



Prof. David Silience, foundation chair of Medical Genetics in the University of Sydney, talks about targeted sequencing for Skeletal Dysplasia.

- Hemoglobinopathies for NBS Program Implementers – aimed at addressing the needs of the newborn screening program in light with the drastic increase in the number of patients who confirmed positive for Hemoglobinopathies
- Wellcome Genome Campus: NGS Analysis for Genetic Diseases – aimed at equipping beginners with a working toolset to analyze and interpret data generated from NGS for identifying candidate causal variants.
- 3rd Genetic Counseling Pre-conference Workshop – promoted ongoing collaboration for genetic counselor professional development and enhanced genetic counseling training, as well as an opportunity to increase awareness and effectiveness on the provision of clinical genetic counseling services in Asia.
- 4th ASEAN Congress on Medical Biotechnology and Molecular Biosciences: Emerging Issues on Hemoglobinopathies in the Asia Pacific Region – discussed a relevant group of hemoglobin disorders that affect millions of people worldwide

PH Hosts . . . from page 1

Therapies for Rare Diseases and for Precision Medicine; Rare Are Common: How Rare Diseases Reveal Molecular Pathways for Common Disorders; Craniofacial Phenotyping in Diverse Populations: Insights from the Asian Populace; and Gearing Up for the Phenomics Era.

Philippine cultural dances, including “pandango sa ilaw,” “tinikling,” and other regional dances, organized by the Tourism Promotions Board of the Philippines, were showcased during the closing ceremony. A post conference featuring the Fourth Volunteer Youth Leaders for Health-Philippines National Leadership Congress was held on November 10-11.

Scientists and experts also shared knowledge and insights on these areas: Genetic Risk Assessment and Counseling in the Era of Genomics; Revolutionizing Newborn Screening: New Developments and New Dilemmas; Prenatal Genetics: How Genetic Technologies are Shaping Reproductive Decision-Making; Hemoglobinopathies: Advances in Diagnosis and Innovative Therapeutics; Advances in the Diagnosis and Therapy of Inherited Metabolic Diseases; Discerning the Phenotypes of Genetic Disorders Through Next Generation Sequencing; Population Genetics: Genetic migration in Asia: From Patterns to Predictions; Elucidating the Genetics of Complex Diseases: Where Are We Now; Understanding Future Trends of Metagenomics, Proteomics and Metabolomics; Solving the Brain Enigma: The Value of Genomics in Neuropsychiatric Disorders; Lysosomal Storage Diseases: Towards an End to Diagnostic Odyssey and Improvement in Care; and Disorders of Sexual Development: Integrating Clinical and Genetic Approaches.

The APCHG is a non-profit organization founded in 2006 and comprised of persons involved or interested in the study of human genetics in Asia Pacific. The membership, which includes scientists, clinical geneticists, genetic counselors, and students, has steadily increased over the past years. It welcomes members from all the countries in the Asia-Pacific region.



Megan Foe (USA, second from right) addresses queries on Thalassemia Advocacy Programs during the ASEAN Congress on Biotechnology and Molecular Biosciences, a pre-conference workshop during the 13th APCHG. She is joined by Genetic Counselor Dr. Ma-am Tumalak (Philippines, leftmost), Director of the National Newborn Screening and Global Resource Center Bradford Therrill, Jr. (USA, second from left), and Director of the Hemoglobinopathy Reference Center Laboratory Dr. Carolyn Hoppe (USA).

Strengthening Patient Management through Satellite Clinics

Stakeholder participation has always been crucial to the success of any public health program. And the NBS Program is fortunate to have the Department of Health–Centers for Health Development (DOH-CHDs) in every region as partners in saving newborns and assuring their optimal growth and development.

Since 2014 when the NBS Continuity Clinics (NBSCCs) were established, DOH-CHDs have continuously stepped up in their support to patient care. One notable CHD is Western Visayas, which is under the visionary leadership of Program Manager Dr. Renilyn Reyes and the able support from coordinators Grace Exmundo and Florence May Osano.

