

Marinduque holds program implementation review



Participants in the PIR on Newborn Screening conducted by CHD-4B on February 12-13 at Eurotel North EDSA.

The Center for Health Development-MIMAROPA (4B) conducted a Program Implementation Review on Newborn Screening last February 12-13 at Eurotel North EDSA, Quezon City with the NBS Coordinators of the eight (8) health facilities in Marinduque including Dr. Honesto Marquez, the Provincial Health Officer. Ms. Abigail Estrada, the Senior Supervising Consultant of Philhealth provided the participants updates on the Newborn Care Package and Case Rates. Dr. April Grace D. Berbozo, Head of the Newborn Screening Center-NIH (NSC-NIH), discussed the genetic and clinical aspects of Maple Syrup Urine Disease. Joanna Decano-Terrado, the Project Development Officer of NSC-NIH, presented the unsatisfactory samples report and the data on the age of collection and transit time of blood samples per health facility. She also discussed the importance of proper blood collection, on ideal time of screening,

and on prompt sending of blood samples. Dir. Jose R. Llacuna, JR. MD, MPH, CESO IV the OIC-Regional Director of CHD-4B, encouraged the participants to continue implementing and advocating NBS. *JATerrado*

Newborn Screening in the Secondary Curriculum

The Center for Health Development-Metro Manila is continuously strengthening its efforts and formulating strategies for the implementation of Newborn Screening (NBS) to intensify the commitment of other stakeholders to meet the 100% target coverage. The importance of the youth is being realized as one of the effective partners in NBS as they are the future leaders and parents. Early advocacy campaign involving them would surely contribute to an increase in NBS coverage.

In this line, CHD-MM initiated a proposal to the Bureau of Secondary Education thru Director Lolita M. Andrada, to include Newborn Screening in the curriculum for Music, Arts, Physical Education and Health (MAPEH) initially at Metro Manila and later in the national level. This proposal has been accepted positively by the Bureau of Secondary Schools, Department of Education and will be included in the curriculum for secondary particularly in Grade 8 under the concept of Family Health.

The NBS Coordinators will meet with them to discuss more about Newborn Screening.

The advocacy of the Newborn Screening through education of the youth will give more children the opportunity to live a normal life. *CAIncastre*

Annual Galactosemia Multidisciplinary Clinic

The Section of Genetics of the Department of Pediatrics of the Philippine General Hospital and the Newborn Screening Center-NIH held the annual Galactosemia Multidisciplinary Clinic on January 24 at the PGH-OPD Genetics Clinic. Around 20 health professionals composed of Geneticists, Pediatric Ophthalmologists, Developmental Pediatrician, Metabolic Dieticians and Nurses for the comprehensive management of patients with Classical and Non-classical Galactosemia were present that day. It was organized primarily to have one day schedule for all the necessary consultations to lessen the transportation expenses of indigent patients. The multidisciplinary clinic is part of the long term follow-up program of the center. *JATerrado*

Visayas rolls-out reorientation programs

At the start of February NSC-Visayas, together with the Centers for Health Development-6, 7 and 8 began a series of Reorientation Programs for the various NSFs of the three regions. The first group was the NSFs from Iloilo, Guimaras and Antique; followed by Negros Oriental, held in Dumaguete City. Next was the group from Leyte and Biliran, held in Tacloban City. When March came the group from Capiz was next, which was held in Roxas City, and the last group for the first half of the year was from Cebu, held in Cebu City.



The Newborn Screening Team of Capiz on Day 2 of the NBS Reorientation and Updates. Capiz is one of provinces in Region 6 that has 85% coverage in newborn screening.

