

RaDaR Rare Disease Group Annual Report

April 2016 – March 2017

Completion of this annual report is a requirement of the Renal Association's Standard Operating Policy for RDGs. Please return this form along with any supporting documentation such as minutes of RDG meetings to the RaDaR Project Support Officer Melanie Dillon (melanie.dillon@renalregistry.nhs.uk) by Friday 31st March 2017.

Rare Disease Group	Fibromuscular Dysplasia
Lead Clinician	Dr Constantina (Tina) Chrysochou
Summary of RDG meetings	<p>Group has grown to include a paediatric nephrologist and further adult nephrologist.</p> <p>Tele-conferences have occurred every month to two months. Discussions have included :</p> <ul style="list-style-type: none"> • Updates on RaDaR recruitment. Updates on centres which can collect and store DNA and biomarker data as part of other recruiting trials until a successful grant obtained • Formulate recommended investigation protocol • Pooling data for outcome analysis where data in the literature is lacking • Linking with Professor Persu and the European FMD association to share best practice, collaborate on projects and learn from their experience which is in a more advanced phase than ours • Discussion of formulating a patient group, the Belgian experience and European perspectives
Summary of patient events	No events as yet. There is a patient representative in the RDG and two other patients who are actively contributing to conversations.
Grant applications submitted	None
Grants awarded	None

Publications and presentations	None
Highlights	<p>Have a slot to present activities of the group and FMD at the Annual Cardio-renal meeting October 2017</p> <p>Have jointly applied to submission of the COST Action Proposal OC-2016-2-21220 'Deciphering the mechanisms and improving the management of arterial dissection and dysplasia' to the COST Open Call OC-2016-2.</p>
Problems	<p>The group is still at an early stage</p> <p>Ensuring centres are aware they can upload FMD to RaDaR</p>