Revised Growth Charts for Children with Down Syndrome

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On behalf of the Down Syndrome Medical Interest Group and the RCPCH Growth Chart Group
What is a growth chart?

- A tool for recording serial measurements
- A pictorial method of assessing a child’s growth trend
- A way of comparing a child’s growth pattern to that of the population
Growth in children with Down syndrome

• Babies with Down syndrome are born earlier (average 38 weeks)
• They may take longer than other babies to get back to their birth weight
• Children and adults with Down syndrome tend to be short
• High prevalence of overweight/obesity
• Pubertal growth spurt starts on average 1 year earlier & is less pronounced
Why special charts for children with Down syndrome?

• Shorter than general population – dedicated charts enable comparison with peer group
• Increased risk of additional medical conditions
• Regular growth monitoring and plotting on appropriate charts can give early indication of problems
Problems that can affect growth

- Congenital heart disease
- Severe gastro-oesophageal reflux
- Oral motor feeding difficulties
- Sleep related upper airway obstruction
- Coeliac disease
- Emotional/physical deprivation & neglect
History: Down Syndrome/DSMIG

- US 1988
- Sicily 1990
- Holland 1996
- UK growth charts 2002
The data

- Healthy children with Down syndrome (congenital heart disease and other major morbidity excluded)
- 15 areas in UK and 1 in ROI
- 1089 children
- 5913 measurements
These charts are based on data from around 6000 measurements of 1100 children living throughout the UK and Republic of Ireland (Styles et al - in preparation). Growth can be charted from term to 18 years. Children with significant cardiac disease or other major pathology were excluded from the study population. In addition, data for those born before 37 completed weeks were excluded up to age two. The charts are therefore representative of healthy children with Down's syndrome growing in the U.K. and Republic of Ireland.

The charts were commissioned by the UK Down's Syndrome Medical Interest Group (DSMIG) and the data collected by Dr Mary Styles on DSMIG's behalf. The centiles were compiled under the guidance of Professor Michael Preece with statistical analysis provided by Professor Tim Cole, both of the Institute of Child Health, London. Data were analysed by Cole's LMS method. Dr Styles' data collection was funded by the Child Growth Foundation and remains the copyright of DSMIG.

PCHR - The charts are also available in A5 format for inclusion with the special PCHR Down's syndrome insert.

Preterm babies - We do not as yet have sufficient information to compile centiles for preterm babies with Down's syndrome. Measurements for those born before 37 completed weeks should not be plotted on the charts until the expected date of delivery (EDD) is reached. Thereafter they should be charted relative to EDD for at least a year. Those born at 38 weeks or later should be charted in the normal way from the EDD line.

More information about growth monitoring for children with Down’s syndrome is included in the Medical Surveillance Guidelines for people with Down’s Syndrome produced by the Down’s Syndrome Medical Interest Group.

Overweight and underweight - Action guidelines:
Many older children with Down's syndrome are overweight and this is clearly reflected in this study population. Hence this reference data should not be used as a standard that children should aim to achieve. As with all children weight must be related to stature. Any child aged 5-18 years whose weight falls within the shaded area above the 75th centile should be charted on the BMI chart (see right). Those above the 98th centile on the BMI charts are significantly overweight and referral for further assessment and guidance should be considered.
PCHR INSERT FOR BABIES BORN WITH DOWN'S SYNDROME


The following pages are extra pages for your baby's Personal Child Health Record Book (the Red Book). They have been produced by the UK Down's Syndrome Medical Interest Group. They are for babies who are born with Down's syndrome. They give additional information which will help you maintain the health and well being of your child. They include special growth charts for BOYS and GIRLS.

Children with Down's Syndrome

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History: RCPCH and growth charts

2008 RCPCH commissioned to design new pre school charts to incorporate new WHO standard

2009 Implementation in England, train the trainer sessions, supporting educational materials, chart images and source data all available via Website / RCPCH

2010 UK-WHO adopted by Scotland, NI, Wales, New Zealand, Eire; work on school age charts begins, educational materials revised, papers written
GIRLS UK-WHO
Growth Chart 0-4 years

Who should use this chart?
Anyone who measures a child, plots or interprets charts should be suitably trained, or be supervised by someone qualified to do so. For further information and training materials see www.growthcharts.rcpch.ac.uk

A growth chart for all children
The UK-WHO growth chart combines World Health Organization (WHO) standards with UK preterm and height data. The chart from 2 weeks to 4 years of age is based on the WHO growth standard, derived from measurements of healthy, non-deprived, breastfed children of mothers who did not smoke. The chart for birth measurements (32-42 weeks gestation) is based on British children measured around 1930. The charts depict a healthy pattern of growth that is desirable for all children, whether breast fed or formula fed, and of whatever ethnic origin.

