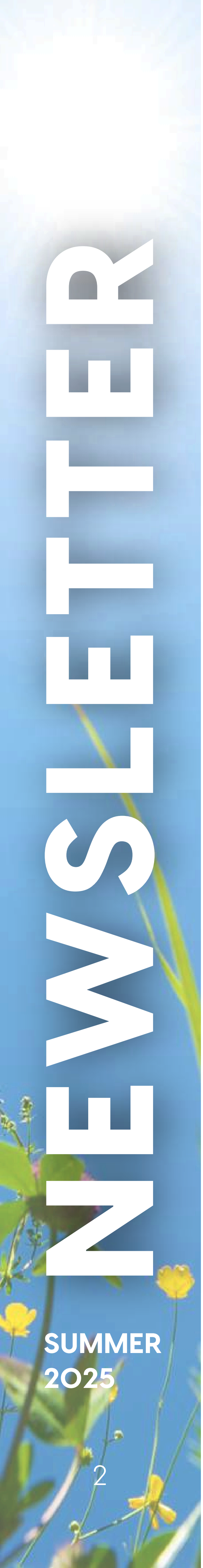
RaDaR Patient Newsletter

SUMMER 2025

RaDaR
Registry of Rare Kidney Diseases

UKKA
UK Kidney Association
Rare Renal



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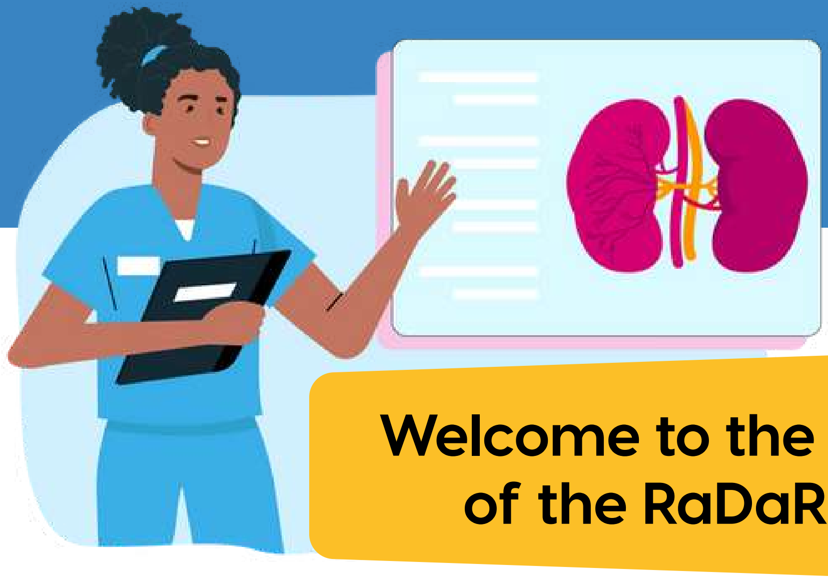


Welcome to the Summer 2025 edition of the RaDaR patient newsletter!

We are thankful for your feedback to date. We have incorporated a new formatting style and have addressed areas of content you asked to hear more about where possible.

We would appreciate any **feedback on this issue** through our three-question feedback form. We will then incorporate what we can into our next issue.

