



kidneytalk

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

COVID-19 and the KPA

Kidney patients are used to feeling vulnerable – whether it's because of needing on dialysis or worries about the results of blood tests after a transplant.

But now Covid-19 has made our risk official: in March the Government asked us to shield ourselves for at least 12 weeks due to our vulnerability. And at the time of writing, we do not know when this lock-down is likely to be lifted.

This has meant huge changes to our lives, and to the delivery of our treatment. It has similarly affected the work of GSTTKPA and publication of our newsletter. We aim to publish Kidney Talk twice a year both in print and online, but we have decided that this issue should be online only. This is because of the need to prevent infection in our dialysis units and kidney clinic, and to avoid any extra burdens for the staff who are working so hard to care for us in these difficult times.

We plan the contents of the newsletter several weeks before it is published, so inevitably many of the articles in this issue

are about projects that are on hold due to the pandemic. We look forward to revisiting these projects when we return to more normal circumstances.

When I first became GSTTKPA Chair, I wrote in this newsletter about how I have found that the challenges of living with kidney failure are compensated for by the close relationships forged with my fellow patients, their family members and GSTT kidney unit staff—all of whom I regard as my 'kidney family'.

Keep safe all of you.

Sue Lyon, Chair, GSTTKPA

Information about coronavirus

GSTT kidney services

<https://www.guysandstthomas.nhs.uk/our-services/kidney/overview.aspx>

Kidney Care UK regularly updated news and information

<https://www.kidneycareuk.org/news-and-campaigns/coronavirus-advice/>

NHS advice

<https://www.nhs.uk/conditions/coronavirus-covid-19/>

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Dela Idowu, Founder of Gift of Living Donation (right) with Hayley Armstrong who donated a kidney to her father in 2019

Let's have a **BIG** conversation!

Held in February, the Big Conversation brought together Black living kidney donors, Black kidney patients, and their friends and family to talk about living kidney donation with GSTT kidney specialists.

The aim of the event was to help Black patients, who are often reluctant to talk about living donation, to start the conversation with loved ones. The event was also designed to encourage and inspire friends and family to consider donating.

KPA Committee member Charles Jaja, who attended the event, said: "The Big Conversation was packed with great learning and take home experiences from the different speakers and comments from the audience. It was a successful event, and this kind of patient and family engagement networking evening should be held at least twice a year to promote living donation in the Black Community."

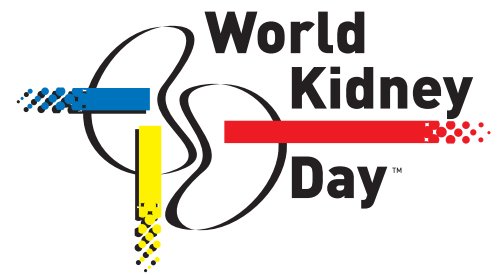
The fear of family and friends' refusal and dealing with the rejection was the number one reason why many patients at the event were reluctant to ask family and friends to donate. For family and friends, the fear of having such a major operation was the number one reason cited as their reason

for not coming forward. Patients attending the event felt that the Big Conversation had given them a lot more confidence to talk to family and friends, and has helped one family member to overcome their fear and come forward as a donor.

According to Gift of Living Donation (GOLD) Founder Dela Idowu: "We need to start having open conversations about living kidney donation in the Black community so that more Black patients affected by renal failure can benefit from having a living kidney transplant."

The Big Conversation is part of the Living Transplant Initiative, a joint project between GOLD and GSTT, and funded by NHS Blood and Transplant.

GSTT Q&A panellists at the event were: Dr Refik Gokmen, Consultant Nephologist; Anita Copley, Clinical Nurse Specialist Living Donation; Miri Vutabwarova, Clinical Nurse Specialist Living Donation.



Thank you to everyone – kidney patients, kidney staff and representatives of Kidney Care UK – who operated the World Kidney Day stand in the lobby of Guy's Hospital in March.

