

SUPPORTING KIDNEY PATIENTS



The central aim of the Guy's and St Thomas' Kidney Patients' Association (GSTTKPA) is to support patients. In the last four years, the GSTTKPA has continued our core projects, which have included providing social activities for dialysis patients, and facilitating both children and adults to attend the British Transplant Games.

On a day-to-day basis, the timeliness of patient transport services continues to be an on-going problem. Most patients who regularly use transport services report an improvement, but there are still persistent problems affecting the most vulnerable patients travelling on or after 6.00pm. Peter Bennett, Guy's and St Thomas' Trust (GSTT) and his team have worked to manage the transport services alongside the robust Patient User Group, who have provided persistent challenge regarding the Trust's transport strategy. Patients who use transport need a reliable and efficient service to support their care, and the GSTTKPA is committed to ensuring there is sustainable improvement in patient transport services. I would like to particularly thank Sheila Pearce for her tenacious endeavours in supporting her fellow kidney patients.

We have undertaken projects working in partnership with the Renal Department and the Trust's art collection department to refurbish the Day Room on Richard Bright Ward, which is almost complete. We also supported a number of initiatives to increase the awareness of living donation and specifically to encourage more black and ethnic minority patients to consider living donation.

Many patients appreciate the life-changing intervention of a kidney transplant, however, for some patients, the transplanted kidney might fail and dialysis may become a pressing need. The GSTTKPA is currently working with the Renal Department and researchers from King's Research Centre to better understand patients' experiences to improve services for patients with failing transplants.

Victoria Hanson, clinical nurse specialist in kidney care, researched and wrote a children's book to help parents and carers affected by renal disease to explain the consequences to young children. The chaplaincy service led by John Watts and Peter Oguntimehim are providing emotional and social support to patients, who are finding dialysis treatment difficult. The GSTTKPA was pleased to fund both of these projects.

Nurses Winifred Yeboah and Sarah Watson organise the annual memorial service for families, carers, friends and staff. They are currently working with the GSTTKPA to provide additional therapies to support and comfort patients receiving end of life care.

As a small charity, the GSTTKPA is indebted to the numbers of fund donors, who remember other kidney patients during their bereavements, following transplantation or to mark a specific, special occasion. We are also grateful to our many supporters, who take part in the London Marathon and Ride London events.

I commend the staff within the Renal Department and underscore the many, many patient narratives regarding their sincere gratitude for the care and support they receive in spite of the apparent difficulties within the health and public sector.

Finally, I would like to express my thanks to the GSTTKPA Trustees and Committee members for all the less visible work they do to support the GSTTKPA charity. I will be handing the 'baton' of the GSTTKPA leadership to Sue Lyon, a veteran kidney patient of more than 40 years.

My best wishes to you all.

Sonia Moorhouse

DATES FOR YOUR DIARY

GSTTKPA Annual General Meeting and social event

Wednesday, 22nd November

5.00pm-7.00pm

The Robens Suite, Tower Wing,

Guy's Hospital

Meet fellow KPA members at our Annual General Meeting from 5.00pm. Then join us to thank our supporters and celebrate the KPA's achievements for the year.

World Kidney Day UK 2018

8th March 2018

Check the website for details:

<http://www.worldkidneyday.co.uk>

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 for details). **Enjoy!**

Lemon baked fish – Serves 4

Baking is a healthy way to cook fish, as it uses only a small amount of fat. You will find the lemon and herbs go well with the fish without the need for salt.

Ingredients

- 4 x 100g/4oz portions white, boneless fish fillets e.g. cod, haddock, snapper, coley
- Juice of one lemon/2 tablespoons of lemon juice
- Grated rind of one lemon (optional)
- 1 tablespoon reduced salt butter or margarine
- 1 pinch dried rosemary or dill
- Black pepper

Method

Preheat the oven to 180°C/350°F/Gas Mark 4.

Place the fish in a single layer in a shallow baking dish.

Mix together the butter or margarine, lemon juice, grated lemon rind, rosemary, and pepper and dot over the fish fillets.

Cover with foil and bake for 25 minutes or until fish flakes easily when tested with a fork.

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

Kidney-friendly cookbooks

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>)

RESEARCH:

Antibodies

Some people have antibodies in their blood that react against a kidney transplant and damage it. Professor Anthony Dorling describes research into antibodies at Guy's and St Thomas's Renal Transplant Clinic.

