



Welcome to the February Q&A!

Trusts represented today include: North Bristol, GSTT, Leicester, Manchester, Dublin, Imperial, Glasgow, Birmingham, Sheffield, Royal Free,

Updates

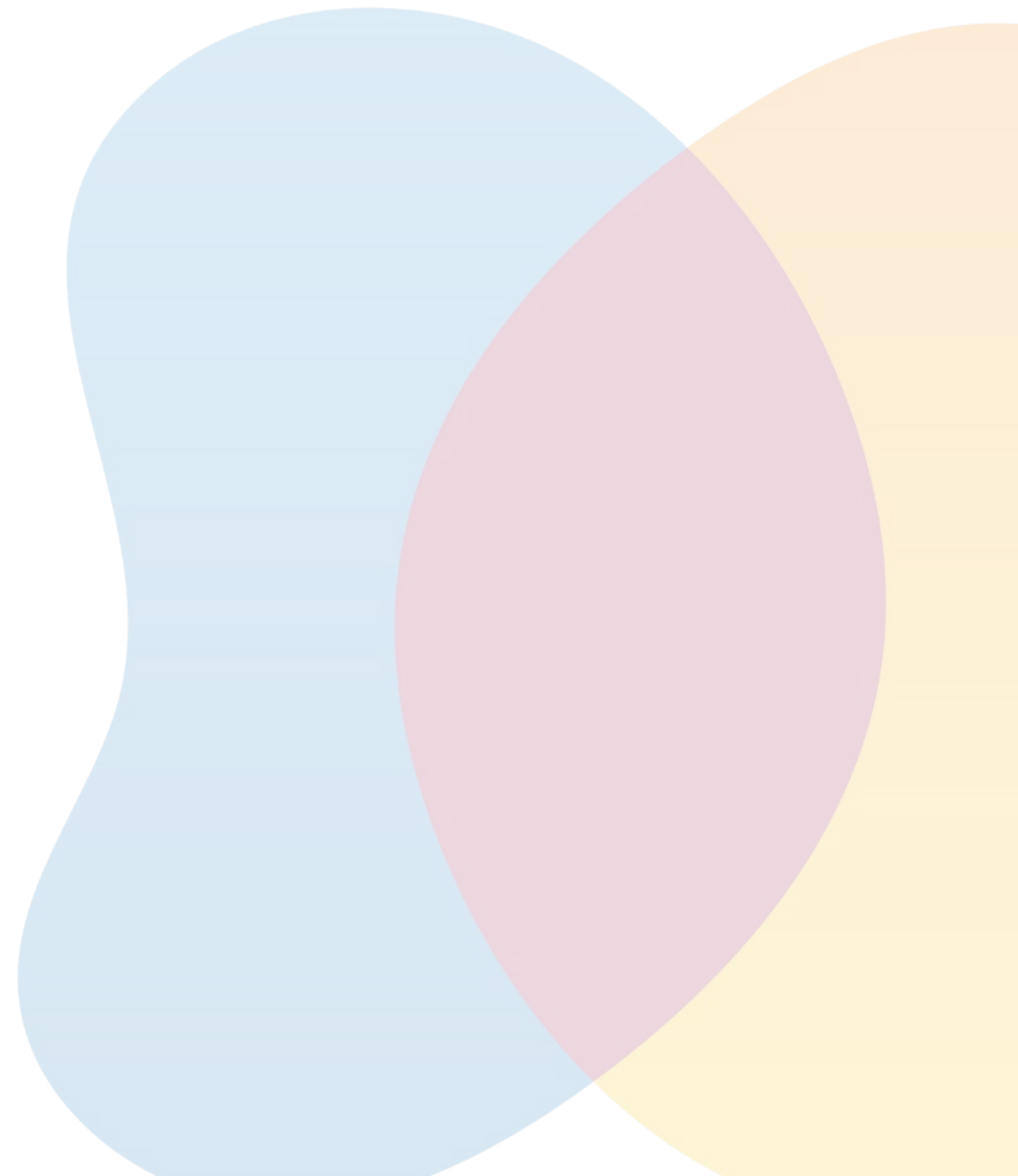


- Reminder to check your RPG membership is up to date
 - Large number of lapsed memberships, currently being checked against the Q&A whastapp group list
- **RPG conference 2024 11th/12th October** - save the date!! 😊
 - Birmingham Arden Hotel
- **UK Kidney week 10-12th June 2024**
 - Edinburgh Conference Centre
 - Liaise with Cathy Pogson to get involved (cathy.pogson@porthosp.nhs.uk)
- Monthly teams chat for advanced/consultant portfolios
 - Email cathy.pogson@porthosp.nhs.uk if you would like to join



RaDaR

Kathrine Parker



What is RaDaR?



- National Registry of Rare Kidney Diseases (RaDaR)
- 31,473 patients recruited into RaDaR from 110 sites across the UK
- Largest rare kidney disease registry in the world
- Approx. 30 rare diseases
- Contains clinical information as well as blood/urine
- Working to get genetic tests and blood biomarker results



What is RaDaR?



