



kidneytalk

Guy's & St Thomas' Kidney Patients' Association Newsletter

KIDNEY CARE IN A PANDEMIC

Sue Lyon, Chair, GSTTKPA

When we published the last Kidney Talk in spring, I wrote about how COVID-19 was already changing our lives and our treatment. It's now clear that these were not short-term measures: our clinic appointments continue to be by telephone or video; we have had to get used to wearing masks when we visit the kidney clinic or dialysis unit; and hand sanitiser has become a shopping-list essential.

As I write, the risk of Covid-19 is rising again and so we must continue to adapt our lives to lower our risk. This is hard for us all, but we know that we owe it to our fellow patients and to the kidney staff who care for us. We can never thank everyone at GSTT enough for their support in keeping us safe.

At GSTTKPA we have also had to adapt our plans. So we have been holding our Committee meetings online, and this year's Annual General Meeting will also be held online on 28 November. If you would like to join us, please email me at chair@gsttkpa.org

The British Transplant Games is one of the highlights of the kidney year, but sadly, the Games were cancelled for this year, and will not take place again until August next year in Leeds. After some indecision, the much-postponed 2020 London Marathon was limited to elite athletes, who ran a circuit in St James's Park. Other competitors were invited to take part in a 'virtual' Marathon, in which they completed the 26.2 miles alone or with a few friends. Our heartfelt thanks and admiration to our runners who completed this demanding race on our behalf (see back page).

We hope that all competitors will be able to take part in a 'real life' London Marathon in October next year. In the meantime, there is an exciting opportunity to become involved in our very own football team. Inside read how Dr Stuart Deoraj aims to bring Young Adult Transplant Football to GSTT and with Covid safety in mind.

Physical activity is a key lifestyle measure to help control blood pressure, which is in turn an essential part of effective kidney care. Turn to the inside spread for all your need-to-know information about blood pressure, what the numbers mean and why they matter for kidney patients.

At a time when the future looks uncertain, it's important to be aware of pinpoints of

light. Organ rejection after a kidney transplant is one of the major concerns for kidney patients. Mr Pankaj Chandak was one of the winners of the KPA Research Competition, and in this issue he discusses his research that is designed to benefit people at high risk of organ rejection after transplantation.

Research, together with hard-won experience, also means that there is now a great deal more knowledge about managing Covid-19 and it's possible that there may be a vaccine in the reasonably near future. So I end by hoping for a brighter future and sending my best wishes to everyone for a happy and safe Christmas and New Year.

Information about coronavirus

GSTT kidney services

<https://www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx>

Kidney Care UK regularly updated news and information

<https://www.kidneycareuk.org/news-and-campaigns/coronavirus-advice/>

NHS advice

<https://www.nhs.uk/conditions/coronavirus-covid-19/>



In late 2019, we launched our first KPA Research Competition for GSTT kidney staff. In this article, Mr Pankaj Chandak, one of our two winners, describes his project and how his research is designed to benefit kidney patients.

Organ rejection after transplantation is a major problem that can lead to loss of the transplant. Approximately 30% to 40% of patients on the kidney transplant waiting list have antibodies capable of causing immediate rejection. This significantly increases their time on the waiting list and some patients may be deemed un-transplantable. Our study is a science study, which is based on trying to solve the problem with aim of benefiting kidney patients at high risk of organ rejection after transplantation.

Our project involves placing a human kidney (offered to us for research purposes from NHSBT) on to a bypass machine with a pump to circulate

warm blood-based solutions (that is oxygenated) into the kidney. These solutions can be mixed with drugs that coat the kidney's blood vessels to help to protect against the effects of antibodies that may harm the kidney and cause it to reject.

This project has been developing over the last few years under the supervision of Professor Nizam Mamode, Professor Anthony Dorling and Mr Chris Callaghan. The first step was to establish a 'working model' of antibody-mediated rejection (AMR) so that we can see how a kidney behaves and judge its appearance when it undergoes this detrimental process. Such a working model would be vital to

ARE YOU A BLACK KIDNEY PATIENT? POTENTIAL LIVING DONOR? WANT TO KNOW MORE ABOUT LIVING KIDNEY DONATION?

TALK TO BLACK LIVING DONORS AND LIVING TRANSPLANT RECIPIENTS

GOLD

THE PEER PHONE BUDDIES SCHEME is a support scheme launched by GOLD. It aims to encourage black patients to talk about kidney donation with their loved ones. It's also for potential living donors to know more about the living donation process.

