The official newborn screening jingle was launched in time for the awareness week celebration. It is one of the major advocacy efforts initiated by DOH-NCR in coordination with NSRC and NSC-NIH.

BLESSING KA BABY

VERSE 1
Mula sa sinapupunan
Siyam na buwan ka naming inalagaan
At ngayon nandito ka na
Di ka namin pababayaan

CHORUS
Oh aming baby, isa kang blessing
Kaya dapat
Magpa-newborn screening

VERSE 2
Love na love ka namin
Kaya ito gagawin
Para sa kalusugan mo
Dapat natin itong sundin

CHORUS
Oh aming baby, isa kang blessing
Kaya dapat
Magpa-newborn screening

BRIDGE (RAP)
Napakadali ng process
Na mag pa-NBS
Ilang patak ng dugo ang kailangan
Para magawa ang test
Makalipas ang 24 oras pag si baby lumabas
Gawin natin ang NBS, alinsunod sa batas

CHORUS
Oh aming baby, isa kang blessing
Kaya dapat
Magpa-newborn screening
Para sa 'yo rin ito, sa kalusugan mo

The NCNBSS Referral and Treatment Networks were also continually strengthened to ensure that babies with positive screens are provided with prompt and appropriate management essential to save them from the consequences of having one of the disorders in the panel. Aside from the continuity clinics, the program conducted regular short- and long-term case audits among stakeholders. Additional Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency confirmatory centers were set up, bringing the number of centers to 18 by the end of the year. Reference laboratories for metabolic disorders and hemoglobinopathies were also set up in 2014.

The NCNBSS continued its support to fellowships for Pediatric Endocrinology and Clinical Genetics and to scholarships for Master of Science in Genetics Counseling (a program offered by the College of Medicine, University of the Philippines Manila). This undertaking ensured availability and better accessibility of specialists in the country. Protocols and algorithms for management of patients were regularly created and revisited to ensure prompt and effective management of patients.

Calls for researches related to the improvement of newborn screening and corresponding policies were consistently made. There were three that were completed in 2014.

Advocacy to promote awareness continued to be one of the major activities of implementers and stakeholders. Various activities were set all throughout the year, especially in October during the National Newborn Screening Awareness Week. Activities ranged from promoting newborn screening through different media channels, regular dialogues and lectures, training, and program orientation to fun runs, physical activities, and the like.

Screening Coverage

National. Aggregated efforts in advocacy and monitoring are reflected in the increase in the newborn screening coverage. In 2014, NCNBSS was able to screen 65 percent of the estimated 1.8 million total live births, 7 percent higher than the previous year. This translates to 1,170,775 newborns that underwent screening in 2014.

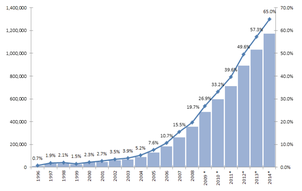


Figure 1. Screening coverage from 1996 to 2014

Below: ENBS brochure translated to Filipino in partnership with UP Sentro ng Wikang Filipino.

Katanungan ukol sa ENBS

Ano ang *expanded newborn screening?*
Ang pinalawak na programa ng newborn screening ay makapagsusuri ng mas maraming sakit mula anim (6) hanggang sa mahigit 20. Magbibigay ang pagsusuring ito ng pagkakataong matiyak ang magandang kalidad ng buhay ng mga apektadong sanggol sa pamamagitan ng maagang pagsusuri at gamutan.

Ano ang pagkakaiba ng *newborn screening* at *expanded newborn screening?*
Ang pagkakaiba ay nasa bilang ng mga sakit na maari nitong masuri. Parehong paraan ng pagsusuri ang isasagawa kung saan kukuha ng ilang patak ng dugo mula sa talampakan ng sanggol. Magkakaiba na pagdating sa pamamaraan ng *laboratory testing*.

Anu-ano ang karagdagang sakit na masusuri sa expanded newborn screening?
Maliban sa anim na kondisyon na dati nang sinusuri – *Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Galactosemia, Phenylketonuria, Maple Syrup Urine Disease* at *Glucose-6-Phosphate Dehydrogenase deficiency* – ang *expanded newborn screening* ay magsusuri ng kabilang sa grupo ng mga kondisyong ito: *hemoglobinopathies*, mga *disorder sa amino acid* at *organic acid metabolism*, *disorder sa fatty acid oxidation*, *disorder sa carbohydrate metabolism*, mga *disorder* sa *biotin metabolism* at *cystic fibrosis*.

