

Bicol Birthing Homes Gather for Series of Updates



Albay Social Workers Undergo NBS Orientation

The DOH-RO 5 NBS Program Managers, with the Bicol Regional Training and Teaching Hospital, NBS Continuity Clinic, and Department of Social Work and Development-Field Office 5, conducted a one-day NBS orientation among city, municipal, and hospital social workers from the different municipalities of Albay at La Roca Veranda Suites and Restaurant, Legazpi City, on February 15, 2017.

The orientation provided the participants with basic information on child rights, highlights of the Newborn Screening Act of 2004, and the need for collaboration in the management of disorders. Financial assistance and referrals were also emphasized because financial constraints are the primary reasons why parents of babies with confirmed positive cases cannot pursue confirmatory tests.

After the orientation, the social workers created action plans on how to refer indigent patients to financial assistance sources in their communities such as the local government units and non-government organizations. *TJLorilla*



Participants of the NBS Orientation in Albay



Participants of the workshop on integrated updates in Sorsogon (top) and Catanduanes

The DOH-RO 5, headed by Dr. Rita Mae C. Ang-Bon, spearheaded a series of integrated updates on various FHC programs in the Bicol region in January and February 2017. The series started in Masbate province on January 31-February 2 and then in Catanduanes on February 7-9, Sorsogon on February 21-23, and Camarines Norte on February 28-March 2.

Attended by doctors, nurses, midwives, and representatives from the provincial DOH offices, the three-day activity aimed to strengthen the Reproductive Maternal Neonatal Child Adolescent Health and Nutrition (RMNCAHN) Service Delivery Network and intensify compliance to various health programs.

Newborn screening accomplishments were also presented in every province, and strategies on how to increase the newborn screening coverage were tackled. Through this activity, DOH-RO 5 linked all the service providers from both public and private health facilities to ensure that Bicolanos are able to access much needed health services at all times. *TJLorilla*

NSCV Turns 11

In 2017, Newborn Screening Center-Visayas (NSCV) celebrates 11 fruitful years of quality newborn screening testing and program implementation. This year, the official celebratory tagline is "Isang paa, isang patak, buhay ni baby gawing ganap." This underscores NSCV's mission of giving all newborns the chance to live a normal life through quality newborn screening.

NSCV started the celebration by sponsoring two tribes during the Dinagyang Ati-Ati competition, with Tribu Salognon of Jaro National High School bagging the overall championship and Tribu Paghidaet of Lapaz National High School placing third. NSCV staff then participated in the Dinagyang parade on January 22 during which NBS brochures and fan memorabilia were distributed to the crowd.

Advocacy drives for newborn screening were likewise conducted in two major universities in Iloilo City: West Visayas State University (WVSU) during the University Week on

NEWBORN SCREENING CENTER VISAYAS
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Top: NSCV banner and web graphic bearing its anniversary theme. Bottom: Distribution of brochures at the Central Philippine University.



NSCV staff distribute flyers and memorabilia during the Dinagyang Advocacy Parade (top) and decorate the stage before the Tiringbanay at WVSUMC (bottom).

January 25-27 and Central Philippine University during its Republic Day on February 16-17. In these events, exhibits on newborn screening were set up, and NBS brochures, ENBS flyers, NSCV t-shirts and calendars were given away.

The celebration culminated on February 24 with a motorcade around the major thoroughfares of Iloilo City. A total of 11 city hospitals joined the motorcade, together with representatives from the Provincial Health Office of Iloilo and DOH-RO 6. The motorcade was led by the upbeat percussions of Tribu Salognon who won Dinagyang Ati-Ati 2017.

After the motorcade, NSCV family gathered for "tiringbanay," the Karay-a word for family gathering, at WVSU Medical Center. Partner NBS practitioners from the various participating NSF's also joined in and were given recognition through certificates of appreciation for their continued support to the NBS program. *YCMDemegillo*

SUCCESS STORY

Perpetual Help Birthing Home

For a private birthing facility, it is difficult to thrive in an environment where several government facilities also offer the same services, charge less, and are given subsidies by the local government.

But Perpetual Help Birthing Home had a different story. The facility is located at Glan, Sarangani, where the economic activity is largely based on agriculture. It started as a newborn screening facility (NSF) on February 13, 2013. At first, the facility had low newborn screening coverage and was plagued by financial constraints, insufficient accommodation for birthing mothers, unattractive location, and non-membership to Philippine Health Insurance Corporation (PHIC). However, instead of dwelling on the negative side, Perpetual Help Birthing Home listened to its clients and zeroed in on giving quality service.