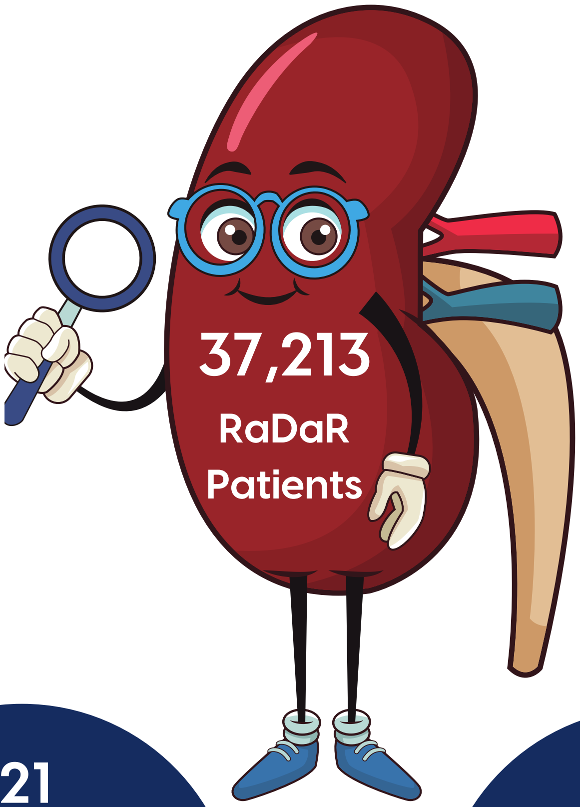
★★★★★

We are unable to respond to individual health queries or provide any medical assistance. If you have concerns about any symptoms, we advise you to contact your doctor or local hospital, or call NHS 111. In an emergency, dial 999 immediately.

Please find links below to some **patient charities**, both of which have a patient helpline:

Kidney Care UK
National Kidney Federation

RaDaR Facts and Figures



37,213

RaDaR Patients

394
primary diagnoses
176
rare conditions

Results have been automatically received for **75%** of RaDaR patients

121
Active users in the UK recruiting & adding data to RaDaR in 2025

250
patients recruited per month
(on average)

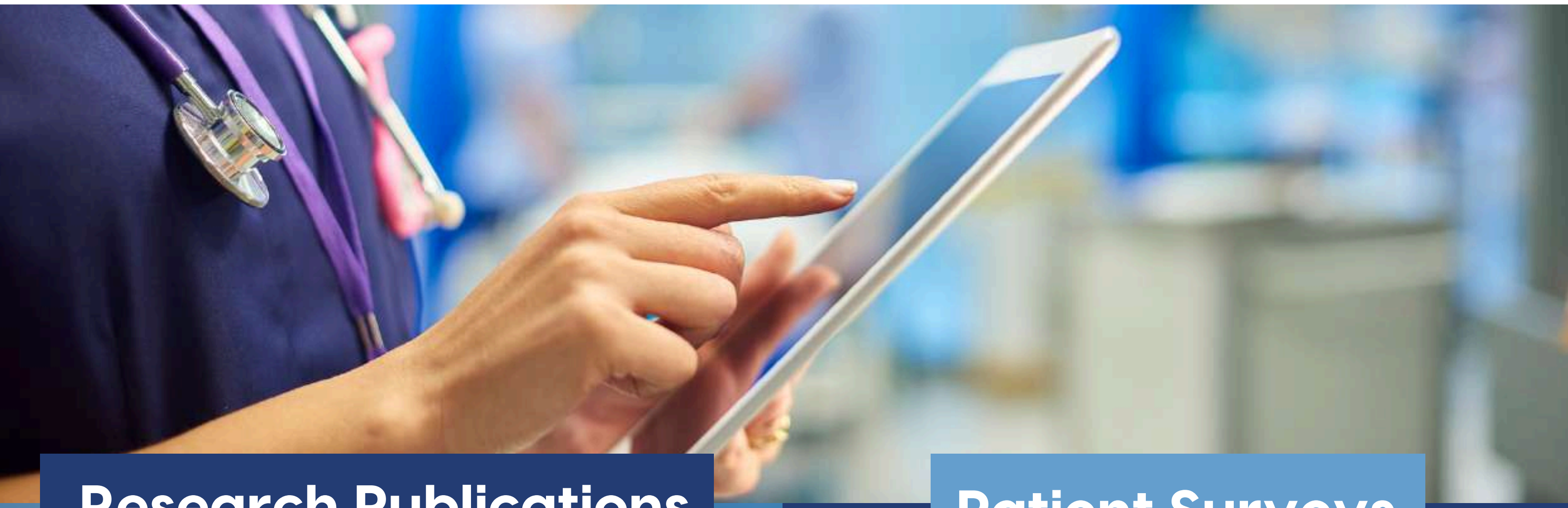
Hospitals that have recruited the most patients to RaDaR overall

