



PCHR insert for babies born with Down syndrome

(Third Edition, June 2011)

© Down Syndrome Medical Interest Group (2011)
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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). They are for babies who are born with Down 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 with Down syndrome.

Babies and young children with Down syndrome have just 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 well being. 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 detailed information written specifically for parents in the Department for Education Early Support materials. Information on how to access this can be found under "Early Support", in the Sources of Help and Advice section on page 14. 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 with Down syndrome. Children with the syndrome are as different from each other as are all children. However, by and large, their development is slower than that of most children. The charts which follow give the usual developmental progress of children with the syndrome. By understanding what is usual for a child with Down syndrome you will be able to recognise any additional problems 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 with Down Syndrome. Information on how to access this can be found under "Early Support", in the Sources of Help and Advice section on page 14. You can download this publication or order it free of charge.

DOWN SYNDROME – DEVELOPMENTAL MILESTONES

Finding out about moving

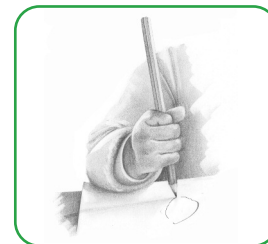


<u>Activity</u>	<u>Children with Down syndrome</u>		<u>Typical Children</u>	
	Average age	Range	Average age	Range
Holds head steady when sitting	5 months	3-5 months	3 months	1-4 months
Rolls over	8 months	4-12 months	5 months	2-10 months
Sits alone	9 months	6-16 months	7 months	5-9 months
Stands alone	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

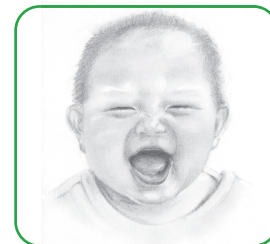


Activity	Children with Down syndrome		Typical Children	
	Average age	Range	Average age	Range
Follows objects with eyes	3 months	1.5-6 months	1.5 months	1-3 months
Reaches out and grasps objects	6 months	4-11 months	4 months	2-6 months
Passes objects hand to hand	8 months	6-12 months	5.5 months	4-8 months
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



<u>Activity</u>	<u>Children with Down syndrome</u>		<u>Typical Children</u>	
	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



<u>Activity</u>	<u>Children with Down syndrome</u>		<u>Typical Children</u>	
	Average age	Range	Average age	Range
Smiles when talked to	2 months	1.5-4 months	1 months	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 PROBLEMS

Children with Down syndrome do not on the whole have health problems which are different from those which can affect any child. Some have very good health whilst some seem to have more than their fair share of illness. Because some problems occur more often among those with the syndrome all should have some extra health checks (see next section) so that if there is a problem it can be identified and treated as quickly as possible.

Heart problems

About half of all children with Down syndrome are born with some sort of heart problem but less than one in five have a serious problem. It is important however to identify any serious problems in the first 2 months because early treatment may be needed. If the checks we recommend are carried out nearly all serious problems can be identified before a child is six weeks old. If these checks are done and your child is given a clean bill of health then he/she is very unlikely to develop a heart problem during childhood.

Vision and hearing problems

Children with Down syndrome are particularly likely to develop hearing problems and long or short sight. It is very important to identify these early on because they can easily be treated. If not treated they can affect your child's developmental progress.

Thyroid problems

The thyroid gland is more often underactive in children with Down syndrome than in other children. If this happens your child's development will slow down unless treatment is given. Treatment is simple and effective. Regular blood tests need to be done to see if this sort of problem is developing.

Constipation

Constipation is a common problem in children with Down syndrome. In most cases it is not due to any underlying bowel problem and can be managed as it would be in any child. If it has been a problem since birth, is severe and persists despite simple measures, then other causes such as Hirschsprung's disease or an under active thyroid should be considered and discussed with your Doctor or health visitor.

Breathing

Children with Down syndrome may be more susceptible to respiratory infections for a variety of reasons including reduced immunity, feeding difficulties, gastro-oesophageal reflux and heart or airway problems. Treatment will focus on tackling these causes, often in combination. Some children also develop irregular breathing and poor quality sleep due to sleep related breathing difficulties. This may need to be checked with sleep studies.

Teeth

Teeth do not necessarily come at the same time or in the same order as other children. As with all children dental hygiene is important and children should visit their dentist regularly.

Blood disorders

Children with Down syndrome should have their blood count checked at birth as many children will have differences in the make up of their blood, and a few may need treatment.

Neck problems

You may hear mention of children with Down syndrome having neck problems. This is very rare and does not require routine screening. However if there are symptoms suggestive of a problem, these may need investigation and treatment. Possible warning signs are pain behind the ear or in the neck, or holding the head and neck in an odd position.

Other conditions

It is not possible in this small booklet to cover all the conditions which may occur more frequently in children with 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. But remember, although a few children seem to have more than their fair share of health problems others enjoy good health.

FEEDING

Many babies with Down syndrome feed just as well as other babies but there are also quite a few who have difficulties, particularly in the first few weeks.

The most common problems are:

- your baby falls asleep soon after starting feeding so doesn't take enough.
- your baby may have a weak suck.
- that the coordination of sucking, breathing and swallowing has not yet matured so your baby gets tired and distressed and again he/she ends up not getting enough milk.

These problems usually get better after the first few weeks but can be very worrying for parents at the time. If your baby does have these problems 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.

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 efficient breast feeding may take longer to establish. Breast feeding support groups such as La Leche League and the National Childbirth Trust provide useful information, some of it specifically about feeding babies with Down syndrome.

If your baby has the early feeding problems mentioned above you may find it helpful to express breast milk for a time and use this to feed your baby. You can then go back to breast feeding as soon as your baby is mature enough to cope. Similarly, if you are advised to give up breast feeding because of poor weight gain it may be worth expressing for a few weeks in case changing to formula makes no difference to weight gain. Your health visitor or breast feeding expert will be able to advise you about these issues.

A few children with Down syndrome have difficulties with feeding at later stages of development - for instance 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 with Down syndrome feed just as well as other children.

DOWN SYNDROME - IMMUNISATIONS AND CHILD HEALTH CHECKS

Immunisations

Children with Down syndrome may be particularly susceptible to infections therefore 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 bronchiolitis. 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 with Down syndrome to have a few extra tests or checks.

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	From age 1 year thyroid function should be discussed annually using results of either <ul style="list-style-type: none">• Annual fingerprick TSH test OR• 2 yearly thyroid blood tests, including thyroid antibodies		
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
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 and impedance check	Annual audiological review as before	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 while growing. (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. Low threshold for further testing using sleep studies			
Blood checks	Newborn blood test to check for abnormal blood film	If blood film is abnormal in first 6 weeks, follow up or repeat blood testing may be necessary until age 5		

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

DOWN SYNDROME - RECORD OF HEALTH CHECKS

Please ask your Doctor and /or Health Visitor to write down the result of thyroid, eye, hearing, growth, heart, breathing and blood checks on this page.

Date	Age	Type of Test	By whom or where	Result (please enter actual figures where possible)

SOURCES OF HELP AND ADVICE

(In case of difficulty contacting the organisations listed below, please check the Links page at www.dsmig.org.uk for updated information).

