

Rare Disease Group Recruitment as of 3rd February 2020

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	6971
ADTKD/FUAN	√	√	190
aHUS	√		256
Alport Syndrome	√	√	816
APRT-D	√		8
ARPKD/NPHP	√	√	217
BK Nephropathy	√	√	25
Calciophylaxis	√	√	44
Cystinosis	√		144
Cystinuria	√		428
Dent Disease & Lowe Syndrome	√	√	59
Fabry Disease	√		44
Fibromuscular Dysplasia	√		37
HNF1-B	√	√	80
Stec HUS	√		150
Hyperoxaluria	√		118
IgA Nephropathy	√	√	3721
MGRS	√		131
MPGN, DDD and C3 Glomerulopathy	√	√	1054
MPGN Study	√	√	256
Membranous Nephropathy	√		2227
Nephrotic Syndrome	√	√	3655
NephroS Study	√	√	1267
Pregnancy & Chronic Kidney Disease	√	√	618
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		136
Tuberous Sclerosis	√		204
Tubulopathy	√	√	326
Vasculitis	√		4241
Withdrawn as not re-consented as an adult	-	-	123
Withdrawn consent	-	-	18