

## Analysis

### Service and Trust: Keys to NBS Success in Sta. Rosa

It has been almost a decade since the Newborn Screening Act of 2004 was passed into law. Looking at the impact this law has made on the well-being of the saved newborns, there is no doubt that this is one of the major health breakthroughs the health sector has done for our country this century for newborn health.

The NBS major stakeholders are tirelessly working to provide newborn screening (NBS) services to ensure the early detection and treatment of heritable conditions which could lead to mental retardation and other severe health conditions. But as in any other undertakings, numerous challenges abound before the dream of having all babies in the country undergo NBS.

One shining example of a tireless worker is NBS advocate Teodora Lucero of Doray's Paanakan in Sta. Rosa City, Laguna. In one of the most progressive and populous cities in the CALABARZON region, Aling Doray, as she is fondly called, caters to more than 500 deliveries per year.

Despite the patients' perennial problem of inadequate finances and lack of awareness about newborn screening, Aling Doray's birthing home was able to provide NBS to almost 90% of her clientele, quite an enormous feat for a lying-in considering the numerous deliveries.

How does she do it? The key according to Hannah Rondina, Aling Doray's daughter and herself a member of the facility's staff, is the intense advocacy and knowledge sharing they do to mothers under their care.

Initially, parents who were apprehensive to have their babies undergo newborn screening were asked what the reasons are for their reluctance

and most if not all of them would say the reason is economics. Some would even say, "Di naman uso yan 'nung panahon namin."

Aling Doray would then talk to them and impart the importance of newborn screening and how it is done. She would put emphasis on the early detection and treatment of the diseases included in NBS. With this simple strategy, many of them would agree to have their babies screened.

Increasing the facility's NBS coverage, however, is not that easy, especially for clients in lower economic bracket. Even if some parents wanted to have their babies screened, they are limited with resources.

In these instances, Aling Doray goes the extra mile and provides newborn screening to these babies for free using her own resources so as not to deprive them of the opportunity to be screened.

For indigent patients who needed to have consultations and laboratory tests in Manila or other areas, Aling Doray provides ambulance and personally accompanies them just to make sure that they are well taken care of.

This kind of work epitomizes the service Aling Doray is known for, and it certainly rubs on to the rest of her staff who also deliver their similar brand of service.

With the genuine concern and care Aling Doray provides her clients, there is no question she has earned the trust not just of the mothers but the whole community of Sta. Rosa and other nearby areas as well.

The Newborn Screening Program is up for more challenges ahead. But with people like Aling Doray and her staff at

## NEWS BRIEF

### NSRC Holds Cystic Fibrosis and Biotinidase Workshop

In preparation for the Expanded Newborn Screening, the Newborn Screening Reference Center in partnership with PerkinElmer, Inc., conducted the Workshop on Cystic Fibrosis and Biotinidase Disorders as part of the capacity and capability building of all Newborn Screening Centers (NSCs) at the Crowne Plaza Hotel, Ortigas Center, Pasig City, August 23.



The NSC Unit and Laboratory Heads pose for photo with Dr. Thomas Maramba and the international experts, Dr. Wiley and Dr. Therell after the workshop of CF and Biotinidase on August 23.

The training workshop aimed at providing the laboratory managers, team captains, analysts, and follow-up nurses with the following:

1. comprehensive information about Cystic Fibrosis and Biotinidase disorders;
2. overview on laboratory screening processes, flow of operation and QC/QA activities; and
3. ideal algorithm for recall of patients with positive screening results.

Dr. Veronica Wiley, Principal Scientist and Department Head of the New South Wales Newborn Screening Program, and Dr. Mary Anne Chiong, Clinical Associate Professor at the Department of Pediatrics of the Philippine General Hospital and Head of Biochemical Genetics Laboratory at the Institute of Human Genetics, served as resource speakers.

Doray's Paanakan as prime examples of tireless NBS workers and advocates, there is no doubt the road to NBS success will be much easier to tread. *EHermoso*

### Visayas Records MSUD Cases in Different Provinces

Since the Maple Syrup Urine Disease (MSUD) was added into the newborn screening panel in NSC-Visayas on April 2013, six patients have already been confirmed positive for the disorder from the following provinces: Capiz, Cebu, Samar, Eastern Samar, and Biliran.

Early diagnosis and dietary intervention are very essential to prevent complications and allow normal physical and mental development of patients with MSUD. Newborn screening elicit best outcome if done shortly after birth; before symptoms and complications set in. It is important to note that asymptomatic newborns with MSUD have a better outcomes compared to infants who are symptomatic upon diagnosis.