First, Perpetual Help Birthing Home took PHIC membership and health programs a priority. The facility offered no billing services to their clients, ensuring that every client enjoyed PHIC privileges, including newborn screening. Second, it boosted accessibility when it provided free transportation to and from the patients' residence. In addition, Perpetual Help Birthing Home offered free board and lodging to clients who live far from the facility. This guaranteed that mother and child could stay there until all the mandated health services were provided to them.

Since its establishment in 2013 when it had 23 deliveries per month, Perpetual Help Birthing Home has now elevated its NBS coverage to 96 percent with an average of 39 deliveries per month (as of end of 2016). *RAguilar*



The personnel of PHBH and the evaluation team from DOH-ROs and NSCM

NSCM Celebrates 8th National Rare Disease Week



DOH-RO 10 and SPMC offices and departments hold up fan-signs to celebrate National Rare Disease Week.

In 2010, through Presidential Proclamation No. 1989, the last week of February was declared National Rare Disease Week. For its eighth year, which coincides also with the 10th World Rare Disease Day Celebration, the Newborn Screening Center-Mindanao (NSCM) held various activities to promote the advocacy with the theme "Research Brings Hope to People Living with a Rare Disease."

The week-long celebration commenced with film-showings and AVP presentations about rare disease cases at the ER and OPD lobbies of the Southern Philippines Medical Center (SPMC). Rare disease posters and PSOD brochures were also circulated in the different parts of the hospital.

To reach its audience online, three former Volunteer Youth Leaders for Health members and now NSCM employees—Ram Christian Cossid, Shane Paul Baula, and Apple Downanie Tadlas—initiated "fan-signing" at the different offices in the hospital and then posted the photos online using the hashtag #CareforRarePH. Meanwhile, Gil Bernard Samante, NBS nurse, led the fan-signing at the different departments of DOH-RO 10.

As a culminating activity, Tadlas, NSCM Birth Defects Surveillance Research Nurse and VYLH Secretariat, gave a lecture-symposium on the current updates about the rare diseases in the Philippines at the SPMC OPD lobby on March 1. *ADTadlas*

DOH-CARO Holds Training for NSF's

The DOH-Cordillera Administrative Regional Office (CARO), in coordination with NSCCL, conducted its first NBS Training for Healthcare Providers for facilities with high unsatisfactory rates at the Crown Legacy Hotel, Baguio City, on February 22-24, 2017.

The training was designed for both previously trained NBS staff needing a refresher course and untrained health workers designated by NSF's to collect samples. The focus of the training was the proper filling out of the NBS filter card and collection of quality samples to help decrease the number of unfit and unsatisfactory samples being received by the NSCCL.

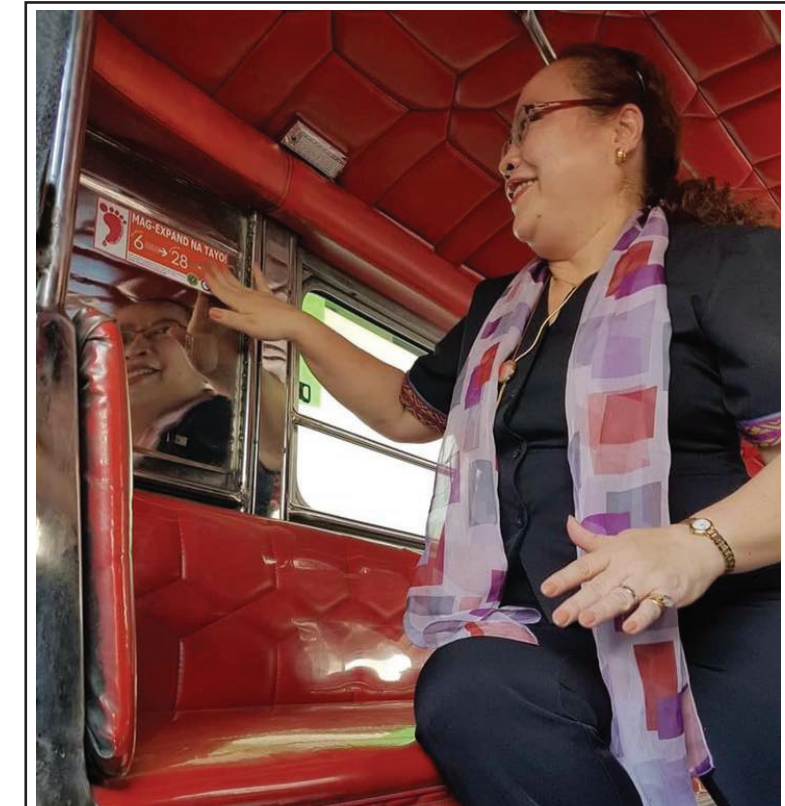
Dr. Virginia L. Narciso, Child and Adolescent Development Cluster Head, discussed the panel of disorders and updates on ENBS. The return demonstration for collecting NBS samples was conducted at Baguio General Hospital and Medical Center, and on the last day of the activity, the participants prepared a re-entry plan on how to decrease the unfit and unsatisfactory samples collected in their respective areas of assignment. Unsatisfactory samples include samples that are contaminated, insufficient, collected after 24 hours, and sent late for testing. *NDelaCruz*

