

# 05/12/2017 Hospital Meeting Notes with Avril

## Appointment flow

- Area 4 to have standing height and weight taken before every clinic
- Height and weight are input into the online system, they're also written on a piece of paper which is filed by the hospital as a backup but not given to the girls
- Turners girls always go to clinic 2, names change to green in the system to mark that they have arrived
- Blood pressure taken at the start of every clinic appointment too
- Urine specimen taken usually with patients over 4 years old.

## Measurement Units

- Height (**cm**)
- Weight (**kg**)
- Height Velocity = (height today - last height) / time interval between the two (**cm per year**)
- BMI
- Blood Pressure (number *over* number)
- Length (cm); rarely used
- Head circumference (cm); hardly ever used, ignore

Age is recorded as a decimal.

The medical professionals always use metric but some patients and parents still request to know measurements in imperial so maybe have metric as default but the option to use imperial.

## BMI

BMI is not given to the patient on visit, will need to calculate it on our end

## Blood Pressure

- About 40% of TS girls have blood pressure problems.
- Measurements should be taken every appointment but sometimes they're taken elsewhere like at school because the girls are anxious and stressed at the hospital and it affects the reading.

## Height

If they come with both parents on first visit, height recorded of both parents and the mid-parental height is plotted with the mid-point and the range expected for the child's height - generally a better projection than the stats based on population, not all patients have British blood.

## Centiles

- Used for assessing growth weight etc by comparison with the rest of the population
- More relevant than pure weight, for example, due to short height of girls
- Doctors don't tend to work in centiles but it is what parents generally understand and are comfortable with
- Usually remain on a single centile throughout, if they drift onto another centile it may be cause for concern

- Centile is complicated to compute but they will be told during the appointment and could input it as a number

## **Z-Score**

Used for assessing growth weight etc by the number of standard deviations from the mean a data point is  
Understood and used by medical professionals but less understood by patients and parents

Calculated by iGrow system  
Is a decimal number

Sometimes useful to have height and weight and BMI Z-scores all plotted together to see how they relate

## **Growth Hormone**

- Most every girl will be on growth hormone
- Always an injection
- Dose based on weight
- Under 12s will probably be taking only this
- Taken once a day, every day.

## **Oestrogen**

- Over 12s most likely on oestrogen
- Tablets or patch (patches sometimes are cut up to reduce dose)
- There are a few different versions of the medicine and patients may not know theirs by name so may make sense to have it titled Oestrogen too rather than only by the pharmaceutical name.
- Taken once a day, every day or once a day, every other day.
- Dosage time does not have to be consistent, a lot of girls take it each night.
- 2mc per 12 months for the first year (from 15 usually), 4mc for the next year, 6mc -> 8mc -> 10mc over the third year.

## **Progesterone**

- 3 different types
- Tablet taken once a day for 7 - 12 days each calendar month generally.
- Doesn't have to be every month, some do this every three months.

## **Thyroxin**

Only some girls will be taking this, once a day every day.

## **Investigations**

Document on Turners Syndrome Society webpage outlines the frequency of these.