

NSC-NL Responds to NBS Challenges



Organizers of the first Northern Luzon Cluster Meeting with NSC-NL Unit Head Dr. Ma. Paz Virginia Otayza pose for a photo with Ma. Elouisa Reyes, Officer-in-Charge of NSRC.

"The effective and efficient implementation of the Newborn Screening Program in Ilocos Region and Cagayan Valley is primarily influenced by the collaborative efforts of the Department of Health-Regional Offices (ROs) 1 and 2, the NSC-Northern Luzon (NSC-NL), and their stakeholders," affirmed UPM Chancellor Carmencita Padilla during the initial accreditation of NSC-NL in May 2017.

Thus, with this marching order, NSC-NL hosted the 1st Northern Luzon Cluster Meeting at Mariano Marcos Memorial Hospital and Medical Center, Batac City, Ilocos Norte, on September 12, 2017.

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partnership of the continuity clinics and endocrinologists, special considerations in premature infants, developmental outcomes in Congenital Hypothyroidism, newborn hearing screening, and the Rare Disease Act. A special plenary on hemoglobinopathies was also conducted, with topics on challenges in screening and confirmatory testing in thalassemias, overview of the current status of screening for hemoglobin disorders in the country, efforts to characterize thalassemia in the Philippines, and implications and considerations in genetic counseling for thalassemias.

Aside from the lectures, the hospitals that comprised the Philippine Newborn Screening Project, which started newborn screening in the Philippines in 1996, were honored and awarded with NBS 20th year commemorative book.

Organized by the Newborn Screening Society of the Philippines, Inc. (NSSPI), this year's convention was presented by the NSRC and co-presented by United Laboratories, Inc. and PerkinElmer, Inc. It was supported by all the Newborn Screening Centers (NSCs) in the country and United Laboratories, Inc. *MJTumalak*

The meeting was attended by the DOH-RO 1 NBS Team composed of Adrian Doctolero, NBS Program Manager; Nicole Marie Bugarin and Manuel Fernandez III, regional NBS coordinators; and Vanessa Mabalo, NBS Continuity Nurse at Ilocos Training and Regional Medical Center. Ma. Elouisa Reyes, Officer-in-Charge (OIC) of NSRC, and all NSC-NL staff led by its Unit Head, Dr. Ma. Paz Virginia Otayza, were also present.

The important role of DOH-ROs in training the newborn screening facilities (NSFs) and in sustaining a strong network of NBS referral system was discussed. NSRC committed to provide updates and technical assistance to ensure a strengthened program implementation in Regions 1 and 2. The NSC-NL, on the other hand, assured its program partners that it would enhance its work flows to provide the best health outcomes for patients. *AJAlmazan*

Cagayan Valley Brings Back Its NBS Awards

In celebration of NBS Week, DOH-RO 2 brought back the Awarding of Performing Health Facilities in Cagayan Valley, which was held at Hotel Carmelita, Tuguegarao City, on October 6, 2017.

Attended by NBS Coordinators from various NSFs in Batanes, Cagayan, Isabela, Nueva Vizcaya, and Quirino Province, the program recognized facilities with exemplary performance in newborn screening. The Newborn Screening Exemplary Awards are given to NSFs whose performance rating meets the criteria set by the DOH-RO for two consecutive years. The event also included a program update delivered by Anthony James Almazan, NSC-NL Program Manager. An open forum was facilitated by Lucia Balisi, DOH-RO 2 NBS Coordinator, while Dr. Brian Niño Galapia, DOH-RO 2 Program Manager, gave the closing remarks. *AJAlmazan*

2nd Visayas NBS Awards Cite Best NSFs



The organizers and staff together with the awardees of the 2nd Visayas-Wide NBS Awards.



Top three finishers in the NBS Fun Run held in Bacolod City organized by DOH-RO 6, PHO Negros Occidental, and CHO Bacolod.

Visayas Regions Kicks Off First Simultaneous Fun Run

In celebration of NBS Week, NSC-V together with the NBS Coordinators of DOH-ROs 6, 7, and 8 conducted the First Visayas-Wide Simultaneous Fun Run.

The activity was the first for Regions 6 and 8, while it was the third for Region 7. Various NSFs were invited to the fun run. Even various runners from various organizations joined in the event as well. There were also other activities such as zumba, parlor games, awarding of the logo making contest, and free newborn screening collection.

