



Wilson's disease for
younger people





Why has it got such a funny name?

Because the doctor who first discovered it was called Wilson.



QUESTION : *What did these people discover ?*
ANSWER :

Sir George Everest



Mount Everest is named after him.

Earl of Sandwich



He was born in 1718.

Rudolf Diesel



In 1890 Rudolf Diesel had the idea to develop a diesel engine.



What is Wilson's disease?

Everybody needs a metal called copper to grow properly. We get copper from food. Food is sent to the liver to be sorted. The liver decides what is needed by the body to grow and what should be got rid of. In people with Wilson's disease the liver is not able to get rid of the unwanted copper; therefore there is too much copper in the liver. When the liver is full, the copper overflows and goes to other parts of the body. This means that there is a lot of copper in the body.

.....you could imagine that your bathtub is your liver and that water is copper, if you fill the bathtub with water, and keep filling it up but don't take the plug out, it will overflow.....



Too much copper makes you sick. Medicine will do the job of getting rid of the excess copper – your body will have the copper it needs to live and grow and the medicine will get rid of the rest.



How did I get Wilson's disease ?



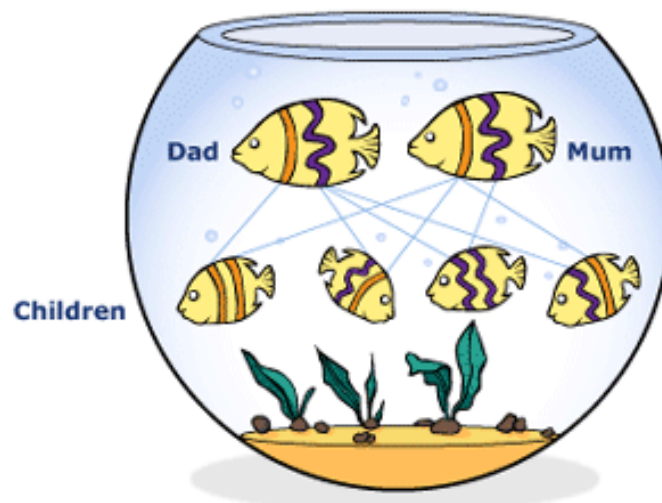
It's nobody's fault.

Wilson's is what we call a genetic disease; this means it's something that you are born with.

Information on genes and genetic diseases



When a child is conceived, one egg from mum and one sperm from dad is brought together to develop the foetus, there is no way of predicting which sperm and which egg will unite to make the baby. Mum's egg and dad's sperm carry information that is responsible for the colour of your eyes, hair etc and will also carry any information that relates to a genetic disease.





Is it catching ?



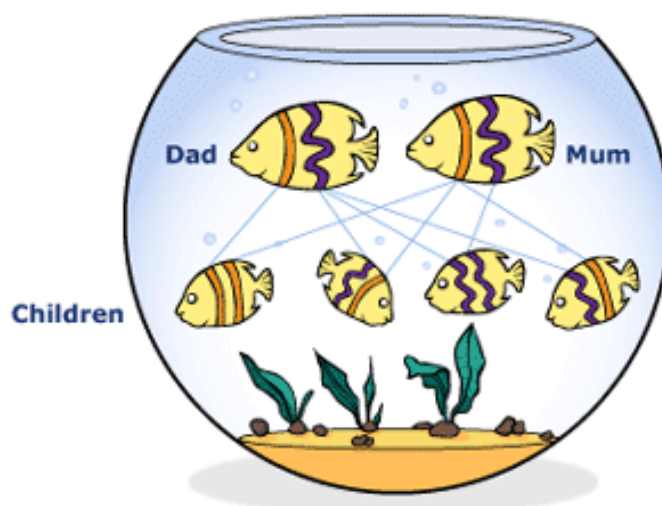
No, it is not catching.

It is not due to a virus or a bug; it is due to a mistake in the genes.

Information on genes and genetic diseases



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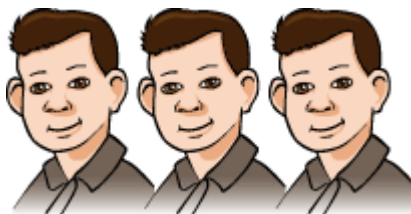




Am I different from everybody else ?



We are all different. Some of us are tall and some short, some clever at school work, and some clever at other things. A person with Wilson's disease just has a medical problem needing treatment..

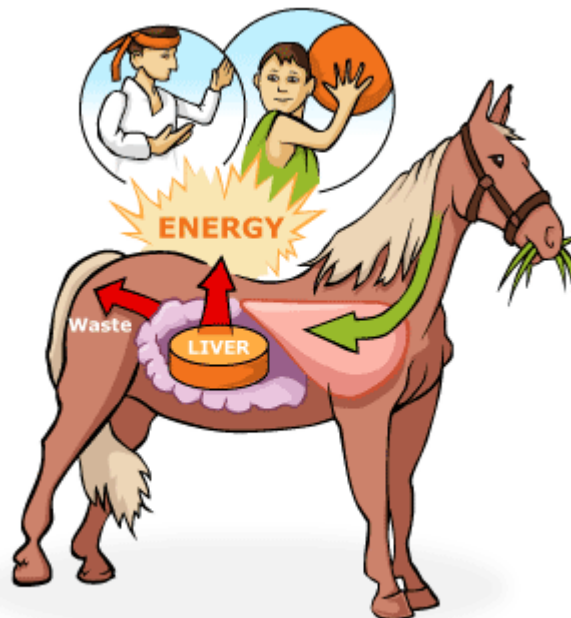


Imagine if we were all the same.



