

NCR Readies Expanded Newborn Screening Advocacy



Tarpaulins around NCR announce NBS activities.

The Department of Health–National Capital Region (DOH-NCR) Office prepares for the implementation of the Expanded Newborn Screening (NBS) Program by scheduling several activities for the first half of 2014.

The region's theme this year, "Ilang Patak, Maraming Sanggol ay Ligtas!", was printed on tarpaulins. These were then distributed to the different local government units.

An Expanded Newborn Screening Program Orientation and Program Implementation Review is scheduled in May, which will be attended by the NBS coordinators and partners from all the DOH hospitals and local government units in the region. The review will orient the participants on the 28 metabolic disorders included in the Expanded NBS as well as on the Newborn Screening Continuity Clinics. Issues and concerns regarding NBS daily operations will also be tackled.

Scheduled in June are four batches of Expanded NBS Orientations, which will gather representatives from all the newborn screening facilities in NCR.

NBS National and Regional Situationer 2013

The numbers are up! And they reflect the success of newborn screening (NBS) in the Philippines.

In 2013, 90,931 newborns were screened positive by the National Comprehensive Newborn Screening System.

These babies were saved from the six disorders included in the newborn screening panel: Congenital Hypothyroidism (CH), Congenital Adrenal Hyperplasia (CAH), Phenylketonuria (PKU), Galactosemia (Gal), Glucose-6-Phosphate Dehydrogenase Deficiency (G6PD deficiency), and Maple Syrup Urine Disease (MSUD).

The total number of health facilities offering newborn screening increased to 4,945, after 682 health facilities were added to the list. These include Department of Health (DOH)-retained hospitals, local government unit hospitals, private hospitals and clinics, regional health units (RHUs), Municipal and Barangay Health Centers, and lying-in clinics.

The DOH, along with its field implementers at the Regional Offices and Newborn Screening Reference Center, has incessantly developed strategies to ensure the accessibility to parents of newborn screening at all levels. These efforts and strategies brought the NBS coverage to 57.3% by end of 2013.

National Scenario

The number of newborns screened increased from 49.6% in December 2012 to 57.3% in December 2013. Figure 1 shows the national newborn screening coverage annually since the

passage of Republic Act No. 9288, the Newborn Screening Act of 2004.

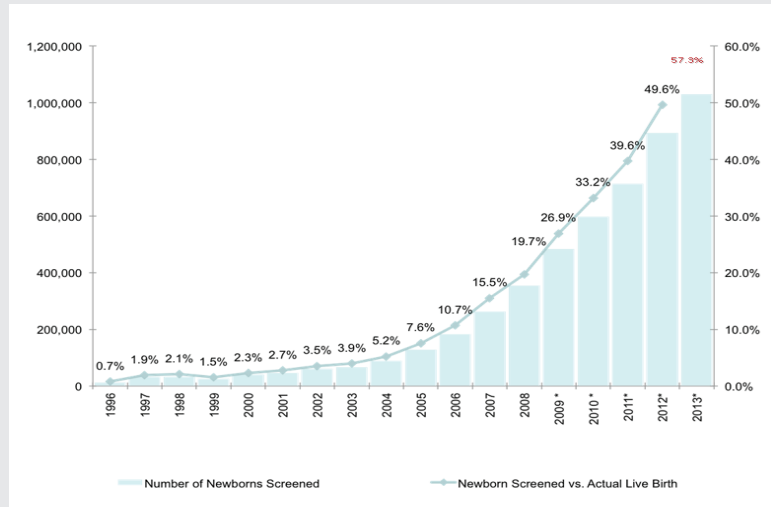


Figure 1. Annual national newborn screening coverage

The enactment of RA 9288 in 2004 gave way for more facilities to launch their newborn screening programs. There was an observable increase per year in facility enrollment and participation after the law had been passed. The number of newborn screening facilities (NSFs) has continually increased up to now. Table 1 shows the annual increase in the number of NSFs in the country from 1996 to 2013.

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Indomitable . . . from page 1

In the afternoon of November 7, 2013, with the storm signal raised in the city, local government units declared class and work suspensions to prepare for the typhoon. But the skies were clear. No winds, no rain. Nothing had been alarming at all.

Then, the next day, the most powerful storm in recorded history made landfall. It showed off its monstrous strength in Guiuan, Eastern Samar.

