Life+ MAGAZINE

2024

Welt-Aids-Konferenz

München

Deutsche Aidshilfe



English

#aids2024 #globalvillage #networkingzone




ME
YOU




AKTIONSBÜNDNIS
GEGEN AIDS
Gesundheit
ist ein
Menschenrecht!


ICW









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TOGETHER FOR DIVERSITY, JUSTICE AND HEALTH!
FROM GERMANY WITH


VISA DENIED


AIDS 2024
iasociety.org
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Global Village



Editorial



Full to the brim: the AIDS2024 community programme

One of the PLHIV community's main demands is 'Nothing about us without us!', and for us, this means that, when the World AIDS Conference comes to town, local communities do, too!

It quickly became clear to us that there are many communities that belong here – and that they belong here together. Collaborating with many networks, groups, and organisations, Deutsche Aidshilfe mobilised our communities for AIDS2024.

Around 150 activists then jointly designed the ‚Networking Zone' at the conference's Global Village, the area set aside for civil society and self-help initiatives, and filled it with life. All of it under the motto ‚Together for Diversity, Justice and Health'.

The aim was to introduce ourselves and to network, to learn from and strengthen each other, and to develop our power together: for a confident and self-determined life, against stigma and discrimination.

A full week of programming included breaking scientific news from the conference as well as political discussions, for example on the criminalisation of breastfeeding while living with HIV. There were crafting activities making conference bags and vulvas, theatrical performances were staged against trauma, and an African storytelling café invited people to share their experiences. And, last but not least, the ‚Helper Cells Against the Far Right' got into formation.

In short, life teemed and buzzed in all its diversity for the entire week. The Networking Zone certainly pulled a crowd at the Global Village, and was often more than full. It enriched the entire conference and created space for perspectives that this event can't do without!

Many returned home with new insights, new contacts, and renewed strength.

It was impressive to see the energy that is unleashed when a diverse range of activists comes together. This issue of Life+ captures some of the beautiful moments and allows everyone to follow the proceedings – including those who couldn't be there in person.

We sincerely thank all those involved and all our guests in the Networking Zone, and we look forward to seeing you again at the Positive Begegnungen (Positive Encounters) conference in 2026!

In solidarity,

The Board of Deutsche Aidshilfe

“My life is no longer about survival. It is about living.”

Scheduled to precede the Munich AIDS Conference was a gathering coordinated by the Global Network of People Living with HIV (GNP+) and hosted by ten international PLHIV organisations. One of the speakers at LIVING 2024 was Katja Schraml. An HIV activist since her diagnosis in 2001, she has been working for Deutsche Aidshilfe in the Office for Medical Issues, Counselling, and Quality Development since 2010. This is a transcript of her speech.

Good morning!

Dear all,

On behalf of the German Community, I have the very great honour to welcome you here, to the ‘LIVING’ Pre-Conference.

I am looking forward to this very much. It’s always like coming home, being in a room full of people living with HIV and our community. Thank you for coming!

This is my second home. As soon as I arrive from Berlin and hear the Bavarian dialect, it feels familiar.

I grew up in a village not far from here. Less than 300 people live there. Only two of them know of my HIV status. (Or at least: I know they know because I told them). 23 years ago. Half of my life! My mum and my (older) sister. Most of them don’t know what I do for a living. Some of them think I work in an office. Which is true. But is it the truth?

I work for Deutsche Aidshilfe, the umbrella organisation for community-based HIV/STI services in Germany, and host organisation for AIDS Action Europe. As an NGO, we provide health information and advocate for the interests of people living with and most affected by HIV. I am one of this diverse and queer and multicoloured crowd that unites under one goal: to improve quality of life for people who face barriers in all kinds of situations, who have to deal with structural discrimination, who are often afraid of persecution. Just because of their status, their background, or their life choices.

Sometimes, when I visit my family, I think about talking more about myself and our work. We’ve achieved so much in some areas that it should be easy to disclose my status, to show myself and say: Hey! Look what we’ve accomplished! My medication’s working. Above all: It’s available. Accessible. Affordable. And acceptable. I’ve been taking some of these pills for more than 20 years! I should appreciate it, and be grateful. My life is no longer about survival. It is about living.

Perhaps I don’t have to talk about it any longer. For example, I no longer live in this village. I don’t have to face them. I can hide. I can live in my safe Berlin Aidshilfe-bubble, pretty privileged.

Am I allowed to be tired of talking and disclosure? This is a chronic disease. Faced with the same issues year after year. Disclose. Explain. Educate. And probably defend and work on anti-discrimination. Do I have to talk again and again about the same stuff? Surely, I shouldn’t have to! We’ve been so successful in regulating this virus in our bodies. U = U. But still: this undetectable virus seems to rule our lives. Our thoughts. And our decisions.

This is a chronic disease. Faced with the same issues year after year. Disclose. Explain. Educate. And probably defend and work on anti-discrimination.

“Should I go to this doctor or not? Do I tell the staff about ‘it’? Is this discrimination – or just routine?” What if? What if they say something



Katja Schraml

or do something like putting this unbearable stigma-sticker on my file: that red dot that says 'infectious'?! Again?! Last year's European stigma report showed no progress compared to 20 years ago. Really?!

There are so many things we still need to work on. My worries about which doctor I go to feel like a privilege compared to those who don't have access to healthcare because they don't have insurance. In this country, people still have to worry about what happens when they are confronted with medical staff that doesn't accept their lifestyle or doesn't welcome people from different backgrounds. This is affecting health, especially when people depend on medical staff for treatment or tests like Hepatitis B, which still can't be carried out by our community-based testing centre staff.

So – as you know: There is no time to be tired. I went through so many different phases in my life: Hiding. Disclosure. Going public. Sometimes I feel like hiding again. Also, privilege. In many situations, I can decide if I want to talk about HIV or not. Sometimes, I just sit down and rest. We also have to use our resources wisely and recharge our batteries. Until it's time to stand up for ourselves again.

There is so much more that has to change. How can we reach those '95' targets if we are too afraid to turn up at a clinic and claim our so-called human right? We have to talk. About discrimination and criminalisation. About punitive legislation, and therefore about political will. There are too many countries – especially in Eastern Europe and Central Asia – where the epidemic is growing. We have to talk about access to treatment. And treatment options! Living with HIV is not the problem. Dying from AIDS is.

If there will ever be a cure, we'll have even more to talk about. Because no medical cure will heal the barriers this infection comes with. This inequality that we face because of our intersectional backgrounds.

What if. 'What ifs' shouldn't rule our world. They shouldn't define who we are. Who I am willing to be and what I am willing to show.

So, let's talk. Let's share. Let's have fun! Come together, inspire and let yourself be inspired by all this positive power here in these days ahead. Let's gather all our resilience and strength to continue building an accepting and welcoming environment. So that those who come next do not have the same issues and traumas, the same shame and stigma to overcome, but can live their lives with all its responsibilities as if they were just challenges, challenges like many others.

After this conference, I'll visit my family – in fact, I have a school reunion coming up, no joke! I still don't know whether I'll go – or if (!) or what I'll tell my classmates. Sometimes I get tired of my own story. But looking at it now, two decades later, and being part of this big international conference in my home town for a whole week, my story is pretty simple: I once had contact with a virus. And it turned out to be a permanent one. That's it. So what? Move on! Go on living!

Thank you! Have a good time and a lot of energising experiences! See you later!

(Special thanks to my work colleagues at Deutsche Aidshilfe: I wouldn't be here without you. Thank you!)

Addendum: Yes, I did go to the 30-year school reunion of class 10a (1993/1994) of the Girls' Middle School in Neumarkt in der Oberpfalz. And I decided (that evening) to 'only' talk about my Aidshilfe work. But some of them have already found my private blog, including my 'living-posithiv' page. We'll see whether we can build on this next time around …





Fotos: Berliner Aids-Hilfe

Picture this!

At the World AIDS Conference, the Berliner Aids-Hilfe (Berlin HIV/AIDS support organisation) youth work team has been testing newly developed methods of engaging migrant adolescents in conversations about empowerment to maintain physical boundaries.

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What lies at the core of these newly designed workshop elements?

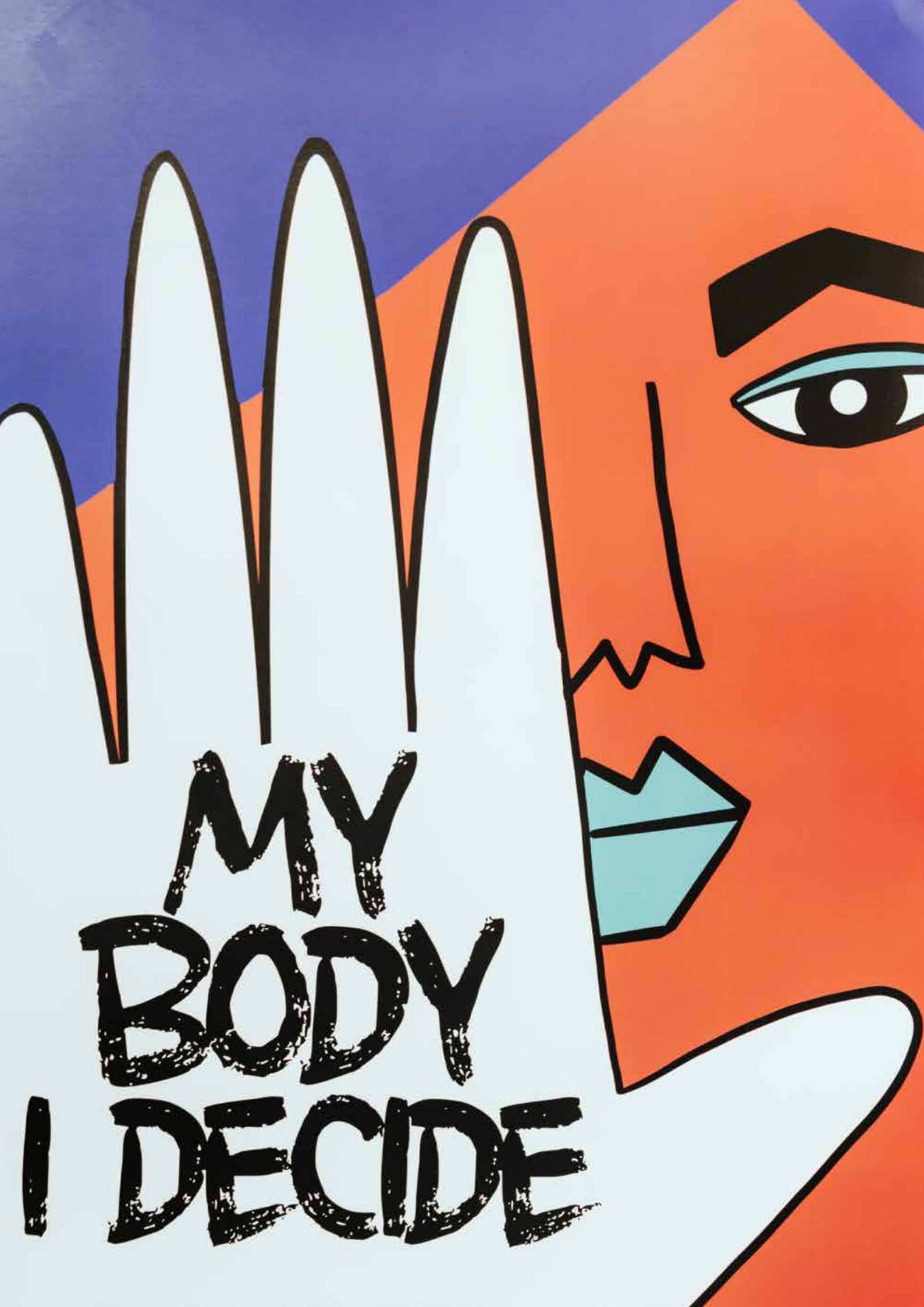
Cora Döhn: "Our current focus in workshops with newly arrived migrant and refugee young people is raising the issue of consent. We call this programme ‚Safer Welcome'. We work within the mainstream structures of 'Welcome Courses' and supported accommodation facilities in Berlin with young people who, in most cases, have not had any school-based exposure to sex education and the topic of physical integrity.

We usually lack a common language in these workshops because the participants have very different first languages, and their German language skills are often only equivalent to levels A2 to B1. This is why we strive to create workshop exercises that use a lot of pictograms to convey the core messages."

What kind of feedback have you received?

"Our participants were pleased that we are prioritising the idea of participation in the development of new teaching materials in this way.

We are very grateful for the numerous diffe-


MY
BODY
I DECIDE

rent aspects and perspectives that our participants have shared with us. Various perceptions exist regarding one's own body, especially when it comes to maintaining boundaries with other people. That was exactly what we wanted to explore using our method."

What's special about your new content? What strategies and goals are you pursuing with your new methods?

"The workshop exercises we presented are about consent. They allow young people to decide – from their own personal perspective – who is allowed to act towards them in certain ways. We place cards on the floor with images of a sports coach, a teacher, a group of friends, and a stranger. The young people each have four cards in their hands with images of the following situations:

1. Taking a photo of me without asking
2. Touching me
3. Hugging me
4. Telling me that I am beautiful

„It's about the young people learning that boundaries are something very individual, and that limits can be set in different ways."

