

RITA-Ireland Vasculitis (RIV)

Registry and Biobank



NEWSLETTER 2024



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



Primary Immunodeficiencies / Autoinflammatory Disorders
Autoimmune Diseases / Paediatric Rheumatic Diseases



Tallaght
University
Hospital

Ospidéal
Ollscoile
Thamhlachta

An Academic Partner of Trinity College Dublin

ABOUT US

The Rare Kidney Disease (RKD) Registry and Biobank was established in 2012 to facilitate research into the rare auto-immune condition ANCA-associated vasculitis (AAV) in Ireland. Development of a networked collaboration across all the major hospital sites in the country enabled effective recruitment of patients presenting with the disease, and the capture of their clinical data and linked blood and urine samples. After joining the pan-European initiative ERN-RITA in 2022, it was renamed the RITA-Ireland Vasculitis (RIV) Registry and Biobank, contributing data to the RITA registry. Hosted within the School of Medicine at TCD, the Registry and Biobank today comprises over one thousand vasculitis recruits, many of whom have been tracked longitudinally, and represents one of the largest bioresources of its kind globally. The Principal Investigator is Professor Mark Little.

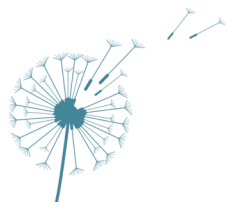
UPDATES



Paradise

The ERA PerMed-funded study PARADISE (PersonAlisation of RelApse risk in auto-immune DISEase), is an ambitious pan-European research project (paradise-project.eu) aiming to generate a predictive AI tool to predict relapse in AAV. The RIV Registry and Biobank is the primary source of material and data for this project. Other key collaborations and outputs over last year are;

- University of Manchester, developing prognostic tools in AAV and anti-GBM disease ([10.1681/ASN.0000000000000274](https://doi.org/10.1681/ASN.0000000000000274), [10.1681/ASN.2022050581](https://doi.org/10.1681/ASN.2022050581))
- CSL-Vifor, as part of the DANDELION SFI Spoke application, which seeks to create an Irish Trusted Research Environment for reuse of routinely collected healthcare data for research and innovation.
- Meath Foundation: successful award of €74,800 examining how ANCA activate monocytes, a key cell type causing AAV
- FAIRVASC consortium ([FAIRVASC.eu](https://fairvasc.eu)) - a federated approach to rare disease data analysis across multiple vasculitis registries in Europe ([10.1136/ard-2023-224571](https://doi.org/10.1136/ard-2023-224571); [10.1016/S2665-9913\(24\)00187-5](https://doi.org/10.1016/S2665-9913(24)00187-5))
- A study on the impact of immunosuppression on cellular and clinical response in COVID-19 ([10.3390/ijms25105239](https://doi.org/10.3390/ijms25105239))
- Our outstanding ICAT fellow Dr Jennifer Scott, obtained her PhD and published a high impact paper describing an algorithm to extract relapse information from unstructured registry data ([10.1136/rmdopen-2023-003962](https://doi.org/10.1136/rmdopen-2023-003962))



GOVERNANCE

Ethical Approval and Informed Consent
REC Approval for each Hospital Site /
Patient Information Leaflet and Informed Consent /
Key Personnel: Hospital Pls', Clinicians, Research Nurses



TCD Data Protection Office/Knowledge Exchange Office
Data Protection Impact Assessment /
Record of Processing /
Data and Material Sharing Agreements

Key Personnel: Evelyn Fox, Imelda O'Keeffe, Lyn O'Reilly

RIV Steering Committee

Medical, Scientific, Legal, and Patient Representation /
Annual Meeting /
Review and Approval of Access Requests/Policies/
Procedures

Key Personnel: Hospital Pl's, TCD DPO, Vasculitis Ireland
Awareness

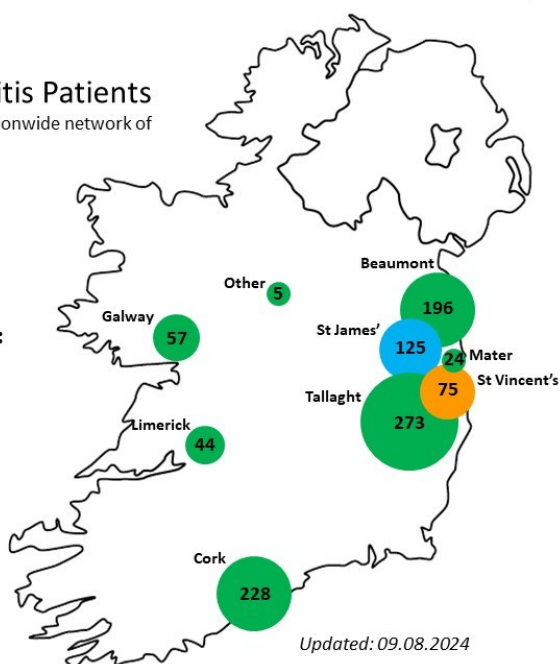
PATIENT RECRUITMENT TO DATE

1027 Vasculitis Patients

Recruited from a nationwide network of
clinical sites

Hospital Unit Key:

- Nephrology
- Immunology
- Rheumatology



CONTACT US

For further information, or to inquire about
potential projects or collaborations, please
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FUNDING PARTNERS & COLLABORATORS

