

British Association for Chronic Fatigue Syndrome/ME (BACME) Constitution

24 September 2009 The WMMEG (West Midlands ME Groups Consortium) received the CCRNC Constitution from Esther Crawley. It states: "The name of the organisation will be the CFS/ME Clinical and Research Network and Collaborative (CCRNC)" This CCRNC constitution was dated December 2008.

Dr Wearden, Assistant Chair of the British Association for Chronic Fatigue Syndrome/ME (BACME), wrote to one of the members of LocalME:

BACME is an organisation of clinicians and researchers working in the field of CFS/ME. It was formed in April of this year from the merging of two previous organisations - the Collaborative of CFS/ME Network Coordinating Centres, and the CFS/ME Network, which was a network of clinicians and researchers working in the field of CFS/ME.

Immediately after the merger, the organisation was called the CFS/ME Clinical and Research Network and Collaborative (CCNRC) but we changed the name to British Association for CFS/ME (BACME).

23 February 2010 Dr Esther Crawley informed the WMMEG that the BACME "constitution is the same with the new name"

www.bristol.ac.uk/ccah/people/peopledetails/?personKey=X3Fac4CMLRx6HSJBRc\%eHIUWBuN0htL
Esther is a medical advisor to the Association of young people with ME, and is Chair of the British Association for CFS/ME (BACME).

Following gives original CNRCC constitution, dated December 2008

CFS/ME Clinical and Research Network and Collaborative (CCRNC)

December 2008

1. Name

The name of the organisation will be the CFS/ME Clinical and Research Network and Collaborative (CCRNC)

2. Aims and objectives

2.1 Aim

The **CFS/ME Clinical and Research Network and Collaborative (CCRNC)** is a multidisciplinary organisation which exists to promote and support the delivery of evidenced based treatment for children, young people and adults with CFS/ME throughout the UK.

2.2 Objectives

- 2.2.1 To champion evidence-based approaches to the treatment of CFS/ME, such as those provided in the NICE guidelines
- 2.2.2 To provide a forum for the monitoring and dissemination of new evidence for the management of CFS/ME as it emerges
- 2.2.3 To advocate for excellence in the provision of, and for equity of access to, clinical services for children, young people and adults with CFS/ME
- 2.2.4 To support the delivery of services and to enable services to maintain standards of care in the treatment of CFS/ME as set out in the NICE guidelines
- 2.2.5 To use clinical expertise and evidence to influence and inform healthcare policy
- 2.2.6 To promote, facilitate and provide training for clinicians and researchers from all disciplines involved in the diagnosis and treatment of CFS/ME
- 2.2.7 To foster research collaborations and communication between clinicians, researchers, professional bodies and charities
- 2.2.8 To facilitate patient involvement in the development of evidence-based services and to promote patient centred care. To foster co-operation and collaboration with teams, charities and individuals that share these principles
- 2.2.9 To encourage and facilitate the systematic and rigorous audit, benchmarking and evaluation of CFS/ME assessment, treatment and services.

3. Membership of the CCRNC

3.1 Membership

Membership of the CFS/ME Clinical and Research Network/Collaborative (CCRNC) will be open to all UK-based healthcare professionals and researchers involved in the diagnosis and/or treatment of CFS/ME using evidence-based practice. At the point of merger, anyone who is currently a member of either the Collaborative of CFS/ME Network Coordinating Centres, or the CFS/ME Network, becomes a member of the new organisation. Clinicians from local multidisciplinary teams that have representation on the collaborative will therefore automatically become members. Individuals can also join the CCRNC. Both types of membership are equal and will:

- 3.1.1 Be located in the United Kingdom
- 3.1.2 Deliver or support evidence-based treatment, directly, through clinical services or via research

3.1.3 Regularly provide or support the provision of training to CFS/ME services

3.1.4 Support their CFS/ME services to deliver effective treatment that is consistent with NICE guidelines or updated best available evidence

3.1.5 Promote and support audit and evaluation among CFS/ME services including encouraging the use of available tools (such as the minimum data set) to benchmark services

3.1.6 Support research for patients with CFS/ME.

3.2 Applying for membership

3.2.1 New members should apply on a membership application form, obtainable from and returned to the secretary

3.2.2 Members will be asked to sign a declaration that they agree to having 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 The secretary will consider all proposals for membership and reserves the right to seek further information, approve, decline or defer proposals as appropriate, consulting the executive when necessary

3.3 Members meetings.

Members of the CCRNC will meet at least once per year at the Annual General Meeting which will be arranged to coincide with a conference or other event. Confirmation of elections to the executive will take place at this meeting (see Section 4.15). Additional meetings may also be arranged if members so wish.

