

Pre-Screening Education and Prenatal Care: Preparing Parents for NBS

Newborn bloodspot screening (NBS) has been a key instrument in the early detection and management of congenital disorders worldwide.¹ NBS is a set of tests performed in the early life of the newborn to screen for conditions that can cause severe illness or death unless detected and treated early.² In the Philippines, the ratification of the Republic Act 9288, known as the Newborn Screening Act of 2004, ushered in a comprehensive policy and national system for ensuring NBS.³ From the six included conditions, the ENBS Program now includes 29 conditions⁴ and is now part of the Newborn Care Package of Philhealth.¹

Pre-screening education is an essential component of the comprehensive NBS system to inform parents about NBS before the procedure.⁵ The goal is to increase testing coverage.⁵ There has been an increasing trend in the uptake of NBS testing since its introduction in 1996. Testing coverage was 80.4% in 2020.⁴ In 2018, the Philippine General Hospital (PGH) reported a 100% testing coverage with all 4,828 live birth deliveries screened.⁶ This success was attributed mainly to the efforts of the Newborn Screening Nurses Core Group, which ensured that all parents of newborns were informed about the availability of NBS.⁶ Health workers must apprise parents of the availability of NBS, its benefits, and the mechanisms involved.³ Parents should also be informed about their duty to provide their newborn with protection from disabilities that are preventable through NBS.³

The relevance of pre-screening education on NBS does not only lie in increasing testing coverage uptake. Of equal importance, preparing parents and teaching them about what to do when they receive a positive testing result on NBS is also included in the pre-screening education.⁷ Parents whose newborn is screened positive may not know what to do next and may be too scared to take appropriate action. Because of this, parents may not likely return for the confirmatory tests. Therefore, the dissemination of correct NBS procedures is necessary.⁸ Literature confirms that parents given information about newborn screening beforehand are more adherent to follow-ups in case of positive screening results.⁹ Increased uptake of confirmatory tests can be facilitated through pre-screening education.

The period before the baby's birth can be a good time for teaching parents about NBS where they are eagerly waiting and are receptive to the information given to them. In addition, information can be provided during antenatal visits when parents are waiting for their turn for a checkup.¹⁰ Formal integration of pre-screening education on NBS in prenatal care will maximize its purpose and benefits. Therefore, health workers in the different facilities, specifically frontliners in the antenatal clinics, should be fully equipped to handle this task.

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REFERENCES

1. Department of Health. Newborn Screening Program [internet]. 2020 [cited 2020 April]. <https://doh.gov.ph/newborn-screening>
2. Centers for Disease Control and Prevention. CDC Grand Rounds: Newborn Screening and Improved Outcomes [Internet]. 2012. [cited 2020 April]. [https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6121a2.htm#:~:text=June%201%2C%202012%20%2F%2061,\(not%20otherwise%20apparent%20at%20birth](https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6121a2.htm#:~:text=June%201%2C%202012%20%2F%2061,(not%20otherwise%20apparent%20at%20birth)
3. Republic Act 9288. Newborn Screening Act of 2004 [Internet]. 2004 [cited 2022 April 21]. Available at https://doh.gov.ph/sites/default/files/policies_and_laws/RA09288
4. National Coverage. 2020. [cited 2022 April 21]. Available at https://www.newbornscreening.ph/index.php?option=com_content&view=article&cid=83:nbs-statistics&catid=32:statistics&Itemid=57
5. Araia MH, Wilson BJ, Chakraborty P, Gall K, Honeywell C, Milburn J, et al. Factors associated with knowledge of and satisfaction with newborn screening education: a survey of mothers. *Genet Med*. 2012; 14(12):963-70. <https://doi.org/10.1038/gim.2012.87>
6. Abad PJB, Sur ALD, & Salve SM. Role of the nurse in newborn screening: integrating genetics in nursing education and practice. *Philip J Nurs*. 2019; 89(1):16-21.
7. Tluczek A, Orland KM, Nick SW, & Brown RL. Newborn screening: an appeal for improved parent education. *J Perinat Neonatal Nurs*. 2009; 23(4):326-34. <https://doi.org/10.1097/JPN.0b013e3181a1bc1f>
8. Ladia MA, Cordero C, Padilla CD, Beltran FD, Silvestre C, Lelis M, et al. Facilitating factors and barriers to newborn screening uptake in the Cordillera Administrative Region V. *Philip J Health Res Dev*. 2018; 22(3). <https://pjhrd.upm.edu.ph/index.php/main/article/view/243>
9. Potter BK, Etchegary H, Nicholls SG, Wilson BJ, Craigie SM, & Araia MH. Education and parental involvement in decision-making about newborn screening: understanding goals to clarify content. *J Genet Couns*. 2015; 24(3):400-8. <https://doi.org/10.1007/s10897-014-9780-x>
10. Fitzgerald C, Heery E, Conneally N, Linnane B, George S, & Fitzpatrick P. An evaluation of pregnant women's knowledge and attitudes about newborn bloodspot screening. *Midwifery*. 2017; 45:21-7. <https://doi.org/10.1016/j.midw.2016.11.007>