

CHILDREN
AND HIV



THE 7TH NATIONAL PEDIATRIC AIDS CONFERENCE



PRE CONFERENCE HANDBOOK



ORGANIZING COMMITTEE

National Youth Front

Musah Lumumba, CYSRA-Uganda /Y+: Co-Chair | **Jacquelyn Alesi**, - UNYPA: Co-chair

Youth Advocacy and communication

Enoch Magala – GYCA-Uganda/ CFYDDI: Co-Chair | **Christine Kaleeba** – Baylor-Uganda: Co-chair

Members of the organizing committee

Allan Njuki -NFSC | **Babirye Prossy** Secretary organizing committee - CFYDDI | **Yoyeta Irene** - MU-JHU
| **Mugagga Brian**- AFCAD | **Nalukenega Sanda** -Baylor Uganda | **Resty Nalwanga**- UNYPA | **Yoyeta Irene**
| **Atuhwere Sandra** –Girl Awake | **Nabimanya Humphrey** – RAHU



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WELCOME REMARKS

Dear fellow young people, welcome!!

It gives us much pleasure to welcome you to the 1st Youth Pre-Conference in the history of National Pediatric AIDS Conferences in Uganda. The 7th National Pediatric AIDS Conference has given us that platform.

We have adopted the theme of the 7th National Pediatric AIDS Conference “Stepping up the pace towards an AIDS free generation; Every Adolescent Counts” highlighting the need to expedite our collaborative efforts in the commitment to ensure that all Ugandans especially Adolescents and young people have access to optimal HIV treatment, prevention, care and support regardless their ability to pay.

We hold this conference at the time when Uganda is adopting the 2013 WHO Adolescent HTC and care and the ARV treatment guidance to enable adolescents as early as 12 years to freely access HIV services without the mandatory parental consent, in a Uganda experiencing a rebounding HIV situation depicted by a raise of HIV prevalence from 6.4 – 7.3% in 2012.

This youth pre-conference is an opportunity to draw everyone’s attention to the fact that Adolescents and young people, are the only group where the AIDS epidemic is concentrating, becoming the number one cause of deaths in Africa and 2nd globally, yet interventions to avert this situation, are a handful. Shall we realize the End of AIDS among Adolescents and young people by 2030?? Lets walk the talk now.

We are honored to have government representatives, members of civil society, the donor community, UNICEF, UNFPA, UNAIDS, friends and colleagues in the AIDS response.

The President has publically demonstrated that increasing uptake of HIV testing and counseling, will be a great window for scaling up access to HIV services in the Country but still many of us don't know our HIV status. The time is now to demand access to HIV services that meet our needs as young people of this Country.

I extend my thanks to the hard working team led by my Co-Chair, Jacquelyne Alesi and all the committee members who have made this pre-conference possible.

Most importantly, our great thanks go to all of you delegates from all over Uganda and beyond, for your commitment towards the End of AIDS in Uganda. Lets learn and exchange ideas and lay strategies how as young people, we can meaningfully contribute to the national AIDS response.

A handwritten signature in black ink, appearing to read 'Jacquelyne Alesi', is enclosed in a thin black rectangular border.

Musah Lumumba and Alesi Jacqueline

Co-Chairs: National Youth Front: The 7th National Pediatric AIDS Conference

GUEST OF HONOUR |

Prof Vinand Nantulya who is a very great friend of the young people, is our guest of honor.



Prof. Vinand is the serving Chairman of the Uganda AIDS Commission since February 2011. He is a Medical Doctor, an Academician, and a former Professor at the prestigious Harvard School of Public Health as well as several US and European universities.

He also served as a Senior Advisor to the Global Fund to Fight HIV/AIDS, TB, and Malaria. He has published a number of articles in international journals. He holds a PHD in Immunology and a Master's Degree in Medicine.