4. The Executive

Members of the CCRNC will be represented by an executive committee which will comprise one representative nominated from each CNCC, eight elected individual members, two to four patient/carer members, and one observer/member from each of a maximum of four National UK CFS/ME organisations which support the objectives of the CCRNC.

4.1 Membership and election of the Executive

4.1.1 Each CFS/ME Network Co-ordinating Centre (CNCC) (See appendix) shall nominate one representative (in addition to patient/carer members - see below) to attend CCRNC Executive meetings and be involved in the Collaborative work streams (see section 4.2.1). These representatives will normally be the CNCC Lead/Champion or equivalent, with the co-ordinator or other identified suitable individual as alternate. The list of centres may subsequently be expanded to include new centres, especially from Wales, Scotland, and Northern Ireland, if and when such equivalent centres are created. Pending that time, designated CNCC Executive representatives may be asked to look after their interests at organisational level. Appropriate co-options (see section 4.1.8) may also be considered.

4.1.2 In addition, eight individual members will be elected from the membership of the CCRNC.

4.1.3 The CCRNC Executive will have no less than two and not more than four patient/carer members.

4.1.3.1 The patient or carer must be nominated by a member of the Executive

4.1.3.2 The patient or carer will be involved in work streams

4.1.3.3 The executive will aim to have both adult and paediatric patients/carers members

4.1.3.4 Each patient and carer member will be asked to serve for two years with the possibility of extending to three years

4.1.3.5 Patient/carers' travel to meetings and other reasonable costs will be met by the CNCC which nominated the patient or carer or by the CCRNC Executive

4.1.4 The CCRNC Executive will invite no more than four people drawn from National UK CFS/ME organisations which explicitly support the aims and constitution of the organisation to sit on the Executive committee as either observers or members

4.1.4.1 These people will be nominated in the same manner as the patient/carers members.

4.1.5 Individual, patient/carers and patient organisation observers/members will be elected for a term of two years, with the possibility of extension to four years, through a ballot of all members. At the end of a term of four years, no member can be re-elected to the CCRNC Executive until after a period of 2 years has elapsed.

4.1.6 A maximum of half of the executive will be up for re-election in any one year, in order to provide continuity of purpose and expertise.

4.1.7 The executive will aim to have representation from each of the following professional groups: Clinical Psychologists, General Practitioner or other primary care workers, Nurse, Liaison Psychiatrists, Occupational Therapists, Occupational Health practitioners, Physicians, Physiotherapists, Dieticians. It will also seek to ensure that it includes members working in Wales, Scotland and Northern Ireland. Appropriate co-options (section 4.1.8) may also be considered.

4.1.8 The CCRNC Executive Committee will have the power to co-opt members, by election, for a fixed period of 2 years.

4.1.9 Elections of individual members to the Executive will take place one month prior to the Annual General Meeting (AGM) by post/email and will be announced at the AGM, to be held in the Autumn each year (usually October)

4.1.10 Elections will use a one member-one vote, first-past-the-post voting system.

4.2 Duties of the Executive

4.2.1 Members of the CCRNC Executive committee, or in the case of CNCC representatives, their named alternate, will normally be expected to attend the Executive Committee meetings.

4.2.2. Executive members will contribute to work streams which will be agreed at each AGM: for example a group working on the implementation of services; research and outcome measures; development of directory of services; training and education; PPI

4.2.3 Executive members have a responsibility to distribute decisions and notes from the meetings and work streams to their clinical or research teams and to the wider individual membership.

4.2.4 Minutes of the CCRNC Executive committee meetings will be made available to all members via the CFS POD.

4.2.5 At the end of their term on the CCRNC 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, a secretary, a treasurer who will be elected by the Executive for a term of two years renewable for a further term

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.

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. The agenda will be sent by hard copy to the patient and carer representatives by hard copy 2 weeks before the next meeting. The agenda will be dispatched to the CFS/ME Clinical and Research Network/Collaborative (CCRNC) through the executive two weeks before the next meeting.

4.4.4 The secretary is 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.

4.5 Decision making process

4.5.1 All representatives will be eligible to vote at meetings

4.5.2 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.

4.5.3 The Chair will not normally vote but, in the case of a tied vote, will have a casting vote

5 Constitution revisions

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

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