



# newborn screening

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

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*The program review team of NSC-Mindanao as they conduct home visits.*

## Patient Recall: The Reasons Behind the Steep Charts

To address the increasing statistics of unrecalled cases, the program review team of Newborn Screening Center (NSC)-Mindanao conducted home visits and ensured successful repeat sample collection.

During the visits, the team identified several factors affecting the outcomes of patient recall.

**Inaccurate and Incomplete Data Entry.** A significant number of errors were encountered during the home visits, which range from “no or incomplete names of the guardians,” “incomplete address,” to “no contact numbers,” which is more prevalent with unwed parents.

To double-check the data, NSC-Mindanao referred to the prenatal records at the barangay health stations and the voters' lists at the barangay halls. It also recommended filling in the filter cards with accurate and complete details to avoid error.

**Geographically Isolated Areas.** Many residents were from far-flung areas, and healthcare providers need to ride *habal-habal*, a modified motorcycle, for several kilometers and to cross rivers and hanging bridges. Unrecalled cases with this kind of problem are usually encountered in understaffed facilities. The review team also cited the areas that have no cellular signal contributed to the difficulty in patient recall.

NSC-Mindanao recommended prompt coordination with the provincial, city, or municipal newborn screening (NBS) coordinators. Barangay Health Workers (BHWs) play an important role during the recall and they have extensive knowledge about the households assigned to them.

*Continued on page 8 . . .*



# 12TH NEWBORN SCREENING CONVENTION

Fiesta Pavilion, Manila Hotel

“Widening the Scope of Care: Implementing the Expanded Newborn Screening”

## SCIENTIFIC PROGRAMME

DAY 1—OCTOBER 28, 2014

8:00am Registration  
1:30pm Opening Ceremonies  
Welcome Remarks  
Ephraim Neal Orteza, MD (President, NSSPI)  
Opening Remarks  
Carmencita D Padilla MD, MAHPS  
Director, NSRC-NIH  
Special Messages  
Generoso T Abes, MD, MPH  
Executive Director, NIH  
Introduction of Keynote Speaker  
Ma. Louisa Peralta, MD (NSSPI)  
Keynote Address  
Enrique T. Ona, MD  
Secretary, Department of Health  
Opening of Exhibit  
2:00pm PLENARY 1 [Chair: Dr. Rizalina Gonzales]  
Updates on the Philippine Expanded NBS Program [Co-Chair: Dr. Leah Umil]  
Carmencita D Padilla, MD, MAHPS  
Director, NSRC-NIH  
2:30pm PLENARY 2  
Fatty Acid Oxidation Defects, Amino Acid Disorders & Organic Acid Disorders: Differences in Management  
Janice Fletcher, MD  
Clinical and Biochemical Geneticist  
University of Adelaide, Australia  
3:00pm Open Forum  
3:15pm PLENARY 3  
Permanent Congenital Hypothyroidism Versus Transient Hypothyroidism: Protocols for Management  
Sylvia C Estrada, MD  
National NBS Follow-up Coord., NSRC-NIH  
3:45pm PLENARY 4  
NBS for Preterm & Low Birth Weight Infants  
J Edgar Winston C Posecion, MD  
Head, NSC-Visayas  
4:15pm PLENARY 5  
Recognizing Hemoglobinopathies in the Philippine Setting  
Reynaldo de Castro Jr, MD, FPPS, FPSHBT  
Pediatric Hematologist  
4:45pm Open Forum

