

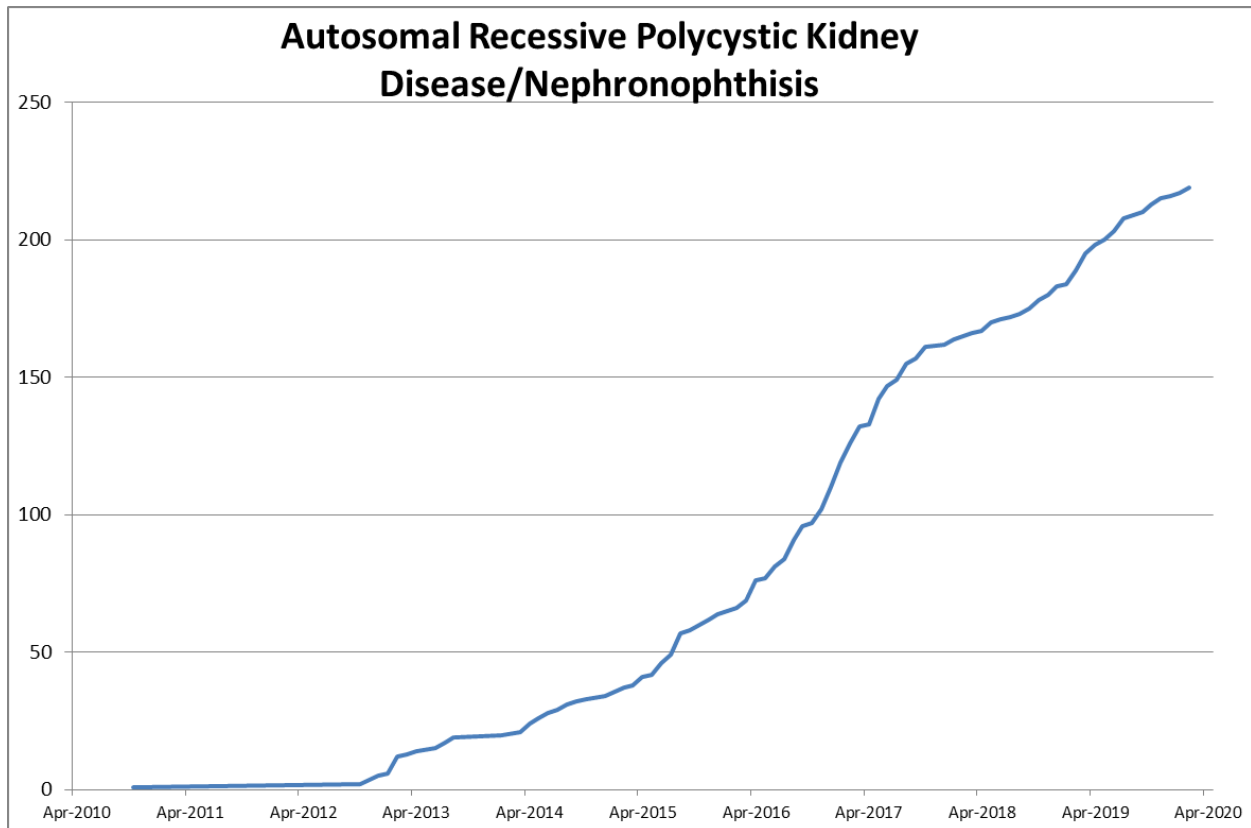
## RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

Rare Disease Group	ARPKD/NPHP
Lead Clinician	Dr Larissa Kerecuk/ Prof Patricia Wilson
Summary of RDG Activity (Meetings, patient events)	<p>Business meeting 10/05/2019</p> <p>Business meeting. 18/4/2020 – online remote - pending decision due to COVID pandemic</p> <p>ARPKD Patient day: Evelina Children’s Hospital, Kings’ College London 29/06/2019.</p> <p>ARPKD/NPHP Patient day: Newcastle 18/4/2020 – postponed due to COVID</p> <p>PKD-charity sponsored patient and carer help-line</p>
Grants awarded that use RaDaR infrastructure or data  (Please do not include other grants awarded to RDG members)	<p>Funder: PKD Charity.</p> <p>Title of project: RaDar database enrichment and expansion of research into children with ARPKD and ADPKD: Biomarker analysis of urinary and blood exosomes.</p> <p>Principal Investigator(s): P. Wilson</p> <p>Amount: 50,000</p>
Conference posters/presentations using and acknowledging RaDaR data	None reported
Publications using and acknowledging RaDaR data  (Please do not include other publications by RDG members)	<p>Guidelines for prenatal cystic kidney disease Contribution to Global AregPKD RA/BAPN guidelines: Care of children with or at risk of PKD</p>
Number of commercial partners using RaDaR data to inform study design or recruitment sites	None Reported

<b>Recruits as of 1<sup>st</sup> April 2019</b>	194
<b>Recruits as of 31<sup>st</sup> March 2020</b>	219
<b>New recruits</b>	25

#### Recruitment Overview Graph



#### Recruits by site

<b>Hospital</b>	<b>Patients</b>
Birmingham Childrens Hospital	32
Stevenage - Lister Hospital	16
Newcastle upon Tyne - Freeman & Victoria Hospitals	13
London - Guy's and St. Thomas' Hospital	13
Carshalton - St Helier Renal Unit	12
London - Royal Free Hospital	11
London - Great Ormond Street Hospital for Children	10
Nottingham - QMC - Children's Kidney Unit	10
Leeds - Childrens Hospital	8
Manchester Childrens Hospital	8
Birmingham - Heart of England NHS Foundation Trust	7
Hull	6

Cardiff - UHW (Adult and Paediatrics)	5
London - King's College Hospital	4
Nottingham City Hospital	4
Liverpool Royal UHT	3
Shrewsbury Royal Hospital	3
Kent and Canterbury Hospital	3
Wolverhampton - New Cross Hospital	3
London - St George's Hospital	3
Oxford - Churchill	2
Aintree University Hospital	2
Torbay Hospital	2
Inverness - Raigmore Hospital	2
Plymouth - Derriford Hospital	2
Sheffield - Northern General Hospital	2
Liverpool - Alder Hey Childrens	2
Belfast - Royal Hospital for Sick Children	2
Edinburgh Royal Infirmary	2
Glasgow - The Royal Hospital for Children	2
Leicester	2
Gloucester - Gloucestershire Royal Hospital	2
Southampton Childrens Hospital	2
Birkenhead - Arrowe Park	2
Cambridge Kidney Unit	2
Dudley - Russells Hall Hospital	1
Dundee Ninewells	1
Hereford County Hospital	1
Kilmarnock - Crosshouse - John Stevenson Lynch Renal Unit	1
Carlisle - Cumberland Infirmary	1
Colchester General Hospital	1
Kings Lynn	1
Glasgow - Queen Elizabeth University Hospital	1
Bristol Royal Hospital for Children	1
Brighton - Sussex Kidney Unit	1
Norfolk and Norwich University Hospital	1
Manchester Royal Infirmary	1
Chelmsford - Broomfield Hospital	1
Stoke -Royal Stoke University Hospital	1
Basildon Hospital	1