

Asia Pacific NBS Experts Issue 2017 Ulaanbaatar Declaration



Seated from left to right: Sumbal Mahmud of Pakistan; Diet Sadiyah Rustama of Indonesia; Erdenetuya Ganbataar of Mongolia; Seema Kapoor of India; Rodney Howell, President of the International Society of Neonatal Screening; Carmencita Padilla, Chancellor of the University of the Philippines Manila; Bradford Therrell, Jr., Director of the National Newborn Screening Global Resource Center (NNSGRC), USA; Annamarie Saarinen of the Newborn Foundation, USA; Zhao Zhengyan of China; Tariq Zafar of Pakistan; and Nguyen Thi Ngoc Lan of Vietnam. Standing from left to right: Farkhanda Ghafoor of Pakistan; Maria Melanie Liberty Alcausin and Ma. Elouisa Reyes of the Philippines; Altantuya Tsevee of Mongolia; Terra Tolley of the Newborn Foundation, USA; Sujeeva Amarasena of Sri Lanka; Laxman Prasad Shrestha of Nepal; Cong Thi Thu Ha of Vietnam; Faisal of Indonesia; Ru Lai Yang and Ying You of China; and Misanul Hasan of Bangladesh.

As a post-conference workshop to the 10th International Society for Neonatal Screening-Asia Pacific Regional Meeting, the 6th workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region was held in Ulaanbaatar, Mongolia, on August 26-28, 2017.

The workshop produced the 2017 Ulaanbaatar Declaration—following the 2008 Cebu Declaration, 2010 Manila Declaration, and 2015 Penang Declaration—which further emphasizes the need for collaborative and cooperative networking, documents

the value of the workshops in the past, and reaffirms their continuing importance.

Participants to the workshops were representatives from Bangladesh, China, India, Indonesia, Malaysia, Mongolia, Nepal, Pakistan, Philippines, Sri Lanka, and Vietnam (while those from Cambodia, Laos, and Palau participated in other workshops), with expert assistance from the United States.



Dr. Mary Ann Abacan (standing), clinical geneticist, provides inputs on how to properly address queries and issues raised by the patient's family.

NSRC Holds Workshop for NSCs, NBSCCs

To improve the integration of short-term and long-term follow-up teams in the total quality care of patients, the NSRC conducted a workshop for key personnel of the NSCs and Newborn Screening Continuity Clinics (NBSCCs) at the National Institutes of Health (NIH) Conference Room, University of the Philippines Manila (UPM), on August 17-18, 2017.

NSCs represent the short-term follow-up component of National Comprehensive Newborn Screening System and are responsible for screening, confirmatory testing, diagnosis, and initial management of confirmed patients. The NBSCCs, on the other hand, represent the long-term follow-up component and are in charge of receiving patients endorsed by the NSCs for continuity of treatment and management to ensure optimal physical, mental, and social outcomes.

The workshop aimed for both components to better integrate effectively in order to strengthen completely the patient care system needed to support children and families of children diagnosed with heritable disorders.

NSC Visayas

For Visayas
West Visayas State University
Medical Center
E. Lopez St., Jaro, Iloilo City
Telefax: (033) 329-3744
Email: nscvis@gmail.com



Region 7 Health Workers Undergo Training

To orient doctors and nurses on the basic management of the disorders included in the newborn screening panel, DOH-RO 7 and NSC-Visayas (NSCV) conducted the Orientation on the Clinical Management of Genetic/Metabolic and Endocrine Disorders of the Philippine Newborn Screening Program at the Crown Regency Residences, Guadalupe, Cebu City, on August 16-18, 2017.

Attended by doctors and nurses of selected hospitals in Region 7, the activity aimed to extend the reach of newborn screening to the different parts of the region, especially the indigents who cannot afford to travel to Cebu City for consultations. *RVValdevesio*

ANNOUNCEMENTS

3rd DOH-RO 7 NBS Fun Run

The 3rd DOH-RO 7 Newborn Screening Fun Run will be held on October 1, 2017. Registration and assembly will be at 3:30 a.m. at the DOH-RO 7 Compound.



