



BATTEN DISEASE FAMILY ASSOCIATION

Bringing light to Batten's



Annual Report 2013-14

Together we *will* make a difference



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Who We Are

The Batten Disease Family Association is the only UK Charity committed to supporting families, raising awareness and funding research into the devastating set of neurodegenerative diseases commonly known as Batten disease. The BDF was founded in 1998 by a small group of parents of affected children and young people who made the commitment there and then that no family should face this journey alone.

We work with the scientific, medical, social care and educational professionals in the UK and worldwide to drive forward towards therapies and to ensure that families living with this diagnosis today have access to the best services available.

What We Do

Support

Our aim continues to be that no family faces the devastating journey with Batten disease alone. Through our family support and advocacy service we aim to improve the quality of life for children and adults affected by Batten disease and support the team of professionals working with them.

Raising awareness

We aim to raise awareness of this set of rare diseases. We also aim to influence policy and service provision for all forms of Batten disease to enable families and professionals to access the best resources and to give the best quality of life to affected children and young people.

Research funding

We aim to provide funding for vital research in institutions both in the UK and collaboratively with our partners worldwide. Scientific research is essential to determine the basic mechanisms of the disease but also to develop effective therapies and ultimately a cure.

Letter from Chair of Trustees & BDFA Chief Executive

Given the ongoing groundswell of support from our members and fundraisers the BDFA continues to grow and consolidate its ability to deliver much needed services to families affected by Batten disease and the professionals around them.

2013-14 saw a number of challenges which our staff and Trustees have met valiantly. This has enabled us to continue to deliver our much needed services in a rapidly changing environment. We will continue to be challenged, as are many rare disease charities facing a changing UK political environment, but we believe that we have made plans to help us better manage these changes for the benefit of our families.

Early summer 2014 saw Matt Hobbs, the BDFA Family Support Officer, leave the BDFA staff team. Given his enormous personal and professional commitment to the families we support, he left a pair of shoes which were very difficult to fill. It has been very challenging to recruit a high quality person into this role but it continues to be a central role to the aims of the BDFA and the services we deliver. We hope to have recruited for this role very shortly.

Along with our Freephone helpline and Small Grants Scheme we know that we are making a real difference in the daily lives of families who are living with Batten disease. Our support work continues from strength to strength and our team will include the new role of Batten disease Clinical Nurse Specialist which is currently being recruited at Great Ormond Street Children's Hospital.

We may be biased, but we firmly believe that our fundraisers are some of the best. We have seen fundraising events ranging from the London Tube Challenge, Tough Mudders, heads being shaved, swims in Scottish Lochs and many more. The ingenuity and commitment of our fundraisers for a small rare disease group like ourselves is humbling, but we know that anyone who is touched by or hears about this disease cannot fail to be moved to do something.

We also continue to be proud of our work in the field of research, from direct funding of projects both in the UK and worldwide, to our

collaborative working with the Pharmaceutical company BioMarin and their Enzyme Replacement Therapy trial for CLN2 (LINCL) disease in the UK and Europe.

We are witnessing some ground breaking times for Batten disease research and believe that we are uniquely positioned to be able to advocate for families to enable their essential voices to be heard.

In Autumn 2014 we will further build on our strong relationships from NCL2012 in London by attending the NCL2014 Congress in Argentina. We have a proud history in the BDFA of working across boundaries to ensure the best use of our limited resources and to share best practice. Our supporters continue to be the bedrock which enables us to fight this devastating set of diseases.

Sometimes we think that if we always look at where we need to get to we run the risk of not acknowledging how far we have come. Without our supporters behind us we could never hope to have achieved what we have and without their continued support we could never reach our goal to beat Batten disease.

Fifteen years ago a group of very courageous parents made a commitment; a commitment that we in the BDFA are very proud to continue to make.

We thank all of you for your hard work and support over the last year – it is only with you that together we WILL make a difference to families in the coming year.



