

## Making your own life choices

**Michael McHugh is an altruistic donor and Registered Nurse. This article follows discussions at Give a Kidney's Annual Conference around the suitability of young people as altruistic donors.**

A friend recently visited his doctor to request a vasectomy after years of planning it, despite being 31, and with his long term partner having never had a desire to have children. His doctor was unwilling to refer him to even speak to someone about it and insisted he went away to think about it. While this may seem sensible given the long term implications, had he and his partner suggested they wanted to have a child the doctor would have written them up for pre natal vitamins, advised on quitting smoking and made other recommendations to see them successful. Most of us would be taken aback to hear a doctor tell us to go away and think if we were really ready for a child, even if some gentle reflection on a decision is always a positive thing.

The NHS is reporting that more and more young people are enquiring about organ donation, and in our recent AGM this topic caused some interesting discussion. Of course what constitutes being young is a subjective term. It is natural to feel protective of those who are just starting out in life, but in many ways people of 18, 21, or 25 already are making some complex decisions which can have long lasting effects. 18 year olds now face the prospect of university debts

still being repaid in their 50's according to a 2014 study. If we are willing to require 18 year olds to take on such large debts for an education, should they be denied the chance to explore whether altruistic kidney donation is the right choice for them?

Youth is often a time when people are labeled as naive and the term "folly of youth" is in the lexicon of our language, but then so too is, "there is no fool like an old fool". It is important not to dismiss someone's intentions or belief system based on their age but to support them in exploring the future impact of any of the potential choices they make today.

Age itself may be a poor criteria for deciding when something such as kidney donation is suitable. A potential altruistic donor at 20 years old who has seen a loved one struggle with dialysis all their life may be more certain of their feelings on the matter than a 50 year old who has watched a documentary on the topic or recently become aware of altruistic donation.



*Unusually, Sam Nagy was only 20 when he donated a kidney*

Similarly anyone about to start a degree, be they 47 or 18, may want to consider postponing it for a few years.

Altruistic donation is a very new topic within medicine itself, and likewise individuals starting their adult life today have very different options available all round than those starting out 40, or even 20 years ago. Traditionally medicine was a very paternalistic

affair with patients doing as they were told to and decision making left to those in the know. Nowadays medicine and nursing are shaped by the fundamental belief that each person is an individual with a unique value system and set of life experiences.

As is always the case, the best person to make a choice about their own body and life is the individual themselves, guided and informed by their clinical practitioner and their individual support network. We as a charity can support them with providing information, connecting them with resources to support their decision making and, most importantly, providing a friendly ear to listen to them.

*Michael McHugh*

## Annual gathering in January well attended

Chair Chris Burns-Cox welcomed over 40 guests from all over the country to the charity's fourth AGM, held in London. The business of Chair's and Treasurer's reporting having been settled, our expert speakers delivered fascinating talks on subjects including how kidneys from altruistic donors are allocated, latest research around altruistic donation, lessons learned from a year promoting altruistic donation in the media and how to keep the momentum going, in the face of evident slowing of the previous rapid increase in altruistic donor numbers. If anyone would like a copy of the Chair's report, circulated on the day, just email [suzannadendulk@gmail.com](mailto:suzannadendulk@gmail.com)



*Give a Kidney supporters at the AGM & conference in January*

On 3rd March Steering Committee members Chris Burns-Cox and Bob Wiggins supported Transplant 2020 at their four-day exhibition for MPs held in the Houses of Parliament. Give a Kidney is a member of Transplant 2020, which is made up of a coalition of patient, clinical and private sector organisations. Whilst Transplant 2013 successfully sought



Give a Kidney Chair (left) with Cotswolds MP Geoffrey Clifton-Brown

Parliament, they also increased MPs' awareness of the valuable work of Give a Kidney and the enormous contribution non-directed living donors make to the organ transplant programme. Both messages were well received and Transplant 2020 will be following up after the general election with those MPs returning to Parliament who have pledged their support.

The work of organisations like Transplant 2020 is important to Give a Kidney meeting its

to increase organ donor registrations, its successor body, Transplant 2020, is now looking to increase the consent rate for the use of deceased organs from just over 60% to 80% over the next five years.

