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Participants and organizers of the Youth Leaders Orientation held in Bangued, Abra.

Ripples: NBS Promotion Reaches CAR Youth Leaders

By Jonah Chaangan

To promote youth participation in the newborn screening (NBS) advocacy, the Volunteer Youth Leader for Health (VYLH)–Philippines conducted the Youth Leaders Orientation CARavan in March and April 2014 where 118 Cordillera youth leaders participated.

The caravans served as a window to solicit more participation from the youth of Cordillera in the fight for better child health services in the country.

There were 46 youth participants from Abra, 26 from Baguio City, and 46 from Apayao who witnessed the importance of NBS promotion and implementation in the country. They were also introduced to other campaigns such as folic acid supplementation and orphan disorders.

The participants took part in the dialogue on the right to quality life of newborns and children and on pregnancy and youth empowerment. They were also acquainted with the pre-emptive capacity of NBS to ensure early medical response to commonly undetected cases of Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Galactosemia, Phenylketonuria, and Glucose-6Phosphate Dehydrogenase Deficiency, and Maple Syrup Urine Disease among newborns.

In the orientation's action planning, the youth leaders proposed ways on how to get involved in the nationwide campaigns and on how to promote and disseminate information to the public.

Gracing the event as resource speakers were Aster Lynn Sur of the Institute of
Continued on page 5 . . .

NSC-NIH Welcomes All New NSFs with a Call

In response to the increasing number of newborn screening facilities (NSFs) in the implementation of newborn screening (NBS), the Newborn Screening Center–National Institutes of Health (NSC-NIH) developed the Welcome Call Protocol as a guide for partner NSFs.

The Welcome Call Protocol was implemented in 2010 and has been reinitiated in April 2014, covering NSFs enrolled at the start of this year and using a devised tool and an interview of the NBS Coordinator.

The scope of the interview involves the following key areas: (a) existence or availability of trainings, (b) manner of purchasing, (c) payment, (d) courier matters, (e) performance, (f) follow-up or recall of patients, (g) receipt of results, and (h) other matters or concerns.

Data on the NSFs' number of samples sent to the laboratory, quality of samples (unfit and unsatisfactory samples), age of collection, and transit time are gathered and reviewed prior to the call to prompt NSFs on the proper and timely collection and sending out of samples.

This innovation was brought about by NSC-NIH's commitment to provide partner NSFs with the technical assistance they need in order to improve their operations. In turn, it also serves as an avenue in which the NSC-NIH can measure and better improve its services. *NFortaleza*

First G6PD Parent Forum in NCR for 2014



Dr. Melissa Mae Baluyot talks about the genetic and clinical aspects of G6PD Deficiency Disorder during the G6PD Parent Forum, April 11.

The Newborn Screening Center–National Institutes of Health conducted the G6PD Parent Forum to educate parents of confirmed G6PD-deficient patient in the National Capital Region (NCR) at the University of the Philippines College of Pharmacy Auditorium, Manila, April 11.

One hundred eighty parents, guardians, and city health workers from the Manila Health Department attended the event.

Invited to speak about the genetic and clinical aspects of G6PD deficiency were Dr. Melissa Mae Baluyot, University Researcher at the Institute of Human Genetics and active consultant in various hospitals, and Dr. Beatriz Gepte, Hematology-Oncology Consultant of the Philippine Children's Medical Center.

After the lecture, an open forum followed where frequently asked questions were accommodated. *NFortaleza*

To read more about the G6PD disorder, you may visit www.newbornscreening.ph.

NSC-Visayas Celebrates 8 Years of Operations

In 2006, Newborn Screening Center (NSC)-Visayas started as the testing laboratory for the Visayas and Mindanao until the opening of Mindanao's own NSC in 2009.

In February 2014, NSC-Visayas celebrated eight fruitful years of successful newborn screening services.

West Visayas State University Medical Center (WVSUMC) kicked off the celebration with a Thanksgiving Mass at the WVSUMC Chapel on February 28, 2014. The Center also offered free newborn screening services to walk-in patients and gave away free shirts as well. It also offered some discounts to patients getting G6PD confirmatory tests.

Like other centers, the NSC-Visayas was subject to periodic external and internal audits to ensure the provision of quality

Newborn Screening Center Visayas

Celebrating 8 YEARS



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Screening.**

services to its stakeholders. The Center did not only capitalize on its comprehensive laboratory tests but also focused on other components of the newborn screening program such as continuing education, patient care, and case management.

As it treads the road to expansion, the NSC-Visayas vows to continuously provide quality newborn screening test and holistic care to its patients and their families.

Visits to Northern Cebu

DOH-RO VII, together with the NSC-Visayas and Provincial Health Office of Cebu, visited eight facilities in northern Cebu on February 19-21, 2014.

