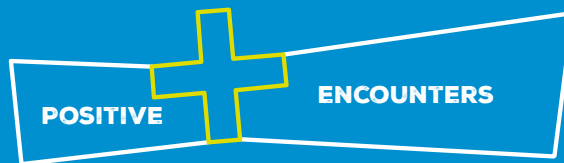


Life+ MAGAZIN



THE CONFERENCE ON LIVING WITH HIV





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A SUCCESSFUL EXPERIMENT!

**Dear PoBe Participants,
Dear Readers,**

You are holding in your hands the documentation of an experiment: In 2022, Europe's largest self-help conference on living with HIV simply provided an open space and invited everyone to use it for encounters under the motto "Celebrating differences together – visible, combative, strong!". Together we filled this space – with vivid events and results that no one could have even imagined before.

After the COVID break, the mere fact of being able to finally meet in person again was exhilarating. Self-help thrives on direct contact and the experience of being part of a community. And this is exactly what we finally achieved again in Duisburg.

And we brought the gathering of the HIV self-help community to a whole new level right away: Many refugees from Ukraine joined us; the red of our ribbons was occasionally interlaced with the blue and yellow of the Ukrainian flag. All in all, Positive Encounters was attended by more people of non-German origin than ever before, with the African community being represented particularly strongly.

It was also the very first PoBe to be officially held in four languages: The plenary sessions were simultaneously interpreted into German, English, Ukrainian and sign language – partly using a smartphone app from Berlin. And it even worked most of the time!

The fact that we all belong together was plain to see at the joint demonstration through the pedestrian precinct of Duisburg's city centre. And it could also be felt when some of us danced together in front of the Mercator Hall for an hour or so after the demonstration.

The participants' topics and creativity brought together the right people in the right groups in the open space. In an exceptionally colourful "Market of Opportunities", the community showed what they had accomplished during the four years since the last PoBe, demonstrating that the COVID pandemic did not mean a standstill: The promising "medication" RESPEKTOMAX and the new campaign "HIV is also female" by XXelle PLUS made their debut here.

New initiatives and networks were formed as well: Young Africans who had to flee from Ukraine and are now facing deportation from Germany joined us and we are now fighting together for their rights under the motto #SchutzFuerAlle (protection for all).

What happens in Vegas stays in Vegas. But everyone should know what happened in Duisburg! It was a unique Positive Encounters that set many things in motion. The community has restructured itself – and it was thrilling. A successful experiment!

In conclusion, it should be mentioned that the open space format also requires a lot of careful preparation. We would like to thank everyone who made this event possible: in the preparation group, the networks, the thematic workshops, in Aidshilfe Duisburg and in Deutsche Aidshilfe. We thank all helpers, sponsors and volunteers. And, of course, we thank the key persons: the participants. See you again in 2024!

The Board of Deutsche Aidshilfe
Björn Beck, Ulf-Arne Kristal, Winfried Holz,
Sylvia Urban, Sven Warminsky



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CREATE SPACE FOR ENCOUNTERS

Dear Readers,

As we are holding the PoBe magazine in our hands, looking at the nice pictures and reading the exciting contributions by so many people who were part of the conference, our hearts fill with joy and gratitude. Not only because it was still summer at the time and now it's cold outside, but first and foremost because of the many open hearts we captured. Because our expectations, hopes and plans did not only come true, but were even exceeded.

We wanted to create space for encounters. Space to take stock, after more than two years of a pandemic associated with many sacrifices. During these two years, the world seemed to be spinning faster in many respects. We all have gone more digital, because virtual encounters were often the only option to get together. We all have come to know what a PCR is, which was not a common term before. Today we are all familiar with the advantages and drawbacks of mobile work, loved by some, dreaded by others.

For others, it felt like the world had slowed down. Many AIDS Service Organisations had to discontinue some of their services. At times, meeting friends and visiting each other was no longer possible. People passed away, and we did not have the chance to say goodbye to them together. People grew lonely, got depressed, shut themselves away and felt lost.

For many people with HIV, this pandemic was also a trigger, reminding them of the early days of AIDS in the 1980s. The uncertainty of not knowing whether the virus is a threat to mankind, the blaming of entire groups, feelings of shame when tested positive, isolation, fear and division of society – COVID-19 brought all this with it, especially in the first few months, and all this had already been present in the 1980s, when the first cases of AIDS occurred in Germany.

All this has changed us, our demands and needs and the way we live together. For us as the preparation team, it meant that we were not able to make the event tie in seamlessly with the PoBe 2018, especially because the PoBe 2020 was cancelled due to the pandemic. By implementing the conference in an open space format, we wanted to give all participants the opportunity to share with us what moves them now, in 2022. We wanted to give space to everyone without giving any guidelines, because we wanted to know where you stand, what motivates you today in self-help, what topics you are interested in, what you would like to discuss and what you want to work on and with whom.

You shared your concerns with us, accepted our invitation, opened your heart and put your thinking caps on. We would like to thank you for doing so. It was a process that involved a lot of work, many ups and downs and sometimes a great deal of stress. But it was worth it, because you turned it into something awesome.

Stay healthy and see you again in 2024!

Your PoBe 2022 preparation team
Abbas, Christian, Daniela, Denis, Dominik,
Ervan, Lillian, Martin, Silvia and Thorsten

DIVERSITY AS AN OPPORTUNITY AND A GIFT

Dear Readers,

It is certainly not every conference management's dream to prepare one and the same conference three times in a row, and I have to admit that I almost ran out of steam shortly before the finale. First, the 2020 conference was cancelled due to the COVID pandemic when the planning was almost completed, then our event venue was cancelled due to the war in April 2022 at a stage where the entire logistics planning of the conference was already finalised. And yet we managed to open Positive Encounters on 7 July 2022.

362 people came to attend Positive Encounters 2022 in Duisburg. 40 percent of them were women (the highest percentage ever) and more than one-quarter were people from the African community (more than ever before). There were also more than 50 participants from Ukraine, people who had to leave their country because of the war and bombings just a few weeks before. I was excited, although still very nervous, because not only the obstacles during the preparation had been giving me a hard time, but also the worries about whether the open space format would be accepted by the participants.

After the presenters had given an introduction to the method, my excitement went through the roof. Shortly, the participants would be asked to stand up and contribute their topics. What if no one stands up? The mood would be spoilt and the PoBe would be over before it even started. Then the moment came and it was overwhelming. A queue of people wanting to present their topics formed instantly. From that moment on, I remembered why I like my job so much and knew that all the previous effort and stress was worth it.

Yes, even after more than ten years, my job still makes me happy; I live for these moments. Opening up spaces for people who want to represent their interests, free themselves from stigmatisation, fight against discrimination and unite to become stronger – that is exactly what I want to do. Enabling, strengthening and promoting self-help is often challenging, but I am deeply convinced of the meaningfulness and social benefits of strong self-representation.

Now it is about maintaining this standard and continuing to stand together as one. I am committed to seeing diversity as an opportunity and a gift to learn from each other and fight together. The HIV-positive community is still a long way from leaving behind sexism, racism, homophobia and trans*phobia, ageism and classism. But this year's PoBe has shown that it is possible and that there is great willingness to approach each other. Let us continue on this path together and meet again to celebrate differences at the next PoBe in 2024.

I am already looking forward to seeing you again and thank all participants and my colleagues from the preparation team for a wonderful PoBe 2022. You give me the energy to prepare conferences even three times.

Your Heike Gronski

CELEBRATING DIVERSITY AND COMMUNITY

TEXT AXEL SCHOCK

The opening event already focused on key topics and aspects of Positive Encounters 2022



What a start! The excitement, anticipation and relief of the many hundreds of conference participants was virtually tangible. “Four damned years” have passed since the last Positive Encounters, as presenter Holger Wicht put it. And this pandemic-related forced break has once again made us aware of how important Europe’s largest conference of this kind is to people with HIV.

The preparation team made every effort to implement the PoBe despite all the adverse circumstances.

Because after it had to be cancelled due to the pandemic in 2020, it was again on the rocks in the spring of 2022. The planned event venue, an industrial building in the Landscape Park Duisburg-Nord, had been converted into an emergency shelter for refugees from Ukraine. Luckily, an adequate replacement was found at short notice in the Mercator Hall.

Language diversity

Apart from the COVID-19 pandemic, the war in Ukraine also had a substantial impact on the PoBe – and not only dominated the opening event, but also made the congress as such a very special one, as DAH's Press Officer Holger Wicht emphasised in his welcome speech.

Both on stage and on the following days, communication took place in four different languages: English, German, Ukrainian and sign language. The PoBe 2022 was also attended by more people from the African community than ever before. And, for the first time, people with and without HIV from Ukraine were among the guests. For this reason, a Ukrainian-German translation app turned out to be one of the most important tools for the following days. Even though there were no technical problems with interpreting at the opening, Holger Wicht was right: "Not everyone will understand everything, but we can get in touch with each other and celebrate ourselves together."

But this year's PoBe also turned out to be very different from the previous conferences in other respects. The pandemic-related break and the developments of the past four years made it necessary to take stock. Some of the plans that had been developed at the PoBe 2018 in Stuttgart could not be implemented as originally planned, as pointed out by DAH's Board Member Ulf Kristal in his opening speech: "This year's Positive Encounters is the time for us to take a look together: Where do we stand? What are our topics? What has changed? What do we need for the coming years? What is our approach to cooperation?"



"Diversity is what makes us strong as people and as a society."

President of the Bundestag Bärbel Bas

Patron of the PoBe, President of the Bundestag Bärbel Bas, who unfortunately was unable to attend the conference due to her professional commitments in Berlin, used her video message to thank the AIDS Service Organisations for having done "real grassroots work" as well as the paid workers and, above all, the many volunteers for "being the backbone of AIDS work".

To Bärbel Bas, such sentences are no empty phrases; she knows exactly what she is talking about. As a health politician, she was involved in HIV/AIDS issues for a long time for her SPD parliamentary group and was already a member of Aidshilfe Duisburg/Wesel District long before that.

