

Charity Registration No. 1084908

OSCR No. SCO47408



BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES REPORT AND ACCOUNTS
FOR THE YEAR ENDED 31 AUGUST 2019

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

Trustees	Pauline Docherty, Co-Chair Roger Cole Catherine Sermon Neil Dunford Amanda Mortenson
-----------------	--------------------------------------------------------------------------------------------------

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

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

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

Independent Examiner	TC Group 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

BATTEN DISEASE FAMILY ASSOCIATION

LEGAL AND ADMINISTRATIVE INFORMATION

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
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(s)
Trustees' Report	1 to 8
Statement of Trustees' Responsibilities	9
Independent Examiner's Report	10
Statement of Financial Activities	11
Balance Sheet	12
Notes to the financial statements	13 to 21

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 year has been one of huge change and challenge, in order to stabilise the BDFA and secure its future going forward.

The board has made the difficult decision to focus entirely on its support function until it is in a more stable position. Trustees made a decision to 'pause' the charity's research function. As a result we lost our scientific officer, Heather Band. This decision was taken with regret and we are very grateful to Heather for all she has achieved for the Batten disease community.

Our CEO Samantha Barber left after a fixed term contract and we would like to take this opportunity to thank her for her exceptional dedication and hard work during a testing and turbulent time. We have appointed a new CEO (who is part-time, in line with our strategy to cut costs). Our previous chair, Amanda Mortensen, took up this position on 24th February 2020. After stewarding the charity through the past few years as Chair she is very pleased to now be able to take the charity forward as CEO.

The BDFA does not receive any government or NHS funding and we hugely rely on the community's support. It is imperative that we diversify our income going forward. Only a small proportion of our income is from trusts and foundations and we are confident we will be able to grow this income. We will soon be in a position to apply to further trusts and foundations as well as larger grant making organisations. Along with many of our rare disease counterparts, we access some funding from pharmaceutical companies but we are careful to remain impartial.

We are currently in the midst of the Covid-19 pandemic and our community fundraising has ceased almost overnight. We are experiencing higher demand for our resources and we are therefore seeking additional assistance. We are approaching funders to un-restrict some restricted funds as well as asking our existing donors if they can support us through this 'crisis'.

Shortly after the year end, we received the news that *Brineura*, a treatment for CLN2 Batten disease, had been approved for use (with a managed access agreement for 5 years) on the NHS. This was a major achievement for us as a small patient organisation. We worked in collaboration with families, whose campaigning and legal action was very effective. There are further drugs in the pipeline for different forms of Batten disease. It is certain that the BDFA's role around access to treatments as well as influencing work to change processes and the patient experience will become a vital part of what we do as a patient organisation.

BATTEN DISEASE FAMILY ASSOCIATION

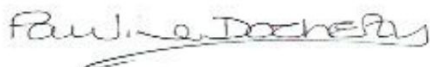
TRUSTEES' REPORT

Thank you to all of those who have supported us this year. The families who fundraise for the BDFA at the same time as caring for a child or children with Batten disease are an inspiration to us all. We are hugely reliant on our community effort. I would particularly like to thank our ex chair and parent Michael O'Connor who has worked tirelessly to run a very successful campaign this year. His campaign "*Passing the Batten on*" has raised over £125,000 this year.

I would also like to thank my fellow Trustees for their continuing voluntary work and Rahul Dubey, who stepped down as Trustee during this year. We have some potential new Trustees waiting in the wings whom we hope to confirm at the AGM but they will be joining meetings in the interim and we will publish details of them prior to the AGM. However more volunteers are always welcome

The BDFA exists to support the families with children or young people with Batten disease. They are the driver behind everything we do. It is crucial that the BDFA continues to provide that support and advocacy so vital to ensuring families receive all the support they need.

While the transformation of the BDFA may not be finished, we are well on the way. I hope that you will continue to support us as we move on to better times.



