



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

# REFLECTIONS AND PRIORITIES

## My First Year as Chair of the GSTT Kidney Patients Association

It is both an honour and a responsibility to take on the role of chair for the Guy's & St Thomas' Kidney Patients' Association (KPA). I want to pay tribute to the new team who have kept the KPA together over this last year.

I have spent much of my career as a renal physician and have seen first hand the profound impact kidney disease has on patients' lives—not only physically but emotionally and socially. This drives my commitment to the KPA and our mission to support all patients with kidney disease at whatever stage of treatment.

### A Year of Challenges and Transformation

A year ago, the association faced significant challenges. We had lost trustees, and the organisation was struggling to find its footing. These difficulties have also provided an opportunity to rebuild. We are so fortunate that we now have a very experienced and committed team to take the KPA forward. We are now on a firm footing.

The patients we support are at the heart of everything we do. Living with kidney disease often means navigating complex treatment options, grappling with emotional strain, and facing limitations in daily life. It's our role to ensure that they are not alone and that their voices are heard and prioritised.

### Priorities for the Year Ahead

As we move forward, my focus will be on three key areas:

**1. Building and Strengthening Governance** Establishing a strong and cohesive board of trustees is a top priority. By bringing together individuals with diverse skills and experiences, we can ensure effective leadership and strategic decision-making.

**2. Enhancing Patient Support** I would like to expand our support networks, creating safe spaces for patients to share experiences and access vital resources. Importantly, it is about hearing from you, our patients, about what we can do to help.

**3. Increasing Awareness** People can underestimate the challenges kidney patients face. We will work to raise awareness about kidney disease and champion the needs of our community.

Thank you for placing your trust in me as chair. I am committed to this role and look forward to what we can achieve in the year ahead.

**Written by Dr Peter Harrison,  
Chair of GSTT KPA**

### LONDON MARATHON

Thank you to our wonderful runners George Luck, Tunde Fasoyiro, Maice Browne, Jas Upaul and Nick and Claire Rodger for taking part in this year's London Marathon. As a collective the runners raised over £14.5k.

The money raised will continue to ensure that we can support as many of our kidney patients as possible.



This year's British Transplant Games took place in Nottingham, from the 1st - 4th August 2024. The KPA supported the Guy's Adult Transplant Team with a grant which helped towards the accommodation costs.

Congratulations to everyone that took part this year and thank you to those individuals who went along to support the competitors. We look forward to supporting next year's event.

**Join the  
KPA!**

Receive 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, go to [www.gsttkpa.org/join](http://www.gsttkpa.org/join) or scan the code



# Introducing our new KPA Trustees



## Hadizat Olanrewaju Company Secretary

Hadizat Olanrewaju is a Corporate Governance Professional with experience working in a large FTSE 100 financial service and professional services firm. In her current role at Aviva Plc, she provides a wide range of governance solutions has a good understanding of UK company law, and corporate governance.

Before joining Aviva, Hadizat was a Company Secretarial Executive at ONE Advisory, a professional services firm in London. She qualified as a lawyer in Nigeria in 2019 and holds a Master's degree in Corporate and Insolvency Law from Nottingham Trent University.

Hadizat enjoys volunteering and in her capacity as Company Secretary she is looking forward to making a difference. She will be supporting the KPA and ensuring full compliance with all relevant legislation and regulations.

Hadizat brings excellent written and verbal communication skills, knowledge of corporate governance and company law including compliance requirements of a registered charity.

Hadizat will be using her skills to help the KPA support Kidney Patients and to 'give back to society'.

Outside of her work and her role at the KPA, Hadizat enjoys cooking.



## Niraj Haria Treasurer

Niraj Haria is a qualified accountant (FCCA) and is the new KPA Treasurer.

Niraj was born in Nairobi, Kenya. Where he completed his schooling there and then moved to the UK where he studied for his accounting qualification. In 2001 Niraj moved to the UK and started working as an asset manager and then as a financial controller. As his career progressed Niraj has worked in and gained experience across the Financial Services and Asset Management industry.

