

Networking in Asia

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&

President, Asia Pacific Society of Human Genetics

Objectives of the Session

Discuss the following issues:

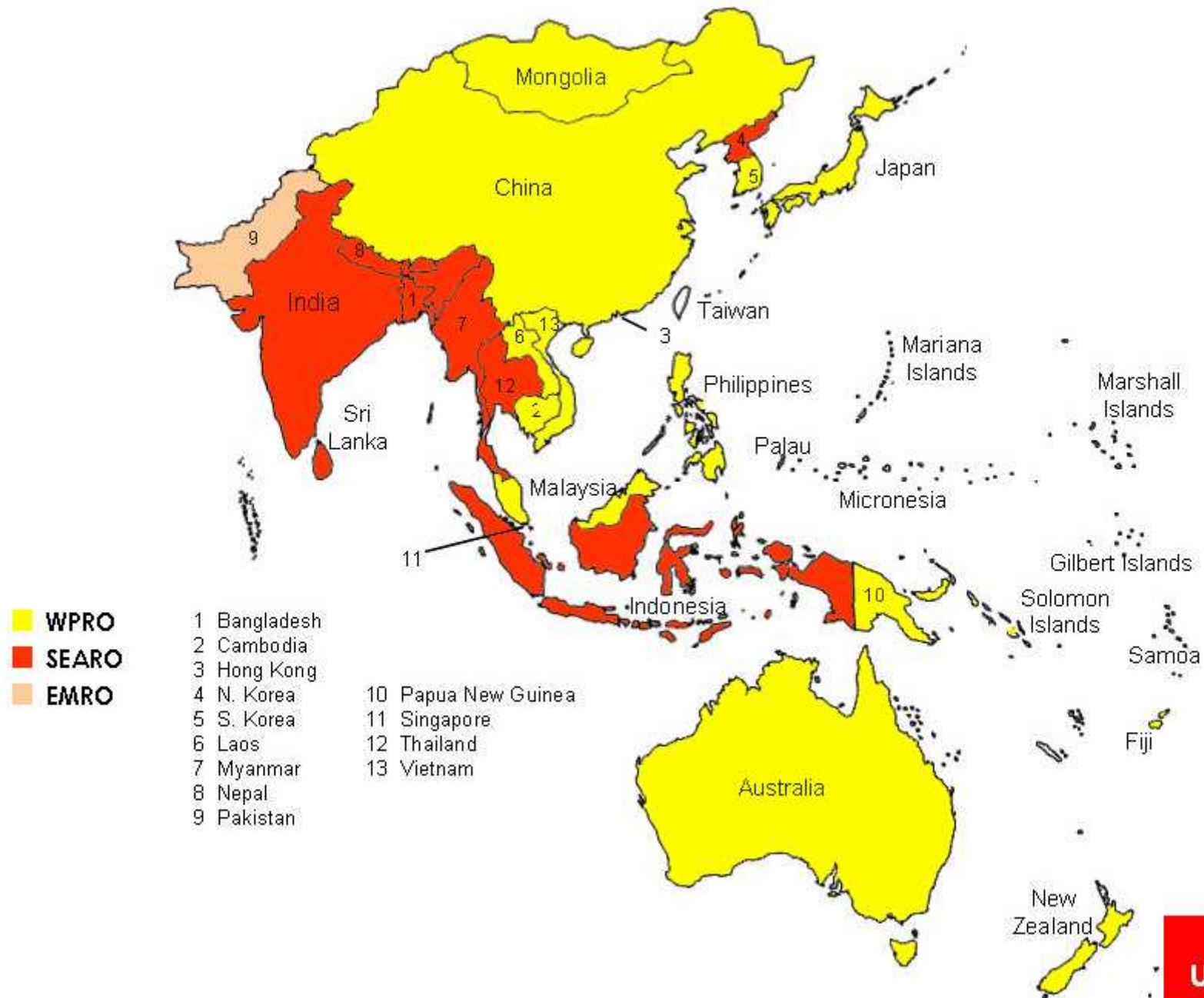
- Present highlights in Asian countries
- Present two (2) networks in Asia
 - Newborn screening
 - Genetics
- Genetic Services in the Philippines

OF 133 MILLION BIRTHS WORLDWIDE, 66.5 M ARE BORN IN ASIA

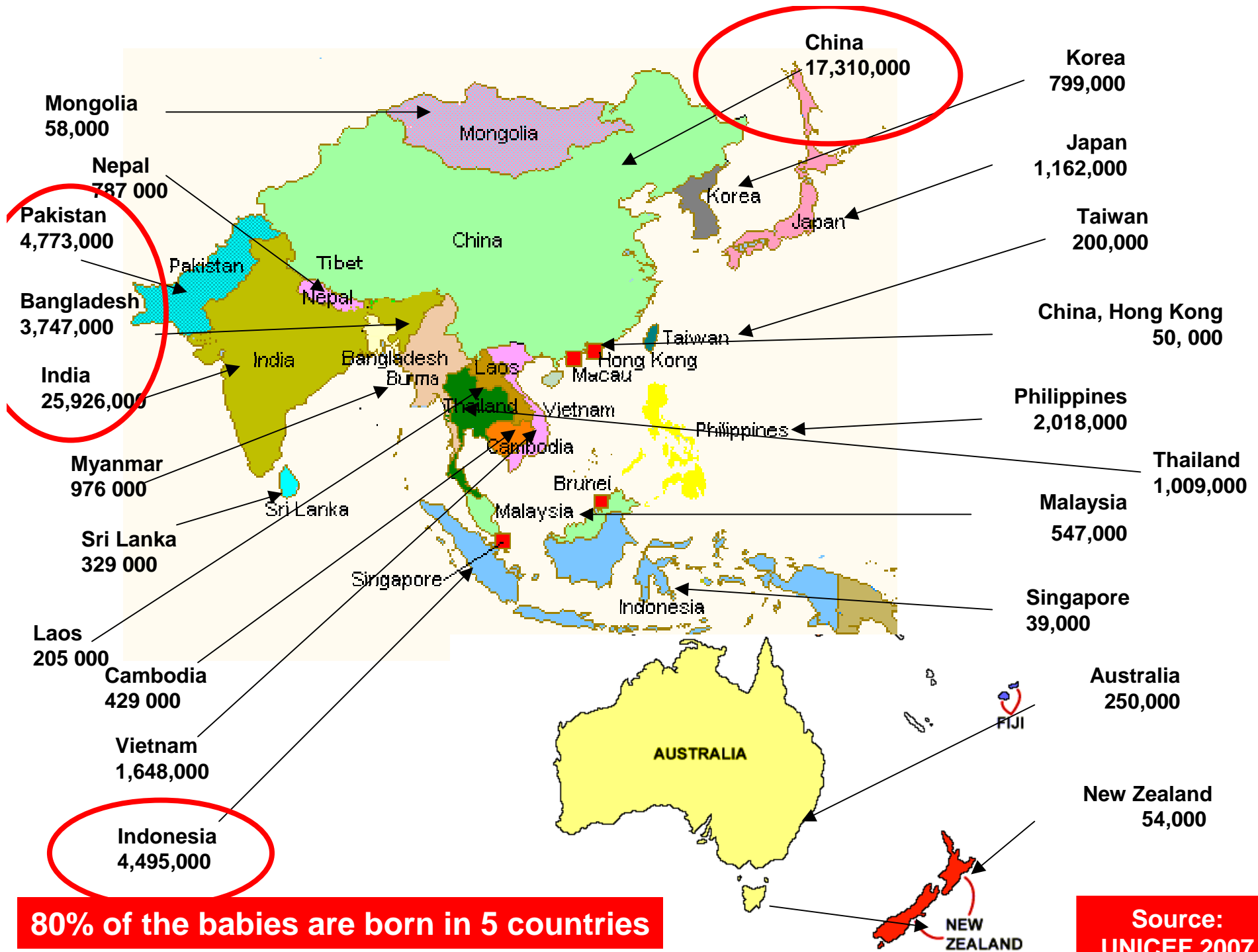


**Source:
UNICEF 2007**

OF 133 MILLION BIRTHS WORLDWIDE, 66.5 M ARE BORN IN ASIA



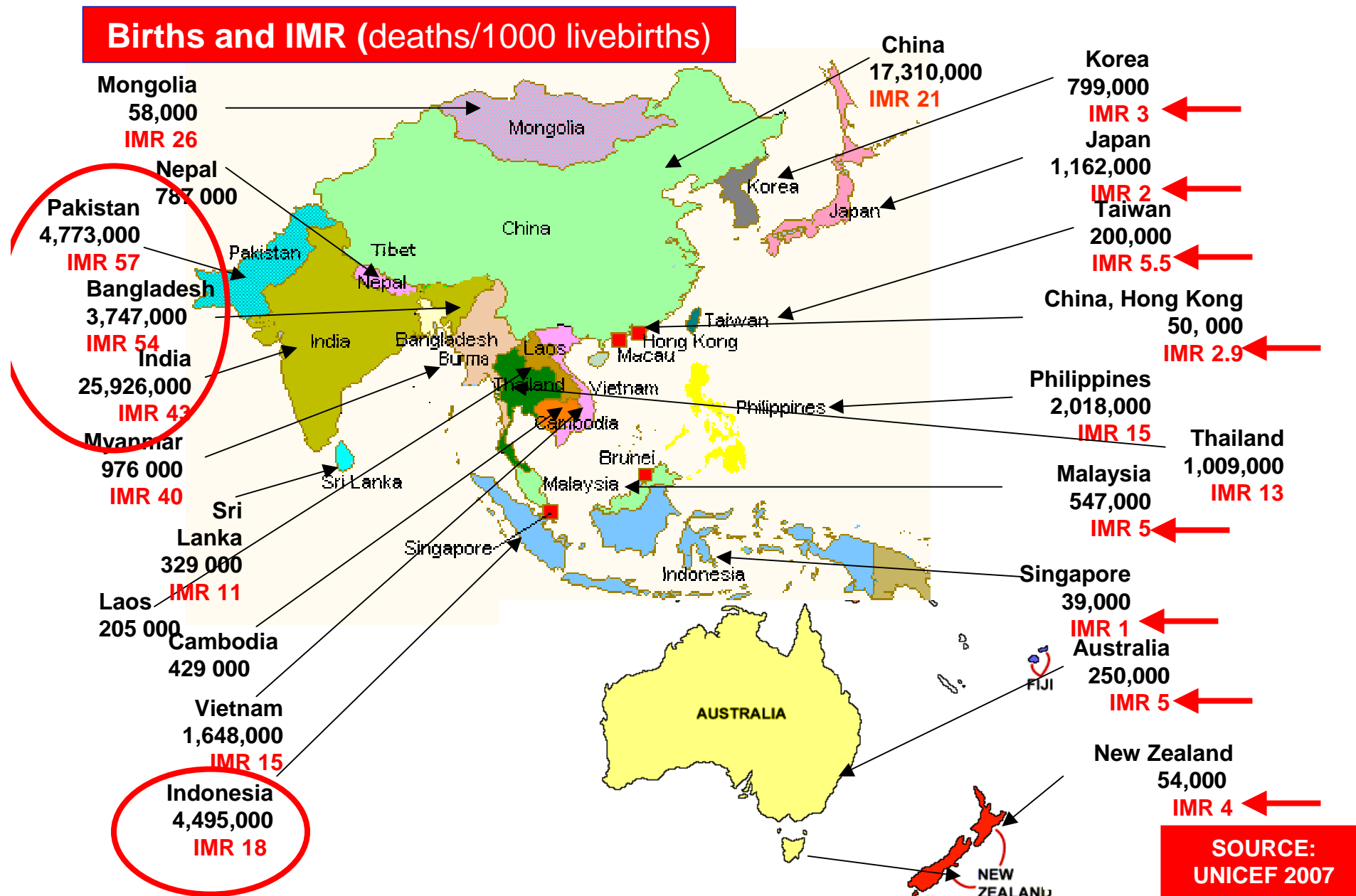
**Source:
UNICEF 2007**



The 5 Asian giants (**India, Pakistan, Bangladesh, Indonesia and China**) alone account for over 2/3 of all people living in rural areas without access to sanitation, underweight children, people living on less than US\$1 a day and of TB cases worldwide.

Population and no of births

Births and IMR (deaths/1000 livebirths)



**SOURCE:
UNICEF 2007**

The Asia Pacific is a vast and diverse region.

As such, the development of genetic programs in the region has been likewise diverse and varied.

Geography



Mongolia

Geography

Philippines

Vietnam

Indonesia





Geography



Philippines
> 7100 islands

Indonesia
> 13 000 islands



Overpopulation









Poverty





Asia Pacific Society of Human Genetics

President – Carmencita Padilla (Philippines)

President Elect – Stephen Lam (Hongkong)

Secretary – MKThong (Malaysia)

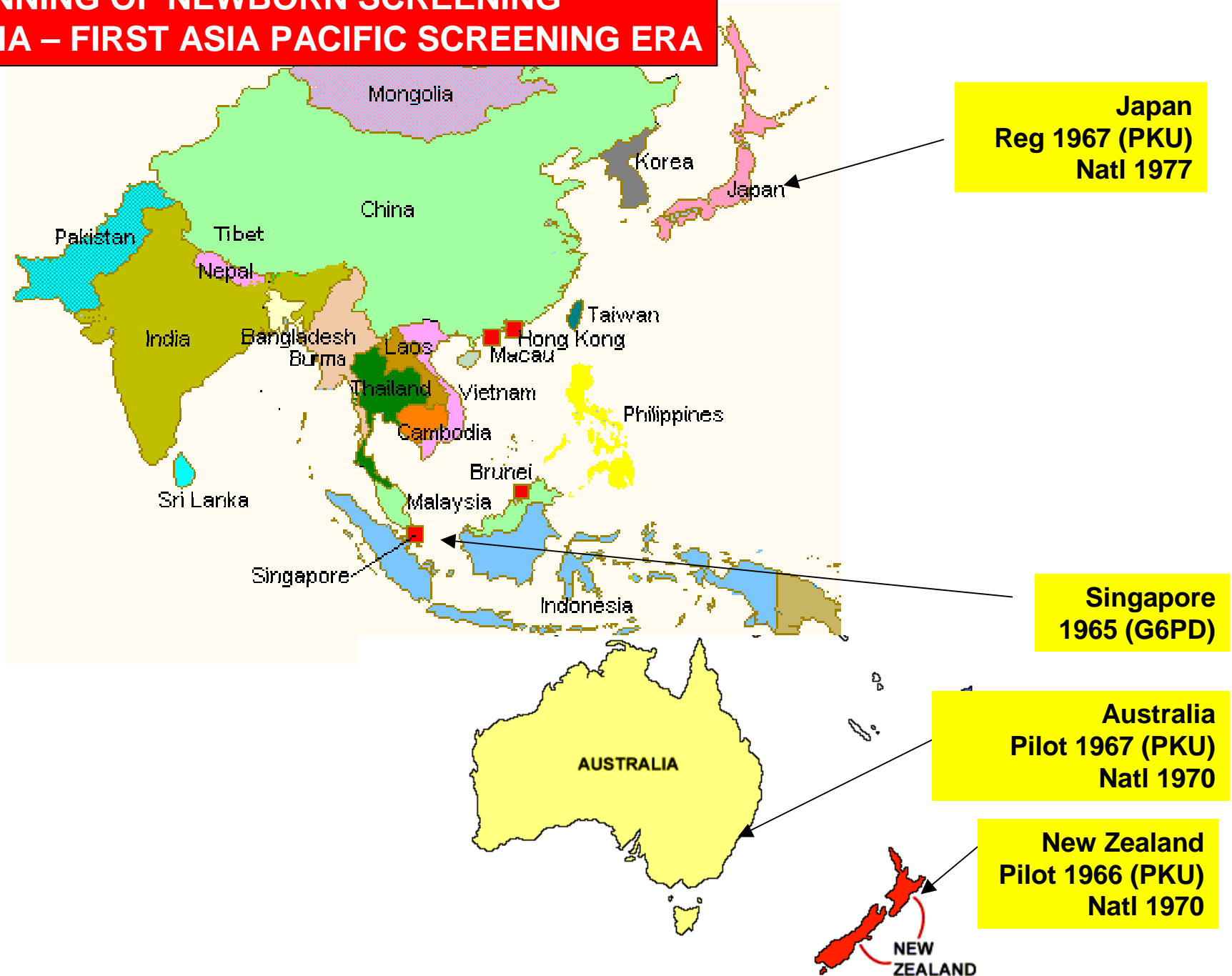
Treasurer – Hai Yang Law (Singapore)

