



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 2022 - August 2023**

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

We have had a challenging, but successful year at the Batten Disease Family Association (BDFA). During this year we have supported 108 families across the UK with 127 children and adults, including 5 new diagnoses. Very sadly, due to the life-limiting nature of Batten disease, 6 children, young people and adults have passed away this year.

Despite the challenges that we faced both financially and with the departures of three team members, we have continued to support families throughout the rising cost of living and long-term effects of the Covid pandemic.

At the time of writing, we have five members of employed staff (4 FTE) and a contracted part time team member, which has enabled us to fulfil our mission and provide the required level and depth of support to families. However, we expect that there will be a need to increase capacity in 2024 to meet the level of need as funding allows.

We continue to partner with specialist charity The Maypole Project (TMP) to deliver our holistic wellbeing service for the whole family. Our Peer Befriending service has grown to now include 8 fully-trained parent befrienders who are supporting other parents, building their resilience and reducing their isolation. A Mums' and Dads' monthly chat groups have also been developed and attendance is growing.

We made significant progress with our research study examining the diagnostic odyssey of Batten disease. The study, led by our Scientific Committee and in collaboration with the Health Policy Partnership will be published in a peer review journal in 2024 and we hope that the findings will help to improve patient diagnostic and care pathways and ultimately lead to earlier diagnosis and better care management for children affected by Batten disease. The BDFA is focused on supporting research for all types of Batten disease and as such we were thrilled to expand Dr Joanna Nightingale's role to Head of Scientific Affairs in April 2023, thanks to generous funding from Flory's Story, a family-led fundraising initiative.

At the beginning of the financial year, in September we held the family conference in Stratford-upon-Avon, which was attended by a number of families and healthcare professionals. Further details are provided later in this report.

We have continued to successfully diversify our income through Trusts and Foundations and we were thrilled that our first Big Give Christmas Challenge for many years was a huge success. During this year we also secured a significant funding partnership with Global's Make Some Noise (funding period commences in 2024) and three families shared their stories on National radio as part of the launch of Global's Make Some Noise funding campaign. This was a wonderful opportunity to raise awareness of Batten disease and the challenges that families in our community face.

A special Christmas charity single in aid of the BDFA was produced and released in December by David McGovern, our kind supporter and record label owner from Newcastle. 'This One's For The Children', a cover of the 'New Kids On The Block' song featured the unique 'Batten Community Children's Choir', made up of children affected by Batten disease, their siblings and other family members, who were invited by David to take part. The single reached no 1 in the official physical singles chart on 31st December 2022, which was an incredible achievement. The official charts also awarded each child who had taken part an 'official charts' no 1 award to keep. This was very special and a unique way to raise awareness of Batten disease. We are very grateful to David for his generous support of our community.

We are very grateful to our committed team of Trustees and we do thank Cath Sermon and Gareth Holmes who both stepped down this financial year.

Despite the financial challenges, which arose from the cost of living crisis affecting individual donations and also an unforeseen lack of capacity in the fundraising team for the first six months, we were greatly encouraged to see a marked improvement to our overall income from June onwards. The successful recruitment of a Fundraising Assistant in March was instrumental to an increase in supporter fundraising towards the end of the financial year.

We are very grateful to the families and their wider communities for their incredible efforts in continuing to raise vital funds for us. This remains an important income stream for the BDFA.

We are looking positively to the future as we continue to grow and develop the organisation, working holistically to meet the needs of our beneficiaries, 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 from the point of diagnosis, throughout their journey and beyond.



Zlatko Sisic, Chair of Trustees



Liz Brownutt, 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 have successfully registered as a CIO (Charitable Incorporated Organisation) and we will complete the transition to the new organisation by the end of 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. Amanda Mortensen stepped down as CEO in June 2023 and we would like to thank Amanda for her leadership of the BDFA over a three-year period.

Liz Brownnutt was appointed to the Interim CEO role from 23rd August 2023.

The staff team members in the year under review were:

- Amanda Mortensen, Chief Executive (left the BDFA June 2023)
- Liz Brownnutt, Head of Fundraising and Interim Chief Executive from August 2023
- Lisa Forsyth, Team Admin Officer
- Dr Joanna Nightingale, Scientific Officer and Head of Scientific Affairs from April 2023
- Mimi Petty, Peer Befriending Coordinator
- Sarah Chandler, Fundraising Assistant (joined the BDFA in March 2023)
- Sian Fisher, Head of Family Support (left the BDFA in June 2023)
- Elizabeth Jones, Family Support Worker (left the BDFA in May 2023)

We would like to thank Sian and Elizabeth for their dedication and support of families during their time at the BDFA.

