Campaign to End Pediatric HIV/AIDS (CEPA)
Update and Progress Report
September 2009

I. EXECUTIVE SUMMARY

Since its launch in May 2009, the Campaign to End Pediatric HIV/AIDS (CEPA) has made considerable progress toward implementing a complex and dynamic advocacy campaign to scale up prevention, treatment, and care of pediatric HIV/AIDS in six focus countries in sub-Saharan Africa: Kenya, Tanzania, Uganda, Zambia, Nigeria, and Mozambique. In particular, the Global AIDS Alliance and our partners have (1) created a strong network that is leading the design of CEPA National Advocacy Action Plans (NAAPs) that will provide a framework for CEPA's overall advocacy strategy, as well as ongoing monitoring and evaluation of the campaign; (2) launched the process of developing NAAPs in six focus countries; (3) launched the Impact Planning, Assessment, Reporting and Learning (IPARL) system as part of the national advocacy action planning process; and (4) begun to develop CEPA's Global Advocacy Action Plan. Importantly, CEPA's network partners have also achieved some key advocacy outcomes and secured high-level institutional support for accelerated action to address pediatric HIV/AIDS from both the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Global Fund to Fight AIDS, Tuberculosis and Malaria.

CEPA's regional initiating partners include the African Network for Care of Children Affected by HIV/AIDS (ANECCA), Paediatric AIDS Treatment for Africa (PATA), and Pan African AIDS Treatment Access Movement (PATAM). The campaign's country-level initating partners include the Kenya Treatment Access Movement, Mozambique Treatment Access Movement, Positive Action for Treatment Access (Nigeria), Treatment Advocacy and Literacy Campaign (Zambia), and Human Development Trust (Tanzania). Additional partners could include the Coalition for Health Promotion and Social Development (HEPS), which is based in Uganda.

II. CONTEXTUAL CHANGES AND LESSONS LEARNED

There have been a number of changes in the external environment that present opportunities—and potential obstacles—for the Campaign to End Pediatric HIV/AIDS.

- The Obama administration is not prioritizing global AIDS as hoped. Instead, the White House views HIV/AIDS as just one component of the evolving Global Health Initiative and has effectively flat-lined funding for both PEPFAR and the Global Fund to Fight AIDS, TB and Malaria. Similarly, stakeholders such as the Bill and Melinda Gates Foundation and the U.K. government have shifted away from prioritizing HIV/AIDS to focusing on global health more broadly. The growing backlash against "AIDS exceptionalism" and global AIDS spending presents clear challenges to achieving CEPA's advocacy goals. Conversely, CEPA is being positioned as a critical means of bridging maternal and child care and achieving the health-related Millennium Development Goals.

- The Obama Administration has launched two key initiatives that could provide significant opportunities for advancing CEPA's advocacy goals: the Global Health Initiative and the Food Security Initiative. CEPA's network partners are working to attempt to impact these initiatives and ensure that they prioritize pediatric HIV/AIDS prevention and treatment.

- Michael Sidibé began his term as Executive Director of UNAIDS on January 1, 2009, and Dr. Eric Goosby was confirmed as the new U.S. Global AIDS Coordinator on June 23, 2009. These changes present key opportunities for advancing CEPA's advocacy agenda, and CEPA's network partners have been in dialogue with both leaders as they develop their policy agendas. On the other hand, the lack of leadership at the U.S. Agency for International Development poses a significant challenge for advancing CEPA's advocacy goals and global HIV/AIDS policy overall.

- As articulated in the July 29, 2009, issue of the Journal of Acquired Immune Deficiency Syndromes, there is a growing scientific consensus that highly active antiretroviral therapy (HAART) should be the new standard treatment for prevention of mother-to-child transmission of HIV in poor countries (http://www.medicalnewstoday.com/articles/159178.php). This consensus will facilitate CEPA's efforts to ensure that WHO guidelines endorsing HAART as best practice for PMTCT are understood and implemented by key policymakers and service providers over the next couple of years.

- The U.S. Food and Drug Administration has granted tentative approval to a number of pediatric formulations of single or combination antiretrovirals. It is not yet clear whether key stakeholders are aware of this new development, or whether these products have been added to the CEPA countries' essential medicines lists or been approved for inclusion in national treatment guidelines.

