



kidneytalk

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

Meet my 'KIDNEY FAMILY'

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

This is my first issue as Chair, and I must begin by thanking Sonia Moorhouse, my predecessor, for her tremendous contribution to GSTTKPA during the last four years. Sonia took over as Chair under challenging circumstances and, with the support of the KPA Trustees and Committee, has ensured that our charity is now on a firm foundation for the future. I am conscious that Sonia is going to be a very hard act to follow, and I am truly grateful for her continuing support and advice as a Trustee and Committee member.

I was a founding member of the committee in 1980 when the KPA was established as Guy's Association for Renal Patients. At that time, I had already spent three years on home haemodialysis, having learned on my admission to Guy's in March 1977 that I had 'crash landed' into kidney failure at the age of 25. Much has changed since then. The one and only dialysis unit is not sited in a large shed on the car park at the back of Guy's, a dialysis machine is no longer the size of a large fridge, the choice of peritoneal dialysis has become available, and many patients are able to dialyse nearer home in a satellite unit.

Despite these and other changes for the better, life on dialysis continues to place a heavy burden on patients and their families. As a charity, GSTTKPA's core aim is to support patients, and we are pleased to continue to

work with the Chaplaincy team to provide emotional and social support to help dialysis patients to cope with their treatment. There can be particular challenges for patients who need to use a haemodialysis line rather than a fistula for their treatment. On page 4, Kevin Evans, Matron for Satellite Dialysis, explains how to look after your line, with essential tips on showering and bathing.

Dialysing at home while I slept gave me the freedom to continue to work in my job in publishing, and to enjoy a much freer diet. I well remember that the prospect of escaping hospital to dialyse at home was a tremendous incentive to learn to put in my own fistula needles. Even so, I needed some support to overcome my fears. So I am especially pleased that the KPA has recently funded a 'practice arm' for use by patients preparing for home haemodialysis at Borough Kidney Treatment Centre.

Life as a kidney patient is undoubtedly complicated, and it's not always easy to take time out from treatment and clinic visits. So the KPA is pleased to continue to support social events for patients at the satellite dialysis units. And we invite all kidney patients, their family and friends, and kidney unit staff to our 4th Family Fun Day on Sunday 15th July. Please see the advertisement on page 6 for details. We look forward to seeing you there.

When I was diagnosed with kidney failure in the 1970s, the first-choice treatment was home haemodialysis. It was comparatively early days for deceased-donor transplants and results were not always happy for the patient. So I waited a few years before asking to be added to the transplant list, and I ultimately received a deceased-donor kidney in March 1986.

A kidney transplant is for most people the best treatment for kidney failure, removing most dietary and fluid restrictions, restoring energy and wellbeing, and making travel and holidays so much easier. Sadly we all know that many people are still waiting far too long for this ultimate gift. Sam Newman, Specialist Nurse – Organ Donation at Guy's & St Thomas' gives us the latest news about organ donation in this issue (page 3).

Some of you may have seen news stories about a machine that keeps deceased-donor organs 'alive' before transplantation and may help to increase the number of transplants. Dr Benedict Phillips reports on page 2 about the research at Guy's that aims to improve this new technology even further. The KPA is delighted to support this research, and we will make sure to share the results in Kidney Talk.

A diagnosis of kidney failure means a lifelong relationship with your kidney team. It is a tribute to the dedication of staff in GSTT kidney unit that they continue to deliver excellence in care when there is increasing demand for kidney services. Even so, living with kidney failure is not easy, and for many KPA members an important compensation is the close relationships forged with fellow patients, their family members and kidney unit staff.

During my term as Chair of GSTTKPA, I look forward to working with the KPA Trustees, Committee, members and kidney unit staff—all of whom I count as members of my kidney family.

Sue Lyon

Recipe corner

What shall we eat tonight?

This familiar problem becomes even more difficult to solve if your diet is limited by kidney disease.

This recipe comes from *Everyday Eating*, a book written by Guy's kidney patients for other kidney patients. This book and other kidney-friendly cookbooks are available to download free of charge (see below). **Enjoy!**

Pork chops with herb crust – Serves 2

Baking is a healthy way of cooking, as it does not use extra fat. The chops can be prepared in advance and kept in the fridge until you are ready to cook.

