

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	UKIVAS (Vasculitis)
Name of Coordinator	Mark Little
Name of Administrator	Laura Woodward
Email address	
Telephone number	
Name of person/person's cleared to work with patient identification	Mark Little / Richard Watts / Paul Brogan / David Jayne / Raashid Luqmani / Afzal Chaudhry / Jacqueline Andrews / Mike Venning / Alan Salama
Email address	
Telephone number	
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>	Please see attached document from Vasculitis UK
Grant applications submitted	NIHR deep phenotyping bid (via both Fiona Karet and the Oxford Rheumatology group): ANCA negative vasculitis NIHR rare disease fellow bid (via both Fiona Karet and the Oxford Rheumatology group): Genetic predisposition to ANCA vasculitis in south Asians Meath Foundation: Towards biobanking of acute untreated patients with vasculitis Specialist Services Commissioning Innovation Fund:

	this fund has since been put on ice
Grants awarded	The Oxford BRC has been awarded the national coordinating role for rare rheumatological diseases. The details remain unclear, but there should be a funding stream to support specific aspects of systemic vasculitis (Churg Strauss syndrome and CNS vasculitis).
Publications and presentations	Abstracts submitted to both RA and BSR meetings, please see attached
Highlights (free text)	<ul style="list-style-type: none"> • We now have 12 sites in the UK and 5 in Ireland recruiting to the registry. The Irish sites are obtaining linked serum, plasma, urine, RNA and DNA. Recruitment now exceeds 700 cases (230 of which are from Ireland) • Version 2 of the data entry application software completed and undergoing beta testing: this allows entry of detailed longitudinal data
Problems (free text)	<ul style="list-style-type: none"> • Despite positive statements from Chrissie Jacobs and Ron Cullen at our meeting in May (see minutes), no progress has been made on formalising a software linkup with RADAR • UK sample collection not funded