



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 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
 National Institutes of Health
 University of the Philippines Manila
 Email add: info@newbornscreening.ph


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
LTFU	Long-term Follow-up
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
STFU	Short-term Follow-up



Newborn Screening

Facilitators' Guidebook

www.newbornscreening.ph

Updated as of November 2022



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ELECTIVE MODULE 1: Newborn Screening Continuity Clinics



This module is optional for refresher courses

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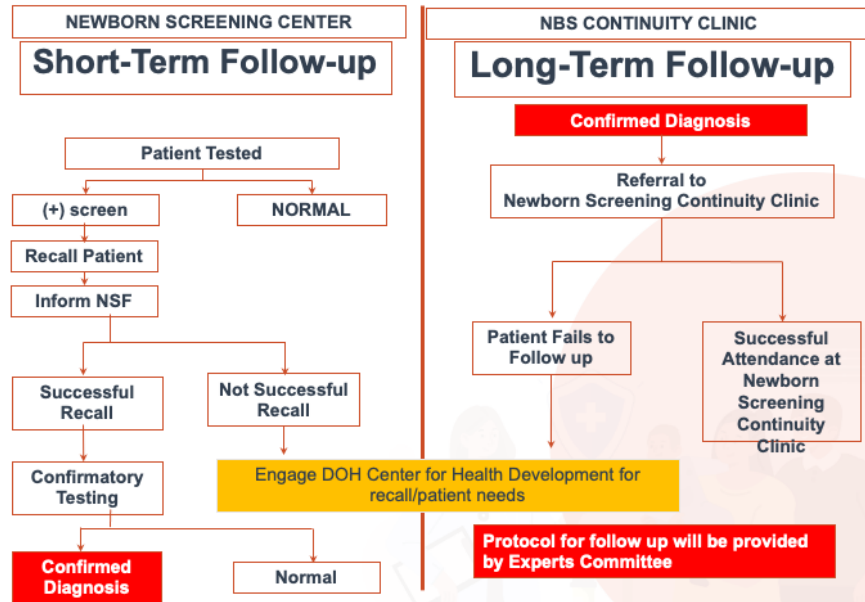
Administrative Order
No. 2014 - 0035

Newborn Screening Reference Center

These Newborn Screening Continuity Clinics were established to address the growing number of referrals and patients being managed in the implementation of expanded newborn screening. This will strengthen the treatment and referral network and ensure the capable management of confirmed positive cases.

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Review of Referral Flow



Newborn Screening Reference Center

The Newborn Screening Centers' (NSCs) role currently extends to the confirmation of the diagnosis and the referral to a specialist for long-term treatment. With the establishment of the NBS Continuity Clinics, the patients diagnosed by the NSCs will be turned over to the NBS Continuity Clinics for long term care and monitoring. The network of NBS Continuity Clinics will definitely improve the quality of life for our diagnosed patients.

Establishment of Continuity Clinics

- The NBS Continuity Clinics shall be established, initially in every region, equipped to facilitate continuity of care of confirmed patients in its area of coverage. Host Facilities of NBSCC shall:
 - Provide a clinic space for patient consultation and a work station for the follow-up nurse and/or genetic counselor.
 - Oversee the selection and hiring of personnel for the NBSCC in their facility;
 - Integrate NBS continuity clinic to the current services of the host facility;
 - Ensure the sustained operation of NBSCC and Birth Defects Continuity Clinic

