

*FEBRUARY 2020*

# Wake up! Our children are dying!

The world is facing a pediatric HIV treatment and prevention crisis.

1.8 million children (<14 years old) are living with HIV worldwide. Approximately 180,000 new HIV infections and 110,000 HIV-related deaths occur among children annually. The world has already failed to deliver on its pledge to achieve a reduction in HIV infections among children to 40,000 by 2018 and 20,000 by 2020. With poor screening, diagnosis and access to treatment, HIV positive adolescents are facing increasing mortality rates. This too is completely unacceptable.

**We are outraged that HIV-positive and HIV-exposed children and their caregivers are suffering the neglect of national governments, PEPFAR, the Global Fund to Fight AIDS, Tuberculosis and Malaria, and UN family organizations.**

In order to confront increasing AIDS deaths, poor retention in care, and dismally low rates of viral load suppression among children who acquired HIV perinatally or through breastfeeding, PEPFAR-funded programs must use the opportunities presented through the COP 2020 planning cycle and the Global Fund 2020-2022 allocation period to prioritize the needs of children with HIV, HIV-positive pregnant women, and HIV-negative pregnant and breastfeeding women. The treatment retention crisis currently experienced by HIV-positive children points to overarching weaknesses in PEPFAR's programs. Fixing the treatment retention crisis for children with HIV will also strengthen the impact of HIV prevention and treatment programs for adults and adolescents.

**The interventions described here, if adopted by PEPFAR-supported countries through COP 2020, will:**

- Accelerate access to lifesaving pediatric treatment; Improve pediatric treatment retention and viral load suppression;
- Reduce vertical transmission;
- Increase retention in care for HIV positive pregnant and breastfeeding women;
- Increase access to effective HIV prevention tools such as PrEP for pregnant and breastfeeding women; and
- Improve the quality of treatment and prevention services for pregnant women—particularly adolescent girls and young women and key populations such as sex workers, women who use drugs, lesbians and transgender people.



## The Basics

Because the numbers of children aged 0-14 living with HIV are dwarfed by the numbers of adults living with HIV, their specific health demands are being ignored. **HIV epidemic control targets globally and nationally can be achieved even if children with HIV continue to die.**

Vertical transmission rates are stalled globally at 12.7% after breastfeeding. In several high burden countries, such as Uganda, Tanzania and Kenya, vertical transmission rates are *increasing*, due to an HIV treatment retention crisis that is affecting HIV positive pregnant and breastfeeding women, as well as lack of access to PrEP and other high impact HIV prevention interventions for pregnant and breastfeeding women. Among some countries, one in three new infections in children are due to pregnant women becoming HIV positive during pregnancy and breastfeeding. Importantly, pregnant women from key population groups face unique challenges in getting the quality, supportive, and stigma-free HIV treatment or prevention services that they are entitled to.

Health systems are not providing the community-led support that women and their families require—they experience stigma, discrimination, long wait times, poor health worker attitudes, and other injustices that drive them from care.

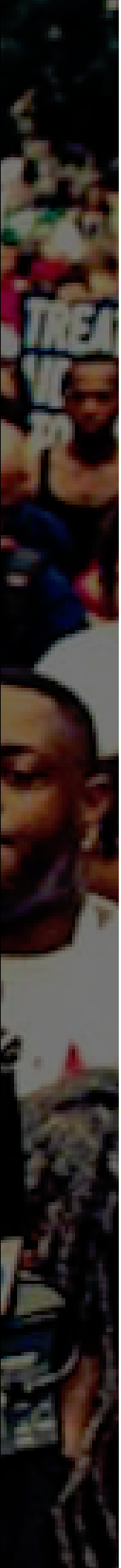
Worldwide, only 54% of children have access to treatment to halt rapid disease progression and death, and to secure a chance at a long lifespan. Even worse, treatment enrollment has flatlined at this extremely low rate for a decade. In 2010, 96,000 children aged 0-14 years were enrolled on treatment. Today, treatment enrollment is about the same, with a net increase of only 2% as of 2018.

Only 52% of children born exposed to HIV have access to an HIV test result the first two months of their lives, and of those who are tested only 19% receive results in 30 days—a flagrant disregard for WHO's scientific guidance that no person should have to wait longer than four weeks for any diagnostic test result.

## Multiple Deadly Disparities

These global inequities between outcomes for adults and children, and adults who are not pregnant or breastfeeding and the general population, mask even greater health disparities at the national level. This is particularly true in West and Central African countries. For example, only 25% children living with HIV in Democratic Republic of Congo (DRC) have access to HIV treatment, less than half the global average of 54%. DRC reports a vertical transmission rate of 27.1%, more than double the global average of 12.7%. O

Only 44% of pregnant women in DRC have access to treatment, and only 20% of infants exposed to HIV are tested within the first eight weeks of life. In Nigeria, only 35% of HIV positive children have access to HIV treatment, and vertical transmission rates of HIV are 24.1% on average. This amounts to discrimination and neglect. We call for an end to business as usual, starting with the PEPFAR COP 2020.



