



FCI Podcast

Messages of Hope by Adolescents and Young people

English

Song Izapita - Bob Muli, Victor Kasong, Sebastian Mutale - Zambia

Brian: Hello everyone. Welcome to the *Messages of Hope* podcast of the Faith and Community Initiative. My name is Brian Otieno. I work with Alfajira network. I am also involved with the PEPFAR Faith and Community Initiative, which, since 2018, has been engaging communities of faith to reach men and children with HIV testing and services, helping to better understand the HIV epidemic; and, since last year, it has been working with leaders in our communities to mitigate the impact of COVID-19.

So, today we are here to listen to the messages of hope by a group of amazing young people. It is my pleasure to welcome Peter, Lea, Whitney, Doreen and Dennis at *The Messages of Hope* podcast.

I am very excited to lead the discussion among these fantastic and dynamic team. I will have some questions for them. Please feel free to be guided by your own personal experience with adolescents and young people, and by your own personal journey as well.

The purpose of our discussion is to share messages of hope for adolescents and young people, with a focus on young people living with HIV.

Before hearing from Peter, Lea, Whitney, Doreen and Dennis, I'd like to invite everyone to visit the website of the Faith and Community Initiative www.faithandcommunityinitiative.org, I'll repeat - www.faithandcommunityinitiative.org. The website has all the communication prototypes that have have developed – with the input of faith leaders from 10 Sub-Saharan Africa countries - to address key gaps toward achieving HIV epidemic control, ensuring justice for children and to mitigate the impact of COVID-19 in our communities.

1: Introductions of speakers

Brian: Peter, welcome and thank you for joining us today at the *HIV Messages of Hope* podcast. Peter, tell us about your work in the community, especially with adolescents and young people.

Peter: I go by the name of Peter Mwangi. I am a young person living with HIV. I represent young people from AHF clinic, basically in Malare but I also work across other facilities for AHF support. I am like the mirror in the community. I see what young people know about HIV in the community, about sexual and reproductive health and what they have in mind, if they have the right information and how I can give them the best out of it.





Brian: Thank you Peter, thank you. Lea, welcome – we are grateful to have you with us today. So, please, introduce yourself.

Lea: Hi, my name is Lea Wanjiru. I am a psychologist and a youth advocate, champion for the rights of women, girls, as well as the male gender.

Whitney: I am Whitney Begon, working with paediatrics since 2019. I have just been on the ground doing peer mentoring and just educating.

Brian: So, thank you Whitney. Doreen, please introduce yourself as well.

Doreen: Hello everyone my name is Doreen Moraa Moracha. I am living with HIV. I am a youtuber. I create content and messages around living with HIV and basically giving the right information to both people living with HIV and the general public. I am the founder of "*I am a Beautiful Story*" which is an initiative aimed at giving people the hope that there is life beyond your HIV status and you are more than your HIV status. I am involved in a number of things in the HIV response. The most recent one is the International Aids Society where we are creating a digital youth hub to be able to bring the voices of young people up by using digital spaces. I am also a member of the Generation Equality Youth Task Force by UNAIDS. Thank you.

Brian: Thank you Doreen, thank you so much. I can see that each one of us is engaged in several activities with adolescents and young people all meant to empower them with information on HIV and hope. We all agree that hope is a great tool for enhancing the demand creation of HIV services but also to support creating purpose and meaning in our lives.

I would like Dennis to introduce himself. Please Dennis.

Dennis: Thank you so much, my name is Dennis Munyoro. I currently work with paediatrics research and I am also a peer mentor, peer educator. My engagement of working as a peer educator, peer mentor and research assistant as such it is quite interesting as I get to hear much, I get to impact a lot, in terms of adolescents living with HIV in the county. And it is actually interesting working as a young person also living with HIV because I get to interact with a lot of people going through a lot of issues, people who have lost hope, people whose dreams have been shattered because of living with HIV. And still, you have to engage with these people and give them hope that there is still life, as much it is hard but we are always trying the best we can with the set of peer mentors that we have around. It is quite interesting to hear the stories and it gives you that sense of "I have impacted someone's life into a positive note, I have changed lives of many young people". We still need much more; we still need to do a lot more.

