

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.

### RaDaR Portfolio Extension

Thanks to the generous support of **Kidney Research UK**, RaDaR will maintain its presence on the NIHR's Research Portfolio until **31/03/2020**.

This ensures that recruiting sites will continue to receive financial support for every patient that they recruit to the rare disease registry.



### Recruitment Update

Top Recruiting Adult Sites	Recruits
London Guys	1187
London Royal Free	827
Oxford Churchill	741
Nottingham City Hospital	728
Lister Hospital, Stevenage	687

Top Recruiting Paediatric Sites	Recruits
Birmingham	462
Manchester	263
Leeds	191
Nottingham	181
Southampton	157

RaDaR is generously supported by:



**KIDNEY  
HEALTH**  
FOR EVERYONE  
EVERYWHERE



14<sup>TH</sup>  
MARCH  
2019



Partnership for  
Kidney Health  
www.kidney.org  
www.kidney.org.uk  
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# Are you kidney aware?

Kidneys are essential to our health and one of the most important organs in the body. Although anyone can develop kidney disease, there are a few things that can increase your risk – diabetes, high blood pressure, cardiovascular (heart) disease or a family history of kidney disease. In addition if you are from a black, Asian or minority ethnic background, you are more likely to develop kidney failure as kidney disease can progress more rapidly.

## How to improve your kidney health



**Keep fit  
and active**



**Monitor your  
blood pressure**



**Don't  
smoke**



**Eat healthily  
and keep  
your weight  
in check**



**Get your kidney  
function checked  
if you are at  
increased risk**



**Keep well  
hydrated**

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



**Contact us...**

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## Review of Fibromuscular Dysplasia (FMD) Patient Information Day

The auspicious date of 19.01.19 saw the UK's first patient information day on Fibromuscular Dysplasia (FMD), held at Salford Royal Hospitals NHS Foundation Trust.

The day was aimed at providing an overview on FMD, an update on international registry data and the most cutting edge clinically relevant research. We were privileged and honoured to have guest speaker, Sally Bee (<https://www.sally-bee.com/>) share her journey, first with spontaneous coronary artery dissection (SCAD) and then FMD; and Prof Alexandre Persu, an international FMD expert and head of the European FMD Registry join us from Belgium. Dr Tina Chrysochou provided an overview of FMD and the UK collaborative effort of the FMD specialist interest group under the Renal Rare Disease Registry (RaDaR).

Following patient requests ahead of the meeting, the day also benefitted from local neurology and neuro-radiology expertise by SRFT colleagues, Dr Martin Punter and Dr Amit Herwadkar. Prof David Adlam, lead for the UK SCAD research group, discussed the latest developments in SCAD. This included his latest collaboration showing genetic susceptibility to FMD and SCAD : PHACTR1 is associated with an increased risk of FMD, cervical artery dissection, SCAD and migraine. Dr 'Bean' Dhaun, consultant nephrologist from Edinburgh shared a case study on an unusual presentation of FMD to highlight how this condition can present in multiple ways, and how clinicians should have a high index of suspicion when cardiovascular events occur outwith the traditional risk factors or atherosclerosis.

The day finished off with a workshop during which patients and carers shared their experiences and devised a wish list for management within clinical services and research ideas for FMD in the UK.

Have a look at **#FMD2019** for tweets from day. Feedback from the meeting was excellent, with all individuals finding it extremely or very worthwhile. We are very grateful to Kidney Research UK (KRUK) and Kidney Care UK (KCUK) who kindly sponsored the event. Their sponsorship also went towards filming the event which will be made publically available.

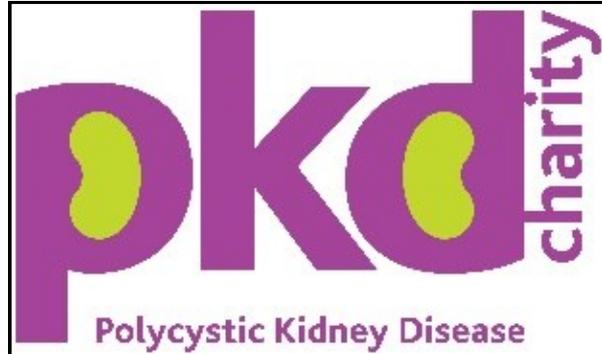


## ADPKD Patient Information Day

The **PKD Charity** will be hosting the next **ADPKD Patient Information Day** on **Saturday, 30 March 2019** from **10:00am – 4:00pm** at **Aintree University Hospital Lower Lane, Liverpool. L9 7AL**

The event is free to attend and will include talks on:

- The Basics of ADPKD
- Genetics
- Diet and Lifestyle
- Research
- Transplants



**Lunch and refreshments included**

To register please visit <https://tinyurl.com/adpkd-march-2019>

## International consensus guide on FMD

The first international consensus guide on the diagnosis and management of Fibromuscular Dysplasia has recently been published. This can be accessed at:

<https://tinyurl.com/FMD-guidelines>

## GDPR Update

To ensure that RaDaR is compliant with the new **General Data Protection Regulations**, which came into force on May 25th 2018, two Privacy Statements have been produced to cover both RaDaR and Rare Renal. The documents detail what data is collected from patients and how it stored, linked and accessed.

