



Dr. Enzo Ranieri talks about how to better implement the Expanded Newborn Screening Program.

ENBS Program Implementers Undergo Workshop

The Department of Health–Disease Prevention and Control Bureau and the National Institutes of Health–Newborn Screening Reference Center (NIH-NSRC) teamed up to conduct the Program Implementation Workshop on Expanded Newborn Screening (ENBS) at Bayview Hotel, Roxas Blvd., Manila, on March 2-5, 2015.

The workshop was divided into two parts. Part 1 included discussions on the ENBS and its definitions, operation, protocols, algorithms, and issues, while Part 2 was the technical training with laboratory exposure for medical technologies at the Newborn Screening Center (NSC)–NIH, UP Ayala Technohub, Diliman, Quezon City.

The event provided an avenue to review the current operational workflow and laboratory screening processes, discuss other possible operational and management issues related to the implementation of ENBS, discuss the current confirmatory process and workflow, and review the current algorithm for recall of patients with positive screening results for ENBS. Additionally, a review of the management protocols for the disorders and recommendations on resolving anticipated issues in the implementation of ENBS was done to help provide skills and knowledge on how to analyze and interpret MSMS results.

Dr. Enzo Ranieri of the South Australian Neonatal Screening Centre, Directorate of Genetic and Molecular Pathology, Women's and Children's Hospital Campus, Adelaide SA Pathology, South Australia, served as the main facilitator of the workshop.

The workshop also recognized the important role of NSCs in the screening, diagnosis, and initial management of the disorders, discussion and review on the operations, current algorithms, and management protocols, as well as the technical training on the analysis and interpretation of results and knowledge on quality control and quality assurance procedures.

The ENBS was implemented nationwide on December 24, 2014, and was offered to parents in all participating facilities as an option to the standard six (6) newborn screening tests. Under the ENBS, the number of disorders in the newborn

screening panel was increased from 6 to more than 20 falling under various types of disorders, namely, hemoglobinopathies, amino acid disorders, organic acidurias, disorders of fatty acid oxidation, disorders of carbohydrate metabolism, disorders of biotin metabolism, cystic fibrosis, and endocrine disorders.

2015 Program Review Focuses on Leadership Strategies

The Department of Health (DOH) and the Newborn Screening Reference Center (NSRC), in coordination with the DOH Regional Offices, held the Annual Joint Review and Evaluation of the Newborn Screening Program Implementation at the regional level.

The activity was in compliance with Section 5: Monitoring and Evaluation of the National Comprehensive Newborn Screening System (NCNBSS) of the Implementing Rules and Regulations of Republic Act No. 9288, or the Newborn Screening Act of 2004. It also provides the regional program implementers with information and analysis to help them formulate leadership strategies and plans to improve the NBS efficiency and effectiveness, especially at the community level.

The monitoring teams are composed of Lita Orbillo, NBS National Program Coordinator, Unit Heads of the Newborn Screening Centers (NSCs), staff from the Newborn Screening Reference Center (NSRC), and program managers from selected Regional Offices.



Left to right: Femy Joy Ingosan, Mark Anthony Duran and Dr. Virginia Narciso of DOH-CAR; Jovy Ann Casamolin of NSRC; Janet Mendoza, Dr. Junneth De Guzman of Bablan Municipal Health Office



Mindanao NSC
 For Mindanao
 Southern Philippines Medical Center
 J. P. Laurel Avenue, Davao City
 Telephone: (082) 226-4595, 224-0337
 Telefax: (082) 227-4152
 Email: nscmindanao@gmail.com

IN FOCUS

RHU Liloy

Liloy was once a barangay under the Municipality of Lingsindangan, Zamboanga del Norte. On August 22, 1951, upon the issuance of Executive Order No. 469, S. 1951, by President Elpidio Quirino, Liloy became an independent municipality.

The Rural Health Unit (RHU) of Liloy, with its Health Center located within the poblacion area, provides basic treatment, including newborn screening, first aid and sanitation service to its constituents. RHU Liloy also strategically placed Barangay Health Stations around the town to serve the immediate health needs of those living outside the poblacion.

