



## “Hello... This is your kidney donor”

The unforgettable day  
I met my kidney donor

Written by Chetan Joshi – WLKPA – Photo: Visit to Kew Gardens – Aug '19

**A**fter receiving my kidney transplant in August 2015 from a living, non-related kidney donor, their identity remained a mystery to me. All I really knew was that she was an elderly lady, about my mum's age. Over the years since, we have been able to communicate with each other by sending greeting cards and letters via our hospitals. (I affectionately call her “My Angel.”) However, this system broke down earlier this year when I grew concerned that I hadn't received a Christmas card from her as I had previously done. I inquired at the hospital if there was any way to find out if my donor was ok. I was naturally concerned for her well being. It was suggested that it could be arranged for the two of us to exchange contact details so we could contact each other directly without the hospitals' intervention. *Continued on page 2 ►*

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My immediate thought was, **“YES!”**

A couple of weeks later, I received a call from my transplant co-ordinator to confirm that I was happy to proceed with the exchange of details. Of course, I said yes. Some time later, I received a call from Ray, my donor's transplant co-ordinator to confirm the same. We chatted for some time. I guess he wanted to make sure there was no potential “cause for concern”. I can imagine this being a delicate topic to initiate. So anyway, life carried on as normal over the next few weeks.

One afternoon, on a sunny day in Spring, I was driving home from a shopping trip. My phone began to ring. I safely pulled over and stopped the car. My initial thoughts were, “Could this be another PPI company? Or maybe a scam call purporting to be from HMRC?” (I've had a few of those).

I answered the call, **“Hello.”**

A softly spoken voice at the other end said, **“Hello...Is this Chetan?”**

**“Hmm. This doesn't sound like a PPI call I've ever had”** I thought.

**“Yes”** I replied. **“Er... this is your kidney donor.”** Came the response.

My heart instantly melted and I became enraptured with a warm, tingling sensation. My eyes began to well up profusely.



*Jean's organ donation journey was featured in The Daily Mail over a few years*

**“IT'S MY ANGEL!”** I thought. My head spontaneously filled with a million questions I wanted ask but I didn't want to come across as a nutter. So, I composed myself and tried to be as normal as I could under the circumstances.

We spoke for a while during which we introduced ourselves and our backgrounds. It felt like we were reuniting, age-old friends. It came as such a surprise to me how well we got on. We do, after all, have a special bond that links us.

I met with Jean Short, my kidney donor a few weeks later at her home in West Mersea, Essex which she shares with her loving husband Ken. Apparently, Jean hadn't received any of my letters and cards which I had sent her throughout the previous year. She naturally feared the worst had happened to me. It had only

recently come to light that a stack of my cards and letters had been discovered at the hospital and they had obviously not been forwarded on to her! We were both so relieved to know that all was okay. At the meeting, I met with Ken and some of Jean's friends along with one of her grandsons, Luke. We all got on so well and had a wonderful afternoon.

Jean told me what had prompted her to want to donate

one of her kidneys. She had read an article in the Daily Mail about a doctor that needed a kidney transplant and she wanted to donate to him. Sadly, she wasn't a suitable match. Nevertheless, she had firmly resolved to help someone else who needed a kidney transplant. So, after contacting NHSBT and having been thoroughly assessed, tested and scanned, I was the lucky soul who was matched with Jean and was prepared to receive this amazing, life saving gift. I had, in the past, heard of and met other patients that had received kidney transplants altruistically but never entertained the possibility of it happening to me. I'm a big Only

Fools and Horses fan and hearing such stories reminded me of a line from the episode “Mother Nature's Son” in which Del Boy quips, “Thats like the parable of the lucky git!” Things like this always seemed to happen to other people, not me.



*Me with Jean, Ken and their grandson Luke*

Jean contacted Caroline Scott, the writer of the article who had previously written a piece about her. She told her of the good news and we all met a couple

of weeks later at Jean's home for an interview. Our story was to be published in the Good Health section of the Daily Mail newspaper. It's Jean's hope that others may be inspired to want to donate after reading the article in the same way that she was. It is also my intention to offer hope to other patients who are waiting for a kidney to not feel sad and dejected when all seems bleak. Kidney disease is not fun but having a positive mental attitude is a great way to deal with it.

