



Supporting and working for kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association Newsletter

Winter 2023

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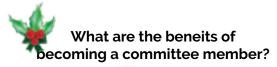
Merry Christmas ana Flappu lew Year

From your friends at West London Kidney Patients' Association

As we prepare to bid farewell to 2023, we would like to extend a welcoming hand to all new renal patients to the WLKPA. We particularly want to engage with the younger adult kidney patients who are transferring to us from Paediatric services.

So, whether you're on dialysis or have received a transplant, we're excited to get to know you and want to involve you in any way that suits you over the coming year and beyond. Being a KPA committee member is a good way to learn new skills that will benefit you in other aspects of your life as well.

Continued on page 2 \rightarrow





...get the chance to engage with other patients from diverse backgrounds

get to know members of staff in a. relaxed environment

...represent the KPA at local and national events

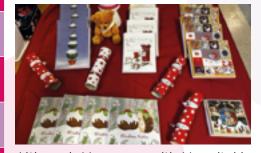
... contribute in deciding how we fund projects

... help devise and plan social, awareness and fundraising events

.. transfer other skills you may have to benefit the work we do

As a West London kidney patient, you are automatically entitled to be a member of the WLKPA. One of the benefits of subscribing is that you receive a copy of the newsletter four times a year at no cost to you. You also get to subscribe to the NKF magazine.

We always aim to produce the newsletters with content that is informative (and sometimes even entertaining!) to keep readers abreast of the latest developments and upcoming events. We currently don't place any advertising and will never sell information such as your personal details to third parties. We have annual fundraising and awareness events namely World Kidney Day in the spring and Organ Donation Week which is commemorated in the autumn. You will also see us in the lead up to Christmas at Hammersmith Hospital.



Although Hammersmith Hospital is our hub, we appreciate that it's not always convenient for patients to travel to and from the hospital. If you attend any of the satellite units and feel that you want to help, why not organise a fundraising event at your own unit with fellow patients. The WLKPA will be pleased to help facilitate this in any way we can.

Throughout the year, we hear of amazing individuals who raise funds on their own initiative on our Just Giving page at www.justgiving.com/wlkpa.

If you have a penchant for baking or making, hiking or biking, climbing or diving or anything else, why not team up with friends and family or in your community and raise funds to help the WLKPA continue to provide support to kidney patients in west London.

The NKF Annual Patients' Event 2023

After a tumultuous couple of years caused by the pandemic, the NKF Annual Patients' Event returned to its regular venue this September at The Radisson Blu Hotel, East Midlands Airport.



Spread over two days from the evening of the 22nd through to the 23rd of September, we got to meet with fellow patients from across the UK and heard from key speakers; David Coyle, NKF Chair. Dr. Sharlene Greenwood - a Consultant Physiotherapist at King's College Hospital, Dr. Auranga Zaib who spoke of the importance of and developments in vascular access, Tess Harris - Chief Executive of Polycystic Kidney Disease (PKD) Charity, Prof David Wheeler – Professor of Kidney Medicine, Daljit Bains -Welfare Rights Officer for Renal, Stephen Cass – London Kidney Network Director & Vicky Ashworth - North West Kidney Network Lead and Andrew McAllister – a kidney patient who gave a talk on "patient's perspective on CKD and

the power of positivity". The talks covered many topics. It was a fairly informal atmosphere with a fun quiz on Friday evening followed with dinner and a dance (for those who felt the urge to shake their hips!) We stayed at the hotel over the weekend and were treated to breakfast and dinner during which we got to meet so many individuals and shared our experiences. There was also an exhibition running concurrently in an adjoining room at which organisations were promoting kidney-related products and services.

If you want to find out more about the event go to the NKF website: <u>www.kidney.org.uk/</u> <u>event/national-kidney-federation-</u> <u>annual-patients-event-2023</u>

Applying sustainable practices in renal transplantation services: What the future holds.

by Nikolaos-Andreas Anastasopoulos – Senior Clinical Fellow in General Surgery, St George's University Hospital, London Vassilios Papalois – Professor of Transplantation Surgery, Hammersmith Hospital, Imperial College, London

The overtly evident climate change we are recently experiencing has led multiple healthcare systems to document the carbon footprint of their services (Table 1) and adopt bundles of measures to reduce it, with the NHS pioneering in this domain. The NHS is the biggest employer in the UK and its emissions account for 4% of the national total. Regular monitoring of carbon footprint, along with a set of measures to reduce it, were implemented since 2008, with the introduction of the Climate Change Act.

