

Manual of Operations for Newborn Screening Continuity Clinics



Version January 8, 2019

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Acronyms

3CA	-	Continuity Clinic Case Audit report
4CA	-	Continuity Clinic Case Conference Audit
AP	-	Attending Physician
CAH	-	Congenital Adrenal Hyperplasia
CCORS	-	Continuity Clinic Online Record System
CH	-	Congenital Hypothyroidism
DOH RO		Department of Health Regional Office
CMS	-	Case Management System
ENBS	-	Expanded Newborn Screening
G6PD	-	Glucose-6-phosphate Dehydrogenase Deficiency Def.
GAL	-	Galactosemia
HC	-	Hospital Coordinator
MS	-	Metabolic Specialist
MSUD	-	Maple Syrup Urine Disease
MT	-	Medical Technologist
NBS	-	Newborn Screening
NBSCC	-	Newborn Screening Continuity Clinics
NC	-	Nurse Coordinator
NCNBSS	-	National Comprehensive Newborn Screening System
NIH	-	National Institutes of Health
NTWG	-	National Technical Working Group on Newborn Screening
NFC	-	National Follow-up Coordinator
NSC	-	Newborn Screening Center
NSRC	-	Newborn Screening Reference Center
PKU	-	Phenylketonuria

1. INTRODUCTION

1.1 Background

As mandated by Republic Act 9288 (RA 9288), otherwise known as the Newborn Screening Act of 2004, the National Comprehensive Newborn Screening System (NCNBSS) should ensure that every baby born in the Philippines is offered the opportunity to undergo newborn screening and thus be spared from heritable conditions that can lead to mental retardation and death if undetected and untreated. The components of the system include education, screening, follow-up, diagnosis, treatment and management, and evaluation.

The NCNBSS is continuously undertaking measures to further improve the program specifically on its follow-up component. This component has two levels: the short term follow-up and long term follow-up. For the short-term part, babies with elevated screening are followed-up, undergo confirmatory testing, and if confirmed to have one of the disorders, are referred to a specialist for initiation of treatment. What happens beyond the screening and initial management falls under the long term follow-up which is the provision for continuity of care for patients found positive for any of the screened disorders. This is a vital aspect of the newborn screening (NBS) program. With the growing number of referrals and confirmed patients being managed, as well as the implementation of an expanded newborn screening, it was necessary that the NCNBSS treatment and referral network be strengthened by setting-up regional newborn screening follow-up clinics in the country to ensure the sustained management of identified positive cases.

Thus, in the 2012 meeting of the National Technical Working Group (NTWG) on Expanded Newborn Screening (ENBS), it was resolved that all patients diagnosed with a condition through NBS be referred to a health facility to ensure the quality and efficiency in care delivery. Ideally, the facility should be accessible and actively engaged in primary and subspecialty services within the health care system and across the community based agencies and services.

Establishment of the Newborn Screening Continuity Clinics (NBSCCs)

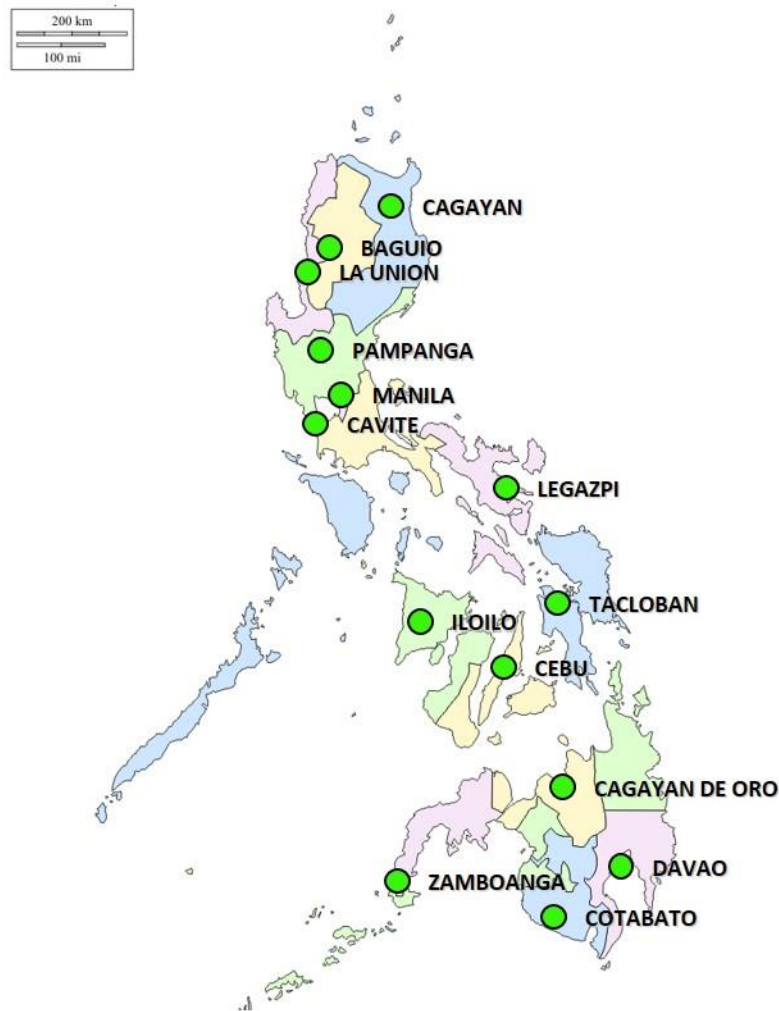
The Department of Health (DOH), defined by RA 9288 as the lead agency tasked to ensure that a network of facilities for referral and management of all positive cases is established, as well as, to develop referral centers and identify teams in strategic areas for referral and management of patients with any of the disorders, spearheaded the endeavor. The DOH developed a roadmap for the establishment and implementation of NBSCCs.

In January 2013, the DOH released Memorandum No. 2013-0035 to call for host facility nominees. The NBS team of DOH Regional Offices (DOH ROs) and the NTWG for NBS conducted a series of consultation meetings and regional visits with nominees in the last quarter of 2013 until the first quarter of 2014. As a result, the first batch of NBSCCs had their orientation workshop in April 2014 and the operations of the clinic commenced in May for 11 regions and additional 3 regions by December 2014. The selected tertiary hospitals to host the NBSCCs are the following:

- Region 1: Ilocos Training and Regional Medical Center
- CAR: Baguio General Hospital and Medical Center
- Region 2: Cagayan Valley Medical Center
- Region 3: Jose B. Lingad Memorial Regional Hospital
- Region 4A: Gen. Emilio Aguinaldo Memorial Hospital
- NCR: Philippine General Hospital
- Region 5: Bicol Regional Training and Teaching Hospital

- Region 6: West Visayas State University Medical Center
- Region 7: Vicente Sotto Memorial Medical Center
- Region 8: Eastern Visayas Regional Medical Center
- Region 10: Northern Mindanao Medical Center
- Region 11: Southern Philippines Medical Center
- Region 12: Cotabato Regional Medical Center

Figure 1. Location of NBSCCs in the map of the Philippines



In October 2014, the DOH issued Administrative Order 2014-0035, which sets the guidelines on the setting-up of NBSCCs. This ensured that NBSCCs shall be established, initially in every region to facilitate continuity of care of confirmed patients in its area of coverage; that Birth Defects Continuity Clinics shall be integrated in the NCNBSS; and that Telegenetics Referral System shall be utilized where subspecialists are not available in the hospital. The policy outlined the roles of major stakeholders which include the DOH as the lead agency in the implementation of NBSCCs; the Newborn Screening Centers (NSCs), in

coordination with respective DOH ROs, to recall, diagnose, and conduct initial treatment and management of patients; and NBSCCs to handle the long-term management of patients as well as its follow-up and timely monitoring.

At present, there are a total of 14 regional health facilities that host the NBSCCs. These clinics function as an ambulatory clinic equipped to facilitate continuity of care of confirmed patients in its area of coverage. Each of these clinics has a pediatrician and a nurse or genetic counselor working together to recall, follow-up, and ensure the early treatment and appropriate management of identified positive cases. Part of the team also includes a neonatologist and a pediatric hematologist. In the treatment and management of a condition, affected individuals and their families may regularly interact with continuity clinic team, with referrals to appropriate specialists as necessary (medical specialists, nutritionists, genetic counselors, social workers and pharmacists among others).

The success of a national program of NBS is measured not only by the number of babies diagnosed but, more so by the quality of life of these infants. The main objective of the long term follow-up component of the program, which is now embodied in the functions of the NBSCCs, is to ensure prompt, continuing and appropriate management of confirmed cases that will enable optimal adult physical, mental and social outcomes of these individuals.

1.2 Objectives

This manual is a working guide for long term follow-up of patients diagnosed with any of the disorders included in the NBS panel of disorders. Currently, the NBS panel of disorders include: disorders of amino acid metabolism, organic acid metabolism, disorders of fatty acid oxidation, carbohydrate metabolism, biotin metabolism, cystic fibrosis, hemoglobinopathies and endocrine disorders.

The specific objectives are:

- 1.2.1. To serve as a guide to the NBSCC personnel on the standard flow/ process of implementation of the Long Term Follow-up Program in the country;
- 1.2.2. To identify the different stakeholders and follow-up team members involved in the Long Term Follow-up Program;
- 1.2.3. To define the roles and responsibilities of different stakeholders and follow-up team members; and
- 1.2.4. To provide standardized report templates, follow-up protocols and mechanisms of the follow-up process necessary for data pooling and analysis.

1.3 Target Users

These guidelines are intended for the use of NBSCC personnel (i.e. Medical Specialist II /Follow-up Heads and Follow-up Nurses) and any authorized individuals involved with the NBS follow-up program.

2. ORGANIZATIONAL FRAMEWORK OF STAKEHOLDERS

Being a national public health program, the DOH shall be the lead agency to provide the overall directions and guidelines for implementation of NBSCCs at the regional level and all local government units. The National Institutes of Health (NIH), as a partner, serves as the technical arm.

As stipulated in the Section 13 of the Implementing Rules and Regulations of RA 9288, the DOH shall ensure that a network of facilities for referral and management of all positive cases is established, and in addition, develop referral centers and identify referral teams in strategic areas for referral and management of patients with any of the disorders.

2.1 National Level

The prime responsibility of the DOH and Newborn Screening Reference Center (NSRC) is to ensure that appropriate policies, standards, logistics and technical assistance are available to all implementing units. The structure and operations at the national level must be supportive and responsive to the ever-changing demands of service delivery at each peripheral unit.

NATIONAL INSTITUTES OF HEALTH

The NIH shall serve as the technical partner of DOH in ensuring the quality of service and sustainability of the NCNBSS. It shall perform this function through the NSRC.

NEWBORN SCREENING REFERENCE CENTER

The NSRC is the central facility based at the NIH that defines testing and follow-up protocols, maintains an external laboratory proficiency testing program, oversees the national testing database and case registries, assists in the training activities in all aspect of the program, oversees content of educational materials, and acts as Secretariat of the Advisory Committee on NBS. In terms of implementation of the NBSCCs, it shall have the following specific functions:

1. Oversee the implementation of activities of NBSCCs and birth defects continuity clinics;
2. Provide salary for the Medical Specialist and Nurse assigned in the NBSCCs;
3. Secure monthly, quarterly and yearly reports from participating units and ensure their timely dissemination to various program stakeholders;
4. Participate in consultation and evaluation activities initiated by the DOH in relation to the NSRC and the NBSCCs' and birth defects continuity clinics' performance and in improving of rules and regulations;
5. Assist in the training activities of the program; and
6. Oversee production and review the content of educational materials.

NEWBORN SCREENING CENTERS (NSCs)

Strategically located in different areas of the country, the NSCs are facilities equipped with newborn screening laboratory which provide all required laboratory tests and has a recall/follow-up system for newborns with heritable disorders. In terms of the different follow-up components of NBS patient care, the NSCs have the following specific functions:

Short Term Follow Up - Diagnosis and Initial Management

- a. Responsible for the monitoring and, in coordination with DOH-ROs, the tracking of newborns with out-of-range screening results to ensure repeat specimen collection, repeat screening and/or confirmatory testing from the NBS laboratories or confirmatory centers;
- b. Facilitate the confirmatory testing for newborns with out-of-range screening results and initiate medical management once with confirmed diagnosis;
- c. Give diagnosis, make proper referral and initiate management for all confirmed NBS patients.

Endorsement to Long-term Management

- a. Refer all newborns who are confirmed positive with heritable disorders to NBS Continuity Clinic long-term follow-up care.
- b. Provide roster of confirmed patients, including their protocols for management and list of follow-up laboratory procedures, to the NBS Continuity Clinic.

NIH – INSTITUTE OF HUMAN GENETICS (NIH-IHG)

The National Institutes of Health – Institute of Human Genetics, specifically the Clinical Genetics Unit, provides comprehensive clinical evaluation and laboratory diagnostic services to families or individuals with or at risk for in heritable disease, and provides support for the Telegenetics Referral System and Birth Defects Surveillance System in the country. In terms of implementation of the NBS Continuity Clinics, it shall have the following specific functions:

1. Establish an efficient system in the procurement and availability of medicines, medical food and other medical requisites needed in the management of patients confirmed with conditions detected through newborn screening;
2. Provide subspecialist (genetics, endocrinology) expertise and technical support for the operations of Telegenetics Referral System;
3. Strengthen the surveillance program for newborns with birth defects in the country; and
4. Establish systems for the referral of patients with birth defects from BDS health facility to NBS Continuity Clinics and Birth Defects Continuity Clinics.

2.2 Regional Level

DOH REGIONAL OFFICES

The main role of the DOH ROs is to act as facilitator and collaborator to enable participating units such as health centers and hospitals to fully implement the program at the local level.

It shall assist in the operations of the NBS Continuity Clinics through, but not limited to, recall of confirmed patients for referral to experts for management and follow-up care, and provide indigency support for confirmatory testing of patients with significantly elevated laboratory results and for treatment and long-term management of confirmed patients in the region.

HOST FACILITIES

The NBSCCs are based in a tertiary hospital identified by the DOH to be part of the NCNBSS. This tertiary hospital, referred to as the host facility, is equipped to facilitate continuity of care of confirmed patients in its area of coverage.

In terms of implementation of the NBS Continuity Clinics, the host facility shall have the following specific functions:

1. Set-up Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic;
2. The respective Chair of Department of Pediatrics to oversee the selection and hiring of personnel for the NBS Continuity Clinic in their facility;
3. Provide clinic space for patient consultation and work station for the follow-up nurse;
4. Assure the best possible outcome for individuals with disorders identified through newborn screening by providing long-term follow-up treatment and management to all confirmed positive patients in the their assigned region/s;
5. Attend to patients with birth defects for long-term care and management.
6. Integrate NBS continuity clinic to the current services of the host facility; and
7. Ensure the sustained operation of NBS Continuity Clinic and Birth Defects Continuity Clinic according to the Operational Guidelines set by the Department of Health and the Newborn Screening Reference Center for NBS Continuity Clinic.

