

Letters to the Editor

Lessons learned from an International Summit on Newborn Pulse Oximetry Screening Programs

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On 7-9 December 2020, key leaders in public health, clinical practice, NGOs, and academic health in Latin America (Mexico, Bolivia, Colombia, Peru, Guatemala, Ecuador, Argentina) along with international experts from the United States, Philippines, Mongolia, China, Pakistan, and India, convened at the 1st Latin American Summit on Early Detection of CHD and Secondary Conditions to share knowledge about research, resources, health policies, and evidence-based implementation strategies to equip stakeholders better to improve neonatal health and survival through earlier diagnosis and access to timely interventions.

This forum was the first in a series aimed at accelerating the adoption of newborn pulse oximetry screening programs in Latin America by establishing a multi-national collaborative. The delegates were representing the countries committed to the principles of equitable, bilateral exchange of knowledge and resources to bolster newborn screening, particularly pulse oximetry screening in regions and nations without programs or in the early stages of implementation/expansion.

This initiative was led by the team from the BORN Project in Mexico, Newborn Foundation, and yielded three main learnings. First and foremost, newborn screening, including newborn Point of Care (POC) Screening for Congenital Heart Diseases (CHD) and secondary conditions, is an essential tool in achieving an earlier diagnosis, referral, and timely intervention – preventing morbidity, mortality, and disability associated with delayed or missed detection of critical health conditions. Newborn pulse oximetry screening has been added to the routine universal screening panel (RUSP) in the United States and a growing number of countries worldwide. As part of a public health program, CHDs have been assessed to affect 9 per 1,000 live births; approximately one-quarter of those children have critical conditions (CCHDs) requiring surgical intervention in the first weeks or months of life. CHD is the most common and deadly birth defect, accounting for 3 percent of all infant deaths and more than 40 percent of all deaths due to congenital malformations. Higher birth rates in low and middle-income countries, such as Mexico, increase disease burden in all parts of the world. Thus, it is vital to use lower-cost tools such as pulse oximetry in countries where the health systems lack economic resources to identify and treat babies with critical medical conditions.

In addition, the forum participants realized we should advocate from both medical education and in partnership with public health and civil societies, to impact the education and promotion of these projects at the population level, to provide the requisite data and frameworks for policymakers to create and implement mandated policies that for routine, uniform, and equitable screening. Screening should be a key component of public health systems in all countries, prioritized at the government level through policies, medical education, and public education. It is important to leverage technologies that complement new-

born screening, including the essential need for data collection and reporting, linking medical centers in the same country and specialized care centers for congenital heart diseases, and other conditions associated with hypoxemia in newborns – allowing seamless collaboration to optimize care and services for families impacted.

Secondly, there is an urgent need for partnership and collaboration between the public and private sector, at the local level, the country level, and between countries. This association has been successfully demonstrated in other regions worldwide and can be modeled for the Latin American collaborative. The BORN Project (Birth Oximetry Routine for Newborns) has been implemented across more than 210 hospitals in 12 countries – utilizing a framework of a hub and spoke pilot programs with robust data collection and routine briefings to public health officials to gain buy-in and ultimately accelerate the adoption of routine screening and standards of care. Additionally, when implementation hurdles are lower in private sector facilities, there should be pathways to inform and support program implementation within the public hospital system. The collaborative as a body agreed that public health mandates must include the private sector and adhere to regulatory requirements that ensure equitable adoption of screening for all newborns. Other international efforts (Pan African Workshop on Newborn Screening and the Asia Pacific Region Collaborative), the Every Breath Counts Coalition, and SDGs 3 (Health and Wellbeing) and 17 (Partnership for the Goals) show that international coalitions and partnership-based initiatives are essential to addressing continued gaps in neonatal health.

Finally, as in every Public Health intervention, there is a need for greater connectivity between early diagnosis, care, and outcomes. Real-time data collection systems aim to improve and assure the quality standards of care. Additionally, data allows stakeholders to have updated information for research aims, algorithm improvements, and optimization of screening as a tool to improve health outcomes. It is critical to bridge the gap between screening as an early identifier and ensuring these ba-

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abies are guided to the follow-up testing and care required. Telemedicine and care across institutional and geographic borders will be essential tools to realizing this need, while governments and funding agencies must rally around the infrastructure needs to ensure every baby requiring life-saving treatment can access it. Unify the results and even improve the public health case definitions. Depending on where a baby is born, these improvements may be local, national, and even international – built on a backbone of electronic information exchange and collaboration. Stakeholders must build routine connections with other data sources, including public health medical systems, and agree upon data to be collected and pathways to data-driven decision processes.

In conclusion, the convening bodies believe that by establishing this formal Multi-national Collaborative and signing onto the foundational “Queretaro Declaration,” the participating members will advance sustainable, scalable systems that can benefit additional countries in Latin American and beyond.

References:

1. *Empowering Newborn Screening Programs in African Countries through Establishment of an International Collaborative Effort -In an effort to explore new knowledge,*

and to develop meaningful collaborations for improving child health the First Pan African Workshop on Newborn Screening was convened in June 2019 in Rabat, Morocco.

2. Consolidating newborn screening efforts in the Asia Pacific region - [Carmencita David Padillo](#), [Bradford L. Therrill, Jr.](#), and on behalf of the Working Group of the Asia Pacific Society for Human Genetics on Consolidating Newborn Screening Efforts in the Asia Pacific Region

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Dear Dr. Orozco:

The importance of the BORN (Birth Oximetry Routine for Newborns) project cannot be overemphasized. As you pointed out, CHD is the most common birth defect and is usually implicated in less than ideal outcomes. Although these screening efforts began in the United States, thanks in no small part to one of your co-authors, universal screening is rapidly becoming worldwide.

The partnership that you speak of is critical in the application of this technology. As you elegantly pointed out, this partnership must transcend all boundaries regardless of socioeconomic or geopolitical considerations. However, screening and identification of CCHD must be coupled with an effective program to treat and, if possible correct those lesions (1) that would otherwise lead to significant morbidity and mortality, especially in areas of the world where strife is rampant. We must intervene for those most at risk.

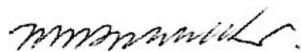
Telemedicine and care relocation must be promoted not only at the level of the individual country but by the region and the world. In this day of highly sophisticated cardiac interventions, it is inexcusable for us not to be able to provide access to all. (2)

I applaud your efforts to effect this change and look forward to great strides in the care of all patients with CCHD. It is my sincere hope that the World Health Organization will adopt and prioritize BORN so that we can achieve an optimal result.

References:

1. Goldstein M. Left Heart Hypoplasia: A Life Saved with the Use of a New Pulse Oximeter Technology. *Neonatal Intensive Care*. 1999;12(1).
2. Goldstein, B. *Humanity Beyond Borders*. *Neonatology Today*. Volume 15 Issue 8 Page 46-47

Sincerely,



Mitchell Goldstein, MD

Editor in Chief



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© 2006-2021 by Neonatology Today ISSN: 1932-7137 (online)

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