

Weight Control

Girls with TS tend to be overweight. This puts them at a higher risk of developing high blood sugar levels (type 2 diabetes). Healthy eating and physical activity starting at an early age may prevent your child develop type 2 diabetes. Your doctor should do a blood test to check blood sugar if your child is overweight or has a family history of type 2 diabetes.

If your child is overweight, she is at greater risk of having high cholesterol. High cholesterol should be treated with healthy diet and physical activity. A dietitian may be able to help you with food choices. Medication is sometimes needed.

- Check blood sugar if there are risk factors. Check cholesterol once during your child's teen years.

Skin Concerns

Many girls with TS are born with puffy hands and feet. It usually improves during the first year, but it may take longer to go away. It may be treated with support stockings and/or medicine.

Moles are more common in girls with TS. They usually do not cause problems, but if they change or grow quickly, tell your doctor.

Girls with TS tend to form thick scars (keloids) after injury or surgery. Remember this if surgery (or even something simple like ear piercing) is planned.

- Have your child checked for lymphedema once a year.

Bone Health

Infants with TS have a higher risk of having dislocated hips at birth. This may be linked to arthritis in the hip later in life. Teen girls with TS have a higher risk of developing a curve in their spine (scoliosis). Your child should see a bone specialist for any bone problems.

Adult women with TS tend to have weaker bones (osteoporosis), so are at greater risk for breaking their bones. Young girls with TS can help make their bones stronger by:

- getting enough calcium and vitamin D in their diet every day
 - doing regular weight-bearing exercise (e.g., walking)
- Have hips checked in infancy. Check for scoliosis once a year. Review calcium and vitamin D intake once a year.

Websites

The Turner Syndrome Society offers support and information about family conferences:

- www.turnersyndrome.ca (Turner Syndrome Society of Canada)
- www.turnersyndrome.org (Turner Syndrome Society of the United States)

health information

What You Need to Know When a Child has Turner Syndrome

Turner Syndrome (TS) is a genetic condition that affects girls. Girls have two X chromosomes. TS is caused when part of or the whole X chromosome is missing. This may be related to some symptoms or health issues.

Height

Most girls with TS are shorter than other girls their age. They are often smaller as babies and grow slowly during childhood. Without treatment, women with TS can expect to be about 20 cm shorter than other girls their age that are in the same ethnic group.

You can talk to your doctor about using a synthetic (man-made) growth hormone (GH). ~~GH can be offered in Canada to girls with TS.~~ Studies show that some girls with TS may increase their adult height by about 7.2 cm after being treated with GH. ~~It is given by injection with a small needle once a day, usually 6 to 7 times per week, for several years until final adult height is reached. GH is very expensive and is not covered by all health insurance plans.~~

- Measure height and weight at least once a year.

Puberty

Without two X chromosomes, the ovaries usually do not completely develop. There is not enough or none of the hormones usually produced by the ovaries (estrogen and progesterone). About 80 percent of girls with TS will need to take hormone replacement to **start puberty**. ~~the physical changes of puberty to occur.~~

Estrogen is given in low doses to start ~~changes of~~ puberty. After about 2 years, progesterone is also given (often combined with estrogen in the birth control pill) to help make the menstrual periods regular. Treatment is usually started between the ages of 12 and 15.

Heart Health

About 1/3 of girls with TS are born with a heart condition. Because this is so common in TS, all girls with TS should see a heart doctor (cardiologist) **and** have an ultrasound test of the heart or an MRI scan of the heart. ~~the time of diagnosis. The cardiologist will suggest more tests or treatment if necessary.~~ ~~Some children should take antibiotics before dental work and some medical procedures to protect against an infection in the heart. Your cardiologist will advise you.~~

Even if your child's heart appears to be healthy, it is still very important to have a complete check-up that includes checking the blood pressure every year. All girls with TS should see a cardiologist again in their early teens for another complete check-up.

- Do a heart exam and blood pressure check once a year.

Intelligence and Behaviour

Most girls with TS have normal intelligence. However, up to 70 percent may have:

- trouble with geometry or following directions (visual-spatial thinking)
- trouble understanding facial expressions or social cues
- trouble with non-verbal problem solving (e.g., math)
- trouble doing several tasks at once (psychomotor skills)

It is important to have specific testing done before starting school (if possible) so that supports can be put in place to help your child learn successfully (e.g., small classes, tutoring, etc.).

Your doctor can arrange for your child to meet with a social worker or psychologist if she needs help with learning or behaviour issues.

- Do educational testing before your child starts school,

then as needed.

Thyroid/Immune System Disease

Girls with TS are more likely to become hypothyroid. This means that the thyroid gland in the neck (the body's "motor") stops working properly. This can happen at any age, but is most common in young adult women. A blood test should be done every 1 to 2 years to check thyroid levels. Hypothyroidism is easily treated by taking a pill every day for life.

Girls with TS are also at higher risk for developing other autoimmune disorders such as arthritis, celiac disease, and inflammatory bowel disease.

- Do a blood test for thyroid function every 1 to 2 years.

Hearing

Girls with TS may have had many ear infections by the time they are 6 years old. Treat these infections right away to protect your child's hearing. Hearing loss is common in TS. It usually happens slowly over time, but may happen in early childhood.

Your child should see a specialist if she has a lot of infections or if there is a concern about hearing. ~~Ear tubes may be needed.~~

- Check ears and hearing once a year.

Kidney Problems

Up to one out of three girls with TS have an abnormality in or around their kidneys. **Most abnormalities do not cause problems.**

Every girl with TS should have an ultrasound of her kidneys soon after diagnosis. Make sure your child's doctor knows if she keeps getting bladder infections or is dribbling urine.

- Check kidneys at time of diagnosis then as recommended.

Eye Health

Females with TS have more eye problems. More females with TS are red-green colour blind. Have your child seen by an eye specialist for any problems.

- Check eyes once a year.