RHU Liloy's newborn screening program was accredited in 2010. However, the program took off only after a municipal ordinance was passed through the initiative of Mayor Felixberto Carillo Bolando, mandating that pregnant women give birth only at birthing facilities. Mayor Bolando set aside annual funds for the purchase of 1,500 kits to be given for free to indigent parents. RHU staff were also sent to NBS trainings to improve their knowledge and skills in collecting newborn screening samples.

Despite geographic barriers, facility-based delivery in Liloy increased. RHU Liloy since then has committed to the advancement of NBS in their municipality and has worked on providing NBS to all its constituents. *CAncheta*



Staff of RHU Liloy in front of the facility



From Old to New: Zamboanga Sibugay Provincial Hospital

Zamboanga Sibugay Provincial Hospital (ZSPH) was one of the flagship programs of Governor Wilter Yap Palma and was established to ensure better healthcare to its populace. It is situated in Ipil, the capital city of Zamboanga Sibugay.

ZSPH Chief and the Integrated Provincial Health Officer, Dr. Ulysses Chiong, and his team have transformed the old hospital into an improved medical center with a more pleasant environment by repairing the facilities and molding the workforce into a service-oriented team.

Under this climate of change in 2012, the newborn screening program was started in ZSPH. Roughly 4% was screened in 2013, but the number increased to 33% in 2014, according to the evaluation by Department of Health monitoring team.

The increase was made possible through capability and capacity building. ZSPH sent staff for training and made NBS kits always available in the hospital. The newborn screening coverage continuously increased through the efforts of Acting Chief of Hospital Dr. Arthur Luspso, Governor Palma, Point of Care, PhilHealth, and MHA.

Today, ZSPH's challenge is to encourage facility-based delivery since majority is still giving birth at home. In 2014, 1,115 outborn babies were screened, and ZSPH hopes to reach more pregnant women to give birth at a health facility and have their babies screened. *JBarbas*

Mindanao News Briefs

NBS Activities in DOH-RO 11

The Department of Health–Regional Office (DOH-RO) 11 held numerous consultative meetings and trainings to promote and improve the newborn screening (NBS) implementation in the region.

On March 6 and April 8, DOH-RO 11 gathered together 86 Municipal Health Officers and NBS Coordinators from various provinces of Davao regions for a consultative meeting.

Led by Clarose Mascardo, NBS Program Manager of DOH-RO 11, the activity provided updates on the status and developments of NBS program in the region and discussed suggestions on how to increase NBS coverage.

Among the major concerns tackled in the program review were the high number of unsatisfactory samples, the lack of personnel for patient recall and continuity care, and the sponsorship for the confirmatory tests of indigent patients. The do's and don'ts of sample collection were also reiterated, and an additional nurse was hired for recall and continuity care.

To further address the high rate of unsatisfactory samples, DOH-RO 11 conducted NBS training on April 16 and 17 at the Apo View Hotel, Davao City. It was attended by 28 health workers in the region. The heel pricking practicum was performed at Southern Philippines Medical center.

DOH-RO 11 continued to allocate budget for confirmatory tests of indigent patients and provide free NBS collection kit to all rural health units and some district hospitals in the region. *PBermudez, BBalio*



Ronald C. Aguilar (left) and Ella June C. Delos Reyes (seated), Chief Nurse, with the members of the Adela Serra Ty Memorial Medical Center NBS team

Mindanao Retained Hospitals Beat Public Sector Challenge

Public health facilities, beset by financial problems, struggle to implement newborn screening successfully.

But several Department of Health (DOH) retained hospitals in Mindanao have proven otherwise and have successfully implemented NBS programs in their own respective hospitals.

