

Rare Diseases Operational Management Board, January 2015

RDG End of Year Report 2014

Dear RDG Coordinator,

Please file a report to the OMB for your activity in the calendar year 2014, and return it to Chrissie Jacobs at UKRR. Ongoing recognition of the RDG by the Renal Association is dependent on receipt of a report.

This report is deliberately minimal and should not take long to complete, not least because some of the information is obtainable centrally by the OMB. Emphasis is placed on the early benefits for patients which focuses on patient support meetings and patient engagement within the RDG.

Please fill out the table below and return the entire word document with any supplements that you wish to be filed, specifically minutes of RDG or patient information meetings.

Name of RDG	Lowe, Dent, Renal Fanconi
Name of Coordinator	Detlef Bockenhauer
Name of Administrator	Chris Thalasselis
Email address	
Telephone number	
Name of person/person's cleared to work with patient identification	Rose Uchi
Email address	
Telephone number	
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	none
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	none
Grant applications submitted	none
Grants awarded	none
Publications and presentations	none
Highlights (free text)	Data fields being compiled
Problems (free text)	Awaiting functional renal data warehouse