



MEETING C

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held on Saturday 06th February 2010 - London

PRESENT Andrew Wakelin (AW), Chairman Hugo Del Mar (HDM) Sue Del Mar (SDM), Treasurer Allan Muir (AM) Ann Phillips (AP) Clive Tonks (CT)	IN ATTENDANCE Kate Phillips (KP), Secretary Luca Venditto (LV) Patrick Phillips (PP)	APOLOGIES Jayesh Pindolia (JP)
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1 Apologies for absence	ACTION
Apologies were received from Jayesh Pindolia.	

2 Chairman's Remarks	ACTION
AW explained the action points system in the minutes. He reported that the only urgent matters handled between meetings need be reported in this section. AW urged all to use their relevant AGSD-UK email addresses and not personal email addresses as this will be a legal requirement going forward. AW said he would issue instructions on how to set up AGSD-UK email accounts, which he and AM were already using effectively .	

3 Minutes of previous meeting	ACTION
The minutes of Meeting B held on 14 th November 2009 were accepted as a true record.	

4 Matters arising	ACTION
A3: Accounting date – agreed a change to the charity year end to 31 March. Two sets of accounts will be prepared this year: <ul style="list-style-type: none"> • one set for the original charity showing a zero balance after funds have been transferred to the new incorporated charity • the second set will be for the incorporated charity 	Completed
A4: Bank Account – still in progress with Lloyds. Andrew is leading this and will update at next meeting.	AW
B2: Dates to be booked for 2011 onwards, on 1 st weekend in November.	Closed
B3: AM and AW to liaise with Genzyme and ask if they would consider Manchester or Birmingham.	Item 8
B4: AW to investigate future conference venues.	Ongoing
B5: AW to instigate publishing of minutes on website.	Completed
B6: Type Coordinators 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.	Item 10
B7: AW to produce draft Treasurer, Chairman & Secretary descriptions.	Ongoing
B8: AW to write to CE to confirm appointment as Type IX representative.	Completed
B9: Protection policy to be implemented and put on web site.	Completed
B10: CT to draft Research Grants Policy.	Item 12
B11: Draft policies to be worked on for future meetings.	Closed
B12: AW and SDM to obtain quotes from other sources and arrange insurance. Due to urgent need for employer's liability cover re Kathryn Wright's employment AW	

<p>has agreed to this year's policy at c£450. AW to display employer's liability certificate on website and to circulate an executive summary of what is covered by the policy.</p>	AW
<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. Further consultation required and LV is to ask Dr Eileen Murphy from the AGSD-UK Scientific Advisory Board (SAB). Also SDM to contact Elaine Murphy.</p>	SDM/LV
<p>B14: The term "spouse or partner" would be added to the full membership clause and junior membership deleted.</p>	Completed
<p>B15: Development Plan - AM/AW and JP to draft a proposal and circulate this to the Trustees. Following feedback this would be submitted to Genzyme.</p>	Completed
<p>B16: AP to write a paper on the role of external representative. This has now been withdrawn. The Board recognised that international liaison is still an important role undertaken by all officers as appropriate.</p>	Closed

5 Officer reports	ACTION
<p>Type 1 Coordinator's Report – Hugo Del Mar Due to other family and business commitments HDM intends to step down as from the 2010 annual conference. He feels that someone else would have more time to lead the Type 1 coordinator role. The Board thanks HDM for all his hard work over many years. The Board will think about a suitable replacement and report at next meeting. HDM indicated his willingness to remain as a Trustee of the Charity.</p>	
<p>Type 2 Coordinator's Report – Allan Muir The issue of the Intensivists role at Great Ormond Street Hospital and the withdrawal of treatment is still ongoing. A meeting in December was impacted by absence of the Manchester delegates due to bad weather. The meeting was followed up by some correspondence.</p> <p>C1: AM to monitor the situation at GOSH.</p>	AM
<p>The new film release of Extraordinary Measures – Genzyme are looking at venues for a special screening of the movie AM has contacted the films PR company and is approaching the film distribution companies to gauge interest.</p>	AM
<p>Type 3 Coordinator's Report – Luca Venditto LV discussed latest updates with heart thickening issue. AP will send LV latest papers on this subject.</p>	AP
<p>LV is to participate in a half marathon in Hastings which we will include in the Spring Newsletter along with the sponsorship link.</p>	KP
<p>Cycle to Italy – sponsorship through justgiving.co.uk must be individually set up by participants directly – LV reported that this is set for Easter 2011. Andy Fordham (Darts Player) is interested in participating. LV to update at next meeting.</p>	LV
<p>Type 5 Coordinator's Report Andrew Wakelin AW will be attending the 2010 AGSD US conference in Florida.</p> <p>AW is arranging a walk from north Wales to south Wales – it is not yet decided if this will be an AGSD-UK event due to insurance issues, but sponsorship will be in aid of AGSD-UK.</p> <p>C2: AW to consider the insurance of the Walk over Wales and report at next meeting.</p>	AW
<p>Treasurer's Report – Sue Del Mar SDM reported that the conference had an excess of around 2k thanks to charitable contributions. AW reported that the General Fund is the only money which is readily available and that funding policies must be agreed to allow the Charity to be able to grow and function.</p>	

