

Rare Diseases Operational Management Board (OMB)

RDG End of Year Report 2013

Dear RDG Coordinator,

Please file a report to the OMB for your activity in the calendar year 2013, and return it to Chrissie Jacobs at UKRR no later than 15th January 2014. 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	Low syndrome, Dent Disease and other renal Fanconi syndromes
Name of Coordinator	Detlef Bockenhauer
Name of Administrator Email address Telephone number	Jazz Dinza
Name of person/person's cleared to work with patient identification Email address Telephone number	Rose Uchi
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	18.09.2013
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)	Inaugural meeting 18.9.2013
Problems (free text)	No registry fields accessible yet Need to register patients