



PCHR for babies who have Down syndrome

(Fifth Edition, January 2020)

© Down Syndrome Medical Interest Group (2020)
c/o Staff Library, Duncan Macmillan House,
Porchester Road, Nottingham NG3 6AA
Tel: 0115 9691300 ex 11186
Email: info@dsmig.org.uk
<http://www.dsmig.org.uk>



All rights are reserved. No part of this insert may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, electrostatic, magnetic tape, mechanical photocopying, recording or otherwise without permission in writing from the copyright owner. All enquiries should be addressed to the publishers.



Printed and Supplied by:
Harlow Printing Limited
Maxwell Street • South Shields
Tyne & Wear • N33 4PU
Tel: 0191 455 4286
Email: sales@harlowprinting.co.uk

INTRODUCTION

The following pages are **extra** pages for your baby's Personal Child Health Record Book (PCHR) which is issued to all new babies in the UK. These extra pages have been produced by the UK Down Syndrome Medical Interest Group (DSMIG UK & Ireland). They give additional information regarding your child's development and common health issues in children who have Down syndrome. They also include specific growth charts for boys and girls who have Down syndrome.

Babies and young children who have Down syndrome have the same needs as any child. You should take your baby for routine child health checks and immunisations in the usual way. (See main PCHR).

It is not possible in this small booklet to cover all topics relevant to your child's health and wellbeing. Your local healthcare team, or one of the agencies listed at the end of this insert will be able to provide more information. You will also find more information for parents in the Health Series on the Down Syndrome Association website (www.downs-syndrome.org.uk). A wide range of information for healthcare professionals can be found on the DSMIG website. (www.dsmig.org.uk)

DOWN SYNDROME – CHILD DEVELOPMENT

There is no such thing as a typical child who has Down syndrome. Children who have Down syndrome are as different from each other as are all children. However, their development is generally slower than most children. The charts which follow give the usual developmental progress of children who have Down syndrome. By understanding what is usual for a child who has Down syndrome you will be able to recognise any additional issues at an early stage.

Many parents like to record developmental 'firsts' on the pages provided in the main PCHR. You may also like to use the Early Support Programme Developmental Journal for Babies and Children who have Down Syndrome. Information on how to access this can be found in the Sources of Help and Advice section on page 15.

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about moving



<u>Activity</u>	<u>Children who have Down syndrome</u>		<u>Typical Children</u>	
	Average age	Range	Average age	Range
Holds head steady when sitting	5 months	3-5 months	3 months	1 - 4 months
Rolls over	8 months	4-12 months	5 months	2-10 months
Sits alone	9 months	6-16 months	7 months	5-9 months
Stands alone	18 months	12-38 months	11 months	9-16 months
Walks alone	23 months	13-48 months	12 months	9-17 months

Adapted with permission from Cunningham. Down Syndrome: An Introduction for Parents and Carers (3rd Edition). 2006. Souvenir Press

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about hands

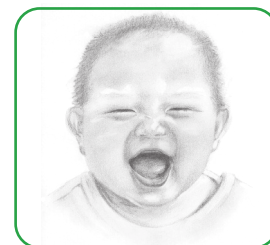


Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Follows objects with eyes	3 months	1.5-6 months	1.5 months	1-3 months
Reaches out and grasps objects	6 months	4-11 months	4 months	2-6 months
Passes objects hand to hand	8 months	6-12 months	5.5 months	4-8 months
Builds a tower of 2 cubes	30 months	14-32 months	15 months	10-19 months
Copies a circle	48 months	36-60 months+	30 months	24-40 months

Adapted with permission from Cunningham. Down Syndrome: An Introduction for Parents and Carers (3rd Edition). 2006. Souvenir Press

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about words



Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Responds to sounds	1 month	0.5-1.5 months	0 month	0-1 month
Babbles "Da-da" and "Ma-ma"	7 months	4-8 months	4 months	2-6 months
Responds to simple instructions	16 months	12-24 months	10 months	6-14 months
First words spoken with meaning	18 months	13-36 months	14 months	10-23 months
2-word phrases	30 months	18-60 months+	20 months	15-30 months

Adapted with permission from Cunningham. Down Syndrome: An Introduction for Parents and Carers (3rd Edition). 2006. Souvenir Press

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about people



Activity	Children who have Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Smiles when talked to	2 months	1.5-4 months	1 month	1-2 months
Plays pat-a-cake or peek-a-boo	11 months	9-16 months	8 months	5-13 months
Drinks from an ordinary cup	20 months	12-30 months	12 months	9-17 months
Dry by day	36 months	18-50 months+	24 months	14-36 months
Bowel control	36 months	20-60 months+	24 months	16-48 months

Adapted with permission from Cunningham. Down Syndrome: An Introduction for Parents and Carers (3rd Edition). 2006. Souvenir Press

DOWN SYNDROME - HEALTH ISSUES

Children who have Down syndrome have health issues that can affect any child. However, some health issues occur more often in children who have Down syndrome. It can sometimes be hard to recognise the health problems and therefore it is recommended to have some extra health checks (see next section) to identify and manage the condition as soon as possible.

Heart

About half of all children who have Down syndrome are born with a heart problem. It is important to identify these in the first 2 months, as early treatment may be needed. It is recommended that all children must have a thorough heart examination, including an echocardiogram, by six weeks of age to enable prompt treatment.

Blood

Children who have Down syndrome should have their blood count and blood film checked within the first three days of birth, to identify any serious blood disorders. A few may need treatment or on-going checks.

Vision and Hearing

Children who have Down syndrome are more prone to have difficulties with their hearing and vision. It is important to identify these early on, so that appropriate help can be given to minimise the effect of a hearing or visual impairment on your child's development.

Thyroid

The thyroid gland is more frequently underactive in children who have Down syndrome. The symptoms of thyroid disorders can be difficult to spot. An underactive thyroid can affect your child's growth, learning and general health. Treatment is simple and effective. It is recommended that your child has an annual blood test to identify the condition early on.

Constipation

Constipation is common in children who have Down syndrome. In most cases it is not due to any underlying bowel condition and can be managed as it would be in any child. If constipation is present since birth, or is severe and persists despite simple measures, then discuss your concerns with your doctor.

Toilet training

Children who have Down syndrome are usually toilet trained by the age of 3.5 - 4 years old. If your child is still in nappies at 4 years old then they need to be seen by a medical specialist to make sure that their bladder and kidneys are working properly.

Coeliac Disease

Although Coeliac disease (sensitivity to a protein in wheat, called gluten) can occur more frequently in children who have Down syndrome, routine screening is currently not recommended. Symptoms of Coeliac disease include bowel problems, tiredness or a change in behaviour. There should be a low threshold for checking for Coeliac disease and, if your child has symptoms seek advice from your doctor.

Breathing

Babies often have nasal congestion. Saline drops and nasal suction can sometimes help. Sleep apnoea occurs more commonly in children who have Down syndrome. Symptoms of sleep apnoea include gasping momentarily stopping to breathe or snoring whilst sleeping. It is recommended for all children who have Down syndrome to have their oxygen levels checked overnight, whilst asleep, at around the age of six months and then once a year until the age of 5. This is an easy procedure which can be done at home. This is to ensure that their breathing pattern and oxygen levels are normal.

Infections

Children who have Down syndrome are more vulnerable to chest infections and other serious infections. They may not show the same signs and symptoms as other children. If you are worried that your child may have a serious infection seek urgent medical advice so that a serious illness such as sepsis or pneumonia can be identified and treated early. Your child should receive all childhood immunisations, including the flu vaccine every year and Pneumovax II at 2 years of age.

Teeth

Baby and permanent teeth often come late and in a different order compared to other children. Gum and teeth infections can occur more commonly and can be serious. Children should brush their teeth twice a day and visit a dentist every six months.

Arthritis

Children who have Down syndrome are more commonly affected by arthritis. They may not easily express the pain that they are experiencing. A change in your child's ability to perform daily living activities, e.g. in their handwriting or walking abilities may be an indication of early onset arthritis. Seek advice from your doctor if your child is experiencing any of these difficulties or if you are concerned.

Neck Instability

Neck instability can occur at any age in children who have Down syndrome and though this is rare, it can be very serious. Routine neck X-ray screening does not help to detect the problem. Children with neck instability, usually have warning symptoms e.g. neck pain, holding their head or neck in an odd position or a change in their motor skills or continence. If your child develops any of these symptoms, seek an urgent medical assessment.

Other conditions

It is not possible in this small booklet to cover all the conditions which may occur more frequently in children who have Down syndrome. Those discussed above are some of the most common. Any concerns you may have about your child's health should be discussed with your local health professionals.

FEEDING

Many babies who have Down syndrome feed just as well as other babies. Some babies may have feeding difficulties, in the first few weeks, especially if they have additional health issues.

If you had decided to breast feed your baby before he/she was born don't change your mind just because he/she has Down syndrome. Most mothers who want to, do breast feed their babies successfully although it may take longer to establish. You may find it helpful to express breast milk for a time and use this to feed your baby. You can go back to breast feeding, if and when your baby is able to manage to breast feed. Your health visitor or a breast-feeding expert will be able to advise you about these issues. Breast feeding support groups such as La Leche League and the National Childbirth Trust provide useful information, some of it specifically about feeding babies who have Down syndrome. The organisations listed on page 15 could help put you in touch with local breastfeeding support/or groups in your area.

