



**Batten Disease Family Association
Minutes of the Annual General Meeting**

Held online via Zoom on Saturday 26th August 2023

In attendance-

Staff- Liz Brownnutt, Lisa Forsyth, Sarah Chandler, Mimi Petty, Sarah Kenrick

Trustees- Bob Thompson, Zlatko Susic (Chair) Richard Whitbread (Treasurer) Pauline Docherty, Mark Thompson.

Other- Stacey Henderson, Ian Henderson, Mike O'connor, Pam Turner.

1. Introduction and welcome

The Chair of Trustees for the BDFFA, Zlatko Susic, welcomed those present to the AGM and all were given to opportunity to introduce themselves.

2. Approval of minutes from 2022 AGM

Minutes of the AGM 2022 were received and **approved by all.**

3. Chair Review of the year from Sept 2021- Aug 2022

Review of the year 2021- 2022 was presented by Liz Brownnutt. Liz started with reminder of the core values of the BDFFA, 'To ensure that everyone living with a diagnosis of Batten disease has access to the best quality services and support to enable them to live life to the full and to change lives by funding research into potential therapies and ultimately a cure'. We provide services, support and information and advocating for families across health, education and social care, with access to therapies and treatment is an essential role of the BDFFA as a patient organisation.

BDFFA supported 105 families during that year and there were 19 new diagnosis. CLN3 and CLN2 are the most prevalent types of Batten disease and the numbers of CLN2 (35%) are growing and almost the same as CLN3 (36%). These two subtypes make up two thirds of the total number of families. All variations are prevalent in the UK.



Our highlights from this financial year within each of our final pillars-

Advocacy

Amanda Mortensen was the Chief Executive over this year. The BDFFA support team was made up of Sian Fisher, Liz Jones with Sarah Kenrick providing additional support. The team worked with 78 local authorities.

The team provided support to families with children with CLN2 with the addition of two new treatment centres for Brineura in Bristol and Birmingham. We began working with families to prepare for the re-evaluation of Brineura in 2024, holding workshops with NICE and meeting with pharma companies and NHS England.

The BDFFA continues to collaborate with other organisations such as the LSD collaborative and working closely with our counterpart charities the BDSRA Foundation in the US and BDSRA in Australia.

Community

The BDFFA launched its Peer Befriending services, appointing Mimi Petty as Peer Befriending Coordinator with the first group of parent volunteers completing their training in July 2022. Over the last year they have been supporting other parents. A further 3 parents have been trained to join the team of volunteer Peer befrienders.

A pilot study was completed for the bereaved community at the end of 2021 to help us understand what parents who are bereaved want from the services. These ideas have been collated and logged for when the BDFFA can secure funding for a further service in the future.

Our sense of community is growing with awareness days and our new annual initiative, the Pride of Batten Awards.

Care and Support

Family wellbeing service has been developed delivered by the Maypole Project. This is now a BDFFA core service. One third of our families are now accessing this service.

The BDFFA continue to partner with GOSH part funding the clinical nurse specialists, and we also provide grants to newly diagnosed families and those families in financial hardship.

The BDFFA continue to support Bertie's helpers run by the Petty family, which up to August 2022 has delivered over 172 Tesco food shops to families.

Research

Progress has been made with the compassionate use programme at GOSH of Brineura in the eyes for CLN2, which started in June 2021. We have also made progress with our first BDFFA led research study examining the diagnostic odyssey of Batten disease with the aim of improving patient care and diagnostic pathways.

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Income Generation

The BDFFA has continued to diversify its income strategy through trusts and foundations with 37 new funders this financial year. Two of those funders were the Charities Aid Foundation and the National Lottery community fund; these funds enabled us to fully establish our Peer Befriending service and to employ Dr Jo Nightingale as the BDFFA Scientific officer. Her role has developed since thanks to generous funding from a family funding initiative.

Community fundraising continues to improve post COVID and we had some amazing fundraising events this year including runner in the London Royal parks half marathon and Ride London, as well as the Great North Run, collaborating with the Nicole and Jessica Rich Foundation. We would also like to mention The Cardboard Box Company who took part in a dragon boat race and raised an amazing £60,000 with some match funding.

The BDFFA are ever grateful for the Batten and wider community for their tireless support in fundraising.

Looking forward with income generation, our strategy is to continue to diversify with trusts and foundations and developing other income streams such as corporate and individual giving.

The BDFFA are pleased to have appointed Sarah Chandler as fundraising assistant, who will continue to focus on community fundraising as well as helping with the development of trust and foundations.

Looking forward

Communication and information- We are currently working on a new website and will be re starting regular newsletters and updating the Orange family folders.

Family Voice- Providing regular town hall style meetings with families to help plan our long-term strategy.

Development of family support and peer befriending services- we want to develop our family support service providing regular training to professionals and families.

MAA (Managed access agreement) - This will be a big focus in the coming year, with the BDFFA submission in early 2024, working with families, NICE, pharma companies and NHS England.

Science and research focus- Clinical trials and new-born screening.

Strengthening our alliances and partnerships- Both in the UK and internationally

Governance- Reviewing and ensuring that our policies and procedures are robust.

Incorporation- we will be discussing further shortly.

Zlatko thanked Liz for her presentation. At this time, Zlatko introduced Liz Brownutt as the new interim CEO of the BDFFA for the next 6 months. The year that we are reviewing (2021-22) the BDFFA was under the

leadership of our previous CEO Amanda Mortensen. The BDFFA would like to recognise Amanda's leadership and significant contribution to what was achieved during this year.

