



# **REPORT ON NATIONAL STAKEHOLDERS' WORKSHOP ON ELIMINATION OF MOTHER TO CHILD TRANSMISSION OF HIV/AIDS**

*21ST AUGUST 2012, SERENA HOTEL*

*KAMPALA, UGANDA*

## **THEME:**

**“Towards Elimination of Pediatric HIV in Uganda:  
A call for improved commitment”**



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## **Acronyms**

ABC	Abstinence, Being Faithful, Condom
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Clinic
ARV	Anti-Retroviral drugs
ART	Anti-Retroviral Therapy
E-MTCT	Elimination of Mother to Child Transmission of HIV
HC II	Health Centre II
HIV	Human Immunodeficiency Virus
MDGs	Millennium Development Goals
MoH	Ministry of Health
MTCT	Mother to Child Transmission of HIV
OAFLA UG	Organization for African First Ladies (Uganda Chapter)
UAC	Uganda AIDS Commission
UNICEF	United Nations Children's Fund
UNAIDS	Joint United Nations Program on HIV and AIDS

## **EXECUTIVE SUMMARY**

The First Lady, under the Organization of African First Ladies Against HIV/AIDS (OAFLA – Uganda) convened an EMTCT stakeholders' workshop to discuss strategies for successful delivery of integrated services. The meeting was attended by government institutions, Members of Parliament, development partners, senior medical personnel, implementing agencies, the media, members of the civil society, religious and cultural leaders. The initiative aimed at creating a platform for dialogue concerning eliminating the risk of HIV infection from mother to child during pregnancy, labor, delivery and breastfeeding. It was addressed by representative players who opened it up to a rich discussion that resulted in resolutions and way forward.

There was a general consensus that the elimination of mother to child transmission of HIV/AIDS is achievable and that there was need for improved commitment to deal with the present constraints. These include policy gaps, inadequate funds and human resources, inefficiencies in delivery systems, corruption, misuse of resources, weak health infrastructure, interrupted supply of commodities and logistics, low involvement of men, private sector, cultural and religious institutions

Arising from the discussions the stakeholders committed themselves to support the First Lady in championing the ECMTCT services in Uganda by mobilizing, educating and empowering communities to take up the services. They also advocated for the reintroducing ABC strategy, male involvement and establishing an HIV trust fund in Uganda to reduce dependency on donors. In her closing remarks, the First Lady resolved to advocate for the return to ABC strategy by educating young people on self control.

The meeting ended with a resolution by the stakeholders to nominate Mrs. Museveni, to champion the Elimination of Mother to Child Transmission – EMTCT of HIV/AIDS in Uganda.

## **BACKGROUND TO THE WORKSHOP**

The First Lady of Uganda organized a high level national EMTCT workshop that brought together about 200 stakeholders to discuss matters related to the prevention of mother to child transmission of HIV and AIDS. It took place on the 21st August, 2012 at the Serena hotel. As chairperson of the sessions, she called upon participants to discuss and dialogue opened so that together we could forge the way forward in terms of achieving virtual elimination of this transmission and ensure healthy babies.

### **About Organization for African First Ladies (OAFLA)**

OAFLA was founded in 2002 by African First Ladies and their representatives at the UN General Assembly in Geneva. The objective of OAFLA is reinforcing policies and programs against HIV/AIDS through advocacy, resource mobilization and development of partnerships for accountability with all stakeholders at all levels. Within this framework, targeted campaigns on different thematic areas to address the various HIV/AIDS issues are conducted nationally in member countries. Since 2010, OAFLA's focus has been 'Prevention of Mother to Child Transmission of HIV (EMTCT).

In Uganda, the first lady has been successfully at the forefront of these campaigns since late 80s. She has been known for advancing the cause of ABC+, that is Abstinence among youth, Be faithful among Married and Condom use among vulnerable group. Of recent, OALFA also advocates for medicine and against stigma and discrimination.

It is against this background that OAFLA Uganda, in partnership with UNAIDS and UNICEF, organized this high level EMTCT stakeholders' workshop.