This program was one of the strategies to address the rising number of unsatisfactory samples, samples deemed unfit for testing due to contamination and/or insufficiency, and samples with errors in data gathering. The program was designed to review the NSFs representatives on the Administrative Protocols and Laboratory Workflow so they better understand the importance of their role in the implementation of Newborn Screening, and to remind them that they are partners in this endeavor. Proper data gathering was also discussed, highlighted by a mini-workshop where the participants fill out an actual filter card and checked by the organizers, afterwards errors made were corrected. As for ensuring quality samples, the participants were given the rare opportunity to examine actual rejected samples. This made them aware of what their samples should not look like. One of the topics discussed was

the Recall Process. It emphasized prompt patient recall and stressed the importance of keeping an updated logbook in their facility. The participants had a preview of the Future of Newborn Screening, which they foresaw as a challenge. With that challenge is a positive outlook that more babies will be saved using advanced technology in determining more disorders. *MMTabaosares*

Baby's day out in Bohol

Since becoming confirmed with either congenital hypothyroidism, congenital adrenal hyperplasia, phenylketonuria, or galactosemia, children from the province of Bohol have become part of the Long Term Follow-up Program of the National Comprehensive Newborn Screening System. Part of the activities being conducted under this program is the holding of an annual Reunion of Saved Babies. It is during this Reunion that children with any of the disorders being screened and their parents get to meet the staff of Newborn Screening Center - Visayas (NSC-V), and more importantly, other children and families who share their condition.



NSC-V, in partnership with Center for Health Development - 7 (CHD-7) and the Provincial Health Office of the Province of Bohol, held the Reunion of Saved Babies in Bohol on January 9 at Gov. Celestino Gallares Memorial Hospital, Tagbilaran City, Bohol. It was a successful event, with attendance of 15 out of 17 confirmed patients and their parents. The children's ages ranged from the youngest at 2 months and the oldest at 5 years. Ms. Aurora C. Flores, Chapter Executive Manager of the Philippine Mental Health Association - Dumaguete Chapter gave a talk on Responsible Parenting. She emphasized in particular the very important responsibility of parents as primary champions of their children's continued good health and well-being. The activity was also graced by Chief of Hospital, Dr. Nenita Po, MHA, who gave the day's opening remarks. Parents and children also benefitted from the visit of Dr. John Uy, visiting consultant and pediatric endocrinologist, who conducted a one-on-one consultation with each patient.

At the end of the activity, parents and their children went home with free giveaways from sponsors; and an assurance that they are not alone in their struggles brought about by their children's disorders. *YCDemegillo*

DOH-CHD Zamboanga Peninsula holds NBS Cluster Meeting with Zanorte Facilities



Participants from Zanorte Cluster Meeting with Apryl Joy Calibot, Nerissa Gutierrez, Dr. Eleonor Du, Dr. Pacita Franco, Dr. Conchita Abarquez, and Sheila Mae Guilaran

Even as the number of enrolled newborn screening facilities (NSFs) increases in the region, NBS coverage in Zamboanga del Norte is still below the target set by the Department of Health, which is at 85%. With this in mind, the Center for Health Development-9, in coordination with Newborn Screening Center-Mindanao, conducted a Cluster Meeting for Zamboanga del Norte's Newborn Screening Facilities on January 31 at Mibang Hotel in Dipolog City.

The cluster meeting was organized to identify the challenges that hamper the increase in their NBS coverage. The meeting was also a good venue to update them on the developments in the program, particularly in their province.

A total of 48 participants attended from 28 Newborn Screening facilities. DOH-Representatives from different municipalities and the technical staff from Zamboanga Norte Provincial Health Office also participated. The Resource speakers were Dr. Conchita Abarquez, Unit Head of NSCM; Dr. Eleonor Du, Head Newborn Screening Follow-up Team; Ms. Sheila Mae Guilaran, Program Manager of NSCM, and Ms. Perly Bermudez, PDO II of NSCM along with the CHD-ZP team: Ms. Nerissa Gutierrez, NBS Program Manager and Ms. Apryl Joy Calibot, NBS Nurse.

