

Minutes of the 2010 Annual General Meeting of DBA-UK

held on Sunday 23rd May 2010 at

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

1. Open

Stuart Graham opened the Annual General Meeting of DBA-UK.

2. Approval of Minutes – AGM 2009

Stuart Graham asked if all members present were in agreement with the Minutes from the 2009 AGM. He confirmed that the Minutes had been published as part of the 2009 post-conference newsletter and emailed to all members of DBA-UK as well as posted on the DBA-UK website. The Minutes were approved and agreed to be a true representation of the meeting.

Proposed: J. Whitaker

Seconded: S. Allen

3. Chairman's report

Stuart Graham presented an overview of the past year for DBA-UK.

He began by saying that it had been an encouraging year, and although slow going at times a lot of preparation work had been undertaken and there was a lot ahead to look forward to. He also confirmed that finances were in great shape.

Stuart reminded all members of the objectives of the charity and its constitution. The Association is established:

- For the relief of sickness of those suffering either directly or indirectly from DiamondBlackfan Anaemia (DBA), and associated conditions.
- To educate the general public through promotion of research and the dissemination of knowledge about Diamond Blackfan Anaemia (DBA).

He discussed how the charity sometimes funds research, holds the conference and funds other initiatives and activities as deemed appropriate by members and the committee. He invited members to contribute with other ideas they felt the charity should be supporting. Suggestions included:

- time spent educating doctors and GPs about DBA as well as the general public
- the need for a professional medical network
- more information materials such as leaflets
- an NHS standard of care document

Building relationships

Stuart reported on the links DBA-UK had been building with medical professionals and groups over the year. He said he and the committee had been talking to lots of people, notably Dr Josu de la Fuente with whom DBA-UK had held regular meetings and planned to continue doing so going forward. He also said he had had some dialogue with

Jeff Lipton (leading DBA consultant in the US) and Sarah Ball who continues to provide support on the periphery.

Stuart gave details of other groups that DBA-UK had established links with over the year:

- UK Thalassaemia Society – Thalassaemia has a lot more critical mass than DBA in the UK, with 10 times more patients. The charity actually has permanent staff working for them. By establishing links with them Stuart expressed his hopes for sharing ideas and gaining some insight into how DBA-UK can up its game.
- Fanconi Hope – Stuart said he had been speaking to Thomas Carroll at Fanconi Hope, who's son and family had featured in a recent BBC documentary ('Having a baby to save my child'). Once again Stuart said he hoped by building a relationship that DBA-UK and Fanconi Hope could share ideas and work together to see if there were any synergies.
- Genetic Alliance UK – Stuart explained that this is a national charity of over 130 patient organisations supporting all those affected by genetic conditions. DBA-UK pays £90 a year to be a member of this umbrella organisation, and hopes that they might help represent DBA-UK with bigger bodies such as the HFEA (Human Fertilisation and Embryology Authority) and NICE (National Institute for Health and Clinical Excellence).

Stuart confirmed that DBA-UK was now on both these organisations' radars which he felt was a positive step, since these are professional bodies with whom DBA-UK needs to engage with. He described how the NICE had the power to stop and start the NHS providing certain medication in England. He said that a review of Desferel and Exjade was being planned by the NICE but that DBA had now been taken off the agenda and it was now just a review for Thalassaemia. Dr Josu de la Fuente commented at this point that the NICE did not cover Scotland which has a dissolved system for healthcare. For those DBA families in Scotland he said it was important that we find out what other organisation may be relevant to them.

- DBA patient group – Stuart said he has been in contact with representatives from the US, Canadian, Italian and Australian groups who he had hoped would be present at this year's conference but unfortunately were unable to attend at short notice largely due to travel restrictions brought about by the Icelandic ash cloud.

Stuart asked all those attending the meeting to contact him if they could think of any more charities or professional bodies that they felt DBA-UK should be talking to.

Communication

Stuart talked about how DBA-UK had been communicating as a charity over the year:

- Newsletters – Stuart confirmed there had been 3 since last year's AGM and conference, and plans were underway to improve on this number over the coming year
- Conference – Stuart encouraged all members to give their feedback on the event, either verbally at the open forum session or in writing on the feedback forms that were to be distributed at the end of the AGM
- DBA-UK website

- Local meetings – Stuart talked about the informal get together in London he had initiated, and said he was keen to see more regional gatherings organised throughout the year. He encouraged members to consider organising their own meetings, and suggested that the charity was there to support such initiatives and might be able to subsidise any meet-ups.
- Member-to-member communication – Stuart reminded everyone of the discussion forum on the DBA-UK website and the yahoo group that many people used. Also the DBA facebook group was mentioned.