DOH Secretary Leads Ceremonial Posting of ENBS Stickers on PUVs

The Newborn Screening Center-Central Luzon (NSCCL), in coordination with DOH-RO 3 and the Land Transportation Franchising and Regulatory Board, launched promotional ENBS stickers for public utility vehicles in Region 3.

The activity was graced by Secretary of Health Paulyn Ubial, who gave an inspirational talk and was the first to post an ENBS sticker on a public utility jeepney. The promotional stickers aimed to promote and raise awareness of the riding public, especially jeepney and tricycle commuters, with regard to ENBS.

Meanwhile, NSCCL Project Development Officers Nikki Dela Cruz and Roland Alcantara went to the Angeles City Public Transportation Regulatory Office (PTRO) on January 13, 2017, to request its head, Mr. Rene Mariano, to likewise facilitate the posting of ENBS stickers on tricycles. NSC-CL provided 500 stickers to PTRO for distribution to tricycle drivers. *NDelaCruz*



DOH Secretary Paulyn Ubial leads the ceremonial posting of promotional ENBS stickers on the interior of a public utility jeepney in Region 3.



Facilitators closely supervise participants of the NBS training for NSF staff in CAR.

NBS Write-shop Yields Training Plan and Module for MS/MS

In the process of ensuring standards across all NSCs and achieving proficiency and competency in performing Tandem Mass Spectrometry (MS/MS) analysis among analysts, a brief assessment on the NSRC training plan was made. The assessment had the following recommendations: (1) include assessment/competency after training, (2) monitor compliance with the training duration, and (3) develop a reference manual for MS/MS.

Two documents were drafted during the workshop: the MS/MS Training Plan and the MS/MS Training Module. The training plan outlines who will facilitate the training, the time frame for achieving the competencies in key areas, and the delivery methods to be employed. The module, on the other hand, is designed to serve as a guide for the analysts and team captains in the actual performance of MS/MS.

The write-shop concluded by integrating all comments and suggestions from Dr. Anna Victoria Sombong, NSCV Laboratory Manager, and Ma. Leah Basa and GERALYN VALEZA, NSC-NIH Team Captain and Laboratory Manager, respectively.



Participants of the training module write-shop discuss how to make the NBS training plan more comprehensive.

NSRC Conducts Quality Audit Workshop

Unit heads and laboratory managers of the five NSCs attended the workshop. Also present to provide support and direction were Dr. Maria Melanie Liberty Alcausin, NSRC Director; and Dr. Juanita Basilio, former DOH-FHO Division Chief, and Dr. Florencio Dizon, former NSCCL Unit Head, both consultants.



Unit heads and laboratory managers of the five NSCs gathered together during the audit workshop to make the NBS program work more effectively.

The NSRC, in partnership with the DOH, worked to establish the Performance Evaluation and Assessment Scheme (PEAS) grounded on the Philippine context of geopolitical and healthcare delivery systems. The Philippine PEAS monitors the quality and improvements in the NBS implementation and provides specific directions for DOH-ROs, NBS facilities, and NSCs in their efforts to increase NBS coverage. It also serves as framework for the data gathering that is so vital in obtaining a realistic picture of NBS program implementation.

