RaDaR Patient Newsletter

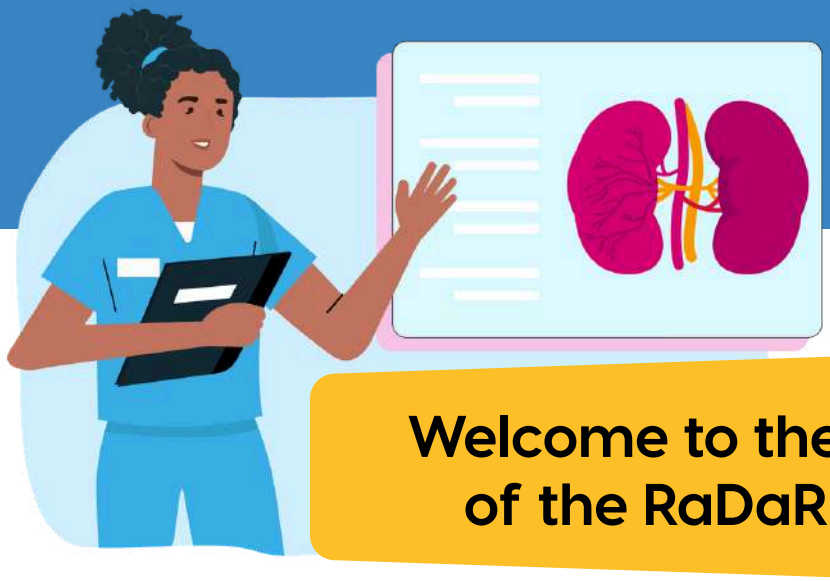
WINTER 2026

RaDaR
Registry of Rare Kidney Diseases

UKKA
UK Kidney Association
Rare Renal

CONTENTS

WELCOME



Welcome to the Winter 2026 edition of the RaDaR patient newsletter!

Happy New Year!

We are thankful for your feedback to date. We 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.

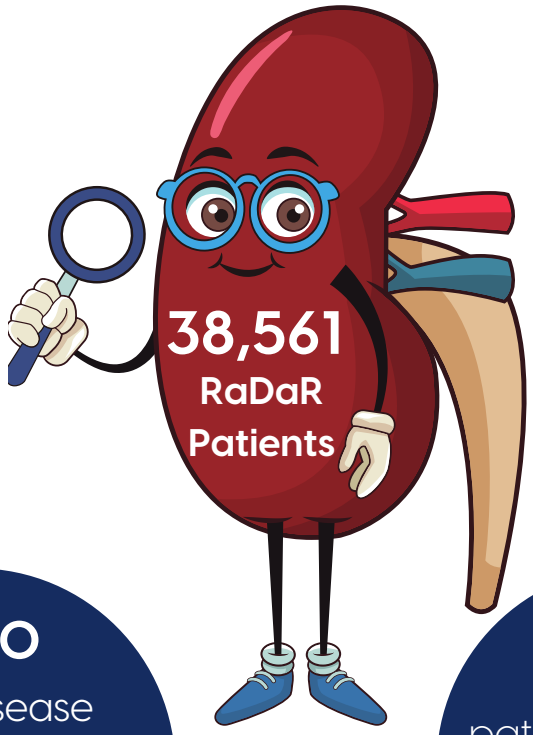
We are unable to respond to individual health queries or provide any medical assistance. If you have concerns about any symptoms, we advise you to contact your doctor or local hospital, or call NHS 111. In an emergency, dial 999 immediately.

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

111
NHS centres or hospitals have recruited to RaDaR



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

>400
Rare Disease Group members (including patient representatives)

300
patients recruited in January 2026

Does RaDaR cover my condition? If you've received this newsletter directly from us, you are a participant in RaDaR and this means that we cover your condition. The diagnoses we cover are here: Current Conditions | UK Kidney Association.

How many other people have my condition? RaDaR doesn't have everyone in the UK with a rare kidney condition - only those who are treated at hospitals that recruit to RaDaR and who have consented to join. You can see how many people are in RaDaR, broken down by Rare Disease Group, here: RaDaR metadata | UK Kidney Association.

How can I find out more about my condition? RaDaR has partnered with Kidney Care UK to produce patient information on rare kidney diseases. Kidney Care UK are experts in providing accessible and accredited patient information. Their Rare Kidney Conditions hub can be found here: Rare kidney conditions | Kidney Care UK.

