

RaDaR

Rare Disease Registry

Melanie Dillon

RaDaR Operations Officer, UK Renal Registry

Background

- The **National Registry of Rare Kidney Diseases (RaDaR)** is a Renal Association initiative designed to pull together information from patients who have certain rare kidney diseases.
- This will give a much better understanding of how these illnesses affect people. It will also speed up research.
- RaDaR is managed by a series of Rare Disease Groups consisting of experts in each condition.

History

- RaDaR began in 2009, recruiting paediatric patients with Steroid Resistant Nephrotic Syndrome (SRNS) and Membranoproliferative Glomerulonephritis (MPGN).
- In 2012 it expanded to other conditions in paediatric centres and then to adult centres in Autumn 2013.
- RaDaR now has UK-wide ethics approval for both adult and paediatric recruits for over 30 conditions.

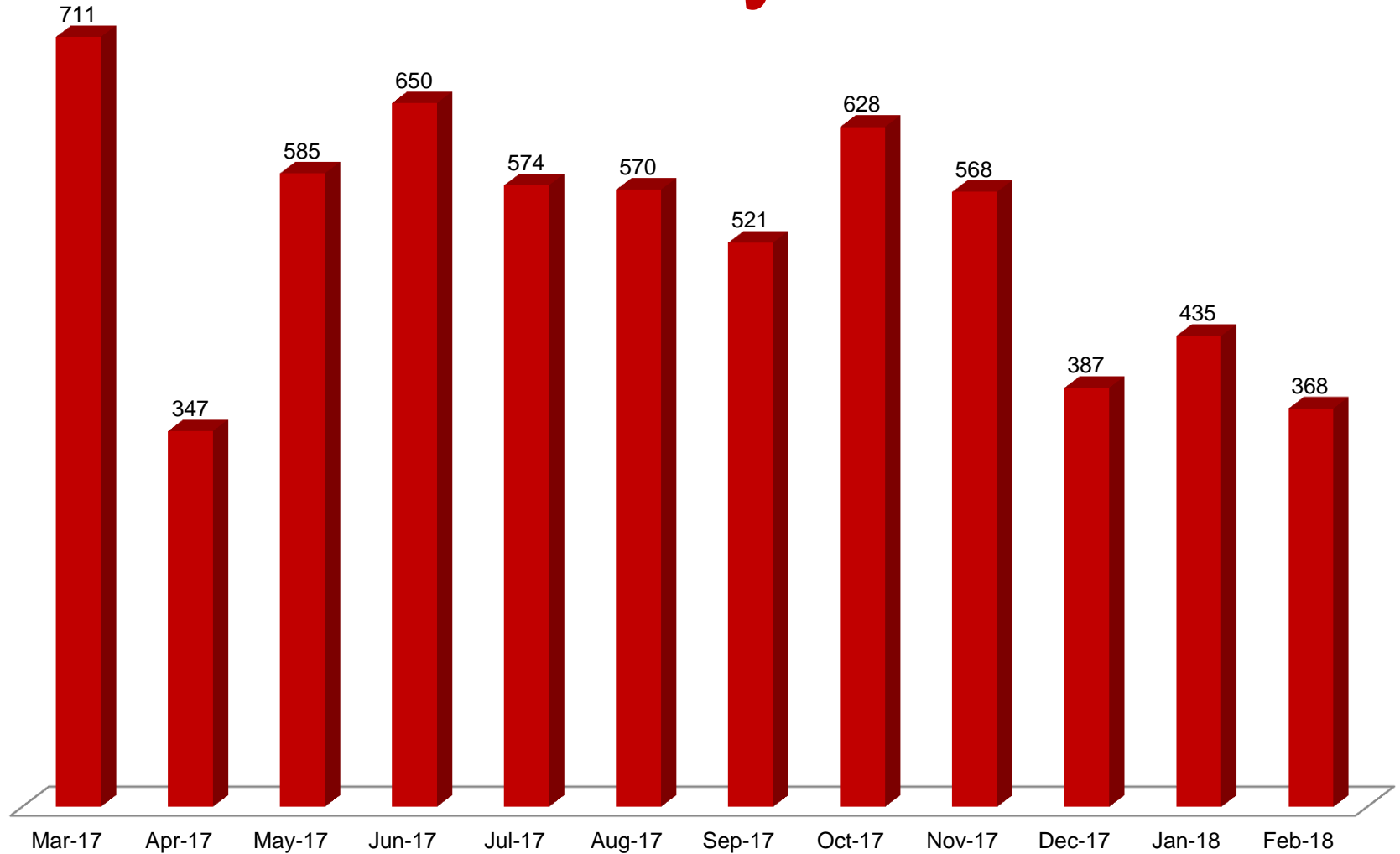
Current Recruitment

- Adenine Phosphoribosyltransferase Deficiency (APRT-D)
- Alport Syndrome
- Atypical Haemolytic Uraemic Syndrome (aHUS)
- Autosomal Dominant Polycystic Kidney Disease (ADPKD)
- Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD)
- Autosomal Recessive Polycystic Kidney Disease (ARPKD)
- Bartters Syndrome
- C3 Glomerulopathy
- Calciphylaxis
- Cystinosis
- Cystinuria
- Dense Deposit Disease (DDD)
- Dent Disease
- Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy Syndrome (EAST)
- Fabry Disease
- Fibromuscular Dysplasia
- Gitelman Syndrome
- Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)
