



Celebrating 10 years of The Hepatitis C Trust

2001-2011



Introduction by Charles Gore, Chief Executive of The Hepatitis C Trust and President of The World Hepatitis Alliance

Although the Trust officially came into existence near the end of 2000, it began operating in 2001, so 2011 marked our tenth anniversary. Looking back we seem to have done an amazing amount in that time – it's hard to remember it all. Not everything has been successful but I would like to think most of it has been of real benefit, especially to those living with hepatitis C.

The four of us who set it up did so because we had each been frustrated by the lack of reliable information and support for people with hepatitis C, as well as by the fact that there were over five hundred HIV charities at the time in the UK and yet not a single one devoted to hepatitis C. The day we received charity commission approval, the other three turned to me and said: '*... You do realise you're going to have to run it, don't you? We're all much too busy ...*' I was astonished (and frankly scared) since I had no experience and, as far as I could see, no relevant skills and, already by then, cirrhosis. As you can see, they talked me into it anyway.

Our wish was for information that was accurate, rather than a mixture of the gloomy and the unclear as it was then. Proper support meant that our first project was to build a really comprehensive website and the second was to set up a helpline. It was something of a struggle to start with because we had no money. So I was a volunteer for the first two years; we had to borrow office space, phones and just about everything else; one of the trustees developed major complications and had to have a liver transplant; and I started on a year's treatment.

The hepatitis C situation in the UK was a challenge too. Only about 25,000 people had been diagnosed in total and just 1,000 were treated in the year 2000 in about fifty hospitals. There was no public awareness and even medical professionals for the most part thought hepatitis C was a relatively benign virus.

Ten years on and 100,000 people have been diagnosed and last year about 6,000 were treated in some 130 hospitals. Of course this is still nowhere near enough but it does represent significant progress, as does the level of awareness. The Trust, through its creation and leadership of the World Hepatitis Alliance, has put hepatitis C, together with hepatitis B, firmly on the global agenda with a World Health Organization resolution that has made World Hepatitis Day an official WHO day and resulted in a comprehensive

The Hepatitis C Trust
27 Crosby Row,
London SE1 3YD
Telephone: 020 7089 6220
Fax: 020 7089 6201

Helpline: 0845 223 4424
(from 10.30 - 16.30pm Monday to
Friday, all calls are confidential)



The Hepatitis C Trust is a Registered
Charity, registered in England No
1104279 and Scotland No SCO39914.

PATRONS

Ms Sadie Frost
Mr Robbie Williams
Miss Emilia Fox
The Marchioness of Bute
Ms Sandie Shaw
Mr Alan McGee
The Lord Mancroft
Dame Anita Roddick
Mr Andrew Loog Oldham
Boy George

TRUSTEES

Dr Noreena Hertz
Dr Iain Murray-Lyon
The Hon Mary Parkinson
Mr Charles Walsh
Ms Francesca Cadbury
Mr Edward Mead
Mr David Enthoven
Dr Magdalena Harris
Mr Borzou Shirazi

THE LAST 10 YEARS

2001

The Hepatitis C Trust starts operating – only about 25,000 people had been diagnosed in the UK

Dr Iain Murray-Lyon becomes a trustee

Charles Walsh becomes a trustee

2002

Department of Health commissions Hepatitis C Strategy for England

Mary Parkinson becomes a trustee

2003

The Hepatitis C Trust website is launched

Participation in UCL IHCA research ensuring that hepatitis C is 1 of 6 disease areas examined

Our first poster campaign on London buses

First version of our lifestyle and treatment questionnaire launched

Our first Department of Health project funding - to examine support requirements for recently clean drug users doing interferon treatment

2004

According to Department of Health figures, an estimated 250,000 people are infected but undiagnosed

On Royal College of Physicians, Edinburgh drafting committee that issues Consensus Statement on hepatitis C

Launch of second version lifestyle and treatment questionnaire

We provide expert patient input to NICE's approval of Pegylated Interferon and Ribavirin for use in patients with moderate to severe HCV

The Hepatitis C Trust Helpline is launched

We launch our first support group

Our benefits advice service becomes available on the helpline

Our advocacy service launched

Our women's support group is launched

Launch of our lobbying website

We are "Highly Commended" by Communiqué Awards

Launch of "live chats" from professionals on our website - interactive question and answer sessions

Department of Health launch "The Hepatitis C Action Plan for England"

WHO global strategy for the prevention and control of viral hepatitis. And nationally hepatitis C has far more profile than it did ten years ago with Action Plans in all four countries and a much greater level of acceptance and awareness, thanks in no small part to Anita Roddick and her work with us.

Over the ten years we have grown from a staff of one to almost twenty in three different offices. This still makes us a small charity but we have always punched well above our weight and this is due to the enormous dedication of our staff, both paid and voluntary. Everyone really does go the proverbial extra mile, partly because they care, perhaps not surprisingly since so many have hepatitis C themselves, but partly also because the Trust is a good place to work. At least I hope it is. That is certainly the intention because the Trust is as much there for its staff as for the people we inform, support and represent. One of the things I'm most proud of is how little staff turnover we've had in 10 years.

When we started the Trust I thought it would only take a few years to sort out hepatitis C and then we could shut down and I could get a proper job and get on with my life, which just shows how incredibly naïve I was. But nonetheless that has always been the ultimate aim of the organisation – to close down. So it is interesting to be celebrating ten years just when, for the first time, hepatitis C really looks like a solvable problem. There are so many new drugs of such promise in development that it is possible to dream of effectively eradicating it in the UK in the foreseeable future.

