

Newborn Screening Continuity Clinics in Davao and Caraga Regions

Genelynne Juruena Beley¹

¹Newborn Screening Center - Mindanao, Southern Philippines Medical Center, JP Laurel Ave., Davao City, Philippines

Correspondence
Genelynne Juruena Beley,
gen_juruena@yahoo.com

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ESTABLISHMENT

Following the enactment of Republic Act (RA) 9288 or the Newborn Screening (NBS) Act of 2004, newborn screening centers (NSC) were established to conduct mandated laboratory tests and provide recall and follow-up services for newborns with heritable disorders.¹ Local government units (LGU) ensured the availability of these services in rural/city health units, lying-ins, and local hospitals, with monitoring performed by physicians, subspecialists, or rural health units.²

In 2014, the Department of Health (DOH) issued Administrative Order 2014-0035, establishing newborn screening continuity clinics (NBSCC) to serve as referral centers for the long-term management of positive cases, including counseling, treatment, monitoring and follow-up.³ Initially, 14 continuity clinics were set up.⁴ Each NBSCC must be based in a tertiary hospital, ideally with one clinic per region, as designated by the DOH. Over time, additional provincial continuity clinics were established. One of the existing clinics is found in the Southern Philippines Medical Center (SPMC), which serves patients from Davao Region (Region XI) and Caraga Region (Region XIII).

The Davao NBSCC was established under Dr. Leopoldo J. Vega, then SPMC Chief of Hospital, and led by Dr. Genelynne Beley. Together with the follow-up nurse, Dr. Beley ensured timely patient recall, appropriate medical management per newborn screening protocols, and referrals to subspecialists and hospital units. Before the NBSCC establishment in SPMC, diagnosed patients were managed by general pediatricians, with no integrated continuity of care within the extended services of the NBS program.

GOALS

In addition to patient consultations, the NBSCC team actively promotes various advocacies, including conducting lay fora and support groups for patients with glucose-6-phosphate dehydrogenase deficiency, congenital hypothyroidism, and congenital adrenal hyperplasia. The team also launched

the annual “Reunion of Saved Babies,” celebrating the lives of diagnosed patients.

Over time, unrecalled and lost-to-follow-up cases have steadily increased. Challenges include failure to return after initial consultation, unrecalled cases, and poor treatment compliance—often due to financial constraints, transport issues, limited awareness about the disorder, family conflicts, and poor access to specialized care, particularly in geographically isolated and disadvantaged areas, as in some parts of Caraga Region.

To address these issues, the NBSCC team developed a long-term plan to establish at least one satellite clinic per province, prioritizing the Caraga Region, followed by the Davao Region. These clinics, aligned with designated NBSCCs, were strategically set up to enhance tracking and follow-up care for patients diagnosed with one of the conditions included in the NBS panel.⁵ The first was launched at Agusan del Norte Provincial Hospital in Butuan City in March 2020, followed by clinics in Surigao del Sur, Surigao City, and Agusan del Sur over the next three years. With these clinics and the hiring of a regional NBS nurse tasked with locating unrecalled and lost-to-follow-up patients, Caraga Region’s recall rate significantly improved. Patient compliance also rose as follow-up visits and repeat laboratory tests became more accessible, eliminating the need to travel to SPMC in Davao City.

In 2022, in collaboration with the DOH Center for Health Development, a satellite clinic was established at Davao Regional Medical Center, later transitioning into a stand-alone clinic. That same year, satellite clinics were also launched at Davao del Sur Provincial Hospital and, in 2023, at Davao Occidental General Hospital. The one in Agusan del Norte Provincial Hospital became a stand-alone clinic, joining 17 others nationwide.

With guidance from the Center for Human Genetics and Services (CHGS) DOH funding, the NBSCC team launched the Multidisciplinary Clinic Consultation (MDC) in October 2023. This one-day consultation brought together specialists from Pediatric Metabolism, Endocrinology,



Developmental Pediatrics, Neurology, Hematology, Gastroenterology, and other departments, including Dental Medicine, Ophthalmology, Otorhinolaryngology—along with geneticists, genetic counselors, dietitians, and social counselors—serving around 50 patients in a single venue. Due to its success, MDCs are now held yearly to reach more patients in Davao Region and nearby regions lacking specialist care. The initiative has since grown into a collaborative effort among different NBSCCs in Mindanao and is being replicated by other clinics, with regional offices now allocating funds for similar programs. The NBSCC team also extended services to patients with birth defects through close coordination with the CHGS.

CURRENT OPERATIONS

Long-term follow-up and management begin once a confirmed positive case is endorsed by the NSC's short-term follow-up team—typically after diagnosis and treatment initiation. The NSCs forward the roster of confirmed patients, along with management protocols and required follow-up laboratory procedures, to the NBSCC. The NBSCC

team contacts patients to arrange treatment, ongoing care, and monitoring. When needed, referrals to subspecialists within the facility or region are made. For genetic consults unavailable locally, the Telegenetics Referral System is used to provide remote evaluations.³

Despite the best efforts of the SPMC NBSCC team, many patients fail to complete follow-ups, hindering progress tracking. To address this, the NBSCC team conducts regular home visits in Davao City to locate lost-to-follow-up and unrecalled patients, aiming to improve recall rates and reduce adverse outcomes.

FUTURE PLANS

Currently, 33 continuity clinics operate within tertiary and government hospitals across all 17 regions of the Philippines.⁵ Over the years, the SPMC NBSCC has seen a significant rise in patient volume, driven by the growing number of children diagnosed through the NBS program. The establishment of satellite clinics in the Davao and Caraga Regions has further improved access to long-term follow-up care, optimizing continuity of care for patients in these areas.

Contributors

GJB conceptualized this article. GJB wrote the original draft, performed the subsequent revisions, approved the final version, and agreed to be accountable for all aspects of this article.

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