

BATTEN FIGHTERS FOREVER

England & Wales · Charity number 1182753

Details

Other names	BFF
Status	Registered
Legal form	CIO
Registered	2019-04-02
Register	View on the Charity Commission register

Contact

Address	4 Ashley Cottages Verwood Road Ashley Ringwood BH24 2DD
Phone	01425477316
Email	battenfightersforever@btinternet.com
Website	www.battenfightersforever.com

Activities

Objects: THE OBJECTS OF THE CIO ARE :FOR THE PUBLIC BENEFIT, THE RELIEF OF SICKNESS AND TO ASSIST IN THE TREATMENT AND CARE OF PEOPLE WITH BATTEN DISEASE, IN PARTICULAR BUT NOT EXCLUSIVELY 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 RESPIRE 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.

Activities: Batten Fighters Forever is a charity supporting people with Batten Disease by raising awareness of the disease, providing information and where practical help/ support can be found and providing grants to support families with the disease, organisations supporting such families and research into treatments.

Classification

- **How:** Makes Grants To Individuals, Makes Grants To Organisations, Provides Advocacy/advice/information
- **What:** Disability

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£14,547	£10,815	-	-
2024-03-31	£5,037	£4,466	-	-
2023-03-31	£4,295	£6,279	-	-
2022-03-31	£15,754	£8,094	-	-
2021-03-31	£7,355	£7,937	-	-

Trustees

Name	Role	Appointed
Andrew George Hover	Chair	2019-04-02
David Worn		2019-04-02
Lisa Kathleen Hover		2019-04-02
Sarah Beverley Helen Horton		2019-04-02
Sarah Louise Sillince		2019-04-02

BATTEN FIGHTERS FOREVER

England & Wales - Charity number 1182753

Accounts

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2025

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 2025

The Trustees present their annual report and financial statements of the charity for the year ended 31st March 2025. 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, home adaptations and other charities.

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 lower than the prior year and the levels expected by the Trustees. The actual income was significantly higher than 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 2025 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £14,547 was almost treble 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 CLN5 variants of Batten Disease across a broad age range. The grants have supported monitoring technology, mobility aids, wheelchair accessible vehicle and home adaptations as well as to the Berties Helpers charity enabling them to continue to support Batten Disease families.
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 and website impact shows a marked increase in interaction:
 - i. The Batten Fighters Forever website has seen significant increases in engagement – 370% in views and 320% increase in visits
 - ii. The BFF Facebook Page reach increased by 74% and interactions increasing by 53% on the prior year

Financial review

The charity's work is almost entirely reliant on income from fundraising events and voluntary donations. We had a total income of £14,547 primarily due to donation generosity. The income was almost three times the target for this operating year set by the Trustees, principally driven by the

Sassy Walk sponsored activity and fundraising events around this. We approved grants totalling £7,655 a which was 23% lower than targetted by the Trustees. £4,870 of the approved grants has been paid, £1785 granted not paid as no longer required and with £1,000 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 £20,000 for grant awards and £10,000 for fundraising for year 7 (2025-26). This would leave a surplus of approximately £8-10,000 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 12th June 2025 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever

Statement of Financial Activities

For the year ending 31st March 2025

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2025	Total funds 2024
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	11,958	-	-	11,958	4,301
Fundraising events	2,089	-	-	2,089	736
Grants	500	-	-	500	-
Total Receipts	14,547	-	-	14,547	5,037
Payments					
Grants Paid	7,990	-	-	7,990	3,828
Costs of generating voluntary donations	180	-	-	180	90
Fundraising costs	2,180	-	-	2,180	112
Governance costs	311	-	-	311	-
Insurance	154	-	-	154	148
Printing, postage, stationary and computer supplies	-	-	-	-	2887
Total Payments	10,815	-	-	10,815	4,466
Net of Receipts/ (Payments)	3,733	-	-	3,733	571
Transfers between funds	-	-	-	-	-
Cash funds last year end	16,334	-	-	16,334	15,763
Cash funds this year end	20,067	-	-	20,067	16,334

