



Children's Liver
Disease Foundation

fighting childhood
liver disease

Children's Liver Disease Foundation

Trustees' Report and Financial Statements for the year ended 31 December 2020

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2020

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Reference and Administrative Details

Registered Charity No: 1067331 (England and Wales) SC044387 (Scotland)

Company No: 03431169

Founders: Mrs Sonya McGough
Mr Peter McGough

Trustees and Directors:

Mrs Mairi Everard (appointed as Chair 27th February 2020)
Mr Thomas M Ross OBE (Chairman, retired 27th February 2020)
Mr Nicholas Budd (retired 27th February 2020)
Professor John Iredale (retired 30 November 2020)
Ms Theresa Legay (retired 1st June 2020)
Mrs Georgina Sugden
Dr Simon Colson
Ms Kate Dinwiddy
Mr Joel Glover
Professor James Neuberger
Mr Phil Orme
Mr Christopher Williamson (appointed 20th April 2021)
Mr Michael Roach (appointed 20th April 2021)

Chief Executive & Company Secretary:
Ms Alison Taylor

Key Management Personnel:

Chief Executive Officer	Ms Alison Taylor
Head of Support	Mrs Michelle Wilkins
Finance Manager	Mrs Gillian Baylis

Registered Office:
36 Great Charles Street
Birmingham B3 3JY

Bankers:
Bank of Scotland
33 Old Broad Street
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Auditor:
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Investment Adviser:
Brewin Dolphin
9 Colmore Row
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The Trustees of Children's Liver Disease Foundation present their report and financial statements for the year ended 31 December 2020.

Objects of the Charity

As a registered charity, Children's Liver Disease Foundation ('CLDF') is regulated by the Charity Commission (England and Wales) and OSCR in Scotland.

The Charity is also a Company Limited by Guarantee and reports to Companies House in this respect.

Charities exist solely to provide 'explicit public benefit' for society as a whole. As such, the objects of the Charity should reflect this. They state:-

1. To promote health education in subjects relating to the paediatric liver and to provide for the rehabilitation, care and relief of and support to those who suffer from paediatric liver diseases and disorders and their families.
2. To undertake and promote medical and scientific research relating to paediatric liver disorders and subjects relative thereto including the incidence, causes, effects, diagnosis, prevention, possible cures and treatment of all such paediatric liver diseases and disorders and research into paediatric liver transplant techniques and other surgical techniques and the dissemination of such useful results of such research by all possible means and as widely as possible to all who can benefit from it and so far as possible the co-ordination of such research.
3. To advance public education and awareness of paediatric liver diseases and disorders, their causes, diagnoses and treatment.
4. To promote such research as above inter alia by creating fellowships and by making grants and providing equipment, facilities, staff and other provision for research and training in paediatric liver diseases and disorders in established paediatric hepatic centres and if thought advisable elsewhere.

In furtherance of the Objects of the Charity, the Charity undertakes the following activities:-

- funding and supporting vital research
- informing and educating healthcare professionals, parents and the public about childhood liver disease and the signs and symptoms
- campaigning to give young people and their families one strong voice
- providing young adults, children and their families with tailored support services

How our activities deliver public benefit

The Trustees have complied with their duty to have due regard to the Charity Commission's public benefit guidance when exercising their powers and duties. Children's Liver Disease Foundation is the leading UK Charity for children and young people with all types of liver disease.

Our vision is a world in which young adults and children are not limited by their liver disease; that childhood liver diseases will be understood, prevented and treated effectively, ensuring

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that babies, children, young people, their families and adults diagnosed in childhood achieve their full potential.

All our charitable activities focus on improving the care and lives of those who are affected by childhood liver disease. All our activities are undertaken to further our charitable purposes for the public benefit.

Programme	Public Benefit
Research	<ul style="list-style-type: none">• Advances knowledge• Encourages young talent in scientific endeavours• Improved treatments• Provides evidence base for treatment regimens• Improved patient outcomes• Improved health economics
Information	<ul style="list-style-type: none">• High quality information available free of charge to the public and professionals• Signposting to other agencies• Packs and information to support families and young people to manage their liver disease
Support	<ul style="list-style-type: none">• Supports families and young people to cope with and adjust to life with their liver condition• Tailor-made services• Innovative family, young people and children's projects to bring families together and develop peer support• Support programme for friends and relatives
Voice	<ul style="list-style-type: none">• Campaigning for equitable services throughout the UK• Taking part in stakeholder engagement in NHS consultations• Highlighting the needs of the paediatric community in the allocation of donor organs for transplantation

Who uses and benefits from our services

Our main beneficiaries are children and young people affected by childhood liver disease and the families and communities which support them. This includes the wider family, and anyone connected with them, such as friends and professionals including health and social care professionals, educators and youth services. Professionals whose work relates to improving the diagnosis, care and understanding of childhood liver disease also benefit from the work of the Charity.

We work with children, young people and their families from birth up until the young person reaches the age of 25.

The Charity's services are open to all, irrespective of race, gender, religion, or sexual orientation. Most of the Charity's services are provided without charge to the individual beneficiary.

Governance

The company is a private company limited by guarantee governed by its Memorandum and Articles of Association dated 27 August 1997, amended on 28 March 2002, 7 March 2005, 29 July 2013 and 25th March 2021. The Trustees are the Directors and the only members of the company.

Trustees

The Board of Trustees sets the strategic direction and is also responsible for ensuring compliance with the Charity's Objects and charity and company law. The Trustees are also Directors for the purpose of company law.

New trustees are recruited by the Board of Trustees for their experience and specialist skills. The Trustees undertake an annual skills analysis and review the composition and skills mix against the needs of the Charity and succession planning.

For all new trustees there is an induction process, which includes safeguarding training and all Trustees have a role description and are subject to a Code of Conduct. The Trustees are aware of the Charity Governance Code and the need to assess Board governance against the principles of the Code. The Trustees intend to formalise the review of the Code's principles. In addition to regular Board meetings, the Trustees receive regular updates and additional away days to focus on specific issues as required. In 2020 we initiated a recruitment campaign, which culminated in two new trustees joining the board in 2021.

Professional liability insurance of £500,000 (2019: £500,000) is in place through Markel at a cost of £286 (2019: £286)

The Charity has three standing sub-committees which support the work of the board. The Scientific Committee, advises the Trustee Board on medical, scientific and research matters, assesses research grant applications and reviews grant reports. Two further sub committees, which comprise of members of the Trustee board, augment the boards oversight of the charity, it's income generation, investments and delivery of beneficiary outcomes. The Governance committee and the Finance and Fundraising committee meet regularly during the year.

The Charity has a Conflict of Interest policy that all Trustees, staff and committee members must comply with. None of the Trustees has any beneficial interest in the Charity.

Risk Management

The Trustees regularly review the risk management protocol which comprises:-

- Regular review of the major risks and uncertainties which the Charity may face
- The establishment of systems to mitigate operational and business risks identified in the annual review
- The implementation of procedures designed to minimise any potential impact on the Charity should those risks materialise
- Establishment and review of the reserves and investment policies, with the oversight of the Finance and Fundraising committee.

Ongoing review of the Charity's strategy, plans and operations ensures that risk management is an integral part of the operation of the Charity.

Covid-19 Pandemic 2020

The Covid-19 pandemic created significant risk for the organisation in 2020.

Initial risks were assessed in late January and preparations were begun to enable a move to a data secure, 'working from home model' should this be required. This plan was put into operation in March and has been further developed throughout the year. In early March the full extent of the financial risks to the organisation became apparent. CLDF is heavily reliant on fundraised income from events, sponsored activity and community fundraising, which have all been significantly affected by social distancing and the financial climate. Many of the charity's support events for beneficiaries have also had to be cancelled and postponed, because of government guidance.

New modes of working with beneficiaries have been developed since March and are discussed within the rest of the report. From March 2020 CLDF focussed on providing its' range of services digitally and supporting beneficiaries and NHS partners through the pandemic, whilst striving to reach newly diagnosed families. Ongoing and planned developmental work is taking place as available staffing resources and ways of working allow.

The Executive and Board have reviewed and re-budgeted expenditure in light of the financial challenges. The board were committed at all stages in the year to safeguarding the future of the charity. CLDF made use of the government job retention scheme to furlough a range of staff. From April 2020 financial and operational reporting to the Board has taken place weekly, so that timely decisions can be made in light of income levels and beneficiary need. Discussions with funders around the use of restricted funds are ongoing, as are emergency funding applications and campaigns. Strategic and operational plans, alongside staffing costs were reviewed and reworked. As a result half of the staff team were furloughed from April 2020. The organisation was restructured in July 2020, sadly resulting in 6 redundancies. These difficult decisions were taken to ensure that the charity continues to provide services to beneficiaries whilst maintaining its' covenanted level of reserves to safeguard the future work of the Charity.

Management and Staffing

The Chief Executive is appointed by the Trustees to manage the day to day operations of the Charity and is accountable to the Board. In turn, the Chief Executive appoints the other members of the Senior Management Team and together they manage the Charity's activities.

