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## First Batch of Zamboanga NSF Staff Undergoes ENBS Training

The first batch of nurses, midwives, trainees in ENBS, while the rest were government units (LGUs), rural health had not received formal training. units (RHUs), and private hospitals in the Zamboanga Peninsula participated in the Expanded Newborn Screening ENBS and updates on the program, Perly (ENBS) Training at Grand Astoria Hotel. Zamboanga City, on January 30-31, samples, and Amerah Matuan explained

of Health-Regional Office (DOH-RO) 9. and Eleanor Arcillas. IRTomas Some of the participants were first-time

and medical technologists from local already implementing the program but

Dr. Conchita Abarquez discussed Bermudez talked about unsatisfactory NSF protocols. On the second day, participants marched to Zamboanga City Thirty-nine staff from these newborn Medical Center for sample collection screening facilities (NSFs) attended the demonstration, onsite training, and heel training organized by the Department prick training facilitated by Jannet Yao



#### CHO-Malaybalay Kicks Off NBS Activities for 2018

The City Health Office (CHO) of Malavbalav. Bukidnon, kicked off its newborn screening program advocacy for the year with a couple of activities in Januarv.

A total of 24 babies, along with their parents and relatives, participated in the Reunion of Saved Babies on January 28, 2018. Pediatrician Dr. Brenda Tricia T Catalon graced the event and discussed the six basic disorders, especially Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency. During the open forum, parents asked about the diet and medications.



On January 30-31, CHO-Malaybalay, in coordination with DOH-RO 10. held a two-day refresher course at The Garden Party Venue in Malaybalay City. Pauline Angela F. Balansag and Gil Bernard

## DOH-RO 10 Holds Consultative Meeting

offices and DOH Retained Hospitals at addressing recurring issues, RAguilar Pearlmont Inn, Cagayan de Oro City, on February 19-20, 2018. The two-day activity was attended by 20 participants and representatives from NSC-M led by its Unit Head. Dr. Conchita Abarquez.

The activity aimed to address problems encountered in 2017 to improve the performance of the region in terms of sample validity, transit time, and positive

OH-RO10 held its annual consultative results, among others. Activities for the Description meeting for NBS Coordinators of year were also discussed as well as provincial and city/municipal health new initiatives taken by coordinators in



D. Samante, Regional NBS Nurse Coordinators, served as facilitators, The activity, which aimed to lessen unsatisfactory samples and common errors in the region, was attended by 65 midwives and nurses. KKLibot

### DOH-RO 12 Trains Staff on ENBS

o educate health personnel in ENBS and emphasize the significance of the quality collection of samples, DOH-RO 12 organized a training for 26 health personnel from both private and government facilities at Greenleaf Hotel, General Santos City, on February 27-28,

Dr. Conchita Abarguez, NSC-M Unit Head, discussed the panel of disorders on the first day, while Perly Bermudez, NSC-M Project Development Officer, talked about unsatisfactory samples and the administrative mechanics of NSC-M. Other resource speakers were Agnes Panton and Rohainna Mua, Program Manager and NBS Nurse Coordinator of DOH-RO 12, respectively. The second day of training was for the heel

prick practicum at Dr. Jorge P. Royeca Hospital in General 🏹 🌽 Santos City. *PBermudez* 



Narvdel F. Credo (seated, third from left) and the team from RHU-Mambajao join the participants in a photo opportunity during for several years. These one of the culmination activities of Pabasa and Purok Household Caregivers classes.

mainly fishing and farming.

The newborn screening program policy. started in the island in 2001 at Camiguin General Hospital in Mambajao. It is the The key to the better reception of the testing. The partnership shoulders eight years until Catarman District Hospital a comprehensive advocacy. Annually, testing center. RAguilar joined the program in 2008. To boost the the Provincial Health Office, along program coverage, the Provincial Health with the coordinators of eight facilities. Office in Pandan, Mambajao, enrolled organizes various activities to ensure as a partner agency to help the program that all women of reproductive age and kick off in other municipalities. Marydel F. expectant mothers have the knowledge Credo, a midwife, was then appointed as on newborn screening and its benefits the NBS Program Coordinator.