There is still a huge amount to do to make that happen – diagnosing those currently infected so that they can benefit from treatment, giving them the information and support they need and greatly increasing our prevention work to stop new infections – but it is now something we can aim for. And I think we can look back over the last ten years and see that there has been real progress and that we have made a difference. So many people have contributed to this - our staff, our volunteers, the medical professionals who have freely given us so much time, the politicians and media who have supported us, our fundraisers and those who have so generously given money or supported us in other ways. Thank you to you all. You have made it possible. What follows is a brief run-through of some of the highlights of what we have achieved.

Policy

The Trust started operating in May 2001, just too late to be involved in the development of the Hepatitis C Strategy for England, which was commissioned two months earlier. Much of our policy work in the beginning was around the ineffectiveness of the Strategy and its accompanying Action Plan, which lacked any timetable or targets.

In particular, although we did what we could to support it, we also worked to change the frankly awful Face It PR campaign, eventually getting the Government to agree to the much better 'Get Tested. Get Treated' campaign and to use advertising not just PR.

In order to keep hepatitis C on the Government agenda we commissioned, with the help of Roche, two reports from the University of Southampton

We take part in the launch of the Department of Health's first hepatitis C awareness campaign "Face It" in Leicester Square (Sam, JJ, Neil, John, Gemma and many others associated with the Trust are featured in the portrait campaign)

We win the "Most Innovative Publicity" award from the Telephone Helplines Association for our "Any Clue" campaign

2005

First ever Early Day Motion on hepatitis C is tabled in Parliament, asking the Government to introduce targets into the Action Plan

First ever adjournment debate in the House of Commons on hepatitis C

Launch of the European Liver Patients Association (ELPA), Charles Gore becomes President

We deliver ELPA's EU-wide petition on HCV to 10 Downing Street

We are designated as the secretariat for All-Party Parliamentary Hepatology Group

We win the Communiqué Award for "Patient Association of the Year"

We contribute to SIGN - a hepatitis C information leaflet for Scotland

Our Cluedo campaign rolled out

We publish "The UK vs. Europe: Losing the Fight Against Hepatitis C" report

Our "Health Day Workshops" are launched

2006

Publication of the Health Protection Agency Report "Eye of the Needle" into UK Surveillance of Significant Occupational Exposures to Blood-borne Viruses in Healthcare Workers

Scottish government launch Phase 1 of the Action Plan

National clinical guidelines for the management of hep C issued by the Scottish Intercollegiate Network

We co-host "Hepatitis C in the Drugs Field" Conference at Royal College of Surgeons

We go on an awareness raising trek to Nepal, with members of staff, volunteers and fellow patients raising over £20,000 for our awareness funds

We publish the "The UK vs. Europe: Ready to Fight Back" report

We secure lottery funding for our South Asian project

Bob Geldof records Interview at the Trust for Hepatitis Awareness Day



highlighting how badly the UK was doing in comparison with comparable European countries like France, Germany and Italy. The first of these, *UK vs Europe: Losing the Fight Against Hepatitis C*, painted a deliberately depressing picture of how far our diagnosis and treatment rates were lagging behind. The follow-up, *UK vs Europe: Ready to Fight Back*, offered solutions as to how to rectify this. We have found this tactic of comparison really works.

Our other problem was that the local NHS, in the form of Primary Care Trusts (PCTs), was not implementing

the Action Plan. We had just taken over, after the 2005 election, the secretariat of the All-Party Parliamentary Hepatology Group (APPHG) of MPs and Peers and this allowed us to conduct a series of audits, on behalf of the APPHG, of what hospitals and PCTs were doing to improve hepatitis C services. The results from the first audit ranged from appalling to excellent but it clearly had a major impact because the second audit showed marked improvements. In 2007 we held a major conference to help PCTs improve their performance at which Anita Roddick was the keynote speaker.

Giving up on the Action Plan, we began calling for a liver strategy and a liver "czar", more correctly called a National Clinical Director (NCD), to develop and then implement it. Two years of relentless pressure paid off in 2009 when the Government announced it would commission a National Liver Disease Strategy and advertised for the post of NCD for Liver Disease. In an extremely unusual move and a reflection of our influence, the Department of Health asked Charles to be one of the four-strong selection panel for the NCD, the other members being the President of the Royal College of Physicians, the NHS Medical Director and the National Clinical Director for Heart Disease. Since then we have been closely involved with the development of the liver strategy, sitting on a number of committees. However, the enormous change that is going on in the NHS has made it extremely difficult to develop a strategy that will drive the improvements we want and we foresee a continuing need for strong advocacy with the Government in England.

In Wales we first met the deputy Chief Medical Officer in 2003 to press for development of a hepatitis C strategy there. Progress was very slow, even though we soon organised a group of 'champions' in the Welsh Assembly Government, one from each political party so we could ensure that hepatitis C received the broadest possible support. We worked extremely closely with the Welsh Public Health Service to develop a Blood-Borne Viral Hepatitis Strategy but the funding continued to be the sticking point. Our 'champions' kept asking questions in the Assembly, we kept writing to the Health Minister and we kept placing articles in the press very critical of the hold-up and eventually in 2010 the Strategy was launched.

