

The RITA-Ireland Vasculitis (RIV) Registry and Biobank was founded in 2012 to facilitate research into the rare autoimmune condition ANCA-associated vasculitis (AAV) in Ireland. Since then, it has become an important international resource, comprising a rich, longitudinal data and biospecimen collection of over one thousand patients with vasculitis. The Registry and Biobank also continues to maintain strong links with the European Reference Network for rare immune disorders, ERN-RITA, contributing valuable data to the RITA registry.

### UPDATES



The ERA PerMed-funded study PARADISE (PersonAlisation of RelApse risk in autoimmune DISEase), of which the RIV Registry and Biobank is a key component, concluded in March with its final Project Meeting in Stockholm. Representatives from each of the study partners gathered to report on the successful outcomes of the past 3 years. Select partners will now continue the development of these study outcomes, working toward implementation of a personalised, predictive AI tool for patient relapse.

**NEW PERMANENT DATA MANAGER:** We are delighted to announce that **Pamela O'Neill** has been appointed as permanent full-time ERN-RITA data manager, funded by the HSE

As part of an industry collaboration with CSL-Vifor, Mark Little and colleagues at the ADAPT Centre, TCD, have been awarded €355,000 for the 'Decision Analysis of immunosuppression Discontinuation in AAV—DAEDALUS study'.



**Other key collaborations and outputs over the last year include;**

**BELONG-EGPA Study**—a real world study of Benralizumab in EGPA

**Monash University**— sharing of plasma exchange fluid to support an experimental medicine project in MPA

**AVAC-EUR**—a real world study of avacopan use in AAV

**AVATAR**—a study of transplantation in patients with anti-GBM disease

**Rewoso**—a collaboration to develop predictive algorithms for relapse in AAV

**University of Bordeaux**—sharing of single cell RNA sequencing data to develop novel clustering methods

**University College Dublin**— a study of extracellular vesicles as a biomarker in AAV

**Leiden University Medical Center**—a study of IgG glycosylation and its role in relapse of AAV

**Irish Blood Transfusion Board**—the HLA regions of all Biobank participants with GPA or MPA have been sequenced, with thanks to **Orla Ryan** for her amazing work on this

# RIV REGISTRY & BIOBANK PATIENT RECRUITMENT AND PUBLICATIONS

Han X, Li Z, Chen S, Zhao M, Little MA, Chen M.  
Real-world safety assessment of avacopan in patients with AAV. *RMD Open*. 2026;12:e006439

Uzzo M, .... Little MA, David Jayne, Federico Alberici. "Kidney Outcomes in ANCA-GN According to Induction Immunosuppression and Histopathology, *Kidney International Reports*, Volume 11, Issue 3, 2026, 103776

Floyd I, ...Egan a, Little MA, ...Matija Crnogorac, "Clinical Presentation and Outcomes of ANCA-Negative Pauci-Immune Glomerulonephritis", *Kidney International Reports*, Vol 10, Issue 5, 2025, Pages 1450-1459

Palacz W, ...Little MA, Krzysztof Wójcik, "Ontology-based integration and querying of heterogeneous rare disease data sources — POLVAS perspective", *Computers in Biology and Medicine*, Volume 185, 2025,109452

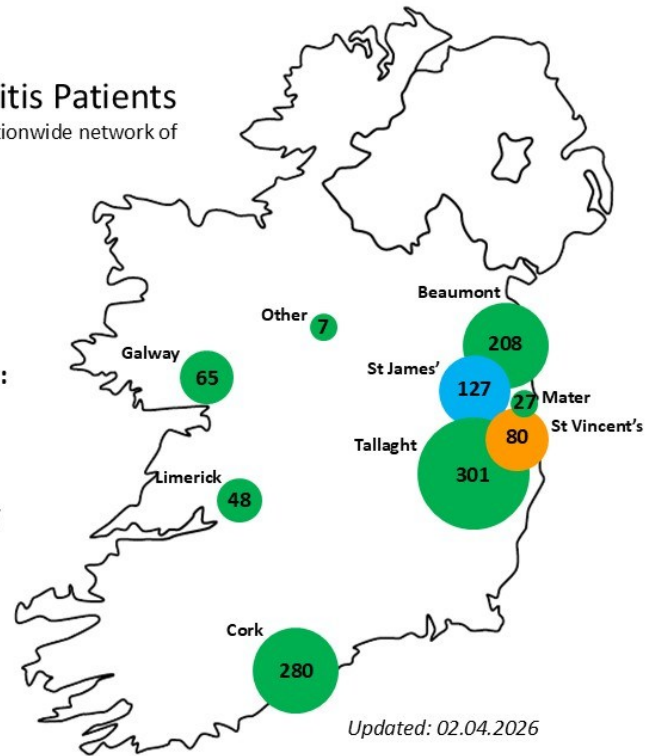
Bayati S, ...Little MA, Peter Nilsson, Elisa Pin, "Autoantibodies towards HFE and SYT5 in anti-neutrophil cytoplasm antibody-associated vasculitis relapse", *Rheumatology*, Volume 64, Issue 5, May 2025, Pages 3142–3150

## 1143 Vasculitis Patients

Recruited from a nationwide network of clinical sites

### Hospital Unit Key:

- Nephrology
- Immunology
- Rheumatology



## OUR GOVERNANCE

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

### TCD Data Protection and Research Contracts Office

Data Protection Impact Assessment /  
Record of Processing Activity /  
Data and Material Sharing Agreements

**Key Personnel:** Lyn O'Reilly, Ursula Shearer



### RIV Steering Committee

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

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

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<https://www.tcd.ie/medicine/thkc/>



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

