

RENALITY

November 2023



New beds
for Epsom!

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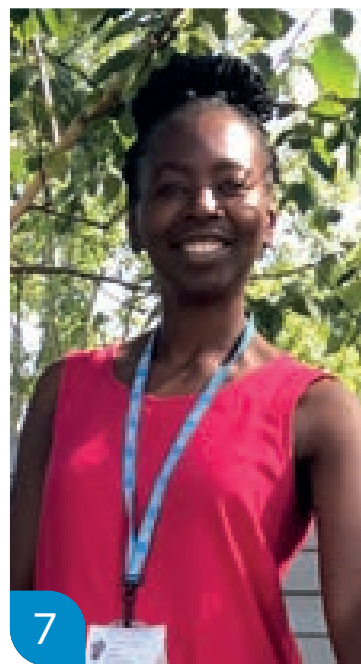
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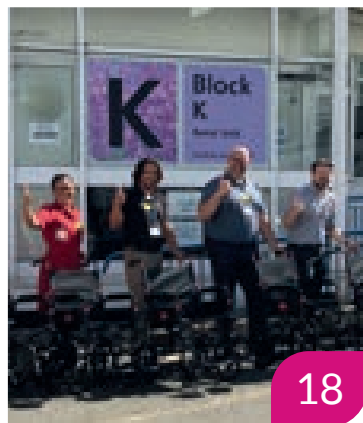
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Renal Unit



Dr Ginny Quan Dr Fiona Harris

Knowledge is Power. Education is the most powerful weapon which you can use to change the world. Amidst the daily grind, we sometimes forget how privileged we are to have a healthcare system available to all. We take for granted that if we or our loved ones fall ill, we will be able to access help. It isn't a perfect system, and the challenges that occur – for patients and staff alike – are in the news day after day. Sometimes, though, something happens that makes you look through a different lens.

Earlier this year, we hosted a doctor from Cameroon, Dr Gobina, supported by a fellowship from the International Society of Nephrology. He spent a number of weeks working very closely with our colleagues Dr Sood, Dr Somalanka, and Dr Virdee. Over the last few years, this team have pushed the boundaries of Interventional Nephrology, that subspecialty of kidney medicine in which we place dialysis lines and peritoneal dialysis catheters using increasingly complex kit, but ultimately with the aims of better quality dialysis and

facilitating dialysis choice.

Dr Gobina returned to Cameroon with a new set of skills and confidence in his ability to use them. Shortly after, a young boy, just 4 years old, had severe Malaria which caused kidney failure. Dialysis in children in the UK is complex. In Cameroon, without the technology that we have access to, kidney failure could be a death sentence. Dr Gobina was able to place a peritoneal dialysis catheter and successfully perform peritoneal dialysis for this little boy, until such time as

his kidneys recovered. Already, Dr Gobina has had more young children referred, and been able to make a difference. He is now working with administrators and political stakeholders to further develop an Interventional Nephrology centre in his own hospital, so that he can share the knowledge and skills that he has learned more widely, and benefit more people who develop kidney failure. The sharing of knowledge and skills by our team has already made a difference, and has acted as a catalyst to change the face of kidney care in Cameroon.

When I heard this story, I really did feel humbled. But it got me thinking more about the importance of education and the power of knowledge. In healthcare, we talk about Shared Decision Making – 'a collaborative process through which a clinician supports a

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 0011 1664
- 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**

USEFUL CONTACTS:

RENAL UNIT reception: 020 8296 2283, 020 8296 3100

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

The opinions and views expressed in this Newsletter are those of the individual or organisation expressing them. There can be no assumption that such views and opinions are supported by any other subscribing organisation or individual.

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 and Sami Young sami.young@nhs.net 0208 296 2384.

patient to reach a decision about their treatment'. In this process, there are three phases: introducing choice, describing options, helping people explore preferences and make decisions. It's a tough one, because the healthcare providers hold the trump card... Knowledge. I'm sure you have been asked to complete the PREM survey this year. Some of the questions are around shared decision making. We know that we, and other units around the country, score less well on this. Nobody seems to have cracked the nut of doing this well. What does that tell us?

Perhaps that we, as healthcare professionals, haven't got the balance right with sharing our Knowledge, and with Educating people living with kidney disease so that they truly understand what choices are available, and what this means for them.

We know that empowering people living with long term health problems leads to better overall well-being, and that empowerment usually comes through involving them in treatment planning, supporting people in making informed decisions about care, and

promoting self-management skills – eg self care on dialysis, or dialysis at home. In other words, sharing Knowledge and Educating people is a good thing.