True to its purpose, four more facilities visits, other advocacy activities included were encouraged to enroll as newborn Pabasa, Infant and Young Child Feeding screening facility in 2010-Municipal sessions, Caregiver's Classes, Purok Health Office Catarman, Rural Health Household Classes, and Behavioral Unit Guinsiliban, Rural Health Unit Change Communication Counseling, Sagay, and Marydel Birthing Home, a Buntis Congress is also conducted Mahinog and Municipal Health Office- Screening Program was promoted to 150 Mambajao then followed in 2011.

realized an angle of the main and the constraints and the constrai Unorthern part of Mindanao under dispatching central, is the close-to-zero implementation led to the recognition of Region 10 and is a well-known tourist late transmittal of samples. Timing of the four out of the eight Camiguin NSFs in lestination. It is divided into five transmittal and running of samples is the recently held Newborn Screening municipalities: Catarman, Guinsiliban, critical for early diagnosis and treatment Awards in Mindanao on November Mahinog, Sagay, and Mambajao, the of babies found positive in one of the 27, 2017. They are Camiguin General provincial capital. In both land area disorders included in the NBS panel. Hospital (Exemplary Award), Municipal and population, Camiguin Province Since 2013, the province has an average Health Office of Catarman (Achiever's is believed to be the second smallest transit time of 3.14 days. The province Award 2015), and Marydel Birthing Home nationwide next to Batanes. Aside remains to have the lowest transmittal and Municipal Health Office of Mahinog from its flourishing tourism industry. time in Region 10 for four years. This (Achiever's Award 2016). the economic activity in the province is was made possible through constant reminder on prompt sending of samples and adherence to the "No Batching" with the non-governmental organization

pregnant mothers.

One remarkable point in Camiquin's Aside from advocacy activities. rogram implementation, despite the the Provincial Health Office provides

### NBS in Camiguin Island

before admission for delivery. Apart from routine lectures during prenatal

additional filter card o newborn screening facilities intended solely or indigent clients both r basic and Expanded IBS. Further, DOH-RO mission of census exceptional reports screening newhorn performance or even uests by facilities ensure availability filter cards at all time. resulted in a inactive NSF facility proactive measures that

made for successful NBS

The local government, in partnership Family to Family Foundation, also helps indigent clients get through confirmatory sole provider of the newborn screening program goes back to the fundamentals confirmatory testing fees and sometimes service in the entire province for almost of program implementation and that is the fare to the nearest confirmatory



Left to right: Ronald C. Aquilar, NSC-M PDO; Cyri Rojo, NSC-M Follow-up Nurse; Dr. Conchita G private facility. Municipal Health Office- annually. In 2017, Expanded Newborn Abarquez, NSC-M Unit Head; Sheila Mae Guilaran, NSC-M Program Manager; Perly Bermudez, NSC-M PDO; Amerah Matuan, NSC-M PDO; and Dr. Glynna B. Andoy, outgoing DOH-CARAGA Program Manager pay a quick

visit at the Provincial Capitol of Camiguin Province during the zonal meeting of

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#### **RHU-San Luis Concocts Creative Ways to Promote ENBS**



Organizers from RHU-San Luis join on stage the winners of Gandang Buntis, a pageant that promotes good maternal nutrition and proper infant and young child care practices.

including 5 geographically isolated and born in health facilities are not discharged disadvantaged areas. They have coastal unless they are screened. Babies born at barangays, which can only be reached by home are screened through mobile NBS. boat. And yet, RHU-San Luis has been a program where healthcare workers go actively providing ENBS since 2015 to all to their houses to screen the babies. infants born in the municipality, whether facility-based or home-delivered.