Niraj has over 20 years' experience in this field as he worked at different institutions developing strong knowledge across many areas including; outsourcing, strategy, client relationships, financial accounting, and budgeting.

Niraj has a keen interest in helping people with kidney diseases, as he has grown up with a close family member with a kidney disease from a very young age. The family member is currently on dialysis.

With strong accounting and management skills the KPA is excited as Niraj steps in to the Treasurer role for Guy's and St Thomas' Hospital Kidney Patients' Association.

Niraj's hobbies include trekking, swimming, movies and socialising amongst others. Niraj has a keen interest in the environment and wildlife conservation.



## Dr Peter Harrison Chair of GSTT KPA

Dr Peter Harrison is the new Chair of Guy's & St Thomas' Kidney Patients' Association.

Peter was a trainee in renal medicine at Guy's & St Thomas'. His career took him to Bristol where he was a consultant in renal medicine. He went on to help set up transplant units in Saudi Arabia and in Malta.

Since then Peter moved to Norwich where he helped train young doctors but has maintained his links with Guy's and is now an elected Governor with Guy's and Thomas' in various roles.

Peter has a long standing affection for Guy's and the opportunity to help support kidney medicine in the area was too strong to resist and he is delighted to have been selected to be Chair at GSTTKPA.

Peter brings a passion for fund-raising – in Bristol he helped raise funds not only for kidney machines but also a combined children, younger persons and adult dialysis unit and an integrated transplant unit.

Away from medicine Peter is a Parish Councillor and a keen gardener having developed from scratch his garden which opened in the National Garden Scheme. He is hugely concerned about climate change, especially for the future for his daughters and grandchildren. Peter has a love of classical music.

# CULTURE AND COMMUNITY

## Filling the gap on Living Donation for black kidney patients



My name is Dela Idowu, and on the 11th of January 2011 I walked into the kidney clinic on the 4th floor to see one of the living donor coordinators as I had come forward as a living donor for my brother and that day was the start of my living donor workup. However, I never could have imagined the incredible journey that decision would take me on.

Sadly, after months of tests I was told that I was not a suitable donor for my brother, this was heartbreaking news as I didn't want my brother to spend years on dialysis which is very common for Black people. Although heartbroken by the news, I knew I wanted to do something with the experience of coming forward as a potential donor, I went from being heartbroken to improving health equity for Black kidney patients by setting up Gift of Living Donation (GOLD) and the Black Living Donor Choir.

In 2023 GOLD came closer to improving health equity for Black patients with their groundbreaking quality improvement pilot project. In collaboration with three London transplant centres, Imperial College Renal, and Transplant Centre, Guy's and St Thomas' (GSTT), King's College Hospital, with support from the London Kidney Network, GOLD conducted a one-year quality improvement project (QIP) to test the effectiveness of implementing a community-led intervention in the patient pathway to increase the number of potential living donors for Black kidney patients coming forward for assessment and to address the huge disparity in the number of Black living donors compared to White living donors.

The pilot project focused on putting patients at the heart of transplantation and empowering them to talk to their family and friends about living donation.

### Community-led intervention

Culture and community are integral elements to the lives of people from the Black community and the community-led intervention implemented in the pilot, the Phone Buddy Scheme (PBS) was co-developed by Black kidney patients and clinicians for this reason. The Phone Buddy Scheme works on a clinical or self-referral basis. The Phone Buddies are trained volunteers and have lived experience of living donation. They are matched with

patients eligible for a transplant to discuss living donation from a cultural perspective.

