



kidneytalk

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

LIVING OUR BEST LIVES

Welcome to the latest issue of Kidney Talk, the newsletter of Guy's & St Thomas' Kidney Patients' Association (GSTTKPA). It doesn't seem long since the last newsletter, but now the leaves on the London plane trees outside my house are piling up in the road, and we are looking forward to Christmas when we all hope that it will be possible to meet our families for the celebrations.

The Covid-19 pandemic has changed our lives dramatically. One of the most obvious changes has been in the way we meet and communicate. This year GSTTKPA's Annual General Meeting will take place online by Zoom (see back page). In case you have never used Zoom, we have included a short 'how to' guide and we will start the meeting with a short explanation of how to use the technology.

In the meantime, we hope that everyone dialysing at home and in the units, as well as people attending the Advanced Kidney Care Clinic, have received their Kidney Kitchen Calendars. We were very pleased to work with our Renal Dietitians (see inside) and Kidney Care UK to make these calendars available to our members, and hope that you will find them useful. Although my kidney transplant took place some years ago, I still remember the difficulty of sticking to a renal diet, and the calendars feature inviting recipes that show you how to use the foods you can eat to produce delicious meals that everyone will enjoy.

Like our Annual Family Fun Day, the British Transplant Games did not take place this summer. The Games were postponed until 2022, when they will be held across Leeds from 28th to 31st July. This does not mean that the Adult Team have been resting; see inside to find out more about their activities and how you can take part. Unlike the British Transplant Games, the London Marathon went ahead. Many congratulations and thanks to all our runners for their support (see inside).

Finally, we were very sad indeed to say goodbye to Zandria Richards (see inside). A kidney patient and a past GSTTKPA Committee member, Zandria made an impression on everyone she met. She worked tirelessly to improve the lives of her fellow patients, empathising especially with people on long-term dialysis. In short, Zandria shows that, by supporting each other we can, with the help of our kidney healthcare team, aim to live our best lives.

Sue Lyon, Chair, GSTTKPA

Join our mailing list

For more GSTTKPA news

Receive regular email updates from GSTTKPA including the digital version of our newsletter, Kidney Talk, by signing up to our mailing list and registering as a member.

It's easy:

Complete the form at <https://gsttkpa.org/stay-in-touch-with-gsttkpa/>
Or email info@gsttkpa.org with your name, email, and postal address.

GSTTKPA will treat your details in confidence and in accordance with current data protection laws. By submitting your details, you consent to their use as set out in our Privacy Policy (<https://gsttkpa.org/privacy-policy>).

Managing your fluid restriction from a dialysis patient's perspective

Zandria Richard's personal experience of dialysis gave her great insight into the burdens experienced by kidney patients, including in dealing with the restrictions imposed by dialysis. She spoke with great authority and humanity at a National Kidney Federation conference about the challenges of living with a dialysis fluid allowance, sharing practical advice with her fellow kidney patients. She also wrote an article on this topic for Kidney Talk, which we are proud to reprint in her memory.

“Small things done consistently, produce extraordinary results”

For patients on haemodialysis managing your fluid is the most difficult aspect for many of us. In our diet if a favourite food is restricted, we can often find an alternative. However, when it comes to fluid, there is ONLY fluid! In dialysis patients, an excessive fluid intake puts a huge amount of strain on the heart causing it to expand in order to pump the extra fluid around our bodies, and over time enlargement of the heart can lead to heart failure.

A major contributing factor to drinking too much is salt intake. Eat less salt and you will find that you need to drink less. Three quarters of our salt intake comes from processed foods so try to avoid tinned soups, processed meats and 'ready meals', etc.