*The full Daily Mail article can be read here: [www.dailymail.co.uk/health/article-7273987/The-angel-risked-health-70s-giving-kidney-total-stranger.html](http://www.dailymail.co.uk/health/article-7273987/The-angel-risked-health-70s-giving-kidney-total-stranger.html)*

## Annual Memorial Darts Fundraiser

Back in May, we had the honour of attending the annual memorial darts fundraiser in memory of renal patient, Bill Duffy. The event was attended by family including his wife Sonia, relatives, friends and associates of Bill who was also a prominent figure in his local community. Bill had a passion for sports in general but darts was among his favorite as it brought people of all abilities and ages together in a family atmosphere. A number of items including sporting memorabilia were auctioned off on the day with proceeds going to the WLKPA.



The event was held at Harrow Borough FC



Bill's wife Sonia taking aim for a 180

## In Memoriam – Helen Philomena Russell 1949 – 2019



Helen (Phil) was born in Southern Ireland. She moved to England, met and married Victor in 1968 and had a daughter, Angela.

She was diagnosed with kidney problems and attended clinics at Hammersmith Hospital. Her sister, Teresa, donated one of her kidneys in 1988 which gave her a better quality of life. Despite having to travel nearly 40 miles she enjoyed seeing people in the clinic.

She lost her hearing, but she never complained and had a cochlear implant at Southampton Hospital.

Phil was in hospital last December and came home for Christmas knowing that life was short. She passed away in Hammersmith Hospital on Good Friday with Victor beside her; she had a smile on her face saying Enough is Enough. Friends and Relatives donated £355 to WLKPA.



From l-r: Kevin O'Dwyer, Charlotte Harvey, Mike Smith, Chetan Joshi, Bobbie Field, Sharon Harris, Terry "Dr Bob" Brushfield-Hodges, Penne Sawford, David Bowditch, Sarah Koutandos, Steve Adderley  
**WLKPA AND HAYES RENAL UNIT ROLL OUT THE RED CARPET FOR BACCES! (British Airways Cabin Crew Entertainment Society)**



British Airways Cabin Crew Entertainment Society

The WLKPA gratefully received a cheque for £1000 from proceeds of the production of BACCES' winter 2018 pantomime SINBAD.

We were delighted to meet with the friendly and talented team of cast and crew at the Hayes Renal Unit earlier in June.

The charity was nominated by BACCES' Musical Director, Bobbie Field, and her husband, Terry "Dr Bob" Brushfield-Hodges, whose son-in-law Wayne suffers from renal failure and has been dialysing for many years.



The BACCES representatives received a fantastic welcome from staff and patients alike. They were given a comprehensive and fascinating tour of the unit by Head Nurse Sharon Harris

The donation will be put towards day excursions, transportation, and other supportive areas directly impacting patients such as organising dialysis machines at home, as is the case for Wayne.

Their next theatrical production is of Snow White and the Seven Dwarfs and it will be running from Wednesday 27<sup>th</sup> November to Sunday 1<sup>st</sup> December 2019 at The Beck Theatre in Hayes. Visit [www.bacces.com](http://www.bacces.com) for more info.

## Team Hammersmith at the British Transplant Games

**The British Transplant Games (BTG) took place this July in Newport, South Wales. Wow, What an unforgettable experience!**

