

"Newborn Screening is a gift of life."

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Interview with Carmencita Padilla, Professor of Paediatrics at the College of Medicine, University of the Philippines.

### MEET PROF. PADILLA



As Newborn Screening Awareness Week approaches in the first week of October, we invited Professor Carmencita Padilla, Professor of Pediatrics at the College of Medicine, University of the Philippines to share the successes and struggles of implementing a NBS programme across the over 7000 islands of the Philippines.

Professor Padilla pioneered the introduction of newborn screening (NBS) in the Philippines and helped author legislation making NBS mandatory in the Philippine Archipelago.

This conversation is the first of a series of interviews with members of the Panel of Experts, a group of over 200 clinicians, researchers, administrators, academics and civil society leaders, supporting the development of the [Global Network for Rare Diseases](#).

### INTERVIEW

#### *Why did you begin to advocate for NBS Programme in the Philippines?*

Newborn screening is a gift of life. It is about valuing and saving lives. I think it should be our responsibility to give every newborn the opportunity to have a normal life. A simple test can offer a future to newborns.

#### *Can you tell us how the NBS programme started and what were the challenges and enablers?*

The NBS programme has been developed and will be sustained thanks to everyone's support – nurses, midwives, physicians, geneticists, and parents – because everyone on the ground passionately believes it saves lives. This commitment was demonstrated throughout the pandemic; practitioners used helicopters, the army and the navy to collect samples from the islands.

The NBS programme was started in 1996 with the support of 24 hospitals, which increased to 300

hospitals when the NBS legislation came into force. It took another decade to expand the NBS programme to 7000 hospitals.

Initially, it was critical to collect data on the ground to secure support from the government, but even with the data, implementation challenges across a large group of islands became a barrier to realizing the NBS programme, so we needed support from all stakeholders.

There were five key enabling factors that supported the launch and implementation of the programme - adopting the NBS law; including insurance coverage of NBS test; building a technical partnership with the government; establishing accreditation and licensing requirements; and putting the responsibility of informing the family with the physician. All these factors were included in the legislation.

### ***What has been the benefit of the programme?***

The NBS programme has already saved more than 200 000 children by providing an accurate diagnosis and enabling them to access the care they need. These people have become champions for NBS, and now they are pushing the government and advocating for the importance of sustaining the programme.

### ***What is the importance of NBS and diagnosis for the Global Network for Rare Diseases?***

The NBS programme provides infrastructure and a network of hospitals and continuity clinics, which we can build on and develop into rare disease clinics.

As we finish the 5-year strategic rare disease plan on Rare Diseases, we are partnering with over 30 professional societies to understand how best we can treat people who have been diagnosed with a rare disease. This expanded model that integrates NBS and rare disease clinics will coordinate screening, diagnosis and care across the country enabling expertise to travel to where the patients live.

The successes and challenges of establishing the NBS programme can be shared in the Global Network, and this sharing of experience will help support and encourage other countries as they set up NBS programmes.

### ***How will you mark NBS week?***

Communities around the Philippines will organize parades, and hospitals plan to host events to raise awareness, share expertise and report NBS data.

Our biggest success is that many more newborns have the opportunity to grow up and fulfil their dreams and live a normal life.





**To mark Newborn Screening Week, you can:**

- Visit the [Newborn Screening Reference Center \(NSRC\)](#).
- Spread the word on social media by adding #2022NBS or #NBSsaves to your post



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