All best wishes

Pauline Docherty

Acting Chair of Trustees

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Report of the Trustees and Financial Statement for Year Ended 31 August 2019 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 2019. 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	Amanda Mortensen (resigned as chair 21 December 2019)
Co-Chair	Pauline Docherty (acting as chair since 21 December 2019)
Treasurer	Roger Cole
	Catherine Sermon
	Neil Dunford
	Rahul Dubey (resigned 10 September 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, Samantha Barber (contract ended December 2019) and supported by the following team in 2018-19:

1. Harriet Lunneman (Full-time) Family Support Officer (resigned December 2018)
2. Wendy Thompson (17.5 hours per week) Family Support Officer (joined March 2019)
3. Catherine McSweeney (17.5 hours per week) Family Support Officer (joined April 2019)
4. Heather Band (32 hours per week) Scientific Officer (redundant May 2019).

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

The Batten Disease Family Association benefits from the services of volunteer educational, medical and research advisers who liaise with the employed Officers and the relevant Trustees as necessary. We are grateful for their support and enthusiasm.

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

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

development of the Charity's mission and aims. Advertisements for new trustees are made on the BDFA website and social media platforms and volunteering websites.

Objectives and activities

Who we are

The Batten Disease Family Association is the only UK charity supporting families, raising awareness and supporting 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.

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).

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.

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. However, we have had to take the decision to pause our research function. We will honour our current commitments but will not be initiating calls for new research for the foreseeable future.

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.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Achievements and performance

The BDFA is focused on getting the best for all our families across the UK by providing bespoke advice to families and by ensuring the public and policy makers are educated about this disease. This year has been the last for the European-funded BATCure project and other research has continued.

We work closely with other charities and stakeholders, such as The Amber Trust, to provide much needed therapies and experiences to children and young adults with Batten disease. We thank them for their continued support.

Support and Advocacy

- The Family Support Service was reconfigured to two part-time Family Support Officers, one in the North and one in the South. This reduces travel time and cost, and enables deeper connection with local professionals working with our families.
- We successfully worked with families and others to secure access to the first ever treatment for any form of Batten disease in Sept 2019. This work has been intensive and is a significant development for all forms of the disease.
- Education advocacy has continued this year. We have a very experienced volunteer, Barbara Cole, who supports us with this. It is vital to make sure that children and young people with Batten disease receive the education that will benefit them the most.
- The book from the Erasmus +, European Union JNCL and Education Project, which focused on children and young people with CLN3, was published and the project concluded. The BDFA has been pivotal in this project.
- The BDFA is a key stakeholder in the MIND Music Therapy Project with the University of Roehampton and Chiltern Music Therapy, investigating the role of music in the lives of children and young people with Batten disease. The report is has just been published and is the precursor to a wider music therapy project for children and young people with Batten disease, launching later in 2020.
- The *Dementia Strikes Children Too* campaign continued following a successful launch last year. The campaign is a small group of rare disease charities working on a specific awareness campaign about a collection of conditions that cause Childhood dementia.
- The BDFA promoted both the UK and international Batten disease Awareness Days. We are grateful to all those who participated.
- One of the Family Support Officers attended the Batten Disease Support and Research Association (BDSRA) conference in the US in July to ensure the interests of the UK community were represented.
- Interaction with a wide range of pharmaceutical companies engaged in drug research and development has increased in order to keep abreast of the latest developments and how they might impact the UK.
- The programme of advocacy and awareness with MPs and Welsh Assembly Members has continued, raising awareness of the disease and the needs of our families.
- We have continued to attend a range of meetings working with our counterparts such as the LSD Collaborative, Specialised Health Care Alliance, Disabled Children's Partnership, Neurological Alliance and others.
- Fundraising has focused on individual events. We are grateful to all those in the Batten community and beyond who raised funds for the charity.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT



Research this year

BATCure. January 2016-August 2019 Developing new therapies for Neuronal Ceroid Lipofuscinosis (NCL) commonly known as Batten disease

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 666918

The BDFA received funding for the project: €62,337.50.

The project work was undertaken by:

Heather Band, BDFA Scientific Officer Work Package Lead, 6 hours per week.

