

BATTEN DISEASE FAMILY ASSOCIATION CIO

England & Wales · Charity number 1205650

Details

Other names BDFFA

Status Registered

Legal form CIO

Registered 2023-11-09

Register [View on the Charity Commission register](#)

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Activities

Objects: THE OBJECTS OF THE CIO ARE: TO PRESERVE AND PROTECT THE HEALTH AND WELLBEING OF PERSONS AFFECTED BY ALL TYPES OF NEURONAL CERIOD 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, IN PARTICULAR BUT NOT EXCLUSIVELY BY SUPPORTING AND CONDUCTING RESEARCH INTO THE MANAGEMENT OF BATTEN DISEASE AND TO PUBLISH THE USEFUL RESULTS THEREOF AND TO SUPPORT ORGANISATIONS PROMOTING RESEARCH INTO BATTEN DISEASE.

Activities: A supportive, informative, national networking organisation for the families, carers and professionals giving care to children and adults with Batten Disease and for promoting awareness of, and research into, the disease

Classification

- **How:** Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research
- **What:** Education/training, The Advancement Of Health Or Saving Of Lives, Disability
- **Who:** Children/young People, People With Disabilities

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-12-31	£491,462	£634,269	-	-
2024-08-31	£0	£0	-	-

Trustees

Name	Role	Appointed
Nigel Lorenzo Nicholls	Chair	2025-05-07
Duncan Jamie MacGregor Mann		2025-06-21
Lucy Anne Rodrick		2025-06-21
Mark Alexander Thompson		2023-11-09
Richard Jonathan Oakley		2025-06-21
Robert James Peter Thompson		2023-11-09
Simon David Sewart		2023-11-09

BATTEN DISEASE FAMILY ASSOCIATION CIO

England & Wales - Charity number 1205650

Accounts



BATTEN DISEASE FAMILY ASSOCIATION

Together we WILL make a difference

Registered Charity in England and Wales 1205650

Annual Report and Financial Statements

For the period

1st September 2024 - 31st December 2025

CONTENTS

- 16 months in the Batten community: Introduction from the Chair and CEO 3**
- About the Batten Disease Family Association CIO 7**
- Delivering the Aims and Objectives of the Organisation - BDFA Strategy..... 8**
- Achievements this Period 9**
- Meet the Board of Trustees and Funders11**
- Legal and Administration Information of Batten Disease Family Association CIO 12**
- Trustees' Report 13**
- Statement of Trustee Responsibilities of Batten Disease Family Association CIO..... 14**
- Independent Examiner's Report to the Trustees of Batten
Disease Family Association CIO 15**
- Statement of Financial Activities 16**
- Balance Sheet 17**
- Notes to the Accounts 18**

16 months in the Batten Community:

Introduction from the Chair and CEO

We have had another successful, also challenging sixteen months at the Batten Disease Family Association CIO (BDFA), this being the first year as a Charitable Incorporated organisation (CIO). This report covers the period from September 2024 to December 2025, to account for a change in the organisation's financial year-end. During this period we have supported 109 families across the UK with 122 children and adults, including 11 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 provide effective support and advocacy for families throughout the year and the continued rise in cost of living crisis, also challenging fundraising landscape.

Our dedicated staff team have continued to provide the required level and depth of support to families, and we were pleased to be able to expand capacity in the fundraising and finance teams. At the time of writing, we have 8 members of employed staff (6.4 FTE).

In autumn 2024 we undertook a 'Values Workshop' with the National Council for Voluntary organisations (NCVO) to help us to define our organisational core values. Core values are essential in guiding decision-making, defining culture, and building essential trust with donors and beneficiaries.

The workshop involved group work in reflecting and discussing values and how they are understood and utilised as core principles that guide our work. We collectively defined 4 core values and subsequently created a framework of behaviours around them:

- Commitment
- Knowledgeable
- Integrity
- Courage

We held our annual team and trustees strategic 'away days' in late September to discuss progress within our long-term strategy and projects. This was an invaluable time of thought-provoking discussion and essential planning for 2026. Our strategy is detailed on page 8 of this report.

Our brand new website that had been years in the making went live at the end of March 2025. We have created a comprehensive platform to provide supportive, informative and accessible resources for anyone seeking information about Batten disease and the work of the BDFA, as well as bringing together practical advice, parent-led guidance, the latest research, fundraising tools, and much more. We could not be prouder of the result.