All new members of staff are provided with a comprehensive induction programme, which includes safeguarding training. All roles have a detailed job description and annual staff appraisals are carried out in addition to more informal supervision meetings. Training requirements are primarily identified by reference to personal work-related objectives and other targets highlighted in the appraisals which are directly linked to the objectives of the Charity.

Strategic Direction

In order to determine our objectives and focus, Children's Liver Disease Foundation held consultations with stakeholders and beneficiaries during 2019 to inform the development of a 2020-2023 strategic direction of travel document. From the strategic plan annual operational plans are formulated which reflect the plan and ongoing risk management; this is further developed to achieve the objectives and monitor performance.

Due to the Covid-19 pandemic, the initial plans for 2020 were continually reviewed and were subject to change in light of the prevailing financial challenges, the needs of our beneficiaries and social distancing requirements.

Achievements and Performance

Research

Research lies at the heart of providing a brighter future for children with liver disease. CLDF recognises it has an important role in contributing to and encouraging a vibrant research environment. It does this through the provision of funds and the work of the newly established Research Hub project.

Historically funds are made available through project grants, CLDF PhD student fellowships, a small grants programme and other vehicles agreed by the Scientific Committee and Board of Trustees.

Grants Programme

During 2020 due to the charity's financial position and the operational challenges for potential applicants and scientific committee members posed by the pandemic, the charity cancelled its annual grant round.

The Scientific Committee met in November 2020 to review progress and outcomes for sixteen ongoing and recently completed CLDF funded research projects. They also considered the potential future research strategy for the charity.

Research Hub

The project promotes research in paediatric hepatology and enables families and young people to provide insights from lived experience to help researchers to hone research questions and project applications.

In 2020 we continued to work with 33 parents and young people affected by childhood liver disease who are active members of the hub. Volunteering their time on an ad-hoc basis, the group take part in research involvement opportunities, as well as reviewing lay summaries of studies and blogs before they are published on our website. In total 13 patient and public involvement research opportunities, and tasks, were supported by members in the year. During the course of 2020, despite the pandemic, the hub was busy with requests for support from a variety of research stakeholders. Digital channels were used extensively to promote and enable participation.

During the year we held our first research webinar with speaker, Dr Hassan Rashidi. He discussed the development of his CLDF funded research project, "Development of a manufacturing platform to generate 3D liver organoids with semipermeable coating for allogeneic transplantation", impact of COVID and a Q&A session. Parents and young people who joined the session provided very positive feedback as well as suggestions for future research sessions. It was noted that they would like sessions like these to continue digitally even after the pandemic.

Continuing the research programme in 2021

Due to the ongoing financial challenges posed by the Covid-19 pandemic the board have taken the decision to focus on Research hub activity during 2021. No grant funding programme is planned during the year. This will be kept under review should the financial situation significantly change.

In 2021 we will continue to consider the future research strategy of the charity to ensure when funding allows that we derive maximum impact from our grant funding programmes.

Education and Information Programme

This programme aims to support the needs of healthcare and allied professionals, the general public, as well as children and young adults (11- 24 years) with paediatric liver disease and the families affected.

The provision of information to children, young people and their families is critical. It empowers individuals and supports them to understand, accept and take responsibility for their liver condition.

CLDF provides medical and nutrition leaflets to all hospitals managing children affected by childhood liver disease. In addition, CLDF provides the liver transplant stepping-stones packs to the three paediatric transplant centres. All are free of charge. Our leaflets and information are also available via our website and can be ordered from our central office.

During the year our medical and support resources and information were made available in the variety of ways as described, with a 105,276 distribution across all means of access.

In 2020 providing clear information and advice to our community about the COVID 19 pandemic and related issues for children, young people and their families affected by childhood liver disease was our top priority.

COVID 19 Related Activity

Since March 2020 the information provision we have prioritised has been related to coronavirus issues. CLDF have provided guidance, explanations of government briefings and how it affects our families, children and young people, as well as providing ongoing updates and blogs to support with various issues including accessing services. A separate section of the website was developed for COVID-19 communications. We worked closely with the three specialist NHS units, NHS Commissioners and Royal College of Paediatrics and Child Health (RCPCH) to ensure accurate and coherent advice was given. All hospitals caring for children with liver disease used our work to inform patients and CLDF became a central resource for professionals and families.

Twenty three statements and guidance articles were published in the year. These ranged from providing advice and support for parents to talking to their child about COVID-19 to shielding guidance and updates on accessing care and transplant services. These resources were viewed over 17,000 times.

Medical and Support Information

During the year we have continued to review and develop our medical and support leaflets to ensure they are concise, patient friendly and updated with the latest information.

The following titles were reviewed with support from medical specialists, updated and reprinted during the year.

Autoimmune Liver Disease, Nutrition, Alagille Syndrome , Liver Transplantation, Alpha 1 antitrypsin deficiency , Wilson's Disease , Portal Hypertension and Ascites, Choledochal Cyst and Acute Liver Failure.

A new series of resources were developed with help from families and young people in 2020. The support series includes three publications:

Support through your child's liver journey contains information on all aspects of living with liver disease, from top tips for clinic visits and hospital stays, to how to access financial support and what to consider when going on holiday. This leaflet is provided around the time of initial diagnosis or within the first few months so that parents can be informed to help them prepare for the journey with information they may need to be aware of (outside of medical information)

Supporting young people: a guide for parents and guardians is aimed at parents of children aged 13 and over and includes guidance on supporting a child as they grow up, moving into adult services, prescription charges, university and careers and direct advice from parents/carers and young people.

Living without a diagnosis explains why some liver conditions are difficult to diagnose, the type of care families should expect for their child even without a confirmed diagnosis, coping strategies and tips for how to manage appointments and investigations and ongoing additional help and signposting.

The information given in this series was separated into minimal key stages. This allows us to follow the support pathway in regards to other communications and packs sent at different stages of the journey in order to have greater impact. The leaflets were reviewed and developed with support of specialist nurses, family support workers and psychologists from specialist centres as well as parents and young people who contributed a wealth of advice based on their own experience.

Yellow Alert

Our Yellow Alert resources help Primary Health Care professionals to spot the signs of liver disease in babies, enabling faster referral to specialist centres where expert care can be given, saving lives. The campaign is endorsed by The British Association for Community Child Health (BACCH), The British Association of Perinatal Medicine (BAPM), The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), The Institute of Health Visiting (IHV), The Royal College of General Practitioners (RCGP) and The Royal College of Nursing (RCN).

During 2020 the campaign was more important than ever. The lockdowns caused significant disruption to primary health care routine visits for new parents and babies. In collaboration with The Institute of Health Visiting (IHV) and The Royal College of Paediatrics and Child

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Health (RCPCH) we promoted our Yellow Alert resources to help empower professionals working remotely with, and directly to, new families.

During the year 21,430 packs and apps were distributed. This represented a 55% increase in activity from 2019 and set another record as the highest number of Yellow Alert resources ever distributed in a single year.

Continuing the education and information programme in 2021

The information leaflets redevelopment project will continue in 2021, with a robust maintenance programme.

New resources that we plan to develop in the year include leaflets relating to:

Primary Sclerosing Cholangitis, Congenital Hepatic Fibrosis, Hepatitis C and Cystic Fibrosis & Liver Disease.

During 2021 we will continue to promote our Yellow Alert resources and campaign to decrease the number of late referrals of neonates for liver disease investigation.

A National Conference will be organised and delivered digitally in 2021. We will continue to seek opportunities to host a number of webinars and digital Q & A sessions on issues relevant to families and young people affected by childhood liver disease.

Our Covid-19 guidance work will continue to be a central focus and prioritised as and when required, with continual liaison with the three specialist centres.

Supporting Families and Young People

A diagnosis of childhood liver disease means a lifetime of medical care. Families, children and young people need to adapt to their new lifestyle, but uncertainty always exists. A diagnosis of liver disease has a huge impact upon the child, family, extended family, friends and work colleagues. The journey is individual. CLDF's role varies according to needs; from helping families to find their new normality, to supporting young people to take responsibility for their liver disease/transplant and ultimately transfer into adult services.

The range of services offered by CLDF includes:-

- Family and young peoples' event programme
- Residential projects for young people
- One to one personal support for families and young people
- Clinic and Ward visits
- Introductory Packs and literature
- Health Unlocked – CLDF's online forum
- Social networking

During the year our ability to record all of our interactions with young people and families was problematic. This was impacted by operating systems remotely and the loss of administrative staff. From March 2020 we recorded activity levels in a different format than those historically used, as, as mentioned above, we unfortunately lost administrative staffing as a result of furlough and restructure.

Hospital ward and clinic visits

The Families and Young Peoples' team clinic visiting programme was suspended in March 2020 due to the pandemic. We attended 21 clinics across the country, connecting with 166 families and young people in the first 3 months of the year.

In March 2020 most routine outpatient clinics at hospitals were curtailed. CLDF's clinic visiting programme was suspended and the charity switched to digital delivery of many historically face to face services.

Family Events

Our events programme during 2020 was significantly disrupted by the restrictions imposed by the pandemic. The purpose of our family event programme is to:-

- Provide families with the opportunity to meet one another and build local peer support networks.
- Provide families with the opportunity to build relationships with CLDF.
- Reduce families' and young people's feelings of isolation and uncertainty.
- Provide families and young people with opportunities to participate in enjoyable events, promoting family cohesion and giving them a break from the daily rigours of managing a chronic liver disease.