2: What is that you do with young people? How do you share messages of hope with them? How do you bring hope to their lives?

Brian: Thank you all for introducing yourself. Did you see our Faith and Community Initiative Messages of Hope? We have WhatsApp messages; colourful and hopeful illustrations. We have calendars with prayers to be used during religious festivals – through them we talk about HIV in faith communities in a simple and accessible manner. We have videos on how mothers, faith leaders and each person of faith can help spread information on the new HIV diagnostic tools and treatments now available. And even much more.





What is that you do with young people? How do you share messages of hope with them? How do you bring hope to their lives?

Doreen: For me I would say most of my work, rather from a day-to-day basis starts with my messages that I give out on my social media accounts. Like every day I have to wake up with a message to people because I have garnered quite a following on social media. That is where I start. Then depending with what I have planned for the day – sometimes you find yourself engaged in different youth activities such as their meetings, the advocacy campaigns that we need to do with the community. And sometimes I have to go to them to be able to get what they want – even though right now with the COVID protocols, when I am unable to reach them directly on the ground then I ensure we have at least some discussions online so I get to hear from them – how are they doing, what do they hope to see better in the HIV response, going to them, talking to them. Encouraging the power of storytelling from them in HIV advocacy and addressing different issues in the HIV response is one of the things I get involved with on a day to day, both digitally and physically.

Brian: Thank you, thank you Doreen for that. What you do is very important! What about you Peter?

Peter: During this COVID-19, a lot has happened. Young people are being left out because everyone is looking beyond COVID-19. For me, as Peter, I come in to play a part like when a parent is not there. Last week I had a number of AYP (Adolescents and Young People) discussing how they run their day-to-day life. Their topic is drugs. Young people are ending up in drugs and their medication that is ARVs. I come in and we discuss who we can implement, bring them into new work, or connecting them with other organisations or initiatives, giving them what to do. Most of the time we talk, we discuss.

Brian: Okay, thank you so much. I see most of us, all of us, are doing quite a lot for the young people in the community. Whitney, would you mind telling us how your day to day with adolescents and young people look like?



Whitney: So for the longest time I have been a link, the ladder between the adolescent and the clinicians and the medical officers. The adolescents had a hard time communicating what they are facing at home, at school, and maybe even interacting with the fellow students who maybe not be our clients. With time, I just transitioned to something different. In the middle I was trying to get the adolescents a friendly environment for them to access everything at one spot. It was a challenge before because adolescents had fear that when they were sitting in the clinics and they coming to access care, they were getting those eyes from the adults saying “so the kid is also sexually active” but they keep forgetting that you can also be born with HIV. That was the biggest concern. There was that fight that helped us get a youth center and it helped a lot because, in one place, they could access contraception, care, nutrition, help, psycho-social care. If you are idle at home you can come there, you can teach yourself a number of things, and with time you can be a facilitator. It was an all-rounded place. Now I am doing research, basically on COVID, doing surveys on COVID-19 as related to HIV. Basically, I spend my days asking adolescents, aged 9-24 about what they understand about COVID-19, how they are protecting themselves, how school is like for them. Things that have been popping up is that adolescents are really in fear that now that they have an underlying condition – like what next for them. We have a section in our survey where we get to educate them about COVID. We give them new, arising information about COVID-19 in related to HIV in as much as we have disposed because now information keeps coming on COVID-19.



Brian: Peter, how is it like for you, as young person living with HIV, to bring hope to the life of your peers?

Peter: First, I would like to say that living with HIV is not an easy thing at all. When I discovered I was HIV positive, I am now 25, you can imagine 25 years living positive, it made me leave my school. You can imagine I couldn't go back to school due to unavoidable circumstances. Now imagine that I don't have any certificate but I need work. Who will give me that? HIV came and destroyed my life in one way. But in another way, it came and impacted me. I am the brand ambassador for these young people living positively. I can imagine telling a young person living positively now that I am living with HIV 25 years now and I am not dead yet. This is an example that I can give to another young person who is losing hope with life – that living with HIV is just a condition – it doesn't define who you are, it doesn't give you a chance to make you feel like you are all run out, but can make you feel great.

