



Lifted from Gian Carlo's reflection on his involvement with VYLH

I am Gian Carlo Zambrano-Abellana, 21 years of age, Volunteer Youth Leaders for Health (VYLH) founding member from Mindanao and a newborn screening advocate.

VYLH-PHILIPPINES is a network of proactive, service-oriented, empowering and visionary leaders equipped with knowledge and skills in mobilizing the youth towards a healthy Philippines. Newborn screening is just one of the advocacies being spearheaded by VYLH-PHILIPPINES.

After attending the 1st VYLH-PHILIPPINES National Camp in Tagaytay on July 16-17, 2009; the drive to advocate for NBS instantaneously boosted. I started using one of my weapons, the famous Newborn Screening Pink Brochure, to motivate, get attention and put a mark on the lives of mothers and other people I talk to. I posted NBS posters in rural areas, distributed almost a thousand brochures, met with people, and advocated NBS even inside public utility vehicles. Likewise, I conducted Mothers Classes in OB wards in different hospitals, both private and public, and discussed the program to mothers during prenatal visits in the health centers. I learned about kindhearted people who sponsor indigents to screen their babies. The local government units and the barangays have programs to encourage mothers to provide babies with NBS.

Being part of the pioneers of VYLH-Philippines is, indeed, of great honor and pride. VYLH is not just an organization but a vocation where dedicated people are called and chosen. At this very young age of mine, I knew I was able to help other people in simple ways.

Some people might say that volunteerism and advocating a cause like NBS is a heck of a thing, but for me, it is PASSION, SERVICE and a sense of being HUMAN.

VYLH Island-Wide Youth Camps and Planning Workshops



LUZON
Hotel Kimberly, Tagaytay City
July 2-4, 2010 (Photo by VYLH)



VISAYAS
El Salvador Beach Resort, Danao City, Cebu
July 16-18, 2010 (Photo by VYLH)



MINDANAO
Brokenshire Resort and Convention Center, Madapo, Davao City
July 29- August 1, 2010 (Photo by VYLH)

The 7th Asia-Pacific Regional Meeting

The Philippine delegation composed of representatives from the Philippine Health Insurance Corporation Inc., Department of Health (DOH), Centers for Health Development (CHDs), Newborn Screening Centers and National Institutes of Health (NIH) Philippines attended the recently concluded 7th ASIA-PACIFIC REGIONAL MEETING of the International Society For Neonatal Screening (ISNS) hosted by the Indonesian Pediatric Society (IPS) and the International Society for Neonatal Screening (ISNS). The Conference with the theme "Universal Coverage for Newborn Screening – A Critical Step Towards Achieving Beyond MDG 4" was held at Bali – Indonesia from October 03 to 06, 2010.



The Philippine Delegation to the 7th ASIA-PACIFIC REGIONAL MEETING held on October 03-06, 2010 at Bali, Indonesia.

Their participation to the said meeting was crucial as the Asia-Pacific Region expands its collaborative and cooperative network in developing a quality newborn screening system in the region. Some of the Philippine delegates served as speakers: Dr. Juanita Basilio of the DOH presented the Philippine Country Report; Dr. Carmencita Padilla, Director of the Newborn Screening Reference Center-NIH, gave a talk on the history of newborn screening in the Asia Pacific; and Dr. Sylvia Estrada of Phenylketonuria (PKU) Experts Committee discussed the Philippine experience in handling patients with PKU.

The conference ensured that the Philippine delegates are kept abreast of the current information on NBS. The group benefited from the conference as it addresses topics ranging from issues on developing, coordinating and maintaining practices and quality standards in scientific knowledge concerning neonatal screening to integration of newborn screening in public health system. Through participation in such conference, it is hoped that the country will continue to be in the forefront of newborn screening in the region. - R Suarez

PGH Pedia Endo Fellows Organize 7th CAH Lay Forum

The Department of Pediatrics' Section of Pediatric Endocrinology and Metabolism of the Philippine General Hospital (PGH) organized the 7th Congenital Adrenal Hyperplasia (CAH) Lay Forum held at the PGH Dietary Conference Hall on December 7, 2010. Parents of children diagnosed with CAH and members of CAHSAPI (CAH sa Pilipinas), a parent support group, were invited to the activity that aimed to educate parents on CAH and parenting skills that would be helpful for its management.

