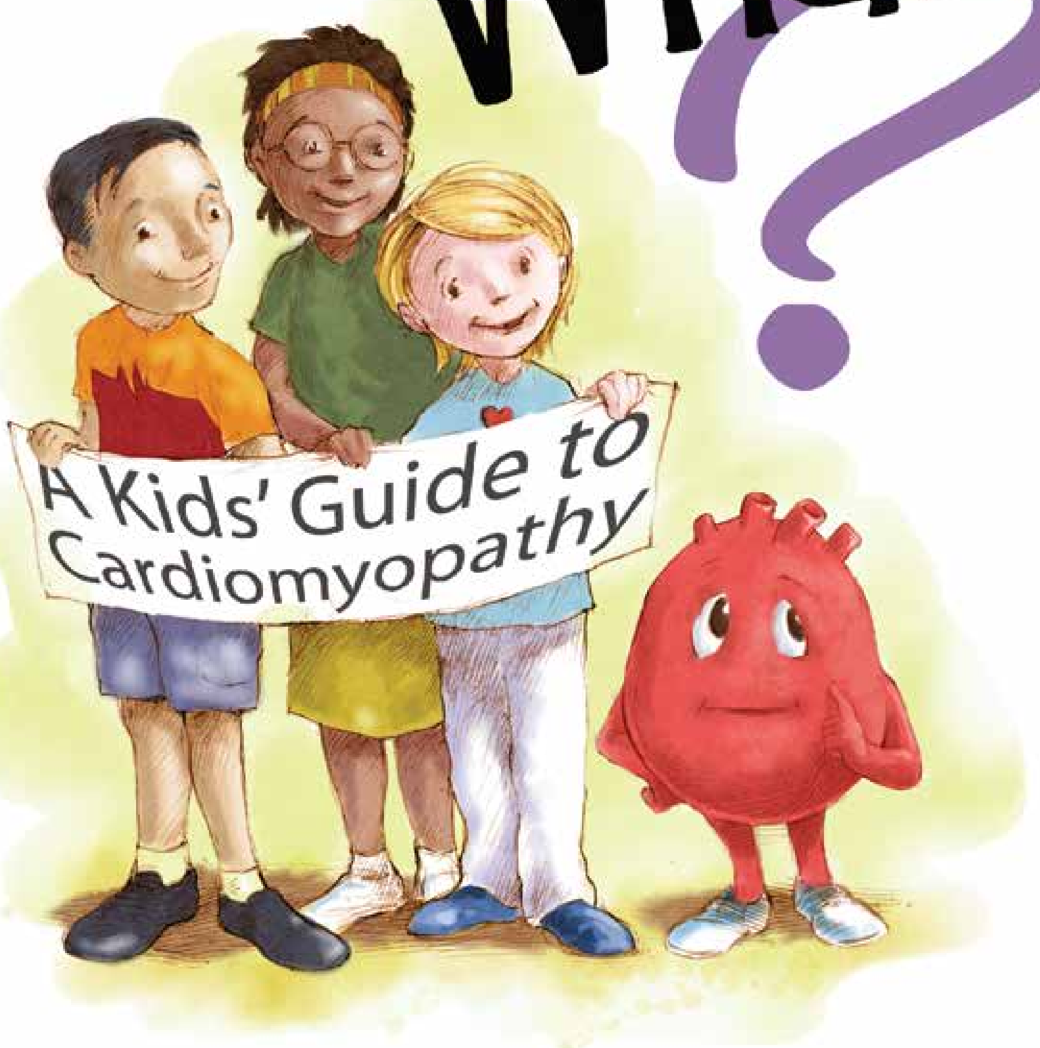
Cardio What?



A Note to Parents:

Welcome to "Cardio What?: A Kids' Guide to Cardiomyopathy." This booklet was written to help children understand their own and/or their family member's diagnosis of cardiomyopathy. More specifically, it addresses information about inherited forms of cardiomyopathy that your cardiologists, genetic counselors or other health professionals have given to your family. "Cardio What?" is useful in various ways depending on the age of your child. The suggested age group for this booklet is 8-13 years old. Each child and family is different, and "Cardio What?" may have information that you have not yet shared with your child at this time. Your child may like reading "Cardio What?" with you, an older sibling, or another adult so that he or she can ask questions and have you help explain some of the concepts. We hope that "Cardio What?" is helpful for you and your family!

NSGC acknowledges the following members for developing and writing the publication and their affiliated institutions for contributions in kind:

Nicole Johnson, ScM[1], Lisa Ku, MS[2], Heather MacLeod, MS[3], and Crystal Tichnell, MGC[1]

[1] Johns Hopkins Medical Institutions, Baltimore, MD
[2] University of Colorado at Denver and Health Sciences Center, Denver, CO
[3] University of Chicago, Chicago, IL

Design & Illustration by Jeffry Byrd

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Cardio What?

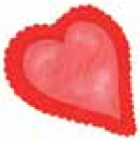
Cardiomyopathy is a long word that means "heart muscle disease." If you take apart the word,

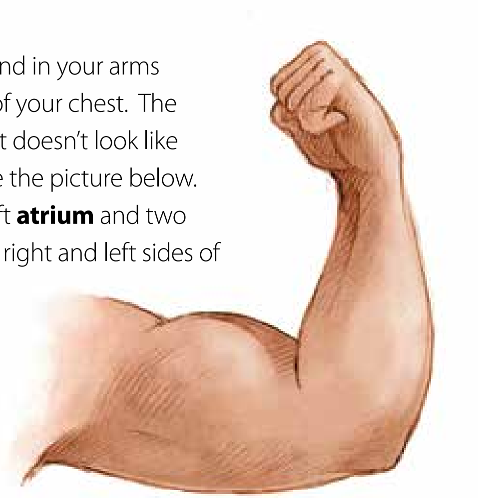
"cardio" means **"heart"**
"myo" means **"muscle"**
"pathy" means **"disease"**

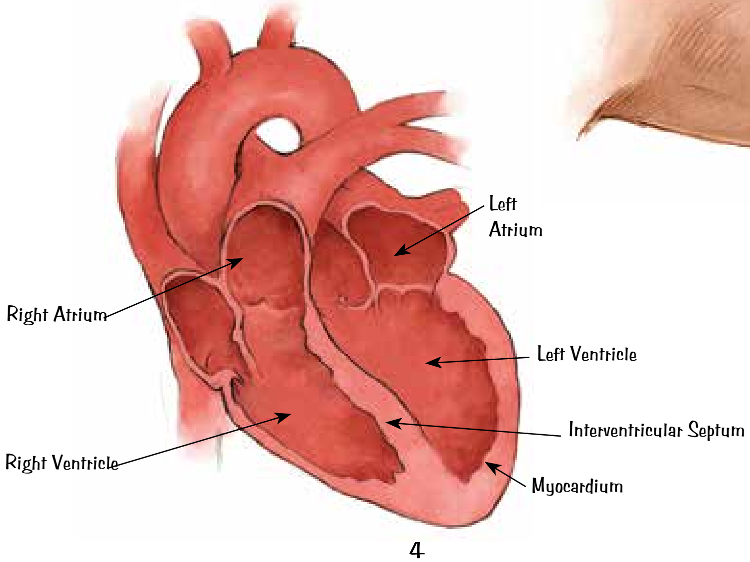
This booklet is for people who have cardiomyopathy or who have it in their family. You may want to read it with your parents or another adult. This booklet has a lot of information about cardiomyopathy. It explains big words and answers questions that kids often ask when they first learn about cardiomyopathy. New words are in **bold** and are listed at the end of the booklet.

How does the heart work?

Did you know that the heart is a muscle just like the muscles found in your arms and legs? The heart is a very strong muscle that sits near the middle of your chest. The heart acts like a pump pushing blood to different parts of the body. It doesn't look like the hearts you see on Valentine's Day, but more like the picture below. A heart has two upper parts called the right and left **atrium** and two lower parts called the right and left **ventricle**. The right and left sides of the heart are divided by a wall of muscle called the **interventricular septum** (IVS for short).

