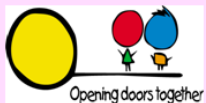


# Health Record for Girls with Down Syndrome

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This booklet is intended as a guide for the parents of a new baby or young child with Down Syndrome.

It has been modelled on similar information produced by the Down Syndrome Medical Interest Group in the U.K and has been modified to Australian standards. This booklet is given to parents as part of the New Baby Kit produced by the Down Syndrome Society of South Australia Inc.

Babies with Down syndrome have the same health problems that can affect any baby. As with all babies some seem to have more illness than others. There are some health issues however that are more likely to affect your baby with Down Syndrome. This guide gives you information about the medical characteristics common to the child with Down syndrome, growth charts, and a resource page for finding further information.



## Heart Problems

Around 50% of babies with Down Syndrome are born with some sort of heart problem and about a quarter of those have a serious problem that will require heart surgery in Melbourne at The Royal Children's Hospital. Your baby will have an ultra-sound scan to determine this early on, or you may have been told of this after your pre-natal scans.

Cardiovascular checks at birth, 1-4 weeks and at 6 months can only be carried out by your paediatrician or G.P. As your baby is more likely to have some sort of problem with their heart it is recommended that these first three health checks be carried out by a doctor.

Every baby will have different appointments with their paediatrician or G.P. depending on their individual needs. However, in between, it is recommended that you take your baby for routine health checks with your local CYH nurse. They are trained to identify any problems that may affect your baby's development.

It is appropriate for your baby to have the recommended immunisations and in some circumstances additional immunisations. It would be best to discuss this with your paediatrician or G.P.

## Vision and Hearing Problems

Babies with Down Syndrome are more likely to develop hearing problems and/or long or short sightedness. In Australia we have a Newborn Screening Protocol for hearing and vision assessment. How your baby fares with these tests will determine what and when future checks occur, but the recommended regular checks are listed in the following pages.



## Feeding

Feeding can be a challenge for the mother of a new baby with Down Syndrome, especially in the first few weeks. If your choice is to breast feed then there is a guide for mothers of babies with Down Syndrome in your new baby kit. Your midwife, a lactation consultant, a speech therapist, or your early intervention consultant can also assist you.



## Bottle Feeding

Bottle fed babies can experience the same difficulties and a guide to bottle feeding your new baby is contained in the New Baby Kit (available from the Down Syndrome Society of South Australia).

More information is available in the recommended reading section contained in the kit.



# Immunisation Schedule

Birth	<input type="checkbox"/> Hepatitis B	12 Months	<input type="checkbox"/> Hepatitis B (or at 6 months)
2 Months	<input type="checkbox"/> Diptheria-Tetanus-Whooping Cough <input type="checkbox"/> Hepatitis B <input type="checkbox"/> Haemophilus Influenzae Type B <input type="checkbox"/> Polio <input type="checkbox"/> Pneumococcal disease		<input type="checkbox"/> Haemophilus Influenzae type b <input type="checkbox"/> Measles-Mumps-Rubella <input type="checkbox"/> Meningococcal C disease
4 Months	<input type="checkbox"/> Diptheria-Tetanus-Whooping Cough <input type="checkbox"/> Hepatitis B <input type="checkbox"/> Haemophilus Influenzae Type B <input type="checkbox"/> Polio <input type="checkbox"/> Pneumococcal disease	18 Months	<input type="checkbox"/> Chickenpox
6 Months	<input type="checkbox"/> Diptheria-Tetanus-Whooping Cough <input type="checkbox"/> Hepatitis B (or at 12 months) <input type="checkbox"/> Haemophilus Influenzae Type B (may be given depending on vaccine type) <input type="checkbox"/> Polio <input type="checkbox"/> Pneumococcal disease	4 Years	<input type="checkbox"/> Diptheria-Tetanus-Whooping Cough <input type="checkbox"/> Measles-Mumps-Rubella <input type="checkbox"/> Polio

