I am Celina, the National Advocacy Officer of INP+ and also the acting President of World Care Council India.

I would like to sincerely thank Dr. Arora and the organizers of this conference for providing me this platform to address TB issues in India, from the perspective of someone who has taken all the pills for TB.

I take this opportunity to share my experiences of HIV and TB in India.

In 1996 I was tested HIV positive along with my husband and during this time, I had my sick husband who was suffering from TB symptoms and due to the ignorance he had to die undiagnosed of TB. I became aware of this only when I joined the NGO sector and in the field of HIV/AIDS. The discrimination of HIV was such that my neighbors had stopped coming to our house after knowing, his own mother was not touching him of fear of infection. Toilet in the house was locked and I had to look after my sick husband till his death in an isolated room which was outside the main entrance of the house. And after my husband’s death, I was thrown out of my inlaws house as they feared that my presence would add on stigma, they feared of getting infection from me through casual contacts and fear of affecting the decent marriage of my brother in law.

There was no support nor information on HIV related opportunistic infections and also on life with HIV and TB. The stigma and discrimination I have faced at home made me realize that there is a lot of work to be done in educating the public on HIV, its modes of transmission and clear myths and misconception. I had two messages to give, one to those living with HIV that they are not alone and that they can live with it and to those at risk of HIV to become aware of their risk and prevent from it.

I STRONGLY BELONG TO THE INP+ AS INP+ HAS THOUGHT ME TO LIVE

From the message that I would live only for some months, to now after 14 years, I am still living. I learnt about life with HIV and tried to teach my community to live and tell people that any one could be at risk of HIV and better prevent from it and support those living with HIV.

TB diagnostics becomes even more difficult in people with HIV. Two years ago I had got swollen lymph nodes and when I consulted with my Doctor, I was given antibiotics but within two months my condition became even worst and since I was responsible for my health, I did chest X-ray, USG abdomen and sputum examination, but the reports came normal. As my
health was not improving, I asked for biopsy of my swollen glands and finally it came as TB lymphocytes. I have taken six months of DOTS as per the Doctors advise but my test report after six months of taking DOTS without missing a dose, came back positive for TB Lymphocytes again. As per the private medical practitioner I went through private treatment for TB which included AKT4 with oflox for two months and then continuation phase of AKT3 for seven months. I have completed my treatment for TB one month ago as per Doctors advise and have started ART for my HIV control.

I was not treated with dignity; but I was lucky because I knew where I can get proper information, and I was responsible.

But almost everyone in India with TB, are denied dignity and are not made aware their responsibilities nor their rights

The RNTCP has began to take steps to address this growing threat, and scale up laboratories, building and training human resources, and strengthening health services is underway. However, as the public sector provides only half of the required services, the private sector is not included in this scale up.

Also not included at all, are the millions of people with TB or who have been cured of TB. Where are they? Why are they not here?

There is a need to have Patients participation in all aspects of TB control and care

Patients organizations, peer support groups and community participation in local , state and national consultations is a must

As a President of World Care Council and the National Advocacy Officer for INP+, I will be writing tonight to the President of the Tuberculosis Association of India, a formal request that at the next national Conference of this association; requesting strongly that there will be a special session on patient and community participation designed, developed and facilitated by patient powered organizations. I will also request that the WCC and INP+ are invited to be a member of the Tuberculosis Association of India.

We need access to diagnostics, drugs and dignity, there by creating an enabling environment for people with TB to participate and take responsibilities.

Taking responsibility is a right, as outlined in the patients charter for Tuberculosis care, endorsed by WHO and a growing number of National and State Governments, but not the RNTCP India.

The Charter explains how Rights and Responsibilities of Patients works to build partnerships, to Stop TB in the community, which is why, it is Component 5 of the WHO Stop TB Strategy. It is not however, in the RNTCP strategy.

I ask you all, as members of the TB Association of India, to endorse the Patients Charter, that this honorable body will formally recommend its adoption by the RNTCP and all private practitioners in India. I hope the Association can act immediately on this – and copies of the Charter are available after this inauguration; Please see Mr. Case Gordon former President of World Care Council, for your copy of the patients charter - also available on the WHO website but not on the RNTCP Website.

We need patient and community involvement and empowerment, otherwise all efforts to stop TB in my country will not be successful, and remain as just nice words and unattainable targets. Will you help us to participate? Will you allow us to take responsibility? Will you assist us to attain our rights to dignity, drugs and diagnostics?.

These questions are the beginning of the national dialogue between professionals and patients. I ask you, individually, to participate in this dialogue – come talk to me or Loon or Case or any of us.

WE ARE ALL IN THIS TOGETHER
THANK YOU