In fact, DOH retained hospitals in Mindanao have consistently showed 90%-98% NBS coverage and are running for the NBS Exemplary Award 2014. These DOH retained hospitals are the Southern Philippines Medical Center in Davao City, Davao Regional Hospital in Tagum City, Adela Serra Ty Memorial Medical Center in Tandag City, DOH CARAGA Regional Hospital in Surigao City, Northern Mindanao Medical Center in Cagayan

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SPMC NBSCC Davao Holds First G6PD Deficiency Forum for 2015

A total of 71 parents and family members of G6PD deficient children attended the G6PD Deficiency Parents' Forum organized by the Southern Philippines Medical Center (SPMC) Newborn Screening Continuity Clinic (NBSCC), Davao City, held at the Mahogany Room, JICA Bldg., SPMC, on April 28, 2015.

Spearheaded by Dr. Genelynn Beley, NBS Head, and Nicolette Liana Salvo, NBSCC Nurse, the activity discussed what G6PD deficiency is and how to manage this disorder. Dr. Jeannie Ong, a pediatric hematologist, enlightened the parents on G6PD deficiency and answered their questions

about the disorder.

A mother of a two-month old G6PD deficient child expressed her gratitude for holding the parents' forum. She said she could now breathe a sigh of relief as her apprehensions and fears were laid to rest. She further said that the parents' forum had provided her knowledge and confidence in managing her son's disorder.

The overwhelming response generated in this forum inspired SPMC NBSCC to hold more parents' forums on metabolic disorders in the coming months. *ADTadlas*



Participants and organizers of the G6PD Deficiency Parents' Forum

NSC Southern Luzon
 For Region IVA
 Daniel O. Mercado Medical Center
 3rd Flr. DMMC-HIS Bldg., 143 Narra St.,
 Mountview Subd., Tanauan City
 Telephone: (043) 702-7715, 702-7719
 Email: nsc.southernluzon@gmail.com

ENBS Orientation Held in CALABARZON

With Expanded Newborn Screening (ENBS) already up and running, the Department of Health–Regional Office (DOH-RO) 4A, together with the Newborn Screening Center–Southern Luzon (NSC-SL), promptly started a series of orientations on ENBS.

Genica Querido, Senior Health Program Officer of DOH-RO 4A, welcomed the NBS Coordinators of the participating Newborn Screening Facilities (NSFs). The NBS Performance for 2014 of the different provinces was then discussed by Aiko Barcelon, NBS Coordinator. Meanwhile, the overview on the ENBS Panel of Disorders was presented by Dr. Alma Panganiban-Andal, NSC-Southern Luzon Unit Head.

Angelita Vanguardia, NSC-SL Program Manager, and Nadine Magpantay, NBS Coordinator, talked about unfit/unsatisfactory samples, administrative protocol (particularly, the ordering of ENBS kits and sending of ENBS samples), and Republic Act 9288. The NBS Continuity Clinic was also presented by Dr. Laura Aguinaldo and Jhonalyn Bantique.



Participants from Batangas during one of the ENBS Orientation roadshows

Region 4A NSF's Attend Heel Prick Training

To ensure proper collection of blood specimen, the Newborn Screening Center–Southern Luzon (NSC-SL), in coordination with the Department of Health–Regional Office (DOH-RO) 4A, conducted an NBS Orientation with Heel Prick Training at Daniel O. Mercado Medical Center, Tanauan City, Batangas, on March 30.

Attendees were the new NBS Coordinators and those who collect the NBS samples from different Newborn Screening Facilities (NSFs) in the region.

The first part of the activity was an overview of the NBS and Republic Act 9288, administrative mechanics, unfit and

NSC-SL Joins Buntis Day

One of the objectives of the Newborn Screening Program is "to ensure that parents recognize their responsibility in promoting their child's right to health and full development."

This guided the Newborn Screening Center-Southern Luzon (NSC-SL) to participate in Buntis Day separately conducted by the Calamba City Health Office and the DMMC OB-Gyne Department at LCC Auditorium Central II, Calamba City, Laguna, and Daniel O. Mercado Medical Center, Tanauan City, Batangas, respectively, on March 10, 2015.

The activities were done in coordination with the Philippine Obstetric and Gynecological Society.

The expectant mothers actively participated in the discussions and games. Selected participants were also given free newborn screening upon their delivery. Topics discussed were prenatal care, newborn care, breastfeeding, newborn screening, and introduction to the Expanded Newborn Screening in the Philippines.



