



BATTEN DISEASE FAMILY ASSOCIATION

Together we WILL make a difference

Registered Charity In England and Wales 1084908 - Scotland SC047408



ANNUAL REPORT 2019/2020



REMEMBERING...

**all of the precious children,
young people and adults we have lost
during this year and all those families
in our bereaved community.**

About Batten Disease Family Association

ABOUT BATTEN DISEASE

Batten disease, or Neuronal Ceroid Lipofuscinosis (NCL), is a family of rare diseases caused by autosomal recessive genetic mutations. It is a lysosomal storage disorder and these genetic mutations disrupt the cells' ability to dispose of 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 two-four births per 100,000 in the UK are affected by Batten disease, though some researchers in the field suggest these numbers are low.

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.

PUBLIC BENEFIT

The Trustees have referred to the Charity Commission guidance on public benefit and used this to help them plan current and future activities.

STRUCTURE, GOVERNANCE AND MANAGEMENT

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. The strategy and oversight of the BDFA are directed by the Trustees. The day-to-day management is delegated to the Chief Executive. Samantha Barber was acting Chief Executive until December 2019 and Amanda Mortensen became Chief Executive in February 2020.

Other members of the team during this year were Wendy Thompson and Cathy McSweeney, both family support workers on 0.5 FTE working in the North and South of England. The BDFA also part-funds the Batten Clinical Nurse specialist at Great Ormond Street Hospital (GOSH) who we work closely with. Laura Lee worked with us for most of this year and Becky Bower has supported us since May 2020 when Laura went on maternity leave. Lisa Forsyth has worked tirelessly in the office to support us.

HR is outsourced to Peninsula Business Services. The Board of Trustees meets at least six times a year with the CEO and members of the staff team to review and formulate strategy. The Board has met monthly since the start of the COVID-19 pandemic in March. We are committed to attracting a diverse range of trustees.

RESERVES POLICY

It is the Board's policy that ideally six to 12 months of operating costs should be set aside as reserves. This is an ambitious target but it is felt necessary given the current uncertainties around the COVID-19 pandemic. The charity has met this ambition this year.

The charity had free reserves of six months at the year end and the Trustees are confident that the improving situation of the past year will continue.



Chair & CEO Report



Pauline Docherty
Acting Chair of Trustees



Zlatko Sisic
Chair of Trustees



Amanda Mortensen
CEO

It has been a very positive year at the BDFA. The charity has stabilised further and is now able to grow to meet the needs of families with Batten disease in the UK.

During this year we have supported 104 families across the UK, with 12 new diagnoses. Late infantile (CLN2) and Juvenile (CLN3) continue to be the most prevalent types of Batten disease. Sadly, eight children, young people and young adults have passed away this year.

One of the major highlights of the year was achieving access to Brineura®, the only treatment for Batten disease. Brineura®, an enzyme replacement therapy (ERT), is a treatment for children with late infantile (CLN2) Batten disease. This was a protracted and very challenging process and the BDFA worked with a range of stakeholders, including families and MPs, to successfully manage the process through NICE's (National Institute of Clinical Excellence) highly specialised technology route. Agreement was reached to provide Brineura® under a managed access agreement (MAA) for a period of five years until September 2024 when it will be reviewed again. Shortly after year end, Brineura® was also approved for use in Scotland. There are several other treatments in the 'pipeline' for several different types of Batten disease and supporting families to access treatments for their children and young people is a key role for the BDFA.

Unsurprisingly, COVID-19 has dominated this year and the BDFA team has worked hard to meet the challenge of supporting families through this unparalleled time. Our interim CEO Samantha Barber left the BDFA in December 2019 and we are very grateful for her

stewardship. Amanda Mortensen, previously Chair, took up the post in February, shortly before the pandemic hit. Families who have children with Batten disease have been disproportionately affected by the pandemic. The majority have shielded and families have had to cope with a new diagnosis and losing a child during lockdown.

The BDFA has proactively put in additional support through this period. The charity ran a programme of support including weekly 'virtual cuppas' (supported by a counsellor), webinars, specialist 'masterclasses' on issues such as epilepsy and financial support with emergency hardship and wellbeing grants.

After a challenging period in 2018, during which we cut operating costs by 50 per cent, the charity is now starting to build back up for a sustainable future. The Board is very pleased to have financial stability. Our accounts show a surplus of £38,738 in respect of unrestricted reserves in the year but a small overall deficit for the year of £4,767 after the movement on restricted funds. Total unrestricted reserves are £103,724.

Since the start of the pandemic, we have successfully attracted funding from new funders and with a new Head of Fundraising newly in post (at the time of writing), we are positive we can successfully diversify our income going forward. The charity has been particularly successful with funding pots targeted at supporting the most disadvantaged through the pandemic.

