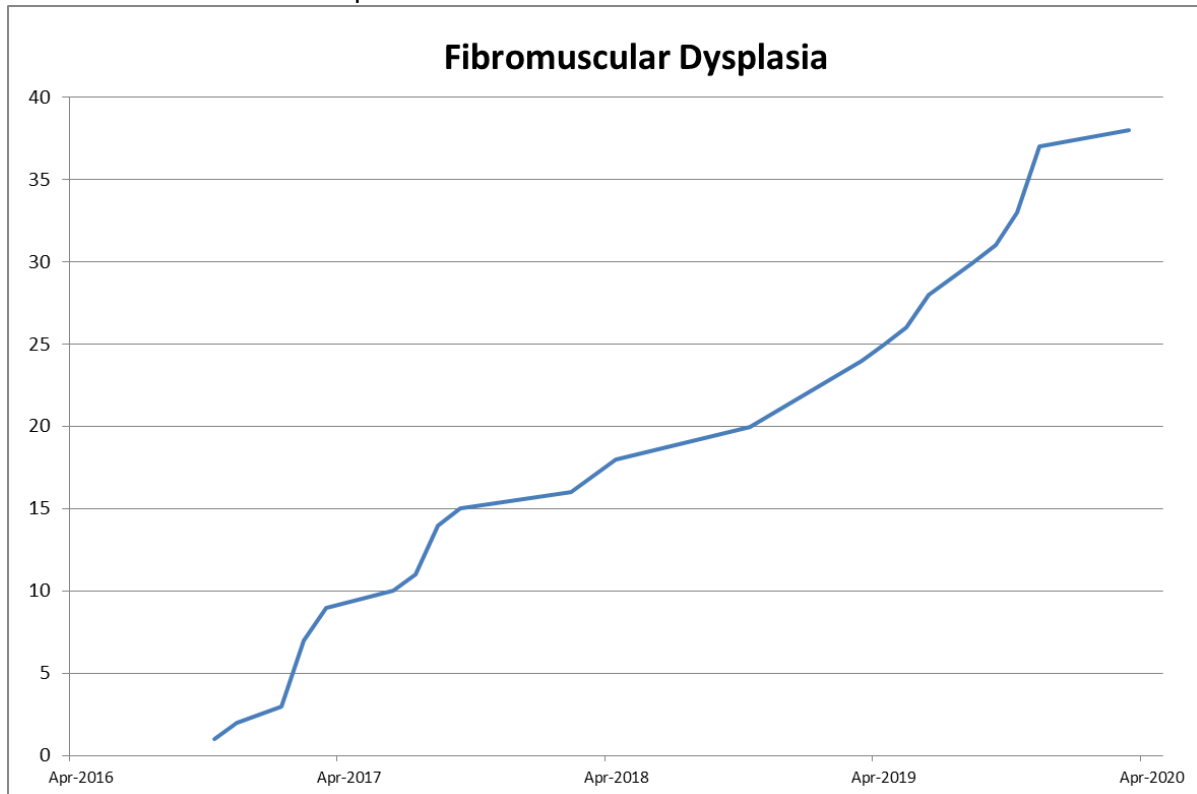


## RaDaR Rare Disease Group Annual Report

April 2019 – March 2020

<b>Rare Disease Group</b>	Fibromuscular Dysplasia
<b>Lead Clinician</b>	Dr Tina Chrysochou
<b>Summary of RDG Activity (Meetings, patient events)</b>	<p>1. Dr Tina Chrysochou has secured £5000 to be used towards setting up an FMD registry aligned with the European FMD registry. We are in discussion with Salford Royal to be the sponsor of this registry.</p> <p>2. A very engaged patient group, led by Karen Rockell and Angeline Young formed the FMD Society of UK and Ireland (@FmdsUK) in 2018 and are a valuable resource to signpost patients to.</p>
<b>Grants awarded that use RaDaR infrastructure or data  (Please do not include other grants awarded to RDG members)</b>	<p>Funder:</p> <p>Title of project:</p> <p>Principal Investigator(s):</p> <p>Amount:</p>
<b>Conference posters/presentations using and acknowledging RaDaR data</b>	DR Chrysochou was an invited speaker to the 2 <sup>nd</sup> international conference on Fibromuscular Dysplasia and associated vascular diseases in Warsaw Nov 2019. This was a valuable forum for networking
<b>Publications using and acknowledging RaDaR data  (Please do not include other publications by RDG members)</b>	
<b>Number of commercial partners using RaDaR data to inform study design or recruitment sites</b>	
<b>Recruits as of 1<sup>st</sup> April 2019</b>	25
<b>Recruits as of 31<sup>st</sup> March 2020</b>	38
<b>New recruits</b>	13

Recruitment Overview Graph



Recruits by site

Hospital	Patients
Salford Royal Manchester	15
Birmingham - Queen Elizabeth Hospital	4
Carshalton - St Helier Renal Unit	4
Derby - Royal Derby Hospital	2
Newcastle upon Tyne - Freeman & Victoria Hospitals	1
Plymouth - Derriford Hospital	1
Gloucester - Gloucestershire Royal Hospital	1
Nottingham - QMC - Children's Kidney Unit	1
London - King's College Hospital	1
Exeter - Royal Devon and Exeter Hospital	1
Torbay Hospital	1
Norfolk and Norwich University Hospital	1
Reading - Royal Berkshire NHS Foundation Trust	1
Bristol - Southmead Hospital	1
London - Great Ormond Street Hospital for Children	1
York	1
Huddersfield Royal Infirmary	1