

Issue Twelve, Winter 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.

Paediatric Patient Re-consenting

Paediatric recruits should be re-consented as adults between the ages of 16-18. **Paediatric sites** - please try to re-consent your patients before they reach 18, using the adult consent forms, and let the central RaDaR team know where they transition to. **Adult sites** - please re-consent incoming patients as adults, as well as your own recruits when they turn 16.

We will be carrying out a data check at the **end of February** and will be freezing the records of any patients **aged over 18** who were consented as children but have not yet been re-consented as adults. The records of these patients will be removed from their original paediatric site listing, as it will be assumed that they have now transitioned to adult care. Their records will be re-activated if they consent as adults.

Recruitment Update

Top Recruiting Adult Sites in 2017	Recruits
London Guys	657
Birmingham Queen Elizabeth	410
St Helier, Carshalton	389
London Royal Free	305
Derby	277

Top Recruiting Paediatric Sites in 2017	Recruits
Manchester	83
Birmingham	65
Southampton	56
Leeds	51
Glasgow	36

Top Recruiting Adult Sites Overall	Recruits
London Royal Free	773
London Guys	805
Lister Hospital, Stevenage	600
Glasgow Queen Elizabeth	582
Nottingham City Hospital	582

Top Recruiting Paediatric Sites Overall	Recruits
Birmingham	380
Manchester	170
Nottingham	168
Leeds	160
Southampton	146

RaDaR is generously supported by:



MRC Stratified Medicine News

We are pleased to announce the success of a major grant application to the **Medical Research Council**, for a project entitled: **NURTuRE – changing the landscape of renal medicine to foster a unified approach to stratified medicine**, led by Professor Moin Saleem at University of Bristol.

This £3.1 million project will use the valuable samples and clinical data collected via RaDaR in the **NURTuRE-NS (NephroS)** and **NURTuRE-CKD registry**, and generate new data and methods that will allow us to redefine the diagnostic categories of Nephrotic Syndrome and CKD. This will help to provide individualised diagnostic tests and new therapies and will be based on deep analysis of patient DNA, blood and biopsy samples provided within this study.

The four-year project is boosted by in-kind industry partner contributions and the continued involvement of **Kidney Research UK, the UK Renal Registry and RaDaR**.

Events

RaDaR are involved in a number of events over the next few months to mark both **Rare Disease Day (28th February)** and **World Kidney Day (8th March)**.

UMOD patients and relatives' information day

Saturday 3rd March 2018
11.00 – 15.00

Wellcome Collection, 183 Euston Road, London, NW1 2BE

Meet medical experts, as well as other patients and families with UMOD renal disease, to exchange thoughts and ideas.

Programme:

- Expert patient perspective
- Expert medical perspective
- Small group discussions on disease & diet management
- Discussion about future direction & research involvement

Free to attend.

Refreshments and lunch will be provided.
Travel grants are available upon request.

Register online: www.bit.ly/UMOD-patient-day-2018

Register by phone: 020 7794 0500 Ext 36596

Medical perspectives:

Prof John Sayer
Dr Shabbir Moochala
Dr Christine Gast
Ms Susana Borja Boluda
Dr Maryam Khosravi

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RARE DISEASE DAY®

28 FEBRUARY 2018

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Delivering Success - an update on pregnancy and kidney disease



This is a World Kidney Day event aimed at obstetricians, midwives, nurses, nephrologists, patients and their families. Patients' real-world experiences will be followed by presentations on recent developments on the topic.

The theme for World Kidney Day 2018 is *Kidney Disease and Women's Health* aligned with International Women's Day. The meeting is generously supported by Kidney Research UK, Kidney Care UK, the Renal Association and the Royal College of Physicians.

The aims of this meeting are to provide education for women with kidney disease (and their families) contemplating pregnancy, and to provide an update for practitioners involved in their care.

**8 March
2018**

10:30 – 11:00	Arrival and Registration	
11:00 – 11:10	Welcome and Introduction	Prof Jane Dacre President of the RCP
11:10 – 11:55	Planning Pregnancy or Not Patient perspective Preconception counselling and contraception	Patient Prof Liz Lightstone Professor of Renal Medicine
11:55 – 12:40	Chronic Kidney Disease and Pregnancy Patient perspective Management and midwifery options during pregnancy in CKD	Patient Dr Kate Bramham Consultant Nephrologist Katherine Clark Specialist Midwife
12:40 – 13:30	Lunch and discussion	
13:30 – 14:15	Pre-eclampsia and Acute Kidney Injury Patient perspective: when things escalate... Update on pre-eclampsia: diagnosis, management, outcomes	Patient Dr Matt Hall Consultant Nephrologist
14:15 – 15:00 Followed by Discussion to 15.30	Renal Transplantation and Pregnancy Patient perspective: what to expect Specific issues in pregnancy and renal transplantation	Patient Dr Nadia Sarween Renal Research Registrar

**@The Royal
College
of Physicians**
11 St Andrews
Place,
Regent's Park,
London NW1 4LE

To get a ticket please visit

<https://deliveringsuccessrenal.eventbrite.co.uk>

Tickets are **£25** for health care professionals and
FREE for patients and families

www.worldkidneyday.co.uk

World Kidney Day in the UK is led by
the Kidney Charities Together Group

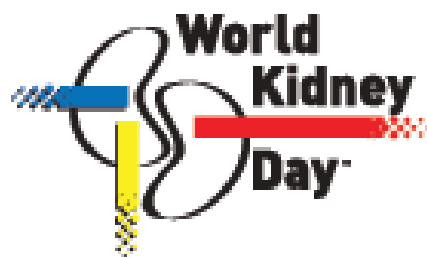
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Kidneys & Women's Health



Include, Value, Empower

8 March 2018



www.worldkidneyday.org

World Kidney Day is a joint effort of



International Society of Nephrology
International Federation of Kidney Foundations

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Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st January 2018** when there were **16,374 UK patients** in RaDaR from **90 hospitals**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	4096
ADTKD/FUAN	√	√	124
aHUS	√		166
Alport Syndrome	√	√	562
APRT-D	√		7
ARPKD	√	√	163
Calciphylaxis	√	√	27
Cystinosis	√		116
Cystinuria	√		351
Dent Disease & Lowe Syndrome	√	√	47
Fabry Disease	√		27
Fibromuscular Dysplasia	√		15
HNF1-B	√	√	64
Stec HUS	√		114
Hyperoxaluria	√		95
Hypokalaemic Alkaloses	√	√	245
IgA Nephropathy	√	√	2156
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	786
Membranous Nephropathy	√		1489
Nephrotic Syndrome	√	√	2335
Pregnancy & Chronic Kidney Disease	√	√	386
Pure Red Cell Aplasia	√		5
Retroperitoneal Fibrosis	√		81
Tuberous Sclerosis	√		82
Vasculitis	√		2917

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

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