

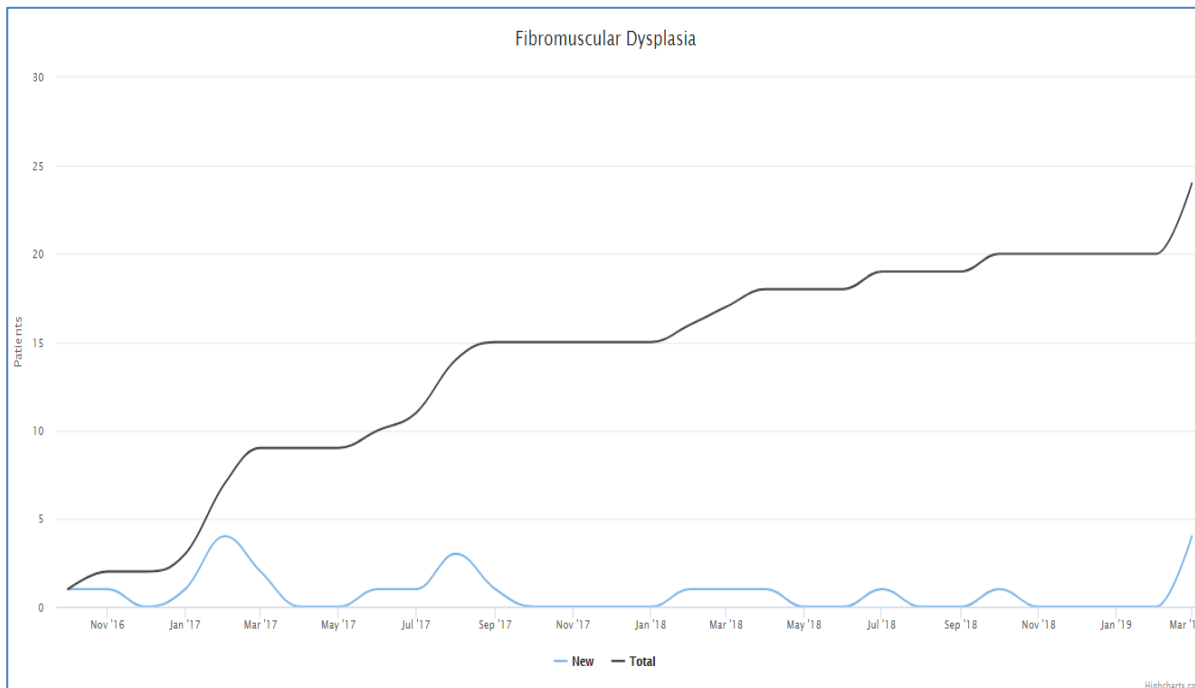
RaDaR Rare Disease Group Annual Report

April 2018 – March 2019

<p>Rare Disease Group</p>	<p>Fibromuscular Dysplasia</p>
<p>Lead Clinician</p>	<p>Dr Tina Chrysochou</p>
<p>Summary of RDG Activity (Meetings, patient events)</p>	<p>1. The UK's first patient information day on Fibromuscular Dysplasia (FMD) was held at Salford Royal Hospitals NHS Foundation Trust on 19.1.2019. The day was sponsored by KRUK and KCUK. Half the money went towards creating a video of the event to ensure the legacy of the day lives on and is accessible to patients and clinicians who weren't able to attend. This video will be made available soon.</p> <p>The day provided an overview on FMD, an update on international registry data and the most cutting edge clinically relevant research. Guest speaker, Sally Bee (https://www.sally-bee.com/) shared her journey with FMD and expert clinician input was given by Prof Alexandre Persu, an international FMD expert and head of the European FMD Registry, Dr Tina Chrysochou, Prof David Adlam and Dr Bean Dhaung from the FMD specialist interest group and a Neurologist and neuro-radiologist.</p> <p>The day finished off with a workshop during which patients and carers shared their experiences and devised a wish list for management within clinical services and research ideas for FMD in the UK.</p> <p>Feedback for the event was very positive and multiple tweets were made using the #FMD2019 hashtag.</p> <p>2. Dr Tina Chrysochou has secured £5000 to be used towards setting up an FMD registry aligned with the European FMD registry. Prof Adlam and Dr Chrysochou are in the process of an ethics application in this regard.</p> <p>3. 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>

<p>Grants awarded that use RaDaR infrastructure or data</p> <p>(Please do not include other grants awarded to RDG members)</p>	<p>Funder:</p> <p>Title of project:</p> <p style="text-align: center;">N/A</p> <p>Principal Investigator(s):</p> <p>Amount:</p>
<p>Conference posters/presentations using and acknowledging RaDaR data</p>	<p>Dr Chrysochou was an invited speaker to the BIHS annual meeting in Cambridge to talk on FMD and used the opportunity to promote RADAR recruitment. She is also been invited to talk on FMD at the Renal Association UK Kidney Week 2019</p>
<p>Publications using and acknowledging RaDaR data</p> <p>(Please do not include other publications by RDG members)</p>	<p style="text-align: center;">N/A</p>
<p>Number of commercial partners using RaDaR data to inform study design or recruitment sites</p>	<p style="text-align: center;">N/A</p>
<p>Recruits as of 1st April 2018</p>	<p style="text-align: center;">17</p>
<p>Recruits as of 31st March 2019</p>	<p style="text-align: center;">24</p>
<p>New recruits</p>	<p style="text-align: center;">7</p>

Recruitment Overview Graph



Patients by site

Hospital	Patients
Salford Royal (Hope Hospital) Manchester	7
Birmingham - Queen Elizabeth Hospital	3
Derby	2
Carshalton - St Helier Renal Unit	3
Newcastle upon Tyne	1
London- Great Ormond Street Hospital for Children	1
Norfolk and Norwich University Hospital	1
Plymouth	1
London – Kings	1
Reading - Royal Berkshire NHS Foundation Trust	1
Gloucester	1
York	1
Nottingham - QMC - Children's Kidney Unit	1