Board of Directors – Taiwan, China, Philippines, Malaysia, Singapore,
Indonesia, Thailand

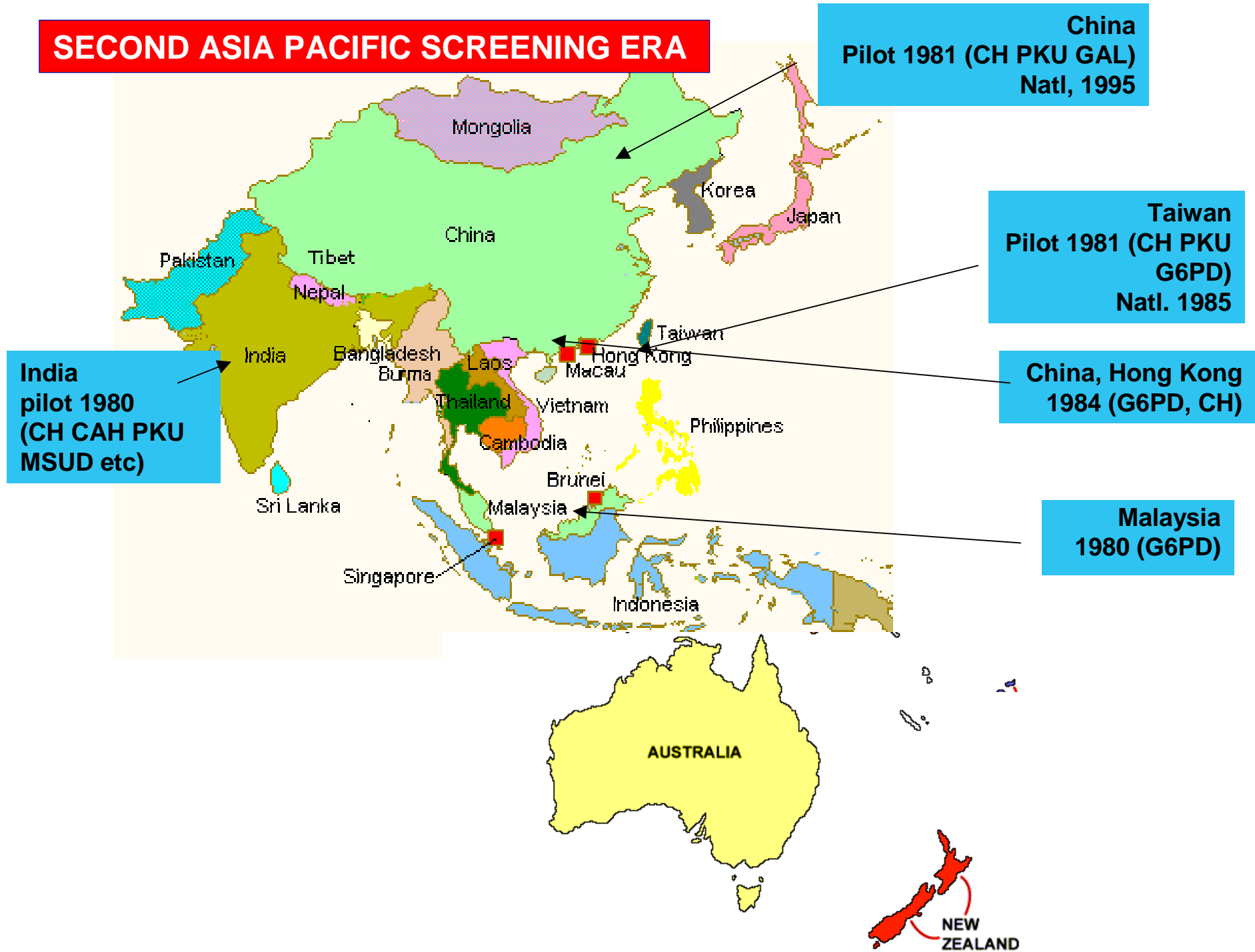
Newborn Screening Services

Bloodspot Newborn Screening
was introduced in '60- '61 by
Dr Robert Guthrie

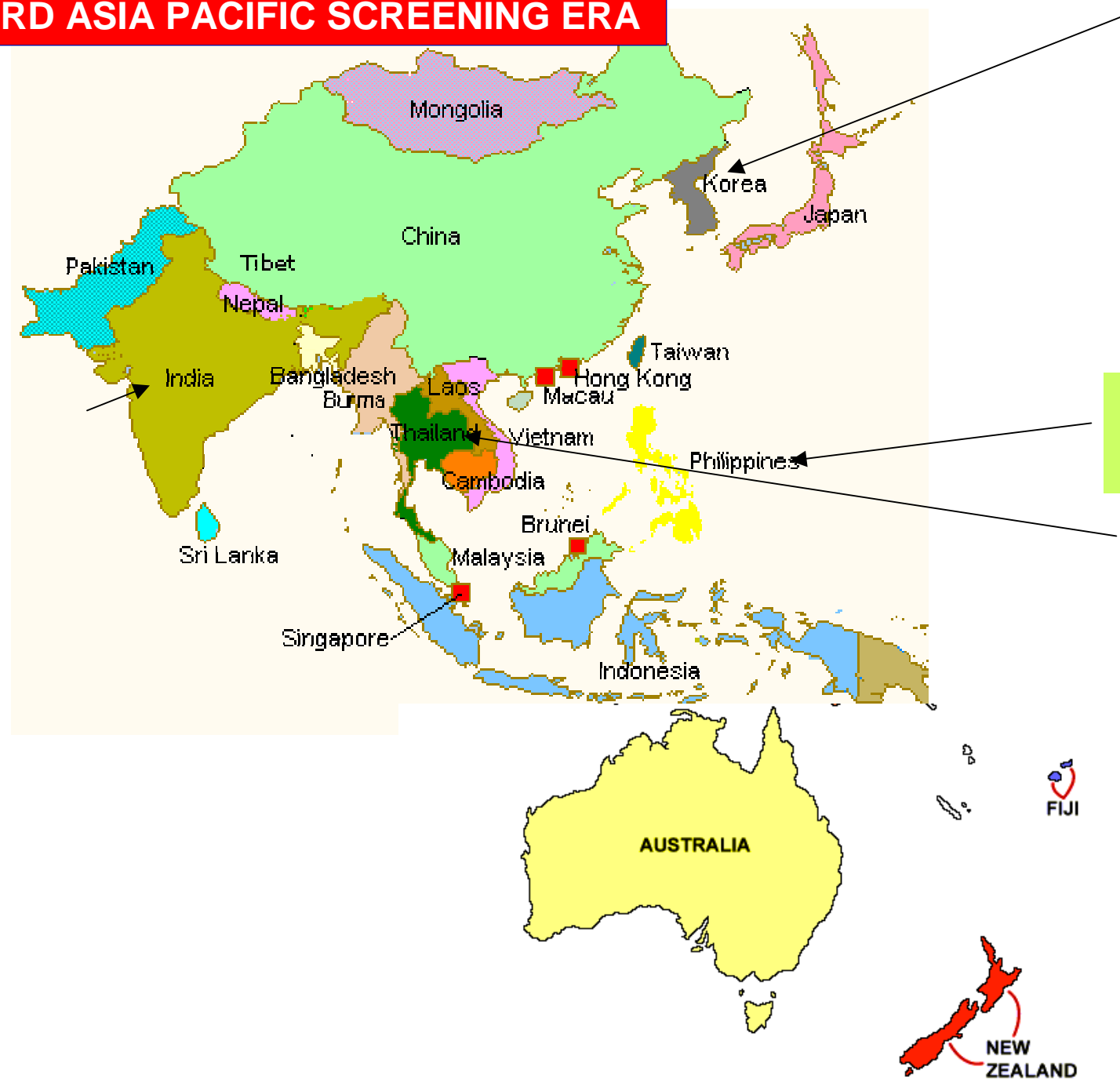
BEGINNING OF NEWBORN SCREENING IN ASIA – FIRST ASIA PACIFIC SCREENING ERA



SECOND ASIA PACIFIC SCREENING ERA



THIRD ASIA PACIFIC SCREENING ERA



**Korea
1991**

**Philippines
1996 pilot
2004 natl**

**Thailand
1991 pilot
1996 natl**

FOURTH ASIA PACIFIC SCREENING ERA

Mongolia Pilot 1999

Pakistan pilot 2006

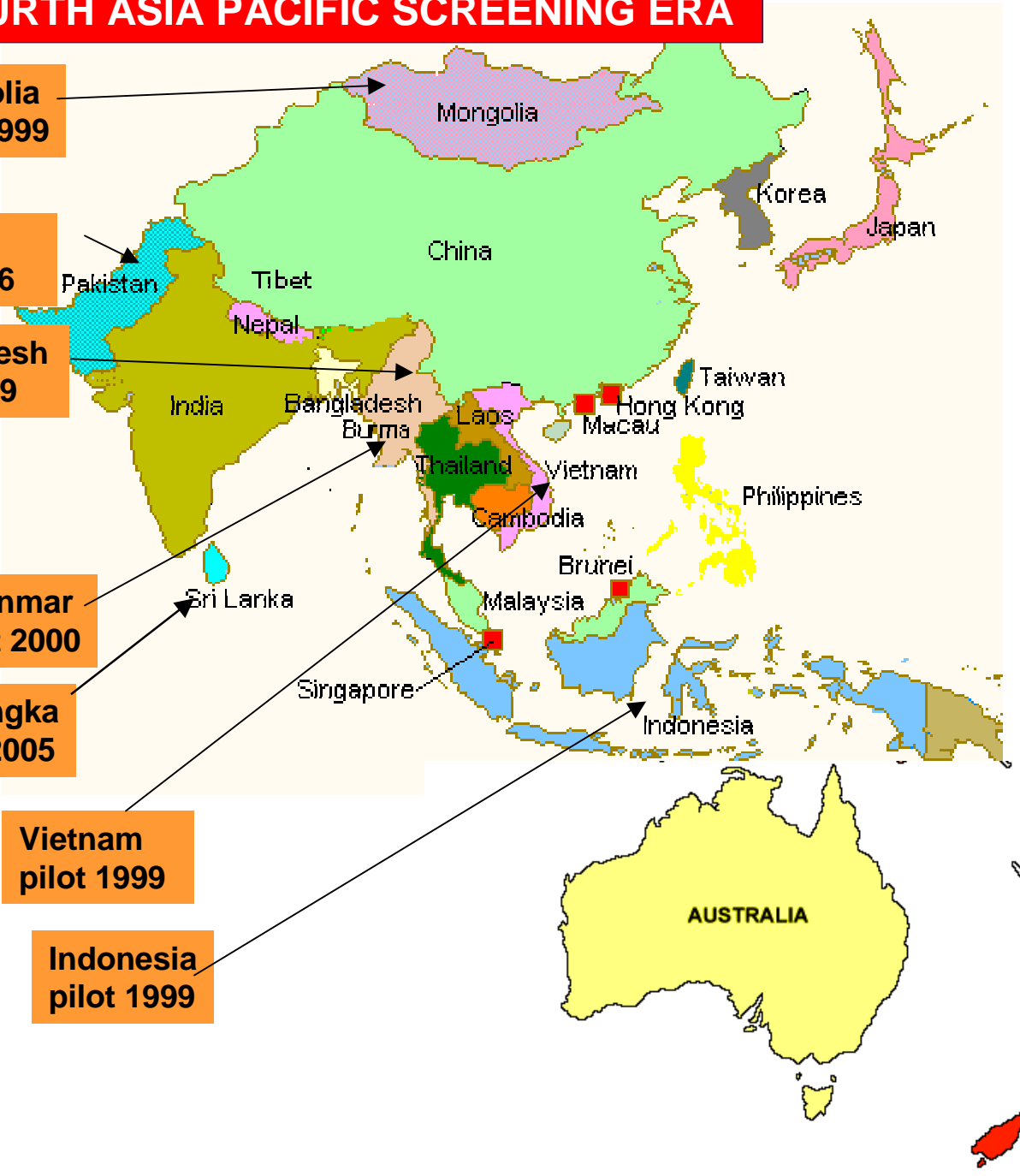
Bangladesh Pilot 1999

Myanmar pilot 2000

Sri langka Pilot 2005

Vietnam pilot 1999

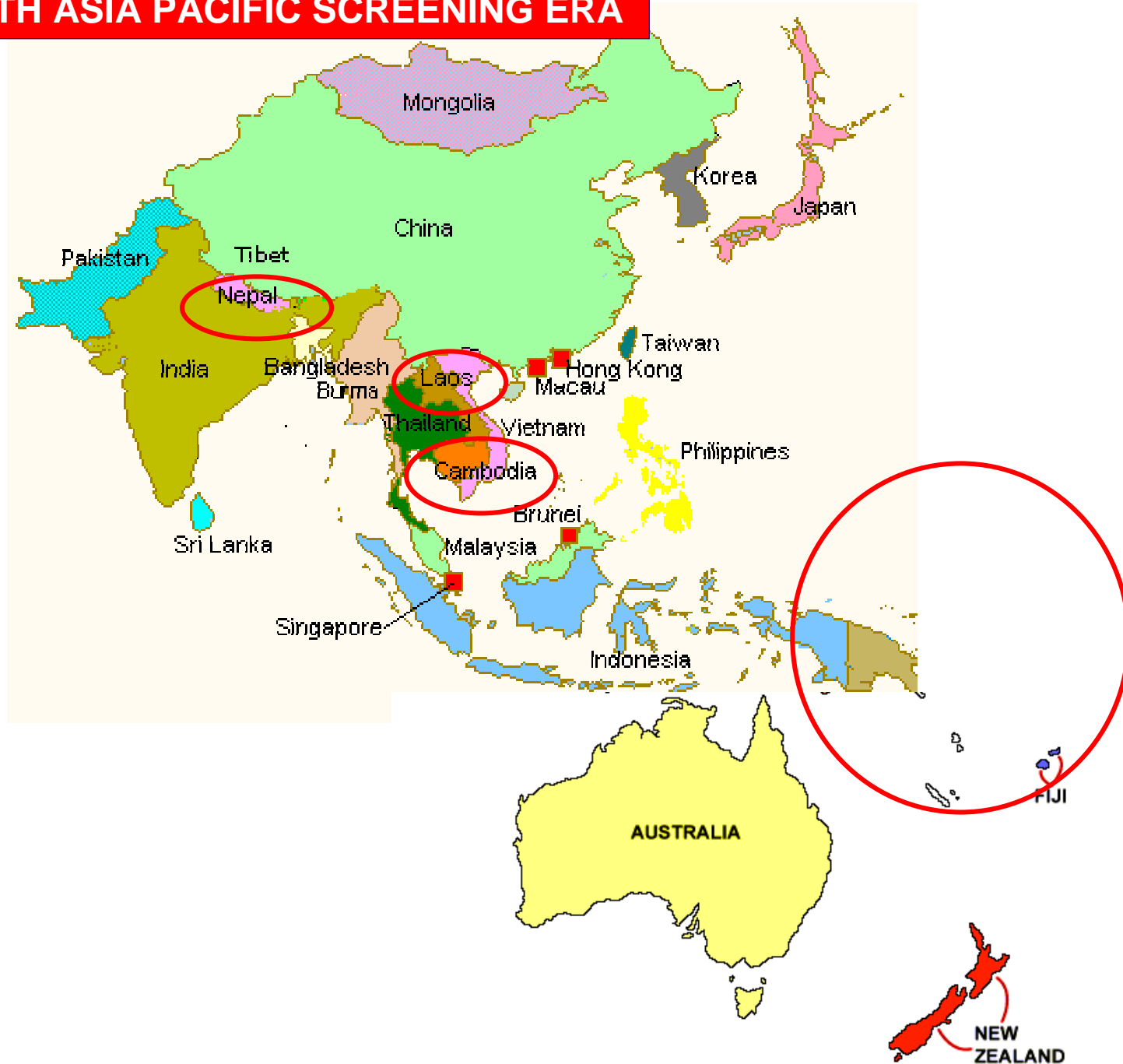
Indonesia pilot 1999



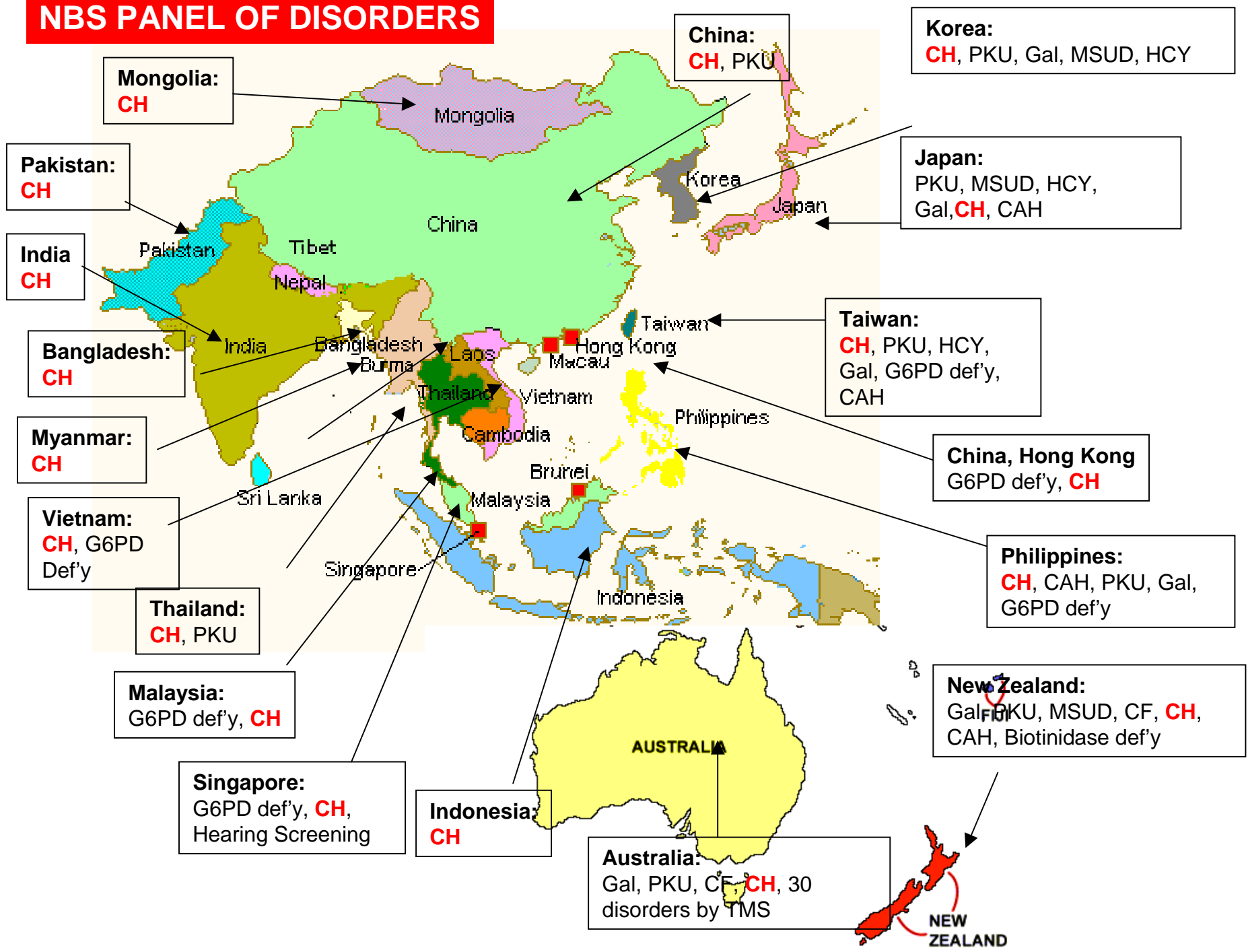
FIJI

NEW ZEALAND

FIFTH ASIA PACIFIC SCREENING ERA



NBS PANEL OF DISORDERS



Integration in the health delivery system

| COUNTRY | ANNUAL BIRTH* | INFANT MORTALITY RATE -/1000* | YEAR NEWBORN SCREENING STARTED | COVERAGE |
|-----------------|----------------------|--------------------------------------|---------------------------------------|-----------------|
| Singapore | 39, 000 | 1.0 | 1965 | >99% |
| Japan | 1,162,000 | 2 | 1967 pilot; 1977 natl | >99% |
| Hong Kong China | 50,000 | 2.9 | 1984 | >99% |
| Korea, South | 457,000 | 3 | 1991 pilot; 1997 natl | 94.2% |
| New Zealand | 54,000 | 4 | 1966 pilot; 1970 natl | 100% |
| Australia | 250,000 | 5 | 1967 pilot; 1970 natl | 100% |
| Malaysia | 547,000 | 5 | 1980 | 95% |
| Taiwan | 200,000 | 5.5 | 1981 pilot; 1985 natl | >99% |
| Sri Lanka | 329 000 | 11 | 2005 pilot | <1% |
| Thailand | 1,009,000 | 13 | 1991 pilot; 1996 natl | 97% |
| Vietnam | 1,648,000 | 15 | 2000 pilot | <1% |
| Philippines | 2,018,000 | 15 | 1996 pilot; 2004 natl | 20% |
| Indonesia | 4,495,000 | 18 | 1999 pilot | <1% |
| China | 17,310,000 | 21 | 1981 pilot | 25% |
| Mongolia | 58,000 | 26 | 1999 pilot | <1% |
| Myanmar | 976 000 | 40 | 2000 pilot | <1% |
| India | 25,926,000 | 43 | 1980 pilot | <1% |
| Bangladesh | 3,747,000 | 54 | 1999 pilot | <1% |
| Pakistan | 4,773,000 | 57 | 2006 pilot | <1% |

Coverage of Screening in Asia

Currently in Asia, only 10% of annual births are offered newborn screening.

Current Scenario for CH

Annual Births in Asia – 66.5 Million

Incidence of CH - 1:3000 (22 200 new cases)

Incidence of CH in iodine deficient areas – 1:500
to 1: 1 000

New CH cases every year – 33 250 to 66 500

Obstacles

- Population and no of births
- General health priorities
- Geography/Logistics
- Home Deliveries
- Lack of government involvement
- Funding

Enabling Factors

- Private-Public Partnership
- Leadership from the private sector or academe



Consolidating Newborn Screening Efforts in the Asia Pacific, May 2008

Countries without screening or less than 50% participated to explore strategies to introduce or increase coverage – Bangladesh, Pakistan, Indonesia, Sri Lanka, India, Philippines, China, Palau, Mongolia

Newborn screening in the Asia Pacific region

Carmencita D. Padilla · Bradford L. Therrell

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Summary The success of blood spot newborn screening in the USA led to early screening efforts in parts of the Asia Pacific Region in the mid-1960s. While there were early screening leaders in the region, many of the countries with depressed and developing economies are only now beginning organized screening efforts. Four periods of screening growth in the Asia Pacific region were identified. Beginning in the 1960s, blood spot screening began in New Zealand and Australia, followed by Japan and a cord blood screening programme for G6PD deficiency in Singapore. In the 1980s, established programmes added congenital hypothyroidism and new programmes developed in Taiwan, Hong Kong, China (Shanghai), India and

