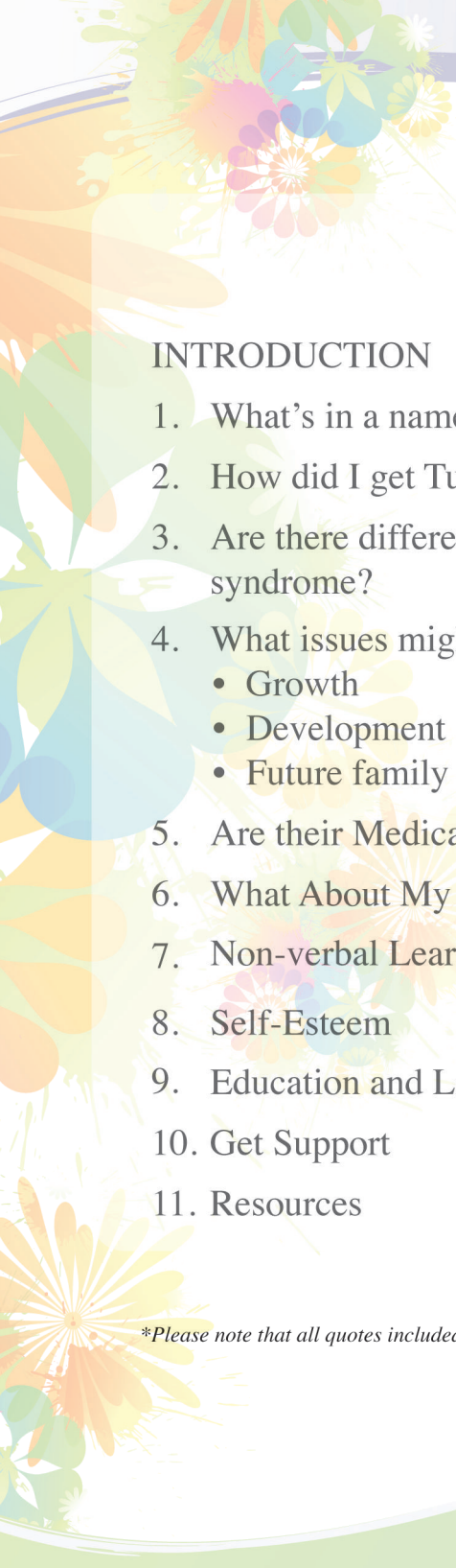




Turner  
Syndrome  
Society  
of the United States

# A Guide For Girls with TS

Ages 11-15



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*\*Please note that all quotes included in this brochure were made anonymously.*

# Introduction

Receiving a diagnosis of any condition can be a scary thing, because you are finding out something you didn't know about yourself. You may be thinking, *Turner syndrome, what is it and what does it mean for me now and in the future?*

This handbook will help you understand Turner syndrome and give you an idea of what it means to be a girl with Turner syndrome.

It will provide you with input and advice from other girls and women with Turner syndrome about the issues they face and how they cope with them.

*“Do not be afraid or discouraged. There are many other young women out there who have the same condition, plus women who have gone on to live completely full and wonderful lives.”*



# What's in the Name?

*Let's break it down into "Turner" and "syndrome"*

Let's break it down into "Turner" and "syndrome." TURNER comes from Dr. Henry Turner, the first American doctor who described the condition in 1938. SYNDROME means a set of symptoms that occur together that have a common cause.

*Turner syndrome has many symptoms, a few of the most common are:*

- Shorter than average height
- Delayed physical development
- Learning challenges
- Physical and health related concerns

Each girl with TS is unique and these symptoms may or may not be a concern for you. Your endocrinologist or geneticist can tell you what symptoms you have.

## *How Did I Get Turner syndrome?*

**T**urner syndrome, (TS), is a condition that only occurs in females. Put 2,000 girls in a room and there will probably be at least one with Turner syndrome. TS randomly occurs in 1 of every 2,000 births, and it is a result of how your cells are formed before birth.

Our bodies are made up of millions of cells. They make up everything from our bones, muscles and organs to our hair, blood, and teeth. Inside each cell is our genetic information in the form of 23 pairs of chromosomes. Instructions within our chromosomes help our bodies to function, develop and grow.

Usually, females are born with one pair of X chromosomes, or XX, in each of their cells. A girl born with only one X chromosome, or one X chromosome plus a part of another X chromosome has Turner syndrome.

