

## ***BASIC MEDICAL SURVEILLANCE ESSENTIALS FOR PEOPLE WITH DOWN'S SYNDROME***

### ***GROWTH***

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

Short stature is a recognised characteristic of most people with Down's syndrome. Average height at most ages is around the 2nd centile for the general population. For the majority the cause of growth retardation is not known<sup>1</sup>. Some conditions leading to poor growth - congenital heart disease<sup>2,3</sup>; sleep related upper airway obstruction<sup>4</sup>; coeliac disease<sup>5,6</sup>; nutritional inadequacy due to feeding problems; and thyroid hormone deficiency<sup>7,8</sup> 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 growth retardation.

UK/Republic of Ireland growth charts for healthy children with Down's syndrome from birth to 18 years are available<sup>9,10</sup>. These reference values are essential for assessing linear growth. However as many older children and adults with the syndrome are overweight<sup>11,12</sup> the reference values for weight should not be used as a standard that children should aim to achieve. BMI data is included on the charts to aid the assessment of overweight.

#### **Recommendations:**

1. We suggest that it is good practice to record and chart height and weight frequently in the first two years using Down's specific charts<sup>9</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 which are over represented in the syndrome
2. Preliminary data suggest that many babies with the syndrome do not regain birthweight until around 1 month<sup>13</sup>. This is not reflected in the charts because of their cross sectional nature. This early failure to thrive is usually due to feeding difficulties many of which resolve after the first few weeks. From 1 month weight should increase parallel to the centiles. Significant failure to do so should be investigated.
3. Of those with measurements below the 2<sup>nd</sup> centile some will have major pathology but some may be failing to thrive for other reasons – eg because of feeding difficulties.<sup>14</sup> Such children should have their dietary intake evaluated and may need to be referred to a paediatrician or paediatric endocrinologist for assessment.
4. The Down's specific charts clearly reflect the tendency to overweight among the UK study sample particularly in later childhood. Hence the reference data should not be used as a standard that children should aim to achieve. Standard BMI charts have been included on the growth charts. We suggest that all those over age 5 with weight above the 75<sup>th</sup> centile should be charted on the BMI charts. Those above the 98<sup>th</sup> BMI centile should be considered for further assessment and guidance. Those above the 91<sup>st</sup> should be carefully monitored.

5. Although there is a high prevalence of overweight/obesity<sup>11,12</sup> people with Down's syndrome are not necessarily overweight in relation to their height. As with the general population weight is influenced by environmental<sup>12,15</sup> as well as biological factors<sup>16</sup>.
6. Appropriate anticipatory guidance regarding diet and physical activity should be given for all those with the syndrome.
7. Thyroid function should always be checked in those with accelerated weight gain.
8. In childhood growth spurts and plateaux occur as in all children but among the Down's population these tend to be more prolonged. They are not reflected in the smoothed curves of a reference chart.
9. The Down's specific chart suggests an absence of pubertal growth spurt. However those with the syndrome do have an adolescent growth spurt. It is usually less vigorous than in the general population and may occur at an earlier age<sup>17</sup>. If early onset of puberty occurs it may have a limiting effect on final height.
10. As with all children head circumference should be measured at birth and 6 weeks and charted on Down's syndrome charts. If there is any cause for concern subsequent measurements should be made.
11. The use of growth hormone in Down's 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>18,19,20,21</sup>.
12. The influence of parental height on target height appears to be variable<sup>22</sup>.

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