

Batten Disease Family Association

Annual Report and Financial Statements

for the Year Ended 31 August 2017

Charity Number : 1084908

OSCR Number: SCO47408

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

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REGISTERED CHARITY NUMBER 1084908

**REPORT OF THE TRUSTEES AND UNAUDITED FINANCIAL STATEMENT FOR THE
YEAR ENDED 31 AUGUST 2017 FOR BATTEN DISEASE FAMILY ASSOCIATION
(BDFA)**

The Trustees present their report with the financial statements of the charity for the year ended 31 August 2017. 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) Regulations 2006 (as amended).

REFERENCE AND ADMINISTRATIVE DETAILS

Registered Charity Number

1084908, SCO47408

Principal Address

The Old Library
4 Boundary Road
Farnborough
Hampshire
GU14 6SF

Trustees

Chair	Michael O'Connor
Co-Chair	Pauline Docherty
Treasurer	Roger Cole
	Catherine Sermon
	James Jeynes
	Neil Dunford
	Dave Mitchell
	Rahul Dubey
	Amanda Mortenson

Independent Examiner

Roffe Swayne Chartered Accountants
Ashcombe Court
Woolsack Way
Godalming
GU7 1LQ

Bankers

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

Santander Bank
Bootle
Merseyside
L30 4GB

REFERENCE AND ADMINISTRATIVE DETAILS

Research Advisors

Professor Sara Mole
MRC Laboratory for Molecular Cell
Biology
UCL
Gower Street
London
WC1E 6BT

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

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

Professor Jonathan D. Cooper, PhD.
Professor of Pediatrics

Los Angeles Biomedical Research Institute
at Harbor-UCLA Medical Center
1124 W. Carson Street, HH1
Torrance, CA 90502

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

Education Advisor

Mrs Barbara Cole, Education Advisor

Medical Advisor

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

2. Dr Barbara Csanyi
Paediatric Neurologist
Great Ormond Street Children's Hospital
London

3. Dr Christine Caren GP (retired)

STRUCTURE, GOVERNANCE AND MANAGEMENT

Governing Document

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

Recruitment and Appointment of New Trustees

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

Candidates are then given information on the roles, interviewed by the current Board and invited to attend a Trustees' meeting. Appointment is then conditional on the approval of Trustees and members at the AGM and is subject to a DBS disclosure and Trustee's Declaration of Eligibility. Trustees have fully documented information packs and job descriptions to support their recruitment and induction to the Board.

Organisational Structure

The Strategy and oversight of the affairs of the Batten Disease Family Association are directed by the Trustees. The day to day management of the Batten Disease Family Association has been carried out by the employed Chief Executive, Andrea West, and supported by the following team in 2016/2017:

1. Harriet Lunneman (Full-time) Family Support Officer
2. Heather Band (32 hours per week) Scientific Officer
3. Lucy Roose (25 hours per week) Office Manager
4. Gaynor Heeson (20 hours per week) Fundraising Administrator (resigned Aug 2017)
5. Sarah Parke (20 hours per week) Fundraising Administrator (resigned July 2017)
6. Kate Shefford (20 hours per week) Fundraising Administrator (resigned Dec 2016)
7. Laura Codd (7.5 hours per week) BATCure Administrator

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

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

Risk Management

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

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

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

Financial Review

The income for the year was £339,250 (2016 £328,506). Expenditure for the year totalled £344,638 (2016 £451,799). This deficit for 2016-2017 of £5,388 refers to expenditure from brought forward restricted funds and does not represent an overspend compared to income.

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 the NCLs (Batten disease)

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

The NCLs (Batten disease) are estimated to affect 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 then dying between the ages of 5 and 30 (depending on the specific diagnosis). There continues to be much research into all forms of the NCLs, but no cure at present.

