

"Talk with us, not about us"

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Maura Elaripe, an HIV-positive treatments activist and one of the founding members of Papua New Guinea's newly-formed national organisation for people living with HIV/AIDS, [Igat Hope](#) [1]Organisation representing people living with HIV/AIDS in Papua New Guinea. ('Igat Hope' means 'There is hope' in Tok Pisin, the national language of PNG)., was invited to speak at the UN High Level Meeting on HIV/AIDS, but due to transport problems was unable to attend. This is the speech she had prepared.

My name is Maura Elaripe I am from Papua New Guinea and I was first diagnosed with HIV in the early 1997. I went through a hard time in my own country as this was the early days of HIV with no proper counselling, care and support system in place.

I learned 'survival of the fittest' was what I needed in order to live. Papua New Guinea, my home in the Pacific, was no longer safe from HIV. I saw people going through emotional pain, people suffering from stigma and discrimination and eventually dying from curable infections. This made me to take a step further into talking about HIV openly.

I came forward with other 19 people and formed an organization for people living with HIV in [PNG](#) [2]Papua New Guinea. And we named our organization 'Igat Hope'. In the Melanesian pidgin of the Pacific, 'Igat Hope' simply means 'there is hope'.

During this time I advocated a lot and I lived with the hope that treatment will be available and guaranteed to all who needed it, that young people will have access to comprehensive sexuality education that will empower them to protect themselves from HIV infection, that women and girls will have their rights protected, that I as a positive woman will have my sexual and reproductive rights respected, that the stigma and discrimination will be eliminated.

Up to this stage, I am still struggling for all this to take place.

Currently in the Pacific and especially in Papua New Guinea, women getting infected with HIV are outnumbering men in certain villages and provinces; new AIDS patients are outnumbering the bed capacity of the main hospital of Port Moresby in PNG; the burials are becoming a daily affair and we even have unclaimed bodies which are buried in mass burials; and we in PNG have a very tiny window of opportunity in which to help us avoid the African scenario.

In other Pacific countries, such as the Solomon Islands and Fiji, they are experiencing increases every year in diagnosed cases with very few care and support structures. It is hard to deal with HIV in the Pacific where you are already struggling financially and have little or no opportunities for employment and no other means of income generation.

In an effort to ensure that positive people in my country have as much information as possible about developments in care, support and treatments, I have actively participated in the Asian Pacific Network of positive people. Representatives from that organisation have ensured that I have been able to attend here today and speak about my experience, the experience of those living in PNG and the experience of people living with HIV/AIDS in the Asia-Pacific region.

What we as positive people need is not just understanding or sympathy. We have developed our own understandings in an articulate manner. One way that we describe our relationship to the HIV epidemic is through a set of principles. Those principles we describe as the Greater Involvement of Positive People in HIV and AIDS. GIPA for short. You can find the description of these principles in the work of the Global Network of Positive People and our own Pacific Regional Network. What those principles spell out is that if there is to be ongoing national, regional and global responses to HIV and AIDS, then those of us living with HIV must be involved in prevention, care and support and treatments rollout and uptake.

I ask that over the next three days you be bold, commit to doing things differently and put the necessary political will and resources behind these commitments to make it happen. Unless we do this our home in the Pacific will be

lost and we will be responsible for one of the greatest failures of the international community.

On behalf of the global community of people living with HIV, I would like to identify three key areas where action is needed urgently. Firstly, access to affordable treatment for everyone who needs it. Secondly, leadership from governments down to address stigma and discrimination. And thirdly, the opportunity to work and earn money to help alleviate the enormous poverty in which many of us and our families live.

My other appeal is to you is this. If resources are allocated for fighting this disease through mechanisms like the Global Fund to Fight AIDS, TB and Malaria to and national plans, then please talk with us PLWH/A when making decisions.

Many people have said it before but I take the opportunity to say it here: talk with us, not talk about us.

- [HIV in our region](#)
- [involvement of positive people](#)
- [The global HIV epidemic](#)

Links:

[1] <http://www.napwa.org.au/glossary/term/392>

[2] <http://www.napwa.org.au/glossary/term/144>