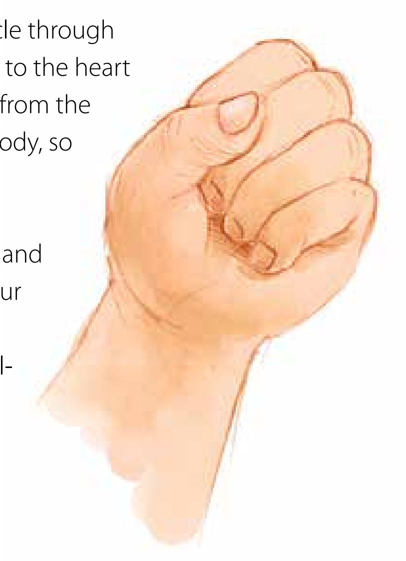






Every time your heart beats, it pushes blood from the right ventricle through your lungs to get **oxygen** from the air we breathe. That blood returns to the heart into the left atrium and then gets pumped out to the rest of the body from the left ventricle. The oxygen in your blood is needed for energy in your body, so having your heart work properly is important!

In most people, the heart is about the size of their fist.



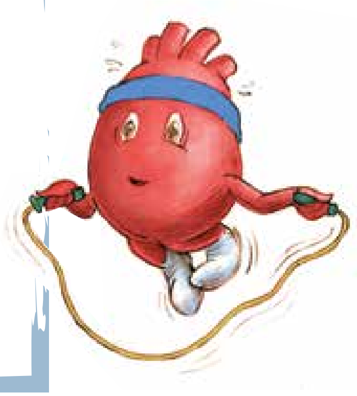
The heart squeezes and relaxes in the same way you can squeeze and relax your fist. Your heart squeezing and relaxing is your heartbeat. Your heartbeat is triggered by a special kind of electricity. This electricity is called the heart's **conduction system**. It travels through the heart telling the muscle when to squeeze and relax.

Usually your heart beats at a steady pace called a **normal rhythm**. When you are excited, scared or playing hard your heart beats faster. When you are sleeping, your heart beats slower.

Do you know how many times your heart squeezes and relaxes each minute?

Next time you see your doctor, ask them what your heart rate is and write it down here.

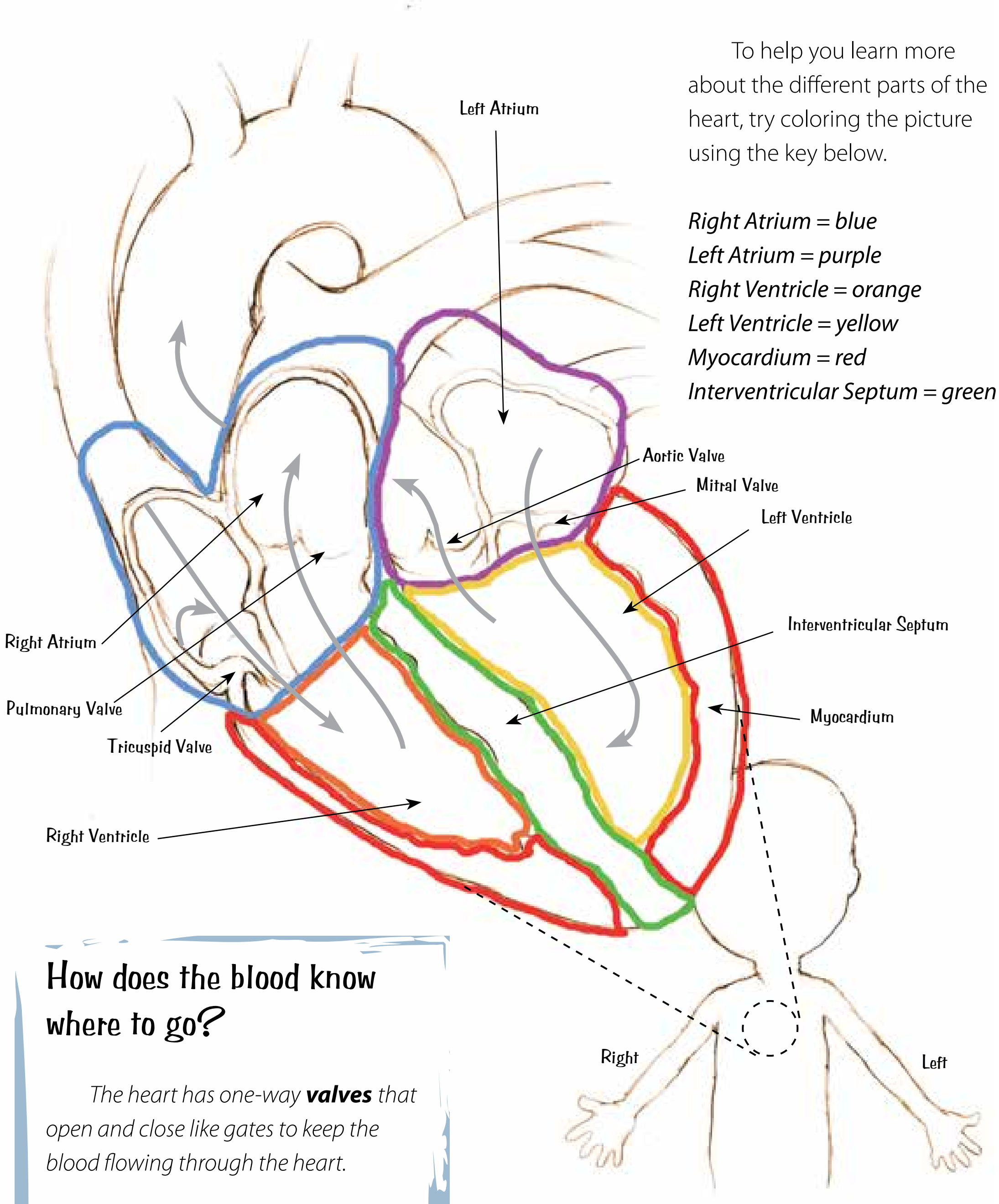
____



Color the Heart

To help you learn more about the different parts of the heart, try coloring the picture using the key below.

Right Atrium = blue
Left Atrium = purple
Right Ventricle = orange
Left Ventricle = yellow
Myocardium = red
Interventricular Septum = green



How does the blood know where to go?

*The heart has one-way **valves** that open and close like gates to keep the blood flowing through the heart.*

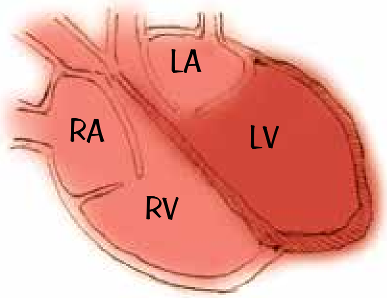
What's different about a heart with cardiomyopathy?

People with cardiomyopathy have hearts that are bigger or stiffer than they should be, and this can sometimes change how the heart works. Remember, the heart's job is to pump blood to the lungs and to the rest of the body. If you have cardiomyopathy, your heart may not be able to do this important job as well as it should.

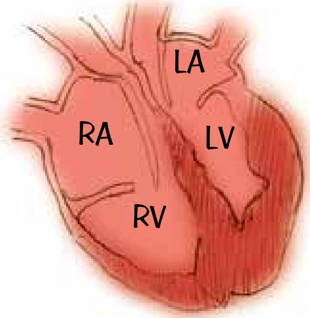
Think of a car that has 4 tires. Each of the tires represents one of the four main parts of the heart: 2 atria and 2 ventricles. You need all 4 tires to be working right in order for the car to drive correctly. If one of the tires is much bigger than the others, then the car won't drive right.

If a part of the heart is bigger or thicker than it should be, it doesn't do its job as well. For some people with cardiomyopathy this means that the heart doesn't pump the blood very well. For other people with cardiomyopathy this means that the electricity in the heart doesn't travel as well. Your heart may beat too fast, too slow, or unevenly.

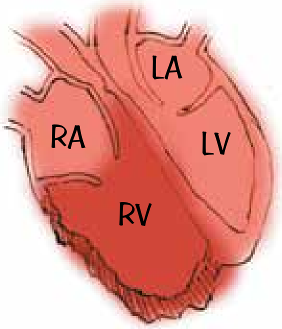
There are a few different types of cardiomyopathy. The four most common types of cardiomyopathy are called **dilated, hypertrophic, restrictive** and **arrhythmogenic right ventricular**. When you put those words together with cardiomyopathy, it is a lot to say, so most people just call them by their "nicknames":



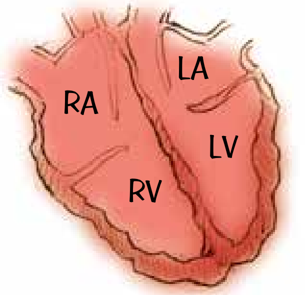
Dilated **c**ardio**m**yopathy = **DCM**. The left ventricle (LV) is bigger and weaker than it should be in a heart with DCM.



