

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.

RareRenal re-design

Following a lengthy consultation process with kidney charities, social media experts and patient representatives, the patient and clinician information website **RareRenal.org**, which supports the RaDaR rare disease registry, has been re-designed to allow for a cleaner navigation and more intuitive user journey. This includes a new logo, more prominent social media links and the option for patients as well as clinicians to sign up for this Newsletter advertising information events and further research studies.

We would welcome feedback on the new design via www.rarerenal.org/contact

**The must attend meeting for
the UK's nephrology experts**

The event is taking place from
19 June – 21 June 2017
at the ACC, Liverpool.



Cystinosis Education Day

A **Cystinosis Patient and Clinician Education Day** will be held on **Tuesday 19th September** from **9.30 – 16.30** at the **Postgraduate Centre, Queen Elizabeth Hospital, Birmingham**. Further details will be available nearer the time but to express an interest in taking part as a speaker please contact:

Michelle.Lowe@uhb.nhs.uk

Top Recruiting Adult Sites	Recruits
London Royal Free	721
Glasgow Queen Elizabeth	549
Lister Hospital, Stevenage	508
Nottingham City Hospital	489
Newcastle Royal Victoria	373

Top Recruiting Paediatric Sites	Recruits
Birmingham	346
Nottingham	167
Leeds	140
London Great Ormond Street	122
Manchester	100

RaDaR is generously supported by:



The National Institute for Health Research (NIHR), want to help people make informed choices about taking part in **clinical trials** and other **research studies**.

They have therefore set up the **UK Clinical Trials Gateway (UKCTG)**. This service helps give people the confidence to join clinical trials by providing useful information about how trials work. It also links potential participants to the researchers running the trials that they might be interested in.

You can find out more information and search for trials that you may be interested in joining at:

www.ukctg.nihr.ac.uk

New Sites

RaDaR is now open in **82 hospitals** across the UK.

The latest sites to start recruiting are:

- Altnagelvin Hospital, Derry
- Belfast Ulster
- Kings Lynn
- Stockport



A full list of currently recruiting sites is available at:
www.rarerenal.org/radar-registry/renal-units

Coming Soon

A further four sites are currently in set-up. They will be open to recruitment shortly.

- Dartford
- Dumfries & Galloway
- Huddesfield
- Peterborough



We are still open to new sites. If you would like to take part please contact:

Melanie.Dillon@renalregistry.nhs.uk



DRINK Study

Cambridge Clinical Trials Unit are looking to recruit patients with **Autosomal Dominant Polycystic Kidney Disease (ADPKD)** to take part in a research study looking at water intake.



The DRINK Study will randomly assign participants to either a daily prescription of high water intake or to continue with their usual drinking practices.

The aim is to determine whether it is possible and safe for people to drink enough water to stop **vasopressin**, one of the key hormones that drives cyst growth in PKD. The study also wants to see if participants can measure their own fluid balance, using a simple urine stick test that can be done at home.

If successful, the study will help researchers to design a larger trial to look at **whether high water intake can affect long term kidney function**.

The researchers also want to include families in the study. If you are interested or have any family members who would like to take part, please contact the study team as below for more information:

Telephone: **01223 349 844**

E-mail: add-tr.drinktrial@nhs.net

You are invited to the
Marvellous Superstar Summer Party
for children, young people & families affected
by rare & undiagnosed conditions

Saturday 22nd July 2017

10 am to 3pm

at Uffculme Centre *



RSVP

Please confirm number & ages of those attending, any dietary requirements by **Friday 14th July** by calling **0121 333 9227** or emailing Kerys.Grainger@bch.nhs.uk

**RARE
REVOLUTION
KIDS!**

Zoo2U®



**Join us for exciting
new & usual fun!**



Birmingham Children's
Hospital Charity's
STARAPPEAL
Lighting the way for children
with rare diseases

*Queensbridge Rd, Moseley, B'ham B13 8QY (disabled access & free parking)

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st May 2017**, when there were **11,891** UK patients in RaDaR from **82** hospitals.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	2513
ADTKD/FUAN	√	√	104
aHUS	√		130
Alport Syndrome	√	√	438
APRT-D	√		6
ARPKD	√	√	133
Calciphylaxis	√	In progress	21
Cystinosis	√		105
Cystinuria	√		303
Dent Disease & Lowe Syndrome	√	In progress	46
Fabry Disease	√		11
Fibromuscular Dysplasia	√		9
HNF1-B	√	√	44
Stec HUS	√		88
Hyperoxaluria	√		78
Hypokalaemic Alkaloses	√	√	209
IgA Nephropathy	√	In progress	1454
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	620
Membranous Nephropathy	√		1237
Nephrotic Syndrome	√	√	1912
Pregnancy & Chronic Kidney Disease	√	√	279
Pure Red Cell Aplasia	√		2
Retroperitoneal Fibrosis	√		58
Tuberous Sclerosis	√		49
Vasculitis	√		2077

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

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