

## Rare Disease Group Recruitment as of 1<sup>st</sup> August 2019

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	6383
ADTKD/FUAN	√	√	180
aHUS	√		240
Alport Syndrome	√	√	762
APRT-D	√		8
ARPKD/NPHP	√	√	208
BK Nephropathy	√		2
Calciophylaxis	√	√	40
Cystinosis	√		137
Cystinuria	√		409
Dent Disease & Lowe Syndrome	√	√	57
Fabry Disease	√		42
Fibromuscular Dysplasia	√		29
HNF1-B	√	√	74
Stec HUS	√		150
Hyperoxaluria	√		111
Hypokalaemic Alkaloses	√	√	307
IgA Nephropathy	√	√	3344
MGRS	√		100
MPGN, DDD and C3 Glomerulopathy	√	√	1000
MPGN Study	√	√	256
Membranous Nephropathy	√		1986
Nephrotic Syndrome	√	√	3324
NephroS Study	√	√	1240
Pregnancy & Chronic Kidney Disease	√	√	572
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		123
Tuberous Sclerosis	√		169
Vasculitis	√		3956
Withdrawn as not re-consented as an adult	-	-	151
Withdrawn consent	-	-	6