



ABOUT THE AUTHOR Leo Schenk (1966) is an award-winning HIV activist from the Netherlands



Leo Schenk (1966) is an award-winning HIV activist from the Netherlands and has been working in the field of HIV for thirty years. He's one of the founders of Poz&Proud and is currently editor-in-chief of hello gorgeous magazine.

INTRODUCTION

HIV has many different facets. There's HIV as a *medical condition*: an initially untreatable virus which, within a fairly short space of time, has become a chronic condition. These days, given the right drugs, it can be managed effectively and is no longer transmissible. Then there's HIV as a *social phenomenon*: in other words, the way in which society perceives HIV. In this respect HIV has changed very little in almost 40 years: it still causes fear and meets with widespread ignorance among the general public.

There's also HIV as a *good cause*: charities, like Aidsfonds here in the Netherlands, raise money in the name of HIV, which is then spent on research and other projects at home and abroad. There's HIV as a *professional field*: a source of employment for policy officers, pharmacists, researchers, hospital consultants, sexual health nurses and many others.

And finally there's HIV as a *personal issue*: the HIV we live with on a daily basis. Everyone who lives with the virus experiences it differently, so this facet of HIV is extremely diverse.

Over the years, a growing gulf has opened up in the Netherlands between these different facets of HIV, particularly between HIV as a personal issue and HIV as a good cause. Many people who live with the virus feel angered or burdened by the outdated image of

HIV that fundraisers cling to in the hope of attracting donations. There was a time when the gap was much less pronounced: back when HIV earned its terrifying image and when HIV-positive people were the modern equivalent of lepers.

From the very beginning there was a strong sense of solidarity among people living with HIV. A community was born – a community of people brought together by the virus, with emotional bonds forged between them.

For a long time gay men were at the forefront, setting the tone and shaping attitudes to HIV in the Netherlands in general, and more specifically within Hiv Vereniging (HV), the Dutch Association of People Living with HIV. In 2018, however, the Dutch HIV community is more visible and diverse than ever before. We are a community of women, men, younger and older people, from a variety of different backgrounds and cultures, determined to defy stigma and increasingly casting off shame and stepping out of the shadows.

HV is an essential part of our community. It has supported many of us at crucial times in our lives by offering a listening ear, providing

And although not everyone with HIV is a member or uses its services, we have all benefited from the work that HV has done since it was founded in 1990.

advice, bringing us into contact with others and lobbying for our

This book tells the story of the Dutch HIV community, and the defining role played within it by HV.

1.

LIVING TOGETHER, DYING TOGETHER

The history of AIDS in the Netherlands began at the end of 1981, when a 42-year-old man called Jan was admitted to the Wilhelmina Gasthuis hospital with serious but unexplained symptoms. At that time Jeannette Kok was working as a nursing assistant at the STI clinic run by Amsterdam's municipal health service. Her job was to ask people diagnosed with STIs about their sexual history and to contact their recent partners if they were unwilling or unable to do it themselves.

Jeannette's boss asked her to talk to Jan – but she didn't manage to do so. "Before I was able to visit him, he had slipped into a coma," she recalled in the book 25+.1

Jeannette talked to Jan's friends about his life in general and about his sex life in particular. "His friends talked openly about their sex lives, so I found out a lot about Jan and about them too. I also learned that they often travelled to America. So immediately there was a suspicion that Jan may have contracted the mysterious 'gay disease' that had been reported in the US."

Jan died a few months later.

¹ The book 25+, about 25 years of HIV and AIDS in the Dutch gay community, was published in 2007 by Poz&Proud, the gay men's division within HV.

interests.

The death toll mounted rapidly. By 1984, 55 cases of HIV/AIDS had been recorded in the Netherlands, and 25 of those people had died. Two years later, in 1986, there had been 256 HIV diagnoses and 117 people had died as a result of AIDS. Almost 90% of the victims were gay men.²

TESTING DISCOURAGED

The first HIV test becomes available.

You might expect that the introduction of the HIV test in 1984 would have prompted many people to get tested. But in contrast to its neighbours, the Netherlands actually discouraged testing. The Health Council of the Netherlands, a government advisory body, decided that testing would be unethical as long as no drugs were available. Another body, the Health Care Inspectorate, concluded that from a policy perspective testing would be pointless: everyone should assume that they had HIV and always take precautions to avoid infecting their partners.

The decision not to actively promote testing was also related to the stigma and self-stigma attached to HIV. The psychological burden of knowing that you had the virus was simply considered to be too heavy. In her 2004 book *Geen Paniek, Aids in Nederland 1982-2004* (No panic, AIDS in the Netherlands) researcher Annet Mooij argues that people with HIV living in the Netherlands didn't actually experience widespread "public" stigma before effective treatment became available. She attributes this mainly to the media, which tended to defer to HIV organisations and gay groups and avoided adopting an overly moralistic tone in its reporting. Any journalist who did write unsympathetically about people with HIV would be called to account by one of the authorities in the field.

There may have been a lack of public stigmatisation and discrimination in this country, but there is plenty of anecdotal evidence that in their private lives, many people with HIV found themselves disowned by family and friends. AIDS was frequently omitted from death notices to avoid embarrassment. There was discrimination in the workplace, where people could be unwilling to share a toilet

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- ³ Schorer was a foundation that promoted LGBT health and welfare. It was declared bankrupt in 2012.
- ⁴ Source: Interview in *Hivnieuws*, issue 100

with an HIV-positive colleague. And there were stories of hospital staff who would steer well clear of beds occupied by AIDS patients. These experiences – and the impact that they had on the lives of people with HIV - were a recurring theme raised in the support groups run by Jeannette Kok and David Stein. David was an Americanborn psychologist who worked for the Schorer foundation.3 Jeannette would refer men to him who had not yet been hospitalised. At first she didn't see much use in the support groups: "Putting all those terribly sick people in a room together, surely that couldn't help?"4 But for people living in great uncertainty, it was essential to be able to share their experiences with one another. Talking about death was very hard for these, often very young, men. Many of them were permanently grieving for friends and lovers who had died of AIDS - and for their own sense of immortality. The impact on the men who lived at the epicentre of the epidemic persists to this day.

