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# newborn screening

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## NBS Implementers Gather to Strengthen NBS Program

"I am very much challenged right now after seeing my region's performance on NBS," relates Dr. Nestor Santiago, Regional Director of the Center for Health Development - Bicol, in his concluding remarks during the annual consultative meeting on Newborn Screening implementation held on October 8, 2008 in Pearlmont Inn, Cagayan De Oro City. Bicol is one of the most challenged regions in NBS performance in terms of coverage against the region's live birth.

In line with the program's goal on sustainable implementation, the meeting assessed the status of the NBS program at both national and regional levels and discussed additional strategies to ensure effective and efficient implementation at the CHD level. This annual activity was organized by the Department of Health, in coordination with the Newborn Screening Reference Center and this year's host region, CHD Northern Mindanao.

CHD-NBS coordinators and Licensing representatives from various regions were the participants of this activity. The event was made more fruitful by the presence of key decision makers - the regional directors from four CHDs: Dr. Rio L. Magpantay - CHD III; Dr. Gloria Balboa - CHD IVB; Dr. Nestor F. Santiago - CHD V; and Dr. Jaime Bernadas - CHD X.

Persistent issues hampering the implementation of the newborn screening program, such as overpricing, difficulties in PHILHEALTH reimbursement, and financing for confirmatory test of indigents were discussed during the meeting. The role of local government units in accelerating NBS implementation was emphasized in the discussions. Top performing CHDs, such as the National Capital Region, headed by Dr. Paz Cor-

rales, NBS Coordinator and former CHD VI Regional Director, Dr. Lydia Depra Ramos, also shared their strategies and key success factors.

The discussions were followed by the participants' renewal of commitment

to strengthen the NBS program implementation and increase coverage. The next action steps were identified, such hiring of CHD NBS nurse coordinators; master listing of birthing homes; increas-

*(Continued on page 3)*



Regional Directors, CHD NBS Coordinators and representatives from DOH Central Office, NSRC, NSC-NIH, NSC-Visayas, and PHILHEALTH discuss pertinent issues on NBS implementation.

## NSC Visayas Celebrates 1st Reunion of Saved Babies in Western Visayas

Approximately 70 babies saved by newborn screening and their parents attended the Reunion of Saved Babies held in Iloilo City on October 18, 2008. The participants, coming from all parts of Region 6, spent the morning doing various fun-filled activities and receiving many surprises at the Conference Hall of the West Visayas State University Medical Center (WVSUMC) in Jaro, Iloilo.

"This is the first time that the Reunion of Saved Babies is held here in Iloilo. The event is an opportunity for parents of the saved babies to meet other parents in the region and share their experiences, most especially in handling children af-

ected with one of the disorders. With this opportunity, we will be able to increase the number of parent advocates, particularly in the Visayan Region," said Dr. J. Edgar Winston Pocesio, Head of the Newborn Screening Center - Visayas.

The reunion culminated in the celebration of the Newborn Screening Awareness Week following the successful convention held in Cebu and Cagayan De Oro City.

The event was organized by the Newborn Screening Center - Visayas WVSUMC, in cooperation with the Center for Health Development - Region 6.



*NSSPI President Dr. Rowena Pua relating the Southern Tagalog experience on NBS*



*Negros Occidental PHO Dr. Luisa Efen shares experience in overcoming obstacles in NBS implementation*



*Metabolic Physician and Pediatric endocrinologist Dr. Sylvia Estrada on follow-up of positive screens*



