

Metro LGUs Meet NSC-NIH in its New Location



Left photo: Wenalyn Viaña, NSC-NIH Program Manager, explains to participants the newborn screening flow of operations. Right photo: Health personnel from City Health Offices in Metro Manila sit down to discuss issues and formulate strategies to improve newborn screening implementation.

Easy does it!

From February to May, the Center for Health Development–Metro Manila (CHD-MM) and the Newborn Screening Center–National Institutes of Health (NSC-NIH) took their time in meeting with Metro Manila local government units' health officials and personnel at NSC-NIH's new location in UP Ayala Land Technohub, Quezon City.

The series of meetings were attended by the NSC staff headed by Ma. Elouisa Reyes, Dr. April Berbos, Wenalyn Viaña, Joanna Decano-Terrado; newborn screening coordinators of CHD-MM; staff of hospitals and lying-in facilities; and personnel of various city health offices.

Met with much enthusiasm and concern for infant health, the activity allowed each city to review its status of newborn screening (NBS) implementation, the health facilities operating in their area, and the problems encountered in the implementation. Hospitals, facilities and city health officials were also able to devise strategic solutions to issues raised in their locale.

The inter-agency meetings followed a format to ensure uniform communication flow. The meetings started with an introduction and overview of the Newborn Screening program and then followed by a tour of the NSC-NIH sections. Guests and participants were allowed to raise questions during the entire meeting.

The schedule of the meetings for each city were February 23, Quezon City; March 8, Caloocan City; March 22, Paranaque City; April 20, Mandaluyong City; April 27, Muntinlupa City; May 4, Taguig City; and May 25, Navotas. *CAIncastre*

NSC-NIH Parallel Tests Neometrics Upgrade

How do you manage newborn screening data generated from around 1,500 samples per day?

Let's leave the answer to technology, shall we?

Since 2004, Newborn Screening Center-NIH has been using Neometrics, a data management system developed by US-based company Natus. Natus specializes in healthcare products that screen, detect, treat, monitor, and track common medical ailments in newborn care.

This year, NSRC-NIH plans to upgrade this database system. Ma. Elouisa L. Reyes, coordinator for the Neometrics upgrade project, and Meiler Rene Manguiat, IT consultant, met with NSC-NIH personnel April 19 for the briefing of activities in preparation for the upgrade.

According to the team, before the upgrade can be adopted, the old and new versions first need to be used simultaneously to correct glitches and make adjustments to the system. The parallel testing at NSC-NIH is expected to end June 2012.

One of the advantages of the new version is that several of the manual interventions done in the old system will be eliminated, making data processing and retrieval faster.

In the Philippines, Neometrics is used by all newborn screening centers to manage newborn demographics, screening results, follow-up actions, and patient management or treatment status for confirmed positive cases.

Through Neometrics, information can be easily retrieved. If an NBS nurse coordinator from a facility asks for the result of a certain patient, the center only needs a few information—such as last name or date of birth—and can search the record from Neometrics. For security and confidentiality, only authorized personnel from the center can access patient information. *IFortugaleza*

Photo Story



Araw ng Buntis 2102 in Visayas: Patio Victoria, Tacloban City

screening to pregnant women and future mothers.

March 10, 2012: Rural health unit and private lying-in clinic personnel participate in a newborn screening orientation and skills training organized by DOH-CHD VIII. Made possible through the help of Eastern Visayas Regional Medical Center, the training addressed the need to expand the program in the community. The region has doubled the number of newborn screening facilities since last year. *DBuensalido*



The parents with their babies and the organizers pose for photo after the successful G6PD Lay Forum held on March 8 in Bacolod.

Favismo III: The Third Phase

Of the five disorders in the Newborn Screening Panel of Disorders, Glucose-6 Phosphate Dehydrogenase (G6PD) Deficiency has the highest prevalence rate—1:46 in Western Visayas.

For this reason, the Newborn Screening Center–Visayas (NSC-V) holds an annual G6PD Lay Forum for parents and families of babies found to have positive screens for G6PD. This year, NSCV held the forum in Bacolod City on March 8.

NSC-V partnered with Dr. Pablo O. Torre Memorial Hospital and Department of Health–Center for Health Development VI in conducting “Favismo III: The Third Phase, A G6PD Lay Forum” at the AV3 of Riverside College, Bacolod City.

Favismo III gathered parents and babies from various municipalities in Negros Occidental who were accompanied by their local health workers, and gave free access to confirmatory testing of their positive G6PD screens.