Malaysia. Programmes developing in the 1990s built on the experience of others developing more rapidly in Korea, Thailand and the Philippines. In the 2000s, with limited funding support from the International Atomic Energy Agency, there has been screening programme development around detection of congenital hypothyroidism in Indonesia, Mongolia, Sri Lanka, Myanmar and Pakistan. Palau has recently contracted with the Philippine newborn screening programme. There is little information available on newborn screening activities in Nepal, Cambodia, Laos and the other Pacific Island nations, with no organized screening efforts apparent. Since approximately half of the births in the world occur in the Asia Pacific Region, it is important to continue the ongoing implementation and

Screening of Newborns for Congenital Hypothyroidism

Guidance for Developing Programmes



Therrell BL and
Padilla CD

2005

Genetic Services in Asia

| COUNTRY | ANNUAL BIRTH* | INFANT MORTALITY RATE -/1000* | NEWBORN SCREENING COVERAGE | CLINICAL/LAB GENETIC SERVICES |
|-----------------|----------------------|--------------------------------------|-----------------------------------|--------------------------------------|
| Singapore | 39, 000 | 1.0 | >99% | YES |
| Japan | 1,162,000 | 2 | >99% | YES |
| Hong Kong China | 50,000 | 2.9 | >99% | YES |
| Korea, South | 457,000 | 3 | 94.2% | YES |
| New Zealand | 54,000 | 4 | 100% | YES |
| Australia | 250,000 | 5 | 100% | YES |
| Malaysia | 547,000 | 5 | 95% | YES |
| Taiwan | 200,000 | 5.5 | >99% | YES |
| Sri Lanka | 329 000 | 11 | <1% | - |
| Thailand | 1,009,000 | 13 | 97% | YES |
| Vietnam | 1,648,000 | 15 | <1% | Lab only? |
| Philippines | 2,018,000 | 15 | 16% | YES |
| Indonesia | 4,495,000 | 18 | <1% | - |
| China | 17,310,000 | 21 | 25% | Lab only? |
| Mongolia | 58,000 | 26 | <1% | - |
| Myanmar | 976 000 | 40 | <1% | - |
| India | 25,926,000 | 43 | <1% | YES |
| Bangladesh | 3,747,000 | 54 | <1% | - |
| Pakistan | 4,773,000 | 57 | <1% | - |

Planned Regional Activities of the APSHG (2008-2010)

- Inventory of Genetic Services (personnel and laboratory)
- Survey on Ethics/Cultural effects on Practice of Genetics
- Workshops on the following topics
 - Newborn Screening
 - Metabolic Genetics
 - Statistics in Genetics
 - Bioinformatics
 - Molecular Diagnostics

Planned Regional Activities of the APSHG (2008-2010)

- Regional working groups for data sharing and drafting recommendations for common genetic conditions in the Asia Pacific
 - Down Syndrome – Pornswan Wasant
 - Newborn Screening – Carmencita Padilla
 - Birth Defects – MK Thong
 - G6PD – Suthat Focharoen
 - Metabolic Disorders – Pornswan Wasant
- Genomic studies for specific disorders in the Asia Pacific region (Pan Asian Consortium)



Genetic Services in the Philippines



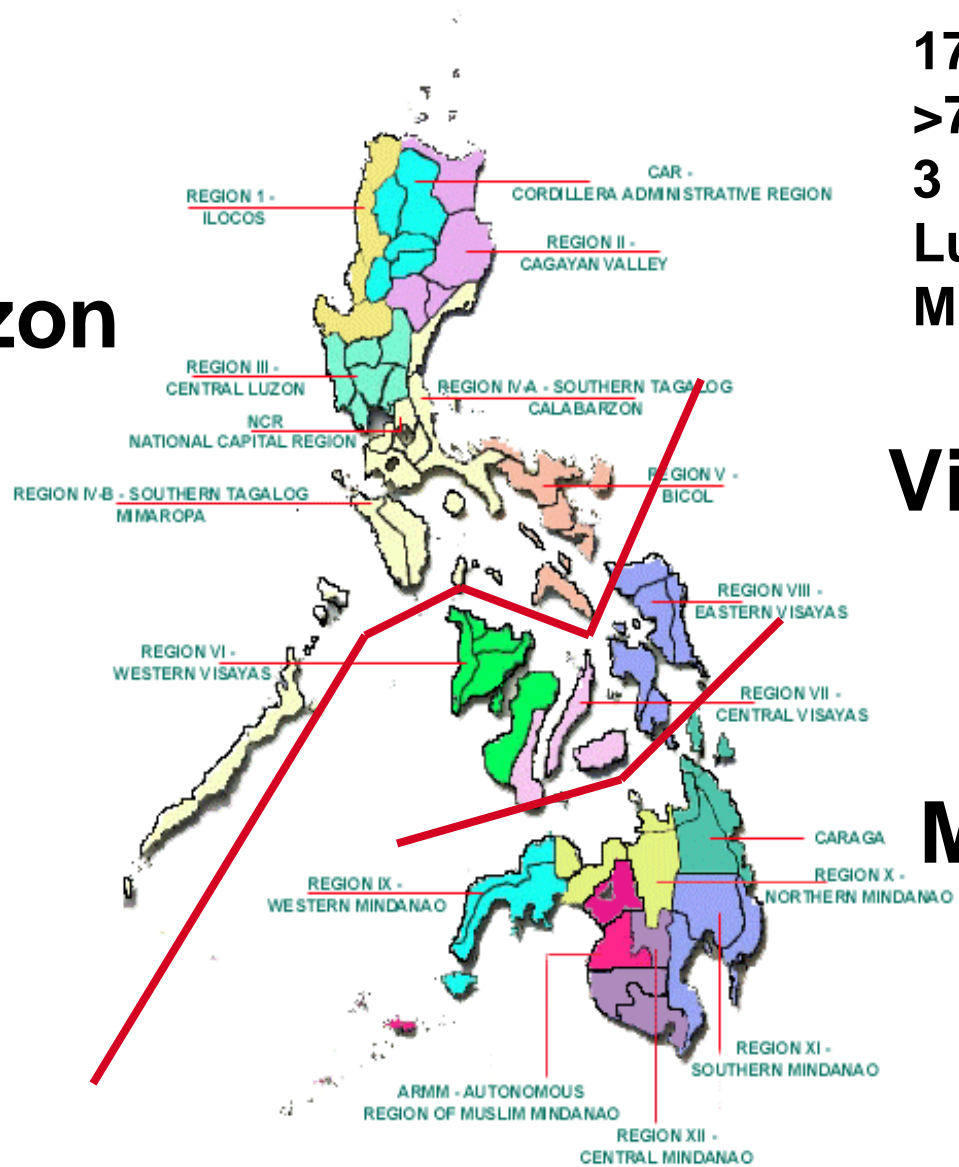
Manila

Population of 80 million
50% of population are children
2 million newborns a year



NBS MAP OF THE PHILIPPINES

Luzon



17 political regions

>7000 islands

**3 major island groups –
Luzon, Visayas and
Mindanao**

Visayas

Mindanao





Institute of Human Genetics - National Institutes of Health

College of Medicine

Institute of Human Genetics

Hospital Proper

Out Patient Dept



Philippine General Hospital

Institute of Human Genetics



The **Institute of Human Genetics** is a center dedicated to making genetic testing available and accessible to Filipinos all over the country.