### **About Elimination of Mother to Child Transmission (EMTCT)**

Globally most children get infected with HIV through mother to child transmission, this account for 10% of all new infections. MTCT is the second major route of HIV transmission and is virtually the only way children under five years of age acquire HIV. A UNAIDS report (2010) states that, out of 370,000 children born with HIV, most of them, are in low- and middle-income countries mainly in sub-Saharan Africa. In Uganda, up to 30,000 out of the annual 130,000 new infections are a result of mother to child transmission; this has

added a burden to the already overstretched health systems in the country and worsened the maternal, infant and child indicators that were already lagging behind the rest of the world. There is a national and global drive to stem new HIV infections, particularly through mother to child transmission of HIV (MTCT). Science has revealed that MTCT can be virtually eliminated if countries address the unmet need for family planning among women and men of reproductive age and early enrolment of expectant positive women together with their partners on antiretroviral drugs (ARVs).

Virtual elimination of MTCT has happened in the developed world and even some countries in Sub-Saharan Africa like Botswana which has registered success in eliminating mother to child transmission to 1%, Unfortunately in Uganda, this is taking a painful slow process because only 18,000 out of 70,000 HIV infected women in the country can access ARVs to prevent transmission to babies. The partners to these women in context are not even taken care of. The Uganda National EMTCT Program has registered success with uptake of about 50% as of June 2010 explaining why the country has a decline from 30% MTCT as of 2000 to 8% as of 2010. However with high HIV prevalence among women of reproductive age, it is estimated that 27,300 babies would be infected through their mothers by 2015 if we don't have reinforcing policies and programs about EMTCT.

The above statistics raised a concern of the first lady, who decided to mobilize stakeholders for dialogue on the way forward. She believes that this state of affairs is not acceptable! It is a child's right to be born HIV negative because it is now possible. She needed stakeholders to come together and share experiences and together work out practical solutions.

### **Goal of the workshop**

To facilitate dialogue among stakeholders about the situation of EMTCT in Uganda and how to make it more efficient in service delivery until there is virtual elimination of mother to child transmission of HIV/AIDS.

### **Objectives of the workshop**

Mobilize key stake holders in EMTCT to identify and strategize against bottlenecks in the successful delivery of EMTCT services together.

Lobby policy makers and leaders in EMTCT interventions for successful delivery of integrated EMTCT services.

**Target audience**

The workshop targeted a national representation of EMTCT and potential EMTCT stakeholders in government, civil society, development partners, private sector, religious, cultural and Opinion leaders.



## REMARKS

The meeting was called to order when the First Lady Mrs. Janet Kataaha Museveni arrived. The first item was the National Anthem led by Mrs. Joanita Muganga, followed by an opening prayer Bishop Stephen Kazimba. Mrs. Muganga presented another song, "Time is out - this is the time" which she specially composed for EMTCT, followed by several songs by Baylor children.

### **Remarks by the First Lady**



The First Lady acknowledged presence of the Honorable Minister of Health, Members of Parliament, Development Partners, Religious and cultural leaders, and the different distinguished invited guests. She thanked them for assembling to address and enhance the Prevention of Mother to Child Transmission of the HIV virus.

The first Lady announced that when the struggle to defeat the physical enemy ended, Uganda started the war against HIV AIDS. She expressed gratitude to the fighters who started the fight against HIV/AIDS are still in the struggle and have mobilized others to defeat the enemy. She believed that community involvement, and mobilization can achieve the objective of the meeting; which is to eliminate mother to child transmission of HIV/AIDS.

She appealed to the stakeholders to begin mobilizing women to fight against HIV AIDS as well as to identify infected children early enough for treatment. She urged them to bear in mind that by implementing EMTCT effectively they would be able to achieve the Millennium Development Goals 3, 4, 5, 6. She reiterated that the Government of Uganda is committed but would still depend on the stakeholders to achieve this.

Urging the stakeholders to hold on to the success gained so far, the First Lady warned that they should be careful with the children who have accessed services not to lose them especially in terms of adherence and disclosure.

In conclusion, she reiterated that OAFILA is committed to work with partners to set up youth friendly services to prevent HIV. And as mother and grandmother she vowed her commitment to eliminate Mother to child transmission of HIV/AIDS.