An NCL diagnosis profoundly changes the child's and their family's life forever. The journey with these diseases is an ever-changing picture of needs. Unlike other diseases where there is huge awareness of the support, therapies and guidance resources needed for the child and family, the families of children and young people with Batten disease are left isolated as most professionals do not understand the course of the disease and the child or family's needs. It

is therefore essential that the families and professionals have a place to turn to for that support and guidance.

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

What we do

Support: Our aim is that no family faces the devastating journey with Batten disease alone. Through our family support and advocacy service we aim to improve the quality of life for families, affected children and adults and also the teams of professionals around them.

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

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

Public benefit: In making decisions regarding the charities purposes and what the charity has done throughout the year, the trustees have had due regard to the commission's public benefit guidance.

ACHIEVEMENT AND PERFORMANCE

BDFA Support and Advocacy Programme

The BDFA delivers a support and advocacy programme centred on the reported needs of UK families affected by a Batten disease diagnosis. In 2017 this support has expanded to cover contact from and support given to families and professionals from over 25 countries worldwide. Given the rare nature of the NCLs it is also important that we are able to provide a programme of support, training and networking to the teams of professionals around families. Only by driving this holistic programme of care are we able to meet the needs that families report to us to enable them and their children and young people to live the best life they can.

1. Our support and advocacy worker, Harriet Lunneman - a qualified social worker with extensive experience of working with children with disabilities, provides non-clinical support and information to families and professionals both remotely and face to face.
2. The BDFA funded Batten disease Clinical Nurse Specialist, at Great Ormond Street Children's Hospital in London provides clinical support and advice to families across the UK.
3. We hold an annual family conference and networking event with an extensive programme of workshops and presentations covering all aspect of care for children, research updates and a comprehensive programme of childcare and activities for both affected children and siblings.

4. We continue to work with the US Pharmaceutical firm BioMarin to deliver a support service to those families enrolled on the BMN190 (and follow-up trials) of enzyme replacement therapy for CLN2 disease in the trial sites in London, Rome and Hamburg.
5. In 2016/17 the BDFA small grant scheme provided 18 families with much needed financial support for items such as driving lessons, passports, play equipment, educational equipment and washing machines.
6. Continuing to provide much needed education advocacy support through our education advisor to ensure that children and young people with an NCL diagnosis receive the best education experience, delivering training workshops to education professionals and as a key stakeholder in the European education project.
7. Updates and new material added to the Family Resources folder based on family feedback. This is free to all family members of the BDFA and provides information on the disease, symptoms, progression, health and social care, education and resources available.
8. We continue to publish a bi-annual member and supporter newsletter. We also send weekly email updates on our work, impact and valuable resources to members which now reaches over 2000 subscribers.
9. We maintain a strong presence on a number of social media platforms to raise awareness, connect families and fund our work.
10. We promote links between UK professionals with clinical, research and educational specialist expertise in Batten disease and those who can give professional guidance to affected families and the teams around them.
11. We work closely with other charities and stakeholders such as The Amber Trust, Dreams Come True, Make a Wish and Roald Dahl's Marvellous Children's Charity to provide much needed therapies and experiences to affected children and young adults.
12. We are working with NICE and NHS England to represent the patient voice in the assessment of Cerliponase Alpha, the treatment for CLN2 (Late Infantile Batten disease)

BDFA Research Programme

Finding successful treatments and potential therapies for all forms of the NCLs is a central aim of the BDFA and we support research for all stages of this process. The BDFA place equal importance on projects which look holistically at all aspects of Batten disease and the lives of families living with it.

The BDFA is constantly active in promoting awareness of Batten disease amongst clinicians, researchers and other related professionals and works with many difference organisations to drive forward rare disease research. The BDFA also has a comprehensive programme of conference and meeting sponsorship.



1. BATCure (2015-2018)

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

The goal of the 3- year project is to advance the development of new therapeutic options for patients and their families living with CLN3, CLN6 or CLN7 Batten disease.

The consortium is made up of groups from seven European countries, co-ordinated by Prof. Sara Mole at UCL, including ten leading scientific research groups, three companies and the BDFA.

