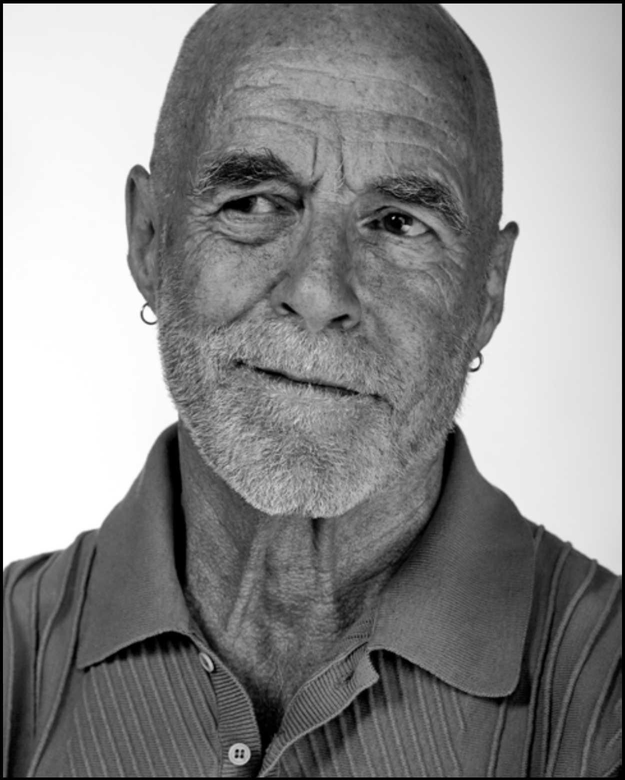
from the beautiful HIV+ community
OCTOBER 2022

# BEAU



## № 2

**EDITOR**
Marc Thompson

**CREATIVE DIRECTOR**
Richard Kahwagi

**PHOTOGRAPHY**
Denis Robinson

**SUB EDITOR**
Jim Fielder

**CONTRIBUTORS**
Ben Collins
Simon Collins
Ian Lawrence
Denis Robinson
Tristan Barber
Jim Fielder
Chris Smith
Scott Agnew
Stephen Hart

**BEAU THANKS**
Garry Brough
Jai Sylla
Will Nutland
Phil Samba
Siân Cook
Tez Anderson
Naz Project London

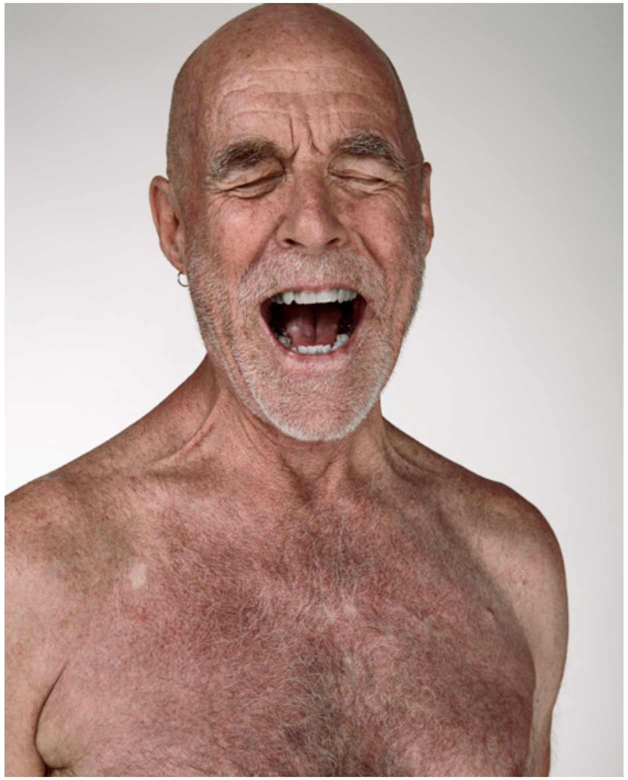
**queerhealth.info/beau**

BEAU is a **Love Tank** production, funded as part of the **Fast Track Cities** ‘*London Stigma Empowerment Programme*’

from the beautiful HIV+ community

SEPTEMBER 2022

# BEAU



№ 2

by Marc Thompson

# We're back, baby!

"When's the next one due?" That's been the most common response to BEAU after we launched the first of these beauties a few months back. The response to Edition One has floored us: we've received messages from across the capital, across the country, and across the world, and we've had offers from readers wanting to take part in the editions that follow. Thank you for that warm response – it's helped us to plough on with getting Edition Two out of the door (that difficult second album, the problematic second child: because the third is already on its way).

Five of last edition's writers joined together for a BEAU special event at the start of September for The Love Tank's monthly Second Tuesday Monologue event. Building on the narratives from Edition One, they took their stories off the page, and into a packed room of people at The Glasshouse in Bethnal Green. It was a stunning night – rounded off by a raucous sing-along (courtesy of me). Watch out for more events, as we build BEAU into more than a magazine!

For this edition, our cover star Ben Collins, brings us a focus on long-term survivors. Ben talks with others who have lived with HIV for decades (and some who were diagnosed before effective treatments became available) and asks what it means to have a life they never imagined. They are powerful narratives, and a timely reminder of the importance of understanding – and remembering – our collective histories.

Learning from history has been equally important across the summer, as an unexpected health outbreak hit many of us within our communities. The rapid development of monkeypox across Europe and the Americas reminded us that not everyone has the health of our communities at heart: media headlines and social media posts harked back to what many of us experienced decades ago. But monkeypox has also shown the resilience of our communities: once again we saw people coming together to educate each other, to push (and push really hard!) for vaccines to be procured and made available, and to take part in research studies, trials and surveys. There's more information about monkeypox at queerhealth.info/monkeypox and i-base.info/monkeypox.

Finally, we extend a warm welcome to Jim Fielder, Head of Living Well at Terrence Higgins Trust and a coach, in this edition. As well as helping us with copyediting (thanks Jim!), he'll be writing our Top Tips feature. Jim explores how coaching can help us all to live our best lives with HIV.

If you'd like to share your story in a future edition of BEAU, we'd love to hear from you. Get in touch and tell us about being part of our beautiful HIV+ community. XX

# News Round-up

with Simon Collins

## The latest in HIV treatment & news

### Promising treatment for monkeypox in a new study

Although cases of monkeypox (MPX) in the UK started falling since the end of August, some people are still unlucky and test positive.

The most promising treatment for MPX – a medicine called tecovirimat – is currently only available to people that need to be treated in hospital. However, a new UK study called PLATINUM is using tecovirimat for people who have less severe symptoms.

If effective, this will make MPX less painful and reduce the time needed to self-isolate.

UK guidelines now include circumstances where isolation can be less than the 21 days that was first recommended.

There is no need to visit a clinic to join the study, but your doctor needs to refer you.

See: *www.i-base.info/htb/43758*

### Pets too – for COVID and MPX

These two cases might sound funny but this is serious. Both diseases will be much harder to eradicate if animals continue to be sources of new infections.

In the first, a vet in Taiwan caught COVID after a cat sneezed in their face. Really – the two viruses matched. You can't mask your cat, but maybe keep a little distance...

See: *www.i-base.info/htb/43644*

In the second, a pet dog developed monkeypox from its owners. A gay couple both had monkeypox and didn't isolate from their pet during the time they were infectious. Luckily, all recovered well.

See: *www.i-base.info/htb/43762*

### Monkeypox vaccines to be given in a new way

By the end of August, more than 30,000 men were given a MPX vaccine. This was to give limited protection to as many people as possible. But used nearly all the UK supply.

More vaccines, expected by the end of September, will let other people at high risk get their first dose. This will hopefully include more sites outside London.

The next vaccines will be given in a slightly different way. A lower dose will be injected just under the skin rather than more deeply. This should be just as effective and will let many more people get protection.

One difference is that it produces a small soft bump where the vaccine is injected. This might become red and itchy for several days but steadily reduces over the next week or so.

Three clinics are already using this approach to check for safety, before being expanded to all vaccine sites.

The US is also giving MPX vaccines this way.

Please remember the vaccine only gives limited protection against catching MPX. It also takes time to work. After four weeks you will then have the strongest immune response.

See: *www.i-base.info/monkeypox*

### RIO study: safely stop HIV meds for six months

The UK is currently running an exciting cure-related study.

This is using immune-based treatments called bNAbs (bee-nabs).

bNAbs work like regular HIV meds but might also work like a vaccine and strengthen your immune response to HIV.

The RIO study uses two new long-acting bNAbs. After receiving two infusions, people in the study stop HIV meds to see how long viral load takes to rebound. In most people this might be 4-6 months but two people lasted longer than a year.

Everyone in the study gets a chance to use the bNAbs - some early and some later. Everyone will be monitored very carefully. You can be financially compensated for the number of hospital visits.

If you were diagnosed soon after infection and started treatment early you could be eligible, see the website below for more details.

See: *www.RIOtrial.org*

Simon Collins is an HIV positive treatment advocate at **i-Base.info** which he co-founded in April 2000. i-Base supports HIV positive people to take an active role in their own health care.

