

## RDG End of Year Report 2012

Name of RDG	aHUS
Name of Coordinator	Tim Goodship
Name of Administrator	Tim Goodship
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 attached
Patient Information meetings :Summary <i>(append written minutes if that is easier)</i>	David Kavanagh and Neil Sheerin both gave presentations at the AGM of aHUSUK on the 1 <sup>st</sup> December 2012. David spoke on his work identifying other genes in aHUS and Neil spoke on kidney transplantation in aHUS. Members of the group are interacting closely with aHUSUK in the ongoing attempts to obtain national funding for eculizumab (see <a href="http://www.ahusuk.org">www.ahusuk.org</a> ).
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)	Facilitating the establishment of aHUSUK following the patient family conference in June 2011 has resulted in an extremely active and now independent patient-family support group. aHUSUK has played a pivotal role in the lobbying that is being undertaken for a national service for aHUS and funding for eculizumab.
Problems (free text)	Establishing the registry of aHUS patients in RaDaR is going to be hard work but is achievable.