



Children's Liver
Disease Foundation

fighting childhood
liver disease

2018

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 everyone affected by a 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 children, young people and their families with tailored support services.

"We are the only UK charity dedicated to supporting every family who faces the shattering diagnosis of liver disease in childhood. We know that our work makes a difference and we are determined to reach even more families to ensure every child with a liver disease can reach their full potential. It's a tough target but, by working hand in hand with our supporters, partners and health care professionals, it's one we believe we can achieve."

Alison Taylor, Chief Executive

Research

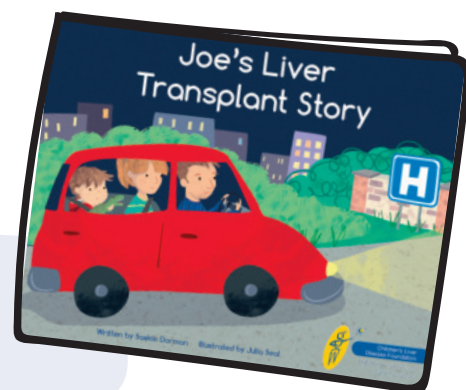
Research lies at the heart of providing a brighter future for children with liver disease. In 2018 CLDF made research funds available via two grant rounds.

Information and Education

We continued to review our medical and support literature to ensure it is concise, patient-friendly and updated with the latest information. It is available to young people, parents and health professionals in leaflet form or via our website. **Last year we distributed 45,742 leaflets using all media channels.**

Our children's story book, 'Joe's Liver Transplant Story' is now being used by specialists as part of their preparation of children for transplant. In September 2018 the book won the Information for Children award from the British Medical Association. The award judges described it as

'A unique resource – vitally important in explaining a life-changing massive operation to young children...it deals with a sensitive topic in a way that is highly accessible to its target audience.'

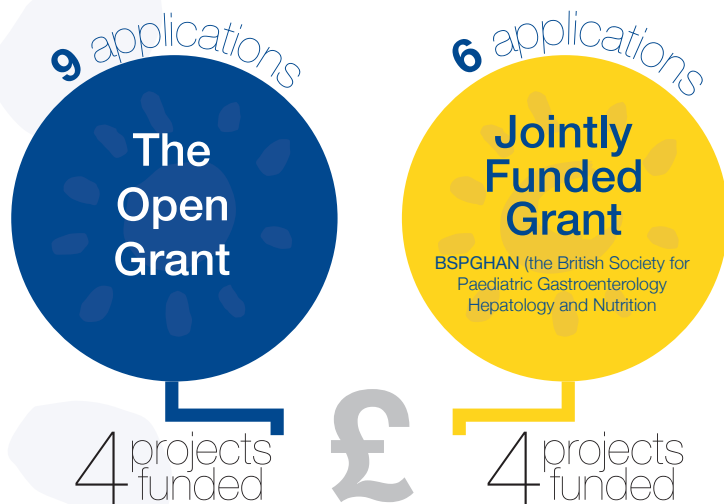


At our National Conference and Family Weekend in Stratford upon Avon in October, experts gave a total of 30 presentations on topics ranging from the latest developments on research into childhood liver disease to the psychological impact of growing up with a liver condition.

"It was information we received from CLDF that helped us to get our heads around what was happening and explain it to other family members."

"Children's Liver Disease Foundation is important to us because they provided us with information about our daughter's rare condition and were there with emotional support through what was an incredibly difficult time."

"The information CLDF provided 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 childhood liver disease means a lifetime of medical care and has a huge impact on the child, their family and friends. CLDF's role varies according to the needs of the individual - from helping families find their new normality to supporting young people to take responsibility for their liver condition and ultimately transfer into adult services.

Throughout 2018



At our CLDF events in 2018



"We would be lost without CLDF's support on our journey with liver disease and through them we have met others on similar paths, many of whom have become our closest supporters."

"She came home with a new support network, full of optimism and a renewed resilience about dealing with the future."

"We love the family weekends they organise here in Northern Ireland, when we get to meet up with other families whose children have liver disease."

Voice

During 2018, members of the CLDF team travelled 10,962 miles to 12 cities to ensure that the interests of our young people and families are represented at a national and international level.

We are actively involved with:

Fundraising

Our small but passionate fundraising team works to provide income which 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.

**During 2018 we received donations from:
48 charitable trusts totaling £107,792**

And in the course of raising funds:

**Over 1,846
miles were run**

**A team of 17 runners took part in the
London Marathon raising**

**4 Heads
were shaved**

£65,347

440

**hand-written
Christmas
cards were sent**

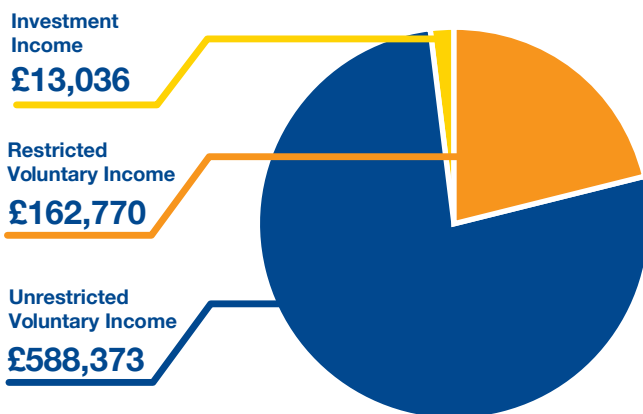
50 varieties of pickle were made

**A HUGE
THANK YOU**

to everyone who took the time
and trouble to raise funds for us in
all manner of ways in 2018. We
simply could not do the work we do
without you.

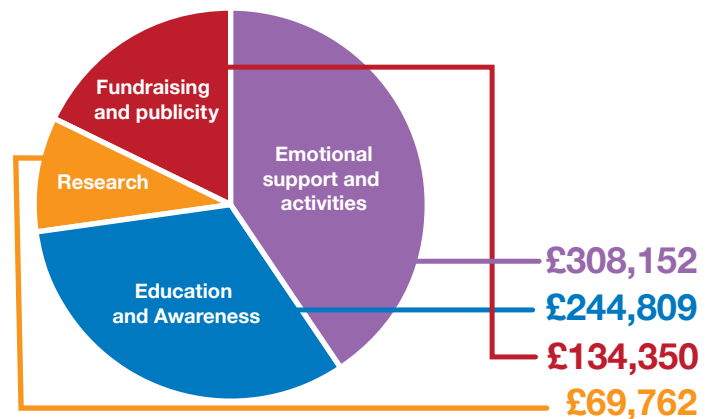
Funding CLDF's work

Incoming Resources



Total: £764,179

Resources Expended



Total: £757,073



"The charity does so much, not just for the children who have to live with a liver disease, but for the parents and siblings on how to cope with the effect it has on the whole family. It's great knowing that there is someone there to listen."