What does my liver do ?

The liver does lots of jobs. It helps to turn food into energy. It gets rid of some waste products from the body. It makes special proteins that we need to grow and be healthy. It lies in the upper part of the abdomen.





If my liver gets worse, will it hurt ?



Liver problems usually do not cause pain. They can cause other things which are a nuisance like yellow jaundice, tiredness



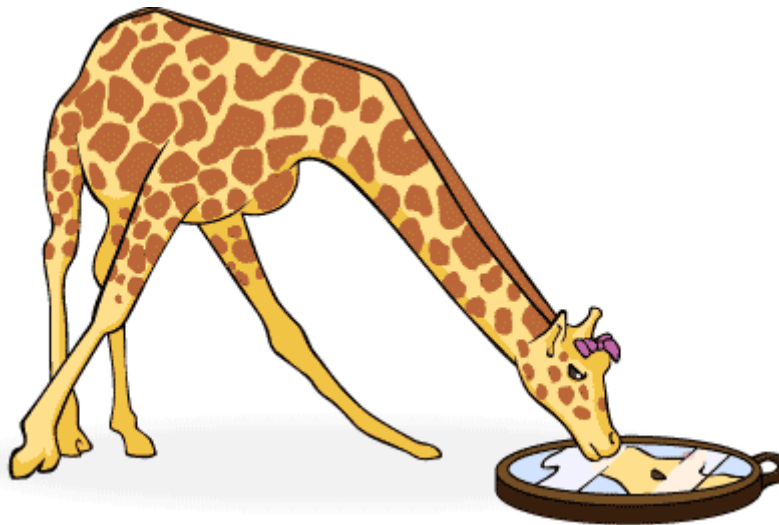
itchiness of the skin,

and sometimes swelling of the tummy.





Why do some people with Wilson's disease eyes go yellow ?

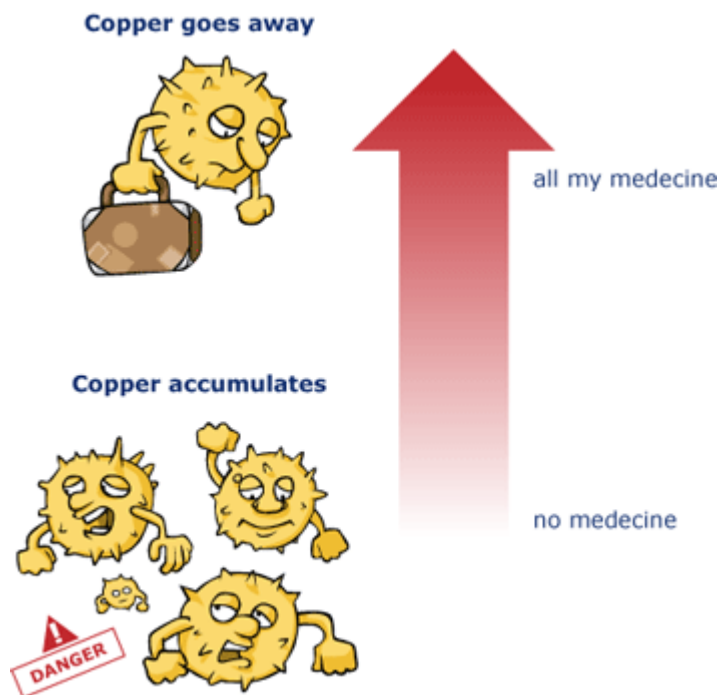


A yellow colour of the whites of the eyes is called jaundice. It is due to a yellow pigment called bilirubin. Normally the liver clears bilirubin away from the bloodstream. If the liver is not working perfectly, the yellow bilirubin may stay in the blood.



Why do I have to keep taking medicines ?

Medicines control the amount of copper which is in the liver causing damage to it. It may be hard for you to take medicines every day and you may sometimes not want to. But not taking your drug will make you sick, even though you may not feel it right away. After a while you WILL start to feel sick.





How long will I have to
keep on taking
medicines?



You will have to go on taking medicines for ever. This sounds like bad news, but taking a few pills every day is much better than getting sick, isn't it?





