



kidneytalk

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

Enjoying your summer

Welcome to the latest issue of *Kidney Matters*, the newsletter of Guy's & St Thomas' Kidney Patients' Association (GSTTKPA). As I write, I can see the leaves and blossom on the trees outside, telling me that spring has definitely sprung.

Many people feel more optimistic at this time of year, especially as society seems to be slowly emerging from the pandemic. However, life continues to be more difficult for people who have been told that they are "clinically extremely vulnerable" – a term no longer used as we are allegedly "no longer at substantially greater risk than the general population", according to government guidance issued on 1 April*. This assessment of risk does not, of course, apply to many people with kidney disease, especially people with kidney transplants, who may not have responded very well to their Covid vaccinations.

If you feel that you still need to take care and need advice, I strongly recommend visiting www.kidneycareuk.org. Kidney Care UK's website hosts the latest advice about Covid-19 for kidney patients, including information on returning to work, Covid-19 testing, and eligibility for 'spring booster' vaccinations.

Kidney Care UK also employs Advocacy Officers, whose role is to take action on behalf of kidney patients who need help. In this issue, we introduce John and Ellen, new Regional Advocacy Officers for London, and explain how they can help kidney patients at GSTT.

As an organisation, GSTTKPA is hoping that we can slowly return to our usual activities. The last two years have

prevented our usual face-to-face activities, but thanks to Zoom the Committee has continued to meet regularly and discuss applications for funding. In this issue you can read how we have continued to support kidney patients at GSTT.

GSTT is a powerhouse of research, and in this issue Professor Anthony Dorling tells us about his research into highly sensitised patients, who have developed antibodies and as a result have to wait far longer than other people for a kidney transplant. Over the years, GSTTKPA has been delighted to support the work of Professor Dorling and his team, and we look forward very much to hearing results from clinical trials.

Despite continuing coronavirus concerns, there is still much to look forward to this year. In this issue you can read about Gift of Living Donation's lunch to be held in June to celebrate black living kidney donors. And there's Ride London in May, the British Transplant Games at the end of the July, and the London Marathon at the beginning of October; you can find out in this issue how to take part.

Keep safe and enjoy your summer.

Sue Lyon, Editor, Kidney Talk

*Department of Health and Social Care/UK Health Security Agency. Guidance for people previously considered clinically extremely vulnerable from COVID-19. 1 April 2022. <https://bit.ly/37sxaFl>.

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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 gsttkpa.org/join-the-gsttkpa/

Or email your name, email & address to info@gsttkpa.org

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>).

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How we've helped

The Covid-19 pandemic has prevented GSTTKPA from holding our usual events, but we have still been able to support our members in 2021-22.



Christmas 2021

Since it was not possible to hold the usual Christmas events in the dialysis units, GSTTKPA funded a £10.00 gift voucher for every patient dialysing in the wards or satellite units, and for people dialysing at home (whether haemodialysis or peritoneal dialysis). We also arranged Christmas cards so that each patient would receive a card from GSTTKPA. Our thanks to George Brown for distributing the cards to the units.



Kidney Kitchen Calendars

As well as the Christmas gift vouchers and cards, we were very pleased to fund the Kidney Kitchen Calendars offered by Kidney Care UK. These were distributed to people receiving in-centre and home dialysis, and to people attending the Advanced Kidney Care Clinic at Guy's.

Our thanks again to the Renal Dietitians for distributing the calendars.

Body composition monitor

If you are on dialysis, your fluid balance (hydration) is critical. Too much bodily fluid increases the risk of uncontrolled blood pressure and serious heart problems. Too little bodily fluid (dehydration) increases the risks of symptomatic low blood pressure, cramps and loss of remaining kidney function.

If you are on dialysis, it can sometimes be difficult to work out whether changes in weight are due to changes in your 'dry weight' or in your bodily fluid. For example, if weight gain is due to more fluid retention (volume overload), you need a lower dry weight and more ultrafiltration when you dialyse. Conversely, an increase in lean muscle mass suggests that you need to increase your dry weight to prevent dehydration. Finally, if weight change is due to increased fatty tissue, you need advice about your diet.

