

NSC-NL Now Offers ENBS

It has been the goal of NSC-NL to fully implement ENBS in its constituent regions, Ilocos and Cagayan Valley. And on January 28, 2019, it finally got the green light to launch the program.

Guided by the strategic framework of the National Newborn Screening System of the Philippines, the implementation of ENBS by NSC-NL makes the program more accessible to the northern part of the Philippines.

The NSRC Quality Assurance Team—composed of Charity Jomanto, Maria Truda Escoreal, and Margarita Aziza Canlas from NSRC and Bryan Digidigan from NSC-V—was present to provide technical support and ensure the smooth operation during the first week of implementation of ENBS. For the first week, NSC-NL tested 838 ENBS samples: 590 from Region 1 and 248 from Region 2.

As part of the launching, NSC-NL offered a thanksgiving Mass on February 1, 2019, followed by the blessing of the offices and laboratory.

NSC-NL plans to build more partnerships for advocacy as the ENBS Program progresses in the said regions. *AJAlmazan*



Staff of NSC-NL join the rare diseases awareness campaign by taking photos holding posters with messages about rare diseases and posting them on their social media accounts.

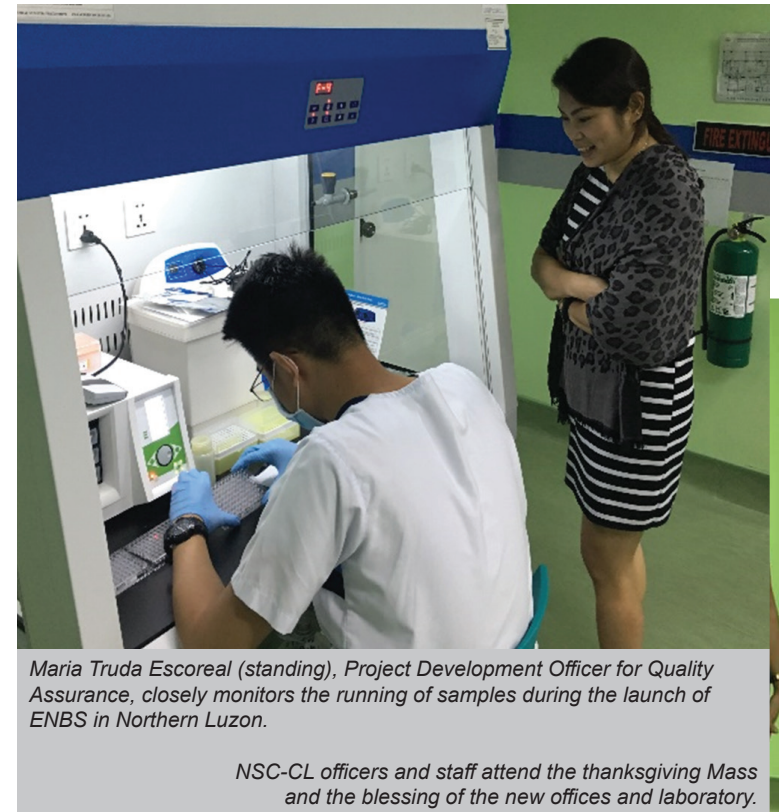
NSC-NL Raises Hands for Rare Diseases

“No act is too small for this noble cause.”

Dr. Bing Otagya, NSC-NL Unit Head, reminded participants during the celebration of the National Rare Disease Week and World Rare Disease Day on February 28, 2019.

Rare diseases affect only a small percentage of the population, but they have devastating impact on the lives of affected patients, their families, friends, caregivers, and the society as well. This is the reason why NSC-NL staff “raised their hands” as part of a social media campaign during the celebration.

Some rare diseases can be detected through ENBS; thus, the implementation of the program could help alleviate the fears of expecting parents in Northern Luzon. *AJAlmazan*



Maria Truda Escoreal (standing), Project Development Officer for Quality Assurance, closely monitors the running of samples during the launch of ENBS in Northern Luzon.



NSC-CL officers and staff attend the thanksgiving Mass and the blessing of the new offices and laboratory.

NSC-CL Releases Proper Specimen Collection Video



Screenshots of the video showing important information about newborn screening and proper instructions for specimen collection

- ✓ Malusog
- ✓ Naka-antibiotic
- ✓ May malubhang karamdaman
- ✓ Preterm
- ✓ Low birth weight

Timely collection of quality samples is vital in newborn screening. Unsatisfactory samples delay testing, as patients must be recalled for repeat collection or for verification before the release of results. In turn, delayed testing leads to late diagnosis and treatment of babies who might be positive for the disorders that are being screened for.