- **London-Royal Free**
- **London-Guys & St Thomas**
- **Oxford-Churchill**

Rare Disease Groups that recruited the most patients in 2025

- **CMV Post Transplant**
- **IgA Nephropathy**
- **Autosomal Dominant Polycystic Kidney Disease**

RaDaR Activities & Outputs



Research Publications

Our most recent publication looks at idiopathic nephrotic syndrome, in particular how the disease progresses and whether the level of protein in a patient's urine is associated with how quickly a patient reaches kidney failure.

This understanding will help clinicians to better understand which patients might get worse more quickly, and it will help to design clinical trials for treatments.

The study looked at over 4,000 patients from RaDaR, both adults and children. These patients were followed up for an average of 8 years.

The findings were:

- People who had a genetic diagnosis had worse outcomes.
- During the period of time that patients were followed up 30% reached kidney failure or died.
- People who had higher levels of protein in their urine were more likely to progress to kidney failure.

Links to RaDaR papers and posters can be found on the Research page of the RaDaR website.

Patient Surveys

Once again, thank you so much to those of you who took the time to respond to our survey on reproductive health and kidney function.

We were struck by the number of you who provided additional information in the free text boxes. We are so very sorry to hear that so many of you have had distressing times.

We are still analysing the data but we have done the following, based on early results:

- We have a paper almost ready to be submitted for publication describing the hormone therapies that people have taken, and looking for demographic differences
- We have requested national kidney menopause guidelines and a Nature Review
- Abstracts have been presented at national and international conferences
- Some early results were shared at our 15 year celebration event

We continue to be very grateful to all of you for supporting so much high quality research.

Upcoming Events

UK Kidney Week Harrogate | 10-12 March 2026. The UK's largest conference for the professional kidney community. RaDaR looks forward to showcasing research outcomes during the event and strengthening the registry's profile amongst clinicians.

Keep an eye on the Rare Renal Events calendar on the RaDaR website for more upcoming events.

Get Involved in Research

The Generation Study is a research study led by Genomics England in partnership with NHS England that aims to recruit 100,000 newborn babies (with their parents' consent). The main aims are earlier identification of 200+ rare genetic conditions in babies that can be treated in the NHS, supporting broader healthcare research to improve testing and discover more treatments, and to explore the risks and benefits of storing an individual's genome over their lifetime.

Genomics England | Generation Study

RaDaR at UK Kidney Week

Bournemouth | June 2025

UK Kidney week saw **three posters** presented by the UKKA RaDaR team:

Kidney outcomes and eGFR slope in patients with Alport Syndrome, using data from the National Registry of Rare Kidney Diseases (RaDaR)
David Pitcher

The effect of proteinuria on kidney outcomes in Alport Syndrome: a longitudinal analysis of 1192 patients from the National Registry of Rare Kidney Diseases
Dane Rogers,
presented by Katie Wong

The Strengths and Challenges of Creating a Large-Scale Real-World Data Rare Disease Registry,
Susan Pywell

RaDaR 15-year Celebration

22 May 2025

RaDaR's first participant was consented in 2010 and 107 people were recruited in its first year. 15 years later **RaDaR is now the largest rare kidney disease registry in the world**. At the time of writing we have more than 37,000 participants. We wanted to take a moment to celebrate the fact that RaDaR has not only survived, it has grown over the past 15 years. This has only been possible because of all of you consenting to let us work with your data to understand rare kidney diseases better. We must also thank NHS staff for their time, support and contributions.

We started the day by looking back 15 years, reminding ourselves of how RaDaR started and how we have arrived where we are today. Presentations were then given by researchers showing how they have used RaDaR data to answer important questions. Topics ranged from the differences in the ages at which people with different rare diseases reach kidney failure, to understanding more about people's lived experiences of loin pain.

