



kidneytalk

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

INTRODUCING THE London Kidney Network

The London Kidney Network (LKN) spans all London hospitals (including GSTT) and brings together experts who are all working towards the common goal of improving kidney care in London.



The network is made up of people with kidney disease and their caregivers, doctors, nurses, dieticians, physios and social workers.

The network's purpose is to improve access, quality, outcomes, value and experience in kidney care across London. Within the network there are workstreams dedicated to prevention, young adult care, dialysis, transplantation, supportive care and psychological aspects of chronic kidney disease (CKD). Each workstream is supported by experts in patient experience and health inequalities to ensure that the focus is always on patients and caregivers.

Patient involvement within the LKN

Jemma Reast, who leads the LKN Patient Partnership Group (and is also a GSTT kidney patient), describes her vision for the LKN:

"As Patient Partnership Engagement Lead, it's my job to ensure that, as a network dedicated to bettering kidney care and management across London, we are always reminded of the NHS manifesto that puts patients and the public first – no decision about me, without me".

"While there are many great ideas and plans under way, these tend to be driven by clinical staff, often without consulting or involving the people most affected – us, the patients! Though the LKN already has some patients involved, we are keen to hear

from as many patients and carers – the people with lived experience – as possible.

"Without first knowing and understanding the patient experience (in all its varying forms), how can the NHS design appropriate strategies, solutions, and take steps toward reducing inequalities and improving the standards of care for London kidney patients? There are many ways that we as individuals can have a positive impact to the care that we and others, receive in the future. The LKN hopes to be able to provide easy avenues to do this via our Patient Partnership Group."

How you can get involved

There is an opportunity to make a real difference to the care you and other kidney patients experience in London. There are also training and personal development opportunities available for those involved.

A Guy's kidney patient who is already involved with the LKN concludes: *"It has been empowering and I am learning more about the experiences of myself and the others who are riddled with chronic kidney failure. I have appreciated being able to convey my concerns about the lack of financial and emotional support for transplant patients across other trusts to the steering group."*

To find out more

To join the LKN mailing list or for more information, email Jemma at jemma.reast@nhs.net

Follow the LKN on twitter [@LondonKidney](https://twitter.com/LondonKidney)

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>).



You are a priority

Extra support for kidney patients from the Priority Services Register

News about possible power cuts this winter and all too frequent reports of burst water mains are very worrying for people with kidney disease. So we are reprinting an article from Kidney Talk spring 2019 by GSTTKPA Committee member Nicholas Palmer, explaining how kidney patients can receive extra support from our utility companies by joining the Priority Services Register (PRS).

What is the Priority Services register?

The PSR helps utility companies look after domestic customers who have additional communication, access or safety needs. It helps them tailor their services to support households who may need extra help and is free to join. As kidney patients managing a long-term condition – through medication, dialysis or a transplant and especially those on home dialysis – we fit that bill.

The PSR is available to domestic customers across England, Wales and Scotland only. Please note that PSR registration is not with the supplier with whom you pay your bills. You need to register with each distribution network that delivers, manages and maintains the infrastructure (you need to register with each network individually because they maintain separate registers).

How do you register?

There are a number of ways to register, including calling your providers directly and asking about Priority Services Register. You will be asked to provide your details and the reasons you qualify for the extra support at the point of registration.

What are the benefits?

The benefits the PRS include:

- Alternative water supplies in the event of an interruption
- Alternative heating and cooking facilities in the event of the delivery of your gas being interrupted
- A dedicated number and specialist team to support you and your family during a power cut
- Keeping you safe on the doorstep with the use of passwords and identification badges
- Priority support in the event of an emergency such as a severe weather incident

You can also register for alternative communication such as large-print correspondence or bills or to send these to an alternative contact at your request.

It is also worth contacting your utilities provider to discuss the range of services that might be right for you and your family, as there is a wide range of support available.

More information

For more information about the Priority Services Register and how to register, go to www.kidneycareuk.org/get-support/



A time to remember

The Renal Memorial Service brings together patients, families and staff

The Renal Memorial Service was held in the Guy's Chapel on 22nd September. Having not been able to hold the event for the previous two years, it was a wonderful to be able to meet again in person and remember together.

The Memorial Service is an opportunity for bereaved relatives/loved ones, patients and staff to come together to remember kidney patients who have died. It is chance for us to honour their memory, celebrate and give thanks for their lives.

The event was very well attended and the service, led by Rev Peter Oguntimehin, consisted of readings, poems, hymns, prayers and an act of remembrance. We lit candles and Glenda Baillie, Head of Nursing, read out the names of those to be remembered.

The bereaved and kidney unit staff joined together over refreshments to reminisce, catch up and console. Feedback to the team suggested that attendees found the service both moving and helpful on their bereavement journey.

The renal team would like to extend our grateful thanks to GSTTKPA for again generously supporting this important event.