The forum also featured a talk on G6PD by Dr. Carmelita Calahong, pediatric consultant with specialty in pediatric hematology and oncology. The talk highlighted important facts about G6PD, symptoms associated with it, complications brought about by the disease, and the importance of preventive measures against such complications. Ultimately, the talk reassured parents that G6PD-positive children can continue to lead normal, healthy, and productive lives through proper management and prevention. *YDemegillo*

Not Just Prayers on Holy Wednesday for Daughters of Mary Immaculate

Last April 4, Holy Wednesday, the Daughters of Mary Immaculate (DMI) of the Holy Redeemer Parish, Butuan City, were not only on their knees and praying.



Women churchgoers listen attentively to Perly Bermudez, NSC-M staff discuss the importance of newborn screening during the NBS Orientation organized by DMI on April 2.

They were also on their feet helping women parishioners.

The DMI sisters conducted a newborn screening (NBS) orientation to 21 indigent women churchgoers. This has been a yearly activity of the religious group where they give gift certificates to participants, which entitle them to a free newborn screening for their babies at the time of their delivery.

DMI invited Perly Bermudez and Amerah Matuan, Project Development Officers of the Newborn Screening Centers–Mindanao, to discuss the importance and benefits of NBS as well as the effects of the five metabolic disorders on the NBS panel. Meanwhile, Nanette Montilla, CHD-Caraga's NBS Nurse Coordinator, was invited to inform the women where to avail NBS and how a PHIC member can avail a free screening.

Besides the gift certificates, participants also received free medicine and vitamins after free prenatal checkups and consultation courtesy of CHD-Caraga. *NMontilla*

Davao City Hosts 2nd CH Forum

For the benefit of congenital hypothyroidism (CH) patients, the Newborn Screening (NBS) Center–Mindanao held its Annual Congenital Hypothyroidism Forum at Southern Philippines Medical Center (SPMC), Davao City, March 1.

The forum featured Dr. Christiana Pedreso, Pediatric-Endocrinology Resident of SPMC, who explained the disorder—from its anatomy to pathophysiology, treatment, and management. Meanwhile, Dr. Eleonor Du, Pediatric Endocrinologist and Chair of Mindanao Follow-up Team, addressed the parents' fears and apprehensions. Clarose Mascardo, NBS Regional Coordinator of Center for Health Development Region 11, gave the welcome remarks.

The event culminated with free follow-up checkups and consultation with Dr. Du.

Twenty-four confirmed CH patients attended the event including the parents, CHD-Region 11, pediatric-endocrinology residents, NBS officers-in-charge, barangay health workers, and NSC-Mindanao staff. *PBermudez*

1st CH Forum in Region 12

While Region 11 had its second annual congenital hypothyroidism (CH) forum, Region 12 conducted its first at Tboli Hotel, General Santos City, March 21.

The Newborn Screening (NBS) Center–Mindanao and Center for Health Development–Region 12, headed by Lucy Decio, partnered to educate parents on congenital hypothyroidism, its management, and the right treatment for their children with CH.

The forum featured Dr. Eleonor Du, Pediatric Endocrinologist and Chair of Mindanao Follow-up Team, who talked about CH and the need for follow-up checkups and monitoring as well as the importance of continuous medications. In the end, Dr. Du himself gave free checkups and consultation.

Present in the event were confirmed CH patients and their parents from Region 12; barangay health workers; representatives from General Santos City Health Office; the NBS Regional Coordinator; Agnes Dimasil, Nurse Coordinator of CHD-12; Dr. Conchita G. Abarquez, Unit Head of NSC-Mindanao; Perly Bermudez; Juloufe Turtal; and Amerah Matuan. *PBermudez*

DOH-CHD 12 Reviews NBS Implementation

To ultimately increase newborn screening (NBS) coverage in the region, the Center for Health Development (CHD)–Region 12 conducted its Program Implementation Review (PIR) on January 24–25, 2012, at T'boli Hotel, General Santos City.

The PIR aimed to assess, review, and strengthen the program implementation of each of the cities and provinces in Region 12.

The event kicked off with presentations of the accomplishments and best practices from North Cotabato, South Cotabato, Saranggani, and Sultan Kudarat. Dr. Conchita Abarquez, Unit Head of NSC-Mindanao, presented updates on the status and performance of each province in the region, while Ms. Lucio Decio, Regional NBS Coordinator of CHD-Region 12, presented strategies and actions to help increase NBS coverage.

