

Rare but it's there!

A forum to better understand Rare Renal Disease, RaDaR and Fabry disease

19th June 2017: Pullman Hotel, Kings Dock, Liverpool, L3 4FP

A meeting organised by Sanofi Genzyme

I am delighted to invite you to this educational meeting on the 19th June during Renal Week at the ACC in Liverpool.

As chair of the Rare Disease Committee of the Renal Association I would like to take the opportunity to highlight the important and exciting work within rare renal disease, initiatives such as the National Registry of Rare Kidney Diseases (RaDaR) designed to pull together information from patients with rare kidney disease to gain a much better understanding of how these illnesses affect people and speed up research, catalyzed by the Rare Disease Groups.

One of these recently formed is the Fabry Disease Group. Fabry disease affects the kidney in almost all male and in many female patients and without timely diagnosis and treatment can result in end-stage renal disease and early death. We are fortunate to have Prof Neil Turner, a member of the Rare Disease Committee and Fabry disease group to provide his insights on the disease, the symptoms, diagnosis and management.

Faculty:

Prof Detlef Bockenhauer, Prof of Paediatric Nephrology, University College London (UCL) Centre for Nephrology (Chair)

Prof Neil Turner, Professor in Nephrology, MRC Centre for Inflammation Research, Edinburgh

Agenda:

19.30 **Opening remarks** *Prof Detlef Bockenhauer*

19.35 **Fabry disease & the kidney, the disease, symptoms, diagnosis and treatment** *Prof Neil Turner*

20.0 **Getting Fabry on the RaDaR: working with the rare renal disease registry, its advantages and challenges**
Prof Detlef Bockenhauer

20.30 **Buffet dinner**

We do hope you can join us on what will be an interesting and educational meeting. The numbers are limited, so to secure your place please contact John Applegate at KOL Communications Ltd, john@kolcommunications.net or 01892 739 588. We will register your place and keep in touch with further information.

Sincerely yours,



Prof Detlef Bockenhauer
Prof of Paediatric Nephrology, UCL