

VOLUNTEER YOUTH LEADERS FOR HEALTH

VYLH Holds Youth Camp in Clark

To strengthen volunteerism and expand the network of youth leaders who help increase public awareness on newborn screening (NBS) and other health issues, the Department of Health–Regional Office (DOH-RO) 3, in collaboration with the Newborn Screening Center–Central Luzon (NSC-CL), organized a camp for the Volunteer Youth Leaders for Health (VYLH) titled “Kabilin: Revolutionizing Health Promotion through Youth Participation” at the Stotsenberg Hotel in Clark Freeport Zone, Pampanga, on October 13-14, 2016.

Student leaders from different universities and members of the Nurse Deployment Program (NDP) in Central Luzon were invited to participate and were introduced to VYLH and its advocacies. Afterward, the participants worked in groups for leadership training and teambuilding. During the socials night, cultural presentations were performed by the different groups.

On the second day, an election of officers was held. Provincial VYLH coordinators and assistant coordinators were elected as follows: Al Francis Yapen for Aurora, Jenalyn Baluyot for Bataan, Mark Anthony Tapispisan for Bulacan, Ella Lavina Domingo for Nueva Ecija, Edison Obsena for Olongapo City, Aileen Magcalas for Pampanga, and Elvin Plantilla for Tarlac.

Later, Madeline Gayle Tayag, DOH-RO 3 NBS Coordinator,

presented the current health situation of the country, DOH programs, and updates on NBS in the region. Dr. Marie Adrienne Salunga, NSC-CL Unit Head, discussed the Expanded Newborn Screening program.

As culminating activity, the participants devised plans to promote the advocacies of the organization. The plans were presented to a panel of reactors from NSC-CL and DOH-RO 3 for feedbacks and recommendations. The program ended with a symbolic imprinting of hand marks to indicate their full commitment to the VYLH network. *NDelaCruz*



Youth leaders from the different provinces in Central Luzon pledge their commitment to VYLH in a symbolic hand mark printing ceremony during the youth camp in Clark Freeport Zone, Pampanga.

COVER STORY

#NBSat20, a Toast to 20 More

Jonas del Rosario and Annamarie Saarinen on screening of Critical Congenital Heart Disease (CCHD); Dr. Mary Antonette Remonte on PhilHealth updates with regard to both NBS and ENBS; and Cynthia Magdaraog on her struggles as a mother to a patient of a rare disease.

Two simultaneous sessions were also held during day 2 of the convention. One session further focused on other newborn screening initiatives—retinopathy of prematurity that may lead to blindness discussed by Dr. Milagros Arroyo and developmental dysplasia screening discussed by Dr. Juanito Javier. Topics in the other sessions included “Enhancing Newborn Screening Program in the Cordillera Administrative Region through Annual Program Implementation Review” by Dr. Florencio Dizon, “Rebuilding Newborn Screening in Region 8” by Dr. Lilibeth Andrade, “ENBS Implementation in an LGU Setting” by Dr. Rosalina Tan, and “NBS Best Practices in Bataan” by Charry Villanueva.

In light of #NBSat20, Padilla, with NSRC, launched the Newborn Screening Book, a project developed to commemorate

NBS throughout the years as well as to celebrate everyone who were involved then and who are involved now. Along with the aforementioned book-launch came the launch of the full video containing basic information about NBS and ENBS as well as accounts of parents and their respective saved or unsaved children. The video provides a different perspective about being on the receiving end of the patient-healthcare provider exchange.

A bonus to this year’s convention is the presence of honored guests, four of the saved babies, one of them being the little girl on the NBS poster that has been in circulation for ages: Janelle (CH), the seven-year-old girl alongside 14-year-old JR in the NBS poster, Daniella (CH), and Danica and Dave (CAH). These saved individuals are a testament to the fact that the cost of NBS and ENBS is incomparable to the worth of a child’s life.

Excerpt from the article written by Angela Misleng and first published on Philippine Star, 6 November 2016.

NSC Visayas

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Visayas Region Steps Up NBS Staff Capacity

In early 2015, the Expanded Newborn Screening (ENBS) became available to all the newborn screening facilities (NSFs) in the Visayas region. The region then saw a steady increase in the number of NSFs offering ENBS to their clients. As a result, more babies were screened for disorders not previously included in the NBS panel. For many health service providers, these new disorders are indeed unfamiliar topics with which they have little or probably even no experience.

