RaDaR Rare Disease Group Annual Report

April 2016 – March 2017

Rare Disease Group	Membranous Nephropathy
Lead Clinician	Prof Paul Brenchley
Summary of RDG meetings	There have been no meetings of the RDG Steering Group during this period. Communication has been via email and telephone. We received a download of the MN RADAR dataset as at the end of August 2016. The main issue has been to upgrade the quality of information contained in the database. A paper was prepared and circulated to the group to use the AUTO-MN dataset to update information on patients pre entry into RaDaR.
Summary of patient events	The first meeting of the National MN Patient Forum met in Manchester in March 2016 as reported last year. There have been no Patient Meetings during this period. The next meeting is planned in 2017-18
Grant applications submitted	Grants were submitted to: 1) NIHR HTA under Biological response modifier drugs for rare autoimmune diseases; 'Use of Rituximab in treatment of immune mediated glomerulonephritis (TURING). Lead is Thomas Hiemstra on behalf of Renal Assoc RCG for £1.5Million Dec 2016. PB representing MN RADAR RDG. 2) NHS England for a CtE on Use of Rituximab in MN. This would involve 30-60 patients in England who have failed first line therapy but remain with active disease. Patients would be registered with MN RADAR for long term followup; Submitted in Sept 2016 by W McKane on behalf of Renal Assoc RCG. 3) Kidney Research UK (Feehally-Stoneygate Award), Interaction of genetics and environment in triggering autoimmune MN: UK BioBank Study submitted by P Brenchley in Sept 2016

Grants awarded	In order as above: 1) Through to Stage 2 awaiting decision in summer 2017 2) Funded awaiting appointment of clinical lead and expecting start in Sept 2017 3) Funded and expected start in summer 2017
Publications and presentations	1: Cattran D, Brenchley P. Membranous nephropathy: thinking through the therapeutic options. Nephrol Dial Transplant. 2017 Jan 1;32(suppl_1):i22-i29.doi: 10.1093/ndt/gfw404. PubMed PMID: 28391348. 2: Sekula P, Li Y, Stanescu HC, Wuttke M, Ekici AB, Bockenhauer D, Walz G, Powis SH, Kielstein JT, Brenchley P; GCKD Investigators., Eckardt KU, Kronenberg F,Kleta R, Köttgen A. Genetic risk variants for membranous nephropathy: extension of and association with other chronic kidney disease aetiologies. Nephrol Dial Transplant. 2017 Feb 1;32(2):325-332. doi: 10.1093/ndt/gfw001. PubMed PMID:28186573. 3: Cattran DC, Brenchley PE. Membranous nephropathy: integrating basic science into improved clinical management. Kidney Int. 2017 Mar ;91(3) :566-574. doi:10.1016/ j.kint.2016.09.048. Epub 2017 Jan 5. Review. PubMed PMID: 28065518. 4: Kanigicherla DA, Hamilton P, Czapla K, Brenchley PE. Intravenous Pulse cyclophosphamide and steroids induce immunological and clinical remission inNew-incident and relapsing Primary Membranous Nephropathy. Nephrology (Carlton). 2016 Oct 24. doi: 10.1111/nep.12955. [Epub ahead of print] PubMed PMID: 27778424. 5: 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. 2016Dec;31(12):2108-2114. Epub 2016 Jan 13. PubMed PMID: 26769682.

Highlights	The success in getting the CtE approved by NHS England means that MN patients who fail to respond to first line therapy and who remain with active disease and whose clinician thinks they will benefit can apply for Rituximab through the CtE. We are hoping to use MN RADAR as the registry for the CtE study.
Problems	There will be a delay in improving the quality of the dataset in MN RADAR using the AUTO-MN data as it looks likely we will have to apply for a Section 251.