

The Renal Association Patient Council



Ron Cullen

Chief Executive, The Renal Association

Ron has over 30 years of experience in the NHS. Starting his professional career as a biomedical scientist he went on to spend a great deal of his time working on the areas of governance and quality improvement. He has had several important roles in these areas including Director of the National Clinical Governance Support Team as well as Head of Healthcare Quality and Standards within the Department of Health. Ron has lectured and presented on quality improvement nationally and worldwide. When not working, Ron likes to spend time with his family and coaches an under thirteen Rugby Team.

Fiona Loud

Chairperson

Fiona's roles at present are Policy Director for Kidney Care UK, and co-chair for the Risk work stream for the Acute Kidney Injury National Programme.

Fiona is Chair of the UK Renal Registry Patient Council, the West Herts Hospital Organ Donation committee and is vice chair at The Local Kidney Patients Association at Lister Hospital. In her spare time (though we find it hard to believe she has any!) Fiona takes things at a more relaxed pace and enjoys activities such as sleeping, reading and going for long walks with the family dog, Ollie.



James Medcalf

*Medical Director, UK Renal Registry
Renal Association Director of Audit and Informatics*

James is a kidney doctor working at the John Walls Renal Unit in Leicester. As well as looking after patients with kidney disease directly he works with the UK Renal Registry and the National Cardiovascular Intelligence Network promoting the use of data to improve quality.



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Katharine Evans

Research Development Manager



Katharine has a PhD in evolutionary biology – possums, birds, trees! She made the leap to kidney care when working in Northern Australia at the Menzies School of Health Research, a research institute which focuses on improving the health and wellbeing of Indigenous Australians. Katharine very much enjoys working at the UK Renal Registry, in particular meeting with the patient council to discuss and shape the analyses and outputs produced by the registry.



Tracey Rose

Tracey first became involved with the UK renal community in 1995 when her eldest daughter was taken ill. Since, then both her daughters have had 3 kidney transplants between them; the cause remains unknown. During this 20+ year span, she has developed a personal insight into most aspects of kidney failure from diagnosis, to dialysis and other treatments. As a living donor herself, together with her family experience, she has developed a wide breadth of knowledge and understanding of the rigours of living with this chronic condition. She is now actively involved within the community, both raising awareness of the disease and working on several projects that aim to improve patient experience and support. Additionally she is a Patient and Public Voice member of the NHS Clinical Reference Group for Renal Services.

Sue Lyon



Sue was diagnosed with renal failure in 1977 at the age of 25, subsequently spending nine years on home haemodialysis until she received a deceased-donor kidney transplant in March 1986. After beginning her career in general publishing, Sue joined the staff of a medical journal and since 2000 she has been a freelance medical journalist, writer and editor. Sue is Vice-Chair of her hospital kidney patients' association, Deputy Editor of the National Kidney Federation's *Kidney Life* magazine, and a member of Kidney Care UK's Patient Advisory Group and of ESPRIT, a multidisciplinary group supporting safe prescribing in transplantation. As a member of the UK Renal Registry Patient Council, Sue's aim is to support the Registry's essential role in providing the data needed to guide the research and evidence-based kidney care that will help to optimise shared decision-making and outcomes for her fellow kidney patients.



THE RENAL
ASSOCIATION
founded 1950

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Claire Corps



Claire is a Doctor of Research Scientist working in the NHS. Claire's education includes her PhD in Energy Kinetics in Preserved Livers which she studied for in Leeds and an MSc in Immunology and Immunogenetics at the University of Manchester, preceded by her BSc (Hons) in Microbiology in Leeds.

Claire's interest and knowledge in the programme is driven by her unique perspective on kidney disease, having had renal failure since childhood and following haemodialysis has been the recipient of both kidney and liver transplants. She is an active Committee Member of West Riding Kidney Patients Association and the Transforming Participation in chronic kidney disease programme.

Amateur dramatics are also on Claire's lists of interests as well as the British Transplant Games and the Transplant Choir. While she describes her guilty pleasures as enjoying listening to Wham! and Abba, she's also a member of MENSA – so probably best not to question her further about this!

Hakeem Adedoja



Having graduated with a degree in Accountancy in Nigeria in 1999, in 2007 during his Master's degree in the UK Hakeem was diagnosed with kidney disease and in 2011 went on dialysis; he was fortunate to receive a transplant in 2016. Hakeem received excellent treatment from the NHS and joining the UK Renal Registry patient council was his way of giving back to the community. Hakeem also runs a charity called the Hadiza foundation, which provides Education and Information about kidney disease, its causes, prevention and management within people of African and Caribbean origin in the UK.

Outside renal, Hakeem's interests include playing basketball and military history.

Guy Richards



Guy is a patient at the Royal Devon and Exeter Hospital and a trustee on their local kidney patient association. Guy is also a Director on the executive of the National Kidney Federation and a Director of Exeter Homes trust. Guy has been a kidney patient for 38 years and has received two transplants, with the first transplant lasting three years and the second transplant lasting nineteen years.



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Ewen MacLean

Ewen is a grandfather of four, who has been a renal patient since 1987 and has tried and tested every modality of renal replacement therapy that exists to date. Transplanted in June 2016, Ewen works as an Advocacy Officer for Kidney Care UK covering Scotland.

Currently, Ewen serves on many renal groups with the hope to improve the lives of chronic kidney disease sufferers everywhere.

Keith Bucknall

Keith Bucknall was diagnosed with nephritis over 20 years ago. His kidney function finally reached the point where dialysis was needed in December 2016. Spending three sessions a week tethered to a machine, being involved in the UK Renal Registry patient council helps pass time and gives him a purpose to support others by sharing his experience. He achieved an MSc in Social Research and hopes this will add value to his attendance at the meetings.

Keith cared for his mum who lived with dementia and belongs to a Service User and Carer group at a University supporting Social Work students. He continues to research dementia and its impact on the person and their families including the additional challenges if kidney failure is also present.



Jack Husband

Jack was diagnosed with chronic disease at the age of 16, now after being on dialysis for just over 2 years. He is a passionate advocate for Nocturnal dialysis, especially in centre Nocturnal dialysis. Working full time as a baker, and part time as a DJ.

Jack is a Representative for all paediatric renal issues, having been on a paediatric unit himself.

Get involved

We are always enthusiastic to hear from patients. Are you interested in finding out more about the UK Renal Registry, what the Patient Council does and how to get involved?

For further information regarding membership of this study group please email jennifer.Barwell@renalregistry.nhs.uk

Members will meet quarterly, physically or virtually with ad hoc tasks and groups between meetings to enable work to be completed. Expenses will be covered by the UK Renal Registry.