RaDaR Activities & Outputs

RaDaR data has helped achieve a major breakthrough for people living with C3 glomerulopathy (C3G)

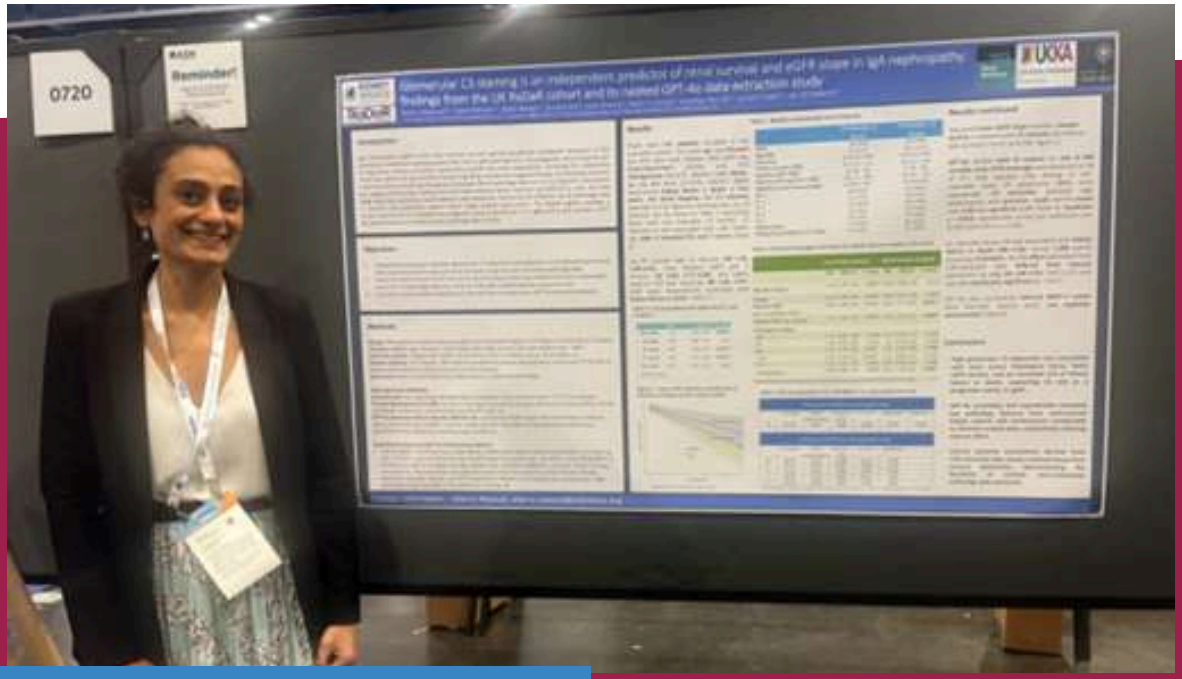
C3G is a very rare kidney condition that affects only about three in every million people. Because patients with C3G are spread across different hospitals and regions, it can be very hard to study the disease or test new treatments. By bringing together years of information from more than 200 people with C3G across the UK, RaDaR researchers were able to show that treatments which reduce the amount of protein leaking into the urine (proteinuria) can help protect the kidneys, slowing damage and preventing kidney failure.

This important evidence supported the global approval of the first ever treatment for C3G – an oral medicine that offers new hope to patients and families affected by this rare disease. Progress stories like these are only possible because of you, the patients who generously share their data through RaDaR. Thank you! We will continue working together to turn shared patient data into better treatments and longer, brighter futures.

Other activity at RaDaR includes:

- We are helping to find participants for several clinical trials.
- We attended the PKD Information & Support Day in Exeter which we thoroughly enjoyed. It was great to see so many patients come together and speak with each other about their experiences. We also managed to convince a few people who weren't in RaDaR to join - if that was you, thank you!
- October was Black History Month and we took the opportunity to bring people together from several different locations in the UK to talk about how we could increase the diversity of our recruitment to RaDaR.

RaDaR Activities & Outputs



RaDaR at ASN Kidney Week

RaDaR had a strong presence at this year's American Society of Nephrology (ASN) Kidney Week, a major international kidney conference held in Houston, Texas in November. Several research studies that used RaDaR data were shared, showing how valuable the registry is for understanding rare kidney diseases.

Dr Sherry Masoud, a kidney doctor and RaDaR Clinical Research Fellow, presented her research on IgA nephropathy. She said it was a great opportunity to highlight how RaDaR data is helping connect real patients' experiences with the development of new treatments for rare kidney conditions.

Additional poster presentations, by Katie Wong and colleagues, showed how different urine tests (albumin-creatinine ratio, protein-creatinine ratio and non-albumin protein levels) may help predict kidney failure in people with rare kidney diseases.

RaDaR Director, Professor Daniel Gale, commented he was pleased to see RaDaR data used widely throughout the conference, including in presentations about clinical trials. This shows how important RaDaR patient data is in helping to develop new treatments.

RaDaR was also highlighted in major sessions and even appeared on a large display at the Novartis booth, reflecting its growing international importance.

