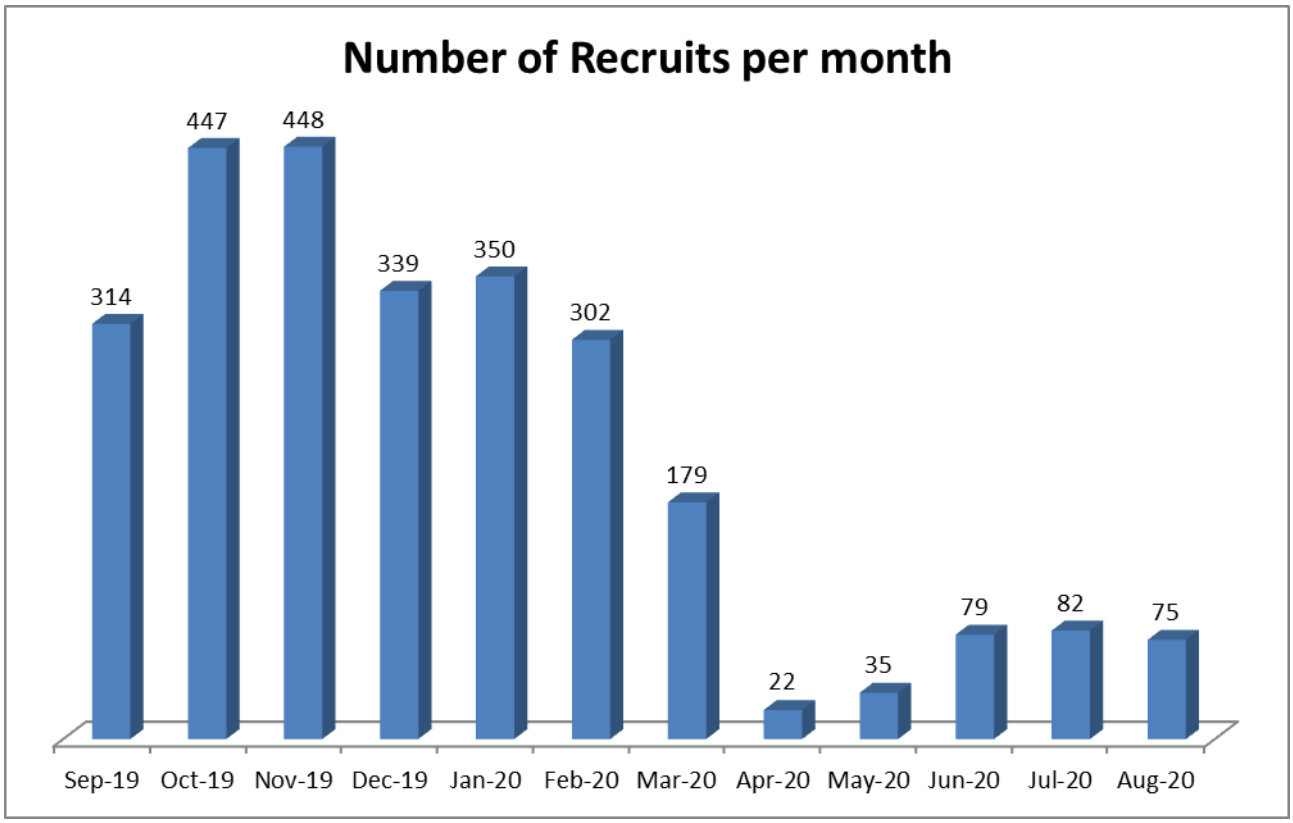
RaDaR

Progress Report

September 2020

Recruitment Update

As of 1st September 2020 there are 26507 UK patients in RaDaR from 103 hospitals. In August there were 75 new recruits.



Top Recruiters

The top recruiting sites in **August** were as follows:

Adult	Recruits
Belfast Ulster	10
Newcastle Freeman & Victoria	8
London – King's College Hospital	7
Cardiff	6
Ipswich	5

Paediatric	Recruits
London - Evelina	10
Belfast Children's	4
Newcastle Freeman & Victoria	2

The top recruiting sites **overall** are as follows:

Adult	Recruits
London - Royal Free Hospital	1167
London - Guy's	1158
Oxford - Churchill	973
Manchester Royal Infirmary	854
Nottingham City Hospital	828

Paediatric	Recruits
Birmingham	513
Manchester	323
Leeds	244
Nottingham	206
Southampton	177

A table showing the number of recruits from all active sites can be found in **Appendix A**.