# Coffee date

## with Ian Lawrence

Each issue, we profile ‘regular’ positive guys and highlight how they live well, and beyond their HIV status. For our second ‘Ordinary Guys Doing Ordinary Things’ we caught up with Ian, an out and proud south Londoner.

Born and raised in south-east London, Ian currently works in the security team at Sky television. A keen cyclist and cook, Ian has recently been appointed a Diversity Role model for LGBTQ+ youth.

**Hello Ian!**
**Tell us a bit about what you do and what you enjoy about it.**
I work in security at Sky in West London. I really enjoy working there. Every day is different, and I get to meet and greet loads of celebrities. Another bonus? I get access to TV shows sometimes before they get aired. When I joined Sky, I worked in the catering department. I'm a pretty good cook, so I use those skills to eat healthily at home.

**How does HIV impact your daily life?**
It doesn't really. I take my medication once a day, which until recently consisted of two tablets. When I first started on treatment, I had to take three tablets a day, one of which had to be refrigerated. This was difficult to manage because I was living with my parents at the time, and they were not aware of my status. I've recently gone back to three tablets a day, which is cool and fits into my routine.

**What do you know now that you wish you'd known when you were first diagnosed?**
When I was first diagnosed in 2003 all I could think about was dying, so I wish I'd been told I would live a normal and long life. I also wish I'd been told it's possible to have children. I never thought that people with HIV could have children without passing on HIV to the child. I now know that a person living with HIV can have children and that if you're undetectable you can't pass it on.

**How do you 'live well' with your HIV?**
I live quite well with it. I take my tablets every day and I go for my check-ups at the clinic twice a year. I like to keep fit by riding my bike and going to the gym regularly. It wasn't always the case. I was suffering from PTSD because of my status, and this affected my mental health. With the right help and support from friends, family, and my clinic things have really improved.

**Who or what inspires you?**
People like Gareth Thomas, who came out and disclosed his status on national news. I think it was brave of him to come out and control the narrative of his life and to challenge HIV stigma. I was inspired to do the same thing on social media after watching another person who inspires me, Marc Thompson, on the BBC Two documentary series 'Saved by a Stranger', where he reunited with his counsellor who had helped him come to terms with his HIV in the 1980s.

**What advice would you give to your 17-year-old self?**
The first thing I'd tell him is to chill out and slow down, ask questions and listen to advice! I'd also tell him to value his friends and keep them close. I've recently become a Diversity Role Model, which I hope will give me an opportunity to share my experience and knowledge with a generation of younger LGBTQ+ people.

**How have you found and connected with other Black gay men living with HIV?**

For a long time, I didn't know any other Black gay men living with HIV, but as I've become more confident, I've made some good connections. Some of my friends are HIV positive, but because of stigma they aren't open about it, so it can limit the conversations about our experience. I've also joined a great support group, run by the House of Rainbow, specifically for men of colour living with HIV. We have meet-ups and hang out. I've found a real sense of community and belonging there.

## Ian's favourite things

**Book**

One of my favourite books is 'Becoming Bulletproof' by Evy Poumpouras. It's about a Secret Service Special Agent who survived the 9/11 attacks. It resonated with me because the author talks about how to make every aspect of your life as impregnable as possible from anyone meaning to do you harm.

**Music**

My music taste is quite eclectic. I listen to everything from pop to UK garage, rap, hip hop, drum and bass, you name it I like it (except heavy metal). I also listen to musical and film soundtracks.

**Film**

The film that I watched recently was 'Everything Everywhere All at Once' (2022). For someone who is a chronic overthinker, I thought this film was brilliant. From the cinematography to the way they told the story and how it all was pieced together – I loved it.

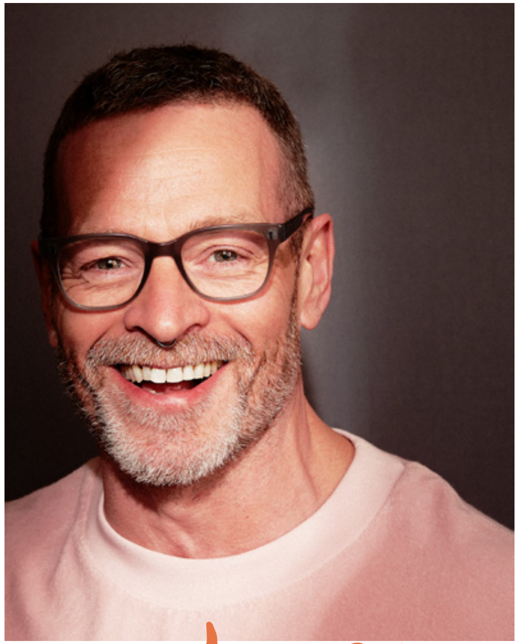
**Theatre**

The last show I saw was Tina the Musical, which my cousin was in. She was meant to be playing the lead role for the two times I was meant to see her but unfortunately, due to a change of plans, she was the sister of Tina in the show.

**TV show**

The series I'm into at the moment is 'Stranger Things 4'. I've been watching the series for a while, and I don't know if it's the 70s style music or the fact that it's a slightly twisted version of X-Files meet Scooby-Doo.

# Denis Robinson



# picture perfect

All photos: Denis Robinson

## Denis Robinson, 53, photographer.

With his diminutive frame, sparkling green eyes and baby blue nail polish, Denis Robinson is a bundle of beautiful energy and creativity. Originally hailing from Belfast NI, Denis has lived in London since 1988. Moving to the city to explore his then career in hairdressing at a higher level than what was on offer at home. A year and a bit after partying hard and being fired from a job for the only time in his life, he decided to take his career seriously and joined the ranks among celebrity hairdresser Charles Worthington's company. He quickly climbed the ranks to management and member of the international artistic team, delivering hair shows and seminars from Reykjavik to Montreal.

After 11 years with CW, Denis left to pursue a role as a session hairdresser, doing hair on set for fashion and beauty shoots, pop promos and commercials. This is when his interest in photography started to spike.

A little over 3 years ago when he was about to turn 50, no longer feeling in any way challenged by the hair industry, Denis wanted to try a new hobby and bought himself a camera. Denis is an all or nothing kind of person and was soon obsessed, doing an online diploma in photography and photo editing.

At the beginning of 2020 having had a number of images published he made the career changing decision and began to withdraw from his creative director position with the UK's leading male grooming company to spend more time developing and nurturing his photography skills.

Then Covid happened. Having always wished to study something other than hair, Denis took this opportunity to really throw himself into learning as much as he could about editing. Denis believes that taking a great shot is only the beginning of the process. A great shot can always be enhanced by an amazing edit.

He also adopted a mentor who he went to for advice and signposting to amazing educators and photographers. The teacher had very much become the student.

As the world came out of the last lockdown in spring 2021, Denis launched an LGBTQ+ portrait project called Proud Portraits. The aim was

to recruit 30-40 people to represent every strand of light of the LGBTQ+ rainbow. He ended up with 147 people participating with a 4-week exhibition in the windows of Fiorucci on Soho's Brewer street during Pride month that year.

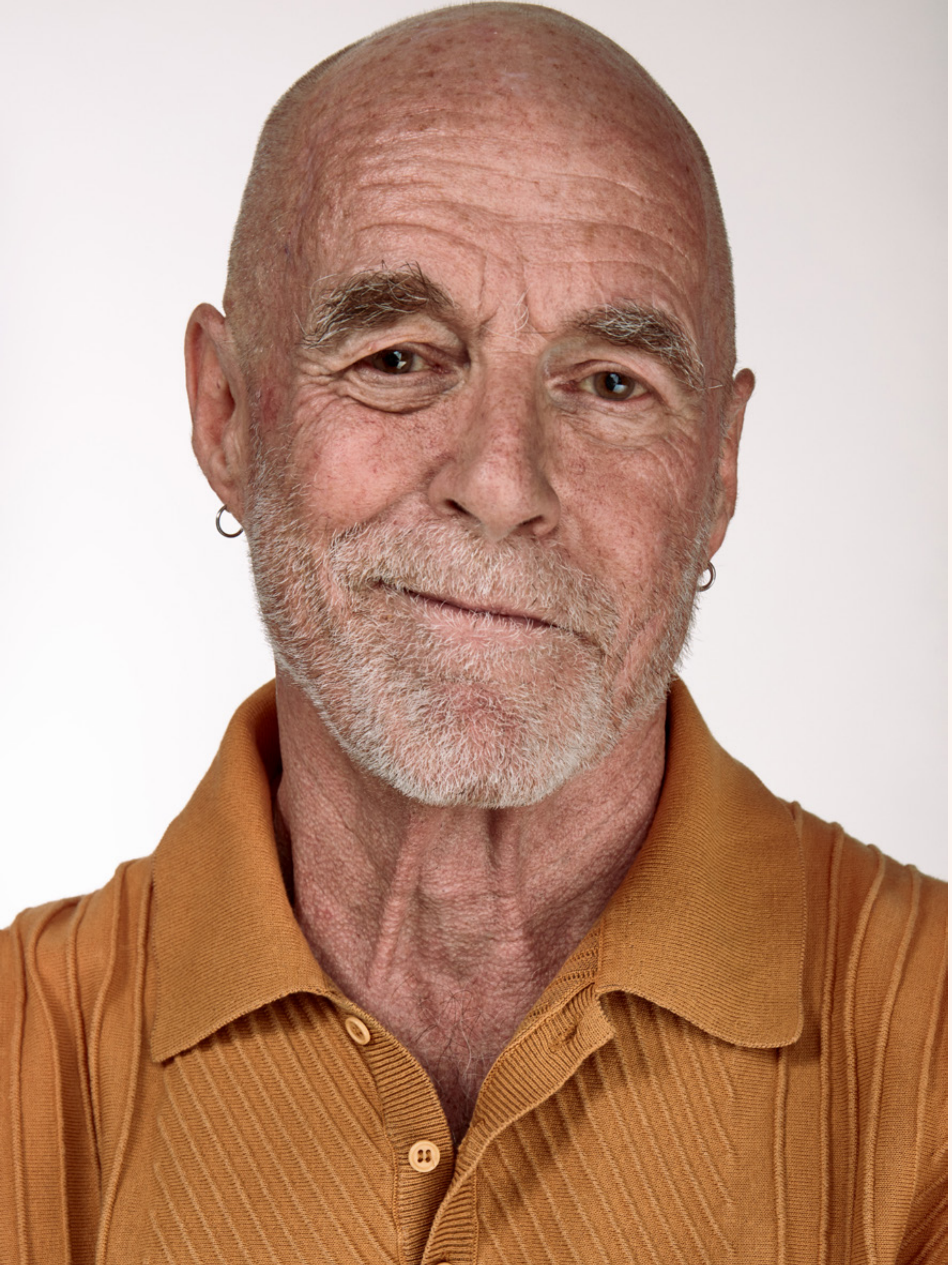
Since then, Denis has increasingly found himself working almost exclusively within the queer community.

