

MEETING D1

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 11.30am on Saturday 27th January 2018 at Wolverhampton Racecourse, Gorsebrook Road, Dunstall Park, Wolverhampton, WV6 0PE.

PRESENT Mike Porter, Chairman (MP) Phil Prosser (PP) Jane Guy (JG) Ailsa Arthur (AA) Heneage Legge-Bourke (HLB)	IN ATTENDANCE Allan Muir, Development Director (AM) Paul Alderson, PST Business Solutions (PA)	APOLOGIES Stuart Alderson (SA) Jayesh Pindolia (JP) Nick Jones (NJ)
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1 Chairman's Remarks

The Chairman welcomed everyone to the meeting, particularly the new trustees – Ailsa Arthur and Jane Guy who were appointed at the last AGM and also Heneage Legge-Bourke who subsequent to the AGM has been co-opted onto the trustee board. In addition, MP welcomed Paul Alderson from PST Business Solutions. Apologies had been received from SA/JP/NJ.

Another very busy agenda was planned for the day and the chairman thanked everyone for agreeing to start the meeting 30 minutes earlier than scheduled.

2 Minutes of the previous meeting

Other than an error regarding the date of meeting B1 the minutes of meeting C1 from 30th September 2017 were taken as read.

ACTION	BY WHOM	DATE
Minutes to note date of meeting B1 was 27 th May 2017	MP	Jan 18

3 Matters arising from the previous meeting

B11, B16, C1, C3, C4, C5, C6, C7, C8, C9, C10, C11, C12, C13, C15, C16, C17, C18, C19, C20, C21, C22, C23, C24, C25, C26 – 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 – C/F to next meeting.

C2: Progress MAB TOR review actions – MP/AM – April 1st 2018

C14: Discuss and agree if appropriate JP's offer of mobile phones and contracts from Nowtel for AGSD-UK use – AM/JP – Feb 18

ACTION	BY WHOM	DATE
D1: Circulate updated treatment centres patient numbers to trustees	AM	Feb 18
D2: - Arrange for remaining staff/trustees to have VPN access and AGSD-UK email accounts. Use of new AGSD email accounts to formally commence from April 1 st 2018	SA/PA/All	Mar 18
D3: - Trustees agreed to appoint HLB as Honorary Treasurer	Trustees	Jan 18
D4: Trustees/AM to review draft CEO role profile and provide feedback to MP	Trustees/AM	Mar 18
D5: - Send out electronic copy of CEO role profile	JG	Jan 18

D6: - Following discussion on NJ email regarding TOIL discussion with Jane Lewthwaite (action item B16) the following additional actions were agreed:		
- Check what 'home working' costs were built into Pompe SCA costs and update trustees.	AM	Feb 18
- Build into home based worker grant application costs – up to two overnight stays per working week, with one additional half day TOIL allowance whenever they exceed two overnight stays in any week.	AM	Ongoing
- Build into employment contracts for new full time permanent staff, additional annual leave allowance linked to length of service – 0.5 extra leave per year after first three years of service up to a maximum of five days. This will mean after serving 13 years long serving staff would accrue one extra week's leave per annum.	AM	Ongoing
- Amend current SCA contract to reflect above.	AM	Mar 18

4 Declaration of Interest

MP asked if any trustee had any declaration of interest to make – no interests declared.
MP asked AA to explain her role with regard to the other charity she is in the process of setting up.
Following the explanation given by AA the trustees were satisfied that there was no conflict of interest with her role as trustee of AGSD-UK.

ACTION	BY WHOM	DATE
D7: Minutes to show that no trustee present had any interest to declare	MP	Jan 18

5 Charity Director's Report

The Charity Directors report was circulated and discussed.

ACTION	BY WHOM	DATE
D8: Trustees authorised AM to negotiate for rent to increase no higher than £4k per annum at Droxford office. If possible to include landlords commitment to improve broadband speed.	AM	Mar 18
D9: - Inform any AGSD-UK attendees at 'One Voice Choir' that attendance is at their own personal risk.	AM	Feb 18
D10: - AA volunteered to attend Westminster Rare Diseases event	AA	Event
D11: AM to take into account attendee feedback from 2017 conference when building programme for 2018 conference.	AM	Aug 18
D12: - MP to invite PST Business Solutions to 2108 conference	MP	Jan 18
D13: - Discuss improving quality of future Type 1 reports with author.	AM	May 18
D14: - Circulate Type 5 report to trustees	AM	Feb 18
D15: - New process for appointing trustees at AGM to be developed and implemented for 2018 AGM.	MP	Aug 18

6 Pompe Specialist Care Advisor (SCA) Report

The SCA report was circulated and discussed.

