



Children's Liver Disease Foundation

Trustees' Report and Financial Statements for the year ended 31 December 2019

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

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

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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 (Chair, appointed 27th February 2020)
Mr Thomas M Ross OBE (Chairman, retired 27th February 2020)
Mr Nicholas Budd (retired 27th February 2020)
Professor John Iredale
Ms Theresa Legay (retired 1st June 2020)
Mrs Karen Redgate (retired 4th December 2019)
Mrs Georgina Sugden
Dr Simon Colson (appointed 4th April 2019)
Ms Kate Dinwiddy (appointed 4th April 2019)
Mr Joel Glover (appointed 4th April 2019)
Professor James Neuberger (appointed 4th April 2019)
Mr Phil Orme (appointed 13th June 2019)

Chief Executive & Company Secretary:

Ms Alison Taylor

Key Management Personnel:

| | |
|-------------------------|--|
| Chief Executive Officer | Ms Alison Taylor |
| Head of Support | Mrs Michelle Wilkins |
| Head of Fundraising | Mrs Sophie Burt – maternity leave 30 th December 2019 |
| | Mr Ian Watson – maternity cover |
| Finance Manager | Mrs Gillian Baylis |

Registered Office:

36 Great Charles Street
Birmingham B3 3JY

Bankers:

Bank of Scotland
33 Old Broad Street
London

Auditor:

Stephen W Jones FCA
King Edward House
82 Stourbridge Road
Halesowen, West Midlands B63 3UP

Investment Adviser:

Brewin Dolphin
9 Colmore Row
Birmingham B3 2BJ

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

The Trustees of Children's Liver Disease Foundation present their report and financial statements for the year ended 31 December 2019.

Objects of the Charity

As a registered charity, Children's Liver Disease Foundation 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 and 29 July 2013. 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. In addition to regular Board meetings, the Trustees receive regular updates and additional away days to focus on specific issues as required. In 2019 we recruited five new trustees to the board.

The Charity historically had one standing sub-committee; the Scientific Committee, which advises the Trustee Board on medical, scientific and research matters, assesses research grant applications and reviews grant reports. The Scientific Committee meets annually and is comprised of leading figures from the health and research community. In 2019 the board developed two further sub committees, which comprise of members of the Trustee board. The Governance committee and the Finance and Fundraising committee will augment the boards oversight of the charity, it's income generation, processes and delivery of beneficiary outcomes.

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.

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Covid-19 Pandemic 2020

The Covid-19 pandemic has created significant risk for the organisation's operations 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. 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 is focussing 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. CLDF has made use of the government job retention scheme to furlough a range of staff. From April 2020 financial and operational reporting to the Board is taking 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 plans and staffing costs are being reviewed and reworked to ensure that the charity maintains 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 2020-2023 strategic plan. 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 our 2020 plans are under continual review and 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.

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

CLDF ran two grant rounds in 2019. The first was a focussed grant round for projects relating to Donor Specific Antibodies and the second an open grant call.

The Donor Specific Antibody Project round was awarded for:-

- A Multi-centre prospective study of Donor-specific antibodies in children following liver transplantation

Dr Girish Gupte, Birmingham Children's Hospital et al

The open grant round received seven applications for funding. The Scientific Committee met in September 2019 to consider applications. Three applications were awarded funding:-

- Interpretable machine learning methods for cross-omic mechanistic signatures of young hepatoblastoma

Dr Claudio Angione, Teeside University

- Development of a manufacturing platform to generate 3D liver organoids with semipermeable coating for allogeneic transplantation

Dr Hassan Rashidi, UCL Great Ormond Street Institute of Child Health

- Gene expression profiling to identify causes of Graft Injury in long term survivors of paediatric liver transplantation

Dr Nicola Ruth at Birmingham Women's and Children's Hospital

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 2019 we recruited and trained 33 parents and young people affected by childhood liver disease who are now 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 18 patient and public involvement research opportunities and tasks, were supported by members in the year. During the course of 2019 the hub has become increasingly busy with requests for support from a variety of research stakeholders.

Continuing the research programme in 2020

Following the success of the Grants programme in 2019, the Scientific Committee had agreed a similar open grant round in 2020. Grants would have been made available for £10,000 and we had envisaged that a number of grants would be made.

In light of the Covid-19 pandemic, it has become clear that the majority of potential applicants and Scientific Committee members will be unavailable to respond and govern the round, due to health service commitments. In late March 2020, with advice from CLDF Scientific Committee, the board ratified the decision to cancel the 2020 grant round.

In 2020 we will conduct a further consultation with beneficiaries about the focus of our Research funding programme to inform future planning.

During 2020 CLDF will focus on increasing opportunities for families and young people to learn more and be involved in research within the field through the Research Hub project. We will work with a variety of partners to increase activity and use digital channels to promote and enable participation.

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 109,000 distribution across all means of access.

In 2019 we conducted a review of our education and information programme to inform future planning. Stakeholder feedback highlighted the importance of this aspect of our work to all of our beneficiaries.

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.

NAFLD (Non Alcoholic Fatty Liver Disease) and Baby Jaundice leaflets were updated and republished during the year.

A new set of resources for young people and families affected by Hepatitis B were also developed.

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Three further packs of information were developed during the period.