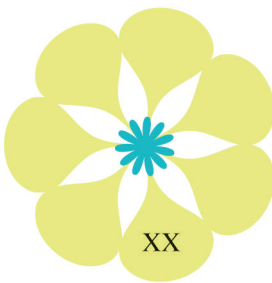
Because part or all of one X chromosome is missing in girls with Turner syndrome, part of the instructions within this chromosome are also missing. For example, some of the missing instructions include telling your body to grow and develop (puberty). This is what causes many of the symptoms of Turner syndrome.

## Are there different types of Turner syndrome?

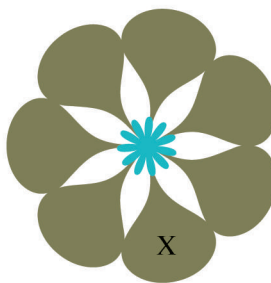
**Y**es, each girl with Turner syndrome (TS) has her own set of features and a separate diagnosis. From a doctor's point of view, your type of TS is determined by your karyotype (diagnosis). Some examples of karyotypes in TS are 45X, 45X/46XX or 45X/45XY. When the diagnosis is other than 45X, doctors use the term mosaic which means a mixture.

### *Here's an example.*

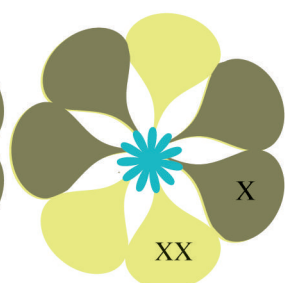
In Turner syndrome, some cells may have one X chromosome, yet others may have two X chromosomes. Imagine it this way, **each flower below represents a cluster of cells, each cell contains chromosomes (the X's). Each petal represents one cell.** Notice that some cells contain the normal amount of two X chromosomes and some do not:



Chromosomes in a girl *without* Turner syndrome



Girls with Turner syndrome



Girls with mosaic Turner syndrome

*There is a mixture of both X and XX cells in mosaic Turner syndrome.*

# What Issues Might I Face?

## GROWTH

Girls with Turner syndrome are generally not as tall as their friends.

For some girls, to help them grow, they are given growth hormone (GH). How tall you become depends on how long you have been taking GH as well as the dose. Some girls have been on GH for a long time and some may have just started. Others don't take GH at all.

How tall you become depends on other factors too, like how tall your parents are. Every girl is different.

## What Exactly is GH?

GH is a chemical that is produced naturally in your body that helps you grow. In girls with TS, their bodies usually have enough growth hormone but they are missing the instructions on how to use the GH. Adding more GH to a girl with Turner syndrome can help her grow taller. GH is given as an injection and is usually taken every night.

*“The nightly shot is nothing to me anymore. I’ve had it since as long as I can remember, since I was diagnosed at 2. I don’t even think about it anymore. It’s like brushing my hair, or my teeth, changing clothes, you get the idea.”*



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## *Development*

Your body may not make enough of the female hormone, estrogen, to go through puberty naturally. Estrogen is made by your ovaries and most girls with TS do not have functioning ovaries. Fortunately, however, you can take estrogen so that breast development and menstruation (your period) occur.

### *Some other benefits of taking estrogen include:*

- *Keeping bones healthy*
- *Helping with learning*

Your doctor will tell you if you need extra estrogen. If so, when to start is a personal decision that you need to discuss together, along with your parents. Most young women start taking their

estrogen through a patch on their skin or a pill around 12 years-old and stop around 50 years old.

*“I feel much better when I am on the estrogen, mentally and physically. I feel more like a woman when I have the cycle that the hormones cause. My hair and skin are also better when I am on the estrogen and it seems to help me keep my weight down.”*





# What Issues Might I Face?

## **WHO IS A PART OF YOUR FAMILY?**

In today's world, families come in all shapes and sizes. In fact, your family is often what you make it. For instance, a couple is a family, even if they don't have any kids. Or a group of close friends may also think of themselves as a family.

## **FUTURE FAMILY PLANS**

Even though extra hormones may help a girl with Turner syndrome go through puberty, most are still not able to become pregnant. These women may adopt a child who needs a loving and caring home or they may be able to use new technologies to help them have a baby. Or she may decide to have a career and not have any children at all. Doctors should help you decide if having a baby could

be harmful to your health since many women with TS have health issues with their heart and/or kidneys.

*“My husband and I adopted a beautiful boy. He is an angel! For me, my body was simply not meant to have children and I knew this a long time ago. I have heard of some women with Turner syndrome becoming pregnant, but I just couldn't see putting myself through treatments.”*



## *What are some of the medical concerns?*

*If you have just been diagnosed with Turner syndrome, you can expect to visit several doctors and have some tests done. At one of your first visits to a cardiologist, he or she will likely perform:*

- An ultrasound of your heart called an echocardiogram (echo). This test is a way to see the structure of your heart. It doesn't hurt at all.
- A test called an electrocardiogram or "ECG" to check how your heart is beating. This test doesn't hurt either.
- A check of your blood pressure.