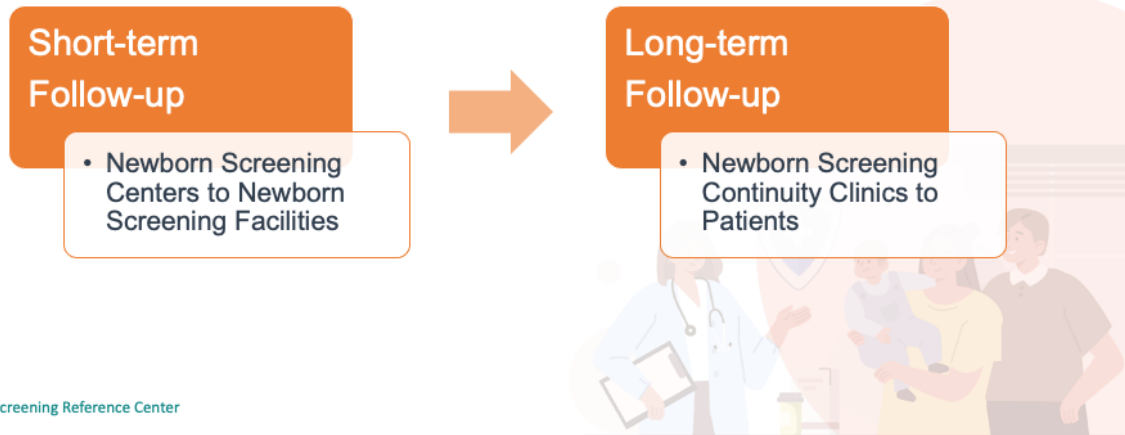
Newborn Screening Reference Center

Initially, one Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic per region shall be set-up. Subsequently, provincial continuity clinics shall be established. There are now 33 Newborn Screening Continuity Clinics in the country.

The roles of the Host Facilities of NBS Continuity Clinics include:

- a. Setting-up NBS Continuity Clinic and Birth Defects Continuity Clinic;*
- b. Providing a clinic space for patient consultation and a work station for the follow-up nurse and/or genetic counselor.*
- c. Overseeing the selection and hiring of personnel for the NBS Continuity Clinic in their facility;*
- d. Integrating NBS continuity clinic to the current services of the host facility;*
- e. Ensuring the sustained operation of NBS Continuity Clinic and Birth Defects Continuity Clinic according to the Operational Guidelines set by the DOH and the NSRC for these clinics.*

Types of Follow Up



Newborn Screening Reference Center

There are two types of follow up:

1. Short Term Follow up was mentioned earlier. The Newborn Screening Center runs the screening samples, facilitates samples for confirmatory testing, and follow-up. Short term follow means following up the patient from confirmatory to diagnosis, then to initial management and initial treatment.

2. Long Term Follow up that takes place once the patient has been diagnosed and referred to specialists for initial treatment. The long-term follow-up handles the management of patients after and ensures that the affected children live to grow normally. The long-term follow-up is done through continuity clinics.

Short-term Follow-up (STFU) Long-term Follow-up (LTFU)

American College of Medical Genetics define STFU as: "those activities that ensure all infants are screened, abnormal results are appropriately and expediently handled, and affected infants are promptly identified, appropriately referred and **treatment initiated** where applicable."

Newborn Screening Centers



The Clinical and Laboratory Standards Institute define LTFU as: "actions commencing after confirmed diagnosis in an affected individual to ensure the screening program can evaluate the effectiveness of their follow-up program"