In addition, the Duisburg-based politician emphasised that HIV is not the only thing and "most certainly not the most important thing that defines a person". To her, the motto of the conference – "Celebrating differences together – visible, combative, strong" – is a credo to which she is fully committed: "Diversity is what makes us strong as people and as a society."

“What could be more beautiful than having our Positive Encounters here in Duisburg, a city that stands for change and diversity. ... To me, the city stands for shaping the future through change and diversity.”

Ulf Kristal

Marie Schellwat, Managing Director of Aidshilfe Duisburg/Wesel District, also took up the conference motto in her welcome speech: “Coherence and solidarity are still essential values in the Ruhr, and AIDS Service Organisations should also work together in solidarity.” It is important to “be visible and, if necessary, also raise our voices”. This is the only way to ensure that HIV-positive people in the country and AIDS Service Organisations receive the support they need to reduce stigmatisation and discrimination and to secure medical care.

The weak points in medical care, the gaps in counselling and research and the forms of discrimination that make the life of the communities difficult were repeatedly addressed in the course of the opening event.

Philine Edbauer pointed out the consequences of “criminalising drug use and non-scientific drug policies for people who use illegal drugs”. The #MyBrainMyChoice campaign, in which the activist is involved, therefore calls for ending the prosecution of people who use drugs as well as their rehabilitation and the restoration of their privacy.

Discrimination continues to make life more difficult

Collins Opiyo reported about his experiences as an interviewer in the “positive voices 2.0” study in a statement. One of the most important, but also most surprising insights from the participatory research project for him personally was the realisation that people with HIV are still facing massive discrimination: in the family, at work, in the healthcare system and also in the communities.

Whereas the surveys and interviews of “positive voices 2.0” have already been evaluated, another research project is still ongoing. The results should be very interesting, because it will be the first large-scale study to collect data in Germany about the needs of trans* and non-binary people concerning sexual health, as Jonas Hamm explained. The data will later serve not only to offer improved and more targeted counselling and healthcare services to this group of persons, but also to support networking structures.





Universal problems and challenges

On behalf of the roughly 50 Ukrainian participants of the PoBe 2022, Tatyana from Kiev described her current life situation, certainly speaking for many others of the thousands of people who had fled the war in Ukraine. She is glad that she and her son have found shelter in Germany and now receive the necessary support and medications. However, she also reported about the administrative barriers for newcomers to continuing the substitution therapy. And she talked about a woman who did not dare to reveal her HIV-positive status to the doctor and have the necessary medications prescribed to continue her therapy.

“She was afraid of being stigmatised for having the medications sent from Kiev via Lviv to Germany and ended up being without ART for three weeks, and that in the 21st century!”, Tatyana said, her disbelief, but also her defiant rage, being clearly noticeable in her voice. One essence of this opening event was therefore the reality of life of many people, which is by no means new, but still relevant, namely that the fears and problems of people with HIV, drug users, sex workers, migrants and other key groups are universal and still exist. Supporting each other is all the more important – beyond national and language borders.

Laura Halding-Hoppenheit has devoted her life to it. No one could really imagine a PoBe without Laura and her pop-up cafés, which she always turned into a central meeting point for the participants with her charm and big heart. But the Stuttgart-based restaurateur, HIV activist and local politician indeed stayed away from the conference for the first time. She actually had more important things to take care of, as she reported in a video message: Together with a delegation, she travelled to her home country to attend the CSD in Bucharest and support the local community. “Sadly, Romania is not making any progress”, Laura said. Queer people are being discriminated against and prosecuted; people with HIV do not receive sufficient support from the government. Therapies even have to be discontinued due to lack of medication.

“Solidarity and presence are all the more important.” Laura was definitely missed at the PoBe Duisburg. But she brought the conference motto to life at the Pride Bucharest simultaneously to the conference in Duisburg in her own way: “visible, combative, strong”. ●



Vogue artists Father Ray, Bree Angels Prodigy, Juana Solar and Prudence 007 choreographed a fulminant dance performance specifically for the opening of the PoBe 2022, giving an impression of the lively ballroom scene in Germany.

TEXT THORSTEN SANDNER

INNOVATION AND RENEWAL

The open space format of Positive Encounters was certainly viewed with scepticism by many people before the event. But the experiment seems to have been successful. Will it remain a one-time project or will it serve as a future model?

The idea to implement the content part of the conference completely in an open space format proposed in the preparation group for this year's Positive Encounters – which I was again allowed to be a member of – met with unanimous consent. Although modules had already been held in this form at the two previous Positive Encounters in 2016 in Hamburg and in 2018 in Stuttgart with extremely positive feedback, the decision to implement the whole conference according to the principle of extended coffee breaks meant a huge step forward and a venture.

The terms “self-responsible” and “self-organised” describe central elements of open space and at the same time key elements of self-help that assertively and confidently advocates its positions and demands at a conference on living with HIV.

The goal of open space is to address a topic in a constructive and target-oriented manner with a number of interested people – where no topics are predefined, but everyone can contribute their personal issues. Those interested in the specific topic meet at the specified time in the speci-





fied place and exchange opinions in a self-organised way, while being allowed to leave or join the group at any time.

A frequently cited point of criticism regarding the content-related design of Positive Encounters in the past was that the predefined topics left no or only little room for personal issues – whether for individuals or for larger groups. Another not-to-be-underestimated factor was the four-year break after the pandemic-related cancellation of the PoBe 2020, making the encounters feel even more like a reunion than usual – both on a large scale and on a personal level.

The open space format takes all these factors into account. In addition, it became apparent in recent years that the format of Positive Encounters requires innovation and renewal from time to time – while preserving traditional elements.

Nevertheless, there is always a remaining risk. Open space can only work – especially at a conference with more than 350 participants – if the participants go along, have understood the principle of self-organisation and contribute topics to a sufficient extent. Although all PoBe visitors had been encouraged to think about possible topics and issues beforehand, it was not possible to estimate

whether and to what extent they would do so. Moreover, the successful implementation of the format requires a high level of organisation and a structural framework – especially to secure the results and ensure that the topics are pursued beyond the conference. The format is also not fully self-explanatory. It requires extensive explanation and introduction, demanding quite a lot of concentration from the audience.

But all these concerns ultimately turned out to be unfounded. The sophisticated seating arrangement and the ceremonial style of the two presenters – accompanied by headnotes attached to the walls and the classification of the participants into “bumblebees” and “butterflies” might have added a touch of esoterism and American church to the introduction to open space – it more than fulfilled its purpose: The principle was generally understood.

There was also no shortage of contributions. People formed long queues to present their topics. It became clear that quite a few of them had prepared for the event and had clear and precise ideas in mind, while others brought forward their issues spontaneously. There was an exceptionally broad range of topics, from dealing with the media in interviews, questions about acquiring volunteers,

the lack of visibility of women in the community of people living with HIV to the economic and emotional worries and problems of gay men in old age and the saving of meetings for HIV-positive people at the Waldschlösschen conference centre. There were both perennial topics, such as the tense relationship between self-help groups and AIDS Service Organisations, and topics that have not yet been discussed at a PoBe in this form, such as prevention of violence against women and children. A theatre workshop and an introduction to German sign language were offered and various issues of participants from Ukraine were addressed. Quite a few topics were directed internally to the community, voicing complaints such as lack of perception and appreciation.

The self-organisation part also worked fairly smoothly; start times and rooms were evenly distributed. Groups that needed a larger room were able to find one. During the implementation, it became apparent that some modules were prepared with clear topics in mind, while others were based on spontaneous exchange.

Central elements for the continuation of open space are the securing of results as well as the consensus to pursue and implement the topics. Again, the participants showed great willingness to do so.

In the final round, many participants reported with great enthusiasm that this format offered them the opportunity to contribute their personal issues for the first time.

So, all's well that ends well and everyone is happy? Well, not quite so. There were certainly also participants, albeit not part of the public plenary sessions, who did not get along well with this format, felt alone, even saying that they no longer felt welcome at the PoBe.

The motto of the PoBe 2022 was "Celebrating differences together". Around the end of the conference, the slight subjective impression took hold that differences do outweigh the commonalities. All people living with HIV are ultimately affected by discrimination and stigmatisation and almost all of them additionally meet with hostility due to gender, skin colour, sexual orientation, substance use, etc. The foreseeable scarcity of resources can and will also entail cuts in the support system of people with HIV. So, there are enough topics to develop joint strategies for counteraction. This could probably have been addressed in more detail.

Open space will most likely not remain a one-time experiment. Whether and to what extent the format will play a role at the upcoming Positive Encounters is up to the next preparation group. ●



Action plan

Numerous open space workshops gave rise to specific ideas and plans, which were presented at the plenary session at the end of the PoBe, along with the invitation to join or continue participating. Participation is still possible in many of these projects and initiatives. The contact details of the initiators can be requested by email (heike.gronski@ah.aidshilfe.de).

Barrier-free services for deaf people

The still-young initiative taube_sexperTs would like to develop a guideline and a checklist on how the community can create barrier-free services – such as publications on social media, events and videos. In addition, it is seeking possibilities of networking with other groups with similar problems.

Artists' collective "VirusRiots" (working title)

The artists' group still to be established is planned to be POZ, radical and diverse, aimed at jointly developing conceptual art and artistic interventions. Networking and initial exchange of ideas is to take place via Telegram.

Further development of the nationwide meetings of HIV-positive people

The nationwide meetings of HIV-positive people at the Waldschlösschen Academy are to become more diverse, but, most importantly, the preparation group of Positiv e.V. needs new fellow campaigners from all communities to make the meetings scheduled for 2023 interesting and worthwhile for all people with HIV. Therefore, they would be pleased to reinforce the team with people of colour, women, people with a migrant background, people with disabilities as well as young HIV-positive people, older and trans people. The first planning meeting is scheduled to be held in December in Cologne.