Re-consenting

The re-consenting of patients on the old (pre-2017) study documents is continuing. The return rate is 34% from a total 13,838 sent out.

Current Conditions

- Adenine Phosphoribosyltransferase Deficiency (APRT-D)
- AH amyloidosis
- AHL amyloidosis
- AL amyloidosis
- Alport Syndrome
- Atypical Haemolytic Uraemic Syndrome (aHUS)
- Autoimmune distal renal tubular acidosis
- Autosomal recessive distal renal tubular acidosis
- Autosomal recessive proximal renal tubular acidosis
- Autosomal Dominant Polycystic Kidney Disease (ADPKD)
- Autosomal Recessive Polycystic Kidney Disease (ARPKD)
- Bartters Syndrome
- BK Nephropathy
- C3 glomerulonephritis with monoclonal gammopathy
- C3 Glomerulopathy
- Calciphylaxis
- Crystalglobulinaemia
- Crystal-storing histiocytosis
- Cystinosis
- Cystinuria
- Dense Deposit Disease (DDD)
- Dent Disease
- Denys-Drash Syndrome
- Dominant hypophosphatemia with nephrolithiasis or osteoporosis
- Drug induced Fanconi syndrome
- Drug induced hypomagnesemia
- Drug induced Nephrogenic Diabetes Insipidus
- Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy Syndrome (EAST)
- Fabry Disease
- Familial Hypomagnesaemia with hypercalciuria and nephrocalcinosis
- Familial primary hypomagnesemia with hypocalcuria
- Familial primary hypomagnesemia with normocalcuria EGF
- Familial renal glucosuria
- Fanconi Renotubular syndrome 1 (FRTS1)
- Fanconi Renotubular syndrome 1 (FRTS1)
- Fanconi Renotubular syndrome 3 (FRTS3)
- Fibrillary Glomerulonephritis
- Fibromuscular Dysplasia
- Focal Segmental Glomerulosclerosis (FSGS)
- Generalized pseudohypoaldosteronism type 1
- Gitelman Syndrome
- Heavy metal induced Fanconi syndrome
- Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)
- Hereditary renal hypouricemia
- Hereditary hypophosphatemic rickets with hypercalciuria
- Hyperuricaemic Nephropathy
- IgA Nephropathy
- Immunotactoid/Glomerulonephritis with Organised Microtubular Monoclonal Immunoglobulin Deposits (GOMMID)
- Inherited Renal Cancer Syndromes
- Intracapillary monoclonal IgM without cryoglobulin
- Intraglomerular/capillary lymphoma/leukaemia
- Isolated autosomal dominant hypomagnesemia, Glaudemans type
- Liddle Syndromes
- Light chain cast nephropathy
- Light chain proximal tubulopathy, crystalline
- Light chain proximal tubulopathy, non crystalline
- Lowe Syndrome
- Membranous Nephropathy
- Membranoproliferative Glomerulonephritis (MPGN)
- Medullary Cystic Kidney Disease
- Minimal Change Nephropathy
- Mitochondrial Disease of the kidney
- Monoclonal Immunoglobulin Deposition Disease (MIDD; includes Light Chain Deposition Disease – LCDD; Heavy Chair Deposition Disease – HCDD; and Light and Heavy Chain Deposition Disease - LHCDD)
- Nail Patella Syndrome
- Nephrogenic diabetes insipidus
- Nephrogenic syndrome of inappropriate antidiuresis