A quote from the Guest of honor, derived from his "Our HIV/AIDS Epidemic: What each one of us must do? A message to you as an individual from the Chairman Uganda AIDS Commission"

The second call in the Strategy is to you the youth in and out of school. Your future is in your hands. You have a clear responsibility, as an individual, to protect yourself and your future. This begins with you keeping yourself HIV negative, rejecting risky behaviors and ensuring that you protect others from infection, while you also support those in need of treatment, care and social support. Those who apply pressure on you will not be by your side when you get infected. The National Prevention Strategy calls upon the health providers to offer you services that are youth-friendly so that you can access interventions like HIV counseling and testing,

information on safe sexual behaviors, safe male circumcision, condom supplies, treatment, care and support for those infected and affected. But the message on circumcision must be very clear: it is not 100% protective; and certainly not a license to be reckless. You will still get infected if you ignore the other complementary interventions like self-restraint against engaging into sex relationships with partners whose sero-status you know not"

ADOLESCENTS, YOUNG PEOPLE AND THEIR **SEXUAL** AND **REPRODUCTIVE HEALTH**

Young women aged 15-24, have HIV infection rates twice as high as in young men, and account for 22% of all new HIV infections and 31% of new infections in Sub-Saharan Africa, where Uganda is found. According to the World's Youth 2013 data sheet by the Population Reference Bureau; Uganda has 12.3 million young people aged between 10-24 years which is about 33% of the estimated 36.9 Million people by mid-2013. This data sheet

also shows that Uganda's adolescent fertility rate is the second highest in Eastern Africa at 124/1000 births, yet the contraceptive prevalence rate for modern method is low at 13 % and 20% among young people aged 15-19 and 20-24 years respectively.

Uganda Demographic and health survey report (2011) revealed that CPR for all methods was lowest (26.9%) in rural communities compared to (45.8%) Urban communities and amongst young people (13.9% and 22.9%) aged 15 -19 and 20-24 years respectively compared older people (37.8% and 37.5%) aged 30 -34 and 35 – 39%. This low CPR among young people is mainly due to lack of youth friendly services, inadequate information on family planning, stigma attached to the Family planning use, myths and misconception among others. The National Adolescent Health Policy guidelines and Service standards of 2011, further approximates that

According to the UNAIDS fact sheet on young people and HIV of 2012, In 2010 young people aged 15–24 accounted for 42% of new HIV infections in people aged 15 and older globally and Among young people living with HIV, nearly 80% (4 million) live in sub-Saharan Africa

52.7% of the population is under 15 years of age, one in every four Ugandans (23.3%) is an adolescent and one in every three (37.4%) is a young person. It further notes that Adolescents and young people lack access to adolescent friendly services

THE YOUTH PRE-CONFERENCE

The Pre-conference is the first national platform as part of the National Paediatric AIDS Conference where all young people in Uganda are meaningfully, actively and substantively participating and responding to policies, programme and services that affect them in relation to HIV prevention, treatment and related care including their general wellbeing and Sexual and Reproductive Health.

It is a life time opportunity for all young people in the country and allies to learn, share, engage, dialogue, and advocate for young people friendly integrated HIV/AIDS and SRH and Rights. It recognises young people's involvement and participation as critical beneficiaries and actors in Uganda's HIV response by ensuring our meaningful representation in the National HIV Pediatric conference

PARTICIPANTS

The pre-conference is bringing together over 100 young and adolescent delegates across all districts of the country. Participants also include representatives from government, civil organizations, academic institutions, public and private foundations, international organizations and the general public, drawn from respective districts in Uganda.

WHAT IS OUR DESIRED OUTCOME?

1. Increased involvement of Adolescents and young people in the national HIV response through learning, networking and experience sharing with key actors attending the conference.
2. Recognition of young people's contribution to the National HIV response through presentations of their respective interventions
3. Link the community of adolescents and young people living with HIV and their

allies to the national, regional and global youth movement in the HIV and SRHR response

4. Gather, analyse and use strategic information more effectively to shape programmes and policies that impact adolescents living with HIV at national, regional and global levels
5. Increased dialogue between National HIV/SRH actors, civil society organizations and government on Adolescent specific policies, programmes and services to better understand the priorities and needs of Ugandan Adolescents and young people.



52.7% of the Ugandan population is under 15 years of age

23.3% of the Ugandan population is adolescent

37.4% of the Ugandan population is an adolescent is comprised of young people

THE SCIENCE OF HIV **CURE & RESEARCH**

A REFRESHER

Human Immuno deficiency Virus (HIV) is a small organism that is responsible for weakening our body immunities to cause Acquired Immuno Deficiency Syndrome (AIDS), the HIV disease. HIV is able to infect cells called CD4+ T-cells, or helper T-cells, responsible for fighting infection. HIV also requires another protein CCR5 or CXCR4 to enter into these cells. In the normal generation of an immune reaction the T-cells are responsible for fighting infections. HIV can also infect other cells in the immune system that control the intensity and function of the immune response. The progression of the HIV virus can be measured by counting the number of virus particles and CD4+ T-cells in the blood – known as the viral load.