Shortly after year end, the BDFA received a large grant from the National Lottery. The future fundraising

landscape will be demanding and we need to carefully plan going forward and look to collaborate with others where appropriate.

The Board is strengthened by new trustees who have essential expertise to take the BDFA forward, including trustees leading on fundraising, medical and scientific strategy and an experienced treasurer with a background in accountancy. We continue to be led by families and 60 per cent of our Board are parents of children with Batten disease. Roger Cole stepped down after four years of service and we are very grateful for all his hard work.

Our new scientific and medical lead, Dr Zlatko Sisic, has been instrumental in helping the BDFA to start a collaboration with the leading experts in Batten disease across the UK. This expert group, which met for the first time just before year end, will advise on projects such as the need to reduce the diagnostic odyssey and development of clinical pathways, disease assessment tools and management Guidelines for Batten disease. At the time of writing, Dr Zlatko Sisic has taken up the post of Chair of Trustees.

Shortly after year end the charity was able to restart its research function. In partnership with families, the BDFA is raising money for a compassionate use programme in The Eyes at Great Ormond Street Hospital (GOSH). This programme is for children with CLN2 Batten disease who are already accessing Brineura®. The BDFA is focused on supporting research for all types of Batten disease going forward.

It has been a very positive year for the BDFA and we are focused on offering the very best support, information and advocacy for families as we move forward in this post COVID-19 landscape.

Pauline Docherty, Acting Chair of Trustees
Zlatko Sisic, Chair of Trustees (from November 2020)
Amanda Mortensen, CEO (from February 2020)

1 September 2019 to 3 August 2020

Roger Cole
(stepped down 21 November 2020)

Cath Sermon
(re-appointed 21 November 2020)

Neil Dunford
(re-appointed 21 November 2020)

Richard Whitbread, Treasurer
(co-opted February 2020, appointed
21 November 2020)

Gareth Holmes, Fundraising Lead
(co-opted February 2020, appointed
21 November 2020)

Zlatko Sisic, Medical and Scientific Lead
(appointed 21 November 2020)

Bob Thompson
(appointed 21 November 2020)

Simon Sewart
(appointed 21 November 2020)

Pauline Docherty
Acting Chair from December 2019
(re-appointed 21 November 2020)

Amanda Mortensen
(stepped down as Chair December 2019,
taking up the role of CEO in February 2020)

Charity registration number 1084908
OSCR number SCO47408



Family Story



THE CLARKE FAMILY FROM SWINDON

Addy Clarke, four, is newly diagnosed with CLN2 Batten disease and accesses Brineura® at Great Ormond Street Hospital twice a month.

“When the paediatrician first uttered the words, Batten disease, life changed in a moment and there was no going back. Our daughter, our precious little girl.... my husband broke down and said: ‘we’re going to have to bury our own child.’”

“The enormity of the diagnosis has been carried on the shoulders of our family, friends, GOSH and the BDFA. We will not ever be able to express how grateful we are to the BDFA for the financial support, for the research and communication with specialists about trials and new treatments and opportunities to connect with other families who are becoming friends and this is only the start of our journey!”

Trustee's Report

OUR MISSION

Our 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 WORK THIS YEAR

SUPPORTING ACCESS TO TREATMENT

As the only patient organisation for Batten disease in the UK, we play a crucial role in supporting families to access treatments. There is one treatment available for CLN2 Batten disease, Brineura® and other treatments in development for other types of Batten disease. The charity works closely with other stakeholders, including pharmaceutical companies, to ensure our families in the UK have equal opportunities to access clinical trials.

CONNECTING WITH OUR COMMUNITY

The BDFA has a strong community of families and COVID-19 has brought families closer together. It ran weekly meetings with families supported by a counsellor (virtual cuppas) and over 50 per cent of our families have attended these. Our COVID-19 family grant scheme provided hardship and wellbeing grants to families and we were able to give grants to 51 families throughout the year. We ran specialist webinars on upcoming treatments, COVID-19 and epilepsy which have been well received by families.

SUPPORT AND ADVOCACY

Support and advocacy are at the core of our work. During this year, our support workers Wendy Thompson and Cathy McSweeney have worked closely with a range of professionals, including school teams, paediatricians, GPs, hospices, educational psychologists, residential care staff, specialist VI teachers and therapists. Barbara Cole, our voluntary lead on education matters, has worked tirelessly through the year to support families. We are very grateful for the



team's hard work and would like to mark our thanks to Wendy, Cathy and Barbara.

