ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LTD

Company limited by guarantee no. 6981121. Registered Charity no. 1132271.

MEETING X

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 12.00 on Saturday 13th February 2016 Parking Eye, Chorley, Lancashire, PR7 7NA



PRESENT	IN ATTENDANCE	APOLOGIES
Mike Porter, Chairman (MP)	Allan Muir, Development Director (AM)	
Stuart Alderson (SA)	Ian Harrison (IH) (part)	
Jayesh Pindolia (JP)		
Shaun Griffin (SG)		

1 Chairman's Remarks

The Chairman (MP) welcomed everyone to the meeting. Following the last trustee meeting in Bedfordshire Wendy Bascal had tendered her resignation as a trustee. Appointment in new full time job left Wendy feeling that she could no longer commit to her obligations as a trustee. MP would like to place on record thanks to Wendy for her support to AGSD-UK.

2 Minutes of the previous meeting		
The minutes of meeting W from 5 th October 2015 were taken as read.		
ACTION	BY WHOM	DATE

3 Matters arising from the previous meeting

U6: - C/F. Review viability of implementing a cost code allocation system via Sage - SG/AM

U9: - C/F. Review of current DD Role - MP/AM

U10:- C/F. Hold DD performance review - MP/AM

U11: - C/F. Produce schedule of activities for MAB TOR's and schedule for reviving newly constituted

MAB. - AM/MP

U29: - C/F. Ensure GSD Giant fundraisers are recognised in next edition of Glisten - AM

V11: - C/F. Identify and approach Caldecott Guardian from MAB – MP/AM

V17: - C/F. Request latest UK GSD prevalence numbers from Simon Heales – AM

W1: - Closed

W2: - Complete

W3: - Complete

W4: - Closed

W5: - Complete

W6: - Complete

W7: - Complete

W8: - Complete

ACTION	BY WHOM	DATE

4 Development Director's Report

The DD talked the trustees through his report of activities since the last meeting and forthcoming activities.

ACTION	BY WHOM	DATE
X1: Keep trustees informed on progress of building work at preferred conference venue. Ensure the venue is configured to improve on previous year's venue and book and after dinner speaker.	AM	30/06
X2: Trustees agreed a hardship grant application of £300.00 towards a wheelchair repair.		
X3: Agree which stakeholder pension scheme should be implemented for AGSD-UK employees.	SG/AM	28/02
X4: Trustees agreed that the Pompe SCA position should be a four day week role. Shortfall in funding to be covered by additional grants from other industry partners but underwritten in year 1 by the Pompe restricted funds.		

5 Updated Financial Position/Fundraising

SG talked the trustees through the updated financial position which in summary was for the 10 months so far in the financial year at break even point.

The Bake or Burn fundraising campaign was agreed in principle.

ACTION	BY WHOM	DATE
X5: 2015/16 year end financial position to be reviewed at next trustee meeting.	SG/AM	
X6: Produce draft 2016/2017 budget/business plan for next trustee meeting.	SG	
X7: Send copy of the 2014/2015 finalised year end accounts to the office.	MP	28/02
X8: Come up with a solution for GSD Giant	AM/JP	30/06
X9: Build pipeline of potential candidates to support submission of smaller grants to charitable trusts and foundations	AM	Ongoing

6 Procedures/Operations Manual

IH provided an overview on the NHS Information Governance (IG) Toolkit to the trustees and AM.

ACTION	BY WHOM	DATE
X10: Agreed to appoint SW as the charity's Senior Information Risk Owner (SIRO) and IH as the Charity's Security Officer. These appointments need to be incorporated in our Operations Manual.	SW	30/06
X11: Other items with regard to NHS IG to be considered for inclusion into the Operations manual include: staff vetting; trustee vetting; web security review, security breach reporting and data protection scope review.	SW	Ongoing

X12: Undertake IG Toolkit registration	IH	Next Mtg
X13: Add IG (quarterly) and Web Security Review (annual) to Rolling Review schedule	MP	Next Mtg

7 Website Update

Due to eye injury to senior user (Andrew Wakelin) progress on gathering user requirements has been delayed.

ACTION	BY WHOM	WHEN
X14: Continue with gathering/developing user requirements.	SW	Ongoing

8 Trustee Training

AM circulated a paper from the FSI who were awarded funding from the cabinet office to expand training, advice and support for small charities in England.

ACTION	BY WHOM	DATE
X15: Individual trustees to identify appropriate training courses to attend. Review of training is part of Rolling Review schedule.	All	Ongoing

9 Any Other Business

Succession planning was discussed and a practical plan should be developed for both permanent members of staff, Type Co-ordinators and trustees.

It was agreed to raise membership fees to £15.00

Next meeting venue to be in London.

ACTION	BY WHOM	WHEN
X16: Develop outline approach to succession planning.	MP/AM	31/12
X17: Details of revised annual membership fees to be presented at next AGM.	MP	31/10
X18: Circulate details of London Trustee meeting venue	JP	31/03

The meeting closed at 16.30pm.