NEWBORN SCREENING CONTINUITY CLINICS

The Follow-up Team is in-charge of the two clinics: the Newborn Screening Continuity Clinics and Birth Defects Continuity Clinics. The principal goal of long-term follow-up is to assure the best possible outcome for individuals with disorders identified through newborn screening and attend to patients with birth defects for long-term care and management. The following are the functions of the follow-up team of the continuity clinics:

Patient/Family-Centered Activities (Main)

1. Encourage family to maintain relationship with Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic to ensure continuous and effective care.
2. Monitor compliance with treatment (facilitate referral to appropriate sub-specialists, therapists, nutritionists).
3. Reinforce schedule of follow-up appointments and work-ups endorsed by the NSC.
4. Provide follow-up counselling and anticipatory guidance to the family.
5. Provide continuing education about the condition to the families and the health professionals.
6. Set up patient/family support groups in coordination with NSRC.
7. Coordinate with CHD in patient recall (lost to follow up cases).

Patient/Family-Centered Activities (Quality Assurance)

1. Prepare and submit reports of the two clinics to NSRC (initial). Participate in monthly patient case audit.
2. Evaluate the extent to which the birth defects or newborn screening long-term follow-up care is effective in improving the patient's health.

Program and Other Activities

1. Collaborate with other agency partners of the program: CHDs, NSCs, Clinical Genetics Units, NSRC, health facilities, health practitioners and Local Government Unit.
2. Attend to related workshops, meetings, seminars and conferences (funded by either CHD, NSC, NSRC).
3. Performs other related functions.

3. NEWBORN SCREENING CONTINUITY CLINIC FOLLOW-UP TEAM

The Continuity Clinics shall be manned by a part-time Pediatrician and a full-time Nurse or Genetic Counselor. They form the follow-up team which are in-charge of the two clinics: the Newborn Screening Continuity Clinics and Birth Defects Continuity Clinics.

3.1 Staffing and Personnel Qualifications

1. Pediatricians shall have a part-time Medical Specialist II item with a grade 23 salary scale while Nurses shall have a full-time Nurse II item with a grade 15 salary scale.
2. The clinic personnel are under the direct supervision of host-facilities, specifically the Department of Pediatrics. These personnel are considered part of the human resource complement of the facilities.
3. The full-time nurse will report from 8:00am-5:00pm or 7:00am-4:00pm (whichever is applicable), Mondays to Fridays.
4. The Pediatricians and Nurses shall have the following minimum qualifications:

3.1.1 Medical Specialist II

1. Registered Doctor of Medicine - Civil Service Commission (CSC) eligible
2. Diplomate of Philippine Pediatrics Society
3. Must be willing to travel within the assigned region
4. Must be recommended by the Chair of Department of Pediatrics

3.1.2 Nurse II

5. Registered Nurse – Civil Service Commission (CSC) eligible
6. At least two years experience in clinical nursing and/or community organizing
7. Must be willing to travel within the assigned region.
8. Must be recommended by the Chair of Department of Pediatrics.

3.2 Roles and Responsibilities of Medical Specialist II:

Patient Care

1. Act as the team leader who will work closely with the follow-up nurse to ensure that the recommended clinical and laboratory parameters are carried out and evaluated properly;
2. Responsible for referring patients to appropriate pediatric specialist (Metabolic, Endocrine, Hematology and Genetics) and nutritionist;
3. Ensure comprehensive and integrated medical care and continued case management of each patient under his/her care;
4. Provide genetic counseling to the families of patients affected by heritable disorders.

Administrative

5. Coordinate with different subspecialists in identifying appropriate medical care for each patient;
6. Check clinical materials for telegenetic consultations;
7. Validate the monthly, quarterly and yearly reports of the newborn screening continuity clinics;
8. Establish collaboration to other newborn screening continuity clinics, CHD, NSC and NSRC;
9. Participate in annual planning of activities related to newborn screening continuity clinic.

3.3 Roles and Responsibilities of Nurse II:

Patient Care

1. Responsible for following-up and tracking all confirmed NBS patients and coordinates the referral to appropriate pediatric specialist (Metabolic, Endocrine, Hematology and Genetics) and nutritionist;
2. Reinforce the planned schedule of follow-up appointments and work-ups for each patient as endorsed by the NSC;
3. Conduct patient advocacy activities for families with patients affected by heritable disorders.

Administrative

4. Prepare clinical materials for telegenetic consultations and ensure that telegenetics is working efficiently;
5. Coordinate closely with CHD in terms of locating patients;
6. Assist in the coordination with the appropriate agencies to facilitate patient medical assistance and/or indigency referral (local government, social service organizations, funding agencies, etc.);
7. Consolidate monthly, quarterly and yearly data of patients being followed-up;
8. Prepare monthly, quarterly and yearly reports of the newborn screening continuity clinic;
9. Participate in annual planning of activities related to newborn screening continuity clinic.

APPLICATION REQUIREMENTS for Nurse II

1. Curriculum vitae (with signature)
2. Photocopy of Diploma
3. Photocopy of Certification as Diplomate of the Philippine Pediatric Society
4. Photocopy of Transcript of Records
5. Photocopy of Certificates of Trainings
6. Photocopy of Certificate of Eligibility (Board Rating)
7. Photocopy of PRC License
8. Photocopy of Certificate of Employment
9. Photocopy of NBI Clearance (local employment)
10. Two (2) copies of passport-size pictures

All photocopied documents must be certified by the Head of Personnel Division or Chair of Department of Pediatrics of the respective Host Facility.

4. LONG TERM FOLLOW-UP AND MANAGEMENT OF PATIENTS

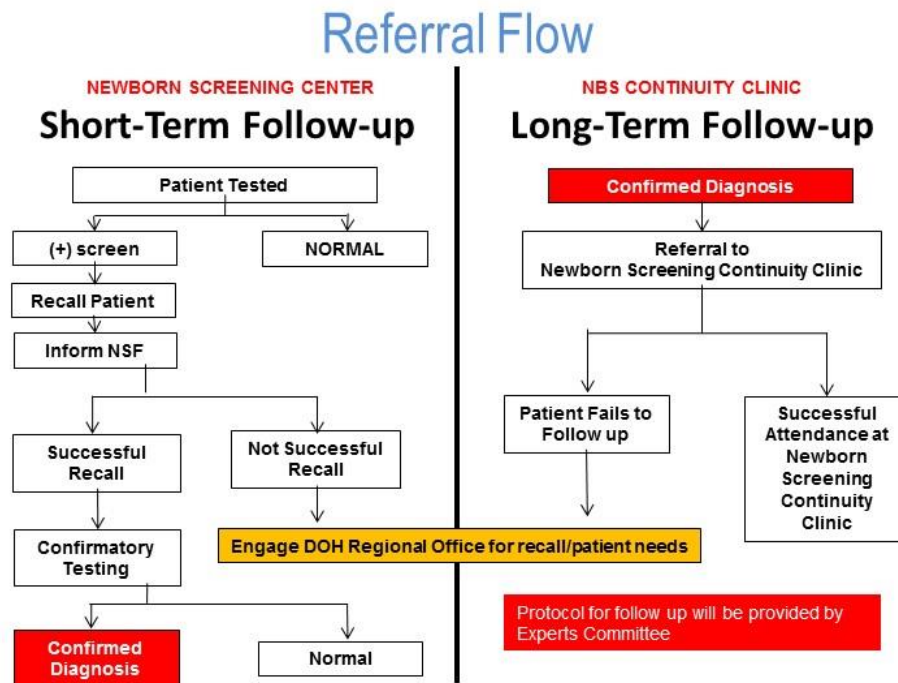
Long-term follow-up comprises the assurance and provision of quality, continuous management, condition-specific treatment, and age-appropriate preventive care throughout the lifespan of individuals identified

with a condition included in the newborn screening panel. Integral to assuring appropriate long-term follow-up are activities related to improving care delivery, including engagement of affected individuals and their families as effective partners in care management, continuous quality improvement through the continuity clinics, research into treatment options, and active surveillance and evaluation of data related to care and outcomes.

Long term follow-up of a patient begins upon the endorsement of the case from the short term follow-up team of the NSC. Specifically, this is after confirmation of a suspected disorder and initiation of treatment.

4.1 Referral Flow

Figure 2. Referral flow from Short Term Follow-up of NSCs to Long Term Follow-up of NBSCCs



1. NSCs transfer the roster of confirmed patients, including protocols for management and list of follow-up laboratory procedures, to the NBSCC using the prescribed Patient Endorsement Forms (please see attachments).

CONFIRMED patients refer to:

- a. those cases which have been diagnosed and closed by short term follow-up.
 - b. those cases whose treatment has already been initiated.
 - c. those who are not considered in medical crisis nor confined in a hospital.
2. Once patients have been endorsed under long-term follow-up care, the Newborn Screening Continuity Clinics are expected to:
 - a. Make every effort, in coordination with respective DOH RO, to contact and schedule patients referred from NSCs so that the necessary treatment and long-term follow-up care shall be given, as well as timely monitoring shall be undertaken.

- b. Facilitate referral of patients needing consults to available subspecialists in their facility or region. In cases wherein genetics evaluation and consultation is needed and this service is not available in their region, the continuity clinic shall utilize the Telegenetics Referral System.

4.2 Panel of disorders (move to Appendix)

The NCNBSS expanded the screening panel of disorders in the latter part of 2014 from six (6) to more than twenty (20) disorders falling under various types of conditions namely: disorders of amino acid metabolism, organic acid metabolism, disorders of fatty acid oxidation, carbohydrate metabolism, biotin metabolism, as well as cystic fibrosis, hemoglobinopathies and endocrine disorders.

Table 1. Disorders included in the NBS 6-test panel and the metabolites tested.

Disorder		Metabolite Tested
Congenital Hypothyroidism	CH	Thyroid Stimulating Hormone (TSH)
Congenital Adrenal Hyperplasia	CAH	17-hydroxy-progesterone (17 α -OHP)
Maple Syrup Urine Disease	MSUD	Leucine
Phenylketonuria	PKU	Phenylalanine
Galactosemia	GAL	Total Galactose
Glucose-6-Phosphate Dehydrogenase Deficiency	G6PD	G6PD enzyme activity
	Def	

Table 2. Disorders included in the Expanded NBS panel and the metabolites tested.

Disorder Group	Disorder		Metabolite Tested
Endocrine Disorder	Congenital Hypothyroidism	CH	Thyroid Stimulating Hormone (TSH)
	Congenital Adrenal Hyperplasia	CAH	17-hydroxy-progesterone (17 α -OHP)
Amino Acid Disorder	Homocystinuria	HCY	Methionine
	Hypermethioninemia/Methionine Adenosine Transferase Deficiency	MAT	Methionine
	Maple Syrup Urine Disease	MSUD	Leucine
	Phenylketonuria	PKU	Phenylalanine
	Tyrosinemia Type I, II		Tyrosine
Fatty Acid Disorder	Carnitine Palmiolytransferase I Deficiency	CPT1	Carnitine Palmiolytransferase I (CPT1)
	Carnitine Palmiolytransferase II Deficiency	CPT2	Hexadecanoylcarnitine
	Carnitine Uptake Deficiency	CUD	Free carnitine
	Glutaric Acidemia Type II	GA II	Butyrylcarnitine

Disorder Group	Disorder		Metabolite Tested
	Long Chain Hydroxyacyl-CoA Dehydrogenase Deficiency	LCHAD	Hydroxyhexadecanoylcarnitine (AC16OH)
	Medium Chain-Acyl-CoA Dehydrogenase Deficiency	MCAD	Octanoylcarnitine
	Short Chain Acyl-CoA Dehydrogenase Deficiency	SCAD	Butyrylcarnitine
	Very Long Chain-Acyl-CoA Dehydrogenase Deficiency	VLCAD	Tetradecanoylcarnitine
Organic Acid	3-Methylcrotonyl CoA Carboxylase Deficiency	3MCC	Hydroxyisovalerylcarnitine (AC5-OH)
	Glutaric Acidemia Type I	GA I	Glutaryl carnitine
	Isovaleric Acidemia	IVA	Isovalerylcarnitine
	Methylmalonic Acidemia	MMA	Propionylcarnitine
	Multiple Carboxylase Deficiency	MCD	Hydroxyisovalerylcarnitine
	Propionic Acidemia	PA	Propionylcarnitine
Urea Cycle Defect	Citrullinemia	CIT	Citrulline
Cystic Fibrosis	Cystic Fibrosis	CF	Immunoreactive Trypsine (IRT)
Hemoglobinopathies	Alpha Thalassemia	HgB	Hemoglobin
	Beta Thalassemia		
	Hemoglobin C		
	Hemoglobin D		
	Hemoglobin E		
	Sickle Cell Disease		
Biotinidase Deficiency	Biotinidase Deficiency	BTND	Biotinidase
Others	Galactosemia	GAL	Total Galactose
	Glucose-6-Phosphate Dehydrogenase Deficiency	G6PD Def	G6PD enzyme activity

4.3 Specific Guidelines for each disorders

The recommended management of each disorder is outlined below. These include parameters that should be covered by periodic clinical evaluation (by the attending physician and medical specialists), biochemical testing and ancillary procedures, timing of formal neuro developmental assessment, and schedule of expected feedback to the NSC.

These are suggested guidelines and are not intended to replace sound clinical judgment of health care providers.

