

# Minutes of the 2015 Annual General Meeting of DBA-UK

Held on Sunday 17<sup>th</sup> May 2015 at

Caythorpe Court, Caythorpe Heath Lane, Caythorpe, Grantham, Lincolnshire

## 1. Open

Peter Redmond opened the Annual General Meeting of DBA-UK as Chair of the meeting.

## 2. Approval of Minutes – 2014 AGM

The minutes of the previous AGM were not ratified as this was not raised, it must be done in next year's AGM.

## 3. Chair's Report

Leisa Batkin presented a list of objectives for the year to date, explaining their status as follows -

Ref	Activity Description	Original Proposed Owner	Comments	Perceived monetary costs
1	Increase visibility worldwide for DBA UK	Committee	Achieved/Ongoing	
2	Maintain links Camp Sunshine	Leisa	Achieved/Ongoing	
3	To establish links with UK charities to offer holiday breaks to families	Leisa	Achieved/Ongoing	
4	To invest in a family directory	Family lead with committee support	Action Required	
5	To maintain the Adult only conference	Hayley	Achieved/Ongoing	
6	To maintain the family conference	Committee	Achieved/Ongoing	
7	To develop a link with disability rights	Committee	Action Required	
8	To become more visible on social media	Kieran	Achieved/Ongoing	
9	To keep families more updated on committee workings	Leisa/Kieran	Achieved/Ongoing	
10	To increase fundraising capability and provide direct support to big events	Martin	Action Required	
11	To provide best practice policy fro events with £5-10k return	Martin	Action Required	
12	To provide merchandise on a as required basis	Martin	Achieved/Ongoing	
13	To set an online shop for the charity	Kieran	Achieved/Ongoing	
14	For each committee member to have a specific role in the committee	Leisa	Achieved/Ongoing	
15	To establish better communication with DBA medic lead	Leisa	Achieved/Ongoing	
16	To establish other ways to raise finance	Martin	Achieved/Ongoing	
17	To fund research following a proposal	Committee	Achieved/Ongoing	
18	To offer merchandise on line	Kieran	Achieved/Ongoing	
19	To consider extending Family event over 3 full days	Committee	Action Required	
20	To fund international conferences	Committee	Achieved/Ongoing	
21	To invite named nurses to conference for 1/2 day networking	Committee	Action Required	

22	To ratify DBAUK pamphlet and distribute nationally	Martin/Kieran	Action Required
23	To keep care pathway live	Committee with Medic support	Achieved/Ongoing
24	Gimme 5 for DBA UK	Committee	Action Required
25	Maintain finances in good state	Pete	Achieved/Ongoing
26	Maintain Skype conference calls	Leisa/Kieran	Achieved/Ongoing
27	Maintain email links within the committee	Committee	Achieved/Ongoing
28	Commence regional support groups	Committee	Action Required
29	To have a lead committee member for welfare rights	Committee	Action Required
30	To have a lead member for educational support	Committee	Action Required

Leisa Batkin reminds families to fill in feedback form as this is critical for us to plan future conferences with and discusses the following points in further detail -

Leisa discusses that Dawn from DBAF allows us to send two families to Camp Sunshine every other year when it is held. Two families have been selected from this year's entries and will report back next year regarding their experiences. We will then look for a further two families to attend the 2017 Camp Sunshine in due course.

Regarding the patient registry that is often discussed, currently DBA UK holds demographic data and Dr De La Fuente holds the clinical data.

Leisa also mentions that from a huge £80,000 target last year, we have done extremely well to raise £63,911.

It is then opened up to our families regarding a potential shift to a Bank Holiday weekend for the next year but we will have to gauge feedback to see if it is worth extending for better breaks and smoother structure. There is an early and late Bank Holiday in May so we can consider both.

Leisa then considers two things for future meetings, a special 'grandparents' Family Weekend every few years to extend the support offered by the charity and a spate 'teen' session on the agenda next year with it's own speaker(s) and adult patient assistance to help the transition between child and adult care.

