



photo: James Pursey/EGPAF



ORGANIZATION OF AFRICAN FIRST LADIES  
AGAINST HIV/AIDS (OAFLA)



Elizabeth Glaser  
Pediatric AIDS  
Foundation

# Advocacy Tool Kit

on Pediatric HIV Treatment

# Contents

---

Introduction	01
Understanding Pediatric HIV Treatment	03
Action Needed by First Ladies to Address Pediatric HIV Treatment	11
Tools for Engagement	13

# Introduction

## Purpose

We are at a critical point in the AIDS epidemic, where concerted efforts and investment now could result in the end of AIDS as a public health threat by 2030.

---

To achieve the ambitious goal for HIV/AIDS as set out by the United Nations Member States in the Sustainable Development Goals, those furthest behind must be reached first—this includes children living with and affected by HIV/AIDS. By addressing HIV in children, the epidemic can be halted and reversed, creating an AIDS-free generation.

Engagement at every level is needed to reach the children most in need, including by presidents, First Ladies, and parliamentarians, among others. Engagement by the First Ladies is critical especially in the countries in which the HIV epidemic has hit hardest. Building on the experiences of the Organisation of African First Ladies against HIV/AIDS (OAFLA), First Ladies are uniquely positioned to use

their political and social influence to effect change in their countries and bring about better access to and uptake of care and treatment services for children living with and affected by HIV. Through education campaigns, policy reform, and awareness-raising events, First Ladies can have a profound impact on the lives of children affected by HIV, and they can usher in a shift in the response to the epidemic that leads to the end of AIDS.

The tool kit provides statistics, messages, and key actions that First Ladies can undertake to address the low pediatric HIV coverage that we see in our countries. Specifically, the tool kit will facilitate the achievement of the goals that OAFLA has developed in its strategic plan of 2014–2018 and beyond.

## About the Organisation of African First Ladies Against HIV/AIDS

OAFLA was founded by 37 African First Ladies in 2002 as a collective voice for Africa's most vulnerable people: women and children infected and affected by HIV and AIDS.

---

Guided by the vision of an Africa free from HIV and AIDS, maternal and child mortality, where women and children are empowered to enjoy equal opportunities, OAFLA works to enable African First Ladies to advocate for effective policies and strategies toward ending the AIDS epidemic as a public health threat, reducing maternal and child mortality, and empowering women and children through strategic partnerships in the spirit of solidarity. OAFLA's mission is to cultivate the exchange of experiences among African First Ladies and increase the capacity of First Ladies and other women leaders to advocate for effective solutions to respond to the AIDS epidemic, as well as fight against HIV/AIDS-related stigma and discrimination.

At the national level, the First Ladies contribute toward efforts in preventing, managing, and eliminating HIV and AIDS.

Given this obligation, the OAFLA secretariat has a mandate to increase the advocacy capacity of First Ladies, as well as develop critical partnerships to mobilize resources; raise awareness; develop and support HIV/AIDS prevention; and promote treatment, care, and support programs. In this spirit, EGPAF and OAFLA collaborated on this tool kit to increase the ability of First Ladies to promote effective solutions to the pediatric HIV treatment gap that we see in African nations.

## About the Foundation

Elizabeth Glaser, one of the co-founders of the Elizabeth Glaser Pediatric AIDS Foundation (EGPAF), contracted HIV through a blood transfusion in 1981 while giving birth to her daughter, Ariel. She and her husband later learned that Elizabeth had unknowingly passed the virus on to Ariel through breast milk and that their son, Jake, had contracted the virus in utero.

In the course of trying to find treatment for Ariel, the Glasers discovered that drug companies and health agencies had no idea that HIV was prevalent among children. The only drugs on the market were for adults; nothing had been tested or approved for children.

Ariel lost her battle with AIDS in 1988. Fearing that Jake's life was also in danger, Elizabeth rose to action. EGPAF originated from three mothers around a kitchen table in 1988. With her close friends, Elizabeth created a foundation that would raise money for pediatric HIV/AIDS research.

Elizabeth lost her own battle with AIDS in 1994. Today EGPAF has become a leading global nonprofit organization dedicated to preventing pediatric HIV infection and eliminating pediatric AIDS through research, advocacy, and prevention and treatment programs in several African countries. Elizabeth's legacy lives on through the Foundation and in her son, Jake, who is now a healthy young adult.

