

## Squeezing every drop out of life

Zandria Richards is grateful for what she's been through, because of the positive impact on her life.



Zandria has suffered from kidney failure for 22 years now. She suspects she was born with poorly functioning kidneys, but it could have been due to being diagnosed with high blood pressure when she was 15, for which she never received treatment.

It all came to a head when she was 32. At the time, she was working all hours - a social worker during the week and college at weekends. She started to feel really unwell, with cramps all over her body and other unnerving signs. She was constantly tired but put it down to the seven-day week. After a visit to her GP she was called back the very next day and told she had severe

kidney failure and she would need dialysis immediately.

On receiving this shock news, her first concern was whether she would be able to fit this inconvenience round her existing routines - or was she so ill her life would be curtailed? Might she even need a wheelchair? Would her employers understand if she took time off or would they think she was malingering? Could she still have fun, go dancing (something she loved)?

"Whatever happens," she voiced to her GP, "...make me able to dance!"

She went on dialysis for three years when her own kidneys failed, and her new, transplanted kidney lasted for over ten years before that too failed. She had no option but to spend another four years on dialysis until her second transplant in 2016.

Unfortunately it was not to last and her second kidney is now failing. She is still not dialysing though, preferring to hold out for a transplant. "Dialysis involves time, food and fluid regimes, intrusion into my life and endless waiting," she explains. "I want to be at the point were I'm begging them to dialyse me. I'm still trying to squeeze every drop of life out of this transplant!"

***"Make me able to dance"***

Zandria describes herself as having "the constitution of an ox", but physically this is far from the truth. However, no-one would question her mental strength.

"I came to the realisation that it could be worse" she said, "and my gratitude eventually kicked in."

"It was a disease that I could to some extent manage," she goes on to explain. "The only 'replacement therapy' for a major organ failure: I could get a transplant and live a fairly normal life. I could hide it from the world, if I wished. It wasn't like a visible disability, like being in a wheelchair or missing a limb. As superficial as it may sound, that was a huge deal for me".

With that realisation came a shift in focus from her own situation to the possibility of helping others with kidney failure, the feeling that she had got kidney failure for a reason.

"When I think of the many who are no longer here, and I still am - that's a blessing."

**Check out Zandria's Instagram 'Kidney Clever' and read more about what she is doing to help mentor others with kidney disease in the next edition of this newsletter.**

## Gabhru Panjab De - Dinner & Dance Ball 2018

Saturday 17th November 2018

@ Supreme Banqueting Suite, West Bromwich, B70 6QP

The evening, dedicated to the memory of GPD's founding member Sukhi Johal, will raise funds for Give a Kidney, The Heera Foundation and MS Society. There will be electrifying live performances from UK's leading Bhangra bands, singers, DJ's, Dhol player and dancers - and a delicious five course meal!

Dress Code: BLACK TIE/FORMAL | Parking: FREE [www.Gabhru.com](http://www.Gabhru.com)



Tickets: £35 (£300 for table of 10).  
Contact: Bindi on 07967 777011  
[info@gabhru.com](mailto:info@gabhru.com)



## Another victory for Give a Kidney swimming relay team at the Transplant Games

Serena Tucker (living donor world record holder 50m freestyle), Roland and Sue Gianstefani and Gill Childs won Gold at the Westfield Health British Transplant Games in Birmingham on 4 August for the Give a Kidney team, competing against Leeds Hospital team. Brendan Clarke also swam as a living kidney donor.



Medal winners Gill Childs, Sue and Roland Gianstefani

## Go Green this Christmas

Please consider making a donation to Give a Kidney in lieu of sending Christmas cards!

Today, two billion greeting cards are sold annually in the UK, costing on average £1.44 each, with postage a minimum of 55p. Plus, there's an environmental impact from paper production, printing and posting. 33% of paper in the UK is not recycled and it can take up to 15 years to break down.

Please consider posting your Christmas greetings on social media or sending them by email, then donating the money you would have spent on cards and postage to Give a Kidney! Your donations will be very gratefully received.



## BRANDENBURG CHORAL FESTIVAL OF LONDON

AUTUMN SERIES  
2018

**Sunday 11th November, 7-9pm**  
at St Mary-le-Bow, Cheapside,  
London EC2V 6AU

Choral concert, Will Todd  
*Remembrance* and *Before Action*  
and Fauré *Requiem* performed  
by The Minerva Consort and  
conducted by John Andrews.

Tickets cost £18 each  
or £5 for children

Once again, the charity will benefit from the proceeds (half of our ticket sales plus any donations) of a choral concert, part of the Brandenburg Choral Festival of London. Please fill a pew! We would be delighted to see you and your friends there.

To order your tickets, please email [info@giveakidney.org](mailto:info@giveakidney.org) indicating how many you would like. To pay for your tickets, you can either post a cheque, payable to Give a Kidney, to 20 Corbyn Street, London N4 3BZ or visit [MyDonate.bt.com](http://MyDonate.bt.com) to pay online. When you tell us why you're donating, please mention this event.

