

# Batten Disease Family Association

Annual Report and Financial Statements

for the Year Ended 31 August 2015

# Batten Disease Family Association

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**Batten Disease Family Association**  
**Reference and Administrative Details**

<b>Charity name</b>	Batten Disease Family Association
<b>Independent examiner</b>	Hilary Parmenter, Chartered Accountant 1 The Willows North Warnborough Hampshire RG29 1DR
<b>Accountant</b>	Jupp Castle Limited 5 Taplins Court Taplins Farm Lane Hartley Wintney Hampshire RG27 8XU

# **Batten Disease Family Association**

## **Trustees' Report**

**REGISTERED CHARITY NUMBER 1084908**

### **REPORT OF THE TRUSTEES AND UNAUDITED FINANCIAL STATEMENT FOR THE YEAR ENDED 31 AUGUST 2015 FOR BATTEN DISEASE FAMILY ASSOCIATION (BDFA)**

The Trustees present their report with the financial statements of the charity for the year ended 31 August 2015. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issues in March 2005.

#### **REFERENCE AND ADMINISTRATIVE DETAILS**

##### **Registered Charity Number**

1084908

##### **Principal Address**

The Old Library  
4 Boundary Road  
Farnborough  
Hampshire  
GU14 6SF

##### **Trustees**

Chair	Michael O'Connor
Co-Chair	Pauline Docherty
Secretary	Sarah Kenrick
Treasurer	Ben Jones
	Barbra Higgins
	Kathryn Thompson - resigned 2014
	Shaun Andrews
	Irena Newcombe - resigned 2015
	Ellen Bletsoe
	David Mitchell - resigned 2015
	Catherine Sermon
	Briony Lumb - resigned 2015

##### **Independent Examiner**

Hilary Parmenter  
Chartered Accountant  
1 The Willows  
North Warnborough  
Hampshire RG29 1DR

##### **Bankers**

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

Santander Bank  
Bootle  
Merseyside  
L30 4GB

# Batten Disease Family Association

## Trustees' Report

### REFERENCE AND ADMINISTRATIVE DETAILS

#### Research Advisers

Dr Sara Mole  
Reader in Molecular Cell Biology  
MRC Laboratory for Molecular Cell Biology  
UCL  
Gower Street  
London  
WC1E 6BT

Dr Brenda P Williams  
Senior Lecturer  
Programme Leader, MSc Neuroscience Distance Learning  
KATTP Summer School Lead  
Departmental Teaching Lead  
IoPPN Assessment and Feedback Lead  
Department of Basic and Clinical Neuroscience  
Maurice Wohl Clinical Neuroscience Institut  
5 Cutcombe Road  
Camberwell  
London SE5 9RX

Dr Claire Russell  
Senior Lecturer in Comparative Biomedical Sciences  
Department of Comparative Biomedical Sciences  
Royal Veterinary College  
Royal College Street  
London  
NW1 0TU

Prof Jonathan D Cooper  
Professor of Experimental Neuropathology  
Department of Basic and Clinical Neuroscience  
Institute of Psychiatry, Psychology & Neuroscience  
King's College London  
Maurice Wohl Clinical Neuroscience Institute  
5 Cutcombe Road  
London SE5 9RX

#### Education Adviser

Mrs Barbara Cole, Education Advocate

#### Medical Adviser

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 UCL Institute of  
Child Health.

### STRUCTURE, GOVERNANCE AND MANAGEMENT

#### 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 New 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 mission and aims. Advertisements for new trustees are made in the Association's newsletter, with volunteer bureaux, on the BDFA website and social media platforms.

Candidates are then given information on the roles, interviewed by the current Board and invited to attend a Trustees' meeting. Appointment is then conditional on the approval of Trustees and members at the AGM and is subject to a DBS disclosure and Trustee's 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, and supported by the following team in 2014/2015:

1. Harriet Lunneman (Full-time) Family Support Officer
2. Heather Band (25 hours per week) Scientific Officer
3. Lucy Roose (25 hours per week) Office Manager
4. Gaynor Heeson (20 hours per week) Fundraising Administrator
5. Kate Shefford (20 hours per week) Fundraising Administrator

All HR and Health and Safety procedures for the BDFA are done under contract with Peninsula Business Services.

# **Batten Disease Family Association**

## **Trustees' Report**

The BDFA has a team of volunteers who assist with office administration and fundraising activities. All volunteers have a defined induction and undergo DBS checks where appropriate. 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.

The Board of Trustees meets 6 times per year with the Chief Executive to review work and formulate strategy.

### **Risk Management**

The BDFA Board of Trustees places a high priority on risk management. Risks identified are categorised as follows:

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

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

### **OBJECTIVES AND ACTIVITIES**

#### **Who we are**

The Batten Disease Family Association is the only UK charity supporting families, raising awareness and funding research into the devastating set of neurodegenerative diseases commonly known as Batten disease. The BDFA was founded in 1998 by a group of parents who were determined that no family should face the journey with this diagnosis alone. We work with the scientific, medical, social care and educational professionals in the UK and worldwide to drive forward towards therapies for all forms of the disease and to ensure that families living with the diagnosis today have access to the best services available.

#### **About the NCLs (Batten disease)**

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

The NCLs (Batten disease) are estimated to affect 130,000 births with there being approximately 200 affected children and young adults in the UK. They are born apparently healthy, before going on to develop epilepsy, lose their sight and speech, their cognitive and motor abilities; and then dying between the ages of 5 and 30 (depending on the specific diagnosis). There continues to be much research into all forms of the NCLs, but no cure at present.

An NCL diagnosis 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 resources 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 a place to turn to for that support and guidance.

The BDFA produces valuable resources, materials and training for families and professionals on all aspects of the NCLs and the holistic care needed for affected children and young adults.

#### **What we do**

**Support:** Our aim is 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 families, affected children and adults and also the team of professionals around them.

**Advocacy and 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 the NCLs to enable families and professionals to access the best resources and to give the best quality of life to affected children and young adults.

# **Batten Disease Family Association**

## **Trustees' Report**

**Research funding:** We aim to provide funding for vital pre-clinical and clinical research in institutions both in the UK and worldwide. Research is vital to both determine the basic mechanisms of the disease and to develop effective therapies and ultimately a cure.

By 2018 the BDFA's drive and vision will have secured us a place as a worldwide leader in advocacy, support and research funding in the field of Batten disease.