Further development of the nationwide Network Women + HIV/AIDS

The nationwide association "Network Women and AIDS" established in 1992 needs new input and fellow campaigners to reinvigorate the advocacy group.

Awareness of racism and discrimination

Pamoja Afrika e.V. Köln would like to raise more awareness of its concept of anti-racism work in society by offering awareness workshops, training courses and counselling services. <https://pamojaafrika.org/>

Fighting HIV-related stigmatisation and racism

How can we raise awareness of stigmatisation of people with HIV who are also affected by racism and reduce (multiple) discrimination?

To this end, workshops, disseminator training courses and political campaigns as well as lobbying work are planned to be developed and implemented.

Workshops on sexuality and body

Krystina would like to create opportunities (training courses, lectures, events, bodywork, e.g. as part of the nationwide meetings of HIV-positive people and the Network Women and AIDS) to openly address sex and sexuality, relationships, body and self-love. She would like to inspire others to open up and embrace their true selves.

Documentary protect "Positive differences"

The project is aimed at jointly developing and implementing the concept for a documentary about people with HIV.

Plus UkrDe

The association of HIV-positive Ukrainians is planning to establish a registered society. In addition, it wants to further expand the communication channels, collaborations and partnerships with other organisations as well as the counselling and support services. To this end, it is seeking fellow campaigners and funding options.

Theatre workshops

The initiators of the "AfroLebenPlus" mobile theatre group would like to break stigma, taboo and trauma, bring together people who celebrate community and raise the visibility of people with HIV beyond the community by organising theatre workshops.

Opening of events to trans*, intersex and non-binary people

How can DAH events, such as Positive Encounters, be designed to be more inclusive? The organisers are collecting ideas and suggestions to forward them to the PoBe preparation team and the DAH head office.

Support for drug users and homeless people with HIV/AIDS

The plan is to develop and implement ideas and projects in a nationwide group.

Protection through PrEP for all!

Safer sex for trans*, intersex and non-binary people and women: The plans include online meetings with stakeholders from the feminist community, collaborations with regional and supraregional organisations as well as campaigns and activities.

"PROTECTING YOUNG PEOPLE IS A KEY ISSUE FOR US"

INTERVIEW
INGA DREYER

Philine Edbauer's initiative #MyBrainMyChoice has been advocating for drug policy reform for many years. In the interview, she talks about her motivations, education, the rehabilitation from alcohol, personal risks and non-discriminatory language.

You use hardly any illegal drugs yourself. How come you are campaigning for a cause that affects you only marginally?

Philine Edbauer: Many people who are campaigning for drug policy reform don't necessarily use drugs themselves. I've been wondering myself why that is. I suppose we are united by having witnessed the consequences of illegality and criminalisation. Even people who use illegal drugs are not necessarily aware. Because they can often remain invisible with their drug use. The illegal market works so well that you can get anything anywhere.

Some people feel that the use of lacing agents is the only problem left. They are calling for drug checking to find out what drugs contain. Apart from that, there is no political pressure to take action. That's only the case when people have their house searched by the police after they ordered something on the Internet, the operator of a website was busted and the prosecution somehow saw the need to classify some of the people on the operator's contact list as potentially dangerous criminals. Only when people learn about the suffering caused by criminalisation will they have the desire to change something.

"Youth protection services must acknowledge that young people are the experts of their generation and their living environments and need honest answers to their questions."

You argue for responsible drug use. But what about children and adolescents? Shouldn't they be especially protected?

Protecting young people is a key issue for us. All those who campaign with us have experienced personally or through their children that the current prevention work is not enough. The slogan is "Say no to drugs!", and that's it. Young people laugh about the things they are taught if they already know all about it from the Internet. Some did their share of experimenting when they were twelve or thirteen years old and wonder why they are supposed to be educated about drugs at sixteen. Education often uses shockingly graphic images as a deterrent – such as those of crystal meth users living in deplorable conditions. That's terribly stigmatising, as if the lives of the people shown were not worth living anymore. At the same time, it's laughable, considering that most meth users cannot be recognised by looking at them.

An age restriction is not enough to protect young people. At least ten percent of minors have experience with weed and other illegal drugs. When reaching out to them, youth protection services must acknowledge that young people are the experts of their generation and their living environments and need honest answers to their questions to be able to be responsible about their health.

What about alcohol? Drinking is legal, but still causes a lot of damage...

In social circles where illegal drugs are used, it's very common to rail against alcohol. They'll be like: "That's legal, but my drug is illegal." Alcohol is strongly associated with violence by men. When they lose all inhibitions, people say: Leave them be, they're just having fun. Women who drink are thought of differently. They are told not to lose control. That's an issue we should tackle. We – especially as women, and by that, I mean all people who identify as female – want to reclaim alcohol and acknowledge its positive aspects. Of course, alcohol has negative consequences, but at the same time, it also has positive effects.

There is currently a new movement of critical debates about the normality of alcohol – and how we are raised to become drinkers from a young age due to the constant presence of alcohol in our society. But I think in order to make progress in dealing with alcohol it is also important to consider under what framework conditions mindless boozing can work out for everybody without worrying about our own safety. Despite the obvious harmful effects, alcohol is a very popular substance. It's easy to consume by drinking, it's a social activity, it loosens you up, the dose is easy to control and the body usually responds reliably to an overdose by vomiting. It's generally a nice way to take a break from thinking for a couple of hours.

That sounds like you are making an advertisement?

No, we don't encourage drug use. Instead of dreaming of a drug-free world that will never exist, we address real-life situations and their connection to drug policy. Every adult should be able to decide for themselves what they consume without having to feel bad about it from the outset, being ashamed if something goes wrong or being afraid of law enforcement authorities.

There is not one substance that is always bad and another that is always good. Some drugs have special risk potential, so you have to pay close attention to the dosing. Almost every bigger city has initiatives for safer use and safer partying with the aim of reducing drug-related harm. They do a very good job and have discussions about risks. It's about learning what works well for you in what situations.

Some people use drugs as a sleep aid, others want to lose their inhibitions or alleviate disease symptoms. I believe that becoming aware of the various reasons contributes to destigmatising drug use.

What risks are you taking with your advocacy?

Very few so far. Sure, I couldn't apply for certain jobs anymore because people know my name now. In a city other than Berlin, it would probably also be more difficult. I suppose I would have to explain myself more often – or people would avoid me. I know from people in rural areas that they are very much alone with this issue. That's why we organise monthly virtual meetings.

I also study drug policy at an international level and try to use the freedom of speech that I enjoy in Germany. For example, in my master's thesis, I investigated drug policy in the Philippines.

On Twitter, I regularly share my thoughts on international developments – like I did recently about Singapore reintroducing the death penalty. This almost exclusively affects people who have been imprisoned for drug possession. Activists in other countries cannot safely express criticism. By comparison, I'm active in a relatively risk-free environment.

You spoke at the PoBe opening panel. How did you get in touch with Deutsche Aidshilfe?

Dirk Schäffer, the senior officer for drugs and prison, has always been a role model for me in my work. We got in touch with each other at our first #MyBrainMyChoice petition in 2020. My fellow campaigner at the time and I were still completely unknown. We were trying to get major players like Schildower Kreis and Deutsche Aidshilfe on board with our campaign.

That's how we got in touch with DAH and have been collaborating since then. At the moment we are also working together on a destigmatisation project. We are developing a proposal for non-discriminatory language – as a discussion proposal to connect with the support system as well as with politicians and journalists.

What is non-discriminatory language when referring to the people you are campaigning for?

We have chosen the term “people who use illegal drugs” because it puts emphasis on the individual person. Using drugs is just one of the many things that this person does. One of our goals is to be precise and give things specific names. That’s why we think this wording is better than the term “drug user”, which is already destigmatising – especially compared to terms like “drug addict” or “drug abuser”.

The fundamental problem with this is that it’s a remote diagnosis. We don’t even know if somebody is an addict. Such a diagnosis should be made by medical professionals. ●

<https://mybrainmychoice.de>

<https://www.entkriminalisierung.info>

“Every adult should be able to decide for themselves what they consume without having to feel bad about it from the outset if something goes wrong.”





THESE ARE THE NEW POSITIVE FACES



As in the past, new PositHIVE Faces were again elected as part of Positive Encounters. The primary task of this body will be to prepare the PoBe 2024. In addition, the members play an important role as an interface between the HIV community and the umbrella organisation and are entitled to propose candidates to represent the community at events such as the German-Austrian AIDS Congress (DÖAK).

Out of the candidates of the PoBe 2022, the following ten persons were selected as new PositHIVE Faces:

Contact by email to posithivegesichter@dah.aidshilfe.de and via the Facebook page of the PositHIVE Faces.

Nils Böhm

Ingo Buck

CorY Hoffmann

Nicole Kamga

Denis Leutloff

Collins Opingo

Ian Parrington-Fester

Lillian Petry Kababiito

Bert Rozowski

Sarah Salvador

INTERVIEW
WERNER BOCK

HOW INTEGRATION CAN BE SUCCESSFUL: TASTER COURSE IN SIGNLANGUAGE

Positive Encounters 2022 was more diverse than ever before. The conference was also attended by deaf visitors. Communication between hearing and deaf people is difficult and often already fails because hearing people are unsure about how to approach deaf people. To build a bridge, the taube_sexperTs network offered two taster courses in sign language as part of the open space.



This offer was gladly accepted by the hearing PoBe participants; the courses were very popular. The participants learnt how to use the finger alphabet correctly as well as a few basic signs: It was quite a challenge, tackled with a great deal of humour. In this casual atmosphere, it was easy to approach people with whom communication is otherwise fairly difficult.

The two course instructors – Fabian from Munich and Marcel from Essen – talk about how they experienced the conference in a joint written interview.

You offered two taster courses in sign language. What was your motivation to do so?

