



# An eventful summer for the KPA

## Welcome to the latest issue of Kidney Talk

Autumn is definitely in the air, with falling leaves and darker evenings. Any time of the year can be difficult for kidney patients – managing fluids in very hot weather can be a real headache on dialysis – but the colder weather can make life much harder. Bad weather can make it more difficult to get to the dialysis unit or to hospital appointments, and people need even more layers than usual to keep warm.

One consolation of the colder weather is the thought of a lovely, warming hot meal when you get home, but that, too, can be a problem if you are on a restricted renal diet. When I was dialysing, I well remember longing for a large bowl of tomato soup when I got home, or a mug of hot chocolate in the evening – and enjoying both so much once I was at home after my transplant.

So I was very pleased to hear about the Kidney Kitchen (see overleaf). This new website, developed by Kidney Care UK, offers step-by-step recipes for delicious kidney-friendly meals. The recipes have been devised by Chef Paul Ripley, with the support of renal dietitians, and take into account the problems of balancing dietary advice if you also have diabetes.

You'll see from other articles in this issue that it's been a very active summer for us. In April our runners did us proud in the

London Marathon, with everyone finishing the course – our thanks to all. Our 5th Family Fun Day, held in June, was again a great success, with some new and old attractions that everyone enjoyed. And we must not forget the British Transplant Games, which were held this year in Newport, Wales. As you will see inside, the Adult Team and the Evelina London VIPs brought home the medals in fine style.

GSTTKPA was also one of the supporters of Jackie Dowding's Transplant Sailing Challenge crew in the Round the Island Race at the end of June (read Jackie's story here). This annual event in the yacht-racing calendar is a great opportunity to publicise the benefits of organ donation and transplantation, especially as Jackie was invited to speak at the post-race press conference. We understand that Jackie has lots of ideas to give more kidney patients the opportunity to join her in promoting organ donation. We are looking forward to hearing from her!

The KPA's activities would be impossible without our all supporters and the Committee members. If you, too, would like to be involved, or hear more about your KPA's activities, why not come along to our Annual General Meeting? It takes place in the morning on Saturday 30th November at Guy's – for more details see the back page.

**Sue Lyon**

## AND THE WINNERS ARE...

We are pleased to announce that the winners of GSTTKPA's first Research Competition for GSTT kidney unit staff are:

- Mr Pankaj Chandak and colleagues for their project: Novel therapies delivered by machine perfusion to improve transplant outcomes
- Dr Hannah Maple and colleagues for their project: Quality of life in dialysis and transplantation

Our thanks to the judges for their help with our first Research Competition:

- Dr Dimitrios Moutzouris, Consultant Nephrologist, GSTT
- John Ogilvie, Trustee, GSTTKPA
- Lisa Silas, Advanced Nurse Practitioner, GSTT

Both winning teams will be writing about their research in a future issue of Kidney Talk.

## KEEP IN TOUCH WITH YOUR KPA



Visit our new website at **gsttkpa.org** to read the latest issue of Kidney Talk and sign up to receive KPA news direct to your inbox.

Join our Facebook group **facebook.com/groups/gsttkpa**

Follow us on Twitter **@GSTTKPA**

# Save your vein

**If there's one experience shared by all kidney patients, it's having lots of blood tests.**

These tests are essential, but the vein is damaged with every blood test or IV line. You need a strong, healthy vein for a successful dialysis fistula or graft. This is why it is so important to protect your veins.

Save Your Vein is an awareness campaign designed to educate and empower kidney patients and teach healthcare professional about the importance of protecting veins for the future. Founded by kidney transplant professionals from the West London Renal & Transplant Centre, Save Your Vein advises that if you are having lots of blood tests, you should ask the nurse or phlebotomist to:

- Take the blood from the back of your hand every time, if at all possible
- If not, alternate the sites on your arm so that the veins have time to heal
- Take extra care when taking blood
- Not duplicate blood tests unnecessarily, and only put in an IV line if absolutely necessary.

To find out more about Save Your Vein, visit [www.saveyourvein.org](http://www.saveyourvein.org)



You can download a patient information card to show to health professionals at <https://bit.ly/2nvcN5>

kidneytalk AUTUMN 2019



Image: Adedayo Olaseinde

## The first UK Black living kidney appreciation event

**In May over 150 African and Caribbean living kidney donors gathered with their recipients in London to be honoured and recognised for their acts of selflessness and bravery.**

The first of its kind in the UK, the event was hosted by Gift of Living Donation (GOLD), and marked the launch of 'Because of You', a celebration to appreciate African and Caribbean living kidney donors in the UK.