As the only UK national Batten disease charity, the BDFA strives to ensure that everyone living with a diagnosis of Batten disease has access to the best quality services and support to enable them and their families to live life to the full and to change lives by funding research into potential therapies and ultimately a cure.

Our stakeholders - including our affected families, related professionals, Batten Clinical Nurse Specialist, international partners, pharmaceutical companies, supporters and donors expect us to

- deliver a high quality, professional support service to affected families and the professionals who work with them
- provide direct and collaborative funding to scientists to drive the NCL research agenda towards potential therapies and ultimately a cure
- to raise awareness and campaign for of all forms of the NCLs to ensure legislative commitment to best quality standards of care and future treatments

### **Support goals**

- To develop a national Batten disease service from screening through to diagnosis and potential therapies.
- To advocate with national Government on the level and quality of service received by families living with a diagnosis of Batten disease.
- To work with statutory and third sector providers to ensure that families receive a person-centred, needs led, high quality level of service across health, education and social care.

### **Research goals**

- To directly support the scientific community to drive innovative research through individual grants and collaborative funding.
- To develop and maintain strong research networks both in the UK and worldwide, attracting new and cutting-edge investigators.
- To engage with pharmaceutical companies to drive the clinical research agenda for all the NCLs.

### **Awareness goals**

- To aid and inspire those both within and outside of the Batten community to improve the lives of those affected through professional service development and holistic support .
- To motivate and encourage fundraising and resource development to underpin essential service delivery and drive the research agenda.

### **A sustainable, effective and efficient organization**

- Robust governance through a strong Trustee Board driving progress and managing risk and change for the BDFA
- Supportive, responsive and dynamic staffing structure to meet the evolving needs of service users and demands of service delivery
- Effective and efficient policies and procedures
- Secure and healthy workplace
- Strong funding strategy underpinning service delivery and meeting goals

### **BDFA Values**

Integrity Professionalism Empathy Family Community

In making decisions regarding the charities purposes and what the charity has done throughout the year to carry out those purposes the trustees have had due regard to the commission's public benefit guidance when exercising any powers or duties to which the guidance is relevant.

# **Batten Disease Family Association**

## **Trustees' Report**

### **Letter from BDFA Chair of Trustees, Mike O'Connor**

I welcome the opportunity to share with you again the positive impact that the work of the BDFA has had over the last year for affected families and the professionals who work with them. 2014-2015 saw us expand our team to include Katie Hanson, the first UK Batten disease Clinical Nurse Specialist, funded by the incredible efforts of our fundraisers and based at Great Ormond Street Children's Hospital. Since starting in April, Katie has already worked with many families both face to face and remotely providing clinical support and advice whilst developing a strong professional network across the UK. We thank all of you for making this vital post a reality and look forward to further great work in the future.

This year also saw a major step for the BDFA when we moved into our first offices and saw an expansion of our team to include a new Support and Advocacy worker and two new fundraising administrators. This has provided the BDFA with a firm foundation for our work and enabled us to access volunteers in the local community who have provided invaluable support to many of our events and day to day tasks. Our support and advocacy service continues to be central to the aims of the BDFA providing a vital point of contact for both families and professionals. As part of this service, this year has seen us continue to provide critical education support as many families struggle to access a good educational experience for their children and young people. This important service is growing and we are proud of our instrumental role in developing a strong UK education network of Batten professionals to meet the needs of children and young people.

We continue to work individually and in collaboration with other patient organizations to influence policy and the services available to affected families. We are very proud to have worked with the Department of Work and Pensions this year to ensure that families living with a diagnosis of a neurodegenerative condition, once their children have reached the higher level of benefit, will not have to constantly reapply for Disability Living Allowance. Families had told us that this was a massive physical and emotional burden and with the support of Greg Mulholland MP and Justin Tomlinson (Minister for Disabled People) we have effected a policy change which will go some way to alleviating this stress for families.

The last year has also seen progress with the BMN190 Clinical Trial by the US pharmaceutical company, BioMarin, for CLN2 (Late Infantile Batten disease). In January, BioMarin announced that early results showed evidence of disease stabilisation and all of the children have now entered the extension phase of the study. We continue to support all of those families enrolled at the sites in London, Hamburg and Rome and work closely with BioMarin and the regulators to ensure that a safe, effective treatment is available to as many children as quickly as possible.

The BDFA's strong commitment to research into all forms of the NCLs has continued this year, with further funding of our key Gene Therapy to the Eye project at University College London and research funding both in the UK and worldwide in the fields of drug discovery, registries and basic disease science. We have a proud history of driving forward a research agenda to bring the hope of a cure for all forms of this disease a step closer and are committed to continuing to fund vital research in the future.

All of our work is only possible with the help and support of our Board of Trustees, staff team, volunteers, members and supporters and I would like to thank each of you for the skill, experience, knowledge and most importantly time that you give to enable us to deliver our work. Each cake sale, each time you share a newsletter or leaflet, or each time you run a 10k takes us a step closer to our vision of a world without Batten disease whilst enabling us to support those families living with the reality of these devastating diseases today. Thank you for helping us to make a difference in 2014-2015 and we look forward to making more of a difference in the coming year.

# **Batten Disease Family Association**

## **Trustees' Report**

### **ACHIEVEMENT AND PERFORMANCE**

#### **BDFA Support and Advocacy Programme**

The BDFA delivers a support and advocacy programme centred on the reported needs of UK families affected by a Batten disease diagnosis. 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 the needs that families report to us to enable them and their children and young people to live the best life they can.

