Background

Despite the tremendous progress in the global fight against HIV and AIDS, including the declining incidence of HIV transmission and expanded access to antiretroviral therapy (ART), decline in AIDS-related deaths have plateaued in recent years. Up to half of the people living with HIV continue to present to care with advanced HIV disease (AHD), and individuals with AHD are at a high risk of death, even after starting ART. Those with AHD are more prone to opportunistic infections, including TB, severe bacterial infections, and cryptococcal meningitis. They also face an increased risk of morbidity and mortality.

The World Health Organization (WHO) defines AHD for adults, adolescents, and children five years and older as having a CD4 count of less than 200 cells/mm³ or meeting the criteria for WHO stage 3 or 4 disease. All children under age five are considered to have AHD.

AHD includes individuals newly diagnosed with HIV, people who have treatment failure and a consequent decline in CD4 cell count, and individuals who previously initiated ART and are re-engaging with care after treatment interruption. Each of these groups highlight failures in the global response across the HIV disease cascade from prevention and early diagnosis to proper treatment and retention in care.

The Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) is a proven leader in the global fight against HIV and AIDS. EGPAF envisions a world where no other mother, child, or family is devastated by the disease. As part of this commitment, EGPAF has recognized the significant burden of AHD and the need for tailored approaches to meet the unique needs of people living with AHD.

Where We Work

Through eight dedicated awards, EGPAF supports comprehensive AHD programs in over 400 sites across five countries: Kenya, Lesotho, Malawi, Tanzania, and Zimbabwe. Scaling to additional sites in Cameroon, Democratic Republic of the Congo, Côte d’Ivoire, and Mozambique is ongoing.

What We Do

Operationalize a comprehensive AHD package of care in alignment with national policies and global best practices

EGPAF’s package of care follows the priority actions to reduce AHD-related morbidity and mortality, outlined in the WHO’s first AHD guidelines in July 2017, as well as subsequent evidence-based best practices. These include several rapid point-of-care diagnostics to allow patients to be diagnosed with AHD more efficiently and faster access to needed counseling, ART regimen changes, and treatment for opportunistic infections. For example, WHO recently recommended a single, high-dose regimen of liposomal amphotericin B to treat cryptococcal meningitis. There are also shorter, more patient-friendly preventive treatments for tuberculosis (TB) — the leading cause of death for people living with HIV. The WHO now supports a three-month regimen of weekly isoniazid (INH) and rifapentine to prevent TB, a regimen that is easier to complete than traditional six-month daily INH TB-preventive therapy.

Strengthen the capacity of sites to adequately screen, treat, and retain clients with AHD through differentiated models of care.

Care models are needed that fit the precise needs of those presenting (and re-presenting) with AHD, ensuring that healthcare workers have the capacity to carry out diagnostics, treatment, and care protocols to manage the complex needs and challenges of these individuals living with AHD.

EGPAF is decentralizing AHD care, including screening, treatment, and prevention, to lower-level health facilities where patients most often access care. We developed a training package and adopted a package of tools to assist healthcare workers in identifying AHD, and we are adapting and delivering differentiated models of care that meet the needs of patients who are presenting or re-engaging in care with AHD. These tools ensure that healthcare workers can effectively use new drugs and diagnostics, without overburdening their already busy workload.

Recognizing that not all aspects of AHD care can be fully decentralized to the primary healthcare level, EGPAF is supporting a hub-and-spoke model of care. The training and tool packages acknowledge that those with AHD are at higher risk of loss to follow-up, so intensified community-based care is needed. Given that comprehensive care for those with AHD may require laboratory samples, and potentially patients, to move across health facilities and community levels, EGPAF’s package suggests strengthened communications and linkages between these hub-and-spoke referral networks.

Generate evidence, develop innovative approaches, and facilitate south-to-south learning, routine M&E, and sharing of best practices for AHD.

In addition to providing AHD care at its own sites, EGPAF plays an active role in research projects designed to estimate the burden of AHD, project demand for AHD products, and optimize a set of tools and models of care for addressing AHD. We believe we can leverage successful implementation of innovative diagnostics, drugs, and care management approaches. We have done exactly this in scaling access to early infant diagnosis and optimal treatment to diseases, such as pediatric TB and adult syphilis.

Most Ministries of Health (MOHs) do not capture and routinely report AHD data. There are no national AHD patient registers nor summary and reporting tools, and therefore most AHD data tends to come from studies. EGPAF has addressed this gap through developing a framework for monitoring and evaluation to standardize AHD reporting, and developed patient level AHD forms, registers and summary tools that enable collection, collation and reporting of AHD data.

EGPAF organizes forums to share best practices for AHD within our programs and continues to engage in south-to-south learning as part of its role as a leader in the global fight against HIV and AIDS.

What We Need

- Many of these diagnostics and treatments are still not accessible to those who need them most – individuals with AHD and the healthcare workers who are trying to provide them with optimal care. Sustainable and reliable supply chains are needed for key AHD commodities, and the high pricing and lack of generic options must be addressed.

- National policies must prioritize implementation of robust and comprehensive training packages to manage advanced HIV disease and the key coinfections associated with it. In addition, countries need to allocate resources for use of innovative technology and for adequate stocks of more effective and tolerable drugs.

- We also desperately need to scale differentiated service delivery models that prioritize attention of highest risk clients alongside continued engagement of more stable HIV-positive clients who need less intensive follow up.