

PodonNet
Clinical Registry and Study of Genetic Risks
for the Steroid Resistant Nephrotic Syndrome

Information Letter for Children

Dear

As you know, your kidneys don't work like those of healthy children. Usually, the kidneys filter poison and water out of your body. If the pores of the filter are too wide though, you will lose essential substances, the proteins, from the blood. This leads to numerous changes in your body. Some of these changes you can notice by yourself. For example, you will gain weight and your arms and legs feel thicker because of excess water.

Many children affected by the same disease feel better quickly with a special medication called "cortisone" or "prednisone". This drug usually fights successfully against what is wrong with your body. Unfortunately, the medication did not work in your case and you must take other drugs and regularly visit our hospital, which is specialised in kidney diseases like yours.

Only very few children are affected with the same kidney disease as yours. Actually, we are not entirely sure why children like you develop this disease and what will eventually be the best treatment. This is why children from all over Europe who suffer from the same kidney problem as you will be observed for three years. The study is meant to improve the ways we treat you and other affected children, in order to protect the proper functioning of your kidney.

What are we going to examine?

The participation in the study is voluntary. At the beginning, we are going to examine you carefully. We will ask you and your parents how and when the kidney problem started and if someone in your family has a similar disease. This will take place during a regular visit in your nephrology clinic. When your doctor draws some of your blood anyway, a few additional drops will be drawn and also urine will be collected for special analyses once a year. You will participate in the study for 3 years.

Your history and blood results will be saved in a big list. Only your doctor knows which information is from you. If the information is passed on to another doctor, it is labelled only with a number instead of your name.

The goal of all these examinations is to find out why your kidney has become sick and how it can be treated in a better way. In order to find that out, we might also examine blood of your parents.

If you do not want to participate in the study any longer you can let us know at any time. Nobody will be angry with you. You can be sure that you will get the same treatment as before.

We would be very happy if you decide to participate in the study!

< Name of principal investigator >

