

Charity Registration No. 1084908

OSCR No. SCO47408

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31 AUGUST 2018

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Michael O'Connor, Chair Pauline Docherty, Co-Chair Roger Cole Catherine Sermon James Jeynes Neil Dunford Amanda Mortenson
----------	---

Charity number	1084908
----------------	---------

OSCR number	SCO47408
-------------	----------

Principal Address	209-211 City Road London EC1V 1JN
-------------------	---

Independent Examiner	Taylorcocks The Courtyard Shoreham Road Upper Beeding Steyning West Sussex BN44 3TN
----------------------	---

Bankers	The Co-Operative Bank 70-72 Cross Street Manchester M2 4JG
---------	---

	Santander Bank Bootle Merseyside L30 4GB
--	---

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Legal Adviser

H3 Solicitors
1 Oak Place
Rosier Business Park
Coneyhurst Road
Billingshurst
RH14 9DE

Scientific Advisers

Prof. Jon Cooper
Professor of Pediatrics
Washington University School of Medicine, St Louis
660 S Euclid Avenue, Campus Box 8208
St Louis, MO 63110

Dr Emyr Lloyd-Evans
Senior Lecturer
Sir Martin Evans Building
School of Biosciences
Cardiff University
Museum Avenue
Cardiff
CF10 3AX

Prof. Sara Mole
Professor in Molecular Cell Biology, UCL
Great Ormond Street Hospital Children's Charity
Professor
MRC Laboratory for Molecular Cell Biology
University College London
Gower Street
London
WC1E 6BT

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

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Dr Sander Smith
Principal Research Associate
Department of Genetics
UCL Institute of Ophthalmology
11-43 Bath Street
London
EC1V 9EL

Brenda Williams
Senior Lecturer
Interim Director of Postgraduate Teaching (PGT)
Programme Lead, Applied Neuroscience. Interim
Programme Lead, Psychology and Neuroscience of
Mental Health
Departmental Teaching Lead
Institute of Psychiatry, Psychology &
Neuroscience, Department of Basic and Clinical
Neuroscience
Room M3.06, PO Box 28
De Crespigny Park
Denmark Hill
London SE5 8AF

Dr Clare Beesley
Clinical Scientist
NE Thames Regional Genetics Service
Great Ormond Street Hospital
Level 6, Barclay House
37 Queen Square
London
WC1N 3BH

Education Adviser

Barbara Cole

Medical Advisers

Prof. Paul Gissen
Wellcome Trust Senior Research Fellow in Clinical
Sciences & Consultant in Paediatric Metabolic
Medicine
Great Ormond Street Hospital
Great Ormond Street
London
WC1N 3JH

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Dr Christine Caren GP (Retd)

Dr Barbara Csanyi
Research Fellow
Somers Clinical Research Facility
Level 1, Frontage Building
Great Ormond Street
London
WC1N 3JH

BATTEN DISEASE FAMILY ASSOCIATION

CONTENTS

	Page
Trustees' Report	1
Statement of Trustees' Responsibilities	11
Independent Examiner's Report	12-13
Statement of Financial Activities	14
Balance Sheet	15
Notes to the financial statements	16-24

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Batten disease is a group of 14 devastating, life limiting, genetic neurodegenerative diseases that usually affect children. The Batten Disease Family Association is here to support families during their journey with Batten disease for as long as they need us. We aim to raise awareness of Batten disease and work with key stakeholders in the rare disease community.

Welcome from the Chair

Dear Families, Friends and Supporters,

This is the 20th anniversary year of the founding of the Batten Disease Family Association and it seems to be one of our most challenging. The charity is at a pivotal point in its evolution and we have had to make some very difficult decisions this year.

You will see from this annual report and accounts that there have been significant challenges in terms of our income. This is a huge cause of concern to the board and, of course, to the wider Batten disease community.

As a small rare disease charity, we do not receive any government or NHS funding. We rely on our community to support and lead our fundraising so we can continue our crucial work with all those affected by this devastating, cruel disease. We can access some funding from pharmaceutical companies but we must ensure impartiality. Due to the current financial situation, we are not able to access large grant making bodies such as the Big Lottery until we are in a more stable position.

It has been a year of momentous change for the Batten Disease Family Association. The BDFA has had to strip back to its core function of support in order to survive. We have restructured our support function employing two part-time support workers in the north and the south, making them more accessible to families and also cutting costs. We have not replaced our office manager and we have reduced our office space in London to a hot desk. We have also paused our popular family conference. We know this is very much missed and hope to reinstate this as soon as we are able.