Education Pack

Starting or changing school is a big event for any child but when your child has a liver condition parents have real concerns about how their needs will be met. For this reason, the Education Pack was redeveloped to be in line with education processes within each of the four countries of the UK due to the differing systems. The pack informs schools, nurseries and colleges what they need to know about having a pupil or student who has a liver disease and the possible support that needs to be in place. The pack is designed for parents/students to have discussions and work in collaboration with teaching staff. Template letters and individual healthcare plans are included for guidance.

Siblings Pack

The purpose of this pack is to enable parents to understand more about how they can support siblings of their liver child and ensure their wellbeing is not adversely affected in the long term. The pack has a specific section for siblings which aims to empower them in supporting their sibling with liver disease and increase their self-esteem and confidence by being involved in different aspects of the care provided. The development of the Siblings Pack came after receiving a number of concerns from parents about how to effectively support siblings and reduce their isolation when their liver child needs extensive care.

Healthcare Professional Packs

The purpose of these packs is to provide paediatric liver units and regional clinics an easy to read and utilise pack of essential CLDF information. The resources within the packs provide information on liver diseases and outline the support we offer professionals as well as patients and families. These packs can be used during induction of new staff involved in supporting families affected by a childhood liver condition (including ward staff, psychologists and family support workers).

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.

In 2019 we managed a full-scale revision of the resources. We are grateful for the support of a number of specialists who reviewed the scientific basis of the algorithms and guidance. Updated and rebranded packs were republished and promoted.

The updated campaign has been endorsed by British Association for Community Child Health (BACCH), British Association of Perinatal Medicine (BAPM), British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN), Institute of Health Visiting (IHV), Royal College of General Practitioners (RCGP) and Royal College of Nursing (RCN).

A project with the Welsh government worked well during the year with a focussed campaign aiming to reach all primary healthcare professionals involved in neonatal surveillance.

During the year 13868 packs and apps were distributed. This represented a 75% increase in activity and the highest number of Yellow Alert resources ever distributed in a single year.

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Conferences

During 2019 we attended a wide range of medical conferences to promote the needs of our beneficiaries, highlight our services, information provision and raise awareness of our Yellow Alert campaign. These conferences included;

British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)
Scottish Society of Paediatric Gastroenterology Hepatology and Nutrition (SSPGHAN)
British Liver Nurses Association (BLNA)
European Society Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN)
Institute of Health Visiting (IHV)
Primary Care Conference
British Association of Paediatric Surgeons (BAPS)

We also attended the British Association of Liver Studies (BASL) conference for the first time to meet with adult hepatologists and discuss our support and information for young people aged 16-25 and those going through transition from paediatric to adult services.

Continuing the education and information programme in 2020

The information leaflets redevelopment project will continue in 2020, with a robust maintenance programme. Thirteen titles from the medical series will be reviewed and updated during the year.

New resources that we plan to develop in the year include;

A new support series of publications, *Support through your child's liver journey*, *Supporting young people: a guide for parents and guardians & Living without a diagnosis*.

During 2020 we will continue to promote our Yellow Alert resources and campaign to decrease the number of late referrals of neonates for liver disease investigation.

In light of Covid-19, CLDF will focus activity on providing our families and young people with information resources to support and inform throughout the course of the pandemic. We will also liaise with the three specialist centres and provide updates to the community as they require, to support the continued care of beneficiaries in light of new arrangements.

In response to stakeholder feedback and strategic review, our original plans for the year included a trial, hosting a number of webinars and digital Q & A sessions. We will incorporate this method of delivery into our pandemic-related information provision.

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.

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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 such as Liver Life
- Health Unlocked – CLDF's online forum
- Social networking

Hospital ward and clinic visits

The Families and Young Peoples' teams have continued with the clinic visiting programme at hospitals across the UK. Attending 88 clinics across the country, the team connected with 900 families and young people in 2019.

The Support Team's contact with families and young people increased during the year:-

- 915 young people between 11 and 24 had contact with/support from CLDF during the year
- The Support Team also had contact with 2375 parents, friends and relatives.

During the year we continued to review how we deliver our clinic visiting programme with the aim of developing ways of working to increase the numbers of families and young people who are introduced to the CLDF community. The CLDF Scotland Support Officer role was fully operational for the whole year and enabled us to reach more families and young people in Scotland. In 2019 we created plans to develop new roles based within hospital teams to extend our reach and ensure more families and young people are met over the coming years.

Family Events

We continued to deliver the events programme during 2019; the number of events decreased, but the family weekend offering remained a key focus of the programme. 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.

Events included family days in Southampton, Oldham and Birmingham, and family weekends in Scotland, Wales and Northern Ireland. 413 people attended a family event during the year.

" Events like this allow children to meet others with liver conditions and have fun together, it helps them understand that their conditions are not life limiting. Seeing other children doing well, sharing experiences has increased wellbeing and our feelings of being supported. It has helped my daughter have friends who she identifies with"- Parents feedback from West Midlands Family Day

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Wild Camp

We held our Weekend Wild Camp in June 2019. Attended by pairs of young people (aged 7-11 years) and parent / carers the groups faced a 24- hour bushcraft survival experience in the heart of Derbyshire.

"Meeting new families and children in similar situations helped my confidence and acceptance of the condition. I was able to discuss medicines with others and spend time away from day to day life. After the project, my son had a new penpal, we are delighted and happy from the experience and he talks about it all the time." - Parent's feedback.

Residential Activities for young people

CLDF Breakaway

CLDF Breakaway ran in May for 12-15 year olds from all over the UK. From team building skills and zip wiring to building shelters, the young people really stretched themselves, trying new things and meeting new people with common issues.

