



kidneytalk

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

GSTTKPA welcomes new pharmacy arrangements

As many readers will know, all renal and transplant prescriptions are now being dispensed from the Lloyds pharmacy in the Harrison Wing at Guy's Hospital. This change in location follows reports by GSTTKPA members of overcrowding and long waiting times at the general outpatient pharmacy on the ground floor.

The change in location applies only to people dropping off their prescriptions or picking up their medicines from Lloyds pharmacy at Guy's. There is no change to transplant homecare medicine deliveries from Sciensus.

To find the new pharmacy location, use Lifts or Stairs C to go to the second floor and follow signs for the Harrison Wing.

The new telephone number for the pharmacy is **0207 403 2988**.

We are very grateful to Renal Pharmacy and Directorate staff who helped make this change for kidney patients at Guy's. If you have any questions about the new service, please email: **RenalPharmacists@gstt.nhs.uk**.

Lloyds Pharmacy opening hours

Weekdays: 9am-6pm

Wednesday: 9am-8pm

Weekends/Bank holidays: Closed

Outside these hours only urgent renal and transplant prescriptions will continue to be dispensed in the main ground floor Lloyds outpatient pharmacy.

True care at Lewisham

Congratulations to Lewisham Dialysis Centre for winning the Diaverum True Care ward.

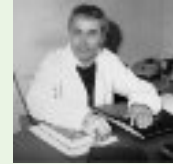
Lewisham Dialysis Centre is based in University Hospital Lewisham and opened in 2019. It has 20 dialysis stations and replaced the smaller unit at Forest Hill. The unit is operated by Diaverum in partnership with GSTT.

According to the Diaverum citation, the Lewisham Dialysis Centre received the True Care award "for its exemplary team

ethic, dedication to patient education and collaborative ethos that contributed to them being awarded the highest possible rating of 'Excellent' by the UK's independent healthcare regulator, Care Quality Commission (CQC)."

Launched in March 2022, the Diaverum Awards celebrate exceptional examples of the company's True care culture, spanning five specific categories.

To find out more, visit <https://tinyurl.com/2t62ttna>



Professor Stewart Cameron

5 July 1934-30 July 2023

GSTTKPA was very sorry to hear of the death of Professor Stewart Cameron. Professor Cameron founded and led the Guy's kidney department, and was an international leader in the field of nephrology. Guy's patients will remember him as a brilliant kidney doctor and a kind supporter of the KPA. We send our sympathies to Professor Cameron's family and friends.

For an appreciation of Professor Cameron, go to <https://ukkidney.org/obituary/john-stewart-cameron>

Join our mailing list

Receive 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/>

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>).

More success for the Guy's Adult 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.

This year saw the largest adult team from Guy's Hospital ever - made up of 54 members, including 23 patients and 6 donors. Our team competed in a huge number of events, and gave it their all, walking away with a new team medal record!

13 Gold Medals
16 Silver Medals
10 Bronze Medals

But the Games aren't all just sports - there are also some great social events! On Thursday night, we had a team dinner after the Opening Ceremony, where old and new friends connected. We welcomed the five new families joining the team, including three families who had graduated from the Evelina Children's Team.

On Friday night, the team headed to the Darts Social, dressed up for the 'Loud Shirt Night' theme, which was in remembrance of members of the transplant community who are no longer with us, and altruistic donors. Some great entertainment as Matt B got through to the semi-finals and the whole team was behind him cheering him on!

On Saturday, we had 23 members participate in the annual Donor Run. This year featured a 7 foot T-Rex and the new Guy's Team mascot, an 11-week old cocker spaniel puppy called Honey. Not only that, Vicky also did a sponsored Donor Run and has raised £620 for GSTTKPA and Guy's Adult Team - well done, Vicky!



Vicky on her sponsored Donor Run

Sunday night was the Gala Dinner, where the team dressed to impress and said a final farewell as the weekend ended.



Dressing to impress

The team has left the British Transplant Games with a huge sense of community spirit and pride - the team group chat is filled with jokes, memes, messages of support and celebrations for kidneyversaries, a recent transplant, and an announcement that one patient's family that will have a new member in December. There is even talk of starting a Guy's Transplant Team Book Club!