- Nephronophthisis (NPHP)
- Oncogenic osteomalacia
- Osteopetrosis with renal tubular acidosis
- Pregnancy and Chronic Kidney Disease
- Primary hypomagnesemia with secondary hypocalcemia
- Primary Hyperoxaluria
- Proliferative glomerulonephritis with monoclonal immunoglobulin deposits – PGNMID
- Proximal tubulopathy without crystals
- Pseudohypoaldosteronism type 2A
- Pseudohypoaldosteronism type 2B
- Pseudohypoaldosteronism type 2C
- Pseudohypoaldosteronism type 2D
- Pseudohypoaldosteronism type 2E
- Pure Red Cell Aplasia
- Renal pseudohypoaldosteronism type 1
- Retroperitoneal Fibrosis
- Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)
- Steroid Resistant Nephrotic Syndrome (SRNS)
- Steroid Sensitive Nephrotic Syndrome (SSNS)
- Thin Basement Membrane Nephropathy
- Thrombotic Microangiopathy with monoclonal gammopathy
- Type 1 cryoglobulinaemic Glomerulonephritis
- Tuberous Sclerosis
- Unclassified Monoclonal Gammopathy of Renal Significance (MGRS)
- Vasculitis

A table showing which conditions are covered by each RDG can be found in **Appendix B**.

The current recruitment figures for each RDG can be found in **Appendix C.**

The contact details for each RDG can be found in **Appendix D.**

Appendix A – Patients per Renal Unit
as of 1st September 2020

Hospital	Date Started	Total
Aberdeen	August 2015	2
Airedale	December 2017	21
Altnagelvin Hospital, Derry	April 2017	21
Antrim	December 2017	29
Ashford & St Peters	April 2017	12
Basildon	June 2017	191
Bath Royal United	June 2016	5
Belfast Children's	August 2011	22
Belfast Ulster	March 2017	83
Birkenhead Arrowe Park	September 2016	75
Birmingham Children's	January 2010	513
Birmingham Heartlands	February 2016	223
Birmingham Queen Elizabeth	November 2013	660
Birmingham Sandwell	November 2017	4
Birmingham Women's	March 2016	135
Blackburn	October 2016	19
Bradford (St Luke's)	November 2014	198
Brighton	December 2013	247
Bristol Children's	January 2010	103
Bristol Southmead	February 2014	179
Burton-on-Trent	February 2018	32
Bury St Edmunds	June 2017	10
Cambridge	October 2012	634
Canterbury	December 2014	403
Cardiff	May 2010	682
Chelmsford (Broomfield)	December 2015	192
Chester	October 2019	4
Colchester	August 2014	99
Coventry	January 2016	631
Cumberland Infirmary	March 2016	120
Daisy Hill, Newry	November 2016	26
Darlington	February 2019	81
Dartford	May 2017	28
Derby	November 2015	472
Doncaster	October 2015	22
Dudley, Russells Hall	November 2016	18
Dumfries & Galloway	June 2017	13
Dundee Ninewells	September 2018	124
Edinburgh	April 2013	126
Exeter	July 2013	559
Glasgow Children's	May 2010	91
Glasgow Queen Elizabeth	June 2015	603
Gloucester	November 2015	255
Hartlepool	November 2018	10
Hereford	January 2019	88
Huddersfield	May 2018	103
Hull	January 2015	251
Inverness	December 2015	158
Ipswich	June 2014	263
Kilmarnock (Crosshouse)	June 2016	41
Kings Lynn	March 2017	39
Leeds Children's	February 2011	244
Leeds St James'	May 2014	202
Leicester	October 2013	663
Liverpool Aintree	June 2015	91
Liverpool Alder Hey	May 2010	98
Liverpool Royal	June 2016	642
London – Barts	July 2015	585
London - Evelina	August 2020	10
London – GOSH	February 2010	167
London – Guys	November 2010	125
London – Imperial	September 2015	225
London - Kings	June 2016	592
London - Royal Free	February 2014	116
London – St George's	September 2016	500
Macclesfield	May 2016	11
Manchester Adults	March 2014	854
Manchester Children's	November 2010	323
Middlesbrough	July 2015	379
Newcastle Freeman and Victoria	August 2010	800
Norfolk and Norwich	April 2016	325
North Tees, Stockton	October 2018	33
Nottingham Adults	February 2014	828
Nottingham Children's	May 2010	206
Oxford Churchill	July 2015	973
Oxford Women's	November 2016	82
Peterborough	May 2017	3
Plymouth	July 2015	437
Portsmouth	May 2014	77
Preston	March 2015	499
Reading	July 2014	119
Romford Queens Hospital	August 2019	17
Salford Royal	May 2014	656
Sheffield Northern General	April 2015	363
Shrewsbury & Telford	July 2014	426
Southampton Children's	November 2010	177
Southend	July 2013	206
St Heliers	February 2016	739
Stevenage (Lister)	March 2014	786
Stockport	February 2017	31
Stoke	February 2014	355
Sunderland	February 2015	262
Swansea	July 2014	61
Swindon Great Western	June 2016	8
Tameside	January 2018	3
Taunton Musgrove Park	July 2016	6
Torbay	January 2018	33
Truro Royal Cornwall	March 2016	311
Walsall Manor	December 2016	14
Warrington	August 2016	5
West Cumberland	May 2019	48
Wolverhampton	June 2015	232
Worcestershire Royal	December 2019	18
York	October 2013	440