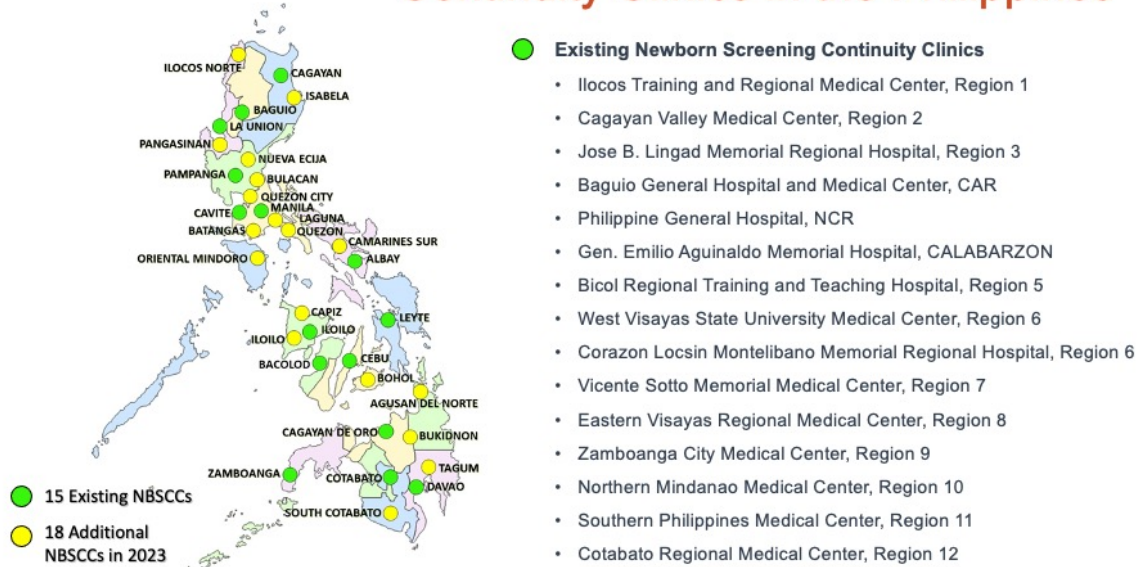
NBS Continuity Clinics

Reference: Association of Maternal and Child Health Programs' Newborn Screening and Genetics Advisory Group. Newborn Screening Long-term Follow-Up Assessment. 2007. AMCH Report.

Definition of STFU focuses on a lot of critical questions: Are we screening on time, are we getting accurate results, are we properly handling positive results? Are we recalling on time? are we initiating timely treatment – time is a crucial element, it could be a matter of life and death.

Whereas for LTFU following the CLSI definition: Perhaps not as immediate or critical question but equally important: Are we achieving our intended goal of improving health outcomes? What good is screening if we are not able to save and ensure the quality of life of confirmed cases?

Continuity Clinics in the Philippines



These continuity clinics are located in tertiary and government hospitals in 14 regions. MIMAROPA region and Rizal from Region 4A are being handled by PGH NCR; Caraga region is being handled by SPMC Region 11 and; BARMM provinces distributed into 3 continuity clinics: Regions X, XI, and XII.

Continuity Clinics in the Philippines



● Additional Newborn Screening Continuity Clinics

- Mariano Marcos Memorial Hospital and Medical Center, Region 1
- Region 1 Medical Center, Region 1
- Southern Isabela Medical Center, Region 2
- Dr. Paulino J. Garcia Memorial Research & Medical Center, Region 3
- Bulacan Medical Center, Region 3
- Philippine Children's Medical Center, NCR
- Quezon Medical Center, CALABARZON
- Batangas Medical Center, CALABARZON
- Dr. Jose P. Rizal Memorial District Hospital, CALABARZON
- Oriental Mindoro Provincial Hospital, MIMAROPA
- Bicol Medical Center, Region 5
- Roxas Memorial Provincial Hospital, Region 6
- Western Visayas Medical Center, Region 6
- Gov. Celestino Gallares Memorial Medical Center, Region 7
- Bukidnon Provincial Medical Center, Region 10
- Davao Region Medical Center, Region 11
- Agusan Del Norte Provincial Hospital, CARAGA
- SOCCSKSARGEN General Hospital, Region 12

In 2023, 18 new continuity clinics were added from the initial 15 continuity clinics.

