



BATTEN DISEASE FAMILY ASSOCIATION

Together we WILL make a difference

Registered Charity in England and Wales 1084908 - Scotland SC047408

Annual Report and Financial Statements

**For the period
September 2021 - August 2022**

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A year in the Batten community: introduction from the BDFA team



During this year we have supported 105 families from across the UK with 19 new diagnoses. Due to the life-limiting nature of Batten disease, 14 children, young people and young adults have passed away this year.

We have continued to support families throughout the ongoing pandemic and the rising cost of living that started during this particular year. We understand that Covid may have a long-lasting impact on our community and we will continue to adapt our support.

At the time of writing, we have seven members of staff (5.3 FTE) which is enabling us to fulfil our mission and provide the required level and depth of support to families.

We partner with a specialist charity The Maypole Project (TMP) to deliver our holistic well-being service for the whole family. We have also launched our Batten peer befriending service from the roots of the community. This is a significant step forward for the charity as we grow our volunteering capacity for the first time. Additionally, we ran a pilot study for our bereaved community, to ascertain what parents want from the service and these ideas have been logged for when we can secure funding to begin the full service in the future.

We have made significant progress with the charity's research function, including the Brineura® in the eyes compassionate use programme for children with CLN2 began at Great Ormond Street Hospital (GOSH) in the summer of 2021. This programme is entirely funded by family fundraising. The BDFA is also leading a research project aimed at evaluating the overall impact of late diagnosis and lack of service provision for patients with Batten disease. This project is focusing in the first instance on CLN2 and CLN3. The BDFA is focused on supporting research for all types of Batten disease.

We have had another successful year at the BDFA and we are very grateful to the families and their wider communities who put considerable effort into fundraising for us. We are looking positively to the future as we continue to grow the BDFA. We aim to work holistically to meet the needs of our beneficiaries, focusing on every individual with Batten disease living life to the full and supporting our families from the point of diagnosis, through their journey and beyond.

About the Batten Disease Family Association

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. We are in the process of becoming a CIO (Charitable Incorporated Organisation).

ABOUT BATTEN DISEASE

Batten disease, or the Neuronal Ceroid Lipofuscinoses (NCL), is a family of rare diseases caused by autosomal recessive genetic mutations. These are lysosomal storage disorders where genetic mutations disrupt the cells' ability to recycle wastes. Cells are thrown out of balance with the buildup of proteins and lipids (fats). There are 13 known forms of Batten disease and you will often hear them referred to as CLN1-CLN14. It is estimated that 2-4 births per 100,000 in the UK are affected by Batten disease, or about 10 a year. Batten disease is neurodegenerative and causes a progressive loss of skills. Children lose their ability to walk and talk, swallow and see. Batten disease also causes childhood dementia and intractable epilepsy. There is one treatment available for CLN2 disease. Other treatments are being developed.

OUR MISSION

The BDFA's mission is to enable everyone who is affected by Batten disease to live life to the full and to secure the care and support they need until we find a cure. The BDFA offers informed guidance and support to families and the professionals who work with them as well as actively increasing awareness of the disease and funding future research to identify potential therapies and ultimately a range of cures.

Our objectives are to:

- Preserve and protect the health and promote the welfare of persons affected by all types of Neuronal Ceroid Lipofuscinosis (NCL) commonly known as Batten disease
- To advance the education of the medical profession and the general public on the subject of Batten disease and its implications for the family
- To promote research into the management of Batten disease and to publish the useful results thereof and to support organisations prompting research into Batten disease

STRUCTURE AND MANAGEMENT

The strategy and oversight of the BDFA are directed by the Trustees. The day to day management is delegated to Amanda Mortensen who has been the Chief Executive since February 2020.

The staff team members in the year under review were;

Amanda Mortensen, Chief Executive

Lisa Forsyth, Team Admin Officer

Liz Brownnutt, Head of Fundraising

Siân Fisher, Head of Family Support and Advocacy

Liz Jones, Family Support Worker

Mimi Petty, Peer Befriending Coordinator

Dr Joanna Nightingale, Scientific Officer

Gurdev Singh, Community Fundraising Officer (left the BDFA August 2022)

During much of the year Sarah Kenrick served as Batten Behaviour, Adult and Transitions Specialist as a contractor for this important work.

