The Newsletter of The Renal Unit | The Kidney Fund | Kidney Patients Association

RENALITY

November 2024

Are you sitting comfortably?

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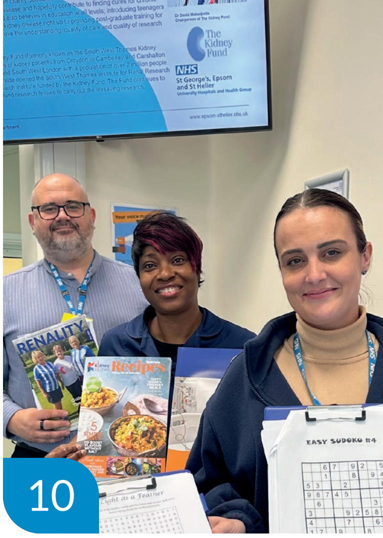
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Kidney Patient Association

Renal Unit

Dr Ginny Quan

Dr Fiona Harris

It is hard to believe that it is already a year since it was last my turn to write an update for *Renality*. It feels as though we have been incredibly busy with Business As Usual operational pressures, but on reflection, I do think we have continued to make progress and there is much that as a unit we should be proud of.

Working with partners in the London Kidney Network, and South West London and Surrey ICBs (Integrated Care Boards), there has been a real drive to make long term change to the lives of people living with kidney disease. A number of pilot projects have been initiated, with the mindset that prevention is better than cure. Our community partners are working hard to ensure that people identified as living with kidney disease are offered medication to help protect kidneys and delay or prevent progression of kidney disease. We are working closely with our colleagues in diabetes and cardiology in a pilot project to improve the health of people living with a combination of heart and kidney problems, who frequently have diabetes, high cholesterol and may be living with obesity. We have a multidisciplinary clinic supported by a Consultant in Elderly Care Medicine as well as a Renal Consultant and Clinical Nurse Specialist, which provides support for our frail, elderly patients when faced with decisions around whether dialysis is likely to be beneficial or whether an approach which focuses on symptom management and support in the community would be their preference. Finally, we have invested in our ward discharge team, in order to try and streamline the processes for discharging people from hospital. It is early days, but so far it feels like these pilot projects are delivering what we had hoped for, and in time we hope that they will become part of usual practice.

In addition, we continue to work closely with partners at St George's Hospital on developing the model for a joint renal service in the future. There are a number of hurdles yet to overcome, but we are optimistic that we will do so, and are privileged to have been able to welcome patient partners to our various workstreams. It is really important for healthcare providers to hear the views of those who use our service. I have already had my perspective broadened by input from our patient partners, and look forward to learning more from our collaboration. I am justifiably proud of the work that clinical and non-clinical colleagues are contributing to this project, and I hope that we can share more updates over the coming months. We are well aware of the limitations imposed by the aged buildings on the St Helier site, and the opportunity to deliver care from a building that is spacious, bright, and modern seems too good to pass up.

On the same theme, feedback from those of you that use the service is so important. I mentioned the Kidney PREM a year ago. This annual survey is underway again, and we look forward to hearing your feedback. However, this is not the only forum to tell us what you think, and we do want to hear from you. We are always pleased to receive positive feedback... after all, we all want to do a good job. However, we are receptive to less positive comments and feedback. This doesn't have to be through a formal survey such as Friends and Family Test or PREM. We are happy to hear from you directly, or through the teams that provide most of your care. We work in this system every day, so may have become blind to those things that trouble you. By listening to your feedback, we can start to see things through a different lens. The Kidney Patient Association are very generous when it comes to funding things that improve the experience of those under our care, so tell us what you need, and how we can improve, and we will do our best to rise to the challenge. My challenge to you – give us your suggestions and next year, I can write about the changes we have made in my article for *Renality*!!

Ginny and Fiona

Pregnancy and having a Kidney Transplant:

My Personal Journey

The joy of discovering one is pregnant is an unparalleled emotion, a mix of excitement, anticipation, and a touch of nervousness. For most women, this journey is filled with routine check-ups, baby showers, and planning for the arrival of the little one. But for someone like me, who has undergone a kidney transplant, the experience is layered with additional concerns, precautions, and an overwhelming gratitude for the miracle of life.

This is an extract of my experience of pregnancy preparations at Guys and St Thomas's hospital London as a transplant patient from my memoir – *'Thanks for my kidney, Mum!'*:

"The pre-pregnancy counselling clinic felt like a VIP service and was such a privilege. We shared a room with my renal consultant, who I knew well by now, along with an obstetric physician and a consultant obstetrician. Three highly skilled medical professionals all interested in helping to support me. After looking at my history and renal transplant, my blood tests and blood pressure, they concluded that I could indeed begin trying to conceive. I was warned that there was a risk that my creatinine level would rise during pregnancy and remain at an elevated baseline following delivery, but the risk of significant damage to my transplanted kidney, either during or after pregnancy, was very low. I felt the risk-to-reward ratio was in favour of having a baby."

My journey with chronic kidney disease (CKD) had been a tumultuous one, filled with its share of ups and downs. But the year 2014 brought with it a new challenge: recurrent cystitis, a painful inflammation of the bladder. Amidst managing this condition and the regular demands of CKD, I found solace in the love and support of my family, especially my mother, who had generously donated her kidney to me.

