Newborn Screening: Research to Policy

Carmencita David-Padilla[1], Juanita A. Basilio[2], Yolanda E. Oliveros[2]

[1]*Department of Pediatrics, College of Medicine and Philippine General Hospital, University of the Philippines Manila*
[2]*Department of Health, Manila, Philippines*

Introduction

Newborn screening (NBS) is a public health activity aimed at the early identification of infants who are affected by certain genetic/metabolic/infectious conditions. Early identification of these conditions is particularly crucial, since timely intervention can lead to significant reduction of morbidity, mortality, and associated disabilities in affected infants. It represents the first population-based genetic screening program, and signalled the integration of genetic testing into public health programs.[1] NBS has been universally accepted for almost about five decades. Historically, it was first used for the detection of phenylketonuria (PKU) with the filter paper screening method developed by Dr. Robert Guthrie.[2] PKU is an inborn error of metabolism, which leads to mental retardation if not treated with a low phenylalanine diet early in life.[3] Since its inception in the 1960's, at least 20,000 affected patients all over the world are now leading normal lives. Today, NBS is being used for a number of other conditions, including metabolic and infectious diseases.[4]

NBS is the term used to describe various types of tests that can be done during the first few days of a newborn's life. NBS separates those who might have the disorder from those who probably do not have the disorder. In contrast, diagnostic or confirmatory testing is performed, to establish the presence of a condition. NBS that is properly timed and performed has the potential for preventing catastrophic health outcomes, including death.[5] Thus, early identification of these conditions is particularly crucial, since timely intervention can lead to a significant reduction of morbidity, mortality, and associated disabilities in affected infants.

NBS is <u>not</u> just a laboratory test. For almost 50 years, NBS has evolved into a *SYSTEM* that relies on smooth integration of the efforts of a number of individuals and processes. The 'NBS System' is comprised of six essential program components: (1) ***Education*** (including health professionals, parents, the general public, and politicians); (2) ***Screening*** (including proper timing and specimen collection, transport, laboratory testing, and reporting); (3) ***Early Follow-up*** (including abnormal test notification, tracking and confirmatory testing); (4) ***Diagnosis*** (including clinical and biochemical evaluation); (5) ***Management*** (including counselling, treatment monitoring and long-term follow-up); (6) ***Evaluation*** (including outcome monitoring and quality assurance throughout the system).[1,5,6,7]

It is this system that must be the focus of infrastructure development in establishing a new program. In order to ensure the highest level of screening quality, all system components should be included in an overall quality assurance plan and quality indicators should be developed for each. The smooth integration of NBS System components must develop locally within individual geographic, economic, and political constraints. Creation of an appropriate and functioning NBS System presents a challenge that requires dedication and perseverance of the organizer(s) in order to succeed. Traditionally, program oversight is a responsibility of the public health department or the health ministry; however, coordination and cooperation with academic centers and private partners [confirmatory laboratories, medical centers, 3rd party payers (e.g. insurance companies), and other non-government organizations] are essential for the success of the overall system.

Newborn Screening in the Philippines

In the Philippines, NBS was introduced by a group of obstetricians and pediatricians from 24 Metro Manila hospitals (Table 1) in June, 1996. The group named itself the Newborn Screening Study Group (NSSG) and its project was called the Philippine NBS Project (PNBSP). The objectives of the PNBSP were: 1) to establish the incidence of 6 metabolic conditions – congenital hypothyroidism (CH), congenital adrenal hyperplasia (CAH), galactosemia (GAL), phenylketonuria (PKU), homocystinuria (HCY), and glucose-6-phosphate dehydrogenase (G6PD) deficiency, and 2) to make recommendations for the adoption of NBS nationwide. The ultimate goal of the project was to gather adequate data to support legislation for a national NBS program.[8]

In 1998, the NSSG presented its research data to the Department of Health (DOH). The first formal acknowledgement of the value of the research data was in March 1999 when the newborn screening was included in Children's Health 2025, (a subdocument of, and DOH's input to CHILD 21, the Philippine National Strategic Framework

Corresponding author: Carmencita David - Padilla, MD, MAHPS
Institute of Human Genetics, National Institutes of Health - Philippines
625 Pedro Gil St., Ermita, Manila 1000, Philippines
Tel/ Fax Number: +63 2 525 7459
Email: cpadilla@upm.edu.ph

Part of the paper was taken from the thesis entitled:
Process Evaluation of the Screening Component of the Newborn Screening Program in Selected Regions in the Philippines: Towards Improved Implementation of Republic Act No 9288 or the Newborn Screening Act of 2004 (C Padilla, May 2005)

Table 1. Pilot Hospitals of the Philippine Newborn Screening Project

Private Hospitals		Government Hospitals
Capitol Medical Center	MCU-FDTMF*	Ospital ng Maynila
Cardinal Santos Medical Center	Medical Center Manila	Philippine Children's Medical Center
Children's Medical Center	Metropolitan Hospital	Philippine General Hospital
Chinese General Hospital	Our Lady of Lourdes Hospital	Quezon City General Hospital
De Los Santos Medical Center	Perpetual Help Medical Center	Quirino Memorial Medical Center
Dr. Victor R. Potenciano Medical Center	St. Luke's Medical Center	Rizal Medical Center
FEU-NRMF*	St. Martin de Porres Hospital	
Manila Doctors Hospital	UERMMMC*	
Mary Chiles General Hospital	United Doctors Medical Center	