From two participants:

"Be prepared, be happy, be brave, make friends and most importantly have fun".

"Made new friends, learnt a new skill, challenged myself and achieved something. Faced my fears. Thank you to all the amazing staff for looking after me while I was away."

From a parent:

"Very positive, came back with more self-confidence about her condition, knowing she had friends she can now contact. Had a fantastic experience, making new friends, and talking with friends about their similar condition. She said she has never laughed so much with new friends."

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 eighth time in 2019 and is a five-day residential project.

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 understood 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.

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Feedback from a participant:

"I enjoyed everything, editing, filming, all the activities in the evening. The young people were kind and understanding when we talked in a group and the staff were always there when we needed them if we needed to talk about the stories. Overall it was an amazing experience and I would recommend it to people. I made amazing friends and really enjoyed my time here"

From parents:

"He was like a different person when I come to pick him up. I think this is because of being with people who had similar conditions to him".

"She understands her own body more. Talks more easily about her condition without getting emotional as she usually did prior to TTT. Her confidence, her understanding of her condition and how it effects all her family and knowing we are all here to talk through our feelings and she is not alone".

The CLDF Weekender

The third CLDF Weekender was held at Derby University in August 2019. Young people (16-24 years) travelled from across the UK to take part in the event. In addition to making new friendships, participants took part in workshops on living independently, emotional wellbeing, managing health and a fantastic drumming session. The programme was designed by some of the young people via a steering group and was very well received.

We are indebted to the team at Derby University for all the support given to the project and we hope to work with them again next year to build on the success of the project.

Feedback from participants:-

"I got to meet and share my journey with people who genuinely understood where I was coming from. All the activities allowed me to feel really included and have a good time"

"It has been absolutely amazing to hear your own struggles and experiences reflected in other people. It really made me feel included and not alone"

Hive

In 2019 the charity reviewed and redeveloped our online community for young people. We launched Hive (for 11-15 year olds) and Hive+ (for 16-25 year olds) in late November. Our Young People's Digital and Engagement 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 2019 we reviewed the provision of support to families and young people and conducted a consultation with beneficiaries to inform the 2020-2023 Strategic Plan.

Continuing the family and young peoples' programme in 2020

The original plans for 2020 included continued provision of family weekends in Scotland, Wales and Northern Ireland, single day events and our programme of residential events for young people. In addition it was planned to continue with our clinic visiting programme and to

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develop a number of new roles to be based in hospital teams to increase the charity's reach and efficiency.

Due to the Covid-19 pandemic the event programmes and clinic visiting have been suspended from March onwards. The recruitment to the first hospital support-based role has also had to be put on hold. We will be guided by advice from public health, our Scientific Committee and our beneficiaries to determine if and when these activities can be resumed.

The support team's work for the period will now focus on providing support and guidance 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 will be provided via all platforms, e.g. digital channels, phone and email, on a one to one basis. Another key focus will be providing opportunities for families and young people to meet together virtually via online platforms for mutual support.

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.

During the year the CEO has been working closely with National Health Service Blood and Transplant (NHSBT) on a variety of initiatives. These included being a member of the core oversight group for the new liver offering system and the Liver Advisory Group.

The Charity has worked with a variety of external campaigns to instigate change. These include those run by the Obesity Health Alliance and Genetic Alliance.

The Charity has supported a variety of changes to policy in relation to organ donation and moving to 'opt out' systems. Throughout the year we have continued to lobby the Department of Health to increase the resources available to the healthcare community to support increased liver transplantation across the UK and the adoption of machine perfusion technology throughout the NHS.

CLDF has continued to campaign throughout the year with a variety of partners to address decreases in and lack of public health funding, which is continuing to cause the significant decrease in Health Visitor numbers in the UK.

The CEO is Vice Chair of the Liver Patients' Transplant Consortium and an active member of the British Society for Paediatric Hepatology Gastroenterology and Nutrition PPP Forum and is the current charity representative on the Council.

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.

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Continuing work with The British Lancet Commission, 'Addressing liver disease in the UK' the CEO continues work as a commissioner, focusing on supporting the implementation of the recommendations, lobbying for change and raising awareness of the needs of the paediatric and transitioning liver patient group. In addition, the CEO has commenced work as a member of the European EASL Lancet Commission.

Work with the European Reference Networks for Rare Liver Disease and Transplant Child has continued throughout the year, alongside active membership of the implementation group for Welsh National Liver Strategy.

Continuing the voice programme in 2020

CLDF will continue to work with organ related charities and NHSBT to promote the implementation of the new organ donation legislation and increase consent rates for organ donation.

Support for the Obesity Health Alliance and Prescription Charging Coalition campaign work and other initiatives which impact on the needs of babies, children, young people and families affected by childhood liver disease will continue throughout 2020.

The CEO will continue work as a Lancet Commissioner at a British and European level.

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.

In light of the Covid-19 pandemic CLDF will work with NHS partners and NICE. The charity will also monitor unintended consequences of changes in the way routine infant health surveillance and paediatric liver care management are delivered. CLDF will campaign, raising awareness of issues as and when required.

Fundraising

CLDF's Fundraising Team works to provide income that can be used to deliver the charitable objectives of the Foundation. CLDF works across all traditional fundraising income streams and benefits hugely from funds raised by the families themselves.