Black patients and their loved ones with trained black peer supporters, who all have personal experience of living kidney donation or receiving a transplant. Talking to someone about living donation can be beneficial. It could be the difference between a pre-emptive transplant or time on dialysis.

If you would like to register for the scheme, email: buddy@giftoflivingdonation.co.uk

www.giftoflivingdonation.co.uk

GOLD Launches telephone support scheme

The Peer Phone Buddies scheme from Gift of Living Donation (GOLD) aims to encourage black patients to talk about kidney donation with their loved ones. It's also for living donors to learn more about the donation process.

The scheme connects black patients and their loved ones with trained black peer supporters, who all have personal experience of living kidney donation or receiving a transplant.

To register for the scheme, email buddy@giftoflivingdonation.co.uk

see if adding treatment interventions prevents this process as we would hope that the kidney is protected.

Our preliminary work, thus far, has defined a model which could be used for drug testing against rejection and with the help of the KPA award we can now begin to take this work forward.

Note

The two winners of the first GSTTKPA Research Competition were Mr Pankaj Chandak and Ms Hannah Maple. You can read about Hannah's research in the 2020 spring/summer issue of Kidney Talk (number 23): <https://gsttkpa.org/kidneytalk/>

TRANSPLANT FOOTBALL

A new goal for young adults

By Dr Stuart Deoraj, ST3 Renal Registrar, GSTT

For many people with kidney failure, transplantation results in a better outcome than the significant burden of long-term dialysis. But there are challenges to transplantation. Careful monitoring and management of long-term medications, repeated blood tests and close interaction with healthcare professionals are no small undertaking. Understandably, life can get derailed.

A few years ago, I was involved in the Young Adult Transplant Football Team in Oxford. On the day of the Big Game, a group of young people who had had transplants were out there on the field, getting to know each other, swapping stories, sharing food and playing a match of football with their peers.

For me, I was seeing people who up until that point were 'patients', and it was such an important reminder to me that when they leave the clinic room, they have a whole separate, unique life outside their kidney care. It was easily one of the most wonderful experiences I have had in my medical career and is likely one of the biggest drivers for me entering Nephrology as a specialty with an interest in Young Adult Transplantation.

So we would like to bring the benefits of Young Adult Transplant Football to Guy's and St Thomas'. There are several potential benefits. Putting aside the known advantages of physical exercise, social interaction and involvement help with feelings of isolation, particularly when meeting people who have had similar life experiences. Additionally, it helps to foster an environment where the clinical staff and the patients get to meet and interact outside the consultation and hospital.

Currently, my team and I are in the process of generating recruitment. Before long, we hope to be out on the field, with 30 minute five-a-side games plus pizza and drinks.

Recruitment will involve a meet-and-greet day, a baseline fitness test and outfitting for uniforms. The games will be inclusive for both men and women with a catchment age between 18-30. A pitch and referee will be available, along with paramedic support.

Covid safety

Of course, with the COVID pandemic, safety is paramount. Any pre-game meet-ups will be in clinic, with appropriate isolation and protective gear. Players and anyone attending will be swabbed within 48 hours of the game and expected to shield, and the side-lines will be appropriately social distanced. In the beginning, small practice pitches will be used with three-a-side practice games to ensure we do not go above the required six person meet-ups. We will of course adapt to meet the changing circumstances of the pandemic.

The bottom line is that the group of young people who have had transplants are diverse, amazing people who have had unique experiences and have lives outside the medical world. What troubles me is the idea that this life can sometimes be isolating and highly sheltered. I want to bring something different into that experience.

Anyone interested in joining, please get in touch with the transplant team, or email at youngadult.transplantfootball@gmail.com

We look forward to seeing you.

ORGAN DONATION WEEK 2020

A socially distanced Organ Donation Week (7-13 September) was always going to be a challenge, but all over the UK people went above and beyond to raise awareness.

The theme of Organ Donation Week 2020 was to open up the discussion and get people to talk to their families about their wishes. This conversation is even more important than before, following the change in the law from an opt-in to opt-out organ donation law (see below).

