POLICY PAPER

Bridging the Gap in The Recall of G6PD Deficient Screened Babies: A Policy Brief

Anthony James F. Almazan, MAN, RN[1] and **Susielyn R. Lozano-Almazan,** MAN, RN[2]

Executive Summary

Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency is an enzyme defect affecting around 400 million people worldwide. In the Philippines, cumulative data from the Newborn Screening Reference Center as of December 2020 unveils 248,285 confirmed babies out of 15,087,251 screened babies or prevalence rate of 1:60 with the national return rate of 18% only (NSRC, 2021). One strategy identified pertaining to the recall of patient is the G6PD Recall Monitoring which resulted in a 76% G6PD return rate, compared to the 31% output of the standard recall done in the Province of Ilocos Norte in CY 2020 (NSC-NL, 2022). Hence, this policy brief on G6PD Recall Monitoring serves as a supplementary policy to bridge the gaps in the recall of G6PD Deficient Patients and increase return rate of G6PD nationwide.

Background and Significance

Baby's first step is a profound phenomenon indicative of a lifelong journey. Hence, newborns deserve the best start in life, to grow up healthy and reach their full potentials. This is the main objective of the Newborn Screening Program in the Philippines. However, not every beginning of a new life plays out a scene like this. Some babies are born with maladies and often times, these babies do not receive appropriate care due to several barriers.

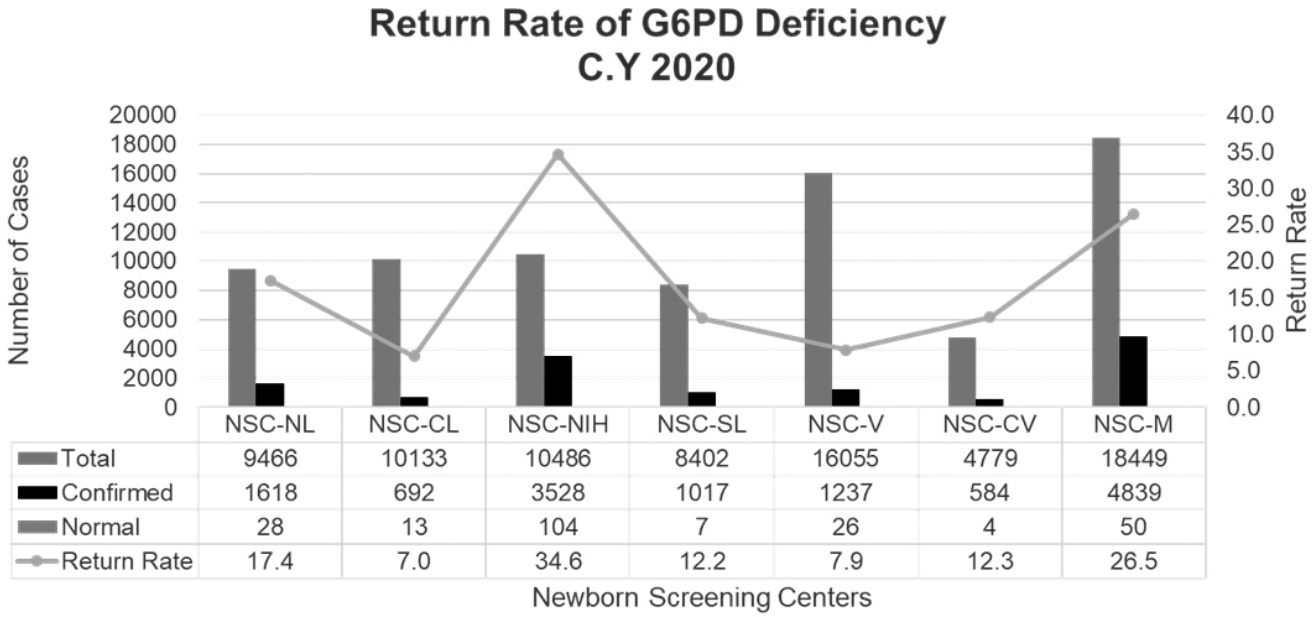
Newborn Screening is recognized internationally as an essential, preventive public health program for early identification of disorders in newborns that can affect their long-term health. Early detection, diagnosis, and treatment of certain genetic, metabolic, or infectious congenital disorders can lead to significant reductions of death, disease, and associated disabilities (National Newborn Screening and Global Resource Center, 2016). Furthermore, most babies with metabolic disorders look "normal" at birth. By doing NBS, metabolic disorders may be detected even before clinical signs and symptoms are present. As a result, treatment can be given early to prevent consequences of untreated conditions (NSRC, 2005).