Trusts and Grants continued to be a growth area for the Charity during the year, with a focus on seeking larger gifts and multi-year funding opportunities. During the year to December 2019 donations were received from 53 charitable trusts totalling £166,325. This included a significant grant from Children in Need for the second year of a three-year project to support children and families affected by liver disease and a one-year project to support young people. Donations of £5,000 or more were received from the following trusts:-

- The Worshipful Company of Actuaries Charitable Trust £5,000
- The PF Charitable Trust £5,000
- Souter Charitable Trust £5,000
- The Basil Samuel Charitable Trust £5,000
- The Stafford Charitable Trust £5,000
- The Adint Charitable Trust £5,000
- Raymond and Blanche Lawson Charitable Trust £5,000

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- The Garfield Weston Foundation £10,000
 - The Robertson Trust £10,000
 - The Sobell Foundation £10,000
 - Michael and Sarah Spencer Foundation £20,000
 - BBC Children in Need £28,636 and £9,410

Community fundraising performed well in 2019 with some very special family led events raising significant sums. An impressive variety of events took place throughout the year and the Fundraising Team rolled out a more personal approach to stewardship including personal calls to supporters and handwritten cards.

Recruitment for popular challenge events remained a priority in the year with the biggest challenge event fundraiser being the London Marathon, bringing in £47,298 in 2019. Interest in the Great North Run continued and this raised £15,164. CLDF continued to promote charity places in a number of popular challenge events nationwide; in 2019 MyMayMarathon virtual challenge event raised £6,168 and CLDF's event, the Big Drop raised £8,196.

The Biennial Chefs Gala Dinner took place at The Jumeriah Carlton Tower in Knightsbridge in March 2019 and raised a magnificent £111,403.

Big Yellow Friday 2019, our annual fundraising day raised £66,787. We were supported this year by BP stores who raised an impressive £27,756.

Corporate fundraising benefitted in 2019 from £9,961 being received from the Bank of Scotland Foundation and £40,600 was received from Global Make Some Noise, a significant charity partnership secured in 2017. Significant work has been done to improve the stewardship and engagement on offer to our corporate partners and to widen our appeal in the sector.

Continuing the development of income generation in 2020

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

The Covid19 pandemic is putting considerable strain on fundraising activity, resources and plans for 2020. The charity will focus on promoting the work we do and the difference we make. Opportunities for supporters to engage with CLDF through individual giving and virtual challenge fundraising will be a central focus. Emergency appeals will be made to new and existing funders, and approaches will be created for new service developments in line with strategic reviews and ongoing planning during 2020.

Financial Review

The Charity prepares an annual business plan and budget, produces monthly management accounts and makes reports to the Trustees. Close financial monitoring has ensured that overheads were contained within budget and in line with changing income levels.

Income for the year to 31 December 2019, £852,993 was 11.6% higher than the year ended 31st December 2018. This is mainly due to the 2019 total including income from the biennial Chefs' Gala Dinner of £111,403; statutory funding of £10,000; and legacy income of £41,061.

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

Excluding income from our biennial Chefs' Gala Dinner from 2019 means that our core income in 2019 decreased by 2.95%. In view of the challenging economic environment within which charities were operating this was a strong performance and the Charity intended to continue to develop streams of income as outlined in the Fundraising section of this report.

The principal sources of funding in 2019 were voluntary income of £838,525 of which £509,736 was received from supporters; £166,325 from charitable trusts (see Fundraising section); £111,403 from the Chefs Gala Dinner; £10,000 of statutory funding and £41,061 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 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 Trustees consider that their investment policy should recognise the need for protection of capital, a good level of income and liquidity. Accordingly, investments are held in short and medium dated fixed income securities.

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 and term 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.

The Trustees, therefore, consider that, based on the 2020 budget, the ideal level of reserves at 31st December 2019 would be between £180,000 and £350,000.

The actual unrestricted fund, excluding the designated £60,000, at 31 December 2019 is £285,150. This equates to covering 4.9 months of core expenditure.

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

The impact of the Covid-19 pandemic is expected to continue to have a significant impact 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.

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

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.

No director/trustee received remuneration or benefits in the year. The directors / trustees were reimbursed expenses to the value of £929 in the year. There were no related party transactions in the year.

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 Trustee retiring by rotation at the next Annual General Meeting is J Iredale who, being eligible, offers himself 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.

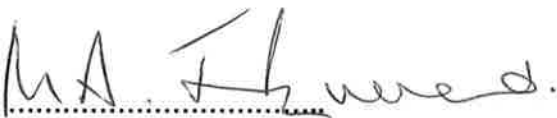
Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

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 black ink, appearing to read 'M. A. Everard', written over a dotted line.

Mrs Mairi Everard
Chairman
09 June 2020

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

I have audited the financial statements of Children's Liver Disease Foundation (the 'charitable company') for the year ended 31 December 2019 which comprise the Statement of Financial Activities, the Charity 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 (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

This report is made solely to the charitable company's Trustees and members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. My audit work has been undertaken so that I might state to the charitable company's Trustees and members those matters I am required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, I do not accept or assume responsibility to anyone other than the charitable company and the charitable company's Trustees and members as a body, for my audit work, for this report, or for the opinions I have formed.

In my opinion the financial statements:-

- give a true and fair view of the state of the charitable company's affairs as at 31 December 2019 and of its incoming resources and application of resources, including its result, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland'; 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 (as amended).