In attendance was the Camden Mayor Maryam Elamdoust, who said "As someone from an ethnic minority background it was an honour and a privilege to be invited to open and speak at such an important event that celebrates the gift of life through living donation."

Dela Idowu, Founder of GOLD, said that the celebration gave living donors and their loved ones the space to share their inspirational stories with others in a positive and relaxed surrounding. She added their reminiscences stories were full of love and compassion.

Many of the donors commented that the event was inspiring, thought provoking and long overdue. Jacqui Govere said: "It was such an amazing event! I didn't realise there were so many Black living kidney donors. I'm sure with more publicity there will definitely be more of us wanting to become donors. Listening to donor stories was really emotional and heart warming and I made some new friends."

Harley Armstrong, who attended the event with her father, a dialysis patient at Guy's Hospital, commented that speaking with other donors had encouraged her, as she had come forward as a donor for her dad.

The lunch was also attended by Shaun Wallace of The Chase TV quiz show and distinguished poet Linton Kwesi Johnson. Both commented that they were really humbled by the donor stories and were delighted to be part of such an important and laudable occasion.

Also present were Orin Lewis, co-founder of the Afro-Caribbean Leukaemia Trust, and Kirit Mistry, Co-Chair of NBTA (National Black, Asian and Minority Ethnic Transplant Alliance). Both consider that it is now time for organisations to work together to bring the voices of the donors to a wider audience to encourage more people from the Black and South Asian communities to come forward as donors.

Lisa Burnapp, NHS Blood and Transplant Lead Nurse for Kidney Donation, concluded: "Gift of Living Donation hosted a truly wonderful event that for the first time in the UK brought together Afro-Caribbean living kidney donors. Their stories were inspiring and as a healthcare professional it highlighted the true heroes of their work."





**In 2019 the British Transplant Games took place in Newport, Wales from 25th to 28th July. Teams from GSTT adult kidney unit and Evelina London Children's Hospital attended the event with support from GSTTKPA.**

### **News from GSTT Adult Team**

Simon Bessant, Adult Team Manager writes: This year, GSTT sent a team of 14 transplant recipients and 3 live donors to compete in sports from athletics to archery. Over the four days of the Games, the team got to meet old and new friends and welcome new members, as well as competing in the Games in honour of our donors.

There were four new competitors this year, including three who had recently transferred from the Evelina children's team and one new adult team member. As always, our team is welcoming to new competitors and their families.

The Games began with snooker, archery, squash and volleyball competitions, followed by the Opening Ceremony. The latter was followed by our team meal, which gives us all a chance to catch up and get to know each other.

Throughout Friday and Saturday the team competed in many different sports, culminating in team members and supporters competing in the donor run (either 3km or 5km walking or running). This is the star event for publicising the Games and the difference organ donation makes to people's lives, and is open to public participation.

On Sunday, after the athletics competitions, the Games closed with a gala celebration. There was much for us to celebrate as we did really well, winning eight Gold, eight Silver and seven Bronze medals. This achievement and our attendance were only possible because of the generosity of GSTTKPA, who helped fund the team.

One of our new competitors comments: "I was a first-year attendee with the Adult Transplant Team at this year's Transplant Games in Newport. After attending the games for many years as a child, I was

looking to a new experience at the Games. I have to say that both competitively and socially it was a fantastic experience for myself and my family from beginning to end, made even more special when I won a Silver medal in the 5k walk. Without the very generous funding from the KPA (due to my Young Adult status), my family and I would not have been able to attend. We appreciate this very much and hope to be able to attend the Games next year in Coventry."

The adult team meets up a couple of times each year before the Games, and we are always welcoming to new people that want to find out more about the games. For more information about the Games, please contact Simon Bessant (Simon\_Bessant@hotmail.com)

### **News from the Evelina VIPs**

Grainne Walsh, Transplant Advanced Nurse Practitioner, writes: 2019 is a milestone year, as Evelina London celebrates its 150th birthday and we entered our largest team ever at the British Transplant Games. And once again we were crowned National Best Kidney Kids Team: a fantastic achievement!

This year, 37 families made up the Evelina London VIPs (Very Important People, Patients and most importantly Penguins!), with competitors ranging in age from 3 to 17 years. Together with their 40 siblings, families, supporters and volunteers, we numbered 165 people—so were definitely seen and heard throughout the Games weekend.

Mia, our three-year-old competitor, found herself in the spotlight, as she was the youngest competitor in the whole Games. Having only recently found herself able to walk, she became a great ambassador for organ donation and transplantation, as her story was covered in national newspapers and on ITN news.

