

An Olympic Year

by Jason Kidd

There used to be four dates in the year that I would always remember - the birthdays of our two children, my wife's birthday and our wedding anniversary. This year on June 27th I'll also be remembering the day that changed my family's outlook on life - the day of our transplant operation.

Last summer my wife, Cathy, donated a kidney to me in a pre-emptive transplant at Hammersmith Hospital. The operation was a culmination of what was a nervous year for us, anticipating what post-transplant life would be like. What's even more amazing about Cathy's gift to me was that it came just seven months after the birth of our second child.

In such a fast moving, over-hyped world, the phrase "life changing" is often overused, but since the transplant operation I have regained so much of the energy I had lost, I'm now able to lead a full and active life with renewed vigour.

I was first diagnosed with chronic kidney disease around 7 years ago. Initially this came as a big shock as we were both young and led active and adventurous lifestyles, without any hint or cause to think otherwise. We'd been fortunate to travel a lot to South America, South East Asia and Europe, and

had lived some time overseas for work. We also both enjoyed sport and outdoor activities, including running eight marathons between us (for charities), so we were greatly concerned our lives would become hindered by the diagnosis and treatment.

Since the transplant I have taken up a new challenge of a completely different kind - being the full time father to our two young children – and realising it's a lot harder than I first appreciated! But I am truly grateful that I'm able to enjoy this important time in our children's' lives free from any significant handicap. My renewed strength has also led me to set my sights on competing in the British Transplant Games in Medway later this year, taking part in both the squash and golf events, which represents a fantastic opportunity to use sport as a means of getting back to full fitness.

The support we have been given by not only our friends and families but also the wider



team at Hammersmith Hospital, has helped us to overcome any fears or concerns we may have had and has carried us to a place in our lives that a year ago seemed impossible. It is in trying to give something back that we have both become actively involved with the West London KPA and the work of the Hammersmith Hospital Renal Team, whom we hope we can repay in a small way, those wonderful people for the limitless care, support and understanding they have given our family.

Finally, to round off what has been a big year for us and our families, Cathy was selected by the London Olympic Organising Committee to be one of 8000 torch bearers in the Olympic Torch Relay this summer. She ran with the aim of raising awareness of organ donation and although the run was a relatively short 300m, it felt like the moment we all crossed the finishing line as a family, after what has been a challenging year.

Where next for the charity?

At the last count there had been 104 altruistic donations in this country. The purpose of Give a Kidney - one's enough is to inform and to support those that might be thinking of taking this step. The charity needs to think of ever more inventive ways to inform the public to dispel the fears and misinformation, and to encourage new donors. We need to inform more people of the ability of any healthy adult to donate and to ask for ideas from members on how to convert this acquired knowledge into actual donors.

Speaking out

Could you be a speaker for GAKOE? A powerpoint presentation is currently being developed - either as an aid for speakers or simply for volunteers to show to groups within their community, which can be followed by a discussion.

Other resources available

A great new information pack has been produced by Sue Jepson - available on request. There are posters, leaflets and badges (for sale at £1 to cover costs). Enquiries to the GAKOE coordinator Suzanna den Dulk at suzannadendulk@googlemail.com



10 things you can do...

1. Encourage people to display posters in your area and circulate info to local businesses and corporations.
2. Join our club (see page 4).
3. Hold an event eg raffle, tea party or cake stall to raise funds.
4. Give a talk or presentation on kidney donation within your local community.
5. Run a marathon, cycle ride or etc in aid of our charity.
6. Buy a badge and wear it!
7. Set people thinking...raise the subject of organ donation in conversation - at least to join the organ donor register.
8. Help GAKOE by sharing your skills resources, talent or knowledge and feed your blue sky ideas to the steering group.
9. Dedicate a concert, folk night or open mic night to the GAKOE campaign.
10. Send in articles to this newsletter!

My story of sudden Kidney Failure

By Karen Brown

I found out I had kidney failure last September. It all happened completely out of the blue: I'd been suffering from bad headaches for sometime, and thought my eyes looked puffy, but the doctors thought it was sinusitis. It wasn't until they checked my blood pressure which was sky high that they thought there was a problem and gave me a blood test. It was that night I got the call to say that my kidneys showed they were functioning at 5%, and I needed to go straight to Brighton Hospital for further tests.

It was devastating. I was only 39, happily married with two children, of 3 and 6 years old. I had also recently given up a career in London to spend more time with my children. As you can imagine my world was turned upside down.

