



MEETING B

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

held on Saturday 14th November 2009

<p>PRESENT Andrew Wakelin, Chairman Allan Muir Jayesh Pindolia Ann Phillips Clive Tonks</p>	<p>IN ATTENDANCE Kate Phillips, Secretary Luca Venditto</p>	<p>APOLOGIES Hugo Del Mar Sue Del Mar, Treasurer</p>
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1 Apologies for absence	ACTION
Apologies were received from Sue Del Mar and Hugo Del Mar.	

2 Chairman's Remarks	ACTION
<p>AW set out new ground rules for future meetings and correspondence:</p> <ul style="list-style-type: none"> • AW as Chairman will set the agenda as he has needs to ensure the Trustees are meeting their obligations. • Issues for discussion at meetings should be submitted to AW well before the meeting. • Papers for discussion will be circulated before meetings to enable all attendees to prepare in advance. • All agenda items will be subject to time slots for discussion at meetings in order to get through business. • When replying to circular emails only to reply to the sender unless it is essential that all recipients are included. <p>B1: All minutes will have action points included in the minutes of meetings.</p>	KP

3 Minutes of previous meetings	ACTION
The minutes of the meetings on 6 th September and 4 th October were accepted as a true record.	

4 Matters arising	ACTION
<p>A3 - Accounting Date It had been discussed that this would be 31st March. Following action to check with accountants, decided this should remain at 31st May. This was accepted. Action closed.</p> <p>A4 - Bank Account SDM is opening the bank account. This will have 4 signatories: SDM, AM, AW, AP. Two signatories will be needed on cheques. It was agreed that if not too late to amend mandate, amounts up to £100 to only need 1 signature. Action closed.</p> <p>A5 - On main agenda A6 - Action completed</p>	

5 AGSD Annual Conference 2010	ACTION
<p>Date: The provisional November date for the conference in 2010 was discussed. This has arisen due to there being no availability in September. October dates clash with ½ term. The next available date is 6/7th Nov. Some concerns were expressed about a date late in the year could have issues of bad weather and delegates not liking to drive in the dark. However, the proposed new format if accepted would mean people could drive in daylight. Spring was suggested as a potential time for conferences, however it was explained this would be problematic due to reporting deadlines. The November date was agreed.</p> <p>B2: Dates to be booked for 2011 onwards, on 1st weekend in November.</p> <p>Location: AM reported that Genzyme will hold the European Pompe Steps Forward conference in UK next year. They have expressed a wish to run this back to back with the AGSD conference, ideally using the same venue. It was agreed that this was very desirable. It was thought that Telford was not suitable due to overseas professionals flying in. As the conference had been in the London area for 2 of the last 3 years it was felt that Manchester or Birmingham would be preferred, but if these were not acceptable to Genzyme then West of London would be acceptable.</p>	AW

<p>Christine Evans had been put forward by SDM as Type IX representative. AP reported that she had known her for 2 years and considered her to be suitable. Her son has Type IX. Appointment approved.</p> <p>B8: AW to write to CE to confirm appointment as Type IX representative.</p>	<p>AW</p>
<p>10 Policies</p> <p>The draft Child and Vulnerable Adult Protection policy had been circulated. Most of the policy has been agreed. The Policy was approved subject to amendment to make it clear that staff and volunteers should NEVER work one to one with children/vulnerable adults.</p> <p>B9: Policy to be implemented and out on web site.</p> <p>CT is working on a Research Grants policy and is researching what other organizations do. AW suggested a cut off date for application submissions to enable all applications to be weighed up side by side. To help guide CT it was discussed that an idea of the size of grants to be issued was needed. This was usually £10-20K or smaller amounts.</p> <p>B10: CT to draft Research Grants Policy.</p> <p>The need for policies on the following was identified: Family/Patient grants, Confidentiality, Privacy, Equal Opportunities and Expenses.</p> <p>B11: Draft policies to be worked on for future meetings.</p>	<p>ACTION</p> <p>AW</p> <p>CT</p> <p>All</p>
<p>11 Insurance</p> <p>AW explained that the charity has a legal obligation to have Employers Liability Insurance as there is an equal duty of care to volunteers as employees.</p> <p>AW has obtained one quote from an insurance company that specialises in charity cover at approx £450 a year. This includes Public Liability, Employers Liability and Trustees Indemnity.</p> <p>B12: AW and SDM to obtain quotes from other sources and arrange insurance.</p>	<p>ACTION</p> <p>AW/SDM</p>
<p>12 Vitaflow</p> <p>At the conference many patients expressed issues with the Vitaflow product. LV felt that Vitapro have taken these issues on board and are re-evaluating the product accordingly. In order to progress the product further Vitapro need to maintain a dialogue with patients. LV asked how we could help promote this dialogue in order that the product is improved.</p> <p>AP felt that it was important that the AGSD was not seen to endorse this product but present the members with an unbiased opinion. AW highlighted the charities responsibility to provide the membership with information on all available options.</p> <p>B13: LV and AW to develop an appropriate wording on Vitaflow for Type I and Type III patients to be circulated to Trustees for comments. The information could then be issued to members.</p>	<p>ACTION</p> <p>LV/AW</p>
<p>13 Membership classes</p> <p>A paper proposing to re-word the membership classes to enable spouses and partners to become Full Members with voting rights was discussed. AW said the word "relative" allows spouses and other relatives to become full members with voting rights and simplifies the wording. Junior membership has been removed as Juniors can join as Associate Members.</p> <p>AP did not like the term "relative" as it was too broad. CT suggested inserting "spouse and partner" instead of the "relative". The proposal was agreed with that amendment.</p> <p>B14: The term "spouse or partner" would be added to the full membership clause and junior membership deleted.</p>	<p>ACTION</p> <p>AW</p>