The Republic Act 9288, otherwise known as “the Newborn Screening Act of 2004”, provides for the establishment of a National Comprehensive Newborn Screening System (NCNSS) that includes screening, recalling and diagnosis of patients as one of its primary provisions to assess long term outcome, patient compliance and quality assurance. Newborn Screening is geared on reducing morbidity and mortality through the implementation of the six-part systems consisting of education, screening, short-term follow-up (tracking and further testing), diagnosis, management and evaluation (Padilla et al., 2022). In addition, Section 4 of the Newborn Screening Act (2004) defines Recall as the procedure for locating a newborn with a possible heritable condition for purposes of providing the newborn with appropriate laboratory to confirm the diagnosis and, as appropriate, provide treatment. It is done by the Short-term Follow-Up of the Newborn Screening Centers, that is composed of a Follow-Up Head (Pediatrician) and Follow-Up Nurses. Every baby with a positive screening must be recalled for confirmatory tests and management.

There are more 28 heritable and metabolic disorders that can be screened through the Expanded Newborn Screening. One of the disorders that has high prevalence is the Glucose-6-Phosphate Dehydroginase (G6PD) Deficiency. G6PD is an enzyme defect affecting around 400 million people worldwide. Enzyme is

[1] Anthony James F. Almazan, MAN, RN; Project Development Officer IV-Program Manager, Mariano Marcos Memorial Hospital and Medical Center
[2] Susielyn R. Lozano-Almazan, MAN, RN; Nurse III-Section Head, San Fernando La Union Treatment and Rehabilitation Center

Figure 1. *Return Rate of G6PD Deficiency C.Y 2020*



	NSC-NL	NSC-CL	NSC-NIH	NSC-SL	NSC-V	NSC-CV	NSC-M
Total	9466	10133	10486	8402	16055	4779	18449
Confirmed	1618	692	3528	1017	1237	584	4839
Normal	28	13	104	7	26	4	50
Return Rate	17.4	7.0	34.6	12.2	7.9	12.3	26.5

needed for the protection of RBC from oxidative substances, which prevents hemolysis (NSRC, 2020). In the Philippines, cumulative data from the Newborn Screening Reference Center as of December 2020 unveils 248,285 confirmed babies out of 15,087,251 screened babies (NSRC, 2021).

Congruently, it was noted that there is a significantly low return rate of newborns needing confirmatory test. Based from the Newborn Screening Reference Center (2021), the national return rate of G6PD Deficiency is only 18%.

According to Teves and Escueta (2016), out of the 3,570 infants who were delivered at a tertiary government medical center on January 2013 to December 2014, 143 (4%) were positive for G6PD deficiency on newborn screening test. Subsequently, the researchers were able to track 62 patients, of which 39 (62.9%) were able to comply with confirmatory testing. Finally, it was noted in the study that the most common reasons for the non-compliance to confirmatory testing were the following: lack of time (47.83%), uninformed (21.74%), and lack of funds (21.74%).

