THE 2011 DSMIG/RCPCH GROWTH CHARTS FOR CHILDREN WITH DOWN SYNDROME.

FACT SHEET

Why do we need special charts for children with Down syndrome?

- Short stature is a recognised characteristic of most people with Down syndrome; average height at most ages is around the 2nd centile for the general population[1;2].
- Children with Down syndrome are at increased risk of additional medical conditions which may further jeopardize growth. These include congenital heart disease[3;4;] sleep related upper airway obstruction[5]; Coeliac disease[6;7]; nutritional inadequacy due to feeding problems[8]; and thyroid hormone deficiency[9;10].
- Regular measurements, together with assessment of children's general health, nutritional and thyroid status are likely to be sensitive early indicators of the medical problems in this population.

The chart design

In 2011 the Down syndrome growth charts were redesigned jointly by the Down Syndrome Medical Interest group (DSMIG) and the Royal College of Paediatrics and Child Health. These new charts use the existing DSMIG reference data (see page 4) and represent the growth of healthy children with Down syndrome. The charts use the same design principles as the 2009 UK-WHO growth charts and provide an important way to assess linear growth in children with Down syndrome from birth to 18 years.

The first page of the chart covers 0- 6 months to allow for more accurate plotting during this time when children's weight is changing more rapidly. The second page now covers 6 months to 4 years and the final page 4 to 18 years.

These charts also contain - 4 SD (standard deviation) low lines. These have been added to help monitor the growth of exceptionally small children. It is anticipated that these children will have additional medical problems and so will be under regular medical review. It must be emphasised that no healthy child would be expected to be on this line and that any child who is not already receiving medical attention and whose growth plots lie on or near this line should be referred for urgent medical evaluation.

It is good practice to record and chart height and weight frequently in the first two years using these charts. Thereafter measurements should be made at least annually throughout childhood.

How to plot and interpret newborn growth data

The charts were produced from data for term babies with Down syndrome. The birth weight of babies born at or after 37 weeks can be plotted from age zero. For preterm babies the UK-WHO Neonatal and Infant Close Monitoring (NICM) chart can be used (see below).

As with the 2009 UK-WHO charts, no lines are printed for 0-2 weeks. This is because, like all babies, early weight gain varies a lot during this time. It is very common for babies with Down syndrome to lose weight after birth. Some evidence suggests they are more likely to lose more than 10% of their birth weight and can take up to 4 weeks to get back to birth weight[11] but more research on this topic is needed. Currently it is recommended that early weight loss greater than 10% which is not quickly recovered, or undue delay in regaining birth weight (>4 weeks) indicates a need for careful clinical evaluation for feeding difficulties or major underlying pathology.

Breast feeding should be encouraged and mothers should be supported to continue breast feeding even if early growth patterns appear discouraging. Mothers of babies with Down syndrome may need extra support with feeding techniques and early referral to specialists, e.g. breast feeding counsellor or specialist speech and language therapist should be considered. Feeding problems occur commonly in babies with Down syndrome, so a baby who is losing more weight than expected or not regaining weight at an appropriate rate should be evaluated for possible mechanical feeding difficulties.

Medical problems affecting growth, such as significant congenital heart disease, should be detected very early in life but a baby whose early growth is not following an acceptable pattern should be carefully assessed for possible underlying medical problems that may have been missed.

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.

Preterm babies

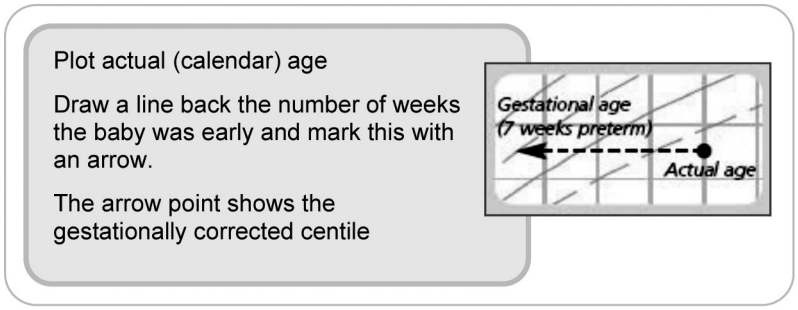
We know that children with Down syndrome are more likely to be born preterm and that growth in-utero up to about 38 weeks is similar to that seen in the general population. Therefore, until the expected date of delivery is reached, it is recommended that the measurements of preterm babies with Down syndrome should be plotted on the UK-WHO Neonatal and Infant Close Monitoring (NICM) chart, as the centile lines on this chart are very similar to those for babies with Down syndrome.[12]