The most common feeding issues are:

your baby falls asleep soon after starting feeding so doesn't take enough

your baby may have a weak suck

your baby's coordination of sucking, breathing and swallowing has not yet matured so she/he gets tired and distressed and again he/she ends up not getting enough milk.

These issues usually get better after the first few weeks but understandably can be very worrying for parents at the time. If your baby is experiencing these issues, you can help by feeding little and often until feeding settles down to normal. You may even need to wake your baby up at night to feed.

Some children may have issues with feeding at later stages of development, for example when moving on to solids. If this happens your Health Visitor will be able to advise and you may need more specialist help from a Speech & Language Therapist.

Remember though, many babies and children who have Down syndrome feed just as well as other children.

DOWN SYNDROME - IMMUNISATIONS AND CHILD HEALTH CHECKS

Immunisations

Children who have Down syndrome may be particularly susceptible to infections and it is very important they have the same immunisations as everyone else (see immunisation section in the main PCHR). For some children, particularly those with heart problems, additional immunisations may be recommended, for instance to protect against seasonal flu and some respiratory infections. You can discuss this with your GP, Paediatrician, Health Visitor or Practice Nurse.

Child health checks

You will find information about routine child health checks in the main part of your PCHR. Your child should be included in just the same way as other children in your area. It is also advisable for children who have Down syndrome to have a few extra tests or checks, as detailed in this insert.

The next page tells you in the first column what sort of extra health checks (thyroid, eyes, hearing, growth, heart, breathing, blood) are needed. The other four columns tell you at what age these should be carried out. Details are given about the actual tests or procedures advised. Your GP or Health Visitor will be able to explain these to you.

Different areas organise their child health services in different ways so the schedule will not always be followed precisely. However if you think that your child has missed out on one of these checks take this book along to your GP or Health Visitor or Paediatrician and ask if you can have the checks carried out.

DOWN SYNDROME - SUGGESTED SCHEDULE OF HEALTH CHECKS

The following are suggested ages for health checks. Check at any other time if there are parental or other concerns.

	Birth - 6 weeks	Special checks under 2 years	Preschool checks	School age
Thyroid blood tests	Newborn routine heel prick - blood spot test	Age 4-6 months and then every year from the age of 1 year or more often if clinically indicated: Venous thyroid blood test including thyroid antibodies <u>or</u> Fingerprick TSH test		
Eye checks	Newborn routine check including congenital cataract check	Age 18-24 months: Formal eye and vision examination including check for squint, and refraction for long or or short sight	Age 4 years: Formal eye and vision examination including check for squint. Refraction and assessment of near and distant vision and visual acuity	Repeat vision test every 2 years , or more frequently if recommended by optometrist or ophthalmologist or if concerns
Visual behaviour to be monitored at every review particularly in first year				
Hearing checks	Universal newborn hearing screen	Full audiological review by 10 months including hearing test impedance check	Annual audiological review or more frequently and if indicated 2 yearly audiological review or more frequently if recommended	
Growth monitoring	Length, weight and head circumference should be checked frequently and plotted on Down syndrome growth charts		Height and weight should be checked and plotted on Down syndrome growth charts at least annually (BMI checked if concern regarding overweight)	
Heart checks	By age 6 weeks , formal heart assessment including Echocardiogram	At all ages low threshold for reviewing heart status if signs or symptoms develop		From adolescence onwards as part of routine health checks listen to heart for signs of acquired heart disease
Breathing checks	Enquire at every review for uneven breathing during sleep and poor quality sleep. Screen with an overnight pulse oximetry once in infancy and yearly until the age of 5, or at any age if there are symptoms or concerns. Low threshold for detailed sleep studies if symptoms persist, despite normal tests			
Blood checks	Within the first three days of life, full blood count and blood film to check for a serious blood disorder	If blood film is abnormal treatment or monitoring may be required		

Detailed recommendations for Medical Surveillance Essentials for children with Down syndrome can be found at www.dsmig.org.uk

SOURCES OF HELP AND ADVICE

In case of difficulty contacting the organisations listed below, please check the Other Organisations page at www.dsmig.org.uk/information-resources/other-organisations for updated information)

Down's Syndrome Association (DSA)

Langdon Down Centre, 2a Langdon Park,
Teddington TW11 9PS
Helpline 0333 1212 300 Mon-Fri 10am – 4pm
Email: info@downs-syndrome.org.uk
<http://www.downs-syndrome.org.uk>
(Services in Wales, Northern Ireland and
England)

Down's Syndrome Scotland (DSS)

Riverside House, 502 Gorgie Road,
Edinburgh EH11 3AF
Tel: 0131 442 8840
Email: familysupportservice@dsscotland.org.uk
<http://www.dsscotland.org.uk>

Down Syndrome Ireland

Unit 3 Park Way House, Western Parkway
Business Park, Ballymount Drive,
Dublin D12 HP70
Tel: 01 426 6500
Email: info@downsyndrome.ie
<http://www.downsyndrome.ie>

Down's Heart Group

Advice and support for families with
children with heart problems.
PO Box 4260, Dunstable, Beds. LU6 2ZT
Tel: 0300 102 1644
Fax: 0300 102 1645
Email: info@dhg.org.uk
<http://www.dhg.org.uk>

Down Syndrome Education International (DSE)

Supports scientific research and delivers
evidence-based advice and information to
improve outcomes for children with Down
syndrome worldwide.
6 Underley Business Centre, Kirkby
Lonsdale, Cumbria LA6 2DY
Tel: 0330 043 0021 Fax: 0330 043 0025
Email: hello@dseinternational.org
<http://www.dseinternational.org>

Down Syndrome Medical Interest Group (DSMIG U.K & Ireland)

c/o Staff Library, Duncan Macmillan House,
Porchester Road, Nottingham NG3 6AA
Tel: 0115 969 1300 ext. 11186
Email: info@dsmig.org.uk
<http://www.dsmig.org.uk>

Contact

209 City Road London EC1V 1JN
Helpline 0808 808 3555 for parents and
families (Mon-Fri 9.30 am– 5.00pm)
Email: info@contact.org.uk
<http://contact.org.uk>
The charity for families with disabled
children. The national helpline also covers
Wales, Scotland and Northern Ireland.

Contact Scotland

The Melting Pot, 5 Rose Street,
Edinburgh EH2 2PR
[https://contact.org.uk/advice-and-support/
local-support/contact-in-your-area/offices/
edinburgh/](https://contact.org.uk/advice-and-support/local-support/contact-in-your-area/offices/edinburgh/)

Contact Wales

[https://contact.org.uk/advice-and-support/
local-support/contact-in-your-area/offices/
cardiff/](https://contact.org.uk/advice-and-support/local-support/contact-in-your-area/offices/cardiff/)

Contact Northern Ireland

63-75 Duncairn Gardens, Belfast BT15 2GB
Tel: 028 9262 7552
[https://contact.org.uk/advice-and-support/
local-support/contact-in-your-area/offices/
northern-ireland/](https://contact.org.uk/advice-and-support/local-support/contact-in-your-area/offices/northern-ireland/)

Developmental Journal for Babies and Children with Down Syndrome

This was part of the Early Support
Programme which has now closed.
The journal is still available at
[https://councilfordisabledchildren.org.uk/
help-resources/resources/downs-syndrome-
development-journal-early-support](https://councilfordisabledchildren.org.uk/help-resources/resources/downs-syndrome-development-journal-early-support)

MENCAP

123 Golden Lane, London EC1Y 0RT
Learning Disability Helpline: 0808 808 1111
Email: helpline@mencap.org.uk
<http://www.mencap.org.uk>
Supporting people with a learning disability
and their families and carers. Offices in
Peterborough, Wales and Northern Ireland.

Enable Scotland

INSPIRE House, 3 Renshaw Place,
Eurocentral, North Lanarkshire ML1 4UF
Tel: 01698 737 000
Fax: 0844 854 9748
Email: enabledirect@enable.org.uk

Local services:

Contact the DSA or DSS to find a local
group in your area. DSA/DSS head offices
will provide information or check their
websites. Child health care is provided in
most areas through the community
paediatric services and child development
centres (CDCs). Your GP and/or health
visitor will be able to tell you how to get in
touch.
Each local authority will have a 'local offer'
website that provides details of services
within their locality.

Further copies of this insert contact:
Harlow Printing Limited, 9-21 Maxwell
Street, South Shields, Tyne & Wear
NE33 4PU.
Tel: 0191 455 4286
Fax: 0191 427 0195
Email: sales@harlowprinting.co.uk
<http://www.harlowprinting.co.uk>

INFECTION ALERT

This page has been included to highlight to health professionals and parents/carers that children who have Down syndrome may respond differently to infections and need special consideration.

If you are worried that your child may have a serious infection please seek medical advice and show this page.