We refuelled with lunch and moved on to the afternoon session, which was dedicated to patient charities. We had presentations from PKD Charity, Kidney Care UK, Kidney Research UK and Alport UK. We were fortunate to hear some recorded messages from patients, talking about their experiences and expressing their wishes and hopes. These were incredibly powerful and reminded us of what we hope to achieve with RaDaR - **better understanding, better treatments, and better quality of life for everyone with a rare kidney disease**.

Rare Disease Spotlight

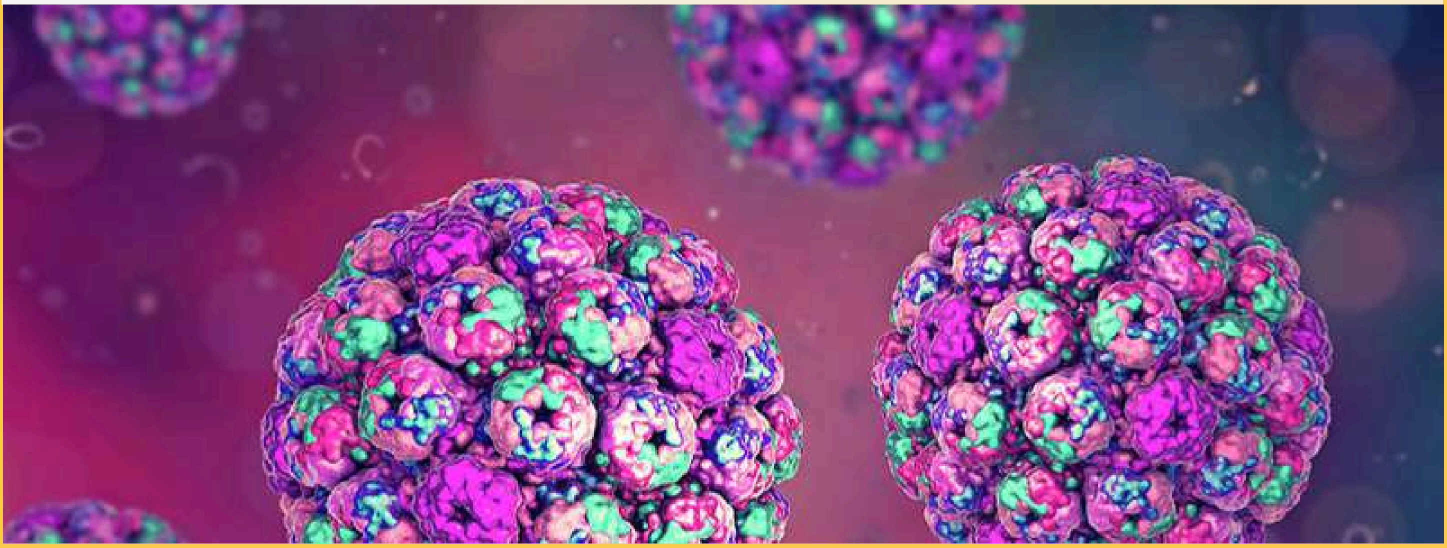
BK Nephropathy (BKN)

BK virus (sometimes known as polyomavirus) is a common virus that most people get in childhood. Symptoms resemble a common cold, and once you've had a BK virus infection it remains dormant.

BK virus can become reactivated when the immune system is weakened. People with kidney transplants, who take immunosuppressant drugs to stop transplant rejection, are particularly prone to reactivated BK infections (known as BK virus-associated nephropathy (BKVAN or BKN)). Around 6% of people who have had kidney transplants will develop BKN within 5 years of having their transplant.

BKN can cause kidney damage and affect the success of a kidney transplant. The vast majority of kidney transplant recipients who develop BKN have no symptoms at all. Hospitals will check for signs of BKN before and after a kidney transplant.

The main treatment is to carefully reduce the strength of the drugs a person takes to suppress their immune system. Anti-viral drugs may also be prescribed. If the virus is detected early, these treatments may be able to take effect before kidney function is adversely affected.



