

5th Newborn Screening Convention Scientific Programme

6th Asia Pacific Regional Meeting of the International Society of Neonatal Screening

## Of being an LGU facility

# The Atang Dela Rama Lying-in Clinic NBS Account

By Dr. Jocelyn B. Denoga, Manila Public Health District II Office

The Atang de la Rama Health Center and Lying in Clinic was one amongst the twelve (12) clinics of the Manila Health Department with a zero newborn screening performance in May 2005. Consequently, I was summoned and sent for NBS training at the CHD-MM on May 3, 5 and 8 respectively.

Reticent to go, nevertheless I obliged, my mind filled with thoughts that seemed to repeatedly nag 'how can we (my staff and I) enforce a 50 Php collection when our clientele could hardly manage a decent life? For the record, we serve a clientele belonging to the lower socio-economic strata of our society. Instinctively, this gargantuan task proved more a challenge than an obstacle.

Shortly after, by August 16 of the same year, we set out to implement the

NBS program at our locality. A staff meeting was called and at best I shared the vision and mission, with emphasis on the program's significance. A brainstorm session ensued and initial resistance became inevitable. After all as the saying goes, nothing is permanent except change. However, it did not take long when my staff begun to own the vision.

Our Health Center's midwife concocted a Savings Program for expectant mothers relentlessly convincing patients to comply despite the attendant cost. Upon direct observation, seeing through the program implementation phase, it soon became an operational policy enforced to all newborn deliveries at our center.

In order to appease the social tension among our clients, we patiently ex-

plained the advantages and long-term benefits of having their babies newborn screened. Still some would refuse to accept, much less understand the legal mandate. At some point, some of them even went as far as threatening us that they would go to the Mayor and create waves about the minimal collection we had imposed upon them. Proof of their bickering were telephone calls we received from some local government officials pestered by these patients for financial assistance.

Through time, our patients finally understood it was not whim on our part but simply complying with a legal, local mandate – that of RA 9288.

Meanwhile, the rest of our staff was not knowledgeable of the heel-prick procedure as it were the physicians

*(Continued on page 4)*



Philippine delegates to the 5th Asia Pacific Regional Meeting for the International Society for Neonatal Screening (ISNS) held in Singapore. See story in page 3

## SEC. DUQUE REITERATES ACCESS TO NBS OF NEWBORNS



Sec. Francisco T. Duque III

DOH Secretary Francisco T. Duque reiterates that every baby born in the Philippines is offered the opportunity to undergo newborn screening and be spared from heritable conditions that can lead to mental retardation and death if undetected and untreated.

In a memo released to all undersecretaries, assistant secretaries, CHD directors, Chief of Hospitals, Medical Directors, Secretary Duque further reiterates

*(Continued on page 4)*



# 5<sup>th</sup> National Newborn Screening Convention

“Bringing Newborn Screening to the Grassroots Level”  
October 3-4, 2007 , Taal Vista, Tagaytay City

## SCIENTIFIC PROGRAMME

7:00 onwards

### REGISTRATION

8:00-9:00 **Opening of Exhibits**  
**Opening Ceremonies**

**Opening Remarks** *Carmencita D. Padilla, MD, MAHPS*  
*Founding President NSSP, Inc.*

**Welcome Remarks** *Benito P. Atienza, MD*  
*President NSSP, Inc. Southern Tagalog Chapter*

**Intro to the Keynote Speaker** *Rita Marie S. Vergara, MD*

**Keynote Speaker** *Francisco T. Duque III, MD, M Sc*  
*DOH Secretary*

### AM SESSIONS:

9:00-9:45 **Newborn Screening PhilHealth Package:**  
**An Update** *Madeleine Valera, MD*

9:45-10:30 **Recognizing Galactosemia**  
**and Phenylketonuria (PKU)** *Mary Anne Chiong, MD*

10:30-10:45 **Coffee/Tea Break/Visit to Exhibits**

10:45-11:30 **Urgent!!! Initial Treatment of Congenital Hypothyroidism**  
**(CH) and Congenital Adrenal Hyperplasia (CAH)** *Carmelita Domingo, MD*

11:30-12:00 **Open Forum**  
*(Moderator: Maita Cruz, MD)*

*AM Emcee: Elizabeth Naval, MD)*

### Simultaneous Luncheon Symposium:

12:00-1:00 **Sanofi Pasteur-Optimizing Childhood Vaccination** *Jaime Santos, MD*  
*(Moderator: Belinda Kalaw, MD)*

**Prevenar-Pneumococcal Conjugate Vaccine:**  
**Frequently Asked Questions** *Nancy Bernal, MD*  
*(Moderator: Julita Debuque, MD)*