Pediatric Endocrinology consultants delivered various lectures on CAH. Dr. Lorna Abad gave an overview of the disorder while Dr. Sioksoan Chan-Cua talked about CAHSAPI and its objectives. Dr. Caridad Santos stressed on the importance of regular follow up and management, while Dr. Sylvia Estrada delivered an informative lecture on Newborn Screening. Dr. Carmencita Padilla, Director of the Newborn Screening Reference Center, gave a brief background on how newborn screening came to the Philippines and thanked the parents for attending the forum. The event was co-sponsored by the Newborn Screening Center-National Institutes of Health, UP Manila.

CAH is an endocrine disorder that leads to severe salt loss, dehydration, and abnormally high levels of male sex hormones in both males and females. If not detected and treated early, babies with CAH may die within 7-14 days. Those who survive may have abnormal development of primary and secondary sex characteristics. - I Fortugaleza



Organizers and parents of CAH patients pose for a group picture after the CAH Forum held at the PGH Dietary Conference Hall on December 7, 2010

PIR & First Regional Awarding Ceremony held in Cagayan Valley

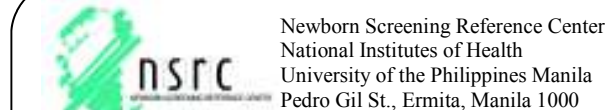
As part of the Newborn Screening Week celebration, the Department of Health-Center for Health Development for Cagayan Valley (CHD-CV) conducted a Program Implementation Review (PIR) and Regional Awarding Ceremony of Newborn Screening Facilities (NSFs) on October 14, 2010 at the Crown Pavilion, Tuguegarao City. The activity was attended by the chiefs/heads and NBS Coordinators of the different newborn screening facilities in the region.



The newborn screening team in Cagayan Valley gives recognition to outstanding newborn screening facilities as part of Newborn Screening Week Celebration.

PIR also served as an opportunity to update NBS stakeholders on the status of NBS in the region. Dr. Rex Cubero of PHIC-Region 2 clarified issues and queries on the Newborn Care Package.

The highlight of the event was the awarding ceremony, the first to be held in the region to recognize and acknowledge the NSFs that have attained the 2009 screening target of 50% and above of total live births. Also recognized were non-birthing rural health units which had helped increase the number of saved babies in the Cagayan Valley. -J Maquera



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Atok District Hospital's NBS Program



Dr. Nora Ruiz, ADH Chief of Hospital receiving the Plaque of Recognition for screening more than 90% of Atok District Hospital's live births. The Plaque is awarded by Dr. Carmencita Padilla, NSRC Director and Atty. Alexander Padilla, DOH Undersecretary.

Atok District Hospital (ADH) is a 25-bed, Level II government hospital located 50 kilometers north of Baguio City. It is one of the health facilities recognized in 2009 during the Awarding Ceremony for NBS Outstanding Achievers.

In 2006, Ms. Elvy Lobeda, a nurse at the hospital, was sent to Manila for NBS training. She echoed to all hospital staff what she learned, including the proper collection of blood samples. In 2007, with the support of the Chief of Hospital and the Chief Nurse, Newborn Screening was fully implemented. Initially, ADH had difficulty in convincing patients mainly because of the high cost of screening. In addition, the concerned staff had quite a

number of contaminated and inadequate samples and experienced difficulty in procuring NBS kits and submitting specimens. To solve these problems, ADH employed the following strategies:

1. Formation of a Newborn Screening Committee to quarterly take up updates or address NBS problems. The members are the following: The Chief of Hospital (Dr. Nora Ruiz); Chief Nurse (Ms. Marjorie Ignacio); NBS Nurse-in-Charge (Ms. Elvy Lobeda)
2. Giving of lectures on NBS to patients during prenatal check-ups and to admitted OB patients.
3. Preparation and distribution of NBS flyers to patients during prenatal check-ups.
4. Discussion of NBS in the Inter-local Health Zone meeting so that the RHUs can help in the advocacy efforts.