Once again, we started calling patients and partners with whom we had spent the Newborn Screening Awards just days ago. We tried to reach 22 awardees who were from Eastern Visayas; two of the worst hit provinces were from this region—Leyte and Eastern Samar.

The devastation in the Tacloban City was unthinkable. All efforts to communicate with newborn screening facilities and patients in the affected areas were futile. It took about 14 days until we started hearing from them again. Many of them had lost their homes and properties. But all were still alive, living with relatives in other regions.

The winds and the storm surge damaged 432 health facilities in MIMAROPA and in Western, Central, and Eastern Visayas. DOH Eastern Visayas regional office was also destroyed.

The Aftermath

To evaluate and assess how NSC-V can help the affected areas, we and the DOH Regional Offices conducted facility visits that started on December 19, 2013.

By the time we had reached the towns in Leyte in January 2014, most of the health facilities were already operational despite an almost complete loss of infrastructure. We had no



Dominic Buensalido (leftmost) and DOH-RO Regional Nurse Coordinator Marvin Allen Guy-Joco (rightmost) visit Leyte Provincial Hospital.



Dr. Benedicto O. Garcia (center), Chief of Hospital, AMDMH, shares his story of Yolanda. According to him, the hospital did not stop its operation during the height of the typhoon.

newborn screening kits, no electricity, a handful of staff, and tons of logistical issues to contend with.

In northern Cebu, we were greeted by torn roofs and broken glass doors and windows. But health facilities continued its services. During the next visit in February, the couriers were already in operation and other logistical alternatives were identified.

Overwhelming Support

It is indeed in times of adversity that we see true *bayanihan*.

Local government officials immediately provided power generators and emergency supplies to their respective areas of responsibility. Foreign volunteers put up tent hospitals to attend to those who need urgent medical attention.

NSC-NIH, NSC-SL, and neighboring hospitals and centers accepted our referrals. These referrals were patients who need urgent medical needs and who were on our recall lists—both in our short- and long-term follow-up programs. NSC-V distributed newborn screening kits to the different affected facilities in the three badly hit regions and replaced damaged cards for free.

Realizations

As part of newborn screening, we have been given the honor and opportunity to work with resilient people. Disasters not only destroy physical structures but also affect hearts and spirits. The task seemed insurmountable at first, but all we needed was to slowly gather the broken pieces and rebuild.

It is now our chance to make a better and more effective system than ever before.

Dominic Buensalido is a Project Development Officer of the NSC-Visayas since 2010. He and his family lost their home in Northern Iloilo to supertyphoon Yolanda.

IN FOCUS

Reaching Out to the Tirurays



Staff and patients show that the NBS program is as active and effective in South Upi Municipal Hospital as in everywhere else.

South Upi, also known as Timanan, is located in Maguindanao and home to most of Tirurays, an ethnic group in the province.

The primary sources of income of the Tirurays are farming, hunting, fishing, and basket weaving. Meanwhile, those living in the mountains engage in dry field agriculture, supplemented by hunting and the gathering of forest products.

But the Tirurays are not of touch from newborn screening (NBS).

South Upi Municipal Hospital started to implement NBS in 2010 from scratch. NBS was not a familiar concept to the community especially in far-flung municipalities, and parents did not recognize the significance of NBS.

Also, parents needed further motivation and convincing to have their babies screened despite economic and accessibility concerns.

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DOH-Regional Office-Region XII Kicks Off 2014 NBS Training

The DOH-Regional Office–Region XII conducted its first batch of Newborn Screening (NBS) Training in 2014 at Villa Princessita Hotel, Koronadal City, February 12-13.

The training provided inputs on the proper sample collection. Some of the participants were among the Newborn Screening Facilities in Sultan Kudarat Province with high unsatisfactory samples in 2013.

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IPHO-Maguindanao Honors NSC-Mindanao

The Integrated Provincial Health Office (IPHO) of Maguindanao recognized Newborn Screening Center–Mindanao (NSC-M) as one of their Valued Health Partners in a testimonial dinner held at the Rizal Garden Oasis, Davao City, on February 20, 2014.