4.3.1 Congenital Hypothyroidism

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline (within one month of age) <ul style="list-style-type: none"> • Weight • Length • Head Circumference • Anterior fontanel 	Endocrinologist: Co-management from onset	Baseline <ul style="list-style-type: none"> • T4 or FT4, TSH • FT3** • Thyroid gland US or thyroid Scan (Tc99) • Bone age** 	<ul style="list-style-type: none"> • 6 months • 12 months • 18 months • 24 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 6 months • 12 months • Yearly until 5 years ❖ Yearly birthday card from NSC (with update form to be filled up by parents)
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts especially Head Circumference • Monthly developmental screening*** 	Endocrinologist: Every 3 months for titration of L-thyroxine	T4 or FT4, & TSH* <ul style="list-style-type: none"> • 2 weeks • 1 month (until within normal range) • Every 3-4 months • Bone age at 12 months • Other labs as recommended by specialist 		

*At DOH accredited laboratory

**Optional

***Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

4.3.2 Congenital Adrenal Hyperplasia

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline within one month of age <ul style="list-style-type: none"> • Weight • Length • Head Circumference • Include phallus length, signs of early puberty, rapid physical growth 	Endocrinologist: Co-management from onset	Baseline <ul style="list-style-type: none"> • 17-OH • RBS, Na, K • Cortisol • PRA** • Chromosomes if with ambiguous genitalia 	<ul style="list-style-type: none"> • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 6 months • 12 months • Yearly until 5 years ❖ Yearly birthday card from NSC (with update form to be filled up by parents)
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly developmental screening* Check hyper-pigmentation of areola, armpits, inguinal area, labio-scrotal folds	Endocrinologist: Every 3 months for titration of medications	Once 17OHP is within normal range, every 3 months; (minimum monitoring is 17OHP, Na, K) Optional cortisol and PRA Other labs as per medical specialist		
Females \geq 8 years Males \geq 9 years <ul style="list-style-type: none"> • Monitor pubertal development • Tanner staging 	Appropriate clinical and lab evaluation Gender identity issues and concerns can be addressed/ referral to appropriate specialist if needed	Bone age if height is taller or shorter than expected norm		

* Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

** Optional

4.3.3 Galactosemia (Classical)

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline within one month of age <ul style="list-style-type: none"> • Weight • Length • Head Circumference • Liver palpation • Eye (lens) opacity check Ensure baseline referral to Ophthalmologist	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Monthly total gal (dried blood spot) • Beyond 1 year, every 3 months • GALT activity at baseline and 1 month 	<ul style="list-style-type: none"> • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3 months • 6 months • 12 months • Yearly ❖ Yearly birthday card from NSC
Monthly follow-up (or at least every 3 months if specialist is doing actual clinic evaluation) <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* 	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • At least monthly in first year • Every 3-6 months thereafter Ophthalmologist <ul style="list-style-type: none"> • At diagnosis • 6 months • 12 months • Yearly thereafter 	Liver US <ul style="list-style-type: none"> • 1 year • Earlier if palpable liver • ALT/AST if with jaundice or palpable liver 		
Monitor pubertal development <ul style="list-style-type: none"> • Do historical review of menstrual irregularities; refer accordingly 	Full evaluation /recommendations as needed	In females (at 12 years) if no pubertal signs/symptoms (risk of ovarian failure) <ul style="list-style-type: none"> • FSH • Estradiol • Pelvic ultrasound Other labs as per MD evaluation		

* Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

4.3.4 Galactosemia (Non-Classical)

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline within one month of age <ul style="list-style-type: none"> • Weight • Length • Head Circumference • Liver palpation • Eye (lens) opacity check Ensure baseline referral to Ophthalmologist	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Monthly total gal (dried blood spot) • Beyond 1 year, every 3 months • GALT activity at baseline and 1 month 	<ul style="list-style-type: none"> • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3 months • 6 months • 12 months • Yearly ❖ Yearly birthday card from NSC
Monthly follow-up (or at least every 3 months if specialist is doing actual clinic evaluation) <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* 	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • At least every 3 months in the first year • Every 3-6 months thereafter Ophthalmologist Eye evaluation <ul style="list-style-type: none"> • At diagnosis • 6 months • 12 months • Yearly thereafter 			
	Full evaluation /recommendations as needed			

* Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

4.3.5 Phenylketonuria (Classical and Mild PKU)

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline then monthly <ul style="list-style-type: none"> • Weight • Length • Head Circumference 	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Phe level • BH4 load • Urine pterins • DHPR 	<ul style="list-style-type: none"> • Baseline • 3 months • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3 months • 6 months • 12 months • Yearly
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* Watch out for: <ul style="list-style-type: none"> • Seizures • Behavioral problems • Developmental delays Facilitate prompt referral to a specialist	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • At least monthly in first year • Every 3-4 months thereafter Nutrition consult for low protein food guidance <ul style="list-style-type: none"> • Monthly for the first year • Every 3-6 months Thereafter Co-morbidities should be co-managed with specialists: Neurology, Rehabilitation Medicine	Phe level <ul style="list-style-type: none"> • Monthly • After 1 year, every 3 months; may be more frequent depending on specialist's evaluation 		<ul style="list-style-type: none"> ❖ Yearly birthday card from NSC

* Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

4.3.6 Mild Hyperphenylalaninemia

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline then monthly <ul style="list-style-type: none"> • Weight • Length • Head Circumference 	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Phe level • Urine pterins • DHPR 	<ul style="list-style-type: none"> • Baseline • 3 months • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3 months • 6 months • 12 months • Yearly
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* Watch out for: <ul style="list-style-type: none"> • Seizures • Behavioral problems • Developmental delays Facilitate prompt referral to a specialist Assumes total medical care prior to starting school (Age 4 years) Refer back to Metabolic specialist/geneticist <ul style="list-style-type: none"> • If child starts a high-protein diet • Pubertal Girls: education on pregnancy risks 	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • Monthly in the first year • Every 3-4 months until 4 years old • Provide temporary discharge letter and advice to AP on general care Nutritionist: <ul style="list-style-type: none"> • Review of diet • Nutritional assessment If with 3 or more levels of Phe >350 <ul style="list-style-type: none"> • Start phenyl-free formula and/or protein restriction Co-morbidities should be co-managed with specialists: Neurology, Rehabilitation Medicine	Phe level <ul style="list-style-type: none"> • Monthly • After 18 months, every 3 months; may be more frequent depending on specialist's evaluation • Annual review anytime at 3 to 4 years of age 		<ul style="list-style-type: none"> ❖ Yearly birthday card from NSC

* Refer to the Basic Information for Physicians (www.newbornscreening.ph)

4.3.7 Tetrahydropterin (BH4) Deficiency

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline then monthly <ul style="list-style-type: none"> • Weight • Length • Head Circumference 	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Phe level • BH4 load • Urine pterins • DHPR 	<ul style="list-style-type: none"> • Baseline • 3 months • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3 months • 6 months • 12 months • Yearly
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* Watch out for: <ul style="list-style-type: none"> • Seizures/posturing • Abnormal tone and movements • Developmental delays Facilitate prompt referral to a specialist	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • Monthly in first year • Every 3-4 months thereafter Co-morbidities should be co-managed with specialists: Neurology, Rehabilitation Medicine	Phe level <ul style="list-style-type: none"> • Monthly for the first 3 months then every 3 months thereafter • May be more frequent depending on specialist's evaluation Plasma Prolactin <ul style="list-style-type: none"> • Prior to start of therapy • Every 3 months; may be more frequent depending on specialist's evaluation 		<ul style="list-style-type: none"> ❖ Yearly birthday card from NSC

* Refer to the Basic Information for Physicians (www.newbornscreening.ph)

4.3.8 Maple Syrup Urine Disease

Clinical evaluation		Laboratory evaluation	Neuro-developmental assessment	Feedback to NSC
Attending Physician/ Pediatrician	Specialist			
Baseline then monthly <ul style="list-style-type: none"> • Weight • Length • Head Circumference 	Metabolic specialist/geneticist: Co-management from onset Genetic counseling	<ul style="list-style-type: none"> • Guthrie card (leu levels) • Urine organic acids** • Plasma amino acids** • Nutritional labs (CBC, TPAG, Na, Ca, K, Cl, SGPT, SGOT, BUN, crea) 	<ul style="list-style-type: none"> • Baseline • 3 months • 6 months • 12 months • Yearly 	<ul style="list-style-type: none"> • Baseline or 1 month • 3months • 6 months • 12 months • Yearly ❖ Yearly birthday card from NSC
Monthly follow-up <ul style="list-style-type: none"> • Plot anthropometrics on WHO growth charts • Monthly milestones or developmental screening* • Parental education on dietary regimen • Supplement knowledge on sick regimen • Precautions when ill • Preventive pediatrics Watch out for: <ul style="list-style-type: none"> • Seizures • Behavioral problems • Developmental delays • Nutritional status (signs of vitamin and mineral deficiencies) Facilitate prompt referral to a specialist	Metabolic specialist/geneticist: <ul style="list-style-type: none"> • At least monthly in first year • Every 3-4 months thereafter Nutrition consult for low protein food guidance <ul style="list-style-type: none"> • Monthly for the first year • Every 3-6 months thereafter • Emphasize sick regimen Co-morbidities should be co-managed with specialists: Neurology, Rehabilitation Medicine, Developmental Pedia	Leu level <ul style="list-style-type: none"> • Monthly • After 1 year, every 3 months; may be more frequent depending on specialists evaluation 		

* Refer to the Basic Information for Physicians & Fact Sheets for Doctors (www.newbornscreening.ph)

** As requested by metabolic specialist or if warranted as per algorithm of eNBS program

4.4 Checklists for first year of life



Congenital Hypothyroidism (Checklist for first year of life)	Base line	2 weeks	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation							
Attending Physician <ul style="list-style-type: none"> • Weight • Length • Head Circumference • Anterior fontanel • WHO Growth charts • Developmental screening 	X		X	X	X	X	X
Note: AP to do monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings							
Specialist <ul style="list-style-type: none"> • Clinical assessment* • Counseling • Management /Treatment • L-thyroxine titration 	X		X	X	X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen at least 4x in the first year							
Laboratory Evaluation							
<ul style="list-style-type: none"> • FT4 or T4, TSH • Thyroid gland US or Thyroid Scan (Tc99) • Bone age x-ray 	X optional	X	X	X	X		X
Neurodevelopmental Assessment					X		X
Feedback to NSC	X				X		X
Information Update (Birthday Card)							X

Congenital Adrenal Hyperplasia (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• Phallus length	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Check hyper-pigmentation of areola, armpits, inguinal area, labio-scrotal folds	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings or hospitalizations for “crisis-like” events.						
Specialist						
• Clinical assessment*	X		X	X	X	X
• Counseling						
• Management /Treatment						
• Titration of medications						
*Ideally, if Specialist within geographic reach, patient must be seen at least 4x in the first year						
Laboratory Evaluation						
• 17-OHP	X	X	X	X	X	X
• Na, K	X	X	X	X	X	X
• RBS	X					
• Cortisol	X					
• PRA (monitoring levels c/o specialist) optional	X					
• Chromosomes if with ambiguous genitalia (plus other diagnostics as per specialist assessment)	X					
Neurodevelopmental Assessment				X		X
Feedback to NSC	X			X		X
Information Update (Birthday Card)						X

Galactosemia (Classical) (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Liver Palpation	X	X	X	X	X	X
• Cataract screen by AP with each clinic visit, refer accordingly	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
• Genetic Counseling	X					
• Management /Treatment*	X	X	X	X	X	X
• Eye evaluation	X			X		X
• Nutrition counseling and diet review	X			X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen at least 4x in the first year						
Laboratory Evaluation						
• GALT enzyme	X	X				
• Total Gal (monthly)	X	X	X	X	X	X
• Liver ultrasound						X
• ALT /AST if with jaundice or palpable liver						
Neurodevelopmental Assessment	X			X		X
Feedback to NSC	X			X		X
Information Update (Birthday Card)						X

Galactosemia (Non-Classical) (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Liver Palpation	X	X	X	X	X	X
• Cataract screen by AP with each clinic visit, refer accordingly	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
• Genetic Counseling	X					
• Management /Treatment*	X	X	X	X	X	X
• Eye evaluation	X			X		X
• Nutrition counseling and diet review	X			X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen at least 4x in the first year						
Laboratory Evaluation						
• GALT enzyme	X	X				
• Total Gal (monthly)	X	X	X	X	X	X
Neurodevelopmental Assessment	X			X		X
Feedback to NSC	X			X		X
Information Update (Birthday Card)						X

Phenylketonuria (Classical and Mild) (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Check for seizures/posturing/behavioral problems	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
• Genetic Counseling	X					
• Clinical assessment* and Management /Treatment	X	X	X	X	X	X
• Nutrition counseling and diet review (monthly)	X	X	X	X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen monthly in the first year						
Laboratory Evaluation						
• Phe level (monthly)	X	X	X	X	X	X
• BH4 load	X					
• Urine pterin	X					
• DHPR	X					
• Other labs as per specialist						
Neurodevelopmental Assessment	X		X	X		X
Feedback to NSC	X		X	X		X
Information Update (Birthday Card)						X

Mild Hyperphenylalaninemia (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Check for seizures/posturing/behavioral problems	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
• Genetic Counseling	X					
• Clinical assessment* and Management /Treatment	X	X	X	X	X	X
• Nutrition counseling and diet review (monthly)	X	X	X	X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen monthly in the first year						
Laboratory Evaluation						
• Phe level (monthly)	X	X	X	X	X	X
• Urine pterin	X					
• DHPR	X					
• Other labs as per specialist						
Neurodevelopmental Assessment	X		X	X		X
Feedback to NSC	X		X	X		X
Information Update (Birthday Card)						X

Biopterin (BH4) Deficiency (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
• Weight	X	X	X	X	X	X
• Length	X	X	X	X	X	X
• Head Circumference	X	X	X	X	X	X
• WHO Growth charts	X	X	X	X	X	X
• Developmental screening	X	X	X	X	X	X
• Check for seizures/posturing/abnormal tone and movements	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
• Genetic Counseling	X					
• Clinical assessment* and Management /Treatment	X	X	X	X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen monthly in the first year						
Laboratory Evaluation						
• Phe level (monthly)	X	X	X	X	X	X
• BH4 load	X					
• Urine pterin	X					
• DHPR	X					
• Prolactin	X		X	X	X	X
• Other labs as per specialist						
Neurodevelopmental Assessment	X		X	X		X
Feedback to NSC	X		X	X		X
Information Update (Birthday Card)						X

Maple Syrup Urine Disease (Checklist for first year of life)	Base line	1 month	3 months	6 months	9 months	12 months
Clinical Evaluation						
Attending Physician						
<ul style="list-style-type: none"> • Weight • Length • Head Circumference • WHO Growth charts • Developmental screening • Check out for seizures/behavioral problems/nutritional status 	X	X	X	X	X	X
	X	X	X	X	X	X
	X	X	X	X	X	X
	X	X	X	X	X	X
	X	X	X	X	X	X
	X	X	X	X	X	X
NOTE: Monthly assessment with Well Baby visits; must coordinate closely with Specialist for any unusual findings.						
Specialist						
<ul style="list-style-type: none"> • Genetic Counseling • Clinical assessment* and Management /Treatment • Nutrition counseling and diet review (monthly) 	X	X	X	X	X	X
	X	X	X	X	X	X
*Ideally, if Specialist within geographic reach, patient must be seen monthly in the first year						
Laboratory Evaluation						
<ul style="list-style-type: none"> • Leucine level (monthly) • Urine organic acids** • Plasma amino acids** • Nutritional labs (CBC, TPAG, Na, Ca, K, Cl, SGPT, SGOT, BUN, crea) done yearly 	X	X	X	X	X	X
	X					X
*As requested by metabolic specialist or if warranted as per algorithm of eNBS program						
Neurodevelopmental Assessment	X			X		X
Feedback to NSC	X			X		X
Information Update (Birthday Card)						X

5. COLLABORATION WITH STAKEHOLDERS

5.1 Parents and family

5.1.2 Guide Script for Parents and family

Overcoming the initial hurdles of establishing trust with the patient's family

When calling a patient's parent or family for the first time, the initial few minutes of conversation may be the most difficult part of a situation wherein our objective is to gain the family's cooperation in the long term management and continuity of care of their child. In the nurse's initial attempt to build trust with the patient's family, it is encouraged that the following fundamental principles in dealing with people be applied: (Note: based on principles by Dale Carnegie)

1. Become genuinely interested in other people.
2. Smile. (the person on the other side of the phone line can tell if you are smiling or can feel your smile).
3. Remember that a person's name is, to that person, the sweetest and most important sound in any language.
4. Be a good listener. Encourage others to talk about themselves.
5. Talk in terms of the other person's interest.
6. Make the other person feel important – and do it sincerely.

