



Dr. Ma. Virginia Paz K. Oatza, NSC-NL Unit Head, shares to the group her insights about "inspired learning" during the culmination activity of the newborn screening training.

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In his message, Dr. Anthony Calibo, National Program Manager, encouraged the participants to continue making a difference in the lives of affected children and their families. He reminded the participants of their responsibilities as part of the public health sector to use the public resources appropriately.

"We are accountable for the funds we get from people's money, from PHIC funds," Dr. Calibo said. "Let this public health intervention be not tainted with selfish and vested interests; rather, let us look at the reason why we are here and that is to save the lives of the children."

The meeting took off with a presentation of updates on the agreements made in 2018 and the resolution of remaining issues, followed by the developments in the program such as the full coverage of ENBS in the PhilHealth Newborn Care Package and the ongoing revision of the administrative order on ENBS to incorporate treatment fund and to integrate regional genetic

centers. The availability of funds, spending analysis, and fund transfer requests were also examined.

On the second day, the participants were encouraged to pay more attention to the recall of patients and the provision of financial support to ensure continuity of care. Data and activities of continuity clinics were presented to show the improvements in the follow-up program and the importance of Newborn Screening Continuity Clinic (NBSCC) monitoring of patients in every region.

Meanwhile, Dr. Mary Ann Remonte, PhilHealth MDG Team Leader, explained the latest newborn care package and addressed queries of the participants during the open forum.

As a culmination, a training of trainers was conducted, in partnership with Future by Design Pilipinas (FBDP), and was facilitated by Dr. Juan A. Kanapi, Jr., and Ana Margarita Cuneta Sanchez. This activity sought to strengthen the capacity of the coordinators and their respective teams as trainers in the field of newborn screening and its implementation. Participants also shared practices and experiences through group activities.



Dr. Mary Ann Remonte addresses issues on the implementation of the expanded Newborn Care Package.



Participants in the NBS training together with Region 6 NBS Program Manager Dr. Renilyn Reyes (first row, fifth from left) and NBS Regional Coordinator Grace Exmundo (first row, 6th from left)

DOH-CHD 6 Conducts NBS Training, Participants Get CPD Units

A total of 31 health staff comprised of nurses, doctors, midwives, and medical technologists attended an NBS training spearheaded by DOH-CHD 6, in coordination with NSC-Visayas (NSC-V) and NBSCC, on June 3-5, 2019.

The three-day capacity building activity consisted of lecture discussions, video presentations, workshops, and a practicum on heel-prick method.

The training design, which followed the Facilitator's Guidebook as reference, was modified by the regional NBS technical

working group to create a localized, comprehensive training for health workers in Western Visayas.

The training, which was applied for Continuing Professional Development (CPD) units through the Human Resource Development Unit of DOH-CHD 6 and DOH Central Office, was officially granted CPD units for the following cadres: Medicine (9.5), Midwife (20.0), Medical Technologist (11.5), and Nursing (to be announced). *GExmundo*

Yugie Demegillo (standing), NSC-V Program Manager, discusses how to educate parents and collect samples from newborns.



Representatives from CLMMRH discuss with heads and program coordinators from DOH-CHD 6 and NSC-V the requirements to open a satellite continuity clinic in Negros Occidental.

DOH-CHD 6 to Establish 2nd NBSCC in Western Visayas

Negros Occidental, which comprises 40 percent of the population of Region 6, has the highest number of NBS cases. To localize NBS services in the said province, DOH-CHD 6 has involved various health facilities, including Corazon Locsin Montelibano Memorial Regional Hospital (CLMMRH), which is currently being developed into the second NBSCC in the region.

CLMMRH is a DOH retained hospital that was initially organized as a Newborn Screening Satellite Clinic. The availability of local specialists in CLMMRH, however, was an opportunity to establish it as a local NBSCC, in addition to West Visayas State University Medical Center located in Iloilo City, which was one of the 14 clinics established nationwide in 2014.

To utilize this opportunity to the maximum so that the CLMMRH can become a venue that provides long-term management to the positive patients in Negros Occidental and nearby areas, DOH-CHD 6 met with the key personnel of CLMMRH, including the chief of hospital, budget and accounting officers, pediatrics department head, administration head, legal officer, nurse supervisors for OPD/NICU, and NBS Team.

The specialists in CLMMRH and the identified partners (NSRC, NSCV,

NBSCC, Negros Occidental Provincial Health Office and Bacolod City Health Office) have arranged the setup and flow of operations for the proposed NBSCC. Series of meetings have been conducted since 2017, and assistance to augment operations was pledged by various stakeholders.