Jan 2016 - June 2019.

Laura Codd, BATCure Administrator, 8 hours per week.

April 2016 - August 2018.

The aim of the BATCure project was to advance the scientific knowledge and development of new therapeutic options for those affected by CLN3, CLN6 and CLN7 disease.

The BATCure consortium was led by Professor Sara Mole, UCL, and brought together ten leading scientific research groups, three companies and the BDFA. The BDFA was chosen as the Patient Organisation representative partner for the BATCure project.

The BATCure consortium are a talented, diverse group with the necessary skills and expertise to offer a novel strategic and integrated approach to a set of very complex diseases. Much needed new research expertise entered the field with over half of the groups involved applying their skills to Batten disease for the first time.

The scientific scope of the project was ambitious and the group utilised a multi-faceted approach. They investigated the natural history of the three types of Batten disease, provided new research models, to elucidate the function of key proteins and to determine disease mechanisms, and developed new therapeutic options.

A ground-breaking part of this project was including the patient voice as central to all the work of the consortium and as such the BDFA, played a significant role representing all those affected by this devastating disease.

The work for BATCure contributed to the charity's objectives and activities across all aspects of our work, support, raising awareness, conducting and supporting research.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

The BDFA's aim is that no family faces the devastating journey alone and the BDFA recognises the importance of research to families in providing hope for the future. The BDFA has previously identified that early involvement of patients and their families is a major factor in progressing research to a successful clinical outcome. BATCure provided a mechanism for the BDFA to advance this objective with direct patient representation in a major scientific initiative. The work also produced a workable template for patient involvement in future research projects.

The charity undertook, as a member of the BATCure consortium, a patient survey (in collaboration with UCL) which was delivered in 10 languages to over 15 countries within the European Union. The survey focused on four main areas identified as the most important to families. Issues around diagnosis, access to quality information on research, participation in the International disease registry and to gain families' thoughts on potential barriers to taking part in clinical trials. The results were communicated to the consortium members, and shared freely within the scientific community and presented at relevant scientific and rare disease meetings and events.

In the first 2 years, Laura Codd, the BATCure Project Administrator established links between the consortium, patients and their families and over 20 Batten disease Patient Organisations and Foundations worldwide. Heather Band & Laura Codd managed communication of the project news, raising awareness and dissemination of the project results. This has achieved public benefit for affected families by raising awareness within the rare disease community and beyond.

The BDFA was also able to utilise its role as a BATCure partner to develop resources and partner with researchers in laboratory open days for affected families, related professionals and the wider scientific community.

Much of the focus for the BDFA, in the final year, was the preparation and delivery of the Patient focused and Public Engagement sessions for NCL2018. This is a bi-annual international meeting for researchers, clinicians, education and other related professionals, industry representatives and affected families. It is the major meeting for all those with an interest in Batten disease. As part of the work for BATCure the BDFA co-hosted the event and was a member of the local organising committee.

BATCure has advanced NCL research significantly and led to a number of publications with many more expected in 2020. Consortium members intend to continue their collaborations and are actively applying for further funding to continue the work. Progress has been made in several key areas,

The BDFA disseminated the reports to key stakeholders and the wider public across the EU and worldwide. The final report was submitted by UCL to the EU in August 2019.

Plans for future periods

The past financial year has been one of substantial change for the BDFA, including a staffing restructure and a programme of cost-reduction. It is expected that the coming financial year will be one of consolidation so that the charity can secure a solid future going forward.

BATTEN DISEASE FAMILY ASSOCIATION

TRUSTEES' REPORT

Our current 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 and then pause our research programme.
- We will continue to focus on stabilising the charity and ensuring it is sustainable going forward.

Financial review

The income for the year was slightly reduced at £373,826 (2018 £442,245). However, expenditure for the year almost halved £279,779 (2018 £506,295), reflecting our efforts to reduce our operating costs. The charity registered a surplus in 2018-19 reflecting the actions taken to reduce the regular costs and the revised structure.