DAY 2—OCTOBER 29, 2014

8:00am PLENARY 6 [Chair: Dr. Ephraim Orteza]  
NBS at Home [Co-Chair: Dr. Bibiano Reyes]  
Conchita G Abarquez, MD  
Head, NSC-Mindanao  
8:30am PLENARY 7  
Diet Issues in Infants with PKU, MSUD and Galactosemia  
Elizabeth Limos, RN-D  
Dietitian, UP-PGH  
9:00am PLENARY 8  
Diet Issues in School for Patients with PKU, MSUD and Galactosemia  
Barbra Charina V Cavan, MD  
Clinical Geneticist  
9:30am Open Forum  
10:00am Simultaneous Session 1 [Chair: Dr. Ephraim Orteza]  
(ABCs of NBS) [Co-Chair: Dr. Christopher Grageda]  
• Basic Elements of NBS  
Alma M Panganiban-Andal, MD  
Head, NSC-Southern Luzon  
• Pitfalls and Tips in Recalling Patients

Florencio Dizon, MD  
Head, NSC-Central Luzon  
• Overcoming Geographical Challenges in Implementation of the NBS Program  
Virginia L Narciso, MD  
NBS Program Manager, CAR Office  
Maria Lilybeth Usama, MD  
NBS Coordinator, Sulu Provincial Hosp.  
• Role of DOH Regional Offices in Short Term and Long Term Care in the Program  
Anthony P Calibo, MD  
OIC, DOH Child Health Division  
Open Forum  
10:00am Simultaneous Session 2 (Crisis Management—The First 24 Hours)  
CHAIR: Dr. Bibiano Reyes  
CO-CHAIR: Dr. Ramil Badajos  
• Congenital Adrenal Hyperplasia (CAH)  
Carmelita Domingo, MD  
Pediatric Endocrinologist  
• Organic Acidurias  
Janice Fletcher, MD  
Clinical and Biochemical Geneticist,  
University of Adelaide  
• Clinical Cases (Resolved and Unresolved) Panel:  
April Grace Dion Berbos, MD  
Mary Ann Abacan, MD  
Clinical Geneticists  
Jedeane Mendoza-Aragon, MD  
Pediatric Endocrinologist  
Open Forum  
12:30nn LUNCH [Chair: Dr. Sandra Litao]  
2:00pm PLENARY 9 [Co-Chair: Dr. Corazon Omalin]  
PhilHealth and NBS  
Mary Antonette Remonte, MD, FPCP  
MDG Team Leader, PhilHealth  
2:30pm PLENARY 10  
NBS Program Amidst Earthquake & Typhoon: The Visayas Experience  
Dominic J. Buensalido, RN  
NSC-Visayas  
3:00pm PLENARY 11 (Implementation Strategies)  
• Telegenetics: Access to Specialist Care  
Melissa Baluyot, MD  
Clinical Geneticist, Institute of Human Genetics, NIH  
• Continuity Clinics: Handling Patients in the Provinces  
Angelica Cecilia Tomas, MD  
Head, Continuity Clinics, NSRC-NIH  
• Rare Disease Bill  
Carmencita D Padilla, MD, MAHPS  
Open Forum  
4:00pm PLENARY 12  
Revisiting G6PD Deficiency  
Maria Beatriz Gepte, MD, MHH, FPPS, FPSHBT  
Pediatric Hematologist  
4:30pm Closing Ceremonies  
Summary  
Conchita Abarquez, MD  
Next Steps  
April Grace Dion Berbos, MD  
Head, NSC-NIH  
Closing Remarks  
Manuel Ferreria, MD (NSSPI)

Masters of Ceremony  
Dr. Regente Lapak and Dr. Rosario Go



## For Visayas

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Medical technologists at Dr. Pablo O. Torre Sr. Memorial Hospital ready a patient for blood extraction. Bottom photo: Hematologist Dr. Connie Rose F. Benjamin answers questions from parents and health workers about G6PD deficiency.

## High Hopes for a Bright Future: The NBS Continuity Clinics in Visayas

Tasked to handle the long-term follow-up and monitoring of all confirmed patients within the Visayas, the Newborn Screening (NBS) Continuity Clinic–Region VI opened at the West Visayas State University Medical Center on May 1, 2014.

