

Children's Liver Disease Foundation

Trustees' Report and Financial Statements for the year ended 31 December 2021

Charity Registration Number: 1067331 (England & Wales) SC044387 (Scotland)
Company Registration Number: 03431169

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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
Mrs Georgina Sugden
Dr Simon Colson (resigned 03rd November 2022)
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, resigned 21st February 2022)

Chief Executive & Company Secretary:
Ms Alison Taylor resigned 14 January 2022
Ms Katherine Myles (interim) appointed 10 January 2022

Key Management Personnel:

Chief Executive Officer	Ms Alison Taylor resigned 14 January 2022
	Ms Katherine Myles appointed 10 January 2022
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:
Crowe U.K. LLP
Rounds Green Road
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West Midlands
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The Trustees of Children's Liver Disease Foundation present their report and financial statements for the year ended 31 December 2021.

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 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	• Advances knowledge • Encourages young talent in scientific endeavours • Improved treatments • Provides evidence base for treatment regimens • Improved patient outcomes • Improved health economics
Information	• 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	• 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	• 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 (2020: £500,000) is in place through Markel at a cost of £286 (2020: £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

From its onset the Covid-19 pandemic has had a significant impact on CLDF. The organisation had been heavily reliant on fundraised income from events, sponsored activity and community fundraising, all of which were significantly affected by social distancing and the financial climate. Many of the charity's support events for beneficiaries had to be cancelled or postponed because of government guidance. The team rapidly adapted to new modes of working in order to diversify fundraising and offer services digitally, providing much needed support to families affected by child liver diseases. Second and third waves meant that this trend continued into 2021, creating uncertainty and challenging conditions both for fundraising and service delivery.

In July 2020 CLDF reviewed and reworked its strategic and operational plans. The organisation made the difficult decision to restructure, making six redundancies in order to safeguard the organisation's sustainability. The remaining team worked hard to maintain a consistent level of service delivery and to stabilise income, leaving the organisation in a relatively stronger position by the end of 2021 than 2020.

While society began to open up and some level of normality was resumed in 2021, the frequency and scale of community fundraising was still much lower than pre-pandemic levels. Many of our supporters are families who are directly affected by child liver disease and have needed to maintain a greater level of caution throughout the uncertainty of the pandemic. As the pandemic has continued, we know that many of our supporters and their networks have faced financial pressures. All these factors have impacted the recovery of our income, but the work to diversify income in light of the unprecedented nature of the pandemic has put the charity on a stronger footing going forward.

The organisation is cautiously optimistic about stabilising its income into 2022. At time of writing the Office for National Statistics reports that 99% of adults as testing positive for Covid-19 antibodies and despite ongoing levels of community infection, social and cultural activities appear to be broadly resumed.

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 work-related objectives, personal development goals 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 strategic direction and ongoing risk management; this is further developed to achieve the objectives and monitor performance.

Due to the Covid-19 pandemic, the implementation of the plans for 2021 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 2021 grant round was also cancelled due to the ongoing challenges of the pandemic. During 2021 we received promising updates on the following CLDF funded research into child liver diseases:

- Dr Deborah Gill - https://childliverdisease.org/genome-editing-of-liver-organoids-for-treatment-of-alpha-1-antitrypsin-deficiency/
- Professor David Wraith, Dr Ye Oo and Naomi Richardson (PhD student) - https://childliverdisease.org/t-cell-epitopes-autoimmune-hepatitis-type-2/
- Dr Jake Mann - https://childliverdisease.org/identification-of-biomarkers-in-paediatric-fatty-liver-disease/

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 2021 we continued to work with partners across the sectors to secure meaningful input from patients and families, ensuring that both research aims and methodologies were well informed by the needs of children with liver conditions.

In 2021 CLDF has played a key role in facilitating patient involvement in a range of research projects which seek to improve the quality of life for children with liver conditions, including Biliary Atresia, Progressive Familial Intrahepatic Cholestasis and Liver Cancer.

CLDF made an organisational submission to the NICE consultation process for a new treatment for Progressive Familial Intrahepatic Cholestasis (PFIC). The charity also facilitated

and supported the parents of children with PFIC to contribute to the NICE process, including making submissions to the appeals process following NICE's original decision not to recommend the drug for the treatment of PFIC. This resulted in the approval of the treatment in early 2022. We are prepared to engage in the NICE approval process for the use of this drug for Alagille Syndrome in 2022

As a member of the European Reference Network Rare Liver CLDF contributed to a publication in JHep Reports before resubmission: "Autoimmune liver disease patients in Europe during the SARS-CoV-2 pandemic: a patient-oriented online survey". CLDF was integral in recruiting participants to study and will be a co-author on the paper when published.