The BDFA has also worked closely with Sarah Kenrick, Seeability's Outreach Liaison Nurse CLN3, who is an expert in Batten disease having managed Heather House, the residential home that has looked after young people and adults with Batten disease, for many years. As well as supporting families, our support workers run training sessions for school staff and other professionals, support parents at meetings, input to Education, Health and Care Plans and support with DLA and PIP claims.

The BDFA's response to COVID-19 has involved specialist webinars, our weekly meetings and our family emergency grant scheme. Our families have been disproportionately affected by COVID-19 and most have been shielding.

OUR CLINICAL NURSE SPECIALIST AT GREAT ORMOND STREET HOSPITAL

The BDFA jointly funds a clinical nurse specialist (CNS) at Great Ormond Street Hospital (GOSH). This is a vital role and the CNS is able to assist the 19 children who access Brineura® at GOSH twice a month. The CNS also has a wider role across the Batten community.

"Support and advice is so important for all families, even more so for those with a rare disease that at times other professionals have never heard of," says CNS Rebecca Bower, pictured here on Batten Disease Awareness Day with a family and other GOSH staff. "My role enables me to offer that support to not only families of patients seen at GOSH but any other young person in the UK with a diagnosis of Batten disease."

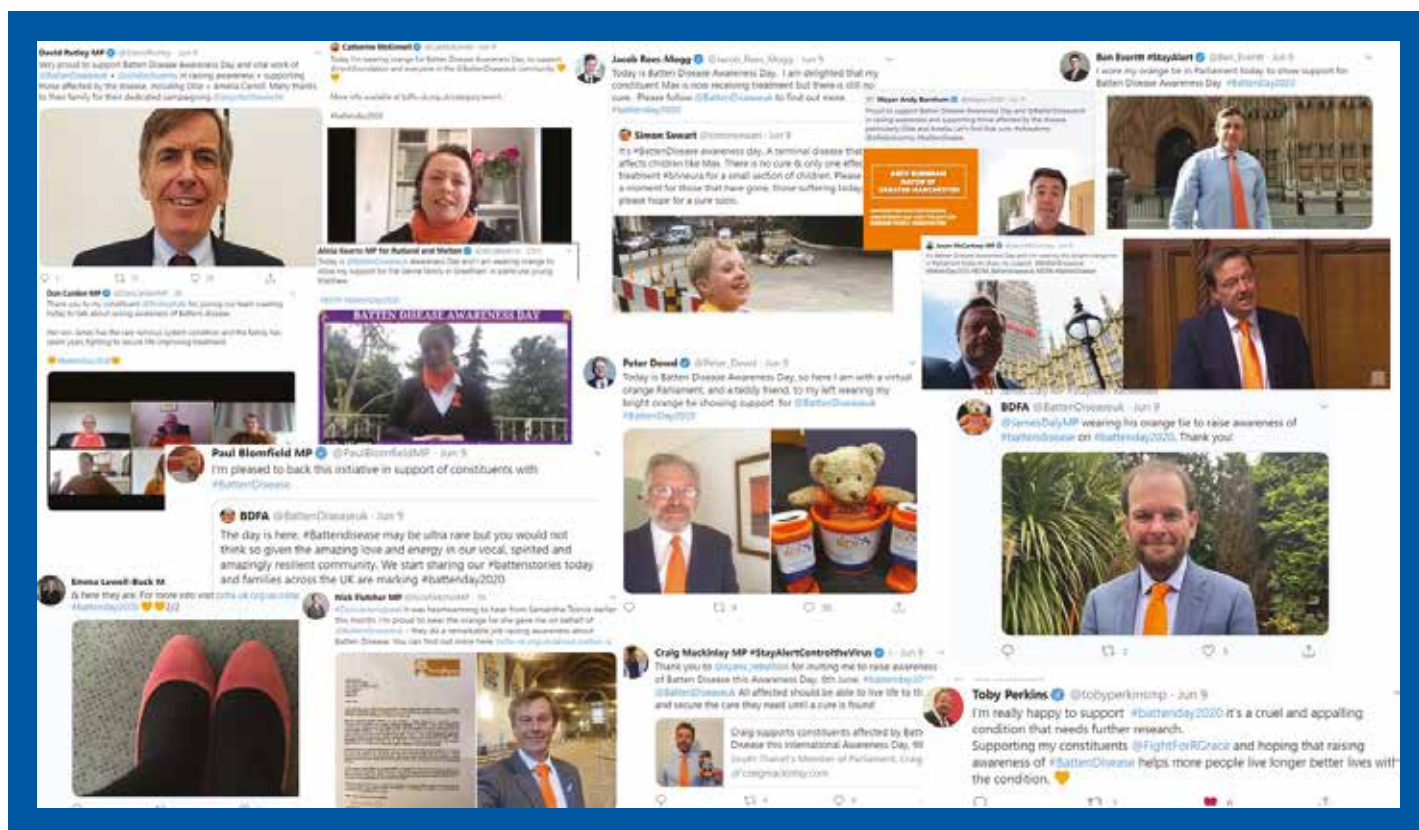


SPEAKING UP FOR BATTEN DISEASE

The BDFA also plays a key role increasing awareness of Batten disease. We ran a successful campaign on Batten Disease Awareness Day in June and 16 MPs wore orange on the day. Families shared their stories on the day for our storytelling project.