HOW THE BOARD WORKS

The Board of Trustees meets four times a year with the CEO to assess progress in relation to strategy and key projects. These meetings are also occasionally attended by members of staff such as the Head of Fundraising and Head of Support and Advocacy to report on progress regarding key activities. Over the year, four Trustees were parents of children or young people with Batten disease.

The difference we have made: delivering the aims and objectives of the organisation

Our strategy runs under four pillars: Advocacy, Community, Care and Support and Research

ADVOCACY:

To advocate for children and young people with Batten disease and their families we will...

- Advocate for families at an international, national and governmental level to raise awareness and achieve access to current and future treatments for Batten disease
- Spearhead the campaign for newborn screening for Batten disease.
- Strengthen our advocacy services for children, young people and adults with Batten disease with all professionals and service providers involved in their care across health, social care and education.
- Utilise strategic alliances and partnerships, in the UK and internationally, across the rare disease sector to press for high level transformational change and the reduction of health inequalities

COMMUNITY:

To grow the Batten community and create opportunities for connection we will...

- Develop the Peer Befriending service growing our volunteer capacity from within the community enriching connection and empowering parents to support each other
- Strengthen our connection with families through a hybrid approach combining online and face-to-face contact and re-establish our annual family conference.
- Develop new services for the bereaved community, grandparents and siblings to strengthen wellbeing of all and the resilience of those impacted by the disease, as and when adequate funding can be secured.

CARE AND SUPPORT:

To increase the amount of care and support we offer to families we will...

- Grow our support team to offer an excellent, holistic and highly specialised service to families from the point of diagnosis and through their journey
- Increase our mental health and wellbeing support to parents, siblings (Siblings Sanctuary) and other family members via our partnership with The Maypole Project.
- Create a specialist LSD clinical pathway for Batten disease in England, working with the NHS to develop new treatment centres close to where families live
- Continue to work in collaboration with (and part fund) the Batten Clinical Nurse Specialist at Great Ormond Street Hospital to provide holistic support to families and for health professionals involved in their care.

RESEARCH:

To raise the standards of care, influence policy and shorten the time to diagnosis we will...

- Commission a BDFA-led piece of research into the burden of illness and burden of care for Batten disease, exploring the diagnostic odyssey.
- Support families through the ongoing Brineura © in the eyes programme at GOSH
- Liaise with industry to ensure families in the UK are kept abreast of the latest information on research and treatments and have opportunities to enrol their children and young people on clinical trials

Achievements this year

ADVOCACY:

- Advocated for families across education, health and social care to ensure their children, young people and adults affected by Batten disease access the services they are entitled to
- Worked with commissioners and alongside families to prepare the set up of a further two treatment centres for Brineura for CLN2 Batten disease in Birmingham and Bristol (at time of writing these are now established)
- We continue to collaborate with other organisations, nationally, such as the LSD Collaborative and we work closely with our counterpart charities in the US, Australia and Europe, working together to give Batten disease support and research a global voice

COMMUNITY:

- Continued with the Virtual Cuppa and online family meetings adopting a hybrid approach as we came out of the Covid-19 pandemic
- Held another successful Pride of Batten Awards, just after the year end, to celebrate best practice across the Batten community
- Fully established our new peer befriending service with our first cohort of parent volunteers completing their training in July 2022

CARE AND SUPPORT:

- Supported 29 families through our specialist well being service, delivered by the Maypole Project
- Provided holistic support to over 100 families via our family support team

RESEARCH:

- Made significant progress with the Brineura® in the eyes compassionate use programme for children with CLN2 at Great Ormond Street Hospital (GOSH)
- Made significant progress with the BDFA-led research study, which is examining the diagnostic odyssey of Batten disease with the aim of improving patient care and diagnostic pathways.

Meet the board of trustees

Zlatko Sisic, Chair of Trustees
Richard Whitbread, Treasurer
Pauline Docherty, Secretary
Bob Thompson
Simon Sewart
Cath Sermon
Gareth Holmes, Fundraising Lead

Funders from the period of 1st September 2021 - 31st August 2022

The BDFA wish to thank all of the fantastic funders who have supported our work during this financial year.