Putting hearing and deaf people in touch with each other is very important to us. In our experience, many hearing people are insecure towards deaf people and often don't find the courage to approach them. The idea of the taster course was born in an effort to break the ice – a step towards more integration.

How did you experience the two workshops?

We were very surprised to see so many people take part. We were very happy about this keen interest. It made us feel like part of the group.

In the course, I saw a great deal of interest, openness and curiosity among the participants. A central question was: How do hearing and deaf people get in touch with each other? I've noticed that I'm a bit unsure myself, not wanting to be pushy or intrusive. What would be an appropriate way to approach deaf people?

First of all, an appropriate way would be to make eye contact. It's helpful when the person speaks slowly and clearly. Of course, you can also use a piece of paper to write something down – or use your smartphone.

It's also okay to gently tap us on the shoulder to get our attention. In our experience, the communication can initially be a bit difficult, but it usually gets easier relatively quickly and basic communication then works well. Hearing people should feel free to reach out and shouldn't be afraid to approach deaf people.

How did you experience the communication at the PoBe during the official programme as well as the non-official parts? Were you approached by hearing participants or did you keep to yourselves? How can the communication be stimulated? Or are there rather narrow limits?

It very much depends on the topic. Some participants tried to approach us directly without an interpreter or used the smartphone or a piece of paper to communicate with us. Others preferred to wait for the interpreter.

It was the same on our part. But deaf people often keep to themselves, because obviously they don't face any communication barriers with each other.

You are both members of the taube_sexperts team. Please tell us more about it. What exactly do you do?

The team consists of volunteers. It evolved from the DAH's existing expert group of deaf people. We see ourselves as a network and have set ourselves the task of offering the best possible education to the deaf community. The deaf community strongly depends on sign language, and unfortunately not all information is available in sign language. Deaf people often miss out on a lot of information. In the future, we need to position ourselves more broadly and establish additional services.

Many of us experience how helpful it is to exchange experiences with other people who are in a similar situation; this is also one of the purposes of the PoBe. What services are offered to queer deaf people? What services are there specifically for HIV prevention?

Sadly, there are very few or no services for queer deaf people. That's also one of the reasons why we established "taube_sexperts" on Instagram. That way, queer deaf people don't have to feel isolated anymore by missing out on information. The DAH website currently merely offers basic information videos in sign language, and there is the counselling service of the AIDS Team for Deaf People in Hamburg. But that's not enough. More services need to be offered, such as exchange meetings for HIV-positive deaf people and the like.

Apart from Positive Encounters: Are you well integrated in AIDS Service Organisations or are there problems in this area? What would you expect from AIDS Service Organisations?

Unfortunately, we are not yet satisfied with the integration in AIDS Service Organisations, for example because the website and the counselling services of Deutsche Aidshilfe are not barrier-free. Recent videos don't feature subtitles or sign language interpretations. It's also problematic that the texts are not in plain language. More visualisations and illustrations are needed.

There is currently no education on monkeypox (MPX) for deaf people. Although the information is available in text form, that's not enough for most deaf people. The reading skills are not sufficient to understand everything. In this respect, more has to be done.

What is your personal conclusion on the PoBe 2022?

We were thrilled and gained a lot of experiences. The integration between hearing and deaf people worked out well. We're really looking forward to the next PoBe. We hope very much that our demands will be heard and more barrier-free services will be offered everywhere. ●



DISCRIMINATION IS CURABLE

TEXT
MATTHIAS KUSKE

It looks like a box of medicine, and its content can actually help improve the lives of patients in the long term: namely through information and education. The PoBe 2022 marked the launch of the new and original anti-discrimination project "RESPEKTOMAX".

The "positive voices 2.0" study has once again impressively confirmed: People with HIV very often experience discrimination at medical practices, hospitals, rehabilitation facilities or in other dealings with the healthcare system. 56 percent of the respondents report that they experienced discrimination in the healthcare system in the last twelve months before the survey. At the same time, marginalisation in the healthcare sector is perceived as being particularly distressing.

The RESPEKTOMAX campaign

Reason enough to launch an anti-discrimination project that is aimed specifically at doctors and medical associations, but also addresses other stakeholders in the healthcare system. That is why the participants of the thematic workshop "positive voices 2.0" developed the RESPEKTOMAX campaign. The campaign was presented at the PoBe in Duisburg and discussed and enhanced together with the participants. The feedback to the initiative and the materials was extremely positive. Both the look & feel and the contents met with a very positive response. The campaign attracted great interest: About 30 participants provided valuable input for further development and implementation.

The campaign material

RESPEKTOMAX consists of a box that resembles a box of medicine. Apart from candies, it contains a package leaflet that conveys current knowledge about HIV, points out the negative effects of discrimination and briefly presents the key results of the "positive voices 2.0" study. The goal is to initiate a reflection process among doctors and other representatives of the healthcare system through information and education. This is to contribute to reducing discrimination in the healthcare system.

Specifically: RESPEKTOMAX is designed to help doctors recognise discriminatory behaviour at their own medical practices and actively reduce fears, prejudice and outdated knowledge so that people with HIV will experience less discrimination in the healthcare system in the future.

Call for participation: Now it's up to you!

The makers have developed RESPEKTOMAX. The finished material can be ordered from DAH. The campaign focuses on the healthcare sector and should also be used there, for example:

- In campaigns before the meetings of delegates of the medical and dentists' associations nationwide
- At medical congresses and similar events
- At nursing schools or events for medical students
- At events for pharmacists and chambers of pharmacists
- At medical practices, hospitals or rehabilitation facilities where discrimination has been experienced
- Among doctors who support us so that they can pass it on to other doctors
- ... wherever RESPEKTOMAX can bring its anti-discriminatory effect to bear.

Join us! RESPEKTOMAX needs your local activities to take nationwide effect! You wish to have more information or suggestions or would like to know when you can start using RESPEKTOMAX? You can find further information at www.aidshilfe.de/respektomax. ●

"VOLUNTEERING MUSTN'T BE JUST A BOX TO TICK"

INTERVIEW
WERNER BOCK

AIDS work would be hardly possible without volunteers. But some of them also experience frustration and disappointment. In the interview, Ralf Rüdiger from Cologne and Harry from Recklinghausen talk about their experiences and share their ideas on how to improve collaboration between paid workers and volunteers.

Ralf, you offered an open space on volunteering at Positive Encounters. What was your motivation to do so?

Ralf: I was motivated by my own – both good and not so good – experiences in volunteering. In addition, I've met people who wanted to get involved in AIDS work, but their ideas fell on deaf ears. In the open space, I just wanted to hear how other volunteers experienced their work and what could be done better.

Despite your mixed experiences: Why is it important to you to do HIV volunteer work?

Ralf: I believe that few are better informed about HIV-related topics than those affected. This expertise should be harnessed whenever possible. In the course of my volunteer work, I've learnt a lot about myself, and I felt in good hands in this environment, especially shortly after I was diagnosed with the infection. Now I'd like to give something back, because now I'm strong enough to advocate for people who are "more vulnerable".

Harry, you are also HIV-positive and have been involved in HIV volunteer work. What were your experiences?

Harry: I've been active in the HIV-positive community for many years. Unfortunately, I've experienced a lot of frustration. I had the impression that volunteering in this area is only welcome if it meets certain ideas of the paid workers.

For example, criticism was not welcome at all. Self-initiative – even though absolutely professional and justified – was seen as the undermining of paid functions. Ideas that pursued individual objectives but still served the community were blocked rather than promoted. I've seen this in various projects – on a local level, but also on a state and federal level.

Harry, you were also active in sexual health and gender identity counselling as a paid worker for several years and worked with young queer people. What were your experiences from that perspective?

Harry: In my experience as a paid worker, there is often a lack of funding and other resources. Finding voluntary supporters was then always helpful, but this support was often unreliable and sporadic, and other personal interests were often put before binding commitments.

Another thing I experienced was that assistance was often offered by socially disadvantaged people with few friends and contacts who were trying to socialise that way. Sometimes it was clearly apparent that they used this involvement more as a form of self-therapy to come to terms with their own history.

Of course, there were and still are many helpers who perform important tasks at the right time and in the right place and do valuable work with their involvement.

“Volunteering requires reliability”

What should people consider before deciding to volunteer or becoming involved in self-help?

Harry: Volunteering also requires reliability and shouldn't be done on a whim. You don't just organise a task and social contacts for yourself, but you also become part of a system and make commitments. Everyone should be aware of this responsibility.

Based on your experiences: What are the major potential sources of conflict or frustration in HIV volunteer work?

Harry: I think the most important source of conflict is that in certain institutions volunteering is apparently seen as just a box to tick, at least in my experience. Someone among the paid workers HAS TO take care of volunteering, but has no experience in the support, supervision and organisation of volunteering and sees it as an additional burden to their actual tasks. Volunteering mustn't be just a box to tick, but should be supported professionally and with sufficient resources.

Ralf: People who want to get involved as volunteers need paid workers as points of contact who are open to new ideas and don't block good ideas, saying: “We've never done it this way. That's always been done this way. That won't work. I'm not sure if that's worth it ...”. Volunteering also includes feedback, reassurance and support – which is unfortunately not always provided or available without any bias.



What should AIDS Service Organisations do to promote volunteering and self-help? What do you think the collaboration should ideally look like?

Ralf: I think establishing a permanent position in every AIDS Service Organisation to take care of volunteering is urgently indicated. This position must be filled by a person who appreciates the work of volunteers and is open to real participation.

In addition, AIDS work urgently needs to establish a space that encourages new ideas to also align or adapt its own HIV work. People must feel welcome and understood. Volunteering must be recognised and actively supported. Invitations must have a wider reach to ensure that as many people as possible get involved and join in.

Harry: AIDS Service Organisations could place a kind of job advert for various volunteer tasks. Such an overview – which could also be organised virtually – shows what tasks are impending and by when they are to be completed. That way, volunteers can choose a task that matches their skills and interests. Volunteers are no “maids-of-all-work”.