Cora Döhn

The young people are then asked to decide which persons are allowed to carry out each of the four different actions. In some cases, no one may be permitted to act towards them in this way.

For this method, we are particularly concerned with encouraging young people to notice their own boundaries, and also to realise that boundaries are something very individual, and that limits can be set in different ways. We want to engage young people in an exchange about how everyone has different needs, and perceives relationships differently. It's not about right or wrong, but about appreciating the needs of each individual."

Why was it important to you to test your concept here at the Global Village first?

"Anyone who designs interactive methods relies on reflecting on them in a professional setting, and on adapting them over and over again. It worked very well to try out the newly developed consent exercises with our participants at the conference, especially because the conference delegates came from different parts of the world.

It is important to us to follow the principle of ‚nothing about us without us' in all aspects of our work. Participation therefore plays a major role. It was a great opportunity for us to invite everyone who had the interest and the time to share ideas.

The World AIDS Conference not only provided the backdrop for this, but also brought together many people with very different perspectives in the one place. This was a tremendous opportunity, and we are glad that we were able to take advantage of it.

Back in Berlin, we immediately made the necessary adaptations to our practice – because we did have to make adjustments at certain points. For example, people did not correctly interpret all the images we had selected. The feedback was very helpful for us, and the adapted workshop exercise will now be used in the new school year."

What did you like most about the Global Village, or what most impressed you?

"The Global Village has managed to bring activism, research, and sharing experiences about living with HIV together in the one place. We think it was very important that access to the Global Village was free for everyone, which meant that a broad audience could take advantage of all that was on offer. Programmes and activities were as diverse as the people we met.

People with many different types of lived experience shared the one space. They didn't just exist alongside each other – as is so often the case - but were connected. A small utopia – if you look at it through rose-coloured glasses – or a purposeful collective, existing right here, in our own setting. The networks and ideas for collaboration that are required for more collective action can be established in spaces like the Global Village. This is what makes it a very special place."

Interviewer: Heike Gronski

HOSTING THE WORLD

For two weeks, Munich hosted more than 10,000 international HIV experts and community representatives. What a great opportunity for the city. But was it used? A conversation with Gabi Trost and Oliver Stein from Netzwerk Münchner Positive (Munich Positive People's Network).



Gabi Trost and Oliver Stein

You've been permanently on duty for the entire duration of AIDS2024, and you've also been planning the Munich Positives People's activities in the lead-up to the conference. How do you reflect on these eventful weeks now?

Gabi: „The conference was a huge thing. I, for example, didn't catch any of the scientific part because I was at the Global Village the entire time. Unfortunately, as a volunteer, you were occupied by so many things during the day that you couldn't make use of all these opportunities for interaction, at least that's what it was like for me."

Oliver: „For me, it was similar. You are sort of hit over the head by the amount of programming going on in each of the halls. It's hardly possible to gain any sort of overview.

But I had thought that these different worlds – the Global Village and the scientific conference – would blend together a little more. During the opening ceremony, the Global Village had been touted as the heart and soul of the conference. But I didn't get much of a sense of this. For me, they revealed themselves as empty words from the conference leadership.

As Munich Positive People's Network, we had applied for a stall at the Global Village, and in hindsight I'm very glad that our request was rejected for lack of available space. This meant that we were able to focus on our social media campaign regarding the Munich AIDS Memorial, and to contribute to the German Networking Zone – for example on the topic of women and HIV – and to our joint after-hours events with AktHIV.de. These events in particular turned out to be







Buddys from Buddy.hiv

extraordinarily successful. We thought that about 15 people might sit together at the farewell evening, but more than 100 people actually turned up."

Was it mostly German delegates that came to these after-hours events?

Oliver: „No, not at all. For example, many people from Ukraine – whom our network has been collaborating with for a while – joined us, but a group of Australians also had a whale of a time with us. Many of these encounters just evolved at the conference, and it was this personal and informal exchange in particular that made the conference so special and enriching in the end."



In your observation, did the Munich community access what the Global Village had to offer? Considering that – in contrast to the scientific programme in the hall next door – you could get in without being a registered delegate.

Gabi: „I did actually spot the odd Munich face among the crowd, but nowhere near as many as you might have wished for."

Oliver: „Quite a few things went wrong as far as communications are concerned, in my view. Many probably thought that everything will be happening in English at the Global Village, and this kind of language barrier will certainly have scared some people off."

Gabi: „Also, all the events took place during the day, i.e. at times when most people are working. This would have made it simply impossible for many to travel out to the exhibition centre. But still, surprising networking opportunities did present themselves. For example, two women approached me who are running an as yet fairly modestly sized women's group in Munich, and as a network we would of course love to support them in their endeavours."

Oliver: „I would have liked to see a little more involvement from the Munich gay/queer communities. After all, how often does it happen that your own city is hosting the World AIDS Conference? Unfortunately, most of the city's institutions missed the chance of contributing actively, or at least making people aware of the event. In hindsight, I did find this very disappointing."

Gabi: „It was all a bit weird, anyway. You are having this huge conference in town and no one really makes it their business. At the beginning, they were planning this great public celebration to



welcome the delegates to Munich for the opening of the conference. That was then cancelled for financial reasons, and without anything to replace it. Munich certainly didn't put its best foot forward on this occasion. A lost opportunity."

What were your personal AIDS2024 highlights?

Gabi: „What meant a lot to me was, for example, a conversation I had with a Nepalese woman, whom I had met by chance at the Global Village. Another highlight was that, after all those years as an activist, I spoke at a protest rally for the first time."

And in English, too!

Gabi: „Correct. As if I hadn't been nervous enough already! But I had to go through with it – I had been one of the instigators, after all. As early as April I had enquired whether – as had been the case at other World AIDS Conferences – a big protest rally was being planned for Munich as well. Apparently, such a demonstration had been envisaged, but then been forgotten about, or they had decided against it. We only found out about this a few days before the start of the conference. So, I joined the effort and did what I could to get a protest happening after all. Even if we weren't as many people as we should have been – the fact alone that we managed to get it happening at all in such a short time, and collaboratively at that, is a great success. It also showed that, here in Munich, we can – despite some frictions – join forces when necessary."

Oliver: „My personal highlight was our evening event at the city's – possible the world's – largest beer garden. To make sure that our guests would be able to find us there, we had decorated our tables with orange tablecloths, including the logo of the Munich Positive People's Network. As a local group, we really just provided a platform, and it was utilised surprisingly well. It just made me very happy that so many different people were able to get together there, away from the conference halls, and have fun together and talk about things that there wasn't anywhere near enough time for at the conference."

Interview by Axel Schock








FEMINISM
for
HUMANISM


PLAY
GAMES
WIN COOL
SWAG


M·PACT
JUST DO IT.





Under One Roof

A wide variety of organisations and community representatives from all parts of the globe introduce themselves at the World AIDS Conference's Global Village. The energy brought by the international PLHIV community keeps ringing in your ears, and sometimes even bursts forth in a dance.

In Munich's exhibition centre halls, two worlds are colliding at the World AIDS Conference. One of them has experts armed with PowerPoint slides and Excel spreadsheets offering up their research results: quietly, matter-of-factly, verifiably. Right next door, the other world, however, assails all your senses – especially your ears. Welcome to the Global Village! Whoever walks through that rainbow gate is plunged into a sea of sound: hundreds of voices in dozens of languages, all melding into one another. Music booms from the loudspeakers, a soprano voice rings out from the main stage, at the sex work stall the audience is warming itself up by dancing and clapping to Zulu songs, and suddenly the chants of a protest rally bellow across an already voluminous soundscape.



A spontaneous protest march snakes its way through the village

First-timers may need some time to steady themselves, but experienced delegates aren't so easily thrown off course by the soundtrack. When the protest march against the Gilead pharmaceutical company's pricing policy the passes by the Indigenous Peoples' stand, chanting „Drop the case!", Margaret Kisikaw Piyesis calmly pauses the conversation with her medical colleague Sean Rourke. Both wait patiently until the demonstration has moved on. „It's great to see activism in action." says Margaret with a smile, and the two continue to discuss how ancestral first nations' knowledge may improve the state of Canadian health care.

While this conversation continues, Claudette L. Cardinal is trying her hand at the traditional arts of her ancestors at the table opposite. The 56-year-old from Vancouver is covering colourful cardboard feathers with symbols made from paper. Among other images, Claudette selects a bear – an animal with which her clan has identified for centuries. Her handiwork doesn't stop Claudette switching from prehistoric times to the latest scientific research at lightning speed: „Are you getting the injectables yet in Germany?", she wants to know from the reporter. „This is a big topic in our counselling practice in British Columbia. Indigenous people in particular are struggling with many life challenges. This makes it all the more important that HIV treatment is as simple as possible."

„Our energy is boundless because it has to be."

Not only Claudette is busy with her hands. Across the Global Village, people are happy to do something practical after the intensive discussions – and happy no longer having to keep their feet still. At the stand of a Ukrainian HIV organisation called ‚100% Life', visitors can write down their wishes and worries on strips of fabric, and weave them into an increasingly tight, military-style camouflage net that envelops one corner of the stall. „Despite the war, we continue to work on prevention", emphasises Nadja from 100% Life. „Our energy is boundless because it has to be."



HIV prevention using football

‚Tackle Africa' is all about moving your legs. This British association has set up a small football goal made from sturdy metal tubes, with a steel ring acting as goalkeeper. Five children are currently taking turns, trying to kick a small version of the European Championship ball into the goal. On the side line stands a grey-haired gentleman wearing a red jersey and a friendly smile. „We turn football drills into HIV prevention messages", explains Tackle Africa's John Miller. Around 500 local coaches in eight African countries are working with young people aged 11 to 18. Here, the message is simple: the goal is the body, the ball is the virus. "This helps young people to quickly understand what matters", says John. "That's the magic of football."

Not everyone is as calmly reserved as John when trying to get people to participate. At the ‚U = U Dancing' event on the main stage, an activist walks along the first row of chairs, grabs those seated there by the hands, and literally pulls them onto the dance floor – like wallflowers at a high school formal. Some of those pushed onto the stage swing their hips rather stiffly at first. But the facilitator won't let up. Skilfully she dances around two purple polystyrene letters ‚U'. „Now it's time to celebrate," she yells into her mic and asks: „Isn't it the greatest time to be living with HIV?" And like in a scene from a holiday camp singalong, the „Yeaaaaah!" bounces back from the audience in unison. After a few minutes, there are so many dancers jostling each other on stage that some have to jump back off the edge.









Let's dance!

Actually, it seems that a globalised village full of committed activists necessarily results in an enormous build-up of energy. And this energy is bursting forth after the closing ceremony on the Thursday night: around 60 young people are hyped up and dancing with abandon – many still with their backpacks and drawstring bags on their shoulders, stuffed full of laptops and papers, plus the corporate gifts and free samples that tend to keep accumulating at conferences. The DJ, however, seems to need a little more practice. When he abruptly interrupts a song with Shakira's ‚Waka Waka', the crowd screams in protest. Now the circle of dancers bunches up into a scrum, and dozens of arms shoot up into the air. „Let's be loud!" the facilitator shouts into her microphone – and no one has to be told that twice at the Global Village!

Philip Eicker



The topics of stigmatisation and trauma were omnipresent at AIDS 2024: in sessions, in abstracts, and at workshops. This shows how central these experiences still are to the lives of people living with HIV.

Snapshots and impressions by Katja Schraml.

My stigma and I

The trauma that we carry within us certainly varies by degree for each of us – and correspondingly large or small is the amount of ‚salvation' or ‚healing' we individually require to recover from these experiences. Perhaps there cannot be one single moment of ‚cure'. Rather, the healing must – like the disease – also become ‚chronic', i.e. ongoing. Why is this so? Because we are more likely to remember negative experiences than positive ones, and because we constantly expect to encounter similar experiences of discrimination again.

The European Stigma Report 2023 recorded as HIV-related stigma



Katja Schraml at the DAH booth.

and discrimination any negative experience or unfair treatment of people living with HIV due to negative attitudes towards this group of people based solely on their HIV status. Across 54 countries in Europe and Central Asia, 3.272 persons living with HIV participated in the survey. One third of participants had not told a single family member about their HIV status – which is equivalent to every third person!

An example: during the ‚dHIVersity ImproTheatre' event at Deutsche Aidshilfe's Networking Zone at the Global Village, I started talking with a woman next to me. She told me that she had fled Ukraine with her family and was working in Poland at an HIV counselling centre, but that none of her family members – not her son, not her parents – knew about her infection. She was so relieved to be in Munich for the conference because she, for the first time, was actually able to be herself there, and to show herself openly as a person living with HIV. It was one of the many emotional moments where I met, spoke with, and hugged people simply because of the fact that we were able to be open with each other there.

Interlocking systems of oppression

We also know this deeply human fear of rejection – which can make us worry because of HIV – from other areas of life, and they can reinforce each other. Interlocking systems of oppression – including racism, classism, sexism, homophobia, and transphobia – are the drivers of HIV-related intersectional stigma and discrimination (HIVISD). Here, the focus is on the entanglement of various factors, which together result in a higher probability of experiencing stigma:

- Health-related (HIV, mental illness ...)
- Socio-demographic (ethnicity, gender, sexual orientation, migration status ...)
- Behaviour (drug use, sex work ...).

