

MATTERS OF THE HEART



A Guide to Cardiomyopathy in Duchenne

*This is Diego—he is living with Duchenne.
He and his parents, Diego Sr. and
Brianna, are paid ambassadors.*



What Is Cardiomyopathy?

Cardiomyopathy is a general term for any disease of the heart muscle.



In Duchenne, the lack of dystrophin can damage the heart muscle. This can cause the heart to weaken over time, making it harder to pump blood throughout the body.

Most children and young adults with Duchenne will develop cardiomyopathy.

In fact, **60% of boys show signs of cardiomyopathy by age 10,**



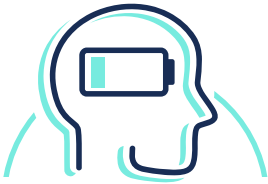
and that number **increases to 90% by age 18.**



Signs and Symptoms

When other muscles decline, the effects may be easy to notice.
But cardiomyopathy can begin before you see it.

Typical signs of cardiomyopathy include:



Excessive fatigue



**Fluttering, rapid, or
irregular heartbeats**



Weight loss



**Respiratory changes
like shortness of breath**



**Vomiting or
stomach pain**

Beginning Your Journey

Over time, most people with Duchenne will develop cardiomyopathy.

Some people don't show signs until cardiomyopathy is advanced. Others may show signs earlier, but it's easy to assume that the symptoms are being caused by other Duchenne complications. That's why educating yourself is so important when it comes to heart health in Duchenne.



A cardiologist can monitor any possible changes in heart health and find the right treatments to address them. Talk to your doctor about meeting with a cardiologist to discuss your child's heart health.

You can also visit [WeSpeakDuchenne.com](https://www.wespeakduchenne.com) and download the Doctor Discussion Guide to help lead your conversation.



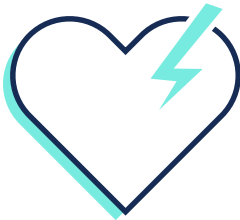
Stages of Cardiomyopathy in Duchenne

Cardiomyopathy by Age



0-10 years

25% show signs
by age 6

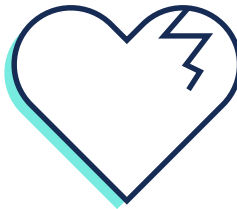


Scarring of the
heart begins



10-18 years

60% show signs
by age 10



Scarring of the heart
muscle is common
over age 15



18+ years

90% show signs
by age 18



Requires close
monitoring and
medicine

Proactive cardiac care can help manage
the effects of cardiomyopathy in Duchenne.

Treating Cardiomyopathy

Ongoing studies are looking at treatments for cardiomyopathy in Duchenne. Your doctor and cardiologist can help create a plan of care.

Prevention

- Diagnosing early could improve outcomes
- Some medicines, like ACE inhibitors, that are used for other heart conditions may also be helpful to people with Duchenne. They may help prevent scarring and preserve heart function

Management

- Treatments range from heart medicines to special devices
- Treatments may be combined as cardiomyopathy and Duchenne progress

Ongoing Monitoring

- Doctors with different specialties can help manage your care plan
- Regular bloodwork and testing will guide treatment decisions

A cardiologist may use tests like an EKG, MRI, or echo to view the heart.



EKG

A simple and quick test that records the electrical signals that make your heart beat to check for any signs of damage.



Cardiac MRI

A special type of test that gives doctors a very detailed picture of the heart. It can take 30 to 90 minutes and requires remaining still during the scan.