**Figure 1. Countries in Africa Where EGPAF Works**



# Understanding Pediatric HIV Treatment

## Prevention of Mother-to-Child Transmission of HIV

More than 90% of all pediatric HIV infections are through mother-to-child transmission (MTCT); therefore, it is important to briefly discuss prevention of MTCT (PMTCT) of HIV interventions.

---

PMTCT is one of the most effective prevention measures in global public health. PMTCT services include: HIV testing for pregnant women; partner HIV testing; the initiation of pregnant women living with HIV on antiretroviral therapy (ART) to reduce the risk of transmission to their children during pregnancy, labor, and delivery and throughout breastfeeding; prophylaxis for infants; and follow-up with mothers and their infants throughout breastfeeding. Transmission rates of HIV from mother to child can be as high as 45% without any interventions. With appropriate interventions, this can be reduced to less than 5%.<sup>1</sup> As a result of ART among pregnant and breastfeeding women, approximately 1.4 million new infections in children were averted between 2000 and 2014.<sup>2</sup>

Despite the established effectiveness of PMTCT, many pregnant women do not know their HIV status and currently only 73% of pregnant women living with HIV globally have access to ART to prevent the transmission of HIV to their infants. As a result there were nearly

---

220,000 new infections in children in 2014—the majority of which occurred in Africa.<sup>3</sup>

Efforts to prevent MTCT of HIV begin during pregnancy and extend through the end of the breastfeeding period, at which time children receive their final HIV test results. Many of the children will be HIV-negative, but some will be HIV-positive and should be referred immediately to HIV care and treatment services. Children living with HIV will need to be initiated on ART and remain in care and treatment programs for the rest of their lives.

Because of the lifelong impact HIV may have on a child, it is important to advocate for services that can prevent the pediatric infection in the first place, as well as advocate for improved pediatric care and treatment services in country. PMTCT is the first step in a series of interventions to help prevent new infections in children, identify HIV-positive children, and link those children living with HIV to treatment.

## Early Infant Diagnosis and Linkage to Care

Identifying children living with HIV can be challenging. Children are dependent on their parents or caregivers to bring them to clinics for HIV testing and treatment. To ensure that all children living with HIV are enrolled early into care and treatment services, children must first be diagnosed. However, most children who are living with HIV never receive a diagnosis.

---

In 2013, only 42% of HIV-exposed infants in developing countries received a specialized virologic test to determine HIV infection within two months of birth as recommended by the World Health Organization (WHO).<sup>4</sup> According to a UNAIDS report, in 2014 only 32% of children living with HIV were enrolled in treatment.<sup>5</sup> This means that the majority of children living with HIV are not receiving lifesaving treatment. These figures are particularly appalling when considering the high mortality rate for HIV-positive children not on treatment. Without treatment, about one-third of children living with HIV will die by their first birthdays, and about half will die by the age of two years.<sup>6</sup> With treatment, children living with HIV can grow up into healthy adulthood.

The most recent WHO treatment guidelines recommend immediate initiation of ART in all children living with HIV. Early initiation of ART in infants living with HIV before their twelfth week of life has been shown to reduce mortality in low-resource settings by 75%.<sup>7</sup> Early initiation of ART has shown increased growth benefits for children, including mitigating the negative impacts of HIV on the development of the nervous system. In addition, early initiation of ART at higher levels of immune function as measured by CD4 count could potentially reduce the long term risk of cardiovascular disease and the onset of chronic lung disease.<sup>8</sup>

---

Early diagnosis and initiation on treatment among HIV-positive infants and children is therefore a critical component of addressing the HIV epidemic. To reach these children, several service areas must be improved.

### 1. Entry Points for Identifying HIV-Positive Children

The traditional entry point for identifying HIV-positive infants has been early infant diagnosis (EID) through PMTCT services for HIV-positive pregnant and breastfeeding women. However, with the growing success of PMTCT, focus also needs to be placed on identifying HIV-positive children outside PMTCT settings. Children living with HIV can be found through other settings, such as immunization or nutrition clinics, or when they seek services when they are ill. This is why HIV testing that is initiated by health care workers should be implemented at more sites to reach those children who are currently being missed through PMTCT.<sup>9</sup> This includes testing children at immunization clinics, maternal and child health (MCH) centers, nutrition centers, inpatient wards, and tuberculosis clinics, among other facility locations, as well as implementing outreach services in the community.