The NICE Re-evaluation of Brineura treatment for patients with CLN2 has continued throughout 2025 and we attended a further two NICE Committee meetings as the representative voice for the community.

B DFA and the community have been steadily building political support throughout the process and we were delighted that our long-standing supporter, Lord Ian Botham and his daughter, Sarah organised a Parliamentary drop-in for us at Westminster in March, inviting MP's who have families affected by CLN2 in their constituencies to attend the event. Prior to the drop-in event, on Wednesday 12th March children affected by CLN2 and their families, alongside the B DFA gathered at Parliament Square to raise awareness of our campaign. The sea of orange and the collective call for NICE to approve Brineura was very moving to witness, and we were delighted that members of the media attended to speak with parents, Lord Botham and B DFA.

Just a few weeks after the parliamentary event, NICE announced that a commercial agreement had been reached between NHS England and the manufacturer, BioMarin to provide permanent access to Brineura for all existing patients under the Managed Access Agreement.

Our fight has since continued to secure approval of Brineura for children diagnosed in the future and involved attendance at 2 further committee meetings and an appeal hearing towards the end of the year. At the time of writing, we are devastated to report that NICE recently dismissed our appeal and issued final guidance rejecting Brineura for newly-diagnosed children. This reflects the inability of NICE and the manufacturer, BioMarin to reach agreement on a price that reflects the clear and meaningful benefits of treatment. We are calling on NICE and BioMarin to urgently resolve their differences and agree a fair deal that reflects the real value of Brineura for children and families. The B DFA will not stop fighting until every eligible child can access this treatment.

B DFA facilitated a meeting in the autumn for families to hear from Clinicians about potential pathways for access to medicines for CLN3 patients, including the potential for a clinical trial. This is being followed up and we are working with the clinical teams to support them in this.

Our research study examining the diagnostic odyssey of Batten disease, which was led by our Scientific Committee and in collaboration with the Health Policy Partnership, was published this year in the Orphanet Journal for Rare Diseases and we will be launching the policy report formally in 2026. This will be a valuable tool with which to advocate and influence policy makers for improved patient diagnostic and care pathways, leading to earlier diagnosis and better care management for children and adults affected by Batten disease.

We have strengthened our relationships with clinicians, scientists, pharmaceutical companies, and patient advocacy groups this year, keeping abreast of all the latest research developments across all CLN subtypes and we were represented at the international NCL Conference in Australia in October and had opportunity to present data on our work.

We have taken steps this year to formalise our Research Review Committee, made up of leading clinicians and scientists in the Batten disease space.

Batten Disease Awareness Day on the 9th of June was once again a day to remember with social media, as well as several municipal buildings across the country lit up orange. Families in our community did an incredible job of raising awareness.

In September, we hosted our first Family Day at Temple Newsam estate in Leeds. We were delighted to have the opportunity to bring families together at this wonderful venue, allowing parents, children and siblings to spend quality time together and connect in person. Families enjoyed sensory activities, visits to the Temple Newsam farm and play barn, arts and crafts, and strolls around the vast grounds. We look forward to exploring further opportunities to bring families from our community together in 2026.

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 continues to thrive, and the Dad's chat and Mum's chat groups for all CLN subtypes are developing well, as are the family-led cooking sessions in the school holidays, which are growing in popularity.

Our Family Wellbeing service, which we commission the Maypole Project to deliver continues to support around one third of the families in our community, providing crucial therapeutic and counselling support and we are working with Maypole to expand the provision to include specialist support for older siblings.

BDFa has been proud to be part of the team that has developed the Childhood Dementia Scotland report. Childhood dementia is poorly understood and is caused by more than 145 rare genetic disorders which are progressive and life limiting. Batten disease is one of the most prevalent of these genetic disorders. 'Childhood Dementia Scotland' led by Alzheimer's Scotland with organisations from Scotland and across the UK began the work to address the challenges around childhood dementia. This includes researchers, academics, BDFa and other groups that work with rarer dementias.