52 Lives
Anton Jurgens Charitable Foundation
The Barbour Foundation
B-CH 1971 Charitable Trust
CAF Resilience Fund Phase 2
Catherine Cookson Charitable Trust
The Christopher Iaing Foundation
DCMS/ Pears Foundation via Contact
Dischma Charitable Trust
Douglas Heath Eves Charitable Trust
Edward Gostling Foundation
Ecclesiastical Movement for Good
FB Coales No.4 Family Trust
The February Foundation
Felicity Wilde Charitable Trust
The Fulmer Charitable Trust
Gledswood Charitable Trust
Harry Bottom Charitable Trust
Hudson Charitable Trust
Irving Memorial Charitable Trust
John Horniman's Children's trust
Ken and Edna Morrison Charitable Trust

Lewis Goldberg Trust
Liz & Terry Bramall Foundation
Anonymous Trust
Wise Music Foundation
Nancie Massey Charitable Trust
The National Lottery Community Fund
Peter Courtauld Charitable Trust
Pilkington Charities Fund
Robert Luff Foundation
Rubin Foundation Charitable Trust
Anonymous Trust
Sir James Roll Charitable Trust
The Charles & Elsie Sykes Trust
The James Wood Bequest Fund
The Meikle Foundation
The Oak Foundation
The Rest Harrow Trust
The Vandervell Foundation
Walter Guinness Trust
Winifred Eileen Kemp Trust
Pedal4Memories

Trustees' Report

Financial Review

The growth in BDFA income has been maintained again this year to £545,653. This reflects restricted funding for our BDFA-led research project and the continued success of diversifying our income through our fundraising strategy. We are pleased to report an increase in unrestricted income from Trusts and Foundations to £137,226 (£119,489 in 2021). Supporter fundraising has increased from last year, which reflects the beginnings of recovery of community fundraising from the Covid-19 pandemic. We are very grateful to the families and their wider communities for their tireless support in raising much-needed funds for the ongoing work of the BDFA.

Reserves Policy

The Trustees have noted the increase in free reserves to reach £178,473 achieved in the financial year. The Trustees have also been aware that the adverse impacts of the Covid pandemic on fundraising are declining and have also noted the improvements in income from trusts and foundations in the 18 months since the appointment of a Head of Fundraising and have maintained the policy on free reserves as the same as the prior year. The Trustees now consider that holding reserves of between 4 and 8 months is more appropriate as the charity redevelops its activities and strengthen its range of services. At the year end the free reserves equated to between 5 and 6 months of core expenditure.

Public Benefit

The Trustees use the Charity Commission guidance on public benefit and acknowledge the additional reporting requirements for charities whose gross income exceeds £500,000 (the BDFA's gross income is over this threshold this year). We have outlined our services and achievements in this report to clearly demonstrate how our work brings public benefit and is beneficial to its beneficiaries.

Key Risks

- Securing sufficient funds to consolidate growth in staff team undertaken
- Maintaining level of support needed for our families through the family support team and peer befriending service
- The impact of the cost of living crisis on our families, 50 percent of whom are already financially challenged
- The impact of the cost of living crisis on household budgets affecting community fundraising and individual giving.

Legal and Administration Information of Batten Disease Family Association

Charity number	1084908	Scientific and Medical Advisers
OSCR number	SC047408	Professor 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
Principal Address	Hamilton House Mabledon Place London WC1H 9BB	
Independent Examiner	TC Group The Courtyard Shoreham Road Upper Beeding Steyning West Sussex BN44 3TN	Professor 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
Bankers	The Co-Operative Bank 70-72 Cross Street Manchester M2 4JG Santander Bank Bootle Merseyside L30 4GB	Dr Ruth Williams Consultant Paediatric Neurologist Evelina London Children's Hospital Westminster Bridge Road South Bank London SE1 7EH

Statement of Trustee Responsibilities of Batten Disease Family Association

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.

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 2022.

Responsibilities and basis of report

As the charity's trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5)(b) of the Act.

Independent examiner's statement

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

I have completed my examination. I confirm that no material 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 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.

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.

