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**39th Union World Conference on Lung Health
Newsmaker Interviews – Lucy Chesire, TB/HIV Advocate
October 19, 2008**

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JILL BRADEN BALDERAS: Lucy Chesire, thanks for joining us today, we appreciate your time. Now you are able to speak to many health issues from a variety of perspectives and a personal standpoint; you are a healthcare professional in Africa, you are HIV positive, you've been infected with TB yourself. I'd like to start with the issue of healthcare in developing countries. Can you paint a picture for us what a TB patient, let's say in your country, home country of Kenya, experiences when they go for treatment.

LUCY CHESIRE: I think when a TB patient goes for treatment in Kenya, the first thing that will basically happen is that they would have to undergo, what do you call it, the check-up's, and that would entail them maybe going for a sputum or going for chest x-ray, which is typically used. And then once their results are out, they've got to go back to the clinic and get a prescription for their drugs, and they have to go to the pharmacy and get their medication and go back home.

Now we say in Kenya that TB treatment is free, but essentially it is not free, because many times the patients have to pay for the chest x-ray, which costs about \$4 or \$3, which is not something really cost effective. But essentially, the TB treatment is provided by the government in terms of the drugs as free of charge.

JILL BRADEN BALDERAS: Are most patients able to even get to a healthcare facility and even get the chest x-ray's? Does everyone have access to that?

LUCY CHESIRE: There are issues around access because for sure in Kenya we have about 1,800 treatment sites, and we have only about 900 diagnostic facilities. So it may mean that a patient has to literally go to the district hospital for them to be able to get a chest x-ray because chest x-ray's are not commonly found within the healthcare centers, and many times it means that the patient has to travel a long distance for them to be able to get a chest x-ray in the district health hospital.

JILL BRADEN BALDERAS: And then, in your case, you didn't actually have tuberculosis in your chest. You had it in other parts of your body. How difficult was that to diagnose?

LUCY CHESIRE: No, my case is very interesting because I did not have pulmonary TB; I had extrapulmonary TB, which is TB outside the lung system. Being a woman living with HIV, there were issues around diagnostics because, for one, my doctor sends me for a chest x-ray when I was immune compromised, and also a sputum, and none of them actually showed that I had TB.

So despite the fact that I continue to present with signs and symptoms that are related to TB, my doctor was not able to make a conclusive decision and actually start me on TB treatment.

And so what happened out of that is that I ended up getting, developing TB of the knee, and also TB of the lymph nodes, and I had to undergo three surgeries and had to stay in the hospital for seven months. Now also the unnecessary suffering and of the challenges that I went through while staying in the hospital, it actually taught me that to make TB diagnostics an issue in terms of advocacy.

And that is what makes me even get engaged internationally because here we are seeing that in an era of HIV and AIDS and coinfection, there is no way we can continue relying on outdated tools like chest x-ray and sputum for us to be able to get a conclusive result for TB in somebody who is adversely HIV infected and also with AIDS.

So it becomes a big issue, what do we do as advocates for us to continually add our voices so that the research world can put more efforts in ensuring that we get tools that are able to diagnose TB within a very short period of time. Look at chest x-ray, it takes a few minutes, yes? Look at sputum. You have got to produce two sputum's; initially it is to do three sputum's on three days, but now they've got it down to on the spot sputum and then one in the afternoon, so you take two tests.

But many of the lab people don't like doing sputum's. You have to realize you give out the sputum, and then it is the last test they actually do before going home. So it means that like the patients who straggle in from out of the district, you

have got to come back the following day to be able to get your results. It's not like HIV ELISA, whereby in 15 seconds you actually have your conclusive HIV test. So that's the challenge we have.

JILL BRADEN BALDERAS: So what would an effective diagnosis tool look like for you?

LUCY CHESIRE: It should look like it should be run very efficient, very effective, very sensitive. It is able to pick up the mycobacterium within a very short period of time. And that's all we are calling; if it means we have a TB ELISA, or having a test that would actually be able to pick up the mycobacterium within a very short period of time, that is what we are calling for.

