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 2023 - August 2024

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A year in the Batten community: introduction from the Chair and CEO

We have had another successful, also challenging year at the Batten Disease Family Association (BDFA). During this year we have supported 105 families across the UK with 120 children and adults, including 7 new diagnoses. Very sadly, due to the life-limiting nature of Batten disease, 5 children, young people and adults have passed away this year.
We have continued to support and advocate for families throughout the year, during this time of a continuing rise in the cost of living.

Our dedicated staff team have continued to provide the required level and depth of support to families, and we were pleased to be in a position to begin recruitment in June 2024 to expand capacity in the fundraising team. At the time of writing, we have 8 members of employed staff (5.5 FTE) as we were able to further increase capacity recently to meet the level of need as funding has allowed.

Towards the end of 2023, the Trustees and team held an in-person strategic planning away day to consider our long-term strategy and projects. We worked on a strategic plan taking into consideration the UK Strategy for Rare Diseases and therefore the direction of travel that we believe is right for us to take as an organisation. Our new strategy is detailed on page 6 of this report.

A large focus throughout this year has been the commencement of the National Institute for Health and Care Excellence (NICE) re-evaluation of Brineura treatment for children with CLN2 disease. The treatment has been available under a five-year Managed Access Agreement (MAA) since 2019, and the reappraisal process began in early 2024. BDFA successfully completed a comprehensive submission of evidence in January 2024, detailing the effects on families living with CLN2 and the benefits of Brineura treatment as gathered from families in the form of a survey and disseminated to form a submission outlining key messages.
The first evaluation meeting was held by the NICE Committee in June 2024 to appraise the cost effectiveness of the treatment and patient experts from the CLN2 Community attended to give evidence about the effectiveness and quality of life benefits for children and their families, alongside the BDFA submission, also evidence from clinical experts. At the time of writing, a second committee meeting has taken place and an extension to the current MAA was subsequently put in place whilst the decision to make Brineura available on the NHS is still yet to be made.

The BDFA is a key stakeholder in the process and the representative voice of the community and as such we continue to advocate for our community, raising awareness in the media, generating political support and holding NICE, NHS England and the manufacturer to account to ensure that approval for Brineura is achieved for all patients with CLN2 now and in the future. This process is ongoing.

We completed our manuscript and policy report for our research study ‘Evidencing the impact of CLN2 and CLN3 Batten disease on families in the UK’. The study was led by the BDFA and our Scientific Committee and in collaboration with the Health Policy Partnership. The manuscript has been submitted to a scientific journal. We plan to launch the policy report formally in the coming months, once Brineura is approved on the NHS, and this will be a valuable tool which we will use to advocate and influence policy makers to improve patient diagnostic and care pathways, ultimately leading to earlier diagnosis and better care management for children affected by Batten disease.

We are continually strengthening our alliances and partnerships, both in the UK and internationally. The BDFA is focused on supporting research for all types of Batten disease and our Scientific Affairs function continues to build and maintain a network with key treatment centres, research organisations, and pharmaceutical companies in the Batten disease space.

We continue to partner with specialist charity The Maypole Project (TMP) whom we commission to deliver our holistic family well-being service for the whole family.

Our Family Support and Advocacy service has strengthened with opportunities to provide advocacy support to families, producing good feedback from parents and professionals.

Our Peer Befriending service has grown to now include 11 fully trained parent befrienders who are supporting other parents, building their resilience and reducing their isolation. Separate Mums' and Dads' monthly chat groups have also been developed, alongside CLN specific group meetings and attendance is growing.

Our incorporation to Charitable Incorporated Organisation (CIO) status completed on the 1st September 2024 just as the financial year ended. As a CIO, the BDFA has a legal status similar to a company and it provides the protection of limited liability for the charity trustees. It therefore takes the BDFA into a safer position and a more sustainable future that we hope will enable us to attract more talent on the board of trustees and the team. This is therefore a significant strategic step, and we look forward to this new chapter in the life of the BDFA.

