

Webinar on Birth Defects: Every Journey Matters

Date: 05 March 2024

Time: 1100 to 1300 hours India time

Concept Note

Background

The South-East Asia Region (SEAR), accounting for 26% of the world's population, had made unprecedented progress in reducing child mortality during the MDG era, and the efforts are being sustained to achieve the SDG targets. As per the 2021 estimates, the regional Under-5 Mortality Rate (U5MR) is 29 per 1000 live births compared to the global U5MR of 38 per 1000 live births. Five Member States (MSs) in the region (DPR, INO, MAL, SRL, THA) have already achieved the SDG-3.2 target for U5MR (that is, 25 or less under-5 deaths per 1000 live births). However, the contribution of birth defects to child mortality in SEAR has increased from 4% to 11% between 2000 and 2021 compared to the global increase from 4.6% to 8% observed during the same period. Birth defects contribute to more than 20% of under-5 deaths in four out of the five MSs which have achieved the SDG-3.2 target (DPRK, MAV, SRL, THA). Congenital heart anomalies, neural tube defects, and other congenital anomalies combined contribute to the maximum mortality from birth defects.

Recognizing birth defects as important causes of childhood death, chronic illness and disability in many countries, the 63rd World Health Assembly (WHA) adopted a resolution (Resolution 63.17) on Birth Defects in 2010 calling all the member countries to promote primary prevention and improve the health of children with congenital anomalies by (a) developing and strengthening registration and surveillance systems; (b) developing expertise and building capacity; (c) strengthening research and studies on aetiology, diagnosis and prevention; and (d) promoting international cooperation.

Since 2014, WHO SEAR has supported all countries of the Region to drive rapid, sustained reductions in maternal, newborn and child mortality, which has included targeted action to prevent, detect, manage and care for birth defects. The region adopted an integrated approach to implement interventions for the prevention and treatment of birth defects in the existing national programmes for RMNCAH, immunization, nutrition, NCD, and related programmes. Presently all eleven countries have national plans for prevention and control of birth defects guided by the Regional Strategic Framework published in 2014. The region further supported national capacity building efforts in Member States for the identification, prevention, and management of birth defects through situation analysis and development of

communication strategies, policy briefs, toolkits, manuals, and standard protocols for specific birth defects contextualized to country needs.

Additionally, SEAR has established a facility-based online surveillance system for birth defects known as the South-East Asia Region Newborn Birth Defect (SEAR-NBBD) in collaboration with CDC Atlanta, USA, with tertiary hospitals in six countries contributing to it (Bangladesh, Bhutan, India, Maldives, Myanmar, Nepal). To date, the database has recorded nearly 4.6 million births in the Region, including 50,000 infants born with birth defects. All countries have initiated routine childhood rubella containing vaccination and the region has achieved an average coverage rate of 92% for the first dose. Five countries (Bhutan, DPR Korea, Maldives, Sri Lanka, Timor Leste) have eliminated rubella and thus not reported any case of congenital rubella syndrome.

In 2022, WHO released the updated guideline “Recommendations on maternal and newborn care for a positive postnatal experience”. One of the key new recommendations was on Universal Newborn Screening (UNS) for three conditions – hearing impairment, eye abnormalities and neonatal hyperbilirubinemia. In order to facilitate implementation in MSs, the SEARO has developed an implementation guidance for all three conditions working together with a group of technical/subject-matter experts from the region.

The World Birth Defects Day has been observed annually on 03 March since the year 2015, to advocate for public health surveillance, research, and prevention of birth defects, along with improved care and treatment for affected individuals. This year SEAR aims to utilize this opportunity to not only bring more visibility for this emerging priority, but also share the regional implementation guidance and training videos with MSs and partners.

General objective

To mobilize commitment and actions for priority attention to ‘prevention and management of birth defects’ among the Member States, and disseminate the Implementation guidance and training videos on Universal Newborn Screening (UNS)

Specific objectives

- To share information about the magnitude of birth defects, its contribution to under-5 deaths, and its prevention and management
- To share best practices and lessons learnt on surveillance of birth defects
- To disseminate the regional implementation guidance and training videos on UNS for three conditions (hyperbilirubinemia, eye abnormalities, hearing impairment)

Expected participants

- Programme managers/professionals/academic and research institutes/NGOs/INGOs interested in prevention and management of birth defects
- Partner agencies (UNICEF, USAID, BMGF, CDC-US, WHOCC, etc)
- Focal Points from WCOs and HQ
- Staff from WHO Regional Office for South-East Asia

Agenda

Time	Topic	Speakers
11:00 – 11:05	Welcome & Objectives	Dr Neena Raina Director, Department of UHC/ Family Health
11:05-11:15	Opening speech	Ms Saima Wazed Regional Director WHO-SEARO
11:15-11:30	Release of the Implementation guidance on Universal Newborn Screening, followed by training videos	
11:30-11:40	Birth defects Prevention and management in South-East Asia Region	Dr Rajesh Khanna Medical Officer Newborn, Child and Adolescent Health
11:40-12:30	Sharing of best practices	
11:40-11:50	Journey from facility-based surveillance to DHIS-II in Bangladesh	Dr. MD Abdul Mannan Professor (<i>Former Chairman</i>) Department of Neonatology Bangabandhu Sheikh Mujib Medical University Dhaka, Bangladesh
11:50-12:00	Experience of facility-based surveillance led by the Ministry of Health, Sri Lanka	Dr Kapila Jayaratne Senior Lecturer (Community Medicine) Faculty of Medicine University of Colombo, Sri Lanka <i>Formerly National Programme Manager (Child Morbidity and Mortality)</i> <i>Family Health Bureau, Ministry of Health</i>
12:00-12:10	Monitoring quality of Newborn Birth Defects Database (NBBD) in South East Asia Region	Dr Neerja Gupta Additional Professor Division of Genetics, Department of Pediatrics All India Institute of Medical Sciences Delhi, India
12:10-12:20	Learnings from 10 years of community-based surveillance of birth defects	Mr. P. Mohanty Director Survival for Women and Children Foundation Panchkula, Haryana, India
12:20-12:30	Universal Newborn Screening in Thailand: introduction and scale-up	Dr Chulaluck Kuptanon, Head of Genetics Division Department of Pediatrics Queen Sirikit National Institute of Child Health Thailand
12:30 – 12.50	Question and Answers	
12:50 – 13:00	Summary and conclusion	