MSUD patients require special diet and frequent monitoring in controlling protein intake with amino acids leucine, isoleucine and valine. At present, NSC-Visayas is thankful for the kindhearted organizations and individuals that provide free MSUD milk formulas to the patients.

It is definite that statistics of babies with this metabolic disorder will continue to increase and the program implementers will face more challenges. Challenges on long-term and diet management will multiply as these babies grow up. This load, however, will be lighter if parents and stakeholders will work together and perform their responsibilities. *MMTabaosares*

### NBS Activities in Central Visayas

Since the start of the third quarter of this year, the Center for Health Development (CHD)-Central Visayas had been busy promoting and integrating the various programs for newborns.

CHD-Central Visayas started off with an orientation of two batches of Central Visayas RN HEALS on newborn screening during the Orientation of Diseases of Public Health Importance in Cebu City on July 4 and 11. It was followed by another orientation and updates in Bohol on August 2 and by the inclusion of the Actual Heel Prick Method during the practicum of Training on Basic Emergency Obstetric and Newborn Care held in Vicente Sotto Memorial Medical Center last August 16-19.

The CHD-Central Visayas and its' partner agencies, including the Newborn Screening Center-Visayas, have put their efforts together to strengthen the program through the following activities: Program Implementation Review of the Newborn Screening Program in Bacolod City; Coordinative Meetings with Licensing Regulation and Enforcement Division and Provincial Health Officers, Provincial Health Team Leaders regarding Birthing Homes; and Facility Assessments wherein newborn screening monitoring was integrated, particularly in Pinangungajan Regional Health Unit last August 2. *MMTabaosares*



Myra Leonor Salvaleon (top) discusses NBS during the Orientation of Diseases of Public Health Importance in Cebu City, while participants strike a pose after the orientation program.

## Success Story

### NBS Victory in MHO-Esperanza

Esperanza is a third class municipality in the province of Sultan Kudarat and consists of 20 barangays. Its sources of livelihood are mainly agriculture, fishery, and small scale mining.

The Municipal Health Office (MHO) of Esperanza started implementing newborn screening in 2012. But after only a year of implementation, MHO-Esperanza maintained good performance in terms of newborn screening sample acceptability and has high recall rate of positive cases.

The accomplishments of MHO-Esperanza in newborn screening would not be possible without the support of Mayor Helen T. Layog and Dr. Gilson L. Laspinas, the Municipal Health Officer. They ensured the delivery of newborn screening services to the citizens.

Besides the basic services, MHO-Esperanza offers a Delivery Package for non-PhilHealth members that costs merely Php 2,000, inclusive of newborn screening. MHO-Esperanza hopes that making delivery and newborn screening services affordable to the public will encourage facility-based delivery within the area.

For cases that need confirmatory testing and medical consultation outside Esperanza, local leaders allow the use of ambulance in transporting patients to health institutions or confirmatory centers in Davao City or Tagum City. When results from confirmatory tests turn positive, the patients were then referred to the in-house pediatrician free of charge.

The most notable contribution to the success of MHO-Esperanza in implementing newborn screening is the linkages established by Dr. Laspinas to government and non-government organizations alike, which provide necessary equipment to the MHO. *AMatuan*



NBS Team of MHO-Esperanza: Nella Yap, NBS Coordinator (3rd from left), Dr. Gilson Laspinas (center), Mayor Helen T. Layog (3rd from right), and PDOs.

### Paving the Road: The NBS of Sulu Provincial Hospital



Dr. Maria Lilybeth Tantoco-Usama (standing, center) and the Newborn Screening Team of Sulu Provincial Hospital.

To jumpstart newborn screening (NBS) program, in November 2010, DOH-ARMM gave the Sulu Provincial Hospital five newborn screening kits in celebration of the region's 21st foundation anniversary.

In the same year, Dr. Fahra Tan-Omar, Sulu's Provincial Health Officer, offered Php 2,500 as starter fund for the procurement of more NBS kits. Sulu Governor Abdu Sakur Tan, for his part, enrolled more than 100 indigents to PhilHealth.

#### Background

The province of Sulu is one of the three island provinces in southwestern Mindanao, collectively known as BASULTA (Basilan, Sulu, and Tawi-Tawi). *Continued on page 8...*

### VSH Spearheads G6PD Deficiency Forum

A total of 65 parents and their children participated in the First G6PD Forum conducted by Valencia Sanitarium Hospital (VSH) in partnership with Valencia City Health Office at the VSH Conference Room, Valencia City, August 29.