For part of the year Sarah Kenrick served as Batten Behaviour, Adult and Transitions Specialist as a contractor and in June, she stepped into the role of Family Support Partner also as a contractor for this vital work.

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

Over the year under review, our strategy ran under four pillars: Advocacy, Community, Care and Support and Research

Advocacy: To advocate for children and adults 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
- Advocate for the CLN2 community to NICE and other key stakeholders through the re-evaluation process of Brineura treatment for CLN2 patients
- To spearhead the campaign for newborn screening for Batten disease
- Strengthen our advocacy services for children 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 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...

- Continue to develop our Peer Befriending service growing our volunteer capacity from within the community enriching and empowering parents to support each other, both on a one-to-one basis and through the development of a Dad's chat and Mum's chat group and chat groups for all CLN subtypes
- Strengthen our connection with families through a hybrid approach combining online and face to face contact and hold a family conference/weekend away
- 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...

- Develop our Family Support function to offer an excellent, holistic and highly specialised service to families from the point of diagnosis and through their journey
- Develop our support services through facilitating training for professionals and families
- Increase our mental health support to parents, siblings and other family members via our partnership with Maypole
- Work with NHS England to create a specialist LSD clinical pathway for Batten disease in England.
- Continue to work in collaboration with the specialist treatment centres across the UK 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...

- Publish the BDFA led piece of research into the burden of illness and burden of care for Batten disease
- Support families through the ongoing Brineura® in the eyes programme at GOSH
- Strengthen our relationships with clinicians, scientists and pharmaceutical companies to ensure families in the UK are 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 - This year we have:

- 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 set up treatment centres for Cerliponase Alfa for CLN2 Batten disease, with further centres opening in Bristol and Birmingham this financial year.
- Applied for CLN2 to be added to the Generation Research Study, by Genomics England in partnership with NHS England. The study will sequence and analyse the genomes of 100,000 newborn babies in England to look for certain treatable genetic conditions.
- Continued to collaborate with other organisations both nationally and internationally to influence work around access to treatments and early diagnosis

Community Achievements

- Held the Family Conference in September 2022
- Commenced quarterly Town Hall meetings with families to regularly connect and keep them up to date with developments in the BDFA and regarding research and clinical trials
- Grew our Peer Befriending service to include regular group chats for parents
- Made significant progress with the new website, which is due to launch in 2024

Care and Support

- Provided holistic support for 108 families over 78 different local authorities via our support team and Family Support Partner
- Enabled families to challenge losses in support provisions and have these decisions successfully turned around
- Supported around a third of the families in our community with crucial therapeutic and counselling support through our Family Wellbeing service

Research

- 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. The Quantitative and qualitative survey and individual family interviews (Phase three) were completed by August
- Continued to support the Brineura in the eyes compassionate use programme for children with CLN2 at Great Ormond Street Hospital (GOSH)
- Expanded Jo Nightingale's role to Head of Scientific Affairs to develop and build the BDFA's scientific and research function

Meet the board of trustees

- Zlatko Sisic, Chair of Trustees (appointed June 2021 for 3 years)
- Richard Whitbread, Treasurer
- Pauline Docherty, Secretary
- Bob Thompson (appointed June 2021 for 3 years)
- Simon Sewart (appointed June 2021 for 3 years)
- Gareth Holmes, Fundraising Lead- (stepped down in May 2023)
- Cath Sermon (stepped down in April 2023)

Funders

from the period of 1st September 2022 - 31st August 2023

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

Access Group Foundation
The Sylvia Aitken Charitable Trust
The Ardwick Trust
The Douglas Arter Foundation
The Barbour Foundation
BDB Pitmans Charitable Trust
The Blyth Watson Charitable Trust
The Broome Family Charitable Trust
The Trevor Catchpole Memorial Trust
The F B Coales No.4 (Family) Trust
The February Foundation
The Frogal Trust
The Edward Gostling Foundation
The Grace Trust
The Walter Guinness Charitable Trust
The Harebell Centenary Fund
John Horniman's Children's Trust
Irving Memorial Trust
Lillie Johnson Charitable Trust
The Christopher Laing Foundation
Anonymous Trust