- Hyperuricaemic Nephropathy
- IgA Nephropathy
- Liddle Syndrome
- Lowe Syndrome
- Membranous Nephropathy
- Membranoproliferative Glomerulonephritis (MPGN)
- Medullary Cystic Kidney Disease
- Pregnancy and Chronic Kidney Disease
- Primary Hyperoxaluria
- Pure Red Cell Aplasia
- Retroperitoneal Fibrosis
- Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)
- Steroid Resistant Nephrotic Syndrome (SRNS)
- Steroid Sensitive Nephrotic Syndrome (SSNS)
- Thin Basement Membrane Nephropathy
- Tuberos Sclerosis
- Vasculitis
- **Coming soon** - Monoclonal Gammopathy of Renal Significance (MGRS)

Current Status of RaDaR

- As of 28/02/2018 there are:
 - 17,175 UK patients in RaDaR
 - From 91 hospitals
- A further 3 sites are currently in set-up - Dundee, Huddersfield and Kirkcaldy (Fife)

Recruits by Month



Recruits by Rare Disease Group

Rare Disease Group	Current data entry		
	Generic	Specific	Recruits
ADPKD	√	√	4352
ADTKD/FUAN	√	√	137
aHUS	√		172
Alport Syndrome	√	√	589
APRT-D	√		7
ARPKD	√	√	165
Calciophylaxis	√	√	29
Cystinosis	√		118
Cystinuria	√		358
Dent Disease & Lowe Syndrome	√	√	49
Fabry Disease	√		28
Fibromuscular Dysplasia	√		16
HNF1-B	√	√	67
Stec HUS	√		119
Hyperoxaluria	√		95
Hypokalaemic Alkaloses	√	√	249
IgA Nephropathy	√	√	2312
MPGN, Dense Deposit Disease and C3 Glomerulopathy	√	√	810
Membranous Nephropathy	√		1534
Nephrotic Syndrome	√	√	2448
Pregnancy & Chronic Kidney Disease	√	√	412
Pure Red Cell Aplasia	√		5
Retroperitoneal Fibrosis	√		83
Tuberous Sclerosis	√		85
Vasculitis	√		3029