NETWORKS AND COLLABORATIONS

The BDFA is part of several networks and collaborations. A key collaboration is the LSD collaborative which is a group of charities that all support families affected by a lysosomal storage disorder. Other networks include membership of Together For Short Lives, The Neurological Alliance, Genetic Alliance, the Disabled Children's Partnership and the Specialised Healthcare Alliance. The BDFA has recently joined a new complex needs coalition led by the national charity SENSE.



THE MAYPOLE PROJECT

The counselling charity The Maypole Project has worked with the BDFA for over five years and this partnership will be strengthened as we move forward, supporting our families with emotional support and hosting our Sibling Sanctuary project.

The Amber Trust Music for Blind Children

We also work closely with The Amber Trust, a charity dedicated to supporting visually impaired children with their musical development and education. The charity's With Music in Mind service launched shortly after year end, a programme specifically designed for our Batten community and others with neurodegenerative conditions.



“I can't wait for the next Zoom. It's so good to know that I have so many new friends now and they know what I'm going through. I feel as if we are one big new family”



A PARENT WHO IS SUPPORTED WEEKLY BY A TRANSLATOR ON OUR VIRTUAL CUPPAS



OUR PLANNED ACTIVITIES FOR THE NEXT YEAR:

Our families' financial wellbeing is vital to their ability to thrive. The BDFA will support families by re-establishing our small grant scheme, focusing on families with a new diagnosis, families facing severe financial hardship and families who need support with funeral and memorial costs.

Our families' wider wellbeing is affected when a child is diagnosed with Batten disease.

Sibling Sanctuary, a new project to support siblings of children with Batten disease, will recognise the impact on siblings and give them a safe space to connect. We carried out a COVID-19 sibling survey and 70 per cent of siblings surveyed told us they were doing more care in lockdown.

Our families' mental wellbeing is essential to their ability to cope with the challenges that Batten disease brings. A new project offering 1:1 counselling in partnership with The Maypole Project organisation that knows our families well will support families from the point of diagnosis and through their journey.

Our families seek hope in the form of research into Batten disease and new treatments. We continue to support our families with access to treatments, having restarted our research function and continue to raise money for research into all types of Batten disease. As part of this work, the BDFA is working with key professionals on a campaign around reducing the time to diagnosis as children are still diagnosed years after first symptoms. This is particularly pressing for children with CLN2 as there is now a life-changing treatment.

Our families need a sustainable organisation for the future. The BDFA will focus on strengthening its infrastructure and ability to meet the needs of our community.



Family Story



THE DODKIN FAMILY FROM WISBECH

The Dodkin family have three boys. Finley, 10, and Harrison, five, have CLN3 Batten disease and their middle child Arthur, seven, is unaffected. The Dodkin family run a family foundation Pedal4Memories.

“Since lockdown began, the BDFA have given us the most wonderful gift and that is an extended family and friends that we know will be part of our lives forever. The virtual cuppas and vines opened up a new avenue of communication between Batten families and this has been the most wonderful thing and has started some very special friendships. We have laughed, cried, supported and opened up to each other and as well as the friendship this has given, the BDFA have worked hard to give us the opportunities to learn, ask and discover new information that has made us feel stronger and more informed as parents. The BDFA also worked so hard to make Awareness Day fun and inclusive and it was a very special and heartwarming day as well as raising such a huge amount of awareness. Thursday mornings will never feel complete again without our 10am cuppa. Thank you to the wonderful staff at the BDFA, you mean such a lot to us all.”

Thank You to our Funders

The BDFA is very grateful to all the many community funders who tirelessly raise money throughout the year (until year end August 2020).