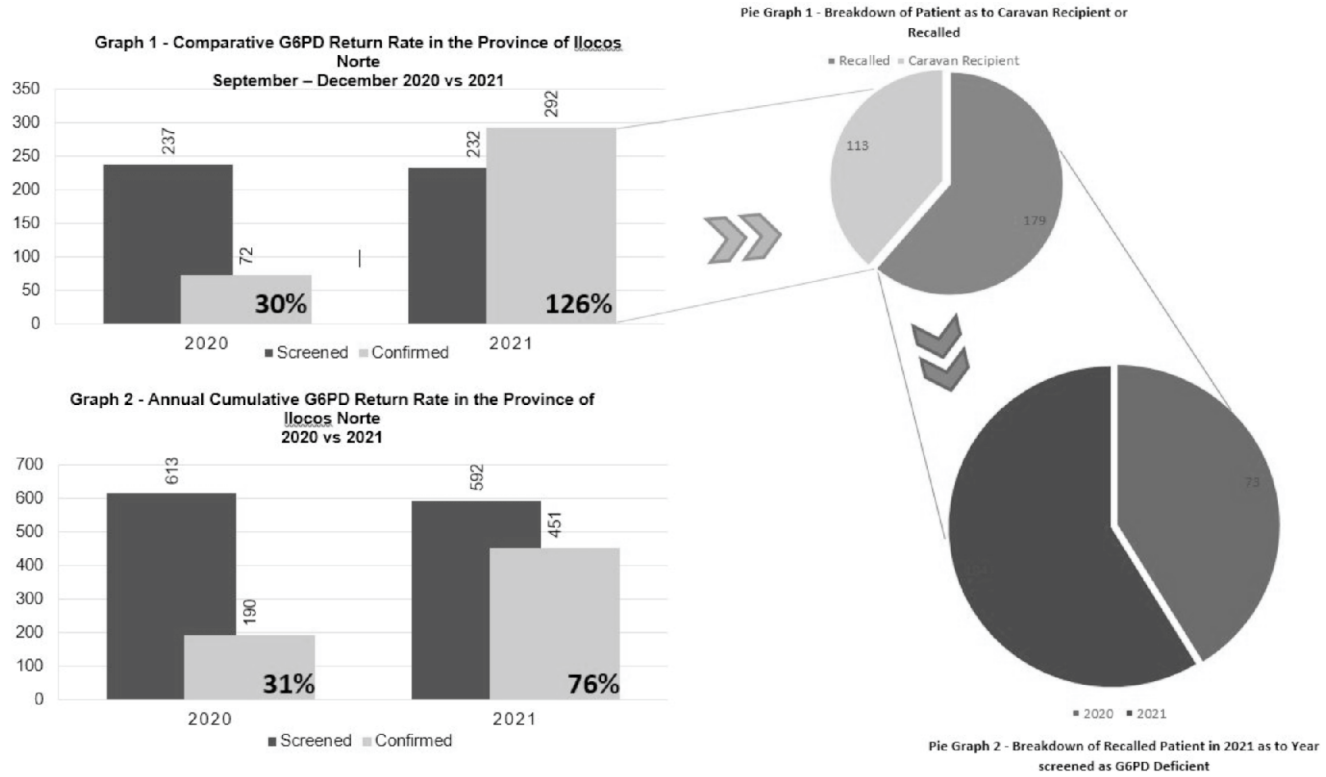
In the study conducted by Tolentino and Santos ( ), the result showed 97 infants were detected G6PD deficiency positive in the newborn screening and more than half of the infants amounting to 51 (52.6%) did not undergo the confirmatory test. Majority is due to lack of knowledge 29 (56.9%), followed by financial constraints 15 (29.4%).

Follow up and recall are identified as one of the major challenges in providing appropriate management of the Inborn Errors of Metabolism (Chardan et al., 2021). Varghese et al., (2021) likewise found out that infants with positive NBS result are unable to undergo confirmatory test because of lost to follow-up, unreachable phone numbers and unwillingness to proceed with the testing.

