



NEWBORN SCREENING REFERENCE CENTER



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# NEWBORN SCREENING in the Communities

Facilitator's Guidebook

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## PREFACE

The updated Facilitator's Guidebook: Newborn Screening in the Communities is a product of a concerted effort of key newborn screening program implementers to come up with an up-to-date instructional material to facilitate easy teaching and learning process. The need to come up with a ready reference arises due to the evident need to support newborn screening facilitators when organizing and running newborn screening orientations. It standardizes the information to be communicated to all health workers.

This version contains new developments in the program, updated statistics and data, and recommendations on how to conduct the training orientation. This guidebook includes slide presentations, scripts, and additional notes that may aid the facilitator in delivering the presentation. The script is based on the usual lines delivered in previous orientations as well as valuable contributions from the newborn screening pool of speakers and input from the Newborn Screening Centers, Centers for Health Development, and Newborn Screening Continuity Clinics.

There are five sections in this guidebook:

**Module 1** contains an overview of the general aspects of the screening program. It describes the history of newborn screening in the Philippines as well as its importance.

**Module 2** presents the highlights of RA 9288 (the Newborn Screening Act of 2004) with an emphasis on the role of health workers and its implications on the health facilities in the country.

**Module 3** is devoted to the procedures for implementing newborn screening in health facilities. The presentation includes the newborn screening flow of operations.

**Elective Module 1** is optional for refresher courses. This module discusses the role of Newborn Screening Continuity Clinics (NBSCCs) in the national newborn screening program.

**Elective Module 2** is also an optional course that discusses each of the disorders in the Expanded Newborn Screening Panel, along with their symptoms and treatment. This course is recommended if the need arises based on the training needs of the participants.

Each of the modules have two versions, one for face-to-face trainings, and another for online trainings. Use the module appropriate for your training's mode of delivery. If you want more information about newborn screening, particularly on the conditions included in the expanded newborn screening panel, you may go through the Fact Sheets for Doctors, NCNBSS Manual of Operations, or visit [www.newbornscreening.ph](http://www.newbornscreening.ph) for more resources and information.

We hope that using this guidebook will be beneficial to you. Any pertinent information (such as local policies) may be incorporated or updated as appropriate. In order to help you the most, we ask for your feedback while you use this guidebook. Every year, NSRC will update this manual to reflect the most recent information, address persistent issues, and give facilitators further guidance on any crucial aspects of the newborn screening program.

Thank you and stay safe!


Contacts:                      Newborn Screening Reference Center  
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University of the Philippines Manila  
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Inserts:                        Newborn Screening AVP and Videos  
Year of Revision:            2023



# HOW TO USE THIS BOOK

## THE FORMAT

ENBS in the Communities: Facilitator's Guidebook



*Now, take a look at this picture? If a child is born in your facility with this kind of genitalia would you classify the baby as a boy or a girl? (generate response from participants)*

*Ambiguous genitalia is one of the manifestations of CAH*

Additional Notes

Congenital adrenal hyperplasia is a group of hormonal disorders characterized by abnormally high levels of male sex hormones in both boys and girls. If not detected and treated early, babies may die within 7 days.

Babies, children or adults with classic congenital adrenal hyperplasia can experience a life-threatening "adrenal crisis," due to inadequate production of cortisol from the adrenal glands. An adrenal crisis can result in a seriously low level of sodium in the blood, diarrhea, vomiting, dehydration, low blood sugar levels and shock. People experiencing an adrenal crisis need immediate treatment.

Although CAH can be life-threatening, affected patients can lead normal lives with early detection and proper treatment which may include surgery in severely virilized girls.

There are classical non-saltwasters who also require treatment.

ISO # "NSRC-INT-04\_I1R2"

Actual slide presentation

Suggested script for the Speaker

Some facts and details/points for discussion and issues that may aid the speaker

The *suggested script* for the speaker is in italics.

Additional notes for the speaker are written at the bottom of the page.

