MINISTRY OF HEALTH

SULTANATE OF OMAN

CONGENITAL HYPOTHYROIDISM

GUIDELINES FOR NEONATAL SCREENING AND MANAGEMENT

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DEPARTMENT OF FAMILY & COMMUNITY HEALTH
DIRECTORATE GENERAL OF HEALTH AFFAIRS

Acknowledgment

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CH	Congenital Hypothyroidism
BBA	Born Before Arrival
BP	Blood Pressure
DFCH	Department of Family & Community Health
EPI	Expanded Programme on Immunization
FT_4	Free T_4
IV	Intravenous
µg	Microgram
MD	Medical Doctor
Mg	Milligram
ml	Milliliter
Mm	Millimetre
MO	Medical Officer
TFT	Thyroid Function Test
TSH	Thyroid Stimulating Hormone
PEAS	Performance Evaluation Assessment Scheme

Foreword

Ministry of Health of Oman is committed to continue its efforts for Reducing the child morbidity and mortality, through improving the extant services and initiating new services, based on the identified needs.

Congenital anomalies and genetic disorders are recognized as major Contributors to the child morbidity and mortality in Oman. Many of the inherited disorders can be prevented or their untoward outcomes reduced through newborn Screening and early intervention, in conjunction with other services such as Premarital screening and counseling, and preconception counseling that can help individuals in making informed decisions.

Congenital hypothyroidism is one of such disorders that when recognized early and treated, the long-term impacts of it in the form of poor mental and physical development can be prevented. Hence, considering the rewarding outcomes of preventing it through an early screening and intervention, Department of Family and Community Health (DFCH) decided to initiate screening for the newborns, as a part of Maternal and Child Health services.

As pre-service step towards commencing the newborn congenital hypothyroidism screening services, a pilot was carried out during the last quarter μOf 2004. The objective of pilot was to test the system designed, assess the logistics and over all feasibility of launching the services, nationally. The option of umbilical venous sampling was selected because of easy access and feasibility of universal coverage of all hospital births within 24 hours.

After the initial trial, TSH 40 mU/L was identified as suitable cut off value for congenital hypothyroidism for regular screening.

Since 2005, all newborns are screened at birth through a blood sample collected from the umbilical vein in the hospital and through capillary blood sample for babies born outside hospital (approximately 2%).

Having launched the newborn screening services nationally, further evaluated by application of Performance Evaluation Assessment Scheme (PEAS) tool, some flaws in the systems were observed. Hence, in order to rectify these flaws, the extant guidelines and flow charts have been updated that can address nearly all issues starting from blood sample collection, dispatch, retrieving tests, clearly specifying roles and responsibilities of providers at each level of health care level, counseling parents and follow up management of the detected cases, and finally documenting and reporting to DFCH.

I must express that apart from the great efforts of staffs of DFCH, several literature reviews on the latest evidence based recommendations on screening for congenital hypothyroidism, many clinician's inputs have gone into the updating of these guidelines. Therefore, we request all health care providers make the best use of these guidelines.

Dr. Yasmin Ahmad Jaffer
Director of Dept. of Family and Community Health
Ministry of Health of Oman

POLICY GUIDELINES

Congenital hypothyroidism screening of neonates is a health service that is provided to all newborns in all health care facilities of the sultanate of Oman, these are, Ministry of Health hospitals, extended health centers, sister government and private health institution.

While screening is provided at all, levels of health care systems, therapeutic management and follow up are provided at the secondary and tertiary health care levels.

The components of neonatal Congenital hypothyroidism screening and management service are :

- ***Screening of neonates through TSH test***

- ***Retesting of neonates with TSH test that have elevated TSH or***
- ***inconclusive or invalid samples***

- ***Initiating treatment for confirmed congenital hypothyroidism***
- ***cases***

- ***Educating and counseling parents of neonates with congenital hypothyroidism***

Cord blood samples will be collected and immediately sent to the laboratory. If the TSH results are elevated or inconclusive the test will be repeated to confirm the reults.

All cases with elevated TSH will be referrd to the secondary health care hospital for further management and follow up.

Parents of the confirmed cases of congenital hypothyroidism will be educated and counseled on the nature of the disease.

Follow up and management plans will be discussed and agreed upon with Parents.

Confirmed cases of congenital hypothyroidism will be notified on the congenital anomaly and genetic disorder notification form.

Confirmed cases will be subjected for advanced investigations and may need referral to tertiary health care level, if necessary.

Introduction

Congenital hypothyroidism occurs in one in every 3,000 to 4,000 births in most geographic areas of the world. When undetected early in neonatal period, it leads to mental retardation and poor physical development of the child. Considering the feasibility of preventing it through early screening and intervention, many countries have initiated routine screening of the newborn for it, and have found it very cost effective.

