

Give a Kidney Swimming Team Wins Gold!



(L - R) Alan Wallet, Denise Young, Serena Tucker and Sue Gianstefani on the podium just before gold medal presentation.
Above: Alan Wallet dives in for the last race.

This year's British Transplant Games, celebrated as 'The Year of the Living Donor', saw three members of Give a Kidney compete in the first ever living donor swimming relay event to take place in the 37 year history of the Games.

The Transplant Games is a national event that sees over 600 organ transplant recipients and, for the first time, living donors coming together from across Britain and from as far away as Australia to compete in a wide variety of sporting events such as swimming, cycling, fishing and track and field events. Held annually in a different city each year, this year's Games took place from July 30th until August 2nd in Newcastle upon Tyne.

After months of training the three Give a Kidney swimmers, Alan Wallet, Serena Tucker and Sue Gianstefani, who have all donated a kidney, traveled to Newcastle from three ends of the country, Aberdeen, Plymouth and London to compete in the four by 50 metre freestyle relay race against other living donors. Denise Young, a living liver donor from the Kings College Hospital team, joined our swimmers at the poolside to complete the team. The Give a Kidney living donor team was delighted to take first place, winning gold.

Next year's Games will be held in Liverpool from July 28th-31st, 2016. We hope more living donors from Give a Kidney will consider competing.

AGM 2016

Saturday 30th January

at the DoubleTree by Hilton London
- West End, 92 Southampton Row
London WC1B 4BH

A day to learn, be inspired, air views and enjoy the company of other donors, recipients, healthcare professionals and supporters.

Give a Kidney's new website is now live! Thanks to JFA systems (site build) and Curious Road (design) for their work. With all the information you need on why there is a need for kidney donors and how to go about donating; personal stories of recipients and donors, find out the latest news and how to become a member of Give a Kidney.

The Twitter feed will keep you bang up to date with what's going on! Don't forget, you can tweet your own comments or retweet anything related to Give a Kidney or kidney donation.

Organ trafficking: a cruel business

Despite international standards set by organisations such as the WHO and the United Nations, the illegal trade in organs is widespread, lucrative and on the rise. 'Transplant tourism' typically occurs from developing to developed nations, females to males, and from non-whites to whites. Reports estimate that 75% of all illegal organ trading involves kidneys, but it's impossible to gauge the extent of the global trade because the crimes can involve so many people in different countries and mainstream health care services can help to 'launder' the transactions.

Disadvantages and dangers

Those who are poorest, homeless and illiterate are frequently targeted because they are the most in need of money.

Traffickers may force or deceive victims into giving up an organ, often paying much less than the promised price, if at all, and the proceeds could quickly be spent on post-surgery care that is not provided by the buyer. There could be longstanding physical and mental health problems resulting in decreased employment opportunities or the inability to do physical labour. Sometimes, healthy organs are harvested during an operation for a possibly non-existent ailment. Those who illegally give away their organs may be reluctant to talk about it, and those who purchase organs are likely to say a relative donated the organ. In extreme cases, criminal networks have kidnapped and murdered victims, including children,



in order to harvest their organs.

Legalisation

Whether or not to legalise the organ trade to combat illegal trafficking and organ shortage is a subject of much debate. Iran is the only country that currently allows the legal buying and selling of kidneys - but only for its own citizens. Some see this as an exemplary system because they have no waiting lists for kidneys, non-profit organisations control the trade of organs with the support of the

Continued on page 2...

government and charities support receivers that cannot afford to pay. With no middlemen involved, the cost of a kidney is a fraction of the black market price. However, the model is not without challenges: 70% of donors are considered poor by Iranian standards and there is evidence of negative outcomes both in health and emotional wellbeing for donors afterwards.

Worldwide, the trend has been increased regulation of organ trading. Both China and India have come under the spotlight for human rights violations related to their organ procurement process. China currently has a waiting list of around three weeks, compared to around three years in the UK, because although involuntary organ harvesting is illegal, it is legal to harvest the organs of executed criminals, with their own or their family's permission - but this is often forcibly obtained. Reliable reports also allege that China has specifically targeted religious groups, particularly Falun Gong practitioners.

