



Our cover stars are Elliott Jackson, 5, from Devon. Elliott has CLN2 Batten disease, with his big sister Faye

# ANNUAL REPORT 2020/2021



BATTEN DISEASE FAMILY ASSOCIATION

*Together we WILL make a difference*

Registered Charity In England and Wales 1084908 - Scotland SC047408





**REMEMBERING...**

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

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# A year in the Batten community: introduction from the Chair and CEO



**Amanda Mortensen**  
CEO



**Zlatko Sisic**  
Chair of Trustees

## **We have had a challenging but successful year at the Batten Disease Family Association (BDFA).**

During this year we have supported 115 families from across the UK with 13 new diagnoses. Due to the life-limiting nature of Batten disease, loss is a reality in our community and four children, young people and young adults have passed away this year.

Much of the year has yet again been shrouded by COVID-19 and we have continued to support families to decipher fluctuating government information and manage throughout the ongoing pandemic. Our community is still picking up the pieces as services and essential therapies start up again. We understand that Covid will have a long lasting impact on our community and we will continue to adapt our support.

The BDFA team has grown significantly this year. At the time of writing, we have seven members of staff (5.3 FTE). This important growth in capacity is enabling us to fulfil our mission and increase the level and depth of support we are able to provide to families.

On that note, we are very pleased to be able to increase the range of support services we are able to offer families, both through our core family support team and new projects. Our partnership with specialist charity The Maypole Project (TMP) to deliver our holistic wellbeing service for the whole family is now well established. At the time of writing we are launching our Batten peer befriending service

and we are very excited about this new initiative, from the very heart of the Batten community. This is a significant step forward for the charity as we grow our volunteering capacity for the first time. We are also currently running a bereavement pilot, with the aim of setting up a service for our bereaved community, led and shaped by parents.

We have made significant progress with the charity's research function, which we were able to restart in 2020. The Brineura® in the eyes compassionate use programme for children with CLN2 began at Great Ormond Street Hospital (GOSH) in the summer of 2021 and eight children are receiving this treatment, with the hope that it will be able to be extended to other children. This programme is unique in that it is entirely funded by family fundraising and families raised over £217,000 to allow the programme to start. We have also announced a BDFA-led research project looking at the diagnostic odyssey of Batten disease and the patient journey, focusing in the first instance on CLN2 and CLN3. The BDFA is focused on supporting research for all types of Batten disease.

We are very grateful to our committed team of Trustees. Over the year, 70 per cent of our Trustees have lived experience of Batten disease. We are grateful to Trustee and father, Neil Dunford, who has stepped down during this financial year. Thank you also to our longstanding volunteer, Barbara Cole, who has stepped down as our Education Advisor after 17 years dedicated service as a volunteer and over two decades working with children and young people with Batten disease.

We have had another successful year at the BDFA. This year saw the start of the BDFA's new fundraising strategy for growth and longterm sustainability. We are very much at the start of this journey of diversifying our income streams but we are beginning to see a growth in grant support, allowing for much needed growth and development.

Supporter fundraising has been impacted by Covid this year but we are positive this will recover as we move out of the pandemic. We are very grateful to the families and their wider communities who put considerable effort into fundraising for us. With a new Community Fundraiser in post, we are also looking

forward to developing community fundraising, with the development of local 'community funding' leaders across the UK.

We are looking positively to the future as we continue to grow the BDFA. We aim to work holistically to meet the needs of our beneficiaries, focusing on every individual with Batten disease living life to the full and supporting our families from the point of diagnosis, through their journey and beyond.

**Zlatko Sisic, Chair of Trustees**  
**Amanda Mortensen, CEO**



## Meet our Board

**Zlatko Sisic, Chair of Trustees** (reappointed June 2021 for 3 years)

**Richard Whitbread, Treasurer** (reappointed June 2021 for 1 year)

**Pauline Docherty, Secretary** (reappointed June 2021 for 1 year)

**Bob Thompson** (reappointed June 2021 for 3 years)

**Simon Sewart** (reappointed June 2021 for 3 years)

**Cath Sermon** (reappointed June 2021 for 2 years)

**Gareth Holmes, Fundraising Lead** (reappointed June 2021 for 2 years)

**Neil Dunford** (resigned June 2021)

Trustees' terms are for different lengths of time to ensure continuity and flexibility.



# About the Batten Disease Family Association

The Batten Disease Family Association was formed in 1998 and became a registered unincorporated charity in 2001. We are starting the process of becoming an CIO (Charitable Incorporated Organisation) in the current financial year (year end August 2022).

## ABOUT BATTEN DISEASE

Batten disease, or the Neuronal Ceroid Lipofuscinoses (NCL), is a family of rare diseases caused by autosomal recessive genetic mutations. These are lysosomal storage disorders where genetic mutations disrupt the cells' ability to recycle wastes. Cells are thrown out of balance with the buildup of proteins and lipids (fats). There are 13 known forms of Batten disease and you will often hear them referred to as CLN1-CLN14. It is estimated that 2-4 births per 100,000 in the UK are affected by Batten disease, or about 10 a year. Batten disease is neurodegenerative and causes a progressive loss of skills. Children lose their ability to walk and talk, swallow and see. Batten disease also causes childhood dementia and intractable epilepsy. There is one treatment available for CLN2 disease. Others are being developed.

## OUR MISSION

The BDFA's mission is to enable everyone who is affected by Batten disease to live life to the full and to secure the care and support they need until we find a cure. The BDFA offers informed guidance and support to families and the professionals who work with them as well as actively increasing awareness of the disease and funding future research to identify potential therapies and ultimately a range of cures.

### Our objectives are to:

- Preserve and protect the health and promote the welfare of persons affected by all types of Neuronal Ceroid Lipofuscinosis (NCL) commonly known as Batten disease.
- To advance the education of the medical profession and the general public on the subject of Batten disease and its implications for the family.
- To promote research into the management of Batten disease and to publish the useful results thereof and to support organisations prompting research into Batten disease.

## STRUCTURE AND MANAGEMENT

The strategy and oversight of the BDFA are directed by the Trustees. The day to day management is delegated to Amanda Mortensen who has been the Chief Executive since February 2020. Other members of the team during this year were Family Support Workers, Wendy Thompson and Cathy McSweeney, who left the BDFA in June 2021. Liz Brownnutt, Head of Fundraising, joined us in January 2021 and has had a very successful first year with the BDFA. Recruited just before year end but commencing in

September 2021 Sian Fisher has joined as our new Head of Support and Advocacy. We were well aware that the support workload was greater than can be managed by an individual so prior to the year end the Trustees had given approval for the recruitment of a further member of the support team, a Behaviour, Adult and Transition (BAT) specialist and to ensure sufficient income, a Community Fundraiser plus once funding was in place a scientific expert - all of which we are pleased to state are either in post at the time of writing or are currently being recruited. Lisa Forsyth has become a permanent member of staff as Team Admin Officer. The BDFA also continues to part fund the Batten Clinical Nurse specialist at Great Ormond Street Hospital (GOSH). Laura Lee has returned from maternity leave and we work closely with Laura and her colleague, Becky Whiteley. Thank you to the staff for their incredible hard work over the year.

