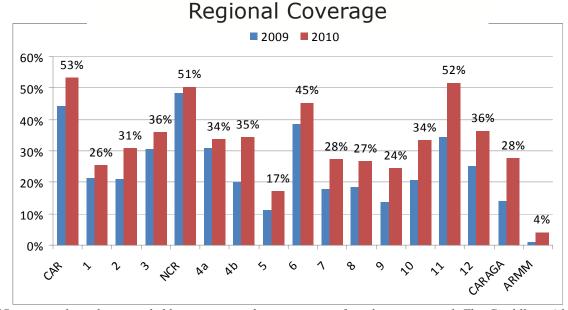


From 28% in 2009, the national coverage for 2010 increased to 35% using the population base of 1.7M. This increase was a result of continuous effort of the newborn stakeholders to educate the health professionals and general public of the importance of program.



All 17 regions showed a remarkable increase in the percentage of newborns screened. The Cordillera Administrative Region has the highest NBS coverage. CAR is followed by Davao Region and National Capital Region with high percentage of newborns screened over the regions' total live births

2010

	Prevalence	as of Decemb	per 201	LO
	CONFIRMED	SCREENED	PRE	VALENCE
CAH	253	2389959	1:	9446
СН	719	2389959	1:	3324
G6PD	44273	2312144	1:	52
GAL	22	2389959	1:	108635
PKU	16	2389959	1:	149372

This table shows the frequency a specific confirmed genetic disorder from the Newborn Screening Panel of Disorders was observed throughout the population screened. The highest prevalence was recorded in G6PD with a positive patient in every fifty-two newborns.

### ------New Publications Available Online

New materials have been made available online for different groups of health workers.

newborn screening. This book is being raised.

A publication of Novborn Screaning Reference Center National Institutes of Health University of the Philippines Manila

I intended to support newborn screening facilitators I relaved to all health workers. This guidebook | have yet to be made. presentations.

Primer for midwives – This primer aims to guide the midwives in 🏅 advocating and performing newborn screening in the communities. The I midwives act as frontliners in the newborn screening implementation

need for additional information for midwives.

screening implementation in a health | (Parish Priest; Mary the Queen Parish). - R Suarez Handoon Schening Reference Com Hadianal Pathoans of Hashi C21 Patho C21 B. Smith, Mania 22 Heliogi anti-shoring ah facility that Chiefs of Hospital need to know. **Basic Information for Physicians** I – This material aims to aid physicians in understanding the five disorders included in the Newborn Screening Panel of Disorders, their management and prognosis, and provides helpful and practical management tips and information for parents. visit To download these materials,

www.newbornscreening.ph. - V Mendoza

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# Creation of the Committee on Use. Retention and Storage of Residua Dried Blood Spots

The introduction of Newborn Screening (NBS) in the Philippines in 1996 and the enactment of the Newborn Screening Act in 2004 are significant milestones in Facilitators Guidebook – The Philippine health. Since then, the National Comprehensive Newborn Screening Facilitators Guidebook on Newborn, System has been developed and in the course of its implementation, has Screening was prepared to keep collected over 2.5 million filter cards containing residual dried blood spots (DBS) newborn screening facilitators | currently in storage at the various Newborn Screening Centers (NSCs). Issues on abreast with new information on the maintenance cost and space requirements of these residual DBS are now

Overseas, residual DBS are often retained for reconfirmation of newborn organize and run orientations on newborn screening analytical results, legal accountability, and evaluation and comparison screening. It aims to standardize the information of new methods or analytical reagents. However, in the Philippines, guidelines

includes slide presentations, scripts and additional To resolve the growing problem of accumulated DBS in each NSC, it was notes that may aid speakers in delivering their agreed during the January 6, 2011 meeting of the National Technical Working Group (NTWG) on Newborn Screening that the NSRC shall develop the policy for storage, use, and disposal of the residual DBS. It was further recommended that a committee be created to propose guidelines on the use, retention, and storage of residual dried blood spots.