## 2. HIV Testing and Receiving Results

Diagnosing HIV in infants can be challenging owing to the remaining antibodies from the mother in the child's system from his or her time in the womb and from breastfeeding. For this reason, it is important that all HIV-exposed infants receive a specialized virologic HIV test to confirm HIV status.<sup>10</sup> This test is different from the rapid HIV test used in adults that provides results within hours. Virologic HIV testing is mostly offered in centralized locations in many developing countries—this means that dried blood spot (DBS) samples must be taken from the infant and sent to a central laboratory for testing and the results sent back to the decentralized location to be given to the caregiver of the child. Studies from sub-Saharan Africa reported that long delays in accessing test results led to significant loss to follow-up of infants.<sup>11</sup> This delay from testing to ART initiation can be between 16 and 23 weeks for infants, which is well past the period of peak mortality for HIV-positive infants of 6 to 8 weeks of life.<sup>12</sup> Implementing point-of-care testing (POCT) technologies at decentralized locations, providing short message service (SMS) printers to receive electronic test results, and supporting blood sample and test result courier services could result in more children receiving their HIV diagnoses and being quickly linked to care.

## 3. Linkage to Care and Retention

Once diagnosed with HIV, the challenge becomes linking the child to care and treatment services and keeping him or her in those services. Some mothers may find it difficult to accept an HIV-positive diagnosis for their infants, and it requires disclosure with spouses, partners, and maybe others for effective treatment of the child. If the mother does not already know her status, she needs to be tested for HIV and needs to receive support disclosing her status at home. Additionally, HIV treatment is for life, and children and their mothers must be linked and enrolled to care and treatment services and retained in those services to keep them healthy. This becomes particularly important when considering the aforementioned weak linkages and substantial delays between diagnosis and initiation of pediatric care and treatment services.<sup>13</sup> In fact, in many countries, 4.6 years is the median age of children living with HIV to be initiated on treatment.<sup>14</sup>

Once children are in care and treatment, it is imperative that they are not lost to follow-up to ensure that their health is monitored and treatment is adjusted as they age or if treatment failure occurs. The low number of health care workers trained and skilled in pediatric HIV/AIDS care also limits access to HIV testing and subsequent linkage to care and treatment. Many health workers stationed at facilities where the infants seek care have limited knowledge of EID; are reluctant to recommend HIV testing for children and adolescents; lack the skills and confidence to identify and manage infants, children, and adolescents living with HIV; and are inexperienced in counseling children and families.<sup>15</sup> “Busy clinics, long wait times, stigma, excessive turn-around times, weak referral systems, lack of integration services” are among lead factors that contribute to children not being retained in care.<sup>16</sup>

**TABLE 1. KEY STATISTICS FROM 2014**

	<b>GLOBALLY</b>	<b>SUB-SAHARAN AFRICA</b>	<b>MIDDLE EAST AND NORTH AFRICA</b>
Pregnant women living with HIV	1,500,000	1,300,000	6,400
Pregnant women living with HIV who received ART for PMTCT	73%	75%	13%
Children living with HIV	2,600,000	2,300,000	20,000
New HIV infections in children	220,000	190,000	2,400
Children living with HIV receiving ART	32%	30%	15%
AIDS-related deaths in children	200,000	130,000	1,000

UNAIDS *How AIDS Changed Everything* Report July 2015

## Key Messages

- Diagnosing children living with HIV as early as possible is critical for their survival.
- Rolling out point-of-care diagnostics at various entry points in health facilities will help increase EID.
- Initiating HIV-positive children on treatment immediately after diagnosis is critical for their survival and overall health.
- Once diagnosed and initiated on treatment, children must be retained in care and treatment services to monitor disease progression and overall health and appropriately adjust treatment regimens.
- Efforts should be made to reduce loss to follow-up among HIV-positive mothers and their infants. Improved training of health care workers is needed to increase capacity for testing, counseling, and treating HIV-positive children.
- Countries should prioritize the adoption of recent WHO guidelines on ART initiation in infants and children.



## Pediatric Formulations

A major factor that contributes to children not being initiated or retained on treatment is the lack of pediatric-friendly formulations of antiretroviral (ARV) drugs to treat HIV.

