CONDITIONS

my SUPPORT

TURNER SYNDROME

Saizen® (Somatropin) is used in the treatment of Turner syndrome (TS). This booklet is intended for the parent or carer of a patient with TS.

MyTreatment
MySaizen® with easypod™

Let's GrO!

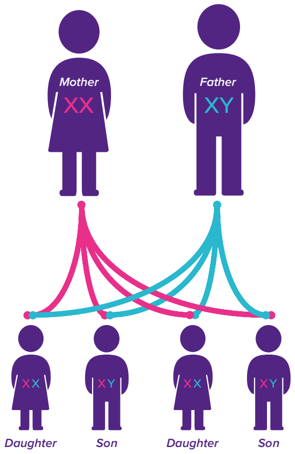
A post-prescription patient support programme produced by Merck

Turner Syndrome

What is it?

One of the causes of growth hormone deficiency (GHD) is called Turner syndrome (TS). This is a genetic condition that only affects girls. Most girls are born with two X chromosomes. TS occurs when one of the X chromosomes is completely or partially missing.

Diagram 1: *Parents have a 50% chance of having either a boy or a girl*



Why does it happen?

Around one in 2,000 girls are affected by TS and it's all down to genes. Every living thing has genes – they are like a set of instructions that your body uses to decide everything about you, from the colour of your eyes to the shape of your mouth and how tall you grow.

The science bit

Chromosomes hold your genes – humans have a total of 46 chromosomes arranged in 23 pairs in most cells of the body. Long before you are born, one of the pairs of chromosomes determines whether you are a boy or a girl. These particular instructions are called the sex chromosomes. There are two types of sex chromosomes, called X and Y. Girls have two X chromosomes and boys have one X and one Y chromosome. So when a man and a woman make a baby, each of the parents passes on only one sex chromosome to the baby, supplying half of the instructions.

Daughter

Diagram 2: *A girl born with only one sex chromosome*

Sometimes a girl can be born with only one full set of instructions instead of two (see Diagram 2), and this condition is known as Turner syndrome. It is named after Dr Turner who discovered it and appears to occur randomly.

How long will it last?

Girls who have TS are born with it and they don't grow as fast as their friends or develop in the same way as other children. The good thing is this can be helped by taking growth hormone injections. Although Turner syndrome is a lifelong condition, girls only usually take growth hormone until their bones have matured.

What happens next? Saizen® treatment

Your daughter's doctor has given her a medicine called Saizen® which is a copy of the growth hormone usually made by the body. It's important she has it as often as her doctor advises so that it works properly, usually every day. Growth hormone doesn't cure TS but it will help the body grow and develop. Your child may also be given other treatments as well as Saizen®.

Lifestyle advice

Although some girls with Turner syndrome may have trouble learning at school or may have other physical problems, your doctor will help you and your child to manage these challenges. Finding ways of encouraging your daughter to eat a variety of healthy foods will help her to respond positively to growth hormone therapy. It's also important that she gets regular exercise and plenty of sleep.

Managing growth hormone treatment

It's really important that your daughter takes her treatment regularly, usually just before she goes to bed. This is because the body normally releases growth hormone during the night. Your child may eventually feel confident enough to administer her own medication. Initially though, she may need your help and support. Both you and your child will receive training from your nurse to administer the medication correctly.

Reporting of side effects:

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at www.mhra.gov.uk/yellowcard In the Republic of Ireland, side effects can be reported online at www.hpra.ie

By reporting side effects, you can help provide more information on the safety of this medicine.

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