### Patient impact and QI pilot success at GSTT

- Over 60 patients were referred to GOLD
- 10 clinicians took part in the pilot project
- 80 Black patients were contacted by GOLD
- 9 people came forward as potential living donors
- 1 successful living donor transplant

### Patient Feedback

- Patients felt it was extremely valuable to speak to someone from the Black community about living donation especially at the start of their journey.
- They had a better understanding of living kidney donation
- They valued the lived experience of Black donors and recipients
- Empowered and confident to have conversations about living donation with family and friends
- Appreciated it was culturally tailored
- Talking with someone from GOLD gave them hope on their kidney journey
- Improved their psychosocial health and wellbeing
- Mind-set shifted to transplant first, dialysis second
- Patients felt their views about CKD and transplantation changed having spoken to GOLD

### Looking to the future

What an incredible journey GOLD has been on so far! More Black people are having conversations about living donation, GOLD is changing the narrative that Black people do donate and celebrating Black living donors. Patients are empowered to talk with loved ones about living donation which is encouraging more people to come forward to be tested as potential donors.



The Black Living Donor Choir use the unique combination of music and donor stories to raise awareness of living donation in the community and that you can live your best life with one kidney. We are campaigning for more resources to be culturally tailored to meet the needs of the diverse renal patient population. We are so working towards stronger community partnerships to bring the expertise of the community into hospitals to fill the gap and help clinicians better understand the cultural nuances of Black patients to improve health outcomes.

But most importantly kidney disease is on the rise, and there is an urgent need to reduce the number of Black patients on dialysis, we want to see a brighter future for Black patients where living donation is the norm.

### Thank you

There are so many people to thank at Guy's for the success of the pilot. We want to thank the clinical working team for agreeing to be one of the pilot test sites. We want to thank the consultants, nephrologists, clinical nurse specialists, the data team, quality Improvement team and the patient safety manager.

It was important that the pilot was patient-focused so a big thank you to the members of the GSTT KPA, patient reps, and Camberwell Dialysis Patient and Carer Reference Group.

by Dr Dela Idowu



### More information

Phone buddy scheme

[www.giftoflivingdonation.co.uk](http://www.giftoflivingdonation.co.uk)

The Black Living Donor Choir

[www.blacklivingdonorchoir.org.uk](http://www.blacklivingdonorchoir.org.uk)

You can read the full pilot report here:

<https://bit.ly/gold-pilot>



# HELP & SUPPORT

There are a range of services available to support renal patients regardless of whether they are an inpatient or outpatient. As well as support available from Guy's, there's also the opportunity to access advice and help from charitable organisations that the KPA liaises with on a regular basis.

## Renal Psychology Service

### What does Renal Psychology Offer?

- Psychological Therapy (Up to 10 sessions)
- Information and Signposting
- Support during key transition points
- Assessment of psychological suitability and preparedness during living donation and transplant work ups
- Inpatient support

A member of your renal team can refer you. You can also self-refer by contacting **020 7188 9770** or **020 7188 7845** (Monday to Friday, 9am to 5pm)

## Renal Social Worker team

Social workers can help you, your family and carers with social care issues related to kidney disease. The social workers may be able to offer you advice and support on a range of issues, such as, housing, practical help at home, moving from hospital to home. To get in touch you can speak to a member of your kidney care team who can refer you. Or you can contact the social work team directly on **020 7188 5684**.

## NKF Helpline **0800 169 09 36**

The National Kidney Federation (NKF) run the only free to call UK Helpline dedicated to kidney patients with two fully trained, personally experienced advisors. Linda and Stephen bring invaluable expertise to the NKF Helpline through both personal experience and direct peer support. Stephen, a kidney patient with two transplants and dialysis experience, offers deep knowledge and empathy, while Linda, a former caregiver, contributes a unique perspective. Together, they provide callers with top-quality information on Renal related matters, along with referrals to specialised services.



The NKF Helpline is a trusted resource for those facing kidney-related challenges with a library of well over 150 leaflets kidney-related medical information leaflets written by Renal professionals in simple language for patients and carers.

You can call the NKF Helpline on **0800 169 09 36** – it is open Monday-Thursday 08:30am-5:00pm and Friday 08:30am-12:30pm.