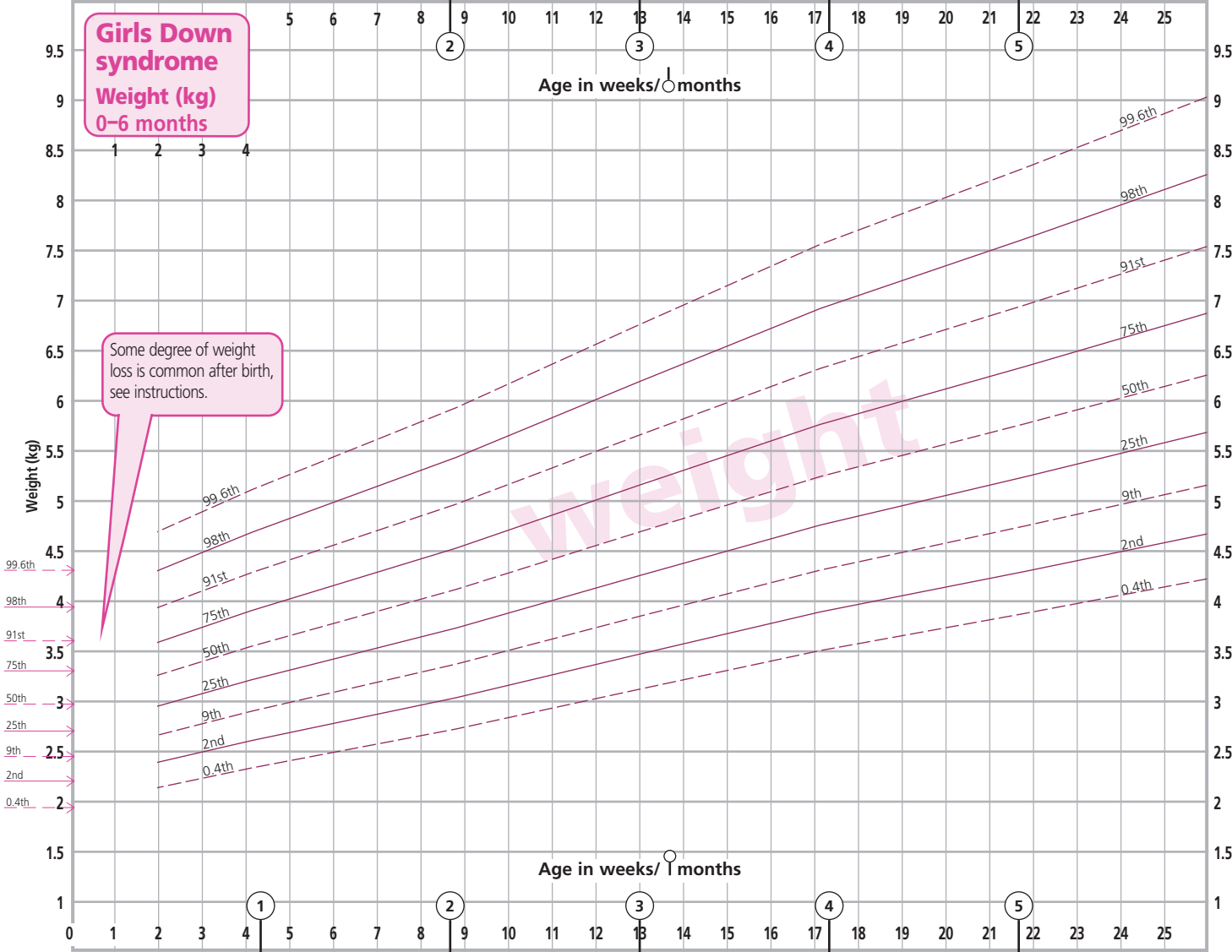
Children who have Down syndrome are more vulnerable to serious infections and may present atypically. They may not 'appear' to be unwell, so checking with their parents/carers about what is usual for them is important.

If a child who has Down syndrome presents with a possible infection, have a low threshold for:

- Suspecting serious infections such as sepsis or pneumonia and seek prompt paediatric advice
- Starting antibiotics and continuing them for double the length of time, e.g. 10 days instead of 5 days
- Arrange to review the child, if a viral infection is diagnosed and antibiotics are not commenced.

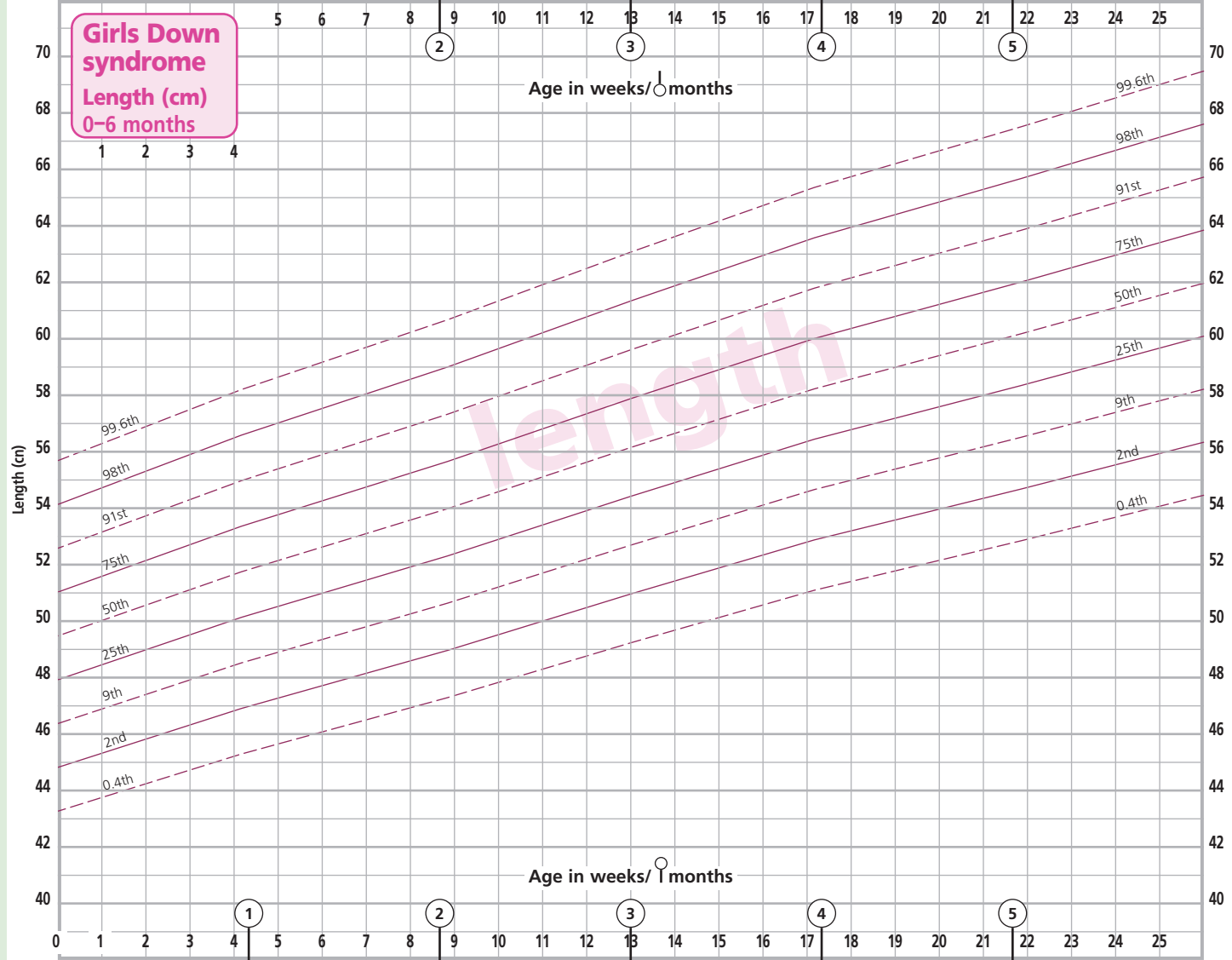
Please offer the recommended universal immunisations as well as, the Flu vaccine every year from the age of 6 months and the Pneumovax II at the age of 2 years.

