



## the work we do

THE HEPATITIS  TRUST

# Our goal is to eliminate hepatitis C

In the UK there are around 215,000 people living with the virus but half remain undiagnosed. Deaths from hepatitis C related end stage liver disease and liver cancer have doubled over the last decade, most of it occurs in people under the age of 60.

However, the arrival of highly effective new drugs will allow us to cure almost everyone who has access to them and cut deaths dramatically. Indeed we now have an unprecedented opportunity to eliminate hepatitis C in the UK by 2030. To do this we need to do three things:

- Prevent new infections.
- Diagnose those already infected.
- Treat those diagnosed.

To achieve these three things we need the political will to seize this opportunity and we need an integrated, strategic approach that is committed to the concept. The Hepatitis C Trust is uniquely placed to make this happen.

## The Hepatitis C Trust

The Hepatitis C Trust is the national UK charity for hepatitis C. It is a patient-led and patient-run organisation: most of its board, staff, and volunteers either have hepatitis C, or have had it and cleared it after treatment. The Trust firmly believes in patient-centred medicine and we are committed to ensuring that all our actions are for the benefit of patients, not for the benefit of other parties. We are also committed to the principle of continually increasing the employment opportunities at the Trust for people with hepatitis C, both as paid staff and as volunteers.

The Trust's ultimate goal is to close down because it is no longer needed and to do so as soon as possible. It's no surprise then that we are wholeheartedly committed to the idea of eliminating hepatitis C in the UK by 2030. Our strategy is based around the three strategic pillars of better prevention, more diagnosis and treatment for all, and we have a range of projects and services to deliver this.

In addition, we provide support and information through our helpline and website, awareness-raising through the media which includes fighting stigma and advice and support to individual patients experiencing discrimination, often in the workplace. We also have a crucial role in international advocacy. Through our leadership of the World Hepatitis Alliance, we have put viral hepatitis, particularly hepatitis C, on the global health agenda by instigating two World Health Assembly resolutions, seeing that viral hepatitis is included in the 2030 Sustainable Development Goals and working very closely with the World Health Organization to make the elimination of viral hepatitis by 2030 a global health goal.

## What we need to make elimination a reality

We currently operate on an annual budget of around £800,000. We need to increase this to £1 million per year. This will permit us to provide all the policy work, support and information, drug services work, awareness and testing projects and patient input necessary to deliver the elimination of hepatitis in no more than 15 years.

## Drug Services

The Hepatitis C Trust has a team of staff dedicated to working in partnership with drug service providers including Addaction, CGL & Blenheim CDP.

### Staff Training

We provide specialised training to drug service staff to help them understand the issues around hepatitis C prevention, transmission, diagnosis, treatment and care. We ensure that drug service staff have the skills, knowledge and confidence to deliver and encourage hepatitis C testing and provide support to those accessing secondary care.

### Peer to Peer Education

Peer Educators use their own stories of injecting drugs and hepatitis C to share key messages. This informal format allows for discussion to be carried back to their networks. The project is now live in prisons.

**“The talk was excellent and really engaging, especially the peer to peer format which is very valuable for our clients”**

### Buddying

We train volunteers to personally support people through testing, treatment and care, helping patients to find their way through the barriers they might be facing accessing care.

## Support Services

### Helpline

The Trust's confidential national helpline 0845 223 4424 or 020 7089 6221 is run by staff and volunteers who have personal experience of hepatitis C, making it much easier for callers to be open and candid. Our main focus is to provide information and support to patients and their families but increasingly we are being used as a resource by a wide range of professionals and others interested in or affected by hepatitis C.

# Our projects and services

## Prison Helpline

We run a separate Freephone helpline service which prisoners can access throughout the UK prison estate to give them much needed support, information and encouragement to get tested and get treated.

**“It felt really good to know that, whoever you spoke with, the person on the end of the phone not only fully understood me, but could offer unbiased advice and guidance”**

## Email Service

Helpline staff provide patient-centred responses to email questions. If we cannot answer a question ourselves, we make use of our expert advisory panel of doctors and consultants.

## Support Groups

We currently host a friendly and informal support group every other Monday at the Trust's London office, open to anyone seeking support and information around hepatitis C.

**“It is the only safe space I know to discuss hep C”**

## Information

### Digital

[www.hepctrust.org.uk](http://www.hepctrust.org.uk) our website is dedicated to providing the most comprehensive information on hepatitis C in the UK. It is annually certified as meeting the Information Standard. This ensures that we provide those affected by hepatitis C with accurate and up to date information. We also provide ongoing email updates, news items and information via social media.