DIVIDING LINE

It was during the support group meetings that the idea for an advocacy group was born. Two of the members suggested setting up a patient association to lobby for the interests of people with AIDS. They wanted Jeannette to be on its board: "Because they said 'we're going to die, but you're not:" The Society for People with AIDS (Bond voor Mensen met Aids or "BMA") was founded in January 1987. It was one of the world's first advocacy groups for AIDS patients.

It may seem inconceivable now, but in those early uncertain years, there was a clear dividing line between people who had been diagnosed with AIDS and people who had HIV but had not yet developed an AIDS-related condition. People with AIDS would often die within a few years, whereas people with HIV could expect to live longer, albeit with a ticking timebomb that could go off at any moment. This gave rise to a different sense of urgency and to a dividing line in advocacy activities. Six months after BMA was set up, the Advo-



MARJOLEIN ANNEGARN 55

Photographer and activist

"My HIV diagnosis came completely out of the blue. It was 1988 and I wanted to be a blood donor, but after I had given blood, I received a call from the blood bank, asking me to come by. I told my father, my sisters and a couple of close friends right away, but after that I kept it to myself for years. When I went through another health crisis after that, I ended up with severe depression. I slowly scrambled my way out of the depths and decided it was high time to do more with my HIV, so I started volunteering for Hiv Vereniging. The talks I've had with my colleagues helped me a lot, and I gradually became more open about my HIV. Ultimately, I decided that I wanted to do more for our community, which also means that you have to show yourself.

Joep Lange (a scientist and activist who died in 2014's MH17 tragedy, ed.) was my internist for a very long time. There were only six years between us and we got along very well: if he hadn't been my

internist, but someone I met in a bar, I'm sure we'd have been good friends. I loved his incredibly cynical sense of humour. He was very honest with me and that's what I need: people who keep telling me how horrible everything is and how sorry they are don't do anything for me. I contributed to Atlas 2018 as a photographer, as well as working on my own exhibition, The Stigma Project, which will also be at the conference. The series includes portraits of people with HIV who still suffer from the enduring prejudices about HIV in society. People can find it very hard to deal with this stigma, making many of them gloomy and anxious. This makes me very sad at times, but also incredibly angry, because of how unnecessary it all is. The key problem is that the general public knows so little about HIV. With this project, I want to show how prejudices affect people with HIV, as well as informing everyone about the current state of affairs regarding HIV.

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cacy Foundation for HIV-positive People (*Stichting Belangenbehartiging Seropositieven* or "BSP") followed.

Both BMA and BSP organised activities for their target groups and participated – separately – in AIDS policy meetings. That separation quickly prompted a chorus of criticism from within both organisations and from other quarters too. After all, people with HIV could expect to develop AIDS at some point down the line. It was also argued that merging the two organisations into one would boost advocacy efforts for both people with HIV and AIDS.

In the end there was a general consensus that a merger was inevitable. Hans Moerkerk, one of the pioneers of Dutch efforts to tackle AIDS, was at that time a member of the National Committee to Fight AIDS (*Nationale Commissie Aidsbestrijding* or "NCAB").6 When he heard that Leonard Bernstein was to host an AIDS benefit at the Concertgebouw, he urged that part of the proceeds should go to BMA and BSP – on the condition that they merged.

A working group was set up to present proposals to both organisations on the specific steps they would need to take in order to "fuse" together. Despite an early awareness that the partnership made sense, a variety of obstacles arose along the way in terms of organisation, substance and personalities, which complicated the process. Agreements were made on how the parties would cooperate, but these proved easier to make than to implement. The complications, which were put down to the fact that the two organisations had developed very different cultures during their brief lives, were very difficult to explain to the outside world.⁷

The key dilemma was how to prevent advocacy efforts for people with HIV from being drowned out by AIDS-related advocacy. There were fears that the government and politicians would focus on the group perceived to be most heavily affected. However, neither BMA nor BSP stood to gain from competition between themselves or from a fragmentation of their advocacy efforts.

In February 1990 the merger became a reality, and the Dutch HIV Association (*Hiv Vereniging* or "HV") was born. The HIV Society

(*Hiv Bond*), which organised medical information evenings, became an independent entity within HV. Jeannette Kok – together with Hans Amesz, who later became editor-in-chief of HV's magazine *Hivnieuws* – were HV's first salaried staff.

WARM WORDS

In 1991 HV relocated from a single room in the Mozeshuis building to grander premises: the bottom floor of Schorer's building on Amsterdam's P.C. Hooftstraat. The opening ceremony was conducted by the late Jos Brink, a renowned actor and TV personality, and by AIDS expert Joep Lange, who died in 2014. The pair used an enormous pair of scissors to cut through a Keith Haring snake, which symbolised the virus.

Jeanette Kok received a warm round of applause and was showered with praise for all her pioneering work, as one of women on the front line of the battle against AIDS in the Netherlands at that time. Having played a founding role in developing HIV/AIDS advocacy in our country, she would go on to spend many more years working tirelessly in pursuit of this cause.

Hans Moerkerk also attended the opening. He expressed the hope that HV would resist the temptation of slipping into a comfortable role within the policymaking machine, with all the trappings that would involve. "The grant money and facilities pose their own risks," he said.

HV was well aware of those risks too. In one particular article in *Hivnieuwsbrief*, its members seemed to be giving themselves a warning: "But we've got to be careful: now that we've got semi-official status, we need to watch out that we don't end up getting swallowed up by the system. And that people with HIV remain in control of policy initiatives."

The subsequent years would demonstrate HV's capacity to take a stand against national HIV and AIDS policy, and stay true to itself while putting the organisation on a more professional footing.

⁶ The NCAB was initially an executive agency of the government. Later it was given more of a coordinating role.

From Hivnieuwsbrief issue 1.