Andrea West

Michael Thomas

About the NCLs

The NCLs are several different genetic, life-limiting, neurodegenerative diseases that share similar features and occur in children and adults worldwide.

The NCLs are estimated to affect 1:30,000 births with there being approximately 200 affected children and young adults in the UK. They are born apparently healthy yet subsequently develop epilepsy, lose their sight, speech, cognitive and motor abilities; before dying between the ages of 5 and 30 (dependent on the specific diagnosis). There continues to be much research into all the NCLs, but no cure at present.

Having Batten disease profoundly changes the child's and their family's life forever. The journey with these diseases is an ever changing picture of needs. Unlike other diseases where there is huge awareness of the support, therapies and guidance mechanisms needed for the child and family, the families of children and young people with Batten disease are left isolated as most professionals do not understand the course of the disease and the child or family's needs. It is therefore essential that the families and professionals have the BDFa to turn to for that support and guidance.

The BDFa continues to produce valuable resources and materials for families and professionals on all aspect of the NCLs and the holistic care needed for children and young adults.

Supporting the educational needs of children who have a diagnosis of NCL (Batten disease)

How will NCL affect my child's education?

Many families affected by the various forms of **Neuronal Ceroid Lipofuscinoses (NCL)**, commonly referred to as **Batten disease**, will be faced with numerous important decisions about education for their child. The **Batten Disease Family Association (BDFa)** aims to help them get the best possible provision, as well as advising and supporting those professionals working with them.

We are able to provide unique support through our **BDFa Education Advisor** (a qualified teacher of the visually impaired who has worked with many children and young people diagnosed with the various forms of NCL).

This leaflet offers information about support available for individuals who have **Special Educational Needs (SEN)** due to a diagnosis of NCL, as well as providing general advice for families who wish to ensure their child receives the best educational experience possible. We recommend families share this document with all the professionals from education, health, social and other services working with them.

The **BDFa** recognises that the **INCL (infantile), JNCL (late-infantile) and JNCL (juvenile)** disease processes impact upon children and young people in varying ways and at different stages of their life. We are developing resources to address issues particularly relevant to each form of the disease (e.g. coordinated support from Early Years Practitioners for those with **INCL**, ensuring medical support is facilitated appropriately and sensitively for those with

LNCL and developing appropriate behavioural strategies for those with **JNCL**.

Each child and family's journey with NCL will differ in some ways to that experienced by others due to many varying factors (e.g. the specific genetic diagnosis, age of onset etc.). However, through drawing upon our experience, insight and knowledge, we aim to offer holistic advice and support regarding the various educational issues that arise at different stages, which will always focus on the individual child and family.

What are Special Educational Needs (SEN)?

SEN refer to the communication, physical, sensory and emotional difficulties experienced by children and young people that require support. Each may need additional or alternative assistance in their education than those children who are not considered to have SEN. Being diagnosed with any form of NCL disease means that a child or young person should be considered to have SEN.

What about planned changes to SEN Law?

The Children and Families Act 2014 introduced changes to the way SEN and disability (SEN/D) will work in England. **Education, Health and Care Plans (EHCPs)** will gradually replace **Statements** and will bring together all the education, health and care needs of the child. Statements already in place will gradually be converted to an EHCP plan by April 2018. There are differences in SEN law in Scotland, Northern Ireland and Wales. Please contact the **BDFa Education Advisor** for advice on this.

What should I do about my child's SEN?

Following a diagnosis of NCL, it should be recognised that your child has SEN and you will need to talk to a relevant professional involved with your family. Depending on the age of your child, this may be a health visitor, someone in their early years' education setting, a teacher or **Special Educational Needs Coordinator (SENCO)** at the school.

You should explain about the diagnosis and share any concerns you have, providing examples of how this could impact on their education. It is important to ask what can be put in place and consider contacting other agencies who may be able to assist. Please contact **BDFa** if you would like assistance or to discuss this.

