



**TRUSTEES' ANNUAL REPORT
AND
FINANCIAL STATEMENTS
FOR THE YEAR ENDED
31ST AUGUST 2008**

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Batten Disease Family Association
Registered Charity No 1084908
Heather House, Heather Drive, Tadley, Hampshire, RG26 4QR.
Tel: 0115 965 4815. www.bdfa-uk.org.uk.

BATTEN DISEASE FAMILY ASSOCIATION
TRUSTEES ANNUAL REPORT
YEAR ENDING 31 AUGUST 2008

1. REFERENCE AND ADMINISTRATIVE DETAILS

| | |
|--------------------------------------|---|
| Address and Registered Office | c/o Heather House Heather Drive Tadley Hampshire RG26 4QR |
| Trustees | |
| Chair | Julie Pickering |
| Secretary | Sarah Kenrick |
| Treasurer | Alison Jenkins (appointed 6 th Oct 2007) |
| Support Trustees | Rachel Griffith Debbie Jordan Pauline Muncey |
| Research Trustees | Heather Band (appointed 6 th Oct 2007) Heather Sickelmore (appointed 6 th Oct 2007) |
| Fundraising Trustees | Steven Boxall Dr Elizabeth Gatrell (appointed 6 th Oct 2007) Pamela Hughes Kathryn Thompson |

James Pickering, Treasurer, and Sasha Scambler retired as Trustees on 6th October 2007. Julie Pickering replaced Rachel Griffith as Chair and Sarah Kenrick replaced Debbie Jordan as Secretary on 6th October 2007.

| | |
|----------------|---|
| Bankers | Alliance and Leicester Commercial Bank BBAM Bridle Road, Bootle, Merseyside GIR 0AA |
|----------------|---|

| | |
|-----------------------------|--|
| Independent Examiner | Rowena Bass ACA 36, Dickerage Road, Kingston upon Thames, Surrey. KT1 3SS |
|-----------------------------|--|

BATTEN DISEASE FAMILY ASSOCIATION

2. STRUCTURE, MANAGEMENT AND GOVERNANCE

Governing Document

The Batten Disease Family Association was formed in November 1998 and became a registered unincorporated Charity on 7th February 2001, constituted as an association. Charity number 1084908.

Recruitment and Appointment of Trustees

Trustees are recruited with a view to diversity, sound experience in a related field or professional expertise in a relevant area. Advertisements are placed in the Association's newsletter and on the website as well as existing Trustees approaching suitable candidates.

Such candidates are then given information on the role, interviewed by the Chair/Secretary and if appropriate, are invited to a Trustees' meeting. Appointment is then conditional of the approval of the Trustees and members at the AGM and subject to CRB disclosure and Trustees Declaration of Eligibility.

Trustees have fully documented information packs and job descriptions to support their recruitment and induction to the board.

Organizational Structure

The policy and general management of the affairs of the Batten Disease Family Association are directed by the Trustees. The day to day management of the Batten Disease Family Association is carried out by the Development Officer, Jan Sablitzky.

As an Executive Committee, the Board of Trustees are divided into the 3 Honorary Officers and 3 groups, Support, Research and Fundraising who have teleconferences at least 4 times a year to discuss detail and check implementation of the strategy. The Trustees then meet with the Charity Development Officer at least another four times a year to review the work and formulate strategy. The Batten Disease Family Association also benefits from the services of Volunteer Educational, Medical and Research Professional Advisors who liaise with the Development officer and the relevant Trustees as necessary.

The website is managed by a volunteer.

Recruitment and appointment of Staff

One part time Development Officer is employed by the Batten Disease Family Association, who is managed by the Chair and Secretary. The recruitment process is guided by the BDFA Recruitment and Selection Policy in accordance with statutory legislation and good practice.

Risk Management

Trustees place a high priority on risk management. Risks identified are categorised as follows:

- Governance and management
- Operational
- Financial
- External and compliance

These risks are reviewed annually and documented. As a result of this process, the Trustees are satisfied that residual risks are minimal.

BATTEN DISEASE FAMILY ASSOCIATION

3. OBJECTS AND ACTIVITIES

Objects

The BDFA's vision is to bring light to Batten Disease by being the central point of excellence in the UK for supporting affected families and to facilitate research into the disease. This is communicated through its Mission Statement and directs the BDFA's Strategic Planning.

The Batten Disease Family Association objectives are to support, guide and facilitate networking of affected families and professionals as well as to increase awareness and facilitate research into Batten Disease. It is the only Batten Disease helpline in the UK. To do this we have already established the foundation support principles for the charity and we are now expanding to offer more informed guidance and support as well as actively increasing awareness of the disease and facilitation of research and clinical trials.