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:

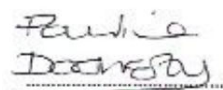
- being a small organisation that needs to operate at the same level as large charities
- declining fundraised income and increased competition
- staff retention.

The Trustees have put in place plans to mitigate the impact of risk to the BDFA. A new Treasurer has been co-opted and he will provide guidance on the activities need to improve controls and reporting as well as management of risks.

Reserves and Going Concern

It is the Trustees' policy that there should be six to twelve months' operating costs set aside as reserves. This is an ambitious target and may be reviewed going forward. The Charity has met this ambition this financial year. Trustees are to consult on a new strategy that includes a greater focus on fundraising and income generation.

The charity had free reserves of £64,986 at the year-end which demonstrates a reversal of the position in the past accounts. The Trustees are confident that the improving situation of the past year will continue.



and signed on its behalf by;

Pauline Docherty

Acting Chair of Trustees

BATTEN DISEASE FAMILY ASSOCIATION

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 2019.

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

Since the company's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the association of Certified Chartered Accountants, which is one of the listed bodies.

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

1. accounting records were not kept in respect of the company as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. 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 have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.



Mr Mark Cummins FCCA, FCIE

On behalf of TC Group

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

Dated: 7 April 2020

BATTEN DISEASE FAMILY ASSOCIATION

STATEMENT OF FINANCIAL ACTIVITIES FOR THE YEAR ENDED 31 AUGUST 2019

		Unrestricted funds	Restricted funds	Total 2019	Total 2018
<u>Income from:</u>	Notes	£	£	£	£
Donations and legacies	2	68,079	65,061	133,140	370,032
Other trading activities	3	149,171	91,450	240,621	72,165
Investments	4	65	-	65	48
Total income		217,315	156,511	373,826	442,245
<u>Expenditure on:</u>					
Raising funds		31,598	28,799	60,397	41,416
Charitable activities		98,529	120,853	219,382	464,879
Total expenditure	5	130,127	149,652	279,779	506,295
Net income/(expenditure)		87,188	6,859	94,047	(64,050)
Transfers between funds	13	5,669	(5,669)	-	-
Net movement in funds		92,857	1,190	94,047	(64,050)
Fund balances at 1 September 2018		(27,871)	117,404	89,533	153,583
Fund balances at 31 August 2019		64,986	118,594	183,580	89,533

The notes on page 13 to 21 form part of these accounts.

All income and expenditure shown above relate to continuing activities.

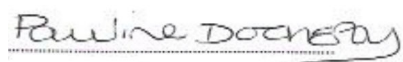
BATTEN DISEASE FAMILY ASSOCIATION

BALANCE SHEET

AS AT 31 AUGUST 2019

	Notes	£	2019 £	2018 £
Current assets				
Stock		2,200	3,623	
Debtors	10	7,593	9,397	
Cash at bank and in hand		236,952	166,898	
		246,745	179,918	
Creditors: amounts falling due within one year	11	(63,165)	(90,385)	
Net current assets			183,580	89,533
Total net assets			183,580	89,533
Income funds				
Restricted funds	13	118,594	117,404	
Unrestricted income funds		64,986	(27,871)	
		183,580	89,533	

The accounts were approved by the Board on 3 April 2020



Pauline Docherty

Acting Chair of Trustees

The notes on page 13 to 21 form part of these accounts.

BATTEN DISEASE FAMILY ASSOCIATION

NOTES TO THE ACCOUNTS

FOR THE YEAR ENDED 31 AUGUST 2019

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 and the Charities Accounts (Scotland) Regulation 2006 (as amended).

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.

The financial statements are prepared in Sterling which is the functional currency of the charity and rounded to the nearest £1.

1.2 Going Concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Association has adequate resources to continue in operational existence for the foreseeable future. For this reason they continue to adopt the going concern basis in preparing the financial statements.

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 2019

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 Stocks

Stocks are stated at the lower of cost or residual value.

1.6 Debtors

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

1.7 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.

1.8 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.

