



Rare Kidney Disease and Vasculitis Registry Newsletter

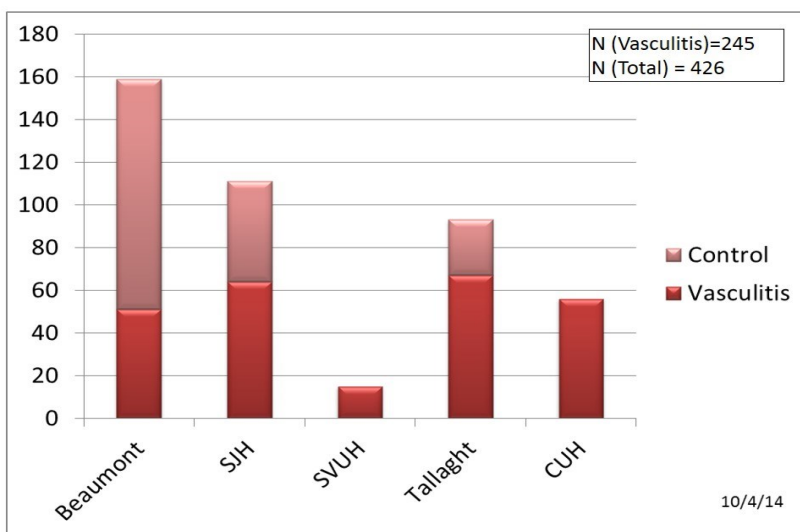
Summer 2014



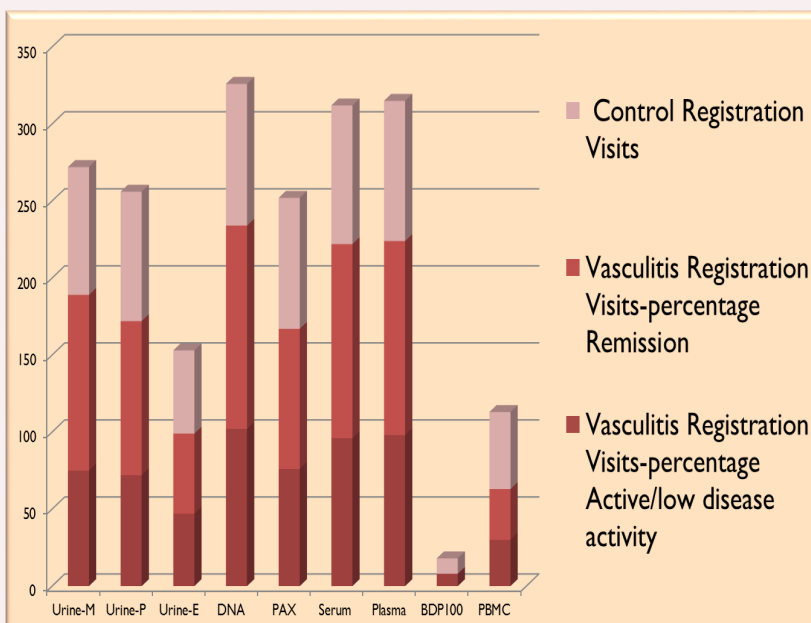
ABOUT THE RKD AND VASCULITIS REGISTRY & BIOBANK

ESTABLISHED IN 2012 WITH THE AIM OF PROVIDING AN INTEGRATED RESOURCE TO ENHANCE THE STUDY INTO RARE KIDNEY DISEASES IN IRELAND. RESEARCH INTO THESE DISEASES IS CHALLENGING AS HOSPITALS WILL ONLY BE PRESENTED WITH A FEW SPORADIC CASES EACH YEAR. THE RKD REGISTRY AND BIOBANK AIMS TO FACILITATE THIS RESEARCH BY BRINGING TOGETHER A LARGE COHORT OF PATIENT DATA AND SAMPLES. IT WORKS IN COLLABORATION WITH HOSPITALS AND RESEARCH CENTRES ACROSS THE COUN-

