

# THE RARE KIDNEY DISEASE REGISTRY and BIOBANK

Facilitating Translational Research in Rare Disease

## 2022 Newsletter



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



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### NEWS UPDATE

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

In this, our 10<sup>th</sup> year of existence, we have surpassed 900 vasculitis patient recruits, banked over 40,000 sample aliquots, and, using these samples and their corresponding clinical datasets, have supported over 50 research studies to date.

During the last year, over 800 patient samples, with clinical data, were supplied to approved research studies investigating ANCA vasculitis. Additional studies into the genetics of kidney disease were also supported by the resource. A selection of publications from the past year involving RKD patient samples and data can be viewed below.

As ever, we are indebted to the patients, consultants, registrars, research nurses, and laboratory personnel who make this resource possible - thank you!

### LATEST RESEARCH FROM RKD PATIENT SAMPLES AND DATA

Study Protocol for DeCOmPRESS: Defining the Disease Course and Immune Profile of COVID-19 in the Immunosuppressed Patient [version 1; peer review: 2 approved with reservations]

Emma Leacy<sup>1,2</sup>, Gareth Brady<sup>1,2</sup>, Niall Conlon<sup>3</sup>, Jennifer Scott<sup>4</sup>, Jean Dunne<sup>5,3</sup>, Thomas Phelan<sup>1,2</sup>, William J. McCormack<sup>2</sup>, Matthew D. Griffin<sup>5,6</sup>, Alan Kennedy<sup>2,4</sup>, Alyssa Verrelli<sup>7</sup>, Eamonn Molloy<sup>8,9</sup>, Declan O'Sullivan<sup>10</sup>, Julie Power<sup>11</sup>, Michael Clarkson<sup>7</sup>, Lina Zgaga<sup>12</sup>, Michelle O'Saughnessy<sup>7</sup>, Mark A. Little<sup>1,2,4</sup>

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

Sergey Moiseev<sup>1,2\*</sup>, Andreas Kronbichler<sup>3,4\*</sup>, Egor Makarov<sup>2</sup>, Nikolay Bulanov<sup>5</sup>, Matija Crnogorac<sup>6</sup>, Haner Direskeneli<sup>5</sup>, Kresimir Galesic<sup>4</sup>, Ummugulsum Gazel<sup>6</sup>, Duvuru Geetha<sup>6</sup>, Loic Guillevin<sup>7</sup>, Zdenka Hruskova<sup>8</sup>, Mark A. Little<sup>9,10</sup>, Adeel Ahmed<sup>11</sup>, Stephen P. McAdoo<sup>12</sup>, Aladdin J. Mohammad<sup>13,14</sup>, Sarah Moran<sup>9</sup>, Pavel Novikov<sup>1</sup>, Charles D. Pusey<sup>12</sup>, Chinar Rahmattulla<sup>15</sup>, Veronika Satrapova<sup>9</sup>, Joana Silva<sup>12</sup>, Benjamin Terrier<sup>7</sup>, Vladimir Tesar<sup>9</sup>, Kerstin Westman<sup>16</sup> and David R. W. Jayne<sup>17</sup>

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

Isabella Batten<sup>1</sup>, Mark W. Robinson<sup>2</sup>, Arthur White<sup>3</sup>, Cathal Walsh<sup>4</sup>, Barbara Fazekas<sup>5</sup>, Jason Wyse<sup>3</sup>, Antonia Buettner<sup>6</sup>, Suzanne D'Arcy<sup>6</sup>, Emily Greenan<sup>7,8</sup>, Conor C. Murphy<sup>7,8</sup>, Zoe Wigston<sup>9,10</sup>, Joan Ni Gabhann-Dromgoole<sup>11</sup>, Edward M. Vital<sup>9,10</sup>, Mark A. Little<sup>6</sup> & Nollaig M. Bourke<sup>12</sup>

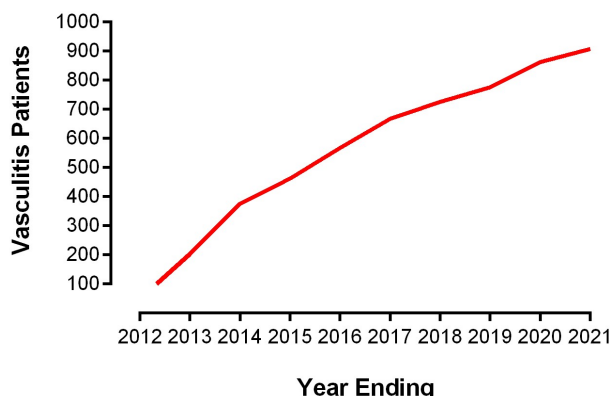
#### Risk Factors for Severe Outcomes in Patients With Systemic Vasculitis and COVID-19: A Binational, Registry-Based Cohort Study

