



kidneytalk

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

SUPPORT FOR YOU AND YOUR FAMILY

Welcome everyone to the latest issue of **Kidney Talk**, the newsletter of **Guy's & St Thomas' Kidney Patients' Association (GSTTKPA)**.

It's hard to believe, but the kidney unit recently celebrated 50 years of transplantation at Guy's & St Thomas' (GSTT). In the last five decades, over 7600 transplants have been carried out at GSTT and so many lives have been transformed including my own. Over the years, the transplant unit has had a record of innovation, including the UK's first kidney transplant using robot-assisted keyhole surgery and a groundbreaking HIV to HIV kidney transplant. You can find out more about these achievements overleaf, where Mr Benedict Phillips writes about other advances, including research supported by GSTTKPA, that is designed to help more people receive and keep a kidney transplant.

As I write this article, the sun is streaming through the window and the weather app on my phone tells me that it's 23°C outside. So it looks like summer really is on the way. The warmer weather brings much to look forward to, including GSTTKPA's annual Family Fun Day on Sunday 9th June. Your Committee has been hard at work organising this event and, while we can't predict a repeat of last year's glorious weather, we can promise a fun afternoon for everyone. See the back page for more details.

However lovely the weather and whatever the time of year, we know that the

challenges of kidney disease continue, but help is available. Did you know, for example, that kidney patients are eligible to receive extra support from the utility companies? Inside this issue, Nicholas Palmer of Kidney Care UK outlines the benefits of joining the Priority Services Register and how you can register free of charge.

Learning that you need to dialyse is life changing, affecting not just you but your whole family. Daily living, work and social life can all too often be an on-going battle, and those hours on dialysis can seem very long indeed. On the back page, Lisa Ancliffe writes how occupational therapy can help you to cope, and about her plans to set up an 'art on dialysis' initiative with support from GSTTKPA. Do get in touch with Lisa if you would like more information on occupational therapy or her project.

It would not be possible for GSTTKPA to support projects like 'art on dialysis' or to offer the Fun Day without our brilliant fundraisers, including the wonderful people listed in this newsletter who are running on our behalf in the London Marathon. There will be a full report on the Marathon in our next issue. In the meantime, heartfelt thanks to all our supporters.

Sue Lyon, Chair

SAVE THE DATE

5th Family Fun Day

Sunday 9th June
1.00pm to 5.00pm
King's College Sports Ground
Brockley Rise/Stillness Road
London SE23 1NW

British Transplant Games

25th-28th July, Newport, Wales
If you are interested in taking part in the Games, please contact Simon Bessant, Guy's & St Thomas' Adult Team Manager
(simon_bessant@hotmail.com)

Organ Donation Week

2nd-9th September

GSTTKPA Annual General Meeting

Saturday, 30th November,
10.00 am to 12.00 pm
Burfoot Court Room
Guy's Hospital

KEEP IN TOUCH WITH YOUR KPA




Visit our new website at gsttkpa.org to read the latest issue of **Kidney Talk** and sign up to receive KPA news direct to your inbox.

Join our Facebook group [facebook.com/groups/gsttkpa](https://www.facebook.com/groups/gsttkpa)

Follow us on Twitter
[@GSTTKPA](https://twitter.com/GSTTKPA)

MY TOP FOUR

The latest transplant research



Professor Nizam Mamode and Mr Pankaj Chandak experimenting with laser-beam technology to assess kidney blood flow

Every year the UK's kidney doctors and nurses come together for the British Transplant Society meeting when we look at the achievements of the past year, and our hopes for the year to come. It is also a great opportunity to showcase some of the research advances from Guy's and St Thomas' Trust. I continue to be in awe of these advances and our contributions, which are making real improvements to our patients' lives.

HERE ARE MY TOP FOUR ADVANCES IN TRANSPLANT RESEARCH FROM OUR HOSPITAL

NUMBER 1: Warm kidney perfusion

Traditionally after a kidney is donated, it is stored in ice before it is inserted into the new recipient. For the last 60 years this has been a good way of ensuring the kidney stays viable while we get ready to do the transplant operation. However, kidneys stored in this way can be a little slow to 'wake up' after the operation, and some people still need a few sessions of dialysis until the kidney starts working. Keeping kidneys warm may be a way of reducing 'sleepy kidney'.