Alongside other organisations in the charity sector, the BDFa has experienced a challenging fundraising climate this year with increasing competition for grants and the continued cost of living crisis impacting individual supporter donations. More than ever, we have been grateful to volunteer groups in our community who have organised fundraising events, participated in running and other physical challenge events and made individual donations. Our community fundraising remains an important income stream for the BDFa, and we will continue to seek funding opportunities from trusts and foundations and expand our corporate network in 2026. Our recent Big Give Christmas Challenge was our most successful to date, raising a phenomenal £22,242.50 towards our family wellbeing service. We are extremely grateful to everyone who supported this matched funding initiative.

Our Chair of Trustees, Zlatko Sisic stepped down from his role on the BDFA Board in May 2025. Zlatko provided excellent leadership to the Board and was instrumental in guiding the charity through some challenging times throughout his time as Chair. We are sincerely grateful to Zlatko for his wisdom and strong leadership during his time with us.

We welcomed our new Chair, Nigel Nicholls to the Board at the end of May 2025. Nigel has a strong background in the pharmaceutical industry and spent over 10 years at BioMarin as Area Director and Country Manager for UK & Ireland. At BioMarin he managed the introductions of NICE managed access agreements for Vimizim® (elosulfase alfa) for Morquio A syndrome and for Brineura® (cerliponase alfa) for ceroid lipofuscinosis 2 (CLN2). We look forward to Nigel's continued support and Board leadership.

We also welcomed three new Trustees during 2025. Lucy Rodrick and Richard Oakley both have a strong background in healthcare communications and policy particularly around rare diseases and Duncan Mann brings knowledge and experience in HR matters. BDFA has thus strengthened it's Board with knowledge and expertise that is invaluable to guiding the direction of travel of the BDFA.

With our clearly defined strategic direction 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.



Nigel Nicholls, Chair of Trustees



Liz Brownnutt, CEO

About the Batten Disease Family Association CIO

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. We successfully transitioned 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.

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.

The staff team members in the year under review were:

- Liz Brownnutt, Chief Executive Officer
- Dr Joanna Nightingale, Head of Scientific Affairs
- Sarah Kenrick, Head of Support & Advocacy
- Lisa Forsyth, Operations Manager
- Mimi Petty, Family Support & Peer Befriending Officer
- Philip Walker, Trusts & Foundations Fundraising Officer
- Arienne Bassett, Accounting & Financial Administration Officer
- Sarah Chandler, Fundraising Assistant left the BDFA in December 2025 and we would like to thank Sarah for her hard work and dedication to the BDFA and Batten Community during her time of employment.

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 Head of Support & Advocacy to report on progress regarding key activities. Over the year, two Trustees were parents of children or young people with Batten disease.

Delivering the Aims and Objectives of the Organisation - BDFA Strategy

The BDFA established its long-term strategy and strategic priorities in 2024. While family support remains at the heart of everything the BDFA does, our focus also includes strengthening our advocacy work to influence policymakers, alongside developing our education, governance, research and fundraising capabilities to deliver lasting and meaningful change for children and young adults affected by Batten disease. This strategy is reviewed annually during the Team and Trustees' away days.



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 Period

Elevate Standards of Care - this period 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 109 families via our Support & Advocacy Team
- Supported around a third of the families in our community with crucial therapeutic and counselling support through our Family Wellbeing service
- Commenced a support group for bereaved parents with the support of Child Bereavement UK
- Ran a soft programme of parent-led discussion topics for families published on our website

Raise Awareness:

- Completed and launched our new website in March 2025
- The policy report manuscript of our research study into the diagnostic Odyssey of CLN2 and CLN3 was published in the Orphanet Journal for Rare Diseases in June 2025. The Policy report will be published and launched in 2026 with the aim of improving patient care and diagnostic pathways.
- Worked with other patient groups to produce the Childhood Dementia Scotland report.
- Had Abstracts accepted into 2 key conferences and presented data on our work at the NCL Conference.

Research:

- Continued to support Tern Therapeutics to begin to reinstate the newly named TTX-381 gene therapy trial at Great Ormond Street Hospital (GOSH).
- Continued to support the Brineura in the eyes compassionate use programme for children with CLN2 at GOSH.
- Collaborated with our Global Partners to strengthen 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 and award the first round of research grants to projects including 3 in the UK.
- Carried out research to explore rejoining DemChild, an established international database with the aim of understanding disease progression, aid in the development of new treatments, and improve clinical care.
- Continued to work with Genomics England with CLN2 included on 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 Period

Advocacy:

- Advocated for the CLN2 Community as a key stakeholder in the NICE reappraisal of Brineura, including participating in a NICE appeal hearing
- 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
- Strengthened work with key politicians to generate political support for the approval of Brineura and longer-term to influence earlier diagnosis and improved patient pathways

Governance:

- Successfully recruited new Trustees to strengthen the Board with specific expertise
- Defined our organisational Values and Behaviours Framework
- Implemented a restructure of the BDFA team and introduced a pay Policy
- Held a successful strategic review meeting involving the Team and Trustees

Meet the board of trustees

- Nigel Nicholls, Chair of Trustees (appointed May 2025 for 3 years)
- 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)
- Lucy Rodrick (appointed June 2025 for 3 years)
- Richard Oakley (appointed June 2025 for 3 years)
- Duncan Mann (appointed June 2025 for 3 years)
- Zlatko Susic (former Chair of Trustees stepped down May 2025)

Funders

from the period of 1st September 2024 - 31st December 2025

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

Anonymous Trust	The Nancie Massey Charitable Trust
The Barbara Ward Children's Foundation	National Lottery Awards for All England
The Barbour Foundation	National Lottery Awards for All Scotland
Broome Family Charitable Trust	The Nicole and Jessica Rich Foundation
Cecil and Hilda Lewis Trust	Pedal4Memories
The Coral Samuel Trust	Pilkington Charities Fund
The Christopher Laing Foundation	Rogers Stirk Harbour + Partners Charitable Foundation
The Dalglish Trust	The Rubin Trust Foundation
Douglas Arter Foundation	ShareGift
Dora Rebecca Fine Charitable Trust	Sheldonia Charitable Trust
The Elizabeth Way Foundation	The Sir James Roll Charitable Trust
Flory's Story	Smile of Hope
The George A Moore Foundation	The Stockwell/Cliffe Charitable Trust
The Grace Trust	The Sylvia Aitken Charitable Trust
Global's Make Some Noise	The Tendril Trust
Himat Tanna Charitable Trust	The Thales Charitable Trust
The Hospital Saturday Fund	The Theodore Maxxy Charitable Settlement
The Ian Mactaggart Trust	Anonymous Trust
The Mabel Cooper Charity	The Vandervell Foundation
The Marsh Charitable Trust	The Vardy Foundation
Marshall & Viggars Charitable Trust	Walter Guinness Charitable Trust
The Michael & Anna Wix Charitable Trust	The W O Street Charitable Foundation
The Michael Marsh Charitable Trust	The Zochonis Charitable Trust

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

Legal and Administration Information of Batten Disease Family Association CIO

Charity number	1205650	Scientific and Medical Advisers
Principal Address	PO Box 379 Shipley BD18 9GE	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
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	Metro Bank PLC One Southampton Row London WC1B 5HA	Dr Dipak Ram Clinical Lead for Paediatric Neurovascular, CLN2 and Inherited White Matter Disorders Services Consultant Paediatric Neurologist, Royal Manchester Children's Hospital Oxford Road, Manchester, M13 9WL
Legal Adviser	H3 Solicitors Suite 1 The Old Pig Styes Brighthams Farm Bines Road Partridge Green West Sussex RH13 8EQ	

Trustees' Report

Financial Review

This is the first trading report of the BDFA CIO. As a result of a Transfer of Assets Agreement all the assets and liabilities of the former BATTEN DISEASE FAMILY ASSOCIATION were transferred shortly after midnight on the 31st August 2024 into this incorporated BATTEN DISEASE FAMILY ASSOCIATION CIO. The Trustees have selected to have 31st December as the Charity's financial year-end and therefore this first Financial Report covers a sixteen-month period from 1st September 2024 to 31st December 2025. (Any references hereunder to prior period performance relate to the former unincorporated charity the Batten Disease Family Association).

The overall income generated by the BDFA in the financial period was £491,462 which, for 16 months, was comparatively significantly lower than the previous 12 months income of £438,139. The first 4 months of the financial period saw strong income generation. By contrast 2025 has seen significant negative deviations from our budgeted incomes; this has impacted both Trust & Foundations income and our community fundraising incomes and reflects a difficult and uncertain economic and geopolitical landscape, both nationally and internationally.

During the financial period the BDFA has continued to maintain strong cost and budgetary controls so that our unrestricted costs of £484,655 for the 16 months were significantly lower than our budget.

