



# Newborn Screening

September 1999 • SPECIAL ISSUE

Official Publication of the Philippine Newborn Screening Project

## Training Orientation on Newborn Screening for DOH Regional Coordinators Successfully Held

All systems are go for the nationwide implementation plan of newborn screening in the Philippines! And nothing can beat the enthusiasm shown by the 30 participants of the Training Program for DOH Regional Coordinators on Newborn Screening last September 13-17, 1999. The important event was made possible by the joint effort of the Department of Health and the University of the Philippines Manila-National Institutes of Health (UP-NIH). Full-packed and brimming with unadulterated excitement, the participants were bombarded with facts and information on newborn screening from day one to the very last day.

Billeted at the very heart of Manila, at the City State Tower Hotel in Ermita, the multicultural group was given a thorough orientation cum overview of newborn screening on their first day. They also heard lectures on the impact of newborn screening on the six inborn errors of metabolism. The next day, they saw lots of action when they visited the Newborn Screening Laboratory and secretariat office at the NIH. Here, they were divided into smaller groups and shown the different laboratory procedures by walking through six stations: the collection, handling, and transport of blood samples; performance of TSH/17 OHP assays; performance of PME/MET assays and G6PD screening; performance of Galactosemia assay; performance of thin layer

Chromatography Method; and, the Secretariat Office. To know more about newborn screening on the hospital level, the four groups were given two hospitals each—one private and one government hospital respectively—to visit on the third day and meet and exchange ideas with the hospital coordinators in charge of newborn screening. On Day 4, the participants picked each other's brains, trying to conceptualize and plan how to make newborn screening work in their own regions. They also tackled the gargantuan task of structuring the future directions of newborn screening. The last day held great promise as the participants—together with distinguished reactors from the DOH Task Force on Newborn Screening, the University of the Philippines Manila, and the Philippine Newborn Screening Project—concretized resolutions and plans to further the cause of newborn screening nationwide. The DOH pledged its support by including



The picture says it all.

the newborn screening agenda in Child 2025, a strategic program for Filipino children. Now, it is the DOH regional coordinators' role to advocate for the screening of all Filipino babies and thus secure their future by shielding them from the crippling effects of metabolic disorders such as mental retardation and death.

From this day forward, may the battle cry be heard from Appari to Jolo: **let's make newborn screening work!**

## DOING IT WITH THE DOH: Task Force on Newborn Screening Created

The Department of Health (DOH) has created a Task Force on Newborn Screening to design a national plan for the eventual development of a nationwide newborn screening program. Chaired by Dr. Susan Pineda-Mercado, DOH Chief of Staff, and co-chaired by Undersecretary Milagros Fernandez of the Office of Public Health Services, the task force is also assigned to oversee the early implementation phase of newborn screening in pilot regions. Various institutions of multifaceted concerns, such as the Department of Interior and Local Government; Maternal and Child Health Service; Hospital Operations and Management Service; Non-Communicable Diseases; Health Manpower Development and Training Service; Family Health Cluster; UP Manila NIH-Institute of Human Genetics; Philippine Newborn Screening Study Group; Senate and House Committees on Health; and the private sector, will have their



First organizational meeting of Task Force on NBS

## Q & A ON Newborn Screening

# facts medical practitioners ought to know about newborn screening

### WHEN SHOULD WE SCREEN THE BABY?

It is highly recommended that samples be taken when the baby is at least 48 hours old and not more than two weeks old. If sample is taken too early, there is a greater chance of false positive results for CH screening due to TSH surge during the first 24 hours of life or false negative results for PKU, galactosemia and homocystinuria due to lack of protein and galactose intake. In such cases, repeat screening must be done within two weeks. On the other hand, if the sample is taken at a much later time, the purpose of early detection and prevention of complications may be defeated.

### HOW DO WE CONVINCe PARENTS?

Convincing parents to try newborn screening for their babies should start as early as the prenatal stage. They should know the important benefits of newborn screening to their child's future health. It's also one way for mommies and daddies to prepare the additional cost.

### DO WE REALLY NEED TO GET THE PARENTS' CONSENT?

Newborn screening (nbs) is considered a routine procedure in countries where it is mandated by law. In the Philippines, however, it is still a relatively new project and obtaining consent ensures that parents understand the test.

### WHAT IF THE PARENTS REFUSED OUTRIGHT?

It is extremely rare to see parents refuse after understanding the merits of newborn screening, particularly when success stories are shared with them. For instance, one of the patients was found to have elevated 17OHP, indicating congenital adrenal hyperplasia. The patient was asymptomatic at discharge. Shortly after, the baby was showing early signs of adrenal crisis. But thanks to newborn screening, the baby was saved.

### WHAT IF THERE'S INSUFFICIENT INFORMATION ABOUT NBS?

The hospital staff can prominently display or

give out information campaign materials in their maternity wards, nurseries, and even lobbies. The newborn screening program can also be included in a short talk during mothers' class. Although materials are easily obtained at the Secretariat Office, we urge the hospital staff to make advance requests before they completely run out of materials.

### ARE THERE BLOOD EXTRACTION METHODS OTHER THAN THE HEEL-PRICK ONE?

Many medical practitioners think the heel-prick method is difficult but it just takes some patience and a little practice. However, if blood extraction is being done for other tests, newborn screening may be included just as well.

### DO NURSES CONDUCT BLOOD COLLECTION?

In countries where newborn screening is implemented nationwide, nurses and midwives assist in sample collection. They are also the ones who convince parents to have their babies screened.

### HOW MUCH DOES NEWBORN SCREENING COST?

For a fee of PhP 450 in participating hospitals, parents can give their child the gift of life. Indeed, the cost is very reasonable, too, since we are using the same technology other countries, like Japan and the US, have in their own newborn screening programs.

### HOW DO WE MINIMIZE DELAY IN PATIENT RECALL?

Devising a pragmatic solution for efficient patient recall, some hospitals provided a logbook of patients' names, including complete addresses and contact numbers.

### WHAT DO WE DO TO CHECK DELAYS IN RELEASING RESULTS?

First and foremost is to submit samples regularly to the Newborn Screening Laboratory. It is a big help when the hospital staff use the official result form with the needed information completely filled in. To avoid confusion, instruct parents where to get the results. We would like to reiterate that the release of confirmation reports is on the 15<sup>th</sup> and the 30<sup>th</sup> of every month. 1

*cont. from page 1*

own representatives in the task force. Rendering their valuable support is a panel of technical experts in diverse fields—in endocrinology, metabolic disorders, genetics, and developmental pediatrics—joined by distinguished members of the Philippine Pediatric Society, Philippine Obstetrical and Gynecological Society, Academy of Family Physicians, Philippine Nurses Association, Integrated Midwives Association of the Philippines, Pediatric Endocrinology and Metabolism Society, Perinatal Association of the Philippines, Fetus as a Patient Institute, League of Government Nurses, League of Government Midwives, and Philippine Health Insurance Corporation. The project is under the Office of Public Health Services of the Department of Health. The Institute of Human Genetics of the National Institutes of Health (NIH) and the Maternal and Child Health Service of the DOH will serve as the secretariat of the formed Task Force.

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**C**yberspace here we come! Check out the latest info on the **Institute of Human Genetics (IHG)** website at <http://human-genetics.jumphealth.com> and know more about us. If you have a gamut of comments, questions, and helpful suggestions—we got (e) mail! Just send your correspondence to [genenih@i-next.net](mailto:genenih@i-next.net).

**W**elcome to the NBS family! Our cheers go to **Central Luzon Doctor's Hospital, Talon General Hospital, and Batangas Regional Hospital** for making newborn screening accessible to our kababayans in **Tarlac and Batangas**. They are now part of our 51-strong circle of participating hospitals all over the country.