Information Sheet for Children with Congenital Hypothyroidism in Scotland

BASIC INFORMATION

ID No. ☐☐☐☐☐☐ CHI number: _____

Hospital Numbers: _____ at _____ hospital

_____ at _____ hospital

Name: _____

Sex: Male ☐ Female ☐ Date of Birth: ☐☐/☐☐/☐☐

Place of Birth: _____

Died: Yes ☐ No ☐ If died, date of death: ☐☐/☐☐/☐☐

Address at time of birth: _____

_____Post code: _____

Change of address since birth: Yes ☐ No ☐ If yes, how many times: ☐☐

Present address (if different): _____

_____Post code: _____

Paediatrician: _____

Address: _____

General Practitioner: _____

Address: _____

_____Post code: _____

Birth and Family Data

Mother Age when child born: ☐☐

Measured height: ☐☐☐ • ☐ (cms)

Ethnicity: UK ☐
Ireland ☐
Asia ☐
Europe (continent) ☐
Other (please specify) ☐

Maternal thyroid disease:

	Y	N	Not known
1. Hypothyroid?:	☐	☐	
If yes, on thyroxine?:	☐	☐	
TPO antibodies?:	☐	☐	☐
TSH R antibodies?	☐	☐	☐
2. Hyperthyroid?	☐	☐	
If yes, on carbimazole/PTU?	☐	☐	

Father Age when child born: ☐☐

Measured height: ☐☐☐ • ☐ (cms)

Ethnicity: UK ☐
Ireland ☐
Asia ☐
Europe (continent) ☐
Other (please specify) ☐

Other family members

Sibling with hypothyroidism: Yes ☐
or raised TSH No ☐

Family history of thyroid : Yes ☐
disease No ☐

If yes, please specify: _____

_____

Child

Birth weight: ☐ • ☐☐ Kgs

Birth head circumference ☐☐ • ☐ cm

Gestation: ☐☐ Weeks

Duration of hospital stay: ☐☐☐ days

	Y	N
Admitted to SCBU?	☐	☐
Required neonatal intensive care?	☐	☐
At age of Guthrie: Ventilated?	☐	☐
Receiving iv fluids?	☐	☐
Receiving antibiotics?	☐	☐
Receiving TPN?	☐	☐
Suffering from NEC?	☐	☐
In conclusion: Sick baby?	☐	☐

If sick baby, please specify:

_____

_____

_____

	Y	N
Dysmorphic syndrome? :	☐	☐

If yes, please specify: _____

	Y	N
Congenital anomalies: Cardiac?	☐	☐
Other?	☐	☐

If yes, please specify: _____

_____

Diagnosis of congenital hypothyroidism

Guthrie test performed?: Y ☐ N ☐

Age when Guthrie sample taken: ☐☐ Age when Guthrie test performed ☐☐

Age at notification: ☐☐☐ Age at start of treatment: ☐☐☐

	Y	N
Hospitalised following notification?	☐	☐
On treatment when notified?	☐	☐
Jaundice >7 days?	☐	☐
Poor feeding?	☐	☐
Other symptoms of hypothyroidism?	☐	☐

If yes to other symptoms of hypothyroidism, please specify:

_____

_____

_____

Repeat samples **before** starting treatment		1	2	3	4	5	6
Guthrie or venepuncture	G/V						
TSH	MU/L						
Free T4	pmol/L						
Age in days when performed	Days						

Isotope scan performed? Yes ☐ No ☐ Thyroid ultrasound performed? Yes ☐ No ☐

Age at scan: ☐☐☐ days TSH at scan: ☐☐☐☐ mU/L Age at ultrasound: ☐☐☐ days

Isotope scan results:

1 Normal uptake & position ☐
2 No uptake at normal position ☐
3 Reduced uptake normal position ☐
4 Uptake one lobe only ☐
5 Increased uptake ☐
6 Sublingual uptake ☐

Right or Left R/L ☐

Ultrasound results:

1 Apparent normal gland ☐
2 No gland visualised ☐
3 Hypoplastic remnant ☐
4 Small gland seen ☐
5 Hemithyroid ☐
6 Enlarged gland seen ☐
7 No result obtained ☐