The BDFA is leading part of the project ensuring that the voice of patients and affected families is heard:

- Develop a methodology to enable patients, patient groups & stakeholders to participate in the project.
- Prepare for future Clinical Trials
- Communication strategy with Public & professional engagement
- Exploitation and Dissemination strategy

The funding has provided for 1 day per week of BDFA SO time and the recruitment of an administrator. Laura Codd joined the BDFA in April 2016.

2. JNCL and Education Project, Erasmus+, European Union (EU)

The BDFA continues to be the patient advocacy lead for this project in collaboration with 6 other European countries. The BDFA delivered the survey of the educational experiences of families with a child or young person affected by CLN3, in the UK. For the final stage of the project we are bringing our considerable expertise to the design of educational tools and a publication on working in education with young people with CLN3 (Juvenile Batten Disease). The project is to be extended to create an assessment tool to be used in schools with children with CLN3 (Juvenile Batten disease).

3. MIND Music Therapy Project

The BDFA is a key stakeholder in a 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.

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

Dr Emyr Lloyd-Evans, Cardiff University

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

Oct 2016-2018

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. In the first-year key changes have already been found and further work is required to see if these can be exploited as potential therapeutic targets.

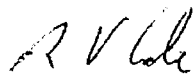
5. Development of a drug screen for CLN5 Batten disease

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

£20 000 BDFA funded on behalf of Battle Batten

July 2016 1-year with 1-year extension

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 (iPS cells) that can then be turned into nerve cells, the cells that die in CLN5 disease. These can then be used to develop a drug screen to find treatments that could make the cells healthier.



Roger Cole
BDFA Treasurer and Trustee

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

I report on the accounts of the charity for the year ended 31 August 2017 which are set out on pages 11 to 20.

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144(2) of the Charities Act 2011 (the 2011 Act) and that an independent examination is needed. The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of ICAEW.

It is my responsibility to:

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

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from you as trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and consequently no opinion is given as to whether the accounts present a "true and fair view" and the report is limited to those matters set out in the statement below.

Other matters

Your attention is drawn to the fact that the charity has prepared the accounts (financial statements) in accordance with Accounting and Reporting by 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 (FRS102) issued on 16 July 2014 in preference to the Accounting and Reporting Charities: Statement of Recommended Practice issued on 1 April 2005 which is referred to in the extant regulations but has since been withdrawn.

We understand that this has been done in order for the accounts to provide a true and fair view in accordance with the Generally Accepted Accounting Practice effective for reporting periods beginning on or after 1 January 2015.

Independent examiner's statement

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

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


Anthony Kelly BSc FCA

Roffe Swayne
Chartered Accountants
Ashcombe Court, Woolsack Way
Godalming, Surrey, GU7 1LQ

Date: 20/11/17.

Batten Disease Family Association
Statement of Financial Activities Report for the Year Ended 31 August 2017

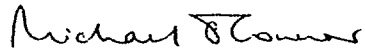
		Unrestricted Funds	Restricted Funds	Total Funds 2017	Total Funds 2016
	Note	£	£	£	£
Incoming resources					
Incoming resources from generated funds					
Voluntary income	2	112,831	137,059	249,890	214,539
Activities for generating funds	3	89,288	-	89,288	113,775
Investment income	4	72	-	72	192
Total incoming resources		<u>202,191</u>	<u>137,059</u>	<u>339,250</u>	<u>328,506</u>
Resources expended					
Fundraising trading	5,6	29,763	-	29,763	43,169
Charitable activities	6	207,596	97,852	305,448	399,762
Governance costs	9, 6	9,427	-	9,427	8,868
Total resources expended		<u>246,786</u>	<u>97,852</u>	<u>344,638</u>	<u>451,799</u>
Net outgoing resources before transfers		(44,595)	39,207	(5,388)	(123,293)
Transfers					
Gross transfers between funds		11,582	(11,582)	-	-
Net movements in funds		(33,013)	27,625	(5,388)	(123,293)
Reconciliation of funds					
Total funds brought forward		42,740	116,231	158,971	282,264
Total funds carried forward		<u>9,727</u>	<u>143,856</u>	<u>153,583</u>	<u>158,971</u>