All delays may cause babies to suffer from mental retardation or early death; therefore, NSC-CL encourages healthcare practitioners to observe proper sample collection and check the quality of samples before sending these to the laboratory.

To address the growing number of unsatisfactory samples received by NSC-CL, the Center created an instructional video on how to properly collect NBS samples. The video highlights the significance of proper specimen collection. Sent to newborn screening facilities (NSFs) in Central Luzon and the Cordillera Administrative Region, the video also shows other important information about NBS such as the ideal time to collect samples, where to collect, and the qualified people to collect samples. It was also posted on social media in order to reach more healthcare professionals. *NDelaCruz*

NSC-CL Recognizes Well-Performing NSFs

To recognize facilities that effectively promote and implement the NBS Program in their respective constituencies, NSC-CL awarded Certificates of Recognition for the first quarter of 2019 to well-performing NSFs in Central Luzon and Cordillera Administrative Region.

- The recognized NSFs have met the following criteria:
- Less than 1% Unsatisfactory Rate in 2017
 - Less than 1% Unsatisfactory Rate in 2018
 - 50% and above initial ENBS samples over the total initial samples in 2017 (with a minimum of 5 samples for the whole year)
 - 60% and above initial ENBS samples over the total initial samples in 2018 (with a minimum of 5 samples for the whole year)

For the full list of awardees, please visit our website <http://www.newbornscreening.ph>.

IN FOCUS

Konsehal Dada: Public Health Servant



It takes a village to raise a child.

This explains the successful follow-up program in Calatagan, Batangas, as Eduarda Gomez, a barangay councilor in charge of social service and health, leads in promoting the importance of responsible parenthood and community support in raising children.

Gomez, a barangay health worker who is fondly called Konsehal Dada, says that her service is not confined to her area of jurisdiction. She extends her support to nearby barangays as well. For instance, she accompanies children from her barangay and nearby barangays to do follow-up checkups. She also attends to parents when they need to go to the municipal office to request for financial aid for laboratory testing.

Gomez also arranges for government vehicles to transport patients to the continuity clinic. She and the health workers in her barangay also help explain the benefits of newborn screening to the parents.

“Parents now have the opportunity to know early what they are dealing with,” shares the public servant. “The earlier they know, the better. Our patients now are living a normal life. The fears of the parents have lessened due to the support provided to them by the local leaders and the continuity clinic.”

Gomez says that she is always ready to provide assistance and there are other local leaders who are also willing to help. She hopes that as they are doing their part, parents should do theirs too.

“Alagaan nyo ang mga bata at kayo ay inaalagaan ko. Galingan nyo at gagalingan ko din,” she says to one of the parents.

Konsehal Dada (standing) with the mothers and patients she regularly accompanies during their follow-up checkups.



Participants from the 27 NSFs and organizers of the program share a group photo during the ENBS training in Zamboanga City.



Zamboanga Peninsula Prepares for ENBS

The Department of Health—Center for Health Development (DOH-CHD) Zamboanga, together with NSC-M, continues to hold continuing education programs not only to train frontliners for ENBS in Zamboanga Peninsula but also to assess the preparation of the facilities for ENBS in the region.

These programs are done at least three times a year, and this year’s first was held in LM Metro Hotel at Zamboanga City, on February 7-8, 2019, with 27 participants from all over Zamboanga Peninsula.

The actual heel-prick and screening of babies were conducted at the Zamboanga City Medical Center. With the assistance of trained personnel, participants were taught the proper techniques in collecting and handling blood samples. The training also addressed unsatisfactory samples and provided tips on how to avoid them.

NSFs now transition from regular NBS to ENBS, and staff require diligence in the program implementation as well as advocacy and public information efforts. Coordination and team efforts among NBS coordinators, department heads, partner agencies, and PhilHealth are also necessary for the newborn screening program to achieve its goals set in the coming years. *AMatuan*

