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**38th Union World Conference on Lung Health
Newsmaker Interviews: Carol Nawina Nyirenda, Treatment,
Advocacy, and Literacy Campaign in Zambia
November 12, 2007**

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JILL BRADEN BALDERAS: Carol Nawina Nyirenda of the Treatment, Advocacy, and Literacy Campaign in Zambia. Thanks for joining us today. TALC started off in HIV/AIDS advocacy but moved into TB work. Can you talk about some of the lessons and the principles that you brought from your HIV/AIDS advocacy into your TB work?

CAROL NAWINA NYIRENDA: Okay. Like the name says [inaudible] Treatment Advocacy and Literacy Campaign. We're doing a lot of work around HIV, more like we're teaching people living with HIV, the basics of HIV so that they can well manage their illness and understand their illness. What happens is most of the people that have HIV, also have had TB, and then after they're cured of TB they forget about the TB and just go straight onto HIV because their medications are for life. But then when we started working with the Orcasite [misspelled?] Institute on TB issues, we realized that it was a good to go back to the TB issues and not to just look at the TB issues as opportunistic infections because there are other people out there who have TB. What we are doing now is the same advocating that we did on HIV around TB.

JILL BRADEN BALDERAS: You're HIV positive yourself, and you have had TB. Tell us about your experience firsthand with the health care system in Zambia from diagnosis to treatment.

CAROL NAWINA NYIRENDA: Okay. At the moment, we get, for HIV; the treatment is free from the public health institution. For example, on a day you go to the hospital, to the HIV clinic, [inaudible] centers. You are assessed and if you are found positive, after counseling, you are told to go back while they do your CD4. You come back after about a week or two for your results. Then you find out whether it's possible that you're on treatment or not. If you are ready to start treatment, you start accessing the drugs from the out-clinic. They will put you on two-week trial to see which combination suits you. Once they find that, you start accessing your drugs from the out-clinic. All the tests currently are free, the CD4 counts and the LTF, the level tests [misspelled?], all the vitals, are done free. You go there sometimes every three months or for the body checkups every month depending on what tests they are [inaudible].

JILL BRADEN BALDERAS: And what about your experience when you actually had tuberculosis?

CAROL NAWINA NYIRENDA: Actually, they split. When I had tuberculosis, I had a bit of a problem, which is why I think we, as activists in Zambia, have a problem with accepting getting IPT as an added preventive therapy in Zambia. For people with HIV, there is a problem in diagnosing TB in us. A lot of us have extra family with TB, where when you are tested they do not find the TB through the chest x-ray or the sputum, which means there is actual comment that you don't have TB when

you actually do have TB. I was tested and I think I had something like four x-rays in a period of about six months. They could not detect the TB. At that point, fortunately, I had a brother who is a doctor who insisted that looking at the clinical science said I think what you have is TB and unusual specimen TB. I've had friends who have gone for three years without having their TB detected and they got really, really sick. I think there's a problem of detecting TB in people living with HIV. For me, I was lucky that I had a brother who is a doctor who insisted that I start my drugs and I keep taking my drugs and I didn't have any problems. I didn't default. I took them for eight months and I've been okay. That was about four years ago. I haven't had a relapse.

JILL BRADEN BALDERAS: And for the people who aren't as fortunate to have a brother, as you said, who is a doctor, what are some of the problems that they encounter with the health care system when it comes to diagnosing and treating tuberculosis and what are some of the ways that TALC is working to improve those health care systems?

CAROL NAWINA NYIRENDA: At the moment some members of TALC are being trained as paralegals. We work with an organization called Zarun [misspelled?] in [inaudible]. It's an AIDS-low [misspelled?] clinic where if a number of the rights of the patients are violated then we could take it up on their behalf. Because maybe [inaudible] bits of actual HIV we'll have situations where a lot of patients reacted to the

D4T, the stuff that was in one of the combination therapies of prevalent HIV/AIDS to the point of where they lost use of their limbs. They would go to the clinic to complain to the clinician. They would say that they have this problem and they need to change their medication. We try to teach them what more to expect and what the side effects should be. A person goes in two or three times and if there is no change, they will come to talk and we try and take that on with the AIDS-low clinic. People with TB, I'm saying who have just gone into the TB section, we haven't done that much work as yet but I think we also take the same route as we have done for HIV.

JILL BRADEN BALDERAS: You were also on the Board of UNITAID, which is a funding mechanism that gets it money from airline taxes. In that role you interact with Members of Parliament and potentially even Presidents of countries. As a community member and an advocate for tuberculosis, what do you want them to hear from you?

CAROL NAWINA NYIRENDA: What I would want them to hear is that as much as we are grateful that they have given us these drugs, and we are really grateful for the shipments of the drugs, I would like them to know that there are people on the ground that are actually swallowing this medicine. I think this one time actually I brought this up to the Board. Most of the time, they are concentrating on giving drugs to the countries and these are second-line drugs. For one to go on second-line drugs you have to be diagnosed and most of the time

there are no diagnostics in countries where problems with free agents, so how do they expect us to go on second-line drugs when we haven't had the diagnosis. What I do to imitate [misspelled?] is I sometimes think the [inaudible] board gets really technical. My job is to bring them down to earth and to bring them back to see that there are people actually taking the medications here.

JILL BRADEN BALDERAS: You talk about the ground level down to earth, when it comes to implementing DOTH or the Stop TB strategy, do you find that this information is actually there at the ground level?

CAROL NAWINA NYIRENDA: Yes, for the DOTH. Actually, DOTH has done a lot; with DOTH at least that is on the ground level because most of the time when doctors use their home-based care people. That is people within the community. These are the people who go into the rural areas. They go to the clinic and the get the drugs and go out into the community and make sure that people swallow their drugs. I think that, at the community level, is working.