In the study conducted by Patel et al. (2020), they stated that repeated telephonic conversation and counseling is crucial in increasing the recall response for the confirmatory testing. Moreover, there is a need to establish efficient systems for quality control, improve patient recall, initiation of treatment and follow-up, effective counseling and communication to families (Verma et al., 2020; Liu & Zhou, 2021). Currently in the Philippines, the nurse-in-charge in the Newborn Screening Center recalls G6PD Positive Screens via one call policy. If not available or if phone is unattended, SMS is sent and await for acknowledgement. Copy of result is sent via email and courier (NSC-NIH, 2017).

Padilla et al., (2020) conducted a study using the Philippine Performance Evaluation and Assessment Scheme (PPEAS) in monitoring and in improving the performance of Newborn Screening System that revealed major issues and concerns under confirmatory testing; hence, recommendations include immediate recall and improve follow-up of babies referred to other facilities for confirmatory testing.

One strategy identified pertaining to the recall is the G6PD Recall Monitoring. According to study (NSC-NL, 2022), the modification in the recall of patients made in the CY 2021 resulted in a 76% G6PD return rate, compared to the 31% output of the standard recall done in the Province of Ilocos



Graph 1. *G6PD Return Rate in the Province of Ilocos Norte 2020 vs 2021*

Norte in CY 2020 (Figure 1). At 5% level of significance, there was a significant increase in the Return Rate from 2020 to 2021, with an increase of 197.96%. This denotes that strategies implemented were effective and even exceeded their target which is 50%.

Based on these evidences, this policy brief would like to propose the imposition of the G6PD Recall Monitoring, as a supplementary policy, to bridge the gaps in the recall of G6PD Deficient Patients and increase return rate of G6PD nationwide.

Policy Statement

The primary purpose of the G6PD Recall Monitoring Policy is to ensure that parents/guardians of screened G6PD Deficient patients are recalled and advised by the Newborn Screening Facilities (NSFs), thereby respecting the right to information. The policy applies to the Follow-Up Nurses (FUN) and Project Development Officers (PDO) in the Newborn Screening Centers (NSCs) who conduct the recall and monitoring of all the Newborn Screening Facilities (NSFs) with G6PD Deficient patients.

With this policy, the FUN shall be responsible in recalling screened G6PD Deficient cases, generating the G6PD Deficient Summary List and emails to the corresponding Newborn Screening Facility, and quarterly monitoring of the G6PD recall of the NSFs. While the **Newborn Screening Coordinator/ Newborn Screening Person-in-charge** shall assist in recalling the parent of the patient to inform the screening result and shall instruct the parent for G6PD Deficient confirmatory testing. In addition, the **Project Development Officers (PDO)** will initiate a facility monitoring to the non-compliant NSFs as reported by the Follow-Up Nurses.

Standard recall shall still be followed, in which the Newborn Screening Center FUN will recall the NSFs NBS Coordinators and will be followed by the NBS Coordinators to the Parents. However, with the gaps identified in the standard monitoring, the G6PD Recall Monitoring shall supplement the existing policy by requiring the recall of NSFs to Parents to be documented by the NBS Coordinators and be monitored by the NSC FUNs and PDOs.

The target recall rate of the NSFs for G6PD Deficient Screened babies is 100%. Moreover, the FUN shall update and maintain

a quarterly worksheet of NSF Recall. The worksheet reflects the total number of screened patients, and the number of recalled patients in a given period, and shall conduct follow-up of the NSFs with no submission of recall monitoring. Non-compliant NSFs will be reported to the Newborn Screening Center and DOH CHD PDOs for buttressing of the policy.

Evaluation shall be collated and reported by the Senior Follow-Up Nurse to the Follow-Up Head, Program Manager, and the Unit Head. The following may be considered measures to evaluate the effectiveness of the monitoring:

a. **NSRC Case Audit Reports (Quarterly):** Quality Indicators such as Follow-Up Recall Rate and Return Rate for G6PD Deficiency
b. **NSRC Reports 4 and 5 (Follow-Up Report, Monthly and Quarterly)**

Policy Position

The supplemental policy brief is based on evidences that recommends restructuring of the current policies on G6PD recall to be more effective and efficient in targeting the goals of the Newborn Screening program, particularly in the recall of G6PD Deficient screened babies. Imposing the policy on G6PD Recall Monitoring does not need to overwrite the existing policy, however, it will appendage the recall of G6PD Deficient babies by ensuring that the patients are recalled by the NBS Coordinators. Ethically, it provides parents their right to information and to know immediately the health status of their children.