The Trustees are disappointed to report that Total Reserves at the end of the financial period are £310,293 which represents a 32% decrease over the prior period end (Aug 2024: £453,100). In these challenging times we are especially 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 £163,768 at the end of the financial period. This is a decrease of £76,318 on the previous period end and reflects particularly on the difficult fundraising environment in which we find ourselves. The Trustees still consider that holding free reserves of between 4 and 8 months is appropriate as the charity develops its activities and strengthens its range of services. At the period end the free reserves equated to 4.9 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

Statement of Trustee Responsibilities of Batten Disease Family Association CIO

Trustees' responsibilities in relation to the accounts

The trustees are responsible for preparing the Trustees' Report and the accounts in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

The law requires the trustees to prepare accounts for each financial period 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 period.

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 CIO

I report to the charity trustees on my examination of the accounts of the above charity for the period ended 31 December 2025.

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 accounts carried out under section 145 of the 2011 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

The charity's gross income exceeded £250,000 and I am qualified to undertake the examination by being a qualified member of the Association of Chartered Certified Accountants.

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

- the accounting records were not kept in accordance with section 130 of the Charities Act; or
- the accounts did not accord with the accounting records; or
- the accounts did 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.



Mark Cummins FCCA FCIE

On behalf of TC Group
Office: Steyning, West Sussex
Dated: 27th May 2026

Statement of Financial Activities

FOR THE PERIOD ENDED 31ST DECEMBER 2025

		Unrestricted funds	Designated funds	Restricted funds	2025
	Note	£	£	£	£
Income from:					
Donations	3	303,170	19,725	3,400	326,295
Other trading activities	4	159,514	-	-	159,514
Investment income	5	5,653	-	-	5,653
Total income		468,337	19,725	3,400	491,462
Expenditure on:					
Raising funds	6	91,692	-	-	91,692
Charitable activities	7	392,963	94,973	54,641	542,577
Total expenditure		484,655	94,973	54,641	634,269
Net income for the period		(16,318)	(75,248)	(51,241)	(142,807)
Transfer of funds		(60,000)	60,000	-	-
Net movement in funds before the net asset transfer		(76,318)	(15,248)	(51,241)	(142,807)
Transfer of assets and liabilities from Batten Disease Family Association (1084908)		240,086	136,355	76,659	453,100
Total funds carried forward	16	163,768	121,107	25,418	310,293

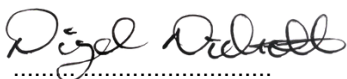
The statement of financial activities includes all gains and losses recognised in the period. All income and expenditure derives from continuing activities.

Balance Sheet

AS AT 31ST DECEMBER 2025

	Note	£	£
Current assets			
Stock		1,646	
Debtors	11	6,286	
Cash at bank and in hand		353,641	
		<u>361,573</u>	
Creditors: amounts falling due within one period	12	(51,280)	
			<u>310,293</u>
Net current assets			<u>310,293</u>
Net assets			<u><u>310,293</u></u>
The funds of the charity:			
Restricted funds	14		25,418
Designated funds	15		121,107
Unrestricted funds	16		163,768
			<u>310,293</u>

The accounts were approved by the Board of Trustees on 27th May 2026



Nigel Nicholls
Chair

Charity Registration No. 1205650

Notes to the Accounts

FOR THE PERIOD ENDED 31ST DECEMBER 2025

1 Legal status of charitable company

Batten Disease Family Association CIO is a charitable incorporated organisation. The organisation's registered number and office address can be found on the Legal and Administrative Information page.

2 Accounting policies

2.1 Basis of preparation

The accounts have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) – (Charities SORP (FRS 102)).

Batten Disease Family Association CIO 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.

The financial statements are prepared in sterling, which is the functional currency of the charity. Monetary amounts in these financial statements are rounded to the nearest pound.

2.2 Going concern

After making appropriate enquiries, the trustees have a reasonable expectation that the charity has adequate resources to continue in operational existence for the foreseeable future. There are no material uncertainties about Batten Disease Family Association CIO's ability to continue as a going concern.

2.3 Income

All incoming resources are included in the Statement of Financial Activities when the charity is legally entitled to the income, it is probable the income will be received and the amount can be quantified with reasonable accuracy.

Donations and other forms of voluntary income are recognised as income when receivable, except insofar as they are incapable of financial measurement.