Convened on February 8, 2011, the Committee is chaired by Dr. Marita V. T. Reyes, co-chairperson of the Philippine Research Ethics Board (PHREB) of the Philippine Council for Health Research and Development. It is expected to come up with a brief report to the Newborn Screening National Technical Working at the level of the barangays and rural areas. This Group by April, 2011. Members are Dr. Eva Maria Cutiongco-de la primer has been developed in response to the Paz (Geneticist; Director, Institute of Human Genetics, NIH); Prof. Peter A. Sv (Ethicist; Director, Diliman Interactive Learning Center); Atty Florin T. Hilbay (Lawyer; UP College of Law); Mrs. Cynthia K. Magdaraog (Parent; President, FAQ for Chiefs of Hospitals - This Philippine Society for Orphan Disorders); Dr. Ma. Virginia G. Ala (Director, primer highlights the basic Health Policy Development and Planning Bureau, Dept. of Health); Dr. Honorata information and the flow of newborn L. Catibog (Director, Family Health Office, DOH); and Fr. J. Cesar R. Marin, S.J.



The DBS Committee Members with Dr. Carmencita Padilla, Resource Person, during the first Committee Meeting held on February 9, 2011 at Diliman Interactive Learning Center, UP Diliman

Comments and questions may be sent to:

Newborn Screening Reference Cente National Institutes of Health. University of the Philippines Manila, 625 Pedro Gil St., Ermita, Manila 1000

or email us at

www.newbornscreening.ph

he Department of Health and the Nation stitutes of Health now accept nominations for wborn Screening Special Awards.

The award recognizes the efforts of an individua group who have made exemplary contribution Newborn Screening Program in the form of th lowing initiatives/innovations: 1) NBS education i e community 2) NBS advocacy in the communit NBS financing scheme 4) Community Support 5 GU Support 6) Linkage/s with other agencies ganizations 7) Other initiatives.

The nominee should be instrumental in the inment of a screening rate of at least 50% in wborn screening facility. Guidelines ination forms are downloadable

Deadline for nominations is **31 May 2011.** 

Continued from page 1

Mendoza of NSRC served as the main training facilitators with the following as resource speakers:

- 1. Ms. Ma. Elouisa Reves (NSC-NIH) Learning from Pioneer NSCs
- 2. Dr. Conchita Abarquez (NSC-Mindanao) Accomplishments for the Past
- 3. Dr. J Edgar Winston Posecion (NSC-Visayas) Challenges in Organization and Management
- 4. Dr. Florencio Dizon (NSC-Central Luzon) *Effective Habits and Practices* for NSCs
- 5. Dr. Carmencita Padilla (NSRC) Ways Forward, Visioning for the Next Three Years

The training used a combination of lectures and workshops based on the principles of adult learning. Facilitation techniques included interactive discussions, group processes, games and structured learning exercises. Discussions from each group were subsequently presented in plenary sessions.

At the end of the training workshop, it was noted that all set objectives were met. In addition, the officers and staff from the four NSCs were able acquire knowledge and information necessary for the efficient and effective performance of their functions. - A Balisi

33,000 newborns every year or 4 babies every hour will be saved from mental retardation and death. for NEWBORN SCREENING.

PhilHealth



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







for 2011 P The newborn screening family poses after 3 days of learning through fun activities that allow display of umaraderie among officers and staff of Newborn Screening Centers. The training needs workshop was held o Meeting among CHD Coordinators held March 18-20, 2011 at the Fontana Leisure Park, Clarkfield, Pampanga. More photos on page 5

Five Years of Unconditional Service t Filipino Newborns P. Capiz Performing Newborn Screening Commendably P.3 NSC-M held Cluster Meeting of NSFs G6PD Poster Making Contest P.4 NSC-M Advancing NBS during a GM Network Event at Araw ng Davao P.4 ISC-M ioins CHD-Zamboanga Peninsula' Launch of Unang Yakap NBS in "Ok si Dok" P. NBS Expert to Revisit NSC-CL P.5 2010 Statistics P.6 New Publications Available Online P. Creation of the Committee on Use Retention and Storage of Residu Call for Nomination for th NBS Special Awards P.8

# to Formulate Strategies P.2 Developing Key Strategies to Meet One Goal: First Newborn Screening Center General Assembly

Developing efficient strategies to meet ONE To strengthen communication with different GOAL – increasing coverage while maintaining high quality service and efficient newborn screening services - was the collective call of the recently-concluded Training Needs Zamboanga City P.4 Workshop for Capacity Building among Newborn Screening Centers (NSCs). This was held on 18-20 March 2011 at the Fontana Newborn Screening at Club 888 P.4 Leisure Park and Casino, CFZ, Pampanga.

