

THE RARE KIDNEY DISEASE REGISTRY AND BIOBANK

Facilitating Translational Research in Rare Disease

2021 Newsletter



KIDNEY CENTRE



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



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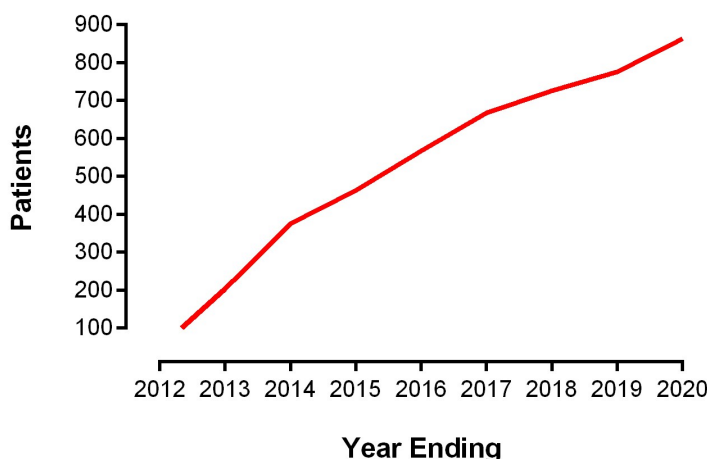
NEWS UPDATE

This year the RKD Registry and Biobank has supported various research projects, many of which were created in response to the COVID-19 global pandemic. This includes the continued role as a key component of the DeCOMPRESS project, which aims to provide better understanding of how the immune system responds to the SARS-COV-2 virus in ANCA-associated vasculitis patients who are taking immunosuppressive medications.

Major grants awarded include the ADAPT Phase 2 – Research Centres Phase 2 project and the COVID Research hub Strategic Partnership, which received €33.1m and €241.1k funding from Science Foundation Ireland, respectively. Additionally, the Cross-Disease Assessment of Granulocyte Phenotypic and Functional Heterogeneity project received €72k funding from the Irish Research Council and the Personalisation of relapse risk in autoimmune disease project received €74k funding from the Meath Foundation.

RECRUITMENT TO DATE

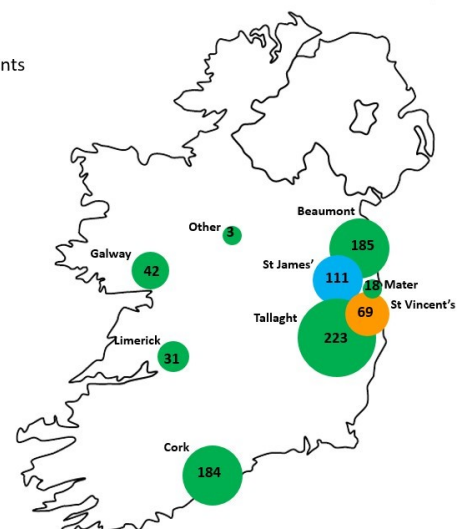
Cumulative RKD Vasculitis Recruitment



- 866 Vasculitis Patients
- 327 Acute
- 250 Treatment Naive

- Rheumatology
- Nephrology
- Immunology

Updated: 15.07.2021



LATEST RESEARCH FROM RKD DATA AND SAMPLES

Pro-inflammatory Stimulation of Monocytes by ANCA Is Linked to Changes in Cellular Metabolism

Eoin C. O'Brien¹, Carla A. White¹, Jason Wyse², Emma Leacy¹, Richard K. Porter³, Mark A. Little^{1*} and Fionnuala B. Hickey¹

OPEN Investigation of type I interferon responses in ANCA-associated vasculitis

Isabella Batten¹, Mark W. Robinson², Arthur White³, Cathal Walsh⁴, Barbara Fazekas⁵, Jason Wyse², Antonia Buettner⁶, Suzanne D'Arcy⁷, Emily Greenan^{8,9}, Conor C. Murphy^{8,9}, Zoe Wigston^{10,11}, Joan Ni Gabhann-Dromgoole^{12,13}, Edward M. Vita^{14,15}, Mark A. Little⁶ & Nollaig M. Bourke^{12,13}

Association of venous thromboembolic events with skin, pulmonary and kidney involvement in ANCA-associated vasculitis: a multinational study

Sergey Moiseev^{1,2,*}, Andreas Kronbichler^{3,*}, Egor Makarov², Nikolay Bulanov¹, Matija Crnogorac⁴, Haner Direskeneli⁵, Kresimir Galesic⁶, Ummugulsum Gazel⁷, Duvuru Geetha⁸, Loic Guillevin⁹, Zdenka Hruskova⁸, Mark A. Little^{10,11}, Adeel Ahmed¹¹, Stephen P. McAdoo¹², Aladdin J. Mohammad^{13,14}, Sarah Moran¹⁵, Pavel Novikov¹⁶, Charles D. Pusey¹², Chinara Rahmatulla¹⁷, Veronika Satrapova¹⁸, Joana Silva¹⁹, Benjamin Terrier²⁰, Vladimir Tesar²¹, Kerstin Westman²² and David R. W. Jayne¹⁷

