



## Role profile

### Patient representative for Miles Frost Fund

#### Background to the project

Miles Frost died suddenly of hypertrophic cardiomyopathy (HCM) in July 2015 aged 31 years. Miles' death devastated his family and friends. It was made all the more painful when they were told Miles probably inherited the condition from his father, Sir David Frost. While medical research has identified effective tests and treatments for HCM, Miles was never offered either because the opportunity to carry out genetic testing in the family was missed when his father died.

Each child of someone with HCM has a 50 per cent chance of inheriting it from the affected parent. Thanks to BHF research, the genes responsible can often be identified and with treatment most people can lead a normal life. However, despite these scientific breakthroughs, rollout of genetic testing for families is slow and it's a lottery as to whether people at risk will be referred. This means people are missing out on a potentially lifesaving treatment.

In Miles' memory, the Frost family has set up the Miles Frost Fund to raise money for the BHF to help set up, or enhance existing, cardiomyopathy cascade genetic testing services in the UK.

The Fund will help ensure that genetic testing for immediate family members of those affected by HCM is available nationwide. This will mean more people are diagnosed with and treated for the potentially life-threatening condition so that the risk of avoidable premature death can be decreased.

The BHF is working closely with the Frost Family to generate £1.5 million to fund cascade testing services.

The Miles Frost Fund is now inviting applications for funding to support activity which will enhance current Inherited Cardiac Condition Services to identify more patients with HCM via cascade genetic testing.

To ensure the new and improved services are best placed to support the needs of patients and their families with inherited heart conditions, we're inviting patient representatives to join the assessment panel and national steering group.

#### Assessment Panel

Applications to the fund will be reviewed by the assessment panel. The assessment panel will be made up of BHF staff, consultant cardiologists and specialist nurses with expertise in inherited cardiac conditions, including representation from NHS England, Health and Social Care Board Northern

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Ireland, NHS Scotland and NHS Wales. It will also include patient representatives.

The panel will meet on 31<sup>st</sup> Oct 2016 to make a final decision on which applications will be awarded funding.

## **National Steering Group**

Once the awards have been made, a national steering group will be formed to oversee the progress of all the funded sites. The steering group will include the patient representatives and key members of BHF staff.

It is anticipated that the group will meet quarterly at BHF's London office.

## **Role Description**

### **Responsibilities**

Patient representatives will be members of the assessment panel and national steering group. You will be expected to:

- read all paperwork sent for review and make comments as appropriate, taking responsibility to seek further information and guidance from your key contact (see following page) as necessary
- attend and contribute thoughtfully and constructively at meetings from the perspective of a patient with, or someone affected by, cardiomyopathy
- share your views in a considered and constructive way maintaining confidentiality when needed.

### **Skills and attributes**

The types of skills and attributes that we are looking for are:

- experience of inherited cardiomyopathy (hypertrophic, dilated or arrhythmogenic right ventricular) and genetic testing. This could be as a patient with cardiomyopathy or someone affected by it, for example a family member.
- objectivity and the ability to consider options for where improvements to the current system could be made
- experience of being part of a steering group
- ability to read and absorb complex information, seeking further information and clarity where needed and from appropriate sources
- confidence to voice your opinions clearly and to participate constructively in group discussion
- good communication skills with an ability to listen to and to respect differing opinions and to express own view clearly and appropriately
- an interest in improving genetic testing for inherited conditions – and a willingness to learn more.

### **Time commitment**

- A briefing/induction session by teleconference or face to face
- Attendance at the assessment panel in London on 31<sup>st</sup> October 2016. Depending on the number of applications received, this could take most the day.
- A couple of hours in the few weeks prior to the assessment panel to individually review the applications
- Attendance at four meetings a year in London (steering group), including some preparation time before each meeting
- Occasional consultation via email in between meetings
- Attendance at a conference or a learning event to share emergent findings

### **Support**

To ensure you are able to contribute effectively in your role, we will assign you a key contact within BHF who will be in regular contact with you through email or telephone for information, advice and support.

### **Expenses**

We are able to reimburse reasonable expenses for travel and overnight accommodation where necessary and agreed in advance. We are able to book your travel and accommodation in advance if necessary.

### **Application process**

If you are interested in applying, please send a brief summary (max 500 words) stating why you would like to get involved in this project and what you think you can bring to the role to [heartvoices@bhf.org.uk](mailto:heartvoices@bhf.org.uk) by **5 October 2016**.

If you have any questions, please contact [heartvoices@bhf.org.uk](mailto:heartvoices@bhf.org.uk) or call 0207 554 0194.