## HOW THE BOARD WORKS

The Board of Trustees has met monthly during the pandemic and now meets four times a year with the CEO and senior members of the staff team to review and formulate strategy. We are committed to attracting a diverse range of Trustees. Over the year, 70 per cent of our Trustees were parents of children or young people with Batten disease. A board review is a priority for the current year, looking at board effectiveness, a skills audit and how we can ensure governance is adhering to the highest possible standards.

We are looking for new Trustees with legal, marketing and medical expertise to join us, as well as parents from our Batten community.



*Liz, Head of Fundraising, Lisa, Team Admin Officer and Sian, Head of Family Support and Advocacy*



# The difference we made: delivering the aims and objectives of the organisation



Our strategy runs under four pillars: **Advocacy**, **Community**, **Care and Support** and **Research**

## ADVOCACY:

**To advocate for children and young people with Batten disease and their families we will...**

- Advocate for families at an international, national and governmental level to raise awareness and achieve access to current and future treatments for Batten disease
- Spearhead the campaign for newborn screening for Batten disease
- Strengthen our advocacy services for children, young people and adults with Batten disease with all professionals and service providers involved in their care across health, social care and education
- Utilise strategic alliances and partnerships, in the UK and internationally, across the rare disease sector to press for high level transformational change and the reduction of health inequalities

## COMMUNITY:

**To grow the Batten community and create opportunities for connection we will...**

- Set up a peer support network growing our volunteer capacity from within the community enriching connection and empowering parents to support each other
- Strengthen our connection with families through a hybrid approach combining online and face-to-face contact and re-establish our annual family conference
- Develop new services for the bereaved community, grandparents and siblings to strengthen wellbeing of all and the resilience of those impacted by the disease

## CARE AND SUPPORT:

**To increase the amount of care and support we offer to families we will...**

- Grow our support team to offer an excellent, holistic and highly specialised service to families from the point of diagnosis and through their journey
- Increase our mental health and wellbeing support to parents, siblings and other family members via our partnership with The Maypole Project
- Create a specialist LSD clinical pathway for Batten disease in England, working with the NHS to develop new treatment centres close to where families live
- Continue to work in collaboration with (and part fund) the Batten Clinical Nurse Specialist at Great Ormond Street Hospital to provide holistic support to families and for health professionals involved in their care

## RESEARCH:

**To raise the standards of care, influence policy and shorten the time to diagnosis we will...**

- Commission a BDFA-led piece of research into the burden of illness and burden of care for Batten disease, exploring the diagnostic odyssey
- Support families through the ongoing Brineura® in the eyes programme at GOSH
- Liaise with industry to ensure families in the UK are kept abreast of the latest information on research and treatments and have opportunities to enrol their children and young people on clinical trials



## ADVOCACY: ACHIEVEMENTS THIS YEAR

### This year we have...

- Advocated for families across education, health and social care to ensure their children, young people and adults affected by Batten disease access the services they are entitled to
- Worked with commissioners and alongside families to set up treatment centres for Brineura® for CLN2 Batten disease, with centres open in Newcastle, opening in Manchester and set to open in Bristol and Birmingham in the future. One young person who is now an adult is accessing treatment at Salford
- In partnership with GOSH, applied for CLN2 to be added to the newborn screening panel in England and been successful in the first stage (but further research is needed)
- Collaborated with other organisations, nationally and internationally, such as Genetic Alliance UK, to work with MPs around issues such as the diagnostic odyssey, representing the BDFA on the All Party Parliamentary Group for rare disease and working closely with the LSD Collaborative on service improvement across the UK



## Brineura® Treatment Centre

The Rich family have two little girls, Nicole, 10, and Jessica, 6, who have CLN2 Batten disease and access Brineura® every two weeks. They have transferred from GOSH to The Great North Children's hospital near their home in Newcastle, in the first Batten treatment centre outside London for children.

"After over four years of packing up and travelling from our home in Throckley to London every fortnight for the girls' treatment, Nicole and Jessica began receiving their treatment in our home city of Newcastle in early September 2021. This would not have been possible without a number of key people at the Newcastle Hospitals NHS Foundation trust who read our emails, listened to us, empathised with our situation and acknowledged how life-changing it would be to have treatment in our local hospital. They were committed to do everything they could as they knew the difference it would make to our lives.

"It was a long process and not without its challenges, but there was never a time when we felt it couldn't be done. Not only has this changed our lives, but it is a lovely feeling to know it will help other families who will be diagnosed with CLN2 in the future and who live in the north of the country. It has also meant that Jessica and Nicole's little friend James, from South Shields, is now getting treatment close to home.

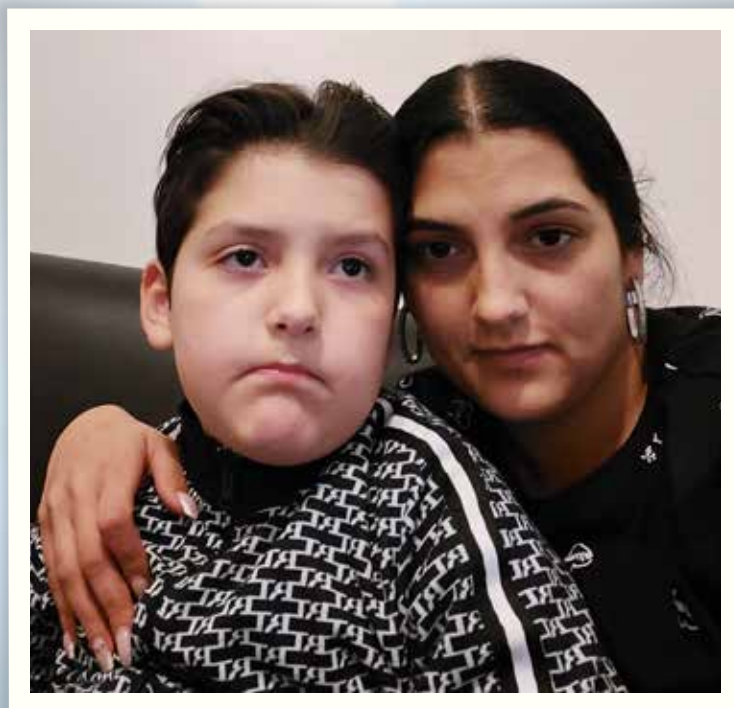
"When Jessica first started the treatment we travelled to Hamburg with Jessica every fortnight whilst taking Nicole to GOSH. We had to separate as a family and leave Louis. It was difficult but it had to be done and so we carried on, always hoping the day would come when we wouldn't need to travel so far. We are now able to drop Louis to breakfast club, drive to the Great North Children's Hospital for the girls' infusions, then we will get back home to Louis and all have our tea together!

"We will always be grateful to what GOSH has done for our girls but we are elated to be so close to home which gives us more time together as a family." **Gail Rich**





# Family Story



## MIKOLAJ KOWALSKI FROM LONDON

**Mikolaj is 8 and has CLN1 Batten disease. He lives in London with his mother, Barbara. Mikolaj was diagnosed in May 2021.**

*“Mikolaj was seen by a paediatrician, a neurologist, a psychologist, an optician. He also had an MRI scan but the specialists concluded he was fine and that he might be a little hyperactive but he would grow out of it.”*

“When Mikolaj was six years old, I began noticing certain changes in his behaviour. He started to lose his abilities, regressing and losing skills (for example, reading and writing, feeding himself) and he slowed down with playing sports, requiring support in the playground. His eyesight was compromised, especially in the evening. He was becoming more demanding, challenging, dependent and gradually louder and louder. I didn’t feel safe leaving him without me being around.

