

# 2021 Impact Report



There are a huge number of different liver diseases which can affect babies, children and young people. The causes are largely unknown; many are life-threatening and all require a lifetime of medical care.

Children's Liver Disease Foundation exists solely to support the needs of UK families affected by childhood liver disease by:

- **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**

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.

# Meeting post pandemic challenges

The Covid-19 pandemic has had a significant impact on CLDF. The charity was 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. The team rapidly adapted to new modes of working in order to diversify fundraising and offer services digitally.

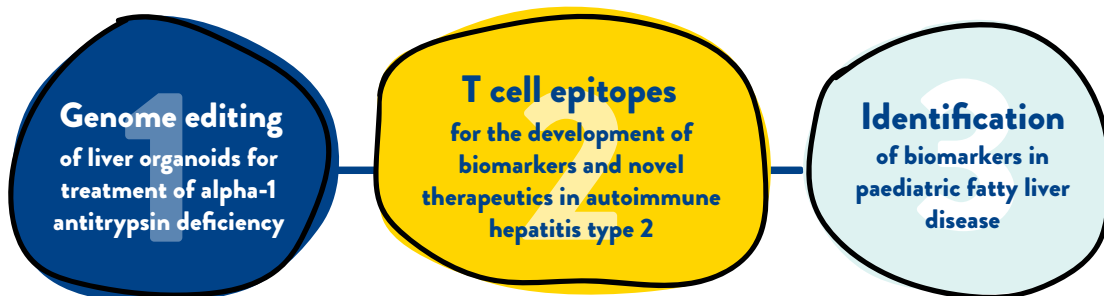
Second and third waves meant that this trend continued into 2021, creating uncertainty and challenging conditions, both for fundraising and service delivery. In July 2020 CLDF reviewed and reworked its strategic plans and made the difficult decision to restructure, making six redundancies. The remaining 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.



CLDF 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.

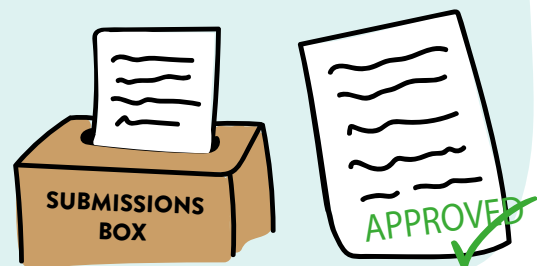


Although the 2021 grant round was cancelled due to the ongoing challenges of the pandemic, during 2021 we received promising updates on three CLDF funded research projects into child liver diseases:



During the year 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.

The charity made an organisational submission to the NICE consultation process for a new treatment for Progressive Familial Intrahepatic Cholestasis (PFIC). CLDF also facilitated and supported the parents of children with PFIC to contribute to this process, including making submissions to the appeals process following NICE's original decision not to recommend the drug. This resulted in the approval of the treatment in early 2022.



## Education and information

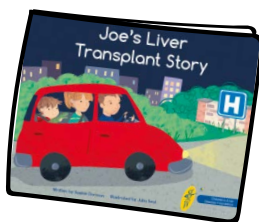
CLDF has continued to provide guidance, explanations, ongoing updates and blogs on how COVID 19 affects our families, children and young people. We worked closely with the three specialist NHS units, NHS Commissioners and Royal College of Paediatrics and Child Health (RCPCH). All hospitals caring for children with liver disease used our work to inform patients.



# Medical support information

In 2021 CLDF provided:

**60** Transplant Storybooks  
to individuals and hospitals



**127**

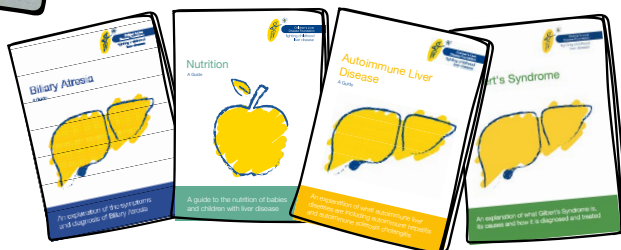
hard copy medical, nutrition and support leaflets to individuals

