

Baby, Kids, and Family Expo Features ENBS

Mediacom Solutions, Inc., partnered with the NSRC to promote the Newborn Screening Program to exhibitors, guests, and participants of the 9th Baby, Kids, and Family Expo Summer Edition at SM Megatrade Hall, Mandaluyong City, on March 9-10, 2019.

The expo is the country's largest trade and consumer event showcasing top baby, kids, maternity, parenting, and family products and services.

This year's expo featured a variety of fun and educational activities for every family member and housed more than 90 exhibitors carrying over a hundred brands. It attracted over 10,000 visitors and provided them with lectures on preconception, birth, newborn care and development, and parenting.

Dr. Anna Lea G. Elizaga, Unit Head of NSC-National Institutes of Health (NIH), gave a lecture titled "The Importance of Newborn Screening" and also provided updates on the program. She discussed the complete list of disorders now being tested in the country and differentiated the outcomes of affected newborns when screened and not screened. She also announced the recent expansion of the PhilHealth's Newborn Care Package, which now covers the Expanded Newborn Screening Program.

Dr. Anna Lea G. Elizaga discusses NBS to the visitors of the Baby, Kid, and Family Expo.



Participants during one of the training programs in Central Luzon

DOH-CHD 3 Conducts Series of NBS Trainings

To ensure that quality newborn screening services are provided to clients of newborn screening facilities (NSFs) in Region 3, the Newborn Screening Team of the Department of Health-Center for Health Development (DOH-CHD) 3, in coordination with the Newborn Screening Center-Central Luzon (NSC-CL), conducted a series of DOH-funded NBS training programs in March and April 2019.

One to two health personnel per facility were invited to the training program, giving priority to (a) facilities applying to become registered NSFs, (b) NSFs whose trained NBS personnel already resigned, retired, or rotated to a different area, and (c) NSFs with high unsatisfactory sample rate.

On-site trainings were also conducted in facilities that had requested training from CHD 3. With this kind of training, more personnel from a particular NSF were oriented about the updates in NBS and trained to collect NBS samples.

The first batch of the DOH-funded training programs was conducted on March 28-29 at the Redd Manor Condotel, with 23 participants from 14 different NSFs in Central Luzon. An on-site training followed at Bulacan Medical Mission Group Health Services Cooperative in Bocaue, Bulacan, on April 1, with 17 participants from the said NSF. Another on-site training was held on April 10-11 at the Greencity Medical Center, a newly registered NSF from San Fernando City, Pampanga, with 21 participants composed of NICU nurses and medical technologists. The third on-site training was held on April 16-17 at the Ospital ng Lungsod ng San Jose in Nueva Ecija, with 48 participants from the said facility and CHO Panganakan ng San Jose.

DOH-CHD 3 has scheduled similar training programs in the coming months to guarantee that NBS is properly advocated to the public, quality samples are collected and properly handled, and prompt recall and follow-up of positive cases are being done by NSFs in Central Luzon. **NDelaCruz**



A hospital staff demonstrates the proper heel prick method to one of the participants.



Doctors and staff behind the reunion: Cyrus Jed Ramos, Vanessa Mabalo, Dr. Alma Estrada, Dr. Sharon Gawagawen, Dr. Lalaine Untalan, Dr. Ivy Rose Valdez, and Nicole Marie Bugarin

Reunion of Saved Babies in Region 1

Through the collaboration of the Philippine Society of Pediatric Metabolic and Endocrinology (PSPME) and the Newborn Screening Continuity Clinic (NBSCC) Region 1, a reunion of saved babies in Region 1 was held on April 4, 2019.

The reunion served to encourage parents to be advocates of newborn screening and to help them better understand congenital disorders and thus help their children cope with their conditions.

The activity was packed with games and giveaways, which filled the atmosphere with thanksgiving, laughter, and joy from both children and parents. Some parents and healthcare professionals shared heartwarming testimonies and stories as

well to demonstrate how NBS works and saves lives.

More than two hundred thousand babies have already been saved from death, mental retardation, and other associated disabilities in affected infants since 1996, when newborn screening was introduced as a pilot project and subsequently mandated by Republic Act No. 9288, or the Newborn Screening Act of 2004.

