

Mother's Pride



It is a widely known fact that receiving an organ donated by a family member can lead to more successful outcomes from transplantation with less risk of organ rejection and other complications. This is an issue that was highlighted in a recently televised live kidney transplant in which a father donated his kidney to his son. For most parents this would be a no-brainer and the decision to donate would require minimal deliberation. Last year Dishna Hirani, a daughter, sister, wife and mother was in a similar situation except... it was her mother that required the much needed transplant.

We met up with Dishna, her husband Mehul and eldest son Rushil to talk about the amazing, life changing decision she made to donate her kidney to her then 61 year old mother in October 2018.

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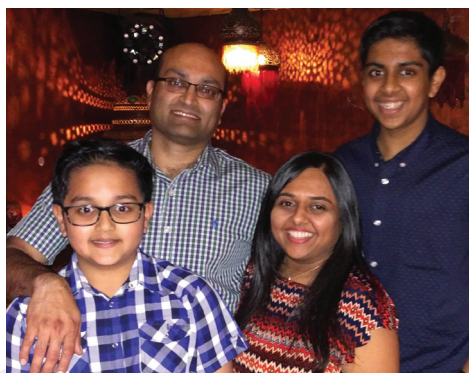
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Dishna explained that her mother had previously been diagnosed with CKD for a number of years and her kidney function was deteriorating with high Creatinine levels throughout 2018. At this point, although at pre-dialysis stage, while on a visit to the hospital, "...the nephrologist told us the chances of receiving a donor from ethnic minorities are slim and went on to explain the reasons why. We discussed living donation, and were told this was the better option." The family concluded that a pre-emptive transplant would negate the need for her mother to go on dialysis. This also gave her mother the chance to continue living a normal life.

As the eldest child, Dishna expressed her intention to donate one of her kidneys. Being a wife and mother of two boys Rushil – aged 14 and Dhiyan – aged 11, at the age of 39 Dishna realised that donating her own kidney was the best option available. She discussed her resolution with Mehul, her children and her sisters who were all very supportive – which is a testament to the unity and strong connections within the family. Her sons were at first, shocked by the news but appreciated the benefits the transplant would bring to the family as a whole. Dishna was



Dishna with husband Mehul and sons Rushil and Dhiyan

also insistent that her decision to donate should not adversely impact upon her relations with other members of her family including her sisters and they shouldn't feel obligated in anyway to follow suit.

The day of the transplant was scheduled for Wednesday 31st October 2018. The date quite conveniently coincided with Dishna's mum's 62nd birthday so they now have another reason for an annual celebration! It was decided that the transplant would be carried out using laparoscopic (keyhole) surgery with hand assistance. Laparoscopic surgery uses a combination of surgical instruments including a laparoscope – a rod connected to a digital camera. This procedure has a number of advantages to the patient over more common open procedure surgery. Some of these

advantages being reduced pain due to smaller incisions and shorter recovery times.

It took longer than expected to return to the ward following the nephrectomy. This was due to unexpected circumstances and although it was an emotional time for everyone concerned, the procedure was a success and both Dishna and her mother were allowed home the following week. As you can appreciate, Dishna remained at home for some time following the procedure and was bed-bound for a few

weeks. It's also worth noting that Dishna's employer was very accommodating and made generous allowances

before and after the transplant. Dishna was off work for a period of four months following the procedure. This gave her time to heal, regain strength and recover. She returned to work earlier this year and is easing herself back in to doing the daily commute.

As for her mother, she is enjoying a new lease of life and has much more energy than before. She's

no longer bound to a restricted diet. She attends clinics regularly thanks to both her son-in-law Raju – who drove her to Hammersmith Hospital initially (post-op) and more recently accompanied by Dishna's father on public transport. While her mother's follow-up appointments were weekly, Dishna's initial follow-up appointment was two weeks after they were discharged and are less frequent. A special mention must go to Raju for his earnestness in this endeavour and



Dishna with her parents and sisters

Bijal – one of Dishna's sisters because they have been on the organ donor register for many years. Well Done Raju and Bijal!