CLDF worked in collaboration with British Paediatric Allergy Immunology & Infection Group and the CEO and Research Hub Manager were co-authors of a paper addressing "The Ethics of Overruling Parental Refusal of Neonatal Hepatitis B Vaccination for Babies Born to Mothers with Hepatitis B Virus Infection" which is due to be published in 2022.

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 94,405 distribution across all means of access.

COVID 19 Related Activity

Throughout the Covid-19 pandemic CLDF has continued to provide guidance, explanations of government briefings and how Covid-19 affects our families, children and young people clinically, socially and educationally. CLDF provided ongoing updates and blogs to support with various issues including accessing services. 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.

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. This included a new leaflet on Primary Sclerosing Cholangitis (PSC) and an update on our Pruritis leaflet in August 2021.

In 2021 CLDF provided:

- 60 Transplant Storybooks to individuals and hospitals
- 2984 medical, nutrition and support leaflets to hospitals
- 2759 medical, nutrition and support leaflet PDF downloads from the website
- 127 hard copy medical, nutrition and support leaflets to individuals

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).

We continue to support maternity ward and neonatal wards in Doncaster and Bassetlaw Hospitals, Ormskirk, Central and North West London, Hertfordshire and Kent areas in providing yellow alert parents leaflets to every new parent in their service.

As a result of developing contacts within the health visiting and midwifery professions, a case study was developed about the impact of Yellow Alert resources on teams at Dorset Hospital. The Advanced Neonatal Nurse Practitioner told us about the impact of Yellow Alert resources: https://childliverdisease.org/why-our-teams-on-yellow-alert/.

In 2021 CLDF distributed 19,523 Yellow Alert resources, including:

10 Yellow Alert packs posted to individuals
786 Yellow Alert packs posted to professionals
16,394 Yellow Alert leaflets distributed including stool charts
1635 downloads of Yellow Alert materials from our website
688 Yellow Alert app downloads

We aim to further develop our reach into maternity and neonatal services in 2022-2023 in line with our available resources.

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 need; from

helping families to find their new normality, to supporting young people to take responsibility for their liver disease/transplant and through their 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
- Facilitating supportive peer networks

86 new families accessed our support over 2021. We are heartened to know that we have been able to continue to reach families despite our access to hospital clinics being curtailed due to the pandemic in 2021.

Contact	Frequency
Requests for general CLDF information (leaflets etc)	110
Phone calls from families	431
Emails/direct messages from families	983
Phone calls from YP	30
Emails/ direct messages YP	650
Website direct messages	64
Zoom sessions	158
Families attended	120
YP attended	315

Hospital ward and clinic visits

Our hospital ward and clinic visiting remained on hold throughout 2021. We continue to explore how we can engage with parents within a clinic setting in order to meet them at the very start of their liver journey while we are unable to physically attend clinics and wards. We have created videos that parents can view at https://childliverdisease.org/parents/talk-to-someone/ and have asked clinical colleagues about sharing with families as a part of their appointment reminder. The Head of Support has also identified CLDF champions within clinical settings who we hope will ensure that parents receive our information and are made aware of our offer. We will continue to explore these alternative approaches while face-to-face work is not possible.

The Children and Families Officer has continued to focus on 1:1 support for families via Zoom drop in opportunities.

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Support has centred on three themes:

Emotional

- reassurance and initial support immediately after diagnosis
- parent anxiety over child's condition
- facilitating peer to peer support
- 1:1 emotional support and advice with families
- drop in opportunities via Zoom twice a month during the day

- mental health and emotional support for parents of children with liver disease and signposting to appropriate support

Advocacy

- advocacy with schools specifically regarding return after the isolation experienced during Covid and with new public health measures
- help with sourcing peer to peer support
- phone and video calls with Headteachers around the country and consultations with SENCOs to ensure adequate support is in place for children with liver disease in mainstream education
- liaising with parents to engage and support schools and nurseries to ensure best care and support is in place for their child
- support with contacting medical teams (reduced face to face appointments has led to decreased face to face time with some professionals, increasing parental anxiety)

Practical

- financial support and help due to ongoing Covid-19-related financial worries including benefits appeals and applications
- information on liver conditions

Our Children and Families Officer has supported families to access and secure individual grants to relieve the financial impact of having a poorly child, as well as gifts in kind so that families can go on holiday.