Following the pilot in last quarter of 2004, Ministry of health of Oman (MoH) initiated screening of newborns for congenital hypothyroidism at national level in the year 2005. The annual number of congenital hypothyroidism cases reported have ranged between 16 to 24 and, incidence ranging from one in 2400 to one in 2700, live births. The case occurrence was found to be sporadic without any predilection for any area or region. 0.5% of newborns were found positive with the initial screen test and 1 in 9 of the initial positives were finally diagnosed as Congenial Hypothyroidism.

To evaluate the functioning of systems and services, Performance Evaluation Assessment Scheme (PEAS) was carried out in the year 2008. The objective of evaluation was to identify deficiencies and rectify them. Although the evaluation indicated overall efficiency of the system, it also highlighted the need for greater elaboration in the guidelines on: the protocols, documentation and data accumulation and summation, and parental counseling, communication and education. Therefore, the guidelines have been updated to address the above issues.

The development of these guidelines has taken place in perspective of recent literature review on the latest evidence based recommendations on screening for congenital Hypothyroidism and review by a panel of national experts and its finalization with common consensus.

This guideline cover the MoH policies; sample collection procedures; follow-up of results and case management; parental counseling; laboratories and related logistics and specifies the role and responsibilities of health care providers at various health care levels.

Procedures for blood sample collection & dispatch at the maternity center of the hospital:

- **Umbilical blood sampling:**

1. Collect 3 ml of cord blood with a 5 ml syringe within 2-3 minutes of birth.
2. Transfer the blood to a 5 ml plain glass tube with red cap.
3. Inform parents about the test and, that they will be notified if test results are abnormal.
4. Ensure that documents accompanying the specimen are appropriate, accurate, and complete.
5. Transport blood to the hospital laboratory (lab.) at room temperature.
6. If health facility that can't process the blood samples, then it should store the sample at 4^0c and later transport it to the regional lab.

- **Venous Blood Sampling:**

1. In the case of invalidity of cord blood sample a repeat venous sample should be drawn from the baby and sent to the lab. Please follow the same procedures described above for sample collection and documenting the reason for invalidity of cord specimen.

For procedure and timing of blood collection in unusual situations, refer to Box 1 "Special considerations" on page No. 5.

Section Three: Blood collection and processing

BOX 1 :

Special considerations
Born Before Arrival (BBA) :
Collect 2-3 ml of blood sample by venous -puncture (not cord blood) as soon as the child arrives and send it to the hospital laboratory as early as possible (placental blood is not acceptable).
Home delivery :
Collect blood sample by venous-puncture at the first contact and send it to a laboratory with facilities for TSH testing as soon as possible. Please note that even if the baby showed up late (later than 6 days) the test should also be done to avoid further damage by hypothyroidism.
Pre-term & low birth weight babies :
It is recommended to repeat the Thyroid Function Test at 4-6 weeks for all preterm neonates of less than 30 weeks of gestation and those with a birth weight less than 1500 grams, as there might be a delayed rise in TSH due to immaturity of pituitary – thyroid feedback mechanism. Neonates born between 30 37 weeks of gestation have almost similar TSH values as compared to those at 37 weeks, therefore, there is no need to re-screen neonates who are older than 31 weeks.
Very sick Neonates:
For example, TSH should be repeated at 2-4 weeks after birth for the Neonates in SCBU, neonates with cardiac disease and those that were on Dopamine administration.
Neonates with hypothalamic/pituitary disorders :
If hypothalamic/ pituitary disorders are suspected, neonate should be referred to endocrinologist for further management and follow up.
In certain conditions :
TSH should be repeated after one year for all Down syndrome cases for which, parents should be informed and a note made in the Child's Health Record.

Follow up of results, recall, and communication:

Guidelines on the follow up of results, recall of positive cases and communication with parents.

- **Definition of Congenital Hypothyroidism:**

All cases with repeat (venous blood sample) TSH values of >40 mU/L should be treated as hypothyroid irrespective of Free T_4 or T_3 value or normal clinical findings.

All cases with repeat (venous blood sample) Free T_4 value less than 10 IU/L should be treated as case of hypothyroidism irrespective of TSH, T_3 value or normal clinical findings.

- **Follow up of the results and recall:**

1. All tests should be recorded in the maternity register by the maternity staff nurse.

2. The maternity staff nurse should also fill the 'Newborn screening for congenital hypothyroidism form,' (annex 2) and send it on daily basis to the hospital laboratory focal person.