We are pleased to announce that we are able to extend our CEO's contract for a further 6 months until the end of December 2019. We are able to do this due to a specific funding stream available due to the ongoing negotiations around Brineura, which are going on for longer than anticipated. This also gives us an additional 6 months to secure more robust funding in order to be able to consolidate our fundraising income and be able then to ideally run without a break in leadership.

Thank you to all of those who have supported us this year. I would like to especially thank all those families who take the time to raise funds for the BDFA whilst caring for a child or children with Batten disease. Your dedication to the cause is inspirational.

We are also fortunate to have a small but plucky band of volunteers who are the power to the staff team's elbow. I thank you for the time, talents and expertise that you bring to your unpaid and most appreciated roles.

I would like to thank my fellow Trustees and the Trustees who have stepped down during this year: Dave Mitchell, James Jeynes, and out-going Chair, Michael O'Connor. Rahul Dubey has also stepped down recently. We are keen to attract new trustees, specifically with skills around finance and fundraising.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Finally, we thank the team members who have left the BDFA this year, all going on to grasp new life opportunities. Andrea West, Lucy Roose, Laura Codd and Harriet Lunnemann, who left in December, have all made massive contributions to the BDFA during their time with the charity and I know that they are missed. On behalf of the whole of the BDFA, I wish them the very best for their exciting new roles.

At the core of everything we do are the families who have a child or young person with Batten disease. Set up by parents 20-years-ago the BDFA is the first organisation parents call on diagnosis. We need to continue to play that core support role and that is our most important task.

We face our new financial year with a smaller organisation, but in a year of change and opportunity and hope that you will join us on that journey.

All best wishes

Amanda Mortensen

Chair of Trustees

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Report of the Trustees and Unaudited Financial Statement for Year Ended 31 August 2018 for the Batten Disease Family Association (BDFA)

The Trustees present their report with the financial statements for the charity for the year ended 31 August 2018. The Trustees have adopted the provisions of the Statement of Recommended Practice (SORP) "Accounting and Reporting by Charities" issued in 2015 in accordance with the Financial Reporting Standard applicable in the UK and Ireland (FRS102) issued on 16 July 2014, and the Charities Accounts (Scotland) Regulation 2006 (as amended).

Details of trustees who served in period

Chair	Michael O'Connor – until 16 May 2018
Chair	Amanda Mortensen – from 16 May 2018
Co-Chair	Pauline Docherty
Treasurer	Roger Cole
	Catherine Sermon
	Neil Dunford
	Dave Mitchell (resigned 24 November 2018)
	James Jeynes (resigned 26 June 2018)
	Rahul Dubey (resigned 7 May 2019)

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.

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 (resigned January 2018), and Samantha Barber (joined May 2018) and supported by the following team in 2017-18:

1. Harriet Lunneman (Full-time) Family Support Officer (resigned December 2018)
 2. Heather Band (32 hours per week) Scientific Officer
 3. Lucy Roose (25 hours per week) Office Manager (resigned June 2018)
 4. Laura Codd (7.5 hours per week) BATCure Administrator (resigned August 2018)
- We were joined by two part-time Family Support Officers, Wendy Thompson for the North (joined March 2019) and Catherine McSweeney for the South (joined April 2019).

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

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 advisers who liaise with the employed Officers and the relevant Trustees as necessary.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

The Board of Trustees meets six times per year with the Chief Executive and members of the staff team to review work and formulate strategy.

Recruitment and Appointment of New Trustees

The BDFA values a diverse Board and recruits trustees based on their experience and 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 for new trustees are made in the Association's newsletter, with volunteer bureaux, on the BDFA website and social media platforms.

Candidates are given information on the roles, interviewed by the current Board and invited to attend a Trustees' meeting. Appointment is 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.

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 Neuronal Ceroid Lipofuscinoses (NCL), 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 Batten disease (NCLs)

Batten disease (the NCLs) are several different genetic, life-limiting neurodegenerative diseases that share similar features and occur in children and adults worldwide. Batten disease is 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, before going on to develop epilepsy, lose their sight and speech, their cognitive and motor abilities, and sadly die 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.

A diagnosis of 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 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 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 Batten disease 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 young people and the teams of professionals around them.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Awareness: We raise awareness of this set of rare diseases by informing a wide range of professionals about the disease, using social and other media to raise awareness with the general public. We also 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 have provided funding for vital pre-clinical and clinical research in universities and research institutions both in the UK and worldwide.