BOYCOTT

2. LET'S HAVE A BALL

⁸ From the first edition of *Hivnieuwsbrief*, 1989. HV's first chairperson was Hans Paul Verhoef. This Dutch activist made global headlines in 1989 when he was arrested at Minneapolis airport while travelling to an AIDS conference in San Francisco. In an interview that year he talked about his arrest: "In Minneapolis the customs officers asked to see my conference invitation. I didn't realise that I'd also handed them a copy of a letter in which I'd asked to be exempted from the conference fees because I have AIDS." He was taken aside to give a sworn statement on his reasons for visiting the US: "They gave me two options: fly back home, or you'll have to appear before a judge. It was Sunday evening and the conference was due to begin on the Wednesday. I thought it would all be sorted out within a couple of days." He was wrong. He had his fingerprints taken, was handcuffed and was then taken to prison in a van.

Before Hans Paul's arrest, many people were unaware of America's entry ban on people with HIV, and the case shone the international spotlight on it. US activists raised 15,000 dollars to cover his bail within a single day, and high-level talks were held to decide whether he could stay. After spending five days in prison, he was finally given permission to attend the conference. He received a hero's welcome and was made an honorary citizen of San Francisco.

In 1990 the Sixth International AIDS Conference was held, once again in San Francisco. The World Health Organization called for a boycott of the event on account of the US entry ban. In response the United States decided to grant people with HIV a waiver to allow them a short stay. But since this would still involve people being registered as HIV positive, many groups – including HV – decided to go ahead with a boycott.

Because the conference was being boycotted, Amsterdam decided to hold an event of its own: the *Seropositive Ball*. This 69-hour protest event included debates, lectures and workshops and was attended by more than 2000 people.

There were real-time connections with San Francisco and Rio de Janeiro, offering individuals and organisations a platform for information sharing. This *O+ Network* was easy to use, even for people who didn't have much experience of computers. Fifteen PCs were available throughout the event for people to leave comments and respond to the contributions of others. The machines were in constant use.

A NEW, COMBATIVE TONE

The Seropositive Ball set the tone for the growing activism activities among the Dutch HIV community. The image of the wretched AIDS victim made way for something new: the combative person living with HIV. Many people decided it was time to stop being passengers; they had to get into the driving seat.

Until that point, women with HIV had been practically invisible. They tended to live in isolation and policymakers paid very little attention to their needs. A number of women decided to take matters into their own hands, and on 11 November 1990, Positive Women (*Positieve Vrouwen*) was founded. The main priority of this new division of HV was to raise the profile of women in the Netherlands living with HIV. The founding of Positive Women was announced in the form of a spoof birth notice. "We're delighted to announce the

The theme for World AIDS Day is "Women with AIDS". For the first time the Dutch professional field focuses extensively on the needs of women with HIV/AIDS.

The first anti-stigma publicity campaign is run. Its slogan is: "Nobody ever caught AIDS from a little understanding".



TOMAS DERCKX 26

Junior Communication Officer Hiv Vereniging (HV)

"I first heard about U=U from a guy I met on Grindr, back in 2013 when I spent a couple of months in New York. The guy told me that he was 'undetectable'. I didn't know what he was talking about so I googled it. When I got back to the Netherlands I looked for more information and that's how I came into contact with HV.

Last year I began working for the association as a junior communication officer. At the start I thought that HV was rather old-fashioned, but my opinion on that point changed very quickly. What surprised me the most is that it's a modern, assertive organisation. Everyone is open to change and everyone's voice gets heard.

I mainly work on our n=n campaign

[the Dutch equivalent of U=U, ed] which we launched in 2017. It will take a while for the message to be embraced, both by people who are positive and people who are not. After years of being conditioned to believe that you've got to

watch out, for instance if a condom breaks, now we're being told that if your viral load is undetectable, you can't transmit the virus.

For the campaign we've produced lots of short videos in which people explain what the message means to them. The videos also feature contributions from healthcare professionals, such as consultants and physicians. They don't just talk about the scientific reasons behind the message, but also about the big impact it has on how people with HIV feel about themselves.

During AIDS 2018 we'll be marching, along with other international organisations and groups, to publicise the message U=U. I'll make sure that everyone has a T-shirt displaying the message in their own language. This will show that ours is a community-based campaign, which is running throughout the world."

birth of a new daughter on 11/11: Positive Women, a new division within the Dutch HIV Association Please don't send us baby gifts – we'd much prefer to receive your support. It may have been an unwanted pregnancy, but we're making the best of a bad situation." The launch party was filled with speeches, song and celebration. Women with HIV came together in solidarity, determined to fight for greater attention and understanding.

That year, the theme for World AIDS Day was "Women with AIDS". At the national World AIDS Day event in The Hague, the professional HIV field and HIV community focused closely on women's needs for the first time ever. Until then their focus had mainly been on how women transmit the virus to men and children; very little consideration had been given to how HIV impacted on the lives of the women themselves. This was encapsulated by a protest slogan from that time: "women don't get AIDS, they just die from it".

By the end of summer 1990, 92 women had been diagnosed with AIDS in the Netherlands. Usually the diagnosis came at a late stage because when a woman first contacted a doctor or gynaecologist with complaints, AIDS would rarely be considered as a possibility. Pregnant women with HIV were left with practically no choice but to have an abortion, since HIV professionals often overestimated the risk of the baby contracting HIV.

When the International AIDS Conference came to Amsterdam in 1992, HIV-positive women took the initiative to organise their own pre-conference at which they discussed plans to put women's needs on the international agenda. ICW, the International Community for Women Living with HIV, was born, and introduced on the conference's main stage. This year – at the opening of AIDS 2018 – the surviving women from those early days will take to the main stage once more.

