In the current study, authors tried the feasibility of screening and recall system for newborn screening for congenital hypothyroidism, galactosemia and biotinidase deficiency, in a rural population of UP, India. They used heel prick sample, collected at 24 hours of life in 13426 newborns, constituting 73% of all deliveries. From those with abnormal screening results, 85% could be recalled for the confirmatory test and they identified 11 babies with congenital hypothyroidism. Compared to Western data, this loss to follow-up is significant but previous experience from India [5] documents even a higher loss to follow-up. As the loss to follow-up will reduce the impact of the program to a great extent, this emphasizes the need for a proper tracking schedule. The Goa screening program has shown that an effective follow-up can be ensured even in a public set up [9].

The authors have shown that the neonatal screening program is feasible even at a rural set up and also demonstrated the high incidence of congenital hypothyroidism. The failure to sample about 27% of newborns and the significant loss to follow-up are the matters of concern. This paper further establishes the need of a nationwide screening strategy and strengthening the follow-up care. The establishment of a screening program in a country like India will require huge investment by the government, but as evidenced by the experience in developed countries, this strategy will be cost effective in the long run. Experience from the public (Goa and Chandigarh) and various private sectors in India should provide the platform to the Government for establishment of an effective neonatal screening program.

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REFERENCES

1. Wilson JM, Jungner YG. Principles and practice of mass screening for disease. Bol Oficina Sanit Panam. 1968;65:281-393.
2. Multicentric study on genetic causes of mental retardation in India. ICMR Collaborating Centres & Central Co-ordinating Unit. Indian J Med Res. 1991;94:161-9.
3. Rao NA, Devi AR, Savithri HS, Rao SV, Bittles AH. Neonatal screening for amino acidaemias in Karnataka, South India. Clin Genet. 1988;34:60-3.
4. Rama Devi AR, Naushad SM. Newborn screening in India. Indian J Pediatr. 2004;71:157-60.
5. Kaur G, Srivastav J, Jain S, Chawla D, Chavan BS, Atwal R, *et al.* Preliminary report on neonatal screening for congenital hypothyroidism, congenital adrenal hyperplasia and glucose-6-phosphate dehydrogenase deficiency: a Chandigarh experience. Indian J Pediatr. 2010;77:969-73.
6. Sahai I, Zytkowicz T, RaoKotthuri S, Lakshmi Kotthuri A, Eaton RB, Akella RR. Neonatal screening for inborn errors of metabolism using tandem mass spectrometry: Experience of the pilot study in Andhra Pradesh, India. Indian J Pediatr. 2011;78:953-60.
7. Van Vliet G, Czernichow P. Screening for neonatal endocrinopathies: Rationale, methods and results. Semin Neonatol. 2004;9:75-85.
8. Gopalakrishnan V, Joshi K, Phadke S, Dabadghao P, Agarwal M, Das V, *et al.* Newborn screening for congenital hypothyroidism, galactosemia and biotinidase deficiency in Uttar Pradesh, India. Indian Pediatr. 2014;51:701-5.
9. The Goa Newborn Screening Program 3 Year Review. Available from: *www.dhsgoa.gov.in/documents/new_born.pdf*. Accessed August 20, 2014.

Newborn Screening: The Critical Importance

Biochemist's Perspective

MANJIT KAUR

From the Department of Genetics, National Reference Laboratory, Dr Lal Path Labs, Rohini, Delhi, India.
Manjeet.kaur@lalpathlabs.com

Newborn screening (NBS) is a public health program designed and developed to screen infants shortly after birth. The principle of NBS Program is to detect potentially harmful disorders that are not clinically evident at birth. Newborn screening is a success story in USA [1,2] and European countries [3] despite different approaches to timing of screening, follow-up testing and intervention [4]. In India, the concept of NBS is in the nascent stages, and as of now is more focused on detecting congenital hypothyroidism, congenital adrenal hyperlplasia, galactosemia, Glucose-6-phosphate dehydrogenase deficiency, biotinidase deficiency and cystic fibrosis. Screening for inborn errors of metabolism, including aminoacidopathies, organic acidemias and fatty acid oxidation disorders are yet to pick up as the costs involved are daunting [5]. False positive alarms and recall rates of a NBS program depend on methodology used and quality of diagnostic services. For

example, as a good quality practice, sample storage and test performance should be carried out at same temperature throughout the year.