Some highlights of the past year are:

1. Recruitment of a new, experienced support officer - Harriet Lunneman - a qualified social worker with extensive experience of working with children with disabilities.
2. Funding and recruitment of the first Batten disease Clinical Nurse Specialist - Katie Hanson - at Great Ormond Street Children's Hospital in London.
3. The Support and Advocacy role continues to provide an advocacy and signposting service through the BDFA Freephone helpline and in face to face meetings with both families and professionals.
4. A move into the first BDFA's first offices in Farnborough, Hampshire and further expansion of the staff team with two fundraising administrators - Gaynor Heeson and Kate Shefford - to meet the growing demands of our incredible supporter fundraising.
5. Collaborative work with the US Pharmaceutical firm BioMarin to deliver a support service to those families enrolled on the BMN190 (and follow-up trials) of enzyme replacement therapy for CLN2 disease in the trial sites in London, Rome and Hamburg.
6. In 2014/15 the BDFA small grant scheme provided 20 families with much needed financial support for items such as driving lessons, passports, play equipment, educational equipment and washing machines.
7. The BDFA continues to be the patient advocacy lead for the European Education Project and in June hosted their London meeting.
8. Continuing to provide much needed education advocacy support through our education advisor to ensure that children and young people with an NCL diagnosis receive the best education experience.
9. Delivery of a Family Networking Conference in collaboration with the RNIB Pear's centre in Coventry which saw an increased attendance from families and the professionals working with them.
10. Production of a Family Resources folder based on family feedback that professionals have little or no information about the disease. This is free to all family members of the BDFA and provides information on the disease, symptoms, progression, health and social care, education and resources available. This will be a valuable resource for families to share with their care teams.
11. The 2015 BDFA annual walk again provided an invaluable social and networking opportunity for families and members to meet and support each other.
12. We continue to publish a bi-annual member and supporter newsletter. We also send weekly email updates on our work, impact and valuable resources to members.
13. We maintain a strong presence on a number of social media platforms to raise awareness, connect families and fund our work.
14. We promote links between UK professionals with clinical, research and educational specialist expertise in Batten disease and those who can give professional guidance to affected families and the teams around them.
15. We hosted a meeting of the Batten Disease International Alliance (BDIA) in London in June 2015.
16. We work closely with other charities such as The Amber Trust, Dreams Come True and Roald Dahl's Marvellous Children's Charity to provide much needed therapies and experiences to affected children and young adults.

# **Batten Disease Family Association**

## **Trustees' Report**

### **B DFA Research Programme**

A key goal of the B DFA is that each year we directly support research in the field of the NCLs both in the UK and worldwide to support the critical work of research scientists. Finding potential therapies for all forms of the NCLs is a central aim of the B DFA and we support research at all stages of this process. Research funding for 2014/15 is as follows:

#### **1. "Gene therapy to treat vision loss in JNCL"**

**Jan- Dec 2015**

**£60,000 (including £30,000 from Beefy's Charity Foundation)**

**Dr Sara Mole at the MRC Laboratory for Molecular Cell Biology**

**Prof Robin Ali, Dr Alexander Smith at the Institute of Ophthalmology, UCL.**

Vision loss is a key symptom of Batten disease and so the quality of life of those affected would improve if at least some vision could be preserved. The aim of this project is to investigate the feasibility of gene therapy to treat visual failure in Batten disease.

This work is being performed by Sophia kleine Holthaus (B DFA 3-year PhD studentship Jan 2012-Dec 2014) under the supervision of Dr Sara Mole at the MRC Laboratory for Molecular Cell Biology, and Prof Robin Ali and Dr Alexander Smith at the Institute of Ophthalmology, UCL.

Sophia's excellent work for her PhD project showed that whilst loss of photoreceptor cells in the eye occurred early on in NCL disease, other cell populations were affected and this would need to be addressed for a successful therapeutic outcome. Therefore, with the project at such a crucial stage, the B DFA funded a further 1-year project in January 2015. This enabled the work to continue without interruption with the added benefit that the knowledge and skills of an exceptional researcher would be retained within the field. The ultimate aim was to further the research to a sufficient level for Dr Mole to be in a position to apply for larger grants. This was recently realised with major EU funding and a Wellcome Trust grant being awarded which will commence in January 2016. This substantial new funding, combined with further B DFA resources (£60,000 for 2016, including £20,000 from Beefy's foundation) will expand the project to cover CLN2, CLN7 and CLN8 for a further 3 years, with two Post Doctoral Scientist positions.

#### **2. Drug discovery in a CLN2 zebrafish model**

**Jan-October 2015 £19,692.75 (Freeman family, CLN2 restricted funds and B DFA research funds)**

**Dr Claire Russell, Ms Gini Brickell, MSc Royal Veterinary College**

In 2013 the B DFA made an award to Dr Russell of £13,500 with funds provided by the Freeman family in memory of their daughter Katie, to provide the capacity to perform high-throughput in vitro drug discovery for LINCL (CLN2 disease) with the purchase of a Daniovision automated tracking system.

Preliminary studies confirmed the viability of using the equipment to screen an FDA-approved library of compounds (approx. 500) purchased by Dr Russell. In January 2015 the B DFA funded Ms Gini Brickell MSc as a Research Assistant for a 9-month project to develop the technique and complete the drug screen.

Gini has exceeded expectations for the predicted workload, as this is very intensive study to be completed in a relatively short time. Several compounds showed initial promise and after further investigation a lead compound has been identified for further study.

#### **3. International Disease Registry Project**

**Dr. Angela Schultz, MD, Lead Coordinator DEM-CHILD NCL patient database consortium**

**University Medical Center Hamburg-Eppendorf**

**B DFA £11 500 contribution to BDSRA awarded research grant of \$55,000.**

This project seeks to perform large-scale retrospective chart analyses in all various forms of NCL.

This project will be performed by the DEM-CHILD NCL patient database consortium, which was initially founded by members of the European Commission funded project DEM-CHILD. The aim is to collect the world's largest, clinically and genetically best characterized, set of NCL patient data.

# Batten Disease Family Association

## Trustees' Report

These data collections will be an indispensable tool for the evaluation and validation of new therapies and the validation and improvement of palliative care of NCL patients.

### 4. Research Grants Completed in 2014-5

a. "Enzyme Replacement Therapy for PPT1-Related NCL".

Sandra L Hofmann, M.D., Ph.D.  
Professor in Internal Medicine  
University of Texas Southwestern Medical Center, USA  
\$76,759 approx. £55,000

Professor Jon Cooper (Histological analysis)  
Kings College London  
£6,250

The CLN1 form of Batten disease is caused by build-up of material in the brain due to lack of an enzyme called palmitoyl-protein thioesterase, or PPT.

The BDFA funded Professor Hofmann's group, through a research award scheme with the BDSRA, to determine the effect of administering PPT directly to the central nervous system of PPT deficient mice by injection into the cerebrospinal fluid, as in a spinal tap.

Currently there is a clinical trial for children with CLN2 Batten disease in which the deficient enzyme TPP-1 (BMN-190) is being administered to the cerebrospinal fluid of the brain. Preclinical mouse studies involving the CLN2 enzyme, similar to those undertaken in this project were an essential part of the development of the CLN2 treatment.