Ingredients

- 2 x pork chops (fat trimmed off)
- 1 teaspoon mustard
- 2 teaspoons oil
- 2 spring onions or 1 shallot, finely chopped
- 1 clove garlic, crushed
- 2 tablespoons of fresh or bought breadcrumbs
- 1 pinch mixed dried herbs or a handful of fresh herbs (e.g. parsley) chopped

Method

Preheat oven to 200°C/400°F/Gas Mark 6.

Spread the mustard over one side of each pork chop and place in a shallow baking dish or roasting tin.

To make the herb crust, mix together the oil, onions, garlic, dried herbs and breadcrumbs.

Press the herb crust mixture on to the top of each pork chop and cover dish with foil.

Bake for 25 minutes, removing the foil for the last five minutes to brown the herb crust.

Serve with boiled potatoes or rice, and a boiled vegetable of your choice.

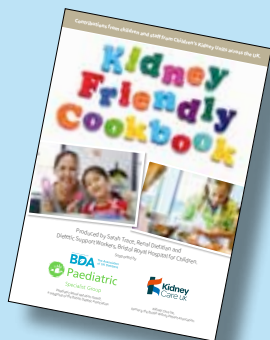
Recipes for kidney patients

New to download from Kidney Care UK: *Kidney Friendly Cookbook*. Designed with kidney patients and their families in mind (<https://bit.ly/2JSIMjI>)

Everyday Eating: tasty recipes and helpful hints for kidney patients by kidney patients (<http://bit.ly/1jowD94>)

Food with Thought: the everyday 'kind to kidneys' recipe collection (<http://bit.ly/2xpPGK6>)

Lawrence Keogh's Rediscovering Food & Flavour (<http://bit.ly/2yfIqyz>)



A RECORD YEAR FOR ORGAN DONATION

But too many people are still waiting for a transplant

2016-17 was a record-breaking year for organ donation and transplantation in the UK, with 4,753 people receiving a life-saving or life-transforming organ transplant. This was made possible thanks to the generosity of 1,413 deceased donors and their families, and 1,043 living donors.

More than 50,000 people in the UK are alive today thanks to organ transplants, but despite this record breaking public commitment to donation, the overall shortage of donated organs remains. There are still around 6,400 people currently waiting for a transplant.

Very few people die in circumstances where their organs can be donated. As organs have to be transplanted soon after a person has died, they can only be used from a patient who has died in hospital. Despite a record 23.6 million people on the NHS Organ Donor Register, fewer than 1500 people who die each year become organ donors.

Organ donation in London

NHS Blood and Transplant has recently launched the Words Save Lives campaign in London. The campaign encourages people to talk more openly about organ donation so their friends and relatives are aware of their wishes. NHS Blood & Transplant (NHSBT) research shows that while more than 80% of people support organ donation, only 49% have ever talked about it. Each year, over 100 potential donors are lost because their families were unaware of their relative's wishes and override their decision to donate.

In London, six in 10 people waiting for a transplant are from black or Asian communities. We know that transplanted organs work better if they are from a donor of the same ethnic background, and we desperately need more people from black and Asian communities to join the organ donor register and share their wishes with their families.

Organ donation at Guy's & St Thomas'

Over the last 10 years, almost 2,500 people have received a kidney transplant at Guy's and St Thomas' (GSTT), and the Trust carries out 20% of all transplants in London. GSTT has an active multidisciplinary Organ Donation Committee with a focus on promoting and facilitating organ donation. The trust also has two in-house Specialist Nurses for Organ Donation: KJ Castronovo and Sam Newman.



The Organ Donor Register

If you would like to join the NHS Organ Donor Register, please ring 0300 123 23 23 or visit www.organdonation.nhs.uk.

And remember to share your decision with your family and friends.

There is no age limit on becoming an organ and/or tissue donor, and you can still donate even if you have a long term-illness or disease. There are a few medical conditions that may prevent you from donating organs, and only a healthcare professional can decide whether your organs or tissue are suitable for transplant based on your medical history.