“Having spent decades trying to figure out where I fit in with the LGBTQ+ community, never quite finding the perfect fit, I now have found this place where I get to spend my life making queer people look and feel great about themselves. Not so very different from hairdressing, as it goes, but much more satisfying”

Denis' latest assignment is being the lead photographer for BEAU magazine, shooting all of our cover models and our ‘Ordinary Guys’.

*To see more of Denis' work, visit:*
denisrobinson.co.uk

> Working with everyone at BEAU has a very special place for me. Having moved away from advocacy activities a few years back as I was convinced everyone must be tired of looking at my face, it feels good to have found a space to highlight our community in the way that feels so natural to me.



# Long term survivors:

## Living the life we never imagined.

by Ben Collins

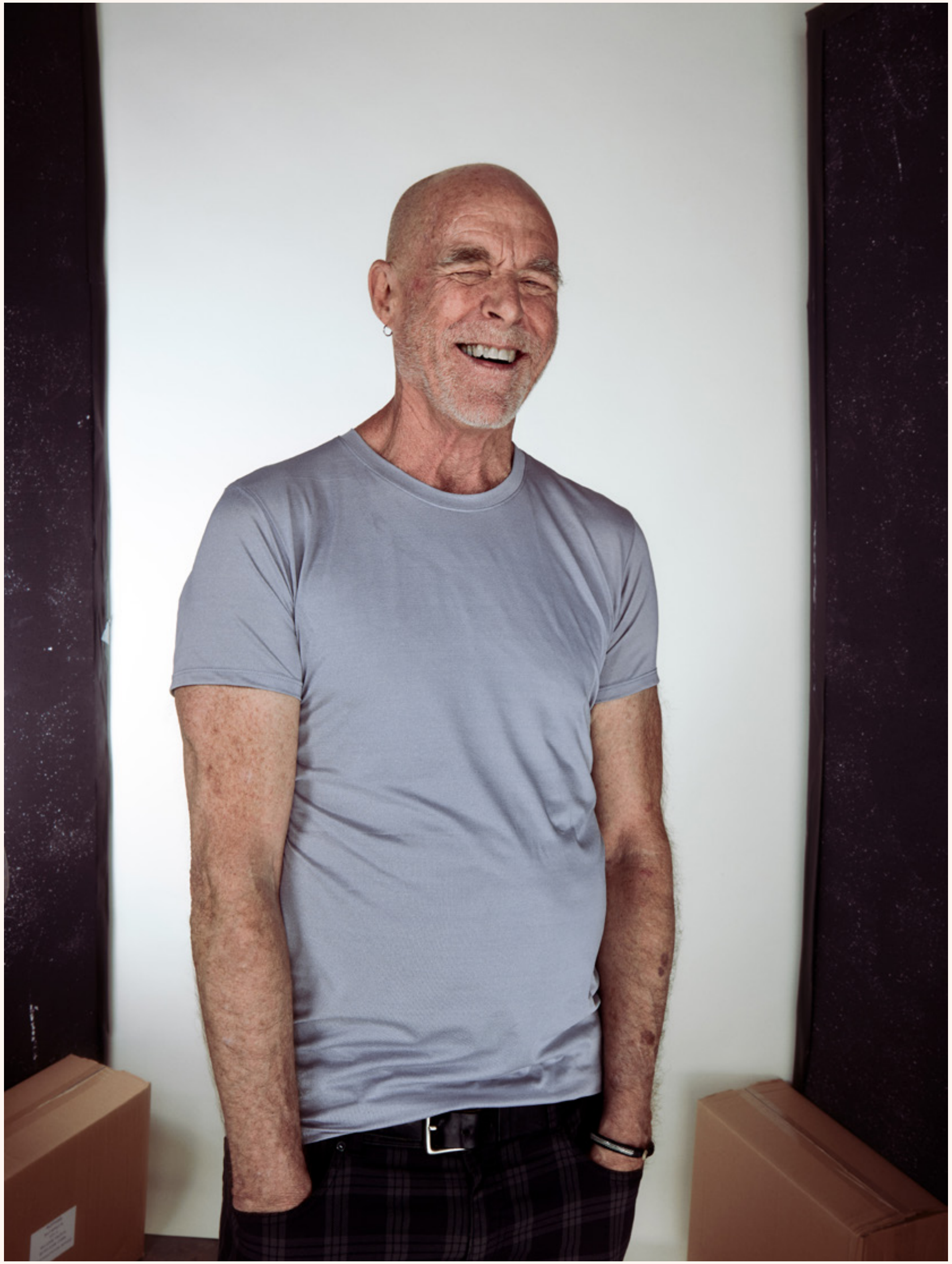
It's a universal truth that we all get older. We all age. If we're fortunate our life's journey is pretty much mapped out. We slide from childhood to youth to middle age and then old age, navigating and negotiating the twists and turns life throws us. We hope the twists, turns, and bumps in the road make us stronger and more resilient.

But what if we didn't expect to reach these later milestones? What happens when our future seems much more uncertain and a long life far from guaranteed?

When I was diagnosed with HIV in 1982, in the earliest days of the pandemic, I was 34. Without life-saving treatment that wouldn't arrive until almost two decades later, life expectancy was at most a few years. As I looked around in those early years, losing so many friends and lovers, the notion of survival was a fantasy. Yet here I am 40 years later. Defined by a term unimaginable all those years ago, I can proudly call myself a **Long-Term Survivor** (LTS). And I am not alone. Thanks to successful HIV treatment, people with HIV are living ever longer, and the percentage of older adults living with HIV is increasing in all regions of the world.

There are a few definitions describing HIV LTS. One refers to those who have been living with HIV since before the modern era of effective HIV drugs, or "highly active antiretroviral therapy" (**HAART**). They are sometimes known as **pre-HAART LTS** or "longest-term survivors." We acquired HIV when the condition was, in most cases, a death sentence. We often spent our early adult lives believing we would die young - and watching our friends die of the health condition we were living with. This traumatic experience has left a lasting mark on some of our lives and affects our mental and physical health, as well as our financial stability and quality of life.

Another definition refers to people who have been living with HIV for more than ten years, and who were diagnosed after 1996. This group is



sometimes known as **post-HAART LTS**. This is considered a very different experience than being diagnosed earlier in the epidemic.

However, not all HIV LTS are older adults. People now in their twenties and thirties who acquired HIV at birth or while very young have also lived with HIV for decades - and may have experienced the loss of loved ones due to the virus. Other groups that are sometimes overlooked in conversations about long-term survival are the HIV-negative partners, companions, carers, community members, activists, and health care providers who directly supported people living with HIV throughout the epidemic. Many **HIV-negative LTS** also experienced tremendous losses and had their lives deeply affected by the epidemic.

In 1990 community organiser Michael Callen wrote a visionary book called 'Surviving AIDS'. A gay man living with HIV, Michael was interested in the mind-body connection's potential to improve people's health. He wrote "*If we could change our paradigm of AIDS, if there weren't that notion that it's all ultimately hopeless and pointless, it might actually increase survival rates… I don't say hope will guarantee you'll beat AIDS, but you've got to have it to be in the running.*"

In an early piece of participatory HIV research, Michael engaged with others living with HIV in a series of interviews and reported that long-term survivors, while diverse in many ways, had three key qualities in common. Firstly, they believed that someone would survive, secondly, they felt a purpose for waking up in the morning and articulate a reason for living. And finally, they were all proactive with their care, drawing on a range of strategies such as taking supplements, having acupuncture, going for massages, and any other means to keep them in good health. Sadly, Michael died at 38 in 1993, but he gave voice to those who believed our lives and futures were not pre-determined by our diagnosis.