Batten Disease is the main paediatric neuro-degenerative disorder in the UK. It affects 1:30,000 births and there are approx 200 affected children/ young adults in the UK each supported by up to 40 professionals. They are born apparently healthy, develop epilepsy, and lose their sight, speech, mental and motor abilities before dying between the ages of 5-30. There are 3 main types of Batten Disease, affecting children at different ages depending on which defective gene has been inherited, traditionally called Infantile, Late Infantile and Juvenile Batten Disease. There is also a congenital form and other variants of the disease. There is much research into all types, but no cure at present.

Activities

The Batten Disease Family Association's core activities are categorised as:-

1. Support and Guidance for families and professionals
2. Increasing awareness
3. Facilitating Research

1. Support and Guidance for families and professionals

The BDFA aims to provide the following services on an ongoing basis:

- A helpline to support families and those around them needing information and to relieve parents and carers in times of distress and isolation. The helpline also supports professionals needing information to help them support the affected child and family.
- A comprehensive website which includes a message board for parents and carers to contact each other ask for mutual support.
- A bi-annual members' newsletter, regular e-bulletins and other information resources.
- Networking opportunities through the annual family conference, annual research update meeting, annual sponsored walk and the ongoing members' network.
- Links to various professionals with specialist expertise in Batten's, who can give professional guidance to the families and other professionals.

2. Increasing awareness

The BDFA aims to educate the general public and professionals about Batten Disease through talks, presentations and providing regular professional development training sessions as well as using national, local media and other organisations where appropriate. The BDFA also seeks out opportunities to educate policy makers about Batten Disease and its effects on family life in order to influence the allocation of appropriate resources for Health, Social and Education across the UK.

3. Facilitating Research

The BDFA facilitates research into Batten Disease by providing grants. It also facilitates finding effective mechanisms for moving towards therapy for Batten Disease and ultimately a cure.

BATTEN DISEASE FAMILY ASSOCIATION

4. ACHIEVEMENT AND PERFORMANCE

The following are the statistics in respect of certain key activities undertaken:-

| | 2007/08 | 2006/07 | % INC/DEC |
|--|----------------|----------------|----------------------|
| Helpline support (initial contact calls) | | | |
| - Individual families | 49 | 54 | -9 |
| - Professionals | 27 | 36 | -25 |
| Message Board Usage (visible postings) | 98 | 81 | 21 |
| Conferences/ meetings/network opportunities for families and professionals | 6 | 3 | 100 |
| Website Hits/month | 18800 | 13700 | 37 |
| General e-mail information and management activity/ month | 628 | 500 | 26 |

As the website continues to develop to provide accessible information and networking forums and with more opportunities for families to meet at conferences and professionals accessing training sessions, the support need is being met through this and the use of the message board and direct email contact with the Development Officer. The Medical Advisor is also completing a project for the BDFA in formulating a Clinical Assessment Tool, which means bi-annual visits to families supporting the project where other issues can be addressed at that time.

In terms of specific achievements for 2007/08, below is a summary:-

1. Support and Guidance for families and Professionals

- Audit on existing patient and family support and guidance completed with a Grant from Jeans for Genes, identifying areas to increase the support by the BDFA and areas that the BDFA need to raise with policy-makers.
- Further improved communication and support with the initiation of e-bulletins to members keeping them updated and access to news flashes, development of the website, promoting usage of the message board and updating existing information leaflets.
- Initiated professional training courses of which both fully attended.
- Contributed to the future NHS management of Metabolic Diseases.

2. Increasing awareness

- Promoted Batten Disease and the BDFA on National Rare Disease Day at the House of Commons.
- Information leaflets distributed at the British Paediatric Neurologist Association's Annual Conference.
- Various individual families supported in raising awareness through the local and national papers.
- Increased the circulation of the bi-annual newsletter to peripheral organisations and donors.
- Held the 3rd Batten Disease Sponsored Walk attracting new fundraisers to walk for Battens as well as raise the profile through justgiving.com and on the day.
- Active participation with other patient organisations for diseases with similarities to Batten Disease.

3. Facilitating Research

- Organised the 1st National Batten Disease Multi-Disciplinary Conference, bringing together scientists, medical professionals and the patient organisation to identify the top priorities to facilitate bringing therapy to Batten Disease.
- Established formal Grant giving procedures and granted 4 project grants.
- Supported and learnt lessons from therapy trials for similar diseases on enzyme therapy in the UK.

