

This edition is being brought forward a little, in order to again publicise Give a Kidney's main event of the year, our **Annual Conference on Saturday 23 March 2019** from 09:30am at the offices of CZWG Architects, 17 Bowling Green Lane, London EC1R 0QB. It's free to attend and we hope as many of you as possible will join us.

You can book through Eventbrite: www.eventbrite.co.uk/e/give-a-kidney-annual-conference-agm-tickets-53306027764

Preceding the conference will be a short Annual General Meeting, when the Trustees will present the annual report and accounts to members, report on the charity's activities for the year and discuss plans for 2019 and beyond.

First Minister and Scottish politicians celebrate ten years of non-directed (altruistic) kidney donation with donors from across Scotland

On World Kidney Day on 14 March, the First Minister of Scotland, Nicola Sturgeon, and politicians from across Scottish Parliament joined with kidney donors from Give a Kidney Scotland to celebrate ten years since the first people in Scotland donated a kidney as living donors to a stranger.

The first non-directed donations in Scotland took place in March 2009 and 78 people in Scotland have now donated a kidney to someone they do not know, having been matched to a high priority person on the national transplant waiting list. More recently, they may have donated into the UK kidney sharing scheme to set in motion up to three transplants.

The event at Holyrood was organised by Give a Kidney Scotland, which aims to raise awareness of non-directed donations and support those going through the process.

Chris Jones, Chairman of Give a Kidney Scotland and himself a kidney donor, said: "We are delighted to receive so much support from politicians from across Scottish Parliament on World Kidney Day.

"Our aim is simple - to raise awareness of this kind of kidney donation and, in turn, to help save lives. Currently there are around 400 people in Scotland on the kidney



Outside Scottish Parliament with cross-party MSPs, including First Minister Nicola Sturgeon and the Minister for Public Health, Sport and Wellbeing, Joe FitzPatrick - along with 14 non-directed living kidney donors from across Scotland.

transplant waiting list. Kidneys from living donors are considered the Rolls Royce of kidneys as they generally work better and last longer than those from deceased donors, and in most cases they open the door to enabling more people to receive a kidney by triggering a 'chain' of transplants through the UK kidney sharing scheme.

"With our campaign we hope that many more people will become aware of this kind of kidney donation and see if it is something they may consider doing themselves.

John Fletcher, one of Scotland's first donors back in 2009, who also attended the event, described it as "the best thing I ever did".

"The way I looked at it, it was a few weeks out of my life to save someone else's. It was major surgery, but the recovery was a lot quicker than I expected, and I was back at work within weeks.

"The feeling I had not been expecting was the sense of wellbeing after I'd donated, knowing I'd transformed another person's life and their future."

Any healthy adult can volunteer to be assessed as a living donor and a kidney from a living donor is the very best treatment option for most patients with kidney diseases.

Give a Kidney Scotland are planning a number of further events during the year to mark the occasion of their tenth anniversary.

WORLD KIDNEY DAY : 14 MARCH 2019



World Kidney Day (WKD) is a global health awareness campaign focusing on the importance of the kidneys and reducing the frequency and impact of kidney disease and its associated health problems worldwide.

It is a joint initiative of the International Society of Nephrology (ISN) and the International Federation of Kidney Foundations (IFKF).

World Kidney Day is on the second Thursday in March every year and observed by over half the countries in the world. *Kidney Health for Everyone Everywhere* calls for universal health coverage (UHC) for prevention and early treatment of kidney diseases.

850 million people worldwide are now estimated to have kidney diseases from various causes, and chronic kidney diseases (CKD) are now the sixth fastest-growing cause of death. CKD and Acute Kidney Injuries (AKI) - an important driver of CKD - also contribute to increased morbidity and mortality from cardiovascular disease, diabetes, hypertension and obesity, as well as infections such as HIV, malaria, tuberculosis and hepatitis.

Despite the growing burden of kidney

diseases worldwide, kidney health disparity and inequity are still widespread. CKD and AKI often arise from the social conditions in which people are born, grow, live, work and age, including poverty, gender discrimination, lack of education, occupational hazards and pollution among others. In fact 85% of AKI cases are found in low and middle-income countries.

