

Awarding Ceremony for CHD-MM Newsletter Writing Competition

To give recognition to the winners and the participating schools, the Center for Health Development-Metro Manila (CHD-MM) held an awarding ceremony of the NBS Newsletter Writing Competition on December 12 at the CHD-MM Amphitheater.



First Place winner, Florentino Torres High School, together with their School Principal Ms. Rosita Herson, adviser, Ms. Celia M. Novenario and CHD-MM coordinators

The first place winner who won a desktop computer showcase and a plaque is the Florentino Torres High School. Coming in second place is Paranaque Science High School who brought home a plaque, a laptop, and a printer. The third place winner who received a plaque and a DSLR camera is Villamor High School. Other participants such as A. Maceda High School, Ramon Magsaysay High School, Jose P. Laurel High School, V. Mapa High School, Manila Science High School, Dr. Arcadio Santos National High School, Macario B. Asistio Sr. High School, Camarin High School, and Cielito Zamora High School, were given certificates of participation.

Guest speaker, Dr. April Grace D. Berbo, head of the NSC-NIH explained to the High School students, teachers and principals the relevance of Newborn Screening and how they can help in the implementation of the NBS program. *HPascua*

CHD-MM conducts 2012 Program Implementation Review

The Center for Health Development-Metro Manila (CHD-MM) recently conducted its annual Newborn Screening (NBS) Program Implementation Review.

The annual gathering of NBS coordinators from all over Metro Manila covered the review of agreements and accomplishments of the region and its cities; planning and commitment workshops of the attendees; and the introduction of the Expanded Newborn Screening Implementation for 2013.



Participants and organizers of the 2012 PIR held on November 21-23 in Camp John Hay, Baguio City

Invited speakers were Dr. Ruben S. Siapno, Division Chief of the Health Operations Division of CHD-MM who talked about the Universal Health Care Aquino Agenda; Ms. Marian Teresa DC Cuenca, representative of the Volunteer Youth Leaders for Health (VYLH) who gave a short background of VYLH and its advocacies; and Ms. Joanna Abigail Decano-Terrado, Project Development Officer of the Newborn Screening Center (NSC) who discussed the Unsatisfactory Samples and other NSC concerns. Also present were Dr. Dominga A. Gadgad, Medical Officer VII, Health Care Delivery Management Division, of Philhealth - CAR who provided detailed information about the Philhealth Newborn Care Package.

As for the planning workshop, representative from each district presented the different cities' action plan for 2013. While some coordinators shared their best practices - which can be replicated in other NBS facilities, other participants explored some strategies to help strengthen the full implementation of NBS.

Another focal point of the gathering was the commitment workshop facilitated by Mr. Nelson R. Mendoza, National Mental Health Coordinator from the National Center for Disease Prevention and Control of the Department of Health Central Office. It was organized to recognize the efforts and commitment of the NBS coordinators from the different local government units and city health offices; and also to strengthen the ties among them thereby renewing their commitment to the program.

The 2012 program implementation review was held on November 21 - 23 at the AIM Conference Center, Igorot Lodge, Camp John Hay in Baguio City. It was attended by 36 NBS coordinators from the different cities and municipalities in Metro Manila. *ALElizaga*

Decoding: 2012 Visayas NBS Update



Participants listen intently to the NBS Updates during the activity held on November 14

On November 14 health program implementers in the province of Bohol gathered for the new developments in the newborn screening program.

The event began with an orientation of the program provided by Ms. Myra Leonora Salvaon, Nurse Coordinator of DOH-CHD 7. It was subsequently followed by a presentation of the laboratory and patient follow-up procedures by NSC Visayas staff Shiela Celeste, RMT, and Maria Leah Borro, RN.

The day progressed with relevant lectures and presentations from experts namely Dr. Maribeth Martinez on interesting cases of G6PD Deficiency; Dr. Barbara Charina Cavan, Clinical Geneticist, on metabolic disorders which include Phenylketonuria, Galactosemia and Maple Syrup Urine Disease; Dr. J. Edgar Winston Posecion, NSC Visayas Unit Head, on the primer of the expanded newborn screening; and lastly, representatives from Philippine Health Insurance Corporation entertained queries on services related to newborn screening.