- The World Health Organization is expected to issue new treatment guidelines by late 2009 or early 2010, which will recommend early initiation of antiretroviral treatment for all people with HIV who have CD4 cell counts below 350 cells per cubic millimetre. (Current WHO guidelines recommend treatment initiation at CD4 counts below 200 cells/mm.) This change will effectively double the number of people who are medically eligible for AIDS treatment—a monumental challenge for both national governments and international service providers, particularly in resource-poor countries. In addition, the new WHO guidelines will create real ethical challenges in terms of determining who receives treatment, i.e., people with lower CD4 counts who may have been waiting longer, or people with higher cell counts who have progressed to clinical AIDS, etc.

- It is becoming clear that South Africa should be included as a focus country in order to maximize CEPA's impact and provide a strong model for scaling up pediatric programs regionally and globally. In addition to having the largest epidemiological burden of pediatric HIV/AIDS in Africa, South Africa is home to strong activist networks and could play a critical role in sharing best practices for prevention and treatment of pediatric HIV/AIDS. Conversely, CEPA can help generate the political momentum needed in order to scale up pediatric prevention and treatment in South Africa.

- The Rwandan Ministry of Health has expressed interest in having Rwanda included in the Campaign to End Pediatric HIV/AIDS.

- Due in part to the global financial crisis, many African governments are cutting back on HIV/AIDS treatment programs. For example, Uganda is not enrolling new patients, and Nigeria is back-tracking on its commitments to achieve universal access. Likewise, growing poverty in developing countries is putting increased budgetary pressure on HIV/AIDS and other health programs. The global economic downturn has also exacerbated the impact of natural disasters such as Kenya's drought, and further discussion is needed around whether and how CEPA should address broader social protection issues related to poverty and children's well-being.

- As part of CEPA's overall advocacy strategy, the campaign will replace the terminology *prevention of mother-to-child transmission*, which further stigmatizes mothers with HIV/AIDS, with *prevention of parent-to-child transmission*, or PPTCT+, a usage that has already been adopted by the Indian government and is gaining currency with some U.N. agencies. (Importantly, the phrase *vertical transmission* does not capture the full array of maternal and child health interventions included in PPTCT+, including treatment for HIV-infected mothers and family planning services.)

III. PROGRAM PROGRESS

As described below, the Campaign to End Pediatric HIV/AIDS has made considerable progress toward implementing a complex and dynamic networked advocacy campaign to scale up prevention, treatment, and care of pediatric HIV/AIDS in Kenya, Tanzania, Uganda, Zambia, Nigeria, and Mozambique.

Key Activities:

- An initial meeting of eight representatives from CEPA's core regional networks was convened in Nairobi, Kenya, from May 18-19, which succeeded in orienting the core partners to the advocacy goals and key components of the Campaign to End Pediatric HIV/AIDS; clarifying organizational roles and responsibilities; mapping the way forward during the initial phase of the campaign; and beginning to build an effective local-to-global advocacy network.

- In conjunction with this meeting, CEPA's network partners convened a roundtable to introduce CEPA to a broader audience, and presented CEPA at a regional meeting of the U.N. Interagency Task Team on PMTCT and Pediatric HIV Care and Treatment. In addition, we organized a press conference that highlighted the failure of the Obama Administration's initial FY2010 budget to provide full funding for PEPFAR and the Global Fund. These efforts generated coverage from the Daily Telegraph (U.K.), Inter Press Service, and Los Angeles Times.

- The network partners have established a CEPA Action Team comprised of representatives from each of the campaign's regional and national initiating partners. This team holds weekly conference calls to review progress on key campaign activities, including the National Advocacy Action Plans; determine next steps and refine CEPA's strategy and implementation as needed; discuss pediatric AIDS and treatment policy shifts at the country level; discuss partner meetings with stakeholders such as government officials, advocates, and donors; and work to align CEPA's global and country-level advocacy strategy.

- As part of a formal advocacy mapping process, CEPA network partners visited Kenya, Uganda, and Zambia in July and August 2009 for a series of meetings with civil-society organizations (CSOs) and other stakeholders.

- On July 8, CEPA convened a meeting of global civil-society advocates to discuss a proposal for pre-approval access to therapies for HIV/AIDS, which would accelerate disbursement of new pediatric formulations in advance of their approval by national regulatory authorities.

- CEPA organized a country partners kick-off meeting in Nairobi from August 19-21, which convened 35 participants, including representatives of GAA, PATA, KETAM, MATRAM, TALC, PATA-Nigeria, HDT, Health GAP, Health Promotion and Social Development, and iScale; ANECCA members; and stakeholders such as The Children's Investment Fund Foundation, UNICEF, Mothers2Mothers, Health Action International, and the Kenya AIDS NGOs Consortium. This meeting achieved several key results, including (1) developing preliminary advocacy outcomes; (2) initiating the country-level

advocacy action planning process; (3) strengthening the CEPA network and CEPA country teams; (4) identifying partner needs related to network communications; and (5) launching IPARL as part of the national advocacy action planning process. Documents from the August meeting are available online at http://www.globalaidsalliance.org/index.php/1277.

