

THE RARE KIDNEY DISEASE REGISTRY and BIOBANK

Facilitating Translational Research in Rare Disease

2023 Newsletter



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

The RKD Registry and Biobank continues to support vital research projects toward better understanding and treatment of the complex auto-immune condition, ANCA Vasculitis.

A highlight of this year was the award of funding for our PARADISE (PersonAlisation of RelApse risk in auto-immune DISEase) research project, via ERA PerMed's JTC2022 call. The study aims to develop a deployable, personalised predictive tool that accurately assesses patient immune system activation. By tailoring medication dosages—or safely discontinuing them altogether—PARADISE aims to redefine how autoimmune diseases are managed, significantly improving patient care and quality of life. At the heart of this effort, is a multi-disciplinary consortium of experts from seven EU countries, integrating cutting-edge expertise in medicine, artificial intelligence (AI), biomarker discovery, and ethics. We are proud of the fact that the RIV Registry and Biobank will be the primary source of data and material for this ambitious project.

LATEST RESEARCH FROM RKD PATIENT SAMPLES AND DATA

ANCA-associated vasculitis in Ireland: a multi-centre national cohort study

Jennifer Scott¹, Eithne Nic An Riogh¹, Shamma Al Nokhatha¹, Cliona Cowhig², Alyssa Verrelli³, Ted Fitzgerald^{1,2}, Arthur White⁴, Cathal Walsh⁵, Louis Aslett⁶, Declan DeFreitas², Michael R Clarkson³, John Holian⁷, Matthew D Griffin⁸, Niall Conlon⁹, Yvonne O'Meara¹⁰, Liam Casserly¹¹, Eamonn Molloy¹², Julie Power¹³, Sarah M Moran^{#1,3}, Mark A Little^{#1}

Plasma Exchange for ANCA-Associated Vasculitis: An International Survey of Patient Preferences

David Collister^{1,2}, Mark Farrar³, Leshia Farrar³, Paul Brown⁴, Michelle Booth⁴, Tracy Firth³, Alfred Mahr⁵, Linan Zeng⁶, Mark A Little⁷, Reem A Mustafa⁸, Lynn A Fussner⁹, Alexa Meara⁹, Gordon Guyatt⁶, David Jayne¹⁰, Peter A Merkel^{11,12}, Michael Walsh^{2,6,13}

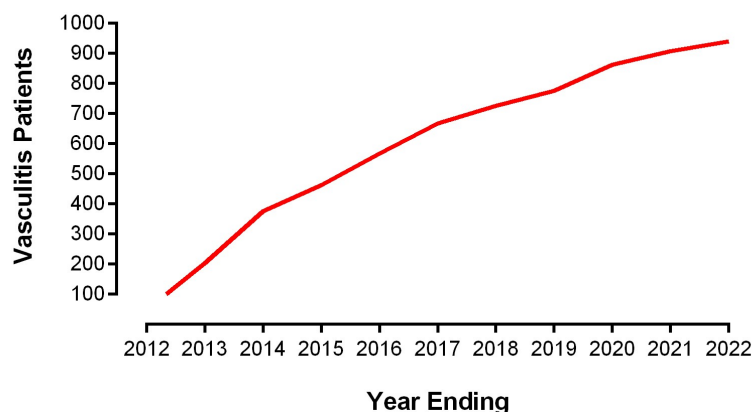
Risk Stratification to Predict Renal Survival in Anti-Glomerular Basement Membrane Disease

Lauren Floyd^{1,2}, Sebastian Bate^{3,4}, Abdul Hadi Kafagi¹, Nina Brown^{1,5}, Jennifer Scott^{6,7}, Mukunthan Srikantharajah⁸, Marek Myslivecek^{9,10}, Graeme Reid¹¹, Faten Aqeel¹², Doubravka Frausova^{9,10}, Marek Kollar¹³, Phuong Le Kieu¹, Bilal Khurshid⁵, Charles D Pusey⁸, Ajay Dhaygude², Vladimir Tesar^{9,10}, Stephen McAadoo⁸, Mark A Little^{6,7}, Duvuru Geetha¹², Silke R Brix^{1,14}

CD163 and CD206 expression define distinct macrophage subsets involved in active ANCA-associated glomerulonephritis