Dr. John A. Colacion, Follow-up Head and a long-time pediatric consultant of the Medical Center, heads the Continuity Clinic, while John Ryan Padernal assists as follow-up nurse.

So far, a total of 47 old confirmed cases have already been endorsed to the NBS Continuity Clinic team, and more confirmed cases will be endorsed in the coming months.

The NBS Continuity Clinic–Region VI team will not be handling patients from the whole Visayas region for long. The NBS Continuity Clinic–Region VII is being established as a result of a meeting between representatives of Newborn Screening Reference Center, Department of Health–Regional Office VII, and Vicente Sotto Memorial Medical Center in Cebu City on July 9, 2014.

Through NBS Continuity Clinics, parents of patients have access to pediatric specialists and consultants who can monitor and evaluate the patients' health, provide treatment and medication, and give the necessary guidance and counseling to parents and caregivers. YCMDemegillo

## NSC-Visayas Battles G6PD Deficiency with 'Favismo IV'

G6PD Deficiency is the most prevalent in the newborn screening (NBS) panel of disorders, and in the Visayas region, it occurs 1 in 73 babies screened.

Region VI, in particular, recorded the highest incidence. From January 1 to April 15 this year, 2,854 babies from Region VI were found positive for this disorder, and 1,194 are from Negros Occidental. Of these babies, only 118 (9.88%) underwent confirmatory testing. Negros Occidental has a Confirmatory Testing Center at Dr. Pablo O. Torre Sr. Memorial Hospital and should have registered a high incidence of confirmatory testing, but that was not the case.

As a response to this need for higher turnout of patients for confirmatory testing, the Newborn Screening Center (NSC)–Visayas, in partnership with the Department of Health–Regional Office VI and Dr. Pablo O. Torre Sr. Memorial Hospital, conducted Favismo IV: The 4th Chapter, a G6PD lay forum.

The guest speaker, Dr. Connie Rose F. Benjamin, a hematologist, talked about G6PD deficiency and the proper care of babies and procedures for health workers. An open forum also allowed participants to raised their specific concerns. MTabaosares



## INSPIRATION

### Help that Came at the Right Time

“*Mas magaan talaga sa loob, Ma’am, kung may problema ka pero marami ka ring karamay,*” said Joyce Madlos after Thymothy, her two-year-old son with G6PD deficiency, had undergone blood transfusion.

Thymothy was Jeson and Joyce’s little bundle of joy on February 27, 2012. But three weeks after birth, Thymothy turned yellowish. Blood tests at the hospital showed hyperbilirubinemia, and when the newborn screening (NBS) result came, he was G6PD positive.

“My brother has G6PD, too,” confessed Joyce, knowing what the result meant. “But I didn’t know my son needed a confirmatory test since our pediatrician did not tell us.”

Joyce later on found out about the confirmatory test through Anton Torralba, a member of the Volunteer Youth Leaders for Health. “It was really hard for us since there was no one to ask about the disorder, not even our doctor,” she said.

On May 1, 2014, by Anton’s invitation, Joyce went to the G6PD Parents’ Forum facilitated by Dr. Conchita Abarquez. “She answered all the questions I had kept to myself for a long time,” admitted Joyce, also signing up as member of the G6PD Support Group, a community of parents of children with G6PD Deficiency.

Little did Joyce know that enlisting for the support group would become useful later. On July 2, 2014, Joyce noticed that Thymothy was pale and, on the following days, had cough, colds, and tea-colored urine. She rushed her son to the hospital, and upon Thymothy’s admission, his hemoglobin level was 73 gms/L, which dropped to 6 gms/L that evening. It was clear that their little boy needed blood transfusion.

Jeson and Joyce called up Christoner Jamier, the president of their support group, and after only an hour, a parade of messages from the members of the group came to Joyce’s cellphone inbox. At midnight, Thymothy had undergone the needed blood transfusion.