Appendix B - Diagnoses and Cohorts

The following table shows which cohort to enter each patient into on RaDaR

Diagnosis	RaDaR Cohort
Adenine Phosphoribosyltransferase Deficiency (APRT-D)	APRT Deficiency
AH amyloidosis	MGRS
AHL amyloidosis	MGRS
AL amyloidosis	MGRS
Alport Syndrome Carrier - Female heterozygote for X-linked Alport Syndrome (COL4A5)	Alport
Alport Syndrome Carrier - Heterozygote for autosomal Alport Syndrome (COL4A3, COL4A4)	Alport
Alport Syndrome	Alport
Anti-Glomerular Basement Membrane Disease (Goodpastures)	Vasculitis
Atypical Haemolytic Uraemic Syndrome (aHUS)	aHUS
Autoimmune distal renal tubular acidosis	Tubulopathy
Autosomal recessive distal renal tubular acidosis	Tubulopathy
Autosomal recessive proximal renal tubular acidosis	Tubulopathy
Autosomal Dominant Polycystic Kidney Disease (ARPKD)	ADPKD
Autosomal Dominant Tubulointerstitial Kidney Disease (ADTKD)	ADTKD
Autosomal Recessive Polycystic Kidney Disease (ARPKD)	ARPKD/NPHP
Bartters Syndrome	Tubulopathy
BK Nephropathy	BK Nephropathy
C3 Glomerulopathy	MPGN
C3 glomerulonephritis with monoclonal gammopathy	MGRS
Calciphylaxis	Calciphylaxis
Crystalglobulinaemia	MGRS
Crystal-storing histiocytosis	MGRS
Cystinosis	Cystinosis
Cystinuria	Cystinuria
Dense Deposit Disease (DDD)	MPGN
Dent Disease	Dent & Lowe
Denys-Drash Syndrome	INS
Dominant hypophosphatemia with nephrolithiasis or osteoporosis	Tubulopathy
Drug induced Fanconi syndrome	Tubulopathy
Drug induced hypomagnesemia	Tubulopathy
Drug induced Nephrogenic Diabetes Insipidus	Tubulopathy
Epilepsy, Ataxia, Sensorineural deafness, Tubulopathy (EAST) Syndrome	Tubulopathy
Fabry Disease	Fabry

Diagnosis	RaDaR Cohort
Familial Hypomagnesaemia with hypercalciuria and nephrocalcinosis	Tubulopathy
Familial primary hypomagnesemia with hypocalcuria	Tubulopathy
Familial primary hypomagnesemia with normocalcuria EGF	Tubulopathy
Familial renal glucosuria	Tubulopathy
Fanconi Renotubular syndrome 1 (FRTS1)	Tubulopathy
Fanconi Renotubular syndrome 2 (FRTS2)	Tubulopathy
Fanconi Renotubular syndrome 3 (FRTS3)	Tubulopathy
Fibrillary Glomerulonephritis	MGRS
Fibromuscular Dysplasia	Fibromuscular Dysplasia
Focal Segmental Glomerulosclerosis (FSGS)	INS
Generalized pseudohypoaldosteronism type 1	Tubulopathy
Giant Vessel Arteritis	Vasculitis
Gitelman Syndrome	Tubulopathy
Glomerulocystic Disease	HNF1b
Heavy metal induced Fanconi syndrome	Tubulopathy
Hepatocyte Nuclear Factor-1 Beta Mutations (HNF1B)	HNF1b
Hereditary renal hypouricemia	Tubulopathy
Hereditary hypophosphatemic rickets with hypercalciuria	Tubulopathy
Hyperuricaemic Nephropathy	ADTKD
IgA Nephropathy	IgA Nephropathy
IgA Vasculitis (Henoch Schonlein)	Vasculitis
Immunotactoid/Glomerulonephritis with Organised Microtubular Monoclonal Immunoglobulin Deposits (GOMMID)	MGRS
Inherited/Genetic Diabetes Mellitus Type II (MODY)	HNF1b
Inherited Renal Cancer Syndrome	Renal Cancer Inherited
Intracapillary monoclonal IgM without cryoglobulin	MGRS
Intraglomerular/capillary lymphoma/leukaemia	MGRS
Isolated autosomal dominant hypomagnesemia, Glaudemans type	Tubulopathy
Large Vessel Vasculitis	Vasculitis
Liddle Syndromes	Tubulopathy
Light chain cast nephropathy	MGRS
Light chain proximal tubulopathy, crystalline	MGRS
Light chain proximal tubulopathy, non crystalline	MGRS
Lowe Syndrome	Dent & Lowe
Medium Vessel Vasculitis	Vasculitis
Medullary Cystic Kidney Disease	ADTKD
Membranous Nephropathy	Membranous Nephropathy
Membranoproliferative Glomerulonephritis (MPGN)	MPGN
Mitochondrial Disease of the Kidney	Mitochondrial