In 2015, DOH-CHD Region 6 came up with a Memorandum of Agreement (MOA) with West Visayas State University Medical Center (WVSUMC), host to the NBSCC in Iloilo City, that effectively allocated P250,000 of downloadable funds each year intended for recall, treatment, and management of patients in the NBSCC. This best practice was soon adopted by DOH-CHD Region 5 and is now being considered by other CHDs.

As early as 2015, the DOH-CHD Region 6 had the foresight to build a network to reach out to the provinces and islands of Western Visayas. They initially thought of the term “sentinel sites” to refer to targeted hospitals that shall serve as a network of clinics that can support the NBSCC based in Iloilo.

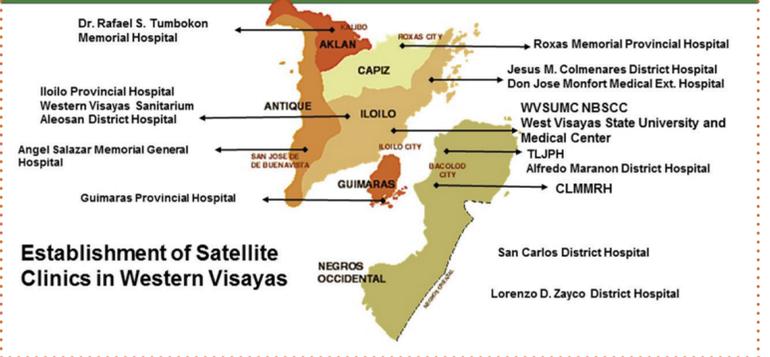
The idea, however, did not come into fruition overnight. It took years of talking to and convincing the right people—pedia chairs and medical center chiefs—to support the idea of a network of clinics for Region 6. From 2015 to 2018, the CHD Team visited identified hosts to become possible “satellite clinics.”

The concept works this way: recalled patients are referred to either the WVSUMC NBSCC or the satellite clinics. The WVSUMC NBSCC communicates to its endorsed patients the nearest satellite clinic in their place of residence. The facility that hosts the satellite clinic incorporates the NBS clinic services in its OPD services. A particular day is allotted to NBS wherein a nurse who is organic to the facility will check the status of NBS patients referred to them. A standard form (which would later evolve into yet another novel “baby book” idea of DOH-CHD Region 6) will be filled up with anthropometric data and date of consultations. These data will be communicated with WVSUMC NBSCC. When there are complications with

the patient, they will be referred to visit the WVSUMC NBSCC or to the nearest specialist who can address such problems. Similarly, in recall of newly endorsed patients, the WVSUMC NBSCC endorses patients to rural health centers or city health offices to help in the recall efforts.

Eventually, the targeted facilities were convinced and agreed to join the network of satellite clinics. To date, there are 14 satellite clinics spread throughout Panay and Negros Occidental islands—each in the provinces of Aklan, Antique, Capiz, and Guimaras; six in Iloilo province; and four in Negros Occidental.

INNOVATION STRATEGIES AND BEST PRACTICES



One of these satellite clinics is Corazon Locsin Montelibano Memorial Regional Hospital (CLMH), a tertiary hospital. It has been serving as a satellite clinic from 2015 to 2018 for the entire Negros Occidental. It is a regional hospital with a roster of specialists, i.e., geneticist, neonatologist, pediatric hematologist, and developmental pediatrician. Right now, CLMH is being identified as a potential host to an NBSCC, which can have a dedicated clinic with a full-time nurse and part-time follow-up head. In case, salary of the nurse will be shouldered by the NSC-Visayas (NSC-V) for the first two years, after which DOH-CHD Region 6 takes over. It is just awaiting complete signing of MOA to fully commence its operation as a new NBSCC.

The satellite clinic concept is a shining example of a CHD’s commitment to long-term patient care and a CHD team’s admirable passion and initiative. This team and the CHD, together with the WVSUMC NBSCC and NSC-V, have indeed blazed the trail toward the achievement of the one of the goals in the Strategic Framework 2030—which is to strengthen patient management by establishing a long term management system for children with NBS disorders. *FDBeltran*

Western Visayas Involves Parents in Management of CH

Region 6 has at least 450 confirmed NBS cases, of which 82 percent are Congenital Hypothyroidism (CH). The management of any of the NBS cases involves resources from various key players and that an efficient NBS management system necessitates the cooperation and support of the families of the diagnosed children.