*FEU-NRMF - Far Eastern University - Nicanor Reyes Memorial Foundation; MCU-FDTMF - Manila Central University - Filemon Dionesio Tanchoco; UERMMMC - University of the East Ramon Magsaysay Memorial Medical Center

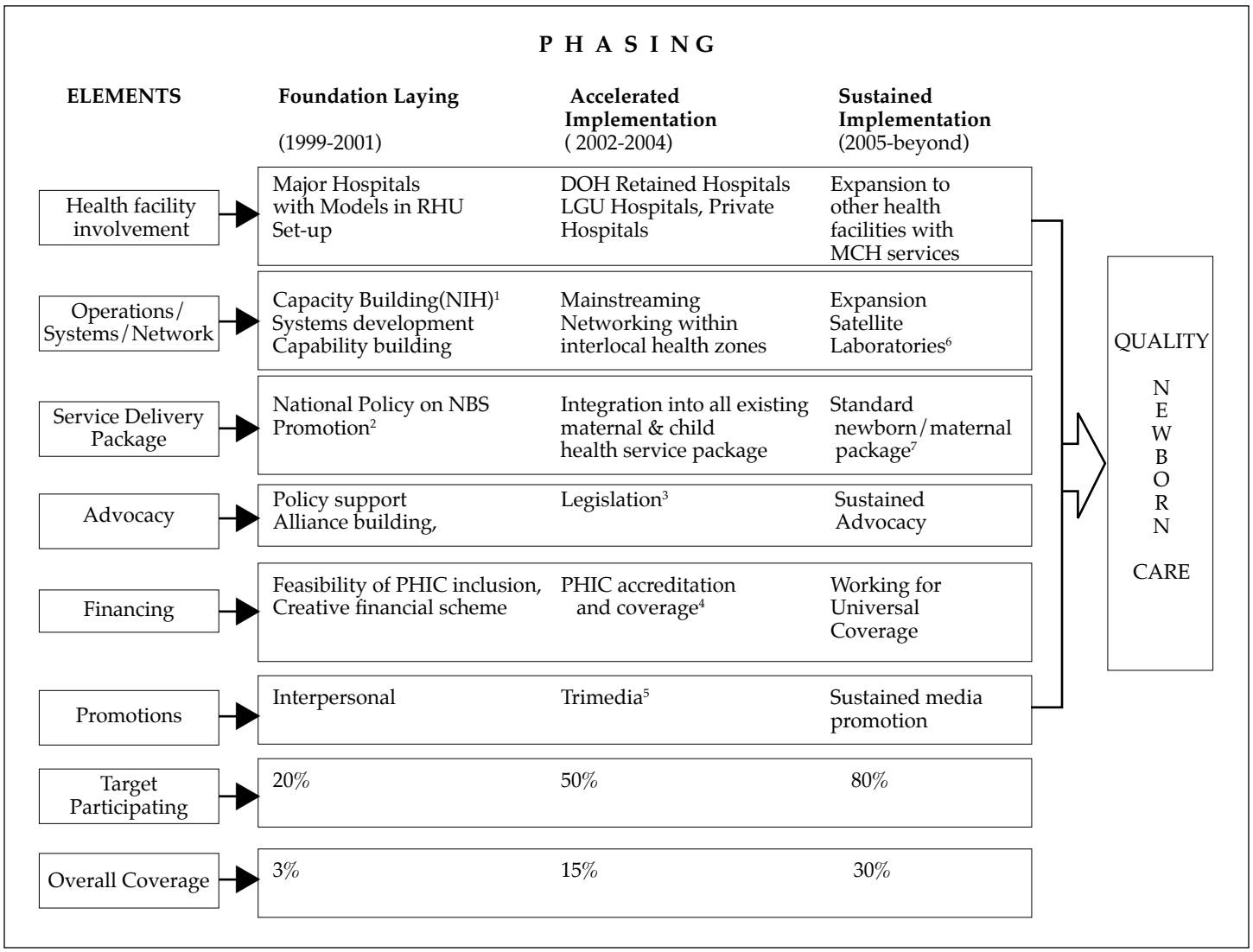

Figure 1. Newborn Screening Strategic Framework for 1999 – 2005.
[1]Series of workshops conducted for CHD/ Regional Coordinators & Directors and DOH Retained Hospital (July 1995-December 1999)
[2]DOH Administrative Order No 1-A s. 2000 Policies on the Nationwide Implementation of Newborn Screening (January 3, 2000)
[3]Republic Act 9288. An Act Promulgating a Comprehensive Policy and a National System for Ensuring Newborn Screening (April 7, 2004)
[4]PhilHealth Board Resolution No. 925, S. 2006. Resolution approving the Newborn Care Benefit Package (July 6, 2006)
[5]NBS in broadsheets, radio, and TV (Magandang Gabi Bayan, 2003)
[6]Opening of Newborn Screening Center-Visayas
[7]PhilHealth Board Resolution No. 925, S. 2006. Resolution approving the Newborn Care Benefit Package

