

A New World with New-born Screening

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Introduction

Newborn screening is such an innovative preventive public health programme – that has saved lives in so many countries. When I first heard about it, I just wanted to read more about it as it sounded interesting. A drop of blood is taken on a filter paper from the baby and the same is tested in a lab subsequently for a disease. This started with one disease but now, it has literally spread for more than 50 diseases in many countries. I decided to study the knowledge, attitude and practices of this in Bangalore, a Cosmopolitan city [1].

Materials and Methods

A simple questionnaire was prepared asking people whether they are aware of newborn screening, what diseases are available for screening and what is its purpose? I gave the survey initially to people in my school (my friends, teachers, allied staff), then in my apartment complex, then to my relatives and after that I asked these questions whenever we traveled in airports, railway station and bus stations. Over a period of 3 months, I collected questionnaires from 472 people in Bangalore [2].

I also sent a question to 23 hospitals in Bangalore asking whether or not they do newborn screening. Four hospitals responded with a yes, fifteen hospitals didn't know anything about it and four hospitals refused to give any answer.

Results

Out of 472 people across strata – the following were the answers:

- Awareness of newborn screening – only 44 out of 472 people knew that there was something like newborn screening.
- What diseases are available for screening? None knew of them.
- What is its purpose? Three people said it is another test which like BCG – a vaccination given to babies at birth. They had no idea of its purpose.

9.32% (44/472) people knew something like newborn screening. But they didn't know the details. Many thought it is something the Paediatrician did at birth if it is important and

they don't have to worry about it. None of them knew about its real purpose.

17% hospitals (4/23) in Bangalore city knew and were practicing newborn screening. Rest were either not doing it nor were aware of it.

Discussion

Newborn Screening “saves lives” and has been doing so for over 50 years around the world. March of Dimes is an organization founded by President Franklin Roosevelt in 1938, as the National Foundation for Infantile Paralysis, to combat Polio. It's a nonprofit organization that works to improve the health of mothers and babies by preventing birth defects, premature birth and infant mortality. It describes the newborn screening as some special tests for serious but rare conditions that your baby has at birth – which include blood, hearing and heart screening. Babies can be born with a health condition but may not show any signs of the problem at first. If a health condition is found early with newborn screening, it can often be treated. This makes it possible to avoid more serious health problems in the future including early death or disability[3].

Ideally new-born screening should happen before the baby leaves the hospital.

Most new-born screening is done with a blood test. A health care provider pricks the baby's heel to get a few drops of blood on to a special filter paper. This is sent to a centralised lab which analyses the sample and gives the results within 3 days to the doctor. Following the timeframes is critical in case the baby has a disorder that needs to be identified and treated as early as possible. For example, if a baby has an under active thyroid, the baby needs to start treatment within 10 days – otherwise the baby will suffer – and the IQ will never be normal. Currently it is estimated that more than 10,000 babies are born with underactive thyroid in India and they are not detected at birth even after this test has been available in the world for over 5 decades and it costs less than a dollar to the test each baby. Similarly, if a baby has an enzyme deficiency to digest protein – they build metabolites in their blood – which may allow them to become sick and doctors can get confused with the baby having an infection and the babies die within few days. In India, with so

many babies dying of infections, one wonders how many of these babies could be dying due to these enzyme deficiencies?

This blood test seems very interesting to me as a student in year 12. A drop of blood can analyse and detect so many diseases which can prevent death and disability makes me feel enchanted. More so this can help the country to progress to a healthy population. It always puzzles me as to why any country, especially like India, even after 5 decades has no public education about this? Why is this not made mandatory in all government hospitals – and as a policy not implemented?

New-born screening is a successful preventive public health activity. In 2008, the US Congress demonstrated once again the broad based support for this important health activity with a unanimous vote for the New-born Screening Saves Lives Act (P.L. 110-204). To fulfil the intention of the law, HRSA and CDC were funded to help support state new-born screening programs and to provide technical assistance in the form of quality assurance for laboratories responsible for evaluating new-born screening tests for heritable disorders that can be treated if the condition is identified immediately after birth [4].

Basic facts of new-born screening

- New-born screening is the early identification of infants affected by certain genetic, metabolic, hormonal and/or functional conditions.
- Screening detects disorders in new-borns that, if left untreated, can cause death, disability, intellectual disabilities and other serious illnesses.
- If diagnosed early, these conditions can be successfully treated.

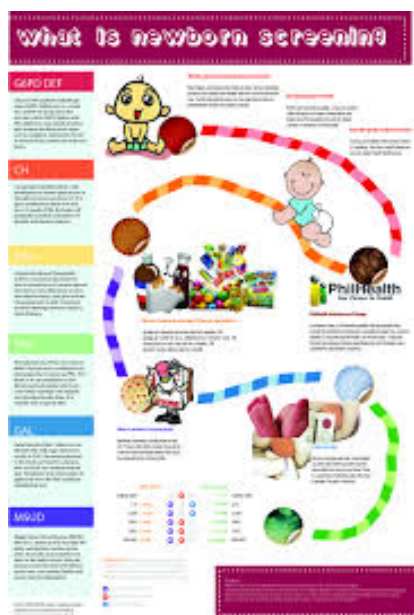


Figure 1: What is newborn screening.

- The American College of Medical Genetics, the American Academy of Pediatrics, the March of Dimes and the

Secretary's Advisory Committee on Heritable Disorders recommend screening all new-born for 29 treatable disorders and reporting on an additional 25 disorders (Figure 1 and 2).

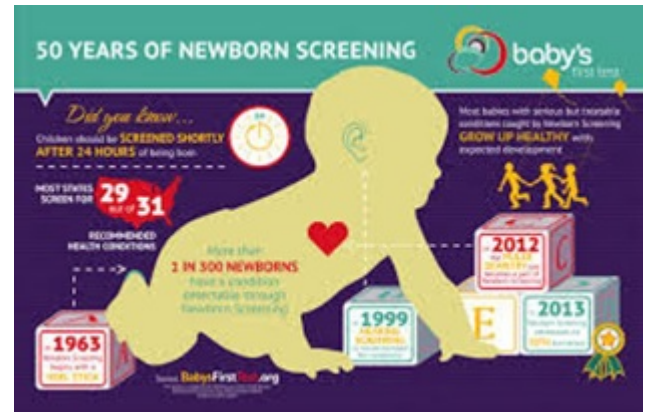


Figure 2: Fifty years of newborn screening.

China has made it mandatory to make this information available to all the prospective parents when they visit their Obstetricians during pregnancy, failing which it is considered as negligence. No laws have been implemented in India to promote new-born screening and our babies are continuing to suffer and die from preventable deaths even after India being “Silicon Valley of the world” – Bangalore being a cosmopolitan city and the Silicon Valley of India – is so ignorant, I can't imagine the rest of India.

It is high time India take notice of this – public private partnerships in this field and the media should learn and write things to educate people rather than reporting the crime and accidents everyday which gives a gloomy picture for the young minds rather than educating them. New-born screening is one of the small steps that can be taken to revolutionise the standard of global health.

Contribution

Adithi Kumar conceptualized the idea and the report, wrote the initial manuscript; Dr. R. Kishore Kumar critically reviewed the manuscript, approved the final draft and will act as guarantor of the paper.

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