On November 14, 2019, in coordination with the NBSCC Western Visayas and NIH-IHG, a 10-member support group composed of parents of children diagnosed with CH was organized. Dr. Renilyn Reyes, Dr. Karen Ventilacion, and Aster Lynn Sur spearheaded and facilitated the focus group discussions to identify the needs of the group.

On November 24, the support group for the CH was officially launched during a mall-based celebration of the National Children’s Month. The NBSCC shall oversee the activities including plans for information dissemination in the community and annual meeting with the parents.



Top: Participants and organizers of the FGD held on November 14, 2019, in coordination with the NBSCC Western Visayas and NIH-IHG. Bottom: Official launching of the CH support group in Eastern Visayas on November 24.

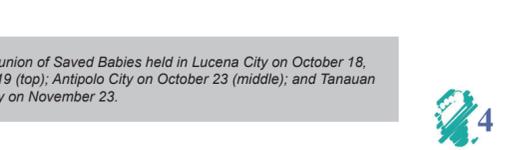
CALABARZON Holds Reunions of Saved Babies

A “reunion,” as all Filipinos are familiar with, is a venue for a kumustahan or knowing how someone has been since they last met.

In October and November 2019, NSC–Southern Luzon (NSC-SL) in collaboration with NBSCC and DOH-CHD Region 4A held the annual provincial Reunions of Saved Babies for the 146 participant- families from CALABARZON.

The reunions were filled with fun games and sharing of experiences among families. The festive atmosphere of the reunion also reflected the timely management efforts of giving a child a better chance to live a normal and healthy life.

The NBS Program does not end in just testing a newborn’s blood sample. Right after screening, management and close monitoring follow. The commitment of program implementers and stakeholders, combined with the dedication of parents and families to give their children a better future despite having a disorder, calls for a celebration of life. *FDimaculangan*



Reunion of Saved Babies held in Lucena City on October 18, 2019 (top); Antipolo City on October 23 (middle); and Tanauan City on November 23.

Central Luzon Conducts Program Implementation Review

To evaluate the status of the program’s implementation in Central Luzon, DOH-CHD Region 3, in partnership with the NSC-Central Luzon (NSC-CL), NBSCC Region 3, and NIH through NSRC, IHG, and the Newborn Hearing Screening Reference Center (NHSRC), conducted the NBS Program Implementation Review at the Mansion Garden Hotel, Subic Bay Freeport Zone, on November 12-13, 2019.

Program implementation review activity covers new updates, issues and challenges, and recommendations and agreements in all components of the newborn screening program: education or advocacy, screening, diagnosis, follow-up and recall, short term and long term management, and quality assurance.

The activity was attended by NBS provincial coordinators, who provided updates, identified interventions that will address the current challenges of the program, and developed strategies and strengthened linkages with one another.

Jovy Casamorin-Lising, NSRC Project Development Officer, discussed the history, plans, and status of the NBS Program as well as updates, issues, and concerns. Grace Dale, representative from PhilHealth Regional Office 3, explained the Enhanced Newborn Care Package challenges and opportunities, while Madeline Gayle Tayag, DOH-CHD Region 3 NBS Nurse Coordinator, presented the regional program updates and consolidation of issues from the previous series of consultative meetings.