BATTEN DISEASE FAMILY ASSOCIATION

5. FINANCIAL REVIEW

Performance in the year

The BDFA raised £98.5k last year, its highest ever amount achieved thanks to all the families, friends and work colleagues through their donations and fundraising. The most significant donation was a very generous one off donation of £40k from a Trust Fund from a family, whose children had passed away with Batten Disease.

Without the £40k, the overall net receipts increase by £26.3k due to the success the BDFA Batten Disease 3rd annual sponsored walk, which raised over £15k more compared with the previous year. The remainder increase is from more external events organized by families and friends and supported by the BDFA as well as donations in memory of individuals.

The restricted funding also increased by 21% due to individual families specifying their money raised to be put into research. With the new grant procedures, the main bulk of this has been spent within the same year.

Employee costs and associated costs were increased by 20% due to the increase in range of activities necessary to ensure delivery of the strategic aims of the charity.

Reserves Policy

Whilst the BDFA is in growth and at a higher potential risk, the charity ensures it has a 1 years future funding spend in hand. Its minimum agreed figure for this purpose is therefore £50k.

It has also reserved a further £70k to ensure funds for payment of its existing and future employees till 2010 to minimize its assessed risk in developing the charity in this period of extensive growth.

6. FUTURE PLANS

Key to the successful delivery and expansion of the BDFA's core services is the number and quality of its staff, both paid and voluntary, and foundation structure. In 2008/09, the BDFA plan to extend the core paid staff to include a part-time fundraiser in September 2008 and recruit a part time Family Support Officer to start in 2009. It also plans to review its future ICT and e-networking to support its growth and service delivery as well as recruit more key volunteers for identified activities.

The BDFA plans to develop its core services provision to families and professionals as well as lobby policy makers for better targeted services, particularly as it has identified key areas where support services and facilitating research into the disease can be improved.

The BDFA will develop its relationship with other relevant organisations and the Media to raise awareness and increase its knowledge. It has already recruited a volunteer PR officer to use in 2008/09 and it also plans to launch a new additional compact newsletter in 2009 to reach a wider targeted audience and utilize its Silverbond London Marathon Place and 4th Sponsored Walk.

It will facilitate moving towards therapy for Batten Disease in the UK from the priorities identified at the 1st National Batten Disease Multidisciplinary meeting in March 2008 as well as continue to administer research grant where funds allow and contribute to the Lysosomal Storage Gene therapy programme.

Specific plans include the establishing of a Batten Disease Registry, identified as a priority at the 1st National Batten Disease Multidisciplinary meeting as well as further establishing and extending the existing family support network to include Grandparents and Siblings.

BATTEN DISEASE FAMILY ASSOCIATION

7. STATEMENT OF TRUSTEES RESPONSIBILITIES

The Trustees are responsible for preparing the Annual Report and Financial Statements in accordance with applicable law and regulations.

The Trustees are required to prepare financial statements for each financial year in accordance with United Kingdom Generally Accepted Accounting Practice (United Kingdom Accounting Standards and applicable law). The financial statements are required by law to give a true and fair view of the state of the charity and of its incoming resources and application of resources of the charity of that period. In preparing these financial statements, the Trustees are required to:-

- Select suitable accounting policies and then apply them consistently
- Make judgments and estimates that are reasonable prudent.
- Prepare the financial statements on an ongoing concern basis unless it is inappropriate to assume the charity will continue on business.

The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the charity. The Trustees are also responsible for safeguarding the assets of the group and charity and hence taking reasonable steps to the prevention and detection of fraud and other irregularities.

The Trustees confirm that to the best of their knowledge there is no information relevant to the audit of which the auditor is unaware. The Trustees also confirm they have taken all necessary steps to ensure that they are aware of all the audit information and that this information has been communicated to the auditor.

8. AUTHORISATION FOR ISSUE

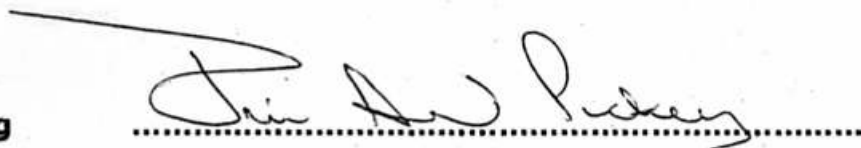
The Trustees authorise the issue of the financial statements on the date they are approved by the board.

On behalf of the Trustees

Julie Pickering

Chair

Date



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4th October 2008
.....

BATTEN DISEASE FAMILY ASSOCIATION

Independent examiner's report to the trustees of the Batten Disease Family Association on accounts for the year ended 31 August 2008.