UK Kidney Association

- Originally funded by MRC, KRUK, KCUK and the PKD Charity
- Now managed and funded by UKKA
- RaDaR Team consists of Danny Gale, Kate Bramham (Directors) and the registry team

Rare disease groups (RDGs)



Alport Syndrome

APRT Deficiency
(APRT-D)

ARPKD & NPHP
(Autosomal Recessive Polycystic Kidney Disease & Nephronophthisis)

Atypical Haemolytic Uraemic Syndrome
(aHUS)

Autosomal Dominant Polycystic Kidney Disease
(ADPKD)

Autosomal Dominant Tubulointerstitial Kidney Disease
(ADTKD)

BK Nephropathy

Calciophylaxis

CKD due to Genetic Factors in people of African ancestry
(CKD-Africa Genes)

Congenital Anomalies of the Kidneys and Urinary Tracts
(CAKUT)

Cystinosis

Cystinuria

Dent Disease & Lowe Syndrome

Fabry Disease

Fibromuscular Dysplasia

Haemolytic Uraemic Syndrome
(Shiga Toxin Associated; STEC-HUS)

Hepatic Nuclear Factor 1B Mutation
(HNF1b)

Hyperoxaluria
(Primary Hyperoxaluria, Oxalosis)

IgA Nephropathy

Inherited Renal Cancer Syndromes

Lupus Nephritis

Membranous Nephropathy

Mitochondrial disease affecting the kidney

Monoclonal Gammopathy of Renal Significance
(MGRS)

MPGN, DDD & C3 Glomerulopathy
(Membranoproliferative Glomerulonephritis, Dense Deposit Disease & C3 Glomerulopathy)

Nephrotic Syndrome
(Steroid Sensitive & Steroid Resistant; SSNS & SRNS)

Pregnancy and Chronic Kidney Disease

Pure Red Cell Aplasia
(PRCA)

Retroperitoneal Fibrosis

Tuberous Sclerosis

Tubulopathy

Vasculitis

- Each RDG has a clinical lead
- Each group has patient members and expert clinicians
- Access this information <https://ukkidney.org/rare-renal/homepage>
- Each group has objectives – may include high quality research or developing clinical policies/pathways

Top level metadata in RaDaR, updated Sept 2023



Rare Disease Cohort	Cohort Size	Lab Results via data feed	Patients on RRT	Number of people with CKD (egfr < 90)	number of people with creatinine readings	Mean number of creatinine readings per person
Alport Syndrome	1021	795	309	605	810	59.0
APRT Deficiency	<10	<10	<10	<10	<10	62.1
Atypical Haemolytic Uraemic Syndrome	299	244	110	168	249	195.8
Autosomal Dominant Polycystic Kidney Disease	8302	6767	2398	6286	6945	68.5
Autosomal Dominant Tubulointerstitial Kidney Disease (FUAN)	233	180	93	165	184	69.6
Autosomal Recessive Polycystic Kidney Disease/Nephronophthisis	254	200	81	133	218	87.2
BK Nephropathy	86	79	52	82	79	205.8
Calciophylaxis	60	48	19	43	47	179.2
CKD due to Genetic Factors in people of African ancestry	110	80	<10	80	80	76.7
Cystinosis	177	151	77	100	153	115.8
Cystinuria	496	337	<10	298	360	19.3
Dent Disease and Lowe Syndrome	64	36	<10	24	40	43.8
Fabry Disease	54	45	18	40	43	69.2
Fibromuscular Dysplasia	51	38	<10	27	37	14.3
HNF1b Mutations	91	58	<10	41	60	31.3
Hyperoxaluria	129	104	33	78	107	67.0
Idiopathic Nephrotic Syndrome	4512	3365	772	2805	3851	98.7
IgA Nephropathy	4642	3967	1701	3798	4040	90.9
Inherited Renal Cancer Syndromes	247	12	<10	<10	12	<10
Membranoproliferative Glomerulonephritis / Dense Deposit Disease	1210	936	431	836	1016	122.0
Membranous Nephropathy	2618	2027	312	1994	2120	66.2
Mitochondrial Renal Disease	<10	<10	<10	<10	<10	<10
Monoclonal Gammopathy of Renal Significance	215	160	46	152	161	90.0
Pregnancy	752	595	179	521	665	82.1
Pure Red Cell Aplasia	<10	<10	<10	<10	<10	165.4
Retroperitoneal Fibrosis	154	96	<10	108	114	50.6
STEC-associated HUS	176	112	70	32	120	37.2
Tuberous Sclerosis	265	180	13	117	187	25.5
Tubulopathy	389	230	<10	154	241	28.9
Vasculitis	5097	3561	672	3363	3726	63.3

RaDaR and RDG review



- AVPs oversight RaDaR met with directors to review membership, objectives and outputs of RDGs
- NO PHARMACISTS in RDGs
- Looking at objectives: Membranous, Vasculitis, Pregnancy in CKD, Lupus Nephritis and BK nephropathy were all groups that would benefit from Pharmacist

Pharmacist input



- Any areas of interest please have a look on the website at objectives
- If wish to join an RDG let me know and I will put you in touch with the lead via registry staff
- Exciting opportunities
- Pharmacist exploring a membranous project as a MSc include:
Developing a future research protocol in MN– medicines data collection to enhance RaDaR data, survey of practice and literature review



Any Questions?