How we achieve Public benefit

The BDFA provides support and advocacy to any family who has a child affected by Batten disease in England, Scotland, Northern Ireland and Wales, and during this financial year has funded research into Batten disease. Activities include support given by telephone, email and face-to-face. There is no charge for our services. The research is conducted by renowned institutions and results shared with researchers and other interested parties in line with normal research practice. The Trustees consider the guidance on public benefit from the Charity Commission when setting strategy and reviewing services offered.

Achievements and performance

The last year has been another busy year for the BDFA as our small team works hard to ensure that children with Batten disease are empowered to live full lives and that the public and policy makers are aware of the challenges they and their families face. Research has continued apace as it is fundamental to the aims and objectives of the BDFA and of special interest to our families. It is a highly specialised area of work and involves working in close partnership with world-class organisations and involves all aspects of the disease, clinical, education, social and laboratory based projects.

We work closely with other charities and stakeholders such as The Amber Trust, Dreams Come True and Make a Wish to provide much needed therapies and experiences to affected children and young adults. We thank them for their continued support.

Support and Advocacy

- We had a full time Family Support Officer who has travelled the length and breadth of the UK to provide support to families and to advocate on their behalf as well as providing remote support and information. This function has been performed by two part-time Family Support Officers from early 2019.
- We held a successful and well-attended Conference for families with a wide range of speakers and activities.
- The first ever BDFA Family Fun Day was held in July and greatly enjoyed by those who attended.
- Our work to support those families on the clinical trial for the enzyme replacement therapy has continued. Additionally, we have appeared at the NICE Highly Specialised Technology (HST) Committee meetings.
- There were six families who received grants from our Small Grants Programme in first half of the year. This Programme has currently been paused for review and to enable fundraising for this project to take place.
- The education advocacy has continued this year. This is vital to ensuring that children and young people with Batten disease receive the education that will benefit them the most.
- The BDFA has been a key partner in the Erasmus +, European Union JNCL and Education Project, which is focused on children and young people with CLN3. A book will be published in 2019 from this project.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

- The BDFA marked our 20th anniversary with a special edition newsletter.
- As part of our work around the enzyme replacement therapy we organised a public petition calling for the treatment to be funded following the first NICE HST Committee meeting. This was delivered to 10 Downing Street by families when it had reached over 295,000 signatures. This is an astonishing achievement for any rare disease charity and we are hugely grateful to everyone who signed.
- The BDFA is a key stakeholder in the MIND Music Therapy Project with Prof. Adam Ockelford, University of Roehampton and Chiltern Music Therapy, investigating the role of music in the lives of children and young people with Batten disease.
- We joined a small group of rare disease charities to input into and then launch an awareness campaign about a collection of conditions that are Childhood dementia. The campaign launched in the Houses of Parliament and included tube station advertising, media articles and videos.
- The BDFA promoted both the UK and international Batten disease Awareness Days. We are grateful to all those who participated.
- This year there has been an increase in the level of advocacy and awareness with MPs and Welsh Assembly Members with numerous meetings, letters and emails being exchanged, raising awareness of the disease and the needs of our families.
- There were two significant fundraising events, one was the London Marathon Walk and the other was a night-time Snowdon climb. We are grateful to all those in the Batten community and beyond who raised funds for the charity.

As well as the activities above, a number of staff from the BDFA have been involved in supporting families who have children participating in the CLN2 clinical trials and on the compassionate use scheme for the treatment. The start of the treatment appraisal process was in early 2018 and is still continuing. This has been a huge undertaking for a small staff team, taking hundreds of hours of staff time for meetings with all stakeholders such as the pharmaceutical company, parents, clinicians, NICE and NHS England and parliamentarians, and preparing documentation. Work on this issue continues at the time of writing.

The high-level of activity on the treatment for CLN2 hampered the charity's ability to focus on fundraising.

Research

In addition to the research programme outlined below, work began to prepare for the global Batten disease conference, NCL2018, which was held in September at Royal Holloway.



BATCure (2016-2018)

This project has received funding from the European Union's Horizon2020 research and innovation programme under grant agreement No 666918.

The goal of the three-year project is to advance the development of new therapeutic options for patients and their families living with CLN3, CLN6 or CLN7 disease. The consortium is made up of 14 different Institutions across the European Union (EU) from seven European countries, co-ordinated by Prof. Sara Mole at UCL, including ten leading scientific research groups, three companies and the BDFA.