A WALKING, TALKING HIV ENCYCLOPEDIA

The Seropositive Ball marked legendary activist Kees Rümke's first involvement with the battle against AIDS. Kees had seen the impact

of AIDS on those around him and the event spurred him into action. At the end of 1990 Kees joined the Dutch chapter of ACT UP!, which was founded due to dissatisfaction with the "consultation culture" that prevailed within the HIV field, with complaints and arguments often being thrashed out behind closed doors. Shortly after Kees joined, one of the founders of ACT UP! died and the activists inherited his computer. It had no hard disk, just two floppy disk drives. But with it they could make contact with *Hivnet*, a computer network founded by people with HIV. The network had its own bulletin board and hosted various HIV-related resources, mainly American magazines. *Hivnet* was a kind of forerunner to the internet, which was not yet as widely available as it is now.

At that time, the best way to reach people was still via the print media. So Kees arranged for a special ACT UP! page to be included in HV's magazine. The magazine, which was initially a co-production by BMA and BSP, began life as *Hivnieuwsbrief* (HIV Newsletter). In 1991 it was renamed *Hivnieuws* (HIV News), and the editorial board decided to turn it into a more serious publication.

The need for HV to have its own magazine had arisen because of the absurd nature of media coverage about HIV and about the impact of the virus on people's lives. *Hivnieuws* challenged the sensational stories that filled the mass media, while also boosting the resilience of people with HIV. Armed with information from *Hivnieuws*, many patients were now in a position to confront their doctors and nurses. In fact, it was not uncommon for readers to be aware of new developments before healthcare professionals.

For many years Kees submitted articles to *Hivnieuws* on medical matters, initially as an activist on behalf of ACT UP! and later in his own name. In 1994 he joined the magazine's editorial board. In his early years on the team, he would take complex information about trials and medical developments and turn it into readable content for subscribers. Later he wrote about the politics of the HIV world and about new preventive strategies, such as serosorting and PrEP. For him, this was also a sort of activism: he believed that given the

1995

right information, people should be able to make their own choices for the sake of their own welfare.

Over the years Kees became the Netherlands' walking, talking encyclopedia on HIV. His knowledge of the subject was unrivalled. In 2000 when HV was looking for a salaried staff member to be responsible for healthcare and medical issues, his appointment was a no-brainer.

That same year HV acquired *Hivnet* and Kees was asked to develop content for a new website. He wasn't a technological wizard, but he knew more about computers than anyone around him. The website finally went online late in 2000, with lots of its content consisting of adapted articles that had previously appeared in Hivnieuws, supplemented with new information. It quickly evolved into an enormous database offering a rich source of information for people with HIV, as well as for healthcare professionals. The advent of the internet enabled everyone with a PC to go onto the world wide web and search for information. You no longer had to depend on your consultant or on Hivnieuws to keep you up-todate on the latest developments. But not all the information out there on the internet is valuable or even accurate. Thanks to the personal efforts of Kees Rümke, as people increasingly made their own efforts to seek out information, HV remained an authority in evaluating the vast quantity of data that had become available.

3. **NEW HOPE**

In 1995 the big breakthrough in HIV treatment finally happened. Thanks to combination therapy, HIV no longer had to be potentially fatal. HV, Aidsfonds and ACT UP! (represented by Kees Rümke) lobbied the political parties to ensure that the new treatment became rapidly available, all the time stressing how crucial it was to public health. Combination therapy had to be made available to everyone with HIV. Otherwise resistance could develop in the course of time, with all the adverse consequences that would entail.

At the start of 1996, the late Els Borst, health minister at the time, decided to speed up access to the new treatment in the Netherlands. The grant scheme to facilitate this access took effect in the summer. Looking back, Kees Rümke said: "With hindsight it all happened very quickly. But when you're facing death, each month is a month too long."

⁹ Interview in *Hivnieuws* issue 100.

SCARS

The first generation of antiretroviral drugs saved many lives, causing what became known as the "Lazarus effect": many people who had been given up for dead found themselves "resurrected".

At that time treatment regimes involved taking a handful of pills a day in accordance with a complex schedule. The pills were quite



PAULINE MORET 43

Volunteer Hiv Vereniging (HV)

"In 2012, I appeared in a documentary that aired on national TV. It was called 'HIV HIV Hurray!' and dealt with what we now know as U=U. It was a different time, back then, and people were not ready to hear what we had to say. The documentary was very one-sided, with the maker interviewing a friend of mine who called me a 'walking, talking gun'. I'm very pleased that the U=U discussion has made its way to our country, but I'm not happy with how I've been portrayed.

When learned of my diagnosis in 2006, I was still in the relationship where I contracted HIV. He was very closed about the whole matter, which also kept me from making my diagnosis public. When the relationship came to an end, I thought: why should I be ashamed? I decided to become an active volunteer for the Hiv Vereniging, among other organisations.

Three years ago, I was planning to take part in the 'HIV out of the Closet', the

first public campaign about living with HIV to be organised by the HIV community itself. Around that time, however, I met a man and decided to withdraw from the campaign, which I regret terribly now. I put someone else's wishes above my own and I've since decided to never do that again! I'm now one of the models for the campaign that the Dutch HIV community is using to welcome visitors to AIDS 2018. It's amazing to see the great diversity among all the visitors. Visibility is a key way to help break taboos.

During the conference, I'll be working on the Positive Lounge. We'll have an area of 1000 square meters at our disposal, completely surrounded by glass, Where people with HIV can sit back and relax, but also network and meet each other. In short, it'll be a great place to escape the hustle and bustle of the conference."

toxic. So many patients paid a heavy price for their new lease of life, in the form of severe side effects. Whereas kaposi sarcoma lesions had been the visible "scars" of those living with AIDS, in this new era, patients on combination therapy visibly bore the effects of lipodystrophy: fat redistribution, resulting in sunken cheeks, swollen stomachs and emaciated buttocks.

HIV healthcare evolved too: specialist AIDS departments were closed down and hospitals increasingly profiled themselves as HIV treatment centres. Viral load became an essential measurement in determining the success of HIV treatment: this meant measuring the quantity of HIV in the blood, to assess the extent to which the drugs were inhibiting the replication of the virus.