Basis for opinion

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

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

Conclusions relating to going concern

I have nothing to report in respect of the following matters in relation to which the ISAs (UK) require me to report to you where:-

- The Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- The Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other Information

The Trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and my Report of the Independent Auditor thereon.

My opinion on the financial statements does not cover the other information and I do not express any form of assurance conclusion thereon.

In connection with my audit of the financial statements, my responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or my knowledge obtained in the audit or otherwise appears to be materially misstated. If, based on the work I have performed, I conclude that there is a material misstatement of this other information, I am required to report that fact. I have nothing to report in this regard.

Opinion on other matters prescribed by the Companies Act 2006

In my opinion, based on the work undertaken in the course of the audit:-

- The information given in the Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has been prepared in accordance with applicable legal requirements.

Matters on which I am required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, I have not identified material misstatements in the Report of the Trustees.

I have nothing to report in respect of the following matters where the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 (as amended) requires me to report to you if, in my opinion:-

- adequate accounting records have not been kept or returns adequate for my audit have not been received from branches not visited by me; 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
- I have not received all the information and explanations I require for my audit; or
- the Trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees Responsibilities, 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.

My responsibilities for the audit of the financial statements

My 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 a Report of the Independent Auditor that includes my 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.

A further description of my 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 my Report of the Independent Auditor.

Stephen W. Jones F.C.A. (Senior Statutory Auditor)



For and on behalf of Stephen W. Jones F.C.A.
Statutory Auditor, Chartered Accountant & Registered Auditor
King Edward House, 82 Stourbridge Road, Halesowen, West Midlands B63 3UP

09 June 2020

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

STATEMENT OF FINANCIAL ACTIVITIES (including Income and Expenditure Account) FOR THE YEAR ENDED 31 DECEMBER 2019

| | Note | Unrestricted Fund | Restricted Fund | Year Total 31.12.19 | Year Total 31.12.18 |
|---|------|----------------------|--------------------|---------------------------|---------------------------|
| | | £ | £ | £ | £ |
| INCOMING RESOURCES | | | | | |
| Income | | | | | |
| Donations and legacies | 4 | 653,668 | 184,857 | 838,525 | 750,243 |
| Trading activities | 4 | 939 | - | 939 | 900 |
| Investments | 4 | 13,526 | 3 | 13,529 | 13,036 |
| Total Incoming Resources | | 668,133 | 184,860 | 852,993 | 764,179 |
| RESOURCES EXPENDED | | | | | |
| Costs of raising funds | | | | | |
| Raising Funds | | 186,744 | 46 | 186,790 | 133,861 |
| Trading activities | | 381 | - | 381 | 489 |
| Total | | 187,125 | 46 | 187,171 | 134,350 |
| Charitable activities | | | | | |
| Education and awareness campaigns | 5 | 200,010 | 26,223 | 226,233 | 244,809 |
| Provision of emotional support | 5 | 231,543 | 121,047 | 352,590 | 308,152 |
| Research grants and expenditure | 5 | 81,689 | 29,898 | 111,587 | 69,762 |
| Total | | 513,242 | 177,168 | 690,410 | 622,723 |
| Total expenditure | | 700,367 | 177,214 | 877,581 | 757,073 |
| Net gains / (losses) on investments | 14 | 7,484 | - | 7,484 | (11,257) |
| Net (expenditure) / surplus and net movement in funds for the year | | (24,750) | 7,646 | (17,104) | (4,151) |
| Reconciliation of funds | | | | | |
| Total funds brought forward at 1 January 2019 | | 369,900 | 136,650 | 506,550 | 510,701 |
| Total funds carried forward at 31 December 2019 | | 345,150 | 144,296 | 489,446 | 506,550 |

The notes on pages 26 to 39 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 2019

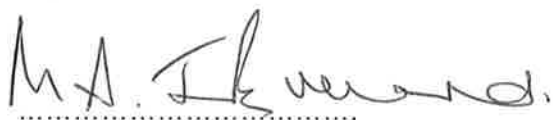
BALANCE SHEET OF THE CHARITY AS AT 31 DECEMBER 2019

| | Note | £ | 31.12.2019 £ | £ | 31.12.2018 £ |
|--|------|----------------|-----------------|----------------|-----------------|
| Fixed assets | | | | | |
| Tangible assets | 13 | | 5,076 | | 8,723 |
| Investments | 14 | | <u>250,714</u> | | <u>243,840</u> |
| | | | 255,790 | | 252,563 |
| Current assets | | | | | |
| Stock and inventory | 15 | 6,860 | | 5,865 | |
| Cash and short-term deposits | 16 | 404,760 | | 465,146 | |
| Debtors due within one year | 17 | <u>34,945</u> | | <u>76,109</u> | |
| | | 446,565 | | 547,120 | |
| Current liabilities | | | | | |
| Creditors due within one year | 18 | <u>212,909</u> | | <u>252,520</u> | |
| Net current assets | | | <u>233,656</u> | | <u>294,600</u> |
| Total assets less current liabilities | | | <u>489,446</u> | | <u>547,163</u> |
| Creditors due after more than one year | 19 | | - | | 40,613 |
| Net assets | | | <u>489,446</u> | | <u>506,550</u> |
| Represented by | | | | | |
| Restricted Funds | 22 | | 144,296 | | 136,650 |
| Unrestricted Funds | 22 | | 285,150 | | 339,900 |
| Designated Funds | 22 | | <u>60,000</u> | | <u>30,000</u> |
| Total Funds | | | <u>489,446</u> | | <u>506,550</u> |

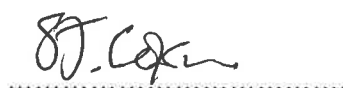
These accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small charitable companies and constitute the annual accounts required by the Companies Act 2006 and are for circulation to members of the company.

