

India has no accurate data of genetic disorders

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"No country-wide or state-wise data on genetic conditions is maintained by the government of India. Also, the government has no specific strategy for genetic counselling and treatment for genetic diseases." This was stated by the Minister of State for Health and Family Welfare, Mr Abu Hasem Khan Choudhury while replying to a query raised in the parliament on March 08, 2013.

The minister while referring to certain figures collected by the Indian Council of Medical Research (ICMR) also mentioned, "However, as reported by ICMR, there may be 1 lakh thalassemics and the same number of sickle cell disease patients and about 65,000 cases of haemophilia in India. It is estimated that about 10,000 new thalassemia cases, 8,000 new sickle cell anemia patients and 5,000 new haemophilia patients are born each year in India."

The minister also highlighted the various initiatives taken by the ICMR in this direction. Among these are the carrying out of National Task Force studies on hemoglobinopathies. Again the micro and macro epidemiologic data on these diseases has been developed. ICMR has helped to set up prenatal diagnostic facilities for haemoglobinopathies in five centres in the country in the states of Maharashtra, Gujarat, West Bengal, Karnataka and Punjab.

The proper record of genetic disorders can certainly be beneficial for the researchers and the medical practitioners in the long run. With the government itself admitting the lack of such database, the time is right is to have coordinated efforts from all the stakeholders to create it as soon as possible.