

Paper 1: *DRAFT* Minutes of UK CFS/ME Research Collaborative Executive Board Meeting 16 October 2019

Present:

Stephen Holgate (SH) – Chair
 Deb Brown (DB)

Charles Shepherd (CS)
 Anna Gregorowski (AG)

Gabrielle Murphy (GM)
 Sonya Chowdhury (SC)

Observing

Denise Ribaroff (DR)
 Alex Ribaroff (AR)

Attended by phone

Opal Webster-Philp (OWP)
 Chris Ponting (CP)
 Carmine Pariente (CPa)

Sam Bromiley (SB)
 Neil Harrison (NH)
 Jim Wilson (JW)

Craig Bullock (CB)
 Colin Smith (CPS)

Apologies

Neha Issar-Brown (NIB)
 Margaret Mar (MM)

Stephen Meader (SM)

Jo Elson (JE)

	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</p> <p>Decision The Board approved the minutes of the last meeting as an accurate record of the meeting</p>	
2	<p>MRC progress</p> <p>SH updated the group on the application to the MRC. They had a strategy board meeting in July. (8th and 9th).</p> <p>The discussions had with the MRC highlighted how it would be good to bring together those interested in the field, those from outside the field. Taking account of the views of an agnostic population.</p> <p>Meeting was held in September with the MRC with a workshop planned for November with a view to get an application off before the end of the year. CP said he hoped to have an outline of the application ready for November meeting.</p>	SH/CP

	<p>It was agreed that communication with patient and carers population would be essential during this process, especially if the recruitment of the large number of people needed if to be successful.</p> <p>MRC at some point will make the community aware there will be a project proposal submission.</p> <p>JW said they have been pushing hard to get early information from MRC. They don't know who on the day will be able to attend yet.</p> <p>SC suggested short films with SH and CP to give as much information in a bright and informative way.</p>	
3	<p>CMRC Working Groups</p> <ul style="list-style-type: none"> • Medical Education Group: SB updated on the work NM has been engaging with health professionals from different fields and assisting SB with the preparation for RCGP conference. GM gave an update on producing learning modules. DB looking to coordinate activity with NM to assist. Physios 4 ME were invited to join the group. • Priority setting partnership: SC updated on the work with the PSP. Looked to get agreement to explore more closely as it is a large piece of work. • Omics and Big Data. Meeting held earlier in the month. CPS spoke on Patients Know Best. It allows you to communicate directly to physicians and access help online. • Mitochondrial biology: JE was unable to attend the meeting • Immunology: CP wishes to step down as leader of this group due to work commitments and we will be looking for a new chair. • PR: OWP talked about her paper and the PR working group. Meeting held in September to discuss driving group forward and being more inclusive. <p>Action -</p> <p>All groups to summarise activity by bullet point</p> <p>Board agreed support toward working for a PSP</p>	SC
4	<p>Conference</p> <p>SC confirmed 12 speakers confirmed with a high number of overseas speakers due to the quality of work being done in other countries.</p>	

	<p>She detailed the draft programme for the two days and the procedure for posters and abstracts. She invited Board members to contact with further ideas.</p> <p>SC detailed the budget for the conference and that there is still money to be raised to fund the speakers. Registration will open 21st October with Early Bird rate. Abstracts launched at the same time. Would welcome people to come forward for peer review of the abstracts.</p> <p>Once registration opened we will send details and ask that everyone markets the details. SC proposed the fees are kept the same as last year with the early bird rate of £299 non-member rate is £375. £425 for full price at the end.</p> <p>Action -</p> <p>It was agreed to keep fees the same as last year</p>	SB
5	<p>Cochrane</p> <p>SC introduced Karla Soares-Weiser to the meeting from Cochrane. She gave an update on the Cochrane review and said she is aware of controversies around this. Acknowledges they need patients at the outset of any full review.</p>	
6	<p>International updates</p> <p>SC confirmed this is an opportunity to update on international work. She gave updates on the restructure of the International Alliance. She will update the group afterwards.</p>	SC
7	<p>AOB</p> <p>SH said there is a fatigue workshop at the Kennedy trust and Versus Arthritis to understand mechanisms of fatigue. CB said happy to work with SH on this.</p>	

Minutes taken by SB 16.10.19

Approved by SH 04.11.19