---

In 2014, of the 29 approved ARV medicines for adults, only 12 had been approved for children.<sup>17</sup> Clinical studies on ARVs for use in the pediatric population often occur years after drugs are approved for adults, which limits the availability of safe and effective ARVs for children. In addition, children often need to switch to second- or third-line drugs because of drug resistance and treatment failure. New and improved first-, second-, and third-line drugs are required to better address the needs of children living with HIV.

Administering treatment to children can be particularly tricky. Pediatric ARV formulations for infants and toddlers are often produced in liquid or syrup form and are difficult for children to take because of the volume and poor taste. These formulations are also problematic for health care workers and caregivers because they may require refrigeration, which is difficult in low-resource settings with limited access to electricity. They are hard to store and transport owing to the large volume, and they have complicated dosing.<sup>18</sup> Formulations for children who can swallow pills are also challenging as a result of the large pill size and/or heavy pill burden. ARV dosages for children depend on age and weight band categories, which can be complicated for health care workers and caregivers to administer.

## Key Facts

---

- **There are limited pediatric formulations for ART, which reduces the options for children living with HIV to access the treatment they require.**
- **Existing pediatric ARV formulations can be poor tasting and difficult to swallow, can be challenging to store, and can have complex dosing instructions.**
- **Approval of new pediatric ARV formulations lags behind that of adult ARV formulations, which means that children do not immediately benefit from research that informs the new formulations.**
- **Smaller markets for pediatric ARV formulations make new drug developments and procurement of approved pediatric formulations challenging.**

---

## Key Messages

---

- **It is imperative that every child living with HIV has access to the medicines he or she needs to stay healthy, grow, and develop to his or her full potential.**
- **Countries should adopt and implement updated WHO treatment options to ensure that optimal treatment regimens are provided to all children living with HIV.**
- **It is important to raise awareness on the challenges with pediatric ARV formulations so that the relevant stakeholders, including government officials, research institutions, and pharmaceutical companies, can take action to address the challenge.**
- **Appropriate forecasting of ARVs is imperative for pediatric HIV given the complex treatment regimens and dosing adjustments.**

---

However, there is progress being made in the development of new and improved formulations of generic ARV drugs for children. In June 2015, for example, the Food and Drug Administration (FDA) gave tentative approval for the use of a novel formulation which has the potential to replace currently used liquid formulation of these drugs with poor palatability.<sup>19</sup>

Even with the development of new and improved pediatric formulations, challenges remain. The development of pediatric formulations and diagnostic tools is often considered an ineffective use of resources because the pediatric HIV market is small compared with the adult market. In addition, procuring pediatric ARVs can be arduous in resource-limited settings.<sup>20</sup> Program data show that stock-outs of ARVs occur significantly more frequently for pediatric formulations than for adult medicines.<sup>21</sup> As new pediatric ARV formulations become available, it is important that countries quickly adopt and implement new treatment options to ensure that optimal treatment regimens for children living with HIV are procured in country and available to those children in need.

## Stigma and Discrimination

It has often been noted that stigma and discrimination significantly affect access to HIV prevention, treatment, care, and support.

---

According to research done by the International Center for Research on Women (ICRW), stigma can result in loss of livelihood, poor care at health facilities, and withdrawal of care and support at home.<sup>22</sup> This is particularly important because children living with HIV depend on their caregivers to bring them to the facility for testing, treatment, and care. Stigma and discrimination deter older children and adolescents living with HIV from seeking care for themselves, and also deter caregivers from seeking HIV testing and treatment services for children.<sup>23</sup> The fear of stigma, discrimination, and even potential violence by family, peers, community, employers, and health workers prohibits the access of children living with HIV to the services they need to survive. If an AIDS-free generation is to be reached, programs and policies must address the “social, cultural, economic, and legal barriers that inhibit access to health services for all people living with and affected by HIV/AIDS.”<sup>24</sup>

### Key Facts

---

- **Stigma directly and indirectly affects the health of people living with HIV.**
- **Stigma and discrimination are often driven by a lack of information on HIV.**
- **Self-stigma is as much an issue for people living with HIV as stigma by others is.**
- **Combating stigma is a long-term battle.**
- **Stigma is one of the reasons people are reluctant to get tested, disclose their HIV status, and begin and adhere to ART.**

---

## Key Messages

---

- **Policies and laws should be adopted that discourage stigma and discrimination based on HIV status.**
- **Laws that criminalize HIV transmission should be changed as they perpetuate stigma and discrimination.**
- **Community sensitization efforts to educate citizens with accurate knowledge on HIV and accept people living with HIV should be taken.**
- **Psychosocial support programs are an effective way to empower children and adolescents living with HIV.**