- CEPA produced a 52-page *On the Road* guidebook to assist country teams in developing national-level advocacy action plans to advance the campaign's goals (http://www.globalaidsalliance.org/page/-/CEPA%20PDFs/ CEPA_Developing_National_Level_Advocacy_Action_Plan_FINAL.pdf).

- CEPA had completed network transfer agreements with seven regional and country-level initiating partners to help lay the foundation for CEPA implementation, including identifying key national-level advocacy partners; engaging in the national advocacy action planning process by prioritizing country bottlenecks, drafting the NAAPs, and preparing country teams for the October CEPA Advocacy Summit; refining and finalizing the CEPA advocacy action plan based on feedback from CEPA's network partners; and introducing CEPA in the individual focus countries.

- Regional partners in each of CEPA's focus countries are now in the process of setting up national working groups and planning workshops or consultations that will provide a key opportunity for providing the targeted technical assistance required to facilitate development of CEPA National Advocacy Action Plans and implementation of the IPARL system. The revised NAAPs that emerge from this process will be presented at the CEPA Advocacy Summit.

- The first CEPA Advocacy Summit is scheduled for October 20-22 in Johannesburg, and will convene as many as 60 representatives from country-level organizations that are essential to designing and implementing the National Advocacy Action Plans at the heart of CEPA's advocacy strategy.

- CEPA's network partners are working to refine the expected advocacy outputs and outcomes of the campaign's global advocacy strategy, as well as Key Performance Indicators related to specific advocacy activities. CEPA's Global Advocacy Action Plan will be finalized based on the National Advocacy Action Plans that are presented and refined at the upcoming Advocacy Summit.

- iScale is supporting the campaign through the development of a multifaceted M&E system that includes action planning, data gathering and monitoring, data analysis and evaluation, action learning, and reporting. This dedicated Impact Planning, Assessment, Reporting and Learning (IPARL) system will facilitate real-time monitoring, learning, and reporting, and allow CEPA's network partners to modify the campaign's strategy and tactics as needed in order to achieve our joint advocacy goals.

- In addition, iScale is supporting CEPA's implementation through the development of a network communications system that can facilitate advocacy communications, network management, and monitoring and evaluation. We are a survey of the CEPA partners' communications needs and will be modifying the network communications strategy accordingly.

- As part of the CEPA network communications plan, we anticipate creating a stand-alone website that will allow both public and password-restricted access to CEPA planning documents and to the campaign's M&E database. In the meantime, there is a CEPA portal on the Global AIDS Alliance website at http://www.globalaidsalliance.org/index.php/1032, which includes a link to all presentations and documents from the August country partners kick-off meeting.

- CEPA's network partners are developing a campaign logo that will be translated into French, Luganda, Swahili, Bemba, Nyanja, and Portuguese.

Key Advocacy Outcomes:

During the first four months of the campaign, CEPA's network partners have achieved several key advocacy outcomes and helped mobilize high-level political support that will be critical to advancing CEPA's advocacy goals.

- CEPA's advocacy helped persuade the Global Fund to Fight AIDS, TB and Malaria board of directors to adopt a decision point calling on the Fund's Secretariat to review its portfolio to identify countries with a high pediatric HIV/AIDS burden and low coverage rates for PPTCT+ and pediatric treatment, and accelerate the implementation of WHO guidelines endorsing highly active antiretroviral therapy as best practice for prevention of mother-to-child transmission.

- CEPA's advocacy helped ensure the new UNAIDS Joint Action for Results Outcome Framework explicitly endorses scaling up access to high-quality PPTCT+ services as an integral part of comprehensive sexual and reproductive health services for women, their partners, and young people, including ongoing care and treatment.

- Graça Machel has agreed to serve as Honorary Chair of the CEPA Advisory Council and to attend the first CEPA Advocacy Summit in Johannesburg.

In addition, we have achieved the following key advocacy outputs:

- CEPA's network partners have conducted high-level meetings with PEPFAR officials to engage them in supporting CEPA, and played a key role in developing the Global AIDS Roundtable's goals and recommendations for PEPFAR's new prevention guidance and program implementation, which outlined essential reforms in 12 key areas, including scaling up prevention of mother-to-child prevention programs.