

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.

Rare Disease Group	Lowe, Dent, Renal Fanconi
Lead Clinician	Detlef Bockenhauer
Summary of RDG meetings	None
Summary of patient events	None
Grant applications submitted	None
Grants awarded	None
Publications and presentations	<p>Long-term renal outcome in children with OCRL mutations: retrospective analysis of a large international cohort. Nephrol Dial Transplant. 2016 Oct 5. pii: gfw350. [Epub ahead of print]</p> <p>This work was also selected for an oral presentation at the 2016 ERA/EDTA meeting in Vienna (presented by Bockenhauer)</p>
Highlights	Above publication
Problems	<ul style="list-style-type: none"> • Our patient representative has medical problems herself. • Until all renal units have renal IT systems, data retrieval still laborious and data sets incomplete