Income from charitable activities comprises grants awarded for activities undertaken by the charity's project partners. Grants are credited to the Statement of Financial Activities in the period in which they are receivable unless a grant is subject to donor imposed conditions that specify the time period in which the expenditure of the resources can take place; in which case they are deferred.

2.4 Expenditure and basis of apportioning costs

Expenditure is accounted for on an accruals basis with the irrecoverable element of VAT included with the item to which it relates and has been classified under headings that aggregate all costs related to the category.

Charitable activities comprises all expenditure directly relating to the objectives of the charity.

Governance costs (included within Support costs) comprises all costs associated with constitutional and statutory requirements with which the charity must comply.

Notes to the Accounts

FOR THE PERIOD ENDED 31ST DECEMBER 2025

2 Accounting Policies (continued)

2.5 Stock

Stocks are stated at the lower of cost and estimated selling price less costs to complete and sell. Cost comprises direct materials and, where applicable, direct labour costs and those overheads that have been incurred in bringing the stocks to their present location and condition.

Stocks held for distribution at no or nominal consideration are measured at the lower of cost and replacement cost, adjusted where applicable for any loss of service potential.

At each reporting date, an assessment is made for impairment. Any excess of the carrying amount of stocks over its estimated selling price less costs to complete and sell is recognised as an impairment loss in profit or loss. Reversals of impairment losses are also recognised in profit or loss.

2.6 Debtors

Trade and other debtors are recognised at the settlement amount due after any trade discount offered. Prepayments are valued at the amount prepaid net of any trade discounts due.

2.7 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 term deposits to maximise the return on monies held at the bank and to manage cash flow.

2.8 Creditors and provisions

Creditors and provisions are recognised where the charity has present obligation resulting from a past event that will probably result in a transfer of funds to a third party and the amount due to settle the obligation can be measured or estimated reliably.

2.9 Fund Accounting

Unrestricted funds are to be used in accordance with the charitable objectives at the discretion of the Trustees.

Restricted funds are to be used for particular restricted purposes within the objectives of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Designated funds are funds set aside by the trustees out of unrestricted income funds for specific future purposes or projects.

2.10 Judgements and key sources of estimation uncertainty

In the application of the charity's accounting policies, the trustees are required to make judgements, estimates and assumptions about the carrying amount of assets and liabilities that are not readily apparent from other sources. The estimates and associated assumptions are based on historical experience and other factors that are considered to be relevant. Actual results may differ from these estimates.

The estimates and underlying assumptions are reviewed on an ongoing basis. Revisions to accounting estimates are recognised in the period in which the estimate is revised.

The trustees do not consider that there are any critical estimates or areas of judgement that need to be brought to the attention of the readers of the financial statements.

Notes to the Accounts (continued)
FOR THE PERIOD ENDED 31ST DECEMBER 2025

3 Income from donations

	Unrestricted funds £	Designated funds £	Restricted funds £	Total 2025 £
Regular monthly donations	7,869	-	-	7,869
Donations gift aid	5,303	-	-	5,303
Donations non gift aid	10,492	-	-	10,492
Donated services	52	-	-	52
Donations- organisations & schools	28,081	19,725	-	47,806
Foundations & trusts	233,613	-	3,400	237,013
Pharmaceutical Grants	388	-	-	388
Gift aid reclaimed	5,427	-	-	5,427
In Memoriam	11,945	-	-	11,945
	<u>303,170</u>	<u>19,725</u>	<u>3,400</u>	<u>326,295</u>

4 Income from other charitable activities

	Unrestricted funds £	Designated funds £	Restricted funds £	Total 2025 £
Supporter fundraising	156,945	-	-	156,945
Fundraising activities	375	-	-	375
Merchandise sales	2,194	-	-	2,194
	<u>159,514</u>	<u>-</u>	<u>-</u>	<u>159,514</u>

5 Investment income

	Unrestricted funds £	Designated funds £	Restricted funds £	Total 2025 £
Interest income	5,653	-	-	5,653
	<u>5,653</u>	<u>-</u>	<u>-</u>	<u>5,653</u>

Notes to the Accounts (continued)
FOR THE PERIOD ENDED 31ST DECEMBER 2025

6 Raising funds

	Staff costs	Other costs	Total 2025
	£	£	£
Cost of raising funds	72,542	19,150	91,692
Total cost of raising funds	<u>72,542</u>	<u>19,150</u>	<u>91,692</u>