Fast forward to September, after a beautiful wedding ceremony, my husband and I embarked on our honeymoon to India. Amidst the adventures of this trip I discovered I was pregnant. The realisation was nothing short of a miracle. I had switched my medications several months prior from mycophenolate to azathioprine, and the stars aligned perfectly for me to conceive during our honeymoon.

As the days turned into weeks, I cherished every moment of my pregnancy. However, being pregnant post a kidney transplant isn't without its challenges. Every decision, every meal, every activity was weighed against the potential risks and benefits. The health of my baby and the functioning of my transplanted kidney were of paramount importance. My training as a naturopath equipped me with the knowledge to make informed choices. I maintained a clean diet, abstained from alcohol, and ensured I was physically active, albeit with necessary precautions.

The journey also brought with it a plethora of emotions. The joy of pregnancy was occasionally overshadowed by the concerns of my kidney's health. Regular hospital visits including scans, blood tests, urine samples, and blood pressure check-ups

became even more crucial. But amidst all this, the support of the medical team and organisations like the Transplant Pregnancy Registry International was invaluable. This organisation, focusing on the effects of pregnancy on transplant recipients, provided a wealth of resources and knowledge, ensuring I was well-informed every step of the way.

In conclusion, my journey of being pregnant post a kidney transplant was a testament to the resilience of the human spirit and the miracles of modern medicine. It was about celebrating the gift of life, twice over – once for the kidney that gave me a second chance and once for the life growing inside me. It's a journey I cherish, filled with challenges, but more importantly, filled with love, hope, and gratitude.

My 5 Top Tips for Being Pregnant after a Kidney Transplant

Consult with Healthcare Professionals: Before attempting to conceive, it's crucial to consult with both your nephrologist and an obstetrician who has experience with high-risk pregnancies. They can provide guidance/ counselling on the best timing for pregnancy, assess the function of the transplanted kidney, and review medications to ensure they are safe for pregnancy.

Monitor Medications: Some immunosuppressive medications taken after a transplant can be harmful to a developing foetus. Your transplant team might adjust your medications before and during pregnancy to ensure the safety of both you and your baby. Never make changes to your medication regimen without consulting your healthcare providers.

Frequent Monitoring: Due to the increased risks associated with pregnancy after a transplant, expect more frequent prenatal visits. Regular monitoring can help detect potential complications early, such as preeclampsia, gestational diabetes, or changes in kidney function.

Maintain a Healthy Lifestyle: As with any pregnancy, it's essential to maintain a balanced diet, stay hydrated, get regular exercise as advised by your doctor such as prenatal Pilates or yoga, and avoid harmful substances like tobacco, alcohol, and recreational drugs. This is especially important for transplant recipients, as a healthy lifestyle can support kidney function and overall well-being during pregnancy.

Be Prepared for Potential Challenges: Understand that there's an increased risk of complications during pregnancy after a kidney transplant, including preterm birth and low birth weight. Being informed and prepared can help you and your healthcare team make the best decisions for your health and the health of your baby.

***Kay Allardyce** is an osteopath and Pilates instructor who has written a memoir about her journey with kidney disease. She describes her experience of undergoing a kidney transplant and life beyond including having two children following transplant surgery. You can buy the book by going to **www.kosteo.co.uk**. **"Thanks for My Kidney, Mum!"** is £12.99 on paperback and £19.99 on hardback.*

Let’s Talk About Sustainability w
The long-term value of proving m

In memory of and with special gratitude to Professor Stephen Ben Walsh for teaching me everything I kn

The World Health Organisation (WHO) estimates that 1 in 2 people do not take their medications as prescribed, to manage their long-term conditions. This leads me to picture a patient who had been compliant with his in-centre haemodialysis for 10 years, before receiving a kidney transplant from a deceased donor. He was admitted to a renal ward refusing to take his immunosuppressants and had shared some important information with me – not taking his medication in some time and having 3-months’ worth of immunosuppressants in his suitcase. This is the reason I find this estimate to be eye-opening and associated to catastrophic outcomes (health & social, financial, and environmental).

This scenario, previously described, takes me back to one of the most important light-bulb sustainability moments I have ever had when I held the role of Lead nurse for chronic kidney disease and Hypertension, in North Central London. We were commissioned to see GP patients with uncontrolled blood pressure (hypertension) prescribed one or more anti-hypertensive medication (up to five). Medication thought to contribute to around 16% of the carbon footprint of the NHS, in America the figure is higher still.

We reviewed this group of patients in the nurse-led Hypertension Community clinic. The first intervention at the first clinic appointment was to prove medication compliance – a patient’s urine sample was sent to the lab with a list of their pharmacological regime, before any medication changes were made. We also empowered them to manage their high blood pressure with lifestyle changes (e.g. tackling high salt and alcohol intake, smoking, stress, obesity, diet, and poor physical activity) introducing them to a catalogue of social activities to self-refer to, so, they could take control back of their health and condition.

Hypertension is one of the most common non-communicable diseases and a major global health burden, due to its associated complications (cardiovascular and kidney disease, stroke, and premature death). More than 1 billion people had hypertension in 2019, double the number since 1990.

