

25 Feb 2013

# **CFS/ME Research Collaborative**

## **Charter**

## **1. Name**

The name of the organisation will be the **CFS/ME Research Collaborative**

### 1.1 History

The CFS/ME Research collaborative (CMRC) developed from the MRC CFS/ME expert group (2008-2011). The CFS/ME research collaborative was formed after wide consultation with researchers, charities and funders.

## **2. Aims and objectives**

### 2.1 Aim

To promote the highest quality of basic and applied evidenced based and peer reviewed research in to CFS/ME

### 2.2 Objectives

2.2.1 Develop inform and update a national strategy for CFS/ME research

2.2.2 Promote the need for world class research into CFS/ME across all fields

2.2.3 Facilitate all high quality peer reviewed research into all aspects of CFS/ME in both adults and children. This will include: basic mechanistic research; translational research; epidemiological research; health resource use research and research investigating all types of treatment and prevention of CFS/ME.

2.2.4 Encourage multidisciplinary research by facilitating links with those already active in the field and involving scientists in other fields to undertake research in CFS/ME.

2.2.5 Facilitate investment in essential research infrastructure e.g. bioresources, technology platforms, well phenotyped patient cohorts to deliver high quality research in CFS/ME and promote increased research capacity in the field.

2.2.6 Work collaboratively to raise the profile of CFS/ME research in the UK in both professional and public domains.

2.2.7 Promote, facilitate and support the development of a good career structure for CFS/ME researchers.

2.2.8 Foster research collaborations and communication between clinicians, researchers, professional bodies, industry and charities with research interests in this field.

2.2.9 Promote conditions in which more research can take place in NHS bodies within the UK, including supporting clinicians and researchers conducting all types of peer reviewed research.

2.2.10 Work collaboratively with funders, charities and researchers to increase the financial support for CFS/ME research in the UK

2.2.11 Raise awareness of the achievements of the CFS/ME research community

2.2.12 Liaise with UK and international agencies and funders to share information and respond to consultations.

## **3. Membership and observers of the CRMC**

### 3.1 Membership

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Membership of the CMRC is open to all UK-based medical practitioners, all other health care professionals, researchers and charities involved in CFS/ME research. Members must:

- 3.1.1 Be located within the United Kingdom,
- 3.1.2 Deliver or support CFS/ME research ~~either by:~~ including funding research, advising and supporting researchers or as clinicians working with researchers in studies/trials,
- 3.1.3. Not take part in the harassment or abuse of researchers including taking part in orchestrated campaigns against those conducting peer-reviewed research.
- 3.1.4 In matters within the scope of the CMRC, to work collaboratively and in a professional manner.
- 3.1.5 Membership of the CMRC does not prevent any member charity or organisation from pursuing its aims and objectives as laid out in its founding documents.

### 3.2 Applying for membership

- 3.2.1 New members should apply on a membership application form, obtainable from and returned to the executive. The membership application form will be created by and updated by the executive.
- 3.2.2 Members are advised that by joining the CMRC, they agree to have their details kept on a password-protected database for purposes of communication, on the understanding that the information will not be passed to other organisations.
- 3.2.3 Members will be required to sign a declaration that they will not take part in the harassment or abuse of researchers. Neither will they take part in orchestrated campaigns against those conducting peer-reviewed research.
- 3.2.4 The executive will consider all proposals for membership and reserves the right to seek further information, approve, decline or defer proposals as appropriate.

### 3.3 Members meetings.

Members of the UK CMRC will meet once a year at the annual general meeting (AGM). At this meeting, workstreams will present their progress in meeting objectives and researchers will be able to present research findings. Confirmation of elections to the executive will take place at this meeting (see Section 4). Additional meetings may also be arranged if members so wish.

### 3.4 Decision making

- 3.4.1 All members will be eligible to vote at the AGM.
- 3.4.2 Voting will ordinarily be using a simple majority, and by a show of hands, but may be by ballot if the Chair so decides, in the event of late submission of items, or if requested by any two members.
- 3.4.3 The Chair will not normally vote but, in the case of a tied vote, will have a casting vote.

### 3.5 Observers

The UK funding agencies will be invited to be observers at all meetings. This will include the NIHR, MRC and Wellcome Trust.

## **4. The Executive**

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Members of CRMC will be represented by an executive committee to organise meetings, co-ordinate public statements, and develop proposals for funding/research strategy. For the first term (3 years), the executive will be formed from those members of the MRC expert group with consideration of new members as necessary.

#### 4.1 Membership and election of the Executive

4.1.1 The executive will include a chair, deputy chair, secretary, a total of 5 researchers and 5 charities.

4.1.2 Members (including the executive) will be unpaid. Potential conflicts of interest will be reported to the chair at the start of each meeting.

4.1.2 Each member will be involved in work streams.

4.1.3 Each member of the executive will have agreed to the terms of CRMC membership.

4.1.4 Each member will be asked to serve for a three year term.

4.1.5 Elections for members of the executive will use a one member-one vote, first-past-the-post voting system. The representatives of the charity members of the executive will be nominated by the charities themselves.

#### 4.2 Duties of the Executive

4.2.1 Members of the CMRC Executive Committee will normally be expected to attend all meetings.

4.2.2. Executive members will contribute to work streams which will be agreed at each members meeting for example: Infrastructure development; promoting CFS/ME research; increasing funding.

4.2.5 At the end of their term on the Executive, members will be expected to hand over responsibilities in a timely manner.

#### 4.3 Officers of the Executive

4.3.1 The officers comprise the chair, the deputy chair and a secretary who will be elected by the Executive for a term of three years. The chair can do a second term of 3 years with the agreement of the Executive.

4.3.2 The Deputy Chair shall deputise for the Chair in their absence, or when a conflict of interest requires that the Chair stand aside on a particular item

#### 4.4. Meetings of the Executive

4.4.1 The Executive committee will meet at least twice a year in addition to the annual members meeting.

4.4.2 The responsibility for setting the dates of the meetings will rest with the Chair who will normally give at least 4 months notice.

4.4.3 The agenda for each meeting will be set by the Chair. Items for inclusion on the agenda must be submitted to the Chair in writing no later than 3 weeks before the next meeting.

4.4.4 The deputy chair will be responsible for ensuring that minutes are taken at the meeting and distributed in a timely fashion after the meeting.

4.4.5 Additional or extra-ordinary meetings may be called where circumstances require, normally at least three weeks from notification. Decisions will be made by the chair with the written agreement of one other executive member.

#### 4.5 Decision making process

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Decisions (including decisions on membership) will be made by the executive on the vote of the chair plus at least 4 executive members (quoracy).

### **5 Constitution revisions**

5.1 This constitution, or any part of it, can be revised at the Annual Members Meeting with 2 weeks written notice of proposed changes.

5.2 Any revision will require a two-thirds majority of those present at the Annual Members Meeting and any members voting prior to the meeting.

### **6. Notice to leave**

Any member of the CMRC may, by giving notice to the executive, cease to be a member immediately.