Weighting and measuring
Height:

Use only class II clinical electronic scales in metric setting. For children up to 2 years, remove all clothes and nappy; children older than 2 years should wear minimal clothing only. Always remove shoes.

Length: before 2 years of age; proper equipment is essential. Use a rigid rule with 1 cm, or stadiometer, the stone’s shoes should be removed.

Head circumference: use a flexible plastic or paper tape to measure where the head circumference is greatest. Any hat or bonnet should be removed.

When to weigh
Children should be weighed in the first week as part of the assessment of feeding and thereafter as needed. Recovery of birthweight indicates that feeding is effective and that the child is well. Once feeding is established, babies should usually be weighed at around 8, 12 and 16 weeks and 1 year at the time of routine immunisations. If there is concern, weigh more often; however, weights measured too close together are often misleading, so babies should be weighed no more than once a month up to 6 months of age, once every 2 months from 6 to 12 months of age, and once every 3 months over the age of 1 year. However, most children do not need to be weighed this often.

BMI look up
• No calculation
• Separate chart not needed

Interpreting the chart
Assessing weight loss after birth
Most babies lose some weight after birth but 80% will have regained this by 2 weeks of age. Fewer than 5% of babies lose more than 10% of their weight at any stage; only 1 in 50 are 10% or more lighter than birth weight at 2 weeks.
Percentage weight loss can be calculated as follows:

\[
\text{Weight loss} = \frac{\text{current weight} - \text{birth weight}}{\text{birth weight}} \times 100\%
\]

For example, a child born at 3.5kg (7 lbs 10 oz) loses 320g (11 oz) at 5 days has lost 35% or 10%; in a baby born at 3.000kg (6 lbs 8 oz), a 300g loss is 10%.

Careful assessment and evaluation of feeding technique is indicated when weight loss exceeds 10% or recovery of birth weight is slow.

What do the centiles mean?
These charts indicate a child’s size compared with children of the same age and maturity who have shown optimum growth. The chart also shows how quickly a child is growing. The centile lines on the chart show the expected range of heights (or lengths) each describes the number of children expected to be below that line (e.g. 50% below 50th, 99% below the 91st). Children come in all shapes and sizes, and 99 out of 100 children who are growing optimally will be between the lower lines (0.4th and 99.6th centiles); half will lie between the 25th and 75th centile lines.

Being very small or very big can sometimes be associated with underlying illness. There is no single threshold below which a child’s weight or height is definitely abnormal, but only 4 per 1000 children who are growing optimally are below the 0.4th centile, so these children should be assessed at some point to exclude any problems. Those above the 99.6th centile for height are almost always healthy. Also calculate BMI if weight and height centiles appear very different.

What is a normal rate of weight gain and growth?
Babies do not all grow at the same rate, so a baby’s weight often does not follow a particular centile line, especially in the first year. Weight is most likely to track within one centile space (the gap between two centile lines, see diagram). In infancy, acute illness can lead to sudden weight loss and a weight centile fall but on recovery the child’s weight usually returns to its normal centile within 2-3 weeks. However, a sustained drop through two or more centile spaces is unusual (fewer than 2% of infants) and should be carefully assessed by the primary care team, including measuring length/height.

Because it is difficult to measure length and height accurately in pre-school children, successive measurements commonly show wide variation. If there are worries about growth, it is useful to measure on a few occasions over time; most healthy children will show a stable average position over time.

Head circumference centiles usually track within a range of one centile space. After the first few weeks a drop or rise through two or more centile spaces is unusual (fewer than 1% of infants) and should be carefully assessed.

Why do the length/height centiles change at 2 years?
The growth standards show length data up to 2 years of age, and height from age 2 onwards. When a child is measured standing up, the spine is extended a little, so their height is slightly less than their length; the centile lines shift downward slightly at age 2 to allow for this. It is important that this difference does not worry parents; what matters is whether the child continues to follow the same centile after the transition.