# Recommended Health Checks



## **Newborns**

- Reflexes
- Cardiovascular, checking for murmur (this can only be carried out by G.P or pediatrician)
- Fontanelles
- Oral, looking for any indicators that could need further investigation
- Umbilicus, healing
- Femoral Pulses working in time with heart
- Hip test for dislocation
- Genitalia
- Anus formed and appearing normal
- Skin

## **Newborns with Down Syndrome**

- Thyroid Function - Guthrie test
- Hearing Test (Newborn Screening)
- Physical Examination as detailed below
- Heart Examination (Echocardiogram)

# Recommended Health Checks

1 - 4 Weeks

## **Babies**

- Reflexes
- Cardiovascular, checking for murmur (this can only be carried out by G.P or pediatrician)
- Fontanelles
- Oral, looking for any indicators that could need further investigation
- Umbilicus, healing
- Femoral Pulses working in time with heart
- Hip test for dislocation
- Genitalia
- Anus formed and appearing normal
- Skin

## **Babies with Down Syndrome**

- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-12 months included in this booklet.
- Eye Check—check the eyes are working together and check for congenital cataract (by 3 Months old)

# Recommended Health Checks

6 - 8 Weeks

## **Babies**

- Reflexes
- Cardiovascular, checking for murmur (this can only be carried out by G.P or pediatrician)
- Fontanelles
- Oral, looking for any indicators that could need further investigation
- Umbilicus, healing
- Femoral Pulses working in time with heart
- Hip test for dislocation
- Genitalia
- Anus formed and appearing normal
- Skin

## **Babies with Down Syndrome**

- Physical Examination
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-12 months included in this booklet.
- Eye Check—check the eyes are working together and check for congenital cataract (by 3 Months old)

# Recommended Health Checks

6 - 8 Months

## **Babies**

- Reflexes
- Cardiovascular, checking for murmur (this can only be carried out by G.P or pediatrician)
- Fontanelles
- Oral, looking for any indicators that could need further investigation
- Umbilicus, healing
- Femoral Pulses working in time with heart
- Hip test for dislocation
- Genitalia
- Anus formed and appearing normal
- Skin

## **Babies with Down Syndrome**

- Hearing—full audiological review (hearing, impedance, otoscopy, continue every 6 months)
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-12 months included in this booklet.
- Eye Check
- Thyroid Function and Coeliac Disease Screen

# Recommended Health Checks



12 Months

## **Babies with Down Syndrome**

- Hearing—full audiological review (hearing, impedance, otoscopy, continue every 6 months)
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-3 years included in this booklet.
- Eye Check
- Thyroid Function and Coeliac Disease Screen

# Recommended Health Checks

18 Months

## Children

- Oral
- Eyes: fixation, following



## Children with Down Syndrome

- Hearing—full audiological review (hearing, impedance, otoscopy, continue every 6 months)
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-3 years' included in this booklet.

# Recommended Health Checks



## Children

- Development (you may discuss this with your Early Intervention Consultant, or your Disability S.A. therapist)
- Oral
- Eyes: fixation, following

## Children with Down Syndrome

- Hearing—full audiological review (hearing, impedance, otoscopy, continue every 6 months)
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-3 years' included in this booklet.
- Dental check (appointment can be made at school dental service, specialist children's dentist, or your family dentist). Refer to our pamphlet 'Caring for your Child's Teeth'.

# Recommended Health Checks



## Children

- Development (you may discuss this with your Early Intervention Consultant, or your Disability S.A. therapist.)
- Oral
- Eyes—fixation, following



## Children with Down Syndrome

- Hearing—full audiological review
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 0-3 years' included in this booklet.
- Dental check

# Recommended Health Checks

4 Years

## Children

- Development (you may discuss this with your Early Intervention Consultant, or your Disability S.A. therapist.)
- Oral
- Audiometry (L/R)



## Children with Down Syndrome

- Physical Examination (continue annually)
- Hearing—full audiological review
- Growth Monitoring—weight, length, head circumference. Refer to growth chart 'Babies with Down Syndrome 2-18 years' included in this booklet.
- Dental check (continue every 6 months)
- Eye Check—visual acuity, refraction and ophthalmic examination (continue annually)
- Thyroid Function and Coeliac Disease (continue annually)
- Paediatric review (continue annually)
- Atlanto-axial Joint X-ray—symptoms of subluxation of the vertebrae may include neck tilt, neck pain, change in gait and loss of urinary or bowel continence.