KidneyCare UK is a charitable organisation that offers advice, support and financial grants and assistance to kidney patients and their families.

Jennifer Salmon is the Kidney Care UK Patient Support and Advocacy Officer for GSTT KPA. Her role is to support anyone affected by chronic kidney disease (CKD) including patients, their loved ones, and carers. Jennifer explains how she can provide support “I can provide information and support on a wide range of issues relating to CKD including treatment options, benefits, housing, and employment. I’m also here to provide emotional support and help people access the services and benefits that they may be entitled to, including how to access our counselling service. If you meet our eligibility criteria, I can tell you how to apply for a Kidney Care UK grant. If you would like support, please email [support@kidneycare.org.uk](mailto:support@kidneycare.org.uk) or call our Support Line free of charge on **0808 801 0000** Monday to Friday 9am to 5pm. We just need some basic details to start with and then the referral will come through to me”.

## KPA funds a patient outing to Southend-on Sea during the Summer

The following feedback from the Unit Manager at the former Camberwell dialysis unit summarised how much the patients enjoyed the event. “We would like to extend our appreciation and gratitude to the KPA for making our seaside mini break possible. We all had a great time relaxing on the beach, sitting back and soaking up the sun, breathing in fresh air, sharing food and most of all Fresh FISH AND CHIPS!!! KPA’s continuous and unwavering support to kidney patients have greatly influenced how they perceived their condition and experiences such as this only goes to show that there is life after kidney ailment”.



## National Kidney Federation Annual Patients' Event

This year's Patient Event in October was a brilliant opportunity for attendees to connect with peers, build new relationships, and receive support in a social kidney community setting.



A range of insightful presentations from professional and patient guest speakers covered a wide range of topics including Peer support, renal social work, understanding medication and much more. For those who were unable to attend, you can watch back all of the sessions through our website at [www.kidney.org.uk](http://www.kidney.org.uk) but we hope to see many more of you at next year's event.

*By Chris Talbot, NKF Membership Development Lead*



# NEW RESEARCH

## Development of novel tests (biomarkers) that can diagnose acute rejection and chronic damage in the kidney transplant

A kidney transplant is the best treatment for patients with kidney failure. This surgery gives a longer and better quality of life with lower NHS costs compared to dialysis. But new kidneys currently have a limited lifespan of 15-20 years. Following transplantation, acute rejection can have a significant impact on allograft survival and can also lead to the development of chronic damage (called interstitial fibrosis/tubular atrophy – IFTA). When the transplant fails, patients have to go back on dialysis or get another transplant.

The monitoring of the kidney transplant relies on the use of biomarkers. A Biomarker is a biological molecule found in body fluids (e.g. blood, urine) or tissues that can indicate a normal or abnormal process, or a condition or disease.

We think the current biomarkers to check the health of the transplant can be improved and help transplanted kidneys last longer. As of now, doctors measure creatinine levels in blood samples from transplanted patients and the protein leak in their urine, but these tests are not perfect. The measurement of creatinine in the blood picks up the problem only after much damage to the transplant is already there. Most importantly, it does not indicate the cause of damage, and a biopsy is then needed to confirm and figure out the best way to treat. Similarly,

significant protein leak in the urine can be associated to conditions other than rejection such as diabetes or hypertension. A biopsy (taking a small piece of the transplanted kidney) is currently the best way to find the type and cause of kidney damage. If done even earlier, as in some studies, it can detect up to 25 % of transplants that have started to reject before we even suspect anything is wrong by the measurement of creatinine or the protein leak in urine. This is because the cells causing transplant rejection can be seen under the microscope. If left untreated, this so-called “sub-clinical rejection” may carry significant damage to the transplant. But because the biopsy is an invasive procedure with a risk of bleeding, it is not a good way to regularly check for early signs of a problem.

The limitations of current biomarkers highlight the need for novel biomarkers that can provide earlier signals of rejection or chronic damage and can also reduce the need for diagnostic biopsies in the future.