By Sarah Watson

Clinical Nurse Specialist Renal Supportive Care, GSTT

Loudest and proudest

The 2022 Guy's Adult Transplant Team

The Guy's Adult Transplant Team travelled to Leeds for the British Transplant Games 2022. The team is made up of over 40 transplant and dialysis patients, friends, family and supporters, all connected to Guy's Hospital and the kidney clinic.

Over the course of the weekend, members took part in a variety of events, including table tennis, badminton, swimming, cycling, archery and athletics.

On Thursday, the Team attended the opening ceremony, which saw teams from around the country representing their hospitals for the start of the events. This was a great opportunity to meet old friends and new, after a two-year break due to Covid.

On Friday, events kicked off with the table tennis, with Guy's being represented by six competitors. After an entertaining series of matches by our members, Guy's Team placed Bronze in Men's 18-29 (our first medal). We also had competitors participating in Bowling, Cycling and Golf warm up, where our medal tally continued to grow.

On Saturday, the team supported each other in Badminton, Football, Golf, Swimming, and the 5K runs. Our medal tally grew, two pairs walking away with silvers in different age categories in Badminton, a bronze in Golf, two golds for the men and women's mini marathons, and a sweep in swimming with two gold, two silver and two bronze in men and women categories.

Many of team also participated in the Donor Run through the city of Leeds, celebrating the gift of life and the sacrifice made by many families. One of our team members stood out, dressed in a neon green ensemble—wig and tutu included!



Sunday, the last day of the Games, the whole team got together for Track & Field. Our competitors smashed the completion, taking part in Long Jump, Discus, Shot Putt, Ball Throw to name a few.

As well as cheering for our team members, we got to properly see and cheer on the Evelina VIPs, including some of the Young Adults that will be joining the Guy's Team for next year's Games.

The final event of the Games was the Relay. We put forward two teams to participate, and we were totally blown away by the speed of our team!

For us, the Games isn't about winning medals, it's about the friendship and support, but we are immensely proud of our team, who smashed it out the park with an incredible:

14 Gold Medals
7 Silver Medals
9 Bronze Medal



We're immensely grateful for the continued support the team receives from GSTTKPA. Many members have stated that access to the Games could not happen without this support and funding.

The team continues to grow with new members joining from the Evelina, on social media and through constant conversation in kidney clinic. The year is not over, with social and sport events running to the end of the year, and then leading up to next year's British Transplant Games in Coventry.

If you'd like to hear more about the Guy's Adults Transplant Team, its social and sport events, or participating in the British Transplant Games next year, please email Team Managers George Newman and Oliver Crawley at guystransplantteam@gmail.com or message on Instagram at [@guystransplantteam](https://www.instagram.com/guystransplantteam).



A Transplant Games to remember

Evelina VIPs make an impact at Leeds 2022

Twenty-two Evelina London VIPs have returned triumphantly from the 2022 British Transplant Games in Leeds. We are so proud of the team, who took part in 17 sports across four days and brought home 38 medals and the Best Kidney Children's Trophy.



The VIPs are so called as they are very important people, patients and importantly Penguins (transplant clinic is in the penguin zone at Evelina London). As we know, the last few years have been incredibly difficult, with uncertainty, fear and isolation. For children and their families transplanted since 2020, isolation was severe with no opportunity for meeting other children, siblings or parents. It meant this year's Games, the first since 2019, were hugely significant to them.

The first hurdle was a national train strike on travel day, however with additional planning we made it to Leeds on time. One of our Transplant Consultants Dr Nick Ware decided against travelling by train and incredibly cycled to Leeds with two of our VIP fathers Tim Stevens and Sheldon Crosby, a total of 386km, raising vital funds for our team!



We stayed at the Holiday Inn, Brighouse, and the team there treated us like the VIPs our children are. A life-size penguin greeted us as we arrived! Throughout the hotel, penguin decorations, messages and games appeared daily – the hotel team were fabulous!



The Opening Ceremony took place in Millennium Square and it was wonderful to see and hear teams from all over the UK cheering very loudly! We were delighted to see so many Evelina London parents in the Live Donor Team.

On Saturday evening 100 of us took part in the Organ Donor Run. This event was a fun way of spreading the continued importance of organ donation message and getting colourful for Evelina London. It also gave us an opportunity to get sponsorship for Games 2023! We said au revoir to three Evelina graduates Kelsey, Rian and Saakshi, who between them had competed at an incredible 27 Games.

We have a lot of people to thank, particularly our 11 wonderful volunteers who never stop. We are so very grateful for the long-term support of GSTTKPA, Kidney Care UK and our primary sponsor the Evelina London Children's Charity. Without all of your support we would not be able to facilitate this vital peer and family support, away from our hospital environment.

Here's to Coventry 2023 and our continued Support through Sport!

