

**Issue Four, Winter 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 Re-Launch**

The RaDaR rare disease registry has now been fully re-launched and can be accessed via NHS computers at <https://nww.radar.nhs.uk>. Your login details will remain the same.

If you are having problems accessing the new site please e-mail [nbn-tr.radar@nhs.net](mailto:nbn-tr.radar@nhs.net)

Key features of the new version of RaDaR include:

- Access to all data fields currently available on Patient View. These will be populated automatically - initially via PV and eventually direct from the renal IT systems.
- 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.

Details of how to enter patients in the new system can be found at <http://bit.ly/RaDaRRecruitGuide>

If you have any questions about RaDaR please e-mail [Melanie.Dillon@renalregistry.nhs.uk](mailto:Melanie.Dillon@renalregistry.nhs.uk)

**New Logo**

The RaDaR logo has been re-designed for the launch of the new website. Please contact [Melanie.Dillon@renalregistry.nhs.uk](mailto:Melanie.Dillon@renalregistry.nhs.uk) if you would like to use the logo for any promotional material for your renal unit or Rare Disease Group.

**RaDaR's Portfolio Status**

Following discussion at the latest Operational Management Board Meeting, it was decided to keep RaDaR on the NIHR Portfolio under the child speciality, co-adopted by renal.

If this is likely to cause a problem for your renal unit in terms of funding allocation we suggest you speak to your R&D department or LCRN.

RaDaR is generously supported by:



**ADPKD Recruitment**

RaDaR is now open to **Autosomal Dominant Polycystic Kidney Disease (ADPKD)** patients. No additional approvals are needed to recruit these 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**

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

| Centre                                   | Recruits |
|--|----------|
| Stoke University Hospital North Midlands | 268      |
| Nottingham University Hospital           | 255      |
| Birmingham Children's Hospital           | 235      |
| Stevenage, Lister Hospital               | 186      |
| Preston                                  | 171      |

## Rare Disease Day

**Rare Disease Day 2016** will take place on **Monday 29th February**. The main objective is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives.

The campaign primarily targets the general public and also seeks to raise awareness amongst policy makers, public authorities, industry representatives, researchers, health professionals and anyone who has a genuine interest in rare diseases.

Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, thousands of events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage.

The political momentum resulting from Rare Disease Day also serves advocacy purposes. It has notably contributed to the advancement of national plans and policies for rare diseases in a number of countries.

The theme for the 2016 event is **Patient Voice**, recognising the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers.

Further details of the day and a list of worldwide events can be found at [www.rarediseaseday.org](http://www.rarediseaseday.org)



## Cystinuria Patient Information Day

A **Cystinuria Patient Information Day** will be held at the **Institute of Transplantation, Freeman Hospital, Newcastle, NE& 7DN** on **Saturday 5th March 2016** from 9.30am to 4pm.

The event is free to attend and is open to patients, families and friends of those affected by Cystinuria. For further details and to register to attend please visit <http://bit.ly/CystinuriaInfoDay2016>

## Nephrotic Syndrome Patient Information Day

A **Nephrotic Syndrome Patient Information Day** will be held at **Royal Manchester Children's Hospital, Oxford Road, Manchester, M13 9WL** on **Wednesday 16<sup>th</sup> March 2016** from 1pm to 5pm. The event is open to patients, families and friends of those affected by Nephrotic Syndrome.

The day will be a chance to:

- Learn more about Nephrotic Syndrome and the latest research
- Put your questions to the medical experts
- Share your experiences with others

The event is free to attend and lunch and refreshments will be provided. For further information and to register please visit <http://bit.ly/NephSynInfoDay2016>

# **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*

# National MN Patient Forum



Are you a patient with  
Membranous Nephropathy  
(MN)?

Would you like to get  
involved in shaping  
research?

Then come and join us!

Saturday 19th March 2016  
11am - 3.30pm

NOWGEN Centre  
29 Grafton Street  
Manchester  
M13 9WU

**BOOKING\*** (please book before Friday 4th March 2016)

Online - please book via this link <https://mnforum.eventbrite.co.uk>

By Post -

Download a Booking Form <http://kidneysforlife.org/news-events/conferences/>

Request a copy by email or telephone

Email [jean.winterbottom@cmft.nhs.uk](mailto:jean.winterbottom@cmft.nhs.uk) / [irene.chambers@kidneysforlife.org](mailto:irene.chambers@kidneysforlife.org)

Tel: 0161 276 7986 (Jean) or 0161 276 6671 (Irene)

Travel Expenses - will be refunded and forms will be available for completion and reimbursement on the day if possible



Get  
involved



10th  
March  
2016



World Kidney Day  
Is a joint initiative of:



Help us unite with one powerful voice for **World Kidney Day 2016** by organising an activity or event to draw public attention to the importance of kidney health, what can be done to protect kidneys before disease strikes, and to assist patients who already have chronic kidney disease. This year there is also a particular focus on kidney disease in children.