**Girls Down syndrome
Weight (kg)
0-6 months**

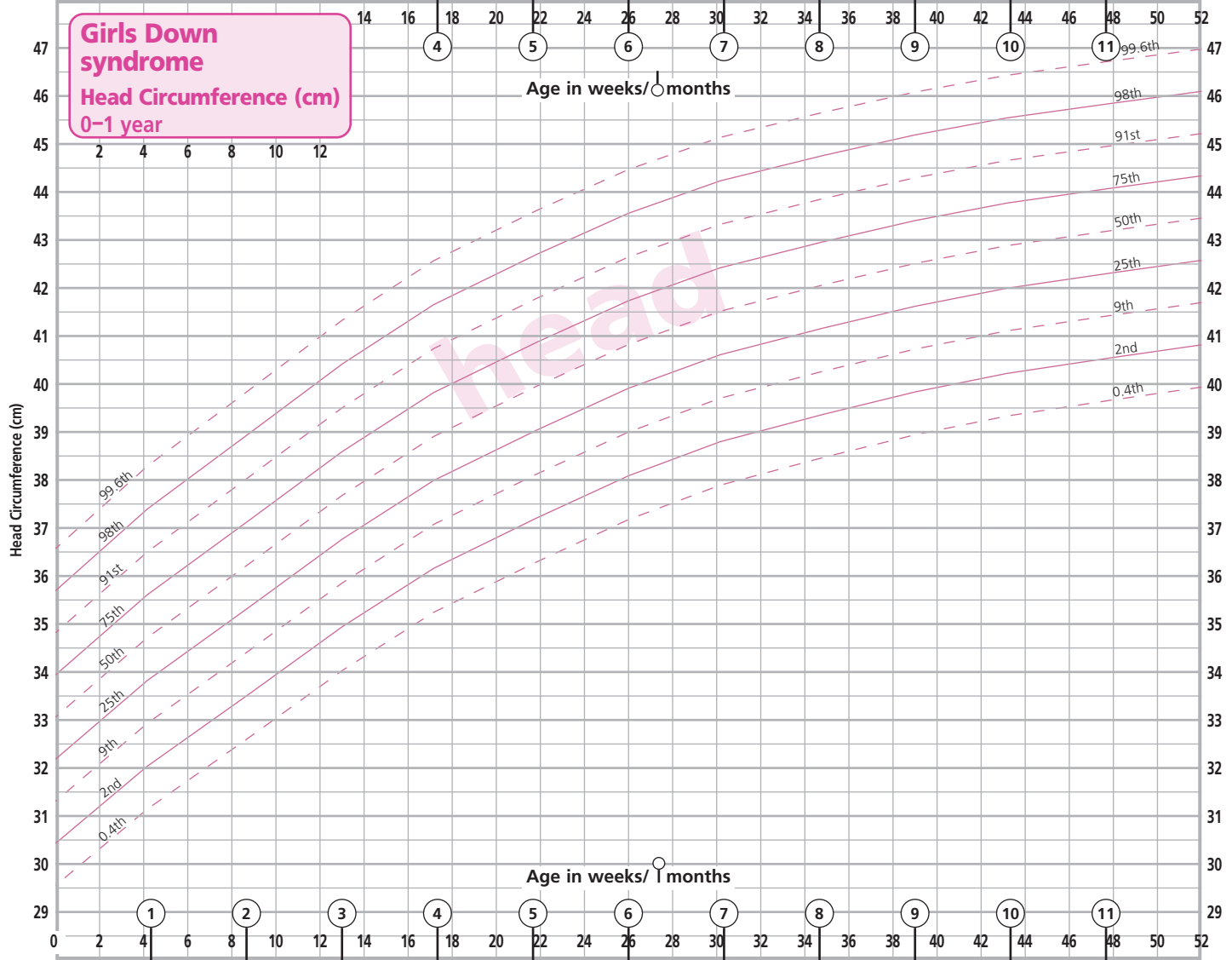


DOWN SYNDROME GROWTH CHARTS

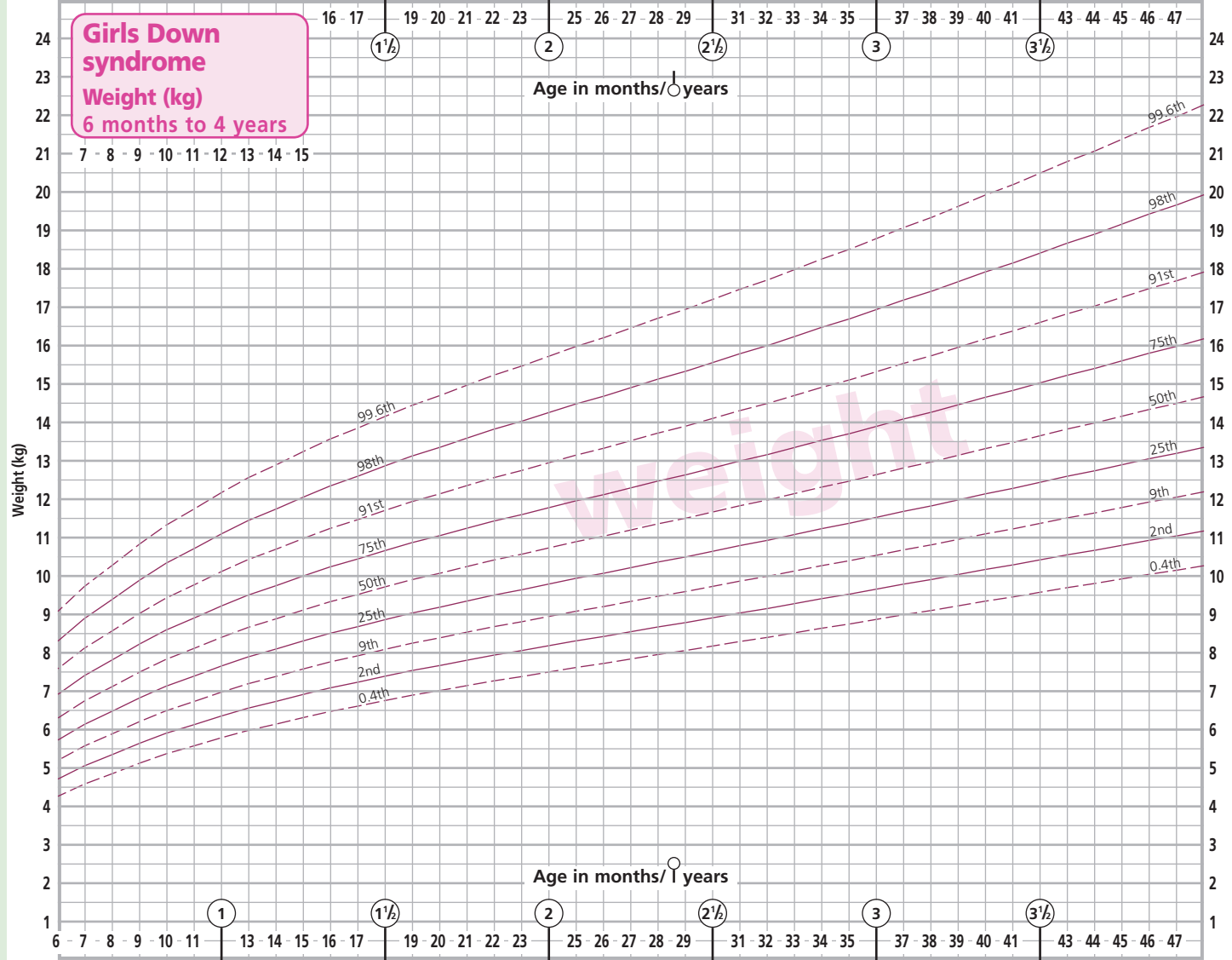
Girls Down syndrome
Length (cm)
0-6 months



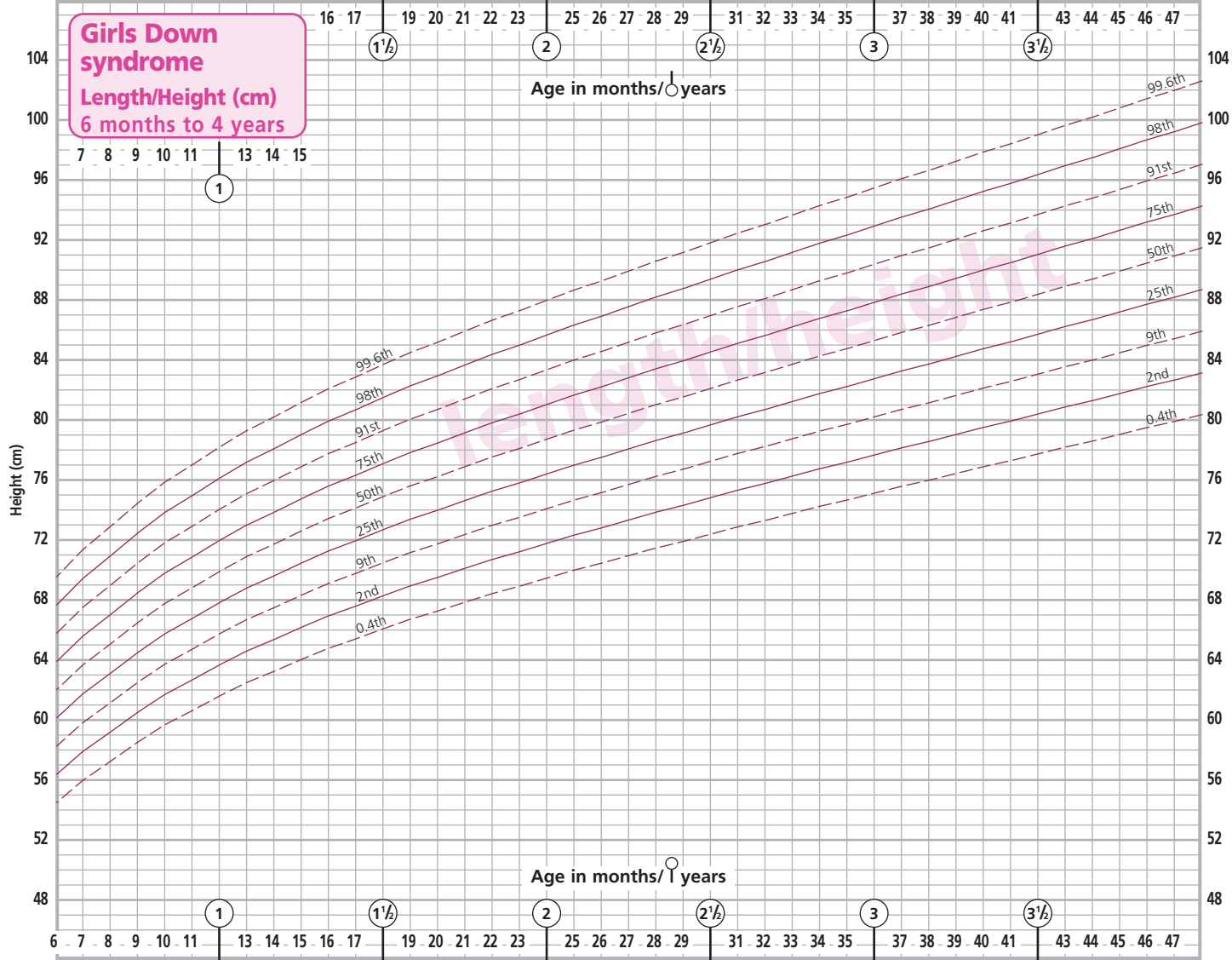
Girls Down syndrome
Head Circumference (cm)
0-1 year