NHS Organ Donation quite aptly shared their story on social media on 31st March – Mothers Day 2019.

Dishna is now very keen to promote organ donation and is keen to offer advice & support. If you would like further information, speak with your GP or renal consultant. Alternatively email us at info@westlondonkpa.org.

Behind the scenes

You may have seen us attending various fundraising events throughout the year. Events such as World Kidney Day in the spring and Organ Donation Week in the autumn gives us the opportunity to meet with fellow patients, their families and staff. We really appreciate all the support and words of encouragement that we receive. Alongside this, we also appreciate the generous donations we receive from passers by. This money is spent on the purchase of both medical and non-medical equipment that you will see in renal units.

Over the past 12 months, we have funded the purchase of various items such as:

- Bariatric (Dialysis) Chair
- TV remotes
- TV/Information Screen
- Ultrasound U-Lite scanners
- PD Bag Warmers

As a charity, we don't receive funding from any other sources other than what we raise and gratefully receive from our supporters. Unlike many other charities, we all work on a voluntary basis for the benefit of renal patients in west London. Thank you for your continued support.

Did you know...?



Three in 10 (31%) of people waiting for a transplant across the UK are from a black, Asian or minority ethnic background.

Over a third of people (35%) waiting for a kidney are from these backgrounds. From spring 2020, the law around organ donation in England is changing so more people go on to donate their organs when they die and save more lives.

From 25 April 2019, NHSBT are running a new public awareness campaign, called Pass It On, to inform people in England that the law around organ donation is changing. The campaign will highlight what is happening, encourage people to make and record a decision whether or not they want to be an organ donor and to share their decision with their family and closest friends.

If someone decides they don't want to donate, they will need to register this decision on the NHS Organ Donor Register.

World Kidney Day (WKD) 2019 – Raffle Winners

Thanks to everyone who purchased raffle tickets (and books) for our WKD 2019 Draw. The Raffles we hold throughout the year help us raise essential funds that allow us to carry out the work that we do. The lucky winners were drawn at the end of March and prizes have been distributed. If you fancy your chances at winning a prize, look out for our next Raffle competition.

1st	£250 Mrs Umashanger
2nd	Bill's Restaurant voucher Mrs D Pearce
3rd	Boden gift voucher Mr J Lane
4th	The House Salon voucher Mrs P McAuliffe
5th	Talk Sport radio experience Master S McHugh
6th	Patisserie Valerie Afternoon Tea Mhairi Munro
7th	Patisserie Valerie Cakes voucher Mrs J Walrond

In Memoriam



*In memory of Victor Chapman
11.7.1935 – 3.1.2019.*

"Vic and I met in 1998. I was 54 and he was 63. We fell in love and started our life together in 1999. Vic worked in a garage, after retiring from British Airways and I was a childminder. We lived with his mum in Feltham, had lots of holidays in our caravan and also went abroad quite a lot. We married in 2003 and moved to Hounslow in 2004. He loved DIY, gardening and was always happy to help anyone. He was very popular and loved by everyone who knew him. In 2007, he had major heart surgery – a 5 bypass op – recovered well and 6 months later we spent 7 weeks touring Australia. In 2011 he was diagnosed with End Stage Kidney Failure and started dialysis. He was not able to have a transplant as he had a couple of mini strokes. We still had a lot of good times together, with family and friends. In 2014 he was diagnosed with Vascular Dementia, so he gradually deteriorated, had good days and bad days, but finally passed away in Hammersmith Hospital on Jan 3rd 2019. He spent most of his time having dialysis at Hayes Renal Unit, what lovely caring staff. He had a good send off and our choice of charity was WLKPA – donations amounted to £691.90. Thank you so much." – Margaret Chapman.

How changing perceptions on organ donation can help BAME kidney patients

Contributing Feature – By **Shaneezah Ally**

More awareness around kidney donation in our communities is needed to help change attitudes towards organ donation.