Viral load tests were not carried out at every hospital, much to the anger of HV. In 1997 the association wrote to all treatment centres, urging them to do the tests. The problem was that these tests had to be funded from the regular budget that the treatment centres received from the government. At the start, some of the bigger hospitals didn't want to use these funds for viral load tests because the costs might have to be offset by staff cuts. HV's position was, however, clear: HIV-related hospital admissions had fallen and money was being saved, so what was the problem?

A CHANGE OF COURSE

HV's tenth anniversary.

¹⁰ From *Hivnieuws*, issue 64.

In 2000 HV marked its tenth anniversary. "Is this really something to celebrate?" its board asked, given the death toll from AIDS.¹⁰ HV had evolved into a "reasonably professional organisation, with a strong central office, lots of thriving divisions and working groups, and several successful regional chapters and support offices. Its magazine [was] of great importance to many professionals and other people." At the same time, there was an awareness – just as there had been when HV was founded – of the need to prevent further professionalisation from causing HV to get bogged down in consultations with other bodies, or reducing the active participation of people with HIV and other stakeholders. "Together we must

ensure that we've always got scope for creative action and dynamic initiatives."

Given the transformation in the needs of people living with HIV, HV decided it was time to change course: to move from lobbying for services to actually providing services. The National Service Point was set up: a central point within the organisation to support the initiatives of HV members. There would also be a single telephone helpline, staffed by volunteers, and available to provide advice and support four days a week, from 2pm to 10pm.

It took staff some time to adjust to this new approach. There were also doubts about whether enough volunteers could be found to operate the helpline. Whereas HV's earlier helplines had been operated by white gay men from Amsterdam, the Service Point sought out and recruited a more diverse body of volunteers. Being HIV-positive was not a requirement – affinity with the subject was sufficient. The Service Point helped new groups and initiatives to get up and running. For instance, a young people's division was set up (*Jongpositief*), as well as a division for families with one or more members with HIV (*Positive Kids*) and a series of discussion groups (*Deel je hiv*, Share your HIV). Attempts were made to help other groups organise themselves – for instance groups for current and former drug users and for straight men – but those efforts didn't always come to fruition.

CHECKPOINT

In the early years of combination therapy, not everyone was immediately convinced of the benefits. Although hospital admissions fell and the number of people dying from AIDS dropped dramatically, the new drugs were not always effective, in particular for patients who had been treated with AZT in the past. This threatened to cause a dividing line between those who were being successfully treated and those who were not.

Many professionals also believed that the long-term effects of the new pills were unclear. This tempered optimism was one of the

2001

reasons why, even several years after combination therapy became available, testing policy remained cautious.

In 2000 HV published a policy paper on prevention, calling amongst other things for a non-moralistic approach to prevention, universal availability of PEP and a more active testing policy. In its paper HV wrote: "Although there are still a few 'ifs and buts' (...) in order to prevent AIDS, there is an urgent need for people to know whether or not they are HIV-positive." 11

¹¹ From the policy paper *Preventie gemoderniseerd* (Modernising Preventive Care).

The paper was not well received by those working in preventive health for gay men. They were already struggling to respond to the changing landscape, in which condoms were no longer regarded as the obvious choice by everyone who wanted to protect themselves and their sexual partners. In 2001, partly as a result of HV's criticisms of testing policy, a – slightly tentative – testing campaign targeted at gay men was finally launched.

Testing was still in its infancy in the Netherlands. At this time only the standard test was used, which meant waiting a fortnight for results. What's more, the municipal clinics only offered HIV tests in combination with a full STI screening. User convenience was not a priority.

In 2002, when Schorer closed down its weekend STI clinic for gay men, the team behind it went in search of new premises. They wanted to modernise testing policy in the Netherlands by introducing a rapid HIV testing service for gay men. When HV heard about this, they offered the team space in their office, on the condition that they would offer the service to everyone, not just gay men, and that people would be given proper pre- and post-test counselling. In summer 2002, Checkpoint opened its doors. The new service was a great success: within 14 months some 1000 tests had been carried out. The rate of positive results was 6.8%, much higher than the rate recorded by Amsterdam's municipal STI clinics. Checkpoint had therefore proven that people were no longer willing to wait a fortnight for their results.

Six years later Checkpoint shut down; its mission to modernise testing had been completed. Many municipal STI clinics had followed its example. The mayor of Amsterdam himself even dropped by when the centre was closing down to express his appreciation for the team's groundbreaking work.



GUIDO ZONNEVELD 46

Social worker

After my diagnosis in 2003, I only told a few friends that I had HIV, but I noticed that it was this closed attitude that really made me sick. I wanted to be more open, and more knowledgeable, which is why I ended up at the Hiv Vereniging (HV). Together with several other men, we founded Poz&Proud.

We were very driven and demanded our right to sexuality. Serosorting was a hot topic at the time, which involved gay men with HIV searching each other out for relationships or sex. The topic of HIV and sex was risqué, even within the HV. Although we had stopped seeing ourselves as victims, some people feverishly clung to that image. There were also conservative forces at play outside the association, which greatly sensationalised serosorting. What was in fact a preventive strategy was reframed by the media and various healthcare organisations as deliberately infecting others with HIV. If they had actually studied the matter even a little,

they would have known that it had nothing to do with that at all.

Our message was completely twisted in a current affairs programme: it was made entirely about gays, HIV and sex. Sensationalism prevailed and nuance was hard to find. A national newspaper published a series about life with HIV, but some of the more optimistic stories were never printed because they were deemed too positive. HIV was meant to scare people off, so sob stories were the name of the game.

From that moment on, I lost my faith in the media. They're inclined to go along with the bandwagon, rather than researching issues properly. The fact that the HV had agreed to institute a period of radio silence was extra frustrating. I wanted us to stand up, develop, continue! In retrospect, however, I think that the association dealt with it well. In the end, all the regional departments went along with our message."

DRY BONES BREATHE

Advocating to improve the position of people with HIV is a long, slow process. Whether you're fighting to improve our social position or secure our rights, or trying to protect people with HIV from stigmatisation and discrimination, you need to keep pushing hard, often in the face of intractable resistance. The push-back has been particularly forceful when it comes to sex.