A Memorandum of Agreement between parties is now being processed to formalize the operations of the new NBSCC. *GExmundo*



Photo by Mark Ramirez from Flickr.com

Clockwise from top left: RHU II Lingayen, RHU Anda, Tumauni District Hospital, Western Pangasinan District Hospital, and RHU Bani



NSC-NL Travels the Region for NSFs Check

Northern Luzon boasts of its rich history, diverse culture, and impressive geography. The heritage city of Vigan, the Hundred Islands in Alaminos City, the Marian Pilgrimage site of Piat, and the otherworldly sceneries in Batanes are just a few of the most visited spots in Ilocos Region and Cagayan Valley.

NSC-NL has set out for a trip in Northern Luzon, not for leisure but for a mission to strengthen newborn screening implementation. NSC-NL, together with the NBS Teams of DOH CHDs Ilocos and Cagayan Valley, visited newborn screening facilities in Regions 1 and 2 in May 2019.

This visit ensured that NSFs are compliant to their roles as stated in the Implementing Rules and Regulation of the Newborn Screening Act of 2004, which include (a) integrating NBS in their delivery of health services; (b) serving as collecting health facility for NBS; (c) coordinating with a duly accredited NSC; (d) ensuring that adequate and sustained NBS services such as information, education, communication, screening, recall, and management of identified cases are being provided in the hospital; (e) establishing an NBS Team that will be responsible for the collection of samples, sending

samples to accredited NSC, prompt recall of positive patients, and referral and management of patients; (f) establishing an appropriate financial system that will ensure effective and efficient collection of fees and payment of NBS services to the NSC; (g) conducting orientation and/or training of hospital staff on NBS; (h) monitoring and evaluating the implementation of NBS within the institution; and (i) defining creative financial packages to make NBS accessible particularly among the economically deprived populace.

The following facilities were visited: Pangasinan—RHU I Bolinao, RHU Anda, RHU Bani, Bolinao Community Hospital, Alaminos City Birthing Center, Western Pangasinan District Hospital, Blessed Family Doctor General Hospital, Elguira General Hospital, Manzon Maternity Care Co., RHU II Lingayen, Lingayen District Hospital, and Jesus Nazarene General Hospital; Isabela—Tumauni District Hospital; Cagayan—Aparri District Hospital; and Nueva Vizcaya—Dupax District Hospital, MHO Dupax del Sur, and Region 2 Trauma and Medical Center. *AJAlmazan*





NSRC Director Noel Juban (seated 8th from left), NBS National Program Manager Anthony Calibo, and NBS National Coordinator Lita Orbillo pose for a group photo with the NBS Regional Coordinators and NSC Unit Heads and Program Managers during the Annual Consultative Meeting on June 26-28, 2019, in Manila.

What's Inside

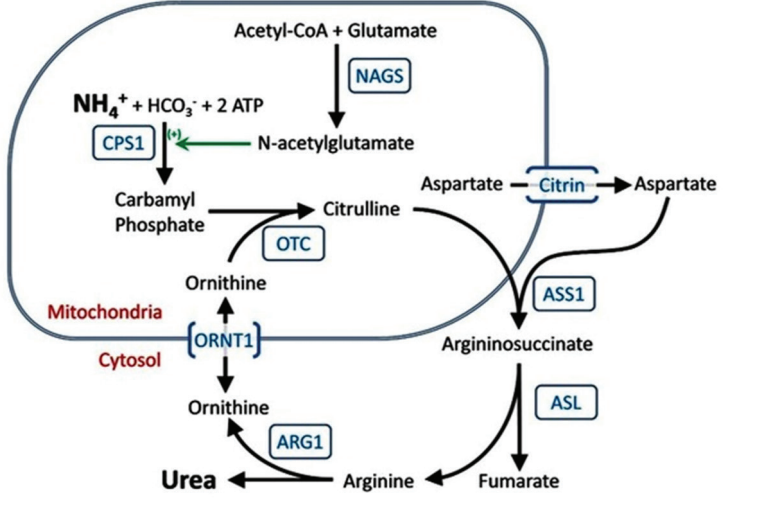
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Number of Babies Screened as of June 2019 : **12,981,629**

IN THE KNOW Argininosuccinic Aciduria

What is ASA?
Argininosuccinic Aciduria (ASA) is an inborn error of metabolism resulting from the deficiency of the enzyme argininosuccinic lyase.