In 2020 the law in England around organ donation will change meaning adults will have to actively opt out of the organ donation register.

Black, Asian and and Minority Ethnic (BAME) patients face a significantly longer wait than white patients on the transplant waiting list. According to the London Assembly report published last month, black and Asian patients waited six months longer than white patients for kidneys and 62% of Londoners currently on the waiting list are from minority groups.

This is a direct consequence of two things, firstly there is a higher demand for organ transplants in BAME communities as these groups have higher rates of blood pressure and diabetes leading to kidney disease. Secondly there are lower consent rates and less people from ethnic minority communities opt to be organ donors, this causes a problem as matches are more suitable where the donor and the recipient are from the same ethnic background.

According to the London Assembly report, communities including faith

leaders should be encouraged to talk more about organ donation to dispel any misconceptions. NHS Blood and Transplant (NHSBT) research found that BAME groups are less likely to donate based on the belief that it is against a person's culture or religion.

The report suggests that we need to urge faith organisations and leaders to openly discuss donation within their community and on social media to help increase understanding of organ donation.

A survey accompanying the report found that 51% of people were unwilling to donate organs because of religious beliefs and 19% based on cultural beliefs.

The report suggested that there is a lack of consensus among religious views and many people are left confused about organ donation, according to the report 13% of people did not know enough about it and 51% were unwilling to donate based on

cultural beliefs. When asked what would make you more willing to donate, 23% of participants said encouragement from their faith or community group and 21% wanted more information on organ donation. Therefore it is important to call on faith and community leaders who have a duty to provide guidance on this subject especially where matters are open to interpretation.

NHSBT statistics from April 2018 to March 2019 shows that 2409 kidney transplants were from deceased donors and 935 from living donors showing that there has been progress but there is still a shortage of donors as 411 people died last year in the UK waiting for a transplant.

NHSBT suggests that transformation in family attitudes is important to increase the number of families consenting to organ donation from a deceased family member, their statistics show that more than 6 out of 10 families agree to organ donation but this needs to be increased to 8 out of 10 families to save more lives.

According to the report, 8% of participants said they would not donate as it may upset family and friends. Family consent can be one of the biggest obstacles to organ donation as only 45% of ethnic families consented last year. More discussion with family about organ donation is needed to make family and friends aware of your decision, this is supported by NHSBT who are working with religions and belief systems in the UK to develop a faith declaration to allow people to state that they would like NHS staff to discuss how organ donation with their family and friends.



So far 11 projects have received money from the government to increase the number of BAME donors in religious communities. The NHS has also produced lesson plans for schools on organ donation and political leaders are urged to work with faith leaders to increase more awareness around BAME donors.

It is important to change perceptions to ensure BAME voices are heard. Visit www.nhsbt.nhs.uk for details.

Fibre-tastic; the nutrient that we don't get enough of

Article supplied by Elena Tsompanaki and Thushara Dassanayake – (Renal Dietician)

The rising temperature, longer days and sunshine means that Spring is all around us. At this time of year we tend to crave more fresh food, particularly as we move into summer.

Fruit and vegetables are packed with fresh goodness, including plenty of fibre. This article is about how to get your fill of fibre while being on a renal diet.

What is fibre and why is it great for us?

Fibre is a type of carbohydrate that feeds the good bacteria living in our gut. Those who eat good amounts of fibre tend to have lower risk of heart disease, diabetes and some cancers, as it helps improve blood sugars and cholesterol levels and helps with constipation.

Foods rich in fibre are fruit and vegetables, beans, legumes, pulses and wholemeal starchy foods (brown rice, pasta etc). But how can someone manage enough fibre, while being on a renal diet?

What does having enough fibre look like in a day?



Half a cup of rolled oats



1 medium pear



2 slices of brown bread



1 cup of cooked lentils



2 boiled carrots



1 medium apple

How can I include more fibre in my diet?