PEPFAR's newly available "Ambition Funds" should be applied in all country COP 2020 planning efforts to fund ambitious "catch up" programs to correct all components of the pediatric treatment access crisis that PEPFAR supported countries are facing. This funding "surge" will provide all of the interventions that children exposed to HIV and their families require: immediate POC EID, powerful and durable treatment regimens, prevention and treatment of the leading killers of children with HIV, and funding to increase the numbers of trained, well paid professional and community health workers who can deliver the comprehensive care and support children with HIV and their caregivers require.

## **All countries should pursue the following interventions through the 2020 COP:**

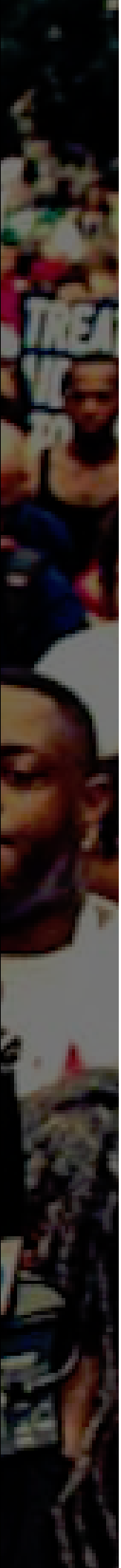
### **1) PrEP for all pregnant and breastfeeding women**

In some settings, particularly in East and Southern Africa, HIV infection during pregnancy and breastfeeding is driving new HIV infections among children. PEPFAR should immediately support the roll out of PrEP for pregnant and breastfeeding women, including through support in rapid shift in national guidelines to ensure PrEP eligibility for pregnant and breastfeeding women (in all age groups).during COP2019.

Policy and legal barriers that obstruct access for adolescent girls and young women, such as age of consent laws and the restriction of PrEP eligibility to sex workers, must be removed immediately. HIV programs must also deliver HIV retesting services for pregnant women.

### **2) Point of care HIV testing for all HIV-exposed infants**

Conventional HIV testing for newborns is substandard and defies WHO's scientific recommendation that all people should have access to diagnostic test results within four weeks of life. Virtually all countries are off track in achieving the goal of testing 90-95% of HIV-exposed infants by age 2 months and linking 95% of infected infants promptly to treatment (Figure 6.3.1). We will not overcome this disparity in access unless all children born exposed to HIV have "point of care" early infant diagnosis (POC EID). COP 2019 funds must immediately be used to course-correct failing national programs that rely on sub-standard conventional EID.



### 3) Quality programs designed to start, retain and support pregnant and breastfeeding women with HIV on treatment

Women face massive challenges when they are pregnant and HIV positive, from higher risks of sexual and physical violence to abandonment to food insecurity. They require health systems to respond to their needs for support, treatment literacy, and other essential comprehensive services such as access to food. Without quality programs women will continue to be lost to follow up at high rates during pregnancy and breastfeeding, leading to poor outcomes for them and their 2645 children. Gaps in access to treatment for pregnant and breastfeeding women in some regions, such as West and Central Africa, are driving new HIV infections among children. Pediatric HIV will never be tackled without accelerating treatment access for pregnant and breastfeeding women, where coverage lags far behind the global average. In other regions, such as East Africa, national treatment coverage among pregnant women is approximately 90%, but loss to follow up rates during pregnancy and breastfeeding are unacceptably high—because treatment programs are of poor quality.

“Mentor Mother”-structured programs, led by trained, remunerated, equipped and supervised community-health workers who are HIV positive mothers themselves and whose community based follow up and support is formally linked with facility-based services, are critical to the success of pediatric treatment programs.

### 4) Accelerate pediatric treatment access

Immediate linkage to effective treatment protects HIV positive children from rapid disease progression and death. Up to 50% of children living with HIV die before their second birthday without treatment. Untreated infants with HIV are at particularly high risk of death in their first three months of life. Along with POC EID, children with HIV need immediate linkage to powerful treatment regimens that can deliver viral load suppression despite high rates of background drug resistance. Given available regimens, for now this means raltegravir granules-based regimens for neonates, solid formulations of lopinavir-ritonavir-based regimens for children under 20kg and dolutegravir-based regimens for children over 20kg. Soon dispersible dolutegravir will be available for younger children as well as the new pediatric “4-in-1” regimen. PEPFAR must support countries to plan now for rapid introduction of these improved regimens in order to prevent disruptions, stock outs and delays. Children also require effective screening, diagnosis, prevention and treatment for the massive threat of paediatric tuberculosis. Progress against pediatric antiretroviral treatment initiation and retention and TB treatment and prevention targets must be expanded over COP 2019 and COP 2020, reported quarterly, and publicly available. Rapid scale up of access to powerful, durable pediatric treatment must be a condition of COP 2020 planning and COP 2019 implementation. Countries must report quarterly on the status of their COP 2020-obligated transition from NNRTI-based regimens to LPV/r- or DTG-based regimens.

### 5) Service delivery models that save children's lives

Children with HIV and their caregivers require HIV programs that guarantee access to community-led service delivery interventions for all. Only with wraparound support including supportive caregiver training, counseling, and comprehensive loss to follow up prevention services featuring home based visits, treatment literacy programs, nutrition support and more will treatment programs deliver viral load suppression and durable retention in care for children and for HIV positive parent(s). National programs must develop public 95-95-95 targets for 2020 at national, sub-national and local levels and must publicly track progress and setbacks, disaggregating program data by age.