# Down Syndrome Society Offices in Australia

Down Syndrome Society  
of South Australia Inc.

Hampstead Primary School  
Muller Road  
Greenacres SA 5086  
PO Box 436  
E-mail: [info@downssa.asn.au](mailto:info@downssa.asn.au)  
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Fax: 9368 4006  
[www.dsawa.asn.au](http://www.dsawa.asn.au)

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Fax: (02) 9841 4400  
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Queensland Inc.

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Phone: (07) 3356 6655  
Fax: (07) 3856 2687  
[www.dsaq.org.au](http://www.dsaq.org.au)

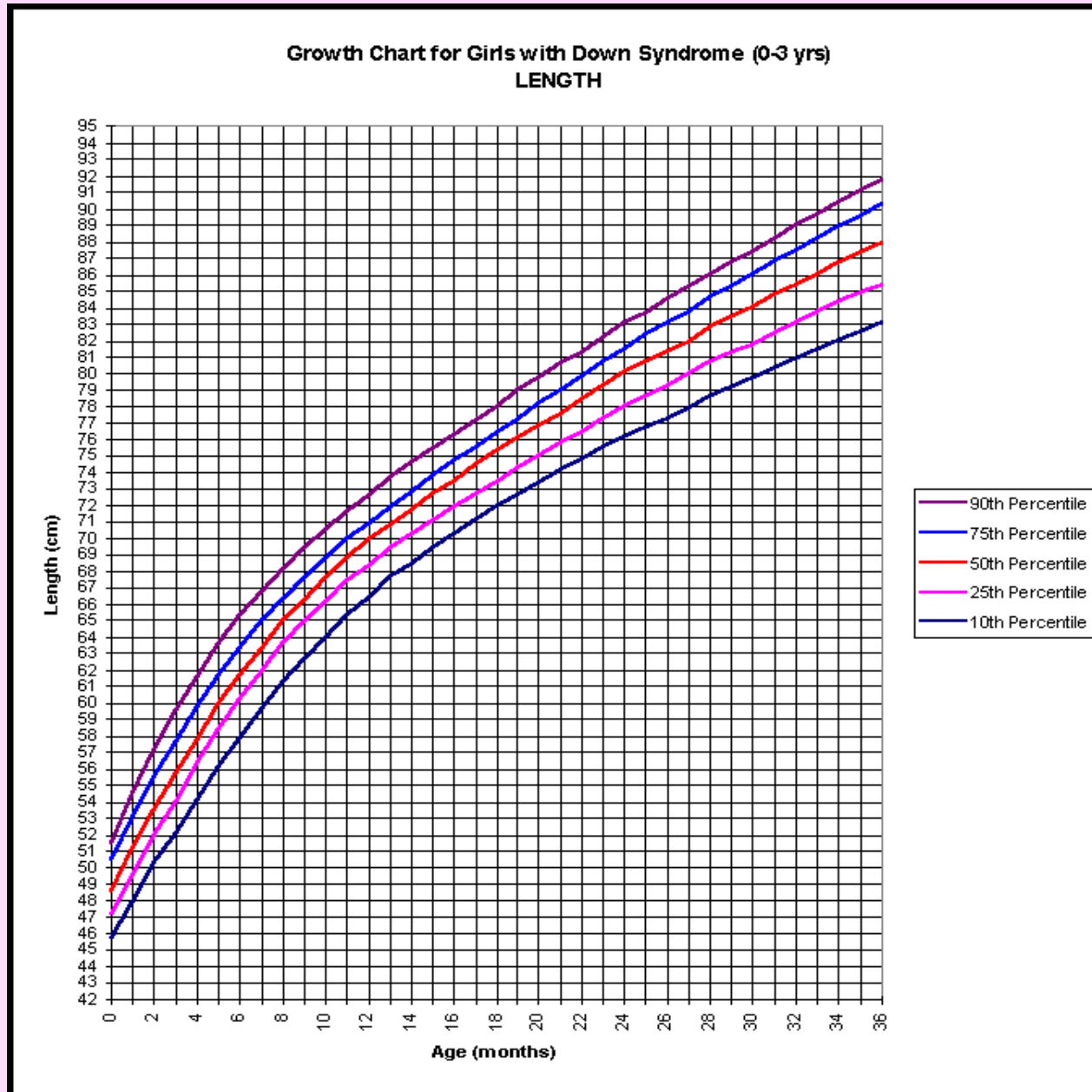
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[www.dsav.asn.au](http://www.dsav.asn.au)

