Top level metadata in RaDaR, updated June 2023

RaDaR Registry of Rare Kidney Diseases

UKKA UK Kidney Association Rare Renal

Rare Disease Cohort	Cohort Size	Lab Results via data feed	Patients on RRT	Number of people with creatinine readings	Mean number of creatinine readings per person
Alport Syndrome	1117	848	423	863	76
APRT Deficiency	10	6	2	8	81
Atypical Haemolytic Uraemic Syndrome	307	248	156	253	240
Autosomal Dominant Polycystic Kidney Disease	8688	7058	3635	7246	85
Autosomal Dominant Tubulointerstitial Kidney Disease (FUAN)	258	201	118	204	86
Autosomal Recessive Polycystic Kidney Disease/Nephronophthisis	265	211	119	230	106
BK Nephropathy	129	123	123	123	302
Calciphylaxis	67	52	59	51	237
CKD due to Genetic Factors in people of African ancestry	394	161	127	161	134
Congenital Anomalies of the Kidneys and Urinary Tracts	60	39	12	45	48
Cystinosis	182	157	101	159	141
Cystinuria	521	344	10	367	28
Dent Disease and Lowe Syndrome	70	40	17	43	79
Fabry Disease	60	49	26	49	81
Fibromuscular Dysplasia	60	43	0	41	20
HNF1b Mutations	111	70	16	75	44
Hyperoxaluria	136	110	43	114	80
Idiopathic Nephrotic Syndrome	4737	3486	1190	3979	120
IgA Nephropathy	4936	4179	2588	4252	109
Inherited Renal Cancer Syndromes	347	15	4	15	68
Lupus Nephritis	50	21	1	28	42
Membranoproliferative Glomerulonephritis	1226	949	632	1035	150
Membranous Nephropathy	2745	2100	598	2196	85
Mitochondrial Renal Disease	5	1	0	1	5
Monoclonal Gammopathy of Renal Significance	238	175	109	177	122
Post Transplant Cytomegalovirus (opening June 2024)	0	0	0	0	0
Pregnancy	792	611	249	690	97
Pure Red Cell Aplasia	9	6	6	6	237
Retroperitoneal Fibrosis	160	104	22	122	70
STEC-associated HUS	184	112	81	122	55
Tuberous Sclerosis	292	202	22	210	35
Tubulopathy	416	244	17	256	48
Vasculitis	5484	3701	1229	3950	88