The continuity clinic nurses shall bear these principles in mind when following the sample guide script below:

Nurse: Good morning po. Pwede po bang makausap ang mga magulang ni baby (state first name and last name of patient)?

Family: Tungkol po saan?

Nurse: Mam /Sir, ako po si Nurse (state first name and family name), ng Newborn Screening Continuity Clinic. Nais po sana namin magabayan ang mga magulang sa pangangalaga kay baby (state first name of patient). Kayo po ba ang magulang ni baby (state first name of patient)?

Family: Hindi e.

Nurse: Maari po bang makausap ang mga magulang ni baby (state first name of patient)?

Family: Wala siya dito e.

Nurse: Ah Mam /sir, mga anong oras po kami maaaring tumawag para makausap ang magulang? Mayroon po bang tumatayong guardian yung bata?

Family: Opo, ako po ang guardian / ako po ang magulang.

Nurse: Ma'm /Sir (mention the first name of the mother based on endorsement form), good morning po. (Smile). Ako po si Nurse (state first name) ng Newborn Screening Continuity Clinic dito po sa (state name of host facility).

Nurse: Ikinagalak ko po kayong makilala (smile). Nais po namin makamusta ang kalagayan ni baby (state first name of patient). Kumusta na po si baby ngayon?

Family: Mabuti naman.

Nurse: Ma'm (state first name of parent) (smile), ang amin pong clinic ay mahalagang bahagi ng National Newborn Screening Program. Ang layunin po ng programa ay siguraduhing ang lahat ng mga batang nagpositibo sa Newborn Screening ay lumaki na may magandang kalidad ng pamumuhay. Kung kaya't ang layunin po ng aming clinic ay masubaybayan ang pangangalaga kay baby (state first name of patient).

Nurse: Nais lang po namin na magtulungan tayo upang siguraduhin na ang inyo pong anak ay patuloy na magpakunsulta sa doctor/espesyalista, patuloy na uminom ng mga kinakailangang gamot o lunas, at patuloy na maipalaboratoryo sa takdang schedule.

Nurse: Mam (state first name of parent), sino pong doktor ang tumitingin kay baby (state first name of patient)?

Response no. 1: (With an attending physician)

Family: Si Dr. _____ po.

Nurse: Ah si Dr. (state complete name of specialist) po. (Smile - Kumpirmahin ang buong pangalan ng doctor). Mabuti naman po at mayroong attending doctor /specialist si baby. Kailan po kayo huling nagpakonsulta kay Dr. (state surname of doctor)?

Family: Noon pong March 2, 2015.

(Nurse shall reinforce partnership with private physicians and educate patient's family about the importance of this partnership)

Nurse: Mam (state first name of patient), si Dr. (state surname of doctor) po at ang aming clinic ay bahagi ng kabuuang programa ng newborn screening. Napakaimportante po na matignan si baby ni (state surname of doctor) sa takdang araw ng pagkonsulta. Ako po ay magsisilbing tagapagpaalala sa inyo na kailangan pong magpakunsulta si baby (state surname of doctor) sa takdang araw.

Response no. 2:

Family: Wala syang doctor na regular na tumitingin.

Nurse: Maaari po bang malaman ang dahilan?

Nurse: Ma'm (state first name of parent), layunin po ng aming clinic na tumugon sa mga gaya ninyo na walang regular na doctor para kay baby. Bukas po ang aming clinic dito sa (state name of host facility) tuwing (banggitin ang araw ng clinic consultation) mula (ganitong oras) hanggang (ganitong oras). Maari niyo pong dalhin si baby dito para makapagpakonsulta sa aming doctor at Head ng aming Continuity Clinic na si (state complete name of doctor /specialist) na isa pong pediatrician.

Nurse: Ma'm (state first name of parent) (Smile), kailan po namin kayo maaasahang bumisita sa aming clinic? Maaari ko po ba kayo maischedule this week?

(Response 1) Family: (does not agree to a schedule)

Nurse: Ma'm Linda, tatawag po akong muli para maischedule ang inyong anak sa aming clinic. Tayo po ay magtutulungan upang masubaybayan ang paglaki ng inyong anak. Maraming salamat po. I look forward po sa susunod nating pag-uusap.

(Response 2) Family: (agrees to a schedule)

Nurse: Mam (state first name of patient) aasahan ko pa na kayo ay makararating sa ganitong petsa. Tayo po ay magtutulungan upang masubaybayan ang paglaki ng inyong anak.

Nurse shall proceed to ask a series of questions to confirm contact details based on the NSC endorsement form)

Nurse: Nais ko lang po makumpirma ang ilang detalye tungkol kay baby Benjie.

Nurse: Mam (state first name of patient), bukod po sa number na ito na tinatawagan ko po ngayon , may iba pa po ba kayong contact number para po may matatawagan ako kung sakaling di ko po kayo macontact sa number na ito?

Nurse: Mam (state first name of patient), bukod po sa inyo, sino pa po ang nag-aalaga kay baby? (kung meron) Maari ko po bang makuha ang kumpleto niya pong pangalan? Pati po yung number niya po?

Nurse: Maraming maraming salamat po Mam (state first name of patient). Aasahan ko po kayo sa susunod nating pag-uusap /o sa pagkonsulta ninyo po sa aming clinic.

- End -

5.1.3 Refusal form

The rights of parents or family to remain private shall be respected, including those who refuse to be followed up by the NBSCCs and prefer to take care of their child through their own health provider. However, those identified without any health provider for the child and still refuse to participate or cooperate in their child's monitoring by the NBSCC, and thereby endangering the welfare of the child, shall be made to sign a refusal form for documentation and legal purposes using the standard form:

Logo of
Continuity
Clinic

NEWBORN SCREENING CONTINUITY CLINIC

Host facility
Address line 1
Address line 2
Email Add:
Contact number:

Logo of
Host facility

Petsa: _____

Ako si _____, nanay/tatay ng batang
si _____, residente ng _____
na dalhin ang aking anak sa doktor para sa follow up check-up sa kadahilanang _____.

Hindi lingid sa aking kaalaman na ang aking anak ay may kondisyong _____ na nakumpirma sa tulong ng Newborn Screening at nangangailangan ng konsulta sa espesyalista at gamutan.

Ano mang panganib na maaring idulot ng hindi ko pagsang-ayon ay lubos na ipinaliwang sa akin at ang aking pagsalungat ay maaring maging hadlang sa paglaki ng maayos at magdulot ng panganib sa buhay ng aking anak.

Inilalahad ko na lubos kong naiitindihan na ang pasilidad na ito at ang Newborn Screening Continuity Clinic ng **(name of facility)** sampu ng kanyang doctor at nars ay walang pananagutang legal dahil ang pagtanggap ito ay sarili kong desisyon.

(lagda sa taas ng pangalan)
NANAY/TATAY

MGA SAKSI:

(lagda sa taas ng pangalan)
Katungkulan sa Komunidad: _____

(lagda sa taas ng pangalan)
Katungkulan sa Komunidad: _____

5.2 Primary and Specialty Care Physicians

5.2.1 Guide Script with Doctors

Communicating through texting

Timing is everything in communicating with doctors, most especially specialists who lead hectic lives.

When calling specialists on their mobile phones, the chances of catching him or her in an appropriate moment (i.e. devoid of distractions like patient concerns) is very slim. Hence, the best alternative course of action is to first *text* the specialist.

Texting is a safer and more polite way of communicating (if done correctly) with doctors, given their busy schedules. It has many advantages, like the message is better absorbed when it is read than when it is spoken, recipient of text message can go back to the message at his or her own convenient time, and there is less pressure and sense of urgency compared to a call.

However, as in any form of communication, there are also ethics to be observed in texting. Here are some general guidelines in texting doctors:

1. As much as possible, ***do not abbreviate***, and that is including “Gudam” in place of “Good morning.” Exemptions could be “Dra.” in place of “doktora”
2. ***Introduce yourself*** appropriately.
3. Use “po” and “opo” appropriately without overdoing it.
4. Use ***proper sentence form and construction***, including which words to begin with capital letters, use of period and comma, proper spelling of words (***strictly no street slang shortcuts***).
5. ***Timing of texts*** varies and depends on the urgency of the situation. Generally, we are assuming that physicians would be most receptive to receiving text messages between 8am to 9am – when their minds are fresh and are less haggard compared to other times of the day. Bear in mind though that this applies only during working days of Mondays to Fridays, and never during weekends.

Example of a Text – may apply to an emergency situation or an ordinary situation

“Good morning po Dra. This is Jackie Licup po of the Newborn Screening Continuity Clinic in JB Lingad Memorial Hospital. On behalf po of Dr. Lalaine Untalan, our follow-up head, we would like to coordinate po an MSUD patient who is under your private care. Said patient po was reported to us by Newborn Screening Center Central Luzon as needing immediate (note: omit immediate if not an emergency) medical attention. We kindly seek your permission po in coordinating the care and management of this patient. Can we call you po at your convenient time”

If doctor does not reply to text messages after a few days (depending on urgency of case), inform and consult your respective follow-up head, who will decide on your next steps.

5.2.2 Referral to Physicians through SBAR Communication

SBAR Strategy – Situation, Background, Assessment, Recommendation

Newborn screening encompasses a comprehensive system of laboratory testing, confirmatory testing and diagnosis, to medical management and care coordination for patients with confirmed disorders. Along a patient's journey, there are multiple referrals from different disciplines with varying hierarchies – from nurses to resident physicians to pediatricians to consultants and specialists that require efficient coordination among each team or players. Across disciplines and individuals, there are differences in communication styles and oftentimes hesitations or difficulties in communicating up the level of hierarchy. Both Short term and Long term follow-up involve periodic assessments of medical outcomes that require coordination with specialists. For instance, acute situations require immediate attention of specialists, and sometimes, especially when stress levels are high, a disorganized referral may result to a delay or inaction in issuing advice that may be crucial for the patient. Thus, there is a strong need for a standardized protocol of communication that would facilitate understanding across disciplines, prevent breakdown in communication and lead to improved health outcomes.

One such tool that has increasingly gained acceptance in the healthcare setting as a solution to communication problems is the SBAR protocol – a tool that structures communication around four components, namely Situation, Background, Assessment, and Recommendation. The SBAR originated from the US Navy before it was adopted in the healthcare setting. Today, SBAR has grown to be a widely recommended tool in healthcare communication. For instance, the NHS National Health Service of UK – the largest, oldest and arguably the most admired healthcare system in the world, is a strong advocate for SBAR. Below is an excerpt from the NHS website that encapsulates the importance of SBAR communication:

Why use SBAR?

Inadequate communication is recognized as a being the most common root cause of serious errors – both clinically and organizationally. There are some fundamental barriers to communication across different disciplines and levels of staff. These include hierarchy, gender, ethnic background and differences in communication styles between disciplines and individuals. Communication is more effective in teams where there are standard structures of communication in place.

- SBAR reduces the incidence of missed communications that occur through the use of assumptions, hints, vagueness or reticence they may be caused by the authority gradient.
- It helps to prevent breakdowns in verbal and written communication, by creating a shared mental model around all patient handovers and situations requiring escalation, or critical exchange of information.
- SBAR is an effective mechanism to level the traditional hierarchy between doctors and other care givers by building a common language platform for communicating critical events, thereby reducing barriers to communication between healthcare professionals.
- As a memory prompt, it is easy to remember and encourages prior preparation for communication.
- Used during handover, SBAR can reduce the time spent on this activity thereby releasing time for clinical care.

How can SBAR help me?

SBAR is an easy to remember mechanism that you can use to frame conversations, especially critical ones, requiring a clinician's immediate attention and action. It enables you to clarify what information should be communicated between members of the team, and how. It can also help you to develop teamwork and foster a culture of patient safety.

The tool consists of standardised prompt questions within four sections, to ensure that staff are sharing concise and focused information. It allows staff to communicate assertively and effectively, reducing the need for repetition.

Using SBAR prompts staff to formulate information with the right level of detail. The tool helps staff anticipate the information needed by colleagues and encourages assessment skills.

Source:

http://www.institute.nhs.uk/safer_care/safer_care/Situation_Background_Assessment_Recommendation.html

In summary, the four components of SBAR communication between a SENDER and a RECIPIENT are:

1. Situation – includes communicating the sender's and patient's name, and the current status or problem of the patient.
2. Background – provides information about the patient's diagnosis, pertinent medical history, current treatment, or change in condition.
3. Assessment – includes current clinical impressions and critical assessment of the situation by the sender.
4. Recommendation – provides information about what action the sender suggests be taken, and specifies precisely when the next communication will take place.

In addition, SBAR dictates that the sender compiles the patient's chart, list of medications, laboratory test results, and have them ready before engaging in conversation with the recipient.

Sample phone conversation of a nurse referring a patient to a specialist

SITUATION	
<ul style="list-style-type: none">• Identify yourself, the site/unit you are calling from	Good morning po dra. This is (state first name of nurse) po from the (state name of host facility) Continuity Clinic.
<ul style="list-style-type: none">• Identify the patient by name and the reason for your report• Describe your concern	This is regarding our patient CGT, from (state province), diagnosed with CH. Due to financial difficulties, patient was not able to seek consultation for more than a year. Patient recently resurfaced in the clinic and is now 2 years old and 3 months.