NBS Program Logo-Making Contest

The DOH-RO 7 Regional Newborn Screening Team calls for entries for the Newborn Screening Program Logo Contest. It is open to all individuals, including staff of newborn screening facilities in Central Visayas. The entries will be judged using the following criteria:

- 40% - Concept
- 30% - Artistry/Impact
- 30% - Originality

All entries must be submitted on or before September 22, 2017, to Dr. Hayce S. Famor-Ramos, Child Care Program Coordinator, or Mr. Ruff Vincent Valdevesio, Regional NBS Coordinator. You may also email your entries to the following address: nbsdohro7@gmail.com. Cash prizes and newborn screening freebies await the best logos.

For inquiries, please contact Mr. Valdevesio at (032) 418-7633 or 0923-424-8791 or 0927-592-4995.

Mindanao NSC

For Mindanao
Southern Philippines Medical Center
J. P. Laurel Avenue, Davao City
Telephone: (082) 226-4595, 224-0337
Telefax: (082) 227-4152
Email: nbsprogram@nscmindanao.ph

Caraga NSFs Hold Consultative Meeting

To ensure the timely diagnosis and management of babies with common metabolic disorders, NSFs must perform the newborn screening sample collection promptly without errors and complete with demographic details. They must also ensure availability of kits at all times. Unfortunately, these key factors to the success of the program are quite a challenge also in the Caraga Region.



Health professionals attend NBS consultative meeting to address newborn screening implementation issues in Caraga.

To address these issues, the DOH-RO Caraga conducted a consultative meeting at the Gateway Hotel, Surigao City, on August 23-24, 2017. Some 50 participants composed of midwives, medical technologists, nurses, and doctors from select facilities in the region attended the activity.

The program included giving emphasis on adherence to implementation guidelines and presentation of performance reports (per facility and province) for the first half of the year 2017, which reflect the total samples received from NSFs, total unsatisfactory samples, unsatisfactory rate, return rate for repeat sample collection, screening age, and transit time.

Nicolette Liana Salvo, Region 11 NBSCC Nurse, spoke about further strengthening the network of stakeholders to increase the return rate of cases for monitoring. Proposal on upcoming activities for confirmed cases was also discussed. For their part, participants presented their plans of action on reactivating the program and improving performance. The plans for the provision of expanded newborn screening kits to give mothers the chance to have their babies screened for the 28 metabolic disorders were also presented.

After the meeting, the facilitators visited to Surigao del Norte provincial health office and conducted facility visit at San Juan District Health Center of Surigao City. *RAguilar*



Philippines NBS Paper Awarded Best Scientific Poster at the Regional Conference

A research paper from the Philippines won at the 10th International Society for Neonatal Screening-Asia Pacific Regional Meeting held in Ulaanbaatar, Mongolia, on August 24-26, 2017.

The paper, titled "Timeliness of Newborn Screening Activities in the Philippines," was presented by its lead author, Dr. Conchita Abarquez, NSCM Unit Head. It was co-authored by Dr. J Winston Edgar Posecion, NSCV Unit Head; Dr. Anna Lea Elizaga, NSC-National Institutes of Health

Continued on page 7...

Dr. Conchita Abarquez stands beside the poster of the winning research paper, which she co-authored with UPM Chancellor and other NSC unit heads, in Ulaanbaatar, Mongolia.



EXPANDED NEWBORN SCREENING

>20

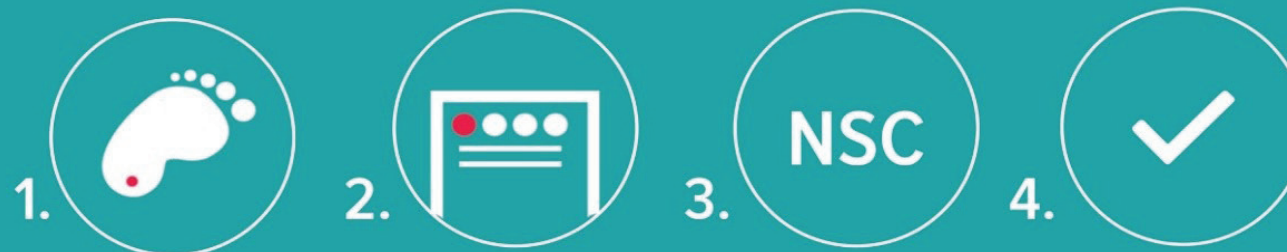
congenital disorders can be tested and identified under the expanded newborn screening

What is newborn screening?

