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Joint written statement* submitted by the Elizabeth Glaser Pediatric AIDS Foundation and the International HIV/AIDS Alliance, non-governmental organizations in special consultative status

The Secretary-General has received the following written statement, which is circulated in accordance with Economic and Social Council resolution 1996/31.

[10 May 2013]

* This written statement is issued, unedited, in the language(s) received from the submitting non-governmental organization(s).

Access to medicines: Children living with HIV*

The Elizabeth Glaser Pediatric AIDS Foundation and the International HIV/AIDS Alliance welcome the report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and the focus of the report on access to medicines.

The International Covenant on Economic, Social and Cultural Rights (ICESCR) calls on States to recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (Art. 12(1)) and the Committee, in general comment 14 (2000), specifically mentions the importance of ensuring that medicines are available, accessible, acceptable and of high quality.

There is no population for which this is truer than for children living with HIV

Access to medicines is a basic right that children often lack, particularly in countries with weak health systems and relatively few resources. Infant mortality in developing countries is many times higher than in developed countries; in sub-Saharan Africa, 1 in 8 children dies before their fifth birthday—nearly 20 times the average for developed regions.[1] Many causes of infant and child mortality are preventable, and lack of access to medicines is one of the main contributing factors in child mortality, particularly for those with HIV infection.

The fact is that thirty years into the HIV epidemic, children continue to be left behind when it comes to accessing HIV medicines. As prevention and treatment of HIV in children is the main focus of the work of the Elizabeth Glaser Pediatric AIDS Foundation, we would like to draw your attention to the significant challenges in access to medicine facing children living with HIV in high- HIV prevalence areas.

Child mortality

An estimated 230,000 children died from AIDS-related illness in 2011 alone—630 every day.[2]

In some of the highest-burden countries, HIV contributes to as much as 28 percent of under-5 deaths – though this figure is likely to be far higher, as many under-5 deaths are attributed to infections related to HIV or affect children not yet diagnosed.[3] The contribution of HIV to mortality of children under age five is continuing to rise.[4]

Since more than 90 percent of HIV-positive children are infected by mother-to-child-transmission during pregnancy, delivery, or breastfeeding, reducing mother-to-child HIV transmission is one of the most effective strategies for preventing HIV infection in children.

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* Drugs for Neglected Diseases Initiative (DNDi) and Medicines Patent Pool (MPP), NGOs without consultative status, also share the views expressed in this statement.

1 UNICEF Press release, "Child mortality rate drops by a third since 1990," 17 September 2010

2 EGPAF, "The Global AIDS Pandemic – Key Facts," at: http://www.pedaids.org/Publications/Fact-Sheets---Brochures/Fact-Sheets-and-Issue-Briefs-(4-26-13)/GlobalStats

3 UNICEF, *Preventing mother-to-child transmission (PMTCT) of HIV*, at: http://www.unicef.org/esaro/5482_pmtct.html

4 WHO, Child mortality, 2011, at: http://www.who.int/pmnch/media/press_materials/fs/fs_mdg4_childmortality/en/index.html

Without access to appropriate medicines, the risk of perinatal HIV transmission is between 30 and 40 percent—but with intervention, that risk can be reduced to less than 5 percent.[5] Despite these stark statistics, about 40 percent of pregnant women living with HIV currently do not have access to the necessary medicines to prevent transmission of HIV to their child.[6]

For these children born to HIV-positive mothers, early diagnosis and timely access to appropriate medicine is crucial to ensuring their survival, due to the rapid disease progression observed in children under two years of age.[7] Without access to medicines, about half of them will die before their second birthday, with 80 percent dying before the age of 5.[8]

This is why, in 2010, the World Health Organization (WHO) recommended that children below the age of two start anti-retroviral (ARV) treatment immediately upon diagnosis – regardless of clinical symptoms, immune status, or viral load— and this is likely to be revised in 2013 to extend to more children.[9] Despite this, the rate of child access to HIV treatment is lagging far behind that for adults. In 2011, ARVs were available to 57 percent of adults who required them, but only 28 percent of children in need.[10]

The result is that children are needlessly dying of complications from HIV infection—whether it is because mothers did not have access to medicine to prevent transmission of HIV to their babies, or because children did not have access to quality HIV diagnosis or medicines.

Treatment of children living with HIV

There are many barriers that prevent infants and children living with HIV in resource-limited settings from accessing HIV diagnosis, treatment and care. Weak health systems, lack of medical personnel trained in treating children, "stock-outs" in countries with high-HIV prevalence and limited medical research of medicines for children living with HIV are all a big part of the problem. All of these barriers contribute to the shortfall in fulfilling children's health rights.

