

Newborn Screening: Why is Asia Lagging Behind?

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Newborn screening is the most important preventive public health programme of the 21st century. It is implemented in majority of the developed countries. India and many countries in Asia are yet to start any publicly funded programme despite this having been established practice in many countries for over 50 years.

The purpose of newborn screening is to identify babies with biochemical or enzymatic disorders, which are NOT obvious clinically even if examined by an experienced Neonatal Paediatrician; and if present can lead to lot of morbidity and mortality in the newborn. It can be described as a silent killer. Detection of a particular disorder must have a clear benefit for the baby and be cost effective when compared to the cost associated with delayed treatment [1]. These criteria have been put forth by Wilson & Jungner & adopted by International Society on Newborn Screening (ISNS), and are being followed by many countries for implementation of screening around the world [2].

Most people in India do not know newborn screening; including many medical professionals - The recent survey in 2006 in Karnataka State in India - included 602 obstetricians, 209 paediatricians, 34 neonatologists, 223 nurses and 210 laymen. The results showed that majority of the obstetricians (79%) were not aware of the newborn screening programme [3]. The study conducted in California showed that improving communication by the state with public regarding newborn screening is going to make a difference to the implementation of the programme [3].

Once a country decides to implement screening - then what to screen for This depends upon several factors - epidemiology, incidence of the diseases, severity of the diseases on the affected person, and the cost of the screening along with facilities for the treatment [4]. We don't have enough data to say which diseases we need to screen for? Each country has to make its own choice of which disorders they need to screen. Some of the European countries screen for anywhere between 6 to 8 disorders. Australia and USA are on the top of the list with screening for nearly 50 disorders including Tandem Mass Spectrometry (TMS). The Asia-Pacific region has a long history in this too - the late Emeritus Professor Wong

Hock Boon in 1965 initiated cord blood Glucose 6 Phosphatase Dehydrogenase (G6PD) screening in Singapore, which virtually eliminated kernicterus (Brain damage due to high levels of jaundice in a newborn baby). Philippines screens for 4 common disorders in their country - hypothyroidism, congenital adrenal hyperplasia, G6PD and Galactosaemia. China has recently made it mandatory for all the Obstetricians and Paediatricians to provide the written information to all parents so that they can make informed choice. Though these are good examples, most Asian countries do not have any national programme for screening.

In India, currently we have enough data to suggest that we can implement screening for 4 major diseases, which are either making our babies die or disabled for no fault of theirs nor their families [5-9]. This is happening because of ignorance and also apathy from the Government. The four diseases which should probably be screened for in India are Congenital Hypothyroidism (where in if a baby has this - the baby will become mentally retarded by 1 month of age), G6PD

Deficiency (if the enzyme is deficient in the baby, the baby can develop severe jaundice making the baby deaf, disabled and also permanently retarded), Congenital Adrenal Hyperplasia (CAH)- is another disease where in a deficiency of an enzyme can make girls look like boys and boys can be deceptively normal, until they die! Galactosaemia - is comparable to Diabetes in adults - a baby who is deficient in an enzyme - Galactose Phosphatase - will not digest a sugar called Galactose (Present in Breast and other milks in large quantities) - leading to severe high levels of the sugar called



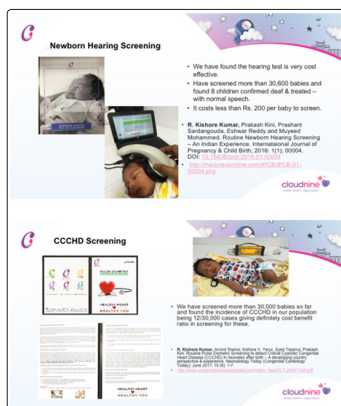
Galactose – where in it causes brain damage and also predisposes the baby for severe infections leading to disability or death.

The incidence of these 4 diseases is much more than the rest of the world and the cost of the screening for these 4 diseases should not be more than Rupees 500 (less than \$USD8 – but most people try and make a huge profit when they offer these 4 diseases screening – which leads to it being rejected by many people for the cost + lack of awareness [10-12].



Though systematic neonatal screening for congenital hypothyroidism was introduced in the early 1970s in many countries; in India an estimated 10,000 babies are born with congenital hypothyroidism every year, yet there is no screening programme for this.

Other screenings include Newborn Hearing Screening – which has virtually eliminated the “dumb” in the world, as people become dumb only if they are deaf and if deafness can be identified within 3 months of birth, the babies can be effectively treated to make them normal rather than being dumb [13].



Congenital Heart Screening is another simple area, which costs less than Rs. 100 per baby – has virtually eliminated the deaths due to severe cyanotic congenital heart diseases in the last few years [14].

The list is growing each year, but India has to make the right decision in this to save our future generation and lot of “high risk” babies can be screened for metabolic diseases which can help reduce the neonatal mortality and

infant mortality rates in a big way.

India ranks number 1 in many things – like infant mortality rates in Asia and at the same India’s GDP is one the highest in Asia – so it is the right time for us to take steps in the right direction to proceed in this and make a national plan for newborn screening – and rest of the world will follow us. Asia accounting for more than 2/3 of the population in the world has to decide about their priorities.

There is enough data present in India to start the screening process for 4 diseases and probably improvise adding few more diseases later – just like Philippines have started. Asia should follow the rest of the world in trying and saving lives – because NEWBORN SCREENING SAVES LIVES.

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