7 Charitable activities

	Staff costs	Other costs	Total 2025
	£	£	£
Expenditure on charitable activities			
Activities undertaken directly	186,216	140,388	326,604
Support costs	51,866	164,107	215,973
Total charitable activities	<u>238,082</u>	<u>304,495</u>	<u>542,577</u>

Analysis of support – other costs (including Governance costs)

	Total 2025
	£
General office and administration	161,587
Governance costs:	
Independent examiners fees	<u>2,520</u>
	<u>164,107</u>

8 Trustee transactions

During the period, 5 trustees were reimbursed expenditure totalling £259.

No trustees received any remuneration for their work during the period.

Notes to the Accounts (continued)
FOR THE PERIOD ENDED 31ST DECEMBER 2025

9 Staff costs

	2025 £
Wages and salaries	284,252
Social security costs	16,994
Other pension costs	9,378
	<u>310,624</u>

The average monthly number of employees during the period was as follows:

	2025
Fundraising	2
Charitable activities	5
	<u>7</u>

There was one employee whose annual emoluments were £60,000 to £70,000.

The key management personnel of the charity comprise of the Chief Executive Officer.

10 Taxation

As a charity, Batten Disease Family Association CIO is exempt from tax on income and gains to the extent that these are applied to its charitable objects.

11 Debtors

	2025 £
Trade Debtors	253
Prepayments	6,033
	<u>6,286</u>

12 Creditors: amounts falling due within one period

	2025 £
Trade Creditors	38,463
Accruals and deferred income	7,020
Other creditors	431
PAYE Payable	5,366
	<u>51,280</u>

Notes to the Accounts (continued)

FOR THE PERIOD ENDED 31ST DECEMBER 2025

14 Restricted funds

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

	Movement in funds				
	Transfer of funds from Batten Disease Family Association	Incoming Resources	Resources Expended	Transfers	Balance at 31.12.2025
Euro Ed project BioMarin	1,366	-	(1,366)	-	-
Fundraising BioMarin	11,952	-	(11,952)	-	-
Brineura Travel costs	5,252	-	(4,792)	-	460
Impact Research Programme	33,097	3,400	(11,539)	-	24,958
Swaffield / Flory's Story	24,992	-	(24,992)	-	-
	76,659	3,400	(54,641)	-	25,418

Euro Ed Project is a Europe-wide education project focused on CLN3.

Fundraising and Management (BioMarin) is specifically to rebuild 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.

Impact Research Programme – A programme commissioned to identify and provide guidance on Early Diagnosis.

Swaffield / Flory's Story – A donation towards the costs of the Head of Scientific Affairs.

15 Designated funds

The funds of the charity include designated funds, representing amounts set aside by the trustees for specific purposes at their discretion:

	Movement in funds				
	Transfer of funds from Batten Disease Family Association	Incoming Resources	Resources Expended	Transfers	Balance at 31.12.2025
Brineura in the Eyes	52,963	-	(14,735)	-	38,228
Berties Helpers	48,925	18,625	(22,450)	-	45,100
Orange Folder	662	-	-	(662)	-
Website reconstruction	33,805	-	(8,888)	(12,500)	12,417
Public Relations	-	-	(3,232)	3,232	-
Family Events	-	1,100	(3,313)	12,000	9,787
Strategy Away Days	-	-	(4,289)	10,000	5,711
Designated NICE	-	-	(36,000)	37,930	1,930
Campaign costs	-	-	(2,066)	10,000	7,934
Bereavement Support Counselling	-	-	(2,066)	10,000	7,934
	136,355	19,725	(94,973)	60,000	121,107

15 Designated funds (continued)

Brineura in the Eyes - Funds received under restricted covenants to meet the costs of the GOSH Compassionate Use Programme.

Berties Helpers - a fund set up to meet the costs of the Berties Helpers programme to support families encountering difficulties by providing a special meal, also providing a special anniversary meal for bereaved families.

Orange Folder- holds funds transferred from unrestricted funds to redevelop our leaflets which are an essential resource for families.

Website reconstruction - funds designated for the development and maintenance of a new website which went live during the period under review.