Table 2. Milestones in the history of newborn screening in the Philippines

1996	
22 February	First organizational meeting attended by representatives from Philippine Pediatric Society (PPS) accredited and Philippine Obstetrical and Gynecological Society (POGS) accredited hospitals in Metro Manila
02 April	Creation of the NBS Study group composed of pediatricians and obstetricians from pilot hospitals. Project name: Philippine NBS Project
27 June	Commencement of the PNBS P - NBS samples were sent daily to the New South Wales NBS Program in Australia for test performance and analysis.
1997	
18 September	Start of operation of the NBS Laboratory at the NIH
1999	
March	Inclusion of NBS in Children's Health 2025[9]
30 July	Creation of the DOH Task Force on NBS composed of representatives from DOH, Institute of Human Genetics-NIH, DILG and other health groups.
2000	
23 January	Issuance of Administrative Order No 1A s 2000 by the DOH stating the Policies for the Nationwide Implementation of NBS[10]
2001	
07 February	Issuance of Department Order No. 29-C s, 2001 by DOH Subject: Creation of the National Technical Working Group on NBS Program, tasked to provide direction and guidance for the nationwide implementation of the NBS program.[11]
2003	
April	NBS bills filed at Congress
May	NBS bills filed at Senate
9 December	Issuance of DOH Administrative Order No 121, s2003, Subject: "Strengthening Implementation of the National NBS System"[12]
2004	
20 January	Issuance of the Presidential Proclamation No 540 entitled "Declaring the First Week of October of each year as "National NBS Awareness Week"[13]
07 April	Enactment of Republic Act No 9288 known as the Newborn Screening Act of 2004[14]
05 October	Signing of the Implementing Rules and Regulations of the Newborn Screening Act[15]
	Signing of the Memorandum of Agreement for the creation of the Newborn Screening Reference Center (NSRC) by the DOH and UP Manila
2005	
02 December	Opening of the 2nd NBS Center at West Visayas State University Medical Center[16]
2006	
22 January	NBS included in licensing requirement of Philippine hospitals; 90% of NBS fee covered by national health insurance[17]
2007	
02 January	Scholarships for Genetics and Endocrinology opened for Regions without specialists[18]
2008	
12 June	Issuance of DOH Memo No. 2008-0123 imposing the following targets: 30%-2008, 50%-2009 and 85% by 2010[19]
08 August	Issuance of AO No. 2008—0026 and 2008-0026A[20] by DOH imposing penalties for non-implementation and/or overpricing of NBS

for Plan Development for Children) which is meant to be the road map for planning programs and interventions that promote and safeguard the rights of Filipino children (survival, development, protection, participation) in the next 25 years (2000-2025).[9] Figure 1 presents a strategic framework on Newborn Screening for 1999-2005 prepared by the National Technical Working Group on Newborn Screening. This framework gives specific targets from foundation laying to sustained implementation. Historical milestones are presented in Table 2.

The major timeline phases in the development of NBS include:

1996 – Creation of PNBSP with routine screening for 6 disorders (CH, CAH, PKU, Gal, HCY, G6PD Deficiency) in the 24 member hospitals in Metro Manila comprising the NSSG.

2000 – Adoption of the PNBSP by the DOH; program evaluation resulting to reduction of the time of sample collection to 24 hours of age (from the initial requirement of 48 hours or older); and discontinuation of screening for HCY; formal inclusion of G6PD deficiency in the NBS panel.

2004 – Enactment of the Newborn Screening Act of 2004 and completion of the Implementing Rules and Regulations.

2005 – Inclusion of NBS in the licensing requirement of hospitals.

2006 – Inclusion of NBS in the Philippine Health Insurance (PHIC) newborn package, covering 90% of the NBS fee.

Current Status of NBS Implementation in the Philippines

Newborn Screening Legislation

NBS was integrated into the public health delivery system with the enactment of Republic Act 9288 or Newborn Screening Act of 2004[14] as it institutionalized the 'National NBS System', which shall ensure the following: [a] that every baby born in the Philippines is offered NBS; [b] the establishment and integration of a sustainable NBS System within the public health delivery system; [c] that all health practitioners are aware of the benefits of NBS and of their responsibilities in offering it; and [d] that all parents are aware of NBS and their responsibility in protecting their child from any of the disorders. The highlights of the law and its implementing rules and regulations are:

– DOH is the lead agency tasked with implementing this law;
– Any health practitioner who delivers or assists in the delivery of a newborn in the Philippines shall prior to delivery, inform parents or legal guardians of the newborns the availability, nature and benefits of NBS;
– Health facilities shall integrate NBS in its delivery of health services;
– Creation of NSRC at the NIH and establishment and accreditation of NSCs equipped with a NBS laboratory

and recall/follow up program;
- Provision of NBS services as a requirement for licensing and accreditation, the DOH and the Philippine Health Insurance Corporation (PHIC)
- Inclusion of cost of NBS in insurance benefits

Key Players in the Implementation

There are major key players in the implementation of the NBS Program both at the national level and local level. The organizational chart for the national implementation of NBS (Figure 2) shows the major partnership of the DOH with NIH with the latter serving as technical partner. Table 3 lists the duties and responsibilities of the various agencies involved in the implementation of NBS as detailed in the Manual of Operations for National NBS Implementation.[22]

NBS is done at an NBS facility (NSF), defined as any health facility that offers NBS services to infants born either within the facility, its catchments area or elsewhere, and has operational recall/follow-up programs for newborns with heritable conditions. An NSF organizes an NBS team who shall oversee the implementation of the program and serve as linkage with the NSC. The NBS team, chaired by an Overall NBS Coordinator, oversees the NBS process, collection of samples, release of results, prompt recall and follow-up of positive cases. The NBS team organizes health education activities to inform parents and clients of the importance of NBS. If the NSF does not have specialists for the positive cases, it is their responsibility to arrange the referral. The NSF can be a hospital with maternity services, lying-in clinics or outpatient clinic such as rural health units, health centers and outpatient department of hospitals.[22] As of December 2008, there are 2,107 NBS facilities, 1,441 hospitals, 498 birthing homes, 151 RHUs, and 17 other facilities offering NBS in the country. Home delivered babies are advised to go to the nearest NSF for NBS. In limited cases, NBS is done at home.

