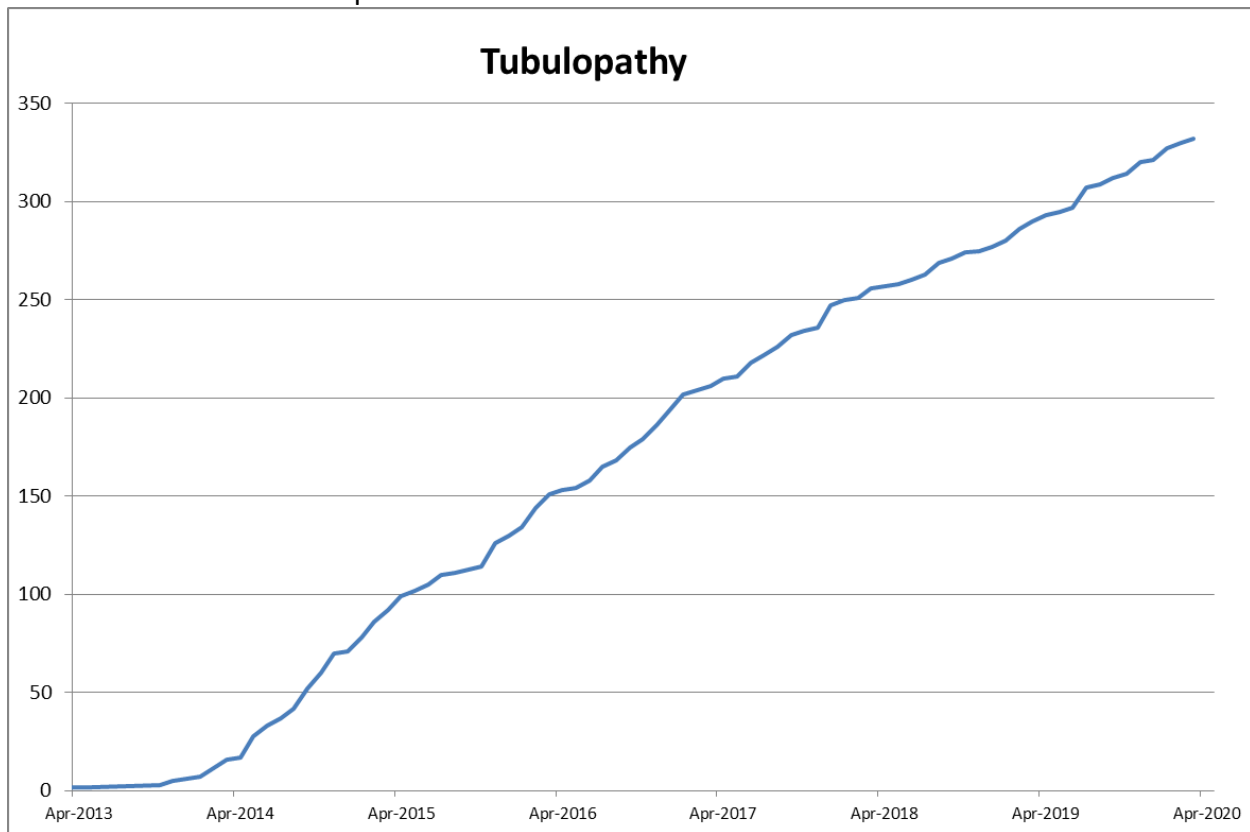


## RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

<b>Rare Disease Group</b>	Tubulopathy
<b>Lead Clinician</b>	Ben Walsh
<b>Summary of RDG Activity (Meetings, patient events)</b>	<p>RDG committee meeting 2020 postponed due to COVID19 crisis. Virtual meeting July 2020.</p> <p>National Gitelman/Bartter patient education day postponed due to COVID19 crisis.</p>
<b>Grants awarded that use RaDaR infrastructure or data  (Please do not include other grants awarded to RDG members)</b>	None Reported
<b>Conference posters/presentations using and acknowledging RaDaR data</b>	None Reported
<b>Publications using and acknowledging RaDaR data  (Please do not include other publications by RDG members)</b>	<p>Treatment and long-term outcome in primary distal renal tubular acidosis Nephrology Dialysis Transplantation, Volume 34, Issue 6, June 2019, Pages 981–991, <a href="https://doi.org/10.1093/ndt/gfy409">https://doi.org/10.1093/ndt/gfy409</a></p> <p>High-throughput sequencing contributes to the diagnosis of tubulopathies and familial hypercalcemia hypocalciuria in adults Kidney International Volume 96, Issue 6, December 2019, Pages 1408-1416 <a href="https://doi.org/10.1016/j.kint.2019.08.027">https://doi.org/10.1016/j.kint.2019.08.027</a></p>
<b>Number of commercial partners using RaDaR data to inform study design or recruitment sites</b>	1-Advicinne
<b>Recruits as of 1<sup>st</sup> April 2019</b>	291
<b>Recruits as of 31<sup>st</sup> March 2020</b>	333
<b>New recruits</b>	42

Recruitment Overview Graph



Recruits by site

Hospital	Patients
Cambridge Kidney Unit	79
London - Royal Free Hospital	34
London - Great Ormond Street Hospital for Children	25
Newcastle upon Tyne - Freeman & Victoria Hospitals	20
London - Guy's and St. Thomas' Hospital	12
Birmingham Childrens Hospital	12
Manchester Childrens Hospital	9
York	8
Gloucester - Gloucestershire Royal Hospital	7
Sunderland Royal Hospital	7
Bristol - Southmead Hospital	6
Salford Royal Manchester	6
Bradford Renal Unit	6
Birmingham - Queen Elizabeth Hospital	6
Middlesbrough - James Cook	5
Coventry and Warwickshire	5
Nottingham - QMC - Children's Kidney Unit	5
Manchester Royal Infirmary	4
Stoke -Royal Stoke University Hospital	4
Leicester	4

Liverpool Royal UHT	4
Exeter - Royal Devon and Exeter Hospital	4
Derby - Royal Derby Hospital	4
Carlisle - Cumberland Infirmary	4
Belfast Ulster Hospital	3
Preston	3
Nottingham City Hospital	3
Norfolk and Norwich University Hospital	3
Bristol Royal Hospital for Children	3
London - St George's Hospital	3
Oxford - Churchill	2
Cardiff - UHW (Adult and Paediatrics)	2
Liverpool - Alder Hey Childrens	2
Southampton Childrens Hospital	2
Basildon Hospital	2
Leeds - Childrens Hospital	2
Plymouth - Derriford Hospital	2
Birmingham - Sandwell	1
Glasgow - Queen Elizabeth University Hospital	1
Airedale General Hospital	1
Kent and Canterbury Hospital	1
Chelmsford - Broomfield Hospital	1
Torbay Hospital	1
Carshalton - St Helier Renal Unit	1
Huddersfield Royal Infirmary	1
Warrington	1
Stevenage - Lister Hospital	1
Peterborough	1
Aberdeen Royal Infirmary	1
Shrewsbury Royal Hospital	1
Dumfries Renal Unit	1
Newry - Daisy Hill Hospital	1
Swansea - Morriston Hospital	1
London - King's College Hospital	1
Edinburgh Royal Infirmary	1
Glasgow - The Royal Hospital for Children	1
Inverness - Raigmore Hospital	1
Birkenhead - Arrowe Park	1