3. The laboratory focal person should ensure that numbers of samples received are as per the form and that all samples received are suitable for processing. If the sample is invalid, please inform the maternity staff nurse to recollect the blood sample and send it for repeat test, while the neonate is still admitted in the birthing facility.

4. In the case of discharge, the birthing facility focal point will trace the case with the assistance of regional focal point and primary health care facility to do so. This can be done by faxing the congenital hypothyroidism screening form to the regional focal point who will collaborate with parent institution focal point in tracing the neonate.

5. If parent institution is unable to trace and recall the neonate by the end of 3 weeks, then they should report to Regional Focal Person.

6. In the case of abnormal results, recall the neonate for a repeat test. This should be preferably done by the pediatrician. Please make use of the standard script provided below, for recalling the case.

7. Make sure to note down the result of the screening in the Child Health Record.

8. Report the final feedback to the regional focal point.

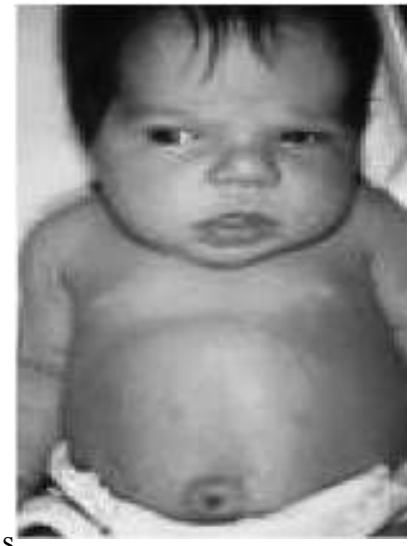
9. Notify all confirmed cases of congenital hypothyroidism on the congenital anomaly and genetic disorder notification form.

10. The regional focal point will send quarterly and annual reports on the number of neonates screened and detected of congenital hypothyroidism screening to the Department of Family and Community Health.

Clinical features of congenital hypothyroidism

Clinical features of congenital hypothyroidism may not be fully apparent at birth and might take time to become recognizable. However, the following features are considered the main clinical features of congenital hypothyroidism:

- Large tongue,
- Hoarse cry.
- Facial puffiness.
- Umbilical hernia.
- Hypotonia.
- Mottling.
- Cold hands and feet.
- Lethargy.
- Large anterior or posterior fontanels.
- Delayed linear growth.
- Goiter.
- Other nonspecific signs: prolonged, un-conjugated hyper-bilirubinaemia (jaundice), prolonged gestation (>42 weeks), feeding difficulties, delayed passage of stools, hypothermia or unexplained respiratory distress in full term infants.



Communication with parents:

Communication with parents is essential for ensuring proper follow up and management of cases.

Inform /explain to the parents

- About the test performed and the results obtained, if available.
- If the test has to be repeated, reasons for doing so.
- If the results are not ready at the time of discharge, how to obtain them later.

Make sure to document the results in the Child Health Record.
If you had to repeat the test because the result is doubtful, call the parents using the standard script provided below (Box 2).
Document details of follow up communication including date, name of person communicating the information and name of person receiving the information.

BOX 2

Standard script
For telephonic conversation with the parents of neonate with positive test results

- Introduce yourself, greet mother and ask about her and about the baby
- Ask, "Do *you remember that your baby's blood was tested for thyroid*
- *function (hormone levels)" test*
- Wait for response and say, "We *would like to retest his/her blood*
- *because the result is doubtful"*
- Ask, " *how soon you can come and bring your baby for the re-test"*
- If she is not proposing to come soon, tell her *"it is important to come*
- *soon because your baby may require treatment after the test result* "
- Request her to come with the baby to perform the test and proceed with the needed management.

Parent's education, Counseling and support :

All parents of cases with confirmed congenital hypothyroidism should be counseled by a specialist (e.g. Pediatrician) at the initiation or soon after initiation of treatment, as follows:

1. Issue the parent brochure 2 and ask parents to read it before counseling
2. Provide counseling as per standard guidelines (see below)
3. Let the parents ask any other questions if they wish
4. Check the understanding of parents at the end of counseling
5. Refer the parents to a family who is successfully managing a child with hypothyroidism (if available and agreed by both families).

Counseling in Hypothyroidism: (Five A) construct

ASSESS

- Assess details of screening and confirmatory tests and re-confirm that treatment is necessary
- Ask about clinical symptoms & look for signs: constipation, prolonged jaundice, coarseness of skin
- Listen to mother's concerns and build confidence with her by reassurance.

ADVICE

Give the following information (please refer to ANNEX 1) :

- Thyroid gland: its position and function in the body (production of thyroxin)
- Thyroxin hormone: can be given by mouth, it is an effective treatment
- The child may require life long treatment
- The disease will have good outcome if treated without interruption.

