



MEETING Z

MINUTES OF A MEETING OF THE BOARD OF TRUSTEES

Held at 19.30 on Friday 14th October 2016

At Tortworth Court Hotel, Wooten-under-Edge, Gloucester, GL12 8HH

<p>PRESENT Mike Porter, Chairman (MP) Jayesh Pindolia (JP)</p>	<p>IN ATTENDANCE Allan Muir, Development Director (AM) Jane Lewthwaite</p>	<p>APOLOGIES Stuart Alderson Shaun Griffin</p>
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<p>1 Chairman's Remarks</p>
<p>The Chairman (MP) welcomed everyone to the meeting. As this meeting was being held on the eve of the annual conference and two of the four trustees were not in attendance it would be a relatively short meeting.</p>

<p>2 Minutes of the previous meeting</p>						
<p>With the exception of a typo on item 2 (should have stated minutes of meeting X – not W) the minutes of meeting Y from 3rd September were taken as read.</p>						
<table border="1"> <thead> <tr> <th data-bbox="177 952 1177 1014">ACTION</th> <th data-bbox="1177 952 1342 1014">BY WHOM</th> <th data-bbox="1342 952 1460 1014">DATE</th> </tr> </thead> <tbody> <tr> <td data-bbox="177 1014 1177 1070"> </td> <td data-bbox="1177 1014 1342 1070"> </td> <td data-bbox="1342 1014 1460 1070"> </td> </tr> </tbody> </table>	ACTION	BY WHOM	DATE			
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<p>3 Matters arising from the previous meeting</p>
<p>U6: - Review viability of implementing a cost code allocation system via Sage – SG/AM – C/F</p> <p>U9: - Review of current DD Role – MP/AM – C/F</p> <p>U10:- Hold DD performance review – MP/AM – C/F</p> <p>U11: - Produce schedule of activities for MAB TOR's and schedule for reviving newly constituted MAB. – AM/MP – C/F</p> <p>V11: - Identify and approach Caldecott Guardian from MAB – MP/AM – C/F</p> <p>V17: - Request latest UK GSD prevalence numbers from Simon Heales – AM – C/F</p> <p>X10: - Appointment of SA as SIRO to be documented in operations manual – C/F</p> <p>X11: - Items from NHS IG to be considered for inclusion into operations manual to include: staff vetting, trustee vetting, web security review, security breach reporting and data protection scope review – C/F</p> <p>X12: - Undertake IG Toolkit Registration – IH - C/F</p> <p>X16: - Develop outline approach to succession planning – MP/AM – C/F</p> <p>Y1: - Complete</p> <p>Y2: - Complete</p> <p>Y3: - Complete</p> <p>Y4: - Closed</p>

Y5: - Develop draft database and populate with appropriate metrics – SA/MP/AM/JL/Andrew Wakelin – Ongoing

Y6: - Complete

Y7: - Complete

Y8: - Complete

Y9: - Write words for inclusion in statutory accounts – AM – C/F

Y10: - Ask KC to extend monthly report to include grant criteria and to copy all submissions into dropbox – AM – C/F

Y11: - Complete

Y12: - Complete

Y13: - Circulate updated pipeline report to trustees – AM – C/F

Y14: - Closed

Y15: - Set up training records and add to operations manual (31/12) – SA – C/F

Y16: - Speak to Andrew Wakelin re CRB check and risk assessment – AM – C/F

Y17: - Forward NSPCC training link to JP and SG. MP and JP to undertake training – MP/JP – C/F

Y18: - Closed

ACTION	BY WHOM	DATE

4 Charity Director's Report

The Charity Directors report is incorporated into the annual review to be presented at the conference. AM updated the meeting with regard to ongoing discussions with BioMarin about their withdrawal from the drug trial.

ACTION	BY WHOM	DATE
Z1: Present annual review at conference plenary session.	AM	16/10

5 Updated Financial Position/Fundraising

MP updated the meeting about the draft statutory accounts for 2015/16 which were to be presented at the AGM.

JP briefed the meeting about a fundraising idea undertaken by his wife – Yoga Sun Salutations.

Fundraising champions/ideas were discussed.

ACTION	BY WHOM	DATE
Z2: Draft statutory accounts to be presented at AGM	MP	16/10
Z3: Fundraising champions/ideas to be acknowledged at conference	AM	16/10

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6 Conference Programme		
AM provided updated the meeting about the final conference programme.		
As a number of industry partners were attending the meeting MP stated the need to be consistent in our key messages when any of the trustees and AM/JL were in dialogue with them over the conference weekend.		
ACTION	BY WHOM	DATE
Z4: Key messages to be delivered consistently	ALL	15/16/10

7 Any Other Business		
MP briefed the meeting on his discussions with a potential new trustee (Phil Prosser). It was agreed that Phil would be co-opted onto the trustee board from January in order that he could attend as a co-opted member through to the 2017 conference when he would be better placed to decide if he would formally like to stand at the AGM.		
MP informed the meeting that our selected Web Design company (Fusing Creativity) would be presenting to the type co-ordinators meeting on Saturday morning. The aim was to agree the process by which an interactive approach to developing our new web site would be implemented utilising the type co-ordinators as a focus group.		
ACTION	BY WHOM	WHEN
Z5: Invite Phil to the January trustee meeting	MP	31/12
Z6: -Type Co-ordinators to agree approach with Fusing Creativity	TC's/FC	15/10

The meeting closed at 8.30pm.