

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	aHUS
Name of Coordinator	Tim Goodship
Name of Administrator	Tim Goodship Newcastle
Name of person/person's cleared to work with patient identification	Tim Goodship
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	Minutes on the RDG website
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	Tim Goodship gave a presentation at the AGM of aHUSUK on the 23 rd November 2013 updating the charity on all aspects of the interim national aHUS service.
Grant applications submitted	Nil
Grants awarded	Nil
Publications and presentations	There have been numerous publications and presentations relating to aHUS from members of the RDG. There have not yet been any "official" aHUS RDG publications.
Highlights (free text)	The establishment of an interim national service for aHUS with funding for eculizumab from NHS England
Problems (free text)	Recruiting patients into RaDaR continues to be hard work.