For instance, if you are HIV positive you may be able to donate to someone who already has HIV. Deceased donors with some cancers may be safely used. However, you cannot be a donor if you have a cancer that has spread within the last 12 months.

For more information, please visit www.organdonation.nhs.uk

KJ and Sam are senior nurses from a clinical background in intensive care. Their role encompasses many different aspects including:

- Identifying potential organ and tissue donors in collaboration with the clinical teams in critical-care environments.
- End-of-life care
- Provision of support and comfort to grieving relatives
- Teaching and education of medical and nursing staff and the general public people

KJ and Sam can be contacted by email at:

- samuel.newman@nhsbt.nhs.uk
- katie-jane.castronovo@nhsbt.nhs.uk

Samuel Newman
Specialist Nurse - Organ Donation Guy's & St Thomas' NHS Foundation Trust

Caring for your haemodialysis line

LOOK AFTER YOUR LINE AND IT WILL LOOK AFTER YOU

A haemodialysis line is a flexible tube, with two openings. One opening takes your blood to the dialysis machine to be cleaned, and the other returns the cleaned blood to your body. The tube is inserted into one of the veins in your neck or groin. It is held securely in place by a cuff under the skin. It is important to take care of your line to prevent infections and help the line last longer.

Keeping your dressing clean and dry

Your line is vital for your dialysis, therefore it is important to ensure that you minimise the risk of an infection:

- If your dressing gets wet or dirty, wash your hands thoroughly and put on a clean dressing.
- Your haemodialysis nurses will usually change your dressing weekly. If it looks dirty, or feels uncomfortable, the nurses will change it more often – please let them know if you have changed your own dressing.
- Do not use talcum powder and creams around the haemodialysis line.

How to spot infection in your line

Please contact your dialysis team if you have any of these symptoms:

- Redness, swelling or new pain around the haemodialysis line or site
- Oozing or bleeding from the area around the haemodialysis line
- Fever and chills
- Feeling generally unwell
- The clamps/caps breaking or falling off
- A tear or hole in the dialysis line.

And remember...

- Don't pull or kink the dialysis line.
- Make sure that the clamps and caps remain closed at all times when your dialysis line is not being used for dialysis.
- Only a trained member of the haemodialysis team should use your dialysis line.
- Your dialysis line should not be used for any purpose other than dialysis.
- On the rare occasion that your dialysis line should come out, apply pressure to the exit site (where the line has become dislodged) and phone 999 immediately.

For more information, or if you have any questions or concerns about looking after your haemodialysis line, please contact the vascular access clinical nurse specialist on 020 7188 7488 or 078 2728 1534 (Monday to Friday, 9.00am to 5.00pm).

Out of hours: please contact Patience Ward on 020 7188 8838.

Kevin Evans
Matron for Satellite Dialysis,
Guy's & St Thomas' NHS Trust

SHOWERING AND BATHING: DO'S AND DON'TS

- We recommend a short, two-minute shower once your line has had time to heal after being inserted (usually after about 14 days).
- We also strongly recommend that you use a shower pouch. This is available on prescription, please inform your dialysis nurse if you would like a supply to be delivered to you, and we will make the necessary referral. A sample box may have been given to you after your line insertion with full instructions; if not, ask your dialysis nurse for a sample.
- Unfortunately, you may not go swimming in a pool, or the sea up to your neck, as the water is full of bacteria and other substances that will increase your risk of infection. This also applies to home bathing for long periods.

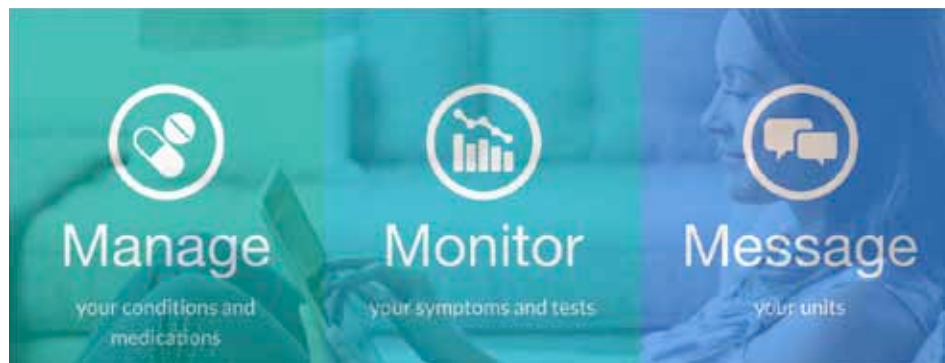
Do:

- Do wear the protective pouch for showering
- Do ensure that your dressing is intact
- Do report any redness or irritation around the site

Don't:

- Don't swim in the sea, or a swimming pool up to the neckline
- Don't remove the protective dressing
- Don't soak in a bathtub up to your neckline

PatientView app now available



PatientView, which gives you access to your latest test results online, plus information about diagnosis and treatment, is now available as an Apple or Android app.

This first version of the App includes the most commonly used features of the PatientView website, and will be followed by regular feature updates and upgrades. More information about the latest functions can be found on the app's description screen in the Apple App Store or Google Play.

If you don't yet have access to PatientView and would like to find out more, go to www.patientview.org

If you want to join, you'll need to fill in some forms. Ask at your dialysis unit or at your next clinic visit.

To install the app:

1. Follow on-screen instructions to download the app and install it on your device.
2. Once your app is installed and opened, enter your usual PatientView username and password. Tap the checkbox to agree to the download of your records, then tap the Login button.
3. You will be asked to enter 3 random letters of your secret word. If you don't have a secret word yet, you will be prompted to create one—this is mandatory to ensure security of the app.
4. You'll then see the dashboard screen and be able to explore all of the app's functions.

Not Just the Incredibles

As many of us know, to have a kidney transplant is to receive an incredible gift. But while a transplant can be a new lease of life, there can be times when our lives with a transplant are painful, distressing or just plain ordinary. Sometimes, this can lead us to feel that we are somehow failing our donor by not living up to an impossible ideal of a special, post-transplant life.

Not Just the Incredibles is the result of a research project exploring these everyday aspects of organ transplantation. The project ran from early 2016 to late 2017.

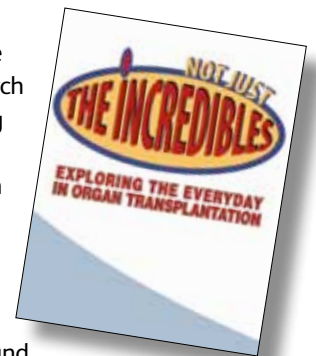
It was initiated and facilitated by artist Tim Jeeves, who himself had a bone marrow transplant in 1998. The research included two workshops held in Liverpool and in London with transplant recipients and laboratory staff, who facilitate such procedures. The workshops were followed by one-to-one conversations with transplant recipients.

To read or download Not Just the Incredibles, visit <https://givingintogift.org/not-just-the-incredibles/>

You can find out more about the future phases of Tim's project and contact him via the Facebook page: <https://www.facebook.com/groups/notjusttheincredibles/about/>

Sign up to the Giving in to Gift mailing list at: <https://givingintogift.org>

Follow on Twitter <https://twitter.com/GivingInToGift>



Patient information leaflets from Kidney Care UK

Kidney Care UK (previously the British Kidney Patient Association) has joined forces with the Renal Association (the organisation for kidney professionals) to produce high-quality patient information for use by patients, families, carers and kidney doctors in the UK.

Leaflets are now available on a variety of topics, including A Healthy Diet and Lifestyle for Your Kidneys, Kidney Biopsy, Pregnancy and Chronic Kidney Disease and Fluid Balance—and more topics are in the pipeline.

To download copies of the leaflets, go to <https://bit.ly/2sgCPqi>

A big thank you to Dr Marlies Ostermann

Dr Marlies Ostermann has stepped down as Clinical Lead for Organ Donation at Guy's & St Thomas'. Anyone who has worked with Marlies will know that she has done incredible work to promote organ donation. KPA members thank her for her contribution, and look forward to working with Dr David Cain, the new Clinical Lead.



