

ATTITUDE OF PEDIATRIC ENDOCRINOLOGISTS TO CONGENITAL HYPOTHYROIDISM

Dear Colleagues;

Although there is a consensus report for the diagnosis and treatment of Congenital Hypothyroidism, there are still points of disagreement and differences in attitude between clinics. This survey has been prepared to obtain information about your attitudes and to plan new research based on the information obtained. It consists of 24 questions and takes approximately 5 minutes to complete. Your participation is precious to us.

Thank you very much for your support.

UCEDD Thyroid Group

1. What is the institution you work for?

- University Hospital
- Ministry of Health Training and Research Hospital
- State Hospital
- Private/Foundation University Hospital
- Others

2. What is your title?

- Fellow
- Consultant
- Assistant professor
- Associated professor
- Professor

3. How many years have you been working in the field of pediatric endocrinology?

4. Your age (please specify years):

5. What tests to confirm the diagnosis in a baby coming from congenital hypothyroidism screening do you want? (Multiple options may be selected)

- fT4
- fT3
- tT4
- tT3
- TSH
- Thyroxine binding globulin (TBG)

6. In which of the following groups of children would you consider requesting a repeat thyroid function test on postnatal days 10-14 due to the possibility of false negatives in the congenital hypothyroidism screening program? (Multiple options may be selected)

- Premature babies
- Low birth weight babies
- Sick babies
- Babies with clinical suspicion of hypothyroidism
- Twin babies
- Babies with Down syndrome
- Babies with congenital anomalies

7. **What is your general approach while serum-free T4 (fT4) is normal in a 1-3 week old baby referred from the screening program, if TSH is between 20-40 mIU/l?** (Tick only one option)

- I will start LT4 treatment immediately
- I decide on treatment based on the fT4 level
- I will monitor it without medication and decide based on the TSH course after 1-2 weeks.
- I would like an examination to make a definitive diagnosis before starting treatment.

8. **In a 1-3 week old infant referred from the screening program, if serum-free T4 (sT4) is normal while TSH is between 6-20 mIU/l, what is your general approach?** (Tick only one option)

- I will start LT4 treatment immediately
- I decide based on the fT4 level
- I will monitor it without medication and decide based on the TSH course after 1-2 weeks.
- Before starting treatment, I would like an examination to make a definitive diagnosis.

9. **In a 3-4 week-old infant referred from the screening program, if serum-free T4 (sT4) is normal while TSH is between 6-20 mIU/l, what is your general approach?** (Tick only one option)

- I will start treatment immediately
- I decide on treatment based on the fT4 level
- I will monitor it without medication and decide based on the TSH course after 1-2 weeks.
- Before starting treatment, I would like an examination to make a definitive diagnosis

10. **How often do you request the following tests to elucidate the etiology of congenital hypothyroidism?** (Tick only one option on each line)

Never Rarely Often Always

- Thyroid USG:
- Thyroid scintigraphy
- Urine iodine:
- Urinary iodine in the mother:
- Breast milk iodine:
- Iodine/creatinine ratio in urine:
- Thyroglobulin:
- Thyroidoantibody level
- Genetic tests:

11. **What is your imaging preference in congenital hypothyroidism cases?** (Tick only one option)

- Thyroid ultrasonography
- Thyroid scintigraphy
- Both together
- I do not want routine imaging

12. **Which material is used when thyroid scintigraphy is performed in your center?** (Tick only one option)

- Technetium 99
- Iodine 123
- I don't know

- 13. Can sodium perchlorate expulsion test along with thyroid scintigraphy be performed at your center?** (Tick only one option)
- Yes
 - No
 - I don't know
- 14. What is your approach to echocardiography screening to detect congenital malformations that may accompany cases with congenital hypothyroidism?** (Tick only one option)
- I want in all cases
 - I would like it in cases diagnosed with thyroid dysgenesis
 - I only ask if there are dysmorphic findings on physical examination.
 - I would never want to
- 15. What is your approach to Abdominal Ultrasonography screening to detect congenital malformations that may accompany cases with congenital hypothyroidism?** (Tick only one option)
- I want in all cases
 - I would like it in cases diagnosed with thyroid dysgenesis
 - I only ask if there are dysmorphic findings on physical examination.
 - I would never want to
- 16. How often do you request knee radiography in cases diagnosed with congenital hypothyroidism?** (Tick only one option)
- Never
 - Rarely
 - often
 - Always
- 17. Which option fits your approach regarding the starting dose of LT4 in Congenital Hypothyroidism?** (Tick only one option)
- I start each case with LT4 at a dose of 10-15 $\mu\text{g}/\text{kg}/\text{day}$.
 - I adjust the dose depending on the fT4 level, ranging from 5-15 $\mu\text{g}/\text{kg}/\text{day}$.
 - I adjust the dose depending on the etiology, ranging from 5-15 $\mu\text{g}/\text{kg}/\text{day}$.
 - I take fT4 and etiology into consideration when adjusting the dose, and adjust the dose to vary between 5-15 $\mu\text{g}/\text{kg}/\text{day}$.
- 18. What is your approach to using original molecules in the treatment of congenital hypothyroidism?** (Tick only one option)
- I always use the original molecule
 - Doesn't matter, I prescribe both.
- 19. What is your approach to the combination of LT4 + LT3 in treatment?** (more than one option can be selected)
- I can use it in cases with thyroid agenesis
 - I can use it in cases with resistant TSH elevation during follow-up.
 - I never use

20. What do you think is the appropriate sampling time for free T4 measurement when evaluating treatment response? (Tick only one option)

- Definitely before purchasing LT4
- At least 4 hours should pass after taking LT4
- 2 hours after taking LT4
- LT4 purchase time does not matter

21. What is your approach regarding the timing of drug withdrawal attempts and re-evaluation in children with congenital hypothyroidism whose thyroid gland is present and who have an LT4 dose of $< 3 \mu\text{g}/\text{kg}/\text{day}$? (Tick only one option)

- Earliest 3-years old
- Earliest 2 years old
- Earliest 1 year old
- 6 months at the earliest
- If TSH is low despite low dose, at any time

22. Would you like genetic analysis in cases diagnosed with congenital hypothyroidism? (Tick only one option)

- Yes
- No

23. If your answer to the above question is yes, in which group of patients would you prefer to perform genetic analysis? (you can tick more than one option)

- All patients diagnosed with CH
- Patients with intact thyroid gland
- Patients with accompanying anomalies or syndromic features
- All patients who are confirmed to have permanent CH at diagnosis, follow-up, or re-evaluation.
- Patients with persistent TSH elevation on re-evaluation

24. Should the congenital hypothyroidism screening program also include cases of central hypothyroidism? (Tick only one option)

- Yes
- No
- I'm undecided