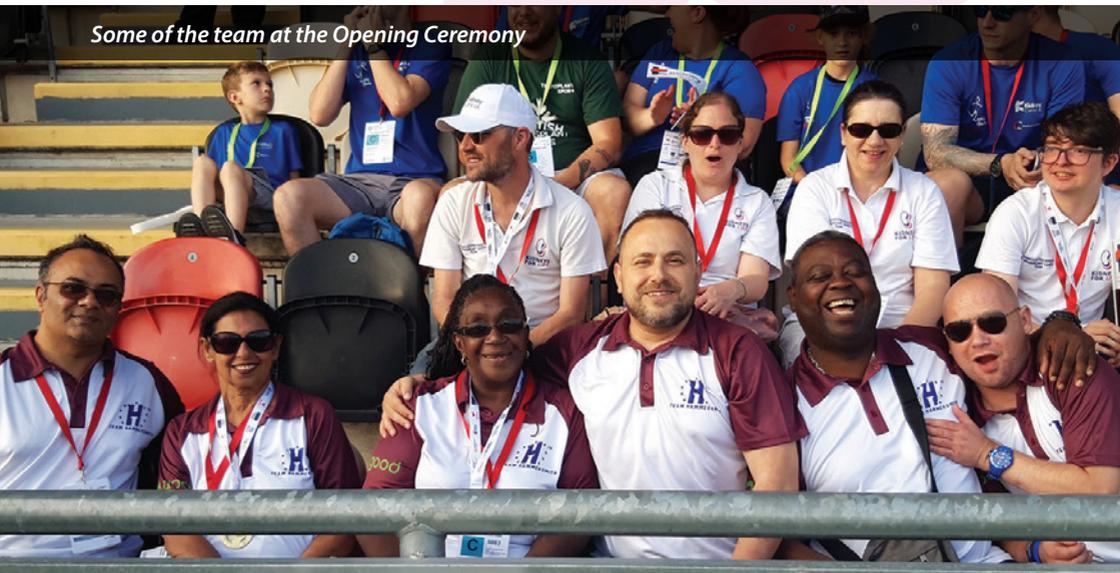
Our team was modest in size but we still came home with an impressive medal haul. The Games are open to all transplant patients whether donors and/or their families or recipients. Although essentially a competitive event, those of us that are built for comfort more so than speed thoroughly enjoyed ourselves along with our peers from across the UK.

As we prepare to go to print, The World Transplant Games will be taking place on home turf this August in Newcastle. If the atmosphere there is anything like how it was in Newport, I'm sure everyone is in for a great time.

The British Transplant Games are now over forty years old. The first Games took place in Portsmouth in 1978. Over recent years they have taken place in;

2018	Birmingham
2017	North Lanarkshire
2016	Liverpool
2015	Newcastle Gateshead

Next year, the 2020 BTG will be held in Coventry. So, whether you are a novice or a seasoned professional, joining Team Hammersmith will certainly open your world to new friends, fun, fitness and experiences.



Some of the team at the Opening Ceremony

Team Hammersmith returned with several medals. Congratulations to all the winners and everyone that took part.



If you would like to be part of Team Hammersmith at next year's BTG, we'd be over the moon to hear from you. The call for participants begins in the new year. To view more images from the Transplant Games, visit the website or our Facebook page.



Strike a pose! The new Kit unified the team at the Games



The Games brought together renal patients of all ages from across the UK

Some of the events available
100m Sprint
Adults 6 a side football
Adult Swimming
Archery
Badminton
Ball Throw
Basketball
Childrens 5-a-side football
Childrens Cycling
Children's Ball Throw
Children's Long Jump
Children's Swimming
Cycling
Darts
Donor Run
Golf
Indoor Bowls
Long Jump
Mini Marathon
Netball
Obstacle Course
Snooker
Sport Stacking
Squash
Table Tennis
Tennis
Ten Pin Bowling
Under 5's Archery & Long Jump
Volleyball
Walk



Ten-pin bowling with new friends

## Organ Donation and Islam & the new Verdict



I joined the KPA following my transplant in 2012. My main purpose was to become involved in promoting organ donation amongst Muslims and ethnic minorities. At the outset I started attending meetings organised by NHSBT, The NKF, and the NBTA (The National Black, Asian & Minority Ethnic Transplant Alliance) <https://www.nbta-uk.org.uk/>. They were working to find solutions to promoting organ donation amongst ethnic minorities. At the same time both my wife (who donated her kidney to me) and I were involved with trying to promote organ donation at events organised by Muslim Organisations including one event at Friday Prayers in Feltham alongside NHS Blood and Transplant. One of the difficulties we found with fellow Muslims was the lack of education regarding Organ Donation. Organ Donation amongst Muslims has always been a sensitive subject due to a lack of knowledge involving the process of organ

donation. Most Muslim friends I spoke to felt to be an organ donor after death was forbidden and some were not sure about live organ donation. Research by NHSBT found that only 31% of Muslims surveyed recently said that they support organ donation, with just 14% of those strongly supporting – while 37% oppose donation, with 25% of them strongly opposing.