So next time you come to clinic, feel free to ask questions. Ask us to share our knowledge with you in a way that helps you understand. Tell us the things that are important to you. Ask us about the things that don't make sense. Maybe then we can make progress towards genuine shared decision making. *Knowledge is Power!*

Ginny and Fiona

Donation of 13 Dialysis machines to the Asaase Foundation's Kidney Care Campaign

The Asaase Foundation extends its warmest greetings to St Helier Hospital Renal Unit. We are a charity foundation set up to support worthy causes especially those involved in marginalized, ill people, women and children. Our main project dubbed Asaase Kidney Care Campaign was launched in February 2022 to provide support for Kidney Care in Ghana through advocacy, education and donation and set up of dialysis machines.

In the first year we commissioned three dialysis centres in hospitals in three regions in Ghana namely,



Bono Regional Hospital, Upper West Regional Hospital and the Tarkwa Municipal Hospital which hitherto had no dialysis centres.

Thank you St Helier Hospital for

your generous donation of 13 state of the art dialysis machines to this cause. The Foundation is extremely grateful and wants to assure you that your kind contribution



will be used in reaching more deprived communities.

Just to bring you up speed on what has happened so far, since we received the units: we are happy to report that seven public health care institutions took part in a brief handing over event.

On 16 June 2023, key stakeholders, government officials and representatives from beneficiary hospitals gathered to witness the foundation's tremendous donation in Accra. Seven of the cutting-edge dialysis machines were handed over to hospitals in Accra, Bolgatanga, Enchi, Hohoe, Obuasi, Sogakope and Sunyani, bolstering their capacity to provide crucial health care to patients in need. These have already been installed, with a further two in the pipeline to be installed by the end of the year.

Ghana has experienced an upsurge in cases of the underlying kidney problems – hypertension, anaemia, diabetes, calcium and phosphate abnormalities, as well as

contaminated water bodies – and we at the foundation are committed to doing our little bit to improve the circumstances of the many afflicted with this complaint, who find haemodialysis treatment out of reach and unavailable. Our hope is to continue to expand the network of haemodialysis centres and improve the availability of machines.

Thank you St Helier Hospital, the foundation appreciates your donation and encourages your continuous support.



With sincere gratitude,

Kojo Mensah
President,
Asaase Foundation



Dear readers

Let me introduce myself...

I am Dr Pauline A Swift and I first joined the Renal Unit as a consultant in 2016. Since then I have been busy with general nephrology, dialysis and blood pressure clinics. In addition to that I am the Director of Research for the Trust and much of my time is spent trying to encourage an ethos of research in the Trust and of course in the renal unit. Here's a photo of the team - Kwame, Laijee, Eva, Josh - you may have seen them on the dialysis unit or in the clinics!

Of course you all know about the research that Mark Dockrell and the team get up to @SWITRR, as Mark writes regularly in Renality; but the type of research that I am involved in, is the local inclusion of our patients in large National and International clinical trials.

In the renal unit alone we have 24 clinical research trials open. Here are just some of the ones

that are open to volunteers - so don't be surprised if a member of the team approaches you to consider being part of a research trial - it is all for the advancement of new knowledge and new treatments for kidney disease.

- **RADAR:** National Registry of rare renal diseases
- **NephroS:** The National Study of Nephrotic Syndrome (NURTuRE)
- **DOPPS:** The Dialysis Outcomes and Practice Patterns Study
- **The UK Calciphylaxis Study**
- **UKIVAS:** UK and Ireland Vasculitis Rare Disease Group (vasculitis registry)
- **NIHR BioResource:** Rare Diseases
- **RCT Prepare for Kidney Care**
- **SIMPLIFIED:** Cholecalciferol in Patients on Dialysis
- **HAVEN:** Hydroxychloroquine



in ANCA vasculitis

- **CARSK study - Screening Kidney Transplant Candidates For Coronary Artery Disease**
- **GAMECHANgER-1:** ReGulatory T cells in highly sensitised pAtients to iMProVE outComes after HLA-Ab iNcompatible Renal transplantation
- **ACHIEVE:** Aldosterone bloCkade (spironolactone) for Health ImproVement Evaluation in End-stage renal disease (ACHIEVE)
- **A Phase 2/3 Adaptive, Double-Blind, Placebo/ Controlled Study of VX-147 Aged 18 Years+ AMKD**
- **A Study of APOL1 in Individuals with Proteinuric Kidney Disease**
- **RESOLVE:** Randomised evaluation of sodium dialysate levels on vascular events

I thought that it might be worthwhile to let you know about new trials that are due to open soon - so that you can approach us for information.

