Challenges which invite discussion are the feasibility of coverage in less well developed areas, hilly terrains and the home deliveries and tribes protected by the inbreeding and social isolation. Tracking of children born to migratory population or high-risk mothers referred to tertiary care hospitals is another challenge. MCTS (Mother child tracking system) an initiative launched by the Government of India once in full implementation may play a pivotal role in this program.

Currently tracking a screen positive newborn is difficult due to the ill informed need and understanding for follow up. Availability of good counselors and a well integrated follow up system needs to be developed so that all screen positive babies can be followed up. The non availability of diets needs to be simultaneously addressed so that we can gear up for the expanded phase later. Making emergency drugs easily available is also likely to ease the process and contribute to improvements n neonatal mortality rate. Generating ethnic cutoffs, ensuring quality compliance, improving availability of confirmatory tests needs to be addressed. The volumes are formidable but also suggest that with high rates of consanguinity and inbreeding one is likely to encounter a significant proportion of these in the country. The most positive aspect is the commitment to this noble cause, which will help us cross and reach the horizon. India is getting geared up for the transition and probably the same holds true for many developing countries.

14 NEWBORN SCREENING FOR HEARING LOSS IN MALAYSIA: ARE WE HEARING IT?

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The High-risk Neonatal Hearing Screening Program (HRHNS) has been introduced in the Ministry of Health, Malaysia (MOH) hospitals since 2001. After 14 years, 25 hospitals have implemented HRHNS and 10 hospitals have progressed to Universal Neonatal Hearing Screening Program (UNHS).To monitor progress toward national goals, the Audiology Technical Committee of MOH collects data from state and district hospitals. This study summarizes findings from the MOH Universal Neonatal Hearing Screening Program and High-risk Neonatal Hearing Screening Program (HRHNS) in 2013 to 2014 and provides a summary of recent efforts to identify infants with hearing loss in Malaysia. Strengths and challenges of the program will be thoroughly discussed in this report.

15 G6PD DEFICIENCY SCREENING: EXTERNAL QUALITY ASSURANCE PROGRAM ISSUE

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Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the most common human enzymopathic disease. The nationwide neonatal G6PD screening program in Taiwan started in 1987. To assess the reliability and assure the quality of the screening and confirmatory tests, external quality assurance (EQA) programs for G6PD screening and confirmatory tests were developed. The QC materials were prepared from human blood with human G6PD. Bimonthly, 10 QC blood spots and 3 lyophilized QC samples sent to screening and referral laboratories, respectively. The test results were submitted online and the summary reports were published on the website (g6pd.qap.tw).

Currently, 46 screening laboratories from 16 countries are participating in the EQA program for screening test. From 1999 to 2015.6, 100 EQA surveys for screening test were performed, 181 (10.6%) unsatisfactory EQA reports were found from 1701 reports. The unsatisfactory results were mainly caused by inappropriate cut-offs. From 1988 to 2015.6, 190 EQA surveys were sent to 21 referral laboratories in Taiwan, 306 (8.7%) unsatisfactory

reports were found from 3,501 reports. Inter-laboratory C.V. for the quantitative test has reached <10% in recent years. The long term (8 years) intra-laboratory imprecision (C.V.) of the referral laboratories in Taiwan has reached 6.1% (0.1~23.5%). Since July 2009, 33 EQA surveys have been carried out for the newly established network of 21 referral laboratories in Philippines. From 2009 to 2015.6, 75 (19.3%) unsatisfactory EQA reports were found from 389 reports. Inter-laboratory C.V. in Philippines were between 6.6% and 25.0%, which is lower than those found in other EQA programs (e.g. CAP, RCPA) for G6PD quantitative test using the same analytical method. These G6PD EQA programs have been useful for monitoring and to improve the G6PD tests quality, and might be a reference for the participating laboratories to adjust the cut-offs for the screening test.

16(i) G6PD DEFICIENCY IN MALAYSIA: ARE WE MISSING OUR G6PD DEFICIENT BABIES?

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Glucose-6-phosphate dehydrogenase (G6PD) deficiency is a common problem in Malaysia, affecting about 6.0% of the population. Cord blood screening for G6PD deficiency using the fluorescent spot test (FTS) is the standard test used in this country over the last three decades. Despite this screening program, the number of newborns admitted to Malaysian hospitals with severe jaundice (total serum bilirubin of ≥342umol/L or 20 mg/dL) remains high. Severe unconjugated hyperbilirubinemia is neurotoxic and when treated late, these severely jaundiced newborns develop kernicteurs, hearing loss, cerebral palsy and, in the worst case, scenario, even death. Studies done locally and elsewhere showed that the FTS is able to detect G6PD deficiency of less than 20% of normal level but fails to detect mild and moderate G6PD deficiency. In recent years, commercial kits for quantitative enzyme assay of G6PD are available, which are able to detect both mild and severe G6PD deficiency. In Malaysia, currently only one university hospital and a few private hospitals use the quantitative enzyme assay. The main disadvantage of the quantitative enzymatic assay method is failure to diagnose the heterozygote females who have normal enzyme levels that can only be diagnosed by molecular method. To use molecular method as an effective and efficient screening test, each country or region has to first identify the common variants affecting its population and design the panel.

In Malaysia, to improve the early detection of G6PD deficiency in newborn infants and the reduction of incidence of severe hyperbilirubinemia, replacement of the FST by the currently most efficient and cost-effective method should be considered.

16(ii) G6PD DEFICIENCY IN MALAYSIA - ARE WE MISSING OUR G6PD DEFICIENT BABIES?

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Glucose-6-phosphate dehydrogenase (G6PD) deficiency is the commonest enzymopathy of human and a globally important cause of neonatal jaundice, which can lead to acute and chronic bilirubin encephalopathy. It can also lead to life-threatening haemolytic crises in childhood and at later ages, by interacting with specific drugs and with fava beans in the diet. WHO recommends that neonatal screening should be routinely performed on cord blood samples in populations with a high prevalence of G6PD deficiency of 3-5% or more in male, in order to monitor these vulnerable neonates for jaundice and institute treatment as early as possible.