Ashford and St. Peter's Hospitals
NHS Foundation Trust

Congenital Hypothyroidism Guideline

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Date	Page(s)	Comments	Approved By
June 2013	New Guideline		
March 2018			
December 2019		Whole document review	Paediatric Guideline Group
June 2026		Whole Document review	Paediatric Guideline Group

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1. Guideline

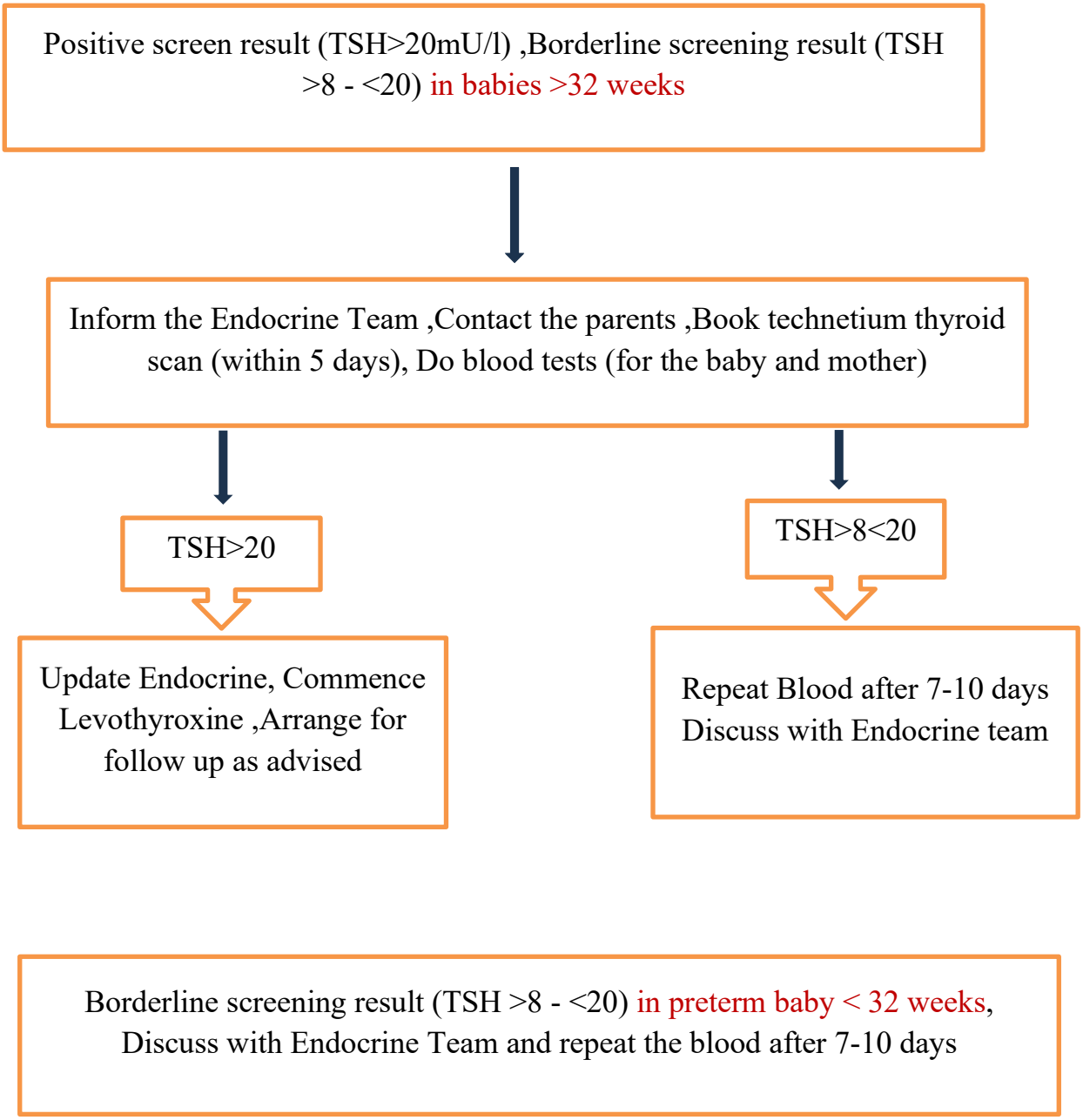
Introduction

Congenital hypothyroidism causes neuro-developmental delay. Although this may in part be related to low levels of thyroxine in utero, delay in diagnosis and treatment will further compound the neurological damage. Hence this is a medical emergency and must be treated as such.

