

Issue Fourteen, Summer 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.

GDPR Update

To ensure that RaDaR is compliant with the new **General Data Protection Regulations**, which came into force on May 25th 2018, a Privacy Statement is currently being finalised which will be held on RareRenal and linked to on RaDaR.

This will detail what data is collected from patients and how it stored, linked and accessed. The document will be circulated once it has been signed off by the UK Renal Registry's Information Governance team.

Recruitment Update

Top Recruiting Adult Sites	Recruits
London Guys	1037
London Royal Free	791
Nottingham City Hospital	661
Oxford Churchill	645
Lister Hospital, Stevenage	640

Top Recruiting Paediatric Sites	Recruits
Birmingham	410
Manchester	233
Leeds	182
Nottingham	171
Southampton	156

Patient View Linkage

If you have **Patient View** at your site you must get the patient added to PV and enable PV extraction on their renal system record to ensure that the data flows into RaDaR.

If you have any questions about this please contact:  
[Fiona.Braddon@nhs.net](mailto:Fiona.Braddon@nhs.net)

Patient Transition

Paediatric sites - please tell the adult hospital that the patient is moving to that they have been recruited to RaDaR so that they can be re-consented as an adult. If you do not know where are moving to please let the central RaDaR team know so we can investigate.

RaDaR is generously supported by:



## New Rare Disease Committee Chair

We are pleased to announce that **Dr Danny Gale**, Senior Clinical Research Fellow, UCL Centre for Nephrology, has taken over from Dr Detlef Bockenhauer as the Chair for the Renal Association's Rare Disease Committee and the lead for RaDaR. **Dr Kate Bramham**, Consultant Nephrologist, Kings College London, has taken on the new role of Deputy Chair. We would like to thank Detlef for all his hard work with RaDaR over the past four years and welcome Danny and Kate to their new roles.

## New RaDaR Cohort – MGRS

RaDaR is now open to a new Cohort of patients – **Monoclonal Gammopathy of Renal Significance (MGRS)** – which covers the following conditions:

- AH amyloidosis
- AHL amyloidosis
- AL amyloidosis
- C3 glomerulonephritis with monoclonal gammopathy
- Crystalglobulinaemia
- Crystal-storing histiocytosis
- Fibrillary Glomerulonephritis
- Immunotactoid/Glomerulonephritis with Organised Microtubular Monoclonal Immunoglobulin Deposits (GOMMID)
- Intracapillary monoclonal IgM without cryoglobulin
- Intraglomerular/capillary lymphoma/leukaemia
- Light chain cast nephropathy
- Light chain proximal tubulopathy, crystalline
- Light chain proximal tubulopathy, non crystalline
- Monoclonal Immunoglobulin Deposition Disease (MIDD; includes Light Chain Deposition Disease – LCDD; Heavy Chain Deposition Disease – HCDD; and Light and Heavy Chain Deposition Disease – LHCD)
- Proliferative glomerulonephritis with monoclonal immunoglobulin deposits – PGNMID
- Thrombotic Microangiopathy with monoclonal gammopathy
- Type 1 cryoglobulinaemic Glomerulonephritis
- Unclassified MGRS

**No new approvals are needed to start recruiting these patients.**

A Crib Sheet of details of the conditions that are included in the MGRS cohort is available to download from <https://tinyurl.com/mgrs-crib-sheet> or from request via [Melanie.Dillon@renalregistry.nhs.uk](mailto:Melanie.Dillon@renalregistry.nhs.uk)

# ADPKD Patient Information & Support Day

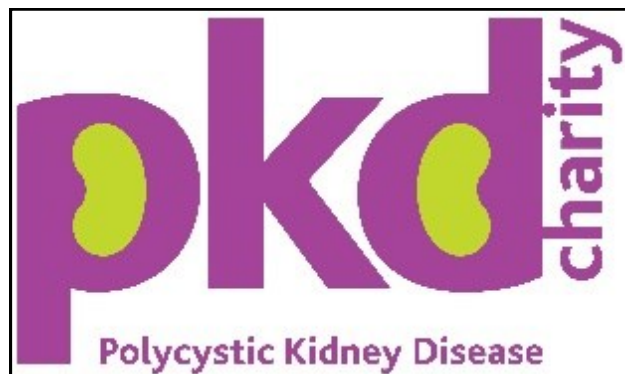
**Place:** Frank Lee Centre Hexagon, Addenbrooke's Hospital,  
Cambridge, CB2 0SN

**Time:** Saturday 15th September 2018, 9.30am to 4pm

**Hosted by:** Professor Fiona Karet and the PKD Charity

## Talks and Workshops on:

- The Basics of ADPKD
- Genetics and Screening
- Diet and Lifestyle
- Research
- Transplants
- New therapies
- Pain



## Registration Information

Online registration [adpkdseptember2018.eventbrite.co.uk](http://adpkdseptember2018.eventbrite.co.uk)

Or contact Esther Wright at [info@pkdcharity.org.uk](mailto:info@pkdcharity.org.uk)

There is no charge to attend but a donation is always welcome.

Refreshments and lunch included.

# **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 15<sup>th</sup> September 2018** at the  
Dorothy Hodgkin Building, Whitson Street,  
Bristol, BS1 3NY*

**REGISTRATION NOW OPEN**

*Please contact Coralie Bingham on: [coralie.bingham@nhs.net](mailto:coralie.bingham@nhs.net) or 01392 406366*

*with your name(s), address, phone number and email and we will send you  
further information*

## Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1<sup>st</sup> August 2018** when there were **19,173 UK patients** in RaDaR from **93 hospitals**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	5023
ADTKD/FUAN	√	√	156
aHUS	√		189
Alport Syndrome	√	√	652
APRT-D	√		7
ARPKD	√	√	173
Calciophylaxis	√	√	30
Cystinosis	√		124
Cystinuria	√		365
Dent Disease & Lowe Syndrome	√	√	51
Fabry Disease	√		34
Fibromuscular Dysplasia	√		19
HNF1-B	√	√	68
Stec HUS	√		134
Hyperoxaluria	√		98
Hypokalaemic Alkaloses	√	√	261
IgA Nephropathy	√	√	2647
MGRS	√	√	2
MPGN, DDD and C3 Glomerulopathy	√	√	871
Membranous Nephropathy	√		1651
Nephrotic Syndrome	√	√	2739
Pregnancy & Chronic Kidney Disease	√	√	476
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		93
Tuberous Sclerosis	√		112
Vasculitis	√		3302

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

**Melanie Dillon** - [Melanie.Dillon@renalregistry.nhs.uk](mailto:Melanie.Dillon@renalregistry.nhs.uk)