Diagnosis	RaDaR Cohort
Minimal Change Nephropathy	INS
Monoclonal Immunoglobulin Deposition Disease (MIDD; includes Light Chain Deposition Disease - LCDD; Heavy Chair Deposition Disease - HCDD; and Light and Heavy Chain Deposition Disease - LHCDD)	MGRS
Multicystic Dysplastic Kidneys	HNF1b
Nail Patella Syndrome	INS
Nephrogenic diabetes insipidus	Tubulopathy
Nephrogenic syndrome of inappropriate antidiuresis	Tubulopathy
Nephronophthisis	ARPKD/NPHP
Oncogenic osteomalacia	Tubulopathy
Osteopetrosis with renal tubular acidosis	Tubulopathy
Pregnancy and Chronic Kidney Disease	Pregnancy
Pregnancy & Lupus Nephritis	Pregnancy
Pregnancy in a Renal Transplant Recipient	Pregnancy
Primary hypomagnesemia with secondary hypocalcemia	Tubulopathy
Primary Hyperoxaluria	Hyperoxaluria
Primary Renal Fanconi syndrome	Tubulopathy
Proliferative glomerulonephritis with monoclonal immunoglobulin deposits (PGNMID)	MGRS
Proximal tubulopathy without crystals	MGRS
Pseudohypoaldosteronism type 2A	Tubulopathy
Pseudohypoaldosteronism type 2B	Tubulopathy
Pseudohypoaldosteronism type 2C	Tubulopathy
Pseudohypoaldosteronism type 2D	Tubulopathy
Pseudohypoaldosteronism type 2E	Tubulopathy
Pure Red Cell Aplasia	PRCA
Renal Cysts & Diabetes Syndrome	HNF1b
Shiga Toxin Associated Haemolytic Uraemic Syndrome (HUS)	STEC HUS
Renal pseudohypoaldosteronism type 1	Tubulopathy
Retroperitoneal Fibrosis	Retroperitoneal Fibrosis
Small Vessel Vasculitis (ANCA Associated)	Vasculitis
Steroid Resistant Nephrotic Syndrome (SRNS)	INS
Steroid Sensitive Nephrotic Syndrome (SSNS)	INS
Thin Basement Membrane Nephropathy	Alport
Thrombotic Microangiopathy with monoclonal gammopathy	MGRS
Tuberous Sclerosis	Tuberous Sclerosis
Type 1 cryoglobulinaemic Glomerulonephritis	MGRS
Unclassified Monoclonal Gammopathy of Renal Significance	MGRS
Uromodulin-Associated Nephropathy (Familial Juvenile Hyperuricaemic Nephropathy)	ADTKD
Variable Vessel Vasculitis	Vasculitis
Vasculitis	Vasculitis