Antibodies against transplanted kidneys in kidney transplant recipients are generally regarded as being 'bad'. They can adversely affect kidney function in one of several ways:

- They can destroy the kidney quickly if present at the time of transplantation.
- They can initiate a 'smouldering' process of so-called chronic rejection, particularly if they develop after kidney transplantation, leading to the eventual failure of the transplant.
- They can act as a marker for other types of ongoing kidney damage.
- At Guy's we are doing research into all three areas.

Antibodies before transplantation

Patients with antibodies prior to their kidney transplant have to wait a very long time for a suitably matched kidney (which will not bind the antibodies that are present). However, we have an active programme to remove antibodies at Guy's that enables us to transplant kidneys that would otherwise be unusable.

In general, this type of approach is not as good as receiving a standard-type transplant, but our research has shown it is as good, in terms of how long patients live, as remaining on dialysis. We know that some patients do very well after this type of transplant, and we have an active laboratory research programme to understand the difference between patients who do badly versus those who do well; if we can understand this, we hope to be able to manipulate treatments so that everyone does well.

Chronic rejection

We are one of the few research centres with the skills in immunology combined with the clinical experience to investigate 'chronic rejection'. We have several ongoing clinical trials, both observational and interventional, that are designed to understand why some antibodies cause problems and others don't. Fascinatingly, we know that some antibodies can protect the transplanted organ from damage.

We have active research programmes trying to understand what factors

underpin these differences, with the goal of being able to prevent damage and promote protection. These run alongside projects testing new drugs to specifically prevent antibody-mediated damage; some of these drugs can be used to pre-coat the organ prior to transplantation.

Damage after transplantation

We are running a large clinical trial called OuTSMART to detect patients who develop new antibodies, with the specific intention of understanding what other types of damage can occur. Our hypothesis is that the antibodies often appear as a marker, or a 'flag', to herald the involvement of immune cells that may have been activated by infections. Sometimes, the antibodies appear many months before the damage begins.

We are therefore testing whether conventional drugs, such as Adoport (tacrolimus) and mycophenolate mofetil (our 'standards'), optimised in a tailored fashion in such patients, can counteract this type of problem and prevent the damage occurring. Our laboratory studies, allied to this trial, are designed to better understand the mechanisms of how cells damage the kidney – work that will have direct benefit for care of all kidney transplant recipients in the future.

All these diverse, but connected areas of research require continual funding and ongoing funding, to enable them to continue.



CELEBRATING 25 YEARS OF FUNDRAISING

A capella singers entertain guests at the Fair, held each year by the Gibbon family

Philippa Gibbon explains why she and her family raise funds for the KPA

Henry failed to put on weight as a newborn and being fourth of four aged under seven, it was all very busy. He did not look the healthy bouncy baby I was used to: pale and quiet. I kept asking what could be the problem.

Concerned, I visited the Scilly Isles hospital when Henry was two weeks old, then our local hospital and doctor for the first four months. Calpol was always the treatment! Eventually we ended up in Casualty and someone took a urine test. Antibiotics were administered, but within a few weeks Henry was on a drip with a full-blown septicaemia. While Henry was on the drip it was the first time I had seen him look animated. Sent home without a scan, he was ill again within weeks. Then they started investigating!

I was devastated that I did not do more, sooner. But there was a young health visitor with no experience, a lovely GP who did not look deep enough, and a busy mother!

We were referred to Guy's with the diagnosis of kidney damage from reflux. Henry spent three years on antibiotic treatment with trimethoprim and waited for an operation. After the fourth admission for IV antibiotics, I called Guy's to ask if we could have the next cancellation; by now he had lost more than 60% kidney function.

I was so relieved to have something done and we wanted to thank all the great staff at Guy's. We gave a donation and then the first Fair was started. Every year on the last week in May, Henry's birthday, we hold the Fair; this year we added an cappella group of singers. My amazing Friends have been supporting me for 25 years, spending their money and driving miles to buy my coffee cake and lunches. In total we have made near £24,000!

Henry is now 26 and is a 6-foot architecture student doing his masters degree in Copenhagen, having had a normal life. His kidney function has deteriorated, so he

is on blood pressure pills to help maintain his function. He has become a vegetarian for ethical reasons, but I think he also believes it is healthier for him.

Henry had a wonderful doctor at the Evelina, who told him the facts of his disease. It is tough what small children who are ill have to go through, but sometimes it makes them tougher.

We are lucky: so far Henry has had a great time travelling widely and making the most of everything that comes his way. We have had have had a few panics during his student days, but he lives life to the full and we are very proud of him. He now sees Dr Pattison yearly unless he has issues.

