

WORLD LEPROSY DAY

GO-NGO co-op needed to eliminate the disease

Parvez Babul

ON NEXT Sunday, 25 January 2015, the World Leprosy Day will be observed across the world. Though leprosy is curable yet there are still millions of people around the world living with this disease and disability. The people in poverty-stricken countries like Bangladesh and other countries are affected most due to poverty, stigma and lack of collaboration and coordination between government and NGOs.

The Leprosy Day was initiated in 1954 by French philanthropist and writer Raoul Follereau, as a way to raise global awareness of this deadly ancient disease. Follereau believed that those affected by leprosy should receive the same respect, dignity and quality of care as any other patients. Additionally, he wanted greater awareness of the disease in order to change attitudes, superstitions and to reduce stigma.

Leprosy is a chronic disease affecting the nerves and the skin. If not treated, sufferers can become blind, lose the sensations in their hands and feet; and become prone to a disability through the threat of injury. Leprosy is one of the oldest diseases known to humankind. It is also known as Hansen's disease, named after Norwegian physician Gerhard Henrik Armauer Hansen. He debunked the prevailing notion of the time that leprosy was a hereditary disease. He showed that the disease had a bacterial cause instead. For thousands of years, people with leprosy have been stigmatized and considered to be at the extreme margins of the society.

The aim of World Leprosy Day is to change this attitude and increase public awareness of the fact that leprosy can now be easily prevented and cured. Government of Bangladesh, NGOs/ Civil Society Organizations, health workers, and media people must work together with effective collaboration to make our Bangladesh free from leprosy. The World Health Organization has urged every state including Bangladesh to give emphasis on leprosy elimination soon.

To realize the plights of the people with leprosy and lack of treatment facilities at government hospitals in Bangladesh, let us go through a case study of one Hamela Begum (60) of Bhola District. She was a day labourer. Due to disability for leprosy she looks ugly; people started to neglect and avoid her. Hamela noticed few pale anaesthetic skin patches on her body about 10 years ago. She did not know the disease. She avoided it and was doing her normal work, because people of that area were actually ignorant. After three years, she went to the local village doctor to show her skin patches and numbness on her hand. The village doctor was unable to diagnose leprosy. Meanwhile, she had to spend huge hard-earned money for treatment, but every effort went in vain. After that she faced extreme poverty and she got claw fingers; both eyes were lagophthalmos (inability to close the eyelids completely), and got ulcer on the right foot along



with other complications. But unfortunately she did not get proper treatment anywhere. In October 2013, Coordination for Advocacy (CAN) Project of the Leprosy Mission International-Bangladesh (TLMI-B) organized an Extended Contact Survey in Bhola District through community volunteers in cooperation with HEED Bangladesh and found Hamela with disability. Though last of all Multidrug Treatment (MDT) was given to her by civil surgeon of Bhola. But in reality, there are thousands of Hamela Begum in our country; poverty itself is a disease for them. So getting proper treatment of leprosy is out of their capacity. Considering the lack of awareness, ignorance and vulnerability of the poor patients, service-providers/ health workers should go forward to the most vulnerable and disadvantaged people like Hamela. We should help them get MDT and other reconstructive surgery facilities in government hospitals through existing medical setups.

The important message from this story is that though the government has declared Bangladesh as a leprosy free county on 2008, but all the government supports were reduced from those districts, though there are still many patients like Hamela. MDT is unavailable in that district. MDT was carried there by CAN project and distributed among the patients like Hamela. She is now hoping to lead a healthy life by the support of CAN project. That is why it perfectly proves that GO-NGO collaboration is must for a leprosy-free Bangladesh.

It is important to mention that there are no government health staffs to treat leprosy at all district and upazila level hospitals. The relevant government health staffs are unable to create public awareness at field level to early case detection. Moreover, Bangladesh government has only three leprosy hospitals; 30-bed leprosy hospital and institute in Mohakhali, Dhaka; 20-bed leprosy hospital in Nilphamari, and 80 -bed leprosy hospital in Sylhet with inadequate medical facilities. Considering the urgent requirement, the government should immediately fulfil the required medical facilities with skilled health practitioners increasing the number of hospitals to provide services for leprosy case and complication management.

There are approximately 30,000 people with leprosy in Bangladesh. Annually, on an average 4000 to 5000 cases are detected in the country. There are about 34,000 to 35,000 people in the country with deformity caused by leprosy.

In fact, for a leprosy-free Bangladesh collective efforts should be taken to promote awareness for reducing stigma and discrimination against people infected by leprosy.