We have therefore been trialling a machine that pumps kidneys with oxygen and blood at body temperature (known as ex vivo normothermic perfusion; EVNP). This research is being led by Mr Chris Callaghan, consultant transplant surgeon. Research into this alternative form of organ storage has been funded by GSTTKPA, and so far about 50 GSTT patients have received kidneys using this new technology. We are so grateful to everyone who has volunteered for this research at the time of their transplant and we look forward to letting you know the results soon!

Bexley Rotary Clubs have joined forces to raise money to fund a second EVNP machine for Guy's transplant unit. If you would like to support this appeal, visit the crowdfunding page at <https://www.justgiving.com/crowdfunding/brian-ward>

NUMBER 2: Monitoring blood flow in kidney transplants

After the transplant operation, the doctors and nurses have to make sure that the blood flow to the new kidney remains strong. An ultrasound scan is requested whenever we need to check that the kidney is receiving plenty of blood.

Our research fellow Mr Pankaj Chandak has been developing a new probe that will provide live, real-time information on how much blood the transplanted kidney is receiving. This probe will sit next to the kidney after the operation and alert the team if blood flow goes down. Early diagnosis of poor blood flow will allow us to fix the problem quicker. It should also reassure the surgeon and patient when the kidney is doing well. Pankaj is working hard to get this new technology ready for patients in the next few years.

NUMBER 3: HIV-positive donors

Previously, HIV-positive people could not donate their kidneys. Given the shortage of kidneys, could these people be considered for donation to recipients with HIV? With promising results from South Africa, Guy's Hospital embarked on the challenge of finding organ donors with the same subtype of HIV as potential recipients. All the necessary approvals were gained, and Guy's became the first UK centre to transplant kidneys from HIV-positive donors. With more kidney donors, this is one strategy to reduce the transplant waiting list.

NUMBER 4: Robotic kidney transplantation

Sounding like something out of a science-fiction movie, surgeons at Guy's are using a robot to both remove a kidney from the donors and transplant it into the recipient. Using a 3D camera, the surgeon controls four robotic arms to perform the operation. The value is faster patient recovery, as it is a less invasive form of surgery. Professor Nizam Mamode, lead transplant surgeon at Guy's Hospital, became the first in the UK to transplant a kidney using the robot. As our experience grows, more patients may benefit from this novel technology.

The team at Guy's and St Thomas' will continue to try and improve the care we give, and we thank GSTTKPA for their ongoing support.

By Benedict Phillips
Clinical Research Fellow,
Specialist Registrar in Transplantation,
Guy's & St Thomas' NHS Foundation Trust

Caring for your fistula or graft at home

This article explains how to care for your arteriovenous fistula (AVF) or arteriovenous graft (AVG) at home, and applies to all kidney patients with these types of haemodialysis (HD) access. If you have any further questions, please speak to your kidney care team.

What is an AVF?

To form an AVF, a surgeon connects an artery (a vessel transporting blood from the heart around the body) directly to a vein (which takes blood back to the heart). This is usually done at your wrist or elbow, and causes more blood to flow through the vein. As a result, the vein grows larger and stronger. This makes it possible to repeatedly insert the needles needed for HD.

What is an AVG?

To form an AVG, a surgeon inserts a piece of synthetic tubing under the skin to join the artery and vein. This makes it possible to repeatedly insert your needles during HD.

Looking after your AVF or AVG

- Check daily for a 'buzzing' sensation known as a 'thrill'. This 'thrill' is caused by the high flow of blood through the fistula or graft, and is a sign that it is working well. If you do not know how to check for the 'thrill', please ask the nurses looking after you. If you cannot feel the 'thrill', let your nursing team know straight away.
- Never let any health professionals take blood from your fistula or graft arm. Blood should always be taken from the veins on the backs of your hands. Please let staff know when you having blood taken.
- Never let anyone check your blood pressure on the fistula or graft arm.
- Do not wear any tight sleeves or watches that may restrict the flow of blood through your fistula or graft arm.
- Be careful not to lie on your fistula or graft arm.
- Do not loop shopping bags over your fistula or graft.
- At the end of dialysis, your needles are removed and a plaster will be placed over the needle site. This plaster can be removed later in the same or the next day. Occasionally the fistula or graft may bleed a little. If this happens, apply pressure and the bleeding should stop. If the bleeding does not stop, please contact us immediately (please see advice below for heavy bleeding).