To inspire the group, Ospital ng Kabataan ng Dipolog, Inc. headed by Dr. Pacita Franco, Medical Director and Ms. Kareen Ocupre shared their best NBS practices that earned them an NBS Award for 2011.

Issues and concerns on implementation, coverage and performance were raised and addressed in the meeting. To put plans into actions, the NSFs worked on their Action Plans and strategies to improve their NBS implementation and increase the number of newborns screened in their respective municipalities. *AJCalibot*



G6PD Parents Forum held in Davao City

The Newborn Screening Center-Mindanao continues to educate parents as it gathered families of confirmed G6PD deficient patients in Region 11 on February 19, 2013 at the Southern Philippines Medical Center in Davao City. This is the first parents forum this year with Dr. Jeannie Ong (front row, center), a Pediatric Hematologist, as the guest lecturer. In attendance are sixty (60) parents and guardians. The Center aims to educate more parents on G6PD deficiency by conducting the same activity on a quarterly basis. *PBermudez*

Cagayan Valley reviews Newborn Screening implementation, awards performers

In pursuit of continually providing quality newborn screening services among its patients, the Center for Health Development-2 (CHD-2) summoned the Newborn Screening Coordinators from all over Region 2 on February 28 at the Crown Plaza Hotel, Tuguegarao City to tackle different issues concerning the implementation of newborn screening in the area. The event also served as a venue to provide updates on the Newborn Screening Program. A total of 132 participants which include provincial health officers, MCHN provincial coordinators, chiefs/heads of hospitals and clinics, municipal

health officers and newborn screening coordinators attended the event.

The opening remark was given by Dr. Leticia Cabrera, CHD-2 NBS Medical Coordinator, followed by her presentation of the NBS accomplishments of region 2. Statistics showed that Cagayan Valley's NBS coverage shoots up from 41% to 51% for 2012.

Christian Monieno, Follow-up Nurse from Newborn Screening Center-Central Luzon discussed updates on the NBS Administrative Mechanics and NBS

Statistical Reports. A report on the PhilHealth Newborn Care Package was then presented by Dr. Baneer Tallud from the PhilHealth Office of Region 2. A forum was then opened to address to the concerns of the newborn screening coordinators.

The awarding ceremony followed afterwards, acknowledging Newborn Screening Facilities with more than 90% coverage. Special awards were also given to organizations providing support to the Newborn Screening Program. *CMonieno*

North and Central Luzon celebrate 4th National Rare Disease Awareness Week

In line with Presidential Proclamation No. 1989 declaring the last week of February as "National Rare Disease Week," the Volunteer Youth Leaders for Health (VYLH) for North and Central Luzon conducted various activities to celebrate the advocacy.

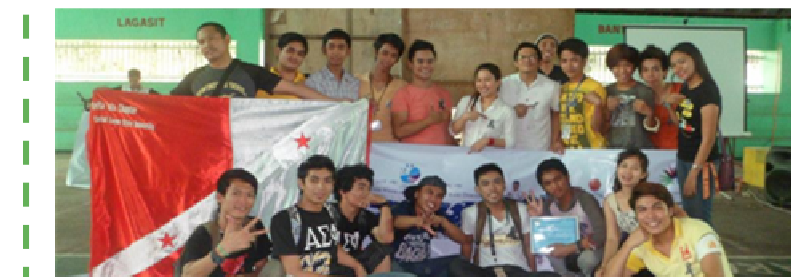
With the theme: Rare Disorders

without Borders, the VYLH spearheaded different events to show support to the Rare Disease Awareness Campaign through disseminating information to different groups, most especially to expectant mothers. Health Awareness Seminars, distribution of information materials and discussions

with the Local Government Units to show support in the lobbying of the Rare Disease Act were done by the young health leaders.

