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P012 -The London Membranous Network

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Introduction

The London Membranous Network is a North London multi-centre collaborative consortium established to develop a clinical & research infrastructure for membranous nephropathy (MN). Established between three large teaching hospitals, Barts Health, Imperial College Healthcare and the Royal Free London, our three centres support a diverse population of over 6 million people.

Our collaborative will observe our cohort longitudinally, characterising and studying prevalent and incident (40 – 60 per annum) idiopathic MN patients. We are collecting detailed demographic, clinical, histopathological, biochemical, immunological and genetic data.

Methods

Informed patients are enrolled with either biopsy-proven MN, or serological (positive anti-phospholipase A2 receptor antibodies [aPLA2Rab] with nephrotic syndrome) autoimmune MN in a minority of cases where biopsy is not possible.

All investigations are part of standard current clinical care. Where not, ethical approval is in place for collection of DNA, histology, urine and serum for agreed studies. Quality of life and impact of disease can be assessed through validated questionnaires. Follow up in the first year will be on a minimum of 3-monthly basis and thereafter 6-monthly.

Results

At present across all three centres we have a total of 383 idiopathic MN patients. 121 adults cared for at Barts, 99 at the Royal Free and 163 at Imperial College. Diagnosis was established ranging between 1978 and January 2019, with follow up ranging from 0 – 40 years. Differences in disease progression, and response to treatment, in different ethnicities are well-described, with our cohort well-positioned to further examine this (ethnicity in London, table 1). We are continuing full data collection in the prevalent cohort, which is limited by these patients being on renal replacement therapy and not under our care in the specialist membranous clinics.

Conclusion

A London-based collaborative caring at scale for a diverse population will offer useful insight into MN, a rare disease. We aim to better understand diagnosis, symptom control, the consequences of disease and its' (non-immunomodulatory and immunomodulatory) treatment, contributing to the UK Rare Diseases Registry (RaDaR) and global studies in partnership. We aim to measure aPLA2Rab in transplant recipients and those on the transplant waiting list so that we can determine how aPLA2Rab affects transplantation outcomes. We will seek to support and inform our patients, understand patient-reported outcomes, determine disease and progression risk predictors, and explore best strategies to prevent and manage complications such as thromboembolism, dyslipidaemia, oedema, infections and death (table 2).