The results obtained CLN1/PPT mice support using the same approach for CLN1 disease, if BMN-190 shows good results for CLN2, late infantile NCL then future experiments would be needed with this work more suited to pharmaceutical company drug development program.

Project completed, grant extended until 30/05/15 to allow for publication. Accepted in Molecular Genetics and Metabolism, May 2015.

b. Professor Jon Cooper

(Dr. Brenda Williams until March 2014)  
Kings College London  
"Cell based systems for drug discovery in JNCL".  
£38,622.00

1-Year grant March 2013- Feb 2014.

Extended to July 2016

The aim of this research is to use human neural stem cell lines that carry the JNCL mutation to generate different brain cell types. Neural stem cells are the founder cells of the central nervous system and may be used to make different brain cell-types a dish in order to study their function or to use them as a drug screen.

### Clinical Trials

#### 1. 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 call 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.

#### 2. CellCept for Treatment of Juvenile Neuronal Ceroid Lipofuscinosis (JUMP)

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This trial is only open to US 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.

### 3. BioMarin CLN2 BMN 190 Clinical Trial

The BDFA 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 BDFA 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 trial is now fully enrolled and many of the children have completed their first year and have entered the subsequent extension study. BioMarin released an interim statement in January 2015 stating that the preliminary results showed signs of disease stabilisation. The BDFA continues to work with BioMarin and the regulatory bodies in Europe to ensure the fastest route to access of a safe, effective drug for affected children.

### OUR FUTURE PLANS

The work continues for the BDFA to enable us to further support families living with this diagnosis and legacy whilst working towards our vision of a world without Batten disease. The BDFA Board continue to prioritise our strategic planning to ensure a robust service that meets the needs of families and drives the research agenda for the future.

**Goal 1: To ensure that everyone living with a diagnosis of Batten disease has access to high quality services and support to enable them to live life to the full.**

#### To achieve this, we will:

- develop a national Batten disease service from screening through to diagnosis and potential therapies.
- advocate with national Government on the level and quality of service received by families living with a diagnosis of Batten disease.
- work with statutory and third sector providers to ensure that families receive a person-centred, needs led, high quality level of service across health, education and social care.

#### By 2018 we will:

- Having implemented the first Batten disease Clinical Nurse Specialist in the UK, we will work towards securing the appointment of a second
- review and drive national advocacy and the position of Batten disease on the UK Health and Social care political agenda to initiate change and service development
- continue to have in place a Batten disease Support and Advocacy service across the UK to meet the needs of the whole of the family's journey with this disease from diagnosis through palliative care and bereavement.
- develop and implement an education advocacy service in the face of increasing need alongside the development of a Batten disease Education Professionals network
- support and continue to develop networking opportunities for families and the professionals who work with them based on the needs identified by these stakeholders

#### Support goals 2015-2018

- To provide a high quality support, signposting and referral service for families through one to one Support and Advocacy service
- To produce a Batten resource pack for each affected family
- To deliver 3 workshops per year of training and support for education, social care and health professionals working with affected families
- To develop and deliver a family needs assessment to better understand the needs of families living with an NCL diagnosis.
- To initiate weekly contact with new and existing allied organisations to share and develop a high quality resource library for families and professionals
- To consolidate and provide an induction for first Batten CNS post and develop programme of integrated working with BDFA

# Batten Disease Family Association

## Trustees' Report

- To recruit a second CNS post (adult services)
- To recruit a further 2 support and advocacy workers by 2018, one in the midlands and one in Scotland/North of England
- To hold an annual family conference that provides networking opportunities, research updates, education and clinical support.
- To hold a review of family networking scheme
- Annual update of all BDFA resources including online, signposting and resource pack.
- To develop diagnostic leaflet in collaboration with GOSH diagnostic team.
- With clinicians, develop clinical care pathways for all those with an NCL diagnosis.

### **Goal 2: To change lives by funding research into potential therapies and ultimately a cure.**

#### **To achieve this, we will:**

- directly support the scientific community to drive innovative research through individual grants and collaborative funding
- develop and maintain strong research networks both in the UK and worldwide, attracting new and cutting-edge investigators;
- engage with pharmaceutical companies to drive the clinical research agenda for all the NCLs

#### **By 2018 we will:**

- spend £300k on research including the development of a collaborative funding relationship with Sparks.
- inspire existing and new funders and donors to invest in this most critical need.
- work with our partners in the scientific, clinical and pharmaceutical communities to campaign for the introduction of clinical trials and to enable affected children and young people to access potential studies.

#### **Research goals 2015-2018**

- £50k funding of Gene Therapy to the Eye Project at UCL
- Support of families on BioMarin BMN190 and extension study
- Represent BDFA and BDIA at key CLN2 expert meetings with BioMarin
- Co-ordinate and deliver CLN2 Burden of disease project in the UK with ICON and BioMarin
- Plan and deliver BDIA London meeting
- Contribute Patient Advocacy to the UCL European Funding application for BATCURE
- Host European Education Project meeting in London
- Deliver £50k of research funding through Spark's partnership
- Deliver £70K of research funding for CLN5 research with Dawkins family
- Review ongoing research funding for recommendation or decline of further funding
- Attendance at Gene, Cell and Molecular therapies meeting, NCL2016, BioMarin CLN2 Expert's meeting.
- Direct funding and support of European registry project
- Identify and engage with two pharmaceutical start-ups who have expressed an interest in NCL therapeutics developments

### **Goal 3: To raise awareness of Batten disease on an UK national and international platform**

#### **To achieve this, we will:**

- aid and inspire those both within and outside of the Batten community to improve the lives of those affected. Motivate and encourage fundraising and resource development to underpin essential service delivery and drive the research agenda.

#### **By 2018 we will:**

- develop and implement a high profile multimedia strategy across the digital space and in local and national press.
- advanced NCL awareness in the legislative and governmental sphere.

#### **Awareness goals 2015-2018**

- Daily updates made to BDFA website to include enhanced news, information, support, fundraising and research resources
- Daily updates to social media pages to significantly increase social media profile
- Weekly mailchimp email to all subscribers
- Deliver staff training on website maintenance

# Batten Disease Family Association

## Trustees' Report

- Monthly review of website and social media analytics
- Produce twice yearly newsletter and Batten bulletin
- Yearly update of BDFA media kit
- Secure quarterly opportunities to engage with local and national media around family, organizational and industry stories
- Engage with key NHS figures to raise the profile of the NCLs to advocate for better services and implementation of potential therapies
- Develop database of Members of Parliament with affected families in their constituency
- Attend meetings of LSD Collaborative, Genetic Alliance UK, Neurological Alliance and Rare Disease UK
- Implement programme of awareness raising for Rare Disease Day and Batten disease awareness Day

### **Organisational capacity.**

Underpinning the strategic aims and goals of the BDFA is a programme to ensure organisational integrity, income development and service delivery effectiveness.