Newborn screening is a public health program for the early identification of disorders that may lead to intellectual disability and death.

Visit us at www.newbornscreening.ph

A CHANCE TO SAVE A LIFE Get your newborn screened!



1. Newborn screening is ideally done 24 hours after birth. A few drops of blood are taken from the child's heel.

2. Blood drops from the child are then blotted on a special absorbent filter card.

3. The filter cards are sent to Newborn Screening Center (NSC) for evaluation.

4. Newborn screening results are available within 7-14 working days from the time samples are received at the NSC.



Republic Act 9288 or the Newborn Screening Act of 2004 ensures every child born is offered newborn screening.



More than 6,000 health facilities in the country offer newborn screening including hospital and health centers.

Newborn Screening Week: October 1-7, 2017



What is Thalassemia Trait/Minor?

This is a mild disorder of the red cells which may result in a slight anemia. In most cases, children are symptom free and will have normal growth and development.

Does this mean that my child will lead a normal life?

Yes. It is important to remember that your baby will only have the trait but will not exhibit the disease as well as the signs of the disease. This trait may be transmitted by the infant to their would-be children, so it is extremely important to have their future partners screened for the trait as their union may result in a baby with severe case of thalassemia or even fetal death. Severe cases of thalassemia will require frequent transfusion for their entire life.

Are there any precautions that I need to do or medications I have to avoid giving my baby?

You should refrain from giving iron supplements. Vitamin C, folic acid, and vitamins E and D are recommended which are available in most multivitamin preparations.

Which doctor or specialist should I bring my baby for regular checkups?

Since the trait is basically silent, your pediatrician may take care of their health needs. You may occasionally need to visit a pediatric haematologist depending on your pediatrician's clinical assessment.

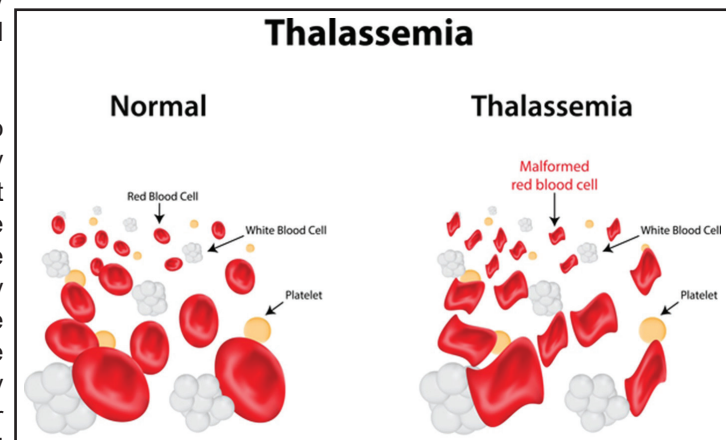
What immunizations should they receive?

They need to receive the usual recommendations of the Philippine Pediatric Society.

It is recommended, though, that they also be given frequent transfusion for their entire life.

Source: *Fact Sheets for Parents (September 2016)* available at www.newbornscreening.ph.

(Image from <https://ghr.nlm.nih.gov/>)



15th NATIONAL NEWBORN SCREENING CONVENTION

BRIDGING the GAPS:
From Screening to Management

OCTOBER 3-4, 2017
Reception Hall, PICC

Organized by: NSRC

Presented by: NSRC

Co-Presented by: PerkinElmer

Supported by: NSCV, UNILAB, etc.

Philippines NBS Paper

... from page 4

(NIH) Unit Head; Dr. Alma Andal, NSC-Southern Luzon (NSCSL) Unit Head; Dr. Crislyn Samia, NSC-Central Luzon (NSCCL) Follow-up Head; and Dr. Carmencita Padilla, UPM Chancellor.

