

## National Study of Nephrotic Syndrome (NephroS)- Consent Form

RaDaR database number

**Please initial  
each box**

I confirm that I have read and understood the parent/ guardian information sheet and I have had the opportunity to ask questions, these have been answered satisfactorily.

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 samples of my child's blood to be taken and used in the study.

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

I agree to for my child to donate urine samples, which can be used in the study.

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

I agree that if my child has undergone/ undergoes a kidney biopsy, the research lab can request a sample of the tissue taken.

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

I agree my child's genetic material can be analysed to search for genes that may be related to Nephrotic Syndrome.

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

I agree that my child's 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 child's medical notes and other health related records.

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

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

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

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

Name of parent/guardian.....Date .....Signature.....

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.*

**OPTIONAL – NephroS BLOOD SAMPLES FROM RELATIVE**

(Please duplicate this page for each family member giving consent for their blood/saliva sample)

Child’s RaDaR database number

**Please initial each box**

Relationship to child: .....

I confirm that I have read and understood the relative’s section of the parent/guardian/family information sheet and I have had the opportunity to ask questions, these have been answered satisfactorily.

I agree for my blood/saliva sample to be taken and tested for the genetic causes of Nephrotic Syndrome.

I agree that I can be contacted with information and research opportunities about Nephrotic Syndrome.

I agree that my samples may be kept by the research team, should they develop new research into Nephrotic Syndrome. My blood/saliva samples have been donated as gifts and therefore these may be stored for future National/International studies.

Name of relative.....Date .....Signature.....

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.*