Hypertrophic **c**ardio**m**yopathy = **HCM** The heart muscle becomes thick and can't relax as well as it needs to in a heart with HCM.



Arrhythmogenic **r**ight **v**entricular **c**ardiomyopathy or **d**ysplasia = **ARVC or ARVD**. The healthy muscle of the right ventricle (RV) gets replaced with fat and scar tissue. The RV can get bigger and have trouble squeezing and relaxing.



Restrictive **C**ardio**m**yopathy = **RCM** The wall muscle of the heart becomes stiff. This makes it hard for the heart muscle to squeeze and relax.

I have ______________________________ cardiomyopathy in my family.
(fill in what type)

Word Search

Circle as many of the words listed below that you can find. The words can be found by reading across, down, up, diagonally up, or diagonally down. These words and their meanings are found throughout the book.

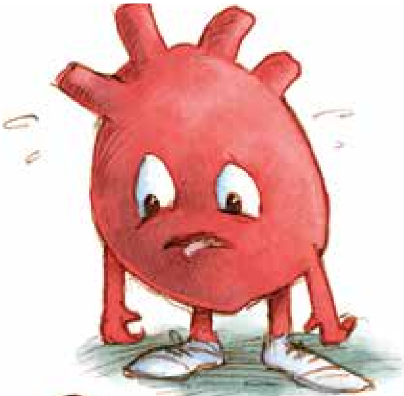
CARDIOMYOPATHY
ATRIUM
HYPERTROPHIC
ECHOCARDIOGRAM
HOLTER MONITOR
ARVD
FAMILIAL
DEVICES
SYMPTOMS
VENTRICLE
HEART
DILATED
MEDICINE
INHERITED
GENES
ELECTROCARDIOGRAM

N	Y	C	T	L	M	Y	D	B	I	S	Z	R	V	B	P	U	P	S
C	A	R	D	I	O	M	Y	O	P	A	T	H	Y	V	L	L	M	T
M	O	P	C	N	X	Z	D	B	U	I	P	L	D	T	R	Y	N	Z
H	B	D	Z	H	R	U	J	Z	D	B	Y	U	H	S	L	E	R	T
E	E	P	Q	E	W	U	R	K	F	A	M	I	L	I	A	L	G	I
Y	A	A	B	R	N	E	Z	A	E	L	O	V	X	A	T	E	B	Z
J	S	R	R	I	Y	U	W	X	H	F	D	J	J	R	V	C	H	G
T	P	K	T	T	Y	G	U	S	R	H	D	C	R	S	L	T	S	E
D	X	D	B	E	R	K	M	D	X	F	F	D	Z	M	I	R	W	N
X	S	H	H	D	R	Q	R	Y	U	I	O	P	P	O	U	O	Q	E
X	B	T	U	Q	S	X	V	M	U	T	W	S	D	T	L	C	Z	S
M	U	K	V	E	N	T	R	I	C	L	E	W	R	P	O	A	D	H
U	K	P	D	G	B	E	N	C	A	Q	E	V	N	M	O	R	A	F
Z	S	E	R	Y	H	F	B	I	L	P	Q	S	G	Y	L	D	X	K
H	O	L	T	E	R	M	O	N	I	T	O	R	E	S	V	I	Z	E
U	M	V	I	P	L	O	U	M	G	B	Y	R	S	C	V	O	N	R
R	E	C	X	A	S	V	G	M	J	Y	B	F	W	X	D	G	I	J
A	B	C	D	H	Y	P	E	R	T	R	O	P	H	I	C	R	I	C
R	N	V	H	D	D	P	L	M	U	R	H	D	Z	X	B	A	I	K
V	P	O	I	G	F	C	X	A	W	S	F	K	I	M	Y	M	C	F
D	X	V	G	Y	K	B	F	S	D	X	V	H	U	I	L	M	C	R
U	E	C	H	O	C	A	R	D	I	O	G	R	A	M	H	M	U	E
V	D	G	I	P	L	D	V	E	C	R	N	S	U	H	F	B	V	D
M	C	E	D	V	Y	J	I	V	U	A	D	M	I	N	S	Q	Y	R
L	P	Y	D	Z	C	Q	J	I	R	B	L	O	O	V	A	Q	E	M
I	L	S	E	R	B	N	M	C	L	P	Q	T	M	U	I	R	T	A
E	F	N	M	Y	K	P	L	E	F	Y	M	P	U	V	Z	A	U	L
D	I	L	A	T	E	D	B	S	O	J	V	M	E	M	K	U	G	Q
T	Q	J	I	M	S	C	T	U	P	Y	M	E	D	I	C	I	N	E

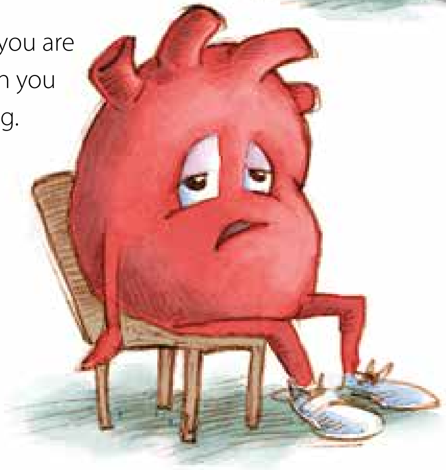
What does it feel like to have cardiomyopathy?

Some people know they have cardiomyopathy because they have **symptoms** when their heart does not work properly. Here are some things that someone with cardiomyopathy might feel:

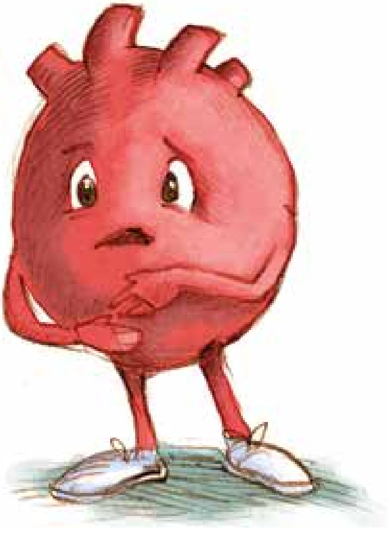
Sometimes it feels like you have a hard time catching your breath.



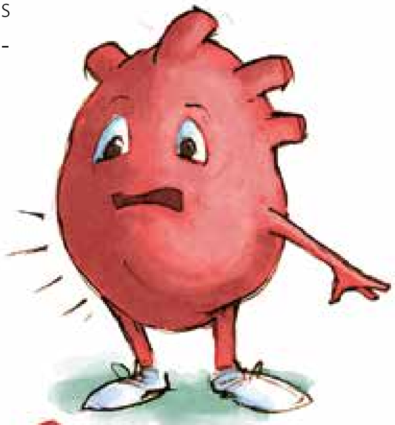
Sometimes it feels like you are tired all the time, even when you haven't been doing anything.



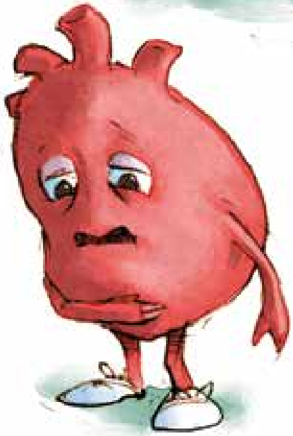
Sometimes your heart feels funny. It might hurt, flutter like a butterfly, or tingle like when your leg falls asleep.



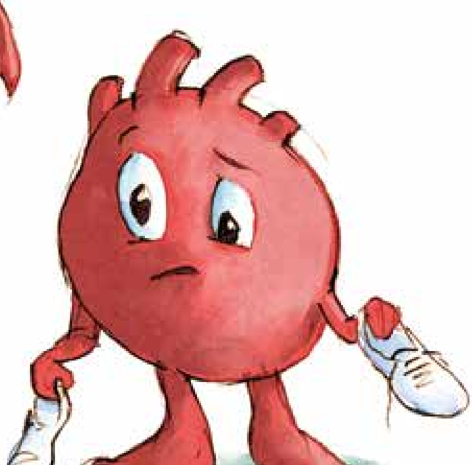
Sometimes your heart makes strange noises, or feels like it's going to jump out of your chest.