The workshop was a joint activity of the Department of Health (DOH) and the Newborn The strategies were hoped to further Screening Reference Center (NSRC) to build increase appreciation of the importance of the capacity of the four Newborn Screening transforming the organization and meet that Centers (NSCs) and strengthen coordination one goal set by the newborn screening Essential Newborn Care Protocol P.4 and networking among them. It provided NSC stakeholders. personnel with information and analysis to further improve their efficiency and Training Design effectiveness and discuss further strategic The course was attended by 86 officers and directional plans

### One Goal and Key Strategies

weaknesses and enhance strengths in newborn screening center. Fourteen DOHproviding services not only for the organization NCDPC and NSRC personnel served as Dried Blood Spots P.7 but also for the national program. The key facilitators of this activity. strategies were as follows:

> To maintain precision and accuracy in analyses;

- stakeholders (Linkages);
- To intensify advocacy efforts using tri-media (especially in remote areas) targeting live births;
- To ensure staff development through continuous professional education; and
- To provide 100% client satisfaction through timely release of results.

staff of four NSCs, including laboratory and administrative staff. It provided a comprehensive understanding of the Each NSC drew up strategies to minimize background, processes, and operations of a

Mr. Anthony John Balisi and Ms. Vina



ents attentively listening to the speakers during the 1st G6PD Deficiency Seminar for 2011 held on February 18 at UP inila College of Pharmacy Auditorium.

## **Rotary Club Charters Continue NBS** upport

Through the years, various chapters of the Rotary Club of The Newborn Screening Center-NIH held its first G6PD the Philippines have supported the Newborn Screening Deficiency Parents' Seminar for 2011 at the UP Manila Program. One such chapter is the Rotary Club of Lucena.

On March 7, 2011, the Rotary Club of Lucena procured Catherine Lynn Silao, Molecular Genetics Program 2,000 newborn screening kits from the Newborn Screening Coordinator, Institute of Human Genetics, spoke on the Center-NIH amounting to PhP 1.1M. The charter handed over genetic nature of the disorder. Dr. Beatriz Gepte, the kits to the Quezon Medical Center (QMC) in Lucena City, I Hematology-Oncology Consultant, Philippine Children's Quezon. Through this generous donation, 2,000 indigent Medical Center, discussed the clinical manifestations, drugs, I babies born at QMC will be given a chance to live normal and and chemicals to be avoided by a G6PD-deficient. NSC-NIH healthy lives.

newborn screening kits on March 29, 2011 amounting to PhP I JA Terrado 275,000.00. The kits were distributed to two newborn screening facilities (NSFs). One hundred fifty (150) kits were granted to the Amang Rodriguez Medical Center, a DOH-1 Development Coordinators held to retained tertiary hospital in Marikina City. The remaining 350 kits were given to the Marikina Diagnostic and Specialty Clinic, a local government diagnostic facility in the same city.

- I Fortugaleza

### For Regions IV, V & NCR National Institutes of Health UP Manila P.Gil Street, Ermita Manila Telephone: (02) 526-1725 Fax: (02) 5269997 nbsadmin.ihg@gmail.com

# **1st G6PD Deficiency Parents'** Seminar for 2011

College of Pharmacy Auditorium on February 18. Around 250 parents and guardians participated in the said event. Dr. I hopes to conduct at least three seminars every year. The next parents' seminar is tentatively set on May 2011. For I Similarly, the Rotary Club of Marikina purchased 500 inquiries, please call (02) 526-1725 or text 09285060960.

# Meeting among Center for Health **Formulate Strategies**

I The Newborn Screening Center-NIH met with the NBS Coordinators from Regions 4A, 4B, NCR and 5 on January I 27, 2011 at the NIH Conference Room. Ms. Hermes Pascua I and Ms. Mariz Ebuen of CHD-NCR, Ms. Ma. Teresa Du of CHD-4B and Ms. Jenica S. Querido of CHD-4A attended the meeting. Mr. Glorioso Velasco of CHD-5 joined the meeting I via online video conference. Data were presented during the meeting particularly the regional coverage and quality of samples coming from the newborn screening facilities within I the region. Follow-up concerns, such as patients for recall, were also part of the agenda. Strategies were formulated to I improve the quality of samples and increase the coverage. A I media plan was also presented as part of the advocacy of the said regions. The next meeting is set tentatively on April 1, 2011. - JA Terrado \*-----



The Newborn Screening Center-Visayas (NSCarted operation five years ago with only five st embers – the Unit Head, Laboratory Manager, t edical Technologists, and a Nurse Coordinator. At the ne, NSC-V was responsible for screening wborns from the Visayas and Mindanao regions. T as not an easy task but the dedication of these peop ade it possible for NSC-V to stand on its own.