Free phone: 0800 020 0200 **bdf-a-uk.org.uk** **www.bdf-a-uk.org.uk**



BDFA Support & Advocacy Programme

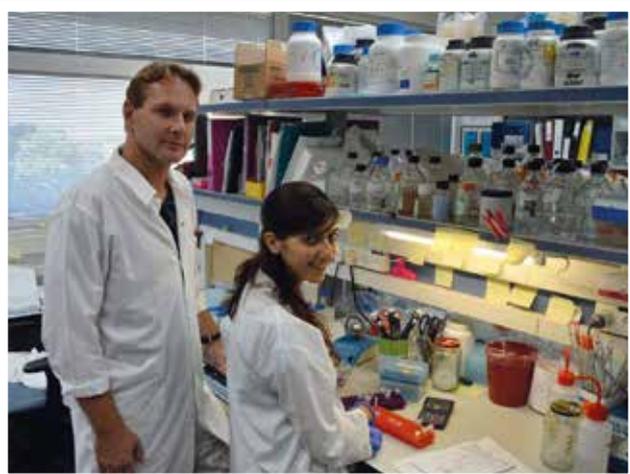
At the BDFA we are very proud of the support and advocacy service which we are able to offer to families affected by this devastating set of diseases. Given the rare nature of the NCLs it is also important that we are able to provide a programme of support, training and networking to the teams of professionals around families. Only by driving this holistic programme of care are we able to meet our aim of enabling families to live the best life they can.

Some of the highlights of the past year are:

- The BDFA Family Support Officer continued to provide a support, advocacy and signposting service to families across a range of areas including housing, benefits, equipment and service provision.
- Through this role we also provide emotional support to families, extended family members and whoever is touched by the devastating effects of Batten disease.
- The BDFA continues to support families on diagnosis with emotional support, resources and the family networking scheme.
- The BDFA has been contracted by the US pharmaceutical company, BioMarin to provide advocacy support for families participating in the BMN190 Enzyme Replacement Trial in sites in London, Hamburg and Rome.
- The BDFA Freephone helpline continues to be a vital resource for families and professionals providing emotional and practical support alongside signposting to other agencies.
- This year the BDFA Small Grants Scheme provided 35 families with much needed financial support for items such as travel to hospital, play equipment, unexpected utility bills and driving lessons to reduce isolation.
- The BDFA is the patient advocacy lead for a collaborative European Education Project for young people with CLN3 (Juvenile Batten disease).
- We have continued to provide much needed extensive education support and advocacy through to Tribunal stage to ensure that children and young people with a diagnosis of an NCL receive the best education experience.
- BDFA Family Networking Conference delivered in collaboration with the RNIB Pear's Centre in Coventry.
- Revision of all of the BDFA disease leaflets and resources produced for families on education, equipment and diagnosis.
- The 2014 BDFA Annual walk weekend again provided an invaluable social and networking event for families to meet and support each other in a relaxed environment.
- We continue to publish a bi-annual members' newsletter and bi-annual supporters' newsletter. We also deliver regular updates by email and have a strong presence on social media to raise awareness and funds for our work.
- The BDFA maintains a comprehensive website, with regularly updated sections on support, research, awareness and fundraising.
- The BDFA promotes links to UK professionals with clinical, research and educational specialist expertise in Batten disease, who can give professional guidance to the families and other related professionals.
- The BDFA works collaboratively with international Batten disease organisations to extend the support available to families and maximise the resources available.
- Recruitment of first UK Batten disease Clinical Nurse Specialist at Great Ormond Street Children's Hospital.
- Advocacy and joint working with other Charities such as the Amber Trust to provide much needed music therapies to children and young people.
- National press family story on Rare Disease Day to highlight the challenges for families living with an NCL diagnosis and to raise awareness on an international stage.

BDFA Research Programme

A key goal of the BDFA is that each year we are able to directly support researchers in the field of Batten disease to fund their crucial work. Finding potential therapies and ultimately a cure for all forms of the NCLs is one of our central aims.



