

MEETING F1

**MINUTES OF A MEETING OF THE BOARD OF TRUSTEES**

Held at 12.00 noon on Saturday 6<sup>th</sup> October 2018 at the Double Tree Hilton, Paradise Way, Walsgrave Triangle, Coventry, CV2 2ST

<p><b>PRESENT</b> Stuart Alderson (SA) Ailsa Arthur (AA) Jane Guy (JG) Nick Jones (NJ) Mike Porter (MP) Rob Seaborne (RS)</p>	<p><b>IN ATTENDANCE</b> Allan Muir, Development Director (AM)</p>	<p><b>APOLOGIES</b> Heneage Legge-Bourke (HLB) Jayesh Pindolia (JP)</p>
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<p><b>1 Chairman's Remarks</b></p>		
<p>The chair thanked everyone for attending and suggested that meeting in a central location for the majority seemed to work well and would be continued for the time being. He reminded trustees of the forthcoming conference in two weeks time and the substantive item around finances on the agenda</p>		
<p><b>ACTION</b></p>	<p><b>BY WHOM</b></p>	<p><b>DATE</b></p>

<p><b>2 Minutes of the previous meeting</b></p>		
<p>It was proposed by AA and seconded by RS that these were a true reflection of the meeting and agreed</p>		
<p><b>ACTION</b></p>	<p><b>BY WHOM</b></p>	<p><b>DATE</b></p>

<p><b>3 Matters arising from the previous meeting</b></p>		
<p>C2: Progress MAB TOR review actions – MP/AM: The Medical Advisory Board Terms of Reference now need reviewing. We like to meet with them periodically but we have struggled recently and AM has been trying to go to the treatment centres and see them in groups, but this has not worked well either. It was agreed that we would now redraft the TORS. We would speak to the MAB and find out how we can work better together. We would like a trustee liaison member to work with AM and RS would consider this role. Members of MAB are all very busy but there should be a quorum there for meetings. We should take the lead and produce a standard agenda to which they could contribute. We need to find a better way of engaging in specific items, e.g. publications. What is in it for them? Do they know what we want them to advise us about? By comparison, the Hepatic meetings are very successful and they are very engaged with us. It was agreed we would want to hold an annual meeting and more if necessary. – Closed and superseded by updated action F1</p>		
<p>D2: Arrange for remaining staff/trustees to have VPN access and AGSD-UK email accounts. Use of new email accounts to formally commence from April 1<sup>st</sup> 2018 – SA: - E-mail NJ and JG not yet using. SA would discuss with HLB. The File Store access is not available for everyone yet. MP suggested that as PSTBS would be attending the conference it would be good to chat through with them there. – Closed and superseded by updated action F2</p>		
<p>D15: New process for appointing trustees at AGM to be developed and implemented for 2018 AGM – MP: Closed - on the agenda for this meeting.</p>		
<p>D39. Independent Examiners. – Closed and superseded by action F3.</p>		
<p>D42: AOB. Raising awareness at the conference and invites to any VIP's. It was too late now to send any special invites to the forthcoming conference. It would be good to consider inviting the Health Secretary to the 2019 Conference. – Closed and superseded by action F4.</p>		
<p><b>E1: Contributors to send reports/PP presentations from trustee training session to RS, JP and NJ. – C/F to next meeting.</b></p>		

E2, E3, E4, E5, E6, E7, E8, E9 – Complete and closed.  
 E10: Propose updated membership fees to the trustees. Closed on agenda for this meeting.  
 E11: - Closed  
**E12: Consider how to improve unrestricted funds. C/F to next trustee meeting.**  
 E13, E14, E15, E16, E17, E18, E19, E20, E21, E22, E23, E24, E25, E26 – Complete and closed.  
 E27: Develop a training plan. – Closed on agenda for this meeting.  
 E28, E29, E30, E31, E32, E33 – Complete and closed.

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>
F1: Produce MAB discussion paper for next meeting.	RS/AM	Jan 19
F2: Ensure all trustees have VPN/File Store access	SA	ASAP
F3: Seek alternative quotes for Independent Examiner work after AGM and add to Jan 19 trustee meeting agenda.	HLB/MP	Jan 19
F4: Add conference VIP attendance to next trustee meeting agenda.	MP	Jan 19
F5: Update GSD community spreadsheet numbers using updated treatment centre numbers.	MP	Jan 19

#### 4 Declaration of Interest

There were no declarations of interest.