To sustain the program, efforts to promote NBS are ongoing. The budget for NBS was already included in the MOOE so that kits would always be available and indigent patients could also be screened. Currently, ADH still screens more than 90% of its total deliveries. - N Ruiz



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The organizing committee poses with Dr. Rowena Pua, NSSPI President (standing first row 4th from left), Dr. Veronica Wiley, International NBS Expert from Australia (standing first row 6th from left) and Dr. Bradford Therrell, International NBS Expert from the US (standing second row 4th from left) during the 8th NBS Convention held on October 1, 2010 at SMX Convention Center.

8th Newborn Screening Convention
NBS Updates and Challenges

The Newborn Screening Society of the Philippines, Inc., in partnership with the Philippine Pediatric Society-Southern Tagalog Chapter, held the 8th Annual Newborn Screening Convention on October 1, 2010 at the SMX Convention Center, SM Mall of Asia Complex.

This year's convention entitled "NBS Updates and Challenges" featured a diverse mix of presentations and challenging cases. The number of attendees almost doubled expectations. Dr. Cristina Magno, Over-all Convention Chair, reported around 1,300 attendees composed of doctors, nurses, medical technologists, midwives, and other stakeholders, and advocates of the newborn screening program.

and Senator Bong Revilla, welcomed the participants and guests on behalf of her mother who commended the program for its commitment in saving newborns from the five congenital metabolic disorders. Invocation and words of inspiration were given by NSSPI President Dr. Rowena Pua and NSRC OIC Dr. Eva Marie Cutiongco-de la Paz, respectively.

Dr. Pua thanked the PPS-Southern Tagalog for planning and hosting the convention. Delegates left SMX with a renewed hope for the future of the newborn screening program in the country.

This year's major sponsors were the Newborn Screening Reference Center, Institute of Human Genetics, Newborn Screening Center-Visayas, and Pediatrica, Inc. - V Mendoza

During the opening ceremonies, Brian Revilla, son of Congresswoman Lani Revilla

The families present at the Reunion of Saved Babies on October 10, 2010 at the UP Bahay ng Alumni, Quezon City. (Photo by PB Cariño)

10-10-10: Reunion of Saved Babies

The Newborn Screening Center- NIH (NSC-NIH), Institute of Human Genetics (IHG) has been organizing the Reunion of Saved Babies since 2009. The October 10, 2010 reunion was a whole afternoon of fun games, surprises, and raffle prizes held at the Ang Bahay ng Alumni, UP Diliman, Quezon City.

More than 200 children with their parents attended the event. IHG gave loot bags for all the kids and grocery baskets for every family while the Center for Health Development–Metro Manila, headed by Dr. Paz Corrales, gave souvenir towels and thermal lunch bags. The kids enjoyed the game booths, photo booth, mascots, puppet show, caricature, balloon twisting, and bubble show.

1st Special Clinic for Mild Variant Galactosemia Babies

The NSC-NIH, IHG in cooperation with the Philippine General Hospital (PGH), recalled babies with mild variant Galactosemia (GAL) for a series of special clinics on November 11 and December 9, 2010. The special clinics aimed to assess the babies for cataract formations and speech delays.

Three developmental pediatricians and two geneticists assessed the 21 patients while two pediatric ophthalmologists checked the patients' eyes. Blood samples were extracted for GAL monitoring at the NSC-NIH laboratory, while complete blood count

The Reunion of Saved Babies seeks to bring together screened and saved children from the Luzon area who were diagnosed with any of the five disorders included in the NBS Panel of Disorders. The event fosters camaraderie and has been the catalyst for the creation of support groups among the parents. It is an annual activity of NSC-NIH as part of the celebration of the Newborn Screening Month.