TC Group

Mark Cummins FCCA, FCIE

On behalf of TC Group

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

Dated: 6 June 2023

Statement of Financial Activities

FOR THE YEAR ENDED 31 AUGUST 2022

		Unrestricted Funds	Designated Funds	Restricted Funds	Total 2022	Total 2021
Income		£	£	£	£	£
Donations and legacies	2	313,390	34,343	88,000	435,733	557,218
Other income	3	107,728	2,035	-	109,763	77,752
Investments	4	157	-	-	157	45
Total income		421,275	36,378	88,000	545,653	635,015
Expenditure on:						
Raising funds		81,318	-	-	81,318	44,662
Charitable activities		275,693	47,987	149,604	473,284	264,276
Total expenditure	5	357,011	47,987	149,604	554,602	308,938
Net income/(expenditure)		64,264	(11,609)	(61,404)	(8,949)	326,077
Transfers between funds	14/15	(60,000)	39,000	21,000	-	-
Net movement in funds		4,264	27,391	(40,604)	(8,949)	326,077
Fund balances at 1 September 2021		174,209	208,269	122,412	504,890	178,813
Fund balances at 31 August 2022		178,473	235,660	81,808	495,941	504,890

The notes on page 13 to 23 form part of these accounts

All income and expenditure shown above relate to continuing activities.

Balance Sheet

AS AT 31 AUGUST 2022

	Notes	£	2022 £	2021 £
Current assets				
Stock		1,000	1,000	
Debtors	10	16,234	5,032	
Cash at bank and in hand		580,107	622,934	
		<u>597,341</u>	<u>628,966</u>	
Creditors: amounts falling due within one year	11	<u>(101,400)</u>	<u>(124,076)</u>	
Net current assets			495,941	504,890
Total net assets			<u>495,941</u>	<u>504,890</u>
Income funds				
Restricted funds	14	81,808	122,412	
Unrestricted funds - general		178,473	174,209	
Unrestricted funds - designated	15	235,660	208,269	
		<u>495,941</u>	<u>504,890</u>	

The accounts were approved by the Board on 1st June 2023



.....
Zlatko Sisic

Chair of Trustees

The notes on pages 13 to 23 form part of these accounts.

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.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

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.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

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:

Designated funds – the trustees have identified that certain activities need to be undertaken widening the support to families and plan to create designated funds to hold the monies to enable the re-instatement of funding for research and other activities, but which remain under the ultimate control of the trustees.

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 4 and 8 months of unrestricted costs. They are currently achieving just under 6 months, which is a slight reduction 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.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

2 Voluntary Income

	Unrestricted funds	Designated funds	Restricted Funds	Total 2022	Total 2021
	£	£	£	£	£
Donations					
Regular monthly donations	8,456	-	-	8,456	8,315
Donations gift aid	858	-	-	858	1,330
Donations non gift aid	9,773	-	-	9,773	9,971
Donated services	1,000	-	-	1,000	
Charitable giving	-	8,343	-	8,343	254,841
Donations – organisations and schools	129,386	-	-	129,386	70,220
Foundations and trusts not restricted	137,226	5,000	-	142,226	119,489
Foundations and trusts restricted	-	-	23,000	23,000	-
Pharmaceutical grants	3,624	21,000	65,000	89,624	85,660
Gift aid reclaimed	3,413	-	-	3,413	5,139
	<u>293,736</u>	<u>34,343</u>	<u>88,000</u>	<u>416,079</u>	<u>554,965</u>
In memoriam donations					
In memoriam	19,654	-	-	19,654	2,253
	<u>313,390</u>	<u>34,343</u>	<u>88,000</u>	<u>435,733</u>	<u>557,218</u>

3 Other income

	Unrestricted funds	Designated funds	Restricted funds	Total 2022	Total 2021
	£	£	£	£	£
Fundraising					
Supporter fundraising	104,169	2,035	-	106,204	74,678
Collection boxes	160	-	-	160	-
Fundraising activities	1,235	-	-	1,235	1,507
	<u>105,564</u>	<u>2,035</u>	<u>-</u>	<u>107,599</u>	<u>76,185</u>
Merchandise income					
Merchandise sales	2,164	-	-	2,164	1,567
	<u>107,728</u>	<u>2,035</u>	<u>-</u>	<u>109,763</u>	<u>77,752</u>

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

4 Investment income

	Unrestricted funds	Designated funds	Restricted funds	Total 2022	Total 2021
	£	£	£	£	£
Interest income	<u>157</u>	<u>-</u>	<u>-</u>	<u>157</u>	<u>45</u>