Prior to their ban in 2008 on the sale of organs, the Philippines was a popular destination for transplant tourists - as was India, who had passed similar legislation 14 years earlier although there are still loopholes in the law. A report from the Voluntary Health Association of India in 2007 estimated that approximately 2000 Indians sell a kidney every year, with a similar figure in Pakistan. Foreign recipients

made up two-thirds of the purchases - including a few in the UK. In 2007 a man in the UK became the first person convicted under the Human Tissue Act 2004 for trying to sell his kidney online for £24,000 in order to pay off his gambling debts.

Potential solutions

Nations need to work together on this issue to combat the serious health implications and the severe human rights violations of the vulnerable victims, but so far response to trafficking in organ trade has not been very robust. Possible solutions may be contentious but need at least to be debated:

- More living donations from unpaid donors
- Decriminalization and regulation of the commercial organ trade, including ensuring that not only wealthy individuals would be able to purchase organs
- Tightened policies, eliminating loopholes and stringent law enforcement against all involved in illegal organ trading, with multidisciplinary collaboration in cross-border offenses, and further police training in dealing with organ trafficking crimes
- Legislation to hold doctors accountable for not reporting suspected organ trafficking, which override confidentiality laws (eg in Spain)
- Laws making long-term care an intrinsic part of any donation agreement
- Much greater public awareness
- Finally, reduce poverty and hence the need for many to trade their organs.

News from the Living Kidney Donation Strategy Implementation Group

In July 2014, NHS Blood and Transplant published its Living Donor Kidney Transplantation (LDKT) Strategy 2020. The document lays out its ambition to match world class performance in living donor kidney transplantation. This aim is underpinned by three key objectives:

1. Increase Living Donor Kidney Transplant (LDKT) activity ensuring that donor safety and welfare is consistently sustained
 2. Maximise patient benefit by ensuring that all suitable recipients have equity of access to LDKT and that the principle of 'transplant first' (ie aiming for transplantation over other treatment options) is embedded across the UK
 3. Maximise the opportunities for suitable donors and recipients to contribute to and benefit from the shared living donor pool
- As part of this, a Strategy Implementation

OUR MISSION

'No waiting for a transplant for want of a kidney'

Group has been established. Chaired by Dr Aisling Courtney, a Consultant Nephrologist at Belfast City Hospital, the group has four key workstreams, to help deliver the strategy up to 2020: Commissioning, Availability and Access, Donor Safety and a group looking at the work around Higher Immune Risk transplants.

Give a Kidney is represented on the Strategy Implementation Group and the Availability and Access sub-group by its PR Officer Jan Shorrocks. The focus of this sub-group is around education and awareness of living donation, including, but not exclusively, non-directed donation.

A five year plan around this work is now in place. One of the first pieces of work has been to revise existing NHS Blood

Obituary: Joanna Kozubska



Joanna Kozubska, the 104th altruistic kidney donor, died on 10th August, aged 69. She had been suffering from Motor Neurone Disease, diagnosed earlier this year.

Joanna trained as a teacher and after spending two years in Africa with VSO, joined the Prison Service at the age of 25 as Assistant Governor at Holloway Prison. During her prison career she was in the news after borstal girls climbed onto the roof of Holloway, demanding that she should not be transferred away from their wing.

She corresponded with many women prisoners after their release, and with some, including Myra Hindley, after she herself left the service. Her experiences and continued concern for the plight of women prisoners resulted in her book "Cries for Help" published last year.

Joanna's subsequent career was in senior management training and she was Professor of Managerial Communications at the International Management Centres and its Vice President, UK, at the time of her death. Throughout her working life, Joanna was committed to developing and affirming other people, and encouraging them to achieve the best they could.

Joanna was one of the founder members of a group of altruistic donors in the Wessex area, the self-named Squeezed Oranges, which is active locally in promoting altruistic donation. Her philosophy is well expressed in her video piece on the Give a Kidney website.