We recovered well from our financial challenges earlier in 2023 and we were greatly encouraged to see a marked improvement to our overall income which we have sustained throughout this financial year. We were particularly pleased to see a slight increase in our Trusts and Foundations Fundraising and we have been thrilled to enter into a significant two-year funding partnership with Global's Make Some Noise Charity, which began in April 2024. Our community fundraising remains an important income stream for the BDFA, and we are sincerely grateful to the families and their wider communities for their strong efforts in continuing to raise vital funds for our work. Our financial year ended with a significant increase to our free reserves, which demonstrates the strong improvement to our finances and efforts of our fundraising team.

We are deeply grateful to our committed team of Trustees, and we do thank Richard Whitbread and Pauline Docherty who both stepped down this financial year.

With our new strategy and strengthened governance we are looking positively to the future as we continue to work to elevate standards of care, raise awareness of the disease and support research, enabling children and adults who are affected by Batten disease to live life to the full and providing families with the care and support they need so they do not walk this path alone.

Zlatko Sisic, Chair of Trustees

Liz Brownnutt, CEO

About the Batten Disease Family Association

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. We successfully completed the transition to a CIO (Charitable Incorporated Organisation) on 1st September 2024.

ABOUT BATTEN DISEASE

Batten disease, or the Neuronal Ceroid Lipofuscinoses (NCL), is a family of rare diseases caused by autosomal recessive genetic mutations. They are lysosomal storage disorders where genetic mutations disrupt the cells' ability to recycle wastes. Cells are thrown out of balance with the build-up 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:

a) 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.
b) To advance the education of the medical profession and the general public on the subject of Batten disease and its implications for the family.
c) 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.

HOW THE BOARD WORKS

The Board of trustees meet four times a year with the CEO to assess progress in relation to strategy and key projects. We are committed to attracting a diverse range of trustees. These meetings are also occasionally attended by members of the team such as the Head of Scientific Affairs and Family Support Partner to report on progress regarding key activities. Over the year, four Trustees were parents of children or young people with 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 the Chief Executive. Liz Brownnutt's Interim CEO role was made permanent in March 2024.

The staff team members in the year under review were:

- Liz Brownnutt, Chief Executive Officer
- Dr Joanna Nightingale, Head of Scientific Affairs
- Lisa Forsyth, Team Admin Officer
- Mimi Petty, Peer Befriending Coordinator
- Sarah Chandler, Fundraising Assistant
- Sarah Kenrick continued in the role of Family Support Partner throughout the year as a contractor for this vital work.

Delivering the Aims and objectives of the organisation- BDFA New Strategy

At the end of 2023 the BDFA team and Trustees held an away day to discuss our long-term strategy. We had opportunity to examine our mission statement along with our strategic imperatives, considering the UK Strategy for Rare Diseases. Although family support remains at the core of what BDFA does, our focus also includes building and strengthening our advocacy capabilities to influence policy makers and strengthening our educational, governance, research and fundraising capabilities to bring about lasting and tangible change for children and young adults affected by Batten disease.

Elevate Standards of Care

- Advocate for the development of personal care plans for patients that brings together health, social and educational services.
- Facilitate the development of transition pathways to adult care.

Raise Awareness

- Educate healthcare, social care and educational professionals about Batten disease to raise awareness and reduce the time to diagnosis.
- Create tools and resources to provide patients, their families and carers with the information and service they need.

Build and Develop the Organisation

- Develop organisational and governance structure to support evolving organisation.
- Develop funding sources to ensure long-term financial stability and growth of the organisation.
- Develop policies and training platforms to ensure ongoing professional development and compliance with laws and regulations.

Support Research

Set up the UK Batten disease registry to:

- Generate and communicate evidence to raise awareness and facilitate the development of specialised patient pathways.
- Develop methods of identifying Batten disease to shorten the time to diagnosis and earlier intervention.
- Facilitate the development of tools for assessing and monitoring disease progression.