VISION

A center committed towards the control of genetically-related deaths and disabilities.

MISSION

Promotion of health by understanding the genetic basis of common diseases in the Filipino population through basic and clinical research.

Provision of services that will allow definitive diagnosis and early detection of potentially treatable genetic conditions.

Implementation of **educational programs** to **increase awareness of physicians and the general public** with regard to common genetic conditions and their prevention.



Institute of Human Genetics Staff

Major Components

- Clinical Services (Philippine General Hospital for both in patient and out patients)
- Cytogenetics laboratory (NIH)
- Newborn Screening Unit (NIH)
- Molecular Genetics Unit (NIH)
- Biochemical Genetics Unit (NIH)
- Training
 - Fellowship program for Clinical Genetics (2 year program)
 - Rotation of Pediatric Residents
 - Elective for Students
 - Rotation for OB and Pediatric Residents of other schools (upon request)

Registries

- Birth Defects Registry (project with MOD)
- Oral Cleft Registry (joint project of ENT and plastic surgeons)
- Metabolic Registry (NIH)

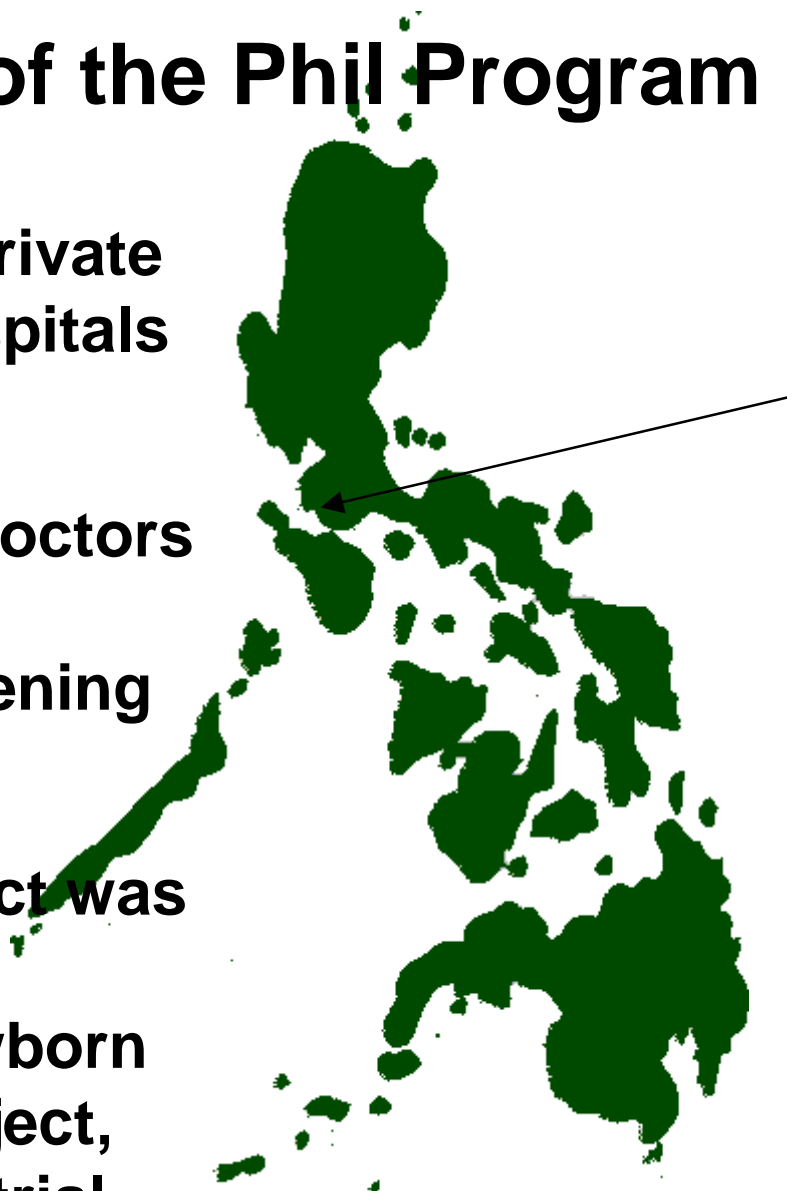
Newborn Screening

Highlights of the Phil Program 1996

Started in 18 private and 6 govt hospitals in 1996

The group of doctors comprised the Newborn Screening Study Group

The pilot project was named the Philippine Newborn Screening Project, a multi-center trial.



24 hosp

METRO MANILA

- Capitol Medical Center
- Cardinal Santos Medical Center
- Children's Medical Center
- Chinese General Hospital
- De Los Santos Medical Center
- Dr. Jesus Delgado Memorial Hospital
- Dr. Victor R. Potenciano Medical Center
- FEU-NRMF
- Hospital of the Infant Jesus
- Jose Reyes Medical Center
- Las Pinas Integrated District Hospital
- Makati Medical Center
- Manila Doctors Hospital
- Manila Sanitarium and Hospital
- Mary Chiles General Hospital
- Mary Johnston Hospital, Inc.
- MCU-FDTMF
- Medical Center Manila
- Metropolitan Hospital
- MPI-Medical Center Muntinlupa
- National Children's Hospital
- Olivares General Hospital
- Ospital ng Maynila
- Our Lady of Lourdes Hospital
- Perpetual Help Medical Center
- Philippine Children's Medical Center
- Philippine General Hospital
- Quezon City General Hospital
- Quezon City Medical Center
- Quirino Memorial Medical Center
- Rizal Medical Center
- San Juan Medical Center
- Santo Tomas University Hospital
- St. Luke's Medical Center
- St. Martin de Porres Hospital
- The Medical City
- UERMMMC
- United Doctors Medical Center

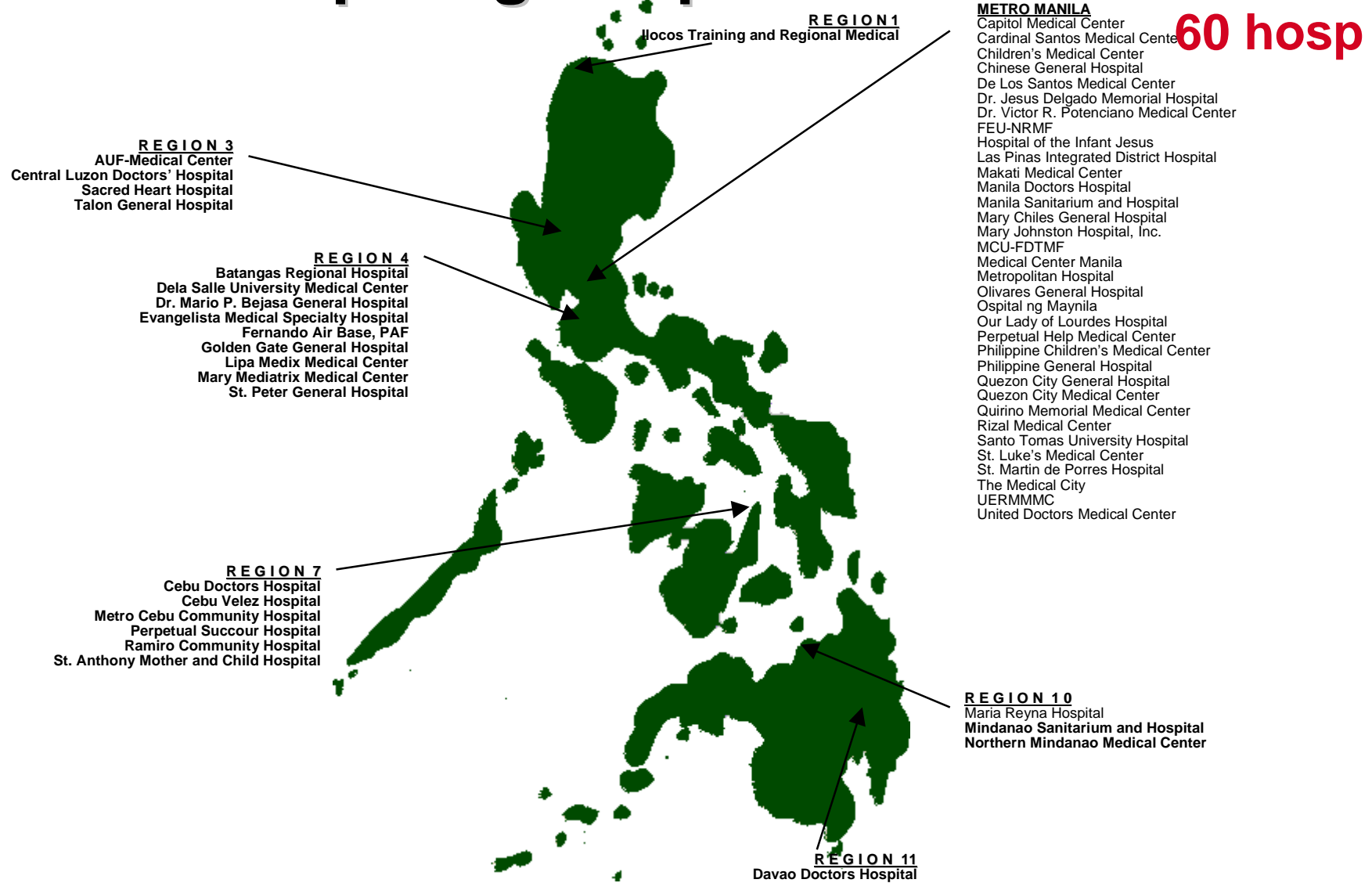
Highlights of the Phil Program

1998 – **Research** data/output given to the Dept of Health (DOH)

1999 – DOH created a Task Force

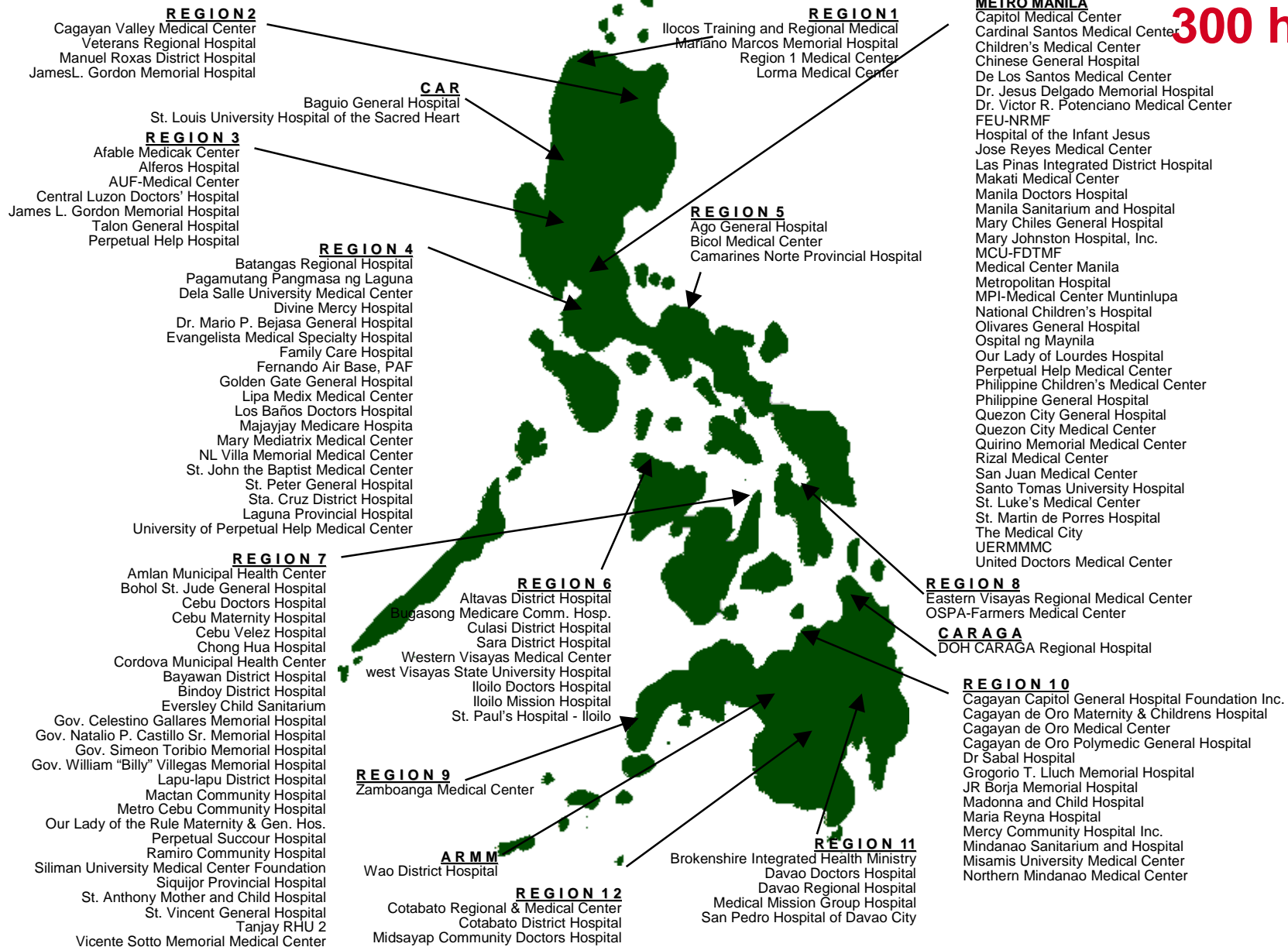
2000 – DOH created a National Technical Working Group (NTWG) to oversee the nationwide implementation