Ask parents for any queries answer and assure accordingly

AGREE

Agree with the client on next steps:

- To start the treatment with thyroxin.
- Thyroid ultra sound/scan (if not done).

ASSIST

Assist in the management plan as follows:

- Prescription for medication
- Give brochure on hypothyroidism and request her to read.

ARRANGE:

- Arrange scan appointment if not done
- Give appointment for follow up visits.

Management :

If the initial TSH value above 40 mU/L, provide Initial management as follows (Annex 3) :

1. Explain to the parents about the initial test result, initial treatment and the need for confirmation by further tests
2. Collect blood for TSH and Free T_4 and send to lab.
3. Start treatment on a temporary basis with thyroxin 10-15 g/ kg/day once given in the morning
4. Review the case with TFT results
5. If repeated TSH is <40 mU/L discontinue treatment
6. If Free T_4 is low start treatment with L-Thyroxin at a dose of 10-15 g /kg
7. Following initiation of treatment If repeat TSH is >40 mU/L and Free T_4 value is >15 mU/L, check for the compliance of medication. Repeat TFT in 2 weeks time if picture remains to be the same refer the case to endocrinologist
8. Treatment should commence at a dose of 10-15 g/kg/day once given in the morning
9. The dose should be titrated according to the biochemical values of free T4 and TSH.

All confirmed cases of hypothyroidism should be managed as follows :

1. Commence treatment with L-thyroxin 10-15 g/kg if Free T_4 value is more than 5 IU/L
2. Commence treatment with L-thyroxin 50 g if Free T_4 is value is 5 IU/L or less
3. Repeat TFT in 2 weeks and adjust dose to maintain TSH below 10 mU/L and Free T_4 at upper half of normal value [normal Free T_4 value (11-24 pmol/L)
4. Continue treatment if the child has clinical signs suggestive of congenital hypothyroidism even if TFT values are normal
5. Suspect non-compliance to treatment If TFT results are not in conformity with the expected levels while the child is on treatment
6. All confirmed cases must be notified to DFCH via the congenital anomalies form.

Follow up of cases with congenital hypothyroidism :

All children under treatment should be followed up rigorously as follows. The child should have TSH, T_3 & T_4 done at all follow-up visits. The child should also be evaluated for clinical signs of hypothyroidism.

1. **The first follow up visit :** 2 weeks after starting the treatment. Please make sure that a request for Brain Stem Evoked Potential test is sent for the patient to get a follow up appointment date (should be done between the first and the third month of life, it is available at Al-Nahdha hospital and at Sultan Qaboos University Hospital SQUH).
2. If there is a facility for thyroid scan, it should be arranged immediately.
3. If there is no facility for a thyroid, scan treatment should commence immediately.
4. **Second follow up visit :** 2 months after first visit.
5. **Third follow up visit :** 2 months after second visit.
6. **Fourth follow up visit :** 3 months after the third visit.
7. **Subsequent visits :** 3 monthly until 4 years of age.
8. **Follow up visits :** at six monthly intervals if the disease is under control.

Case Re-evaluation:

All children under treatment should be re- evaluated at 3 years as below :

1. If thyroid scan was not done during the neonatal period, it should be done after completing 3 years of age. Thyroxin should be stopped for one month before the thyroid scan
2. Perform TSH, T_3 & Free T_4 (Child should be off treatment for 4 weeks before the test).
3. If thyroid ultrasound and scan, TSH, T_3, Free T_4 are normal and child has no clinical signs discontinue treatment and notify
4. If child has clinical signs of hypothyroidism continue treatment even if test results are normal.

1) Reception of Specimens and Accompanying Documentation :

A. Specimens received for screening are checked for :

a) Quantity of blood is sufficient (>2 ml)
b) Blood collected is in the correct container (plain container – clotted blood)
c) There are no leakages
d) The container is unbroken
e) The age of the specimen is acceptable (<3 days and has been stored at 4° c) i.e. Cold chain has been verified.
f) That the specimen is not in any other way invalid[1].

B. The documents accompanying the specimen :

a) Are legible
b) Patient identification is complete
c) Dates, time of sampling etc. are complete.

C. Notification of problems associated with the specimen or documentation :

a) Specimen submitter or birthing facility focal point (BFFP) is notified about any problems associated with the sample/documentation within 24 hours of receipt
b) The BFFP is informed of the reason for the invalidity of the specimen so that a repeat sample from the subject can be initiated as soon as possible
c) A written record is kept of each incident of non-compliance with the specimen or documentation protocol
d) A copy of the record of sample or documentation non-compliance is sent to the BFFP

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[1] If the specimen did not meet the above requirement then it will be called as **invalid** screening test and if the screening results are outside of the expected range of the testing result, then it is known as **out of range.**

D. Sample Entry

After verification of sample integrity and compliant documentation, each specimen will be entered into the laboratory computer and assigned a unique laboratory number according to standard laboratory protocols for the receipt of all laboratory specimens.