The support team's work for the majority of 2020 period focussed on providing support to existing families and young people to help them to navigate the practicalities of getting through the pandemic and managing their children's liver disease, alongside ensuring that newly diagnosed families are able to access our services.

This support was provided via all platforms, e.g. digital channels, phone and email, on a one to one basis. Another key focus was providing opportunities for families and young people to meet together virtually via online platforms for mutual support.

Zoom peer support for families

We held 12 virtual peer support sessions in 2020, attended by 112 families. Families enjoyed the opportunity to explore their experiences, sharing hints and tips about managing the wide ranging challenges posed by lockdown and shielding. Parents reported that these have been really helpful, learning and sharing, knowing that everyone understood their concerns and worries.

"I just wanted to thank you for the unshielding zoom session last week. I really got so much from this and thought it was all so well organised and set up. It's also the first time I've spoken with other parents with children with liver disease and I felt strangely emotional - for the first time like someone understood how I was feeling about everything. If there are any more parent zooms in the future, I'd definitely love to join". Parent feedback

Scotland Digital Family Weekend

In 2020 we delivered a digital family weekend to connect, inform and provide peer support for Scottish families. Our first virtual conference featured a programme of presentations provided by clinical nurse specialists, psychologists and liver consultants along with young people talking about their journey's. Thirteen families joined us for the weekend attending

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the daytime conference, with activities for children run in parallel and an evening family quiz. On the Sunday families re-joined the activities with a scavenger hunt and a feedback session. We will be using the insights gained to inform the development of a UK wide conference in 2021.

Post event feedback showed that 100% of attendees agreed that the event had allowed them to meet families from previous events and also to meet new families, they rated the event a 4/5 for enjoyment and content. All agreed that they would attend future digital events as they are more accessible and appropriate within the current social distancing confines. Parents provided feedback on how their children have benefited from digital family activities:

"My daughter listened to each of the girls that have moved onto adult services. She got a lot out of this. Listening to them talk about their journeys and how they have moved onto university, how their liver journey has influenced them but not defined them and how their scars are important to them. She's talked a lot about each of these things since the conference".

"My daughter has recently been reluctant to let anyone see her scar, feeling its private and sometimes getting upset if anyone sees it. Since the conference she's been openly showing off her scar in the house and saying it is part of her and she never wants it to go away. I'm hopeful this will help her as she moves into adolescence and becomes more aware of her body image".

One to one support for families

During the year we experienced a significant increase in families contacting us directly for help. Between March and December we received 1365 phone calls and emails asking for information, guidance and support.

Intensive 1:1 casework support was provided to 91 individual families by the Children and Families Officer (CFO) or Scotland Support Officer (SSO), with 47 zoom sessions undertaken. This included support with financial concerns and helping families to apply for mortgage holidays due to COVID. Families were supported to find out what they are entitled to receive and were helped with benefits claim and appeals processes. To assist with financial challenges staff applied to several grant making trusts on behalf of families, these included the Talisman Charitable Trust, Ben Hardwick Fund, Matt's Mission and Dream Makers.

During the pandemic support was given to families experiencing anxiety of their children returning to school, with liaison taking place with several schools across the UK. CLDF staff spoke with school staff to help reassure anxious parents about their children returning to school. We worked with several families who felt it was too soon for their child to return and were able to offer advocacy to develop a plan with the school and the family for phased return reducing anxiety for both the child and parent. Support and information was also provided for parents recognising that they might have different anxieties from their children.

In addition to the CLDF COVID 19 advice and guidance publications, in 2020 we sent a weekly newsletter to support families. The weekly email brought together all the latest government, specialist centre and health advice, featuring blogs and helpful tips to support the family holistically. The publication was received weekly by 1283 families who agree to receive email contact from the charity.

"Kate helped us at a really difficult time. We were dealing with our daughter's diagnosis at the same time as facing real financial difficulties as we've lost our jobs during COVID. She helped us break it down and supported us to understand the tests my daughter was having to take away the worry. She's helped us sort the financial pressure we were under at least in the short term and we are so grateful for the support CLDF offer."

"I was feeling overwhelmed with loads of things going on and worried about my daughter. One of the things I was struggling with was her prescription which I couldn't get at my local hospital. With just one call Kate sorted this out along with some other questions I had about her treatment and appointments. It was a weight off my mind and let me just focus on my daughter."

Young People's Programme

Talk, Tell, Transform

Talk, Tell, Transform offers a space for young people (aged 16-18 years) with a liver disease to take time out, reflect on their life journey and create a film that represents them. This unique project brings young people together, helping them to build a strong community, supporting young people to reduce their isolation. Talk, Tell, Transform ran for the ninth time in 2020 and is a five-day residential project. It was held in February and was the last physical event we were able to hold in the year. Twelve young people took part.

The digital 'story telling' residential experience enables young people to share, in a safe environment, their feelings about being seriously ill. Trained staff help them to share these experiences. They develop relationships with peers who understand their situation, learning new skills such as how to express their emotions and stories in a positive way. As well as team-building exercises, the group is guided through the process of making a video to tell their story, devising, editing and producing the film. The participants are offered the opportunity to share their films with the wider paediatric liver community and 10 films were released this year.

Feedback from a participant:

"This has been the most cathartic experience of my entire life and has given me real insight into the extent of my own feelings and the feelings of others. This process has encouraged me to talk unashamedly, giggle uncontrollably and love unconditionally. I could not be more thankful to everyone who made this process possible - I can't wait to see everyone again."

From parents:

"All she wished for was people her own age she could relate to and understood her - at TTT this was mission accomplished. She pushed herself to complete her film, something I knew she would find difficult but I believe with the support of not only the staff but her new friends too she did it and I know she's so proud of herself for doing so - so am I."

'has massively grown in confidence accepting who she is and has stopped comparing herself to others. Her attitude now is more 'what I can do' rather than 'what I can't do' L also doesn't feel so alone in her health struggles and has found it inspiring being with other young people in similar situations."

CLDF Breakaway

CLDF Breakaway was planned for May 2020. The project is for 12-15 year olds from all over the UK. From team building skills and zip wiring to building shelters, the young people really stretch themselves, trying new things and meeting new people with common issues.

Unfortunately we had to cancel this event, 10 young people had already enrolled on the programme. We redeveloped the project into virtual Breakaway including an activity booklet which consisted of 10 challenges to complete during the half-term week ending with a Zoom meet up on Friday where they took part in their final eating challenge – edible bugs which we provided in their pack. 5 young people participated in the virtual challenge week completing their booklet and joining staff for the final challenge.

One to One and Peer Support for Young People

2020 was a very challenging year for young people affected by liver disease. Lockdowns increased their sense of isolation and many were advised to 'shield' for the majority of the year. Between March and December 2020 we received 627 phone calls, emails and messages from young people.

The Young Persons Officer supported young people on a 1:1 basis and within a group setting throughout the year via Hang Outs/Drop-Ins that were delivered via Zoom. In total 30 sessions were offered providing opportunities for 1:1 and peer to peer support. Young people have reported that the impact of these initiatives have improved their mental health and resilience at what was an incredibly difficult time. Our moderated Social media groups Hive and Hive+ were also utilised to enable ongoing peer support.

"It has been so lovely to have someone on the CLDF team who can really relate to what you are saying. It has been a great support knowing that they understand what you are going through and can help you with whatever you may need."

"Throughout lockdown, Hive Hangouts gave me something to look forward to each week. It was brilliant to meet lots of new people who I know were also facing similar challenges as myself. Shielding felt very isolating at times but having support from CLDF was something I am very grateful for. From joining the hangouts, I have been able to make some new friends and also build on friendships I had recently made."

Hive

We launched Hive (for 11-15 year olds) and Hive+ (for 16-25 year olds) in 2019. Our Young People's Officer uses the platform to offer direct support, advice and guidance to young people. The platforms allow young people with liver disease to interact, ask questions, and make friends with others affected. A group of young people have been recruited and trained as HIVE ambassadors to provide peer support and help to moderate the groups.

During 2020 we increased membership from 44 to 82 young people. During 2021 we will work to increase membership and review the impact of the provision.

Continuing the family and young peoples' programme in 2021

On the basis of feedback received in 2020 we will continue to provide the much valued remote support services for families and young people affected by liver disease.

Opportunities for further peer support for families and young people will be explored and digital events will be further developed. Group support sessions delivered via Zoom will continue throughout the year. We will consider how best to meet the needs of families and young people with different conditions and at different stages in their journey.

We will work with care staff at the 3 specialist units to increase the number of newly diagnosed families accessing our services, mitigating the decreases caused by the suspension of clinic visits.

During the year we will consider how the charity might be able to develop projects to enable family volunteers to support newly diagnosed families.

The Hive project will be reviewed during the year to inform further developmental opportunities for our work with young people affected by liver disease.

Voice

The needs of the families, children and young adults diagnosed in childhood remains at the heart of CLDF's work. Representing their needs has become an increasing role for CLDF over the past decade. Ensuring services are configured to give equity of access and treatment is vital. This lies at the heart of CLDF's voice programme.