Our Children and Young People's Officer provided a weekly briefing to parents from January to July, and fortnightly from August to December as restrictions were lifted. The briefing is sent at the start of each week and helps to build relationships with families.

Feedback from parents:

"Found the information so helpful, I was feeling really worried when I contacted CLDF and they were so reassuring and nice and helpful".

"Thanks for the information and understanding, we had got scared using google and didn't know a lot of things. It's nice to meet other families going through the same thing".

"Took the weight off my shoulders when my son has to go back to school. CLDF supported me and him and helped him with school".

"Helpful and supportive when we weren't sure what we needed".

Family Zooms

Throughout 2021 we provided a fortnightly drop in Zoom for families on a Thursday which allowed parents to chat to the Children and Families Officer and to other parents. For the first four months of 2021 when restrictions were in place we also hosted a monthly evening community catch up for parents and children to both join before splitting into separate rooms with fun activities for the children and a social catch-up for parents.

Scotland Digital Family Day

We ran the 2021 Scotland Digital Family Day in November which was very well received despite low numbers. We attributed this to both 'zoom fatigue' and other commitments.

We also ran a successful workshop titled 'Create your own calm' which we hope to roll out across the UK for families in 2022.

Hive Hang Outs

Young people continue to enjoy the opportunity to drop in at any time between 10 and 1pm fortnightly to see friends they already know and meet new young people with whom they can build relationships. They have used the time to talk through anything that is on their mind including the ongoing pandemic, the vaccine and their own health issues. The Hang Out is also an opportunity for social chats and for young people offer advice and support to their peers. They have also used this time to have 1:1 chats with CLDF staff.

"Being a part of the Hive community really is like being a sorry of a big family (I know it sounds cringe!). You are able to simply be yourself and everyone will give you a warm welcome and they also have an understanding of where you are coming from and the obstacles you have overcome to be where you are today. I wouldn't be where I am without them all!"

"HIVE has been amazing, because you get to speak to people who understand what it's like to have a liver disease and go through processes such as transplantation as well as day to day life with liver disease. It's been very helpful for me to be able to speak to people who fully understand any anxieties and symptoms of living with a liver disease, I'm so grateful for the group!"

Wellbeing and Being Human Programme

We have worked in partnership with Kings College Hospital in 2021 to deliver a wellbeing programme with 6 young people. The course focused on self-care tools and techniques and allowed the group time to look at ways to feel brighter, happier and more relaxed during an ongoing period of worry and concern both relating to their condition and the external environment. The sessions were two hours per week over Zoom for 8 weeks.

"Thanks to the practical, well-considered and thoughtful tips that I have learned during the course, I know that there are ways of coping with challenging situations on the spot and supporting myself in the more challenging moments rather than just letting them happen to me. I have learned that it is the power of my thoughts that creates a knock on effect for how I will be from then on".

BounceBack

In 2021 we developed a new project called BounceBack as a digital alternative to our annual residential Breakaway, which focuses on mental wellbeing and resilience and is designed to be done within the home environment over Zoom.

The project aimed to:

- help young people feel better through sharing experiences with other young people similar to them
- increase their ability to cope in difficult times

- increase their confidence through group work and challenges
- develop wider skills, such as how to support others, reflect on what has been happening recently and problem solve
- ensure that they know that they are not alone after a time of isolation

Seven young people participated in resilience building activities including making a Bounceback box, designing their own mask, cooking, an escape room, ice-breaker sessions and quizzes. The programme was completed over Zoom and young participants were provided with their own Bounceback pack and resources.

During their reflection session and subsequent feedback the young people reported enjoying the week:

"My overall experience, astonishing! I enjoyed getting to know all the other children and their different types of liver conditions."

"I would advise other kids with similar problems to come and join because it has taught me not to stress about it and it's a time and space where I can be free from stress."

"[I'm] more confident in my liver disease and in me."

"Loved all the activities and everyone I met. Bounceback Box is my treasure."

Parents also provided their feedback on the impact:

"Although E only managed one session, she loved it! She was very nervous and resistant before the session and insisted she wanted to keep her mic and camera off but joined in straight away and said it was great."

"A great initiative, enthusiastic staff, really well organised and creative ideas. E really enjoyed it and I can now use the experience next time she resists a new situation to remind her how nervous she was about meeting others on Bounceback and how quickly she adapted. Thanks so much."

"K was very nervous and wasn't sure she wanted to join in but you guys made her feel very welcome. She is now asking more questions about her condition. K has made new friends that she is keeping in touch with. Thank you CLDF for this opportunity."

"It provides a fun, safe space for children to meet other children with similar issues which allows them to realise they are not alone."

