

September 2022

TOGETHER  
WE CAN

Terrence  
HIGGINS  
TRUST



# trust living

The newsletter for Terrence Higgins Trust's valued supporters

## 40th anniversary edition



40 • FORTY YEARS •  
FOUNDED 1982 •



# The Carson Family Legacy

## The People Behind The Plaque

By **David Lawson**

*Executor of the Carson legacy*

A new plaque displayed at Terrence Higgins Trust's head office commemorates a large legacy gift donated by a couple in memory of their sons. Anne and Alex Carson gave money to Terrence Higgins Trust for years. Two of many retired people who regularly post off cheques to charity, quietly supporting from home.

Their connection to Terrence Higgins Trust came from their youngest son, and my former partner, Justin Carson, who was diagnosed with an HIV-related cancer in 1992. A shock to a family genetically blessed with good health. Justin lived through lymphoma and a toxoplasmosis legion on his brain before a final infection proved fatal in 1999. He was 44. Between extreme illnesses, Justin enjoyed periods of wellbeing. Information provided by Terrence Higgins Trust contributed to the quality of a life lived in full.

Twelve years later, Justin's older brother, Simon Carson, died from heart failure, brought on by stress and depression. He was 60. An entrepreneurial businessman, Simon lived life like a rock star. Live fast, die young. From the eighties onwards, HIV and AIDS caused many parents to bear the unnatural grief of losing an adult child. Anne and Alex lost both their sons but they themselves carried on living until their mid-nineties.

I met Justin in 1987 when we were members of an organisation set up to support people with HIV and AIDS, at a point when medical treatments were still in their infancy. The toxicity of drugs in the eighties often caused more issues than the medications resolved. Stressed medical staff were working blind to provide appropriate care. Consultants at a couple of London hospitals courageously gave permission for a collective of spiritual healers and complementary therapists to visit the wards, providing treatments for any patient who requested it. My subsequent relationship with Anne and Alex endured for over thirty years.

If you would like more information about leaving a gift in your will, please complete and return the enclosed form. Alternatively, you can find out more by visiting [ttht.org.uk/legacy](http://ttht.org.uk/legacy).



Anne, Simon and Justin in the late 1950s





## The Heart of Terrence Higgins Trust

"My vibrant, hilarious friend Terry Higgins collapsed while partying at Heaven nightclub and never left the hospital – becoming the first named person to die of an AIDS-related illness in the UK. The nightclub's then logo had a red heart at its centre. It seemed a no-brainer for this to evolve as the symbol at the heart of the organisation we set up in Terry's memory with a determination to humanise the epidemic and provide desperately needed care to the fast-growing number of people impacted by HIV. That our charity and the symbol have stood the test of time is a tribute to 40 years of AIDS activists and the life changing work of Terrence Higgins Trust."

**Martyn Butler**

Co-Founder  
Terrence Higgins Trust



10-11-92  
Euston Station:  
Terrence Higgins Trust  
Collection Day sticker.

have a safer pride



The Terrence Higgins Trust

## Terry Higgins portrait unveiled as Welsh Government outlines HIV action plan

A new portrait of a childhood photo of Terry Higgins has been unveiled in the Senedd to mark 40 years since the Welshman became the first named person in the UK to die of an AIDS-related illness.

The unveiling, held on 15 June, was part of an event held by the Welsh Government marking the past, present and future of HIV in Wales. The release of the Government's ambitious draft action plan for ending new HIV cases in Wales by 2030 is a look forward to a future where no-one else in Wales contracts HIV.

**Artist Nathan Wyburn, who painted Terry's portrait, said:**

When Terry died 40 years ago no one even knew what HIV was and it wasn't until 1996 that effective treatment became available. Now the goal is for Wales to become one of the first countries in the world to end all new HIV cases by 2030.



“As an artist who comments on and reflects the key social issues, and a proud gay man, being asked to mark the 40th anniversary of Terrence Higgins Trust is a huge honour. I've stayed with my unusual way of using everyday relatable items to make the art – this time it's stamps in the shape of the charity's heart logo.”

## An update on the HIV Action plan for England

Last year, over 3000 of you called on your MP or the Chancellor to back the HIV Action Plan in England. Thanks to your support, we welcomed the government backed HIV action plan and £20 million commitment to fund opt-out testing. It's a momentous step forward.