The simultaneous fun run was conducted through the efforts of NBS Coordinators from the different regions of Visayas: Dr. Renilyn Reyes, Grace Panes, and Florence Osano from Region 6; Dr. Hayce Famor-Ramos and Ruff Vincent Valdevieso from Region 7; and Dr. Lilibeth Andrade and Wenonah Tutaan from Region 7.

The activity aimed to increase the awareness of people on the NBS Program as well as to continue to promote newborn screening to the different health facilities in their catchment areas. *LOPanes*

More than 250 facilities from various regions in the Visayas attended the 2nd Visayas-Wide Newborn Screening Awards at the Grand Convention Center of Cebu, Cebu City, on October 26, 2017.

Various awards such as the Exemplary Award, Achievers Award, and Special Citation Award were given to outstanding facilities that, through their hard work and passion, made newborn screening a successful program.

The event was hosted by DOH-RO 7, in cooperation with NSC-Visayas (NSC-V) and the NBS Coordinators of DOH-ROs 6, 7, and 8. Giveaways such as shirts, pins, and handwoven bags were also given to NSFs, which were represented by their respective NBS Coordinators, staff, and even officials of their respective local government units.

Ma. Elouisa Reyes, OIC of NSRC, served as keynote speaker and enjoined the awardees to continue their love and care for Filipino newborns. *LOPanes*



Regional program managers and nurses in Visayas together with project development officers from the NSC-V.

DOH-RO 12 Observes NBS Week in Cotabato City

Intensifying the advocacy on ENBS was the primary objective of DOH-RO 12 when it celebrated NBS Week in Cotabato City on October 11, 2017, at the City Mall Convention Hall.

The activity started at 7:00 a.m. with a motorcade from the city plaza to the convention hall. Dr. Anna Liza G. Alo, Cotabato City Development Management Officer, delivered the welcome remarks, while Dr. Amabella G. Taruc, DOH-RO 12 Local Health Support Division Chief, gave an inspirational message. City Health Officer Dr. Suher Tadsma Guinomla-Ibrahim and NBS Program Manager Mary Agnes Pantan were also present. Dr. Conchita Abarquez, NSC-Mindanao (NSC-M) Unit Head, gave a talk about the updates on ENBS.

During the program, free newborn screening tests were given to 14 babies, and 10 NBS kits with alcohol and cotton were also given to the 8 NBS facilities who came early. Other participants were given freebies such as CDs and booklets. The program was attended by some 220 participants, including representatives from government and private NSFs, the academe, local government units, and the City Health Office of Cotabato City. *RMua*

DOH-RO 10 Holds ENBS Orientation Series

Awareness is the key to successful implementation. This was what DOH-RO 10 believed when it held a series of Expanded NBS (ENBS) Program Orientations at the Pearlmont Inn, Cagayan de Oro City, on September 28-29, 2017.

Attended by 50 participants composed of doctors, nurses, medical technologists, and midwives, the activity addressed the lukewarm reception to ENBS due to its bigger price tag and that it is not fully covered by PhilHealth. *RAguilar*



One of the batches of the orientation series held in Cagayan de Oro City



Fourteen newborns receive free expanded newborn screening during NBS Week celebration in Cotabato City.

Cagayan de Oro City Celebrates NBS Week



Kids enjoy games and prizes during the NBS Week celebration in Cagayan de Oro City.

In celebration of NBS Week, DOH-RO 9, in partnership with the NBSCC Region 10, held a whole-day program at the Pearlmont Inn, Cagayan de Oro City, on October 27, 2017.

In the morning, free newborn screening was given to 22 babies, many of whom were delivered at home. The screening, together with advocacy lectures for parents, was done by the DOH-RO 10 NBS team, coordinators from the City Health Office of Cagayan de Oro, Barangay Health Stations, and the Northern Mindanao Medical Center.

In the afternoon, a Reunion of Saved Babies was held, where Dr. Conchita G. Abarquez, NSC-M Unit Head, talked about updates on the metabolic disorders to help parents in the management of their babies' disorders. *RAguilar*

NSC-SL Marks Its 4th Year

With over half a million babies screened for heritable congenital disorders, NSC-Southern Luzon (NSC-SL) marks its fourth anniversary on September 24, 2017.

NSC-SL was one of the six NSCs created through the Newborn Screening Act of 2004. Located in Tanauan City, Batangas, and hosted at Daniel O. Mercado Medical Center, NSC-SL caters to the newborns of Region 4A, or the CALABARZON Region. Since its establishment in 2013, the center has upheld its mandate of saving babies from mental retardation and death through newborn screening.