DOWN SYNDROME GROWTH CHARTS



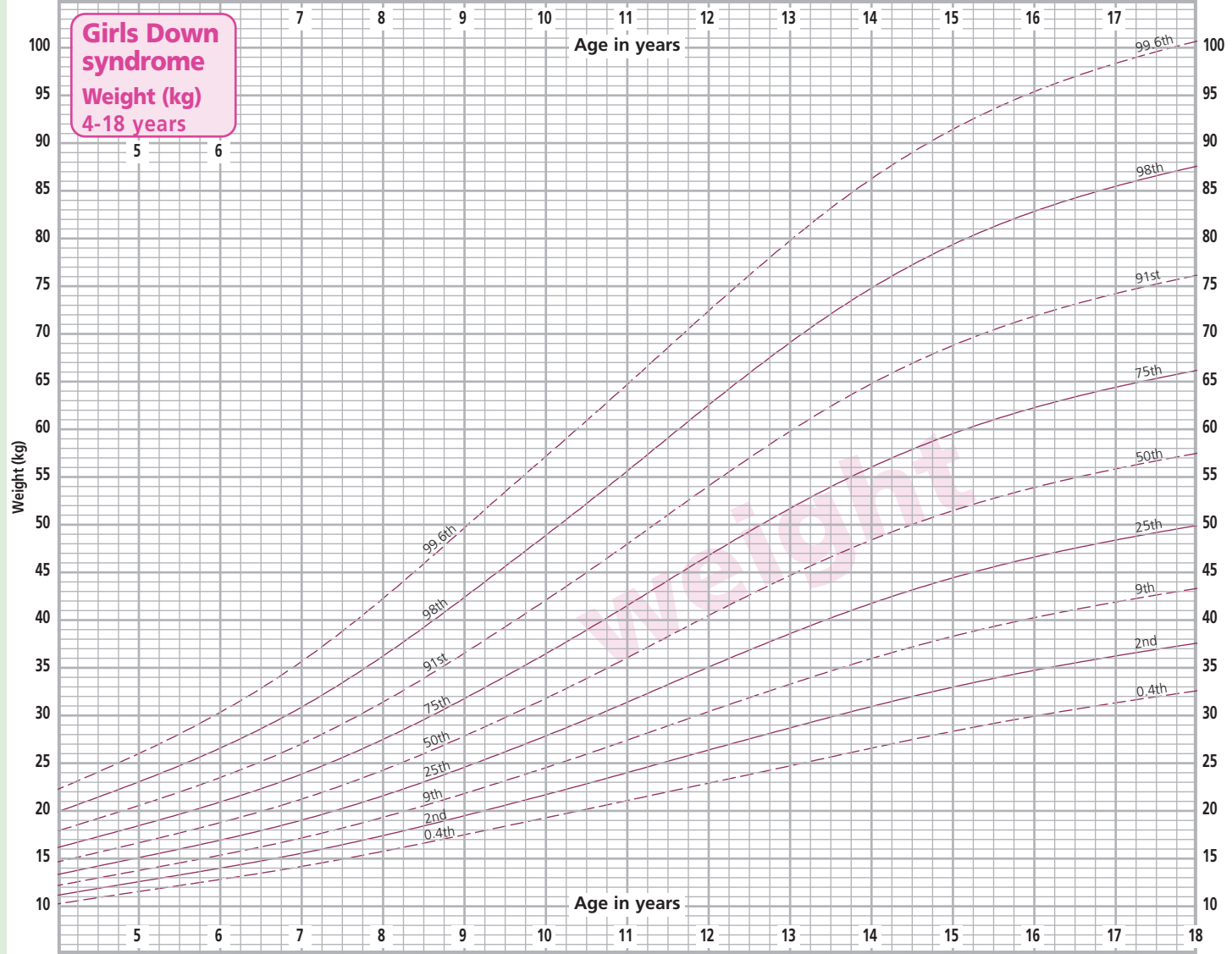
Girls Down syndrome
Length/Height (cm)
6 months to 4 years