The study evaluated the timeliness of newborn screening activities in the Philippines, determined areas in the system that can be improved, and identified issues that affected the timeliness and how stakeholders can address these issues. The paper used data from 2012 to 2016.

Dr. Abarquez shared the award not only with her co-authors but also, more importantly, with the beneficiaries of the newborn screening program. "This is a very important paper," she said. "It will benefit not only the program implementers and stakeholders but also the babies and their families."

Themed "Racing to Expand Newborn Screening in the Asia Pacific Region and in Mongolia," the intensive three-day conference, along with the pre- and post-conference workshops, provided updates on newborn screening and management of genetic diseases and congenital anomalies across the Asia Pacific region. Participants from 29 different countries had the opportunity to discuss the new conditions for consideration in newborn screening.

The Mongolian National University of Medical Sciences, Mongolian Academy of Pediatrics, Mongolian Society of Newborn Screening, and the International Society for Neonatal Screening hosted the regional meeting.

Chancellor Padilla, Dr. Abarquez, and Dr. Andal were accompanied by Dr. Maria Melanie Liberty Alcausin, Ma. Elouisa Reyes, and Riza Concordia Suarez from NSRC.

EDITORIAL STAFF

Comments and questions may be sent to:
Newborn Screening Reference Center
National Institutes of Health
University of the Philippines Manila
Unit 304 New Bond Gold Building
1579 F. T. Benitez, Malate, Manila

Or email us at: info@newbornscreening.ph
Website: www.newbornscreening.ph
Follow us on Twitter: [@newbornscreenph](https://twitter.com/newbornscreenph)

Executive Editor: Riza Concordia N. Suarez
Managing Editor: Vina G. Mendoza
Associate Editor: Emerson Kim J. Lineses
Layout Artist: Emerson Kim J. Lineses
Contributors: Ronald Aguilar, Sheila Mae Guilaran, Amerah Matuan, Ruff Vincent Valdevieso
Circulation: Richard Alipasa, Marjorie Dandan, Jesusa Jalad, Juvelyn Reyes, Mary Grace Opon, Ma. Agnes Algarme
Adviser: Ma. Elouisa L. Reyes

Directory of Newborn Screening Centers

- For Regions 1 and 2
Unit Head: Dr. Ma. Virginia Paz K. Otayza
Newborn Screening Center-Northern Luzon
• Mariano Marcos Memorial Hospital and Medical Center
• 4F/5F MMMHMC Laboratory Bldg.,
• Brgy. 6, San Julian, Batac City, Ilocos Norte
• Email: nscnorthernluzon@gmail.com

- For Region 3 & CAR
Unit Head: Dr. Bernadette C. Halili-Mendoza
Newborn Screening Center-Central Luzon
• Angeles City University Foundation Medical Center
• MacArthur Highway, Barangay Salapungan, Angeles City
• Contact Number: (045) 624-6571
• Email: nscaufmc@gmail.com

- For Region 4A
Unit Head: Dr. Alma P. Andal
Newborn Screening Center-Southern Luzon
• Daniel O. Mercado Medical Center
• 3F DMMC-HIS Bldg., 143 Narra St.,
• Mountview Subd., Tanauan City
• Contact Numbers: (043) 702-7715, 702-7719
• Email: nsc.southernluzon@gmail.com

- For Regions 4B, 5, & NCR
Unit Head: Dr. Anna Lea G. Elizaga
Newborn Screening Center-National Institutes of Health
• Building H, UP Ayala Land Technohub Complex,
• Commonwealth Avenue, Brgy. UP Campus, Diliman, Quezon City
• Contact Numbers: (02) 376-0962, 376-0964, 376-0965, 376-0967
• Email: NSC-NIH@upm.edu.ph

- For Visayas
Unit Head: Dr. J Winston Edgar C. Posecion
Newborn Screening Center-Visayas
• West Visayas State University Medical Center
• E. Lopez St., Jaro, Iloilo City
• Contact Number: (033) 329-3744
• Email: nscvis@gmail.com

- For Mindanao
Unit Head: Dr. Conchita G. Abarquez
Newborn Screening Center-Mindanao
• Southern Philippines Medical Center
• J.P. Laurel Avenue, Davao City
• Contact Numbers: (082) 226-4595, 224-0337, 227-4152
• Email: nbsprogram@nscmindanao.ph

NBS in Marawi ... from page 1

The Newborn Screening Center-Mindanao (NSCM) has rerouted deliveries of NBS kits to Iligan City so that other NSFs in Lanao del Sur can claim them without passing by Marawi City; other orders are still pending and might eventually be cancelled. NSFs in Maguindanao informed NSCM that payment for their orders would be delayed because claiming of PhilHealth reimbursement from the PhilHealth Regional Office located in Marawi City has become impossible.

