Patient Benefits of Joining RaDaR

- Access to your clinical data online via Patient View
- Ability to be contacted about potential research studies or patient information events
- Contribute to the increase in knowledge about your condition

Clinician Benefits of Joining RaDaR

- Portfolio study – Renal, co-adopted by Child Health
- UK-wide Ethics and classed as a research registry so no additional HRA approvals required
- Share knowledge with other colleagues
- Access to genetic testing for selected conditions

Contact Details

For more information please contact **Melanie Dillon, RaDaR Operations Officer** - Melanie.Dillon@RenalRegistry.nhs.uk

RaDaR is supported by:

RaDaR

The **National Registry of Rare Kidney Diseases (RaDaR)** is a Renal Association initiative designed to pull together information from patients with certain rare kidney diseases.

This will give a much better understanding of how these illnesses affect people. It will also speed up research.

Over 12,500 patients have been recruited so far, from 85 hospitals.

PatientView

RaDaR draws information from **Patient View**, an online system which records renal patient's results, medications and clinic letters.

Recruited patients are provided with a secure log-in to Patient View to access and check their own information online.

RareRenal
Information on rare kidney diseases

RareRenal.org provides information for both patients and clinicians on the current RaDaR conditions.

The website also provides details of patient support groups, personal stories and adverts for forthcoming patient information events.

Current Conditions

- Adenine Phosphoribosyltransferase Deficiency (APRT-D)
- Alport Syndrome
- Atypical Haemolytic Uraemic Syndrome (aHUS)
- Autosomal Dominant Polycystic Kidney Disease (ADPKD)
- Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD)
- Autosomal Recessive Polycystic Kidney Disease (ARPKD)
- Bartters Syndrome
- C3 Glomerulopathy
- Calciphylaxis
- Cystinosis
- Cystinuria
- Dense Deposit Disease (DDD)
- Dent Disease
- Epilepsy, Ataxia, Sensorineural Deafness, Tubulopathy (EAST) Syndrome
- Fabry Disease
- Fibromuscular Dysplasia
- Gitelman Syndrome
- Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)
- Hyperuricaemic Nephropathy
- IgA Nephropathy
- Liddle Syndrome
- Lowe Syndrome
- Membranous Nephropathy
- Membranoproliferative Glomerulonephritis (MPGN)
- Medullary Cystic Kidney Disease
- Pregnancy and Chronic Kidney Disease
- Primary Hyperoxaluria
- Pure Red Cell Aplasia
- Retroperitoneal Fibrosis
- Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)
- Steroid Resistant Nephrotic Syndrome (SRNS)
- Steroid Sensitive Nephrotic Syndrome (SSNS)
- Thin Basement Membrane Nephropathy
- Tuberous Sclerosis
- Vasculitis