*You will also see other doctors who will perform these tests:*

- Ultrasound to look at your kidneys.
- Hearing tests are important especially if you have had a lot of ear infections when you were younger, or you still may get them often now. Ear infections may damage your hearing.
- Evaluation for scoliosis (curvature of the spine).
- A "hormone doctor" is known as an endocrinologist. He or she will check your hormone levels in your blood and may suggest that you consider taking GH or estrogen.
- A physical exam and blood work.

# What do I need to know about my future health?

*If you have already been diagnosed with Turner syndrome, here is what you can expect as you grow older:*

- Depending on what your first echocardiogram and ECG (heart tests) show, you may need to see a cardiologist to check your heart regularly.
- Yearly visits to your doctor to have your blood pressure monitored and blood work.
- Continued visits to an endocrinologist. Depending on the levels of certain hormones in your blood, he or she may recommend that you take estrogen.
- Visit the orthodontist. Some girls with Turner syndrome have a narrow mouth that may cause teeth overcrowding as well as shorter roots in their teeth.

- As you get older, if you notice that you are having a hard time hearing, your doctor may recommend another hearing test.

*“Be informed of potential problems. However, don’t anticipate that you will have any particular one. Be prepared to deal with any that may occur.”*



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# Non-verbal Learning Disorder (NLD) and TS

Some girls and women with TS have difficulties with non-verbal learning. This means they have to work harder at some subjects more so than others, such as math. Or they may have trouble keeping a room or school subjects organized.

It may also mean having trouble with a sense of direction or coordination. NLD also means not understanding people's body language such as facial expressions and hand gestures. If this is one of your challenges, you probably prefer someone tell you something rather than show you.

## SCHOOL SUCCESS TIPS FROM OTHER TS GIRLS:

*"Take advantage of all the resources that are out there, and study with friends."*

*"Don't let it stop you from being and achieving all you want to."*

*"I struggled in some areas in school but I think I benefited from having to work harder. My advice would be to take all the help that is available to you."*

*"Find out your strengths in learning (preferred learning style) and use this to compensate in difficult subjects. For example, if verbal ability is a strength, use it."*



Whether you realize it or not, most teenagers have some insecurities about how they look. For girls with Turner syndrome, other people may think you are younger than you really are. This can be frustrating and hurtful.

## What can help?

*“Almost everyone has something that is ‘different’ about them. Learn the things that you do well and try to excel in one you really enjoy doing.”*

*“Find courage to communicate your feelings, your needs and concerns with your family, teachers and health care providers. Let caring people you trust*

*help you transition into the person you were born to be! Connect with other Turner syndrome people at local chapter meetings and online support groups.”*

*“I think the only way to cope is to just try and not let it get to you. The more and more looks and comments the easier it is to just brush them off.”*



# Education and Life Goals

Never let Turner syndrome stop you from achieving your goals in life!

*Some careers that women with Turner syndrome hold include:*

**D**octors, Corporate Presidents, Teachers, Comedians, Actresses, Lawyers, Legal Assistants, Judges, Nurses, Professors, Writers, Editors, Personal Trainers, Mothers, Medical Assistants, Social Workers...

*... the list goes on and on!*

**W**hat kind of career will you be seeking?

“ I have never let Turner syndrome get in the way of pursuing my goals and I would urge other young women to do the same. Don't let Turner syndrome keep you from doing something you really want to do. The world is your oyster and there is so much to explore and so many professions and dreams to pursue.”



## *Where to Turn for Support*

*Family and friends are the best people to turn to for help. In school, you may need to ask your teacher for help. Attending a local chapter meeting or TSSUS annual conference is a great way to meet other girls with TS. Finally, your doctor can help you with many of your medical questions.*

*“I think one main thing is to get involved with the Turner Syndrome Society of the United States when you are first diagnosed. Getting involved and meeting other girls with Turner syndrome definitely helped me. You can talk and make great friends in the process. It is also good to get involved because then you can get all the knowledge and current research about Turner syndrome (education is key).”*

### *Friends and Family*



## *More Support Resources*

*Turner Syndrome Society of the United States is the foremost resource for materials and information about Turner syndrome.*

*The national website contains a **Family Guide**, which has in-depth information about TS.*

*On our website you can also find out how to get an email or texting pal. Have a parent or guardian contact TSSUS, if you are interested.*

*Find local Chapter activities and information about the annual conference on the website as well.*



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