Over the past three years the BDFA has played a leading role in the project ensuring that the voice of patients and affected families is heard. The funding has provided for 6 hours per week of BDFA Scientific Officer, Heather Band (W09 Work Package Lead) and 1 day per week for an administrator, Laura Codd (April 2016- August 2018).

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

The BDFA work package involves 4 main areas:

- Developing a methodology to enable patients, patient groups & key stakeholders to participate in the project.
- Preparation for future Clinical Trials (e.g. supporting Orphan drug applications)
- Communication strategy with public & professional engagement
- Exploitation and Dissemination strategy (with UCL).

The focus for this year has been the implementation and delivery of a family survey across 15 different countries, in nine languages to gain information from patients and their families. The results on the perspectives of understanding of research, patient registry, and readiness to participate in clinical trials will be used to inform the work of the consortium, key stakeholders and feed into the current and future exploitation plans for the project. A full report and presentation was given at the BDFA AGM and family conference in 2017. The Executive summary has been produced and disseminated to all members and key stakeholders.

The BDFA has taken a leading role in the dissemination process throughout the project, producing a range of products across different media, including a BATCure newsletter.

The consortium is seeking a 6-month extension to further enhance the project and the BDFA will play a major role in the final dissemination tasks in 2019. The BDFA expects to participate in the next phase as consortium members apply for further funding from a range of sources in 2018.

BDFA Research Projects

1. *Gene Therapy to treat visual failure in Batten disease.*

Prof. Sara Mole at the MRC Laboratory for Molecular Cell Biology, UCL

Prof Robin Ali, Dr. Alexander Smith, Dr. Sophia Holthaus, Dr. Mikel Aristorena at the Institute of Ophthalmology, (IOP).

Jan 2016- Dec 2019

£72 785 BDFA (with contributions from Beefy's Foundation, Nicole Rich Foundation and Ollie's Army)

Funded by Wellcome Trust and BATCure Project

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 approach to treat visual failure in Batten disease.

The BDFA provided the initial funding in 2012 to set up the project with the award of a three-year PhD studentship, with contributions from Beefy's Foundation, under the UCL Impact award scheme. The work was very successful and Sophia Kleine Holthaus obtained her doctorate in 2016. Since then the project has expanded, as part of the BATCure project and with funding from the Wellcome Trust.

The BDFA continues to drive forward this research and has co-funded two Post-Doctoral positions. Currently work is progressing for CLN2, CLN3, CLN5, CLN6 and CLN7 disease, with some projects approaching the pre-clinical stage.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

2. Uncovering fundamental difference in the cell biology and biochemistry of CLN5 disease.

Dr Emyr Lloyd-Evans, Cardiff University, (PhD student Katie Shipley)

October 2015-2018

£25 000 (funded by BDFA on behalf of Battle Batten with matched funding from Cardiff University)

The aim of this 3-year co-funded PhD studentship is to identify key differences in cells made from CLN5 patients compared to healthy unaffected cells. The group has identified differences in the cells, which could be exploited to develop potential therapies.

In this system a drug was found that partially corrected the calcium defects as well as improving other harmful changes to compartments previously observed in the cells. The drug is currently being used in patients with CLN5 disease on a compassionate basis.

3. Development of a drug screen for CLN5 Batten disease

Professor Paul Gissen, Dr. Dan Little, Prof. Sara Mole, and Dr Robin Ketteler, UCL

July 2016-Jan 2019

£20 000 (funded by BDFA on behalf of Battle Batten)

The aim of this project is to use patient's skin cells, which have the mutation or "mistake" in the CLN5 gene to create a type of cell (iPScells) that can then be turned into nerve cells, the cells that die in CLN5 disease. The group at UCL have generated CLN5 the nerve cell lines and identified two key differences compared with control lines. They have performed a drug screen and identified three compounds, which in preliminary experiments may have therapeutic activity in CLN5 patients.

4. To generate preliminary data to support a further grant proposal(s) to test the efficacy of novel compounds for treating seizures in CLN2 disease.

Dr Claire Russell, Royal Veterinary College, (RVC), London

June 2018 1-year

£ 1500

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

This work identified a lead compound and in 2018 further funds were awarded to undertake further studies with the aim to secure further external funding in 2019.

5. Characterising the fundamental cell biology of CLN8 disease for the purpose of developing drug strategies, biomarkers and potential therapies for the NCLs and lysosomal diseases.