The activity was part of the regular program monitoring and checking of health facilities after the devastation of supertyphoon Yolanda, which brought structural damages to health facilities.

The facilities visited were Cebu Provincial Hospital in Bogu; Bantayan District Hospital and Rural Health Unit in Bantayan; Sta. Fe Main Health Center and Rural Health Unit in Madridejos; San Remegio Birthing Center, Daanbantayan District Hospital, and Rural Health Unit in Daanbantayan; Rural Health Unit in Medellin; and City Health Office in Bogu.

Local government and health officials, for their part, attended to the immediate needs of their respective constituencies, such as power generators and medical supplies.

In addition, NSC-Visayas and DOH-RO VII gave out free filter cards to facilities affected by supertyphoon Yolanda.



Participants from Aklan and Guimaras provinces attend NBS Orientation Program in Iloilo City on March 12-13.

IN FOCUS

Buluan District Hospital



Patients at the Buluan District Hospital in Maguindanao sit and wait behind the hospital's mission statement and promotional posters.

Buluan is a fourth class municipality in Maguindanao and currently serves as the provisional capital of Maguindanao Province (the former was Shariff Aguak) after the infamous massacre in 2010. The Buluan District Hospital is the only government health facility here.

Buluan District Hospital applied for as a newborn screening facility (NSF) in 2009 but started implementing newborn screening (NBS) in the last quarter of 2010 with NBS coverage of 2%. The coverage rose to 21% in 2011 and then to 25% in 2012.

To further increase the number of babies screened in the municipality, the hospital implemented several initiatives in the program. One initiative was the production and distribution of local information, education, and communication (IEC) materials that were culturally sensitive and easily understood by locals.

The IEC materials emphasized the importance of newborn screening and called on expectant parents and guardians to have their babies screened.

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NBS Day Series in Region X

The first week of October is Newborn Screening (NBS) Awareness Week. But for Department of Health Regional Office (DOH-RO)-Northern Mindanao, it lasts for more than that.

DOH-RO Northern Mindanao held a series of Newborn Screening Day Celebrations at the different barangays and municipalities in the region to promote awareness on NBS.

Date	Venue	No. of Babies Screened	Positive
February 10, 2014	Lapasan, Cagayan de Oro City	10	0
February 11, 2014	Bulua, Cagayan de Oro City	10	0
February 13, 2014	Pangantucan, Bukidnon	268	26-G6PD Deficiency
February 14, 2014	Kallangan, Bukidnon	123	14-G6PD Deficiency
March 19, 2014	Mambajao, Camiguin	37	0
March 27, 2014	Libona, Bukidnon	120	4-G6PD Deficiency
March 28, 2014	Malitbog, Bukidnon	106	5-G6PD Deficiency
April 10, 2014	San Fernando, Bukidnon	170	1-CH 16-G6PD Deficiency
April 29, 2014	Talakag, Bukidnon	74	1-CH 1-G6PD Deficiency
May 2, 2014	Lantapan, Bukidnon	115	
Total No. of Babies Screened		1,033	

Table 1. Schedule and results of the NBS Day Celebrations in Region X

For each leg in the series, an NBS orientation was given to the parents and followed by sample collection from the babies. In some areas, pregnant women were also invited to attend and become NBS advocates in their respective communities.

The NBS programs were made possible through the collaboration with Northern Mindanao Medical Center and local government units. *GJacot*

NSC-Mindanao Holds G6PD Deficiency Parents Forum



A total of 56 parents attended the G6PD Deficiency Parents Forum in Davao City conducted by Newborn Screening Center-Mindanao (NSC-Mindanao) at the Mahogany Room, Southern Philippine Medical Center (SPMC), on April 1, 2014.

The forum provided useful information to parents with children confirmed with G6PD Deficiency Disorder, the most common disorder found through newborn screening.

Dr. Jeannie Ong, a pediatric hematologist and consultant at SPMC, gave a lecture on the disorder and later accommodated questions and concerns from the attendees.



Ripples: NBS Promotion Reaches CAR Youth . . . from page 1



Participants from Baguio and Benguet universities take part in the Baguio City leg of the VYLH-Philippines North Luzon Cluster Orientation CARavan.

Human Genetics–National Institutes of Health, University of the Philippines Manila; Francia Bartolata, Ryan Pascual, Rufus Adducul, and Edbert Jasper Jover of VYLH-Philippines NCR-South Luzon; and Roland Alcantara of Newborn Screening Center–Central Luzon (NSC-CL) and VYLH-Philippines North Luzon Cluster Secretariat.

