

WOMEN LIVING WITH HIV UNITE TO CHALLENGE THE WORLD HEALTH ORGANIZATION UGANDA



THE CHALLENGE

Introduction

Community-led advocacy and campaigning have changed the landscape of the HIV and AIDS response worldwide. The Partnership to Inspire, Transform and Connect the HIV response (PITCH) invests in community-led organisations to uphold the rights of populations most affected by HIV by engaging in effective advocacy, generating robust evidence and developing meaningful policy solutions.

The advocacy campaign from PITCH partner International Community of Women living with HIV Eastern Africa (ICWEA) shows the power and potential of communities uniting to assert their rights to make an informed decision to their sexual and reproductive health and rights.

 "You are empowering people to advocate for themselves. The lived experience of people, their voices: that's what matters."

For years people living with HIV have suffered the side effects of different drug regimens. Research shows that popular antiretroviral drug Dolutegravir (DTG) has advantages over other drug regimens, including better rates of viral load suppression, higher tolerability and a lower pill burden. And it costs less too. This has made DTG an important option for use by women in the region.

Angel Ntege, who has been living with HIV for 11 years, says switching to DTG gave her "the best times" during her eight years on antiretroviral treatment (ART) so far.

"Previous regimens had not worked, but DTG was so comfortable, so easy," the 32-year-old explains. "Any person would want to take it over the ones we were taking previously, because of its benefits."

Angel's experience was typical. Executive director of ICWEA Lillian Mworeko adds:

"There is a serious problem of adherence among young women. But DTG – they spoke so well about it. There was an excitement."

Right to choose denied

Then, in May 2018, the World Health Organization (WHO) issued a note of caution¹ about the use of DTG by women and girls of childbearing age living with HIV, after the findings of a preliminary study from Botswana linked DTG use to neural tube defects (NTDs) – serious birth defects of the brain and spine.

Health ministries in some countries, including Uganda, changed their prevention, care and treatment guidelines, restricting DTG's use. Almost overnight, women and girls in Uganda and many other countries had a potentially life-changing treatment option snatched away from them.



"Believe it or not, not every woman wants a baby"

"Suddenly, it was 'wait a minute, there's a problem'. There was a plan to review the guidance," says Lillian. It reminded the ICWEA team of vertical transmission initiatives, where programmes explicitly met the needs of the unborn child, not the mother.

"There was a feeling of frustration and betrayal – that nothing is about women, that we don't matter at all."

ICWEA believed the blanket decision to prohibit DTG use was hasty and heavy-handed. They saw the wider impact of restricting DTG use. Denying access to a drug known to have high viral load suppression could push women and girls of reproductive age to present late with a high viral load.

'Treatment is prevention', ICWEA argued, so access to a high viral load suppression drug such as DTG should be assured as one of the ways to prevent the spread of HIV.

Angel Ntege was pregnant when DTG was introduced in Uganda, but wanted to remain on the regimen.

It was the views of Angel and other young women living better, healthier lives on DTG that underpinned ICWEA's strategy to challenge the Ministry of Health's new guidance.

THE CHANGES

Uniting to challenge

Margaret Happy, ICWEA's Advocacy Manager, explains: "What came in my mind was 'have they consulted with the community, have they heard from women'. Of course, none of us had been consulted. We had very good grounds for challenging WHO.

In the weeks that immediately followed the WHO announcement, ICWEA and its partners – national organisations of people living with HIV, key populations and human rights groups – spoke with women living with HIV across Uganda, gathering rich information and data on their experiences of accessing DTG and informing them on their right to access the regimen.

They spoke to their existing coalitions and networks, including the Woman Today coalition and the Uganda

Network of Young People Living with HIV & AIDS (UNYPA). They held regional dissemination meetings where the DTG issue was on the agenda. They also contacted young women working as champions in communities in many districts under the PITCH programme.

ICWEA also used mainstream and social media engagement, including radio talk shows, to reach audiences across Uganda including other marginalised people living with or affected by HIV.

"This was to make sure information was being shared with the public. People were being denied treatments and they did not know why that was happening," says Lillian. "On each radio programme there was a district health leader – as people called in, it was one way of holding them accountable."

A portrait of Lillian Mworeko, Executive Director of ICWEA. She is a Black woman with her hair in braids, wearing a white top with a floral pattern. She is smiling and looking towards the camera. The background is slightly blurred, showing what appears to be an outdoor setting with a building and some greenery.

Lillian Mworeko
Executive Director
ICWEA



(www.unaids.org/en/keywords/women-and-girls (2020)).

Every week, over
6000 AGYW
(aged 15–24 years)
become newly
infected with HIV

UGANDA



“Very quickly we had to mobilise women in all our diversity – trans, sex workers, adolescents. We wanted to hear what women were saying about DTG. Women are not homogenous. We are not all the same.”

Margaret Happy

Giving Ministry of Health a reality check

As the Ministry of Health continued to review its HIV guidelines, ICWEA took the opportunity to present its findings.

“Everyone was concerned about the “Botswana Study”. But everyone seemed more concerned about unborn children, [than about women’s treatment],” says Lillian Mworeko. “Even one child with a birth defect matters, but we challenged the ministry and WHO for double standards.

“We argued the first step should be talking about women’s needs and priorities – it was the first time they had heard this. Our proposition was the right to full information, so women can make an informed decision.”

Lillian and her ICWEA colleagues soon realised how to make their advocacy efforts even more effective.