Today, the center has expanded tremendously, with 725 active NSFs distributed throughout the region. Twenty-three percent of the NSFs offers ENBS, and the number is continuously increasing. Through a strengthened partnership with different institutions such as DOH-RO 4A, local government units, various medical specialists, and health institutions, the center is continuously gearing toward a successful NBS program implementation.

The center has also extended its advocacy by organizing various activities such as CH-CAH Forum, G6PD Forum with Free Confirmatory Tests, NBS Caravans, Reunion of Saved Babies, and Buntis Congress. These activities aim to strengthen information dissemination as well as to give chance to saved babies and their parents to build a network of support. Continuous trainings for the NSFs were also put



Current NSC-SL staff together with the local and international newborn screening accreditors during the renewal of the laboratory's accreditation

in place to equip personnel with the necessary skills and knowledge required for proper implementation.

In its fourth year, NSC-SL also marks another milestone: gearing towards ENBS. The center aims to offer ENBS in the near future, thereby expanding the services it offers and helping a lot more newborns.

Through strengthened quality assurance, comprehensive trainings, effective information dissemination, and meaningful partnerships, NSC-SL strives to overcome the barriers for NBS Program implementation and ultimately achieve its vision to be recognized as a premier institution providing quality newborn screening services in Southern Luzon. *FDimaculangan*

IN THE KNOW: CONGENITAL ADRENAL HYPERPLASIA

What is Congenital Adrenal Hyperplasia (CAH)? Congenital Adrenal Hyperplasia (CAH) is a group of disorders resulting from enzymatic defects in the biosynthesis of steroids. There are many enzymes involved in the synthesis of adrenal hormones, but about 90 percent of CAH may be due to 21-dihydroxylase deficiency. Others are due to cholesterol desmolase 11β-hydroxylase deficiency, 17β-hydroxylase deficiency, and 3β-hydroxysteroid dehydrogenase. All forms of CAH are inherited in an autosomal recessive pattern. The Philippine NBS data as of December 2013 reports that 1 out of 13,350 screened newborns has CAH.

Clinical Features
 • Salt-wasting
 • Simple virilizing
 • Late onset
 Neonates with the salt-wasting (SW) form manifest adrenal crisis in the first two to four weeks of life, characterized as poor feeding, vomiting, loose stools or diarrhea, weak cry, failure to thrive, dehydration, and lethargy. If untreated, the affected newborn will die in a severe salt-losing crisis with hypoglycemia and hypotension. The baby who survives may have brain damage. Affected females usually present with ambiguous genitalia.

Pathophysiology. 21-hydroxylase deficiency results in decreased cortisol and aldosterone production, which in turn causes increased adrenocorticotropic hormone (ACTH) secretion. High ACTH levels result in hyperplasia of the adrenal cortex. The precursor steroids behind the block are diverted to the androgen biosynthetic pathway, resulting in excess production of androgens that cause virilization in females and precocious puberty in males. The decrease in the production of aldosterone in CAH results in salt and water imbalance.

Diagnosis. Newborn screening for 21-hydroxylase deficiency is done by measuring the 17-OHP level on dried blood spot. Infants with normal birth weight and a mild elevation of 17-OHP undergo repeat dried blood spot collection. Infants with moderate to severe elevation of 17-OHP and those who have low birth weight with mild elevation are referred to a pediatric

endocrinologist for evaluation. Plasma 17-OHP, Na, K, cortisol, and RBS are requested to confirm the condition. In cases of discrepancies between the plasma 17-OHP and clinical parameters, more extensive diagnostic evaluation is recommended: ACTH stimulation test and/or DNA mutation studies.

Treatment and Monitoring. The mainstay of treatment in CAH is glucocorticoid and mineralocorticoid replacement therapy, which corrects the cortisol deficiency and reverses the abnormal hormonal patterns. Patients with deficiencies of mineralocorticoids require the appropriate replacement hormones. Glucocorticoid replacement must be increased during periods of stress. The majority of female patients with prenatal virilization requires surgical repair. Heterozygous carrier detection, prenatal diagnosis, and prenatal therapy are available for families with 21-hydroxylase deficiency and are often used in 11 β -hydroxylase deficiency. Regular endocrine clinic visits for monitoring of physical growth and development as well as biochemical 17-OHP and/or cortisol measurements are recommended for optimal management. Genetic counseling is recommended.