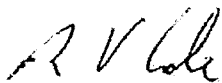
**Batten Disease Family Association
Balance Sheet Statement as at 31 August 2017**

	Note	£	2017 £	£	2016 £
Current assets					
Debtors	12		6,649		6,511
Cash at bank and in hand			<u>164,641</u>	171,290	<u>167,503</u>
					174,014
Creditors: Amounts falling due within one year	13		(17,707)		(15,043)
Net current assets			<u>153,583</u>		<u>158,971</u>
Net assets	17		<u>153,583</u>		<u>158,971</u>
The funds of the charity:					
Restricted funds in surplus			143,856		116,436
Restricted funds in deficit					
Biomarin			-		(205)
Total restricted funds			<u>143,856</u>		<u>116,231</u>
Unrestricted funds					
Unrestricted income funds			9,727		42,740
Total charity funds	16		<u>153,583</u>		<u>158,971</u>

Signed on behalf of the board of Trustees on 20 November 2017 by:

Michael O'Connor (BOFA Chair of Trustees)





Roger Cole
Treasurer

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

1 Accounting policies

Basis of preparation

The accounts (financial statements) have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Ireland (FRS102) issued on 16 July 2014.

The charity constitutes a public benefit entity as defined by FRS102.

Fund accounting policy

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

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

Further details of each fund are disclosed in note 16.

Incoming resources

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

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

Shop 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 FRS102 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.

Resources expended

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

Costs of generating funds 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.

Batten Disease Family Association

Notes to the Financial Statements for the Year Ended 31 August 2017

..... continued

Resources expended

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

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

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

Governance costs

Governance costs include costs of 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

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

Research and development expenditure is written off as incurred.

Operating leases

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

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.

Debtors

Debtors (including trade debtors and loans receivable) are measured on initial recognition at settlement amount after any trade discounts or amount advanced by the charity. Subsequently, they are measured at the cash or other consideration expected to be received.

Creditors

The charity has creditors which are measured at settlement amounts less any trade discounts

Provisions for liabilities

A liability is measured on recognition at its historical cost and then subsequently measured at the best estimate of the amount required to settle the obligation at the reporting date

Basic financial instruments

The charity accounts for basic financial instruments on initial recognition as per paragraph 10.7 FRS102 SORP. Subsequent measurement is as per paragraphs 11.17 to 11.19, FRS102 SORP

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

2 Voluntary income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2017 £	Total Funds 2016 £
Donations				
Regular monthly donations	4,854	-	4,854	4,999
Donations gift aid	4,435	-	4,435	6,064
Donations non gift aid	16,572	-	16,572	6,321
Charitable giving	11,539	137,059	148,598	120,706
Gift aid reclaimed	10,499	-	10,499	22,343
Donations - organisations and schools	18,049	-	18,049	17,879
Foundations and trusts not restricted	30,600	-	30,600	9,864
Workshop income	-	-	-	1,261
Conference income	13,299	-	13,299	22,714
	<u>109,847</u>	<u>137,059</u>	<u>246,906</u>	<u>212,151</u>
In memoriam donations				
In memorium	2,984	-	2,984	2,388
	<u>112,831</u>	<u>137,059</u>	<u>249,890</u>	<u>214,539</u>

3 Activities for generating funds

	Unrestricted Funds £	Restricted Funds £	Total Funds 2017 £	Total Funds 2016 £
Fundraising				
Supporter fundraising	49,442	-	49,442	61,428
Collection boxes	845	-	845	135
Fundraising activities	38,312	-	38,312	51,612
	<u>88,599</u>	<u>-</u>	<u>88,599</u>	<u>113,175</u>
Merchandise income				
Merchandise income	689	-	689	600
	<u>89,288</u>	<u>-</u>	<u>89,288</u>	<u>113,775</u>