“Recognition and appreciation are crucial”

What is your conclusion on the two open spaces on volunteering?

Harry: Volunteering is and will remain important. To recognise this, a greater and sometimes different awareness is needed among both paid workers and the volunteers themselves. Many people want to get involved, but this involvement also requires certain rules for both sides.

Assistance and support by paid workers must be reliably available; this task mustn't be neglected. The volunteers themselves also need to become more reliable in performing their tasks.

Recognition and appreciation are crucial. That starts with the question of how seriously volunteering is taken in the organisation. But the level of tasks to be taken over by volunteers is also important, as is an appreciative attitude that is also expressed in the manner of communication and information transfer – and also includes a plain thank-you every now and then.



Ralf: Firstly, I realised that some people who got involved as volunteers in the past are no longer able or willing to do so. Secondly, I also recognised the great and diverse potential of volunteers. Many of them have actually more skills than they show or are allowed or want to show. I was impressed to see the great variety of different social and thematic skills and experiences.

But these skills and experiences should be properly supported and actively promoted. When you realise that you can contribute, shape and influence or even change something in the “positive” sense, that’s true self-help. ●

MESSAGE IN A BOTTLE

The velvet cloth laid out flat in front of the big red ribbon is blue like the sea. Many little bottles with swing tops are floating around in it, containing small rolled-up slips of paper. As in the past, the participants of Positive Encounters in Duisburg again had the opportunity to remember deceased people, friends, fellow campaigners and family members as part of a collective tribute. In the course of the conference, many of them accepted the invitation of the “Message in a Bottle” installation to send their messages: words of empathy, love or remembrance. Apart from paper and pens, bottles were provided in which the messages could be symbolically sent on a journey.



INTERVIEW
AXEL SCHOCK

“ENABLING PEOPLE WITH HIV TO LIVE FREE FROM DISCRIMINATION AND RACISM”

Positive Encounters in Duisburg was attended by more people from the African community than ever before. Omer Idrissa Ouedraogo, DAH's Officer for Migration, explains what contributed in this success.



The PoBe 2022 was more diverse than ever before, also because the African community was widely represented for the first time. How did that work out?

Omer Idrissa Ouedraogo: The DAH's migration work is based on the principles of participatory practice, meaning working together with migrants and refugees on equal terms. We aim to promote the self-determination of this target group, strengthen their communities and improve their overall access to healthcare. At the same time, we want them to experience that they can overcome challenges and bring about change by their own effort when they see themselves as part of this society.

One of the reasons why this worked out at the PoBe 2022 is that we at the department of migration closely and continually worked together with the communities. At the nationwide meeting of African projects in Potsdam, for example, we discussed the importance of the active involvement of African communities, specifically why it is important to take part in a market of opportunities, why networking is worthwhile and what positive effects all this can ultimately have on personal life.

What can be learnt from this experience? What should definitely be considered when addressing the community as part of other events and campaigns?

In my opinion, events and campaigns require reaching out to the community early on to enable real participation. Because the community has its own know-how and should understand the purpose and benefits of working together beforehand. And the African community wants to play an active role in implementing events. We need to use various approaches to reach this group. For example, it needs to be checked whether participation fees for events represent an obstacle for some communities, given that migrant communities in particular have very limited financial resources. Since many migrants and refugees have already experienced multiple discrimination and racism, it is crucial to create safe spaces, an environment where people enjoy working together rather than getting (re-) traumatised or hurt.

What feedback did you receive from the African PoBe participants? Are there any suggestions for improvement?

Gladly, the feedback was positive. For example, DAH received recognition for supporting African refugees from Ukraine who experience political inequality and are still facing legal obstacles.

Since diversity can also lead to problems, a small team of trusted people tried to create awareness at the PoBe. We strongly recommend employing a qualified team to raise awareness of multiple discrimination and racism when hosting events of this size that are attended by participants with so different backgrounds. We have to work together towards enabling people with HIV to live free from discrimination and racism. We need to create an anti-racist environment for the future prevention work with the African community. ●

TEXT
MARTIN REICHERT

“NO ONE SHOULD MAKE ME FEEL LESS WORTH”

While diversity has always been a major strength of the HIV community, the percentage of participants of African origin has never been as high as it was at Positive Encounters 2022. Their backgrounds and personal stories may be very different, but their experiences with discrimination and racism are similar.



Kaningiriue
Jatamunua



Positive Encounters 2022 were more diverse than ever before. The percentage of women has grown considerably. More than fifty participants had fled Ukraine because of the war, and the overall majority of the people in the room at the opening event had non-German roots, with many of them being of African descent.

The presence of the latter is owed mainly to Omer Idrissa Ouedraogo, Deutsche Aidshilfe's relatively new Officer for Migration. He himself is from Burkina Faso, has only been living in Germany for a few years – and is well connected. If HIV-positive PoC ever were reluctant to reach out to Deutsche Aidshilfe, Omer Idrissa Ouedraogo has put many of them at ease.

That's also how a group of young students with African roots came to Duisburg after having to flee Ukraine. Many of them are from Nigeria, most of them are medical students – some are HIV-positive and/or members of the LGBTIQ* community. At the PoBe, they found a safe space that offered them opportunities for exchange and networking as well as an opportunity to share their problems.

Second-class war refugees

Kaningiriue Jatamunua is one of them. She is a Herero from Namibia. She wears glasses, speaks flawless English and seems alert and exhausted at the same time. She went to a German school in Windhoek and also speaks a little German – her parents had the idea that this could be a good way for children to make peace with the colonial past and the genocide by members of the German armed forces. And yet, she and most of her fellow students do not have a chance of a decent future in Germany because they have only been taken in temporarily, while Ukrainian refugees are fast-tracked and can already work in hospitals (where they are needed).

Traumatising escape experiences

The students are outraged and exhausted by the unequal treatment and the double standard they face after making an escape that has already been a more than traumatising experience: “In Kiev, we initially weren’t allowed to board the train. We were told it was ‘only for Ukrainian women and children’. But we finally did get in and rode for 16 hours without stopping, with twelve people in one compartment. No place to sit. No water.”

In Lviv, they were forcefully removed from the train. “One of my fellow students even had a gun pointed at his head”, Kaningiriue Jatamunua tells the group, visibly shaken by having to recount her ordeal: “At the Polish border, the Ukrainian border officials wouldn’t let us through. When we asked, we were told: One foreigner per ten Ukrainians. They kept sending us back. We stood there for hours, others for days. By the way, PoC from the UK were not let through, either – so, it wasn’t about the country of origin; it was about skin colour. Racial profiling.”

“No one should make me feel less worth.”

Axel, a young man, tall and bespectacled, rises from the group because he has something to say: “I’m not here by choice. I had plans for my life. But I’m not welcome here. Germany has a double standard for Ukrainian refugees and those from Africa. But no one should make me feel less worth.”

These young, well-educated people suddenly became “displaced persons” who have nowhere to go. They cannot work and are told to attend German language classes, which they have to pay for themselves. Their length of stay in Germany is uncertain, their way back to Ukraine is blocked – and going back to their families, who put all their hopes and a lot of money into sending their child to study in Europe, is not an option.



The group at the PoBe is headed by Helene Batamona-Abeke from Colone-based Pamoja Afrika e.V., an association that does anti-racism work and currently also supports Ukrainian refugees, mainly those with an African background.

At Pamoja, they can get a hot meal every day (even though the organisation is not specifically set up for it) and psychosocial counselling. “Bombs and guns know no skin colour,” Helene Batamona-Abeke says. She is wearing a red-and-yellow dress and a multi-coloured cloth in her hair. Some of the refugees in the group call her “mother”. She attends to the needs of the individuals, represents their interests to the outside (“These people want to be needed”) and knows from her own experience that the integration into a foreign country is not always easy: “It took me five years to understand how waste sorting works. And what ‘quiet hours’ mean.”

But Batamona-Abeke also knows how to empower people: “Integration is not a one-way street. And it’s a fact that people have more problems the darker their skin colour is.”

In Germany, the English word “empowerment” is more commonly used than its German equivalent, “Ermächtigung”, for good reason. After all, it is simply about giving people the power to defend themselves against discrimination, oppression and racism or to just overcome it – and people who are discriminated against in multiple ways and put under pressure particularly need to be empowered. Unfortunately, this is often the case with HIV-positive people of colour. They not only suffer day-to-day and systemic racism by the majority society, but additionally carry the burden of stigmatisation for being HIV-positive, which they need to keep secret, especially in their own community, to avoid becoming outcasts.

“It’s a fact that people have more problems the darker their skin colour is.”

“Integration is not a one-way street”

That is why there has also been a self-help organisation for the black community within Deutsche Aidshilfe for many years: “Afrolieben+”. One of its co-founders is Abbas Teouri from Togo.

Together with 16 other members from across the country, he travelled to the PoBe, where Afrolieben+ offers a theatre workshop, among other things. When Abbas Teouri arrived in Munich, Germany, as a political refugee, he had to take a mandatory HIV test, which revealed that he was HIV-positive. “Thank God I’m not alone with this,” the burly man says with a smile. “I first heard about DAH way back in 2001 when they hosted a meeting for PoC in Berlin-Spandau. And that’s where I went.” He enjoys the self-help programme, “and these gatherings have been like family reunions to me ever since.”

Like many other people with an African background, he is afraid to talk about his status with his extended family. “Dealing with HIV is a taboo subject. The same goes for sexuality in general. I still remember how much trouble I got into at home when my mother found a condom that I had got in sex education at school.”





Helene
Batamona-Abeke



Of course, his own family knows. Abbas Teouri is married and has two children. Have they also experienced racism? “It was more difficult for my son. He had serious problems in kindergarten. Today, the two only hang out with other foreign children. I’m not happy about it, but you can’t force it,” he says with a laugh.