RELIEF

Thanks to the arrival of effective combination therapy in the mid 1990s, many people with HIV got their lives back. Many also rediscovered their appetite for sex. While the professional HIV field clung stubbornly to the mantra "always use condoms", gay men developed a new way of preventing HIV transmission: serosorting. This meant seeking out sexual and relationship partners with the same HIV status to avoid new infections. Following the example set in Australia, prevention workers introduced this strategy here in the Netherlands as "negotiated safety". Under certain conditions, the strategy permitted HIV-negative people within relationships to stop using condoms. But when HIV-positive people began to adopt serosorting as well, all hell broke loose in the Netherlands.

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¹² Published in 1998.

While gay men were finding new ways to live and love in the post-AIDS era, the professional HIV field and the media were still stuck in the mindset of the days when sex and death were inextricably linked. In his book Dry Bones Breathe, Gay Men Creating Post-Aids Identities and Cultures¹² the American gay rights and HIV activist Eric Rofes wrote: "Rather than encouraging gay men to understand changes occurring in our everyday lives in their full complexity, journalists, public health officials, drug company executives, and leaders of AIDS organizations have united to gently coerce the nation's gay male population into misrecognizing what was in front of our faces. Instead of taking advantage of a very real breathing space that is opening up in gay male communities and offering a moment's respite from the constant battles of the past fifteen years, we are being ordered to remain crouched in our bomb shelters, heads tucked between the legs, firmly locked in a state of emergency until the real cure arrives."

"RECKLESS DRIVERS"

On 30 May 1997 a public debate was held in Amsterdam. Its Dutch title *Seropositieve spookrijders* can be roughly translated as: HIV-positive reckless drivers. The debate's main focus was "the responsibility of people with HIV to stick to safe sex". There had been an increase in STIs diagnoses, "barebacking" had emerged as a new buzzword for "consciously fucking without condoms" and serosorting was at that time generally interpreted as meaning "gay HIV-positive men having unsafe sex". Initially only HIV-negative speakers were invited to share their pearls of wisdom on this subject. At the last minute, the HV chairperson was permitted to join them.

One of the speakers at the debate thought that HIV-positive people should adopt an altruistic approach. "It takes two to tango, but only one can be in charge". Another said that ideas like this would lead to a form of apartheid being practised against people with HIV. "In the Netherlands the state always assumes that citizens

Poz&Proud finds itself at the centre of an outbreak of sexual hysteria in the Netherlands.

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have the right of self-determination. Self-protection is part of self-determination and it has a much bigger impact on behaviour than altruism."

The HV chairperson said that referring to HIV-positive people as "reckless drivers" was offensive. "What about HIV-negative people who don't stick to safe sex? And what about people who aren't aware that they're positive?" He said that the framing of the debate topic mainly reflected the fears and preoccupations of some prevention workers. "It looks like this is now regarded as an acceptable way to talk about people with HIV. And if experts from the AIDS field talk like this, what can we expect from the general public, the gay press and the national media?"13 In the years that followed, the fact that HIV-positive people were regarded as carrying a greater burden of responsibility led to the apportionment of blame. This cleared the way for prosecutions of HIV-positive people, accused of having sex without disclosing their HIV status to partners in advance. A number of gay and straight people with HIV found themselves dragged before the courts by embittered partners. At the start of 2007 a ruling by the Dutch Supreme Court, coupled with intense lobbying by HV and others in the HIV field, put an end to the prosecutions.

13 Hivnieuws,

issue 47

PROUD GAY MEN

In 2006 we celebrated ten years of combination therapy in the Netherlands, and although the virus had now become a chronic but manageable condition, people with HIV increasingly felt burdened by society's outdated perceptions. The average person in the street still thought that HIV amounted to a death sentence and that people with the virus only had themselves to blame. These attitudes prevented people with HIV from being open about their status.

HV still had the image of being a bastion of white gay men and was determined to do something about it. The association wanted to open up to everyone with HIV and stepped up its efforts to

reach and facilitate other groups. That posed a risk to its advocacy activities for gay men with HIV, however, precisely at a time when this group was persistently being demonised and stigmatised by health workers, the media and in the gay scene. So I decided to place an item in *Hivnieuws*, arguing for HV to establish its first division for gay men with HIV.

In April that year, twelve of us met at HV's office, and Poz&Proud was born. Our first act was to draw up a manifesto, which aimed to usher in a new era in advocacy efforts for gay men with HIV. "More and more gay men have long stopped regarding themselves as weak or as victims. The ongoing improvements in HIV treatment make it possible for us to look to the future and to live our lives as proud gay men. A growing group of gay men with HIV object to the moralistic tone that has been adopted on homosexuality and HIV-prevention." Poz&Proud could see that the poor information that was available on HIV resulted in the stigmatisation of positive men in the gay scene. "People's general perceptions of HIV have long ceased to match reality. This mismatch has become a burden to us, so we want to help eliminate the stigma associated with HIV. The first step is to increase the visibility of HIV," wrote the late Ton Stevens, one of the driving forces behind Poz&Proud.14

¹⁴ Press release, November 2006.

RESISTANCE

The new division was a breath of fresh air in the HIV landscape. On the basis that "if we don't do it, nobody else is going to do it for us", Poz&Proud took the initiative to organise a variety of different events. These included popular information evenings for HIV-positive gay men on health-related subjects that were of common concern in the gay scene: serosorting, Hepatitis C, ageing and HIV, and anal health. During Pride the division ran a Test&Tell campaign to encourage men to get tested for HIV and disclose their status to their sexual partners. By organising these events Poz&Proud was taking matters into its own hands, providing gay men with sexual health information free of any kind of moralising - some-



TAINA KONG 35

Volunteer Hiv Vereniging (HV)

"When I heard that I had HIV in 2004, I wasn't ashamed or scared and I didn't cry. Right away, I saw it as my destiny, something I just had to deal with. I draw strength from my faith in God, much like others draw their strength from Buddha. Everyone is given the cross that they can bear.

