Ospidéil OL
UL Hospitals

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

CONSENT FORM

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

3. I understand that sections of my **medical notes** may be looked at by research staff where it is relevant to my taking part in research. I give permission for these individuals to have access to my records. ☐

4. I agree to take part in **part 1** of the study: entry of my clinical data into the registry ☐

5. I agree 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 samples will not be given to me**. I agree that the samples I have given and the information gathered from me 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 me, 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 me. ☐

8. I understand that further research using the samples I give 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 me personally. This research may involve sharing of my coded DNA sample with other research groups. ☐

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

10. I understand that **there are no direct benefits to me** from participating in this study. I understand that I 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 I NEED TO. ☐

12. I consent to my 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