---

In addition, children who are diagnosed with HIV can face stigma and discrimination at home, at health facilities, within their communities, and at school. This can be particularly challenging for children who are already going through many other emotional changes as they develop from children to adolescents and into adults. Children who face stigma and discrimination are at risk of not adhering to treatment, thus weakening their overall health outcome. To combat stigma and discrimination, “efforts to normalize HIV and ensure that adults and children have accurate information about the virus are essential.”<sup>25</sup>

One way to combat stigma and discrimination is through psychosocial support programs. For example, in Zambia, EGPAF works with local partners to offer psychosocial support to adolescents living with HIV through the Tisamala Teen Mentors program. Through this program teens are provided with educational information on HIV, the importance of drug adherence, gender and sexuality, risky behavior, and dealing with grief and loss. These programs offer a safe place for adolescents living with HIV to ask questions, share common experiences, and feel supported. As a result of this work, individuals who participated in the program expressed a greater knowledge of HIV and felt empowered to make more positive decisions.<sup>26</sup>

# Action Needed by First Ladies to Address Pediatric HIV Treatment

African First Ladies can drive change in their respective countries, helping alleviate the pediatric HIV treatment gap and ensuring that progress is made toward achieving an AIDS-free generation.

First Ladies have power to influence the behavior of their citizens because they are regarded as “mothers of the nation.” Although their clout is often invisible, it is significant and can result in positive change in the issues they are passionate about. First Ladies are perceived as strong collaborators, bringing different

stakeholders to the table on an issue to drive action in a way that crosses the political divide and touches all citizens. This section identifies three broad areas that need action by African First Ladies to drive the biggest change in the reduction of the pediatric HIV treatment gap.

---

## Raise Awareness

One way to improve pediatric HIV treatment is by raising awareness on the issue. This is an important role that First Ladies can play in changing the epidemic. For example, by raising awareness at the community level, families and health care workers will better understand the importance of EID and initiation of treatment, leading to improved health outcomes for HIV-exposed and HIV-infected infants. Some ways to raise awareness are as follows:

- Meet with government officials, health care providers, and organizations to get the latest information about the HIV epidemic in country.
- Visit hospitals and service providers to gather firsthand knowledge of the challenges families face in getting testing and treatment for their children and to gain an understanding of how HIV testing of newborns and children is performed and followed up. While visiting facilities, take note of the achievements made in reaching families with these services to use those as examples to further advocate for scale-up of successful interventions at additional facilities throughout the country.
- Enhance public understanding of pediatric HIV and the barriers facing children in accessing care and treatment, including by holding public meetings and awareness-raising events such as races or media campaigns.
- Promote HIV testing of infants, children, adolescents and adults as an important aspect of health services.
- Educate the public about the commitment of the government to ensuring universal access to HIV treatment by children who need it.
- Speak out against HIV-related stigma and discrimination affecting children at home, in schools, and in the community and also affecting their caregivers.
- Encourage families and caregivers of infants and children who are HIV-exposed to go for testing, know their status, and for those who are HIV-infected to receive treatment and care, and adhere to the appointments and medications.

## Mobilize Resources

Adequate funding is necessary to effectively reach children with lifesaving HIV services. First Ladies can utilize their influence to mobilize resources to support service delivery, health care worker training, pediatric-specific HIV support groups, and other vital components of the AIDS response specifically for children.

Financial, material, and technical resources are paramount in addressing the pediatric HIV treatment gap. First Ladies have the wherewithal to bring various partners and stakeholders together to ensure that there are adequate and sustainable resources to facilitate pediatric HIV treatment. Public-private partnerships and corporate social responsibility are valuable approaches to consider and promote. The following items are also important:

- A thorough understanding of resource gaps in the response to pediatric HIV treatment in country will enable First Ladies to advocate for budget allocations for pediatric HIV services to bolster HIV treatment for all children who need it.
- First Ladies can work with credible local organizations to advocate for additional domestic and international resources for increasing children's access to HIV treatment and support services.
- First Ladies can collaborate with other like-minded leaders to advocate for increased resources for pediatric-focused HIV research and promote expedited adoption and availability of improved pediatric ARV formulations.
- Engaging in strategic partnerships with public and private actors will help address gaps in programs, services, or technologies.