Participating Hospitals as of 1999



Participating Hospitals as of 2002

300 hosp



Highlights of the Phil Program

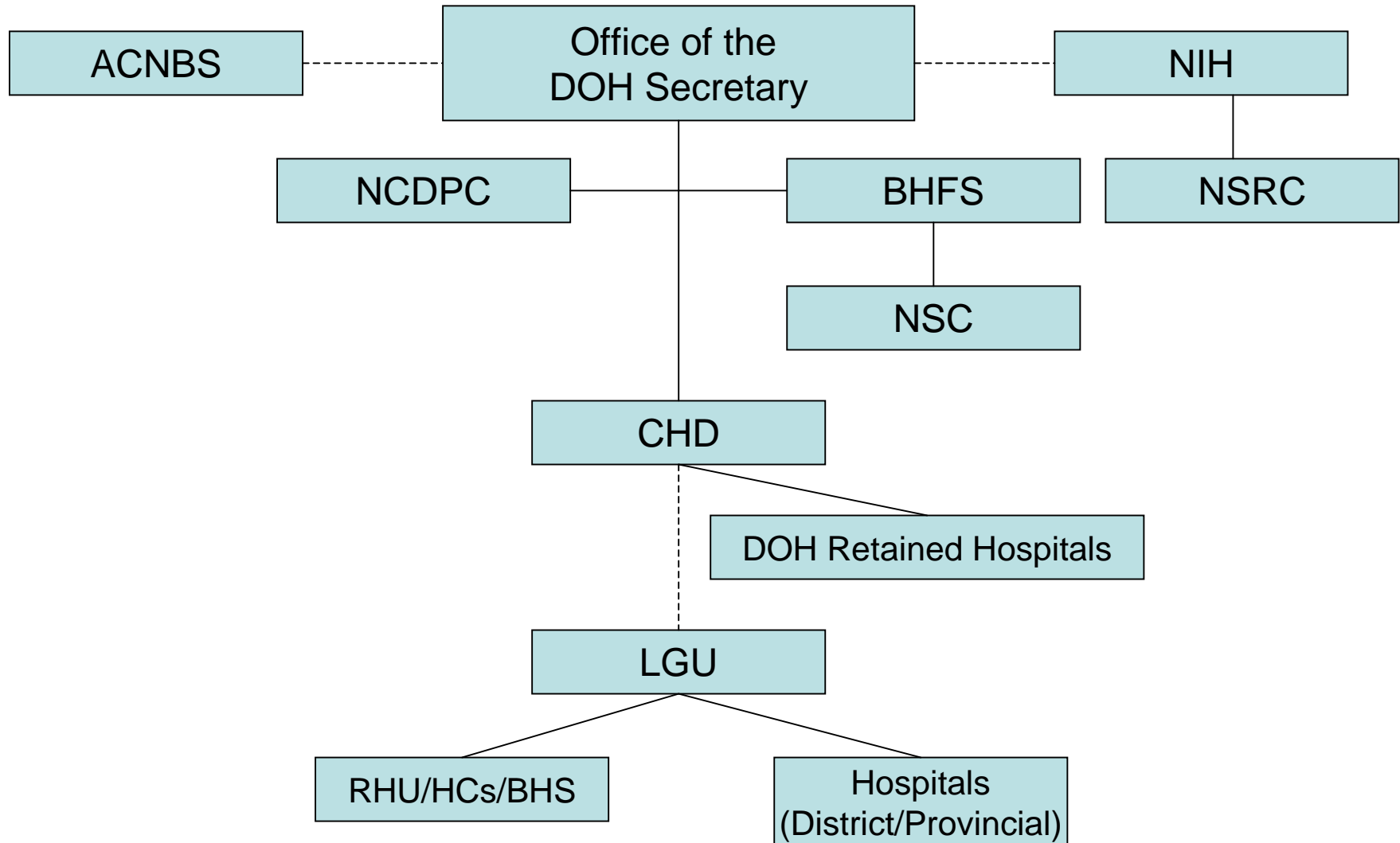
2003 – Presidential Proclamation declaring the 1st week of Oct as Newborn Screening Week

2004 – Newborn Screening Act of 2004
(Newborn Screening Law)

Cost Benefit Analysis

2006 - NBS required in licensing requirement of the hospitals

National Comprehensive Newborn Screening System OrgChart



NBS MAP OF THE PHILIPPINES

NSF as of MAY 2006 -> 925

REGION 4

- Batangas Regional Hospital
- Pagamatang Pangnasa ng Laguna
- Dela Salle University Medical Center
- Divine Mercy Hospital
- Dr. Mario P. Bejasa General Hospital
- Evangelista Medical Specialty Hospital
- Family Care Hospital
- Fernando Air Base, PAF
- Golden Gate General Hospital
- Lipa Medix Medical Center
- Los Baños Doctors Hospital
- Majayjay Medicare Hospita
- Mary Mediatrix Medical Center
- NL Villa Memorial Medical Center
- St. John the Baptist Medical Center
- St. Peter General Hospital
- Sta. Cruz District Hospital
- Laguna Provincial Hospital
- University of Perpetual Help Medical Center
- Batangas Provincial Hosp.
- Calapan City Health & Sanitation Dept.
- Gen. Emilio Aguinaldo Mem. Hosp.
- Jomalig Rural Health UTM
- Magsaysay Mem. Dist. Hosp.
- Mahal na Virgen Ma. Sto. Rosario Dist. Hosp.
- Martin Marasigan Mem. Hosp.
- Nagcarlan Dist. Hosp.
- Quezon Memorial Hosp.
- San Jose Dist. Hosp. - Batangas
- San Jose Dist. Hosp. - Occ. Mindoro
- UPLB Health Service
- Panlalawigan Pagamatun ng Laguna
- Antipolo City Medical Hosp.
- Antipolo Doctors Hosp.
- Balibago Polyclinic & Hosp.
- Batangas Health Care Hosp.
- Bauan Doctors General Hosp.
- Biñan Doctors Hosp.
- C.P. Reyes Hosp.
- Calamba Doctors Hosp.
- Calamba Medical Center
- Cavite Medical Cente
- Celis Maternity Clinic
- Clinica Miranda Lying In
- Community Hosp of SPC
- Daniel Mercado Hosp.
- Divine Love General Hosp.
- DLSU-Dr. Rodolfo Poblete Mem. Hosp
- Dr. Jose Rizal National Medical Research
- Dr. Romeo Isara Rosales Gen. Hosp.
- Estrella Hosp.
- First Filipino Saint Hosp.
- Gamez Hospital
- Gonzales Medical & Children's Hosp.
- Holy Family Medical Clinic
- Immaculate Concepcion Hosp.
- Laguna Doctors Hosp.
- Lipa Doctors Hosp.
- Lopez St. Jude General Hosp.
- Lucena MMG General Hosp.
- Lucena United Doctors Hosp.
- Ma. Estrella General Hosp.
- Manila East Medical center
- Medical Mission Group of Oriental Mindoro
- Metro South Medical Center
- Molave Doctors Hosp.
- Mt. Carmel Diocesan Gen. Hosp.
- Naic Doctors Hosp.
- Nasugbu Doctors Gen. Hosp.
- Ospital ng Tagayay
- Our Lady of Calasasay
- Our Lady of the Pillar Medical Center
- Palma-Malabanan Hosp.
- Panamra Medical Center
- Perpetual Succor Hosp & Maternity
- Peter Paul Philippine Corporation Hosp.
- Pinamalayan Doctors Hosp
- Queen Mary Help of Christians
- Rugay Maternity and General Hosp.
- Saint Martin Maternity & Pediatric Hosp
- Saint Patrick's Hosp Medical Center
- San Diego de Iacala General Hosp
- San Pablo Doctors Hosp
- Santisima Trinidad Hosp
- SPC Medical center
- St. Anne General Hospital
- St. Dominic Medical Center
- St. Francis Medical Center
- St. James Hosp.
- St. John the Baptist Medical center
- Sto. Tomas General Hosp.
- Sto. Rosario Hosp.
- St. Francis & Paul General Hosp.
- Taal Polymedic Hosp.
- Tayabas Community Hosp.
- Unciano Medical center
- Untalan General Hospital

REGION 3

- Afable Medicaac Center
- Alferos Hospital
- AUF-Medical Center
- Central Luzon Doctors' Hospital
- James L. Gordon Memorial Hospital
- Talon General Hospital
- Perpetual Help Hospital
- Bulacan Maternity and Children's Hosp.
- Bulacan Provincial Hospital
- Jose B. Lingad Mem. Regional Hosp.
- La Paz Medicare & Community Hosp.
- San Marcelino District Hosp.
- Heart of Jesus Hosp.
- Immaculate Conception Polyclinic Hosp.
- Isaac & Catalina Medical Center
- Jecsons Medical Center
- Malolos Maternity Hosp. & Eye Care
- Mary Immaculate Maternity Hosp
- Mary the Queen Maternity
- Mother & Child Hosp
- Nazarenes College Found. Hosp.
- Nueva Ecija Doctor's Hospital
- Our Lady of Mt. Carmel Medical
- Plaridel Emergency Hosp.
- Premiere General Hosp.
- Ramos General Hospital
- Rosario Memorial Hospital
- Rugay Maternity
- San Fernando Hosp.
- Santisima Trinidad Hosp.
- St. Jude Family Hosp.
- St. Paul Hosp.
- Sto. Niño Hospital
- Talon General Hosp.
- V.L. Makabali Mem. Hosp.
- Women's Hospital

REGION 7

- Amlan Municipal Health Center
- Bohol St. Jude General Hospital
- Cebu Doctors Hospital
- Cebu Maternity Hospital
- Cebu Velez Hospital
- Chong Hua Hospital
- Cordova Municipal Health Center
- Bayawan District Hospital
- Bindoy District Hospital
- Eversley Child Sanitarium
- Gov. Celestino Gallares Memorial Hospital
- Gov. Natalio P. Castillo Sr. Memorial Hospital
- Gov. Simeon Toribio Memorial Hospital
- Gov. William "Bily" Villegas Memorial Hospital
- Sapugay District Hospital
- Mactan Community Hospital
- Metro Cebu Community Hospital
- Our Lady of the Rule Maternity & Gen. Hos.
- Perpetual Succor Hospital
- Ramiro Community Hospital
- Silman University Medical Center Foundation
- Siquijor Provincial Hospital
- St. Anthony Mother and Child Hospital
- St. Vincent General Hospital
- Tanjay RHU 2
- Vicente Sotto Memorial Medical Center

REGION 9

- Zamboanga Medical Center
- Zamboanga del Sur Cooperative Hosp
- Igano Community Hosp
- J. Cabahug Hosp.
- Pagadian City Medical Center

REGION 1

- Ilocos Training and Regional Medical
- Mariano Marcos Memorial Hospital
- Region 1 Medical Center
- Lorma Medical Centre
- Abra Provincial Hospital
- Carasi Rural Health Unit
- Bethany Hospital
- Dagupan Doctors
- Divine Mercy Foundation
- Eguira General Hospital
- Holy Child General Hospital
- Aruon Medical Center
- Metro Vigan Cooperative Hospital
- Nazareth General Hospital
- Urdaneta Sacred Heart Hospital

REGION 2

- Cagayan Valley Medical Center
- Veterans Regional Hospital
- Manuel Roxas District Hospital
- Aparri Christian Hospital
- Sanitarium and Hospital
- Callang General Hospital
- De Vera's General Hospital
- Isabela Doctors General Hospital
- St. Paul Hospital

METRO MANILA

- Air Force General Hosp.
- AFP Medical Center
- Amang Rodriguez Medical Center
- Alabang Medical Center
- Alabang Medical Clinic
- Alejandro Doctors Medical Clinic
- Amisola Maternity Hospital
- Asian Hospital and Medical Center
- Bernardino General Hospital - I
- Bernardino General Hospital - II
- Calalang General Hospital
- Capital Medical Center
- Cardinal Santos Medical Center
- Children's Medical Center
- Chinese General Hospital
- Cattleya Well Family Clinic
- Christ the King Maternity and Lying In Ho
- De Los Santos Medical Center
- Dr. Fe Del Mundo Memorial Medical Center
- Dr. Montano G. Ramos General Hospital
- Dr. Jesus Delgado Memorial Hospital
- Dr. Jose Fabella Memorial Hospital
- Dr. Victor R. Potenciano Medical Center
- Fatima Medical Center
- FEU-NRMF
- Fort Bonifacio General Hosp
- Jose Reyes Medical Center
- General Hospital
- General Miguel Malvar Foundation
- Gat Andres Bonifacio Mem. Medical Center
- HolyLife Health Specialist Clinic and Lying
- Hospital of the Infant Jesus
- Jesus Delgado Memorial Hospital
- J.P. Sison General Hospital and College
- Jose Reyes Medical Center
- Las Pinas Integrated District Hospital
- Las Pinas Doctors Hospital
- Las Piñas City Medical center
- Lazarte Medical Maternity Clinic
- OSPAs-Farmers Medical Center
- Bethany Hospital
- Divine Word Hospital
- Remedios Trinidad Romualdez Hospital

CAR

- Baguio General Hospital
- St. Louis University Hospital of the Sacred Heart
- Far North Luzon General Hospital
- Barlig District Hospital
- Benguet General Hospital
- Bontoc General Hospital
- Itoyan Municipal Hospital
- Juan M. Duyan Mem. Dist. Hosp.
- Kalinga Provincial Hospital
- Pines City Doctors Hosp.

REGION 5

- Ago General Hospital
- Bicol Medical Center
- Camarines Norte Prov'l Hosp
- Eastern Bicol Medical Center
- Dr. Amando Cope Mem. Hosp.
- Mother Seton Hospital
- Sorsogon Medical
- St. Peter & Paul Hosp

REGION 8

- Eastern Visayas Regional Medical Center
- OSPAs-Farmers Medical Center
- Bethany Hospital
- Divine Word Hospital
- Remedios Trinidad Romualdez Hospital

CARAGA

- DOH CARAGA Regional Hospital
- Municipal Health Office, Kitcharao
- Nasipit District Hospital
- Butuan Doctors Hospital
- Manuel J. Santos Hospital

REGION 10

- Cagayan Capitol General Hospital Foundation Inc.
- Cagayan de Oro Maternity & Childrens Hospital
- Cagayan de Oro Medical Center
- Cagayan de Oro Polymedic General Hospital
- Dr Sabal Hospital
- Grogorio T. Luich Memorial Hospital
- Benji Borja Memorial Hospital
- Madonna and Child Hospital
- Maria Reyna Hospital
- Mercy Community Hospital Inc.
- Mindanao Sanitarium and Hospital
- Misamis University Medical Center
- Northern Mindanao Medical Center
- Mayor Hilaron A. Ramiro Sr. Regional Training
- Gingoog City Health Office
- Bukidnon Provincial Hospital
- Bukidnon Provincial Hospital - Maramag
- Misamis Occidental Provincial Hospital
- Municipal Health Center of Maramag
- Bethel Baptist Hospital
- Caminquin General Hospital
- Faith Hospital
- La Vina General Hospital

REGION 12

- Cotabato Regional & Medical Center
- Cotabato District Hospital
- Midsayap Community Doctors Hospital
- Lanao Del Norte Provincial Hosp
- Gregorio Luich Mem. Hosp
- Cotabato Prov'l Hosp
- Kidapawan Doctors Hospital
- Maranding Community Hosp.
- Mercy Community Hosp.
- Mindanao Sanitarium and Hosp.
- Tubod Community Hosp.