After receiving a medication compliance report from the lab, we objectively explained and confirmed to patients the cause of their uncontrolled blood pressure – non-compliance to treatment. Every patient had a different reaction/response to their lab results. We reassured them we wanted to rationalise their medications, because in fact, they had been prescribed too many medications and that was a contributing factor to poor adherence as they could forget taking some medications at different times of the day.

I think this was a genius and generous intervention. We re-distributed risk factors to identify patients not compliant to treatment and we intervened achieving optimal outcomes; rationalised polypharmacy, compliance to treatment, controlled blood pressure according to the patient’s target and referring them back to their GPs. Similarly, paying justice to those patients compliant to treatment (up to five medications) with resistant hypertension.

There are other ways of proving*

ith Dr Deb Gompertz: nedication compliance

ow about Hypertension Community clinics and Medication Compliance.

By Gloria Munoz-Figueroa

medication compliance and given the WHO estimate, we urge healthcare professionals, patients, relatives, friends and carers to get involved. The environmental damage associated with healthcare and kidney care, is unforgiving. This is an important decade to make positive changes, but we must do it all together to protect our health, our planet and our NHS's future. What strikes me the most is that we are using low-carbon behaviours and improving health outcomes to motivate change. Unexpectedly, this appears not to be enough until we mention the financial benefits. Is this really the absolute driver of SusQI projects? (Sustainability in Quality Improvement)

To raise awareness, I asked Dr Deb Gompertz, to spare some time to talk to *Renality* readers, so she can share her knowledge, experience and understanding of how we can work with people to include them and engage them in a valuable structured medication review.

Dr Deb Gompertz is a GP with an extended role in complex care and frailty. She works in a Primary Care Network in Somerset and across different organisations including the community and secondary care. She is also the Deputy Honorary Secretary of the British Geriatrics Society and an NHSE clinical entrepreneur.

Deb recognises and highlights the value of comprehensive assessments in people, which includes a well-structured medication review. She developed the **"Show Me Your Meds"** project shifting from a local to regional and hopefully a national intervention.

Can you tell us about your role and why we need to involve all clinicians, patients, relatives, friends, and carers in medication compliance?

I tend to do comprehensive assessment in people, because we believe that people's problems are often multifactorial and can be medical, functional, social, and cognitive problems altogether. We talk to peoples' relatives as well as their carers. It's very much person-centred care, and what matters most to people. I think that's helpful for gauging our conversations. I work in a small team with extended connections, as part of the neighbour team, with district nurses, rehab team, social care, because we all bring something to that pot, which helps look after people.

Relationship building is key with people, especially around medicines. You must be very sensitive as well. As part of our assessment, we always look at people's medications. We have been doing it since about 2021, because we realised that the group of people that we look after, probably one in four, aren't taking large amounts of medication. And that can often be the cause of why we are going to see them. They may have swollen legs because they are not taking their Furosemide, for example, or they might be falling because they are taking the medication not quite right. So, with the medication, it is a bit like being a detective, having professional curiosity and you do have to ask, where else have you got the medication? Where else do you store it? Where else have you put it? Have you got some upstairs? Is it downstairs? And check the dates on the packets, but sensitively.

"I often say prescribe for the person with the illness, not just the illness"

This is everybody's business, and we need to enable people to have conversations with their prescribers so that people feel in control of what medications they are taking. Some people may get side effects. Others may just not get on with their medication, but they may not want to disappoint their prescribers. Some people, it might be involuntary. For instance, they are not sure how to process it or how to remember to take those medicines.

In our initial study, we found that a third of the patients had a new cognitive impairment that had not been picked up. So, we need to work with their families or carers to prompt them to take the medicines, look at the regime and make it fit for the person that we're prescribing for.

Medicines are good when they are used in the right cases for the right illnesses, following the right guidelines and evidence. But I also think that we might not have enough time in consultations to pause and think, 'Ok blood pressure, exercise or we need to be referring to social groups to be getting people active, we need to be getting green and blue prescribing. That can be difficult in the population depending on where you are. I am in a rural population looking after quite often an older population, so there aren't necessarily those groups, those facilities for people to go to get that support. Those are barriers really for people. And then working with our pharmacy teams is important, absolute key to have pharmacy text community, pharmacists, clinical pharmacists, they're a big part of my work.

What are your views on proving medication compliance, do you think it is ethical?

I don't really think it is proving. I think it is good care and safe medicine to know what people are taking or what they are not taking. Because how can we prescribe for someone if we don't know what they are taking? How do we add more medicines to someone when we don't know what the basis are? I think that causes risks and it is absolutely part of what we should be doing- yes, very much so.

Do you think outcomes would be the same if we did a medication compliance survey instead of proving medication compliance in the lab?

No, because I don't think everyone tells you so. I think people worry about saying they are not taking their medications because they don't want to upset the prescriber. So, I think if you've just done a survey, you might not get the same outcomes. Well, you might think if it was anonymous, you could get the right results, but you would not necessarily achieve the differences and benefits by just doing a survey. I personally believe it's the time and the relationship building with people that makes a difference.

"As prescribers, we also need to look at what we can do differently"

Having the right conversations and explaining why the medicines are important but also enabling people to make those decisions for themselves. And making sure we are prescribing appropriately and removing those medicines that are not working and use a different one.

