



Batten Disease Family Association CIO

Report and Financial Statements

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

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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 Brownnutt, Chief Executive Officer
- Dr Joanna Nightingale, Head of Scientific Affairs
- Lisa Forsyth, Team Admin Officer
- Mimi Petty, Peer Befriending Coordinator
- Sarah Chandler, Fundraising Assistant
- Sarah Kenrick, 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 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 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	



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