One trial about to open is the RESOLVE Trial, which aims to



resolve

Randomised Evaluation of Sodium
dialysate Levels on Vascular Events

see if a higher or lower dialysate sodium concentration is better for overall health. It will be

coming to a dialysis unit near you soon!!!

<https://www.resolve-trial.co.uk/>

I would also like to thank all of the 100s of patients that have participated in clinical research

trials over the years. Without your contribution, the research is nothing...

For more information about the resolve trial or any of our research studies, please contact the team.

Patient Experience - *your voice matters!*

Earlier this year the Kidney Patients Association kindly agreed to fund a Patient Experience Officer post for a period of twelve months to help in their quest to recruit much needed KPA Committee Members and also to help the renal team with a number of projects we have been hoping to get underway for some time. We are delighted that Toyah Bubu has recently taken up this post.

Toyah has been in the renal team for fifteen years, mainly working in the renal POD booking and scheduling patient appointments and she is really looking forward to getting out and about to Satellite Units to meet patients and staff. One of Toyah's initial projects will be to promote the annual Kidney Patient Reported Experience Measure (PREM) survey. This year the survey is digital only

so she will be arranging for tablets to be available in units so that as many patients as possible can take part even if they don't have their own electronic device. The QR code for this year's survey is below. When the results are published early next year, Toyah will support teams to act on the feedback received so please do have your say!

<https://www.kidneycareuk.org/news-and-campaigns/news/kidney-prem-2023/>



You'll also have seen in recent editions of *Renality* that KPA Chair Dave Spensley has been calling for Volunteers who would be interested in joining the KPA as Committee Members. Toyah will be talking to patients in outpatient departments and Dialysis Units to spread the word so if you are



interested or want to find out more please let her know.

The proposals to bring together St Helier and St George's inpatients services together are moving forward so over the next few months Toyah will also be working to set up patient Focus Groups so that your voice can be heard.

A very busy year ahead for Toyah and we all wish her every success in her new role!

Toyah can be contacted by email - toyah.bubu@nhs.net

Cookery Corner



Did you know that UK Kidney Care have produced a fantastic library of kidney friendly recipes created by professional chefs working in partnership with experienced renal dieticians. Each recipe has been modified to suit people living with kidney disease and has informative Food Facts so that you can check if the dish meets your individual needs.

As well as downloadable recipe cards there are videos that can help you create delicious meals – step by step to help you develop your kitchen skills.

We wanted to share some of these recipes with you in *Renality Magazine* and we were totally spoiled for choice – but here is just one of our favourites with a photo of Ciara and Louise from the renal team giving **Cornflake and Ginger cookies** a try!

Best of all – these resources are free (including the *Eat Well Spend Less Magazine*) – so why not test out your bake off skills and check out some of these lovely recipes?

All the recipes are available on the UK Kidney Care website www.kidneycare.org

Bon appetite!!





Special occasion

Vegetarian



✓	Low phosphate	✓	Low protein
✓	Low potassium		Low salt
20g	Carbohydrate	150kcal	Energy

Nutrition values are calculated per serving • Kidney diet guidelines vary for each individual • Consult your dietitian or doctor for the specific diet that is right for you.

Cornflake & Ginger Cookies

Prep: 15 mins • Cook: 15 mins • Serves: 12

For a special treat this simple cookie recipe is low in potassium, phosphate and protein.

- Ingredients**
- 100g unsalted butter
 - 75g golden caster sugar
 - 130g self raising flour
 - 1 egg
 - 40g cornflakes
 - 60g stem ginger

Carbohydrate The main sources of carbohydrate in this dish are the flour, sugar, cornflakes and stem ginger. Carbohydrate values have been provided for those trained in insulin adjustment.

Phosphate/potassium Following the quantities provided these cookies are low in potassium and phosphate so you can enjoy one as a special treat when following dietary restrictions.

Protein These cookies are low in protein and therefore can be enjoyed as an occasional treat if following a low protein diet.

Special diets

Gluten free: These cookies can be made with gluten free flour and cornflakes.

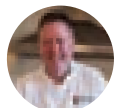
Healthier option These cookies are just over the criteria to be classed as low salt, which is likely due to the salt added to cornflakes. When buying cornflakes, it is best to check the nutrition label and to opt for the one with the lowest salt per 100g.

To reduce the fat and calorie content of these cookies you could try baking with a low fat spread in place of the butter.

Cheaper option Normal caster sugar can be used instead of golden caster sugar which may help reduce the cost.

