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Need for a National Newborn Screening Programme in India: Pilot Study Data

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Abstract : Newborn screening (NBS) is a part of routine newborn care in many countries worldwide to detect early any rare treatable conditions and inborn errors of metabolism (IEM). India has not started this program yet. In an attempt to understand the challenges in implementing a national newborn screening program in India, we initiated a pilot newborn screening project funded by the Government of Canada. Along with initiating the newborn screening at Kasturba Hospital, Manipal in South India, for screening six disorders (Congenital Hypothyroidism(CH), Congenital Adrenal Hyperplasia (CAH), Galactosemia, Biotinidase deficiency, Glucose-6-Phosphate Dehydrogenase deficiency (G-6PD) and Phenylketonurea), we also studied the awareness of various stakeholders on the newborn screening. In a period of nine months from August 2017 to March 2018 we could screen 1915 newborns (999 male and 916 female). The result showed that there were seven babies screened positive. This interim result points to an incidence rate of 1 in 270 children for these rare disorders collectively. This includes three confirmed cases of CH, two cases of G-6PD deficiency, and one case each for Galctosemia and CAH. A questionnaire based study to understand the awareness among various stakeholders revealed that there is little awareness among parents, adolescents and anganwadi workers (public health worker). The interim data points to the need for a national newborn screening programme in India. There is also an immediate need to undertake large-scale awareness programme to create knowledge on NBS among the various stakeholders.

Keywords : awareness, inborn errors of metabolism (IEM), newborn screening, rare disease
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