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.

Alport UK Easter Social | 21 March 2026 Register here or email your details (name, address, phone number and email) to: info@alportuk.org

Get Involved in Research

To make sure we can continue to contact you about relevant research projects and clinical trials - **if you change your email address, please ensure that your hospital has your new address.** Your email address in RaDaR comes from your hospital record.

If you are the parent of a child who is in RaDaR, your child should be approached when they turn 16 to consent to RaDaR as an adult. If this has not happened and your child would like to continue to be in RaDaR, please get in touch with your child's hospital and ask if your child can be consented as an adult. This ensures that we can continue to contact your child and offer them the opportunity to participate in research if they would like to.

Rare Disease Spotlight

Nephrotic Syndrome (NS)

Nephrotic syndrome (NS) is the name given to a condition where large amounts of protein leak into the urine, causing fluid retention and swelling (oedema) most commonly around the eyes, abdomen, feet and legs. It can occur at any age and is caused by damage to the glomeruli (the tiny filters in the kidney). When the cause of nephrotic syndrome is not known it is referred to as idiopathic nephrotic syndrome (INS).

Blood and urine tests can confirm NS, and treatments can be given to deal with the symptoms, complications and causes. Response to treatment varies a lot depending on the underlying cause of the NS.

Updates from the RDG Lead

I am Moin Saleem, a paediatric nephrologist in Bristol with a particular interest in Nephrotic Syndrome. I founded RaDaR in 2008. Nephrotic Syndrome was one of two pilot patient groups at the beginning of RaDaR.

Nephrotic Syndrome is now one of the largest Rare Disease Groups. The research that has been done with Nephrotic Syndrome patient data has helped us understand the differences between patients and how patients should be treated. Our research is also a key part of a gene therapy project which will lead to a trial for a genetic therapy for patients with inherited Nephrotic Syndrome.

We continue to build the Nephrotic Syndrome group. We also recruit to the national renal biobank, NURTuRE, which again pioneered Nephrotic Syndrome as one of the pilot patient cohorts.

Rare Disease Spotlight

NeST – the Nephrotic Syndrome Trust

Many people with Nephrotic Syndrome face a difficult journey – exhausting treatments, hospitalisations and challenging side effects. Our hope is for new, more effective therapies for all types of Nephrotic Syndrome, especially treatments that prevent recurrence in transplanted kidneys.

Wendy Cook, Director & Fundraising Co-ordinator, NeST

NeST: 25 Years of Hope and Progress

Nephrotic Syndrome Trust (NeST) was founded in 2005 by David Yearsley after his son's diagnosis. Thanks to our incredible supporters, we've grown steadily–funding vital research led by Professor Moin Saleem, Professor Gavin Welsh, and their team at the University of Bristol. This July, we celebrated our 25th anniversary at the research labs, honouring the world-leading work of our inspirational team.

NeST's mission is to:

- Raise awareness of Nephrotic Syndrome
- Fund research for new treatments
- Provide a hub of knowledge and support for patients and carers

Find out more about the Nephrotic Syndrome Trust and its work:

- Visit the NeST website
- Join our main Facebook (closed) group: NeST (Nephrotic Syndrome Trust)
- For young adults (16–30), join the NeST Young Ambassadors Support Group
- Find your local regional group (scroll to "Facebook Support")
- Watch our story
- Raising Awareness

Save the Date: NeST Annual Conference. The next conference will be held in Manchester at the Michael Smith Building lecture theatre on Friday, 13 March 2026. For questions about the event, support, or fundraising, please email: wendy@nstrust.co.uk

Patient Perspective

A Mother's Journey: Strength Through Uncertainty

My son was diagnosed with Nephrotic Syndrome (FSGS) at just five years old. I'll never forget the fear and helplessness I felt hearing those words—uncertain of what lay ahead or how it would shape our family's life. The renal team offered wonderful support, but no one could predict his path. Now I understand why: every person with Nephrotic Syndrome walks a unique journey, even when treatments are similar.

In those early days, reliable information was scarce. I quickly learned that while some respond well to first-line treatments like steroids, others do not. He never achieved remission and still hasn't, even as an adult.

Two and a half years after diagnosis, my son's kidneys failed. He began peritoneal dialysis, which he endured for 14 months before receiving a transplant. Though the transplant was initially successful, Nephrotic Syndrome tragically recurred in his new kidney. More treatment followed—plasma exchange, hospital stays, and difficult decisions.

Yet through it all, my son has shown extraordinary resilience. He's earned two degrees and now works abroad. His kidney function is slowly declining, but he continues to live life to the fullest.

We are exceptionally grateful to mother and son for sharing their story.

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 so that we can improve future editions of this newsletter.

Thank you!

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