Storage Once cooled, store in an airtight container and consume within 1 week.

Tips For an alternative flavour to stem ginger, 60g of dried cranberries could be used and the recipe remains low in potassium, phosphate, salt and protein.



Cooking in the kitchen with Chef Paul Ripley

With crunchy cornflakes and warming ginger these cookies make a really lovely indulgence for a special occasion.



Preheat oven to 200°C / gas mark 6. Line 2 baking sheets with greaseproof paper.



Cream together butter and sugar until light and fluffy, then whisk in the egg until smooth. Add the flour, cornflakes and chopped stem ginger. Mix to a soft dough.



Roll into 12 walnut sized balls, place onto baking tray and slightly press down with fingertips, leaving plenty of space between cookies.



Bake for 15 minutes until the cookies are golden, then transfer onto a cooling rack.



The Kidney Kitchen was created by Kidney Care UK to support patients and their families live well with kidney disease. Recipes have been developed by our professional chefs and modified to fit more closely with the various needs of people living with chronic kidney disease, which have been approved by the British Dietetic Association (BDA) Renal Nutrition Specialist Group.

www.kidneykitchen.org



Watch online

Visit the website for more recipes, videos and dietary information.

If you have made this dish, we would love to see it. Share your photos online and don't forget to tag us #KidneyKitchen

Get in touch with Kidney Care UK
info@kidneycareuk.org
 01420 541 424
 (Lines open 9am-5pm, Mon-Fri)

[f kidneycareuk.org](https://www.kidneycareuk.org) [@kidneycareuk](https://www.kidneycareuk.org) [@kidneycareuk](https://www.kidneycareuk.org)

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Dear Kidney Fund Supporters



You'd be forgiven for wondering where the year has gone. Summer is fast receding and autumn looms. It is worth a recap on what has happened so far. With regard to fund-raising efforts, we have had people participate in and support various activities including the London Marathon, the Kingston Rotary Dragon Boat race and the Camberley car show. Dr Fiona Harris, joint Clinical Director for Renal services 'laced up' her running shoes and didn't stop until she'd run 50 kilometres to raise funds for us and last month, Robin and Nick Ford organised the Kidney Fund gala ball at the RAC in Epsom. It was a grand occasion and I was once again humbled to see the depth and breadth of support for us.

We have also had donations from people who kindly left part of their legacies to the Kidney Fund, and we are very grateful for this.

3 years ago, as the second wave of the pandemic was about to start, the outlook seemed bleak for so many

things, including Renal Research at St. Helier. 3 years later, thanks to the support from all of you, things are looking so much brighter.

This leads me on to an event coming up next month. It is 25 years since renal research was started at the South west Thames Institute of Renal Research (SWTIRR) at St. Helier. We plan to mark this with presentations from invited guests – people who have been instrumental to building the Institute and those who have benefited from the training in Research there. It will involve trips down 'memory lane', bits to bring us up to speed with what is happening at present in SWTIRR, and a glimpse into the future.

It is going to take place on **Wednesday November 22nd**, between 13:00 and 16:00 at the Whitehall lecture theatre in the Postgraduate Medical Centre at St. Helier hospital. We will start off with The Kidney Fund AGM at 13:00, then at 14:00, move seamlessly into the SWTIRR 25 year celebration.

It would be great to see you there if you can make it.

Lastly, we are still looking for help with the running of the charity. We currently have vacancies at Trustee level in the positions of Vice Chair, Treasurer, and Fund-raising lead. In my last *Renality* article, I referred to the quote "*many hands make light work*". I think it is also true that "*many hands will make the work light*". So, if you, or someone you know, is interested in helping, please contact me or one of the other Kidney Fund Trustees to discuss this.

This will be the last edition of *Renality* this year, so till the next one, I'd like to end with one of the traditional Irish blessings:

*May the road rise up to meet you.
May the wind be always at
your back.
May the sun shine warm upon
your face;
The rains fall soft upon your
fields and until we meet again,
May God hold you in the palm
of His hand.*

Dr David Makanjola

Kidney Fund Ball

The annual ball hosted by Robin Ford at the RAC Club in Woodcote Park Epsom was a tremendous success this year! The event was a delightful dinner dance that brought together a wonderful group of individuals for a night of elegance and festivities. The ambiance was nothing short of enchanting, with beautiful decorations and a live band that kept everyone on their feet.

