

Spring 2020 Newsletter

News Update

This past year has seen the RKD Registry and Biobank undergo a significant re-boot in response to enactment of the General Data Protection Regulation (GDPR) and Health Research Regulations (HRR), and recommendations arising from an independent external review by the Institute for Innovation through Health Data (i~HD). Outcomes include the implementation of revised ethical approvals at all major sites and migration of clinical data to the secure database platform, REDCap. The ethical framework for the vasculitis and familial kidney disease genomics have been separated. This work was supported by the Irish Kidney Association.

Major grant awards include the FAIRVASC project- building registry interoperability to inform clinical care- which received €2.3m funding from the European Joint Programme. This joins the €4.2m HELICAL innovative training network as major vehicles for RKD translational research.

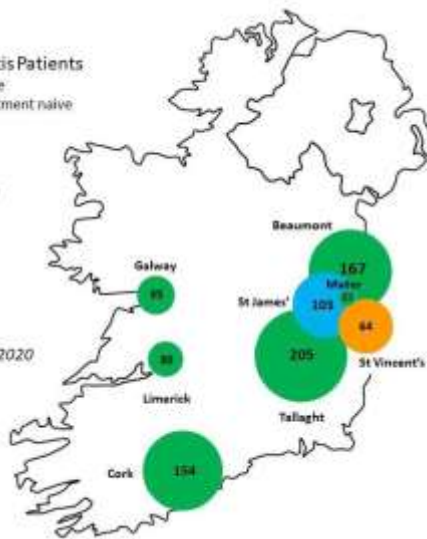
With the emergence of the SARS-CoV2 global pandemic this year, Prof Little has been awarded HRB funding through the 'Rapid Response Covid-19 Call'. The project, entitled DeCoMPRESS (Defining the Disease Course and Immune Profile of COVID-19 in the Immunosuppressed Patient), aims to assess infection in patients with systemic autoimmune disease. The Biobank and Registry act as a key component in support of the study.

Recruitment to Date

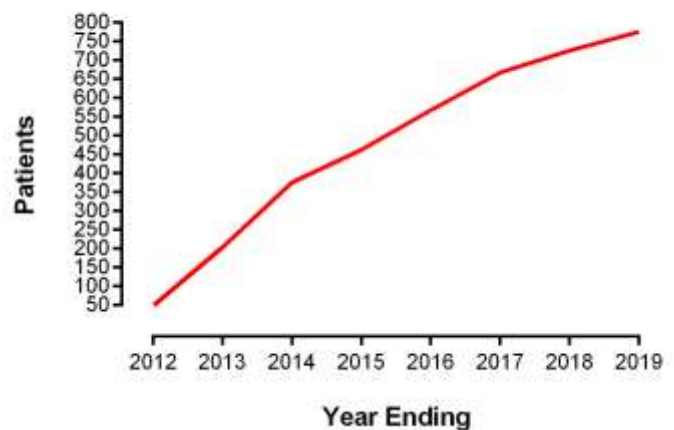
- 776 Vasculitis Patients
 - 298 acute
 - 119 treatment naive

- Rheumatology
- Nephrology
- Immunology

Updated: 04/02/2020



Cumulative RKD Vasculitis Recruitment



Latest Research Publications deriving from RKD data and samples

Low Density Granulocytes in ANCA Vasculitis Are Heterogenous and Hypo-Responsive to Anti-Myeloperoxidase Antibodies

Aiding Uí Mhuinnigh¹, Alica M. Coughlan¹, Annelise Daniels¹, Jack Hartnett¹, Joana Cabral¹, Barry Moran¹, Aina Brennan^{1,2}, Sarah L. Doyle^{1,2}, Katherine Hughes¹, Rosemary Lacey¹, Anthea Flanagan¹, Ursula Fearon¹, Susan McGrath¹, Sarah Connican¹, Aine De Bhalla¹, Eleanor J. Molloy¹, Gareth Brady¹ and

Genome-wide association study of eosinophilic granulomatosis with polyangiitis reveals genomic loci stratified by ANCA status

Sarah Connican¹, Claire Kennedy^{1,2}, Dervia M. Connaughton^{1,3,4}, Patrick O'Kelly¹, Susan Murray^{1,2}, Martina Zivná⁵, Stanislav Kmoch⁵, Neil K. Fennelly⁶, Katherine A. Benson^{1,3}, Eoin T. Conlon³, Gianpietro L. Cavallari⁷, Claire Foley^{1,7}, Brendan Doyle⁸, Anthony Dorman^{2,9}, Mark A. Little^{1,10}, Peter Lavin⁹, Kendrah Kidd^{1,7}, Anthony J. Bleyer⁹, Peter J. Conlon^{1,7}

Renal Failure

Autosomal dominant tubulointerstitial kidney disease (ADTKD) in Ireland

S. Connican, D. M. Connaughton, C. Kennedy, S. Murray, M. Zivná, S. Kmoch, N. K. Fennelly, P. O'Kelly, K. A. Benson, E. T. Conlon, G. Cavallari, C. Foley, B. Doyle, A. Dorman, M. A. Little, P. Lavin, K. Kidd, A. J. Bleyer & P. J. Conlon

Renal transplant outcomes in patients with autosomal dominant tubulointerstitial kidney disease

Sarah Connican¹ | Claire Kennedy^{1,2} | Dervia M. Connaughton^{1,3,4} | Patrick O'Kelly¹ | Susan Murray^{1,2} | Martina Zivná⁵ | Stanislav Kmoch⁵ | Neil K. Fennelly⁶ | Katherine A. Benson^{1,3} | Eoin T. Conlon³ | Gianpietro L. Cavallari⁷ | Claire Foley^{1,7} | Brendan Doyle⁸ | Anthony Dorman^{2,9} | Mark A. Little^{1,10} | Peter Lavin⁹ | Kendrah Kidd^{1,7} | Anthony J. Bleyer⁹ | Peter J. Conlon^{1,7}

Personnel Network

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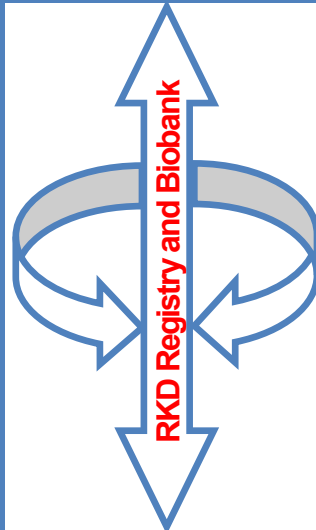
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RKD Biobank

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Senior Technician
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Welcomes, Farewells and Thanks

The past year saw the recruitment of Research Nurse, Ms Caroline Kosgei, filling the vacancy created by the departure of Ms Jane Richardson. We welcome Caroline to the group. We also wish Jane all the very best in her new post.

To all patients and control individuals who have so kindly taken part. To all consultants for generously allowing access to their patients. To the ever expanding list of registrars, whose willingness to recruit, sample and re-sample patients is central to the success of the Registry and Biobank. To Jess Braun and Juliusz Filipowski for help with establishing the REDCap database. To Fergal Seeballuck for indefatigable assistance with the RKD reboot.

Finally, to all interns, research assistants and doctoral students who make a substantial contribution to the efficient day-to-day operational running of the RKD Biobank— a huge thank you!

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The Meath Foundation
Healthcare, Research and Education at the Hospital in Tallaght



HRB Health Research Board

VIA Vasculitis Ireland
AWARENESS