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 and development of national policies through digital channels.

National Screening Committee Submission

In collaboration with specialist centres we proposed in 2021 that Yellow Alert stool charts be utilised in the personal child health record to support screening for Biliary Atresia. As a result of this proposal the committee decided to expand the scope of their evidence map to include questions on the accuracy of stool colour cards to identify biliary atresia, whether their use improves time to surgery, and the time to surgery in the UK. The output from this exercise will inform the next UK NSC decision on whether the evidence is sufficient to commission further review work.

Birmingham Children's Hospital 30th Anniversary Conference Care closer to home and virtual appointments – patient views

CLDF collected views from 100 patients and carers about their experiences of care via virtual consultations during the pandemic. The results were shared by the CEO at this international virtual meeting. The data was also used at the 2021 Annual CQUINN Audit meeting of NHS commissioners.

CLDF has provided expert input to inform the development of the following services:

NHS England Highly Specialised Services - providing feedback on the NHSE digital care document/guidance and rare disease framework.

Northern Ireland Organ Donation Consultation – providing comments on the consultation regarding Northern Ireland moving to a deemed consent approach and shared the public consultation opportunity on social media.

NHS Blood and Transplant (NHSBT) - reviewing the draft website for liver transplants (adults) for those on the transplant waiting list as we have a cohort of young people who may be accessing this site.

We continue to work closely with NHSBT. The emphasis this year has been promoting messages regarding the change in organ donation law in England since May 2020 using the real-life story of families of those who have donated. We have supported the new NHSBT organ donation campaign called 'Leave them certain' through social media platforms and supported the communications campaign celebrating and highlighting the law change anniversary in May.

Membership of boards and committees

National Paediatric HCV MDT Steering Group (HCV pMDT)

The CEO sits on the steering group for this national project to roll out treatment and elimination of Hepatitis C in the UK paediatric population. The charity provides patient perspective and reviews patient centred practice and communications. During the period the charity reviewed stakeholder articles for circulation announcing National HCV pMDT ODN and published communications about this development to both members and professionals via CLDF channels: https://childliverdisease.org/national-paediatric-multidisciplinary-operational-delivery-network-for-treating-hepatitis-c-goes-live/

The CEO is Vice Chair of the **Liver Patients' Transplant Consortium** and worked with the leaders of three other liver charities to formally review the business case for NHSBT commissioning additional liver transplant units in the UK (Liverpool and Plymouth). A formal response was developed and submitted as the Liver Patient Transplant Consortium. The need for greater capacity and geographic spread was highlighted but also the need for staff with the necessary expertise and highly specialised skills. In response, NHS England have committed that a full formal review of the liver transplant service pathway will be undertaken to ascertain where investment should take place to improve patient outcomes.

2022 will see the Liver Patients' Transplant Consortium superseded by a new UK Liver Patient Alliance, and CLDF will continue to play a key role.

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.

2021 saw the **UK Lancet Commission 'Addressing liver disease in the UK'** draw to a close, concluding CLDF CEO's work as a commissioner. The final Lancet Commission report was released in April 2021. The UK Lancet Commission will be succeeded by the UK Liver Alliance which will continue to bring clinicians and patient groups together to advance liver knowledge and influence policy across all four nations of the UK.

The charity's CEO was also a co-author of The European EASL Lancet Commission on Liver Disease's first report which was published in December 2021 https://www.thelancet.com/commissions/liver-disease-europe

The Charity has worked with a variety of external campaigns to instigate change that will improve outcomes for our beneficiaries, including:

- **AMRC #ResearchAtRisk campaign,** calling on government to back charity funded research.
- **Institute of Health Visiting campaign,** highlighting funding needs during the pandemic
- **National Voices campaign,** calling for clear and consistent communication during the pandemic
- **Scotland Human Tissue Update,** supporting the campaign, engaging and sharing their communications through our channels.
- **Obesity Health Alliance** CLDF supporting the joint letter to the Prime Minister re-stating the case for the policy assessment calculations that aims to show the benefits of the policy, in terms of calories removed from children's diets, at a population level.
- **Prescription Charges Coalition** Announcement to families and young people about a further rise in prescription charges on 1st April despite ongoing campaigning. CLDF supported the coalition in their call to Jim Bethell to review the exemption list urgently.
- **Rare Disease Day** Supporting awareness days for rare diseases

Fundraising

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

While 2021 was a better year for the charity than 2020, fundraising was still very much affected by the public health situation and there was not a return to pre-pandemic levels of income. CLDF channelled efforts into diversifying income and reducing the charity's dependence on those fundraising activities which involve face-to-face interactions and group gatherings. This challenge was exacerbated by the reduction in fundraising staffing.

