

newborn screening

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Consolidating Newborn Screening Efforts in the Asia Pacific Region

Last June 4-5, 2010, representatives from various Asian countries gathered at the Traders Hotel Manila for the “2nd Workshop on Consolidating Newborn Screening Efforts in the Asia Pacific Region.” This was a follow-up to the assembly in 2008 where key policy makers, service providers, researchers, and consumer advocates met to firm up the following strategies:

1. Identify the current status of newborn screening and related researches within the South East Asia and Western Pacific Regions;
2. Explore national and regional health care delivery and research infrastructure needs for maximizing research/service collaborations;
3. Identify strategies for developing regional and international collaborative research groups; and
4. Define research activities emanating from newborn screening that can complement existing collaborations and assess resource needs, identify available resources, and develop information about other possible resources.

As part of the workshop, 10 participating countries (Bangladesh, China, India, Indonesia, Laos, Mongolia, Pakistan, Philippines, Sri Lanka, and Vietnam) presented their respective Newborn Screening Program status reports and developments since the first workshop in 2008.

Dr. Bradford L. Therrell, Jr. of the



(Top L-R) Dr Erdentuya Ganbaatar of Mongolia, Dr Anthony Calibo of DOH Philippines, Dr Bradford Therrell of NNSGRC, Dr Tariq Zafar of Pakistan, Dr Saysanasongkham Bounnack of Laos, Dr Mizanul Hasan of Bangladesh, Dr Le Anh Tuan of Vietnam, Dr Xuefan Gu of China, Dr Mujaddid Djalal of Indonesia, Dr Faridul Alam of Bangladesh, Mr. Ngo Toan Anh of Vietnam, Dr Gerelmaa Zagd, (Bottom L-R) Drs Gurjit Kaur, Madhulika Kabra, and Seema Kapoor of India, Dr Tahmina Banu of Bangladesh, Dr Carmencita Padilla of the Philippines, Dr Damayanthi Nanayakkara of Sri Lanka, and Dr Diet Sadiyah Rustama.

National Newborn Screening and Genetics Resource Center, Texas talked on the following topics:

1. Quality Assurance Efforts for International NBS;
2. Storage, Retention and Use of Residual Dried Blood Spots; and
3. Choosing Newborn Screening Conditions.

Focused group discussions were held to deliberate on certain issues in various levels (Ministry of Health, regional and country levels) for the development of possible action steps. A Manila Declaration was crafted as renewal to the Cebu Declaration established during the first workshop. The declaration summarized the various commitments of the countries in terms of their progress in newborn screening.

In this new declaration, the

participants recognize and embrace the need to continue collaborative, cooperative networking to facilitate the development of a quality newborn screening system in all nations. In order to facilitate continuation of such a collaborative network, they recognize the value to set up structures for increased communication across the region and establish a regional advisory committee.

With the participation of 26 delegates from 10 countries as well as the sponsorship of the PerkinElmer Life & Analytic Sciences, Bio-Rad Southeast Asia, Lifeline Diagnostics and Supplies, GE Healthcare, and the Institute of Human Genetics – NIH, the 2nd workshop organized by the Newborn Screening Reference Center achieved its objectives.

(M Reantaso)

Philippine PEAS Tool Revised

To better address the Newborn Screening Program's issues and concerns as well as other operational challenges, the Department of Health and the Newborn Screening Reference Center established the Philippine Performance Evaluation and Assessment Scheme (PPEAS).

This is a tool that provides specific directions for Centers for Health Development (CHDs), Newborn Screening Facilities (NSFs) and Newborn Screening Centers (NSCs) in their efforts to increase coverage and serve as framework for data gathering that is vital to obtaining a realistic picture of newborn screening program implementation.

While the Philippine PEAS is patterned after the US PEAS, it is grounded on the realities of the Philippine health care delivery systems. Particularly, the Philippine PEAS is anchored on the provisions of Newborn Screening Act of 2004, the strategic framework and the manual of operations of the National Comprehensive Newborn Screening System.