Sometimes you might feel like you are dizzy or going to faint... or be sick to your stomach.

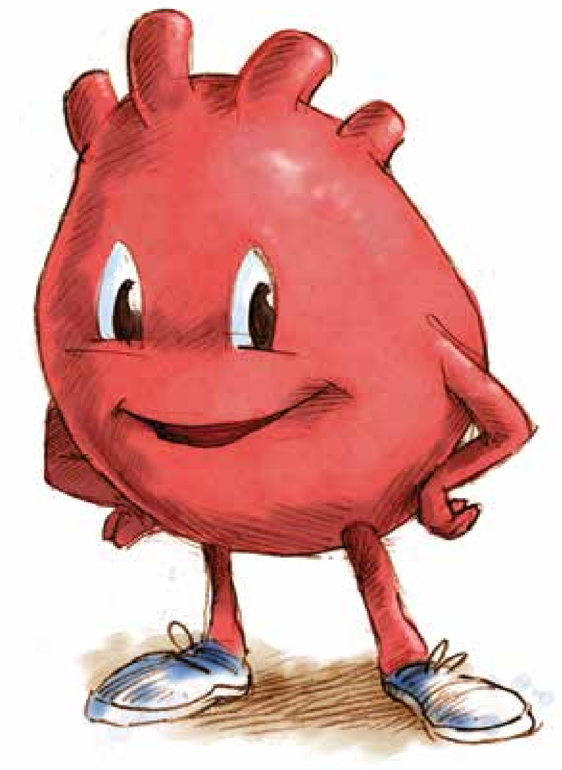


Sometimes your legs and feet will swell up like they are filled with water.



Some of these symptoms happen to people who do not have cardiomyopathy. So remember, just because you have one of these feelings does not always mean you have cardiomyopathy. If you are wondering or worried about your heart, you should tell your parents and your doctor.

On the other hand, some people with cardiomyopathy don't feel any symptoms at all. That is why it is a good idea to get checked regularly by your doctor even if you don't feel bad.



It can be scary to think about having a cardiomyopathy, but remember that your parents and doctors are here to help make sure you are healthy.

So, even if you think:

- It's hard to talk about cardiomyopathy
- You're not sure if a symptom is important
- Your symptoms might go away over time
- You don't want anyone to worry
- You are afraid of going to see the doctor
- You don't want anyone to tell you that you have cardiomyopathy

The person I talk to most about cardiomyopathy is...

____

IT'S OKAY TO TALK TO SOMEONE ABOUT IT

How do doctors check for cardiomyopathy?

Cardiologists are doctors that take care of hearts. Cardiologists check for cardiomyopathy by:

1) Listening to the heart
2) Looking at pictures of the heart
3) Looking at the heart beat

My cardiologist is

Dr. ______________________

Listening to the heart:

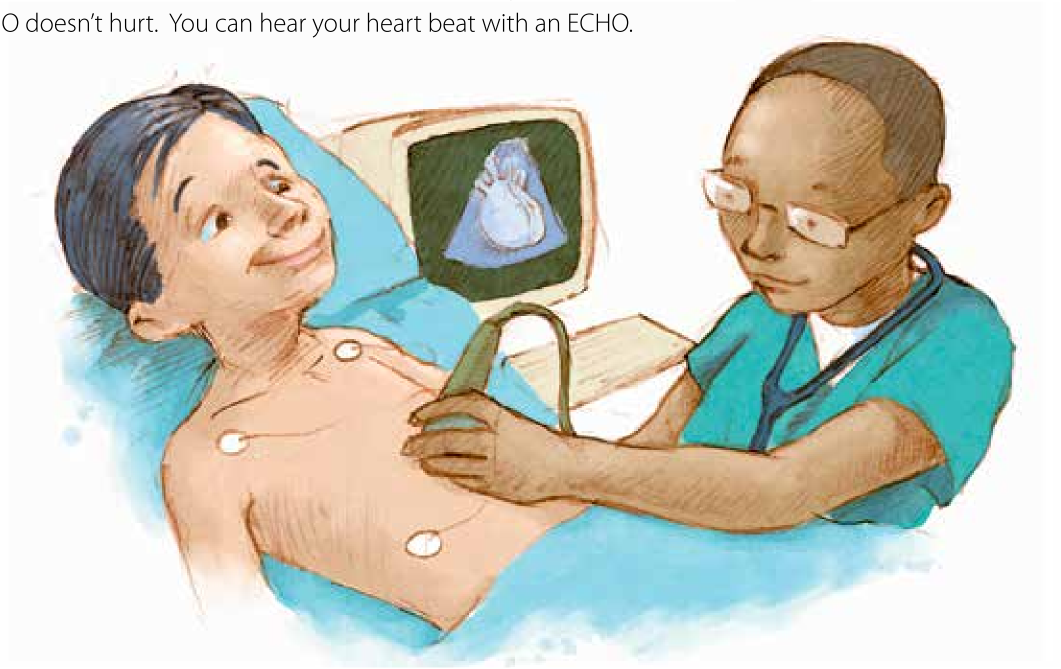
Cardiologists listen to your heart with a **stethoscope** to see how the heart is working. This is just like when you go to get a check-up by your regular doctor.

Looking at pictures of the heart:

Cardiologists use pictures of your heart to see how big each part is and how well your heart is pumping blood to the rest of your body.

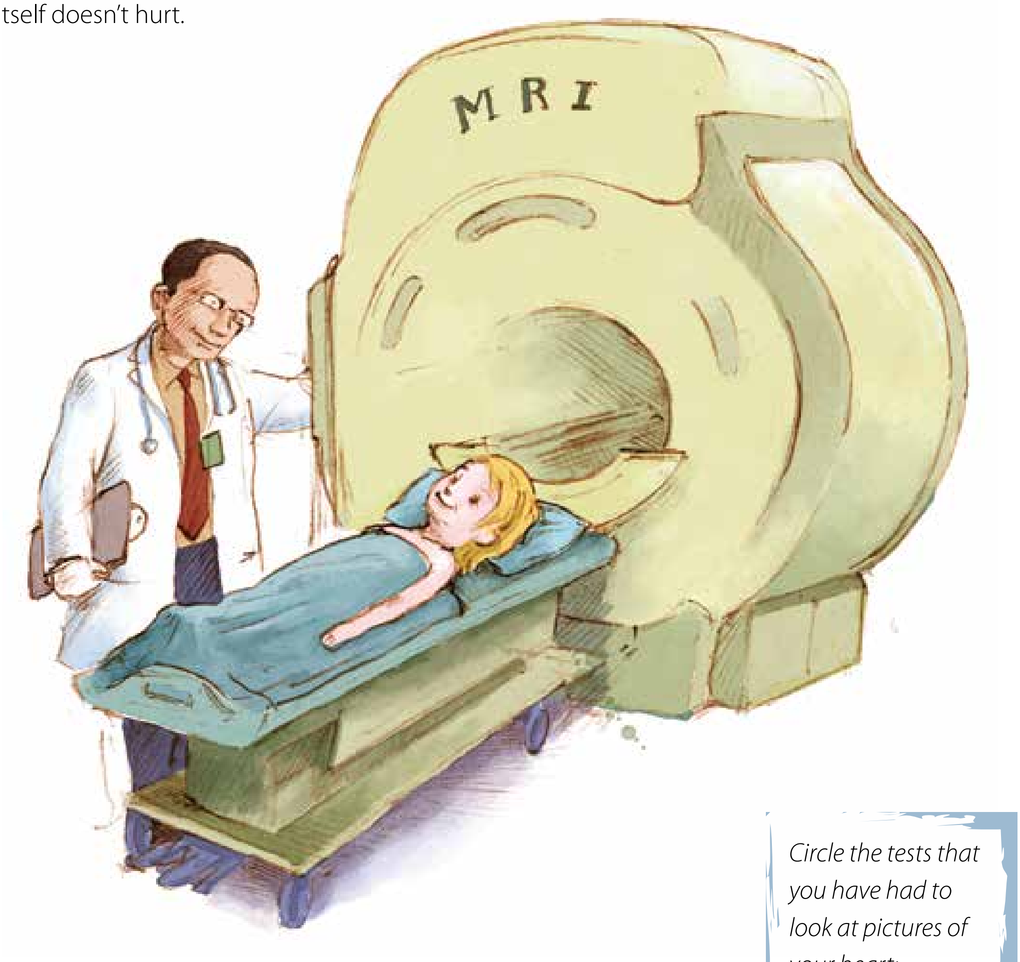
One common test is called an **echocardiogram** (ECHO).