"Saved babies" refer to those with genetic condition detected through newborn screening and consequently saved from death and mental retardation after receiving prompt, proper, and continuous management of their conditions. **CJRamos**



Attendees of the Reunion of Saved Babies

DOH-CHD 10 Holds NBS Training

In preparation for the full implementation of ENBS, DOH-CHD 10 gathered together 30 program coordinators from the provinces of Bukidnon, Lanao del Norte, Misamis Occidental, and Misamis Oriental for a training at De Luxe Hotel in Cagayan De Oro City on March 14-15, 2019.

Dr. Conchita G. Abarquez, Newborn Screening Center-Mindanao (NSC-M) Head, discussed the panel of disorders, while NSC-M project development officers talked about NSF protocols, program quality indicators, and annual performance report for 2018.

The training aimed to guide participants on the management of newborn screening service in their respective facilities and provide orientation on the changes brought by ENBS implementation. Sample collection practicum was conducted at the Northern Mindanao Medical Center (DOH-retained hospital) and J. R. Borja General Hospital (city hospital). **RAguilar**

Participants of the NBS training in Northern Mindanao.



DOH-CHD 12 Conducts 1st NBS Training for 2019

The NBS team of DOH-CHD 12 and NSC-M conducted the Orientation on Expanded Newborn Screening and Heel Prick Training, its first training for the year, on February 20-21, 2019.

On the first day of the activity, lectures on newborn screening were given by Rohainnah Mua, Regional NBS Nurse Coordinator; Dr. Conchita G. Abarquez, NSC-M Unit Head; Perly Bermudez, PDO of NSC-M; and Juledene Mendoza, NBSCC Nurse. Sample collection demonstration

was conducted on the second day at the Dr. Jorge P. Royeca Hospital in General Santos City.

IEC materials such as ENBS booklets, handouts, brochures, posters, fans, tarpaulins, and knapsack bags were distributed to all the 32 participants, who were nurses, midwives, and medical technologists from government and private health facilities in the provinces of South Cotabato, Sultan Kudarat, and North Cotabato and in General Santos City. **RMua**



Parents and guardians of patients undergo interview with the participants as part of the latter's practicum in the hospital.



Republic of the Philippines
Department of Health
OFFICE OF THE SECRETARY

MAR 29 2019

ADMINISTRATIVE ORDER
No. 2019- 2014-0045-A

SUBJECT: Amendment to Administrative Order No. 2014-0045: Guidelines on the Implementation of the Expanded Newborn Screening Program

Pursuant to Section 11 of Republic Act No. 9288, otherwise known as the Newborn Screening Act of 2004, the Advisory Committee on Newborn Screening (ACNBS) shall review and recommend the newborn screening (NBS) fee to be charged by the Newborn Screening Center (NSCs) in order to ensure that NBS will be accessible to all newborns.

During the meeting of the ACNBS held last 04 October 2018, the price adjustment in the expanded newborn screening (ENBS) fee of One Thousand Seven Hundred Fifty Pesos (Php1, 750.00) has been approved. The said price will apply to all new NBS filter cards purchased from the NSCs upon effectivity of this Order. In view of this, the following provision of Administrative Order No. 2014-0045 dated November 19, 2014 is hereby amended:

FROM:
VI. Specific Guidelines/Implementing Mechanism

- D. Budget Source**
- The NBS Fee**
 - The cost of the tests shall be as follows (*Per recommendation of the ACNBS on August 19, 2012*):
 - Option 1 (6 disorders) - Php550.00
 - Option 2 (expanded newborn screening) - Php1,500.00.
 - For PhilHealth members, P550 shall be covered by PhilHealth. For Option 1 (6 disorders), the total cost shall be covered. For Option 2 (expanded NBS), only Php 550.00 shall be covered by PhilHealth and the balance shall be an out-of-pocket expense of the family.

TO:
VI. Specific Guidelines/Implementing Mechanism

- D. Budget Source**
- The NBS Fee**
 - The cost of the tests shall be as follows (*Per recommendation of the ACNBS on October 04, 2018*):
 - Option 1 (6 disorders) - Php550.00
 - Option 2 (Expanded Newborn Screening) - Php1,750.00.
 - For PhilHealth members, the total cost shall be covered by PhilHealth (*Per PhilHealth Circular 2018-0021 on Enhancement of Newborn Care Package*):
 - Option 1 (6 disorders) - Php 550.00
 - Option 2 (Expanded Newborn Screening) – Php 1750. 00

Option 1 (6 disorders) shall be offered until April 30, 2019 only. Effective May 1, 2019, all infants born in accredited facilities shall be tested for expanded newborn screening panel (Option 2) only.