MOVING OUT OF THE ICE-AGE

New technology in kidney transplantation

Guy's Hospital has introduced new technology to bring kidney transplantation out of the 'ice-age'. For the last 60 years, deceased-donor kidneys have been preserved on ice at 4°C before being transplanted. This has been an effective and inexpensive way of keeping kidneys viable. However, there is an injury associated with keeping organs at low temperatures for too long.

We now have a machine that can preserve kidneys without cold storage. It is called 'ex vivo normothermic perfusion' (EVNP), and the machine pumps the kidney with blood and oxygen at body temperature. The advantage is that the kidney remains in a working and living state, even producing urine. This allows surgeons to get a better idea of how the organ will work after transplantation.

EVNP may provide the transplant team with more information about whether or not the kidney is suitable for transplantation, and it may also allow the kidney to start working sooner. After transplantation, some kidneys take a few days or weeks to start working, and some patients need a few sessions of dialysis until the kidney is in full swing.

EVNP may reduce the risk of 'sleepy' kidney, and the medical tests that are needed as a result. The introduction of EVNP at Guy's Hospital is still in its early stages, which means that only certain types of kidneys and recipients are eligible. If eligible, patients will be approached by one of the members of the EVNP team on Richard Bright ward on the day of their transplant.

Thanks to funding kindly provided by GSTTKPA, I am now working on improving the machine further. In particular, I am looking at ways of removing the donor's white blood cells from within the kidney to see if this further improves its function. Donor white blood cells have been linked with the inflammation that occurs in the kidney after transplantation, and they may even provoke kidney rejection.

While I look to remove these harmful cells from the kidney, I am also investigating the ability to deliver back into the kidney regenerative cells that are able to repair damage. This may be ideal for kidneys from deceased donors, which have experienced wear and tear. The overall aim is to enhance the durability and function of kidneys prior to transplantation to provide transplant recipients with the best possible organ.

Without the generous funding from the KPA, this exciting research would not be possible. While the results of the research are eagerly awaited, there seems to be a bright future for kidney transplantation.

Benedict Lyle Phillips
Clinical Research fellow, Specialist Registrar in Transplantation, Guy's and St Thomas' NHS Foundation Trust



Main image: A kidney undergoing EVNP in the operating theatre. The surgeon keeps a careful eye on the kidney while the machine pumps it with warm oxygenated blood. The kidney itself is not visible, but lies in the metallic box in the centre of the photograph

Insert image: Oxygen, nutrients and medications are added to the blood before entering the kidney

London Marathon

Many congratulations and a very big thank you to all our runners, who completed the 26.2 miles of the hottest-ever London Marathon to raise funds for the KPA:

- Simon Amor
- Glen Brooks
- Joe Gregory
- Simon Perry
- Tabitha Warley
- Fran Williams
- Sadie Welch



And many congratulations also to Guy's Kidney Unit's very own Maddy Warren, who ran on behalf of Kidney Care UK, and who became the first woman on dialysis to run the Marathon.

Well done, everyone!



FAMILY FUN DAY

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

Free barbecue
Raffle
Face painting
Cake sale stall
Bouncy castle

Sack race
Egg-and-spoon race
Five-a-side football
Prizes for best fancy dress
(children aged 12 or less)

Venue

King's College Sports Ground
Brockley Rise/Stillness Road
London SE23 1NW

Buses: P4, 122, 185

Nearest station: Honor Oak Park (Rail and Overground)

Remember...

The fun will continue under cover if the weather is wet.

The venue is wheelchair accessible.

SAVE THE DATE

4th Family Fun Day

Sunday 15th July,
1.00 pm to 5.00 pm

King's College Sports Ground,
Brockley Rise/Stillness Road,
London SE23 1NW

British Transplant Games

Thursday 2nd to
Sunday 5th August

Birmingham

For more information:

<http://www.britishtransplantgames.co.uk/birmingham-2018/>

Organ Donation Week 2018

3rd to 9th September

Raising awareness of the important need for families to talk about organ donation to help save lives

Annual Memorial Service

4th October
3.00 pm

Guy's Hospital Chapel
For bereaved relatives and staff to remember patients who have died.



GSTTKPA Annual General Meeting

Saturday 1st December,
10.00 am to 12.00 pm

Robens Suite, 29th Floor,
Tower Wing, Guy's Hospital,
London SE1 9RT