An ECHO has a wand that is moved around your chest. The wand helps make a picture of your heart that shows up on a TV monitor. The wand listens to your heart and makes a picture from the sound. An ECHO doesn't hurt. You can hear your heart beat with an ECHO.



Another test that cardiologists sometimes use to look at pictures of the heart is called magnetic resonance imaging **(MRI)**.

An MRI looks like a big tube that you slide into for the test. Special magnets inside the MRI help to create a picture of your heart that shows up on a TV monitor. An MRI machine can be very loud, but the test itself doesn't hurt.



Sometimes cardiologists need to do other tests to look at pictures of your heart. A **chest x-ray** can show the size of your heart. A **cardiac catheterization** is a test where a long tube is put in one of your blood vessels. This tube travels all the way to your heart. Kids are given medicine called **anesthesia** to help them sleep during this test.

Circle the tests that you have had to look at pictures of your heart:

Chest X-ray

MRI

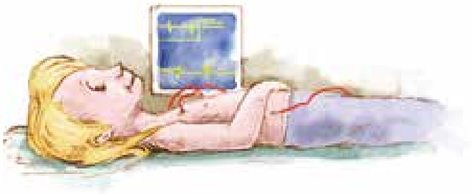
ECHO

Cardiac Catheterization

Looking at the heart beat:

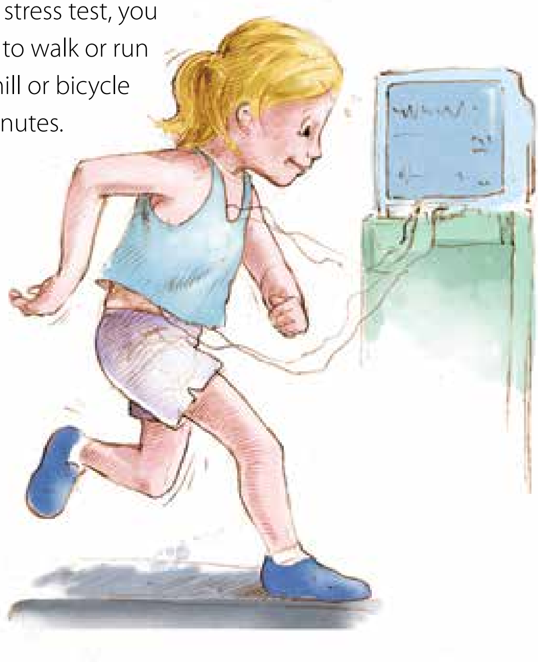
Cardiologists use several different tests to measure the electricity in the heart. These tests can tell if your heart is beating too fast, too slow, or unevenly. The most common tests are called an **electrocardiogram** (ECG or EKG), a **Holter monitor** and a **stress test**. For all of these tests, small sticky patches that are connected to wires are placed on your skin. These tests don't hurt – you can't even feel them.

For the ECG you just have to lay still for a few minutes.



You might have to wear a Holter monitor for a day or two, but you can still do your regular everyday activities.

For the stress test, you might have to walk or run on a treadmill or bicycle for a few minutes.



Circle the tests that you have had to look at your heart beat:

ECG

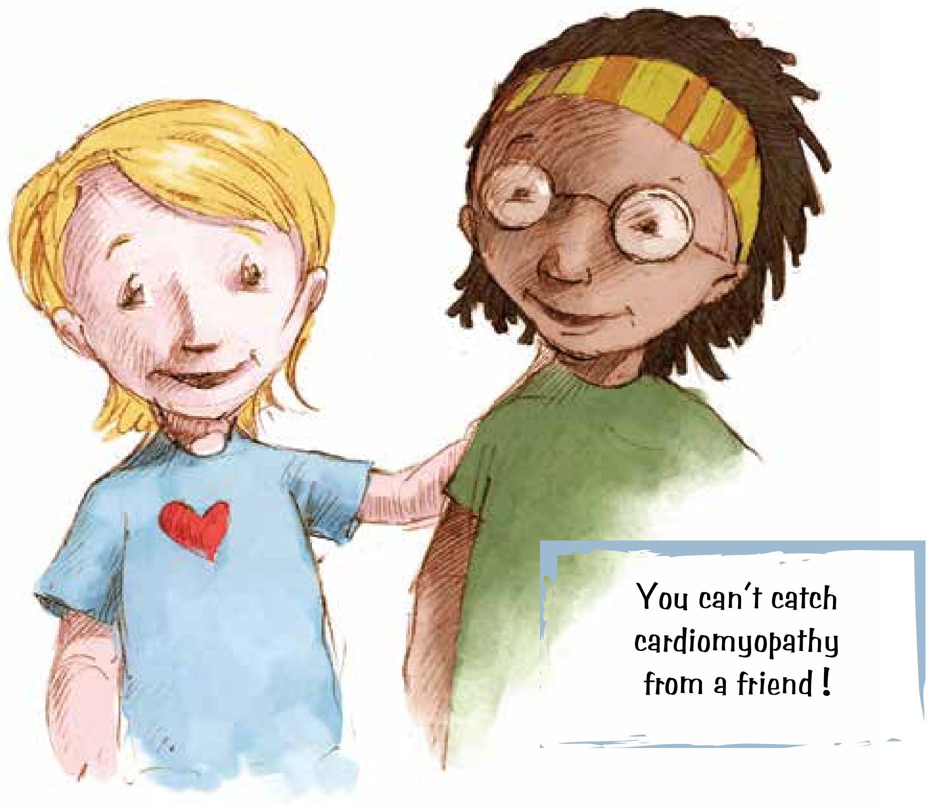
Holter Monitor

Stress Test

How do you get cardiomyopathy?

There are many different ways for people to get cardiomyopathy. There are some people who get cardiomyopathy and their cardiologists never know why.

Some people get cardiomyopathy when they have been sick from a virus that infects the heart. Some people get cardiomyopathy from certain types of medicines to treat cancer. Some people get cardiomyopathy because they are born with a heart that didn't form normally before they were born. Some people develop cardiomyopathy as part of an overall health condition.



You can't catch cardiomyopathy from a friend!

And some people get cardiomyopathy because they have inherited it in their family. In some families, medical conditions are passed on from grandparents to parents to their kids. This is called an **inherited** condition. Sometimes we say that an inherited condition "runs in the family" or is "familial."

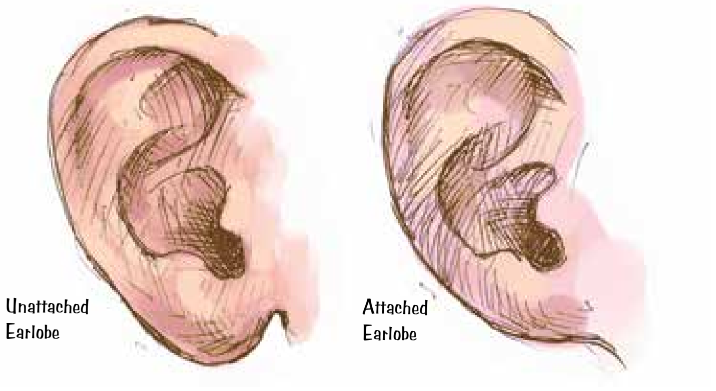
What is FAMILIAL cardiomyopathy?

When cardiomyopathy is inherited, we call it **FAMILIAL cardiomyopathy**. This means that people in the same family can have cardiomyopathy (like your parent, brother or sister, grandparent, aunt, uncle, or cousin). Familial cardiomyopathy can run in a family when it is in your **genes**. Genes are like a recipe for making a person – they tell your body how to look and how to work.

Kids get their genes from their parents. Half of your genes come from your mom and half come from your dad. Someone may have told you that certain things about you (like your smile or the shape of your nose) make you look like one of your parents. Here are some funny features that can run in families.

Tongue rolling: Some people can roll up the edges of their tongue, while others can't. The ability to roll your tongue is inherited.

Earlobe shapes can run in families too.