To help us dialysis patients manage our fluid restrictions, I decided to put together this hints and tips guide:

- Large pieces of ice have less surface area so it's less fluid than the smaller pieces and lasts longer. Wait for it to melt instead of crunching through it.
- Never finish a drink, leave a couple of inches, or throw the remainder away. Alternatively share drinks.
- When socialising, go for a spirit and a chaser rather than a pint.
- Reduce your salt and sugar intake and watch your thirst reduce drastically.
- Larger supermarkets sell small 150mls cans of fizzy drinks - get the fizz without the volume!
- Measure out your total allowance for the day in the morning and keep a record of your entire fluid intake including the hidden fluid in foods.
- Don't leave drinks in arm's reach: 'out of sight out of mind'.
- Buy the smallest cups you can find.
- Urges last seven minutes; try waiting and you may forget you wanted a drink.
- For a special event try and restrict your fluid intake the day before.
- Eat a few grapes or cut up a piece of fruit, bearing in mind your potassium levels or eat sugar-free sweets.
- Avoid foods with hidden fluid such as rice, custards, jellies and soups.
- Eat soup or cereal with a fork instead of a spoon.
- If your mouth is dry, brush your teeth, rather than have a drink.
- Weigh yourself regularly to keep an eye on your fluid gain.
- Create a fluid schedule i.e. a drink after a meal or when taking medication.
- Get physical and keep busy.
- Ask yourself, 'am I really thirsty?'

“No one gets it right all of the time, but the ones who get it right a lot of the time, are the ones who try most of the time.”

More information

You can download a Kidney Care UK leaflet on Managing your fluid and salt levels at <https://bit.ly/3mJjt9E>





THANK YOU Zandria

GSTTKPA members pay tribute to Zandria Richard's, whose death was announced earlier in 2021.

Zandria was a remarkable person, a vibrant and courageous woman, and her passing is a great loss to GSTT kidney patients and the wider kidney community.

Dela Idowu of GOLD (Gift of Living Donation) writes: "The black kidney community pay tribute to Zandria. She campaigned tirelessly and was a passionate advocate for black kidney patients. We want her family and friends to know that Zandria had the chance to make a difference in the world and she did it too! She changed the world of many black people affected by kidney disease. When we die, we can't take anything with us, but we can leave something behind. Zandria left behind a legacy of hope."

A tour de force

Zandria was a tour de force: passionate, capable, and not easy to compromise her beliefs regarding the need for exemplary patient care.

At GSTT, Zandria was instrumental in initiating an occupational therapy programme including art and other activities at New Cross Gate dialysis unit. Although it was postponed by the pandemic, it is hoped that a similar project, supported by GSTTKPA, will be rolled out across GSTT dialysis units.

“Zandria left behind a legacy of hope”

In the wider kidney community Zandria also made a great impact. She was not afraid to use the media to actively promote awareness regarding the feat of staying alive as a long-term dialysis patient—in one instance bringing Channel 4 TV cameras into a GSTT dialysis unit, which sparked further media coverage. Even when she was transplanted, the challenges within dialysis care and her profound identification with patients undergoing this form of treatment never left her consciousness.

Zandria continually tried to provide basic insights into the lives of renal patients, for example, people who are on machines are still sentient individuals. In other words, she helped units (staff and patients) to be less institutionalised and mobilised patients to use their 'voices'. Her belief in holistic patient care, her indomitable focus, and her resources to move on from detractors helped many patients.

Zandria will be greatly missed by her family and everyone who had the privilege of knowing her.



London Marathon

A huge thank you to all our runners

Due to last-minute injuries GSTTKPA had two runners—Ben Moorhouse and Julie Cherry—in the main Virgin Money London Marathon. In addition, Mark Mears ran the Virtual Marathon, completing the 26.2 miles within 24 hours.

We are very grateful indeed to Ben, Julie and Mark for their kindness in fundraising for GSTTKPA:

Ben Moorhouse
£3,076.40

Julie Cherry
£1,643.38

Mark Mears
£1,195.00

Many commiserations to Edmund Quiery, David Hatch, Matteo Congedo and Tim Arlington for having to withdraw for this year's Marathon due to injury, with thanks for 'rolling over' to 2022. Our thanks to Charlie Crawford and Beth Brown for pledging to run the London Marathon in 2022 and 2023, respectively, on behalf of GSTTKPA.

If you would be interested in running a future London Marathon to support GSTTKPA, please contact events@GSTTKPA.org



The Kidney Kitchen 2022 calendar is here!