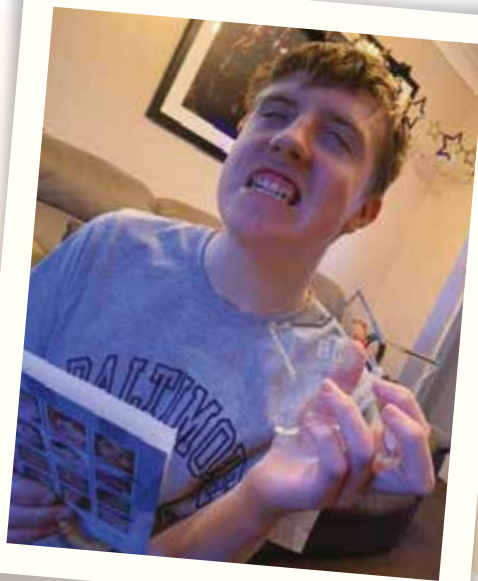
CAF (Charities Aid Foundation)
52 Lives
The Fore Raft Fund
ICE Clear Finance
Steel Trust
The February Foundation
Batten Fighters Forever
The Blyth Watson Charitable Trust
Pedal4Memories
Manchester Guardian Society
The Edward Gostling Foundation

PARTNERSHIPS

Beefy's Foundation
BMS Insurance

A special thanks also to **Mike O'Connor**, our previous Chair and a father, who raised over **£70,000** this year in his mission to raise a total of £1,000,000 since he became involved with the BDFA.

A special mention to Ryan Buggins, 15, who has CLN3 Batten disease. Ryan walked every day through August and raised almost £2,000. WHAT A SUPERSTAR!



“The work you guys do at the BDFA really is incredible and hopefully the money will go some way to supporting that”

A FUNDER





“Helpful, attentive and supportive. My life would have been so much harder without you!”

A PARENT



Legal and Administration Information of Batten Disease Family Association

Charity number	1084908	Scientific and Medical Advisers
OSCR number	SCO47408	Professor Sara Mole Professor in Molecular Cell Biology, UCL Great Ormond Street Hospital Children's Charity Professor MRC Laboratory for Molecular Cell Biology University College London Gower Street London WC1E 6BT
Principal Address	209-211 City Road London EC1V 1JN	
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	The Co-Operative Bank 70-72 Cross Street Manchester M2 4JG Santander Bank Bootle Merseyside L30 4GB	Dr Ruth Williams Consultant Paediatric Neurologist Evelina London Children's Hospital Westminster Bridge Road South Bank, London SE1 7EH

Statement of Trustee Responsibilities of Batten Disease Family Association

The Charities Act 2011 requires the Trustees to prepare accounts for each financial year which give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including the income and expenditure, of the charity for that year.

In preparing these accounts, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP;
- make judgements and estimates that are reasonable and prudent; and
- prepare the accounts on the going concern basis unless it is inappropriate to presume that the charity will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charity and enable them to ensure that the accounts comply with the Charities Act 2011. They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Independent Examiner's Report to the Trustees of Batten Disease Family Association

I report to the charity Trustees on my examination of the accounts of the charity for the year ended 31 August 2020.

Responsibilities and basis of report

As the Trustees of the charity you are responsible for the preparation of the accounts in accordance with the requirements of the Charities and Trustee Investment (Scotland) Act 2005 ('the 2005 Act'), the Charities Accounts (Scotland) Regulations 2006 (as amended) ('the 2006 Act') and the Charities Act 2011 ('the 2011 Act'). You are satisfied that your charity is not required by charity law to be audited and have chosen instead to have an independent examination.

I report in respect of my examination of the charity's accounts as carried out under section 44 (1) (c) of the 2005 Act and section 145 of the 2011 Act. In carrying out my examination I have followed the requirements of Regulation 11 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and the applicable Directions given by the Charity Commission under section 145(5)(b) of the 2011 Act.

Independent examiner's statement

Since the charity's gross income exceeded £250,000 your examiner must be a member of a body listed in section 145 of the 2011 Act. I confirm that I am qualified to undertake the examination because I am a member of the association of Certified Chartered Accountants, which is one of the listed bodies.

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

1. accounting records were not kept in respect of the charity as required by section 386 of the 2006 Act; or
2. the accounts do not accord with those records; or
3. the accounts do not comply with the accounting requirements of section 396 of the 2006 Act 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; or
4. the accounts have not been prepared in accordance with the methods and principles of the Statement of Recommended Practice for accounting and reporting by charities applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102).

I have no concerns and have come across no other matters in connection with the examination to which attention should be drawn in this report in order to enable a proper understanding of the accounts to be reached.

TC Group

Mr Mark Cummins FCCA, FCIE

On behalf of TC Group

The Courtyard, Shoreham Road
Upper Beeding, Steyning
West Sussex
BN44 3TN

Dated: 7 April 2021

Statement of Financial Activities

FOR THE YEAR ENDED 31 AUGUST 2020

	Notes	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2020 (£)	TOTAL 2019 (£)
INCOME FROM:					
Donations and legacies	2	81,180	32,442	113,622	133,140
Other trading activities	3	160,723	-	160,723	240,621
Investments	4	62	-	62	65
Total income		241,965	32,442	274,407	373,826
EXPENDITURE ON:					
Raising funds		45,627	-	45,627	60,397
Charitable activities		179,734	53,813	233,547	219,382
Total expenditure	5	225,361	53,813	279,174	279,779
Net income/(expenditure)		16,604	(21,371)	(4,767)	94,047
Transfers between funds	13	22,134	(22,134)	-	-
Net movement in funds		38,738	(43,505)	(4,767)	94,047
Fund balances at 1 September 2019		64,986	118,594	183,580	89,533
Fund balances at 31 August 2020		103,724	75,089	178,813	183,580

The notes on page 18 to 26 form part of these accounts.