Leisa also stresses the fact that key research spends have been made this year and this further highlights the need for fundraising. The report was accepted by the meeting.

#### 4. Treasurer's Report

Peter Redmond reported financial figures for 2014 as follows -

Income for 2014	Amount £	Expenditure for 2014	Amount £
Fundraising	17,678	Merchandise, Printing & Postage	7,515
Donations	11,401	Fundraising Event Registration	3,203
Just Giving Online Payments	26,466	Charity Administration	1,428
<b>Paypal</b>	<b>548</b>	Bank Charges including Bankline	555
CAF Donation	297	Just Giving Monthly Charges	216
Charities Trust Payments	255	Annual Subscriptions	190
The Giving Machine	58	Research Projects	50,000
Gift Aid	5,407	ICC Atlanta 2014	13,312
Bequests	738	Charitable Contributions	460
Sale of DBA merchandise	294	Euro DBA Conference 2014	353
Collection Boxes	654	Family Weekend 2014	16,979
Bank Interest	114	Family Weekend 2015 (deposit)	5,610
		Adult Conference 2014	5,211
<b>Total Income £</b>	<b>63,911</b>	<b>Total Expenditure £</b>	<b>105,032</b>

#### Summary of Cash Accounts for 2014

Income for 2014	Amount £
Fundraising & Donations	56,704
Gift Aid	5,407
Bequests	738
Sale of DBA merchandise	294
Collection Boxes	654
Bank Interest	114
<b>Total Income £</b>	<b>63,911</b>

RBS Bank Account Summary	£
Opening Balance on 01/01/13	243,127
* Total Income including Bank Interest	63,363
Total Expenditure	-105,032
Calculated Balance	201,457
Closing Balance on 31/12/14	200,964
** Uncleared Income at 31/12/14	493
Closing Balance + Uncleared Funds	201,457

\* Not including Paypal Account

\*\* 2 number cheques paid into account on 31st December 2014

Expenditure for 2014	Amount £
Research & Charitable Contributions	64,125
Charity Administration & Operating Costs	13,108
Family Weekend 2014	16,979
Family Weekend 2015 (deposit)	5,610
Adult Conference 2014	5,211
<b>Total Expenditure £</b>	<b>105,032</b>

Accounts Summary	£
RBS Bank Savings Account	200,964
Uncleared Income	493
Paypal Account Online	548
<b>Total cash at 31<sup>st</sup> Dec 2014</b>	<b>£ 202,005</b>

Peter stresses that Just Giving is a key source of income for us and as such is worth the fees, particularly based on the extra Gift Aid available to us, compared to the lengthy process of claiming it manually. This current year we have spent more than we have brought in but that we are spending it in the right places, if anyone needs to question this or suggest better ideas, we are open to suggestions. We have had two key research expenditures this past year which have been very promising and interesting paths.

It is also important to offer ongoing support for the Family Weekend and as such we aim to ring fence funds for three years which is around £80k

The report was accepted by the meeting.

## 5. Elections

Kieran Teasdale opened the elections, confirming that self-nominations must have been received 14 days prior to the AGM.

As per constitution, the following people have stepped down – Peter Redmond, Alison Micklethwaite, Jennifer Hamshere, Joe Fletcher.

The currently existing committee members who have not stepped down remain on the committee – Kieran Teasdale, Leisa Batkin, Jayson Whittaker, Martin Winter, Hayley Teasdale, Sam Robinson and June Kynoch.

Elections onto the committee then took place for the open places.

Peter Redmond offers to stand again –

*Proposed – Kieran Teasdale*

*Seconded – Allan Webb*

James Dent, Stacey Skepper, Helen Till and Paul Hubbard have self-nominated to join the committee as per the constitution –

*Proposed – Peter Redmond*

*Seconded – Jenifer Hamshere*

## 6. Any Other Business

Peter again raises that the cost of conference per person is approximately £120 per person and any contributions towards this are greatly welcomed. In order to protect future conferences, approx. £30,000 needs to be ring-fenced for each year's Family Weekend.

The AGM was then closed.