Representing Paediatric Liver Disease and the needs of patients

CLDF has ensured during the year that families and young people are given the opportunity to become directly involved in the evaluation of national policies and developments through digital channels.

A considerable amount of work during the year was focussed on providing our insights in the development of a wide range of processes, guidance and resources produced by the NHS, Commissioners and Royal Colleges. These initiatives specifically related to the pandemic and the provision of specialist advice and the provision of ongoing care for our beneficiaries. These included;

- **National Paediatric Liver Service** emergency capacity and management protocols
- **Royal College of Paediatrics and Child Health** and British Society Paediatric Gastroenterology Hepatology and Nutrition, – Shielding guidance produced and further developed at various stages in the year.
- **NHS England and Improvement** – Patient information pack for second coronavirus wave. This pack provided general resources, articles and advice applicable to patients.
- **National Institute of Clinical Excellence (NICE) Guidelines** ; COVID guidelines for paediatric hepatology and gastroenterology and NICE COVID guidelines for immunosuppressed children and young adults.
- **Scottish Government consultation** on specific medical condition COVID advice guides:

During the year the charity has worked closely with **National Health Service Blood and Transplant (NHSBT)** on a variety of initiatives. These included COVID related issues. Other areas of focus included promoting messages regarding the change in organ donation law in England which came into effect in May 2020. We continue to be a key partner, sourcing case studies throughout the year for use at a national level by the NHSBT team. Liaison with the

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Scottish government also took place around the campaigns that will roll out to support the change in organ donation law in Scotland which will come into effect in 2021.

The CEO is Vice Chair of the **Liver Patients' Transplant Consortium**. During the year work included a formal review of the business case for NHSBT commissioning additional liver transplant units in the UK. A formal response was developed with other charities and submitted.

The CEO is a member of the **Liver Steering Group for Paediatric services**, alongside clinicians from the Specialist units, to support national service development with commissioners.

The Charity has worked with a variety of external campaigns to instigate change that will improve outcomes for our beneficiaries. These include those run by the **Obesity Health Alliance**. Campaigns and consultations we have supported during the year include; the new obesity strategy, junk food advertising and funding for local public health obesity initiatives. In June we supported the **Global Liver Institute's International NASH Day**, which raised awareness of the impact of Non-Alcoholic Fatty Liver Disease on the health and lives of those who are affected and developments in the treatment and research field.

Throughout our history the charity has been passionate in trying to establish the best possible means of identifying liver disease in babies. It was the driver for the development of our Yellow Alert campaign and the ongoing work of educating primary healthcare. A number of distinct pieces of work have taken place which relate to our mission in this area during the year which include;

- Working with the **Institute of Health Visiting (IHV)** to call for a more sustainable and well-funded health visiting workforce to ensure that new parents and babies receive all the checks required, especially during the pandemic. These checks are key in identifying liver disease in new-borns.
- Initiating discussions with **RCPCH**, the **Institute of Health Visitors**, NHS Commissioners, Lead consultants, **ESPGAN** and **Public Health England (PHE)** around concerns about a significant reduction in referrals for Biliary Atresia investigations during the first wave of the pandemic. Communications work was then undertaken with Professionals, Societies, CCGs and Health organisations to highlight the issue and promote the use of CLDF Yellow Alert resources.
- Making Yellow Alert resources / Stool charts available to all new parents has been a key aim for many years. During the year there has been progression in this endeavour. Alongside Professor Deirdre Kelly (BWCH) and Professor Anil Dhawan (Kings) and Dr Serena Erini (Leeds) the CEO made formal representations to **RCPCH** about including these resources in the Red Book (The Children's Health Record), which is given to all new parents, to help spot the signs of liver disease in neonates. Later in the year a detailed proposal was developed and submitted by the group to the **National Screening Committee**. It is expected that we will learn the outcome during 2021.

The charity is a key member of the **Prescription Charges Coalition**. The coalition campaigns to reform the prescription exemption criteria in England, and make prescriptions free for people living with long term conditions. This is a major concern for our young people, where medication adherence is so important, prescription costs add to the challenges. During the year we shared communications, lobbied, provided input to articles and provided case studies for the campaign. We were incredibly proud when one of our young people, Joanna Howe responded to our appeal for campaign contributors. Her involvement resulted

Trustees' Report for the year ended 31 December 2020

in a Radio 4 documentary, where she presented a programme to bring attention to the issue. 'My Name is Joanna' was broadcast in February 2020.

The British Lancet Commission, 'Addressing liver disease in the UK' continued with the CEO working as a commissioner, focusing on supporting the implementation of the report's recommendations, lobbying for change and raising awareness of the needs of the paediatric and transitioning liver patient group. The final Lancet Commission report is due to be released in early 2021. **The European EASL Lancet Commission on Liver Disease** began in 2020, and the CEO is part of the working group considering paediatric and rare liver conditions. The first report is expected to be published in 2021.

We continue to work closely with the **European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN)** on a variety of shared interests and promotion of resources and collateral to raise awareness of paediatric liver disease across Europe. The partnership between ESPGHAN and CLDF saw Big Yellow Friday launched on the European stage for the first time, raising awareness on a much wider scale. As part of this collaboration, several infographics and videos were created and calls to policy makers were produced to help increase awareness and understanding of liver disease in children. The campaign was very successful with more than 280,000 views of the manifesto, 1112 twitter engagements, 43700+ twitter impressions, 7600+ video views on YouTube and a reach of 585700+ twitter users. CLDF supported ESPGHAN in the promotion of the new clinical advice guide on the treatment of chronic hepatitis C virus (HCV) infection in children. It is aimed at assisting paediatricians and patients, considering the causes of childhood HCV, as well as the natural history and treatment of chronic HCV infection and a section on approved drugs. It also provides recommendations for treatment in children both under and over the age of 12.

Other work conducted to represent the needs of our beneficiaries in the year has included;

- Supporting awareness days for specific liver conditions and **Rare Disease Day**
- Taking part in campaigns run by **Genetic Alliance, National Voices, The Specialised Healthcare Alliance (SHA)** and the **Association of Medical Research Charities (AMRC)**
- Providing ongoing input to the **European Reference Networks for Rare Liver Disease**.
- Active membership of CEO in the implementation group for **Welsh National Liver Strategy**.
- Involvement with the **British Paediatric Infectious Diseases Group** providing the patient and parent voice for the debate into hepatitis B vertical transmission and vaccine refusal, which subsequently lead to a Lancet publication.
- Providing views on what are the key areas in the transition process for childhood liver conditions and the experiences of those we support (both parents and young people). This work was undertaken to inform the National Confidential Enquiry in Patient Outcome and Deaths (**NCEPOD**) Transition from child to adult health services study.
- Working with **NICE** on technology appraisals for new drug treatments for cholestatic liver diseases which began in the year and will continue throughout 2021.

Continuing the voice programme in 2021

CLDF will continue to work with organ related charities and National Health Service Blood and Transplant (NHSBT) to promote the increase in consent rates for organ donation and to continue the development of care outcomes.

The charity will continue its' support for the Obesity Health Alliance and Prescription Charging Coalition's campaign work. Other initiatives which improve the lives of babies, children, young people and families affected by childhood liver disease will be supported throughout 2021 and beyond.

In the charity's communications and awareness raising, it will continue to broaden its' range of activity, incorporating the voices of our families and young people wherever possible.

CLDF will respond to other key issues and consultations as they arise. It will be a priority for the charity to keep our supporters informed of this aspect of our work during the year.

Fundraising

CLDF works across all traditional fundraising income streams and benefits hugely from funds raised by the families we support.

2020 was a very difficult year for the charity. Heavily reliant on fundraising activities which involve people 'getting together' and taking part in the challenges, the effects of social distancing relating to the pandemic were far reaching. We experienced a considerable decrease in our historic income levels.

Community fundraising was severely impacted. In 2020 our income from this fundraising stream was £42,678 In comparison to £66,787 in 2019. Big Yellow Friday 2020, our annual fundraising day was also affected raising £37,460 a 44% decrease on the previous year.

Challenge events are another key area of fundraising income for the charity. All of the key marathon events in the year were cancelled. We are indebted to our intrepid supporters who managed to continue to find ingenious ways to challenge themselves and raise money for the charity during the year. Income from challenge fundraising amounted to £71,696 a 48 % decrease on income received in 2019.

Trusts and Grants income had been an area of continued growth for the Charity over the last few years. In 2020 we found that many trusts were unable to meet to take funding decisions, with others changing their priorities to local community COVID related causes. During the year to December 2020 donations were received from 30 charitable trusts totalling £84,003, an almost 50% reduction on the income received in the previous year. This included a significant grant from Children in Need for the third year of a three-year project to support children and families affected by liver disease and a project to support young people. Donations of £5,000 or more were received from the following trusts:-

- The PF Charitable Trust £5,000
- Souter Charitable Trust £5,000
- The Sobell Foundation £10,000
- BBC Children in Need £40,003

In response to a number of urgent appeals for financial help during the year our supporters responded with a huge increase in personal donations £46,477 was received which represented a 244% Increase on the level of support given in 2019. Without these much needed funds the charity could potentially have had to close or at the very least discontinue providing the levels of support and guidance that we exist to deliver. We are hugely indebted to each and every person who donated to the charity in 2020.