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	20,067	-	-
	Total cash funds	20,067	-	-
Liabilities	Grants approved, not yet paid (at 31 st March 2025)	1,000		
	Total current liabilities	1,000		

Approved by the Trustees on 12th June 2025 and signed on their behalf by:



A. Hover, Chair of Trustees

BATTEN FIGHTERS FOREVER

England & Wales - Charity number 1182753

Accounts

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

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

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

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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 To the nearest £	Restricted funds To the nearest £	Endowment funds To the nearest £	Total funds 2024 To the nearest £	Total funds 2023 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 To the nearest £	Restricted funds To the nearest £	Endowment funds 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

BATTEN FIGHTERS FOREVER

England & Wales - Charity number 1182753

Accounts

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2023

Charity Number: 1182753



Batten Fighters Forever

Reference and administrative information

Trustees

Andrew Hover, Chair of Trustees

Lisa Hover, Treasurer

Sarah Sillince

Sarah Horton

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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. The charity was established by the current Trustees and no Trustees have been added or removed.

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.

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 an expected reduction in 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, iPads, 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 similar to the prior year but lower than expected by the Trustees. The actual income was slightly lower than targeted by the Trustees however the surplus of funds meant no restriction to the Trustees supporting eligible grant applications. 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 2023 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £4,295 was below the charity's fundraising target for the year of operating by 14%. The income target was set at a lower level for this operating year due to the expected reduction in fundraising activities. 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 CLN3 variant of Batten Disease across a broad age range. The grants have supported monitoring technology, mobility aids and home adaptations.
3. 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 35.2% on the prior year
 - ii. BFF Facebook Page visits increased by 173.4%
 - iii. BFF Facebook Page new likes increased by 50%
 - iv. Instagram reach has decreased 40.5%
 - v. Instagram profile visits decreased 35%

Financial review

The charity's work is almost entirely reliant on income from fundraising events and voluntary donations. We had a total income of £4,295 primarily due to donation generosity. The income was 14% lower than targeted for this operating year by the Trustees. We paid grants totalling £5,275 which was 47% lower than expected by the Trustees. 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 much higher 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 5 (2023-24). This would leave a surplus of £9,000 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.

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Approved by the Trustees on 8th June 2023 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever
Statement of Financial Activities
For the year ending 31st March 2023

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2023	Total funds 2022
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	4,105	-	-	4,105	11,653
Fundraising events	190	-	-	190	4,101
Total Receipts	4,295	-	-	4,295	15,754
Payments					
Grants Paid	5,275	-	-	5,275	6,987
Costs of generating voluntary donations	21	-	-	21	110
Fundraising costs	107	-	-	107	242
Governance costs	-	-	-	-	-
Insurance	148	-	-	148	148
Printing, postage, stationary and computer supplies	727	-	-	727	606
Total Payments	6,279	-	-	6,279	8,094
Net of Receipts/ (Payments)	(1,984)	-	-	(1,984)	7,660
Transfers between funds	-	-	-	-	-
Cash funds last year end	17,747	-	-	17,747	10,087
Cash funds this year end	15,763	-	-	15,763	17,747

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	15,763	-	-
	Total cash funds	15,763	-	-

Approved by the Trustees on 8th June 2023 and signed on their behalf by:



A. Hover

Chair of Trustees

BATTEN FIGHTERS FOREVER

England & Wales - Charity number 1182753

Accounts

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2022

Charity Number: 1182753



Reference and administrative information

Trustees

Andrew Hover, Chair of Trustees

Lisa Hover, Treasurer

Sarah Sillince

Sarah Horton

Chris 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 2022

The trustees present their annual report and financial statements of the charity for the year ended 31st March 2022. 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. The charity was established by the current trustees and no trustees have been added or removed.