Renal transplant outcomes in patients with autosomal dominant tubulointerstitial kidney disease

Sarah Cormican¹, Claire Kennedy^{1,2}, Dervla M Connaughton^{1,3,4}, Patrick O'Kelly¹, Susan Murray^{1,2}, Martina Živná⁵, Stanislav Kmoch⁵, Neil K Fennelly⁶, Katherine A Benson^{1,2}, Eoin T Conlon¹, Gianpiero L Cavalleri², Claire Foley^{4,7}, Brendan Doyle⁶, Anthony Dorman^{2,6}, Mark A Little^{4,8}, Peter Lavin⁹, Kendrah Kidd^{5,9}, Anthony J Bleyer⁹, Peter J Conlon^{1,2}

Towards European harmonisation of healthcare for patients with rare immune disorders: outcome from the ERN RITA registries survey

Ricardo Papa¹, Andrew Cant², Christoph Klein³, Mark A. Little⁴, Nico M. Wulffraat⁵, Marco Gattorno⁶, Nicolino Ruperto⁷ and on behalf of ERN RITA Council

Utility of Genomic Testing after Renal Biopsy

Susan L. Murray^{a,9}, Anthony Dorman^{b,c}, Katherine A. Benson^e, Dervla M. Connaughton^{a,d}, Caragh P. Stapleton^e, Neil K. Fennelly^b, Claire Kennedy^a, Ciara A. McDonnell^a, Kendrah Kidd^f, Sarah M. Cormican^a, Louise A. Ryan^a, Peter Lavin^h, Mark A. Little^h, Anthony J. Bleyer^f, Brendan Doyle^b, Gianpiero L. Cavalleri^e, Friedhelm Hildebrandt^d, Peter J. Conlon^{a,9}

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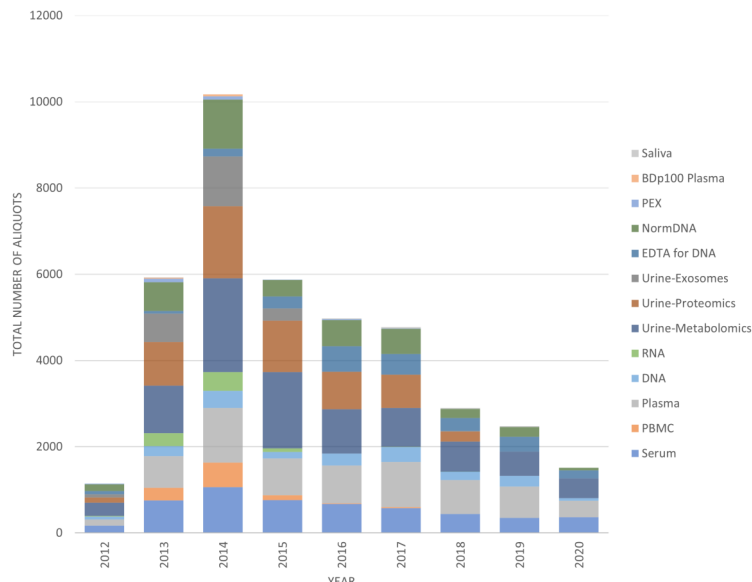


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SAMPLE COLLECTION



WELCOMES, FAREWELLS AND THANKS

The past year saw the departure of Claire Foley as Beaumont Hospital research nurse. We thank her for her many years of service to the RKD Biobank. We are lucky to have on the ground support from Pamela O'Neill on the Tallaght site, a reflection of our pivot towards data curation over sample collection. We also welcome research nurse Vicki Carr, who has migrated over from the AVERT project to take charge of data quality in RKD.

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 Evelyn Fox, TCD research data protection officer, for helping us to navigate the Health Research Regulation waters. But mostly to Jen Scott, ICAT fellow, who has poured many hours into ensuring the RKD clinical data is well structured and accurate.

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!



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn



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



PERSONNEL NETWORK

Principal Investigator

Prof Mark Little

Consultant Nephrologist

Local Study Contacts

Beaumont Hospital:

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Cork University Hospital:

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Dr Alyssia Verrelli, Consultant Nephrologist

Ms Aisling Murphy, Research Nurse

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Mater Misericordiae University Hospital:

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Ms Caroline Kosgei, Research Nurse

Ms Pamela O'Neill, Research Nurse

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RKD Biobank

Dr Alan Kennedy

Co-ordinator & Senior Technician

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