

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2024

Charity Number: 1182753



Reference and administrative information

Trustees

Andrew Hover, Chair of Trustees

Lisa Hover, Treasurer

Sarah Sillince

Sarah Horton

David Worn

Registered Office

4 Ashley Cottages, Verwood Road, Ringwood, BH242 DD

Charity Number

1182753

Bank

Barclays Bank, 6-8 High Street, Ringwood, BH24 2BZ

Report of the Trustees for the year ending 31st March 2024

The Trustees present their annual report and financial statements of the charity for the year ended 31st March 2024. The financial statements have been prepared in accordance with the charity's constitution and the Charities Act 2011.

Structure, governance and management

Batten Fighters Forever is a registered charity, number 1182753, and was constituted as a charitable incorporated organisation on 2nd April 2019.

At the Trustees' meetings, the Trustees agree the broad strategy and areas of activity for the charity, including consideration of grant making, fundraising, awareness raising, reserves and risk management policies as well as monitoring the performance of the charity. The day to day management of charity activities, including but not limited to the administration of grants and handling of grant applications prior to review by the Trustees, is delegated to the Chair of Trustees and the Treasurer.

All Trustees give of their time freely and no trustee remuneration was paid in the year. There were no trustee expenses paid in the year. Trustees are required to disclose all relevant interests, register them and in accordance with the charity's policy withdraw from decisions where a conflict of interest arises.

Changes to Trustee Board

Chris Horton resigned as a Trustee on 14th June 2024 following 5 years as a Trustee and significant contribution.

Risk Management

The Trustees have considered the major risks to which the charity is exposed, have reviewed those risks and established systems and procedures to manage those risks.

The Trustees have established a data protection policy and implemented practices to reduce exposing sensitive information of anyone supporting or being supported by the charity in line with requirements of the General Data Protection Regulations.

There were no operational risks anticipated by the Trustees for the period covered by this report. The Trustees factored expected fundraising activity into the income forecast for the year. Grant applications will only be approved by the Trustees where funds allow and without impacting the reserves policy.

Objectives and activities for the public benefit

The objects of the charity are to assist in the treatment and care of people with Batten Disease by:

1. Providing information about Batten Disease and where practical help and support can be found.
2. Raising public awareness about Batten Disease and how research into the disease and support for people with the disease, their families and carers will improve the conditions of life for people with Batten Disease.
3. Making grants to
 - a. Pay for personal care, equipment and home adaptations for people with Batten Disease
 - b. Assist in the provision of practical help, advice, support and respite care for people with Batten Disease, their families and carers
 - c. Fund research into Batten Disease and the treatment of the disease, provided the useful results of such research are published.

The charity carries out these objectives by:

1. Providing and continually developing the Batten Fighters Forever website and printed materials as resources to explain about Batten Disease and provide links to practical advice and agencies able to assist people with Batten Disease, their families and carers. Additionally, the website contains blogs, details of the charity, fundraising events and activities.
2. Utilising Facebook, Instagram and Twitter as an integrated social media programme to publish news, updates, information, campaigns, appeals and lobbying.
3. Grant making to assist families and others supporting children with Batten Disease or to support research into treatments for Batten Disease. The grant making is the primary focus of all fundraising activities.

By focussing on these areas, and with regard to the Charities Commission's public benefit guidance, the Trustees' achieve the strategic priorities of the charity.

Grant making policy

The charity has established a grant making policy to achieve its object for the public benefit to provide funds:

- To provide support to children with Batten Disease and their families

- To provide support to other charities and organisations that support children with Batten Disease and their families
- To fund research into the disease and the development of medicines for the treatment of Batten Disease

The grant making policy is reviewed annually to ensure that it reflects the charity's objects and thereby advances public benefit.

The beneficiaries of our grant making programme this year have been supported in a variety of ways including mobility aids, seizure monitoring and home adaptations.

We continue to coordinate with the Batten Disease Family Association (BDFA) both in regard to a number of family grant applications via their family support officers and also to ensure clear delineation between our grant making programme and any small grant provision by the BDFA.

The number of enquiries regarding the grant programme, submitted applications and the total value of grants awarded this year was higher than the prior year but lower than expected by the Trustees. The actual income was in line with the target set by the Trustees and the surplus of funds meant all eligible grant applications received support. We will continue to publicise the grant making programme as broadly as possible and encouraging applications from families who require support.