Inspiring talks from two parents of confirmed patients were pleasant features of the day. Both shared their experiences on how they take care of their children. Such heartwarming testimonies are surefire success indicators of the program.

The activity was sponsored by the DOH-CHD 7 in partnership with the Newborn Screening Center - Visayas and the Provincial Government of Bohol. It was held at Bohol Tropics Resort and Convention Center in Tagbilaran City. *DJBuensalido*

Newborn Screening Fest 2012



The winners of the NBS-themed contests receive their Plaque of Recognitions from VYLH and NSC-V

Newborn Screening Center-Visayas (NSC-V) supported the VYLH activity spearheaded by the Alliance of Young Nurse Leaders and Advocates, International - Iloilo Chapter entitled "Newborn Screening Fest 2012" held at Central Philippine University.

The first part of the activity was a seminar entitled "Nurses' Heel: Role on Newborn Screening." It was attended by nursing graduates and school organizations on October 16, 2012 with Mr. Dominic Buensalido, RN, Project Development Officer of NSC-V, as the guest speaker.

In the second part, invited representatives from the different nursing and medical schools in Iloilo City participated in the Newborn Screening-themed contests namely Poster-making, Extemporaneous Speaking and Quiz Bee on December 10, 2012. The following emerged as winners:

- Poster-making Contest:**
1st: St. Paul University Iloilo - College of Nursing
2nd: [Alliance of Young Nurse Leaders and Advocates \(AYNLA\)](#)
3rd: West Visayas State University - College of Medicine

- NBS Quiz Bee:**
1st: West Visayas State University - College of Medicine
2nd: University of Iloilo - College of Nursing
3rd: St. Paul University Iloilo - College of Nursing

- Extemporaneous Speaking:**
1st: Nadine Simeon (West Visayas State University - College of Medicine)
2nd: Diane Aranda (St. Paul University Iloilo - College of Nursing)
3rd: John Rex Balatazar (St. Paul University Iloilo - College of Nursing)

The Newborn Screening Fest 2012 was held to strengthen the collaboration with more youth leaders in schools and communities in Iloilo City through informative and friendly competition. *ALMillares*

NSC Mindanao's research on G6PD Deficiency wins 1st place

Dr. Jenny Pearl Carrasco won the 1st prize in the Annual Residents Inter-hospital Oral Research Contest conducted by the Philippine Pediatric Society, Incorporated-Davao Southern Mindanao Chapter held on November 24 at Davao Doctors College, Davao City.

The research paper entitled "Optimal Screening Cut-off Point for Predicting Confirmatory Results of G6PD Deficiency Among Term Neonates with G6PD Screening Values of 1.3 to 2.6 U/g" was authored by Dr. Carrasco, Dr. Alvin Concha and Dr. Conchita Abarquez. The research aims to determine the optimal cut-off point for G6PD deficiency newborn screening test which best predicts confirmatory test results with minimal or no false negative results.

The success of the study is also a realization of one of the missions of NSC-Mindanao which is to conduct and engage in relevant and high standard researches that will impart new knowledge and enhance recognition of the disorders included in the newborn screening panel.

The research was funded by Newborn Screening Center Mindanao. Congratulations and thank you for making NSC-Mindanao proud!
PBermudez

NSC Mindanao receives a plaque of recognition from IPHO Maguindanao

Newborn Screening Center-Mindanao was acknowledged for its contribution and commitment in improving health service delivery in Maguindanao province.

In the 2012 year-end staff conference themed "Kalusugaan Pangkalahatan sa Pagtataguyod ng IPHO-Maguindanao" Provincial Health Officer, Dr. Tahir Sulaik gave NSC Mindanao a plaque of recognition for its efforts in saving lives of new born babies.

The event was attended by 3,500 rural health physicians, chief of hospitals, public health nurses, medical technologists, midwives and



Dr. Tahir B. Sulaik, Provincial Health Officer of IPHO-Maguindanao, together with Dr. Elizabeth Samama gives the Plaque of Recognition to Sheila Mae Guilaran and Amerah Matuan, NSC-Mindanao representatives

barangay health workers and non-medical employees of IPHO-Maguindanao. Department of Health Assistant Secretary Dr. Paulyn Jean Rosell-Ubial and the Honorable Vice-Governor of the province Honorable Dustin V. Mastura. A Matuan were among the notable guests who graced the occasion. It was held on December 15, 2012 at the Notre Dame University Gymnasium Cotabato City. *AMatuan*

Reunion of Saved Babies



An afternoon of fun, laughter, games and NBS family bonding at the Abreeza Mall, Davao City on November 5

Reunion of Saved Babies in Davao City was a day of fun and thanksgiving.