Dr Emyr Lloyd-Evans, Cardiff University, (PhD student Rafael Andres Badell Grau)

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

2016-2019

£ 36 000 (Co-funded with £40 000 from the Life Sciences Research Network Wales (LSRNW))

CLN8 disease is caused by changes in the *CLN8* gene. There are currently no treatments and the disease is not well understood. This project is investigating how cells from patients with CLN8 disease behave to better understand exactly what is not working correctly. In CLN8 patient cells the group have found a range of abnormal cell functions that they are currently in the process of characterising.

6. NCL Resource - A gateway for Batten disease

This site serves as a global gateway for clinicians, families, researchers and those offering professional support, who have an interest in or are affected by Batten disease or who wish to find out more.

Prof Sara Mole has developed and maintained the NCL resource at UCL. The BDFA awarded £125 at the bequest of a donor in recognition of her contribution to this valuable resource and the field of NCL research.

Plans for future periods

The Trustees and staff held a strategic planning day to formulate a new one-year strategy for 2018-19. This financial year will be one of significant change for the charity and will lead to the creation of a stable, modern charity that provides excellent services for the families and children and young people impacted by Batten disease. A further long-term strategy will be developed in consultation with families during the year. The key strategic objectives are:

- We will provide excellent support and advocacy services to families and children and young people with Batten disease.
- We will fund those research projects we are currently committed to.
- We will create and manage a well-run, modern, efficient and sustainable organisation.

The full strategy document can be found on our website: www.bdfa-uk.org.uk

Financial review

The income for the year was £442,245 (2017 £339,250). Expenditure for the year totalled £506,295 (2017 £344,638). This deficit for 2017-2018 of £64,050 is partly due to a substantial invoice for the previous year which was paid this year and a decrease in our fundraised income.

Key risks and uncertainties

Principal risks and uncertainties trustees see us facing and the plan and strategies for managing those risks

The Trustees are mindful of the need to manage risk. They have identified some specific key risks:

- being a small organisation that needs to operate at the same level as large charities
- declining fundraised income and increased competition
- staff retention.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

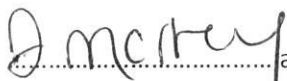
The Trustees are formulating plans to mitigate these risks and where this is not possible to mitigate the impact of the risk to the BDFA. Members for an Audit and Risk Committee will be sought from the Batten disease community and beyond. The risk register will be reviewed by the Board at least three times a year.

The Trustees report that they have submitted two Serious Incident Reports to the Charity Commission during this year.

Reserves and Going Concern

It is the Trustees' policy that there should be nine months' operating costs set aside as reserves. The Charity has not met this ambition this financial year. Trustees have put in place a new strategy that includes a greater focus on fundraising and income generation.

The charity had negative free reserves at the year-end, which is a huge concern. However, the trustees are confident that the above strategy will see the financial position improve.

 and signed on its behalf by;
15th May 2019

Amanad Mortensen
Chair of Trustees

BATTEN DISEASE FAMILY ASSOCIATION
(LIMITED BY GUARANTEE)
STATEMENT OF TRUSTEES' RESPONSIBILITIES

The Charities Act 2011 requires the trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that year.

In preparing these accounts, the trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

BATTEN DISEASE FAMILY ASSOCIATION

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF BATTEN DISEASE FAMILY ASSOCIATION

I report to the charity trustees on my examination of the accounts of the Charity for the year ended 31 August 2018.

Responsibilities and basis of report

As the trustees of the Charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 (the '2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the Charity's accounts as carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

I have completed my examination. I have identified a matter of concern in my report because I have concerns that there has been material action which appears not to be in accordance with restrictions placed on the use of restricted funds, and a breach of trust.

The accounts disclose that £27,871 of restricted funds has been used to fund activity which is not in accordance with restricted funders' wishes. During the year the movement in unrestricted funds was an outflow of £37,598. With only £9,727 funds brought forward from the previous year the charity has bridged the gap by utilising restricted funds held.

I confirm that no other matters have come to my attention in connection with the examination giving me reasonable cause to believe that in any material respect:

1. accounting records were not kept in respect of the Charity as required by section 130 of the Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.
4. except for the matter of concern noted above the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities [applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102)].

I confirm that there are no other matters to which your attention should be drawn to enable a proper understanding of the accounts to be reached.