Dr. Edson Pama of PhilHealth Region 12 answered questions on PhilHealth, and Ms. Lita Orbillo from the DOH-National Center for Disease Prevention and Control provided the regional performance vis-à-vis the nationwide coverage and reported updates and current developments on the NBS program.

The PIR also commended exemplary and outstanding NBS facilities. The awardees were Well-Family Midwife Clinic-Enriquez (General Santos City), Antipas Medical Specialists Hospital, Inc. (Antipas), Mlang Doctors Hospital, Inc. (Mlang), The Doctors Clinic and Hospital, Inc. (Koronadal City), Lake Sebu Municipal Hospital (Lake Sebu), Polomolok Municipal Hospital (Polomolok), ZMK Doctors Clinic and Hospital (Tacurong City), Sandig Medical Clinic and Hospital (Tacurong City), Mindanao Medical Center (General Santos City), and Kidapawan Medical Specialists Center, Inc. (Kidapawan City).

Free NBS kits were also given to RHU Bagumbayan of Sultan Kudarat and the Cotabato Regional and Medical Center in Cotabato City to widen the NBS coverage.

The participating newborn screening facilities (NSFs) also came up with plans highlighting strategies and actions to improve the NBS programs with the end goal of increasing the number of babies screened in their respective facilities.

At present, there are 160 NSFs in the region that support the implementation of NBS. *MADimacisil*

North and Central Luzon Map 2012 Program

Old network, new means of communication.

This is the concept that Newborn Screening Center–Central Luzon and Centers for Health Development–Regions 1, 2, 3, and CAR envision for their newborn screening (NBS) programs when they met at Angeles University Foundation, Angeles City, March 19-21.

Inspired by the term *diaspora*, a Greek word that means “scattering or dispersion,” the new program takes into consideration the movement and migration of people, especially Filipinos, around the globe.



The Regional NBS Coordinators and NSC-CL staff map out strategic places to further improve NBS in Northern and Central Luzon.

At the assembly, Northern and Central Luzon program movers discussed issues and concerns regarding the implementation of newborn screening and created strategic plans and program maps viable within their respective areas.

Personnel from the Newborn Screening Center–Central Luzon participated in the event, including regional coordinators Mary Michelle Lewis (Region 1), Joyce Maquera (Region 2), Norrice Fortaleza (Region 3), Adelina Cabrera (Region 3), and Joycelyn Rillorta (CAR). *CMonieno*

A Day for Pregnant Women

In celebration of the National Pregnant Women's Day, VYLH-Philippines in partnership with Newborn Screening Centers—NIH, Visayas and Mindanao joined the Philippine Obstetrics and Gynecological Society (POGS) in its Araw ng Buntis 2012, March 10.

Themed "Maabilidad na P-nay, Malusog na Nanay," Araw ng Buntis 2012 was special as it attempted to set the Guinness World Record for the Largest Prenatal Class in Multiple Venues.

The simultaneous one-hour prenatal class aimed to stress the importance of proper nutrition and prenatal checkup. The program included lectures, free ultrasound and laboratory exams, and freebies for the participants, and ended with the Ginang Buntis pageant.

VYLH-Philippines participated in three cities—Pasay City, Iloilo City, and Davao City. With a booth provided by POGS, VYLH-Philippines volunteers were able to distribute promotional materials that contained information on newborn screening and particularly on the importance of folic acid supplement in the prevention of birth defects. Volunteers also sponsored a signature campaign for the passage of the Rare Disease Act.

It was also the first time for VYLH-Philippines to join a national event to advance its advocacies: prenatal health, in particular increasing the public's awareness on the importance of folic acid in the prevention of birth defects.

Araw ng Buntis 2012 was made possible by POGS National President, Dr. Rey de los Reyes, the POGS National Secretariat, and local POGS members and officers including Dr. Amelita Jover (San Juan de Dios Hospital, NCR), Dr. Kathlynn Ann dela Llana (WVSUMC, Iloilo), Dr. Maureen Fortuna (President, POGS-Iloilo), Dr. Elmer Chua (Regional Director, POGS-Southern Mindanao), and Dr. Michelle Ong (Event Organizer, POGS-Southern Mindanao). This annual event is pursuant to Presidential Proclamation 569 signed in 2004. *RJPascual, MTCuenca, ALMillares, EJJover*



Araw ng Buntis 2012 in Luzon: Cuneta Astrodome, Pasay City



Araw ng Buntis 2012 in Visayas: Robinson's Place, Iloilo City



Araw ng Buntis 2012 in Mindanao: Ateneo de Davao Grade School Campus, Davao City

VYLH-Philippines Goes Back to School

This time, they take it back to the classrooms!