Continuing the development of income generation in 2021

The Covid19 pandemic will continue to put considerable strain on fundraising activity, resources and planning for 2021. The charity will focus on promoting the work we do and the difference we make. A key focus will be stewardship of supporters who are actively engaged in raising funds for the charity, these include participants in major challenge events which we hope will restart in the second half of the year.

Opportunities for supporters to engage with CLDF through individual giving, campaigns and virtual challenge fundraising will be maximised.

Unfortunately the Biennial Chefs Gala Dinner planned to take place at The Savoy, London in March 2021 has had to be cancelled. It will be difficult to replace this income during the year.

The Charity will continue to seek multiyear grant opportunities with a focus on developing larger funding packages and overarching projects and themes.

During 2021 we will consider new sources of funding and redevelop our fundraising strategy.

Financial Review

The Charity prepares an annual business plan and budget and produces monthly management accounts.

In early 2020 the immediate impact of the pandemic was a significant reduction in income. The CEO and the Board made the decision to furlough 7 members of staff whilst assessing the continuing effect of the pandemic upon income. This led to restructuring the charity with 6 members of staff (mainly the administrative support staff) made redundant, the remaining staff agreed to be paid at 80% of their salaries for 6 months.

A revised operational plan and budget were produced, and close financial monitoring has ensured that overheads were contained within the revised budget and in line with changing income levels.

Income for the year to 31 December 2020 of £514,156 was 39.7% lower than the year ended 31st December 2019. However, the 2019 total includes income from the biennial Chefs' Gala Dinner of £111,403. The 2020 total includes £35,558 of furlough income support from the government.

Excluding the furlough and Chefs' Gala Dinner income shows our core income in 2020 decreased by 35%. The impact of the Covid 19 pandemic on the income streams is outlined in the Fundraising section of this report.

The principal sources of funding in 2020 were voluntary income of £501,323 of which £372,833 was received from supporters; £84,003 from charitable trusts (see Fundraising section); £4,730 of statutory funding and £4,200 from legacies.

The Covid-19 pandemic is having a significant impact upon fundraising activity – see the Risk Assessment section for the Charity's actions to minimise the impact this decrease in income upon its reserves position.

Investment Policy and Returns

Under the Memorandum of Articles of Association the Charity has the power to invest in any way the Trustees wish. The Finance and Fundraising Committee keeps the investment portfolio's under review and makes recommendations for the board consideration. The Board of Trustees reviewed the investment policy in December 2020 as the investment approach of producing an income of circa £12,000 per annum had become unsustainable without increasing the risk in the valuation of the investment portfolio. It was agreed to change the approach from using the portfolio for income generation to one of using it as a strategic reserve and for a more diversified portfolio to be held which will allow it to grow and maintain its real value in line with inflation.

The Trustees also require a level of liquidity to be maintained to cover the funding of projects. Therefore, available funds are kept in interest bearing deposit accounts to maximise resources. Investments are reviewed by the Trustees as needed, but on an annual basis, as a minimum.

Reserves

The Trustees reviewed the Charity's reserve policy during 2017 and determined that the policy should, as far as possible, require the free reserves in the unrestricted fund (excluding designated funds) to be sufficient to cover three to six months' core expenditure. However, in view of the current economic climate and the Covid 19 pandemic it is deemed prudent to hold a higher level of reserves in the general fund to minimise the effect of the anticipated continuation of the reduction in income generation for most of 2021.

The Trustees, therefore, consider that, based on the 2021 budget, the ideal level of reserves on 31st December 2020 would be between £240,000 and £300,000.

The actual unrestricted fund, excluding the designated £60,000, on 31 December 2020 is £358,535. This equates to covering 9.5 months of core expenditure. This level of reserves has been achieved by significant reduction in the costs of infrastructure and staffing whilst maintaining the charitable activities and by renegotiations of the use of funds with funders of restricted projects to achieve the outcomes but with different delivery methods.

The Trustees considered this level of reserves would enable CLDF to continue to provide services to families and young people.

The impact of the Covid-19 pandemic is expected to continue to have a significant effect upon the Charity's income and, therefore potentially its reserves – see the Risk Assessment section for the Charity's actions to minimise this decrease in income upon its reserves position.

Explanation of voluntary help and donations in kind

Children's Liver Disease Foundation has numerous volunteers around the country supporting the work of the Charity by fundraising and promoting the Charity. It also has regular office volunteers who contribute greatly to the work of the Charity and has continued with its project of training clinic volunteers. The Trustees wish to record their appreciation of the tremendous support the volunteers provide.

Pay policy for senior staff

The Chief Executive and senior management team comprise the key management personnel of the Charity. The pay of senior staff is reviewed annually and normally reflects increases in the retail prices index and average earnings, although pay freezes have on occasion been implemented. In view of the size and location of the Charity pay is benchmarked (lower to mid-point) against similar sized charities in similar areas.

Trustee Responsibilities

Directors and Trustees

All directors of the company are also trustees of the Charity and there are no other trustees.

Trustees can appoint additional trustees if they consider it appropriate to do so. The Trustees retiring by rotation at the next Annual General Meeting are Prof James Neuberger, Dr Simon Colson and Ms Kate Dinwiddy who, being eligible, offer themselves for re-election.

The Directors are responsible for preparing the financial statements in accordance with applicable law and United Kingdom Generally Accepted Accounting Practice. Company law requires the Directors to prepare financial statements for each financial period which give a true and fair view of the financial activities of the Charity and of its financial position at the end of the period. In preparing these financial statements, the directors are required to:-

- a) Select suitable accounting policies and then apply them consistently
- b) Make judgements and estimates that are reasonable and prudent
- c) State whether applicable accounting standards have been followed, subject to any material departures disclosed and explained in the financial statements and
- d) Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the Charity will continue.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure the financial statements comply with the Companies Act 2006. They are responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

Statement as to disclosure of information to auditor

So far as the Directors are aware at the time of approving our annual report:-

- There is no relevant audit information, being information needed by the auditor in connection with preparing the audit report, of which the company's auditor is unaware, and
- The Trustees, having made enquiries of fellow directors and the auditor have taken all steps that he or she is obliged to have taken as a director in order to make themselves aware of any relevant audit information and to establish that the company's auditor is aware of that information.

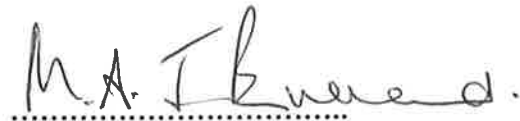
Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2020

Auditors

A resolution proposing the appointment of Crowe as auditor in accordance with the Companies Act 2006 will be put to the Annual General meeting.

By Order of the Trustees

A handwritten signature in dark ink, appearing to read 'M. A. Everard', is written over a dotted line.

Mrs Mairi Everard
Chairman
22 June 2021

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

REPORT OF THE INDEPENDENT AUDITOR TO THE TRUSTEES AND MEMBERS OF CHILDREN'S LIVER DISEASE FOUNDATION

Opinion

We have audited the financial statements of Children's Liver Disease Foundation for the year ended 31 December 2020 which comprise the Statement of Financial Activities, the Income and Expenditure Account, the Balance Sheet, the Statement of Cash flows and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2020 and of income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustee Investment (Scotland) Act 2005 and Regulation 8 of the Charities Accounts (Scotland) Regulations 2006.

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the trustee's use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the charitable company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the trustees with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information contained within the annual report. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

Our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether this gives rise to a material misstatement in the financial statements themselves. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion based on the work undertaken in the course of our audit

- the information given in the trustees' report, which includes the directors' report and the strategic report prepared for the purposes of company law, for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the directors' report included within the trustees' report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In light of the knowledge and understanding of the charitable company and their environment obtained in the course of the audit, we have not identified material misstatements in the strategic report or the directors' report included within the trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 requires us to report to you if, in our opinion:

- adequate and proper accounting records have not been kept; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit.

Responsibilities of trustees

As explained more fully in the trustees' responsibilities statement set out on page 21, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with the Acts and relevant regulations made or having effect thereunder.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Details of the extent to which the audit was considered capable of detecting irregularities, including fraud and non-compliance with laws and regulations are set out below.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Extent to which the audit was considered capable of detecting irregularities, including fraud

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We identified and assessed the risks of material misstatement of the financial statements from

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2020

irregularities, whether due to fraud or error, and discussed these between our audit team members. We then designed and performed audit procedures responsive to those risks, including obtaining audit evidence sufficient and appropriate to provide a basis for our opinion.

We obtained an understanding of the legal and regulatory frameworks within which the charitable company operates, focusing on those laws and regulations that have a direct effect on the determination of material amounts and disclosures in the financial statements. The laws and regulations we considered in this context were the Companies Act 2006, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 together with the Charities SORP (FRS 102). We assessed the required compliance with these laws and regulations as part of our audit procedures on the related financial statement items.