REGION 11

- Davao Doctors Hospital
- Davao Regional Hospital
- Medical Mission Group Hospital
- San Pedro Hospital of Davao City

ARMM

- Wao District Hospital

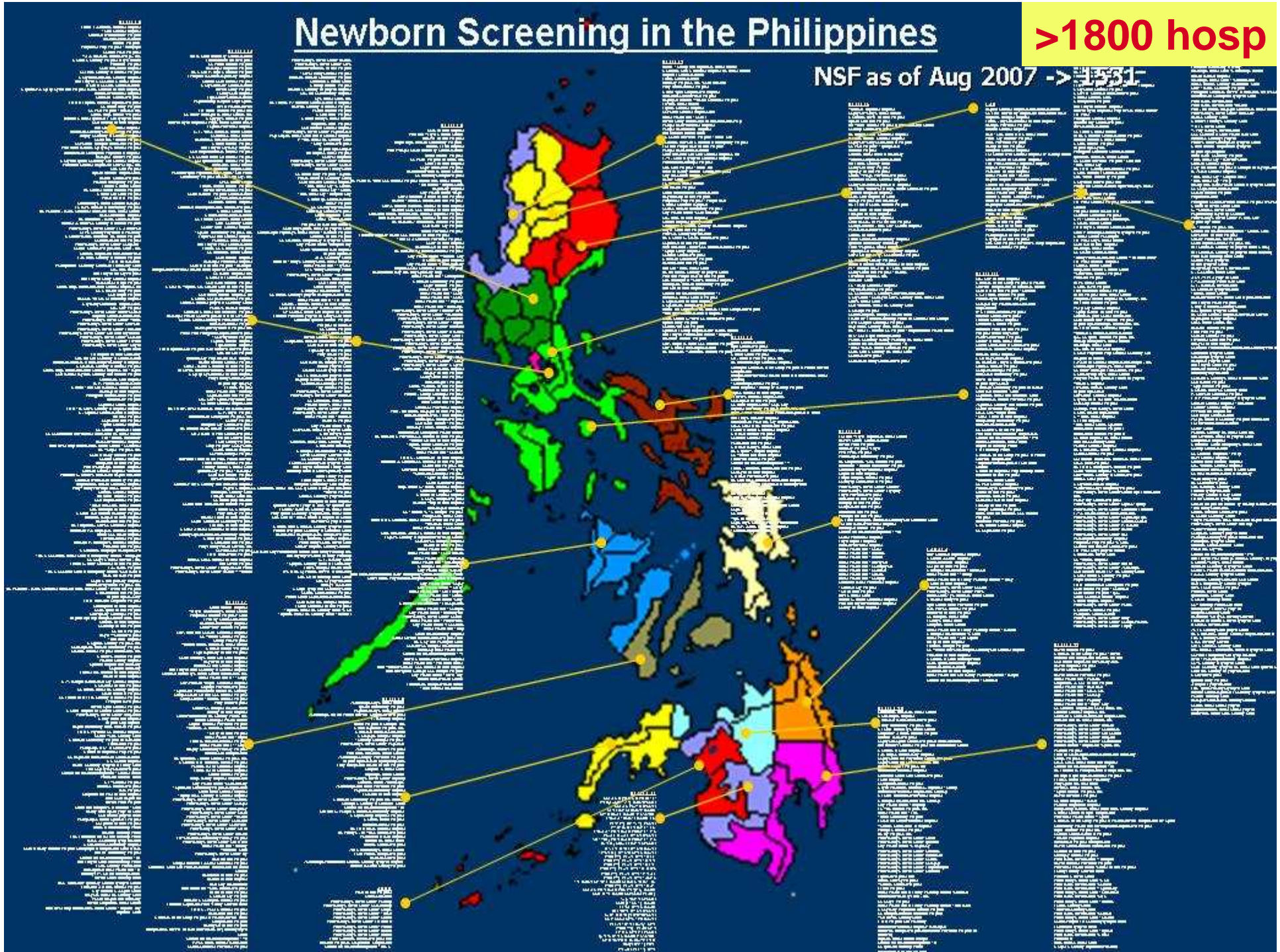
Highlights of the Phil Program

- Dec 2006 - guidelines for coverage of NBS by national health insurance
 - 90% of the NBS will be covered for the membership

Newborn Screening in the Philippines

>1800 hosp

NSF as of Aug 2007 -> 1531



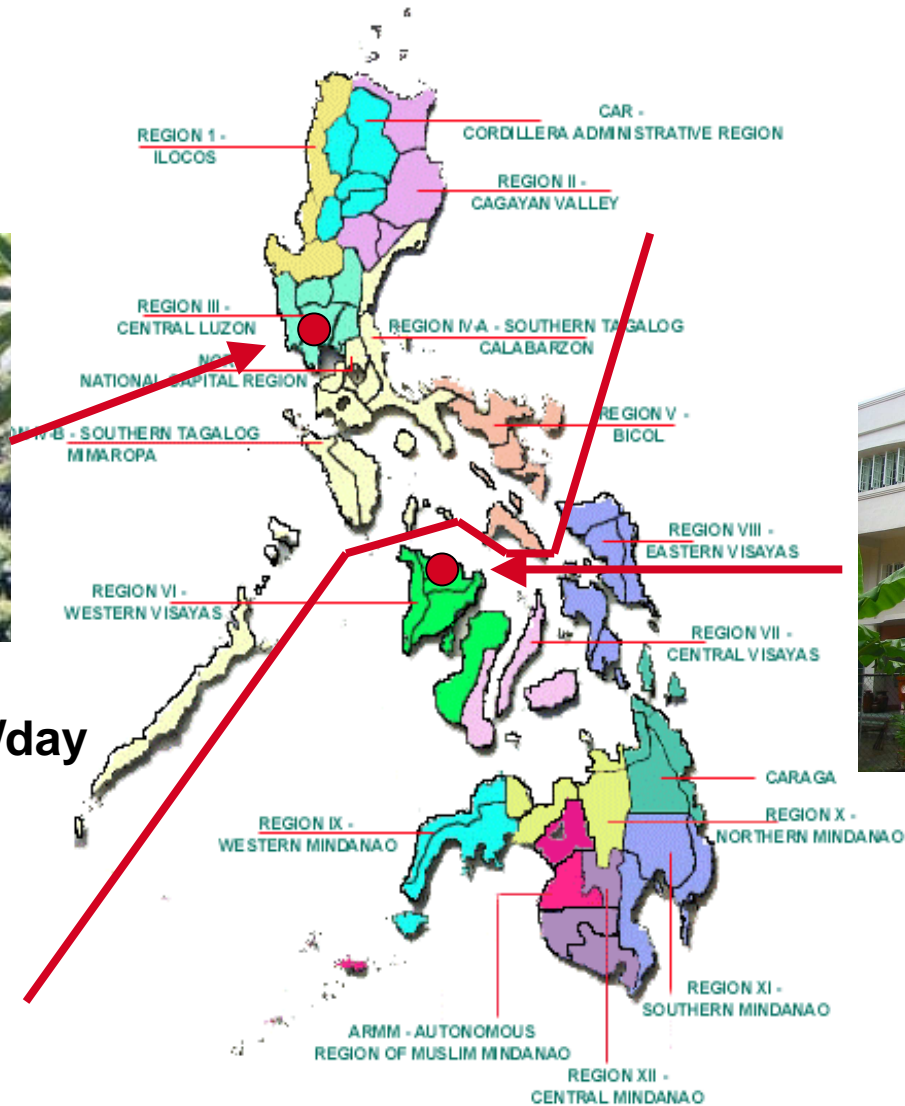
Newborn Screening Laboratories



1997

1000 to 1500 samples/day

1996 - partnered
with Children's
Hospital, Sydney
Australia



2006

500 samples/day



**National Institutes
of Health. Manila**

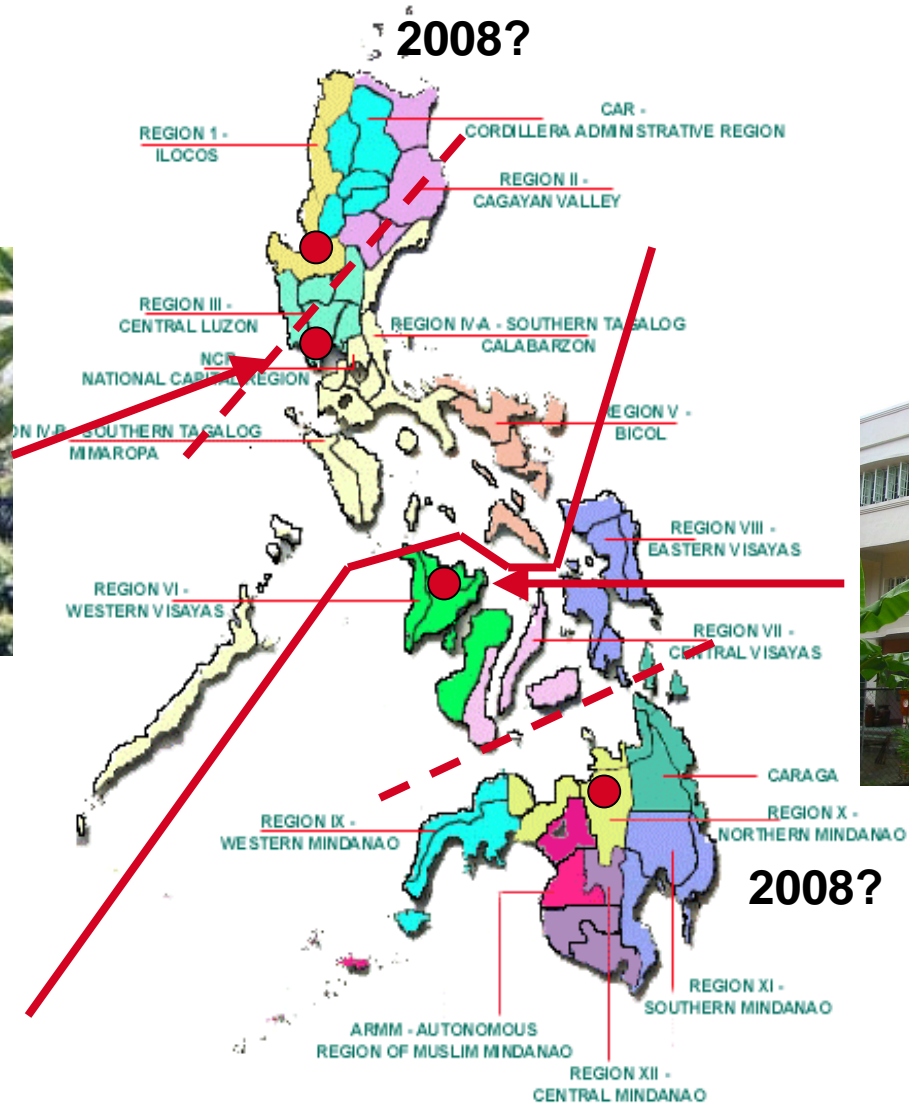
**West Visayas State
University, Iloilo**



Newborn Screening Laboratories



1997



2006

Getting Support from Professionals

- Physicians (pediatricians, obstetricians, family physicians, general physicians)
- Nurses
- Midwives

Neonatologist



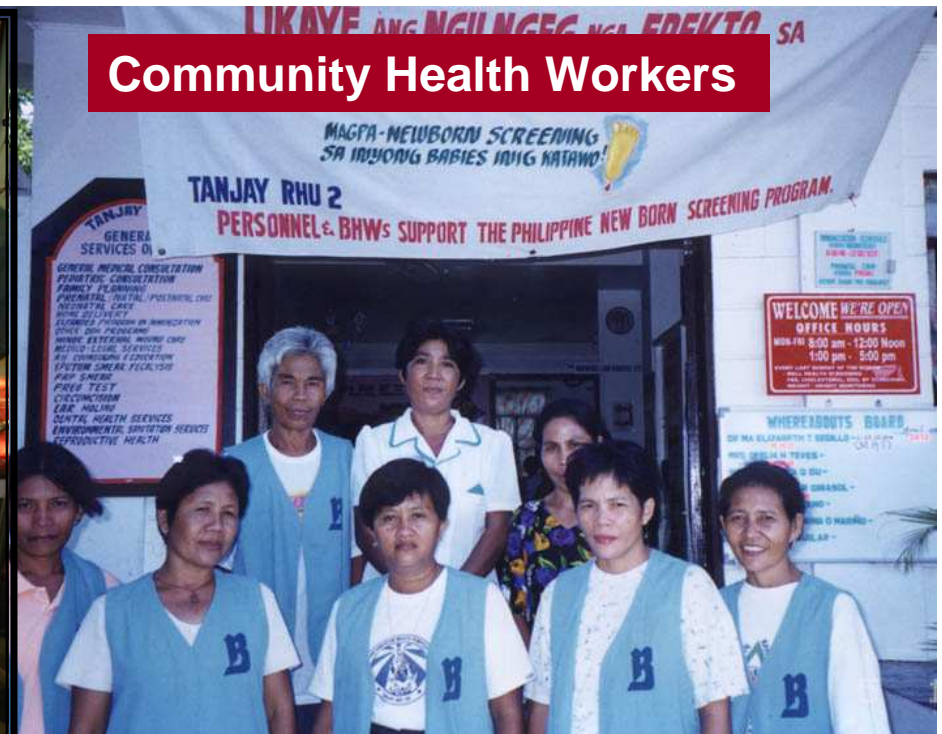
Nurse



Nursery Team



Community Health Workers





Door to door campaign to Obstetricians



Door to door campaign to Pediatricians



Consultation with Endocrinology group, July 2002

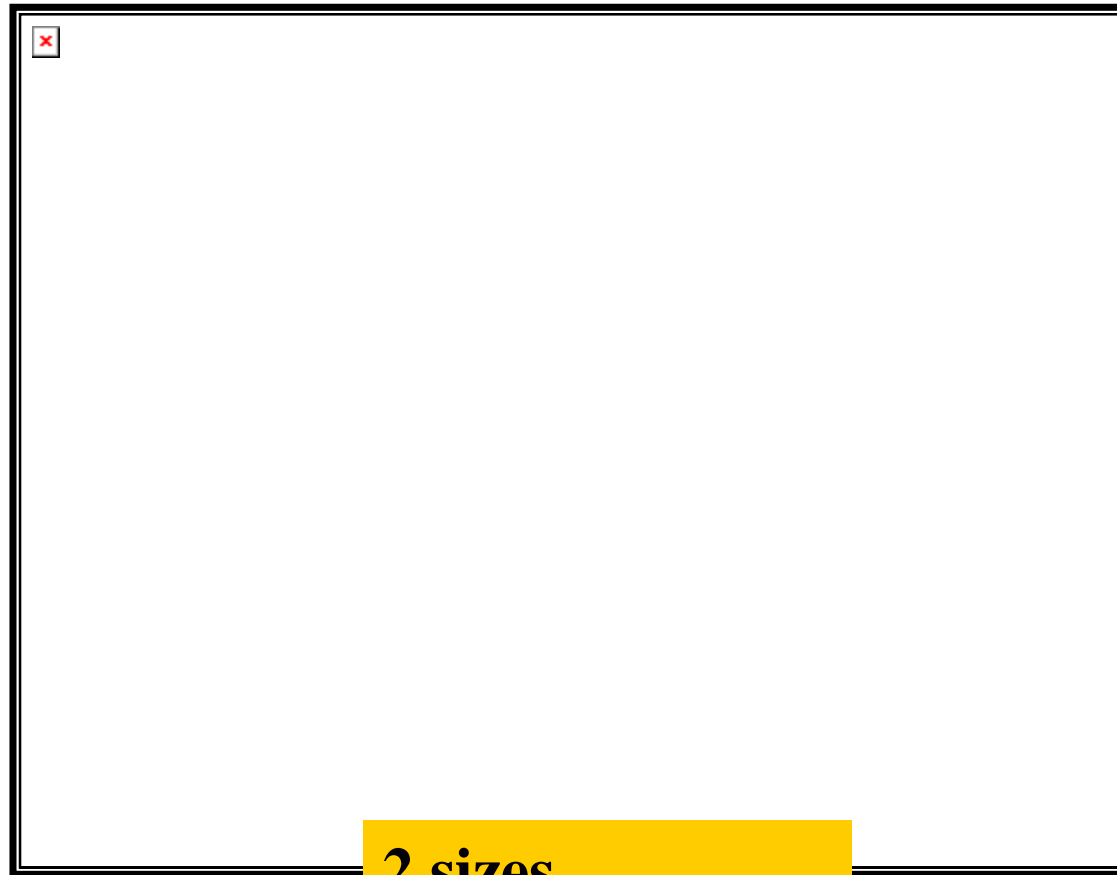


**Awarding Ceremonies for Outstanding Hospital Coverage
October 2007**

Tools for the Practitioners

Health Promotion/Campaign

- Development of advocacy materials for different target groups (Philippines)
 - Flipcharts for health workers



2 sizes

Small size US\$5



Information Materials on Metabolic Disorders

Reaching the Families

- Newborn screening was competing with other financial priorities at home
- Payment of the NBS fees
(insurance will cover only deliveries of membership)

Health Promotion/Campaign

Translation of NBS brochure into major dialects

Pagtulungan nating iligtas ang 33,000 na mga bata na maaring maapektuhan sa mga sakit na ito.