References
1. www.who.int/chd/growthlen

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History : DSMIG

• UK growth charts 2002
• New PCHR insert 2011
• Reformatted charts, using same data but conforming to UK90-WHO layout, 2011
• RCPCH approval 2012
• Available from Harlow Printing
Personal Child Health Record

My personal child health record

PCHR insert for babies born with Down syndrome

DOWN SYNDROME – DEVELOPMENTAL MILESTONES
Finding out about people

<table>
<thead>
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<th>Stage</th>
<th>Milestone (Down syndrome)</th>
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Down Syndrome Grant 8 March 2011
Growth Charts
GIRLS Down syndrome 0-18 years

These charts are based on data from around 5000 measurements of 1000 children with Down syndrome who were growing up in the UK and Republic of Ireland between 1980 and 2000 (Stiles et al. 2002). Children with significant cardiac disease or other major pathology were excluded from the study population. In addition, data for those born before 37 completed weeks were excluded up to age two years.

The charts were commissioned by the Down Syndrome Medical Interest Group (DSMIG UK and Ireland) and the data collected by Dr Mary Styles on DSMIG’s behalf. The centiles were compiled under the guidance of Professor Michael Preece with statistical analysis provided by Professor Tim Cole, both of the UCL Institute of Child Health, London. Data were analysed by Cole’s LMS method. Dr Styles’ data collection was funded by the Child Growth Foundation and remains the copyright of DSMIG.

PCRH

The charts are also available in A5 format as part of the Personal Child Health Record insert for babies born with Down syndrome.

Preterm babies (born before 37 completed weeks)

Measurements for preterm babies should not be plotted on this chart until the expected date of delivery (EDD) is reached. The neonatal and infant close monitoring (NICU) is valid until this point. Thereafter the Down syndrome charts should be used and measurements plotted using gestational correction until age 36 weeks (corrected age) for those born before 32 weeks gestation.

Newborns and young babies

The chart at age 0 represents birthweight data for those born at 37 weeks or later and showing the baby’s birth centile. Those born at 32 weeks or later should be plotted from this point. There are no centiles on the chart between age 0 and 2 weeks. Most babies lose some weight after birth, a loss up to 10% is considered acceptable. For those with Down syndrome early losses may be more than 10% and it often takes longer than 2 weeks to regain birthweight. 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 similar delay in regaining birthweight (4-6 weeks) indicates a need for careful clinical evaluation for major underlying pathology and feeding difficulties.

After 4 weeks growth rates will vary from baby to baby, so weight alone does not follow a particular centile line, but usually tracks within one centile space. It is not unusual for growth of those with Down syndrome to proceed in plateaus and spurts.

Underweight

The charts show the growth of children without medical problems. Hence some healthy babies will be below the 2nd centile (2 in 100). However children with heart problems, other additional medical needs and feeding difficulties are over-represented among those with Down syndrome and are likely to be on lower centiles. Babies below the 2nd centile for weight may need evaluation for additional pathology and/or feeding difficulties and appropriate action taken. If they then grow roughly parallel to their centile this is reassuring, but if they fall away from the lowest centiles they may need specialist feeding advice or extra supplementary feeding.

Children over age 2 with BMI below the underweight threshold (BMI conversion chart) may be underweight, but this may also reflect a small build, so further assessment should be undertaken before advice is given.

The standard deviation (SD) low lines

The 4.5 SD lines below the centile lines are included to help assess the growth rate of exceptionally small children. Many of these will have additional medical problems and/or feeding difficulties (see above) and should be under medical supervision.

Overweight

Many older children with Down syndrome are overweight and the chart reflects this. Hence the weight chart should not be used as a healthy standard that children aim to achieve. Children over age 2 can be charted on the BMI conversion chart (see below) if there are concerns about overweight or if their weight lies above the 75th centile. Those with BMI above the overweight or very overweight thresholds should be encouraged to lose weight and offered specialist referral for guidance if appropriate.

Weight-height BMI conversion chart for Down syndrome

The BMI cut off used corresponds precisely to the absolute threshold used in the UK1990 chart. This has been derived from both the Down Syndrome and UK1990 charts.

