International Community of Women Living with HIV Eastern Africa

Give Women Living with HIV full information on the benefits and risks of DTG, Contraceptives for them to exercise choice

On May 18, 2018 - World Health Organization (WHO) issued a statement on HIV antiretroviral drug Dolutegravir (DTG) following the identification of a potential safety issue related to neural tube defects in infants born to women living with HIV who were taking DTG at the time of conception in a study in Botswana. Shortly, the Ministry of Health in Uganda reviewed guidelines to exclude women 15-49 years from the use of DTG except for those on long term family planning methods and sterilization. Data from the Tsepamo Study show that 0.9% of babies (4 of 426 babies) who were exposed to Dolutegravir had neural tube defects. The neural tube defects were reported only in babies of some of the women who were taking Dolutegravir at the time of conception--there were no reported neural tube defects among more than 2,500 babies born to women who began taking Dolutegravir after conception.

ICWEA is deeply concerned about the four NTD cases in the Tsepamo study and any study that shows such results matters to us. Based on that, ICWEA carried out a consultation with 38 women living with HIV in Uganda, majority of who were Adolescents Girls and young women in their reproductive age. The aim was to get insights to inform ICWEAs stand on the DTG and to promote treatment literacy. (Out of 38 participants, 31 were below 30years). There was representation from sex workers, PMTCT mothers over the last 1 year and transgender women. A total 95% of the participants had sexual partners). 17 of the participants reported that they were using contraceptives, 7 were not using contraceptives and the rest of the participants, did not share whether they were using contraceptives or not. Only three of the participants had been initiated on DTG at the time of the consultations.

The perspectives of the AGYW living with HIV and other women living with HIV during the consultation was based on full information on DTG received from an AfroCAB member and Ministry of Health official.

The consultation revealed that:

1.The needs and priorities of women living with HIV in relation to contraceptive use, conception and HIV treatment are diverse therefore we cannot have a one size fits us all situation when it comes to issues of contraception and HIV treatment. Some women are of reproductive age and have no plans to have children in the near future, others have had the number of children they are happy with and have no plans to have more. Some women were having problems with the current regimen and wished for a change to DTG or any other drug that would give them better health outcomes with less adverse effects.

"I was given a combination which has efavirenz, I had weird dreams. I could over sleep. When I went back for refill, I explained to the doctor and requested that they change my combination. I was put on a combination with niverapine. Within 2 weeks, I over reacted to the treatment. It burnt my whole body. I was switched again to a combination with efavirenz. I have been struggling with it and having challenges with adherence. My viral load was ever high because of poor adherence. However, when I was initiated on DTG, my viral load is now undetectable. I have been on DTG for only one month. The drug is small, easy to swallow, I do not experience any of the side effects which I used to struggle with when I was on DTG. I cannot accept to be put off DTG".

"Am a Trans woman in reproductive age and this really does not concern me much because I do not plan to get children. I feel I should be given DTG if I express the need to have DTG – Transgender woman living with HIV

Everyone needs to adhere to treatment and this means that individuals with different needs and preferences are taken into account and choices that best suit individuals are offered. There are very many women who are comfortable with efavirenze based regimens and may not necessarily want to get off the current regimen. However, there are those who are facing adverse effects of efavirenze and would do well on alternative regimens. DTG is a welcome idea as it will offer women living with HIV more choices in access to treatment.

"I have well tolerated efavirenz and its side effects. Am not thinking of changing right now. But I feel there are women who deserve to be on DTG because they are having a hard time with the side effects of Efavirenz. These should be given an opportunity to improve their health with a good drug like DTG"

All Anti retroviral treatments come with some side effects. DTG, like all ARVs, is associated to risks of side effects, including adverse birth outcomes. Studies have indicated adverse birth

outcomes with use of efavirenz (EFVs) at 36 percent.[1] However, women living with HIV have continued to use it even in pregnancy without alarm bells as have been sounded in DTG. We have continued to use EFV because the benefits outweigh the risks associated to it. Similarly we must weigh the benefits of using DTG in women and their unborn babies to the risk. It is not fair for government to come up with a blanket statement which does not even take into account the voices of women on the use of DTG.

3. DTG is an opportunity for the country to improve on Family Planning services since it works best when women are on family planning. It is important that women are given the information to support their choice of family planning method as opposed to prescribing for them what they should or should not use. Family planning is one of the guiding principles of prevention of mother to child transmission of HIV and includes providing appropriate counselling support and contraceptives to women living with HIV. Women who opt for DTG must be supported to prevent unintended pregnancies. The benefits of contraception are far-reaching, ranging from healthier mothers and children, reduced cases of maternal and neonatal mortality and morbidity to increased family savings and productivity, better prospects for education and employment, and ultimately improvement in the status of women living with HIV. Despite the existence of legal and policy provisions within human rights standards that give the opportunity for all women (including women living with HIV) to choose or refuse any form of family planning option, many women living with HIV continue to face stigma, discrimination and violations of their sexual reproductive health rights which include lack of information to make informed choices on the type of contraception to use, shortage of contraception commodities to prevent unintended pregnancies and in some cases forced and coerced contraception and sterilization are documented.

4. Benefits of Dolutegravir (DTG) – The challenges with viral load suppression were confirmed in the Uganda Population HIV Impact Assessment 2017 that revealed that suppression of viral load among women living with HIV aged 15-24 was at 35%. DTG is a good opportunity for this group to viral suppress as well as adhere to treatment. Beyond viral suppression, DTG has proved efficacy, tolerability and has a high barrier to resistance.

"Women of reproductive age should not be denied the opportunity to use this magic drug. Instead, the government should solve the problems such as lack of access and choice for contraceptives. All that we need is to be supported so that we can have planned pregnancies. We want this good drug but we also want to give birth to children safe from NTDs - says a young TLD beneficiary"

"DTG should be given to adolescent girls and young women to overcome issues that we have with adherence"

[1] Zash R. 9thIAS Conference Abstract MOAX0202LB

5.The Double Standards at WHO: In 2017, WHO released consolidated guidelines on the Sexual Reproductive Health and Rights of women living with HIV[2] Box 4.3 of the Guidelines provided for a human rights based approach to antiretroviral therapy on ART. The current WHO guideline on DTG shows a lack of commitment and a violation of its own guidelines. It is important that while WHO may have taken a public health approach to the issue, WHO failed in putting the women at the fore of this decision. WHO in its guidance on DTG has successfully put a policy that will ensure that women living with HIV continue to lag behind in the response to HIV and access to contraceptive yet they are the most affected.

ICWEA strongly urges WHO, our governments and various stakeholders to ensure that:

- **All women living with HIV irrespective of age should access full information on all Anti-retroviral treatment including DTG and contraceptives for them to make decisions and choice on what best suits them. Family Planning and SRHR services must be integrated in all ART clinics in the country. This will improve access to family planning for women living with HIV but also better support those who choose to go on DTG to plan pregnancies.**

- **Adolescent girls and women living with HIV who would wish to be initiated or switched to DTG are NOT forced and or coerced to using long term methods of contraception. Early adopters of DTG like Botswana have demonstrated that with support from the facilities, information on DTG, family planning and access to services, women can effectively use DTG with effective family planning methods without being coerced to use long term methods.**

- **Networks of women living with HIV are at the heart of discussions on the risks and benefits of ARVs and policy decision making on HIV drugs and family planning services. More importantly that networks see this as an opportunity to improve treatment literacy among members.**

"Nothing for us without us"

[2] http://www.who.int/reproductivehealth/publications/gender_rights/srhr-women-hiv/en/