Out of the 80 confirmed cases, 30 were VSH patients and the rest of the 65 participants came from other health facilities in and around Valencia City.

"We felt a great need to promote newborn screening and at the same time answer the many questions lingering in the minds of parents with G6PD-deficient children. *Continued on page 8...*

### Calumpit and Limay Make Central Luzon Proud

Calumpit and Limay have good things to share to all newborn screening facilities (NSFs) around the country.

Their best practices are budget-friendly and start as early as prenatal and even pre-marriage to help parents save for newborn screening (NBS) after birth.

Calumpit District Hospital implements the Partial Prenatal Payment Scheme (PPPS) to prepare parents mentally and financially and enable them to comply with NBS. Aside from this, NBS is being advocated regularly during prenatal checkups and rounds at the Out-Patient Department. To help spread the word, mothers who had their own babies undergone NBS share their testimonials to future and expectant mothers.

Meanwhile, Lamao Health Center, a barangay health station from the municipality of Limay in Bataan, has its own methods in delivery and advocacy of the program. This health facility provides free services to indigent families who seek medical consultations, medicine, and laboratory examination that includes NBS. A resolution was also issued adapting RA 9288, the Newborn Screening Act of 2004, in which the Barangay Council allotted funds for its newborn screening services. Since its implementation in 2007, local officials has adapted the resolution until the present. *NFortaleza*



### NSC-Central Luzon and AUF-School of Medicine Partner in NBS Advocacy



The newborn screening (NBS) advocacy in Central Luzon got a boost as Newborn Screening Center (NSC)-Central Luzon partners with Angeles University Foundation, School of Medicine in raising the consciousness of pregnant women, health care providers, and local government officials about NBS.

The partnership began when Dr. Florencio C. Dizon, NSC-Central Luzon Unit Head, spearheaded a program orientation by the Project Development Officers (PDOs) for sophomore Medicine students in July 2013. More than a hundred students participated in the orientation, which was held in four batches, one every Monday of the month.

The PDOs explained the significance of NBS, the diseases included in the panel, and the proper collection of samples. The students also had a tour inside the Center to get a glimpse of the Center operates.

After the orientation and to send them off in their new advocacy, the students received NBS brochures, which they will distribute to expectant mothers, health care providers, and government officials. *NDelaCruz*

# VOLUNTEER YOUTH LEADERS FOR HEALTH



## Celebration

### Youth on Fire: VYLH Marks Four Years of Health Advocacy



Supporters and partners of VYLH Philippines flash fan signs, greeting the Network on its fourth founding anniversary.

July 18, 2009, a spark ignites. July 18, 2013, four years after, the Volunteer Youth Leaders for Health (VYLH) is now a wildfire.

Young health advocates all over the country came together as VYLH Philippines celebrated its fourth anniversary. VYLH from different clusters—Luzon, Visayas, and Mindanao—commemorated four years of health advocacies, volunteerism, and solid friendship.

“As we celebrate our fourth anniversary in our own unique and creative ways, we light four white candles representing our growth and fly four colored balloons with our wishes,” opened VYLH Philippines President Christian Emmanuel Enriquez.

The celebration aimed to remind the youth of the common objective to promote a more health-conscious community. VYLH celebrated through cluster gatherings, chat and teleconferences via Skype, and commemorative “selfies” posted on Facebook days before the celebration.

#### Youth Leaders Speaks

Christine Querubin, VYLH NCR and South Luzon Vice

### VYLH and GeneSoc Bring Medical Mission to Laguna

A total of 107 residents got free general checkups and 20 received free dental checkups when the Volunteer Youth Leaders for Health (VYLH) and UPLB Genetics Society Chapter (GeneSoc) conducted their annual medical mission at Barangay Bagong Silang, Laguna, July 28.

The outreach program also involved information campaign and free medicine.

Veronica Page Chavez, VYLH committee head for AY 2013–2014, and Gessa Ramos, VYLH Regional Coordinator for Region 4, along with other members of the organization, shared the importance of folic acid with the female residents of the barangay. Folic acid is a water soluble vitamin which is commonly found in leafy green vegetables, breads, and cereals. This vitamin plays a vital role in fetal development, specifically in the neural tube.

In addition, the team stressed the importance of newborn screening in the early detection of congenital metabolic disorders even before clinical signs and symptoms are present.

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President, declares, “Friendship is one of the greatest treasures in life and I have gained hundreds of amazing friends because of VYLH. The best part is that we share the collective desire to become harbingers of change and for four years now, we have become the change we want to see in the world.”

