



AGSD

MEETING D

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held on Saturday 24th April 2010 - London

PRESENT Andrew Wakelin (AW), Chairman Sue Del Mar (SDM), Treasurer Allan Muir (AM)	IN ATTENDANCE Kate Phillips (KP), Secretary Luca Venditto (LV) Patrick Phillips (PP)	APOLOGIES Jayesh Pindolia (JP) Ann Phillips (AP) Clive Tonks (CT) Hugo Del Mar (HDM)
----------------------------------------------------------------------------------------------------	------------------------------------------------------------------------------------------------------	---------------------------------------------------------------------------------------------------------

1 Apologies for absence	ACTION
Apologies were received from Jayesh Pindolia, Hugo Del Mar, Clive Tonks and Ann Phillips.	

2 Chairman's Remarks	ACTION
AW apologised that due to business commitments he had struggled with meeting AGSD commitments in recent months.	

3 Minutes of previous meeting	ACTION
The minutes of Meeting C held on 10 February 2010 were accepted as a true record. A vote of thanks was passed to PP and KP for production of the minutes.	

4 Matters arising	ACTION
A4: Bank Account – still in progress with Lloyds. Andrew is leading this and will update at next meeting.	AW
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.	Completed
B13: LV and AW to develop an appropriate wording on Vitaflow for Type I and Type III patients.	Item 5
C1: AM to monitor the situation at GOSH.	Completed
C2: AW to consider the insurance of the Walk over Wales and report at next meeting.	Item 7
C3: SDM to adopt the designation "Support, Development and Grant Making" in the next accounts.	Completed
C4: AM to update a paper on joint annual fund raising event for the next meeting.	AM
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.	Completed
C6: AM to collate information and put forward the Brian Bigger application to the SAB. The application had been circulated, positive feedback received and approved.	Completed
C7: AW is to include the overall objectives of the charity into the Job Descriptions. PP to assist in this.	AW/PP
C8: AP to develop a job description for her role of publications monitor. PP to assist AP in this role.	AP/PP
C9: PP to help devise a decision flowchart on research applications.	PP
C10: LV to make enquiries of other charities grants schedules and report to CT/AW.	LV

C11: CT and AW to further develop the research grant making policy.	CT/AW
C12: AW to draft the roles of Patron and President.	AW

5 Officer Reports	ACTION
<p>Type 1 Coordinator's Report – Sue Del Mar SDM reported on HDM's behalf. There were a number of enquires and a steady flow of new registrations.</p> <p>Type 2 Coordinator's Report – Allan Muir Extraordinary Measures – the film showing was a mixed success with some local press coverage.</p> <p>Pompe Bulletin – the committee thanked Allan for the production of an excellent publication. The Association would aspire to this quality for all its publications.</p> <p>AM reported on a patient's experience with a vibration plate machine and will investigate with Dr Schosser who has pioneered its use in Germany.</p> <p>AM raised the MDC regional networking meetings and asked whether AGSD-UK could benefit from being more involved – the Trustees agreed that it was a good thing to encourage participation in this forum.</p> <p>Type 3 Coordinator's Report – Luca Venditto LV has seen an increase in requests for information regarding Vitaflow. In particular LV pointed out the existence of an adult metabolic information centre. LV reported on the current situation with Vitaflow - the association is not in a position to recommend the use of Vitaflow but wants to keep a relationship with them. The issue of formally approving Vitaflow remains.</p> <p>D1 LV to give update on Vitaflow at the next meeting.</p> <p>LV reported that due to the ongoing heart thickening issue his daughter Jodie's care will be under the cardiology department. LV noted that AP has some information on heart involvement.</p> <p>D2 AP to pass on Type 3 heart involvement information to LV so that he can pass this to the cardiologists.</p> <p>It was understood that AP had previously mentioned about a possible candidate for Type 3 Coordinator role.</p> <p>D3 AP to pass details of possible candidate for Type 3 Coordinator role to LV.</p> <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> <p>Italian Job, cycle ride to Italy – sponsorship through justgiving.co.uk can be individually set up by participants directly – LV reported that this is set for Easter 2011. Andy Fordham (darts player) is interested in participating which may help attract press coverage.</p> <p>Type 5 Coordinator's Report – Andrew Wakelin Vodafone grant has been completed by Dr Katherine Wright. The first draft is almost complete and AW reported this will have some editing.</p> <p>AW will be attending the 2010 AGSD U.S. conference in Florida in October.</p> <p>AW is arranging a walk from north Wales to south Wales – as awareness raising and fund raising.</p> <p>Treasurer's Report – Sue Del Mar SDM reported that income was £6670 above expenditure.</p> <p>Outgoings this period included the most significant costs will be the auditor and insurance</p>	<p>AM</p> <p>LV</p> <p>AP</p> <p>AP</p> <p>LV</p> <p>AW</p>

<p>AW reported on the details known to date 6 walkers – 230 miles (staggered) AW has agreed the PL insurance cover – and the event is attracting international interest including Australia who are looking to undertake virtual walks over Wales</p> <p>The paper was approved by the committee for LV to continue with preparations and fund raising.</p>	Closed
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------

<p>8 Update on Development Plan</p> <p>AW and AM reported that draft 4 of the development plan had been issued on 1 April and this had now been discussed with Genzyme. They were happy with the plan and were passing it to their legal department for preparation of a contract. No response as yet but their board meeting is on 20 June.</p>	ACTION
---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------

<p>9 Recruitment process for Development Officer</p> <p>AW reported that development officer role was being muted for a July start – initially applications will be invited through the membership.</p> <p>The committee agreed that the advert for the role can be issued but we need to make it clear it is <i>subject to funding</i>.</p> <p>Allan Muir was not part of this discussion.</p> <p>AW reported that he had checked with the Charity Commission and it was acceptable for a Trustee to apply for a paid role. They would only need to resign as a Trustee if successful in the application.</p> <p>The committee agreed on the formation of an appointments board comprising AW, SDM and PP who will assist in developing an interview and appointment process</p>	<p>ACTION</p> <p>AW/SDM/PP</p>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------

<p>10 Data Protection</p> <p>Deferred to be discussed at the next meeting.</p>	ACTION
---------------------------------------------------------------------------------------	--------

<p>11 Any other business</p> <p>KP reported that due to personal and work commitments she would like to stand down from the role of Secretary but will still assist in the production and editing of articles for the newsletters until a replacement is made. The committee thanked Kate for her help over the past year.</p> <p>PP volunteered to act in this capacity and to assist in minute taking and other duties as the Trustees require. The Trustees gratefully accepted and appointed PP as Secretary.</p> <p>There was no other business.</p>	ACTION
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------

Date of next meeting – Saturday 4 September 2010.

Meeting closed at 4.00 pm.