In the past 4 years, the Centers for Health Development (CHDs) have taken a more active role in NBS implementation. The CHDs have an NBS Program Desk at the CHDs to address problems and issues encountered in the day-to-day implementation of the program. Every CHD has a regional NBS coordinator that reviews the performance of all facilities in their respective region, organizes trainings and orientations, and assists in the recall of patients with positive screens and referral to experts. [Note: The Philippines has 17 CHDs corresponding to the 17 political regions.]

In 2004, the establishment of the Newborn Screening Reference Center (NSRC) marked a major initiative in addressing the needs of the NBS system. The NSRC was envisioned to provide technical assistance to DOH and other NBS stakeholders and assume a leadership role in examining the totality of the NBS system, including the necessary linkage to health facilities and birthing homes. The charge to the NSRC was to review and evaluate the issues and challenges facing the nation's NBS program and to make recommendations to strengthen the program.[15,22]

During its four years of operation, the NSRC has outlined major recommendations for national, local, and other technical partners in addressing the identified barriers and needed enhancements of the National Comprehensive Newborn Screening System (NCNBSS). It has appropriately involved many groups and individuals from within and outside the NBS, pediatrics, and genetics communities, representing a diversity of views and expertise. Today, manifestations of the NSRC's recommendations are evident, many of which occurred in partnership with the DOH.

Testing of samples is done at the NBS Centers (NSCs). The NSC is a facility equipped with a NBS laboratory that complies with the established standards and provides all required laboratory tests and recall/follow-up system for newborns with heritable conditions.[15,22] There are currently 2 NSCs and a third one will open soon in Mindanao.

Newborn Screening Statistics (1996-2008)

As of December 2008, there are 1,328,144 babies that have undergone NBS and based on these data, the incidences of the following disorders are: CH (1: 3,548); CAH (1: 7 842); PKU (1 : 134,102); Gal (1 : 89,401) and G6PD deficiency (1 : 54). The program has saved the following numbers of newborns from complications and/or death: 378 from CH, 171 from CAH, 15 from Gal, 10 from PKU and 23 557 from G6PD deficiency.

Coverage

As of December 2008, the coverage of NBS remains low at 21%. The following reasons have been identified as causes for the low percentage of newborn population covered: 1) not all health practitioners are yet convinced of the merits of NBS; 2) most parents do not yet fully understand the merits of NBS; 3) cost of screening; 4) no penalties for NSFs not complying with the licensing requirement; 5) there is no organized advocacy campaign. Additionally, the estimated percentage of hospital deliveries is only 40% of the total while the remaining 60% are delivered at home.[23] Strategies are needed to target the home delivered babies.

To ensure that the NBS is made more accessible and affordable to the general public, DOH released a Department Memorandum on June 12, 2008, setting the following targets for NBS coverage at all health facilities: 30% coverage for 2008; 50% for 2009; and 85% for 2010.[24]

This action is in accordance with the national comprehensive NBS system's move towards more sustainable program implementation by increasing coverage and strengthening participation at all levels and in both public and private health facilities.

Table 4 presents the newborn screening statistics on number of NSFs, number of confirmed cases, number of newborns screened and national Coverage (1996-2008). These data show that by the end of December 2008, only 357,543 babies were screened or only 21% of the 1.7 million estimated annual live birth. This is below the 30% target set by DOH for 2008.

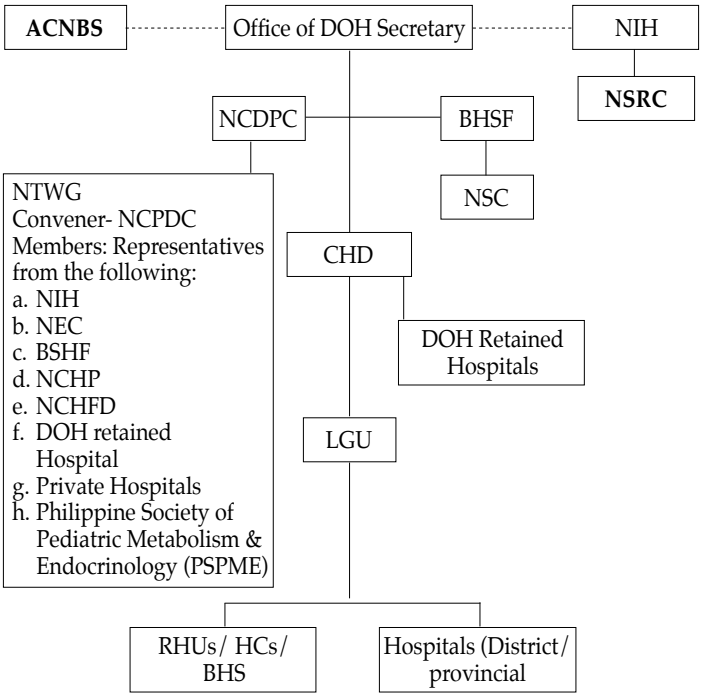

Figure 2. Organizational Chart of National Implementation of NBS after the enactment of RA No 9288.