“God is really good,” cheered Joyce to Nanette Montilla, the NBS Nurse Coordinator of DOH-Regional Office XIII. “The forum and the support came to us at the exact time. *Hindi na talaga ako nag-iisa.* Thank you so much.” *NMontilla*

## Parents’ Forums Held in Three Cities

As more confirmed cases were recorded every month, parents’ education has been deemed equally important to treatment. More parents now seek to understand the disorder afflicting their children as well as how these disorders will affect their lives.

Thus, for the months of May and June, three parents’ forums were held in three different cities in Mindanao.

Department of Health–Regional Office XIII held its first G6PD Parents’ Forum at Luciana Convention Center, Butuan City, on May 2. A total of 40 parents and children attended the event.

The participants created their own support community, named it Agusan del Norte G6PD Parents’ Support Group, and elected their officers after the forum. After some initial planning, the group agreed to meet quarterly to plan for the next activities.



Participants, speakers, and organizers in the Parents Forum held in Butuan City (top photo) and Maramag Bukidnon.

On May 22, it was Bukidnon Provincial Hospital (BPH)–Maramag that held the G6PD Deficiency, CH & CAH Parents’ Forum to promote the newborn screening (NBS) program. There were 60 parents and babies who attended: 45 are parents with G6PD-deficient children, 13 for CH, and 2 for CAH.

A free CH and CAH consultation was also conducted by Dr. Eleonor Du after the program. The NBS



## DOH-Regional Office CAR Holds First G6PD Forum

Sixty-six parents of patients with Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency and health care providers from Abra, Apayao, Baguio City, Benguet, Kalinga, Ifugao, and Mt. Province attended the first G6PD Deficiency Forum conducted by the Department of Health–Regional Office Cordillera Administrative (CAR) at Eurotel Hotel in Baguio City, May 22-23.

The forum opened with Dr. Virginia Narciso, Child and Adolescent Health and Development Cluster Head and NBS Program Manager, who gave an overview of G6PD Deficiency. Meanwhile, Dr. Florencio C. Dizon, NSC–Central Luzon Unit Head, presented the basic facts of G6PD Deficiency to help parents develop a better understanding regarding the health condition of their babies.

Dr. Eleanor Cuarte, neonatologist, and Aster Lynn Sur, nutritionist and dietitian, gave lectures on the treatment, especially on nutritional management using the World Health Organization feeding recommendations as basis.

As highlight of the event, Dr. Narciso organized the G6PD Deficiency Community Support Groups in the different provinces of the region to sustain and intensify advocacy and information dissemination on NBS, particularly G6PD Deficiency.



*Participants from Abra, Apayao, Baguio City, Benguet, Kalinga, Ifugao, and Mt. Province take part in the DOH-RO CAR G6PD Deficiency Forum.*

Each group came up with re-entry plans on how to make the support groups functional and beneficial to G6PD patients in their respective areas through the assistance and supervision of the NBS at the different levels.

The forum culminated with the signing of the pledge of commitment led by Dr. Dizon.

G6PD deficiency is the most common congenital condition in the Philippines occurring in the newborn screening (NBS) panel of disorders, with a prevalence of 1 out of 55 newborns. This is a congenital hemolytic condition where the body lacks an enzyme called Glucose-6-Phosphate Dehydrogenase which is essential in protecting the red blood cells from harmful oxidative substances that may lead to its destruction.

Babies with G6PD deficiency may have hemolytic anemia, which is most often triggered by bacterial or viral infection or by certain medications such as some antibiotics and drugs to treat malaria, after eating fava beans or exposure to chemicals like moth balls.

In CAR, there were 43,295 newborns screened positive for G6PD Deficiency in 2010-2013 and 11,057 (25.53%) were confirmed cases. Raising awareness of parents with G6PD deficient babies on the implication of exposure to these oxidative substances is one of the approaches to decrease the incidence of hemolytic crises in the area.

