

**UK CFS/M.E. Research Collaborative Executive Board
Summary of Discussion 23 May 2013**

Present:

Professor Stephen Holgate (SH), Southampton University - Chair
Dr Esther Crawley (EC), Bristol University – Vice Chair
Sonya Chowdhury (SC), Action for M.E. - Secretariat
Dr Charles Shepherd (CS), ME Association
Mary-Jane Willows (MJW), Association of Young People with M.E.
Clive Kerfoot (CK), CFS Research Foundation

Observers present:

Joe McNamara (JM), Medical Research Council
Ed Sykes (ES), Science Media Centre

Apologies:

Matthew Wright (MW), Association of Young People with M.E.
Professor Peter White (PW), Barts and The London School of Dentistry and
Medicine
Peter Muir (PM), CFS Research Foundation
Professor Paul Little (PL), Southampton University
Dr Neil Abbott (NA)/Sue Waddle (SW), ME Research UK
Professor Hugh Perry (HP), Southampton University
Professor Julia Newton (JN), Newcastle University

1. Welcome and introductions

SH opened the meetings and welcomed ES to the group who has now joined as an observer. SH noted that as this was a follow-up debriefing meeting from the launch, the number of participants was lower than would be expected in future meetings, with a higher number of researchers committed to attending.

2. Launch event

The event was well attended with approximately 120 people including some dignitaries such as the Duke of Kent. The feedback forms were predominantly positive with some negative comments about the venue such as lack of space for the poster presentations. All the feedback will be collated and circulated to the Board to inform future events. Most attendees expressed an interest in becoming a member of the Collaborative.

3. Publicity and future handling of press releases

Some of the charities received negative feedback regarding some aspects of the press release and the notes to editors prepared by Bristol University. It was acknowledged that there are differences in some areas such as prevalence rates and that we need to produce information that best reflects the range of positions for future use. SC has coordinated a teleconference for the charities to discuss this and to prepare a draft for approval by the Board. It was reiterated that there was not an expectation that independent positions should be compromised.

4. Membership of the Collaborative

There have already been a number of expressions from people wanting to become members. This includes people that are not researchers but have an active interest in the field. The Board agreed that we want to take an inclusive approach to engaging with a wide range of people but that the predominant focus for membership is for the research community itself. There is a need to ensure a 'bottom-up' approach. It was agreed that we would further clarify the membership structure which includes introducing Associate Membership and an appropriate nominal fee structure that would support activities such as a website and administration.

It was noted that Action for M.E., through the specific support of a private donor, has made a financial contribution to provide some secretariat support/meeting costs but that if the Collaborative is to meet its aim of bringing researchers together, increasing funds into research, stimulating interest from areas outside of M.E., providing a website and forum for researchers etc. then a small amount of additional administration will be required.

For future meetings, the Executive Board will have a number of observers which includes all three main research funders (Medical Research Council, National Institute for Health Research, Wellcome Trust) and BACME (to represent clinicians). It would be good to have parliamentary input and this will be discussed with the All Party Parliamentary Group.

The Executive Board itself is representative of all key disciplines (immunology, virology, epidemiology etc.) but there is a gap re nursing. SH will seek to fill this vacancy.

5. Workstreams

5.1 Funding

One of the aims of the Collaborative is to stimulate more funding for research and to support a strategic approach for future funding.

The Medical Research Council has four identified priority areas within their Highlight Notice but there are other gaps that the Collaborative may wish to prioritise in respect of their activity. Research priorities identified were severely affected and epidemiology (including sub grouping/ phenotyping). Signing up to the research priorities would in no way undermine the charities' independence with regard to their own research activities.

It was therefore agreed that all charities would provide a summary of their research priorities by the end of June to identify where the differences and alignments exist.

Alongside subject areas, the Collaborative could explore studentships, joint fellowships and bursaries to increase access to research in the field for early career researchers.

5.2 Awareness & publicity

An attendee at the event who has a journalism background has put forward some great suggestions regarding the development of a website. However, it was acknowledged that we need to plan in this work and get the sub group in place to take this forward.

5.3 Other workstreams

Increasing Capacity and Organisation are the other two workstreams and work will be identified by these groups once they are established. The Board discussed the potential for having 'severely affected' as a workstream but felt that the need was such that it should be put forward as a research priority to ensure that activity was cross-cutting and that the focus is on increasing funding to enable more research into this area.

There has also been an expression of interest in working with the Collaborative from a pharmaceutical company. It was agreed to invite them to present to the Board to identify what value they would create and what they could contribute to support the workstreams, especially with a focus on funding.

6. Annual conference

There will be an annual event for researchers which could provide a combination of learning/development through showcasing of research projects alongside time to develop collaborations for new research projects. JM offered to combine the workshop for the MRC-funded researchers in this field to maximise the use of resources, learning and collaboration. SH offered to contribute to the cost of venue etc. and could offer facilities through Southampton University. These generous offers were welcomed by the Board.

7. Future meeting dates

SC will send out a poll to set dates for the rest of the year. JM offered to provide a room for meetings at the MRC at no cost.