The PEAS tool evolves as the program advances. For the last four years, DOH and NSRC have been using the same Philippine PEAS Tool to monitor the program. Hence, both entities conducted the PEAS Tool Review Workshop on April 9 to 11, 2010 at the Summit Ridge Hotel, Tagaytay City. The review had the



The review participants with Dr. Bradford Therell evaluating the PEAS Tool for newborn screening facilities during PEAS Tool Review Workshop held on April 9-11, 2010 at Summit Ridge Hotel, Tagaytay City.

following objectives: to evaluate if the tool is practical; assess if the current PEAS measures what it needs to measure; gauge if the indicators are relevant to the present day needs of the program; and recommend measures for improvement.

International NBS expert Dr. Bradford L. Therell Jr., Director of the US National Newborn Screening and Genetics Resource Center, participated in the said review and provided directions in revising the tool. The review was facilitated by Dr. Juanita A. Basilio, Medical Officer VII, DOH-Central Office and Dr. Carmencita D. Padilla, NSRC Director.

Other review participants were Ms. Lita Orbillo, Nurse V of the Family Health Office; Ms. Riza Suarez, NSRC Program Manager; Ms. Vina Mendoza and Ms. Marian Reantaso, both NSRC PDO III; Ms. Jesusa Jalad, NSRC Administrative Officer; Ms. Ma. Elouisa Reyes, Unit Head, Newborn Screening Center-NIH; Dr. Ma. Paz Corrales, NBS-NCR Medical Coordinator; Dr. Ellenietta Gamolo, Region X NBS Medical Coordinator; Ms. Ma. Lizandra Sante, Region VI NBS Coordinator; and Ms. Clarose Mascardo, Region XI NBS Coordinator.

(V Mendoza)

PROGRAM REVIEW HELD IN REGIONS 4B AND NCR USING THE REVISED PEAS TOOL



The newborn screening team in Center for Health Development MIMAROPA, headed by Dr. Teresa Castillo (sitting in the middle), presented their work and financial plan together with their accomplishments to the Program Review Team.

Last May 11 and 19, 2010, the program review team facilitated the review at the Centers for Health Development in Region IVB (MIMAROPA) and NCR (National Capital Region), respectively.

It was the first set of program review conducted using the revised Philippine PEAS Tool. The review team was composed of Dr. Carmencita D. Padilla, Ms. Lita L. Orbillo, Ms. Riza Concordia Suarez, Ms. Marian J. Reantaso and Ms. Vina G. Mendoza. The Newborn Screening Center Unit Heads - Dr. Edgar Winston Posecion, Dr. Conchita Abarquez, and Ms. Ma. Elouisa Reyes - observed the review at NCR.

The review aimed to assess and identify gaps and solutions to assist the CHDs in implementing newborn screening at the regional level. It is done yearly to ensure the quality and sustainability of the the program. The review looks into five components: Operational Structure; Plan of Action; Systems in Place; Health Promotion; and Innovation Strategies and Best Practices. *(V Mendoza)*

NEWSBRIEFS

NSC Managers Meeting

The Newborn Screening Center (NSC) managers and staff of NSRC, met last May 18, 2010 to discuss accomplishments for the first quarter of 2010 and plans for the remaining months of the year.

With the DOH mandate of 85% coverage by the end of 2010, NSCs' efforts are geared towards various activities that could help attain this target.

The following projects will be considered for implementation in 2010: 1) individual patient results; 2) budget allocations for researches, additional personnel and publications; 4) barcoding system; 5) continued increase of G6PD confirmatory centers; 6) program reviews and; 7) hiring/ renewal of contracts of full time NBS staff for selected CHDs. *(M Reantaso)*

Resolutions on Increased Coverage, Other Concerns Formulated in Meeting with DOH, Philhealth

In a recent meeting with Department of Health (DOH) Assistant Secretary Nemesio T. Gako and Philhealth representatives Dr. Giovanni Roan and Dr. Arlene Cabradilla, resolutions/recommendations were formulated pertaining to critical Newborn Screening concerns.

Some of the resolutions/recommendations arrived at were increased coverage through DOH reiteration of the stipulated NBS target coverage as per Dept. Memorandum 2008-0123 and Admin. Order 2008-0026A and increased screening for home deliveries; Centers for Health Development coordination with Local Government Units for the list of birthing homes/lying-ins in their jurisdiction; inclusion of newborn screening coverage and monitoring in the PhilHealth Benchbook; review of the possibility of separating newborn screening from other newborn services; and the conduct of a study on the inclusion of the Maple Syrup Urine Disease in the NBS Panel of Disorders.