Meanwhile, the inclusion of NBS in the licensure requirements for health facilities in 2006 has led to a dramatic increase in the number of NSFs offering NBS service over the past three years. Figure 2 shows the number of NSFs by category per region as of December 2007.

The DOH continually appeals to all health professional groups to assist in increasing screening coverage. The Advisory Committee for NBS, chaired by the Secretary of Health, has leaders of health professional groups, among its members. Workshops, lectures, focused group discussions are conducted year-round. In addition to their regular activities, the DOH and the NIH launched a tri-media campaign in 2008, including: TV, cinema, and radio commercials; printed advertisements in broadsheets and tabloids; and distribution and installation of billboards in strategic locations all over the country.

Globally, NBS is considered the most successful population-based genetic screening program that has been integrated into the public health systems. Most developed countries and some developing countries with coverage of 100% validates this statement. The Philippines must take advantage of lessons that can be learned from other NBS programs.

The Philippines program provides unique insights into strategies for improved implementation of the NBS program throughout the country using the Center for Health Development (CHD) as the foundation. The program desk at the CHDs was established to address problems of implementation and offers strategies to key players of DOH. The CHDs provide capability-building activities to strengthen the knowledge of the health professionals as

Table 4. Newborn Screening Statistics for the period 1996-2008.

Year	Live Births*	NSFs	Newborn Screened	Confirmed Positive Cases												National Coverage %
				CH		CAH		GAL		PKU		G6PD				
				Annual	Cumulative	Annual	Cumulative	Annual	Cumulative	Annual	Cumulative	Annual	Cumulative			
1996	1,608,468	24	11,992	4	4	2	2	0	0	0	0	0	0			0.70
1997	1,653,236	24	32,301	8	12	3	5	0	0	1	1	0	0			1.90
1998	1,632,859	41	33,432	7	19	4	9	2	2	0	1	0	0			2.10
1999	1,613,335	53	24,572	7	26	5	14	2	4	2	3	274	274			1.50
2000	1,766,440	153	40,888	10	36	2	16	2	6	0	3	725	999			2.30
2001	1,714,093	210	46,535	21	57	10	26	2	8	1	4	740	1,739			2.70
2002	1,666,773	248	60,269	19	76	16	42	2	8	0	4	1,041	2,780			3.50
2003	1,669,442	325	66,784	16	92	13	55	3	11	0	4	1,331	4,111			3.90
**2004	1,669,442	366	88,938	38	130	13	68	4	15	0	4	1,555	5,666			5.20
**2005	1,669,442	760	128,815	39	169	12	80	7	22	1	5	2,578	8,244			7.60
**2006	1,669,442	1231	175,694	41	210	22	102	9	31	2	7	3,399	11,643			10.30
**2007	1,669,442	1618	260,381	83	293	22	124	12	43	2	9	3,889	15,532			15.30
**2008	1,669,442	2107	357,543	85	378	47	171	15	58	1	10	8,025	23,557			21.00

*Source: 2007 Philippine Statistical Yearbook
**based on 2003 Actual Live Births

Table 3. Duties and Responsibilities of Agencies in the Implementation

National level	
National Center for Disease Prevention and Control (NCDPC)	Oversees the operations and nationwide implementation of NCNBSS.
National Technical Working Group for Newborn Screening (NTWG- NBS)	Sets the goals of the program for long-term and medium-term target-setting and planning. Ensures that all policies, guidelines and standards of the program adhere to overall internationally accepted standards and ethical considerations.
NIH through the NSRC	Serves as the technical partner of DOH in ensuring the quality of service and sustainability of the NCNBSS. Responsible for the national testing database and case registries, training, technical assistance and continuing education for laboratory staff in all NSCs as stipulated in RA 9288.
Advisory Committee on NBS (ACNBS) (Office of the Secretary of the DOH)	Annually reviews and recommends conditions to be included in the NBS panel of disorders; Reviews and recommends the NBS fee to be charged by NSCs; and Reviews the report of the NSRC on the quality assurance of the NSCs and recommend corrective measures as deemed necessary.
National Epidemiology Center (NEC)	Responsible for developing a surveillance system for heritable conditions
Bureau of Health Facilities and Services (BHFS)	Responsible for regulating health facilities performing NBS procedures through: a. Accreditation procedures and monitoring for compliance and quality assurance; b. Development of needed rules and regulations pertaining to the regulation of the same; and c. Monitoring and evaluation of the NSCs.
National Center for Health Facility Development (NCHFD)	Provides technical assistance and leadership for the continuous effective and efficient implementation of NBS in hospitals in coordination with the Center for Health and Development (CHD)
National Center for Health Promotion (NCHP)	Acts as the lead office in the promotion of NBS and shall develop advocacy materials for dissemination to all partner agencies (LGUs, academe, NGO's) and stakeholders
Regional Level Centers for Health Development (CHDs) at the Regional Level	Facilitates and collaborates with health centers and hospitals to fully implement the program at the local level.
Local Level Local government units (LGUs) and their health facilities (LGUs through the Chief of Hospital and Municipal Health Officers)	Ensures that adequate and sustained NBS services such as information, education, 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); Establishes a functional case management referral system with strategically accessible tertiary hospitals; Establishes coordination and networking among concerned agencies in NBS implementation; Monitors and evaluates the NBS implementation in their localities; and Defines creative financial packages to make NBS accessible particularly among the economically deprived populace

well as the relevant public on the importance of NBS. As of December 2008, CHD-NCR and CHD-6 have demonstrated the strength of CHD in the implementation. Likewise, CHD-NCR and CHD-6 take the lead in NBS coverage.

