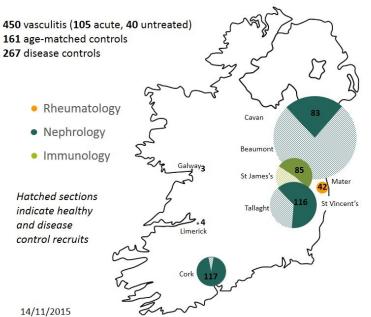


## **The Rare Kidney Disease Registry** and **Biobank**

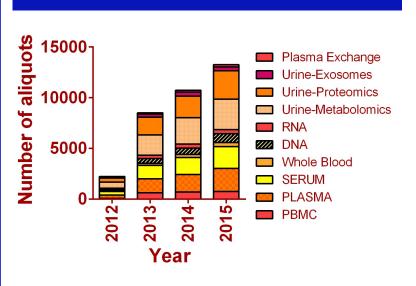
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The study of rare kidney disease is challenging as only a few sporadic cases present at hospitals each year. The RKD and Vasculitis Registry and Biobank aims to provide an integrated resource to facilitate such research, working with hospitals and research centres across the country to bring together a large cohort of patient data and biological samples, thus generating a substantial body of detailed clinical information.

**Recruitment to Date** 



Number of recruits to RKD Biobank since inception; many have multiple longitudinal samples at different stages of the disease



#### **Currently Supported Studies**

- Prognostic significance of single nucleotide polymorphisms genes encoding cyclophosphamideof metabolising enzymes in patients with ANCA vasculitis in collaboration with Dr A Vaglio University Hospital of Parma, Italy
- 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 polyangitis
  - **Rituximab Response**
- C3 Glomerulopathy in collaboration with Peter Conlon (Beaumont) and Imperial College London.
- Urinary CD25 in renal vasculitis, in collaboration with Peter Heeringa, Groningen, The Netherlands
- Familial Membranoproliferative glomerulonephritis, in collaboration with Imperial College London.
- Familial Spastic Paraparesis and Chronic Kidney Disease in collaboration with Duke University, North 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
- Dr Ruth Pepper at University College London investigating the association of urine Calprotectin and disease Activity in ANCA associated Vasculitis
- Dr Roger Preston investigating mechanisms of immunothrombosis in ANCA vasculitis

### **Sample Collection**



# The Rare Kidney Disease Registry and Biobank

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### **Welcomes and Farewells**

New sites:

University Hospital Galway (Susie Murray leading the charge)

• Mater Misericordiae Hospital (with 3 recruits within days)

The Meath Foundation-funded national recruitment strategy, ably supported by a highly effective Whatsapp group, has dramatically enhanced recruitment such that all new diagnoses of systemic vasculitis in major Irish centres are now being recruited, with most being sampled before treatment.

 And a fond Au Revoir to Fionnuala Hickey, who has managed the biobank for 3 years, to Valerie Logan, who expertly oversaw its birth, Sharon Casey, Research Nurse extraordinaire, and to Michelle Ryan, who processed the acute samples from the country when everyone else had left for the pub.

### World Kidney Day 2016

Members of the Trinity Health Kidney Centre contributed to the campaign by distributing public information resources and raising vital funds for Vasculitis Ireland Awareness (www.vasculitis-ia.org) via a bakesale at the Institute of Molecular Medicine, St James' Hospital.



#### **Contact Us**

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## **Key Personnel**

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### Thanks









BRIAN KEOGH Festschrift Award

Bechets Disease Ireland



To all patients and control individuals who have so kindly taken part. To all consultants for generously allowing access to their patients. To registrars Paul O'Hara, Claire Kennedy, Sarah Moran, Dervla Connaughton, Tammy Wanigasekera, Limy Wong, Dearbhla Kelly, Yvelynne Kelly, Radzi Rodzlan, Conor Judge, Amy Hudson, Susie Murray, Louise Ryan and Mark Canney who help us recruit extremely valuable acute patients. To John McCourt and Conor Judge for ongoing database support. And to Joe McPartlin for providing the biobank with a home.