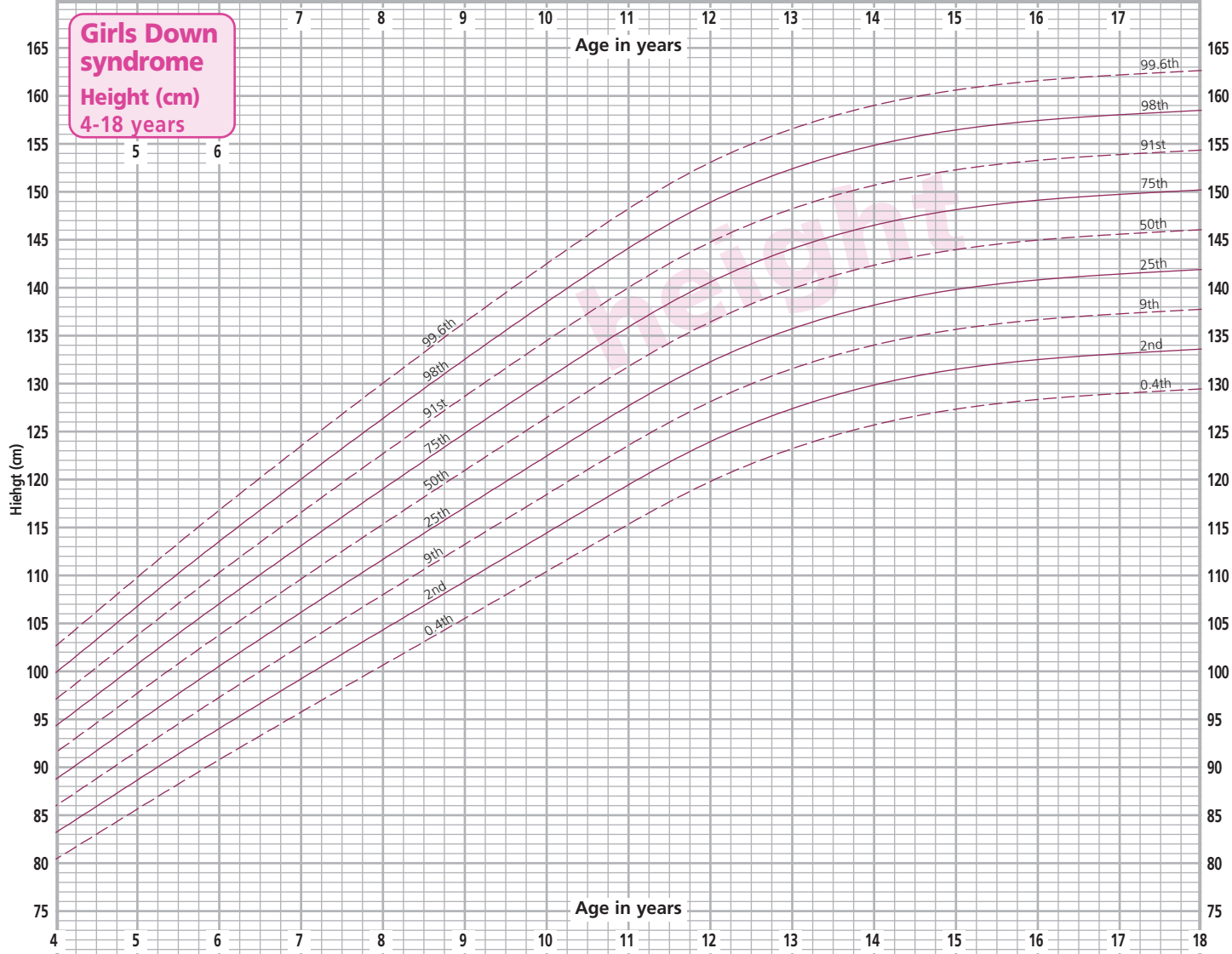
DOWN SYNDROME GROWTH CHARTS

DOWN SYNDROME GROWTH CHARTS

Girls Down syndrome
Weight (kg)
4-18 years



Girls Down syndrome
Height (cm)
4-18 years



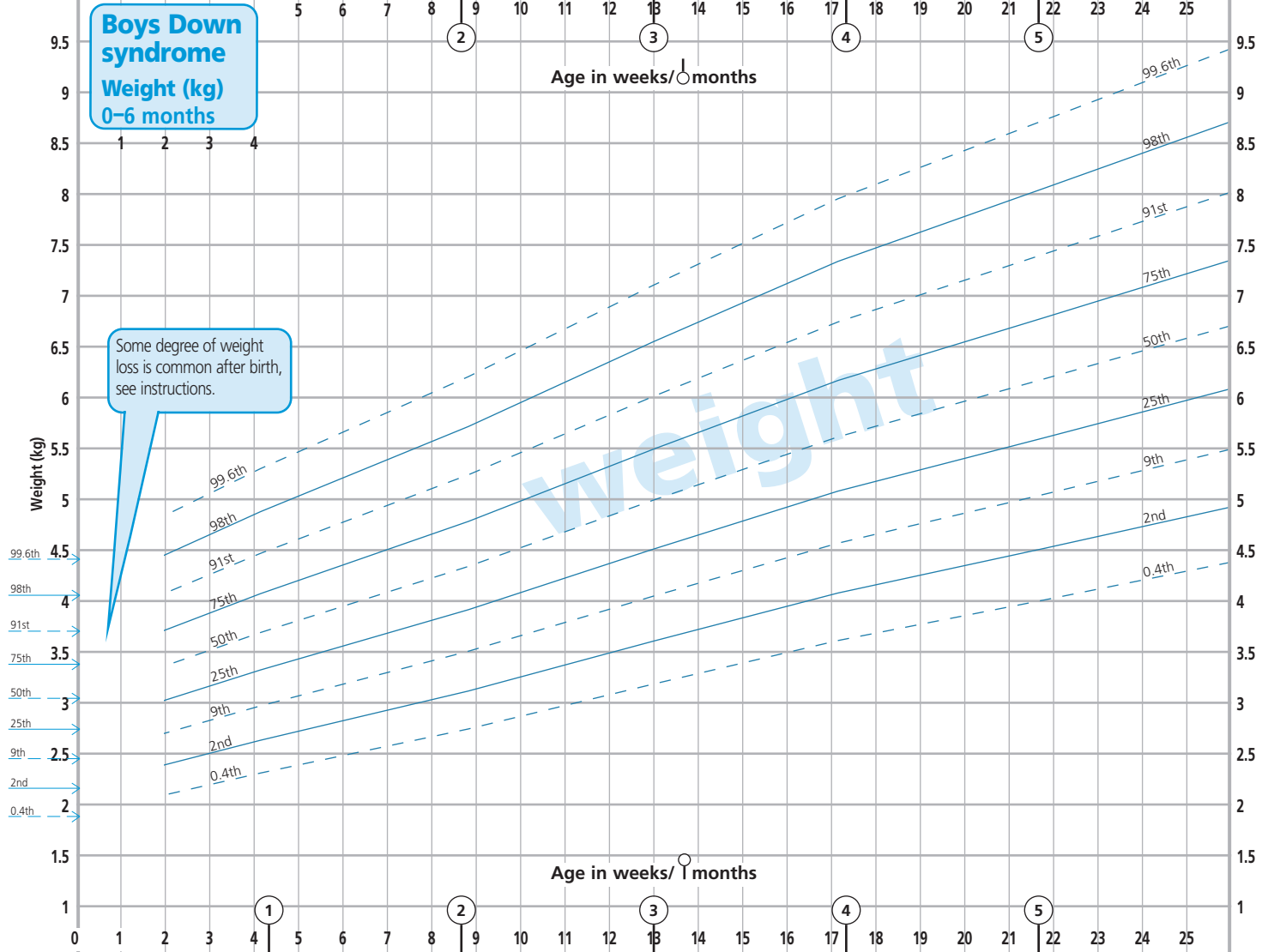
DOWN SYNDROME GROWTH CHARTS

Boys Down syndrome
Weight (kg)
0-6 months

Age in weeks/ months

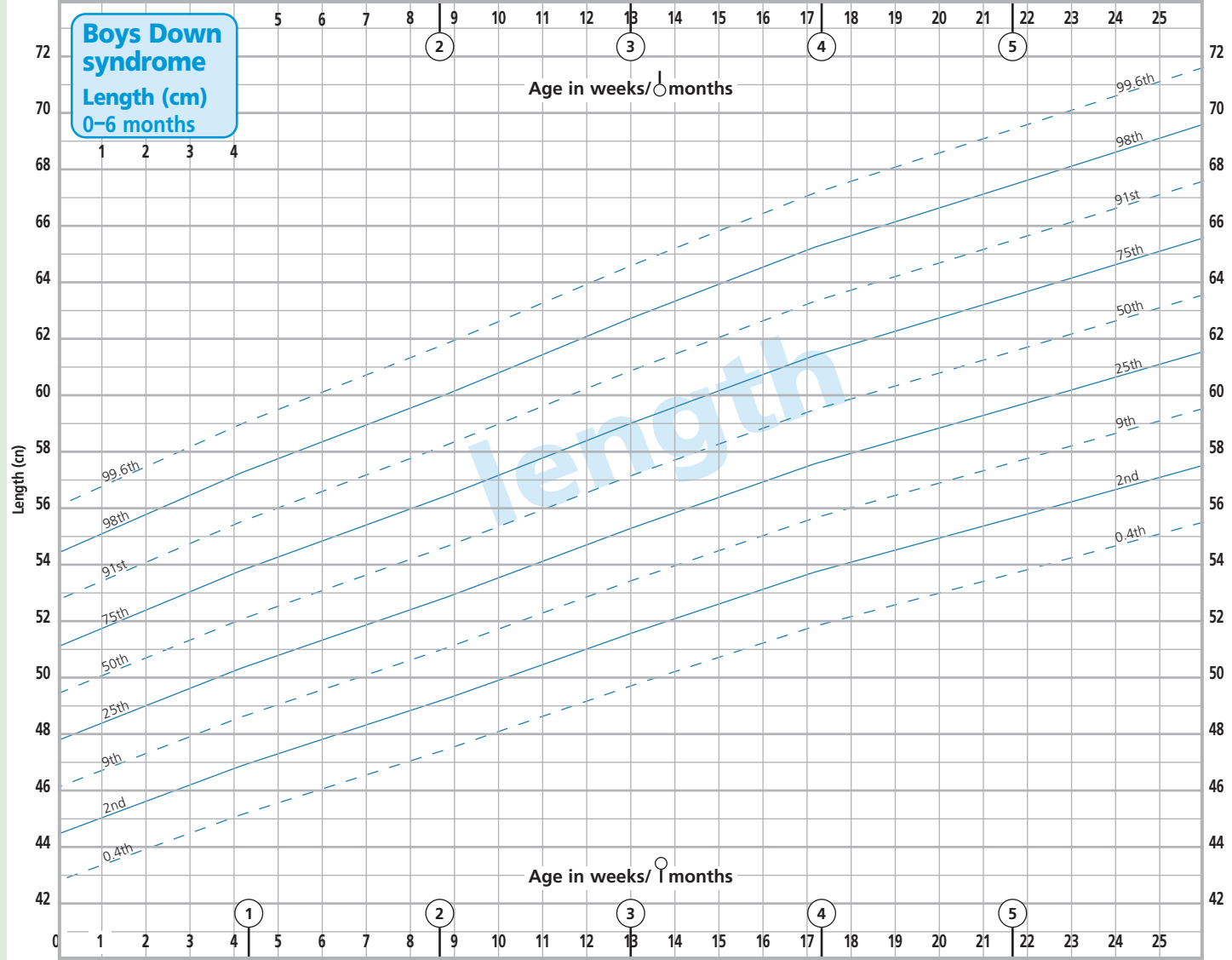
Age in weeks/ months

Some degree of weight loss is common after birth, see instructions.

