RaDaR

Registry of Rare Kidney Diseases

RaDaR Rare Disease Summit 2026

Sunday 29 & Monday 30 November

Millennium Point Conference Centre, Birmingham

The research and therapeutic landscape for rare kidney diseases is evolving at an unprecedented pace. Novel therapies are increasingly entering clinical development, with some already available to patients and others expected to reach clinical practice in the near future.

RaDaR has played a central role in this progress by quantifying unmet need, defining natural history and outcomes across a wide range of rare kidney diseases, facilitating recruitment to clinical trials, and informing trial design and interpretation - including helping to establish surrogate endpoints acceptable to regulators.

However, important challenges remain. These include demonstrating the health economic value of rare disease therapies, ensuring that approved treatments are funded and implemented consistently across the NHS, and developing service models that provide equitable access to innovation for all patients.

The RaDaR Rare Disease Summit 2026 will bring together clinicians, researchers, patient representatives and industry partners to address these opportunities and challenges. The meeting will provide a forum to share the latest disease-specific advances, explore emerging therapeutic strategies, understand evolving regulatory and health economic requirements, and plan the next generation of impactful rare kidney disease studies.

Join colleagues from across the rare kidney disease community at Millennium Point Conference Centre, Birmingham, to explore the latest developments in research, therapeutics, service delivery and patient-centred care, and help define the next generation of rare kidney disease research and treatment in the UK.

Sunday 29 November: Clinical education and therapeutic updates

An educational programme for renal specialists, trainees and other healthcare professionals, featuring expert-led updates from Rare Disease Groups across a range of areas, including genetic kidney diseases, IgA nephropathy, vasculitis, nephrotic syndrome and lupus nephritis. The programme will support clinicians to interpret emerging evidence, understand evolving treatment pathways, and counsel patients as therapeutic options expand.

Monday 30 November: Research methodology, strategy and partnership

A forward-looking programme focused on rare kidney disease research methodology and the future of national and international study design. This will bring together RaDaR team members, patient representatives, clinicians, academics, industry partners and other key stakeholders to help shape the next phase of rare kidney disease research.
The programme will consider how RaDaR can integrate large-scale genomic, histology, imaging and health data resources, alongside patient-reported outcomes and other patient-centred measures to generate deeper disease insights, improve trial readiness, support precision medicine, and enable more powerful observational and interventional studies.

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Educational Day

Sunday 29 November, 09:30 - 16:30

Chair TBC

09:30 - 09:50	**Welcome and overview of rare kidney diseases and their importance**	**Danny Gale**
09:50 - 10:20	**The patient perspective on rare kidney disease**	**Susie Gear** Alport UK
10:20 - 10:40	**IgA Nephropathy**	**Chee Kay Cheung**
10:40 - 11:00	**Membranous Nephropathy**	**Durga Kanigicherla**
11:00 - 11:20	**Vasculitis**	**Steve McAdoo**
11:20 - 11:40	**Break and networking with sponsors**	
11:40 - 12:00	**Lupus nephritis**	**Rachel Jones**
12:00 - 12:20	**Alport syndrome**	**Neil Turner**
12:20 - 12:40	**ADPKD**	**Omid Sadeghi-Alavijeh**
12:40 - 12:50	**Morning Close**	
12:50 - 13:50	**Lunch, networking with sponsors and posters**	

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Educational Day Continued....

Sunday 29 November, 09:30 - 16:30

	Stream 1	Stream 2
13:50 - 14:10	APOL-1 related kidney disease Kate Bramham	CAKUT Melanie Chan, Joanna Clothier, Lucy Plumb
14:10 - 14:30	MGRS Jenny Pinney	ADTKD John Sayer
14:30 - 14:50	FMD Tina Chrysochou	Hyeroxaluria and cystinosis Shabbir Moochhala
14:50 - 15:00	Break and networking with sponsors	
15:00 - 15:20	Retroperitoneal fibrosis Fred Tam	Tubulopathies Rhys Evans
15:20 - 15:40	IC-MPGN and C3 glomerulopathy TBC	Cystinuria Kay Thomas, Richard Coward
15:40 - 16:00	HNF1b mutations Rhian Clissold	ARPKD, NPHP and Ciliopath Shalabh Srivastatva, Pat Wilson
16:00 - 16:20	Idiopathic nephrotic syndrome TBC	
16:20 - 16:30	Closing	

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Rare Kidney Disease Research Skills and Strategy Day

Monday 30 November, 09:00 - 16:30

Chair TBC

What has RaDaR done and what can it do?

09:00 - 09:20	**PARASOL: A new start for FSGS?**	**Laura Mariani**
09:20 - 09:40	**How RaDaR data transformed IgA nephropathy**	**TBC**
09:40 - 10:00	**Quantifying unmet need and tracking natural history**	**Katie Wong**
10:00 - 10:20	**Health economic analyses, HES and NICE appraisals**	**Lexy Sorrell**
10:20 - 10:40	**Real-world data and regulatory approvals**	**Alex Mercer**
10:40 - 11:00	**Validating potential clinical trial endpoints in rare glomerular diseases**	**David Pitcher**
11:00 - 11:20	**Break and networking with sponsors**	
11:20 - 11:40	**Clinical trial recruitment and RaDaR Collaboration**	**Zoe Plummer**
11:40 - 12:00	**PROMs and QOL assessment**	**Devin Peipert**
12:00 - 12:20	**NPIC, national enrichment of biopsy and image data and AI**	**Sherry Masoud**
12:20 - 12:50	**Genomics and RaDaR outlook**	**Danny Gale**
12:50 - 14:00	**Lunch and networking with sponsors**	
12:50 - 14:00	**Working Lunch** **RaDaR One-on-One Sessions** Attendees can engage in private, 1:1 discussions with members of RaDaR. These sessions provide a focused opportunity to exchange knowledge, ask questions, discuss collaborations or just connect.	

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Rare Kidney Disease Research Skills and Strategy Day continued

Monday 30 November, 09:00 - 16:30

Chair TBC

What do people want from RaDaR and how can we collaborate to make that happen?

14:00 - 14:30 **Voices to vision session - Metro Room**

	Auditorium	Metro Room
	Target audience: Healthcare professionals, clinicians	Target audience: Funders and collaborators
14:30 - 15:30	**Rare kidney disease research skills session: Understanding surrogate trial endpoints and how mechanistic data informs trial interpretation** **TBC**	Discussion session 1 **How can RaDaR be a driver for change in clinical practice both nationally and internationally?** **Smeeta Sinha, Danny Gale**
15:30 - 16:00	Rare kidney disease research skills session: Case based discussion **Which analysis method at what time for which patients?** **Lexy Sorrell**	Discussion session 2 **Defining data needs and using RaDaR to acquire, collate, and analyse insights** **TBC, Kate Bramham**

16:00 - 16:30 Open discussion, tea, networking with sponsors and close

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Thank you to our event sponsors:

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