Prognosis. Newborn screening makes early diagnosis and early treatment possible. Early treatment to prevent adrenal crisis is lifesaving in cases of salt-wasting CAH. Early diagnosis prevents inappropriate sex assignment for affected females of the simple virilizing (SV) form. This is very important due to the psychological and legal implications of wrong gender assignment. Progressive effects of excess androgens such as short stature and psychosocial disturbance in male and female patients are also prevented if appropriate treatment is given and monitored closely.

Source: Fact Sheets for Doctors (May 2016) available at www.newbornscreening.ph.



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DOH-RO 12 Intensifies ENBS Implementation



Left: The organizers, speakers, and participants of the ENBS Training in Kidapawan City organized by DOH-RO 12. Right: Participants practice heel-pricking at Cotabato Provincial Hospital.



To arm NBS implementers in Region 12 with new knowledge and skills on ENBS, DOH-RO 12 held a two-day ENBS Training at Eva's Hotel, Kidapawan City, North Cotabato, on September 5-6, 2017.

The training was attended by 27 NBS health personnel from private and government hospitals in North Cotabato, Cotabato City, South Cotabato, General Santos City, Sultan Kudarat, and Sarangani.

A comprehensive discussion on the panel of disorders, program updates and administrative mechanics of NSC-M, types of NBS samples, and highlights of Republic Act 9288 was given on the first day of training. The topics were presented by Dr. Conchita Abarquez, NSC-M Unit Head; Perly Bermudez, Project Development Officer; and Mary Agnes Pantan, NBS Program Manager of DOH-RO 12. Also present in the event was Dr. Nikki Regine D. Pader, Family Health Division Head. On the second day, participants underwent a workshop on the proper way of filling up NBS cards and had practicum in heel-pricking. *P.Bermudez*

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DOH-RO 9 Holds Reunion of Saved Babies



Parents and children join the officers and staff of DOH-RO 9 during the Reunion of Saved Babies.

Despite the bad weather, some 38 parents and their children attended the Reunion of Saved Babies organized by the DOH-RO 9 in coordination with NSC-M and the NBSCC Region 9 held at Grand Astoria Hotel on October 17, 2017.

During the activity, Dr. Conchita Abarquez, NSC-M Unit Head, discussed the different disorders covered under NBS, while Dr. Ernesto Florendo, Head of the NBSCC, provided consultation to patients. Parents and children also enjoyed parlor games prepared by the organizers. *ITomas*

DOH-RO 11 Celebrates NBS Week in Digos City

Offering free newborn screening has been an annual tradition of the DOH-RO 11 as a way to commemorate the NBS week in the region and to reach out to patients. In 2017, the NBS Team gave free screening to the patients of Digos City Health Office and Davao Del Sur Provincial Hospital on October 27.

A total of nine babies from both facilities received the free screening. Louie Gelacio, nurse at the Southern Philippines Medical Center, and Amerah Matuan and Perly Bermudez of NSC-M led the sample collection. *P.Bermudez*



Louie Gelacio (left) of Southern Philippines Medical Center prepares the NBS filter card prior to sample collection.

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Thank you for reading our newsletters! We would 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.



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14th National NBS Convention:
Bridging the Gaps
Toward 100% Implementation

NSSPI President Dr. Neal Orteza (leftmost), DOH Assistant Secretary Dr. Eric Tayag (center), UPM Chancellor Dr. Carmencita Padilla (second from right), and UPM Vice Chancellor for Research Dr. Eva Maria Cutiongco-Dela Paz (rightmost) award the representatives from the newborn screening pioneering hospitals.

More than 2,000 delegates from all over the country attended the 14th National Newborn Screening Convention held at the Philippine International Convention Center, Pasay City, on October 3-4, 2017.

With the theme "Bridging the Gaps: From Screening to Management," the convention gathered together 421 medical doctors, 830 nurses, 441 midwives, 269 medical technologists, 5 chemists, and 65 other professionals. Sixteen distinguished speakers also shared their expertise in identifying gaps and giving strategies toward 100 percent implementation of newborn screening in the country.

Genetic and newborn experts who graced the convention include former Newborn Screening Reference Center (NSRC) Director Dr. Maria Melanie Liberty Alcausin, clinical geneticists Dr. Mary Ann Abacan and Dr. Conchita Abarquez, pediatric endocrinologists Dr. Sylvia Estrada and Dr. Caridad Santos, pediatric hematologist Dr. Reynaldo de Castro, Jr., molecular geneticist

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