IPHO-Maguindanao cited the unwavering support given

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DOH-Regional Office-Region XIII Holds Implementation Review

Aiming to increase the newborn screening coverage, the DOH-Regional Office–Region XIII conducted a Program Implementation Review (PIR) among coordinators of Agusan del Norte on January 28-29 and Agusan Del Sur on January 30, 2014.

The Agusan del Norte PIR was attended by more than 50

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IPHO-Lanao Del Sur Holds NBS Training

The Integrated Provincial Health Office (IPHO)–Lanao del Sur under Dr. Alinader Minalang and in cooperation with the Newborn Screening Center–Mindanao (NSC-M) conducted Newborn Screening Training at Jim's Coffee, Marawi City, on February 11-13, 2014.

The activity gathered 30 health personnel from 15 different Rural Health Units (RHUs) in Lanao del Sur and

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NSC-CL Conducts First Reunion of Saved Babies



To protect and promote the right of affected children to survival and full and healthy development, the Newborn Screening Center–Central Luzon (NSC-CL) held the Reunion of Saved Babies at the PS Building, Angeles University Foundation, Angeles City, January 11.

Eleven saved babies who were confirmed to have conditions under the panel of disorders being tested under the Newborn Screening Program (except G6PD) and their parents or guardians from Region 3 attended the said activity.

Dr. Florencio Dizon, NSCCL Unit Head, gave the welcome remarks, while Dr. Michelle Miranda, Laboratory Manager, delivered an inspirational message.

Dr. Wilson Cua, a pediatric endocrinologist and medical consultant of the NSCCL, gave a lecture on congenital metabolic disorders and their prompt managements.

DOH-Regional Office-Region XII

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Dr. Conchita Abarquez, Newborn Screening Center–Mindanao (NSC-M) Unit Head, and Sheila Mae Guillaran, NSC-M Program Manager, were among the resource speakers, together with Mary Agnes Panton, DOH-Region XII NBS Nurse Coordinator.

At the end of the training, the participants committed to practice the proper way of collecting the NBS samples and to motivate the parents as well as other health workers on the importance of NBS.

a testimonial and shared her experiences on how newborn screening helped save her child's life.

Also part of the program were parlor games, which were facilitated by Roland Alcantara, Project Development Officer.

Maria Elissa Veronica Benipayo, Program Manager, gave the closing remarks and also thanked the participants and the supporters of the program.

Courier partners and laboratory supplies providers of the Center helped fund the activity. *NDelaCruz*



Participants of the DOH-RO-Region XII NBS Orientation and Heel Prick Training pose for a quick photo during the training sessions.

DOH-RO-Region XII plans to conduct three batches of NBS Training in 2014 to update the new NBS Coordinators as well as to refresh health workers on proper sample collection which will eventually help increase the region's coverage. *MAPanton*

NBS National . . . from page 2

Year	Annual Total	Annual Cumulative
2004	70	393
2005	369	762
2006	471	1,233
2007	386	1,619
2008	507	2,126
2009	391	2,517
2010	600	3,117
2011	547	3,664
2012	599	4,263
2013	682	4,945

Table 1. National cumulative growth since the enactment of RA 9288, 2004-2013

At the end of 2013, there are more than 4900 NSFs throughout the country—an increase of 13.7% from its annual cumulative count.

Regional Scenario

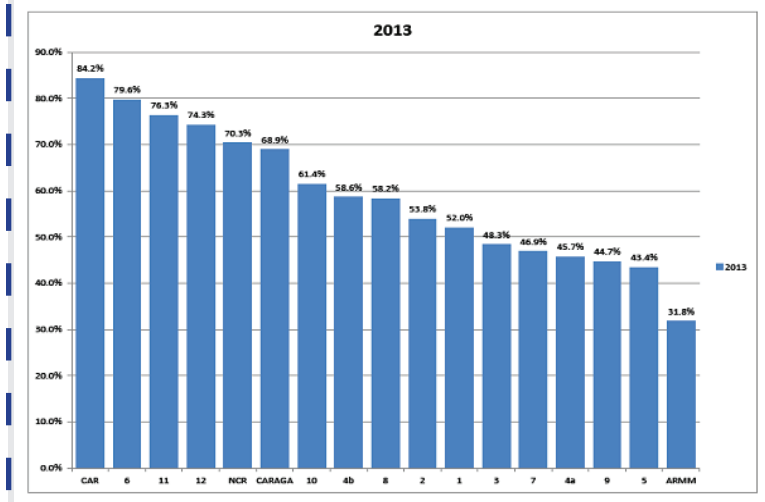


Figure 2. 2013 coverage of each region

In general, the number of newborn screened increased in all regions.