HU-San Luis, Aurora, faces one of the first newborn screening facilities The most challenging past in the to offer ENBS in the country. NBS was implementation of newborn screening— institutionalized in the municipality in poor accessibility due to geographical 2014 through Municipal Ordinance 2014locations of the barangays they serve. 003, which imposed that all newborns should be screened from congenital The RHU services 18 barangays, heritable disorders. As a result, babies

When there are significant findings in the newborn screening result, parents or RHU-San Luis was listed among guardians of the babies are immediately done to promote ENBS. JJJReyes

informed about them and are advised regarding the next action to take. Financial assistance and transportation are given to the parents of the babies who need confirmatory tests.

RHU-San Luis also conducts "Buntis Party" twice a year where all pregnant mothers are invited to participate. Part of the topics discussed in this event is the importance of ENBS. "Gandang Buntis in San Luis" is one of the activities during the Buntis Party, where pregnant mothers represent their respective barangays in a pageant-style contest. Participants have to meet certain criteria such as a complete prenatal checkup to be included in the pageant. Contestants may win free ENBS tests, financial assistance, free laboratory checkup, free ultrasound, and free PhilHealth enrolment.

Mothers' classes are also being conducted by the RHU and one of the topics discussed is Expanded NBS since more patients avail themselves of this service once they were made fully aware of its benefits. Home visits are also being

### **RHU-Minalin Goes the Extra Mile**

You can start right where you stand and By NBS performance alone, apply the habit of going the extra mile by rendering more service and better service than you are now being paid for. – Napoleon Hill

riving the extra effort in order to free transportation for mothers Oprovide Filipino newborns the normal and newborns to and from the and healthy life that they deserve is the Newborn Hearing Screening example set by the RHU and Lying-In Test Center. A midwife even Clinic in Minalin, Pampanga.

Minalin is a fourth class municipality sure that every baby has his or in the province of Pampanga with a land her hearing screened area of about 48.27 square kilometers. Under its territorial jurisdiction are 15 arangays

RHU-Minalin already has something to boot: it does not discharge babies born there without being screened. And as an added service, it provides accompanies the mother and baby to the center and makes

Continued on page 6.



Hearing Screening Test Center.



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### NBS Partnerships Prompt Training Programs in Laguna, Rizal



Jose Antonio Yap (center), Regional NBS Coordinator, explains how to properly collect newborn screening samples to the training participants.

As part of the partnership among the performance and to lessen the Athe Provincial Health Office of unsatisfactory rate of NSFs. The review Laguna, the Municipal Health Office of also identified the gaps, needs, and Cainta, Rizal, NSC-SL, and DOH-RO strategies in improving the quality of CALABARZON for Newborn Screening newborn screening implementation in Training Programs, an NBS training and Laguna. Service Implementation Review was conducted at Villa Evanzueda Resort in San Pablo City, Laguna, on February screening orientation was conducted 1-2. 2018.

Meanwhile, in Cainta, Rizal, a newborn on February 27. Twenty-one health and administrative personnel from Bagong Twenty-one participants from Cainta Municipal Hospital attended the private and public NSFs attended the orientation and listened to lectures on activity, which aimed at assessing the importance of newborn screening.

he orientation included the highlights of Republic Act 9288, or the Newborn Screening Act of 2004, disorders included in the panel, NSC administrative mechanics, and collection of satisfactory samples. *IEMalabanan* 

### **CALABARZON Holds** Reunion of Saved Babies

▲ **/**ith the theme "Saving lives, giving **V** quality lives," the annual Reunion of Saved Babies organized by NSC-SL in collaboration with DOH-RO 4A, was held in Cavite, Laguna, Batangas, Rizal, and Quezon on November 4, 11, 18, 25 and December 2, 2017, respectively.

The program included several presentations and games participated in by both babies and parents. Tokens and raffle prizes were given as well.

### NSC-SL Holds G6PD Forum CALABARZON-Wide

6PD Deficiency is the most prevalent  $\mathbf{U}$ (1 in every 58) among the congenital disorders detected through newborn screening in the Philippines. This X-linked enzyme deficiency can be easily triggered when the patient is exposed to oxidative substances, which can result in hemolytic anemia or, worse, mental retardation.

