



**ANNUAL GENERAL MEETING OF THE
BATTEN DISEASE FAMILY ASSOCIATION
SATURDAY 19 NOVEMBER 2016 at 10AM**

**AT THE CROWNE PLAZA HOTEL,
BRIDGEFOOT, STRATFORD UPON AVON CV37 6YR**

Present: See attached sign-in sheets

Minutes: Taken by Lucy Roose, BDFA Office Manager

1. Introduction and Welcome (Catherine Sermon, BDFA Board of Trustees)

Cath Sermon welcomed families on behalf of the BDFA Board to a welcoming space to attend sessions, meet others or to spend time alone and thanked everyone for coming. She explained that it is a legal requirement for a charity to hold an AGM to explain what it does and how. She advised that the BDFA has had a phenomenal year, so many families are present and that the Board hopes this will continue to be a basis for growth as there is still so much more to do.

2. BDFA 2015/16 Review of the Year (Andrea West, BDFA CEO)

Andrea West introduced the staff team – a small team which achieves a huge amount- which is supported by a Board of Trustees. Many Board members are parents too and AW asked anyone who is potentially interested in this role to speak to her or a Trustee. The BDFA is also supported by medical, education and research advisors as well as its body of volunteers and supporters. AW thanked all present as the BDFA could not function without its supporters for which it is hugely grateful. The BDFA has three aims: to support families and professionals who work with them; to raise awareness and advocate for better treatment/services; and to directly fund research into potential therapies and ultimately a cure.

In 2015/16 the BDFA has provided:

- A support and advocacy service with a full time Support & Advocacy Partner and a Freephone helpline supporting over 100 families
- Funding for a Clinical Nurse Specialist at Great Ormond Street Hospital
- Support to families and pharmaceutical companies in preclinical and clinical trials
- A small grant scheme (15 families supported in 2015/16)
- Education advocacy (including 3 training workshops for professionals)
- Annual conference
- Family folder (continually updated and sent to all affected families)

- Twice yearly newsletter and weekly email updates
- A social media presence (including closed groups for family members – please speak to Harriet Lunnemann if you would like more info)
- An increase in its international work – including support of professionals and families from other countries and through collaborative work with other organisations and charities
- Research funding into all forms of NCL– see attached – including a European education project, a MIND music therapy project, BioMarin CLN2 Burden of Disease project, BATCure, and individual families funding research. The BDFA Scientific Officer advises others on how to fund research to make sure it is driven forward. £210,000 has been spent on research in the last four years and £437,000 will be spent in the next three years.

3. Treasurer's 2015/16 Report and Future Budget (Andrea West, BDFA CEO on behalf of Ben Jones, BDFA Treasurer)

- As Ben Jones was not present, Andrea West presented the Treasurer's Report on his behalf. A full breakdown is attached. AW advised the BDFA had another successful year with total income rising from £305,000 to £325,000 (8% increase) and with 9 months' of funds carried forward. Income highlights include £61,000 of supporter fundraising and there have been no sizeable overspends. The aim for 2016/17 is to increase income by 30% with 2 larger charitable events. The Treasurer thanked the BDFA team and especially Andrea West and Lucy Roose for their support to him.

Questions were asked as follows:

- Julie Pickering asked where the Board felt the balance should be in terms of reserve funds. AW advised that moving into office premises had been an investment to grow the BDFA and that this increase in operating costs had depleted reserves which are gradually being built up again.
- Julie Pickering raised a question about the 3 year fundraising strategy. Cath Sermon advised that the costs of outsourcing fundraising had been high and therefore the staff team had been invested in instead. Ellen Bletsoe had developed a fundraising strategy which has been in operation for the last year, James Jeynes is now using his knowledge of membership organisations to help the BDFA generate a sustainable income. Even without a professional fundraiser the BDFA income has continued to grow. Staff member Gaynor Heeson is receiving some skills training to consider the areas of BDFA fundraising work which AW will share when available.

4. Ordinary Resolutions

a. Resolution 1: the minutes of the 2015 AGM be adopted as a true record of that meeting.

This was proposed by David Mitchell, seconded by Ellen Bletsoe.

b. Resolution 2: The BDFA Report and Financial Statements for the year ended 31st August 2016 be received and adopted.

This was proposed by David Mitchell, seconded by Sarah Kenrick.

c. Resolution 3: Constitutional changes as requested for inclusion in the Scottish Register of Charities:

- i. **Item 11 Receipts and Expenditure an addition at (b) in the BDFA Constitution**
 - a. **None of the Association's assets may be distributed or otherwise applied (on being wound up or at any other time) except to further its charitable purposes**
- ii. **Item 12 Property an addition at (c)**
 - a. **Nothing in this constitution shall authorise an application of the property of the charity for purposes which are not charitable in accordance with section 7 of the Charities and Trustee investment (Scotland) Act 2005.**

This was proposed by Sarah Kenrick, seconded by Julie Pickering.

5. Trustee Elections

The following were elected to the BDFA Board of Trustees:

Roger Cole (proposed by Sarah Kenrick, seconded by Ellen Bletsoe)

Neil Dunford (proposed by Julie Pickering, seconded by Ellen Bletsoe)

James Jeynes (proposed by Ellen Bletsoe, seconded by David Mitchell)

- Presentations were made and thanks given to Sarah Kenrick and Ellen Bletsoe as they resign from the Board of Trustees. Pauline Docherty is also stepping down due to length of service as is Barbra Higgins.
 - A final presentation and thank you was made to Barbara Cole in recognition of her amazing, but voluntary, contribution as a member of the BDFA team.
6. **Keynote speaker: Professor Sara Mole (UCL), BATCure Coordinator introduced BATCure and Dr Sander Smith (UCL Institute of Ophthalmology) presented the work of the Institute of Ophthalmology (IOP) within BATCure and BDRA-funded projects on Gene Therapy to treat visual loss in NCL.**