



Children's Liver
Disease Foundation

fighting childhood
liver disease

2019 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 and young people with liver disease can achieve their full potential.”

Alison Taylor, Chief Executive

Research

Research lies at the heart of providing a brighter future for children with liver disease. CLDF ran two grant rounds in 2019. The first was focussed on projects relating to Donor Specific Antibodies, an issue which impacts children receiving liver transplants. This was awarded to Dr Girish Gupte of Birmingham Children's Hospital. Three further projects were funded in an open grant round.

4 Projects Funded

8 applications

**2019
Grant
Rounds**

In 2019 we formally launched CLDF Research Hub to promote research in paediatric hepatology and enable families and young people to provide real life insights to support further research and research design.



**33 parents
& YPs
recruited
and trained**

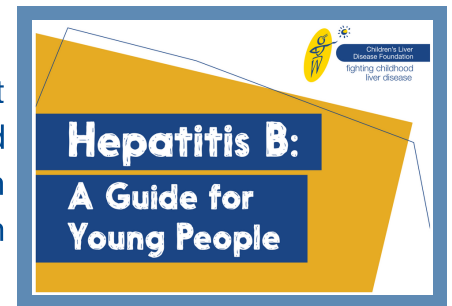
**18 projects &
opportunities
supported**



Education and Information

The provision of information to children, young people and their families is critical. Our information is available in leaflet form and via our website.

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. New publications have also been developed. These include new guides for Hepatitis B, education support, siblings and healthcare professional packs.



**8 conferences
attended**

**75% increase
in Yellow
Alert Activity**

Our Yellow Alert campaign was updated and relaunched during the year, with 13,868 resources distributed.

**109,000
support & medical
leaflets distributed**



We use the yellow alert pack and all agree that it is a fantastic resource with lots of useful information. The stool charts are used regularly in consultations and are valuable to show parents what to look for.

feedback from a GP

....it gave me a much greater understanding of her liver disease and that helped me to become a better, 'more together' parent

Supporting families and young people

A diagnosis of liver disease has a huge impact upon a child and everyone around them. 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.

Throughout 2019

We attended



88

hospital clinics
across the UK



Connecting with

900
families &
young people

915 young people
had contact with CLDF



We also had 2,375
contacts with parents, friends and relatives.

At our CLDF events in 2019

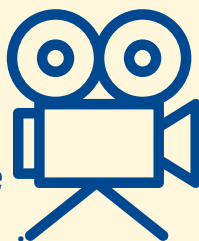
23

Woodland
shelters were
built



12

Young people
made films
about their liver journey



58

Mocktails
were created



She understands her own body more and talks more easily about her condition without getting as emotional as she usually did

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

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

Voice

Representing the needs of our families and young people has become an increasing role for CLDF over the past decade. During 2019 we have ensured that families and young people are given the opportunity to become directly involved in the evaluation of national policies and developments through a wide variety of channels. We are actively involved with a wide variety of consultations and groups to ensure the needs of children, young people and families are heard.

Fundraising

CLDF works hard to attract income that can be used to deliver our objectives. CLDF works across all traditional fundraising income streams and benefits hugely from funds raised by the families themselves.

During 2019 we received donations from:

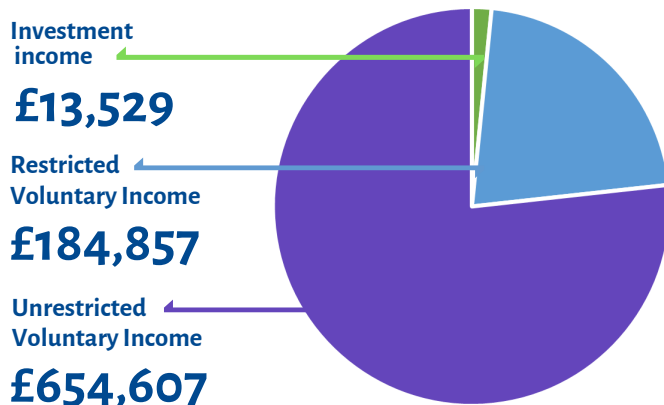
Big Yellow Friday activities, raising £66,787
201 diners at our Gala Dinner spending £111,403
BP garages partnership generating £ 27,756
Marathon & Great North running - £62,462
Regular givers, cake bakers, parachute jumpers, carbooters, singers, head shavers, knitters, raffle sellers, gamers, too many to mention

A HUGE THANK YOU

to everyone who donated and raised funds for us in 2019. We could not do the work we do without you.

Funding CLDF's work

Incoming Resources



Total: £852,993

Resources Expended



Total: £877,581



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