“Mikolaj was seen by a paediatrician, a neurologist, a psychologist, an optician. He also had an MRI scan but the specialists concluded he was fine and that he might be a little hyperactive but he would grow out of it.

“When Mikolaj was 7, we went to Poland to see a private paediatrician. She referred Mikolaj to a psychologist who asked to see his MRI scan (the first one, done 5 months earlier). Having seen the scan results he felt it could be worrying and Mikolaj might have a genetic condition. We were sent for specialist genetic tests. After three weeks, the results came in confirming severe brain atrophy. I was told it was a rare genetic disorder... and then I heard, for the first time, ‘Batten disease CLN type 1’. This was in May 2021.

“I don’t really know how to express my huge gratitude for the support, help and presence I’ve been receiving from the BDFA. I’m very thankful for the provision of much useful information, assisting me with solving issues and problems I encounter on a regular basis, for suggestions and advice in situations where I simply do not know what to do.

“Mikolaj has started attending school, for the first time ever! With the BDFA’s involvement and perseverance Mikolaj has a chance to learn, to be in a different, safe environment, spend time with his peers and make friends. I’m very grateful.” **Barbara, Mikolaj’s mother**

## COMMUNITY: ACHIEVEMENTS THIS YEAR

### This year we have...

- Continued with the Virtual Cuppa and online family meetings, continuing to work flexibly with families around the ongoing pandemic
- Launched our new Pride of Batten awards, just after year end, a new annual initiative, celebrating best practice across the Batten community
- Grown our awareness day with our storytelling project, support in parliament from MPs and buildings lit up across the UK
- Laid the groundwork for our new peer befriending service, with training due to start April 2022

## Pride of Batten Awards

Just after year end, we had our inaugural Pride of Batten awards. These annual awards will celebrate best practice across the UK in the Batten community. All of our winners and those specially commended were nominated by families for “going the extra mile”, their kindness and support and insight. Families nominated people across four categories: **Education, Health, Social Care** and **Other**.



### PRIDE OF BATTEN STORY

#### Education Winner Kath Black,

#### 1:1 Teaching Assistant, Poynton, Stockport

Kath was nominated by the Carroll family, who have two children with CNL2 Batten disease, Ollie, 11, and Amelia, 9.

“Back in November 2021 the BDFA held their very first Pride of Batten Awards. We nominated Amelia’s wonderful TA at her mainstream school. Kath looked after Amelia from reception up until she left to go to a special school in September 2021. Kath has always gone the extra mile not only for Amelia but for us as a family. Amelia has such a strong bond with Kath, it was so easy for us to drop her at school knowing she was loved and cared for.

“Throughout lockdown whilst Amelia was isolating, Kath would come to our door with toys and games from school and also lovely treats. She would offer to do our shopping and would always be checking how we all were.

“Throughout Amelia’s school years Kath attended training sessions to help support Amelia as her needs changed, she also made sure she was up to date with



*Kath Black with Amelia Carroll*



Batten disease. In September when Amelia transferred across to her new school we were so worried about how Amelia would cope due to her vision loss and lack of schooling due to Covid rules.

“Amelia wasn’t in a great place. She was struggling and was very scared due to her lack of vision. Kath volunteered to go to Amelia’s new school with Amelia to help settle her in. This helped Amelia and ourselves massively, knowing Amelia would have someone there who she was close to and trusted whilst she settled took a weight off us.

“Kath travelled to and from Amelia’s school for weeks slowly reducing her hours until Amelia became confident in her new environment and got to know her new teachers. We knew that our nomination for Kath was up against some other fantastic professionals.

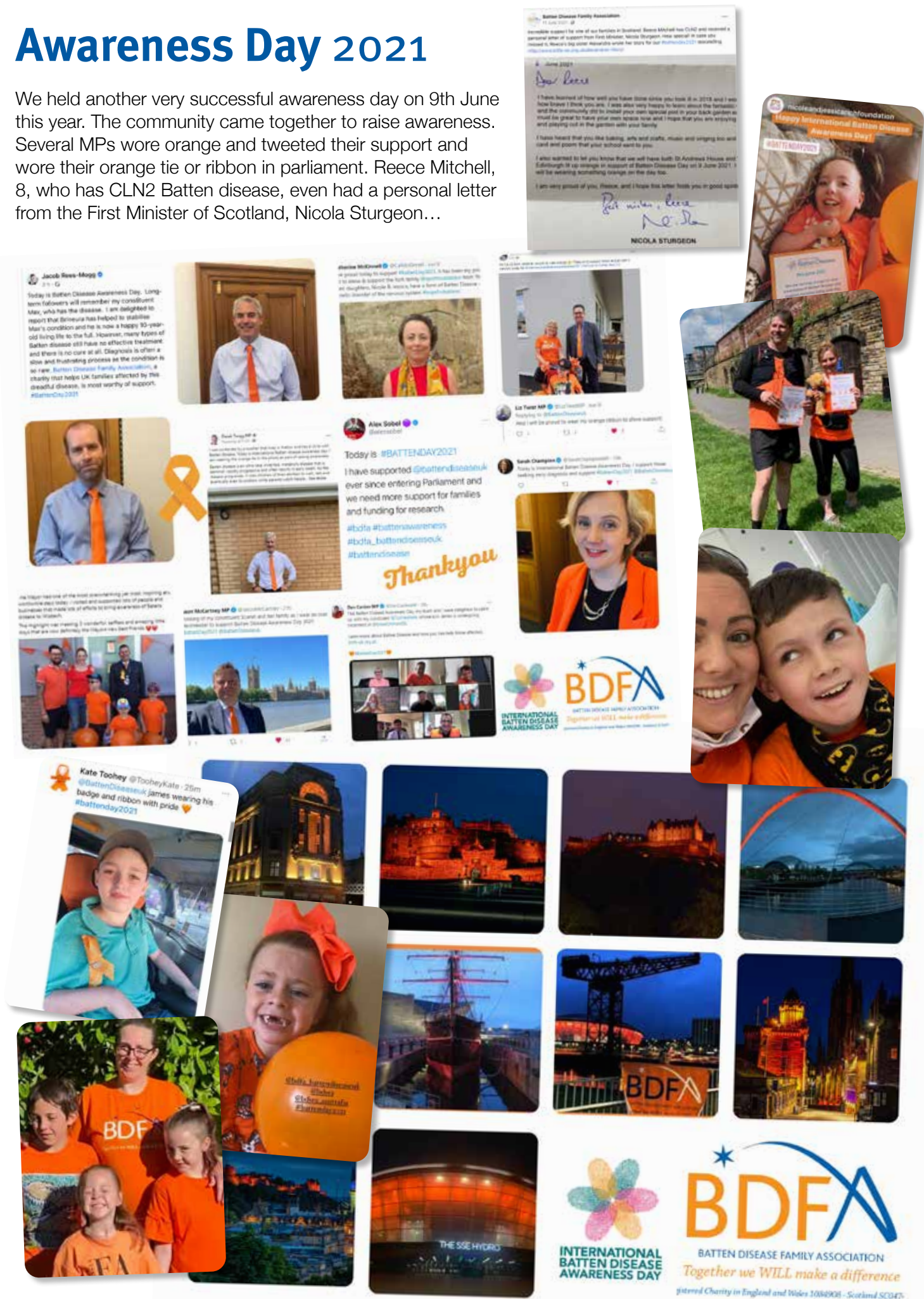
“We are so proud to say that Kath won this year’s Pride of Batten Award under the category Education!