ACTION	BY WHOM	DATE
D16: - Develop membership survey for conference regarding AGSD-UK services.	AM	Aug 18

7. Lunch break

8 Financials

MP updated meeting that the 2016/2017 final accountants had been filed with Companies House and AM confirmed that they had been filed with Charity Commission. MP explained that final income figure for 2016/17 was much higher than budget primarily due to including for the first time 'donations in kind,,'

though this figure had also been recognised as an expenditure item. There was however a real over performance against budget when stripping out the 'donation in kind' income and expenditure, with higher income achieved (budget £200055/actual £206953) and a lower expenditure achieved (budget £195719/actual £172160). It was agreed that capturing 'donation in kind' income would be adopted on a go-forward basis.

It was agreed that due to HLB only recently joining as Honorary Treasurer and the limitations of operating on a very old version of Sage financial software it was not possible to provide the trustees at this meeting with an accurate year-to-date position for the income and expenditure for 2017/18 financial year. It was also agreed that the 'income pipeline' report would be revised to capture 'in year' income.

HLB updated the meeting on a discussion paper from the bookkeeper to move away from Sage to Quickbooks for FY 2018/19 in order to provide more timely and accurate financial reporting. The cost of the move, including migration, should be minimal. PA informed the meeting that PST Business Solutions use Quickbooks for their own accounting and that it works very well.

HLB proposed that the trustees should adopt a new timetable for completing the year end accounts with the intent to formally sign them off at the September trustee board meeting. Trustees agreed to new timetable.

MP agreed to develop revised budget numbers for next financial year with HLB/AM using existing 5 year budget assumptions as the starting point. MP also stated that the budget income and expenditure line items should match the line items in the annual report and should be reported to the trustee board in this format.

The meeting discussed and agreed the need to also develop a set of words (Business Plan) that drives and supports the budget numbers.

ACTION	BY WHOM	DATE
D17: - Revise Income Pipeline report	MP/HLB	Mar 18
D18: -Circulate initial Quickbooks discussion paper from bookkeeper.	HLB	Feb 18
D19: -Agree which Quickbooks licence option we should adopt.	HLB/AM	Feb 18
D20: - Circulate final proposal option/costs on Quickbooks to trustees for approval.	HLB	Mar 18
D21: - Capture 'donations in kind' income for current financial year.	AM	Apr 18
D22: - Update and circulate 5 year budget sheet with actual for 2016/17 and addition of anticipated donation in kind for 2017/18 budget	MP	Feb 18
D23: - Develop budget numbers for 2018/19 budget and also first draft of Business Plan wording.	MP/HLB/AM	Mar 18

9 Fundraising

JG and AM updated the meeting on funding submissions to both existing industry partners and to trusts and foundations. Requests for funding from industry partners has been relatively successful and there have been a couple of small submission successes to trusts and foundations, however larger submissions aimed at recruiting additional SCA staff are in the early stages and will not materialise this financial year. It is anticipated therefore that there will be a shortfall in the fundraising income line.

JG proposed that the next meeting of the Fundraising Sub Committee (FSC) should convene in March in order to further progress existing actions and develop additional potential income targets.

JG briefed the meeting that she had been discussing with MP/AM the need to create a glossy annual report that would key in the support of funding applications and also to update members. MP added that JG had asked about the possibility of putting a screen shot of the new website home page on the existing site, as until the new website went live it would be helpful with potential funders to demonstrate that we are in the process of moving to a new professional site.

AM updated the meeting on a number of forthcoming fundraising events.

ACTION	BY WHOM	WHEN
D24: - Arrange next meeting for FSC	JG	Mar 18
D25: - Check and agree what a screen shot of new website would look like on existing site	AM/JG	Feb 18
D27: - Circulate outline Annual Report content page to trustees/AM	JG	Jan 18
D28: - Discuss design/production of Annual Report with Gary O'Donnell	AM	Feb 18

10 PST Business Solutions

PA provided the meeting with an overview of PST, their experience and customer base and the benefits to AGSD-UK of partnering with a professional IT company that can provide a secure IT environment.

An informative discussion was held regarding the pros and cons of laptops/devices and the software running on them, both from a functionality perspective and a security perspective. In order to aid the discussion and also to guide AGSD-UK on what specification PST proposes be used from an optimum price/performance perspective for desktop and notebook computers, a 'Recommended Specification' document was circulated.

PA briefed the meeting on the forthcoming European General Data Protection Regulations (GDPR) based on his experience and on attending various seminars on the subject. In support of this he circulated a briefing document along with a 12 point ICO issued guide to help prepare for the new regulation.