Down Syndrome Association (DSA)

Langdon Down Centre, 2a Langdon Park,
Teddington TW11 9PS.
Tel: 0845 230 0372 (Mon – Fri 10am – 4pm)
Fax: 0845 230 0373
Email: info@downs-syndrome.org.uk
<http://www.downs-syndrome.org.uk>
(Regional offices in Wales and Northern Ireland)

Down Syndrome Scotland

158/160 Balgreen Road,
Edinburgh EH11 3AU.
Tel: 0131 313 4225 Fax: 0131 313 4285
Email: info@dsscotland.org.uk
<http://www.dsscotland.org.uk>

Down Syndrome Ireland

Citylink Business Park, Old Naas Road,
Dublin 12.
Tel: (00353) 1 426 6500
Fax: (00353) 1 426 6501
Email: info@downsyndrome.ie
<http://www.downsyndrome.ie>

Down Heart Group

Advice and support for families with children with heart problems.
PO Box 4260, Dunstable, Beds. LU6 2ZT.
Tel: 0844 288 4800 Fax: 0844 288 4808
Email: info@dhg.org.uk
<http://www.dhg.org.uk>

Down Syndrome Education International (DSE)

Advancing the development of children with Down syndrome worldwide.
The Sarah Duffen Centre,
Belmont Street, Southsea. PO5 1NA.
Tel: 023 92 85 5330 Fax: 023 92 85 5320
Email: enquiries@dseinternational.org
<http://www.dseinternational.org/en/gb/>

Down Syndrome Medical Interest Group (DSMIG)

A network of doctors and nurses with a specialist interest in Down syndrome.
Information Service,
The Children's Centre,
City Hospital Campus,
Hucknall Road,
Nottingham NG5 1PB.
Tel: 0115 8831158 Fax: 0115 8831146
Email: info@dsmig.org.uk
<http://www.dsmig.org.uk>

Contact a Family

209-211 City Road
London EC1V 1JN
Tel: 020 7608 8700 Fax: 020 7608 8701
Helpline 0808 808 3555 for parents and families (Mon-Fri 9.30 am– 5.00pm)
Email: info@cafamilly.org.uk
<http://www.cafamilly.org.uk>
(Local and regional offices, family workers and volunteer parent representatives throughout the UK.)

Early Support

Free information resources for families in England, who have a disabled child under 5 years of age. There are two publications about Down syndrome, specifically,

- Information for Parents: Down Syndrome
- Developmental Journal for Babies and Children with Down Syndrome

These can be located by entering "Down Syndrome" in the search box at: <http://publications.education.gov.uk/>. Both publications can be downloaded. Alternatively if you register with the website, <http://www.education.gov.uk/publications>, or telephone 0845 60 222 60, they can be ordered free of charge.

MENCAP

Supporting people with a learning disability and their families and carers. Offices in Wales and Northern Ireland.
123 Golden Lane, London EC1Y 0RT.
Helpline: 0808 808 1111
Tel: 020 7454 0454 Fax: 020 7608 3254
Email: information@mencap.org.uk
<http://www.mencap.org.uk>

ENABLE Scotland

Support for people with learning disabilities in Scotland.
2nd Floor, 146 Argyle Street,
Glasgow G2 8BL.
Tel: 0141 226 4541 Fax: 0141 204 4398
Email: enable@enable.org.uk
<http://www.enable.org.uk>

Local services:

There may be a local group of the DSA in your area. DSA head office will provide information.

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.

Your local social services department will also be able to give information about local provision. You will find their number in the phone book.

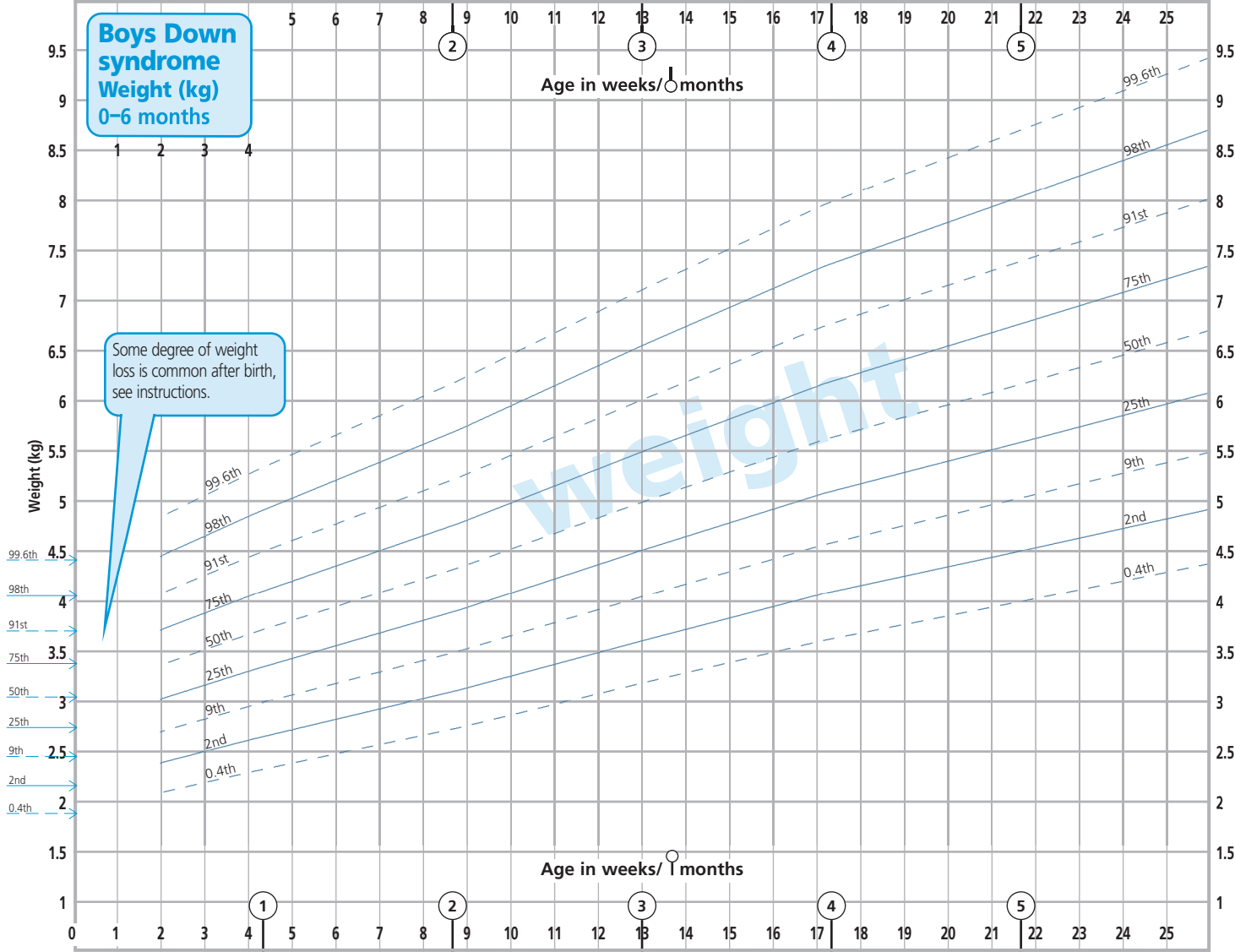
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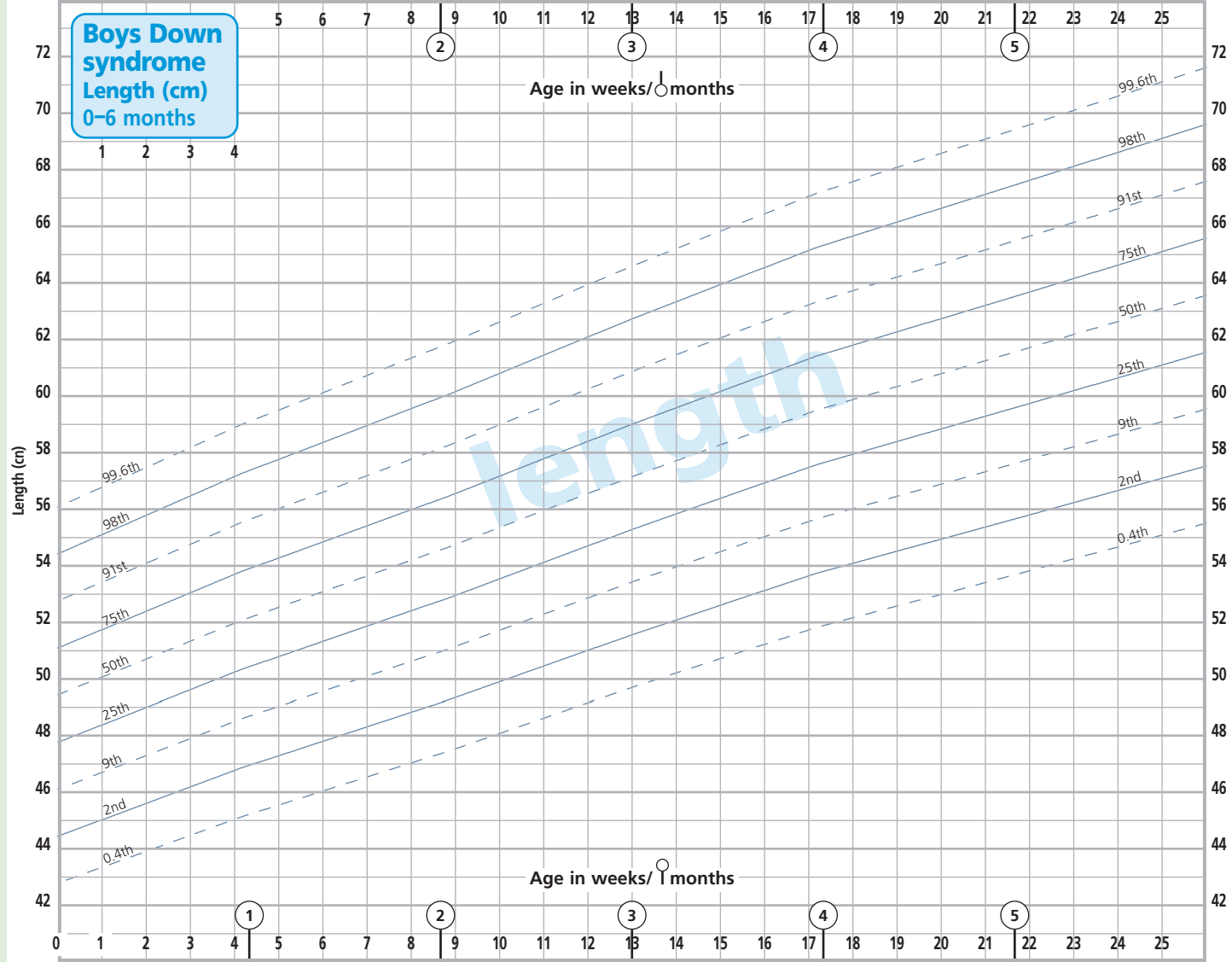
Boys Down syndrome Weight (kg) 0-6 months