Below are the activities spearheaded by the VYLH in different areas:

Date	Activity	Participants
February 22, 2012	Health Awareness Seminar, San Quintin, Pangasinan	Expectant mothers and Rural Health Units
February 22-28, 2012	Signature campaign to support to the Rare Disease Act	Nursing Students and Faculty of Central Luzon State University, Nueva Ecija
February 28, 2012	Signature campaign to support to the Rare Disease Act	City Health Office of Santiago, Isabela



Members of VYLH and Alpha Sigma Phi with Mary Michelle Lewis, CHD-1 NBS Nurse Coordinator (standing 6th from left,) and Mr. Christian Leandro Monieno, North and Central Luzon VYLH secretariat (standing 7th from left)



Students from CLSU show their support to the Rare Disease Awareness Campaign.

VOLUNTEER YOUTH LEADERS FOR HEALTH

Raising awareness to the fullest

February marks another milestone distribution and wearing of maong for the Volunteer Youth Leaders for jeans in solidarity with the Global Health-Mindanao after they Genes Project's "Wear that you Care" successfully participated in the 4th Rare campaign during the Rare Disease Awareness Week and the 6th Day. Rare Disease Day last February 28, 2013. The dynamic volunteers of The Newborn Screening Center-VYLH-Mindanao led the advocacy Mindanao employees, spearheaded by campaign in different areas as far as Dr. Abarquez, once again showed their the provinces of Surigao del Sur, support for the occasion by marking Misamis Oriental, Bukidnon and the special day as an official blue jeans Davao. Schools, communities and day! The wearing of maong jeans and even the public and private sectors the pinning of denim ribbons signified were engaged in this noble act of the personnel's call-for-solidarity with advocating. Philippines Medical Center staff and employees and patients also joined the week-long PSOD video film showing, signature campaign, and lectures in PSOD's theme song "Lalaban Kami" in the different areas like the OPD, SPMC Radyo ni Juan, signature campaign for the enactment of Rare Disease Act of the Philippines, display of PSOD's Without Borders", this year's main institutions as well as group lectures objective was to create awareness on and room-to-room orientation to the different orphan and rare disorders, selected students of Xavier University, not only locally but globally as well. Central Mindanao University and ATadlas community high schools in Davao. The event's highlight was the denim ribbon



DMSFH opens as G6PD confirmatory testing center in Davao City

Early this year, the Department of Health (DOH) and the Newborn Screening Reference Center (NSRC) accredited the Davao Medical School Foundation Hospital (DMSFH), a private tertiary hospital in Davao City, as a confirmatory testing center for those with positive screen on G6PD disorder. DMSFH serves patients from Davao City, Davao Del Sur and other neighboring provinces. Currently, there are three (3) G6PD Confirmatory Centers in Mindanao namely the Tagum Doctors' Hospital, Cagayan de Oro Polymeric Medical Plaza and Davao Medical School Foundation Hospital. The Center is looking forward to the establishment of more G6PD confirmatory testing centers in every region in Mindanao. *P.Bermudez*

Announcements

Application for Newborn NBS Special Award Call for Screening Centers

Pursuant to Section 12 of the Republic Act 9288, otherwise known as the Newborn Screening Act of 2004, "The DOH shall ensure that Newborn Screening Centers are strategically located in order to be accessible to the relevant public and provide services that comply with the standards approved by the Committee upon the recommendation of the NIH."

In compliance, the Department of Health and the National Institutes of Health through the Newborn Screening Reference Center opened the application for four (4) more laboratories in strategic areas of the country in addition to the existing laboratories located in Davao, Iloilo, Pampanga and Quezon City. The Department of Health is now accepting applications for Newborn Screening Centers (NSCs) for the following areas: Region 4A, Northern Luzon, Region 7 and Region 10.

NSC - VISAYAS Reunion of Saved Babies in Negros Occidental

NSC-Visayas will hold a Reunion of Saved Babies on March 26 at the Provincial Capitol, Negros Occidental. Confirmed patients, totalling 134 with ages

ranging from 6 years to several months old from the province of Negros Occidental have been invited to the event. For organizations which are willing to give donations for this event - be it in the form of medicines (levothyroxine and hydrocortisone), special milk (Isomil or Nursoy) for our galactosemia patients, goodies for the giveaways, and the like - your kindness would be much appreciated! Please call (033)3293744 for details.