Around 84 children were convened at the Abreeza Mall, Davao City on November 5. It was the second time for the Newborn Screening Center-Mindanao under the leadership of Dr. Conchita Abarquez to conduct the Reunion of Saved Babies. It was a day filled with laughter, games, and family bonding for the whole NBS family - who continuously support and promote the newborn screening program.

It was a day made more memorable by some parents who shared their experiences, and their family's journey in raising their children in a normal way. Of the 84 children attendees, 46 are confirmed with Glucose-6-Phosphate Dehydrogenase Deficiency; 30 with Congenital Hypothyroidism; 4 with Phenylketonuria; 3 with Congenital Adrenal Hyperplasia; and one with Galactosemia.

The reunion was made possible by the VYLH-Philippines - Mindanao Cluster volunteers, specifically in Region 11 and the Philippine Pediatrics Society (PPS) - Southern Mindanao Chapter. *RCRamos*

Newborn Screening Training for Service Providers in Maguindanao

The Integrated Provincial Health Office (IPHO) Maguindanao in collaboration with the Department of Health (DOH) Central Office and NSC Mindanao conducted an NBS Training for Service Providers in Maguindanao on November 12-14 at Mahogany Room, JICA Bldg on, SPMC, Davao City.



Participants of the NBS Training with Dr. Geraldine Macapeges (seated second from left) Dr. Conchita Abarquez (seated third from left), Ms. Lita Orbillo (seated ninth from left) and Ms. Aster Lynn Sur (first row tenth person standing from left)

The participants comprised of physicians, nurses, midwives and medical technologists were from 34 Rural Health Units of the Maguindanao province. Also in attendance were the Municipal Health Officers and Public Health Nurses of the different municipality and the IPHO Technical Chief of Dr. Geraldine Macapeges.

The workshop was organized to orient health professionals and workers, particularly those involved in Newborn Screening, on their main role in implementing the Republic Act 9288. Included in the workshop was a hands-on training on heel pricking was done at Southern Philippines Medical Center, to develop their skills in the standard collection of samples.

One of the speakers, Mr. Abdulkader Lingkob of the Philippine Health Insurance Inc. (PHIC) Maguindanao addressed the concerns in Newborn Care Package and other issues on PHIC claims and benefits. *AMatuan*

Mindanao CHDs conducts NBS Program Implementation Review for 2012

In the last quarter of 2012, the different CHDs in Mindanao conducted an Annual Program Implementation Review (PIR) to tackle and resolve issues and concerns of newborn screening facilities. The regional accomplishments were reported by the different CHD NBS coordinators while the performance of the NSF's from the different regions was presented by NSC Mindanao's Unit Head, Dr. Conchita G. Abarquez.

Also parts of the discussion were topics on Maple Syrup Urine Disease (MSUD) and expanded newborn screening

Caraga - The Center for Health Development (CHD) Caraga PIR was held in Luciana Convention Center, Butuan City on October 29 and 30. It was attended by 125 Newborn Screening Facility Coordinators from all over Caraga. PHIC representative clarified issues on Philhealth claims and MCP application requirements. Coordinators also took the opportunity to share good practices and suggestions in improving other facilities coverage. There was also an awarding ceremony on the second day to reward facilities with more than 90% screening of live births.

SOCCSKSARGEN - CHD-12 held its NBS PIR on November 14 at Pheta Grande Hotel in General Santos City. More than 50 NBS coordinators attended the review with provincial health officers reporting the newborn screening status and performance of their provinces. NSF's with more than 90% NBS coverage were given a certificate of recognition.