We provide expert patient input to NICE's approval of Pegylated Interferon and Ribavirin for use in all patients with HCV

Our What Not To Share campaign is launched

A Matter of Chance: An Audit of Hepatitis C Healthcare in England - our first PCT audit

2007

Anita Roddick announces she has hepatitis C enormously increasing the profile of hepatitis C

We contribute to the Royal College of General Practitioners' Guidance for the Prevention, Testing, Treatment and Management of Hepatitis C in Primary Care

Our "Living with hep C" group is launched to provide a forum for those who cannot do treatment or for whom treatment has been unsuccessful

We run the "Improving Hep C Healthcare" conference in Birmingham

Anita Roddick becomes a patron

A follow up to our first PCT Audit - a review of all the PCTs across the UK to see how they are responding to hep C in their areas

We publish "Improving Public Awareness of Viral Hepatitis and Other Key Healthcare Concerns"

We undertake a student survey on hepatitis C awareness at five universities

Launch of Louie, Me and Hep C, a documentary about a patient dealing with treatment

World Hepatitis Alliance is formed

Death of Anita Roddick

2008

8196 people diagnosed in England, according to Health Protection Agency Report

Publication of NHS Scotland's Report "Hepatitis C Action Plan for Scotland Phase II: May 2008 – March 2011"

Andrew Loog Oldham becomes a patron

We are Highly Commended by Communique for "Best Patient Campaign" for What Not To Share

We launch the first ever support group for gay men with hep C

Launch of the first World Hepatitis Day and 12 MPs get tested to highlight the '1 in 12' global campaign and parliamentary debate focuses on liver disease, particularly hepatitis C

In Scotland we were asked to be part of the drafting committee for the Edinburgh Hepatitis C Consensus Conference in 2004 that set the scene for the Scottish Hepatitis C Action Plan. Charles was responsible for the concluding statement of the Consensus Statement that said: *'What is certain is that, if we do not invest adequately now, we will not be able to afford the consequences of failing to tackle this epidemic.'* We then worked closely with Health Protection Scotland on Phase I of the Action Plan, sitting on the Oversight Board, and then leading on aspects of Phase II on behalf of the Scottish Government.



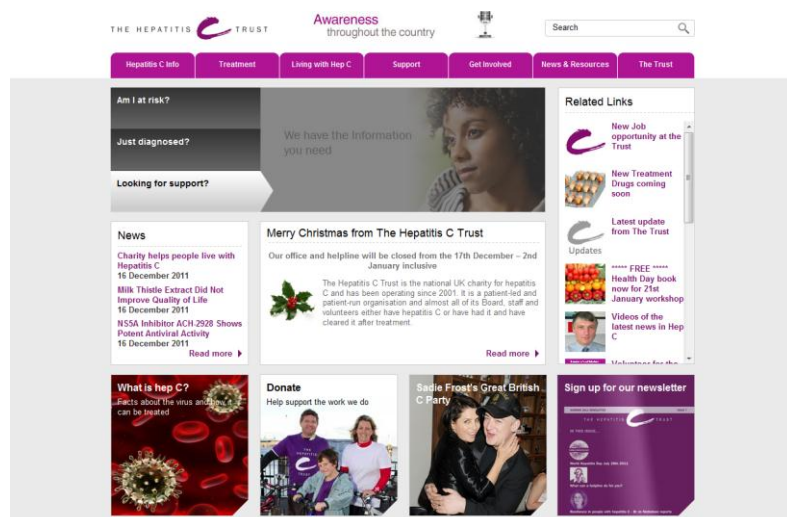
In 2009 we opened an office in Edinburgh so that we could increase our work in Scotland. We have worked hard to develop very good relations with MSPs in order to ensure that hepatitis C has had the cross-party support necessary to secure its funding, first in the Action Plan and now in the Sexual Health and Blood-Borne Virus Framework. In 2009 at our request Scotland became the first country in the world to sign up to the World Hepatitis Alliance's 12 Asks. In 2010 we held a reception in Holyrood with MSPs, clinicians and over 50 patients from around Scotland to inform MSPs first-hand about the reality of living with hepatitis C. Before the last election one-quarter of MSPs signed up to our Pledge to keep hepatitis C as a priority.

For a number of years we have campaigned for better payouts for those infected with hepatitis C through the NHS and in 2010 the Government announced significantly increased payments, although still way short of the level of payments made in other countries such as Ireland.

Information and Support

WEBSITE

One of the primary motivating factors behind the creation of the Trust was the lack of adequate information and support for people living with hepatitis C in the UK. So the very first thing we did was to set about creating a really comprehensive website. Over the years we have had two major redesigns of the site, the last in 2011 to reflect the growing use of social media.



We host our first Medicine, Me and Hep C conference at the Royal Society of Medicine

Our revised website is re-launched

“Divided Nations: Tackling the Hepatitis C Challenge Across the UK” report is launched

“Location, Location, Location: An Audit of Hepatitis C Healthcare in England” report is launched

More Transplants, Saving More Lives: The Future for Organ Donation in the UK report is launched

The helpline taken just under 15,000 calls to date

‘The information you sent me has answered so many questions that sadly no doctor ever did’

‘I am a harm reduction practitioner and wish I had contacted the helpline earlier, it has provided a wealth of information and will undoubtedly benefit our service users.’

2009

Publication of the Archer Inquiry Report “NHS Supplied Contaminated Blood and Blood Products”

Sadie Frost becomes a patron

Francesca Cadbury becomes a trustee

Ed Mead becomes a trustee

We launch the first ever HIV and hep C co-infection group for gay men

Our Scottish office opens

We launch a published version of The Hepatitis C Trust newsletter

We send out a testing bus to Cardiff, Glasgow and London

Our Get Tested! Project is launched

Our pharmacy testing pilot shows much higher yield than testing in GP surgeries

‘I was made to feel welcome at the support groups and it was great to compare notes with other patients’

‘Since I have come out about my disease it was wonderful to be with others who know exactly what I am going through.’