The activity was organized by Dr. Virginia Narciso, Regional NBS Program Manager, Regional Office–Cordillera Administrative Region (RO-CAR), and Joyce Rillorta, NBS Nurse Coordinator, RO-CAR. They were assisted by Baguio City youth leaders Crissa Siki, Saint Louis University; Safrone

Dicam, Benguet State University; Jonah Chaangan, University of the Philippines Baguio; and Keith Dakimas and Sheema, University of Baguio.

With the caravan’s success, VYLH-Philippines and partner agencies NSC-CL and RO-CAR look forward to mobilizing more youth participants when they visit other parts of the region.

Jonah Chaangan is a senior BA Communication student at the University of the Philippines Baguio. He joined the Network in April 2014 and was listed as member of the batch E4 (Educate, Empower, Engage, Experience).

Bantay MHO Boasts Success of *Alkansya Para Kay Baby*

In 2009, the Local Government of Ilocos Sur issued an ordinance supporting newborn screening (NBS) and allotted funds to start up its implementation. On July 15, 2010, the Municipal Health Office (MHO) of Bantay, Ilocos Sur, launched *Alkansya Para Kay Baby* in response to the challenge of poverty.

In pursuit of the 85% NBS coverage target set by the Department of Health, *Alkansya Para Kay Baby* proved effective in four years as it dramatically improved NBS coverage from 19% in 2009 to 95% in 2013.

Alkansya Para Kay Baby is a financial scheme for expectant mothers that allows them to save money for newborn screening during the span of their pregnancy. At the start of the program,

the MHO puts up and safeguards a savings box where mothers can gradually deposit any amount of money, with a maximum of P600, every pre-natal checkup.

Along with the savings scheme, expectant mothers are also given orientation on the nature, importance, and benefits of newborn screening during their pre-natal visits. With these innovative practices, the local government promotes responsible parenthood where mothers are equipped with knowledge and skills to provide their children with the right and proper care.

Behind *Alkansya Para Kay Baby* are Dr. Lioba Cecilia Tolentino, Municipal Health Officer; Vivencia De Leon, Public Health Nurse; Hon. Floro P. Parilla, Municipal Vice-Mayor; and Mary Michelle Cristobal-Lewis, Region I NBS Nurse Coordinator.



Getting Better and Better



Participants of the First Newborn Screening Consultative Meeting and Planning Workshop conducted by DOH-RO VIII, March 28.



Representatives from DOH-RO VII, NSC-Visayas, and Provincial Health Office of Cebu visit eight facilities in northern Cebu, including Daanbantayan District Hospital.

Successful newborn screening means getting new facilities. And new facilities need to be equipped with staff with basic knowledge and skills on newborn screening.

That is why the Department of Health Regional Office (DOH-RO) VI conducted the Newborn Screening Orientation Program at Sarabia Manor Hotel, Iloilo City, on March 12–13, 2014.

Representatives from the provinces of Guimaras and Aklan attended the event where they were able to get a first-hand experience on blood sample collection through heel prick method at the Western Visayas Medical Center.

Meanwhile, DOH-RO VII oriented health team members from new and inactive facilities on March 12 and March 13–14 in Bais City and Mabinay, Negros Oriental, respectively.

Furthermore, DOH-RO VIII conducted the First Newborn Screening Consultative Meeting and Planning Workshop at the Directors Conference Room, Tacloban City, on March 28.

The activity reviewed the status of the newborn screening program in the province and developed strategies to cope with emergencies and natural calamities. Representatives from the different local government unit hospitals from Leyte province attended the event.

Continuity Clinics Personnel Attend Workshop

To help Newborn Screening Program's key personnel in the follow-up and management of confirmed positive patients, the Family Health Office–Department of Health and the Newborn Screening Reference Center–National Institutes of Health held a consultation and orientation workshop on Expanded Newborn Screening and Continuity Clinics at Traders Hotel Manila, April 22–25.

The activity provided the participants with the necessary knowledge and understanding of the concept of Newborn Screening Continuity Clinics and Birth Defects Continuity Clinics and the proper management of confirmed patients affected by heritable disorders included in the Expanded Newborn Screening panel.

The Newborn Screening Continuity Clinics were established in various parts of the country in line with the growing number of referrals and patients being managed and the implementation of expanded newborn screening. The clinics were envisioned



Continuity Clinics' doctors and nurses, national and regional newborn screening coordinators, dietitians, follow-up nurses, and genetic counseling students gamely pose for a photo after the consultation and orientation workshop.

to strengthen the treatment and referral network and ensure the capable management of identified positive cases.

Currently, there are 14 clinics in operation, which are strategically and geographically accessible to its main clients. They provide medical care and counselling to the family of patients confirmed with one of the conditions in the newborn screening panel.



DOH-RO XI Holds NBS Consultative Meeting



Participants of the First NBS Consultative Meeting for Provincial Pediatricians, MHOs, and Family Physicians of Davao del Sur.