Community fundraising continued to be severely impacted by the pandemic in 2021. Our income from this fundraising stream was £37,190 (£42,678 in 2020 and £66,787 in 2019). Big Yellow Friday 2021, our annual fundraising day was also affected raising only £8,944 compared to £37,460 in 2020, largely due to the 2020 event falling just before the onset of the pandemic.

Challenge events are another key area of fundraising income for the charity. In 2021 our incredible supporters took part in the London Marathon raising £23,498 (2020 £33,228) and the Great North Run raising £8474 (2020 £2930). Income from challenge fundraising totalled £82,726 in 2021 (2020 £71,696) while remaining significantly lower than pre-pandemic levels

Trusts and Grants income have been an area increased focus in order to offset the drop in community and events income. However, competition for grant funding intensified as much of the charity sector faced serious limitations across most other income streams. During the year to December 2021 donations were received from 27 charitable trusts totalling £105,425 (2020 £84,003). This included the first year of a significant award from BBC Children in Need. While 2021 saw an increase in grant funding relative to 2020, the 2021 total grant income was approximately 50% of the grant income received in 2019.

Donations of £5,000 or more were received from the following trusts:-

- The PF Charitable Trust £10,000
- The Robertson Trust £10,000
- The Adint Charitable Trust £5,000
- Souter Charitable Trust £5,000
- BBC Children in Need £41,178

In 2021 we received £35,522 in personal donations (2020 £46,477). This level of personal donations was significantly higher than pre-pandemic levels, reflective of our responsive and committed supporters who rallied to support the charity through the pandemic. We are very thankful to each and every person who donated to the charity in 2021.

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.
A revised operational plan and budget were produced for 2020 and this revised structure has continued in 2021 to ensure overheads are contained and in line with changing income levels.

Income for the year to 31 December 2021 of £570,818 was 11% higher than the year ended 31st December 2020. However, the 2020 total includes £35,558 of furlough income support from the government.
Excluding the furlough income shows our core income in 2021 increased by 19% but is still significantly below pre- Covid levels. 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 2021 were voluntary income of £516,849 of which £304,241 was received from supporters; £105,425 from charitable trusts (see Fundraising section); £30,700 of statutory funding and £76,483 from legacies.

The Covid-19 pandemic continues to have 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 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 and this has continued during 2021.

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 2020 and in view of the current economic climate and the Covid 19 pandemic it was 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 continue to deem it prudent to hold higher level of reserves as it is expected income levels for 2022 will develop slowly.

The Trustees, therefore, consider that, based on the 2022 budget, the ideal level of reserves on 31st December 2021 would be between £320,000 and £400,000.

The actual unrestricted fund, excluding the designated £60,000, on 31 December 2021 is £436,424. This equates to covering 11.6 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. During 2020 and 2021 much of this work has been performed remotely. 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 Mrs Georgina Sugden, Mr Joel Glover and Mr Philip Orme 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

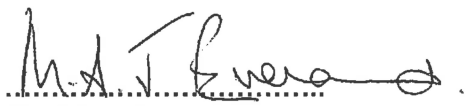
So far as the Directors are aware at the time of approving our annual report:-

- 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.

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



Mrs Mairi Everard
Chairman
28 June 2022

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

Independent Auditor's Report 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 2021 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 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 2021 and of its its 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 200, 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 trustees' 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 its 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 requires us to report to you if, in our opinion:

- adequate 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 16, 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

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.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed 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 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, designated audit procedures over income 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

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

Date: 25 July 2022

STATEMENT OF FINANCIAL ACTIVITIES (including Income and Expenditure Account) FOR THE YEAR ENDED 31 DECEMBER 2021

	Note	Unrestricted Fund	Restricted Fund	Year Total 31.12.21	Year Total 31.12.20
		£	£	£	£
INCOMING RESOURCES					
Income					
Donations and legacies	4	419,423	97,426	516,849	501,324
Charitable activities	4	34,200	13,914	48,114	
Trading activities	4	494	-	494	722
Investments	4	5,361	-	5,361	12,110
Total Incoming Resources		**459,478**	**111,340**	**570,818**	**514,156**
RESOURCES EXPENDED					
Costs of raising funds					
Raising Funds		48,998	-	48.998	80,150
Trading activities		156	-	156	266
Total		49,154	-	49,154	80,416
Charitable activities					
Education and awareness campaigns	5	149,248	29,832	179,080	170,078
Provision of emotional support	5	176,313	69,787	246,100	257,749
Research grants and expenditure	5	15,232	3,564	18,796	36,114
Total		340,793	103,183	443,976	463,941
Total expenditure		**389,947**	**103,183**	**493,130**	544,357
Net gains / (losses) on investments	14	5,858	-	5,858	(4,451)
Transfers between funds	22	2,500	(2,500)	0	0
Net surplus / (expenditure) and net movement in funds for the year		77,889	5,657	83,546	(34,652)
Total funds brought forward at 1 January 2021		**418,535**	**56,267**	**474,802**	509,454
Total funds carried forward at 31 December 2021		**496,424**	**61,924**	**558,348**	474,802

