Transcript: A Positive Papua New Guinean Speaks Out Against Stigma

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Regan Hofmann interviews Maura Elaripe Mea, the first HIV-positive woman to come forward publicly in her country. Through Igat Hope, the national network of people living with HIV/AIDS in PNG, Maura and others fight AIDS discrimination while spreading information and hope. Below is the transcript. To see the video click here.

Hi. Well, first of all, tell me how to pronounce your name correctly.

Maura Elaripe Mea.

Say that one more time.

Maura Elaripe Mea.

And you are from…?

Papua New Guinea

Which we keep mispronouncing. And we heard you speak last night at the opening ceremonies of IAS and you were talking about how you're a woman living with HIV. What made you come forward and share your status?

I saw people dying when I was admitted to the hospital, the major hospital. And I saw people dying from infections that could have been treated. And also one of the things that made me come forward was the first baby I had was refused treatment and I was made to wait with her in the emergency [room] for twenty-four hours before she died.

I'm so sorry.

And that just made me so angry and it made me come forward and talk about HIV.

Do you have other children?

No.

How long have you been living with HIV?

This year is going to be the tenth.

A big anniversary.

Exactly.

Well you look well and you're on treatment?

I am. I'm on treatment. I started treatment in 2002.

I'm also HIV positive and I've been positive for just over ten years and I've been on treatment the entire time. One of the questions I've been asked around the world is, "How do people in other countries access treatment?" Can you get good care and treatment in Papua New Guinea?

That's a big question and that's a thing that I'm always struggling for. We have treatments which has been brought in by the Three-By-Five Initiative, but the rollout has been so slow and it's only in the capital city, Port Moresby, and in a couple of major towns. But it's not reaching into places where positive people are.

And I imagine it's hard for people to get into these big cities and towns to get the treatment.

Exactly. People live in rural communities and they need bus fares and, you know, fares to get there because, you know, people are unemployed and it's just crazy.

And HIV only adds to the poverty when, even in the United States, we struggle to pay for our care and treatment of the disease, so those living with the disease have financial concerns and then, often, people aren't well enough to work so that makes it even more complicated. Does the government provide any support in your country?

Our government doesn't provide any support, no.

What is it like being a woman living with HIV in Papua New Guinea? Do you experience stigma and discrimination?

At first, yes. I experienced stigma and discrimination for three years.

What kinds of things happened?

From my family—my brothers' wives didn't want me to talk to or hold their children and it was something that I was so sad about. And they got over it and I educated them on HIV and now we are friends. And around the community people were so, kind of, scared about me. Scared of me and they were always gossiping, but then it took me a couple of years to work with my community to break that stigma down and my whole community is very supportive of me.

That's a great message. You know in my own town when I came out as being HIV positive I was terrified about what my friends and family would think. My family had known since the beginning, but when we told the people in my town and got the information to them, they were very, very compassionate. Would you say that if people are educated about HIV they *can* come around? Right? They *can* understand the disease.

Exactly.

Yeah, and I think that people living with the disease need to know that people like us

can talk to others and when others are afraid maybe, be patient with them and give them information and let them come around because even people who, in the beginning don't seem to be accepting, can. Right?

They have misconceptions and they have their own fears, like fear of getting infected and all that. It's also a big challenge to us, as positive people, to take a step forward and be prepared to confront that discrimination and stigma that surrounds us.

Where do you find your inner-strength to do that?

I find my strength mainly when I'm patient with people. I'm patient with people and I have a compassion. Being a nurse, I don't see anybody differently. I see people as— whether you're black or white, you're fat or thin, you're rich or poor—we are all human beings. I'm very compassionate towards people, that's one of my strengths that I have. And the other thing that I have is I'm very patient. I don't normally rush or all that stuff, so when things don't happen I just wait.

That's amazing. I think having the patience and the understanding to forgive people who don't understand us and who fear us is a very difficult thing. But, like you, I've been rewarded when I sit tight and wait for people to come around to the information, the facts, and I realize that it is their own fear and their fear of the virus, not their fear of me and, for me, it was separating that to know that they weren't rejecting *me*, they were rejecting the virus and the virus just happens to live inside my body, but *I* am not the virus. So that was one way that I separated it. You're a nurse still? Are you working as a nurse?

No. I decided not to work in the hospital. It was too demanding.

Do you work now?

I do a lot of consultancy work. So, the national organization with PNG, I support them in their work, but I'll be starting work with Oxfam.

Great. Tell me about the organization. Did you start the organization in Papua New Guinea for people living with HIV/AIDS?

Yes, myself and nineteen other people, we started the organization. And now I'm so glad to see it growing to the other provinces of Papua New Guinea.

What's it called?

It's called Igat Hope.

What does that mean?

That means "There is hope" in the Melanesian Pidgin.

And you seem like a very hopeful person. As a nurse, do you think it's very important for people with HIV to have a good mental attitude and to be upbeat and happy?

Exactly. I don't see any reason why people should be depressed because they have HIV. I mean, who cares? We all have HIV, I mean, I'm well, I've been living with HIV for ten years. I have other friends who are just diagnosed and when they get so scared I say, "Look at me. I'm living a normal

life. I enjoy parties, I enjoy going to see friends." It's normal—just being a normal person.

I think that's what people need to see. More people need to see people like you in the world who are happy and living a complete life and living a healthy life, because I think that's what makes people fear the disease. We have these old images of death and illness and we need to come forward as a community of people living with it to show people that we're not scary and we're okay and we're in a good mood, right?

Yeah. Sometimes people just overreact. It's always good to be a bit…I mean, we all have our…we self-stigmatize ourselves sometimes, so that's one thing that, with proper counseling, that can be overcome.

I think that's a big job we have among the community to help people living with the disease realize that they don't have to be isolated or ashamed or alone and that they have every right to a good life like everybody else and that they don't have to wear this mantle of shame, you know. For me, it took forgiving myself to be able to come forward. It took me ten years. But did you have any reservations about coming forward or did you have to think differently about yourself before you did?

I was scared about coming forward, but then I said, "I'm not doing this because of myself. I'm doing it for those who are going to come after me", so I was the first woman who came out in public in PNG. So I said, "I'll have to do this to save other women's lives." So when I came forward, today other women who are coming after me have easy access to everything and I'm proud to look back, you know. They're getting counseling and having to get treated and some of the services that they are accessing, not all, services are in place, but at least they are accessing some services, which is good.

Well you're a very brave woman and I really admire you very much for being the first in your country to come forward and I think that many countries around the world would be lucky to have someone like you and I hope that you continue to have good health and good success. Thank you very much for talking to us to day.

You're welcome.

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