The event was made possible through the kindness of the following organizations and companies: Newborn Screening Society of the Philippines, WWWExpress, Landbank of the Philippines, Lifestyle, Impexcos and 2GO. - J Terrado

(CBC) and SGPT (Liver Function Test) were performed at the Manila Endocrine Laboratory. The specialists were assisted by four nurses, one medical technologist from IHG and two resident pediatricians from PGH. There is a plan for more special clinics by 2011.

The clinics were done at the Genetics Clinic, Pediatrics Department of PGH and led by Dr. Sylvia C. Estrada, Head of the Follow-up Unit of NSC-NIH and Pediatric Endocrinologist and Metabolic Specialist Consultant of the Department. - J Terrado

CAHSAPI: A Parent Support Group

It was early 2005 when my wife and I began to get more in touch with the PGH Pedia-Endocrinology Section a month after our only child was born and diagnosed with Congenital Adrenal Hyperplasia (CAH). Fortunately, we have Dr. Sioksoan Cua and the rest of the fellows for getting us even-keeled as we spent anxious months trying to give the best possible care to our kid.

I became part of the formation of CAH group Dr Cua had in mind years before. It wasn't long after the planning to make a Filipino support group of our own. Dr. Cua has worked with Dr. Kate Armstrong of CLAN-Australia to deal with the unavailability of most CAH medicines in the country. PGH has been instrumental in keeping together a number of families dealing with CAH. By December 2005, we had organized the first of many annual meetings under the name CAHSAPI.

CAHSAPI was coined from the Tagalog word "kasapi" which means to be a member or part of a group. True enough, it is mostly the sense of being alone that is most burdensome for parents.

If bringing the group together for support to each other was the primary mission, we knew that this wouldn't be attainable without getting the basic treatment available for everyone. Since both drugs - hydrocortisone and fludrocortisone - are not available in the country, CAHSAPI, with help from Kate and CLAN along with timely donations from individual and kind-hearted souls, established the group's foundation.

So far, things are looking brighter for CAHSAPI. Most of all, just seeing the kids and parents present, year after year, alive and thriving, is great news enough to make us continue to reach and achieve more. - A Yap

**Excerpts from the article of Mr Alain Benedict Yap. Mr Yap is a Registered Nurse and a father of a CAH patient. Full article is available at www.newbornscreening.ph.*

Rising in the East

To better understand the status of the newborn screening program in Eastern Visayas, NSC-Visayas visited several newborn screening facilities as the last leg of its facility visits for 2010.

Despite the geographic and economic constraints, NSC-V found out that facilities in the region still managed to run the newborn screening program and even accomplish a lot. Two of the outstanding facilities were the Burawen District Hospital (BDH) and Western Leyte Provincial Hospital (WLPH).

In 2009 and 2010, DOH set target coverage of 50% and 85%, respectively. WLPH screened 88% and 90% of its total live births for these years. For its part, BDH intensified efforts to better implement NBS in the facility and raised coverage to 93% in 2010 from only 32% in 2009.

These hospitals have proven that they can be at par with other facilities in rendering quality health services. They are not only focused on their facility performance but also reach out to their community to increase public awareness on newborn screening. *Dj Buensalido*

Helix-5: A Newborn Screening Update

Over 150 health professionals and health administrators from Region 6 and Negros Oriental attended a seminar entitled "Helix-5: A Newborn Screening Update" held on October 21, 2010 at the Westown Hotel, Iloilo City.

Guest speakers, Dr. Barbra Charina Cavan and Dr. Margaret Jane Galilea, captivated the audience with clear and in-depth explanation of the five congenital metabolic disorders, namely Congenital Adrenal Hyperplasia (CAH), Congenital Hypothyroidism (CH), Phenylketonuria (PKU), Galactosemia (GAL), and G6PD deficiency. They stressed the importance of newborn screening in the early detection and management of these metabolic disorders before irreversible damage manifest.