Selected case studies provide models of successful implementation that can be used in other parts of the country. Data also show that private-public partnerships are integral to helping health managers/administrators and other health care providers reach their goals of increased NBS coverage. A Performance and Evaluation Assessment Scheme (PEAS) tool was initiated in collaboration between the DOH and the NSRC to develop a usable Philippine PEAS, based on the PEAS indicators and experiences in the U.S. to help ensure and improve NBS quality at regional and local NBS health facilities. Two evaluation tools were envisioned: (1) an evaluation tool for CHDs as regional implementers of NBS; and (2) an evaluation tool for NSFs, as participants in the screening processes. Knowing the gaps in program implementation, better guidelines and policies can be crafted to augment existing policies.

Financing

In order to make the NBS more accessible and affordable to the general public, the DOH issued Administrative Order 2005-0005 standardizing the NBS Fee at P550 and setting the maximum allowable service fee at P50.[25] One year later, in 2006, as stipulated in the law, NBS became a mandatory DOH hospital licensing requirement. Likewise, NBS was included as part of Philippine Health Insurance Corporation (PHIC) accreditation of health facilities, and 90% of the screening cost is paid by the national social health insurance as part of the PHIC standard newborn care package.[17]

NBS is included in the PHIC Newborn Care Package (NCP). NCP may be availed by any qualified PhilHealth dependent delivered in accredited hospitals and non-hospital facilities for Maternity Care Package that are certified as a newborn screening facility.[17] However, there is a large gap between amount of PHILHEALTH utilization for the Maternal Care Package (MCP) covering the mother's normal delivery expenses and the Newborn Care Package (NCP). In the first half of 2008, there were only 1,196 claims worth 1.28 million Pesos for NCP while there were 46,572 MCP claims amounting to 243 million Pesos (Figure 4). This means that the utilization of NCP is only less than 1% of the MCP and the newborn care package is far from being maximized.

Several health facilities and LGUs have addressed NBS financing through innovative actions in their communities. These actions include LGUs that have allocated budget items for NBS support payments that can be used by their constituents,[26] local ordinances making NBS to all newborns mandatory,[27] a partial prenatal payment scheme,[28] and inclusion of NBS in the benefit package of community micro-health insurance policies,[29] among others.