The Guy's Adult Transplant Team is incredibly grateful for the continued support of GSTTKPA. We hope to continue to work and support the KPA with their social events, fundraise and connect patients with their services, as well as inviting more patients to join the Guy's Adult Team.

The Guy's Team isn't just a sports team - it's a community of people with lived and shared experiences, who lift and celebrate the great moments, but are there to support in the bad ones. If you're interested in finding out more about Guy's Transplant Team and how you can get involved, or even join us at next year's British Transplant Games, please email team managers **George Newman** and **Oliver Crawley** at guystransplantteam@gmail.com and follow us on **Facebook**, **Instagram** (@[guystransplantteam](https://www.instagram.com/guystransplantteam)) and **Twitter** (@[guystxteam](https://twitter.com/guystxteam)).

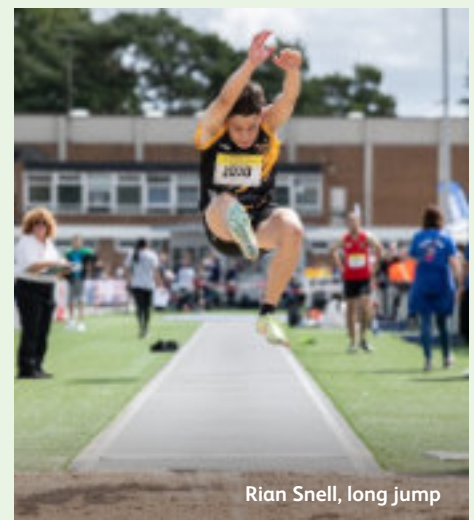
The Snell Family at the Games with Guy's Adult Team

Matthew and Karen, Transplant Parents and Live Donor

Having been with the Evelina VIPs since 2009, the thought of our son transitioning into the Guy's Adult Team initially felt very daunting for both him as a competitor and us as supporters.

However, the support we all received from everyone in the Guy's Adult Team meant our overall transition was seamless and felt so natural. Vital connections were made during our final year with the Evelina VIPs, the sensitive approach from the Guy's Team managers ensured that we were fully aware of what to expect and their additional detailed knowledge of the event was excellent.

Representing the Guy's Transplant Team was an absolute honour. We were welcomed, supported, loved and wholeheartedly felt part of the amazing family that is Guy's Team.



Rian Snell, long jump

Rian Snell,
Transplant Recipient

Coventry 2023 was outstanding, thank you GSTTKPA for your support, which enabled me to realise my dreams, inspiring others, to share the word about Organ Donation while celebrating my own wonderful gift of life, alongside my organ donor, my mum, my hero.



Triumph for the Evelina VIPs

Thirty-five children with transplants and their families represented Evelina London Children's Transplant at this year's British Transplant Games, held in Coventry at the end of July. We were definitely seen and heard, as we all together numbered 170 people!

Children's transplantation is rare. Currently there are approximately 800 children living with a kidney transplant in the UK, with around 90 of those cared for at Evelina London. Children will often have to travel long distances to clinic, which can make it difficult for families to attend events/support at the hospital. The Transplant Team at Evelina London call the Transplant Games 'Support Through Sport', as we facilitate much-needed support away from the hospital. What begins as support often develops into lifelong friendships and it's wonderful to see families co-ordinate appointments so they can meet up during the year.

Very Important Penguins

We VIPs are known as the Very Important Penguins because our Transplant clinic is in the Penguin Zone of Evelina London Children's Hospital. The wonderful team at DoubleTree by Hilton Hotel in Coventry were incredible! They turned their hotel into a Penguin Colony for our stay, which was so appreciated by us all. Everywhere we looked there were penguins, including a staff member, who dressed up as a penguin and volunteered as a judge in our team talent show and danced the night away during our Gala disco! We are so grateful to the team there for helping us make special memories.

The opening ceremony was held in the centre of Coventry and we lined up for the parade in the atmospheric ruins of the old cathedral. We featured on the BBC

news, in our wonderful new fluorescent orange team gear! The competitors were joined by members of the Donor Family Network and live donors at the opening ceremony – always an emotional time.