Where, then, do we start in order to reduce such experiences and the fear that is attached to them? According to the concept of structural prevention – or according to the ‘stigma and discrimination health framework' presented here – at all levels: individual, interpersonal, and socio-political, as well as at the level of organisations and community.

For example, the US National Institutes of Health (NIH) are working at the global level to reduce intersectional stigma with interventions focusing on the area where people living with HIV experience the most barriers: in the healthcare system. One quarter of Stigma Report respondents reported being afraid of being treated differently



Lillian Petry in conversation with DAH board member Sylvia Urban.



by health care personnel. And 16% reported not attending any healthcare facility at all, for fear of being treated differently. These fears are based on real experiences: close to one quarter reported ever having been denied healthcare, or having had healthcare interventions postponed, because of their HIV status, and 7% reported this for the previous year. Of the respondents, 33% generally felt they were being treated poorly in the healthcare system.

A strong, engaged community as a key factor

Whether it is about HIV testing and PrEP for MSM in Ghana or trans women in Brazil, the interventions NIH presented were most effective in addressing intersectional stigma when they were designed to target several levels and/or employed a range of strategies: training staff at all levels with the involvement of peers, organisations and policy makers, and using a range of methods such as education, structural change, individual skills training etc. The programme showed, however, how difficult it is to achieve long-term success when faced with short funding periods, especially when it comes to reducing stigma. Projects performed best where community had been involved from the development stage. This means that a strong, engaged community is a key factor in driving tangible – and therefore measurable – change.

Raising awareness for the topic of ‚trauma', especially among workers in health care and other counselling settings, seems particularly important in this context. Old experiences (e.g. of rejection and exclusion) can easily be triggered in current situations (e.g. in the event of being refused treatment at the dentist's). It does not matter in each individual case whether the person carries the memory of a unique event or many years of such experiences – people react with different levels of resilience.

What matters is whether these experiences negatively affect the person, and whether they have a detrimental effect on health as a result. It is therefore crucial that staff are sensitised to the fact that people who experience intersectional stigma may also be traumatised to varying degrees. Instead of responding with „What's wrong with you?" to a person whose reactions seem incomprehensible, the goal is to promote an approach in institutions that asks: „What happened to you? What can we do to help you feel safe and stay healthy?" And which follows up with a focus on healing: „What is strong within you?"

This last question was at the centre of a workshop by ‚Beyond Stigma', a programme aiming to counteract internalised stigma, i.e. that which we have already stored inside ourselves as ‚believable information'. Using a creative and individual mix of cognitive and emotion-based methods, negative thoughts and feelings that (may) arise in us when we are facing discrimination and rejection are addressed, questioned and – in the best-case scenario – resolved. The young people from Zimbabwe, who led this workshop with professional support, invited participants to try a range of approaches themselves, including breathing and cognitive questioning techniques that gently try to open an inner space that has been occupied by negative thoughts to positives again.

To one participant's question regarding what this was going to be good for when you're being rejected by a clinic because of your HIV status, the workshop leader responded empathetically. In every situation in which we feel treated unjustly or hurt, we are again faced with the question „What do I do now? Do I have the strength to oppose this in some way? Or do I let it go, can I maybe go somewhere else instead?" Or: „Could I also decide not to take it personally, not to let it get to me at all? Is that possible?"



This last response appears to be a high art when faced with stigma and discrimination. How is anything going to change if we don't fight back at the crucial moment? On the other hand, maybe it is exactly because we need help and

are not in the best state of mind for a confrontation that we end up so vulnerable in such situations.

One, however, does not exclude the other in the end. What is clear is that in a situation in which I am facing another person while I am hurt, triggered, and therefore speechless, there is little I am able to achieve for myself. What I can do, as was shown during the workshop, is to take good care of myself. To be aware of what or whom I need, and what it is that I can do. Working on internalised stigma also has a very practical side: acquiring skills, being able to regulate emotions and thoughts, knowing about resources, and practicing self-care in order to create a small, safe(r) space inside myself, which can be expanded step by step to make room that I can ultimately claim for myself – through music and dance, for example.

Not only this workshop, which concluded with singing a song

> „How is anything going to change if we don‘t fight back at the crucial moment?“

together, but the entire conference demonstrated how important it is, perhaps in spite of all our experiences, to again and again have the courage to open up our innermost being to others – and to use it as an opportunity for fresh encounters and therefore fresh experiences: „Wakakosha! You are worth it!“



Democracy needs many helper cells

HIV-positive self-help initiative ‚NRW POSITHIV' from North-Rhine Westphalia (NRW) is responding to the increasing spread and normalisation of right-wing populist and right-wing extremist movements in Germany with a publicity campaign.
Gottfried Dunkel, the Aidshilfe NRW staff member responsible for HIV-positive self-help initiatives, explains the intent behind the slogan ‚HELPER CELLS AGAINST THE FAR RIGHT – LIVING DEMOCRACY – ACTING POSITHIVELY'.

Every year, ACTING POSITHIVELY chooses a new motto. With ‚HELPER CELLS AGAINST THE FAR RIGHT – LIVING DEMOCRACY – ACTING POSITHIVELY', this time it seems to be very partisan, even if the AfD (Alternative for Germany, the far right political party) is not explicitly mentioned.

"It's political, but not party-political – because ultimately, we do not issue voting recommendations for particular parties, but we are warning against political trends. We want to ask people to consider that the electoral success of certain parties may possibly lead to their own rights being curtailed."

Was the choice of motto obvious, or were there several suggestions to select from?

"Right from the initial brainstorm, it became clear that we had to respond to current social developments that worry us all, and put a clearly political annual motto at the centre of our activism. This doesn't mean that the mottos of recent years have not also been political. With ‚POSITHIVE DIVERSITY', for example, we wanted to point out that the HIV-positive community is made up not only of gay white cis men, but is much broader. We wanted to give more space and voice to these diverse lived realities. The motto ‚NATURALLY POSITHIVE' was supposed to encourage people to openly stand by their own HIV-positive status.

The most recent decidedly political motto was ‚POSITHIVELY CRIMINAL', used to oppose the threat of criminalisation, which people living with HIV were exposed to when having sex with people who were not HIV-positive."

What are the fears on the minds of people living with HIV in the face of a rising political right?

"People living with HIV are not only stigmatised on the basis of their infection, but are also exposed to other forms of discrimination. Because they are, for example, queer persons, or have a migration background, because they use drugs, or because they are sex workers. Or because, as women, they continue to be disadvantaged in a patriarchal society. This



Gottfried Dunkel is committed to fighting the far right.

is also reflected in the fact that most late diagnoses, often already at the AIDS stage, are made in heterosexual women.

We are already called upon to tackle stigma and discrimination in many areas. What will happen if those right-wing trends, which already question these identities now, are given the political opportunities to fight them, and/or to make them scapegoats?"

What specific risks have you identified in the event of a political rise of the far right?

"We are already noticing, for example, how attempts are made to influence the education of children and adolescents, i.e. that traditional, heterosexual family models are propagated while alternative models of family, marriage and partnership are delegitimised. If the right wing came to power, it would have access to structural levers in the responsible state and federal ministries, for example to block the work of ‚undesirable' structures and institutions by cutting their funding.



However, I am not interested in creating horror scenarios, because that won't be of any help to us. We should also avoid fighting fire with fire by stoking fear in the same way the far right is doing. The Aidshilfe movement, as I have come to know it over the years, stands for factual education that enables people to make self-determined decisions, as well as for respect and acceptance of a wide range of lifestyles and lived realities. There are certainly reasons for concern that some political camps will oppose this. But we should not be paralysed by fear."

However, we are witnessing that the way the far right is stoking fear and discrimination on social media, and painting certain groups as enemies, does not remain without consequences in the real world. We need only think of the disinhibition and verbal threats on social media that later turn into physical violence as well.

"This is real, and it is important to be clear about it. And this is exactly one of the aims of our campaign: to show what would happen should those on the far right gain even more influence over our lives. Our slogan ‚I AM A HELPER CELL AGAINST THE FAR RIGHT, BECAUSE FAR RIGHT PATHOGENS ARE DANGEROUS' is to be understood as a warning in this context. I especially like the slogan ‚I AM A HELPER CELL AGAINST THE FAR RIGHT, BECAUSE DEMOCRACY NEEDS MANY HELPER CELLS' on account of the metaphor it contains: we people living with HIV need an intact immune system in order to continue to live healthy lives and not to become ill. And democracy needs many helper cells that will preserve it and stand up for its values – no matter their political persuasion – except for the parties on the far right."

How are you getting your slogans out there?

"Shortly before the European Parliamentary Elections, we started a photo and video based social media campaign using our statements. This means that people living with HIV showed their faces and positioned themselves as ‚HELPER CELLS AGAINST THE FAR RIGHT'. In similar campaigns in years past, it hadn't always been easy to find people who had the courage to come out as HIV positive. But this time it was different. Many people felt encouraged and motivated to take this step for the first time.

We are now continuing this campaign. At the official reception for the Christopher Street Day pride events in Cologne, for example, well-known politicians also showed their solidarity and had their photo taken. At the Munich World AIDS Conference's Global Village, people from all over the world participated in the photo campaign. It's encouraging to see that interest and involvement in politics is greater than it has been in a long time. That's certainly also the case because everyone knows what is at stake when parties come to power that are not sympathetic to us. We want to continue the campaign until the state elections and beyond, where, according to forecasts, the risk that the AfD could become the strongest party is unfortunately very high. This is worrying and dangerous. In this respect, we will keep at it and see how we can create public interest. Because the time for silence is over. If it gets to the point where we have to hide again, it may be too late."

Were there any internal objections to the campaign?

"Only very few. For example, 'What's your problem with right-wing populism all the time, when there's left-wing extremism as well?' While this is true, we are not aligning ourselves with other extremist trends either, we merely identify and name those that pose a risk to us. In this case it's related to current events such as the rise of the AfD, which has already gathered so much strength, and in whose party policies you can already read in detail what we would have to expect should they actually assume government responsibility."

Interview by Axel Schock

„We take a clear stand against the normalisation of the shift to the far right in our society! Racism, anti-Semitism, anti-queer sentiment, and anti-feminism are putting everything we are advocating for at risk."

POSITHIV HANDELN NRW about their campain

Tradition and progress

Lillian Petry, who grew up in Uganda, has not only been a tireless HIV activist for over 20 years, but has also provided important support for numerous projects, as well as serving as a contact person for migrants, especially for the African community.

You have been working for the African community in Germany, and also for the PLHIV community, for many years. Where are you at right now?

I often have the feeling that too little has happened over the last 20 years – despite all the international conferences and projects. While the situation for people living with HIV (PLHIV) has improved significantly in many countries, there are still many people without access to medical care, without sufficient information. Even the ‚U=U' message has not got through everywhere. Even some hospital doctors and dentists still make a fuss when we tell them that we are HIV positive. So, we need to come up with new plans on how to achieve our dream of ending AIDS by 2030. I say ‚dream' on purpose, because without a plan it remains a dream.

How do you experience the situation for the African PLHIV communities in this country?

I have been known as an HIV positive person in Germany for over 20 years, and as a result many black people who are looking for advice and assistance contact me. However, many of them are afraid that their HIV status could become known. Stigma and discrimination are still too great. On this topic, too, I wish we were much further along.

Why do you think people living with HIV have such a hard time in African communities?

So far, it has mainly been people who are HIV positive themselves who have taken information about HIV and AIDS into the African communities. For many in those communities, however, these people don't have credibility.

It would be important that other, universally respected people – such as nurses – also educate communities about HIV, and eliminate existing fears and prejudices. So, we still have a lot of work to do, and we also have to work at the structural level.

An important step has certainly been that we were able to recruit some pastors within African Christian communities, who, for example, encourage people to start HIV treatment, and then also to take their HIV drugs regularly. But many of them are not up to dealing with this topic. At the AIDS conference in Munich, for example, I encountered a priest who cares about HIV education, but who also states emphatically that sex outside of marriage is a sin. Homosexuality is also considered a sin among many practising Christians and within the African communities. Anyone who, like me, works for and with gay men, or is friends with them, is therefore considered suspicious.

How well are people from the African communities who are living with HIV in Germany currently being reached?

Deutsche Aidshilfe has already built very good networks over recent years. This is a very hard job that could not be done without the tireless efforts of people like Alphonsine.

However, we also need many more courageous Black people who are openly HIV positive. Because within the communities, HIV is still a taboo subject, and dismissed as a disease of gay men and prostitutes. In the Saarland, I'm supporting more than ten women myself, and even I haven't managed to persuade them to attend a nationwide PLHIV meeting.

So, what would have to happen to better reach People of Colour – be it for testing, treatment or support?

On the one hand, I think we need more diverse structures. Many local Aidshilfe organisations already offer a variety of services for migrants, but Aidshilfe organisations are not an ideal place for all people. We would therefore have to invest more in the existing community structures, so that people can also be tested, and receive good counselling there.

This is because Africa is a very diverse continent, and therefore we need diverse multipliers. Just think of the many languages and the different faiths such as Islam, Protestantism, Catholicism, and the traditional African religions. There are also large cultural differences. For example, let's not forget that female genital mutilation still



Lillian Petry acts as a mediator between communities and cultures.

occurs in some countries.

