RaDaR Newsletter

Issue One, Spring 2015

The National Registry of Rare Disease (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, both adult and paediatric.

Ethics Update

Following a recent re-application to Ethics we have now received a five year extension for RaDaR, taking us through to 2019. The Patient Information Sheets and Consent Forms have been re-written to make the language more user friendly, following feedback from various sites. Minor changes to the Protocol have also been made to reflect up-to-date data storage procedures.

There is no need to re-consent any existing patients but please use the new documentation going forward. For any queries please contact:

christine.jacobs@renalregistry.nhs.uk

Version Control

The latest study documents for RaDaR are as follows:

- Protocol, v9 15.07.2014
- Children's Information Sheet, v4 15.07.2014
- Adolescent Information Sheet, v8 12.12.2014
- Adult Patient Information Sheet, v8 15.07.2014
- Parent/Guardian Information Sheet, v7 12.12.2014
- GP/Consultant Information Sheet, v4 15.07.2014
- Adult Patient Consent Form, v6 15.07.2014
- Adolescent Assent Form, v3 15.07.2014
- Parent/Guardian Consent Form, v6 12.12.2014

The latest versions of all consent documents can be found at:
www.rarerenal.org/radar-registry/criteria-and-consent

NephroS Study Update

The Steroid Resistant Nephrotic Syndrome (SRNS) Study is expanding to include Steroid Sensitive Nephrotic Syndrome (SSNS) patients. These patients will shortly be included in RaDaR itself with the option of taking part in the additional study which provides genetic testing through the University of Bristol. For further information please contact:

NephroS@rarerenal.org

Upcoming events

World Kidney Day -Thursday 12th March 2015

Cystinuria Patient Day - Saturday 18th April 2015

ARPKD Patient Day - Saturday 11th July 2015

Fur further details please visit **rarerenal.org**

RaDaR is generously supported by:

Top Recruiters

39 UK Renal Units are currently recruiting to RaDaR with another 24 in set-up. The table below shows the top five recruiting sites as of February 2015.

Centre	Recruits
Stoke University Hospital North Midlands	234
Birmingham Children's Hospital	164
Nottingham University Hospital	155
Stevenage, Lister Hospital	127
London - Guy's and St. Thomas' Hospital	90

Recruitment Update

The table below shows the current recruitment figures for each condition as of February 2015 where there were 1,884 UK patients in RaDaR from 39 Renal Units.

Diagnosis	Rare Disease Group	Current data entry		Number of recruits
		Generic	Condition specific	
Adenine Phosphoribosyltransferase Deficiency (APRT-D)	APRT-D	√		0
Alport Syndrome/Thin Basement Membrane Nephropathy	Alport Syndrome	√		105
Atypical Haemolytic Uraemic Syndrome (aHUS)	aHUS	√		40
Autosomal Recessive Polycystic Kidney Disease (ARPKD)	ARPKD	√		41
Cystinosis	Cystinosis	√		38
Cystinuria	Cystinuria	√		120
Dent Disease/Lowe Syndrome	Dent Disease & Lowe Syndrome	√		15
Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)	HNF1-B	√		20
Hyperuricaemic Nephropathy/Medullary Cystic Kidney Disease	Familial Uromodulin Associated Nephropathy	√		23
Hypokalaemic Alkaloses (Bartters Syndrome; Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy Syndrome (EAST); Gitelman Syndrome; Liddle Syndrome)	Hypokalaemic Alkaloses	√		81
Membranous Nephropathy	Membranous Nephropathy	√		232
Membranoproliferative Glomerulonephritis (MPGN)/ Dense Deposit Disease (DDD)/ C3 Glomerulopathy	MPGN/DDD/ C3 Glomerulopathy	√	√	243
Pregnancy and Chronic Kidney Disease	Pregnancy & Chronic Kidney Disease	√		20
Primary Hyperoxaluria	Hyperoxaluria	√		38
Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)	HUS	√		35
Steroid Resistant Nephrotic Syndrome (SRNS)	SRNS	√	√	370
Vasculitis	Vasculitis	√		463

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

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