### Print

We produce a range of information resources, including leaflets, cards and posters providing up to date information on hepatitis C.

## Outreach

### Mobile Outreach

We have run a mobile outreach van since 2011. In that time we've tested over 3,000 people and engaged more than 6,500 in discussions around hepatitis C. Just as important as testing people, we have also found the mobile outreach to be an invaluable resource in helping services put in place new and more effective pathways for people so they are linked into secondary care.

**“Since I have taken your advice regarding diet, managing stress and lifestyle I have been feeling much better mentally and physically”**

### Hard to Reach Communities

The Trust is committed to addressing health inequalities by raising awareness and promoting testing in hard-to-reach groups, such as homeless and migrant communities. Our South Asian Officer has forged many vital links and works with a number of nurses, as well as running an annual program of testing at Melas and mosques throughout the UK.

**“Thank you so much for your care, compassion and experience. You have helped me enormously and I feel much clearer about my choices and future”**

## Training

We offer a wide range of training from hepatitis C basics to specialised courses on pre-and post-test discussion and dry blood spot testing, and are happy to design tailor-made training to meet specific needs.

## Fundraising

**Art on a Postcard** (AoaPC) raises money for The Hepatitis C Trust through an annual secret postcard auction each November. In 2017 AoaPC has branched out into an audio visual event, Art on Ukulele which includes great names such as Mick Rooney RA, Allen Jones RA, Anne Desmet RA and Cathie Pilkington RA who have all painted ukuleles to be played by The Ukulele Orchestra of Great Britain at a gig in September.

We are also doing Photography on a Postcard in October, which will include some of the most exciting names in photography such as Dougie Wallace, Martin Parr, Laia Abril, Simon Norfolk, Liz Collins and Lottie Davis.

Art on a Postcard is an innovative way to fundraise in today's economic climate that has caused such drastic cuts for charities. AoaPC has an online shop, which sells limited edition prints and merchandise using the images created for our auction/lotteries. All of the money raised by Art on a Postcard goes towards The Trust's campaign to eliminate hepatitis C by 2030.



Grayson Perry CBE, RA

# Representation

## Advocacy

All of our staff work very hard to ensure that patients get the care and treatment to which they are entitled, be it advocating on behalf of a benefits claimant, addressing issues within the NHS, or pushing for better testing and treatment pathways in drug services.

## Patient Council

We set up the National hepatitis C Patient Council to provide patient input into all 22 networks delivering hepatitis C treatment because we believe that people living with and affected by hepatitis C have an expertise that is of equal importance to professionals and should be involved in every decision made that affects them.

## HCV Action

The Hepatitis C Trust provides the secretariat for HCV Action, a network which brings together GPs, specialist nurses, clinicians, drug services, public health practitioners, healthcare staff and commissioners, as well as the pharmaceutical industry to improve the patient pathway.

## Parliamentary Work

The Policy and Parliamentary team work across the UK Parliament and the devolved administrations in Scotland, Wales and Northern Ireland to ensure that hepatitis C is prioritised at a political level, and that the voices of people with hepatitis C are represented to key policy decision makers. At Westminster we provide secretariat support to the All Party Parliamentary Group on Liver Health, and in Scotland we co-ordinate the Hepatitis C Parliamentary Champions.

## Research

The Trust is involved in a wide range of hepatitis C research projects and has provided the patient perspective in the design and implementation of a number of important studies.

This demonstrates a welcome realisation amongst researchers that it is essential to involve patients in research that is ultimately intended for our benefit.

## Scotland

The Hepatitis C Trust represents the interests of patients with hepatitis C and contributes to a number of advisory boards in order to provide a patient voice. We also co-ordinate patient activism activities in Scotland, and have been instrumental in establishing and running the National Patients Forum and the Hepatitis Voices training programme.

## Consulting

The Trust provides the patient perspective to a wide range of organisations including NICE, the Department of Health, the Scottish Government, the Welsh National Public Health Service and the Scottish Medicines Consortium.

# International

## European Liver Patients Association (ELPA)

The Trust is a founding member of ELPA, an umbrella organisation with 30 member associations in 24 countries founded in 2004. Our Chief Executive served as ELPA's first president.

## International Alliance of Patients Organisations (IAPO)

The Trust is an active member of IAPO whose philosophy of promoting the voice of patients in healthcare exactly matches the Trust's.

## World Hepatitis Alliance (WHA)

The Trust set up the WHA in 2007 to run World Hepatitis Day, which it continues to do on behalf of the World Health Organisation (WHO). The WHA provides global leadership in hepatitis advocacy and has instigated two WHO resolutions on viral hepatitis. Our Chief Executive is also the WHA's President.

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