Once they have reached their expected date of delivery they can be plotted on the specialist charts for children with Down syndrome, taking into account the degree of prematurity, using the arrow drawn back method (see figure 1 below). As with all preterm babies, this correction for prematurity should be made at least until the end of the first year (corrected age) for infants born 32-36 week gestation and up to 2 corrected age years for <32 weeks.

Figure 1

The arrow drawn back method of gestational correction to be used from term onwards for moderately preterm infants, 32-36 completed weeks gestation

The method avoids the need for calculation and ensures that the age adjustment is evident to subsequent chart users.



Older infants and children

It is not unusual for the growth of children with Down syndrome to follow a pattern of spurts and plateaux, so this should be taken into account when reviewing their charts.

After the age of 4 weeks a baby's weight may not follow a particular centile line but usually tracks within one centile space. In considering poor growth patterns at any age it is always important to assess the child's overall state of health and consider further evaluation and investigation as certain problems which affect growth and feeding difficulties are more common in Down syndrome.

As the charts have been constructed from data obtained in healthy children with Down syndrome, those with additional medical needs, including commonly those with congenital heart problems, are likely to be on the lower centiles. Some babies with additional medical problems may be very underweight and for this reason the -4 standard deviation line has been included on the charts. This enables professionals to gain an idea of whether such children are growing at a reasonable rate, and whether they are showing signs of "catch up" growth.

Puberty

Youngsters with Down syndrome do have an adolescent growth spurt, but this is less marked and often occurs earlier than in the general population. Final height may be achieved earlier[13;14] and may be limited if early onset of puberty occurs.

Other aspects of puberty are generally similar in timing and sequence to the general population without the syndrome. Although menarche is reached at a similar age, there are a number of reports of girls starting their periods before other signs of puberty are established. Development of axillary, pubic or facial hair in boys often occurs later than in other adolescents.

As for any young person, precocious or delayed puberty may be due to underlying medical problems, (some of which may be more common in Down syndrome - e.g thyroid dysfunction) and should be appropriately investigated.

Overweight and obesity

There is a high prevalence of overweight and obesity among people with Down syndrome and these charts clearly reflect the tendency to overweight amongst the UK study sample particularly in later childhood and adult life[15;16]. The weight centiles on the back page chart (from 4-18 years) should therefore not be used as a standard that children should aim to achieve and children whose weight lies above the 75th centile maybe considerably overweight.

A Down syndrome BMI conversion chart is included on the back page to aid interpretation of the child's weight. This should be used for children over the age of 2 where there are concerns that they may be overweight or where their weight lies above the 75th centile. To allow for the high prevalence of overweight in the sample from which the charts were made the lines on this chart reflect lower centiles than those commonly used to define obesity in the general population. For this Down syndrome chart a BMI over the 75th centile is considered overweight and the 91st line is considered the cut off for obesity. These correspond to the 91st and 98th centiles on the UK 1990 charts.

How were the charts constructed?

These charts were produced from retrospective data gathered in 2001 using heights, weights and head circumferences recorded in the medical notes of healthy children with Down syndrome aged 19 years or less at the time[17]. The study sample was drawn from 15 discrete areas of UK and one from the Republic of Ireland. These areas were known to have adequate special needs registers to identify all children with Down syndrome living in the area. Data from an additional group of 27 young adults recruited from a further education college and aged 20-24 was also used to aid the centile construction in later teenage years.