## Influence Policymakers and Agenda Setters

Instituting policies to better address the needs of children and infants is one way to improve pediatric HIV treatment. First Ladies have the ability to galvanize various stakeholders around an issue that they care about. Addressing pediatric HIV treatment can result in tangible gains for the country in having a healthy and developing young population. The following are some suggestions:

- Become educated on the types of pediatric HIV treatment available and the gaps in country, as well as the areas where various stakeholders would require greatest support; then lend it to them.
- Identify the key influencers and policymakers to “champion” pediatric HIV in country and have roundtable discussions with them to raise awareness on the issues and get them involved.
- Build support with appropriate stakeholders to address the needs of children living with HIV and explore what remedies can be put in place through government action.
- Advocate for changes in the policies and practice that allow inclusion of EID in MCH centers, nutrition centers, hospital in-wards, and other relevant health programs.

# Tools for Engagement

The following list of tools includes proposed steps for First Ladies and their staff members to take actions forward and further pediatric HIV treatment efforts in country. Most of these actions are currently being used by First Ladies to advance issues related to HIV and maternal, newborn, and child health (MNCH). The following tools will assist First Ladies in adapting existing actions and taking on new ones for issues pertaining to pediatric HIV. This is not a comprehensive list, but rather a compilation of potential opportunities for engagement.

---

## Engagement with Diverse Leaders

There are many levels of leadership in the countries and the communities that First Ladies can engage with to educate them on pediatric HIV treatment and to gather their support for action. These include political figures, community leaders and members, religious authorities, civil society leaders, and members of the media, among others.

- Organize and participate in roundtable discussions with community leaders about pediatric HIV/AIDS, including issues faced in the community, and emphasize the importance of EID, early initiation of pediatric ART, and retention in care. This will help educate community leaders on the importance of and challenges to pediatric HIV treatment, as well as provide them with an opportunity to express their concerns and suggest constructive solutions to issues faced.
- Organize and lead meetings or workshops with political figures, religious leaders, civil society leaders, members of the media, and so on, on the importance of and challenges to pediatric HIV treatment. The First Lady can provide remarks at these workshops to encourage leaders to continue existing programs and strengthen programs that address these issues.
- Engage with partner organizations and stakeholders around pediatric HIV program launch events or close out events to provide remarks supporting this important work.

- 
- Meet with Ministry of Health, Ministry of Finance, and other government officials to discuss the status of pediatric HIV/AIDS in country and the steps taken to improve EID and pediatric treatment, and discuss the opportunity for collaboration, through public speaking opportunities, joint campaigns on the issue, support of legislation, and so on.

## Sport

Sporting events have been used over the years to break the barriers of age, color, tribe, and gender, among others, and can have the effect of focusing people on an issue they did not realize needed attention. With sport, the public cares about winning together as a nation—and succeeding—and this is a great opportunity to rally the public to raise awareness and funds to support pediatric HIV treatment.

- Organize a sporting event to raise awareness about pediatric HIV treatment and the importance of EID and early initiation of ART. This could include a run/walk or a community activity day with several sport activities for children that incorporate an education booth for parents and guardians. These events can even be fund raisers and could also include a merchandising element to allow for longer-term impact of the event messaging (i.e. through T-shirts, caps, bottles, and other items with pediatric HIV messaging).

---

## Culture/Arts/Music

Similar to sport, cultural events, art shows, and musical performances all have the ability to bring community members together for a common interest. These events are seen as entertaining and non-threatening activities that the whole family can enjoy. By incorporating educational messaging on health issues, such as pediatric HIV, community members are provided a unique opportunity to learn about lifesaving interventions they may otherwise have avoided because of social barriers such as stigma and discrimination.

- Host cultural events involving musicians, artists, and actors that raise awareness around pediatric HIV treatment. Community members would attend these events for the entertainment while taking away lifesaving information on pediatric treatment and the importance of EID. These events could result in increased uptake in pediatric services due to community awareness.

---

## Community Events

Because many citizens appreciate the role of the First Lady as the “mother of the nation,” her direction and mentorship are taken seriously at the community level. The First Lady can engage in various community-level activities that raise awareness and increase uptake of HIV services due to reduced stigma and discrimination at home and in the community.