By Grainne Walsh

Paediatric Advanced Nurse Practitioner,
Transplant Team, Evelina London

SAVE THE DATE

GSTTKPA AGM

Saturday 26th November, 10am-12pm

Due to rising cases of Covid-19, we have decided to hold the meeting by Zoom again. We'll share the Zoom link on our Facebook page, in the Guy's kidney clinic and with our mailing list.

To join, visit <https://gsttkpa.org/join-the-gsttkpa/>

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>

Help with money worries

More and more people, including many people with kidney disease, are worried about the rising costs of food and energy. Several organisations are offering free, confidential advice about money.

Kidney Care UK has introduced an online Benefits Calculator to help you find out about the benefits you may be able to claim. The Calculator takes about 10 minutes to complete, is free to use, and the details you provide are anonymous.

The Benefits Calculator and other advice on making your money go further is at www.kidneycareuk.org

Community Money Advice Centres help thousands of people, from all walks of life, take back control of their finances by providing free, fully confidential advice and practical support.

For your nearest centre, go to: www.communitymoneyadvice.com

Citizens Advice provide free help and advice with the cost of living, benefits and bills, and debt advice.

Visit www.citizensadvice.org.uk

National Debtline host a cost-of-living hub and provide free, independent advice about becoming debt free.

Call for free telephone advice on **0808 808 4000** or webchat with an advisor at www.nationaldebtline.org

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Because of you

Celebrating Black living kidney donors



Inspirational, educational, and informative were just some of the words echoed by African and Caribbean kidney patients who attended the Because of You lunch to celebrate Black living kidney donors, thanks to GSTTKPA.



Photograph by AMC Media

The theme for the lunch was 'My proudest moment', and family, friends, donors and healthcare professionals all shared their proudest moments of living donation.

At the lunch, patients heard moving and heart-warming stories from living-donor recipients on how their lives have been transformed. Colins, a patient who attended the lunch, said: *"The lunch inspired hope for many Black patients, and it was wonderful to speak with Black patients who have been on the same journey as mine, but who are living better quality lives because of living donation."*

Dela Idowu, founder of Gift of Living Donation (GOLD) and host of the lunch, said: *"It was great to be back after two years to celebrate our community of Black living donors. Being a living kidney donor is an amazing and incredible thing to do as it transforms a person's life, and as a community it is important that we recognise and appreciate that."*

This year's lunch was extra special as we invited Black kidney patients to meet and chat with Black living donors and recipients."

The informal and relaxed environment, with light entertainment and a scrumptious six-course African-Caribbean buffet, provided the perfect setting for patients and their loved ones to hear about living kidney donation from people with lived experience from their own community. It could empower them to make an informed decision about living donation – and in one patient's case it did just that!

The lunch also gave Black patients from GSTT the opportunity to say a final goodbye to one of their much-loved kidney transplant surgeons, Professor Nizam Mamode, who recently retired from the Trust. As one of the keynote speakers, he joked after hearing the Black living donor choir sing on their debut performance that if he had not retired, he would join them!

Congratulating the living donors for making a difference in the lives of others, Professor Mamode commented that their community needed to hear these inspirational stories to encourage more Black people come forward as living donors. He commended the peer phone buddies and their support to Black patients who wanted to know more about living donation.

Carleen Kerr of GSTT kidney clinic also congratulated the living donors for their contribution to organ donation and transplantation. She highlighted the peer buddy scheme as a resource where Black patients could get education and information on living donation from their own community. She ended with a passionate speech, saying that the Black community must be the change they want to see.

One lucky patient from GSTT won tea for two at Harrods in the raffle draw. As the event ended, patients, living donors, loved ones, friends and special guests danced the evening away to the afrobeat sounds of Burna Boy, new friendships were made, numbers exchanged, hope ignited and the promise to be back next year!

GOLD is passionate about improving health outcomes for black kidney patients and would like to thank GSTTKPA for making it possible for Black kidney patients to attend the lunch.

If you would like to know more about GOLD and the phone buddy scheme, visit www.giftoflivingdonation.co.uk

London Marathon

Thank you to everyone who ran the London Marathon on behalf of GSTTKPA: **Richard Harper, Edward Norton, Rocco Profet, Matteo Congedo**, and very special thanks to mother and daughter team **Clare Barron** and **Isobel Barron**, who raised a fabulous £5,152.

Anna Gilbert-Duggal had to withdraw from this year's London Marathon due to injury but had already raised £650 and will be running for GSTTKPA next year. Unfortunately, Thomas Nuttall had to withdraw shortly before this year's race due to being struck down

by Covid but had already raised £921 and will also be running next year.

Finally, a big thank you to Arti Promotions, www.artipromotions.com, who supplied all GSTTKPA's personalised running tops

If you're inspired to run next year's TCS London Marathon (23 April 2023) on behalf of GSTTKPA, please apply at www.crunch.org.uk/gsttkpa