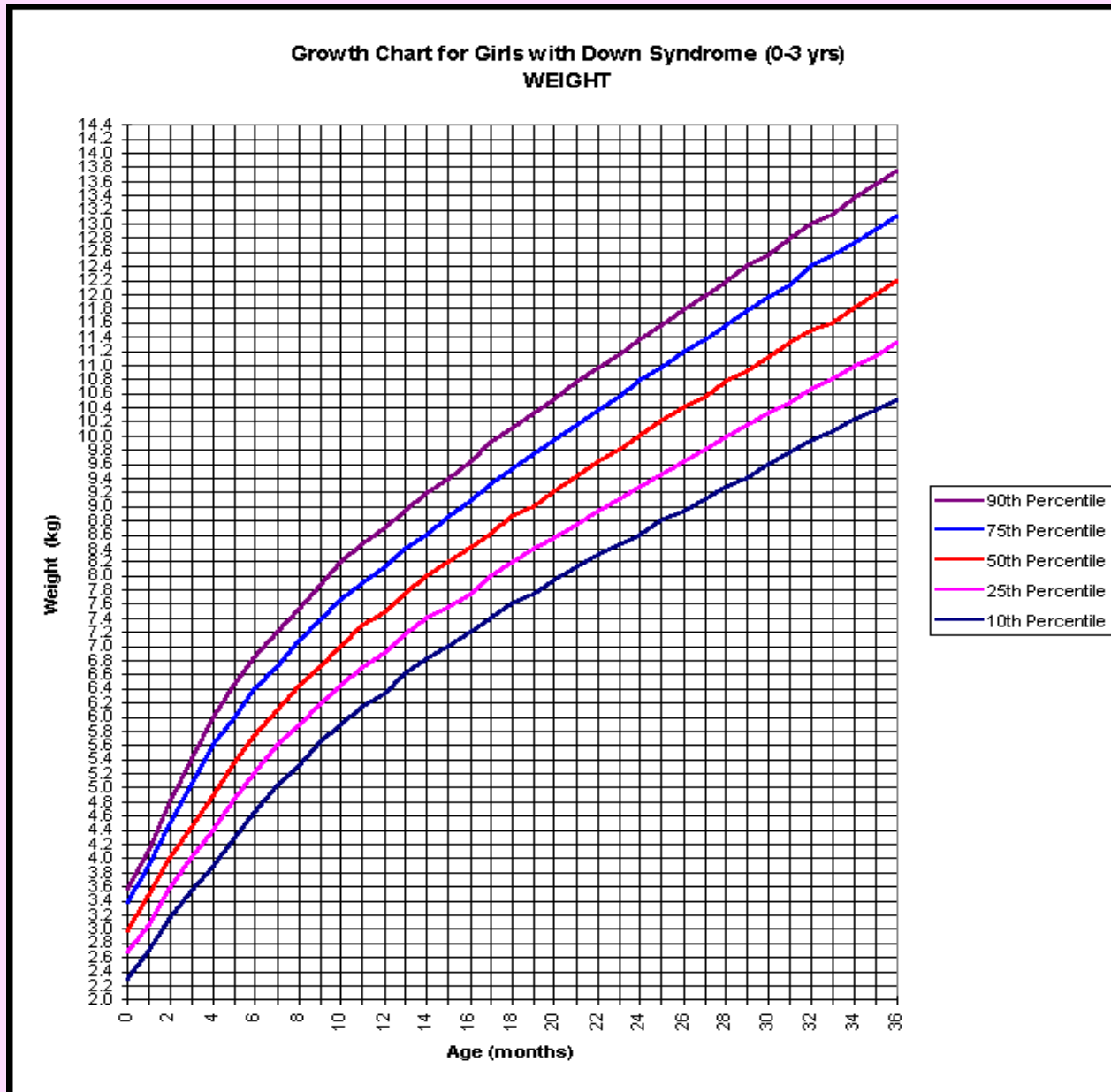
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