To increase awareness of parents whose babies are confirmed with the disorder, NSC-SL conducted a series of lectures in the provinces of CALABARZON, A G6PD forum was held in Rizal Province on August 16, 2017, and was attended by 35 families. The which is a lifetime ailment, and how second leg was held on September 15 in to deal with it. Dr. Alma Panganiban- The open forum gave the participants Cavite, with 67 families. Lastly, Laguna Andal, NOC-OL OTHE LIEAU, GROUDDER AND STREET, Street Cavite, with 67 families. Lastly, Laguna Andal, NSC-SL Unit Head, discussed an opportunity to clarify some



Representatives from the NSC-SL and NBS Coordinators of DOH-CALABARZON pose for a photo with the attendees of one of the G6PD fora conducted in different provinces.

In all the lectures, the participants were drug intake of patients with G6PD introduced to the nature of the disorder. deficiency. recommendations regarding food and FDimaculangan

#### DOH-CARO Orients Frontline Health Care Providers on ENBS

o provide frontline health service providers relevant knowledge on ENBS and the management of common heritable disorders in the region, DOH-Cordillera Administrative Region (CARO) conducted an orientation for 31 participants composed of municipal health officers, nurses, medical technologists, and midwives at Crown Legacy Hotel, Baguio City, on 22-23 February 2018.

Dr. Virginia Narciso, DOH-CARO NBS Medical Coordinator, discussed the NBS situation in the region, the guidelines in the implementation of ENBS, and the basic and expanded NBS disorders. Dr. Wilson Cua, pediatric



Dr. Virginia Narciso (standing) discusses updates on newborn screening in the region.

-lyperplasia,

16<sup>th</sup> NATIONAL NEWBORN SCREENING CONVENTION ave the Date OCTOBER 2018 **RECEPTION HALL** PHILIPPINE INTERNATIONAL CONVENTION CENTER NSSPI SECRETARIAT 2018nbsconvention@gmail.com (+63) 921 305 5094



endocrinologist, explained the basic and G6PD Deficiency. Dr. Bernadette facts and management of Congenital Mendoza, NSC-CL Unit Head, discussed Hypothyroidism, Congenital Adrenal Organic Acid Disorders and Fatty Acid Hemoglobinopathies, Disorders, which are present in the region

> The orientation focused on the importance of early identification of disorders and early management of conditions, especially because positively screened patients from far-flung areas require immediate management, considering that CAR has mostly mountainous terrain and medical specialists are not immediately accessible. *NDelaCruz*

### In Focus: RHU-Minalin . . . from page 4

Hearing screening was institutionalized in the country in 2009 through Republic Act 9709, also known as the Universal Hearing Screening and Intervention Act, to prevent and diagnose early congenital nearing loss among newborns. As nandated by the law, all newborns in the Philippines, with the consent of the parent(s) or guardian, should be subjected to universal hearing screening.

The NBS staff of the facility coordinates with the municipal office in arranging the transportation of patients. The ambulance used also ferries the patients to confirmatory centers whenever there are positively screened babies that need onfirmatory tests.

RHU-Minalin began providing newborn screening services to its area of jurisdiction in 2009; at present, it offers Expanded NBS. ERMNiturada