The heartwarming testimony of Mrs. Ria Connie Duquesa, mother of Kian, the first confirmed and saved CAH patient in the Visayas, generated empathy and affirmation of how this simple procedure can save a life.

An open forum followed the seminar sponsored by the Newborn Screening Center-Visayas. - AL Millares

In line with the celebration of Newborn Screening Week, poster-making and jingle composition contests were held in Iloilo. Winners are as follows:

- Poster-making Contest: Ma. Krizia Ledesma, RN – 1st; Jan Ree Sompia, RN – 2nd; Marc John Carcellar – 3rd
- Jingle Composition Contest: Esteban Cuenca, RN

Nurse's Notes

Most young nurses are dreaming of working in a premiere health facility here or abroad, and only few opt to stay. But life, indeed, is full of surprises, twists and turns.

The Newborn Screening Center–Visayas is one of the facilities that opened new opportunities for nurses. It is a new avenue for us to practice our profession in a different perspective. Its distinctive feature of preventive care is a challenge for all of us. But opportunity only comes to those who are brave enough to try and explore new things. At the onset of 2011, another fellow nurse joined the newborn screening team to render more efficient and quality service.

Time flies and it's been a year of working in the center. It was, however, the most rewarding experience for all of us. Our journey started in our quest for gainful employment. We applied, underwent training and luckily, got hired.

This new experience signifies that nurses are not only restricted to the hospitals, empowered by our curative skills, taking care of critically ill patients. In newborn screening, we are in a unique world of preventive care. Our goal is early diagnosis and treatment of different inborn metabolic disorders. We are here to save lives and prevent babies from complications and death. - Dj Buensalido

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**NSC
Mindanao**

NSC-M Celebrates Newborn Screening Week 2010

NSC-M celebrated the 2010 Newborn Screening Week by conducting several promotional activities to intensify NBS in the Mindanao area.

The commemoration started by presenting videos of NBS at the main lobby, waiting areas and OB ward of the Southern Philippines Medical Center (SPMC), Davao City. Flyers and posters were also put up in strategic areas in SPMC. NBS tarpaulins were given to the city health offices of Davao City and Malaybalay Bukidnon.

Lectures on NBS were conducted for expectant mothers at the SPMC OB-OPD and OB-Ward of the hospital. NBS was also promoted at "Kulukabildo sa Radyo Rapido," a radio segment hosted by

Sammy Lauron at DXAM–Radyo Rapido. The radio show covers Davao del Sur and Davao del Norte and reaches as far as Compostela Valley.

Lastly, the Mindanao G6PD Deficiency Support Group; led by its President, Ana Theresa Basilio and Vice President, Mr. Charlie Casane; conducted a Parents Day for G6PD Deficiency families on the last day of the NBS Week. Held at the NCCC Mall Davao, the activity aimed to unify the members of the group through fun activities.

The activities were featured at the Mindanao Daily Mirror, one of the local newspapers in Davao City, during the first and last day of the NBS Week. -P Bermudez

Caraga held its Newborn Screening Assemblies

The Center for Health Development – Caraga held its Newborn Screening Assemblies at Surigao City and Tandag City on the 3rd and 5th of November 2010, respectively. The assemblies were aimed to actively engage the LGUs in the implementation of NBS in the region and increase the number of new and active NBS facilities in Caraga.

The November 3 assembly in Surigao City was participated in by 32 officials and health professionals from 21 provinces of Surigao del Norte and Dinagat Islands. For the November 5 assembly in Tandag City, representatives from 19 municipalities attended.

Topics during the assemblies included the Caraga NBS situationer, RA 9288 and the roles of LGUs in the implementation of newborn screening, the five disorders in the NBS Panel, the PhilHealth Newborn Care Package, as well as the steps in the implementation of NBS program in the facility, sample collection, and ideal time for NBS.