“The words ‘thank you’ will never seem enough for all Kath has done. We are so proud that she has won this award and hope that she sees how much she means to us.” **The Carroll Family**



# Awareness Day 2021

We held another very successful awareness day on 9th June this year. The community came together to raise awareness. Several MPs wore orange and tweeted their support and wore their orange tie or ribbon in parliament. Reece Mitchell, 8, who has CLN2 Batten disease, even had a personal letter from the First Minister of Scotland, Nicola Sturgeon...





## CARE AND SUPPORT: ACHIEVEMENTS THIS YEAR

### This year we have...

- Supported 27 families through our specialist wellbeing service, delivered by The Maypole Project. Families have accessed therapeutic support through counselling, couples therapy and sibling support
- Worked with a parent to launch a new service for families, Bertie's Helpers

## Our CNS Nurse at GOSH

**Laura Lee** and **Becky Whiteley** have supported us throughout the year. "The Batten disease CNS based at Great Ormond Street Hospital works alongside the BDFA support team to provide holistic care for all children with an NCL diagnosis and their families from diagnosis, throughout their life and beyond. We have had to adapt and re-think how we support families during the Covid pandemic with more virtual meetings but this has also opened up new opportunities and new ways of working which families around the UK can benefit from," says Laura Lee.



## THE MAYPOLE PROJECT

The Maypole Project has supported many of our families through its holistic offer of support, including 1:1 counselling, couples therapy and sibling sessions. Support is open to the whole family and is available from the point of diagnosis throughout the entire journey with Batten disease.



**“Thank you so much Phil and the team at The Maypole Project for the fantastic Sibling Sanctuary magic and activity sessions this week!**

**Louis loved it! It is so lovely to see him enjoying time just for him.**

**It is such a wonderful initiative for siblings who deserve this special time!”**

Sibling Louis Rich, 11, enjoys the virtual sessions with The Maypole Project. Louis has two sisters with CLN2 Batten disease, Nicole, 10, and Jessica, 6.



# Spotlight on Bertie's Helpers

Set up by Mimi Petty, who also joined the BDFA as our Peer Befriending Coordinator, **Bertie's Helpers** has had a very busy year, delivering 49 special Tesco shops to families and extending its offer to bereaved families...

"On a night when Addy simply won't eat anything, Mimi and Andrew Petty from Bertie's Helpers have given us a lifeline as Addy will eat some cake! It makes all the difference as Addy will wake up probably 4-5 times throughout the night for milk if she doesn't eat.

"Bertie's Helpers is an initiative that aims to provide a gift of healthy nutritious meals for families who have a child diagnosed with Batten disease.

"Andrew and Mimi have first-hand experience of this horrific disease as they tragically lost their beautiful son Bertie to the same disease Addy has... and so they have set up this project in honour of their son. They know that sometimes the evenings can be the hardest, and that at the end of the day providing a nutritious meal for the family and then washing up is THE last thing the family needs."

*"On a night when Addy simply won't eat anything, Mimi and Andrew Petty from Bertie's Helpers have given us a lifeline as Addy will eat some cake!"*



## BDFA Family Grants

At the start of the year, one of the first actions undertaken, in the light of our improved financial position, was to fully reinstate our assistance to families through the small grants process, which had been withdrawn some years ago. Although last year we ran a limited programme in response to Covid we were able to reinstate a full programme with grants of up to £500 to assist with a new diagnosis, to assist with hardship and in the event of bereavement.

A simpler application form was introduced and the process was streamlined. We were able to directly assist 14 families in the year and it is likely the number helped during the current year will be greater. We are very aware of how much this assists the families under great pressure and are hoping to find ways of extending this assistance during the new financial year.

**"The family grant helped massively just after Jeffrey's diagnosis as we travelled to and from GOSH in London from our home on the train a lot in the weeks post diagnosis. We were also off work, but still needed to pay bills for our home during this time. It was an absolute blessing and we are so grateful to be able to get some financial help at a time when we couldn't think straight."**

**Jeffrey was diagnosed with CLN2 Batten disease in May 2021**



# How the BDFA has supported us



## LEO OLIVACCE FROM LONDON

**Leo is 14 and lives in London with his family. Leo has CLN3 Batten disease**

*“The BDFA really does champion any and every child with Batten disease and I really don’t know what we would do without their support.”*

“I would definitely say that for us the BDFA has become a reliable and extremely meaningful source of support.

“The BDFA has provided practical support in terms of advocating for us as a family, by being both actively involved and supportive in professional meetings, as well as offering free and bespoke Batten disease training when needed.

“It has also provided a sense of emotional support, always letting us know that although we are going through this absolutely devastating journey of Batten disease, we are not alone and that it is always there for all families affected by Batten disease.

“The BDFA really does champion any and every child with Batten disease and I really don’t know what we would do without its support. The BDFA has just become a part of our lives now and has provided us with so much support over the years,” says **Leo’s mum, Lara**



## RESEARCH: ACHIEVEMENTS THIS YEAR

### This year we have...

- Started our first BDFA-led research project looking at the diagnostic odyssey and patient journey in CLN2 and CLN3 disease
- Worked alongside GOSH and families on the development of the Compassionate Use Programme (CUP) for Brineura® in the eyes which started in July 2021

## Brineura® in the eyes

### Kavy, 9, is one of the children on the Brineura® in the eyes Compassionate Use Programme

As the patient organisation, the BDFA plays a key role in working with stakeholders to enable new treatments and research. Eight children with CLN2 Batten disease are taking part in an eighteen-month compassionate use programme (CUP) at Great Ormond Street Hospital (GOSH).

This unique programme was brought to life by the extraordinary fundraising efforts of the families, who raised over £200,000 to make this possible. The eight children on the programme, which started in the summer of 2021, were the first in the world to test the effects of Brineura® given as an intravitreal treatment into the back of the eye. It is hoped that this treatment will become available to other children as new treatment centres for Brineura® open across the UK. Brineura® is the only treatment for Batten disease. It is an enzyme replacement therapy and treats CLN2 Batten disease. It is effective in slowing down the progression of the disease but it does not prevent children losing their eyesight as it cannot reach the nerves in the eyes.

“Treatments given under compassionate use are always subject to very rigorous assessment and at GOSH we have a long history of pioneering these carefully-considered treatments for children who have no other option,” says Paul Gissen, honorary consultant in paediatric metabolic diseases at GOSH. “If successful, we hope our work on this programme can pave the way to saving the sight of more children with this disease to preserve their quality of life for as long as possible.”

