



RaDaR

Rare Disease Registry

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Background

- Limited medical expertise on rare kidney diseases
- RaDaR aims to create an online database of patient information to share best practice guidelines
- Managed by a dedicated Rare Disease Group of experts in each condition
- May lead to future research studies on new treatments or ways of diagnosis

Information Security

- Data is encrypted and password protected
- Participants provided with a secure log-in to access and check your own information
- Identifiable data only available to your doctor so they can contact you if needed
- Members of the Rare Disease group will only see anonymised data – numbers rather than names

To take part...

- If your child is treated at BCH:
 - Collect an information sheet
 - Sign the consent form
 - Hand back to me
- If you or your child are currently treated elsewhere:
 - Collect an information sheet
 - Take to your doctor at your next appointment
 - Ask them to register you

RareRenal.org

- Patient and doctor information on rare kidney diseases
- Written by Rare Disease Groups and managed by the Renal Association
- Recently re-launched with ARPKD Patient and family information
- Today's presentations will be uploaded shortly