This was the reference point when I started thinking about a feature on long-term survivors.
Surviving a lifetime overshadowed by the threat of illness, death and the experience of loss and stigma is an achievement in itself. But surely, we also want and deserve a good and long life? Or to put it another way, what have we long-term survivors needed to do to not only survive, but also to thrive? What can we all learn from those who have 'made it through'?

To find out what it takes to 'thrive' I set out to speak with three other long-term survivors; Garry, Jai and Marc. Each of us was diagnosed at different times in the epidemic and at different points in our lives. Admittedly, we're an unusual group, all having careers and roles in HIV activism.

I'm the eldest of the bunch: an Irish-American, aged 74. Marc, an African-Caribbean Londoner, was 17 when he was diagnosed in the spring of 1986. Garry, a Welshman seroconverted in London aged 23 in 1990. Finally, Jai, of Afro-Spanish descent, was 23 when he seroconverted in 1993.

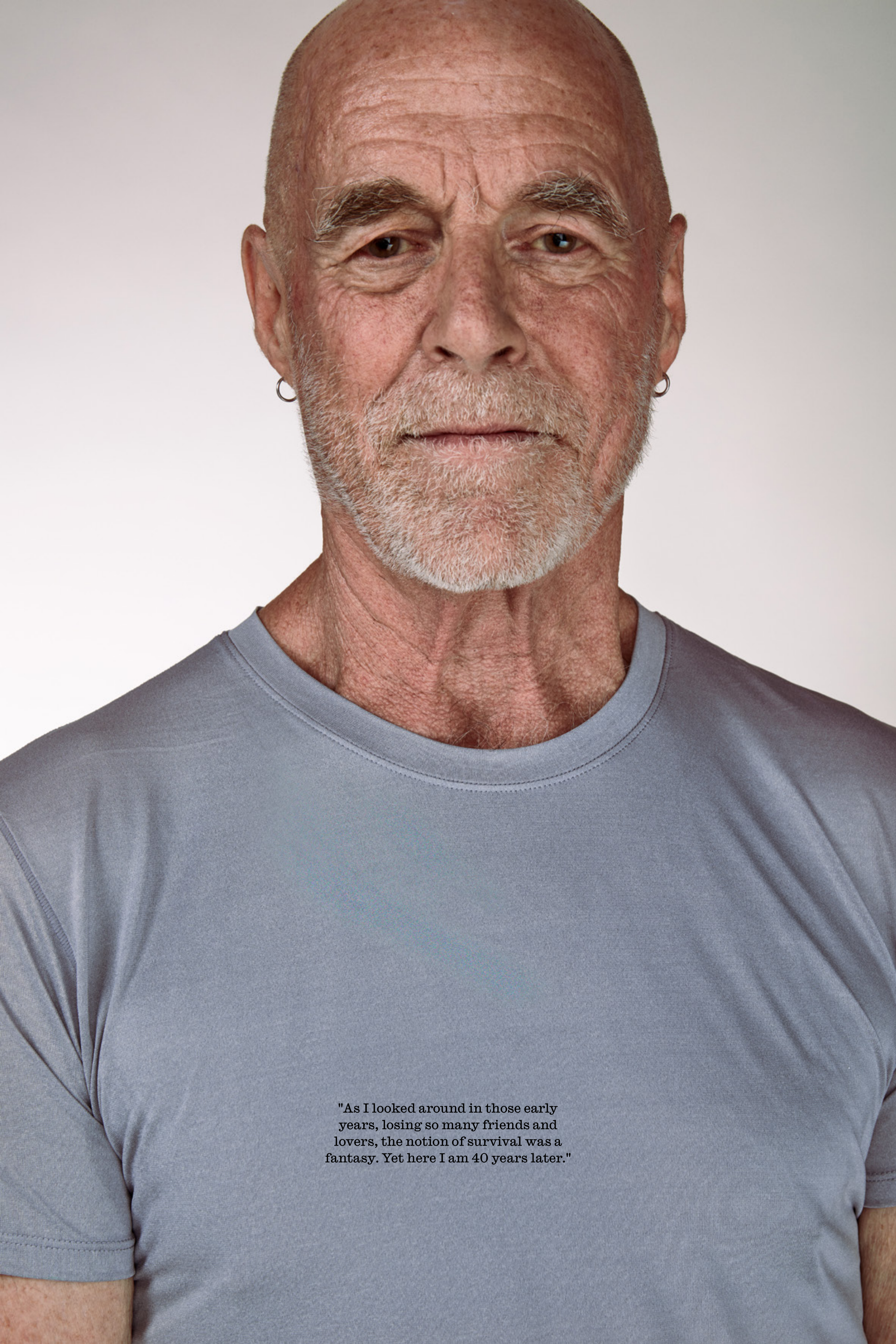
All of our HIV "journeys" have been quite different. Marc and I lived many years without effective treatment yet have never been seriously ill; Garry became symptomatic early after his diagnosis and had a series of near-death experiences; Jai also managed 19 years without the need for treatment. Marc and Garry developed nurturing relations with their families of origin; Jai and I found more nurturance outside our families. Substance use has played a more destabilising role for Garry and I, less so for Marc and Jai. Learning of and negotiating my HIV status in San Francisco, where there were very high levels of HIV, was also different from Marc, Garry and Jai's experiences in Europe where levels were lower. Even though I was diagnosed earlier than the others, my experience of HIV stigma and fear was more shared within the community, whereas Marc, Garry and Jai's early years of living with HIV were lonelier.

But despite these differences, overall, our experiences share similarities to Michael's 1990 survivors. We believed (and still believe) in a good future, and we don't associate HIV with hopelessness. We were purposeful and proactive in our care and remain consciously engaged in living today.

But If Michael were alive today, in this unsettling and chaotic period of confusion, division and rapid change, I'm sure he'd register one other key aspect of surviving and thriving that didn't register in 1990. This is that Jai, Garry, Marc and I have all been fortunate to live long lives with HIV because we made life-saving connections to others. People made connections for us and to us. We developed the habit of connecting, and we continue to connect today.

Having lived in Michael's time, I think that perhaps he wouldn't have even noticed the importance of connection quite simply because it permeated everything. In 1990, with no treatment for HIV and very few treatments for related infections, living with HIV was a shared calamity without any relief except for the solidarity of others living with the condition and their allies in pockets of fear and support around the world.

Today when people tell me they're living with HIV, I always say, "I'm sorry to hear that. I know it can be rough. How are you doing?" Invariably



"As I looked around in those early
years, losing so many friends and
lovers, the notion of survival was a
fantasy. Yet here I am 40 years later."

they tell me they're fine. But when we talk more, I find that too often, many have not made a solid connection to services, and they're not linked to peer support. They might not feel comfortable speaking with others about their status and may only be talking about it with their healthcare provider, if at all. Deep down, they might be paralysed with fear of rejection. All told, they may think they are fine but are not. As the activist Beatrice Nabulya once explained to me and a crowded room of HIV positive people “Your doctor’s going to tell you you’re fine; the drugs work”, she explained. “And they’re right. The drugs do work. But they won’t tell you the lesson we’ve learned. To really live with HIV, you need a good two or three years of learning, paying attention and peer support.”

> People made connections for us and to us. We developed the habit of connecting, and we continue to connect today

I don’t know how one applies Beatrice’s guidance without committing to building lasting connections with others and seeking the necessary support. I was humbled to listen to Marc, Garry and Jai explain their years of learning to me. Marc found connection to his Caribbean resilience through his mother and father, which gave him the focus to put one foot in front of the other and make things right. For Garry, the love and support of his workmates and friends helped him to move on and devote his life to rebuilding his health with the support of his parents and a fantastic number of carers. Eventually, he developed peer support services for himself and others. Jai learnt to manage his diagnoses with the support of his new family of choice, peers and various health professionals, while embarking in media studies and charity work in his drive to shed light into the experience of living with HIV.

FURTHER INFORMATION AND SUPPORT

Positively UK
Positive East
THT Positive Voices

## MAKING IT THROUGH TO SURVIVE & THRIVE

POSTSCIPT *by* BEN

There are lessons and strategies that all people living with HIV can learn from those who are Long Term Survivors which enable us to stay resilient and not only survive, but also thrive throughout life.

### Take charge of your health

Learning about your HIV medication, having a good relationship with your health care providers, and keeping on top of your diet and exercise are all key parts of coping with the challenges of living well.

### Reach out for support

The importance of social support for HIV LTS cannot be underestimated. A healthcare provider can be a source of support as can a coach, counsellor, peer mentor, or support group. They can help you connect with activities, family and friends, and even groups of other people living with HIV.

### Tell your stories

Speaking your truth is part of healing and also makes important contributions to our community's history. You can share your story in a support group, with friends or family, at events and speaking engagements, online, and more.

### Find your purpose

Taking part in an activity that excites you, working or volunteering for something you believe in, continuing your education, and rediscovering your talents are just a few ways to experience pleasure and be productive, which can help you gain a sense of purpose in your life.