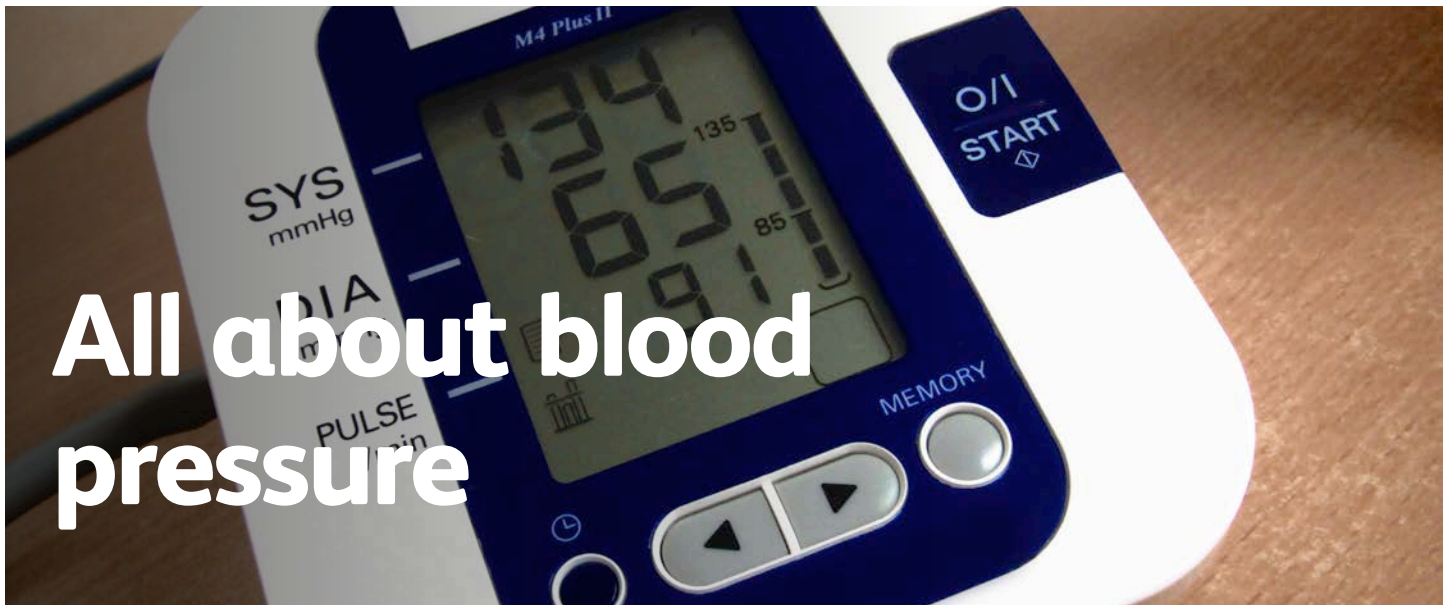
All over the UK, buildings were lit up in pink and social media was awash with support for organ donation. And thanks to the inspiration from the London Organ Donation Team, people walked, ran and cycled to create a heart-shaped virtual map on their smartphones to post on their social media channels. Your GSTTKPA Chair attempted a kidney-shaped walk, which proved quite a challenge thanks to the local street plan!

THE ORGAN DONATION LAW HAS CHANGED

The organ donation law in England has changed to an opt-out system. This works on the understanding that all adults agree to become organ donors when they die, unless they have made it known that they do not wish to donate. If you have not recorded an organ donation decision and you are not in one of the excluded groups (e.g. people who lack mental capacity), it will be considered that you agree to donate your organs, when you die.

It's still for you to decide whether or not you want to become an organ donor, and doctors will always ask your family to support your decision. So whatever you choose, it's really important that you let them know. Your faith, beliefs and culture will continue to be respected.

To register your decision and for more information, go to www.organdonation.nhs.uk



All about blood pressure

As kidney patients, we are very used to hearing about our blood pressure, whether it's too high, too low, or (sometimes) just right. But what exactly is blood pressure and why is it so important in people with kidney disease?

By Dr Ellie Asgari, Consultant Nephrologist, GSTT

What is blood pressure?

Blood pressure is the amount of force that your heart uses to pump blood in your arteries (the major blood vessels in your body). This pressure is measured by millimetres of mercury (mmHg) and has two components. The first is the systolic blood pressure, which is the pressure in the vessels when the heart contracts (or beats). The second is the diastolic blood pressure and this is the pressure in the vessel when the heart is resting before the next beat.

What is high blood pressure?

High blood pressure or hypertension is when blood pressure is above 140 mmHg systolic and 90 mmHg diastolic: 140/90 mmHg. If you have kidney disease your blood pressure should ideally be less than 130/80 mmHg.

How can hypertension be diagnosed?

By measuring your blood pressure. You can do this at your GP surgery, at some pharmacies or by using a blood pressure machine at home.

How common is high blood pressure?

It is estimated that one third of the UK adult population have high blood pressure. In chronic kidney disease (CKD), 60-90% people have high blood pressure, depending on the cause of their kidney disease and how advanced it is.