BMI weight-height (BMIwH) indicates how close a child is to his or her height, and should be used to identify fatteness and distress from 2 years. The chart converts weight and height centiles of children with Down syndrome to BMI centiles, to use it, plot the child’s weight centile against their height centile, and see in which region the point falls.

Weight height to BMI conversion chart for Down syndrome


This is a new chart design which is still being evaluated and any feedback will be appreciated via info@dsming.org.uk

References


The charts are also available in A5 format as part of the Personal Child Health Record insert for babies born with Down syndrome.
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The charts are also available in A5 format as part of the Personal Child Health Record insert for babies born with Down syndrome.

Preterm babies (born before 37 completed weeks)

Measurements on preterm babies should not be plotted on this chart until the expected date of delivery (EDD) is reached. The neonatal and infant close monitoring (NCM) is valid to give guidance until term. Thereafter the Down syndrome charts should be used and measurements plotted using gestational age until a year (corrected age) for infants, from 22–36 weeks gestation and to 2 years (corrected age) for those born after 32 weeks gestation.

Newborns and young babies

The charts at age 0 represent birthweight for those born at 37 weeks or later and show the baby’s birth weight. Those born at 27 weeks or later should be plotted from this point. There are no lines on the charts between age 0 and 2 weeks. Most babies lose some weight after birth, a loss up to 10% is considered acceptable. For those with Down syndrome early loss may be more than 10% and is often taken longer than 2 weeks to regain weight. By 4 weeks, if there is no serious medical problem, most will be on a centile close to their birth weight. Early weight loss greater than 10% is not a good reason for sending a baby for advice or feeding difficulties.

After 4 weeks growth rates will vary from baby to baby, so weight often does not follow a particular centile line, but usually tends within one centile space. It is not unusual for growth of those with Down syndrome to proceed in piecemeal steps.

Underweight

The charts show the growth of children without medical problems. Hence some healthy babies will be below the 2nd centile (2 in every 100). However children with heart problems, other additional medical needs and feeding difficulties are over-represented among those with Down syndrome and are also likely to be on lower centiles. Babies below the 2nd centile for weight may need evaluation for additional pathology and/or feeding difficulties and appropriate action taken. If they then grow roughly parallel to their centile this is reassuring, but if they tail away from the lowest centile they may need specialist feeding advice or extra supplementary feeding.

More information about growth monitoring for children with Down syndrome is included in the Medical Surveillance Guidelines for people with Down syndrome produced by the Down Syndrome Medical Interest Group.

This is a new chart design which is still being evaluated and any feedback will be appreciated via info@dsigm.org.uk

References

What’s new?

- Expanded section for ages 0 to 6 months
- - 4 SD “low line” for monitoring exceptionally small children
- BMI “look-up” chart
How to use the redesigned charts

• Plot measurements from term
• For pre-term babies use standard UK90 Neonatal and Infant Close Monitoring Chart
• Use BMI conversion chart to assess weight especially for those in upper centiles

For this population

BMI > 75\textsuperscript{th} centile = overweight

> 91\textsuperscript{st} centile = obese
NICM chart:
- Large scale
- SD low lines for assessment of very small infants
- Date boxes

For preterm infants, before starting plotting fill in the date boxes for accurate calculation of gestational and corrected age.
Infants and toddlers

Body Mass Index (BMI) lookup

- Read off the weight and height centiles from the growth chart.
- Plot the weight centile (left axis) against the height centile (bottom axis).
- Read off the corresponding BMI centile from the slanting lines.
- Record centile with date in the data box.
- Accurate to \( \frac{1}{4} \) centile space.

BMI = 91st

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wwwgrowthcharts.rcpch.ac.uk
Weight-height conversion chart for Down Syndrome
Charts are a tool

• And need to be interpreted
• Use alongside clinical assessment of child’s wellbeing
• Healthy babies may lose > 10% of their birth weight and take up to 4 weeks to regain birth weight
• After 4 weeks most babies’ weight tracks within one centile space ...BUT
• Pay careful attention to babies that are growing slowly – consider overall health AND possible feeding problems
More information...

• www.dsmig.org.uk

• www.growthcharts.rcpch.ac.uk (educational materials)

• www.harlowprinting.co.uk
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