To better implement newborn screening (NBS) in the region, the Department of Health–Regional Office (DOH-RO) XI held the First Consultative Meeting with Pediatricians, Municipal Health Officers, Family Physicians, and General Practitioners for Davao del Sur at the Marco Polo Hotel, Davao City, on March 21.

Also attended by NBS Nurse Coordinators, the meeting addressed problems in recall and management and strengthened the skills of health specialists from public and private facilities.

Dr. Conchita Abarquez, Unit Head of NSC-Mindanao, and Dr. Eleonor Du, a pediatric endocrinologist, discussed the clinical conditions including the diagnosis, management, and referral of Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Galactosemia, Phenylketonuria, G6PD Deficiency, and Maple Syrup Urine Disease. Dr. Abarquez presented data and updates on the positive and confirmed cases in Davao del Sur.

Meanwhile, Dr. Emma G. Lutero, a pediatrician at the Gonzales Maranan Clinic and Hospital and a consistent NBS awardee of the region, shared good practices done at her facility. *ARVillaroel*

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Knowing Better Is Doing Better

When you know better, you do better!

And the Department of Health (DOH) and Newborn Screening Center (NSC)–Mindanao could not agree more.

The two agencies, together with the Bayugan City Health Office, provided newborn screening (NBS) training to 16 midwives from private lying-ins and Barangay Health Stations in Bayugan City at Jasmin's Place, Bayugan Gardens, Bayugan City, Agusan del Sur, on March 3–7.

Dr. Conchita Abarquez, NSC-Mindanao Unit Head, discussed the benefits of NBS and the disorders that NBS is trying to address. She was accompanied by Dr. Glynnna Andoy, DOH-RO CARAGA NBS Program Manager; Nanette Montilla, DOH-RO CARAGA NBS Nurse Coordinator; Helen Saligan, CHO-Bayugan Provincial Health Nurse; Dr. Jeanne Maningo, Bayugan City Health Officer; Jocelyn Cañete, PhiHealth representative; and members of the Volunteer Youth Leaders for Health–CARAGA.

The training introduced new approaches in promoting and implementing NBS. After two days of lectures, participants under the supervision of the NSC-Mindanao visited patients in their homes for sample collection. These patients were babies delivered at newborn screening facilities (NSFs) but were not brought back for NBS. Fifteen babies were tracked down at their barangays and screened for free.



Participants and organizers of the NBS Training for CHO-Bayugan, Agusan del Sur.

The activity allowed the trainees to experience first-hand how to track patients and collect NBS samples outside NSFs.

The training design was developed after the DOH-RO CARAGA held its NBS Implementation Review for NSFs in Agusan del Sur in January 2014, where one of the challenges identified was the lack of trained personnel to track and follow up patients that were discharged early from a birthing facility. Early discharge of babies was identified as one of the reasons for low NBS coverage in the area.

With the knowledge and skills gained by the participants from the training, NSC-Mindanao and DOH-RO CARAGA hope to increase Agusan del Sur's NBS coverage. *PBermudez*





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OCTOBER 28-29, 2014

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A Double Treat for Patients and Parents in Region X **Buluan . . . from page 4**

The Department of Health—Regional Office Region X offered a double treat to parents and patients—G6PD and CH Forum and Reunion of Saved Babies—at the Chali Beach Resort, Cagayan de Oro City, April 23, 2014.

The G6PD Deficiency and CH Forum gathered more than 100 parents and babies confirmed with the disorders from the provinces in the region: Bukidnon, Camiguin, Misamis Oriental, Misamis Occidental, Lanao del Sur, and Lanao del Norte.

Dr. Ellenietta N. Gamolo, Assistant Regional Director and DOH-RO X NBS Program Manager, delivered the welcome note, while Dr. Eleanor Du, a pediatric endocrinologist, presented a comprehensive lecture on G6PD and CH disorders.

Meanwhile, at the other hall, the “Reunion of Saved Babies” treated children to food and lively activities. Also adding fun to the event was the mascot “Blue” from the TV show *Blue’s Clues*.
ADTadlas



The increased newborn care package offered by PhilHealth also contributed to more babies screened in Buluan District Hospital, while delivery packages were still affordable to non-PhilHealth patients.

Another contributing factor was the continuous support and tireless efforts by the Provincial Health Officer, Municipal Health Officer, and the NBS Coordinator in the successful implementation of the hospital’s NBS program.

Buluan District Hospital’s efforts proved to be effective as the hospital achieved a coverage of 93% at the end of 2013. Because of its captivating success story, Buluan District Hospital is the first NSF in Maguindanao to become a nominee at the NBS Awards in 2015. *AMatuan*

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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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