All income and expenditure shown above relate to continuing activities.

Balance Sheet

FOR THE YEAR ENDED 31 AUGUST 2020

	Notes	2020		2019	
		(£)	(£)	(£)	(£)
CURRENT ASSETS					
Stock	10	1,000		2,200	
Debtors		2,720		7,593	
Cash at bank and in hand		244,634		236,952	
		248,354		246,745	
Creditors: amounts falling due within one year	11	(69,541)		(63,165)	
Net current assets			178,813		183,580
Total net assets			178,813		183,580
INCOME FUNDS					
Restricted funds	13		75,089		118,594
Unrestricted income funds			103,724		64,986
			178,813		183,580

The accounts were approved by the Board on 7 April 2021.



Zlatko Sisic
Chair of Trustees

The notes on page 18 to 26 form part of these accounts.

Notes to the Accounts

FOR THE YEAR ENDED 31 AUGUST 2020

1. Accounting policies

1.1 Basis of preparation

The accounts have been prepared in accordance with Accounting and Reporting by the Charities Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) - (Charities SORP (FRS 102)), the Financial Reporting Standard applicable in the UK and Republic of Ireland and the Charities Accounts (Scotland) Regulation 2006 (as amended).

Batten Disease Family Association meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s). In accordance with Section 7 of FRS 102 the charity is claiming exemption from the requirement to prepare a cash flow statement on account of its size.

The financial statements are prepared in Sterling which is the functional currency of the charity and rounded to the nearest £1.

1.2 Going concern

After making appropriate enquiries, the Trustees have a reasonable expectation that the Association has adequate resources to continue in operational existence for the foreseeable future. This includes considering the impact of the COVID-19 pandemic on the income generation of the charity. For this reason they continue to adopt the going concern basis in preparing the financial statements.

1.3 Income

Voluntary income including donations and legacies is recognised where there is entitlement, certainty of receipt and the amount can be measured with sufficient reliability.

Incoming resources from tax reclaims are included in the SoFA at the same time as the gift to which they relate.

Merchandise income is recognised as earned (that is, as the related goods or services are provided). Investment income is recognised on a receivable basis.

There has been no offsetting of assets and liabilities, or income and expenses, unless required or permitted by the FRS 102 SORP or FRS 102.

Grants and donations are only included in the SoFA when the general income recognition criteria are met (5.10 to 5.12 FRS 102 SORP).

Gift Aid receivable is included in income when there is a valid declaration from the donor. Any Gift Aid amount recovered on a donation is considered to be part of that gift and is treated as an addition to the same fund as the initial donation unless the donor or the terms of the appeal have specified otherwise.

1.4 Expenditure

Liabilities are recognised as soon as there is a legal or constructive obligation committing the charity to the expenditure. All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs to the category.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

Costs of raising funds comprise the costs associated with attracting voluntary income and the costs of trading for fundraising purposes.

Charitable expenditure comprises those costs incurred by the charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Grants payable are payments made to third parties in the furtherance of the charitable objectives. Where the charity gives a grant with conditions for its payments being a specific level of service or output to be provided, such grants are only recognised in the SoFA once the recipient of the grant has provided the specific service or output. Grants payable without performance conditions are only recognised in the accounts when a commitment has been made and there are no conditions to be met relating to the grant which remain in the control of the charity.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing of the grant or the amount of grant payable. Governance costs include costs for the preparation and examination of the statutory accounts, the costs of trustee meetings and the cost of any legal advice to the trustee on governance or constitutional matters.

Support costs include central functions and have been allocated to charitable activities or fundraising expenses on a basis consistent with the use of resources, for example staff costs by the time spent and other costs by their usage. Research and development expenditure is written off as incurred.

1.5 Stocks

Stocks are stated at the lower of cost or residual value.

1.6 Debtors

Trade and other debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

1.7 Cash at bank and in hand

Cash at bank and in hand includes cash and short-term highly liquid investments. The Trustees seek to use short- and medium-term deposits where possible to maximise the return on monies held at the bank and to manage cash flow.

1.8 Financial instruments

The charity only has financial assets and financial liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value.

