



4TH INTERNATIONAL
CONFERENCE ON
**Small Island
Developing States**
27-30 MAY, 2024
ST. JOHN'S, ANTIGUA AND BARBUDA

SIDS4 Conference Side Event

Investing in Tomorrow: Strengthening Newborn Screening for Resilient and Prosperous Futures in Small Island Developing States

**29 May 2024
7:00 to 9:00 pm EDT
Remote Zoom Event**

**Organized by: CLAN (Caring & Living As Neighbours),
@MATES4Kids (Maximising Access To Essential Supplies
For Children), Lehigh University, and ISNS (International
Society for Neonatal Screening)**

Background on the event

Despite occupying less than 0.5% of the world's surface, Small Island Developing States (SIDS) are spread across three key regions: the Caribbean; the Pacific; and the Atlantic, Indian Ocean, and South China Sea (AIS). SIDS are at the forefront of multiple global crises. These remote economies are highly vulnerable to natural disasters and constantly face a cycle of environmental challenges and recovery efforts, testing their resilience and ability to sustain their communities and economies. This side event emphasizes the urgent need to scale newborn screening (NBS) efforts to improve health outcomes for in children in SIDS. Universal NBS programs enable early diagnosis and management of treatable childhood non-communicable diseases (NCDs), helping to reduce inequitable and preventable mortality and morbidity. Currently, most low, lower-middle, and even some upper-income countries do not universally screen all newborn for the most common childhood NCDs, which otherwise lead to severe disability and death. The lack of universal NBS programs exacerbates child health inequities and imposes an unacceptable burden of preventable child morbidity and mortality in lower-income countries. Achieving equitable access to universal NBS programs is critically needed.

Key Issues discussed

- *Summary Overview of NBS Data Relating to SIDS. How do we Compare Globally? Brad Therrell & Carmencita Padilla.* Presenters demonstrated a comparative analysis of NBS across different regions including Latin America and the Caribbean, Sub-Saharan Africa, North America, and the Asia Pacific. The analysis highlights that very few SIDS have comprehensive NBS programs. On average, SIDS are among the poorest countries globally, with 22 out of the top 100 countries being SIDS, making NBS development a challenge. Global collaboration is needed to improve NBS in SIDS.
- *Clinical Perspective of NBS in the Pacific, Paul Hofman.* To establish and expand screening programs in the Pacific, key elements are needed: local advocates, financial commitment, proper infrastructure for blood testing and follow up/repeat testing, and patient assessment expertise. NBS in limited-resource SIDS settings faces challenges due to isolation. Currently, NBS in the Pacific is available only in wealthier countries like Australia, New Zealand, and USA (Hawaii). Expansion efforts include American Samoa and discussions initiated in the Solomon Islands. Fiji has shown interest but lacks government support, highlighting the need for Department of Health backing.
- *Newborn Bloodspot Screening for Congenital Hypothyroidism in Honiara- A Pilot Project Using Cord Blood, Shubha Srinivasan & Titus Nasi.* A three-year pilot project for NBS for Congenital Hypothyroidism (CHT) is being developed in Honiara, with plans to expand to the rest of the Solomon Islands once feasibility is established. The project aims to improve early diagnosis and treatment of CHT, enhancing long-term outcomes for affected children and preventing permanent developmental disabilities and stunted growth. It also seeks to determine the incidence of CHT in children in Honiara and build local capacity for NBS on-site at National Referral Hospital.
- *Challenges and Barriers to Newborn Screening in the Pacific, Sir Collin Tukuitonga.* Pacific SIDS face numerous challenges to NBS: small, scattered populations, inadequate infrastructure, workforce shortages, outdated healthcare facilities, unreliable pharmaceutical and medical supplies, and insufficient healthcare financing. Climate crises like rising sea levels, ocean acidification, contaminated water sources, and extreme weather events worsen these issues. Typically, 5% of a country's GDP should be

allocated towards healthcare, but many SIDS spend less than the recommended amount (Fiji, Papua New Guinea, Samoa, Solomons, Tonga, Vanuatu). These significant challenges impact healthcare delivery in Pacific SIDS, particularly for implementing and sustaining NBS programs.

- *What Can We Learn from Other Countries? Update from Indonesia, Muhammad Faizi.* In 2023, Indonesia established Congenital Hypothyroid screening as a national program. The country has had a focus on training healthcare workers for NBS screening. The 2024 goals are to increase the coverage of babies screened and add screening for Congenital Adrenal Hyperplasia (CAH), Glucose-6-Phosphate Dehydrogenase (G6PD), critical congenital health diseases, and hearing impairments. NBS coverage rapidly expanded in Indonesia from 2.3% in 2022 to 65% in 2023, with a target of 90% in 2024.
- *Community Development Grants, Kate Armstrong.* @MATES4Kids has awarded six community development grants to five CAH communities around the globe. Colombia and Sri Lanka have taken steps towards supporting CAH communities by organizing CAH Club meetings to share necessary medical information, develop resources, and build a support network for children and families living with CAH. During the 77th World Health Assembly, @MATES4Kids awarded grants to CAH communities in Uganda, Solomon Islands, and Kenya to aid in reducing preventable mortality associated with CAH by 30% by 2030.

Key recommendations for action

- Establish a structured approach to exchanging knowledge, sharing successes, and learning from experiences of others to contribute towards scaling access to NBS and achieving universal coverage in SIDS.
- Promote a comprehensive approach to NBS that addresses the WHO's Six Building Blocks for Health System Strengthening and promotes and protects the rights of children diagnosed with NCDs through NBS.
- Engage Departments of Health to aid in securing funding and developing nationwide NBS protocols.
- Facilitate a Heads of Health Meeting for Asia-Pacific region to bring together heads of government, Ministry of Health officials, WHO representatives, and other key stakeholders to secure ministerial commitment and political support for NBS.
- Acknowledge the power of a regional approach to driving change. Where possible endorsement of NBS by regional managers and leveraging local data to inform funding and policy decision making.
- Raise awareness of the benefits of NBS to children and countries with specific focus on cost-benefits.
- Share the @MATES4Kids Consensus Statement and CLAN Child-Friendly Rights Flyer to help with ongoing capacity building and awareness raising.