General Practitioner of:

Patient name: ____

Date of Birth: ______________________________

Patient Address: ____

____

____

Consultant: ____

Dear Doctor

As you know the above named patient has Adrenal Hypoplasia Congenital (AHC). This is a complex condition we feel it would be most valuable to set out our objectives and include ways in how we might provide the best and most appropriate joint care. We do appreciate the support you already give and we have set out the following outlines.

Hospital Responsibilities
We will take charge of monitoring of the above named patient with respect to the following:-

- Height and weight.
- Blood pressure monitoring.
- Medication dose changes.
- Arrangement of specialist hospital appointments.

General Health
From the Family Practitioner standpoint we would like you to provide general health care as you would in any child without AHC including the full range of immunisations and developmental checks.

Emergency Care
There are several aspects that we would welcome your help with:

1. Arranging and ensuring the continuation of "Open Access" with the local Paediatric Team to avoid unnecessary delays in Accident and Emergency. The endocrinologist can this off but it would be really helpful if you could check that this is in place as it can lapse sometimes
2. Have a copy of the Emergency letter for all Health care Professionals at hand along with Emergency Guidelines.
3. Allowing priority appointments with you for the above named patient when unwell and family telephone in for appointment.
4. Ensuring that your Practitioner Nurses and Out of Hours Services are aware of the emergency protocol and are familiar with importance of increasing steroids when ill, as well as the correct dose of hydrocortisone which should be administered IM.
5. That the patient's condition is flagged on your system, so locum doctors, practice nurses are alerted that the patient is adrenal insufficient and steroid dependant.

6. Although we cannot demand that patients wear a medic alert we strongly advise they do this and the wording used should be 'adrenal insufficiency' and if you could support us in trying to reinforce the importance of wearing a medic alert at all times, it would be really helpful.

Drug Interactions
This is important to consider especially with hydrocortisone as we often think of it as simply replacement therapy which it is.

However certain medications can alter and affect the way it delivers cortisol.

The main interaction we see is with the prescription of the oral contraceptive. This is associated with a need to alter the hydrocortisone dosing so always best if you are considering such a prescription to let their consultant endocrinologist know beforehand. It would be helpful if this issue could be flagged on your system in female patients with AHC for future reference.

A full list of interactions is contained in our leaflet on hydrocortisone.

School and Nursery Care
We have made available a protocol example sheet for schools and nursery care which give detailed instructions on what to do in illness and emergencies. What would be helpful is if patients are issued with a repeat prescription of at least 4 vials of hydrocortisone for emergency care, as well as syringes and appropriate sized needles.

Please find attached a summary Care Sheet for your records.

Yours sincerely

Adrenal Hypoplasia Congenita
http://www.cahisus.co.uk

SUMMARY PROTOCOL CARE SHEET FOR GENERAL PRACTIONERS

Patient flagged to be seen as soon as possible

EMERGENCY CARE
HYDROCORTISONE IM DOSES

Age range (years)	Dose (mg)
0 – 1	25
1 – 5	50
over 5	100

GENERAL ILLNESS
Level 1
Patient is unwell and has a temperature of 38ºC and over. He/she is taking fluids.

1. In this situation then the hydrocortisone dose should be doubled or trebled.
2. If using twice a day hydrocortisone increase the frequency of dosing to three times per day by adding dose at lunchtime.
3. Fluids that contain some sugar should be encouraged.

Level 2
The situation as in Level 1 but there is also associated vomiting.

If the patient has vomited 2-4 hours after the last dose of hydrocortisone then the last dose has probably been absorbed. But if he/she vomits within 2 hours of the last dose then

1. Give repeat double or triple dose orally. If this stays down fine and continue with double or triple dose orally.

2. If not and vomits it back within 2 hours then intramuscular hydrocortisone should be administered.

Following the administration of the intramuscular injection of hydrocortisone the patient should be admitted to hospital for observation for at least 12 hours.

Please note that the IM injection although a high dose, does not last in the body as cortisol longer, so double/triple dose should be given when the next dose is due, or 4 - 6 hours after initial injection.

General
All vaccines should be given (doses should be doubled if temperature develops in response to vaccine)

For females with AHC please flag that any contraception medication should be discussed with endocrinologist, due to the known altered clearance of hydrocortisone.

Encourage patients to wear medic alert.