### **To achieve this, we will:**

- Ensure that the BDFA's operations are compliant with all applicable laws and policies.
- Deliver a successful and dynamic fundraising strategy that will enable the BDFA to deliver its vision.
- Develop funds through diversified income streams to support BDFA programmes and activities.
- Monitor and evaluate all aspects of BDFA service and activity to ensure best practice, and optimize use of resources.

### **By 2018 we will:**

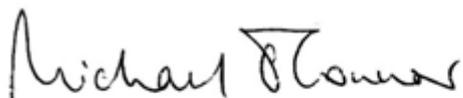
- Have relocated into the first BDFA offices and completed policies and procedures necessary for this expansion.
- Consolidation of offices and procedures to provide a secure base for strategic organizational growth
- Expanded and consolidated the BDFA staff team to meet growing demand for support and fundraising.
- Develop and review monitoring and evaluation systems for all aspects of BDFA service delivery.

### **Organisational goals 2015-2018**

- Conduct annual accounts audit and Charity Commission filings in professional and timely manner.
- Implement HR requirements for staff and office location to support staff recruitment and development.
- Renew contracts on renewal to assure best pricing
- Deliver BDFA Fundraising Strategy
- Develop and implement a Trustee board recruitment and review process to ensure strong governance for the BDFA
- Recruitment of new medical, education and research advisors to the BDFA team to support and strengthen the professional network available to service users
- Qualitative and quantitative metrics compiled monthly on support service delivery including service user feedback.
- Review and application for potential accreditations for BDFA services

Approved by order of the board of trustees on .....9/10/15..... and signed on its behalf by:

Michael O'Connor (BDFA Chair of Trustees)



**Independent Examiner's Report to the Trustees of  
Batten Disease Family Association**

I report on the accounts of the Trust for the year ended 31 August 2015, which are set out on pages 14 to 21.

**Respective responsibilities of trustees and examiner**

The trustees are responsible for the preparation of the accounts. The trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011(the 2011 Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the 2011 Act;
- follow the procedures laid down in the General Directions given by the Charity Commission under section 145 (5) (b) of the 2011 Act; and
- state whether particular matters have come to my attention.

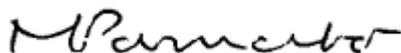
**Basis of independent examiner's report**

My examination was carried out in accordance with the 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 you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

**Independent examiner's statement**

In connection with my examination, no matter has come to my attention:

- (1) which gives me reasonable cause to believe that in any material respect the requirements:
  - to keep accounting records in accordance with section 130 of the Act; and
  - to prepare accounts which accord with the accounting records and comply with the accounting requirements of the 2011 Acthave not been met; or
- (2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.



.....  
Hilary Parmenter, Chartered Accountant

15 October 2015

1 The Willows  
North Warnborough  
Hampshire  
RG29 1DR

## Batten Disease Family Association

### Statement of Financial Activities for the Year Ended 31 August 2015

		Unrestricted Funds	Restricted Funds	Total Funds 2015	Total Funds 2014
	Note	£	£	£	£
<b>Incoming resources</b>					
Incoming resources from generated funds					
Voluntary income	2	175,156	129,551	304,707	285,060
Total incoming resources		175,156	129,551	304,707	285,060
<b>Resources expended</b>					
Costs of generating funds					
Costs of generating voluntary income	3	278,786	151,722	430,508	266,837
Total resources expended		278,786	151,722	430,508	266,837
Net movements in funds		(103,630)	(22,171)	(125,801)	18,223
<b>Reconciliation of funds</b>					
Total funds brought forward		232,634	175,431	408,065	389,842
Total funds carried forward		129,004	153,260	282,264	408,065

The notes on pages 16 to 21 form an integral part of these financial statements.

**Batten Disease Family Association**  
**Balance Sheet as at 31 August 2015**

		2015		2014	
	Note	£	£	£	£
<b>Current assets</b>					
Debtors	10	6,438		1,146	
Cash at bank and in hand		<u>301,700</u>		<u>415,737</u>	
			308,138		416,883
<b>Creditors: Amounts falling due within one year</b>					
	11		<u>(25,874)</u>		<u>(8,818)</u>
<b>Net current assets</b>			<u>282,264</u>		<u>408,065</u>
<b>Net assets</b>			<u><u>282,264</u></u>		<u><u>408,065</u></u>
<b>The funds of the charity:</b>					
<b>Restricted funds in surplus</b>			163,884		175,431
<b>Restricted funds in deficit</b>					
Gerilindup effies fund			(2,164)		-
Roald dahl			-		-
Biomarin			(6,514)		-
Richard brownnutt			-		-
In memory of katie freeman			(1,946)		-
Susan black jnel research			-		-
Magic book in memory of ben pickering			-		-
Ward & partners infantile magic book			-		-
Ascot london 10k runners juvenile book			-		-
General donations			-		-
Rock solid			-		-
Boshier-hinton foundation			-		-
Rotary club of fleet			-		-
Per pro landulph pcc carol service			-		-
<b>Total restricted funds</b>			<u>153,260</u>		<u>175,431</u>
<b>Unrestricted funds</b>					
Other reserves		232,634		258,398	
Unrestricted income funds		<u>(103,630)</u>		<u>(25,764)</u>	
<b>Total unrestricted funds</b>			<u>129,004</u>		<u>232,634</u>
<b>Total charity funds</b>			<u><u>282,264</u></u>		<u><u>408,065</u></u>

The financial statements have been prepared in accordance with the Financial Reporting Standard for Smaller Entities (effective April 2008).

# **Batten Disease Family Association**

## **Notes to the Financial Statements for the Year Ended 31 August 2015**

### **1 Accounting policies**

#### **Basis of preparation**

The financial statements have been prepared under the historical cost convention and in accordance with the Statement of Recommended Practice 'Accounting and Reporting by Charities (SORP 2005)', issued in March 2005, the Financial Reporting Standard for Smaller Entities (effective April 2008) and the Charities Act 2011.