- In 2013/14 we continued our funding of Sophia Kleine-Holthaus, a PhD student working on the Gene Therapy to the Eye project with Dr Sara Mole at University College London and Professor Robin Ali. The BDFA recognises the importance of this research and has committed to further future funding in our plans for 2014/15.
- With the support of the Freeman family we were able to award funding to Dr Claire Russell at the Royal Veterinary College to continue her work on drug discovery in a zebrafish model of the NCLs.
- Professor Jon Cooper and Dr Brenda Williams of King's College London, UK have been awarded funds for their work on cell based systems for drug discovery in JNCL. The work will be undertaken by Greg Anderson, (NCL-Stiftung funded PostDoc) and Jenny Lange (King's College funded MRC-PhD student).
- Prof Jeffrey Gerst, Weizmann Institute of Science, Israel has recently appointed Osnat Zontag-Cohen. Her PhD studies will form the basis of a project on the development of a cell-based assay for identifying downstream effectors of CLN3 and use in drug screening.
- We have also funded Davide Marotta at Dr Sara Mole's lab at UCL working on yeast models of the NCLs.

Other Research Projects

The BDFA is committed to ensuring that science is accessible and we work closely with the key labs in the UK to enable them to provide hands-on experience of their work to families and interested professionals.

In June 2014 the BDFA and Professor Jon Cooper co-hosted a lab day at the Lysosomal Storage Disorders lab at King's College, London.



Weill Cornell Medical College

The Department of Genetic Medicine at Weill Cornell Medical School is conducting a gene therapy study for the CLN2 gene. Patients with the diagnosis of CLN2 (Late Infantile Batten disease), who meet the eligibility criteria, would be enrolled in the study for 18 months.

The study aims to determine whether gene transfer surgery, in which an experimental drug called AAVrh.10.cuhCLN2 is administered to the brain, can be achieved safely and whether the procedure will slow down or halt the progression of the disease.

There is no compensation for participating in this study. The costs of travel and accommodation are also not covered. There are no costs associated with the tests and procedures that are conducted under the scope of the research study.

For more information please contact Denesy, Research Manager at dem2026@med.cornell.edu or visit www.clinicaltrials.gov and please search for "Safety Study of a Gene Transfer Vector (Rh.10) for Children with Late Infantile NCL".



CellCept for Treatment of Juvenile Neuronal Ceroid Lipofuscinosis (JUMP)

This trial is only open to U.S. patients who meet the eligibility criteria. It is based at the University of Rochester Medical Center (UMRC) and is aiming to learn if mycophenolate (CellCept) is safe and well tolerated in children with JNCL. The JUMP study focuses on evaluating CellCept and its effects on the symptoms of JNCL.

As the trial is ongoing no data is available to be released at present. So far, 14 patients have completed the trial, a further two are enrolled at present and UMRC are continuing to recruit and enrol the remaining patients. There is more information regarding the trial itself on the website provided by the U.S. National Institutes of Health, www.clinicaltrials.gov.

B:OMARIN

BioMarin CLN2 BMN190 Clinical Trial

The BDFFA continues to work very closely with the Californian pharmaceutical company, BioMarin, to deliver the BMN190 clinical trial of enzyme replacement therapy for children with a diagnosis of CLN2 (Late Infantile Batten disease). Alongside the medical teams at each of the trial sites and the home country patient organisations, the BDFFA has been supporting families to meet the challenges of participating in a clinical trial.

We would like to thank the A-NCL Associazione Nazionale Ceroido Lipofuscinosis in Italy and the German patient organisation NCL-Gruppe for their continued work in their own countries to support families and medical teams involved in the trial.

The Bambino Gesù Hospital IRCCS, Rome is now recruiting to the trial and Dr Nicola Specchio (Head of the Epilepsy Surgery Unit at the Hospital) will be the Principle Investigator for the study. The Bambino Gesù Hospital has expertise in caring for children with complex and challenging medical disorders and is

an established centre for the diagnosis and management of children with Batten disease. Trial recruitment has ceased at the Evelina London Children's Hospital and it is hoped that another site will open at Great Ormond Street Children's Hospital in London in the near future, with Professor Paul Gissen as the Principle Investigator.

