



NEWBORN

Official Publication of the Institute of Human Genetics, National Institutes of Health and the Philippine Newborn Screening Program

Screening

DOH advocates Newborn Screening

The Department of Health (DOH) is now at the forefront of another program aimed at safeguarding the lives of babies against mental retardation and death through newborn screening (NBS) of certain metabolic disorders. This is part of DOH's commitment to improve the health of all Filipino children by ensuring their survival, full growth and development.

"We have several existing programs where NBS can be integrated and DOH is currently preparing comprehensive technical guidelines that will set high standards of service for all components of the program," DOH Secretary Manuel Dayrit said.

The guidelines will define the following: the integration of NBS in all programs of DOH and in the country's health care delivery system; the establishment of a network for the recall, management and monitoring of patients found positive in any of the disorders; the definition of the roles of various stakeholders; the conduct of seminars and workshops to increase the capability of implementers; the identification of sources for logistical needs, the identification of financial schemes that will make NBS available to all babies; and the formulation of the criteria for the establishment of future NBS facilities in the country.

During a recent visit to the Philippines to evaluate the progress of Newborn Screening Program, Dr. Brad L. Therrell, director of the US National Newborn Screening and Genetics Resource Center,

found the program to be progressive and satisfactorily moving in the appropriate direction. "I believe that DOH now has an outstanding opportunity to improve the health of all children throughout the country through its leadership in supporting, improving, and expanding NBS," he told Dayrit in a letter.

Dr. Therrell described the national planning process as well underway and cited the crucial role of DOH in moving rapidly to provide guidance in the setting up of NBS facilities.

At present, the program covers screening for five metabolic disorders: congenital hypothyroidism, congenital adrenal hyperplasia, galactosemia, phenylketonuria, and glucose-6-phosphate dehydrogenase deficiency. Of 1.5 million babies born annually, only 3% are being screened.

The program will utilize DOH's existing infrastructure and network of local health offices at the regional, provincial, municipal and barangay



Health Secretary Manuel Dayrit meets with Dr. Brad Therrell, director of the U.S. National Newborn Screening and Genetic Resource Center.

levels to increase and widen coverage of newborns, especially in the rural areas where many deliveries are made.

To ensure quality and affordable service to the public, DOH will enforce regulatory measures, especially in the setting up of NBS facilities. The health secretary has enjoined hospitals planning to set up such facilities to cooperate and coordinate with DOH by integrating their efforts with the national program which is being run jointly with the Institute of Human Genetics, National Institutes of Health, University of the Philippines Manila.

In February 2001, DOH issued

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Outstanding Newborn Screening advocates fêted

One way to celebrate life is to honor those who fight to protect its quality.

Last February 21, at the Manila Midtown Hotel, that was exactly what the Newborn Screening Society of the Philippines (NBSSP) did: it awarded its advocates for exemplary performance in the past year.

Newborn screening is a medical practice for determining congenital anomalies in newborns. Through the screening of five drops of blood gathered with the heel-prick method, it can be found out if a newborn is in danger of severe mental retardation or death. These sick babies are then given medicine to keep their illnesses in check.

Newborn screening has been around for more than 30 years in advanced countries, but only made its debut in the Philippines in 1996. It was introduced here by the Newborn Study Group (NBSG) headed by pediatricians/geneticists Drs. Carmelita Domingo and Carmencita Padilla of UP Manila.

Newborn screening advocates are

people usually health professionals and their medical units (clinics, health centers, hospitals) who are involved in spreading this piece of good news.

As the advocates grew from 24 hospitals to 253 hospitals and centers in 2002, the smallish, 'family-type' NBSG evolved into the complex organization that is NBSSP to better manage its burgeoning offspring, the Newborn Screening Program of the Philippines (NBSPP).

With only silent support from the Department of Health (because it wanted to do some 'capability-building' first before giving institutional support), the NBSPP grew until, by the end of 2002, it has saved more than 3,000 babies from death and mental retardation. (However, advocates claim, if newborn screening had been implemented nationwide, they calculated that about 70,000 babies could have been saved since 1996 which means roughly 10,000 babies each year are born with congenital anomalies.)

