

BDFa Financial and Organisation Update May 2020

We held a zoom meeting earlier this month to discuss the BDFa's accounts (year-end August 2019) and we were joined by 11 parents as well as professionals working in the Batten arena.

Here is a summary of our financial position and plans going forward.

The BDFa's financial position (year-end August 2019): key points

- The BDFa has made major operational changes with a reduction in activities and cost base following a poor financial position at the year-end August 2018
- The financial position at year-end August 2019 is significantly stronger. In the 12 months to August 2019 income was £373k against expenditure of £280k
- Importantly unrestricted income was £217k against a reduced expenditure of £130k
- The charity ended the last financial year with reserves of £65,000 which, with our stripped back budget, represents about 6 months of running costs
- To view the final accounts, please follow the link to our website here <http://www.bdfa-uk.org.uk/wp-content/uploads/2020/04/BDFa-Final-accounts-03042020.pdf>

Our Board

We have a number of new trustees joining our board including a new treasurer and trustees leading on fundraising and our medical and scientific strategy. We are committed to our board having significant representation from parents and, out of 9 trustees, 5 are currently parents. Due to our constitution we aren't able to co-opt all our new members until our official AGM (as no more than a third of our board can be co-opted). Pauline Docherty, one of the founders of the BDFa, is currently acting Chair but, after more than 20 years, Pauline is looking to step down at the our formal AGM. The AGM has been delayed due to the current situation with Covid-19 but will be in the autumn.

We are currently seeking a new Chair for the BDFa and we are keen for this to be somebody from the parent community with the requisite skills.

Acting Chair: Pauline Docherty

Pauline is one of the founder members of the BDFa. Both her children had juvenile Batten disease. Joanna passed away in 2008 at the age of 23 and James passed away in 2016 at the age of 26. Pauline has now been involved with the BDFa for over 20 years.

Treasurer: Richard Whitbread (currently co-opted)

Richard has a wealth of financial experience with 25 years as a Senior Financial Manager in the Consumer Goods industry until he retired 6 years ago. Richard is a bereaved parent and his daughter, Stephanie, who had juvenile Batten disease died in 2013 at the age of 22

Secretary: Neil Dunford (parent to Yanna, 9, who has late infantile Batten disease. Neil is to be re-elected for a term of 3 years at the formal AGM in October)

Neil works with families of disabled children and has set up a community led network in East London

New trustees:

Gareth Holmes (lead on fundraising, currently co-opted)

Gareth is marketing and fundraising director at the Helen Bamber foundation. Gareth is an experienced fundraising consultant.

Dr Zlatko Susic (lead on medical and scientific strategy) . To be elected at our AGM

Zlatko is the Executive Medical Director, Head of Medical Affairs, for BioCryst. Zlatko held a senior position at Biomarin and worked closely with the Batten community during this time.

Bob Thompson (parent to Frank, 12, late infantile Batten disease). To be elected at our AGM

Parent of Frank Thompson (CLN2) and also a producer, business consultant and lecturer specialising in animation for film and television.

Simon Sewart (parent to Max, 9, late infantile Batten disease). To be elected at our AGM

Simon has a varied career and is currently a web applications developer and KST practitioner. He also is a trained Chiropractor.

Continuing trustees:

Cath Sermon (to be re-elected for a term of 3 years at our AGM)

Cath is god mother to a young woman with juvenile Batten disease. Cath is currently Campaigns and Content Director at Business in the Community.

Roger Cole (to be re-elected for a term of 3 years at our AGM)

After a career with BT, Roger has been a trustee with the BDFA for X years. Roger's wife Barbara is the BDFA's volunteer Education Adviser.

Our work

We currently work directly with 97 families and 108 children, across the UK. There are approximately 50 more families who get in touch intermittently. We have approximately 100 families on our database who are bereaved and this is an important area we need to explore.

There are 14 different types of NCL. CLN3 is the most prevalent and we currently work with 46 affected children and young people with juvenile Batten disease. We work with 31 children with CLN2 (late infantile Batten disease). We then work with 9 children with infantile Batten disease (CLN1), 5 with CLN5, 4 with CLN6, 7 with CLN7, 1 with CLN14 and 5 with currently CLN unknown.

We have a team of two support workers, Wendy and Cathy, who cover the whole of the UK. Wendy is based in the north and Cathy in the south. Our support workers visit families at home soon after diagnosis and provide emotional and practical support. They work with professionals involved with the family, run training for teaching staff, work with social workers and health teams. They support families to bring in extra income, signposting them to funding sources (Family Fund for example) and supporting them to apply for key benefits. They put families in touch with others who are further on their 'journey'. Some of our families need very intensive support working with numerous different teams.

Our Clinical Nurse Specialist at Great Ormond Street works alongside the support workers to provide advice around the management of symptoms such as epilepsy and also raises awareness and understanding of Batten disease across medical teams in the UK.

Since Covid-19 we have been offering more community support via Zoom. Up to 13 families have joined us on Zoom to check in each week and we have invited different 'professionals' on to the call including Sarah Kenrick, Seeability nurse, Sally Flatteau-Taylor, from Maypole (an organisation supporting for families with complex needs), and Barbara Cole, our education adviser. We have also held a medical webinar with Professor Gissen from GOSH and Professor Simonati, a leading expert in NCLs from Italy. More virtual support is planned and it is working so well we will continue with this post the current crisis as a way of bringing our community together across the UK.

We made the decision as a board to reintroduce our family grant scheme as a direct response to the pandemic and this has been very well received with 40 grant applications, 70 per cent of which are from families on low incomes. This year we have also supported (and worked alongside) families during the very stressful process around securing access to Brineura, the first treatment for Batten disease.

Future plans

We are committed to a future strategy that is shaped by our community. The BDFA will carry out its first family survey for several years to reach out to families to shape the direction and strategy of the organisation going forward. The BDFA is committed to its original objects and retaining its commitment to research.

Current priorities:

- **Database:** moving to a new, more efficient database that will also measure impact. We are also implementing other ways to measure the impact of the work we do using a measurement system called Outcome Star.
- **Support:** areas of growth identified are for development are support of our families who are bereaved and support for the wider community (particularly siblings). We are looking to grow our volunteer base and peer support is one area we will consider going forward.
- **Research:** the BDFA is developing a medical and scientific strategy, led by new trustee Zlatko Sisic. We plan to ensure the BDFA is at the forefront of research globally as well as collaborating with patient organisations.
- **Fundraising:** diversification of income through trusts and foundations and partnerships will secure the BDFA's future.
- **Communication:** aiming to improve our communication with the community with a livelier presence on social media and a newsletter.
- **Membership:** as an unincorporated organisation the BDFA is legally a membership organisation. We will be approaching all of the contacts on our database to formally become members to enable a proper AGM to be held to enable election of the trustees mentioned earlier (plus others who may want to put themselves forward and to provide the right governance for the future of the association).