Updates from the RDG Lead

Matthew Welberry-Smith

I am Matt Welberry-Smith, a kidney transplant doctor from Leeds. I am passionate about kidney transplantation but very aware of the problems that kidney transplant patients can have – one of those is BK virus, a virus that almost everyone carries, but only causes problems when someone is taking anti-rejection medications. Unfortunately, we don't have any treatments for BK. We reduce the immunosuppression, but that runs the risk of precipitating rejection. I am delighted to be chairing the RaDaR **Rare Disease Group on BK Virus** to try and tackle this problem.

We have run two **patient engagement events** jointly with Kidney Research UK to help us understand the patient experience of BK, and to help us prioritise research areas. We are **recruiting patients** who get BK virus problems after their kidney transplant – if that is you and you haven't already been added to the BK-RaDaR data collection, please talk to your transplant research team about making sure that you are!

The group has brought scientific colleagues and kidney transplant trainee doctors across the UK on board to help tackle the BK virus problem. We are interested in more patient representation in the group - I am happy to be contacted if that could be you! (01132064534)

A detailed **national audit** of practise and outcomes for patients with BK virus is being set up with the support of NEPHWork, and we are n the process of looking at how BK virus testing can be standardised across the UK to enable more research.

Lots of our members contributed to the first ever UK **guideline on BK virus** produced by the British Transplant Society, and some of us worked with patients to help design a patient information leaflet which you can read **here**.

Patient Perspectives on BKN

Janice Richardson

I contracted BK virus within a couple of months of receiving a kidney transplant from my sister. I didn't feel anything unusual in particular, I just thought I was recovering from the operation. I was admitted to hospital because the renal team noticed changes in my blood and urine test results - the initial diagnosis was that my transplant was probably rejecting. I was devastated as you can imagine - my sister had given me the chance of a normal life again, and had also gone through major surgery to give me that chance.

After further tests and procedures I was told that I had contracted BK virus and that it was prolific. The consultants couldn't tell me very much about the condition when this happened back in 2011. The team were in talks with a renal team in the USA about the virus and how to treat it. I was left feeling pretty much in the dark and very worried about the consequences, but initially it didn't sound as serious as rejection, so there was some hope. Unfortunately I did lose my transplant - the virus was so advanced due to a late diagnosis.

Despite this I am now living a very healthy and fulfilling life after my third transplant in 2019! I'm so happy to hear that research on BK virus, in the UK and worldwide, is advancing and hopefully it will reduce and/or prevent loss of transplanted kidneys.

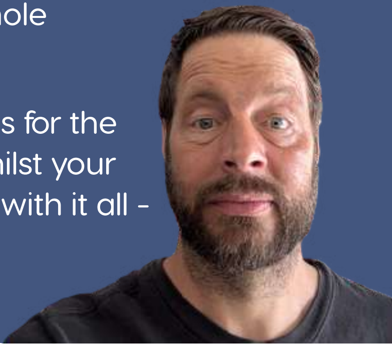
Wayne Crowcroft

I was first told I had the BK virus in December 2024 after I'd only been transplanted for 6 months – it hadn't been entirely straightforward even before hearing about the BK virus. My first thought was "what is BK virus?!" so straight away (as you do) I went on google and *bang* that's when my world was turned up side down and panic set in because everything I was reading wasn't good and the first thing it said was there was no treatment!

That's when it started affecting my mental health. Depression, and then anxiety, and palpitations, started kicking in. It was so stressful, I wasn't myself with my family, really out of character for me. I'd been doing everything by the book – everything that the transplant team had asked of me (and much more!) - and all of a sudden control was taken out of my hands. Nothing prepares you for something like that.

I was at a clinic appointment with a consultant I'd known before my transplant - that's when I started to get a bit more understanding and insight about BK virus. He explained to me how the majority of people get it as a child (and never know about it) and the reasons why it shows it's ugly face in kidney transplant patients. He told me about the ongoing research into the virus which settled me down a bit and stopped me from panicking as much. It helped me with the whole thought process.