The NBS data in Central Luzon and the quality of samples received by the NSC-CL were shown, and their implications were explained by Dr. Bernadette Halili-Mendoza, NSC-CL Unit Head, while discussions about the challenges, opportunities, and activities for 2020 were facilitated by Maria Elissa Veronica Benipayo, NSC-CL Program Manager. Dr. Crislyn Samia, NSC-CL Follow-up Head, discussed the disorders being screened in the ENBS panel and the number of positive screens and confirmed positive cases per province. Maria Regina Yutuc, NSC-CL Follow-up Officer, presented the challenges encountered by the short-term recall and follow-up team in the region. Dr. Ma. Victoria Macalino, NBSCC Region 3 Follow-up Head, discussed the roles of the NBSCC and updates regarding long-term follow-up, and Maria Francesca Retomarta, NBSCC Long-term Follow-up Nurse, talked about the challenges encountered in the long-term follow-up clinic and the efforts of the NBSCC in strengthening the continuity of care of confirmed positive patients. Aster Lynn Sur, IHG-NIH Metabolic Nurse, shared inspiring NBS success stories and how the program overcame the challenges it faced for the past two decades. The NBS provincial coordinators identified the issues and concerns with the different stakeholders of the program, with Dr. Shiela Mae Y. Geronimo, Development Management Officer IV of the Bulacan province, facilitating.

Parents of the saved babies gave testimonials and shared to the other attendees what it is like to have a child with a congenital disorder. They also wrote messages to their children, their families, and the community and placed them on the “promise wall.”

There were also fun activities and games for the attendees. An inflatable playground was set up for children to enjoy themselves during the event. Medical specialists also gave free consultation to the patients during the activity. *NDelaCruz*

By the end of the activity, Tayag presented the proposed program activities of the DOH CHD Region 3 in 2020. *NDelaCruz*



Aster Lynn Sur, genetic nurse from IHG, shares inspiring success newborn screening stories to the families that attended the reunion.

DOH-CHD Region 3 Conducts Reunion of Saved Babies

DOH-CHD Region 3, in partnership with the NSC-CL, NBSCC Region 3, Volunteer Youth Leaders for Health (VYLH)-Philippines, and the City Disaster Risk Reduction Management Office of San Fernando, Pampanga (CSFP-CDRRMO), conducted a Reunion of Saved Babies at the Heroes Hall of the San Fernando City on November 26, 2019.

Attended by more than 140 patients and their parents and guardians, the activity served as a venue to foster camaraderie between the stakeholders and the families of the children with heritable disorders. It became a catalyst in strengthening various support groups among parents and the community.

Atty. Atlee Viray, San Fernando City Administrator, gave an inspiring message and officially opened the program. Dr. Crislyn Samia, NSC-CL Follow-up Manager, discussed the importance of routine monitoring of the patients, while Dr. Maria Victoria Macalino, NBSCC Region 3 Follow-up Head, explained the importance of the Continuity Clinic and the compliance of patients to long-term follow-up care. Inspiring success stories were also shared by Aster Lynn Sur, after which Aris Jae Lacson from CSFP-CDRRMO talked about safety and disaster preparedness for families with children with special needs.

Parents of the saved babies gave testimonials and shared to the other attendees what it is like to have a child with a congenital disorder. They also wrote messages to their children, their families, and the community and placed them on the “promise wall.”

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VYLH-Philippines Launches 4th Advocacy in 4th National Leadership Congress

Participants of the Fourth National Leadership Congress of the VYLH-Philippines during the cultural night.



On its Fourth National Leadership Congress, the Volunteer Youth Leaders for Health (VYLH)-Philippines fittingly highlighted the launch of its fourth principal advocacy—preconception health campaign—joining expanded newborn screening (ENBS) promotion, folic acid awareness campaign, and rare disease support.

With the theme “Padayon: Empowering the Next Generation of Volunteer Youth Leaders for Health in the Era of Genomics,” the congress was a post-conference event of the Asia Pacific Conference on Human Genetics and centered on the network’s advocacies and the youth’s role in promoting health.

The congress was held at the Makati Shangri-la Hotel on November 9-11, 2019, and gathered together nearly a hundred proactive volunteer youth leaders from all over the country in celebration of the network’s 10th anniversary. The event was supported by the Department of Health, IHG-NIH-UPM, March of Dimes, Asia Pacific Society of Human Genetics, Newborn Screening Reference Center, and the country’s Newborn Screening Centers (NSCs).

The congress kicked-off with a special talk on Volunteerism and Transformational Leadership by University of the Philippines System Pahnungod Director Dr. Grace Aguilin-Dalisay. Team building activities facilitated by IHG and NSRC staff members were also held during the congress’ first night.