After the First Lady's opening remarks, the Master of Ceremonies requested Professor Nantulya to invite Minister of Health to give her speech.

Professor Nantulya expressed concern about Uganda's fall from grace as forerunners in the fight against HIV/AIDS, during the recent, Washington conference on HIV/AIDS. Nevertheless, he was challenged by first lady's opening remarks and committed to start again. He remarked that infections from mother to child come from the father thus need to involve men in EMTCT of HIV/AIDS. At this juncture he invited the Honorable Minister of Health, Dr. Christine Ondo to give her speech.

#### **Remarks by the Honorable Minister of Health, Dr. Christine Ondo**



The minister acknowledged the presence of the First Lady Mrs. Janet Museveni, Honorable Members of Parliament, and the UN Resident representative, development partners, members of the Diplomatic corps, religious and cultural leaders and the invited guests.

She thanked the participants for their willingness to share ideas on prevention of Mother to child transmission of HIV/AIDS and its virtual elimination by 2015, and the Office of First Lady for convening the meeting.

The minister gave an overview of the global impact of HIV/AIDS and was especially concerned that a decade ago, the prevalence in Uganda had reduced but the trend was being reversed. Nevertheless she was optimistic that Uganda would soon regain its lost glory in the fight against HIV/AIDS.

The minister highlighted the different levels of prevalence for young people, children under five years, widows/widowers, people who have never been married and young

people. She noted these are windows of hope and areas where the stakeholders should concentrate the intervention efforts.

She highlighted challenges to implementation of the new policy; which include inadequate funds, poor distribution of human resources, lack of follow up of mothers and exposed babies, few deliveries in health facilities, poor male involvement, and low utilization of Family Planning services by the HIV positive women.

The Honorable Minister concluded by thanking First Lady for her efforts to scale up the policy for the EMTCT and requested for support on sustainable funding and promoting male involvement especially at the leadership level. At the end of her speech, the minister thanked Mrs. Museveni again for convening the meeting and supporting the progress in the elimination of mother to child transmission of HIV/AIDS.

After the Honorable Minister's presentation, the panel presentations began and were chaired by the First Lady, Mrs. Janet Museveni.

## **PANEL PRESENTATIONS**

### **Presentation 1: Current status of HIV/AIDS funding in Uganda: a Case for EMTCT by Dr. David Kihumuro Apuuli (Director General - UAC)**



The presenter gave a background to the Uganda AIDS Commission and the mandate of UAC which is to provide overall leadership to the multi-sector HIV/AIDS response in policy development, planning, coordination, resource mobilization, community mobilization, advocacy, and strategic information management monitoring and evaluation.

He informed the audience that the UAC undertook a study to find out sources of funding for HIV/AIDS and how they are utilized. Dr. Apuuli also presented the different spending categories for the different forms of treatment and reiterated that the biggest treatment is prevention. Therefore it is important to mobilize resources internally. He acknowledged

the contribution of donors and thanked them. Regarding EMTCT the presenter reported that the resources required over the years is US \$270million

Dr. Apuuli also presented the Building Blocks of Uganda HIV/AIDS partnership which are made up of the HIV/AIDS Partnership Forum and UAC, Line Ministries and Self Coordinating Entities (SCEs) and the Partnership Committee (PC). These three building blocks are undergirded by the HIV/AIDS Partnership Fund which is a basket fund to support implementation of coordination activities by any one member of the PC. He emphasized the importance of the partnership having a common vision.

Lastly he presented the Conceptual Combination of HIV prevention interventions in the general population which includes behavioral interventions, biomedical interventions, Health & Community systems strengthening and Structural interventions.

**Presentation 2: Elimination of Mother to Child Transmission of HIV in Uganda by  
Dr. Jane Ruth Achieng, Director General Health Services**



Dr. Achieng began her presentation with a resolution to reverse the humiliation that the Ugandan delegates faced in Washington during the HIV/AIDS conference. She presented the four prongs for the elimination of Mother to child transmission for HIV. The four prongs are: the UN resolution for Zero New Infections, addressing of unintended pregnancies, scaling up Family Planning and Prevention of Mother to Child Transmission of HIV/AIDS.

