



# 2014-15

## Impact Report

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Children's Liver  
Disease Foundation

fighting childhood  
liver disease



## Building on strong foundations

Children's Liver Disease Foundation (CLDF) exists solely to support the needs and improve the lives of all those affected by a childhood liver disease.

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

Four pillars underpin our work: information, support, research and voice. Each is as vital as the other, helping to ensure that young people with a liver disease fulfil their potential in life.

## Forward into the future

2014-15 was a year of consultation – with young people of all ages, parents and carers plus healthcare professionals – to shape CLDF's future. It was also a year which saw CLDF build on strong foundations and touch more lives affected by childhood liver disease. However there's much more to do.



*It was clear from the consultation that our ambition to reach out, represent and support all those affected by childhood liver disease is endorsed wholeheartedly. We now look forward into the future buoyed up by that mandate – bolder and braver than ever before.*

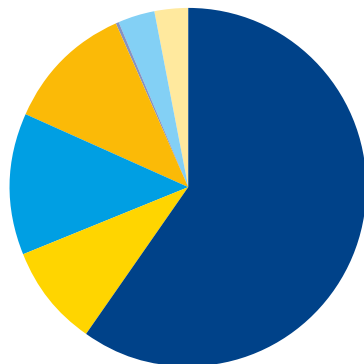
Alison Taylor, Chief Executive



# Funding CLDF's work - 1 April 2014 - 31 March 2015

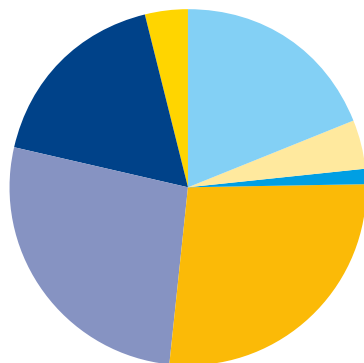
## Incoming resources

Unrestricted voluntary income	500,401
Restricted voluntary income	77,534
Big Yellow Friday	107,535
Chefs' Gala Dinner	96,787
Income from Charitable activities	2,663
Sale of purchased goods	28,651
Investment income	23,597
<b>Total</b>	<b>837,168</b>



## Resources expended

Fundraising and publicity	207,199
Events	46,306
Fundraising trading goods	16,392
Education and awareness	291,340
Emotional support	290,137
Research	190,248
Governance	40,665
<b>Total</b>	<b>1,082,287</b>



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 and research

## Information highlights

CLDF leaflets distributed, including downloads	16,718	40% increase on previous year
Number of unique visitors to <a href="http://childliverdisease.org">childliverdisease.org</a>	93,650	40% increase on previous year
Number of visits to all CLDF websites	147,145	40% increase on previous year
Number of pieces of media coverage*	372	10% increase on previous year

\*including major pieces in national newspapers, magazines and healthcare trade press

To ensure that our young people have access to vital information and support on the move, CLDF launched a mobile version of its young people's website [cldf-focus.org](http://cldf-focus.org).

In October 2014 CLDF held its biennial National Conference and Family Day – the largest to date with 194 delegates. We are indebted to the many eminent medical professionals who chaired workshops and made presentations. And for the first time, researchers working on CLDF-funded projects attended, presenting posters to inform families of the research they are undertaking and took part in general discussions.

The year saw CLDF build on and enhance its networks with medical professionals via attendance at key conferences. During the year we attended 13 major events including these annual conferences:

- British Liver Nurses Forum
- Royal College of Midwives
- British Society of Paediatric Gastroenterology, Hepatology and Nutrition

For the first time CLDF attended the British Transplant Games to support participants and raise awareness of its work: a truly inspirational experience.

CLDF also strengthened its relationship with NHS Blood and Transplant, taking an active role in National Transplant Week 2014.



“ *The publications, website and social media posts are great. Everything is written in practical terms; there's no scaremongering. Google can be a scary place when you first find out your child has liver disease, or when things change. Having a website we can trust to provide us with accurate information is invaluable. CLDF helps us face each milestone.* ”

Parent



*The many leaflets available have been a Godsend to our family. I don't know what we would have done without your support.*

Parent



## Research highlights

Research lies at the heart of providing a future to children with liver disease and Children's Liver Disease Foundation recognises it plays an important role in contributing to and encouraging a vibrant research environment.