Abbas Teouri has found his place in Germany – including in Bavaria. He is a Muslim who works as a chef and knows how to make a good Schweinsbraten (roast pork). He does not attend a mosque, but he does not go to Oktoberfest, either. “I think the last time I went there was five years ago.” He has not experienced any serious racism. Or has he? “Well, if you’re looking for a flat, things get difficult. Ultimately, your only option is public housing.”

Black people face particular challenges as refugees and therefore need even more solidarity and support. In response to the precarious situation of the Ukrainian students, a petition was started at the PoBe calling on Federal Minister of the Interior Nancy Faeser and others to accept BIPOC* who fled the war in Ukraine. The petition was initiated by human rights activist Peter Emorinken-Donatus and environmental activist Tino Pfaff and has already been signed by more than 30,000 people.

“Dealing with HIV is a taboo subject. The same goes for sexuality in general.”

The Senate of Berlin has now planned a last-minute special regulation before the deadline expires at the end of August, granting said students from third countries such as Nigeria and Cameroon the right to stay and improved support opportunities. Students from third countries will then receive a “fictional certificate”, a temporary residence permit for another six months. A similar regulation has already been in place since the end of April in Hamburg and Bremen. However, this still does not actually solve the problem for the students, because they will be facing the same issues when the deadline expires. If they cannot present a credible reason for asylum, they will have to return to their home countries. Alternatively, they could apply for a residence permit to study in Germany, but there are tough hurdles to overcome for them: In addition to having to show proof of high-level language proficiency (C1), they need to prove that they have at least €10,000 to support themselves. This means that the students from Ukraine are still far from having a secure living situation. ●



"I'VE NEVER MADE MY STATUS PUBLIC"

INTERVIEW
INGA DREYER

Tatiana runs the Ukrainian Union of Women Who Use Drugs, "VONA" (tag), a network of regional coordinators working with female drug addicts. Tatiana came to Germany because of the war. In the interview, she talks about her experiences as an HIV-positive drug-using mother, activist and refugee.

What are the goals of your organisation?

Tatiana: We are a network of specialists working in various regions with women who use drugs, defending their rights and advocating for their interests and mobilisation. For example, we provide legal assistance in cases of police brutality or failure to provide medical care. Our legal assistants give advice, help with drawing up simple legal documents, accompany clients to court, if needed, and support them until the lawsuit is concluded. We also organise training courses that offer a controlled and safe environment for women who use drugs and doctors to meet and work together. We believe that this can improve the situation in western Ukraine, for example, where many people try to solve problems by praying instead of seeking medical care.

In the Ukrainian society, men who use drugs are perceived more positively than women. That's why many feminist initiatives are trying to raise awareness of this problem and offer gender-sensitive services that consider the needs of women.

Ukraine's drug policy is highly corrupt. You could go free after trafficking drugs – or be sent to prison for holding an empty syringe in your hand. It depends on whether you have money or not.



“Positive Encounters is a safe space for me.”

What was it like for you living in Ukraine as an HIV-positive woman?

I’ve never made my status public. As an activist, I talked about my drug substitution therapy, but never about HIV. If it weren’t for my son, I would have been open about it. But if his classmates’ parents had known about my status, he would have been stigmatised. The daughter of an activist friend of mine was cruelly bullied in school because her mother is HIV-positive. And that was in Kiev!

When my son was born, the way I was treated at the hospital was very different from how a young mother should be treated. We have an organisation called “Positive Women”, which supports HIV-positive women during pregnancy and offers psychotherapy. But it doesn’t include women who use drugs. That’s another issue our organisation is working on.

What was your experience coming to Germany?

I live in Augsburg and went to a doctor there to continue my drug substitution therapy. I was told: You don’t have insurance, so we can’t help you. I thought to myself: In Ukraine, I at least had medication, why am I here now? I eventually found a doctor in Munich. I now drive to drug substitution therapy sessions on Mondays, Wednesdays and Fridays. Continuing antiretroviral therapy without health insurance was also difficult. In the end, Deutsche Aidshilfe staff helped me get medication.

I’ve heard from many Ukrainian women that they had problems – especially in Bavaria. In Berlin, everything is really easy. I was really touched by the story of an acquaintance who was taken in with her three daughters by a family in Augsburg. She is afraid she would get kicked out if she opened up about being HIV-positive. That’s why she didn’t go to a doctor. I went to great lengths to bring medication from Zaporizhzhia to Munich via Lviv. The bizarre thing is that she and her daughters could have been killed in the war. And her self-stigmatisation is so high that she risks dying without HIV medication after her escape.

Do you talk about your infection in Germany?

Positive Encounters is a safe space for me. But I live in Augsburg with two other Ukrainian women whose experiences are very different from mine. I don’t tell them about my status – because I’m afraid that their attitude towards me would change and that I may even have to move to a different flat. ●

“Ukraine’s drug policy is highly corrupt.”

TEXT
INGA DREYER

"I HAVE HIV. THAT'S MY LIFE."

At the PoBe, young Ukrainians talk about discrimination and destroyed dreams, but also about hopes and the importance of networks. Varvara Shevtsova, for example, advocates for LGBTQI+ and girls with HIV in the group "Yunka + 100 girlfriends".

She actually wanted to become a policewoman, Valeria says. The 18-year-old is standing in the middle of a seminar room in Duisburg's Mercator Hall. She prepared a workshop for the PoBe together with a group of young Ukrainians who had come to Germany because of the war. German-speaking listeners follow the translation of their reports over headphones.

She was not allowed to become a policewoman in Ukraine due to her HIV infection, Valeria says, so she eventually decided to study law. A young man from the group explains that he wanted to become a chef, but was rejected by the training institution when his status became known. A young woman suggests starting a petition so that HIV-positive people can also work for the police, for example. "You and others whose dreams have been destroyed could join forces", she says to Valeria, who lost her mother at young age. When she was 11, her mother died as a result of drug use, the student says. Her mother escaped the responsibility of having to raise an HIV-positive child, she concludes. "I can't love or respect a woman who acts so irresponsibly."

The young Ukrainians share experiences of loss, discrimination and missed chances. They campaign at a congress where most participants are older and speak a different language. This open and confident attitude is also a generational thing, Daria says. The 18-year-old comes from Kiev and, like Valeria, she was born with HIV. Sitting on a couch in the hallway of the conference centre, she speaks in Ukrainian, and an interpreter translates.

Her foster family advised her against talking about her HIV infection, saying that other people would not understand it. Until half a year ago, only Daria's friends and family members had known about her status. But then she decided not to hide anymore. "I have HIV. That's my life", Daria says. If people no longer want to have contact with her for this reason, they are not worth it anyway. Daria has been in touch with other young HIV-positive people

via networks and organisations since the age of 14. A lot has changed, Daria says. Her generation has access to information, conferences and also medication.

After Russia, Ukraine has the second largest HIV epidemic in Eastern Europe/Central Asia. According to estimates, about 260,000 people are living with HIV in the country. Experts fear that the numbers could rise further due to the consequences of Russia's war of aggression, such as lack of medical care.

"At school, you are always at risk of being bullied and harassed."

One problem is a lack of sex education, Varvara Shevtsova says. "We only have one biology class at some point in the ninth grade." The activist and feminist runs "Yunka + 100 girlfriends". The feminist organisation for LGBTQI+ and girls with HIV was established in 2019 by members of the national organisation "Teens Ukraine".

Living with HIV in Ukraine is still difficult for young people, the activist says. "At school, you are always at risk of being bullied and harassed." That is why networks like Yunka want to create safe spaces. "For example, we organise art exhibitions to fight for equality and against stigmatisation."

Yunka means "young girl" in Ukrainian. The symbol of the activists is a doll that was found in a settlement near Kiev in April after a Russian attack. "Dolls are beautiful, but they are also strong", says Varvara Shevtsova, who lives in Scotland and is trying to keep together the community spread across different countries. The activists currently supply 50 girls all over Ukraine with hygiene kits and pay for their mobile Internet connection so that they can stay in touch with each other. The members discuss feminist issues at online meetings. Because it is important to



Varvara und
Krystina (r.)



also talk about something other than the war from time to time, Varvara Shevtsova says.

Until the beginning of Russia's war of aggression, the medical care for HIV-positive people was good, Varvara says. Now there are problems with the supply of medication. "Of course, this has raised concerns among people living with HIV." She knows about some members of Yunka who came to Germany with only small remainders of their HIV medications. Luckily, they quickly received new ones. Before the flight, the young women had their doctors in Ukraine precisely document what medications they need, enabling the German family doctors to quickly find a replacement, the activist explains.

The supply of HIV medication has been uncertain since the beginning of the war

At the PoBe, some Ukrainians talk about difficulties getting medication promptly in Germany without health insurance. But for Daria things went smoothly. She arrived at Berlin Central Station in mid-March and was then taken to an accommodation for unaccompanied minor refugees, because she had not yet turned 18. Later on, she moved to a flat-sharing community with other Ukrainians. The social workers there also took care of her medications.

It is important that refugees can continue their antiretroviral therapy right away, Varvara Shevtsova says. Otherwise, the stress could cause additional adverse health effects. "These people come from a war zone, are HIV-positive, some of them are LGBTQI+, use drugs, some might be traumatised. They need quick support." ●

TEXT
AXEL SCHOCK

"MAKE LOVE, NOT WAR. NO SHAME - JUST LOVE."

The demonstration as part of "Positive Encounters" has by now become a tradition. Some 200 participants marched through Duisburg's city centre.



“Visible, combative, strong” – after the end of the conference, the motto of the 21st Positive Encounters conference was also carried into the streets.

Many of the roughly 200 participants wore the blue PoBe T-shirt with the central slogan, with a banner showing the demo motto “Many people, one goal: Living with HIV without discrimination” leading the way.

Before the event, a great number of the PoBe participants had seized the opportunity to write their individual messages on posters.

They also reflected the language diversity of the conference. Apart from messages in German, there were also some in Ukrainian and English (“I’m a VIP with my HIV”).