“Kavyansh (Kavy, as we all call him) turned 9 this January. It’s been five years since he was diagnosed with CLN2 Batten disease. He was very fortunate to be promptly started on the Intravitreal Brineura® brain infusion. It’s been quite a journey we all, as a family, have been on together over these years with an addition of Kavy’s brother Shree to our family.

“This treatment has undoubtedly made a remarkable difference to his overall development. However, his vision continued to deteriorate over these years as the enzyme was not reaching the back of the eyes.

Seeing Kavy lose his vision over these years and we as parents not being able to help him, had been more painful and devastating to us than knowing the fact that Kavy has a life-limiting condition.

“After 3 years of continued effort from clinicians, families and BDFA, in June 2021 Great Ormond Street Children Hospital started the Intravitreal Brineura® injections in the eyes under a compassionate use programme. This is the first ever enzyme therapy trialed in the eyes and is aimed to preserve the vision, which will mean so much to these children. Kavy has been one of the eight children who have been receiving this injection in one of his eyes. So far there has been no adverse effect of this new treatment and Kavy has tolerated it very well. He is still able to enjoy his TV, play with his iPad, his favourite toys and look into our eyes when we are very close to him, which means a lot to us. Even if we could save whatever little vision is left in one of his eyes, it would be a blessing to prevent him from living in darkness for the rest of his life.”

**Dr Rahul Dubey, Kavy’s dad**



# Focus on Fundraising

The growing success in securing new Trusts and Foundations partners and the resurgence in community fundraising led to a strategic decision at the close of the financial year, to appoint a Community Fundraising Officer. This will further bolster community fundraising income potential into the new financial year and allow our Head of Fundraising to fully focus on the continuing growth of trusts and foundations income, as well as to plan the launch of an individual giving campaign later in 2022.

## Thank you to our funders...

### 52 Lives

**HM Government in Partnership with The National Lottery Community Fund, COVID-19 Response Fund**

**CAF Resilience Fund**

**The True Colours Trust**

**The Fineman Trust**

**Broome Family Charitable Trust**

**Santa Barbara Heights Charitable Trust**

**The Arnold Clark Community Fund**

**Pears Foundation/DCMS Funding via Contact**

**Oak Foundation**

**Douglas Arter Foundation**

**The Edward Gostling Foundation**

**The February Foundation**

**The Grace Trust**

**Anonymous Trust**

**Anonymous Trust**

**Batten Fighters Forever**

**Demelza Children's Hospice**

**The N Smith Charitable Settlement**

**The Blyth Watson Charitable Trust**

**Anonymous Trust**

**The WO Street Charitable Foundation**

**W.G. Forsyth Fund**

**ICE Futures Europe Limited**



**“We are sincerely grateful to faithful funders that have repeated grants this year and to all our new funders who have recognised the crucial work that the BDFA is doing to support families affected by Batten disease.**

**A special thank you also to our amazing supporters and fundraisers who continue to work tirelessly in their communities to raise awareness and much-needed funds for the ongoing work of the BDFA.”**



Thank you to our partners **Beefy's Charity Foundation** and **BMS Insurance**.

Thank you to **all the families** who work so hard undertaking small but essential fundraising in all forms to enable coverage of overheads. Thank you to **Duncan Brownnutt**, a bereaved father from our community, for all his hard voluntary work with social media communications throughout our Batten Awareness campaign in June. Duncan's two children Ellie Mae and Caleb had CLN2 Batten disease and passed away aged six and nine.

Thank you to all the families and their wider contacts who worked tirelessly to raise the funding for the Brineura® in the eyes Compassionate Use Programme at GOSH.



**“Sunrise brings light and hope to a new day. Yellow is the colour of hope and also the last colour the children/young adults see... so I hope Ben's walk brings a little more light and hope to a new day in the BDFA Charity chapter.”** Julie Pickering with her walking group. Julie's son Ben was 12 when he passed away from CLN2 Batten disease in 2009. Julie Pickering raised £2,818 for the BDFA.





## Fundraising Heroes

Schools were really engaged in our awareness day fundraiser and 10 schools raised money for the BDFA through various initiatives. **Wickersley Northfield Primary School** and all the other schools in the **White Wood Primary Academy Trust** in Rotherham, South Yorkshire raised an incredible £3,164 towards the challenge. The school ran a 13-station obstacle walk/run for the children on the 9th June and a 13km walking/running challenge for the staff team. This was a wonderful example of the school community coming together, for a “cause close to their hearts”, as quoted on the school's JustGiving page. Sam and Alice Evans, who both have CLN3 Batten disease, attend the school. The BDFA is very grateful to Wickersley Northfield Primary School and everyone who took up our 13 for 13 challenge.



***“I want to do it to help children like me with poorly brains. Please support us if you can by donating, every little penny helps someone.”***

Evie, 12, has CLN3 Batten disease and did a fundraising walk with her sister Isla. Evie has lost her sight and has limited mobility and her sister joined her blindfolded for the mile-long walk. The sisters raised over £1,500 for the BDFA.



***“It was worth it to get to the children's hospital in Manchester and see our family there in their orange t-shirts and balloons.”***

Two children in Stephen's family have Batten disease. Harper, 4, and Hayden, 5, are siblings who have CLN2 Batten disease. Stephen raised £3,022 for the BDFA.

We would like to say a **special thank you to David McGovern of the Beyond Vinyl Record Store** in Newcastle, for his incredible hard work and dedication to the BDFA and Batten community through the release of his special charity single for Batten Awareness day. The single *Beautiful Girl* (a cover of the INXS song) released in June 2021, was performed and produced by David, with the primary aim of raising awareness of Batten disease nationally and with all profits of the sales going to the BDFA. David, who is a well-known supporter within the Batten community, included the names and photos of many Batten children, past and present, in the CD booklet and this was a wonderful dedication and tribute to them all. The single peaked at number 5 in the official physical chart, which was a tremendous achievement. David's tireless support in raising awareness continued with a further single at Christmas and he continues to support the community in raising awareness. We are indebted to him for his constant support and for his care for all Batten families.

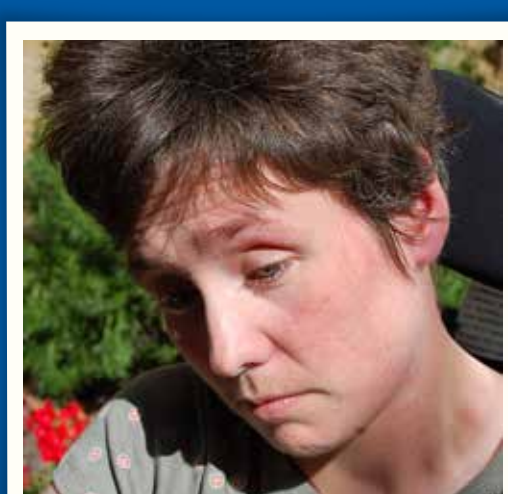


***“The families of the children with Batten disease are some of the bravest, strongest, positive and hopeful parents I have ever come across and I really admire them.”***