Achievements this year

Elevate Standards of Care - This year we have:

- Further strengthened our advocacy capabilities 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.
- Provided holistic support for 105 families via our Family Support Partner and Peer Befriending Coordinator
- Supported around a third of the families in our community with crucial therapeutic and counselling support through our Family Wellbeing service
- Strengthened our relationships with clinicians and nursing teams at treatment centres for Brineura for CLN2 Batten disease

Raise Awareness:

- Submitted our BDFA-led research study into the diagnostic Odyssey of CLN2 and CLN3 to a Scientific journal. Policy report to be published in 2025 with the aim of improving patient care and diagnostic pathways.
- Created educational resources for the website about Batten disease
- Ran a programme of educative sessions for health, social and education professionals
- Contacted clinicians and scientists to plan a programme of educative sessions for professionals and parents
- Made significant progress with the new website, which is due to launch in March 2025

Research:

- Supported Tern Therapeutics as they entered into a global licensing agreement with REGENXBIO Inc. for RGX-381 and RGX-181 to form its initial therapeutic pipeline and begin to reinstate the newly named TTX-381 gene therapy trial at GOSH
- Continued to support the Brineura in the eyes compassionate use programme for children with CLN2 at Great Ormond Street Hospital (GOSH)
- Completed the manuscript and policy report for our research study into the diagnostic odyssey of CLN2 and CLN3 Batten disease
- Collaborated with our Global Partners to form the Batten Disease Global Research Initiative (BDGRI) a consortium of leading patient advocacy organisations worldwide that share the common goal of driving and investing in research for all forms of Batten disease.
- Began work to understand the key regulatory requirements for setting up a UK Batten disease registry
- Worked with Genomics England as CLN2 was added to the Generation Research Study, in partnership with NHS England. The study is sequencing and analysing the genomes of 100,000 newborn babies in England to look for certain treatable genetic conditions.

Achievements this year

Advocacy:

- Advocated for the CLN2 Community as a key stakeholder in the NICE reappraisal of Brineura
- Continued to collaborate with other organisations both nationally and internationally to influence work around access to treatments and early diagnosis
- Built and further strengthened relationships with organisations/alliances/groups that align with the BDFA
- Began to work with key politicians to generate political support for the approval of Brineura and longer-term to influence earlier diagnosis and improved patient pathways
- Worked in partnership with an external Communications company on our comms strategy around the NICE reappraisal process

Governance:

- Completed the transition to a Charitable Incorporated Organisation (CIO)
- Developed policies to ensure ongoing professional development and compliance with laws and regulations
- Established annual strategic planning meetings involving the team and Trustees to plan projects and budgets for the following year
- Established a 3-year strategic planning cycle

Meet the board of trustees

- Zlatko Sisic, Chair of Trustees (appointed June 2021 for 3 years and extended to May 2025 in agreement with co-Trustees and the board)
- Mark Thompson, Treasurer (appointed September 2023 for 3 years)
- Bob Thompson (appointed August 2023 for 3 years)
- Simon Sewart (appointed August 2023 for 3 years)
- Richard Whitbread (stepped down September 2023)
- Pauline Docherty (stepped down September 2023)

Funders

from the period of 1st September 2023 - 31st August 2024

The BDFA wish to thank all the amazing funders who have supported our work during this financial year:

Ardwick Trust
Barbara Ward Children's Foundation
The Barbour Foundation
The Barcapel Foundation
Barnard Kenneth Hufton Trust
Broome Family Charitable Trust
The Christopher Laing Foundation
The David Family Foundation
The Dagleish Trust
Douglas Arter Foundation
FB Coales No 4 (Family) Trust
The February Foundation
Flory's Story
The Fulmer Charitable Trust
The Goodman Foundation
The Grace Trust
Global's Make Some Noise
The James Wood Bequest
John Horniman's Children's Trust
The Hospital Saturday Fund
Linmardon Trust
Liz and Terry Bramall Charitable Foundation
The Mabel Cooper Charitable Trust
Margaret Butters Reekie Charitable Trust
May Hearnshaw Charitable Trust
Anonymous Trust
The Meikle Foundation
The Nicole and Jessica Rich Foundation
Pedal4Memories
The Rubin Trust Foundation
Robert Luff Foundation
Sheffield 1000 Charity
Sheldonia Charitable Trust
St James's Place Foundation
The Tendril Trust
The Thales Charitable Trust
Anonymous Trust
The Vandervell Foundation
W G Beloe Trust
The Zochonis Charitable Trust

Our special thanks to Beefy's Charitable Foundation for their generous ongoing support.

Tribute to Barbara Cole

BDFA and the Batten Community were deeply saddened to hear of the passing of Barbara Cole in June 2024.

Barbara was a huge part of the BDFA for over 15 years, giving up her time to volunteer and was the educational specialist for the BDFA for many years.
During this time Barbara supported the BDFA team and fought tirelessly to support families affected by Batten disease in the educational needs of their children and young people.

In 2022 the BDFA presented Barbara with an award for her years of service to the Batten community, which we were so proud to present to her at our family conference. Barbara made a significant contribution to Batten disease-related research, which resulted in overall improvements in the education and care of children diagnosed with the disease.

She cared deeply about the families and even after Barbara officially stepped down from her role with BDFA, she was still on hand to help if she could. We know families who Barbara supported cared for her too. She is sadly missed.

Quotes from families:

“With Barbara fighting your corner anything was possible! Barbara was such huge advocate for us in the early stages of our daughter’s diagnosis. Without her we wouldn’t have known how to navigate the situation we found ourselves in. She showed such compassion and kindness and we think of her often with such fondness.”

“A wonderful lady with the biggest heart. I learnt so much from Barbara, her passion to help the Batten Community radiated from her.”

“Barbara was so passionate about our children & fighting for what they needed & deserved. She was so kind & caring & will be greatly missed.”

Trustees' Report

Financial Review

The overall income generated by the BDFA in the financial year was £438,139 which was significantly lower than the previous year's £540,139. However, incomes in unrestricted and undesignated activities were £387,411 which represents an increase over the previous year'£347,207. The trustees are pleased with this increase in unrestricted income which was broadly in line with their budget expectations.
During the previous financial year the BDFA had significantly restructured and reduced the administrative cost-base whilst maintaining our level of service and representation to the Batten community. As a result of those actions the Trustees are pleased to report that the unrestricted costs for this financial year were £286,619 which was significantly lower than the previous year's £386,600 and also below the budget for the year.
The Trustees are pleased to report that Total Reserves at the end of the financial year are £452,881 which represents a 4.2% increase over the prior year (2023 £434,707). We are very grateful to the families and to their wider communities for their tireless support in raising funds for the ongoing work of the BDFA.

Reserves Policy

The Trustees note that our free reserves were £239,867 at the end of the financial year. This is an increase of £100,792 on the previous year and reflects particularly on the Charity's actions to reduce our administrative cost base. We have continued our strategy to diversify our income and develop grant funding relationships, and this has continued to successfully attract new funders to the BDFA. The Trustees still consider that holding free reserves of between 4 and 8 months is appropriate as the charity develops its activities and strengthen its range of services. At the year end the free reserves equated to 7.2 months of anticipated core expenditure.

Public Benefit

The trustees use the Charity Commission guidance on public benefit and used this to help them plan current and future activities. 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

- We need to maintain robust fundraising methods and ensure that funding bids are of the highest quality to compete with the demand for funding from Charitable Trusts and Foundations
- The impact of the rising cost of living on our families, 50 percent of whom are already financially challenged
- The impact of the rising cost of living affecting community fundraising and individual giving.