Because the DOH still hasn't given

institutional support to the program--despite assurances to the top honchos by Dr. Domingo and Dr. Padilla that no DOH funding is needed participating units thought of ways to propagate and implement newborn screening. One Manila-based hospital made it a necessary part of child and maternal health screening and is done with or without the consent of the parents. One provincial center made it a part of an affordable maternity package with parents paying the center in installments once pregnancy starts.

Some units offered the program in their Mothers' Classes. Others invited people to advocacy meetings, while some visited the families in their area.

It was and continues to be so advocacy, grassroots-style. The Bayanihan ethos resurfacing to help Filipinos in need. (Someday, I believe, this ethos will be the saving of the nation.)

This, then, is the list of 2002 NBSSP honorees:

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What is Newborn Screening?

Newborn Screening is a simple blood screening used to identify many inherited diseases before serious or life-threatening symptoms begin.

What are conditions included in Newborn Screening?

Included in the panel of the Philippine Newborn Screening Program are 5 disorders namely: Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, G6PD deficiency, Galactocemia and Phenylketonuria.

Why should my baby undergo newborn screening?

Most of the babies affected with any of these conditions appear perfectly healthy or normal at birth. This is why it is difficult for physicians to diagnose these conditions at birth. By the time doctors are able to recognize and identify the disorder, irreparable damage to the baby has already taken place. The babies will be mentally retarded or in worst cases, may even die. This is why newborn screening is important in identifying these disorders early so that management could be instituted immediately.

Should I still have my baby screened even if we don't have any history or congenital defect in the family?

The answer is yes. There are affected children who are born from healthy families without any history of congenital defect. By having each and every baby undergo newborn screening, we are minimizing the chances of not being able to identify newborns who are affected with any of the five disorders.

My baby seems perfectly well. Do I still need to have him/her undergo newborn screening?

As mentioned earlier, most babies with any of the five disorders appear perfectly normal at birth. They may seem healthy with no trace of any abnormality. With this kind of normal presentation, doctors will find it impossible to detect or diagnose the disorder. Through newborn screening, affected newborns will be identified early and given proper management and treatment.

How are the tests done?

About 2 to 6 days old, or just before hospital discharge, a few drops of blood will be obtained from your baby's heel. The blood sample will be placed on a special filter paper and allowed to air dry. Once it is dried, it is mailed (thru courier) directly to the Newborn Screening Laboratory at the National Institutes of Health in Manila.

How soon after birth should I have my baby screened?

The blood sample is ideally taken 2 to 6 days after birth or on the day before discharge from the hospital. Taking the blood samples too early (e.g. immediately after birth or before 24 hours) will give false positive results.

How will I know the results of the test?

The results of the test will be mailed, e-mailed or faxed to the hospital where the blood sample was taken. If the results of the test indicate that your baby needs further tests, the hospital where the blood sample was taken or your baby's doctor will be immediately notified by phone, fax or e-mail.

How soon will the results be available?

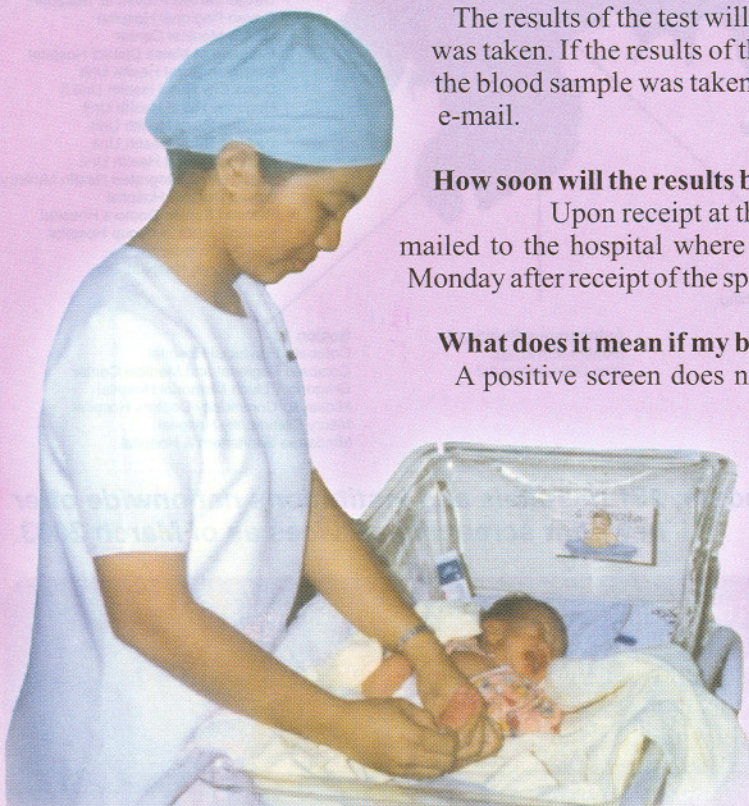
Upon receipt at the laboratory, it will take 7 days before the results can be faxed or e-mailed to the hospital where the sample was taken. Mailing or results are done the following Monday after receipt of the specimen in the laboratory.

What does it mean if my baby tested positive for the screening?

A positive screen does not necessarily mean that your baby absolutely has any of the five disorders. Further tests will still be needed to confirm the diagnosis. The hospital where the blood sample was taken or your baby's doctor will be notified about the need for these additional tests.

I have been informed that my baby's test needs to be repeated. What does that mean?

There are a number of reasons why a screening test has to be performed again. It can be due to an unsatisfactory specimen (not enough blood, not properly dried, contaminated, etc.), unreliable specimen (blood taken too early e.g. before 24 hours) or abnormal test result (may need to undergo a confirmatory test).



Map of Participating Hospitals/Institutions As of March 2003

Cordillera Autonomous Region

Baguio General Hospital
St Louis University Hospital
of the Sacred Heart

Region 2

Cagayan Valley Medical Center
Veterans Regional Hospital
Manuel Roxas District Hospital
Aparri Christian Hospital

Region 3

James L. Gordon Memorial Hospital
Afaile Medical Center
Alferos Hospital
AUF-Medical Center
Central Luzon Doctor's Hospital
Malolos Maternity Hospital and Eye Center
Perpetual Help Hospital
San Fernando Hospital
Talon General Hospital
V L Makabali Memorial Hospital
Women's Hospital

National Capital Region

Jose Reyes Medical Center
Las Pinas Integrated District Hospital
National Children's Hospital
Ospital ng Maynila
Philippine Children's Medical Center
Philippine General Hospital
Quezon City General Hospital
Quirino Memorial Medical Center
Rizal Medical Center
San Juan Medical Center
Valenzuela General Hospital
Alabang Medical Center
Alejandro Doctors Medical Clinic
Capitol Medical Center
Cardinal Santos Medical Center
Children's Medical Center
Chinese General Hospital
Christ the King Maternity and Lying-In Hospital
De Los Santos Medical Center
Dr. Victor R. Potenciano Memorial Hospital
Fatima Medical Center
FEU-NR Medical Foundation Hospital
Hospital of the Infant Jesus
Jesus Delgado Memorial Hospital
Las Pinas Doctors Hospital
Las Pinas City Medical Center
Makati Medical Center
Manila Doctors Hospital
Manila Sanitarium and Hospital
Mary Chiles General Hospital
Mary Johnston Hospital
MCU-FDTMF Hospital
Medical Center Manila
Metro Manila Medical Center Paranaque
Metropolitan Hospital
MPI Medical Center Muntinlupa
Olivarez General Hospital
Our Lady of Lourdes Hospital

Region 4

Batangas Regional Hospital
Fernando Airbase, PAF Hospital
Pagamutang Pangmasa ng Laguna
Majayjay Medicare Hospital
Sta Cruz District Hospital
Laguna Provincial Hospital
UPLB Health Service
Panlalawigan Pagamutan ng Laguna
Binan Doctors Hospital
Calamba Medical Center
Community Hospital
Daniel Mercado Hospital
Dela Salle University Medical Center
Divine Mercy Hospital
Dr. Mario P Bejasa General Hospital
Evangelista Medical Specialty Hospital
Family Care Hospital
Golden Gate General Hospital
Lipa Medix Medical Center
Los Banos Doctors Hospital
Lucena United Doctors Hospital
Mary Mediatrix Medical Center
Molino Doctors Hospital
Mt. Carmel Diocesan General Hospital
Nasugbu Doctors Hospital
NL Villa Memorial Medical Center
Our Lady of Caysasay
San Diego de Alcalá General Hospital
San Pablo Medical Center
SPC Medical Center
St John the Baptist Medical Center
St Peter General Hospital
Unciano Medical Center
University of Perpetual Help Medical Center

Region 1

Ilocos Training and Regional Medical Center
Mariano Marcos Memorial Hospital
Region 1 Medical Center
Bethany Hospital Inc. of San Fernando
Holy Child General Hospital
Lorma Medical Center
Metro Vigan Cooperative Hospital

Region 5

Bicol Medical Center
Camarines Norte Provincial Hospital
Ago General Hospital
Mother Seton Hospital
Sts Peter and Paul Hospital

Region 6

Allavas District Hospital
Bacolod Sanitarium and Hospital
Bugasong Medicare Community Hospital
Culasi District Hospital
Sara District Hospital
Western Visayas Medical Center
West Visayas State University Hospital
Capiz Emmanuel Hospital
Iloilo Doctors Hospital
Iloilo Mission Hospital
Riverside Medical Center
St Anthony College Hospital
St Paul's Hospital Iloilo
Midsayap Community Doctors Hospital
Mercy Community Hospital
Mindanao Sanitarium and Hospital

Region 8

Eastern Visayas Regional Medical Center
Hinunangan Community Hospital
Dr Gregorio B Tan Memorial Hospital
Betheny Hospital
Divine Word Hospital
OSPA Farmers Medical Center
Remedios Trinidad Romualdez Hospital
Philphos Hospital

Region 7

Bayawan District Hospital
Bindoy District Hospital
Eversely Child Sanitarium
Gov Celestino Gallares Memorial Hospital
Gov Natalio P Castillo Sr Memorial Hospital
Gov Simeon Toribio Memorial Hospital
Gov William "Billy" Villegas Memorial Hospital
Lapu-Lapu District Hospital
Negros Oriental Provincial Hospital
Siquijor Provincial Hospital
St Anthony Mother and Child Hospital
Vicento Sotto Memorial Medical Center
Amlan Municipal Health Center
Cordova Municipal Health Center
Tanjay RHU 2
Vicente Mendiola Memorial Clinic of RHU 1 Naga
Bohol St Jude General Hospital
Cebu Doctors Hospital
Cebu Puericulture and Maternity Hospital
Cebu Velez Hospital
Chong Hua Hospital
Holy Child Hospital
Mactan Community Hospital
Metro Cebu Community Hospital
Our Lady of the Rule Maternity and General Hospital
Perpetual Succour Hospital
Ramiro Community Hospital
Silliman University Medical Hospital
St Vincent General Hospital
Tagbilaran Puericulture Center and Maternity House
Vicente M Mendiola Memorial Hospital

Region 9

Zamboanga Medical Center

Region 10

Bukidnon Provincial Hospital
Bukidnon Provincial Hospital-Maramag
JR borja Memorial Hospital
Mayor Hilarion A Ramiro Sr Regional Training & Teaching
Misamis Occidental Provincial Hospital
Northern Mindanao Medical Center
Bethel Baptist Hospital
Cagayan Capitol General Hospital Foundation, Inc.
Cagayan de Oro Maternity-Children's Hospital
Cagayan de Oro Medical Center
Cagayan de Oro Polymedic General Hospital
Camiguin General Hospital
Dr Sabal Hospital
Faith Hospital
Madonna and Child Hospital
Maria Reyna Hospital
Misamis University Medical Center
Simbulan Santo Niño Hospital

**Autonomous Region of
Muslim Mindanao**

Wao District Hospital

Region 12

Cotabato Provincial Hospital
Cotabato Regional and Medical Center
Gregorio T Lluch Memorial Hospital
Midsayap Community Doctors Hospital
Mercy Community Hospital
Mindanao Sanitarium & Hospital

CARAGA

DOH CARAGA Regional Hospital

Region 11

Davao del Sur Provincial Hospital
Davao Regional Hospital
Davao Medical Center
Gregorio M Matas District Hospital
Bansalan Rural Health Unit
Digos City Rural Health Unit II
Hagonoy Rural Health Unit
Malalag Rural Health Unit
Padada Rural Health Unit
Sta Maria Rural Health Unit
Brokenshire Integrated Health Ministry
Davao Doctors Hospital
General Santos Doctors Hospital
Medical Mission Group Hospital
San Pedro Hospital
St Elizabeth Hospital, Inc

NBS Update: 261 hospitals and institutions nationwide offer newborn screening services as of March 2003.