**Natrpharm-Sepsis in Newborn, WHO Guidelines** *Emilio Hernandez, MD*  
*(Moderator: Madeline Sosa, MD)*

### PM SESSIONS:

1:30-2:15 **Clearing the Myths and Giving the Facts about G6PD** *Ernesto Yuson MD*

2:15-2:45 **Summing up the NBS Experience in**  
**Southern Tagalog Region** *Rowena A. Pua, MD*

2:45-3:30 **Merienda Symposium: "The First Hour"** *Ma. Asuncion Silvestre, MD*

3:30-4:45 **Target: Newborn Screening to the Barangay Level**  
**"The Lipa Experience"**  
*(Panel Discussion):* *Ariel Lescano, MD*  
*Mrs. Zenaída Verdera*  
*Gov. Vilma Santos-Recto*

4:45 -5:00 **Open Forum**  
*(Moderator: Resa De Jesus, MD)*

5:00 **Closing Ceremonies / Awarding of Certificates /Induction of Officers & New Members**  
**Closing Remarks** *Lygia Isidoro MD*  
*(PM Emcee: Arnold Lintag, MD)*

NEWBORN SCREENING SOCIETY  
OF THE PHILIPPINES, INC.  
*Southern Tagalog Chapter*

Secretariat Rm. 211 MAB  
Mediatrix Medical Center  
JP Laurel Hi-way, Lipa City

NAME: \_\_\_\_\_

ADDRESS  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Cell No. \_\_\_\_\_

|             | Pre-<br>Registration | On Site |
|-------------|----------------------|---------|
| Doctors     | PHP 700              | PHP 900 |
| Non-Doctors | PHP 600              | PHP 800 |

Pre registration until August 31, 2007

For particulars contact:

NSSPI Secretariat

Tel/Fax 043—7571983  
Cel No. 0906-5868442

Or  
Newborn Screening  
Reference Center

Tel/Fax 02- 5224396  
info@nsrc-nih.org.ph

## ANNOUNCEMENT

5th National Newborn Screening  
National Convention

October 3, 2007 • (1:00-5:00 pm)

**PRE-CONVENTION  
WORKSHOP :**

Newborn Screening Orientation  
Hotel Domingo, Tagaytay City





## 6th Asia Pacific Regional Meeting of the International Society for Neonatal Screening (ISNS)

# Keeping Abreast on Current Information on Newborn Screening

The International Society for Neonatal Screening (ISNS) held the 6<sup>th</sup> Asia Pacific Regional Meeting for ISNS on 29 August–1 September 2007 at the Furama Riverfront Hotel, Singapore with the theme “*Improving Child Health through Universal Newborn Screening*”.

Taking the opportunity to be kept abreast of the current information on newborn screening, the Philippines sent a delegation composed of key policy makers, manager, and implementers at the national and regional level, health and technical personnel at the laboratory, and experts in the field of genetics. The team is the largest contingent to the conference. The Philippine delegation were representatives from different DOH offices, Newborn Screening Center NIH, Newborn Screening Center-Visayas, Newborn Screening Reference Center, CHD- Western Visayas, and CHD – Metro Manila.

Dr. Carmencita Padilla delivered a talk on “*Towards Universal Newborn Screening in Developing Countries: Ob-*

*stacles and the Way Forward*” and Symposium lecture on “*Elimination of Iodine Deficiency: Obstacles and Removal*”; Dr. Sylvia C. Estrada presented “*Newborn Screening for Phenylketonuria: Outcome and Follow-up*”, and; Dr Carmelita Domingo served as one of the speaker during the *Meet the Expert Session: Congenital Hypothyroidism, Organization of Screening, Quality Issue, IEM Diagnosis, Fatty Acid Oxidation Effects*.

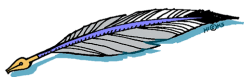
Aside from the plenary and symposium sessions, there were also debates conducted on newborn screening issues. One such debate entitled, *Universal Newborn Screening for Galactosemia Spends More Money than it Saves*, was participated in by Dr. Padilla taking the side against.

Other members of the Philippine contingent submitted researches for poster presentation.

On the whole, the Conference was a huge success with around 200 participants from various countries in the Asia Pacific Region sharing and learning from each others experi-

ences in terms of developing and implementing newborn screening. The conference has achieved its initial objective of providing the participants with the necessary information and insights to push for the development of newborn screening. It is expected that knowledge and insights received during the conference will translate to a committed, enlightened and determined team effort to push toward improving child health through newborn screening.

The Asia Pacific Regional Meeting (APRM) of the International Society for Neonatal Screening (ISNS) is held once every three years. It brings together international experts on neonatal screening to discuss new information, strategies and issues on newborn screening. APRM was conceived by forerunners in the field of newborn screening to ensure that people wishing to develop a good screening system in their own region is provided venue where they may have access to accurate and detailed information.