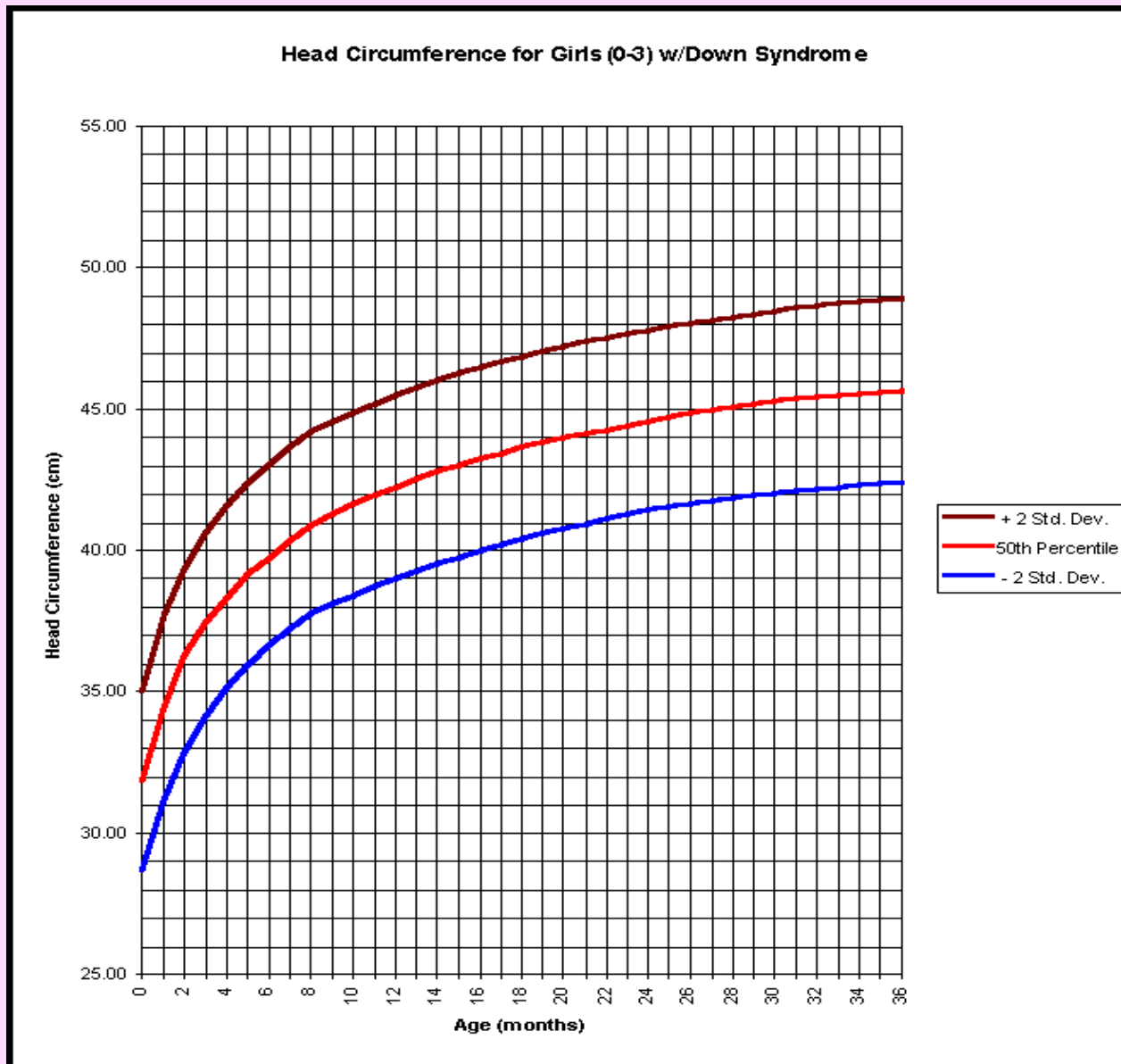
# Growth Chart for Baby Girls with Down syndrome, Length (0-3 years)