Change of Charitable Status

The Trustees report that this will be the final Report and Financial Statement of the BDFA in its current form. As a result of a Transfer of Assets Agreement all of the assets and liabilities of the BATTEN DISEASE FAMILY ASSOCIATION were transferred shortly after midnight on the 31st August 2024 into the newly incorporated BATTEN DISEASE FAMILY ASSOCIATION CIO (registered charity number 1205650) which will continue to undertake the activities of the charity.

Legal and Administration Information of Batten Disease Family Association

Charity number 1084908

OSCR number SC047408

Principal Address
PO Box 379
Shipley
BD18 9GE

Independent Examiner
TC Group
The Courtyard
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Bankers
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70-72 Cross Street
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Legal Adviser
H3 Solicitors
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Scientific and Medical Advisers

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
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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

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 2024 which are set out on pages 15 to 27.

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 Charity as required by section 130 of the 2011 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: 12 May 2025

Statement of Financial Activities

FOR THE YEAR ENDED 31 AUGUST 2023

		Unrestricted Funds	Designated Funds	Restricted Funds	Total 2024	Total 2023
Income from:		£	£	£	£	£
Donations and legacies	2	261,791	40,728	10,000	312,519	449,179
Other income	3	118,550	-	-	118,550	87,944
Investments	4	7,070	-	-	7,070	3,016
Total income		387,411	40,728	10,000	438,139	540,139
Expenditure on:						
Raising funds		61,861	-	-	61,861	93,476
Charitable activities		224,758	52,643	80,703	358,104	507,897
Total expenditure	5	286,619	52,643	80,703	419,965	601,373
Net income/(expenditure) and net movement in funds		100,792	(11,915)	(70,703)	18,174	(61,234)
Fund balances at 1 September 2023		139,075	148,270	147,362	434,707	495,941
Fund balances at 31 August 2024		239,867	136,355	76,659	452,881	434,707

The notes on pages 16 to 27 form part of these accounts.

On 1 September 2024 the activities of the charity were transferred to the Batten Disease Family Association CIO (registered charity number 1205650), including all the above funds.

Balance Sheet

AS AT 31 AUGUST 2024

	Notes	£	2024 £	£	2023 £
Current assets					
Stock		1,000		1,000	
Debtors	10	1,414		4,022	
Cash at bank and in hand		461,140		496,812	
		463,554		501,834	
Creditors: amounts falling due within one year	11	(10,673)		(67,127)	
Net current assets			452,881		434,707
Total net assets			452,881		434,707
Income funds					
Restricted funds	14		76,659		147,362
Unrestricted funds - general			239,867		139,075
Unrestricted funds - designated	15		136,355		148,270
			452,881		434,707

n 1 September 2024 all of the above assets and liabilities were transferred to the Batten Disease Family ssociation CIO (registered charity number 1205650).

The accounts were approved by the Board on 7th April 2025

Zlatko Sisic

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Zlatko Sisic

Chair of Trustees

Charity number: 1084908

Notes to the Accounts

FOR THE YEAR ENDED 31 AUGUST 2024

1. 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 2019) - (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

On 1 September 2024 all of the activities, assets and liabilities of the charity were transferred to the Batten Disease Family Association CIO (registered charity number 1205650). Therefore the going concern basis in preparing these accounts is not appropriate. No adjustment to the accounts is necessary as a result of this.

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.

1.0 Accounting policies (continued)

1.1 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.

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.

1.0 Accounting policies (continued)

1.5 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.

1.6 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.

1.7 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.

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

1.9 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 over 7 months which is an 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.

