



Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM for parents/guardians

Title of Project: Irish Rare Kidney Disease Registry and Bioresource

Name of Researcher: Professor Mark Little

Please initial box

1. I confirm that I have **read and understand** the information sheet dated
(version) for the above study and have had the opportunity to ask questions.
2. I understand that my child's **participation is voluntary** and that my child is free
to withdraw at any time, without giving any reason, without medical care or legal
rights being affected.
3. I understand that sections of any of my child's **medical notes** may be looked at by
research staff where it is relevant to taking part in research. I give permission for
these individuals to have access to these records.
4. I agree for my child to take part in **Part 1** of the study: entry of clinical data into the
registry
5. I agree for my child to take part in **Part 2** of the study: provision of urine, blood and
saliva samples, and use of any biopsy tissue that is taken for clinical reasons only.
6. I understand that results from the **analysis of my child's samples will not be
given to me**. I agree that the samples given and the information gathered from my
child can be stored in computer or manual format and be looked after by Prof Little
based at Trinity College Dublin.
7. I understand that all **medical information pertaining to my child, including
blood, tissue and urine samples**, will be protected by the principles of
confidentiality and by both national and EU data protection. Any clinical data or
samples sent out of Ireland will not be identifiable as coming from my child.





8. I understand that further research using the samples given may include genetic research aimed at understanding the genetic influences and risks related to renal disease and its treatment, but that the results of these investigations are unlikely to have any implications for my child personally. This research may involve sharing of a coded DNA sample with other research groups.

9. I understand that prior to any future studies using the samples given, the studies will be reviewed and approved by a local ethics committee

10. I understand that there are no direct benefits to my child from participating in this study. I understand that I or my child will not benefit financially in any way if this research leads to the development of a new treatment or medical test.

11. I KNOW HOW TO CONTACT THE RESEARCH TEAM IF NEEDED.

12. I consent to my child's G.P. / Hospital Consultant being informed of my participation in this study.

Name of Patient

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Researcher

Date

Signature

1 copy for parent/ guardian; 1 copy for researcher; 1 copy to be kept with hospital notes