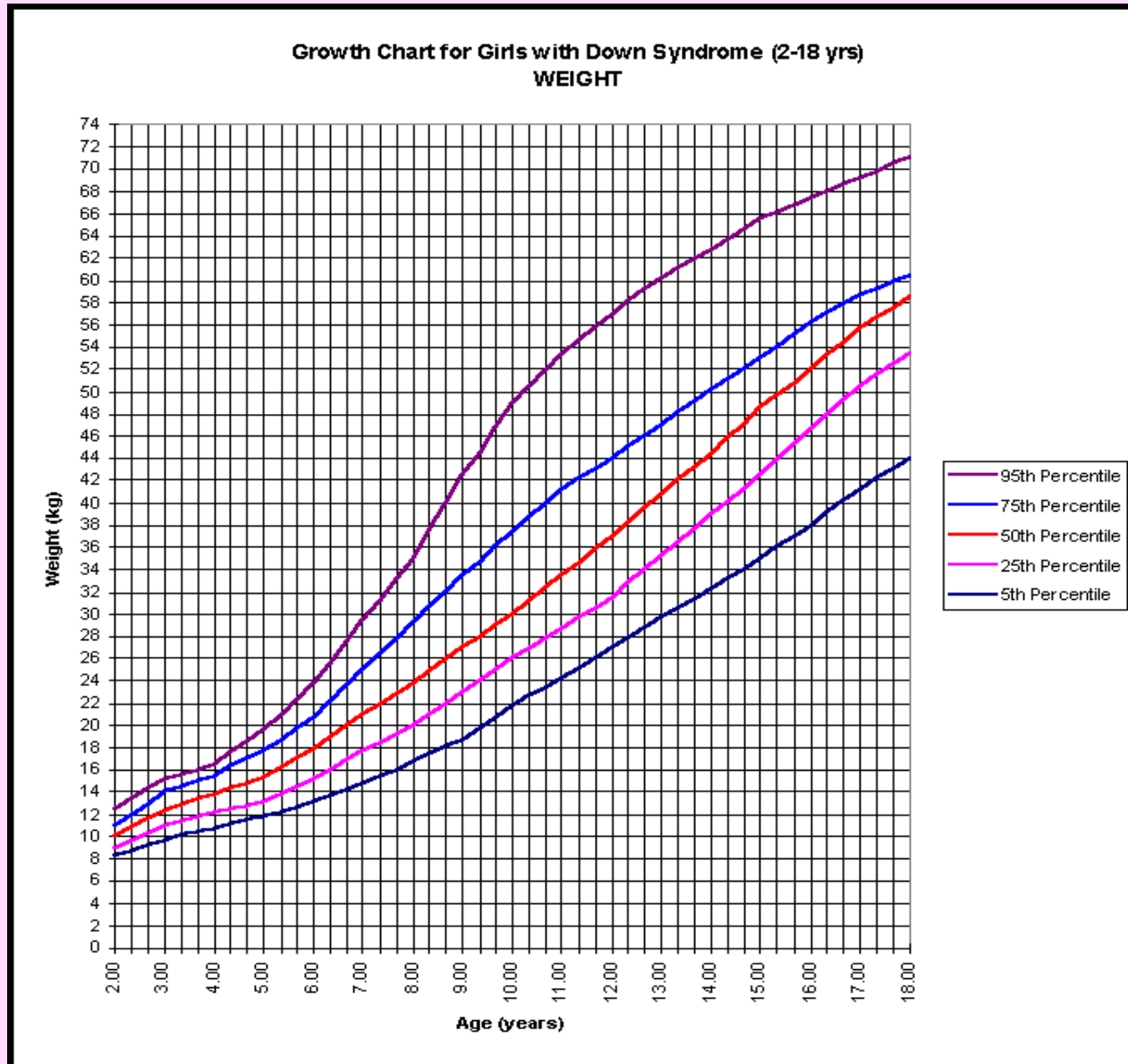
# Growth Chart for Baby Girls with Down syndrome, Weight (0-3 years)