Financing initiatives for NBS need to be explored further,

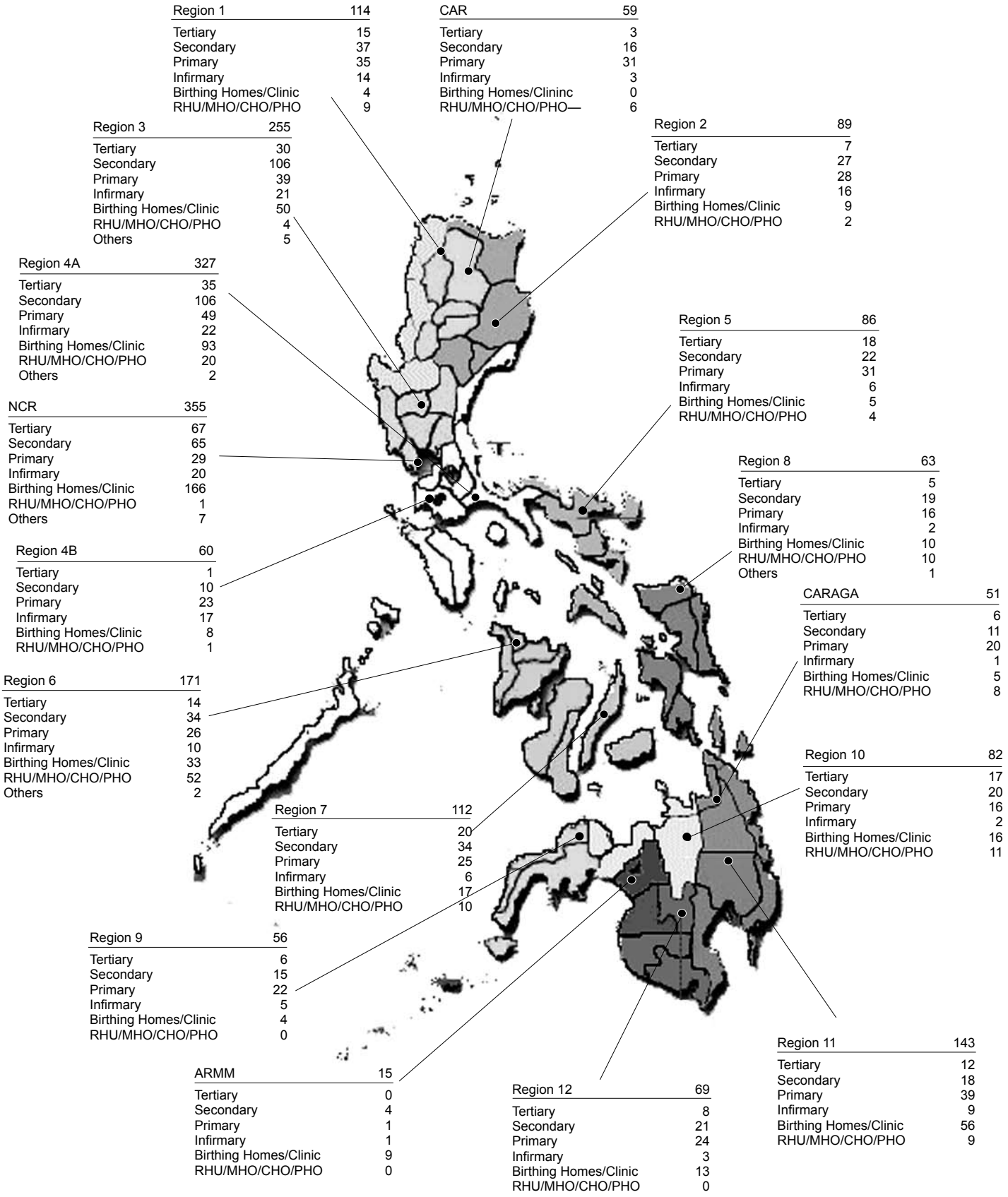

Figure 3. Number of Newborn Screening Facilities (NSFs) by Category per Region as of December 2008.

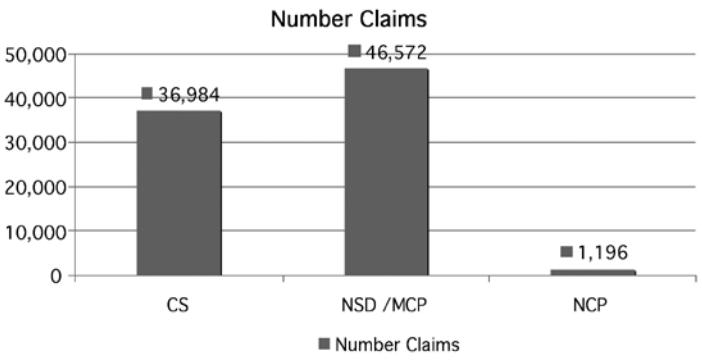

Figure 4. Utilization of Maternal Care Package and Newborn Care Package, 1st Semester 2008 (Source: Dr. Giovanni M. Roan, Benefits Development & Research Department, PhilHealth).

particularly, variations of community financing actions that have been successful in several communities. Proper documentation and research into these methods will be useful in replicating these activities in other communities. Community and family empowerment through prenatal education can also help parents plan and prepare for the cost of NBS. Partnerships with private organization and linkages with micro-finance institutions may also provide a framework to address financing concerns.

Future Directions

In 2008, approximately 357,000 or 21% of 1.7 million newborns were screened in the Philippines. This is far below the 30% DOH target for 2008. If all babies were screened, approximately 33,000 babies could be saved annually from adverse consequences of the five metabolic disorders. The challenge is to strengthen the NBS program at the community level in order to capture and assist all newborns with metabolic disorders.

Today, the lead agency for implementing NBS, the DOH, its partners, and other program stakeholders, remain aggressive in their efforts to increase the coverage of screened babies across the nation, and to ensure quality standards in the implementation of the NCNBSS. In September 2008, NBS was included in the maternal and newborn service package as essential service for the newborn through an Administrative Order on Rapid Reduction of Maternal and Newborn Deaths in the Philippines to fully institutionalize the program.[30]

The program's strategic direction is geared towards promoting awareness on NBS and increasing the number of newborn screened in the community by identifying and selecting additional key players that have powerful influence at the grassroots' level such as the midwives, women's organizations, and other interest groups in the informal sector. Exploring the possibility of establishing partnerships with these organizations in advocating for NBS and ensuring effective implementation of the NBS program at the community level will bring valuable contributions towards achieving our goal of saving more Filipino newborns.

One of the major efforts of DOH to encourage good performance on health delivery services and increase NBS coverage in LGUs is to provide performance-based grants. This grant is assessed against a set of priority indicators for public health. The inclusion of NBS in the assessment criteria will serve as leverage for the LGUs to make sure all their MCP accredited facilities are performing NBS package.

Program evaluation criteria are also continuously developed and applied to determine whether interventions are having the intended effect and which components contribute most to the overall effectiveness of the program. The DOH is continuously working on improving regulatory system to ensure strict implementation of the Law and the IRR and strengthen the capacity of the CHDs and LGUs in regulatory and monitoring aspects. Furthermore, DOH and NIH are currently working on the expansion of reference laboratories to make NBS accessible through the establishment of Newborn Screening Center in Mindanao and G6PD confirmatory center in every region.

While financing remains a challenge, the DOH and PHILHEALTH will need to work closely to improve coverage of enrolment in the national health insurance system especially among the indigents and include NBS service in the Provincial/Municipal Investment Plan for Health. PHILHEALTH also need to improve information dissemination on what are the benefit packages available for their clients and the reimbursement procedures for health facilities and health practitioners need to be clarified.