As thus amended, all other provisions of Administrative Order No. 2014-0045 shall remain in full force and in effect.

This order shall take effect fifteen (15) days after publication in the official gazette or newspaper of general publication.

FRANCISCO T. DE QUE III, MD, MSc
Secretary of Health

MESSAGE

To all of you, staunch believers in NBS, welcome to the 17th Annual National NBS Convention! Our convention date has been moved earlier to October 1-2, 2019 to be held at the PICC.

The good news is that PhilHealth, which is our country's largest purchaser of health care services, has approved the Expanded Newborn Care Package that will cover ENBS. With this development, ENBS is expected to increase its national coverage from a measly 9-12% that we got last year. Another development, as I am writing this message, is the passage of the Universal Health Care Law just a few weeks ago. How this will impact the steady increase of our ENBS national coverage is something to look forward to. All newborn babies, as in 'ALL', whether they are babies of 'indirect' and 'direct' members of PhilHealth will now be checked for all the diseases in our ENBS panel. We are still waiting for the IRR but we are hopeful that it will support what we have started in our NBS program.

In our convention, again we will discuss problems/solutions that commonly beset us in our day to day NBS practice. Some interesting clinical presentations will be given by our speakers as a testament that the program truly finds positive cases of babies who are saved from mental retardation and death.

Our convention will once again bring together all the important stakeholders of NBS --- the true staunch believers of NBS, which is I say is one of the best health programs in our country today.

Mabuhay tayong lahat! Welcome, again, to our 17th Annual NBS Convention!

EPHRAIM NEAL C. ORTEZA, MD, MHA
President, NSSPI



17th NEWBORN SCREENING CONVENTION
Reception Hall, PICC, Pasay City
October 1-2, 2019
"Enhancing Coverage, Communication and Collaborations towards a Successful Expanded Newborn Screening Program"

TOPICS

- Progress Report of the Newborn Screening Program
- Impact of Universal Health Care on the Newborn Screening Program
- Medical Management
 - Crisis Management
 - Basic genetics education
- ABCs of Newborn Screening
 - Basic Principles in the Nutritional Management of Inborn Errors of Metabolism
 - The Role of Dietitians in the Long Term Management of Patients with IEM
 - Nutrition Care Process for Inborn Errors of Metabolism
- Family Experiences after Diagnosis: Care, Resources and Support
- Impact of Vigilant Follow-Up
- Thalassemia
- Issues in Genetic Counseling for Thalassemia
- New Communication Strategies for the Newborn Screening Program
- Best Practices/Success Stories
- Critical Congenital Heart Disease
- Newborn Hearing Screening
- Vision Screening for Kindergarten

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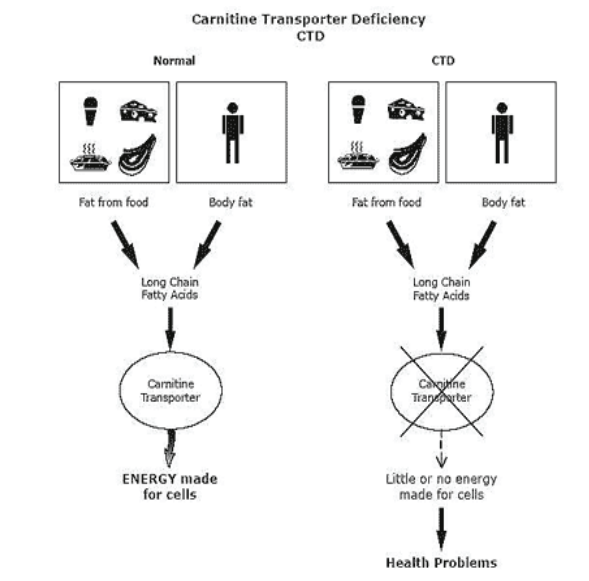
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IN THE KNOW

Carnitine Uptake Defect (CUD)

What is CUD?

Carnitine Uptake Defect (CUD) is also known as Carnitine Transporter Deficiency. It is due to an abnormality in the transport that facilitates carnitine's entry into certain cells. In some instances, it has been found that neonates who test positive for this condition do not actually have the condition but instead reflect the decreased levels of their mothers.



Source: <https://www.newbornscreening.info>

Overview of Disease Management

Oral carnitine therapy at 100 mg/kg/day into four divided doses is recommended.

Prognosis

Patients on long-term therapy report normal skeletal muscles tone, no episodes of metabolic decompensation, and essentially normal intellect.

