

## Basic Medical Surveillance Essentials for people with Down syndrome

### GROWTH (Revised 2012)

*One of a set of guidelines drawn up by the  
Down Syndrome Medical Interest Group (DSMIG UK)*

Short stature is a recognised characteristic of most people with Down syndrome<sup>1,2</sup>. Average height at most ages is around the 2nd centile for the general population. Some children however also have additional medical conditions which may further jeopardize growth. These include congenital heart disease<sup>3,4</sup>; sleep related upper airway obstruction<sup>5</sup>; coeliac disease<sup>6,7</sup>; nutritional inadequacy due to feeding problems<sup>8</sup>; and thyroid hormone deficiency<sup>9,10</sup> which all occur more frequently among those with the syndrome. Regular surveillance of growth, general health, nutritional and thyroid status should aid in early identification of pathological causes of poor growth.

UK/Republic of Ireland growth charts for healthy children with Down syndrome from birth to 18 years are available and have been revised in 2011.<sup>11,12</sup> These reference values are essential for assessing linear growth. However as many older children and adults with the syndrome are overweight<sup>13,14</sup> the reference values for weight should not be used as a standard that children should aim to achieve. Body Mass Index BMI information is included on the charts particularly to aid the assessment of those who may be overweight.

#### Recommendations:

1. We suggest that it is good practice to record and chart height and weight frequently in the first two years using the 2011 revised Down syndrome specific charts<sup>11</sup>. Thereafter measurements should be made at least annually throughout childhood and at regular intervals in adult life. Regular measurements of this sort are likely to be sensitive early indicators of the many medical problems that are over represented in this population.
2. As in all children growth spurts and plateaux occur but among those with Down syndrome these tend to be more prolonged. They are not reflected in the smoothed curves of a reference chart.
3. As with all children head circumference should be measured at birth and 6 weeks and charted on the Down syndrome charts. Subsequent measurements can be made as clinically indicated.
4. **Preterm babies**  
There are no published birth weight charts for preterm babies with Down syndrome who are born before 37 completed weeks. However as these weights differ little from the general population<sup>15</sup> the neonatal and infant close monitoring (NICAM) chart may be used to give guidance until term<sup>16</sup>. Thereafter the Down syndrome charts should be used and measurements plotted using gestationally corrected age for at least a year.

## 5. Newborns and young babies

For babies with Down syndrome early weight loss may be more than 10% and it often takes longer than 2 weeks to regain birthweight<sup>17</sup>. By 4 weeks, if there is no serious medical problem, most will be on a centile close to their birth centile. Early weight loss greater than 10% which is not quickly recovered or undue delay in regaining birthweight (>4 weeks) indicates a need for careful clinical evaluation for feeding difficulties or major underlying pathology. Breast feeding should be encouraged and supported.

## 6. Underweight

Children below the 2<sup>nd</sup> centile for weight need evaluation. Some will be perfectly healthy. However some with heart problems, other additional medical needs, and feeding difficulties are also likely to be on lower centiles. If they grow roughly parallel to their centile this is reassuring, but if they fall away from the lowest centiles they should be assessed by a paediatrician and may need specialist feeding advice and possibly extra supplementary feeding.

## 7. Overweight

- There is a high prevalence of overweight and obesity among people with Down syndrome<sup>13,14</sup>. As with the general population weight is influenced by environmental<sup>14,18</sup> as well as biological factors<sup>19</sup>.
- Appropriate anticipatory guidance regarding diet and physical activity should be given for all those with the syndrome.
- The Down syndrome specific charts clearly reflect the tendency to overweight among the UK study sample particularly in later childhood and adult life<sup>11,12</sup>. Hence the reference data should not be used as a standard that children should aim to achieve. Children over age 2 can be charted on the BMI conversion chart (see growth charts) particularly if there are concerns about overweight or if their weight lies above the 75<sup>th</sup> centile. Those with a BMI above the overweight or very overweight thresholds should be encouraged to lose weight and offered specialist referral for guidance if appropriate.
- Thyroid function should always be checked in those with accelerated weight gain.

## 8. Puberty

The Down syndrome specific chart suggests an absence of pubertal growth spurt. However these children do have an adolescent growth spurt. It is usually less vigorous than in the general population and may occur at an earlier age. Final height is achieved earlier than in the general population<sup>20,21</sup>. If early onset of puberty occurs it may have a limiting effect on final height.

## 9. Growth hormone

The use of growth hormone in Down syndrome is still being evaluated. There is no evidence that it should be prescribed except in the unusual situation of concurrent primary growth hormone deficiency<sup>22,23,24</sup>.

10. The influence of parental height on target height appears to be variable<sup>25</sup>.

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