

## Annual Conference

**Saturday 24th March 2018, 9.30am - 3.30pm**

at the offices of CZWG Architects, 17 Bowling Green Lane, London EC1R 0QB

We look forward to seeing many friends and members at our Annual Conference, when we will have the opportunity to discuss issues around non-directed (altruistic) kidney donation, including annual numbers, donor experience and how the charity can impact these to best effect.

Speakers will include Lynsey Williams, a researcher working on the BOUnD Project at the University of Plymouth, who will report on latest findings on the study of professionals involved in transplantation; Dr Aisling

Courtney, Consultant Nephrologist and clinical lead for transplantation at Belfast City Hospital; and Lisa Burnapp, Lead Nurse, Living Donation, Organ Donation and Transplantation NHSBT.

We will also have a presentation to help us better understand the recipient's experience. Once again the event will be held at the offices of CZWG Architects in London EC1 and we are very grateful to Hon Treasurer Sanjiv Gohil and colleagues for making the space available at no cost to the charity.

A GIFT  
FOR NEXT  
VALENTINE'S  
DAY?



**This year World Kidney Day falls on International Women's Day, so the 2018 theme is:**

**Kidney Disease and Women's Health**



## Review aimed at increasing donation rates in the black and minority ethnic (BAME) communities: a report from the House of Commons event on 6th February

Eleanor Smith, the black Labour MP for Wolverhampton South West (Enoch Powell's old seat) is launching a review to help understand why donation rates are so low in BAME groups and how to increase them. The opening event was held on 6th February in Portcullis House, Westminster and attended by a large number of interested groups including Sanjiv Gohil and Paul van den Bosch for Give a Kidney.

The question is particularly important as BAME groups have the disadvantages

of low numbers of donors and a high incidence of diseases that require donated tissues. As well as kidney failure there are problems needing regular blood transfusion and bone marrow such as sickle cell and thalassaemia. There is even a third disadvantage because the factors that increase the risk of kidney disease, such as diabetes and high blood pressure, are particularly prevalent in BAME groups and this further reduces the pool of available donors.

As several of the speakers pointed out, there is still much to be done in helping to overcome some of the myths and exaggerated anxieties about donation. They could have been describing our raison d'être in Give a Kidney.

We need stories like that of a young black lady whose interview was screened at the meeting. "Would you do it again?" she was asked. "In a heartbeat" was her instant reply.

*Paul van den Bosch, Trustee, Give a Kidney*



## Paul Dixon: how one man can achieve so much



I have been on the Organ Donor Register since the 1970's, but admit that I knew nothing about living donation until I happened to catch the last couple of minutes of a programme my wife Shirley was watching on TV, in which a gentleman called Richard Pitman was telling how he had donated one of his kidneys to a complete stranger. My first thought was 'I didn't know you could do that'. My second thought was 'Maybe I could do that'.

Later that day I found the number for the Royal Liverpool Hospital and left a message to say I was interested in finding out more about being a living donor. I was invited over to the Royal the following week for an appointment, and was taken through the many technical, medical and surgical tests and examinations I would have to go through to ensure I would be healthy enough to donate. I decided at this first meeting to give it a go, and it took almost a year to successfully complete all

the tests. I was part of the paired scheme, and I donated at the Royal on my 65th birthday (a few years ago now). I was discharged from hospital 48 hours after my operation, I didn't suffer any pain or need any medication, and was back in the pool swimming 14 days later.

I first helped out at Wirral University Teaching Hospital during National Transplant Week in 2013, and shortly after was asked if I would like to join the Trusts Organ Donation Committee as a lay person, so I did. A short time after that I was invited to join the same committee at the Royal, which I did. After attending a few meetings, I realised that nobody was actively promoting the Organ Donor Register within the hospitals, so I decided to become a volunteer at both Trusts to try to make a difference and sign more people to the Register.

I started at both hospitals in January 2015, and by the time of our next AGM will have signed over the magic 10,000 to the register, but I'm greedy, I always want more! I work one full day each week in each hospital, and I absolutely love doing it, particularly at the Royal, because it's a major transplant centre for kidneys, with 114 kidney transplants last year, and I get to see first hand the difference a transplant can make to the recipient, with lives totally transformed. Donating a kidney is definitely the best thing I've ever done.

## Talking with your GP

I am a GP and donor and know all too well that my colleagues are often unaware of the possibility of non-directed donation. There have been numerous articles in the medical press as well as the mainstream media, but we are bombarded by huge amounts of medical information and it is impossible to keep up with everything. We have to be selective readers so an article about transplantation, which might be recognised as important, is glossed over in favour of more frequently encountered conditions.