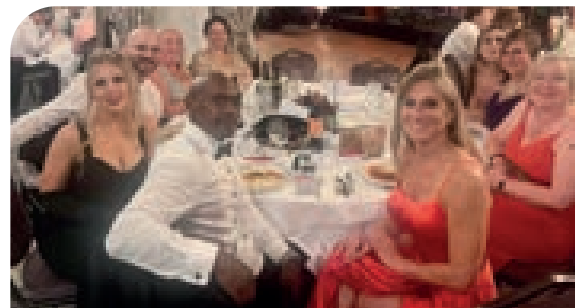
Not only was the ball a memorable evening, but it also had a positive impact on the community. Thanks to the generosity of Robin and the attendees, a donation of just over seven thousand pounds was made. This contribution will undoubtedly make a significant difference in supporting worthy causes and initiatives.

The success of this year's annual ball is a testament to Robin Ford's dedication to

creating a remarkable experience for all involved. It provided an opportunity for people to come together, enjoy each other's company, and make a meaningful impact on the lives of others.

Overall, the event was a delightful combination of elegance, entertainment, and charitable giving. It showcased the true spirit of community and generosity, leaving a lasting impression on everyone who attended.

We already have a date for next year's event which will again be held at the RAC Club in Epsom. It will be a **Masquerade Ball** after the success of the previous



one, so please add the date of **Saturday 14th September 2024** into your diaries! It will start at 6.30pm with welcome drinks. Please contact Robin Ford on **07785 352594** to book tickets.

ANNUAL GENERAL MEETING

of the Kidney Fund and Celebrating 25 Years of Research

Wednesday 22 November 2023 • 1.00pm – 5.00pm

The Whitehall Lecture Theatre, St Helier Hospital

Join us as we celebrate 25 years of the Renal Research Institute. 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! Everyone is invited.*

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

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

Funding = Research Research = Cure!

Greetings Renaliteers,



Dr Mark Dockrell

It's been a while since I've written my piece for our wonderful *Renality* magazine, for that I should apologise. As many of you know, since the COVID pandemic the Institute has been running on a skeleton staff. Well the skeleton was stripped to its bare bones last summer – at least temporarily – when our lovely Sarah took maternity leave to give birth to a beautiful healthy baby. A big congratulations to Sarah. Of course, that did mean that Ekram and I had more to do to keep things going. Any of you who have had the privilege to meet Dr Ekram Nabi will know that I couldn't have asked for a more dedicated hard working co-worker.

The Institute is now turning the corner and getting back to doing what we do best; research into causes and better treatments of kidney diseases; and educating the next generation of experts in kidney disease. This is largely due to the support of **Ekram**, **Dr David Makanjuola** and The Kidney Fund. I cannot thank them enough.

As usual I'm the last contributor to submit their article to *Renality*. This is because I've had the pleasure of building and strengthening our team. Last year **Dr Phanish** and I visited the headquarters of Kidney

Research UK. Dr Phanish set in place a new agreement that meant our Kidney Fund and Kidney Research UK would co-fund a new PhD studentship. This is a brilliant innovation that allows the Kidney Fund to get more "bang for its buck". Dr Makanjuola signed the agreement and on Monday I was able to appoint an excellent student as The Kidney Fund/ Kidney Research UK PhD student at The SWT Institute for Renal Research. You'll hear more from her in the spring, but I'm so excited about this project I can't help giving you a little taste. Our last PhD student, **Xinlu Pan**, completed a great PhD studying how the diabetes medicines SGLT2 inhibitors affect human kidney cells. As usual, innovative projects like this lead to further work. Building on Xinlu's work this new project investigates the possibility of designing a new therapeutic drug that will mimic some of the effects of SGLT2 inhibitors but targeting the effects more precisely. This could be a new way of treating diabetic kidney disease.

In addition to appointing a new PhD student, in the last week I have been ensuring that a new post doctoral research fellow will be starting work with us. Last December **Dr Zakeya Baalawy**

visited the Institute and worked with me for a month. I know Zakeya, she did her PhD at King's College London with my friend and colleague **Professor Bob Price**. **Professor Christer Hogstrand**, also from King's, and I had been trying to recruit Zakeya to work on a new collaborative project with us. The last 9 months have thrown up all kind of "challenges" to this plan. However, working with The Kidney Fund, we secured a substantial new donation to fund a three year post-doctoral fellowship. Christer and I battled with administrators, filled in form after form and negotiated that King's College London would employ Zakeya even though she'll work with me at St Helier as well as Christer at King's. Most importantly, Zakeya herself pushed and pushed and pushed again to make this happen. I met with Zakeya last week and arranged for her to come to The Institute next week and start her project.