HIV enters the T-cell and incorporates its viral RNA genome into human DNA. Using protein from the cell it has infected new virus particles (virions) are made – this process is called replication. The virus proteins then assemble at and bud from the cell surface. Before the virions can be infective, they must go through a process called maturation. The virus is then able to infect other cells.

HIV infection reduces the number of T-cells in the body, making the immune system vulnerable. The body then becomes susceptible to other infections, called opportunistic infections. These are the infections that we normally fight off but, a weakened immune system makes the body more susceptible and a person with HIV can become sick more easily. This is called acquired immunodeficiency syndrome (AIDS). AIDS is defined as a CD4+ T-cell count of less than 200 cells/mm or multiple opportunistic infections. Other infections, like tuberculosis (TB), cytomegalovirus (CMV), malaria, and hepatitis (hep B and hep C) can also cause

more damage to the body more quickly than in a HIV negative person.

Virus replication is blocked by combination antiretroviral therapy (cART). cART blocks the viral life cycle at multiple steps therefore reducing the viral load. The immune system is able to recover and the number of CD4+ T-cells in the body increases to normal levels. Today a person living with HIV on cART can live a normal life.



Despite treatment, the HIV virus can stay in the body in a hidden or latent state, usually in central memory T-cells. These cells survive as long as the person does and are not susceptible to cART. HIV can also hide in the cells of the gastrointestinal tract (GUT) the brain and in lymphoid or immune organs.

Long term cART and viral infection also comes with some complications. People living with HIV often experience an increased risk of age-related illnesses such as cardiovascular disease, diabetes and susceptibility to cancer. The reason behind this remains unknown but this does highlight the need for a HIV cure and vaccine rather than treatment.

HOW IS HIV TREATED?

There are many treatments now that can help people with HIV. As a result, many people with HIV are living much longer and healthier lives than before.

Currently, medicines can slow the growth of the virus or stop it from making copies of itself. Although these drugs don't eliminate the virus from the body, they keep the amount of virus in the blood low. The amount of virus in the blood is called the viral load, and it can be measured by a test.

There are several types of anti-HIV drugs. Each type attacks the virus in its own way. It's similar to the way the military plans an attack using the different strengths of the Army, Navy, Air Force, and Marines.



HOW ARE THE DRUGS TAKEN?

Most people who are getting treated for HIV take 3 or more drugs. This is called combination therapy or “the cocktail.” (It also has a longer name: Anti-Retroviral Therapy (ART) or Highly Active Anti-Retroviral Therapy (HAART.) Combination therapy is the most effective treatment for HIV.

People who are HIV positive need to work closely with their doctors to decide when to start treatment and which drugs to take.

IS IT HARD TO TAKE THESE DRUGS?

HIV medicines have become much easier to take in recent years. Some newer drug combinations package 3 separate medicines into only 1 or 2 pills, taken once a day, with minimal side effects. For the great majority of people, HIV medicines are tolerable and effective, and let people infected with HIV live longer and healthier lives. Still, for some people taking medicine for HIV can be complicated. Some of the drugs are difficult to take, can cause serious side effects, and don't work for everyone. Even when a drug does help a particular person, it may become less effective over time or stop working altogether.

Once on medications, patients must work with their health care providers to monitor how well the drugs are working, deal with side effects, and decide what to do if the drugs stop working.

The good news is that experts are learning more about the virus and creating new treatments for HIV, making it easier to take these medicines.

DO YOU HAVE TO BE TREATED FOR THE REST OF YOUR LIFE?

Right now, there is no cure for HIV infection or AIDS. So, once you start treatment, you have to continue to be sure the virus doesn't multiply out of control.



CURVES
DON'T LIE
EVEN
THOUGH
AM P+

THE NATIONAL YOUTH ACTION PLAN 2014–2015

This year, Uganda is holding its first Youth Pre-Conference in the history of National Pediatric AIDS Conferences, today the 30th September 2014 preceding the 7th National Pediatric AIDS Conference at Hotel Africa.

As members of the National Youth Front, we have come up with the 2014 Youth Action Plan that has prioritized actionable goals in the post-2015 AIDS era where we are committing to the End of AIDS by 2030 in Uganda especially among adolescents and young people. Created by and for adolescents and young people, these goals serve to focus and unite the youth response during 7th National Pediatric AIDS Conference and beyond.