To address this concern, the Department of Health–Regional Office (DOH-RO) 6, in partnership with the Newborn Screening Center (NSC)–Visayas, the Newborn Screening Continuity Clinic (NBSCC), and the provincial health offices in Region 6, held the first orientation on the clinical management of newborn screening disorders on September 14-16, 2016.

The activity helped capacitate health service providers in the management of patients with NBS disorders during their acute



The organizers of the orientation on the clinical management of NBS disorders

or chronic episodes of the illness. The participants were teams of doctors, nurses, and medical technologists from selected hospitals in Western Visayas provinces.

Pediatric specialists Dr. Margaret Jane Galilea, Dr. Barbra Charina Cavan, and Dr. Maria Lita Fe Paclibar talked about the management of the endocrine and metabolic disorders and hemoglobinopathies. Dr. Hazyl Brillantes-Villareal, pediatric neurologist, discussed the assessment of developmental milestones of children, and Dr. Roxanne Tuvales, NSC-Visayas Follow-Up Head, lectured on the short-term follow-up recall process of the NBS program. *YCDemegillo*

Region 6 Shows Off NBS Progress



The forum on congenital hypothyroidism led by Dr. Reyes and Dr. Ventilacion

Since its establishment in 2014, the Newborn Screening Continuity Clinic–Region 6 has worked very closely with the Department of Health–Regional Office 6 in the recall, follow-up, and monitoring of confirmed patients. This year, they convened 36 patients with congenital hypothyroidism in the Reunion of Saved Babies held at Sarabia Manor Hotel, Iloilo City.

Dr. Karen Ventilacion held medical consultations and was assisted by volunteer physicians from West Visayas State University Medical Center, Don Jose S. Monfort Medical Center Extension, and Jesus M. Colmenares District Hospital.

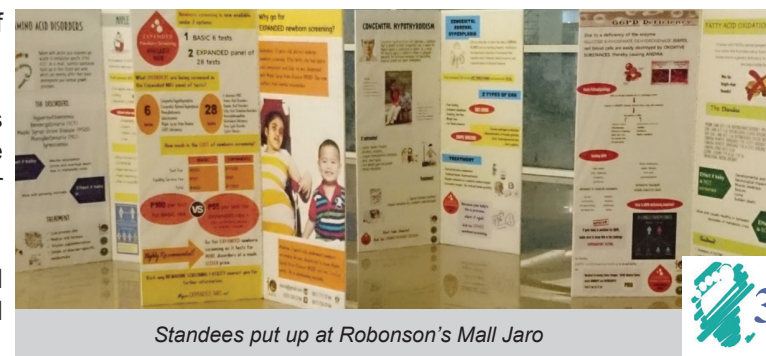
The consultation sessions were followed by a lecture and forum on congenital hypothyroidism by Dr. Renilyn Reyes and Dr. Karen Ventilacion. *YCDemegillo*

NSC-Visayas Brings ENBS to the Mall

To promote newborn screening more widely to the public, the Newborn Screening Center (NSC)–Visayas partnered with Robinson’s Mall Jaro in its information dissemination campaign as part of the Newborn Screening Awareness Week.

From October 17 to October 21, 2016, NSC-Visayas put up standees bearing vital information on the 28 disorders being screened in the Expanded Newborn Screening (ENBS) Panel. The disorders were grouped according to the following categories: amino acid disorders, fatty acid oxidation disorders, organic acid disorders, and hemoglobinopathies. The six-panel disorders also had its own standee.

The mall campaign also included general information on and the steps involved in newborn screening. *MMTabaosares*



Standees put up at Robinson's Mall Jaro

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MINDANAO NEWS BRIEFS

Select Indigents in Davao City Get Free NBS

The Newborn Screening Center–Mindanao treated select indigent patients in various parts of Davao to free newborn screening as part of this year’s NBS Week.

A total of 146 participants and 14 babies received NBS on three separate occasions—Malabog, Paquibato District, Davao City, on October 3, 2016; Brgy. Callawa, Davao City, on October 5; and Talaingod, Davao del Norte, on October 7. The event was a success thanks to the staff of Callawa Health Center, Malabog Lying-in Clinic, and Rural Health Unit–Talaingod.

Meanwhile, the NBS Team of the Department of Health–Regional Office 11 also gave free screening to 34 newborns at the Compostela Valley Provincial Hospital–Montevista and at the Rural Health Unit–Monkayo, Compostela Valley, on October 21, 2016. *PBermudez*



Select babies in Davao City receive free screening during NBS Week.

