

National Study of Nephrotic Syndrome (NephroS) Adult Consent Form

RaDaR database number

**Please initial
each box**

I confirm that I have read and understood the patient information sheet for the above study and I have had the opportunity to ask questions, which have been answered satisfactorily.

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

I agree for samples of my blood to be taken and used in the study.

I agree for my plasma exchange samples to be taken and used in the study.

I agree to give urine samples, which can be used in the study.

I agree to consider visiting the hospital at times at relapse to donate samples.

I agree that if I have undergone/undergo a kidney biopsy, the research lab can request a sample of the tissue taken.

For future routine biopsy operations, I agree that a small amount of tissue can be taken for research purposes.

I agree that genetic material from my samples can be analysed to search for genes that may be related to Nephrotic Syndrome.

I agree to cell lines (that can continue to grow in the laboratory indefinitely) being generated from my donated samples.

I agree that my General Practitioner can be informed regarding study participation and may have correspondence concerning the study.

I give permission for the NephroS study investigators to access my medical notes and other health-related records

I agree that the results of any gene testing may be fed back to my local kidney specialist to pass onto me in order to discuss fully if a mutation is found.

I understand that my samples have been donated as gifts and will be stored for further National/International studies into Nephrotic Syndrome.

I understand that this research may include the participation of commercial companies and that I will not benefit financially if this research leads to new treatments and medical tests.

I agree to take part in the National Study of Nephrotic Syndrome (NephroS).

Name of patient.....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. Original in local study file.