#### ASSOCIATION FOR GLYCOGEN STORAGE DISEASE (UK) LTD

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

MEETING Y

## MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 12.00 on Saturday 3rd September 2016 Parking Eye, Chorley, Lancashire, PR7 7NA



PRESENT	IN ATTENDANCE	APOLOGIES	
Mike Porter, Chairman (MP)	Allan Muir, Development Director (AM)		
Stuart Alderson (SA)			
Jayesh Pindolia (JP)			
Shaun Griffin (SG)			
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#### 1 Chairman's Remarks

The Chairman (MP) welcomed everyone to the meeting, remarking that we have a busy agenda not least because it had been 6 months since the previous meeting.

Since the last meeting we received confirmation back from the Big Lottery Fund (BLF) that we had not been successful in our application. The BLF do not provide feedback on their decision however it could be for any number of reasons including but not limited to: already/recently given funds to a similar charity/cause, different criteria applied by different reviewing panels. Notwithstanding it was felt that we submitted a good application and we are not precluded from submitting again in the future.

MP apologised to SA for assigning the wrong initials to him in the last minutes (minutes X).

It was planned to have both Jane Lewthwaite and Vanessa Casey attend the meeting but following a discussion with AM it was felt that as we were so close to the conference we should invite them to the trustee meeting held at the conference.

MP reaffirmed the desire to recruit new additional trustees, particularly individuals who are sufferers from a GSD condition. On the same subject there is an individual (father of a sufferer) who has expressed an interest in joining the trustees.

2 Minutes of the previous meeting		
The minutes of meeting W from 13 <sup>th</sup> February were taken as read.		
ACTION	BY WHOM	DATE

#### 3 Matters arising from the previous meeting

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

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

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

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

U29: - Closed

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

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

X1: - Closed

X2: - Complete

X3: - Complete

X4: - Closed

X5: - Complete

X6: - Complete

X7: - Complete

X8: - Closed

X9: - Closed

X10: - On Agenda

X11: - On Agenda

X12: - Undertake IG Toolkit Registration - IH - C/F

X13: - Complete

X14: - Closed

X15: - Closed

X16: - Develop outline approach to succession planning - MP/AM - C/F

X17: - Closed

X18: - Closed

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
Y1: Change wording in Meetings & Conferences section to reflect that IMD Scotland Patient Day will be attended by the AGSD-UK Chairman and a PST member.	AM	14/10
Y2: Agreed to add succession planning process to the Operations Manual and to the Rolling Review Schedule	MP/SA	31/12
Y3: Circulate updated Rolling Review Schedule	MP	14/10
Y4: Continue dialogue with BioMarin and keep trustees updated	AM	Ongoing
Y5: - Develop a draft database for SCA to populate with appropriate metrics	SA/JL	31/12

# 5 Updated Financial Position/Fundraising

SG talked the trustees through the updated financial position and circulated an updated financial document.

MP presented a draft budget document for 2016/17 - 2018/19 period.

The draft accounts for 2015/16 have not yet been completed by Crowe Clark Whitewell.

The external fundraising consultant (KC) has submitted to-date 35 applications with a total value of £172,000.

Trustees agreed to adopt the 2016/17 - 2018/19 draft budget developed by MP/SG

ACTION	BY WHOM	DATE
Y6: Trustees agreed to adopt the draft 2016/17 – 2018/19 budget. Copy to be circulated to Trustees and AM.	MP/SG	14/10
Y7: Chase accountants for draft accounts	SG	16/09
Y8: Hold call to discuss draft accounts	SG/MP	13/10
Y9: Write Charity Directors words for Statutory Accounts	AM	31/10
Y10: Ask KC to extend her monthly report to include grant criteria and also to copy all submissions into Dropbox	АМ	31/10
Y11: Review KC contract at end of current period	Trustees/ AM	31/10
Y12: - Jane Lewthwaite to contact JP to discuss/agree corporate fundraising contacts	AM/JL/JP	31/10
Y13: - Circulate updated Pipeline report to Trustees	AM	31/10

### **6 Conference Programme**

AM provided an update on the conference programme. Some of the speakers have not yet confirmed attendance. As usual the final program will remain fluid until the last minute.

AM had received a request from a member to video the Type 3 workshop in order that it could be shared via social media.

ACTION	BY WHOM	DATE
Y14: The Trustees declined a request to video the Type 3 workshop. Requester to be informed of decision and rationale – issues of quality and privacy	AM	14/10

## 7 Operations Manual

SW updated the meeting on development of Operations Manual. Further meaningful progress will not be made until the IT infrastructure project is delivered.

ACTION	BY WHOM	WHEN
Y15: Set up training records and add to Operations Manual	SA	31/12
Y16: - Speak to Andrew Wakelin re CRB and risk assessment	AM	31/10

Y17: - Forward NSPCC training link to JP and SG. MP and JP to undertake	MP/JP	31/12
training		

# **8 Any Other Business**

MP asked if all trustees had received a copy of the Animal Aid letter and brochure. It was agreed that AGSD-UK do not currently fund any research using animals.

Next meeting venue – Tortworth Court, Glos.

ACTION	BY WHOM	DATE
Y18: No action required with regard to Animal Aid.		

The meeting closed at 16.00pm.