I want to thank The Kidney Fund, the staff of the Renal Unit and I want to thank all of you for your support. As Dr Makanjuola will tell you, my dear departed mum used to tell me, "if you want to go fast, go alone but if you want to go far, go together". We've got a long journey ahead but together we will find new treatments and better diagnostics for kidney disease.

Dr Mark Dockrell

Philip Thomas Ringrose

1st April 1949 – 22nd October 2021

Philip was born on the 1st April 1949 and lived in and around the South Wigston area of Leicester.

His early life was closely connected to St. Thomas's Church in South Wigston where he was a choir boy. Philip had the most beautiful voice and eventually became the Church's head chorister. He also became a Sunday School teacher and enjoyed a good social life within the church.

He was also a member of the YMCA Operatic society in his 20's performing shows which included Oklahoma, South Pacific and various pantomimes. Philip continued to enjoy his singing and joined the Wigston and District male voice choir. He had a love of classical music and opera making a number of trips to Birmingham, Covent Garden and the Coliseum.

After his school years Philip went into the grocery trade which led to a successful partnership called Thornton and Ringrose. They were very entrepreneurial for the time, even creating their own reward stamp system! He then moved to work as a porter at the Leicester General Hospital, he was very outgoing

and friendly and always had a word for everyone when pushing trolleys along the hospital corridors. New Geriatric wards opened and Philip joined the Geriatric Social Work Department as a Social Work Assistant, his gentle, caring, jovial nature was perfect for this role, putting his elderly patients at their ease. Encouraged by friends Philip studied and became a qualified Social Worker however this proved to be a stressful role and he moved to work at Wigston Day Centre for people with learning difficulties which was a role he really enjoyed.

Philip was a very sociable person and had many friends. He took part in all social events; skittles, after work tennis, camping weekends and cycle rides around the Leicestershire countryside. He also had a love of walking and took part in Christian Aid sponsored walks and walked across the fields each Sunday to join his father for a lunchtime pint at the local village pub. He was very close to his parents and offered great support to his mother in later life. Philip never married but was always hopeful, often beginning sentences with, "*My wife and I!*"



He always had a great love for East Devon and eventually made the decision to move to live in Budleigh Salterton in 1997. Here he started his Private Car Hire Business and commenced a new chapter in his life. He became well known in Budleigh and this was demonstrated by the full church at his funeral.

It was from his early twenties that Philip lived with bipolar disorder. This caused some difficult times in his life and the side effects from his medication sadly caused his kidney failure and the need for his kidney dialysis at the Exeter hospital during the latter years of his life. It gave Philip some comfort to know that his bequest to the Kidney Fund may help others in the future and that his life might have made a difference.

You have now raised over **£100,000.00** through our **Lottery!**

I hope you are all well and have been able to enjoy the summer?

It gives me enormous pleasure to be able to let you know that I have been able to transfer well over **£100,000.00** to The Kidney Fund since we started our lottery in July 2010 with over **£92,000.00** paid out in prizes – all these £1.00 most certainly do add up.

This is a truly amazing amount and I am sure you will all be pleased as me to know how much we are actively helping to support the fantastic research team.

Our numbers have remained pretty stable since I last reported earlier this year but it would be nice if we could start to welcome new members or if previous members felt able to rejoin us!

I know that the financial

predicament in these trying times is not easy for most of us, and I certainly wouldn't ask anyone to stretch themselves beyond what they can reasonably afford, but these funds do help towards the much needed research carried out on all our behalves.

So if you are able, and have not already done so, then it would be lovely to welcome you to our group and just as nice to see you returning if you have previously been a subscriber.

If any of you that have not kept your subscription going would like to rejoin us then do let me know by emailing me **lottery@kidneyfund.org.uk** so we can sort out your renewal or just complete the form on the back page and send it to me.

Should anyone wish to join us and has access to online banking

then email me at the same address and I will let you have the details to set up a subscription, alternatively complete the mandate on the back page and send it to me.

Every £1.00 weekly entry gives 50p in winnings and, more importantly, 50p to research – with no minimum to the number of entries you can have.

Don't forget to ask your family and friends to see if they also would like to join and don't forget that there's no limit on the number of entries anyone is allowed!!

Please come and join our group and invite as many others as you can, together we can help to make a difference and add to the fantastic amount that we have already been able to contribute.

Best wishes to you all and please stay as healthy as you are able to.