I didn't tell anyone around me about my diagnosis at first, but after three months I told my boyfriend at the time. He was so afraid that I'd infect him that he only wanted to have sex with gloves on. I came to realise that I deserved better and broke up with him.

I told my family one by one. My brother had a lot of questions, but my mother responded very calmly and didn't make an issue of it at all. I told my father last, a very conservative man. Because he never lets me finish speaking, I sent him a long message, so that he wouldn't be able to interrupt me. Fortunately, he responded well.

I've been out of the closet with my HIV for two years now. I felt that I was constantly trying to hide something and simply couldn't live with my secret anymore. I wanted to be myself, openly telling people why I take medication and which cause I volunteer for. I've never regretted it and feel incredibly free. I'm a peer counsellor at HV, where I support women who've just heard that they have HIV, or women who haven't accepted it yet. I tell them my story in the hope that this will be a source of motivation for them. I'm now working with a woman who I'll see for the second time soon. She's had HIV for 15 years, but she doesn't know much more about the virus than someone who's only been diagnosed recently. She never did anything with her diagnosis and didn't tell a soul. After our first meeting, she told me that I'd given her the strength she needed to tell her son. It's a very gratifying job."

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thing that the established HIV organisations were largely failing to do at that time.

Poz&Proud quickly attracted a large number of gay men with HIV, both members and non-members of HV. The group also met with a lot of resistance, however. In the early years that resistance came mainly from within HV itself. A faction within HV found the new division too loud and brash and thought that it glamorised living with HIV. Following a clash with the then chairperson of HV about a moralistic speech he gave on World AIDS Day, an attempt was made to eject Poz&Proud from HV. Ultimately, at an April 2007 meeting of HV's members, Poz&Proud survived the attempt by just one vote. 15

¹⁵ On the same evening Poz&Proud celebrated its first anniversary.

SEXUAL HYSTERIA

Later that summer, the Netherlands was shocked by reports that in Groningen, three gay men with HIV had held sex parties at which they had drugged guests and injected them with HIV-infected blood. The case quite rightly caused a great deal of outrage, but also an outbreak of sexual hysteria.

The national media set its sights on Poz&Proud, and the division became the main players in a Kafkaesque drama. The smear campaign to which it had been subjected within HV was now played out in the national newspapers and on TV. Poz&Proud was accused of promoting unsafe sex and organising "subsidised sex parties"; serosorting was explained as meaning "deliberately infecting others with HIV".

The then managing director of HV countered the claims as best as he could and said that rather than encouraging unsafe sex, Poz&Proud was actually promoting sexual health. But to no avail. The justice minister threatened the Poz&Proud team with prosecution and the health minister threatened to cut off HV's grant unless it removed all references to sex without condoms from its website within 24 hours. Since that would have been utterly impossible, HV decided to take its website offline.

This dark chapter in HV's history was traumatic for everyone involved, in particular for the Poz&Proud team. Poz&Proud had agreed with HV not to talk to the media, so was unable to respond to all the untrue stories and unfounded accusations that were flying around.

Following an internal investigation Poz&Proud was cleared of all blame. After initially being denounced by the professional HIV field, the division subsequently came to be respected as a partner they could engage in dialogue with. Poz&Proud had been at the forefront of efforts to fight for the rights of people with HIV in the Netherlands.

Now it was time to get everyone else on board.

MOVING FORWARD TOGETHER

In 2018, the Dutch HIV community is more diverse and more visible than ever before. Although coping with an HIV diagnosis can be difficult for many, an increasing number of people with HIV are succeeding in living good lives, free from shame and guilt. Living with HIV isn't much of a problem from a medical point of view; it's the prejudice of others that forms the greatest obstacle. Despite the increasing visibility of people with HIV in Dutch society, we still haven't reached a stage where we can finally leave the old image of HIV behind us forever.

In the years before the advent of combination therapy, HV frequently spoke out against the media's eagerness to portray the stories of people with HIV as being full of suffering. Not much changed after the introduction of effective HIV inhibitors, but people with HIV did start to suffer from this negative portrayal to an increasing extent. HIV rapidly changed from a potentially fatal disease to a chronic condition, but in the eyes of society, a HIV diagnosis meant you had one foot in the grave.

In the late nineties, the association took a rigorous decision. In Je lust of je leven (Lust or Life, 2005) former chairman Martijn Verbrugge said the following: "The HV took up a firm position: we will no longer provide talk shows with 'victims' who share

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16 Je lust of je leven (Hiv-preventie voor homoseksuelen mannen 1982 -1995) by Tim Dekkers Lust or Life (HIV prevention for gay men 1982 -1995).

2015

their pitiful personal stories. It is no longer about us dying of AIDS. It is about us learning to live with HIV."16

THE SWISS WAY

After the Groningen sex scandal of 2007, it seemed as if everyone with HIV retreated back into the closet, with the emancipation of the HIV community coming to a standstill. In the following year, however, a group of Swiss HIV experts published major news, which proved to herald a major breakthrough in how people with HIV see themselves and how others look at us. When the Swiss statement was published, it was as if a bomb exploded in the international world of HIV, as the Swiss were the first to publicly state that HIV cannot be transmitted with an undetectable viral load. This was not appreciated by scientists and healthcare professionals at the time, because it would give HIV-positive people free rein to have unprotected sex. Hivnieuws had been writing about the impact of HIV treatment on the chance of HIV transmission for a number of years, and the association immediately proclaimed its support for the Swiss position. The rest of the Dutch HIV field was not convinced of the truth of the Swiss statement guite as easily. As they put it, there simply was not sufficient scientific proof to back such claims. The sex panic that erupted after the Groningen sex scandal was still fresh in their memory. It seemed as if professionals were scared of hurting their own reputation by addressing the implications of the Swiss statement: the fact that successful HIV treatment means that people with HIV no longer pose a risk of infection. This was at odds with what had often been announced in the media during the smear campaign against Poz&Proud. In the years that followed, a number of other countries would share their own positions with regard to the infectiousness of an undetectable viral load. The HV urged other organisations to publish a Dutch response to the statement, primarily because this would mean that HIV-treating physicians could give people with



MARK VERMEULEN 39

Manager of General Affairs for Aidsfonds

"My HIV diagnosis in 2007 was fairly unexpected. The very same day I told a few of my closest friends, who responded well. I was very relieved, because I had been rather afraid of negative reactions. The Hiv Vereniging (HV) meant cisely because it's not always an easy a lot for me when I had just found out that I had HIV, with their website being a great source of information. Actually going to the HV for discussion groups or other activities, however, was a bridge too far for me at first: if people saw me there, they'd know that I have HIV straight away. I didn't know anyone else with HIV, but I wanted to talk to someone else who wasn't a doctor or a nurse. I found someone through a friend and enjoyed our talks very much.