- Educate women, children and families on the importance of pediatric HIV treatment through participation in community days. These provide an opportunity for the First Lady to engage directly at the community level. This is a day where information is shared, questions can be answered, perhaps HIV testing is offered, and families are encouraged to bring their infants in early for HIV testing and initiation on treatment.
- Sensitize community members and leaders on HIV through other planned activities within the community to help reduce stigma and discrimination.
- Reduce stigma and discrimination through educational events at schools. First Ladies can lead campaigns, develop educational material, and speak with students on the importance of pediatric HIV treatment and adhering to ART. Reducing stigma in schools makes children more likely to remain in schools and to be able to stay on treatment without fear of stigma and discrimination by their peers.



---

## Media Engagement

In today's world, people stay connected through various forms of traditional and new media. By engaging with community members and leaders through print news, radio, and digital and social media, First Ladies have the opportunity to spread an important message to a diverse audience with incredible reach. This helps further amplify the important messages around pediatric treatment that could result in increased uptake of services and reduced stigma and discrimination.

- Reach out to media outlets, including radio and TV, about giving interviews on the importance of pediatric HIV treatment to raise awareness across the country on this issue.
- Work with media outlets to author an opinion/lifestyle piece from the First Lady on the issue of pediatric HIV treatment, the importance of EID and pediatric treatment, and what still needs to be done. Media pieces authored by the First Lady are likely to get significant attention because of their important stature in country.
- Reach out to media outlets to educate them on pediatric HIV treatment so that they are better informed when writing on the issue. When media personnel are educated on these issues, they will be able to produce more compelling pieces that will help shed light on the specific challenges to pediatric treatment in country.

## Issue-Specific Campaigns

First Ladies have the incredible opportunity to leave a lasting legacy to their time as First Lady. One way to do this is through issue-specific campaigns. Making pediatric HIV your landmark issue will help you usher in an AIDS-free generation in your country.

---

This is something that will not only resonate with your citizens now but will be remembered in years to come.

- Participate in an awareness-raising campaign to garner political and community support for pediatric treatment through engagement with high-level political figures, as well as celebrities.
- Visit health facilities and hospitals across the country to speak on the importance of EID and pediatric HIV treatment in support of issue-specific campaigns.

## Raise Funding and Resources for Pediatric Treatment

By supporting resource mobilization for pediatric HIV, First Ladies can highlight the important role that funding plays in closing the pediatric HIV treatment gap. Without resources, all the interventions that are proven successful will not be able to be implemented. Strong resources for pediatric HIV are crucial to addressing the treatment gap and ensuring that children living with HIV have access to the care and treatment they need to survive and thrive. First Ladies are in a position to help advocate in country for these needed resources.

- Mobilize funding for specific pediatric HIV treatment initiatives in country through the First Lady's foundation/office and the OAFLA secretariat. These resources could be used to scale up pediatric HIV testing and service delivery, fund research for new treatment, and support training for health care workers, among other activities.

# Opportunities for Regional and National Collaboration

First Ladies can work in their sub-regions or collaborate at the continental level to motivate, educate, and communicate on pediatric HIV treatment. Many of the activities can be done jointly as part of a continent-wide approach or individually by country.

---

OAFRA, which was primarily established to be a collective voice for some of Africa's most vulnerable people, has evolved into an institution capable of providing continent-wide leadership through advocacy in the field of HIV and the wider scope of MCH. By virtue of having a strong secretariat, there are many opportunities that exist for the First Ladies to work in concert with one another and to leverage one another's knowledge and experience.

---

First Ladies can also leverage the technical knowledge and experience with the various implementing partners, such as EGPAF, to ensure they have current and accurate information to be able to address the challenges that are highlighted in this document. Through inviting partners to sit in their national steering committees, they can benefit from the technical expertise that these partners bring. Additionally, First Ladies may be able to tap into other financial and material support to enable implementing partners to be effective in their work and help the African continent get to the end of AIDS.