The notes on pages 26 to 39 form part of these financial statements.

Signed on behalf of the Trustees on 09 June 2020.



Mrs M Everard



Dr S Colson

STATEMENT OF CASH FLOWS FOR THE YEAR ENDED 31 DECEMBER 2019

| | Note | 31.12.2019 £ | 31.12.2018 £ |
|---|------|-----------------|------------------|
| Cash used in operating activities | 24 | (73,249) | (128,040) |
| Cash flows from investing activities | | | |
| Interest Income | | 13,529 | 13,036 |
| Disposal of investments | | 25,377 | 55,929 |
| Purchase of investments | | (24,767) | (51,636) |
| Purchase of tangible fixed assets | | (1,276) | (2,241) |
| Cash provided by investing actions | | 12,863 | 15,088 |
| (Decrease) in cash and cash equivalents in the year | | (60,386) | (112,952) |
| Cash and cash equivalents at the beginning of the year | | 465,146 | 578,098 |
| Total cash and cash equivalents at the end of the year | | 404,760 | 465,146 |

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 £17,104. Prior to the Covid – 19 pandemic the trustees had reviewed the five-year strategy report, the budgets for 2020 incorporating the results of these developments and the reduction in some operating costs and on these bases they considered that the Charity is a going concern.

The Executive and Board have reviewed and amended the charity's operations, re-budgeted income and expenditure and on these new bases 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 2019 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 2018.

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 2019 the trustees designated £60,000 of the unrestricted fund towards research.

e) Income

Income 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.

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.
- **Research projects** are included for the full value (in accordance with the Charities SORP FRS 102) at the point at which a project is accepted for funding by the trustees. Where it has been agreed with the research institution that no further claim will be made in respect of the approved expenditure, unexpended balances are brought back into the appropriate funds.

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 and amounted to £10,477 (Year to 31.12.2018 £6,534).

Children's Liver Disease Foundation

Trustees' Report for the year ended 31 December 2019

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. The contributions amounted to £7,438 (Year to 31.12.2018 £6,600).

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 and 29 July 2013 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 2019 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 | 31.12.19 | | Year | 31.12.18 | |
|---------------------------------|--------------------|------------------|----------------|--------------------|------------------|----------------|
| | Unrestricted Funds | Restricted Funds | Total | Unrestricted Funds | Restricted Funds | Total |
| Incoming Resources | £ | £ | £ | £ | £ | £ |
| Donations & legacies | | | | | | |
| Donations | 454,604 | 55,132 | 509,736 | 573,373 | 62,078 | 635,451 |
| Income from Chefs Gala Dinner | 103,903 | 7,500 | 111,403 | - | - | - |
| Statutory Funding | - | 10,000 | 10,000 | - | - | - |
| Charitable Trusts | 54,100 | 112,225 | 166,325 | 7,100 | 100,692 | 107,792 |
| Legacies | 41,061 | - | 41,061 | 7,000 | - | 7,000 |
| | 653,668 | 184,857 | 838,525 | 587,473 | 162,770 | 750,243 |
| Trading activities | | | | | | |
| Sales of merchandise | 939 | - | 939 | 900 | - | 900 |
| Investments | | | | | | |
| Listed securities - UK | 12,385 | - | 12,385 | 12,191 | - | 12,191 |
| Listed securities-Overseas | 499 | - | 499 | 487 | - | 487 |
| Bank interest | 642 | 3 | 645 | 348 | 10 | 358 |
| | 13,526 | 3 | 13,529 | 13,026 | 10 | 13,036 |
| Total | 668,133 | 184,860 | 852,993 | 601,399 | 162,780 | 764,179 |

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 |
|--|-----------------------------------|--------------------------------|---------------------------------|----------------|
| | £ | £ | £ | £ |
| Main Grant Programme – release of grant not utilised | - | - | -1,127 | -1127 |
| Small grants programme | - | - | 70,873 | 70,873 |
| Research Hub – working with stakeholders & medical professionals | - | - | 22,651 | 22,651 |
| Working with beneficiaries and stakeholders | 46,932 | 114,763 | - | 161,695 |
| Medical Conferences | 10,854 | - | - | 10,854 |
| National Conference & Family Weekend | - | - | - | - |
| Communications, awareness, representation and campaign activity | 57,088 | 28,543 | 3,537 | 89,168 |
| Provision of information via literature and packs | 47,029 | - | - | 47,029 |
| Family Event programme | - | 59,546 | - | 59,546 |
| Residential activities for young people | - | 49,578 | - | 49,578 |
| Attendance at hospital clinics | - | 35,830 | - | 35,830 |
| Support costs (note 6) | 52,542 | 52,543 | 12,704 | 117,789 |
| Governance costs (note 6) | 11,788 | 11,787 | 2,949 | 26,524 |
| Total | 226,233 | 352,590 | 111,587 | 690,410 |

Expenditure on charitable activities was £690,410 (year to 31.12.2018: £622,723) of which £513,242 was unrestricted (year to 31.12.2018: £471,336) and £177,168 was restricted (year to 31.12.2018: £151,387).