The notes on pages 27 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.

BALANCE SHEET OF THE CHARITY AS AT 31 DECEMBER 2021

	Note	£	31.12.2021 £	£	31.12.2020 £
Fixed assets					
Tangible assets	13		3,824		3,989
Investments	14		233,811		233,131
			237,635		237,120
Current assets					
Stock and inventory	15	5,176		4,580	
Cash and short-term deposits	16	418,687		322,496	
Debtors due within one year	17	41,962		43,608	
		465,825		370,684	
Current liabilities					
Creditors due within one year	18	115,112		103,002	
Dilapidations provision	19	30,000		30,000	
Net current assets			320,713		237,682
Total assets less current liabilities			558,348		474,802
Net assets			558,348		474,802
Represented by					
Restricted Funds	22		61,924		56,267
Unrestricted Funds	22		436,424		358,535
Designated Funds	22		60,000		60,000
Total Funds			558,348		474,802

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 28 June 2022.

M. A. J. Everard.

Mrs M Everard

Mr P Orme

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31 DECEMBER 2020

	Note	31.12.2021 £	31.12.2020 £
Cash used in operating activities	23	89,679	(103,961)
Cash flows from investing activities			
Interest Income		5,361	12,111
Disposal of investments		185,666	45,530
Purchase of investments		(180,488)	(32,398)
Purchase of tangible fixed assets		(4,027)	(3,546)
Cash provided by investing actions		**6,512**	**21,697**
(Decrease) in cash and cash equivalents in the year		96,191	(82,264)
Cash and cash equivalents at the beginning of the year		322,496	404,760
Total cash and cash equivalents at the end of the year		**418,687**	**322,496**

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 surplus of £83,546, which arose mainly from a substantial and unexpected legacy. 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 2023 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 2021 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 2020.

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 2021 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.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

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.

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

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued

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.

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 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.

NOTES TO THE FINANCIAL STATEMENTS

1 Accounting Policies (continued)

q) Pension

The Charity operates 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.

The charity paid into an individual defined contribution pension scheme for the CEO, Ms A Taylor. This ceased when Ms Taylor left in January 2022. The interim CEO became a member of the defined contribution scheme, as will the new CEO.

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 2021 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.

NOTES TO THE FINANCIAL STATEMENTS

4 Incoming Resources Notes

	Year	31.12.21		Year	31.12.20	
	Unrestricted Funds	Restricted Funds	Total	Unrestricted Funds	Restricted Funds	Total
Incoming Resources	£	£	£	£	£	£
Donations & legacies						
Donations	304,241	-	304,241	372,833	-	372,833
Statutory Funding	-	30,700	30,700	-	4,730	4,730
Charitable Trusts	38,699	66,726	105,425	23,100	60,903	84,003
Legacies	76,483	-	76,483	4,200	-	4,200
Coronavirus Job Retention Scheme	-	-	-	35,558	-	35,558
	419,423	**97,426**	**516,849**	**435,691**	**65,633**	**501,324**
Trading activities						
Sales of merchandise	**494**	**-**	**494**	**722**	**-**	**722**
Charitable activities						
Activities involving beneficiaries	**34,200**	**13,914**	**48,114**	-	-	-
Investments						
Listed securities - UK	3,347	-	3,347	11,500	-	11,500
Listed securities-Overseas	1,986	-	1,986	508	-	508
Bank interest	28	-	28	101	1	102
	5,361	**0**	**5,361**	**12,109**	**1**	**12,110**
Total	**459,478**	**111,340**	**570,818**	**448,522**	**65,134**	**514,156**

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	-	-	11,637	11,637
Working with beneficiaries and stakeholders	38,994	147,559	-	186,553
Medical Conferences	-	-	-	-
Communications, awareness, representation and campaign activity	50,704	24,375	592	75,671
Provision of information via literature and packs	30,278	-	-	30,278
Family Event - digital programme	-	6,000	-	6,000
Residential actual / digital activities for young people	-	7,400	-	7.400
Attendance at hospital clinics	-	-	-	-
Support costs (note 6)	36,657	38,320	4,073	79,050
Governance costs (note 6)	22,447	22,446	2,494	47,387
Total	**179,080**	**246,100**	**18,796**	**443,976**

Expenditure on charitable activities was £443,976 (year to 31.12.2020: £463,941) of which £340,793 was unrestricted (year to 31.12.2020: £322,120) and £103,183 was restricted (year to 31.12.2020: £141,821).