Why do some people develop high blood pressure?

The cause of high blood pressure is mostly unknown. However, older age, excess weight, eating too much salt, drinking too much alcohol, smoking, a family member with high blood pressure or being from African or Caribbean descent increases your risk. Kidney disease itself can cause high blood pressure as kidneys have a significant role in controlling your blood pressure.

What are the risks of high blood pressure?

Over long periods of time, high blood pressure puts excess pressure on your blood vessels and different organs such as heart, brain, kidneys and eyes. It also increases your risk of cardiovascular disease (CVD), including heart disease, stroke, vascular dementia and peripheral arterial disease (narrowing of the blood vessels in the legs). It also increases the risk of CKD.

What are the symptoms of high blood pressure?

High blood pressure often has no symptoms and that is why it is referred to as a 'silent killer'. Sometimes high blood pressure presents with headache, chest pain, irregular heartbeat or change in vision. In the long term, high blood pressure can cause a significant drop in kidney function and lead to CKD.

How is high blood pressure treated?

Lifestyle changes such as regular exercise, losing weight (if you are overweight), reducing salt in diet, reducing alcohol intake, stopping smoking

Medication: most people with hypertension will need medication in addition to lifestyle changes to achieve normal blood pressure. NICE (National Institute for Health and Care Excellence) has useful guidance on the medication used for high blood pressure (see below).

Why is treating high blood pressure important in CKD?

Kidney disease is a risk factor for CVD and having high blood pressure significantly adds this risk. High blood pressure also increases the rate that kidney disease gets worse. Good blood pressure control reduces the risk of heart attacks and stroke, as well as slowing down the progression of kidney disease.

More information about blood pressure

Guidance from NICE about medication: <https://bit.ly/2JfPrcv>

Advice on choosing a blood pressure monitor from the British and Irish Hypertension Society: <https://bihsoc.org/bp-monitors/for-home-use/>

What shall we eat tonight?

This familiar problem becomes even more difficult to solve if your diet is limited by kidney disease. A new book from celebrity chef and kidney patient Lawrence Keogh aims to put the inspiration back into mealtimes.

Taste! Healthy eating for a modern lifestyle includes recipes for breakfast, snacks, vegetarian and vegan dishes, main courses and sweet treats. The recipes range from the kind of simple food you can make quickly to more elaborate meals for when you have more time.

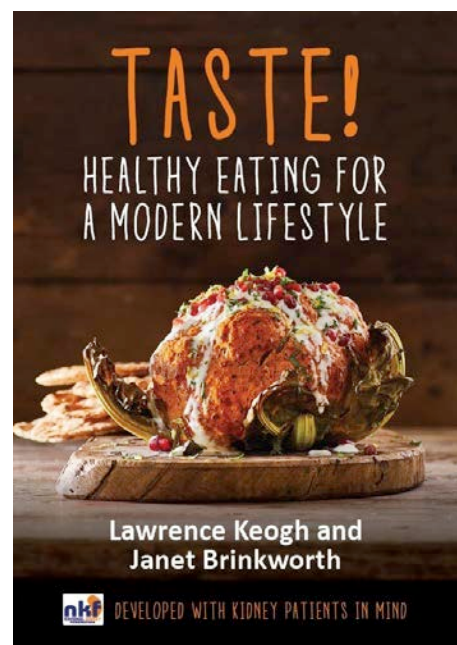
I live alone and, while I want to eat well, I don't want to invest a lot of time in preparing meals just for me. So I prefer recipes that are quick to prepare, and I can really recommend dishes like Salmon with fresh mushy peas, Spanish braised hake (works with haddock as well), and Grilled lamb cutlets with minted vegetable bulgur wheat.

The book has been developed with kidney patients in mind. So all the recipes take account of not only potassium, phosphate and salt restrictions, but also fat and sugar content. Pasta is a great mealtime time standby, but many sauces either contain tomatoes or lots of fat and salt. See right a clever recipe for a deliciously savoury sauce for pasta taken from Lawrence's recipe for Italian meatballs and spaghetti with no-tomato pasta sauce.

You can buy *Taste! Healthy eating for a modern lifestyle* by Lawrence Keogh and Janet Brinkworth from the National Kidney Federation (NKF) for £7.50 (recommended price £15.00): www.kidney.org.uk/shop/nkf-cook-book

Everyone at GSTTKPA was delighted to read that Lawrence has received his second kidney transplant after nearly four years of dialysis.