Guy's and St Thomas' Hospitals have always been there for us, and the staff are second to none in their kindness, support and care. Thank you from the bottom of our hearts, The Gibbon family.

Our grateful thanks in return, and our best wishes to you all. We hope that Henry continues to stay well and living life to the full. The KPA Committee



MEET THE MEMBERS OF Our sporting Hall of Fame

Much of GSTTKPA's work to support Guy's & St Thomas' kidney patients would be impossible without the energy and commitment of our runners and riders, who raise funds for us by taking part in charity sporting events. Here is our sporting Hall of Fame for 2017.

Peter Warren ran the London Marathon this year for the first (and last) time at the age of 72. As part of his training, Peter ran several sections of the course several times, and says that on Marathon day he ran the whole course "at the stunning pace of a fast shuffle". He adds that—for a one-year only special offer—he has given us two marathons for the price of one.

Peter wanted to thank GSTTKPA for the charity's support when his daughter Madeleine developed kidney failure as a young teenager. Following an unsuccessful living-donor transplant, Madeline has now been dialysing for the last 17 years. She is an active supporter of kidney charities herself, and an ardent ambassador for home nocturnal dialysis, because it makes her feel so well, with lots of energy, enabling her to perform such feats as climbing Ben Nevis and skydiving!

Jo Austin was born in Guy's Hospital and bred in South London, and decided it was time to raise money and pay back Guy's for all their support. Jo also has direct experience of kidney problems, especially in children, since her son has been monitored for a duplex kidney – which thankfully has never become serious.

David Goddard's journey began when his son Tai was born in 2003 with posterior urethral valves, which left him with kidney failure. In 2010 Tai had a kidney transplant performed at the Evelina London. David says that his family has been lucky to be supported by the KPA and they would like to give something back in return.

Alice Green is donating a kidney altruistically (to a stranger) at Guy's as part of a pooled match. She decided not only to raise funds for the KPA before her

operation by taking part in the London Marathon, but also to run it as an ultra-marathon. This meant running the Marathon course twice: once at 3.00 am from the finish line to the start, then turning around and joining 40,000 others to run it the right way round. 52 miles in all!

Both Shanti Mayo and her Mum have polycystic kidney disease, and her grandmother recently died from the disease. Shanti's run was in support of her Mum, who lives in Australia and recently started dialysis.

Paula Cozens ran the London Marathon in memory of her father-in-law, who died of kidney failure.

Tabitha Warley was sadly forced to withdraw from the Marathon due to injury/illness, but her place will be rolled over to next year's event.

Would you like to join our sporting Hall of Fame?

If you are interested in raising funds for GSTTKPA, applications are open for places in these events:

Vitality London 10000:
Monday, 28th May 2018

Prudential Ride-London Surrey 100:
Sunday, 29th July 2018

Virgin Money London Marathon
Places are filled for 2018, but you can apply for 2019 (with plenty of time to train)

For more information, please contact teresa.gsttkpa@outlook.com

PRUDENTIAL RIDE LONDON-SURREY 100

Our thanks to three intrepid ladies and one intrepid gentleman, who rode 100 miles in the Prudential Ride London-Surrey 100 to raise funds for GSTTKPA:

Linda Ross, Highly Specialist Renal Transplant and Urology Pharmacist

Elaine Lyons, Clinical Pharmacist (Sleep Medicine/ Respiratory)

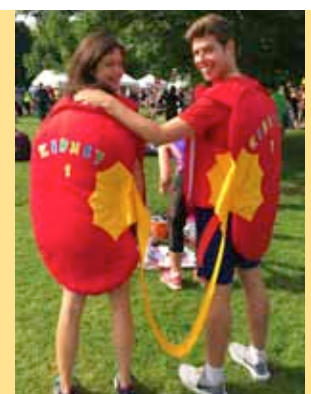
Carol Ann Jones, Renal Pharmacist

Nicholas Ware, Consultant Nephrologist at the Evelina London.

VITALITY LONDON 10,000

Sophie Ellse and her partner Tom Pullen ran in the Vitality London 10,000 dressed as kidneys.

Sophie's mum made the fabulous bespoke outfit, which we hope to see gracing the streets of London again next year.



A busy year for GSTTKPA!

Here are just a few of the events supported by Guy's & St Thomas' KPA so far this year.