NSC - NIH G6PD Deficiency Seminar for Parents



The Seminar for Parents which will cover Genetic and Clinical aspects of G6PD Deficiency is set on 12 April 2013, 1:00 - 4:00pm at the UP Manila College of Pharmacy Auditorium. Should you wish to attend the seminar, please call (02) 3760962/ 3760964/ 3760965/ 3760967.

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From page 1

From 1996 to 2004, there has been a steady increase in the number of newborns screened. Enactment of RA 9288 in 2004 gave way for more facilities to launch their newborn screening programs resulting to considerable increase of newborns screened toward 2006.

From 2006 onwards, there had been a steady increase of screening activity among the newborn screening facilities. Linking the current screening rate with 2012 screening coverage, the NBS system shows that it is close to saturating all of the facility-based deliveries.

The 49.6% coverage is above halfway from the target that was set in 2010 which is 85%. Home births still remains a challenge posting 55.4% of the Philippines' annual live birth population. A significant task for the DOH and other NBS implementers is to have all babies delivered at hospitals and health facilities. This would also ensure that each of these newborns delivered will have the necessary newborn care. Thus, guaranteeing a greater coverage for newborn screening.

1.3. Regional Scenario

In general, the number of newborn screened increased in all regions.

- The top three regions are the following:
1. Cordillera Administrative Region (CAR) - 73.19%
 2. Regions 6 (Western Visayas) - 70.85%
 3. Region 11 (Davao) - 67.94%

Figure 2 shows the 2012 coverage of each region.

NCNBSS Accomplishment Report on National and Regional Situations, 2012
 NSCB Philippine Statistical Yearbook, 2011
 Field Health Service Information System Report, 2008

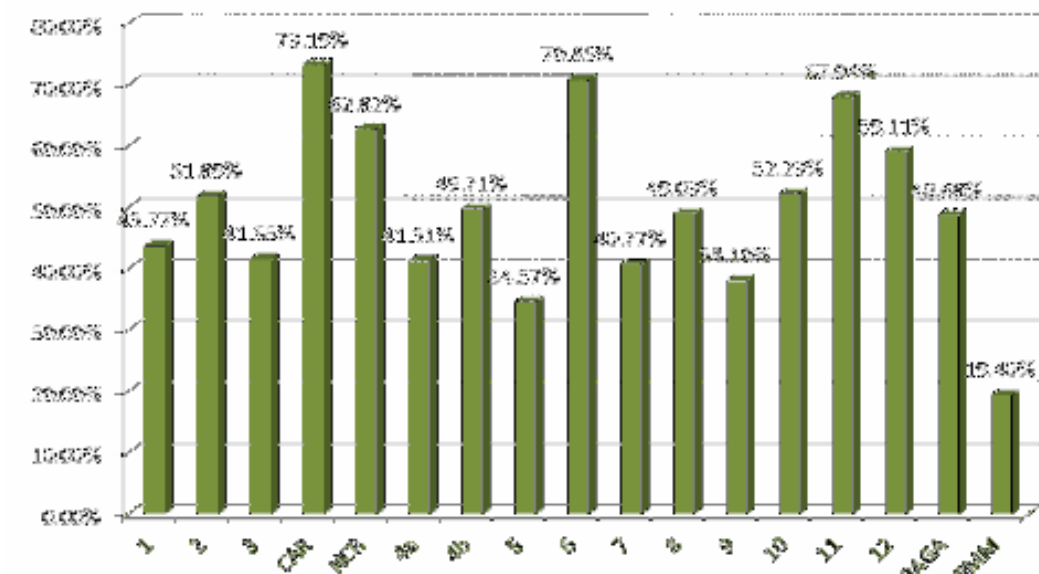


Figure 2: NBS coverage per region using the live birth data of 2008 (NSCB 2011).