### Take your rightful seat at the table

Long-term survivors are experts in living a long life with HIV, and must be part of organisational and policy decisions that impact the lives of LTS. You can help make sure LTS voices are heard by becoming a community advocate.

### Commemorate June 5, HIV Long-Term Survivors Awareness Day (NHLTSAD)

Acknowledged for the first time in 2014, NHLTSAD is not just an awareness day, but a call to action to keep the needs, issues, and journeys of HIV LTS front and centre in the HIV community.

# BEAU Basics: HIV Treatment

In the five decades of the HIV epidemic, we've travelled a long way. From people living with HIV having no treatments at all, through to people taking multiple pills a day (the impacts of which have sometimes resulted in debilitating and life changing side effects), and right up to today where most people take one or two daily pills and experience few or no side effects. The future is one that includes long lasting injectables and beyond this, who knows what other advancements will appear.

26 Y THE NEW YORK TIMES **MEDICAL SCIENCE** TUESDAY, APRIL 18, 1989

## Early Tests Promising For a New AIDS Drug

Doctors study an extract from a Chinese plant.

By GINA KOLATA

For the first time, researchers have found a drug that seems to kill only those immune system cells that harbor the AIDS virus.

The drug has been tested only in the laboratory, so there are no data on its effects when administered to humans. But some experts on AIDS drugs say they are intrigued by its effectiveness in the tests and by its apparent safety in animal studies.

The drug, called GLQ223, is a purified form of a medicine derived from the root of a Chinese cucumber plant, Trichosanthes kirilowii. The plant extract has been used in China since A.D. 300 to induce abortions. Unlike other drugs that have been tested against AIDS, GLQ223 destroys only cells that are infected with the virus, leaving other cells alone.

It is also the only drug that deals directly with macrophage cells, which serve as a reservoir for the virus in the body. The macrophage cells are part of the immune system, and peo-

Patricia J. Wynne

Drug is derived from root of plant, Trichosanthes kirilowii.

McGrath said, explaining why he waited to publish.

Because animals cannot become infected with the AIDS virus, Dr. McGrath and his colleagues have been unable to use them to test the

In just a few years, an inevitably fatal disease has turned into a manageable and still chronic but not yet curable condition. The development of antiretroviral therapy represents not only the bright history of scientific advancement, but is the result of a passionate effort towards a common goal between an alliance of researchers, doctors and nurses, pharmaceutical industries, regulators, public health officials and the community of patients living with HIV. It's a unique achievement in the history of medicine.

In the UK, of the 106,890 people living with HIV in 2020, 95% were actually diagnosed, with 99% of those diagnosed receiving treatment and 97% virally suppressed, which means they have an undetectable viral load and can't pass the virus on. If you're reading this, you're likely to be one of them and for most of us living with HIV, taking our anti-retroviral (ARV) medication is a daily routine which we incorporate, often unthinkingly, into our lives. But when do we ever ask ourselves - "how does this pill keep me undetectable?" or "what makes up my drug combination?" We're unlikely to even know the names of our meds because we're just happy that they work and allow us to get on with our lives.

Since the first medications to control the virus were identified in the 1980's followed by great advances in treatment, ARV's have saved millions of lives globally. This has enabled many of us to live long, healthy lives and not pass HIV onto our partners. But how did we get here? Let us take you through a brief history of HIV treatment, how it works, and why taking our meds is so important.

# Timeline: The story of drugs that treat HIV

## 1981 - 1987

**The darkest years**

For six terrifying years after the first cases of HIV/AIDS were detected, there were no drugs to treat HIV at all– there were only drugs to treat its associated infections. And there weren't many of those either.

## 1987

**AZT – the first breakthrough HIV drug**

In 1987, Azidothymidine (AZT) was approved. Belonging to a class of HIV drugs called a 'nuke', it was a cancer drug from the 1960s, but not a particularly good one. The dose prescribed was it turned out too high - 2400 mg a day, split into 4 or 6 doses. People who were already ill suffered very badly from its side effects. It worked, but only for a short time.

## 1988 - 1993

**The Concorde Study**

AZT had been approved based on one small study with less than 300 people who were already ill - and the study was stopped early. It was then made available to anyone living with HIV, even those with a high CD4 count.

The UK-French ‘Concorde’ study was much bigger (1,750 people) and ran for much longer. The results made headline news for showing no benefit for most people with a high CD4 count. Unfortunately, people taking it just developed drug resistance. But even knowing this, many still kept on taking AZT because it was all there was.

## 1991 - 1994

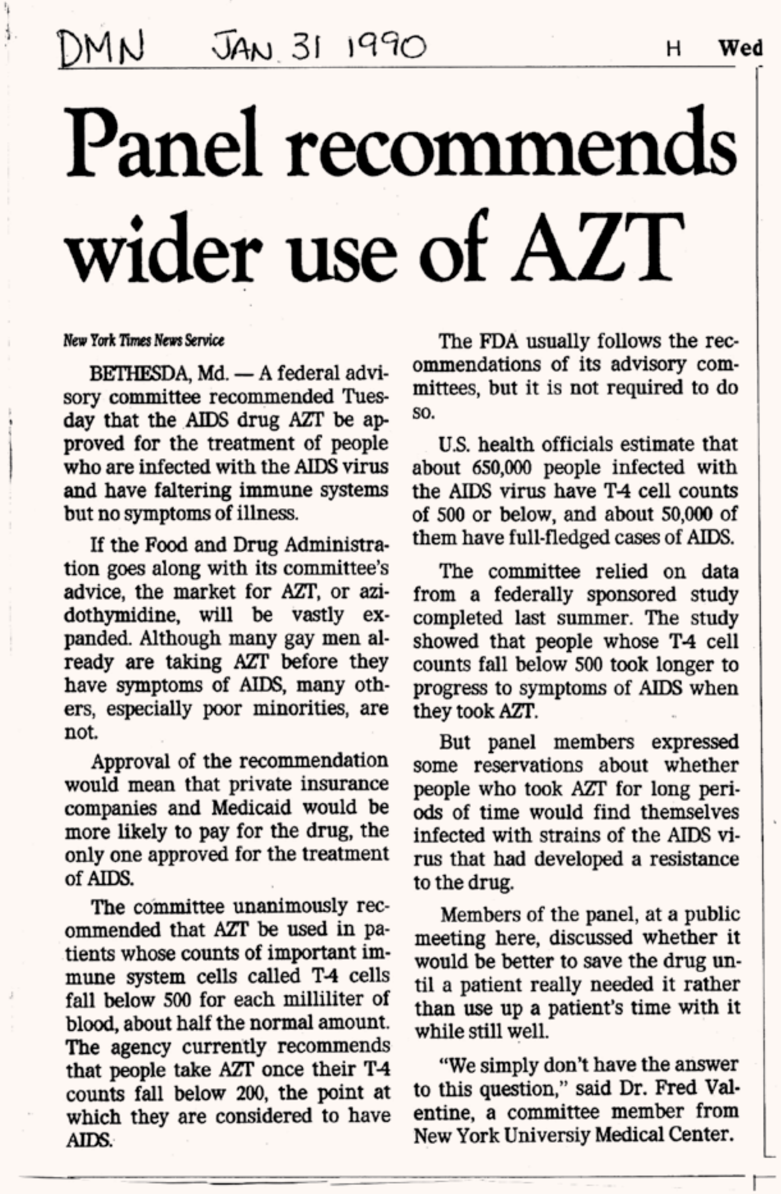
**Three more ‘nukes’ approved known as the 'd' drugs.**

Some were invented by the same scientists that discovered AZT. These drugs showed limited benefit and also resulted in unpleasant side effects. Used as single drugs or in two-drug combinations, they too invariably led to drug resistance.

## 1995 - 1996

**New drugs, new classes and triple combinations.**

In 1996 the results of triple combinations using these new drugs produced astonishing and sustained results. This was shown by using viral load tests with people on these combinations becoming ‘undetectable’ for the first time.



DMN JAN 31 1990 H Wed

# Panel recommends wider use of AZT

*New York Times News Service*

BETHESDA, Md. — A federal advisory committee recommended Tuesday that the AIDS drug AZT be approved for the treatment of people who are infected with the AIDS virus and have faltering immune systems but no symptoms of illness.

If the Food and Drug Administration goes along with its committee's advice, the market for AZT, or azidothymidine, will be vastly expanded. Although many gay men already are taking AZT before they have symptoms of AIDS, many others, especially poor minorities, are not.

Approval of the recommendation would mean that private insurance companies and Medicaid would be more likely to pay for the drug, the only one approved for the treatment of AIDS.

The committee unanimously recommended that AZT be used in patients whose counts of important immune system cells called T-4 cells fall below 500 for each milliliter of blood, about half the normal amount. The agency currently recommends that people take AZT once their T-4 counts fall below 200, the point at which they are considered to have AIDS.

The FDA usually follows the recommendations of its advisory committees, but it is not required to do so.

U.S. health officials estimate that about 650,000 people infected with the AIDS virus have T-4 cell counts of 500 or below, and about 50,000 of them have full-fledged cases of AIDS.