We previously developed a blood biomarker that can predict rejection up to six weeks before any clinical signs such as a higher creatinine level (KALIBRE study). How did we do this? We collected several blood samples from transplant patients over the first 12 months after transplantation.

Some then went on to have clinical rejection and some did not. We did molecular tests and compared these two groups. We used the information from this study and designed our blood biomarker.

Blood and urine samples and blood cells from the patients that took part in the KALIBRE study are currently stored in the TIN-TIN Biobank at King’s College London. We now aim to use these blood samples to develop new biomarkers that will be able to diagnose rejection and chronic damage better and earlier. We will use novel methods, the so called “omics”. “Omics” are technologies that enable the study of all biological factors (e.g. DNA, proteins, metabolites etc) within body fluids (blood, urine) or specific cells. The various “omics” analysed in blood and blood cells from the transplant patients, will generate large and complex data sets that will require analysis by special methods and software tools (bioinformatics).

We are grateful to the Guy’s and St Thomas’ Kidney Patients’ Association for funding our pilot study on the development of a novel biomarker of rejection. This pilot study will provide the evidence for a substantial grant application to established grant-giving organisations to complete the “omics” work.

With these technologies we believe we will be able to understand how genes are turned on in different cells, and how this may contribute to the development of rejection and chronic damage. This may uncover new ways to treat rejection with fewer side effects and may also improve our ability to predict rejection and chronic damage better and earlier. It might also reduce the need for biopsies, therefore minimising the risk of significant complications. Finally, it can also allow a programme of work to develop tests which can be used to tailor anti-rejection treatment to an individual patient allowing us to find the right balance in order to prevent rejection while also avoiding unnecessary side effects.

**Written by Dr. Theodoros Kasimatis<sup>1, 2, 3</sup> and Dr. Paramit Chowdhury<sup>3</sup>**

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2. King’s Kidney Care, King’s College Hospital, King’s College Hospital NHS Foundation Trust, London, UK
3. Department of Nephrology and Transplantation, Guy’s Hospital, Guy’s and St. Thomas’ NHS Foundation Trust, London, UK

# Thanks

The KPA is solely run by volunteers who give their time freely to ensure that the charity continues to flourish and help as many kidney patients as possible. Unfortunately, a number of people have stepped down from our Trustee board and Committee Members group this year. This includes John Oglivie, Janice Stephens, Margaret Rodgers and Charles Jaja.

We would like to thank them for everything that they have done for the KPA over the years and wish them all the best for the future.

Lastly, a special thank you to Sue Lyon who worked exceptionally hard over the years whilst undertaking various roles on the Trustee board. We hope you are enjoying your retirement and all the best for the future.

# We need you!

We are seeking to recruit new volunteer Committee Members, so we can continue to support kidney patients and their families.

These voluntary roles are essential as they ensure that the Trustees can deliver large scale events such as the annual family fun day. Ideally, we would like to recruit individuals with commitment, enthusiasm and a good understanding of the challenges and opportunities associated with being a kidney patient. In return, the successful applicants will join a warm and friendly team that works collaboratively to support each other as well as our kidney patients.

If you are interested in finding out more then please get in touch by emailing [info@gsttkpa.org](mailto:info@gsttkpa.org) to arrange an informal chat.

## DONATE

Donate to the  
KPA by text:  
enter code **WGXI22**  
Add the amount.  
Send to **70070**

**JustGiving™**  
[www.justgiving.com](http://www.justgiving.com)

## Wordsearch

Find the hidden words - the theme of our wordsearch is 'Home Inspection'.

APARTMENT  
APPLIANCES  
ATTIC  
BASEMENT  
BUYER  
CHECK  
COOLING  
CRACKS  
DETAIL  
ELECTRIC  
FLOOR  
FOUNDATION  
HEATING  
HOUSE  
INSECTS  
PORCH  
PROPERTY  
ROOF  
SIDING  
WALLS

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