

Paper 1: *DRAFT* Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 26 June 2019

Present:

Stephen Holgate (SH) – Chair
 Jim Wilson (JM)
 Countess of Mar (MM)

Charles Shepherd (CS)
 Deb Brown (DB)

Gabrielle Murphy (GM)
 Anna Gregorowski (AG)

Attended by phone

Opal Webster-Philp (OWP)
 Colin Smith (CPS)
 Craig Bullock (CB)

Sam Bromiley (SB)
 Chris Ponting (CP)
 Carmine Pariente (CPa)

Jo Elson (JE)
 Neil Harrison (NH)

Apologies

Mark Jones (MJ)
 Patrick Chinnery (PC)

Neha Issar-Brown (NIB)
 Sonya Chowdhury (SC)

Stephen Meader (SM)

	Agenda Item	Action
	<p>Welcome & Introductions SH opened the meeting and introductions made.</p>	
1	<p>Minutes and Matters Arising</p> <p>Slight amendments made to the minutes for accuracy, including removing GM as lead for PR Working Group.</p> <p>JM referenced ToR and the need to co opt members onto the working groups. Agreed this would be minuted.</p> <p>Decision The Board approved the minutes of the last meeting as an accurate record of the meeting</p>	
2	<p>MRC Strategy Board</p> <p>SH updated the group on the application to the MRC. They have a strategy board meeting in July. (8th and 9th).</p> <p>SH will email MRC and state that people in the M.E./CFS community would like to know more about the plans and that the CMRC Board are looking to draft a statement once Strategy Board minutes are released.</p> <p>CP spoke about the need to prepare for future NIHR and MRC applications in case of approval in July. Board acknowledged that their remit does not</p>	SH

	<p>extend to putting forward applications for funding but seek and encourage collaborative work among researchers.</p> <p>JM to circulate other additions to terms of reference to the other board members.</p>	JM
3	<p>CMRC Working Groups</p> <ul style="list-style-type: none"> • Medical Education Group: CS updated the group. New members have been co-opted on including a physiotherapist to talk about training they receive. Looking to get other health professionals involved. Special thanks to Nina Muirhead for her hard work on this. • Priority setting partnership: SH updated that SC will be pursuing this upon her return. • Omics and Big Data. CPS talked about ongoing genetics studies and informed group on a study he is looking for funding for. • Mitochondrial biology: JE gave an update on the work being done by the group and the areas being looked into. • Immunology: SH to speak to CPa and see what help he can offer to progress things and offer support. • PR: OWP talked about her paper and the PR working group. There is a need for us to communicate better with each other and the M.E. community. It was agreed that there is a need to communicate the science. MM to chair the group. <p>Action - Board agreed that the minutes of the working groups will be distributed to the board alongside papers for the meeting.</p>	
4	<p>Conference</p> <p>SB confirmed the conference will be Tuesday 10th and Wednesday 11th of March 2020 in Bristol at the same venue (Future Inn Bristol).</p> <p>SH detailed that financial support for the conference was received from MRC and Versus Arthritis previously. CB confirmed that Versus Arthritis are happy to contribute again.</p> <p>SH confirmed that he has been waiting for confirmation of funds before invites are sent out. SB suggested a working group be formed to progress things outside of the Board meeting.</p> <p>GM highlighted that work on abstracts would need to be done soon to increase the calibre. Someone in the working group to be a lead on the abstracts.</p>	

	Action - SB to set up working group for the conference. This will involve CB, NH, GB, CS, DB and a representative of the PAG.	SB
5	<p>Budget</p> <p>JM queried how much the PAG have in their budget. SB to look into and report back to JM.</p> <p>Action – SB to provide figures for PAG ahead of the next board meeting.</p>	SB
6	<p>AOB</p> <p>None</p>	

Minutes taken by SB 26.06.19

Approved by SH 05.07.19