The committee relied on data from a federally sponsored study completed last summer. The study showed that people whose T-4 cell counts fall below 500 took longer to progress to symptoms of AIDS when they took AZT.

But panel members expressed some reservations about whether people who took AZT for long periods of time would find themselves infected with strains of the AIDS virus that had developed a resistance to the drug.

Members of the panel, at a public meeting here, discussed whether it would be better to save the drug until a patient really needed it rather than use up a patient's time with it while still well.

“We simply don't have the answer to this question,” said Dr. Fred Valentine, a committee member from New York Universiy Medical Center.

# Timeline: The story of drugs that treat HIV (continued)

New drugs included another 'nuke' (lamivudine, still used today), Protease Inhibitors or PI's (saquinavir, indinavir and ritonavir) and an NNRTI (nevirapine).

This triple combination therapy was dubbed Highly Active Antiretroviral Therapy (HAART). It was a medical breakthrough - if you were able to get treatment. Some people hoped that taking HAART for three years might cure HIV (unfortunately this turned out not to be true).

## 1997 - 2000

**More new drugs but also side effects**

This period was a real turning point because deaths started to fall. People who were extremely sick became well again. By 1998, strange side effects of the earlier drugs started to become clear. These included body changes - either losing or gaining fat, nerve damage and lactic acidosis (sometimes fatal).

New drugs at this time included another NNRTI (efavirenz) and more PI's (nelfinavir and amprenavir, neither very good. Other drugs failed in development.

There were now about seven to eight pharma companies producing HIV drugs that were either approved or in development. This created a competitive market and lots of money was spent on marketing, often leading to dishonesty around side effects. Many drugs were dosed either too low or too high.

Because HAART required taking lots of pills every day, many people experienced side effects from the drugs before they really needed to start treatment. This drove many people to quit their HIV therapy. At one point, more people were stopping drugs than starting them, if they had a good CD4 count.

## 2000 - 2003

**Generic drugs and global access**

HIV drugs were still priced high and protected by patents. And as most people living with HIV were in low-income countries, getting medicines to Africa, Asia and South America became a political and ethical issue. In 2003, Cipla, an Indian company, put three drugs into a single generic pill for less than a dollar a day.

"All the News That's Fit to Print"

The New York Times

NEW YORK, WEDNESDAY, FEBRUARY 7, 2001

Ex-Aide to bin Laden Describes Terror Campaign Aimed at U.S.

Identity of Witness Is Revealed at Bombing Trial

U.S. SAID TO FOCUS CAMPAIGN INQUIRY ON TORRICELLI ROLE

FUND-RAISING IN '96 RACE

SHARON EASILY OUSTS BARAK TO BECOME ISRAEL'S PREMIER; CALLS FOR A RECONCILIATION

RIGHT WING ELATED

Largest Victory Margin, and Lowest Turnout, in Nation's History

Indian Company Offers to Supply AIDS Drugs at Low Cost in Africa

## 2006

**The three-in-one pill**

Atripla was approved - a single pill containing three drugs. This really started to open the way for people needing to take less pills and was made possible by collaborations between drug companies.

## 2007 - 2011

**Treating drug resistance**

Many people using early treatments experienced extensive drug resistance which limited the treatments available to them. During 2007 and 2008 several new drugs became available that got around this and saved many lives: Darunavir (PI), Etravirine (NNRTI), Maraviroc (entry inhibitor), Raltegravir (the first integrase inhibitor). Rilpivirine was also approved in 2011.

## 2012 - 2022

**Modern ART and the future...**

In 2012, Dolutegravir was approved, and this was followed by Bictegravir in 2016. These second-generation integrase inhibitors are the basis of modern HIV treatment - now called ART. They are highly effective, easy to take, with few side effects or drug interactions. TAF (a new version of tenofovir) was also approved in 2016.

In 2015, the SMART study proved that ART had benefits for all people living with HIV, regardless of their CD4 count. This produced evidence leading to the universal treatment for all people living with HIV across the world.

In 2021, the first long-acting injectable ART was approved. Cabotegravir/Rilpivirine (CAB/RPV-LA) is given by two injections every two months.

In 2022, Lenacapavir was approved in Europe to treat drug resistance. It is given using one injection every six months - but it still needs to be taken with other drugs, or resistance can quickly develop. Today, there are now 11 single-regimen pills available.

[Newspaper clippings: AIDS trials], clipping, 1990; (https://digital.library.unt.edu/ark:/67531/metadc916859/m1/3/), University of North Texas Libraries, UNT Digital Library, https://digital.library.unt.edu; crediting UNT Libraries Special Collections.

Kolata, Gina. [Newspaper clippings: Early Tests Promising For a New AIDS Drug], clipping, April 18, 1989; New York, NY. (https://digital.library.unt.edu/ark:/67531/metadc915739), University of North Texas Libraries, UNT Digital Library, https://digital.library.unt.edu; crediting UNT Libraries Special Collections.

[Newspaper clippings: Indian Company Offers to Supply AIDS Drugs at Low Cost in Africa], clipping, February 7, 2001, Section A, Page 1, The New York Times. https://www.msf.org/access-campaign-20-years), https://www.nytimes.com/2001/02/07/world/indian-company-offers-to-supply-aids-drugs-at-low-cost-in-africa.html.

# Telling people about my HIV at work – should I or shouldn't I?

by Tristan J Barber

Photo by: Tristan J Barber

**Dr Tristan Barber is a Consultant Physician in HIV Medicine at the Ian Charleson Day Centre, Royal Free Hospital, and an Honorary Associate Professor at the Institute for Global Health, University College London. He is a British HIV Association (BHIVA) Trustee and Executive Committee member, and Chair of the Board of Trustees for Positively UK. Tristan has been living with HIV since 2002 and has a personal and professional interest in HIV, frailty, and ageing.**

As a doctor and an HIV specialist I used to question the relevance of being open about my own personal life and lived experience. Surely in the clinic my energies should be focussed on those I was caring for? It was, after all, about 'them' and not 'me', right? Whilst there is some truth to this, over time I have become more comfortable with my own authenticity. I've realised there is value in being yourself, whatever your role in life. As Oscar Wilde said, 'be yourself, everyone else is already taken'. So, as I reflect on my 20th anniversary of living with HIV, and where I have got to with being open about my status, where would my advice sit for those in other walks of life? I have been fully open about my status for ten years. The advantages have been clear to me, both on a personal and a professional level. For one, I am happier showing my vulnerabilities. I am comfortable telling my patients that I am living with HIV when I think it might be helpful, which it often is. On the one hand it breaks down barriers and, on the other it lends more credibility to my thoughts or advice on what they might consider. Nonetheless I am aware that I'm in a privileged position. Privileged to work in healthcare, in my specialty of HIV, to work in London, and in 2022. All told, I don't experience HIV related stigma.

So, what does the law say about coming out with our status at work? How are we protected, and what might be some of the pros and cons of sharing a positive status with our employers and colleagues?

For most jobs there is no requirement to tell your employer about your HIV diagnosis. If you are worried about your confidentiality being breached or concerned that you'll be treated differently in any way then you may want to consider this carefully. A key benefit is that if employers are aware of your status they have a responsibility under the law to make 'reasonable adjustments' for you (for example, time off for clinic appointments). People with HIV who disclose their HIV status are protected under the Equality Act 2010[1], and this protection is from the point of diagnosis, not from the day that you tell your employer. Employers cannot legally ask questions about your health until an offer of employment has been made, and once this happens any information they collect should not be used to treat you unfairly. After a job offer has been made I would recommend that you answer health questionnaires honestly because if your employer finds out about something later it could be seen as a breach of trust. The Data Protection Act[2] states that records of your HIV status held by your employer must be kept confidential.

What about specific careers? Having HIV does not stop you from working in professions where there is close human contact, such as in the caring industry, working as a teacher or hairdresser, or where food preparation is involved. There have been huge advances in some sectors. For instance, changes in the law for healthcare workers means that dentists, surgeons, midwives, and others performing 'exposure-prone procedures' can now undertake these jobs provided they are on HIV treatment, have an undetectable viral load, take three-monthly viral load tests, and are registered with occupational health. Despite this there have been some areas that have been slower to change, but progress is being made. The case of James Bushe made headlines when he became the first person openly living with HIV in Europe to receive a commercial pilot's licence. Subsequently the Civil Aviation Authority have made, and continue to make, changes to their guidance to better accommodate and support new and existing pilots living with HIV in the UK. The UK Armed Forces have also made progress and have committed to 'ensure that being HIV positive is no longer a barrier to entry for candidates wishing to serve in uniform', with further changes planned in 2022. With any job that involves international travel it is important to remember that some countries may restrict entry to those with an HIV diagnosis although if your employer knows your status then they should make reasonable adjustments in light of this.

Despite all of this, ultimately the decision to tell others or not should be yours. There are only a few instances when your employer would need to know. Many people don't want to talk about having HIV because they feel it is a private matter, or that it is not relevant to their working life. Fear of poor treatment at work or of breaches of confidentiality may also be reasons why people choose not to share their status in the workplace.

