RaDaR Newsletter

RareRenal.org
Information on rare kidney diseases

Issue Seven, Autumn 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.

Wall of Fame!

We greatly appreciate all the hard work and support that every member of the research teams at our 73 participating hospitals puts into making RaDaR a success. We would like to take this opportunity to express particular thanks to the following individuals for their promotion of RaDaR:

- **Dr Cath Byrne**, Consultant Nephrologist at Nottingham University Hospitals NHS Trust, who has personally recruited over 100 patients to RaDaR.
- **Hayley King & Faye McMeeken**, Senior Research Nurses at Glasgow Clinical Research Facility, who presented a poster on being a nurse PI for RaDaR at NHS Research Scotland's Annual Conference.
- **Maria Kokocinska**, Rare Diseases Research Coordinator at Birmingham Children's Hospital, who presented posters on RaDaR and the ARPKD Rare Disease Group at the IPNA Congress in Brazil.

Data Entry Instructions

Detailed condition specific data entry instructions for RaDaR are now available.

These can be found under the green cohort tab once a patient has been registered.

The full list of instructions is also available at **bit.ly/RaDaR-Instructions**

Recruitment Target Increase

The 7,500th patient was recruited to RaDaR in September which is an amazing achievement.

In order to reflect the recent surge in recruitment, we intend to increase our overall NIHR recruitment target from 10,000 to 25,000 patients.

Retroperitoneal Fibrosis Patient Study

The Retroperitoneal Fibrosis Rare Disease Group have set up a patient focused online study to understand the un-met medical needs of patients with this condition.

The survey is open until 31 March 2017 and can be accessed via **bit.ly/RPF-Survey.** All entries are anonymous.

Top Recruiters

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

Centre	Recruits
Lister Hospital, Stevenage	422
Glasgow Queen Elizabeth	420
Nottingham City Hospital	412
London Royal Free	326
Royal Stoke University Hospital	312

RaDaR is generously supported by:

RaDaR opens to two new conditions

RaDaR has recently opened to two new conditions - **Fibromuscular Dysplasia** and **Fabry Disease.**