HELPLINE

After the website, our next priority was a helpline. Launched in 2004, we wanted it to do two things. First, of course, we wanted a resource for people to be able to access not just reliable information but also emotional support, allowing people living with hepatitis C to discuss such issues as their experience of stigma or discrimination or whether to do treatment with someone who also had hepatitis C and could therefore truly understand what is involved. Secondly, we wanted to provide an opportunity for people with hepatitis C to do voluntary work that would be rewarding and enjoyable in a supportive atmosphere and perhaps offer some of them a way back into work. In fact, about half of our helpline volunteers have ended up working full-time, often for us but also elsewhere.

As part of our helpline service we took on a new member of staff in 2006 to provide an advocacy service. There has always been a consistent demand for this type of service to help with issues like housing, benefits, discrimination and access to services but from 2006 when NICE ruled that treatment should be available to everyone with hepatitis C regardless of the degree of liver damage, demand increased hugely because Primary Care Trusts began refusing to fund treatment. Our advocacy was so successful that within two years PCTs had all accepted their obligation to fund it but we are now faced with a similar situation as PCTs are reluctant to fund the latest drugs.

As well as taking ever more calls the helpline is now the focal point for the counselling being offered by the Government to those infected with hepatitis C through the NHS. We are providing triage and solution-based therapy as well as the administration for the scheme.

HEPATITIS COVENTRY

In 2010 we started a project for Coventry City Council to provide support in testing and during treatment for current drug users with hepatitis C. Working with a local council is a new departure for the Trust.

NEWSLETTER

Our original newsletter, little more than a simple printed Word document, was launched in 2004 with a readership of just under 150, but as it became clear there was a demand for a more detailed regular source of information, we re-launched a professionally published version in 2009 which by the end of 2011 had a readership of over 3500 patients and professionals around the UK.

SUPPORT GROUPS

Since our support groups started, we have seen a little under a thousand people attend. Personal contact with others affected by hepatitis C is often a key factor in helping people to come to terms with their illness, discover the best ways of managing their lifestyle, getting support through the treatment process and feeling less stigmatised.



We publish a report "Hepatitis C: Out of Control"

David Cameron MP, Leader of the Opposition, raises hepatitis C as a key area of public health that needs attention: "And perhaps the most shocking rise in modern disease has been Hepatitis C - since 1997 the number of cases reported each year has almost trebled. While the latest official figures show that 60,000 people in England have been infected, the Department of Health estimates that the real figure is more like 200,000. But The Hepatitis C Trust believes that you can double that number - with nearer 400,000 people in England being infected."

2010

David Enthoven becomes a trustee

Our Helpline is added to the global prison telephone list, enabling prisoners to contact us directly

Welsh Blood-Borne Viral Hepatitis Plan 2010 - 2015 launched

We host a Christmas party for over 100 patients from our Patients Association

We win the Communique award for "Best Healthcare Policy"

Our national pharmacy testing programme starts

The new Public Health Minister, Anne Milton MP, makes her first public engagement after the General Election at the World Hepatitis Day Parliamentary Reception which is also attended by over 20 parliamentarians, celebrity supporters and patients from across the country

The Government announce their plan to create a National Liver Disease Strategy following sustained campaigning and pressure from The Hepatitis C Trust, patients and MP champions

Our Hepatitis Coventry office is opened

We are invited to join senior Department of Health working groups to develop a National Liver Strategy

After extensive lobbying by The Hepatitis C Trust, other charities and NGOs and a long Parliamentary campaign led by Lord Morris of Manchester, an increased package of support for people infected with hepatitis C from contaminated blood and blood products is announced by the Government

International Advocacy

The Trust's leading role, as the driving organisation behind the World Hepatitis Alliance, began modestly with participation in a meeting of European hepatitis C patient groups in London in December 2002. Following this, patient groups decided to hold a European Hepatitis C Awareness day on October 1st. Also, over the next two years, the Trust became involved in the creation of the European Liver Patients Association (ELPA) and Charles was elected its first President in 2004.



This put the Trust at the forefront of European advocacy as we worked to establish ELPA as a credible organisation with sustainable funding, to build relations with European doctors and to lobby the European Parliament for action resulting in a Written Declaration on hepatitis C signed by 460 MEPs.

By now October 1st had become European Hepatitis Awareness Day (adding hepatitis B) but we could not persuade non-European groups to participate. So after Charles finished his term as president in 2006, we contacted all the patient groups we knew worldwide and asked them to choose one representative from each region to come to a meeting in Barcelona in April 2007 to discuss a World Hepatitis Day.

The idea of a World Hepatitis Day was easily agreed, the first to be on May 19th 2008. The Trust raised the money from international donors to employ an agency, since organising it was a huge task and the Trust could only afford to second one staff member, Raquel José, to do it. It was clear that channelling all that funding through the Trust would seriously unbalance our accounts so we set up the World Hepatitis Alliance of patient groups in Switzerland, where the World Health Organization (WHO) and international NGOs like the Red Cross are based. Charles was elected President.



It became apparent whilst organising the day that many governments were refusing to support it, because it wasn't in the WHO calendar. So we decided we would have to get it endorsed by the 193 countries of WHO in a WHO resolution. There followed two years of relentless advocacy by the Alliance (i.e. Charles and Raquel) and by patient groups around the world. This involved us writing to all 193 governments on numerous occasions, talking to individual Ministries of Health and Charles addressing the WHO Executive Board and the WHO World Health Assembly.

The result in May 2010 was the adoption of the first ever WHO resolution on viral hepatitis, establishing World Hepatitis Day as only the fourth disease-specific official day (with AIDS, TB and malaria), giving hepatitis B and C a much higher global priority and requiring a global strategy to tackle them. This global strategy has now been drafted by WHO and we will be working to ensure it is the basis for national hepatitis strategies throughout the world.