Emily and Lilly's father Tim and friend Rob cycled from their home in Surrey to Newport with huge support from John, to meet us at the hotel in time for the Opening Ceremony, not only raising vital funds but much needed awareness. So thank you, guys, and a huge well done!

The Opening Ceremony was held in Rodney Parade, home of Newport AFC. It was so exciting being welcomed into a crowded, cheering stadium. The event became emotional when the living donor group were welcomed in and our team were proud to count many of our parents amongst them. The final group who entered the stadium were the Donor Family Network team, who deservedly received a prolonged standing ovation.

Our team took part in 17 different sports (track & field, tennis, table tennis, badminton, cycling, swimming and archery) over the four competition days, and did us proud by bringing home 58 medals!

The Organ Donor Awareness run is traditionally held during the Games and it was great to see over 150 of us get colourful and help raise awareness as we toddled, were pushed, ran or walked the route.

We were incredibly proud of Rian and George who competed for the Junior Great Britain & NI team at the World Transplant Games just a few weeks after the British Games, and are thrilled to report they both won medals.

We stayed in the Marriot St Pierre Hotel and the team there were incredible in making our stay memorable. They had penguins dotted all around the hotel from the housekeeping carts to main reception. There was also a craft station to help when children needed some quiet time and a penguin-themed welcome zone on our arrival. It was really special!

This year we wanted to reduce our single-use plastic consumption. Usually a team our size will get through hundreds of water bottles, so this year all the VIPs were given a refillable sports bottle, decorated with great penguin stickers made by Kitty's VIP uncle Clive. Our hotel kept penguin-themed water urns available throughout our stay and we all felt very proud of the difference we made.

The Transplant Games are an annual highlight, not only encouraging transplant recipients to get fit and compete in sport, but allowing the Evelina London Transplant team to facilitate much-needed support for our children, their siblings and parents. Having such a big team is amazing; this year saw 40% of our patients compete, which is wonderful but it doesn't come cheap. As ever, we would like to acknowledge the ongoing support of our KPA and say a very big thank you!



# Welcome to the Kidney Kitchen

Food is one of the great pleasures of life, whether it's a celebration meal with family and friends, a romantic dinner for two, or movie night at home with the family. But all this changes if you have kidney disease. Instead, each meal turns into a minefield, especially if you have diabetes or other health conditions.

The Kidney Kitchen, developed by Kidney Care UK, is a single online destination for delicious, kidney-friendly recipes that will fit into eating plans given to you by your renal dietitian. The aim is to show you that, even with kidney disease, food can still be fun and enjoyable.

The Kidney Kitchen website ([www.kidneykitchen.org](http://www.kidneykitchen.org)) includes step-by-step recipes showing you how to prepare and cook delicious, kidney-

friendly meals. These recipes have been devised by Paul Ripley, a renowned chef with over 35 years of experience.

You can visit the Kidney Kitchen Youtube channel to cook along with Paul at <https://bit.ly/2mqTg2U>

Each recipe has been developed with the support of the British Dietetic Association Renal Nutrition Specialist Group. So each recipe comes with a comprehensive set of Food Facts: how the recipe fits into your kidney diet; vegetarian, healthier or cheaper options; and how to store your dish so that you can safely eat any left-overs on a day when you don't feel up to cooking. (But bear in mind that we are all different, so check with your own renal dietitian that a recipe is suitable for your needs.)

## Other kidney-friendly recipes are available

**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 (<https://bit.ly/2VGK5cz>)

Lawrence Keogh's **Rediscovering Food & Flavour** ([lawrencekeogh.com/books.php](http://lawrencekeogh.com/books.php))

# THE RENAL ASSOCIATION NEEDS YOU!

If you a kidney patient, a family member or carer of someone with kidney disease, it's your chance to help improve kidney care by becoming a member of the Renal Association Patient Council.



## What is the Renal Association Patient Council?

Founded in 2014, the Patient Council is a group of kidney patients (dialysis and transplant) and family members. Patient Council members work as a team to support the Renal Association, the organisation that represents kidney health professionals and aims to ensure that everyone receives the best kidney care.