As kidney patients, we know that all too often the general public, and sometimes our friends and families, seem to be unaware of the impact of kidney failure on our lives. So this year's campaign, **#KidneysMatter**—the BIG topic everyone is ignoring, aimed to show the importance of kidneys, what can happen when they go wrong, how to keep them healthy, and how to reduce the risk of kidney disease.



The campaign featured a big yellow kidney—which was indeed hard to ignore. The yellow kidney was shared on social media and at awareness events across the country. The Kidney Charities Together Group, which co-ordinates the World Kidney Day activity in the UK, hopes to build on this success in 2021.

World Kidney Day is an annual campaign, held on the second Thursday of March every year. It is designed to raise awareness of kidneys and educate people about kidney health. For more information on World Kidney Day, visit <https://worldkidneyday.co.uk>.

The Kidney Charities Together Group consists of the British Renal Society, Kidney Care UK, Kidney Research UK, the National Kidney Federation, the Polycystic Kidney Disease (PKD) Charity and the Renal Association.



Living Well on Dialysis

"I really appreciated the Satellite Chaplain's visits, it made dialysis much easier to cope with."

In 2017 the KPA provided an innovation grant to the GSTT Chaplaincy team to help people who were having difficulty living on dialysis. The Living Well on Dialysis (LWD) programme ran for two years in the New Cross Gate unit and has now been expanded to run in both New Cross Gate and Camberwell satellite units. The programme followed another two-year trial, the Living Well Programme, which targeted people wishing to work at improving their quality of life on dialysis.

By Revd Peter Oguntimehin, Renal Chaplain

Some patients participating in the programme have been on dialysis a number of years and have given up many activities of daily living due to chronic pain, symptoms, and lack of energy. The programme set realistic targets—one or two improvements in six-month period—which most participants achieved, although most also wished to receive ongoing support after the programme was over.

Kidney failure has a wide-ranging impact on people's lives, and even those who normally cope well experience crises from time to time. The Satellite Chaplain has two different roles: first, to deal with hard-to-reach patients by building relationships, enabling them to be open and engage with others and staff.

Second, the Chaplain offered spiritual care to the patients based on their needs. This included both spiritual and religious care, and pastoral work—solving particular crises as they arose.

In practice, both these roles were closely related; arguably one could not happen without the other.

The basic problem for hard-to-reach patients is that they have complex needs, but often will not accept the help they need. The Chaplain was regularly present on the unit, and engaged with patients and staff. This in turn enabled him to build a relationship of trust with hard-to-reach patients so that they could begin to get the help they needed, including specialist help; i.e. referral to social services, physiotherapist, etc.

During the course of the LWD programme, the unit manager referred 30 patients to the Chaplain for extra help. Following an initial assessment, the Chaplain made 12 follow-up visits over a six-month period. Results have been encouraging; patients have valued the extra support provided.

Overall the programme has made a significant difference in the lives of the patients who participated. The long-term aim is that all satellite units should have and enjoy the benefits of the LWD programme. This will require more funding, so that every unit/shift may receive a Chaplain visit once a fortnight. The benefits of the programme are, first, the work done with the original target group and, second, the regular availability of the Satellite Chaplain on demand for other patients needing help.

Find out more about the Living Well on Dialysis programme

Contact Revd Mia Hilborn, Hospitalier, Head of Spiritual Health Care and Chaplaincy Team Leader (0207 188 1187), Rev Peter Oguntimehin, Renal Chaplain (0207 188 1185), Revd Barth Orji (Satellite Chaplain).

RESEARCH AND INNOVATION

How the KPA helped

By Steven Sacks

Former Director of the MRC Centre for Transplantation

As a young consultant in the renal unit at Guy's Hospital, one of the challenges I faced was to build up a programme of research alongside my clinical duties. Moving from Oxford to the Guy's renal unit in 1988, I was lucky to have colleagues who supported my research aspirations. Among them I would count the late Alex Schwarz, who was Chair of the Kidney Patients Association at Guy's at the time I joined.

Those who knew Alex will remember him as a remarkable person, for his military demeanour and commanding business approach. He had immediate grasp of the importance of research for the future of kidney patients and transplantation, with substantial commitment to helping those patients in the long term.