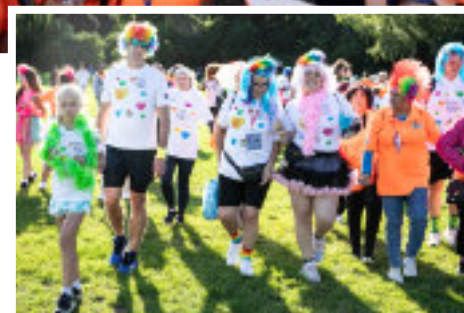
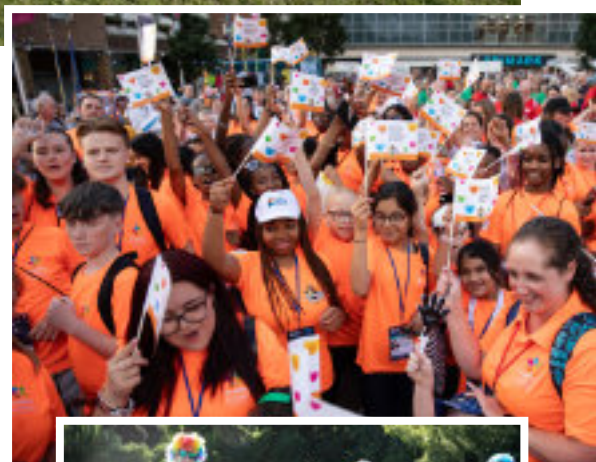
One hundred and fifty of us took part in the Organ Donor Run during the Games weekend. This fun run aims to highlight and thank organ donors, and it was great to dress up and really celebrate what organ donation has done for our VIPs and their families – a real celebration of life.

Our VIPs aged from 5 to 17 years competed in multiple events including archery, swimming, cycling, and a whole range of racquet and track & field events. They scooped 45 medals, which was fantastic, and were awarded the National Best Kidney Kids Team award.

We celebrated five VIPs who were graduating to the adult clinic and whose final children's Games this was. We really hope to see them compete with the Guy's Adult Team at next year's Games. It was great the adult team managers had come to meet these young people at one of our team events earlier this year.

A big thank you

The Evelina London Children's Charity is the major sponsor of our team. They have recognised how important the Games are to our children, who will be patients for life, and their families and have ensured we have their future support, having awarded



us a multi-year grant this year. We are so very grateful!

We are also very grateful to you, our Friends at GSTKPA, for your ongoing support of the team and to our friends at Kidney Care UK for their long-term support. The Games do not come cheap and we never want money issues to prevent a child and family from joining the team and experiencing the amazing experience the Games offer.

As we recover from this year's adventure we look forward to next year's Games, which will be held in Nottingham in August 2024.

By Grainne Walsh
Paediatric Advanced Nurse Practitioner,
Transplant Team, Evelina London

Photography Damien Argi



Keep moving with Kidney Beam

We are all advised to keep active to improve our wellbeing, but this can be especially hard if you are living with kidney disease, its symptoms and treatments. Kidney Beam is here to help.

Kidney Beam is an online resource, where you can access fun exercise that's tailored for you and your health needs.

You can exercise along with on-demand classes at a time that suits you, or join a live class that allows you to interact with the instructor and other Beam members. Or, if you need extra motivation or interaction, you can join a group where you can connect with physiotherapists, instructors and other

people living with similar challenges.

If you haven't been active for a while, it's best to check with your doctor, nurse or physiotherapist that Kidney Beam is right for you.

Kidney Beam is free to join for people with kidney disease at GSTT. It's subscription service, so you'll need to set up an online account.

Find out more at <https://beamfeelgood.com/home>

SAVE THE DATE

GSTTKPA AGM

Saturday 25th November
10.00am-12.00pm

We have decided to hold our Annual General Meeting online this year.

We'll share the link on our Facebook page, in the Guy's kidney clinic and with our mailing list.

2023 FAMILY FUN DAY

Back – and better than ever

After an absence of three years, GSTTKPA was delighted to hold our Annual Family Fun Day on Sunday 16 July at King's College Sports Ground at Honor Oak Park

It was wonderful to see so many of you there, and we hope you had a wonderful time. Thank you to all the volunteers who made Fun Day possible, to GSTT staff, Patient Transport, and of course to the staff of King's College Sports Ground.

We hope to see you next year!

DONATE

Donate to the KPA by text:

enter code **WGJ22**

Add the amount.

Send to **70070**

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www.justgiving.com