Donors, prospective donors and others who are interested can have an important role in telling their GPs. Given the time constraints of an appointment I suggest making two or three points which can be delivered in less than half a minute. A short leaflet which can be shared with others in the practice might also help – Give a Kidney can supply these should you wish to take one in to your local practice.

Now that the number of donors has risen above 630, we are no longer such a small group and there is an opportunity to help make GPs more aware of the value of non directed donation. While we cannot expect GPs to be transplant experts, we don't want them telling those interested in becoming donors that it is unreasonable or impossible.

*Paul van den Bosch*

## Organ donation opt-out plans launched

Health Secretary Jeremy Hunt has called on people to overcome a "fatal reluctance" to talk about organ donation with relatives, as he launches a major public consultation on plans to introduce a new opt-out system.

Three patients die every day needing a new organ. Figures from NHS Blood and Transplant show that in the past year around 1,100 families in the UK decided not to allow organ donation because they were unsure, or did not know whether their relatives would have wanted to donate an organ or not.

In October, the Prime Minister announced that the Government will change to an 'opt-out' system in a bid to save the lives of 6,500 people currently waiting

for a transplant, shifting the balance of presumption in favour of organ donation.

Currently, 80 percent of people say they would be willing to donate their organs but only 36 percent register to become an organ donor. It is hoped that changing the system to an opt-out model of consent will mean more viable organs become available for use on the NHS, potentially saving thousands of lives.



Over three months following the launch of the consultation in December, the Government is asking for comments on the defining issues of the new system:

1. How much say should families have in their deceased relatives' decision to donate their organs?
2. When would exemptions to 'opt-out' be needed, and what safeguards will be necessary?
3. How might a new system affect certain groups depending on age, disability, race or faith?

The consultation can be found here: <https://engage.dh.gov.uk/organdonation>

*From KidneyCareUK.org December 2017*



There are some exciting developments to report from NHS Blood and Transplant (NHSBT), not least of which is the launch last week of the living organ donation section on the promoting organ donation hub. Through the following link <https://www.nhsbt.nhs.uk/get-involved/promoting-donation-hub/download-digital-materials/> you can access and order a range of promotional materials, link to all the current educational resources that are available at [www.organdonation.nhs.uk/livingdonation](http://www.organdonation.nhs.uk/livingdonation) and find out about other projects that are spreading the word about living donation. Jan Shorrock continues to work with members of the LDKT 2020 Strategy Implementation Group and other patient representatives to develop the portfolio of on-line educational information about living kidney donation on the NHSBT website. The plan is to publish a series of on-line factsheets based upon frequently

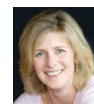
asked questions or concerns that will help people decide if they wish to consider donation. More next time!

In October last year, NHSBT hosted a workshop for transplant teams and clinical scientists to discuss and agree new developments in the UK Living Kidney Sharing Schemes. One of the outcomes from the meeting means that all non-directed donors are now registered into the Schemes' quarterly matching runs to create an altruistic donor chain of up to three transplants. The change came into effect for the first time in January and will apply to everyone who volunteers to donate as a non-directed donor from now on, unless there is a higher priority patient identified on the national transplant list who would still receive the kidney instead. Since 2012, when 'chains' were introduced into the kidney sharing schemes, 156 additional transplants have been made

possible by non-directed donors donating into the schemes but only 1 in 3 donors currently chooses to create a chain. This new development means that we can make a difference to many more patients' lives with every donation. To do this, we know that making it as easy as possible for people to be assessed and to donate within their preferred timeframes is really important and we are working hard to achieve this so that we can do the best for everyone who donates and receives a kidney.

Finally, a very big thank you to the 87 of you who donated a kidney in 2017- a slight increase from 85 in 2016. The 'kindness of strangers' transforms lives and your generosity is so very much appreciated.

Lisa Burnapp  
Lead Nurse - Living Donation  
NHS Blood and Transplant



## The British Transplant Games 2-5 August 2018 in Birmingham



Over the past 35 years The British Transplant Games have grown to a four day, annual event, with over 800 transplant recipients aged from two to 80+ taking part in over 20 different sports, with over 1,000 supporters watching!

The Games take place annually at a different location throughout the UK. This year it is Birmingham's turn to play host, from Thursday 2nd to Sunday 5th August and bring together the transplant community to celebrate the gift of life.

There are numerous events during the Games which are open to living donors, including relay races with transplant recipient teams and the Donor Run, which takes place each Saturday evening.