Moreover, it will deliver opportunities for the program partners for capacity building among the NBS Coordinators from various NSFs, with the aide of the Department of Health Centers for Health Development around the Philippines; and it will intensify program advocacy together with the G6PD Confirmatory Testing Centers, NBS Continuity Clinics and others stakeholders.

Finally, the implementation of the Universal Health Care will further define and strengthen the referral network of the newborn screening program, specific for those screened positive for G6PD Deficiency, and amongst the identified program partners.

Policy Recommendation

The inclusion of G6PD Recall Monitoring in the standardized protocol of the Newborn Screening Centers is recommended. In line with this, the incorporation of the policy in the Philippine

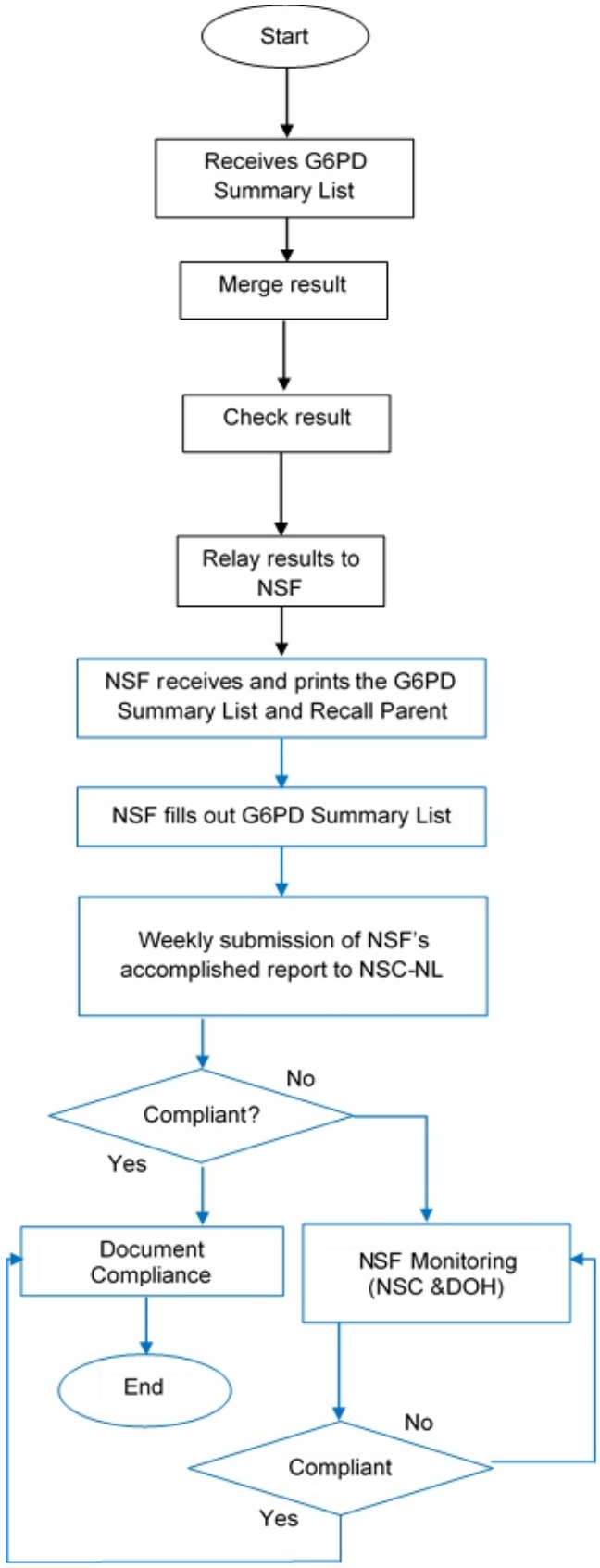


Figure 2. *G6PD Recall Monitoring Matrix*

Performance Evaluation and Assessment Scheme (PPEAS) Tool for Newborn Screening Centers and Newborn Screening Facilities will be helpful to achieve the targets of the policy. A separate PPEAS Tool for the G6PD Confirmatory Testing Centers may also abet in sustaining the implementation of the policy, particularly in observing the timeliness and regular submission of G6PD confirmed patient reports.

As part of the capacity building among the program partners, the policy recommends the development of a simulation program in Patient Recall as part of the NBS Sample Collection Training by the Department of Health Centers for Health Development. This will ensure that NBS Coordinators are observing proper phone call etiquette in informing the parents about their newborn's screening result. Furthermore, it will entail a point-person in the NSFs to implement the recall monitoring.

Local government units play an important role in the financing of indigent patients who need confirmatory testing and consultation with medical specialist. Hence, the policy suggests creation of health support scheme among the local government units for indigent patients, with the technical assistance of the Department of Health Centers for Health Development.

To further understand the nature of the healthcare gap, more quantitative researches is recommended. This will provide the primary stakeholders and implementers a better insight of having low G6PD Return Rate in the country and develop more effective strategies to address the problem.

Policy Action Step

The following actions steps were determined

