

Trinity Health Kidney Centre,
Trinity Translational Medicine Institute,
St. James' Hospital,
James' Street,
Dublin 8,
Ireland.
[DATE]

Re – Revised consent for the Rare Kidney Disease and Vasculitis Biobank and Registry

Dear [ENTER PARTICIPANT NAME]

You may have been kind enough to agree to be part of a research study investigating vasculitis and related diseases. You may have donated blood or urine samples for use in studies to help us better understand the mechanism and genetics of vasculitis. This study is called the Rare Kidney Disease (RKD) Biobank and Registry; it stores samples of blood, urine and healthcare data for use in medical research.

Your samples and data have helped us discover things that have had a positive impact on patient care (described here: www.tcd.ie/medicine/thkc/research/rare).

Because of new data protection regulations around medical research we are contacting everyone who was part of this study to update their consent to ensure that we use their data in the best possible way for future research. This consent does not ask you to consent to any extra tests or study visits. But it will tell us how you would like us to use your data in the future.

Please find enclosed a revised information leaflet and consent form. I would be obliged if you could read the leaflet and, if in agreement, initial and sign the consent form. I have included a stamped, addressed envelope in which you can return the signed form. If you have any questions, please do not hesitate to contact me on 01-221-4493 or j.holian@svuh.ie.

We appreciate greatly the time and effort taken to do this. Without it, we will not be able to use your information for future research.

Your sincerely,

Dr John Holian

Consultant Nephrologist