We need to use a different language. For instance, we should not say it's a painkiller because it might not take away all the pain. We should not say this is a lifelong medication because it might not be.

I did my talk called **'Me, my medicines and the environment'** to residents in retirement villages, and they responded well to the sustainability bit and then they started collecting medicines in a locked box that the pharmacist from down the road collected to dispose of correctly. But they took ownership in this retirement village over it. I think people want to make a difference to the planet, which is a good way of harnessing that sort of enablement for people.

What Sus QI project are you working on?

We are spreading **'Show me your meds'** across the county. We are also working with a hospital to see how we can do **'Show me your meds'** in the hospital as well, on the everyone's business bit. We encourage people to take their medicines into hospital with them because they will use them. So that saves waste. We are also looking at discharge pathways with medicines, and care home waste as well.

I think I was a bit naive about sustainability, but when you find lots of carrier bags of medicines not being used, it's hard not to be aware of it. People do put medicines down the toilet or put it in the bin and with everything that's going on in the world, we do need to do something a little bit different. The more you talk to people, the more you realise this is happening at a bigger scale. These people have had medication reviews previously that had not picked up the problem. Any professional from the community team can conduct the medication review. They don't have to be medically trained.

Congratulations on your fantastic work, Deb. How can we standardise these projects nationally? How can we start?

I know, that would be a great achievement, and we are working towards a national target. We had Steven Power come and visit and David Webb, the Chief Pharmaceutical Officer and Tony Avery, the national prescribing lead. And we were saying, how do we do this nationally? So, they said get it better in Somerset first, but they said they would go away and think about it. I think we need to keep going and networking, talking to people like you, talking to anyone who does it, anyone interested in medication compliance and preventing medication waste.

In addition, I think the sustainability aspect of medication compliance and well-structured medication reviews is rising people's agendas.

In terms of the Sus QI value equation and the triple bottom line (carbon cost/benefit, money cost/benefit and social impact) how would you summarise the benefits of proving medication compliance and structured medication reviews?

I always say the benefits are individualised person-centred care, saving the NHS money and having a positive impact for the environment. This is a massive impact according to our initial carbon cost analysis.

> Medicines are good when they are used in the right cases for the right illnesses, following the right guidelines and evidence...

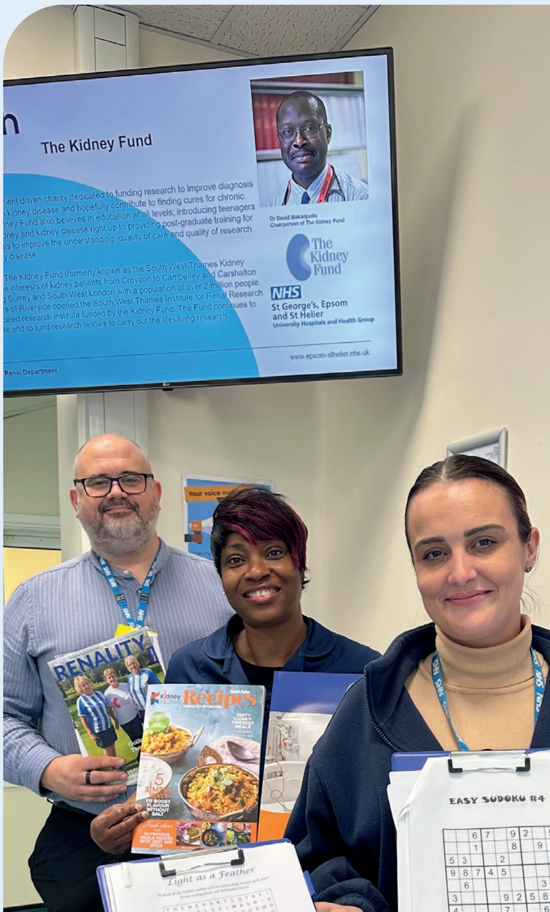
Are you sitting comfortably…

The renal outpatient team would like to say a big thank you to the St Helier and Surrey Kidney Patients Association for paying for the lovely new seating in the Renal Outpatients waiting area at St Helier hospital.

James, the Outpatients Manager said *'sometimes patients have to spend quite a bit of time in the waiting area so comfortable seating is really important. The new seating replaces furniture that had certainly seen better days. The new chairs are lovely and bright with different colours for each part of the outpatient waiting area including – you've guessed it – red for in the area for blood tests!'*

Another recent addition to the waiting area are the two large information screens which are updated regularly with latest news and information for renal patients. There are also magazines, word searches and crosswords available to help pass the time.

We hope that waiting times aren't ever too long but we do our best to make any time spent in the outpatients department as comfortable as possible.



Tell us about your experience – *your voice matters to us!*

By the time this edition of *Renality* reaches you, the **Kidney Patient Reported Experience Measure** survey will be well underway.

This annual survey, also known the PREM survey, takes place in hospitals and dialysis units across the whole Country and helps to build a national picture of renal care across the UK – importantly purely based on real experiences of patients living with kidney disease.

On a local level, here at St Helier and across all of our dialysis units and renal services, we are aiming get the biggest response to the survey as possible so that we can get a strong understanding of the things that you are happy with – so that we can do more of the same – and of course very importantly, any areas that you feel we can do better at. The survey is completely anonymous.