Magkano ang *expanded newborn screening?*
Maaring pumili ang mga magulang ng pagsusuri na kanilang nanaisin para sa kanilang sanggol. Maari silang magpasuri para sa anim na sakit sa halagang ₱550. Kasama ito sa *newborn care package* para sa myembro ng Philhealth. Maari din namang hilingin ang *expanded newborn screening* na magsusuri sa higit 20 mga kondisyon sa halagang ₱1500.

Bahagi ba ang expanded screening ng Philhealth?
Sa kasalukuyan, tanging ₱550 lamang ang nasa ilalim ng Philhealth. Kung ang magulang ay myembro ng Philhealth, at pinili nila na sumailalim sa *expanded newborn screening*, babayaran nila ang karagdagang halagang ₱950 upang mabuo ang kabuuang halaga na ₱1500.

Ano ang dapat gawin kung positibo sa pagsusuri sa isa sa mga kondisyon ang aming anak?
Ang positibong resulta ay hindi nangangahulugan na mayroong kondisyon ang inyong anak. Ang *newborn screening* ay nagsusuri kung ang mga sanggol ay maaring magkaroon ng sakit. Ang pagkakaroon ng abnormal na resulta ng *screening test* ay nangangahulugan ng karagdagang pagsusuri at *referral* sa espesyalista upang matiyak ang kondisyon ng inyong anak.

Regional. The number of newborns screened in all regions increased. Compared to other regions, CAR still has the biggest performance with an almost 90 percent coverage. Region 12, which ranked fourth in 2013, managed to move up its performance to rank second. Region 11 and Region 6 remained in the top four positions. CARAGA Region and Region 9 also had the biggest leap in terms of performance in 2014. Region 8, in spite of being hit by disasters which resulted in the closing down of most of its facilities, managed to land the eighth place.

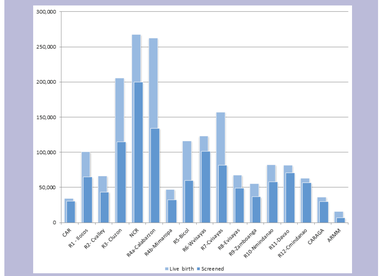


Figure 2. Regional screening coverage in 2014 versus live birth

Implementation of the Expanded Newborn Screening Program

The move and preparations to expand the number of disorders being screened from 6-test to more than 20 disorders started in 2012. With the infrastructure and protocols already in place at the Newborn Screening Center–National Institutes of Health (NSC-NIH), a pilot run was conducted mid-2014. Upon the release of Administrative Order No. 0045 on Expanded Newborn Screening on December 24, 2014, the NSC-NIH began accepting orders and samples from NSFs for expanded screening.

Expanded Newborn Screening (ENBS) is being offered as an option to the mandatory screening of six disorders (NBS 6-test).

- NBS 6-test is still packaged at P550 (plus P50 service fee for collection of blood sample).
- ENBS is packaged at P1,500 (plus P50 service fee for collection of blood sample).

GROUP OF DISORDERS	WITH NBS AND TREATMENT	WITHOUT NBS AND TREATMENT
ORGANIC ACID DISORDERS	• Alive • Most will have normal development with episodes of metabolic crisis	• Developmental delay • Breathing problems • Neurologic damage • Seizures • Coma • Early death
FATTY ACID OXIDATION DISORDER	• Usually healthy in between episodes of metabolic crises • Alive	• Developmental and physical delays • Neurologic impairment • Sudden death • Seizures • Coma • Enlargement of the heart & liver • Muscle weakness
HEMOGLOBINOPATHIES	• Alive • Reduces the frequency of painful crises • May reduce the need for blood transfusions	• Painful crises • Anemia • Stroke • Organ failure • Death
AMINO ACID DISORDERS	• Alive • Normal growth • Normal intelligence for some, learning problems to others	• Mental retardation • Coma and death from metabolic crisis

Table 1. Group of disorders included in the Expanded Newborn Screening Panel

Prevalence

More babies were identified having one of the conditions being screened by the newborn screening program. To ensure that newborns were rightfully diagnosed and managed, the follow-up program was intensified in 2014.