With his help I am slowly getting there – I've just had a negative test for BK virus for the first time! The numbers fluctuated up and down, and that's stressful in itself whilst your transplant doctors reduce your anti-rejection drugs. I've sort of come to terms with it all - and what I really hope for is that a treatment can be found which will help thousands of transplant patients just like me.



We are exceptionally grateful to Janice and Wayne for sharing their stories.

Polycystic kidney disease (PKD) Charity

Celebrating 25 Years of Progress

In 2025, PKD Charity marks **25 years** as the UK's only charity dedicated to improving the lives of an estimated 70,000 people living with polycystic kidney disease (PKD). Their work continues to evolve - providing trusted information, support, and raising awareness of the real impact PKD has. Their commitment is stronger than ever to drive vital research forward and bring hope through better treatments.

PKD Charity are proud to work closely with **RaDaR**, a unique UK kidney patient database holding information from thousands of individuals—including over 7,000 adults and children with ADPKD and the rarer form, ARPKD. This data is a goldmine for researchers, helping uncover new insights and develop personalised care—always with patient privacy fully protected.

Looking ahead, 2025 is packed with activity. Their popular **educational events** continue with a live Q&A on PKD Treatments & Research on 8 September with Professor Pat Wilson, and PKD in Children and Young People on 23 September, featuring experts from Great Ormond Street and Evelina London. Recordings of past sessions are available on their website. Plus, their next **Information Day** takes place in Exeter on 8 November—don't miss it!

PKD Events

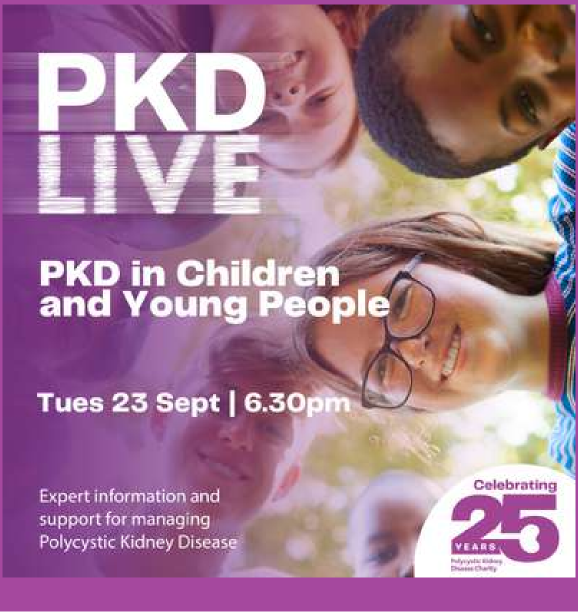
PKD events: https://bit.ly/pkdc-events
Recordings of past talks: https://bit.ly/PKDevtalk

ADPKD Treatments & Research
Where are we now & where are we headed?

Monday 8 September 2025
6.30 PM
Live Online - Zoom

Expert information and insights for the polycystic kidney disease community

Prof Pat Wilson



PKD in Children and Young People

Tues 23 Sept | 6.30pm

Expert information and support for managing Polycystic Kidney Disease

Get Involved

Exciting research developments are on the horizon, including new **clinical trials**. PKD Charity will share more updates soon across their channels.

Later this summer, they will launch their **Research Hub**—a new initiative involving patients directly in shaping research and trials. If you'd like to be involved, they would love to hear from you.

Visit pkdcharity.org.uk for further information about PKD, research, support available and helpline details.

Celebrating
25
YEARS
Polycystic Kidney Disease Charity

For more information about this newsletter or the RaDaR National Registry of Rare Kidney Diseases, please contact:

radar@ukidney.org

National Registry
of Rare Kidney Disease

A reminder to please complete our three-question feedback form so that we can improve future editions of this newsletter. Thank you!

RaDaR
National Registry of Rare Kidney Diseases

UKKA
UK Kidney Association
Rare Renal