

## Vacancy for Lead Clinician of the Cystinosis Rare Disease Group

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After over five highly successful years in the role, Dr Graham Lipkin is stepping down as lead for the Cystinosis Rare Disease Group and a replacement is now being sought.

This is a real opportunity to lead an enthusiastic group of clinicians, in partnership with patients and Industry, to support improvement in patient service, clinical care and research of an ultra-rare disease at an exciting time of drug development and change in service model.

Candidates should be UK-based Nephrologists with a specific interest and expertise in Cystinosis. It is expected that the Rare Disease Group Leads are members of the Renal Association.

The main responsibilities of the role are as follows:

- To support the recruitment of Cystinosis patients into the **RaDaR rare disease registry**
- To promote research into Cystinosis, both in the UK and overseas, in collaboration with patient support groups, academic researchers and commercial companies
- To maintain the condition specific pages on the patient and clinician information website **RareRenal**, in accordance with the **Information Standard accreditation** and with the support of the RaDaR Operational Manager
- To abide by the terms and conditions set out in the Rare Disease Group **Standard Operating Policy** - available on request from the RaDaR Operational Manager as below
- To organise and promote Patient and Clinician Information events to facilitate patient involvement and researcher engagement

Please send expressions of interest to **Melanie Dillon, RaDaR Operational Manager** ([Melanie.Dillon@RenalRegistry.nhs.uk](mailto:Melanie.Dillon@RenalRegistry.nhs.uk)) by **Friday 27<sup>th</sup> October**.

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