

## **Avril Meeting Summary**

Summary of today that I sent to Teresa and Baryab so that they know what happened.

Students taken to outpatients to show them a bit of patient journey - booking in, height and weight, clinic area.

I have mentioned that things that families would like are:

Height, weight, and BMI and with the centile or SDS (but that families are most likely to understand a centile which they could input themselves at clinic as creating references for the app would be a whole project in itself). I also mentioned that some families ask for height in feet and inches if it would be possible to interchange between centimetres and feet and inches.

Height velocity as an absolute number in centimetres/yr which they could input themselves at clinic

Blood pressure as the absolute values (systolic and diastolic) and as centile or SDS which families would input at clinic

Treatment - most common medications being:

Growth Hormone daily,

oestrogen (with option of patch or tablet) with option of alternate day and daily

progesterone to be taken on 7-12 days of calendar month either monthly, every 2nd month or every 3rd month, and

Thyroxine daily.

With option of setting reminders for all of these

We will not include dose as this may become a bit confusing

Clinic appointments:

Common appointments being Endocrine, Audiology, Cardiology, ENT and Renal as possible clinics that they may attend

Investigations:

I have shown them the table in the new consensus document and thought it might be useful to include:

Bloods - annually

ECHO - either 5-10 years, 3-5 years or annually

DXA - every 5 years from 16 years

Contact:

Medical Secretary

GP

Local chemist

Endocrine Consultant

Endocrine Nurse Specialist

Link to TSSS

I have sent all of this to one of the students to circulate amongst both teams.

Avril