Have you taken away something for yourself from this conference? For example, did you have any exchange with people from your home country Uganda?

I actually visited all the organisations from Uganda that were represented at the Global Village with a booth, and we exchanged views on the situation in the country. One topic that we kept focusing on is the situation of LGBTIQ people there. Homosexuality won't be legalised in Uganda any time soon, because the majority of society is not behind it, and it will take a long time for this attitude to change.

What do you think are the reasons?

In Uganda, both homosexuality and polygamy had been completely unremarkable phenomena over a very long period of time, and for both it had worked out well at the structural level. There was even a gay king at some point. But with colonialism came the Christian religion, which demonised both practices. Men who were married to several women had to separate from them in order to embrace this Western faith. As a result, many polygamous families faced disaster. And now it's again the white Europeans who are coming in, this time saying „Hey, why don't you let men marry men?" This demand may be justified from a European point of view, but implementing such a change requires a process that must emerge from the people themselves, it mustn't be imposed from the outside again. The Ugandan president knows that he has the majority of the population behind him when it comes to laws on homosexuality. Should the general mood change, however, he will backpaddle. I'm sure of it.

The staff of the Ugandan organisations can't understand why countries such as Germany don't take these vulnerable people in, i.e. facilitate their claims for asylum instead of exposing them to this real and present danger.

What special impressions do you take home from Munich?

I take a lot of positive vibes with me. This was my second World AIDS Conference, but here in Munich there were far more people from the African continent than in Amsterdam at the time. Especially this exchange with the activists and representatives from these countries benefited me a lot. I was also very happy that dissatisfaction with the prices of medicines was expressed so vehemently and clearly. Above all, this was a protest in which many different stakeholders from all parts of the world participated, and which showed that we must tackle such shortcomings and injustices together.

In addition, Deutsche Aidshilfe's Networking Zone once again showed me how many networks are united under the umbrella of this organisation. The conference was a very nice opportunity to get to know many of them. At the conference, it also became particularly clear to me how important it is that people around the world take supporting their communities into their own hands. While international organisations and pharmaceutical companies presented themselves at large booths in the exhibition hall, the people whom it's really about are reached by community organisations, no matter how small they may be. This is why it's all the more important that they have opportunities for professional development, to empower themselves, and to finance their work. Many of them do not receive any money from their own governments. Some have offered homemade jewellery, clothing, and even furniture for sale at their stalls at the Global Village. I was very impressed and moved by this, and I think that these activists deserve our support.


HIV

Visibly female

It has been in existence for 15 years now, and is probably the longest-standing women's HIV activist group in Germany. Johanna Verhoven has now been part of XXelle PLUS for ten years. She explains why women living with HIV are entitled to a large piece of the pie, and why they need their own groups and services.

For those not yet familiar with the North Rhine-Westphalian PLHIV community, the name of your group might be confusing. You call yourselves XXelle PLUS, but there is also XXelle NRW. Please briefly explain the difference.

"XXelle is the name of the Landesarbeitsgemeinschaft Frauen, HIV und Aids (State Working Group for Women, HIV and AIDS) at the Aidshilfe North-Rhine Westphalia (NRW). It is mainly a network of those employees of Aidshilfe member organisations who work with HIV-positive women. And then there is also our HIV-positive women's group in NRW. We feel that we are part of the State Working Group in terms of the issues, but that we are a bit more than that, namely activists. That's why we call ourselves XXelle PLUS."

You've been part of the group for over ten years.

"I received my diagnosis twelve years ago and have accessed peer support a lot in all those years. However, I increasingly felt the need to give something back, to get involved politically as well, and to advocate for women. This was important to me also in terms of how I deal with HIV myself. That's how I ended up at XXelle PLUS."

Activism can drain your resources, and it takes time and energy. What does your involvement give you in return?

"First of all, this is a very empowering group. Over the years, comrades-in-arms have become friends. Moreover, the issues we deal with are by no means becoming more boring or fewer, on the contrary. New ideas are constantly emerging that we can contribute, as well as problems that we have to draw attention to. We are in a good position in North Rhine-Westphalia, as we are also well supported financially by Aidshilfe NRW, which makes many activities possible."

How many women are active in XXelle PLUS?

"The number varies – as tends to be the case with groups – but we are usually around ten women. Of course, we always welcome new members, and they do keep on coming, but some also have to take a break now and then. One of our women has just become a mother, but she is still actively involved, and always has her child and her husband in tow. It's good to see what can be made possible."

The existence of an active women's group is by no means to be taken for granted in regional Aidshilfe organisations. Why do you think that is?

"It really does vary a lot from one town to the next. In Paderborn, where I lived for a long time, we never managed to establish a women's group. There were always only two of us, although there were far more women living with HIV in the town. They felt comfortable in the general PLHIV groups and

Visibly.

did not feel the need for services especially for women. In Bielefeld, where I later worked, on the other hand, there was a large and very active group of women. In larger cities with corresponding population sizes, women's groups are, of course, easier to establish, but this doesn't mean that there aren't any women living with HIV in smaller towns. It might be that they just don't manage to find their way to an Aidshilfe organisation."

How could the pathway to a women's group be made easier for these women?

"It is important, for example, that Aidshilfe and counselling services are tailored to people's lived reality. The days when every person living with HIV was a pensioner, and therefore completely flexible in terms of time, are simply over. Many of the women living with HIV, and of course the men, too, are working full-time. They may only have the weekend at their disposal to participate in a group, and may also have to arrange childcare in advance."

What are the topics on the agenda for women's groups, including for XXelle PLUS?

"I think it is first of all ‚typically female' topics that we are exercised by: wanting to have children, families, relationships, or how I tell my child. Of course, these topics often overlap with those that concern gay and heterosexual men. But many women also feel the need to meet peers with similar lives in a protected space, to share experiences and to encourage each other. For us activists, there's also the political level. What can we do about the structural discrimination of women living with HIV in the health system? How do women with a migration background experience intersectional discrimination – based on their origin and their HIV status? Last but not least, we are also concerned with female sexuality and women's visibility."

Can you give an example where women are underrepresented in the context of HIV?

"We noticed that there always used to be this one special workshop for women at conferences and meetings. And we asked ourselves why women wouldn't be present and thought about everywhere.

Why is research conducted the way it is, namely that women are not automatically included in studies? Then, as a justification, we get to hear from among the Aidshilfe organisations that it's the simple fact that women make up only 20% of people living with HIV in Germany. At some point we thought: yes, we are 20%, but that's actually quite a lot. We're just not being seen. We then developed a campaign with a logo that combines HIV and a vulva, showing that HIV is also female. With this campaign, we also wanted to position ourselves specifically within the Aidshilfe movement, and make it clear that we want more visibility and support from Aidshilfe organisations and the community. I don't want to keep having to argue with HIV-positive men about why it is that we are getting a separate women's workshop. As if there weren't any services specifically for gay men."

How has the status of women in the Aidshilfe movement changed over the years?

"Historically, these structures have been very much dominated by gay men in many places.

But I think a lot has changed. Ultimately, however, it depends on the individual Aidshilfe organisation and the community. In North Rhine-Westphalia, we have wonderful and appreciative colleagues at the Aidshilfe. Many felt very affected by our campaign and supported us in our demands.

I am also on the board of Aidshilfe NRW and can put women's issues on the agenda without having to

fight particularly hard. Some time ago, we also started to collaborate with POSITHIV HANDELN NRW (Positive Action NRW) to jointly look at how we can benefit from and strengthen each other. But I also know about Aidshilfe organisations whose structures are very outdated, and who lack the commitment to rethink these structures."

How did you experience the Munich conference?

"I've already been to the German-Austrian AIDS Conference several times, and other conferences, but this was my first World AIDS Conference. And I can only say that it is absolutely wild, but also very, very tiring. There is just so much on, and the whole time I had the feeling of missing out on something, somewhere. In the main conference programme alone, there were five or six parallel sessions. And in addition to that, there was the comprehensive programme at the Global Village.

I find it especially valuable that here, HIV is seen more from an international perspective again, and you realise how privileged we are in Germany. To see and to hear about what it's like for people in other countries: women who aren't able to make decisions about their reproductive rights or their sexuality, who suffer the worst of female genital mutilation practices – during which many of them also become infected with HIV. When I go to see my doctor and say „There's this new drug and I would like to have it", then we check whether it's suitable for me, and then I will get it. Covering the cost is not an issue. And then there are countries where you are lucky if you get anything at all, and lucky if you aren't criminalised when you try to access medication."

Which of the current areas of research have you been particularly interested in?

"On the one hand, research about long-acting treatment, but also PrEP for women, of course. I think that's an important topic that for a long time wasn't tackled in Germany. The gays fought for PrEP access for themselves, and that's right and proper. But then we didn't take the next step, demanding PrEP for everyone. For me, conferences like this one are also important because they push you forward and, above all, they give you plenty of energy and the desire to address issues."

Did you get the chance to make direct contact with other women's organisations?

"I was in the big Women's Networking Zone at the Global Village several times, and it's just great how quickly you can make contact there, and how easy the different German networks are making it to get talking to other women from around the globe.

As the State Working Group XXelle NRW and also as the XXellePLUS activist group, we've been looking to have this kind of exchange on a range of levels. Including in quite a demonstrative fashion – through our vulva-making workshop. We were intentionally looking for an activity that would get people – and not only women – to stop and engage with the vulva as a genital.

Because, if we're being honest, penises have a massive presence in Aidshilfe organisations, and vulvas rather less so. That's why we've got to ensure more female visibility there as well."

Interview by Axel Schock

www. xxelle-nrw.de

Female.

Sasha Gurinova



“It‘s extremely difficult for women to get hold of PrEP.”

Sandra Bischoff



Sophie Strachan during her lecture.



Pill bottleneck

Pre-exposure prophylaxis – PrEP for short – reliably protects against HIV. Nevertheless, almost all PrEP prescriptions go to cis men. This workshop was held to discuss the reasons, and called for an end to this injustice.

„Really, you'd need to drop a bomb on the health system and rebuild it from the ground up." Such radical statements, too, can be heard at a World AIDS Conference. But anyone following Sophie Strachan's presentation knows that this British woman isn't planning a terror attack, she is denouncing a scandal: women aren't getting PrEP – not even in her wealthy home country.

Why do almost all PrEP prescriptions go to men? In Germany, it's 99 percent. On July 24th, Sophie Strachan is talking with experts from all over Germany in Deutsche Aidshilfe's Networking Zone about why women so rarely get PrEP, and how this situation could be improved.

Sophie Strachan's criticism is aimed at the UK's National Health Service (NHS) – famous for free access, notorious for long waiting times. The Sophia Forum, a network of women living with HIV co-founded by Sophie Strachan, also collaborates with this public health service provider. „Practically every week, I hear from a woman who has assessed her own HIV risk, then went to the NHS sexual health service but didn't get PrEP there. That's not OK!"

Strachan reports that the UK's PrEP guidelines are currently being revised. But they are not the only problem, as community-based research has shown. The greatest barrier for women is precisely these sexual health service locations: „They are not used to the same extent by women as they are by gay and bisexual men."

Sasha Gurinova, Deutsche Aidshilfe's officer for international affairs, adds that the PrEP guidelines for Germany and Austria have been listing sex workers as an additional target group since 2024. Nevertheless, women hardly feature when it comes to PrEP, as workshop participants confirm. A general practitioner reports that there are only two women among his approximately 130 PrEP patients. And Sandra Bischoff from Aidshilfe Leipzig states: „It's just extremely difficult for women to get PrEP if they want it."

Olivia Green, community coach and anti-discrimination consultant, points to one of the barriers: few women know about PrEP, and those who do are sceptical. For Deutsche Aidshilfe's ‚What do sex workers need?' study, Olivia Green interviewed several sex workers in her role as a peer researcher. „Basic awareness levels are low", she summarises the results, „hardly anyone knows that PrEP is a reliable prevention method, and that its side effects are not comparable to a hormone-based intervention such as the contraceptive pill." In the BIPoC community, there is also great distrust of health services in general. The reason is that „Especially in gynaecology, a lot of knowledge is based on abusive research conducted on black women", she explains. „This level of mistrust also affects PrEP." A possible solution would be „PrEP counselling by peers who enjoy the trust of the community".

Peer-based PrEP counselling

Immediately, the hum of a lively exchange of experiences develops among the experts. Caspar Tate, trans activist and also one of the peer researchers in the sex work study, confirms Olivia Green's impression: Many cis sex workers do not see themselves at great risk of contracting HIV. „When I inform them about PrEP in one-on-one consultations, then the free STI test is a more effective argument." As part of PrEP, such testing is conducted as standard every three months, and is paid for by statutory health insurance.

Facilitator Sasha Gurinova supports Green's call for peer-based counselling: „It's not only important how you provide information about PrEP, but also who is providing it."

Another overdue step is 'on-demand' PrEP for women, as everyone agrees. „That would be a great relief for many", explains Olivia Green. „Many study participants found it difficult to take a pill every day. And they're worried about losing protection if they miss a dose."

At the end of an hour of intensive discussions, Sophie Strachan articulates her vision for the future: „My dream is that women everywhere will have access to PrEP – and that it won't be health professionals who decide whether they need it or not."