**All points to be emphasized** are in italic bold format.

This book comes with an 8-minute AVP to highlight steps for implementing newborn screening at the community level.



## ACRONYMS

DOH	Department of Health
DOH-RO	Department of Health-Regional Office
ENBS	Expanded Newborn Screening
HFSRB	Health Facilities and Services Regulatory Bureau
IRR	Implementing Rules and Regulations
LGU	Local Government Unit
NBS	Newborn Screening
NBSCC	Newborn Screening Continuity Clinic
NCP	Newborn Care Package
NIH	National Institutes of Health
NSC	Newborn Screening Center
NSF	Newborn Screening Facility
NSRC	Newborn Screening Reference Center
PHIC	Philippine Health Insurance Corporation
RHU	Rural Health Unit



# Newborn Screening

Facilitators' Guidebook

[www.newbornscreening.ph](http://www.newbornscreening.ph)



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# 2

## Module 2: Highlights of RA 9288



*To ensure that all Filipino newborns are given the opportunity to be screened, a bill on newborn screening was proposed in 2003. A year after, the bill was signed into law.*



**Enactment of the  
Newborn Screening Act of 2004**  
(APRIL 6, 2004)

**Signing of the  
Implementing Rules and Regulation  
of RA 9288**  
(OCTOBER 5, 2004)

Newborn Screening Reference Center



*Let us run through the next few slides containing some highlights on the Implementing Rules and Regulations of RA 9288 or the Newborn Screening Act of 2004.*

## Additional Notes

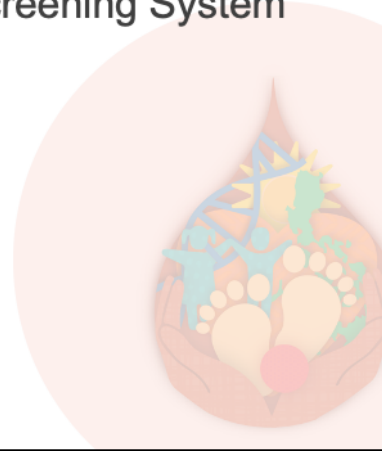
The next few slides compose Module 2. It discusses the Republic Act 9288 or the Newborn Screening Act of 2004. The facilitator must read the law in advance. A copy of the law and its IRR are supplied in the last pages of this Facilitator's Guidebook

## Highlights of RA 9288

### Sec 2. Declaration of Policy:

- Institutionalize a National Newborn Screening System
  - **Comprehensive.**
  - **Integrative.**
  - **Sustainable.**
  - **Collaborative.**
- Opportunity for every baby born in the Philippines to undergo NBS

Newborn Screening Reference Center



*The state shall institutionalize a National Newborn Screening System that is COMPREHENSIVE, INTEGRATIVE, SUSTAINABLE and COLLABORATIVE.*

*The state shall ensure that every baby born in the Philippines is offered the opportunity to undergo NBS and be spared from heritable conditions that can lead to mental retardation and death.*

*Thus, the need to make it really part of the newborn routine care.*

## Highlights of RA 9288

Sec 5: **Obligation of Health Workers** to inform parents or legal guardians of the newborn about newborn screening

Sec 9: DOH and PHIC shall require health institutions to provide newborn screening services as a condition for **licensure and accreditation**

Newborn Screening Reference Center



*The health workers have an obligation to inform their clients about newborn screening. Later on, there will be a discussion on the ways and means of motivating clients or the parents on the importance of newborn screening. The NSRC, together with the Department of Health (DOH), have also produced some materials to help in the dissemination of information about newborn screening.*

*DOH and PHIC require health institutions to provide newborn screening services as a requirement for licensure and accreditation.*

### Additional Notes

- Q. What are some examples of creative advocacy activities conducted?
- A. Some examples are:
1. Inclusion of the importance of ENBS in reproductive health lectures;
  2. Inclusion in multimedia broadcasting programs pro bono