Steven Clark

Winners since the last edition are as follows:-

10/03/2023	101240	South Croydon	£125.50
17/03/2023	101073	Horsham	£127.50
24/03/2023	101205	New Malden	£127.50
31/03/2023	101217	Enfield	£127.50
07/04/2023	101229	Purley	£127.50
14/04/2023	101303	Ashford	£127.00
21/04/2023	101071	Weybridge	£127.00
28/04/2023	101058	Ash	£127.00
05/05/2023	101354	Banstead	£127.00
12/05/2023	101130	Ash	£127.00
19/05/2023	101187	Bearsted	£126.50
26/05/2023	101145	Farncombe	£126.50

02/06/2023	101175	Broughton	£126.50
09/05/2023	101347	Woldingham	£126.00
16/06/2023	101244	Dorking	£126.00
23/06/2023	101043	Aldershot	£126.00
30/06/2023	101077	Farnham	£125.50
07/07/2023	101363	Redhill	£125.50
14/07/2023	101002	Carshalton	£125.50
21/07/2023	101185	Bearsted	£125.50
28/07/2023	101341	Tolworth	£126.00
04/08/2023	101152	Badgers Mount, Kent	£127.00
11/08/2023	101168	West Molesey	£127.00
18/08/2023	101345	Woldingham	£126.50
25/08/2023	101312	Wallington	£126.50

St Helier and Surrey Kidney Patients Association

A message from your Chairman

I am nearing the end of my seventeenth year as Chairman, and I am more than happy to continue for another year, albeit I need to start thinking about handing over the reins.

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 arranging meetings at times, but 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.

As we begin to live with Covid things have been very different within the renal unit than they were pre Covid. 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.

The KPA servery counter remains closed, albeit we have had discussions about reopening on a smaller scale.

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

The merger of St Helier & St Georges renal services is ongoing. Discussions for the new inpatient unit due to be built on the St Georges site have moved along, but the delay has meant the build cost



has increased, so additional funds need to be found.

I'm sure the Clinical Leads report will update on this.

About the KPA, we have 936 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

- 10 Wheelchairs for various Satellites
- 10 bag warmers for P.D.
- 4 Beds for Epsom Satellite
- Dialysis & P.D. Mannequins + Biopsy Mannequin + Spares for existing Mannequin
- Funding of a Patient Engagement/KPA Promotion position
- Veinspy vein finder machines
- 40 Venous Access Monitors

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

During our 2022/2023 financial year we have purchased equipment valued at over £50,000 for St Helier and its Satellites.

To date we have agreed and are committed to purchasing equipment valued at almost £69,000 for the period 1st April 2023 to 30th September 2023.

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'll see how things go for next year.

AGM/Committee/Patient Representatives

The KPA Annual General Meeting is scheduled for **Tuesday 14th November**. It will be in the 2nd floor 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.

Committee is desperate for new members. We have lost 2 members over the last couple of years and 2 more have stood down due to health issues. It would be lovely to have every Satellite represented. We still need reps for all Satellites with the exception of Mayday.

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

KPA Memorial Donations

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

- Kieran Grogan
- Janice Smith
- Maria George-David

Kidney Beam: St Helier Kidney Patient Association

Natasha Wynn
Beam Studio Manager

What is Kidney Beam?

Kidney Beam is an exercise and lifestyle management app that has been designed for anyone living with a kidney condition. The app provides encouragement and support to keep people active in the long term. Designed in collaboration with the renal team at King's College Hospital, Kidney Beam offers progressive programmes, live and on-demand classes, and community and motivational support, with an aim to improve self-management skills, community connections, and physical and mental health. All sessions are led by specialist instructors either living with or working in kidney disease, and are tailored to different interests, health needs and stages of disease. On Kidney Beam, you can find a wide variety of exercise classes including strength training, yoga, Pilates, dance and cardio fitness, addressing needs such as regulating blood pressure, diabetes management and mobility, as well relaxation, pain management, and bone density improvement.

How can Kidney Beam help you?

With over 3,000 people living with kidney disease signed up to use the platform, Kidney Beamers range from those who are newly diagnosed, to people who are on dialysis, post-transplant, or with PKD, each with different movement goals and levels of ability.

For example, one particular kidney patient in his 80s, regularly takes live and on-demand classes on Kidney Beam to improve his mobility and stamina. Starting with the Beginner's Programme, and adapting sessions to remain seated when he needs, he has found that Kidney Beam has helped him gain confidence and has resulted in improved health that has been noticed by both him and his family. He says, *"As a result of my almost daily use of Beam sessions my confidence has now increased such that now I can also do 10 minutes of exercises most days, together with 10 minutes of COPD physio exercises on most days too."*

The *Get Active, Stay Active* live classes on Kidney Beam occur Monday to Thursday, and always have the option to remain seated and still gain all the benefits from movement. Run by the renal rehab team at King's College Hospital, you're in safe hands as



they guide you through a circuit-style session for both strength and cardiovascular health.