RECRUITMENT TO DATE



SAMPLE COLLECTION



CURRENT STUDIES SUPPORTED BY THE

BIOBANK

- ◇ Serum and Urine soluble CD163 as a biomarker of active disease in Vasculitis Patients with promising results presented at the Renal Association meeting in Glasgow.
- ◇ Collaborating with Agilent Technologies and Ken Mok (TCD) using high throughput mass spectroscopy to investigate Urine Metabolomic biomarkers in Vasculitis.
- ◇ Genome Wide Association Studies, in collaboration with the European Vasculitis Genetics Consortium:
 - ◇ PR3 ANCA vasculitis
 - ◇ MPO ANCA vasculitis
 - ◇ Eosinophilic granulomatosis with polyangiitis
- ◇ C3 Glomerulopathy, in collaboration with Peter Conlon (Beaumont) and Imperial College London.
- ◇ Familial Membranoproliferative glomerulonephritis, in collaboration with Peter Conlon and Imperial College London.
- ◇ Familial Spastic Paraparesis and Chronic Kidney Disease in collaboration with Peter Conlon and Duke University, N Carolina
- ◇ aHUS (Atypical Hemolytic Uremic Syndrome) in collaboration with Peter Conlon and groups in Cardiff and Newcastle.
- ◇ Familial Interstitial Nephritis in collaboration with Anthony Bleyer, Wake Forest Baptist Health, Salem North Carolina.
- ◇ Fibrocytes in ANCA Vasculitis in collaboration with Peter Margetts, McMaster University, Canada.
- ◇ Familial Kidney Disease Genomics-This is an ongoing collaboration with Peter Conlon and Dervia Connaughton (Beaumont Hospital) and Dr. Friedhelm Hildebrandt at Harvard Medical School, Boston Children's Hospital
- ◇ Collaborating with Dr. Ruth Pepper at University College London investigating the association of urine Calprotectin and disease Activity in ANCA associated Vasculitis



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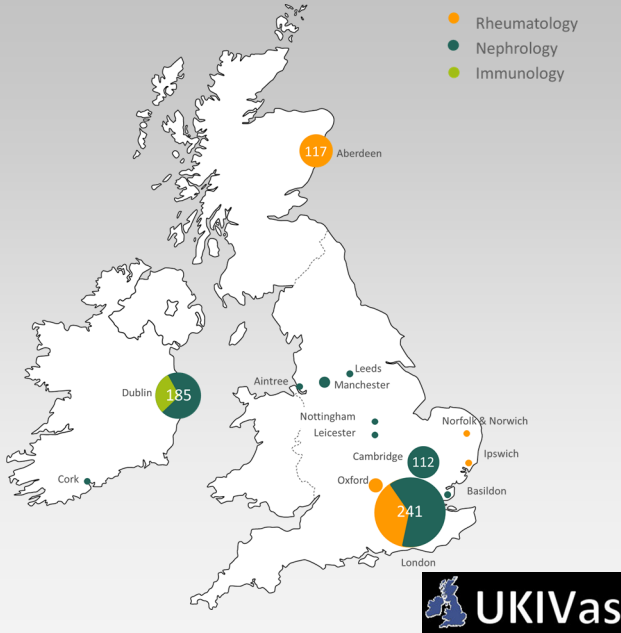


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UKIVas www.ukivas.org

The UKIVAS registry is a component of the Vasculitis Rare Disease Group of UK and Ireland (rarerenal.org/rare-disease-groups/vasculitis-rdg/). It aims to create a database of patients with vasculitis attending numerous centres across the British Isles. The long term vision is to link these data to carefully processed clinical samples, as is currently practiced in the Irish centres. To date, over 1000 patients have been

recruited, making this one of the largest such registries in the world.



World Kidney Day 2014



On 13th March 2014 members of the [Trinity Health Kidney Centre](#) helped raise awareness for World Kidney Day at the Institute of Molecular Medicine. This global event focuses on the importance of kidneys to overall health to aims to reduce the frequency and impact of kidney disease. Around 600 million people worldwide suffer with some form of kidney disease. The theme of this year's World Kidney Day was

chronic kidney disease (CKD) and aging. While CKD can occur at any age it is more common with increasing age; and the incidence of CKD is predicted to increase by 17% over the next decade. Overall, the campaign was a huge success. The team passed out information leaflets on kidney disease, detection and prevention to raise awareness of CKD, and raised over €300 for Vasculitis Ireland Awareness. Further infor-

THANK YOU!

To all the consultants for generously allowing access to their patients. To registrars **Claire Kennedy, Limy Wong, Radzi Rodzlan, Mark Canney and Heather Gunning** who help us recruit extremely valuable acute patients. Big thank you to **Sarah Moran** who has single handedly made Cork the lead recruiter of acute patients. To **Paul O'Hara, Emma Connolly, Eóin O'Brien and Fionnuala Hickey** for stepping up when acute samples needed to be processed. To **John McCourt and Rakesh Patel** for ongoing database support. To **Joe McPartlin** for providing the

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