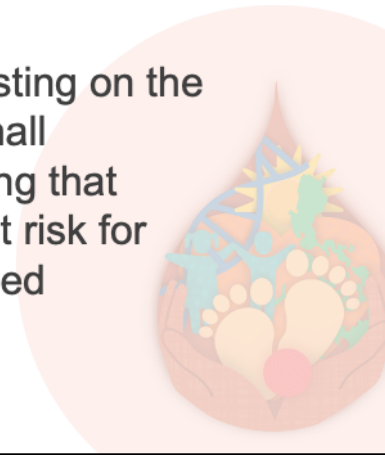


## Highlights of RA 9288

### Sec. 7 Refusal to be Tested

A parent or legal guardian may refuse testing on the grounds of **RELIGIOUS BELIEFS**, but shall acknowledge in writing their understanding that refusal for testing places their newborn at risk for mental retardation or death of undiagnosed heritable conditions.

Newborn Screening Reference Center



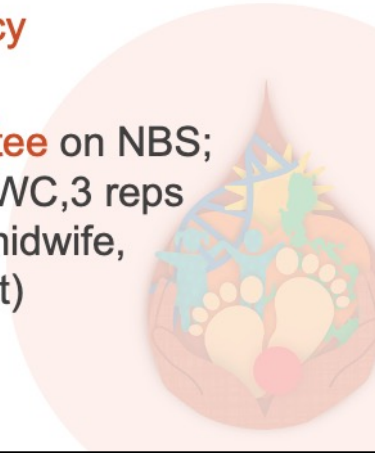
*A copy of this refusal documentation shall be made part of the newborn's medical record and refusal shall be indicated in the national NBS database.*

## Highlights of RA 9288

Sec 10: Defining **DOH** as the lead agency

Sec 11: Creation of an **Advisory Committee** on NBS;  
Composition: DOH, DILG, NIH, NSRC, CWC, 3 reps  
(pediatrician, obstetrician-gynecologist, midwife,  
family physician, pediatric endocrinologist)

Newborn Screening Reference Center



*DOH is the lead agency in the implementation of RA 9288 and the Secretary of Health chairs the Advisory Committee or ACNBS.*

### Additional Notes

Q. What is the composition of the Committee?

A. The Committee shall be composed of eight members:

Secretary of Health acting as Chairperson

Executive Director of the NIHP as the Vice Chairperson

Undersecretary of the DILG

Executive Director of the Council for the Welfare of the Children

Director of the NSRC

Three representatives appointed by the Secretary of Health who shall either be a pediatrician, obstetrician, endocrinologist, family physician, nurse or midwife from either the public or private sector.

Q. How many times does the ACNBS convene?

A. The ACNBS convenes at least 2x a year.

## Highlights of RA 9288

Sec. 12 Establishment and accreditation of NSCs

Sec. 13 Establishment of NSRC

- National testing database and case registries
- Training, technical assistance, and continuing education program for laboratory staff in all NSCs

Newborn Screening Reference Center



*The reason why the laboratory is called as a center, is because the NSC has both laboratory testing and follow-up programs for infants with a positive screen. Newborn Screening Centers shall:*

- *Have a certified laboratory performing all tests included in the newborn screening program.*
- *Have recall/follow-up programs for infants with a positive screen in any and all heritable disorders.*
- *Be supervised and submit to DOH accreditation and reaccreditation.*

*The RA 9288 also states the establishment of Newborn Screening Reference Center (NSRC) and shall be responsible for:*