Updates

- NICE TA: Empagliflozin (Jardiance) published December 2023
 - CKD/DKD/Proteinuria
- NICE TA: Budesonide (Kinpeygo) published December 2023
 - IgA Nephropathy
- UKKA Expressions of interest:
 - PD guidelines (closed)
 - BBV guidelines (due soon)
 - MPT Chair for patient education committee
 - MPT Chair for IPC



Updates



- UKKA membership - Please can all members log into the website to check your renewal status
 - A number of Whatsapp members have lapsed membership and we are working to ensure all active Q&A members have a current membership
 - Check your contact emails +/- spam boxes as some of the renewals appear to be going there

A screenshot of the UK Kidney Association (UKKA) website. At the top, there is a dark blue navigation bar with social media icons (LinkedIn, Twitter, Instagram, YouTube) on the left and 'Login', 'Join UKKA', 'Donate', and a search icon on the right. Below this is a header section with the UKKA logo on the left, the UK Renal Pharmacy Group logo in the center, and a grey button with the text '« Return to The UK Kidney Association' on the right. A large green arrow points down from the UK Renal Pharmacy Group logo to the 'Members' link in the main navigation menu. The main navigation menu includes 'Home', 'About us', 'Annual Conference', 'Renal Reference Texts', 'New to Renal Pharmacy', 'Members', 'Members Q&A', and 'Contact Us'. Below the navigation is a section titled 'Members' with the text: 'The following content is only accessible to UK RPG members. If you are not logged in already, you can log in now to view or sign up and become a member'. A large green arrow points left from the right side of this text towards the 'Members' link in the navigation menu. At the bottom, there is a grey box containing three white cards: 'Guidelines' (NICE accredited clinical practice guidelines), '25th Annual Report' (Analyses about the care provided to patients at UK renal), and 'UKRR AKI Report' (A report on the nationwide collection of AKI warning test).



Q&A Themes – Supply Issues

- MPA 360mg
- Sando K
- Slow sodium
- Sando phos
- Taurolock U25000
- Urokinase 100,000 available
- Alteplase 2mg (imports available – expensive ULM option)
- Basiliximab
- Sodium bicarb IV 1.26% and 1.4% - back in stock
- Lidocaine 1% and 2% with adrenaline both out of stock (?alternate pack sizes/ULMs)

Q&A Themes - Guidelines

- UKKA draft commentary on tolvaptan
- Fondaparinux for HD with HIT
- Imlifidase guidelines
- Apixaban in dialysis
- Vancomycin in CKD/HD



Q&A Themes - Renal



- Hyperkalaemia with LMWH
- Commissioning of belimumab
- LASAR – mercaptopurine/mercaptopamine
- MHRA quinolone alert
- National Shared Care Agreement – MMF
- RDD update
 - Funding
 - Access (password lock-outs issue can be fixed by adding additional users with individual logins)
 - Huge thanks to Emily Horwill and the T&F team
- Methylpred within Ponticelli
- EPO commissioning
- Ceftazidime dosing in CKD



Q&A Themes - Dialysis

- ACS treatment with fondaparinux
- Osteoporosis treatment
- UFH infusion whilst dialysing
- Argatroban flushes
- Flu treatment
- Wegovy in HD
- Tenofovir dosing for Hep B
- Cefazolin dosing on non-HD days for endocarditis
- Drug removal via PD
- Pregnancy and HD
- Lokelma and HD
- WDA/Supply arrangements for satellite units
- Pethidine for PD insertion

Q&A Themes - Transplant

- Formulary info – envarsus
- Campath access
- Avacopan for ABMR
- Enhanced recovery programmes
- Sirolimus -> ciclosporin





Q&A – New Qu

- Clinical sub group looking for new members 🤩
- RDD monograph team looking for new members :D

- D-Mannose for prevention of UTIs
 - Recommended by Urologists, available OTC as a supplement. Action – binds to bladder wall.

- Dialysis patients with previous HIT- possibility of rechallenge with LMWH?
 - Liaise with ICU group?

- Fluoroquinolones safety alert
 - Safely use where no other alternatives

- Lokelma pre-op – is there any risk of aspiration?

February Q&A - Close



Thank you for attending!

Next Q&A: Tuesday 19th March

Keep in touch throughout the month on **WhatsApp Q&A Group**

- >100 participants throughout UK and Ireland
- Useful real time forum for clinical Q's
- Please consider joining!