Philip Eicker



Activist Veronica Hotzel from Lübeck

GIRL POWER GONE GLOBAL

For many years, Veronica Hotzel has been active in migrant organisations such as the intercultural social network Regenbogenfrauen Lübeck (Rainbow Women Lübeck) and the Afrikanisches Gesundheits- & HIV-Netzwerk in Deutschland (African Health & HIV Network in Germany, AGHNiD). Although she has participated in numerous meetings and conferences in this area, AIDS2024 was her first World AIDS Conference.

What impressions are you taking back to Lübeck?

I'm quite overwhelmed! It is so beautiful to see how such different people come together at the Global Village, as colourful and diverse as the rainbow – which is also in the name of our network in Lübeck.

We try to give migrant women a place where they feel safe and welcome. And we want to be a point of contact for them, one where they can get support and assistance from the community. Especially when it comes to health problems.

This feeling of solidarity and community, which, as ‚rainbow women', we would like to offer, I sense is also being realised here at the Global Village.

Apart from that, it's just great for me personally that I have met so many people from all corners of South Africa, and that I was able to speak many of the languages and language variants of my home country again.

Have you also been able to talk with people from other countries about your work in the HIV context?

Of course, and not only with people from Africa, but also from many other countries: Brazil, India, China, Malaysia, and many more. It is truly a gift. Even when I just think of the workshop where Russian and Ukrainian women shared experiences with African women. Where else would such a meeting have been possible?

What was particularly impressive or surprising for you in these encounters?

I was impressed by how well women in other countries are organised and networked. In Germany, large nationwide meetings of women with HIV only take place two or three times a year, and only on account of Deutsche Aidshilfe's support. In Kenya, for example, there are national organisations run by and for women living with HIV, who can support each other this way. Not least through good online services.

Another realisation for me was that, while these networks may be larger and more professional – not least because more women and girls are living with HIV in these countries – the central issues that move us as women are ultimately the same everywhere. And, at its heart, it's always about making sure that women are not left alone but receive local support, and that they receive it from their own community.

Interview by Axel Schock

Against their better judgement: HIV criminalisation

The Republic of Tajikistan, located in Central Asia at the foot of the Pamir mountain range, is known for its breathtaking natural beauty and traditional Asian hospitality. Behind the idyllic façade, however, lurk difficult legal and social problems.

Tajikistan is one of the remaining 73 countries in the world where HIV transmission is still subject to criminal prosecution. Current laws contain penalties for both deliberate infection and exposure to HIV. Neither the informed consent of sexual partners nor using a condom, nor a low viral load where HIV is not transmissible, are taken into account.

As in many patriarchal societies, the law disproportionately affects women in Tajikistan. This leads to severe discrimination and restricts women's access to all kinds of resources, including support from their own families. The criminalisation of HIV has a direct impact on the sexual and reproductive rights of the women concerned.

Breastfeeding mothers face harsh penalties, including custodial sentences.

Women living with HIV in Tajikistan are often faced with being refused medical care. Instead of receiving the required treatment, they are advised to refrain from sexual contact and not to have children. Although medical evidence supports breastfeeding for women living with HIV, breastfeeding mothers run the risk of criminal prosecution – even if their treatment is working well and they have no detectable viral load. The argument is that they are putting a minor at risk. This type of crime attracts harsh penalties, including incarceration, even if no infection results.

At AIDS 2024, Tahmina Haidarova, head of the Tajik Network of Women Living with HIV, expressed concern about the negative impact of HIV criminalisation on women's sexual and reproductive rights. She stressed that, contrary to medical recommendations, this law restricts women's ability to breastfeed their children, which increases the children's vulnerability to health problems.

But there is also some reason for hope. Tahmina Haidarova reported on a decision towards the decriminalisation of HIV transmission and exposure taken by the full bench of the Tajik supreme court in December 2023. This new resolution aims to more objectively examine criminal liability under Article 125 of the Tajik penal code. Courts are asked to consider recent scientific evidence that meets international standards and recommendations, including the concept of U = U. This development is supported by UNAIDS and the World Health Organization. It will take some time yet to reach a decision on this matter, and it remains unclear whether this legal test will have a positive effect on the rights of breastfeeding mothers as well.

Sasha Gurinova





LIVING PROOF



The “City of Hope Patient” Paul Edmonds and the “Düsseldorf Patient” Marc Franke (right).

Three people who have put HIV behind them completely also got together in Munich. We met two of them, Paul and Marc, for a conversation about medical miracles, a chat group for the cured, and

LIVING PROOF

A World AIDS Conference offers the rare opportunity to meet several exceptional people all at once: these three have completely eliminated HIV from their bodies – thanks to stem cell transplants. We met two of them for a conversation: Marc Franke from the Münsterland, also known as the ‚Düsseldorf Patient', and the ‚City of Hope Patient', Paul Edmonds, from Palm Springs. Both were a little tired as they had been celebrating Paul's 69th birthday the previous evening. „I'll have to re-join the living first „, Marc had texted in the morning. But, in the afternoon, the pair is sitting down relaxedly at the press centre, and they look as fresh and cheerful as if they had never had leukaemia.

Paul, you celebrated your birthday yesterday. Congratulations!

Paul: "Thank you! And I'm looking forward to my 70th, it's knocking on the door already. And I'm very grateful that I have survived all this. So many people I knew did not."

Who was part of the birthday celebration?

Marc: "Well, of course there were we, the ‚three Musketeers' – this is the name of our WhatsApp group, which, in addition to Paul and me, also comprises Adam, the ‚London patient'. We all now belong to this distinguished circle of ‚cured patients'. I think there will be a few more 'Musketeers' joining us over time. And Anna, my stem cell donor, was also there yesterday. I am grateful that I was able to get to know her."

What kinds of things are you writing about in your chat group?

Marc: "We let each other know where we are in the world, and whether we can meet up. Every now and then we have a zoom meeting so that we can see each other in between times. It's just great that, here in Munich, we're all in the one place for only the second time ever!"



Paul Edmonds

Do you sometimes feel like a medical miracle?

Marc: "No, not at all. After all, the HIV cure was merely a side effect of stem cell transplantation – which became necessary because I got leukaemia. I can't recommend going through this to anyone. It's a very rough journey! Those who turn up in the media are the ones who made it through – you don't hear about the many who didn't."

Paul: "I was diagnosed with HIV in 1988. After having lived with HIV for over 30 years, I found it difficult at first to understand that it was now over. But I do believe it! (laughs) It's still an incredible feeling. I know how important it is to tell my story in order to instil hope – among people living with HIV, and among researchers. Here in Munich, I noticed again that people are just excited to see us, as living proof."



Marc Franke

Is HIV behind you – or do you sometimes have doubts?

Marc: "No, I don't have any doubts. But my doctor, Björn, for example, for a long time didn't use the word ‚cure'. Yet I know that he is being teased by his colleagues: „Hey, how's our miracle worker doing?" (laughs)

Paul: "Actually, we don't call it ‚cured', we say, 'I'm in remission.'"

Paul uses the term ‚remission' from the field of cancer medicine. It means that tumour cells can no longer be detected. The same applies to HIV particles. Although Paul hasn't taken any HIV medication for more than three years, the virus has not returned. Marc has been living without ART even longer, for five years. Nevertheless, doctors are careful with using the word ‚cure'. A recurrence (recidivism) cannot be ruled out. But now that seven cases have been documented worldwide, it seems that HIV really can be eliminated from the body. Although Paul and Marc no longer have to take HIV treatment, they still see their doctors frequently. Not only have they had a lot of blood taken, but also tissue samples from the intestines and lymph nodes, where HIV-infected T helper cells may lie dormant. Paul still has many doctor's appointments, explains his husband Arnold, who is still living with HIV himself.

Arnold, what has changed since Paul has been free of HIV?

Arnold: "Well, the doctor's appointments continue, although there aren't quite as many as before. (both laugh) Above all, I am very grateful that Paul got rid of the cancer. It was only yesterday at the party that I realised how important this was. I just don't know what I'd do without him. So, with HIV or without, I'm still happy!"

Paul: "I now feel safe again. I'm getting used to travelling and meeting a lot of people. I've never done public speaking before. This is something totally new for me."

Arnold: "Yes, you are more confident talking in front of a group. And we have been working hard for a long time to become computer-savvy. We're not very good with computers, but we're trying."

And what was it like for you, Marc?

Marc: "HIV hasn't been weighing on me so much. I know people for whom the pill alone represents stigma – because it reminds them every day that they are living with HIV. This was not the case for me. During the stem cell transplant, I took up to 40 tablets a day. A single one seems even more harmless to me now."

Do you sometimes feel like a guinea pig?

Marc: "No, for the sake of research I'd do anything that's more or less safe for me. I will be donating stem cells next. Researchers from the USA want to use them to create a stem cell line that their colleagues around the world can then work with. It's just a blood donation in the end, but I get royalties for it!" (laughs)

Did you hesitate at first to go public?

Paul: "No, I had already decided that I wouldn't remain anonymous if it worked out. It would have felt like I was hiding. I grew up in the Southern United States in the 1960s. It was very difficult for me to come out as gay at that time. I didn't like that feeling, so I swore to myself that I wouldn't go back in the closet again!"

Marc: "At first, it was quite convenient for me that everyone thought the ‚Düsseldorf patient' also lived in that city. I always went to the university hospital there for interviews. I was terrified of what the media would do with my story. But, so far, my experience has been largely positive. And somehow it's a great feeling when you make it onto the front page of the newspaper."

Do people recognise you in the street?

Paul: "Neither of us go out much anyway. (Paul and Arnold laugh) In early 2023, I was on TV, on ‚Good Morning America' and ‚Nightline', which didn't change my life much. But, of course, we go to community events and conferences like here in Munich. I'm surprised how many people want to be have their photo taken with me. This is something new that I still have to get used to."

Marc: "People love taking selfies, and that's just great! During our last session, people kept taking pictures for about 15 minutes – until they threw us off the stage!" (laughs)

Why did you come to Munich?

Marc: "Among other things, the Deutsche AIDS-Stiftung (German AIDS Foundation) invited me to present my case from a personal point of view. This was interesting for the doctors, because they only knew of it from a medical perspective. It is important that there is also a name and a face attached to the successful treatment."

And how has the feedback been?

Marc: "Wonderful! Every now and then, people come up to me when I walk across the exhibition grounds here, thank me for the presentation, and wish me all the best. And yesterday I ran into Professor Gaebler at the entrance. I immediately went up to him and asked him, 'Do you know who I am?' He said ‚Yes, I know your face'. And then I was able to convince him to report his new ‚Berlin patient' to IciStem."

The international IciStem consortium collects all medical cases where cancer patients living with HIV have received a stem cell transplant. In addition, the data of potential stem cell donors born with a rare gene mutation are documented. The mutation prevents HIV from attaching to the immune cells. At the World AIDS Conference, Christian Gaebler, professor at Berlin's Charité hospital, presented the seventh case of an HIV cure occurring this way. The special factor in the case of this ‚Berlin patient': his stem cell donor had inherited the mutation only from one parent – yet HIV apparently still didn't stand a chance. It remains unclear why this is so. Gaebler hopes to find important clues for a possible HIV cure, but warns against neglecting other important lines of enquiry.

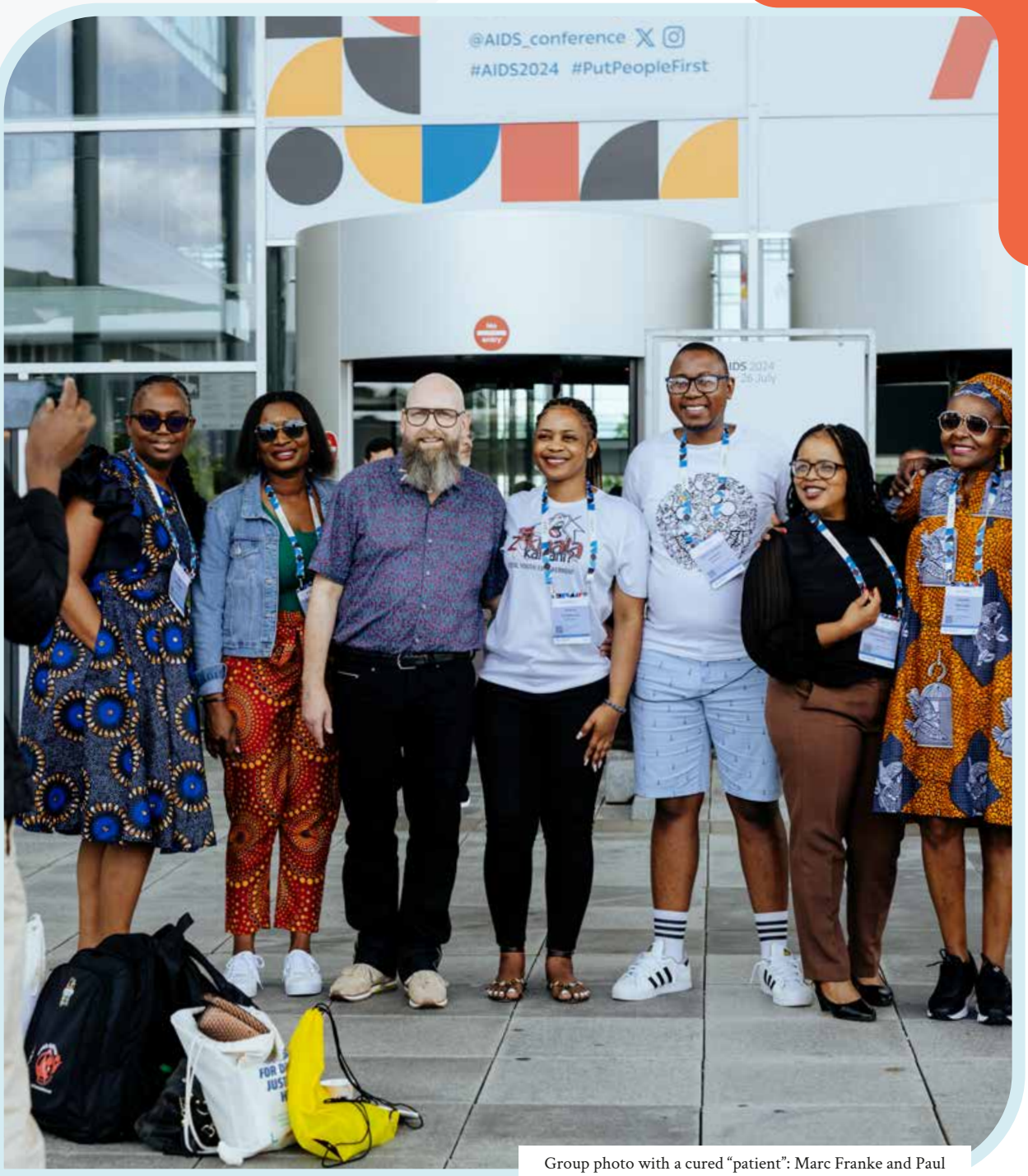
Marc, why was the conversation with Professor Gaebler important to you?