The four key themes of the 2014 -2015 Youth Action Plan and the National Youth Front Advocacy Messages, TREAT, PREVENT, EDUCATE and LOVE, were identified following a 2 month-long community consultations with young people carried out by the National Youth Front.

Issues from each theme have been discussed, analyzed and debated by us, the 100 youth delegates from across the country, one and half day Pre-Conference. Following experiences and reflection in follow up workshops and discussions, these actionable time and result oriented goals have been finalized and agreed upon by all Youth Pre-Conference delegates. The actions and objectives will form the 2014 Youth Action Plan; a plan of tangible goals, a youth call to action, and a path towards the first AIDS-free generation. We, the youth of National AIDS 2014, are Stepping up the Pace towards an AIDS free generation, recognizing that every one of us counts in the AIDS Response.

Below you will find a brief summary of each of the four 2014 Youth Action Plan themes, and the demands that were refined following analysis of the NYF community consultations.

TREAT

- We demand optimal HIV treatment for all.
- We need universal access to affordable and accessible quality HIV drugs achieved only through country ownership of the AIDS response, meaningful funding to health sector and scaling up of adolescent treatment programs.

As young people, we want to carry out community based advocacy for better treatment programs for all adolescents and young people living with HIV.

REFORM

We demand the removal of punitive, discriminatory and restrictive laws that impede adolescents and young people from accessing HIV testing, treatment and preventive services. As young people, we need laws and policies that protect Adolescents and recognize our right to safe and satisfying sexual and reproductive Health life. As young people, we want to advocate for a safe and enabling policy, legal and social environment that will enable us access services that meet our needs.

EDUCATE

We demand education about our Sexual and Reproductive Health, the science of HIV, HIV treatment, side effects, positive health and dignity through evidence informed Comprehensive Sexuality Education programs. We need information, and access to the commodities that will support us in applying this knowledge; to take ownership of our health; and to be active partners in the National HIV response.

LOVE

We demand respect and compassion for all regardless of age, gender, HIV status or religion. Just like you, we need to love and be loved, at home, school and place of work.

Stigma and discrimination is debilitating to individual health, communities, and progress in the AIDS response.

We want to talk about HIV, we are not sick we are only living with HIV just like you can live with Hypertension, Sickle cells, Albinism and Diabetes

ORGANIZING COMMITTEE

NATIONAL YOUTH FRONT



Babirye Prossy;

Prossy Babirye works with the Centre for Youth Driven Development Initiatives (CFYDDI) as the Behavior Change and Communications Manager. Prossy has worked extensively in the field of health promotion, HIV/AIDS projects to include issues on maternal Health in Uganda. Her tasks involve planning and running HIV prevention and testing program in schools and communities for youth. Graduating from University, Prossy holds a Bachelors Degree in Organizational Studies with a Masters in Human Resource Management. Babirye Prossy has served as a pre-conference General Secretary for youth Pre- Conference planning committee for the 7th National pediatrics Conference



Enoch Magala

Has over 9 years work experience in SRHR issues with special interest in advocacy for economic rights and youth health rights. Enoch serves as the National focal Point (NFP) person for the Global Youth Coalition on HIV/AIDS (GYCA) - Uganda and he is the Program Director for The Centre for Youth Driven Development Initiative (CFYDDI). Graduating from University he has earned a bachelor's degree in Commerce from Makerere University Kampala. Enoch has served as a pre-conference Co- Chair for The Youth Pavilion, Advocacy and Communication Sub-Committee for the 7th National pediatrics Conference



Jacquelyne Alesi

At the age of 28 years old now, Jacquelyne Alesi is a committed young woman openly living with HIV who works with Uganda Network of Young People Living with HIV (UNYPA) as the Director Programs and the first woman and real young person to be given this position. I currently represent Young people and children on the board of National Forum of People living with HIV Networks in Uganda (NAFOPHANU) and the only young person who has ever become the Policy, Advocacy and Programmes (PAP) Committee Chairperson in over 13 years when this committee was formed. This is one of the committees that is respected and only committee that makes decisions on behalf of the National Forum of People Living with HIV in Uganda, which means being in position I have been able to make decisions on behalf of that organization



