**Summary of RDG meetings**

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<th>Rare Disease Group</th>
<th>Lead Clinician</th>
<th>aHUS Rare Diseases Working Group Meeting 27th November 2015</th>
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**Agenda**

1. Minutes of last meeting (20th October 2014)
2. aHUS database (Amy Osborne)
3. National aHUS service
   a. Adults (David Kavanagh)
   b. Paediatrics (Sally Johnson)
4. Autoantibody associated aHUS (Vicky Brocklebank)
5. aHUSUK and aHUS Alliance developments (Len Woodward)
6. 100K project and aHUS (Danny Gale)

**Attendees**

- David Kavanagh (Chair)
- Tim Goodship
- Vicky Brocklebank (Secretary)
- Sally Johnson
- Kevin Marchbank
- Len Woodward
- Amy Osborne
- Danny Gale
- Steve Perkins
- Claire Harris
- Anna Richards
- Terry Cook

**Summary of patient events**


Chairs - Emma Woodward & David Kavanagh

**Programme**

- Complement and aHUS - Dr Kevin Marchbank
- aHUS penetrance in Families - Prof Tim Goodship
- The World of aHUS - Len Woodward
- aHUS - Many Variants Many Triggers - Dr David Kavanagh
- The Pregnancy Trigger - Dr Edwin Wong
- The Transplant Trigger - Prof Neil Sheerin
- The NICE Research Update - Prof Neil Sheerin
- The Logistics of Research and Registries - Dr Detlef Bockenhauer
- Funding Research - Sandra Currie

**Grant applications submitted**

- Nil

**Grants awarded**

- Nil
<p>| 3 | Sheerin N*, Kavanagh D*, Goodship TH*, Johnson S*. A national specialised service in England for atypical haemolytic uraemic syndrome - the first year’s experience. <em>QJM</em> 2015 109 (1) 27-33 *These authors made equal contributions to this work |</p>
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<tr>
<th>Highlights</th>
<th>Successful Second aHUS Patient Families’ Conference</th>
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<td>Problems</td>
<td>Delayed award of national centre for aHUS</td>
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