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VARIETY

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Focusing on the need to prevent and treat birth defects among newborns

Recently, the helpline of the Spina Bifida Foundation in Mumbai received a call from the father of a six-day-old newborn from a faraway town near Jodhpur in Rajasthan. The distraught father mentioned that his wife had delivered a baby girl a few days ago, and that the girl had a swelling on her lower back and was unable to move her legs properly. Doctors in Rajasthan told him that “nothing could be done and to take the child home.” Except for the bubble-like swelling on her back and weakness in her legs, the baby was otherwise normal. This girl was born with a birth defect of the spinal cord called spina bifida.

Dr Santosh Karmarkar (M. Ch. Consultant Pediatric Surgeon, Lilavati Hospital and Founder Trustee of Spina Bifida Foundation, India) says, “Spina bifida is a type of a group of birth defects of the central nervous system (which includes the brain and spinal cord), collectively called Neural Tube Defects (NTDs). NTDs are the commonest birth defects in India. Globally, around 300,000 births are affected by NTDs, and a large proportion of these cases occur in India. Most of these occur due to a deficiency in the mother-to-be of a simple vitamin called folic acid and can be easily prevented by an adequate intake of the vitamin before and during pregnancy.”

Unfortunately, the family from Rajasthan had neither heard of folic acid nor of spina bifida. Each week, the helpline of the foundation receives such calls from young parents from all over India. Additionally, it is contacted by families who have elder children who were born with this birth defect and are now living with varying degrees of childhood paralysis, urinary and bowel incontinence because of spina bifida. In India, it has been estimated that at least four to five children out of every 1,000 may be born with these defects.

He adds, “Like spina bifida, there are many other birth defects that appear as structural or functional abnormalities at the time of birth. They can be caused by several risk factors, including genetic, environmental or a combination of the two. Major birth defects such as heart defects, NTDs, Down's Syndrome etc. can have complications and require lifelong care.”

The World Health Organization (WHO) states that birth defects are “preventable through improved nutrition in women of reproductive age, prenatal counselling and folic acid supplementation, adequate antenatal care, including vaccination

and screening, prevention and treatment for infectious diseases during pregnancy, like syphilis and rubella.”

Since 2015, March 3 is recognised as ‘World Birth Defects Day’ and its aim is to raise awareness about birth defects in countries worldwide. NTDs form during the fourth week of pregnancy, an early period before most women are prescribed

iron and folic acid tablets. In India, about 130,000 births are impacted by NTDs every year; and folic acid can avert about 90 per cent of these cases. Folic acid is known to play a crucial role in promoting a healthy central nervous system during the early weeks of gestation.

Dr Karmarkar says, “Fortunately, we have ways to improve folate levels in the human body through simple measures. The mother-to-be taking a simple folic acid vitamin pill in adequate doses prior to conception is one way, but requires awareness and pregnancy planning. One of the most efficient ways to build adequate stores of folate in the body is by eating foods that are fortified with folic acid. Food fortification seems to have an advantage reaching most vulnerable groups of women of reproductive age at the right time during pregnancy to prevent NTDs. On World Birth Defects Day (March 3), we urged concerned authorities to update the standards of folic acid and B12 food fortification, so we are able to deliver effective public health measures to women of reproductive age and contribute to healthy pregnancies in India.”

He explains, “Children born with spina bifida and their families face an uphill task from the

beginning. Firstly, there is a generalised lack of awareness about the proper and timely treatment of this condition. Thus, many children do not receive the right treatment. Major clinical effects of spina bifida are varying degrees of paralysis of the legs or lower limbs, accumulation of excessive fluid in the brain (called hydrocephalus), urinary and bowel incontinence, bone and muscle deformities. The full and proper medical treatment and rehabilitation entails specialised operations during the first five years of childhood and then regular medical care at least until they reach adulthood. The silver lining to this so-called dark cloud is that almost all these children have a normal IQ. Thus, if proper and prompt treatment is available, they will lead productive and happy lives.”

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Dr Santosh Karmarkar

NEURAL TUBE DEFECTS ARE THE COMMONEST BIRTH DEFECTS IN INDIA. MOST OCCUR DUE TO A DEFICIENCY OF FOLIC ACID IN THE MOTHER-TO-BE AND CAN BE PREVENTED BY AN ADEQUATE INTAKE OF FOLIC ACID AND VITAMINS BEFORE AND DURING PREGNANCY