



# BHF launch new programme to implement cascade testing services for cardiomyopathy



In January 2016, together with the family of Sir David Frost, the BHF launched the Miles Frost Fund in memory of Sir David's son, Miles, who died suddenly of an undiagnosed heart condition in 2015.

Miles was an incredibly fit 31 year-old in the prime of his life when he was struck down by a cardiac arrest out of the blue. He had gone out for a run and was found by his youngest brother George in the driveway of the Frost family home.

Later it was found that Miles had hypertrophic cardiomyopathy (HCM) – an inherited heart condition which it is thought he inherited from his father. Although Sir David Frost's death was not caused by the condition, his post mortem showed HCM was present. Despite this, Miles was never tested.

## A deadly inheritance

Each child of someone with HCM has a 50 per cent chance of inheriting a gene mutation that can lead to developing the condition. The majority of these people are undiagnosed and will have no symptoms. However, for some - like Miles - HCM can lead to sudden death at a young age, often without warning.

Every week in the UK 12 people aged 35 and under die of an undiagnosed heart condition. HCM is the biggest cause of these deaths and around 120,000 people are living with the condition across the country.



## Genetic testing, nationwide

BHF research by Professor Hugh Watkins and Bill McKenna at the University of Oxford led to the identification of faulty genes underlying the condition which paved the way for genetic testing services for HCM in the UK.

This meant for the first time, parents, siblings and children of someone known to have a disease-causing mutation could find out if they also had it, and get help to prevent a potential tragedy.

The initial trial found nearly 700 people with gene mutations and the test was so cost-effective it was approved as an NHS service. However, despite these breakthroughs, rollout of genetic testing for families has been slow and it's a lottery as to whether people at risk will be referred. This means

people are slipping through the net and many could lose their lives having missed out on potentially lifesaving treatment.

The Miles Frost Fund will help ensure more people at risk of HCM are referred for genetic testing and get the treatment that could save their life.

## Call for expressions of interest

The Fund, which launched on 31 January, will raise money to set up a national cascade testing service for family members of those who have died of, or have been diagnosed with, HCM. This will ensure more people receive testing, screening and treatment.

The BHF is now inviting expressions of interest from organisations across the UK to apply for Miles Frost Fund/ BHF funding.

The funding will primarily be used to enhance and join up existing services including the provision of additional specialist nurses/genetic counsellors to work within inherited heart condition clinics to improve referral and diagnosis for families affected.

It will also support the infrastructure needed to create a nationally coordinated service and raise awareness of the benefits of genetic testing. A total of £1.5 million is available across the whole programme and flexibility will be given as to how the money is spent.



Chief Executive of the BHF, Simon Gillespie said: "BHF researchers were among the first to find the gene mutations underlying the deadly heart condition which caused the tragic death of Miles Frost. Thanks to this pioneering discovery, genetic testing for HCM and other inherited heart conditions is now available in the UK, but it's a lottery if people will be referred for it.

"The Miles Frost Fund will help to establish a fully functional, UK-wide cascade testing service for parents, siblings and children who could be at risk. Working with the Frost family, our aim is to ensure people who have HCM are identified and treated to prevent a needless loss of life."



## Help end the heartache

At the end of the funding, the BHF hope that the NHS will sustain the nursing and counsellors posts created by the Miles Frost Fund and roll out the service nationally. This will ensure more people receive the investigations and treatment they need to potentially save their life.

If the Fund raises more than £1.5 million, additional funds will support BHF research in to inherited heart conditions including HCM.

With your support, the Frost family can stop more young people like Miles needlessly losing their lives to this deadly heart condition.

Wilfred Frost, Miles younger brother said, "If the Fund helps to prevent just one similar death occurring, then Miles will not have died in vain."

For more information about the Miles Frost Fund visit [www.milesfrostfund.com](http://www.milesfrostfund.com)