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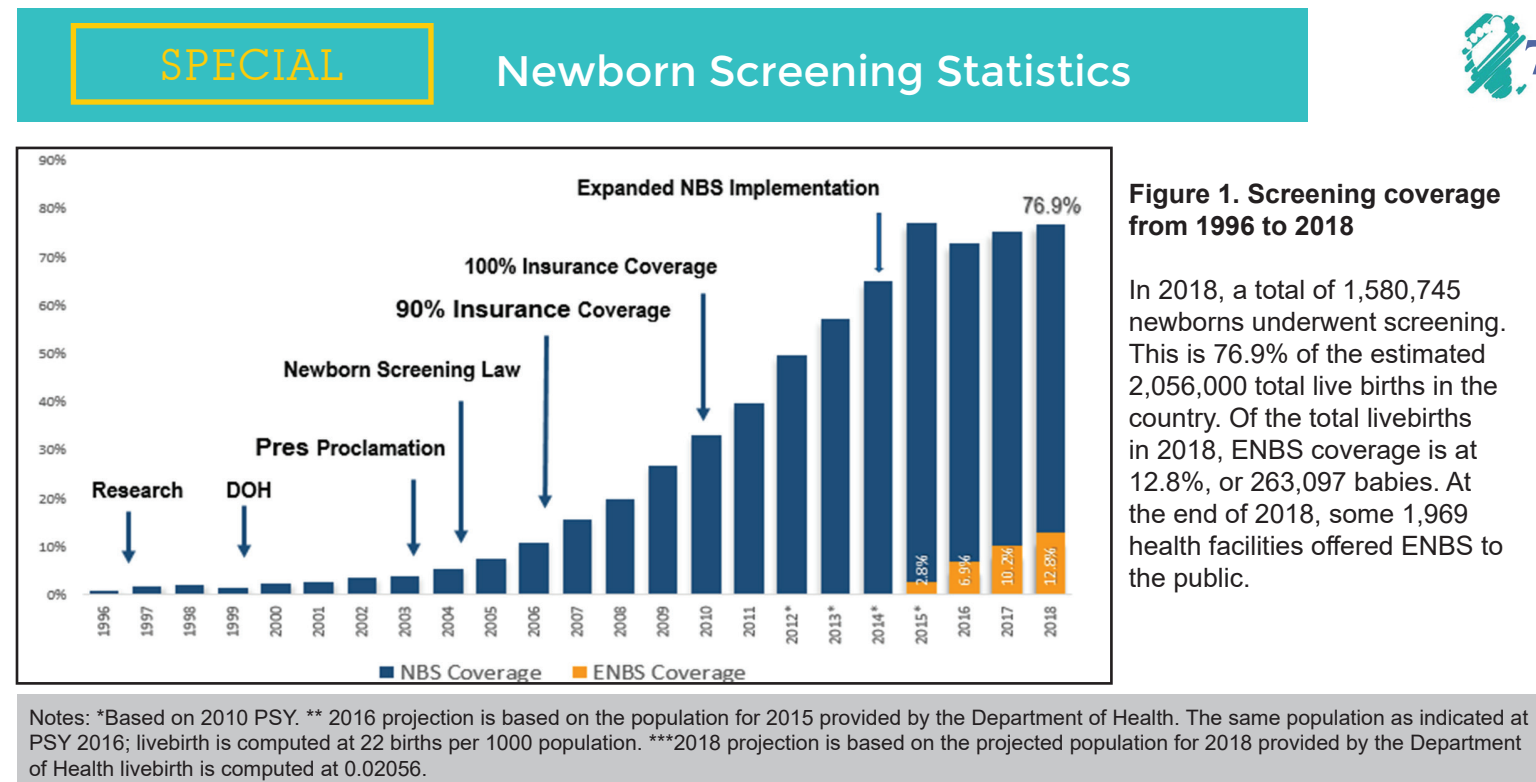


Table 1. Prevalence of disorders among Filipino newborns as of December 2018

At the end of 2018, a total of 202,440 babies were confirmed, having one of the conditions being screened by the newborn screening program. Now, based on the number of confirmed cases, G6PD Deficiency still has the highest incidence rate of 1 for every 61 newborns.

Disorders	Screened	Confirmed	Prevalence
Endocrine Disorders			
CH	12,233,971	4,360	1:2,805
CAH	12,233,971	622	1:19,668
Amino Acid Disorders			
PKU (Classic, Mild, PTPS, Def, Hyperp)	12,233,971	91	1:134,439
MSUD	8,345,480	122	1:68,406
Fatty Acid Disorders (8 MCADD, 10 VLCAD, 2 CUD)	665,578	20	1:33,278
Organic Acid Disorders (2 MMA, 7 3MCC, 7 GA1, 1 PA)	665,578	17	1:39,151
Urea Cycle Defect (1 CIT, 4 ASA)	665,578	5	1:133,115
GAL (Classical, Non-Classical)	12,233,971	91	1:134,439
G6PD Deficiency	12,028,523	198,175	1:61
Hemoglobinopathies	665,578	476	1:1,387