Brian: Doreen you have been an inspiration to young people in the community and you have been like a lamplight to most people in the community, portraying a positive life. So tell us, how do you feel like living with HIV as a young person?

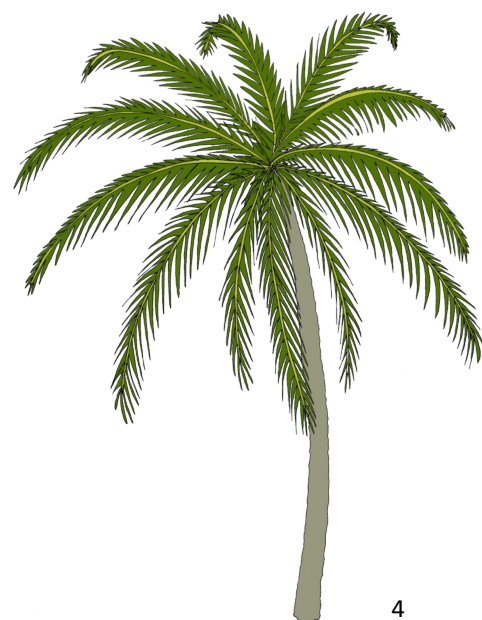
Doreen: The good times are that you are alive, which is a very important and overlooked blessing. Peter has said he has lived with HIV for 25 years, I have lived with HIV for 28 years. So, you see, that right there is our blessing, that light that guides us every day and keeps us going. Also, we are living in a time where there is a lot of research going on, there is better medication than when we first started medication. So, I think these are good things. Bad things is basically having to take medication every day because it is not easy, it is a lifelong commitment. And you know treatment fatigue is real. So you have to give them something to keep them going – you know it's a long time but you can do it. Other people have done it and its time you find that one purpose that makes you be able to take your medication every day. Because with medication you need pep talks every day and even sometimes within the day to remind yourself that today at the specific time I take my ARVs I am going to take them because I have to stay alive for my own sake.

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3: What gives you hope?

Brian: Thank you all for what you have just shared. About the good and the bad – as Doreen just said. About how the challenges you had to face helped you grow. There is positive in all of this from what I can hear from all of us. What is that one thing that gives us hope, that keeps us going? Maybe I will start with Doreen. What give you hope to keep on pushing, ongoing?

Doreen: What keeps me going is the fact that somebody sees my story and gets to just draw up from it. That I was diagnosed with HIV at a time where there were no ARVs at all, that I started ARVs, I stopped ARVs because I thought I had been healed... and here I am. I lived to tell my story, I lived beyond my status. So one of the things that keeps me going is it is not just a story, it is my lived experience, it's me waking up every day – you know when someone says HIV is just like a cold – NO! It isn't like a cold – a cold goes away in seven days – and HIV has been with me for the last 28 years. So, it's not a cold, but it's my reality and I get to live with it every day but I also get to give someone else hope that you can do it. If I made it this far, you can also make it this far, you are beyond your status. You are just hosting a tiny virus that cannot speak. Stop





giving it power! So as long as I give that hope out there, injecting hope to young people who are struggling with accepting their HIV status, then I know we are making the world a better place.

Brian: Wow, Wow. So Doreen's hope comes from giving hope to other people. Her strength is built on giving hope. Lea, as a person who works with young people living with HIV, do you think there is hope for people living with HIV and what is that hope for you?

Lea: I would say this, when someone accepts their status of HIV and AIDS, we say that is the number one thing for that person because their attitude and behaviour are changed towards positivity. It means for that person that they are going to have good health, they are going to adhere to their medication, as well as they are going to have a good support system and also hearing other people's story is already a good win for someone already who probably has a million viral load and given up hope on their life. When you hear stories, I guess that instils for some else – you know they can do, if she did it so why not me? Also, I think having peer support groups is a win because if peers are connected and share information together, we notice that they cope well with life and even peer pressure. So we find that it also a way for them to cope with life.

Brian: So over to you Peter, what does hope look like for you? What is that one thing you look forward to as a young person living with HIV.