February 27, 2011 marked another milestone in i story, being NSC-V's fifth anniversary. To make the team members. lebration meaningful, the center gave free newbo reening services to walk-in patients. Patients 6PD confirmatory tests were also provided with ecial discounts. Freebies were given to clients, su T-shirts, infant's wear, and sweet treats. A mass was fered as a thanksgiving for the guidance ar essings received by the Center.

Now one of the established NSCs in the country nposed of 22 committed staff members w come ideas for improvement and advancement, if nking way beyond newborn screening. The Newbo eening Center will not stop in its mission to save the es of children with inborn metabolic disorders. It mmitted to maintain a standard that will ensu reening of all newborns in the future and provide v to build a brighter future for them. - R Barrios ensalido



According to Dr. Ana Mae Belasoto, Municipal Health Officer, starting the program was a challenge at first. Their passion and dedication to save babies enabled them to stabilize the program using their own resources. Maximum utilization of Philhealth benefits and coordination with the local government were some of the factors which helped in increasing coverage. The facility also provides comprehensive health education and intensive information dissemination on the advantages of newborn screening and facility-based deliveries. NSC-V acknowledges the efforts of the Capiz Provincial Health Office,

lears of commitment in saving live 5 years of compassionate service



### Capiz Performing Newborn Screening Commendably

The province of Capiz is popular for its sumptuous seafood. Apart from its gastronomic delights, the province is setting a good record in newborn screening. Behind the laidback and serene ambiance, Capiz is at par with other big provinces in the Visayas region when it comes to newborn screening program implementation.

Capiz houses a total of 30 Newborn Screening Facilities, ninety-seven percent (97%) of which are active as of December 2010. Most of these facilities achieved their target coverage of 85% for 2010 and this was made possible by the hard work and commitment of all the newborn screening

The Rural Health Unit-Dumalag, one of the towns in Capiz, has a commendable achievement in newborn screening. Since it started the program in April 2007, the facility has been consistently posting 100% coverage of all newborns delivered here.

headed by Dr. Samuel Delfin, for its unwavering support to the newborn screening program. Various activities were planned by the office to help improve the NBS coverage and the referral and management of all positive patients. - AL Millares/ D Buensalido

### **For Mindanao**

Southern Philippines Medical Center J.P. Laurel Avenue, Davao City Telephone: (082) 226-4595 / 2<u>24</u>-03<u>37</u> Telefax (082) 227-4152 nscmindanao@gmail.com

> NSC-M held Cluster Meeting of NSFs in Zamboanga City



*In photo: Participants with Drs. Conchita Abarquez (center) and Eleonor Du (center right)* 

Peninsula Region on January 20, 2011 Regional Nurse Coordinator. (ZCMC).

Mindanao conducted a Cluster representatives Dr. Cheryl Rebollos, Davao. - S. Guilaran Meeting for newborn screening Child Program Medical Coordinator, facilities (NSFs) in the Zamboanga and Ms. Nerissa Gutierrez, NBS

and privately-run NSFs in Region 9, programs in their facilities.- S Guilaran guests. - S Guilaran

### G6PD Deficiency Poster Making Contest

The Davao G6PD Deficiency Parents Support Group held a poster making contest on February 12, 2011 at NSC-Mindanao, Davao City. Led by its President Ms. Ana Theresa Basilio, parents and friends of the Support Group showed their creative side in creating posters around the theme, "United in Managing G6PD Deficiency as a Family." Parents May Fernandez and Bernard Angeles won the first and second prize, respectively. - S Guilaran

### Newborn Screening at Club 888

Dr. Conchita Abarquez was guest speaker during he Club 888 held at the Marco Polo Hotel on March 2011. Topic of her talk was how newborn screening can help detect abnormalities in newborns and how these babies can be helped. Club 888 is The Newborn Screening Center- CHD-Zamboanga Peninsula Davao's premier media forum at Marco Polo Hotel