#### **Fund accounting policy**

Unrestricted income funds are general funds that are available for use at the trustee's discretion in furtherance of the objectives of the charity.

Restricted funds are those donated for use in a particular area or for specific purposes, the use of which is restricted to that area or purpose.

Further details of each fund are disclosed in note 13.

#### **Incoming resources**

Voluntary income including donations and legacies is recognised where there is entitlement, certainty of receipt and the amount can be measured with sufficient reliability.

Where facilities are provided to the charity as a donation that would normally be purchased from our suppliers, this contribution is included in the financial statements at an estimate based on the value of the contribution to the charity where this can be quantified.

The value of services provided by volunteers is not incorporated into these financial statements. Further details of the contribution made by volunteers can be found in the Trustee's Annual Report.

Incoming resources from tax reclaims are included in the statement of financial activities at the same time as the gift to which they relate.

#### **Resources expended**

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category.

Costs of generating funds are the costs associated with attracting voluntary income.

Grants payable are payments made to third parties in the furtherance of the charitable objectives. Where the charity gives a grant with conditions for its payment being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specific service or output.

Grants payable without performance conditions are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable.

#### **Support costs**

Support costs include central functions and have been allocated to activity cost categories on a basis consistent with the use of resources, for example, allocating property costs by floor areas, or per capita, staff costs by the time spent and other costs by their usage.

#### **Research and development expenditure**

Research and development expenditure is written off as incurred.

## Batten Disease Family Association

### Notes to the Financial Statements for the Year Ended 31 August 2015

..... continued

#### Operating leases

Rentals payable under operating leases are charged in the statement of financial activities on a straight line basis over the lease term.

## 2 Voluntary income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Donations</b>				
Regular monthly donations	4,894	-	4,894	-
Donations gift aid	31,094	-	31,094	-
Donations non gift aid	2,557	-	2,557	284,352
Membership fees	254	-	254	-
Charitable giving	58,592	129,551	188,143	-
Gift aid reclaimed	16,644	-	16,644	-
Donations - organisations and schools	17,595	-	17,595	-
Foundations and trusts not restricted	16,535	-	16,535	-
In memorium	3,270	-	3,270	-
Supporter fundraising	20,974	-	20,974	-
Collection boxes	448	-	448	-
Other Fundraising	402	-	402	-
Other income	-	-	-	306
Merchandise Income	1,281	-	1,281	-
Workshop income	270	-	270	-
Income from other unlisted investments	-	-	-	402
Interest income	346	-	346	-
	175,156	129,551	304,707	285,060

## Batten Disease Family Association

### Notes to the Financial Statements for the Year Ended 31 August 2015

..... continued

#### 3 Costs of generating voluntary income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2015 £	Total Funds 2014 £
<b>Grants</b>				
British Society for Gene and Cell Therapy	1,526	-	1,526	-
NCL Stiftung	158	-	158	-
NCL2014	6,551	-	6,551	-
NCL2015	51	-	51	-
Royal Veterinary College	10,050	-	10,050	-
Grants payable - individuals	6,607	-	6,607	-
	<u>24,943</u>	<u>-</u>	<u>24,943</u>	<u>-</u>
<b>Costs</b>				
Fundraising costs	-	-	-	51,970
Restricted costs	-	151,722	151,722	-
Other fundraising costs	-	-	-	469
Fundraising expenses	16,879	-	16,879	-
Merchandise for resale	3,276	-	3,276	-
Wages and salaries	138,442	-	138,442	-
Staff NIC (Employers)	13,866	-	13,866	-
Recruitment expenses	3,871	-	3,871	-
Staff training	815	-	815	-
Rent	10,191	-	10,191	-
Rates	129	-	129	-
Insurance	633	-	633	-
Premises expenses	1,659	-	1,659	-
Telephone and fax	1,607	-	1,607	-
Office equipment	4,788	-	4,788	-
IT costs	5,919	-	5,919	-
Printing, postage and stationery	5,445	-	5,445	-
Advocacy	203	-	203	-
Sundry expenses	896	-	896	-
Research and development	9,603	-	9,603	-
Travel and subsistence	599	-	599	-
Customer entertaining (disallowable for tax)	684	-	684	-
Accountancy fees	5,829	-	5,829	-
Governance costs	2,822	-	2,822	-
Legal and professional fees	5,021	-	5,021	-
HR support	2,128	-	2,128	-
Bank charges	240	-	240	-
Exceptional administrative expenses	-	-	-	9,974
Support costs allocated	18,298	-	18,298	204,424
	<u>253,843</u>	<u>151,722</u>	<u>405,565</u>	<u>266,837</u>
	<u>278,786</u>	<u>151,722</u>	<u>430,508</u>	<u>266,837</u>

## Batten Disease Family Association

### Notes to the Financial Statements for the Year Ended 31 August 2015

..... continued

#### 4 Support costs

	<b>Costs</b>	<b>Total</b>
	<b>£</b>	<b>£</b>
Employment costs	18,298	18,298
Research costs not capitalised	-	-
	18,298	18,298

#### 5 Grantmaking

	<b>Grants to institutions</b>	<b>Grants to individuals</b>
	<b>£</b>	<b>£</b>
Grants	18,336	6,607

The support costs associated with grant making are £0.

#### 6 Grants to institutions

<b>Name of Institution</b>	<b>Activity</b>	<b>£</b>
British Society for Gene and Cell Therapy	Grants	1,526
NCL Stiftung	Grants	158
NCL2014	Grants	6,551
NCL2015	Grants	51
Royal Veterinary College	Grants	10,050
		18,336

#### 7 Trustees' remuneration and expenses

The trustees were reimbursed for travel and fundraising costs of £2,822 during the year.

#### 8 Employees' remuneration

The aggregate payroll costs of these persons were as follows:

	<b>2015</b>	<b>2014</b>
	<b>£</b>	<b>£</b>
Wages and salaries	138,442	-
Social security	13,866	-
	152,308	-

## Batten Disease Family Association

### Notes to the Financial Statements for the Year Ended 31 August 2015

..... continued

#### 9 Fees for examination or audit of the accounts

	2015	2014
	£	£
Accountancy fees	500	300
Independent examiner's fees	400	720
	<u>900</u>	<u>1,020</u>

#### 10 Debtors

	2015	2014
	£	£
Other debtors	168	-
Prepayments and accrued income	6,270	1,146
	<u>6,438</u>	<u>1,146</u>

#### 11 Creditors: Amounts falling due within one year

	2015	2014
	£	£
Bank loans and overdrafts	2,670	-
Trade creditors	7,584	-
Taxation and social security	3,863	-
Accruals and deferred income	11,757	8,818
	<u>25,874</u>	<u>8,818</u>

## Batten Disease Family Association

### Notes to the Financial Statements for the Year Ended 31 August 2015

..... continued

#### 12 Related parties

##### Controlling entity

The charity is controlled by the trustees.