Present during the meeting were NSRC Director Dr. Carmencita D. Padilla and DOH National Coordinator for Newborn Screening Lita Orbillo. *(R Suarez)*

Center for Health Development - Bicol to Increase NBS Coverage

The Center for Health Development-Bicol conducted the second consultative meeting last June 25, 2010 at Casablanca Hotel, Legazpi City. This is a biannual activity of CHD that serves as venue for updates; discussion of issues and concerns in program implementation, and sharing of good practices among government and private health facilities. The first meeting was held last May 12, 2010.

NBS coordinators of private and government newborn screening facilities (NSFs), including birthing homes and lying-in clinics from the Bicol Region, attended the meeting. Participants pointed out that monetary constraint is the common hindrance to implementation.

Ms. Wenalyn U. Viaña of the Newborn Screening Center-NIH reiterated the importance and benefits of NBS. She reviewed the proper collection and handling of specimen for screening and confirmatory testing. Together with Ms. Joanna Abigail B. Decano-Terrado, they discussed the factors that affect the performance of a newborn screening facility. To inspire the group, Ms. Leticia Carillo, NBS Coordinator of the Jaime Berces Memorial Hospital in Tabaco City, Albay, one of the awardees of the 2009 NBS recognition in Manila, presented the hospital's best practice using the word "CODE" that stands for C-omply, O-bligation, D-o your Best, and E-valuate. Team collaboration was also emphasized. Using the CODE formula, they were able to maintain an NBS coverage of above 90%.

On the part of the Catanduanes Provincial Health Office, a representative shared that clinical instructors of Catanduanes State University were challenged to include Newborn Screening in their subjects/topics. This is to strengthen the advocacy and, at the same time, enable their nursing students to learn the essential benefits of NBS.

The open forum at the end of the program brought out the problems and concerns faced by the different NSFs. *(G Velasco)*



Regional Medical Coordinator for Region V, Dr Carla Orozco (sitting 6th from left) together with the NBS Team in the Region and participants in the Consultative Meeting held on June 2010 in Legazpi City.

8th Newborn Screening Convention

2010 NBS Organizing Committee



MESSAGE



Greetings! On behalf of the Philippine Pediatric Society – Southern Tagalog Chapter and the Newborn Screening Society of the Philippines, Inc., I would like to invite our fellow health practitioners and allied health professionals to attend the 8th Newborn Screening Convention on **October 1, 2010** to be held at the **SMX Convention Center, Manila, Philippines.**

This year's interesting topics are as follows: 2010 Philippine Status of Newborn Screening(14th year), Neuro-developmental Outcomes of Congenital Hypothyroidism Detected Through Newborn Screening, Newborn Screening in Preterm Infants, Psychological Impact of Positive Newborn Screening/Cases on Families, and others.

We look forward to seeing you in Manila for this one day of fruitful, enjoyable and intellectual convention on its 14th year of saving babies from mental retardation through newborn screening.

Mabuhay!

Cristina P. Magno
 Cristina P. Magno, MD, MPH, FPPS
 Over-all Chair, Newborn Screening Convention
 2010-2012 PPS-STC President

PRE-CONVENTION
(Sept. 30, 2010) - P750.00
(limited to 100 participants only)
(please confirm before August 15, 2010)

CONVENTION PROPER:
(Oct. 1, 2010)
Pre-reg :till Aug 15: P1,000.00 MDs
P 850.00 others
On-site : P1,200.00 MDs / P1,000 .00
Others

Contact Person:
 Cristina P. Magno, MD ..09175034295
 Rowena A.Pua, MD..... 09175000502
 Corazon A. Omalin, MD..09177931302
 Lea V. Umil, MD09193095943

For Bank Deposits, deposit to:
 Account Name: Lea V. Umil
 Account No.: 729-5-04052-6
 Bank Name: BPI Family Savings Bank
 Bank Branch: Alabang-C. Madrigal
 Branch

Email deposit slip with names of attendees along with the Pre-registration Forms to: leavumil@yahoo.com

or Fax to tel. # : (049)536-1225/
 (02)808-3448

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Co chair Adelfina Simbul, MD

CALL FOR POSTERS

The Research Committee of the 8th Newborn Screening Convention invites all residents and consultants to submit research papers for poster research presentation and contest.