Newborn Screening Reference Center
 National Institutes of Health
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Newborn Screening National and Regional Situationer 2012

Republic Act 9288 established the National Comprehensive Newborn Screening System (NCNBSS) to ensure that a) every baby born in the Philippines is offered newborn screening (NBS); b) a sustainable NBS System is established and integrated within the public health delivery system; c) all health practitioners are aware of the benefits of NBS and of their responsibilities in offering newborns to undergo NBS; and d) parents recognize their responsibility of protecting their child from any of the disorders. The Department of Health through the Centers for Health Development and Newborn Screening Reference Center (NSRC) together with other stakeholders conduct continuous follow-up, diagnosis, management/treatment, quality assurance monitoring per NCNBSS strategic plan to ensure that the objectives of RA 9288 are met.

responsive in terms of providing services to the Filipino people. The program is moving forward towards assuring quality newborn care.

1.1. Status of NBS Coverage

The DOH, along with its field implementers at the CHD and with NSRC, has incessantly developed strategies to ensure the accessibility of parents to newborn screening at all levels.

Efforts and strategies brought the NBS coverage to 49.6% by end of 2012. This accounts mostly for facility-based deliveries which are at 37.8% of the total live births.

1.2. National Scenario

The number of newborns screened increased from 713,580 (39.6%) in 2011 to 892,051 (49.6%) in December 2012. Figure 1 shows the number of newborns screened annually since the inception of newborn screening. **Continue on page 8**

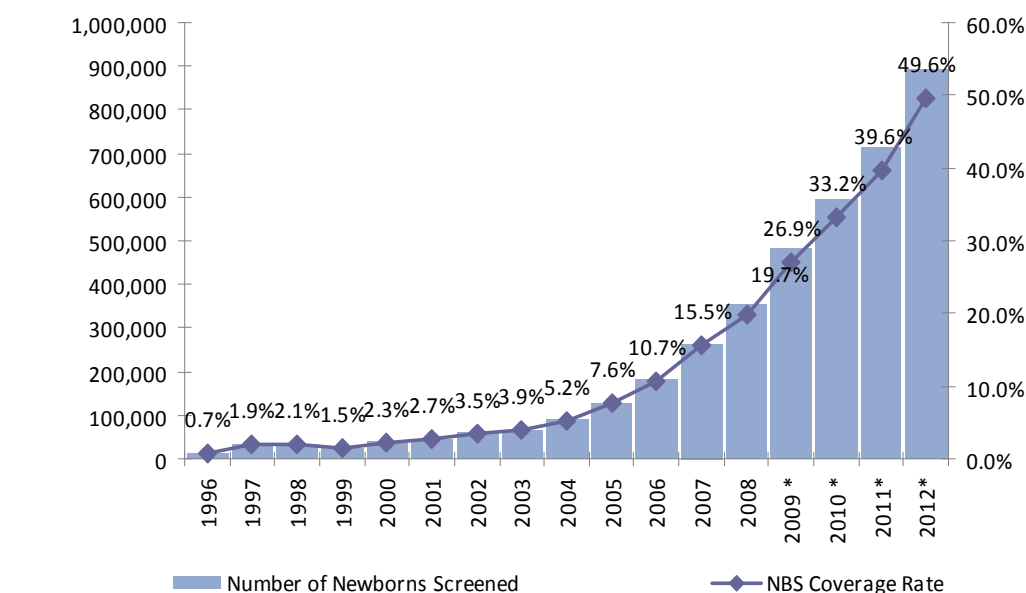


Figure 1: Newborn screening count and coverage rate in relation to annual live birth from 1999 to 2012. The NSO 2008 data was used in computing for the coverage rate.

Number of Babies Screened as of February 2013
COUNTER: 4,181,187