

## Spring 2019 Newsletter

### GDPR - Implications for Registry and Biobank

The enactment of the General Data Protection Regulation (GDPR) and Health Research Regulations (HRR) since our last meeting have created concern for clinical researchers in Ireland. Interpretation of these regulations by the Department of Health have placed Ireland in a unique position relative to other European countries, and full compliance will lead to a significant impediment to clinical research activity and, ultimately, patient care.

The Irish Academy of Medical Sciences commissioned a review about the impact of the HRR on clinical research in Ireland. We have used this major shift in policy to perform a root and branch analysis of RKD operations, including an independent external review by the Institute for Innovation through Health Data, funded by the Irish Kidney Association. This was led by Fergal Seeballuck, regulatory manager in the HRB-SJH CRF, and has informed a revised ethics application and DPIA. One outcome is the retirement of the end-of-life Distiller database software; it will be fondly missed!

The RKD Biobank is committed to working with regulators to ensure that we are compliant with the GDPR, and to ensuring that samples and data donated by patients before GDPR was enacted will be available as intended in the new regulatory framework.

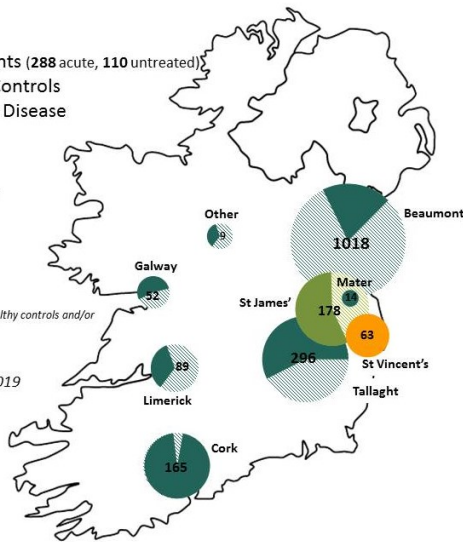
### Recruitment to Date

- 726 Vasculitis Patients (288 acute, 110 untreated)
- 343 Age-Matched Controls
- 667 Familial Kidney Disease

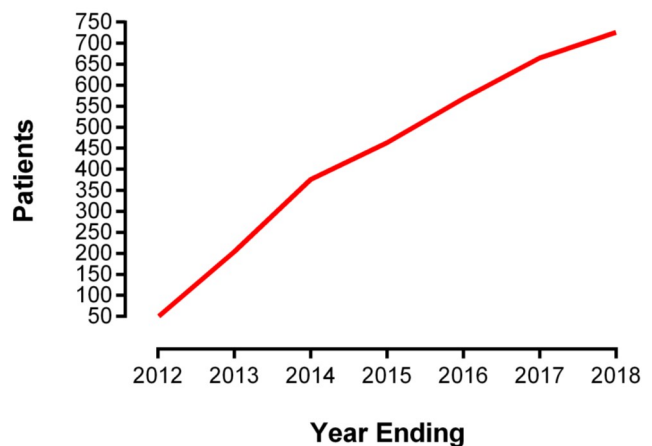
- Rheumatology
- Nephrology
- Immunology

(Hatched sections indicate healthy controls and/or FKDG recruits)

Updated: 04/02/2019



### Cumulative RKD Vasculitis Recruitment



### Latest Research Publications and Grants

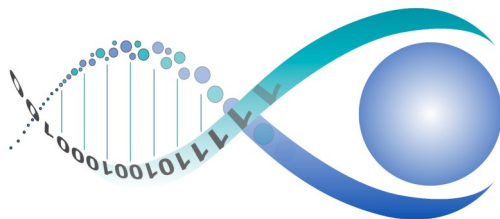
Nephrol Dial Transplant (2018) 1-9  
doi: 10.1093/ndt/gyf300



Urinary soluble CD163 and monocyte chemoattractant protein-1 in the identification of subtle renal flare in anti-neutrophil cytoplasmic antibody-associated vasculitis