2) Analytical Procedure

a) The specimen is centrifuged and the serum separated and stored frozen until ready for analysis.

b) The specimen will be analyzed in the normal way following the procedures prescribed in the Standard Operating Procedures (SOP) for TSH analysis along with other clinical specimens.

c) Any abnormal result will be repeated on the original sample for TSH.

d) If the TSH is high the BFFP of the birthing facility from where the sample was collected and sent, will be notified immediately in order to facilitate a follow-up blood specimen collection and dispatch (see Positive Sample Follow-up Procedure (PSFP).

e) All required Quality Control (QC) samples would be run in conjunction with the test samples.

f) Only when all QC samples are in compliance with acceptable criteria will the test results be accepted and released.

g) All test results and QC results will be maintained on the host computer (test results) and on the instrument file (QC results).

h) A hard copy of all test results along with unique identifying number will be retained in the laboratory.

I) A copy of all cord blood TSH results will be sent to the BFFP.

BLOOD SAMPLE

3) Sample Follow-up Procedure

a) When a blood sample is found positive i.e. a test result on a cord blood that exceeds the cut-off limit (currently >40 mU/L) the test will be repeated on the same (first) sample

b) If the TSH is >40 mU/L on the repeated test sample, the birth facility focal point is to be contacted immediately and a request to made for a repeat (second) sample.

c) When the repeat (second) sample is obtained following an initial confirmed positive result and the repeat TSH is still high (>40 mU/L) a confirmatory Free T_4 will be done. The TSH and Free T_4 results will be documented and the BFFP immediately informed by phone and in writing, using the prescribed documentation for follow-up.

4) Reporting of all normal TSH results

a) Results will be issued as soon as verified and within the prescribed period (no later than 5 days of receipt of blood sample).

b) The reports are to be sent to the birthing facility focal point by mail (internal or external) unless otherwise requested by the birthing facility focal point and a feedback to be sent to the regional focal point.

Section Seven: Data Management

Data accumulation and summation:

The delivery health facility carries the responsibility of keeping records of cases and dispatching them appropriately to respective health care facility. The following section highlights the process and necessary requirements.

Documentation, accumulation, and summation data includes :

- Number of live born
- Number of TSH tests performed
- Number of results tracked
- Numbers confirmed
- Numbers lost with documentation of reasons
- Date of diagnosis (confirmation after the second blood sample).

Appropriate follow up data should be reported/sent to :

- MCH/Child Health coordinator (Regional Focal Person)
- DFCH to maintain data base on congenital hypothyroidism screening.

Final case disposition (affected, not affected, lost to follow-up) from the secondary care should include :

1. Date of evaluation to confirm screening results
2. Date of diagnosis/case disposition
3. Date of initiation of Treatment/intervention (if applicable)
4. Test results on which diagnosis was based
5. Name of person who communicates the diagnosis information
6. For diagnosed cases (i.e. affected), referral and follow up information to the primary care
7. For cases with uncertain diagnosis, clinical surveillance and action plan to achieve case resolution
8. Identification of the person recording/entering the information.

NB. A monthly report of the identified cases of high TSH level in the birthing institutions should be sent to the parent institution to keep it in their records.

Annex 1.

Information for Counseling Parents of a Child with Hypothyroidism

What is congenital hypothyroidism?

This is a disorder that affects infants from birth (congenital), resulting from the severe defficency of thyroid function (hypothyroidism), normally due to failure of the thyroid gland to develop correctly. Sometimes the thyroid gland is absent, or ectopic (in an abnormal location). As a result, the thyroid gland does not produce enough thyroxine/T_4 after birth. This may result in abnormal growth and development, as well as slower mental functions.

The thyroid is a gland located in the neck and is part of the endocrine system. This gland is responsible for secreting a hormone called thyroxine (T_4) which plays a vital role in normal growth and development in children. This gland, like other glands in the endocrine system is controlled by the pituitary gland. It works very much like a thermostat. The brain senses the amount of T_4 and then signals the thyroid with another hormone, thyroid stimulating hormone (TSH) to produce more or less T_4. When the thyroid gland produces enough T_4, no extra stimulation is needed and the TSH level remains at a normal level. When there is not enough T_4, the TSH rises. These characteristics of the T_4 and TSH hormones allow for screening of newborns to assess if the infant has normal or abnormal thyroid funtions.