Respective responsibilities of trustees and examiner

The charity's trustees consider that an audit is not required for this year (under section 43(2) of the Charities Act 1993 (the Act), as amended by s.28 of the Charities Act 2006) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts (under section 43 of the Act, as amended),
- to follow the procedures laid down in the General Directions given by the Charity Commission (under section 43(7)(b) of the Act, as amended), and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with General Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently I do not express an audit opinion on the accounts.

Independent examiner's statement

In the course of my examination, no matter has come to my attention:

1. which gives me reasonable cause to believe that in, any material respect, the trustees have not met the requirements to ensure that:
 - proper accounting records are kept (in accordance with section 41 of the Act); and
 - accounts are prepared which agree with the accounting records and comply with the accounting requirements of the Act; or
2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.

Rowena Bass ACA
Independent Examiner

Rowena A C Bass

36, Dickerage Road
Kingston upon Thames
Surrey
KT1 3SS

Date signed

4 October 2008

BATTEN DISEASE FAMILY ASSOCIATION

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 AUGUST 2008

| | Unrestricted Funds 2008 £ | Restricted Funds 2008 £ | Total Funds 2008 £ | Total Funds 2007 £ |
|---------------------------------|------------------------------------|----------------------------------|-----------------------------|-----------------------------|
| <u>Receipts</u> | | | | |
| Donations | 51,931 | 11,051 | 62,982 | 24,829 |
| Sponsorship Events | 26,703 | | 26,703 | 11,726 |
| Merchandise | 1,658 | | 1,658 | 1,174 |
| Conference Income | 1,495 | | 1,495 | 0 |
| Interest income | 5,711 | | 5,711 | 3,765 |
| Total Receipts | <hr/> 87,498 | 11,051 | 98,549 | 41,494 <hr/> |
| <u>Payments</u> | | | | |
| Research & Grants | 0 | 18,135 | 18,135 | 28,240 |
| Employee costs | 13,417 | | 13,417 | 11,210 |
| Other Charitable Activities | 4,642 | | 4,642 | 5,416 |
| Merchandise | 2,189 | | 2,189 | 2,626 |
| Sub Total | <hr/> 20,248 | 18,135 | 38,383 | 47,492 |
| Governance | 1,387 | | 1,387 | 1,500 |
| Total Payments | <hr/> 21,635 | 18,135 | 39,770 | 48,992 <hr/> |
| Net of receipts/ (payments) | <hr/> 65,863 | (7,084) | 58,779 | (7,498) <hr/> |
| Cash funds last year end | 75,330 | 9,122 | 84,452 | 91,950 |
| Cash funds this year end | <hr/> 141,193 | 2,038 | 143,231 | 84,452 <hr/> |

**BATTEN DISEASE FAMILY ASSOCIATION
STATEMENT OF ASSETS & LIABILITEIS
AS AT 31 AUGUST 2008**

| | Unrestricted Funds £ | Restricted Funds £ | Total £ |
|------------------------|-------------------------------------|-------------------------------|--------------------|
| Cash Funds | | | |
| 30 Day Deposit account | 111,500 | 2038 | 113,538 |
| Business Account | 29,540 | 0 | 29,540 |
| Current Account & Cash | 153 | 0 | 153 |
| Total | 141,193 | 2038 | 143,231 |

The accounts have been drawn up on a receipts and payments basis which is consistent with the previous year.

Approved by the Trustees on 4/10/08 and signed on their behalf

| | |
|--|---|
|  Julie Pickering BDFA Chair |  Alison Jenkins BDFA Treasurer |
|--|---|

NOTES TO THE ACCOUNTS FOR THE YEAR ENDED 31 AUGUST 2008

1. **Accounting Policies**
The principal accounting policies are summarized below. The accounting policies have been applied consistently throughout the year and in the preceding year.
 - (a) **Basis of accounting**
The financial statements have been prepared under the receipts and payments basis as laid down by the charities commission CC16.
 - (b) **Fund accounting**
Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity.
Restricted funds are subjected to restrictions on their expenditure imposed by the donor or through the terms of an appeal.
 - (c) **Incoming resources**
The value of services provided by volunteers has not been included in these accounts.
 - (d) **Resources expended**
Expenditure includes any VAT which cannot be fully recovered, and is reported as part of the expenditure to which it relates.
2. **Staff Costs and Numbers**
The charity employed one part time Development Officer during the financial year.
3. **Trustee Remuneration & Related Party Transactions**
No members of the Board of Trustees received any remuneration during the year. No Trustee or other person related to the charity had any personal interest in any contract or transaction entered into by the charity during the year (2007-Nil).
4. **Purpose of Restricted Funds** - Research.