The trial continues in Germany at the Children's Hospital, University Medical Centre, Hamburg-Eppendorf where children are being recruited to the study with Dr Angela Schulz.

The trial is enrolling approximately 22 patients for a treatment duration of 48 weeks and families have been admitted to the trial centres from across the world. The BDFFA has produced a patient information leaflet for the BMN190 trial which can be obtained from: admin@bdfa-uk.org.uk. We have also produced a general leaflet describing the process of clinical trials.

The BDFFA recognises the decisions around clinical trials can be very challenging for families and is able to support families considering these issues and to put them in touch with other families who have taken part in clinical trials. As always, all questions about a child's medical care should be directed to the relevant health professional.





The Future of the BDFa

To enable us to support families to manage the effects of an NCL diagnosis and to drive forward plans for a robust UK Batten disease service, the future for the BDFa will be a busy one. The Board have prioritised our strategic planning to enable us to best manage these changes for the benefit of the charity but most importantly the families and professionals we support. Our priorities include:

- Review of 3 year plans for the Charity.
- Move into office premises to strengthen our infrastructure and staff team.
- Changes in staff team to consolidate fundraising and administrative support.
- Review of national advocacy and position of Batten disease on the UK Health and Social Care political agenda.
- Continue collaborative working with BioMarin on BMN190 trial and future Batten disease work both in the UK and with our collaborative international partners.
- Continue to deliver Freephone helpline via Support and Advocacy Partner role.
- Development of education advocacy service in face of increasing need alongside the development of a Batten disease Educational Professionals network.
- Maintenance of Small Grants programme.
- Delivery of an annual Family Networking Event.
- Further development and consolidation of regional support and fundraising groups.
- Implementation of Batten disease Clinical Nurse Specialist.
- Patient Advocacy lead for BATCURE project with Dr Sara Mole at UCL.
- Continued delivery of lab days for UK Labs in 2015.
- Attendance at NCL2014 in Argentina and delivery of lay feedback for families in the UK.
- Batten Disease International Alliance meeting in 2015.
- Review of service provision for UK Batten disease patients within the NHS.
- Recruitment of new trustees to the Board.
- Recruitment of new medical, and research advisors to the BDFa team.
- Patient advocacy lead for European JNCL education project.
- Project on national needs assessment of families living with Batten disease.

Financial Review

Performance in the Year

The BDFA raised £285,060 in 2013-2014 against £277,884 the previous year, thanks to the continuing invaluable support of all the families, friends, grant making bodies and work colleagues via their donations, grants and continuing commitment to fundraising events.

The BDFA spent £266,837 on its immediate strategic objectives as well as continuing to build the employee and organizational infrastructure to take the organization forward to meet its future goals.

Receipts

Our donation income and grant income continue the pattern of previous years with increases of 31% and 56% respectively. As with all of the BDFA financial planning and in light of these figures, the strategic income planning for 2014-2015 reflects the need for diversification beyond events sponsorship which can be unpredictable and the need to spread our income streams.

£68k of restricted funding was spent on the PhD studentship, research and the CLN1, CLN2 and CLN3 resource packs.

The current level of restricted funding of £175,431 is for specific projects including:

- The remainder of the PhD studentship funding
- The funding allocated to the Clinical Nurse Specialist role
- Gene Therapy to the Eye project funding from Beefy's Charitable Foundation
- LINCL research funding
- Battle Batten CLN5 research funding
- BMN190 advocacy funding
- Helpline costs
- Production of impact report
- Resilience weekends
- CLN3 research