ACTION	BY WHOM	WHEN
D29: - Review the PST and ICO documents and develop action plan to ensure that AGSD-UK is compliant.	AM/SA	Mar 18

11 Policy Manual

JG updated the meeting on the Implementation Plan which had fallen slightly behind the agreed timetable. The meeting agreed a revised timetable and varied some of the trustee responsibilities. Based on an earlier discussion regarding fundraising targets JG suggested that AGSD-UK should consider having an 'ethics' policy.

SA had, prior to the meeting, circulated an update paper relating to various items he had been working on. Included was an action to create a Deficiency Log and the meeting agreed to its incorporation into the Policy Manual and to review it as a standing agenda item at each trustee meeting.

The trustees agreed that there was a requirement for an Information Governance (IG) policy.

MP circulated the current list of policy owners and asked following Noor Abdul-Ghani standing down as a trustee, who from the current trustee board should these be allocated to. AA agreed to take responsibility for both Equality & Diversity and Safeguarding. MP requested that now we have a larger trustee board composition the trustees should look at the full list of owners and based on their own skills and experience see if some policies can be re-allocated to spread the workload.

ACTION	BY WHOM	WHEN
D30:- Circulate revised policy implementation plan to trustees/AM	JG	Jan 18
D31: - Research and circulate a draft ethics policy for review.	JG	Jan 18
D32: - Add Deficiency Log to standard agenda items	MP	May 18
D33: - Incorporate appropriate IG policy into policy manual	SA	Mar 18
D34: - Review policy owner list and advise MP of any suggested changes	Trustees	Apr 18

12 Website Update

MP updated the meeting on the progress of the design and development of the new website. One element of the deliverables from our design partner was the creation of training material for AGSD-UK to manage and update the content of the new site once it goes live. MP reminded the meeting that the agreement we

had with Fusing Creativity (FC) was for them to create an agreed design and working functionality using an element of what content was going to be included on the new site and after that AGSD-UK would be responsible, post training, for loading the remainder of the content and managing content thereafter. FC has now created training videos for review and agreement.

MP briefed the meeting on the major milestones required to be able to go-live with the new website by April 1st 2018. One of the critical milestones is agreeing what is the minimum level of content required to go-live, recognising that additional content can be added on a phased basis. MP proposed that as the bulk of the content on the new website would be Pompe and McArdle, AM and Andrew Wakelin should advise MP/SA what minimum content is required.

ACTION	BY WHOM	WHEN
D35: - Provide access for AM/Andrew Wakelin to training videos and solicit feedback.	MP	Jan 18
D36: - AM to confirm minimum Pompe content and MP to request same from Andrew Wakelin.	AM/MP	Jan 18

13 OMR

MP briefed the meeting that a 4 hour induction day programme has been developed for new trustees. The aim was for AA/HLB/JG to attend but MP thought that it would be useful for NJ and PP to also attend. JG suggested that given that an Equality & Diversity training day was also being scheduled it would be more efficient to attempt to deliver both programmes on the same day for all trustees/AM. The meeting agreed that a training day be scheduled for the day before the next trustee meeting (date tbc) for somewhere in the Midlands with an overnight stay/dinner.

MP circulated the latest version of the Key Role Succession Plan document.

HLB requested that annual competitive quotations be sought for our accountancy/audit work and the meeting agreed.

ACTION	BY WHOM	WHEN
D37: - Circulate and agree date for next Trustee board meeting	MP/trustees	Feb 18
D38: - Review Succession Plan 2 nd draft document and feedback to MP suggested names for gaps.	Trustees	Mar 18
D39: - Seek competitive quotations for accountancy/audit work.	HLB	Annually

14 AOB

MP briefed the meeting on correspondence received by Andrew Wakelin from the clinical director at the Walton Hospital which may be categorised as a complaint.

JG proposed that HLB be added to the bank signatory list, this was seconded by MP and agreed by trustees.

AA briefed the meeting that she and Jane Lewthwaite had been working on setting up a Type 3 support group which would work in a similar way as the Pompe support group. AA also briefed the meeting that she had developed and delivered a rare diseases talk to a group nursing staff and would be looking to roll this out to further hospitals.

It was suggested that in order to raise awareness, AGSD-UK should offer a formal invitation to the Health Secretary to attend/speak at the annual conference.

MP informed the meeting that he will be overseas from 4th – 15th February.

ACTION	BY WHOM	WHEN
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D40: - Send documentation set to complaint policy owner (PP). PP to review and advise trustees on whether to categorise as a complaint and what next steps should be.	MP/PP	Feb 18
D41: - Add HLB to the bank signatory mandate.	AM	Feb 18
D42: - Send formal invitation to Health Secretary to attend 2018 conference	AM	Feb 18

The meeting closed at 4.30pm.