It is important to have certain testing done early (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.).

Learning issues that are present in childhood continue into adult life. Knowing what the problems are and planning around them can help you be successful. Career planning for women with TS (as with anyone else) should be done based on their strengths.

Ask your doctor if you can meet with a social worker or psychologist if you need help with learning or behaviour issues.

#### **Bone Health**

Females with TS tend to have poor bone health. Teens with TS have a higher risk of developing a curve in their spine (scoliosis). You should see a bone specialist if you have problems with your bones.

Adult women with TS tend to have weaker bones (osteoporosis), so are at greater risk for breaking their bones. Broken bones are more common in women with TS after age 45 than in other women the same age without TS. Women with TS should have a bone mineral density test in their early 20's.

To help make your bones stronger make sure you get enough calcium and vitamin D in your diet or by taking supplements. Make sure to do weight-bearing exercises (e.g., walking) every day.

☐ Check bone health once a year. Review calcium and vitamin D intake once a year.

## Weight Control/Type 2 Diabetes

Girls and women with TS may 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 you from developing type 2 diabetes.

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

☐ Do blood tests for blood sugar and cholesterol every 2 years.

## **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. Tell your doctor if you keep getting bladder infections or are dribbling urine.

 $\square$  Do blood tests to check kidney function every 2 years.

### **Eye Health**

Females with TS have more eye problems. More females with TS are red-green colour blind. Your doctor should check your eyes at every visit. See an eye specialist for any problems.

 $\square$  Check eyes once a year.

### **Skin Concerns**

If you had lymphedema when you were born, it may become a problem again when you start estrogen therapy. It can be treated with exercises, support stockings, and/or medicine.

Moles are more common in females 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.

#### 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 You are an Adolescent or Young Woman with Turner Syndrome Adolescents and young women with Turner Syndrome (TS) have different health needs. They may also have a higher risk of certain health problems over time.

## **Puberty and Reproductive Health**

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 replacements to start puberty or help it continue normally. Of the few girls who begin puberty on their own, the ovaries are likely to stop working early in adulthood (premature ovarian failure).

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. The timing of estrogen treatment may affect your final adult height. Be sure to talk to your doctor about your feelings about your sexual development.

Because of ovarian failure, most women with TS can't get pregnant. Those who can have a higher risk of miscarriage or having a baby with a chromosome problem. Women with TS that can get pregnant should try to have children early in their adult life because of the risk of early ovarian failure and other health concerns related to TS. Pregnant women with TS should be cared for in a major hospital with access to medical specialists.

Women with TS should continue hormone replacement at least until the usual age of menopause. All women taking replacement hormones should have regular check-ups.

☐ Talk with your doctor about hormone replacement. See a specialist if you have fertility issues but would like to become pregnant.

## Height

Women with TS who have not been treated with growth hormone (GH) can expect to be about 20 cm shorter than other women their age that are in the same ethnic group. Studies show that some girls with TS may increase their adult height by about 7.2 cm after being treated with GH. For the best results, GH treatment should continue until you have stopped growing. This is usually in your mid- to late teens or early adulthood.

#### **Heart Health**

About one of three 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.

Some people should take antibiotics before dental work and some medical procedures to protect against an infection in the heart. Your cardiologist can advise you.

Even if your heart seems to be healthy, it is still 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.

Adult women with TS must have regular check ups with a cardiologist, including an echocardiogram/ or MRI. Women with TS who do not have a heart problem should still have an echocardiogram or MRI and see a cardiologist every 3 to5 years because new problems may develop that change your heart health. All women with TS who are thinking about becoming pregnant should see a cardiologist before and during pregnancy.

Up to 40 percent of women with TS have high blood pressure. High blood pressure should be treated right away.

 $\hfill\square$  Do a heart exam and blood pressure check once a year.

## **Thyroid/Immune System Disease**

Girls and women with TS are more likely to become hypothyroid. This means that the thyroid gland in the neck (the body's "motor") stops working properly. One out of four women with TS will become hypothyroid. A blood test should be done every one to two years to check thyroid levels. If hypothyroidism develops, it is easily treated with a pill taken daily for life. Girls with TS are also at higher risk for developing other autoimmune disorders such as arthritis, celiac disease, and inflammatory bowel disease.

 $\square$  Do a blood test for thyroid function every 1 to 2 years.

## Hearing

Some adolescents and young women with TS continue to have ear infections. These infections should be treated right away to protect your hearing.

Hearing loss is common in TS. It usually happens slowly and over time. One out of four women with TS will need hearing aids by the time they are in their 40's.

Your doctor should check your ears at each visit, and send you to a specialist if you have repeated infections or if there is a concern about your hearing.

☐ Check ears and hearing once a year. Do formal hearing tests in early adulthood and then as recommended.

# Intelligence and Behaviour

Most women 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)