I realised very quickly I had to go on dialysis to stay alive, I opted for the water based dialysis and two operations later I had a tube coming out of my tummy, which I connected to bags of water, and drained in and out every four times a day, this effectively was cleaning the toxins out of my body, a substitute for what my kidneys would normally do. The good thing was that I was able to do this from home, but it was difficult to manage with two young children around too.

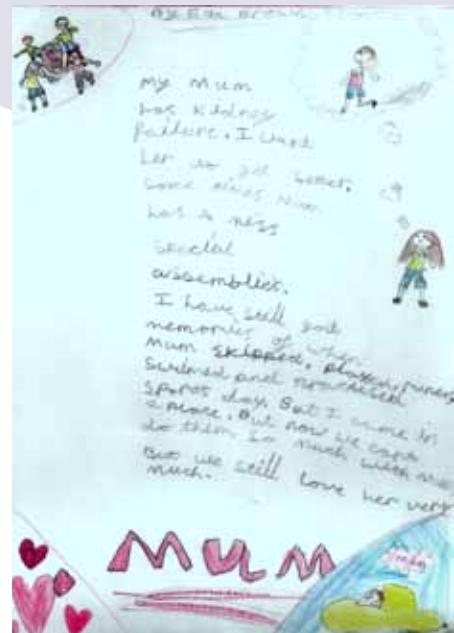
Things took a turn for the worse just before Christmas 2011. One day my vision suddenly started to go strange and the next thing I knew I was in an ambulance on the way to A&E. I had suffered a provoked

seizure (basically a fit) from fluid overload, and as a result my blood pressure had gone through the roof. This happened right in front of my children. I could not imagine how they were feeling, or my husband as he tried to deal with me in this state. After two days in intensive care and a week in hospital, I returned home. I changed to an overnight water-based dialysis, which I was told was better for me as the fluid cleanses your tummy in short but regular timings.

Because of the fit, I was told that I couldn't drive for at least 6 months, which was a really harsh blow. I've had to rely on my husband, elderly parents and friends to do a lot of running around for the children and me.

In January the tube started to protrude out of my tummy, and after a couple of weeks it started to create a blister and cause me excruciating pain. I was rushed in to hospital to get it urgently removed as there was concern for infection. As a result I had no way of dialyzing until I could get a 'line' placed in my neck and move onto haemodialysis for an interim period. I waited a week for this operation, which was pretty horrible, and quite painful, but it meant I now had an access point to connect up to a haemodialysis machine and get my blood cleaned.

I now go down to Brighton's Haemodialysis department three times a week. I'm up at 5.30am, get picked up and taken in by the Transport team, who are wonderful



Drawn by Karen's daughter Ella

volunteer drivers, and get home about 1pm. My husband takes the children in to school and nursery and gets into work late. Before using Transport, he was driving me down to Brighton all the time, he has had so much time off, in fact it was his first full week this February since September last year. I have no idea how other people manage; we are very lucky that Matt has an amazing employer who has been completely supportive throughout. Matt too has been absolutely amazing, so I am blessed to have such a wonderful husband.

Recently I had another op for a new tummy tube, and am hoping to be back on the overnight dialysis at home very soon, that's if all goes to plan, and everything has been successful.



Pictured above: Karen with her family

Karen's husband has set up a Facebook page to generate interest in her case. Sadly, only 2 potential donors have come forward to date and neither has been a match, so the search continues.
<http://www.facebook.com/BrownsSearchForAHero>

What is ALTRUISM?

Alter huic (latin) meaning 'to this other'.

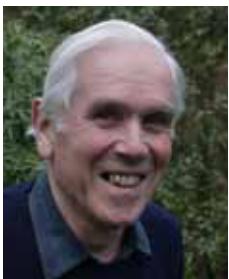
The word was coined about 1850 by French philosopher, founding father of sociology Auguste Comte (supported after his nervous breakdown by the English JS Mill and George Grote).

Wikipedia defines 'pure' altruism as:

'... sacrificing something for someone other than the self (e.g. sacrificing time, energy or possessions) with no expectation of any compensation or benefits, either direct, or indirect (for instance from recognition of the giving).'

The current NHS use of altruism in relation to living kidney donation refers to non-directed donation to a stranger.

Trust me, I'm a patient



It is nearly a year since I first got in touch with my transplant centre, and began what turned out to be one of the most momentous years of my life, culminating in my left kidney being removed.

My only previous experience of being a patient having been tonsillectomy at the age of ten, I found it difficult to work out the medical hierarchy. I would be deferential to someone who looked important, only to find out that he was the car park attendant and the next moment shoulder aside a scruffily dressed individual on entering the lift whom I find later is an eminent consultant.