Age in weeks/ months

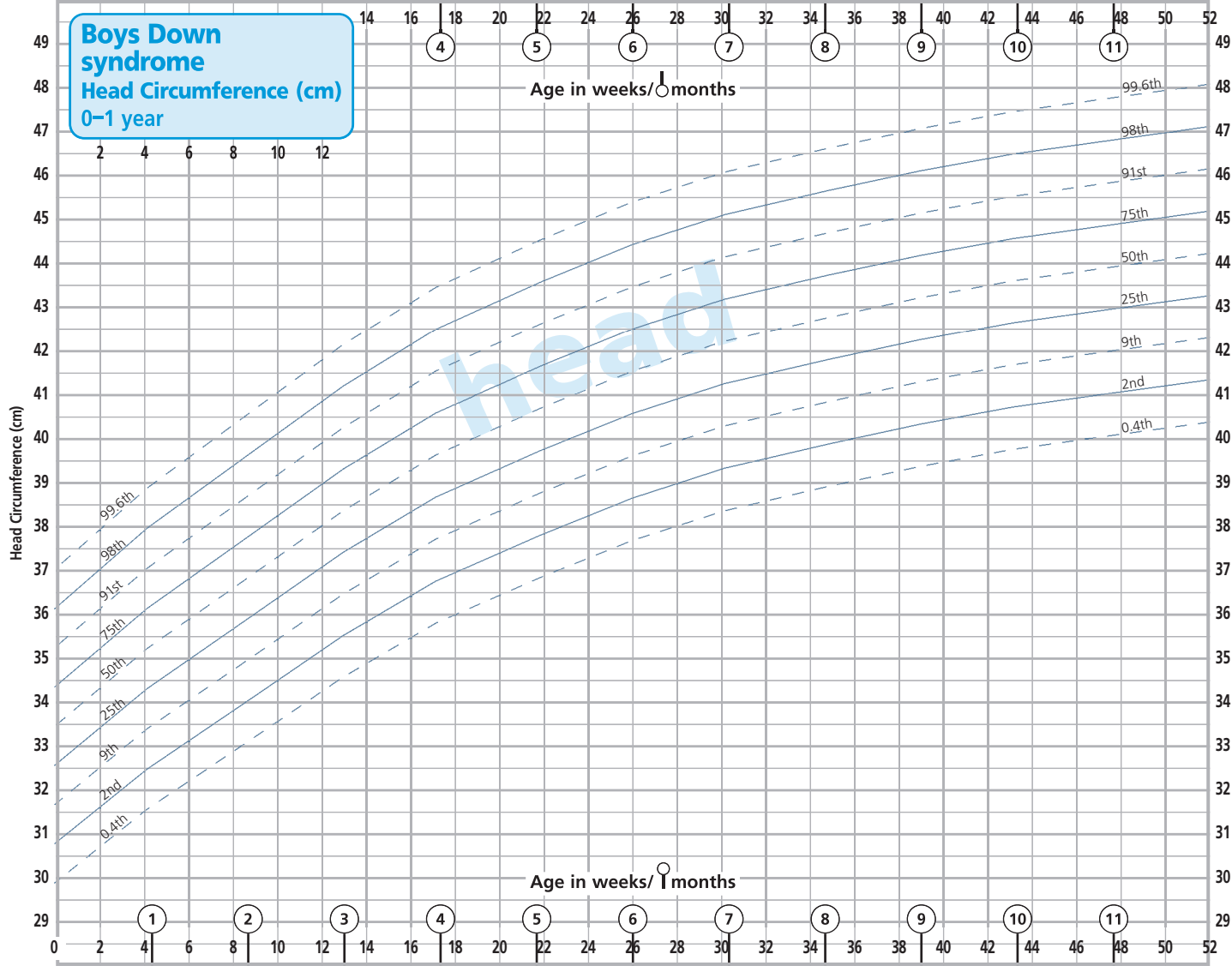
Age in weeks/ months

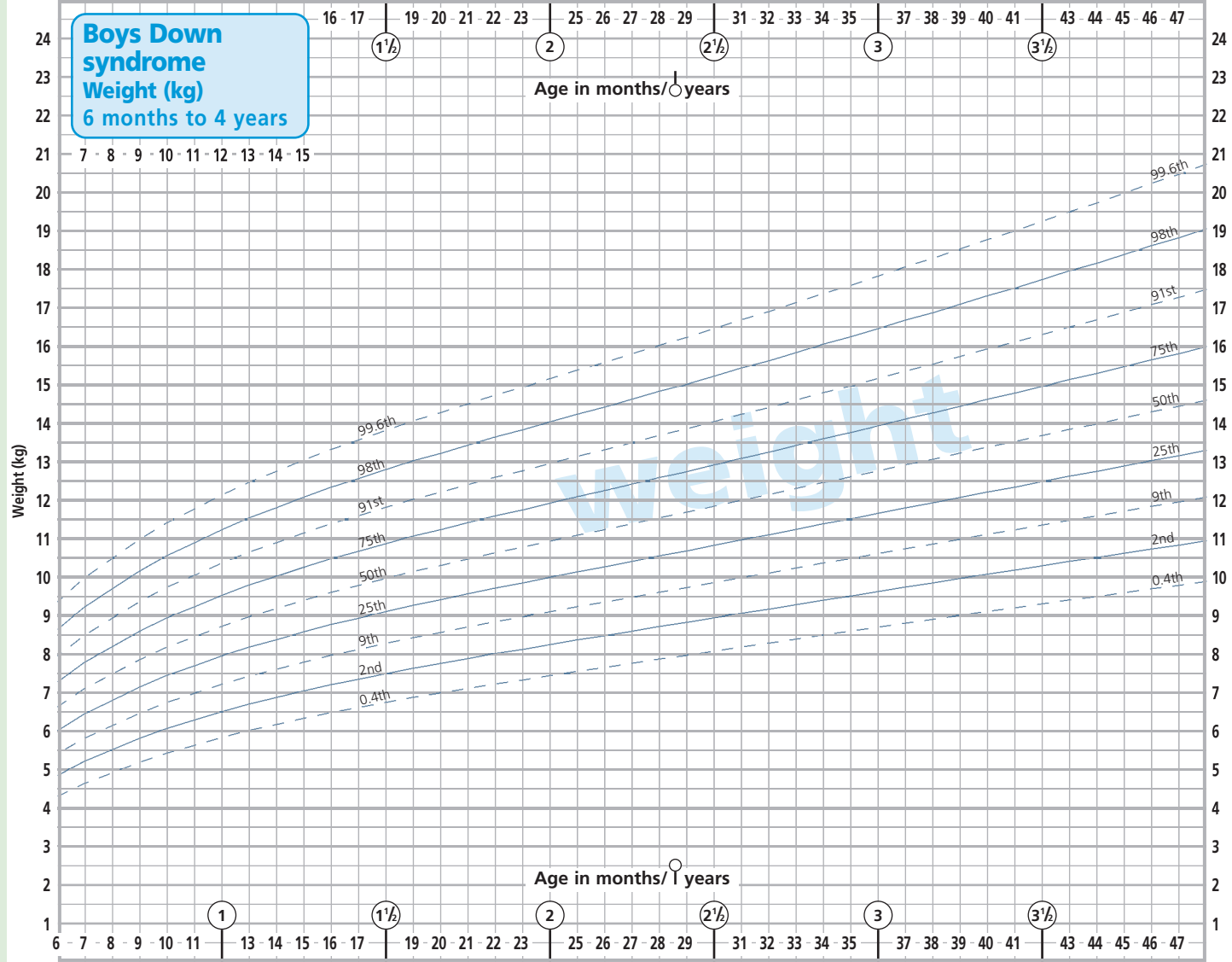
Some degree of weight loss is common after birth, see instructions.



