



MINUTES OF THE BATTEN DISEASE FAMILY ASSOCIATION

ANNUAL GENERAL MEETING

Held at the Crowne Plaza Hotel, Bridgefoot, Stratford-upon-Avon, CV37 6YR

on Saturday 25th November 2017 at 10am

1. Introduction and welcome - Michael O'Connor (BDFA Chair of Trustees)

The Chair of Trustees welcomed everyone to the conference. He reflected that numbers attending and the conference itself seem amazing this year and how wonderful it is to see this, and the impact the BDFA has had, over the 5 years he has been involved. He thanked the BDFA team for all their hard work in bringing this together.

2. BDFA 2016/17 Review of the year – Andrea West (BDFA CEO)

The CEO advised that 2018 will be the BDFA's twentieth anniversary year. At the same time there is fantastic news of a first ever treatment for CLN2 disease. This has occurred because of the Batten community which should be very proud of itself. However, the treatment is, as yet, not paid for in the UK for children currently being diagnosed. The BDFA has a key role to advocate for these children. NHS Wales has agreed to pay for a child and the BDFA is working with NHS England and NICE to achieve this in England too.

The CEO listed other achievements of the BDFA in 2016/17 as:

- continued funding of the only Batten Disease Clinical Nurse Specialist in the UK
- funding of a PhD studentship funding and delivery of the BATCure project
- funding of projects in collaboration with family foundations
- increasing BDFA services for support and education advocacy
- increasing the profile of Batten disease with Government, NHS and legislators
- increasing funding and partnerships to underpin the work of the BDFA

Plans for 2017/18 include:

- further high quality research
- accessible treatment for CLN2
- more accessible services where they are needed
- increased support and education advocacy

The CEO advised that the BDFA operates on the shoulders of giants. It works for every parent and carer now and who have gone before, for every child and family who fights the disease, but cannot do this alone. There are increasing challenges to continue to fund our services and it is important that the Batten community works together for this. The CEO thanked everyone for the last 20 years and encouraged all to make sure we can continue to make a difference in the future.

3. Treasurer's 2016/17 report and future budget – Roger Cole (BDFa Treasurer)

For the year ending 31 August 2017, income was £340,000 and expenditure £345,000. The deficit refers to use of restricted funds and is therefore not an overspend. The Treasurer expressed gratitude to all the BDFa's amazing fundraisers. More and more families are approaching the BDFa and increased funding is necessary to support them.

Income is from two sources – restricted (what it can be spent on is defined by donors) and unrestricted. Restricted income has increased and unrestricted income has decreased and this is problematic for gaining income from Trusts and Foundations which could be a significant source of income. He stressed that moving forward it is necessary to increase the BDFa's unrestricted reserves which are necessary for operating costs, advocacy, support and education services.

Monthly donations to the BDFa have not increased and all present were encouraged to set up a regular donation to the BDFa including Gift Aid if possible. The Treasurer advised that the other significant area of revenue is pharmaceutical companies and that for reasons of impartiality it is important that we benefit from more than just BioMarin.

The Treasurer concluded that the BDFa is financially in good shape but the increase in demand for family support means more unrestricted funds are needed.

Pauline Docherty asked whether restricted funds can be used for research and what the plans were to use this up to access other funding. The CEO advised that some restricted funding is already allocated and that family foundations are looking at how they wish their restricted funds to be spent. It was stressed that the money has to be actually spent on research and that allocation for the future is not enough.

4. Ordinary Resolutions

- a. **Resolution 1:** the minutes of the 2016 AGM be adopted as a true record of that meeting.
Accepted – proposed by Michael O'Connor, seconded Ruth Williams with no dissensions
- b. **Resolution 2:** The BDFa Report and Financial Statements for the year ended 31st August 2017 be received and adopted.
Accepted – proposed by Gail Rich, seconded by Cath Sermon with no dissensions.

5. Trustee elections

The following new Trustees were elected to the Board

- Rahul Dubey - proposed by Pauline Docherty, seconded by Ruth Williams, agreed and elected
- Amanda Mortensen - proposed by Christine Caren, seconded by Roger Cole, agreed and elected

The following existing Trustees were re-elected to the Board

- Michael O'Connor (1 yr term) - proposed by Pauline Docherty, seconded Roger Cole, agreed and elected
- Catherine Sermon (3 yr term) proposed by Brian Morrison, seconded by Michael O'Connor, agreed and elected.