## What does the Patient Council do?

The Patient Council meets four times a year, and its work includes:

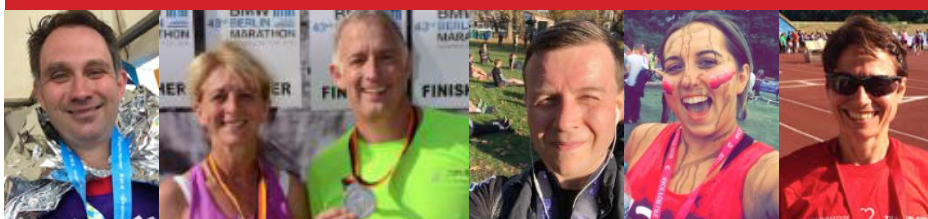
- Getting involved in new work designed to improve patient experience and outcomes
- Helping to produce new patient information, including leaflets, reports and posters
- Discussing new research and survey proposals, and how information from the kidney centres is being used
- Support on how data is managed and used, and patient consent
- Encouraging discussion between patients and clinicians to promote patient involvement in kidney centres, as well as regionally and nationally.

Patient Council members are unpaid, but there is an allowance for attendance at meetings, plus travel costs. Any training you need will be provided, together with continuing support.

## Would you like to know more?

If you think you would like to join the Patient Council team, please get in touch with Jen to find out more or to ask for an application pack at: [jennifer.barwell@renalregistry.nhs.uk](mailto:jennifer.barwell@renalregistry.nhs.uk)

## Congratulations to our London Marathon Winners



It's a very long way to run...26.219 miles through the streets of London. But our amazing runners all completed the London Marathon to support of the KPA. Our thanks to you all for your support for kidney patients and their families.

**You are all winners!**

**Tom Beasor**  
**Emma Clare**

**Dave 'Mavis' Grain**  
**Tamara Harries**

**Les Frost**  
**Aled Lewis**

**Shannon Wade**  
**Henrietta Walker**



# Round the Island Race for organ donation



In June, following a successful World Kidney Day Sail, a Transplant Sailing Challenge crew took part along with 1300 other yachts in the famous Round the Island Race, an annual event covering 50 sea miles around the Isle of Wight. Jacque Dowding reports.

I believe that the inception of the project was when I promised my surgeon Mr Georgios Papadakis (while waiting in the ward before my transplant) that I would somehow organise a sailing event for transplant recipients and my Renal and Transplant Teams. This would be a way of saying thank you, and of showcasing the success and life transformation that can result from a transplant. Equally important for me was to thank my donor and their family, by demonstrating that I now had my freedom to do something that I was passionate about in the element that I love.

I originally began to plan for a Round Britain Sail. However, the logistics and timeframes did not allow the project to go through, and I was very weary from writing and calling for sponsorship and speaking to the media in my very tight spare time.

So I thought I would continue by going back to Square One.

The World Kidney Day Sail (WKDSail) may have been only one day, but it had an impact. On board we were honoured to be joined by Professor Nizam Mamode, as well as crew made up of transplant recipients. We were also joined by ITV Meridian News, and I gave some local radio interviews.

Following that day, I saw another opportunity on the horizon. The Round the Island Race (RTIR) is a famous event in the racing calendar for yachts of all sizes. Their slogan is: A Race for All. I had some funds left from WKDSail and entered the race. I then needed a boat again and a crew.

I found most crew members through contacts and people I had sailed with



before. Some were complete novices, though one took a four-day course and another came with me on a trip in Chichester harbour and a few hours with another crew member.

Then Mr Papadakis followed up my invitation from two years ago and came on board with us. Race day was coincidentally my transplant's second anniversary. What a massive bonus with my surgeon by my side!

Once again we chartered our chariot, Cascadeur, a 41 foot yacht, from a colleague. Then, we needed to raise funds, I began by contributing our own money, and fundraising really took off.

The start of the race was at 0840. Anxiety mixed with excitement meant that the atmosphere on board was electric and we cheered loudly going over the Start Line. That was the spirit that continued to dominate throughout the race.

The wind increased as we headed for the south of the island and so did the strength of the sun. Then the wind started to die, until there was none and we were rolling like a barrel with the sails flogging, the crew roasting for over two hours...as skipper I had to make a difficult decision. We retired—along with 851 other boats.

But we were winners from the start and felt like winners, from beginning to end. We have been twice blessed and will never lose. After the race, we had several media interviews and plugged away with our message supporting organ donation, and the importance of people sharing their wishes with their families.

The crew and I would like to thank everyone who made this possible: our donors, their families, Transplant Teams, the media and, of course, our sponsors. And many thanks to the KPA Committee for their support in our endeavour.

