

MEETING B1

## MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 11.30am on Saturday 27<sup>th</sup> May 2017 at The Manchester Conference Centre  
Sackville Street, M1 3BB

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

### 1 Chairman's Remarks

The Chairman welcomed everyone to the meeting and in particular Noor Abdul-Ghani who volunteered to be co-opted to the trustee board. He also thanked everyone's attendance following the recent bombing in Manchester. Once again there was another busy agenda to be covered and part of the meeting was to be held with Trustees only in attendance.

The Chairman had received a letter of resignation from Shaun Griffin who felt he could not continue as a trustee at this time due to on-going family issues. The Chairman would like to place on record his thanks to Shaun for his work and guidance on financial matters during his time as a trustee.

### 2 Minutes of the previous meeting

The minutes of meeting A1 from 21<sup>st</sup> January 2017 were taken as read.

ACTION	BY WHOM	DATE

### 3 Matters arising from the previous meeting

U6, U9, X10, X11, X12, X16 (agenda item), Y5, Y10, Y16, Y17, A1, A2 (agenda item), A3, A4, A5, A6, A7, A8, A9, A10 (agenda item), A11, A12, A13, A14, A15, A16 (agenda item), A17 (agenda item),: - Closed.

U10:- Hold DD performance review – MP/AM – C/F to next meeting

U11: - Produce schedule of activities for reviewing MAB TOR's and frequency/type of MAB meetings. – AM/MP – End of July 2017.

V17: - Request latest UK GSD prevalence numbers from Simon Heales – AM – End of July 2017.

Y15: - Set up training records and add to operations manual – SA – C/F to next meeting.

A18: - Send out letters to members confirming increase in membership fees to £15 – AM – C/F to next meeting.

ACTION	BY WHOM	DATE
B1: - Include request for Caldecott Guardian from MAB (linked to U11)	AM/MP	Dec 17
B2: - Seek advice from Jane Guy re trustee training requirements and then propose training plan.	MP/SA	Dec 17

#### 4 Charity Director's Report

The Charity Directors report was circulated and discussed.

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>
B3: - Follow up with Amicus to ensure that their £32k commitment is sterling amount - not USD.	AM	Next Mtg
B4: - Circulate a copy of Jane Lewthwaite's (JL) work plan to trustees	AM	Next Mtg
B5: - Build a 'Special Recognition' award into conference programme. Agreed that recipient this year should be Deborah Corcoran.	AM	Oct 17
B6: - Trustees agreed that the 2017 conference delegate fees to be set at £90/single and £140/double respectively.	AM	Oct 17
B7: - Circulate to trustees a copy of the McArdle Type report	PP/AM	Next Mtg

#### 5 Pompe Specialist Care Advisor (SCA) Report

The SCA report was circulated and discussed. Trustees were impressed with the content and quality of the Year One Report produced. It was felt that this type of qualitative metric capture was what was required in order to support further grant submissions.

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>
B8: - PP to follow up with JL to have exploratory discussions re his offer to provide additional SCA type support to GSD community. AM to talk to JL in first instance.	PP/AM	Next Mtg

#### 6 Financials/Fundraising

MP informed the meeting that it was now time that we started work on preparing and finalising the accounts for 2016/17. A draft excerpt would be available as usual for the AGM and the final version to be filed with Companies House and the Charity Commission in line with current requirements.

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.

Trustees reviewed the status of the current level of restricted funds being held to determine whether they remained appropriate.

Trustees agreed members of Fundraising Committee should be – AM/NJ/MP/JL supported by Jane Guy.

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>
B9: - Start work with accountants on 2016/17 statutory accounts	AM	Next Mtg
B10: - Update agreed budget numbers and circulate to trustees/AM	MP	Next Mtg
B11: -Type 1/Pompe/McArdle to be discussed with Type Coordinators/PST to see if any funds can be released to general fund.	JP/NJ/AM	Next Mtg
B12: - Initial fundraising workshop to be scheduled to discuss: outline workplan, actions and owners, potential income figures.	AM	July 17

#### 7 Policy Manual

SA updated the meeting on the progress of developing an appropriate set of policies and procedures. The trustees agreed the formal sign off of the policies listed in the AGSD-UK Policy Manual.

