

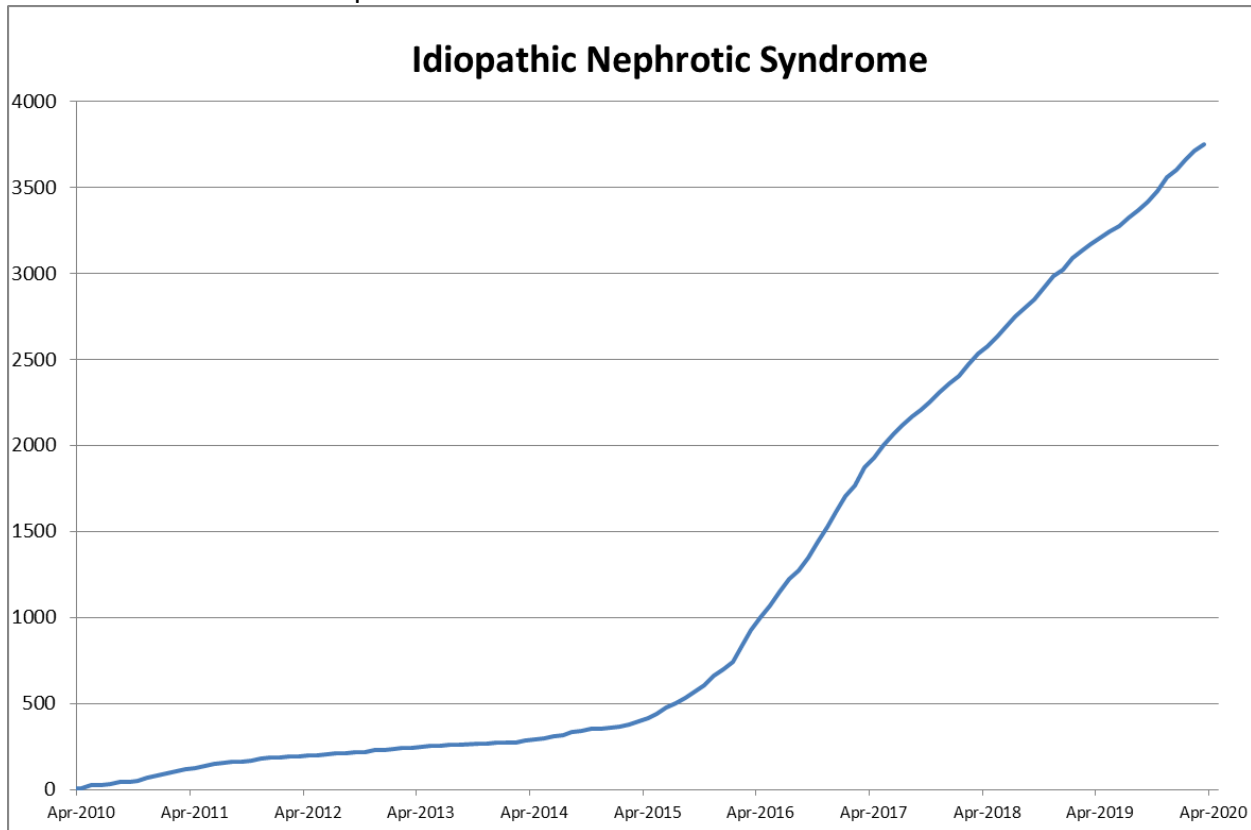
RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

<p>Rare Disease Group</p>	<p>Nephrotic syndrome</p>
<p>Lead Clinician</p>	<p>Moin Saleem</p>
<p>Summary of RDG Activity (Meetings, patient events)</p>	<p>The 5th annual National Nephrotic Syndrome Patient Day took place at the Nottingham Playhouse Theatre on Thursday 2nd of May 2019. The day was sponsored by the Nephrotic Syndrome Trust (NeST), Kidney Research UK and the British Kidney Patient Association.</p> <p>A patient App is currently under development. Before the COVID-19 lockdown roadshows were taking place across different cities in the UK. The most recent roadshow took place on March 12th 2020 in Bristol, UK.</p>
<p>Grants awarded that use RaDaR infrastructure or data</p> <p>(Please do not include other grants awarded to RDG members)</p>	<p>Funder: MRC</p> <p>Title of project: MICA: NURTuRE – changing the landscape of renal medicine to foster a unified approach to stratified medicine</p> <p>Principal Investigator(s): Moin Saleem</p> <p>Amount: 3.4 million gbp</p>
<p>Conference posters/presentations using and acknowledging RaDaR data</p>	<p>ASN Kidney Week, Washington DC, 2019</p> <ol style="list-style-type: none"> 1. Genetic polymorphisms in glomerular basement genes enriched in paediatric Nephrotic Syndrome patients. 2. Incidence of single heterozygous variants in ‘nephrotic’ genes in non-genetic paediatric SRNS <p>UK Kidney Week 2019</p> <ol style="list-style-type: none"> 1. Genetic risk factors in UK paediatric nephrotic syndrome cohort. 2. Analysis of intensified immunosuppression response in genetically-stratified steroid resistant nephrotic syndrome (SRNS) patients predicts outcomes and suggests distinct immune

	mechanisms
<p>Publications using and acknowledging RaDaR data</p> <p>(Please do not include other publications by RDG members)</p>	<p>Molecular stratification of idiopathic nephrotic syndrome. Saleem MA. Nat Rev Nephrol. 2019 Dec;15(12):750-765. doi: 10.1038/s41581-019-0217-5. Epub 2019 Oct 25. PMID: 31654044</p> <p>Response to First Course of Intensified Immunosuppression in Genetically-Stratified Steroid Resistant Nephrotic Syndrome. Mason AE, Sen ES, Bierzynska A, Colby E, Afzal M, Dorval G, Koziell AB, Williams M, Boyer O, Welsh GI, Saleem MA; UK RaDaR/NephroS Study. Clin J Am Soc Nephrol. 2020 Apr 21:</p> <p>A role for OCRL in glomerular function and disease. Preston R, Naylor RW, Stewart G, Bierzynska A, Saleem MA, Lowe M, Lennon R. Pediatr Nephrol. 2020 Apr;35(4):641-648.</p> <p>TBC1D8B Loss-of-Function Mutations Lead to X-Linked Nephrotic Syndrome via Defective Trafficking Pathways. Dorval G, Kuzmuk V, Gribouval O, Welsh GI, Bierzynska A, Schmitt A, Miserey-Lenkei S, Koziell A, Haq S, Benmerah A, Mollet G, Boyer O, Saleem MA, Antignac C. Am J Hum Genet. 2019 Feb 7;104(2):348-355</p>
Number of commercial partners using RaDaR data to inform study design or recruitment sites	1
Recruits as of 1st April 2019	3178
Recruits as of 31st March 2020	3758
New recruits	580

Recruitment Overview Graph



Recruits by site

Hospital	Patients
London - Guy's and St. Thomas' Hospital	225
Birmingham Childrens Hospital	189
London - Royal Free Hospital	148
Carshalton - St Helier Renal Unit	128
Glasgow - Queen Elizabeth University Hospital	126
Manchester Childrens Hospital	124
Cardiff - UHW (Adult and Paediatrics)	123
Oxford - Churchill	122
Stevenage - Lister Hospital	121
Salford Royal Manchester	118
Leeds - Childrens Hospital	98
London - West - Imperial	89
Stoke -Royal Stoke University Hospital	88
London - St George's Hospital	86
London - Great Ormond Street Hospital for Children	84
Birmingham - Queen Elizabeth Hospital	82
Manchester Royal Infirmary	81
Coventry and Warwickshire	78
Newcastle upon Tyne - Freeman & Victoria Hospitals	77
Nottingham - QMC - Children's Kidney Unit	75

Southampton Childrens Hospital	73
Bristol Royal Hospital for Children	73
Leicester	71
Nottingham City Hospital	58
Exeter - Royal Devon and Exeter Hospital	54
Norfolk and Norwich University Hospital	52
Sheffield - Northern General Hospital	49
Liverpool - Alder Hey Childrens	49
Derby - Royal Derby Hospital	49
Shrewsbury Royal Hospital	49
Middlesbrough - James Cook	47
Plymouth - Derriford Hospital	44
Liverpool Royal UHT	42
Bristol - Southmead Hospital	42
Glasgow - The Royal Hospital for Children	41
Chelmsford - Broomfield Hospital	40
York	40
London - Barts Health	37
Leeds - St James's Hospital	36
Birmingham - Heart of England NHS Foundation Trust	35
Gloucester - Gloucestershire Royal Hospital	34
Preston	33
Cambridge Kidney Unit	28
Kent and Canterbury Hospital	27
Sunderland Royal Hospital	26
Ipswich Hospital	25
London - King's College Hospital	25
Colchester General Hospital	23
Wolverhampton - New Cross Hospital	23
Brighton - Sussex Kidney Unit	21
Truro - Royal Cornwall Hospital	19
Hereford County Hospital	17
Basildon Hospital	15
Inverness - Raigmore Hospital	15
Blackburn - Royal Blackburn Hospital	14
Aintree University Hospital	11
Bradford Renal Unit	11
Huddersfield Royal Infirmary	11
Carlisle - Cumberland Infirmary	11
Airedale General Hospital	9
Swansea - Morriston Hospital	9
Macclesfield District General Hospital	7
Birkenhead - Arrowe Park	7
Swindon - Great Western Hospital	6
Walsall Manor Hospital	6

Chertsey - Ashford & St Peters Hospital	6
Bath - Royal United Hospital	6
Stockport	6
Dundee Ninewells	5
Dudley - Russells Hall Hospital	5
Burton Hospital	5
Belfast Ulster Hospital	4
Romford - Queens Hospital	4
Bury St Edmunds - West Suffolk	4
Taunton - Musgrove Park Hospital	3
Tameside General Hospital, Ashton Under Lyne	3
Darlington	3
Hull	3
Chester - Countess of Chester	3
Stockton-on-Tees-North Tees	3
Southend	2
Hartlepool	2
Edinburgh Royal Infirmary	2
Kilmarnock - Crosshouse - John Stevenson Lynch Renal Unit	2
Warrington	2
Doncaster Royal Infirmary	2
Torbay Hospital	2
Belfast - Royal Hospital for Sick Children	1
Kings Lynn	1
Whitehaven -West Cumberland Hospital	1
Dumfries Renal Unit	1
Aintree- Waterloo Day Hospital	1