Continuity Satellite Clinics



17 Satellite Clinics

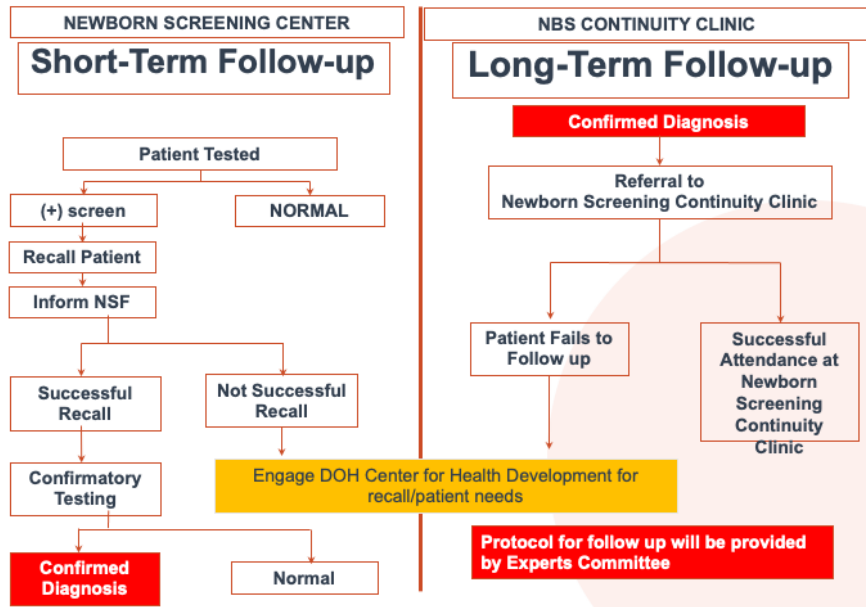
- Eastern Bicol Medical Center
- Sorsogon Provincial Hospital
- Bicol Region General Hospital and Geriatric Medical Center
- Dr. Rafael S. Tumbokon Memorial Hospital
- Angel Salazar Memorial General Hospital
- Teresita L. Jalandoni Provincial Hospital
- Western Visayas Sanitarium
- Aleosan District Hospital
- Don Jose S. Monfort Medical Center - Extension Hospital
- Lorenzo D. Zayco District Hospital
- Iloilo Provincial Hospital
- Jesus M. Colmenares District Hospital
- Dr. Catalino Gallego Nava Provincial Hospital
- Alfredo E. Maranon Memorial Hospital
- San Carlos City Hospital
- Adela Serra Ty Memorial Medical Center
- Caraga Regional Hospital

These satellite clinics function as a network of medical facilities to assist the NBSCCs in patient management. The satellite clinic's host facilities integrate NBS clinic services into their OPD services.

Contact details of the continuity and satellite clinics are available at https://www.newbornscreening.ph/index.php?option=com_content&view=article&id=205&Itemid=85

NOTE: *The presenter/facilitator may include in the presentation their region's continuity clinic and/or satellite clinic team members' composition and clinic schedules.*

Review of Referral Flow

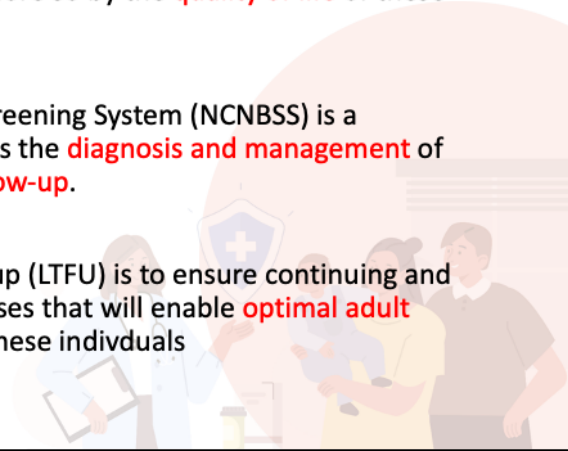


In detail, this is how the follow-up system or network referral look like

NBS Principles of Patient Follow-up

- The success of a national program of Newborn Screening is measured not only by the number of babies diagnosed but, more so by the **quality of life** of these infants.
- The National Comprehensive Newborn Screening System (NCNBSS) is a nationwide integrated system that includes the **diagnosis and management** of babies with positive screens and their **follow-up**.
- The major objective of Long Term Follow-up (LTFU) is to ensure continuing and appropriate management of confirmed cases that will enable **optimal adult physical, mental, and social** outcomes of these individuals