For this year's first quarter, health volunteers visited students and teachers from different schools for its information, education and campaign activities on newborn screening (NBS) and rare disorders.

Recognizing that the academic community is a good partner in information campaign, VYLH-Philippines joined the Genetics Camp of the University of the Philippines Los Baños Genetics Society (UPLB GeneSoc) and sponsored the Schools for Rare Campaign.



The network saw a great opportunity in UPLB GeneSoc's 6th Genetics Camp and joined forces with Institute of Human Genetics and the Newborn Screening Reference Center (NSRC) to go ahead with an information campaign. Themed "GENEtervention: Beware. Be Aware. Screen for Rare," the camp focused on the importance of newborn screening and orphan disorders in the Philippines.

The camp, which ran January 21 and 22, was attended by more than a hundred students and faculty throughout Luzon and featured lectures and contests such as essay writing, poster and slogan making, and a quiz bee.

VYLH-Philippines promotes advocacy to high school students. The photo shows students display NBS posters in Schools for Rare in Luray II National High School.

Meanwhile, VYLH-Philippines launched in February the Schools for Rare Campaign in time for the Third National Rare Disease Week.

The campaign hopped from school to school to discuss orphan disorders and NBS to high school students. With the battle cry "Juan for Rare: Let's make every-Juan aware of the fight and plight of Filipinos with rare disorders," the campaign followed the international call-for-solidarity theme "Rare But Strong Together."

During the school visits, VYLH-Philippines volunteers also collected signatures in support of the Rare Disease Act.

The Schools for Rare Campaign ran in Los Baños National High School, Maquiling School Inc. in Los Baños, Laguna, Luray II National High School in Cebu; University of Iloilo-PHINMA Basic Education Department, Philippine Science High School Western Visayas Campus, West Visayas State University Integrated Laboratory School in Iloilo, San Andres High School in Bukidnon, and Lumbocan National High School in Butuan City. *RJPascual*



Photo shows students attend lectures during the UPLB Genetics Society's Genetics Camp.

Editorial Staff

Executive Editor: Riza Concordia N. Suarez
 Managing Editor: Vina G. Mendoza
 and Layout Artist: Emerson Kim J. Linesses
 Associate Editor: Carmencita D. Padilla, MD, MAHPS
 Adviser: Claire Alincaestre, Perly Bermudez, Dominic Buensalido, Marian Cuenca, Yugie Caroline Demegillo, Mary Agnes Dimacasil, Irel Fortugaleza, Edbert Jasper Jover, Vina Mendoza, Anna Leah Millares, Christian Leandro Monieno, Nanette Montilla, Ryan John Pascual
 Contributors: Felix Alipasa, Marijoie Castillo, Marjorie Dimaano, Susan Jalad

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

NBS Information Brochure Now in Four Languages

Can you explain "newborn screening" in Cebuano?

Now you can with the Newborn Screening (NBS) Information Brochure printed in English, Filipino, Cebuano, and Hiligaynon.

The Sentro ng Wikang Filipino—Unibersidad ng Pilipinas Manila, Newborn Screening Reference Center, and Newborn Screening Centers—Visayas and Mindanao worked out to translate and bring much needed NBS information to more Filipinos.

The NBS brochure is designed to help the general public and health workers better understand the importance and benefits of newborn screening. It provides answers to many of the frequently asked questions about the procedure. It explains the five disorders being screened and the Maple Syrup Urine Disorder, which will be included in the panel soon.

The brochure includes various reminders to parents of patients with Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency, the most common condition among the disorders.

All translations can be downloaded from the resources page of www.newbornscreening.ph in PDF format. The translation in Ilocano will also be made available online by end of June. *VMendoza*



Newborn Screening Reference Center
 National Institutes of Health
 University of the Philippines Manila
 Pedro Gil St., Ermita, Manila 1000