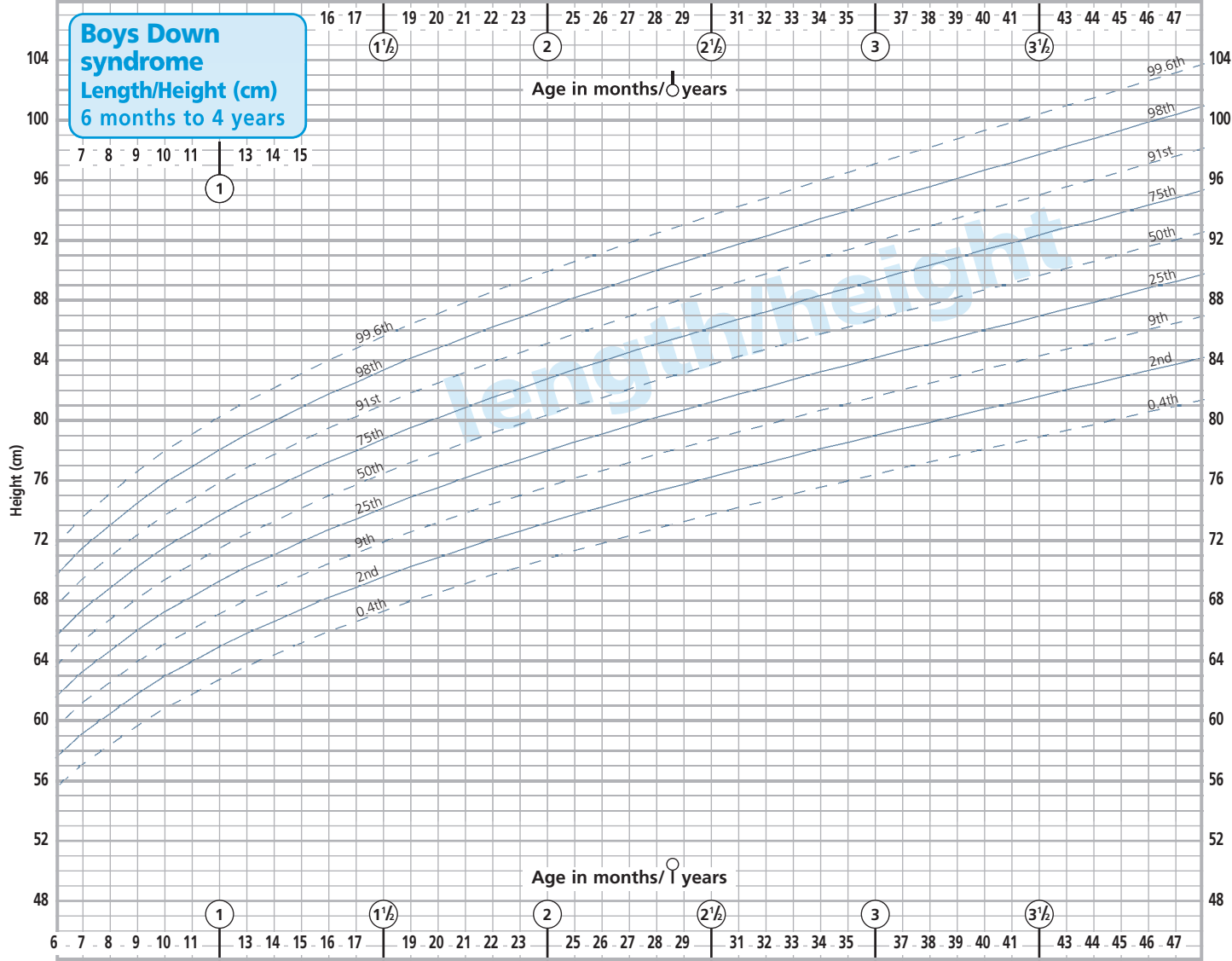


**Boys Down syndrome
Head Circumference (cm)
0-1 year**

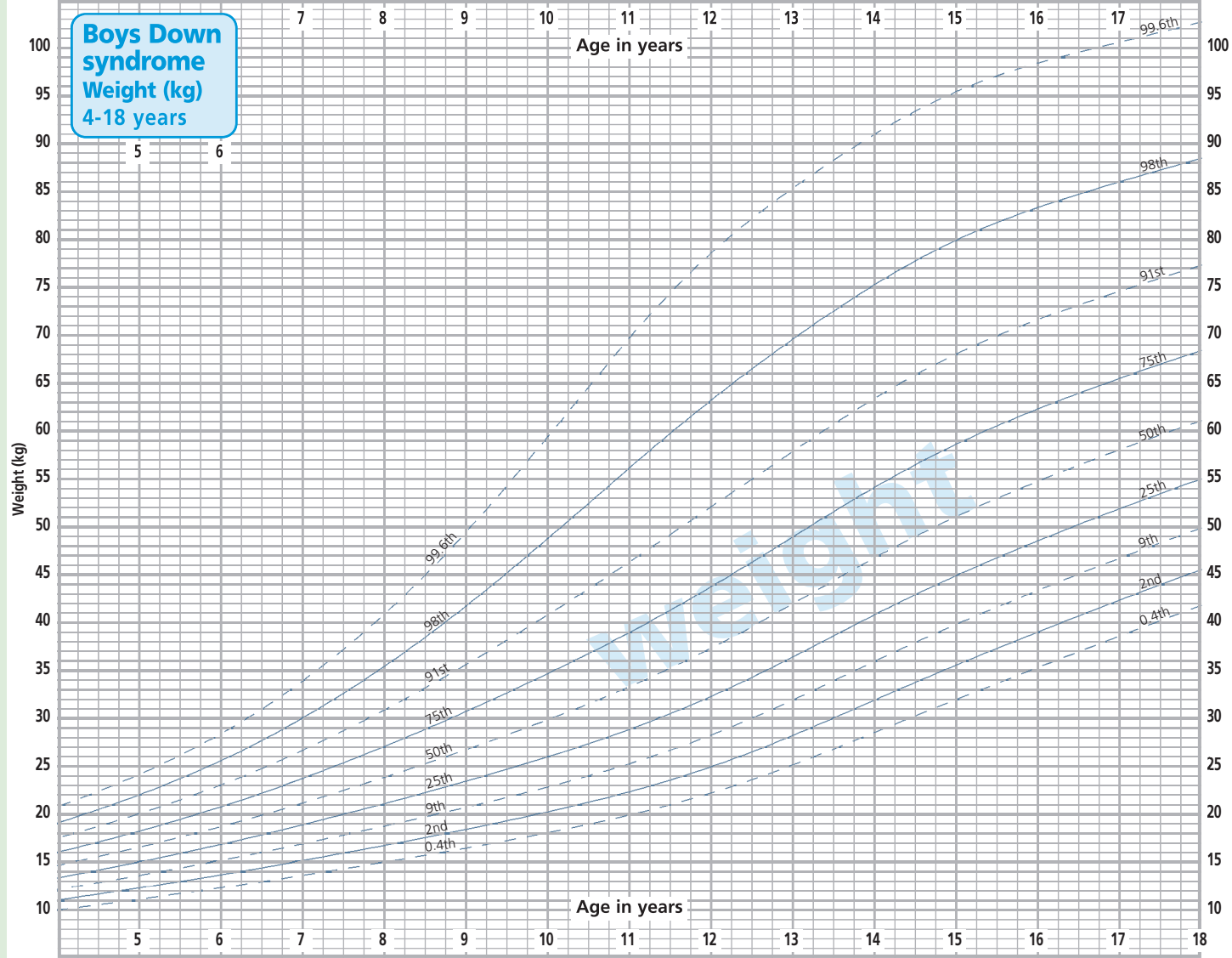




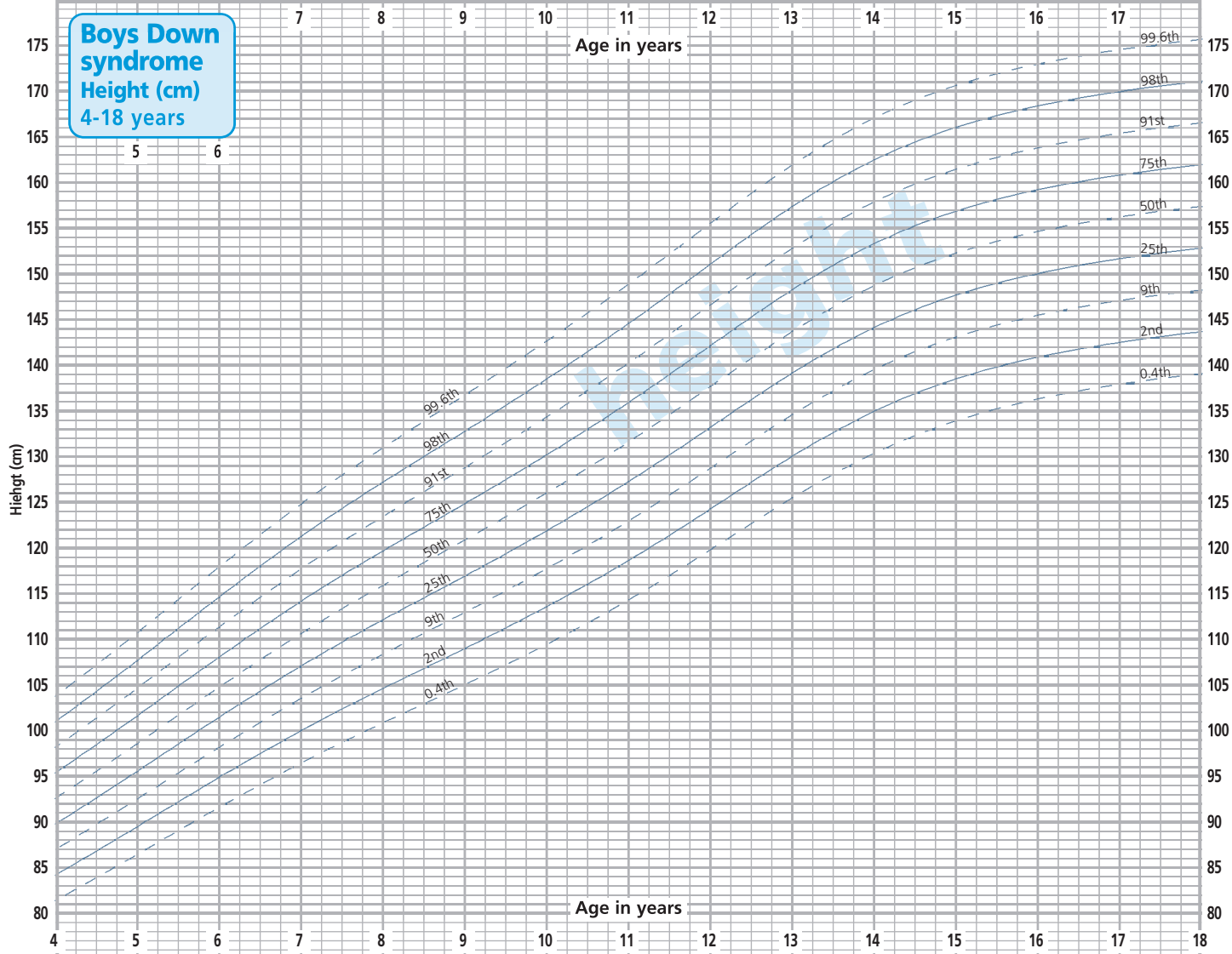
Boys Down syndrome
Length/Height (cm)
6 months to 4 years