Buntis Day celebrated at LCC Auditorium Central II, Calamba, Laguna

unsatisfactory samples, the NBS panel of disorders, and blood sample collection using heel prick method. The second part was the demonstration and actual blood sample collection by the participants, which was done at Laurel Memorial District Hospital, Tanauan City, Batangas.

One of the regional NBS coordinators demonstrate proper blood sample collection.



VOLUNTEER YOUTH LEADERS FOR HEALTH

VYLH-UPM Lights Up . . . from page 1

born with rare diseases are usually “orphaned” by society through social abandonment and lack of medical help.

Health research revealed that 1 in every 20,000 Filipinos are born with rare or orphan disorders.

Celebrating Bravery

VYLH-UPM Co-Project Head Feliss Sanchez said that UPM chapter’s “I Am Rare” program recognizes the kids’ courage in facing daily challenges and that was a success in terms of giving the children what they truly deserve.

“We did this event to celebrate the strengths of these rare kids who go through the daily struggles of rare diseases, to celebrate the childhood of these kids,” she added.

Together with Cluster Secretariat Marian Therese Cuenca and participating UPM student organizations, namely, UP Health Sciences & Pre-Medicine Society (HS+PM), ALAB and College Student Council of UP College of Public Health (CPH), AWSAMS and Volunteer Corps of UP College of Allied Medical Professions (CAMP), YEARN of UP College of Nursing (CN), ProPharm of UP College of Pharmacy (CP), Biological Sciences Society, Biochemistry Society, and OMAKE of UP College of Arts and Sciences (CAS), VYLH prepared several presentations and booths for the children.

Disney-themed characters presented different theatrical plays for the kids who were given “student buddies” to guide them throughout the day. Moreover, the UP College of Medicine Choir sang the national anthem, while UPM’s Indayog dance varsity, CAMP Synergy, and Pharm Jam also performed for the children.

Fight for Quality Life

During the commitment ritual led by National Secretariat Aster Lynn Sur, parents and guardians of the rare kids expressed their deepest gratitude to the National Institutes of Health (NIH), VYLH, PSOD, and UPM students for inspiring the kids to fight another day.

“Malaki ang pasasalamat namin sa inyo dahil bilang isang magulang, basta makita namin silang masaya ay masaya na rin kami,” expressed a parent of a child with Gaucher’s disease.

To cap off the program, selected children performed a dance number to the tune of PSOD theme song, *Lalaban Kami*. The song encourages the children further to continue their fight for a better life. *FSanchez*



Announcements

NATIONAL NEWBORN SCREENING CONVENTION 2015
ENHANCING NEWBORN CARE, NURTURING MINDS,
BRIGHTENING THE FUTURE AND SAVING MORE LIVES

SAVE THE DATE

October 6-7, 2015
Fiesta Pavilion, Manila Hotel

REGISTRATION STARTS 01 JUNE 2015
REGISTER EARLY!
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EDITORIAL STAFF

Executive Editor:	Ma. Elouisa L. Reyes
Managing Editor:	Vina G. Mendoza
Associate Editor:	Emerson Kim J. Lineses
Layout Artist:	Emerson Kim J. Lineses
Contributors:	Ronald Aguilar, Cherie Ancheta, Rhoebelle Anne Balio, Jesusa Barbas, Perly Bermudez, Dr. Hermilyn Casio, April Joy Calibot, Sheila Mae Guilaran, Amerah Matuan, Ferdin Sanchez, Apple Dowannie Tadlas
Circulation:	Richard Alipasa, Marjorie Dimaano, Susan Jalad, Juvelyn Lumabas, Mary Grace Opon, Girlie Villaruel
Adviser:	Maria Melanie Liberty B. Alcausin, MD

Comments and questions may be sent to:
Newborn Screening Reference Center
National Institutes of Health
University of the Philippines Manila
Unit 104, Building Alpha, UP Ayala Land
Technohub, Brgy. UP Campus
Diliman, Quezon City