<ul style="list-style-type: none"> • Firstly, describe the specific situation about which you are calling, including the patient's name, consultant, patient location, resuscitation status, and vital signs. 	<p>Upon our physical examination, patient's growth and development is now delayed for her age – weight of 9.5 kgs and 74 cms tall – and with signs of mental retardation. She had episodes of constipation. Other prominent PE findings include presence of macroglossia, flat nasal bridge, abdominal distention, umbilical hernia, and edema of the hands and feet.</p>
BACKGROUND	
<ul style="list-style-type: none"> • Give the patient's reason for admission • Explain significant medical history • Overview of the patient's background: admitting diagnosis, date of admission, prior procedures, current medications, allergies, pertinent laboratory results and other relevant diagnostic results. For this, you need to have collected information from the patient's chart, flow sheets and progress notes. 	<p>Patient was diagnosed with CH at 14 days old, and was started on L-thyroxine 50mcg 1 tab OD.</p> <p>The family was not able to comply with lab tests and follow-up consultation for more than a year.</p> <p>Her most recent lab results taken last week are: high TSH (>100) and low T4 (12.85).</p> <p>Her current medication is still L-thyroxine 50mcg 1 tab given OD.</p>
ASSESSMENT	
<ul style="list-style-type: none"> • Vital signs • Clinical impressions, concerns <p>For example:</p> <ul style="list-style-type: none"> • You need to think critically when informing the doctor of your assessment of the situation. This means that you have considered what might be the underlying reason for your patient's condition. • If you do not have an assessment, you may say: "I am not sure what the problem is, but I am worried." 	<p>Dra., we are concerned that her current L-thyroxine medication may be underdosed, and that the patient may need to be admitted.</p>
RECOMMENDATION	
<ul style="list-style-type: none"> • Explain what you need - be specific about request and time frame • Make suggestions • Clarify expectations <p>Finally, what is your recommendation? That is, what would you like to happen by the end of the conversation with the physician? Any order that is given on the phone needs to be repeated back to ensure accuracy.</p>	<p>Dra., we need to schedule the patient with you asap, within this week, for your clinical evaluation. The patient is indigent and has no funds for consultation. Kailan po kayo available?</p> <p>Thank you po dra.</p>

5.3 NSC

5.3.1 Endorsement form

Logo of NSC

PATIENT ENDORSEMENT FORM

To: **<Name of Follow-up Head>**
Follow-up Head, NBS Continuity Clinic
<Region>

This is to endorse Baby <sex> <name> for long-term follow-up care under the NBS Continuity Clinic of <region>. The patient was born on <date> at <name of facility> and confirmed positive of <disorder/s> upon confirmatory testing.

Recall Summary

The initial sample was collected on <date> and was received at the Newborn Screening Center on <date>. The result of initial blood sample (indicate figure) was released on <date> and relayed to <name of person at the NSF>.

A repeat blood sample was collected on <date> and was received at the Newborn Screening Center on <date>. The result of repeat blood sample (indicate figure) was released on <date> and suggested <disorder/s>. <confirmatory test> was recommended. The patient was referred to <name of specialist>, <field of specialization>.

Details of confirmatory test/s are as follows:

Test	Date of collection	Laboratory	Result	Normal Range	Remarks

(indicate other details of recall)

Diagnosis

Based on the results of confirmatory tests and upon consultation with <name of specialist>, the patient was diagnosed with <disorder>. Treatment was started on <date> with the following medications:

1. (indicate medications, including dosage)
2. (indicate medications, including dosage)

(indicate other details of diagnosis, including hospital admission, specific schedule of next visits, specific schedule of obtaining laboratory tests, etc.)

(for old patients, indicate history of management and management plan/s)

(indicate contact details of attending physician/s taking care of the patient)

Attachments

1. (indicate attachments e.g. patient demographic profile, copies of laboratory results, etc.)

Prepared by:

Noted by:

<Name of Follow-up Nurse>

Designation

<Name of Follow-up Head>

<Designation>



5.3.2 Patient Profile form

Logo of NSC

PATIENT PROFILE

Demographic Data

Case Number			
Name of Patient			
Date of Birth		Place of Birth	
Mother's Name		Contact Number/s	
Address			
Father's Name		Contact Number/s	
Address			
Alternate Contact Person		Contact Number/s	
Address			

Clinical Data

Age of Gestation		Birth Weight	
Hospital of Birth			
Hospital of Collection			
Name of Attending Physician/s		Contact Number/s	
Name of Specialist/s		Contact Number/s	
Date of Collection (initial)		Age of Patient upon Initial Collection	

Date First Sample was Received at the NSC		Age of Patient upon Initial Sample was Received at the NSC	
Date of Collection (repeat)		Age of Patient upon Repeat Collection	
Date Repeat Sample was Received at the NSC		Age of Patient upon Repeat Sample was Received at the NSC	
Diagnosis			
Date of Diagnosis			
Date of Treatment		Age of Patient when treatment was started	

5.4 DSWD

5.4.1 Endorsement form

Logo of Continuity Clinic	NEWBORN SCREENING CONTINUITY CLINIC Host facility Address line 1 Address line 2 Email Add: Contact number:	Logo of Host facility
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DATE

To: **Department of Social Welfare and Development**
(Municipality)
Province of _____

Dear Sir / Madam,

Good day!

The newborn screening continuity clinic's principal goal is to assure the best possible outcome for individuals with disorders identified through newborn screening. The long term follow-up comprises the assurance and provisions of quality chronic disease management, condition-specific treatment and age-appropriate preventive care and education throughout the lifespan of the individual.

In line with this, (Patient's Name), (Age), daughter of (Mother's Name) and a resident of (Address) is in need of medical assistance for her routine laboratory procedures and a Certificate of Indigency.

The child is a confirmed case of (disorder) based on Newborn Screening results and is obliged to undergo (laboratory procedure) as a monitoring tool for his/her continuous medication and follow up.

The family's financial status has made it difficult for the family to address the child's needs. The Department of Health Regional Office is willing to provide financial assistance as long as that they can present a Certificate of Indigency from your good office as a requirement.

Hoping for your favourable response. Thank you very much!

Sincerely,

Name
Nurse II/ Follow Up Nurse

Name
Medical Specialist II / Follow Up Head



5.5 DOH RO

5.5.1 Letter of Assistance and Support

Logo of Continuity Clinic	NEWBORN SCREENING CONTINUITY CLINIC Host facility Address line 1 Address line 2 Email Add: Contact number:	Logo of Host facility
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Date

Regional director

Department of Health Regional Office IV-A

THRU: **Nbs Coordinator**
Senior Health Program Officer
DOH RO IV - A

Dear Sir / Madam,

Greetings!

The newborn screening continuity clinic's principal goal is to assure the best possible outcome for individuals in the region with disorders identified through newborn screening. The long term follow-up comprises the assurance and provisions of quality chronic disease management, condition-specific treatment and age-appropriate preventive care and education throughout the lifespan of the individual.

However, in the course of our implementation, we encounter several challenges in locating some of our patients and providing assistance in their medication and routine laboratory procedures.

In line with this, we would like to ask (support from your good office in recalling these patients so that they can be seen in the clinic and cared for properly / for financial support for the patient). Attached herewith are the patient profiles for your reference.

We are hoping for your kind response regarding this matter.

Thank you and God bless.

Sincerely,

Name

Nurse II /Follow Up Nurse

Name

Medical Specialist II /Follow Up Head

NEWBORN SCREENING CONTINUITY CLINIC -

Host facility
Address line 1
Address line 2
Email Add:
Contact number:

PATIENT PROFILE

Name of patient:	
Date of Birth:	
Place of Birth:	
Name of Guardian:	
Complete Address:	
Contact Details:	
Date of Collection: (initial NBS)	
Place of Collection: (initial NBS)	
Result of initial NBS:	
Specific Lab. exams done to the patient:	
Date of last lab exam and result:	
Complete diagnosis of the patient:	
Referral for assistance:	HOME VISIT RECALL

	FINANCIAL ASSISTANCE (brief explanation)
--	----------------------------------------------

Name
Follow Up Nurse

Name
Follow Up Head



5.6 LGUs

5.6.1 Letter of Assistance and Support

Logo of Continuity Clinic	NEWBORN SCREENING CONTINUITY CLINIC Host facility Address line 1 Address line 2 Email Add: Contact number:	Logo of Host facility
---------------------------------	----------------------------------------------------------------------------------------------------------------------------------	--------------------------

Date

LGU Official

Name of Government Office

Dear Sir / Madam,

Greetings!

The newborn screening continuity clinic's principal goal is to assure the best possible outcome for individuals in the region with disorders identified through newborn screening. The long term follow-up comprises the assurance and provisions of quality chronic disease management, condition-specific treatment and age-appropriate preventive care and education throughout the lifespan of the individual.

However, in the course of our implementation, we encounter several challenges in locating some of our patients and providing assistance in their medication and routine laboratory procedures.

In line with this, we would like to ask (support from your good office in recalling these patients so that they can be seen in the clinic and cared for properly / for financial support for the patient). Attached herewith are the patient profiles for your reference.

We are hoping for your kind response regarding this matter.

Thank you and God bless.

Sincerely,

Name

Nurse II /Follow Up Nurse

Name

Medical Specialist II /Follow Up Head

NEWBORN SCREENING CONTINUITY CLINIC -

Host facility
Address line 1
Address line 2
Email Add:
Contact number:

PATIENT PROFILE

Name of patient:	
Date of Birth:	
Place of Birth:	
Name of Guardian:	
Complete Address:	
Contact Details:	
Date of Collection: (initial NBS)	
Place of Collection: (initial NBS)	
Result of initial NBS:	
Specific Lab. exams done to the patient:	
Date of last lab exam and result:	
Complete diagnosis of the patient:	
Referral for assistance:	HOME VISIT RECALL FINANCIAL ASSISTANCE (brief explanation)

Name

Follow Up Nurse

Name

Follow Up Head



5.7 NSRC

5.7.1 Administrative Guidelines in work and processing of salaries

Working Schedule

Each facility is responsible for maintaining records of actual time worked of employees. These records must be maintained and shall be used by UP Manila to determine salary entitlements. All time and attendance records are subject to examination and must be kept at all times.

Hours of Work

1. For nurses, the regular workday is 8 hours and the normal workdays are Monday through Friday. The regular workweek is 40 hours. For physicians, at least 20 hours of work per week must be rendered.
2. The starting and ending work hours may depend on the operations of the Out-Patient Department of respective facilities, but will follow the required 8 hours a day and Monday to Friday workdays.

Attendance

1. Nurses must punch his/her own Daily Time Record (DTR) or biometrics upon arriving in the morning and upon leaving the clinic at the end of the day. Depending on the facility, employee may also log in the logbook upon entering and leaving the building premises.
2. Physicians shall fill-out 2 copies of Certificate of Service (COS) form as proof of attendance.
3. Punching any other DTR or tampering with timecard in any way may cause for a disciplinary action under the CSC ruling.
4. It is not necessary to punch "OUT" and "IN" when leaving the workplace on authorized official business. Any change or manual entry from the biometrics or bundy clock records on DTR must be attested by the Department Chair and supported by a Manual Entry form.
5. In cases of official travels, nurses and physicians need to secure Certificate of Appearance and/or training/conference certificate, whichever is applicable. This needs to be certified by the Department Chair.
6. Nurses and physicians must submit the duly signed DTR/COS to NSRC every 16th day and end of the month.

Official Uniform and Identification Card

Nurses are required to wear proper uniform as prescribed by their corresponding host facility. Clinic employees shall be provided by an identification card by the host facility. An official ID from UP Manila can personally be obtained provided that Contract of Services has already been approved.

Eligibility for Overtime

Nurses are not permitted to render overtime in their clinic without the prior approval of their supervisor/s. Copy of the approved request for overtime must be submitted together with the DTRs.

Holidays and Work Suspensions

Even if clinic employees are under UP Manila organization, they shall not be covered by any local holidays and work suspension in Manila. In cases wherein work suspension is declared in the municipality/city or

host facility where the NBS Continuity Clinic is located, memorandum or policy related to this directive shall be forwarded to NSRC to serve as attachment in the processing of salary.

Salary

Nurses need to submit their DTR and physicians need to fill-out and submit their COS every 16th and end of the month. For the payroll covering the first 15 days of the month, scanned copy of duly signed DTRs and COS shall be sent through electronic mail to jplumabas@up.edu.ph whereas for the payroll covering the remaining days of the month, original signed DTRs and COS shall be sent to NSRC through courier to:

Ms. Juvelyn P. Lumabas-Reyes
Newborn Screening Reference Center
Unit 304, New Gold Bond Building
1579 F.T. Benitez St., Ermita Manila

Contact Details:

Trunk lines: (02) 247 6002/ 247 6004 /247 6006

NSRC E-mail: info@newbornscreening.ph

5.7.2 Guidelines on submission of receipts for liquidation

1. All receipts for submission should be official receipts, and addressed to /or Received from "NSRC" or "NSRC UP Manila."
2. Tape each receipt on the clear side of a used bond paper.
3. Photocopy a receipt printed on thermal paper before the print fades out. Then tape the actual receipt beside the photocopied image.
4. Always attach a cover summary for all receipts - whether for reimbursement or liquidation of a cash advance.

5.7.3 Guidelines on Travel

The NBSCC Team is required to submit several Pre-travel and Post-travel documents for all domestic travels, with or without expenses, incurred while on official time.

For a complete list of these travel documents, please refer to Appendix 8.1 NSRC Internal Memo 2018-005. This memorandum enumerates the pre-travel and post travel documents needed to be submitted to NSRC for all domestic travels and the guidelines on when to submit these documents.

For personal travels abroad, the contractual nurse is required to follow the procedures of UP Manila i.e. submit approved application for leave, approved travel authority, and other supporting documents to Human Resources Department Office of UP Manila.

5.7.4 Guidelines on Application of Leave

Note: Please refer to Appendices for copies of Memoranda as basis.

1. NBSCC staff informs NSRC, c/o Project Development Officer for Patient Care, of his/her whereabouts thru email.
2. There should be proper filing of appropriate leave form and/or travel documents. The necessary forms are saved in a shared google drive:

https://drive.google.com/drive/folders/17GAP1wSP-VII6n6-0aOuku_YSV6D8rOT

3. Scanned copy of the original related document shall be emailed to PDO for Patient Care. The original document together with the DTR or COS must be sent to NSRC every end of the month. Failure to notify the office shall be dealt with accordingly.
4. For official travels involving the whole NBSCC team, the activity proposal is accomplished by the PDO for Patient Care. For individual travels, please comply with the procedure stipulated in the memo in Appendix.
5. Local holidays and office suspensions shall be observed provided that NSRC will have a copy of the issuance related to the said local holiday/suspension.

The contractual NBSCC nurse are entitled to different types of leaves. Hereunder are the definition of the various types of leaves, including the allowable number per type of leave:

1. SICK LEAVE (SL)
 - a. Earned 1.25 every month
 - b. Can be filed in advance for check-ups and appointment for health reasons; Must be filed one day after the applied leave.
 - c. Medical Certificate must be attached if 3-5 consecutive days or more.
2. VACATION LEAVE (VL)
 - a. Earned 1.25 every month
 - b. Tardiness and undertime may be deducted to VL
 - c. Must be filed 5 days in advance.