The second day featured health talks from experts and key personalities in the field of birth defects. Lectures included

the Genetics of Birth Defects and Preterm Births, Expanded Newborn Screening in the Philippines and Understanding the ABCs of Rare Disease and the Law from Dr. Eva Cutiongco-de la Paz, Dr. Mary Ann Abacan, and Dr. Carmencita Padilla, respectively.

March of Dimes Vice President for Global Programs Dr. Salimah Walani graced the event as the keynote speaker and talked about preconception health’s importance in the prevention of birth defects and preterm births. She emphasized that intervening only after a woman is pregnant is already too late and it is high time that preconception health is put forward in improving the lives of mothers and children in the country.

Furthermore, one of the goals of the congress was to facilitate exchange of learning and experiences in the promotional work of the network. Discussions on the best practices in advocating eNBS and rare diseases were facilitated by Floyd Edrea and Edbert Jasper Jover. An award-winning program initiated by Ruth Basas, Kabilin Kalusugan for LB Nanays, opened new doors and enriched thinking for more innovative and better-quality advocacy programs.

VYLH-Philippines also highlighted the successes of the social media campaigns such as #FolicAcidPh and #WorldBDDay, which were done by the network and reported by Ryan John Pascual. Future plans on the folic acid awareness and preconception health campaign were presented by Rufus Thomas Adducul, while opportunities in the rare disease advocacy were discussed by Karen Panol.

The cultural night showcased talents and unity amidst diversity among the four clusters representing the different island groups: Luzon, Visayas, and Mindanao. The event also paid tribute to the unwavering support of the network’s partners and the significant contributions of Professor David Silience in the field of genetics. The Outstanding Volunteer Awards were also given to Katrina Dee Guro, Anthony Toralba, John Paul Oira, Edbert Jasper Jover, Ramonito Nuique, and Christian Emmanuel Enriquez, while the Exemplary Volunteer Awards were handed to Ryan John Pascual and Floyd Edrea.

In addition to the network’s advocacies, the congress was also an avenue to discuss global developments and emerging advocacies such as the Sustainable Development Goals (SDGs) and the importance of mental health. On the third day of the congress, the work of two national youth organizations, namely, the 2030 Youth Force in the Philippines and the Youth for Mental Health Coalition, were presented by Brex Arevalo and Alyannah Ysabel Lagasca, respectively.



The Outstanding Volunteer awardees (standing left to right): Ramonito Nuique, Edbert Jasper Jover, Christian Emmanuel Enriquez, Katrina Dee Guro, John Paul Oira, and Anthony Toralba.

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The congress concluded with the proclamation of the fresh roll of national officers led by the third national president, Rufus Thomas Adducul. The four vice presidents elected for North and Central Luzon, NCR and South Luzon, Visayas, and Mindanao were Ameal Bartolazo, Jean Ruth Basas, Marielle Buscato, and Shane Paul Baula, respectively. Other newly elected national officers were Charity Hope Ponce (Secretary), Ram Nuique (Treasurer), Melboy Bulan (Auditor), Trisha Isabel Guioguio (Public Information and Relations Officer), and Stephanie Kate Pepino (Membership Officer).

With another set of empowered national officers and younger batch of new volunteer youth leaders, the VYLH-Philippines will continue to lead the youth in its role in nation-building with renewed courage and burning desire to effect change in our country. Emmanuel Enriquez, the network’s immediate past president, challenged the new breed of leaders saying, “If you are called to be there, make sure your presence has an impact.” *TIFGuioguio*

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LGU San Antonio Holds Buntis Party

In order to promote a healthier pregnancy, DOH in partnership and coordination with the Local Government Unit (LGU) of San Antonio, Nueva Ecija, conducted the Buntis Party at the Dr. Jose Lapuz Salonga Gymnasium, San Antonio, Nueva Ecija, on December 18, 2019. Attended by 84 pregnant women the activity was themed “Inang Sagana sa Kaalaman, Malusog na Sanggol Makakamtan.” It is one of the special breakthrough activities of the DOH that aim to rapidly reduce maternal and child morbidity and mortality and to promote the health of women and newborns. The topics discussed during the activity were safe motherhood, essential newborn care, ENBS, folic acid supplementation, family planning, and HIV, syphilis, and Hepatitis B screening. *JSicut*



Pregnant mothers line up for an activity during the Buntis Party.