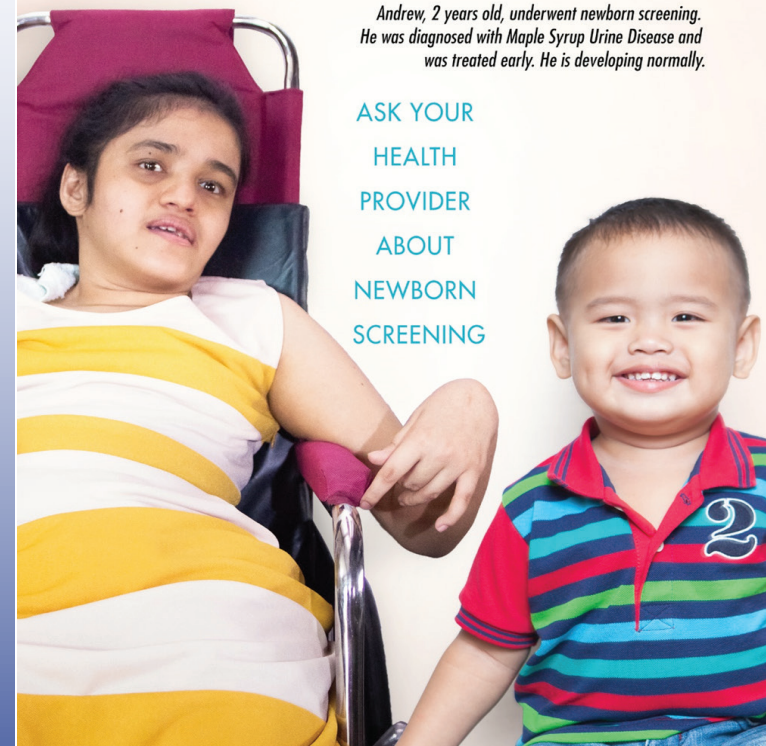
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SAVE YOUR BABY FROM MENTAL RETARDATION

Genevieve, 22 years old, did not have the benefit of newborn screening. She had sepsis with convulsions and later on was diagnosed with Maple Syrup Urine Disease. She now suffers from mental retardation.

Andrew, 2 years old, underwent newborn screening. He was diagnosed with Maple Syrup Urine Disease and was treated early. He is developing normally.

ASK YOUR
HEALTH
PROVIDER
ABOUT
NEWBORN
SCREENING



Newborns with Maple Syrup Urine Disease (MSUD) have sweet smelling urine, like the odor of maple syrup. If left untreated, they may have convulsions, be in coma or may die within the first few weeks of life. MSUD is one of more than 20 conditions that can be detected through expanded newborn screening.



Mindanao Retained . . . from page 4

de Oro City, and Amai Pakpak Medical Center in Marawi City.

The hospitals’ approaches in implementing NBS programs may vary, but the commitment and perseverance are the main ingredients for a successful NBS program. The best practices in these hospitals include a committed NBS team, full support from their respective administrations, effective inventory management system (that is, the hospital rarely ran out of NBS kits), full support from DOH Regional Offices through technical training and provision of free NBS for indigent patients, extensive NBS advocacy program, well-informed hospital staff on the availability of NBS in their hospital, maximized utilization of PhilHealth benefits, and efficient hospital system in ensuring that all inborn babies are screened.

The success of the NBS program in these hospitals was partly due to the support of the DOH Retained Hospital Chiefs Dr. Leopoldo Vega of Southern Philippines Medical Center, Dr. Romulo Busuego of Davao Regional Hospital, Dr. Ponciano S. Limcangco of Adela Serra Ty Memorial Medical Center, Dr. Andres M. Dolar, Jr., of DOH CARAGA Regional Hospital, Dr. Jose C. Chan of Northern Mindanao Medical Center, and Dr. Amer Saber of Amai Pakpak Medical Center. *Dr. Hermilyn Casio, PBermudez, AMatuan, RAguilar, SMGuilaran*



NSC-M team with Dr. Janice T. Patiño and Dr. Andres M. Dolar, Jr., at the DOH Caraga Regional Hospital

DOH-RO 9 Conducts Cluster Meetings and PIRs

The Department of Health–Regional Office (DOH-RO) 9 held a series of Cluster Meetings and Program Implementation Reviews (PIRs) on March 24-27, 2015, covering the entire provinces of Zamboanga Peninsula.