There will be a service in celebration of her life at the end of September.

and Transplant patient materials around living donation as mentioned in the NHSBT article on Page 3 of this Newsletter.

Jan, along with other patient representatives, is also working on a new leaflet specifically around non-directed living kidney donation.

Research has been undertaken with transplant units across the UK into what would enable them to undertake more living donations, and a UK-wide educational roadshow with the aim of increasing awareness and understanding of living donation amongst medical professionals is currently being developed.

You can find the full strategy at: http://odt.nhs.uk/pdf/ldkt_2020_strategy.pdf

September saw the arrival of National Transplant Week (7th-13th September) after many months in the planning at NHSBT. This year's campaign

- '7 days to say yes I donate' - focused on encouraging people to sign up to the Organ Donor Register and discuss their wishes with loved ones. It is vital that people who pledge to donate organs after their death are not denied the opportunity to do so because their families do not know their wishes. Although the central theme was deceased donation because of the need for multi-organ donors, living donation also featured in this year's campaign with key messages, including non-directed altruistic donation, appearing on social media and twitter feeds throughout the week.

To accompany the campaign, all the donor and recipient educational materials for living donor kidney transplantation have been revised and rebranded. They will be launched this month, initially as downloadable pdf documents from NHSBT's website

NATIONAL TRANSPLANT WEEK 7-13 SEPTEMBER 2015
7 DAYS TO SAY YES I DONATE

at www.organdonation.nhs.uk and later as printed leaflets. I am greatly indebted to Jan Shorrocks who, together with donor and recipient representatives, Dela Idowu and Henry Kimbell, led on the revisions as part of the 'Living Donor Kidney Transplantation Strategy 2020' (LDKT 2020) work. Collectively, they aimed to bring a new look and feel to the information, with the NHSBT website being the 'go to' place for information about living donation. Whilst there is still more work to do on the branding of the leaflets, developing the content is a major achievement. A really exciting addition to the portfolio is a completely new leaflet about altruistic donation and, once it is available in a printed format, I will be working with colleagues at NHSBT to make these available at blood donation sessions; I know that this is something that 'Give a Kidney' members have hoped

to see happen for some time.

In the last Newsletter, I wrote about the introduction of the 'long' altruistic donor chains where a single donation from an

altruistic donor can trigger a chain of up to three transplants in the National Living Donor Kidney Sharing Schemes. Thanks to the generosity of donors and the hard work of colleagues in transplant centres and kidney units across the UK, I am delighted to say that these are now firmly embedded within the Sharing Schemes - most of the chains identified in the April and July matching runs were long chains, benefiting more patients than ever with a successful transplant. This is a fantastic step forward and we hope has set the trend for future altruistic donors to donate into a chain.

I look forward to updating you on progress on all these items in the next Newsletter. In the meantime, thank you all for your continued commitment and support - it really makes a difference.

*Lisa Burnapp
Lead Nurse - Living Donation*

Be an Ambassador for Give a Kidney

Over the coming year we will be looking to launch a Give a Kidney Ambassador Programme designed to promote and support members willing to raise awareness about non directed living kidney donation (NDLKD). As one of the first steps, we are developing an Ambassadors' Charter.

Give a Kidney's success has been entirely dependent upon the passion and enthusiasm of our members who regularly speak about NDLKD, attend meetings and conferences, support those considering NDLKD as well as support the administration functions of the charity itself.

Give a Kidney's position as a credible voice among the transplant community, within the media and with other interested groups, has only been possible by engaging with transplant professionals and working to shape policy and perceptions in a collaborative manner which we believe is the best way of meeting our objective to increase the number of non-directed kidney donors.

NDLKD presents many challenging ethical, moral, social and medical issues so it is not surprising that views vary within

the medical professional, society generally and within our own broad membership. Give a Kidney welcomes constructive debate relating to these issues and whilst we respect all views held by our members and their right to express those views in a personal capacity, it is important that anyone representing Give a Kidney should abide by the principles of the Charity in order to maintain and build on the solid reputation and credibility of Give a Kidney both within and outside of the transplant community.

The Ambassadors' Charter will help ensure that members are aware of the importance of adhering to our principles when representing Give a Kidney.