The KPA funded the production and printing costs of *The Little Book about Kidneys*, written by Victoria Hanson, clinical nurse specialist in kidney care. Trying to discuss kidney failure and its treatment with young children can be daunting for adults in the family. In this beautifully illustrated book, Dougal the Dog guides young children through how the kidneys work, and how kidney failure is treated with dialysis and transplantation. The book is available free of charge from Guy's Kidney Clinic and satellite units, or you can download it as a PDF at <http://bit.ly/2hhJ3pt>.



Renal study day

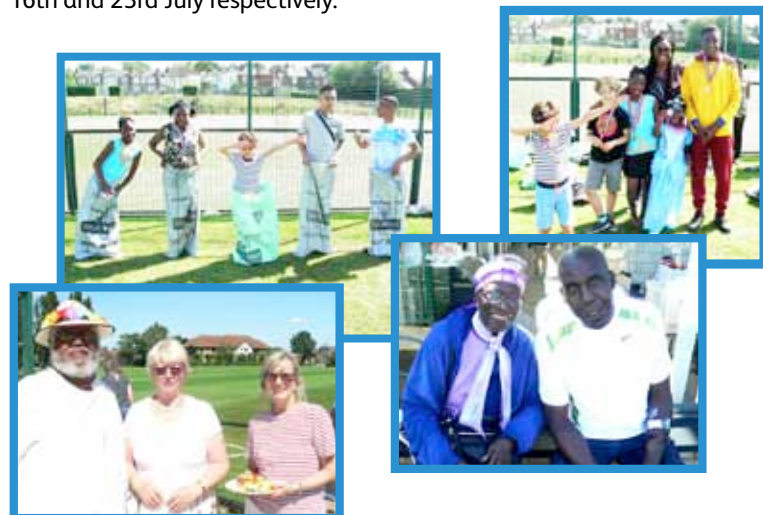
Reverend Peter Oguntimehin hosted a renal study day on 25th May for patients and chaplains to consider the complexities of kidney disease. A number of patients told their inspiring experiences of managing dialysis and transplantation. The GSTTKPA thanks the chaplaincy service, particularly those providing services to renal patients.

Kidney Care UK open day

Kidney Care UK (formerly the British Kidney Patients' Association) held an open day to promote home dialysis in the kidney clinic on 26th June, in partnership with GSTT Kidney Department. The objective of the day was to raise awareness of the home dialysis options, with the help of experienced patients, clinicians and Baxter professionals.

GSTTKPA Funday

The annual GSTTKPA Funday was held on 2nd July; the weather was perfect and the event was well attended. Our special thanks to Ruth and Naomi Brown who manned the barbecue! Other summertime social events were held by the New Cross and Camberwell dialysis units on the 16th and 23rd July respectively.



DIABETES

15 Healthcare Essentials

Need-to-know information from Diabetes UK

Having the right care is essential for the wellbeing of everyone with diabetes. As well as looking after yourself, there are 15 vital checks and services—the 15 Healthcare Essentials—that everyone with diabetes should get for free from their healthcare team.

You can use this list to talk to your healthcare team about your individual needs as part of your annual care planning review. This is where you should agree your priorities, discuss your personal targets and agree a written plan of action to help you reach them.

What are the 15 Healthcare Essentials?

The 15 Healthcare Essentials are the minimum level of healthcare everyone with diabetes deserves and should expect.

If you aren't getting all the care you deserve, take the 15 Healthcare Essentials checklist to your diabetes healthcare team and discuss it with them.

What to do if you're not receiving your essential checks

If you have any questions or concerns about your checks, or if there are any checks you are not receiving, it is important to discuss this with your doctor or healthcare professional.

Published by courtesy of Diabetes UK

*Learn more at the Diabetes UK website: <http://bit.ly/2yKwPLh>

THE 15 HEALTHCARE ESSENTIALS

1. Get your blood glucose levels measured (HbA1c blood test)
2. Have your blood pressure measured
3. Have your blood fats measured
4. Have your eyes screened for signs of retinopathy (damage to the blood vessels in the eye)
5. Have your feet and legs checked
6. Have your kidney function monitored
7. Get ongoing, individual dietary advice
8. Get emotional and psychological support
9. Be offered a local diabetes education course
10. See specialist healthcare professionals
11. Get a free flu vaccination
12. Receive high-quality care if admitted to hospital
13. Have the chance to talk about any sexual problems
14. If you smoke, get support to quit
15. Get information and specialist care if you are planning to have a baby

A farewell message from Professor David Goldsmith



It is with a mixture of sadness and excitement that I now face leaving the Guy's Kidney Unit where I have spent many happy, rewarding and enjoyable years working. It has been a privilege and a pleasure to be a consultant these last 20 years working in a team such as the one at Guy's, striving to do their best, often against considerable head-winds, to provide focused, high-quality and appropriate medical and surgical care for patients with chronic kidney diseases (CKD).

