

MEETING E1

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 11.30am on Saturday 9th June 2018 at Wolverhampton Racecourse, Gorsebrook Road, Dunstall Park, Wolverhampton, WV6 0PE and following a trustee training day.

<p>PRESENT Stuart Alderson (SA) - Part Ailsa Arthur (AA) Jane Guy (JG) Heneage Legge-Bourke (HLB) Rob Seaborne (RS)</p>	<p>IN ATTENDANCE Allan Muir, Development Director (AM)</p>	<p>APOLOGIES Stuart Alderson (SA) Jayesh Pindolia (JP) Nick Jones (NJ) Mike Porter</p>
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1 Chairman's Remarks

Due to MP's family bereavement absence it was agreed that JG would chair the meeting. She welcomed everyone to the meeting, particularly Rob Seaborne. Trustees had agreed by email that RS should be co-opted onto the trustee board and this was now ratified. Everyone introduced themselves to RS. As RS had missed the trustee training session from the previous day it was agreed that all those who had contributed with reports/PP presentations would circulate these directly to him.

ACTION	BY WHOM	DATE
E1: Contributors to send reports/PP presentations from trustee training session to RS.	MP/SA/JG/HLB	ASAP

2 Minutes of the previous meeting

The minutes with track changes were agreed as a true record of the meeting. Proposed by HLB and seconded by AA.

ACTION	BY WHOM	DATE

3 Matters arising from the previous meeting

Y15: - Set up training records and add to Policy Manual – SA. The maintenance of training records is an on-going management activity and the maintenance of the training schedule is also a management activity – Recorded and closed.

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

C2: Progress MAB TOR review actions – MP/AM – C/F to next meeting

C14: AM reported that JP had sent a PAYG Sim card to Jane Lewthwaite (JL) but the trial was inconclusive; it does not seem to solve the current problem of poor coverage and high charges. AM has upgraded the existing BT mobile account and is in discussion with BT regarding the best solution for JL until broadband coverage improves at her home office – Actioned and closed.

D1: AM reported that updated patient numbers were included in his PP slides from the trustee training day. The numbers still require a little tweaking but give a good indication of current numbers – Actioned and closed.

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 1st 2018 – SA. This work was continuing but we would all endeavour to make contact with PST to ensure compliance – C/F to next meeting.

D3, D4, D5, - Complete, closed

D6: Home working costs built into JL contract:

- £500 pa IT equipment upgrades and contracts
- £1000 pa Office space, heating etc (with 2% uplift pa from 2016)

- £2000 pa Contingency (with 2% uplift pa from 2016)

JL's contract has been amended to reflect the changes proposed – Actioned and closed.

D7: Now actioning at each meeting – Closed.

D8: Update on this agenda – Closed.

D9: - Complete – Closed.

D10: AA attended this event which was successful and enjoyable – Closed.

D11: AM intends to report back to 2018 conference on feedback received from 2017 conference – Closed.

D12: Actioned and closed.

D13: AM has spoken to author of GSD 1 report – Actioned and closed.

D14: The report was distributed to trustees on 29/01/18 – Actioned and closed.

D15: **New process for appointing trustees at AGM to be developed and implemented for 2018 AGM – MP – C/F to next meeting.**

D16: JL has taken responsibility for collating the membership survey – Actioned and closed.

D17: Actioned and closed.

D18: HLB briefed the meeting that he, Jackie Henson (JH -bookkeeper) and AM had agreed to purchase Quickbooks accounting software to replace old unsupported version of Sage. It offered improved reporting and several other functions to be explored by bookkeeper and the new package is working well – Closed.

D19: HLB reported that we have a full licence for Quickbooks and AM confirmed that the licence is registered to AGSD-UK – Actioned and closed.

D20: As cost of Quickbooks was fairly modest HLB has instructed AM to proceed and purchased – Closed.

D21: Now included by auditors in the annual accounts – actioned and closed.

D22: HLB having just received the figures would review and circulate updated budget sheets to trustees – superseded by action item E4. Closed

D23: HLB stated that 18/19 budget would be circulated as soon as possible after he had integrated the pipeline forecast and agreed figures with MP. Business plan draft wording to be completed by MP and reviewed initially at next Fund Raising sub committee – superseded by action items E4, E5. Closed.