She presented practical steps towards this mission which include targeting Health Center II, because these are nearest to the communities. However she observed that there is urgent need for recruiting qualified midwives by September 2012. She talked of the need for the Local Councils to work with the village health teams to support women to go to Health Centers, encourage quality childbearing through Family Planning and increased Anti Retroviral Therapy coverage pointing out that the current coverage is inadequate hence need for additional funding.

The presenter reported that presently treatment Option A is being used to combat transmission of mother to child infections but it has challenges. She advocated for option B+ which means a client would be on drugs for life, however there are financial implications. She concluded by advocating for close cooperation of partners so that their resources are not spread too thin to ensure maximum impact.

**Presentation 3: Elimination of Mother to child transmission of HIV using a  
Community based approach Reach Out Mbuya HIV/AIDs Initiative  
By: Dr. Stella Alamo – Talisuna**



The presentation was a case study of an effective way of eliminating mother to child transmission of HIV, using community based initiative by a faith based organization employing a combination of methods which address the various aspects of HIV/AIDS transmission. The aspects include access, utilization, and uptake of services, initiation-implementation of programs, utilizing qualified staff and volunteers (including people living with HIV/AIDS), satellite clinics in the community which reduce access barriers, successful use of community health workers, peer led model/Nurse led model, mobile clinics, nutrition, economic empowerment, and provision of school fees

Notwithstanding the above achievements, Dr. Alamo highlighted the challenges which include unmet needs for family planning, HIV testing, ART access, ART limitation, couple counseling/testing and delay of ART initiation, human resources, health systems, long waiting times, referral linkages, financing, reliance on international funding, and delayed implementation of best practices.

In conclusion, the presenter said that the success of Mbuya Outreach is from skepticism to optimism which is a combination of Behavioral-biomedical and structural interventions. This has been achieved through a close follow up of clients at household level, integration of maternal and child health services; ensuring that babies remain HIV negative and emphasis on community engagement including the beneficiaries of the project.

The Chairperson commended the presenter and said the presentation is educational makes it more personal, brings it alive by unpacking all the technical jargon clarifying the roles of the various stakeholders.

**Presentation 4: Role of men and women living with HIV by Ms. Lillian Mworeko  
Regional Coordinator, International Community of women living  
with HIV (ICW Eastern Africa)**



Ms. Mworeko expressed her own and her colleagues' (women, men and young people living with HIV) excitement about the "Global Plan to Eliminate New HIV Infections among Children by 2015 and Keeping their Mothers Alive."

She gave her personal testimony struggling with the decision to have a baby as a person living HIV. She overcame the struggle by support obtained from her support group and her partner.

She advised that to succeed at EMTCT, programs should ensure women who are HIV negative remain that way while ensuring treatment and support for women, babies and families affected by HIV/AIDS.

In conclusion, she advocated for the utilization of people living with HIV/AIDS because they have a niche, they are found everywhere and they have empathy.



**Remarks by Honorable Rosemary Najjemba Minister of State for Urban Planning,  
(Chairperson Parliamentary Committee on HIV/AIDS)**



The presenter made reference to the committee report that was presented at parliament and reiterated that HIV/AIDS still a problem but insisted that Ugandans, should take ownership of the problem. Thus she appreciates donor support but Ugandans should be seen at the forefront of fighting against HIV/AIDS.

Therefore she suggested that Uganda establish a special fund for HIV/AIDS the way other countries have done. She also advocated that Ugandans should use strategies which worked before like the ABC strategy that is why youth have lower prevalence of HIV/AIDS. However, she admitted that strategies like abstinence might not be sustainable hence need for a multi-sector approach be employed.

**TESTIMONIES OF THREE COUPLES**

Three couples were given chance to share their personal experiences regarding EMTCT. One couple had both spouses HIV Positive; the other one represented a discordant couple, and the third one represented HIV Negative spouses. They were each asked three questions on: i) How they decided to test for their HIV Status, ii) How they have managed to keep themselves safe, iii) How they have kept their children HIV Negative. They had this to say:



**HIV positive couple:**

The wife reported that when her husband developed a skin rash he was laid off his job he went for an HIV test and found he was positive. The couple was advised that if any is found positive there should be no blaming. The wife revealed that by the time

they were found HIV Positive she was already pregnant. The counselor advised them about PMTCT, and Family Planning. The child is now 8 years and HIV Negative.