Recruits by Hospital

Hospital	Recruits	Hospital	Recruits	Hospital	Recruits
Aberdeen	2	Derby	439	Newcastle Royal Victoria	541
Airedale	68	Doncaster	12	Norwich	300
Altnagelvin Hospital, Derry	18	Dudley, Russells Hall	13	Nottingham Adults	604
Antrim	6	Dumfries & Galloway	6	Nottingham Children's	168
Ashford & St Peters	5	Edinburgh	109	Oxford Churchill	507
Basildon	75	Exeter	415	Oxford John Radcliffe	55
Bath Royal United	3	Glasgow Children's	78	Peterborough	2
Belfast City Hospital	1	Glasgow Queen Elizabeth	583	Plymouth	399
Belfast Ulster	17	Gloucester	120	Portsmouth	26
Birkenhead Arrowe Park	32	Hull	196	Preston	377
Birmingham Children's	389	Inverness	122	Reading	64
Birmingham Heartlands	25	Ipswich	99	Salford	503
Birmingham Sandwell	4	Kilmarnock (Crosshouse)	7	Sheffield Northern General	297
Birmingham Queen Elizabeth	583	Kings Lynn	18	Shrewsbury & Telford	351
Birmingham Women's	119	Leeds Children's	193	Southampton Children's	150
Blackburn	16	Leeds St James'	144	Southend	112
Bradford (St Luke's)	111	Leicester	391	Stevenage (Lister)	615
Brighton	105	Liverpool Aintree	68	St Helier's	451
Bristol Children's	75	Liverpool Alder Hey	83	Stockport	14
Bristol Southmead	120	Liverpool Royal	363	Stoke	334
Burton-on-Trent	6	London – Barts	315	Sunderland	134
Bury St Edmunds	6	London – Evelina & Guys	887	Swansea	1
Cambridge	400	London – GOSH	125	Swindon Great Western	4
Canterbury	317	London - Kings	335	Tameside	1
Cardiff	382	London – Imperial	156	Taunton Musgrove Park	6
Chelmsford (Broomfield)	145	London - Royal Free	775	Torbay	1
Colchester	99	London – St George's	86	Truro Royal Cornwall	228
Coventry	412	Macclesfield	11	Walsall Manor	13
Cumberland Infirmary	23	Manchester Adults	352	Warrington	3
Daisy Hill, Newry	11	Manchester Children's	10	Wolverhampton	201
Dartford	24	Middlesbrough	327	York	184

Link with Patient View

- RaDaR draws information from Patient View, an online system which records renal patient's results, medications and clinic letters.
- Recruited patients are given access to Patient View to see their data online.
- The majority of renal units in the UK use Patient View. Those that don't can still take part in RaDaR but have to enter the patient's data manually.

Generic Data Capture - 1

RaDaR Cohorts Hospitals Patients Users News Stats Admin Logged in as test

JAKE THOMPSON ID 81 DOB 06/10/1920 Gender Male CHI 0107145456 Recruited On 18/06/2015 Recruited By bot Recruited At RaDaR Cohort Cystinosis

Hospital Swansea - Morriston Hospital Hospital Bradford Renal Unit Hospital Oxford Women's Centre [Hide Demographics](#)

RaDaR **Demographics** Consultants Cohorts Hospitals More...

Cystinosis Primary Diagnosis Genetics Family History Renal Imaging Lab Results Medications Dialysis Kidney Transplants

Demographics

List View

First Name*	JAKE	Home Number	01977 309772
Last Name*	THOMPSON	Work Number	01448 302461
Date of Birth*	06/10/1920	Mobile Number	07362418230
Date of Death	DD/MM/YYYY	Email Address	jake.thompson@exampl
Gender*	Male		
Nationality			
Ethnicity			

Generic Data Capture - 2

RaDaR Cohorts Hospitals Patients Users News Stats Admin Logged in as test

JAKE THOMPSON ID 81 DOB 06/10/1920 Gender Male CHI 0107145456 Recruited On 18/06/2015 Recruited By bot Recruited At RaDaR Cohort Cystinosis