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Region 6 serves as model facility for NBS

With the envisioned nationwide implementation of Newborn Screening, several models were developed to assist all health facilities that will offer NBS.

At present, there are models for hospitals at all levels, lying-ins and birthing centers and communities. DOH and NIHP posed the urgent need for a regional model and the Center for Health Development for Western Visayas (Region 6) decided to take the challenge. With the support of DOH Regional Director Lydia S. Depra-Ramos who initiated the Regional Development Council Resolution of the NBS Program, the full operation of NBS in Region 6 is within the wings of the Regional Office. Key strategies that led to its success were the creation of a regional technical working group for NBS; the designation of a full time nurse dedicated to NBS; an intensified advocacy campaign at all levels; the conduct of more than 100 orientation seminars; the active recruitment of health facilities; the integration of advocacy efforts in all health promotion activities in all child health activities, in Family



DOH Region 6 Regional Director Lydia S. Depra-Ramos and Dr. Jo Olvido, Region 6 NBS Coordinator receive "Model Region Award" from Undersecretary Margarita Galon.

Planning & Reproductive Health/Gender and Health Trainings of CHD 6, the strengthening of multi-sectoral linkages; and the solicitation of support from other partners (ECD-RPMO-DSWD, media, etc.)

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LIST OF AWARDEES

Health Facilities with exemplary performance for year 2002 (Plaque)

- Midsayap Community Doctors Hospital
- Los Baños Doctors Hospital, Inc.
- Mary Mediatrix Medical Center
- Cattleya Well Family Midwife Clinic
- Chinese General Hospital and Medical Center
- Evangelista Medical Specialty Hospital
- The Medical City
- Olivarez General Hospital
- Mary Johnston Hospital, Inc.
- Capitol medical Center
- Bayawan District Hospital
- SPC Medical Center
- United Doctors Medical Center
- St. Paul's Hospital
- Cardinal Santos Medical Center
- Hospital of the Infant Jesus
- Holy Child General Hospital
- University of Perpetual Help Medical Center Biñan
- Dr. Victor R. Potenciano Medical Center
- Las Piñas Doctors Hospital
- San Diego de Alcala General Hospital
- Manila Doctors Hospital

- Pagamutang Pangmasa ng Laguna
- Makati Medical Center
- St. Luke's Medical Center
- Ago General Hospital
- Medical Center Manila
- Golden Gate General Hospital
- Central Luzon Doctors Hospital
- Community Hospital of San Pablo City, Inc.
- Bethel Baptist Hospital, Inc.
- Divine World Hospital
- FEU-Nicanor Reyes Medical Foundation Hospital
- Siliman University Foundation Medical Center
- St. Patrick's Hospital Medical Center
- Family Care Hospital
- De Los Santos Medical Center
- Lipa Medix Medical Center
- Manila Sanitarium and Hospital
- Tanjay-Rural Health Unit

- Center
- Evangelista Medical Specialty Hospital
- Hospital of the Infant Jesus
- Los Baños Doctors Hospital, Inc.
- Mary Mediatrix Medical Center
- Metropolitan Hospital
- Olivarez General Hospital
- The Medical City

SPECIAL AWARDS

Model Community

Tanjay Rural Health Unit 2

Model Local Government Hospital Utilizing community based health care financing 567

Bayawan District Hospital

Model DOH Regional Health Office

Center for Health and Development for Western Visayas-DOH Region 6
Dr. Fe del Mundo Memorial Medical Center

Awardees (Hospital with consistent 70% and above coverage for the past three years 2000-2002)

