**CONGENITAL HYPOTHYROIDISM**

**(Pathway for Investigation)**

When the initial screening TSH result (from heel prick) for a particular infant is greater than 5mU/L, the result is confirmed by repeat analysis using the blood collection card. The confirmed TSH result is passed on to one of the Endocrine team, (Dr Hawkes/Dr Pryce at the Royal Gwent Hospital /Dr Shetty at Nevill Hall Hospital) who will then arrange for the baby to be reviewed within 24 hours. (If notification is received on a Friday parents are not usually notified until Monday)

**On ward, baby needs:**

* blood samples for free T4, Free T3, TSH and thyroglobulin (2mL li hep blood)
* if jaundiced split bilirubin (1.0mL lithium heparin)
* Thyroid scan (Ultrasound + uptake scan – either technetium or iodine – to discuss with radiology re availability of tracer and timing – please inform radiology+ submit forms and discuss with consultant )

Thyroid scan booking should not delay other investigations and treatment. Please liaise with radiology department.

**Parents need:**

* to see member of endocrine team for explanation of investigations
* leaflet about congenital hypothyroidism (see appendix 2)
* Mother needs blood taken for TSH, Free T4, Free T3 and TSH-R blocking antibodies. (5mls Li Hep)

The results of the assays on the liquid blood specimen will normally be available on the same day and decisions about treatment with thyroxine can be made swiftly.

A 123I or 99technetium uptake scan and neck USS will need to be booked, with Dr Jenny Haslam, Dr Jon Bainbridge or Dr Brian Huey (consultant radiologist).

(Although technetium is more readily available and exposes infant to less radiation, iodine produces less false positive results – tracer is usually only available on the 1st 3rd and 5th Thursday of the month))

Ideally the uptake scan should be carried out the next working day, however due to logistical problems it should be carried out within 5 days. In order to interpret the scan the TSH needs to be elevated (ideally >15mU/l) therefore if there is a delay in obtaining the scan and treatment has been initiated a repeat TSH on the day of the scan should be obtained (needs to be done prior to the scan being done)

If hypothyroidism is confirmed, commence baby on 10microgrammes/kg of Thyroxine (usually 25 or 37.5microgrammes) crushed tablets (T4), or Evotrox suspension. Arrange to review the baby in clinic in 2 weeks time, for repeat T4 and TSH measurement.

**If a delay in getting the TFT result is anticipated:**

**Action:**

1. If screening TSH was >50mU/l

Or) scan is abnormal

Or) the baby has clinical signs of hypothyroidism

Commence baby on 10microgramme/kg of Thyroxine (usually 25 or 37.5mcg) crushed tablets (T4). Arrange to review the baby in clinic in 2 weeks time, for repeat T4 and TSH measurement.

1. If screening TSH was <50mU/l

Or) the scan is normal

Or) the baby has no clinical signs of hypothyroidism,

Wait for the results of the formal blood testing.

Appendix

Management of Infant with Positive Screening Result for Congenital Hypothyroidism

Positive screening result for congenital hypothyroidism

(TSH >5mU/l)

Call family to arrange to come to CAU for assessment (if notification occurs on Friday delay calling parents until Monday)

Briefly explain results and need for further tests

* CAU assessment - see appendix 1
* weight/length /HC
* History + examination (document signs of hypothyroidism)
* Infant – TFTs + thyroglobulin (if jaundiced split bilirubin )
* Mother TFTs + Thyroid receptor antibodies
* Give prescription for Thyroxine tablets or Evortrox suspension – to start 10microgramm/kg – either 25 or 37.5 mcg – if TSH raised or T4 low (to start when contacted)
* Inform parents re scans – Ultrasound + Uptake scan
* Liaise with radiology re uptake scan + Ultrasound

(D/W Dr Jenny Haslam/Dr Brian Huey/Dr Jon Bainbridge)

* Chase results + contact parents to start thyroxine if TSH >50, T4 low

Liaise with Dr R Pryce/Dr D Hawkes (RGH) or Dr A Shetty (NHH) re follow up appointment

Rpt TFTS prior to clinic appt in ~2 weeks

**\***Ideally uptake scan should be done asap and prior to commencing thyroxine.

If there is a delay in obtaining the scan and the TSH >40mU/l or free T4 is low then start thyroxine.

Ideally the scan should be performed within 3 days of commencing thyroxine – please arrange for repeat TSH at time of cannula insertion in order to interpret scan.

CAU

1. To include in initial assessment

**Medical History**

Information to be obtained + documented;

Birth details – mode of delivery, birth weight etc

Feeding – establish if gaining weight - breast or bottle

N.B. soya milk can interfere with TFTs so need to know about

General alertness – I.e. waking for feeds or lethargic

Jaundice – has this resolved

Bowel habit

Document if infant passed newborn screening hearing check (some forms of hypothyroidism associated with hearing impairment)

Family history (any consanguinity)

Any history of thyroid /endocrine problems

**Examination**

Please document;

Alertness

Pulse rate

Presence of jaundice

Size of anterior fontanelle /any other fontanelles

Macroglossia

Presence of goitre

Umbilical hernia

**Appendix 2**

**Leaflet for parents;**

**Accessible at** [**http://www.newbornbloodspot.screening.nhs.uk/cht**](http://www.newbornbloodspot.screening.nhs.uk/cht)

**CHT is suspected leaflet**

**CHT and your child leaflet**

**References**

1. Paediatric Endocrine Management Guidelines (All Wales /UHW ) 2004
2. Great Ormond Street Guidelines /Management of congenital hypothyroidism <http://cms.ich.ucl.ac.uk/clinical_information/clinical_guidelines/cmg_guideline_00079>. Viewed on 16/5/2010
3. **Update of Newborn Screening and Therapy for Congenital Hypothyroidism**

American Academy of Paediatrics, Susan R. Rose, and the Section on Endocrinology and Committee on Genetics, American Thyroid Association, Rosalind S. Brown, and the Public Health Committee, and Lawson Wilkins Paediatric Endocrine Society  
Paediatrics 2006 117: 2290-2303.

Created R Pryce 2010, revised 2014