1.9 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 2019

1.10 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.

1.11 Operating leases

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

1.12 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. The trustees have considered the level of free reserves held at the year end. Ideally they would like this to be between 6 and 2 months of unrestricted costs. They're currently achieving just under 7 months, a significant improvement on the prior year.

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.

1.13 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 2019	Total 2018
	£	£	£	£
Donations				
Regular monthly donations	5,434	-	5,434	5,105
Donations gift aid	9,098	-	9,098	24,830
Donations non gift aid	6,587	-	6,587	2,547
Charitable giving	-	65,061	65,061	255,265
Gift aid reclaimed	-	-	-	5,289
Donations – organisations and schools	6,125	-	6,125	14,593
Foundations and trusts not restricted	36,591	-	36,591	4,487
Conference income	-	-	-	27,162
Hey Charlie	5	-	5	-
Great North Run	1,255	-	1,255	-
	65,095	65,061	130,156	339,278
In memoriam donations				
In memoriam	2,984	-	2,984	30,754
	68,079	65,061	133,140	370,032

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2019

3 Other trading activities

	Unrestricted funds	Restricted funds	Total 2019	Total 2018
	£	£	£	£
Fundraising				
Supporter fundraising	104,337	-	104,337	55,331
Collection boxes	-	-	-	30
Fundraising activities	43,891	91,450	135,341	16,424
	<u>148,228</u>	<u>91,450</u>	<u>239,678</u>	<u>71,785</u>
Merchandise income				
Merchandise sales	943	-	943	380
	<u>149,171</u>	<u>91,450</u>	<u>240,621</u>	<u>72,165</u>

4 Investment income

	Unrestricted funds	Restricted funds	Total 2019	Total 2018
	£	£	£	£
Interest income	65	-	65	48

5 Total expenditure

	Staff costs £	Other Costs £	Total 2019 £	Total 2018 £
Costs of raising funds				
Fundraising costs	18,467	28,420	46,887	32,173
Support costs	11,516	1,994	13,510	9,243
	<u>29,983</u>	<u>30,414</u>	<u>60,397</u>	<u>41,416</u>
Charitable activities				
Activities undertaken directly	58,663	88,294	146,957	403,098
Support costs	34,547	37,878	75,425	61,781
	<u>93,210</u>	<u>126,172</u>	<u>219,382</u>	<u>464,879</u>
Total expenditure	<u>123,193</u>	<u>156,586</u>	<u>279,779</u>	<u>506,295</u>

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2019

6 Support costs - other

	Total 2019	Total 2018
	£	£
Rent	8,158	12,704
Rates	-	759
Premises expenses	425	449
Postage, freight and courier	75	504
Telephone	1,545	1,029
Computer expenses	2,969	5,703
Office equipment	47	179
Insurance	1,396	1,264
Organisational membership and legal and professional fees	7,527	1,548
Accountancy fees	8,980	3,736
Book keeping	4,171	3,376
Bank charges	39	46
Recruitment expenses	701	6,600
Staff training	300	345
Website costs	-	955
HR	2,990	1,868
Trustee costs	549	1,508
	39,872	42,573

These costs include amounts payable to the independent examiners of £8,980 (2018: £3,736) for independent examination and other services.

7 Trustees

The trustees were reimbursed £549 (2018: £1,508) 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 2019

8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2018

	Unrestricted funds	Restricted funds	Total 2018
Income from:	£	£	£
Donations and legacies	114,767	255,265	370,032
Other trading activities	72,165	-	72,165
Investments	48	-	48
Total income	186,980	255,265	442,245
Expenditure on:			
Raising funds	41,416	-	41,416
Charitable activities	291,764	173,115	464,879
Total expenditure	333,180	173,115	506,295
Net income/(expenditure)	(146,200)	82,150	(64,050)
Transfer between funds	108,602	(108,602)	-
Net movement in funds	(37,598)	(26,452)	(64,050)
Fund balances at 1 September 2017	9,727	143,856	153,583
Fund balances at 31 August 2018	(27,871)	117,404	89,533

