

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	UKIVAS (Vasculitis)
Name of Coordinator	Mark Little
Name of Administrator Email address Telephone number	Chrissie Jacobs
Name of person/person's cleared to work with patient identification Email address Telephone number	Mark Little / Richard Watts / Paul Brogan / David Jayne / Raashid Luqmani / Afzal Chaudhry / Jacqueline Andrews / Mike Venning / Alan Salama
RDG meetings: Summary <i>(append written minutes if that is easier)</i>	See attached minutes
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	Joint conference planned with Vasculitis UK April 2015
Grant applications submitted	
Grants awarded	
Publications and presentations	Abstracts submitted to ASN, RA and BSR meetings, please see attached
Highlights (free text)	We now have 18 sites in the UK and 5 in Ireland recruiting to the registry (including a paediatric centre). The Irish sites are obtaining linked serum, plasma, urine, RNA and DNA. Recruitment now exceeds 1600 cases (300 of which are from Ireland)
Problems (free text)	Parallel recruitment of over 200 vasculitis patients to the RaDaR registry. These have been recruited

	without the knowledge of the RDG and the cases held within are thus orphaned. Efforts are underway to transfer the data to UKIVAS, but unlikely to be fully resolved until end 2015 at least.
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