With the recent revisions made in all PEAS tools in December 2016 and the new members of the Audit Teams, there is a need for a workshop that would ensure that the audit or monitoring conducted annually conforms to a set of standards. Hence, NSRC and Synergy at Work Learning and Development Corporation conducted the Newborn Screening Audit Workshop at the University of the Philippines College of Dentistry on March 2-3, 2017. The objective of the workshop was to enhance the skills and competencies of personnel on Internal Quality Audit based on the PEAS Tools, ISO 19011:2011, and ISO 9001:2015 requirements.

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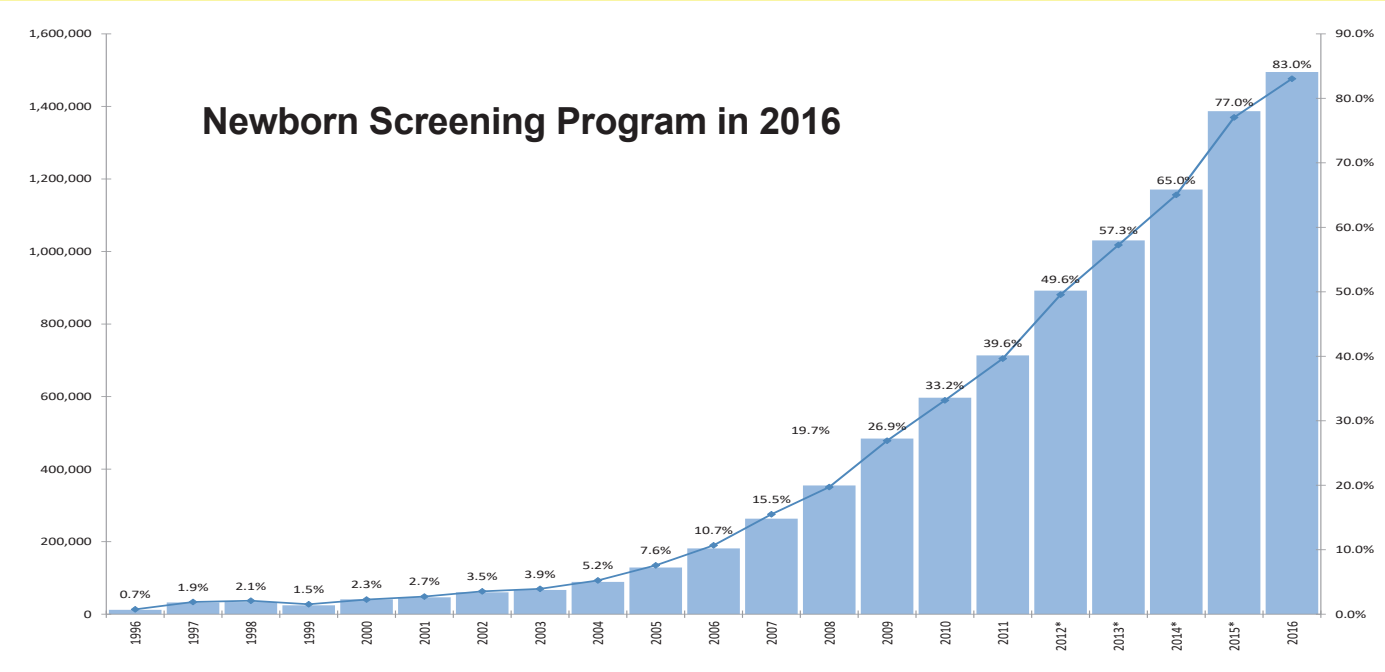
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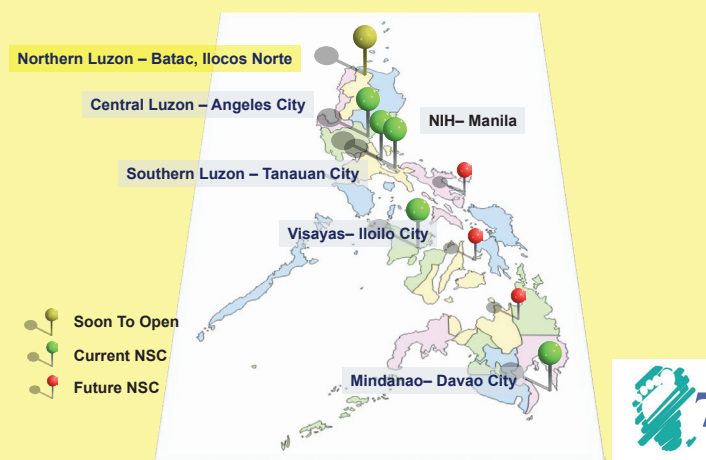
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NBS STATISTICS



A total of 1,494,825 newborns underwent screening in 2016. This is 83 percent of the estimated 1.8 million total live births in the country. In 2014, expanded screening was made available as an option for newborn screening. Of the total screened in 2016, expanded newborn screening coverage is at 7.91 percent, or 142,419 babies. Currently, 1,200 health facilities offer expanded newborn screening to the public.