5 Total expenditure

	Staff costs £	Other Costs £	Total 2022 £	Total 2021 £
Costs of raising funds				
Fundraising costs	60,113	21,205	81,318	43,938
Merchandise costs	-	-	-	724
	<u>60,113</u>	<u>21,205</u>	<u>81,318</u>	<u>44,662</u>
Charitable activities				
Activities undertaken directly	83,936	310,384	394,320	184,373
Support costs	33,058	45,906	78,964	79,903
	<u>116,994</u>	<u>356,290</u>	<u>473,284</u>	<u>264,276</u>
Total expenditure	<u>177,107</u>	<u>377,495</u>	<u>554,602</u>	<u>308,938</u>

Activities undertaken directly encompass the following charitable activities: Family Support, Peer Befriending, Scientific and Medical Support, Advocacy and management time and resources.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

6 Support costs - other

	Total 2022	Total 2021
	£	£
Other costs		
Rent	14,039	6,007
Postage, freight and courier	1,518	1,248
Telephone	240	374
Computer, software and IT support	5,719	3,856
Office equipment	313	-
Legal and other professional fees	(321)	23,119
Office stationery	659	50
Insurance	1,227	1,215
Organisational membership and legal and professional fees	1,710	1,872
Accountancy fees	4,800	4,700
CEO expenses	2,081	811
Book keeping	4,612	4,280
Bank charges	48	54
Recruitment expenses	1,249	805
Staff training	4,747	6,618
Admin outsourced charges	1,603	6,423
Website costs	88	86
HR	1,520	1,334
Trustee costs	54	-
	45,906	62,852

These costs include amounts payable to the independent examiners of £1,000 (2021: £1,000) for independent examination and £3,800 (2021: £3,700) for other services.

7 Trustees

One trustee was paid £2,223 (2021: £565) from the appropriate restricted fund, in connection with travel costs to enable a child to attend for Brineura treatment at Great Ormond Street Hospital, in common with similar support payments to other affected parents.

In 2022 £54 was paid to one trustee (2021: £nil) 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.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2021

	Unrestricted funds	Designated funds	Restricted funds	Total 2021
Income from:	£	£	£	£
Donations and legacies	264,877	207,228	85,113	557,218
Other income	77,752	-	-	77,752
Investments	45	-	-	45
Total income	342,674	207,228	85,113	635,015
Expenditure on:				
Raising funds	44,662	-	-	44,662
Charitable activities	210,527	15,959	37,790	264,276
Total expenditure	255,189	15,959	37,790	308,938
Net income/(expenditure)	87,485	191,269	47,323	326,077
Transfer between funds	(17,000)	17,000	-	-
Net movement in funds	70,485	208,269	47,323	326,077
Fund balances at 1 September 2020	103,724	-	75,089	178,813
Fund balances at 31 August 2021	174,209	208,269	122,412	504,890

9 Employees

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

	Total 2022	Total 2021
Charitable activities	3	2
Advocacy	2	1
	5	3
Employment costs	Total 2022 £	Total 2021 £
Wages and salaries	161,983	99,995
Social security costs	9,744	2,971
Pension costs	5,380	2,506
	177,107	105,472

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

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

The key management personnel of the charity is comprised of the Chief Executive Officer. The total aggregate employee benefits paid during the year were £52,588 (2021: £48,902).

None of the Trustees received any remuneration or other benefits from the charity or any connected body. Other volunteers contributed to the charity in a variety of ways and the Trustees thank them all for their efforts

The charity is significantly developing the use of volunteers in its activities. The employment of a Peer Befriending Co-ordinator has allowed us to train a small team of individuals who can then provide additional support to families alongside our traditional family support methods and we envisage this expanding as resources become available. Separately the Bertie's Helpers facility has continued to assist families at times of greatest need and the Trustees would like to offer their thanks to all involved these volunteer activities.

During the period payments of £3,900 (2021: £5,000) were made with regards to the termination of employment contracts.