Robert Luff Foundation
Michael Marsh Charitable Trust
Nancie Massey Charitable Trust
Theodore Maxxy Charitable Trust
The Edith Murphy Foundation
Pilkington Charities Fund
The Rest-Harrow Trust
Rubin Foundation Charitable Trust
Anonymous Trust
The Stockwell/Cliffe Charitable Trust
Stella Symons Charitable Trust
The St James's Place Foundation
The Vandervell Foundation
The Wise Music Foundation
Sir Samuel Scott of Yews Trust
The Zochonis Charitable Trust
Pedal4Memories
The Nicole and Jessica Rich Foundation
Flory's Story
SAGA Ltd

The BDFA is also grateful for the ongoing support of Beefy's Charity Foundation

Conference

In September 2022 we held a family conference in Stratford-upon-Avon. 30 families attended with 27 children and young people with all types of Batten disease and of all ages. It was a connecting event, for the families, for the team and for the professionals working with children and families with Batten disease. It was a full weekend programme with activities for children and young people with Batten disease including a sensory drama group, a farm, a bubble specialist and we were joined by national charity SENSE who ran art and sensory activities and Guide Dogs. There were also scientific and research updates throughout the weekend programme.

The Maypole Project led a full Siblings programme, including sporting activities and a river cruise trip.

We were joined by scientists from around the UK and for many it was the first time they had met a child with Batten disease.

The BDFA would like to thank all the professionals and groups who were involved in the programme.



Trustees' Report

Financial Review

The overall income generated by the BDFA was broadly stable in the financial year at £540,139 (2022 £545,653). However, incomes in unrestricted and undesignated activities fell to £347,202 (2022 £421,275). The fall reflects the cost of living crisis affecting individual donations and also an unforeseen lack of capacity in the fundraising team for the first six months. The BDFA reacted quickly to the income shortfall, to lower our administrative cost-base whilst maintaining our level of service and representation to the Batten community.

The Trustees are pleased to report that Total Reserves at the end of the financial year are £434,707 though this is 12% lower than prior year (2022 £495,941). 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 £139,075 at the end of the financial year. This is a decrease on the previous year and reflects the financial challenges that we experienced within this year in review. 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. We were pleased to note an improvement to income from June onwards and as such the Trustees still consider that holding reserves of between 4 and 8 months is appropriate as the charity redevelops its activities and strengthen its range of services. At the year end the free reserves equated to 4.5 months of 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

- Maintaining sufficient capacity in our fundraising team to meet the growing financial needs of the organisation
- 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

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	PO Box 379 Shipleigh BD18 9GE	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
Independent Examiner	TC Group The Courtyard Shoreham Road Upper Beeding Steyning West Sussex BN44 3TN	Dr Ruth Williams Consultant Paediatric Neurologist Evelina London Children's Hospital Westminster Bridge Road South Bank London SE1 7EH
Bankers	The Co-Operative Bank 70-72 Cross Street Manchester M2 4JG Santander Bank Bootle Merseyside L30 4GB	
Legal Adviser	H3 Solicitors Suite 1 The Old Pig Styes Brighthams Farm Bines Road Partridge Green West Sussex RH13 8EQ	

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 2023 which are set out on pages 14 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 the Association of Chartered Certified 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:16th.May.2024.....

Statement of Financial Activities

FOR THE YEAR ENDED 31 AUGUST 2023

		Unrestricted Funds	Designated Funds	Restricted Funds	Total 2023	Total 2022
Income from:		£	£	£	£	£
Donations and legacies	2	256,242	44,038	148,899	449,179	435,733
Other income	3	87,944	-	-	87,944	109,763
Investments	4	3,016	-	-	3,016	157
Total income		347,202	44,038	148,899	540,139	545,653
Expenditure on:						
Raising funds		93,476	-	-	93,476	81,318
Charitable activities		293,124	131,428	83,345	507,897	473,284
Total expenditure	5	386,600	131,428	83,345	601,373	554,602
Net income/(expenditure) and movement in funds		(39,398)	(87,390)	65,554	(61,234)	(8,949)
Fund balances at 1 September 2022		178,473	235,660	81,808	495,941	504,890
Fund balances at 31 August 2023		139,075	148,270	147,362	434,707	495,941

The notes on page 17 to 27 form part of these accounts.

All income and expenditure shown above relate to continuing activities.