A regular to the Beam live classes, kidney transplant patient Chris found that having the set time to be online made it easier to stick to the routine of getting active. He says *"Kidney Beam provides discipline of turning up for the class at a certain time and being professionally guided to do the exercise is brilliant. You start moving muscles you had forgotten about, and you finish feeling on good form! As the weeks go by your body feels fitter and in a better shape. You begin to enjoy the company of your virtual friends, all trying to improve. It is a supportive environment."* Feeling the benefits from both his transplant and a regular exercise regime, Chris has been able to enjoy more of his hobbies and passions, including flying in a spitfire!

Kidney Beamer Shohana has been on the kidney transplant list since 2018 and is aware of the benefits of staying active in preparation for a transplant. Fitting physical activity around other activities and hobbies means that the on-demand library on Kidney Beam suits



her perfectly – *“It is lovely to have exercise classes designed specifically for kidney patients. Also, you can do the classes at your own pace. All the instructors are so friendly, encouraging and understanding. I have done a few live classes but mostly I do on-demand classes as I can be more flexible around my other hobbies – I play Bridge 3 times a week”.*



Join Kidney Beam now and benefit from all the classes we have on offer. Head to kidneybeam.com and click ‘Sign Up’, making sure you enter your clinic details during sign up to get free access.

The Kidney Beam service is run in partnership with King’s College Hospital and with support from various Renal Networks across the NHS, Kidney Research UK, Kidney Care UK, National Kidney Federation, UK Kidney Association, Kidney Wales

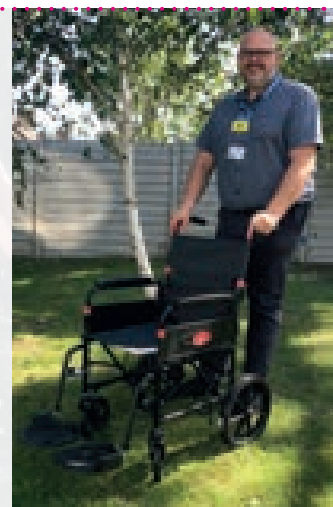
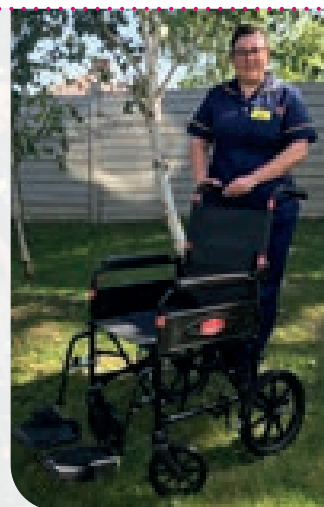
and The Punchestown Kidney Research Fund in the Republic of Ireland.

Gloria Munoz, Interim Associate Director of Nursing for Renal at St Helier hospital, volunteered as a Kidney Beam champion because she is increasingly impressed with the programme benefits and the progress, they have made in the last three years. She believes Southwest London population should be provided with equal opportunities to access and experience the benefits of physical activity

tailored to people living with chronic kidney disease. Some of the fantastic benefits include improved mental health, social and physical function, higher energy levels and patient activation (skills, knowledge and confidence). And the team looks forward to our population feedback and reported experience.

By recruiting more champions, both staff and patients, we would like to support this vision and make many others aware of this transformational platform.

The KPA supplied **beds** to Epsom and **wheelchairs** to Croydon, Epsom and Kingston, and there are more wheelchairs on order



St Helier & Surrey KPA Committee Members 2023/2024

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Position Vacant

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Meheret Moyo

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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



The Kidney Fund

Over £8,000 in winnings paid out in the last year!

£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 <input type="checkbox"/>	

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:	<input type="text"/>	number of entries @ £4.34 per month	=	£ <input type="text"/>	& thereafter each month
Quarterly Payment:	<input type="text"/>	number of entries @ £13 per quarter	=	£ <input type="text"/>	& thereafter each month
Half-Yearly Payment:	<input type="text"/>	number of entries @ £26 per half-year	=	£ <input type="text"/>	& thereafter each month
Annual Payment:	<input type="text"/>	number of entries @ £52 per year	=	£ <input type="text"/>	& thereafter each month

OPTION 2 – Cheque Payment

Title:	Initials:	Surname:
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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

* 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.