BATTEN DISEASE FAMILY ASSOCIATION

INDEPENDENT EXAMINER'S REPORT TO THE TRUSTEES OF BATTEN DISEASE FAMILY ASSOCIATION (CONTINUED)

Mr Mark Cummins FCCA, FCIE

On behalf of



The Courtyard
Shoreham Road
Upper Beeding
Steyning
West Sussex
BN44 3TN

Dated: 23 May 2019

BATTEN DISEASE FAMILY ASSOCIATION

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 AUGUST 2018

		Unrestricted funds	Restricted funds	Total 2018	Total 2017
<u>Income from:</u>	Notes	£	£	£	£
Donations and legacies	2	114,767	255,265	370,032	249,890
Other trading activities	3	72,165	-	72,165	89,288
Investments	4	48	-	48	72
Total income		186,980	255,265	442,245	339,250
<u>Expenditure on:</u>					
Raising funds		41,416	-	41,416	47,084
Charitable activities		291,764	173,115	464,879	297,554
Total expenditure	5	333,180	173,115	506,295	344,638
Net income/(expenditure)		(146,200)	82,150	(64,050)	(5,388)
Transfers between funds	13	108,602	(108,602)	-	-
Net movement in funds		(37,598)	(26,452)	(64,050)	(5,388)
Fund balances at 1 September 2017		9,727	143,856	153,583	158,971
Fund balances at 31 August 2018		(27,871)	117,404	89,533	153,583

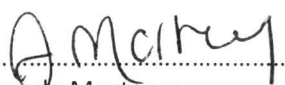
The notes on page 16 to 24 form part of these accounts.

BATTEN DISEASE FAMILY ASSOCIATION

BALANCE SHEET AS AT 31 AUGUST 2018

	Notes	£	2018 £	2017 £
Current assets				
Stock		3,623	-	
Debtors	10	9,397	6,649	
Cash at bank and in hand		166,898	164,641	
		<u>179,918</u>	<u>171,290</u>	
Creditors: amounts falling due within one year	11	(90,385)	(17,707)	
Net current assets			<u>89,533</u>	<u>153,583</u>
Total net assets			<u>89,533</u>	<u>153,583</u>
Income funds				
Restricted funds	13		117,404	143,856
Unrestricted income funds			(27,871)	9,727
			<u>89,533</u>	<u>153,583</u>

The accounts were approved by the Board on 15th May 2019


Amanda Mortensen
Chair of Trustees

Company Registration No. 108490

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

1.0 Accounting policies

1.1 Basis of preparation

The accounts have been prepared in accordance with Accounting and Reporting by the Charities Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland.

Batten Disease Family Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s).

In accordance with Section 7 of FRS 102 the charity is claiming exemption from the requirement to prepare a cash flow statement on account of its size.

1.2 Going Concern

The trustees recognise that the financial position at the year-end was not satisfactory and puts the charity at risk.

A new income generation strategy will be implemented during 2018/19, which the trustees are confident will improve the charity's financial position. The trustees feel it's appropriate to prepare these accounts on a going concern basis.

1.3 Income

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

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

Merchandise income is recognised as earned (that is, as the related goods or services are provided). Investment income is recognised on a receivable basis.

There has been no offsetting of assets and liabilities, or income and expenses, unless required or permitted by the FRS 102 SORP or FRS 102.

Grants and donations are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS 102 SORP).

Gift Aid receivable is included in income when there is a valid declaration from the donor. Any Gift Aid amount recovered on a donation is considered to be part of that gift and is treated as an addition to the same fund as the initial donation unless the donor or the terms of the appeal have specified otherwise.

1.4 Expenditure

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 to the category.

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

Costs of raising funds comprise the costs associated with attracting voluntary income and the costs of trading for fundraising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

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 payments 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. Governance costs include costs for the preparation and examination of the statutory accounts, the costs of trustee meetings and the cost of any legal advice to the trustee on governance or constitutional matters.

Support costs include central functions and have been allocated to charitable activities or fundraising expenses on a basis consistent with the use of resources, for example staff costs by the time spent and other costs by their usage.

Research and development expenditure is written off as incurred.

1.5 Debtors

Trade and other debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

1.6 Cash at bank and in hand

Cash at bank and in hand includes cash and short term highly liquid investments. The Trustees seek to use short and medium term deposits where possible to maximise the return on monies held at the bank and to manage cash flow.