I looked forward to my visits to the unit. For it is quite different visiting a hospital when there is nothing wrong with you. Medical folk are trained to make ill

people better, and are disconcerted when faced with the task of making a well person worse. They are not pleased to be placed in such a position where they no longer hold the initiative. Doctors find themselves in the unusual position of being on equal terms with the kidney donor, who can say with truth, "Trust me, I'm a patient."

I have been reported as saying that I found the whole process enjoyable, and indeed that is true. How can you fail to enjoy something that is not only absorbingly interesting, but involves meeting a whole lot of nice people, and on top of which is painless? In fact, I felt slightly short-changed by my surgeon in that he did not make me suffer, which made me feel rather a fraud and unworthy of the compliments that were paid me.

Like many donors before me, I wish that I had another kidney to give. But I have been assured me that as soon as they start doing liver transplants the centre will be on the line to me.

Sam Nagy - youngest donor at 20

People often say, 'sorry seems to be the hardest word', maybe, but I'm pretty sure these people don't have the problem of having to tell those closest to themselves that they are wanting to donate a kidney to a stranger!

Normally, I'm quite good with words, I can make people see and understand things from my perspective, but when it comes to telling those closest to you that you want to put yourself in danger (albeit a small risk) to help someone you haven't met or are likely to never meet it suddenly becomes quite difficult, and naturally you find yourself trying to remind them there are positives among the negatives. People ask 'why', not because they want your reasoning, but more like doing your bit to help a stranger isn't enough - there must be something I'm not telling them about.

Over the last few months, I've thought to myself, why is it so many people have misconceptions about what life with one kidney is like. From the first to the last person I've told, I find myself fighting against misinformation. Yes, I'll be able to continue an active lifestyle. No, I'm not at a higher risk of kidney problems. But strangely a question I never thought would arise which



has several times, is "are you getting a financial gain?". Nope, and given the facts and figures about kidney failure, the waiting times and risks to donors, I'm sure many more people would actively donate.

Give a Kidney - one's enough (GAKOE) is a charity and support network for many donors and renal specialists, who are happy to answer any possible question you can imagine. Real people, real stories and easy to digest information. Why not take a look? www.giveakidney.org.uk

Sam Nagy

Since writing this - part of his blog (<http://donatelifetumblr.com/>) - Sam has successfully donated his kidney. See his blog for an updated account.

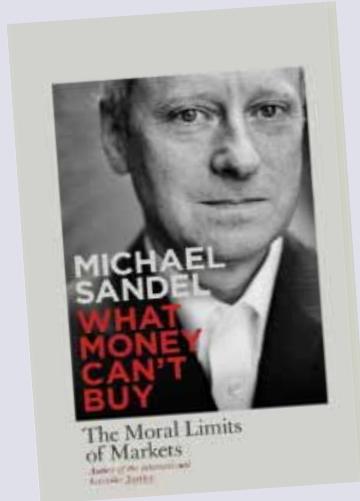
Book review

What money can't buy

- *the moral limits to markets*

by Michael Sandel, 2012

(published by Allen Lane) £20 hardback, or £13.10 from Amazon



What were non-pecuniary actions are now buyable and sellable in the market place. Whilst inefficiency in business and production should be improved on, something is lost in the change and there are times when the introduction of the market is counterproductive.

A village in Switzerland was chosen as technically the safest place to dispose of nuclear waste, 51% of villagers accepted the risk, apparently through a sense of civic duty. When asked if giving financial inducement to the villagers would affect their decision, the proportion accepting the waste fell to 25%. Perhaps the offered bribe was humiliating.

The US and other capitalist societies are now market societies not just market economies. The rich pay for people to queue for them for sports or free public concerts. Markets suit those with the money but not those without, so are unfair. In the UK we are suffering from a growing surfeit of inequality.

Sandel is worried by corruption. Money changes one kind of relationship with its own values to another.

This short book is very worth reading but here is no 'answer' to the question about the buying and selling of kidneys despite the benefits of the market in terms of freedom and speed. There is an awareness that something real but hard to define is lost by sacrificing altruism to the financial transactions of the market.

GAKOE cannot be faulted in trying to enable citizens to act altruistically outside the market.



Facebook in organ donation push

The NHS and social networking site Facebook have joined forces in an attempt

to increase the number of organs being donated. People will be able to register as an organ donor through the website and share their intentions with family and friends.

Three people die every day while waiting for a transplant and around 10,000 people in the UK are on the waiting list for an organ. NHS Blood and Transplant said the partnership was an "exciting new way" to encourage donation.

'Life event'

The NHS said only half of registered organ donors told their families that they wanted to donate their organs after death.