Marc: "It is important to me that researchers come together to find out what the deciding factor is in the success of this kind of treatment. It would be a pity if we didn't find the crucial piece of the puzzle only because the researchers aren't sharing their data. I don't care who gets the Nobel Prize for it. I want there to be a cure for everyone."

Paul, what is your message to the World AIDS Conference 2024?

Paul: "I'm looking forward to the day when HIV is no longer a whole sentence, only a footnote in history. I have learnt a lot about new HIV treatment approaches here. Researchers are investigating in so many different directions, for example on CRISPR and other gene therapies. After these many conversations, I have the feeling that I may still see a cure for HIV in my lifetime. I was already here when the epidemic started – and I want to be here when it ends."

Interview: Philip Eicker



Group photo with a cured "patient": Marc Franke and Paul Edmonds were celebrated like pop stars in Munich.

Glad tidi side effe

It raised great expectations, this new, clear-cut ‚U = U' prevention message. Yet by now, one thing is clear: it's also causing new irritations – and the bell has sounded for the next round in the fight against HIV stigma.



No one can get past U = U at the Munich AIDS Conference. The equation is emblazoned on posters and T-shirts, it's stuck to a wall in Styrofoam letters, and it's being chanted during protest rallies. Ilyas has also noticed it. „I only heard about this abbreviation here", admits the employee of Pakistani HIV prevention organisation Humraz. Ilyas does know the medical fact that U = U stands for: ‚undetectable = untransmittable' (or ‚N = N, nicht nachweisbar = nicht übertragbar' in German). When – thanks to antiretroviral treatment – HIV is no longer detectable in the blood, then it can't be transmitted, either.

In Karachi, where Ilyas works, this has not yet become a campaign slogan. „Very few people know about it there", believes Ilyas. Right now, he's in the audience at a Deutsche Aidshilfe panel discussion, and he's about to hear about the side effects of this short and to-the-point prevention message as well.

„U = U actually is the best message ever", says Gerhard up on stage, and recounts how he first found out about it in 2015. „My HIV-specialist GP explained it all in detail to me at the time because I was starting treatment. And then, as an aside, he says ‚by the way, and you also won't be infectious any longer'. At that point I thought ‚Wow! Why didn't he mention this until right at the end?'."

„For me, U = U means freedom"

This feeling of relief is confirmed by all participants in the discussion who are living with HIV, including peer educator Melike, who's also part of the panel. „For me, U = U means freedom, because from that point on I knew that I couldn't infect my child during the birth!" Since then, however, Melike has also noticed ‚side effects', for example in her Aidshilfe counselling sessions with other women: „The responsibility mainly rests with the HIV-positive person. The message that is received by HIV-negative people is more like ‚Why would I even bother using condoms now?'"

High expectations were put on U = U. The slogan was supposed to reduce the stigmatisation of people living with HIV. By know it has become clear that, aside from the reassuring prevention message about (undetectable) viral load, many also hear a second one, which is misleading: 'Always keep an eye on viral load!'

ngs with cts



Edgar, active in anti-discrimination work.

Especially in the health sector, where levels of basic medical knowledge should be high, ‚viral load' is making some staff nervous. „People living with HIV are being asked to provide data on their viral load" reports Kerstin Mörsch from her work at Deutsche Aidshilfe's antidiscrimination contact point, "for example before an operation, or during occupational health assessments."

Does U = U help against stigma?

Both on and off the stage, several participants report such incidents. One audience member comments: „It's worrying that there's a predominant expectation in the health system that I, the patient, am taking medical responsibility for infection control so that the staff feel more comfortable."

Facilitator Anke Hellauer asks the audience this core question: „Does U = U even help at all against the stigmatisation of people living with HIV?"

The statements made in reply demonstrate the emotional charge of this topic. For Swiss HIV activist Michelle Meyer, this development represents „a personal drama. I have been fighting to make sure everyone was aware of U = U. And now I realise that we are still letting others play us off against each other. On this side, there's the ‚good' HIV-positive person who is undetectable, and over there, the ‚bad' one."

Gerhard, who supports people after their HIV diagnosis as part of a buddy system, emphasises the difference between the more scientific ‚U = U' statement and the more practice-oriented ‚treatment as prevention' message. „This is where it can help to take away the fear. That's why U = U is a tool we will continue to need."

Kerstin Mörsch also considers the slogan to be a good "foot in the door", but says „this doesn't take the topic of discrimination off the agenda. We as a community, and as Aidshilfe organisations, have to make it clear in which context this information is important – and in which it is not."

Philip Eicker



Emotional roller coaster

At the World AIDS Conference, Viennese microbiologist and HIV expert, Birgit Leichsenring, closely followed the presentations on current scientific studies. In addition to some medical science highlights, for her the presentations confirmed her assessment that the fight against HIV no longer takes place on a scientific, but mainly on a social level.





Birgit Leichsenring

When I had the opportunity to persent, together with former Deutsche Aidshilfe medical project officer, Armin Schafberger, our personal conference highlights at the Deutsche Aidshilfe booth during the World AIDS Conference in Munich, I did not realise what an emotional roller coaster ride this conference was going to be. As a delegate, I was constantly torn between the excitement over great successes on the one, and intolerable injustices on the other hand, between the limited possibilities inherent in our own working environments and life settings, and the needs and legitimate demands of the many activists present. I would like to illustrate this emotional state using two examples.



Scary HIV Statistics

The latest statistics from UNAIDS – the UN's joint programme on HIV/AIDS – can indeed be fear-inducing: compared to the previous year, neither the number of new HIV infections nor the number of HIV-associated deaths have been reduced. In 2023, the number of people who died as a result of HIV infection was 630,000, which is equal to more than one person per minute. The number of new HIV infections for 2023 is estimated to be 1.3 million. Globally, 4,000 infections in women and girls aged between 15 and 25 years occured each week, including 3,100 in sub-Saharan Africa. While global HIV prealence is 0.8%, it is reported to be 3% higher for persons in sex work, 7.7% higher for men who have sex with men, and 9.2% higher for trans people. The unequal treatment of people by society is particularly evident in these figures.

A turning point for the HIV epidemic

The UNAIDS motto ‚AIDS at a Crossroads' underlines that we find ourselves at a critical turning point. The goal of reducing deaths to below 250,000 and new HIV infections to below 370,000 by 2025 is utopian. Calculations show that a further 34.9 million new infections and 17.7 million deaths can be expected by 2050 if these targets are not met. But a turning point towards a positive future is also coming into view. Approximately 40 million people are currently living with HIV. This is about as many as have died since the epidemic became known. It shifts the statistical dynamic in favour of people living with HIV who are alive today. However, this trend depends on treatment availability. In 2023, one in four persons living with HIV, or 9.2 million people, lacked access to HIV treatment.

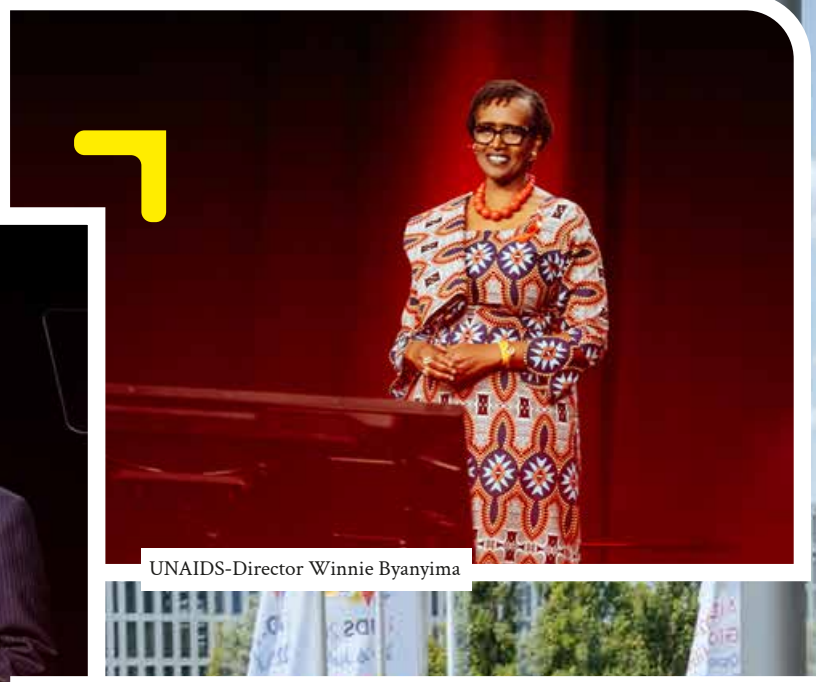
Meaningful quotes

With regard to these statistics, two statements made at the conference summed up the situation for me personally: „It's never just the ‚product.' New options can't solve everything." In other words, effective HIV medications are needed for both treatment and PrEP, but whether people are actually able to use them is ultimately determined at a completely different level. And the statement „There is no time for failure" not only sums it all up, but should also commit everyone involved to intensifying their efforts.

Long-acting meds are on trend

At this conference, too, the focus was on long-acting therapeutic formulations, i.e. the idea of long-acting forms of medication. In this context, ‚long-acting' is a rather rubbery term. The current HIV treatment standard is one tablet once per day. ‚Long-acting' therefore includes anything requiring less frequent administration. This may be once per week, every two months, every six months, or at even larger intervals. Incidentally, how the active ingredients are administered is also irrelevant when we talk about 'long-acting'. This may include tablets, injections, and even intravenous infusions and implants. The concept itself is not HIV-specific, and is already established in other medical fields, e.g. in relation to some hormone preparations, antipsychotics, and cholesterol-lowering medications.

However, these approaches have a particularly large potential for the field of HIV. On the one hand, they can simplify the daily treatment routine, ensuring the effectiveness of lifelong treatment and increasing quality of life. On the other hand, long-acting therapeutic formulations can reduce anxiety and



UNAIDS-Director Winnie Byanyima



German Chancellor Olaf Scholz





IAS-President Sharon Lewin



discrimination because their application is less obvious, and involuntary disclosure becomes less likely. This applies to both HIV treatment and the use as HIV PrEP.

Standing ovations for long-acting HIV PrEP

One of the hottest topics at the conference was the PURPOSE-1 study, whose presentation received a standing ovation. It is one of several studies investigating lenacapavir (LEN) used as HIV PrEP in diverse populations and settings. LEN is a new, long-acting HIV drug already approved for very specific situations in the treatment of HIV. For use as HIV PrEP, however, it is still in the reasearch phase. Over 5,300 cis women and girls across 28 study centres in South Africa and Uganda participated in the trial. One group received LEN as a 6-monthly injection, two other groups received tablet-based PrEP. The number of HIV infections documented during the trial was 55. Not a single infection occurred among the women receiving LEN as PrEP! As a result of these interim findings, the trial was discontinued and all participants were offered injectable HIV PrEP with lenacapavir.

HIV PrEP: Self-determination as the driving factor

It has been emphasised time and again not to underestimate that for women, for example in sub-Saharan Africa, taking tablets every day presents an enormous challenge. Many conference presentations rightly focused on the lives of women and girls. Self-determination in life and sexuality is often unattainable, and all areas of life are dominated by external factors. This also has an impact on oral PrEP.

The SEARCH Dynamic Choice HIV Prevention study conducted in Uganda and Kenya made this emphatically clear. It was based on offering different forms of HIV PrEP (injections and tablets). The rationales participants reported for opting for injectable PrEP spoke for themselves: 42% said they wanted to avoid anyone watching them taking the tablets. 22% reported that their partner would not allow them to take tablets.