**2984**

medical, nutrition and support leaflets to hospitals

**2759**

medical, nutrition and support leaflets PDF downloads from the website



## Yellow Alert

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



**796** Yellow Alert packs  
posted to individuals and professionals

**688** Yellow Alert  
app downloads

**16,394** Yellow Alert leaflets  
distributed including stool charts

**1,635** Yellow Alert materials  
downloaded from our website

## Support

**90** new families  
accessed our support over 2021



**1736**  
individual interactions  
with parents in 2021

**2096**  
individual interactions with  
young people (11 – 24)

**39** family briefings

Our Children and Families Officer issued these which helped keep parents connected when they couldn't meet us face to face

**Support Centres**  
on three main themes:  
emotional, advocacy  
& practical

Fortnightly  
**catch-ups**   
for families on Zoom



**Hospital and Clinic**  
visiting remained on hold for  
2021 but 1 to 1 support  
remains

**Regular Hive**  
hangouts  
for young people

**7** young people  
joined in Bounceback  
digital alternative to Breakaway  
which focused on mental  
wellbeing and resilience



# Fundraising

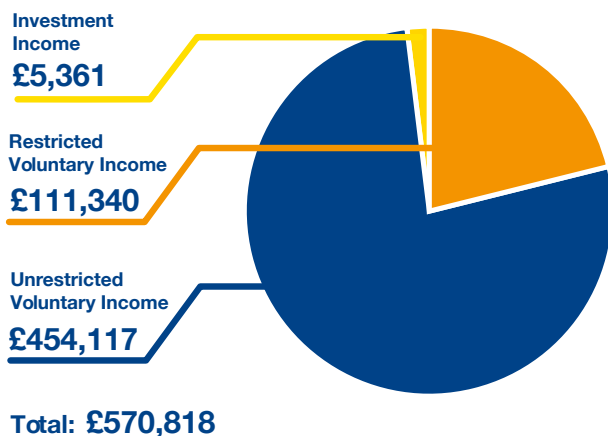
CLDF works across all traditional fundraising income streams and benefits hugely from funds raised by the families we support. While 2021 was a better year than 2020, fundraising was still very much affected by the public health situation and there was not a return to pre-pandemic levels of income. This challenge was exacerbated by the reduction in fundraising staffing.

In 2021 we received £35,522 in personal donations. 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.

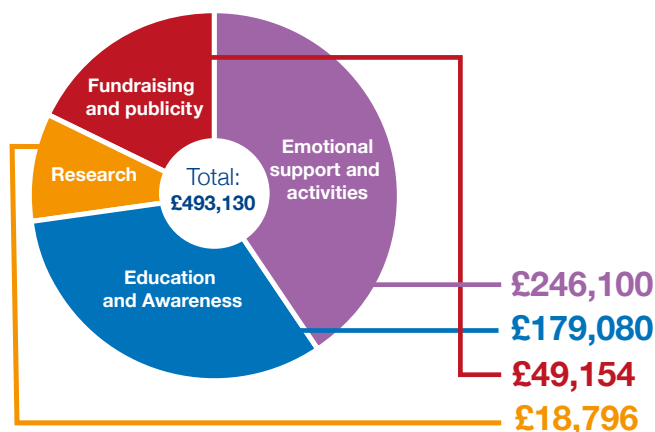


## Funding CLDF's work

### Incoming resources



### Resources expended



## Voice

Representing the needs of families, children and young adults has become an increasing role for CLDF over the past decade. Highlights in 2021 included:

### National Screening Committee Submission

In collaboration with specialist centres, we proposed that Yellow Alert stool charts be utilised in the personal child health record to support screening for Biliary Atresia. As a result 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 and whether their use improves time to surgery. The output from this exercise will inform the next UK NSC decision on whether the evidence is sufficient to commission a further review.

### Sharing patient views on an international stage

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 an international virtual meeting hosted by Birmingham Children's Hospital. The data was also used at the 2021 Annual CQUINN Audit meeting of NHS commissioners.