Why a child develops congenital hypothyroidism?

In most hypothyroid babies, there is no specific reason why the thyroid gland did not develop normally, although some of these children have an inherited form of this disorder. The parents should not feel the blame, as congenital hypothyroidism is NOT caused by any life style pattern or behavior of the family.

What are the symptoms of congenital hypothyroidism?

Often these babies appear perfectly normal at birth, that is why screening is so vital. However, some may have one or more of the symptoms such as puffy face, swollen tongue, hoarse cry, low muscle tone, cold extremities, persistent constipation, lack of energy, excessive sleep, not growing etc.

What tests are done for confirming congenital hypothyroidism?

The thyroid functions (TFT) test including TSH, T_4 & T_3 are confirmatory. A thyroid scan may be done to determine the location, or absence of the thyroid gland. Sometimes the scan may be done when the baby is three years old if it cannot be done before starting treatment.

How does one treat congenital hypothyroidism?

Treatment for congenital hypothyroidism is replacement of missing thyroid hormone in tablet form. It is extremely important that these tablets are taken daily for life because, thyroxine (T_4) is essential for all body functions. In general, the average starting dose for L-thyroxine or Levothyroxine (synthetic T_4) in a newborn is between 25 and 50 g per day or 10 to 15 g/kg of body weight. This value increase is dependent upon the individual needs of the child. The tablet can be crushed, and then administered in a small amount of breast milk while the child is still an infant.

Please be aware that L-thyroxine should not be mixed with Soy formula or with iron supplements as these products interfere with absorption. Blood tests will be done on a regular basis to ensure that the hormone levels are in a normal range. Thyroid hormone is necessary for normal brain and intellectual development and such development can be delayed when there is a lack of L-thyroxine.

What type of medical attention should the child receive?

Frequent visits to the doctor will be necessary with blood drawn to check if the laboratory values show normal thyroid levels. Once normal levels are reached, the blood tests will become less frequent. Generally, children are seen every 2 - 3 months, for the first three years, once normal levels have been established. The goal is to maintain the concentration of T_4 in the mid to upper half of the normal range (11-24 pmol/l) for the first years of life. The TSH level should be maintained within the normal reference range for infants. The treatment for hypothyroidism is safe, simple, and effective. Successful treatment, however, depends on life long daily medication with close follow up of hormone levels. Making this procedure of taking medication on a routine basis needs to become a part of the lifestyle of the child in order to assure optimal growth and development.

Will other children have the disorder?

There is a small chance that the next child may have the same problem and will need to be screened after birth.

What is the out come for a baby with hypothyroidism?

There is no cure but the serious effects of the disorder can be lessened and often prevented if medical treatment is started early and continued for life. There are a small proportion of children who have temporary (transient) congenital hypothyroidism for a period of time after birth. It is impossible to distinguish these transient hypothyroid babies from those with true congenital hypothyroidism and so these infants will be treated as well. The child will need to be reviewed and retested after 3 years treatment to decide if the child will need lifelong treatment. In any case treatment should NOT be discontinued before 3 years. With early replacement of adequate thyroid hormone and proper follow up and care, the outcome would be favorable.

Annex 2

NEONATAL SCREENING FOR CONGENITAL HYPOTHYROIDISM & FOLLOW – UP SYSTEM FOR NEWBORNS TESTED FOR TSH

NEWBORN SCREENING FOR CONGENITAL HYPOTHYROIDISM FORM

LIST OF LIVE BIRTHS IN THE LAST 24 HOURS (DATE : .....)

Hospital : ..... Region : ..... Focal person name : ..... Designation : .....

	I.P. No.	Date of Birth	Mothers' Name	ANC No.	Parent Inst.	Contact No.	TSH Result		Remarks
							Value	Pending	If need to repeat the sample
1									
2									
3									
4									
5									
6									
7									
8									
10									

a.The Delivery Units
- All information should be completed by the labour room staff, then send to the lab. on daily 24 hrs. basis. (Source of information is the Maternity Register.

a.The Hospital Laboratory
- The Last 2 shaded columns are for lab. use. The lab. will fill the needed data and then fax it to regional focal point in the next 48 hours.

a.The Region
- The regional focal persons will fax it to all parent institutions focal persons.