San Jose Koop Picks Ospital ng San Jose del Monte for Charity Drive

San Jose Koop chose the patients from Ospital ng San Jose del Monte in Bulacan as recipients of its annual public service and charity drive.

It gave away ten free ENBS kits on November 27, 2019. This initiative was led by Carol Dave, with their two Board of Directors Lydia Forest and Romeo De Jesus. The Chief of Ospital ng San Jose del Monte Dr. Catherine Misoles and staff in the NBS program also took part in making this initiative happen. *FCalliao*



Beneficiaries of the public service drive of San Jose Koop

We would love to hear your feedback. Please let us know how we can improve our bimonthly newsletters by answering our [feedback form](http://www.newbornscreening.ph) at www.newbornscreening.ph. If you would like to write an article, please contact us at info@newbornscreening.ph. We will do our best to keep you informed about current and relevant newborn screening issues.

Your Feedback Is Important To Us



The organizers from NSC-NL and the nurse-trainees from Gaoat General Hospital

NSC-NL Helps Train Nurses at Gaoat General Hospital

NSC-NL’s program development officers were invited as resource speakers in the in-service training of the Nursing Department of Gaoat General Hospital in Batac City on November 20, 2019.

With the theme “Expanded Newborn Screening: Revisiting Knowledge Towards Successful Practice,” the activity aimed to raise the awareness and enhance the skills of the nursing staff for a better implementation of ENBS.

Anthony James F. Almazan, NSC-NL Program Manager, provided a background on the NSC-NL and discussed the National Comprehensive Newborn Screening System, emphasizing on the NBS Sample collection, the law that governs the implementation of the Newborn Screening Program, the roles of health practitioners and parents, and the importance of the program in saving the lives of babies.

Derice Geoff A. Rayoan, NSC-NL Project Development Officer, discussed the contents of the administrative mechanics in line with the implementation of the NBS in the regions and emphasized the significance and the contribution of a newborn screening facility to the program.

Finally, Dr. Ramon M. Gaoat, Hospital Administrator of Gaoat General Hospital, extended his gratitude to the members of the NBS Team for their continuous desire to learn about how to improve their services, to Mariano Marcos Memorial Hospital and Medical Center for its pursuit to provide health services to all, and to NSC-NL for assisting their institution in the implementation of the NBS Program. *DGRayoan*



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Overall chair of the 13th APCHG Dr. Carmencita D. Padilla (fourth from left) and DOST Secretary Fortunato dela Peña (fifth from left) cut the ribbon to signal the opening of the international conference. They are assisted by UP Executive Vice President Teodoro Herbosa (third from left) and Dr. Eva Maria Cutiongco Dela Paz (fifth from right), APCHG President.

PH Hosts 13th Asia-Pacific Conference on Human Genetics

The Philippines, through the University of the Philippines Manila (UPM), successfully hosted this year’s Asia-Pacific Conference on Human Genetics (APCHG) at the Makati Shangri-la Manila on November 7-9, 2019. This is the second time the country has hosted the event; the first was in 2008.

Led by the Institute of Human Genetics (IHG), National Institutes of Health (NIH), the conference carried the theme “Advancing Translational Medicine and Collaborations in Genomics” and provided an excellent venue for a community of faculty, scientists, researchers, and students from the Asia-Pacific region and different parts of the world to discuss the use of new knowledge in genomics into clinical practice and the generation of further research in the field of genetics and genomics.

Plenary sessions included the following topics: Two Tales of Translational Genomics: Pediatric Genetics and Inherited Breast and Ovarian Cancer; Precision Medicine: Making Sense of DNA Variants; Oncogenomics: Closing the Cancer Gap; A Paradigm for Precision Public Health: Right Intervention at the Right Time; Organs on Chip: Microphysiological Systems to Advance

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Number of Babies Screened as of December 2019: 13,791,941

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