Eight months on, opt out HIV testing in A&E departments has been successfully introduced in areas with the highest HIV prevalence. A national HIV implementation steering group has also now been established, which will play a role in advising and overseeing the implementation of the action plan.

In the 40th year of HIV in the UK, it's incredible news that new HIV transmissions could end by 2030. But this goal is by no means certain - we'll only get there with a step by step plan and the funding to back it. Now that the building blocks are in place, the real work begins. The inequalities in access to PrEP must be addressed and the roll out of opt-out testing needs to reach more areas.

The next few months are a real opportunity to set us on the right track to end new HIV transmissions by 2030.

## The New Strategy: Growing our ambitions

Our strategy for the future embraces our roots as radical and ambitious activists. It's an exciting and historic time. As we celebrate our 40th anniversary, and look back on four decades of fighting for change, we are also looking to the future and will do everything in our power to end to new cases of HIV by 2030.

As we continue to support people living with HIV, we aim to expand our ambitions around sexual and reproductive health, alongside promoting good sexual health for all and being unashamedly sex positive. We'll look to innovate and expand our service offers to embrace a wider range of service users aimed at reducing health inequalities, disadvantage, and marginalisation.

Our commitment to equity, diversity and inclusion runs throughout our new strategy. We will work with a renewed vision to become a truly anti-racist, anti-sexist and inclusive organisation that challenges systemic health inequalities. To meet the needs of the communities we serve, we will ensure that our leadership and staff team reflect those communities. We'll keep ourselves on track with clear targets and milestones so that we can see what we are changing, and ensure our service users are integral to the design and development of everything we do every step of the way.

**The progress made so far has only been through the dedication and generosity of supporters like you, and for that we are truly grateful. We ask once more for your help, to make our ambitions a reality.**

## Your Impact

In 2021 your support helped achieve

184

The provision of **184** financial grants for people struggling to afford basic necessities.



13,752



Emotional support and advice to a staggering **13,752** queries through our helpline, THT Direct, which is here for people who are worried about their sexual health.

**THT DIRECT** > 0808 802 1221



You also supported **72** people through the work and skills programme.

The delivery of **2,792** counselling sessions and **82** peer support workshops for people living with HIV.





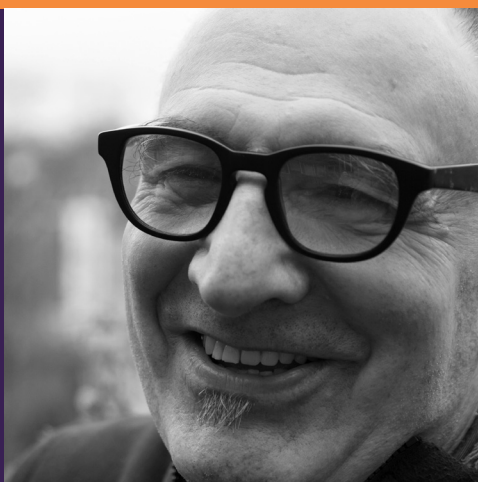
## Ageing with HIV services

Last Autumn, we conducted a detailed review of services and support we offer to people growing older with HIV. With over half of people living with HIV in the UK projected to be over 50 by next year, meeting their needs is becoming ever more important.

Using data collected from an online survey and a series of group discussions and phone conversations with service users, we identified some key areas on which to focus over the next three years. Improving and maintaining emotional and mental wellbeing, physical health and social connectedness were identified as the three top priorities. We will now be involving service users in the design and delivery of new projects and services that address these.

We're especially keen to support older people in having healthy relationships and sex lives, motivating people to stay active through diet, nutrition, physical activity and managing co-morbidities and the effects of medication and polypharmacy.

To tackle the fear and stigma faced by older people with care needs, we'll be building on the work Terrence Higgins Trust has been doing to improve HIV knowledge within healthcare by extending this further into the social care sector.



## “I was born with HIV but my partner and children are all negative”

When I found out I was pregnant for the first time in 2005, I was absolutely terrified. As someone who is part of the first generation to be born with HIV, my pregnancy was like living in the unknown.