*Dr. Beatriz Gepte giving a lecture on myths and facts about G6PD deficiency*

### Scientific Program

7:00 AM	Registration	
8:00—9:00	Opening Ceremonies	
	Opening Remarks	
	Welcome Remarks	Carmencita D Padilla, MD, MAHPS <i>Director, NSRC</i>
	Introduction of Keynote Speaker	Rowena A Pua, MD <i>President, NSSPI</i>
	Keynote Speaker Address	Francisco T Duque III, MD, MSc <i>Secretary, DOH</i>
	Overview of Seminar & Introduction of	Barbra Charina V Cavan, MD (Cebu) <i>Chair, Organizing Committee - Cebu</i>
9:00—9:15	Lecturers	
	Maximizing Newborn Screening Philhealth Package	Narisa Portia J Sugay, MD (Cebu) Dr. Giovanni Roan, MD (CDO) <i>Philhealth</i>
9:15—9:55	Recognizing Early Signs of Galactosemia and Phenylketonuria	Mary Anne D Chiong, MD <i>Head, Biochemical Unit, IHG-NIH</i>
9:55—10:35	Coffee/Tea Break	
	Clearing the Myths and Giving Facts About G6PD Deficiency	Maria Beatriz P Gepte, MD <i>Pediatric Hematologist, PCMC</i>
10:35—10:50	Open Forum	
10:50—11:30	Abstract Presentation	Fidencio Aurelia, MD (Cebu) Arvin Escueta, MD (Cebu) / Mary Anne Ilaos, MD, DPPS (CDO)
12:00—12:20	Lunch	
12:20—1:30	Treatment of Congenital Adrenal Hyperplasia	Carmelita F Domingo, MD (Cebu) <i>Chair, NSSPI</i> Lorna Abad, MD (CDO) <i>President, DSPME</i>
13:30—14:15	Overcoming Obstacles in the Implementation:	
14:15—15:00	Learning from Successful Implementers	
	Luzon	Rowena A Pua, MD <i>NBS Coordinator, Los Baños Doctors Hospital</i>
	Visayas	Luisa B Efen, MD, MATS, MPH <i>Prov. Health Officer, Negros Occidental</i>
	Mindanao	Florencio T Flores, MD <i>Mayor, Malaybalay, Bukidnon</i>
	Coffee/Tea Break	
15:00—15:15	Lingering Problems in Follow-up of	Sylvia C Estrada, MD, FPPS <i>Metabolic Physician and Pediatric Endocrinologist Unit Head NSC-NIH</i>
15:15—15:45	Positive Screens	J. Edgar Winston C Posecion, MD, DPPS <i>Neonatologist, Unit Head, NSC-Visayas</i>
15:45—16:15	Different Roles of Stakeholders in the Newborn Screening Program	
16:15—16:45	Open Forum	
	Closing Remarks	J. Edgar Winston C Posecion, MD, DPPS <i>Co-Chair, Organizing Committee</i>



*Dr. Narisa Sugay and Dr. Mary Anne Chiong during the open forum*



*NBS proponent Dr. Carmelita Domingo on the treatment of CAH*



*NSRC Director Dr. Carmencita Padilla (2nd from left) and NSSPI President Dr. Rowena Pua (right) with Malaybalay Mayor Florencio Flores (left).*



## 6<sup>th</sup> Newborn Screening Convention: Sustained Implementation Towards a More Responsive Newborn Health Care System

Hundreds of health professionals and several local chief executives attended the recently-concluded Newborn Screening Convention held last October 3 and 7, 2008 in Cebu and Cagayan De Oro City, respectively. The convention's theme, "Sustained Implementation Towards a More Responsive Newborn Health Care System" was geared towards ensuring the long-term sustainability of the program.

The highlight of the activity was the discussion on the five congenital metabolic disorders being screened. Attendees were informed about the panel of disorders and the roles of various stakeholders in the NBS program. Dr. Giovanni Roan, a representative from PHILHEALTH discussed how the Newborn Screening Facilities (NSFs) and health professionals can maximize benefits from the Newborn Care Package. He also discussed the reimbursement procedures to address issues on returned claims. Other resource speakers were Dr. Lorna Abad, Dr. Barbara Charina Cavan, Dr. Mary Ann Chiong, Dr. Carmelita Domingo, Dr. Sylvia Estrada, Dr. Beatriz Gepte, and Dr. Edgar Posecion.

Successful program implementers from various parts of the country, such as Dr. Luisa Efren, PHO of Negros Occidental, Dr. Rowena Pua, NBS Coordina-



*Organizing Committee poses with the successful NBS implementers from Luzon, Visayas and Mindanao*

tor of Los Baños Doctors Hospital and Mayor Florencio Flores of Malaybalay, Bukidnon, shared strategies on successfully implementing Newborn Screening in their respective communities.