JILL BRADEN BALDERAS: Now you're an advocate for both TB, the fight against TB and the HIV, and you have the experience that you told us about with the TB in the hospital and how that opened the door for you to actually get your antiretroviral treatment. Does that happen often?

LUCY CHESIRE: Actually, I always look at my experience at one in a million because not many people are as lucky as I was. What made me lucky was one, I was working in a healthcare facility as a nutritionist, and so I was closer to the healthcare service. And despite being closer to the healthcare service, it actually meant that they couldn't be able to detect what I had, so the service was not of any use to me.

And many times, not many people are as lucky as I am because we get to see many patients who are coming into the healthcare facility, they are immunocompromised, they undergo the same tests. The doctor does not put them on treatment, and you know very well that if somebody is immune compromised and they are not able to detect their TB and they are not put on treatment based on the clinical signs and symptoms, it means that within the span of a month the person will actually die.

So I have watched many people die just because a doctor is not confident of his clinical symptoms for them to be able to diagnose them and actually put them on treatment. TB is not like HIV. With HIV you can live long with it, but TB, it gets worse as long as the treatment does not get started and that is what kills many people. And that is why TB is actually now the leading killer of people living with HIV, because once you miss it, it means it is more or less like a death sentence. The person living with HIV will definitely die.

JILL BRADEN BALDERAS: Now there is some talk about considering providing preventive treatment, preventing tuberculosis treatment for people who are living with HIV. Do you have an opinion on that?

LUCY CHESIRE: Absolutely. I surmise it as very, very critical. The essence of giving preventative treatment for TB is there so that we can be able to prevent persons living with HIV from developing TB, considering that we have a very high

chance of having recurring TB or even the latent TB becoming active.

And so the basic essence in terms of IPT is for you to be able to get protected, and having over 50-percent chance of not being able to develop TB, which is really critical when it comes to the management of HIV. So IPT has a very big role when it comes to preventing development of TB, even a person living with HIV.

JILL BRADEN BALDERAS: Do you take a treatment like that?

LUCY CHESIRE: I haven't taken IPT because apparently once I finished my TB treatment, my CD4 went up. And what I see the practice being is that it's given to those who have not received antiretroviral therapy, and they have a moderate CD4 and it normally takes about six months, but some countries are actually doing it for nine months.

JILL BRADEN BALDERAS: And in order to implement something like that, there obviously has to be coordination between TB treatment and HIV treatment in the civil societies for those two diseases. How would you rate currently the coordination between those two?

LUCY CHESIRE: The coordination between the two is quite a challenge and that is why basically part of the global plan to target was to have 1.2 million persons living with HIV being put on IPT. It's such a shame that we only have 27,000 people who are currently on isoniazid preventive therapy, which

means that, one, it's like it's not yet globally accepted as the right thing to do, and of course there's also the challenge whereby people look at how do we rule out active TB because that is a prerequisite.

If you cannot be able to rule out active TB in a person living with HIV, then it means you are not going to be able to put them on ITP, and that is where the challenge is. And so it means that even when you look at the strategy that the World Health Organization is currently using, we are all seeing the three I's: infection control, isoniazid preventive therapy, and intensified case finding. It is the total responsibility of the HIV and AIDS programs.

Now these are the very programs who have not totally embraced TB/HIV collaborative activities, so you get the TB programs, have gone ahead of HIV testing to their TB patients, yet the HIV programs have not yet even started screening persons living with HIV for TB.

So you realize there is an issue there between coordination and collaboration, and that is why part of this touch strategy with building an interim policy is to make sure how do the TB programs realize, and the HIV programs, basically realize that these are two diseases in one patient. We need a joint response. We don't need to divide the patient so that if Lucy is having HIV, she is sent to the HIV clinic; once she gets TB she is sent to the TB clinic. That's a whole waste of time. We need one response that should be able to address both

TB and HIV, and that is purely the essence of the TB and HIV collaborative activities.

JILL BRADEN BALDERAS: And you work with a lot of civil society groups who focus on either TB or HIV, or perhaps both of the diseases in one. What do you advise them to do to collaborate better?