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	11,922	32,944	44,866	20,662	On time allocation
Property	33,298	-	33,298	-	Occupancy
I T	19,563	-	19,563	1,030	Staff numbers
General Office	14,267	-	14,267	751	Staff numbers
Audit	-	9,070	9,070	480	Governance
Legal & other professional fees	-	5,373	5,373	280	Staff numbers
Total	**79,050**	**47,387**	**126,347**	**23,203**	

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	31.12.21	31.12.20
	£	£
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

	31.12.21 £	31.12.20 £
Net- outgoing resources are stated after charging:		
Depreciation on owned assets	4,192	4,633
Auditor's remuneration for the statutory audit	9,550	10,000
Operating leases	25,426	37,835

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

	31.12.21 £	31.12.20 £
Salaries	286,718	351,791
Employers National Insurance	24,830	31,685
Pension costs (defined contribution schemes)	12,630	14,833
	324,178	398,309

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, and the Finance Manager. The total of employee benefits of key management personnel of the Charity was £176,564 (year to 31.12.2020: £181,384 – this included the Head of Fundraising who left in December 2020).

The Trustees were not paid nor received any emoluments or benefits during the year (year to 31.12.2020 £0). The trustees were reimbursed £125 for their expenses in the year (31.12.2020 £0).

10 Staff numbers

The average monthly number of employees during the year was 9 (31.12.2020 : 14) and the average number of full-time equivalent employees during the year was:

Average number of employees by category:	31.12.21 No.	31.12.20 No.
Family Support	3	3
Information & Raising Awareness	1	2
Research	1	1
Raising Funds	1	2
Infrastructure	2	2
	8	10

During 2020 six employees were made redundant when the charity was restructured. There were no redundancy payments in 2021 (31.12.2020 : £4,201). Amounts outstanding to be paid at the year-end date were £0 (31.12.2020 : £0)

NOTES TO THE FINANCIAL STATEMENTS

10 Staff numbers (continued)

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:-

	31.12.21 No.	31.12.20 No.
£60,001 - £70,000	0	1
£70,001 - £80,000	1	0

11 Related party transactions

The Charity has one subsidiary, CLDF (Trading) Limited (company registration number 01584165).
Related party transactions include unrestricted donations of £4,820 from trustees and / or relatives of trustees..

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 2021	53,901	43,293	97,194
Additions	4,027	-	4,027
Disposals	(25,990)	(8,752)	(34,742)
At 31 December 2021	31,938	34,541	66,479
Depreciation			
At 1 January 2021	51,452	41,753	93,205
Charge for the year	2,652	1,540	4,192
Disposals	(25,990)	(8,752)	(34,742)
At 31 December 2021	28,114	34,541	62,655
Net book value			
At 31 December 2021	3,824	0	3,824
At 31 December 2020	2,449	1,540	3,989

NOTES TO THE FINANCIAL STATEMENTS

14 Investments

Shares in subsidiary	31.12.21	31.12.20
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	31.12.21	31.12.20
	£	£
Market Value at 1 January 2021	233,129	250,712
Disposals	(185,666)	(45,530)
Purchases	180,488	32,398
Realised gains / (losses) on disposal	5,878	(2,135)
Net unrealised (losses)	(20)	(2,316)
Market value at 31 December 2021	233,809	233,129
Historical cost as at 31 December 2021	231,200	218,413

15 Stock and inventory

	Charity	
	31.12.2021	31.12.2020
	£	£
Stock of literature	4,166	3,450
Goods for resale	1,010	1,130
	5,176	4,580

16 Analysis of cash and cash equivalents

	Charity	
	31.12.2021	31.12.2020
	£	£
Cash in hand	250	250
Current accounts	402,569	309,185
Cash held by Investment management Company	15,868	13,061
	418,687	322,496

17 Debtors due within one year

	Charity	
	31.12.2021	31.12.2020
	£	£
Other debtors	2,000	10,000
Prepayments and accrued income	39,962	33,610
	41,962	43,610