One thing that does drive secrecy is the fear of being on the receiving end of stigmatising attitudes, particularly from those who hold false beliefs or are misinformed. What can be powerful about opening up is the opportunity it gives us to challenge these beliefs, to educate and inform colleagues, and to demonstrate how living with HIV is not a barrier to success, or to happiness. If we can do this it can be a powerful statement, it smashes barriers for others, and can also allow us to be more whole and authentic as people. But, of course, this takes strength and courage, and no one should feel obliged or under any pressure to tell others when they are uncomfortable doing so.

For me today, seeing people with HIV working in the careers they've chosen, living open, full, and happy professional lives, as well as personal ones, is such an incredible, life affirming, truly positive thing to see. In my own life my health, my work and my personal life are all the better by being open about my status, and helps the world to see that HIV might be a badge I wear, but it is neither a burden that I carry, or a barrier that I have in my way. If that can encourage others to do the same, then I feel proud indeed.

## HELPFUL RESOURCES:

National AIDS Trust
Terrence Higgins Trust
Aidsmap

---

[1] https://www.legislation.gov.uk/ukpga/2010/15/contents

[2] https://www.legislation.gov.uk/ukpga/1998/29/contents

Photo by: Jim Fielder

### by Jim Fielder

# 5 key things I've learnt through being coached

**Jim Fielder is Head of Living Well at Terrence Higgins Trust and works as a life coach. He's currently studying for a Diploma in Coaching Psychology at Birkbeck University.**

**For more information on 1-2-1 coaching with Jim or to book a place on our Connect workshops please email hello@thelovetank.info.**

I'm sure I'm not alone when I tell you that my HIV diagnosis was one of those moments which pulls you up short and makes you ask deeper questions about your life. I was in my early forties, living in Brazil after losing my job in London. The redundancy had knocked me sideways and my confidence had taken a hit. I felt adrift and rudderless, finding solace in sex and substance use – both readily available. Then came the diagnosis, and after moving back to London I was fortunate to be signposted by my clinic to an HIV organisation for support. This led me to access coaching and the experience transformed things for me, coming at the right time. Seven years later I still see the same coach; I now think of him as one part of my support network – and although we don't always meet on a regular basis, I know he's there if I need help to work on some aspect of my self-development.

Let's face it, modern life is complicated. We all have to grapple with uncertainty, constant change and competing priorities. From making ends meet, navigating relationships, finding meaning and purpose in what we do, understanding our journey and trying to settle into our various and often intersecting identities. It's no surprise that we struggle, lose our way and at times lose confidence. This I think is where coaching can help. It's different from counselling in that a therapist usually starts from the position that something about you is broken and needs fixing and so will work with you to uncover those 'wounded' aspects of yourself. This of course can be helpful, but coaching or mentoring starts from a different perspective. It doesn't assume you are broken at all, instead seeing you as whole, a unique product of your own journey through life. Coaching tries to untangle and bring into focus the issues you are facing, but the emphasis is more on identifying your strengths, looking for the positives, and building on them to find practical solutions. It recognises that you have most of the answers inside you; you just need some expert help to bring them out and to become your true self, or at least a better version of yourself.

Coaching can help with a wide range of issues, and a good coach will draw on a variety of tools and techniques to best address what you need help with. Here are 5 key things I've learnt through being coached:

## 1. Know your strengths

Because we all have them. Spend time figuring out what you're best at and enjoy most (and also what you're worst at and enjoy least). Building a better self-awareness around our own abilities can help us to move forwards with more intention, and help us decide where it's worth focussing more energy and where it isn't.

## 2. Try things out

We all have dreams and plans of things we want. It might be a different job, a change in career or a new hobby. But making those larger decisions can feel scary and if they don't work out can sometimes have big consequences for us. Better to build up to a change gradually and set goals you know you can achieve. Talk to people who do the thing you want. Learn about it. Try it out in a safe way. Experiment with it.

## 3. Reach out to others

Don't think that asking for help or advice is a weakness or that people won't have time for you. It's often quite the opposite. People love nothing more than being tapped up (even by a stranger) and asked 'I can see you're doing well at the thing you do, and I'd love to know how you got there and any advice you can give me'. Try it out, I bet you'll be pleasantly surprised by the reaction.

## 4. Avoid negative self-talk

The words we use to talk to ourselves and describe our abilities are very important, particularly if we have low self-esteem or feel like an outsider in some way. I would say to my coach sometimes 'Oh I can't do that!' and he'd give me a look. It's better, he'd tell me, to say you have difficulty with something rather than saying it's impossible as it keeps the door open for you and allows the possibility for change to emerge.

## 5. Work to be yourself

If you're reading BEAU, you've probably experienced either actual or perceived negativity by others towards some aspect of your identity. I'm not saying this is easy, but actively work at accepting who you are. Be in control of how you want to define yourself. This is the most powerful thing you can ever have.

---

BEAU PRESENTS

## LifeClubs Connect Sessions

lifeclubs Connect

Do you want to make changes in your life but feel a bit stuck, lack the motivation or simply don't know where to start? Maybe you'd like to improve your communication skills, feel more confident and resilient, improve your relationships with friends, family and partners or build better connections to achieve your goals?

The Connect programme might be the answer you've been looking for.

Connect is a series of hour-long workshops, developed by LifeClubs, experts in personal development, self-care training and coaching.

Over fifteen years, LifeClub workshops have been proven to help participants reach self-acceptance and feel more positive.

Connect is all about creating understanding, community, empathy, support, warmth, and mental well-being.

Our structured workshops have been designed to help participants develop a sense of belonging and connect better with themselves, each other, and their communities.

**Over the course of seven sessions participants will explore:**

- The Connect toolkit
- Developing communication skills and an understanding of how we connect
- Getting organised and taking control of our lives
- Identity and self-awareness
- Setting goals and action planning
- Building confidence and resilience
- Celebrating success

At the end of the programme participants can expect to feel more motivated, focused, resilient, and better able to set goals and make decisions.

Beau will be delivering the Connect programme for gay and bi men living with HIV in London from November 2022.

**To find out more and to book a FREE place please email:**
hello@thelovetank.info

Chris Smith, Baron Smith of Finsbury, is a former Labour MP and Secretary of State for Culture, Media and Sport. He was the first openly gay male British MP, coming out in 1984. In 2005 he was also the first MP to publicly acknowledge he was living with HIV.

# This much I BEAU

## by Chris Smith

**Interviewed by:** Scott Agnew
**Photo by:** Roger Harris, UK Parliament

It was at a rally in Rugby. The City Council had changed political control and the incoming Tory leader of Rugby council made it very clear that he did not want LGBT people coming to work for the council and that he was changing its employment discrimination policy. What happened next was almost a spur of the moment decision. I had thought for some months previously that I needed to say something publicly about myself, but I didn't quite know when. I was walking into that hall and there were a thousand people there. As I got up onto the platform, I suddenly thought to myself: this was the moment. I was absolutely scared stiff. My knees were knocking together and my hands were shaking, but I stood up and I began my speech saying: “My name is Chris Smith I’m the Labour MP for Islington South and Finsbury and I’m gay.” At that point the entire room got up and gave me a standing ovation. It’s the only moment I've ever had a standing ovation 20 seconds into a speech.

It's easier now to be an openly gay or lesbian MP, but to be openly trans is much more difficult. There is of course one MP who has now done that, but the place is teeming with openly gay and lesbian MP's now. When I did it, I was the only one, and for nine years I was still the only one. It was difficult and a bit scary. It wasn't a particularly welcoming social environment generally outside of parliament for people who were openly gay, but I have to say I've never regretted for a single moment my decision to come out publicly.

When New Labour came to power in 1997, I think I'm right in saying that I was the first openly gay cabinet minister anywhere in the world. The remarkable thing was that no one noticed. In all the Press about the new cabinet and who's doing what and so on, it wasn't mentioned and that showed me we had made quite a lot of progress. I didn't draw attention to it at the time because it didn't make the blindest bit of difference.

When I made the announcement about my HIV in 2005, I'd been diagnosed for about 15 or 16 years. For a long time, I had thought about saying something, but opening up publicly about your health is much more difficult than talking publicly about your sexual orientation. Nelson Mandela's son had died of AIDS and Mandela made a very moving speech at the funeral where he said, “we mustn't hide this, we must speak out about it, we must be open about it because that's the only way in which we will begin to counter the prejudice that still surrounds this horrible disease.” I just thought right there, that I needed to say something. So I talked to The Sunday Times. I was just trying to say two things. Firstly, that since my diagnosis, I could demonstrate that it is perfectly possible to live with HIV and make a wholly valuable and worthwhile contribution to society; and secondly, in a peculiar kind of way, I've been lucky. I'd acquired HIV in a country where there was a National Health Service, where there were medical responses available to people who were affected, there was counselling and support and so on. There are millions of people around the world who aren't in that lucky position, and we need to do what we possibly can to help them too.

I remember walking into my House of Commons office on Monday morning and there was a little note on my desk saying, “please ring Mr Mandela”. I rang his telephone number and at the other end of the line was Nelson Mandela saying I just wanted to say thank you and well done and what you've done has made a real difference.

Well, that sort of made it all worth it.