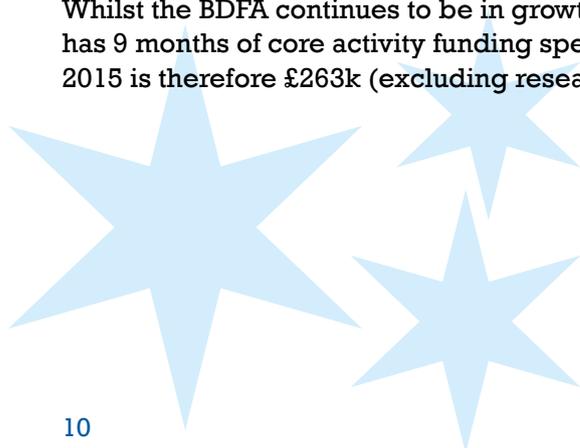
Payments

£49,051 of research funding this year was spent on the projects as outlined in the research programme section of the report. £4,990 was spent on the Small Grants Programme.

Fundraising costs decreased against income and Governance costs showed a small increase alongside an increase in the number of Trustees.

Reserves Policy

Whilst the BDFA continues to be in growth and therefore at a higher potential risk, the charity ensures it has 9 months of core activity funding spend in hand. Its minimum agreed figure for this purpose for 2014-2015 is therefore £263k (excluding research and restricted spend).



Statement of Trustee 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 on a receipts and payments basis. 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 for 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 and prudent
- Prepare the financial statements on an ongoing concern basis unless it is inappropriate to assume the Charity will continue in business

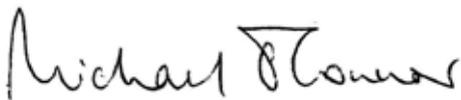
The Trustees are responsible for keeping proper accounting records that disclose with reasonable accuracy at any time the financial position of the Charity. The Trustees are also responsible for safeguarding the assets of the Group and Charity and hence taking reasonable steps in the prevention and detection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

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

Authorisation of Issue

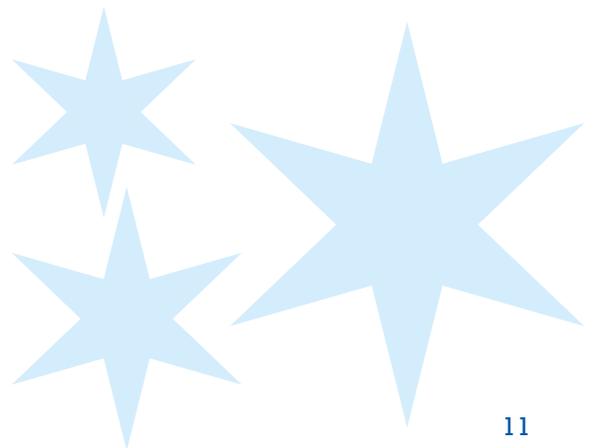
The Trustees authorise the issue of the financial statements on the date they are approved by the Board.

On behalf of the Trustees



Mike O'Connor BDFA Chairperson

Date: 23 October 2014



Reference & Administrative Details

Address and Registered Office:

BDFA
PO Box 504
Fleet
GU51 9GE

Trustees:

Chair:

Michael O'Connor

Co-Chair:

Pauline Docherty

Secretary:

Sarah Kenrick

Treasurer:

Alison Jenkins - resigned 2013

Barbara Higgins

Kathryn Thompson

Ellen Bletsoe

Shaun Andrews

Irena Newcombe

David Mitchell

Co-opted Board members

Ben Jones

Catherine Sermon

Briony Lumb

Professional Volunteer Advisors:

Research:

Professor Jon Cooper, Professor of Experimental
Neuropathology, Institute of Psychiatry, King's College London

Dr Sara Mole, Reader in Molecular Cell Biology, MRC
Laboratory for Molecular Cell Biology, University
College London

Dr Claire Russell, Senior Lecturer in Comparative BioMedical
Sciences, Department of Comparative BioMedical Sciences,
Royal Veterinary College

Dr Brenda Williams, Programme Leader, Institute of Psychiatry,
King's College, London

Education:

Mrs. Barbara Cole, Educational Advocate

Medical:

Professor Paul Gissen, Consultant in Paediatric Metabolic
Disease, Great Ormond Street, Children's Hospital London and
Wellcome Trust Senior Research Fellow in Clinical Sciences at
the UCL Institute of Child Health.

