

## RaDaR Rare Disease Group Annual Report

April 2016 – March 2017

Completion of this annual report is a requirement of the Renal Association's Standard Operating Policy for RDGs.

<b>Rare Disease Group</b>	Vasculitis
<b>Lead Clinician</b>	Mark Little
<b>Summary of RDG meetings</b>	22/4/16 (Leeds) 7/12/16 (Cork)
<b>Summary of patient events</b>	Irish group annual meeting 15/11/16 Numerous local meetings throughout UK
<b>Grant applications submitted</b>	VUK project grant call 2016 "AVERT, autoimmunity relapse prediction", unsuccessful  H2020 Marie Curie ITN application (HELICAL: Health data linkage for clinical benefit), pending
<b>Grants awarded</b>	"LONG-TERM SURVEILLANCE STUDY OF RITUXIMAB (MABTHERA)-TREATED PATIENTS WITH GRANULOMATOSIS WITH POLYANGIITIS (GPA) OR MICROSCOPIC POLYANGIITIS (MPA) – "RIVAS" Roche, post-marketing surveillance project
<b>Publications and presentations</b>	"The UK & Ireland Vasculitis Registry (UKIVAS): Cross-sectional data on the first 3195 patients with a focus on anti-neutrophil cytoplasm (ANCA) associated vasculitis (AAV) and giant cell arteritis (GCA)": BSR 2016 and International Vasculitis workshop 2017

<p><b>Highlights</b></p>	<p>Ongoing strong recruitment to both RaDaR and UKIVAS platforms; movement of UKIVAS governance to University of Oxford with launch of new software interface; establishment of formal linkage of UKIVAS and RaDaR; Creation of “Vasculitis Europe” pan-European patient organisation, with UKIVAS/Vasculitis UK as founding partner</p>
<p><b>Problems</b></p>	<p>Ongoing challenge of registry sustainability; strong efforts undertaken to align with NHS England requirements for high cost drug monitoring as a means of mainstreaming into NHS</p>