1. Presentation of the Policy Brief to the Newborn Screening Reference Center (NSRC), and the release of memorandum pertaining to the implementation of the G6PD Recall Monitoring Policy.
2. Advocate the Policy Brief to the NBS stakeholders
    - Advocate to Department of Health Centers for Health Development, Newborn Screening Centers, G6PD Confirmatory Testing Centers during the National or Regional Consultative Meetings.
    - Advocate to NBS Coordinators of Newborn Screening Facilities during cluster meetings.
    - If possible, presentation of the policy brief during the National NBS Convention, which targets wide number of healthcare professionals and program partners from different sectors
3. Provision of Technical Assistance to stakeholders
    - Incorporation of Patient Recall Simulation in the NBS Training (Department of Health Centers for Health Development)
    - Standardized Protocol of G6PD Recall Monitoring (Newborn Screening Centers)
    - Conduct of Recall Monitoring
    - Development and/or improvement of Online Platform for the recall of patients.

References

Chandran, J., Bellad A, Ramarajan, MG., Rangiah, K. (2021). Applications of quantitative metabolomics to revolutionize early diagnosis of inborn errors of metabolism in India. Analytical Science Advances, 2:546–563. https://doi.org/10.1002/ ansa.202100010

Liu, Yan., & Zhou, X. (2021). Screening results of neonatal diseases and exploration of management mode in Yichang in 2017-2019. Journal of Public Health and Preventive Medicine, (6): 146-149. wpr-906641

Newborn Screening Act, RA 9288, Sec. 4 (2004). https://doh.gov.ph/sites/default/files/policies_ and_laws/RA09288.pdf

Newborn Screening Center – National Institute of Health (2017). Follow-Up Manual. National Institute of Health – University of the Philippines – Manila

Newborn Screening Center – Northern Luzon (2022). Unearthing Stratagems for a Higher G6PD Return Rate. Mariano Marcos Memorial Hospital and Medical Center, Batac City

Newborn Screening Reference Center (2021). Case Audit Reports (Powerpoint Slides). https://mail.google.com/mail/u/0/?tab=rm&ogbl#search/ case+audit+2021/FMfcgxwKkbrPXDjZkgmcmNpnSDdhWDNt?projector=1&messagePartId=0.2

Newborn Screening Reference Center (2020). Fact Sheets: Information for Doctors about the disorders included in the Expanded Newborn Screening Panel. https://www.newbornscreening.ph/images/stories/ResourcesTechnicalDocuments/Expanded%20Screening%20Fact%20Sheets_Doctors_NSRC-INT-05_I1R1.pdf