Over the 20 years I have been here I am proud to have helped develop links to diabetes teams (as diabetes is such an important part of CKD), with Siew Mien Cohen; and also to have worked hard to enhance the quality of the chronic care we give to renal transplant patients, initially with Helen O'Sullivan (now sadly deceased) and more recently with Sharon Frame; and for the last 10 years or so I have been the consultant lead for peritoneal dialysis, working for many years with Caroline Willis. All four of the individuals I have just mentioned have shown tremendous professionalism and dedication to making patients' lives better. There are so many more similar professional and dedicated people in the many areas the renal unit covers, both at Guy's and in the large number of satellite or peripheral sites where we treat patients. We are truly lucky to have such individuals working with us.

I have also worked with genetics, developing the von Hippel Lindau syndrome clinic, and more recently, the Bardet-Biedl syndrome clinic. I have taken a significant interest in vitamin D, and in the treatment of the problems of bone disease in CKD, as many patients who have seen me over the years with these problems will know. In the last 18 months, I have spearheaded the clinical adoption at Guy's of tolvaptan therapy in polycystic kidney disease patients.

When you work somewhere for 20 years (or longer) you can certainly make strong links with patients, and there are many patients whom I have treated for that long (and a few who have the misfortune to remember me as a junior doctor, perhaps 30 years ago!). I shall remember many interactions, but rather than select a few at random,

I will say that I remain hugely impressed and deeply humbled by the amazing way so many patients can manage to overcome the daunting challenges that chronic kidney disease can throw at people, and families, and come through not only coping, but often smiling. I always tried to have a cheery or optimistic disposition, where possible, in my clinic and on the wards, to try to help provide some reassurance and hope.

In the end, it is only through successful kidney transplantation that we can offer any semblance of future good health for patients with progressive kidney disease, and so the transplanting achievements of the Guy's Kidney Unit, with the teamwork shown between doctors and surgeons, is the true badge of honour for the Unit. It is a sadness to me that so few new treatments in CKD or in dialysis have emerged over the last 30 years I have been involved in nephrology - I can honestly say that none of those I have seen has made a major impact or provided lasting benefit. This is truly tragic, but I earnestly hope that this might change before too long.

I will be stopping patient-facing activities, and will be leaving Guy's & St Thomas' NHS Trust, in late September 2017. I will then be doing other types and kinds of work in the field of medicine and drug development, in another setting. I wish everyone here at Guy's the best for their futures, and hope and trust that the Kidney Unit will reach even greater successes in the coming years.

With my very best wishes

David Goldsmith
Consultant Nephrologist

Let's talk about it

Organ Donation Week 2017

Most people support organ donation, but a family must agree before deceased donation can go ahead even if the donor has signed up to the Organ Donor Register. Families may hesitate to agree to donation, or may even refuse, if they are uncertain of their loved one's wishes.

Each year between 4th and 10th September, NHS Blood and Transplant (NHSBT) organises Organ Donation Week to promote the importance of people discussing their organ donation decision with their families, and to highlight how not doing this leads to many missed transplants. This year there was a focus on the power of donation and donors, with one organ donor having the potential to save or transform up to nine lives.

Guy's & St Thomas' supported the campaign with events on Wednesday 6th September at St Thomas' and Thursday 7th September at Guy's. People were able to ask any questions they had about organ donation and encouraged to join the Organ Donor Register.

On Wednesday 6th September, KPA members attended an event at the House of Commons at Westminster to raise awareness of organ donation. The event, co-hosted by NHSBT and Kidney Care UK, aimed to increase support in Parliament for organ donation and transplantation, as well as raise awareness of kidney disease. Over 60 MPs attended the event, as well as a similar number of patients, donors, health professionals, staff and supporters.

On 9th September, a 'Family Fun and Open Day' was held at Queen Mary's Hospital Sidcup to celebrate the centenary of the hospital. Members of the KPA, the Trust's organ donation committee and kidney unit staff joined the event to raise awareness of organ donation. Thirty people completed the form to sign up to the Organ Donation Register and many more took details of the website site to join online. A number of local dignitaries, including the Mayor of Bexley and local MP James Brokenshire, stopped by the stand to offer their support.

Note: Figures recently published by NHSBT reported that in 2016-17 more patients received a kidney transplant from a living donor at Guy's and St Thomas' NHS Foundation Trust than at any other transplant unit in England.