## When the organ co-ordination transplant team is called to action

The team is aware of people in need of a transplant, and you might be forgiven for thinking that they are so eager to receive organs for their patients that they might not give due care and respect for the person who has died. It's not like that. There are procedures to follow, logistically and humanely.

A potential donor is identified, who for instance might be gravely ill and being kept alive by a ventilator, so medical checks are undertaken to identify any conditions which could halt a potential donation. The family is consulted to establish their preliminary agreement, then full consent must be given voluntarily by the family (who can in fact overturn a donor's wishes).

Brain stem tests are carried out to check whether there is any possible chance of recovery for the potential donor, and blood tests identify if the donor is free of hepatitis, HIV, etc.

Once the patient is brain stem deceased, family members may spend some time with the donor to pay their last respects before he/she is taken away and the organs to be transplanted are removed - depending on the availability of a specialist surgical team and an intensive care bed for the recipient.

The organs are packed in ice and taken to the recipient's hospital where the transplant takes place. Meanwhile, the donor's body is made ready to be returned to their family in a respectful and cared-for way. At every point, the family's wishes are honoured.

It's a very difficult job, asking families in the depths of grief to consider organ donation. More than half the families asked to go ahead with an organ donation refuse. People wishing to become donors should tell relatives about their wishes, as relatives ultimately give the go-ahead. They may be more likely to agree if they know it is their loved one's wish. You can register on the National Donor Register at [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk)



Hampshire non-directed kidney donors group 'The Squeezed Oranges' meet to swap notes and encourage and inform others thinking about becoming donors. The Wessex area - Dorset, Hampshire and the Isle of Wight - has had the highest number of non-directed kidney donors per head of population in the country, with 55 donors between 2007 and 2017.



Latest statistics show that 41 people donated as a non-directed donor (NDD) between January and end of August with 58% initiating an altruistic donor chain of up to two or three transplants in the UK Living Kidney Sharing Scheme (UKLKSS). Despite the fall in overall numbers of donors, the proportion of people donating into a chain has more than doubled in less than a year and continues to increase, which is exactly the change we hoped to achieve with the new allocation scheme. Most of the remaining donors benefitted a high priority recipient on the national transplant list and a small number were unmatched in a chain and chose to donate to the list rather than wait for the next matching run.

Fluctuations in donation rates are inevitable but the fall in NDD activity in the past few months is disappointing.

We continue to monitor it and to raise awareness through our social media platforms and various communication strategies. Our aim is to ensure that people are aware that non-directed donation may be an option to consider, have easy access to the information and support that they need to make the right donation decision for them and enjoy a positive experience once they have entered the programme. Constructive feedback and innovative ideas are always welcome and help us to improve what we do. Please feel free to contact me via the 'Give a Kidney' office or at [lisa.burnapp@nhsbt.nhs.uk](mailto:lisa.burnapp@nhsbt.nhs.uk)

Website development has been a priority at NHSBT in recent months to upgrade on-line resources for recipients, potential donors and clinical teams. The living donation pages have been given a fresh

look and feel with updated content, tools and resources and improved navigation. The long-awaited on-line 'Expression of Interest' form for NDDs will be launched on the new [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) website and will be available in early October. Please encourage interested volunteers to access the information and films in the 'living donation' section and to register their interest at the transplant centre of their choice using the on-line form.

Thank you for your support.

*Lisa Burnapp*  
Lead Nurse - Living Donation  
NHS Blood and Transplant



## Running for a gift greater than gold: Jasie Rai

The Swindon Half Marathon, held on Sunday 9 September, was held at the end of National Organ Donation Week 2018. Kidney patient Jasie Rai, who has several times organised very successful 'East Meets West' fundraising dinners for Give a Kidney, turned her enthusiasm this year to this different style of event. Jasie has always believed in the benefits of physical activity to well-being, and the half marathon provided an alternative focus to the problems with her health, the prognosis of which is not good: without a transplant, dialysis is inevitable within the next couple of years.

"If I am lucky enough to receive a kidney transplant in the future, this will be one of the greatest gifts anyone can ever give when the time comes" she says. "Accepting such a gift is difficult to come to terms with ... I would feel forever indebted to my donor".

Post transplant, Jasie hopes to be able to continue to make a positive contribution to help others affected by this silent disease.

When she signed up for the Swindon Half Marathon, after being given the medical go-ahead, the furthest she'd ever run was seven miles, so the 13 mile course was going to be a huge challenge. She expected to walk much of the route, especially the inclines. But as runners so often report, the support of the crowds and other runners along the way was very



*Jasie Rai (left) with her running friends*

motivating and she did manage to run most of the way. This was also due to rigorous training runs, which really paid off as she finished the course in 2 hours 10 minutes - well within her personal estimated time.

She found the whole experience very rewarding. It was tough going, particularly fitting in practice runs on busy days or when she didn't feel that well. Blood pressure was monitored regularly. Yet the benefits of the extra exercise were remarkable and impressed her kidney consultant.