#### VYLH Milestones

Remarkable accomplishments mark four vibrant years of VYLH. The network hosted a youth camp in Tagaytay, conducted three cluster-wide camps in different areas of the country, and ran two nationwide congresses, among others.

Besides these gatherings, the diverse activities of each volunteer contribute to the success of VYLH. Volunteers conduct and implement programs in various institutions and in the communities, promoting VYLH’s three main advocacies: folic acid awareness campaign, newborn screening promotion, and support for rare orphan disorders.

In November 2013, VYLH will take an active role in the International Conference on Birth Defects and Disabilities in Cebu City. *JBarredo*



### VYLH and GeneSoc . . . from page 6



Members of the UP Los Baños GeneSoc reaches out to the community through Medical Mission 2013, in partnership with VYLH Philippines.

Early detection results in the prevention of the consequences of untreated conditions.

The talks given by VYLH were in line with two VYLH advocacies: Folic Acid Awareness Campaign and Newborn Screening Awareness Campaign.

GeneSoc’s Medical Mission 2013 concluded with the awarding of certificates of recognition to Dr. Gracielle Banares, Dr. Yucel Estrada, Dr. Resa de Jesus, and Dr. Gerald Avendano. Certificates were also given to Brgy. Bagong Silang and its officials for accepting the medical mission team.

Jamaica Ann Caras, the outreach advocacy committee head, closed the event by thanking the residents who participated, the volunteers who helped, and everyone who made the activity possible. *GRamos*

### VYLH Expands Network in UP Diliman

Five organizations accepted the invitation of the Volunteer Youth Leaders for Health (VYLH)—UP Diliman Chapter when it conducted an orientation for university organizations about health volunteerism at the Institute of Biology Pav 4, UP Diliman, August 16.

Thirty-two students from UP Psychology Society, UP Buklod-lsip, UP Red Cross Youth, UP Zoological Society, and Philippine Association of Nutritionist—Alpha attended the event.

The orientation aimed to further expand the network of volunteers in UP Diliman. Currently, only UP Psychology Society is affiliated with the Network.

The history and background of VYLH were presented to the attendees followed by discussions on folic acid, newborn screening, and rare diseases, which are the three main advocacies of the VYLH.

VYLH volunteers Ryan John Pascual, Gina Valera, and Alexei Flores spoke in the event. The network expansion orientation was spearheaded by the UP Psychology Society headed by VYLH NCR Assistant Coordinator Gina Valera with collaborative efforts from other VYLH UP Diliman Volunteers France Bartolata, Trina Villanueva, and Polo Reyes.

Letter invitations were sent to organizations, while online publicity campaigns were circulated as well to encourage walk-ins and non-affiliated students to attend. Posters were also placed around the campus to invite participants. *GValera*



Volunteers of VYLH Philippines visit UP Diliman to conduct orientation on the programs and advocacies of the organization.

### FACING the CHALLENGES of Expanded NEWBORN SCREENING

October 3 - 4, 2013 | Manila Hotel Tent City



2013 NEWBORN SCREENING NATIONAL CONVENTION

### Editorial Staff

Executive Editor:	Riza Concordia N. Suarez	Newborn Screening Reference Center National Institutes of Health University of the Philippines Manila 625 Pedro Gil St., Ermita, Manila 1000	or email us at: <a href="mailto:info@newbornscreening.ph">info@newbornscreening.ph</a> Website: <a href="http://www.newbornscreening.ph">www.newbornscreening.ph</a>
Managing Editor:	Vina G. Mendoza		
Associate Editor:	Emerson Kim J. Lineses	Follow us on Twitter <a href="https://twitter.com/newbornscreenph">@newbornscreenph</a>	
Layout Artist:	Emerson Kim J. Lineses		
Adviser:	Carmencita D. Padilla, MD, MAHPS		
Contributors:	Joan Barredo, Nikki Dela Cruz, Norrice Fortaleza, Emmanuel Herboso, Amera Matuan, Robin Charles Ramos, Gessa Ramos, Meryll Mae Tabasaes Gina Valera, Dr. Maria Lilybeth Tantoco-Usama		
Circulation:	Felix Alipasa, Girlie Villaruel, Marjorie Dimaano, Susan Jalad		

Comments and questions may be sent to:

### Paving the Road. . . from page 4

It has 19 municipalities, 11 of which are in the mainland and 8 are islands, and more than half of the population live below poverty level. Jolo, the capital of Sulu, is where Sulu Provincial Hospital is located.