## Endnotes

1. Mother-to-child transmission of HIV. World Health Organization Web Site. <http://www.who.int/hiv/topics/mtct/en/>. Accessed December 8, 2015.
2. UNAIDS. How AIDS changed everything. Published July 2015, p. 33.
3. UNAIDS. How AIDS changed everything. Published July 2015, pp. 33–34.
4. UNAIDS. The gap report. Published September 2014, p. 238.
5. UNAIDS. How AIDS changed everything. Published July 2015, p. 108.
6. UNAIDS. The gap report. Published September 2014, p. 229.
7. Violari A., Cotton M., Gibb D., et al. Antiretroviral therapy initiated before 12 weeks of age reduces early mortality in young HIV-infected infants: evidence from the Children with HIV Early Antiretroviral Therapy (CHER) Study. Special session: 4th IAS Conference on HIV Pathogenesis, Treatment and Prevention: Abstract no. WESS103.
8. World Health Organization. Guidelines on when to start antiretroviral therapy and on pre-exposure prophylaxis for HIV. Published September 2015, p. 39.
9. UNAIDS. The gap report. Published September 2014, p. 238.
10. WHO. Early detection of HIV infection in infants and children. Guidance note on the selection of technology for early diagnosis of HIV in infants and children: summary of recommendations, p. 1.
11. Sibanda EL, Weller IVD, Hakim JG, Cowana FM. The magnitude of loss to follow-up of HIV-exposed infants along the prevention of mother-to-child HIV transmission continuum of care: a systematic review and meta-analysis. *AIDS*. 2013;27(17):2787–2797.
12. UNAIDS. How AIDS changed everything. Published July 2015, p. 108. Also see UNAIDS PCB. Gap analysis on paediatric HIV treatment, care and support. December 9–11, 2014, pp. 7–8.
13. IATT. EID IATT Laboratory & Child Survival Working Group: GSG Mid-Term Review Meeting, December 6–7, 2012, p. 3.
14. UNICEF. The double dividend. Published December 2013, p. 2.
15. Persaud D, Gay H, Ziemniak C, et al. Absence of detectable HIV-1 viremia after treatment cessation in an infant. *N Engl J Med*. 2013;369(19):1828–1835.
16. IATT. EID IATT Laboratory & Child Survival Working Group: GSG Mid-Term Review Meeting, December 6–7, 2012, p. 2.
17. UNAIDS PCB. Gap analysis on paediatric HIV treatment, care and support. December 9–11, 2014, p. 9.
18. Drugs for Neglected Diseases *initiative*. Urgent need to develop and deliver antiretroviral treatment formulations for infants and children with HIV/AIDS: A situational overview from the Drugs for Neglected Diseases *initiative* (DNDi) and HIV i-Base. November 2013, p. 3.
19. UNITAID. Food and Drug Administration (FDA) approves child-friendly treatment for infants and young children living with HIV. <http://www.unitaid.eu/en/resources/press-centre/3-news/press/1444-child-friendly-formulation-of-who-recommended-treatment-now-approved-by-the-us-fda-for-children-living-with-hiv>. Published June 3, 2015. Accessed December 8, 2015.
20. Elizabeth Glaser Pediatric AIDS Foundation. Haba Na Haba technical bulletin: spotlight on pediatric HIV care and treatment. June 2015, p. 5.
21. Gibb D. Streamlining investments in clinical trials regulatory pathways. Paper presented at: UNITAID HIV Market Forum; April 2014; Geneva, Switzerland.
22. International Center for Research on Women (ICRW). Common at its core: HIV-related STIGMA across context. <http://www.icrw.org/sites/default/files/publications/Common-at-its-Core-HIV-Related-Stigma-Across-Contexts.pdf>, Published 2005. Accessed December 8, 2015. pp. 30–31
23. UNAIDS. Children and HIV fact sheet. Published 2013, p. 2.
24. PEPFAR. 2015 annual report to Congress. March 2015, p. 11.
25. UNAIDS. Children and HIV fact sheet. Published 2013, p. 1.
26. Elizabeth Glaser Pediatric AIDS Foundation. Tisamala: HIV-positive teens taking care of one another. <http://www.pedaids.org/blog/entry/tisamala-hiv-positive-teens-taking-care-of-one-another>. Published December 9, 2013. Accessed December 8, 2015.

**For additional information contact:**

**Fassika Alemayehu**

*Programme Officer*

Organisation of African First Ladies  
against HIV/AIDS (OAFLA)

Tel: +251-115-508069/+251-118-962998

Email: [fassika@oafila.org](mailto:fassika@oafila.org)

Website: [www.oafila.org](http://www.oafila.org)

**Rhoda Igweta Murangiri**

*Associate Director,*

Public Policy and Advocacy  
Elizabeth Glaser Pediatric AIDS  
Foundation

Tel: +254-204-454081/2/3

Email: [rigweta@pedaids.org](mailto:rigweta@pedaids.org)

Website: [www.pedaids.org](http://www.pedaids.org)