What other parts of you came from your mom and your dad? Write them down below.

Mom: ______________________________

____

____

____

____

____

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Dad: ______________________________

____

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____

____

Genes also decide if you will get certain health problems like cardiomyopathy. Changes in a gene, also called **mutations**, make a gene not work the right way. People with familial cardiomyopathy are born with a gene mutation.

Finding changes in genes...

Genes are like sentences. Letters of the alphabet are put in a certain order to make words and sentences like this:

The cat is in the room.

The letters of a gene sentence are also put in order to code for certain things like the color of your hair or the color of your eyes. Changes in the gene sentence can sometimes cause health problems like cardiomyopathy.

The cat is in the room. OR The bat is in the room.

This change still makes a sentence. If this were a gene, maybe it would still work in the body. How about:

The cat is in the room. OR The aat is in the room.

Does this change still make a sentence? No. This gene would not be understood and would not work in the body anymore. This is called a gene mutation.

What is the chance that I may inherit Familial Cardiomyopathy?

If one of your parents has familial cardiomyopathy, you have a chance of getting it too. For some types there is a 50% chance, or 1 chance in 2, that you will inherit a gene mutation that causes cardiomyopathy. This is called **autosomal dominant inheritance**. This means you also have a 50% chance of not inheriting a gene mutation for cardiomyopathy. This chance is the same for every kid in the family.

A 50% chance is just like the chance of a coin landing heads up when you flip it. Flip a coin 10 times. How many times does it land heads up?

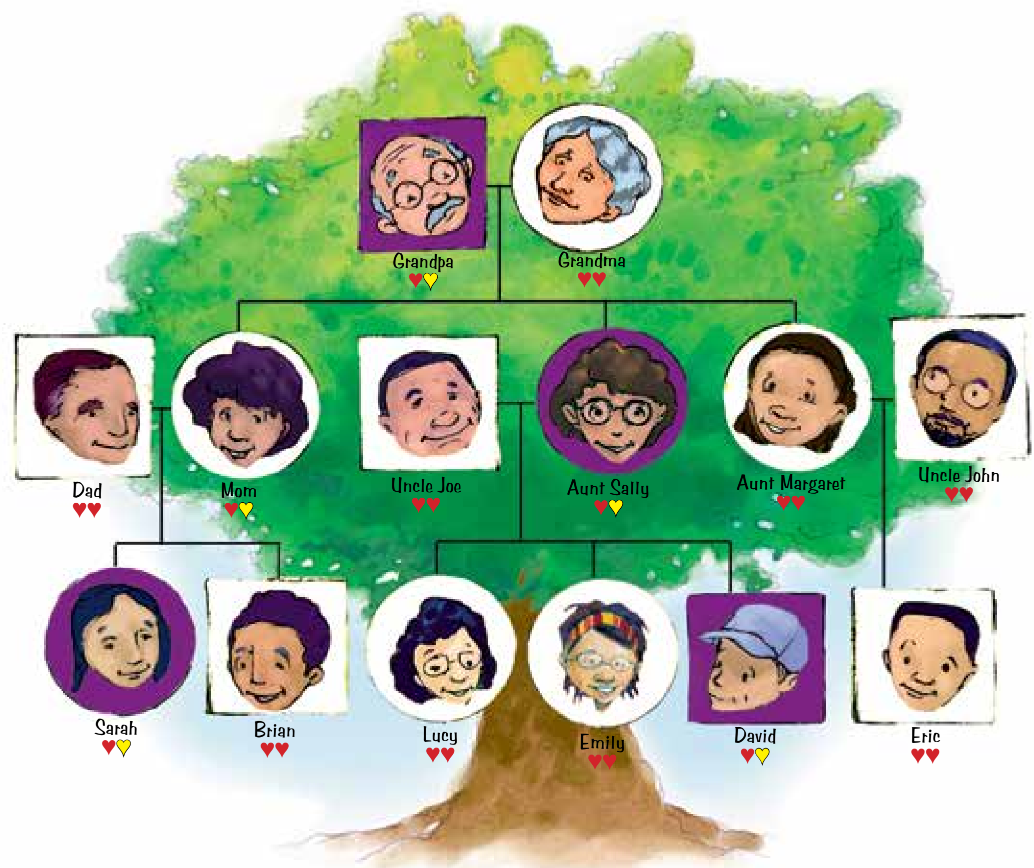
There are many different ways cardiomyopathy can be inherited. In some cases, brothers and sisters in a family or cousins in a family will have cardiomyopathy but no one else will have it. This fits with a pattern of inheritance known as **autosomal recessive inheritance**. Sometimes, only boys in a family will have cardiomyopathy. This fits with a pattern known as **X-linked inheritance**. It is not always easy to determine what pattern of inheritance is present in a family. A **genetic counselor** or **geneticist** can help you and your family figure out what type of pattern is present in your family.

Who are Genetic Counselors and Geneticists?

Genetic counselors and geneticists work as part of a health care team to give information and support to families with inherited conditions. They are specially trained as family history detectives. They will meet with you and your family and ask questions about family members and their health. They use this information to help you and your family understand more about familial cardiomyopathy.

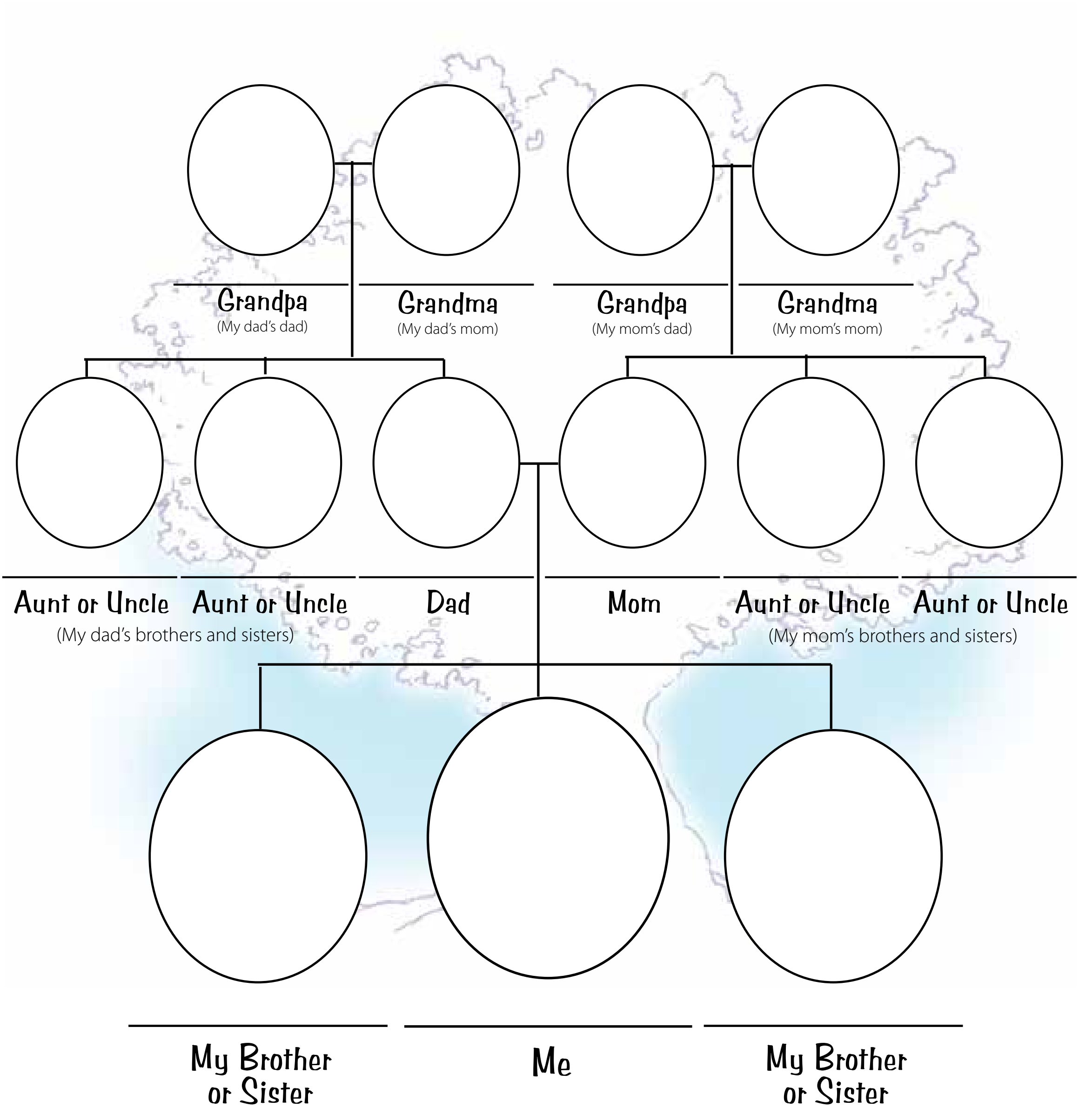
Does everyone who has a gene for familial cardiomyopathy GET cardiomyopathy?