Alex inspired the membership of the KPA with this vision, so that at an early meeting where I was present the KPA committee took a monumental decision to support a longer-term programme of laboratory research, as distinct from support for immediate clinical benefit.

The KPA also showed foresight by funding laboratory staff as well as equipment to sustain long-term investment in this research. I remember there was controversy about the length of time it would take to move new ideas from the laboratory to the bedside. Nonetheless, the KPA – initially under Alex's leadership and later several others—committed to a long-term research programme, which I think has paid off.

FROM RESEARCH TO TREATMENT

Let me explain. Kidney transplantation had been successful in allowing many patients to come off dialysis and return to a healthy lifestyle. But while many kidneys last for a good number of years, there are others where the transplant works well for a shorter period of time than expected. The strategy of the KPA was to support research into the reasons for the shortened life of these kidneys and developing new approaches to overcome these limitations.

With over 25 years of KPA support, the research has identified two main problems:

- Early damage caused by inflammation during the transplant procedures
- Rejection of the donated organ despite being given drugs to prevent this.

As a result of the research, we have been able to find new treatments that can be planted in the donor organ and prevent inflammation and clotting in the transplant.

One such treatment (mirococept), which prevents inflammation, is part of the Emprikal trial, in which some GSTT patients have participated. Another such treatment (thrombalexin) stops clotting in the donor organ where antibodies deposit, and this is ready to be tested in patients. The treatments, known as 'protein therapies', are expected to be safe because they are designed to remain in the donor organ after transplantation and not to enter the recipient.

Another part of the research has focused on 'cell therapies': the use of white blood cells harvested from the recipient and increased in number and ability to suppress rejection before being given back to the patient. This approach, intended to make the patient tolerant to the transplant, is part of ongoing work to evaluate the safety and effectiveness, at Guy's and other centres.

THE FUTURE

It is 12 years since the Medical Research Council decided to site its Centre for Transplantation at Guy's and its partner organisations, not least because of its excellent record of clinically orientated research and the support of the KPA. This has allowed the work to proceed at a greater pace in its mission to deliver patient benefit and to train a new generation of research leaders in the transplant field.

As a result of this joined-up endeavour, to which the KPA has contributed about £1 million in total, there have been over 22 clinical trials since the Centre began, many of which have involved transplant patients, several ongoing. These include diagnostic tests known as 'biomarkers' that can distinguish which patients are likely or unlikely to reject, and this may allow changes of treatment in good time to prevent further complications of receiving either too much or too little treatment. This contributes to the goal of what is now known as 'precision medicine'.

In its promise to improve the life of the transplant and of the patient through innovative research, the research team has long been aware of the strategic importance of working in partnership with the KPA; we are all privileged to work with its members on a common goal.

PATIENT EXPERIENCE NATIONAL SURVEY RESULTS



In the summer of 2019, 493 Guy's kidney patients kindly completed the Patient Reported Experience Measure (PREM).

This is a national survey of kidney care in the UK – you may remember being asked to complete a yellow questionnaire either in the kidney clinic or in your dialysis centre.

The aim of the PREM survey is to help renal teams understand patients' experience of care and to show where improvements can be made. The results of this survey have now been published and we were pleased to see that Guy's scored the highest of all the London renal centres for overall patient satisfaction. We also had the highest response rate of all the London renal centres.

Our highest scores were in these sections:

- Scheduling and planning of appointment times and consultations
- Patient information
- Access to the renal team (answering questions, contacting the team)
- Privacy and dignity
- Environment.

The results showed room for improvements in the following:

- Transport
- Needling with as little pain as possible
- Shared decision making.

The areas where we do well and the areas where we need to improve are the same as most other renal centres across the country. Our aim is to work in partnership with patients to continually improve your experience; please let us know if you have any suggestions or would like to be involved in developing our services.