In 2009, I started working for STOP AIDS NOW! as a lobbyist and I now work at Aidsfonds. We're involved in fundraising, among other things, to raise money for the fight against AIDS, and the HV represents the interests of people with

HIV. Sometimes, we have conflicting interests, which can lead to friction. at times. We'd do well to remember, however, that the Dutch fight against AIDS has become so successful preprocess. In that respect, Aidsfonds and the HV have come very far. You could take the 2016 campaign run by Aidsfonds as an example. Organisations like the HV highlighted that people with HIV felt stigmatised by this campaign, which is why we decided to discontinue it. As a foundation, we're always looking for new ways to get the message through to the general public that the fight against AIDS hasn't been won yet, not even here. It's becoming increasingly difficult, though, which is why we try to test the limits. Unfortunately, that campaign didn't work out too well, but we did learn a lot from it."

2017

HV begins its own n=n campaign (the Dutch equivalent of undetectable=untransmittable).

The tenth national information day on HIV is held at Carré theatre. It brings together 700 people with HIV, their families and allies, and healthcare professionals.

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HIV unambiguous advice in line with the Swiss statement. Ultimately, however, the Dutch Association of HIV-treating Physicians (NVHB) showed itself unwilling to sign the document in 2011, after a joint declaration had finally been drawn up. According to the NVHB, further scientific evidence was needed in the form of a large-scale study that would prove that the likelihood of transmitting HIV during anal sex was virtually zero with an undetectable viral load. When this evidence finally emerged, two years later, the HIV-treating physicians signed the declaration.

INCREASING CONFIDENCE

The HIV community was liberated from that which had worried them most for so long: the risk of infecting other people. For years, we had been conditioned to be scared of what would happen if a condom tore or if we had a little wound. That fear had a paralysing effect on many. With the Swiss statement, which would later evolve into U=U, we finally rid ourselves of that fear, providing an opportunity to increase the visibility of people with HIV.

All sorts of initiatives were proposed, stimulating increasing confidence among people with HIV. Fred Verdult, for example, who once started off as a volunteer at HV, has been organising the national information days for people with HIV and their loved ones for more than a decade. Each year, approximately 700 people come to this event, and they find inspiration in the stories told on stage.

Together with a group of friends, I came up with the plan to subject the image of HIV in Dutch society to a much-needed makeover by publishing a glossy magazine about a positive life with HIV. Since the first edition was published in 2012, many people have been able to share their life story in *hello gorgeous*. After two years, we thought that the pool of people who were willing to appear in our magazine, face and all, had dried up. Thanks to the beautiful design, gorgeous photos, and dignified stories, however, an increasing number of people showed themselves to be keen to feature in our magazine.

Together with the HV hello gorgeous published the first public campaign about living with HIV in 2015. This campaign was centered around five people with HIV, who debunked the five greatest myths surrounding HIV in a positive way. In addition to informing the general public about what life with HIV looks like today, this was the first time that people with HIV could see a diverse group of role models appear in public, on posters.

HV also developed a successful series of workshops for people who had just been told that they had HIV, or who were about to start doing more in relation to their HIV. The workshops were given by people who had been living with HIV for some time and addressed all sorts of issues, including mental health and sexuality. In the space of a few years, the *Positive Life* series of workshops has managed to inspire dozens of people, some of whom even became workshop leaders themselves.

STAYING SHARP

The emancipation of the HIV community is in full swing. Although we are not where we need to be yet, we are capable of offering sufficient resistance when we have to. That turned out to be the case in late 2016, when Aidsfonds launched a new campaign, with the intention of informing Dutch people that AIDS was not over yet.

A major role in the campaign, which could be seen throughout the country in TV and radio commercials, as well as large bill-boards, had been reserved for the virus itself, which told the Dutch public that it was the "greatest ladykiller" and that it "murdered three hundred children every day".

Many people inside and outside the HIV community were furious with Aidsfonds, criticising the personification of the virus (which made it seem that people with HIV were ladykillers) and a complete lack of context.

The HV had been given the opportunity to see the concept and comment on it in advance. The HV and Aidsfonds got into an

argument about how much of the eventual campaign had actually been shared with the HV and about whether Aidsfonds had made any changes to the parts that it had shared based on the comments they received.

Ultimately, the HV requested that Aidsfonds withdraw the campaign, at the urging of several activists. Aidsfonds complied, constituting the very first time in the history of our country that an HIV campaign was discontinued after criticism from the HIV community.

The disaster surrounding the Aidsfonds campaign did not just demonstrate the resilience of the HIV community, but also showed that the HV should always be vigilant that something like this never happens again. It is very important to keep a critical attitude at all times and to make sure to frequently listen to members, as well as to people and groups outside the association.

Together, we're all working towards the end of AIDS in 2030. As long as living with HIV isn't normalised, however, AIDS will never disappear. To get there, we need people with HIV who can be and are brave enough to be visible. People who show that there's life, and a good one at that, after a diagnosis. Protecting the interests of people with HIV has an essential role to play in this matter. Without a strong Hiv Vereniging that represents our interests and receives sufficient (financial) support from our partners in the HIV field, HIV will never be normalised.

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