# IN THE KNOW

#### What is Galactosemia?

metabolic disorder that is inherited in The GALT enzyme enables the body Treatment and Monitoring an autosomal recessive manner. It is an to break down galactose into glucose inborn error of carbohydrate metabolism The second type of galactosemia is due characterized by elevated levels of to a deficiency in uridine diphosphate products containing lactose is the galactose and its metabolites due to galactose 4-epimerase (GALE). Its treatment for all types of galactosemia. enzyme deficiencies involved in its severe type clinically resembles classic There is no chemical or drug substitute mainly in milk and dairy products. It is a deficiency in galactokinase (GALK), infant diagnosed with galactosemia will also produced by the body. Milk contains and presents primarily as cataracts in have to be on a soy-based formula. a sugar called lactose, and during untreated patients. digestion, lactose is broken down into the sugars glucose and galactose. Glucose Clinical Features can immediately be used as a source of energy by the body, but galactose needs to be further broken down before it can problems, failure to thrive, hepatocellular metabolic team is important for optimal be utilized. The birth incidence of classic damage, bleeding, and sepsis in treatment. galactosemia is about 1 per 47,000 in untreated infants. In approximately 10% the Caucasian population. The Philippine of individuals, cataracts are present. Prognosis NBS data as of December 2013 gives a Failure to thrive is the most common initial prevalence\* of 1:33.645.

#### Pathophysiology

STAFF

**ITORIAL** 

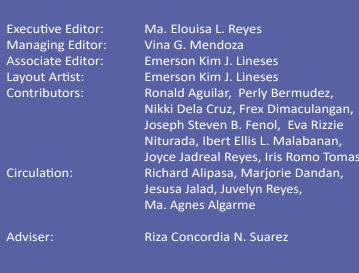
ED

with multiple enzymatic steps is shown. some patients. Cataracts have been These include speech problems, poor 1-phosphate and uridine diphosphate patients with classic galactosemia. glucose (UDP glucose) to glucose-1-

or classic galactosemia, the enzyme that children, bone mineral density problems is reduced or missing is called galactose- and ovarian failure in girls. Galactosemia is a rare genetic 1-phosphate uridyl transferase (GALT).

clinical symptom of classic galactosemia. Vomiting or diarrhea usually begins within long-term complications have been The galactose metabolic pathway by the severe hemolysis occurring in endogenous galactose production.

phosphate and UDP-galactose by GALT The association of jaundice and (2) and the interconversion of UDP- hemorrhagic diathesis in the first two glucose and UDP-galactose by GALE weeks of life is a clinical presentation in (3). Children with galactosemia have very which galactosemia must be considered. little or entirely lack an enzyme that helps Coagulopathy may also be present in the body break down galactose. There galactosemia with little evidence of liver are three different enzyme problems that disease. Galactosemia also causes can lead to galactosemia. In the first type learning and language problems in



## BALACTOSEMIA



Dietary elimination of milk and milk metabolism. Galactose is the sugar found galactosemia. The third type, is due to for the missing enzyme at this time. An Dietary management under the close supervision of a metabolic dietician and a metabolic doctor is a must. Regular monitoring of blood galactose levels Patients can present with feeding and regular evaluation by the genetic

Despite an early galactose-free diet, a few days of milk ingestion. Jaundice of noted in older children and adults intrinsic liver disease may be accentuated with classic galactosemia because of The enzymes allow the subsequent observed within a few days of birth. intellectual function, neurologic deficits conversion of galactose to galactose- There appears to be a high frequency of (predominantly extrapyramidal findings 1-phosphate by GALK (1); galactose- neonatal death due to E. coli sepsis in with ataxia), and ovarian failure in females. Thus, the need for regular monitoring and evaluation is important.

> Source: Fact Sheets for Doctors, May 2016, accessed at www.newbornscreening.ph on February 26, 2018.

\*Prevalence of 1:81,373 as of December 2017





Left to right: Dr. Ernie V. Vera, Dr. Arnulfo Carandang, Dr. Rita Mae C. Ang-Bon, Twinkle Jean P. Lorilla, Abner Henry A. Tud, Dr. Edgar F. Garcia, Oscar H. Cristobal, Fulbert Alec R. Gillego, Ma. Janelita Bulawan, Cyrene Sale, Jr., Lyn D. De La Cruz, Dr. Renato B. Bolo, Jr., Salvacion Ballesteros, Nilda Agnes Dela Paz, Shiela Estipona, Ma. Cristina P. De Leon, Estrella Revoltar, Hagos, Dr. Myrna J. Listanco, Joseph Steven B. Fenol, Dave Isidore E. Plopinio, and DOH Regional Director Napoleon Arevalo

IVI officers, program implementers, ordinance or resolution, support provided recognition of best performing health 2017.