Bankers:

The Co-Operative Bank
PO Box 250
Skelmersdale
WN8 6WT

Santander Bank
Bootle
Merseyside L30 4GB

Independent Examiner:

JKAB Accountancy
Unit 8
Kiln Workshops
Pilcot Road
Crookham Village
Hampshire GU51 5RY

Structure, Management & 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

The BDFA values a diverse Board and recruits Trustees based on their experience and on the skills and expertise they can bring to the Charity. The Board maintains a balance between those who have direct experience of Batten disease as family members and those with other skills relevant to the development of the Charity's mission and aims. Advertisements are placed in the Association's newsletter, its website and in social media.

Such candidates are then given information on the role, interviewed by the Chair and Secretary and if appropriate, are invited to a Trustees' meeting. Appointment is then conditional on the approval of the Trustees and members at the AGM and is subject to DBS disclosure and Trustees' Declaration of Eligibility. Trustees have fully documented information packs and job descriptions to support their recruitment and induction to the Board.

Organisational Structure

The strategy and oversight 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 has been carried out by the employed Chief Executive, Andrea West, supported by the following part-time team for 2013/14.

- Matt Hobbs, Family Support Officer
- Heather Band, Scientific Officer

The team of employees were supported by:

- Naked Fundraising (fundraising contractor)
- Lucy Rose (administrative services contractor)
- Carole Cairns (bookkeeping services)

The recruitment process of new staff is guided by the BDFA Recruitment and Selection Policy in accordance with statutory legislation and good practice.

The Board meets with the Chief Executive and members of the staff team at least 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 Advisors who liaise with the employed Officers and the relevant Trustees as necessary.

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 as part of an annual process and as a result of this process, the Board are satisfied that residual risks are minimal.

Statement of Financial Activities for the year ended August 2014

	Unrestricted funds 2014 (£)	Restricted funds 2014 (£)	Total funds 2014 (£)	Total funds 2013 (£)
Incoming resources				
Voluntary income	171,389	112,963	284,352	277,186
Activities for generating funds	306	-	306	347
Investment income	402	-	402	351
Incoming resources from charitable activities	-	-	-	-
Other incoming resources	-	-	-	-
Total incoming resources	172,097	112,963	285,060	277,884
Resources expended				
Costs of generating funds				
Fundraising costs	52,439	-	52,439	55,652
Charitable activities	135,448	68,976	204,424	255,546
Governance costs	9,974	-	9,974	9,741
Total resources expended	197,861	68,976	266,837	320,939
Net income/outgoing resources before transfer	25,764	43,987	18,223	43,055
Gross Transfer between funds	-	-	-	-
Net incoming/outgoing resources before other recognised gains/losses.	25,764	43,987	18,223	43,055
Other recognised gains/losses				
Gains and losses on investment assets	-	-	-	-
Net movement in funds	25,764	43,987	18,223	43,055
Total funds brought forward	258,398	131,444	389,842	432,897
Total funds carried forward	232,634	175,431	408,065	389,842

Statement of Assets & Liabilities

	Unrestricted runds (£)	Restricted Income funds (£)	Total this year (£)	Total last year (£)
Fixed Assets				
Tangible assets	-	-	-	-
Investments	-	-	-	-
Total fixed assets	-	-	-	-
Current assets				
Debtors	1146	-	1146	13
Cash at bank and in hand	240306	175431	415737	395570
Total Current assets	241452	175431	416883	395583
Creditors	8818		8818	5741
Net current assets	232634	175431	408065	389842
Total assets less current liabilities	232634	175431	408065	389842
Charity Funds				
Unrestricted	232634		232634	258398
Restricted		175431	175431	131444
Total charity funds	232634	175431	408065	389842

