

## RaDaR Rare Disease Group Annual Report

April 2015 – March 2016

Rare Disease Group	Membranous Nephropathy
Lead Clinician	Paul Brenchley
Summary of RDG meetings	There have been no meetings of the RDG Steering group during this period. PB and CG have attended meetings of the Renal Association Clinical Trials Group to discuss the next National Clinical Trial In MN. There is an opportunity for grant funding from NIHR for a new MN trial NIHR in 2016 and the RDG will have input into that study.
Summary of patient events	The RDG has supported the establishment of a National MN Patient Forum which met in Manchester in March 2016 with approx.40 MN patients attending from Scotland and England. This is reported on the RDG webpage. A patient committee was formed with a new patient lead for the RDG group.
Grant applications submitted	Two major grants were submitted for researching MN; one to KRUK March 2015 (lab research on MN mechanism) and one to NIHR i4i July 2015 (new therapy for MN). Both were successful (see below)
Grants awarded	<p><b>Kidney Research UK.</b> Blocking PLA2R receptor activation on podocytes with soluble epitope peptide can modulate the pathological effects of anti-PLA2R: a new therapy for preventing relapse in membranous nephropathy. P Brenchley, R Lennon, T Jowitt, E Mckenzie. Sept 2015- Feb 2018. £198,359</p> <p><b>NIHR i4i:</b> Developing PLARIA immunoadsorption therapy for patients with MN. P Brenchley, S Mitra, P Slater, W Tindale, A McCarthy, S Russell, D Kanigicherla. £550,000 Sept 2016-Aug 2018</p>
Publications and presentations	<p>Results Of Survey On Management Of Membranous Nephropathy In United Kingdom - MN-Radar Survey. Durga A K. Kanigicherla, et al on behalf of MN RADAR. Abstract presented at EDTA-ERA Meeting London May 2015.</p> <p>Kanigicherla DA, Short CD, Roberts SA, Hamilton P, Nikam M, Harris S, Brenchley PE, Venning MC. Long-term outcomes of persistent disease and relapse in primary membranous nephropathy. Nephrol Dial Transplant. 2016 Jan 13. pii: gfv435. [Epub ahead of print] PubMed PMID: 26769682.</p>

<b>Highlights</b>	I think the highlight of the year was the formation of the National MN Patient Forum. The rapid increase in numbers of patients consented to MN Radar over the last 12 months (approx. 357 to a total of 677) shows patients are interested in knowing more about the disease. The potential for funding the next clinical trial in MN for 2017-2019 is encouraging.
<b>Problems</b>	None