You can find out more about PREM and take part in this year's survey on line by visiting the following website: **www.kidneycare.org/PREM** or scanning the QR code.

SCAN ME

This year's survey started on 16th September and finishes on 11th November so there is still time for you to take part and have your say.

Your voice really does matter – please complete the survey today!

Your voice matters!

Take THE kidney patient survey today

Share your experience to help your unit improve!

Survey open 16 September - 11 November 2024

Scan the QR code or visit **www.kidneycareuk.org/PREM** to learn more and take part

This unit is committed to helping you to take part in the National Kidney Patient Reported Experience Measure (PREM).

If you would like assistance, please ask a member of staff.

SCAN ME

UKKA UK Kidney Association

BAPN British Association for Paediatric Nephrology

Kidney Care UK

Dear Kidney Fund Supporters

The last time I wrote, Spring was peeping through the windows. Now, to coin a phrase from the Nat King Cole song, it is the Autumn leaves that are starting to drift past the windows. Time flies. The 'upcoming' events which I spoke of at the time included the Dragon Boat Race at Kingston in July, the Camberley Collective car show in August and the summer ball at the RAC in Epsom, and they have been and gone.

The **Dragon Boat race** was well attended by volunteers who took part in the boat races, and well-wishers who cheered us on. We came third (out of three boats) in each race. As Dr Bending said, it is a question of perspective whether you say we were last or that we got the bronze medal both times! I would like to say thanks to all who attended. The weather held out and it was an enjoyable day.

I would like to thank Tom Gibson, as well as Gemma Dunleavy and her family, who helped with the Kidney Fund stall at the **Camberley Car Show**. There were lots of vintage cars, but the one I was particularly thrilled to see, being a great fan of *Only Fools and Horses*, was the *'Trotters Independent Trading mobile'*, that great three-wheeler, with one of our Kidney Fund collection buckets on its roof *(see picture)*. I had thoughts of me pulling up in the three-wheeler and walking into that pub in Peckham where dear departed Trigger would have said to me *"Alright Dave, how's it going"?*, to which my reply would have to be *"Lovely Jubbly"*.

The **Kidney Fund Ball** was a great evening out. Robin Ford excelled again at organising it. Unfortunately, Nick Ford was unable to attend as he was unwell. He was greatly missed, and we hope he is much better now.

As the year speeds on, we have the **AGM** in December, and I would love to see as many of you who can attend. We will bring you up to speed with our Fund-raising efforts and our aspirations for the future, including some ideas for events to mark **World Kidney Day** in March next year.

I know it is a bit early, but I would like to wish you all compliments of the season as Christmas approaches. Once again, thank you for all your help and support

as we continue to support research and education to improve our understanding, and to reduce the burden, of kidney disease.

Dr David Makanjoula

> I had thoughts of me pulling up in the three-wheeler and walking into that pub in Peckham where dear departed Trigger would have said to me *"Alright Dave, how's it going"*?, to which my reply would have to be *"Lovely Jubbly"*.

Sign up for a PDF - make sure you always get your copy of "Renality"!

Did you know... If your appointments at the Renal Unit drop to 2 or less per year, you will be removed from the ***'RENALITY'*** mailing list and will no longer receive the newsletter. You can receive a PDF of ***'RENALITY'*** by email - just email **Graham.Morrow@kidneyfund.org.uk** and he will add you to PDF distribution list.

Receiving a PDF will not stop you receiving the postal copy if you are on the mailing list. You can receive both, and share the PDF with family and friends.

However, if you are happy to receive your news online rather than receiving a copy through the post email **anita@kidneyfund.org.uk** and we will remove you from the mailing list.

Greetings Renaliteers,

It is my great pleasure in once again giving you an update on some of the goings on in SWTIRR.

Dr Mark Dockrell

It has been pointed out to me that occasionally I mention something towards the end of one of these pieces but then fail to follow up on it. So, to try and make amends I want to return to a previous occasion when I may have left you hanging.

I'll forgive you if you don't remember but you might just recall I mentioned the possible importance of zinc and the kidney.

Many of us have heard about zinc because it's used in so many common place items. Zinc is used in cars, lampposts, suspension bridges, batteries and many more. As important as all of those things are that's not why I'm interested in it. My interest is driven by the importance of zinc in health.

Zinc is what we call an essential mineral; we can't make it in our bodies and we can't live without it. I've heard the term micronutrient used a lot and I guess zinc is a micronutrient. We don't need a lot of it but we do need it. Its role within the human body is extensive. It's important in reproduction, immune function, wound repair, the list goes on. Despite being one of the most abundant trace elements in the human body, zinc cannot be stored in significant amounts and hence in order to maintain our bodies' balance we need regular intake. Zinc deficiency is surprisingly common. It's more prevalent in developing countries but it is also surprisingly common in the UK. Early signs are flaky skin and thinning of hair. We get zinc through food; beef, fish and some vegetables are all good sources. But if you want to keep a balance it's not just how it comes in but also how it goes out – you get my meaning? The current thought is that you don't lose much zinc in your urine so the kidneys aren't that important. But I believe that's not the full story, and I hope that you know me well enough to know that my beliefs are based on evidence. It's very new evidence. With some of my colleagues at King's College London we have shown that the kidney handles a huge amount of zinc. So what's going on?