## NSC-M Advancing NBS during a GMA Network Event at Araw ng Davao

at the Zamboanga City Medical Center The meeting started with a NSC-M, in coordination with NSC-NIH, showcased presentation of the region's newborn screening in a booth exhibit during a GMA The meeting discussed the target accomplishments for 2010, followed by Network show as part of the celebration of the Araw coverage set by DOH for 2011 and its NBS performance. At the end of the ng Davao on March 15, 2011. Held at SM Davao, clarified issues and problems on meeting, having listened to the four NBS tarpaulins were hanged at the walls of the newborn screening in the region. achievements of the respective NSFs, venue, while NSC staff members distributed NBS Present at the meeting were the participants were motivated to brochures, showed NBS videos, and answered representatives of non-government improve and strengthen their NBS questions on newborn screening from interested

### NSC-M joins CHD – Zamboanga Peninsula's Launch of Unang Yakap : Essential Newborn Care Protocol

The Newborn Screening Center-Mindanao participated in the CHD-Zamboanga's Launch of Unang Yakap: Essential Newborn Care Protocol held on February 2, 2011 in Zamboanga City.

Unang Yakap is a campaign to spread the use of the Essential Newborn Care Protocol ir

representatives of different hospitals and birthing facilities in the region. In his keynote



the country. The event was attended by In photo (seated from left to right) Dr. Nimfa Torrizo, Dr. Aristides Tan, Dr. Anthony Calibo, Dr. Julius Lecciones, Dr. Eduardo Janairo, Dr. Sheila Masangkay, Dr. Conchita Abarquez and Dr. Rodelyn Algulos.

speech, Dr. Julius Lecciones, Executive Director of the Philippine Children's Medical Center (PCMC) shared PCMC's experiences on Essential Newborn Care and how it decreased the Center's maternal and infant mortality rates.

<sup>1</sup> The two other guest speakers were Dr. Eduardo Janairo, Director of the DOH National Center for Disease Prevention and Control (NCDPC), and Dr. Anthony Calibo, Supervising Program Coordinator also from DOH-NCDPC.

I Dr. Conchita Abarquez, Head of NSC-M, presented updates on the newborn screening program as well as the region's performance in terms of newborn screening coverage, active and inactive facilities, total number of samples sent, and the acceptability of the I 4 samples. - S Guilaran 

### NBS in "OK si Dok"



rogram and to increase public awareness on Newborn Screening he Central Luzon Broadcastin Corporation (CLTV36) will feature ne NBS in "Ok si Dok," – one of its flagship broadcasts.

Ok si Dok is a one-hour program that disseminates important health

information and issues which directly affect the lives of its target audience. It tackles the pressing health concerns of the society using a friendly and comprehensible approach and dispenses advice geared to promote healthier living.

To discuss the nature of the program and the panel of disorders included in newborn screening in a future episode is Dr. Wilson Cua, Pediatric Endocrinologist and Fellow of the Pediatric Society of the Philippines. The episode will be aired on April 28, 2011 at 8:30 pm, which will be replayed on April 29, 2011 at 9:30 pm. - C Monieno

### **NBS Expert to Revisit NSC-CL**

On September 29 and 30, 2010, the Newborn Screening Center-Central Luzon was granted accreditation by a team from the Department of Health, Newborn Screening Centers and experts from the United States and Australia. During the said accreditation process, the team assessed the capability of the Center to run newborn screening tests for Regions 1, 2, 3 and CAR.



Dr. Bradford L. Therrell, Jr., Director of the U.S. National lewborn Screening and Genetics Resource Center and aboratory certification consultant to the Department of Health since 2006., together with Ms. Charity Jomento, Newborn Screening Reference Center Quality Assurance

Officer, is expected to revisit the NSC-CL on April 4, 2011 to see the progress made by the Center since their accreditation was granted. Dr. Therell will review the work flow of the Center and give updates on the latest trends in newborn screening in the United States and other countries. - C Monieno

For Regions I, II, III & CAR Angeles University Foundation edical Cente MacArthur Highway, Barangay Salapungan, Angeles City nsc@aufmc.org

Photos below: Each team poses for camera before they face the las hallenge of the Newborn Screening Center General Assembly. Th articipants in the Assembly were divided into five teams. Each team ecognizing the importance of the *tries to win every challenge in each workshop*. Story on page 1



