Newborn screening in Nepal: Early Diagnosis Matters

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A two days program on Newborn Screening (NBS) was organized by Bench to Clinic Research Center (BTC), Nepal, under the auspices of the International Federation for Clinical Chemistry and Laboratory Medicine (IFCC) and of the International Society for Neonatal Screening (ISNS) on 7-8 November 2025, with the objective to build a consensus on initiating a sustainable and equitable NBS Program in Nepal.

Day 1: Close Country Meeting, 7th November 2025, Hotel Square, Lalitpur, Nepal

Close country Meeting on Newborn Screening (NBS) successfully convened key national stakeholders and international partners, including representatives from WHO Nepal, UNICEF Nepal, Bench to Clinic Research Center (BTC), Nepal Pediatric Society, Nepalese Association for Clinical Chemistry (NACC), Nepalese Association for Medical Laboratory Sciences (NAMLS), Rare Diseases Society Nepal (RDSN), Paropakar Maternity and Women's Hospital (PMWH), Institute of Medicine, TUTH, Kathmandu University School of Medical Sciences, IFCC and ISNS on November 7, 2025. This meeting featured presentations on the current status, challenges, global best practices, as well as a robust roundtable discussion. A strong consensus emerged on the urgent need for a phased, collaborative approach and drafting policy framework as a foundational roadmap to initiate NBS in Nepal.

Opening Session
Dr. Vivek Pant (BTC) welcomed the participants, emphasizing that NBS is a critical public health intervention for preventing disability and mortality from congenital disorders, aligning with Nepal's commitments to child health and the Sustainable Development Goals.

Current Status of NBS
Dr. Santosh Pradhan (BTC) presented current status of NBS in Nepal including various activities on NBS from different stakeholders, studies done on NBS, currently available diagnostic platforms and availability of trained manpower for NBS.

Evidence and Clinical Need
Dr. Bijaya Mishra (RDSN) and Dr. Shailendra Bir Karmacharya (PMWH) presented compelling data from Nepali cohorts and clinical cases, demonstrating that late diagnosis of inborn errors of metabolism leads to severe, irreversible outcomes, underscoring the cost-effectiveness of early detection through NBS. Dr. Karmacharya discussed the feasibility of NBS programs in Nepal citing the work done at PMWH. Dr. Prajwal Paudel (PMWH) outlined major challenges: infrastructure gaps, need for trained human resources, logistical hurdles for sample transport, data management and ensuring equitable access across all regions.

Roundtable Discussion/Global Support
Prof. Dr. Dianne Webster, member of IFCC/ISNS Task Force on Global Newborn Screening, provided a global perspective, showcasing successful models from other low-and-middle-income countries and offering technical support for capacity building and protocol development. Dr. Rajesh Khanna, WHO SEAR, shared UNS guidelines and emphasized its role in providing normative guidance, policy advocacy, and technical assistance to integrate NBS within the National Health Policy. Ms. Chahana Singh Rana, UNICEF Nepal, introduced the "Early Identification and Early Interventions (EIEI)" tool including "Every Women Every Child" (EWEC) guidelines, highlighting its potential for training healthcare workers and creating family support pathways.
Dr. Aysha Habib Khan, Co-chair of IFCC/ISNS Task Force on Global Newborn Screening, suggested identifying a champion or a lead, followed by identifying the conditions to be screened and develop a feasibility plan. Prof. Dr. James R. Bonham (Virtual attendance), Co-chair of IFCC/ISNS Task Force on Global Newborn Screening, emphasized the importance to recognize Newborn Screening not just in terms of mortality, but also by the rest of its impact, the iceberg of morbidity addressed by it. He highlighted Newborn Screening as the pathway and processes, and advised to focus on foundations,

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connectivity and organization of Newborn Screening from early stage of its establishment for long term benefit. Dr. Balwinder Singh Chawla, Team Lead, Immunization Preventable Disease, WHO Nepal, focused on preparing the standard operating procedure, forming strong expert technical team and emphasized on NBS related researches.

Key Consensus Points

a. Phased implementation is critical: Start with a pilot program in 1-2 major tertiary hospitals focusing on 2-3 conditions including Congenital Hypothyroidism (CH)
b. Strong governance is essential: Establish a National NBS Committee under Ministry of Health and Population, Nepal, with sub-committees for technical oversight, laboratory quality, and training.
c. Public-Private Partnership (PPP): Leverage the expertise of professional societies for laboratory service, research and awareness.
d. Workforce Development: Training programs for nurses, midwives, and lab technicians on sample collection, handling, and reporting.

Day 2: CME, 8th November 2025, at Hotel Vivanta, Lalitpur, Nepal

Around 80 participants joined the CME which was approved by Nepal Medical Council CPD Unit with 5.5 CPD points. Pediatricians, obstetricians, laboratory professionals, midwives, and nurses were actively engaged in the program and had a fruitful discussion on establishing Newborn Screening in Nepal.

Highlights

Dr Aysha highlighted the contribution of IFCC and ISNS in global NBS. Dr. Jeevan Adhikari, Pathologist in Standalone Laboratory, shared his experience on establishing the NBS set up. Ms. Marika Kase, member of IFCC Task Force on Global Newborn Screening, explained on various technologies that can be used for NBS. Prof. Dr. Carmencita Padilla (Recorded Session) highlighted on different models that can be implemented for starting NBS. She foresighted the challenges that might be encountered during initial stages of establishing NBS. Dr. Aysha and Dr. Shreehari M Nair form Kerala Health Services, India, shared their experiences in starting the NBS in Pakistan and Kerala respectively. Prof. Dr. Webster enforced that Congenital Hypothyroidism (CH) could be the first candidate to start NBS in Nepal and discussed various clinical and laboratory aspects of CH.

The day successfully concluded emphasizing the importance of stakeholders including clinicians, laboratory professionals, national societies, and hospitals working on NBS, to work as a single unit under the governance of Health Ministry of Nepal for sustainable nationwide screening program. International societies including IFCC, ISNS and United Nation agencies WHO Nepal and UNICEF Nepal, committed to provide technical support for this initiation.



CME participants



Speakers, Organizers, Volunteers and Sponsors at closing session

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Organizers with IFCC/ISNS representatives



Participants for Close Country Meeting



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