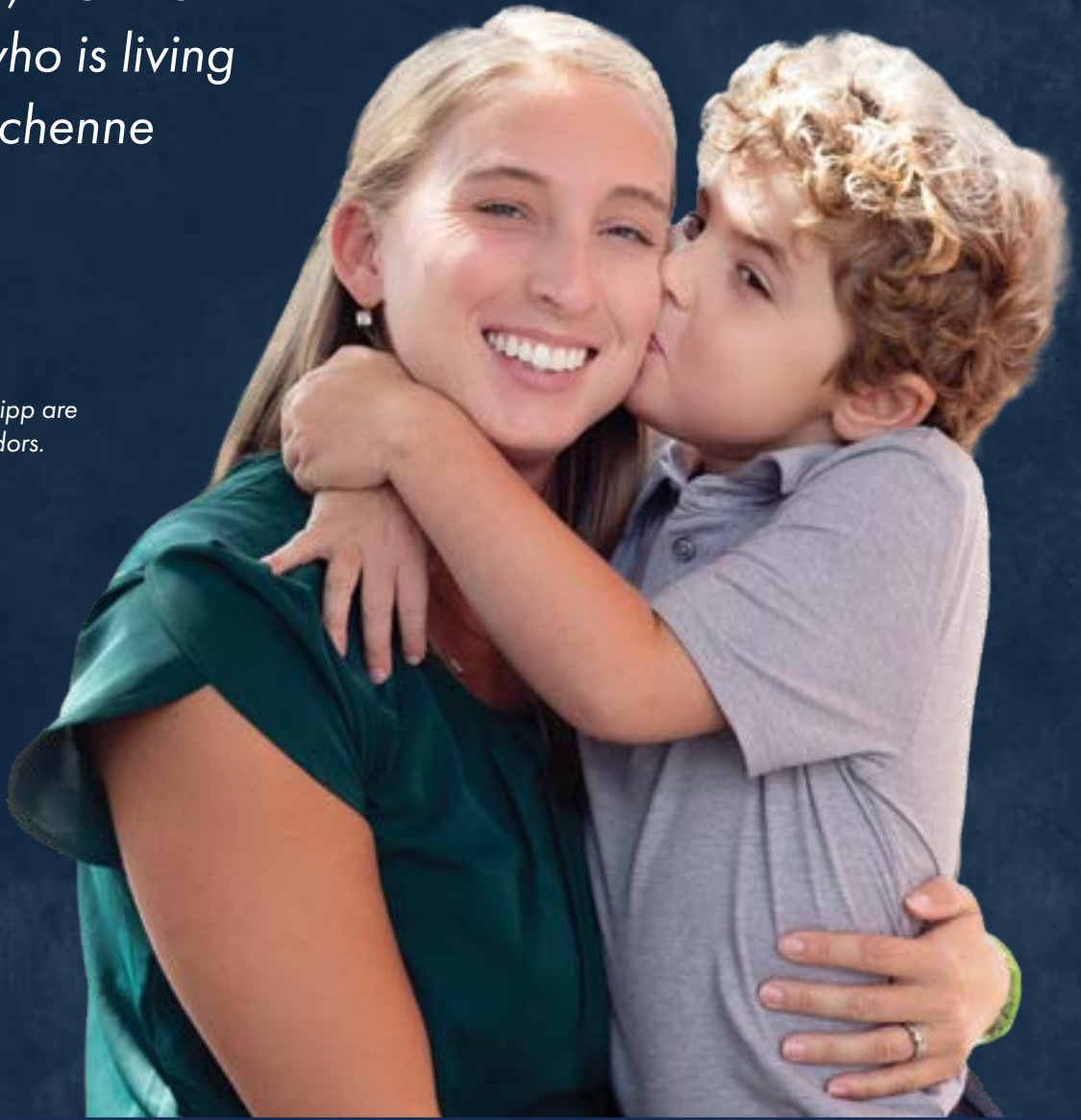
Echo

A simple test that uses sound waves to create moving pictures of the heart.

“When we talk about the muscles, the heart is not always top of mind. It’s important to remember that it is a muscle and to be proactive about heart health.”

–*Summer, mom to Tripp, who is living with Duchenne*

Summer and Tripp are paid ambassadors.





"I talk about heart health quite a bit with my care team. I've been seeing a cardiologist for as long as I can remember. I have regular tests for monitoring and am on a couple of medicines to help support my heart function."

Colin *living with Duchenne*

Colin is a paid ambassador.



Looking to start a conversation about heart health with your own care team?

Visit **[WeSpeakDuchenne.com/Resources](https://www.wespeakduchenne.com/Resources)** to download a helpful doctor discussion guide.



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