What should I do if I have a problem?

Once you are having dialysis and your fistula or graft is being needled, complications can occasionally develop. Report any changes to your dialysis nurses promptly so they can assess your fistula for you:

- Bruising or swelling: this can occur due to the needle piercing the wall of the fistula or graft. This is less likely to occur as the fistula or graft matures.
- Infection: report any redness, pain, swelling or heat around your fistula or graft.
- Aneurysm: this is a swollen area that can develop over time, and can be due to the needles being put in the same area. You or your nurses should rotate your needling sites, if possible, to help avoid this. If your skin becomes thin or shiny or you can see a pulse under the skin in the aneurysmal area, please tell the dialysis nurses immediately.
- Allergies: if your fistula or graft becomes red or itchy after applying anaesthetic cream or following cleaning or dressing application.
- Steal syndrome: this is due to a reduced blood flow to your hand, and may cause pain, coldness or tingling in the fingers or hand on your fistula or graft arm.
- Blocked fistula or graft: this causes the thrill in the fistula or graft to stop, or become fainter. The cause can be a narrowing of the vein or a blood clot. A blocked fistula or graft may require further surgery or another procedure to unblock it, so it is important to tell the dialysis nurses immediately.
- Scab: if a scab over your needle site does not heal quickly or gets larger, please let your dialysis nurse know. A non-healing scab can put you at risk of bleeding and may need a review with the vascular access team.
- Bleeding during dialysis: if blood oozes around your needle sites during dialysis, let your dialysis nurse know immediately.
- Bleeding after dialysis: if you have prolonged bleeding from a needle site once you have had the needle removed (more than 15 minutes), please inform your dialysis nurse.

If you have any questions or concerns about your AVF or AVG, please contact the access nurse specialist on 020 7188 7488 or 07827 281 534 (Monday to Friday, 9.00 am to 5.00 pm) or call the hospital switchboard on 020 7188 7188 and ask for the bleep desk. Ask for bleep 1414 and wait for a response. This will connect you to the access nurse specialist directly.

Out of hours, please contact

Astley Cooper Dialysis Unit (Monday to Saturday 7am – 9pm) T: 020 7188 8824

Patience Ward

(overnight and on Sundays)

T: 020 7188 8838

HEAVY BLEEDING

Heavy bleeding from your fistula or graft between dialysis sessions is very rare, but it is a medical emergency and could be life threatening. So you and your family need to be aware of what to do. This sounds alarming, but being aware of the possible complications shown left, and reporting them promptly should ensure that you do not experience heavy bleeding.

If you do experience heavy bleeding from your fistula or graft between dialysis sessions:

- **Seek help** immediately from anyone who is around. Heavy bleeding can make you feel faint, so please alert someone as quickly as you can.
- **Dial 999** for an emergency ambulance and tell the emergency team that you have heavy bleeding from a dialysis fistula or graft.
- **Apply firm pressure with a small clean dressing:** place a clean dressing or material over the bleeding site and apply firm pressure over the bleeding fistula or graft site with your fingers. Do not use a large dressing such as a towel, which may prevent you applying enough pressure in the right place.
- **Lie down and lift the arm:** if the bleeding isn't stopping, lie down and ask someone to help you by supporting your arm over your head. Make sure you are pressing in the right place.
- **Stay calm:** bleeding can usually be stopped with enough pressure. It may take more pressure than usual.
- **Go to the emergency department:** if the bleeding stops before an ambulance arrives, you should still go to the Emergency Department (A&E) to get your fistula or graft checked. Please also contact us.



YOU ARE A PRIORITY

Extra support for kidney patients from the Priority Services Register

Power cuts and water supply interruptions are rare these days. But should they occur, we are eligible as kidney patients to join the Priority Services Register (PSR) and receive extra support from our utility companies.

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, and need as much extra support as we can get to make sure our basic needs are being met.

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.

Nicholas Palmer
Head of Advocacy, Kidney Care UK

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 for example 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 you can register, visit <https://bit.ly/2U8c6ai>



THE RENAL ASSOCIATION NEEDS YOU!

If you a kidney patient, a family member or carer of someone with kidney disease, it's your chance to help improve kidney care by becoming a member of the Renal Association Patient Council.

What is the Renal Association Patient Council?

