

Imphal, Manipur (India)
Dated, the 15th February, 2012

To
Mr Anand Grover
UN Special Rapporteur on Health.
New Delhi

IN THE MATTER OF :- *An urgent appeal praying for facilitating access to testing, diagnosis and treatment for Hepatitis C Virus (HCV) in Manipur State (India).*

Honourable Sir,

We, the undersigned, take this opportunity of introducing ourselves as People Living with hepatitis C with majority of us co-infected with HIV as well, from the state of Manipur which is located at one of the remotest corners of North-East India bordering Myanmar. We also have a history of drug use, through which hepatitis C virus (HCV) transmits, and many are managing our lives through Opioid Substitution therapy

As you are aware, People Living with hepatitis C have extreme difficulties and hardships in trying to access HCV testing, diagnosis and treatment in spite of widespread prevalence. Data from independent studies that has been carried out by researchers and medical professionals shows an extensively alarming prevalence of HCV in the state. Some of the studies indicated prevalence rates of 92%¹, 90.4%², 92% in Imphal and 98% in Churachandpur³, 78%⁴ and yet, there are no responses from either the Union Government of India or the State Government of Manipur to respond to the HCV epidemic. We as a collective group request upon you in your position to address these issues and barriers through proper government channels.

Currently, many barriers impedes People who Use Drugs (PUD) and people living with hepatitis C from accessing testing, diagnosis and treatment and to be informed about our status on hepatitis C; take an informed decision on whether to opt for treatment and knowing how well we are living with the infection. Some of the facts are:

- a) Neither the Union Government of India nor the State Government of Manipur provides access to testing for HCV as a part of any public health program responding to drug use knowing well the correlation between HCV transmission and Drug use.
- b) Non availability of any treatment guideline or counselling protocol leaves the medical professionals, health care service providers and person living with HCV uncertain on the support system and clinical care required further.

¹ Prevalence of HCV & HBV infection amongst HIV seropositive intravenous drug users & their non-injecting wives in Manipur, India. Saha MK, Chakrabarti S, Panda S, Naik TN, Manna B, Chatterjee A, Detels R, Bhattacharya SK

² Devi KS, Singh NB, Mara J, Singh TB, Singh YM. Seroprevalence of hepatitis B virus and hepatitis C virus among hepatic disorders and injecting drug users in manipur - A preliminary report. Indian J Med Microbiol 2004;22:136-7

³ Indian Council of medical Research (ICMR) 2001

⁴ Mahanta J, Medhi GK, Paranjape RS, Roy N, Kohli A, Akoijam BS, Dzuwichu B, Das HK, Goswami P, Thongamba G: Injecting and sexual risk behaviours, sexually transmitted infections and HIV prevalence in injecting drug users in three states in India. *AIDS* 2008, 22(Suppl 5):S59-68

- c) Lack of information amongst PUD and also the general population at large has put the risk of HCV becoming a public health disaster in the next few years.
- d) Lack of treatment education and preparedness amongst people who are living with HCV has jeopardized patients decision making ability to prevent further infections, taking care of themselves and also the decision to opt for treatment or not.
- e) The current cost of the standard of care (Pegylated interferon and Ribavirin) is so prohibitively high that simply people cannot afford it and many continues to die of a curable/treatable disease.
- f) No recognition as yet either from the Union Government of India or the State Government of Manipur on the need to respond to issues around hepatitis C.

These debilitating factors deprive the basic Human Right of free access to health care and life. It is pertinent to mention herein that though PLHIV live longer on antiretroviral treatment, the report dated 6th August, 2010 submitted to the General Assembly of the United Nations by the Commission concerning the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health adequately documented the growing concerns on the need for an increased focus on Human Rights within drug control measures and their various impacts on the increased focus on the enjoyment of the Right to health. The global AIDS epidemic has received its ample share of attention and intervention, without prejudice to its significance and impact. However, the severity, pernicious implications and impact of HCV infection has been grossly underestimated mostly due to lack of accurate data and fewer studies assessing the prevalence of HCV, co-infection with HIV, and existing policies, if any, are not adequately addressing this rapidly growing epidemic that is needlessly causing the deaths of many among the PUD community.

We repose our firm convictions in the belief that such barriers impeding the fight against HCV infection may be overcome with a Right-based approach to life and health, thereby giving way to freer access to healthcare and treatment facilities, including affordability of current standard of care– Pegylated interferon (PEG-IFN) and Ribavirin (RBV).

Moreover, various studies have perceptibly invalidated the major argument that the twin combination drugs are too expensive after taking into consideration the long-term cost factor, both economically and in terms of patient quality of life, of **not** treating HCV. The main economic benefit to treating people with HCV is that it lowers the cost and amount of medical care need for IDU with HCV, including expensive treatment for severe liver disease.⁵ Moreover, successfully treating people with HCV prevents new infections owing to the simple equation that people who have been cured cannot transmit HCV to others.

Therefore, we the undersigned appeal to your good office for facilitating with the Union Government of India and the State Government of Manipur, where appropriate, to,

- Integrate HCV testing and diagnosis in the current HIV program, for all who needs it, and especially people with a history of drug use.

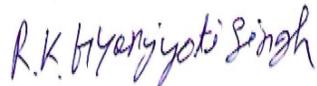
⁵ Thai AIDS Treatment Action Group (TTAG), Esq., Illuminating a Hidden Epidemic: The Public Health Crisis of HIV/HCV Co-infection Among Injecting Drug Users (IDU) in Thailand.

- Develop a national guideline on HCV testing, diagnosis and treatment, including, counselling protocols.
- Include Pegylated interferon and Ribavirin on Indian Essential Medicines Lists.
- Design and implement government aided programs to provide HCV awareness, prevention, treatment education and preparedness.
- Negotiate for price reduction with patent holders of Pegylated interferon.
- Providing national level data collection on HCV incidence and prevalence among Indians, with special emphasis on the North-East region. Increase political commitment and support to produce generic versions of Pegylated interferon.
- Increasing political commitment and support for the Indian Government officials to exercise legal, TRIPS flexibilities in order to gain access to cheaper HCV treatment.

We hope that you will take up the matter with the respective Government departments both at the central and state level to ensure that People's Right to health are upheld and protected.

We look forward to hearing from you.

Yours Faithfully,



(Mr. R.K Gyanjyoti)
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