### PUBLIC CORNER

She was there at the beginning, when newborn screening was barely getting started in Lipa, Batangas. A medical technologist, Lisa meekly discharged her functions in the heel prick method that saved lives at Lipa Doctors Hospital. Their NBS coordinator sought greener pastures abroad and without qualms Lisa continued screening babies and preparing reports, filling up the filter cards that found their way to the laboratories of the National Institutes of Health, Institute of Human Genetics.

Little did she think that one day, it

would be the lives of her nieces she was to spare from G6PD deficiency. Today, as she recalls three years back, she feels fulfilled in diligently undertaking the tasks, no one even notices, with a note of gratitude.

Her nieces, bubbling with energy and life, live normal lives every child their age would. She goes and visits them, if only to remind the parents of the diet precaution.

“*It certainly paid off. Thanks to newborn screening, my nieces are ok! It spared my sister the pangs of emotional stress and financial burden,*” she quips in high spirits.

There will be thousands of Liza’s out there, doing the job as the invisible woman, yet the advocacy that lives in their hearts continue to live on for a better Lipa City. Only years could tell.

Note: Glucose-6-Phosphate Dehydrogenase Deficiency or G6PD Def is a condition where the body lacks the enzyme called G6PD. Babies with this deficiency may have hemolytic anemia resulting from exposure to oxidative substances found in drugs, food and chemical.





The participants of the 2007 Newborn Screening Training of Trainers conducted at Hotel Kimberly on July 4 - 6, 2007

## NBS Training of Trainers 2007 held

With the thrust of increasing the number of Newborn Screening Pool of Speakers and Trainers nationwide who can be tapped for orientations and re-orientations, the National Center for Disease Prevention and Control conducted a 3-day Training of Trainers at the Kimberly Hotel on July 4 - 6, 2007.

The intensive training was well attended by chosen medical health officers and personnel from different provinces including Nueva Vizcaya, Zamboanga Sibugay, Maguindanao, Leyte, Dinagat Island, Agusan Sur, Quezon, Northern Samar, Cotabato City, Batangas, Tawi-Tawi, Ilocos Norte, Basilan, Lanao Del Sur, Dipolog, Sulu, Oriental Mindoro, Occidental Mindoro, Surigao Del Sur,

The training covered concepts on newborn screening, components of the National Comprehensive Newborn Screening System, detailed discussion on the NBS Panel of Disorders, heel pricking session at Jose Fabella Memorial Hospital, role playing and presentation techniques.

The training of trainers is in partnership with the Newborn Screening Reference Center (NSRC) and the Center for Health Development - Metro Manila.

## NSRC conducts NBS orientation on Sub-committee on Children with Disabilities

NSRC conducted an orientation on Newborn screening to the Sub-Committee on Children with Disabilities last July 13, 2007 at the Council for the Welfare of Children (CWC), Quezon City.

The orientation was intended to create awareness among the participants about the importance of newborn screening being a preventive technology. More so, it highlighted the outcome of babies which are positive in one of the disorders but were not able to undergo newborn screening. Fur-

ther, the Republic Act 9288 or the Newborn Screening Act was also discussed focusing on the role of CWC.

The said event was attended by representatives from various agencies and organizations namely DILG, DOH, DOLE, Autism Society Philippines, Norfil Foundation, AKAPIN Inc., The Down Syndrome Association of the Philippines, STAC Parents Association, AD/HD Society of the Philippines, Liliane Foundation of the Philippines and Parent Advocates for Visually Impaired.

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that the DOH and the Philhealth Insurance Corporation (PHIC) shall require health institutions to provide newborn screening services as a condition for licensure or accreditation as stipulate in RA 9288 or the Newborn Screening Act of 2004.

The memo was released in response to the country's 2006 newborn screening coverage of an alarming 12%.

*"Every day 90 babies are lost to mental retardation and death. Everyone is therefore enjoined to work towards saving babies from mental retardation and death," - Sec. Duque.*

*(Continued from page 1)*

mainly implementing the procedure. During its early implementation phase, I tried doing all the procedural implementation. But as the demand for newborn screening grew, my staff of nurses and midwives needed training, if only to cope with the regular deliveries our center had been accommodating. Up until now, all midwives and nurses can implement the newborn screening.

Looking back, I fondly recall how it took a lot of patience, determination

and commitment in explaining, teaching, advocating, plus innovating promotional practices while not forgetting religiously to undertake the administrative steps of reporting, consolidating filter cards, including isolated cases of the retrieval process, as necessitated.

Presently, we are running our operations smoothly, not as a matter of obligation, rather a commitment to the newborn cause. We try our best to do our share as public servants.