RaDaR Newsletter

RareRenal
Information on rare kidney diseases

Issue Thirteen, Spring 2018

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 hospitals, both adult and paediatric.

RaDaR Portfolio Extension and Consent Document Update

We are delighted to announce that the **NIHR portfolio support** for RaDaR has been renewed for the 2018 - 2019 financial year, thanks to the generous support of **Kidney Research UK**. This provides accrual support for RaDaR up to **31/03/2019**.

In the 2017 - 2018 financial year, over 6,000 patients were recruited to RaDaR, taking us up to over 17,500 UK patients. We are well on track to reach our target of **25,000 recruits** by the current study end date of **December 2019**.

Recruitment Update

Top Recruiting Adult Sites	Recruits
London Guys	968
London Royal Free	782
Lister Hospital, Stevenage	625
Nottingham City Hospital	619
Glasgow Queen Elizabeth	583

Top Recruiting Paediatric Sites	Recruits
Birmingham	392
Manchester	213
Nottingham	171
Leeds	169
Southampton	150

Consent Document Update

In has now been six months since the latest amendment for RaDaR was approved in October 2017. **All sites should now be using the new consent documents.** The option of selecting the old documents has now been removed from the Consent pages on RaDaR so the new documents (all those dated 20.09.2017) must be used for all new patient consents.

We hope to have news on plans to re-consent existing patients shortly and will let you know when these have been finalised.

RaDaR is generously supported by:

Kidney Care UK · Kidney Research UK · NHS England · pkd charity · The Renal Association founded 1950 · Renal Association UK Renal Registry

100,000 Genome Project and RaDaR

Several of the RaDaR conditions are also eligible for inclusion in the **100,000 Genome Project**, led by Genomics England. This now includes **Familial IgA Nephropathy** and **Henoch-Schönlein Purpura (HSP).** Please consider recruiting such patients to both studies.

For more information please contact **Jonathan Barratt** at **jb81@leicester.ac.uk** or visit **www.genomicsengland.co.uk/the-100000-genomes-project**

Data Protection

You are receiving this e-mail because you have expressed an interest in the RaDaR rare disease registry, either through your work or by signing up directly via RareRenal.

If you no longer wish to receive such communications please contact **melanie.dillon@renalregistry.nhs.uk** and you will be removed from the mailing list.

Fibromuscular Dysplasia Inclusion Criteria Reminder

While the majority of RaDaR conditions are renal-specific, the **Fibromuscular Dysplasia (FMD)** cohort includes all arterial beds so patients without any current renal involvement are still eligible.

For more information please contact the FMD Rare Disease Group Lead **tina.chrysochou@srft.nhs.uk**

New Patient Information Leaflets

The **Renal Association's** Patient Information Sub-committee aims to develop and maintain a high quality patient information resource for use by kidney doctors, patients, families and carers in the UK. The work is carried out in partnership with **Kidney Care UK**

The first round of leaflets includes one on **Pregnancy and Chronic Kidney Disease**, which was written by the **Pregnancy and CKD RaDaR Rare Disease Group.**

The leaflets are available online at: **www.renal.org/information-resources/patient-leaflets**

We are looking for more authors and reviewers for this project - both patients and clinicians. If you would like to be involved please contact **melanie.dillon@renalregistry.nhs.uk**

Vacancy – Rare Disease Committee Chair

The Renal Association invites expressions of interest from its members for the position of Chair of the Rare Diseases Committee.

The chair of the **Rare Disease Committee (RDC)** has a key role in the development and delivery of the Rare Renal Disease strategy of the **Renal Association (RA).** They are responsible for all aspects of the Committee's activity as well as oversight of the 25 Rare Disease Groups (RDGs). The Chair and committee work closely with and have strategic input into the operation, management and development of the **UK Registry for Rare Kidney Diseases (RaDaR).** RaDaR is funded through capitation from each Renal Unit. The Chair will be the professional and public face of the RAs rare disease initiatives. The role of Chair of the RDC is supported by an Operations Manager, employed by the UK Renal Registry.

This is an exciting opportunity to leverage clinical service and research opportunities offered by the large cohorts of patients with rare kidney diseases already collected by RaDaR. The research opportunities could be achieved by analysis of current cohort data, 'Big data' linkage and investigator led or pharma input into projects.

Person specifications

Essential:

- Active member of the Renal Association in good standing
- An interest in rare renal diseases
- Excellent communication skills
- Leadership experience.

Desirable:

- Track record of excellence in delivering clinical services for rare renal disease
- Membership of one of the rare disease groups
- Research experience in a rare renal disease
- Experience in patient and public involvement
- Experience in rare disease education and training.

Please direct all formal expressions of interest in writing directly to the Renal Association Secretariat, via email **renal@renal.org** no later than the deadline of **Sunday 13 May 2018**. Candidates are asked to provide a maximum of a 1 side of A4 letter of application and a brief CV.

UK KIDNEY WEEK® 2018

The Renal Association and British Renal Society are delighted to be hosting a joint conference in 2018.

The conference will take place at Harrogate Convention Centre from 19-21 June and will be the biggest multi-disciplinary UK event for the renal community in 2018.

The full programme is available on the website and includes home therapies, transplantation, CKD, anaemia, renal science, career development opportunities for the MDT, patient safety and many more.

Registration for the event is now open and we hope that you will be able to join us for this exciting event.

Visit www.ukkw.org.uk for more information

UKKW
UK Kidney Week 2018

19-21 June 201

Harrogate Convention Centr

UKKW2018® is a multi-disciplinary event co-organised by

THE RENAL ASSOCIATION
founded 1950

BRS
British Renal Society
Multi-professional working

HNF1B support day

Our third national HNF1B support day is for both patients and their families

- ✓ *A chance to meet others and share experiences*
- ✓ *Talks from a panel of experts with the opportunity to ask all your questions*
- ✓ *Help develop a UK patient support network*
- ✓ *Lunch and refreshments provided*
- ✓ *Free!*

Join us Saturday 15th September 2018 at the Dorothy Hodgkin Building, Whitson Street, Bristol, BS1 3NY

REGISTRATION NOW OPEN

Please contact Coralie Bingham on: coralie·bingham@nhs·net or 01392 406366 with your name(s), address, phone number and email and we will send you further information

RaDaR

Kidney Research UK
Funding research to save lives

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st May 2018** when there were **18,061 UK patients** in RaDaR from **92 hospitals.**

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	4664
ADTKD/FUAN	√	√	145
aHUS	√		176
Alport Syndrome	√	√	611
APRT-D	√		7
ARPKD	√	√	168
Calciphylaxis	√	√	29
Cystinosis	√		123
Cystinuria	√		359
Dent Disease & Lowe Syndrome	√	√	50
Fabry Disease	√		28
Fibromuscular Dysplasia	√		18
HNF1-B	√	√	68
Stec HUS	√		125
Hyperoxaluria	√		96
Hypokalaemic Alkaloses	√	√	255
IgA Nephropathy	√	√	2451
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	833
Membranous Nephropathy	√		1580
Nephrotic Syndrome	√	√	2561
Pregnancy & Chronic Kidney Disease	√	√	450
Pure Red Call Aplasia	√		5
Retroperitoneal Fibrosis	√		91
Tuberous Sclerosis	√		87
Vasculitis	√		3140

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

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