*Eilidh Borrowes-Currie, aged 4 & Cameron Borrowes-Currie, aged 2  
CLN1*



*Amy Hughes, aged 42, CLN1*



*Jeffrey Charles*



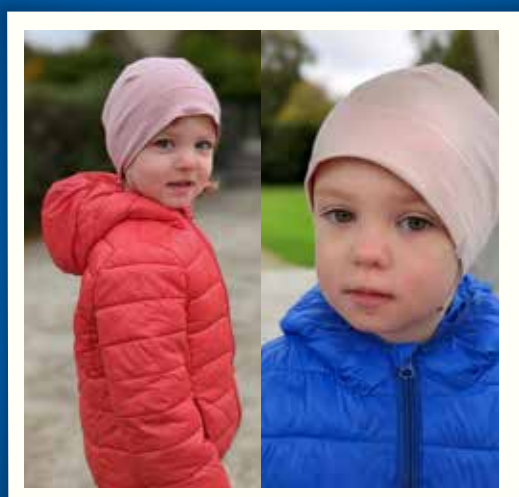
*Annabelle Hover, aged 16 & Robbie Hover, aged 9, CLN3*



*Annabel Yarrow, aged 13, CLN3*



*Jordan, aged*



*Nina and Lena Walotka, aged 4,  
CLN2*



*Alice Evans, aged 6 & Samuel Evans,  
aged 11, CLN3*



*Florence Swaffield,*

**These are just some of the children and young people we support from across the UK (from Lancashire, Sussex, the West Midlands, Yorkshire, to name a few, and as far as Northern Ireland and Scotland).**





sworth, aged 5, CLN2



Albert, aged 7, with his brother  
CLN7



Reece, aged 8, CLN2



d 22, CLN3



Sheyne Bowling, aged 15, CLN2



Tiffany Holubova, aged 9, CLN7



aged 3, CLN2



Henry Johnson, aged 9, CLN3



Ava Bella Hartigan, 10, CLN6,  
with her baby brother

# Family Story



## JOSHUA GLOVER, GLOUCESTER

**Joshua Glover, 9, has CLN6 Batten disease and lives with his younger brother Andrew and family in Gloucester**

*“A friend gave me the number of the BDFA but I wasn’t ready to talk to anybody for a few months. Eventually I spoke to the support worker who was lovely”*

“Josh was diagnosed ‘by chance’ in early 2020 through the 100,000 genomes project. We were totally thrown by the diagnosis as we attended the genetics appointment feeling relieved we would finally find out what was going on with him. Neither of us has considered that Josh would get a terminal diagnosis. It was completely devastating. We were told there was nothing that could be done, just to go away and ‘make memories’. It was very strange as after having lots of medical appointments they all stopped for a while. Now we had the diagnosis there was a sense there was nothing more to be done. It was eerily silent.

“Following the diagnosis, we have had to find our ‘new normal’. Initially I didn’t speak to anybody. A friend gave me the number of the BDFA but I wasn’t ready to talk to anybody for a few months. Eventually I spoke to the support worker who was lovely.

“It’s been so helpful to have somewhere to go. It’s been vital to have something to connect to. I started joining the virtual cuppas which started in lockdown and then started to get more involved, talking to other families and I made a video with families for the awareness day. Josh’s brother started accessing support from the BDFA’s wellbeing service, with The Maypole Project, and Andrew still attends weekly art sessions, now online. We have been quite proactive, we put the house on the market so we could move to a more suitable property that we could adapt. The prognosis for CLN6 is not good, with children expected to pass away between the ages of 8 and 12. We just didn’t know how long we had and we were worried about losing Josh mid-house move. Two years on, he is doing really well. He is still on his feet and talking and eating.

*“Batten disease is rare but it doesn’t feel rare when you are in touch with the community”*

“Our friends and family have really got behind the BDFA and my sister did the Kilt walk, another contact of ours who is a curate did a gaming fundraiser and we have done bake sales to raise money. Batten disease is rare but it doesn’t feel rare when you are in touch with the community. Just to have an organisation to listen and put you in touch with other families is so beneficial.” **Joshua’s mum, Ali**



# Trustees' 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.

## Financial Review

The BDFA's income has grown significantly this year to £635,015 (£274,407 in 2020). This reflects a substantial new research project with over £200,000 raised by families as well as success growing and diversifying our income through our new fundraising strategy. We are pleased to report an increase in unrestricted income from trusts and foundations to £119,489 (£47,627 in 2020). Supporter fundraising has been impacted by Covid-19 this year but we are hopeful this will recover as we move out of the pandemic. We are very grateful to the families and their wider communities who put considerable effort into fundraising for us.

## RESERVES POLICY

The Trustees have noted the increase in free reserves to reach £174,209 achieved in the financial year. The Trustees have also been aware that the adverse impacts of the Covid pandemic on fundraising are declining and have also noted the improvements in income from trusts and foundations in the months since the appointment of a Head of Fundraising and have determined that the policy on free reserves can be relaxed slightly. The Trustees now consider that holding reserves of between 4 and 8 months is more appropriate as the charity redevelops its activities and strengthen its range of services. At the year end the free reserves equated to between 5 and 6 months of core expenditure.

## PUBLIC BENEFIT

The Trustees use the Charity Commission guidance on public benefit and acknowledge the additional reporting requirements for charities whose gross income exceeds £500,000 (the BDFA's gross income is over this threshold this year). We have outlined our services and achievements in this report to clearly demonstrate how our work brings public benefit and is beneficial to its beneficiaries.

## KEY RISKS

- Securing sufficient funds to maintain our growing staff team
- The impact of Covid-19 as we move out of the pandemic but with further risks of new variants
- The level of support needed for our families, who live in 75 local authorities and the postcode lottery of support, with the BDFA often playing an essential 'key worker' role with the need to grow this vital lifeline of support
- The impact of the increased Cost of Living hitting our families, 50 per cent of whom are already financially challenged with an disproportionate effect on families with children with Batten disease, a profoundly disabling, neurodegenerative condition



**“I would just like to say a big thanks for the kind gift of a rose for my daughter, Nichola (who has passed away). It was a lovely surprise and both my husband and I really appreciated the thought.”**



# Legal and Administration Information of Batten Disease Family Association

<b>Charity number</b>	1084908	<b>Scientific and Medical Advisers</b>
<b>OSCR number</b>	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
<b>Principal Address</b>	Hamilton House Mabledon Place London WC1H 9BB	
<b>Independent Examiner</b>	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
<b>Bankers</b>	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 2021.

## Responsibilities and basis of report

As the charity's Trustees you are responsible for the preparation of the accounts in accordance with the requirements of the Charities Act 2011 ('the Act').

I report in respect of my examination of the charity's accounts carried out under section 145 of the Act and in carrying out my examination I have followed all the applicable Directions given by the Charity Commission under section 145(5) (b) of the Act.

## Independent examiner's statement

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

I have completed my examination. I confirm that no material 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 company 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 applicable requirements concerning the form and content of accounts set out in the Charities (Accounts and Reports) Regulations 2008 other than any requirement that the accounts give a 'true and fair' view which is not a matter considered as part of an independent examination.