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>

#### 5 Charity Director's Report

The Charity Directors report was circulated, noted and discussed as follows:

- Lots of work done during the review period. On the Active Volunteer front the GSD 4 co-ordinator needs replacing and the GSD 6 has asked to be replaced due to family commitments. It is an ongoing piece of work to keep our volunteer group populated and engaged.
- The interaction and scope of IPA and IAMD and the work of AGSD-UK was discussed and the trustees would like more clarity.
- E-Learning module. To date there has been only a small uptake when given the funding and effort on this project there should be more. Is there anything further we can do with the project group to increase the uptake and module completion?
- Newsletter: It was agreed that Glisten will now be named a magazine rather than a newsletter.
- Conference in Barcelona will cost us approx. £2,000 for AA, JL and AM to attend. All international trips have to be agreed first by trustees. This conference attendance was agreed by trustees.
- On the proposed AGSD-UK Calendar AM was concerned that there are 2 references on 2 of the months to God although not a specific God. These are not the views of the charity and it was agreed that we would prefer not to have any religious terms in any of our publications.
- **Membership Criteria & Fees.** Full membership is for those with a GSD and their families and Associate membership is for all others. Written definitions are currently in place. At the conference lanyards will identify each type. They also colour code to signify workshop choices. We need to consider what fees, services, voting rights, etc. are available for each type of membership. A hard copy of the Annual Report perhaps should be given. With circa 1200 registered on our contact database we should try to convert them to membership. Can we encourage our members to make regular donations? We should have a corporate membership too.
- **Conference Update.** AM reported that the programme is nearly finalised. Pompe is complete and the plenary sessions are organised. We have a research theme throughout the conference to encourage participation in trials. The food should be better this year. RS will not be there but all other trustees should be there. Currently numbers are down by about 30 on previous year

<b>ACTION</b>	<b>BY WHOM</b>	<b>DATE</b>
F6: Obtain explanatory scope paper from IAMD from Andrew Wakelin and AM to provide similar for IPA.	MP/NJ/AM	Jan 19
F7: Investigate low uptake reasons on GP E-Learning module and report back at	AM	Jan 19

next trustee meeting.		
F8: Remove/change religious references from calendar before publication.	AM	ASAP
F9: Circulate current membership criteria and draft a discussion paper for trustees proposing what membership we should have, at what levels and what benefits accrue to those members/levels.	AM	Jan 19
F10: Update AGM that the trustees would be reviewing membership.	MP	Oct 18
F11: Confirm that JP and HLB are attending the conference	MP	Oct 18

## 6 Pompe Specialist Care Advisor (SCA) Report

The SCA report was circulated and noted. It was agreed that the SCA model is delivering significant and measurable benefits and we should actively seek funding for further SCA(s).

ACTION	BY WHOM	DATE

## 8 Financials

- **2017/18 final accounts.** MP reported significant progress in getting our statutory accounts completed in a timely manner and in line with what we agreed we should aim for. Historically we did not get the accounts signed off until the January after the relevant financial year had been completed. MP said these could have been ready as early as June but were delayed by our accountants making too many basic errors. The soft copy version that HLB's circulated was unfortunately password protected. The full accounts will be circulated to trustees but members would get the short version included in the Annual Report. The newly implemented financial accounting software (QB) is working well for us.
- **Budget.** The summary sheet with this year's budget developed by MP/HLB/AM and agreed by trustees has been circulated.
- **Pipeline report review.** This is the income forecast which had been updated and had been previously circulated. Changed; grants have increased slightly, Virgin Money Giving has reduced. There are a few ups and downs. Overall weighted value has increased by £3,000. There were no major changes. This report would be reviewed by trustees at each trustee board meeting and by the chairman, treasurer and charity director on a monthly basis.
- **2018/19 income and expenditure to-date.** This report had been circulated just ahead of the meeting and taking into account that HLB had not been able to attend and talk the trustees through it, trustees were asked to review and submit any queries direct to HLB.
- **2018/21 Business Plan.** The trustee training day session last January had started looking at the Business Plan which we can start to share with volunteers, staff, potential funders, etc. This is usually derived from a strategic plan but ours became overly onerous to manage and is now out of date. A lighter touch approach had been agreed and the strategic direction focus has now been reviewed. 7 strategic direction statements were agreed in January and another one added at the recent fund raising committee meeting. Trustees have the document template now. April 1<sup>st</sup> 2019 will be the launch of the new plan and we now need to populate it. A set of AGSD-UK values should be agreed by trustees. MP presented a set for consideration. Should we add 'confidential' to values? MP asked for help with the template development on section 6 - public benefit need and section 8 - how and where will we promote our services. KPI's to be completed near the end and ditto for exec summary. Section 5 - our goals - trustees should discuss and agree at January meeting.

