

Issue Eight, Winter 2017

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 better understanding of how these illnesses affect people and will also speed up research. Recruitment to RaDaR is now open to all UK renal centres, adult and paediatric.

RaDaR recruits its 10,000th UK patient!

The 10,000th RaDaR patient was an ADPKD recruit, entered by Nottingham University Adult's Hospital on January 21st 2017. Given that our initial recruitment target was just 50 patients, reaching the 10,000 mark is a fantastic achievement and a testament to the hard work of all the renal units and RDGs involved.

The overall recruitment target has now been increased to 25,000 patients by December 2019, which is when our current Ethics approval expires, although this may be extended.

Congratulations and here's to the next 10,000!

Kidney Research UK Funding

Thanks to the generous support of **Kidney Research UK (KRUK)**, RaDaR will remain on the NIHR Portfolio for a further 12 months, taking us up to 31/03/2018.



Happy birthday RaDaR!



The first RaDaR patient was recruited by **Bristol Children's hospital** on **18th January 2010**. We are now 7 years old!

Re-consenting Reminder

Paediatric consent for RaDaR is capped at age 16. Patients should then be re-consented as adults. If this does not occur by the time they reach 18, their record is frozen and the patient will no longer be able to be contacted by their Rare Disease Group.

It is the responsibility of the renal units to ensure that correct consent procedures are followed.

- Paediatric units - please inform the adult unit during transition that a patient has consented to RaDaR
- Adult units - please re-consent such patients as adults when they transition into your care or when they reach 18 if they have been with you as a child

Top Recruiting Adult Sites	Recruits
London Royal Free	550
Glasgow Queen Elizabeth	486
Lister Hospital, Stevenage	472
Nottingham City Hospital	462
Stoke	326

Top Recruiting Paediatric Sites	Recruits
Birmingham Children's	321
Nottingham Children's	155
London Great Ormond Street	120
Leeds Children's	118
Manchester Children's	95

RaDaR is generously supported by:



Rare Disease Day



Tuesday 28th February 2017 marks the tenth international Rare Disease Day. Hundreds of patient organisations from all over the world will be holding events designed to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.



The theme for 2017 is **research**. Rare disease research is crucial to providing patients with the answers and solutions they need, whether it's a treatment, cure or improved care.

Patient involvement in research has resulted in more research, which is better targeted to the needs of patients. Patients no longer solely reap the benefits of research; they are empowered and valued partners from the beginning to the end of the research process.

Patients can:

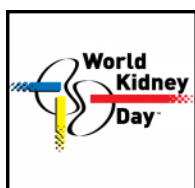
- **Advocate** for research on a specific disease or across diseases. They know where research is needed and work to influence research bodies and companies to prioritise these areas in their research.
- **Fund** research. Individuals or patient organisations often raise money for clinical trials or research projects, on their own or in partnership with private funding initiatives.
- **Partner** in research projects and are included in the governance of research.
- **Participate** as subjects in clinical trials and also in the design of these trials. They therefore help to ensure that the development of a medicine takes into account their real needs, so that the patient perspective is not overlooked.

RaDaR and **RareRenal.org** are proud to support **Rare Disease Day** and the campaign to boost research into rare diseases.

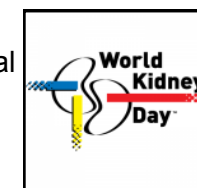
Further details of the day and a list of worldwide events can be found at www.rarediseaseday.org



World Kidney Day



Thursday 9th March 2017 marks **World Kidney Day (WKD)** - an annual global awareness and education event.



This year the theme is **Kidney Disease and Obesity**.

Every year, countless local, national and international events are organised by kidney charities, healthcare professionals, patient groups and individuals.

We encourage everyone to get behind the campaign and try to organise an activity or event to draw public attention to the importance of kidney health - what can be done to protect kidneys before disease strikes, and to assist patients who already have chronic kidney disease.

Further details can be found at the World Kidney Day UK website www.worldkidneyday.co.uk

The UK initiative is led by the **Kidney Charities Together Group**:



Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st February 2017**, when there were **10,233 UK** patients in RaDaR from **78 Renal Units**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	1985
ADTKD/FUAN	√	√	91
aHUS	√		112
Alport Syndrome	√	√	396
APRT-D	√		6
ARPKD	√	√	118
Calciophylaxis	√	In progress	18
Cystinosis	√		92
Cystinuria	√		262
Dent Disease & Lowe Syndrome	√	In progress	42
Fabry Disease	√		5
Fibromuscular Dysplasia	√		3
HNF1-B	√	√	42
Stec HUS	√		83
Hyperoxaluria	√		73
Hypokalaemic Alkaloses	√	√	199
IgA Nephropathy	√	In progress	1195
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	561
Membranous Nephropathy	√		1139
Nephrotic Syndrome	√	√	1695
Pregnancy & Chronic Kidney Disease	√	√	225
Pure Red Cell Aplasia	√		2
Retroperitoneal Fibrosis	√		47
Tuberous Sclerosis	√		28
Vasculitis	√		1846

If you are having problems with recruitment or in getting your site set-up please contact:

Melanie Dillon - melanie.dillon@renalregistry.nhs.uk