D24: A meeting of the fund raising sub committee had been held and the minutes circulated – Actioned and closed.

D25, D27 - Actioned and closed.

D28: Gary O'Donnell has agreed to desk top publish the Annual Report and was currently working on it – Actioned and closed.

D29, D30, D31, D32, D33, D34, D35, D36, D37, D38 – Complete and closed.

D39: **HLB would seek quotes after October AGM. He would look for companies who were accessible for the office but also who were part of a UK network so that if our offices moved we could continue with the same company. Input from the bookkeeper would be sought – C/F to January 19 meeting.**

D40: (AOB) A health professional had raised concerns that one of our Type volunteers had given conflicting advice to a patient but this transpired not to be the case. JG had reviewed the correspondence and agreed that no further action was required – Actioned and closed.

D41: (AOB) HLB has now been added to the signatory list for CAF and Lloyds and can now authorise appropriate payments – Actioned and closed.

D42: **(AOB) AM reported that raising awareness was ongoing and that the conference programme would**

need to be developed and completed before any invitations were made - C/F to next meeting.

ACTION	BY WHOM	DATE
E2: Check that the Policy manual details that maintenance of training records and training schedule is a management activity.	SA	ASAP
E3: Circulate updated treatment centre patient numbers to trustees	AM	Jun 18
E4: Circulate updated 5 year budget sheet to trustees and AM	HLB	ASAP
E5: Prepare draft of Business Plan wording for review at next fund raising meeting.	MP	Sep 18
E6: - Circulate final draft of Annual Report after designer has completed his work.	JG/AM	Jun 18

4 Declaration of Interest

JG explained the importance of this standard agenda item for RS's benefit. There were no declarations of interest.

ACTION	BY WHOM	DATE
E7: Minutes to show that no trustee present had any interest to declare	JG	Jun 18

5 Charity Director's Report

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

- **Over the Wall.** AM stated that JL wanted to be involved but this had not been agreed with the organising parties. As yet we had not been able to take up all the free spaces offered and the event would take place in September.
- **Privacy policy/GDPR.** This was moved to agenda item 11.
- **Jackie Henson Work Plan.** JG commented that while this was very helpful she felt it was unrealistic given that she had a maximum of 15 hours per week. JG also felt that some direction of priority should be set recognising that some items were time limited, e.g. helping with the conference and implementing policies. After some discussion it was agreed that JG would discuss further with MP who would then amend the work plan appropriately. JG asked AM to ensure that the chairman was alerted if priority work could not be achieved by the due dates.
- **Membership Campaign.** AM reported that we had 1,200 contacts on the database and there were 800 patients in the UK with a GSD condition, but only 100 members with it on our database. JH has recently written to those who could become members to encourage them to do so. AM would undertake an analysis of the database. There was a lengthy discussion on whether to charge a membership fee and if so how much, whether there should be a tiered system to allow easy access for those who relied on benefits, whether we could charge for a starter pack for new members only. There were lots of members who had not paid any subscription. AM reiterated the importance of sending out hard copies of the newsletter to members. JG said we were not clear who could vote at the AGM when we did not describe a member. It was agreed that we would defer this item for AM to prepare a paper with a recommendation and discuss this as an agenda item at the next meeting.
- **2018 Conference.** AM reported that he intended giving feedback from last year's conference, e.g. not so much sweet food. He has gathered lots of ideas and was putting the schedule together. The Type Co-ordinators were involved in the planning and he would shortly be inviting speakers. AM recommended the fees should be the same as last year when they had increased from the previous year. There were two different fees; for our members and for health professionals who were expected to cover the full costs whereas member's places were subsidised by the sponsors. There are different booking forms for each group. The prices were on the website and there were fees for families and singles and for additional Friday night bookings. HLB asked AM to provide him with a budget for the conference.
- **Droxford Office.** AM reminded trustees that they had approved a rent increase but this had not yet happened. It should not be retrospective.
- **Glisten.** JG praised AM for another excellent publication.

ACTION	BY WHOM	DATE
E8: Discuss tasks and priorities of JH work plan.	JG/MP	ASAP
E9: Put membership criteria on agenda for next meeting.	MP	Oct 18

E10: Propose updated membership fees to the trustees.	AM	Oct 18
E11: Prepare conference budget and submit to HLB.	AM	ASAP

6 Pompe Specialist Care Advisor (SCA) Report

The SCA report was circulated and noted.