Children's Liver Disease Foundation

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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 | 31,278 | 20,106 | 51,384 | 9,177 | On time allocation |
| Property | 51,297 | - | 51,297 | - | Occupancy |
| I T | 13,420 | - | 13,420 | 3,355 | Staff numbers |
| General Office | 21,794 | - | 21,794 | 2,422 | Staff numbers |
| Audit | - | 5,000 | 5,000 | - | Governance |
| Legal & other professional fees | - | 1,418 | 1,418 | 897 | Staff numbers |
| Total | 117,789 | 26,524 | 144,313 | 15,851 | |

7 Net income from trading activities

The Charity has one dormant wholly owned subsidiary, CLDF (Trading) Limited, 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 | 31.12.19 | 31.12.18 |
|--|----------|----------|
| | £ | £ |
| 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

| | 31.12.19 | 31.12.18 |
|--|---------------|---------------|
| | £ | £ |
| Net- outgoing resources are stated after charging: | | |
| Depreciation on owned assets | 4,923 | 7,573 |
| Auditor's remuneration for the statutory audit | 5,000 | 6,000 |
| Operating leases | <u>41,454</u> | <u>40,342</u> |

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

| | 31.12.19 | 31.12.18 |
|--|----------------|----------------|
| | £ | £ |
| Salaries | 426,224 | 389,322 |
| Social security costs | 36,653 | 31,727 |
| Pension costs (defined contribution schemes) | <u>17,915</u> | <u>12,834</u> |
| | <u>480,793</u> | <u>433,883</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 £189,143 (year to 31.12.2018: £176,611).

10 Staff numbers

The average monthly number of employees during the year was 13 (31.12.2018 : 12) and the average number of full-time equivalent employees during the year was:

| Average number of employees by category: | 31.12.19 | 31.12.18 |
|--|-----------|-----------|
| | No. | No. |
| Family Support | 4 | 4 |
| Information & Raising Awareness | 2 | 2 |
| Research | 1 | 1 |
| Raising Funds | 4 | 3 |
| Infrastructure | <u>2</u> | <u>2</u> |
| | <u>13</u> | <u>12</u> |

The Trustees were not paid nor received any emoluments or benefits during the year (year to 31.12.2018 £Nil). The trustees were reimbursed £929 for their expenses in the year (31.12.2018 £Nil).

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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:-

| | 31.12.19 No. | 31.12.18 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). 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 2019 | 49,079 | 43,293 | 92,372 |
| Additions | 1,276 | - | 1,276 |
| Disposals | - | - | - |
| At 31 December 2019 | 50,355 | 43,293 | 93,648 |
| Depreciation | | | |
| At 1 January 2019 | 48,029 | 35,620 | 83,649 |
| Charge for the year | 1,746 | 3,177 | 4,923 |
| Disposals | - | - | - |
| At 31 December 2019 | 49,775 | 38,797 | 88,572 |
| Net book value | | | |
| At 31 December 2019 | 580 | 4,496 | 5,076 |
| At 31 December 2018 | 1,050 | 7,673 | 8,723 |

NOTES TO THE FINANCIAL STATEMENTS

14 Investments

| Shares in subsidiary | 31.12.19 | 31.12.18 |
|---|-----------------|-----------------|
| Cost | £ | £ |
| At 1 January 2019 and at 31 December 2019 | <u>2</u> | <u>2</u> |

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 | 31.12.19 | 31.12.18 |
|---|-----------------|-----------------|
| | £ | £ |
| Market Value at 1 January 2019 | 243,838 | 259,388 |
| Disposals | (25,377) | (55,929) |
| Purchases | 24,767 | 51,636 |
| Realised (losses) on disposal | (92) | (416) |
| Net unrealised gains/ (losses) | 7,576 | (10,841) |
| Market value at 31 December 2019 | <u>250,712</u> | <u>243,838</u> |
| Historical cost as at 31 December 2019 | <u>233,904</u> | <u>236,314</u> |

15 Stock and inventory

| | Charity | |
|---------------------|-------------------|-------------------|
| | 31.12.2019 | 31.12.2018 |
| | £ | £ |
| Stock of literature | 4,870 | 3,845 |
| Goods for resale | <u>1,990</u> | <u>2,020</u> |
| | <u>6,860</u> | <u>5,865</u> |

16 Analysis of cash and cash equivalents

| | Charity | |
|--|-------------------|-------------------|
| | 31.12.2019 | 31.12.2018 |
| | £ | £ |
| Cash in hand | 250 | 151 |
| Current accounts | 403,225 | 461,901 |
| Cash held by Investment management Company | <u>1,285</u> | <u>3,094</u> |
| | <u>404,760</u> | <u>465,146</u> |

17 Debtors due within one year

| | Charity | |
|--------------------------------|-------------------|-------------------|
| | 31.12.2019 | 31.12.2018 |
| | £ | £ |
| Taxation recoverable | 2,500 | 1,500 |
| Prepayments and accrued income | <u>32,445</u> | <u>74,609</u> |
| | <u>34,945</u> | <u>76,109</u> |

Children's Liver Disease Foundation

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NOTES TO THE FINANCIAL STATEMENTS

18 Creditors due within one year

| | Charity | |
|---------------------------|----------------|----------------|
| | 31.12.2019 | 31.12.2018 |
| | £ | £ |
| Research grants (note 21) | 67,312 | 88,249 |
| Accruals | 134,384 | 154,030 |
| Taxes and social security | 11,213 | 10,241 |
| | <u>212,909</u> | <u>252,520</u> |