Jasie is very grateful to her running friends, family, supporters and Swindon Harriers and praised the Swindon Half Marathon organisers and sponsors who put on such a great event.

To date, Jasie's fundraising from the event has raised £800 plus Gift Aid for Give a Kidney and Wiltshire Air Ambulance.

## Support Give a Kidney - one's enough

When you shop at [smile.amazon.co.uk](http://smile.amazon.co.uk), Amazon Donates

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Each time customers shop at [smile.amazon.co.uk](http://smile.amazon.co.uk) Amazon will donate 0.5% of the net purchase price for millions of eligible products (excluding VAT, shipping fees and returns). There is no additional cost or charge to customers or charities for this.

Customers who shop with AmazonSmile can choose a charity to support before they start shopping. They can change to another charity at any time, should they wish.

There is still an opportunity to support her efforts and increase the funds raised to her target £1000 plus Gift Aid:

<https://mydonate.bt.com/fundraisers/jasierai1>

### East Meets West

The fourth of these (almost) annual fundraising events will be **15 March 2019**. Put that date in your diary now as it's always a sell-out!



## Give a Kidney in Scotland: five years on

Five years ago I met John Fletcher at a function in Edinburgh for non-directed kidney donors in Scotland. Neither John nor I liked the term 'altruistic', as we both felt that sounded far too saintly, and we most certainly did not feel like that!

Immediately we discussed how we could get the message of living kidney donation awareness into the wider arena in Scotland. We were then fortunate to meet Colin McLachlan - another non-directed donor - and his enthusiasm in 'getting the message out there' was equal to ours. Following discussions we agreed to join forces and Give a Kidney in Scotland was established.

Over the past five years, and with the active support and co-operation of NHSBT and the Transplant Coordinators, Give a Kidney Scotland are now proud to represent some 25 non-directed donors in the country. We have been successful in gaining a good amount of media coverage promoting living kidney donation, and many of our members are also active in speaking to local interest groups - all helping to get the message across.

### Working with NHSBT

At Give a Kidney Scotland's meeting on 5 September Jen Lumsdaine gave an update on NHS activity in Scotland. Pop-up altruistic donor posters promoting non-directed kidney donation are now on show in Edinburgh and Glasgow blood donor centres and have also been sent to every GP surgery in

Scotland, with the website address for Organ Donation Scotland.

### Give a Kidney UK 10th Anniversary

Objectives for the tenth anniversary campaign were agreed, including generating positive coverage around non-directed donation, using case studies - especially the first non-directed kidney donors in Scotland, Matilda Hall and John Fletcher - and drawing attention to the number of people currently awaiting a kidney transplant. The campaign will run from January and the main focus will be World Kidney Day on 14 March 2019.



Matilda Hall



John Fletcher

Give a Kidney Scotland are currently pro-active in applying for fundraising to assist with its planned campaigns.

Members' ideas on how best to celebrate the anniversary would be welcome, along with personal donation/recipient stories for the media.

*Chris Jones, Chair, Give a Kidney Scotland*

**Give a Kidney Scotland meets every three months in Edinburgh. The next social and business get-together is on Wednesday 5 December at the Hilton Grosvenor, at 6pm. All are welcome.**



### John Newmark's epic ride for charity

126 miles along the total length of the Liverpool-to-Leeds canal on a recumbent trike ([www.icetrikes.co/products/sprint-recumbent-trike](http://www.icetrikes.co/products/sprint-recumbent-trike)) in one go was always going to be a bit of an unknown, but in the event it was rather easier than I thought it would be. It took almost exactly 18 hours, starting at 5.45am and finishing just before midnight. I was supported by good friends who rode both the first half and the latter stages, and my wife supported in the car along the way. Route-finding was a bit of a problem for her, but a last minute purchase of a £50 tracker was unexpectedly very useful in marking my progress and enabling her to gauge my position. And for me, following the purple line of a GPX track was reassuring as it marked the miles completed and to go.

I was tired at the end, but experienced nothing like the agony as when I completed the same route on a 'normal' ie diamond frame (DF) bike some years ago. But then, not many people know that the Land End to John O'Groats record is held by a similar recumbent trike, *not* a DF - and that recumbent cycles are banned in most cycle races as they would out-perform those rather odd upright things! I am not sure why there are not more of us around!"

To date Jim has raised £1,670.00 for Give a Kidney and Williams Syndrome Foundation. You can still visit his fundraising page at <https://mydonate.bt.com/fundraisers/jimnewmark1>

### 10 things you could say to someone with an invisible illness

1. How are you doing today?
2. Is there anything I can do to make things easier?
3. I am here for you, whatever you need.
4. It must be very difficult to have a disease where you feel so awful on the inside but it doesn't show on the outside.
5. I am so sorry that you are going through this.
6. I wish I could take away your pain.
7. I hope you are feeling better soon.
8. I will keep you in my thoughts and prayers.
9. I may not completely understand your disease or what you are going through, but I would like to.
10. I am so sorry I judged you before understanding your disease.

### Contact us

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