We take over the secretariat of HCV Action - 'the voice of the hepatitis C professional community'.

We hold a reception at our Edinburgh office for patients, clinicians and MSPs and also host an information stall at Holyrood over three days to encourage MSPs to sign up to the pledge

We collaborate with Addaction and Imperial College on the "Hep C and Drug Use in London" conference

We publish a report "Diagnosing Viral Hepatitis in the Community" on our three month pharmacy testing pilot

"In the Dark: An Audit of Hospital Hepatitis C Services Across England" is published

"Improving the Lives of Liver Patients: A Report of the Work of the All-Party Parliamentary Hepatology Group in the 2005-10 Parliament" is published

We publish the results of the first ever post-treatment survey

Our Peer to Peer project is launched

The premiere of the film "A little bit of Tom Jones" raises funds for the Trust

Our GP Awareness project is launched

Our CEO addresses 193 Ministries of Health at WHO Geneva

The World Hepatitis Alliance secures the first WHO hepatitis resolution

We send a testing bus to London, Manchester, Blackpool, Bridlington and Newcastle

Awareness-raising bus goes to Inverness, Perth, Dundee, Edinburgh, Glasgow and Stirling

We host a Christmas party for people with living with HCV with celebrity waiters and waitresses

We receive Communiqué's "Best Healthcare Policy Program" award

2011

Boy George becomes a patron

The All Party Parliamentary Hepatology Group hosts a workshop for patient groups called "Putting Patients at the Heart of the Liver Strategy", which is attended by the National Clinical Director for Liver Disease.

Boy George's photos of celebrities dressed as 1980s icons go on display at HMV Oxford Street

Our second Medicine and Me conference is held at the Royal Society of Medicine

Research

Research has never been a top priority for the Trust, although it is one of our charitable 'objects', but we have undertaken it where we think it is necessary and no-one else is doing it. Our first project was to look at people's experience of both interferon treatment and alternative and complementary medicine as well as diet, exercise, stress management and spiritual practices. This provided a useful insight into what patients found most useful in coping with hepatitis C. One of the findings that emerged from this was that people who had contracted the virus through drug use seemed to find interferon treatment harder to tolerate. This, coupled with cases we came across in which people were started on treatment almost immediately after stopping addictive drug use, with disastrous consequences, led us to run a series of workshops with hepatitis specialist nurses to research the issue and develop guidelines for treating people with a history of addictive drug use.

At the same time we were asked by University College London to participate in research into how people use, and what they want from, Interactive Health Communications Applications such as websites. We agreed to take part as long as hepatitis C was one of the six disease areas examined. Results from this study were extremely useful for the design and content of our own website.

Our third piece of research was instigated by Professor Graham Foster of Barts and the Royal London NHS Trust, who was finding the beds in his liver unit filling up with people from the South Asian population dying of hepatitis C. He knew that the prevalence in some parts of South Asia was high and wanted to find out if that applied to South Asians living in the UK. We applied to the Big Lottery Fund and received a £350,000 grant over three years to research the prevalence of hepatitis C (and hepatitis B as well) in South Asians in the UK and also how best to raise awareness. The results, showing much higher prevalence in first generation Pakistanis in the UK, has made this population a key target for awareness for both the Government and the Trust and our findings about the best methods of awareness-raising have determined how we have gone about it.

We then became concerned about the on-going after-effects of treatment and conducted an online survey of 500 people. To speed this up we did it retrospectively, which made the findings less robust, but nonetheless the unequivocal conclusion was that it is an issue and so more research is essential. We are very pleased that this further research has now been started at the London School of Hygiene and Tropical Medicine.

Recently, funders of research have become increasingly insistent that those who will potentially benefit are involved in the research itself and, as a consequence, we are being asked to become research partners in more and more projects. We are currently involved in a major project to assemble a bank of 10,000 blood samples from people with hepatitis C that will be an unparalleled resource for future research.

Boy George does concert at Jazz Café for us with Adam Ant

Dr Magdalena Harris becomes a trustee

We launch a training programme for prisons and BBV teams

We achieve the Information Standard from the Department of Health, an accreditation for the information on the website and in our leaflets

Our new look website launched

Scottish Sexual Health and BBV Strategy is published

We host a Parliamentary reception with the APPHG to promote South Asian awareness

The first new treatments in almost a decade are launched using direct acting anti-virals (DAAs)

We win the APPSUK (Association of Pakistani Physicians and Surgeons of the UK) Affiliate award

Borzou Shirazi becomes a patron

Our custom-made hepatitis C testing van hits the road

PM David Cameron issues statement for World Hepatitis Day: "With more people being tested for hepatitis C and treatments improving all the time, an early diagnosis can make a real difference. But it's critical that people who could be at risk continue to be tested, as it's a disease that can go undetected for years. We are looking at how we can strengthen efforts to prevent and control hepatitis C in the future as part of our strategy for combatting liver disease. But today, on World Hepatitis Day, I urge everyone who could be at risk to go and get checked out."



Our first campaign – not high visibility!

Representation and Consulting

Right from the beginning we have felt that the Trust should be very active in providing the patient perspective in a whole range of settings. As a result we have been regularly involved with the NHS at a strategic level in England, Scotland and Wales, although not in Northern Ireland, and also increasingly at a regional level, whether with the Health Boards in Scotland and Wales or regional networks in England.