Founded in 2014, the Patient Council is a group of kidney patients (dialysis and transplant) and family members. Patient Council members work as a team to support the Renal Association, the organisation that represents kidney health professionals and aims to ensure that everyone receives the best kidney care.

What does the Patient Council do?

The Patient Council meets four times a year, and its work includes:

- Getting involved in new work designed to improve patient experience and outcomes
- Helping to produce new patient information, including leaflets, reports and posters
- Discussing new research and survey proposals, and how information from the kidney centres is being used
- Support on how data is managed and used, and patient consent
- Encouraging discussion between patients and clinicians to promote patient involvement in kidney centres, as well as regionally and nationally.

Patient Council members are unpaid, but there is an allowance for attendance at meetings, plus travel costs. Any training you need will be provided, together with continuing support.

Would you like to know more?

If you think you would like to join the Patient Council team, please get in touch with Jen to find out more or to ask for an application pack at: jennifer.barwell@renalregistry.nhs.uk

NEW FOR YOU: KIDNEY INFORMATION FILMS

A series of four short films has been released for adults with kidney disease. The films were generously funded by Guy's and St Thomas' Charity and aim to inform you about the different options for managing your condition so that you can make informed choices about your treatment. They also tell you what to expect from the Guy's and St Thomas' kidney service.

The films feature interviews with patients and clinicians. Sue Lyon, Chair of GSTTKPA, introduces the first film, and in the final film Sue talks about the importance of taking control of your kidney condition.

Film 1: Living with early stage kidney disease

The first film concentrates on early stage chronic kidney disease (CKD), self-management and the importance of a healthy lifestyle. Glenn explains how making changes to his lifestyle has enabled him to slow down the progression of his CKD.

Film 2: Having dialysis

Kevin Evans, Dialysis Matron, explains how dialysis works and introduces the different types: haemodialysis, peritoneal dialysis and home dialysis. We then hear first-hand from Adisa, Amaka and Enoch about their treatment and how it fits into their lives.

The films are available on YouTube and can be viewed on the Trust website: <https://bit.ly/2G1bl9g>

Film 3: Having a kidney transplant

A transplant surgeon talks about the different options for transplantation. Jillian, Christian, George and Cheryl talk about their experiences and explain how having a transplant has benefited them.

Film 4: Supporting you to manage your kidney condition

Sue discusses how she has developed her own coping strategies over the years and a psychologist talks about common feelings associated with living with a long-term condition. We also hear from a social worker about her role.

A BIG thank you!

Our best wishes to everyone running in the London Marathon on behalf of GSTTKPA:

Tom Beasor

Emma Clare

Dave 'Mavis' Grain

Tamara Harries

Les Frost

Aled Lewis

Shannon Wade

Henrietta Walker

Huge thanks to you all for your support for kidney patients and their families.

Look out for our Marathon report in the next issue of *Kidney Talk*.

How are we doing?

RESULTS OF THE LATEST PREM SURVEY

Last summer, 380 Guy's and St Thomas' kidney patients took part in the national Patient Reported Experience Measure (PREM) survey of kidney care in the UK—you may remember being asked to complete a yellow paper questionnaire. The aim of the survey is to help renal teams understand patients' experience of care and to show where improvements can be made.

The PREM results have just been published and at Guy's our highest scores were in the following sections:

- Privacy and dignity
- Access to the renal team (answering questions, contacting the team)
- Patient information
- How the renal team treats you (listening, caring, taking you seriously)
- Understanding the reasons for tests and the results
- Scheduling and planning of appointment times and consultations.

The results showed room for improvements in the following:

- Helping you to access patient support groups
- Sharing decisions
- Transport
- Needling with as little pain as possible.

The overall score for patient experience in UK renal units was high and Guy's compares very favourably with other inner-city renal units. The areas where we do well and the areas where we need to improve are the same across the country.



Our aim is to work in partnership with patients to continually improve our services; please let us know if you have any suggestions or would like to be involved in developing our services.

Ros Tibbles, Service Improvement Nurse
Ros.tibbles@gstt.nhs.uk
Tel: 020 7188 7552

MORE INFORMATION

The annual PREM survey is supported by Kidney Care UK and the UK Renal Registry. To read the PREM report, visit <https://bit.ly/2GaR5rQ>

WHAT IS OCCUPATIONAL THERAPY? AND WHAT CAN IT DO FOR YOU?