### **Discordant couple:**

The husband reported that he started falling sick with a persistent cough. He and his wife went for testing. He was found HIV Positive and his wife HIV negative.

They revealed that they have use condoms, to keep safe. The couple has two children who were tested, and found HIV negative and their parents have counseled them to keep that way. He advocated for male involvement in this fight.

### **HIV Negative Couple**

The husband reported that they decided to test for their HIV Status because they were planning to get married. They were found HIV Negative and vowed to remain that way through faithfulness to each other. They joined the Married's club at AIDS Information Center and reported that they do periodic testing as a way of building mutual trust.

## **OPEN DISCUSSIONS, QUESTIONS AND ANSWERS**

The participants had opportunity to ask questions, give comments, suggestions and the members of the panel responded accordingly. The following were the general thoughts:

There was lobbying and advocacy for the following:

- Retaining strategies that worked before – specifically the ABC with emphasis on the A and the B and not on C because C seems not to be working given the current rising rates despite abundance of condoms. Some people felt that people need to be equipped with life skills in behavioral change for example self-control and living focused lives
- Establishment of an HIV trust fund in Uganda. However, others felt that there should be one Trust fund which would cater for other diseases as well.
- Need for male involvement in the control of HIV/AIDS and for them to play their role as fathers and husbands.
- Access to all the options, that is A, B, C, D, and E.
- Need for EMTCT in Ante Natal Clinics to be revisited, because presently women are only tested on their first visit and if found negative are not tested again.



- Improvement of doctors' working conditions and recruitment of more medical personnel.
- Address misinformation on male circumcision, - messages imply that if the men are circumcised they don't get HIV/AIDS, and do not transmit it.

In response, panel members made the following comments:

- They advised the stakeholders to lobby Members of Parliament so that the ban on recruitment of medical personnel is lifted.
- Regarding antenatal care when mothers test negative, they are educated throughout pregnancy and even after having their babies. Those found positive are followed up with education and treatment.
- On integration of ABCDE/EMTCT it has been considered however the implementation has to be thought of seriously especially sustainability of the financial implications. Additionally, with the onset of the HIV/AIDS epidemic it was deemed necessary to give it special attention so that it could be reduced. There is concern that if services are integrated the Ministry of Health would lose focus. If the services are to be integrated it would require the optimum numbers of staff.
- Young unmarried mothers who are not in school and young uneducated mothers are targeted by the HIV/AIDS Control programs and are empowered.

#### **REMARKS BY THE UN RESIDENT COORDINATOR – MS. AHUNNA EZIAKONWA ONOCHIE**

The UN Resident Coordinator spoke on behalf of the development partners. She commended The First Lady for being a champion of the EMTCT and said she was challenged to join her on the cause. She reiterated that it is timely; bold, courageous, ambitious, absolutely necessary but possible. This is because there is a medical miracle in our hands; treatment can actually prevent a child from inheriting a disease from its mother. She reiterated that Uganda has the best plans as presented by the Director General of the Uganda AIDS Commission. She wondered why it was not happening on top of the strongest development partners supporting development programs in the country. She said that it is possible because Uganda has been there before - at the helm of glory of the world. She emphasized that Uganda has what it takes to eliminate transmission of mother to child of HIV/AIDS.

Regarding money, she was in support of mobilization of national resources even if there is still external help, because external resources are drying up. Referring to the need for regular testing, even those who are not infected have expenses to meet and wondered how they get the money. She reiterated that society has to figure it out because we cannot afford new infections.

She asserted that the champions of EMTCT also have to insist on ZERO tolerance to abuse of available resources as efficiency is key. She also called on the champions to continue working hand in hand with the partners to make the resources work, though donors can no longer be counted on. She concluded by thanking the First Lady again for providing the example on championing a cause.

## **RESOLUTIONS BY THE EMTCT STAKEHOLDERS PRESENTED BY MR. JOSHUA MUSINGUZI**

Mr. Musinguzi, thanked the First Lady, on behalf of all the stakeholders for her interest and involvement in the control of HIV/AIDS. He also appreciated the leadership of President Yoweri Museveni in the current control of HIV/AIDS in the country and applauded him for all the past commitment. After those remarks he presented the resolutions of the stakeholders' meeting (as attached).