LUCY CHESIRE: One of the things I advise them to do and actually build their capacity, one, because to be honest, an advocate that is not informed cannot be able to do their job. And this is a green area. In HIV and AIDS, we realize that you have got to empower the patient. And that is why they look at a person living with HIV having a very critical role when it comes to their care.

That hasn't happened in TB because for many years, TB has been seen as a doctor's thing. It's the doctor who calls the shots. The patient has a very minimal role. So it means even bringing the civil society on board, making them understand the issues around TB care, prevention, and support. And then once they understand those issues, they are better placed now to start even advocating for the coordination between the HIV program and the TB programs, and that is the essence, also, of the TB/HIV collaborative activities.

And so civil society are really critical when it comes to the implementation. I am going to give you an example of what we've done in Kenya. Kenya is one of the countries around the world that is a role model when it comes to TB/HIV

collaborative activities, but it's always Rwanda that we have done very little when it comes to the three I's.

When you look at something like IPT, IPT is only given in such institutes, in specific HIV programs where it's still undergoing research. When you look at infection control, not every person is actually having the opportunity for them not to be able to get TB because when you get somebody who is sitting on the line sitting next to somebody who is coughing, they could be having TB. Here you are a person living with HIV and are variable.

How many countries actually have guidelines for infection control, and yet we know that nosocomial infection is one of the greatest things that's happening in most of the healthcare facilities because we are resource limited settings. And then, of course, also the issue of IPT, which has not been scaled up globally, and so it means that they have not been able to rule out TB, people are not using IPT, very few countries have infection control measures for TB, and then worse off now they are not screening each and every person living with HIV for TB. And that's the unfortunate part of it.

JILL BRADEN BALDERAS: Do you feel like TB is stigmatized?

LUCY CHESIRE: Absolutely TB is stigmatized, and with evidence of HIV and AIDS, we are actually now seeing a double stigma because many times, and I don't blame them because like still giving another example in Kenya, 60-percent of our TB

patients are not HIV positive, that's a very high coinfection rate. And so you're looking at people having their association and thinking as soon as you have TB you must also have HIV, not considering the fact that we have the 40-percent who are not HIV infected.

And so it's really critical that we send out messages, the kind of messages that we develop should not contribute to stigma in any way, but they should be bringing down the stigma that already exists in the community because you can imagine if you are having both HIV and TB, it means that you are being stigmatized twice and that's the essence behind double stigma. You have TB, you have HIV, you are stigmatized at the end of the day.

JILL BRADEN BALDERAS: My last question for you; at conferences like this and in your work with a wide variety of groups, including the United Nations, you have access to political leaders and health leaders. What do you try to express to them from an advocates point of view and a patient's point of view that is important for human rights of TB patients?

LUCY CHESIRE: The things that we try to express to the leaders is, one, let them understand from a human perspective. Put a human face to TB/HIV, that's really critical because many times I've sat down with some of the world leaders and as soon as I mention I have been TB/HIV coinfectd, they tend to listen to you because you are talking about it from a very personal

point of view. And then, of course, the second thing is the issue of what it takes for the two diseases to get addressed, having a good plan.

And then, most importantly, ensuring and putting forward the requests that without having sufficient resources like, for example, for us to be able to address TB/HIV coinfection and for us to be able to reach the targets for the many development goals we require about \$19 billion. That's quite a lot of money.

So to ask would be how much are you going to contribute and what role can you play to raise the profile of the diseases so that more donors can continue funding it and people can benefit, whether it is funding through the Global Fund or through PEPFAR, whether it's funding through the Clinton Foundation, the most important thing is how do people on the ground who require the services benefit from them, and then, of course, the issue, also, of new diagnostics whereby for many years we've had the same challenge.

The TB drugs we're using are over 50 years old, the diagnostics that we're using are over 100 years. Honestly, we don't have a TB vaccine, which means now more money going into research so that we will be able to have better tools that should be able to address TB if we really want a world that is free of TB by 2050.

JILL BRADEN BALDERAS: Lucy Chesire, thanks so much for joining us.

LUCY CHESIRE: You are welcome.

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