Appendix C - Rare Disease Group Recruitment as of 1st September 2020

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	7207
ADTKD/FUAN	√	√	196
aHUS	√		263
Alport Syndrome	√	√	831
APRT-D	√		9
ARPKD/NPHP	√	√	219
BK Nephropathy	√	√	32
Calciphylaxis	√	√	47
Cystinosis	√		146
Cystinuria	√		435
Dent Disease & Lowe Syndrome	√	√	60
Fabry Disease	√		44
Fibromuscular Dysplasia	√		39
HNF1-B	√	√	81
Stec HUS	√		155
Hyperoxaluria	√		118
IgA Nephropathy	√	√	3829
Inherited Renal Cancer Syndromes	√		0
MGRS	√		147
MPGN, DDD and C3 Glomerulopathy	√	√	1068
MPGN Study	√	√	257
Membranous Nephropathy	√		2271
Mitochondrial Renal Disease	√		1
Nephrotic Syndrome	√	√	3797
NephroS Study	√	√	1275
Pregnancy & Chronic Kidney Disease	√	√	644
Pure Red Call Aplasia	√		6
Retroperitoneal Fibrosis	√		140
Tuberous Sclerosis	√		210
Tubulopathy	√	√	336
Vasculitis	√		4358
Withdrawn as not re-consented as an adult	-	-	121
Withdrawn consent	-	-	23

Appendix D - Rare Disease Group Contact Details

Rare Disease Group	Lead	E-mail
ADPKD	Richard Sandford	rns13@medschl.cam.ac.uk
ADTKD	Fiona Karet John Sayer	fek1000@cam.ac.uk john.sayer@newcastle.ac.uk
aHUS	David Kavanagh	David.Kavanagh@newcastle.ac.uk
Alport Syndrome	Neil Turner	Neil.Turner@ed.ac.uk
APRT-D	Shabbir Moochala	smoochhala@nhs.net
ARPKD/NPHP	Pat Wilson (Interim) Larissa Kerecuk (ARPKD Shalabh Srivastava (NPHP)	patricia.wilson@ucl.ac.uk larissakerecuk1@nhs.net shalabh.srivastava@newcastle.ac.uk
BK Nephropathy	Sian Griffin	Sian.Griffin2@wales.nhs.uk
Calciphylaxis	Smeeta Sinha	Smeeta.Sinha@srft.nhs.uk
Cystinosis	David Game	David.Game@gstt.nhs.uk
Cystinuria	Kay Thomas Richard Coward	Kay.Thomas@gstt.nhs.uk Richard.Coward@bristol.ac.uk
Dent Disease & Lowe Syndrome	Detlef Bockenhauer	d.bockenhauer@ucl.ac.uk
Fabry Disease	John Sayer	john.sayer@newcastle.ac.uk
Fibromuscular Dysplasia	Tina Chrysochou	tina.chrysochou@srft.nhs.uk
HNF1-B	Coralie Bingham	c.bingham@exeter.ac.uk
Stec HUS	Aoife Waters	aoife.waters@ucl.ac.uk
Hyperoxaluria	Shabbir Moochala	smoochhala@nhs.net
IgA Nephropathy	Jonathan Barrett	jb81@leicester.ac.uk
Inherited Renal Cancer Syndromes	Richard Sandford	rns13@medschl.cam.ac.uk
Membranoproliferative Glomerulonephritis, Dense Deposit Disease and C3 Glomerulopathy	Edwin Wong	Edwin.Wong@nuth.nhs.uk
Membranous Nephropathy	Durga.Kanigicherla@mft.nhs.uk	Durga.Kanigicherla@mft.nhs.uk
MGRS	Jenny Pinney	Jennifer.Pinney@uhb.nhs.uk
Mitochondrial Disease	John Sayer	john.sayer@newcastle.ac.uk
Nephrotic Syndrome	Moin Saleem	m.saleem@bristol.ac.uk
Pregnancy and Chronic Kidney Disease	Matt Hall	matthew.hall@nuh.nhs.uk
Pure Red Cell Aplasia	Ash Mikhail	Ashraf.Mikhail@wales.nhs.uk
Retroperitoneal Fibrosis	Fred Tam	f.tam@imperial.ac.uk
Tuberous Sclerosis	Chris Kingswood	Chris.Kingswood@bsuh.nhs.uk
Tubulopathy	Ben Walsh	ucgbsbw@ucl.ac.uk
Vasculitis	Oliver Flossman	Oliver.Flossmann@royalberkshire.nhs.uk