9 Employees

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

	Total 2019	Total 2018
Scientific Officer (until May 2019)	0.5	1
Charitable activities	1	2
Advocacy	1	1
	2.5	4
Employment costs	Total 2019 £	Total 2018 £
Wages and salaries	111,170	124,823
Social security costs	8,618	8,975
Pension costs	3,405	4,069
	123,193	137,867

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

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2019

10 Debtors

	2019	2018
	£	£
Trade debtors	7,593	2,414
Prepayments and accrued income	-	5,735
Other debtors	-	1,248
	<u>7,593</u>	<u>9,397</u>

11 Creditors: amounts falling due within one year

	2019	2018
	£	£
Trade creditors	18,096	12,951
Other creditors	39,736	71,180
Accruals	3,128	2,400
Taxes and social security	2,205	3,854
	<u>63,165</u>	<u>90,385</u>

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 £3,405 (2018: £4,069).

Contributions totalling £352 (2018: £427) 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 2019

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 2018	Income	Expenditure	Transfers between funds	Balance at 31 August 2019
George Young	6,704	10	(7,398)	684	-
The Nicole Rich Foundation *	18,467	15,636	(27,849)	(6,254)	-
Batten Fighters Forever *	19,747	335	(20,000)	(82)	-
Isabel's Sparkle *	-	86	(69)	(17)	-
Euro Ed Project	6,852	-	(2,821)	-	4,031
Battle Batten CLN5	15,789	5	(8,749)	-	7,045
In Memory of Katie Freeman	2,608	962	-	-	3,570
Bat Cure	9,673	7,844	(17,517)	-	-
Olivlacce CLN3	2,479	-	-	-	2,479
BioMarin	-	23,183	(23,183)	-	-
Beefy's	30,000	10,000	-	-	40,000
Ollie's army	-	7,000	-	-	7,000
McFarland	5,085	-	-	-	5,085
Fundraising and database (Biomarin)	-	47,450	(30,200)	-	17,250
Scotland (Biomarin)	-	40,000	(11,866)	-	28,134
Gene Therapy Day	-	4,000	-	-	4,000
	117,404	156,511	(149,652)	(5,669)	118,594

- George Young funds research for CLN5.
- The Nicole Rich Foundation fund is for CLN2 late Infantile Batten disease research.
- Batten Fighters Forever is for CLN3 junior Batten disease research.
- Isabel's Sparkle funds CLN2 research.
- Euro Ed Project is a Europe wide education project focussed on CLN3.
- Battle Batten fund is for CLN Batten disease research to identify key differences in cells in CLN5 patients and healthy unaffected cells.
- In memory of Katie freeman is for CLN5 research.
- 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.
- BioMarin is a pharmaceutical company (that developed Brineura). Biomarin funds specific projects such as a project analysing the school reports of children with CLN2.
- Beefy's foundation is a charity supporting research projects into new treatments for Batten disease.
- Ollie's army raises funds for CLN2 research and any project that benefits children and young people with CLN2.

(continued on next page)

BATTEN DISEASE FAMILY ASSOCIATION
NOTES TO THE ACCOUNTS (CONTINUED)
FOR THE YEAR ENDED 31 AUGUST 2019

- McFarland is for CLN5 research.
- Fundraising and database (Biomarin). It is specifically to build capacity within the BDFA to diversify its income, shape a fundraising function and create a new database.
- Scotland (Biomarin) is to enable the BDFA to support patients in Scotland to access Brineura.
- Gene Therapy day funds is money from two pharmaceutical companies, ReginxBio and Spark Therapeutics. This is specifically for a day looking at new gene therapies that are in the pipeline.

* 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.

14 Analysis of net assets between funds

	Unrestricted funds £	Restricted funds £	Total £
Fund balances at 31 August 2019 are represented by:			
Current assets	100,066	146,679	246,745
Creditors due within one year	(35,080)	(28,085)	(63,165)
	<u>64,986</u>	<u>118,594</u>	<u>183,580</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.