▲ A ore than 300 LGU leaders, health coverage, legislative efforts through and a Plaque of Appreciation. and partner agencies witnessed the to patient, and guality sample collection.

Sorsogon; and City Health Office of NBS Program Manager; Twinkle Jean P. recognize the significant contributions of Php 50,000, respectively. For the LGU partners in the successful implementation Hospital category, the efforts and initiative In 2018, the program coordinators of various health programs of the of Dr. Fernando Duran Sr. Memorial plan to raise the scale higher by adding government. For newborn screening, two Hospital, Sorsogon City, proved to be more criteria in the citation for Best categories were recognized: RHU/CHO unwavering as they maintained the status Implementers in Newborn Screening category and LGU Hospital category. The of best implementer in this category for including Hearing Screening. JSBFenol criteria for these awards included facility 2017. The hospital received Php 100,000

Amelina Ordiz, Fatima Intia, Maricel Banzuela, Dr. Gladys D. Escote, Joseph

Steven B. Fenol, Dave Isidore E. Plopinio, and Dr. Napoleon Arevalo

Thank you for reading our newsletters!

Present also were Dr. Napoleon Arevalo, DOH OIC Regional Director: Dr. facilities in Bicol Region during the Salud Under the RHU/CHU category, the Ernie V. Vera, Assistant Regional Director: Bikolnon 2017 held at the Tent, Avenue City Health Office of Legazpi City, Albay; Dr. Rita Mae C. Ang-Bon, Family Health Plaza Hotel, Naga City, on December 4. Rural Health Unit of Sta. Magdalena. Cluster Head: Dave Isidore E. Plopinio. Ligao, Albay, were recognized. Besides a Lorilla and Joseph Steven B. Fenol, NBS Salud Bikolnon is an annual awards Plague of Appreciation, the three facilities Coordinators; and Abner Henry A. Tud, ceremony organized by DOH-RO 5 to received Php 100,000, Php 75,000, and Newborn Hearing Screening Coordinator.

Vour Feedback Is Important to Us!



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ments and questions may be sent to:

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Twinkle Jean P. Lorilla, Abner Henry A. Tud, Legazpi City Vice Mayor Robert

We would love to hear your feedback. Please let us know how we can improve our bi nonthly newsletters by answering our feedback form at www.newbornscreening.ph. If yo 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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National Institutes of Health, University of the Philippines Manila



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**DOH-CARO** Orie

n The Know:



# NSRC-CLASP Workshop Reinforces Good Laboratory Practice

To ensure continuous good laboratory Meanwhile, Dr. Sombong, also NSRC Newborn Screening Centers (NSCs), the that are commonly employed in multirule Newborn Screening Reference Center QC procedure. She guided the participants (NSRC), in partnership with the Center in predicting the type of analytical error for Internal Advisory Services Philippines expected on the basis of control rule Incorporated (CIASP), conducted the violations. Quality Control (QC) and Quality Assurance (QA) Workshop at the National Institutes of Health, University of the Philippines Manila, of CIASP, discussed the key concepts of on January 24-25, 2018.

development officers from NSRC.

control and the features of a quality and individual audit engagement. assurance program. He also gave tips in preparing for an audit and ISO accreditation.

practice among the technical staff of QA Consultant, defined the control rules

For his part, Pol Mirafuentes, President internal control, including governance and risk management. On the second day, he The workshop was participated in by provided feedback and recommendations to unit heads, laboratory managers, and the presentations made by the participants team captains from NSCs and project during the group activities. He also continued his lecture, which covered internal auditing, understanding NBS risk profile and risk Dr. Florencio Dizon, NSRC QA Consultant, model, understanding key processes and delivered a lecture on the basics of quality priority areas, and preparing an audit plan

Number of Babies Screened as of February 2018 : 10,901,956