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



**Mr Mark Cummins FCCA, FCIE**

### On behalf of TC Group

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

Dated: 27th April 2022

# Statement of Financial Activities

FOR THE YEAR ENDED 31 AUGUST 2021

	Notes	UNRESTRICTED FUNDS (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>INCOME FROM:</b>						
Donations and legacies	2	264,877	207,228	85,113	557,218	113,622
Other trading activities	3	77,752	-	-	77,752	160,723
Investments	4	45	-	-	45	62
<b>Total income</b>		<b>342,674</b>	<b>207,228</b>	<b>85,113</b>	<b>635,015</b>	<b>274,407</b>
<b>EXPENDITURE ON:</b>						
Raising funds		44,662	-	-	44,662	45,627
Charitable activities		210,527	15,959	37,790	264,276	233,547
<b>Total expenditure</b>	5	<b>255,189</b>	<b>15,959</b>	<b>37,790</b>	<b>308,938</b>	<b>279,174</b>
<b>Net income/(expenditure)</b>		<b>87,485</b>	<b>191,269</b>	<b>47,323</b>	<b>326,077</b>	<b>(4,767)</b>
Transfers between funds	15	(17,000)	17,000	-	-	-
<b>Net movement in funds</b>		<b>70,485</b>	<b>208,269</b>	<b>47,323</b>	<b>326,077</b>	<b>(4,767)</b>
Fund balances at 1 September 2020		103,724	-	75,089	178,813	183,580
<b>Fund balances at 31 August 2021</b>		<b>174,209</b>	<b>208,269</b>	<b>122,412</b>	<b>504,890</b>	<b>178,813</b>

The notes on page 24 to 35 form part of these accounts.

All income and expenditure shown above relate to continuing activities.



# Balance Sheet

FOR THE YEAR ENDED 31 AUGUST 2021

	Notes	2021		2020	
		(£)	(£)	(£)	(£)
CURRENT ASSETS					
Stock	10	1,000		1,000	
Debtors		5,032		2,720	
Cash at bank and in hand		622,934		244,634	
		628,966		248,354	
Creditors: amounts falling due within one year	11	(124,076)		(69,541)	
Net current assets			504,890		178,813
Total net assets			504,890		178,813
INCOME FUNDS					
Restricted funds	14		122,412		75,089
Unrestricted funds - general			174,209		103,724
Unrestricted funds - designated	15		208,269		-
			504,890		178,813

The accounts were approved by the Board on 27th April 2022



Zlatko Sisic  
**Chair of Trustees**

The notes on page 24 to 35 form part of these accounts.

# Notes to the Accounts

FOR THE YEAR ENDED 31 AUGUST 2021

## 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 Statement of Financial Activities (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 2021

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 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 2021

## 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 widening the support to families and plan to create designated funds to hold the monies to enable the reinstatement 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 4 and 8 months of unrestricted costs. They are currently achieving just under 6 months, which is a slight reduction on the prior year.

*Restricted funds* – Donations, bequests or incoming resources for 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 (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>DONATIONS</b>					
Regular monthly donations	8,315	-	-	8,315	4,644
Donations gift aid	1,330	-	-	1,330	946
Donations non gift aid	9,971	-	-	9,971	35
Charitable giving	-	169,728	85,113	254,841	32,442
Memberships	-	-	-	-	15
Donations – organisations and schools	70,220	-	-	70,220	3,500
Foundations and trusts not restricted	119,489	-	-	119,489	47,627
Pharmaceutical grants	48,160	37,500	-	85,660	-
Great North Run	-	-	-	-	11,007
Gift aid reclaimed	5,139	-	-	5,139	-
	<b>262,624</b>	<b>207,228</b>	<b>85,113</b>	<b>554,965</b>	100,216
<b>IN MEMORIAM DONATIONS</b>					
In memoriam	2,253	-	-	2,253	13,406
	<b>264,877</b>	<b>207,228</b>	<b>85,113</b>	<b>557,218</b>	113,622



# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

## 3 Other trading activities

	UNRESTRICTED FUNDS (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>FUNDRAISING</b>					
Supporter fundraising	74,678	-	-	74,678	154,686
Collection boxes	-	-	-	-	25
Fundraising activities	1,507	-	-	1,507	4,857
	<b>76,185</b>	<b>-</b>	<b>-</b>	<b>76,185</b>	<b>159,568</b>
<b>MERCHANDISE INCOME</b>					
Merchandise sales	1,567	-	-	1,567	1,155
	<b>77,752</b>	<b>-</b>	<b>-</b>	<b>77,752</b>	<b>160,723</b>

## 4 Investment income

	UNRESTRICTED FUNDS (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>INVESTMENT INCOME</b>					
Interest income	45	-	-	45	62

## 5 Total expenditure

	STAFF COSTS (£)	OTHER COSTS (£)	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>COSTS OF RAISING FUNDS</b>				
Fundraising costs	29,462	14,476	43,938	43,882
Merchandise costs	-	724	724	1,745
	<b>29,462</b>	<b>15,200</b>	<b>44,662</b>	<b>45,627</b>
<b>CHARITABLE ACTIVITIES</b>				
Activities undertaken directly	58,959	125,414	184,373	144,923
Support costs	17,051	62,852	79,903	88,624
	<b>76,010</b>	<b>188,266</b>	<b>264,276</b>	<b>233,547</b>
<b>Total expenditure</b>	<b>105,472</b>	<b>203,466</b>	<b>308,938</b>	<b>279,174</b>

# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

## 6 Support costs – other

	TOTAL 2021 (£)	TOTAL 2020 (£)
<b>OTHER COSTS:</b>		
Rent	6,007	5,762
Postage, freight and courier	1,248	562
Telephone	374	423
Computer, software and IT support	3,856	12,342
Office equipment	-	1,510
Legal and other professional fees	23,119	-
Office stationery	50	-
Insurance	1,215	1,402
Organisational membership and legal and professional fees	1,872	888
Accountancy fees	4,700	7,700
CEO expenses	811	3,879
Book keeping	4,280	4,024
Bank charges	54	26
Recruitment expenses	805	395
Staff training	6,618	307
Admin outsourced charges	6,423	8,230
Website costs	86	86
HR	1,334	1,435
Trustee costs	-	713
	<b>62,852</b>	<b>49,684</b>

These costs include amounts payable to the independent examiners of £1,000 (2020: £1,000) for independent examination and £3,700 (2020: £6,700) for other services.

## 7 Trustees

One trustee was paid £565 from the appropriate restricted fund, in connection with travel costs to enable a child to attend for Brineura® treatment at Great Ormond Street Hospital, in common with similar support payments to other affected parents.