Region 10 NBS Coordinators showing their certificate of recognition

Northern Mindanao - CHD-10 held its PIR on November 27-28 in Villa Paraiso Mambajao, Camiguin. It was participated by 85 selected

NSFs in Region 10. Two of the highlights of the program were the renewal of NBS commitment through a symbolic lighting of candles and signing of NBS tarp; and the recognition of NSF's which screened more than 90% of their deliveries.

Davao Region - On November 29, CHD-11 held its PIR at the Waterfront Insular Hotel, Lanang, Davao City. The event was attended by more than 65 NBS coordinators from Region XI. *NMontilla, MADimacisil, GJacot, ARVillareal*

CAH Forum: A Continuing Education for Parents



CAH Children and their Parents with Dr. Eleonor Du, NSC-M follow-up consultant, and staff of NSC Mindanao

Continuing education of parents, guardians, and caregivers of children with metabolic disorders, is crucial in advocating the relevance of newborn screening. In an effort to support this cause, the Newborn Screening Center in Mindanao conducted its first Parents Forum on Congenital Adrenal Hyperplasia on December 11.

The activity gathered ten parents and guardians of CAH positive children in Davao City with Dr. Eleonor Du, pediatric endocrinologist as the resource speaker. As the primary caregivers of the children, Dr. Du emphasized that parents need to understand the disorder affecting their children to make them better caregivers.

The forum was organized for parents so they too could become effective NBS advocates. It was held at Lauan Room, JICA Building, Southern Philippines Medical Center, Davao City. *PBermudez*

Philippine Society for Orphan Disorders



A rare and magical Christmas experience for children with orphan disorders

In the Philippines, a disease is considered rare if it affects no less than one in every 20,000 individuals. Most babies with these disorders appear normal at birth. Rare diseases or disorders can affect anyone.

Like in many countries, Filipinos born with rare disorders are "orphaned" by society. They suffer from social abandonment because of lack of existing network of support to aid them. Medical help is elusive under the condition of the country's health priority. The nature of their illness is hardly known due to lack of information and only a handful of medical professionals in the country are aware of these disorders and know how to diagnose and address these conditions.

Because the nature of rare disorders are long-standing, life-threatening, progressive, and require multi-disciplinary care, available essential treatment such as drugs, therapies, medical supplements, monitoring laboratory tests likewise require life-long administration. Until such time further breakthroughs happen, without help from the government and the private sector, life-long treatment is elusive for the patients due to its extremely prohibitive cost and accessibility — beyond the reach of most Filipino families.

Recognizing the rarity of the conditions and needs of children with rare or orphan disorders, the Philippine Ballet Theater chose the Philippine Society for Orphan Disorders, Inc. (PSOD), a non-profit organization promoting the welfare of Filipinos afflicted with these conditions, as a beneficiary for one of its performances this November.

The Philippine Ballet Theater's presentation of 'The Nutcracker' on November 10, 2012, 1 pm at the CCP Main Theater, was specially staged to support PSOD's awareness campaign and to raise funds for the Philippine Society for Orphan Disorders, Inc. (PSOD). As an additional and rare treat Maestro Gerard Salonga and the ABS-CBN Philharmonic Orchestra performed the music live.

Funds raised went to PSOD's Emergency Medical Fund to help patients in critical need of hospitalization or emergency treatment, and to its Care for Rare Fund which is utilized to subsidize the following: diagnostic/confirmatory tests of patients suspected to have a rare disease, diagnostic tests critical to the periodic monitoring and the management of the disease, enzyme replacement therapies and other treatment, as well as purchase of assistive devices to improve patients' quality of life. *KPanol*



The Parco brothers (center stage, in sky blue, orange and red), afflicted with Hunter Syndrome, performing in one of scenes of the ballet (Photo by Martin Dimayuga)

The Philippine Ballet Theater presents **The Nutcracker** for the benefit of the **Philippine Society for Orphan Disorders Inc.**

10 Nov 2012 (Sat) | Gates open at 11 AM Show starts at 1 PM

Platinum Sponsors: genzyme, MeadJohnson Nutrition, ZEN ZEST

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Bronze Sponsors: INTELLICARE, Reyes Barbecue, FORUM

PSOD joins PWD Thanksgiving Celebration

Thirty-eight (38) children with rare or orphan disorders had a fun-filled day at the Manila Zoo on December 1, 2012 for the PWD Thanksgiving Celebration together with nearly 300 kids and young adults with special needs. The children and a thousand other guest including family members, advocates and supporters enjoyed the various performances and activities prepared by each participating organization. The activities enjoyed by the children include face painting, art show, balloon twisting, mask making, bubble show, bead art and chocopisicle making.