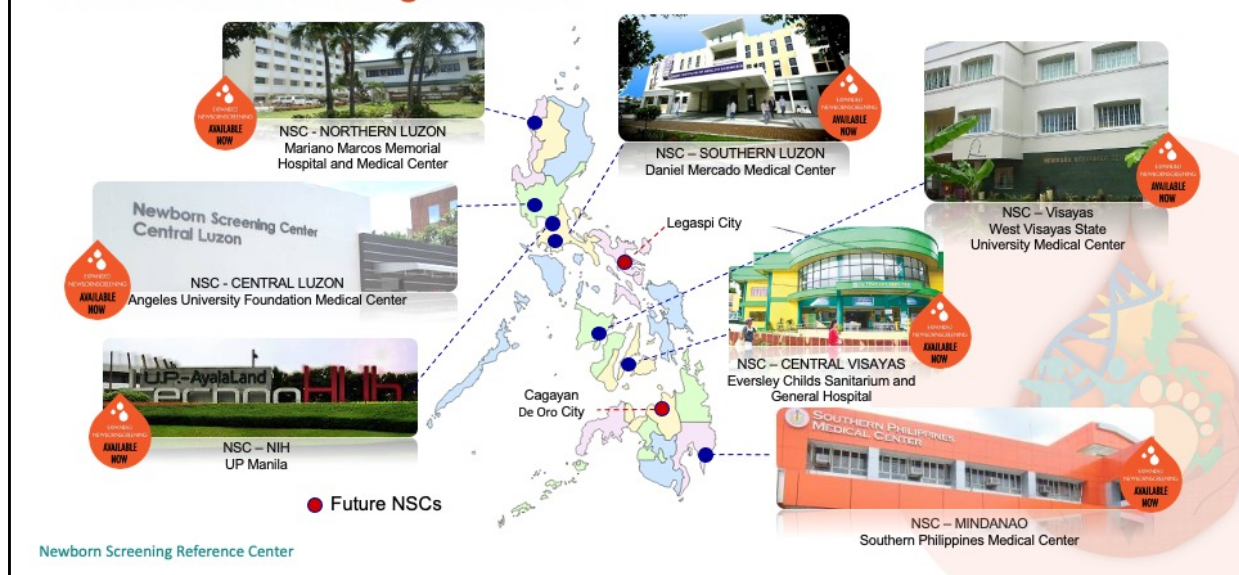
*National testing database and case registries*

*Training*

*Technical assistance and continuing education program for laboratory staff in all NSCs.*



## Newborn Screening Centers



The RA 9288 defines the establishment and accreditation of Newborn Screening Centers (NSC).

Newborn Screening Centers are the centralized laboratories of newborn screening. All samples collected are sent and processed in these laboratories. An NSC is unique because it not only operates as a laboratory but also has a follow-up program.

Presently, there are seven operational NSCs in the country:

1. Newborn Screening Center - NIH of UP-Manila, which caters to samples collected in Metro Manila and Regions IVB and V;
2. Newborn Screening Center – Visayas located at West Visayas State University Medical Center that serves Regions VI and Regions VIII;
3. Newborn Screening Center – Mindanao located at the Southern Philippines Medical Center (formerly Davao Medical Center) that screens the samples from Mindanao.
4. Newborn Screening Center – Angeles University Foundation Medical Center in Central Luzon in Angeles City, Pampanga, which caters to samples in CAR and Region III.
5. Newborn Screening Center – Daniel Mercado Medical Center in Southern Luzon was opened in Tanauan City to run the samples from Region IVA.
6. NSC-Northern Luzon at Mariano Marcos Memorial Hospital and Medical Center in Ilocos Norte runs the samples from Regions 1 and 2
7. 7<sup>th</sup> NSC Eversley Childs Sanitarium and General Hospital is opened in Central Visayas early 2020 and now runs all samples from Region VII.

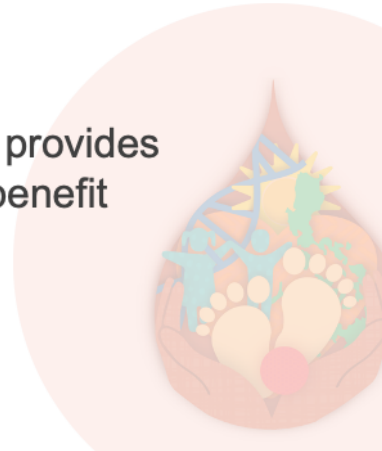
Northern Mindanao Medical Center which will house the NSC Northern Mindanao is currently undergoing training and preparations. The one in Bicol will soon start its construction.