Well most of you know that the kidney is great at recovering lots of important continents of blood so we don't lose them in urine like vitamins, salts, sugars and I believe the same is true of zinc. Now, this fits with some new data that came out of Italy a couple of years ago. They showed that patient with Chronic Kidney Disease had low zinc levels in their blood but high zinc levels in their urine and the worse their CKD the worse the problem was. They concluded by saying they didn't know why this was. I think I do know and I think this is really important. Well it doesn't matter if the taps are on you can't fill a bath if the plug is out. If you have chronic kidney disease you're losing zinc and making you much more susceptible to all sorts of other conditions.

I'm working with **Dr Zakeya**, the Kidney Fund Post-Doctoral Fellow on some experiments to get evidence to support these ideas. Zakeya is really working on kidney cancer but she's been amazingly helpful with this as well as her day job.

This is a very new field and it will be hard to convince funders of its importance but most of them don't have kidney disease. I need to get some data and our Kidney Fund has always believed in supporting new ideas. Let's face it if we're going to make things better for kidney patients we need new ideas. My hope is that with the help of The Kidney Fund I can work with my colleagues at King's and we can lead the kidney research community on a new strategy to make the lives of kidney patients better.

Thank you so much for your support.

Dr Mark Dockrell

Funding = Research ... Research = Cure!

The Kidney Fund

ANNUAL GENERAL MEETING

Friday, 6th December 2024 • 2:00pm
at The Whitehall Lecture Theatre, St. Helier Hospital

This is your chance to meet some of the people who are raising funds for kidney research, hear about the exciting work that has been done throughout the years, meet the scientists and doctors who are conducting the research. It is also an excellent chance for them to meet you!

We encourage anyone suffering from kidney disease or who knows and cares for someone suffering from kidney disease to attend.

Everyone is Invited.

All will be made very welcome and light refreshments will be provided.

The Kidney Fund

YOU ARE INVITED TO THE

CHARITY BINGO

PLAYING TO SUPPORT A CAUSE

MONDAY 2ND DECEMBER 2024
6.30PM FOR 7PM START

THE FOX, COULSDON COMMON
CATERHAM, CR3 5QS

TEL: 01883 340737

£2 BINGO TICKETS, 6 TICKETS
£1 STRIP RAFFLE TICKETS

THE KIDNEY FUND UPCOMING EVENTS

London Marathon | Sunday 27th April 2025

Dragon Boat Race | Sunday 20th July 2025

The Kidney Fund Ball | 11th October 2025

Please contact Gemma for further details
gemma@kidneyfund.org.uk

Your **Lottery** is still going strong, join from just **£1** per week!!

We must have been doing something right for the last 14 and a half years as I seem to hear of a new lottery starting up almost every week for various other charities, I believe the phrase is that imitation is the highest form of flattery!!

I know times are difficult, and our numbers are not as high as they once were, but we are still going along quite nicely and we're all aware that every £1.00 we generate goes towards helping the research by the fantastic team at St Helier's so I thank those of you that are still members and would encourage any new or returning members to join us.

We currently have just under 270 entries so are paying out around **£134.00** in winnings each week and am able to pass the same amount to The Kidney Fund but it would be lovely to be able to pay out more.

The very pleasing news is that around the middle of November the amount having been paid out in winnings will exceed **£100,000.00**!

Including donations and prepayments at that point we will have been able to transfer in excess **£109,000.00** towards this vital research which is a staggering amount that you have raised.

PLEASE, PLEASE, PLEASE would you encourage your families, friends, colleagues, neighbours or anyone else you know to join us and for any of our past members I would love to welcome you back so just send me an email at **lottery@kidneyfund.org.uk**.

If you are able to then why not take out another subscription or 2 yourselves, it increases your chances of winning while contributing more to the cause?

Entry is £1.00 for each number per week and you can have as many numbers as you want!!!

Thank you all for your continued support of OUR lottery, good luck and stay safe from Steven Clark (administrator of The Kidney Fund Lottery).

Winners since the last copy of *Renality* are (this was written a little while before publication so does not have the most recent winners shown):-

09/02/2024	101169	West Ewell	£130.50
16/02/2024	101037	Surbiton	£130.50
23/02/2024	101082	Ashtead	£130.50
01/03/2024	101206	New Malden	£130.50
08/03/2024	101379	Sunbury-on-Thames	£130.50
15/03/2024	101271	Shamley Green	£130.50
22/03/2024	101344	Mitcham	£130.50
29/03/2024	101222	Royal Wootten Bassett	£130.50
05/04/2024	101010	Woking	£130.50
12/04/2024	101310	Farnborough	£130.50
19/04/2024	101334	Sutton Common	£131.00
26/04/2024	101062	Horsham	£131.00

03/05/2024	101029	Old Coulsdon	£131.50
10/05/2024	101126	Belmont	£131.50
17/05/2024	101377	Esher	£132.50
24/05/2024	101198	Tufnell Park	£132.50
31/05/2024	101051	Raynes Park	£132.50
07/06/2024	101348	Bury	£132.00
14/06/2024	101149	New Malden	£132.00
21/06/2024	101267	Guildford	£132.00
28/06/2024	101280	Sutton	£132.00
05/07/2024	101144	Belmont	£132.00
12/07/2024	101258	Carshalton	£132.00
19/07/2024	101162	Farnborough	£132.00

St Helier and Surrey Kidney Patients Association

A message from your Chairman

The most important thing I have to report upon is the death of Pat Harris, our Honorary Secretary. Pat has supported the KPA and the Kidney Fund for over 25 years.

