



2017

Impact Report

Together we make a real difference

Children's Liver Disease Foundation exists solely to support the needs of all those affected by a childhood liver disease.

There are over 100 different diseases which can affect babies, children and young people. The causes of these diseases are largely unknown; many are life-threatening; all require a lifetime of care.

We work hand in hand with our families, young people, supporters and clinical professional partners to provide our services, we are indebted to them all.

Our work is focussed in four streams: information, support, research and voice. Each is critical to help ensure that each baby, child, and young person reaches their full potential and that each family knows they have somewhere to turn.



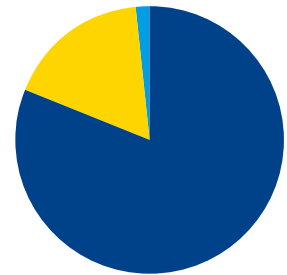
2017 was another year of new innovations and ongoing challenges. Our dedicated supporters and staff team have made this possible in the midst of continuing financial pressure. We know that what we do makes a real difference to our families and young people and we will continue to push forward more determined than ever before to reach all of the families affected in the coming years. We can't do this on our own but know that with the help of our supporters, partners and the health care professionals we work alongside our goal is achievable.



Funding CLDF's work

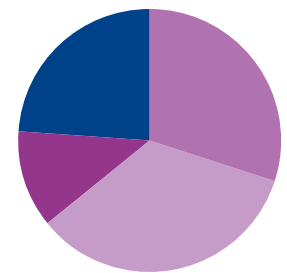
Incoming Resources

Unrestricted Voluntary Income	£739,867
Restricted Voluntary Income	£159,701
Investment Income	£13,723
Total	£913,291



Resources Expended

Education and awareness	£254,641
Emotional support and activities	£290,929
Research	£100,690
Fundraising and publicity	£202,122
Total	£848,382



This summary is taken from our financial statements. To request a copy of our full audited accounts, please contact the charity.

Signed on behalf of the Board of Trustees:

Thomas M Ross OBE
Chairman

Information Highlights

Knowledge is power – armed with accurate information, families and young people can make informed decisions.

CLDF leaflets distributed including downloads	16,219	decrease on same period in previous year
Number of visits to our websites	211,762	similar to the same period in previous year
Number of pieces of media coverage	220	10% increase on same period in previous year

Spreading the word to medical professionals is an essential element of our work. During the year we had a presence at ten conferences including:

- CPHVA - Community Practitioners and Health Visitors Association
- BSPGHAN-British Society of Paediatric Gastroenterology, Hepatology and Nutrition

In addition to our ongoing work we published Joe's Liver Transplant Story to help children to understand what a liver

transplant is and to learn about the processes involved.

“The storybook is wonderful. It's clear and concise and relevant to both younger (with their parent's help) and older children. It will help children waiting for a transplant immensely. Sometimes it's so hard to talk to your child when you're trying to hide your own upset, so it will be very helpful to have something that the child and parents can read together. Thank you so much for making it happen”

- Feedback from one of the first recipients.

Support Highlights

Children's Liver Disease Foundation's support service is there for everyone affected by a childhood liver disease whenever they need it.

CLDF's support team attended 98 clinics across the country connecting with 686 families and young people.

688 young people between 11 and 24 had contact / support with CLDF during the year.

The support team also had 2009 contacts with parents, friends and relatives.

CLDF held three family weekends – in Scotland, Northern Ireland and Central England, as well as Wild Camp for patients aged 7 to 11 and a parent. Special residential events for young people were Breakaway for 12 – 15 year olds and Talk Tell Transform for 16 – 18 year olds.

... “
My daughter thoroughly enjoyed the event and was very well looked after, she has been transformed by the experience. Words cannot describe how much. She has come back with newly gained skills, made a lot of friends and has a new confidence. - Parent
..... ” ...

The charity ran the inaugural CLDF Weekender in 2017. The weekend conference for 16-24 year olds held in partnership with Derby University was attended by 31 young people and received exceptional feedback.

... “
The event exceeded all my expectations. I have met some amazingly lovely people, had a chance to just have fun as well as share with others who understand, who have been in my position. The seminars and workshops were really helpful and enjoyable. - Feedback from one of the participants
..... ” ...

Research

Research projects funded by CLDF not only enhance understanding, improve treatment and quality of life, but also give young people and their families hope for a better future. CLDF currently has 13 research projects ongoing.

Highlights:

Projects Awarded 2017:

Genome editing liver organoids for treatment of liver disease

Dr Deborah Gill – Oxford University

Identification of biomarkers in paediatric fatty liver disease

Dr Jake Mann - Department of Paediatrics, Addenbrooke's Hospital

Diagnosis of covert hepatic encephalopathy in young people with biliary atresia: a feasibility study

Dr Marianne Samyn – Kings College Hospital

Voice Highlights

Children's Liver Disease Foundation gives thousands of young people and their families one strong voice to effect change in the diagnosis and treatment of childhood liver disease.

This year CLDF's Chief Executive Alison Taylor has consulted with and represented patients and families on a range of projects which include:

NICE guidelines and NHS strategies and working with the Welsh government on their Liver Strategy

Co chairing The Liver Patients Transplant Consortium and working with NHSBT on arrangements for the new liver offering system

Being the lead paediatric patient advocate on the European Reference Network for Rare Liver disease

Yellow Alert is CLDF's campaign to promote the early diagnosis and appropriate referral for liver disease in newly born infants. Early diagnosis saves lives.

The number of Yellow Alert resources distributed this year, including download and apps:

9,898

Visits to Yellow Alert Website:

20,950



Fundraising Highlights

Our sincere thanks goes to all those individuals and organisations who so kindly supported Children's Liver Disease Foundation in 2017.

Thousands of people give generously to us throughout the year, these donations are critical and make our work possible.

44 charitable trusts kindly supported us providing £100,800 to support key projects.

Our biennial Chefs Gala Dinner 2017 raised £130,475

Our work with corporate partners has increased, many coming through links with families. These relationships are invaluable to us. During the year we secured a partnership with Global's Make Some Noise that will fund a variety of support events over the coming two years.

... “

The work that CLDF do is amazing, at my lowest point I found the charity who helped me more than you would imagine. Always people to talk to, they hold events where all the children can get together and enjoy themselves. I can't thank them enough. That's why I'm asking you all please support us in raising money to help CLDF keep growing and helping families like my own.

Laura a parent and supporter

..... ” ...



On behalf of all our inspirational young people and their families, a sincere thank you to everyone, we couldn't do it without you.