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IN THE KNOW Fatty Acid Oxidation Disorders (FAODs)

What are FAODs? FAODs are a group of autosomal recessive disorders caused by the deficiency or absence of any of the enzymes needed for beta-oxidation. Children born with this condition appear normal at birth, but untreated patients may present with low blood sugar, which can lead to seizures, coma, and death. One type of FAOD, VLCAD (or very long chain acyl-CoA dehydrogenase deficiency) may present with cardiomyopathy and increased creatine kinase (CK) levels. FAODs include:

- Medium chain acyl co-A dehydrogenase deficiency (MCAD)
- Very long chain acyl Co- A dehydrogenase deficiency (VLCAD)
- Long chain hydroxyacyl co-A dehydrogenase deficiency (LCHAD)
- Trifunctional protein deficiency (TFI)
- Carnitine Palmitoyl Transferase Deficiency Type 1
- Carnitine Palmitoyl Transferase Deficiency Type 2
- Carnitine Uptake Defect
- Glutaric Aciduria Type 2

VLCAD, collect samples for serum CK. May request for other investigations (i.e., CBC, blood gas) as needed. May give fluid boluses if patient requires.

- Start D10% 0.3 NaCl 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). Check for the color of urine.

If unwell and is able to tolerate oral intake:

- Insert oro- or nasogastric tube and start continuous feeding with a high glucose formula.
- Insert IV access. Monitor glucose levels. For patients with VLCAD, collect samples for serum CK. May request for other investigations (i.e., CBC, blood gas) as needed. May give fluid boluses if patient requires.
- Start D10% 0.3 NaCl at 5-10 cc/hr.
- Monitor input and output strictly (q6 hours). Check for the color of urine.

Notes. 1. Patients with VLCAD may have rhabdomyolysis. Monitor CK levels and hydrate adequately. If CK levels continually rise, hemodialysis may be indicated. 2. Inform metabolic doctor on call for further guidance regarding ongoing management.

NSC Summit . . . from page 1

while Sheila Guilaran, NSC-Mindanao (NSC-M) Program Manager, gave a lecture on "power" and how it applies to the setup of NSCs. Anthony Almazan, NSC-Northern Luzon (NSC-NL) Program Manager, discussed the domains of strength and the competencies of each member of the team, while Joanna Terrado, Project Development Officer at NSC-National Institutes of Health (NSC-NIH), defined "failure" and shared the steps being done by NSC-NIH in managing anticipated risks. Dr. Anna Victoria Sombong, NSC-Visayas (NSC-V) Laboratory Head, defined "negativity" and shared some tips on how to minimize it in an organization. She also encouraged everyone to have the courage to take a stand against negative behavior. Lastly, Veronica Benipayo, NSC-Central Luzon (NSC-CL) Program Manager, shared seven steps on how to recover from burnout and regain energy to break the cycle and make a full recovery to become productive again.

As culmination, staff who were with the program for at least five years were awarded with a Plaque of Recognition. University of the Philippines Manila Chancellor Carmencita D. Padilla, proponent of the newborn screening program and consultant of the Newborn Screening Reference Center (NSRC), closed the event by thanking everyone for their contributions to the program and expressed her hopes that people would stay to witness how all plans would prosper and materialize.

Treatment of FAODs. Treatment is through the dietary restriction of fat. VLCAD patients are treated with a special milk formula containing medium chain triglycerides.

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 and prevent hypoglycemia.

What to Do

If unwell and cannot tolerate oral intake:

- Nothing per oral
- Ensure patient's airway is secure
- Insert IV access. Monitor glucose levels. For patients with

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NSC Summit Renews Staff Commitment to NBS Program

Dr. Anna Victoria Sombong shared some tips on how to minimize negativity in the workplace.

What's Inside

2. NSC-NL Now Offers ENBS • NSC-NL Raises Hands for Rare Diseases
3. NSC-CL Releases Proper Specimen Collection Video • NSC-CL Recognizes Well-Performing NSFs
4. In Focus Konsehala Dada: Public Health Servant
5. Zamboanga Peninsula Prepares for ENBS
6. Special Newborn Screening Statistics
7. In The Know Fatty Acid Oxidation Disorders (FAODs)

Continued on page 8 . . .

Number of Babies Screened as of February 2019 : 12,493,963