We are in constant contact with public health bodies like the Health Protection Agency in England, Health Protection Scotland and Public Health Wales and we also provide the patient perspective to the agencies that decide on which drugs the NHS should prescribe – the National Institute for Health and Clinical Excellence (NICE) and the Scottish Medicines Consortium (SMC). NICE has a longer and more formal process than the SMC and we have acted as the patient group and provided the patient expert input for the assessments of pegylated interferon and ribavirin for moderate to severe HCV (TA 75 2004), for mild HCV (TA 106 2006) and for retreatment (TA 200 2010), and now for the assessments of the new protease inhibitors.

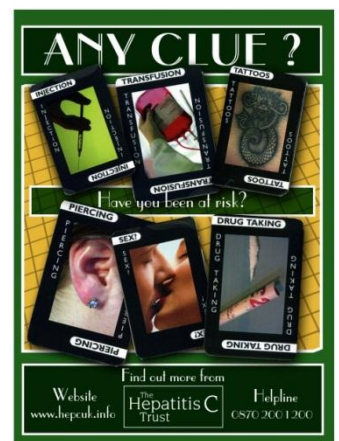
Awareness and Testing Campaigns

In the UK in 2001 the vast majority of people with hepatitis C were undiagnosed and there were about 12,000 new infections each year. Yet in 2001 we were only diagnosing about 5,000 cases. Awareness, especially around the need for testing, has therefore always been a Trust priority.

We started small in London in 2003 with a campaign on the backs of London buses. As it was our first campaign, we did it in partnership with another organisation. Originally a hepatitis C campaign, our partners unilaterally changed it to a blood-borne virus campaign and unfortunately decided to use red posters on red buses, not really a winner in terms of visibility.

The next year we used the Cluedo theme to produce a range of cards in 2004 highlighting transmission routes, using the strapline 'Have you got a clue?' We produced posters and leaflets based on the cards that we gave out to GPs and hospitals but we had no money for billboards in public spaces.

We then became involved in the making of *Louie, Me and Hepatitis C*, Gemma Peppé's film about living with hepatitis C and her experience of treatment. The film exceeded all our expectations. For a year or so the Community Channel on Sky and Virgin showed it twice monthly. On its first showing it got the "digital pick of the night" in *The Daily Telegraph*, *The Daily Mail* and *The Guardian*. In 2007 we had a mass screening of the film in over 500 venues across the UK and we even had



requests from Australia to show it. It ended up reaching tens of thousands of people across the world, raising awareness of hepatitis C and helping to reduce the stigma attached to it and Gemma ended up working for the Trust.



WHAT NOT TO SHARE.COM

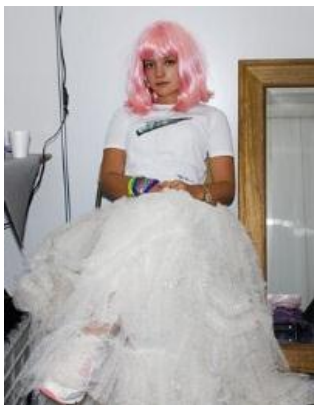


Mark Ronson

Our next campaign, which is ongoing, was also about transmission routes. Called 'What Not To Share' it was a reference to the then ubiquitous Trinny and Susannah TV show 'What Not To Wear'. We created some very strong images of notes, razors, toothbrushes and needles and produced a series of T-shirts and postcards with information on the back.



This time we used large posters in key sites throughout universities in the UK, the sites very generously donated by Redbus, the outdoor advertising company that specialises in universities. To kick off the campaign we held parties in 30 different clubs all over the UK which got us wide coverage.



Lily Allen

To take it to the next level we enlisted the support of high-profile celebrities such as Lily Allen, Russell Brand, Sadie Frost and Mark Ronson and Charlotte MacMillan shot a series of photographs of them and many others which we exhibited at City Hall in London.

Anita Roddick's offer to help us raise awareness gave us a huge opportunity. She generated a vast amount of media coverage, both in the UK and around the world, the day she announced that she had hepatitis C.

She continued to help us raise awareness, regularly doing features in magazines. Even when she wasn't actively promoting hepatitis C awareness for us, the press had associated her with it and no article appeared about her, no matter that it was completely unconnected with her health, without mentioning hepatitis C.

We had so much planned but unfortunately her sudden death put an end to those plans. Nonetheless in just six months she made an enormous difference.

I had hepatitis C for more than 30 years without knowing it. If you think you could have been at risk, talk to your GP about a test or call The Hepatitis C Trust

The late Dame Anita Roddick, Founder of The Body Shop and Patron of The Hepatitis C Trust

NO FEAR

THE HEPATITIS C TRUST

Helpline 0845 223 4424
www.hepctrust.org.uk

Photograph Trevor Leighton Registered Charity 1104279

These are the risks...

Blood transfusions (prior to 1992)
Injecting drugs, even once
Unsterile tattoos/piercings
Medical/dental procedures abroad
Other blood to blood contact

Discuss with your GP
whether to get tested
for hepatitis C

Find out more at www.hepctrust.org.uk
or call our helpline: 0845 223 4424

THE HEPATITIS C TRUST
The Hepatitis C Trust is patient-led and is the national UK charity.
All calls are confidential and are charged at the national rate
that may be more than a mobile.
We are a member of the Hepatitis Association.
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Susan's story



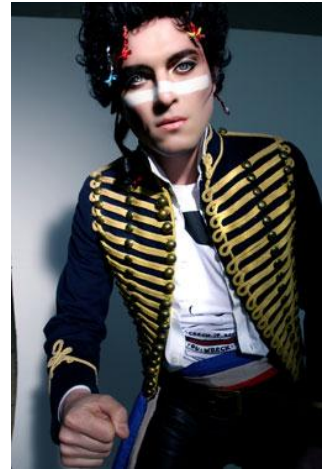
Ten years is a long time when you have hepatitis C - and increasing memory loss and brain fog make it difficult to recall accurately what has happened and when over that time. What I do remember is two bouts of treatment, both unsuccessful, a succession of biopsies and different types of scans over the years (reaching a peak of one every six weeks) to track the growth of tumours on my liver, and the eventual diagnosis of cancer. It sounds horrific on paper, but in reality the traumatic times were far outweighed by the pleasures of getting on with my life - travelling, socialising, working at The Hepatitis C Trust, but above all enjoying watching my kids growing up (though living with teenagers and coping with hepatitis C is challenging for all involved).