Newborn Screening Reference Center



Roles and Responsibilities of NBS Continuity Clinic Team

Newborn Screening Reference Center



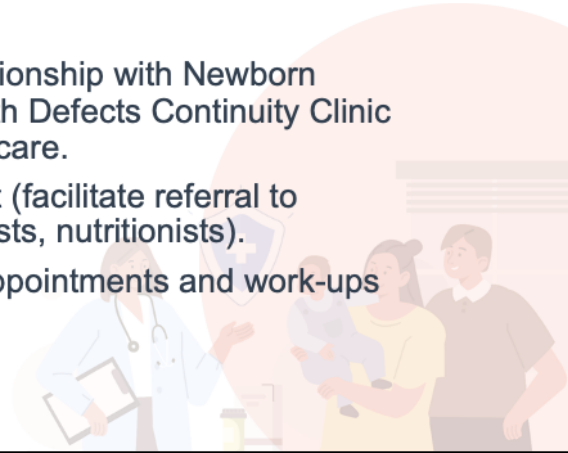
The main role of the NBS Continuity Clinic Team

NBS Continuity Clinic Team

Patient/Family-Centered Activities (Main)

- Encourages family to maintain relationship with Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic to ensure continuous and effective care.
- Monitors compliance with treatment (facilitate referral to appropriate sub-specialists, therapists, nutritionists).
- Reinforces schedule of follow-up appointments and work-ups endorsed by the NSC.

Newborn Screening Reference Center



The main role of the NBS Continuity Clinic Team:

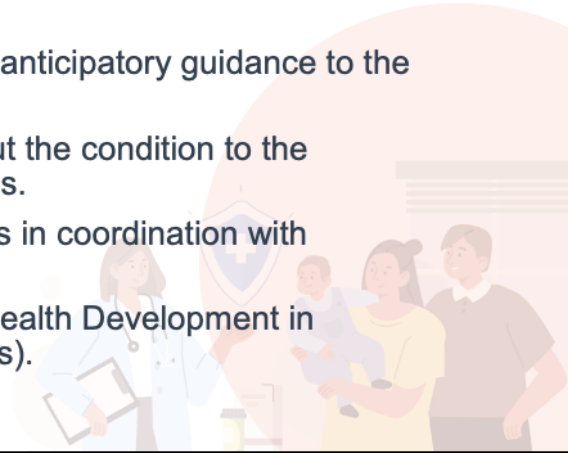
- *Encourages family to maintain relationship with Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic to ensure continuous and effective care.*
- *Monitors compliance with treatment (facilitate referral to appropriate sub-specialists, therapists, nutritionists).*
- *Reinforces schedule of follow-up appointments and work-ups endorsed by the NSC.*

NBS Continuity Clinic Team

Patient/Family-Centered Activities (Main)

- Provides follow-up counselling and anticipatory guidance to the family.
- Provides continuing education about the condition to the families and the health professionals.
- Set up patient/family support groups in coordination with NSRC.
- Coordinates with DOH Center for Health Development in patient recall (lost to follow up cases).