Cluster meetings were held in Dipolog City on March 24 for Newborn Screening Facilities (NSFs) from Zamboanga del Norte; March 25 for NSFs from Zamboanga Del Sur in Ipil City; March 26 for NSFs from Zamboanga Sibugay in Pagadian City; and March 27 for NSFs in Zamboanga City.

There were 42 participants in Dipolog City, 58 participants in Pagadian City, 58 in Ipil, and 46 in Zamboanga City. The series of cluster meetings updated all NBS coordinators on the performance of NBS in Region 9 as well as to discuss NBS issues and concerns in the region and the availability of Expanded Newborn Screening (ENBS). *ACalibot*

Your Feedback Is Important to Us!

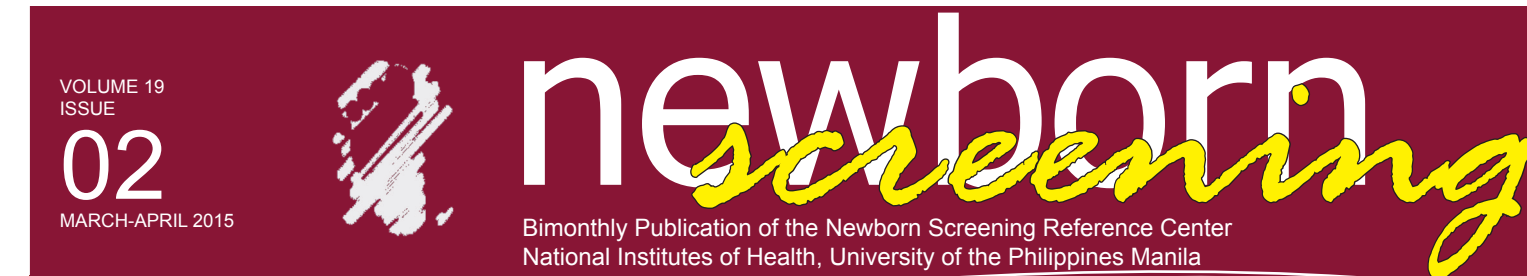
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If you would like to write an article, please contact us at info@newbornscreening.ph. We will do our best to keep you informed about current and relevant newborn screening issues.



Newborn Screening Reference Center
National Institutes of Health
University of the Philippines Manila
Unit 104, Bldg. A, UP Ayala Land Technohub
Diliman, Quezon City 1101



VYLH-UPM Lights Up Charity Drive for ‘Rare’ Kids

Members of the VYLH-UPM read to the kids during the storytelling activity of the charity drive.

In its commitment to empower the youth toward optimal health, the Volunteer Youth Leaders for Health–University of the Philippines Manila (VYLH-UPM) held *I Am Rare: Alone We Are Rare, Together We Are Strong*, a pilot standalone advocacy project for children with rare disorders, at the Tipunan grounds, UPM, on April 25.

This year’s program gathered 40 kids from its affiliate institution, the Philippine Society for Orphan Disorders (PSOD). The day-long charity drive was held to uplift the children’s spirits by evoking physiological and psychosocial awareness for young patients with rare diseases. UP Manila Chancellor Dr. Carmencita D. Padilla, who is also the National Program Coordinator and Founding Adviser of VYLH Philippines, graced the event.

“Isa akong proud na Chancellor ng UP Manila dahil sa event na ito ay mabibigyan natin ng kasiyahan ang mga batang may rare disorders,” Dr. David-Padilla said in her opening remarks.

Orphaned by Society

According to Rufus Thomas Adducul, VYLH–National Capital Region (NCR) South Luzon Cluster Coordinator, Filipino children

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Number of Babies Screened as of April 2015

COUNTER: 6,617,078