So what is happening now? Well, I was placed on the liver transplant waiting list, and at the end of 2010 was given my new liver. And here I am back at work at the Trust, being supported and teasingly insulted in equal measure by 'amusing' colleagues. My life has been saved by the wonderful staff in the liver unit at King's College Hospital in London, and continues to be enhanced by the love of family and friends.

Since 2008 our general, as opposed to targeted, awareness activity has had two parts - World Hepatitis Day each year and our ongoing Get Tested! campaign. Thanks to the generosity of Clear Channel and Redbus giving us poster and billboard space we have been able to place up to 1,000 posters around the UK in key locations every year in the period leading up to World Hepatitis Day.

Our Get Tested! campaign was originally intended to draw in celebrity supporters from the music industry and started through our association with the International Music Summit, the annual dance music industry event held each year in Ibiza since 2008. As their official charity partner we have been involved from the beginning and, as the profile of IMS grows, so does ours.

**GET
TESTED!**
THE HEPATITIS C TRUST



Celebrity supporters are extremely important because the media want to feature celebrities all the time. This means they can easily get us media coverage. They also help to destigmatise hepatitis C by making it more mainstream. Year by year the numbers have grown and, although now we have celebrities in other fields than music, like Sadie Frost, Gizzi Erskine and Beatrice Ong, most of our supporters are from the music industry. What is important to us is that these are not rent-a-celebrities but people who are genuinely devoted to the cause for a whole variety of reasons. We have been very lucky in their continual commitment to helping us, whether it is by designing T-shirts for us, holding concerts, throwing dinner parties or simply just doing press pieces.

Most recently many were involved as models in a series of photographs Boy George took for us of current celebrities dressed up as 1980s icons to get people to think about what they were doing in the 1980s that might have put them at risk of hepatitis C. The photographs received widespread media coverage and were auctioned off to support the Trust at a concert at the Jazz Café in London.



For World Hepatitis Day 2011 we branched into the concept of liver friendly meals that we called C Parties. Gizzi Erskine took the lead on this, getting her many celebrity chef friends to contribute menus so that people around the UK could host their own C Parties. She then cooked with Friday Food Club's Lee Behan a meal for celebrities at Sadie Frost's house which got us a three-page spread in *The Sunday Times*.

Get Tested! is an ongoing campaign and you can follow us on Twitter and Facebook.

Sadie's story



Ten years ago I already knew about hepatitis C as my father had it and as a result of the complications it brings, he sadly passed away in 2003. He was diagnosed very late so he never had the chance to receive proper treatment and care.

I wanted to know more about the disease and what I could do to help, so when The Hepatitis C Trust approached me I jumped at the chance to become a patron.

I have become very involved with the charity. I have helped raise both awareness and funds. I designed a T-shirt with the 'check it before you wreck it' tag-line for The GET TESTED! campaign and I've had a key role in organising events such as exhibitions, gigs and dinners. I've also helped the Trust by introducing them to high profile people who have helped them to get much needed press. I also made a speech on World Hepatitis Day 2010 at the House of Commons which was a nerve-wracking experience, but very rewarding as the event was attended by some great celebrities, plus a lot of the new MPs who had just formed the new Government that very week.

It has meant so much to me to be involved with The Hepatitis C Trust. All the people I have met along the way have been amazing. It has been the most fulfilling experience and, ultimately, brought me closer to my father.

Work in the South Asian Community

As a result of the research we did with Barts and the Royal London NHS Trust showing the high prevalence of hepatitis C among Pakistanis in the UK we began a targeted awareness campaign that has involved distributing English/Urdu leaflets in mosques, as well as testing and awareness events at *melas* and a South Asian awareness event in Parliament.

GP Awareness

We have also over the years targeted GPs to try to improve their knowledge and increase the numbers they diagnose. They are notoriously difficult to engage because they are so busy. We started by mailshotting all GPs in the UK with a letter and an awareness poster for their surgeries. We then contributed to the Royal College of GPs' *Guidance for the Prevention, Testing, Treatment & Management of Hepatitis C in Primary Care* and to the RCGP's hepatitis e-learning programme. More recently in 2010 and 2011 the primary care teams of both MSD and Roche have distributed our posters and leaflets while visiting GPs to talk about their products.

Work in prisons

We now offer training to prison staff to raise awareness and promote testing in prisons. Up to 20% of prisoners may have hepatitis C (we don't have exact figures because no prevalence survey has been done since the 1990s) and prisons are clearly a potentially excellent setting for testing and treatment, yet very little is being done. We are involved in a pilot scheme in Strangeways prison in Manchester carrying out training and testing and we have agreed with the prison governor that prisoners can telephone our helpline for free.

