**Rare Disease Group (RDG) Application Form**

We invite applications from UK based Nephrologists who wish to set up a Rare Disease Group (RDG) for a condition not currently recruiting to the RaDaR rare disease registry. A list of current conditions and groups can be viewed here: [Rare Disease Groups | The UK Kidney Association](https://ukkidney.org/rare-renal/rare-disease-groups). The applicant should be the proposed RDG Lead.

An application is likely to be successful if the following criteria can be met:

1. The condition is rare (European Union definition: fewer than 1 in 2,000 people within the general population. US definition: a condition that affects fewer than 200,000 people).
2. The condition is well defined.
3. The condition has a definite renal involvement (current or future) and is primarily managed by Nephrology.
4. The applicant is a UK based Nephrologist.
5. At least one patient representative has been identified.
6. Membership of the group will be inclusive, welcoming members from all four devolved nations and including multi-disciplinary representation if applicable.

Applicant to complete the following information as thoroughly as possible:

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|  | **Applicant response** | **Guidance notes** |
| RDG Title |  |  |
| Definition of the spectrum of condition to be included. |  | Please include phenotype, genotype and SNOMED-CT terms and codes if applicable. https://termbrowser.nhs.uk |
| Prevalence |  | Should be fewer than 1 in 2,000 people within the general population. |
| Inclusion criteria |  |  |
| Exclusion criteria |  |  |
| RDG Lead | Title:  Surname:  Forename:  Institute:  Email address: | Must be a UK based Nephrologist and the person completing this application form. |
| Patient representative | Title:  Surname:  Forename:  Associated Charity/Institution (if applicable):  Email address: | Every RDG should have at least one patient representative. |
| Other members | Title:  Surname:  Forename:  Institute:  Email address: | We recommend that each RDG has at least one trainee, nurse, clinical and non-clinical expert. The Lead should attempt to recruit members from all devolved nations and all applicable disciplines. If the RaDaR Operational Management Group do not feel there is sufficient representation, an advert will be sent out on behalf of the RDG inviting expressions of interest from UKKA members. |
|  | Title:  Surname:  Forename:  Institute:  Email address: |  |
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|  | Title:  Surname:  Forename:  Institute:  Email address: | *Please insert further rows as needed* |
| Is expertise outside renal medicine / paediatric nephrology required? If so, how has this been addressed? |  | |
| List any other national or international collaborative groups working on this condition, and how the RDG relates to them. |  | |
| Does the RDG have the expertise and capacity to provide educational information for both patients and clinicians? See [**rarerenal.org**](http://www.rarerenal.org/) |  | |
| What research areas might this RDG be interested in? | *Delete as appropriate:*  Natural history  Epidemiology  Clinical practice  Interventional studies/Trials  Observational studies  Patient reported experience measures  Patient reported outcome measures  Other (please specify) | |
| Please outline any specific research proposals |  | |
| Please list any condition specific data fields you wish to collect |  | |
| Please indicate any known conflicts of Interest within the membership proposed | Please note that no member can be employed by (or own shares in) any biotech/pharma/commercial organisation. In addition, no member can be employed by a private healthcare delivery provider. | |

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| **RDG Lead Declaration**  I hereby agree to fulfil the role of RDG Lead and to be responsible for:   1. Attending the 1-day annual RDG Lead meeting. 2. Providing and maintaining information for clinicians and patients/carers to be published on   rarerenal.org.   1. Maintaining an up-to-date RDG membership list to appear on rarerenal.org. 2. Submitting an annual report to the RaDaR Operational Management Group by 31st March each year. 3. Timely communication with the RaDaR Operational Management Group (considered to be 10 days for   email responses).   1. Reviewing the content of this form every 3 years. 2. Succession planning (the term of office is 3 years, extendable at the discretion of the Rare Disease   Committee).  **Name of RDG Lead: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Signature of RDG Lead: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Clinical Director/Head of Department Declaration**  I hereby agree, on behalf of the applicant’s institution, that we support this application and will ensure that the applicant has the support needed to fulfil their responsibilities as outlined above.  **Name of Institution**  **representative: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Signature of Institution**  **representative: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Date: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Position:** Clinical Director/Head of department*(delete as appropriate)*  **Institution: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Email: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Telephone: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_**  **Completed applications and all correspondence should be sent to** [radar@ukkidney.org](mailto:radar@ukkidney.org) |