Despite these difficulties, many NSFs in Lanao del Sur still found ways to provide newborn screening to their constituents. NSFs sent samples through courier to other facilities in Iligan City and Cagayan de Oro City. Newborn screening was provided in evacuation centers. The Department of Health-Regional Office (DOH-RO) 10 also instructed nearby NSFs to accommodate babies from Marawi City for free and claim replacement cards from the regional office.

Today, it is still difficult to assess the overall effect of the Marawi City siege. The number of babies who missed screening and the number of babies who would be saved from lifelong diseases could only be guessed at the moment. Health workers and newborn screening advocates, for now, could only pray and hope that the conflict will end soon so that people in Marawi could resume their normal lives. *AMatuan, SMGuilaran*

NSRC Joins NSTW



Newborn screening booth at NSTW

NSRC participated in the celebration of the 2017 National Science and Technology Week (NSTW), led by Department of Science and Technology (DOST), at the World Trade Center, Pasay City, on July 11-15, 2017.

With the theme "Science for the People," this year's celebration aimed to bring science and technology closer to the people by featuring its latest innovation technologies including the available programs and services that the DOST has to offer to public. Besides exhibits, other activities included science and technology forums, exhibits, career talks, film showing, and journalism workshop.

Your Feedback Is Important to Us!

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.

NSRC
Newborn Screening Reference Center
National Institutes of Health
University of the Philippines Manila
Unit 304 New Bond Gold Building
1579 F. T. Benitez, Malate, Manila



NBS in Marawi City: Effects of the Maute Siege

WHAT'S INSIDE

- 2 NBS Experts Issue 2017 Ulaanbaatar Declaration
- 2 NSRC Holds Workshop for NSCs, NBSCCs
- 3 Region 7 Health Workers Undergo Training
- 3 Region 7 Announcements
- 4 Caraga NSFs Hold Consultative Meeting
- 4 Philippines NBS Paper Awarded Best Scientific Poster at the Regional Conference
- 6 In The Know: Thalassemia
- 7 Directory of Newborn Screening Centers
- 8 NSRC Joins NSTW

May 23, 2017, was a day to remember for Filipinos. The Maute group, an ISIS-linked band of extremists, invaded the city of Marawi.

The next three months since the siege saw thousands of families losing their homes, loved ones, livelihood, and cultural heritage, as military forces fought to gain control of the city. Up until today, the fighting ensues and martial law is still in effect in the whole of Mindanao.

As the only city in the Autonomous Region in Muslim Mindanao (ARMM), Marawi City serves not only as the capital of Lanao del Sur but also as conduit that connects all the localities in the province. No one goes in and out of Lanao del Sur without passing through Marawi City, as this is the safest route within the province before the conflict.

Lanao del Sur has the highest number of newborn screening samples in ARMM, as people moved freely from province to province within the region. The province

also houses a total of 50 newborn screening facilities (NSFs), of which 14 are in Marawi City. The largest and the only tertiary hospital in the province is Amai Pakpak Medical Center. It is in the downtown area and was the first to be hit by the armed group when the conflict began.

The Maute siege heavily affected newborn screening in Marawi City. All 14 NSFs in the city closed down, 5 of which were reported to be destroyed due to military air strikes.

Besides screening, other aspects of newborn screening operations were affected. Samples collected before the conflict were lost or burnt, and repeat collection on these patients would prove to be a challenge. Results could not be sent to NSFs outside of the conflict areas because routes are impassable. Likewise, recall of positive cases could not be done because families have already moved out of the danger zone and are already difficult to locate.

Continued on page 8 ...