

## EDITORIAL

# Newborn screening in Bangladesh - Awareness is essential

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Newborn screening is the process of testing newborn babies for genetic, endocrinologic, metabolic and hematologic diseases. Dr. Robert Guthrie, American microbiologist in the 1960's first used dried blood spot testing. In late 1972, Dr. Jean Dussault MD, developed a new blood test for congenital hypothyroidism. Dried blood spot test is used now for PKU, cong. hypothyroidism, sickle cell disorder, HIV, galactosemia etc. The development of Tandem Mass Spectrometry screening by Edwin Naylor and others in the early 1990s led to a large expansion of potentially detectable congenital metabolic diseases that affect blood levels of organic acids. This Tandem Mass Spectrometry detects more than 31 disorders of urea cycle, amino acid, fatty acid, lysosomal storage diseases with a single specimen of blood. Criteria of newborn screening are ethically safe simple and cost effective, clinically & biochemically well-defined disease, known incidence in population and diseases associated with significant morbidity & mortality, and also effective treatment should be available. This screening test is performed on one tiny sample of blood obtained by pricking the baby's heel. The blood is allowed to dry on a piece of filter paper which is sent for testing to the Lab. Western countries started newborn screening long back, even our neighbouring country Thailand started 40 years back but screening for number of diseases varies in different countries. India, Pakistan and Bangladesh are doing test to detect cong. hypothyroidism and finding out its incidence with the help of International Atomic Energy Commission. Other countries like Nepal & Bhutan are still unable to start this test.

Newborn screening is very important in our country although we don't have national data of incidence of

any metabolic disease but if we look at recent Goa study in India which was done by Tandem Mass Spectrometry shows incidence of inborn error of metabolism is 1:500 that means we may have similar incidence that is about 300,000 out of 150 million people, are suffering from inborn error of metabolism in our country, among them only cong. hypothyroidism is about 75,000 (as incidence is 1:2000). A large study is going on by Atomic Energy Commission that includes 300,000 children all over Bangladesh to see the incidence of cong. hypothyroidism. If we do a rough estimate then we can see what a tremendous financial load is bearing our country. Suppose if we spend at least 2000 taka per head per month that cost about 7200 million taka per year for rearing up of these 300,000 people of inborn error of metabolism and about 1800 million taka per year only for children suffering from congenital hypothyroidism. As because it is an individual family spending we can't see it, but it is a national expenditure.

If we estimate the total cost of nationwide newborn screening: we have 4000000 birth/year i.e, about 11000 birth/day. Cost of a single test is taka 200, so total cost of newborn screening is  $11000 \times 200 \times 365$  days = 800 million per year approximately where as total cost of rearing up of 75000 child with congenital hypothyroidism is  $75000 \times 2000 \times 12 = 1800$  million taka per year. At this moment Tandem Mass Spectrometry is the best method for newborn screening to detect many diseases of inborn error of metabolism with a tiny drop of blood but due to high cost it is not fully implemented even in many developed countries, so it is unimaginable in our country at this time.

Many countries of the world are doing newborn screening to detect congenital hypothyroidism only

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as its incidence is high, so after seeing this tremendous national financial loss we should start it immediately. Not only financial loss there is a lot of family burden socially and emotionally. Now how can we start it, answer is newborn screening by heel prick dried filter paper test(Guthrie test). Before introducing large scale heel prick newborn screening for cong. hypothyroidism, the developing countries' newborn screening (DCNBS) can be adopted. We can start it immediately by increasing awareness among people: sending SMS in bengali via mobile phone, health bulletin in TV, Radio and health news in news paper. Newborn screening should also be included in Integrated Management of Childhood Illness (IMCI). Our field worker will visit a neonate on day 3 and 7, will ask three questions; a) how many times baby passed stool in these 7 days after birth if it is less than 2 - 3 times and hard stool, b) whether the baby has good cry, if the answer is no, it is broken

voice or little cry, c) how is the movement, if it is less or the baby is sleepy. Out of these three if question 'a' is positive along with question 'b' or 'c'. field worker send this baby to upzila health complex. where doctor will do one test - X-ray of left knee joint and if it shows absence of femoral epiphysis, start thyroxine and then send the baby to specialized centres for further investigation, treatment, counseling of parents and for long term follow up. Ministry of Health will be the Chief Coordinator and different Medical Colleges, Dhaka Shishu Hospital and NGOS will be given the responsibility of different districts for monitoring DCNBS programme. I am giving importance to detect congenital hypothyroidism within 2 weeks of life because if we can start treatment within 21 days of life with good compliance and adequate follow up, this baby will have normal life with normal physical, social and mental development.