Achievements and Performance

For the year ending March 31st 2024 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £5,037 was just above the charity's fundraising target for the year of operating. Voluntary donations continue to be the largest source of funds.
2. A number of families have received direct support via the charity's grant programme. This has supported children this year suffering from the CLN2, CLN3 and CLN6 variants of Batten Disease across a broad age range. The grants have supported monitoring technology, mobility aids, wheelchair accessible vehicle and home adaptations.
3. The charity has also provided funds to Berties Helpers, an organisation that works alongside the BDFA to provide a grocery shop for a week for a family that have been nominated by the Batten community.
4. We continue the focus on raising awareness of Batten Disease and the support needs of people with the disease and their families.
 - a. Key metrics that we monitor for social media impact shows a mixed picture with Facebook being the primary platform for interaction:
 - i. The BFF Facebook Page reach increased by 18.7% on the prior year
 - ii. BFF Facebook Page visits increased by 73.1%
 - iii. BFF Facebook Page new likes decreased by 10.1%
 - iv. Instagram reach has increased by 202.5%
 - v. Instagram profile visits increased by 119.9%

5 Year Achievements and Performance

March 31st 2024 marks the completion of five years of operation for the charity so an appropriate milestone to summarise the achievements and performance over that time.

Over this timeframe the charity has raised £41,044 in funds from voluntary donations and events including sponsored challenges, fairs, discos and raffles. This has enabled grant provision to support

36 children across the full spectrum of Batten Disease variants and finances to support to the work of other charities that help Batten Disease families.

The charity has increased the awareness and support for Batten Disease through media locally and nationally and social media with an international reach. Over the last three years (as far back as we can report) the BFF Facebook Page has generated 1149 followers, 6700 likes or other interactions and 110,900 impressions.

Financial review

The charity's work is almost entirely reliant on income from fundraising events and voluntary donations. We had a total income of £5,037 primarily due to donation generosity. The income was just above the target for this operating year set by the Trustees. We approved grants totalling £8,948 a which was 10% lower than expected by the Trustees. £3,828 of the approved grants has been paid with £5,120 of approved grants not yet paid, as at the end of the operating period. After expenses, we have a surplus greater than that planned by the Trustees.

Reserves policy

The Trustees aim to maintain an unrestricted reserve of £1,000 for the purpose of cash flow to manage expenditures for the running of the charity. Reserves at the end of this year are slightly higher than targeted by the Trustees as a result of the surplus carried forward from the prior year and lower than target grant provision.

Plans for the future

The Trustees have set a target of £10,000 for grant awards and £5,000 for fundraising for year 6 (2024-25). This would leave a surplus of approximately £5,000-6,000 to support grant awards and activities of the charity in future years.

Trustees' responsibilities in relation to the financial statements

The Trustees are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law. Section 133 of the Charities Act 2011 allows charitable incorporated organisations in England and Wales with income of less than £250,000 per year to prepare receipts and payments accounts for each financial year.

The Trustees are responsible for keeping accounting records which disclose with reasonable accuracy the financial position of the charity and enable them to ascertain that the financial statements 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. The Trustees are responsible for the maintenance and integrity of the charity and financial information included on the charity's website.

Approved by the Trustees on 19th June 2024 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever
Statement of Financial Activities
For the year ending 31st March 2024

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2024	Total funds 2023
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	4,301	-	-	4,301	4,105
Fundraising events	736	-	-	736	190
Total Receipts	5,037	-	-	5,037	4,295
Payments					
Grants Paid	3,828	-	-	3,828	5,275
Costs of generating voluntary donations	90	-	-	90	21
Fundraising costs	112	-	-	112	107
Governance costs	-	-	-	-	-
Insurance	148	-	-	148	148
Printing, postage, stationary and computer supplies	2887	-	-	2887	727
Total Payments	4,466	-	-	4,466	6,279
Net of Receipts/ (Payments)	571	-	-	571	(1,984)
Transfers between funds	-	-	-	-	-
Cash funds last year end	15,763	-	-	15,763	17,747
Cash funds this year end	16,334	-	-	16,334	15,763

Assets and liabilities at the end of the period

Categories	Details	Unrestricted funds	Restricted funds	Endowment funds
		To the nearest £	To the nearest £	To the nearest £
Cash Funds	Barclays bank account	16,334	-	-
	Total cash funds	16,334	-	-
Liabilities	Grants approved, not yet paid (at 31 st March 2024)	5,120		
	Total current liabilities	5,120		

Approved by the Trustees on 19th June 2024 and signed on their behalf by:



A. Hover, Chair of Trustees