Newborn Screening Reference Center



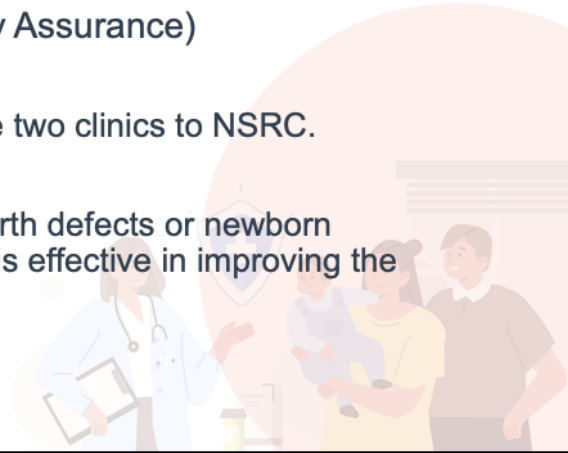
- *Provides follow-up counselling and anticipatory guidance to the family.*
- *Provides continuing education about the condition to the families and the health professionals.*
- *Set up patient/family support groups in coordination with NSRC.*
- *Coordinates with DOH Center for Health Development in patient recall (lost to follow up cases).*

NBS Continuity Clinic Team

Patient-Centered Activities (Quality Assurance)

- Prepares and submits reports of the two clinics to NSRC.
- Evaluates the extent to which the birth defects or newborn screening long-term follow-up care is effective in improving the patient's health.

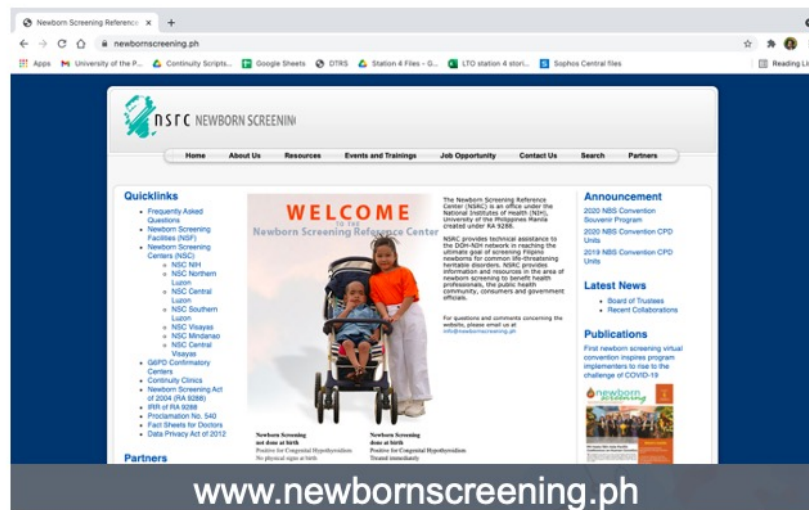
Newborn Screening Reference Center



The NBS Continuity Clinic Team also:

- *Prepares and submits reports of the two clinics to NSRC.*
- *Evaluates the extent to which the birth defects or newborn screening long-term follow-up care is effective in improving the patient's health.*

Elective Module 1: NBSCC



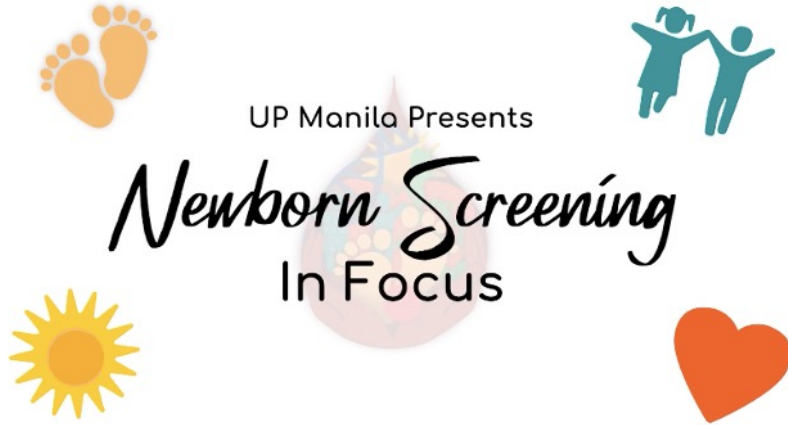
Newborn Screening Reference Center

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

www.newbornscreening.ph

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Watch Newborn Screening in Focus at
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.



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Updated as of November 2022



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