HIV PrEP: Choice as a success factor

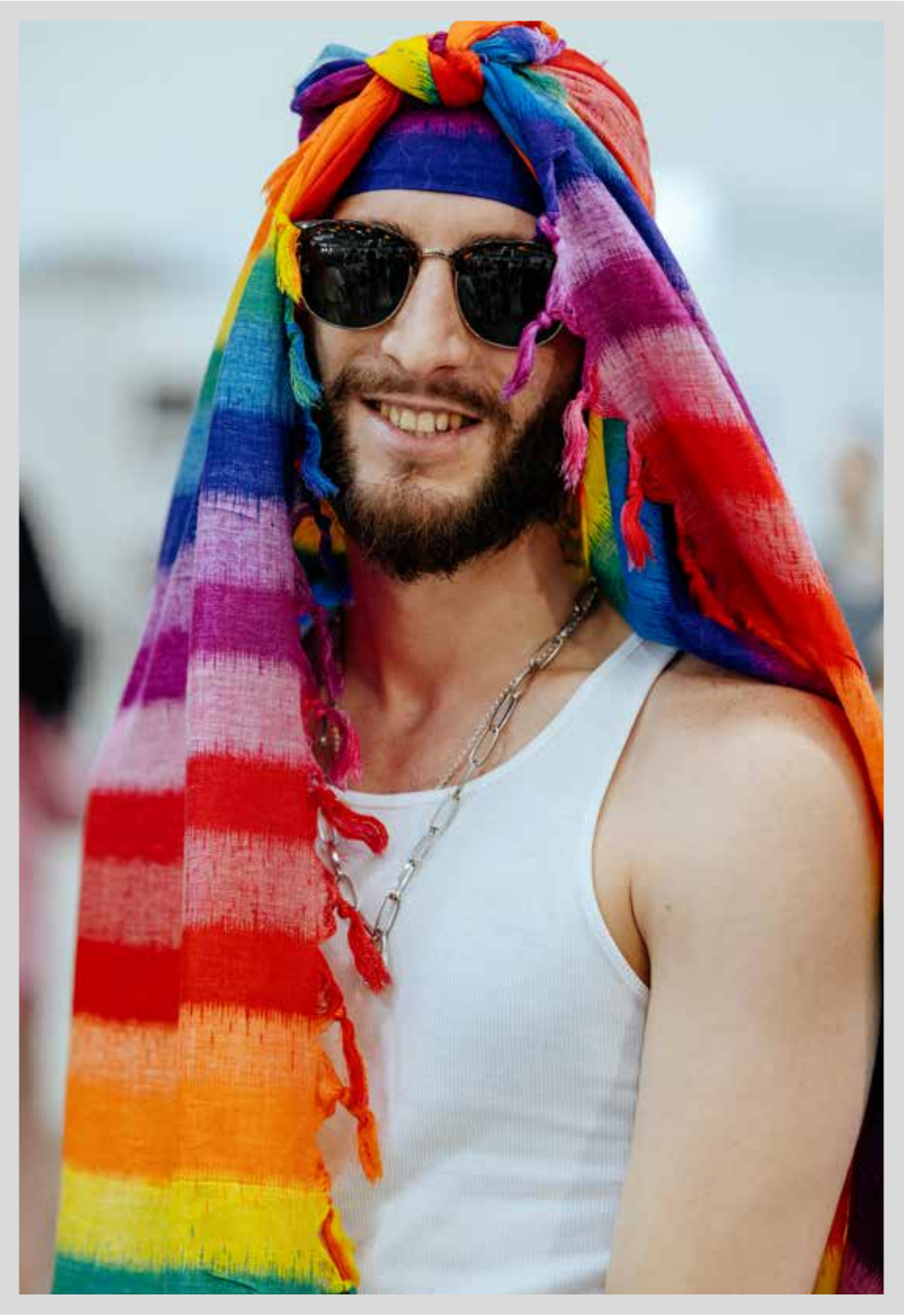
Of course, these statements stand in stark contrast to what is clearly the goal: it would be so important to enable many more women and girls to be protected against HIV in high-prevalence regions such as sub-Saharan Africa. After all, women and girls account for about 60% of all new HIV infections in this region. This is why the influence of choice and flexibility on PrEP success as shown by this study was all the more poignant. When oral PrEP was offered in a standardised setting, it achieved a coverage of 13.3%. However, if participants were offered both oral and injectable PrEP, and, among other things, the option to switch between the two at any time, almost 70% opted for PrEP. Not only the long-acting formulation itself, but also offering flexibility massively increased individual acceptability.

A quote full of emotion

The standing ovation for PURPOSE 1 was thus not only intended to honour the development of lenacapavir as a new long-acting treatment and possible new PrEP medication. People mainly rose to their feet in support of the grand vision of being able to offer women and girls more options and better quality of life.

And one other aspect was emphasised several times: in the long term, successes in individual regions or population groups are not enough to stop a global epidemic. We can only succeed together. And so I take the liberty of concluding with a favorite quote from the 2024 World AIDS Conference: „Without women, we have no chance of stopping HIV.“



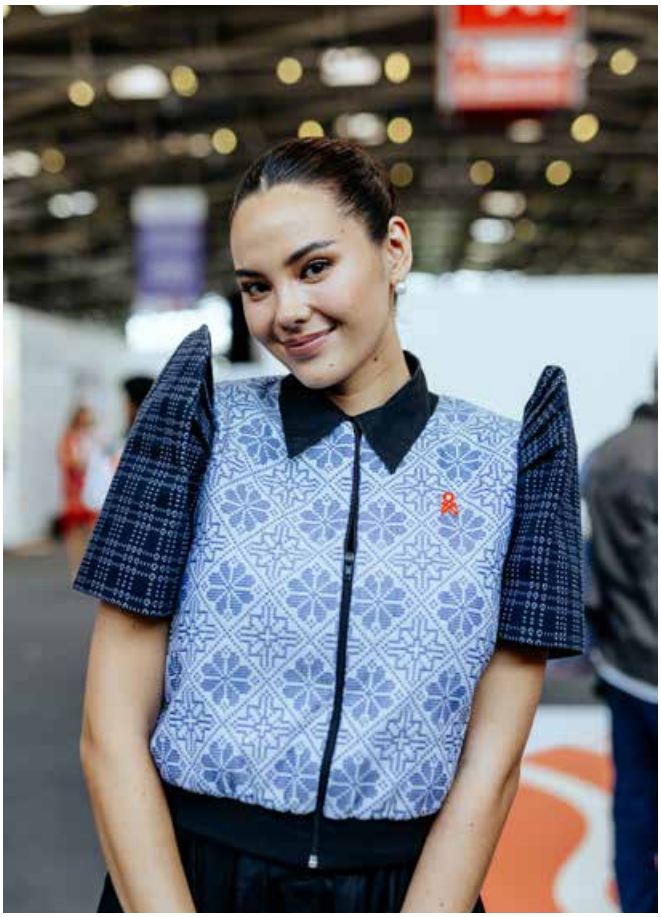


From around the world

People in the Global Village,
portrayed by photographer ***Johannes Berger****.*










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Sex?
SEX IS
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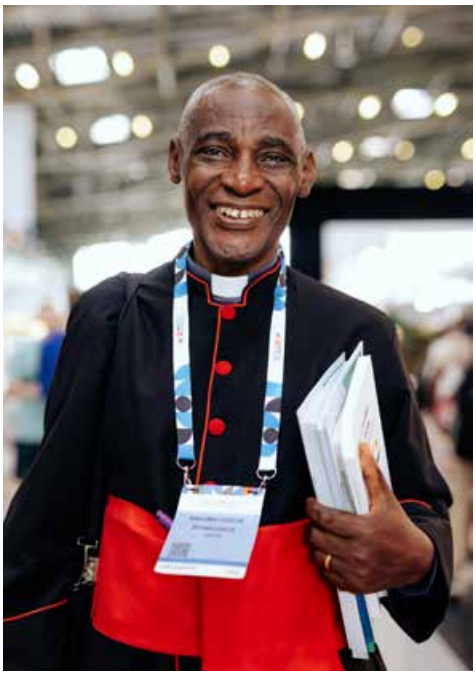

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HELFERZELLEN
GEGEN RECHTS
POSITHIVHANDELN NRW

“Doubt takes root faster than courage”

No breastfeeding, separate toilet in the delivery room: even in obstetrics departments of all places, mothers living with HIV sometimes face blatant discrimination. When women experts discussed counter-strategies, they arrived at the following conclusion: abolish the patriarchy!

“A pregnant woman walks into a birthing centre …”– a phrase that could be the opening line of a running joke. But the case studies that were the subject of the ‚Women living with HIV and obstetrics‘ panel discussion are dead serious. How about this example: a pregnant woman goes to a renowned university hospital to give birth, and is assigned a separate toilet – ostensibly to prevent transmission to other patients!

What sounds like a reminder of 1980s AIDS hysteria is actually a case from recent years. Hannah Harms is aware of many similar reports from her counselling practice. Together with her XXelle PLUS colleagues (HIV-positive women activists in North Rhine-Westphalia), she recounts the ‚classics‘ of discrimination: at the beginning of their pregnancy, many women are – thanks to the counselling they receive at Aidshilfe organisations and HIV-focused medical practices – well informed, and determined to give birth without caesarean section and to breastfeed. Both are easily possible thanks to HIV treatment. But then they start looking for a midwife and a birthing centre. And the staff there often know less about HIV, and they doubt their patients‘ expertise. “Doubt takes root much faster than courage“ says Hannah Harms. „Even if the woman knows the current official HIV treatment guidelines, it‘s enough if one person says “You are putting your child at risk” – and this message becomes and remains the loudest voice in the woman‘s internal dialogue.

„Pregnant women are not activists. They shouldn‘t have to fight for their rights when they‘re in the delivery room.“

Hannah Harms

One of the most important tasks for counselling centres therefore remains „to empower women so that they trust themselves“, Harms emphasises. Actually, medical professionals should be up to date with the scientific evidence, and advise women accordingly. „Pregnant women are not activists. They shouldn‘t have to fight for their rights when they‘re in the delivery room“, says Harms.

In order to improve the situation, obstetrics in Germany must be changed „inside and out“, demands Alexandra Frings from XXelle PLUS. The network has developed training for midwives and the nursing professions. On the other hand, women living with HIV should be given information about their rights and complaint options. For example, each case can be reported anonymously to Deutsche Aidshilfe‘s contact point for HIV-related discrimination.

Despite the serious topic, there are laughs throughout the discussion because the level of cluelessness about HIV can appear absurd. Just like at the university hospital mentioned in the case study above. After the regional Aidshilfe organisation had made enquiries and discussed the issue with the senior



Discussion in the Networking Zone



Right to left: Kerstin Mörsch, Birgit Körbel (XXelle Plus), Hannah Harms, Alexandra Frings, Anka Hellauer (Deutsche Aidshilfe Contact Point for HIV-related Discrimination)



physician, the separate toilet was abolished – but only for pregnant women with undetectable viral load. „When it comes to toilets in particular, HIV viral load has no bearing at all“, explains Kerstin Mörsch from Deutsche Aidshilfe‘s discrimination contact point. „I understand that in such a large institution, ancient infection control regulations may still lie dormant. But when they‘re discovered, they should be disposed of like a rotten egg.“

Deutsche Aidshilfe‘s offer to update the hospital‘s infection control rules was rejected. “They didn‘t even share them with us, either because they do not exist, or because they are extremely embarrassing“, Kerstin Mörsch suspects. “This is what makes our job so difficult. It‘s enough material to write a comedy routine.”

Lack of knowledge and a misogynistic worldview

But jokes aside, the reasons for discrimination against women living with HIV – and their children – include not only a lack of knowledge, but also a misogynistic worldview. „The topic of HIV must be given more room in training institutions and universities“, emphasises Sandra Bischoff from Aidshilfe Leipzig at the end of the panel discussion „but it is just as problematic that women‘s expertise is so often discredited in the hospital setting. I think that the grand solution to all our problems is abolishing the patriarchy.“ This might be even more difficult than convincing the Consultant Physician at a university hospital – but the audience‘s cheering shows that those present are ready for anything!

Philip Eicker



Life live



on stage

For many years, psychologist, Alona Khlystik, has worked as a project manager and coordinator in non-governmental organisations in Ukraine. Since the full-scale invasion of her home country, she has been living in Germany, and has launched GRUND – the Ukrainian Playback Theatre project in Berlin.

In the Global Village's community networking zone, the ensemble twice offered others an insight into their approach – moving, impressing, and touching many people in the process.

Life live on stage

Alona, how did you get into Playback Theatre?

"I learned about Playback Theatre at a festival in Dnipro. When I was diagnosed with HIV in 2019, I joined the ensemble myself. It was very difficult for me to accept my infection and not to stigmatise myself. Participating in Playback Theatre helped me a lot with accepting the diagnosis, and to talk about it openly. Many people got tested for the first time when I told them about my infection. And they were less afraid of it because my story showed them that they would be able to live with HIV."

What exactly is Playback Theatre?

"Playback Theatre means ‚playing it back to you' without judgement. It's a form of social improvisation theatre, whereby people from the audience share personal experiences, and the actors and musicians then enact them on stage. Using physical expression, improvisation, and music, stories from people's lives are transposed in such a way that they suddenly seem to gain a new depth and beauty, and thus enable people to see their personal experiences in a new light."

