

## **RaDaR Patient Representatives' Meeting 2024**

Friday 12<sup>th</sup> July 2024, 11am – 3pm

Registration from 10am

Conference Hall, Resource for London, Holloway Road, N7 6PA

10:00-11:00	Registration with tea/coffee/pastries
11:00-12:30	Getting new therapies approved: the rare disease problem – Danny Gale
	Presentations on patient surveys: <ul style="list-style-type: none"> <li>• Female Reproduction, Educational and Developmental Attainments in offspring</li> <li>• Loin pain in kidney disease</li> <li>• Kidney Patient Reported Experience Measure (PREM)</li> </ul>
	Discussion: RaDaR annual survey - what are the important questions we should be asking?
12:30-13:15	Lunch and networking
13:15-15:00	Presentation: Developing a rare disease patient support group (Beacon: for rare diseases)
	Discussion and future plans
	Round up of day and summary of next steps
15:00	Close