If somebody is on the register then legally the organs can be used for transplantation. However, organs are not taken if the family is too upset by the prospect. The NHS said relatives who

knew the person's wishes were far more likely to consent. People can now say they are an organ donor as part of their "Facebook Timeline".

It is marked as one of their life events alongside getting married, having a new job or moving home.

It will also mean people can register to become an organ donor through the NHS's own pages on the social networking site.

Inspired by friends

Simon Milner, the UK policy director at Facebook, told the BBC: "This is about making it easier for families in that highly emotional time as somebody dies, that they know this person is a registered organ donor.

"The second thing is to encourage people who may have thought about it in the past, but have just not got round to it or who might be inspired by finding out that 10 of their friends are organ donors, or 100 of their friends are organ donors, that they want to do it too. We think there'll be a

double benefit from this."

NHS Blood and Transplant's director of organ donation and transplantation, Sally Johnson, said Facebook was a "fantastic way" of getting families to talk about organ donation now instead of at "the worst possible time".

She said: "We need more people to sign up to the register and share their wishes with their friends and family, our job is to make that as quick and easy as possible.

"This is an exciting new way to use the power of social media to reach a huge audience and encourage people to think about it, act, and share that information."

Initially, similar partnerships will be launched in the US, Australia and the Netherlands. Facebook then hopes to widen the scheme to other countries.

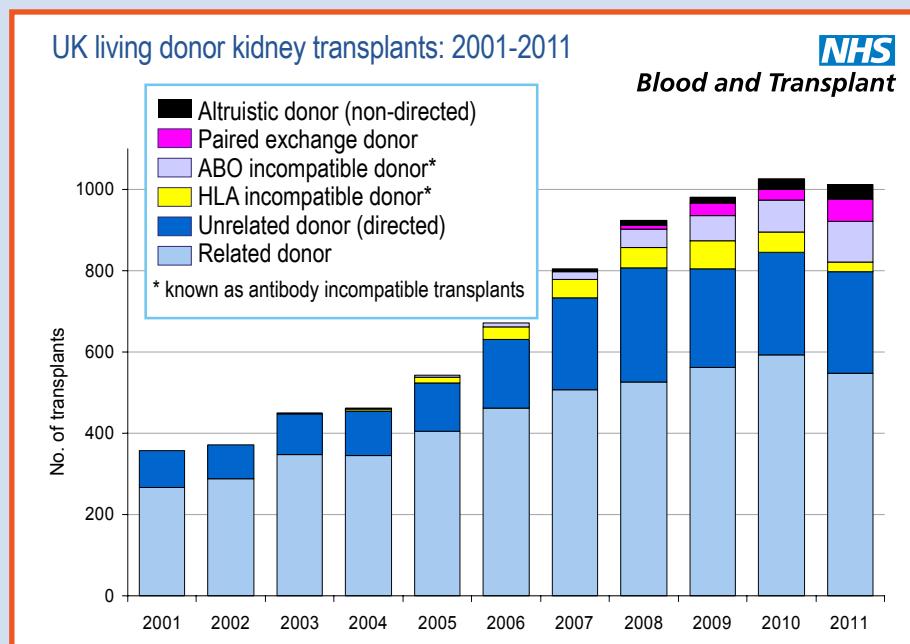
www.facebook.com/organdonationuk

Abridged from an article by James Gallagher
Health and science reporter, BBC News
May 2012

In January 2012 NHS Blood and Transplant (NHSBT) launched the first UK Strategy for Living Donor Kidney Transplantation. The Strategy has been developed to build upon the expertise and best practice that has been established in living donor kidney transplantation during the past decade in the UK and to offer more patients the benefit of a transplant in future. The data from NHSBT in this graph shows that the choices in living donation have already increased during this period and new sources of donors and innovations to achieve a successful transplant have opened up the choices for patients with kidney disease.

The Strategy focuses on 3 main areas:

1. Increasing the numbers of transplants without compromising donor safety
2. Increasing the opportunity for patients to be transplanted before dialysis
3. Developing the National Living Donor Kidney Sharing Schemes in which altruistic donation plays a crucial role.



Our club could be your club

If you've donated a kidney altruistically, you already understand what it means to 'make a difference'. If you would like to be a supporter of our charity to continue to make a difference why not join our club! Simply visit our website www.giveakidney.org.com to sign up, or email us at giveakidney@gmail.com with your name, email address and your areas of interest so that we know what you enjoy doing and know when to ask if you'd like to be involved with our various activities.

You will be added to our supporters' list and receive news about our events, activities and links to interesting news stories.



Contact us

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