Balance Sheet

AS AT 31 AUGUST 2023

	Notes	£	2023 £	£	2022 £
Current assets					
Stock		1,000		1,000	
Debtors	10	4,022		16,234	
Cash at bank and in hand		496,812		580,107	
		<u>501,834</u>		<u>597,341</u>	
Creditors: amounts falling due within one year					
	11	(67,127)		(101,400)	
Net current assets					
			434,707		495,941
Total net assets					
			<u>434,707</u>		<u>495,941</u>
Income funds					
Restricted funds	14		147,362		81,808
Unrestricted funds - general			139,075		178,473
Unrestricted funds - designated	15		148,270		235,660
			<u>434,707</u>		<u>495,941</u>

The accounts were approved by the Board on 15th May 2024



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Zlatko Sisic
Chair of Trustees

The notes on pages 17 to 27 form part of these accounts.

Cash Flow Statement

AS AT 31 AUGUST 2023

	Notes	2023 £	2022 £
Cash flows used in operating activities:			
Net cash used in/by operating activities	17	(80,279)	(42,670)
Cash flows from investing activities:			
Interest received		(3,016)	(157)
Net cash provided by investing activities		(3,016)	(157)
Change in cash and cash equivalents in the year		(83,295)	(42,827)
Cash and cash equivalents at the beginning of the year		580,107	622,934
Cash and cash equivalents at the end of the year		496,812	580,107

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 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).

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 2023

1.4 Expenditure (continued)

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.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

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.

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 4.5 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 charity 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 2023

2 Voluntary Income

	Unrestricted funds	Designated funds	Restricted Funds	Total 2023	Total 2022
	£	£	£	£	£
Donations					
Regular monthly donations	11,260	-	-	11,260	8,456
Donations gift aid	-	-	-	-	858
Donations non gift aid	3,716	-	-	3,716	9,773
Donated services	450	-	-	450	1,000
Charitable giving	35,834	-	-	35,834	8,343
Donations – organisations and schools	24,960	44,038	-	68,998	129,386
Foundations and trusts not restricted	143,937	-	-	143,937	142,226
Foundations and trusts restricted	-	-	148,899	148,899	23,000
Pharmaceutical grants	13,112	-	-	13,112	89,624
Gift aid reclaimed	4,932	-	-	4,932	3,413
	238,201	44,038	148,899	431,138	416,079
In memoriam donations					
In memoriam	18,041	-	-	18,041	19,654
	256,242	44,038	148,899	449,179	435,733

3 Other income

	Unrestricted funds	Designated funds	Restricted funds	Total 2023	Total 2022
	£	£	£	£	£
Fundraising					
Supporter fundraising	84,889	-	-	84,889	106,204
Collection boxes	246	-	-	246	160
Fundraising activities	979	-	-	979	1,235
	86,114	-	-	86,114	107,599
Merchandise income					
Merchandise sales	1,830	-	-	1,830	2,164
	87,944	-	-	87,944	109,763

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

4 Investment income

	Unrestricted funds	Designated funds	Restricted funds	Total 2023	Total 2022
	£	£	£	£	£
Interest income	3,016	-	-	3,016	157

5 Total expenditure

	Staff costs	Other Costs	Total 2023	Total 2022
	£	£	£	£
Costs of raising funds				
Fundraising costs	63,632	29,844	93,476	81,318
	<u>63,632</u>	<u>29,844</u>	<u>93,476</u>	<u>81,318</u>
Charitable activities				
Activities undertaken directly	110,068	300,918	410,986	394,320
Support costs	38,845	58,066	96,911	78,964
	<u>148,913</u>	<u>358,984</u>	<u>507,897</u>	<u>473,284</u>
Total expenditure	<u>212,545</u>	<u>388,828</u>	<u>601,373</u>	<u>554,602</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 2023

6 Support costs - other

	Total 2023	Total 2022
	£	£
Other costs		
Rent	16,614	14,039
Postage, freight and courier	1,834	1,518
Telephone	286	240
Computer, software and IT support	4,659	5,719
Office equipment	-	313
Legal and other professional fees	2,102	(321)
Office stationery	804	659
Insurance	1,671	1,227
Organisational membership and legal and professional fees	2,865	1,710
Accountancy fees	5,700	4,800
CEO expenses	5,452	2,081
Book keeping	4,752	4,612
Bank charges	88	48
Recruitment expenses	1,287	1,249
Staff training	2,788	4,747
Admin outsourced charges	2,335	1,603
Website costs	88	88
HR	4,741	1,520
Trustee costs	-	54
	58,066	45,906

These costs include amounts payable to the independent examiners of £1,500 (2022: £1,000) for independent examination and £4,200 (2022: £3,800) for other services.