NBS Week in Mlang, Cotabato

Some 57 parents and 50 health workers attended the Newborn Screening Awareness Week activities conducted by the Mlang Specialists Medical Center at Mlang, North Cotabato, on October 16, 2016.

Dr. Ruel Sarillo, president of the Center, gave the welcome remarks, while Dr. Conchita Abarquez, Newborn Screening Center–Mindanao Unit Head, presented the updates on the program. Dr. Eleonor Du spoke about Congenital Hypothyroidism and Congenital Adrenal Hyperplasia, and Dr. Benatu Dalandag discussed newborn hearing screening. The activity also had an open forum where parents mostly asked about the management of glucose-6-phosphate-dehydrogenase (G6PD) deficiency disorder. *SMGuilaran*

Dr. Conchita Abarquez (right) talks about updates on the NBS program.



DOH-RO 12 Hold the 3rd Batch of ENBS Orientation

To continuously capacitate private and government health workers with knowledge and skills on the implementation of the newborn screening program, the Department of Health–Regional Office (DOH-RO) 12 conducted the third batch of the Orientation on Expanded Newborn Screening (ENBS) and Heel-Prick Training at Phela Grande Hotel, General Santos City, on September 21-22, 2016.

The activity was attended by 26 nurses, midwives, and medical technologists from North Cotabato, South Cotabato, Sultan Kudarat, and Cotabato City. *RMMUa*

DOH-RO 9 Holds ENBS Training

The Department of Health–Regional Office (DOH-RO) 9, in coordination with the Newborn Screening Center–Mindanao and Zamboanga City Medical Center, held the last batch of this year’s Expanded Newborn Screening (ENBS) Training at LM Metro Hotel, Zamboanga City, on October 19-20, 2016.

Forty health workers from different rural health units and health centers in the Zamboanga region participated in the two-day training. *ITomas*

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Peñarrubia RHU’s Simple Solution Proves Useful

As part of providing appropriate management for children diagnosed with G6PD Deficiency, the Rural Health Unit of Peñarrubia, Abra, designed the “G6PD Card” and started distributing it to mothers of affected newborns on February 15, 2015.

According to Peñarrubia Public Health Nurse and Newborn Screening Program Coordinator Antonio Caoagas Japson, Jr. The card, which provides information on contraindicated drugs and foods, is a great help to mothers and families of children with G6PD Deficiency.

Dr. Virginia Narciso from the Department of Health–Cordillera Administrative Region Office said that from the 95 confirmed positive cases of G6PD Deficiency in the Province of Abra from January 2015 to May 2016, two were from the town of Peñarrubia.

Besides the cards, Peñarrubia also has the Newborn Screening Mobile Patrol and other traditional strategies such as counseling, patient follow-up, and distribution of information and



A mother and her baby with G6PD Deficiency consult one of the Peñarrubia RHU personnel.

education materials.

Recently, two major awards were given to the Rural Health Unit of Peñarrubia for achieving 100% newborn screening accomplishment rating and for being Functional Newborn Screening Mobile Team early this year by Harmonized Regional Gawad Kalusugan at Crown Legacy Hotel, Baguio City. *AJapson*



Staff of Peñarrubia RHU distribut G6PD cards such as those shown above to mothers and families of babies with the disorder.

Bicol Celebrates 20 Years of NBS

To get people even more aware of newborn screening (NBS) and its importance to the health of future generations, local health units all over the Bicol region held various activities to mark the 20th anniversary of NBS in the Philippines in October.

In Camarines Sur, the City Health Office of Naga conducted mother's classes that covered four barangays and involved 63 expectant mothers. Meanwhile, the City Health Office of Iriga collaborated with private health facilities to conduct public awareness campaigns. Bicol Sanitarium also discussed NBS during the GP month celebration on October 24 with attendees from the nearby barangays of Cabusao, Camarines Sur.

To heighten the campaign, the Provincial Health Office of Albay used radio broadcasts to spread the word about NBS and the disorders included in the screening panel. Further, in Dimasalang, Masbate, Department of Health staff and local government health personnel organized the "20 years of Newborn Screening and Buntis Congress," where some 70 expectant mothers attended and received "Buntis Kits." *JSFenol*

Top: Milwida Racho, Provincial NBS Coordinator, and Joseph Steve Fenol, Regional NBS Coordinator, sit as guests in a radio program show that featured newborn screening in Legazpi City.

