

Issue Two, Summer 2015

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.

Upcoming events

Several of the Rare Disease Groups are hosting patient and family events over the coming months. All events are free to attend and are open to patients, families and friends of those affected by the conditions. Interested clinicians are also very welcome to attend. Full details of the events along with registration information can be found on rarerenal.org

Gitelman and Bartter Syndrome Patient Day - Saturday 13th June 2015 - London

aHUS Patient Day - Saturday June 27th 2015 - London

ARPKD Patient Day - Saturday 11th July 2015 - Leeds

Presentations and reports from previous patient events, including the Nephrotic Syndrome patient day held in Birmingham in April, are now available at rarerenal.org.

NephroS Study Update

The Steroid Resistant Nephrotic Syndrome (SRNS) Study has recently expanded to include Steroid Sensitive Nephrotic Syndrome (SSNS) patients. This amendment also allows for the collection of blood samples at times of relapse and remission.

A further amendment will shortly be submitted to allow for the collection of saliva rather than blood samples from relatives in order to confirm genetic results.

For further information please contact:

NephroS@rarerenal.org

Personnel Update

Chrissie Jacobs will be leaving the programme at the end of June. Melanie Dillon will be taking over in the interim looking after RaDaR on a part-time basis.

Top Recruiters

42 UK Renal Units are currently recruiting to RaDaR. The table below shows the top five recruiting sites as of June 2015.

Centre	Recruits
Stoke University Hospital North Midlands	235
Nottingham University Hospital	196
Birmingham Children's Hospital	188
Stevenage, Lister Hospital	168
London Royal Free	113

RaDaR is generously supported by:

Recruitment Update

The table below shows the current recruitment figures for each condition as of June 2015 when there were 2,395 UK patients in RaDaR from 42 Renal Units.

Diagnosis	Rare Disease Group	Current data entry		Number of recruits
		Generic	Condition specific	
Adenine Phosphoribosyltransferase Deficiency (APRT-D)	APRT-D	√		1
Alport Syndrome/Thin Basement Membrane Nephropathy	Alport Syndrome	√		141
Atypical Haemolytic Uraemic Syndrome (aHUS)	aHUS	√		48
Autosomal Recessive Polycystic Kidney Disease (ARPKD)	ARPKD	√		41
Cystinosis	Cystinosis	√		46
Cystinuria	Cystinuria	√		132
Dent Disease/Lowe Syndrome	Dent Disease & Lowe Syndrome	√		19
Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)	HNF1-B	√		24
Hyperuricaemic Nephropathy/Medullary Cystic Kidney Disease	Familial Uromodulin Associated Nephropathy	√		40
Hypokalaemic Alkaloses (Bartters Syndrome; Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy Syndrome (EAST); Gitelman Syndrome; Liddle Syndrome)	Hypokalaemic Alkaloses	√		104
Membranous Nephropathy	Membranous Nephropathy	√		319
Membranoproliferative Glomerulonephritis (MPGN)/ Dense Deposit Disease (DDD)/ C3 Glomerulopathy	MPGN/DDD/ C3 Glomerulopathy	√	√	283
Pregnancy and Chronic Kidney Disease	Pregnancy & Chronic Kidney Disease	√		28
Primary Hyperoxaluria	Hyperoxaluria	√		43
Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)	HUS	√		38
Nephrotic Syndrome (Steroid Sensitive and Steroid Responsive)	SRNS	√	√	433
Vasculitis	Vasculitis	√		655

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

Melanie Dillon - melanie.dillon@bch.nhs.uk - 0121 333 9233