# Role profile Patient Advisory Group Member

## Background

The BHF funds over £100 million of research every year into heart and circulatory conditions (including stroke, diabetes and vascular dementia). We help scientists undertake pioneering research into many different heart and circulatory conditions, their causes, prevention, diagnosis and treatment.

We receive more than 500 research grant applications each year from research teams all over the UK. Eligible applications are reviewed by experts in the field, and their judgments inform the funding decisions made by our research grant committees, which are made up of independent scientists.

This objective and rigorous review process ensures we fund only applications of the highest scientific quality. We are a response-mode funder, believing that the most effective way of tackling heart and circulatory conditions, is to allow the research community to identify the gaps in knowledge and generate the research ideas and approaches needed to fill those gaps. We support a broad portfolio of basic science, through to translational and clinical research, totaling around 1,000 active research grants at any one time.

As outlined in our 2015-2020 <u>Research Strategy</u>, BHF aims to support more clinical research, which is research undertaken on patients in hospitals and clinics. Trials of new or established treatments lead to better patient care, and our ambition is to fund more clinical trials either independently or in partnership with other funders.

Our Clinical Studies Committee (CSC) decides which clinical research applications are awarded funding from the BHF. To help ensure the applications we fund are important and relevant to the needs of patients, two lay members (also called patient representatives) sit on the CSC. The lay members are supported by, and are also part of, a wider Patient Advisory Group (PAG).

### **Clinical Studies Committee**

The CSC is made up of approximately 14 members, including two lay members. Other members include scientists and other experts in the field.

The CSC meets twice a year (in May and November) to assess the high value clinical study applications that have been received over the previous six months. The CSC will make the final decision on which grants are awarded funding and which are rejected.

## Patient Advisory Group (PAG)

The PAG supports the role of the lay members who sit on the CSC. It is made up of 12-15 members who have been affected by heart and circulatory conditions.

The PAG will meet prior to each CSC meeting, to discuss and provide feedback on all the applications. The PAG will particularly focus on assessing:

- the quality of the plain English summaries
- the importance of the research question to people affected by heart and circulatory conditions, and whether they feel it is a priority
- commitment to patient and public involvement (PPI), both in the development of the research question and design, and proposed plans for ongoing involvement
- study recruitment plans and any unnecessary burden on patients or barriers to people with heart and circulatory conditions taking part in the research

Lay members will be responsible for sharing feedback from PAG at the CSC.

## The impact you'll make...

The Patient Advisory Group gives people with experience of heart and circulatory conditions the opportunity to influence which clinical research projects are funded by the BHF. As a PAG member you will help to ensure that the BHF invests in research that will make a difference to people affected by heart and circulatory conditions, ensuring it is conducted in a way that has maximum benefit to patients.

## **Role Description**

## Responsibilities

PAG members will be expected to:

- attend and contribute thoughtfully to at least two PAG meetings per year (face to face) In March and September
- participate in mandatory training and other activities as agreed
- prepare in advance for meetings this includes reviewing research grant applications
- respond in a timely manner to all email communication between PAG members as required
- contribute thoughtfully and constructively to discussions from the perspective of a patient with, or someone affected by a heart or circulatory condition
- share your views in a considered and constructive manner
- treat all applications that you review as confidential
- provide ongoing feedback to help further develop and refine the process for involving patients in the review of clinical research funding applications

## Skills and attributes

PAG members must have the following skills and attributes:

• have a personal experience of a heart or circulatory condition such as stroke, diabetes and vascular dementia, either as a patient or carer, and an awareness of how heart and circulatory conditions can affect people

- be enthusiastic about research, and willing to familiarise yourself with medical and research language
- ability to read and absorb complex information, seeking further information and clarity where needed from appropriate sources
- good communication skills with an ability to listen to and to respect differing opinions, and to express your own view clearly and appropriately
- confidence to voice your opinions clearly and to participate constructively and objectively in meetings with a large number of other people
- IT literate grant applications are viewed using an online system
- it is desirable that some PAG members have experience of taking part in a clinical trial.
- it is desirable that some PAG members have links to other people with heart and circulatory conditions (e.g. through a support group). To help broaden the diversity of the group we're especially looking for people with experience of stroke, younger people and BAME communities.

### Length of membership

Membership to PAG is for 3 years, after which the membership will be reviewed.

#### Time commitment and dates

- Mandatory training and induction session on 5<sup>th</sup> and 6<sup>th</sup> February 2019 in London (this will run from approx. 11am-3.30pm on both days, and we will cover any travel or accommodation costs).
- A minimum of two meetings of PAG a year, approximately six weeks prior to the CSC meetings which take place in May and November. The first meeting will take place on 13<sup>th</sup> March 2019.
- A couple of days to prepare and review applications prior to each PAG meeting (from home).

### Support

To ensure you can contribute effectively in your role, you will be asked to attend a mandatory training and induction session. We will also 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 will reimburse reasonable expenses for travel and overnight accommodation where necessary and agreed in advance. We are also able to book your travel and accommodation for you prior to any meetings / training if necessary.

### Application process

To apply for the role of Patient Advisory Group member please complete the expression of interest form, and return this to <u>heartvoices@bhf.org.uk</u>. The deadline for applications is **16**<sup>th</sup> **December 2018**.

Those who are shortlisted for the role will be invited for a telephone interview on the week commencing **7 January 2019**. If you have any questions, please email <u>heartvoices@bhf.org.uk</u> or call 0207 554 0394.