A secondary hospital, the Sulu Provincial Hospital has a 100-bed capacity and is the referral center of all the municipalities in Sulu, including high risk pregnancies. Hence, it averages 1,400 deliveries annually. The hospital is also PhilHealth accredited.

#### The NBS Program

The Sulu Provincial Hospital officially started offering newborn screening in April 2011. The first year was quite difficult with most parents refusing the procedure due to financial constraints.

The hospital was able to screen only 3.4% of the deliveries, with almost all of the screened patients coming from the private ward. As a result, all of the private ward staff were trained in the newborn screening procedure.

Subsequently, the newborn screening advocacy widened to the whole hospital personnel, focusing on staff at the Delivery Room, OB-Gyne Ward, and Out-Patient Department. By 2012, the hospital’s performance rating rose to 26%.

Advocacy in newborn screening was then extended and intensified in the community through radio programs and lectures including one in Sulu Medical Society that was participated by nursing students during their Medicine Week.

In July 2013, Sulu Provincial Hospital increased its screening rate to 43%. This led to improvements in live births, including those born at home and in other facilities.

Information dissemination and the collaboration of all the health care providers were the key to the acceptance of the procedure.

The Sulu Provincial Hospital acknowledged that it was a good start but also admitted that there is still more room for growth. The hospital is now pushing to ensure that all PHIC members can avail of the newborn screening package. The hospital is also making provisions on how babies of non-PHIC members can get the procedure. *MLUsama*

### VSH Spearheads . . . from page 4

And we felt that organizing this forum will be a big help,” explained Lylibeth Halasan, VSH Chief Medtech and one of the main organizers of the program explained.


“I am very happy I attended,” testified Ciita Q. Quitoy, one of the participants and whose granddaughter has G6PD. “I’m thankful for the organizers. They really urged me to come. I really learned a lot especially about what I can or cannot feed my apo.”

“Good for me, I attended. Dr. Abarquez has really done a good job explaining the details,” pointed out Marieta Dojello, one of the participants as well, referring to Dr. Conchita Abarquez who was the resource speaker.

Glen Galario, Valencia City councilor, gave the welcome remarks on behalf of Mayor Jose Galario, Jr. He urged the participants to advocate for newborn screening as this would detect disorders early and more could still be done to arrest later complications. He promised to try his best to raise the city annual subsidy for newborn screening, which is currently pegged at Php 200,000. Dr. Marlyn Agabayani, City Health Officer, meanwhile, delivered the closing remarks.

During the forum, the participants created a G6PD Parent Support Group to lay down the program and activities of the Newborn Screening Week in October 2013, the Reunion of Saved Babies, and the 2nd G6PD Forum.

The success of the program was made possible through the support of the City Health Office—Valencia, the Newborn Screening Center—Mindanao, and the Volunteer Youth Leaders for Health Philippines—Mindanao Cluster. *RCRamos*



Newborn Screening Reference Center  
National Institutes of Health  
University of the Philippines Manila  
Pedro Gil St., Ermita, Manila 1000

## Getting Ready: FGDs to Pre-Test NBS Materials

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VYLH Expands Network in UP Diliman



The participants and mobilizers of the two FGDs held in Bataan with Limay’s Barangay Captain Restituto Reyes (standing 2<sup>nd</sup> from left)

You can never be too early. Prior to the full implementation of the Expanded Newborn Screening, the Newborn Screening Reference Center (NSRC) will launch a campaign that would turn parents’ attention to the benefits of expanded screening. And the message is crystal clear: more babies will be saved from mental retardation and death through Expanded Newborn Screening. The campaign will feature print ads such as billboards, calendars, and posters in combined Filipino-English language.

In addition, on August 28–29, NSRC arranged a pre-test exercise through a Focus Group Discussion (FGD) in Makati City and Lamao, Bataan, to seek views on and inputs in the campaigns’ target audience. The FGDs were facilitated by the Project Development Officers from the Newborn Screening Centers, Irel Manansala from the National Institutes of Health, and Roland Alcantara from Central Luzon. Each FGD had 6 to 7 respondents and took about 30–45 minutes to accomplish.

The FGD respondents were mobilized with the help of Cattleya Well-Family Midwife Clinic in Makati City and Limay Community Health Center in Lamao, Bataan, where the pre-tests were conducted.

Makati, being the country’s top business district, was selected to represent parents and expectant parents from highly urbanized areas. Limay, a second class municipality in Bataan province and located around 140 kilometers away from Manila, was chosen to represent parents in rural areas.

The results of the FGDs will be used to improve the existing campaign concepts and serve as reference for the future newborn screening advocacy materials.