chest pain and fainting. True or False?
9. Children with cardiomyopathy typically look sick and miss a lot of school. True or False?
Many diagnosed children have mild or no symptoms and therefore appear healthy even though their heart is not functioning properly.
10. Reviewing your family heart history is not always necessary. True or False?
Many sudden cardiac death cases associated with undiagnosed cardiomyopathy could have been prevented with an understanding of a family's heart history and identifying certain risk factors.