Thyroid imaging further details: _____

_____

	Y	N			
TPO antibody test performed?	☐	☐	Results: _____	Age at test	☐☐ months
TSH receptor ab test performed?	☐	☐	Results: _____	Age at test	☐☐ months
Thyroglobulin measured?	☐	☐	Results: _____	Age at test	☐☐ months

Final diagnosis:

1 Definite hypothyroidism ☐
2 Probable hypothyroidism ☐
3 Hypothyroidism uncertain ☐
4 Transient raised TSH ☐

Thyroxine treatment started Y ☐ N ☐

Cause of hypothyroidism:

1. Unknown ☐
2. Ectopic thyroid ☐
3. Absent thyroid ☐
4. Hypoplastic thyroid ☐
5. Dyshormonogenesis ☐
6. Other (specify below) ☐

_____

_____

Growth and treatment data – Year 1 (to be completed after first birthday)

Date												
Height (cm)												
Weight (kg)												
OFC (cm)												
Free T4 (pmol/L)												
TSH (mU/L)												
Thyroxine Dose (mcg/day)												
Tablets (T) or Syrup (S)												
Concerns with compliance? Y/N												

Developmental assessment

Walks independently?: Yes ☐ No ☐ If yes, age achieved: _____ months
Walks with one hand held? Yes ☐ No ☐ If yes, age achieved: _____ months
Points with index finger? Yes ☐ No ☐ If yes, age achieved: _____ months
First word with meaning?: Yes ☐ No ☐ If yes, age achieved: _____ months
Waves bye bye? Yes ☐ No ☐ If yes, age achieved: _____ months
Hearing test? Yes ☐ No ☐ If yes, date tested: _____

Growth and treatment data for year 2 (to be completed after second birthday)

YEAR 2

Date											
Height (cm)											
Weight (kg)											
OFC (cm)											
Free T4 (pmol/L)											
TSH (mU/L)											
Thyroxine Dose (mcg/day)											
Tablets (T) or Syrup (S)											
Concerns with compliance? Y or N											

Developmental assessment

	Y	N	
Joins 2-3 words to make a sentence?:			If yes, at what age?: _____
Engages in make believe play readily?:			If yes, at what age?: _____
Tries to kick a ball?:			If yes, at what age?: _____
Turns pages of a book singly?:			If yes, at what age?: _____
Can make a tower of 6 (1 inch) cubes?:			If yes, at what age?: _____

Growth and treatment data for year 3 (please complete after third birthday)

Year 3

Date								
Height (cms)								
Weight (kgs)								
Free T4 (pmol/L)								
TSH (mU/L)								
Thyroxine Dose (mcg/day)								
Tablets (T) or Syrup (S)								
Concerns with Compliance? Y/N								

Developmental assessment

	Y	N	
Walks alone up steps one foot at a time?	☐	☐	If yes, at what age?: _____
Can draw a circle?	☐	☐	If yes, at what age?: _____
Knows the name of at least one colour?	☐	☐	If yes, at what age?: _____
Understands sharing?	☐	☐	If yes, at what age?: _____

Diagnosis challenged? Yes ☐ No ☐ If yes, still on T4?: Yes ☐ No ☐

Please complete data for visit nearest to birthday

YEARS 4 - 16

YEAR	4	5	6	7	8	9	10	11	12	13	14	15	16
Date													
Height (cm)													
Weight (kg)													
Free T4 (pmol/L)													
TSH (mU/L)													
Thyroxine Dose													
Tablets (T) or Syrup (S)													
Concerns with compliance? Y or N													

Educational history

Age of patient (years)	**5**	**7**	**11**	**15**	**16**
In appropriate class for age (Y/N)					
Extra help in mainstream (Y/N)					
Attending special needs school (Y/N)					

Was a record of needs taken out?: Yes ☐ No ☐

Number of state exam passes: At standard grade (or equivalent) _____

At higher grade (or equivalent) _____

Number of exams passed Type of exam taken _____ Age taken? ☐ yrs

Number of exams passed Type of exam taken _____ Age taken? ☐ yrs

Number of exams passed Type of exam taken _____ Age taken? ☐ yrs

Please give brief details of any further/higher education or employment undertaken (if appropriate)

_____

_____

_____

_____