Transplantation is considered the



most cost-effective treatment of CKD, but with shortage of organs and other barriers, dialysis is the default option in many countries. Prevention and treatment of kidney diseases are often lacking, and this year, World Kidney Day sets out not only to raise awareness of the high and increasing burden of kidney diseases worldwide, but highlight the need for strategies for the prevention and management of kidney diseases.

Specifically, WKD calls on everyone to advocate for concrete measures in every country to improve kidney care:

- Encourage and adopt healthy lifestyles (access to clean water,

exercise, healthy diet, tobacco control). Many types of kidney diseases can be prevented, delayed and/or kept under control when appropriate prevention measures are in place.

- Make screening for kidney diseases a primary healthcare intervention, including access to identification tools (eg. urine and blood tests). Screening of high risk individuals and early diagnosis and treatment is cost-effective to prevent or delay end-stage kidney diseases.
- Ensure kidney patients receive basic health services they need (eg. blood pressure and cholesterol control, essential medications) to delay disease progression without suffering financial hardship.
- Call for transparent policies governing equitable and sustainable access to advanced health care services (eg. dialysis and transplantation) and better financial protection (eg. subsidies) as more resources become available. Breaking down socio-economic barriers and expanding access to comprehensive services in order to meet the needs of the population is essential to guarantee equitable kidney care and increase quality.

Around the globe people came together to mark World Kidney Day on 14 March 2019. Please let us know if you did anything to mark the day so we can publicise your event or activity.

BRINGING TOGETHER KEY PEOPLE IN ORGAN DONATION

The NHSBT Organ Donation and Transplantation and British Transplantation Society joint congress took place at the Harrogate Convention Centre from 6-8 March. Based around the theme of communication, the three-day event aimed to unite clinicians, surgeons, laboratory scientists, nurses, transplant co-ordinators, volunteers and others interested in organ donation and transplantation. It was also the occasion to celebrate the achievements of those involved with organ donation: read about the Awards on page 4.

APPEAL FOR NEW GIVE A KIDNEY TRUSTEES



The closing date has passed for nominations for new Trustees at the AGM, but if you are interested or know someone who is, please let us know, as the Trustees can appoint two people during the year. We currently have seven Trustees, but ideally need more.

As I write, the 1000th transplant in the UK living kidney sharing scheme has happened. I cannot think of a better way to mark World Kidney Day nor to acknowledge the contribution of non-directed donors in achieving this astonishing milestone. Nearly half of all the transplants that are identified in the kidney sharing scheme are now due to non-directed donors initiating a chain, creating opportunities for patients who are the most difficult to match as well as increasing the overall number of kidneys available for people

in need of a transplant.

Using this story, NHSBT used World Kidney Day to shine a spotlight on living donation and non-directed donation. Despite some obvious competition from Brexit and 'opt-out' legislation, we saw some national and regional uptake, good activity on social media and increased visits to the www.organdonation.nhs.uk/livingdonation website to download information throughout the week. It is too early to assess the impact of this and other campaigns, such as the 10th Anniversary celebrations in Scotland, but we know that the more often people hear about donation, the more they consider volunteering to donate.

This time next year it is likely that 'opt out' legislation will come into force and a new UK strategy for organ donation and transplantation will be on the verge of being launched. Both offer great opportunities for the donation and transplantation communities to work to-

gether to ensure more successful transplants for more people. In the meantime, we continue to keep the profile of living donation high and make sure that people across society know about it and have an opportunity to consider if it they wish to.

On a final note, I wish to acknowledge the award that was presented to Dr. Aisling Courtney and her colleagues in Belfast for living donation at the inaugural UK Awards for Excellence in Organ Donation and Transplantation at the joint NHSBT / British Transplantation Society Congress this month. As Chair of the LDKT 2020 Strategy Implementation Group, Aisling has done so much to drive the agenda for living donation in the UK and this award is a truly deserved accolade in recognition of her personal commitment and achievements and that of the whole team in Belfast.

I look forward to seeing many of you at the Give a Kidney AGM and Conference very soon.

