>

Title: Need to have proper treatement and prevention policy for Haemophilia patients in the country.

DR. RAM CHANDRA DOME (BIRBHUM): With your kind permission I would like to raise an important health related problem. Sir, looking after the health condition of persons suffering from Hemophilia in our country -- though is not a major problem -- but it is un-cared for. As per WHO standards, the incident rate is one per 10,000 persons. In this backdrop, at least 1,25,000 persons are suffering from Hemophilia disease, but till today only approximately 10,000 persons have been identified as suffering from this disease. Out of these 10,000 patients 7,500 have been identified by non-Governmental organisations like Hemophilia Federation of India[R7] .

Sir, the huge difference in the number of identified *versus* total estimated is because of lack of diagnostic facilities in our country. The issues related to this problem are many. Many persons with hemophilia also suffer from HIV/AIDS and critical viral disorders. It leads to permanent disability if the treatment is not provided in the childhood. A medicine called Anti-Hemophilia Factor is the remedy for this disease. The disease is not caused by any organism or metabolism. It is totally a genetically inherited disease. It continues for life long. So, only Anti Hemophilia Factor is the remedy. With this drug, the patients can maintain their normal life. Sir, I know that you are also concerned about this problem as you have told us about this disease.

So far as the treatment is concerned, the recommended minimum dosage of Anti Hemophilia Factor as per WHO guidelines is 20,000 units per person per annum. In our country, the average consumption is pathetically low at 1,500 units only. This is because most of the persons with hemophilia fall under the poorest of the poor category in our country and they cannot afford the expensive medicine. So because of the terrible lack of access to affordable medicines, they are becoming HIV/AIDS, Hepatitis B and Hepatitis C virus positive. They are also becoming disabled.

Therefore, action is very much required in this respect. The Ministry of Health and Family Welfare needs to intervene and provide adequate funds for procurement of Anti-Hemophilia Factor at the Central level. It should also include Hemophilia Care in the National Health Programme. This would prevent spread of HIV/AIDS and disability amongst persons with hemophilia.

Another part of this relates to the social justice. The persons suffering with hemophilia should be covered under the Persons with Disability Act. The national amendment committee has already recommended this in the year 1998 but this has not yet been covered under the Persons with Disability Act, 1995. So I urge upon the Government to take urgent steps.

MR. SPEAKER: This is a matter which should be looked into.