Preliminary/Initial Management during Metabolic Crisis

Metabolic crises may be caused by illness, prolonged fasting or stressful situations such as surgery, and severe infection. The goal of treatment is to reverse the catabolic state, correct the acidosis, and prevent essential amino acid deficiency.

What To Do

- If unwell and cannot tolerate oral intake:
- Nothing per oreum
 - Ensure patient's airway is secure
 - Insert IV access. Monitor glucose levels. May request for investigations (i.e., CBC etc.) as needed.
 - May give fluid boluses if patient requires.
 - Start D10% 0.3NaCl at full maintenance. Assess patient clinically; if there is need to increase fluid, may do so up to 1.2 or 1.5x the maintenance.
 - Monitor input and output strictly (q6 hours).

If unwell and can tolerate oral intake:

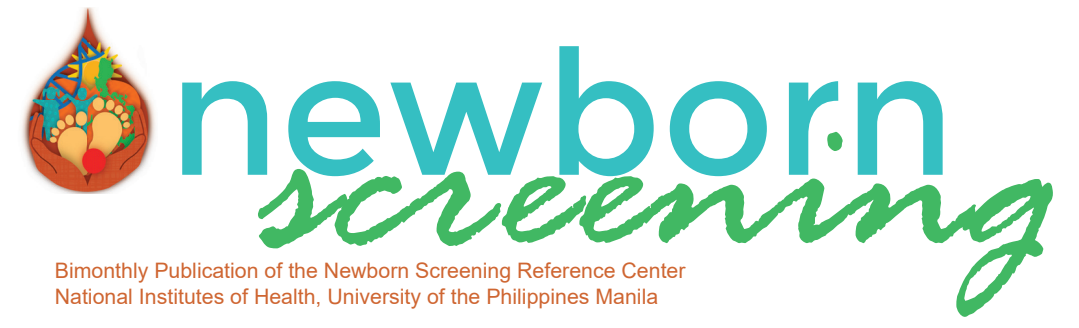
- Encourage regular feeding
- Insert IV access. Monitor glucose levels. May request for investigations (i.e., CBC etc.) as needed.
- Start D10% 0.3NaCl at 5-10 cc/hr
- Monitor input and output strictly (q6 hours)

Inform metabolic doctor on call for further guidance regarding ongoing management.

Source: *Fact Sheets for Doctors, May 27, 2019, accessed at www.newbornscreening.ph.*

Thank you for reading our newsletters! We would love to hear your feedback. Please let us know how we can improve our bimonthly newsletters by answering our feedback form at www.newbornscreening.ph. 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.

Your Feedback Is Important To Us



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Dr. Carmencita D. Padilla (seated, third from left) leads the participants of the RTD on Genetic Metabolic Dietetics at the UP-PGH Board Room.

IHG, NSRC Hold RTD on Genetic Metabolic Dietetics

The Institute of Human Genetics (IHG), in partnership with the Newborn Screening Reference Center (NSRC), held the Round Table Discussion (RTD) on Genetic Metabolic Dietetics in the Philippines at the University of the Philippines–Philippine General Hospital (UP-PGH), Manila, on April 3, 2019.

The RTD aimed to define the role and capabilities of the different nutrition-dietetics societies and organizations in addressing the needs of patients with Inborn Errors of Metabolism (IEM) detected through the expanded newborn screening test.

Karen Asuncion Panol, NSRC Quality Assurance Unit Head, and Aster Lynn Sur, IHG Genetic Nurse, presided over the event, while Dr. Carmencita David-Padilla, UP Manila Chancellor, delivered the opening remarks and inspirational message.

Panol started the discussion by introducing newborn screening, some program updates, and the full implementation of the expanded newborn screening (ENBS). She also shared the challenges and strategies in program implementation, highlighting the role of program implementers and the significance of securing the active participation of key healthcare providers in the management of patients.

Dr. MaryAnn Abacan, member of the Expert Committee on Metabolic

Continued on page 2 . . .

Number of Babies Screened as of April 2019 : 12,736,458

What's Inside

- Baby, Kids, and Family Expo Features ENBS
- DOH-CHD 3 Conducts Series of NBS Trainings
- Reunion of Saved Babies in Region 1
- DOH-CHD 10 Holds NBS Training • DOH-CHD 12 Conducts 1st NBS Training for 2019
- Announcements
- In The Know Carnitine Uptake Defect (CUD)