A draft copy of a 2017/18 implementation plan was circulated and discussed.

Trustee ownership of the AGSD-UK Policy manual was discussed and agreed as follows:

ICT – SA  
 Lone Working – PP  
 Recruitment – NJ  
 Supervision & Support – PP  
 Managing Volunteer Performance – PP  
 Statement of T&C's of Employment– NJ  
 Induction for Paid Staff – NJ  
 TOIL – NJ  
 Disciplinary – NJ  
 Grievance - NJ  
 Whistle Blowing – SA  
 Handling Complaints – PP  
 Safeguarding – NAG  
 Financial Procedures – MP  
 Expenses – MP  
 Risk Assessment – MP  
 Dignity – JP  
 Equality & Diversity - NAG  
 Conflict of Interest – JP  
 Declaration of Interest - JP

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
B13: - Trustees agreed that they should become the 'expert owner' responsible for their allocated policies.	ALL	Ongoing
B14: -Trustees to review their allocated policies and propose any changes through change control as documented in the manual.	ALL	Ongoing
B15: - A policy review schedule/record to be developed and circulated	SA	June 17
B16: - Discuss feedback on TOIL policy with JL.	NJ/AM	Next Mtg

### 8 Website Update

MP briefed trustees on the Web Design and Implementation Planning Meeting held with Fusing Creativity (FC) in mid May in Milton Keynes. Key outcomes were as follows:  
 Formal launch date to be at the 2017 conference – FC to attend and present.  
 Process for agreeing lower level menu requirements and content to be moved was agreed.  
 Major milestones for build and implementation agreed.  
 End user testing would be iterative throughout the build but 2 weeks prior to conference launch selected users would be invited to view and provide feedback.

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
B17: - MP to liaise with FC/AM and Andrew Wakelin to ensure content is provided.	MP	Ongoing
B18: - Arrange workshop for Type Coordinators to discuss implementation plan and delivery of content to FC.	AM	June 17

### 9 IT Infrastructure Update

SA updated meeting on IT infrastructure work.

Under the Declaration of Interest policy SA informed the meeting that while he has no personal business interest, the Managing Director of the proposed IT Services company (PST Business Solutions) is his brother. On that basis he excused himself for the rest of the agenda item which was to discuss, and if agreed, authorise the costed proposal for the provision of a Managed IT Services Contract for AGSD-UK.

MP briefed the meeting on the proposal and costings for the provision of the agreed services. The trustees agreed to commit to the agreement as documented (dated 12/07/17).

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
B19: Inform PST Business Solutions and send copy of agreement (dated 12/07/17) to AM for filing.	MP	June 17

## 10 Succession Planning and Organisation

For this agenda item AM was excused – primarily because one of areas the trustees would be discussing would be the role of the Charity Director.

MP circulated a discussion paper aimed at providing a framework for trustees to discuss what organisational model would likely be required for the future and what would be needed to implement that model and in what timeframe. It also looked to discuss succession planning and risk management for key staff.

Trustees agreed to set up an Organisational and Management Review (OMR) sub-committee to review the discussion paper and agree next steps. OMR members were agreed as MP/SA/NJ supported by Jane Guy.

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
B20: - Arrange meeting for OMR sub-committee and provide feedback to trustees.	MP	June 17

## 11 AOB

MP proposed to the trustees that in light of late arrival difficulties and the heavy schedule of meetings over the conference weekend that the trustee meeting that is usually scheduled for the Friday evening prior to the conference is cancelled and that the trustee board moves to meet three times a year – January/May/September.

It was agreed to hold the next meeting in London on or around the end of September 2017.

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
B21: - Trustees agreed to move to a 3 times a year trustee board meeting schedule.	ALL	Ongoing
B22: MP to send out suggested dates for next trustee meeting.	MP	June 17

**The meeting closed at 3.45pm.**