Table 1.

Environmental footprints of different healthcare services in the last decade.

COUNTRY	YEARS	CARBON FOOTRPINT	NATIONAL CONTRIBUTION
Australia	2014-15	35772 kilo tonnes CO2e	7%
Canada	2009-15	33 million tonnes CO2e	4.6%
China	2012	315 million tonnes of CO2e	2.7%
NHS	2019	25 million tonnes of CO2e	4%
US	2018	554 million tonnes of CO2e	9-10%

Recent evidence shows that End Stage Renal Disease (ESRD) constitutes a growing healthcare issue interchangeably linked to climate change and kidney transplantation has been shown to be the golden standard for its treatment, both for the patient and the healthcare system, as well. Haemodialysis, currently the most common modality of renal replacement treatment, has one of the gravest environmental footprints amongst medical therapies, comprised of water consumption, waste production and carbon footprint. In the UK alone, its estimated annual carbon footprint per patient is 3.8 tonnes of CO2, with water consumption and infectious waste generation reaching 500 litres and 2.5 kg per patient per session, respectively.

Despite the well-known environmental impacts of haemodialysis, there is no clear documentation of the environmental impact of kidney transplantation. In this text, we want to highlight the necessity for recording accurately the environmental impact of kidney transplant services and propose a bundle of measures to improve it, alongside providing top quality patient care. As shown in Table 2, they comprise of structured interventions that aim to improve service quality, reduce hospital stay and use before, during and after kidney transplantation by following all the principles of enhanced recovery protocols.

Table 2.

Suggested measures to improve the environmental footprint of kidney transplantation services.

Collaboration of ALL the stakeholders			
Attempt to increase PRE-EMPTIVE kidney transplantation			
Increase LIVING donor pre-emptive kidney transplantation			
Employ ENHANCED RECOVERY to reduce length of stay			
Increase deceased donor pool by employing MACHINE PERFUSION			
NON-INVASIVE and remote follow-up			
Utilise modern immunological tools to STRATIFY REJECTION			

We aspire that with intense research and the collaboration of all the stakeholders involved we will be able to provide 'greener' transplant services for the patients, benefiting them on an individual basis along with the planet that they dwell.

If you are a Kidney patient in West London, the WLKPA welcomes you to join us to help support fellow kidney patients.

In the first instance please email Sarah at secretary@westlondonkpa.org



Meet Rocky Opoku, Live Kidney Donor Coordinator at Hammersmith Hospital.

Before becoming a Live Kidney Donor Coordinator, I have had 13 years of experience working in the dialysis unit. During this period, I have witnessed the long wait dialysis patients go through before getting a transplant.

I share the pain and frustration that they go through when they are on dialysis.

The feeling of isolation they go through within the society that they live in, and the economic challenges they face with regards to keeping their families can be distressing. I admire their sense of resilience and strength.

As a nurse, I like to celebrate all those who

have donated their organs to improve others' lives. I have the privilege to educate and empower others to follow suit and say to them that you can actually donate one of your kidney's and still live a perfect life.

Kidney transplant can come from living donors, who are usually family members, spouses or friends of the patient. Transplant can also come from deceased donors. Let's beginning to talk about it to see if we can have a potential donor. Do not live in silence.

> My inspiration has come from people who have donated a kidney and are still able to live a perfect life and those of dialysis patients that have had a transplant, focusing on their lives without any health problems. They have made huge difference in

the society.

As a renal nurse, I always feel a sense of pride when I see my patients in the community, having had their transplant and enjoying their life. The therapeutic relationship that exists between me as a nurse, patients and their families is always amazing.

Let begin to talk about it especially minorities in the UK to educate people about transplants and its benefit.