LEAVE PRIVILIGES OF EMPLOYEES

1. CNA (SICK LEAVE)
 - a. Maximum: 5 days
 - b. Can be availed on any working day
 - c. Medical Certificate must be attached if 3-5 consecutive days or more.
2. REHABILITATION LEAVE FOR JOB-RELATED INJURIES
 - a. Maximum: 6 months
 - b. Requirement/s: Medical Certificate and evidence showing that the wounds/injuries were incurred in the performance of duty.
3. SPECIAL LEAVE PRIVILEGES (SLP/SPL)
 - a. Maximum: 6 days
 - b. Must be filed in advance unless emergency reasons.
 - c. To be used in any of the following
 - i. Birthdays
 - ii. Emergencies/calamities, in case of earthquakes, typhoons, floods and other natural and/or man-made disasters, calamities or accidents, subject to certification from the proper authorities;
 - iii. Enrolment;

- iv. Graduation;
 - v. Hospitalization for immediate members of the family (Med. Cert. must submit)
 - vi. Weddings and honeymoons;
 - vii. Wedding anniversaries
 - viii. Relocation (subject to the submission of a certification from the barangay captain of the place where the employee relocated);
 - ix. Burial/mourning, in case of death of the employees' spouse, any of his/her children, parents, brothers, or sisters;
 - x. Government transaction; and
 - xi. Domestic emergencies
4. SPECIAL LEAVE PRIVILEGE FOR HOSPITALIZATION OF IMMEDIATE MEMBERS OF THE FAMILY
 - a. Maximum: 2 days
 - b. Requirements: Medical certificate of immediate member/s of the family
 5. SPECIAL LEAVE PRIVILEGE FOR NURSING MOTHERS
 - a. Maximum: 2 days
 - b. Can be availed until the 6 months of age of the baby
 - c. No requirement/s needed.
 6. MATERNITY LEAVE
 - a. Maximum of 60 days for those who rendered in the agency for 2 years (as of March 14, 2017)
 - b. Requirements: Medical certificates, Fit-to-work from attending OB
 7. PATERNITY LEAVE
 - a. 7 days
 - b. Qualification: Married male
 - c. Availment: Up to four (4) deliveries of his legitimate spouse with whom he is cohabitating
 8. PARENTAL LEAVE under Solo Parent Welfare Act of 2000 (RA 8972)
 - a. 7 days
 - b. Requirements: Proof of solo-parent (ID, Certificate, etc.)
 - c. If the child happens to be sick/check-up: Medical Certificate must attach to the leave form.
 9. SPECIAL LEAVE BENEFITS FOR WOMEN under RA 9710 (An Act Providing for the Magna Carta of Women)
 - a. Maximum of two (2) weeks up to two (2) months.
 - b. Requirements: CS Form 6, SLB Form, Medical Certificates and Fit-to-work from attending physician.
 10. TEN-DAY LEAVE under RA 9262 (Anti-Violence Against Women and their Children Act of 2004)
 - a. Maximum: 10 days
 - b. Requirements: Cs Form 6, Brgy Protection order, Temporary/Permanent protection from the court. Certificate of requesting Protection Order, Police Report and Medical Certificate

GRANT OF COMPENSATORY TIME-OFF (CTO)

1. Application should be filed in advance and approval is subject to the exigency of service

2. The CTO may be availed of in blocks of four hours (half day) or eight hours (whole day)
3. An employee may use the CTO up to five (5) days consecutively but not to exceed forty hours in a month.

5.7.5 Continuity Clinic Case Conference Audit (4CA)

The main objective of the audit is to ensure that confirmed positive cases endorsed to the NBSCCs are provided prompt and appropriate management. Challenging and problematic cases such as in terms of barriers to recall, laboratory testing, and treatment are discussed.

The 4CA provides a valuable forum for the Newborn Screening Continuity Clinics (NBSCCs) to share experiences, best practices and ideas on how to optimize patient care through the presentation of Interesting Cases. The conference also serves as a venue to review patient data and statistics of the operations of the clinics in a timely manner with specific parameters.

The groupings are as follows:

Cluster	NBS Continuity Clinic Teams
Cluster A	Ilocos Region Cagayan Valley Cordillera Administrative Region Central Luzon CALABARZON
Cluster B	National Capital Region Bicol Region Western Visayas Central Visayas Eastern Visayas
Cluster C	Zamboanga Peninsula Northern Mindanao Davao SOCCSKSARGEN

The guidelines in holding quarterly case audits are presented below:

A. Submission of Patient Data every Month

NBSCCs are required to submit patient data on or before the 10th day of the month, indicating the following details:

1. Number of endorsed cases
2. Number of recalled cases, unrecalled cases, actual consults, treatment compliant, indigent, lost to follow up, expired, discharged/well baby
3. Details of patients who have been confirmed and endorsed.
4. Details of those who expired (based on medical abstract or death certificate)

B. Presentation of Interesting Cases

Each NBSCC must prepare at least one interesting cases for discussion. Interesting cases can have different meanings i.e. problematic because of borderline values, challenging recall, failed

recall, delay in management, etc. The NBSCC Follow up Head shall present the interesting case. The presentation of cases should include the same four sections as the abstract.

1. **Introduction** – The introduction should provide a clear idea of what is particularly interesting about the case the NBSCCs want to discuss or an explanation of why the case is novel or merits review. If there is something especially challenging about the diagnosis or management of the condition the NSCs are describing, this is the chance to bring that out.
2. **Case Presentation** – This is where the raw data are introduced – reason for confinement, information obtained from the history-taking, results of clinical examination, working diagnosis or clinical impression of the patient. The case presentation should only include information that pertains to the case and refrain from providing confusing and superfluous data. The presenter should establish a causal and temporal relationship and indicate the effect of treatment, any unanticipated effects, the patient’s final outcome, any further proposed treatments, and the patient’s present status at the time of the presentation.
3. **Management and Outcome** – In this section, the NBSCCs should clearly describe the plan for care, as well as the care which was actually provided, and the outcome – how long the patient was under care and how many times s/he was treated. It is useful also to discuss an indication of how and why treatment finished. Did the pediatrician decide to terminate care, and if so, why? Did the parent/guardian decided to withdraw the patient from care or did the NBSCC refer to specialist?
4. **Discussion** – This is where the presenter may want to identify any questions that the case raises. If there is a well established item of physiology or pathology which illuminates the case, the NBSCCs may discuss it. Finally, summarize the lessons learned from this case.

The National Long Term Follow-up Coordinator shall preside the audits. All Follow-up Heads are required to attend and participate in this activity. Every NBSCC is requested to analyze their data prior to the case audit.

5.8 DOH RO

5.8.1 PPEAS Tool for NBSCCs

Note: Please refer to Appendix 8.2 for the actual PPEAS Tool.

The PPEAS Tool is the Philippine Performance Evaluation and Assessment Scheme (PPEAS) – a tool based on a PEAS developed by the US National Newborn Screening and Genetics Resource Center. The NSRC has partnered with the DOH to develop a tool for the Philippines to monitor quality and improvements made in the regional NBS program. Currently, there are PPEAS for NSCs, DOH ROs, and the latest is the one for the NBSCCs.

The objectives of the PPEAS Tool for the NBSCCs are to:

1. Assess the progress of the long term follow up component of the NBS program, its strengths and weaknesses, best practices and barriers.

2. Provide solutions to identified problems, particularly the problems which impact on the goal of ensuring recall and appropriate long term management of endorsed confirmed cases, and,
3. Recommend ways to improve the implementation of the long term follow up component of the NBS program in the region and throughout the country.

6. INFORMATION MANAGEMENT SYSTEM

6.1 Continuity Clinic Case Audit Report (3CA)

The NBSCCs are required to submit patient data on or before the 10th day of the month. Data is in an Excel form containing 2 Excel sheets:

1. Details sheet – this sheet contains inputs of details of patients such as date of birth, date of NBS collection, age of patient upon collection, province where NBS was collected, province where patient resides, sex, initial nbs screening results, results of repeat test, confirmatory tests done, results of confirmatory tests, final disposition, date treatment was started, name of specialist, name of attending physician, date of latest visit with attending physician, and other comments and concerns.

In the Other comments and concerns column are nurses' noted pertaining to updates about the patient including date of next follow up appointment.

Each patient is classified under several categories, which are defined in Section 6.2 below.

Furthermore, each patient's physical growth is monitored for the last measurement taken for height and weight and the date when this measurement was taken. The patient's Z scores (for height for age and weight for age) is computed based on the WHO growth charts. The patient is then classified for stunting and underweight using the following WHO criteria:

- Stunting: height for age < -2 SD of the WHO Child Growth Standards median
- Underweight: weight for age < -2 standard deviations (SD) of the WHO Child Growth Standards median

In addition, each patient is classified with their current age, whether they are attending school, and if yes, whether they are attending regular or Special Education (SPED) school. Each patient is also classified whether they are seen by a Developmental Pediatrician, and if yes, date of last assessment, age at time of assessment, and brief details of the results of assessment.

2. Summary sheet – this sheet contains the total counts of:
 1. Number of endorsed cases
 2. Number of recalled cases, unrecalled cases, actual consults, treatment compliant, indigent, lost to follow up, expired, discharged/well baby
 3. Number of patients with normal physical growth, who are stunted, underweight, attending school, being seen by a Developmental Pediatrician.

6.2 Categories of Patient Status

The patient database in the Continuity Clinic Case Audit Report or 3CA Report contains several categories of patient status wherein each endorsed patient to the NBSCC are classified into. Hereunder are the different categories and their respective operational definition:

1. Recalled – refers to families of patients whom the CCs are able to make regular contact or communication, within a period of six months.

These include:

- a. Actual consults - patients who: actually consult with the CCs
- b. Recall compliant or treatment compliant - patients not seen at the CCs but who are being seen by specialists or primary physicians as their private patients, or being seen by training institutions; The CCs have the responsibility to monitor their compliance to treatment. This includes patients who report that they are complying to treatment plan.
- c. Recall uncompliant - patients who maintain communication with the continuity clinic but are unable to comply with treatment plan (e.g. financial reasons or unforeseeable circumstances)

2. Unrecalled –

- a. patients with non-working or erroneous contact information (phone number, address of residence).
- b. patients whom the CCs are unable to contact or communicate within a period of 6 months and thereby missed two successive schedule of follow up based on their age-appropriate checklist

3. Indigent – families certified by DSWD or authorized agencies like the Municipal Office as having insufficient financial capacity for subsistence of the family.

4. Lost to follow up – unrecalled patients classified as lost to follow up by the DOH RO. A certificate attesting to LTFU status coming from DOH is ideally needed.

5. Expired – patients who die while in the long term care of CCs. Efforts must be done by the NBSCC to secure medical abstracts in order to ascertain the cause of death.

6. Discharged /Well baby – patients ruled out as discharged or well baby by an accredited specialist who exercised sound clinical judgment based on laboratory monitoring tests and physical examination of the patient.

6.3 Continuity Clinic Online Record System (CCORS) (Refer to existing manual)

CCORS stands for Continuity Clinic Online Record System – a software program born out of the need for an efficient and secured system of data management for the long term follow-up team.

CCORS aims to consolidate all information about the patients with confirmed disorders – from their demographic profile, pertinent history, physical findings, laboratory test results, medications taken, work-ups done, to impressions including doctors’ and nurses’ notes, and general and specific plans for the patient. These information shall be readily available and accessible online and shall serve as the backbone for the daily operations of the continuity clinics and their monthly conference case audits.

6.4 Protection of Patient Privacy

Foremost consideration should be given to protecting the patient's basic right to privacy and confidentiality. Access to patient database shall be limited to ONLY the Continuity Clinic Team – namely the Follow-up Head and the Continuity Clinic Nurse.

NBSCCs have the responsibility of protecting their usernames and passwords. Use of CCORS should be limited to personal devices or official computers used in the clinic. Use in shared public computers, like in internet shops, is strongly discouraged.

Granting of access to patient database and to CCORS shall be at the discretion of the Newborn Screening Reference Center. Requests for access to patient data by outside parties shall need a written letter of request addressed to and requiring the approval of the Director of NSRC.

7. REFERENCES

Basic Information for Physicians (Newborn Screening Reference Center, NIH, UP Manila, October 2010). Edited by: Chiong, MA D, Domingo, C F, Estrada S C, Gepte, MB P.

Manual of Standards for Newborn Screening Center in the Philippines. (Institute of Human Genetics, NIH, UP Manila, 2005)

Newborn Screening Follow-up; Approved Guideline. Clinical and Laboratory Standards Institute. I/LA 27-A Vol. 26 No. 18.

Nutrition Landscape Information System (NLIS) country profile indicators: interpretation guide. World Health Organization. 2010.

8. APPENDICES

8.1 DOH Administrative Order 2014-0035



Republic of the Philippines
Department of Health
OFFICE OF THE SECRETARY

OCT 20 2014

ADMINISTRATIVE ORDER
No. 2014 - 0035

Subject: **Implementing Guidelines on the Setting-up of Newborn Screening Continuity Clinics**

I. Rationale

Pursuant to Section 13 of the Implementing Rules and Regulation of Republic Act 9288, otherwise known as the Newborn Screening Act of 2004, the DOH being the lead agency shall ensure that a network of facilities for referral and management of all positive cases is established. In addition, it shall develop referral centers and identify referral teams in strategic areas for referral and management of patients with any of the disorders.

Recognizing this need and of the mandate to develop referral centers, the Department of Health and the National Institutes of Health are setting-up Newborn Screening (NBS) Continuity Clinics in the country to strengthen the National Comprehensive Newborn Screening System Treatment Network and ensure the early treatment and appropriate management of identified positive cases.

Initially, one Newborn Screening Continuity Clinic and Birth Defects Continuity Clinic per region shall be set-up. Subsequently, provincial continuity clinics shall be established.

II. Objective

To provide policies and guidelines for the setting-up and implementation of NBS Continuity Clinics and Birth Defects Continuity Clinics for referral and management of all screened-positive newborns.

III. Scope and Coverage

This Order shall apply to all Newborn Screening Centers, DOH – Regional Offices (DOH-ROs), National Comprehensive Newborn Screening System Treatment Network and all other agencies and stakeholders concerned in the implementation of the newborn screening program.

IV. Definition of Terms

National Comprehensive Newborn Screening System Treatment Network refers to a network wherein total management of patient with confirmed diagnosis shall be referred to. It follows the DOH-approved clinical protocol in the management of patients diagnosed in any of the disorders included in the newborn screening panel.

National Institutes of Health – Institute of Human Genetics (NIH-IHG) refers to the unit at the National Institutes of Health that provides comprehensive clinical evaluation of

Building 1, San Lazaro Compound, Rizal Avenue, Sta. Cruz, 1003 Manila • Trunk Line 651-7800 Direct Line: 711-9501
Fax: 743-1829; 7431786 • URL: <http://www.doh.gov.ph>; e-mail: osec@doh.gov.ph

families or individuals with or at risk for heritable conditions; it provides support for remote, real-time referral (the Telegenetics Referral System) and Birth Defects Surveillance System in the country. It also offers laboratory and diagnostic services pertinent to the management of heritable conditions.

Newborn Screening Panel of Disorders refers to the list of disorders tested under the Philippine Newborn Screening Program. The panel includes newborn screening for the following disorders: Congenital Hypothyroidism, Congenital Adrenal Hyperplasia, Phenylketonuria, Galactosemia, G6PD Deficiency and Maple Syrup Urine Disease. By mid-2014, an expanded newborn screening panel shall be offered as an option increasing the number of disorders from six (6) to twenty-eight (28) falling under various types of disorders namely: hemoglobinopathies, amino acid disorders, organic acid disorders, disorders of fatty acid oxidation, disorders of carbohydrate metabolism, disorders of biotin metabolism, cystic fibrosis and endocrine disorders.