Newborn Screening Reference Center (2005). Manual of Operations of the National Comprehensive Newborn Screening System. National Institute of Health – University of the Philippines – Manila

Padilla, C. D., Therrell, B. L., Panol, K., Suarez, R., Reyes, M., Jomento, C. M., Maceda, E., Lising, J., Beltran, F., & Orbillo, L. L. (2020). Philippine Performance Evaluation and Assessment Scheme (PPEAS): Experiences in Newborn

Screening System Quality Improvement. International journal of neonatal screening. 6(4), 95. https://doi.org/10.3390/ijns6040095

Padilla, C.D.; Therrell, B.L., Jr.; Alcausin, M.M.L.B.; Chiong, M.A.D.; Abacan, M.A.R.; Reyes, M.E.L.; Jomento, C.M.; Dizon-Escoreal, M.T.T.; Canlas, M.A.E.; Abadingo, M.E.; et al. (2022). Successful Implementation of Expanded Newborn Screening in the Philippines Using Tandem Mass Spectrometry. International journal of Neonatal Screening. 8,8. https://doi.org/10.3390/ ijns8010008

Patel S, Padhi P, Priya R, Naik T, Nanda R, Mohapatra E. A cross-sectional study on parental awareness for newborn screening and assessment of the burden of congenital hypothyroidism and glucose 6-phosphate dehydrogenase deficiency. (2020). Indian Journal of Community Family Medicine. 6:132-6. 10.4103/IJCFM.IJCFM_16_20

Teves, M., & Escueta, A. (2016). Caregiver compliance to confirmatory testing for G6pd deficiency at a tertiary government medical center. Longdom.org. http://dx.doi.org/10.4172/2161-0665.C1.031

Tolentino, L ., & Santos, W. (n.d). Factors associated with Non-compliance on Confirmatory Test for G6PD Positive Infants In De La Salle University Medical Center from 2009 to 2010. https://projects.pchrd.dost.gov.ph/index.php?view=research&cid=51680#studyDetails

Varghese, S., E, El Otol R., H, M, Al Olama F., S, Elbadawi S, A, M. (2021). The Importance of Early Detection of Genetic Diseases. Dubai Medical Journal;4:133-141. doi: 10.1159/000514215

Verma, J., Roy, P., Thomas, D. C., Jhingan, G., Singh, A., Bijarnia-Mahay, S., & Verma, I. C. (2020). Newborn Screening for Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, and Glucose-6-Phosphate Dehydrogenase Deficiency for Improving Health Care in India. Journal of pediatric intensive care, 9(1), 40–44. https://doi.org/10.1055/s-0039-1698424

ABOUT THE AUTHORS

Anthony James F. Almazan, MAN, RN is the Project Development Officer IV - Program Manager of the Newborn Screening Center – Northern Luzon in Mariano Marcos Memorial Hospital and Medical Center. He is presently taking his Ph.D. in Nursing at St. Louis University, Baguio City. He earned his Bachelor of Science in Nursing at Lorma Colleges, San Fernando City, La Union, and his Master of Arts in Nursing at University of Northern Philippines, Vigan City.

His research interest revolves around public health, maternal and child nursing, and disaster management.

Susielyn R. Lozano - Almazan, MAN, RN is affiliated at the San Fernando La Union Treatment and Rehabilitation Center as Nurse III – Section Head. She is a graduate of Bachelor of Science in Nursing at Lorma Colleges, San Fernando City, La Union. She completed her Master's Degree in Nursing at University of Northern Philippines, Vigan City and is currently completing her Doctor of Philosophy in Nursing at St. Louis University, Baguio City.

She is interested in conducting researches in Public Health Programs, specifically related to Infectious Diseases and Substance Use Disorders.

Nurses are a unique kind.
They have this insatiable need to care for others, which is both their greatest strength and fatal flaw.

- Jean Watson