

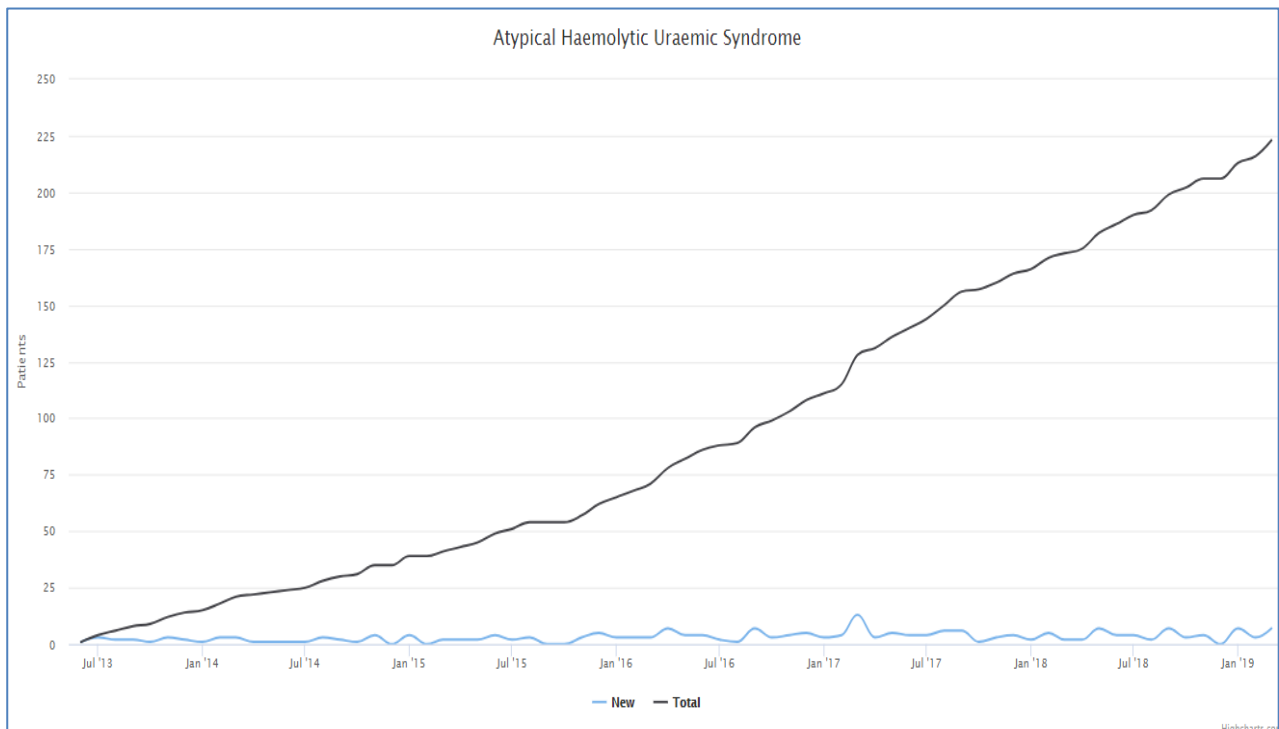
## RaDaR Rare Disease Group Annual Report

April 2018 – March 2019

<b>Rare Disease Group</b>	aHUS
<b>Lead Clinician</b>	Prof David Kavanagh
<b>Summary of RDG Activity (Meetings, patient events)</b>	<p>aHUS Rare Disease Working Group Meeting 7<sup>th</sup> December 2018 Newcastle</p> <p>NRCTC aHUS patient roadshows in Durham, Manchester, Bristol.</p> <p>aHUS patient focus group Newcastle</p> <p>Introduction of patient website and information videos (<a href="http://www.atypicalhus.co.uk/ahus/what-is-ahus/">http://www.atypicalhus.co.uk/ahus/what-is-ahus/</a>)</p> <p>Introduction of patient information packs</p> <p>Patient experience survey initiated and overseen by Picker</p>
<b>Grants awarded that use RaDaR infrastructure or data</b>  <b>(Please do not include other grants awarded to RDG members)</b>	<p><b>Funder:</b></p> <p><b>Title of project:</b></p> <p style="text-align: center;">N/A</p> <p><b>Principal Investigator(s):</b></p> <p><b>Amount:</b></p>
<b>Conference posters/presentations using and acknowledging RaDaR data</b>	N/A
<b>Publications using and acknowledging RaDaR data</b>  <b>(Please do not include other publications by RDG members)</b>	<p>The annual report of the National Renal Complement Therapeutics Service is available online <a href="http://www.atypicalhus.co.uk/wp-content/uploads/2018/10/NRCTC-Annual-report-2017_18.pdf">http://www.atypicalhus.co.uk/wp-content/uploads/2018/10/NRCTC-Annual-report-2017_18.pdf</a></p>

<b>Number of commercial partners using RaDaR data to inform study design or recruitment sites</b>	1
<b>Recruits as of 1<sup>st</sup> April 2018</b>	174
<b>Recruits as of 31<sup>st</sup> March 2019</b>	227
<b>New recruits</b>	53

### Recruitment Overview Graph



### Patients by site

Hospital	Patients
Newcastle-Freeman	29
Birmingham Childrens	23
Exeter RD&E	15
Brighton	11
Leeds - Children's	11

Hospital	Patients
Glasgow - QEUH	9
London - Guy's	9
London-Royal Free	9
Nottingham-Children's	9
Nottingham City	7
Hull	7
Birmingham-QEH	6
Oxford-Churchill	5
Coventry	5
London - Barts	5
Cardiff - UHW	4
Plymouth	4
York	4
Bristol-Children's	4
Southampton-Childrens	4
Dumfries	3
Manchester Children's	3
Kent and Cant	3
Manchester RI	3
Wolverhampton-NC	3
Sheffield	3
Stoke	3
Derby	3
Bristol - Southmead	3
Middlesbrough JC	3
Stevenage-Lister	3
Peterborough	2
Taunton	2
Leeds - St James's	2
London-West-Imperial	2

<b>Hospital</b>	<b>Patients</b>
Sunderland	2
Reading	2
Leicester	2
Carshalton-St Helier	2
Torbay	1
Macclesfield	1
Inverness	1
Kilmarnock-Crosshouse	1
Swansea	1
Chelmsford - Broomfield	1
Doncaster	1
GOSH	1
Salford Royal	1
Norfolk and N	1
Carlisle	1
Birmingham-Heartlands	1
Gloucester	1
Cambridge	1
Colchester	1
Bradford	1
Belfast - Children's	1