10 Development Plan	ACTION								
<p>HDM proposed that that the Board should thank AW for doing a fantastic and thorough job in drafting the Development Plan. This was seconded by the Board.</p> <p>AW summarised the situation. Genzyme has pledged £120k over the next three years (subject to contracts being signed). Genzyme are likely to slowly withdraw support after three years so it is essential that the Board agree the necessary procedures quickly to capitalise on this period of external support.</p> <p>AW set out that the Charity has three types of funds;</p> <p>Restricted Funds – money pledged by supporters to certain types of GSD research Designated Funds – raised from sponsored events and designated to grant making (the trustees have the power to change this designation and report this via the newsletter). This includes the Vietnam and Costa Rica bike ride fund. General Funds – the only free reserves, which can be used as the Trustees think fit. This fund needs to be increased to underpin the operations of the charity.</p> <p>AW suggested that we publicize to the Charity that some of any Restricted Funds go into the general pot and asked that this could be agreed – outcome –</p> <p>HDM observed that the surplus in Grant Making fund is a reflection that insufficient projects have been put forward and supported (endorsed) by the AGSD-UK SAB.</p> <p>AW suggested that following stages are followed for the Board’s approval.</p> <p>PRIORITY 1 - appoint fund raiser A.S.A.P. 1 day a week suggested. LV is to be involved in the interview process.</p> <p>PRIORITY 2 - defer Development Officer appointment until July 2010</p> <p>PRIORITY 3 - recruit administrator after geographic location of Development Officer is known. This will allow the geographical location of the office to be known.</p> <p>Predicted financial performance of Business Plan on basis of above actions are as follows;</p> <table border="1" data-bbox="188 1205 1385 1323"> <thead> <tr> <th>2010</th> <th>2011</th> <th>2012</th> <th>2013</th> </tr> </thead> <tbody> <tr> <td>7K LOSS</td> <td>16K LOSS</td> <td>24k PROFIT</td> <td>Break Even[1]</td> </tr> </tbody> </table> <p>[1] – Genzyme grant finishes in 2012 but it is possible that it might be extended at a lower level.</p> <p>AW indicated that the financial success of the business plan success is based on allowing a change to the policy which allows all new donations to be split between general (60%) and (40%) research (the designated fund) – this Board agreed this change for fund raising activities. The Trustees agreed that the funds designated for “Grant Making” (currently standing at £89,173) be re-designated to be for “Support, Development and Grant Making” (SDGM). It was agreed that this was in line with the spirit of the promotional material and sponsorship forms which had been used when raising sponsorship through the two bike ride events.</p> <p>C3: SDM to adopt the designation “Support, Development and Grant Making” in the next accounts.</p>	2010	2011	2012	2013	7K LOSS	16K LOSS	24k PROFIT	Break Even[1]	<p>AW/LV</p>
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<p>The Trustees agreed to set aside a budget of £20k to underwrite the proposed Development Plan. Progress will be reviewed by the Board at each meeting.</p>	<p>SDM</p>								

11 Joint annual fund raising event	ACTION
<p>AM summarised the current situation regarding this development of an annual fund raising event. It is being considered by the lysosomal disorders charities and we are invited to join in. It was understood that a significant investment of would be required from the Associatoin but should return many times that amount. It was agreed it was worth exploring this option.</p> <p>C4: AM to update a paper on joint annual fund raising event for the next meeting.</p>	<p>AM</p>