Peter: What I can say is for what I went through that I set my goal – what is the best for me, what is the best for my siblings, what is best for this life I have. I realized that I can do a lot even if I am HIV positive. I can do a lot, not about being HIV, putting HIV aside, waking up in the morning, taking your medication then forgetting about it tomorrow morning. So, it doesn't matter on my side. That's the only thing that kept me alive and gave me hope – I can do a lot and create an impact in the community, ensuring that, that one young person that feels like there is something new in their body. How can they cope up with this thing? How can they cope with this education whereby they know that there is not one day where they will stop taking it? So that is where I come and play like a mirror, giving them hope, giving them an example, creating a support group, doing a one-on-one session, being there every step of the way, talking with them, guiding them, making sure that at least in the next few years they are like me, building their own future, their own hope.

Brian: That is quite interesting as well, wow – looking forward and setting goals. That is a hope we can look at in terms of targets you set for yourself in your life. Whitney, over to you, what does hope look like for you?

Whitney: To me, my biggest hope is that picture we give to the next generation. I just feel, to me, that HIV has to end with me, with us, you know. At some point, we used to say our parents didn't have maybe the knowledge or the ability to get prevention for us. Now things have changed, big things are coming and I just want to see a generation which is HIV free, I want to see it end with me (laughs) and that is what motivates me every day. And also, I know we still have a long way, but in as much as the little things that we do, I mean it changes everything we do – I tell the kids everyday it is not by chance it was given to you. Don't start blaming people, don't blame yourself, take it as if you were chosen for some reason, because you are stronger. It could have been given to someone else and maybe they could have suffered and maybe by now, they won't be where you are. And you are going to lead and someday you will do something and they will look to you and ask you how you did it and that they want to do something and prove to the





ones who are looking at us that it is doable, something reachable. So these are some of the hopes, or motivations, that I have.

Brian: Thank you, thank you so much Whitney. Another key word – AIDS needs to end with us. Wow. That is quite a big punch that I think we really need to embrace – AIDS needs to end with us. And finally, Dennis, what does hope look like for you?

Dennis: If you can change the life of that one person, if I can impact that one person, if I can be the light... I look myself as a relic, as an icon, who other young people are coming up and looking at, saying – I want to be like him. I am hope for someone else, I am hope for other people who are living with HIV and want to live their dreams who want to get this information, who want to make an impact.

4: What would be one message of hope for young people?

Brian: Wow, wow, wow, wow! This is quite full of nice messages of hope and inspiration, yeah. As we finish, just looking at the discussions we have had, if you have to give a message of hope, what would that be? What is that one message for that young person out there?

Doreen: My message of hope to that one young person out there would be you are greater than HIV. Just live life beyond that.

Brian: Yeah! Your life matters! Live productively, strong & long with HIV treatment for life. You are greater than HIV. What a wonderful message. So live life beyond that. Beautiful! Thank you, thank you for that message.

Dennis: Yes, HIV does not define anyone. HIV is a small part, a small challenge that life has given to us and you are greater than that as Doreen has just said.

Brian: Lea, what is that one message of hope you would give?

Lea: I would advocate for someone to have hope because there are people who have managed before, so if they have, then why not you... We are in this together and he/she should not feel alone

Brian: Whitney, as we conclude, what is the one thing you would leave us with as a message of hope?

Whitney: There is light at the end of the tunnel, it's not doomsday. Life is hard, yeah, it's hard for everyone. Like Doreen says, there are those tiny hopes that we have, like waking up and having a breath, there is somebody else fighting for their life somewhere else, so you have just been put into a position to take a tiny pill so it's not a big deal and we will conquer.

Brian: Stay on treatment and you will live a healthy and productive life. We are not on this alone! When you feel – treatment fatigue – when you feel stigmatized, remember what our friends here today have just shared: you are not alone. There are peer support groups and other young persons living with HIV who have managed this.

It's quite an insightful session for all us and thank you so much for sharing your stories everyone and for being so inspirational during this session – I really loved everything you said. I just hope that our listeners will feel as hopeful and inspired as I have been myself. And I thank you, thank you, thank you very much to all of you.

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