The spectrum ranged from catchy and subversive slogans (“Anal intercourse instead of capital movement”) to very personal, provocative texts (“Think about it: 59, gay, HIV-positive and grandpa, it’s possible...”).

One protester even wore a horned Viking helmet to emphasise his message “Fight stigmatisation of HIV-positive people”.

The colourful, high-spirited procession through the pedestrian precinct was eyeballed with some scepticism and irritation, but also with interest. There were no negative reactions or hostilities.

At the final rally in front of the Mercator Hall, individual participants once again summarised their causes in passionate, or at least very personal speeches. “We are united by HIV. We stand for a normal life with HIV, for variety and diversity. We stand for tolerance and acceptance”, conference participant Judith said. “We don’t want to be stigmatised and discriminated against, neither in daily life nor at work or at the doctor’s. We don’t want to hide anymore and want to be visible.” So she encouraged everyone: “Don’t be afraid: Be visible, combative and strong.”





In his speech, Abbas from the AfroLebenPlus network added aspects from the perspective of migrants with HIV: “We stand for diversity and solidarity. We say no to multiple discrimination, we say no to racism.” No one should be left behind. So he called for “HIV therapy for all, health for all!”.

Ukrainian activist Varvara drew attention to the situation of African students who fled from Ukraine and are now living in a highly uncertain situation in Germany. (see article on p. 38)

Cristina, also from Ukraine, once again summed up the spirit of Positive Encounters 2022 in her spontaneous statement.

“I’ve been living with the virus for six years now. But HIV is no reason to be ashamed; it can help you find out how to take care of and love yourself. It’s okay to be different. We are HIV-positive, HIV-negative, with different skin colours, from different countries.” And, in her final sentence, she managed to put a message into just eight words that surely touched the hearts and minds of most participants of the PoBe 2022: “Make love, not war. No shame – just love.” ●



WILL MEDICAL PRACTICES SPECIALISING IN HIV SOON BE A THING OF THE PAST?

Medical care for people with HIV has always been poor in rural regions. But the specialised treatment of HIV patients also needs to be ensured in the long term in cities.

It is an announced emergency situation: In the foreseeable future, a Duisburg medical practice specialising in HIV will close its doors. Despite every effort, Aidshilfe Duisburg/Wesel District has so far not been able to find a successor. Bad news for people with HIV in the District of Wesel in the Lower Rhine region, who will now have to travel long distances for a doctor's visit in another city.

Specialised medical care in Germany has grown over time, and now the generation that did pioneer work in this field in the 1980s and 1990s is successively retiring.

"It is important to maintain the existing good care structures", Robin Rüsenberg, Managing Director of the German Association of Practicing Physicians Treating HIV-Infected Patients (dagnä), explains. However, HIV medicine does not differ from other medical specialist groups in this respect.

The situation in Duisburg gave rise to an open space as part of the PoBe, where the participants tried to identify the causes of this trend and develop solutions on how to win medical professionals for the treatment of people with HIV.

The discussion once again made clear the importance of local specialist medical practices for people with HIV. The specialists have known their patients and their medical histories for years, enabling them to individually adapt the medication. Various other conditions are also taken into account and included in the treatment plan. At the university hospitals, as pointed out by some participants, the doctors usually change on a quarterly basis, so the medical history has to be taken anew on every visit.

In fact, there are no medical practices dealing exclusively with HIV, but this domain is usually combined with other disciplines, such as primary care, internal medicine or oncology. "HIV centres that are large enough to offer interdisciplinary services offer attractive framework conditions for a new generation of medical professionals", Robin Rüsenberg explains.



But such medical practices are only profitable in big cities and metropolitan areas with a correspondingly high need for medical care. They often also cover adjacent catchment areas: For example, specialist medical practices in Berlin are also visited by people from Mecklenburg-Western Pomerania and Brandenburg. For the patients, however, these visits are associated with long travel times, high costs and additional expenditure of time. For working people, this can mean having to take a day off for a medical examination.

Could HIV treatment not simply be performed by more general practitioners?

“Even though medical progress has made the treatment easier, the treatment of HIV patients is no one-size-fits-all medicine, but requires expertise and experience”, Robin Rüsenberg emphasises. This is difficult to implement at medical practices in rural areas with few HIV patients; at the same time, comprehensive medical care is particularly important in these areas, especially because the patients are now getting older, but not necessarily more mobile.

This concern was also expressed by some participants of the open space, especially regarding HIV treatment in care facilities far away from big cities.

In the long term, this problem can only be solved by developing new care concepts, expanding digital medicine and intensifying the collaboration between local general practitioners and a medical practice specialising in HIV in a big city nearby. Routine check-ups and the regular prescriptions of medicines could then be carried out by local general practitioners, while more complicated HIV-specific treatments would be performed at the specialist medical practice.

But how can we get the next generation of medical professionals interested in HIV medicine?

The brainstorming at the PoBe produced a whole train of ideas: In collaboration with the universities, the local AIDS Service Organisations could raise awareness of the problem among doctors-to-be and offer HIV training. In addition, HIV should be consistently taken into account in the various training curricula.

Moreover, the “Let’s talk about sex” project, which is aimed at improving the communication skills of medical students, doctors and practice teams when talking about sexuality, HIV and STIs, could make an important contribution.

The dagnä also recognises the need to keep HIV treatment attractive for the next generation of medical professionals. This aspect has so far been completely neglected in medical discussions about HIV, Rüsenberg explains.

He hopes that the nationwide introduction of specialty training in internal medicine and infectious diseases, which was decided in May 2021 at the 124th German Medical Assembly, will provide a major impetus. Previously, it was only possible to complete one year of additional training in the field of infectious diseases. Numerous state chambers of physicians have already made the decision to introduce the new specialty training, but it still has to be implemented by most chambers of physicians. ●

TEXT
MATTI THIEBO
AIDS-HILFE DUISBURG/
KREIS WESEL E.V.
AXEL SCHOCK

INTERVIEW
INGA DREYER

"WE WANT TO CREATE VISIBILITY"

With their new campaign "HIV is also female", the North Rhine-Westphalia-based group XXelle PLUS aims to empower and encourage women while raising their visibility. Female activists Alex Frings and Johanna Verhoven explain what's behind the campaign.

XXelle PLUS is intended to raise the visibility of women with HIV. Why is such a campaign necessary?

Alex Frings: The idea came about during one of the annual networking meetings of XXelle PLUS, our group for women's issues in North Rhine-Westphalia. We were looking into preconceived notions we encounter – in our society, the medical system as well as in our own community. The argument that women only account for 20 percent of the community is often used to marginalise our needs. That's what gave us the idea to start a campaign. The T-shirts with our logo that we presented at Positive Encounters are just the beginning.

What are these preconceived notions, needs and problems?

Johanna Verhoven: It starts with HIV often being diagnosed late in women. They are simply not seen as sexual beings that could be infected – especially when they are living in a partnership. They are often only diagnosed when they are pregnant. It's often said that women only make up 20 percent. But we say: We are 20 percent! That's a pretty big group within a community.

People often assume that HIV-positive women are sex workers or drug users. Of course, there are HIV-positive sex workers and drug users, but there are also HIV-positive housewives, social workers, mothers, aunts and grandmas. HIV has many different faces and does not only occur within one specific group.

What are the goals of your campaign?

Alex Frings: Firstly, the campaign is directed at HIV-positive women. We want to empower them and show that HIV is also female – just like self-determined sexuality is also female. Secondly, we want to raise awareness of the stereotypes people have in mind. We want to create visibility and show how diverse just our group of women at XXelle PLUS alone is. We have different origins, ages and backgrounds.

Johanna Verhoven: But we also want to reach into the community. Many conferences only include a single workshop on women's issues. The 30 women who signed up for it will be there, but hardly any of the men will show up. We say: Not all women's issues need to be treated separately. It would be great if they could simply be included in other workshops and always be discussed along with everything else. It's not enough to offer some token women's workshop. It's also not enough to have just one woman sitting in a planning group. There could be two or three women





every now and then. We also want to encourage women to be part of an executive board or a preparation team. That may also inspire more women to attend such events. I was very happy to see that this year's PoBe had a lot of female representation.

The campaign kicked off with your appearance at the opening event of Positive Encounters. What's next for you?

Johanna Verhoven: The kick-off was a big success. As representatives of XXelle PLUS, we would have been about six or seven women. That's why we also asked other people who are active in various networks to show their solidarity by wearing one of our T-shirts. They all agreed right away. Many of them were really excited. Now it's essential for us to maintain this visibility. For example, we are using a postcard campaign to reach out to doctors, because they are the ones who diagnose women and also work with HIV-positive women. In this way, we want to reduce prejudice and prevent stereotypes from being perpetuat-

ed. We also use Instagram to communicate our messages and reach more of the general population.

Alex Frings: We will also maintain a presence at HIV-related conferences – whether it's with an information stand, our T-shirts or stickers. We want to show that we are approachable for everyone. We are primarily North Rhine-Westphalia-based activists, but it would be great if we could make a difference beyond the borders of our state so that other women with HIV also benefit from it. The more we reach, the better. ●

TEXT
HOLGER WICHT

I WANT MEDIA ATTENTION!

We all want good media coverage about living with HIV. Volunteers step forward! But how to make the media appearance a success story?

For many people, talking about their lives with HIV in public is a big step. On the one hand, it offers the opportunity to counter prejudice. On the other hand, anyone who ventures into the media gives up control over their own story – the outcome and the consequences cannot be reliably predicted.

How to make the media appearance a success story? How to avoid disappointments? We addressed these questions in a workshop as part of Positive Encounters.

The press office of Deutsche Aidshilfe (German AIDS Service Organisation) is using the results to develop a handout on dealing with the media for people with HIV. We would like to already publish some basic rules and tips in this documentation. Because having inner clarity and being well prepared is crucial in dealing with the press, radio and television.

You have rights!

First of all: Anyone who gets involved with the media does not have to leave their personal rights at the door. You have a say in what happens, what is discussed and what is not. And you can say no – to individual questions or even the interview as a whole.