<p>12 AGSD-UK Annual Conference 2010</p> <p>It had been agreed to tie up with the Pompe Steps Forward conference in order to get best attendance from professionals and overseas Pompe people at our conference. Although Manchester had been agreed there was now a proposed change in location to West London and the date to the end of November. AW proposed this is accepted by the Board to enable the two events to run concurrently and raise the international profile. The Board agreed to this proposal and insertion in the Spring Newsletter.</p> <p>Genzyme were offering additional funding to enable as many people as possible to attend at a low cost. AW to advise on what external support for families to attend is going to be available, details to follow on after issue of the newsletter.</p> <p>C5: The date and location of the AGSD-UK conference is to be advised as soon as possible to KP so that the Spring Newsletter can be finalised.</p>	<p>ACTION</p> <p>AW/KP</p>
<p>13 Funding Application Brian Biggar</p> <p>AM reported that Brian Biggar has made a request for funding of a research project. He originally asked for £45k, we offered £25k and his new application asks for a £30k investment. It was agreed that if approved the funding could be £10k from the Pompe fund and £20k from the SDGM fund. Agreed to put the funding application forward for technical approval by the ASGD-UK Scientific Advisory Board. If approved the funding could be awarded as above. The outcome is to be reported to the next Board meeting.</p> <p>C6: AM to collate information and put forward the Brian Biggar application to the SAB.</p>	<p>ACTION</p> <p>AM</p>
<p>10 Job Descriptions</p> <p>GSD Type Coordinator Role</p> <p>The Board agreed to final draft of the GSD Type Coordinator role which had been circulated.</p> <p>C7: AW is to include the overall objectives of the charity into the Job Descriptions. PP to assist in this.</p>	<p>ACTION</p> <p>AW/PP</p>
<p>11 Appointments</p> <p>Publications Monitor</p> <p>It was suggested that there was a useful role to monitor all available magazines, newsletters, research papers and other publications and be responsible for bringing relevant sections to the attention of GSD Coordinators and other officers as appropriate. Where material was useful for the AGSD-UK Newsletter, to obtain permission from the author and publisher and pass to the Newsletter Editor. The Board agreed to this new role and the appointment of AP.</p> <p>C8: AP to develop a job description for her role of publications monitor. PP to assist AP in this role.</p>	<p>ACTION</p> <p>AP/PP</p>
<p>12 Policies</p> <p>Rsearch Funding Policy</p> <p>CT summarized his draft policy proposal as outlined in the paper presented at the meeting.</p> <p>The Board all agreed that the draft was an excellent paper and a good starting point. To allow it to be developed further it was agreed that Conditions 2 and 4 could be extracted into a separate procedure called "Small Grants" for requests for funding below £500. It was also acknowledged that the procedures would be clearer to explain if they were presented in the form of a flow chart (or decision tree).</p> <p>C9: PP to help devise a decision flowchart.</p> <p>It was agreed that funding decisions should be carried out annually to enable prioritisation decisions to be made by the Board within the total amount available for grants. The Board should get feedback from the likely research bodies / academic bodies on what time of year most funding applications are made so that the Charity's policy and procedure can reflect this.</p>	<p>ACTION</p> <p>PP</p>

C10: LV to make enquiries of other charities grant schedules and report to CT/AW.	LV
C11: CT and AW to further develop the research grant making policy.	CT/AW
Expenses Policy Due to tie constraints consideration of the draft Expenses Policy was deferred until the next meeting.	

13 Data Protection	ACTION
A discussion on the need for adhering to Data Protection procedures was deferred until the next meeting.	

14 Patron and President	ACTION
AW suggested that consideration be given to instigating the positions of President and Patron of the Association to help raise our profile. This may be easier now that we have limited liability and an improved structure, policies and procedures. This was discussed and it was agreed that we should seek suitable individuals who would fit the criteria: <p>President – A well respected medical expert could be appointed to act as a figurehead and to assist in resolving any dispute at Board level. They might attend the Annual Conference, etc.</p> <p>Patron – Someone with a high profile with the public to assist with raising awareness through events, public relations and press events.</p>	
C12: AW to draft the roles of Patron and President.	AW
C13: All to consider contacts and possible names for Patron and President to be collated and discussed at a future meeting.	ALL

15 Any Other Business	ACTION
There was no other business.	

Date of next meeting – It was agreed to change the date of the next meeting to **24 April 2010** to avoid the May bank holiday weekend.

Meeting closed at 4.00 pm.

SUMMARY OF ACTION STATUS FOR NEXT MEETING

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B4: AW to investigate future conference venues.	AW
B7: AW to produce draft Treasurer, Chairman & Secretary descriptions.	AW
B12: AW to display employer's liability certificate on website and to circulate an executive summary of what is covered by the policy.	AW
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C2: AW to consider the insurance of the Walk over Wales and report at next meeting.	AW

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C7:	AW is to include the overall objectives of the charity into the Job Descriptions. PP to assist in this.	AW
C8:	AP to develop a job description for her role of publications monitor. PP to assist AP in this role.	AP
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