Prognosis
Prognosis for intellectual development probably depends on the nature of the initial hyperammonemia, especially in duration or the nature of recurrent episodes.

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 ore
 - Ensure patient's airway is secure
 - Insert IV access. Collect sample for serum ammonia. May request for investigations (i.e., CBC, etc.), as needed
 - May give fluid boluses if patient requires
 - Start 012.5% 0.3NaCl at full maintenance
 - Assess patient clinically; if there is need to increase fluid, may do so up to 1.2 to 1.5x of maintenance
 - Start IV sodium benzoate loading dose (250mg/kg) to run for 1-2 hours
 - Start IV arginine loading dose (250mg/kg) to run for 1-2 hours
 - Monitor input and output strictly (q6 hours)

- If unwell and CAN tolerate oral intake:
- Insert oro- or nasogastric tube and start continuous feeding with protein-free formula at maintenance rate
 - Insert IV access. Collect sample for serum ammonia. May request for investigations (i.e., CBC, etc.), as needed
 - May give fluid boluses if patient requires
 - Start 012.5% 0.3NaCl at 5-10 cc/hr.
 - Start IV sodium benzoate loading dose (250mg/kg) to run for 1-2 hours
 - Start IV arginine loading dose (250mg/kg) to run for 1-2 hours
 - Monitor input and output strictly (q6 hours)
- *Children should not be protein restricted for longer than necessary (24-48 hours).

If patient does not improve with the initial management (within 12 hours), hemodialysis may be indicated. Monitor patient clinically; the necessity of hemodialysis will depend on patient's clinical status.

*Inform metabolic doctor on call for further guidance regarding on-going management.

Clinical Manifestation
The classic presentation of Argininosuccinic Aciduria is an overwhelming illness in the newborn period, presenting with vomiting, lethargy progressing rapidly to deep coma, apnea, seizures, and death. Patients may also have hair abnormalities (trichorrhexis nodosa).

Pathophysiology
Argininosuccinate lyase is an enzyme that converts argininosuccinic acid to arginine, the absence of which causes an increase in argininosuccinic acid, citrulline, and ammonia.

Inheritance: Autosomal recessiveA

Confirmatory Testing
Confirmatory testing may be done through plasma amino acid analysis (increased argininosuccinic acid, increased citrulline, and decreased arginine), increased orotic acid, and presence of argininosuccinic acid in the urine. Enzyme analysis may also be done on fibroblasts.

Overview of Disease Management
Long-term management, as with other urea cycle disorders, consists of a low-protein diet supplemented with special milk formula and provision of arginine and sodium benzoate or phenylbutyrate.

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



Story from page 6: Facility coordinators from local government units health facilities (left) and NBS Facility Coordinators from DOH hospitals in NCR (right).

Integrating Genetics in the Philippine Nursing Practice

The Institute of Human Genetics (IHG), National Institutes of Health, University of the Philippines Manila will be conducting a series of continuing education program activities this 2019 intended for nurses, doctors, dietitians, and other health professionals. This is in response to the attainment of the institute's vision to increase awareness and capability of health professionals in the provision of genetics services at all levels of the health care delivery system.

This July 22-23, 2019, IHG will be conducting a workshop entitled "Integrating Genetics in the Philippine Nursing Practice," which aims to increase the awareness of Filipino nurses in applying the nursing process in rendering holistic care to patients with genetic disorders.

As key players in the implementation of the National Comprehensive Newborn Screening System, it would be helpful that newborn screening nurses receive formal training on the genetic basis of disorders included in newborn screening panel and understand the concepts of genetics in a nursing perspective. The two-day workshop also aims to enhance participants' anticipatory skills in providing nursing care to genetic patients.

To register, visit bit.ly/IHG-GeneticsNursing. Payment instructions are also on the link. For other queries, call (02) 3101780.