1.9 Creditors and provisions

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

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

1.10 Pensions

The charity operates a defined contribution pension scheme. Contributions are charged in the statement of financial activities as they become payable in accordance with the rules of the scheme.

1.11 Operating leases

Rentals payable under operating leases are charged in the statement of financial activities on a straight line basis over the lease term.

1.12 Accumulated funds

Funds held by the charity are either:

Designated funds – the Trustees have identified that certain activities need to be undertaken to widen the support to families and plan to create designated funds to hold the monies to enable the re-instatement of funding for research and other activities, but which remain under the ultimate control of the Trustees.

Unrestricted general funds – these are funds which can be used in accordance with the charitable objects at the discretion of the Trustees. The Trustees have considered the level of free reserves held at the year end. Ideally they would like this to be between six and 12 months of unrestricted costs. They're currently achieving just over six months, a slight reduction on the figure for the prior year.

Restricted funds – Donations, bequests or incoming resources which the donor has earmarked for a specific purpose are treated as restricted funds.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

1.13 Taxation

The charitable company is registered as a charity and all of its income falls within the exemptions under Part 11 of the Corporation Tax Act 2010.

2 Voluntary income

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2020 (£)	TOTAL 2019 (£)
DONATIONS				
Regular monthly donations	4,644	-	4,644	5,434
Donations gift aid	946	-	946	9,098
Donations non gift aid	35	-	35	6,587
Charitable giving	-	32,442	32,442	65,061
Memberships	15	-	15	-
Donations – organisations and schools	3,500	-	3,500	6,125
Foundations and trusts not restricted	47,627	-	47,627	36,591
Hey Charlie	-	-	-	5
Great North Run	11,007	-	11,007	1,255
	67,774	32,442	100,216	130,156
IN MEMORIAM DONATIONS				
In memoriam	13,406	-	13,406	2,984
	81,180	32,442	113,622	133,140

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

3 Other trading activities

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2020 (£)	TOTAL 2019 (£)
FUNDRAISING				
Supporter fundraising	154,686	-	154,686	104,337
Collection boxes	25	-	25	-
Fundraising activities	4,857	-	4,857	135,341
	159,568	-	159,568	239,678
MERCHANDISE INCOME				
Merchandise sales	1,155	-	1,155	943
	160,723	-	160,723	240,621

4 Investment income

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2020 (£)	TOTAL 2019 (£)
INVESTMENT INCOME				
Interest income	62	-	62	65

5 Total expenditure

	STAFF COSTS (£)	OTHER COSTS (£)	TOTAL 2020 (£)	TOTAL 2019 (£)
COSTS OF RAISING FUNDS				
Fundraising costs	12,161	31,721	43,882	46,887
Merchandise costs	-	1,745	1,745	13,510
	12,161	33,466	45,627	60,397
CHARITABLE ACTIVITIES				
Activities undertaken directly	8,107	136,816	144,923	146,957
Support costs	51,049	37,575	88,624	75,425
	59,156	174,391	233,547	219,382
Total expenditure	71,317	207,857	279,174	279,779

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

6 Support costs – other

	TOTAL 2020 (£)	TOTAL 2019 (£)
OTHER COSTS:		
Rent	5,762	8,158
Premises expenses	-	425
Postage, freight and courier	562	75
Telephone	423	1,545
Computer, software and IT support	12,342	2,969
Office equipment	1,510	47
Insurance	1,402	1,396
Organisational membership and legal and professional fees	888	7,527
Accountancy fees	7,700	8,980
Bookkeeping	4,024	4,171
Bank charges	26	39
Recruitment expenses	395	701
Staff training	307	300
Website costs	86	-
HR	1,435	2,990
Trustee costs	713	549
	37,575	39,872

These costs include amounts payable to the independent examiners of £7,700 (2019: £8,980) for independent examination and other services.

7 Trustees

The Trustees were reimbursed £713 to three Trustees (2019: £549 to one Trustee) for travel and fundraising costs during the year. None of the Trustees (or any persons connected with them) received any remuneration during the year or previous year.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2019

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2019 (£)
INCOME FROM:			
Donations and legacies	68,079	65,061	133,140
Other trading activities	149,171	91,450	240,621
Investments	65	-	65
Total income	217,315	156,511	373,826
EXPENDITURE ON:			
Raising funds	31,598	28,799	60,397
Charitable activities	98,529	120,853	219,382
Total expenditure	130,127	149,652	279,779
Net income/(expenditure)	87,188	6,859	94,097
Transfers between funds	5,669	(5,669)	-
Net movement in funds	92,857	1,190	94,097
Fund balances at 1 September 2018	(27,871)	117,404	89,533
Fund balances at 31 August 2019	64,986	118,594	183,580

9 Employees

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

	TOTAL 2020	TOTAL 2019
Scientific Officer (until May 2019)	-	0.5
Charitable activities	1	1
Advocacy	1	1
	2	2.5

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

EMPLOYMENT COSTS	TOTAL 2020 (£)	TOTAL 2019 (£)
Wages and salaries	66,542	111,170
Social security costs	3,375	8,618
Pension costs	1,400	3,405
Total expenditure	71,317	123,193

There were no employees earning more than £60,000 in the current or previous year.