ACTION	BY WHOM	DATE

8 Financials

- **2017/18 draft accounts.** HLB reported that he had only just received these the previous evening. Income for the year was just under £300,000 and was in line with the previous year. Expenditure was down from £266,000 to £232,000 so the surplus was double to the previous year at £67,000. This was a good result. HLB raised concern regarding the balance between restricted and unrestricted funds leaving little free reserves with approximately £48,000 unrestricted, he would review this as soon as possible. HLB commented that we should be mindful of the high level of our cash position (£186,000) in the bank as this could provoke our funders to query why we had not yet spent the money which they had given us. There also seems to be items that would need further examination, e.g. our computer costs the previous year had been £40,000 but for last year £10,000. HLB would prepare a treasurer's report for inclusion into the Annual Report and highlight such matters.
- **2018/19 budget.** HLB would now look at the budget for last year and integrate with the updated pipeline report for 18/19 which he would review with MP and AM and when agreed circulate a final budget number to trustees for agreement.
- **Petty Cash.** AM reported only a few transactions. We were proceeding mindful of the Financial Procedures Policy.
- **Expenses.** AS JL often had to spend money on our behalf on her personal credit card it was agreed that we would apply for a credit card for her with a limit of £1,000. Any expenditure above £500 should first be authorised by AM. This was proposed by HLB and seconded by RS and agreed by the trustees present. It was noted that any expenditure over £1,000 had to be authorised by HLB.

ACTION	BY WHOM	DATE
E12: Consider how to improve unrestricted funds.	HLB	ASAP
E13: Prepare treasurer's report submission for Annual Report.	HLB	Jun 18
E14: Work on 18/19 budget and agree with MP/AM and then circulate to trustees ensuring business aims are costed in.	HLB	ASAP
E15: Apply for a credit card for JL.	AM	ASAP

9 Fundraising

- **Annual Report.** JG reported that this has now been drafted and was with the designer. She was waiting for the I & E figures and Balance Sheet for 17/18 and a Treasurer's Report from HLB. The designer has been asked to complete the work by the end of June. JG would then circulate this to all trustees for sign off.
- **Events.** AM reported that these had been included in the recent issue of Glisten.
- **Fundraising sub-committee actions.** JG reported that the minutes of the meeting held in March had been circulated. We would hold another meeting in September to reflect on funds raised achieved from events and prepare to make grant applications after the Oct 18 conference

ACTION	BY WHOM	WHEN
E16: Circulate Annual Report to trustees for sign-off when design is complete.	JG	Jun 18
E17: Arrange fund raising sub-committee meeting for September.	JG	ASAP

10 IT

SA said most of this has been covered the previous day. He and MP were working closely with PST to get all staff and trustees access to the management files and with AGSD email addresses. Two of the trustees have company PCs which will already be secure but we will need their employers to consent to using for AGSD work.

ACTION

E18: Hold IT Services review with PST.

BY WHOM

SA/MP/AM

WHEN

Jul 18

E19: Ask if JH can also attend.

SA/AM

Jun 18

11 Policy Manual

- **Deficiency log review.** JG reported that there were only 2 items left; the lack of a Caldicott Guardian and in the absence of this SA was taking responsibility, and no formal information governance was included in the Policy Manual. It was agreed that from now on we would have a Privacy Policy, Privacy Notice and also a Data Protection Policy, which could be included in the Policy Manual and then this second item could also be closed.
- **New Policies.** JG reported that we now needed to approve the Privacy Policy, Privacy Notice, Data Protection Policy and Ethics Policy. These had been circulated with the trustees meeting papers. It was agreed that for the moment we would not consider the comments sent in by Andrew Wakelin as it would delay matters and we must have the Privacy Policy in place as the new GDPR was already law. This was agreed. The policies listed above were approved unanimously, proposed by AA and seconded by HLB. AM would report back to Andrew and correct some of the errors in his comments.
- **Policy reviews.** JG had slightly amended the Complaints Policy to clarify that complaints relating to privacy matters should be dealt with as described in the Privacy Policy. AA has reviewed the Equality & Diversity Policy. JG had also amended the TOIL Policy as agreed at the last meeting. All these were also adopted. Proposed by AA and seconded by HLB.
- **Implementation Plan update.** Unfortunately the date set at the last trustees meeting had not been met, but JG was hopeful that this work could be complete by the end of June. Some of the policy ownerships were changed in the right hand column as follows:- Lone Working, Dignity at Work & Handling Complaints – JG, Supervision & Support – NJ, Managing Volunteer Performance – AA, Finance – HB, Conflicts of Interest, Declaration of Interest Form and Ethics – RS, Data Protection, Privacy and Privacy Notice – SA.
- **Annual Review.** JG agreed should now read through the remaining policies due for review and ask those trustees responsible for each one to review those with her. These would then be brought back for trustee approval at the October meeting.