Appendix E - Membership of the Membership of the Rare Disease Committee

- Fiona Braddon, UK Renal Registry
- Kate Bramham, Kings College London (Deputy Chair)
- Paul Bristow, Kidney Care UK *
- Ron Cullen, UK Renal Registry
- Sandra Currie, Kidney Research UK *
- Elaine Davies, Kidney Research UK *
- Garry King, UK Renal Registry
- Danny Gale, London Royal Free (Chair)
- Matt Hall, Nottingham University Hospital
- Tess Harris, PKD Charity
- Graham Lipkin, University Hospital Birmingham
- Fiona Loud, Kidney Care UK *
- James Metcalf, UK Renal Registry
- Moin Saleem, Bristol Children's Hospital
- Retha Steenkamp, UK Renal Registry
- Peter Storey, Kidney Research UK *
- Neil Turner, Edinburgh Royal Infirmary

* Representatives from Kidney Care UK and Kidney Research UK may alternate their attendance at RDC meetings

Appendix F - Process for approving new Rare Disease Groups

Purpose of this paper

This paper details the steps required for a Rare Disease Group (RDG) to be approved by the RaDaR Operational Management Board (OMB) on behalf of the Renal Association (RA), its Rare Disease Committee (RDC) and the Renal Information Governance Board (RIGB).

Background

The prospective RDG should fairly represent national expertise for the disorder. This should include clinicians (at least one must be currently licensed to practice with the General Medical Council), scientists, and members of allied professions. The prospective group must also include active patient and/or carer representation, ideally an active representative of an established patient support group.

In order to be approved by the Renal Association the prospective RDG must comply with the requirements set out in the Standard Operating Policy (SOP). This is issued when a new RDG is formed and is renewed every five years or more frequently subject to the requirements of the OMB.

Eligibility

The establishment of new RDGs is welcomed and encouraged. Criteria for the approval are as follows:

- The disease to be studied is rare, that is <1:2000 (EU definition of rare disease). It is understood that the exact incidence of a rare disease is often unclear and that differing estimates may exist. Approval may be provided if the estimates are roughly in the area of 1:2000 and the other criteria are met.
- A least one patient representative is included in the proposed RDG membership listing
- Relevant medical specialties involved in the care of the respective disease are represented.
- RDG members have the appropriate expertise based on their current activity and/or publication record.
- Collaboration with international registries is encouraged.

Approval Process

The process for approving new RDGs is as follows:

1. The application form is sent to the proposed lead clinician.

2. The completed form is returned to Garry King, the RaDaR Operations Officer, for checking.

3. The accepted form is sent to Ron Cullen, Chief Executive of the UK Renal Registry for initial approval.

4. The form is then sent to Danny Gale as the Chair of the Renal Association's Rare Disease Committee.

5. The application is reviewed by the Rare Disease Committee with any queries fed back to the proposed lead clinician.

6. Upon approval, the new RDG Lead is notified that their application has been successful and are asked to sign the SOP to confirm their acceptance of its regulations.

7. RaDaR's funders (Kidney Research UK and Kidney Care UK) are notified that a new condition has been approved.

8. The new RDG Lead is advised how to start writing their rarerenal.org pages, with the help of the Editorial Board. Guidelines on how to write for a non-medical audience can be found on rarerenal.org. The Patient and RDG information pages are essential before a condition can open for recruitment on RaDaR, along with defined inclusion-exclusion criteria. The Clinician's information is optional at this stage and can be worked on at a later date.

9. The new condition opens for recruitment on RaDaR with generic data fields. Condition-specific data fields are requested from the RDG lead and are added subject to UKRR programmers' availability.

10. All currently recruiting sites are informed of the new condition and a News article is placed on rarerenal.org.

Appendix G – Membership of the RareRenal.org Editorial Board

- Kate Bramham, Kings College London
- Ron Cullen, Chief Executive of the UK Renal Registry
- Garry King, and Project Support Officer for RaDaR and RareRenal.org
- Danny Gale, London Royal Free
- Julie Slevin, Project Support Officer for Think Kidneys and Social Media specialist
- Detlef Bockenhauer, former Chair of the Rare Disease Committee and Medical Editor responsible for the scientific accuracy of content