



# 2016

## Impact Report

### Continuing to make a 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 and all require a lifetime of care.

We work hand in glove 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 these inspirational young people fulfil their potential in life.

During 2016 the board approved the decision to change our accounting year to increase efficiency, as a result this report covers the nine month period from 1st April to 31st December 2016.

### Meeting the challenge

“ 2016 was another year of challenges and triumphs. We have continued to develop our support and information provision and have reached an incredible number of families and young people. Our fantastic supporters and staff team have made this possible in the midst of continuing financial pressure. Our families and young people continue to tell us of the huge difference we make to their lives and that's what we hold dear to our hearts. We exist solely to support their needs and everything we do across all our work streams is focussed on that. Together we'll make sure we are here for all those who need us.

Alison Taylor, Chief Executive

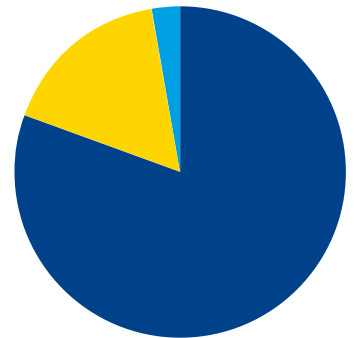


# Funding CLDF's work

## 1 April 2016 - 31 December 2016 (9 months)

### Incoming resources

Unrestricted voluntary income	£447,290
Restricted voluntary income	£93,135
Investment Income	£13,892
Total	£554,317



### Resources expended

Education and awareness	£216,993
Emotional support and activities	£214,137
Research	£64,984
Fundraising and publicity	£143,321
Total	£639,435



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 inc. downloads	16,320	Increase on same period in previous year
Unique visitors to <a href="http://childliverdisease.org">childliverdisease.org</a>	133,277	Increase on same period in previous year
Number of pieces of media coverage	168	33% 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 five conferences including:

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

We also delivered our National Conference and family weekend in Warwickshire with 147 family delegates and 76 children and young people taking part. The new weekend format received great feedback.



# Support highlights

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

CLDF's families and young people's teams attended 74 clinics across the country, a 10% increase on the previous year

780 young people between 11 and 24 had contact with CLDF during the year, a 7% increase on the previous year

The support team also had 1944 contacts with parents, friends and relatives, a 12% increase on previous year

Our Liver App, launched in partnership with Coventry University, supports young people through transition from children's to adult services and supports self-care and management

CLDF held three residential events for young people; Breakaway for 12- 15 year olds, Talk, Tell, Transform Reunion project for those aged 16 + and 'Wild Camp' for patients aged 11+ and a parent. All received exceptional feedback

“ *It was a wonderful experience; I especially enjoyed the way it challenged my daughter and how well she did. I learnt a great deal about her that I didn't already know.* ”

Parent feedback from the Wild Camp

## Research

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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 twelve research projects ongoing.

### Highlights:

Projects awarded 2016:

**T cell epitopes for the development of biomarkers and novel therapeutics in autoimmune hepatitis type 2 (AIH-2)**

Professor David Wraith, Institute of Immunology and Immunotherapy University of Birmingham

**Global effects of maternal smoking on the human fetal liver protein profile**

Dr Panagiotis Filis, University of Aberdeen

Two projects received funding in a jointly funded grant round with the British Society for Gastroenterology Hepatology and Nutrition (or BSPHGAN)

**Congenital porto-systemic shunts and the development of liver tumours**

Professor Richard Thompson, Kings College Hospital

**Association of stool microbial profile with short-term outcome in infants with biliary atresia after Kasai Portoenterostomy**

Dr Vandana Jain, 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:

Sitting on The Lancet Commission 'Addressing liver diseases in the UK' The NHSBT Liver Advisory Group and British Society for Paediatric Hepatology Gastroenterology and Nutrition, representing patient interests

The Hep B campaign for universal vaccination which came to fruition in the year with the announcement that all babies will be vaccinated from 2017



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

11,643

Visits to Yellow Alert Website

13,761

# Fundraising highlights

Our sincere thanks goes to all those individuals and organisations who so kindly supported Children's Liver Disease Foundation in 2016.

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

18 charitable trusts kindly supported us providing £76,619 to support key projects

Our monthly giving programme raised almost £49,000 in the period covered by the report. Our work with corporate partners has increased over the last nine months, many coming through links with families. These relationships are invaluable to us

Nearly 270 people took part in a sponsored activity for us including head shaves, runs and swims – a 14% increase on the same period in the previous year



CLDF does not receive Government funding. We are reliant on voluntary donations. On behalf of all our inspirational young people and their families, a sincere thank you to everyone, we couldn't do it without you.

For more information on any aspect of CLDF's work visit [childliverdisease.org](http://childliverdisease.org)

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