The trauma I experienced growing up with HIV meant that I couldn't enjoy my pregnancy. I wasn't diagnosed until I was five years old – I had chickenpox and struggled to recover from it so the doctors took a blood test and found out I had contracted it from my mum during labour. At this point, I was given a six-week life expectancy. I didn't want the same thing for my child.

My HIV status wasn't discussed with me at all at the time – I was so poorly and I didn't have any idea what was happening. Being a child with HIV in the 1990s was not easy. My family kept my HIV diagnosis a secret from me because of how difficult the stigma was. I was a very confused and rebellious child.

When I was 15, I found out about my HIV status after being tested while in A&E for a broken arm. I was shocked, angry and terrified – I thought I was going to die.

My life spiralled out of control when I lost my mum to AIDS-related illnesses. Like me, my mum wasn't medicated because of HIV stigma – her health deteriorated so rapidly, one minute she was here and the next she was gone.

After she died, I isolated myself from the outside world for three months and tried to take my own life. I didn't use HIV services at all until I was admitted to hospital with pneumonia. I knew that if I didn't get onto treatment I was going to have the same fate as my mum.

I managed to turn my life around. By 2013, I was solidly on treatment with my partner's support. I fully came to terms with my diagnosis. I became committed to educating others on the reality of living with HIV. I joined Terrence Higgins Trust's



Sasha Goodman and her family

Positive Voices programme and delivered talks to audiences across the UK about my experiences.

Sharing your story is still nerve-racking, but it is so rewarding to help educate and support others. Although I had accepted my diagnosis, being a mother living with HIV was a struggle. Advancements in medical treatments mean that today, people living with HIV who are on effective treatment are able to give birth to HIV negative children – but there are unique challenges that they have to face.

I was never given the opportunity to have a natural birth or to breastfeed in order to minimise the risk of passing on HIV. I felt like I didn't get to have the same choices as everybody else.

Not only did I experience my own guilt for not being able to breastfeed, I was also shamed by other people for it, including parents and midwives. There are an alarming amount of people that still don't know that effective treatment means you can have HIV negative children – there's clearly an urgent need for more education.

As a member of the first cohort of children born with HIV, I don't know for certain what my future will be – but so far it's looking pretty good.

Effective treatment means I can't pass it on. I'm getting married next year, my children are healthy, and my life is looking healthy.

Going forward, I'm not scared anymore.

– **Sasha Goodman**  
Positive Voices speaker



## Volunteering at THT

This year, our volunteers have continued to be a huge and integral part of the work that we do across the UK. We now have an amazing **621** volunteers who offer their support and have given us over **13,250 hours** of their invaluable time this last year. We would be unable to undertake the vital work needed without them. We would like to offer a huge thank you for all that they do.

There are many reasons why people choose to volunteer with us. Some may have experience of sexual health issues, while others may have lost friends, family or loved ones as a result of HIV. Others may just want to help or gain some experience! If you would like to get involved please contact our volunteer office at **volunteer.office@ttht.org.uk**



## Pride

Pride has always been important to Terrence Higgins Trust, ever since we started our work 40 years ago. The LGBTQ+ community has been at the forefront in the fight against HIV – from the first cases of HIV in the 1980s to today. This year, staff, volunteers and supporters celebrated Pride together in the sunshine as we looked back on how much we've achieved and gave thanks to those whose shoulders we stand on.



## Ribbon Walks

Back in April we saw our first ever Ribbon Walks in Glasgow, Brighton and London which were a huge success. Each walk began from key LGBTQ+ venues in each city such as, Speakeasy in Glasgow, Charles Street Tap in Brighton and the iconic Royal Vauxhall Tavern in London.

Across all three cities we saw an amazing **200 supporters** take on 10km to help smash HIV stigma, remember loved ones, and help end new transmissions of HIV in the UK by 2030. It was an amazing day topped off with a performance from the London Gay Men's Chorus on the London route.

A huge thank you to all our amazing supporters that took part (including the dogs!).

If you would like to get involved in 2023 please keep a look out for further information in the fundraising section on our website.



## Terrence Higgins Trust online shop

Check out our online shop where you can buy iconic Terrence Higgins Trust branded items to help raise awareness and support people living with HIV. Every purchase helps fund our vital work. Together we can end HIV transmissions by 2030 and smash stigma. Go to **shop.ttht.org.uk**