

Appendix 1

Access to Fludrocortisone and to Hydrocortisone in Children with Congenital Adrenal Hyperplasia in the WHO Eastern Mediterranean Region

Survey questionnaire

Personal information

- In what country and city are you working?
- What is your medical specialty?
- What is your email address for communication?
- Did you previously fill out the CAH survey in 2017 (online version)?

General questions

- Is there a Newborn Screening Program for CAH in your country?
- Do you know what the estimated incidence rate of CAH is in your country?
- Do you know the number of patients who have CAH in your country (prevalence of CAH for children and adults?)

Questions regarding access to each drug for CAH treatment

Fludrocortisone:

- Is fludrocortisone registered in your country?
- Is fludrocortisone available in the public system?
- If not available in the public system, can a patient buy it privately?
- What is the strength of fludrocortisone tablets in your country?
- What is the approximate cost to families (ie per 100 tablets of 0.1 mg)
- How available is fludrocortisone to patients in your country? (Never, < 25%, 50%, > 75%, Always)

Oral Hydrocortisone:

- Is oral hydrocortisone registered in your country?
- Is oral hydrocortisone available in the public system?
- If not available in the public system, can a patient buy it privately?
- What is the strength of oral hydrocortisone tablets in your country?
- What is the approximate cost to families (ie per 100 tablets of 10 mg)
- How available is oral hydrocortisone to patients in your country? (Never, < 25%, 50%, > 75%, Always)

Injectable Hydrocortisone:

- Is injectable hydrocortisone registered in your country?
- Is injectable hydrocortisone available in the public system?
- If not available in the public system, can a patient buy it privately?

- What is the strength of injectable hydrocortisone vials in your country?
- What is the approximate cost to families (ie per vial)
- How available is injectable hydrocortisone to patients in your country?
(Never, < 25%, 50%, > 75%, Always)
- Do CAH families in your country have hydrocortisone injection kits in their home for use in emergencies?