ARISE TRAINING FOR RELEASING RESULTS OF NEWBORN SCREENING (NBS)

Background:

Studies have shown that about 33% of the global burden of sickle cell disease (SCD) is found in Nigeria with about 100,000-150,000 affected infants born annually and the number is projected to increase by about 80-100% by 2050 (*ASH*, 2021 & Archer et al., 2022). This significantly contributes to morbidity and mortality among Nigerian newborns and the under-five population (Nnodu et al., 2018 & Mohammed-Nafiu, 2020). Despite concerted efforts by public and private, government and non-governmental health sectors through child screening during immunization programmes, neonatal screening programmes, pre-conception counselling, haemoglobin phenotype testing (Yarhere et al., 2019 & Babalola et al., 2019), the disease is still on the rise. Newborn screening has been adopted as a basic health intervention which is appropriate and timely because it allows for early prophylactic treatment, education to caregivers and comprehensive management (Inusa, 2015; & *Buguzi* 2022)

Rationale for NBS

The rationale for newborn screening for sickle cell disease could have a high impact on the patient, healthcare experts, families, government, and the society which includes but is not limited to the following:

1. Significant reduction in mortality and morbidity.
2. Improving the quality of life of people living with SCD from childhood
3. Ensuring diagnosis within the shortest possible time and creating opportunity for immediate enrolment into treatment pathways for better health outcomes
4. Having a planned National Health Insurance Scheme to include NBS package
5. Increasing community education and disseminating information about the disease
6. Establishing structures for programme management
7. Attracting funding
8. Implementing preventive strategies of the disease

Aim: To train NBS staff/personnel on the protocol for releasing NBS results

Specific Objectives;

- To provide participants with an overview of the Kaduna State newborn screening (NBS) program pathway.
- To outline the types of results generated via the NBS
- To introduce participants to a simple approach to breaking 'difficult' news
- To delineate potential areas of concern to parents/caregivers of affected children

Target Audience: nurses, community health extension workers, primary health physicians, specialist physicians

Methodology: Virtual meeting via GoToMeeting platform

Number of Participants: 39 from Africa, UK and Europe

Duration: 2 hours

Agenda:

- Arrival & welcome
- House keeping
- Opening remarks by L. Ruggieri
- Presentation by Ifeoma P. Ijei-Enesi
- Q&A- interactive
- Feedback for improvement
- Closing remarks
- Departure

Summary of presentation content:

a. Overview of NBS in Kaduna (SCD burden; complications and management; and aims and objectives of NBS in Kaduna)
b. Newborn Screening Results (inconclusive, not suspected, carrier, suspected)
c. Challenging results/cases: FSA (Hb Sβ-thalassaemia) and FAS (Sickle cell trait); preterms

d. Process of breaking difficult news:
    i. Staff capacity- Clinical knowledge and background
    ii. Laying a foundation with truth and empathy
    iii. Use ICNS principles of counselling- Informative, confidential, non-directive, and supportive)
e. Breaking the news (face-to-face and be prepared for a range of emotions and questions)
f. Adopting the SPIKES framework (setting-up, perception, invitation, knowledge, emotion/empathy and summary).

Q & A:

The interactive session was quite engaging with questions coming in from participants from across multiple sites. Participants shared personal and professional challenges encountered during their work with patients living with sickle cell disease. Some of the areas of interest are highlighted below.

1. How long does it take to get a result from the day of testing?
2. What is the rationale of indicating that only people with health/clinical background can disseminate difficult results?
3. How to reach potential clients that are located at a physical distance from testing site.
4. How to reach potential clients whose children have been tested but refuse to come in for results
5. How to handle a couple who had previously been given results of Hb phenotype that didn't indicate risk of haemoglobinopathy to offspring (e.g., during pre-marital counselling) who now have an affected infant.
6. What to do when the number of trained counsellors is insufficient for the number of sites.
7. Which cadre of health care professional is best suited for genetic counselling.
8. Comparing and contrasting HPLC and IEF as testing platforms and interpretation of results generated.
9. How to improve paternal involvement in the NBS process.

References

Archer, N. M., Inusa, B., Makani, J., Nkya, S., Tshilolo, L., Tubman, V. N., McGann, P. T., Ambrose, E. E., Henrich, N., Spector, J., & Ohene-Frempong, K. (2022). Enablers and barriers to newborn screening for sickle cell disease in Africa: Results from a qualitative study involving programmes in six countries. *BMJ Open*, *12*(3), e057623. https://doi.org/10.1136/bmjopen-2021-057623

Babalola, O. A., Chen, C. S., Brown, B. J., Cursio, J. F., Falusi, A. G., & Olopade, O. I. (2019). Knowledge and health beliefs assessment of Sickle cell disease as a prelude to neonatal screening in Ibadan, Nigeria. *Journal of Global Health Reports*, *3*, e2019062. https://doi.org/10.29392/joghr.3.e2019062

Consortium Initiates Newborn Screening Program for Sickle Cell Disease in Nigeria and Ghana—Hematology.org. (n.d.). Retrieved November 14, 2022, from https://www.hematology.org:443/newsroom/press-releases/2021/consortium-initiates-newborn-screening-program-for-sickle-cell-disease-in-nigeria-and-ghana

Mohammed-Nafiu. (n.d.). *Pattern of haemoglobin phenotypes in newborn infants at the national hospital abuja using high performance liquid chromatography*. Retrieved November 14, 2022, from https://www.npmj.org/article.asp?issn=1117-1936;year=2020;volume=27;issue=3;spage=190;epage=195;aulast=Mohammed%2DNafiu

Nnodu, O. E., Adegoke, S. A., Ezenwosu, O. U., Emodi, I. I., Ugwu, N. I., Ohiaeri, C. N., Brown, B. J., Olaniyi, J. A., Isa, H., Okeke, C. C., Bene, B. A., Balogun, M. T., Okocha, E. C., Aneke, J. C., Lawson, J. O. J., Usman, A. M., Diaku-Akinwumi, I. N., Okolo, A. A., Israel-Aina, Y. T., … Adekile, A. D. (2018). A Multi-centre Survey of Acceptability of Newborn Screening for Sickle Cell Disease in Nigeria. *Cureus*, *10*(3). https://doi.org/10.7759/cureus.2354

Sickle Cell Disease Screening in Northern Nigeria: The Co- Existence of B- Thalassemia Inheritance. (n.d.). Retrieved November 14, 2022, from https://www.longdom.org/open-access/sickle-cell-disease-screening-in-northern-nigeria-the-co-existence-of-914-thalassemia-inheritance-40098.html

Sickle cell screening urged for newborns in Africa. (n.d.). Novartis. Retrieved November 14, 2022, from https://www.novartis.com/stories/sickle-cell-screening-urged-newborns-africa

Yarhere, I. E., Jaja, T., Briggs, D., & Iughetti, L. (2019). Newborn screening in Nigeria: Will incorporating congenital hypothyroidism with sickle cell disease improve neonatal screening programme? SCD and CH combined screening. *Acta Biomedica Atenei Parmensis*, *90*(2), Article 2. https://doi.org/10.23750/abm.v90i2.8485