When I was diagnosed, back in 1987, there was no combination therapy available – there wasn't even AZT yet. I can remember thinking “Oh my God I'm going to die in six months' time.” I also remember one of my doctors saying something important to me, too. He said “I don't know what the prognosis is going to be for you. You might be able to carry on living well for quite a few years yet or you might catch an opportunistic infection, and something could happen anytime.” He continued, “the thing you need to be able to do is to learn to live with uncertainty.” And that was the best piece of advice. Actually, it's not a bad recipe for dealing with life generally, let alone for anyone diagnosed with HIV.

There are times in life when you really do need to shout things from the rooftops and there are other times when silence is much more powerful. Arguably, today there are too many politicians who assume that the former is the only mode in which they want to operate, whereas I believe you need to be able to do both.

Changing attitudes travels along on a bit of a spectrum. You start with overcoming the fear and ignorance which gives rise to prejudice, violence, hatred and abuse. Then you move to tolerance and on to something you might call acceptance, where we generally are now.

But I believe, where we want to arrive at is: Celebration.

We still need to get to a place where we can genuinely celebrate the fact that society is full of difference, that this is a good thing and it is this difference and diversity between people that brings a great richness to the world.

# Joyful Noise Choir

Sing your heart out

All photos: Joyful Noise

Stephen Hart has always loved to sing.

As a child he had big dreams of performing in the West End or on Broadway. A lifelong dream that led him on a path to study musical theatre and a plan for a long and successful career on the stage.

But after his diagnosis in 2006, his agent told him there was no way a person living with HIV would ever have a lead role in the West End or on Broadway.

Devastated, Stephen felt that there wasn't a place for him in the theatre community anymore, so he gave up his dreams and stepped away completely for many years.

Then Stephen discovered the Joyful Noise Choir run by the Naz Project in London. It turned out to be a powerful and transformative experience, enabling Stephen to reconnect with his passion for singing and performing whilst celebrating his life with HIV.

The Joyful Noise Choir is a place where people living with HIV are free to be heard, it's a place for community, fun and connection. It's also a supportive and safe space for us to come together and find joy in singing our hearts out. The choir challenges HIV stigma and prejudice, and completely transforms lives.

The choir is made up of a diverse range of people from different countries, religions, gender identities, and sexual orientations - a truly inclusive and inspirational collective.

Joyful Noise was originally set up as a 10-week pilot project by NAZ Project in 2013; coming out of a belief that creativity could be used for social change, to tackle loneliness and boost good health and well-being.

The choir has since grown to become a much loved and needed group that is open to anyone living with HIV who just wants to sing.

Joyful Noise has celebrated winning the Social Sciences Community Award in 2014 and several sold-out public performances (including one with Prince Harry attending).

Because of stigma, not all choir members are out publicly about their diagnosis. Joyful Noise gives them a voice and allows them to be heard in the way that feels comfortable for them. It is open to all people living with HIV with an aim to encourage social participation and reduce isolation. It creates a sense of community and has developed into one of the most vibrant services for positive people in London.

Each week, choir members explore different aspects of musicality. These include breath control, expression, voice control, vocal blending, vocal dynamics, exploring harmonies, singing with a band, interactive singing, singing rhythmically, and connecting with the emotion of the song through using their own personal narratives.

Stephen and Angelina, who have been part of Joyful Noise for a few years, told us, "Joyful Noise is like a second home for us. It gives us joy, respite, and companionship. We get to exercise the cockles of our throat with our sisters and brothers, it enables us to shine. Every time we go home from Joyful Noise, we feel energised. Long may it continue".

Fraser, another choir member said "Joyful Noise cheers me up and makes me giggle. It is full of lovely people singing in beautiful harmony; it boosts my mood and improves my health" Parminder Sekhon, CEO at Naz smiles as she tells us that after the Wednesday night rehearsals, people can be heard singing as they leave the building and head home.

Research shows that singing can be good for you, it may help boost immunity and lung function as well as improving mental health, so not only do you get to meet new people, but you also get to boost your health in the process!

Joyful Noise is always glad to welcome new members to the family, which gets together on Wednesday evenings from 6:30pm until 8:30pm.

**FOR MORE INFORMATION**
Joyfulnoise@naz.org.uk
07904016328

# From the archives:

## In every issue we choose a couple of items from the archives, to celebrate and recognise our history and the creativity of our beautiful HIV community.

Visuals and messages have been key to shaping people’s perception and understanding of HIV since the start of the epidemic.

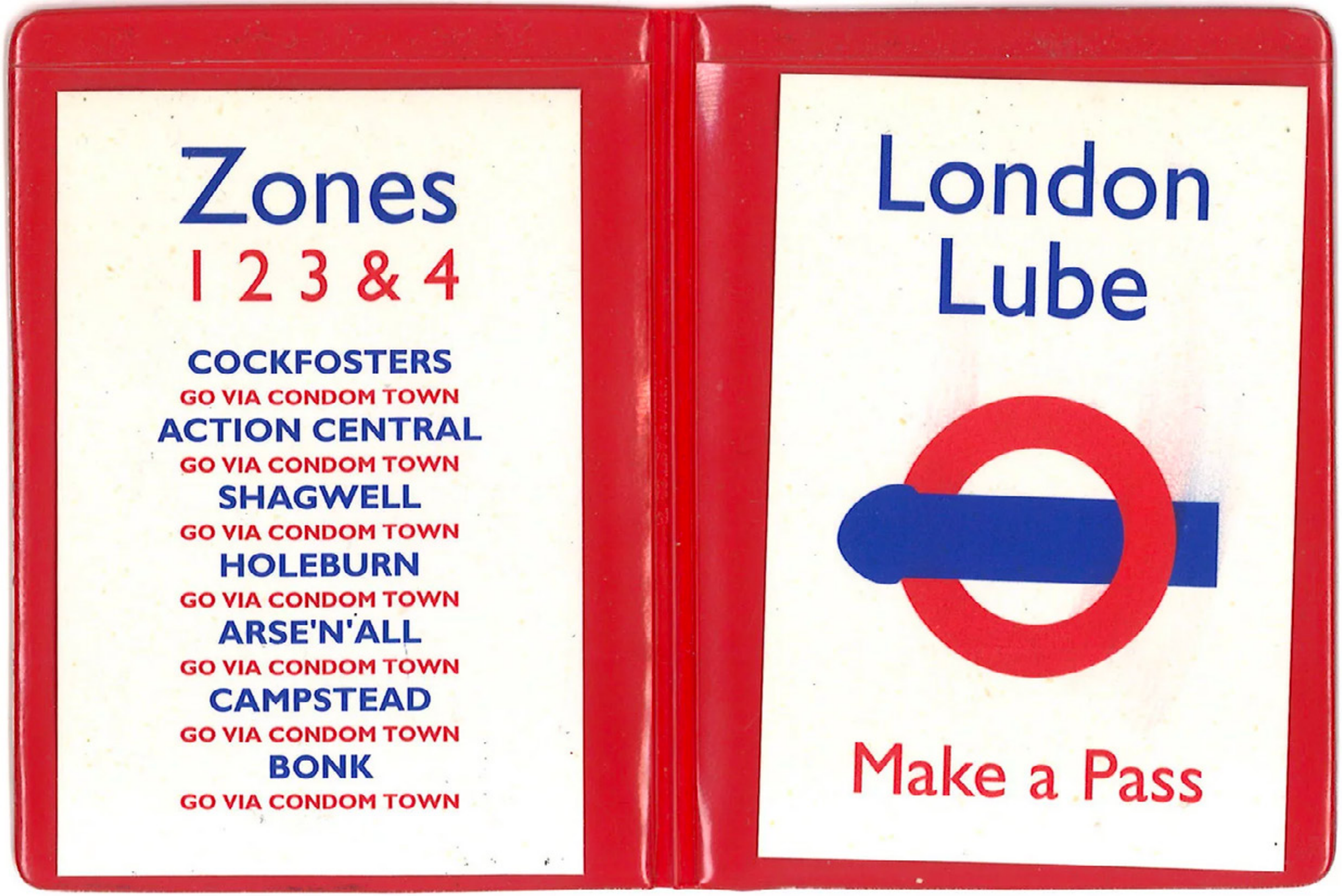
Most people remember the Tombstones/Iceberg campaign (better known as the *Don’t Die of Ignorance* campaign) or the Act Up *Silence=Death* reclaiming the pink triangle.

We want to acknowledge the role of design and creativity in changing the narrative on HIV, combating HIV and empowering people living with HIV.

The following images are kindly provided to us by *HIV Graphic Communication* – a historic visual archive of promotional campaigns and graphic ephemera from the UK.

**ACROSS: ORAL SEX**
TRADE (part of Men’s Sexual Health Project), Leicester. Postcards: 1 of set of 4.
A6 mono. circa mid 90s.

**LONDON LUBE**
GMFA. Travel card holder. 1993.



**TOP, VERS OR BOTTOM PREP WORKS!**
Prepster. Postcard: 98x210mm, B&W, mono reverse. Photograph: Ajamu. circa 2019.

from the beautiful HIV+ community

OCTOBER 2022

# BEAU

## № 2