## Highlights of RA 9288

Sec. 14 Quality Assurance

Sec. 16 Newborn Screening Fees which provides for the inclusion of NBS in the newborn benefit package of the PHIC

Newborn Screening Reference Center



*Added to this is Quality Assurance to ensure that tests and other aspects of the program are within international standards.*

*The law also states that the Philippine Health Insurance Corporation, Inc (PHIC) shall include NBS in its benefits. Currently, the PHIC has covered ENBS in full, under the enhanced Newborn Care Package.*

### Additional Notes

Sec.14 of RA 9288: The NIH Newborn Screening Reference Center shall be responsible for drafting and ensuring good laboratory practice standards for newborn screening centers, including establishing an external laboratory proficiency testing and certification program. It shall also act as the principal repository of technical information relating to newborn screening standards and practices, and shall provide technical assistance to newborn screening centers needing such assistance.

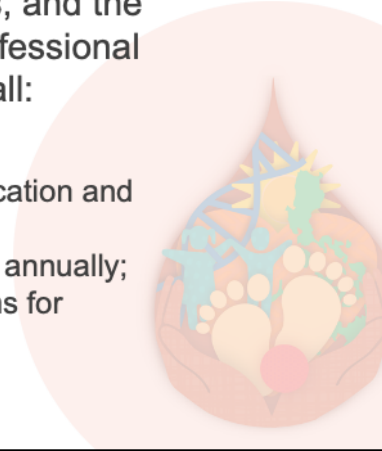
PHIC has recently issued PHIC Circular No. 2018-0021 or the Enhancement of Newborn Care Package that covers expanded newborn screening in full.

## Sec 12 of the IRR- Continuing Education, Re-education and Training of Health Personnel

Awareness of all health personnel, DOH, LGUs, and the academe, and other government agencies, professional societies and non-government organization shall:

- Conduct continuing information, education, re-education and training programs for health personnel;
- Disseminate information materials on NBS at least annually;
- Integrate information in existing education programs for medical and paramedical professionals.

Newborn Screening Reference Center



*To ensure awareness of all health personnel, the DOH, LGUs, and the academe with the assistance of the NIHP and other government agencies, professional societies and non-government organization shall:*

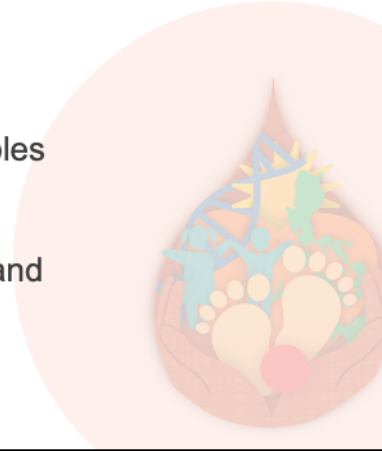
*Conduct continuing information, education, re-education and training programs for health personnel;  
Disseminate information materials on NBS at least annually;  
Integrate information in existing education programs for medical and paramedical professionals.*

## Highlights of RA 9288

### Sec 14- A of the IRR- Roles of Health Facilities in the Implementation of RA 9288

- Integrate NBS in its delivery of health services
- Serve as collecting health units for blood samples for NBS
- Coordinate with duly accredited NSC
- Inform, educate, communicate, screen, recall and manage identified cases
- Establish an NBS Team

Newborn Screening Reference Center



*The health facilities have the following responsibilities:*

- 1. NBS should already be part of their health services;*
- 2. Serve as collecting health units for blood samples for NBS;*
- 3. Coordinate with a duly accredited NSC*
- 4. Provide information, education, communication, screening, recall and management of identified cases;*
- 5. Establish an NBS Team that will be responsible for collection of samples, sending of samples to accredited NSC, prompt recall of positive patients, referral, management and follow up of patients;*