No, sometimes people inherit a gene mutation that causes cardiomyopathy but they do not develop problems with their heart. The drawing on this page shows a **family tree**. The people shown with a purple background have familial cardiomyopathy. You can see that Grandpa, Aunt Sally, and David all have cardiomyopathy. Sarah also has cardiomyopathy but her mom does not. It looks like cardiomyopathy "skipped" Sarah's mom, but she still has the gene mutation for cardiomyopathy. We do not know why some people in the family who have the gene mutation for cardiomyopathy get it and why some people don't. It is still important for Sarah's mom to get her heart checked regularly to see if she will one day get cardiomyopathy.



♥💛 = Gene Mutation
♥♥ = No Gene Mutation
☐ = Doesn't Have Cardiomyopathy
🟪 = Has Cardiomyopathy

Now it's your turn to draw your family tree! Draw pictures of your family members and put their names underneath. Use a different background color for those family members that have cardiomyopathy. If you would like to add more family members, make a family tree on a separate piece of paper and find out where cardiomyopathy came from in your family and who has it now.

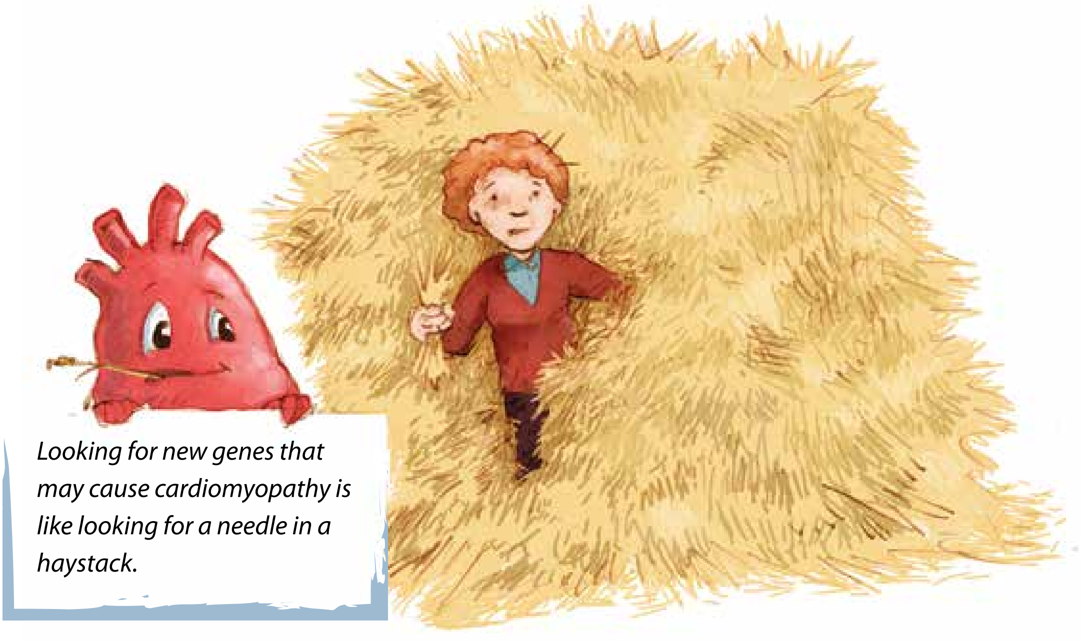


Can you test to see if I have a gene for familial cardiomyopathy?

Right now we know some of the genes that can cause cardiomyopathy in a family. There are probably many other genes that we just don't know about yet. **Researchers** are still trying to find these other genes. There may be a test available to look for the gene that causes cardiomyopathy in your family. This is called a **genetic test**.

First, you need to find out if genetic testing will be useful for you. Usually, someone in your family who already has cardiomyopathy has to be the first person tested. Sometimes the results of a genetic test can be very hard to understand. It is a good idea for you and your parents to talk with your doctor and genetic counselor about genetic testing.

If you decide to have a genetic test, you may have a little blood drawn. Some people are scared of this because it is done with a needle. Most people say it just feels like a pinch on the arm. It may take a long time to get the answer back, depending on the type of genetic test done.



Looking for new genes that may cause cardiomyopathy is like looking for a needle in a haystack.

How can I take care of myself?

If you have early signs of cardiomyopathy or if you are at risk to develop cardiomyopathy, there are ways for you to help take care of your heart.

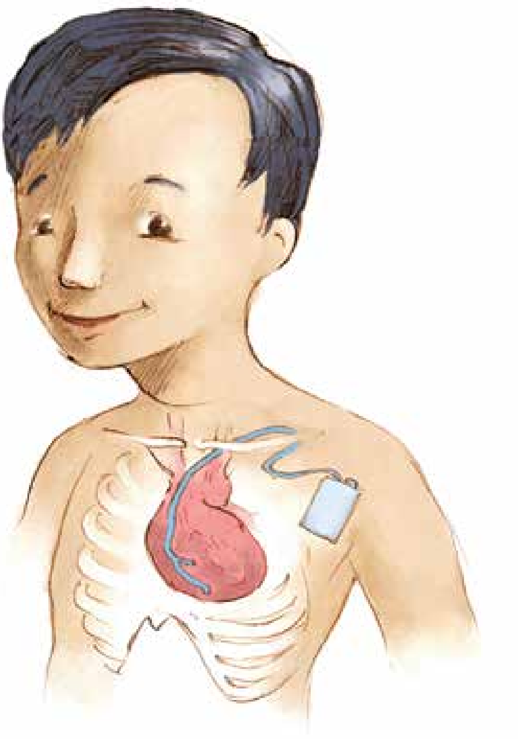
HEALTHY HABITS: Help your body stay healthy by eating good foods low in salt and **don't smoke, drink alcohol or use illegal drugs!**

EXERCISE: Exercise and sports are not always good for your heart when you have cardiomyopathy. You and your parents will need to talk to your doctor about what type of exercise and sports are okay for you to play.

REGULAR CHECK-UPS: Make sure that you see your cardiologist often so that you can tell him or her how you are feeling. Your cardiologist will probably have you come in for testing at least once a year.

MEDICINE: Your doctor will probably give you medicine to take if you have cardiomyopathy. It is important to follow the directions for taking this medicine to help your heart stay healthy.

DEVICES: If your heart needs some extra help beating with a steady rhythm, you may have a small device put inside of you that will help your heart. The two most common devices are called an **implantable cardioverter defibrillator** (ICD) and a **pacemaker**.



SURGERY: Some people with cardiomyopathy will need an operation to help the blood flow through their heart better.

HEART TRANSPLANT: Some people who feel really sick, weak, or whose treatment doesn't work, will get better with a new heart.

NEW TREATMENTS! Cardiologists and researchers are working very hard every day to make new medicines and treatments for kids and families with cardiomyopathy. In the future there will be many more ways to help you and your heart if you have cardiomyopathy.

How will cardiomyopathy change my life?

Kids with cardiomyopathy or who may develop cardiomyopathy can do many of the same things other kids do. You can still play, have friends, go to the movies, and do all kinds of fun things.

Sometimes kids with cardiomyopathy cannot play certain sports that make the heart work too hard. You and your parents should talk to your doctor about which activities are safe for you.

Kids with cardiomyopathy sometimes have to do things that other kids don't have to do, like take heart medications, go to the doctor more often and/or get some extra types of tests.

Having cardiomyopathy can make you feel many different ways, and you can have different feelings every day.