1.10 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. Donations and legacies

	Unrestricted funds	Designated funds	Restricted Funds	Total 2024	Total 2023
	£	£	£	£	£
Donations					
Regular monthly donations	18,251	-	-	18,251	11,260
Donations gift aid	2,445	-	-	2,445	-
Donations non gift aid	2,777	-	-	2,777	3,716
Donated services	-	-	-	-	450
Charitable giving	34,113	-	-	34,113	35,834
Donations – organisations and schools	25,288	40,728	-	66,016	68,998
Foundations and trusts not restricted	151,362	-	-	151,362	143,937
Foundations and trusts restricted	-	-	10,000	10,000	148,899
Pharmaceutical grants	21,864	-	-	21,864	13,112
Gift aid reclaimed	4,070	-	-	4,070	4,932
	260,170	40,728	10,000	310,898	431,138
In memoriam donations					
In memoriam	1,621	-	-	1,621	18,041
	261,791	40,728	10,000	312,519	449,179

3. Other income

	Unrestricted funds	Designated funds	Restricted funds	Total 2024	Total 2023
	£	£	£	£	£
Fundraising					
Supporter fundraising	117,004	-	-	117,004	84,889
Collection boxes	67	-	-	67	246
Fundraising activities	147	-	-	147	979
	117,218	-	-	117,218	86,114
Merchandise income					
Merchandise sales	1,332	-	-	1,332	1,830
	118,550	-	-	118,550	87,944

4. Investment income

	Unrestricted funds	Designated funds	Restricted funds	Total 2024	Total 2023
	£	£	£	£	£
Interest income	7,070	-	-	7,070	3,016

5. Total expenditure

	Staff costs	Other Costs	Total 2024	Total 2023
	£	£	£	£
Costs of raising funds				
Fundraising costs	48,844	13,017	61,861	93,476
	48,844	13,017	61,861	93,476
Charitable activities				
Activities undertaken directly	76,709	191,175	267,884	410,986
Support costs	24,912	65,308	90,220	96,911
	101,621	256,483	358,104	507,897
Total expenditure	150,465	269,500	419,965	601,373

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

6. Support costs - other

	Total 2024	Total 2023
	£	£
Other costs		
Rent	**3,781**	16,614
Postage, freight and courier	**2,676**	1,834
Telephone	**380**	286
Computer, software and IT support	**2,765**	4,659
Legal and other professional fees	**3,839**	2,102
Office stationery	**1,475**	804
Insurance	**2,252**	1,671
Organisational membership and legal and professional fees	**22,465**	2,865
Accountancy fees	**5,702**	5,700
CEO expenses	**6,294**	5,452
Book keeping	**4,841**	4,752
Bank charges	**192**	88
Recruitment expenses	**1,309**	1,287
Staff training	**3,079**	2,788
Admin outsourced charges	**1,207**	2,335
Website costs	**1,094**	88
HR	**1,550**	4,741
Trustee costs	**407**	-
	65,308	58,066

These costs include amounts payable to the independent examiners of £1,800 (2023: £1,500) for independent examination and £3,492 (2023: £4,200) for other services.

7. Trustees

In the year, one trustee was paid £105 (2023: £2,223) 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 2024, £nil (2023: £1,003) was paid to one trustee 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.

8. **Comparative funds – Statement of Financial Activities for the period ended 31 August 2023**

		Unrestricted Funds	Designated Funds	Restricted Funds	Total 2023
Income from:		£	£	£	£
Donations and legacies	2	256,242	44,038	148,899	449,179
Other income	3	87,944	-	-	87,944
Investments	4	3,016	-	-	3,016
Total income		347,202	44,038	148,899	540,139
Expenditure on:					
Raising funds		93,476	-	-	93,476
Charitable activities		293,124	131,428	83,345	507,897
Total expenditure	5	386,600	131,428	83,345	601,373
Net income/(expenditure) and net movement in funds		(39,398)	(87,390)	65,554	(61,234)
Fund balances at 1 September 2022		178,473	235,660	81,808	495,941
Fund balances at 31 August 2023		139,075	148,270	147,362	434,707

9. **Employees**

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

	Total 2024	Total 2023
Charitable activities	3	3
Advocacy	2	2
	5	5

Employment costs	Total 2024 £	Total 2023 £
Wages and salaries	136,240	194,349
Social security costs	8,750	12,404
Pension costs	5,475	5,792
	150,465	212,545

9. Employees (continued)

There were no employees earning between £60,000 - £70,000 in the current year (2023: one).