Public Relations - This fund was transferred from unrestricted reserves to cover costs associated with our campaign to ensure continuing access to Brineura. Unspent sums were reallocated to the more general "Designated NICE Campaign Costs"

General Reserve - During the period €60,000 was allocated by the Trustees out of unrestricted reserves – these sums have subsequently been allocated to specific designated cost areas.

Family Events - Part of the General reserve was set aside to fund events that enabled families to come together. One such event was held during this financial period.

Strategy Away Day - Part of the General reserve was set aside to fund the annual meeting at which all staff and Trustees come together to review the status of the charity and to agree strategic direction.

Designated NICE Campaign costs - Part of the General reserve and reallocated PR reserve this fund supports our campaign to persuade NICE to enable continuing treatment of Brineura for affected children. Includes legal, PR and lobbying costs.

Bereavement Support Counselling - Part of the General reserve that has been set aside to finance two years of a new counselling programme for families suffering loss.

16 Analysis of net assets between funds

	Unrestricted funds	Designated funds	Restricted funds	Total
	£	£	£	£
Fund balances at 31 December 2025 are represented by:				
Current assets	215,048	121,107	25,418	361,573
Creditors: amounts falling due within one period	(51,280)	-	-	(51,280)
	<u>163,768</u>	<u>121,107</u>	<u>25,418</u>	<u>310,293</u>

17 Ultimate controlling party

The charity was under the control of the Trustees during the period under review.

18 Transfer of net assets and operations

On the 1st September 2024, the net assets and operations of the former Batten Disease Family Association (unincorporated charity) were transferred to the Batten Disease Family Association CIO. The net assets transferred totalled £453,100.



BATTEN DISEASE FAMILY ASSOCIATION
Together we WILL make a difference
Registered Charity in England and Wales 1205650

Batten Disease Family Association CIO
PO Box 379, Shipley, BD18 9GE

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@battendiseaseuk



@bdfabattendisease



@batten-disease-family-association



BATTEN DISEASE FAMILY ASSOCIATION CIO

England & Wales - Charity number 1205650

Accounts



Batten Disease Family Association CIO

Report and Financial Statements

**For the period
9th November 2023 - August 2024**

CONTENTS

About the Batten Disease Family Association	3
Meet the Board of Trustees	4
Trustees' Report	5
Legal and Administration Information of Batten Disease Family Association CIO	6

About the Batten Disease Family Association

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. The BDFA CIO became a registered charity on the 9th November 2023 and 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.

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.

During the period under review, the charity was incorporated but not operational. Upon the successful transition to a CIO on 1st September 2024 the following staff team members are employed:

- Liz Brownnut, 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, Family Support Partner, as a contractor

Meet the board of trustees

Upon incorporation, the following were appointed to act as trustees of the charity and were trustees throughout the period of review.

Under the rules of the constitution the trustees must retire at the first Annual General Meeting.

- Zlatko Sisic, Chair of Trustees
- Mark Thompson, Treasurer
- Bob Thompson
- Simon Sewart

Trustees' Report

Financial Review

During the period under review the BDFA CIO was incorporated but not operational. There were no financial activities and therefore no balance sheet to report.

During this period activities were focused upon establishing new banking relationships and registering with governmental and taxation authorities.

On 8th August 2024 a transfer agreement upon Incorporation was signed by BATTEN DISEASE FAMILY ASSOCIATION (BDFA) (charity number 108908) and BATTEN DISEASE FAMILY ASSOCIATION CIO (BDFA CIO) (Charity number 1205650).

Under this agreement all of the assets and liabilities of the BDFA were transferred to the BDFA CIO shortly after midnight on the 31st August 2024.

From the 1st September 2024 the activities of the charity are being undertaken by the BDFA CIO.



Nigel Nicholls
Chair of Trustees BDFA



Mark Thompson
Treasurer, BDFA

18th June 2025

Legal and Administration Information of Batten Disease Family Association CIO

Charity number	1205650	Scientific and Medical Advisers
Principal Address	PO Box 379 Shipleigh BD18 9GE	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
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	Metro Bank PLC One Southampton Row London WC1B 5HA	Dr Ruth Williams Consultant Paediatric Neurologist Evelina London Children's Hospital Westminster Bridge Road South Bank London SE1 7EH
Legal Adviser	H3 Solicitors Suite 1 The Old Pig Styes Brighthams Farm Bines Road Partridge Green West Sussex RH13 8EQ	



Batten Disease Family Association CIO
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@batten-disease-family-association