

## DRAFT Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 10 October 2017

**Present:**

Stephen Holgate (SH)	Sonya Chowdhury (SC)	Ed Sykes (ES)
Esther Crawley (EC)	Ana Atunes-Martin (AAM)	Neha Issar-Brown (NIB)

**Joined via phone:**

Carmine Pariante (CP)	Chris Ponting (CPP)	Claire Kidgell (CK)
Mark Edwards (ME)		

**Apologies:**

Paul Little (PL)	James Brodie – GWPharma (JB)	Mark Jones - UCB (MJ)
Mike Dalrymple (MRCT)	Gabrielle Murphy (GM)	Jo Elson (JE)
Patrick Chinnery (PC)	Chris Macdonald/Craig Bullock (CM/CB)	

	Agenda Item	Action
1	<p><b>Welcome &amp; Introductions</b></p> <p>SH opened the meeting and welcomed members.</p> <p>It was formally noted that Julia Newton has resigned from the CMRC Board due to a promotion and work commitments alongside Hugh Perry. The Board noted the resignation and SH has written to thank them formally for their input to date.</p> <p>SH welcomed new members who have joined but unable to attend this meeting due to short notice period: JE (Newcastle University); PC (Cambridge University); CM/CB (Arthritis Research UK).</p> <p>SH will be writing to invite another person to join.</p>	
2	<p><b>Minutes &amp; Matters Arising</b></p> <p>The minutes of the last meeting (6 June 2017) were approved as an accurate record of the last meeting.</p> <p><b>Matters Arising</b> All actions have been completed or will be discussed as part of the main agenda.</p>	
3	<p><b>Conferences 2017 &amp; 2018</b></p> <p>3.1 <b>2017</b> SC introduced the report regarding the recent conference outlining some key highlights:</p> <ul style="list-style-type: none"> <li>• There were 95 delegates from a number of countries. 75 delegates were professional members, 12 were student members and 12 were associate members. There were several researchers for whom this conference was their first CMRC conference.</li> <li>• Most speakers’ gave consent for filming and these were available within</li> </ul>	

3.2	<p>24 hours (most within just a few hours) of the presentations. Filming mitigated all the audio/visual issues experienced previously with livestreaming.</p> <ul style="list-style-type: none"> <li>• Feedback was excellent with lots of good suggestions for next year’s conference. Evaluation forms score all aspects of the conference well or highly.</li> <li>• ME feedback that the workshop he ran was very interesting with a real drive, from participants, for a research conference chaired and run by associate members/people with M.E. to gain a broader range of voices from all perspectives.</li> <li>• Social media reach was good with films having been viewed over 5,500 times within a couple of weeks.</li> <li>• Feedback was elicited from each member present. The quality of science was deemed to be very high with insight gained from senior researchers in other fields.</li> <li>• The CMRC conference report will be launched soon – people with M.E., researchers/students are all writing up presentations currently.</li> </ul> <p><b>2018</b></p> <p>SC has already begun organising next year’s conference and would like ideas and suggestions for speakers. The venue has been held and the budget was approved. All ideas for speakers to be sent to SC as soon as possible.</p>	All
4	<p><b>RS Meeting on Neurobiology of Fatigue</b></p> <p>This was a two-day meeting attended by a number of leading researchers co-facilitated by Raymond Dolan, Queen Square. SH reported that the meeting was targeted on fatigue only rather than CFS and focused on the neurobiology with a great presentation from Julia Newton on CFS/ME. There were excellent presentations from US presenters and across Europe and Australia.</p> <p>There is quite a lot of progress being made in this area with new pathways being identified through imaging, pharmacology and immunology. None of this has yet been seen in our conferences to this degree. There is a need to better engage with the developments in this area alongside technological advances.</p> <p>SH proposes that we should explore synergies and insight with speakers from the meeting for our next conference and to explore how to generate new collaborations to benefit from development in other areas.</p>	
5	<p><b>CMRC Purpose &amp; Objectives</b></p> <p>SH outlined that as we are entering the fifth year, it is good practice to revisit the purpose and future of the CMRC. There was a discussion regarding the importance of scientific debate and the role of CMRC with this. SH proposed a specific session that he will host in Southampton, to focus on this at the next meeting. This should drive the action planning and reporting for the CMRC.</p>	SH/SC
6 6.1	<p><b>Ongoing Actions</b></p> <p><b>High level report</b></p> <p>Given the impact of the IOM report in the US, there is a need to secure something similar for the UK. SH has been exploring possibilities. Essential that ‘patient’ advocates are an active part of this process.</p>	SH

6.2	<p><b>Funders' Workshop Action Plan</b></p> <p>There is an action plan being developed and implemented following this meeting. There are ongoing discussions with funders to populate this and should form part of the CMRC's future plans in tandem with the discussions re purpose and objectives.</p>	SH/SC
6	<p><b>MEGA Update</b></p> <p>EC is meeting with MRC after the meeting for feedback from the recent application.</p>	
7	<p><b>AOB</b></p> <p>The news that the UK Biobank has received funding from NIH was welcomed.</p>	

Notes taken by SC  
Approved by SH:

