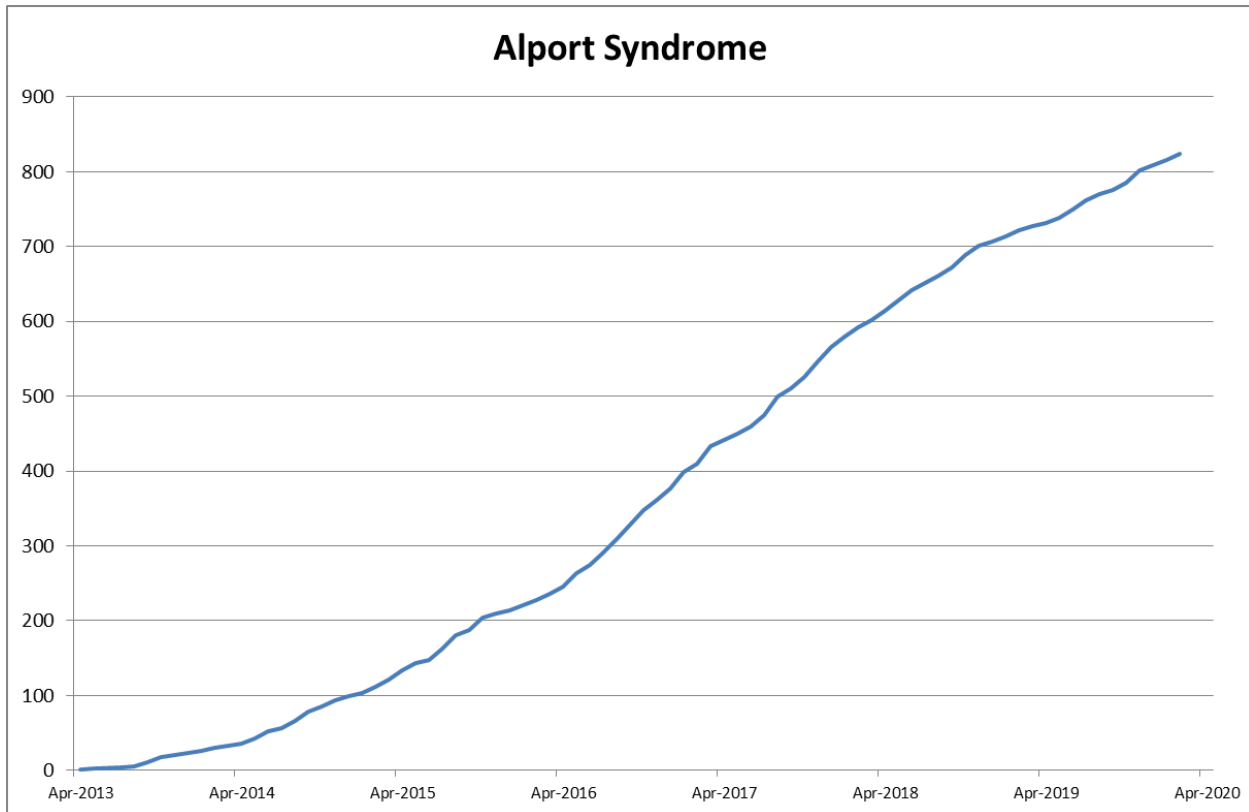


RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

Rare Disease Group	Alport Syndrome
Lead Clinician	Neil Turner
Summary of RDG Activity (Meetings, patient events)	<p>Patients, researchers and clinicians joined in the International Alport workshop in Siena in October 2019 – the UK group were prominent in organising and attendance. https://youtu.be/QH8mDTmKaVU</p> <p>Coronavirus made it necessary to postpone the 2020 conference in China until 2021, but plans for regular online information events to promulgate Alport research are bearing fruit, see https://bit.ly/2B0LEvP</p> <p>We are in discussion with pharma about initiatives to support work to enrich Radar data.</p>
Grants awarded that use RaDaR infrastructure or data (Please do not include other grants awarded to RDG members)	None Reported
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)	None Reported
Number of commercial partners using RaDaR data to inform study design or recruitment sites	None Reported
Recruits as of 1st April 2019	727
Recruits as of 31st March 2020	824
New recruits	97

Recruitment Overview Graph



Recruits by site

Hospital	Patients
London - Royal Free Hospital	59
Nottingham City Hospital	54
London - Guy's and St. Thomas' Hospital	43
Birmingham Childrens Hospital	43
Edinburgh Royal Infirmary	40
Manchester Childrens Hospital	32
Newcastle upon Tyne - Freeman & Victoria Hospitals	32
Oxford - Churchill	30
Southampton Childrens Hospital	22
Norfolk and Norwich University Hospital	21
Cambridge Kidney Unit	21
Glasgow - Queen Elizabeth University Hospital	18
Liverpool Royal UHT	18
Derby - Royal Derby Hospital	17
Manchester Royal Infirmary	17
Nottingham - QMC - Children's Kidney Unit	17
Preston	17
London - King's College Hospital	16
Coventry and Warwickshire	16
Birmingham - Queen Elizabeth Hospital	14

Leeds - Childrens Hospital	14
Stoke -Royal Stoke University Hospital	13
Portsmouth - Wessex Renal and Transplant Service	13
Plymouth - Derriford Hospital	12
Reading - Royal Berkshire NHS Foundation Trust	12
London - Barts Health	11
Leeds - St James's Hospital	11
Truro - Royal Cornwall Hospital	10
Hull	9
Exeter - Royal Devon and Exeter Hospital	9
Cardiff - UHW (Adult and Paediatrics)	8
Kent and Canterbury Hospital	8
Ipswich Hospital	8
Shrewsbury Royal Hospital	8
Middlesbrough - James Cook	8
Basildon Hospital	8
Sheffield - Northern General Hospital	8
Stevenage - Lister Hospital	7
Bristol - Southmead Hospital	7
Carshalton - St Helier Renal Unit	7
London - St George's Hospital	7
Liverpool - Alder Hey Childrens	6
Inverness - Raigmore Hospital	5
Birmingham - Heart of England NHS Foundation Trust	5
Wolverhampton - New Cross Hospital	5
Sunderland Royal Hospital	4
Glasgow - The Royal Hospital for Children	4
Birkenhead - Arrowe Park	3
Dundee Ninewells	3
Bradford Renal Unit	3
Leicester	3
Kilmarnock - Crosshouse - John Stevenson Lynch Renal Unit	3
Salford Royal Manchester	3
Huddersfield Royal Infirmary	3
Gloucester - Gloucestershire Royal Hospital	2
Colchester General Hospital	2
Kings Lynn	2
Chertsey - Ashford & St Peters Hospital	2
Bury St Edmunds - West Suffolk	2
Hereford County Hospital	2
York	2
Chelmsford - Broomfield Hospital	2
Southend	1
Darlington	1
London - West - Imperial	1

Newry - Daisy Hill Hospital	1
London - Great Ormond Street Hospital for Children	1
Whitehaven - West Cumberland Hospital	1
Carlisle - Cumberland Infirmary	1
Swansea - Morriston Hospital	1
Bristol Royal Hospital for Children	1
Dumfries Renal Unit	1
Aberdeen Royal Infirmary	1
Altnagelvin Hospital - Derry	1
Walsall Manor Hospital	1