## Highlights of RA 9288

### **Sec 14- A of the IRR- Roles of Health Facilities in the Implementation of RA 9288**

- Establish an appropriate financial system for an effective and efficient collection of fees and payment of NBS services to the NSC
- Conduct orientation and /or training of hospital staff on NBS
- Monitor and evaluate the implementation of NBS within the institution
- Define creative financial packages to make NBS accessible

Newborn Screening Reference Center

6. *Establish an appropriate financial system for an effective and efficient collection of fees and payment of NBS services to the NSC;*
7. *Conduct orientation and /or training of hospital staff on NBS;*
8. *Monitor and evaluate the implementation of NBS within the institution;*
9. *Define creative financial packages to make NBS accessible particularly among the economically deprived populace.*

*For the RHUs or LGUs you can work on your local government unit for some funding schemes.*

## Highlights of RA 9288

**Sec 19-B of the IRR**– The government and private health facilities are highly encouraged to develop a scheme providing partial and full subsidy depending on the financial capability of parents

**Sec 19-D of the IRR**– A health facility may collect a reasonable fee for the collection of samples, which shall not be greater than the maximum allowable service fee prescribed by DOH

**Sec 21-A of the IRR**– All hospitals, birthing facilities, rural health units, Health Centers and other collecting health facilities throughout the country shall have NBS Specimen Collection Kits at all times

Newborn Screening Reference Center

*The government and private health facilities are highly encouraged to develop a scheme providing partial and full subsidy for the screening fee depending on the financial capability of parents.*

*A health facility may collect a reasonable fee for the collection of samples, which shall not be greater than the maximum allowable service fee prescribed by DOH which is P50.*

*All hospitals, birthing facilities, RHUs, Health Centers and other collecting health facilities throughout the country shall have NBS Specimen Collection Kits at all times.*

### Additional Notes

AO 2008-0026 A was released to amend to the Rules and Regulations Implementing Republic Act No. 9288, otherwise known as the Newborn Screening Act of 2004. The following administrative fines will be imposed on health facilities that refuse to provide NBS services and/or collect more than the maximum allowed NBS fee:

First offense	-	warning
Second offense	-	administrative fine of fifty thousand pesos (P50,000.00)
Third offense	-	administrative fine of one hundred thousand pesos (100,000.00)



## Highlights of RA 9288

### Sec 14-C of the IRR- The Roles of the Local Government Units (LGUs):

- Develop capabilities of health workers
- Issue local ordinances and resolutions that integrate NBS in the health care delivery system
- Ensure that adequate and sustained NBS services are being provided in all LGU-managed health facilities
- Establish a functional case management referral system
- Monitor and evaluate NBS implementation in their localities
- Explore/encourage creative financial packages to make NBS accessible

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*Local government units also play an essential role in the implementation of the NBS. Since they are devolved from the DOH by virtue of the Local Government Code or RA 7160, the LGUs are tasked to implement, monitor and ensure sustainability of the project. Thus, it is expected that they will:*

- 1) develop the capacities of health workers under its supervision;*
- 2) issue local policies that integrate NBS in the local health care delivery system; and*
- 3) ensure that adequate and sustained NBS services such as information, education, communication, screening, recall and follow-up are being provided in all LGU-managed health facilities.*
- 4) establish a functional case management referral system anchored on strategically accessible NCNBSS treatment network.*
- 5) monitor and evaluate the implementation of NBS in its jurisdiction.*
- 6) explore/encourage to develop financial packages especially for the economically marginalized pregnant women in its populace.*
- 7) perform other roles and responsibilities deemed necessary for the implementation of this Act.*



## Highlights of RA 9288

### **Sec 14-D of the IRR- The Roles of the Academe, Health Professional Societies, National Organizations of Health Professionals**

- Ensure that all its members are aware of the significance of NBS to their clients, their families and the society at large
- Define mechanism that will ensure and monitor that its members are doing their obligations to inform parents about the significance of NBS
- Recommend the inclusion of NBS as part of the curricula of all allied health professions

Newborn Screening Reference Center

### Additional Notes

**Other related policies that may be mentioned:**

[REPUBLIC ACT No. 10747]