So GSTTKPA was very pleased to support an application from Dr Dimitrios Moutzouris to enable the purchase of a body composition monitor. This portable, non-invasive device will be used to give regular, objective assessment of fluid balance; it will complement standard methods to identify volume overload/dehydration so that target dry weight/dialysis regimen can be adjusted accordingly.

We hope that practical benefits for patients will include:

- Better assessment of volume status, especially in patients with problems such as heart failure
- Helping avoid symptoms of excess fluid removal such as cramps, postural hypotension, loss of residual kidney function
- Helping prevent over-hydration and optimise fluid status
- Assessing nutritional status and muscle mass; identifying at an earlier stage patients who are maintaining weight but in reality losing muscle mass.



If you are a haemodialysis patient and you are admitted to St Thomas', you will dialyse in the hospital's four-bedded unit. Being admitted to hospital is depressing and stressful, especially if you are dialysing, and you definitely need some distraction.

It is not possible to install televisions in St Thomas' dialysis unit, so GSTTKPA was pleased to fund the cost of four iPads to help entertain patients while they are dialysing at St Thomas'. Thanks go to Adora Beleno-Harriot, Matron for in-patient dialysis, for suggesting the purchase.



JOIN US

Join the GSTTKPA Committee

Committee members help us to:

Supply patient amenities in kidney clinics, wards and dialysis units

Fund social events for kidney patients and their families

Support the British Transplant Games for adults and children

Publish our newsletter Kidney Talk and regular email updates

Maintain our website, www.gsttkpa.org

Raise awareness of kidney disease and the needs of patients

Promote World Kidney Day and Organ Donation Week

If you are interested in joining the Committee and would like more information, email info@gsttkpa.org

We look forward to hearing from you!

Supporting GOLD



GSTTKPA is proud to support a forthcoming lunch to promote living donation in the black community.

More donated organs are needed from people in the black community

Shortage of kidney donors sadly affects people of all ages and ethnic backgrounds, but more donated organs are needed from people in the black community. This is partly because of the low proportion of people from the black community on the organ donor register, but also because African Caribbean people are more likely to develop illnesses such as diabetes and high blood pressure that can cause kidney failure. Living kidney donation could reduce the length of time that some African Caribbean patients wait for a transplant.

Creating awareness of living kidney donation in the black community

Founded by Dela Idowu in 2010, GOLD (Gift of Living Donation) works to promote and create awareness of living kidney donation in the black community. Among many other activities, GOLD holds an annual celebratory lunch to say a special thank you to black living donors.

GOLD's annual lunch

This year, GSTTKPA is proud to support some black kidney patients from Guy's to attend the lunch, talk with black living donors and donor recipients, and find out more about living donation.

This year, GOLD's annual lunch will be held in London in June, and we look forward very much to hearing all about it in the next issue of Kidney Talk!

More information

Visit www.giftoflivingdonation.co.uk for more information about GOLD, including the Telephone Buddy Scheme, which links black kidney patients with black living donors or black transplant recipients to talk about living kidney donation.



Highly sensitised patients: improving transplant outcome

Professor Anthony Dorling writes about cutting-edge research, supported via GSTTKPA, to make transplantation easier and safer in highly sensitised patients.

‘Sensitisation’ in an immunological context refers to the development of antibodies against other human beings; these can develop after an organ transplant, blood transfusion, or after pregnancy. These antibodies can influence the chance of being offered an organ, and after a new transplant they can cause rejection. In a group of patients who are ‘highly sensitised’, the large number of different antibodies can severely impact the time spent waiting for a transplant.

Antibody Incompatible Transplant programme

The Antibody Incompatible Transplant programme at Guy’s is one of the few in the UK that is still involved in clinical trials in this area. We are hoping that the latest trial, involving a drug called imlifidase, will start in late 2022. Allied to this programme, my research is exploring ‘next generation’ solutions to the problems faced by highly sensitised patients. I have been privileged to receive several donations via GSTTKPA over the last few years to enable some of this work, and I want to use this opportunity to thank GSTTKPA for their generous support.

In one project (‘SIKP’) we are collecting samples from dialysis patients sensitised by a kidney transplant and comparing the immune cells in their blood to those found in patients sensitised by pregnancy. The background is that antibodies developing after pregnancy behave differently, and are associated with slightly different problems, to those developing after a kidney transplant. By understanding why, we might be able to devise a strategy to exploit these differences for the benefit of all.