Lisa Burnapp
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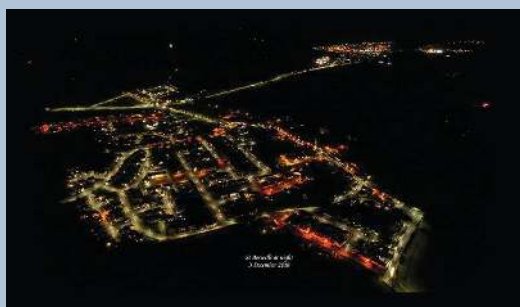
Changes to legislation on organ donation

Every day across the UK around three people, who could have benefited from a transplant, die because there aren't enough organ donors. To help mitigate this crisis, the Government has announced plans for a 'presumed consent' system of organ donation to take effect from Spring 2020. Under the system, you would be a donor unless you register a decision not to donate. Families will still be able to object to donation, so it's important that you make their decision easier at a difficult time by also telling them that you want to donate.

One donor can save or transform up to nine lives through organ donation, and even more lives by donating tissue.

Innovative fundraising idea

Give a Kidney supporter John Farquhar has sold some prints of a photograph he recently took: a night-time aerial view of his village. A local restaurant agreed to mount one of the prints in a prominent position and different sizes were sold, with all of the net proceeds going to Give a Kidney. This is a good example of how a simple idea can generate funds and raise awareness within the local community. Thank you John!

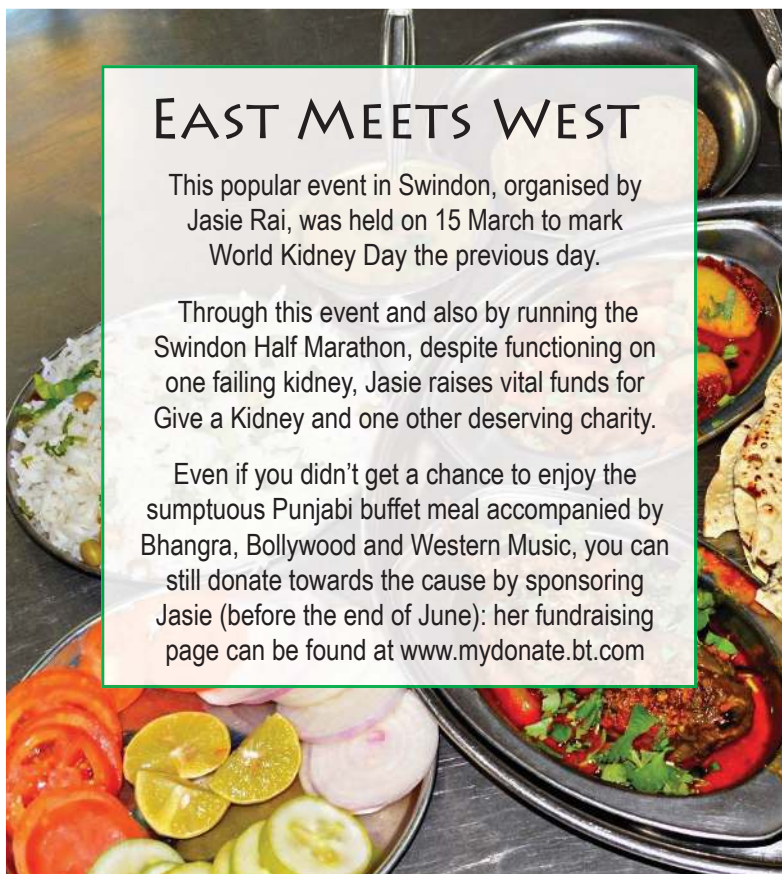


EAST MEETS WEST

This popular event in Swindon, organised by Jasie Rai, was held on 15 March to mark World Kidney Day the previous day.

Through this event and also by running the Swindon Half Marathon, despite functioning on one failing kidney, Jasie raises vital funds for Give a Kidney and one other deserving charity.