In addition, we considered provisions of other laws and regulations that do not have a direct effect on the financial statements but compliance with which might be fundamental to the charitable company's ability to operate or to avoid a material penalty. We also considered the opportunities and incentives that may exist within the charitable company for fraud. The key laws and regulations we considered in this context were General Data Protection Regulation, health and safety legislation and employee legislation.

Auditing standards limit the required audit procedures to identify non-compliance with these laws and regulations to enquiry of the Trustees and other management and inspection of regulatory and legal correspondence, if any.

We identified the greatest risk of material impact on the financial statements from irregularities, including fraud, to be within the timing and completeness of income recognition and the override of controls by management. Our audit procedures to respond to these risks included enquiries of management and the Finance & Fundraising Committee about their own identification and assessment of the risks of irregularities, sample testing on the posting of journals, reviewing accounting estimates for biases, reviewing regulatory correspondence with the Charity Commission, and reading minutes of meetings of those charged with governance.

Owing to the inherent limitations of an audit, there is an unavoidable risk that we may not have detected some material misstatements in the financial statements, even though we have properly planned and performed our audit in accordance with auditing standards. For example, the further removed non-compliance with laws and regulations (irregularities) is from the events and transactions reflected in the financial statements, the less likely the inherently limited procedures required by auditing standards would identify it. In addition, as with any audit, there remained a higher risk of non-detection of irregularities, as these may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal controls. We are not responsible for preventing non-compliance and cannot be expected to detect non-compliance with all laws and regulations.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006, and to the charitable company's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body for our audit work, for this report, or for the opinions we have formed.

Kerry Brown 
Senior Statutory Auditor

For and on behalf of

Crowe U.K. LLP

Statutory Auditor

Black Country House, Rounds Green Road, Oldbury, West Midlands, B69 2DG

10 August 2021

**STATEMENT OF FINANCIAL ACTIVITIES (including Income and Expenditure Account)
FOR THE YEAR ENDED 31 DECEMBER 2020**

	Note	Unrestricted Fund	Restricted Fund	Year Total 31.12.20	As Restated Year Total 31.12.19
		£	£	£	£
INCOMING RESOURCES					
Income					
Donations and legacies	4	435,691	65,633	501,324	838,525
Trading activities	4	722	-	722	939
Investments	4	12,109	1	12,110	13,529
Total Incoming Resources		448,522	65,634	514,156	852,993
RESOURCES EXPENDED					
Costs of raising funds					
Raising Funds		79,808	342	80,150	186,790
Trading activities		266	-	266	381
Total		80,074	342	80,416	187,171
Charitable activities					
Education and awareness campaigns	5	151,106	18,972	170,078	226,233
Provision of emotional support	5	159,183	98,566	257,749	352,590
Research grants and expenditure	5	11,831	24,283	36,114	111,587
Total		322,120	141,821	463,941	690,410
Total expenditure		402,194	142,163	544,357	877,581
Net (losses) / gains / on investments	14	(4,451)	-	(4,451)	7,484
Transfers between funds	21	11,500	(11,500)	0	0
Net surplus / (expenditure) and net movement in funds for the year		53,377	(88,029)	(34,652)	(17,104)
Total funds 2019 – as previously stated					506,550
Correction of a prior period error	22				20,088
Reconciliation of funds					
Total funds brought forward at 1 January 2020		365,158	144,296	509,454	
Total funds carried forward at 31 December 2020		418,535	56,267	474,802	509,454

The notes on pages 29 to 43 form part of these financial statements.

The statement of financial activities includes all gains and losses recognised in the year.

All the above results are derived from continuing operations of the Charity.

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2020

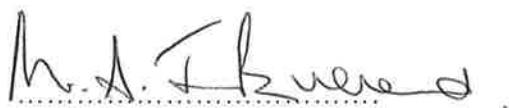
BALANCE SHEET OF THE CHARITY AS AT 31 DECEMBER 2020

	Note	31.12.2020		As Restated 31.12.2019	
		£	£	£	£
Fixed assets					
Tangible assets	13		3,989		5,076
Investments	14		233,131		250,714
			<u>237,120</u>		<u>255,790</u>
Current assets					
Stock and inventory	15	4,580		6,860	
Cash and short-term deposits	16	322,496		404,760	
Debtors due within one year	17	43,608		34,945	
		<u>370,684</u>		<u>446,565</u>	
Current liabilities					
Creditors due within one year	18	103,002		162,901	
Dilapidations provision	19	30,000		30,000	
				<u>192,901</u>	
Net current assets			<u>237,682</u>		<u>253,664</u>
Total assets less current liabilities			<u>474,802</u>		<u>489,446</u>
Net assets			<u>474,802</u>		<u>509,454</u>
Represented by					
Restricted Funds	23		56,267		144,296
Unrestricted Funds	23		358,535		305,158
Designated Funds	23		60,000		60,000
Total Funds			<u>474,802</u>		<u>509,454</u>


These accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and constitute the annual accounts required by the Companies Act 2006 and are for circulation to members of the company.

The notes on pages 29 to 43 form part of these financial statements.

Signed on behalf of the Trustees on 22 June 2021.



Mrs M Everard



Dr S Colson

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31 DECEMBER 2020

	Note	31.12.2020 £	31.12.2019 £
Cash used in operating activities	23	<u>(103,961)</u>	<u>(73,249)</u>
Cash flows from investing activities			
Interest Income		12,111	13,529
Disposal of investments		45,530	25,377
Purchase of investments		(32,398)	(24,767)
Purchase of tangible fixed assets		(3,546)	(1,276)
Cash provided by investing actions		<u>21,697</u>	<u>12,863</u>
(Decrease) in cash and cash equivalents in the year		(82,264)	(60,336)
Cash and cash equivalents at the beginning of the year		404,760	465,146
Total cash and cash equivalents at the end of the year		<u>322,496</u>	<u>404,760</u>

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies

The principal accounting policies adopted, judgements and key sources of estimation in the preparation of the financial statements are as follows:-

a) Basis of accounting

Children's Liver Disease Foundation 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.

The financial statements of the charitable company have been prepared in accordance with the Charity SORP (FRS102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and the Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland', the Companies Act 2006, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

A separate income and expenditure account has not been included because the Charity does not have endowment funds.

b) Preparation of the accounts on a going concern basis

The Foundation reported a net deficit of £34,652. When the Covid – 19 pandemic arose fundraising income declined immediately. The Executive and the Board reviewed and amended the charity's operations making significant reductions in operating costs in order to maintain the financial reserves.

The Executive and Board have reviewed the charity's operations, re-budgeted income and expenditure for the period to June 2022 and consider that the Charity remains a going concern.

c) Financial statements

At 31 March 2015 the trustees decided to transfer the trading activities to the Charity from 01 April 2015. CLDF Trading Ltd is a dormant company. The Charity has, therefore, taken advantage of the exemption in preparing group accounts on the grounds of the immateriality of the subsidiary; the investment in which is stated in the Charity's balance sheet under investments.

The financial statements for the year to 31 December 2020 consist of the Charity's SOFA and a balance sheet for the Charity as do the comparative financial statements for the year to 31 December 2019.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

d) Funds

The Charity's funds consist of unrestricted, restricted and designated amounts. Unrestricted amounts are available to spend on activities that further the charitable activities of the Charity, and these can include designated funds. Restricted funds represent income contributions which are restricted to a particular purpose, in accordance with the donor's wishes. Designated funds represent unrestricted income which the Charity's trustees have allocated for a particular purpose. As at 31 December 2020 the trustees have designated £60,000 of the unrestricted fund towards research.

e) Income

Income from charitable donations and grants is recognised when the Charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

Donations and grants with conditions attached to them are credited to restricted funds and any unspent amounts are shown on the balance sheet in restricted funds.

For legacies, entitlement is taken as the earlier of the date on which the estate account is finalised or the cash is received. Receipt of a legacy is considered probable when the amount can be measured reliably and the Charity has been made aware of the executor's intention to make a distribution. If the Charity is aware of a significant legacy but the criteria for income recognition have not been met the legacy would be disclosed as a contingent asset.

Income received in advance of an event or a charitable activity is deferred until the criteria for income recognition are met.

Interest on funds held on deposit or from investments is included when receivable and can be measured reliably by the Charity; this is normally upon receipt.

f) Donated services

Donated goods and professional services are recognised as income when the Charity has control over the item; the receipt of economic benefit is probable and can be measured reliably.

On receipt, these are included at an amount equivalent to that which the Charity would have to pay to purchase the donated item on the open market; a corresponding amount is recognised in expenditure in the period of receipt.