19 Creditors due after more than one year

| | Charity | |
|---------------------------|------------|---------------|
| | 31.12.2019 | 31.12.2018 |
| | £ | £ |
| Research grants (note 21) | <u>-</u> | <u>40,613</u> |

20 Analysis of net assets between funds

| | Restricted Funds | Unrestricted Funds | Total |
|--|---------------------|-----------------------|----------------|
| | £ | £ | £ |
| Fund balances at 31 December 2019 are represented by:- | | | |
| Tangible fixed assets | - | 5,076 | 5,076 |
| Investments | - | 250,714 | 250,714 |
| Current assets | 144,296 | 302,269 | 446,565 |
| Current liabilities | - | (212,909) | (212,909) |
| Total net assets | <u>144,296</u> | <u>345,150</u> | <u>489,446</u> |

NOTES TO THE FINANCIAL STATEMENTS

21 Research grants (notes 18 and 19)

The following research projects have been granted funds by Children's Liver Disease Foundation. Amounts have been charged in the financial statements based upon the budgeted expenditure forecast. The following amounts represent the balance of accrued funding remaining unspent at the year end.

| | 31.12.19 | 31.12.18 |
|---|---------------|----------------|
| Project Reference | £ | £ |
| 2013 CLDF grant award – joint research project in Hepatology | - | 1,327 |
| 2015 CLDF grant – Professor Amin Rostami-Hodjegan, University of Manchester: optimising drug regimens in paediatric liver disease using experimentally-derived simulation tools | 13,550 | 29,076 |
| 2016 CLDF grant – Professor David Wraith, University of Birmingham: Development of biomarkers and novel therapeutics in autoimmune hepatitis type 2 | 50,432 | 76,159 |
| 2017 CLDF authorised grant expenditure | 3,330 | 12,500 |
| 2017 CLDF grant – Dr Luke Boulter, Institute of Genetics and Molecular Medicine: using single cell sequencing to determine how bile ducts form | - | 9,800 |
| | 67,312 | 128,862 |

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NOTES TO THE FINANCIAL STATEMENTS

22 Analysis of charitable funds

Analysis of movements in unrestricted funds

| | Movement in Funds | | |
|-------------------|-------------------|----------------|----------------|
| | At 1 January 2019 | Incoming | Outgoing |
| | £ | £ | £ |
| All General Funds | 369,900 | 668,133 | 692,883 |
| Total | 369,900 | 668,133 | 692,883 |

| Name of unrestricted fund | Description, nature and purposes of the fund |
|---------------------------|---|
| General Fund | The "free" reserves after allowing for all designated funds |
| Designated Fund | 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.

| | Movement in Funds | | |
|--|-------------------|----------------|----------------|
| | At 1 January 2019 | Incoming | Outgoing |
| | £ | £ | £ |
| Research into biliary atresia fund | 5,377 | 3 | - |
| Research hub | 51,154 | - | (23,308) |
| Website | 1,868 | - | (1,868) |
| Clinic Visits – 2018 | 5,660 | - | (4,239) |
| Welsh government funding of liver strategy | 16,837 | 10,000 | (22,253) |
| YP Events | 2,500 | 6,380 | (3,680) |
| Children in Need :Children & Families Officer post | 11,996 | 28,635 | (31,804) |
| Global Make Some Noise – funding for family and YP events | 12,443 | 40,600 | (35,339) |
| Yellow Alert literature | 2,500 | 11,300 | (11,906) |
| Scottish Family Event Weekend 2019 | 3,000 | 11,000 | (14,000) |
| Remote Support Workers – England | 14,000 | 20,500 | - |
| Remote Support Workers – Scotland | 8,922 | 25,461 | (13,200) |
| Project - development of volunteers | 393 | - | (46) |
| Family events | 0 | 7,071 | (6,071) |
| Research | 0 | 9,500 | (9,500) |
| Information | 0 | 5,000 | - |
| Children in Need :Young People's Digital & Engagement Officer post | 0 | 9,410 | - |
| Total | 136,650 | 184,860 | 177,214 |

NOTES TO THE FINANCIAL STATEMENTS

23 Research commitments

At 31 December 2019, 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

| | 31.12.19 £ | 31.12.18 £ |
|---|-----------------|------------------|
| Net movement in funds | (17,104) | (4,151) |
| Depreciation charge | 4,923 | 7,573 |
| Interest income shown in investing activities | (13,529) | (13,036) |
| (Gains) / Losses in valuation of investments | (7,484) | 11,257 |
| (Increase) in stock | (995) | (1,249) |
| Decrease in debtors | 41,164 | 16,046 |
| (Decrease) in creditors | (80,224) | (144,480) |
| Net cash used in operating activities | (73,249) | (128,040) |

25 Financial commitments

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

| | 31.12.19 £ | 31.12.18 £ |
|----------------------------|---------------|---------------|
| Expiring within five years | | |
| – broadband contract | 5,200 | 5,200 |
| – serviced office rental | <u>41,454</u> | <u>40,400</u> |

26 Future commitments

At 31 December 2019 the Charity has charged all expenditure on research grants in the financial statements. There are currently no further commitments.

At 31 December 2019 the general fund (excluding the designated £60,000) was £285,150; this equates to 4.9 months of cover for core expenditure which is in line with the Trustees' reserves policy of covering core expenditure for three to six months.