In a second project, we have been trying to dissect which cells control the development of antibodies. The background is that some patients, exposed to the same conditions, will develop lots of antibodies and others will develop none, and we believe the difference is due to the presence of ‘suppressor’ cells in some people. This work has already allowed us to describe the different populations of antibody-producing precursors and how they can be suppressed. More recently, we have shown that suppressor T-cells can inhibit antibody-producing cells. This work has been selected as a contender for the prestigious Medawar Medal at the 2022 British Transplantation Society meeting.

GAMECHANgER-1

Both these projects have helped my team obtain a large (£2 million+) grant from the Medical Research Council (MRC) to perform a clinical study in highly sensitised patients on the Guy’s, King’s and St Helier transplant lists.

This trial, called GAMECHANgER-1, involves purifying blood suppressor cells, expanding the numbers in the laboratory, and then giving them back to patients in a single infusion. By massively expanding the patient’s own population of suppressor cells, we hope to suppress the activity of the underlying immune system and reduce the level of antibodies, thereby making subsequent transplantation easier and safer. This trial, which builds upon the advanced, world-leading skills we have built up at Guy’s, is expected to start in March or April 2022.

This is a good example of how the support of individuals, via GSTTKPA, for ongoing research in patients is helping to drive progress and keep Guy’s at the cutting edge of research in this area.

By Professor Anthony Dorling



Introducing Kidney Care UK Advocacy Officers for London

These are difficult times for everyone, but people with kidney disease face particular challenges. Jonathan Bartley and Ellen Hill, Kidney Care UK's regional Advocacy Officers, are available to support and represent you, your families, and carers.

Jonathan and Ellen have been trained to help with a range of issues relating to kidney disease, including treatment options, welfare and benefits, emotional support, and dialysis away from base. As you would expect, their advocacy service is sensitive, compassionate, and completely confidential.

Advocacy Officers work with you one-to-one and, if necessary, can arrange further support offered by Kidney Care UK, including the telephone counselling service and financial grants programme. Financial support is available to those on a low income and can help to pay for household items, travel expenses and towards training courses.

As part of its work improving care services, Kidney Care UK actively supports the Kidney PREM, which stands for Patient Reported Experience Measure. This anonymous annual survey is undertaken in partnership with the UK Kidney Association (UKKA, formerly known as the Renal Association) and it is used nationally to look at how care is provided and promote the sharing of best practice. Locally, the results help kidney units understand how their patients really feel about their care, highlight what's working well and identify the areas where improvements could be made.

Like the rest of the Advocacy team, Jonathan and Ellen will be looking closely at the results and supporting units, kidney patient associations and patients to come together and improve services. If you would like to read more about this year's kidney PREM, go to www.kidneycareuk.org/prem

For an advocacy referral, financial help, or support with any other issues, call Kidney Care UK on 01420 541424 (Mon-Fri, 9am-5pm) or send an email to info@kidneycareuk.org

SAVE THE DATE

Ride London-Essex

27-29 May

A new route for this festival of cycling
To take part on behalf of GSTTKPA, email
events@gsttkpa.org

British Transplant Games

Leeds

28-31 July 2022

www.britishtransplantgames.co.uk/leeds-2021

For more information about attending the Games,
email guystransplantteam@gmail.com

Organ Donation Week

19-25 September

<https://bit.ly/3rwby1G>

Renal Memorial Service

Chapel, Guy's Hospital

Thursday, 22 September

3.00-4.00 pm

TCS London Marathon

Sunday, 2 October

Support GSTTKPA runners along the route

www.tcs londonmarathon.com

GSTTKPA

Annual General Meeting

Saturday 27th November, 10am-12pm

Venue to be confirmed



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- On your first visit to smile.amazon.co.uk, you need to select a charitable organisation to receive donations from eligible purchases before you begin shopping. In the 'Pick your own charitable organisation' box, search for Guy's and St Thomas' Hospital Kidney Patients' Association and click the 'Select' box on the next page.
- Amazon will remember your selection, and then every eligible purchase you make through AmazonSmile will result in a donation to GSTTKPA.
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