Policy boosts care for blood disorders

People living with Thalassaemia, sickle cell anaemia and other variant haemoglobins can now look forward to better screening and treatment, based on the Union Health and Family Welfare Ministry's new policy.

The Ministry recently released a policy on the Prevention and Control of haemoglobinopathies in India.

Supported by the National Health Mission, Blood Cell and the Rashtriya Bal Swasthya Karyakram, the guidelines provide for screening of pregnant women during antenatal check-up, pre-marital counselling at college level and one-time screening for variant anaemia in children.

The Minister of State (Health and Family Welfare) Anupriya Patel stated this in a written reply in the Rajya Sabha on July 18.

Thalassaemia and sickle cell anaemia are the most frequently encountered 'rare blood disorders' in the country and impose a significant economic burden on families. The policy aims at creating treatment protocol benchmarks, to improve the quality of life of patients.

It is also a guide on prevention and control, which includes antenatal and prenatal testing to reduce the incidence of live haemoglobin disorder births (currently pegged at 10,000-15,000 live births a year).

Using public health awareness programmes and education, it highlights various haemoglobinopathies. The guidelines include the creation of a national registry to plan future patient services. The registry will also collect useful data, such as the location of patients to identify areas of high concentration, ethnicity or other characteristics, age distribution, records of deaths and their cause.

Shobha Tuli, president of the Federation of Indian Thalassaemics, who contributed to the policy, said it was a big step to prevent haemoglobinopathies.

'Provide all drugs'

"Since not more than 20% of patients can afford treatment, the government should ensure that all patients get it free. Such free treatment is given in States such as Rajasthan, Uttar Pradesh, West Bengal, Odisha and Karnataka besides Delhi, and others should follow suit. All chelation drugs should be made available free because one drug does not suit all," she said.

The policy, however, makes no reference to carrier testing for relatives of patients.

Namitha A. Kumar from the Centre for Health Ecologies and Technology (CHET), who is also living with Thalassaemia said people with the genetic disorder unknowingly pass it on to their children, as preventive checks are not the norm in India.

"In Pakistan, a law making carrier testing compulsory for relatives of Thalassaemia patients was passed in February. A similar system is in place in Dubai, Abu Dhabi and Saudi Arabia. I wish it could be made compulsory here too," she said.

Cecil Reuben Ross, Head of the Department of Medicine and Haematology in St. John's Medical College Hospital, hailed the policy but said testing had to be voluntary.

“There is more awareness about the condition now, especially after the Indian Council of Medical Research took up screening of 50,000 antenatal mothers and 50,000 college students a few years ago. “Testing cannot be made compulsory and people should opt for it. A concerted effort by people as well as government will help ,” Dr. Ross said.

Lifestyle-related risk factors are being cited, compounded by an inadequate number of treatment centres in the region

Without policies to stop the worrying spread of antimicrobial resistance, the mortality rate could be disturbing

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