At the quarterly 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.

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.

Our main operational risk that was anticipated for the period covered by this report was the remaining impacts of the COVID 19 pandemic on fundraising and awareness raising opportunities. Similar to the previous year, the Trustees factored this into the income forecast for the 2021-22 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 travel equipment, mobility aids, iPads, seizure monitoring, physio equipment 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 similar to the prior year. The actual income surpassed the forecast significantly which meant no restriction to the Trustees supporting eligible grant applications. 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 2022 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £15,754 exceeded the charity's fundraising target for the year of operating by 85%. This is a great achievement. The income target was set at a level slightly higher than the prior year but still lower than original business plans due to the anticipated continued impact of the COVID 19 pandemic on fundraising. 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 CLN2, CLN3 and CLN6 variants of Batten Disease across a broad age range. The grants have supported monitoring technology, physiotherapy equipment, travel aids, mobility aids and home adaptations.
3. We continue the focus on raising awareness of Batten Disease and the support needs of people with the disease and their families.
 - a. Although the following of BFF via social media continues to grow it appears that this is becoming a more crowded space and is having less of an impact. Key metrics that we monitor demonstrate this:
 - i. The number of BFF Facebook page visits increased by 11.4% on the prior year
 - ii. New Facebook page likes has reduced by 10.2% on the prior year
 - iii. Facebook page reach has reduced by 48.4% on the prior year
 - iv. Instagram profile visits have increased 208% on the prior year
 - v. Instagram reach has increased 225% on the prior year

Financial review

The charity's work is almost entirely reliant on income from fundraising events and voluntary donations. We significantly exceeded our year 3 income target and had a total income of £15,754 due to some exceptional fundraising and donation generosity. We paid grants totalling £6,987. 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 much higher as a result of the surplus carried forward from the prior year, higher than target income 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 4 (2022-23) to recognise a reduction in fundraising activity. This would leave a surplus of £12,000 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 15th June 2022 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever
Statement of Financial Activities
For the year ending 31st March 2022

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2022	Total funds 2021
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	11,653	-	-	11,653	6,558
Fundraising events	4,101	-	-	4,101	797
Total Receipts	15,754	-	-	15,754	7,355
Payments					
Grants Paid	6,987	-	-	6,987	7,197
Costs of generating voluntary donations	110	-	-	110	71
Fundraising costs	242	-	-	242	413
Governance costs	-	-	-	-	-
Insurance	148	-	-	148	160
Printing, postage, stationary and computer supplies	606	-	-	606	96
Total Payments	8,094	-	-	8,094	7,937
Net of Receipts/ (Payments)	7,660	-	-	7,660	(582)
Transfers between funds	-	-	-	-	-
Cash funds last year end	10,087	-	-	10,087	10,669
Cash funds this year end	17,747	-	-	17,747	10,087

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	17,747	-	-
Total cash funds		17,747	-	-

Approved by the trustees on 15th June 2022 and signed on their behalf by:



A. Hover

Chair of Trustees

BATTEN FIGHTERS FOREVER

England & Wales - Charity number 1182753

Accounts

Batten Fighters Forever
Trustee Report and Financial Statements
Year Ended 31st March 2021

Charity Number: 1182753



Reference and administrative information

Trustees

Andrew Hover, Chair of Trustees

Lisa Hover, Treasurer

Sarah Sillince

Sarah Horton

Chris Horton

David Worn

Registered Office

4 Ashley Cottages, Verwood Road, Ringwood, BH24 2DD

Charity Number

1182753

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

Report of the trustees for the year ending 31st March 2021

The trustees present their annual report and financial statements of the charity for the year ended 31st March 2021. 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. The charity was established by the current trustees and no trustees have been added or removed.

At the quarterly 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.

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.