1.7 Financial instruments

The Charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

1.8 Creditors and provisions

Creditors and provisions are recognised where the Charity has a present obligation resulting from a past event that will probably result in the transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

1.9 Pensions

The charity operates a defined contribution pension scheme. Contributions are charged in the statement of financial activities as they become payable in accordance with the rules of the scheme.

1.10 Operating leases

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

1.11 Accumulated funds

Funds held by the Charity are either:

Unrestricted general funds – these are funds which can be used in accordance with the charitable objects at the discretion of the Trustees.

Restricted funds – Donations, bequests or incoming resources for which the donor has earmarked for a specific purpose are treated as restricted funds.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

1.12 Taxation

The charitable company is registered as a charity and all of its income falls within the exemptions under Part 11 of the Corporation Tax Act 2010.

2 Voluntary Income

	Unrestricted funds	Restricted funds	Total 2018	Total 2017
	£	£	£	£
Donations				
Regular monthly donations	5,105	-	5,105	4,854
Donations gift aid	24,830	-	24,830	4,435
Donations non gift aid	2,547	-	2,547	16,572
Charitable giving	-	255,265	255,265	148,598
Gift aid reclaimed	5,289	-	5,289	10,499
Donations – organisations and schools	14,593	-	14,593	18,049
Foundations and trusts not restricted	4,487	-	4,487	30,600
Conference income	27,162	-	27,162	13,299
	84,013	255,265	339,278	246,906
In memoriam donations				
In memoriam	30,754	-	30,754	2,984
	114,767	255,265	370,032	249,890

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

3 Other trading activities

	Unrestricted funds	Restricted funds	Total 2018	Total 2017
	£	£	£	£
Fundraising				
Supporter fundraising	55,331	-	55,331	49,442
Collection boxes	30	-	30	845
Fundraising activities	16,424	-	16,424	38,312
	<u>71,785</u>	<u>-</u>	<u>71,785</u>	<u>88,599</u>
Merchandise income				
Merchandise sales	380	-	380	689
	<u>72,165</u>	<u>-</u>	<u>72,165</u>	<u>89,288</u>

4 Investment income

	Unrestricted funds	Restricted funds	Total 2018	Total 2017
	£	£	£	£
Interest income	<u>48</u>	<u>-</u>	<u>48</u>	<u>72</u>

5 Total expenditure

	Staff costs	Depreciation	Other Costs	Total 2018	Total 2017
	£	£	£	£	£
Costs of raising funds					
Fundraising costs	18,383	-	13,790	32,173	29,763
Support costs	7,113	-	2,130	9,243	17,321
	<u>25,496</u>	<u>-</u>	<u>15,920</u>	<u>41,416</u>	<u>47,084</u>
Charitable activities					
Activities undertaken directly	91,033	-	312,065	403,098	245,590
Support costs	21,338	-	40,443	61,781	51,964
Total	<u>112,371</u>	<u>-</u>	<u>352,508</u>	<u>464,879</u>	<u>297,554</u>
Total expenditure	<u>137,867</u>	<u>-</u>	<u>368,428</u>	<u>506,295</u>	<u>344,638</u>

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

6 Support costs - other

	Total 2018	Total 2017
	£	£
Rent	12,704	12,249
Rates	759	951
Premises expenses	449	798
Postage, freight and courier	504	757
Telephone	1,029	380
Computer expenses	5,703	1,584
Office equipment	179	471
Insurance	1,264	1,014
Organisational membership and professional fees	1,548	2,295
Accountancy fees	3,736	1,300
Book keeping	3,376	3,600
Bank charges	46	20
Recruitment expenses	6,600	-
Staff training	345	184
Website costs	955	1,584
HR	1,868	3,609
Trustee costs	1,508	918
	42,573	31,714

These costs include amounts payable to the independent examiners of £600 (2017: £400) for independent examination and other services.

7 Trustees

The trustees were reimbursed £1,508 (2017: £369) for travel and fundraising costs during the year. None of the Trustees (or any persons connected with them) received any remuneration during the year or previous year.