KIDNEY PATIENTS' COVID-19 AUTUMN BOOSTER GUIDE 2023



	Who	Eligibility	Autumn Booster	When & How
	Adults aged 65 years and over	All	~	From 3 months after last Covid vaccination, starting in mid-September 2023 and completing by early December 2023
	Adults/children aged 16-64 years	 Chronic kidney disease (CKD) stages 3, 4 or 5, chronic kidney failure or nephrotic syndrome Dialysis patients Transplant patients Immunosuppressed individuals Household contacts (aged 12 and over) of an immunosuppressed person Carers (receiving carer's allowance or primary carer of an elderty or disabled clinically vulnerable person) Living in a care home for older adults 	*	England – The NHS will contact you if your NHS record suggests you may be eligible. Those eligible can use online booking, the NHS App or call 119 from 18 Sept Wales – wait to be invited by your Local Health Board Scotland – wait to be invited by email, text or letter. If not registered with a GP, call 0800 030 8013 to register
Ż	Children aged 6 months-15 years	 With a chronic kidney condition Immunosuppressed individuals Household contacts (aged 12 and over) of an immunosuppressed person 	(Age- appropriate dose)	for a vaccine and receive an invitation Northern Ireland – make yourself aware of your own GP surgery's or community pharmacist's vaccination arrangements and work with them to be vaccinated

Being fully vaccinated can reduce your risk of becoming seriously ill, hospitalisation or death from Covid-19.

You may be eligible for both the flu and the Covid-19 vaccines. If you're offered both vaccines, it's safe to have them at the same time.

If you are taking part in a clinical trial relating to treatments for Covid-19, check with your study team about timing of vaccinations.

Full definitions of clinical risk groups are in the Green Book, Chapter 14a, Table 3 (ages 16 and over) and Table 4 (under 16 years).

PROTECT YOURSELF . STAY CAUTIOUS . SEEK ADVICE







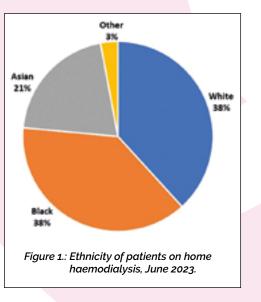


Patient Reported Experience Measure (PREM) of Home Haemodialysis at the West London Renal and Transplant Centre.

by Oshini Shivakumar, Emily Davenport, Neill Duncan, Eden Jeanne Cacal, Sally Punzalan, Normandy Coloma.

Home dialysis allows patients to dialyse in the comfort of their house, in a familiar environment allowing you a degree of flexibility to continue with your regular lifestyle. You have the freedom of choosing your dialysis schedule thereby allowing you to continue with studies, work, or spending time with your loved ones. The recently published GIRFT (Get It Right First Time) report recommends seven actions to support patients to choose home dialysis, thereby encourage you to have control over your dialysis treatment. One important factor to improve our service of home dialysis is feedback of your experience on home dialysis as recorded by tools such as a PREM questionnaire. This study used an adapted version of a such a questionnaire developed by Dr Rivera and his team in Canada.

We approached all patients receiving home haemodialysis in June 2022, then in June 2023 to obtain feedback on their experience at our dialysis centre. Our home haemodialysis population group has grown from 29 to 50 patients over the last 12 months, with slightly more women than men (58% female, 42% male). More than half the patients had been on home haemodialysis at our centre for more than one year. Figure 1 demonstrates that patients on home haemodialysis at our centre come from various ethnic backgrounds. It is important we continue to appreciate and acknowledge cultural differences to remain inclusive of everyone.



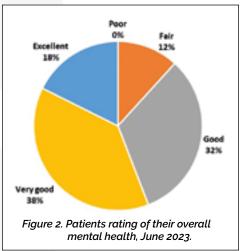
This study revealed a greater number of patients felt the home haemodialysis staff spent enough time with them and listened carefully to them this year (June 2023), compared to last year (June 2022). More than 90% of the patients felt they were involved as much as they wanted in choosing the treatment for their kidney disease that was right for them. More than 90% of the patients felt the kidney doctor made sure that their home haemodialysis treatment plan worked for them. When patients were asked to rate our haemodialysis centre, 89% of patients gave a score of 8 or above, out of 10 last year. Whereas all patients (100%) gave a score of 8 or above, out of 10 this year.

100%	100%
Knew how to	Felt very
take care of their	confident to
dialysis access,	perform their
i.e. Fistula	dialysis safely
or Line.	at home.