In accordance with the Charities SORP (FRS 102) general volunteer time is not recognised – the trustees' annual report refers to their contribution.

g) Expenditure

Expenditure is recognised when there is a legal or constructive obligation to make a payment to a third party, it is probable that settlement will be required and the amount can be measured reliably.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

Expenditure is allocated to the relevant activity categories as follows:-

- **Costs of raising funds** include costs relating to activities where the primary aim is to raise funds and the associated support costs. The cost of communications staff has been allocated 75% and 15% respectively to "education and public awareness" and "provision of emotional support" within charitable activities. The cost of fundraising staff has been allocated 25% to "education and public awareness" within charitable activities.
- **Costs of charitable activities** include all costs relating to education and awareness campaigns, provision of emotional support and research grants and expenditure including the associated support costs.
- **Other expenditure** represents those items not included in any other heading.
- **Dilapidation provision** represents the estimated cost to put back the office at the end of the lease into the same condition it was when the lease commenced. The estimate is based on advice from a real estate agent but is not absolute.
- **Research projects** are accounted for the full value when authorised, when the award of the research project has been specifically communicated to the recipient or when paid if there is no communication with the recipient in advance (in accordance with the Charities SORP FRS 102).

h) Allocation of support costs

Support costs are those functions that assist the Charity in raising funds and delivering its charitable activities. Support costs include property, information technology, administration, personnel, finance, payroll and governance costs. The bases on which support costs have been allocated are set out in note 6.

i) Tangible fixed assets and depreciation

Tangible fixed assets are included at original cost (or, if donated, the value at the date of receipt). Assets below the value of £150 are not capitalised.

Depreciation is provided on all tangible fixed assets at rates calculated to write off the cost over their estimated economic useful lives, as follows:

Computer equipment	25 - 33% straight line
Office equipment	20 - 33% straight line

j) Investments

Investments are stated at mid-market value at the year end.

Net realised and unrealised investment gains or losses for the year are disclosed in the statement of financial activities.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

k) Stock

Stock is included at the lower of cost and net realisable value, due allowance being made for obsolete items. Stock consists of educational literature available to families and healthcare professionals and goods purchased for resale.

l) Operating Leases

The Charity classifies the lease of the office and broadband as operating leases; the title to the equipment remains with the lessor. Operating lease payments are written off in the statement of financial activities in the period in which they are incurred.

m) Debtors

Debtors are recognised at the settlement amount due. Prepayments are valued at the amount prepaid.

n) Cash at bank and in hand

Cash at bank and cash in hand includes cash and short-term deposits with a maturity date of less than twelve months from the opening of the deposit.

o) Creditors

Creditors and provisions are recognised where the Charity has a current obligation resulting from a previous event that will probably result in a payment to a third party and the amount can be measured or estimated reliably.

Research grants usually are for periods of two to three years and the value of the grants have been included at the agreed amounts and have not been discounted for their future values as this would not be material.

p) Financial instruments

The Charity's financial assets qualify as basic financial instruments and are recognised at transaction value.

q) Pension

In January 2015 the Charity set up a defined contribution pension scheme operated by Royal London which employees were entitled to join upon completing one year's service. The employer matches the employee's contribution to a maximum of 4% of salary. The Charity acts as an agent in collecting and paying over employee pension contributions. The scheme qualifies as suitable for automatic enrolment and was used when the Charity's staging date of 01 January 2017 was reached.

The contributions made for the year are treated as an expense.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

q) Pension (continued)

In December 2013 an individual defined contribution pension scheme for the CEO was set up.

2 Legal status of the Charity

The company is a private company limited by guarantee governed by its Memorandum and Articles of Association dated 27 August 1997, amended on 28 March 2002, 7 March 2005, 29 July 2013 and 25 March 2021 and is registered as a charity with the Charity Commission and the Office of the Scottish Charity Register. The Trustees are the only members of the Charity and every member undertakes to contribute up to a maximum of £10 in the event of the Charity winding up.

3 Financial performance of the Charity

The statement of financial activities for the year 31 December 2020 is for the Charity only as is the comparative year. From 01 April 2015 the trading activities of the subsidiary were transferred to the Charity and the subsidiary is now dormant.

4 Incoming Resources Notes

	Year 31.12.20			Year 31.12.19		
	Unrestricted Funds	Restricted Funds	Total	Unrestricted Funds	Restricted Funds	Total
Incoming Resources	£	£	£	£	£	£
Donations & legacies						
Donations	372,833	*	372,833	454,604	55,132	509,763
Income from Chefs Gala Dinner	-	-	-	103,903	7,500	111,403
Statutory Funding	-	4,730	4,730	-	10,000	10,000
Charitable Trusts	23,100	60,903	84,003	54,100	112,225	166,325
Legacies	4,200	-	4,200	41,061	-	41,061
Coronavirus Job Retention Scheme	35,558	-	35,558	-	-	-
	435,691	65,633	501,324	653,668	184,857	838,525
Trading activities						
Sales of merchandise	722	-	722	939	-	939
Investments						
Listed securities - UK	11,500	-	11,500	12,385	-	12,385
Listed securities-Overseas	508	-	508	499	-	499
Bank interest	101	1	102	642	3	645
	12,109	1	12,110	13,526	3	13,529
Total	448,522	65,134	514,156	668,133	184,860	852,993

NOTES TO THE FINANCIAL STATEMENTS

5 Analysis of expenditure on charitable activities

	Education and awareness campaigns	Provision of emotional support	Research grants and expenditure	Total
	£	£	£	£
Research Hub – working with stakeholders & medical professionals	-	-	28,009	28,009
Working with beneficiaries and stakeholders	36,222	119,031	-	155,253
Medical Conferences	2,296	-	-	2,296
Communications, awareness, representation and campaign activity	46,240	26,122	755	73,117
Provision of information via literature and packs	19,183	-	-	19,183
Family Event - digital programme	-	9,902	-	9,902
Residential actual / digital activities for young people	-	22,023	-	22,023
Attendance at hospital clinics	-	12,238	-	12,238
Support costs (note 6)	49,561	51,857	5,508	106,926
Governance costs (note 6)	16,576	16,576	1,842	34,994
Total	170,078	257,749	36,114	463,941

Expenditure on charitable activities was £466,941 (year to 31.12.2019: £690,410) of which £325,120 was unrestricted (year to 31.12.2019: £513,242) and £141,821 was restricted (year to 31.12.2019: £177,168).

NOTES TO THE FINANCIAL STATEMENTS

6 Analysis of governance and support costs

The Charity identifies the costs of both the support and governance functions and these are apportioned across the three charitable activities and the costs of raising funds on the relevant bases (see below).

	Charitable Outcomes			Income generation	
	General Support Costs	Governance Support Costs	Total Support Costs	Fundraising Support Costs	Basis of allocation
	£	£	£	£	
Salaries and related costs	17,301	24,483	41,784	8,990	On time allocation
Property	45,918	-	45,918	-	Occupancy
I T	14,928	-	14,928	785	Staff numbers
General Office	28,779	-	28,779	2,804	Staff numbers
Audit	-	9,500	9,500	500	Governance
Legal & other professional fees	-	1,011	1,011	53	Staff numbers
Total	106,926	34,994	141,920	13,132	

7 Net income from trading activities

The Charity has one dormant wholly owned subsidiary, CLDF (Trading) Limited; Registered office 36 Great Charles Street, Birmingham B3 3JY which is incorporated in the UK and registered in England. The accounts are filed at Companies House. The trading activities were transferred to the Charity from 01 April 2015 and are included in the SOFA and are as shown in Note 4.

Summarised balance sheet of CLDF (Trading) Limited	31.12.20	31.12.19
	£	£
Current assets	2	2
Creditors: amounts falling due within one year	0	0
Net Assets	2	2
Called up share capital	2	2
Profit and loss account	0	0
	2	2

NOTES TO THE FINANCIAL STATEMENTS

8 Net outgoing resources

	31.12.20	31.12.19
	£	£
Net- outgoing resources are stated after charging:		
Depreciation on owned assets	4,633	4,923
Auditor's remuneration for the statutory audit	10,000	5,000
Operating leases	<u>37,835</u>	<u>41,454</u>

9 Analysis of staff costs, trustee expenses, and the cost of key management Personnel

	31.12.20	31.12.19
	£	£
Salaries	351,791	426,225
Employers National Insurance	31,685	36,653
Pension costs (defined contribution schemes)	14,833	17,915
	<u>398,309</u>	<u>480,793</u>

Pension costs are allocated to the activity that the staff are engaged in and are charged to the unrestricted fund.

The key management personnel of the Charity are the Chief Executive Officer, the Head of Support, the Head of Fundraising and the Finance Manager. The total of employee benefits of key management personnel of the Charity was £181,384 (year to 31.12.2019: £207,819).

The Trustees were not paid nor received any emoluments or benefits during the year (year to 31.12.2019 £Nil). The trustees were reimbursed £0 for their expenses in the year (31.12.2019 £929).

10 Staff numbers

The average monthly number of employees during the year was 14 (31.12.2019 : 17) and the average number of full-time equivalent employees during the year was:

Average number of employees by category:	31.12.20	31.12.19
	No.	No.
Family Support	3	4
Information & Raising Awareness	2	2
Research	1	1
Raising Funds	2	4
Infrastructure	2	2
	<u>10</u>	<u>13</u>

NOTES TO THE FINANCIAL STATEMENTS

10 Staff numbers (continued)

During the year six employees were made redundant when the charity was restructured. Total redundancy payments were £4,201 (31.12.2019 : £0). Amounts outstanding to be paid at the year-end date were £0 (31.12.2019 : £0)

The number of employees whose emoluments, including benefits in kind and expenses, but excluding pension contributions, were in excess of £60,000 and disclosed in bands of £10,000 were as follows:-

	31.12.20 No.	31.12.19 No.
£60,001 - £70,000	<u>1</u>	<u>0</u>
£70,001 - £80,000	<u>0</u>	<u>1</u>

11 Related party transactions

The Charity has one subsidiary, CLDF (Trading) Limited (company registration number 01584165). The Charity does not have any related party transactions.