ACTION	BY WHOM	DATE
F12: Circulate password for final accounts.	HLB/MP	ASAP
F13: Review Restricted and Unrestricted reserves and report back to trustees	HLB	Jan 19
F14: Submit any queries on the Income and Expenditure report directly to HLB.	All	ASAP
F15: Circulate draft 'Values' to trustees for consideration/agreement. Add business plan to next trustee meeting agenda.	MP	ASAP
F16: Continue to populate draft business plan for review at next trustee meeting.	MP	Jan 19

## 9 Fundraising

- **Annual Report.** Copies have been circulated. It will be available to members and sponsors at the AGM.
- **Events.** AM provided an updated list of completed and planned events. It was agreed that framed certificates would be presented to significant fundraisers at the conference. It was also agreed that we should acknowledge all fundraising efforts with at least a letter and certificates if appropriate.
- **Fundraising sub-committee actions.** We intend to concentrate on improving work with children and early next year researching new funders and drafting funding applications in the spring. A calendar and new recipe book for sale are to be launched at the conference. It was agreed that we would circulate copies of our Annual Report to past funders and potential funders. MP circulated a definition of Patron and Ambassador for trustees to consider.

ACTION	BY WHOM	WHEN
F17: Prepare fundraising certificates for conference.	AM	Oct 18
F18: Post list of fundraising ideas on (new) website and update contact database to capture previous and potential funders.	AM	Jan 19
F19: Share Patron/Ambassador definition and rationale with conference attendees requesting any suggestions/contacts that attendees may have would be most welcome.	MP	Oct 18

## 10 IT

SA reminded trustees that in order to be security compliant we must all use AGSD-UK e-mails now. Most of the co-ordinators and trustees have now got AGSD-UK e-addresses. We have a control sheet showing who has email addresses, access to the VPN, Filestore and Contact Database and who controls what. The control sheet is kept by our IT service provider and Andrew Wakelin is the authority for the Contact Database.

This is a major step forward in terms of securing our data. We are in the process of moving all relevant documents to the central Filestore as these will then become our control versions. SA also reminded the meeting that we are paying an extremely competitive rate for this service so we sometimes have to be patient with our supplier.

ACTION	BY WHOM	WHEN
F20: Send email to all AGSD-UK email holders explaining rationale for using our secure IT environment and also re-introducing PSTBS.	MP	Oct 18

## 11 Policy Manual

- **Deficiency log review.** We now only need a Caldicott guardian.
- **Policy additions/amends.** JG reminded trustees that all policies were reviewed annually and spread out throughout the year. For this meeting the ICT, Lone Working, Disciplinary and Dignity at Work policies had been reviewed by the policy 'owner' and JG and required no changes. This was agreed. There were very minor amendments to three other policies; Grievance, Whistle Blowing & Safeguarding, which JG ran through with trustees. All these policies were agreed with the amendments. SA reported that all policies were now contained in a large policy manual. This is the 2<sup>nd</sup> issue of it.

SA said we need a separate Information Governance manual, but to do this we may have to become even more robust and it could be very expensive to meet NHS rules.

- **Implementation Plan update.** JG was delighted to report that all work was now complete or very much in progress, e.g. Business Planning.