To read Lawrence's kidney story, go to www.kidney.org.uk/blog/lawrences-story



NO TOMATO PASTA SAUCE

- 1 tsp olive oil
- 500 g frozen roasted Mediterranean vegetables
- 200 g frozen carrots
- 500 g cooked beetroot
- ½ tsp smoked paprika
- 1 reduced-salt vegetable stock cube

1. Set the kettle to boil. Place the frozen vegetables and carrots into a saucepan. Add enough cold water to cover, then set over a high heat and bring to the boil. When the contents of the pan return to the boil, turn down the heat and simmer for 2 minutes, then drain. Discard the cooking water.
2. Heat a large sauté or saucepan until medium hot. Add the oil, frozen roasted vegetables, carrots and beetroot to the pan and stir fry for a couple of minutes.
3. Add the smoked paprika and stock cube, and cook for another minute. Then add 500 ml boiling water. Return to the boil, cover and simmer for five minutes.
4. Carefully transfer to a blender and blitz to a fine puree.

When it's cooled, the sauce can be frozen in portions for when you don't want to cook from scratch. Boiling the vegetables and discarding the cooking water helps to reduce the potassium content of the sauce, but do take into account the potassium in the beetroot.

And remember: every kidney patient is unique, so please check with your dietitian if you are unsure about your own personal dietary guidelines.

Our thanks to the NKF for permission to reproduce the extract from the book.



London Marathon

Ben Moorhouse (right), with friends Adam Francis (left) and Ali Philpott (centre)

On Sunday 4 October, while the elite athletes completed the 26.2 miles of the 40th Virgin Money London Marathon in St James's Park, 45,000 runners from 109 countries ran a 'virtual Marathon', often alone and without the support of fellow competitors and spectators.

GSTTKPA is very grateful to two amazing virtual Marathon participants, who ran for us in these very difficult circumstances:

Ben Moorhouse who has raised a total of £2,840

Tim Arlington who has raised £1,210.

Next year's London Marathon is scheduled to take place along the usual course on 3 October, and both Ben and Tim hope to take part. Our thanks to Julie Griffin and Beth Brown who have also deferred their entries for this year's event.

If you would like to know more about supporting GSTTKPA at the London Marathon, please email info@gsttkpa.org

Mrs Elizabeth Ward OBE 1926-2020

GSTTKPA were very sad to hear of the death of Kidney Care UK's founder, Mrs Elizabeth Ward OBE, who died at the age of 93 on Monday 20 July 2020.

Mrs Ward founded the Kidney Care UK, then known as British Kidney Patient Association, in 1975 when her son Timbo started dialysis. Over more than three decades, Mrs Ward made a huge difference to many thousands of people with kidney disease. She pioneered the very first organ donor card, and set up the first holiday dialysis facilities in the UK and Europe.

Guy's Hospital had a special connection with Mrs Ward because Timbo was a Guy's patient. Subsequently, the British Kidney Patient Association was instrumental in enabling the unit to treat more patients, including children with kidney failure.

Mrs Ward also made an important contribution to the establishment of GSTTPA (then the Guy's Association for Renal Patients). In 1980, a group of kidney patients and families began the slow process of setting up our KPA. Somehow, word reached Mrs Ward and she presented us with a cheque as a start-up fund for our KPA, which was a real boost for morale.

There will be a Thanksgiving Service for Mrs Ward's life when we can meet face to face again.

amazon smile

Join AmazonSmile and help your KPA

Shopping online helps keep us safe during the pandemic, and now you can support your KPA when you shop at Amazon because GSTTKPA has signed up to AmazonSmile.

To shop at AmazonSmile:

- Go to smile.amazon.co.uk on your web browser or activate AmazonSmile on your Amazon Shopping app on your iOS or Android phone (found under 'settings' on your app).
- On your first visit to smile.amazon.co.uk, you need to select a charitable organisation to receive donations from eligible purchases before you begin shopping. In the 'Pick your own charitable organisation' box, search for Guy's and St Thomas' Hospital Kidney Patients' Association and click the 'Select' box on the next page.
- Amazon will remember your selection, and then every eligible purchase you make through AmazonSmile will result in a donation to GSTTKPA.
- On your internet browser, you may also want to add a bookmark to smile.amazon.co.uk to make it even easier to return and start your shopping at AmazonSmile. When you're using the app, always check for the AmazonSmile logo to ensure you're activated for AmazonSmile.

Thank you for your support!

SAVE THE DATE

GSTTKPA Annual General Meeting

Saturday 28th November, 10.00-12.00

We will be meeting virtually by Zoom

For more information and to join the meeting, please email chair@gsttkpa.org