

UK CFS/ME Research Collaborative Minutes of Annual General Meeting 27 April 2016



Present:

Stephen Holgate (SH)	Sonya Chowdhury (SC)
Jan McKendrick (JM)	Hugh Perry (HP)
Esther Crawley (EC)	Ed Sykes (ES)

Joined via phone:

Paul Little (PL)	Carmine Pariante (CP)
Neha Issar-Brown (NIB)	Mary Jane Willows (MJW)
Julia Newton (JN)	

Apologies:

Zoe Gotts (ZG)	Alastair Miller (AM)	Charles Shepherd (CS)
Mark Edwards (ME)	Allison Wallace (AW)	Des Walsh (DW)
Raliza Stoyanova (RS)	Chris Ponting (CPP)	Steph Girfield-Birbeck (SGB)

Welcome and introductions

SH opened the meeting and welcomed those viewing the meeting via livestream.

Annual report 2015 – 16

SH outlined that the Collaborative (CMRC) is going from strength to strength. It has received good support, including financially, from the MRC and Wellcome Trust.

At the conference last year, it was evident that the research effort is increasing and we are seeing good collaboration. There are lots of new interactions developing within the UK and situations where discussions have taken place about sharing and exchanging samples, for example.

The network of communication is improving in the UK and we are seeing this develop further at an international level with a number of participants attending the conference from overseas. SH stated that while this is necessary and should be supported, the focus of the CMRC remains within the UK.

The strength of the CMRC has been advanced by bringing in specialisms from outside the field through the Grand Challenge, for example. Additionally, the conferences have provided a good forum for engagement with people with the illness which has enabled us to build the dialogue and has informed planning for this year's conference.

As a result, SH stated that the mood music in the field is shifting and that there is now more optimism for progress within the research field and that this wider endeavour and focus on the illness from experts outside the field is reflected in the multi-disciplinary representation in the membership and on the Board.

SH encouraged people to find out more about the conference on the website and highlighted the excellent presentation that was given last year by George Davey-Smith.

EC reported that the Grand Challenge workshop was held a few weeks ago and brought together UK leaders from outside the CFS/ME field bringing insight from fields such as genetics, epigenetics, proteomics, metabolomics, routinely collated data, infection, sleep, pain, primary care with expertise from those currently researching the illness.

The focus was to explore how to advance the field using this expertise and there was a real exchange of ideas between the participants. The plan is to submit a grant later this year. Any start date of the study is dependent on securing the required funding. If successful, this will be the largest resource of blood and urine samples.

SH added that many of the workshop participants had not had any involvement in the CFS/ME field previously and that they are the very best in the UK; a dream team. The project will be “a world first.”

There will be two distinct phases to the study which will include recruitment of patients and controls (data of the controls is already collected) and the NHS clinics would need to assist. Therefore engaging with clinicians through BACME is required to support recruitment.

SH continued to state that there is a commitment to engaging with patients and potential participants as part of the process. There will also be blogs to keep people updated and in due course, more details outlined the plans. The scientists will also be explaining what their expertise and input can add to the field. SH also highlighted that there are no promises about this study taking place as it is subject to securing funding.

SH stated that this year’s conference will take place in Newcastle again this year as it was a good venue that works well for our needs on 28-29 September. The preliminary programme is very exciting and as we finalise it, it will be available on the website.

SH outlined a number of presentations (details can be found on the [CMRC web page](#)) and highlighted the workshops that will take place on day one which includes participation from Associate Members. The main workshop will focus on clinical trials and specifically explore patient/community engagement with input and presentations from experts in the field. There are also workshops on severe M.E. and POTS.

Additional work currently being undertaken by the CMRC includes commissioning and inputting into a report mapping research activity in the UK and overseas over the last ten years and developing a website specifically for the CMRC.

Charter

SC stated that proposed revisions have been made to the Charter to clarify a few points and to introduce a couple of changes. A revised version was circulated to all CMRC members in advance of the AGM.

These changes included:

- expanding membership to include non-UK residents.
- providing clarification of what constitutes an orchestrated campaign. SC stated that the CMRC did not exist to stifle scientific debate and therefore the wording has been changed to reflect this.

SC highlighted that no questions or dissent were received prior to the AGM about the changes proposed. A need for further work was discussed in the preceding Board meeting and it was now proposed that work would be undertaken to reduce the length of the Charter and to develop terms of reference for the Board, which would be appended, to add further clarification. These will be circulated to all members for approval.

Membership of the Board

SH stated that it is essential that there is diversity on the Board to ensure skills and expertise from a range of disciplines to ensure that there is the right movement of science to deliver new treatments for patients. One gap that has been identified is in relation to the pharmaceutical industry so the Board will be recruiting an expert in this area to address this.

SH concluded the meeting by stating that CFS/ME is no longer viewed as a single disease-entity and that the team intend to “use the modern ways of interrogating complex datasets” to cut up the spectrum of ME/CFS into subtypes, each of which might have different causative pathways and therefore there is a need for targeted treatments. We therefore need to understand the biology behind the illness or spectrum of illnesses. The role of the CMRC is to promote collaboration and to explore new avenues to increase research into the illness.

Minutes taken and typed by SC 27.04.16

Chair approved 28.04.16

Post-meeting notes

The AGM was livestreamed but as filming was taking place through SC's laptop to circumnavigate internet/software issues with the facilities at the venue, it was not possible to read the comments and questions throughout the streaming; these were blocked by the pop-outs which appear on screen during streaming.

SC ensured there was a capture of questions immediately after the streaming ended. Any questions posted later were not collated. The following questions have been responded to by the Chair post-event. Please note, comments/views on individuals/statements have not been responded to:

Will it be possible for severe patients to be represented at the patient forum at the conference? - asked by Nicholas

The presentations will be live-streamed and people will be able to ask questions if they are able to interact in this way. Additionally, we are exploring a virtual discussion group in lieu

of roundtable discussions at pertinent points during the workshop. This will enable those who are able to engage and input. In previous conferences, we have had carers attend and represent those that they care for who are severely affected. If you have any further suggestions about how we can engage better and overcome the challenges that exist in engaging with/achieving representation from those who are more severely affected, please contact us [by email](#) or telephone 0117 927 6637 and leave a message for SC to contact you.

Please comment on the PACE Trial/release of data – asked by Jennifer/Atos Hound

The CMRC does not comment on individual research. The appeal against the release of data from the trial is being considered by the Information Commissioner's Office Tribunal and a ruling is anticipated later this month.

You keep talking about bringing new researchers. How do you plan to do this? – asked by Keith Geraghty

The conferences have attracted researchers from outside the field and stimulated interest. Alongside this, the Grand Challenge team includes a majority of experts from a range of backgrounds who are leaders in their respective scientific fields who will now bring their expertise to bear in the ME/CFS field.