

Rare Disease Group Recruitment as of 1st September 2019

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	6459
ADTKD/FUAN	√	√	180
aHUS	√		243
Alport Syndrome	√	√	770
APRT-D	√		8
ARPKD/NPHP	√	√	209
BK Nephropathy	√		7
Calciophylaxis	√	√	40
Cystinosis	√		137
Cystinuria	√		410
Dent Disease & Lowe Syndrome	√	√	58
Fabry Disease	√		42
Fibromuscular Dysplasia	√		30
HNF1-B	√	√	76
Stec HUS	√		148
Hyperoxaluria	√		111
Hypokalaemic Alkaloses	√	√	309
IgA Nephropathy	√	√	3380
MGRS	√		105
MPGN, DDD and C3 Glomerulopathy	√	√	1008
MPGN Study	√	√	256
Membranous Nephropathy	√		2017
Nephrotic Syndrome	√	√	3361
NephroS Study	√	√	1246
Pregnancy & Chronic Kidney Disease	√	√	578
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		124
Tuberous Sclerosis	√		170
Vasculitis	√		3985
Withdrawn as not re-consented as an adult	-	-	151
Withdrawn consent	-	-	7