DISORDERS	CONFIRMED	SCREENED	CUMULATIVE PREVALENCE
(1) CAH	431	6 107 742	1: 14 171
(2) CH	2285	6 107 742	1: 2 673
(3) G6PD Deficiency	116 629	6 028 644	1: 52
(4) Gal (all types)	164	6 107 742	1:37 242
GAL – Classical	20	6 107 742	1: 305 387
GAL – Non Classical	58	6 107 742	1: 105 306
Gal – Variant	86	6 107 742	1:71 020
(5) MSUD	37	2 494 177	1: 67 410
(6) PKU (all types)	62	6 107 742	1: 98 512
PKU – BH4 Defects	7	6 107 742	1: 872 535
PKU – Classical	13	6 107 742	1: 469 826
PKU – Hyperphenylalanemia	29	6 107 742	1: 210 612
PKU – Mild	13	6 107 742	1: 469 826

Table 2. Prevalence of disorders among Filipino newborns (1996–2014)

Reunion of Saved Babies in Mindanao held in 2014 to celebrate the positive change in the affected newborns' lives.

Operationalizing Continuity Clinics

While capacity building and identification of possible sites were the main focus in the establishment of continuity clinics in various parts of the country in 2013, setting up and operationalizing them were realized in 2014. By the end of the year, 14 continuity clinics were fully set up and operationalized. Continuity clinics also serve as birth defects center.

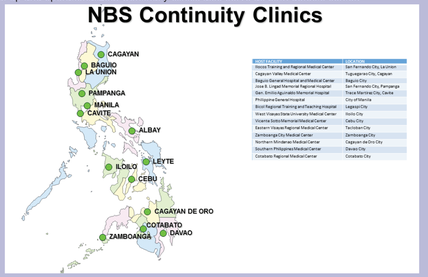


Table 3. List of continuity clinics

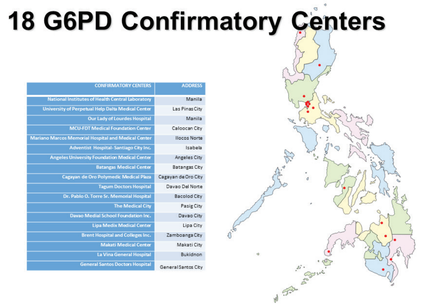
Continuity clinics conduct regular monitoring and assessment of patients confirmed with heritable disorders. All the continuity clinics are manned by at least a full-time nurse and a part-time pediatrician. They ensure that newborns confirmed to be having the disorders in the panel are followed up regularly and get to live normal lives. Their core responsibilities include performing patient- and family-centered activities. The team maintains a continuous relationship with the family of patients; monitors their compliance to treatment through scheduling, follow-up appointments and workups; facilitates referral of patients to available subspecialists in their facility or region; and provides continuing education to patient, family, and support group. The team collaborates with other agency partners of the program (DOH Regional Offices, NSCs, Clinical Genetics Units, NSRC, health facilities, health practitioners, and local government units) in the course of fulfilling their responsibilities.

UP Manila Chancellor and former Director of NSRC Dr. Carmencita Padilla (fifth from right) with the officers and staff of Baguio General Hospital and Medical Center and NSRC.

Additional Confirmatory Centers

Reference Laboratories for Hemoglobinopathies and Metabolic Disorders. With the expanded newborn screening enforced, confirmatory centers for hemoglobinopathies and for metabolic disorders were set up and operationalized at the Institute of Human Genetics, University of the Philippines Manila, in 2014.

G6PD Confirmatory Centers. In 2014, two centers were given licenses to be G6PD Confirmatory Centers bringing the total to 18 across the country. Six are still awaiting their licenses and are expected to be granted by the first quarter of 2015.



CONFIRMATORY CENTERS	ADDRESS
National Institutes of Health-Central Laboratory	Manila
University of Perpetual Help Dalta Medical Center	Las Pinas City
Our Lady of Lourdes Hospital	Manila
MCU-FDT Medical Foundation Center	Caloocan City
Mariano Marcos Memorial Hospital and Medical Center	Ilocos Norte
Adventist Hospital- Santiago City Inc.	Isabela
Angeles University Foundation Medical Center	Angeles City
Batangas Medical Center	Batangas City
Cagayan de Oro Polymedic Medical Plaza	Cagayan de Oro City
Tagum Doctors Hospital	Davao Del Norte
Dr. Pablo O. Torre Sr. Memorial Hospital	Bacolod City
The Medical City	Pasig City
Davao Medical School Foundation Inc.	Davao City
Lipa Medix Medical Center	Lipa City
Brent Hospital and Colleges Inc.	Zamboanga City
Makati Medical Center	Makati City
La Vina General Hospital	Bukidnon
General Santos Doctors Hospital	General Santos City

Table 4. List of G6PD Deficiency confirmatory centers as of December 2014

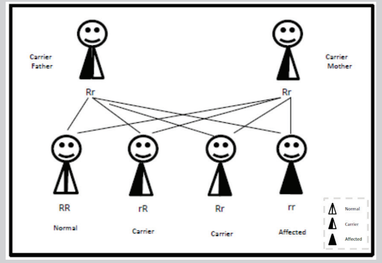
Frequently Asked Questions on 3-MCC

What is 3-Methylcrotnyl CoA Carboxylase Deficiency?