“We were all older women in the room. Our next strategy was bringing younger women who were actually on DTG. We had to bring real voices into the room – real women speaking about the issues themselves and telling their experiences.”

The principles of GIPA (greater involvement of people living with HIV) and ‘nothing about us, without us’ became the beating heart of the campaign. At the next meeting, DTG users of childbearing age attended in person to address the Ministry of Health.

“It’s better to talk about it if you have experienced it. If it’s something about us, we should be the ones who talk – we are the very people involved.”

Angel Ntege

DTG users explaining its benefits proved convincing. “They had been switched to DTG – they had great stories to share,” says Margaret.

From a national issue to a global movement

At the 2018 International AIDS Conference (AIDS2018) ICWEA sought partnerships with other global activists and opportunities to build momentum around DTG access.

UNAIDS and WHO convened a side event to talk about DTG. “We influenced the discussion and conversation and provided evidence from the meeting we had held with women in Kampala. Sylvia Nakalanzi, as a young woman, spoke of her experiences,” says Lillian. “We emphasised how important it was that the choices and options of women were considered.”

ICWEA also attended a meeting attended by the WHO Director General where issues around DTG were raised, while ICWEA staff took part in a march at the event calling for a rethink on use of the drug.

References

¹ www.who.int/medicines/publications/drugalerts/Statement_on_DTG_18May_2018final.pdf

² www.who.int/news-room/detail/22-07-2019-who-recommends-dolutegravir-as-preferred-hiv-treatment-option-in-all-populations

Front cover photo: Copyright Marten van Dijl at AIDS2018

The Uganda Population-Based HIV Impact Assessment Report in 2017 put HIV prevalence among women of reproductive age (15-49 years) at **7.5%**. In Uganda, HIV prevalence is almost four times higher among women than men aged 15 to 24.

UGANDA



"We joined with colleagues from UK and other countries," Lillian explains. "We shared our experiences from Uganda. We worked together with women from the Global North."

Margaret adds:

"It was so strategic that the AIDS 2018 was happening. We linked local and global level advocacy together very well."

"Our key message was 'we want options and information, allowing us to make decisions. We won't let the Ministry of Health and WHO make decisions about what is good for us,'" says Margaret.

Communities can move mountains

In July 2019, at the International AIDS Society Conference on HIV in Mexico, WHO released updated guidance² based on new research findings on DTG, which further downplayed fears around its use.

The Ugandan Ministry of Health accepted ICWEA's proposal to amend its official guidelines. Women of reproductive age who wanted to use DTG would be given information and counselled about the benefits and risks, allowing them to make informed choices on their regimen and family planning.

An initial requirement for women of childbearing age to sign a consent form to take DTG was removed in February 2019 after further lobbying from ICWEA and its partners, following the PEPFAR COP Regional Meeting. Access to DTG is now effectively unrestricted for everyone in Uganda who needs it, irrespective of their age, gender or whether or not they are planning to have children family circumstances.

ICWEA's advocates and activists are following up with the Government and at community level to ensure access to DTG is guaranteed, that it is quickly rolled out in ART clinics across

the country to all women and girls living with HIV that want it. According to the Ugandan Ministry of Health, 540,000 people had been started on DTG by the end of 2019.

"Following the meetings we organised, a Ministry of Health representative wrote a report [of the discussions and views of DTG users], which in my opinion contributed to the change of the guidelines," says Lillian.

Margaret adds:



"We were so happy WHO listened to our voices, listened to our communities. It was a huge achievement – we saw how impactful the voices of the community can be."

Margaret Happy

LESSONS LEARNT

Building capacity and passing on knowledge

The DTG success has seen new approaches embedded at ICWEA. "We now have a mentorship programme for young women. When we plan opportunities, we find younger women to be involved," explains Lillian.

There have been similar challenges with DTG access in other countries and ICWEA has strategised with like-minded organisations in Kenya and across the region. In Burundi, Kenya, Rwanda and Tanzania efforts are now being made to ensure women in those countries also have full access to the regimen.

Margaret adds: "With science evolving there will be other options for HIV treatment. But they should not impose what is right for communities or not. Communities can make informed choices, tailored to their own needs and preferences."

ICWEA's work has allowed women in Uganda, in all their diversity, to access HIV treatment of their choice. They believe this is a fundamental human right, leading to better lives for young women

living with HIV, whose adherence and retention of care is still low.

A key lesson is that major decisions should not be made based solely on preliminary findings, and people living with HIV should not take every decision made by policy makers as final and sacrosanct. Avenues for further engagement, research and advocacy should always remain open.

Communities and people living with HIV have played a critical role in ensuring ongoing positive change in HIV prevention, treatment and care.

Angel Ntege, who in early 2020 took a job as an ICWEA project coordinator, provides the proof.



"I had to advocate for every woman to have it – it's a good drug. Women should have it," she says. "If you are given everything on a plate, it's up to you to choose whether you eat it or leave it."

Angel Ntege



The Partnership to Inspire, Transform and Connect the HIV response (PITCH) strengthens community-based organisations' capacity to uphold the rights of populations most affected by HIV by engaging in effective advocacy, generating robust evidence and developing meaningful policy solutions.

PITCH is a strategic partnership between Aidsfonds, Frontline AIDS and the Dutch Ministry of Foreign Affairs.

aidsfonds.org fronlineaids.org



International Community of Women Living with HIV Eastern Africa

Thank you to the International Community of Women living with HIV Eastern Africa (ICWEA) for sharing their stories.