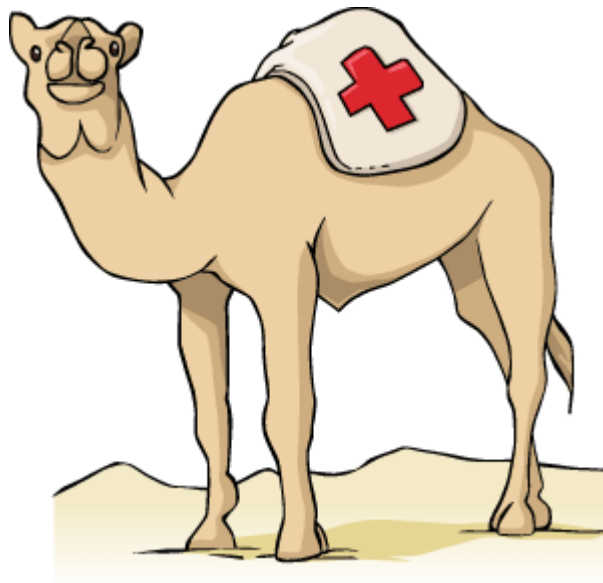
What will happen if I take my medicines every day?

You will feel much better and you will be able to do much more and have much more fun !





What will happen if I stop taking my medicines?



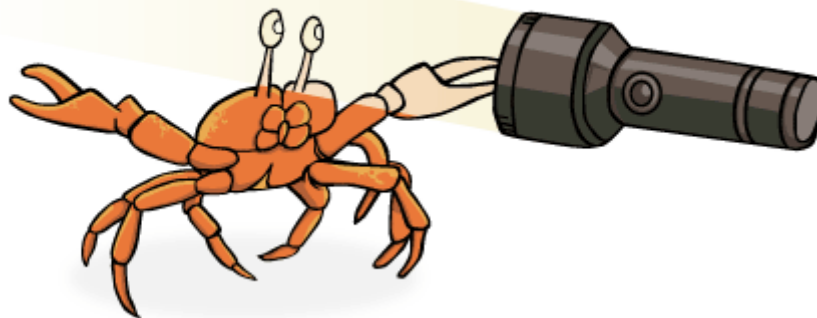
You won't notice anything straightaway, but your liver will be being more damaged and after a little while you might get very ill indeed. Do not stop taking your medicine!



Why did the eye doctor look at my eyes with a special light?



Sometimes children with Wilson's disease have got a special little feature in the eye which has got a complicated name (the Kayser-Fleischer ring). This copper coloured ring does not change your vision. It helps to make the diagnosis of Wilson's disease.



QUESTION : *Why do you think it has a complicated name?*

CLUE :

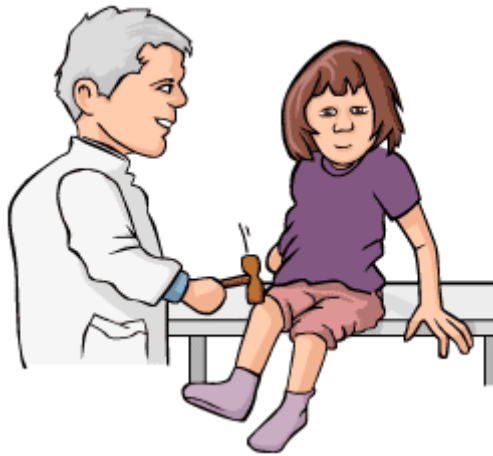
It has something to do with the men that discovered it

ANSWER :

In 1902 a man named Kayser and in 1903 a man named Fleischer discovered a copper coloured ring in the eye. Because they discovered this at almost the same time, it was named after both of them Kayser-Fleischer.



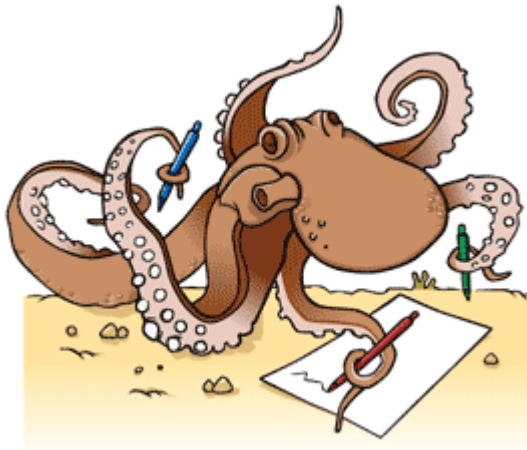
Why do some people with Wilson's disease have a tremor or shake?



Sometimes people with Wilson's disease have too much copper in the brain. This can cause problems like tremor which is shaking of the hands. If this happens you will need to see a neurologist.



Why does my doctor look
at my handwriting?



Sometimes people with Wilson's disease have too much copper in the brain. This can cause problems like tremor which is shaking of the hands, or sometimes difficulties in talking, writing or buttoning up clothes. Medical treatment will get rid of the copper slowly and prevent or stop these symptoms.



Why does my doctor keep doing blood tests?



Blood tests are needed to check how well your liver is functioning and whether the treatment is improving the liver.



Am I allowed to...?



Play on a computer? YES

Play games? YES

Eat anything I want? You can eat anything your mum and dad and doctor say you can.

Go to parties? Definitely!



Do other people need to know?

It is probably best that your school teachers know that you have Wilson's disease and your parents will probably talk to them about this.





Do my friends need to know?



It is up to you whether or not you tell your friends. It is usually best to tell your good friends that you've got a medical problem, so they understand why you have to have medicines.





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www.eurowilson.org