We also were able to identify areas for improvement. Although more patients felt they were provided with access to patient support groups this year, this was still around 56% of all patients on home haemodialysis. 85% of our patients reported they 'Usually' or 'Always' received results of investigations arranged by our dialysis unit. We also noted around 9% of our patients felt there was 'Usually' or 'Always' problems with communication among the home haemodialysis staff. Only 58% of our patients reported of good communication between

our dialysis centre and their GP (General Practioner), whilst 30% of patients reported they did not know. This reflects patients with kidney disease generally have a complex medical history and seem to rely more on their renal centre for well-being of general health.

Figure 2 demonstrates that a large proportion of patients on home haemodialysis rated their overall mental health as 'Good', 'Very Good' or 'Excellent'.



In conclusion this study resonates that patient satisfaction is important to sustain a home dialysis programme. This is achieved through good communication, approachable staff, prompt trouble-shooting and patient well-being. Hence, implementing this questionnaire at regular time points provides valuable feedback to improve patient experience and outcome.

Kidney Care UK by Jonathan Bartley – Patient Support & Advocacy Officer

Kidney Care uk

We believe that no-one should face kidney disease alone. For over 45 years we have been committed to improving kidney care services and helping everyone affected by kidney disease. We give you our total support to ensure you can live your life to the full, providing practical advice, emotional support, and financial assistance.

Jonathan Bartley and Ellen Hill, your regional Patient Support and Advocacy Officers, are available to support and represent you, your families, and carers. We can help you with a range of issues relating to kidney disease including treatment options, welfare and benefits, emotional support, and dialysis away from base. As you would expect, our service is sensitive, compassionate, and completely confidential. We will work with you one-toone and if necessary, we can arrange further support offered by Kidney Care UK including our telephone counselling service, money and energy advice service, and financial grants programme. Financial support is available to those on a low income and can help to pay for household items, travel expenses and towards training courses.



Jonathan Bartley

The opportunity to take a break with family can make a huge difference to your physical and emotional wellbeing but can too often feel out of reach either practically or financially. If you are on dialysis and looking to take a break in the UK in the future, we fund the Kidney Care UK Dialysis Freedom service, which can help you plan and organise your dialysis away from base. We can also offer grants to help cover the cost of a respite break or contribute to a family holiday in the UK or overseas.



Ellen Hill,

We continue to work collaboratively with a number of KPAs, through our Hospital Grants Programme to improve patient outcomes by funding improvements to local kidney services. We provide grants for staff posts, projects, and equipment, as well as invest in major renal projects. Some examples of how we are doing this include jointly funding a Youth Worker at Southampton Children's Hospital, with the Wessex KPA; providing a small financial grant to the North Staffordshire KPA to help them set up their new website; and supporting the Tayside KPA to fund a caravan in Scotland that can

be used by kidney patients and their families to enjoy a short break. If you think we can support your KPA with a project, please get in touch.



As part of our work improving care services, we actively support the Kidney PREM, which stands for Patient Reported Experience Measure. This anonymous annual survey is undertaken in partnership with the UK Kidney Association (UKKA, formerly known as the Renal Association) and it is used nationally to look at how care is provided and promote the sharing of best practice. Locally the results help your renal unit understand how their patients really feel about their care, highlighting what's working well and identifying the areas where improvements could be made. Our Patient Support and Advocacy team look closely at the results in their regions and supporting units, KPAs and patients to come together and improve services. If you would like to read more about this year's kidney PREM, go to www.kidneycareuk.org/prem

If you need support, get in touch with us on 01420 541 424, or you can find out more about the charity and our services at www.kidneycareuk.org

3D-printed organs could solve kidney transplant shortage, startup says *Taken from an article written by Thomas Macauley*

first published on www.thenextweb.com October 19, 2023

You can already buy 3D-printed houses, cars, rocket engines and sneakers but can I interest you in a 3D-printed kidney?

t's an offer that Vital3D plans to make a reality. The Lithuanian startup is among a growing wave of companies that want to "bioprint" body parts.

Approaches to the task are varied. In the Vital3D system, lasers precisely deposit living cells and biomaterials in 3D patterns. The company says this creates functional, scalable, and reproducible tissue constructs.