12 Corporation Taxation

The Charity is exempt from tax on income and gains falling within section 505 of the Taxes Act 1988 or section 252 of the Taxation of Chargeable Gains Act 1992 to the extent these are applied to its charitable objects.

13 Tangible fixed assets

	Computer Equipment £	Office Equipment £	Total £
Charity			
Cost			
As at 1 January 2020	50,355	43,293	93,648
Additions	3,546	-	3,546
Disposals	-	-	-
At 31 December 2020	<u>53,901</u>	<u>43,293</u>	<u>97,194</u>
Depreciation			
At 1 January 2020	49,775	38,797	88,572
Charge for the year	1,677	2,956	4,633
Disposals	-	-	-
At 31 December 2020	<u>51,452</u>	<u>41,753</u>	<u>93,205</u>
Net book value			
At 31 December 2020	<u>2,449</u>	<u>1,540</u>	<u>3,989</u>
At 31 December 2019	<u>580</u>	<u>4,496</u>	<u>5,076</u>

NOTES TO THE FINANCIAL STATEMENTS

14 Investments

Shares in subsidiary	31.12.20	31.12.19
Cost	£	£
At 1 January 2020 and at 31 December 2020	2	2

The investment in the subsidiary company represents 100% of the ordinary issued share capital of CLDF (Trading) Limited, a company incorporated in the UK and registered in England.

UK quoted - Fixed interest bonds	31.12.20	31.12.19
	£	£
Market Value at 1 January 2020	250,712	243,838
Disposals	(45,530)	(25,377)
Purchases	32,398	24,767
Realised (losses) on disposal	(2,135)	(92)
Net unrealised (losses) / gains	(2,316)	7,576
Market value at 31 December 2020	233,129	250,712
Historical cost as at 31 December 2020	218,413	233,904

15 Stock and inventory

	Charity	
	31.12.2020	31.12.2019
	£	£
Stock of literature	3,450	4,870
Goods for resale	1,130	1,990
	4,580	6,860

16 Analysis of cash and cash equivalents

	Charity	
	31.12.2020	31.12.2019
	£	£
Cash in hand	250	250
Current accounts	309,185	403,225
Cash held by Investment management Company	13,061	1,285
	322,496	404,760

17 Debtors due within one year

	Charity	
	31.12.2020	31.12.2019
	£	£
Other debtors	10,000	2,500
Prepayments and accrued income	33,610	32,445
	43,610	34,945

NOTES TO THE FINANCIAL STATEMENTS

18 Creditors due within one year

	31.12.2020	Charity As Restated 31.12.2019
	£	£
Research grants (note 21)	36,621	47,304
Trade creditors	30,664	47,887
Accruals	28,952	56,497
Taxes and social security	6,765	11,213
	<u>103,002</u>	<u>162,901</u>

19 Dilapidations Provision due within one year

	31.12.2020	Charity 31.12.2019
	£	£
Estimate costs of returning office to original condition at end of lease	<u>30,000</u>	<u>30,000</u>

20 Analysis of net assets between funds

	Restricted Funds	Unrestricted Funds	Total
	£	£	£
Fund balances at 31 December 2020 are represented by:-			
Tangible fixed assets	-	3,989	3,989
Investments	-	233,131	233,131
Current assets	56,267	314,417	370,684
Current liabilities	-	(133,002)	(133,002)
Total net assets	<u>56,267</u>	<u>418,535</u>	<u>451,794</u>

21 Research grants (note 18)

The following research projects have been granted funds by Children's Liver Disease Foundation. The following amounts represent the balance of accrued funding remaining unspent at the year end.

NOTES TO THE FINANCIAL STATEMENTS

	31.12.20	As Restated 31.12.19
Project Reference	£	£
2015 CLDF grant – Professor Amin Rostami-Hodjegan, University of Manchester: optimising drug regimens in paediatric liver disease using experimentally-derived simulation tools	6,197	13,550
2016 CLDF grant – Professor David Wraith, University of Birmingham: Development of biomarkers and novel therapeutics in autoimmune hepatitis type 2	30,424	30,424
2017 CLDF authorised grant expenditure	-	3,330
	36,621	47,304

22 Prior year adjustment

The prior year adjustment has been made to align the Research Projects creditor position in line with the revised accounting policy as outlined in note 1 regarding the recognition criteria for Research Projects. The adjustment amounted to £20,088 and this has been reflected in the SOFA and the opening Funds analysis has been updated accordingly.

23 Analysis of charitable funds

Analysis of movements in unrestricted funds

	At 1 January 2020	Incoming	Movement in Funds Transfers from Restricted Fund	Outgoing	At 31 December 2020
	£	£	£	£	£
Unrestricted Funds	305,158	448,522	11,500	406,645	358,535
Designated Funds	60,000	0	0	0	60,000
Total	365,158	448,522	11,500	406,645	418,535

Name of unrestricted fund

Description, nature and purposes of the fund

Unrestricted Funds

The "free" reserves after allowing for all designated funds

Designated Funds

The reserves designated by the trustees for the purpose of funding research

NOTES TO THE FINANCIAL STATEMENTS

23 Analysis of charitable funds (continued)

Analysis of movements in restricted funds

The income funds of the Charity include restricted funds comprising the following unexpended balances of restricted income held to be applied for specific purposes.

During 2020 the CEO negotiated with donors of restricted funds as the delivery of projects was unable to take place as planned because of the restrictions imposed by Covid 19 pandemic. Some funds were transferred to other restricted revised methods of delivery of projects and £11,500 was agreed to be released to the unrestricted general fund.

	Movement in Funds				
	At 1 January 2020	Incoming	Transfers	Outgoing	At 31 December 2020
	£	£	£	£	£
Research into biliary atresia fund	5,380	1	0	0	5,381
Research hub (1)	27,846	0	0	(24,282)	3,564
Clinic Visits – 2018	1,421	0	500	(1,921)	0
Welsh government funding of liver strategy	4,584	4,730	0	(7,482)	1,832
YP Events	5,200	2,150	(3,500)	(3,150)	700
Children in Need :Children & Families Officer post (2)	8,827	30,405	0	(29,481)	9,751
Global Make Some Noise – funding for family and YP events	17,704	0	0	(17,704)	0
Yellow Alert literature	1,894	0	0	(1,894)	0
Remote Support Workers–England (5)	34,500	0	(19,500)	0	15,000
Remote Support Workers–Scotland (5)	21,183	1,500	(2,500)	(19,387)	796
Project - development of volunteers	347	0	0	(347)	0
Family events	1,000	1,500	0	0	2,500
Information	5,000	0	0	(5,000)	0
Children in Need :Young People's Digital & Engagement Officer post (3)	9,410	9,598	0	(9,410)	9,598
Support Service	0	0	3,500	(3,500)	0
Capital Equipment	0	750	0	(750)	0
Core Costs (4)	0	10,000	10,000	(12,855)	7,145
Scotland Family Weekend	0	5,000	0	(5,000)	0
Total	144,296	65,634	(11,500)	(142,163)	56,627

NOTES TO THE FINANCIAL STATEMENTS

23 Analysis of charitable funds (continued)

Explanation of the purpose of material restricted funds:

1. Research Hub

The research hub provides a platform for families to provide details of their experiences to researchers which assists with the design of projects and methods of working.

2. Children in Need – Children & Families Officer post

This role works directly with patients and families providing emotional support; offering practical support.

3. Children in Need – Young People's Digital & Engagement post

This role works with young people across digital mediums to offer support, peer to peer contact and practical support

4. Core costs

Due to the Covid-19 pandemic some projects were unable to take place but the support offered by the activities was provided via different mediums. Some restricted funders agreed to the change of use of the funds whilst keeping the the funds restricted.

5. Remote Support Workers

These roles were for support officers based at the 3 main centres; this would enable more families to be met directly and offered the support of CLDF. The pandemic has meant these roles have had to be deferred.

Sufficient resources are held in an appropriate form to enable each fund to be applied in accordance with any restriction.

24 Research commitments

At 31 December 2020, the Charity had charged all the expenditure on research grants funded by both the general and restricted funds in compliance with Charities SORP FRS 102.

25 Reconciliation of net movement of funds to net cash flow from operating activities

	31.12.20	31.12.19
	£	£
Net movement in funds	(34,652)	(17,104)
Depreciation charge	4,633	4,923
Interest income shown in investing activities	(12,111)	(13,529)
Losses / (Gains) in valuation of investments	4,451	(7,484)
Decrease / (Increase) in stock	2,280	(995)
(Increase) / Decrease in debtors	(8,663)	41,164
(Decrease) in creditors	(59,899)	(80,224)
Net cash used in operating activities	(103,961)	(73,249)

NOTES TO THE FINANCIAL STATEMENTS

26 Financial commitments

The company is committed to making the following payments in the coming year in respect of operating leases.

	31.12.20	31.12.19
	£	£
Expiring within five years		
– serviced office rental	<u>24,180</u>	<u>41,454</u>