- The top three regions are the following:
- Cordillera Administrative Region (CAR), 84.2%
 - Region VI (Western Visayas), 79.6%
 - Region XI (Davao), 76.3%

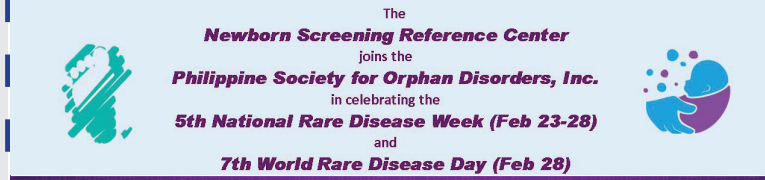
IPHO-Lanao Del Sur . . . from page 4

featured lectures from Amerah Matuan and Perly Bermudez, NSC-M Project Development Officers.

The lectures were followed by a three-batch practicum on actual heel pricking. The first batch went to Amai Pakpak Medical Center on the first day, while the second and third batches headed to Bubong and Ramin RHUs and to Marawi Doctor's Clinic, respectively, for their hands-on.

IPHO-Lanao Del Sur has five district hospitals, two RHUs, and other private hospitals which are already accredited as newborn screening facilities.

Through the training, both NSC-M and IPHO-Lanao del Sur are hopeful that there will be more facilities in Lanao del Sur providing newborn screening in their areas. *SADescallar*



VOLUNTEER YOUTH LEADERS FOR HEALTH

VYLH Promotes Awareness on Rare Diseases



Rare Disease Day participation from the active students of Mountain View College | Mt. Nebo, Valencia City | February 28, 2014 | Plendy Catalan

Presidential Proclamation No. 1989, issued on February 8, 2010, mandated the Philippine adaptation of the Rare Disease Day. The proclamation declared the fourth week of February as the National Rare Disease Week.

This year, the 7th World Rare Disease Day has the theme "Join Together for Better Care." The Volunteer Youth Leaders for

Health (VYLH) helps in the international information campaign for public awareness on the nature and medical management of rare diseases and for full support from both public and private sectors for the special needs of children affected by rare diseases.

In Mindanao, VYLH adopted diverse strategies in the observance of the celebration. Volunteer youth leaders from Caraga organized a university-wide pinning of blue gene ribbons, posting of Rare Disease fansigns, playing of PSOD-AVP presentations in the school lobby, and hand-printing a "Tree of Hope."

Meanwhile, there were room-to-room campaigns, public address announcements, and wearing of gene ribbons spearheaded by students and professors of Mindanao State University-College of Medicine, San Isidro College, Impasugong and Balila Elementary Schools, and the Mountain View College.

Stakeholders, too, were in it as expressions of support were heard from Jinglong Electronic Billboards, E&G Learning Center, Globe Telecommunications Company in Bukidnon, Bounty Fresh Food, Inc., St. Louis Review Center in Pagadian, Oro Integrated Cooperative in Aglayan, BPH-Maramag, CHO-Malaybalay, CHO-Butuan, Don Carlos-LGU, Parish Youth Apostolate, and Southern Philippines Medical Center.

EDITORIAL STAFF

- Executive Editor: Riza Concordia N. Suarez
 Managing Editor: Vina G. Mendoza
 Associate Editor: Emerson Kim J. Lineses
 Layout Artist: Emerson Kim J. Lineses
 Contributors: Dominic Buensalido, Nikki Dela Cruz, Alia Descallar, Sheila Mae Guilaran, Amara Matuan, Nanette Montilla, Mary Agnes Panton, Richard Alipasa, Marjorie Dimaano, Susan Jalad, Juvelyn Lumabas, Mary Grace Opon, Girlie Villaruel
- Adviser: Carmencita D. Padilla, MD, MAHPS

Comments and questions may be sent to:
 Newborn Screening Reference Center
 National Institutes of Health
 University of the Philippines Manila
 625 Pedro Gil St., Ermita, Manila 1000

or email us at: info@newbornscreening.ph
 Website: www.newbornscreening.ph
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Mindanao State University-College of Medicine supports World Rare Disease Week celebration by wearing denim ribbons for the "Wear that you Care" campaign | February 22-28, 2014 | Mench Pamanay

Reaching Out . . . from page 4

NBS Strategy

The implementation of NBS for the Tirurays requires special strategies. For example, the so-called "pipe-in" program features a tape recording of all health programs including the importance of NBS. These recordings are played in the Nurses Station and simultaneously heard in all wards.