Vital3D believes the tech can bridge the gap between organ demand and supply. It's a gulf that's widening each year especially for kidneys. In the US alone, over 90,000 people are on the kidney transplant waiting list, while only 25,000 actually received one last year.

Bioprinting is a promising solution, but an immensely complex one. The process requires highly specialised equipment, sourcing materials, and medical expertise to replicate extremely intricate anatomy. Kidneys are particularly complicated to recreate. Each kidney contains around 1 million nephrons, which provide the organ's functionality. If the nephrons in both kidneys were arranged hypothetically end to end, they would stretch to a distance of around 16 km.

"To recreate such an elaborate structure, we're often at a crossroads, having to choose between speed and accuracy," said Vidmantas Šakalys, CEO of Vital 3D. "Even the most advanced bioprinters, as of now, may take up to a fortnight for an intricate print, which is hardly conducive for live cells."

In search of a balance between pace and precision, Vital3D developed a patent-pending technology called FemtoBrush.

At the tool's core is a spatial light modulator, which dynamically adjusts the shape of the laser beam. According to Vital3D, this adds "unprecedented versatility" to the process.

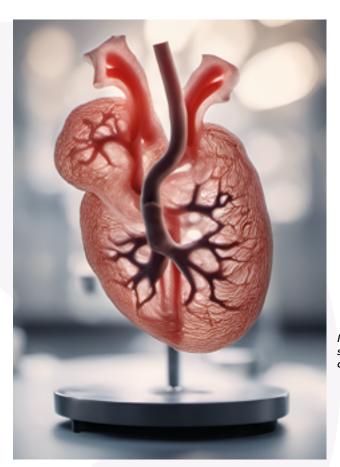




Image generated by AI showing the vascular network of a 3D printed kidney

The system promises precision down to one-thousandth of a millimetre — as well as rapid speeds.

"Our aim with this innovation is transformative," Šakalys said. "We aspire to print the kidney's expansive vascular network, within just a 24-hour period."

Šakalys acknowledges that the tech is still in its nascent stages. Intensive testing will be required to ensure that the organs are both safe and functional. There are also immense regulatory barriers to hurdle.

Nonetheless, the technology is steadily advancing. Bioprinted organs might not be available very soon, but they're making impressive progress in the lab.

Renal Counselling & Social support team

The Renal Counselling & Social Support Team at Imperial College Healthcare Trust are continuing to offer counselling and social support. We are able to see patients for face to face booked appointments in the hospital setting and also offer telephone counselling and social support. We look forward to offering our continued support and assistance to all our patients.

We are aware that for some people the winter months can be a difficult time generally, but for some it can be particularly challenging if they experience a condition known as Seasonal affective Disorder (SAD).

Seasonal affective Disorder (SAD)

Seasonal affective disorder (SAD) is a type of depression that comes and goes in a seasonal pattern. The exact cause of SAD is not fully understood, but it is often linked to reduced exposure to sunlight during the shorter autumn and winter days.

Symptoms of SAD can include:

- A persistent low mood
- A loss of pleasure or interest in normal everyday activities
- Irritability
- Feelings of despair guilt and worthlessness
- Feeling lethargic (lacking in energy) and sleeping during the day
 - Sleeping for longer than normal and finding it hard to get up in the morning
 - Craving carbohydrates and gaining weight
 - Difficulty concentrating
 - Decreased sex drive

For some people these symptoms can be severe and have a significant impact on their day to day activities.

When to see a GP

You should consider seeing the GP if you think you might have SAD and you're struggling to cope. The GP can carry out an assessment to check your mental health. They may ask you about your mood, lifestyle, eating habits and sleeping patterns, plus any seasonal changes in your thoughts and behaviour.

Treatments for SAD

A range of treatments are available for SAD. The GP will recommend the most suitable treatment programme for you.

The main treatments are:

Lifestyle measures – including getting as much natural sunlight as possible, exercising regularly and managing stress levels.

Light therapy – where a special lamp called a light box is used to simulate exposure to sunlight.