But a change was about to come. A few years back I was invited to a meeting organised by NHSBT regarding Islam and Organ Donation. It was there that I had the opportunity to meet a fellow Kidney Transplant Patient Amjid Ali, who had been on dialysis for over 20 years and finally received his Transplant. Amjid had started to volunteer with NHSBT and led the drive to bring about a better understanding of Organ Donation and Islam. One of the issues is that although 17% of people waiting for an Organ are from the Asian community, only 2% of the Asian community are on the NHS Organ Donor register. Asians were waiting longer to receive transplants too. Amjid arranged further meetings involving groups of high profile Imams from all backgrounds, transplant patients, Organ

Transplant Surgeons, Doctors and many more, to discuss Organ Donation and Islam. Following these meetings and after extensive research, on 19th June a new Fatwa (Islamic religious edict) was published by Mufti Muhammad Zubair Butt outlining guidance for Organ Donation amongst the Muslim Community in the UK. The key outlines of the Fatwa permitting Organ Donation in Islam are:

- *The transplant of pure animal organs and tissue is permissible, but the transplant of impure animal organs and tissue is not permitted unless there is no permissible alternative.*
- *Replant and autotransplant of human organs and tissue is permissible.*
- *Living/altruistic organ donation is permissible provided harm to the donor is negligible or relatively minor that it does not disrupt the life of the donor.*
- *Organ donation after circulatory determination of death (DCDD) is permissible provided the point of elective irreversibility has lapsed*
- *Organ donation after neurological determination of death (DDDB) following complete and irreversible loss of brain function, is permitted only once the point of elective irreversibility has lapsed and the heart has stopped.*
- *Deceased organ donation and transplantation of all organs/tissues besides the gonads is permissible.*

Mufti Mohammed Zubair Butt has said: "I sincerely hope that this fatwa will bring some clarity on a variety of widely held concerns around the permissibility of organ donation and transplantation and will serve as a catalyst for Imams, Muslim chaplains and scholars to discuss the issue amongst themselves and with their congregations and audiences."\*

Amjid Ali has added "In my mind, to have any chance of changing attitudes and action around organ donation among British Muslims, guidance needed to come from respected and suitably experienced Independent Islamic scholars, and most crucially for the majority of Muslims in the UK, Islamic scholars with an expertise in Islam and medical ethics."\*

With the new Opt Out Organ donation law coming in to effect in 2020 the introduction of the Organ Donation Fatwa has come at the right time. I hope and pray that more people from my faith will take the opportunity to talk about Organ Donation with their families and Imams.

– *Mohamed Ayyaz Kasmani*

The full Fatwa is available to view at <https://nhsbt.dbe.blob.core.windows.net/umbraco-assets-corp/16300/organ-donation-fatwa.pdf>

\*Quote from <https://www.organdonation.nhs.uk/get-involved/news/new-fatwa-published-to-clarify-islamic-position-on-organ-donation/>

## 1st UK black living kidney appreciation event

On 18th May, over 150 African and Caribbean living kidney donors and their recipients, gathered at the Holiday Inn, Bloomsbury, London to be honoured and recognised for their acts of selflessness and bravery.



*Jubilant and proud donors and recipients at the event  
Photo credit: Adedayo Olaseinde*



*Dela Idowu pictured with colleague Tayo and the Mayor of Camden*

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

In attendance was the Mayor of Camden, 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 Gift of Living donation (GOLD) said that the celebration gave living donors and their loved ones a platform to share their inspirational stories and meet one another.

Many of the donors from the Royal Free Hospital commented that "It was such an amazing event, inspiring, thought provoking and long overdue! It was great to meet other black living donors and hopefully our stories will encourage other black people to donate to a loved one".

Lisa Burnapp, Consultant Nurse Living Donation, NHS Blood and Transplant said, "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 health care professional it highlighted the true heroes of their work."



## Hilary's Story



**M**y name is Hilary Rose. I've been a kidney patient at Hammersmith Hospital since 1992 as my kidneys were failing due to scarring in the kidneys. When the time came for me to have a transplant, my husband came forward along with other family members. My husband gave me his kidney in 2007. Sadly it failed which was very hard for the family. I am now back on dialysis but I'm ever so grateful for my husband's act of love.

The 1st black living donor event, "Because of You" was such a lovely event and it was overwhelming to hear peoples' stories of the love they were shown by their donors and their loved ones. We heard stories from partners, siblings, parents and children. It was so touching,

It meant so much to me to be able to publicly thank my husband. I hope as a group we can highlight the benefits of coming forward as a living donor for a loved one especially in the black community where more donors are needed.