The key management personnel of the charity is comprised of the Chief Executive Officer. The total aggregate employee benefits paid during the year were £48,844 (2023: £73,957).

None of the Trustees received any remuneration or other benefits from the charity or any connected body. The Trustees had great assistance during the year from a number of volunteers all of who we thank for their valued but financially unrecognised contributions.

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 £nil (2023: £29,616) were made with regards to the termination of employment contracts.

10. Debtors

	2024	2023
	£	£
Trade debtors	**-**	1,499
Prepayments and accrued income	**1,414**	2,523
	1,414	4,022

11. Creditors: amounts falling due within one year

	2024	2023
	£	£
Trade creditors	**1,673**	25,164
Other creditors	**-**	440
Accruals	**9,000**	9,000
Deferred income	**-**	29,390
Taxes and social security	**-**	3,133
	10,673	67,127

12. Deferred income

	2024	2023
	£	£
Deferred income at 1 September 2023	**29,390**	64,876
Income recognised during the year	**(29,230)**	(70,073)
Income deferred during the year	-	34,587
Deferred income at 31 August 2024	-	29,390

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 £5,475 (2023: £5,792).

Contributions totalling £Nil (2023: £nil) 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 2023	Income	Expenditure	Transfers between funds	Balance at 31 August 2024
Euro Ed Project	1,365	-	-	-	**1,365**
Fundraising and Management (BioMarin)	11,952	-	-	-	**11,952**
Brineura Travel Costs (BioMarin)	5,358	-	(105)	-	**5,253**
Research Programme	69,815	10,000	(46,718)	-	**33,097**
Swaffield / Flory's Story	58,872	-	(33,880)	-	**24,992**
	147,362	10,000	(80,703)	-	**76,659**

- Euro Ed Project is a Europe-wide education project focussed on CLN3.
- Fundraising and Management (BioMarin) is specifically to build capacity within the BDFA to diversify income, shape fundraising and enhance resources.
- Brineura Travel Costs (BioMarin) – BioMarin have provided additional funds to cover travel costs to GOSH to counter delays in opening other treatment centres.
- Research Programme – newly commissioned research programme to identify and provide guidance on Early Diagnosis.
- Swaffield / Flory's Story – Swaffield donation towards costs of Head of Scientific Affairs.

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 2023	Income	Expenditure	Transfers between funds	Balance at 31 August 2024
Brineura Compassionate Use Programme	90,699	-	(37,738)	-	**52,961**
Bertie's Helpers	21,832	40,728	(12,083)	(1,550)	**48,927**
Orange Folder	662	-	-	-	**662**
Website Reconstruction	33,805	-	-	-	**33,805**
Bertie's Helpers – Bereaved	1,272	-	(2,822)	1,550	-
	148,270	40,728	(52,643)	-	**136,355**

- 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.

From 1 September 2024, the Batten Disease Family Association and funders have agreed that the Bertie's Helpers and the Bertie's Helpers – Bereaved funds will be combined into one designated fund.

16. **Analysis of net assets between funds**

	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Fund balances at 31 August 2024 are represented by:				
Current assets	250,540	76,659	136,355	**463,554**
Creditors due within one year	(10,673)	-	-	**(10,673)**
	239,867	76,659	136,355	**452,881**

	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Fund balances at 31 August 2023 are represented by:				
Current assets	206,202	148,270	147,362	**501,834**
Creditors due within one year	(67,127)	-	-	**(67,127)**
	139,075	148,270	147,362	**434,707**

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.

BATTEN DISEASE FAMILY ASSOCIATION

Together we WILL make a difference

Registered Charity in England and Wales 1084908 - Scotland SC047408

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