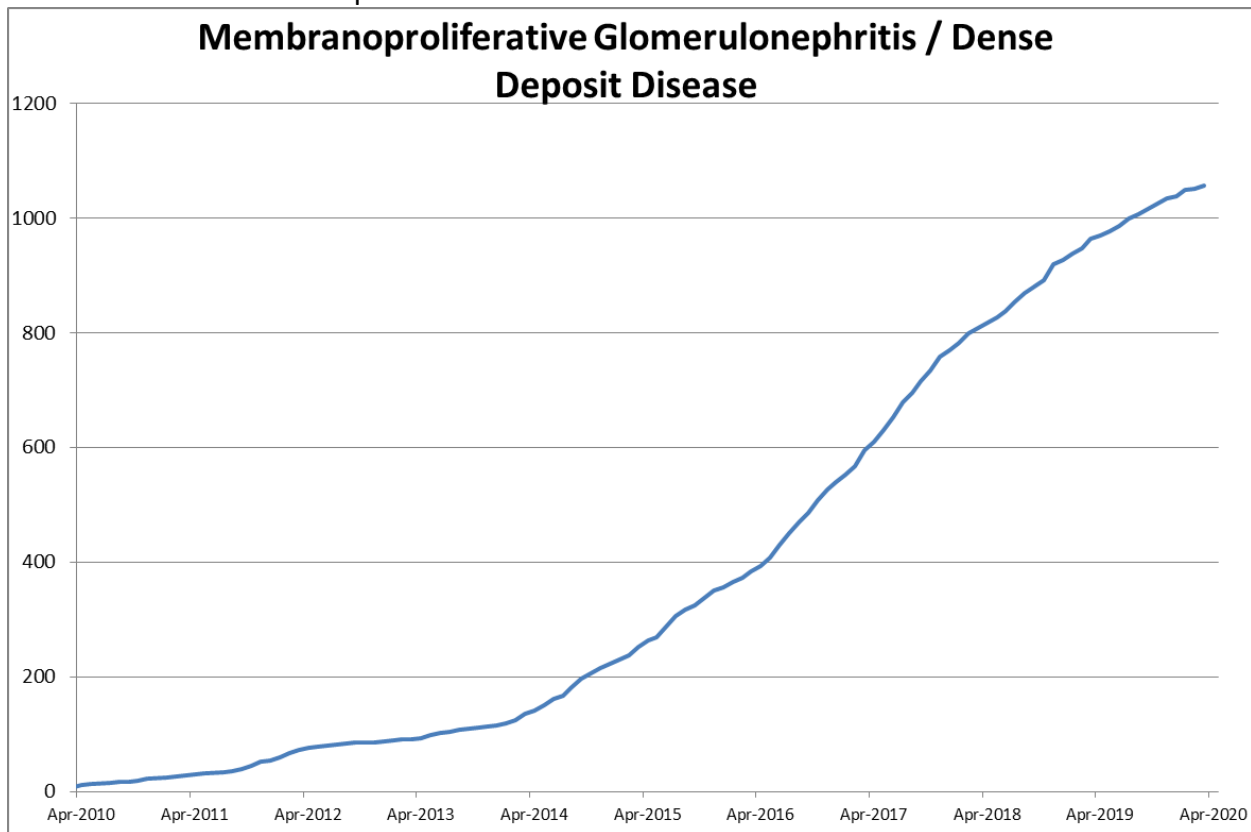


RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

Rare Disease Group	MPGN, DDD and C3G
Lead Clinician	Edwin Wong
Summary of RDG Activity (Meetings, patient events)	Annual general meeting of MPGNDDD patient group (16 th November 2019), Birmingham. C3G patient roadshow (28 th September 2019), Birmingham
Grants awarded that use RaDaR infrastructure or data (Please do not include other grants awarded to RDG members)	Funder: Title of project: Principal Investigator(s): Amount:
Conference posters/presentations using and acknowledging RaDaR data	
Publications using and acknowledging RaDaR data (Please do not include other publications by RDG members)	AP Levine, M Chan, O Sadeghi-Alavijeh, EKS Wong et al. Large-Scale Whole-Genome Sequencing Reveals the Genetic Architecture of Primary Membranoproliferative GN and C3 Glomerulopathy, JASN 2020 doi 10.1681/ASN.2019040433
Number of commercial partners using RaDaR data to inform study design or recruitment sites	Currently 2 clinical trials of complement inhibition in C3G open in UK
Recruits as of 1st April 2019	966
Recruits as of 31st March 2020	1061
New recruits	95

Recruitment Overview Graph



Recruits by site

Hospital	Patients
Newcastle upon Tyne - Freeman & Victoria Hospitals	55
London - Guy's and St. Thomas' Hospital	50
Stoke -Royal Stoke University Hospital	45
Cardiff - UHW (Adult and Paediatrics)	42
London - Royal Free Hospital	36
Middlesbrough - James Cook	33
Manchester Royal Infirmary	32
Glasgow - Queen Elizabeth University Hospital	29
Exeter - Royal Devon and Exeter Hospital	28
Stevenage - Lister Hospital	27
Oxford - Churchill	25
Liverpool Royal UHT	25
London - St George's Hospital	23
Nottingham - QMC - Children's Kidney Unit	23
Nottingham City Hospital	23
Glasgow - The Royal Hospital for Children	23
Wolverhampton - New Cross Hospital	22
Birmingham Childrens Hospital	22
Coventry and Warwickshire	22
Preston	21

London - Great Ormond Street Hospital for Children	20
Leicester	19
Sheffield - Northern General Hospital	19
Leeds - St James's Hospital	18
London - Barts Health	18
Carshalton - St Helier Renal Unit	17
Birmingham - Queen Elizabeth Hospital	17
York	17
Plymouth - Derriford Hospital	17
Shrewsbury Royal Hospital	16
Derby - Royal Derby Hospital	16
Birmingham - Heart of England NHS Foundation Trust	15
Manchester Childrens Hospital	15
London - King's College Hospital	14
Hull	14
Kent and Canterbury Hospital	14
Gloucester - Gloucestershire Royal Hospital	14
Sunderland Royal Hospital	11
Liverpool - Alder Hey Childrens	11
Leeds - Childrens Hospital	11
Truro - Royal Cornwall Hospital	10
Norfolk and Norwich University Hospital	10
Salford Royal Manchester	9
Bristol Royal Hospital for Children	8
Kings Lynn	8
Ipswich Hospital	7
Basildon Hospital	7
Birkenhead - Arrowe Park	7
Chelmsford - Broomfield Hospital	6
Southampton Childrens Hospital	5
Reading - Royal Berkshire NHS Foundation Trust	5
Brighton - Sussex Kidney Unit	5
Bradford Renal Unit	5
Inverness - Raigmore Hospital	5
Stockton-on-Tees-North Tees	4
Cambridge Kidney Unit	4
Whitehaven -West Cumberland Hospital	3
Colchester General Hospital	3
Edinburgh Royal Infirmary	3
Dundee Ninewells	3
London - West - Imperial	3
Portsmouth - Wessex Renal and Transplant Service	3
Carlisle - Cumberland Infirmary	2
Belfast Ulster Hospital	2
Bristol - Southmead Hospital	2

Doncaster Royal Infirmary	2
Torbay Hospital	2
Aintree University Hospital	1
Belfast - Royal Hospital for Sick Children	1
Southend	1
Dumfries Renal Unit	1
Darlington	1
Swansea - Morriston Hospital	1
Hereford County Hospital	1
Hartlepool	1
Newry - Daisy Hill Hospital	1