RaDaR Newsletter

RareRenal.org
Information on rare kidney diseases

THE RENAL ASSOCIATION founded 1950

Issue Five, Spring 2016

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 5,000th UK patient!

The 5,000th UK patient was recruited to RaDaR by Cardiff on April 27th 2016. This is a fantastic achievement and a testament to the hard work of all the renal units and Rare Disease Groups involved.

Congratulations and here's to the next 5,000!

Renaming of FUAN RDG

The FUAN Rare Disease Group which covers Hyperuricaemic Nephropathy and Medullary Cystic Kidney Disease has been renamed **ADTKD** for **Autosomal Dominant Tubulointerstitial Kidney Disease**.

For any queries relating to the recruitment of these patients please contact adtkd@rarerenal.org

RareRenal Updates

A review of the recent Membranous Nephropathy National Patient Forum is now available at http://bit.ly/MN-patient-forum

Presentations from the recent HNF1B Patient Information Day are now at http://bit.ly/HNF1B-Patient-days

Retroperitoneal Fibrosis Recruitment

RaDaR is now open to **Retroperitoneal Fibrosis (RPF)** patients. No additional approvals are needed to recruit these patients.

For further information on all eligible conditions please visit **rarerenal.org** or e-mail:
Melanie.Dillon@renalregistry.nhs.uk

RaDaR's Portfolio Status

The majority of new recruits to RaDaR are now adults. Following discussions with the NIHR it has therefore been decided to move RaDaR from the Child Theme to Renal.

This change came into effect as of 1st April 2016. All patients recruited before this date will be classified under the Child theme and those recruited afterwards will be counted as Renal.

Accruals will still go to the recruiting Trust.

If the change in speciality is likely to cause a problem for your renal unit in terms of funding allocation, please contact your R&D department or LCRN.

Top Recruiters

65 UK Renal Units are currently recruiting to RaDaR. The table below shows the top five recruiting sites as of 1st May 2016.

Centre	Recruits
Nottingham City Hospital	317
Lister Hospital, Stevenage	297
Royal Stoke University Hospital	295
Birmingham Children's Hospital	273
London - Royal Free	232

RaDaR is generously supported by:

British Kidney Patient Association – improving life for kidney patients
Kidney Research UK
NHS England
pkd charity – Polycystic Kidney Disease
The Renal Association founded 1950
Renal Association UK Renal Registry

Proposed Ethics Amendment - Postal Consent

The RaDaR Operational Management Board are considering putting in an amendment to Ethics to allow for postal consent. This would be an optional procedure, with face-to-face consent remaining as the preferred option. The intention is to make it easier for sites to recruit patients who may only be seen in clinic once a year.

Patients will not need to be re-consented with the new documents and should continue to be recruited using the existing paperwork in the meantime. Feedback on this proposal would be appreciated. Please contact **Melanie.Dillon@renalregistry.nhs.uk** by **Friday 20th May**.

RaDaR on Social media

We now have a social media presence for both RaDaR and RareRenal.org. Our Facebook page is **@RenalRadar** and our Twitter feed is **#RenalRadar**.

We will be using these platforms to post updates on recruitment figures, new conditions, patient information days etc. Comments/likes/re-tweets much appreciated!

Condition specific data fields

Condition-specific data fields are now available on RaDaR for the following cohorts of patients:

- Alport Syndrome
- HNF1B
- Hypokalaemic Alkaloses
- Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy
- Nephrotic Syndrome
- Pregnancy & Chronic Kidney Disease

Detailed instructions for the data entry of Idiopathic Nephrotic Syndrome and MPGN/DDD patients are now available. Instructions for the remaining conditions will follow shortly. In the meantime, please fill in the following pages for all patients:

- Demographics
- Primary Diagnosis
- Consultant
- Clinical Diagnosis

Re-consenting paediatric patients as adults

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

A **Re-Consent** button will shortly be made available on the patient page in RaDaR for adult units to record that a patient has re-consented as an adult. Transitioned patients can be added to an adult site by registering them as a new patient, as this will then transfer the record.

If you have any questions about this please contact **Melanie.Dillon@renalregistry.nhs.uk**

Please pass this information on to any interested patients in your renal unit.

ARPKD Family Conference 2016

Learn , share and have fun!

- Keynote talks about ARPKD from the experts
- Roundtable discussions between parents, patients, doctors & scientists
- Supervised entertainment & activities for younger children
- Movie-making for the teenagers

Online Registration
arpkd2016.eventbrite.co.uk

ARPKD Family Information Day

When: Saturday, 16th July 2016 10:00 to 16:00

Where: Kingston University, Kingston Hill, Kingston upon Thames, Surrey KT2 7LB. Travel bursaries available

Organisers: The PKD Charity and ARPKD Study Group

Host: Dr Evi Goggolidou and Kingston University

Sponsored by: Sparks

pkd charity
Polycystic Kidney Disease

Run by people with PKD for people with PKD

http://www.pkdcharity.org.uk/ | info@pkdcharity.org.uk

Recruitment Update

The table below shows the current recruitment figures for each condition as of 1st May 2016 when there were 5,026 UK patients in RaDaR from 65 Renal Units.

Diagnosis	Rare Disease Group	Number of recruits
Adenine Phosphoribosyltransferase Deficiency (APRT-D)	APRT-D	2
Alport Syndrome/Thin Basement Membrane Nephropathy	Alport Syndrome	42
Atypical Haemolytic Uraemic Syndrome (aHUS)	aHUS	79
Autosomal Dominant Polycystic Kidney Disease (ADPKD)	ADPKD	296
Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD)	ADTKD	69
Autosomal Recessive Polycystic Kidney Disease (ARPKD)	ARPKD	76
Calciphylaxis	Calciphylaxis	11
Cystinosis	Cystinosis	56
Cystinuria	Cystinuria	169
Dent Disease/Lowe Syndrome	Dent Disease & Lowe Syndrome	29
Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)	HNF1-B	34
Hypokalaemic Alkaloses (Bartters, EAST, Gitelman and Liddle Syndromes)	Hypokalaemic Alkaloses	152
IgA Nephropathy	IgA Nephropathy	362
Membranous Nephropathy	Membranous Nephropathy	705
Membranoproliferative Glomerulonephritis (MPGN) / Dense Deposit Disease (DDD) / C3 Glomerulopathy	MPGN/DDD/ C3 Glomerulopathy	413
Pregnancy and Chronic Kidney Disease	Pregnancy & Chronic Kidney Disease	114
Primary Hyperoxaluria	Hyperoxaluria	53
Pure Red Call Aplasia	Pure Red Call Aplasia	1
Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)	Stec HUS	52
Nephrotic Syndrome (Steroid Sensitive and Steroid Responsive)	Idiopathic Nephrotic Syndrome	991
Retroperitoneal Fibrosis	Retroperitoneal Fibrosis	Newly opened
Vasculitis	Vasculitis	1126

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

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