More information

Find out more, and download the report from Kidney Care UK at www.bit.ly/2yvPlbd

The complete results can be accessed via the UK Renal Registry's online data portal: <http://bit.ly/2x5uVFC>

By Ros Tibbles, Service Improvement Nurse

Complementary therapies and dialysis **A PILOT STUDY**

By Sarah Watson and Winifred Yeboah

Cancer charities throughout the UK offer complementary therapies that can be used alongside conventional medical treatments. These therapies are associated with benefits like an improved sense of wellbeing, better symptom control and an overall improvement in quality of life. However, kidney patients do not routinely have access to such treatments.

Our experience as kidney supportive-care nurses, backed up by evidence from research, informs us that people on haemodialysis can experience many symptoms including fatigue, cramps and pain that can lead to poor quality of life equal to people with cancer. The kidney supportive care team, in conjunction with the GSTT Dimpleby Cancer Care Charity therapies team, undertook a pilot project to bring reflexology (a type of therapeutic massage that involves applying pressure to reflex points on the hands and feet) to patients on dialysis. The project was generously supported by GSTTKPA.

We identified 30 patients from the Astley Cooper dialysis unit for the pilot. We involved patients with difficult symptoms, who were older, frail, those just starting dialysis, and patients overwhelmed by the demands of their treatment. Each patient received weekly reflexology treatment to their hands or feet for 30 minutes over four sessions, delivered during their haemodialysis treatment. The complementary therapists administered the treatment while supportive care nurses assessed patients' symptoms using the approved renal patient outcome score tool. This was done before the start of treatment and at the end of the course of treatment for comparison.

Three-quarters (75%) of patients who participated reported a general improvement in their overall symptom score. A few reported no change or even increased symptom score with the most dominant symptoms recorded as pain and anxiety/depression.

Feedback from patients was encouraging and included the following comments:

My urine output increased and I was able to lift my left leg (stroke side). Loved it, was what I expected and more!

I feel a lot better—it has helped me sleep.

I can move my feet more, ankles are released, I have contacted my GP and physio for exercise.

Very relaxing—am sleeping a bit better and for longer.

Awesome, ankles stop hurting and no more cramping.

Enjoyable and relaxing, it's improved my wellbeing. Feels like the nerves are starting to work in the right order

Feet were like coming out in pins and needles, am feeling relaxed & enjoyed it.

It has helped me continue coming three times a week for dialysis

In conclusion, it was a positive experience for patients as demonstrated in the feedback. We extend thanks and appreciation to the GSTTKPA and therapists from the Dimpleby Cancer Care charity for supporting the project.

And the winner is...

In the last issue of Kidney Talk, we announced the winners of our KPA Research Competition. In this article, Ms Hannah Maple, one of our two winners, describes her project and how her research will help support kidney patients' quality of life.

Mr Nicos Kessarar and I are delighted to have won one of the KPA Research Grants to further pursue our research into quality of life outcomes in dialysis and transplant patients. We have been collecting data from patients transplanted at Guy's Hospital for the last eight years and this has taught us a number of different things.

We have learned that while a transplant clearly has psychosocial benefits over remaining on dialysis, the outcomes vary considerably. Most significantly we have learned how important quality of life and psychosocial outcomes are to patients, whose lives are inevitably affected in lots of different ways by kidney disease. The importance of psychosocial wellbeing, and strategies to improve this as much as possible, cannot be over-emphasised.

The aims of our project are to further understand how quality of life improves after transplantation and to find out why some patients do not do as well as others. Until now it has only been possible to

collect data from patients after their transplant, and very few studies have been able to follow patients through the transplant experience. This is mainly because the timing of a transplant is very unpredictable.

We intend to achieve our aims by integrating a quality-of-life assessment into the transplant workup currently conducted by our team of kidney transplant nurses and doctors. We aim to do this by asking patients who attend the surgical transplant assessment clinic to complete a quality-of-life questionnaire prior to being activated on the deceased-donor waiting list, or being listed for a living-donor transplant. We will also ask those already activated on the list whether they would like to participate.