ACTION	BY WHOM	WHEN
F21: Circulate changed policies and update policy manual.	JG/SA	ASAP

## 12 Website Update

MP gave some background to the problems we have been experiencing. We had appointed a developer but due to their inability to satisfactorily resolve some technical issues we have decided to terminate their services and get another developer. We have drafted a new specification and put out to tender to 3 new potential suppliers. A small group (SA/MP/Andrew/external consultant) have now selected a company in Cheshire. The aim now is to get as close to a working site as possible in time for the annual conference. We have not paid the existing developer their last invoice. The original quote was for £11,700 but this also included work on the new logo and branding. We have paid them £8,800 to date and they have now invoiced for a further £1,500 which has not been paid. We have now negotiated that they will give us everything that has been developed on our behalf to date and we now have all the files. MP has agreed with them that we will hold back £3,214 which will mean a small refund and non payment of the invoice outstanding. The quotation from the new supplier to complete the specified work is for £2,600 and Andrew Wakelin has personally agreed to underwrite any further spend up to £5,000 if required.

Once we go live at or around the end of November this will conclude Phase 1 of the project and the outstanding technical issues will be resolved. Changes requested by trustees at previous meeting will be built into new development. It was agreed by trustees that MP would send a concluding letter to terminate the contract as indicated above. The refund due would be for £279 which would be sent to us immediately. The hosting of the site will be done by Word Press. For ongoing support we will need to clarify what we want, etc. but we don't envisage this will be very expensive. Trustees expressed thanks to MP for his work in finding a solution

ACTION	BY WHOM	WHEN
F22: Send formal termination letter to Fusing Creativity and obtain refund..	MP	Oct 18

## 13 Organisation & Management Review (OMR)

- **Trustee appointment process.** Historically we have previously co-opted or invited people at AGM to put their name forward to be trustees. Any co-options are ratified at the following AGM. In order to minimise trustee turnover and we would now like to minimise any emotional spur of the moment decisions by potential trustees. A new nomination form has been prepared by MP. The proposed cut off date for new applications is the TB meeting before the AGM. In future the nomination form will be on the new website and proposers can put forward nominations with a due process. For the 2018 AGM members will be briefed and printed copies of the new form will be available
- **Trustee election/re-election.** Phil Prosser has resigned since the last AGM. SA and JP under the rotation rules are due to resign and re-stand. SA is willing to re-stand but we were waiting for JP to respond.
- **Trustee skills audit.** Only JP is outstanding.
- **Position of chair.** MP informed trustees that he will be standing down as a trustee. He feels that he needs to spend more time with his family and that the time has come to hand the baton over to someone else to take AGSD-UK through the next phase of their development. After over 6 years as a trustee and nearly five as chairman he feels that by the time he steps down he will have completed the six major goals he set himself for the charity to achieve during his tenure:
  - Stabilise and maintain appropriate income and expenditure levels
  - Develop and implement a new up-to-date website
  - Develop and implement a comprehensive set of robust governance policies and procedures, ensuring we meet and maintain legal and regulatory compliance
  - Strengthen the trustee board with regard to numbers, skill set and diversity
  - Gain funding for a Specialist Care Advisor demonstrating the value of the model
  - Position AGSD-UK to be able to successfully bid for larger funding grants

As he wants to ensure that some current outstanding work – website and business plan is completed he plans to step down after the next trustee meeting in January.

ACTION	BY WHOM	WHEN
F23: Add Charity Commission website link for new trustee guidance and eligibility to the trustee nomination form.	MP	Oct 18

F24: Inform AGM of change to trustee nomination process.	MP	Oct 18
F25: Chase JP for his completed Trustee Skills Audit Form.	MP	Jan 19

**14 AOB**

- **Patient registries.** AA said that this is something that patients get involved with and which the Medical Advisory Board may want to get involved with as well. It can be as little or a large as they like. We can get researchers involved. Registries were very important for rare diseases and can bring together all the information that is available into one place. If NICE approval is needed having a registry in place makes it much easier. Trustees need to give this further consideration.
- **Andrew Wakelin Birthday recognition.** It is Andrew's Big 70th coming up on 29<sup>th</sup> March next year. JL is preparing a card to be sent to Andrew on his birthday and it will also be recognised at next year's conference with an appropriate presentation.

<b>ACTION</b>	<b>BY WHOM</b>	<b>WHEN</b>
F26: Add Registries to the next trustee meeting agenda	MP	Jan 19

**The meeting closed at 4pm**