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS (CONTINUED) FOR THE YEAR ENDED 31 AUGUST 2018

8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2017

		Unrestricted funds	Restricted funds	Total 2017	Total 2016
Income from:	Notes	£	£	£	£
Donations and legacies	3	112,831	137,059	249,890	214,539
Other trading activities	4	89,288	-	-	113,775
Investments		72	-	72	192
Total income		202,191	137,059	339,250	328,506
Expenditure on:	5				
Raising funds		29,763	-	29,763	43,169
Charitable activities		217,023	97,852	314,875	408,630
Total expenditure		246,786	97,852	344,638	451,799
Net income/(expenditure)		(44,595)	(39,207)	(5,388)	(123,293)
Transfer between funds	14	11,582	(11,582)	-	-
Net movement in funds		(33,013)	27,625	(5,388)	(123,293)
Fund balances at 1 September 16		42,740	116,231	158,971	282,264
Fund balances at 31 August 2017		9,727	143,856	153,583	158,971

9 Employees

The average full time equivalent number of employees during the year was:

	Total 2018	Total 2017
Fundraising	1	1
Charitable activities	2	2
Advocacy	1	1
	4	4
Employment costs	Total 2018 £	Total 2017 £
Wages and salaries	124,823	102,581
Social security costs	8,975	13,475
Pension costs	4,069	4,532
	137,867	120,588

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2018

There were no employees earning more than £60,000 in the current or previous year.

10 Debtors

	2018	2017
	£	£
Trade debtors	2,414	-
Prepayments and accrued income	5,735	5,735
Other debtors	1,248	914
	9,397	6,649

11 Creditors: amounts falling due within one year

	2018	2017
	£	£
Trade creditors	12,951	11,326
Other creditors	71,180	1,783
Accruals	2,400	1,200
Taxes and social security	3,854	3,398
	90,385	17,707

12 Pension scheme

Defined contribution pension scheme

The charity operates a defined contribution pension scheme. The pension cost charge for the period represents contributions payable by charity to the scheme and amounted to £4,069 (2017: £4,532).

Contributions totalling £427 (2017: £502) were payable to the scheme at the end of the period and are included in creditors.

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2018

13 Restricted funds

The income funds of the charity include restricted funds comprising the following unexpended balances of donations and grants for specific purposes:

	Balance at 1 September 2017	Income	Expenditure	Transfers between funds	Balance at 31 August 2018
George Young *	834	25,983	(13,409)	(6,704)	6,704
The Nicole Rich Foundation *	20,732	53,675	(39,917)	(16,023)	18,467
Batten Fighters Forever *	21,531	53,488	(39,490)	(15,782)	19,747
Isabel's Sparkle *	-	1,545	(1,927)	382	-
Euro Ed Project	4,471	2,881	(500)	-	6,852
Battle Batten CLN5	50,001	9,188	(8,400)	(35,000)	15,789
In Memory of Katie Freeman	859	1,749	-	-	2,608
Key worker support **	11,930	-	-	(11,930)	-
Clinical Nurse Specialist Funding **	22,093	-	-	(22,093)	-
Bat Cure	8,926	13,477	(12,730)	-	9,673
Olivlacce CLN3	2,479	-	-	-	2,479
BioMarin	-	25,290	(25,290)	-	-
Beefy's	-	30,000	-	-	30,000
Ollie's army	-	30,000	(30,000)	-	-
McFarland	-	5,085	-	-	5,085
Fair Warrior Foundation	-	2,904	(1,452)	(1,452)	-
	143,856	255,265	(173,115)	(108,602)	117,404

The Nicole Rich Foundation fund is for CLN2 late Infantile Batten disease research.

Batten Fighters Forever is for CLN3 junior Batten disease research.

Battle Batten fund is for CLN Batten disease research to identify key differences in cells in CLN5 patients and healthy unaffected cells.

The Clinical Nurse Specialist Funding is from Great Ormond Street Hospital to fund clinical support and advice.

The Bat Cure fund is from the E.U. Horizon 2020 research and innovation programme with the intention to advance therapeutic options for those suffering from Batten disease.

Olivlacce fund is to fund CLN3 JUNIOR Batten disease research.

The key worker support fund is to support the key worker role.

Transfers

- * During the year transfers have been made from the restricted funds to unrestricted funds. These transfers represent a percentage from the MOU funding agreements which have been allowed for the running of the charity. Some transfers also represent funds which specific funders have agreed can be allocated for unrestricted activity.
- ** This income was incorrectly restricted in prior years. The transfers represent funds reallocated as unrestricted.

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2018

14 Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total £
Fund balances at 31 August 2018 are represented by:			
Current assets	(7,717)	187,635	179,918
Creditors due within one year	(20,154)	(70,231)	(90,385)
	<u>(27,871)</u>	<u>117,404</u>	<u>89,533</u>

15 Related party transactions

There were no related party transactions during the current or previous year.

16 Control

The charity is controlled by the trustees.