Committee priorities 2010/2011

Stuart outlined key agenda items for the year ahead. These included:

- Medical Research – Stuart said a funding pitch had been received, but it was slow going and needed to be well specified before any work could begin. Stuart said he had been surprised by how joined up discussions had been between all the doctors around the world on this. He took the opportunity to thank Josu de la Fuente for all his help with this to date, and said he hoped DBA-UK would be able to start funding some research soon, potentially in collaboration with the US.
- Standard of Care Document – Stuart stressed his commitment to this and the importance of having one for all consultants and medical. He explained that it was not a legal document but a set of guidelines describing all about the condition and how to treat it. He described it as less science and more practical treatment. Stuart confirmed that Thalassaemia already have a Standard of Care Document. He said these are very big (approx 120 pages long) and involve a lot of work from lots of people in the medical community – doctors, consultants, pharmacists, gastro enterologists etc. He stressed that this was going to be a tough job and would likely take a couple of years to pull together, but that the process itself would be beneficial by getting senior medical people together to talk and provide consensus. Stuart said that it really required somebody to facilitate it from the outset, since as a voluntary based charity DBA-UK were prohibited. Despite the obstacles Stuart expressed his commitment to helping make this happen over the next few years.

Governance

Stuart said he felt this had improved over the past year. He explained how the Committee meet every 3 weeks on Skype, and how better roles and responsibilities had been scoped over the year which he hoped to make further improvements on during the year ahead.

Stuart reminded all those present how to contact anyone at DBA via the website (<http://www.diamondblackfan.org.uk>) or by the phone number (0845 094 1548) which goes through to one of the Committee members. He also mentioned the facebook group (DBA UK and Diamond Blackfan Anaemia in the UK) and yahoo groups (DBA-UK and Blackfan (US)).

Stuart closed the chairman's report and contact details and 'permissions' forms as well as feedback forms were distributed for all those attending to complete.

4. Treasurers Report

The Treasurers Report was delivered by Alan Dewick who provided figures for 2008 to use as a comparison. He then gave the figures for 2009 which were as follows :

Accounts 2009		
Income	£	£
Great North Run	17,218.81	
Coast-2-Coast Cycle	5,004.50	
Other Runs	3,051.00	
Conference	3,020.00	
Legacy	3,161.45	
Gift Aid	3,357.97	
Other	10,066.42	
		44,880.15
Cost of fundraising		
JustGiving Fees	1,654.63	
GNR Entry & T Shirts	1,707.86	
		3,362.49
Net income		41,517.66
Expenditure		
Printing & Postage	491.89	
Other	20.00	
Conference 2009	11,644.19	
		12,156.08
Excess for year		29,361.58

With a profit of £29,361.58, Alan confirmed that it had been a great year. He drew attention to the significant increase in fundraising income, thanking everyone involved for their efforts, in particular the Redmond family for the incredible amount they raised doing the Great North Run. The report was accepted by the meeting.

Alan then showed figures for DBA-UK's bank balance, standing at £125,994.40. He said this looked very healthy, but that costs for this year's conference needed to be accounted for here as well as any future plans to contribute to research projects as presented by Dr Josu de la Fuente. He also highlighted that interest earned had been incredibly low over the year due to bank interest rates being so poor. He discussed the possibility of moving money into Bonds to get a better interest return, but stressed this had limitations in terms of tying up funds with no instant access facility, which could be problematic when needing to pay for research projects once they have been approved.

5. Elections

Jayson Whitaker opened the elections stating that they were being run by constitution which meant anyone wishing to self elect was required to have given at least 14 days notice prior to the AGM. He mentioned that a few committee members had expressed their disappointment in not being able to re-elect themselves having missed the deadline. However Jayson re-iterated that the deadline had been communicated to everyone in the Spring newsletter and in some of the pre-conference information that was sent out. Vilma

Reid queried this and her and Jayson agreed to discuss this issue in further detail outside the meeting. The elections proceeded as follows:

Election of a trustee:

John Carty – stood down this year and was re-elected

Proposed – J. Whitaker

Seconded – A. Dewick

Election of secretary from trustees:

John Carty

Proposed – J. Whitaker

Seconded – A. Dewick

Election of treasurer from trustees:

Alan Dewick

Proposed – J. Whitaker

Seconded – R. Dewick

Election of committee:

Stuart Graham

Steve Moore-Haines

Sarah Allen

Matt Filer

Jennifer Corcoran

June Kynoch

Joe Fletcher

Election of Chairperson from remaining committee and trustees:

Stuart Graham

Proposed – J. Whitaker

Seconded – N. Dewick

Election of Deputy Chairperson from remaining committee and trustees:

Steve Moore-Haines

Proposed – J. Fletcher

Seconded – S. Graham

Non-elected 'volunteer' roles:

Jane McCarthy – parent contact

Michelle Whitaker – conference coordinator

The AGM was closed at the end of the elections.