An Act Promulgating a Comprehensive Policy in Addressing the Needs of Persons With Rare Disease

[REPUBLIC ACT NO. 9709]

An Act Establishing a Universal Newborn Hearing Screening Program for the Prevention, Early Diagnosis and Intervention of Hearing Loss

[REPUBLIC ACT No. 11148]

An Act Scaling Up the National and Local Health and Nutrition Programs Through a Strengthened Integrated Strategy for Maternal, Neonatal, Child Health and Nutrition in the First One Thousand (1,000) Days of Life, Appropriating Funds Therefor and for Other Purposes

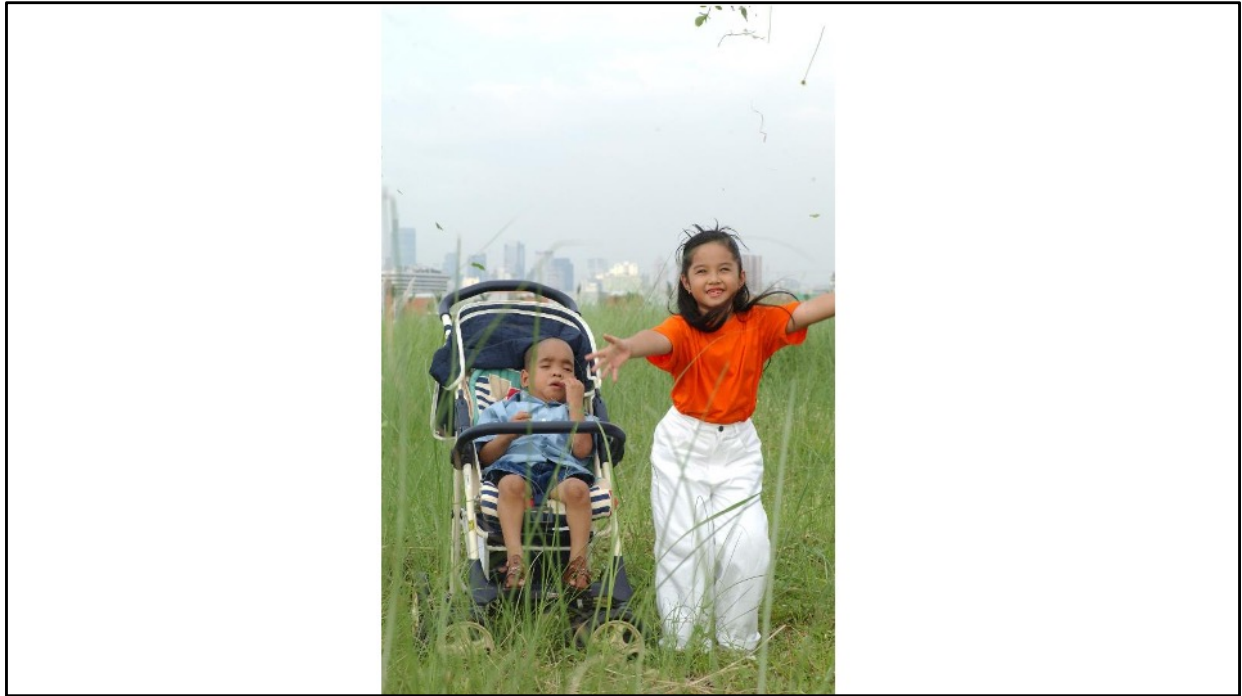
[DSWD Administrative Order No. 9 Series of 2010]

Guidelines of the National Inspectorate Committee for DSWD Centers and Residential Care Facilities

MNCHN Strategy Manual of Operations

[DILG Memorandum Circular 2011-57]

Ensuring Adherence to DILG Memorandum Circular No 2005-160 Dated on the Subject, "Implementation of RA 9288 or the Newborn Screening Act of 2004"



*If we fully implement newborn screening, we will save more JRs and Janelles.*

## Quiz Question no. 3

What is the lead agency in the implementation of newborn screening?