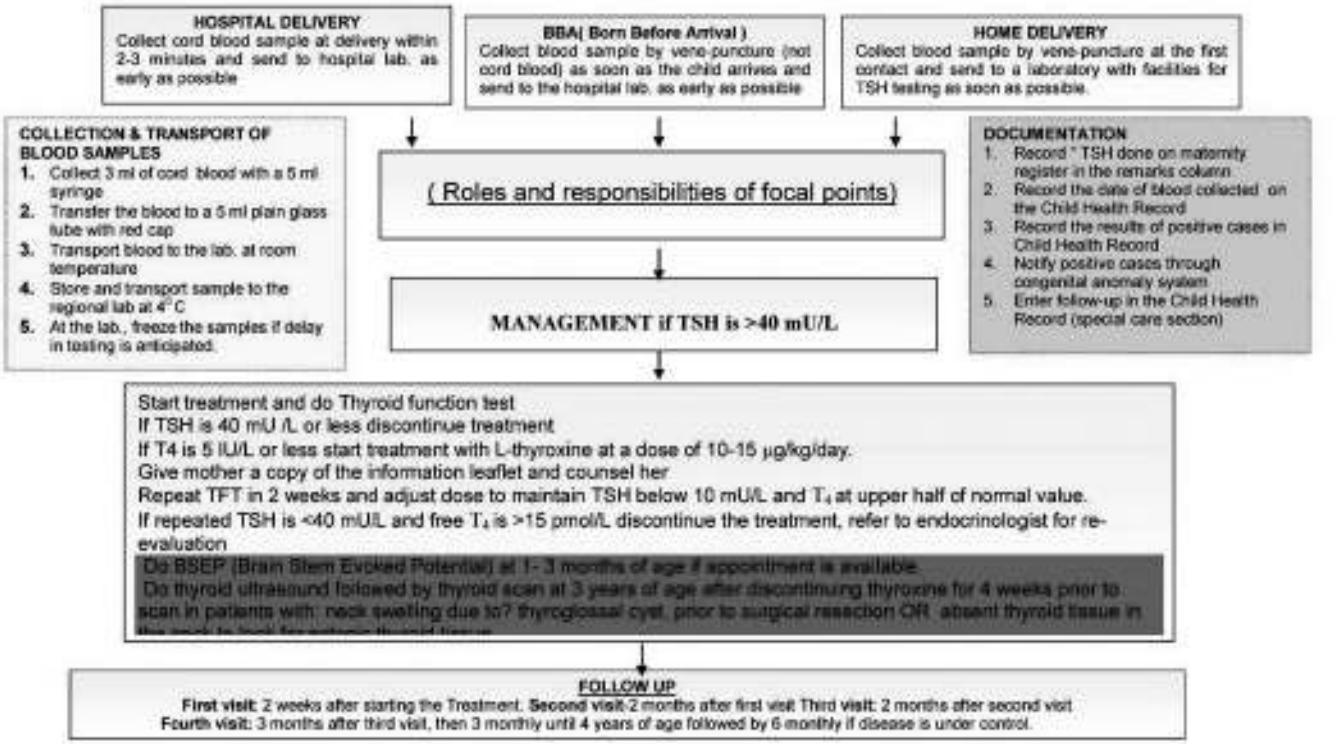
a.the Parent Institutions
- The EPI focal persons will note down the value of TSH on the child health Record during the first visit of the child in the child health clinic.
- EPI focal persons will recall the babies who need a repeat sample & a venous sample will be collected in the parent institution. Write down the lab request form & fill the special Neonatal TSH request form label as Neonatal TSH – missed & send to lab.

a.the Hospital Laboratory
- The laboratory focal person should continue updating the list of Newborns tested for TSH -missed. Send the new list to the Regional Focal persons after obtaining the latest results.

Annex 3

Department of Family & Community Health, D.G.H.A-MOH

NEONATAL SCREENING AND FOLLOW UP SYSTEM FOR CONGENITAL HYPOTHYROIDISM



Note : if the child has clinical signs suggestive of congenital hypothyroidism treatment should be started even if TFT values are normal. If TFT results are not in conformity with the expected levels while on treatment suspect non-compliance to treatment.

***Annex 4* :**

Roles and responsibilities of focal points in respective locations

Focal point in the labour room :

Fill the details of all newborns, born within the last 24 hours in the enclosed form (Annex) 1
Send the form to the lab. of the same health institution
In case if the lab is in another health institution use fax to report to the lab.
Repeat the test if required and if the baby still in the hospital.

Focal point in the lab. :

Fill in the section of above form (annex 1) related to the TSH of the same cohort of newborn within 48 hours and send it to the regional focal point
Newborns with TSH values above 40 mU/L or invalid samples, please report as soon as possible to the focal point in the labour room and if the baby is discharged report to the regional focal point
Complete the data regarding TSH values and send it to the regional focal point.