Newborn Screening Centers



Rare disease advocates represented by (left to right) Ma. Nelia C. Ruta, Trisha Isabel Guioquio, and Ram Christian Cossid took to the airwaves in promoting awareness on rare diseases during the World Rare Disease Day.

Rare Disease Day Hits the Airwaves

The rare disease advocates on February 27, 2017, were guests on *Ateneo Voices*, a regular radio program on 89.9 Spirit FM, to shed light on the celebration of World Rare Disease Day.

The activity was through the initiative of Trisha Isabel Guioquio, faculty member at the Ateneo de Davao University (ADDU) College of Nursing and member of Volunteer Youth Leader for Health.

During the two-hour program, Ma. Nelia C. Ruta, ADDU Community Extension and Advocacy Head; Ram Christian Cossid, NSCM Follow-up Nurse; and Ms. Guioquio discussed frequently asked questions on rare diseases and how patients with rare conditions fight those diseases. Also tackled were advocacies on birth defects and the newborn screening program and how healthy lifestyle and regular check-ups could help expectant mothers during pregnancy.

Rare Disease Day is a global celebration held every February 28. According to the University of the Philippines-Institute of Human Genetics, a rare disease is any condition that affects fewer than 200,000 people nationwide. A disease is considered rare when it affects 1 in every 20,000 individuals or less. *RCossid*

NBS Program Implementers Hold Consultative Meeting

The DOH-FHO, in collaboration with the NIH-NSRC, conducted a consultative meeting at Bayview Hotel Manila on February 15-16, 2017, to resolve common issues in program implementation and to bridge the gap toward effective and high-quality program operations.

Attended by the national NBS program coordinators, regional program managers and nurse coordinators, NSC unit heads, and representatives from NSRC and PHIC, the meeting also opened discussions on salary standardization for regional NBS coordinators, revised guidelines for the 4 percent fund utilization, updates from the continuity clinics, strategic plan report, manual of operations, program review results, and updates from PHIC.

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Dr. Anthony Calibo speaks during the Continuity Clinic Assessment and Review Workshop.

Continuity Clinics After 2 Years: An Assessment of Operations

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“Health care system is now more dynamic. If *magkanya-kanya tayo*, we will not achieve our goals,” explained Dr. Anthony Calibo, OIC for Children’s Health Development Division, during the Continuity Clinic Assessment and Review Workshop held at Bayview Hotel Manila on February 23-24, 2017.

Dr. Calibo emphasized the importance of engagement and collaboration between different stakeholders and the Newborn Screening (NBS) Continuity Clinics toward achieving the goals of the Philippine Health Agenda. He reminded the participants to be accountable to those they serve for the quality of healthcare delivered.

Organized by the Department of Health-Family Health Office (DOH-FHO), in collaboration with the National Institutes of Health-Newborn Screening Reference Center (NIH-NSRC), the activity aimed to assess and review clinic operations with regard to long-term medical management and care coordination of confirmed patients. The workshop specifically aimed at identifying the clinics’ strengths and

weaknesses, sharing best practices, and offering solutions to common problems.

Prior to the workshop, the continuity clinic teams attended the First Philippine Symposium on Rare Disease, an activity of the Philippine Society for Orphan Disorders, held at Century Park Sheraton Hotel, Manila, on February 22. NBS Continuity Clinics are also important stakeholders in the effective implementation of the Rare Disease Act of the Philippines.

Strategically located in 14 different regions in the country, NBS Continuity Clinics are staffed by a pediatrician and a nurse. Their responsibilities include tracking and recall of all endorsed cases from the Newborn Screening Centers, monitoring of patients’ growth and development and compliance to treatment, facilitating referral to specialists, and planning the follow-up appointments and laboratory work-ups. In addition, Continuity Clinics need to improve care delivery, collaborate with stakeholders such as the DOH-Regional Offices (ROs), and monitor and evaluate data related to patient care and outcomes.

Number of Babies Screened as of February 2017

9,332,633