The stakeholders resolved to nominate Her Excellency the First Lady of Uganda to be the Champion of EMTCT in Uganda.

## **CLOSING REMARKS BY THE CHAIRPERSON, MRS. JANET MUSEVENI**

The chairperson thanked the participants for their patience, and hard work to make the meeting a success and made the following observations:

- The Chairperson wondered why stakeholders are not talking about a way of stopping HIV/AIDS that does not require money. She believed it was possible to fight this battle and win it by finding self-control. When everyone felt shy to talk about self-control it required sending children to clinics. She remarked that the nation does not have money for clinics for grownups yet there is a growing need to obtain money for young people's clinics.

- She said that if other people are ashamed of talking about abstinence to young people she is not ashamed. She asserted that the young people should abstain until they get married. The First Lady emphasized that the youth must abstain from sex as a necessity.
- The Chairperson urged Ugandans to wake up, especially after the reportedly humiliation the international conferences. She advocated for the return to ABC and reiterated that young people don't need sex until they are married.
- The Chairperson also pointed out that when HIV rates among married people are rising it shows that they went into marriage without self-control in the first place and it is a shame
- The First Lady resolved to advocate for the return to ABC; educate young people on self-control not just about AIDS, but also control in using money that is not theirs.
- She advised that although circumcision has some impact it is not true that one cannot get infected with AIDS; it is a miscommunication that they are safe after circumcision.

Mrs. Museveni concluded by saluting the leaders in all their capacities; she referred to the UN Coordinator's observation who said that Uganda has good leaders at all levels and invoked them to remain committed. She reported that these are leaders in health, parliament and communities.

The First Lady gave special thanks to UNAIDS and UNICEF for the work they are doing to support the work at OAFLA. She ended by saying that she believes starting that day, (21st August 2012) the stakeholders will begin to mobilize the people and show them the way forward.

## **OBSERVATIONS**

The workshop that attracted key people from all corners of Uganda kicked off well and ended well with maintained momentum. Attendance was good and the atmosphere was conducive for productive and professional dialogue. The only obstacle was time - more people would have loved to share their views but there had to be an end. However, the truth about bottlenecks came out and practical solutions were also suggested. One could feel the genuine concern and desire to deal with the issues once and for all. The discussions, sharing of personal experiences, comments, questions and answers were very

informative and value- adding. If there is regular follow up on commitments, EMTCT will defiantly be achieved in Uganda and beyond.

## **CONCLUSION**

On the whole, the workshop was a big success with great achievement of the objectives. The presentations were clear and relevant, covering all key aspects of EMTCT. Participants shared freely and openly about their concerns. It was unanimously agreed that where as it is possible to achieve virtual elimination of MTCT, there was need for concerted effort and improved commitment for success in handling the identified bottlenecks. The first lady, who was nominated as the EMTCT champion, displayed and represented political good will. She pledged to play an active role until the set targets are achieved. She said follow up activities would be planned accordingly and regularly. The workshop ended on a high note and excitement due to renewed hope and faith.

## APPENDIX

- I. Welcome remarks by the First Lady
- II. Speech by the Honorable Minister of Health, Dr. Christine Ondo
- III. Presentation One: Current status of HIV/AIDS funding in Uganda: a case for EMTCT  
By Dr. David Kihumuro Apuuli (Director General - UAC)
- IV. Presentation Two: Elimination of Mother to Child Transmission of HIV in Uganda  
Dr. Jane Ruth Achieng (Director General Of Health Services)
- V. Presentation Three: Elimination of Mother to child transmission of HIV using a  
community based approach Reach Out Mbuya HIV/AIDs Initiative By: Dr. Stella  
Alamo – Talisuna (Executive Director)
- VI. Presentation Four: Role of men and women living with HIV by Ms. Lillian Mworeko  
Regional Coordinator, International Community of women living with HIV (ICW  
Eastern Africa)
- VII. List of participants
- VIII. Workshop Program.