**Department of Health (DOH)**



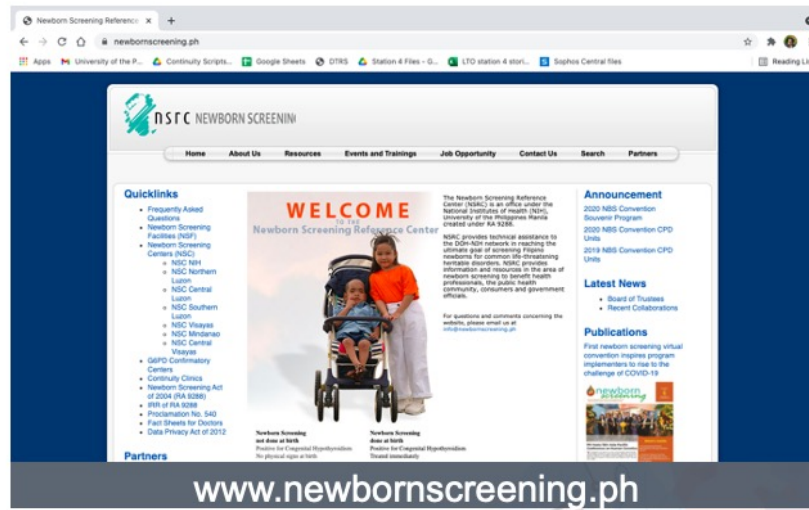
## Quiz Question no. 4

Whose role is the issuance of local ordinances and resolutions to integrate NBS in the health care delivery system?

**LGUs**



## Module 2: Highlights of RA 9288

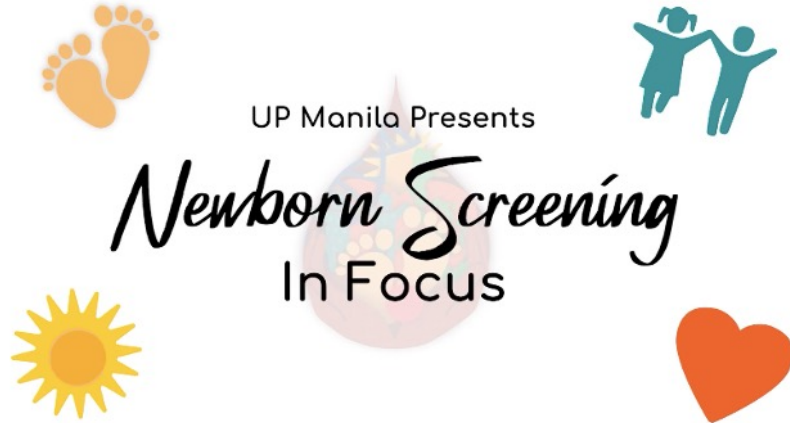


Newborn Screening Reference Center

*For more information about newborn screening, you can visit the newborn screening resource/portal site:*

[www.newbornscreening.ph](http://www.newbornscreening.ph)

Watch Newborn Screening in Focus at  
[youtube.com/@TVUPPh](https://youtube.com/@TVUPPh) or Cignal TV channel 101



Newborn Screening Reference Center

*Newborn Screening in Focus is a video series that uncovers the wonderful story of Newborn Screening in the Philippines, zooming in on what makes Newborn Screening a comprehensive program for every Filipino.*

*NBS in Focus features the humble beginnings of the Newborn Screening Program and its evolution into a national health program. The series also presents the very process of newborn screening from the moment the child is born, and into the continuing care available for newborns confirmed to have a disorder included in the panel. Features and management of the disorders from the newborn screening panel are also discussed in individual episodes. Finally, the series presents the Newborn Screening program network, and how the program managed to give quality service despite the limits brought about by disasters such as the COVID-19 pandemic.*

*Watch the live airing of NBS in Focus every Saturday 7-8 pm at Cignal TV 101 or online at [youtube.com/@TVUPPh](https://youtube.com/@TVUPPh).*



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