Another program is the efficient follow-up and recall of patients by establishing linkage with the barangay council, especially with the Barangay Captain.

Parents Testimonial

According to parents, the importance of having their babies screened for NBS tests is effectively stressed by health practitioners.

But their concern is the financial aspect; the cost ranges from P550 to P600. Their income primarily depends on the harvest and whatever they could earn out of it.

Financial Assistance

To address the financial concern that hindered the Tirurays from getting NBS, the Local Health Board was asked to allocate budget for NBS of babies from indigent parents.

Meanwhile, South Upi Municipal Hospital has started to offer an affordable delivery package that already includes NBS. The package costs P2,000.

The Local Government Unit, in addition, provided PhilHealth membership to indigent Tirurays. And in August 2013, Newborn Screening Center-Mindanao provided ten free NBS kits to South Upi Municipal Hospital. *AMatuan*

IPHO-Maguindanao . . . from page 4

by NSC-M to the province's newborn screening program and continuous efforts in saving babies in the province.

The testimonial dinner, where IPHO-Maguindanao honored partners and employees who provided inspiration and volunteerism to the people devastated by Yolanda, was the highlight of IPHO-Maguindanao's Program Implementation Review and 2014 Planning Workshop. *SMGuilaran*

DOH-Regional Office-Region XIII . . . from page 4

participants that included Municipal Health Officers, chief nurses, PHNs, and midwives, while the Agusan del Sur PIR had 25, including chiefs of hospitals and nurse coordinators.

Dr. Conchita Abarquez, Newborn Screening Center-Mindanao (NSC-M) Unit Head, presented the program status in Caraga and discussed the panel of disorders. A brief review of the NSF Protocols was presented by Shiela Guilaran, NSC-M Program Manager, while Perly Bermudez, NSC-M Project Development Officer, presented unsatisfactory samples and how these could be minimized or prevented.

The PIR ended with agreements to conduct series of training programs for all the medical technologists, including monitoring with supervision and mentoring. *NMontilla*

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Thank you for reading our newsletters!

We'd love to hear your feedback. Please let us know how we can improve our bimonthly newsletters by answering our feedback form at www.newbornscreening.ph.

If you would like to write an article, please contact us at info@newbornscreening.ph. We will do our best to keep you informed about current and relevant newborn screening issues.



The sun shines over the ruins of Albino M. Duran Memorial Hospital in Balangiga, Eastern Samar. Days before the typhoon, the hospital was acknowledged as one of the facilities with exemplary performance in the implementation of newborn screening program.

Indomitable Visayan Spirit

By Dominic Buensalido

The Earthquake

On October 15, 2013, everyone was enjoying the national holiday in observance of Eidul Adha (Feast of Sacrifice) when a 7.2 magnitude earthquake hit the Central Visayas at 8:12 a.m.

Immediately, we at the Newborn Screening Center-Visayas (NSC-V) tried reaching out to co-workers, program partners, and patients, especially those living in Bohol and Cebu. News reports said that those were among the worst-hit areas. But communication lines were out.

Reports said that the quake had killed at least 28 people and had damaged properties and historical structures across the Visayas region. Health services were hampered because 11 hospitals were damaged and 2 were shut down. But days after the quake, conditions slowly turned better.



Inside tents, medical technologists work in a makeshift laboratory. Newborn screening was also done here at the wake of supertyphoon Yolanda.

With the resumption of newborn screening operations in the affected health facilities, the NSC-V was optimistic that all will return to normal.

The Supertyphoon

While we restored the program in Bohol and other affected areas, we were unprepared for the devastation that is supertyphoon Yolanda.

Three days before landfall, we successfully held our first Newborn Screening Awards-Visayas Cluster in Iloilo City to give recognition to best performing newborn screening facilities, individuals, and organizations in the Visayas.

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