Research abstracts on NBS were also presented during the convention by Dr. Fidencio Aurelia, Dr. Arvin Escueta and Dr. Mary Anne Ilaos.

The convention was aimed at achieving the ultimate goal of screening all Filipino newborns for common life-threatening congenital metabolic disorders. This can only be achieved if newborn screening services are integrated in the entire health care delivery system with the active participation of various stakeholders. As the newborn screening program expands, developing and enhancing collaborative relationships with public and private partners is critical.



*Dr. Fidencio Aurelia on the Negros Oriental Newborn Screening experience*



*Neonatologist Dr. J Edgar Winston Posecion talks on the roles of NBS stakeholders*

*(Continued from page 1)*

ing NBS coverage in DOH retained hospitals; and strengthening of NBS implementation through the conduct of zonal consultative meetings; prioritizing the tracking of patients positive for any of the four (4) disorders screened; and finalizing cost reduction for confirmatory test for G6PD and conducting separate mass campaigns for parents with G6PD positive newborns to have their babies undergo confirmatory testing.

## NSC-Visayas Sponsors Regionwide LGU Assembly

Section 14 (Major Stakeholders Letter C-c) of the Implementing Rules and Regulations (IRR) of RA 9288, also known as the Newborn Screening Act of 2008, stipulates that the Local Government Unit (LGU) shall "ensure that adequate and sustained Newborn Screening services, such as information, communication, screening, recall and follow-up are being provided in all LGU health facilities (Rural/Health Unit/City Health Unit, Lying-ins, City/Municipal/District/Provincial Hospitals)..."

To assist LGUs in fulfilling this mandate, the Newborn Screening Center Visayas and the Center for Health Development Western Visayas held an Assembly last November 13, 2008 at the West Visayas State University Medical Center, Iloilo City. The assembly aimed to promote awareness and strengthen the implementation of the Newborn Screening program in Western Visayas. It was also geared towards achieving the 2010 NBS national coverage target of 85%.

Representatives from Pandan, Antique and San Enrique, Negros Occidental attended the assembly to be updated

on recent developments on NBS and thresh out their problems and strategies on program implementation and newborn screening advocacy.

Among the panelists was Mr. Alberto C. Mandurriao, PhilHealth Regional Office VI Assistant Vice President, who presented updates on PhilHealth Newborn Care Package. Agencies involved in the national and regional implementation of the program were represented by the following: Dr Edgar Winston Posecion, Newborn Screening Center-Visayas; Dr. Sophia Chua and Ms. Lizandra Sante, Center for Health Development; Ms. Lita Orbillo, DOH Central Office and; Ma. Elouisa Reyes and Vina Mendoza, Newborn Screening Reference Center.

To further encourage the LGUs, Ms. Reyes of NSRC shared ways of promoting the program at the community level. She suggested that LGUs should look into the practice of Batanes, Bulacan, and Negros Oriental in putting the program forward and achieving far above the target NBS coverage.

## Dr. Padilla Challenges DOH Regional Directors to boost NBS performance

To provide information to the Department of Health Center for Health Regional Directors, DOH Retained Hospital Chiefs of hospitals and the Directors of DOH-attached agencies, Dr. Carmencita Dr. Padilla, Director of the Newborn Screening Reference Center, presented an update on the newborn screening status in the Philippines and Asia Pacific during the DOH Field Implementation Management Office 2nd Zonal Visayas-Mindanao (VISMIN) Meeting on November 20, 2008 at General Santos City.

Dr. Padilla challenged the facilities as she discussed the low performance in newborn screening of most DOH-retained hospitals and its overall effect on the status of the program in the region. She further stressed the need to set up a newborn screening center (laboratory) in Mindanao and Northern Luzon.

As of December 2007, only 15% of the estimated 1.7 million babies born in the year have been screened. According to Dr. Padilla, everyone must be challenged to increase the number of babies screened and those that can be saved from the complications of congenital metabolic disorders. An estimated 33,000 babies born every year in the Philippines can be saved from mental retardation or death if all newborns are screened.

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