**APPLY NOW FOR YOUR SUPPORT PACK** via [info@worldkidneyday.co.uk](mailto:info@worldkidneyday.co.uk)

To help with your event, the **Kidney Charities Together** team have produced a **Support Pack** containing:

- 2 A4 kidney health awareness **posters**
- A number of double-sided A5 kidney health awareness **flyers** (please confirm how many you need)
- World Kidney Day logo **stickers** (in sheets of 48 per A4 page – please confirm how many sheets)
- A poster to help **advertise your event** (an electronic version is available on the website to customise and print out yourself)
- 2 '**How to Guides**' – *A guide to working with the media* and *A guide to using social media* to help get the press interested and also spread the message far and wide
- A sample **press release** to try and get local media along to your event or to cover something about it in the local paper, on the radio or even, TV (an electronic version on the website which you can customise and use)

Further details on getting involved are available on the UK website [www.worldkidneyday.co.uk](http://www.worldkidneyday.co.uk) along with more hints, tips and ideas for activities and additional downloadable resources.

We would love to hear about what you have planned, so please let us know by emailing [info@worldkidneyday.co.uk](mailto:info@worldkidneyday.co.uk), or posting on the **World Kidney Day UK Facebook** page ([www.facebook.com/worldkidneydayuk](http://www.facebook.com/worldkidneydayuk)).

If you use **Twitter**, follow [@kidneydayUK](https://twitter.com/kidneydayUK) and use [#worldkidneyday](https://twitter.com/worldkidneyday).

Look out for our series of **kidney facts** which we will be releasing through our Facebook page and Twitter feeds in the 7 days leading up to 10<sup>th</sup> March. Please share and 're-tweet' as widely as possible.

We very much hope you will be happy to join in with this exciting annual campaign.

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

BRITISH KIDNEY  
Patient ASSOCIATION  
*improving life for kidney patients*

Kidney Research UK

Kids Kidney Research

nkf  
SUPPORTING KIDNEY PATIENTS

pkd  
charity  
Polycystic Kidney Disease

Contact us

[info@worldkidneyday.co.uk](mailto:info@worldkidneyday.co.uk) • [www.worldkidneyday.co.uk](http://www.worldkidneyday.co.uk)



[@kidneydayUK](https://twitter.com/kidneydayUK) and use [#worldkidneyday](https://twitter.com/worldkidneyday)



[www.facebook.com/worldkidneydayuk](http://www.facebook.com/worldkidneydayuk)

## Recruitment Update

The table below shows the current recruitment figures for each condition as of 1st February 2016 when there were 3,913 UK patients in RaDaR from 64 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                            | 217                |
| <b>Atypical Haemolytic Uraemic Syndrome (aHUS)</b>   | aHUS                                       | 65                 |
| <b>Autosomal Dominant Polycystic Kidney Disease (ADPKD)</b>  | ADPKD                                      | Newly opened       |
| <b>Autosomal Recessive Polycystic Kidney Disease (ARPKD)</b>   | ARPKD                                      | 65                 |
| <b>Calciphylaxis</b>   | Calciphylaxis                              | 7                  |
| <b>Cystinosis</b>  | Cystinosis                                 | 52                 |
| <b>Cystinuria</b>  | Cystinuria                                 | 163                |
| <b>Dent Disease/Lowe Syndrome</b>  | Dent Disease & Lowe Syndrome               | 27                 |
| <b>Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)</b>  | HNF1-B                                     | 33                 |
| <b>Hyperuricaemic Nephropathy/Medullary Cystic Kidney Disease</b>  | Familial Uromodulin Associated Nephropathy | 67                 |
| <b>Hypokalaemic Alkaloses (Bartters, EAST, Gitelman and Liddle Syndromes)</b>                            | Hypokalaemic Alkaloses                     | 134                |
| <b>IgA Nephropathy</b>   | IgA Nephropathy                            | 195                |
| <b>Membranous Nephropathy</b>  | Membranous Nephropathy                     | 612                |
| <b>Membranoproliferative Glomerulonephritis (MPGN) / Dense Deposit Disease (DDD) / C3 Glomerulopathy</b> | MPGN/DDD/ C3 Glomerulopathy                | 392                |
| <b>Pregnancy and Chronic Kidney Disease</b>  | Pregnancy & Chronic Kidney Disease         | 94                 |
| <b>Primary Hyperoxaluria</b>   | Hyperoxaluria                              | 52                 |
| <b>Pure Red Cell Aplasia</b>   | Pure Red Cell Aplasia                      | 0                  |
| <b>Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)</b>  | Stec HUS                                   | 49                 |
| <b>Nephrotic Syndrome (Steroid Sensitive and Steroid Responsive)</b>                                     | Idiopathic Nephrotic Syndrome              | 732                |
| <b>Vasculitis</b>  | Vasculitis                                 | 954                |

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)