Matthew A. Rutherford<sup>1</sup>, Jennifer Scott<sup>2</sup>, Maira Karabayas<sup>3</sup>, Marilina Antonelou<sup>4</sup>, Seerapani Gopaluni<sup>5</sup>, David Gray<sup>6</sup>, Joe Barrett<sup>6</sup>, Silke R. Brix<sup>7</sup>, Neeraj Dhaun<sup>8</sup>, Stephen P. McAdoo<sup>9</sup>, Rona M. Smith<sup>5</sup>, Colin C. Geddes<sup>10</sup>, David Jayne<sup>9</sup>, Raashid Luqmani<sup>11</sup>, Alan D. Salama<sup>12</sup>, Mark A. Little<sup>13</sup> and Neil Basu<sup>13</sup> on behalf of the UK and Ireland Vasculitis Rare Disease Group (UKIVAS)

#### Acute renal allograft failure in a patient with vasculitis

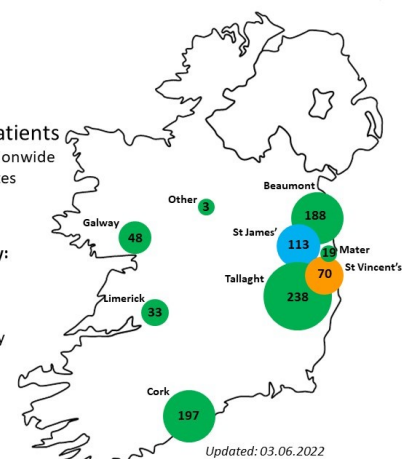
Cliona Cowhig<sup>1,\*</sup>, Jennifer Scott<sup>2,\*</sup>, Anthony M. Dorman<sup>1</sup>, Mark A. Little<sup>3</sup> and Declan G. de Freitas<sup>1</sup>

### RECRUITMENT TO DATE



908 Vasculitis Patients  
Recruited from a nationwide  
network of clinical sites

Hospital Unit Key:  
● Nephrology  
● Immunology  
● Rheumatology

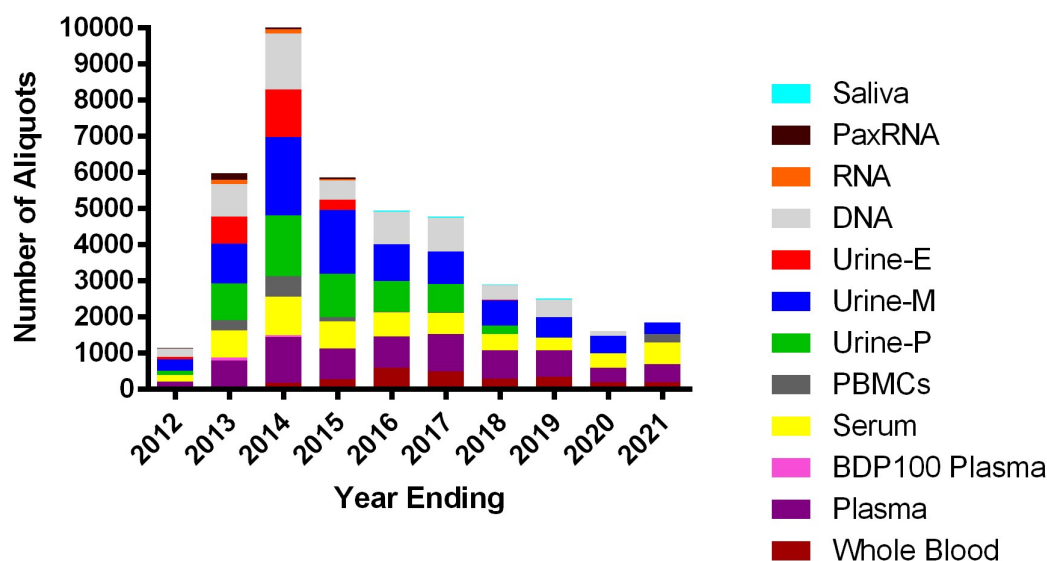


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### SAMPLE COLLECTION



### 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 Biobank

**Dr Alan Kennedy,** Biobank Manager & Senior Technician

#### RKD Registry

**Ms Vicky Carr,** Data Manager

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St James' Hospital, Dublin 8, D08 W9RT.

Web: [www.thkc.ie](http://www.thkc.ie) / Twitter: @THKC1

### 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