NOTES TO THE FINANCIAL STATEMENTS

18 Creditors due within one year

	Charity	
	31.12.2021	31.12.2020
	£	£
Research grants (note 21)	36,621	36,621
Trade creditors	31,027	30,664
Accruals	41,276	28,952
Taxes and social security	6,188	6,765
	115,112	103,002

19 Dilapidations Provision due within one year

	Charity	
	31.12.2021	31.12.2020
	£	£
Estimate costs of returning office to original condition at end of lease	30,000	30,000

20 Analysis of net assets between funds

	Restricted Funds	Unrestricted Funds	Total
	£	£	£
Fund balances at 31 December 2021 are represented by:-			
Tangible fixed assets	-	3,824	3,824
Investments	-	233,811	233,811
Current assets	61,924	403,901	465,825
Current liabilities	-	(145,112)	(145,112)
Total net assets	61,924	496,424	558,348

NOTES TO THE FINANCIAL STATEMENTS

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.

Project Reference	31.12.21 £	31.12.20 £
2015 CLDF grant – Professor Amin Rostami-Hodjegan, University of Manchester: optimising drug regimens in paediatric liver disease using experimentally-derived simulation tools	6,197	6,197
2016 CLDF grant – Professor David Wraith, University of Birmingham: Development of biomarkers and novel therapeutics in autoimmune hepatitis type 2	30,424	30,424
	36,621	**36,621**

NOTES TO THE FINANCIAL STATEMENTS

22 Analysis of charitable funds

Analysis of movements in unrestricted funds

		Movement in Funds			
	At 1 January 2021	Incoming	Transfers from Restricted Fund	Outgoing	At 31 Decembe 202
	£	£	£	£	
Unrestricted Funds	358,535	459,478	2,500	384,089	436,42
Designated Funds	60,000	0	0	0	60,00
Total	**418,535**	**459,478**	**2,500**	**384,089**	**496,42**

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

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 2021 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 £2,500 was agreed to be released to the unrestricted general fund.

NOTES TO THE FINANCIAL STATEMENTS

		Movement in Funds			
	At 1 January 2021	Incoming	Transfers	Outgoing	At 31 December 2021
	£	£	£	£	£
Research into biliary atresia fund	5,381	0	0	0	5,381
Research hub (1)	3,564	0	0	(3,564)	0
Christopher J Tromans Foundation	0	1,000	0	(0)	1,000
Welsh government funding of liver strategy	1,832	30,700	0	(7,041)	25,491
YP Events	700	0	0	(0)	700
Children in Need :Children & Families Officer post (2)	9,751	23,389	0	(24,342)	8,798
Yellow Alert literature	0	4,497	0	(3,401)	1,096
Remote Support Workers–England (5)	15,000	0	(14,500)	(500)	0
Remote Support Workers–Scotland (5)	796	19,000	0	(13,665)	6,131
Family events	2,500	0	(1,500)	0	1,000
Supporting PFIC families	0	3,550	0	(1,200)	2,350
Children in Need :Young People's Digital & Engagement Officer post (3)	9,598	9,790	0	(9,411)	9,977
Support Service Costs	0	0	10,000	(10,000)	0
CLDF Information Services & Yellow Alert (6)	0	13,914	0	(13,914)	0
Core Costs (4)	7,145	0	0	(7,145)	0
Supporting children, young people & families	0	5,500	3,500	(9,000)	0
Total	**56,267**	**111,340**	**(2,500)**	**(103,183)**	**61,924**

NOTES TO THE FINANCIAL STATEMENTS

22 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. During 2021 £14,500 of this funding was agreed with the funders to be redesignated to fund the support services.
6. **CLDF Information Services and Yellow Alert**
   During 2021 an application was made to companies for funding to support the costs of the provision of the information service and yellow alert

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

23 Research commitments

At 31 December 2021, 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.

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

	31.12.21 £	31.12.20 £
Net movement in funds	83,546	(34,652)
Depreciation charge	4,192	4,633
Interest income shown in investing activities	(5,361)	(12,111)
(Gains) / Losses / in valuation of investments	(5,858)	4,451
(Increase) /Decrease in stock	(596)	2,280
Decrease / (Increase) in debtors	1,646	(8,663)
Increase / (Decrease) in creditors	12,110	(59,899)
Net cash used in operating activities	**89,679**	**(103,961)**

NOTES TO THE FINANCIAL STATEMENTS

25 Financial commitments

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

	31.12.21 £	31.12.20 £
Serviced office rental		
Within one year	22,664	24,180
2 – 5 years	13,221	0