Talking therapies – such as counselling and CBT

Antidepressant medication – such as selective serotonin

reuptake inhibitors (SSRIs)



Renal Counselling & Social support team continued

With winter approaching, now is a good time to make sure that you have applied for the financial support you are eligible for. Take the time to go through this ticklist to ensure that you are making the most of what is available.

Water Bills

Discount on yearly charge – Both Thames Water and Affinity water have a low income scheme which can reduce your annual bill by 50%. Call you water supplier and ensure that you receive the discount.

Are you paying extra for water arrears with Thames Water. They have a customer matching scheme which matches the arrears payments that you make. Speak to Thames Water Customer services to see if you are eligible.



Broadband Social Tariff

Broadband social tariffs are not widely advertised but can save you a lot on broadband costs. To qualify you need to be receiving certain government benefits. Jobseekers on Universal credit who don't have an internet connection can check their eligibility for 6 months free TalkTalk connection. Eligibility is determined via jobcentre staff. Speak to your Broadband provider about their social tariff – even if you are on a contract with them.



Medication

Have you checked if you are eligible for free medication? You are eligible with certain conditions or if you have a low income. You can check online here Who can get free prescriptions - NHS (<u>www.nhs.uk</u>) or call the NHS Help with Health Cost Helpline on 0300 330 1343. or call the Medical Exemption Helpline on 0300 330 1341.

If you are not eligible and you have more than 12 prescriptions in a year, consider a Pre Payment certificate. With this certificate, you pay a fixed cost of £31.25 for 3 months or £111.60 for 12 months of prescriptions – no matter how many you have. Apply at www.gov.uk/get-a-ppc



Travel Costs for hospital travel

Hospital travel costs can really add up, especially if you are going to dialysis three times per week. The NHS Healthcare Travel Cost Scheme means that you can claim for the money back for making your own

way to hospital for planned appointments / treatment (public transport). You are eligible if you are receiving certain means tested benefits or are on a low income. Speak to your dialysis units or call the Low Income Scheme Helpline on 0300 30 1343.



You can also claim for a reimbursement of the ULEZ charge. Please note that the charge needs to be paid by you and you can claim for a reimbursement via the hospital.



Freedom Pass / Taxicard / Blue Badge

Do you know that you can apply for these without having PIP? The assessment is based on your ability to walk. While PIP may mean that you have automatic eligibility, any chronic health condition or disability that impact a person's ability to walk means that you can apply. Contact your local council for applications forms or use their website to download them.



Recently stopped work but not eligible for Universal credit?

New Style Employment and Support Allowance is a little known benefit that supports people who are restricted from working due to chronic health or disability. It is based on National Insurance Contributions so it is not means tested and not considered a Public Fund. You are eligible if you have paid enough National Insurance Contributions in the past 2-3 tax years. Apply here New Style Employment and Support Allowance - GOV.UK (www.gov.uk)

If you are in debt, get specialised help. You can contact Stepchange Debt Charity for free expert advice and fee-free debt management. You can contact them on 0800 138 1111 or via their website StepChange Debt Charity - Free Expert Debt Advice.

And finally, two of my favourite places have discounts for people in receipt of means tested benefits.

Kew Gardens is amazing in the winter. They have a fantastic playground for children and it is a great place to leave the hustle and bustle of London. Contact customer services on 0208 332 5655 for more details.

London Zoo are also offering tickets for as little as £3.00/per person if you are in receipt of means tested benefits. These tickets can only be booked online in advance. Essential Carers can get a free ticket. You can book via the link <u>www.londonzoo.org/plan-your-visit/london-zoo-</u> <u>tickets/universal-credit-tickets</u>

Festive Feasting – by Hannah Boot, Specialist Dietitian

Did you know that almost 270,000 tons of food waste is produced over the festive period¹? Planning meals ahead can help dramatically cut down on food waste by knowing what you are going to eat, how much and when, then buying accordingly! And it saves money! So, by being food savvy and planning ahead – you can be food safe as well as eco-friendly!

Here are some top tips for reducing food waste and keeping kidney food safe over the festive season (and save a few pennies).



1. Think about your storage space How many times have you had to throw out food before you've had a chance to enjoy it? Organise your fridge (and freezer) in the run up to the season - dig into the corners of your freezer and have a good clear out! Make space for your purchases and leave space for leftovers from your festive dinner¹. Leftovers can be used to make a festive bubble and squeak or turkey and vegetable sandwiches. Remember if you've had a kidney transplant keep your fridge at 5°C or lower, check use-by dates and ensureto store cooked food in the fridge for no longer than 2 days.