The children afflicted with rare disease together with their, parents and PSOD staff during their dance number

The event was initiated by Photography With a Difference, an advocacy group headed by advertising photographer, John K. Chua, with the support of its partners Canon and its Canon Advocacy Team, as well as by SM, Jollibee Food Corporation, Leslie Food Corporation, the Philippine Air Force and Navy, and many more, whom are all committed to promote awareness for persons with disabilities through photography.

Participating organizations also include the ADHD Society, Autism Society of the Philippines, Down Syndrome Association of the Philippines, Inc., Parents Advocate for Visually Impaired Children, Philippine Society for Orphan Disorders, Inc., and Parent Council for the Welfare of Hearing Impaired Children.

According to Tony Pasia, Chairman of DSAPI, it was "a wonderful occasion to celebrate life together with other PWD organizations, advocates and supporters, bringing the best in all of us to show how much we love and care for our special children. That PWD's have as much reason to be part of mainstream society if only we can give them a space in our hearts."

As the occasion was also an early Christmas celebration, gifts from the sponsors abound. "Napakagandang pagkakataon po na nakapagbonding kami na pamilya, hindi po madalas na mangyari ito, at ang saya-saya na may mga bago kami na nakilala. At Masaya kami sa mga regalo nanatangap namin" quips Tes Picones, mother of Patrick, a patient afflicted with Hunter Syndrome.

Agnes Lapeña, one of the event coordinators, summed up the event succinctly: "It was absolutely awesome and I believe it surpassed our expectations. God blessed us with perfect weather, a good attendance from all organizations, lots of gifts from our generous partners and new friends, incredible volunteers, no untoward incident, and tons of smiles from everyone. What was even more amazing was how the different organizations interacted not just with each other but also with the partners. It was truly a fun family day and with our changing horizons, it seems like this one big family is here to stay! *KPanol*

The Newborn Screening Reference Center National Institutes of Health University of the Philippines Manila

in solidarity with PWD in celebrating PWD

4TH NATIONAL RARE DISEASE WEEK and 6TH WORLD RARE DISEASE DAY

rare disorders without borders

Rare Disease Day

Supported by: CARES, Canon, PWD

Continued from page 1

In 2012, RHU-Linamon saw the formulation and approval of two resolutions on newborn screening: SB Resolution No 15 s2012, Adopting RA 9288, and that all babies born in the health facility must undergo Newborn Screening (NBS), and the SB Resolution No 26 s2012, Ensuring Maternal Deliveries must be a Facility Based Delivery. In addition, RHU-Linamon implemented the No Billing Policy for Philhealth members, while the LGU supported the newborn screening of indigent patients.

The three years of dedicated work to successfully implement newborn screening finally paid off in 2012 - a 100% NBS coverage; and a new NBS Facility opened at the newly constructed MCP-DOH through the Health Enhancement Facility Program of the Newborn Screening.

RHU-Linamon has shown that formula for success is a combination of persistence and perseverance, key ingredients that enabled them to successfully implement newborn screening program. *SMGuilاران*

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REMINDER: IDEAL TIME FOR NEWBORN SCREENING

Newborn screening should be done on the 24 to 72 hours after birth, except for sick and premature babies who must be screened by the 7th day of life regardless of weight and age of gestation.

If sample is taken earlier than 24 hours, there is a greater chance of false positive results for Congenital Hypothyroidism (CH) and false negative results for Phenylketonuria (PKU) and Galactosemia (Gal). In cases where there are false positive (for CH) and false negative (for PKU and Gal) results, repeat screening should be done not later than 2 weeks.

The timing of the test is critical for early diagnosis and treatment. Every disorder has a "golden period". Golden period, from the medical perspective is that short period of time when the baby should be able to receive intervention for his/her medical condition to increase her chances of living a normal life. Failure to provide intervention during this time would mean lifetime effects or death of the baby.