University of the Philippines Manila National Institutes of Health Institute of Human Genetics	
INTEGRATING GENETICS in the NURSING PRACTICE	
22-23 July 2019	
PROGRAM & SPEAKERS	
Day 1	
Basic Principles of Human Genetics	Dr. Ma-am Joy Tumalak, MSc Genetic Counselor
Family History and Principles of Risk Assessment	Angela Pascua, RN, MSc Genetic Counselor
Application of Genetics in Various Areas:	
• Dysmorphology	Dr. Maria Melanie Liberty Alcausin Clinical Geneticist, PGH
• Metabolic Genetics	Dr. Mary Ann Abacan Metabolic Specialist, PGH
• Cancer Genetics	Dr. Eva Cutiongco-de la Paz Clinical Geneticist, PGH
• Prenatal Genetics	Dr. Gayluz Talapian Obstetrician, SLMC
Workshop 1	Facilitators
Day 2	
Provision of Education, Care and Support for Families affected with Genetic Disorders	
Communicating Genetics Information to patients and Families	Peter James Abad, RN MSc Genetic Counselor
Supporting and Empowering patients and families	Facilitators
Workshop 2	Facilitators
Workshop 3	Facilitators
Genetics Services in the Philippines and Roles of Nurses in Public Health Genetics	Aster Lynn Sur, RN-D, RN Genetics Nurse
Ethical, social, and legal issues in Genetics	Dr. Mary Ann Abacan Metabolic Specialist, PGH
Cultural competence in Genetics	Aster Lynn Sur, RN-D, RN Genetics Nurse

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Ilocos Region Holds First Thalassaemia and G6PD Deficiency Forum

To address the increasing number of G6PD Deficiency and Thalassaemia cases in the Ilocos Region, NSC-NL, in partnership with DOH-CHD 1 NBS Team and the ITRMC NBS Continuity Clinic, conducted the G6PD Deficiency and Thalassaemia Forum at the Mariano Marcos Memorial Hospital and Medical Center, Batac City, Ilocos Norte, on June 20, 2019.

Dr. Maria Lydia Ramirez and Dr. Katrina Ortega, both pediatric hematologists from the Ilocos Region and Medical Center, San Fernando City, La Union, served as resource speakers. Meanwhile, Dr. Modesty Leaño shared her experience as a mother of children with G6PD Deficiency. *AJAImazan*



Dr. Modesty Leaño (standing), NSC-NL Laboratory Manager and mother of a child with G6PD Deficiency, shares how she took an active role in taking care of her child.

Parents of patients screened and diagnosed with G6PD Deficiency and Thalassaemia attended the forum to learn how to prevent the occurrence of life-threatening hemolytic crisis and how to manage these disorders. The importance of Newborn Screening program was also emphasized during the forum.

Thalassaemia is an inherited blood disorder in which the body makes an abnormal form or inadequate amount of hemoglobin. The imbalance in the production of globin chain results in a hemolytic anemia or precipitation of the red cells in the bone marrow or a process known as ineffective erythropoiesis. G6PD deficiency, on the other hand, is a condition where the body lacks the enzyme called G6PD. Babies with this deficiency may have hemolytic anemia resulting from exposure to oxidative substances found in drugs, foods, and chemicals.

SJDMWD Sponsors ENBS of Indigent Patients

In celebration of its 39th anniversary, San Jose Del Monte Water District (SJDMWD) in Bulacan paid for the ENBS fees of 39 patients from Ospital ng Lungsod ng San Jose Del Monte on July 10, 2019. The sponsored patients were indigent and those whose parents are not members of PhilHealth.

The activity was spearheaded by Enrique Delos Santos, Chairperson of SJDMWD, together with Vice Chairperson Nida Nicolas and Board of Directors Rowena Camua, Rel Jose, and Jovita Mateo. The Ospital ng Lungsod ng San Jose Del Monte was represented by Priscilla Centeno, Supervising Administrative Officer; Estelita Lorenzo, Chief Nurse and NBS Activity Program Coordinator; Simonette Gravador, Nurse Supervisor/HEPO; Ferdinand Calilao, NBS Coordinator; and Mary Ann Calderon, Medical Technologist. *NDelaCruz*

The Water District made it an annual way of celebrating its anniversary by giving back to the community. The number of years it celebrates equals the number of babies that it sponsors. This tradition has been going on for more than five years.

CHD-NCR Holds Series of Consultative Meetings

Coordinators from 17 local government units (LGUs) and DOH and LGU hospitals attended the series of consultative meetings on the full implementation of ENBS organized by the DOH-CHD at the BSA Twin Towers, Mandaluyong City, on May 30, June 18, and June 20, 2019.



Representatives from local government units together with the NBS Team in DOH-NCR and NSC-NIH Unit Head Dr. Anna Lea Elizaga (seated second from left. More photos on page 7)

The meeting aimed to provide updates on the Enhanced Newborn Care Package offered by PhilHealth and the national NBS and ENBS status as well as to discuss the monitoring, reporting, and patient's recall strategies.

The activity started with a short discussion of Republic Act 9288, or the Newborn Screening Act of 2004, emphasizing the role of an LGU or facility in the recall of patients. Citywide and facility coverage in 2018 and issues, concerns, and future plans were also discussed. *CAIncastre*