In his report, the Special Rapporteur mentions that "despite momentous gains in the past decade, only 8 million out of 14.8 million people living with HIV globally receive

[5] UNICEF, *Preventing mother-to-child transmission (PMTCT) of HIV*, at: http://www.unicef.org/esaro/5482_pmtct.html

[6] In 2011, 57 percent of pregnant women living with HIV in low- and middle-income countries received the medicines they needed to prevent transmission of HIV to their babies. EGPAF, "The Global AIDS Pandemic – Key Facts," at: http://www.pedaids.org/Publications/Fact-Sheets---Brochures/Fact-Sheets-and-Issue-Briefs-(4-26-13)/GlobalStats

[7] Violari et al., "Early Antiretroviral Therapy and Mortality among HIV-Infected Infants," N Engl J Med. 2008, November 20; 359(21): 2233–2244. See: http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2950021/

[8] WHO/UNAIDS/UNICEF, *Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access*, 2011, at: http://www.who.int/hiv/pub/progress_report2011/en/index.html

[9] WHO, *Antiretroviral Therapy for HIV Infection in Infants and Children: Towards Universal Access - Recommendations for a public health approach, 2010 revision*, at: http://whqlibdoc.who.int/publications/2010/9789241599801_eng.pdf

[10] UNAIDS, *A progress report on the Global Plan towards the elimination of new HIV infections among children by 2015 and keeping their mothers alive*, 2012, at: http://www.unaids.org/en/media/unaids/contentassets/documents/unaidspublication/2012/JC2385_ProgressReportGlobalPlan_en.pdf

necessary treatment."[11] However, it is important to stress, as already noted above, that although ARV treatment coverage for adults continues to grow and now reaches more than half of those currently in need, HIV medicines only reach about 28 percent of children.

One of the problems is a lack of treatment options. Less than half of FDA-approved adult ARVs are approved for neonates and infants—a sign that these drugs are either not being studied for use by children or are found unsafe for their use.[12] Many of the pediatric formulations available are unpalatable or difficult for young children to swallow, and some pediatric formulations require refrigeration, a resource unavailable to many caregivers in developing countries.

One possible reason for the current lack of options for pediatric HIV patients is that pharmaceutical companies do not see a return on investment in pediatric ART research. They argue that since HIV infection in children has been virtually eliminated in the US and Europe, and preventing mother-to-child transmission of HIV programmes in the developing world are becoming increasingly available, pediatric ARV demand will continue to decline—leaving them with less financial return on their investment.[13]

The fact that children present a smaller market for ARVs than adults has an additional impact—since countries and organizations are purchasing fewer HIV medicines for children, there is not the economy of scale that exists for adults. This also means that there is also little incentive for generic manufacturers to produce pediatric medicines, which reduces the number of manufacturers for each formulation. All of this directly impacts the health and welfare of children living with HIV, resulting in a violation of their health rights.

The international community can and must do more to ensure access to medicines by mothers to prevent children from acquiring HIV, and by children to effectively treat their HIV infection.

In his report, the Special Rapporteur urges States to adopt a detailed national plan of action on medicines that prioritizes access to medicines with the public health budget and allocates resources accordingly. The Elizabeth Glaser Pediatric AIDS Foundation and the International HIV/AIDS Alliance ask States to ensure that these national plans of action specifically mention the particular needs and requirements of children when to comes to accessing medicines, including the needs of children living with HIV in countries with high-prevalence rates.

Recommendations:

The Elizabeth Glaser Pediatric AIDS Foundation and the International HIV/AIDS Alliance urge the Member States of the Human Rights Council to:

- affirm that access to appropriate, affordable and quality medicines are central to children's enjoyment of the right to health;
- ensure that access to medicine by children is a stated priority in any national plan of action on medicines that is adopted, pursuant to the recommendation of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health;

[11] A/HRC/23/42

[12] Polly Clayden, *The Pediatric Antiretroviral Pipeline*, November 2012, at: http://www.pipelinereport.org/TOC/pediatric-ARV

[13] Drug for Neglected Diseases Initiative (DNDi), *Assessment of R&D needs for pediatric antiretroviral treatment*, at: http://www.dndi.org/images/stories/pdf_portfolios/paed-hiv_needsassessment.pdf

- urge the pharmaceutical industry to develop less expensive fixed-dose combination drugs (FDCs) suitable for infants and children living in resource-poor settings and make necessary pediatric medicines locally available at the lowest possible cost.