Right: Department of Health and local government health personnel with the "Buntis Kits" during the Buntis Congress in Dimasalang, Masbate.

Bottom: Personnel from private health facilities in Iriga City display their banner celebrating the NBS Week, which was supported by the City Health Office and Iriga City Mayor Madeline Y. Alfelor.



Reunion of Saved Babies in Zamboanga City

The Department of Health–Regional Office (DOH-RO) 9, in coordination with the Newborn Screening Center–Mindanao and the Newborn Screening Center Continuity Clinic–Zamboanga City Medical Center, held a Reunion of Saved Babies at LM Metro Hotel, Zamboanga City, on October 18, 2016.

The reunion brought together 83 patients and their families, including 14 babies that had glucose-6-phosphate dehydrogenase (G6PD) deficiency and 11 that were saved from congenital hypothyroidism (CH).

Apryl Joy Gresones, DOH-RO 9 Nurse Coordinator, led the event, which included games and magic show for the families present. There were also lectures and educational materials distributed to the attendees. *ITomas*

Facility Visits Highlight NBS Week in Bohol



The DOH-RO 7 and PHO Bohol team during one of the facility visits

Bohol has 101 newborn screening facilities, 38 of which are inactive. And facility visits are a great way to monitor the implementation of the newborn screening (NBS) program as well as offer immediate solutions to issues and concerns in the facilities.

The Department of Health–Regional Office (DOH-RO) 7, in partnership with the Provincial Health Office of Bohol, visited four facilities on October 18, 2016, namely, Don Emilio Del Valle Memorial Hospital, Rural Health Unit I in Ubay, Birthing Center of Ubay Rural Health Unit II, and Alicia Main Health Center–Birthing Center.

The NSF's, including the NBS coordinators and staff, were evaluated in terms of number and quality of samples as well as patient recall and follow-up. The visiting team also recognized the best practices in the NSF's, particularly the utilization of the network of rural health midwives and barangay health workers in the location and the recall of patients. *MMTabaosares*

ANNOUNCEMENTS

G6PD Parents Seminar

A seminar for parents about glucose-6-phosphate-dehydrogenase (G6PD) deficiency will be held on December 2, 2016, 1:00-4:00 p.m., at UP-PGH Science Hall, Manila. For reservations, please call (02) 376-0962, (02) 376-0964, (02) 376-0965, or (02) 376-0967.

Newborn Screening Book

In partnership with the Newborn Screening Society of the Philippines, the Newborn Screening Reference Center launched the Newborn Screening Book, a project developed to commemorate newborn screening throughout the years. The book will be available in January 2017 at PHP 300.00.

Newborn Screening AVP

The Newborn Screening Reference Center launched the new 12-minute awareness campaign video on the 20th year of newborn screening in the country. The AVP features testimonials from parents and saved and unsaved patients and aims to educate the general public about the importance of newborn screening and to provide program partners, stakeholders, and the general public relevant and timely information about the Expanded Newborn Screening Program.

Reunion of Saved Babies in Bohol

Out of the 272 confirmed patients (except for G6PD deficiency) in Region 7, Bohol has 58. And the Reunion of Saved Babies is a perfect venue for patients and their families to get together and become a support group for one another. This year, the reunion was held at JJ's Seafood Village, Tagbilaran City, on October 19, 2016.

For the Newborn Screening Continuity Clinic, it was an opportunity to get to know the patients and their families. Members of the Volunteer Youth Leaders for Health also helped in the event by providing entertainment and games for the participants. *MMTabaosares*

Tacurong City Celebrates NBS Week



Tacurong City Mayor Lina Montilla (center) with staff from DOH-RO 12

A total of 160 students, health workers, and patients and their families from Sultan Kudarat were accommodated at the Girl Scout of the Philippines Training Hall in Tacurong City for the celebration of the NBS Week led by the Department of Health–Regional Office 12 on October 6, 2016.

The event started with a motorcade from Sultan Kudarat Provincial Capitol. Afterward, Tacurong City Health Officer Dr. Giovanni Deles welcomed the participants and Tacurong City Mayor Lina Montilla gave an inspirational message. Dr. Conchita Abarquez, Newborn Screening Center–Mindanao Unit Head, also gave a talk on NBS updates.