JILL BRADEN BALDERAS: You mentioned earlier the difficulty sometimes in diagnosis; do you propose solutions as well for how diagnosis can be improved? What are some of the ways that it can be improved?

CAROL NAWINA NYIRENDA: At the moment, like I said earlier, we're trying to look at laboratory strengthening. For us, as activists, it has been very difficult but that is one

thing that we feel, as long as that is not put in place. Even if we did bring more, there is a problem of health care workers in Africa. I'm sure you know that. Even if we did bring on more health care workers, as long as there are problems with labs then the health workers will not be able to do their work well. Like I'm saying, these are second-line drugs, even if it is beyond second-line drugs. You have to be tested. You have certain tests for you to go on those drugs. They could put in as much money as they want, but if there are no diagnostics to put those people on second-line drugs then at the end of the day, there won't be any point in doing that. For me, it's really the lab strengthening because [inaudible] which isn't about using the same labs in [inaudible] area of TB and HIV testing.

JILL BRADEN BALDERAS: Community health workers, what role do they play? How important are they?

CAROL NAWINA NYIRENDA: Community health workers?

JILL BRADEN BALDERAS: Yes, in terms of TB and getting messages out and helping people take their drugs.

CAROL NAWINA NYIRENDA: They play a very important role but, like we said at one of the meetings that we had here, the problem is that they're always expected to do their work for free. Most of them homes that are very impoverished, they'll come and get their medications and go out into the community work. They're willing to work, especially people who have had TB or people that are living with HIV and AIDS. They are

committed to work. Like we always say, if there could be a given a type of stipend, I think they would do more. At the moment, you also are talking about task shifting. I think we had some meeting to talk a week ago. What we are saying is that maybe certain tasks should be shifted. A few of the tasks that are done by the doctors should be brought to the nurse, then the tasks done by the nurse should be brought to the health care workers and adjusted so that the burden is lessened on the doctors and nurses. The health care workers come into the communities [inaudible] representatives, people living with HIV, are willing and ready to do work like adherence counseling and if it is possible, if they are trained in the basics, they could actually even do the testing. I think that would take down the load from the nurses and the doctors.

JILL BRADEN BALDERAS: You presented earlier today on some research that you helped conduct that sometimes these community health workers are not always accepted because they are not actually medical professionals. Can you talk about how there can be improved communication in how these community health workers can actually be more accepted among, whether it's government officials or health care workers themselves, as a part of the team?

CAROL NAWINA NYIRENDA: I think what I would say, like you rightly said, I did mention even in today's sessions to say that first the problem where you walk into a doctor's office.

Okay. He's done his training, he's an expert. What they have

to do now is accept us, the people living with the disease, as experts. For example, go and talk to a doctor on HIV. He is a doctor who has read about side effects in a book. I have suffered several side effects. Like I said, I have had TB, I have had Kaposi's sarcoma; I have gone through it all. It is good if we can help each other. Let the doctors do their part and they should learn to listen to us whether they like it or not. The time has come when they should listen to us. Once upon a time, like even when they get people to sit on these international boards like UNITAID, you would go there and sit there as they are talking. People would go there for one year and sit there and not say anything. What I am saying is those days are gone. We want to learn. For example, this [inaudible] partnership. At the moment, we are actually asking them to train us, more capacity building for us. Then, even help us with communications. Most of us don't have computers or internet access. We should have more knowledge. I guess at our own level, not [inaudible] doctor level, but we should also be at a capacity to build a different level where we can at least communicate with the doctors. Whether they like it or not, they cannot run away from this. It's a time when they should engage communities at whatever level.

JILL BRADEN BALDERAS: There was a press conference earlier as a part of the Union Conference that talked about competition as opposed to collaboration between TB programs and

HIV programs and how it is quite prevalent. Is that something that you've seen, and if so, how can that be improved?

CAROL NAWINA NYIRENDA: People say for lack of a better term, they say that HIV work is sexier and TB work is not. In a way, I think it's this situation where TB has been always kept as a medical illness and much less brought out for the common man to understand. When TB people are talking about it, their TB work, the HIV people will say that is your work and vice versa. For now, the problem that we have of people having the colon [misspelled?] infection, it is important that the two communities come together. Most of the time, people that have HIV have TB as well. What I would like to note is that collaborative activities have to come together. That's within the [inaudible] people. I think you work on the presentation. You saw the slides that I showed. Here is someone who has extrapulmonary [misspelled?] TB. They are already weak from the TB and then they have HIV. It's really become very difficult in [inaudible] to infections. One of the fights or [inaudible] that they have to come together.

JILL BRADEN BALDERAS: Last question for you. The Global Plan to Stop TB that came out about a year and a half ago called for \$56 billion over a 10 year period to help in the fight against TB. Two-thirds of that is supposed to come from high-burden countries. Number one, do you feel like high-burden countries are contributing that much to begin with, and

then do you feel like it's actually realistic to ask that of high-burden countries?

CAROL NAWINA NYIRENDA: I think maybe they are not contributing that much. In a way I think it's not realistic. They could contribute something; I think for them to take ownership of the programs. I think high-burden or low-income countries should contribute because like in UNITAID actually, we have 18 recipient countries that are also contributing onto UNITAID. I think it is okay for them to contribute but I think the amount is a bit large.

JILL BRADEN BALDERAS: Carol Nawina Nyirenda of Treatment Advocacy Literacy Campaign in Zambia. Thanks for joining us today.

CAROL NAWINA NYIRENDA: Thank you.

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