

MEETING C1

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 12.00 noon on Saturday 30th September 2017 at 2nd Floor Anchor Brewhouse, 50 Shad Thames, London, SE1 2LY.

PRESENT	IN ATTENDANCE	APOLOGIES
Mike Porter, Chairman (MP) Jayesh Pindolia (JP) Stuart Alderson (SA) Nick Jones (NJ) Phil Prosser (PP)	Allan Muir, Development Director (AM)	

1 Chairman's Remarks

The Chairman welcomed everyone to the meeting. He informed the trustees that he had received written notice from Noor Abdul-Ghani that she no longer felt that she could continue as a co-opted trustee. Having attended the previous trustee meeting in May she now realises that the role of trustee does not meet her skill set, though she is happy to continue to work on behalf of AGSD-UK giving support wherever she can.

2 Minutes of the previous meeting

The minutes of meeting B1 from 21st January 2017 were taken as read.

ACTION	BY WHOM	DATE

3 Matters arising from the previous meeting

U10, U11, V17, A18, B1, B3, B4, B5, B6, B7, B8, B9, B10, B12, B13, B14, B15, B17, B18, B19, B20, B21, B22 – Closed

Y15: - Set up training records and add to Policy Manual – SA – Ongoing

B2: Seek advice from Jane Guy re trustee training requirements and then propose training plan – MP/SA – Dec 17.

B11: - Type 1/Pompe/McArdle restricted funds to be discussed with Type Co-ordinators/PST to see if any funds can be released to general fund. – JP/AM/NJ – Jan 18

B16: Discuss feedback on TOIL policy with Jane Lewthwaite – NJ/AM – Jan 18

ACTION	BY WHOM	DATE
C1: Ask treatment centres for updated patient numbers	AM	Jan 18
C2: - Progress MAB TOR review	MP/AM	Apr 1
C3: - PP to liaise with SCA/Type Co-ordinators regarding on-going support work	PP	Ongoing8

4 Declaration of Interest		
MP asked if any trustee had any declaration of interest to make.		
ACTION	BY WHOM	DATE
C4: Minutes to show that no trustee had any interest to declare	MP	Jan 17

5 Charity Director's Report		
The Charity Directors report was circulated and discussed.		
ACTION	BY WHOM	DATE
C5: Remind members at AGM that membership fees have risen to £15 per annum	AM	Oct 17
C6: - Contact Deborah Corcoran to establish if she is attending the annual conference to receive a 'Special Recognition' certificate and flowers to recognise her London Marathon achievement.	AM	Oct 17
C7: - Collate time spent by Type Co-ordinator and PST in order to consider if it can be counted as 'donated services' in the year end accounts.	AM	Nov 17
C8: Trustees requested that AM circulates a draft proposal for utilising Bookeeper to provide ongoing administration support until end of March 2018.	AM	Oct 17
C9: - Agreed that NJ would chair the AGM in MP's absence. MP to provide detailed presentation material to NJ.	NJ/MP	Oct 17

6 Pompe Specialist Care Advisor (SCA) Report		
The SCA report was circulated and discussed.		
ACTION	BY WHOM	DATE

7 Financials/Fundraising		
MP provided an update on progress with regard to preparing and submitting the year end accounts. Discussions with our accountants about the inclusion of 'social capital/donated services' and what level of social capital/donated services would be allowable, were ongoing.		
A discussion was held about the 2017/18 draft budget and it was agreed that the budget numbers should be amended to reflect changes in assumptions: removal of additional SCA income/costs reduction in fundraising income reduction in conference income		
A copy of the notes of the initial Fundraising Workshop held on 25 th July was circulated.		
Trustees agreed to proposed approval limits for funding submissions: Below £10,000 – delegated to DD and individual members of Fundraising Sub Committee £10,000 - £250,000 – delegated to quorum of Fundraising Sub Committee Above £250,000 – requires approval of trustee board		
ACTION	BY WHOM	DATE
C10: - Continue dialogue with accountants on 2016/17 statutory accounts	MP/AM	Dec 17
C11: -MP to circulate revised budget for 2017/18	MP	Jan 18
C12: -Confirm who holds AGSD-UK debit cards	MP/AM	Jan 18
C13: - Provide relevant wording to Jane Lewthwaite regarding what specification of IT kit we need from any potential funder.	SA	Jan 18

C14: Discuss and agree if appropriate JP's offer of mobile phones and contracts from Nowtel for AGSD-UK use.	AM/JP	Jan 18
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8 Operating manual / Procedure

SA updated the meeting on the progress of the policy implementation plan. A draft copy of a 2017/18 implementation plan was circulated and discussed.

ACTION	BY WHOM	WHEN
C15: - A 'Policy Deficiency Log' to be developed and circulated for review and agreement	SA	Jan 18
C16: - Re-allocate policies originally allocated to Noor Abdul-Ghani – AM to speak to Jane Lewthwaite regarding taking interim operational lead on Safe Guarding and Equality & Diversity with MP taking interim board responsibility for same	AM/MP	Oct 17

9 Website Update

MP briefed trustees on the Web Design and Implementation Plan.

ACTION	BY WHOM	WHEN
C17: - MP to liaise with FC regarding presentation at the annual conference	MP	Oct 17

10 IT Infrastructure Update

SA updated meeting on IT infrastructure work.

ACTION	BY WHOM	WHEN
C18:- Speak to PSTBS regarding arranging a meeting between Paul Alderson and Allan Muir	MP	Oct 17
C19: - Speak to PSTBS re issues regarding broken appointments.	MP	Oct 17
C20: - Arrange for PSTBS to set up NJ/PP/JP/Jane Guy/Jane Lewthwaite with access to VPN and setting up of AGSD-UK email accounts.	SA	Dec 17
C21: - Circulate 'email footer document' to trustees	MP	Dec 17

11 Organisation & Management Review (OMR)

MP circulated a draft 'succession planning document' for key roles and the document was discussed. It was agreed that the document would be formally adopted and incorporated into the Policy manual under the Risk Register.

Trustees discussed the need to further strengthen the trustee board, particularly filling the vacant treasurer role and to help continue with the policy implementation and fundraising work.

ACTION	BY WHOM	WHEN
C22: - OMR Sub Committee to agree names and populate the short term cover and potential/nominated successor columns.	OMR SC	Mar 18
C23: - Circulate draft outline CEO role profile to trustees	MP	Dec 17
C24: - Post vacant treasurer role on REACH website	MP	Oct 17

C25: - Speak to Jane Guy prior to AGM to establish if she would be interested in joining trustee board	SA	Oct 17
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12 AOB		
Next meeting date agreed to be last Saturday in January (27 th) with a venue in the Midlands to be sourced.		
ACTION	BY WHOM	WHEN
C26: - Source and book appropriate venue and circulate details to trustee board.	AM	Dec 17

The meeting closed at 4pm.