Maximise your fruit and vegetable portions according to your allowances:

These could be 2 portions of low potassium fruit and 2 portions of low potassium, boiled vegetables per day, or more. Ask your renal dietitian if you can include another portion or two of low potassium fruit and veg per day

- Fruits like blueberries, apples and pears (eaten with the skin), satsumas are a good source of fibre and are lower in potassium
- Vegetables like carrots, peas, cabbage, sweetcorn are good sources of fibre but not high in potassium
- Have fruit and vegetables with the skin or peels (except potatoes)
- Eat whole fruit rather than their juice
- Add boiled sweetcorn or peas on your rice side dish
- Instead of a cake and custard, have stewed fruit (peach, pear, apple) and yoghurt/custard as a dessert



Cooking to lower potassium

Boiling vegetables and throwing the water away will decrease their potassium content but not their fibre content

Choose vegetarian meals more often:

Legumes like dhal, lentils, chickpeas, beans are high in fibre and also give you protein. They can substitute meat in a curry, stew or a salad

Change to whole meal carbs:

such as brown pasta, brown rice, brown bread have more fibre than their white equivalents

- Consider having porridge or Weetabix for breakfast instead of toast
- Try adding 1 tablespoon of flaxseeds or golden linseeds in your yoghurt or cereal
- Buckwheat, couscous, barley, bulgur wheat can also be eaten as a starchy side and are high in fibre

Thought you were ALONE?

Consultant nephrologist Dr Emma Salisbury brings you a list of FAMOUS people fighting kidney disease too!



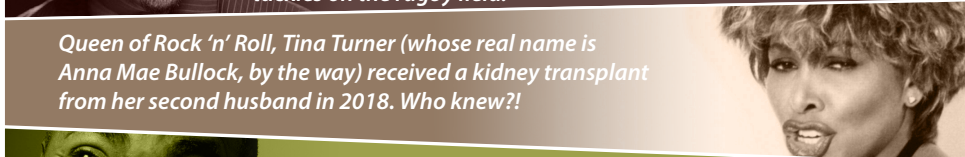
Actress & award-winning recording artist, Selena GOMEZ developed kidney failure as a result of lupus nephritis. She received a kidney transplant from her friend in 2017!



Modern Family sitcom star, Sarah HYLAND was born with dysplastic kidneys. She received a kidney transplant from her Dad in 2012.



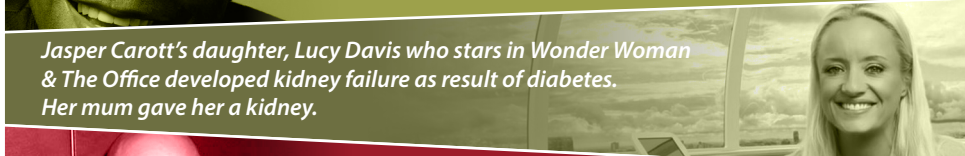
The late Legendary All Blacks New Zealand rugby player, Jonah Lomu started haemodialysis via a fistula over which he wore a special guard when playing rugby! He went on to have a transplant where the kidney was placed under his rib cage, safe from further shoulder tackles on the rugby field.



Queen of Rock 'n' Roll, Tina Turner (whose real name is Anna Mae Bullock, by the way) received a kidney transplant from her second husband in 2018. Who knew?!



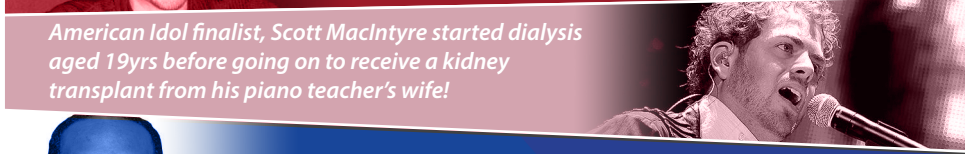
American actor and comedian, Tracy Morgan developed kidney failure as a result of diabetes. His ex-girlfriend gave him in a kidney in 2010! Would YOU give your ex a kidney?!



Jasper Carrott's daughter, Lucy Davis who stars in Wonder Woman & The Office developed kidney failure as result of diabetes. Her mum gave her a kidney.