The key management personnel of the charity comprises of the Chief Executive Officer (S Barber until 31 December 2019 and A Mortensen from 1 February 2020 to date). The total aggregate employee benefits paid during the year were £40,537 (2019: £61,556).

None of the Trustees received any remuneration or other benefits from the charity or any connected body. The Trustees had great assistance during the year from a number of volunteers including the Education Advisor and we thank them for their valued but financially unrecognised contributions.

10 Debtors

	TOTAL 2020 (£)	TOTAL 2019 (£)
Trade debtors	-	7,593
Prepayments and accrued income	2,720	-
	2,720	7,593

11 Creditors: amounts falling due within one year

	TOTAL 2020 (£)	TOTAL 2019 (£)
Trade creditors	10,244	18,096
Other creditors	52,337	39,736
Accruals	5,697	3,128
Taxes and social security	1,263	2,205
	69,541	63,165

12 Pension scheme

Defined contribution pension scheme

The charity operates a defined contribution pension scheme. The pension cost charge for the period represents contributions payable by the charity to the scheme and amounted to £1,400 (2019: £3,405).

Contributions totalling £321 (2019: £352) were payable to the scheme at the end of the period and are included in creditors.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

13 Restricted funds

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

	BALANCE AT 1 SEPTEMBER 2019	INCOME	EXPENDITURE	TRANSFERS BETWEEN FUNDS	BALANCE AT 31 AUGUST 2020
Euro Ed Project	4,031	-	(1,540)	-	2,491
Battle Batten CLN5	7,045	-	(7,000)	-	45
In Memory of Katie Freeman	3,570	-	-	-	3,570
Olivacce CLN3	2,479	-	-	-	2,479
Beefy's Foundation	40,000	-	(40,000)	-	-
Ollie's Army	7,000	-	-	-	7,000
McFarland	5,085	-	-	-	5,085
Fundraising and database (BioMarin)	17,250	2,108	(780)	-	18,578
Scotland (BioMarin)	28,134	-	-	(28,134)	-
Gene Therapy Day	4,000	-	-	-	4,000
Schools Contract (QMU BioMarin)	-	10,334	(4,493)	-	5,841
Brineura® Travel Costs (BioMarin)	-	20,000	-	6,000	26,000
	118,594	32,442	(53,813)	(22,134)	75,089

- Euro Ed Project is a Europe-wide education project focused on CLN3.
- Battle Batten fund is for CLN5 Batten disease research to identify key differences in cells in CLN5 patients and healthy unaffected cells.
- In memory of Katie Freeman is for CLN2 research.
- Olivacce fund is to fund CLN3 Batten disease research.
- Beefy's Foundation is a charity supporting research projects into new treatments for Batten disease.
- Ollie's Army raises funds for CLN2 research and any project that benefits children and young people with CLN2.
- McFarland is for research.
- Fundraising and database (BioMarin). It is specifically to build capacity within the BDFA to diversify its income, shape a fundraising function and create a new database.
- Scotland (BioMarin) – BioMarin agreed to release these funds to unrestricted funds to support the Association during the COVID-19 pandemic.
- Gene Therapy day – due to COVID-19 it was not possible to hold this during the year and it has now been delayed until 2021 at the earliest.
- Schools Contract (QMU BioMarin) – funding provided to provide “real world” data and insight into the development of children accessing Brineura®.
- Brineura® Travel Costs (BioMarin) – BioMarin provided additional funds to cover travel costs to GOSH to counter the delays in opening other treatment centres.

Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2020

14 Analysis of net assets between funds

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL (£)
FUND BALANCES AT 31 AUGUST 2020 ARE REPRESENTED BY:			
Current assets	173,265	75,089	248,354
Creditors due within one year	(69,541)	-	(69,541)
	103,724	75,089	178,813

	UNRESTRICTED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL (£)
FUND BALANCES AT 31 AUGUST 2019 ARE REPRESENTED BY:			
Current assets	100,066	146,679	246,745
Creditors due within one year	(35,080)	(28,085)	(63,165)
	64,986	118,594	183,580

15 Related party transactions

There were no related party transactions during the current or previous year.

16 Control

This charity is controlled by the Trustees.