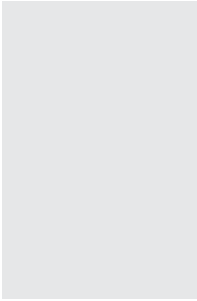
Musah El-nasoor Lumumba

Musah who is the Co-chair of the National Youth Front of the 7th National Paediatric AIDS Conference, is a 28 year old HIV and Sexual Reproductive Health and Rights activist. Musah leads the HIV treatment team within Y+; The Global Network of Young People Living with HIV, hosted and supported by the Global Network of People Living with HIV (GNP+). He also represents young people to the United Nations Inter-Agency Task Team on HIV and Young People (UN-IATT/YP), in addition to representing Y+ to the PACT, a collaborative framework of over 25 youth led and serving organisations working on HIV/AIDS and SRHR issues, supported by UNAIDS. Within the PACT, Musah leads the priority that exists to mobilise young people including Adolescents and YPLHIV for optimal HIV prevention, treatment and related care services. He is also a member of the first cohort of IPPF's emerging leaders on SRHR.

Musah is a clinician, with much emphasis in HIV treatment, Safe Male Circumcision and family planning especially for young people, and has been advancing HIV and SRH issues right from 2004 while still at high school when he founded a straight talk club. Locally, Musah leads the Uganda Youth Coalition on Adolescent Sexual and Reproductive Health and HIV/AIDS – CYSRA-Uganda.

Nalwanga Resty;

She works with uganda network of young people living with HIV & AIDS, as a sexual reproductive health and rights officer. she has experience in advocacy., counseling and guidance. for adolescent, youth and children living with HIV & AIDS, Family planning counseling and key populations. she holds a diploma in guidance and counseling and has been a member of the planning committee.



Sandra Nalukenge;

Has a certificate in secretarial, currently working as an administrator, she one of Baylor Uganda`s peer support leader. Sandra has been part of the clinic for over 10 years. Sandra has been part of the Youth Pre-Conference Sub-committee for the 7th National pediatrics Conference.



Mugaga Brian Committe

LIST OF YOUTH ORGANIZATIONS

- Uganda Network of Young people living with HIV&AIDS (UNYPA)
- Centre for Youth Driven Development Initiatives (CFYDDI)
- Y+: The Global Network of Young people Living with HIV/GNP+
- Uganda Youth Coalition on Adolescent Sexual and Reproductive Health and HIV/AIDS – CYSRA-Uganda)
- Namugongo Fund for Special Children
- Baylor College of Medicine - Youths
- Reach A Hand Uganda
- The East African Youth Alliance on SRHR & HIV/AIDS – EAYA-SRH & HIV

NATIONAL YOUTH FRONT PRE -CONFERENCE PROGRAM

VENUE: HOTEL AFRICANA

Monday 29th September 2014	
TIME	SESSION
4:00pm	Arrival of Up country National Delegates at Grand Global Hotel
2:00pm	Draft Action plan by all committee co chairs.
Tuesday 30th September 2014	
8:45am	Delegation arrival and register
9:00am	Opening remarks; Prof Nantulya -UAC, Dr. Tindyebwa -ANECCA, Musah Lumumba -Y+
9:30am	Post 2015, young people and AIDS /ACT 2015 panel discussion by UNFPA (TBC), The PACT (TBC) and Musa - UNAIDS
11:00am	"Know your national HIV guidelines" panelists MoH (TBC), Dr. Steve Okwonkwo- UNICEF, UNYPA, CHAI
12:30Pm	Comprehensive Sexuality Education verses Sexual and Reproductive needs for YPLHIV by; UNESCO, UNYPA, MAI and Baylor.
1:00pm	Lunch Break
2:00pm	Peer led innovations; HTC, Treatment, Care and Support by; NFSC, NTHC, RAHU and UNYPA
3:30pm	Performance Break
3:45 pm	High Level Panel discussion on Policies for effective AIDS/SRHR Verses Leveraging social media for effective HIV/AIDS prevention messaging and communication. Presenters: UAC, RAHU, MoH, KCCA, Musa-UNAIDS, UNFPA and AY+; Q&A Session
5:10pm	Reading of the draft youth Action Plan - TBC Closing remarks UNFPA, UNICEF, MoH and Musa- UNAIDS, Enoch- CFYDDI
6:00pm	Logistics issues to all youth participants and Departure



MINISTRY OF HEALTH



African Network for Care of Children Affected by HIV/AIDS



Children are our future



The 7th National Paediatric HIV & AIDS Conference