NB. Secondary hypothyroidism will not be detected by the Newborn Blood Spot Screening (measures TSH) and may only present with other signs of congenital hypothyroidism eg. prolonged jaundice (thus thyroid function tests still required).

Please inform Endocrine team of all new cases as soon as possible.

Flow Chart



Borderline screening result (TSH >8 - <20) in preterm baby < 32 weeks, Discuss with Endocrine Team and repeat the blood after 7-10 days

Management

Clinical assessment and investigations

- 1-Contact the parents and Inform about the result and need of further blood and imaging.
- 2-Arrange for imaging: Thyroid USS & Isotope scan
- 3-Detailed History and examination.
- 4- Blood tests from baby and the mother

1-Contact parents: The baby should be seen within 12-24 hours of notification of a positive screen result (TSH>20mU/l). Contact the parents with the date of attendance and explain the Newborn Blood Spot Screening result and plan for further tests.

2-Images:

Obtaining Ultrasound and radioisotope scan helps to establish whether the condition is likely permanent. It can show if the thyroid gland is:

- Absent
- Ectopic
- Normally situated but abnormal in size and shape
- Normally situated and normal in size and shape

A- Book the technetium thyroid scan with the Nuclear Medicine Department (at Royal Surrey Hospital) They will need to know the baby's birth weight.

Book the scan as soon as possible and not later than 5 days after starting therapy.

B-The thyroid ultrasound scan: can be performed at any stage and not need to be confined to neonatal period.

Initiation of treatment should not be delayed while waiting for an isotope scan, which can be performed up to 5 days after starting therapy

3-History and Examination:

History

Including maternal thyroid status (previous history of thyroid dysfunction, maternal anti-thyroid medications), maternal diet (for example a vegan or other low iodine diet) and family history of thyroid disease.

Examination

Babies with Congenital hypothyroidism are more likely to have associated anomalies, particularly congenital heart defects and hearing loss, this require careful neonatal examination and follow up.

Other examination includes underlying dysmorphic syndromes, prolonged jaundice, signs of infection, hypotonia, umbilical hernia and dry skin.

Record and plot weight, length and head circumference.

Check the red book to make sure the hearing screening has been done, and whether passed or not.

4- Blood from baby and the mother:

From baby:

Insert intravenous cannula (if having Technetium scan). Blood taken from baby for:

- Free T4 and TSH

- Anti-thyroid antibodies

- Thyroglobulin

- Liver function tests if jaundiced

From the mother:

1-Free T4&TSH

2-TSH Receptor antibodies in mothers with a current or previous history of autoimmune thyroid disease.

(Ensure documentation of the mother's details on the patient's medical record name, D.O.B and NHS number).

In babies >32 weeks with borderline raised TSH (>8 - <20) on Newborn Blood Spot Screening, book a thyroid USS and repeat blood as above (after 7 -10 days) but await results before deciding on treatment.

In preterm babies (<32 weeks) with borderline TSH levels, discuss management with the Consultant. Most of them are transient and will simply need to have their thyroid function monitored (ideally in 7-10 days).

Treatment: (To be guided by Endocrine Team)

Aim:

Is to increase T4 close to the upper age-appropriate reference range within the first 2 weeks of the treatment and to normalise the TSH within the first month.

Levothyroxine.

Commence baby on Thyroxine 25mcg once daily once the bloods have been taken. There is no need to wait for the results as adjustments to the dose can be made subsequently.

The Thyroxine should be given as tablet. The first dose should be given on the ward under nursing supervision.

Levothyroxine should be taken first thing in the morning on an empty stomach at least 30 minutes prior to eating or drinking anything.
It can be mixed with water. Although there is some evidence that it may also be mixed with milk, co-administration with milk may reduce absorption and overall exposure.

Follow up arrangements:

Follow up appointments should be made in the next available Endocrine clinic.

- The baby should have repeat TFT's, weight and general review in 2 weeks.

- Subsequently, TFT's will need to be arranged at 4 weekly intervals for the first 3 months

-Then, at 2month intervals for the next 3 and

-Then, 3 monthly between 6 and 12 months.

-Thereafter, 4 monthly until 2 years and 4-6 monthly afterwards.

Supporting References

- https://www.gov.uk/government/publications/congenital-hypothyroidism-initial-clinical-referral-guidelines/congenital-hypothyroidism-initial-clinical-referral-guidelines Published 27 March 2020.

