

# **The National Study of Steroid Resistant Nephrotic Syndrome in Childhood**

## **Information Sheet for Children**

Hello! Thank you for reading this. Please ask if you don't understand.

Your kidney doctor thinks you have an illness which is making your kidneys sick – it is a type of 'nephrotic syndrome'. We call it SRNS. There are other children in the country and the UK who also have this.

There is a group of doctors and scientists who want to find out more about it (SRNS). They want to try and find out why some children get it and some don't and why some get sicker than others.

Some children with this illness get very sick kidneys and need a new kidney – this is called a transplant.

Very sadly the illness can come back to that new kidney as well.

So, the group doing this project, want to find out more about the illness (SRNS) and why it comes back after a kidney transplant.

They will do this by asking all the children in the country and the UK with the same illness (SRNS) to join in this project. They will collect information on things like how old you were when you got sick and what medicine your doctor gave you.

They would also like to do a blood test. It would mean that next time you had a blood test they took a little extra – it would not mean more blood tests than normal.

If you were one of the children who had a kidney transplant (a new kidney) your doctors would need to test your blood and urine before and after – in this case a little extra blood and urine would be taken for this project.

So that's it! Do you want to ask any questions?