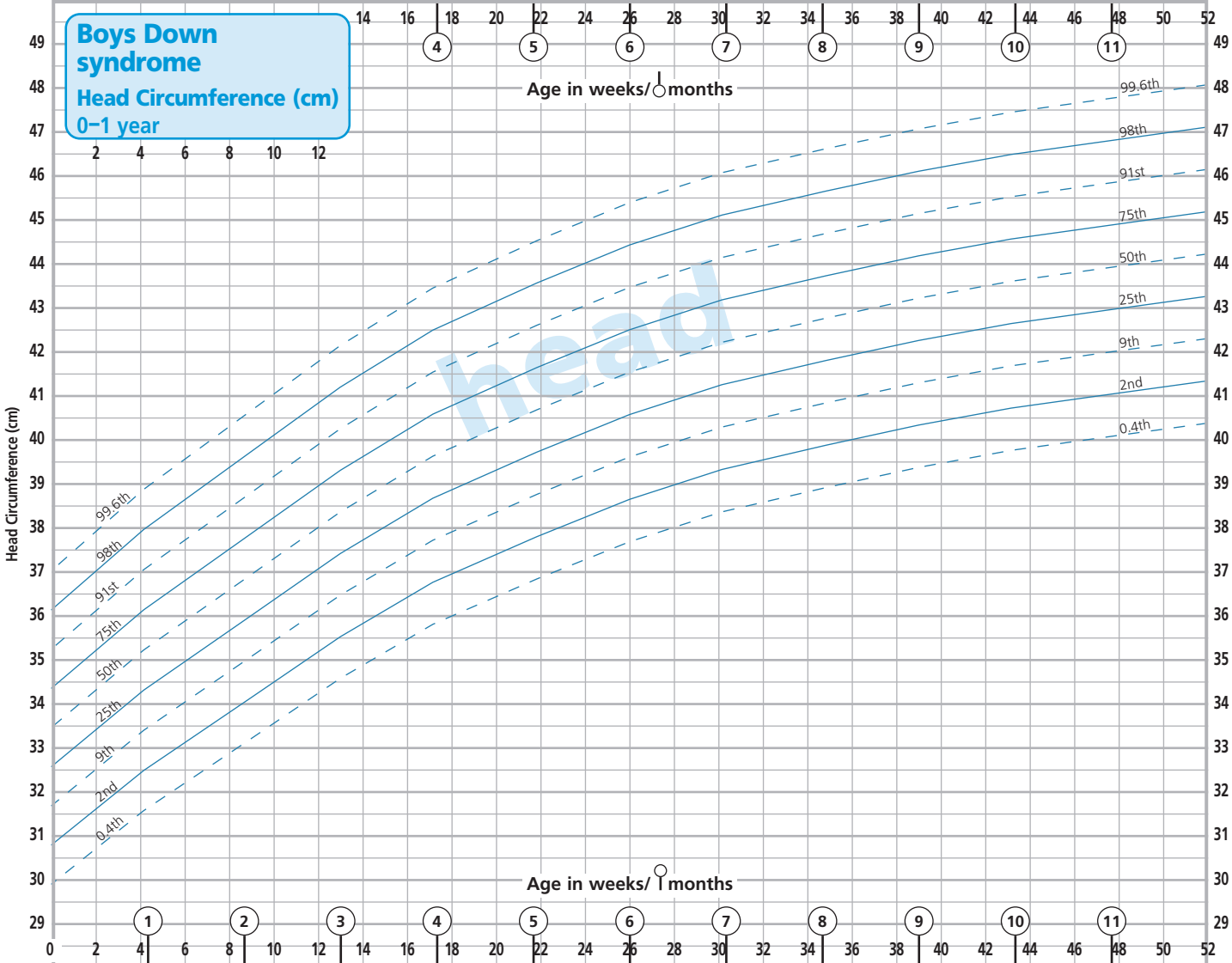


DOWN SYNDROME GROWTH CHARTS

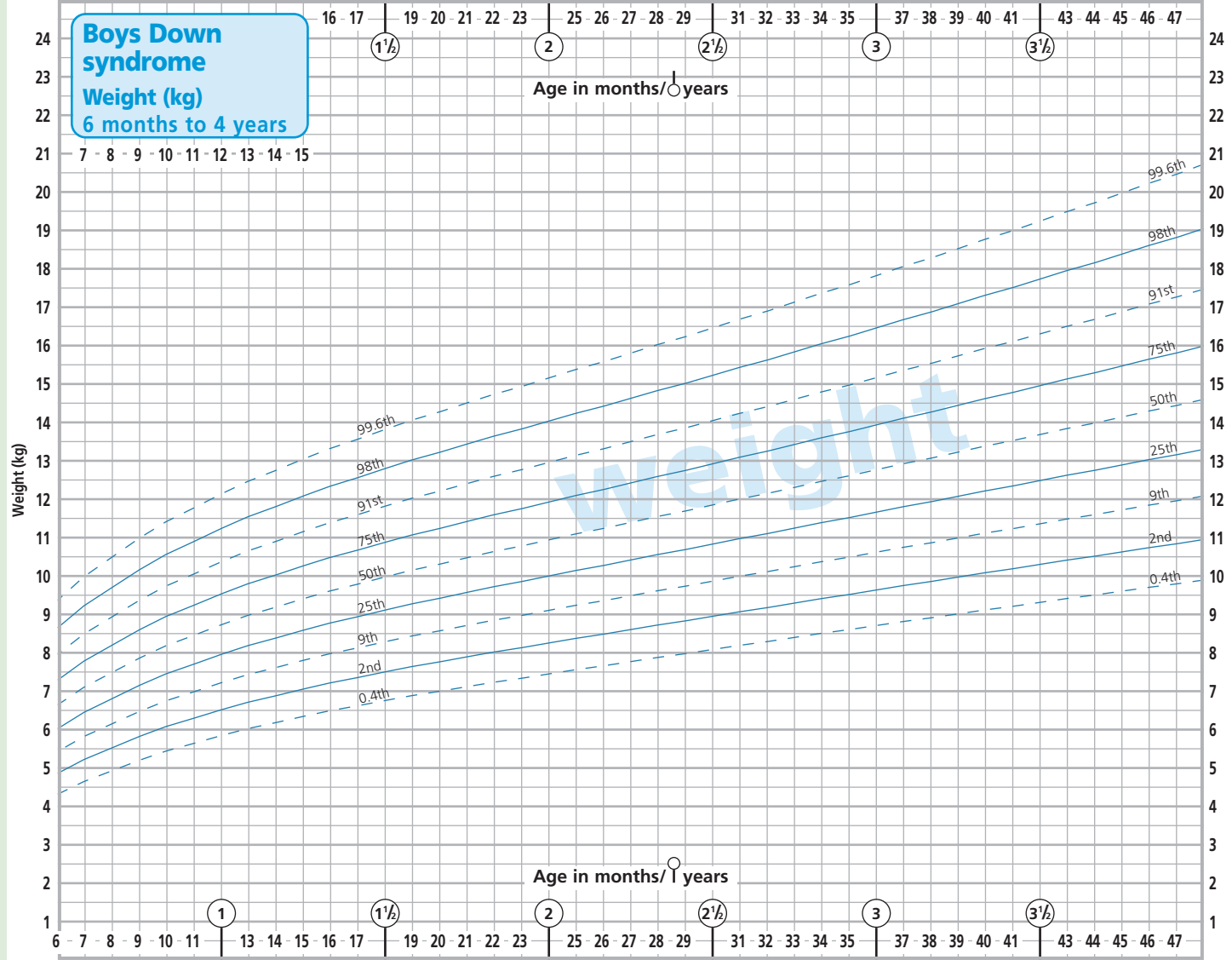
Boys Down syndrome
Length (cm)
0-6 months



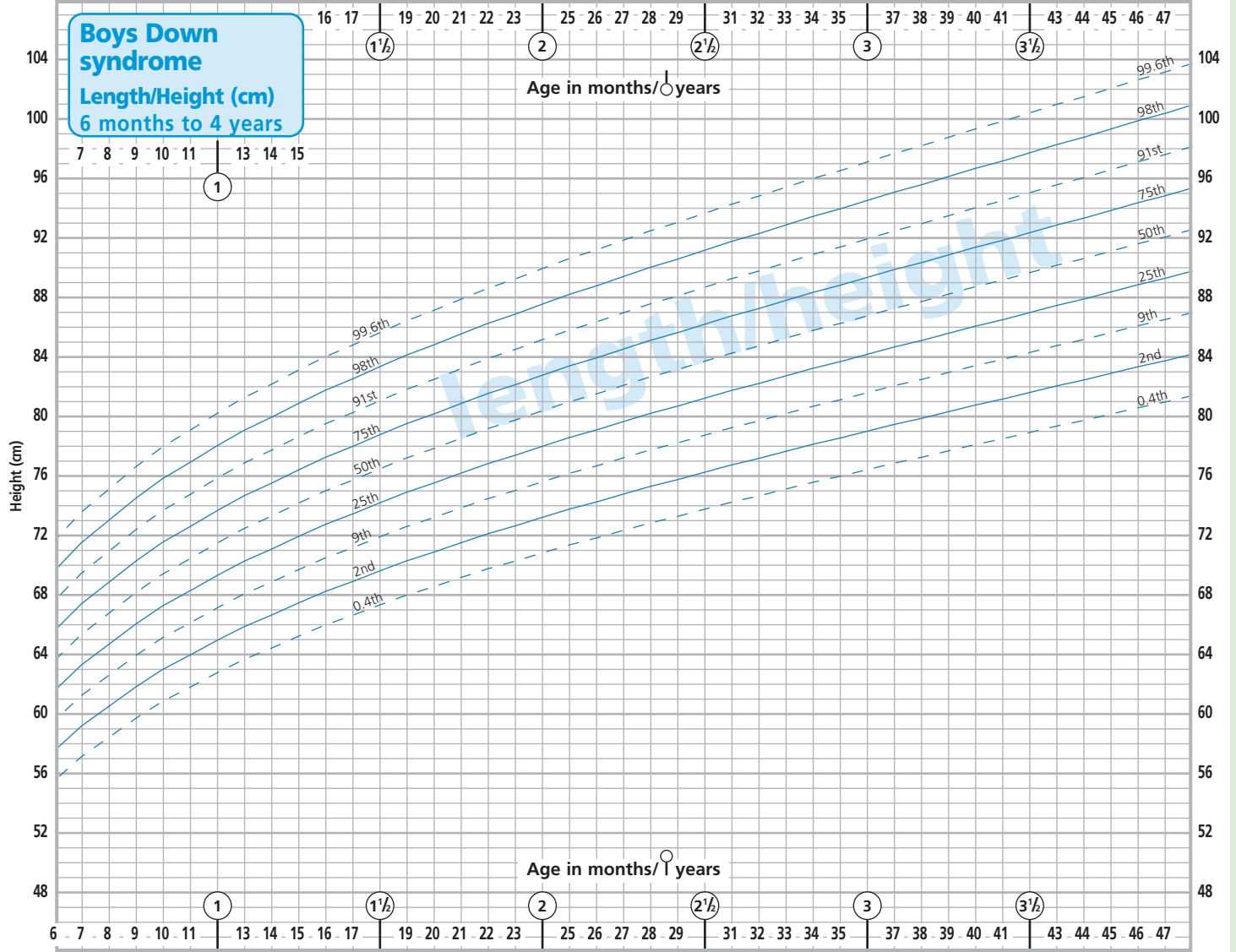
Boys Down syndrome
Head Circumference (cm)
0-1 year