3-Methylcrotnyl CoA Carboxylase Deficiency (or 3-MCC) is a condition due to a deficiency in an enzyme or chemical scissors called 3-methylcrotonyl CoA carboxylase, which is needed to breakdown an amino acid called leucine. Amino acids are the building blocks of protein. Children with this condition will look normal at birth. Untreated children may remain without symptoms, while others may have seizures, drowsiness, low muscle tone, poor appetite, and failure to thrive. This disorder can be detected through newborn screening. However, neonates who test positive for this condition in expanded newborn screening do not actually have the condition but instead reflect the increased levels of the metabolites of their mothers. Thus, further investigation of the mother should be done as well.

What causes 3-MCC?

To efficiently use the food we eat, our body breaks it down to smaller units. Due to a lack of an enzyme or chemical scissors, children with this condition cannot effectively break down the amino acid leucine. The accumulation of leucine causes the signs and symptoms of this condition.



3-MCC is an inherited condition. The gene for the 3-methylcrotonyl CoA carboxylase enzyme is contained in the genetic material that we inherit from our parents. Because one part of the genetic material comes from the father and the other from the mother, the gene comes in pairs. In order to work correctly, at least one of the pairs should be working.

Parents of children with 3-MCC have one working and one non-working gene coding for a particular enzyme needed in the breakdown of fat. They do not manifest the disease but can pass them on to their children. They are known as carriers.

If the child inherits the non-working gene from both parents, he or she will have a 3-MCC. Thus, in each pregnancy, there is a 25 percent chance that the child will have the disorder, 50 percent chance of being a carrier and 25 percent chance of having two working genes.

What are the signs and symptoms of 3-MCC?

Children with this condition will look normal at birth. Untreated children may remain without symptoms, while others may have seizures, drowsiness, low muscle tone, failure to thrive, and poor appetite.

What is the treatment of 3-MCCC?

The main treatment of a 3-MCC is through a low-protein diet. If the child is well or does not have any illness, he or she should eat a low-protein diet. Glycine and/or Carnitine, a medication that helps boost energy, is also given.

What should I do when my baby is unwell?

Children with 3-MCC may have a metabolic crisis which is a serious health condition caused by the buildup of toxic substances in the blood. A metabolic crisis occurs when a child is sick, has not eaten, or has not drank well or during stressful events such as surgery and severe infection. Your child may present with lethargy, seizures or convulsions, irritability and vomiting. If not treated properly and immediately, it might lead to serious brain damage or death. Once these signs and symptoms are present, please bring your child to the hospital for management and alert your pediatrician or metabolic physician.

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If you would like to write an article, please contact us at info@newbornscreening.ph. We will do our best to keep you informed about current and relevant newborn screening issues.

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VOLUME 19
ISSUE
01
JANUARY-FEBRUARY 2015

newborn screening

Bimonthly Publication of the Newborn Screening Reference Center
National Institutes of Health, University of the Philippines Manila

Year in Review: Newborn Screening in 2014

Sixty-five percent of an estimated 1.8 million newborns were screened in 2014, an increase of 7 percent from 2013 (57.9 percent). The number of newborns screened per region also increased, with the Cordillera Administrative Region (CAR) still leading the list of most number of babies screened, overpassing the 85 percent national target for 2014.

More health facilities were added to the growing number of facilities offering newborn screening. A total of 675 facilities were added to the number of newborn screening facilities (NSFs). More newborns were identified and confirmed as having one of the disorders in the panel, bringing the number of babies saved to more than a hundred thousand.

The year 2014 also brought a new set of milestones to the program. Expanded Newborn Screening (ENBS) has been finally added to the National Comprehensive Newborn Screening System (NCNBSS) service delivery after two years of preparation. From 6-test panel, NCNBSS now offers screening for more than 20 disorders including endocrinologic and metabolic disorders and hemoglobinopathies. In addition, 14 Newborn Screening Continuity Clinics providing long-term follow-up management were fully operationalized in 2014.

All efforts in 2014 were to carry out the NCNBSS mandate. In ensuring that newborn screening tests were accessible and quality of testing was monitored, five Newborn Screening Centers (NSCs) were maintained and regularly subjected to external audits, reaccreditation processed by the Department of Health-Bureau of Health Facilities Services (BHFS), and external quality assurance programs.

Number of Babies Screened as of February 2015 COUNTER: 6,422,785