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DATE

**National Registry of Rare Kidney Diseases – access to confidential database**

Dear (name of child) and Parent/Guardian - if older child

OR

Dear Parent/Guardian of (name of child) – if young child

OR

Dear (name of patient) – if adult

Thank you for consenting to participate in the National Registry of Rare Kidney Diseases (RaDaR Study), for which I have enclosed a copy of your signed consent forms. Your support is much appreciated in helping researchers and clinicians gain a greater understanding of rare kidney diseases.

I am writing to tell you about two initiatives which we hope will help improve your own understanding of your/your child's condition. The first is the patient-focused website **RareRenal.org** which contains information on all conditions covered by the RaDaR Study, as well as contact details of support groups and details of forthcoming patient information days. The site can be accessed at [www.rarerenal.org](http://www.rarerenal.org).

Secondly, I am writing to confirm name/your login-in details which will allow you to view clinical information about his/her/your condition and treatment, which is stored on our secure computer system.

To do this you will need to access the **Patient View** website at [www.patientview.org](http://www.patientview.org). Your username for the site is: XXX. Your password is your/your child's date of birth in the format DD/MM/YYYY (to be set by PV administrator). You can change this once you have logged in for the first time.

Please remember that your continued participation in this study is entirely voluntary and that you are free to withdraw your consent at any time without any effect on treatment or medical care.

I have enclosed an information sheet which explains how Patient View works but if you have any further questions please feel free to call me on XXX.

Yours sincerely,