Hospital Swansea - Morriston Hospital Hospital Bradford Renal Unit Hospital Oxford Women's Centre [Hide Demographics](#)

RaDaR [Demographics](#) **Consultants** [Cohorts](#) [Hospitals](#) [More...](#)

Cystinosis [Primary Diagnosis](#) [Genetics](#) [Family History](#) [Renal Imaging](#) [Lab Results](#) [Medications](#) [Dialysis](#) [Kidney Transplants](#)

Consultants

List View

From Date* 21/08/2017

To Date DD/MM/YYYY

Consultant* ANDY WILLIAMS (Nephrologist) ▼

Cancel

Generic Data Capture - 3

RaDaR Cohorts Hospitals Patients Users News Stats Admin Logged in as test

JAKE THOMPSON ID 81 DOB 06/10/1920 Gender Male CHI 0107145456 Recruited On 18/06/2015 Recruited By bot Recruited At RaDaR Cohort Cystinosis

Hospital Swansea - Morriston Hospital Hospital Bradford Renal Unit Hospital Oxford Women's Centre Hide Demographics

RaDaR Demographics Consultants Cohorts Hospitals More...

Cystinosis Primary Diagnosis Genetics Family History Renal Imaging Lab Results Medications Dialysis Kidney Transplants

Primary Diagnosis Cystinosis

Edit

Data Source	RaDaR (RADAR)
Diagnosis	Cystinosis
Symptoms Date	01/05/2010 (89 years)
Diagnosis Date	01/06/2015 (94 years)
To Date	-
Prenatal Diagnosis	✗
Confirmed by Gene Test	✗
Confirmed by Biochemistry	✓
Confirmed by Clinical Picture	✓
Confirmed by Biopsy	✗
Comments	Test patient

Information Security

- Data is anonymised and password protected
- Participants provided with a secure log-in to access and check their own information via PV
- Identifiable data only available to patient's clinician and unit administrator
- Members of the Rare Disease Groups will only see anonymised data – numbers rather than names

Patient benefits of joining RaDaR

- Access to your clinical data online via Patient View
- Ability to be contacted about potential research studies or patient information events
- Contribute to the increase in knowledge about your condition

Clinician benefits of joining RaDaR

- Portfolio study – Renal, co-adopted by Child Health
- UK-wide Ethics and classed as a research registry so no local or HRA approvals required
- Share knowledge with other colleagues
- Access to genetic testing for selected conditions

Current Problems

- Lots of patients recruited but minimal data entered
- Big variation in recruitment between the sites
- Minimal research usage at present
- Patients lost to follow-up when transfer to adult care – c.100 to date

October 2017 Ethics Amendment

- Joint RaDaR and Patient View consent
- The ability to link RaDaR to other registries, databases and bio-banks that the patient has consented to
- The ability for Rare Disease Group Leads to contact patients directly about future studies
- We are looking at ways to re-consent existing patients with the new documents

Star Registry

- Key part of Birmingham Children's Hospital new Rare Disease Centre
- Non-renal version of RaDaR for all rare diseases
- Includes SWAN – syndromes with a name – patients
- Potential to expand to other centres in the future

International Plans

- RaDaR is predominately aimed at UK patients.
- International recruits consented in the UK by an NHS hospital are also eligible.
- Two of the RaDaR conditions – Idiopathic Nephrotic Syndrome and IgA Nephropathy - have established an international version of RaDaR.
- Plans are to extend this to other conditions.

RareRenal.org

- Patient and Clinician information on all conditions covered by RaDaR
- Links to patient support groups and personal stories
- Advertising for patient information events



Contact Details

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

- RaDaR - <https://nww.radar.nhs.uk> - patient registry for professional access via NHS computers
- RareRenal - www.rarerenal.org - public information about rare kidney diseases
- PatientView - www.patientview.org patient accessible health records

Supporters

RaDaR is generously supported by:

