Wilson's disease for younger people
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.
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.
It’s nobody’s fault.

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

- Normal gene
- Wilson’s gene
- Child does not have Wilson’s disease
- Child does not have Wilson’s disease but carries one Wilson’s gene like mum and dad
- Child carries 2 Wilson’s genes and has Wilson’s disease
No, it is not catching.

It is not due to a virus or a bug; it is due to a mistake in the genes.
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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.
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.
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.
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 some people with Wilson's disease eyes go yellow?
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.

Why do I have to keep 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?
You will feel much better and you will be able to do much more and have much more fun!

What will happen if I take my medicines every day?
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!
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.
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.
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.
Blood tests are needed to check how well your liver is functioning and whether the treatment is improving the liver.

Why does my doctor keep doing blood tests?
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!
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.
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.

Do my friends need to know?
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www.eurowilson.org