ACTION

E20: Amend Deficiency Log as agreed above.

BY WHOM

SA

WHEN

ASAP

E21: Update Policy Manual with new policies.

SA

ASAP

E22: Update Policy manual with policy reviews.

SA

ASAP

E23: Update Policy Implementation Plan with changes in ownership.

JG

ASAP

E24: Notify those absent who have new ownerships.

JG

ASAP

E24: Review remaining policies with owners.

JG

ASAP

12 Website Update

SA gave the background to the creation of the new website as the current one was considered dated and uninspiring. Funding had been provided for this purpose. Trustees had selected a small website development company who had made some progress. SA demonstrated this on the screen. The main banners were now fixed and SA estimated there were approx. 7/10 days of development needed, although realistically this would likely take 8 weeks as they had other work to do as well. We are now able to upload content, though Alan, Andrew and Type Co-ordinators need to be trained to do so.

There is a standard footer for all pages and uniform page layouts. AA asked whether we could change the wording from 'medical professionals' to 'health professionals' and SA believed this could be achieved and would follow that up. On the 'contact us' page, it was suggested we should include a telephone number

unless it was deemed unnecessary. Trustees could view the development site at, <http://agsduk.wpenqine.com> Trustees should provide feedback on this to MP, cc to SA, before 22 June. The designers are only responsible for the functionality and cannot produce content and this will be primarily down to AM and Andrew Wakelin as the content owners for McArdle and Pompe. AW/AM will decide when there is enough information there for us to launch the site. MP, SA and AM will continue discussing this regularly.

We will need a training plan for those who are providing/uploading content to use the edit function and we will need one main editor, and hopefully lots of contributors. If anyone has any comments please write to MP and copy in SA.

ACTION	BY WHOM	WHEN
E25: Change wording to 'Health Professionals'	SA/MP	ASAP
E26: Decide if we need a telephone contact number when visitors to the site want to make contact with us.	SA/MP	ASAP
E27: Develop a training plan.	AM	ASAP

13 Organisation & Management Review (OMR)

- **Trustee skills audit.** Trustees present completed the form. JG will send forms to MP
- **McArdle clinic volunteers.** AM explained the background and AA asked what was involved. As we will have to sign an agreement we had asked A Wakelin for more information and this was now to hand. After some discussion it was agreed that AA will discuss this with MP and subject to their agreeing to proceed the board will support their proposal.

ACTION	BY WHOM	WHEN
E28: Send completed skills audit forms to MP. Send electronic forms to absent trustees for completion.	JG/MP	ASAP
E29: Discuss what McArdle clinic volunteers will do, who, when and what process we need in place first.	AA/MP	ASAP

14 AOB

- The **dates of the next two meetings** were provisionally set for 6th October and 2nd February 2019.
- Our independent examiners have asked s to sign their **GDPR agreement**. This was agreed and AM would sign on our behalf.
- **RS's email address** will change shortly to robseaborne@gmail.com until such time as he has an AGSD email address. Ensure RS is set up with an email address.

ACTION	BY WHOM	WHEN
E30: Note the dates of the next two trustee meetings.	Trustees/Staff	ASAP
E31: Sign our Independent Examiners GDPR agreement.	AM	ASAP
E32: Note RS's new email address.	All	ASAP
E33: Ensure RS is set up with a AGSD-UK email address	AM	ASAP

The meeting closed at 11:35am.