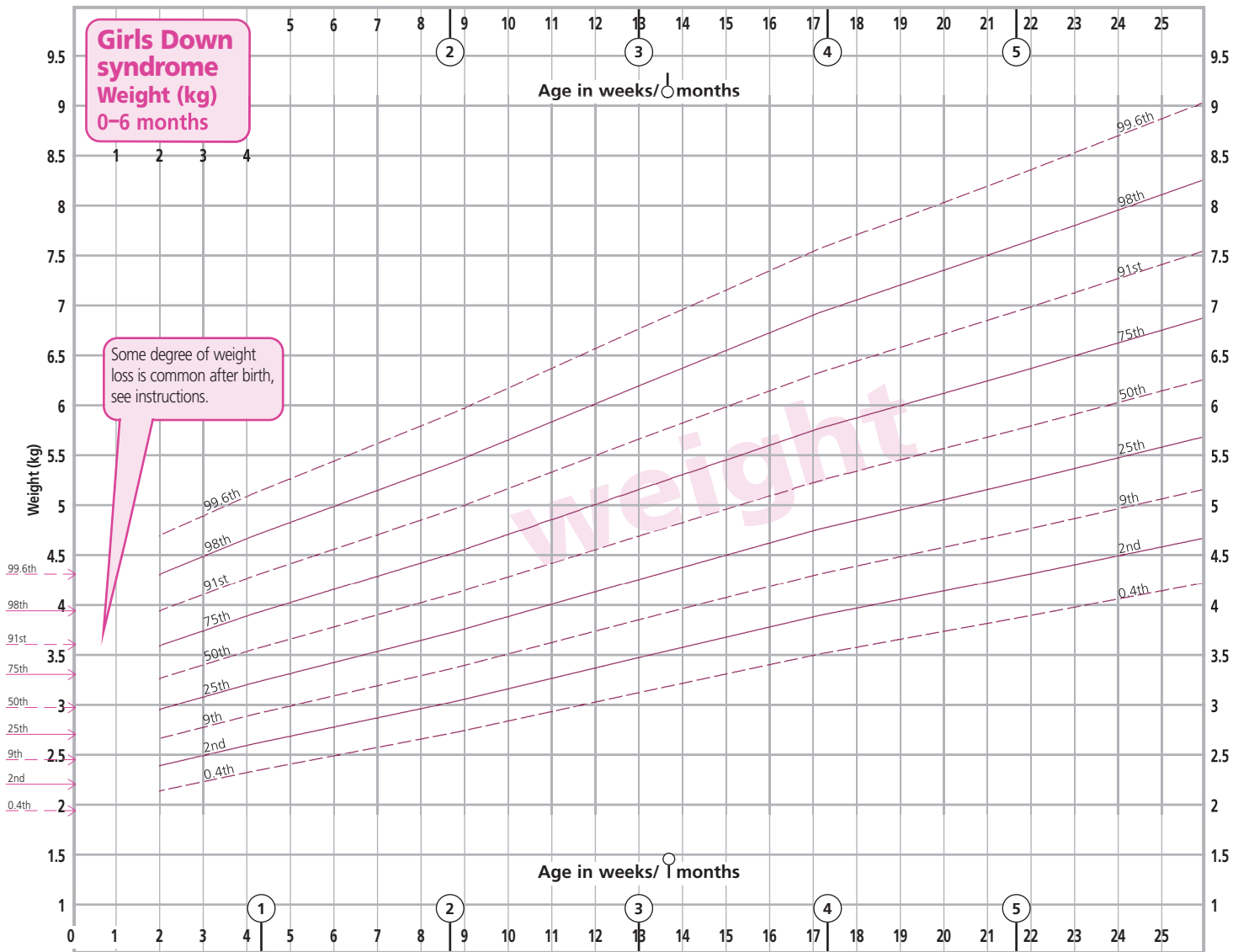
DOWN SYNDROME GROWTH CHARTS



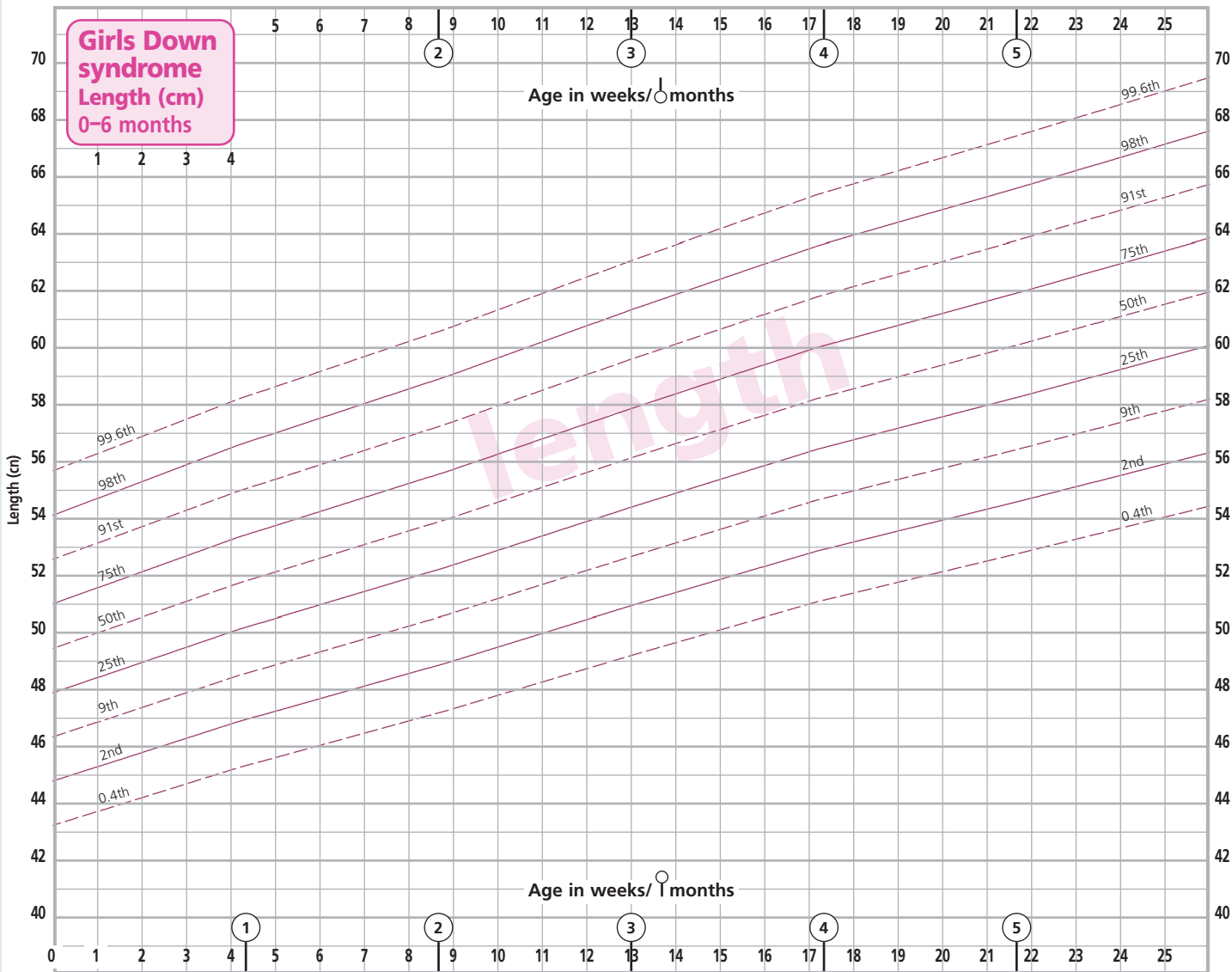
Boys Down syndrome