'Screening window', defined as the period between the development of the abnormal test result of NBS and development of symptoms in the infant, may vary from disorder to disorder. It will be most ideal to collect sample on fourth day of life. Samples can be collected from home by trained nurse/phlebotomist. There are many riders associated with interpretation of blood samples collected in the first few days of life; often a repeat testing may be warranted. This not only increases the costs but can also lead to false alarm and cause panic in parents and families. However, defining age-appropriate cut-offs – as in the study in this issue of *Indian Pediatrics* [6] – may circumvent the problem of loss to follow-up. It is important to define criteria for permanent and transient hypothyroidism and exclude cases of transient hypothyroidism [7]. Workshops and pilot studies are required for standardization of diagnostic criteria for congenital hypothyroidism.

Screening and surveillance should go hand in hand. Newborn screening model should comprise screening, follow-up, diagnosis, management, and education. Teaching guide for parents should be made available as public awareness of these disorders is very poor in India. Success of any newborn screening program depends on coordination of efforts of many stakeholders.

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REFERENCES

1. Therrell BL, Adams J. Newborn screening in North America. J Inherit Metab Dis. 2007:30:447-65.
2. Lloyd-Puryear MA, Tonniges T, van Dyck PC, Mann MY, Brin A, Johnson K, *et al.* American Academy of Pediatrics Newborn Screening Task Force recommendations: How far have we come? Pediatrics. 2006;117(5 Pt 2):S194-211.
3. Loeber GJ. Neonatal screening in Europe; the situation in 2004. J Inherit Metab Dis. 2007;30:430-8.
4. Olney RS, Grosse SD, Vogt RF. Prevalence of congenital hypothyroidism – Current trends and future directions: Workshop Summary. Pediatrics. 2010;125(suppl):S31-6.
5. Kapoor S, Gupta N, Kabra M. National newborn screening program still a hype or a hope now? Indian Pediatr. 2013;50:639-43.
6. Gopalakrishnan V, Joshi K, Phadke S, Dabadghao P, Agarwal M, Das V, *et al.* Newborn screening for congenital hypothyroidism, galactosemia and biotinidase deficiency in Uttar Pradesh, India. Indian Pediatr. 2014;51:701-5.
7. Shapira SK, Lloyd-Puryear MA, Boyle C. Future research directions to identify causes of the increasing incidence rate of congenital hypothyroidism in the United States. Pediatrics. 2010;125(Suppl2):S64-8.

Post-discharge Growth of Extremely Low Birth Weight Neonates

SRIPARNA BASU

From the Neonatology Unit, Department of Pediatrics, Institute of Medical Sciences, Banaras Hindu University, Varanasi, India.
drsriparnabasu@rediffmail.com

Rapid advances in perinatal and neonatal care in the last two decades have led to a dramatic increase in the survival of extremely low birth weight (ELBW; birth weight <1000 g) neonates.

This assurance of survival has now shifted the main focus of concern from short term outcome to the adequacy of growth and development in later life. Extra-uterine growth failure is extremely common in this group of infants; weight at discharge of almost 90% is below 10th percentile of reference value, despite planned nutritional management, including total parenteral nutrition and trophic feedings in the first few days of life [1]. There is paucity of literature regarding the long-term growth trajectory of ELBW infants. The usual norms for the growth of infants with higher birth weight may not be applicable to this group. Moreover, growth in the small for gestational age (SGA) ELBW infants is characterized by great heterogeneity with remarkable variability [2].

Nutrition of the ELBW infants after hospital discharge is an area of growing interest. Though the goal of nutrition is to maintain the rate of growth and the body composition comparable to that of a normal fetus of the same postmenstrual age [3], both high and low nutrient intakes as well as fast and slow rates of growth have been shown to have some long-term adverse effects. On one hand, studies have shown that inadequate early nutrition at a vulnerable period of brain development may exert an adverse