

The National Study of Steroid Resistant Nephrotic Syndrome in Childhood - Consent Form

(Name of Patient)

RaDaR identifying number of patient.....

Please initial each box

I confirm that I have read and understood the information sheet for the above study and I have had the opportunity to ask questions

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I agree for my child to take part in the study.

☐

I understand my child's participation is voluntary and that my child is free to withdraw at any time without giving any reason, and without my child's medical care or legal rights being affected.

☐

I agree for my child's blood sample to be taken and tested for genes know to cause FSGS

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I agree for my child's blood and urine samples to be taken and used in the study should they undergo transplantation.

☐

I agree for my child's plasma samples to be taken and used in the study should they require plasma exchange for recurrence of disease post transplantation

☐

I agree that my General Practitioner may have correspondence concerning the study

☐

I agree that the results of the gene testing be fed back to my local kidney specialist to pass onto us in order to discuss fully if a mutation is found (there is an approximately 20% chance of the disease being caused by one of the gene mutations being tested for)

☐

I agree that if new genes that cause SRNS/FSGS were to be found that my child's samples could be tested for these.

☐

I agree that should that the samples may be kept by the research team, should they develop new research into SRNS/FSGS

☐

Name of parent/guardian.....DateSignature.....

Name of person taking consent.....Date.....Signature.....
(if different from local investigator)

Local investigator.....Date.....Signature.....

Copies 1 for patient, 1 for hospital notes