To support the introduction of the Ambassador Programme we are reviewing the Statement of Principles and developing a package of support, materials and training for Ambassadors. Watch for the roll out of the Ambassador Programme and we look forward to welcoming you as a Give a Kidney Ambassador.

Bob Wiggins

DRAFT

Give a Kidney AMBASSADORS' CHARTER

When representing Give a Kidney as an Ambassador I recognise:

- The importance of the credibility and high reputational standing of the Charity within and beyond the transplant community.
- Views expressed and information provided by me should be consistent with the Charity's Statement of Principles.
- Other views should be expressed in a wholly personal capacity and any divergence be made clear to audiences.
- Interaction with the press or other media should only be made in a personal capacity and not as a representative of Give a Kidney.
- I should act in a way to promote and enhance the reputation and credibility of the charity.

ZEE LONDON mela

SUNDAY 6 SEPTEMBER 2015
GUNNERSBURY PARK W3

A
celebration
inspired by
South Asian
culture



Give a Kidney had a stall at this action packed event to raise awareness of altruistic kidney donation in the run-up to National Kidney Week.

Below: Sanjiv Gohil from Give a Kidney talks to an interested listener about altruistic kidney donation



Challenging the Euro-sceptics?

Give a Kidney's second meeting with health officials and practitioners from The Netherlands

A meeting was held in London earlier this year between representatives from Give a Kidney and NHSBT and a team from the Erasmus Medical Centre in Rotterdam, the largest center in Europe for living kidney donation, and further talks will take place in Amsterdam on 5th October.

The Netherlands is not new to altruistic non-directed kidney donation, but a Foundation has now been set up to build capacity and this is where Give a Kidney's experience in helping to grow altruistic donor numbers through media and other activity could be helpful.

In the UK we have had TV crews from France, Denmark, Germany and Ukraine making documentaries on

altruistic donation, so there is clearly considerable interest in the issue, and although legislation is not yet in place to allow altruistic donation in many European countries, this meeting could be an important step in helping to influence some currently negative attitudes. As Chris Burns-Cox, Chair of Give a Kidney and one of the UK delegation, comments:

"As well as sharing our knowledge and experience, this is also an opportunity to gain some press interest and hence enable the public in both our countries to be more aware of the benefits and increase the number of volunteer donors who we are sure can be found in numbers in any society."

The last temptation

In my home-made anthology compiled some fifteen years ago, there is only one entry for T.S. Eliot, from *Murder in the Cathedral*. In the play, Thomas à Becket concludes that something that he might do which is good in itself would turn to ashes if it were pursued through bad motives. And so he concludes,

*"The last temptation is the greatest treason
To do the right deed for the wrong reason."*

We seldom do anything 'good' without there being some benefit to ourselves. It either makes us feel better, or look better, or both. If sympathy allows us to please ourselves by pleasing others, are we being selfish or altruistic? So how can we be sure that the philanthropic reasons for doing whatever it is are not eclipsed by the selfish ones; and, as long as the deed is genuinely 'good', does it actually matter?

Non-directed donation - the giving of a kidney to a stranger that you do not know and will probably never meet - raises interesting issues. The feelings that motivate a person to make a serious sacrifice for a stranger need to be examined. Is the donor trying to compensate for depression or low self-esteem, seeking media attention, or hoping to become involved in the life of the recipient? Is he embarking on a personal glory mission? There are other reasons that may not be so obvious. Some people help others to relieve their own unhappiness, or because being kind to others sustains their view of themselves as being kind, sympathetic people.

As human beings we can have more than one motive at a time. Pretty well everything we do is the product of an amalgam of higher thoughts and baser instincts. We do things because we are able to, because we think we ought to, because we want to, because it feels right, because it looks good. But the main thing is we do them.

I was too old to be a volunteer and not rich enough to be a benefactor. So being a kidney donor seemed to be all that I might be good at. It made me feel satisfied, knowing that I had done something useful - but had I done it for the right reason?

What would Becket have thought?

Nicholas Crace

Contact us

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