RaDaR Newsletter

RareRenal
Information on rare kidney diseases

Issue Fifteen, December 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.

2018 successes

Over the last twelve months we have:

- Recruited over 5,000 new patients to RaDaR
- Opened six new sites
- Added 19 new conditions
- Hosted a joint patient & clinician Rare Disease Day event and multiple patient information days
- Welcomed a new Rare Disease Committee Chair and Deputy Chair (Danny Gale & Kate Bramham)

Thank you for all your hard work and support.

Happy Holidays!

Recruitment Update

Top Recruiting Adult Sites	Recruits
London Guys	1151
London Royal Free	798
Oxford Churchill	713
Nottingham City Hospital	702
Lister Hospital, Stevenage	671

Top Recruiting Paediatric Sites	Recruits
Birmingham	440
Manchester	253
Leeds	183
Nottingham	175
Southampton	156

ADPKD Guidelines

A new Renal Association Clinical Practice Guideline has been published on **Monitoring children and young people with, or at risk of developing Autosomal Dominant Polycystic Kidney Disease (ADPKD)**, co-written by members of the ADPKD Rare Disease Group. www.renal.org/guidelines

RaDaR Recruitment Milestone

The 20,000th patient was recruited to RaDaR on the 4th October. The milestone recruit was a Membranous Nephropathy patient from Ninewells Hospital, Dundee. Congratulations!

20,000!

RaDaR is generously supported by:

Kidney Care UK · Kidney Research UK · NHS England · pkd charity · The Renal Association founded 1950 · Renal Association UK Renal Registry

New RaDaR condition

RaDaR is now open to a new condition – **Nephronophthisis (NPHP). No amendments or further approvals are needed to start recruiting these patients.**

These patients should be entered into the renamed **ARPKD/NPHP** cohort on RaDaR. It is vital that sites then select either **ARPKD** or **NPHP** on the **Primary Diagnosis** tab so that we know which condition these patients have. For any questions please contact **Melanie.Dillon@renalregistry.nhs.uk**

Fibromuscular Dysplasia Patient Information Day

UK and Ireland's First Patient Information Day on Fibromuscular Dysplasia (FMD) will take place on **Saturday 19th January 2019** at **Salford Royal Hospital**

Fibromuscular Dysplasia (FMD) is evolving from a rare disease of renal arteries accounting for a minority of cases of secondary hypertension in young women, to a 'systemic' vascular disease which can also affect cervico-cephalic, coronary, and iliac arteries. This patient information day will aim to explain what FMD is, challenge previous misconceptions about FMD and highlight the latest work being undertaken by registries and research.

Come and hear from expert international guest speakers such as Prof Alexandre Persu (lead for European FMD registry) and Prof David Adlam (UK expert in spontaneous coronary artery dissection (SCAD)), as well as celebrity chef and FMD/ SCAD sufferer, Sally Bee. This day will be of interest to clinicians, patients and carers alike. For further information, contact **tina.chrysochou@srft.nhs.uk**
Please note - Patients with FMD in any arterial bed can be uploaded to FMD RADAR.

NURTURE
National Unified Renal Translational Research Enterprise

NURTuRE (the National Unified Renal Translational Research Enterprise) is a unique kidney biobank for chronic kidney disease (CKD) and idiopathic nephrotic syndrome (INS), covering England, Scotland and Wales, which has the potential to unlock answers to some of the biggest questions about CKD and INS.

Biological samples (plasma, serum, urine, DNA and tissue) from 3,000 patients with CKD and over 800 patients with INS are being collected and stored under strict Standard Operating Procedures for both academic and industry research worldwide. This will lead to a greater ability to identify patients who will benefit from better, earlier diagnosis and person-specific new treatments, leading to better health outcomes.

We need patient volunteers for **NURTuRE -** no extra hospital visits… just your consent to be involved in this exciting, pioneering study.