14 Strategic vision for the association	ACTION
<p>Genzyme meeting - AM reported back on meeting with Genzyme. They are keen to help the association to develop as they feel the charity needs to grow in size and have paid staff to facilitate growth. AM and AW proposed the appointment of an administrator and a development officer. Genzyme said they would be interested in supporting the charity on a 3 year agreement and requested a formal proposal with view to the charity becoming self-funding after that.</p> <p>Development - AW and AM had prepared and shared a staff possible organizational structure and job descriptions. CT questioned the name Executive Director and it was agreed Development Officer was a better title.</p> <p>AM/AW feel that in order to progress it is critical to have a paid professional administrator dealing with all essential admin. Ideally all documentation would be held in a small office and this would help ensure all day-to-day matters could be dealt with more coherently. AM felt to become self sufficient would require a professional fundraiser to be hired at least part time.</p> <p>AM/AW outlined a vision of having:</p> <ol style="list-style-type: none"> 1) Central office with professional administrator. 2) Development Officer to promote and develop the association and to assist and encourage the Type coordinators, making their role more effective. <p>The meeting was asked if this was the direction the charity wanted to take. CT liked and supported this idea. He raised concerns about the amount of input Genzyme would expect in return for their sponsorship. He said it was imperative we went into this with "eyes open" and felt that the charity should still be impartial and not tied to any pharmaceutical company. AP read out the code European Pharmaceutical Industry code of conduct on such relationships which Genzyme is signed up to. AM reported that his experience of Genzyme was good so far and they were aware that AGSD also dealt with their competitors.</p> <p>LV felt that the charity had a real need for the paid administration role, especially to take on the large job of organizing a conference. AM raised possibility of job share.</p> <p>AW felt this was best achieved by recruiting a paid member of staff and this should be advertised in order to find the best person for the job.</p> <p>Home working in the first instance was discussed but it was felt that sharing with another charity would offer the appointed person more support. The possibility of renting a fully serviced desk space had been investigated and £4,000 a year is the approx cost in central London. However partnering with other medical charities was a preferred option. London was muted as convenient location but Manchester or Birmingham also possible. AM has emailed charities to explore the shared resource possibility and is awaiting responses.</p> <p>The question was raised: Would the Development Officer need to have GSD knowledge or would a generic knowledge of charity management be better? It was noted that Type Coordinators have the specialist knowledge. They could become paid staff. In this case the Development Officer could have a more managerial role.</p> <p>LV pointed out that following the end of the Genzyme funding the emphasis would need to be on fundraising expertise.</p> <p>Budget - Development hopefully to start May 2010. A draft 5-year budget was discussed. It was noted that the charity had little reliable income. Current income is from membership and donations. This is c. £8-10K a year. There would be a need to generate income through more donations, legacies, individual sponsored efforts and a big fundraising event every 2 or 3 years.</p> <p>It was felt that the financial projections would be hard work but were achievable. During the period of funding from Genzyme it would be important to build free reserves to a robust level.</p> <p>AP commented on the need for legal advice regarding contracts. AW asked for help on the development team. JP volunteered to help.</p> <p>AW raised the issue that some AGSD designated funds may be needed to initiate this development. It was discussed that as the Bike Ride literature stated that money raised would be used for "research" was it acceptable to use some of it for this purpose. It was agreed that it was. CT suggested that using the term "in furtherance of research" in the future would avoid this problem.</p>	

<p>B15: AM/AW and JP to write a proposal and circulate this to the Trustees. Following feedback this would be submitted to Genzyme.</p> <p>AM declared interested in that he may apply for one of the paid roles discussed. If successful he would need to resign as a Trustee. The position was understood and accepted by the Trustees.</p>	<p>AW/AM/JP</p>
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<p>15 AOB</p> <p>15.1 AM circulated updated membership forms.</p> <p>15.2 AP spoke about her continuing role within the association and attending conferences on behalf of the charity.</p> <p>B16: AP to write a paper on the role of external representative.</p>	<p>ACTION</p> <p>AP</p>
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Meeting closed at 4.00 pm.

SUMMARY OF ACTION STATUS AT CLOSE OF MEETING

A1: AW to investigate venues/bookings for the 2010 annual conference.	AW	Completed
A2: AW to approach Kate Phillips about becoming Secretary.	AW	Completed
A3: AW to check accounting requirements with our accountants.	AW	Completed
A4: SDM to open bank account.	SDM	Closed
A5: All to consider the child and vulnerable adult protection policy before the next meeting.	All	Completed
B1: All minutes will have action points included in the minutes of meetings.	KP	
B2: Dates to be booked for 2011 onwards, on 1 st weekend in November.	AW	
B3: AM and AW to liaise with Genzyme and ask if they would consider Manchester or Birmingham.	AW/AM	
B4: AW to investigate future venues.	AW	
B5: AW to instigate publishing of minutes on website.	AW	
B6: Job description to be refined by AP, JP and AW. Next draft to be released via email then issued on a provisional basis and ratified at the next meeting.	AW/JP	
B7: AW to produce draft Treasurer, Chairman & Secretary descriptions for next meeting.	AW	
B8: AW to write to CE to confirm appointment as Type IX representative.	AW	
B9: Policy to be implemented and out on web site.	AW	
B10: CT to draft Research Grants Policy.	CT	
B11: Draft policies to be worked on for future meetings.	All	
B14: The term "spouse or partner" would be added to the full membership clause and junior membership deleted.	AW	
B12: AW and SDM to obtain quotes from other sources and arrange insurance.	AW/SDM	
B13: LV and AW to develop an appropriate wording on Vitaflow for Type I and Type III patients to be circulated to Trustees for comments. The information could then be issued to members.	LV/AW	
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