How did your Playback Theatre ensemble form here in Berlin?

"When I came to Berlin because of the war in Ukraine, I started to totally reshape my social environment. Together with a colleague from Odessa, I founded a Playback Theatre studio, and we began offering lots of workshops.

Later, we founded the Ukrainian Playback Theatre ensemble called GRUND. At the same time, I'm also co-founder of PlusUkrDe, an organisation supporting people living with HIV from Ukraine who are living here in Germany. I know how this method effectively creates a space of trust and support, and contributes to overcoming discrimination, stigma, and self-stigmatisation. Playback Theatre is about re-enacting personal stories, which creates empathy and compassion. This kind of experience is very important for people living with HIV, as well as for people who had to leave their home country."

What was it like for you to perform at the Global Village?

"It was a great honour for our theatre ensemble to participate in the conference. It was important to us to hear different stories and give them space. The language barriers and the noise levels were challenging, but we managed to create an atmosphere of trust and compassion.

I am very much looking forward to offering a workshop at the nationwide meeting of people living with HIV in November. I know how Playback Theatre has affected me, and I see it as my calling to make this method available to others. Playback Theatre helps build and heal communities."

The questions were asked by Heike Gronski





You're great – just the way you are!

Familiar faces: at the Munich conference, four participants in the 2023 World AIDS Day campaign talk about why they went public, and about what it is that they owe to the HIV positive community.

At the Munich World AIDS Conference, you meet people from all over the world – as well as a few familiar faces. Including, for example, those fronting the World AIDS Day campaign ‚Living with HIV – not what you think?'. Denis, Hildegard, Kristina and Lillian are sitting on the softwood steps of the German pavilion and talk to Deutsche Aidshilfe's public relations officer Holger Wicht about their experiences with the campaign. Switching between German and English, they reflect on why they went public in 2023, and how much their activism has helped them.

Wearing a bright yellow dress and in her early 50s, Lillian is the oldest in the group. She is also the most experienced: she has been standing proud and strong for the Aidshilfe movement for around 15 years. Now a grandmother, small talk about the grandchildren leads her directly to her activism – almost a quarter of a century ago, many wanted to talk her out of having a child at all. "My doctor in Halle told me at the time that I was too weak, and that my child may die during the birth." Fortunately, she knew better – through information she had received from Aidshilfe HIV organisations. "This gave me the strength to fight for my child", Lillian says." My doctor in Halle was scared – and he made me scared, too. Unfortunately, there are still doctors around in 2024 who don't know the facts, but fortunately we have our communities and share the information."

Overcoming fear – your own and other people's

With her public statement for World AIDS Day, Lillian wanted to help others overcome fears about HIV – their own and other people's. "One result of the campaign was that people saw us – we said publicly that we are HIV-positive, and that we've been continuing to live our lives after diagnosis. And that nothing bad happened. We are happy. This gives many people courage, especially in the African community in Germany."

Although Kristina is around 15 years younger than Lillian, she can still remember that queasy feeling: "In the past, I've always been afraid to come out as HIV positive. It felt like an excuse: ‚Be careful when you're near



The faces of the nationwide World AIDS Day campaign in Germany.

me!' Today it feels more intimate: ‚I trust you so much that I'm sharing something important with you.'" So far, everyone has returned Kristina's trust. "They felt that they, too, could open their hearts and trust me with something important." It's been clear to Kristina ever since that "We HIV activists can change the way people talk about certain things. We use a language of love."

> "We HIV activists can change the way people talk about certain things."
>
> Kristina

When Denis tells his story, it seems like he's been the least scared of these four. A martial arts practitioner from Leipzig, he had come out to his coach before the start of the campaign. Not fussing about, the coach had immediately called the team together so that Denis would be able to tell them all at once. He'd assured Denis beforehand that anyone who had a problem with it would be barred from the gym. But instead of protest, nothing but applause had been coming from his teammates. "That felt great," Denis says. "Now I know for sure: I have the support of my entire sports club." The 44-year-old sees himself as part of a long line of activists in the fight for visibility and respect. "Just as I had a role model who motivated me to become an HIV activist, after the campaign I was approached by people who said: ‚Great! You motivated me.'"

"Involvement in and with the HIV-positive community apparently confers ‚superpowers'", observes interviewer Holger Wicht at the end of the hour-long conversation. Hildegard can only confirm this. Now, ten years after her diagnosis, this postwoman from Fürstenzell no longer feels as alone as a "goldfish in its bowl", but part of a community. "My life has become more colourful thanks to my Aidshilfe organisation. For example, I came into contact with gay men who said 'You are great – just the way you are! You are one of us and you are not alone.' These days, I go to the Pride march, and I came here, to this conference. Now I'm a part of it – and I think that's great!"

Philip Eicker

www.welt-aids-tag.de/kampagne



Women only!

Drug use and addiction not only permeate all social classes, they affect men and women alike. The fact that their needs differ is still not taken into account enough by support and counselling services.



Tatjana Lebed, Alla Bessanova, Sabrina Sánchez (left to right)

According to experts, addictive disorders in women are more readily seen as taboo, and stigmatised, and are therefore more likely to be concealed by those affected. According to a report by the International Narcotics Control Board (INCB), women access treatment services such as substitution much later and, most importantly, less than men do.

As Sabrina Sánchez, activist and managing director of the European Sex Workers' Rights Alliance, notes, it is not surprising that women avoid consumption rooms and other drug use support facilities: „it is simply self-protection."

Consumption rooms as safe spaces

„Women are exposed to male violence everywhere, even in consumption rooms, and trans women and sex workers even more so," she emphasised at an event in Deutsche Aidshilfe's Networking Zone. That's why women-only services are so important. Alternatively, such consumption rooms could – if financially supported – also be organised informally, perhaps even within circles of friends. However, it is important that support and health services for women who use drugs are also operated by women. „No matter how committed men are to harm reduction", says Sabrina Sánchez, „they will never be trusted as much as another woman."

Tatjana Lebed, who advocates for women who use drugs in Ukraine, agrees. „There are just so many women-specific topics that men may not automatically consider, or cannot discuss on a peer-to-peer basis. For example, when women who use drugs become pregnant or already have a child to care for", she explains. In Ukraine, an association of women who use drugs is planning to set up five peer-based contact points nationwide, where, in addition to providing medical care for women, tuberculosis vaccinations can also be provided to their children, for example.

Back in 2017, the German Federal Government's then Commissioner for Drugs, Marlene Mortler, had found that there were too many barriers preventing women from seeking treatment. One of them is being disowned by one's family, and the shunning of addiction as a taboo subject in general. However, some particular problems reach even deeper. For example, women are more heavily stigmatised regarding their drug use because this behaviour stands in contrast to social expectations of women as mothers.

> „I would like to feel like a woman – free from stigma, and without fear of going to prison."
>
> Alla Bessanova

"As a mother and a partner, my drug use makes me constantly feel like a criminal, but I would like to feel like a woman – free from stigma, and without the fear of going to prison", explains Alla Bessanova from the Eurasian Women's Network on AIDS management team. „I have no choice but to live with the self-stigmatisation."

In some European countries, support services tailored to the needs of women who use drugs have been established for many years. In France and Portugal, such specific interventions are even prescribed in programme guidelines on drug use support services and harm reduction. One Belgian housing project, for example, which is primarily for women who are single parents, also aims to improve the mother-child relationship. During the day, the children attend a day care centre or go to school, while the mothers participate in a treatment programme.

In Germany, female-specific services are rare. In the addiction treatment centre ragazza e. V., Hamburg has had a supportive drop-in centre with consumption room exclusively for women drug users since 1991. The women's addiction counselling centre LAGAYA in Stuttgart has existed even longer, since 1984. However, these are stand-alone projects, and comprehensive, target group-oriented support services across Germany, as called for by the Federal Drug Commissioner herself, are still lacking today.

Axel Schock

Jump-start for a positive life

The Germany-wide buddy.hiv project is a successful model – and a unique and inspirational example of its kind.



Team-Meeting Buddy.hiv

For almost a decade now, these ‚buddies' have been supporting people in dealing and learning to live with their recent HIV diagnosis. More than ten of the currently around 60 volunteer buddies came to the Global Village to present their project. They offered insights into the training that all buddies go through, presented their website at buddy.hiv, and shared their experiences of accompanying people on their journey after a positive test result. Over 75% of people who contact one of the buddies have received their diagnosis in the preceding 12 months. This means that the project really is reaching the group it intends to reach.

Michael, one of the original buddies, had done some research in advance of the Munich gathering, trying to find comparable international examples with the intention of using the conference to establish an international network of buddy projects. His search results, however, were sobering: there are only a few similar projects. What makes buddy.hiv special, and what the buddies identify with to a large extent, is first and foremost the peer principle. This means that people who are living with HIV share their experience directly with other people who are living with HIV. Many buddy projects in other countries, however, work differently. There, buddies are trained to support people with HIV in various areas of life, but aren't living with HIV themselves.

Positive examples of living with HIV – naturally!

Another principle of buddy.hiv is that, on the website, all buddies have their own profile where they briefly introduce themselves, and through which they can be contacted directly. No intermediaries intercede between the two parties. These profiles provide information about age and gender, the region in which the buddies live, but also about their interests and hobbies. As a result, the buddies' personal backgrounds become apparent in the profiles to some extent, and those interested can select someone they think might be a good match. Experience shows that many of those looking for support benefit even from just reading the profiles because they already paint a picture of how people are living with HIV today. This picture includes women living with HIV who had children; people living with HIV who found the love of their life despite HIV; people who climb the career ladder, who work, travel, play sports, and who hardly feel restricted by their HIV infection in everyday life at all. To read about these lives, and to see photos of people from all age groups – without being able to tell from the way they look that they have HIV – is in itself a great relief for many readers. Another welcome side effect is that these small glimpses into life with HIV are also read by people who are not living with HIV themselves, which breaks down prejudice and corrects outdated perceptions. According to Michael's research, only two other projects are still following this approach, one in Poland and one in Upper Austria – and both were modelled on buddy.hiv. All other comparable initiatives only offer an initial contact point from which users are then referred on.

The third special feature, which apparently is found only in a few other projects, is the principle of self-determination. The idea for buddy.hiv came from people living with HIV, who designed the project themselves. Both training new buddies as well as further development and quality assurance are carried out by people living with HIV. While the project is sponsored by Deutsche Aidshilfe, its overriding principle is „Put people first". This is one more reason why buddy.hiv just had to feature at AIDS 2024.

Heike Gronski

Diversity is strength

'Together for Diversity, Justice and Health' – united by this international motto, conference participants from all over the world and supporters from the Munich community gathered for a protest march through the city centre.

At previous World AIDS Conferences, these events were always part of the official programme: large protest rallies coordinated by local organisations, carrying the topics of the conference and the demands of HIV activists and organisations out of the auditoriums and into society in the respective host cities. Not so in Munich. Deutsche Aidshilfe – together with seven other organisations, including the European Harm Reduction Network, AIDS Action Europe, and the Munich Positive People's Network – decided to register their own protest rally. The crowd of around 200 people who gathered at Gärtnerplatz looked comparatively small in relation to the approximately 10,000 conference participants, but it was large, loud, and colourful enough to cause a stir and attract some attention in the early evening of July 25th.

„Migrants with HIV" – „Support for all" – „Nothing about us without us" were some of the slogans carried at the head of the march on a large, hand-painted banner.

Against racism, stigma, and discrimination

Placards in different languages opposed not only racism, stigma, and discrimination, but also Russia's attack on Ukraine, and advocated for human rights around the world.

„It feels good to show Munich and the world that we are united, that we are loud, that we are diverse, and that we all stand for worldwide solidarity", said Gabi Trost of the Munich Positive People's Network at the rally.

Tobias Weismantel, Aidshilfe Munich's managing director, directed people's attention from the global to the local situation, and, with reference to the Bavarian parliament just a few hundred meters away, pointed out that Bavaria continues to oppose drug consumption rooms – standing in the way of the prevention of infections and the saving of lives. Gabi Trost reminded the audience of another scandalous Bavarian peculiarity: to this day, refugees are, without exception, forced to undergo HIV tests.

Gannah Dovbakh of the Eurasian Harm Reduction Association drew attention to the situation of people who use drugs, not only in her native Ukraine, but all over the world. „Support, don't punish" is an important message because it makes it clear that people who are addicted to drugs need support in order to survive. „This is why we must campaign for decriminalisation – of people who use drugs, of people living with HIV, and of queer people."

'Together for justice, diversity and health'

„When I look around me, I see a diverse community. We are people speaking different languages, from different religions and age groups, with different skin colours, places of origin, lifestyles, and different genders and sexualities", emphasised Deutsche Aidshilfe board Member Ulf Kristal in his speech. "It is this diversity that makes our community strong." When he takes a look at the world, Ulf says, „we need that strength to stand up against those who are fighting us – be it through anti-LGBTIQ + laws such as in Russia, Uganda, and Hungary, or through the ban on gender-neutral language here in Bavaria."

His closing statement is both an appeal and a task: „Let's fight together against stigma and discrimination: together for justice, diversity and health."

Axel Schock



Gannah Dovbakh



Gabi Trost and Tobias Weismantel (r.)


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