Joop P Aendekerk¹, William F Jiemy², Elisabeth Raveling-Eelsing³, Nele Bijnsens¹, Myrurgia A Abdul-Hamid⁴, Inge M Strating³, Gerjan J Dekkema³, Jan-Stephan F Sanders⁵, Coen A Stegeman⁵, Jan G M C Damoiseaux⁶, Mark A Little⁷, Peter Heeringa³, Pieter van Paassen⁸

RECRUITMENT TO DATE

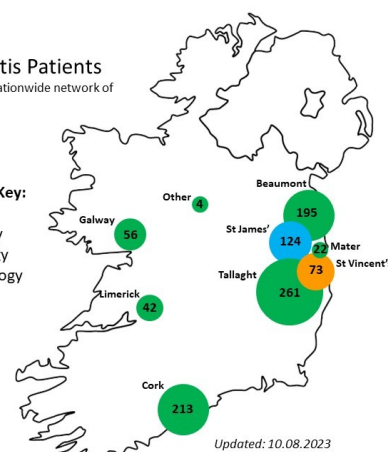


990 Vasculitis Patients

Recruited from a nationwide network of clinical sites

Hospital Unit Key:

- Nephrology
- Immunology
- Rheumatology

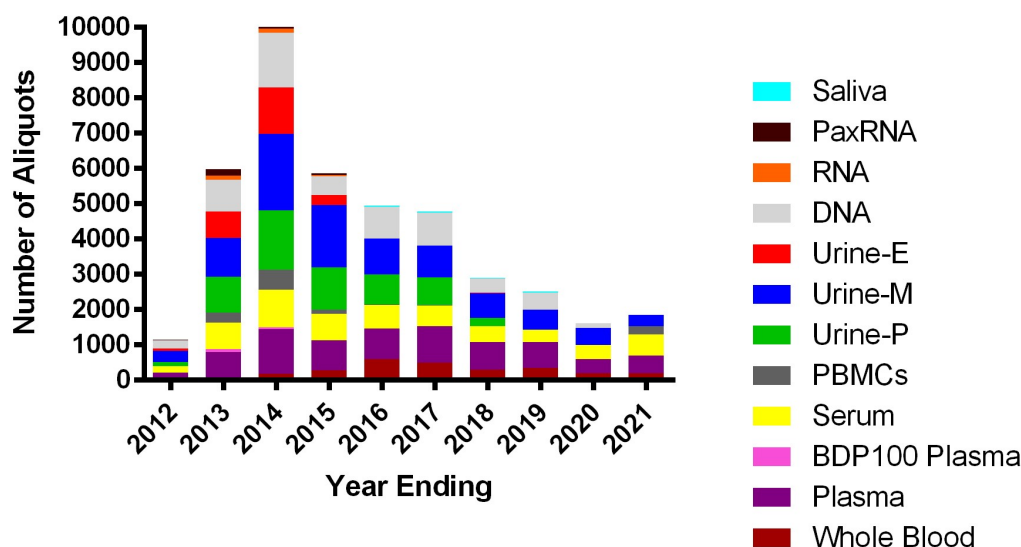


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SAMPLE COLLECTION



PERSONNEL NETWORK

Principal Investigator

Prof Mark Little,
Consultant Nephrologist

Beaumont Hospital:

Prof Mark Little, Consultant Nephrologist

Cork University Hospital:

Prof Mike Clarkson, Consultant Nephrologist

Limerick University Hospital:

Dr Liam Casserly, Consultant Nephrologist

Mater Misericordiae University Hospital:

Prof Yvonne O'Meara, Consultant Nephrologist

St. James' Hospital:

Dr Niall Conlon, Consultant Immunologist

St. Vincent's University Hospital:

Dr Eamonn Molloy, Rheumatology Lead

Tallaght University Hospital:

Prof Mark Little, Consultant Nephrologist

University Hospital Galway:

Prof Matt Griffin, Consultant Nephrologist

RKD Registry

Ms Vicky Carr, Data Manager

RKD Biobank

Dr Alan Kennedy, Biobank Manager & Senior Technician

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FUNDING PARTNERS AND COLLABORATORS



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



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