10 Debtors

	2022	2021
	£	£
Trade debtors	11,000	-
Prepayments and accrued income	5,234	5,032
	16,234	5,032

11 Creditors: amounts falling due within one year

	2022	2021
	£	£
Trade creditors	15,702	9,189
Other creditors	7,310	6,424
Accruals	9,000	25,000
Deferred income	64,876	81,560
Taxes and social security	4,512	1,903
	101,400	124,076

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

12 Deferred income

	2022 £	2021 £
Deferred income at 1 September 2021	81,560	20,446
Income recognised during the year	(75,560)	(20,446)
Income deferred during the year	58,876	81,560
Deferred income at 31 August 2022	64,876	81,560

13 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 £5,380 (2021: £2,506).

Contributions totalling £995 (2021: £550) were payable to the scheme at the end of the period and are included in creditors.

14 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 2021	Income	Expenditure	Transfers between funds	Balance at 31 August 2022
Euro Ed Project	2,491	-	-	-	2,491
Olivacce CLN3	2,479	-	(2,479)	-	-
Fundraising and Management (BioMarin)	18,104	-	-	-	18,104
Gene Therapy Day	4,000	-	-	(4,000)	-
Brineura Travel Costs (BioMarin)	9,095	15,000	(19,408)	-	4,687
Brineura Compassionate Use Programme	86,243	-	(86,243)	-	-
Research Programme	-	72,000	(40,474)	25,000	56,526
52 Lives Xmas Fund	-	1,000	(1,000)	-	-
	122,412	88,000	(149,604)	21,000	81,808

- Euro Ed Project is a Europe-wide education project focussed on CLN3.
- Olivacce fund is to fund CLN3 Batten disease research, redirected to assist a new research programme in 2022.
- Fundraising and Management (BioMarin) is specifically to build capacity within the BDFA to diversify income, shape fundraising and enhance resources.
- Gene Therapy Day – planned events help within Family Conference Oct 22 and funds transferred.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

- Brineura Travel Costs (BioMarin) – BioMarin have provided additional funds to cover travel costs to GOSH to counter delays in opening other treatment centres.
- Brineura Compassionate Use Programme – funds received under restricted covenants to meet the costs of the GOSH Compassionate Use Programme.
- Research Programme – newly commissioned research programme to identify and provide guidance on Early Diagnosis.
- 52 Lives Xmas Fund – fund to allow 5 x £200 family grants at Christmas.

15 Designated funds

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

	Balance at 1 September 2021	Income	Expenditure	Transfers between funds	Balance at 31 August 2022
Brineura Compassionate Use Programme	132,459	2,035	(15,238)	-	119,258
Bertie's Helpers	16,415	13,343	(11,025)	-	18,733
Orange Folder	4,500	-	(3,522)	-	978
Website Reconstruction	50,000	-	(15,030)	-	34,970
Bertie's Helpers – Bereaved	4,895	-	(1,797)	-	3,098
Family Conference	-	21,000	(1,375)	39,000	58,625
	208,269	36,378	(47,987)	39,000	235,660

- Brineura Compassionate Use Programme – funds received under restricted covenants to meet the costs of the GOSH Compassionate Use Programme.
- Bertie's Helpers is a fund to meet the costs of the Bertie's Helpers programme to support families encountering difficulties by providing a special meal.
- Orange Folder holds funds transferred from unrestricted funds to redevelop our leaflets which are an essential resource for families.
- Website reconstruction – during the year funds were transferred from unrestricted funds to support a new website with the work now in progress.
- Bertie's Helpers – Bereaved is linked to Bertie's Helpers and is a separate fund intended to provide an anniversary meal for the family of each child lost to Batten Disease.
- Family Conference – Funds for the holding of a Family Conference in October 2022.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2022

16 Analysis of net assets between funds

	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Fund balances at 31 August 2022 are represented by:				
Current assets	279,873	235,660	81,808	597,341
Creditors due within one year	(101,400)	-	-	(101,400)
	<u>178,473</u>	<u>235,660</u>	<u>81,808</u>	<u>495,941</u>
	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Fund balances at 31 August 2021 are represented by:				
Current assets	298,285	208,269	122,412	628,966
Creditors due within one year	(124,076)	-	-	(124,076)
	<u>174,209</u>	<u>208,269</u>	<u>122,412</u>	<u>504,890</u>

17 Related party transactions

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

18 Control

The charity is controlled by the trustees.



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