Regional focal point (who can be the child health coordinator or the MCH) :

Locate from the forms the parent institution of newborns with TSH value above 40 mU/l or with the invalid samples that must be repeated

Fax the form to the focal point to the respective parent institution to take action

To send the congenital hypothyroidism quarterly report to the DFCH.

Focal point at the parent institution :

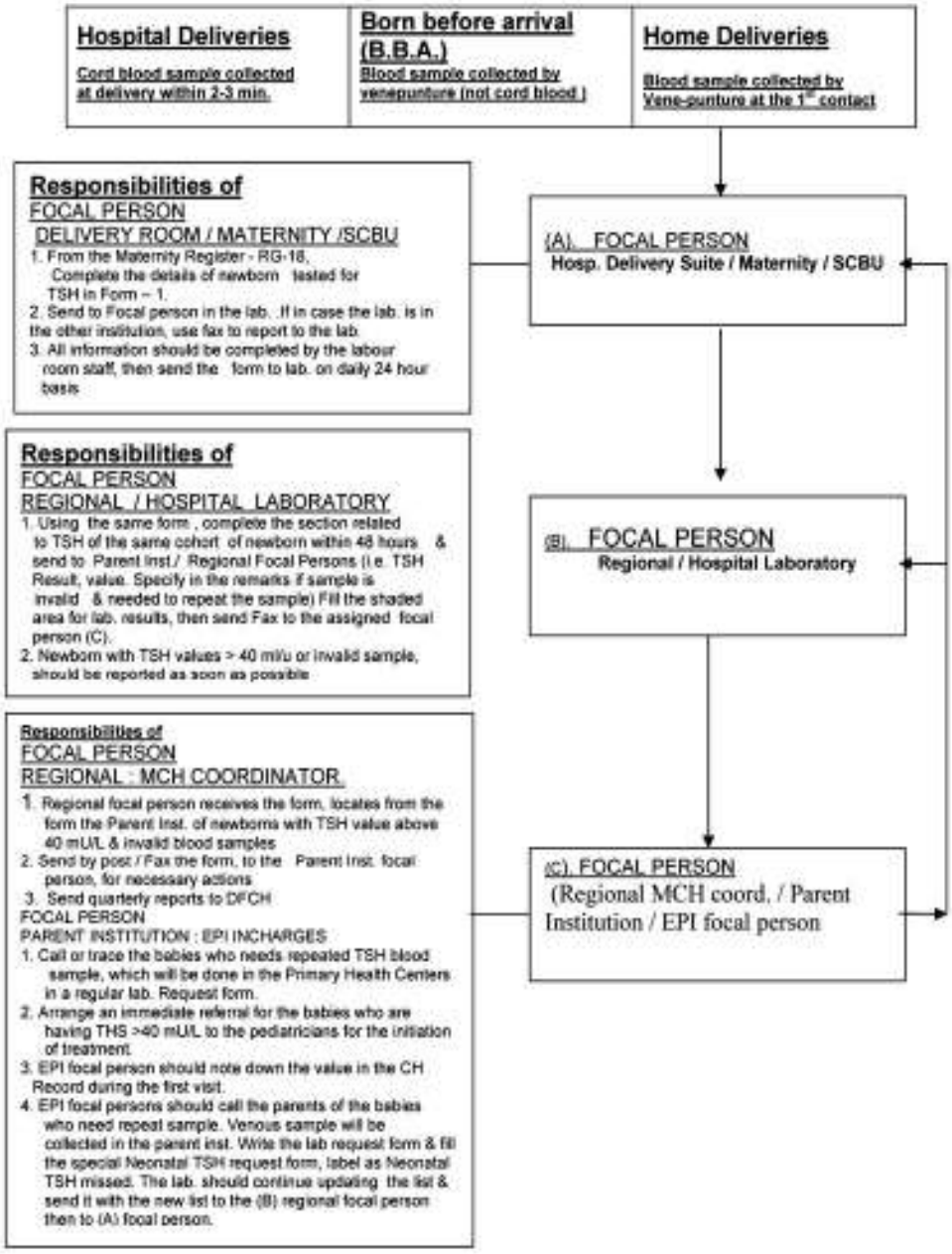
Receive the form from the regional focal point and call the babies who need to have a repeat TSH blood sample because of invalid samples. This sample will be a venous sample and it will be done in the primary health center in the usual lab request form
Arrange an immediate referral of the baby who has THS >40 mU/L to the pediatrician for the initiation of treatment and for repeating TSH sample.

***Annex 5*:**

Department of Family & Community Health, D.G.H.A-MOH

NEONATAL SCREENING FOR CONGENITAL HYPOTHYROIDISM

FOLLOW – UP SYSTEM FOR NEWBORNS TESTED FOR TSH



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