

RaDaR Rare Disease Group Leads Meeting 2024

Friday 2nd February 2024, 11am – 3pm, Conference Hall

Resource for London, Holloway Road, N7 6PA

Registration opens from 10am with tea/coffee available. 11am start

	Agenda
11.00	Introduction and Welcome – Prof Danny Gale
11.05	Rare Disease Group Impact IgA Nephropathy Long term outcomes paper - Video from Prof Jonathan Barratt
11.20	Research <ul style="list-style-type: none"> • Clinical predictors of long-term outcomes in C3G and IC-MPGN - Sherry Masoud
11.35	<ul style="list-style-type: none"> • Predict Study – Dr Kate Bramham
11.50	<ul style="list-style-type: none"> • RaDaR enrichment and clinical trials – Prof Danny Gale
12.10	RaDaR Operations - Garry King, RaDaR Manager
12.20	Patient Entered Data <ul style="list-style-type: none"> • IgA Nephropathy Loin pain questionnaire - Dr Haresh Selvaskandan • Discussion
12.45	Lunch Networking and posters
13.45	Patient representative perspective – Tess Harris
14.00	Running a RaDaR group and driving research - John Sayer
14.20	Rare Renal Disease Strategy Review – Zoe Plummer, UKKA
15.00	Close of meeting