Working with drug users

During the first few years of the Trust's operations we did little to raise awareness amongst drug users because we felt at least they should have been provided with hepatitis C information by the drug services, while there was nothing for everyone else. Unfortunately, the drug services have not done a good job and there is a surprising and disturbing ignorance about hepatitis C in those working in the drug services. We therefore decided both to offer training to drug workers and to set up our own peer-to-peer education programme for drug users. We currently have two members of staff who contracted hepatitis C through intravenous drug use ('peers') who visit drug rehabilitation projects on a continuous basis giving drug users three simple messages about the importance of getting tested, the right to treatment and how the virus is transmitted. We will be expanding the programme to involve many more peer educators because we believe that, if we can relentlessly impart the correct facts about hepatitis C to this community, we can dispel the many myths and misapprehensions that currently exist.



David's story



What an interesting and sometimes challenging period the past ten years have been. I was diagnosed HIV positive in 2001 and those years, although anxiety filled, turned out to be somewhat of a damp squib as I thought, quite wrongly, that because my CD4 count remained high for the next 8 years that I was destined to be a long-term non-progressor, one of those whose immune system wouldn't come crashing down despite the virus. That all changed in 2008 when what I hoped would not happen did and I had no option but to start HAART (highly active anti-retroviral therapy).

Having got over this challenge I was then diagnosed hep C positive in 2009, something of a shock as I didn't know that I was being tested for it so the first I knew was when my doctor asked if I had considered starting treatment for chronic hep C. After 60 weeks on a course of interferon and ribavirin (I was genotype 4 but as I didn't go undetectable at 4 weeks they wanted me to do a lengthier treatment) I still have 6 months of suspense at the time of writing this, to see if I have achieved SVR.

No matter what this outcome I hope and believe that I can face the challenges of the next ten years with the fortitude of the past ten.

I am now delighted to be a volunteer on the helpline at the Trust.

Pharmacy Testing

In 2007 Boots approached Anita Roddick and asked her to write a piece about hepatitis C for their in-house magazine. She agreed to do this on one condition: that they let us do a pilot testing day in their flagship store in Nottingham. Based on this we decided to do a bigger pilot lasting three months in pharmacies in five PCT areas. Although the number of tests was not large, 15% of them were positive, compared to just 4% in GP surgeries. This persuaded the Department of Health to give us a grant to roll the scheme out nationally.



Mobile testing

2011 has seen the Trust take another big step forward in promoting awareness and testing with the commissioning of our van which will allow us to take these services not only around the country but into hard-to-reach communities. We have spent a lot of time learning from the experiences of the 'Find and Treat' project which is a similar initiative for TB in London.

Funding

Over the years we have received about 45% of our funding from grant-making trusts, about 15% from individuals and about 20% each from Governments and the pharmaceutical industry. We are enormously grateful to everyone who has contributed, from a patient who wanted to thank us for all the helpline support they received by giving us £5 a month to the enormously generous £500,000 grant from the Gawaine Stamp Fund. It is your kindness and support that has allowed us to achieve all that we have in the past 10 years.

Community Fundraising

A huge thank you to all of you who raised funds for the Trust in myriad ways, some quite mind-bogglingly original.

We have been constantly amazed by how people have chosen to show their support. For many, getting involved and raising funds for the Trust is a personal decision following their own experience with hepatitis C. Patients, family members, friends, and even doctors and nurses have all contributed.



Richard Galbraith raised nearly £5000 running the Marathon de Sables, the toughest race in the world - a 6 day 250km race across the Sahara Desert.



Dr Mark Hallam, below, achieved a successful ascent of Mount Aconcagua, at 22,840ft the highest mountain in the world outside of the Himalayas. Mark also raised nearly £5000 for us on this incredible journey.



Natalie Richardson, far left, ran the London Marathon for us.

And to all the countless others who have run, cycled, hiked, jumped out of planes, held C Parties, baked

cakes, shaved their heads, donated items, a huge thank you - we really appreciate your support.

Finally, a story from one of the people we work for, one of the hundreds of thousands living with hepatitis C

I would like to say that I think The Hepatitis C Trust is fantastic. From the day I was first diagnosed to post-treatment, the assistance and support they have been able to offer has been immeasurable. As soon as I was diagnosed in 2006 I was able to ring the Trust for information and from the time I left my doctor's surgery frightened and in shock I knew they were always there.

The information I was able to obtain from the website was again immeasurably helpful as my GP knew very little. I think she just gave me a leaflet with an NHS website on it which was not very informative, although once I started treatment she was very supportive.

I downloaded all the information from the Trust website and read it through thoroughly as although I had a suspicion that I might have had hep C due to my past behaviour as a foolish 20 year-old, actually having it confirmed was very scary, particularly when discovering how difficult the treatment could be. I felt the more knowledgeable I was, the better I would be able to deal with the whole experience.

Fortunately I live in London so was able to attend the monthly support group meetings as well as the women's group once I had started treatment and had been dismissed from my job (due to my illness) - another battle I had to fight. Again these support groups were invaluable. As all will know who have gone through the treatment, it can be a very lonely and isolating experience. Despite being well-prepared and deciding that I would not suffer from any of the side effects, I did, and doing the treatment with no real support as I live on my own was tough. Again, knowing there were friendly, knowledgeable, non-judgmental voices on the other end of the phone who had felt the same as me was of great comfort.

I started treatment in 2007 and eventually found another job in 2008. I still get extremely tired and I am sure it is because of the treatment, although it could be that I am in my mid-fifties, but I am sure treatment must have some residual effect. Therefore on a personal level I would like to see more research done into post-treatment. On a general level, more needs to be done to raise awareness, as always, but of course there are so many causes vying for attention.

I am clear of the virus and the nightmare of 2006 and 2007 is a diminishing memory, but I will never forget the support and assistance I received from everyone at the Trust.

With all best wishes for the future and let's hope there is no need to be sending feedback in another 10 years.

Yvonne Hersevoort