But there are some rules. You don't have a say in everything; it would be contrary to the rules of journalism. Sometimes contributions are finalised by the editorial staff rather than by the interviewers. Depending on the specific medium and format, you need to trust the interviewers to some extent.

As a rule: You usually have no control over the way you are presented in the end, but you can estimate and influence in what direction things are heading. And it's solely up to you to decide on what terms you take part in an interview or report.

What story is to be told?

Journalists usually have a clear idea of the "story" they want to tell. Their perspectives and opinions will have an influence on the report about you. Their idea does not necessarily coincide with the story you want to tell. You should therefore discuss with the media professionals beforehand what they are planning, what you are willing to discuss and what you are not – and make binding arrangements.

Asking certain questions can be helpful, such as: What would you like to communicate? What is the contribution supposed to look like in the end? What topics do you consider particularly important? Once you know the answers, you can decide whether you want to be a part of this contribution at all and check whether the interviewer is open to suggestions for changes.

Journalists are often willing to learn something new during the interview and adapt their plans. But they are not always able or willing to follow our ideas. If you have the feeling that things are going in the wrong direction, don't take part.

Conclusion

Many journalists do a good job and make an effort to deal with their interview partners responsibly, especially when it comes to sensitive topics like HIV. But don't count on that; be well prepared in dealing with the media – then there is a good chance of a great outcome.

More information will be available shortly at: www.aidshilfe.de/leben-mit-hiv/medien ●

CHECKLISTS

Preparation (self-reflection)

What do I want to communicate? (For example, you can note down core messages beforehand so you don't forget them.)

What do I want to talk about and what do I prefer not to talk about? Where are my limits?

What do I want to disclose and what do I want to keep for myself? (e.g. only first name, anonymisation, no shoot in your home)

Do I trust the medium and its makers? What are their intentions?

Who could recognise me and can I handle it?

Do I want to have professional support (e.g. from the AIDS Service Organisation)?

Implementation

Make clear what is important to you and ask whether it matches the planned contribution.

Advertise your personal topics and views.

Make clear arrangements, preferably in writing (e.g. no disclosure of last name, approval before publication)

Standard approval procedure for printed texts: Quotes are sent to you in advance for approval. Whether or not you will receive the whole text is subject to negotiation. Note: Headlines and captions are often made by different editors later on.

TV and radio reports are usually not submitted for approval.

Don't assume anything that has not been discussed; ask if in doubt.

Follow-up

You can distribute good reports via social media and also participate in the discussion.

For good comments: Activate the community and friends.

Have any errors corrected! (this is possible online)

Get feedback and reflect for yourself: Did my message get through? What do I want to do differently next time?

Thank the journalists and/or communicate any criticism.

In case of major errors or if your rights have been violated: Defend yourself. Get support from the press office of Deutsche Aidshilfe or other pros.

Celebrate your grand appearance!

PRESS REVIEW

Under the motto “Celebrating differences together – visible, combative, strong”, Deutsche Aidshilfe (DAH) is organising Europe’s largest conference on living with HIV in Duisburg from tomorrow to Sunday. About 400 people with and without HIV look into the diversity of the HIV community and develop strategies against discrimination. (...)

With its diversity and solidarity towards each other, the HIV community has always been a good example of an open, diverse society. At Positive Encounters, different people pull together: gay men, people who use drugs, heterosexual women and men, trans people, migrants from countries with high HIV prevalence and young people born with HIV – to name just a few groups. The participants also include staff members of AIDS Service Organisations and other people who deal with HIV in their professional or private lives.

Braunschweiger Zeitung, 6.7.2022

Marie Schellwat, Managing Director of Aidshilfe Duisburg/Wesel District, criticised on Wednesday in Duisburg that some AIDS counselling centres in the regions are dramatically underfinanced. Above all, there is a lack of specialist medical practices in rural areas: For the big city of Duisburg and the rural District of Wesel, there is only one medical practice specialising in HIV and it operates well above capacity. This also entails problems in HIV prevention.

General-Anzeiger Bonn, 6.7.2022

Diversity is an attribute that definitely applies to the participants of “Positive Encounters”, as Heike Gronschi emphasised at the opening press conference in the Mercator Hall. “We are a very diverse conference with very diverse participants”, she said. Sexual orientation, gender, origin – the diversity of society is also reflected by HIV-positive people. Since the infection is often more widespread in other countries than in Germany, the community is very multicultural.

Rheinische Post, 7. 7.2022

Deutsche Aidshilfe (DAH) calls for medical care for refugees with AIDS regardless of passport and residence status. People without residence documents often have no access to the medical system, DAH’s Board Member Winfried Holz said on Wednesday in Duisburg. “This leads to AIDS cases that could have been prevented.”

Die Welt, 6.7.2022

Conference leader Heike Gronschi criticised that many HIV-positive people continue to be discriminated against in everyday life, as confirmed by the DAH’s nationwide study “positive voices 2.0”. They only get medical appointments at off-peak hours to prevent contact with other patients and experience career disadvantages and rejection when revealing their condition.

Süddeutsche.de, 6.7.2022

Deutsche Aidshilfe considers the event a great success: “Many encounters were very emotional. Beyond the common denominator of HIV, we were able to get to know each other, find things we have in common and make new contacts. By joining forces, we can now advocate for the rights of people with HIV even more effectively”, conference leader Heike Gronschi said.

Mannschaft.com, 11.7.2022

And a very special acknowledgement to the PoBe organisation team:

The conference proved to be a really inclusive event in all respects. It was productive and positive. No one was left out at this event.

We thank Deutsche Aidshilfe for providing the conference venue and giving us the opportunity to work in groups and discuss common topics. (...) We only received positive feedback on the event, the organisation and the activities. All involved in the conference worked with great enthusiasm and were inspired to pursue new goals and projects in the future.

Association “HIV-Positive Ukrainians in Germany”



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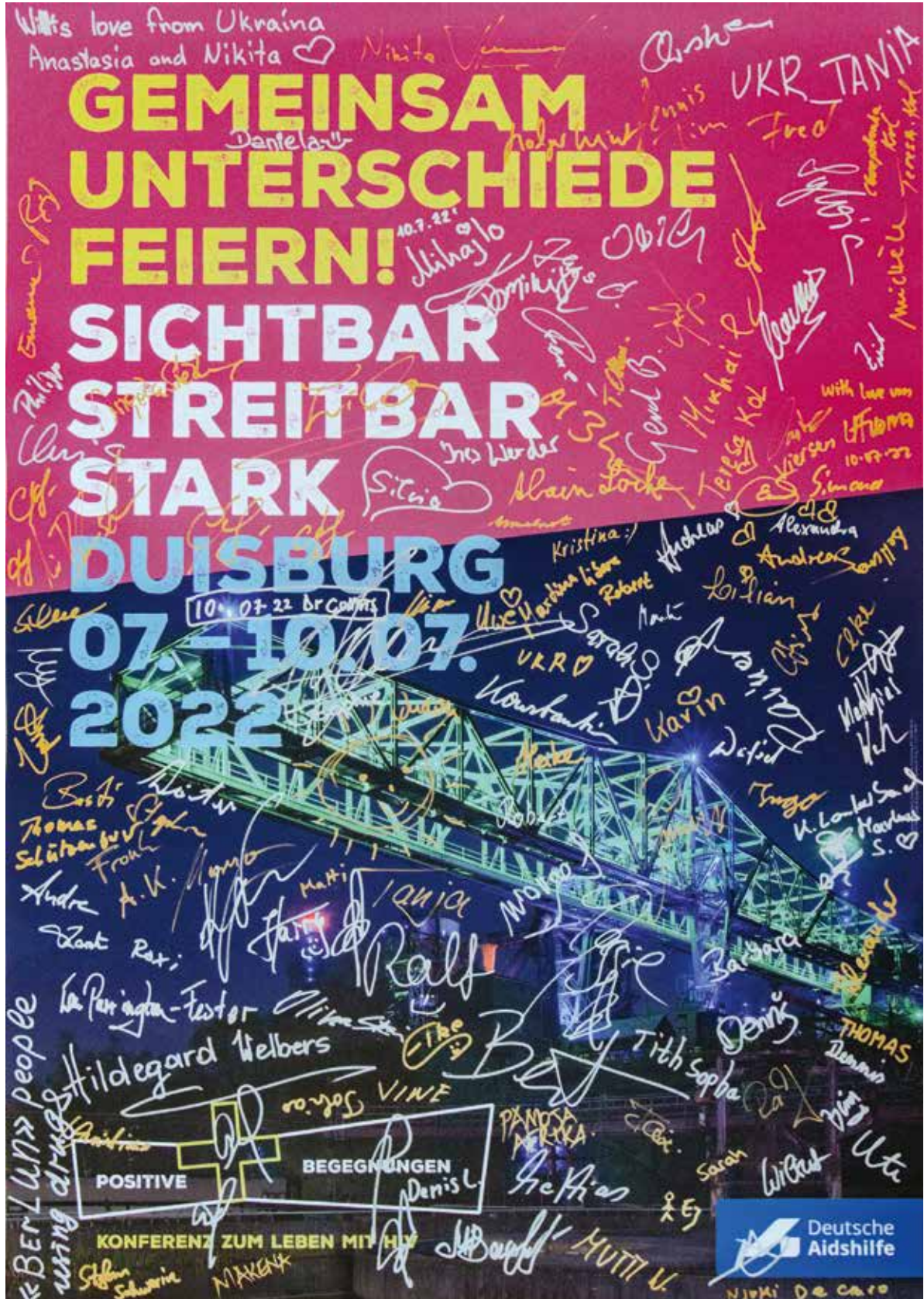
With love from Ukraine
Anastasia and Nikita

GEMEINSAM UNTERSCHIEDE FEIERN!

SICHTBAR STREITBAR STARK

DUISBURG

07.-10.07.
2022



«BERLIN» people
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