Magtanong tungkol sa Newborn Screening sa inyong mga health workers

Sa kasalukuyan may limang sakit na sinusuri ang newborn screening. Ito ay ang mga sumusunod:

- 1. Congenital Hyperthyroidism (CH)**
Ang CH ay resulta ng kakulangan o kawalan sa thyroid hormone. Ang thyroid hormone ay mahalaga sa pisikal at mental na paglaki ng isang tao. Kung hindi kaagad masusuri at mabibigyan ng hormone sa loob ng 4 na linggo, tuluyan ng mauudlot ang paglaki at magiging ganap na "mentally retarded" and mga batang may CH.
- 2. Congenital Adrenal Hyperplasia (CAH)**
Ang CAH ay nagdudulot ng sobrang kawalan ng asin sa katawan, pagkatuyo o dehydration at mataas na antas ng "male sex hormones" sa katawan ng babae o lalaki. Kung hindi kaagad masusuri at mabibigyan ng karampatang lunas sa loob ng 7-14 araw, maaaring mamatay ang sanggol.
- 3. Galactosemia (GAL)**
Ang GAL ay isang kondisyon kung saan ang katawan ay walang kakayahang iproseso ang "galactose" o asukal na galing sa gatas. Ang sobrang galactose sa katawan ay nakapagdudulot ng pagkasira ng atay at utak, at pagkakaran ng katarata sa murang edad.
- 4. Phenylketonuria (PKU)**
Ang PKU ay isang kondisyon kung saan ang katawan ay walang kakayahang iproseso ang "phenylalanine". Ang phenylalanine ay isang importanteng sangkap sa paggawa ng protina na kailangan ng ating katawan. Ang sobrang phenylalanine sa katawan ay nakapagdudulot ng pagkasira sa utak.
- 5. Glucose 6 Phosphate Dehydrogenase Deficiency (G6PD def)**
Ang G6PD Deficiency ay isang kondisyon kung saan ang katawan ay kulang sa enzyme na G6PD. Ang mga batang kulang sa G6PD ay madaling magkarron ng Hemolytic Anemia kapag nalantad sa ilang mga gamot, kemikal, at pagkain.

Para karagdagan katanungan, makipag-ugnayan sa inyong mga health workers

○

Newborn Screening Reference Center
National Institutes of Health
University of the Philippines Manila
625 Pedro Gil St., Ermita, Manila 1000

E-mail: info@nbs-nih.org.ph
URL: <http://www.nbs-nih.org.ph>

Newborn Screening Center
Institute of Human Genetics
National Institutes of Health
University of the Philippines Manila
625 Pedro Gil St., Ermita, Manila 1000

E-mail: info-nbs@humangenetics.com.ph
URL: <http://www.humangenetics.com.ph/newborn.html>



**ILIGTAS
ANG INYONG
MGA ANAK
Mula Sa
Mental Retardation**

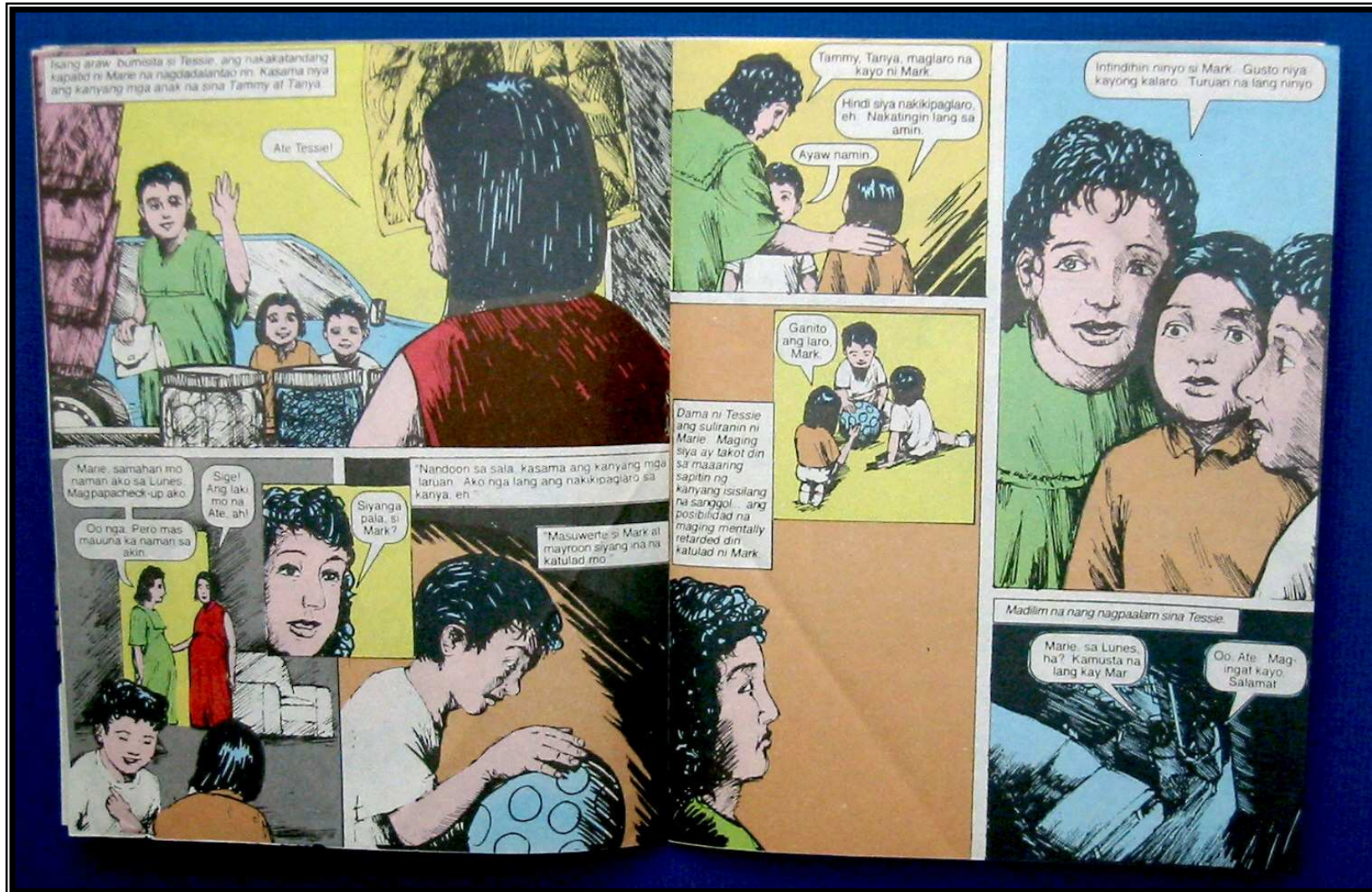
Education – Parent

Comic Book for Mothers



Education – Parent

Comic Book for Mothers





BILLBOARDS ALL OVER METRO MANILA AND PROVINCES IN COOPERATION WITH LOCAL GOVERNMENT UNITS

Buntis!
ipa-**NEWBORN SCREENING**
mo si baby, ha?

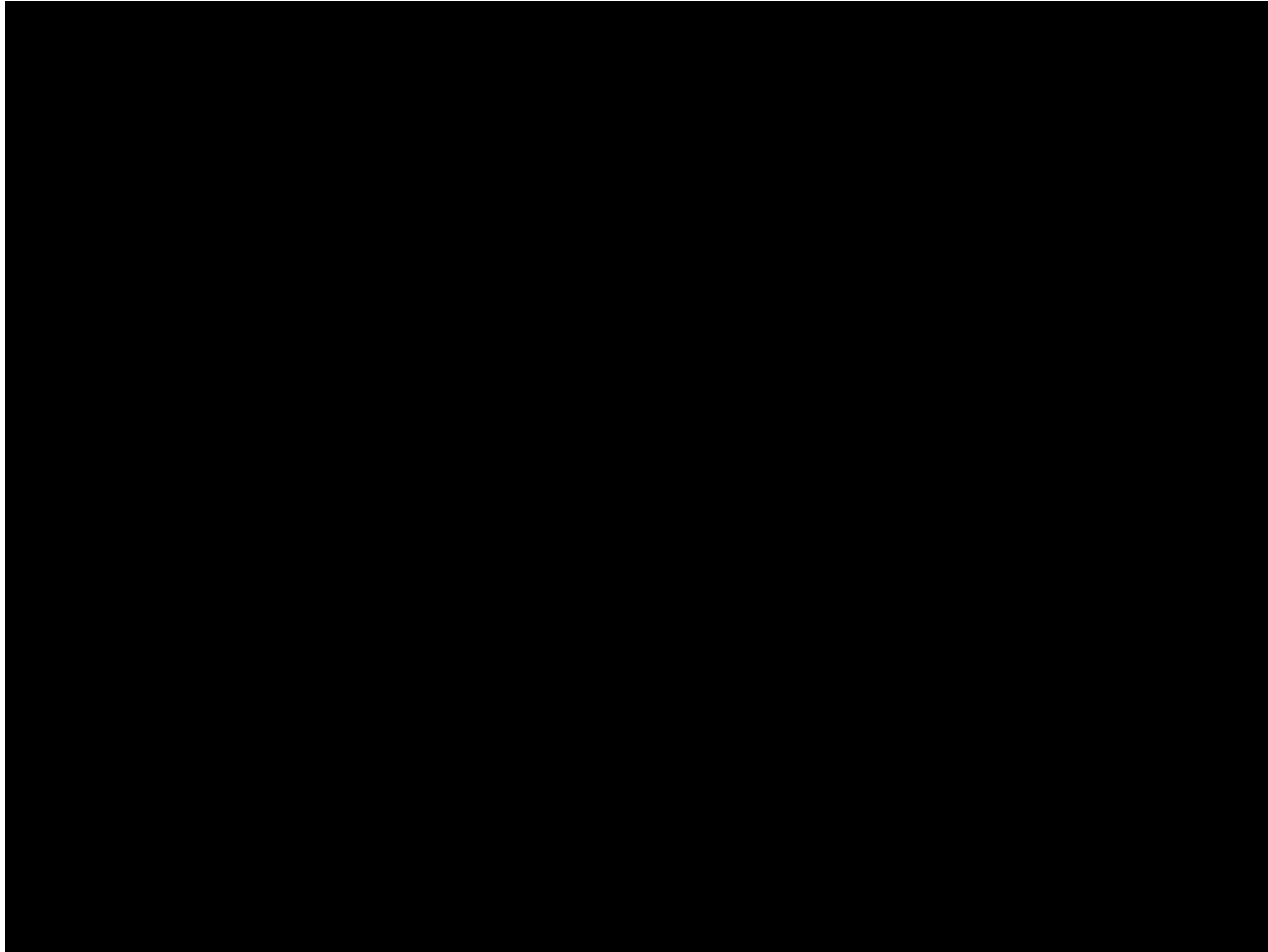
Ang **Newborn Screening** ay isang blood test na ginagawa sa bagong panganak na sanggol. Sa pamamagitan nito, nalalaman kung may delikadong kondisyon si baby na nagdudulot ng mental retardation o ng maagang pagkamatay. Abot-kaya ang Newborn Screening at covered ng PhilHealth.

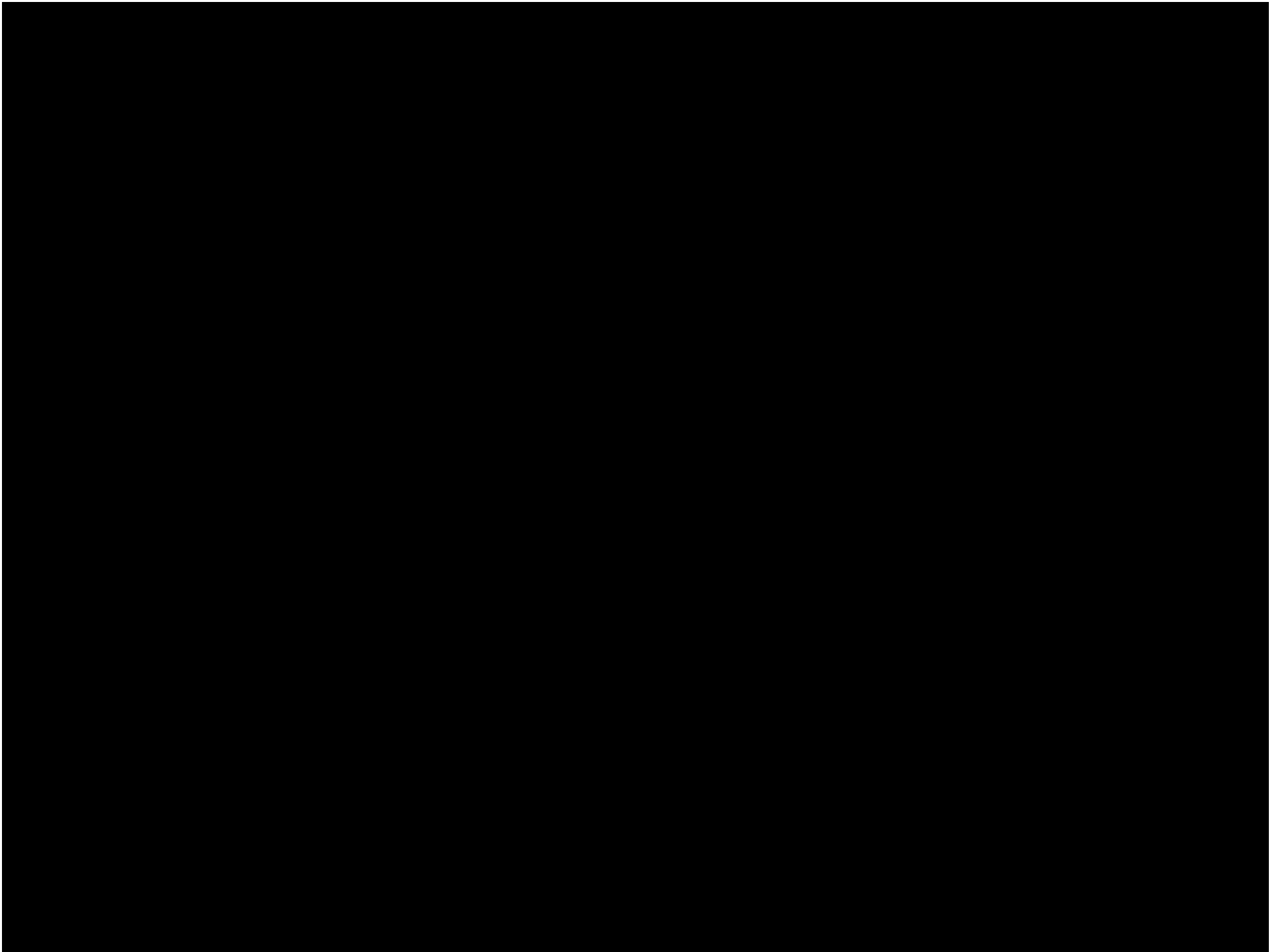
Karapatan ni baby ang mabuhay nang malusog.
Karapatan ni baby ang Newborn Screening.
Magtanong sa ospital o sa inyong doktor tungkol dito.

