



## Vision

Finding solutions for  
infant myocarditis

## Mission

1

To improve awareness and the  
knowledge base around the  
prevention and treatment of  
myocarditis in infants

2

To provide information,  
counselling and practical  
assistance to those affected by  
infant myocarditis

# The Conor James Foundation: A Legacy

In November 2017, Michelle and Michael Funke's three week old son, Conor James Funke, passed away after contracting a virus.

Conor was born perfect and healthy, but at just a few days old was diagnosed with Coxsackievirus B, which attacked his heart and left him with myocarditis, left ventricular infarction and cardiogenic shock. At a week old he went into heart failure and was transferred to a specialist cardio-thoracic intensive care unit (CTICU) for more focused treatment. While there was some hope for his recovery, the damage to his heart from the viral infection was severe. In neonates it's difficult to know what to expect; they could either recover completely or deteriorate rapidly.

A week after being in the CTICU he developed pneumonia and went into multiple organ failure. Conor had to be put onto life support – extracorporeal membrane oxygenation (ECMO). Despite best medical efforts, Conor passed away on 17 November 2017.

Conor's condition was rare and there were limited medical options for him as a neonate. During their journey with Conor, Michelle and Michael

were challenged by the lack of reliable information available on myocarditis in infants as well as what to expect on the road ahead.

The lack of information and support for infant myocarditis, due to its rarity, along with the fact that treatment options for neonates are limited due to their size, moved them to create a legacy for their son. Their vision was a non-profit organisation that would positively impact the lives of others through providing guidance, support, knowledge and ultimately contributing towards finding effective prevention and treatment options for infant myocarditis.



## Three key focus areas

And so, in Conor's honour, his parents established the Conor James Foundation, which has three key focus areas:

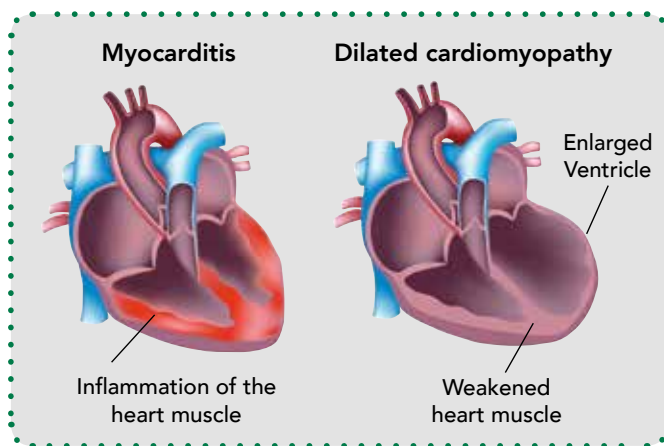
- 1 Awareness**  
To create awareness around infant myocarditis, and closely related conditions, in the medical community and among parents through the development of educational material
- 2 Support**  
To establish counselling and resource support for families whose children are affected by infant myocarditis
- 3 Research**  
To raise funds for further research into myocarditis, especially in neonates and infants up to six months old.

As a private, non-profit organisation The Conor James Foundation relies on the generosity of donations to achieve its objectives.



## What is myocarditis?

Myocarditis is inflammation of the heart muscle (myocardium). Myocarditis affects both the heart muscle and the heart's electrical system, causing rapid or abnormal heart rhythms (arrhythmia) and reducing the heart's ability to pump blood effectively.



Myocarditis can affect the muscle cells of the heart, the valves and the blood vessels. In severe cases, the extent to which myocarditis weakens the heart can also affect its ability to supply the rest of the body with oxygenated blood.

Infant myocarditis is usually more severe due to the infants' underdeveloped immune system, which often leads to other organs, such as the liver and kidneys, being affected.

When myocarditis causes the muscles of the heart to weaken and heart chambers to become enlarged, referred to as dilated cardiomyopathy, a heart transplant may be required as patients have an increased chance of going into heart failure. Heart failure is when the heart can no longer pump adequately to supply the body with the blood flow and nutrients it requires. The organs particularly affected in heart failure are the kidneys, the liver and the brain.

There is currently no prevention or cure for myocarditis, especially in neonates and infants, so supportive care is the primary treatment for this disease. Infants and children will require hospitalisation for the management of potential heart failure and arrhythmia.

Treatment usually consists of administration of intravenous cardiac medicines to support the work of the heart, although a temporary pacemaker may also be necessary. In many cases, children will need to be put onto a ventilator (breathing machine) to support the additional work the heart is doing to maintain breathing. In severe cases, extracorporeal membrane oxygenation (ECMO) may be necessary to allow the heart to recover. This treatment option mostly serves as a bridge to heart transplantation.

Once the acute phase has passed, surviving patients may recover completely or have long term heart problems. A heart transplant may offer the best chance for long term survival when there is progressive dilated cardiomyopathy with declining cardiac function.

“ *There is currently no prevention or cure for myocarditis, especially in neonates and infants* ”

### High mortality rates

While some children recover completely from myocarditis, or suffer no serious consequences from the disease, severe cases of myocarditis are commonly linked to high mortality rates around the world.



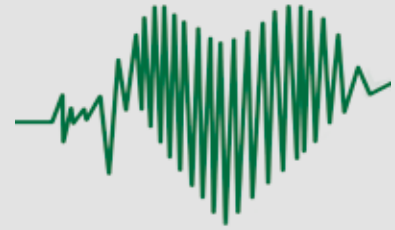
# How you can get involved

1

Cash



Your monetary donation can be made via our website



2

Calories



Sign up to the Conor James Foundation's Beats for Bucks programme and participate in one of our established sporting events, or register for your own event, where you earn donations on our behalf. Find out more on our website.

**Beats  
for  
Bucks**

3

Creativity



We would love to hear your ideas for fundraising events and any other input you may have to further our foundation.

However you decide to participate, your **CASH, CALORIE** or **CREATIVITY** donation will go towards one of the many projects that the foundation has planned to change the lives of those infants affected by myocarditis and their families.



You can also volunteer to personally assist us at one of our fundraising events.

We would love to hear from you!

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 Follow us: [ConorJamesFoundation](https://www.facebook.com/ConorJamesFoundation)

 **Conor James  
Foundation**  
*For little hearts because every beat counts*

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