Papers on newborn screening-related topics will be accepted. Please submit your abstracts on or before **August 15, 2010** to Dr. Cristina P. Magno with contact number, 09175034295 and email address, cristinamagno02@yahoo.com.

Prizes for first, second and third best papers are Php 5000, Php 4000, and Php 3000, respectively.

NSC-Mindanao Corner

Panabo Polymedic Hospital Strengthens NBS through Radio

When the Department of Health introduced Newborn Screening in the Davao Region, the Panabo Polymedic Hospital was one of the private institutions in Davao del Sur that energetically implemented the NBS Program by laying its basic structural and manpower mechanisms.

Headed by NBS Coordinator Dr. Richard T. Mata, the hospital incorporated NBS in its operations with the issuance of a policy integrating NBS in its routine newborn orders on all babies delivered in the hospital. At present, the facility is promoting NBS through a series of radio programs with Mellow Touch 94.7. Through "Health and Issues," Dr. Mata intensifies advocacy efforts on Newborn Screening and emphasizes the need to increase coverage. Today, the hospital has a 95-100% coverage that also includes babies born outside. (*S Guilaran*)

Photo on left: (Standing from left to right) Roy Ryan Ruiz, Dr. Richard Mata, Dr. Rosana Bitoy, Louthgarda Pantua, RN



Training of Trainers for ARMM Health Workers held in Davao



Second batch of health professionals who underwent ARMM Trainers' Training for NBS, with the Secretariat, Dr. Abarquez, Ms. Aster Lynn Sur and Ms. Lita Orbillo

The Center for Health Development-Autonomous Region in Muslim Mindanao (ARMM), in collaboration with the Department of Health and NSC-Mindanao, held the Training of Trainers on Newborn Screening on April 12-16, 2010 in Davao City. Two batches of health workers from government and private hospitals and rural health units (RHUs) were trained. Each batch was allocated two and half days of training. In attendance were nurses, midwives, doctors, medical technologists, several chiefs of hospitals from Basilan, Lanao del Sur, Maguindanao, Marawi City, Sulu and Tawi-Tawi. Ms. Aster Lynn Sur of the Institute of Human Genetics, served as lead facilitator. The actual sample collection was performed at the Southern Philippines Medical Center.

The training aimed to equip the health workers on newborn screening and intensify the awareness of health providers on increasing newborn screening coverage in ARMM. Issues, problems and solutions in implementing the program were also discussed. At the end of the activity, all health facilities not yet categorized as a newborn screening facility submitted their membership forms to CHD-ARMM. (*A. Matuan*)

DAVAO'S G6PD SUPPORT GROUP FORMED

On June 8, 2010, about 100 parents gathered together at the Mahogany Room of the Out Patient Department-JICA Building, Southern Philippines Medical Center to attend the first G6PD Deficiency Support Group Forum in Davao City.

The parents were from Davao City, Panabo City, Comval Province, Davao del Sur, General Santos City, Caraga and Sultan Kudarat. Mindanao's only pediatric geneticist and unit head of Newborn Screening Center-Mindanao, Dr. Conchita G. Abarquez, discussed the facts and cleared the myths on the G6PD Deficiency disorder. Dr. Abarquez's lecture made the parents aware of the nature and effects of the disorder and provided a venue for discussion and sharing of experiences.

Due to the overwhelming support of the parents, a set of officers were elected that same day to lead the Davao's Parents Support Group on G6PD Deficiency. The elected officers were Ana Theresa Basilio, president; Charlie Casane, vice-president; Eastern de Guzman, treasurer; Dr. Cherry Ann Alalong, secretary; and Elinor Marcelino, public relations officer. The officers planned to meet on the third week of June to set up their vision and mission as well as other activities to help disseminate information on G6PD Deficiency. (*R Ruiz*)



The participants during the first Mindanao Support Group Forum for G6PD Deficiency last June 8 at Southern Philippines Medical Center





NSC-Visayas Corner

BAYAWAN DISTRICT HOSPITAL On Higher Ground

The Bayawan District Hospital (BDH) banishes the wrong impression on how government institutions handle and run health programs. Bucking notion that facilities in the bigger cities and which are usually owned by private entities perform well in newborn screening, BDH has always been recognized for its zealous implementation of the NBS program.