## VYLH Spearheads Orientation in Ilocos

To empower the youth in advocating maternal and child health, the Volunteer Youth Leaders for Health (VYLH)–North Luzon, in collaboration with the Department of Health–Regional Office (DOH-RO) Ilocos and Newborn Screening Center–Central Luzon, conducted a VYLH Orientation to 50 youth leaders at the Don Mariano Marcos Memorial State University College of Nursing and Midwifery in La Union, May 16.

Since 2009, VYLH Philippines has widened its network of proactive young leaders to promote infant health, particularly on issues concerning folic acid awareness, newborn screening promotion, and the plight of Filipinos with orphan disorders. The Network promotes its vision through promotional and educational activities in different local communities.

*Continued on page 6 . . .*

# Partnership for Service Excellence



Members of the NSC-Mindanao Program Review Team

Every year, the review team of Newborn Screening Center (NSC)–Mindanao conducts newborn screening facility (NSF) visits to discuss the issues and concerns encountered during program implementation and discover good practices to help other facilities increase their coverage.

One of the factors identified in the success of the program is a supportive local government. The Municipality of Lala in the Province of Lanao del Norte is one of the best examples.

The root of the success of NBS in the town of Lala started during the local program implementation review in 2010.

Dr. Ava O. Liwanag, RHU-Lala NBS Coordinator and Municipal Health Officer, and Maria Glenda Villagonzalo, Assistant NBS Coordinator, presented the statistics of the program to the municipal council—83.69% coverage.

After the presentation, Mayor Allan J. Lim declared to push for 100% coverage. As a result, an ordinance for mandatory newborn screening was passed.

**Advocacy.** During health activities, Mayor Lim would always speak and reiterate the importance and benefits of facility-based delivery. To address the concerns of non-PHIC members, RHU-Lala offered a P1,500 delivery package, which includes newborn screening. The members of the Community Health Team (CHT) and Barangay Health Workers were also oriented as advocates of the program. Routine lectures during pre-natal checkups, Family Development Seminars (FDS), and post-deliveries were also practiced.

**Results.** In 2011, RHU-Lala had 479 total live births, of which 472 were screened, giving the facility a 98.54% NBS coverage. In 2012, it had 589 live births and 582 screened newborns, giving 98.81% coverage. These numbers put the Municipality of Lala among the top performing facilities in Mindanao, and it was recognized during the Sixth Newborn Screening Awards for the Mindanao Cluster on November 22, 2013.

In 2013, RHU-Lala broke its own record and tallied 100% coverage for 2013, while in the first quarter of 2014, NBS coverage reached 101.70% since the facility offered NBS to outborns. This only goes to show what the Local Government Unit and the NBS program implementers could achieve if they work hand in hand. *RAguilar*

## Parents' Forum . . . from page 4

Committee of BPH-Maramag, headed by its NBS Medical Coordinator, Dr. Mary Ann Alvisor, initiated the forum after an overwhelming census of confirmed cases of the three disorders.

In Davao City, meanwhile, NSC-Mindanao held its second G6PD Deficiency Forum at Mahogany Room, OPD Building, Southern Philippines Medical Center, on June 23. A total of 89 families of confirmed G6PD deficient patients attended the event.

The parents learned from no less than an expert on pediatric hematology, Dr. Jeannie Ong, who discussed the fundamentals of the G6PD Deficiency disorder and cleared out parent's misconception during the question-and-answer session. *NMontilla, ADTadlas, PBermudez*

## VYLH Spearheads. . . from page 5

The VYLH Orientation was composed of a series of discussion centering on volunteerism and membership, child and maternal health campaigns, and action planning.

Among the notable resource speakers were Roland Alcantara, Project Development Officer of Newborn Screening Center–Central Luzon; Mary Michelle Lewis, DOH-RO Ilocos Nurse Coordinator; Marie Kris Lacuata, DOH-RO Ilocos Nurse Coordinator; and Robin Albinto, VYLH Coordinator for Ilocos and Central Luzon.