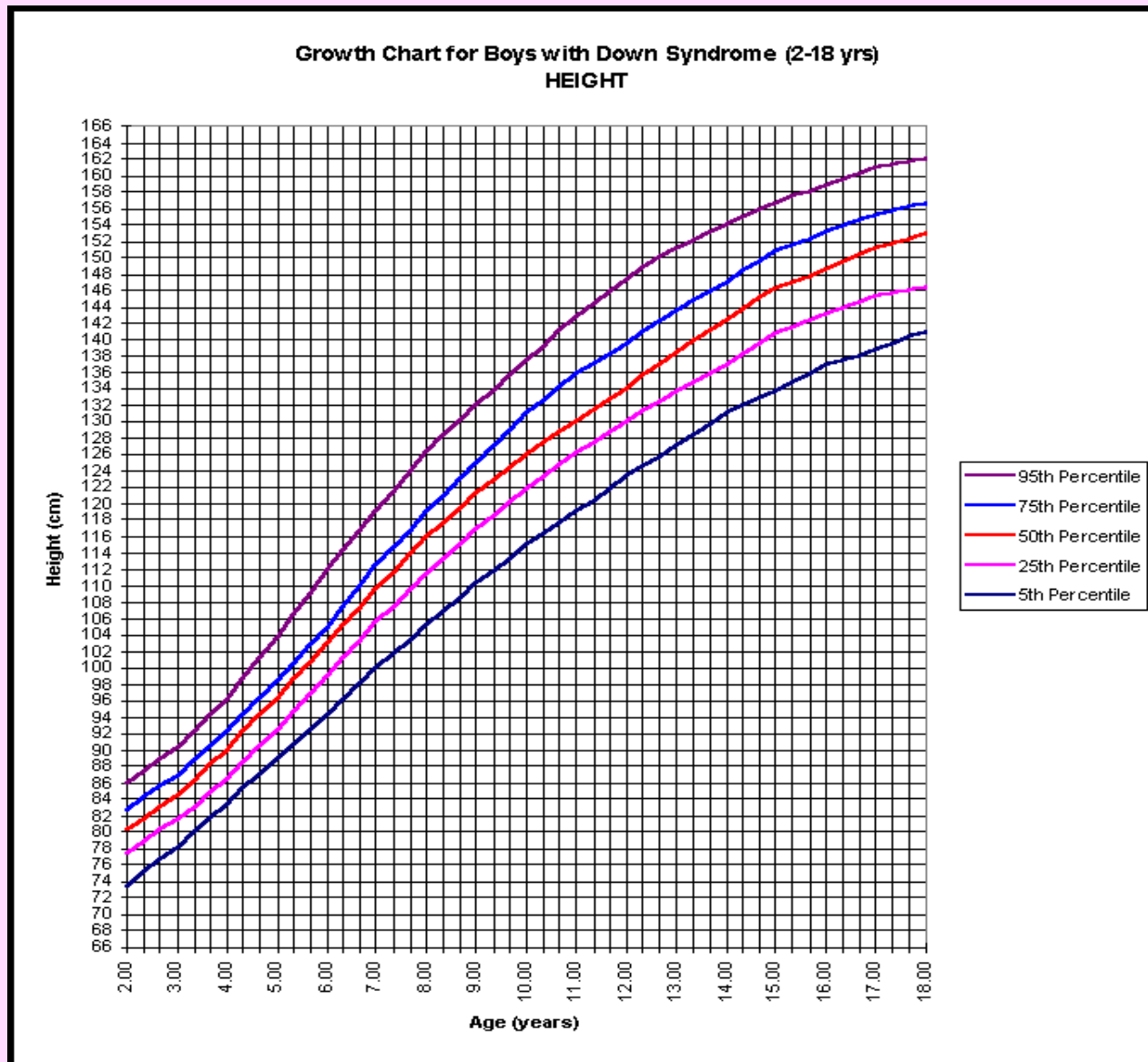
# Growth Chart for Baby Girls with Down syndrome, Head circumference (0-12 months)