In 2020 £713 was paid to three Trustees 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 2021

## 8 Comparative funds – Statement of Financial Activities for the period ended 31 August 2020

	UNRESTRICTED FUNDS (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL 2020 (£)
<b>INCOME FROM:</b>				
Donations and legacies	81,180	-	32,442	113,622
Other trading activities	160,723	-	-	160,723
Investments	62	-	-	62
<b>Total income</b>	<b>241,965</b>	<b>-</b>	<b>32,442</b>	<b>274,407</b>
<b>EXPENDITURE ON:</b>				
Raising funds	45,627	-	-	45,627
Charitable activities	179,734	-	53,813	233,547
<b>Total expenditure</b>	<b>225,361</b>	<b>-</b>	<b>53,813</b>	<b>279,174</b>
<b>Net income/(expenditure)</b>	<b>16,604</b>	<b>-</b>	<b>(21,371)</b>	<b>(4,767)</b>
Transfers between funds	22,134	-	(22,134)	-
<b>Net movement in funds</b>	<b>38,738</b>	<b>-</b>	<b>(43,505)</b>	<b>(4,767)</b>
Fund balances at 1 September 2019	64,986	-	118,594	183,580
<b>Fund balances at 31 August 2020</b>	<b>103,724</b>	<b>-</b>	<b>75,089</b>	<b>178,813</b>

## 9 Employees

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

	TOTAL 2021	TOTAL 2020
Charitable activities	2	1
Advocacy	1	1
	<b>3</b>	<b>2</b>

# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

EMPLOYMENT COSTS	TOTAL 2021 (£)	TOTAL 2020 (£)
Wages and salaries	99,995	66,542
Social security costs	2,971	3,375
Pension costs	2,506	1,400
<b>Total expenditure</b>	<b>105,472</b>	<b>71,317</b>

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

The key management personnel of the charity is comprised of the Chief Executive Officer. The total aggregate employee benefits paid during the year were £48,902 (2020: £40,537).

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 all of whom we thank for their valued but financially unrecognised contributions. In particular we accepted with regret the resignation of our Education Advisor after many years of assistance to the families.

One new volunteer proposed a completely new additional facility for families in the form of Bertie's Helpers and has undertaken the associated fundraising and operating of the service, which has been a significant addition to our services.

During the period payments of £5,000 (2020: £nil) were made with regards to the termination of employment contracts.

## 10 Debtors

	TOTAL 2021 (£)	TOTAL 2020 (£)
Prepayments and accrued income	5,032	2,720
	<b>5,032</b>	<b>2,720</b>

## 11 Creditors: amounts falling due within one year

	TOTAL 2021 (£)	TOTAL 2020 (£)
Trade creditors	9,189	10,244
Other creditors	6,424	31,981
Accruals	25,000	5,697
Deferred income	81,560	20,446
Taxes and social security	1,903	1,263
	<b>124,076</b>	<b>69,541</b>



# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

## 12 Deferred income

	TOTAL 2021 (£)	TOTAL 2020 (£)
Deferred income at 1 September 2020	20,446	-
Income recognised during the year	(20,446)	-
Income deferred during the year	81,560	20,446
<b>Deferred income at 31 August 2021</b>	<b>81,560</b>	<b>20,446</b>

## 13 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 charity to the scheme and amounted to £2,506 (2020: £1,400).

Contributions totalling £550 (2020: £321) were payable to the scheme at the end of the period and are included in creditors.

## 14 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 2020	INCOME	EXPENDITURE	TRANSFERS BETWEEN FUNDS	BALANCE AT 31 AUGUST 2021
Euro Ed Project	2,491	-	-	-	<b>2,491</b>
Battle Batten CLN5	45	-	(45)	-	-
In Memory of Katie Freeman	3,570	-	-	(3,750)	-
Olivacce CLN3	2,479	-	-	-	<b>2,479</b>
Ollie's Army	7,000	-	-	(7,000)	-
McFarland	5,085	-	(5,085)	-	-
Fundraising and database (BioMarin)	18,578	-	(474)	-	<b>18,104</b>
Gene Therapy Day	4,000	-	-	-	<b>4,000</b>
Schools Contract (QMU BioMarin)	5,841	-	(5,841)	-	-
Brineura® Travel Costs (BioMarin)	26,000	-	(16,905)	-	<b>9,095</b>
Brineura® Compassionate Use Programme	-	85,113	(9,440)	10,570	<b>86,243</b>
	<b>75,089</b>	<b>85,113</b>	<b>(37,790)</b>	<b>-</b>	<b>122,412</b>

# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

- Euro Ed Project is a Europe-wide education project focussed on CLN3.
- Battle Batten fund was for CLN5 Batten disease research and has been utilised.
- In Memory of Katie Freeman is for CLN2 research and it is being used as part of the funding for the Brineura® Compassionate Use Programme.
- Olivacce fund is to fund CLN3 Batten disease research and agreement has been reached that it may be redirected to assist a new research programme in 2022.
- Ollie's Army fund is for CLN2 research and it is being used as part of the funding for the Brineura® Compassionate Use Programme.
- McFarland was for research and has been utilised.
- Fundraising and Management (BioMarin) is specifically to build capacity within the BDFA to diversify income, shape fundraising and enhance resources.
- Gene Therapy Day – due to Covid-19 it was not possible to hold this during the year and we plan that this will be spent in 2022.
- Brineura® Travel Costs (BioMarin) – BioMarin have provided additional funds to cover travel costs to GOSH to counter delays in opening other treatment centres.
- School Reports Contract – we undertook a special report on the impact of COVID-19 on schooling matters.
- Brineura® Compassionate Use Programme – funds received under restricted covenants to meet the costs of the GOSH Compassionate Use Programme.

## 15 Designated Funds

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

	BALANCE AT 1 SEPTEMBER 2020	INCOME	EXPENDITURE	TRANSFERS BETWEEN FUNDS	BALANCE AT 31 AUGUST 2021
Brineura® Compassionate Use Programme	-	132,459	-	-	<b>132,459</b>
Bertie's Helpers	-	22,269	(5,854)	-	<b>16,415</b>
Orange Folder	-	-	-	4,500	<b>4,500</b>
Sibling Sanctuary	-	10,000	(10,000)	-	-
Website Reconstruction	-	37,500	-	12,500	<b>50,000</b>
Bertie's Helpers – Bereaved	-	5,000	(105)	-	<b>4,895</b>
	-	<b>207,228</b>	<b>(15,959)</b>	<b>17,000</b>	<b>208,269</b>

- Brineura® Compassionate Use Programme is the funds raised by the families to support the GOSH programme.
- Bertie's Helpers is a fund to meet the costs of the Bertie's Helpers programme to support families encountering difficulties by providing a special meal.
- Orange Folder holds funds transferred from unrestricted funds to redevelop our leaflets which are an essential resource for families.
- Sibling Sanctuary – this was an initial part of the Family Wellbeing Support programme provided by a third party supplier.

# Notes to the Accounts (continued)

FOR THE YEAR ENDED 31 AUGUST 2021

- Website reconstruction – during the year funds were transferred from unrestricted funds to support a new website with the work now in progress.
- Bertie's Helpers – Bereaved is linked to Bertie's Helpers (overleaf) and is a separate fund intended to provide an anniversary meal for the family of each child lost to Batten disease.

## 16 Analysis of net assets between funds

	UNRESTRICTED FUNDS (£)	DESIGNATED FUNDS (£)	RESTRICTED FUNDS (£)	TOTAL (£)
<b>FUND BALANCES AT 31 AUGUST 2021 ARE REPRESENTED BY:</b>				
Current assets	298,285	208,269	122,412	<b>628,966</b>
Creditors due within one year	(124,076)	-	-	<b>(124,076)</b>
	<b>174,209</b>	<b>208,269</b>	<b>122,412</b>	<b>504,890</b>

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

## 17 Related party transactions

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

## 18 Control

This charity is controlled by the Trustees.





BATTEN DISEASE FAMILY ASSOCIATION

*Together we WILL make a difference*

Registered Charity In England and Wales 1084908 - Scotland SC047408

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