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**Health Data for Clinical Benefit (HELICAL) Project:** H2020 ITN funded (€4.05m). The RKD Biobank is a key infrastructural plank of this international programme.

www.kidney-international.org

clinical investigation

### Monogenic causes of chronic kidney disease in adults

Dervla M. Connaughton<sup>1,2,3</sup>, Claire Kennedy<sup>2</sup>, Shirlee Shril<sup>1</sup>, Nina Mann<sup>1</sup>, Susan L. Murray<sup>2</sup>, Patrick A. Williams<sup>2,4</sup>, Eoin Conlon<sup>2,4</sup>, Makiko Nakayama<sup>1</sup>, Amelie T. van der Ven<sup>1</sup>, Hadas Ityel<sup>1</sup>, Franziska Kause<sup>1</sup>, Caroline M. Kolvenbach<sup>1</sup>, Rufeng Dai<sup>1</sup>, Asaf Vivante<sup>1,5</sup>, Daniela A. Braun<sup>1</sup>, Ronen Schneider<sup>1</sup>, Thomas M. Kitzler<sup>1</sup>, Brona Moloney<sup>2</sup>, Conor P. Moran<sup>6</sup>, John S. Smyth<sup>6</sup>, Alan Kennedy<sup>3</sup>, Katherine Benson<sup>4</sup>, Caragh Stapleton<sup>7</sup>, Mark Denton<sup>2</sup>, Colm Magee<sup>2</sup>, Conall M. O'Seaghdha<sup>2</sup>, William D. Plant<sup>7</sup>, Matthew D. Griffin<sup>8</sup>, Atif Awan<sup>9</sup>, Clodagh Sweeney<sup>9</sup>, Shrikant M. Mane<sup>10</sup>, Richard P. Lifton<sup>10,11</sup>, Brenda Griffin<sup>3</sup>, Sean Leavey<sup>12</sup>, Liam Casserly<sup>13</sup>, Declan G. de Freitas<sup>14</sup>, John Holian<sup>14</sup>, Anthony Dorman<sup>15,15</sup>, Brendan Doyle<sup>15</sup>, Peter J. Lavin<sup>16</sup>, Mark A. Little<sup>3</sup>, Peter J. Conlon<sup>2,4</sup> and Friedhelm Hildebrandt<sup>1</sup>

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Urinary and serum soluble CD25 complements urinary soluble CD163 to detect active renal anti-neutrophil cytoplasmic autoantibody-associated vasculitis: a cohort study

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## Personnel Network

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RKD and Vasculitis Registry and Biobank

## Welcomes, Farewells and Thanks

The past year saw the arrival of Ms Amrita Dwivedi and the departure of Dr Yanmei Huang at the Trinity Health Kidney Centre. We welcome Amrita to the group and thank her for her already substantial contribution to the work of the Biobank. We also wish Yanmei all the very best in her new post.

To all patients and control individuals who have so kindly taken part. To all consultants for generously allowing access to their patients. To registrars Paul O'Hara, Claire Kennedy, Sarah Moran, Dervla Connaughton, Adrian Whelan, Heather Gunning, Tammy Wanigasekera, Limy Wong, Dearbhla Kelly, Yvelynne Kelly, Radzi Rodzlan, Conor Judge, Amy Hudson, Susan Murray, Louise Ryan, Brona Maloney, Elshaeima Mohamed, Aine de Bhallis, Adeel Rafi Ahmed, Ted Fitzgerald, Tze Liang Goh, Julio Chevarria, Laura Slattery, Vicki Sandys, Jennifer Scott, Hannah O'Keefe, Sarah Cormican, Samar Medani, Donal Sexton and Mark Canney, who have helped us recruit extremely valuable acute patients. To John McCourt for database support. Finally, to all our interns, who make a substantial contribution to the efficient day-to-day operational running of the RKD Biobank— a massive thank you!

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

**HRB** Health  
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**VIA** Vasculitis Ireland  
AWARENESS