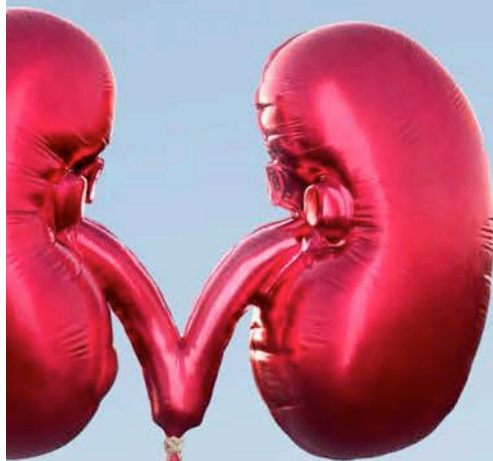
Finally, watch this space. There are plans afoot that could involve you!

## KIDNEY INFORMATION FILMS WIN AWARD

In the last issue of Kidney Talk, we told you about a series of four short films for adults with kidney disease, which feature patients and staff from GSTT kidney unit. We are delighted to let you know that the films were 'commended' in the recent British Medical Association (BMA) Patient Information Awards. Our congratulations to everyone involved in making the films.

Funded by Guy's and St Thomas' Charity, the films aim to inform you about the different options for managing your condition so that you can make informed choices about your treatment. They also tell you what to expect from the Guy's and St Thomas' kidney service.

The films can be viewed at <https://bit.ly/2Gbl9g>



# Organ Donation Week 2019

Despite record levels of organ donation, refusal by families remains the main reason why deceased donation does not go ahead. Families are far less likely to consent if they do not know what their relative wanted. So Organ Donation Week 2019 (2nd-9th September) continued the campaign to raise awareness of the importance for families to talk about organ donation.

Family discussions will become even more essential in March 2020, when the law in England will change to an opt-out system. This law—also called ‘Max and Keira’s Law’—means that all adults in England will be considered to have agreed to be an organ donor when they die, unless they have recorded a decision not to donate or are in one of the excluded groups. This new system is a ‘soft’ opt-out since family members will continue to be consulted about donating their late relative’s organs. So in the lead-up to the change in law, NHS Blood and Transplant is urging families across England to talk about their organ donation decision, with the campaign message ‘Pass it on’.

GSTT patients and staff played their part in passing on the message about organ donation, with stands in Guy’s foyer and St Thomas’ birdsong corridor during Organ Donation Week.

Gift of Living Donation (GOLD) held a photographic display of the portraits of 16 living kidney donors from the Black community to help raise awareness and encourage more living donors from this community. The photographs, together with personal stories, are included in Changing Perceptions, a booklet designed to help newly diagnosed patients to talk about living donation with their family and friends. Copies of the booklet are available from the Guy’s kidney clinic.

GSTT was also represented on the first-ever London Organ Donation Walk. Over 250 kidney patients, families and staff from all over London walked a total of 1295 miles to represent the 1295 people listed for a transplant in London. At the end of the walk, participants gathered at Westminster to honour deceased donors and pay respects to people who have died while waiting for a transplant.

To find out more about Max and Keira’s Law, go to <https://bit.ly/2WfpAmq>

## PASS IT ON

## 5<sup>TH</sup> FAMILY FUN DAY

The KPA’s 5th Family Fun Day was held on 9th June. Once again, it was a great success, with over 120 patients, family members and kidney unit staff enjoying the afternoon at King’s College Sports Ground. As in previous years, people enjoyed the barbecue, face painting, raffle and other entertainment. But this year there was a new attraction: a London to Brighton stationary bike ride, using exercise bikes kindly loaned by Ballantyne Health Clubs.

The KPA is very grateful to everyone who made the event such a success. This includes the many people who donated raffle prizes, cakes and fruit; the staff at King’s College Sports ground; the patient transport team; George Brown and Teresa Durkin, the event organisers; and John Ogilvie, who arranged with Ballantyne for us to borrow the exercise bikes for the event.

We are already starting to plan next year’s Family Fun Day, and will share the date as soon as we can. In the meantime do get in touch if you have any ideas for Fun Day 2020 or would like to help with the organisation.

## SAVE THE DATE

### GSTTKPA Annual General Meeting

**Saturday 30th November**  
**10.00 am to 12.00 midday**  
**Burfoot Court Room (off the colonnade), Guy’s Hospital**

Come along to support your KPA, and hear from our speakers:

- Mr Pankaj Chandak about advances in transplantation
- Dr Hannah Maple about quality of life for kidney patients
- Winifred Yeboah & Sarah Watson about a GSTTKPA-supported study into the benefits of complementary therapy for dialysis patients.

### World Kidney Day 2020

**Thursday 12th March**

The 2020 campaign will highlight the importance of preventive measures to avert the onset and progression of kidney disease.

There will be more information nearer the date at [www.worldkidneyday.co.uk](http://www.worldkidneyday.co.uk)