Our main operational risk for the forthcoming period will be the remaining impacts of the COVID 19 pandemic on fundraising and awareness raising opportunities. The Trustees reduced the income forecast in the charity's business plan for the 2020-21 year to recognise the number of planned fundraising events that had to be cancelled. Thankfully this reduced forecast was exceeded but income was 55% lower than the prior year. As the UK recovers from the pandemic, we are hopeful that we are able to organise more fundraising events this year however do not anticipate a completely normal year – the Trustees have again factored this into the income forecast for the 2021-22 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, iPads, 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. We have supported the BDFA with funds to update and produce information folders issued to families with Batten Disease.

The number of enquiries regarding the grant programme increased significantly and the number of submitted applications increased by 50% compared to the prior year. The total value of grants awarded this year was similar to the prior year. The drop in income did not prevent the Trustees supporting all grant applications that were submitted. 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 2021 the following provides a summary of achievements and performance of the charity:

1. Funds raised totalling £7,355 exceeded the charity's fundraising target for the year of operating by 47%. The income target was reduced significantly by the Trustees to account for the impact of the COVID 19 pandemic. 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 CLN1, CLN2, CLN3 and CLN6 variants of Batten Disease across a broad age range. The grants have supported equipment purchases, mobility aids and home adaptations.
3. Progress has been made with raising awareness of Batten Disease and the support needs of people with the disease and their families.
 - a. The already fairly large following of BFF on social media has grown over the year. Facebook continues to be the medium that provides the most opportunities for interaction and has seen the most activity. Key metrics that we monitor demonstrate this:
 - i. number of people following the page has grown by 9% (increase prior year was 7%)
 - ii. number of people liking the page has grown by 8% (6% prior year)

Financial review

The charity's work is entirely reliant on income from fundraising events and voluntary donations. We exceeded our year 2 income target and had a total income of £7,355. We paid grants totalling £7,197. 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 much higher as a result of the surplus carried forward from the prior year, higher than target income and lower than target grant provision. The trustees, however, believe that the target reserve of £1000 is appropriate and will aim to maintain this into next year.

Plans for the future

Our income target for year 2 (2020-21) was adjusted to £5,000 in our business plan to reflect the anticipated impact of the COVID 19 pandemic on our fundraising activities. The income target for year 3 has been adjusted to £8,500 to recognise the easing of restrictions due to the pandemic and to provide a target for diversification of our income channels. We will be focussing on attracting more regular voluntary donors and donations from the commercial sector, not for profit organisations, trusts and foundations.

In the next 12 months we plan to attract grant applications to consume the available funds while maintaining our target reserve.

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 8th June 2021 and signed on their behalf by:



A. Hover

Chair of Trustees

Batten Fighters Forever
Statement of Financial Activities
For the year ending 31st March 2020

Receipts and Payments

	Unrestricted funds	Restricted funds	Endowment funds	Total funds 2021	Total funds 2020
	To the nearest £	To the nearest £	To the nearest £	To the nearest £	To the nearest £
Receipts					
Voluntary donations	6,558	-	-	6,558	12,988
Fundraising events	797	-	-	797	3,275
Total Receipts	7,355	-	-	7,355	16,263
Payments					
Grants Paid	7,197	-	-	7,197	4,045
Costs of generating voluntary donations	71	-	-	71	1,242
Fundraising costs	413	-	-	413	686
Governance costs	-	-	-	-	590
Insurance	160	-	-	160	160
Printing, postage, stationary and computer supplies	96	-	-	96	84
Total Payments	7,937	-	-	7,937	6,807
Net of Receipts/ (Payments)	(582)	-	-	(582)	9,456
Transfers between funds	-	-	-	-	-
Cash funds last year end	10,669	-	-	10,669	1,213
Cash funds this year end	10,087	-	-	10,087	10,669

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	10,087	-	-
	Total cash funds	10,087	-	-

Approved by the trustees on 8th June 2021 and signed on their behalf by:



A. Hover

Chair of Trustees