Participants will be given further questionnaires at set timepoints while they wait for their transplant so that we can assess the ongoing psychosocial impact of waiting for a kidney to become

available. Once a patient has had their transplant, we will ask them to complete the questionnaire again on a couple of occasions thereafter, so that we can see what difference a transplant makes. Additional questions about the operation and the recovery period will also be included.

Collection of data before a transplant will allow us to understand the impact of dialysis and kidney disease on a range of psychosocial factors and also understand what it is like waiting for a transplant. Collection of data after a transplant will allow us to understand how the life of a patient with kidney disease changes once they are free from dialysis.

Our longer-term aims are to use this data to help patients achieve the best quality of life possible, both before and after they have a transplant. We would like to improve patients' education and wellbeing on dialysis so that, when an organ becomes available, they make the smoothest possible transition into becoming a transplant patient and are able to fully benefit from all that a transplant has to offer.

We are grateful to the KPA for their support in this project.

Note: A future issue will include an article by our second winner, Mr Pankaj Chandak.

INTRODUCING

The London Transplant Collaborative

I have luckily not experienced kidney failure, but I suspect I would be devastated if I were on the waiting list for a kidney transplant and, after a long wait, an organ became available, yet the transplant did not proceed due to a lack of access to an operating theatre. It was in part to solve such a problem that the Pan-London Transplant Collaborative (PLC) was set up.

By Nizam Mamode, Professor of Transplant Surgery, GSTT

The PLC grew out of a national meeting in 2018, organised by the British Transplant Society and NHS Blood and Transplant, entitled 'A sustainability and resilience summit'. In the face of tremendous successes in increasing deceased-donor transplants by over 50% in less than a decade, these bodies had become aware that clinical staff were reporting difficulties in managing the dramatic increase in emergency work.

One theme that emerged was that transplant units were often faced with multiple organ offers, yet only had access to a single emergency operating theatre. This led to difficulties in successfully transplanting all the recipients, particularly as there are limits to the of time the kidney can be kept on ice (the cold ischaemic time).

The PLC was initially a loose alliance, formed by representatives from each of the five London transplant units, with the aim of addressing some of these problems. It has subsequently developed into a more formalised structure, supported by NHS Blood and Transplant, chaired by Dr Gareth Jones from the Royal Free Hospital. The PLC considers how collaboration can help us deal with busy periods, as well as considering staffing, training and research. The first success has been the establishment of an

organ-sharing pathway across London, led by Professor Mamode of Guy's Hospital.

The PLC's principle is that no transplant recipient should be denied a transplant simply because their transplant unit is faced with a high number of organ offers that exceeds capacity in the operating suite. The idea is that if such a situation arises, consideration should be given to transferring a recipient, along with the kidney, to be transplanted in another London centre. While this means that the patient would be treated by a different team, it would mean that they could still obtain a transplant that otherwise might not be possible, or might lead to substandard results due to a long wait for access to theatre.

Certain principles were key: patients could choose not to be transferred, even if this meant the transplant could not go ahead. Only low-risk patients would be transferred, and on discharge from the other hospital they would be returned for care under their usual hospital.

The pathway has been a fantastic example of effective collaboration—surgical teams have had to trust each other, agree the same work-up parameters and arrange transfer of data in a secure fashion. As such, this is a great template for further such collaborations across the country, particularly given the likely further rise in transplants following the opt-out legislation.

SAVE THE DATE

The dates below may be subject to change due to coronavirus pandemic. For more information, please check the website for each event.

Ride London

prudentialridelondon.co.uk

15th-16th August

If you are interested in entering Ride London on behalf of the KPA email events@gsttkpa.org

London Marathon

virginmoneylondonmarathon.com

Sunday 4th October

Support our runners on this rescheduled date.

British Transplant Games

britishtransplantgames.co.uk

This year's event has been cancelled. The next Games will take place in summer 2021 in Leeds.

If you are interested in joining the GSTT Adult Team email events@gsttkpa.org

GSTTKPA Annual General Meeting

**Saturday 28th November
10.00-12.00**

Burfoot Court Room,
Guy's Hospital