Empowerment through education can also be helpful in helping parents plan and prepare for the cost of having their baby undergo newborn screening. Specifically, DOH strongly advocates for the development of a birth plan for the pregnant women. A birth plan is being done to determine where the woman will deliver, what transportation she will use, what things she will prepare and what service she and her newborn should be entitled to which include NBS. A Women's Health Team or Barangay Health Team provides guidance to the expectant mothers. The CHDs will continuously provide capability building activities to increase the knowledge of the health professionals as well as the parents on the importance of NBS.

References

1. American Academy of Pediatrics, Newborn Screening Task Force. Serving the family from birth to the medical home - Newborn screening: a blueprint for the future. Pediatrics. 2000;106(suppl):383-427.
2. Guthrie R, Susi A. A simple phenylalanine method for detecting phenylketonuria in large populations of newborn infants. Pediatrics. 1963; 32:338-343, 1963.
3. Bickel H, Gerrard J, Hickmans EM. Influence of phenylalanine intake on phenylketonuria. Lancet. 1953;265:812-813.
4. Therrell BL. U.S. Newborn screening policy dilemmas for the twenty-first century. Molec Genet Metab. 2001:74;64-74.
5. Therrell BL, Panny SR, Davidson A, et al. U.S. newborn screening system guidelines: statement of the Council of Regional Networks for Genetic Services (CORN). Screening. 1992;1:135-47.
6. Pass KA, Lane PA, Fernhoff PM, et al. U.S. Newborn Screening system guidelines II: follow-up of children, diagnosis, management and evaluation – statement of the Council of Regional Networks for Genetics Services (CORN). J Pediatr. 2000;137:S1-46.
7. McCabe LL, Therrell BL, McCabe ERB. Newborn screening: rationale for a comprehensive, fully integrated public health system. Molecular Genetics and Metabolism. 2002;77: 267-73.
8. Padilla C, Domingo CF. Implementation of newborn screening in the Philippines. Phil J Pediatr. 2002;51:2-10.
9. Child Health and Development Strategic Plan Year 2001-2004. Available at http://www.doh.gov.ph. Accessed on February 17, 2009.
10. DOH Administrative Order 2000 1a, 2000. Policies on the Nationwide Implementation of Newborn Screening, January 3, 2000.
11. DOH Department Order No. 29-C s, 2001. Creation of the National Technical Working Group on Newborn Screening Program, February 7, 2001.
12. DOH Department Order No. 121 S. 2003. Strengthening Implementation of the Newborn Screening System, December 9, 2003.
13. Proclamation No. 540. Declaring the 1st Week of October of each Year as "National Newborn Screening Week", January 20, 2004.
14. Republic Act No 9288 or Newborn Screening Act of 2004. Available at http://www.newbornscreening.ph. Accessed on February 17, 2009.
15. DOH Circular No.333 s. 2004. Rules and Regulations Implementing Republic Act No.9288 otherwise known as the "Newborn Screening Act of 2004". October 22, 2004.
16. DOH Memorandum. Authorized Newborn Screening Centers. October 28, 2005.
17. PhilHealth Board Resolution No. 925, S.2006. Resolution approving the Newborn Care Benefit Package, July 6, 2006.
18. DOH Memorandum. Newborn Screening Grant for Pediatric Endocrinologist and Clinical Geneticists, January 2, 2007.
19. DOH Department Memorandum No. 2008-0123. Newborn Screening Coverage. June 12, 2008.
20. DOH Administrative Order No. 2008-0026. Addendum to the Rules and Regulations Implementing Republic Act No. 9288, otherwise known as the "Newborn Screening Act of 2004".
21. DOH Administrative Order No. 2008-0026A. Amendment to the Administrative Order No. 2008-0026 on Addendum to the Rules and Regulations Implementing Republic Act No. 9288, otherwise known as the "Newborn Screening Act of 2004".
22. Basilio JA, Casiño MTP, Estrada SC, Sur ALD. Manual of Operations of the National Comprehensive Newborn Screening System. Philippines. 2005.
23. Maternal & Child Health NSM Presentation, 2006. Available at http://www.doh.gov.ph. Accessed on February 17, 2009.
24. DOH Department Memorandum No. 2008-0123. Newborn Screening Coverage. June 12, 2008.
25. DOH Administrative Order No. 2005-0005. Cost for the Newborn Screening & Maximum Allowable Service Fees for the Collection of Newborn Screening Samples in all Newborn Screening Collecting Health Facilities. February 8, 2005.
26. The Lipa City NBS Experience. Newborn Screening Publication Volume 11, No. 4. October-December 2007.
27. Provincial Tax Ordinance No. 2003-004 Series of 2003. An Ordinance amending Provincial Tax Ordinance No.92-002 S. 1992, otherwise known as the Revised Provincial Revenue Code of the Province of Negros Occidental, November 2003.
28. BCMH policies push coverage to 90%. Newborn Screening Newsletter Volume 12, No. 1. January-March 2008.
29. PESO for Health. Available at http://www.bayawancity.gov.ph. Accessed on February 17, 2009.
30. DOH Administrative Order No. 2008-0029. Implementing Health Reform for Rapid Reduction of Maternal and Neonatal Mortality, September 9, 2008.