# Mindanao Cluster Strengthens NBS Skills and Facilities



Participants of the DOH-RO XII NBS training listen to Cristabel Chua, DOH-RO XII Nurse Staff, as she discusses the answers to the pre-test questions.

The Department of Health–Regional Offices (DOH-RO) XII and Caraga, together with the Newborn Screening Center (NSC)–Mindanao and the Provincial Health Office of Agusan del Norte, held newborn screening (NBS) training and capacity-building in their respective regions.

DOH-RO Caraga, along with NSC-Mindanao, trained 20 midwives, nurses, and medical technologists from the Rural Health Office and Family Planning Center–Carmen, Agusan del Norte, on May 26-28.

The group was headed by Dr. Bonifacio F. Wong-Marcon, Carmen Municipal Health Officer, and Gertrudes Corazon S. Gonzales, NBS Coordinator. Participants were shown actual sample collection.

Meanwhile, DOH-RO XII conducted its last batch of NBS Orientation and Heel Prick Training for the health workers of North Cotabato and Sarangani Provinces at Villa Princessita Hotel, Koronadal City, on June 25-26. A total of 26 participants attended and completed the course.

The training was the third batch conducted by the region in 2014. Participants were selected from among the facilities with high unsatisfactory samples in 2013. Among the speakers were Dr. Conchita Abarquez, Sheila Guilaran, and Mary Agnes Panton. The group had their practicum at the South Cotabato Provincial Hospital.

Finally, the Provincial Health Office of Agusan del Norte, DOH-RO Caraga, and NSC-Mindanao trained 13 health staff from district hospitals and rural health centers in Agusan del Norte on June 26-27.

The group was headed by Dr. Elizabeth N. Campado, the Provincial Health Officer, and Armie Escatron, NBS Provincial Coordinator. The heel prick practicum was held at Agusan del Norte Provincial Hospital. *SMGuilaran, APanton*

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*Home of some of the indigent patients and families visited by the NSC-Mindanao Program Review Team.*

with significantly elevated TSH levels, economic reasons hinder confirmatory testing for CH. This problem has long been addressed by the DOH Regional Offices and NSC-Mindanao during Program Implementations Reviews, NBS trainings, and Parents' Forums. NBS Coordinators should relay the concern to NSC-Mindanao and regional coordinators for assistance especially on indigent babies, and they could also tap the local government units and social services for assistance to indigent families.

**Inefficient Information System.** The team found out that two cases that were visited were found to have already expired. On further investigation, parents said that the babies were actually admitted in the intensive care units of the same facility, but the NBS coordinators were not aware of the death and failed to provide further details to NSC-Mindanao.

After two months of intensive home visits in Bukidnon, Compostela Valley, Misamis Oriental, Lanao del Norte, Davao Oriental, Agusan del Sur, Maguindanao, and North and South Cotabato, 16 out of 24 cases (or 67%) were tracked. Twelve babies underwent a repeat sample collection or confirmatory testing, two cases have expired, and two families refused further tests for their babies. In addition, eight cases were still unrecalled because of no known present address.

As NBS advocates, NBS coordinators must exhaust all means to recall positive cases. One should never give up on any case.  
*RAguilar*

## Patient Recall . . . from page 1

**Change of Residency.** Several cases were also left unresolved due to change of residency. The team was able to talk with some immediate relatives; however, on cases of parents who stowed away, contact information was quite difficult to retrieve.

**Safety.** Parents residing in critical or dangerous areas were reached through the Community Health Team (CHT) and were guided to the safest area possible for a repeat sample collection.

**Misunderstanding and Miscommunication.** Positive response on confirmatory tests usually depends on the delivery and approach of the health personnel. During interviews, the parents shared with the team that the inconsistent instructions of the facility personnel made them more hesitant. NSC-Mindanao recommends that only trained personnel should give the instructions to avoid confusion.

**Financial Constraints.** More common in families of babies

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