Newborn Screening Reference Center (NSRC) refers to the central facility at the National Institutes of Health that defines testing and follow-up protocols, maintains an external laboratory proficiency testing program, oversees the national testing database and case registries, assists in training activities in all aspects of the program, oversees content of educational materials and acts as the Secretariat of the Advisory Committee on Newborn Screening.

Newborn Screening Center (NSC) refers to a facility equipped with a newborn screening laboratory that complies with the standards established by the National Institutes of Health, and provides required laboratory tests and recall/follow-up programs for newborns with heritable conditions.

Newborn Screening Continuity Clinic refers to an ambulatory clinic based in a tertiary hospital identified by the DOH to be part of the National Comprehensive Newborn Screening System Treatment Network. It is equipped to facilitate continuity of care of confirmed patients in its area of coverage.

Birth Defects Continuity Clinic refers to an ambulatory clinic based in regional and provincial referral centers identified by the DOH. It specifically caters to patients with birth defects for the purpose of diagnosis and management.

Telegenetics Referral System refers to provision of remote genetic clinical consults to physicians in the provinces for their patients over a computer network.

V. **General Guidelines**

- A. 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. Subsequently, the NBS Continuity Clinics shall be established in the provincial level.
- B. The Birth Defects Continuity Clinics shall be integrated in the National Comprehensive Newborn Screening System. The Birth Defects Continuity Clinics will share the same infrastructure and personnel of the Newborn Screening Continuity Clinics.
- C. The Telegenetics Referral System shall be utilized by the NBS Continuity Clinics and Birth Defects Continuity Clinics where subspecialists are not available in the hospital.
- D. Memoranda of Agreement shall be executed between NSRC, NSC, DOH-RO, Host Facility, and IHG for every regional/provincial Continuity Clinic.



VI. Specific Guidelines

A. Patient Care

In terms of the different components of NBS patient care, the following shall be considered in the implementation of the NBS Continuity Clinics and Birth Defects Continuity Clinics:

1. Diagnosis and Initial Management

- a. In coordination with the DOH-ROs, the NSCs shall be responsible for the tracking of newborns with out-of-range screening results to ensure repeat specimen collection, repeat screening and/or confirmatory testing from the NBS laboratories or confirmatory centers.
- b. The NSCs shall facilitate the confirmatory testing for newborns with out-of-range screening results and initiate medical management for patients with confirmed diagnosis.

2. Long-term Management (including counseling, treatment, monitoring and follow-up).

- a. The NSCs shall refer all newborns who are confirmed positive with heritable disorders to NBS Continuity Clinic for long-term follow-up care.
- b. In coordination with the DOH-ROs, every effort shall be made by the personnel of the continuity clinics to contact and schedule patients referred from NSCs so that the necessary treatment and long-term follow-up care shall be given, as well as timely monitoring shall be undertaken.
- c. The continuity clinics shall facilitate referral of patients needing consults to available subspecialists in their facility or region. In cases wherein subspecialists are not available, the continuity clinics shall utilize the Telegenetics Referral System.

B. Operations of NBS Continuity Clinics

In terms of the different components of the newborn screening program, the following shall be considered in the implementation of the NBS Continuity Clinics and Birth Defects Continuity Clinics:

1. Selection, Recruitment and Hiring of Personnel

- a. The continuity clinics shall be manned by a part-time Medical Specialist and a full-time Nurse or Genetic Counselor.
- b. The Department of Pediatrics of every host facility shall be responsible for overseeing the recruitment and selection of personnel for the continuity clinic in their facility.
- c. The host facility shall make the necessary recommendations for the hiring of their personnel.

2. Funding

The operational expenses of these clinics, including, but not limited to communication and travel expenses, as well as financial support for indigent families, shall be shared responsibilities of NSRC, NSCs, DOH-ROs and host facilities.

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C. Capacity Building

Long-term management of patients, require enhancement of skills and competencies and will be supported with a capacity building program organized by the DOH in partnership with NSRC.

D. Information Education and Communication

1. Information on the establishment of the continuity clinics and the Telegenetics Referral System, shall be disseminated to all agencies concerned;
2. Information on the long-term follow-up treatment and management of the disorders included in the NBS panel shall be made available to health professionals, parents, and the general public at all continuity clinics, NSCs and DOH-ROs.

E. Monitoring and Evaluation

A monitoring and evaluation plan shall be developed to provide the mechanism for monitoring and evaluation of the continuity clinics implementation and the key indicators for impact monitoring.

F. Roles and Responsibilities

1. Department of Health

The DOH shall be the lead agency in the implementation of expanded newborn screening. Its roles and responsibilities are stated in Section 13 of the Implementing Rules and Regulations of RA 9288.

a. Family Health Office shall:


1. Review and update guidelines on the operations of the NBS Continuity Clinics and Birth Defects Continuity Clinics.
2. Formulate and issue a monitoring and evaluation tool pursuant to the operations of these clinics.

b. Regional Offices shall:

1. Establish a mechanism for recall of confirmed patients for referral to experts for management and follow-up care;
2. On the basis of availability of funds, provide indigency support for confirmatory testing of patients with significantly elevated laboratory results and for treatment and long-term management of confirmed patients in the region.

2. Newborn Screening Reference Center shall:

- a. Oversee the implementation of activities of NBS Continuity Clinics and Birth Defects Continuity Clinics;
- b. Secure monthly, quarterly and yearly reports from participating units and ensures their timely dissemination to various program stakeholders;
- c. Participate in consultation and evaluation activities initiated by the DOH in relation to the NSRC and the NBS Continuity Clinics' and Birth Defects Continuity Clinics' performance and in improving of rules and regulations;
- d. Assist in the training activities of the program;
- e. Oversee and review content of educational materials as well as the production of the materials.

4


3. **Newborn Screening Centers** shall:
 - a. Give diagnosis, make proper referral and initiate management for all confirmed NBS patients;
 - b. Provide roster of confirmed patients, including their protocols for management and list of follow-up laboratory procedures, to the NBS Continuity Clinic.

4. **Host Facilities of NBS Continuity Clinics** shall:
 - a. Set-up NBS Continuity Clinic and Birth Defects Continuity Clinic;
 - b. Provide a clinic space for patient consultation and a work station for the follow-up nurse and/or genetic counselor.
 - c. Oversee the selection and hiring of personnel for the NBS Continuity Clinic in their facility;
 - d. Integrate NBS continuity clinic to the current services of the host facility;
 - e. Ensure the sustained operation of NBS Continuity Clinic and Birth Defects Continuity Clinic according to the Operational Guidelines set by the Department of Health and the Newborn Screening Reference Center for these clinics.

5. **Institute of Human Genetics** shall:
 - a. Strengthen the surveillance program for newborns with birth defects in the country;
 - b. Establish systems for the referral of patients with birth defects from BDS health facility to Birth Defects Continuity Clinics;
 - c. Provide support in the operations of Telegenetics Referral System;
 - d. Establish an efficient system in the procurement and availability of medicines, medical food and other medical requisites needed in the management of patients with birth defects and confirmed patients detected through newborn screening.

VII. Repealing Clause

All orders and issuances, rules and regulations or parts thereof inconsistent with the provisions of this Order are hereby amended, modified or repealed accordingly.

VIII. Separability Clause

If any provision of this Order is declared invalid, the other provisions not affected thereby shall remain valid and subsisting.

IX. Effectivity

This Order shall take effect fifteen (15) days after its approval and publication in the official gazette or newspaper of general circulation.



ENRIQUE T. ONA, MD
Secretary of Health

Philippine Performance Evaluation and Assessment Scheme
PPEAS for Newborn Screening Continuity Clinics
Program Implementation Review
Newborn Screening Reference Center
National Institutes of Health, UP Manila



** Based on the PEAS (version 8/25/06) developed by Health Resources and Services Administration, Maternal and Child Health Bureau, Genetic Services Branch, and National Newborn Screening and Genetics Resource Center, Department of Pediatrics, The University of Texas Health Science Center at San Antonio.*

Version: 23 April 2018

COMPONENTS

- I. **Operational Structure**
 - a. Team members
 - b. Operations and management
- II. **Facility Support**
 - a. Infrastructure
 - b. Funding support for patients
- III. **Information System**
 - a. Electronic /Online information
 - b. Manual filing system
- IV. **Clinical Management and Referral network**
 - a. Care coordination with health providers
 - b. Network and linkages with program partners
- V. **Advocacy Activities**
 - a. Communication plan for parents and health providers
 - b. Implementation of Health Promotion activities
- VI. **Monitoring and Evaluation**
 - a. Patient tracking
 - b. Medical management and patient outcome data
- VII. **Administrative**
 - a. Timeliness of submission of reports to NSRC, DOH RO, and NSC
 - b. Quality of reports
 - c. Staff Development
 - d. Others
- VIII. **Innovation Strategies and Best Practices**
 - a. Projects of the clinic
 - b. Training of personnel
- IX. **Significant findings, agreements, and recommendations**

OBJECTIVE: The PPEAS Tool for the Continuity Clinic aims to:

4. assess the progress of the long term follow up component of the NBS program, its strengths and weaknesses, best practices and barriers.
5. Provide solutions to identified problems, particularly the problems which impact on the goal of ensuring recall and appropriate long term management of endorsed confirmed cases, and,
6. Recommend ways to improve the implementation of the long term follow up component of the NBS program in the region and throughout the country.

I. OPERATIONAL STRUCTURE

	Indicators	Yes	No	In Progress	Remarks
A.	Team members				
1.	Trained staff are available to administer the program composed of				
	Follow-up head				
	Follow-up nurse				
2.	Diagram showing the relation of the CC team to the host facility exists				
3.	Written defined roles and responsibilities (include written roles and responsibilities as attachment)				
B.	Operations and management				
1.	Manuals of operations exist that include but are not limited to: administrative policies, program operations, contingency plan when team member/s is/are replaced, clinical protocols, etc.				
2.	Flowchart of operations exists (indicating who are responsible for patient registry, lab tests, consultation, counselling, etc.)				
3.	Services available and provided				
4.	Updated government license and/or MOA with host facility				

II. FACILITY SUPPORT

	Indicators	Yes	No	In Progress	Remarks
A.	Infrastructure				
1.	Sufficient infrastructure are in place to ensure an efficient operations of the clinic:				
2.	IT system that is acceptable to enable the clinic to function in its operations (i.e. able to perform data management of input, filing, storage/backup, printing, and maintenance)				

3.	Internet or Wifi capability that is acceptable to ensure efficient conduct of 4CA (Continuity Clinic Case Conference Audits) and CCORS (Continuity Clinic Online Record System) data management				
4.	Availability of cellphone for official communication with patients' families and NBS partners				
5.	Availability of necessary office equipment and supplies (computer, printer, filing cabinet, bond paper, report forms, envelopes, etc.)				
B.	Funding support for patients				
	Provision for laboratory testing, treatment, food medications				
	Provision of supplemental budgets for activities (sources, type, amount, is it regular support?)				

III. INFORMATION SYSTEM

	Indicators	Yes	No	In Progress	Remarks
	Information system (organized, secured and protected)				
1.	Manual filing system of documents				
2.	Electronic filing system (including CCORS online database)				
3.	Patient charts				
4.	Patient Directory including address, contact details of parents /guardians, etc.				
5.	Endorsement letters of patients from NSCs				
6.	Directory of specialists for referral and case management with contact details and clinic hours				
7.	Directory of DOH ROs, health facilities, and other partners /stakeholders				
8.	Official correspondences from NSRC				
9.	Correspondences to stakeholders (DOH-RO, DSWD, others)				
10.	Documentation of monitoring and evaluation reports of activities				
11.	Records are easily retrievable within 15 minutes				
12.	Monthly 3CA data reports (Continuity Clinic Case Audit)				
13.	Accomplishment reports				
14.	Memorandum of Agreements (MOAs)				

IV. CLINICAL MANAGEMENT and REFERRAL NETWORK

	Indicators	Yes	No	In Progress	Remarks
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A.	Care coordination with health providers				
1.	Access to a specialist (directory of specialists)				
2.	System of referral to specialists, physicians, dieticians, other health providers (including telegenetics referral system); referral forms				
B.	Network and linkages with program partners				
1.	Established network /relationship with program partners (i.e. DOH RO, NSC, DSWD, LGU)				
2.	Funding support mechanisms from DOH ROs (indicate amount or %)				
3.	Provision for laboratory testing, treatment, food medications from partners				
4.	Provision of supplemental budgets for LGU activities (sources, type, amount, is it regular support?)				
5.	Existence of MOA with DOH RO				
6.	Existence of monitoring tool of DOH RO or other partners' support				
7.	Existence of MOAs or written agreement with DOH ROs, LGUs & others				

V. ADVOCACY ACTIVITIES

	Indicators	Yes	No	In Progress	Remarks
A.	Communication Plan for parents and health providers				
1.	IEC/reference materials available				
2.	Posters				
3.	Brochures				
4.	Flipcharts				
5.	Innovations (IEC materials)				
6.	Parents are periodically asked to evaluate medical services provided and to identify other possible needs that could be met through the newborn screening program.				
7.	Activity proposals and plans for stakeholders (including lobby for funds)				
B.	Implementation of Health Promotion Activities				
1.	Active participation in NSC and other partners-sponsored activities				
2.	Conducts lectures on NBS with different stakeholders (mothers, parents, health providers)				
3.	Effective organization and successful implementation of PSPME Follow up clinic				

VI. MONITORING AND EVALUATION

	Indicators	Yes	No	In Progress	Remarks
A.	Patient tracking				
1.	Acceptable Recall Rate (>80%) of patients endorsed by the NSCs (indicate current recall rate)				
2.	System of monitoring patients' consultation to other physicians' clinic /OPD of training institutions (e.g. maintenance of physical or electronic logbook)				
3.	System of following up patients' compliance to lab tests and medications (e.g. maintenance of physical or electronic logbook)				
4.	System of scheduling patients for consultation to continuity clinic (maintenance of physical or electronic schedule of appointments)				
5.	System of time management in a working week (maintenance of calendar with defined tasks and timeframe each working day)				
B.	Medical management and patient outcome data				
1.	Acceptable (1 to 2 days per week) clinic schedule of follow-up head				
2.	System of measuring patient status indicators - i.e. no of patients with /who are: <ul style="list-style-type: none"> • Recalled /Unrecalled • Actual consults to continuity clinic • Treatment compliant /non-compliant • Indigent • Expired • Discharged • Lost to follow up 				
3.	System of monitoring outcome indicators /patient status and progress (including growth and development) <ul style="list-style-type: none"> • At par /Stunted /Underweight • School attendance • Dev Ped assessment 				
4.	Availability of equipment and instruments to measure outcome indicators (e.g. weighing scale, height chart, tape measure, etc.)				
5.	Effective communication and counseling skills; ability to build rapport and empathy with patients				