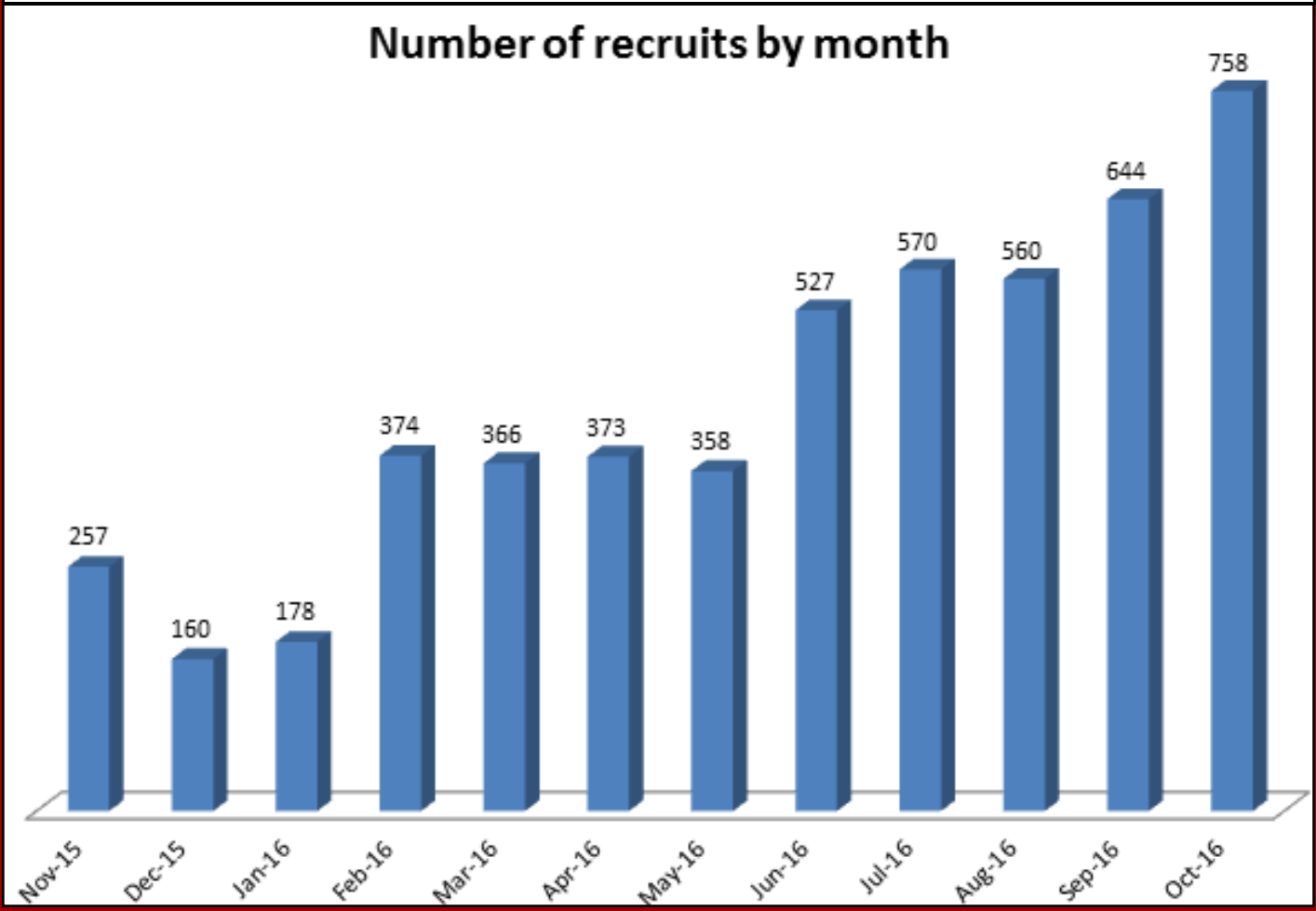
No additional approvals are needed to recruit these patients.

For further information on all eligible conditions please visit **rarerenal.org** or e-mail:

Melanie.Dillon@renalregistry.nhs.uk

Recruitment Boost

Recruitment to RaDaR has once again seen a massive increase over the last quarter, with over 750 patients being recruited in October 2016, making it our best recruiting month by far.



RaDaR Patient Leaflet and Slide Set

A new patient-focused leaflet is now available to advertise RaDaR to patients and family members. The leaflet lists the conditions currently eligible for inclusion and explains the benefits for both patients and clinicians in joining RaDaR.

The leaflet can be downloaded from **bit.ly/Radar-Patient-Leaflet-2016**

Printed copies of the leaflet and other promotional material for RaDaR, including a customisable slide-set, are available on request from **Melanie.Dillon@renalregistry.nhs.uk**

Please contact us for the latest recruitment figures and statistics if you would like to do a presentation or poster on RaDaR and we would be happy to help.

Please pass this information on to any interested patients in your renal unit.

Oxalosis & Hyperoxaluria Foundation
STEPPING STONES TO A CURE

Birmingham Children's Hospital NHS
NHS Foundation Trust

PRIMARY HYPEROXALURIA UK PATIENT DAY
SATURDAY 28TH JANUARY 2017 10.30am -3.30pm
EDUCATION CENTRE, BIRMINGHAM CHILDREN'S HOSPITAL

Welcome
Dr Sally Hulton
Consultant Paediatric Nephrologist, Birmingham Children's Hospital

Welcome from the OHF
Kim Hollander,
Executive Director, OHF

The history of Primary Hyperoxaluria (PH) and understanding how it occurs
Professor Christopher Danpure,
Emeritus Professor of Molecular Cell Biology, University College London