Even if you didn't get a chance to enjoy the sumptuous Punjabi buffet meal accompanied by Bhangra, Bollywood and Western Music, you can still donate towards the cause by sponsoring Jasie (before the end of June): her fundraising page can be found at www.mydonate.bt.com



Professionals and volunteers are recognised in the first national Organ Donation and Transplantation Awards

Outstanding professionals and volunteers in the field of organ donation and transplantation from across the UK have been honoured in the first awards of their kind.

The winners of the new UK Awards for Excellence in Organ Donation and Transplantation were announced before a 600-strong audience at the NHS Blood and Transplant and British Transplant Society joint congress at the Harrogate Convention Centre on 6 March.

The two organisations launched the awards to recognise individuals and teams making an exceptional contribution, in paid and voluntary roles, to saving and improving lives. Nominations were invited from across the organ donation and transplantation community and a total of 185 nominations were received. The winners and highly commended nominees were selected by a judging panel made up of clinicians representing NHS Blood and Transplant, the British Transplant Society and the Intensive Care Society, and representatives from nursing, The Donor Family Network, patients and lay representatives.

Give a Kidney nominated **Dr Aisling Courtney of Belfast Health and Social Care Trust**, and **Lisa Burnapp, Lead Nurse for Living Donation at NHS Blood and Transplant**. Lisa Burnapp was Highly Commended in the Excellence in Patient Care award, and the living kidney

donor team at Belfast Health and Social Care Trust, led by Dr Aisling Courtney, were named winners of the Excellence in Transplantation Performance award in honour of their success in revolutionising Belfast's living donation programme, a leader in the UK. Over the last eight years they have developed the programme to the extent that the living donor transplant rate now exceeds the yearly deceased donor rate. In 2016/17 Belfast performed more living donor transplants than any other unit in the UK, and its living donor transplant rate per million of population was almost double that of any other UK unit. Currently Northern Ireland is the leading country in the world for living donation.

Other winners were:

The Royal Papworth Hospital for Excellence in Organ Retrieval, which also recognised the entire hospital staff. Papworth was nominated in recognition of their world-leading innovative heart transplantation programme and for performing a record-breaking five transplants in 36 hours.

Campaigners Jay and Sina Patel were named Exceptional Volunteers for their 'outstanding' contribution to raising awareness of organ donation.

Melinda Poh Chuo Yui, sister-in-



charge of liver transplant theatre at King's College Hospital, for Excellence in Delivering Patient Care.

Gavin Pettigrew at the University of Cambridge for Excellence in Innovation and Research.

The **NHS Blood and Transplant North West team of Specialist Nurses** won the Exceptional Organ Donation Services Team award.

Dr Paul Glover was named Exceptional Clinical Lead for Organ Donation for his work in Northern Ireland.

Olive McGowan and her team at NHS Blood and Transplant received the Excellence in Education award.

John Forsythe, Medical Director of Organ Donation and Transplantation for NHS Blood and Transplant, said: "I send my warmest congratulations to the winners and highly commended nominees of our first UK Awards for Excellence in Organ Donation and Transplantation.

"With the British Transplant Society, we launched these awards to celebrate the vital lifesaving work happening every day across the field of organ donation and transplantation, and shine a spotlight on those exceptional individuals and teams whose efforts are often unseen.

"It is fitting that we share their successes at our joint congress and provide inspiration to people across our community as we continue to strive to increase donation and transplant rates and save more lives."

World Kidney Day Sail in the Solent

Skipper and kidney patient Jacquie Dowding (inset) and her First Mate Richard Ayres chartered a yacht, *Cascadeur*, to mark World Kidney Day on 14 March by sailing from Southampton to Portsmouth and back to raise awareness of kidney health and transplantation.

Transplant Surgeon Professor Nizam Mamode from Guys Hospital and four transplant recipients were among the crew, one of whom had received her kidney only two weeks ago, yet made the effort to come along to be interviewed by ITV Meridian. Jacquie gave further interviews with the press including BBC Radio Sussex.

The next fundraising initiative is to enter the *Round the Island* race on 29 June, sailing around the Isle of Wight. They are seeking about £3,500 in sponsorship.



Contact us

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