Many of you will remember her from the St Helier servery counter where she worked every Wednesday until the servery's closure once Covid struck.

Pat was my KPA secretary for nearly 20 years and was an absolutely lovely lady who helped me tremendously and supported so many renal patients.

R.I.P Pat, you were a diamond.

I am nearing the end of my eighteenth year as Chairman, and I am more than happy to continue for another year, albeit I plan to hand over the Chairmans reins in November 2026, my 20th anniversary.

I said, back in 2006 that I'd do 5 years, so I may have overdone things.

I hope that the KPA members, patients, and the renal unit staff are pleased with the work that the KPA's Committee has done on your behalf over the last year, it's been a challenge after the passing of Paul Connolly and Jackie Moss, two of our committee. We have hopefully found 3 new members to help. We're slowly learning how to do virtual meetings for those unable to attend on the night.

On a personal note, I would like to thank all the Committee members together with the Renal Unit staff all of whom provide invaluable support to the KPA throughout the year.

The inpatient wards have moved to the 6th floor of the main hospital, which has proved difficult due to the lack of space and more recently the unbearable temperatures within the space. The renal unit are looking at what can be done before next Summer.

To the best of my knowledge the new inpatient centre at St Georges is on schedule, hopefully it won't succumb to the raft of cuts being made by our new Government. I'm sure the Clinical Lead will have more information on the build timescale.

The Coulsdon Satellite is up and running. A new location for the Kingston Satellite is being sought.

About the KPA, we have 945 members, so we're kept busy dealing with the many and varied requests which we receive from both patients and the renal unit. As in previous years I thought it would be good to show how we have distributed our funds during the past year, these include:

- Renal Overlays & Fleece Blankets for St Helier and its Satellites
- 2 Ultrasound Machines (in memory of Paul Connolly)
- 20 bag warmers for P.D.
- 4 Blood Pressure machines Dialysis & P.D. Mannequins + Biopsy Mannequin + Spares for existing Mannequin
- Funding of a Patient Engagement/KPA Promotion position
- Veinspy vein finder machines
- Venous Access Monitors
- Replacement seating for outpatient areas

This has all been possible due to the generous donations and legacies that we have received.

During our 2023/2024 financial year we have purchased equipment valued at over £84,000 for St Helier and its Satellites.

To date we have agreed and are committed to purchasing equipment valued at almost £70,000 for the period 1st April 2024 to 30th September 2024.

With the October edition you would normally find our Grand Draw tickets but with the current economic situation and cost of living increases we have again decided that it wouldn't be right to hold the draw and ask people to contribute. We don't have any plans to reintroduce our draw.

AGM/ Committee/Patient Representatives

The **KPA Annual General Meeting** is scheduled for **Tuesday 12th November**. It will be held in the 2nd floor RMT meeting room of the renal unit starting at 18.30. You must be a KPA member to attend, please contact me if you wish to attend so I can update you if anything changes.

As I said earlier, Committee have 3 new members. It would be lovely to have every Satellite represented. We still need reps for all Satellites with the exception of Mayday, Epsom & Coulsdon.

Most of the present Committee have served for several years and I'm sure they won't mind me saying, but we're all getting older and it's vital to find new Committee members to ensure the continuity of the KPA, after all it's there to help us, the patients.

Ideally, we would love to have some younger Committee Members to enable us to represent the entire age range of St Helier's patients.

The position isn't onerous; we meet every two months in the within the Renal Unit at St Helier at 18.30 normally on the second Tuesday of the month. Members don't need to attend every meeting; reports can be submitted by email or similar and as I said earlier in my message we've even moved onto virtual attendance.

We are currently considering holding our meetings on a Quarterly basis.

If you can help, please talk to your Consultant or contact me on **01483 426276** or email **daspensley@btinternet.com**.

I think that is all I must report on so may I be one of the first to wish you all a very Happy Christmas and a happy and healthy New Year.

Best Wishes

Dave Spensley,
Hon Chairman

London Underground Engineering Workshop (REW) smashes Three Peaks Challenge for late colleague

Climbing Ben Nevis, Scarfell Pike and Mount Snowdon in 24 hours – it was the kind of adventure that would bring me (Production Manager Becky Cooper), and my colleagues to the lowest of lows and highest of highs *(pardon the pun)*. But we did it.

This May, sixteen of us guys and girls mainly from the Railway Engineering Workshop (REW) in Acton took on the Three Peaks Challenge. It was truly brutal but we smashed it: covering 42km, more than 3,000m of ascent, not to mention 11 to 12 hours of being cramped in a minibus between the mountains.

We embarked on this crazy adventure in memory of a dear colleague and friend **Kieran Grogan** who suddenly passed away in April 2023.

Kieran had endured many difficulties with his health over his adult life – having a kidney transplant 28 years before his passing and beating stage 4 cancer too – but his death still came as a shock to all of us last year as he died of something completely unrelated.