Genes and Primary Hyperoxaluria: understanding the different types and the tests that help make a diagnosis
Dr Gill Rumsby
Consultant Biochemist & Clinical Lead, HSL Analytics LLP, University College London

Managing Primary Hyperoxaluria with medicines
Dr Sally Hulton

Understanding dialysis
Senior Dialysis Sister
Birmingham Children's Hospital

Managing stones with operations – new developments
Urology Department
Birmingham Children's Hospital

Managing Primary Hyperoxaluria with transplants of the liver and kidney – understanding the operation
Dr K Sharif
Consultant Transplant Surgeon, Birmingham Children's Hospital

Long term with Primary Hyperoxaluria: future with transplants and new ideas
Dr G Lipkin
Consultant Nephrologist, University Hospital Birmingham

Understanding research studies and what they mean for the future
Dr Sally Hulton and Kim Hollander

Registration on the OHF website or: https://www.flipcause.com/secure/cause_pdetails/OTIxMQ

Please pass this information on to any interested patients in your renal unit.

Calling all those with Gitelman or Bartter Syndromes and their families....

The third national Gitelman and Bartter Syndromes Support Day will be on

Saturday Dec 3rd 2016

- **a chance to meet others and share experiences**
- **your questions answered**
- **panel of experts**
- **discussion groups**
- **lunch and refreshments**

FREE!

Venue: Resource for London,
356 Holloway Road, London N7 6PA

Time: 10.30 a.m. - 4.00 p.m.

Reasonable travel costs can be reimbursed.*

*Limited to the price of an advanced off-peak train ticket. See Eventbrite for full details.

Registration opens on October 12th. Book on EVENTBRITE

https://www.eventbrite.co.uk/e/gitelman-and-bartter-syndromes-support-day-tickets-28329952651

Any queries? Please contact Kathryn Irons by email ki260@medschl.cam.ac.uk or telephone 01223-254605

Full programme to follow in November at:
www.gitelmansyndrome.co.uk & www.rarerenal.org

Supported by

NHS National Institute for Health Research

Please pass this information on to any interested patients in your renal unit.

Cambridge Clinical Trials Unit

The DRINK study is looking to recruit patients with polycystic kidney disease (known as ADPKD or PKD) to take part in a research study to determine how much water to drink. Participants will be randomly assigned to either a daily prescription of high water intake or to continue with their usual drinking practices.

The aims of the study are:

1. To determine whether it is possible and safe for people to drink an amount of water large enough to stop the body making a hormone called vasopressin.
2. To see whether participants can effectively use a home urine test to measure whether or not they have had the right amount to drink

This study will give us the information we need to design a larger study to see whether drinking the right amount of water can preserve kidney function for longer.

If you are interested in taking part, please contact us:

Telephone: 01223 596471

Email: add-tr.drinktrial@nhs.net

It would be particularly helpful to us to have more than one member of the same family in the study. If you have a relative with PKD, please pass this information to them.

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of 1st November 2016, when there were 8,436 UK patients in RaDaR from 73 Renal Units.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	1410
ADTKD/FUAN	√	√	82
aHUS	√		100
Alport Syndrome	√	√	344
APRT-D	√		5
ARPKD	√	√	95
Calciphylaxis	√		17
Cystinosis	√		75
Cystinuria	√		216
Dent Disease & Lowe Syndrome	√		38
Fabry Disease	√		Newly Opened
Fibromuscular Dysplasia	√		1
HNF1-B	√	√	40
Stec HUS	√		73
Hyperoxaluria	√		62
Hypokalaemic Alkaloses	√	√	177
IgA Nephropathy	√		908
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	√	√	517
Membranous Nephropathy	√		1032
Nephrotic Syndrome	√	√	1432
Pregnancy & Chronic Kidney Disease	√	√	174
Pure Red Call Aplasia	√		2
Retroperitoneal Fibrosis	√		34
Vasculitis	√		1342

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

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