The RaDaR notice is at:

<https://rarerenal.org/radar-registry/privacy-notice/>

And the RareRenal one is at:

<https://rarerenal.org/terms-and-conditions/>

## Royal Society of Medicine events

### Frontiers in Glomerulonephritis II, Royal Society of Medicine - UK Kidney Research Consortium GN Clinical Study Group Collaboration

**Thursday 21st March 2019, Max Rayne Auditorium, Royal Society of Medicine, London**

This meeting explores current understanding of glomerular diseases with an autoimmune aetiology. It dissects the histological and pathological features that underpin this spectrum of diseases. We are hosting this in association with the UK Kidney Research Consortium GN Clinical Study Group Collaboration. This year we are focusing on all of the major GN topics, with panel discussions and update on clinical trials. Therapeutic mechanisms, clinical trials and management strategies are explained, along with expert panel discussions. Updates will include newer therapies in vasculitis, the evolving story of lupus nephritis and novel insights into the management of IgA nephropathy.

<https://www.rsm.ac.uk/events/nephrology/2018-19/nem03/>



**Rare Diseases and the Kidney, Royal Society of Medicine in collaboration with RaDaR**

**Wednesday 8th May 2019, Salford University Media City campus. M50 2HE. Room 3.11**

**CPD: 6 credits**

The RSM is coming to Salford, Manchester! Join us for this exciting meeting where you will have the opportunity to hear from experts in a variety of renal rare disease areas. The agenda includes the latest research and clinical updates from nine RADAR rare disease groups. There will also be discussion on the UK Renal Research Network, the NIHR BioResource for Translational Research and opportunities for future research using the RADAR network. Places are limited, please book early to avoid disappointment.

<https://www.rsm.ac.uk/events/nephrology/2018-19/nem04/>

## 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](http://www.cystinuriauk.co.uk) website - [www.cystinuriauk.co.uk/patient-day](http://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



**UKIVAS Education Day May 16<sup>th</sup> 2019**

**Salford Royal Foundation Trust, HBLT1 Mayo Building**

Attendance is free but to register please email [hugh.cahill@addenbrookes.nhs.uk](mailto:hugh.cahill@addenbrookes.nhs.uk) by the 18<sup>th</sup> April

9.30-9.40	Welcome and introduction	Nina Brown Consultant Nephrologist
9.40-10.20	ANCA Associated Vasculitis	Edmond O'Riordan Consultant Nephrologist
10.20-11.00	Large Vessel Vasculitis/ Giant Cell Arteritis	Ann Morgan Professor of Rheumatology
11.00-11.15	<i>Break</i>	
11.15-11.45	Respiratory manifestations in vasculitis	David Allen Consultant Respiratory Physician
11.45-12.25	Behcet's	Robert Moots Professor of Rheumatology
12.25- 13.30	<i>Lunch</i>	
13.30- 13.45	<i>Patient story</i>	
13.45- 14.25	IgA vasculitis	Louise Oni Senior Lecturer and Honorary Consultant in Paediatric Nephrology
14.25-14.55	Skin disease in vasculitis	Anja Weidmann Consultant Dermatologist
14.55-15.15	<i>Break</i>	
15.15-15.30	<i>Patient story</i>	
15.30-16.00	ENT disease in vasculitis	Chaitanya Gadepalli Consultant ENT Surgeon
16-16.30	Peripheral nerve involvement in vasculitis	Tim Lavin Consultant Neurologist
	<i>Close</i>	

Unrestricted sponsorship for the refreshments and lunch break has been provided by Vifor Pharma UK Ltd



Travel bursaries for speakers have been provided by Vasculitis UK



## Recruitment Update

The table below shows the recruitment figures and data entry fields for each condition as of **8th March 2019** when there were **21,987 UK patients** in RaDaR from **98 hospitals**.

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	5897
ADTKD/FUAN	√	√	174
aHUS	√		221
Alport Syndrome	√	√	722
APRT-D	√		8
ARPKD/NPHP	√	√	190
Calciophylaxis	√	√	36
Cystinosis	√		128
Cystinuria	√		397
Dent Disease & Lowe Syndrome	√	√	55
Fabry Disease	√		37
Fibromuscular Dysplasia	√		22
HNF1-B	√	√	72
Stec HUS	√		145
Hyperoxaluria	√		108
Hypokalaemic Alkaloses	√	√	289
IgA Nephropathy	√	√	3097
MGRS	√	√	82
MPGN, DDD and C3 Glomerulopathy	√	√	950
Membranous Nephropathy	√		1866
Nephrotic Syndrome	√	√	3139
Pregnancy & Chronic Kidney Disease	√	√	545
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		110
Tuberous Sclerosis	√		140
Vasculitis	√		3695

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)