#### 13 Analysis of funds

	At 1 September 2014	Incoming resources	Resources expended	At 31 August 2015
	£	£	£	£
<b>General Funds</b>				
Unrestricted income fund	232,634	175,156	(278,786)	129,004
<b>Restricted Funds</b>				
Geri Lindup Effies Fund	875	373	(3,412)	(2,164)
St James Place	2,500	7	(1,477)	1,030
Cutler Trust	1,500	1,000	(1,500)	1,000
Roald Dahl	3,300	1,000	(4,300)	-
James Toohey	-	4,684	-	4,684
Sylvia Kapp Legacy	-	5,000	-	5,000
Isabel Sparkle	-	10,214	(7,365)	2,849
Euro Ed Project	-	6,571	(458)	6,113
Battle Batten CLN5	34,965	38,183	-	73,148
BioMarin	22,573	28,934	(58,021)	(6,514)
Beefys Charity Foundation	20,000	30,052	(37,036)	13,016
Richard Brownnutt	2,229	1,304	(3,533)	-
In Memory of Katie Freeman	-	2,224	(4,170)	(1,946)
In Memory of Melvyn Hancock	679	-	(490)	189
Susan Black JNCL research	50	5	(55)	-
Clinical Nurse Specialist Funding	84,188	-	(29,905)	54,283
Ascot Research Funding	1,376	-	-	1,376
LINCL Research	1,196	-	-	1,196
	175,431	129,551	(151,722)	153,260
	408,065	304,707	(430,508)	282,264

#### 14 Net assets by fund

	Unrestricted Funds	Total Funds 2015	Total Funds 2014
	£	£	£
Current assets	308,138	308,138	416,883
Creditors: Amounts falling due within one year	(25,874)	(25,874)	(8,818)
Net assets	282,264	282,264	408,065

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

	Unrestricted income fund 2015	Unrestricted income fund 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	175,156	172,097
Total incoming resources	<u>175,156</u>	<u>172,097</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	278,786	197,861
Total resources expended	<u>278,786</u>	<u>197,861</u>
Net movements in funds	(103,630)	(25,764)
<b>Reconciliation of funds</b>		
Total funds brought forward	232,634	258,398
Total funds carried forward	<u><u>129,004</u></u>	<u><u>232,634</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	Geri Lindup Effies Fund 2015	Geri Lindup Effies Fund 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	373	6,389
Total incoming resources	<u>373</u>	<u>6,389</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	3,412	5,514
Total resources expended	<u>3,412</u>	<u>5,514</u>
Net movements in funds	(3,039)	875
<b>Reconciliation of funds</b>		
Total funds brought forward	875	-
Total funds carried forward	<u><u>(2,164)</u></u>	<u><u>875</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	St James Place 2015	St James Place 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	7	2,500
Total incoming resources	<u>7</u>	<u>2,500</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	1,477	-
Total resources expended	<u>1,477</u>	<u>-</u>
Net movements in funds	(1,470)	2,500
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>2,500</u>	<u>-</u>
Total funds carried forward	<u><u>1,030</u></u>	<u><u>2,500</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	Cutler Trust 2015	Cutler Trust 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	1,000	1,500
Total incoming resources	<u>1,000</u>	<u>1,500</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	1,500	-
Total resources expended	<u>1,500</u>	<u>-</u>
Net movements in funds	(500)	1,500
<b>Reconciliation of funds</b>		
Total funds brought forward	1,500	-
Total funds carried forward	<u><u>1,000</u></u>	<u><u>1,500</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	Roald Dahl 2015	Roald Dahl 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	1,000	3,300
Total incoming resources	<u>1,000</u>	<u>3,300</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	4,300	-
Total resources expended	<u>4,300</u>	<u>-</u>
Net movements in funds	(3,300)	3,300
<b>Reconciliation of funds</b>		
Total funds brought forward	3,300	-
Total funds carried forward	<u><u>-</u></u>	<u><u>3,300</u></u>

**Batten Disease Family Association**

**Statement of financial activities by fund Year Ended 31 August 2015**

..... *continued*

	<b>James Toohey 2015</b>	<b>James Toohey 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	4,684	-
Total incoming resources	<u>4,684</u>	<u>-</u>
<b>Reconciliation of funds</b>		
Total funds carried forward	<u><u>4,684</u></u>	<u><u>-</u></u>

