Information for young people about a research project for people with Wilson's disease

EuroWilson

Please will you help us with some research?

Have you seen the leaflet called "Wilson's disease for younger people" or the web-site called www.eurowilson.org ? They tell you loads about Wilson's disease.

Now we want to tell you about some research that is going on, and ask you to be a part of it. Research means we find out more about diseases and how to treat them. We are going to find all the patients who turn up with Wilson's, right across Europe, and put their details on a computer. We hope this will be OK with you. Your family have also been given a leaflet so they know all about it too.

What is the research all about?

We already know lots about Wilson's, but we need to find out more. Like –

1. How many people have got it?
2. Why do some get an upset liver and some get other things like the shakes
3. What's the best test for it?

Why have I been chosen?

Just because you have Wilson's. We want to know about every single person with it.

What will happen to me if I take part?

You don't have to do anything at all. There will not be any extra tests or hospital visits. What will happen is this. A doctor will enter facts about your illness and your tests into a computer. Your name will not be put on the computer, You will be given a special number which only your doctor will know. This data will go to a computer in France which will collect data about people from all over Europe and keep it safe.

The doctors who are looking after you will send a blood sample to a special genetics laboratory to test for Wilson's. If there is any sample left, we want the laboratory to keep it.

Why?

1. To try out better and quicker tests in the future.
2. To check that every lab in Europe is doing the tests as well as the rest
3. To do other research about Wilson's

Do I have to join in?

It is up to you. If you say yes you will be asked to sign a consent form. You can still change your mind later

Will my details be kept secret?

Yes.

What sort of stuff about me will go on the computer?

Things like
How old are you?
Are you a boy or girl?
Did your eyes go yellow?
What did your blood tests show?
Your treatment
How you are 1 year later

Do I get anything for being in this research?

No. This research will help people like you in the future.

I've got some more questions. Who can I ask?

The doctor who gave you this form. And take another look at the web-site, www.eurowilson.org

There is also an information sheet for the grown-ups in your family.

What will happen to the results of all this research?

It will be published in medical journals and put on the website. Your name won't appear anywhere.

Who is paying for all this?

Brussels. No, not Brussels Sprouts but the European Union.

Thank you very much for reading this. This is a copy for you to keep. You will also be able to keep a signed consent form.

UNIVERSITY OF SHEFFIELD

www.eurowilson.org

CONSENT FORM FOR A YOUNG PERSON

Title of Project: Wilson Disease: Creating a European Clinical Database and designing randomised controlled clinical trials.

Name of Researcher: Professor Stuart Tanner, University of Sheffield, Tel 0114 271 7303

	Please initial box
1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study and have had the opportunity to ask questions.	☐
2. I understand that I only need to take part if I want to, and it won't alter my treatment if I say no	☐
3. I agree to data from my notes being included in a European database, provided that my name and address is kept secret	☐
4. I give permission for any spare sample left over from my genetic blood test to be used as in the information sheet.	☐
5. Please tell my own GP I am going to be in this database	☐
6. It is OK for coded data about me relating to this study to be sent to countries that do not have the same data protection laws as the UK.	☐

Name of patient | Signature | Date

Name of Person taking consent | Signature | Date

Researcher | Signature | Date

1 copy for patient; 1 for researcher; 1 to be kept with hospital notes