For further information and participating sites please see **www.nurturebiobank.org/patients/**

National Cystinuria Patient Day

Saturday March 30th 2019

Robens Suite, 29th Floor Tower Wing, Guy's Hospital, London

The event is free to attend for patients and relatives but registration is essential via the **CystinuriaUK** website - **www.cystinuriauk.co.uk/patient-day**

Provisional Programme:

9.30	**Registration - water, tea, coffee, biscuits**
10.00	**Welcome** Kay Thomas, Urologist, Guy's and St. Thomas' Hospital, London
10.05	**Update on RADAR recruitment and news** Richard Coward, Nephrologist, Bristol Royal Hospital for Children
10.15	**History of cystinuria and research ideas** Matt Lewis, Director of Metabolic Profiling, Imperial College London
10.30	**Patient Stories (30mins)**
11.00	**Break – water!**
11.10	**Why do I need to see a Nephrologist?** David Goldfarb, Nephrologist, NYU
11.30	**What does the surgeon do?** Matthew Bultitude, Urologist, Guy's and St. Thomas' Hospital
11.45	**The problem with urinary cystine measurements** Shabbir Moochhala, Nephrologist, Royal Free Hospital
12.00	**Break – Water!**
12.10	**What should I eat and drink? Dietary advice for the cystine patient** Rachel Davies, Senior dietician, Guy's and St. Thomas' Hospital
12.30	**What's new and exciting in research for cystinuria?** John Sayer, Nephrologist, Newcastle
12.45	**Ask the Experts … questions and answers** All Faculty
13.00	**LUNCH**
13.45	**Updates from America** David Goldfarb, Nephrologist, NYU
14.00	**Genetics … Why do I have it and will my children get it?** Kay Thomas, Urologist, Guy's and St. Thomas' Hospital, London
14.15	**Discussion in breakout groups (all faculty to assist)** 1 Patient stories/experience/self-help **[Lead: David Game]** 2 Surgical models – try to be a stone surgeon! **[Lead: M Bultitude]** 3 Diet – preventing future stones **[Lead: Rachel Davies]**
15.45	**Summary and close.**

CystinuriaUK

Do you have Atypical Haemolytic Uraemic Syndrome?

If so, you can help us to improve experiences of care received by patients living with aHUS.

How can you help?

Picker is a healthcare research organisation. We're developing a new survey to understand the experiences of those living with aHUS for the National Renal Complement Therapeutics Centre. We need some help to understand what is important to patients regarding their experiences of the care that they receive.

This would involve an informal, one to one chat of about 30 minutes, over the telephone at a time that suits you in November 2018

As a thank you for your time you will be given a £20 'love to shop' or Amazon voucher.

Note: Research is still open in December 2018.

Picker

To find out more or to volunteer, please email take_part@pickereurope.ac.uk or call our freephone 0800 1975273.
Picker is a not-for-profit health and social care research organisation working with the National Renal Complement Therapeutics Centre

David Gold-

farb, Nephrol-

Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **1st December 2018** when there were **20,855 UK patients** in RaDaR from **96 hospitals.**

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	5546
ADTKD/FUAN	√	√	167
aHUS	√		207
Alport Syndrome	√	√	701
APRT-D	√		8
ARPKD	√	√	181
Calciphylaxis	√	√	35
Cystinosis	√		125
Cystinuria	√		385
Dent Disease & Lowe Syndrome	√	√	54
Fabry Disease	√		37
Fibromuscular Dysplasia	√		20
HNF1-B	√	√	69
Stec HUS	√		144
Hyperoxaluria	√		103
Hypokalaemic Alkaloses	√	√	274
IgA Nephropathy	√	√	2817
MGRS	√	√	55
MPGN, DDD and C3 Glomerulopathy	√	√	921
Membranous Nephropathy	√		1777
Nephrotic Syndrome	√	√	2971
Pregnancy & Chronic Kidney Disease	√	√	498
Pure Red Call Aplasia	√		6
Retroperitoneal Fibrosis	√		100
Tuberous Sclerosis	√		127
Vasculitis	√		3555

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

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