

THE IRISH 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



Tallaght University Hospital
An Academic Partner of Trinity College Dublin

Ospidéal Ollscoile Thamhlachta

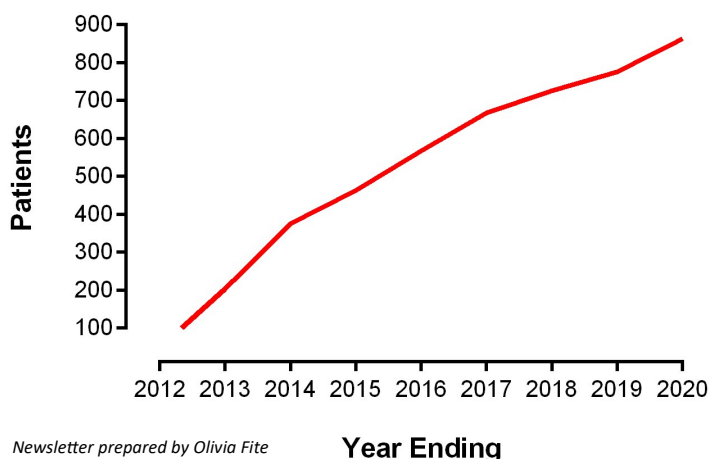
NEWS UPDATE

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 patients 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 €324,992 and €241,100 direct funding from Science Foundation Ireland. Additionally, the Cross-Disease Assessment of Granulocyte Phenotypic and Functional Heterogeneity project received €72k funding from the Irish Research Council to support a PhD project for Amrita Dwivedi, and the Personalisation of relapse risk in autoimmune disease (PARADISE) project received €74k funding from the Meath Foundation.

RECRUITMENT TO DATE

Cumulative RKD Vasculitis Recruitment



Newsletter prepared by Olivia Fite

Year Ending

LATEST RESEARCH FROM RKD DATA AND SAMPLES IN 2020

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. Robinson³, Arthur White³, Cathal Walsh¹, Barbara Fazekas⁵, Jason Wyse⁷, Antonia Buettner⁸, Suzanne D'Arcy⁸, Emily Greenan^{7,8}, Conor C. Murphy^{7,8}, Zoe Wigston^{9,10}, Joan Ní Gabhann-Dromgoole¹¹, Edward M. Vital¹⁰, Mark A. Little⁶ & Nollaig M. Bourke^{12*}

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 Guillevin⁷, Zdenka Hruskova⁹, Mark A. Little¹⁰, Adeel Ahmed¹¹, Stephen P. McAdoo¹², Aladdin J. Mohammad¹³, Sarah Moran¹⁴, Pavel Novikov¹, Charles D. Pusey¹², Chinar Rahmatulla¹⁵, Veronika Satrapova⁸, Joana Silva¹⁶, Benjamin Terrier¹⁷, Vladimir Tesar², Kerstin Westman¹⁸ and David R. W. Jayne¹

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 Lavin⁸, 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

Riccardo Papa¹, Andrew Cant², Christoph Klein³, Mark A. Little⁴, Nico M. Wulffraat⁵, Marco Gattoro⁶, Nicolino Ruperto^{7*} and on behalf of ERN RITA Council

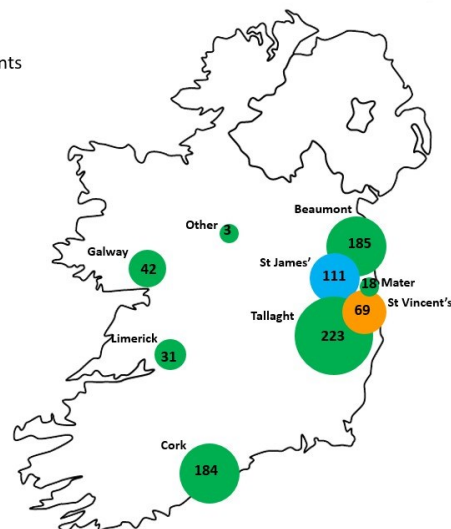
Utility of Genomic Testing after Renal Biopsy

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^e Anthony J. Bleyer^f Brendan Doyle^b Gianpiero L. Cavalleri^e Friedhelm Hildebrandt^d Peter J. Conlon^{a,9}

- 866 Vasculitis Patients
- 327 Acute
- 250 Treatment Naive

- Rheumatology
- Nephrology
- Immunology

Updated: 15.07.2021



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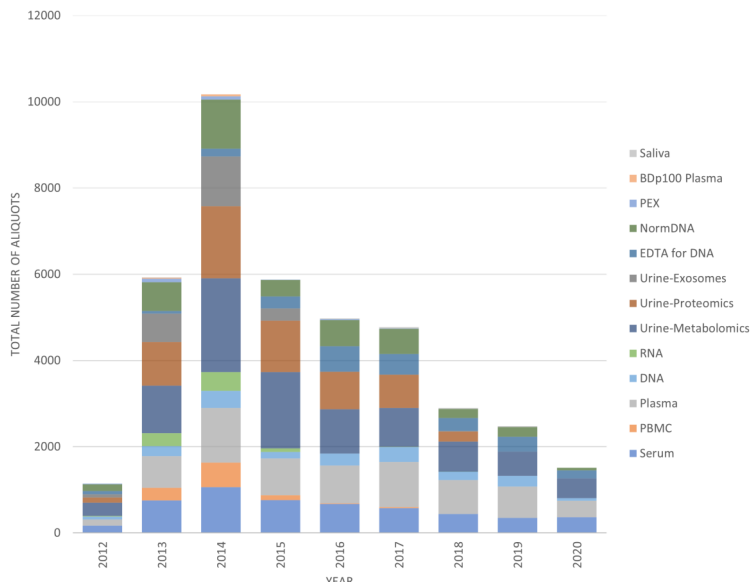


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ANNUAL SAMPLE COLLECTION



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.

THANKS: To all people who have so kindly donated their samples and data. To all consultants for generously allowing access to their patients. To the 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 us establish 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!

PERSONNEL NETWORK

Principal Investigator

Prof Mark Little

Consultant Nephrologist

Local Study Contacts

Beaumont Hospital:

Prof Mark Little, Consultant Nephrologist

Cork University Hospital:

Prof Mike Clarkson, Consultant Nephrologist

Dr Michelle O'Shaughnessy, Cons. Nephrologist

Dr Alyssia Verrelli, Research Fellow

Ms Aisling Murphy, Research Nurse

Limerick University Hospital:

Dr Liam Casserly, Consultant Nephrologist

Mater Misericordiae University Hospital:

Prof Yvonne O'Meara, Cons. Nephrologist

St. James' Hospital:

Dr Niall Conlon, Consultant Immunologist

Ms Caroline Kosgei, Research Nurse

Tallaght Hospital:

Prof Mark Little, Consultant Nephrologist

Dr Jennifer Scott, ICAT Fellow

Ms Caroline Kosgei, Research Nurse

Ms Pamela O'Neill, ERN coordinator

University Hospital Galway:

Prof Matt Griffin, Consultant Nephrologist

St. Vincent's University Hospital:

Dr Eamonn Molloy, Rheumatology Lead

Dr John Holian, Consultant Nephrologist

RKD Biobank

Dr Alan Kennedy

Coordinator & Senior Technician

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