Height (cm)
4-18 years



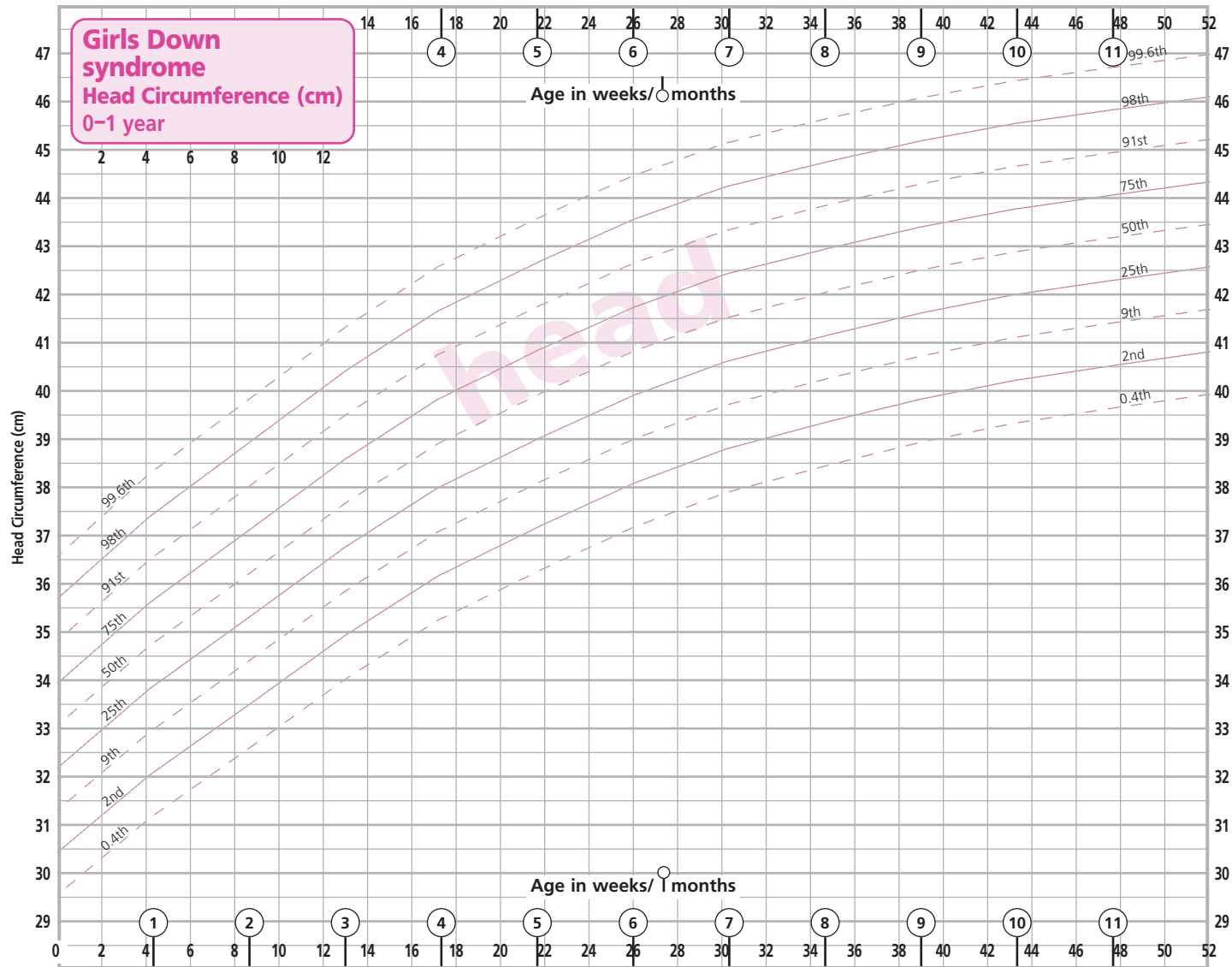
**Girls Down syndrome
Weight (kg)
0-6 months**