The aim of the charts is to represent healthy children so data was only included from live children with either no cardiac abnormality or only a small ASD or VSD or a patent ductus arteriosus that was asymptomatic. Measurements from preterm children (born less than 37 weeks) were only included after 2 years of age. Measurements from children with multiple or major pathology were also excluded.

1507 children were identified from within the 16 areas. Following exclusions detailed above 5913 measurements from 1089 children were included and used to produce the charts. Centiles were fitted to the data using the LMS method.

Reported measurement techniques in the study areas were variable over time both within between areas. This large sample and the varied techniques used is felt to represent normal practice around the country in the current measurement of children and so these charts form a useful reference for day to day clinical practice.

Reference List

1. Myrelid A, Gustaffsson J, Ollars B, Anneren G. Growth Charts for Down's syndrome from birth to 18 years of age. *Arch Dis Child* 2002;**87**:97-103.
2. McCoy EE. Growth Patterns in Down's Syndrome. In Lott IT, McCoy EE, eds. *Down Syndrome:Advances in Medical care*, Wiley-Liss, 1992.
3. Greenwood RD,.Nadas AS. The clinical course of cardiac disease in Down's syndrome. *Pediatrics* 1976;**58**:893-7.
4. Torfs CP,.Christianson RE. Anomalies in Down syndrome individuals in a large population-based registry. *Am J Med Genet* 1998;**77**:431-8.
5. Stebbens VA, Samuels MP, Southall DP DJCC. Sleep related upper airway obstruction in a cohort with Down's syndrome. *Arch Dis Child* 1991;**66**:1333-8.
6. Jansson J,.Johansson C. Down syndrome and Celiac disease. *J Pediatr Gastroenterology and Nutrition* 1995;**21**:443-5.
7. George EK, Mearin ML, Bouquet J, Von Blumberg BME. High frequency of coeliac disease in Down syndrome. *J Pediatr* 1996;**128**:555-7.
8. Spender Q, Stein A, Dennis J, Reilly SF, Percy E, Cave D. An exploration of feeding difficulties in children with Down syndrome. *Dev Med Child Neurol* 1996;**38**:681-94.
9. Sharav T, Collins RM, BaaB PJ. Growth studies in infants and children with Down's syndrome and elevated levels of thyrotrophin. *AM J Dis Child* 1988;**142**:1302-6.
10. Karlsson B, Gustaffsson J, Hedov G, Ivarsson SA, Anneren G. Thyroid dysfunction in Down's syndrome: relation to age and thyroid autoimmunity. *Arch Dis Child* 1998;**79**:242-5.
11. Chilvers M. Time for children with Down's syndrome to regain birth weight. *Nottingham Audit Findings presented at DSMIG meeting Sept* 1997.
12. Cole TJ. Dennis J, Morris JK. Birthweights of babies with Down syndrome born preterm. *Personal communication.*
13. Kimura J, Tachibana K, Imaizumi K, Kurosawa K, Kuroki Y. Longitudinal growth and height velocity of Japanese children with Down's syndrome. *Acta Paediatr* 2003;**92**:1039-42.
14. Arnell H, Gustaffsson J, Ivarsson SA, Anneren G. Growth and pubertal development in Down's syndrome. *Acta Paediatr* 1996;**65**:1102-6.
15. Prasher VP. Overweight and obesity amongst Down's syndrome adults. *J Intellect Disabil Res* 1995;**39**:437-41.
16. Chumlea WC,.Chronk CE. Overweight among children with Trisomy 21. *J Intellect Disabil Res* 1981;**25**:275-80.
17. Styles ME, Cole TJ, Dennis J, Preece MA. New cross sectional stature, weight and head circumference references for Down's syndrome in the UK and Republic of Ireland. *Arch Dis Child* 2002;**87**:104-8.

This fact sheet written by the RCPCH/DSMIG Down syndrome growth chart steering group May 2012

RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

Down Syndrome
Medical
Interest
Group

Printed by Harlow Printing Limited in support of Down Syndrome Medical Interest Group.