



**Batten Disease Family Association
ANNUAL GENERAL MEETING
held at the Village Hotel, Coventry
on Saturday 17 October 2015 at 10am**

Present: Signature list attached
Minutes: Lucy Roose (BDFFA Office Manager)

Introduction & Welcome

Andrea West welcomed everyone to the weekend and was delighted to see so many people present.

Michael O'Connor, Chair of Trustees welcomed everyone to the weekend and introduced himself as a parent with a 13 year old daughter diagnosed with Juvenile Batten disease six years ago. He thanked Andrea West and the BDFFA team for their work over the year and for organising the conference and also the recent newsletter noting that its content shows great hope in the work on Battens. He stressed that none of this would happen without the amazing work of all the BDFFA's fundraisers.

Approval of 2014 Minutes

The 2014 minutes were approved (proposed by Ellen Bletsoe, seconded by Debbie Norris). Julie Pickering asked if there was a list of attendees and AW confirmed that this is on file.

BDFFA 2014/15 Our Vision: A World without Batten disease (Andrea West – BDFFA CEO)

AW showed a slide of early parent trustees in 1998 and stressed that the BDFFA would not be where it is today without the voices of all our families and that it is therefore important that their voices continue to be heard. She thanked Julie Pickering and Irena Newcombe for their continuing support as founding members.

The BDFFA mission remains the same - that no family faces this disease alone. Support is available for the whole family and their professional team. Moving into the first BDFFA offices has provided a position in the community which is beneficial in terms of working with volunteers, local press and MPs. There have been new staff this year – a Support & Advocacy Partner, two new part-time fundraising administrators and a Batten disease Clinical Nurse Specialist based at GOSH and funded by the BDFFA.

Family Support & Advocacy 2014/15

Specific focuses in the last year have been:

- Family folder – AW thanked the Pickering family and the Truemark Trust for their support which enables this to be available to each family. It provides information on

the disease, care, education etc for families to their appointments. Every family was invited to collect a copy from Harriet Lunnemann. They will be mailed to those not present. They are available for purchase by professionals and all feedback is welcome.

- BDFFA Small Grant programme – up to £500 can be applied for from the BDFFA or Harriet Lunnemann can help source other funding.
- Education - Barbara Cole works with families to access appropriate education. She is a volunteer and it is hoped to expand this provision over the next couple of years.
- Parliamentary lobbying – The BDFFA has worked closely with Greg Mulholland MP who has become a champion for rare diseases and for the BDFFA in particular. Families should no longer have to re-apply for the higher rate of care and mobility so please feed back any problems with this.
- Annual Family Conference which is growing annually.
- Future plans involve continuing BMN190 trial work with pharmaceutical companies and regulatory bodies, more workshops for groups of professionals, complete needs analysis for each family, improvements in the journey to diagnosis, development of clinical care pathways as well as aiming to have an adult CNS and an additional Support & Advocacy Partner.
- Awareness – 2015 included the first Batten Disease Awareness Day which will be held in early June each year. The aim was “to turn the world orange” via social media and all forms of publicity.

Research Funding 2014/15

AW advised that scientific researchers will be present at the Conference and their posters could be viewed in the Vibe Suite. Research is critical for the BDFFA which aims to fund research in all forms of NCLs. The BDFFA is delighted to announce

- two CLN5 research projects due to outstanding fundraising by Battle Batten
- £50,000 is being awarded via a Sparks call to Prof Jon Cooper
- European funding for BatCure
- Involvement in a European Education project

Each will be presented at the conference. All were also urged to attend Dr Ruth Williams' session on a Registry. All conference sponsors were thanked in terms of their time as well as resources.

Treasurer's 2015/16 Report and Future Budget – (Ben Jones BDFFA Treasurer)

BJ said all could share in the success of these figures. The BDFFA Board ensures the growing charity is run as a tight ship and reported another successful year. Now that income exceeds £250,000, returns are submitted on an accruals basis. A full breakdown of income and expenditure can be requested from Ben Jones, Andrea West or Lucy Roose. The accounts have been independently verified and will be lodged with Charity Commission.

Points highlighted by the Treasurer were:

- Income is up 7% to £304,000 and 10% on two years ago.
- 9 months of reserves are held, made up of £170,000 of restricted funds and rest is unrestricted monies.
- In the 2014/15, approximately £400,000 has been spent including some reserves - £25,000 on grants, £140,000 of restricted funds including BioMarin, Beefy Charity money and CNS support.

- Wages and salaries are rising as the charity aims to do more each year as well as due to bringing fundraising staff costs in-house.
- The move to offices resulted in £11,000 spent on rent and investments in related equipment. This is a considerable but very pleasing investment. There have been no sizeable overspends except deposit on office lease of £6000.
- Next year's target is £350,000 (15% increase).
- Next year's grant target is £170,000 dependent on income and it is hoped to have a large income-generating event too.

Julie Pickering asked about the accounting format and the "pence in the pound" ratio. AW advised this is 14p and that a change in accountancy firms has resulted in the change of format. The growth in work on the accounts also means it is a challenge to have the accounts ready for an October AGM. It was agreed that comparative accounts are much easier to review and this will be possible next year.

Nominations for Trustees Seeking Election and Re-Election to BDFA Board

There were no nominations.

Keynote Speech by Dr Sara Mole, announcing the BATCure European Consortium Project and how this ground-breaking funding of 6 million Euros will impact on the field of Batten disease research

Dr Sara Mole and Heather Band, BDFA Scientific Officer were introduced by Mike O'Connor. Sara Mole advised that the success rate for accessing this EU funding is 3% so all should be congratulated on their success. The research focusses on three types of membrane diseases and is a three year programme from Jan 2016-18 looking at pre-discovery, discovery and preclinical phases. The work will be undertaken by Principal Investigators from 13 organizations in different countries, half of whom have not worked on Batten disease before. 40% of the money is coming into the UK and the project is being coordinated at UCL. 62,000 Euros come to the BDFA – Heather Band will be a Work Package Leader and a part-time (1 day per week) researcher will be recruited to work with her.

Heather Band explained the BDFA and patient involvement and identified 3 main tasks for the BDFA:

- To develop methodology to enable all patients/patient groups to engage and participate in the study; (an interactive website will be hosted at UCL for scientists, researchers and families)
- To prepare for future clinical trials;
- To develop public and professional engagement and communication strategy

She urged all families to complete surveys when requested as the family voice is critical in this process. Families were also asked to speak to Sara Mole or Paul Gissen about blood/urine samples for the UCL Metabolomic Study.