During the year we committed to a PHD Fellowship and the following projects:

### **Global Registry for Outcome of Varices in Children**

Dr Tass Grammatikopoulos; King's College Hospital

### **Which Genes are Regulated by Notch Signalling in the Neo-Natal Bile Duct**

Dr Luke Boulter; Institute of Genetics and Molecular Medicine



*CLDF continues its tradition of supporting research. The clinical topics will have an immediate benefit to children and their families; the basic research is an excellent investment that will contribute to our understanding of how the liver works in health and disease. In the future this knowledge will be translated and applied to improved clinical management of children.*

Dr Patrick McKiernan, Consultant Paediatric Hepatologist and former medical adviser to CLDF



*I support CLDF and for me, it's about funding research into treatments to give us hope that one day there may be a cure for childhood liver disease, although we know that is a long way off.*

Parent



In 2015-16, CLDF will make £20,000 available in the Small Grants programme as well as undertaking a review of the programme.

Following its consultation, CLDF will look to work with allied organisations to jointly fund the Main Grants round during 2015-20,

which will alternate with a PhD Fellowship on a two-year cycle. It will also create projects which increase opportunities for families and young people to learn more and be involved in research projects.

*CLDF currently has nine research projects ongoing.*

# Support

Each journey with childhood liver disease is unique and Children's Liver Disease Foundation's support service is there for everyone affected - whenever they need it and for as long as they need it.

During our consultation it was clear that both young people and families highly value our programme to bring them together and share experiences.

## Highlights

937 people attended CLDF supportive events during the year - a 47% increase on the previous year.

CLDF's families and young people's teams have continued to increase their presence in hospitals this year, attending 71 clinics across the country and reaching 639 families and young people through these visits.

The support team also had 2931 contacts with parents, friends and relatives.

798 young people between 11 and 24 had contact and support with CLDF during the year - a 10% increase on the previous year.

CLDF's residential events are a vital element of its vision that young people are not limited by their liver disease. During the year three such events took place: Closer to the Edge; Talk, Tell, Transform and Wild Camp.



“ My son confronted his fears. With CLDF's support and in the Closer to the Edge environment he was helped to gain confidence. When he got back he was proud of what he had accomplished, excited to tell family what he had done and little bit sad that it was over. ”

“ I came back from Talk, Tell, Transform a completely different person - more knowledgeable and understanding, a happier and more realistic person. I feel I have put a lot to rest and have decided my path in life after college! ”

# Voice and influence

As the UK's only charity dedicated to fighting all liver diseases of childhood, CLDF is in a unique position to seek to influence understanding, priorities and improve outcomes.

## Highlights

CLDF was invited to participate in a Lancet Commission 'Addressing liver diseases in the UK' and worked closely with Birmingham Children's Hospital, King's College Hospital, London and Leeds Royal Infirmary in representing patients' needs.

Relationships developed with a number of professional and public bodies including joining coalitions to highlight the needs of our beneficiaries including Rare Disease UK, Specialised Healthcare Alliance and National Voices.

Campaigning for a universal vaccination against Hepatitis B gained momentum during the year.

“ *It is always a pleasure to be involved with CLDF's National Conference and Family Day, which provides a wonderful opportunity for professionals and families to learn from each other. It is an opportunity to meet many patients and families from all over the UK in an informed way and give them the opportunity to ask questions from a range of experts. The charity is a huge support to all those affected by paediatric liver disease and we're fortunate to have an organisation with such a strong voice to speak up on their behalf.* ”

Professor Deirdre Kelly, Professor of Paediatric Hepatology, Birmingham Children's Hospital



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

As a result of CLDF's awareness-raising campaign, Hertfordshire Community NHS Trust has made training in the Yellow Alert protocol mandatory for all health visitors employed by the local authority. During the year CLDF's Chief Executive Alison Taylor delivered a training day to over 200 individuals, which was highly successful.

Number of Yellow Alert resources distributed this year, including downloads:

11,769

Visits to [yellowalert.org](http://yellowalert.org) website:

18,486\*

\*a 14% increase on 2013-2014

# Our Supporters

Whether you jumped out of a plane, ran a marathon or dropped your change in a collecting tin, you made a huge difference to the young people and families we support.

Here are just a few fundraising highlights for 2014/15:



## Trusts and Foundations

We received donations from 33 trusts including BBC Children in Need, which continued to fund Talk, Tell, Transform, the Hoover Foundation, which funded our Cardiff clinic visit programme and Worshipful Company of Actuaries, which funded Essential 5 packs.

## Individuals

356 people supported us through a regular gift and 494 people made a one off single donation. Over 250 sponsored activities took place raising £168,694.



## Events

Big Yellow Friday raised a record-breaking £107,535, with over 3,000 people taking part, raising funds and awareness.

We also held our 7th Chefs' Gala Dinner at The Dorchester which raised £96,787.

*A sincere thank you goes to each and every one of our fundraisers and supporters.*

[childliverdisease.org](http://childliverdisease.org)  
[cldf-focus.org](http://cldf-focus.org)

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