

RDG End of Year Report 2012

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| Name of RDG | Systemic Vasculitis |
| Name of Coordinator | Mark Little / Richard Watts |
| Name of Administrator | Laura Woodward |
| 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 |
| RDG meetings: Summary <i>(append written minutes if that is easier)</i> | Please see minutes arising from meetings 18/4/12 and 27/11/12 |
| Patient Information meetings : Summary <i>(append written minutes if that is easier)</i> | None yet, although patients are invited to the afternoon session of the above meetings, which include a series of presentations. A formal link has been established with the Vasculitis UK web portal, which already acts as an excellent resource for patients |
| Grant applications submitted | Vasculitis UK, Lauren Currie Foundation, Healthcare Improvement Partnership (HQIP), SFI President of Ireland young researcher award, Dublin Centre for Clinical Research, Kidney research UK, TCD Med Day |
| Grants awarded | Vasculitis UK: £33,250 (to fund registry software development, server maintenance, meetings for 5 years) HQIP: £15,330 (to fund registry software development) Kidney research UK: £91,000 (to fund registry development and genetic study) SFI President of Ireland young researcher award: €971,000 (€243,000 reserved for establishment of Irish component of the UKVAS registry and biobank) Dublin Centre for Clinical Research: 0.5 WTE research nurse support to manage recruitment and sample collection in the Irish component of UKVAS TCD Med Day: €20,000 (to fund Irish biobank storage facility) Total: £336,580 |
| Publications and presentations | |
| Highlights (free text) | Commencement of formal recruitment using a specifically designed web accessed Adobe AIR application in Sep 2012 |

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| Problems (free text) | Underestimation of challenges involved in software and database development Sample collection in the UK not currently funded |
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