



**Irish Kidney Gene Project (IKGP)
Polycystic Kidney Gene Research Program
Patient Information Sheet**

Autosomal Dominant Polycystic Kidney Disease (ADPKD) is the commonest genetic condition leading to kidney damage. This means that one or more of your genes are faulty, which results in you making many cysts in your kidneys. Inheriting a faulty gene of autosomal dominant means that each child that you have has a 50:50 chance of inheriting the faulty gene and also developing the condition. The disease develops very slowly, vary from person to person, and therefore symptoms and problems usually do not develop until adulthood. Because the affected kidneys get bigger, you may experience pain in the tummy or lower back, blood in the urine, passing kidney stones and symptoms related to high blood pressure.

Although the kidneys are the main site affected, cysts may also develop in other parts of the body such as cysts in the liver. Many people with ADPKD remain well and free of problems for years after the condition is diagnosed. No particular treatment may be needed for a time. You would be offered an annual follow up for blood pressure check and blood tests to monitor your kidney function.

Beaumont Hospital is undertaking research to help understand the genes that cause ADPKD. We are looking for volunteers to help us with this project. Our goal is to understand the genes that cause kidney failure and why patients might have different clinical course. The Research involves a ten-minute telephone conversation in which a kidney doctor from Beaumont Hospital will call you or talk to you while at clinic, talk to you a about your kidney condition and a brief family history. With your permission we will also review your medical records.

We will either take a blood sample when next at clinic or send you by post a detailed patient information sheet, consent form and a DNA spit tube in which we will ask you to give us a spit sample which will also use this sample to study your DNA to help better understand why you could kidney disease.

If you are interested in helping us writ us at **IrishKidneyGeneProject@Beaumont.ie**

Peter Conlon