Some days you may feel:

Happy

Sad

Mad

Okay

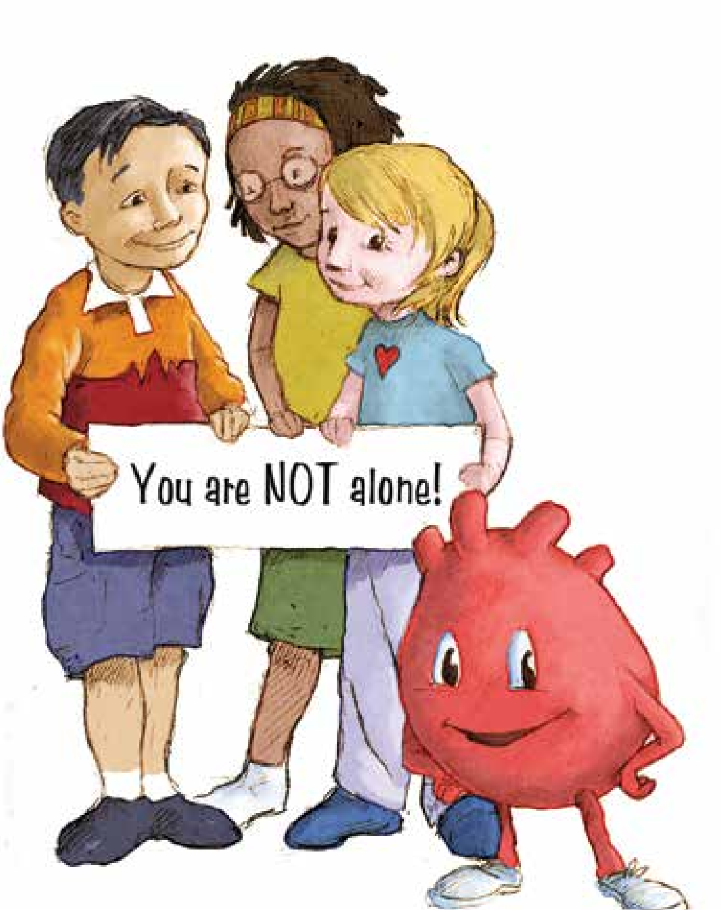
Worried

Hopeful

How do you feel today?

It's okay to talk about how you feel with your parents or another adult.

How can I contact other kids?



Cardiomyopathy can happen to people of all ages, shapes, sizes and color. It also affects both boys and girls.

Sometimes it can help to know other kids who have cardiomyopathy, or who have a brother, sister or parent with cardiomyopathy. There are lots of other kids out there who may feel just like you do. More than anyone else, they know what it's like to have cardiomyopathy or know someone in their family who has it.

One way to get in touch with other kids is to ask your doctor or genetic counselor if they know another boy or girl around your age who has or is at-risk for cardiomyopathy. You could find out if he or she would be willing to talk to you in person, on the phone, or even by e-mail.

Another way you could contact other kids is by joining a support group or going to a camp for kids with cardiomyopathy. Your parents can help you learn more about local organizations or help you find information on the Internet.

By reading this booklet, we hope that you now know a whole lot more about cardiomyopathy, what symptoms to look for, and how you can take care of yourself. But if you still have questions, it is ALWAYS okay to ask someone.

RESOURCES

American Heart Association
1-800-242-8721
www.heart.org

ARVD support group online
www.cardiomyopathy.org/shared-experiences/
online-support-group-arvc

Camp del Corazon
(818) 754-0312
www.campdelcorazon.org

Camp Taylor, Inc.
(209) 545-3853
www.kidsheartcamp.org

Cardiomyopathy Association
www.cardiomyopathy.org

Children’s Cardiomyopathy Foundation
(866) 808-CURE (2873)
www.childrenscardiomyopathy.org

“CRY” Cardiac Risk in the Young
email: cry@c-r-y.org.uk
www.c-r-y.org.uk

Hypertrophic Cardiomyopathy Association
www.4hcm.org

National Society of Genetic Counselors
www.nsgc.org

Sudden Arrhythmia Death Syndromes
(SADS) Foundation, (801) 948-0654
www.sads.org

Author Affiliated Resources

The Johns Hopkins Medical Institute
The ARVD Program
410-502-7161
www.arvd.com

University of Chicago
Cardiovascular Genetics Research
773-702-4310
http://home.uchicago.edu/~emmcnall/

The Johns Hopkins Medical Institute
Inherited Heart Disease Program
Center for Inherited Heart Disease
www.hopkinsmedicine.org/heart_vascular_institute/specialty_
areas/center_inherited_heart_diseases.html
(410) 502-2578

WORD LIST

Anesthesia: a medicine you take to help you sleep during special tests

Atrium: the upper parts of the heart that help pump the blood to the ventricles

Autosomal Dominant (AD): In AD inheritance, if a parent has a gene mutation that causes familial cardiomyopathy, their child has a 50% chance of inheriting that same gene mutation that can lead to cardiomyopathy

Autosomal Recessive (AR): In AR inheritance, both parents "carry" a gene mutation but do not actually have cardiomyopathy. Each of their children has a 25% chance of inheriting both of their parents' gene mutations that can lead to cardiomyopathy

Cardiac catherization: a test that uses a long tube to look at how your heart works

Cardiologist: a doctor who takes care of hearts

Cardiomyopathy: heart muscle disease

Chest x-ray: A test that takes a special picture that shows the size of your heart

Conduction system: another word for the heart's special electrical system. This is what tells the heart when to beat

Echocardiogram (ECHO): a test that uses sound waves to make a picture of your heart

Electrocardiogram (ECG): a test that measures the electrical activity of your heart

Familial cardiomyopathy: a genetic disease that causes a problem within the heart muscle

Family tree: a drawing that shows how individuals in a family are related

Genes: instructions that tell your body how to grow and work

Geneticist: a type of doctor that specializes in genetics

Genetics: the study of the way traits and characteristics get passed down in a family. Also the study of how specific genes work, such as the ones that cause familial cardiomyopathy

Genetic Counselor: a person specially trained to talk to parents and kids about familial cardiomyopathy or other genetic conditions

Genetic test: a test that can look for changes in your genes

Holter monitor: a small device that you wear (like a small tape recorder) that records your heart beat for 24 or 48 hours, just like an ECG

Inherited: passed down in a family through the genes (like blue eyes vs. brown eyes) from grandparents to parents to kids

Implantable Cardioverter Defibrillator: a device that can detect when the heart's electrical system is not working correctly and can help to get the heart back into normal rhythm

Interventricular septum: a wall of muscle that divides the left side of the heart from the right side

Inheritance: the pattern of how a condition runs in a family

MRI: Magnetic Resonance Imaging, creates detailed pictures of the heart using magnets

Mutation: a change in a gene that can make a gene stop working properly

Myocardium: heart muscle

Normal rhythm: a regular heart beat that is steady and not too fast or too slow

Oxygen: a chemical in the air we breathe that helps give us energy

Pacemaker: a device that helps the heart to stay in a normal rhythm

Researcher: a scientist who looks very closely at a health condition to learn new facts that may help people with the condition one day

Stethoscope: a tool used to listen closely to sounds in the body, like the heart beat

Stress test: a test that measures how the heart works during exercise, usually while walking on a treadmill

Symptoms: feelings in your body that let you know something is not right or make you not feel well

Valve: parts of the heart that control the flow of blood from one part to the other

Ventricle: the lower parts of the heart that must pump the blood to either the lungs (right ventricle) or the body (left ventricle)

Virus: a type of germ that is very tiny and can make you sick. When a virus infects the heart it can sometimes make a person get cardiomyopathy

X-Linked (XL): In XL inheritance, if a mother has a gene mutation that causes familial cardiomyopathy, her children have a 50% chance of inheriting the same gene mutation, but boys who inherit the gene mutation are more likely to develop cardiomyopathy than girls

NOTES

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Children's
™
Cardiomyopathy
Foundation

"A Cause for Today.... A Cure for Tomorrow"

The Children's Cardiomyopathy Foundation (CCF) is a national non-profit organization dedicated to finding causes and cures for pediatric cardiomyopathy through the support of research, education, awareness and advocacy.

Children's Cardiomyopathy Foundation, Inc.
24 West Railroad Avenue, Suite 408, Tenafly, NJ 07670
Toll free: 1-866-808-CURE (2873) | Fax: 201-227-7016
info@childrenscardiomyopathy.org | www.childrenscardiomyopathy.org

To order copies of this booklet please contact the Children's Cardiomyopathy Foundation at: info@childrenscardiomyopathy.org or www.childrenscardiomyopathy.org.

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