2. Plate up your own meal: Allow everyone to plate up their own meal. Amazingly, just this can reduce food waste¹ but can also allow you to choose your portion size of the potassium rich foods.

 Make use of frozen and tinned foods, and shop in advance
 Frozen sprouts, carrots, parsnips and even roast potatoes can normally be picked up for around £2 a bag from most supermarkets.
 Measure out how much you need for each person and the rest can stay stored in the freezer.

Remember tinned foods vegetables and boiled vegetables will be lower in potassium. And 5 is the magic number with sprouts!

4. Managing your fluids

If you have to limit your fluid, spread your fluid intake across the day and limit salty and spicy foods. A good tip is to use FoodSwitch – a free app that suggests lower salt food options after you scan your food item.

5. Alcohol

You can drink alcohol as part of your fluid restriction. We recommend drinking no more than 1-2 units per day. Drinks like port, sherry, spirits and liquors are lower in potassium than cider, lager and red wine. If you are taking medications and are unsure, check with your doctor or pharmacist.

6. Cheese

Remember if you have had a kidney transplant, we would recommend you avoid soft and/ or mouldy cheeses such as Brie, Camembert, Goats cheese, Gorgonzola, Roquefort or Stilton. Cheese is also high in phosphate so don't forget your binders!

Mental health

Ensure to look after yourself, taking time to relax and do the thing you enjoy. For help managing your mental health and wellbeing consider accessing sites such as NHS every mind matters or NHS approved apps which provide easy practical advice on managing mood, sleep and anxiety³. Additionally, you can check online to see what support your local council offer.⁴



References:

1: Grundig (2018) How much food goes to waste during Christmas and how can we prevent it?. Accessed online at <u>www.respectfood.com/article/how-</u> <u>much-food-goes-to-waste-during-</u> <u>christmas-and-how-can-we-prevent-it</u>

2: Williams, I (2019) How to make Christmas dinner on a budget. Accessed online at <u>www.cashfloat.</u> <u>co.uk/blog/money-borrowing/</u> <u>christmas-dinner-on-a-budget</u>

3: NHS (2020) NHS every mind matters. Accessed online at <u>www.</u> <u>nhs.uk/oneyou/every-mind-</u> <u>matters</u>

4: Gov.uk (2020) Find your local council. Accessed online at www.gov.uk/find-local-council



Our Decorated 2023 Transplant Games Athlete Leon Winsky - By Chetan Joshi

The British Transplant Games (BTG) is a truly inclusive event where all transplant patients are welcome to participate whether they are young or young at heart, regardless of experience. Meet Leon Winsky who, at the age of 76 has two Transplant Games under his belt and an impressive collection of gold medals around his neck!

At a time when many are considering changing gear and slowing down their pace of life, Leon is full of vim and choosing to remain active. I spoke with him about his kidney journey...

Leon suffers from Ankylosing spondylitis which is a form of arthritis that causes chronic spine inflammation. Leon believes this was caused by slipping on wet grass many decades earlier as a teenager. However, it was during a routine visit to the hospital in 2014 when he was first alerted to the early signs of kidney failure. While his eGFR was 60 at the time, it steadily declined over the following years. Leon eventually began dialysis at Northwick Park Hospital in 2018. His veins weren't strong enough for a fistula so he dialysed with a Tesio line.

Following a successful transplant a couple of years later, Leon is now able to indulge in his passion for singing and entertaining while also handling the responsibilities of being a full time carer for his wife who is recovering from

a stroke.

Talking about his BTG experience, Leon was surprised to notice a lack of participants in his age bracket and he'd like to encourage everyone to take part next year. Mind you, with a dearth of competitors in his age aroup, no wonder he's happy to continue adding to his haul of medals! So, to all you shy, armchair athletes out there. consider the gauntlet thrown!

Leon says that he has had a very positive experience at both Transplant Games he's attended and says that the atmosphere is like one big happy family.