Cardinal Santos Medical Center
Chinese General Hospital and Medical

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Pagamutang Pangmasa ng Laguna
 Makati Medical Center
 St. Luke's Medical Center
 Ago General Hospital
 Medical Center Manila
 Golden Gate General Hospital
 Central Luzon Doctors Hospital
 Community Hospital of San Pablo City, Inc.
 Bethel Baptist Hospital, Inc.
 Divine World Hospital
 FEU-Nicanor Reyes Medical Foundation Hospital
 Siliman University Foundation Medical Center
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Center for Health and Development for Western Visayas-DOH Region 6
 Dr. Fe del Mundo Memorial Medical Center

KNOW YOUR HOSPITAL



Senior Nursing Staff of NICU of Mary Mediatrix Medical Center. From L-R: Jeri Castillo, Myra Garing, Cedy Eje, Deserie Mercado.

Personal Approach ensures success of Mary Mediatrix's Newborn Screening Program

For the past three years now, the Mary Mediatrix Medical Center's (MMMC) Newborn Screening Program has consistently posted at least 70 percent screening rate. This success can be attributed to a lot of factors.

From the time of the mother's prenatal check up, the obstetrician already primes her about newborn screening. The importance of having her baby screened is reiterated by the pediatrician after she gives birth.

The major contributing factor, however, is the work done by the dynamic nursing staff of the Neonatal Intensive Care Unit (NICU). Once their babies are admitted to the nursery, nurses explain thoroughly to the mothers the basic aspects of newborn screening. They also distribute pamphlets to inculcate in them the need for and the benefits of the procedure.

They interact with the mothers in their daily nursing visits such that "bonding" is likewise established between them. By the time the baby is ready for rooming in or discharge, the nurses have already gained the mother's trust and confidence, thus, consent for screening is, more often than not, willingly given.

Their perseverance and sincerity in persuading the parents put the latter at ease such that they readily entrust their babies for screening. The nurses then do the extraction themselves, being already skilled in the proper technique and taking care to avoid the pitfalls of collecting unfit samples.

They coordinate with the National Institutes of Health of UP Manila which runs the Newborn Screening Program and with FedEx on pick up schedule of samples and communicate with their staffmembers directly to facilitate sending and delivery of samples. In case of a positive result, information is relayed to NICU and the nurses recall the patient for confirmatory tests.

This personal touch which the NICU staff employs from the time the mother learns about newborn screening up to the time she learns the results is the key to the continued high rate of the newborn screening program of MMMC.

DOH ADVOCATES p.1

Department Order No. 29-C s 2000 creating a National Technical Working Group on Newborn Screening (NTWG-NBS) to oversee the development of policies, guidelines and standards for a more effective and efficient implementation of the program. The group is composed of representatives from DOH, NIH, the Philippine Society of Pediatric Metabolism and Endocrinology, and representatives from both government and private agencies.

Six years ago, the Philippine Newborn Screening Program was introduced by a group of pediatricians and obstetricians from 24 hospitals in Metro Manila to establish the incidence of six metabolic conditions; and make recommendations for the adoption of NBS nationwide.

Data gathered so far from the 250 participating institutions confirmed that at least 2000 babies have been saved from mental retardation and death since 1996. Based on the local incidence of the 5 disorders, at least 10,000 newborns annually can be saved from mental retardation and death if NBS is implemented on a nationwide scale. A cost-benefit analysis of the national NBS program conducted by Dr. Carmencita Padilla, director of UP Manila's Institute of Human Genetics and one of the prime movers of the NBS Program, showed a net benefit of 500 million pesos annually if every newborn in the country could be screened. According to Dr. Eduard Banzon, Vice-President of Phil Health Insurance, several studies are being undertaken to explore the feasibility of including newborn screening among the items for reimbursement by Phil Health.

Newborn screening is already an accepted component of quality newborn care. Developed countries screen almost 100% of their newborn population. In the East Asia region, 12 developing countries are currently working towards a greater coverage of their newborn population. Among the successful developing programs in the region are Thailand and Korea which now covers 87% and 92% of their newborn population respectively. Newborn screening started in the US in the '60s and currently is mandated by US state laws.