Both groups accepted the NBS challenge through signing of their commitment and support to RA 9288. -SG Guilaran

Region 10 NSF's Assembly Conducted in Ozamiz City

The Center for Health Development–Region 10, conducted a Newborn Screening Assembly on December 9, 2010 in Ozamiz City. The activity, led by Dr. Ellenietta Gamolo, was attended by 74 representatives from newborn screening facilities (NSFs) in Region 10.

Dr. Rachel Micarandayo, Provincial Health Officer of Misamis Occidental; Ms. Lita Orbillo, the National NBS Coordinator; Mr. Marlon Nino Arrabaca, PhilHealth Officer; Ms. Mary Ann Galleros Cagayan De Oro Polymeric Plaza's Medical Technologist; Dr. Lorraine Babayan, Licensing Officer of Region 10; and Dr. Clynnia Andoy, NBS Regional Coordinator of CHD-Caraga were there to attend to queries of the participants and facilitate identifying of obstacles that caused low coverage and prevented NSFs from performing well. CHD-10 expressed commitment to continue supporting performing facilities by providing free NBS kits and subsidizing the fees of confirmatory testing for indigent patients. -P Bermudez



Participants in the Regional Cluster Meeting organized by NSC-CL and CHD-I

CHD I spearheads Regional Cluster Meetings

In a bid to strengthen the partnership of the Newborn Screening Center (NSC), Center for Health Development (CHD) and the Newborn Screening Facilities (NSF), CHD 1 led a Program Implementation Review on Newborn Screening last November 19 and 25, 2010 at Dagupan City, Pangasinan and Caoayan, Ilocos Sur, respectively. This is expected to augment the strict implementation of NBS in the region and clarify administrative protocols among partner agencies/institutions. A total of 143 participants took part in the program review.

With the CHD 1 staff, were Ms. Joanna Abigail Terrado, PDO NSC-NIH and Mr. Christian Leandro

CHD – III holds Regional Cluster Meetings

The Center for Health Development 3, in collaboration with the NSC-NIH, NSC-Central Luzon, and the Department of Health, conducted a one day cluster meeting to four provinces in Central Luzon to ensure the smooth implementation of NBS in the region. The cluster meetings were held in the following areas:

- Pampanga (Century Resort Hotel and Restaurant, Balibago, Angeles City) November 11, 2010
- Bulacan (Malolos Club Royale Resort and Hotel, City of Malolos, Bulacan) November 26, 2010
- Bataan and Zambales (Crown Royale Hotel, Balanga City, Bataan) November 26, 2010.

Monieno, PDO NSC-CL who tackled the newborn screening data and the NSC-CL Administrative mechanics, respectively.

During the open forum, the participants' queries on the program were addressed, particularly those related to the mechanics of its administration. Likewise, coordinators shared experiences and practices in implementing NBS.

One of the highlights of the event was the Action Plan Writing where the coordinators were tasked to identify possible strategies to improve NBS services and boost the coverage of the program. -C. Monieno

**NSC
Central
Luzon**

1st LGU Assembly held at Cagayan Valley

The Center for Health Development Cagayan Valley facilitated its first Regional Newborn Screening Local Government Unit Assembly last December 14, 2010 at the Crown Pavilion, Tuguegarao City. This aimed to establish and integrate a sustainable newborn screening program with the public health delivery system in Region 2.

The event was participated in by various leaders from the different provinces of Cagayan Region.

Christian Leandro S. Monieno, PDO, and Dr. Florencio C. Dizon, Unit Head of NSC-CL, discussed the importance of NBS and the role of the local government units in the implementation of the program.

An open forum was carried out to address questions and concerns regarding the program. The event was concluded with the participants signing a Memorandum of Agreement expressing support for the program. -C. Monieno



CHD-II with representatives from NSC-CL during the NBS Regional LGU Assembly held on December 14, 2010 in Tuguegarao City