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The Rare Kidney Disease & Vasculitis Registry & Biobank



Newsletter - Summer 2015

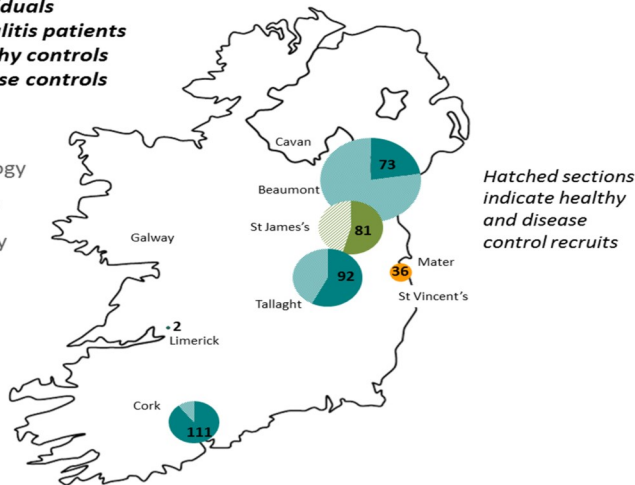
ABOUT THE RKD AND VASCULITIS REGISTRY & BIOBANK

AIMS TO PROVIDE 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 COUNTRY TO COLLECT BIOLOGICAL SAMPLES AND GENERATE DETAILED CLINICAL DATA.

RECRUITMENT TO DATE

- 797 Individuals
- 395 vasculitis patients
- 154 healthy controls
- 248 disease controls

- Rheumatology
- Nephrology
- Immunology

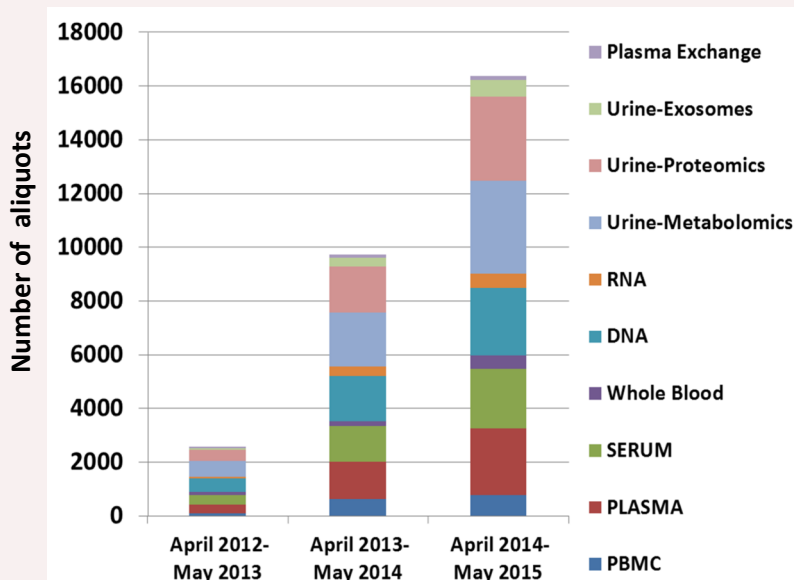


29/04/2015

Many Vasculitis patients have contributed biological samples on more than one occasion.

185 vasculitis patients had samples collected when they had active disease & 131 contributed samples at both active and remission disease stages.

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
 - ◇ Rituximab Response
- ◇ 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 Dervla 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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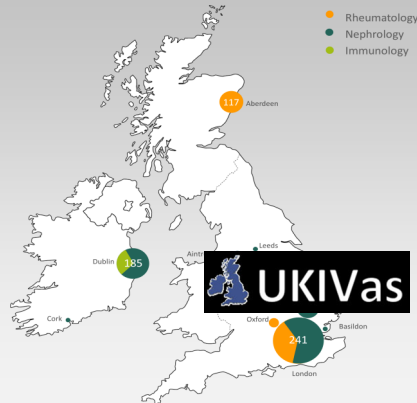


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UKIVas WWW.UKIVAS.ORG

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

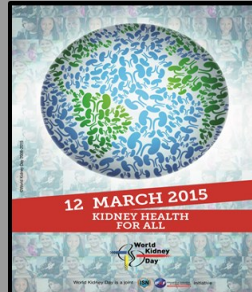
have been recruited, making this one of the largest such registries in the world.



The RKD Biobank has been included in the MERIL database of EU research infrastructure. To achieve this, the biobank must reach certain standards of quality and governance. This will form the basis for meeting the standards required of the upcoming ISO TC 276



World Kidney Day 2015. On 12th March 2015 members of the Trinity Health Kidney Centre helped raise awareness for World Kidney Day at the Institute of Molecular Medicine. Around 600 million people worldwide suffer with some form of kidney disease. If detected early, Chronic Kidney Diseases can be treated—thereby reducing other complications and dramatically reduce the growing burden of deaths and disability from chronic renal and cardiovascular disease. The incidence of CKD is predicted to increase by 17% over the next decade. The team passed out information leaflets on kidney disease, detection and prevention to raise awareness of CKD, and raised €316 for Vasculitis Ireland Awareness. Further information about World Kidney Day is available at www.worldkidneyday.org



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