

Rare Disease Group Recruitment as of 1st July 2019

Rare Disease Group	Current data entry		Number of recruits
	Generic	Condition specific	
ADPKD	√	√	6258
ADTKD/FUAN	√	√	179
aHUS	√		236
Alport Syndrome	√	√	749
APRT-D	√		8
ARPKD/NPHP	√	√	203
BK Nephropathy	√		1
Calciophylaxis	√	√	38
Cystinosis	√		136
Cystinuria	√		407
Dent Disease & Lowe Syndrome	√	√	57
Fabry Disease	√		41
Fibromuscular Dysplasia	√		28
HNF1-B	√	√	74
Stec HUS	√		150
Hyperoxaluria	√		111
Hypokalaemic Alkaloses	√	√	297
IgA Nephropathy	√	√	3275
MGRS	√		91
MPGN, DDD and C3 Glomerulopathy	√	√	987
MPGN Study	√	√	256
Membranous Nephropathy	√		1950
Nephrotic Syndrome	√	√	3279
NephroS Study	√	√	1215
Pregnancy & Chronic Kidney Disease	√	√	567
Pure Red Cell Aplasia	√		6
Retroperitoneal Fibrosis	√		116
Tuberous Sclerosis	√		156
Vasculitis	√		3899
Withdrawn as not re-consented as an adult	-	-	158