7 Trustees

In the prior year, one trustee was paid £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 2023 £1,003 was paid to one trustee (2022: £54) 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 2023

8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2022

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

9 Employees

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

	Total 2023	Total 2022
Charitable activities	3	3
Advocacy	2	2
	5	5
Employment costs	Total 2023	Total 2022
	£	£
Wages and salaries	194,349	161,983
Social security costs	12,404	9,744
Pension costs	5,792	5,380
	212,545	177,107

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

9 Employees (continued)

There was one employee earning between £60,0001 - £70,000 in the current year (2022: none).

The key management personnel of the charity is comprised of the Chief Executive Officer. The total aggregate employee benefits paid during the year were £73,957 (2022: £52,588).

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 £29,616 (2022: £3,900) were made with regards to the termination of employment contracts, which included payments in lieu of notice and accrued holiday pay.

10 Debtors

	2023	2022
	£	£
Trade debtors	1,499	11,000
Prepayments and accrued income	2,523	5,234
	<u>4,022</u>	<u>16,234</u>

11 Creditors: amounts falling due within one year

	2023	2022
	£	£
Trade creditors	25,164	15,702
Other creditors	440	7,310
Accruals	9,000	9,000
Deferred income	29,390	64,876
Taxes and social security	3,133	4,512
	<u>67,127</u>	<u>101,400</u>

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

12 Deferred income

	2023	2022
	£	£
Deferred income at 1 September 2022	64,876	81,560
Income recognised during the year	(70,073)	(75,560)
Income deferred during the year	34,587	58,876
Deferred income at 31 August 2023	<u>29,390</u>	<u>64,876</u>

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 £5,792 (2022: £5,380).

Contributions totalling £Nil (2022: £995) 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 2022	Income	Expenditure	Balance at 31 August 2023
Euro Ed Project	2,491	-	(1,126)	1,365
Fundraising and Management (BioMarin)	18,104	-	(6,152)	11,952
Brineura Travel Costs (BioMarin)	4,687	15,000	(14,329)	5,358
Research Programme	56,526	58,000	(44,711)	69,815
Swaffield / Flory's Story	-	75,000	(16,128)	58,872
Hardware Support	-	899	(899)	-
	<u>81,808</u>	<u>148,899</u>	<u>(83,345)</u>	<u>147,362</u>

- 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.
- Hardware Support – specific donation received to fund hardware needed by one family.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

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 2022	Income	Expenditure	Transfers between funds	Balance at 31 August 2023
Brineura Compassionate Use Programme	119,256	30	(28,589)	-	90,697
Bertie's Helpers	18,733	15,907	(12,808)	-	21,832
Orange Folder	978	-	(316)	-	662
Website Reconstruction	34,970	-	(1,165)	-	33,805
Bertie's Helpers – Bereaved	3,098	1,250	(3,076)	-	1,272
Family Conference	58,625	16,851	(75,476)	-	-
Resilience Fund	-	10,000	(10,000)	-	-
	235,660	44,038	(131,428)	-	148,270

- 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.
- Resilience Fund – CAF grant used entirely for enhancing Charity Resilience.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2023

16 Analysis of net assets between funds

	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)
	<u>139,075</u>	<u>148,270</u>	<u>147,362</u>	<u>434,707</u>
	Unrestricted funds £	Designated funds £	Restricted funds £	Total £
Fund balances at 31 August 2022 are represented by:				
Current assets	279,283	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>

17 Reconciliation of net income/expenditure to net cash flow from operating activities

	2023 £	2022 £
Net income/expenditure for the year	(61,234)	(8,949)
Interest from investments	3,016	157
(Increase) / decrease in debtors	12,212	(11,202)
(Decrease) in creditors	(34,273)	(22,676)
	<u>(80,279)</u>	<u>(42,670)</u>

18 Related party transactions

There were no related party transactions during the current or previous year, except those disclosed in note 7.

19 Events after the reporting date

It is planned for the Charity to move all assets, and legalities with regards to donations pledged, to the CIO company, with effect of the 2024 financial year.

20 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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