BDH adopted a scheme called *People Empowerment Serving Others* more widely known as the PESO for Health program. PESO is a community-based insurance program which aims to ensure quality, equitable, and accessible healthcare to its beneficiaries. This was made even stronger with the support of the participating local government units of STA. BAYABAS (Sta. Catalina, Bayawan City, Basay) Health Zone. Each LGU allocates fund for the healthcare needs of its constituents. With the help of the PESO Program, Bayawan District Hospital was able to screen babies from indigent families and made newborn screening available to everyone.

The people behind the PESO program made a big jump towards better health care delivery. Indeed, BDH is an inspiring example for other hospitals and health facilities in making quality health care services accessible to all Filipinos. (*D Buensalido*)



The Newborn Screening Evaluation Team for the Visayas Region with the Bayawan District Hospital heads.

NSC-V Conducts Favismo – A Seminar on G6PD Deficiency

It was an afternoon of learning and interaction as the Newborn Screening Center – Visayas (NSCV) sponsored a two-hour symposium on G6PD Deficiency on May 28, 2010 at the West Visayas State University - Rehearsal Room. The seminar was spearheaded by Dominic Buensalido, Project Development Officer of NSCV.

There were 143 attendees composed of parents, babies with G6PD Deficiency, and health workers consisting of nurses, doctors and midwives.

Dr. Ma. Lita Fe Paclibar, pediatric hematologist and oncologist, served as resource speaker for the said event. She gave a comprehensive lecture on G6PD deficiency, providing information on disease complications and management.

Glucose-6-Phosphate Dehydrogenase (G6PD) Deficiency is an x-linked recessive hereditary disease characterized by abnormally low levels of G6PD, an enzyme important in the metabolism of red blood cells. Individuals with the disease may exhibit hemolytic anemia, where there is an abnormal breakdown of red blood cells (RBCs) either in the blood vessels or elsewhere in the body. This in response to a number of causes, most commonly infection or exposure to certain medications or chemicals and food. Because G6PD deficiency is the most common human enzyme defect, awareness is very important to avoid possible triggering factors that may lead to complications.

An open forum between the parents and Dr. Paclibar highlighted the importance of preventive care and early detection. The seminar aimed to educate not only the parents but also the health workers and the community on the nature of the disorder. This is the second G6PD symposium conducted by NSCV with Dr. J Edgar Winston Posecion, DPPS as unit head. (*S Catedral*)



Dr. Paclibar (seating in the middle) posed with the attendees and organizers of Favismo, a seminar on G6PD held on May 28, 2010 at WVSUMC, Iloilo City.

ACTIVITIES

Visits to Newborn Screening Facilities in Marinduque

The Newborn Screening Center-NIH and the Extension Office of the Center for Health and Development 4B (MIMAROPA) in Marinduque visited four Newborn Screening Facilities in the province from June 3 to 4, 2010. Visited were the Rural Health Unit – Gasan, Dr. Damian J. Reyes Memorial Hospital, Sta. Cruz District Hospital and Torrijos Municipal Hospital. The visit addressed concerns and reviewed the implementation of NBS in the said facilities. The monitoring team also visited Rural Health Units of Buenavista, Torrijos and Boac, health facilities that are not yet implementing newborn screening. RHU-Buenavista had already submitted its institutional membership form and is sending blood samples for newborn screening. CHD 4B plans to conduct trainings in the remaining health units and for all the midwives in Marinduque as a means to increase the NBS coverage of the province.

1st Consultative Meeting in Romblon

The 1st Consultative Cluster Meeting in Romblon was held on June 11, 2010 at the Rencio's Resort in Odiongan. The five Newborn Screening Facilities, namely, Don Modesto Formilleza Sr. Memorial Hospital, Romblon District Hospital, Romblon Provincial Hospital, San Jose District Hospital-Romblon, and Tablas Island District Hospital were in full attendance. Ms. Teresa M. Du, Regional Coordinator of the Center for Health and Development 4B (MIMAROPA), and Ms. Nilda E. Noceja, Administrative Assistant IV, assisted Ms. Joanna Abigail B. Decano-Terrado, Project Development Officer of NSC-NIH, in facilitating the meeting. Ms. Wenalyn U. Viaña, Program Manager of NSC-NIH, presided the meeting. Discussed were the program updates; 2009 regional coverage; provincial profile in terms of number of deliveries; number of unsatisfactory samples; and review of administrative, follow-up recall and management protocols.