Occupational therapy aims to take a whole-person approach to support both mental and physical health and wellbeing. The term 'occupation' refers to any day-to-day activity that allows someone to live independently and have a sense of identity; this could be around self-care, work or leisure tasks.

Occupational therapy works towards a preventive approach to minimise risks and provide support with the aim of adapting routines and environments before people reaching a crisis point.

At Guy's, our occupational therapy team covers both of the inpatient renal wards. We have also started to provide an outpatient service covering the Astley Cooper dialysis unit and are available to see people in the Kidney Clinic.

We know from patient feedback and experience that starting dialysis is a huge life change and can lead to difficulties in managing daily tasks. Starting treatment can be daunting and people can withdraw from social activities, which can in turn lead to an increase in anxiety and/or depression.

There is a growing body of evidence showing the benefits on health and wellbeing from engagement with the arts. It has been reported that participation in art-based activities—which could include crafts, dance, film, literature, music, singing, cooking and gardening—can help towards managing

long-term conditions, the needs of an ageing population, loneliness and mental health problems. Engagement in creative activities has also been shown to improve anxiety, depression and stress, as well as boosting resilience and overall wellbeing.

At Hammersmith hospital, an artist volunteers at the dialysis unit; feedback shows that patients create emotional artworks that can distract from treatment. The experience offers stimulation during dialysis and is a way for patients to express themselves and find a voice. Artwork is displayed around the unit, providing patients with a sense of community and pride in their work. A similar project facilitating participation in activities has also been running at the New Cross dialysis unit for many years. Initiated by Zandria Richards, the project is supported by the GSTT volunteer programme.

Plans are under way to set up an 'art on dialysis' programme at Guy's & St Thomas' (GSTT). Patients attending Borough Kidney Treatment Centre will be surveyed

regarding their interest in participating in creative activities during dialysis and the activities they would like to do. Based on feedback, a proposal will be put forward for volunteer support to initiate activities. If successful, the scheme may then be able to be rolled out to other units.

Occupational therapy has also been expanding its service provision on the Astley Cooper Dialysis Unit. We now provide regular relaxation sessions, fatigue and sleep management support as well as one-to-one therapy assessments and interventions.

Moving into the future, we will be continually looking at how we can build our service across all of our dialysis units. We will also continue to promote the role occupational therapy can play in supporting and improving the lives of dialysis patients.

Lisa Ancliffe
Senior Specialist Occupational Therapist,
Renal & Urology, GSTT

MORE INFORMATION

If anyone feels they may benefit from an occupational therapy assessment or would like to be involved in the development of our services/projects, then please send me an email on lisa.ancliffe@gstt.nhs.uk or call on 0207 188 4185.



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

Sunday 9th June 1pm-5pm

5TH FAMILY FUN DAY

Guy's & St Thomas' Kidney Patients Association invite kidney patients, friends and family, Guy's & St Thomas' renal staff.

- Bingo
- Five-a-side football
- Cake sale stall
- Face painting
- Free barbecue
- Bouncy castle
- London to Brighton stationary bike ride
- Family sports (egg and spoon race, sack race)
- Raffle

Venue
King's College Sports Ground
Brockley Rise/Stillness Road
London SE23 1NW
Buses: P4, 122, 185
Nearest station: Honor Oak Park (Rail & Overground)

Remember...
The fun will continue under cover if the weather is wet.
The venue is wheelchair accessible.
Transport will be provided to and from certain dialysis units.

LOOKING FORWARD TO SEEING YOU!



Holiday caravan for hire

Would you like a holiday, but not sure if you want to travel abroad?

North East Kidney Patients Association is offering hire of its holiday caravan. The caravan sleeps six and is wheelchair friendly, and is sited on the Cayton Bay Holiday Park, near Scarborough.

For prices, further details and booking enquires, contact Victoria Harrison at victoria.10harrison@btinternet.com or on 07985 781364. Or on Facebook, search for NEKPA Caravan – Cayton Bay

To find out more about Cayton Bay Holiday Park, visit www.facebook.com/nekpacaravancaytonbay/

If you need dialysis while on holiday, it can be arranged at Scarborough Hospital (4 miles away) and Bridlington Dialysis Unit (11 miles away), but always check availability before you book your holiday.