# Growth Chart for Baby Girls with Down syndrome, Weight (2-18 years)



# Growth Chart for Baby Girls with Down syndrome, Height (2-18 years)



# Growth Record

<b>Date</b>	<b>Age</b>	<b>Height/Length</b>	<b>Weight</b>	<b>Head Circumference</b>	<b>Signature</b>

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# Further Information

## **Celiac Disease**

Celiac disease is an autoimmune disorder that affects the small intestine. When someone with celiac disease eats gluten (which is found in wheat, barley and rye) the immune system attacks the small intestine and destroys the villi, which are the tiny finger like projections that absorb the nutrients in food. Children with Down Syndrome have a slightly increased risk of developing Celiac Disease.

Early signs of Celiac disease are stomach bloating, frequent bowel motions often reported as foul smelling, weight loss, lack of growth and fatigue. It can be hard to spot the symptoms as it is easy to attribute low weight and slow growth to Down Syndrome.

A blood test can determine whether further more invasive testing is indicated. Speak to your G.P. or Paediatrician if you are concerned that your child may have Celiac Disease. The Celiac Association in your capital city can help with information and guidance in managing a child with Celiac disease.

## **Autism**

Autism is an inexplicable developmental disability that affects a child's social communication and language development. Listed below are some indicators of what can be expected of typically developing children. Keep in mind that you need to modify the age range to compensate for your child's individual developmental progress.

By 18– 24 months;

- Engages in pretend play such as feeding a doll or making a toy dog bark
- Using many spontaneous single words and some two word phrases.
- Shows interest in siblings and peers
- Brings you items to look at
- Follows your gaze to locate an object when you point.

If you are concerned speak to your GP or Paediatrician for an autism assessment. Further information can be obtained by contacting the Autism Association in your capital city.

# Further Information

## Leukaemia

Leukaemia is a cancer of the white blood cells in the blood. Children with Down Syndrome have a slightly increased risk of developing Leukaemia. Over the past 20 years there have been great advances in treatments , so that in children it is curable in most cases. However the treatment is long and difficult for the family.

Symptoms of leukaemia include;

- Repeated infections
- mouth sores, sore throats, fevers, sweats, coughing, urinary infections, infected cuts and scratches and boils
- Anaemia: Where too few blood cells can cause paleness, weakness, tiredness and breathlessness during effort. If the leukaemia is progressing slowly or if it is in the early stages none of the usual symptoms may be noticed and it may be picked up by a blood test done for another reason.
- Increased bruising and bleeding: The lack of platelets can cause bruising without a bump or a knock, frequent nose bleeds , or bleeding gums.

The Cancer Council Australia, and the Leukaemia Foundation can provide more information and support

For further information about Down Syndrome contact:

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of South Australia Inc.  
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Greenacres

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