VII. ADMINISTRATIVE

	Indicators	Yes	No	In Progress	Remarks
A.	Timeliness of submission of reports to NSRC, DOH RO, and NSC				
1.	Monthly 3CA data (Continuity Clinic Case Audit)				
2.	Accomplishment report				
3.	Interesting case presentation for 4CA - Continuity Clinic Case Conference Audit				
4.	Other reports or data requested by NSRC				
B.	Quality of reports				
1.	Submits well-organized, completely filled-out and accurate reports				
2.	(%) of endorsed patients entered in CCORS database with updated information				
C.	Staff development				
1.	Attendance and punctuality to 4CA				
	Follow-up head				
	Follow-up nurse				
2.	Attendance and punctuality to NSRC sponsored trainings				
	Follow-up head				
	Follow-up nurse				
3.	Attendance and punctuality to DOH /NSRC sponsored annual strategic meeting				
	Follow-up head				
	Follow-up nurse				
D.	Others				
1.	Attendance and punctuality in the clinic				
2.	Prudent and judicious usage of cellphone and other resources				

VIII. INNOVATION STRATEGIES AND BEST PRACTICES

	Indicators	Yes	No	In Progress	Remarks
1.	Projects implemented by the clinic to promote NBS advocacy to different stakeholders (please list)				

2.	Updated training of the personnel (please list)				

IX. SIGNIFICANT FINDINGS, AGREEMENTS AND RECOMMENDATIONS





8.3 Internal Memo 2018-005 – Policies on Travel



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

Unit 304 New Gold Bond Building, 1579 F.T. Benitez Street., Ermita, Manila 1000 Trunklines: (+632) 247 6002/ 04/ 06 Fax: (+632) 247 6008
Email Address: info@newbornscreening.ph Website: http://www.newbornscreening.ph

28 March 2018

INTERNAL MEMO 2018-005

FOR: NEWBORN SCREENING REFERENCE CENTER STAFF

FROM: *Riza N. Suarez*
RIZA CONCORDIA N. SUAREZ
Officer-in-Charge

SUBJECT: POLICIES ON TRAVELS

All NSRC staff including NBS Continuity Clinic personnel are reminded on the policies on travels (local and foreign) and the liquidation or reimbursement of travel-related cash advances.

For all travels, with or without expenses incurred from the University but on official time, please submit the following forms:

Pre-Travel		Post-Travel	
Documents	Submit to	Documents	Submit to
1. Approved Activity Proposal or Activity Outline for requested service	Exec Unit	1. Actual Itinerary of Travel	Admin Unit
2. Approved Authority to Travel using the appropriate form:	Admin Unit	2. Certificate of Attendance or Appearance	
i. Local Special Details – if local official travel is 15 days or less		3. Official receipts, tickets, boarding passes, RERS, Certification of expenses not requiring receipts	
ii. Request for Travel Authority – for local travel of more than 15 days and travels abroad	Admin Unit	4. Transportation forms	
3. Proposed Itinerary of Travel		5. Certificate of travel completed	
		6. Justification letters for deviations during travel (i.e. extended travel, rebooking, additional expenses not factored in the budget, expenses that exceeded the budget)	
		7. Travel Report	Unit Head
		8. Liquidation Report	
		9. Accomplished evaluation/feedback form, for ISO and PBB compliance (for requested service)	

* filepath of all necessary forms attached

Submission of documents:

1. Approved Activity Proposal/Outline exactly two (2) months prior the scheduled activity.
2. Approved Authority to Travel and Proposed Itinerary of Travel 15 days before the travel.
3. All post-travel documents for:
 - a. Domestic travels – three (3) calendar days upon return to office
 - b. International travels – 15 days upon return to office

In addition to these, please be reminded that we are not entitled to travel allowances when attending training/workshop/conference/convention within Metro Manila in reference to EO 298 as relayed by UP Manila Accounting Office.

For personal travels abroad, you need to submit approved application for leave, approved travel authority and other supporting documents to HRD Office.

FILEPATH OF FORMS (IM 2018-005)

Pre-Travel Documents	Filepath
1. Activity Proposal	\\nsrc\NSRC Files\NSRC - Forms\Advocacy, Training & IT Forms\ Activity Proposal (Training) or (Non-Training)
2. Activity Outline	\\nsrc\NSRC Files\NSRC - Forms\Advocacy, Training & IT Forms\ Activity Outline
3. Request for Travel Authority	\\nsrc\NSRC Files\NSRC - Forms\HR Forms\ Request for Travel Authority for Official Travel
4. Local Special Details – if local official travel is 15 days or less	\\nsrc\NSRC Files\NSRC - Forms\Acctg Forms\ Local Special Detail
5. Request for Travel Authority – for personal travel abroad	\\nsrc\NSRC Files\NSRC - Forms\HR Forms\ Request for Travel Authority (Personal travel abroad charged to Leave credits)
6. Itinerary of Travel	\\nsrc\NSRC Files\NSRC - Forms\Acctg Forms\ Itinerary of Travel
7. Certificate of Appearance	\\nsrc\NSRC Files\NSRC - Forms\HR Forms\ Certificate of Appearance
8. Transportation form	\\nsrc\NSRC Files\NSRC - Forms\Acctg Forms\ Transportation Form
9. Certificate of travel completed	\\nsrc\NSRC Files\NSRC - Forms\Acctg Forms\ Certificate of Travel Completed
10. Reimbursement Expense Receipt	\\nsrc\NSRC FILES\NSRC - Forms\Acctg Forms\ Reimbursement Expense Receipt
11. Certification of expenses not requiring receipts	\\nsrc\NSRC Files\NSRC - Forms\Acctg Forms\ Certification of Expenses not Requiring Receipts
12. Travel Report	\\nsrc\NSRC Files\NSRC – Forms\ Travel Report
13. Evaluation/feedback form, for ISO and PBB compliance	\\nsrc\NSRC Files\NSRC - Reports\2018\PBB\ UPM Technical Services Form 18Jan2018_NSRC

8.4 Internal Memo 2018-001 – Policies on Leave Application



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

Unit 304 New Gold Bond Building, 1579 F.T. Benitez Street, Ermita, Manila 1000

Trunklines: (+632) 247 6002/ 04/ 06


Fax: (+632) 247 6008

Email Address: info@newbornscreening.ph Website: <http://www.newbornscreening.ph>

5 March 2018

INTERNAL MEMO 2018-001

FOR: **NEWBORN SCREENING REFERENCE CENTER STAFF**

FROM: 
RIZA CONCORDIA N. SUAREZ
Officer-in-Charge

SUBJECT: **POLICIES ON LEAVE APPLICATIONS**

With the release of the Memorandum Order No. CCDP-2018-26, all NSRC staff are reminded to observe the policies on applications for leave.

For sick leaves and emergency cases, submit supporting document like medical certificate of family member/s, if hospitalized; if not, specify the reason of emergency in the leave form. Also, staff are reminded to notify their immediate supervisor AND the office of such leaves/cases. These will be noted along with the filed leaves in the google calendar of NSRC Whereabouts.

This is also to reiterate the previously released documents on filing of leaves (see attachments):

- Types of leaves
- Filing of leaves for government transactions

For your guidance and compliance.

8.5 Memorandum Order No. CCDP 2018-26 – Policies on Application for Leaves



University of the Philippines Manila
The Health Sciences Center
Office of the Chancellor
8/F Philippine General Hospital Complex, Taft Avenue, Manila 1000, Philippines
Telefax (632) 526-8419 – Telefax (632) 521-0184 | Email: upm-oc@up.edu.ph



HRDO10005395

13 February 2018

MEMORANDUM ORDER NO. CCDP–2018– 26

TO : **Deans/Directors/Heads of Offices**
Attention: Administrative Officers

FROM : *Carmencita D. Padilla*
CARMENCITA D. PADILLA, MD, MAHPS
Chancellor

SUBJECT : **POLICIES ON APPLICATIONS FOR LEAVE**

Pursuant to the Civil Service Commission Omnibus Rules on Leave and as amended by CSC MC No. 41, s. 1998, all employees are hereby reminded of the following:

1. Sick Leave application **should be filed immediately** upon the employee's report to duty.
 - 1.1. Sick Leave for more than 5 days shall require a medical certificate (CSC Form No. 41) and must be validated by the Employees' Clinic, (CSC Form No. 41 is downloadable from the HRDO website).
 - 1.2. In case of doubt, the immediate supervisor may require the employee to submit a medical certificate even if the sick leave is 5 days or less.
 - 1.3. Sick Leave may be filed in advance when the employee will undergo medical procedure or advised to rest duly supported by a medical certificate.
 - 1.4. Application for half-day sick leave is allowed provided that it is also **supported by a medical certificate.**
2. The following Leaves must be filed **at least 5 days in advance**:
 - 2.1. Vacation/Forced or Mandatory Leave.
 - 2.2. Special Privilege Leave (SPL). SPL must be availed of for a minimum of one (1) full day (Half-day is not allowed).
 - 2.3. Solo Parent Leave (except for emergency cases)
 - 2.4. Compensatory Time-Off (CTO).

Note: The head should exercise due diligence in approving/granting leave of absence of employees and should act promptly on leave applications.

3. Applications that do not follow the above policies shall become unauthorized leaves and may be covered by the Policy on Absenteeism. Quoted hereunder is the CSC MC no. 4, s. 1991 on the relevant policy:

"A. Habitual Absenteeism

1. *An officer or employee in the civil service shall be considered habitually absent if he incurs unauthorized absences exceeding the allowable 2.5 days monthly leave credit under the leave law for at least 3 consecutive months during the year.*

x x x

C. Sanctions

1. *The following sanctions shall be imposed for the violation of the above guidelines*
 - (a) *for the first violation, the employee, after due proceedings, shall be meted the penalty of six (6) months and one (1) day to one (1) year suspension without pay;*
 - (b) *for the second violation, and after due proceedings, he shall be dismissed from the service."*

For your information, guidance and strict compliance.

8.6 National Institutes of Health Memorandum – Filing of Leave for Government Transactions



NATIONAL INSTITUTES OF HEALTH

G/F National Institutes of Health Bldg. UP Manila, 623 Pedro Gil St. Ermita, Manila 1000 Philippines
Tel Nos. (632) 5264266, (632) 5264349 Telefax No. (632) 5250395 Website <http://nih.upm.edu.ph/nihrdms>



03 November 2016

To: Research & Administrative Personnel

From: *Eva Maria C. Cutiongco de la Paz*
EVA MARIA C. CUTIONGCO DE LA PAZ, MD, FPPS
Vice Chancellor for Research, UPM and
Executive Director, NIH

Subject: Filing of Leave for Government Transactions

The use of the Special Privilege Leave (SPL) is one of the means to be used by employees in transacting business with government offices like passport application and renewal, GSIS matters, PAG-IBIG and other government transactions.

To avoid use of the official time that can result to disruption of our services at the NIH and OVCR, we enjoin personnel to kindly apply for SPL prior to engagement of said transactions.

Thank you for your cooperation.

NSRC

Received by: *Austin*

Date: 11-04-16

University of the Philippines Manila
THE HEALTH SCIENCES CENTER

TYPES OF LEAVE

1. SICK LEAVE (SL)

- a. Earned 1.25 every month
- b. Can be filed in advance for check-ups and appointment for health reasons; Must be filed one day after the applied leave.
- c. Medical Certificate must attached if 3-5 consecutive days or more.

2. VACATION LEAVE (VL)

- a. Earned 1.25 every month
- b. Tardiness and undertime may be deducted to VL
- c. Must be filed 5 days in advance.

LEAVE PRIVILIGES OF EMPLOYEES

1. CNA (SICK LEAVE)

- a. Maximum: 5 days
- b. Can be availed on any working day
- c. Medical Certificate must attached if 3-5 consecutive days or more.

2. REHABILITATION LEAVE FOR JOB-RELATED INJURIES

- a. Maximum: 6 months
- b. Requirement/s: Medical Certificate and evidence showing that the wounds/injuries were incurred in the performance of duty.

3. SPECIAL LEAVE PRIVILEGES (SLP/SPL)

- a. Maximum: 6 days
- b. Must be filed in advance unless emergency reasons.
- c. To be used in any of the following
 - i. Birthdays
 - ii. Emergencies/calamities, in case of earthquakes, typhoons, floods and other natural and/or man-made disasters, calamities or accidents, subject to certification from the proper authorities;
 - iii. Enrolment;
 - iv. Graduation;
 - v. Hospitalization for immediate members of the family (Med. Cert. must submit)
 - vi. Weddings and honeymoons;
 - vii. Wedding anniversaries
 - viii. Relocation (subject to the submission of a certification from the barangay captain of the place where the employee relocated);
 - ix. Burial/mourning, in case of death of the employees' spouse, any of his/her children, parents, brothers, or sisters; Government transaction; and
 - x. Domestic emergencies

4. SPECIAL LEAVE PRIVILEGE FOR HOSPITALIZATION OF IMMEDIATE MEMBERS OF THE FAMILY

- a. Maximum: 2 days
- b. Requirements: Medical certificate of immediate member/s of the family

5. SPECIAL LEAVE PRIVILEGE FOR NURSING MOTHERS

- a. Maximum: 2 days
- b. Can be availed until the 6 months of age of the baby
- c. No requirement/s needed.

6. MATERNITY LEAVE

- a. Maximum of 60 days for those who rendered in the agency for 2 years (as of March 14, 2017)
- b. Requirements: Medical certificates, Fit-to-work from attending OB

7. PATERNITY LEAVE

- a. 7 days
- b. Qualification: Married male
- c. Availment: Up to four (4) deliveries of his legitimate spouse with whom he is cohabitating

8. PARENTAL LEAVE under Solo Parent Welfare Act of 2000 (RA 8972)

- a. 7 days
- b. Requirements: Proof of solo-parent (ID, Certificate, etc.)
If the child happens to be sick/check-up: Medical Certificate must attach to the leave form.

9. SPECIAL LEAVE BENEFITS FOR WOMEN under RA 9710 (An Act Providing for the Magna Carta of Women)

- a. Maximum of two (2) weeks up to two (2) months.
- b. Requirements: CS Form 6, SLB Form, Medical Certificates and Fit-to-work from attending physician.

10. TEN-DAY LEAVE under RA 9262 (Anti-Violence Against Women and their Children Act of 2004)

- a. Maximum: 10 days
- b. Requirements: Cs Form 6, Brgy Protection order, Temporary/Permanent protection from the court. Certificate of requesting Protection Order. Police Report and Medical Certificate

GRANT OF COMPENSATORY TIME-OFF (CTO)

- 1. Application should be filed in advance and approval is subject to the exigency of service
- 2. The CTO may be availed of in blocks of four hours (half day) or eight hours (whole day)
- 3. An employee may use the CTO up to five (5) days consecutively but not to exceed forty hours in a month.