VOLUME 16
 ISSUE
02
 March—April
 2012



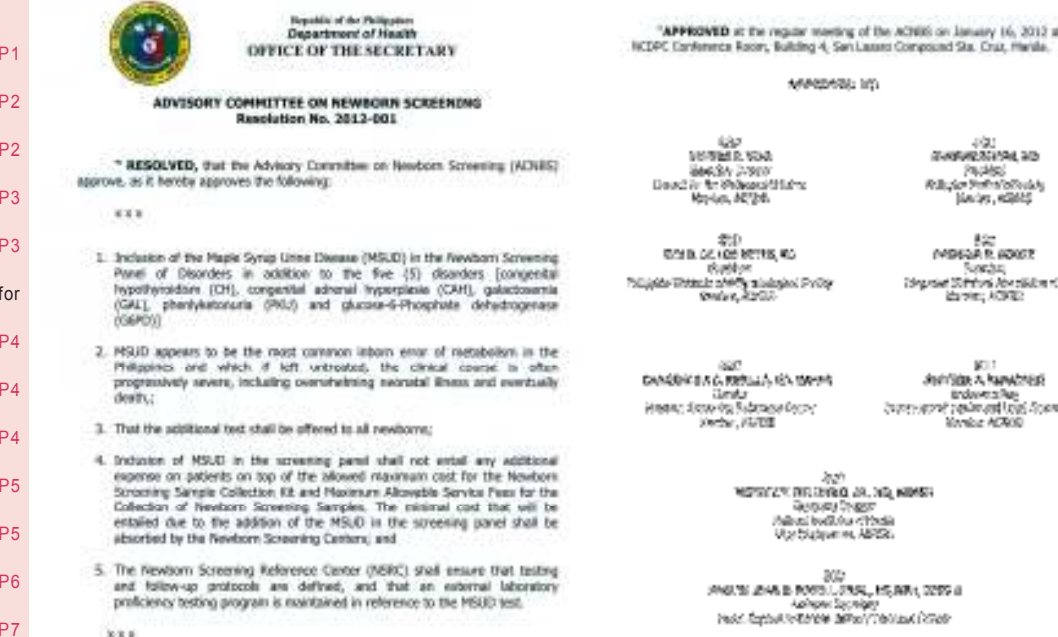
newborn screening

Bimonthly Publication of the Newborn Screening Reference Center
 National Institutes of Health, University of the Philippines Manila

In this issue

- ACNBS Approves Testing for Six Disorders **P1**
- Metro LGUs Meet NSC-NIH in its New Location **P2**
- NSC-NIH Parallel Tests Neometrics Upgrade **P2**
- NSC Visayas Photo Story **P3**
- Favismo III: The Third Phase **P3**
- Not Just Prayers on Holy Wednesday for Daughters of Mary Immaculate **P4**
- Davao City Hosts 2nd CH Forum **P4**
- 1st CH Forum in Region 12 **P4**
- DOH-CHD 12 Reviews NBS Implementation **P5**
- North and Central Luzon Map 2012 Program **P5**
- A Day for Pregnant Women **P6**
- VYLH-Philippines Goes Back to School **P7**
- NBS Information Brochure Now in Four Languages **P8**

ACNBS Approves Testing for Six Disorders



In a move toward true free health care, the Advisory Committee on Newborn Screening (ACNBS) has approved the inclusion of Maple Syrup Urine Disease (MSUD) in the current newborn screening panel of disorders, raising the number of disorders in the panel from five to six.

In Resolution No. 2012-001, the Committee allowed the offering of the additional test to all newborns at no additional cost.

MSUD, the most common inborn errors of metabolism in the Philippines, joins the list of the five disorders in the newborn screening panel: congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, G6PD deficiency, and phenylketonuria.

MSUD is a genetic metabolic disorder resulting from the defective activity of the enzyme branched chain alpha-keto-acid dehydrogenase (BCKAD) complex. The accumulation of the branched chain amino acids is toxic to the brain and can lead to mental retardation or death.

The clinical presentation of classic MSUD includes the following: maple syrup odor, irritability and poor feeding, signs of deepening

encephalopathy, and, ultimately, coma and central respiratory failure. The first signs of MSUD are non-specific and may mimic those of neonatal sepsis.

Treatment is mainly dietary in nature, including the removal of sources of essential amino acids like leucine, isoleucine, or valine.

Since 1992, there have been 101 cases diagnosed in the Philippines even without newborn screening. Out of the 101 diagnosed, only 26 are living.

Low-level clinical suspicion among health practitioners cause the high mortality for patients with MSUD in the country.

With the addition of MSUD in the current panel of diseases, the disorder will be better diagnosed and managed early to prevent irreversible complications.

The full implementation of the ACNBS resolution follows this schedule: NSC-NIH, July; NSC-CL, August; NSC-Visayas, October; and NSC-Mindanao, December. *VMendoza*

Number of Babies Screened
 as of April 2012
COUNTER: 3,397,574