DOWN SYNDROME GROWTH CHARTS

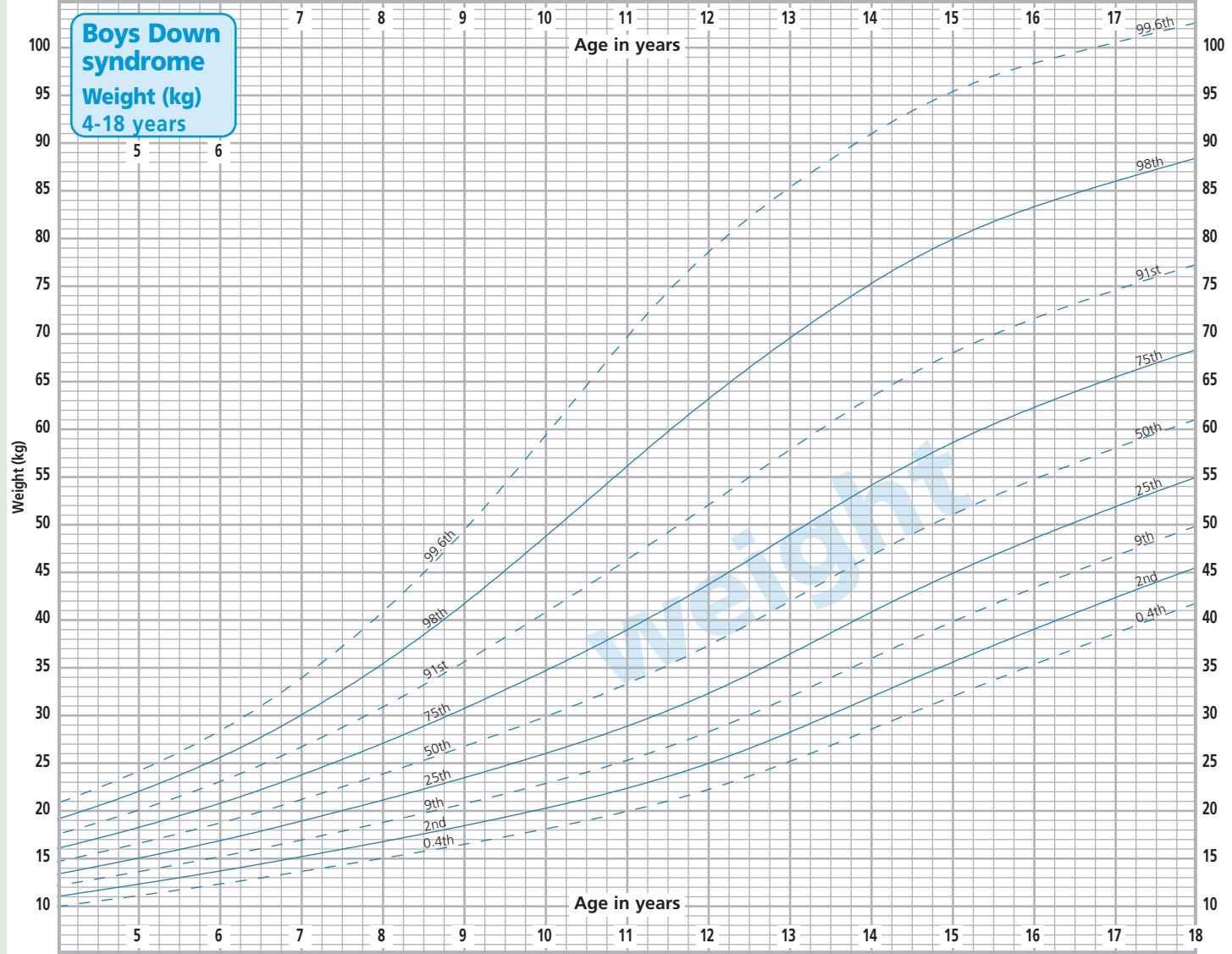


Boys Down syndrome
Length/Height (cm)
6 months to 4 years

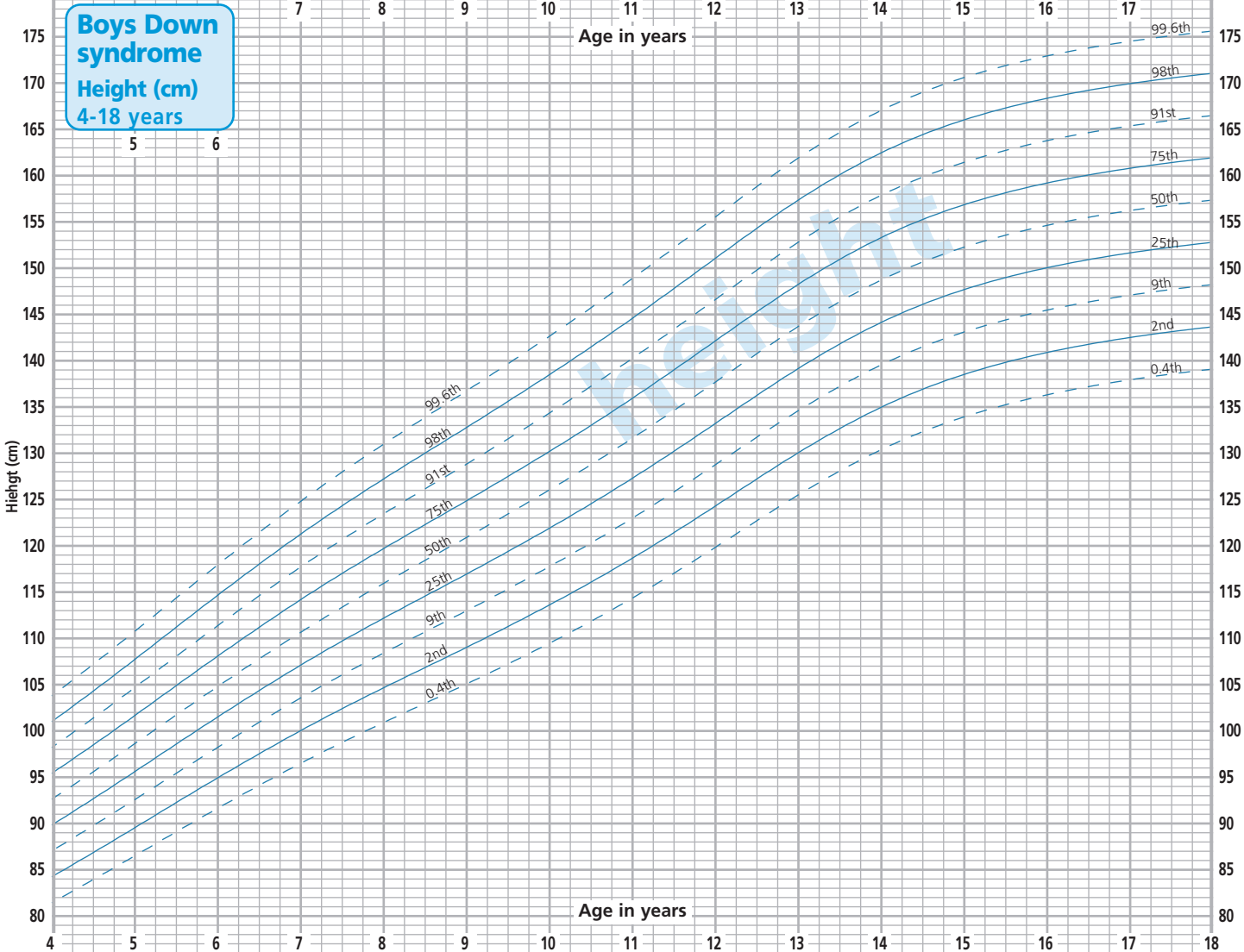


DOWN SYNDROME GROWTH CHARTS

Boys Down syndrome
Weight (kg)
4-18 years



Boys Down syndrome
Height (cm)
4-18 years



DOWN SYNDROME GROWTH CHARTS