Disorder	Golden Period	Outcome if NOT managed
CH	2 weeks	Mental retardation
CAH	7-14 days	Death
PKU	3 weeks	Mental retardation
Gal	2 weeks	Death, cataract
G6PD deficiency		Kernicterus, Hemolytic Anemia
MSUD	10 days	Death

For references, please see the Facilitator's Guidebook: Newborn Screening in the Communities by Newborn Screening Reference Center; the Manual of Operations of the National Comprehensive Newborn Screening System by the Institute of Human Genetics; and the Blood Collection on Filter Paper for Newborn Screening Programs: Approved Standard – Fourth Edition by the National Committee for Clinical Laboratory Standards.

Accredited Pediatric Endocrinologists and members of the Society of Pediatric Metabolism & Endocrinology (PSPME)

Below is the list of specialists performing Pediatric Endocrinology and their respective areas of practice. The following are members of Philippine Society of Pediatric Metabolism & Endocrinology (PSPME):

- Manila**
 - Lorna Ramos-Abad, MD
 - Melinda Millares-Atienza, MD
 - Leticia A. Buenaluz, MD
 - Susana Padilla-Campos, MD
 - Sioksoan C. Cua, MD
 - Wilson C. Cua, MD
 - Carmelita Fagela-Domingo, MD
 - Sylvia Capistrano-Estrada, MD
 - Eve G. Fernandez, MD
 - Ludivina Garcés-Holst, MD
 - Caridad M. Santos, MD
 - Catherine Pangiliinan-Vasquez, MD
- Cavite**
 - Cynthia Garcia-Feliciano, MD
- Laguna**
 - Jedeane Mendoza-Aragon, MD
- Cebu**
 - John S. Uy, MD
- Davao**
 - Eleonor C. Du, MD
- Iloilo**
 - Margaret Jane Cabalum-Galilea, MD

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Reaching Success in Implementing NBS: the RHU-Linamon Story



2012 RHU-Linamon Health Personnel with Dr. Gemma Deano, Municipal Health Officer of Linamon (first person standing from left, second row)

The Municipality of Linamon is the smallest town in the province of Lanao del Norte and the first town from the City of Iligan. It consists of eight barangays with five barangays located in the coastal area while the three in the interior of the town. It is a fifth class municipality that has a total population of 17,460 and 3,057 households.

Despite the geographical and economic obstacles, RHU-Linamon is one of those Newborn Screening Facilities that successfully implements newborn screening in Mindanao. With the support of key enablers, the Unit has reached its goal of screening 100% of their babies for the span of three years. The people who greatly contributed to this milestone include the Municipal Mayor Honorable Noel N. Deaño, SB Chairman on Health Honorable Vene Vede Veché Ozaragga, and RHU-Linamon's Municipal Health Officer, Dr. Gemma Deano.

From January to October 2012, RHU-Linamon has reported a 100% newborn screening coverage. How did they do it? This is their story.

Beginning

The year 2009 is the start-up year for the newborn screening program of RHU-Linamon, with CHD 10 providing full support to the Unit. After attending the training on Newborn Screening held at Hotel Conchita, Cagayan de Oro that year, RHU-Linamon formed their NBS team and started campaigning for newborn screening. They purchased their first 10 NBS kits from LGU Trust fund and concentrated in the program's

COUNTER: 4,021,109

implementation, including pick-up arrangement with a local courier.

Campaigning

The next year was the period of advocacy campaign on newborn screening for RHU-Linamon. They advocated newborn screening to pregnant women during mothers' classes and on prenatal days the whole year round. They also participated in barangays' assemblies to introduce newborn screening to local government officials, and regularly meet with the Baranggay Chairmen of eight barangays during ABC meetings to promote newborn screening. RHU-Linamon also set a G6PD Deficiency Day every last Friday of the month, where the patients enjoyed a regular free laboratory work-up and participated with related activities.

Gaining momentum

It was in 2011 and 2012 that the local government officials became actively involved in the implementation of newborn screening in the municipality.

In 2011, RHU-Linamon initiated an NBS orientation to newly elected barangay officials, especially to the local Chairman of Health, to get their commitments. The Unit also participated in Sangguniang Barangay sessions to push and support local resolutions on the implementation of newborn screening, and to screen all babies born in their municipality.

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