4. Treasurer Financial Review of the year 2021-2022

Treasurer Richard Whitbread presented the financial review of the year- showing trends over the last 4 years. This year's income did dip slightly from the prior year as that year had a significant fundraising for Brineura in the eyes. The key to the charity being able to run successfully is the unrestricted funds, as designated and restrictive funds are for specific purposes. In 2021 there is a huge rise in designated funds to £207k, this was mostly for Brineura in the eyes. The core unrestricted funds in 2021- 22 grew from £342K to £421K.

Total expenditure went up this year as we were spending the funds in relation to Brineura in the eyes. This was also increased by the growing our staff numbers.

Our net income over this period for unrestricted funds, we were within £4,000 of balancing the books, so effectively the charity itself broke even during this period. The other funds of designated and restricted funds took the BDFFA to a small loss of £9,000. This is not a bad thing, as typically the funds are raised in one year and spent in the next.

The BDFFA's total reserves did decline slightly from £505k in 2021 to £496k. However, the unrestricted funds grew from £174k to £178k.

2021-2022 was almost an ideal year financially, as the income and expenditure are largely aligned. We will not be increasing the amount of reserves next year as they currently support our ongoing activity.

The year-end reserves were around 5 months of core expenditure and our target is between 4-8 months. This is where we wish to be as if the reserves are too low the charity will have cash flow issues and if they are too high then some funders are reluctant to assist funding.

Looking ahead to 2022-23- The budget was built in June 22, but it's fair to say that with the impact of inflation and cost of living has effected the ability of people giving to charity. In consequence of this our expenditure will be greater than the income.

It has been decided by the trustees that the BDFFA will no longer be part funding the clinical nurse specialist at GOSH, as there are more treatment centres across the UK, and we believe it would not be appropriate to assist just one of these centres, but to rather support them all in some way going forward.

Zlatko then thanked Richard for his report.

5. Receive the Report and Accounts for the year ended 31 August 2022 Vote was held to accept the accounts- VOTE PASSED

6. To re-appoint Taylor Cocks as independent examiner for the year 2022-2023

Vote was held to re-appoint Taylor Cocks as independent examiner for the year 2022-2023, **VOTE PASSED.**

7. To resolve that the Trustees may negotiate appropriate fees for the examiner

Also to accept for the BDFFA to negotiate appropriate fees- **VOTE PASSED**

8. Trustees and Constitution

Zlatko informed the members of the updated situation. The current Constitution requires 7 Trustees. The quorum required at meetings is three and we have legal advice that the charity can continue with only three Trustees providing all are present for formal decisions.

- Cath Sermon resigned on 11 March 2023
- Gareth Homes resigned on 28 April 2023
- Pauline Docherty has stated that she will resign on 31 August 2023
- Richard Whitbread has stated that he will resign on 30 September 2023

The BDFFA wishes to thank Cath Sermon and Gareth Homes for providing significant support and expertise during this difficult time for the BDFFA.

Pauline Docherty is a founding member of the BDFFA and will be leaving her role at the end of August, and over the years Pauline has given so much support and hard work to the organisation. We wish to thank her for offering stability over the years.

Pauline said that she has enjoyed her time with the BDFFA over the past 25 years and though there have been challenging times she wishes the best for the BDFFA in the years to come.

Richard Whitbread will be leaving his role as treasurer at the end of September. Richard has given the BDFFA his wealth of expertise in financial areas, legal and HR over the last few years. He helped enormously to keep the organisation stable over this time. He is a big loss to the BDFFA and we really appreciate everything he has done. Thank you so much Richard.

Richard said, Big thanks to Pauline for her dedication to the BDFFA. The last year has been a rollercoaster, it is good to know we were able to overcome large challenges.

Zlatko said that the role of trustees is a volunteer role and it takes a lot of hard work and he wishes Richard and Pauline all the best.

If anyone wishes to become a Trustee to aid the shortfall then please advise and we will arrange a discussion and briefing and if then agree a co-option to the Trustees

Zlatko then asked for the remaining trustees Bob Thompson, Simon Sewart and himself, Zlatko Sisic would like to continue in their roles as trustees until the current charity is dissolved and the new incorporated charity is established.

Vote was held- **VOTE PASSED.**

9. The Trustees propose that a CIO charity be formed as Batten Disease Family Association (CIO) with the constitution attached to this notice, adopting identical aims to the current constitution and all other constitution clauses as attached or are as amended by the Charity Commission and legal advice.

Zlatko spoke about the intention to dissolve the current BDFFA to then be formed into the Batten Disease Family Association CIO.

Vote was held to approve- **VOTE PASSED.**

10. The Trustees propose that once the new Charity is established then the Trustees undertake the transfer of all assets, liabilities, staff and other contracts and all other items to the new charity through a novation contract with formal legal advice.

Vote was held to approve- **VOTE PASSED.**

11. In accordance with paragraph 21 of the current Constitution the Trustees seek authorisation for the dissolution of the existing charity but only once the new Charity has been formed and the transfer of all rights and responsibilities of the existing charity have been completed as above.

Vote was held to approve- **VOTE PASSED.**

12. Any other business - To deal with any matters raised at the meeting

Final thoughts from Zlatko, in 2021-22 was a successful year, it has been a fantastic experience and privilege to be in this role with the whole team. We are a tiny organisation, and according to the Charity commission 22 thousand charity dissolved last year, lots were bigger than the BDFFA, so with this in mind he wished to give thanks to the whole community and especially the staff for their dedication and hard work.

With the upcoming incorporation, this will take the charity into a safer position and a more sustainable future that will be able to gain strategically more talent on the board of trustees and team. With the loss of some long standing trustees, we are grateful to Mark Thompson for agreeing to help with the financial side in the coming year.

Meeting closed.