

**Issue Three, Autumn 2015**

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 Re-Launch**

RaDaR has seen a huge surge in recruitment over the last year. To ensure that it remains fit for purpose, with room for further expansion and development, the UK Renal Registry have decided to build a new version of RaDaR in-house.

**RaDaR 2** will be re-launched on **Monday 18th January 2016** but please continue to recruit patients as normal in the meantime. We will let you know when we need to freeze recruitment in order to transfer the data.

Key features of RaDaR 2 will include:

- Access to all data fields currently available on Patient View. These will be populated automatically for sites with PV and can be filled in manually for those without.
- The ability to search for patients by unit, patient ID, condition etc.
- Patients being able to belong to more than one diagnosis e.g. Pregnancy and Alports.
- Graphical representations of the various lab results, recruits per conditions/renal unit etc.

Further communication will follow towards the end of the year but if you have any questions about RaDaR 2 or would like to see a demo version of the new system please e-mail [Melanie.Dillon@renalregistry.nhs.uk](mailto:Melanie.Dillon@renalregistry.nhs.uk)

**Cystinuria Patient Information Day**

The third Cystinuria Patient Day will be held on **Saturday 5th March 2016** at **Freeman Hospital, Newcastle**.

For further details and to register to attend please visit [bit.ly/Cystinuria 2016](http://bit.ly/Cystinuria2016).

**New conditions**

RaDaR has recently opened to two new conditions: **Calciophylaxis** and **IgA Nephropathy**.

In January 2016 we will open for **ADPKD** patients.

For further information on all eligible conditions please visit [rarerenal.org](http://rarerenal.org) or e-mail:

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

**Top Recruiters**

56 UK Renal Units are currently recruiting to RaDaR. The table below shows the top five recruiting sites as of November 2015.

Centre	Recruits
Stoke University Hospital North Midlands	257
Birmingham Children's Hospital	228
Nottingham University Hospital	225
Stevenage, Lister Hospital	179
London Royal Free	139

RaDaR is generously supported by:



## Rare Disease Group Updates

Please share the following pages with any relevant patients in your unit.

# Membranous Nephropathy RaDaR Patient Forum

## Calling all patients registered with Membranous Nephropathy (MN) on RaDaR

Thank you for registering with RaDaR. If you have registered with the MN RaDaR project, it is likely that you are interested in understanding more about the condition and helping researchers to develop a better understanding of the disease in order to bring about more effective treatments.

If you want to help further, you can do so by joining up with fellow MN patients to form a **National MN Patient Forum** as part of the MN RaDaR Rare Disease Group. Other national RaDaR patient groups have been formed in the last couple of years and we would like to encourage MN patients to do the same.

The MN RaDaR Rare Disease Group will sponsor a national meeting in the New Year (date to be arranged for February or March 2016). Depending on how many people want to attend and where they are based, we will hold the meeting either in London, Peterborough or Manchester to keep travel to a minimum.

For those people attending the meeting, we will reimburse all travel expenses so that you will not be out of pocket.

Items on the agenda will include:

- New breakthroughs in research
- Developing new treatments
- How patients can help shape and design new research proposals
- Getting the most out of RaDaR
- Patients helping patients - share your experience

If you are interested in knowing more about this new initiative please contact:

**Professor Paul Brenchley**, Chair MN RaDaR Rare Disease Group:  
[paul.brenchley@manchester.ac.uk](mailto:paul.brenchley@manchester.ac.uk)

**Dr Jean Winterbottom**, National Renal Research Nurse:  
[jean.winterbottom@cmft.nhs.uk](mailto:jean.winterbottom@cmft.nhs.uk)

# **HNF1B support day**

*OUR SECOND 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!*
- ✓ *Travel bursaries available if your journey costs more than £30 (with receipts)*

*Join us Saturday 27<sup>th</sup> February 2016 at the  
Nowgen Centre, 29 Grafton Street, Manchester  
([www.nowgen.org.uk](http://www.nowgen.org.uk))*

**REGISTRATION NOW OPEN**

*Please contact Rhian Clissold or Coralie Bingham on: [rhian-clissold@nhs.net](mailto:rhian-clissold@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 current recruitment figures for each condition as of 1st November 2015 when there were 3,295 UK patients in RaDaR from 56 Renal Units.

Diagnosis	Rare Disease Group	Number of recruits
<b>Adenine Phosphoribosyltransferase Deficiency (APRT-D)</b>	APRT-D	2
<b>Alport Syndrome/Thin Basement Membrane Nephropathy</b>	Alport Syndrome	200
<b>Atypical Haemolytic Uraemic Syndrome (aHUS)</b>	aHUS	55
<b>Autosomal Recessive Polycystic Kidney Disease (ARPKD)</b>	ARPKD	59
<b>Calciophylaxis</b>	Calciophylaxis	0
<b>Cystinosis</b>	Cystinosis	48
<b>Cystinuria</b>	Cystinuria	155
<b>Dent Disease/Lowe Syndrome</b>	Dent Disease & Lowe Syndrome	23
<b>Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)</b>	HNF1-B	31
<b>Hyperuricaemic Nephropathy/Medullary Cystic Kidney Disease</b>	Familial Uromodulin Associated Nephropathy	60
<b>Hypokalaemic Alkaloses (Bartters, EAST, Gitelman and Liddle Syndromes)</b>	Hypokalaemic Alkaloses	114
<b>IgA Nephropathy</b>	IgA Nephropathy	16
<b>Membranous Nephropathy</b>	Membranous Nephropathy	524
<b>Membranoproliferative Glomerulonephritis (MPGN) / Dense Deposit Disease (DDD) / C3 Glomerulopathy</b>	MPGN/DDD/ C3 Glomerulopathy	359
<b>Pregnancy and Chronic Kidney Disease</b>	Pregnancy & Chronic Kidney Disease	31
<b>Primary Hyperoxaluria</b>	Hyperoxaluria	49
<b>Pure Red Cell Aplasia</b>	Pure Red Cell Aplasia	0
<b>Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)</b>	HUS	47
<b>Nephrotic Syndrome (Steroid Sensitive and Steroid Responsive)</b>	NephroS	604
<b>Vasculitis</b>	Vasculitis	917

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)