Newborn Screening
www.newbornscreening.ph

Celebrity endorser In posters and billboards

TV Commercial







On-air radio promotions on Newborn Screening

OCTOBER 2006, REUNION OF SAVED BABIES

Reunion of Saved Babies, 70th VCO Anniversary Alumni, UP Diliman



Maraming Salamat po!



From NEWBORN SCREENING REFERENCE CENTER, NIH, UP MANILA



Website dedicated to Newborn Screening

www.newbornscreening.ph



The screenshot shows the homepage of the Newborn Screening Reference Center (NSRC). At the top left is the NSRC logo, which consists of a stylized map of the Philippines in green and blue, followed by the text 'nsrc' in a bold, lowercase font and 'NEWBORN SCREENING REFERENCE CENTER' in a smaller, uppercase font below it. To the right of the logo is a green button with the text 'Newborn Screening Center - Visayas'. Below the logo and button is a green navigation bar with the text 'About Us', 'What's New', 'Resources', 'Events', and 'Contact Us'. On the left side of the page is a sidebar with a green header 'QUICK LINKS'. Below this header are several links: 'FAQs', 'List of Newborn Screening Facilities', 'How to Set-up Newborn Screening Services', 'How to Set-up Newborn Screening Center (NSC)', 'Newborn Screening Orientation Schedule', 'Republic Act 9288', and 'IRR'. At the bottom of the sidebar is the NSRC contact information: 'NSRC', 'Newborn Screening Reference Center', 'N.I.H., U.P. Manila', 'Pedro Gil St., Ermita', 'Manila, Philippines', and the phone number '003270'. The main content area features a large 'WELCOME TO THE Newborn Screening Reference Center' banner with a photograph of a young girl in an orange shirt pushing a stroller with a baby inside. To the right of the banner is a paragraph of text: 'The Newborn Screening Reference Center (NSRC) is an office under the National Institutes of Health (NIH), University of the Philippines Manila created under RA 9288. NSRC provides technical assistance to the DOH-NIH network in reaching the ultimate goal of screening Filipino newborns for common life-threatening heritable disorders. NSRC provides information and resources in the area of newborn screening to benefit health professionals, the public health community, consumers and government officials.' Below this text is a green header 'October Highlights' followed by several news items: 'Launching of Newborn Screening Awareness Week', 'DOH Visayas and Mindanao Celebrate NBS Week in Iloilo', 'OUTSTANDING ACHIEVERS IN NEWBORN SCREENING', and 'Special Feature: A TALE OF TWO FAMILIES'. Below the news items is a green header 'Reference and Materials' followed by three images: 'NBS Brochures', 'Sample Collection CD', and 'Inherited Disorder CD'. At the bottom of the page is a footer with the text: 'Last updated: January 15, 2006. For questions and comments concerning the website, please email us at info@nsrc-nih.org.ph'. In the bottom right corner of the page is an 'Internet' icon.



Newborn Screening Center - Visayas

QUICK LINKS About Us What's New Resources Events Contact Us

- FAQs
- List of Newborn Screening Facilities
- How to Set-up Newborn Screening Services
- How to Set-up Newborn Screening Center (NSC)
- Newborn Screening Orientation Schedule

Republic Act 9288
IRR

NSRC
Newborn Screening Reference Center
N.I.H., U.P. Manila
Pedro Gil St., Ermita
Manila, Philippines

003270

WELCOME TO THE Newborn Screening Reference Center



Newborn Screening not done at birth
Positive for Congenital Hypothyroidism
No physical signs at birth
Not treated immediately
14-year old retarded boy

Newborn Screening done at birth
Positive for Congenital Hypothyroidism
Treated immediately
Normal 7-year old girl

The Newborn Screening Reference Center (NSRC) is an office under the National Institutes of Health (NIH), University of the Philippines Manila created under RA 9288.

NSRC provides technical assistance to the DOH-NIH network in reaching the ultimate goal of screening Filipino newborns for common life-threatening heritable disorders. NSRC provides information and resources in the area of newborn screening to benefit health professionals, the public health community, consumers and government officials.

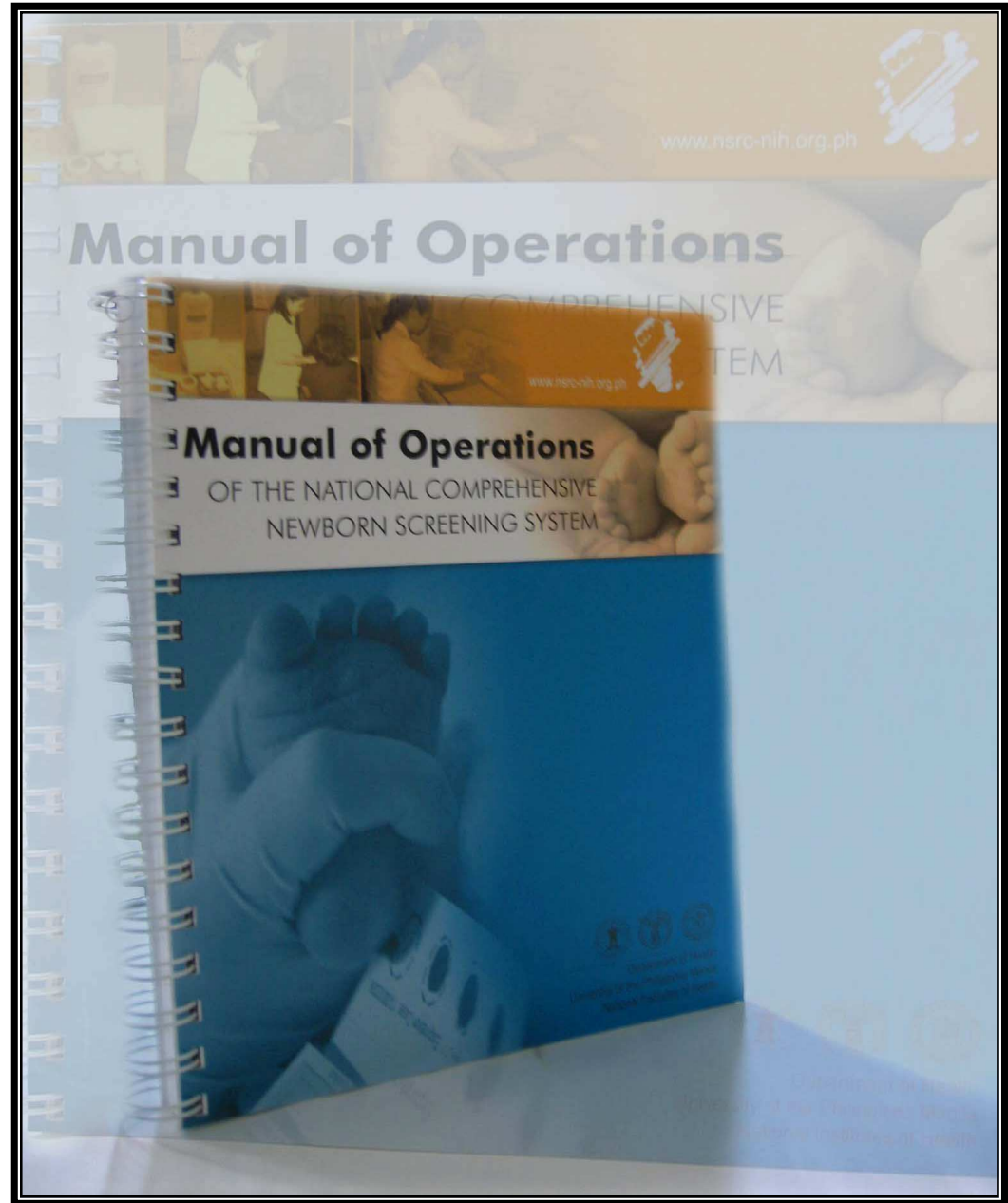
- October Highlights
- Launching of Newborn Screening Awareness Week ^{NEW!}
- DOH Visayas and Mindanao Celebrate NBS Week in Iloilo ^{NEW!}
- OUTSTANDING ACHIEVERS IN NEWBORN SCREENING ^{NEW!}
- Special Feature: A TALE OF TWO FAMILIES ^{NEW!}



Last updated: January 15, 2006
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Policy and Standards

- **Manual of Operations for the Philippine Comprehensive Newborn Screening System**

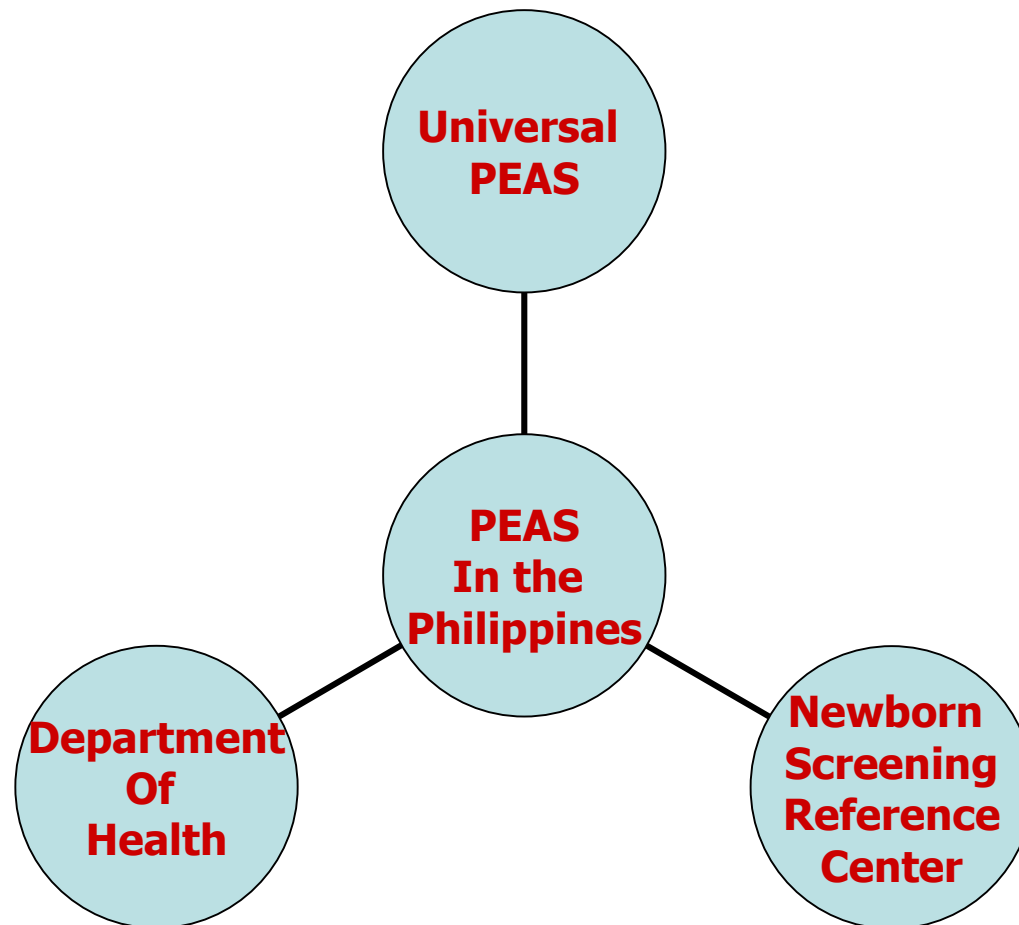


Quality Improvement in Newborn Screening Programs in the Philippines



**Performance Evaluation Assessment
Scheme
(PEAS)**

How PEAS came to be in the Philippines





Performance
Evaluation and
Assessment
Scheme
For Newborn Screening

Brad Therrell, Ph.D.
University of Texas Health Science Center at San Antonio,
Newborn Screening and Genetics Resource Center
Austin, Texas



Categories of PEAS

- PEAS for the Newborn Screening Centers (laboratories)
- PEAS for the Center for Health Development (Regional Implementers)
 - Evaluation of NBS Program implementation in the Region
- PEAS for the Newborn Screening Health Facilities (hospitals and community health centers)
 - Assessment of the NBS Program in the Health Facilities

**Enactment of the
Newborn Screening Act of 2004**
(April 6, 2004)

**Signing of the
Implementing Rules and Regulation of
RA 9288 (October 5, 2004)**

Newborn Screening Law

- Integration in the health delivery system
- Health practitioners shall fully inform the parents, or legal guardians of newborn about the availability, nature and benefits of NBS;
- Includes newborn screening the licensure requirement of hospitals
- Includes newborn screening as a benefit of the national health insurance

Newborn Screening Law

- DOH as the lead agency
- Setting up of laboratories
- Quality assurance
- Follow of cases



Former Secretaries of
the Department of
Health display a
newborn screening
poster
Jan 2000

Education – Political

Lobbying at the Senate Committee

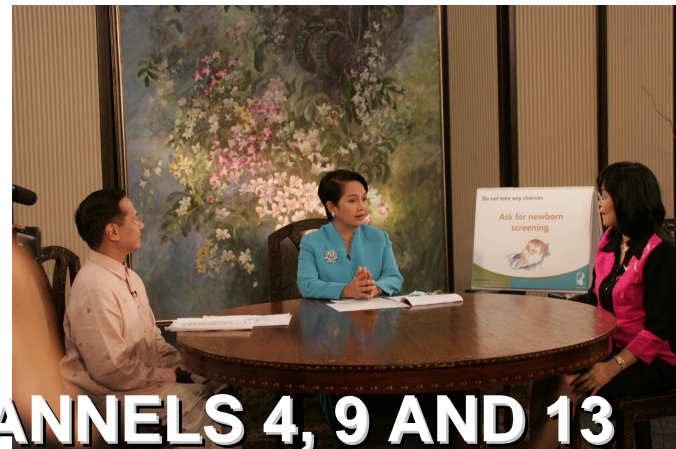


Support of Senators and Congressmen





**President Arroyo discusses Newborn Screening
in her Monthly TV show, Oct 2006**



Needs

- Geneticists.....geneticists.....geneticists
- Genetic counsellors
- Physicians with a good understanding of genetics
- Policy makers sensitive to the needs of a fraction of the population
- General public sensitive to the needs of the special children/adults
- Needs assessment!!!!!!!!!!!!!!!

Plans

- Active recruitment for potential candidates for Clinical Genetics Fellowship from the various regions
- Masters Program for Genetic Counsellors
- Preparing 3 bills → laws
 - Orphan Disease Act
 - Folic Acid supplementation/fortification
 - Birth defects registration

Lessons from the Newborn Screening Program

- Plan Data Collection/Use – incidence/prevalence, case reports, cost benefit analysis
- Involve all stakeholders – professionals, policy makers, consumers (networking)
- Create policies – to help push the program
- Learn from other programs (both developed and developing)
- Develop meaningful partnerships for success

Thank you