One of the highlights of the activity was the ceremonial screening of six babies. Six NBS facilities who were the day's early birds received free filter cards, while some participants also received bags, t-shirts, and other prizes. *RMMua*

PSPME Holds First NBS Follow-up Clinic in Region 10

The Philippine Society of Pediatric Metabolism and Endocrinology (PSPME) and the Newborn Screening Reference Center conducted the First PSPME Follow-up Clinic in Region 10 at the Northern Mindanao Medical Center (NMMC), Cagayan de Oro City, on September 20, 2016.

The activity served 17 congenital hypothyroidism (CH) and 2 congenital adrenal hyperplasia (CAH) babies. The PSPME Follow-up Clinic was composed of Dr. Jedeane Aragon, Dr. Marichu Mabulac, and Dr. Carolyn Boongaling, while the NMMC medical team was headed by Dr. Rona Ocho, NMMC NBS Continuity Clinic Head, and Udall Armand H. Cabading, follow-up nurse. Also present were pedia residents Dr. Yrogyrog and Dr. Yap, nurses Pottensha Pache Labutog and Aiza Zwiza Mesorado, and Gil Bernard Samante, NBS Coordinator of the Department of Health–Regional Office 10. *UAHCabading*

ERRATUM: JULY-AUGUST 2016 ISSUE

- *NBS Caravan Stops By Sorsogon City*: NBS Caravan is also in coordination with the Provincial Health Office of Sorsogon.
- *DOH-RO 5 Orientation Shines Spotlight on Midwives*: Provincial DOH Office (not Provincial Health Office) spearheaded the orientation. Dr. Gladys Escote is the Provincial DOH Officer/Development Management Officer V (not the Provincial Health Officer.) *Provincial DOH Office is under the DOH-RO 5, while the Provincial Health Office is under the Provincial Government (LGUs).

Your Feedback Is Important to Us!

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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#NBSat20, a Toast to 20 More

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Number of Babies Screened
as of October 2016

8,825,714

On October 26 and 27, 2016, the 14th Newborn Screening Convention took place at the Philippine International Convention Center (PICC), Pasay City. The event was made even more special as 2016 marks the program's second decade of existence, progress, and development in the country, hence the theme "Celebrating 20 Years of Newborn Screening: Towards Overall Quality Screening and Management."

The annual convention serves as a platform for passionate and hardworking individuals to unite towards the ultimate goal for every Filipino child: the right to quality life beginning at birth.

This year, in celebration of #NBSat20, the Newborn Screening Society of the Philippines, Inc. (NSSPI), in cooperation with the Newborn Screening Reference Center (NSRC), National Institutes of Health, University of the Philippines (UP) Manila, welcomed a total of 1800 delegates and guests eager to celebrate as one and learn more about the program from experts all over the country and abroad.

UP Manila Vice Chancellor for Research and National Institutes of Health Executive Director Dr. Eva Maria Cutiongco-dela Paz and Department of Social Welfare and Development (DSWD) Undersecretary Florita Villar delivered inspirational messages, while Disease Prevention and Control Bureau Director Lyndon Lee Suy delivered the keynote address on behalf of DOH Secretary Pauly Jean Rosell-Ubial in

this year's convention.

Dr. Carmencita Padilla, Chancellor of UP Manila, opened the first day of plenary sessions by discussing the challenges, successes, and the future directions of newborn screening. Her lecture was followed by a series of scientific discourses on both the clinical and administrative sides of NBS: Dr. Maria Melanie Liberty Alcausin on the current situation and expansion of

the general program and the infrastructure catering to it from; Dr. Reynaldo de Castro, Jr., on thalassemias beyond the newborn period; Dr. Angelica Tomas on the history, cases, statistics, and future directions regarding the continuity clinics; and Dr. Renilyn Reyes, Dr. Nancy Honor, and Dr. Genelynne Beley on quality services, best practices, and challenges faced by the continuity clinics in their two-year existence so far.

The second day of the convention featured lectures from noted specialists in the country and abroad: Dr. Conchita Abarquez on timeliness in newborn screening; Dr. J Edgar Winston Posecion on ENBS for pre-term, low birth weight, and sick newborns; Dr. Maria Beatriz Gepte on G6PD deficiency and cases, complications, and management; Dr. Meow-Keong Thong on fatty acid oxidation disorders and cases in Malaysia; Dr. Mary Anne Chiong on cases and management issues in organic acid disorders; Dr. Sylvia Estrada on disorders of sex differentiation; Dr. Charlotte Chiong, on Newborn Hearing Screening; Dr. Jose

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