– Hilary

## Dates for your diary

### Organ Donation Week 2-8 September 2019

The WLKPA will be celebrating this important time of year at the Hammersmith Hospital main entrance and the Renal Building throughout the week.

### Renal Expo 2020 (Open to ALL to attend)

Planning is underway for a renal expo to be held in the new year. Patients wishing to register their interest in attending should email

info@westlondonkpa.org and please put **Renal Expo 2020** in the subject field and state roughly how many people you wish to bring to the event.

### WLKPA AGM 2019 24th October 6:30pm

The WLKPA Annual General Meeting (AGM) will be held on Thursday 24th October. If you wish to attend please email info@westlondonkpa.org with **AGM** in the subject field.

## Eating for a more sustainable planet

Article supplied by Anri Horne, Renal Dietitian, Nutrition & Dietetics, Imperial College Healthcare

It is difficult to have a conversation about food these days without hearing the words “vegan,” “plant-based” or “sustainable living.” As people are becoming more aware of climate change and the impact our consumption is having on the world’s food systems, more and more people are adopting plant-based diets and reducing their meat consumption. But what does this mean for a person with renal disease?

### Why do we need to eat more sustainably?

The planet is in trouble, and the way we eat is one of the main causes of this. Our food system is causing high greenhouse gas emissions, using too much land and fresh water, contributing towards deforestation, destroying wildlife and polluting the oceans and rivers. After the United Nations Paris Agreement conference in 2015, the UK pledged to further reduce their greenhouse gas emissions and fresh water use, as well as reducing waste and increasing recycling.

### What can you do?

The “planetary health diet” was created by an international commission seeking to draw up guidelines that provide nutritious food as well as addressing the major role of farming – especially livestock – in driving climate change. This does not mean you have to banish meat and dairy products completely, but rather that you get most of your protein from plant-based sources such as beans, lentils and tofu.

### Where do I start?

- If you eat meat every day, this is the first big change you need to make:
  - Start reducing your intake of red meat to once a week
  - Have two portions of chicken, and the same of fish per week
- Have Quorn, beans, lentils, pulses, tofu or eggs with plant-based meals
- Limit dairy milk and yoghurt to 1/3 pint per day (about 200ml) or use a non-dairy alternative such as almond, oat, soya or rice milks and yoghurts.
- Choose higher protein starches like wholegrain bread and brown rice

### Plant-based food that provide 15-20g of protein



1 cup cooked lentils



2 vegetarian sausages



1 cup cooked chickpeas



1 cup of tofu



1 cup of edamame beans



1 tin of beans

### Is there anything else I could be doing?

One of our targets is to produce less waste. Reducing the use of disposable plastic will go a long way to achieving this goal:

1. Buy a reusable water bottle and coffee cup	5. Store your food in glass containers and jars
2. Avoid using plastic cutlery; bring your own from home instead	6. Find alternatives to plastic sandwich bags, like beeswax wraps or silicone stasher bags
3. Bring your own grocery bags when you shop and avoid using plastic produce bags	7. Support businesses and restaurants that use sustainable packaging
4. Use recyclable paper cups and plates when necessary	8. Reuse and recycle the plastic you already have as much as possible



## Summer Day Trips 2019



Our series of Day Trips this summer was a runaway success for the 6<sup>th</sup> consecutive year. Everyone that joined us at the five destinations on offer this year thoroughly enjoyed themselves. (We'll gloss over the dodgy weather we had on our first Isle of Wight trip!) This trip was followed by Longleat Safari & Adventure Park, Isle of Wight (trip 2), Eastbourne and the final trip on 1<sup>st</sup> September to Bournemouth. If you missed out on these wonderful days out, **WHY?**

We really want ALL renal patients (and staff) in west London to benefit from our social events. We welcome comments and suggestions to help us improve the way we communicate with you all. Unfortunately, we can't physically make multiple trips to each unit on

every shift to do this. If you would like to volunteer to be a patient representative from your renal unit, please get in touch. The role will mainly involve putting up posters and handing out leaflets. Simple! Call Sarita on **07538 224156** or email [info@westlondonkpa.org](mailto:info@westlondonkpa.org)



**Contact us: [info@westlondonkpa.org](mailto:info@westlondonkpa.org)**  
**Or visit [www.westlondonkpa.org](http://www.westlondonkpa.org)**

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