The day the news came through that he had died sent a dark cloud of sadness over the shop floor.

Kieran worked within the Brakes team at REW and was a beloved member of staff. His positivity was infectious, and he made everyone's day a little brighter just by being around.

Due to his knowledge with pneumatics systems, Kieran was one of the first points of contacts for any new starters as he was most often the one to carry out their training. He was everyone's confidante and massively supported people on every challenge they undertook, whether physical or emotional.

We decided that we needed to honour Kieran's memory by raising money for a charity that had supported Kieran and his wife Beryl throughout his life, the St Helier & Surrey Kidney Patients Association. And so the *"Team Kieran"* Three Peaks Madness was organised!

The sixteen team members laughed together and cried together, but most importantly supported each other through the gruelling 24 hours. What made it even more worthwhile is that between us we raised more than £10k for SHKPA.

Fourteen members of his family, many hailing from Ireland, met us at the foot of Mount Snowdon, cheering us all over the finish line and giving us well earned drinks and snacks to celebrate!

It was brilliant to come together to remember Kieran and contribute to such a fantastic cause that was so dear to Kieran and Beryl.

KPA Donations

St Helier and Surrey KPA would like to thank those of you who have donated to us during the period since the last *Renality*.

- James Lewis
- J.S. Price
- Joanne Jonson

KPA MEMORIAL DONATIONS

St Helier and Surrey KPA would like to thank all of those individuals who have donated in memory of:

- Kieran Grogan
- James Smith
- Maria George-David
- Derek Gascoigne
- Jackie Moss

There are many many ways in which you can help **The Kidney Fund** and help ensure the future of Kidney Research. Further information on all of them can be accessed via the 'support us' page on our new website – or, if you do not have computer access and would like to know more, please do call **020 8296 3698**.

Make a **one-off donation** online, text **KIDNEY** (amount) to **70450**, or by cheque to: The Kidney Fund, Renal Unit, St Helier Hospital, Wrythe Lane, Carshalton SM5 1AA

- Create a **standing order**
- Donate via **payroll giving**
- Join our weekly **lottery** and play to win!
- Shop 'til you drop and **Give as You Live!**
- Recycle your old car at no cost via **GiveaCar**. Call them on 020 7736 4242
- Sell an item on **ebay**
- Volunteer **your time** (we can give you all sort of ideas!)
- Buy our **Christmas Cards**
- Donate **shares**
- Donate your **tax refund**

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USEFUL CONTACTS:

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SWTIRR & SWTKF: 020 8296 3698
www.swtirr.org.uk

THE KIDNEY FUND: info@kidneyfund.org.uk
www.kidneyfund.org.uk

ST HELIER & SURREY KPA: Dave Spensley, Chairman 01483 426276
www.shskpa.org

RENALITY is sent to all patients of the Renal and Satellite Units automatically unless they have asked not to receive it. If you do not wish to receive this newsletter, please contact Beverley Searles beverley.searles@nhs.net 0208 296 2587.

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2024/2025

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PLAY OUR WEEKLY
LOTTERY

Over £75,000
raised so far for
The Kidney Fund!!

50% of all money raised goes to the winner and the other 50% goes directly to The Kidney Fund

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The Kidney Fund

Over £8,000
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£160 Average weekly prize*

To join the Lottery please complete the form below and return it to the address on the form.

Once received, we will contact you to let you know your unique number or numbers.

IMPORTANT please return to: The Lottery Office, c/o 10 Pelton Avenue, Belmont, Surrey, SM2 5NN

Title: Initials: Surname:

Address:

Post Code: Home Phone: Mobile:

Email: Add me to the Kidney Research Supporter Email Group ☐

Please note that to save on postage we prefer to communicate by email or telephone. Please tick here ☐ if you require a letter

There are TWO ways to pay. Please choose ONE of the following:

OPTION 1 – Standing Order Mandate

Title: Initials: Surname:

My Bank's Name: Branch: Post Code:

My Account No: Sort Code: Date of 1st Payment:

Name: Signed:

Pay to: Kidney Fund Lottery **Bank:** CAF Bank Ltd, West Malling **Account No:** 00019588 **Sort Code:** 40-52-40

Monthly Payment:	☐	number of entries @ £4.34 per month	=	£	& thereafter each month
Quarterly Payment:	☐	number of entries @ £13 per quarter	=	£	& thereafter each month
Half-Yearly Payment:	☐	number of entries @ £26 per half-year	=	£	& thereafter each month
Annual Payment:	☐	number of entries @ £52 per year	=	£	& thereafter each month

OPTION 2 – Cheque Payment

Title: Initials: Surname:

I wish to buy ☐ entry(s) each week for ☐ 13 weeks, ☐ 26 weeks, ☐ 52 weeks and remit a cheque for £

(each entry costs £1 per week). Please make cheques payable to: The Kidney Fund Lottery & return to the address on the form.

If you have any questions or would like more information, please call 020 8296 3968 or email: lottery@kidneyfund.org.uk
The Kidney Fund: Registered charity number: 800952

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* Based on the average of the last years weekly winning prizes. The weekly prize amount is not guaranteed and is dependant on the number of entries paying into the lottery that week.