It has been another busy year at Northwick Park by Claire Edwards

We have continued to support and train patients in ShareHD and then transition into home dialysis. Some of our superstars have featured in our dialysis video. Get in touch if you have not seen it - it may change your minds about home dialysis!

We have had 7 new international nurses join our team in the past twelve months or so, they bring with them a variety of experience, knowledge and skills and we are delighted to have them join us.

The team has welcomed 3 baby girls so far this year with another due in December - congratulations to Aneena, Joy, Wayne and Nina.

Over the past 6 months we have worked collaboratively with London North West Diabetic Services with the aim of improving patients time in range blood glucose monitoring using the Libre device prior to transplantation. The result of this will be shared in due course and we hope the project will continue & be available to all.

We would like to thank the KPA for their support as ever and wish our patients, families and friends a very happy Christmas and best wishes for 2024.









Join Your Local Kidney Patient Association (KPA)

Supporting Local Kidney Patients & Families



Be part of your local support network

Your local KPA is

West London Kidney Patients' Association

Name: Sarita Khurana

Email: info@westlondonkpa.org

Tel: 07950758305

Kidney Patient Associations (KPAs) provide support for kidney patients on a local level and are members and the council of the National Kidney Federation (NKF).





Support a local Charity this Christmas Christmas Cards 2023



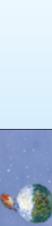
are Royal Mail 'standard All our cards letter' size



Cards are supplied in packs of 10 with envelopes



ww091 x 911 əzis



card sales days at Hammersmith To find out dates for Christmas

secretary@westlondonkpa.org at the end of September

Hospital please email



Christmas List

ww091 x 911 əzis

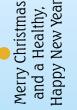
Season's Greetings

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Hungry Hedgehog



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A Festive Spot-the-Difference Puzzle

Can you find the ten differences between these two festive scenes?

(Answers revealed on the website)



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	Postage and Packing	Postag	~	ust tick the box belov	In order to Gift Aid your donation you must tick the box below: I want to Gift Aid my donation to WLKPA.
	Total Cost of Cards		£3.50 up to 6 packs	- N	Postage and packing: £2.50 up to 3 pac £5.50 7-10 packs
		£3.00	01	140 x 140mm	Hungry Hedgehog
		£3.00	01	116 x 160mm	Christmas List
		£3.00	01	116 x 160mm	Golden Trees
		£3.00	10	116 x 160mm	Topiary Robins
Total	No. of Packs	Price per pack No. of Packs	Qty per pack	Card Size	Card Title

Please fill in your name, address, phone number or e-mail All payments should accompany orders. Cheques / P.O. payable to "West London Kidney Patients' Association"

Contact Name

Address

Tel. No. / E-mail (in case of query)

Please return your order form to: -West London Kidney Patients' Association </o SARAH ILIC, 22 Hanger Court, Hanger Green, London W5 3ER Registered Charity No. 275771

contact Sarah on 07988 081295 or email secretary@westlondonkpa.org It you wish to buy any packs of Christmas cards from last year please

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE			
Hammersmith Hospital				
Auchi Acute Dialysis Unit	020 3313 6627			
Pam Sassoa Unit (PIU), Hammersmith Hospital	020 3313 6682			
Renal Dietitians, Nutrition & Dietetics	020 3311 1034			
Renal Home Therapies (HD)	020 3313 6649			
Renal Home Therapies (PD)	020 3313 6647 / 020 3313 6665			
Transplant & Renal Outpatients	020 8383 8333			
Brent Renal Centre, Central Middlesex Hospital, Renal Unit	020 8453 2017			
Charing Cross Hospital , Renal Dialysis Unit, 1 South	020 3311 1752/020 3311 1034			
Ealing Hospital, Renal Unit	020 8967 5737			
Hayes Renal Unit	020 37048 450/020 3704 8444			
Northwick Park Hospital, Renal Unit	020 8869 3245			
St Charles Dialysis Unit	020 3704 6519/020 3704 6510			
St Mary's Hospital, Renal Clinic	020 3312 1267/020 331 22491			
Watford General Hospital Renal dialysis unit	01923 217243			
West Middlesex Hospital Renal dialysis unit	020 8321 2543			

Contact us: info@westlondonkpa.org Or visit www.westlondonkpa.org

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