**Batten Disease Family Association**

**Statement of financial activities by fund Year Ended 31 August 2015**

..... *continued*

	<b>Sylvia Kapp Legacy 2015</b>	<b>Sylvia Kapp Legacy 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	5,000	-
Total incoming resources	<u>5,000</u>	<u>-</u>
<b>Reconciliation of funds</b>		
Total funds carried forward	<u><u>5,000</u></u>	<u><u>-</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	Isabel Sparkle 2015	Isabel Sparkle 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	10,214	-
Total incoming resources	<u>10,214</u>	<u>-</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	7,365	-
Total resources expended	<u>7,365</u>	<u>-</u>
<b>Reconciliation of funds</b>		
Total funds carried forward	<u><u>2,849</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	Euro Ed Project 2015	Euro Ed Project 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	6,571	-
Total incoming resources	<u>6,571</u>	<u>-</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	458	-
Total resources expended	<u>458</u>	<u>-</u>
<b>Reconciliation of funds</b>		
Total funds carried forward	<u><u>6,113</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>Battle Batten CLN5 2015</b>	<b>Battle Batten CLN5 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	38,183	34,965
Total incoming resources	<u>38,183</u>	<u>34,965</u>
Net movements in funds	38,183	34,965
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>34,965</u>	<u>84,188</u>
Total funds carried forward	<u><u>73,148</u></u>	<u><u>119,153</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>BioMarin 2015</b>	<b>BioMarin 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	28,934	38,000
Total incoming resources	<u>28,934</u>	<u>38,000</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	58,021	15,427
Total resources expended	<u>58,021</u>	<u>15,427</u>
Net movements in funds	(29,087)	22,573
<b>Reconciliation of funds</b>		
Total funds brought forward	22,573	-
Total funds carried forward	<u><u>(6,514)</u></u>	<u><u>22,573</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>Beefys Charity Foundation 2015</b>	<b>Beefys Charity Foundation 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	30,052	20,000
Total incoming resources	<u>30,052</u>	<u>20,000</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	37,036	-
Total resources expended	<u>37,036</u>	<u>-</u>
Net movements in funds	(6,984)	20,000
<b>Reconciliation of funds</b>		
Total funds brought forward	20,000	-
Total funds carried forward	<u><u>13,016</u></u>	<u><u>20,000</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>Richard Brownutt 2015</b>	<b>Richard Brownutt 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	1,304	2,229
Total incoming resources	<u>1,304</u>	<u>2,229</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	3,533	-
Total resources expended	<u>3,533</u>	<u>-</u>
Net movements in funds	(2,229)	2,229
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>2,229</u>	<u>-</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>2,229</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>In Memory of Katie Freeman 2015</b>	<b>In Memory of Katie Freeman 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	2,224	3,351
Total incoming resources	<u>2,224</u>	<u>3,351</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	4,170	6,070
Total resources expended	<u>4,170</u>	<u>6,070</u>
Net movements in funds	(1,946)	(2,719)
<b>Reconciliation of funds</b>		
Total funds brought forward	-	2,719
Total funds carried forward	<u>(1,946)</u>	<u>-</u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	In Memory of Melvyn Hancock 2015	In Memory of Melvyn Hancock 2014
	£	£
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	-	679
Total incoming resources	<u>-</u>	<u>679</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	490	-
Total resources expended	<u>490</u>	<u>-</u>
Net movements in funds	(490)	679
<b>Reconciliation of funds</b>		
Total funds brought forward	679	-
Total funds carried forward	<u><u>189</u></u>	<u><u>679</u></u>

This page does not form part of the statutory financial statements.

**Batten Disease Family Association**

**Statement of financial activities by fund Year Ended 31 August 2015**

..... *continued*

	<b>Susan Black JNCL research 2015</b>	<b>Susan Black JNCL research 2014</b>
	<b>£</b>	<b>£</b>
<b>Incoming resources</b>		
Incoming resources from generated funds		
Voluntary income	5	50
Total incoming resources	<u>5</u>	<u>50</u>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	55	-
Total resources expended	<u>55</u>	<u>-</u>
Net movements in funds	(50)	50
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>50</u>	<u>-</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>50</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	Clinical Nurse Specialist Funding 2015	Clinical Nurse Specialist Funding 2014
	£	£
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	29,905	-
Total resources expended	<u>29,905</u>	<u>-</u>
Net movements in funds	(29,905)	-
<b>Reconciliation of funds</b>		
Total funds brought forward	84,188	-
Total funds carried forward	<u><u>54,283</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>Magic Book in memory of Ben Pickering 2015</b>	<b>Magic Book in memory of Ben Pickering 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	2,114
Total resources expended	<u>-</u>	<u>2,114</u>
Net movements in funds	-	(2,114)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>2,114</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>Ward &amp; Partners Infantile Magic Book 2015</b>	<b>Ward &amp; Partners Infantile Magic Book 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	2,500
Total resources expended	<u>-</u>	<u>2,500</u>
Net movements in funds	-	(2,500)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>2,500</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

**Batten Disease Family Association**

**Statement of financial activities by fund Year Ended 31 August 2015**

..... *continued*

	<b>Ascot Research Funding 2015</b>	<b>Ascot Research Funding 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	26,976
Total resources expended	<u>-</u>	<u>26,976</u>
Net movements in funds	-	(26,976)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>1,376</u>	<u>28,352</u>
Total funds carried forward	<u><u>1,376</u></u>	<u><u>1,376</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>Ascot London 10K Runners Juvenile Book 2015  £</b>	<b>Ascot London 10K Runners Juvenile Book 2014  £</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	1,591
Total resources expended	-	1,591
Net movements in funds	-	(1,591)
<b>Reconciliation of funds</b>		
Total funds brought forward	-	1,591
Total funds carried forward	-	-

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>General donations 2015</b>	<b>General donations 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	3,465
Total resources expended	<u>-</u>	<u>3,465</u>
Net movements in funds	-	(3,465)
<b>Reconciliation of funds</b>		
Total funds brought forward	-	3,465
Total funds carried forward	<u>-</u>	<u>-</u>

This page does not form part of the statutory financial statements.

**Batten Disease Family Association**

**Statement of financial activities by fund Year Ended 31 August 2015**

..... *continued*

	<b>Rock Solid 2015</b>	<b>Rock Solid 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	4,569
Total resources expended	<u>-</u>	<u>4,569</u>
Net movements in funds	-	(4,569)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>4,569</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>Boshier-Hint on Foundation 2015  £</b>	<b>Boshier-Hint on Foundation 2014  £</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	300
Total resources expended	<u>-</u>	<u>300</u>
 Net movements in funds	 -	 (300)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>300</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	<b>Rotary Club of Fleet 2015</b>	<b>Rotary Club of Fleet 2014</b>
	<b>£</b>	<b>£</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	250
Total resources expended	<u>-</u>	<u>250</u>
 Net movements in funds	 -	 (250)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>250</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

This page does not form part of the statutory financial statements.

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... continued

	<b>Per Pro Landulph PCC Carol Service 2015  £</b>	<b>Per Pro Landulph PCC Carol Service 2014  £</b>
<b>Resources expended</b>		
Costs of generating funds		
Costs of generating voluntary income	-	200
Total resources expended	<u>-</u>	<u>200</u>
 Net movements in funds	 -	 (200)
<b>Reconciliation of funds</b>		
Total funds brought forward	<u>-</u>	<u>200</u>
Total funds carried forward	<u><u>-</u></u>	<u><u>-</u></u>

## Batten Disease Family Association

### Statement of financial activities by fund Year Ended 31 August 2015

..... *continued*

	LINCL Research 2015	LINCL Research 2014
	£	£
Net movements in funds	-	-
<b>Reconciliation of funds</b>		
Total funds brought forward	1,196	1,196
Total funds carried forward	<u>1,196</u>	<u>1,196</u>

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