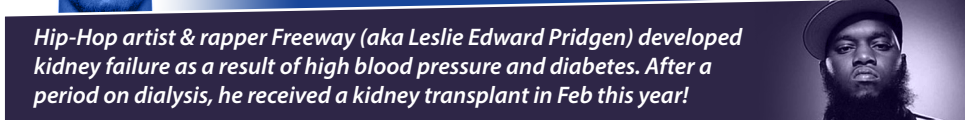
Aron Eisenberg, who plays Nog in Star Trek, was born with only one partially functioning kidney. He now has a kidney transplant.



American Idol finalist, Scott MacIntyre started dialysis aged 19yrs before going on to receive a kidney transplant from his piano teacher's wife!



American football player, Donald Jones developed kidney failure as a result of IgA nephropathy aged 25yrs. After a brief period on dialysis, his Dad gave him a kidney transplant.



Hip-Hop artist & rapper Freeway (aka Leslie Edward Pridgen) developed kidney failure as a result of high blood pressure and diabetes. After a period on dialysis, he received a kidney transplant in Feb this year!

... and here are some famous diabetics too!



Gorgeous, Oscar winning actress Halle Berry



Prime Minister (at the time of writing!) Theresa May

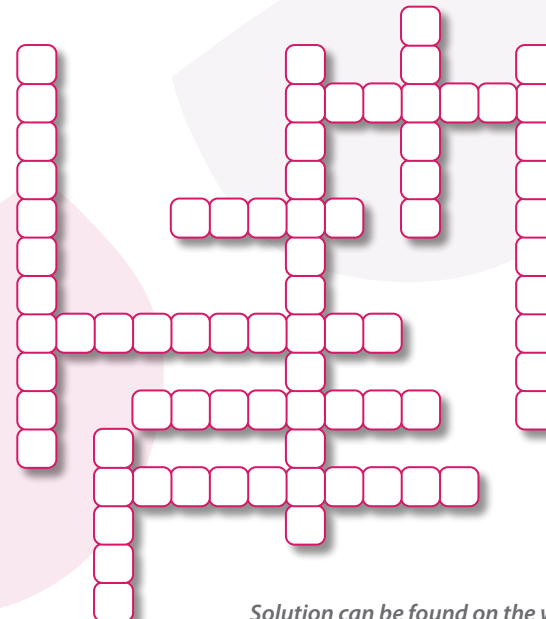


5x Olympic rowing gold medallist Steve Redgrave



Hollywood legend Tom Hanks

So, keep smiling! You are not alone!



Renal Criss-Cross Puzzle?

Can you fit all of the words below into the boxes?

- ABDOMEN, ACUTE, ANTIBODIES, BIOPSY, CREATININE, DIALYSER, DONOR, HAEMODIALYSIS, NEPHRECTOMY, TRANSPLANT



Solution can be found on the website

British Transplant Games 2019



Our call for participants to join Team Hammersmith this July at **The British Transplant Games (BTG)** was met with an

Team Hammersmith logo which will adorn our kit.

If you missed out on joining the team this year, we hope you will come to Newport, south Wales as a spectator this summer or join the team next year. We'd love for you to join us.

encouraging response. We have pleasure in informing you that we now have a team of 15 competitors who will be representing all of the renal units within west London. The renal units are each represented by a star on the new

For further information, please visit the British Transplant Games website, you can also email the Team Hammersmith manager Dino at dinopremier@googlemail.com or the WLKPA chair Penne at chair@westlondonkpa.org.

Just in case you need reminding...

Registration for our summer day trips has been open for a few weeks and many seats have already been reserved. There are still plenty of spaces available. Please visit the website over the coming weeks to purchase your tickets. All details are on the website www.westlondonkpa.org/2019daytrips and on leaflets you will find in your clinics. For further info, call Sarita: 07538 224156.



Contact us: info@westlondonkpa.org
Or visit www.westlondonkpa.org

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