3. Guideline Governance

a. Scope

This guideline is relevant to all staff caring for all children from 0-18 years old across the emergency department, inpatient ward and outpatient department.

b. Purpose

i. This guidelines aims to facilitate a common approach to the management of children. At times deviation from the guideline may be necessary, this should be documented and is the responsibility of the attending consultant.

ii. This guideline is subject to regular review to ensure ongoing evidence based practice.

c. Duties and Responsibilities

All healthcare professionals responsible for the care of all children 0-18years should be aware of practice according to this guideline.

d. Approval and Ratification

This guideline will be approved and ratified by the Paediatric Guidelines Group.

e. Dissemination and Implementation

i. This guideline will be uploaded to the trust intranet 'Paediatric Guidelines' page and thus available for common use.
ii. This guideline will be shared as part of ongoing education within the Paediatric Department for both medical and nursing staff.
iii. All members of staff are invited to attend and give comments on the guideline as part of the ratification process.

f. Review and Revision Arrangements

a. This policy will be reviewed on a 3 yearly basis by the appropriate persons.
b. If new information comes to light prior to the review date, an earlier review will be prompted.
c. Amendments to the document shall be clearly marked on the document control sheet and the updated version uploaded to the intranet. Minor amendments will be ratified through the Paediatric Guidelines Group. A minor amendment would consist of no major change in process, and includes but is not limited to, amendments to documents within the appendices.

g. Equality Impact Assessment

Background • Who was involved in the Equality Impact Assessment
Dr Eiman Haj-Ahmed, Dr Shailini Bahl
Methodology • A brief account of how the likely effects of the policy was assessed (to include race and ethnic origin, disability, gender, culture, religion or belief, sexual orientation, age) • The data sources and any other information used • The consultation that was carried out (who, why and how?)
All groups of staff and patients were taken into consideration and there is no bias towards or against any particular group.
Key Findings • Describe the results of the assessment • Identify if there is adverse or a potentially adverse impacts for any equalities groups
There is no evidence of discrimination.
Conclusion • Provide a summary of the overall conclusions
There is no evidence of discrimination.
Recommendations • State recommended changes to the proposed policy as a result of the impact assessment • Where it has not been possible to amend the policy, provide the detail of any actions that have been identified • Describe the plans for reviewing the assessment
This guideline is appropriate for use.

h. Document Checklist

To be completed (electronically) and attached to any document which guides practice when submitted to the appropriate committee for approval or ratification.

Title of the document: Congenital Hypothyroidism guideline

Policy (document) Author: Dr Eiman Haj-Ahmed, Dr Shailini Bahl

Executive Director: N/A

		Yes/No/ Unsure/NA	Comments
1.	**Title**		
	Is the title clear and unambiguous?	**Yes**	
	Is it clear whether the document is a guideline, policy, protocol or standard?	**Yes**	
2.	**Scope/Purpose**		
	Is the target population clear and unambiguous?	**Yes**	
	Is the purpose of the document clear?	**Yes**	
	Are the intended outcomes described?	**Yes**	
	Are the statements clear and unambiguous?	**Yes**	
3.	**Development Process**		
	Is there evidence of engagement with stakeholders and users?	**Yes**	
	Who was engaged in a review of the document (list committees/ individuals)?	**Yes**	**Paediatric Guideline Group**
	Has the policy template been followed (i.e. is the format correct)?	**Yes**	
4.	**Evidence Base**		
	Is the type of evidence to support the document identified explicitly?	**Yes**	

		Yes/No/ Unsure/NA	Comments
	Are local/organisational supporting documents referenced?	**Yes**	
5.	**Approval**		
	Does the document identify which committee/group will approve/ratify it?	**Yes**	
	If appropriate, have the joint human resources/staff side committee (or equivalent) approved the document?	**No**	
6.	**Dissemination and Implementation**		
	Is there an outline/plan to identify how this will be done?	**Yes**	
	Does the plan include the necessary training/support to ensure compliance?	**NA**	
7.	**Process for Monitoring Compliance**		
	Are there measurable standards or KPIs to support monitoring compliance of the document?	**NA**	
8.	**Review Date**		
	Is the review date identified and is this acceptable?	**Yes**	
9.	**Overall Responsibility for the Document**		
	Is it clear who will be responsible for coordinating the dissemination, implementation and review of the documentation?	**Yes**	
10.	**Equality Impact Assessment (EIA)**		
	Has a suitable EIA been completed?	Yes	

Committee Approval (Paediatric Guidelines Group)			
If the committee is happy to approve this document, please complete the section below, date it and return it to the Policy (document) Owner			
Name of Chair	**Dr Alexandra Jones**	**Date**	**10/7/2026**
Ratification by Management Executive (if appropriate)			
If the Management Executive is happy to ratify this document, please complete the date of ratification below and advise the Policy (document) Owner			
Date: n/a			