July 2017 saw the biggest ever British Transplant Games take place in North Lanarkshire. Several Give a Kidney members won medals, swimming being a popular event, while Give a Kidney Scotland members manned a stand at the event - as we hope to do again in 2018.

Registration will open soon. Visit [Britishtransplantgames.co.uk](http://Britishtransplantgames.co.uk) for details.



## Working with the Royal Free Hospital in London, Celia Kent sets up Ambassador group

At Give a Kidney's Ambassador Scheme launch in June 2016, I heard about a kidney donors group which had been set up in Scotland to support donors who were keen to spread the word about altruistic donation. I decided to set up a similar group in North London, where I live.

Eight donors came to the initial meeting in November 2016 and agreed to offer talks on altruistic donation, run a stand at the Royal Free Hospital on World Kidney Day in March 2017 and support each other in our efforts to tell people about this wonderful opportunity.

We have had some success: Kay Mason has already given two talks and has more lined up and although the World Kidney Day stand wasn't overrun, perhaps seeds were sown in the minds of those who stopped and talked. However, it has been difficult to arrange further meetings as everyone's so busy.

But I didn't want the idea to sink without trace so I met with Jan Shorrock, Give a Kidney's Executive Officer and Catherine O'Malley, who had been my own co-



ordinator, at the Royal Free just before Christmas. We thought it might be best to channel our efforts through the Hospital and its Kidney Patients Association.

We agreed to hold a Live Donation Awareness open evening - possibly in St Albans where Catherine lives

and where there's a willing recipient who would sit on a panel with me and other donors/recipients and Jan. The recipient has a local radio programme so publicity could be wide.

Catherine also asked for cards to give to new donors, inviting them to join the group and telling them about Give a Kidney; these have now been printed, thanks to Suzanna den Dulk.

Members of the original group have pledged support but we need to make sure our efforts are clearly focused and people are asked to contribute in specific ways. I shall be at the Give a Kidney Annual Conference on 24 March and would be very happy to talk to anyone with ideas for taking this forward.

## First non-directed kidney donor, Kay Mason, on *Songs of Praise*

When a researcher from the BBC *Songs of Praise* programme approached Give a Kidney for a contributor to an episode on altruism, I was asked if I could take part. This resulted in several telephone calls negotiating the logistics; the transmission date had already been fixed and filming would have coincided with a talk I was scheduled to give to a church wives group. So the organiser of that group offered to host the filming at her house, with a hastily invited group of women from several churches in Welwyn Garden City. The producer requested a health care professional to provide technical information and statistics and we were happy to be joined by Lisa Burnapp from NHSBT.

Lisa and I were interviewed by JB Gill who was recognised by several of our group following his successful music career, which he has now given up in favour of farming and presenting *Songs of Praise* - then we all participated in a question and answer session followed by tea and cakes. One of the participants has since told me she is planning to offer to donate a kidney.

Kay Mason

## Marsha's journey

Twelve years ago Marsha Eastward saw a TV documentary about organ donation that sowed the seed for a decision that would profoundly affect someone else's life. But it wasn't until a few years later and another programme, *Lorraine Kelly*, which featured an interview with a kidney donor and a recipient, that she was fired up again and asked her GP where the nearest transplant hospital was. However, she hit a stumbling block. She was overweight so couldn't be considered for organ donation at that time. Undeterred, Marsha joined a gym club and, in only six months, managed to lose three stone!

And so the process began: she met three surgeons, a psychiatrist and an independent assessor and had the necessary x-rays, scans and tests. There was invaluable support throughout: she was in constant touch with the Transplant Co-ordinator and was also allocated a 'buddy', John Fletcher, who lived nearby and who had previously donated a kidney.



At last a match was found with a potential recipient, but sadly the operation had to be postponed as Marsha contracted a virus, but after blood tests confirmed all was well, the operation was quickly re-scheduled.

Marsha is 65 and leads an active life. Amongst many other things she took part in a 3km Donor Run as part of the British Transplant Games held in Lanarkshire in 2016.

She describes her donation as a

truly amazing experience and the single most important event in her life. She has since joined a 'Give a Kidney' volunteer group who meet regularly at the Hilton in Edinburgh with the aim of continuing to raise awareness of living kidney donation.

In Scotland, Andy Douse, Ray Duffy, Tracey Jolliffe and Richard de Soldenhoff have all given well-received talks about kidney donation. Richard is a serious climber and recently made his way to Annapurna base camp in Nepal, but was back home in time for Christmas.

### Contact us

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