Series of Cluster Meetings held in CALABARZON

The Newborn Screening Center-NIH, in partnership with the Center for Health and Development 4A (CALABARZON) conducted a series of cluster meetings in all the Newborn Screening Facilities (NSFs) in the provinces of Laguna, Cavite, Quezon, Rizal, and Batangas. Below is a summary of all the cluster meetings conducted in the region:

Date	Location	Participants
May 20-21, 2010	Republic of Cavite, Trece Martires City	79
May 25, 2010	Tierra de Oro Hotel, San Pablo City, Laguna	54
May 26, 2010	Alpa Hotel, Batangas City	53
May 28, 2010	Queen Margarrette Hotel, Quezon	40
June 8, 2010	Bougainville Suites and Resorts, Rizal	42



The participants in the cluster meeting organized by CHD 4A and NSC-NIH

The aim of the cluster meeting is to update the staff of all NSFs on the NBS program and review the protocols and processes in implementing NBS. The regional coverage and the provincial statistical profile are presented to make the NSFs aware of the percentage of their home deliveries so they can create advocacy plans to bring NBS closer to the communities. The meeting also serves as a venue to express issues and concerns and share the best practices of health facilities with high percentage of NBS coverage.

The CALABARZON consultative meetings were facilitated by Ms. Wenalyn U. Viaña, Program Manager, and Ms. Joanna Abigail B. Decano-Terrado, Project Development Officer of NSC-NIH with Ms. Malou Malana, Regional Coordinator, and Ms. Jenica Querido, Nurse Coordinator of CHD 4A. A total of 268 NBS health facilities attended. The 123 NSFs without representatives will be visited by CHD 4A personnel. (J Terrado)

UPCOMING ACTIVITY

The Philippine General Hospital in cooperation with the Newborn Screening Reference Center and NSC - NIH

32ND NATIONAL DISABILITY PREVENTION AND REHABILITATION WEEK

JULY 17 - 23, 2010

Theme: "Sa Istrukturang Accessible, Lahat ay Able"

Buntis! ipa-newborn screening mo si baby na!

The Newborn Screening Center – National Institutes of Health will join the National Disability Prevention and Rehabilitation (NDPR) Week Celebration on July 17 to 23. This celebration is spearheaded by the National Council on Disability Affairs (NCDA) by virtue

of Proclamation No. 361. The primary objective of the NDPR Week is to stimulate public awareness on disability issues and concerns that will strengthen the involvement of different government and non-government organizations.

This year, the 32nd NDPR Week with the theme, "SA ISTRUKTURANG ACCESSIBLE, LAHAT AY ABLE" will include activities, such as family fun day of persons with disabilities, livelihood exhibits of products made by persons with disabilities, poster making contest, and sports activities. (I Fortugaleza)



A Birthing Home that Screens more than 90% of its Total Deliveries



Mrs Gertrudes giving NBS lecture to pregnant mothers waiting for their ultrasound.

Mrs. Luderico Gertrudes is a midwife and owner of Well-Family Midwife Clinic - Gertrudes, one of the recipients of the 2009 Exemplary Performance Award given to health facilities with 90% or above newborn screening coverage for 2007-2008 during the celebration of Newborn Screening Week.

WFMC-Gertrudes provides newborn screening among other basic maternal and child health services and maintains various brands of health care products. It is part of the Well-Family Midwife Clinic Partnerships Foundation, Inc. (WFPI), a foundation formed by WFMC midwives and their partner NGOs to sustain their business and social development operations.

The clinic is one of few successful birthing homes implementing newborn screening in Metro Manila. It is one of three Well-Family Midwife Clinics with commendable newborn screening coverage along with WFMC - Cattleya and WFMC - Enriquez.

With a monthly average of 36 deliveries, WFMC-Gertrudes is able to screen 93% of its total deliveries. Mrs. Gertrudes makes sure that all expectant mothers coming to her clinic during their prenatal visits are given essential information and fully understand the benefits of newborn screening. She has been an active advocate of NBS since 2005 and is now part of the Pool of Trainers for Midwives. (*V Mendoza*)

Newborn Screening Centers Directory

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