4 Investment income

	Unrestricted Funds £	Restricted Funds £	Total Funds 2017 £	Total Funds 2016 £
Interest income	72	-	72	192
	<u>72</u>	<u>-</u>	<u>72</u>	<u>192</u>

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

5 Fundraising expenses

	Unrestricted	Restricted	Total Funds	Total Funds
	Funds	Funds	2017	2016
	£	£	£	£
Fundraising				
Expenses	6,093	-	6,093	15,276
Employment costs	23,399	-	23,399	27,516
	<u>29,492</u>	<u>-</u>	<u>29,492</u>	<u>42,792</u>
Merchandise income				
Cost of goods sold	271	-	271	377
	<u>29,763</u>	<u>-</u>	<u>29,763</u>	<u>43,169</u>
	<u><u>29,763</u></u>	<u><u>-</u></u>	<u><u>29,763</u></u>	<u><u>43,169</u></u>

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

6 Total resources expended

	Grants	Fundraising	Mercha ndise income	Charitable activity	Governance	Total 2017	Total 2016
	£	£	£	£	£	£	£
Grants payable -institutions	508	-	-	-	-	508	107,335
Grants payable - individuals	9,464	-	-	-	-	9,464	4,779
Fundraising support costs	-	-	-	55,962	-	55,962	29,571
Restricted costs	-	-	-	97,852	-	97,852	61,784
Fundraising expenses	-	6,093	-	-	-	6,093	12,914
Merchandise for resale	-	-	271	-	-	271	377
Education costs	-	-	-	1,816	-	1,816	6,617
Eurodis Expenditure	-	-	-	-	-	-	1,944
Employment costs	-	23,399	-	97,374	-	120,773	162,449
Rent	-	-	-	12,249	-	12,249	8,267
Insurance	-	-	-	1,014	-	1,014	731
Premises expenses	-	-	-	951	-	951	4,447
Telephone and fax	-	-	-	380	-	380	199
Office equipment	-	-	-	471	-	471	378
IT costs	-	-	-	1,584	-	1,584	4,149
Printing, postage and stationery	-	-	-	757	-	757	453
Advocacy	-	-	-	5,229	-	5,229	3,762
Sundry expenses	-	-	-	2,294	-	2,294	1,827
Research and development	-	-	-	2,890	-	2,890	9,793
Support work	-	-	-	14,499	-	14,499	19,109
Volunteer expenses	-	-	-	134	-	134	69
Customer entertaining	-	-	-	-	-	-	19
Accountancy fees	-	-	-	-	4,900	4,900	4,895
Governance costs	-	-	-	-	918	918	1,320
Legal and professional fees	-	-	-	-	-	-	1,992
HR support	-	-	-	-	3,609	3,609	2,593
Bank charges	-	-	-	20	-	20	26
	<u>9,972</u>	<u>29,492</u>	<u>271</u>	<u>295,476</u>	<u>9,427</u>	<u>344,638</u>	<u>451,799</u>

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

7 Grantmaking

Grants to institutions	Grants to individuals
£	£
508	9,464
<u>508</u>	<u>9,464</u>

Grants

The support costs associated with grant making are £0.

8 Grants to institutions

Name of Institution	Activity	£
NCL Stiftung	Grants	508
		<u>508</u>

9 Governance costs

	Unrestricted Funds	Restricted Funds	Total Funds 2017	Total Funds 2016
	£	£	£	£
Accountancy fees	4,900	-	4,900	4,895
Legal and professional costs	-	-	-	60
Governance costs	918	-	918	1,320
HR Support	<u>3,609</u>	<u>-</u>	<u>3,609</u>	<u>2,593</u>
	<u>9,427</u>	<u>-</u>	<u>9,427</u>	<u>8,868</u>

Included within governance costs:

	2017	2016
	£	£
Independent examiners' fees	<u>600</u>	<u>500</u>

10 Trustees' remuneration and expenses

The trustees were reimbursed £369 (2016:£1,320) for travel and fundraising costs during the year. The trustees were not paid any remuneration during the year (2016: £nil).