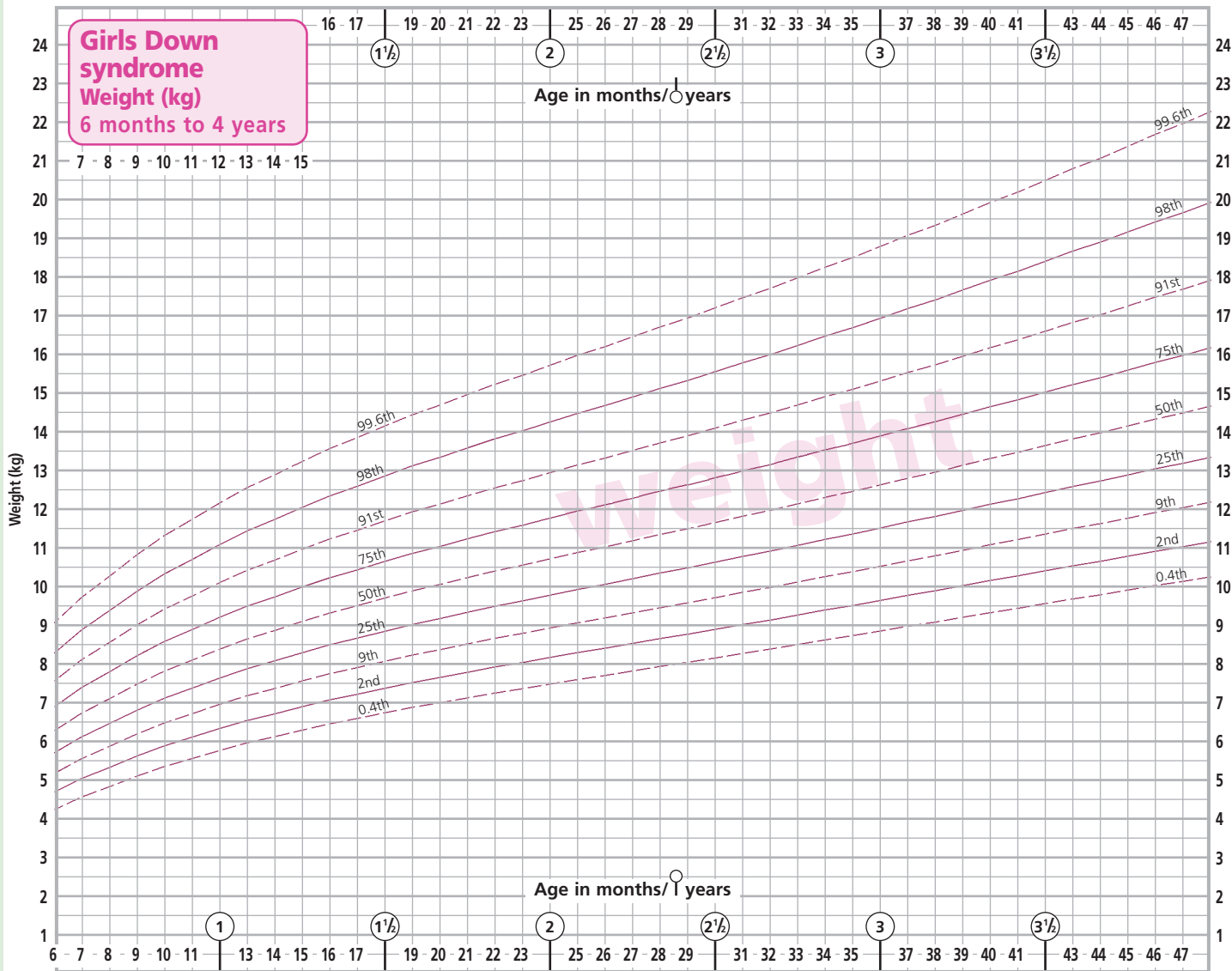
DOWN SYNDROME GROWTH CHARTS



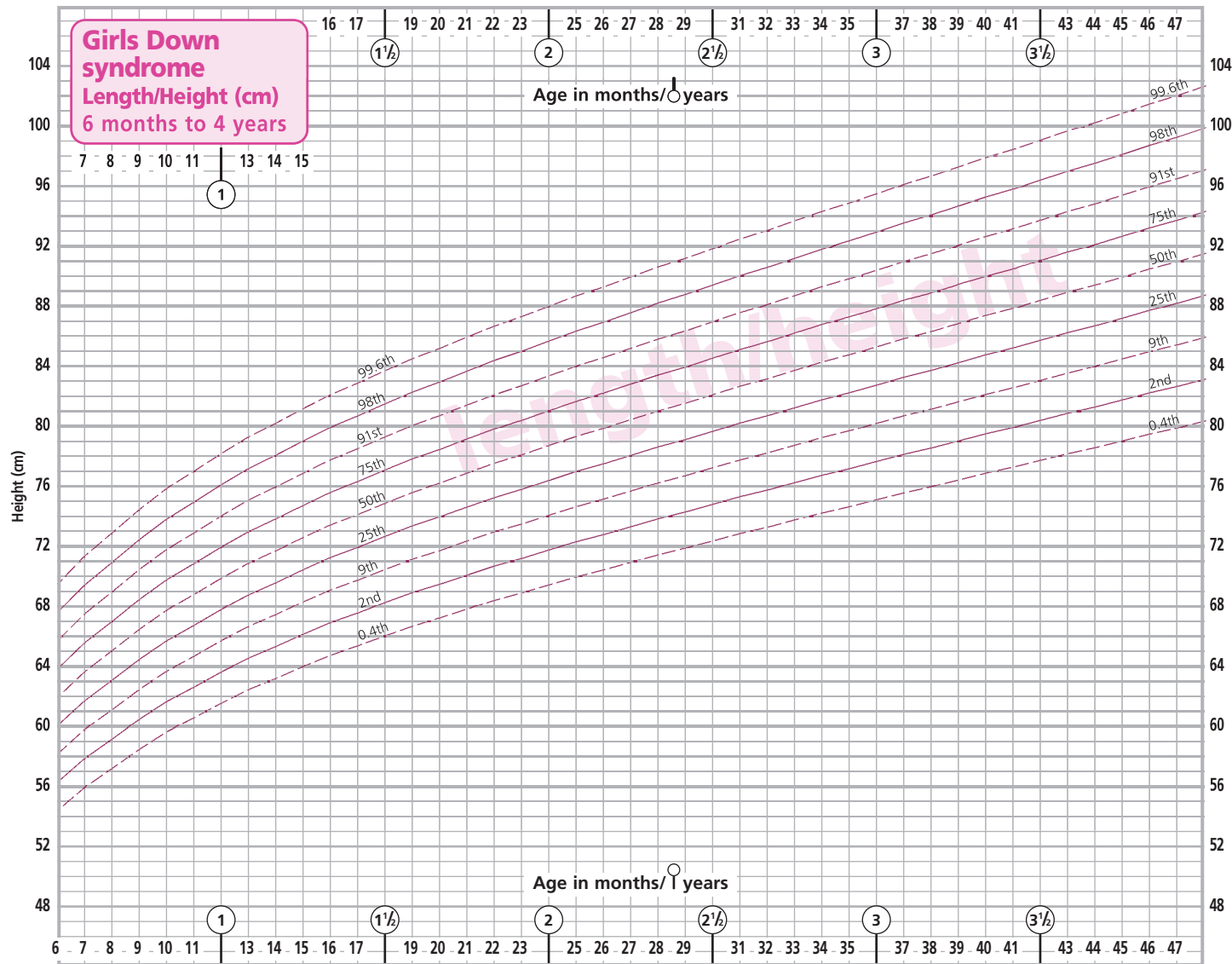
**Girls Down syndrome
Head Circumference (cm)
0-1 year**