GSTTKPA purchased Kidney Kitchen 2022 calendars for dialysis (haemo- and peritoneal) and advanced kidney care patients at GSTT. Our thanks to GSTT Renal Dietitians for distributing the calendars.

Produced by Kidney Care UK, the 2022 calendar includes tasty, kidney-friendly recipes with space to note your appointments and reminders. This year's recipes include:

- Red lentil bolognese
- Sweet and sour prawns with basmati rice
- Jam sponge cake
- Pork medallions with apples and mustard
- Spicy cherry tomato pasta
- Nathan Outlaw's baked sea bass with soured veg
- Chicken kebabs with herby couscous salad

- Salad niçoise
- Black bean tacos
- Red velvet cake
- Dal Makhani
- Steamed Christmas pudding

Each recipe includes step-by-step instructions, nutritional information, and world flavours to help you modify each recipe to your individual needs and your taste-buds.

In other words, it's about what you can eat, not what you can't.

Guy's Adult Transplant Games Team

The British Transplant Games had to be cancelled in 2020 and 2021 due to the coronavirus pandemic. The next British Transplant Games are scheduled to take place in Leeds from 28 to 31 July 2022. In the meantime, the Guy's Adult Transplant Team are staying active.

Football Team



The Guy's transplant football team competed in their first major event in September, playing games against other transplant teams, including Nottingham, Oxford, Liverpool, and Team Wales. The Guy's team came third overall in the tournament. This is a great achievement, and the team are eager to continue training, and plan to host friendly games against Team Wales to improve on their success in the next event.

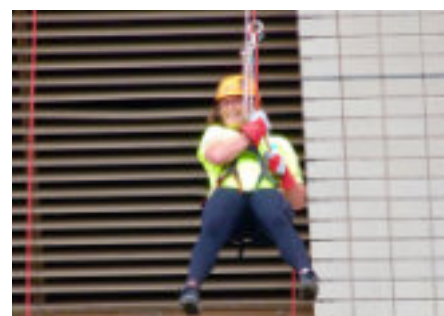
Social Picnic

Also in September, the team held a picnic in the park, with lots of food and drink, and a not-very-competitive game of rounders. The team is planning future events, which will be posted on the team's social media pages.

Fund Raising



The team is busy fundraising to support their activities, and for their contributions Mark Mears and Olivia Bell channelled Spiderman/Woman to complete the St Thomas' Abseil. The pair of daredevils tackled the building on 11 September, maintaining their smiles throughout.



To find out more

If you would like to know more about the Guy's Adult Transplant Games Team's activities, contact guystransplantteam@gmail.com

SAVE THE DATE

GSTTKPA AGM

Saturday 27th November, 10am-12pm

We will be meeting virtually by Zoom.

Our speakers will include:

Mr Benedict Phillips, who will discuss progress in his GSTTKPA-funded research designed to improve outcomes of transplantation

Dr Dimitrios Moutzouris, who will talk about peritoneal dialysis

There will be time for questions.

Join our mailing list (see front page) or follow us on Facebook and Twitter for information on how to join the meeting.

A simple guide to Zoom

If you are unfamiliar with Zoom, here is some advice about this technology.

You can join a Zoom meeting from a desktop computer, laptop, tablet (e.g. iPad) or smartphone. Before joining a Zoom meeting, it's best to download the Zoom app (program) from <https://zoom.us/download>. Otherwise, you will be prompted to download and install the app when you click a 'join' link.

Joining the AGM using the Zoom app

A few days before the AGM, we will circulate a meeting invitation to people on our mailing list. We will also post the information on our Facebook page.

To join from the email details, click on the link in the email. Your web browser (e.g. Chrome, Safari or

Firefox) will open and you will be prompted to open the Zoom app.

Follow the instructions on your screen, providing the password if necessary. Before joining the meeting, you can test your device's audio settings to make sure that they are working.

At the start of the meeting, we will explain all the icons at the bottom of the Zoom screen so that you can take part in the meeting.

More information about Zoom

You can find more advice on the Zoom website. Here you can also join a test meeting to familiarise yourself with Zoom.

Go to <https://bit.ly/3bcM8NW>



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!

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Add the amount.

Send to **70070**

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