11 Employees' remuneration

The aggregate payroll costs of these persons were as follows:

	2017	2016
	£	£
Wages and salaries	102,581	147,493
Social security	13,475	11,387
Other pension costs	<u>4,532</u>	<u>2,219</u>
	<u>120,588</u>	<u>161,099</u>
Average full time equivalent head count	No.	No.
Fundraising	0.6	2
Charitable activities	2.4	1.75
Advocacy	<u>1</u>	<u>1</u>
	<u>4</u>	<u>4.75</u>

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

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

12 Debtors

	2017	2016
	£	£
Other debtors	914	-
Prepayments and accrued income	5,735	6,511
	<u>6,649</u>	<u>6,511</u>

13 Creditors: Amounts falling due within one year

	2017	2016
	£	£
Trade creditors	11,326	7,918
Taxation and social security	3,398	3,523
Other creditors	1,783	2,703
Accruals and deferred income	1,200	899
	<u>17,707</u>	<u>15,043</u>

14 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 £4,532 (2016 - £2,219).

Contributions totalling £502 (2016 - £694) were payable to the scheme at the end of the period and are included in creditors.

Batten Disease Family Association
Notes to the Financial Statements for the Year Ended 31 August 2017

- 15 **Related parties**
Controlling entity
The charity is controlled by the trustees.
- 16 **Analysis of funds**

	At 1			At 31	
	September 2016	Incoming Resources	Resources expended	Transfers	August 2017
	£	£	£	£	£
General Funds					
Unrestricted income fund	42,740	202,191	(246,786)	11,582	9,727
Restricted Funds					
George Young	-	834	-	-	834
The Nicole Rich Foundation	-	37,477	(16,745)	-	20,732
Batten Fighters Forever	-	21,531	-	-	21,531
Isabel's Sparkle	1,782	1,964	(2,113)	(1,633)	-
Euro Ed Project	1	9,027	(4,557)	-	4,471
Battle Batten CLN5	56,296	2,005	(8,300)	-	50,001
BioMarin	(205)	49,203	(49,065)	67	-
Beefys Charity Foundation	10,016	-	-	(10,016)	-
In Memory of Katie Freeman	-	859	-	-	859
Key worker support	-	11,930	-	-	11,930
Clinical Nurse Specialist Funding	22,093	-	-	-	22,093
BAT Cure	25,999	-	(17,073)	-	8,926
Olivacce CLN3	249	2,230	-	-	2,479
	<u>116,231</u>	<u>137,060</u>	<u>(97,853)</u>	<u>(11,582)</u>	<u>143,856</u>
	<u>158,971</u>	<u>339,251</u>	<u>(344,639)</u>	<u>-</u>	<u>153,583</u>

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

Batten Fighters Forever fund 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 the clinical support and advice.

The BAT Cure fund is from the E.U. Horizon2020 research and innovation programme with the intention to advance therapeutic options for those suffering from Batten disease.

Olivacce fund is to fund CLN3 junior Batten disease research.

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

- 17 **Net assets by fund**

	Unrestricted Funds	Restricted Funds	Total Funds 2017	Total Funds 2016
	£	£	£	£
Current assets	27,434	143,856	171,290	174,014
Creditors: Amounts falling due within one year	<u>(17,707)</u>	-	<u>(17,707)</u>	<u>(15,043)</u>
Net assets	<u>9,727</u>	<u>143,856</u>	<u>153,583</u>	<u>158,971</u>

- 18 **Transition to FRS102**

The accounts for the year ended 31 August 2016 were prepared under SORP 2005. The charity has adopted SORP (FRS102) for the first time in the year ended 31 August 2017.

In adopting SORP (FRS102) there has been no impact on the charity's reported financial position. Accordingly, no reconciliations of the charity's funds or surplus have been reported.