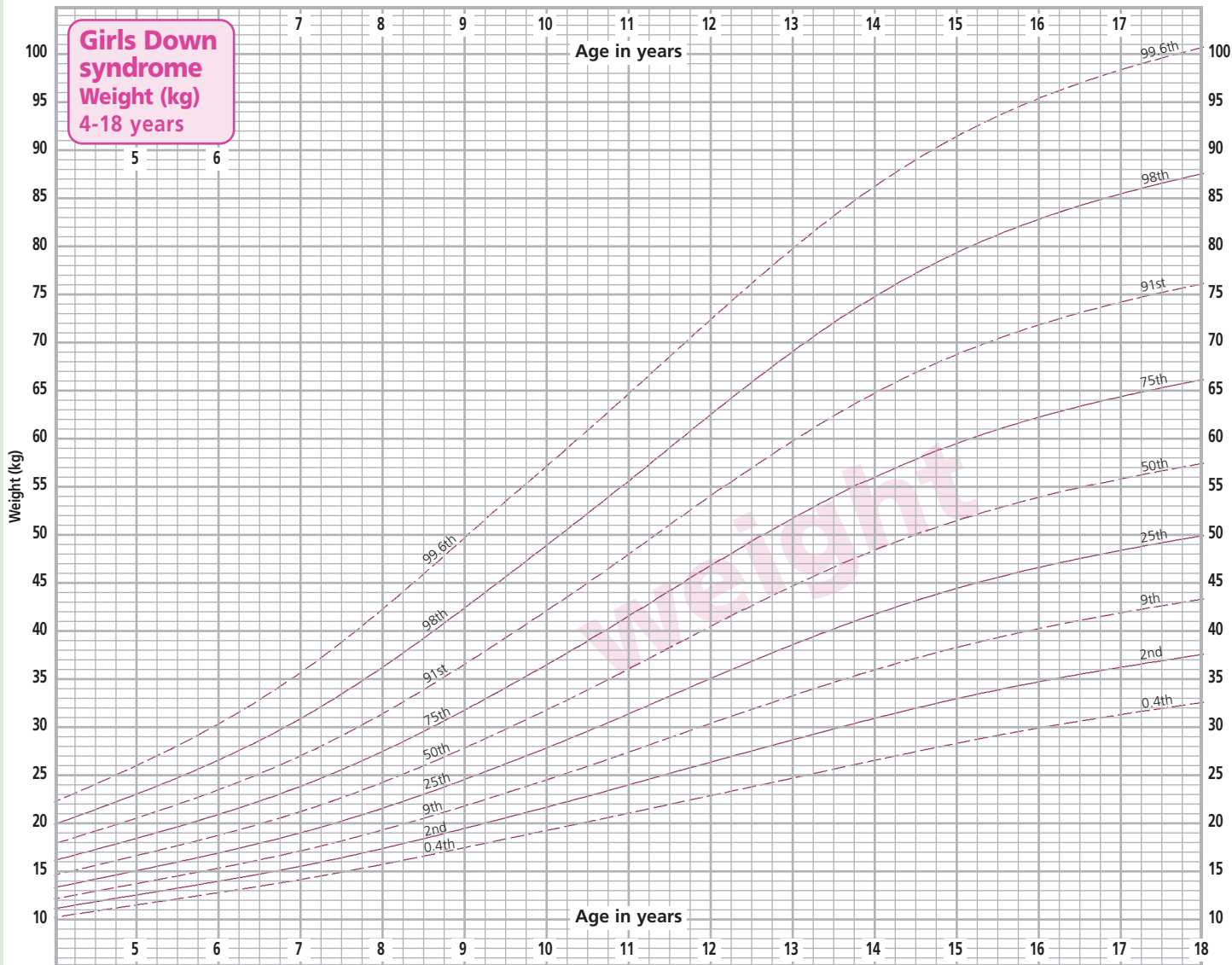
DOWN SYNDROME GROWTH CHARTS

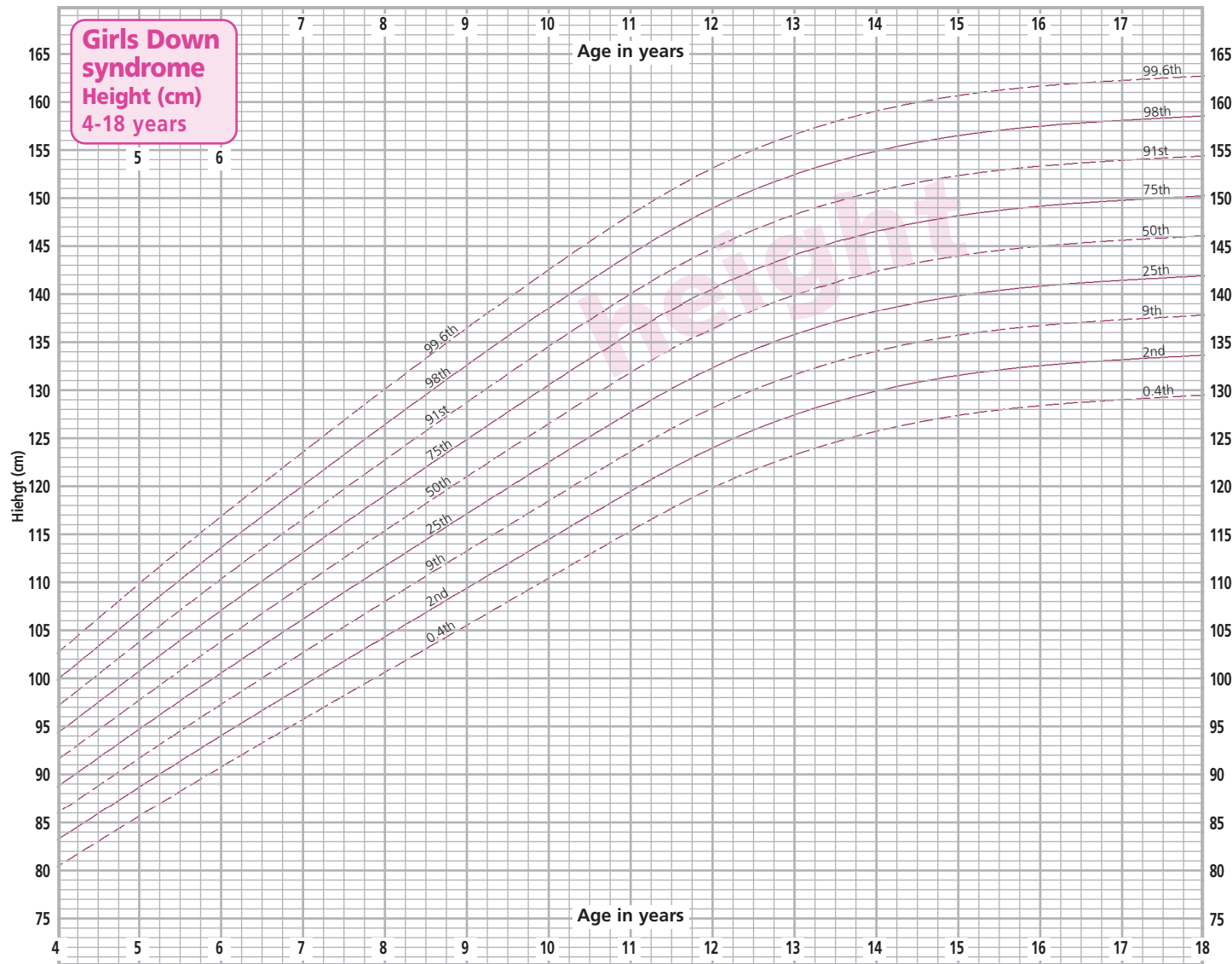


Girls Down syndrome
Length/Height (cm)
6 months to 4 years



DOWN SYNDROME GROWTH CHARTS





MEASUREMENT RECORD

Date	Age	Ht/Lth	Wt	H/C	Signature

Date	Age	Ht/Lth	Wt	H/C	Signature