Whilst Chris and Bob were primarily there to discuss with MPs how they could be more active in supporting the aims of Transplant 2020 over the course of the next

goals, as increased awareness and dialogue about organ donation in general, whether deceased or living, will not only help to shrink the organ transplant waiting list itself, but any increased publicity about organ donation will assist the work of Give a Kidney in connecting with potential non-directed kidney donors.

The Transplant 2020 website can be found at [www.transplant2020.org.uk](http://www.transplant2020.org.uk)

## A new resource:

Give a Kidney has produced an informative leaflet to help raise awareness of non-directed living donation and provide basic information. Leaflets are available for anybody giving talks, manning stalls and generally helping to spread the message of the charity. Leaflets are available from [suzannadendulk@gmail.com](mailto:suzannadendulk@gmail.com)



## Pause for Thought...

*"Human aggression could bring a nuclear war that would end civilisation and perhaps the human race. Instead, humans should have more empathy, to bring us together in a peaceful, loving state".*

Prof. Stephen Hawking  
The Independent, 20 February 2015

## Remembering Andy Loudon



Give a Kidney was very sorry to hear of the death of Andy Loudon on 25th February from mesothelioma. Andy was the recipient of a kidney from the UK's second altruistic kidney donor Barbara Ryder, and they were the first altruistic donor and recipient in this country to meet.

Since the transplant operation in 2007, Barbara has been in regular touch with Andy and his wife Hilary. Give a Kidney sends its heartfelt condolences to the Loudon family.

## Unspecified Living Kidney Donation in the UK: Barriers to Implementation and Delivery

Following on from our hugely successful research study conducted in 2012/13, we are delighted to be embarking on further research into unspecified (altruistic) donation. The results from our first study demonstrated that there were no significant differences in psychosocial outcomes between unspecified donors and those donating to someone they knew. This was across a range of measures, such as mood, stress, anxiety and general wellbeing. This study also provided valuable information about how donors were made aware of unspecified donation, what motivated them to donate, and whether they had been in touch with their recipient after donation. Our results also demonstrated a variety of donor experiences across the country, adding further to the research conducted by Alexis Clarke and her colleagues at the University of Plymouth.

The next stage of our research is a

nationwide prospective study. This will be conducted over the next five years and will be funded by the National Institute for Health Research. The aim of the study, titled "Unspecified Living Kidney Donation in the UK: Barriers to Implementation and Delivery", is to provide a comprehensive assessment of unspecified kidney donation in the UK.

There are three main research questions:

1. Is there variation in transplant professionals' practice and attitudes, which is preventing some unspecified donations?
2. Are psychosocial and physical outcomes after unspecified donation equivalent to those after specified donation?
3. What is the economic benefit from unspecified donation?

This study will involve questionnaires, interviews and focus groups with donors and members of the transplant

community. We will be looking to recruit as many unspecified donors as possible from each of the UK transplant centres.

The research team comprises a mixture of clinicians, academics and unspecified donors from institutions across the country (including Guy's and St Thomas' NHS Foundation Trust, Portsmouth Hospitals NHS Trust, University of Plymouth, University of Birmingham, King's College London and NHS Blood and Transplant), and David Hemmings and Jan Shorrocks from Give a Kidney will provide the unspecified donor perspective on the study steering committee.

The research team would like to extend their thanks to all those at Give a Kidney who helped with putting this grant together. We will be providing regular updates and results throughout the study period, so please do watch this space!

Hannah Maple



## Kidney brothers



On Saturday morning (21st Feb) Dave, his wife Di, my partner Susie and I met at a cafe in Cirencester to commemorate five years since our operation.

It has been around three years since we last met at a Give A Kidney event in London, and although we exchange occasional emails and Dave sends me an annual birthday card celebrating the 'adoption' of my kidney, he's rarely far from my mind.

It was a wonderful opportunity to catch up and for me to see how amazingly fit and healthy he looks. He exercises very

regularly, runs marathons and eats healthily. I truly could not have wished for a better custodian of my kidney.

When I set out on the path to donation I had fully prepared myself for never knowing the outcome, never mind the recipient, and I'll be eternally grateful to Kay (the transplant co-ordinator)

at Southmead Hospital in Bristol for deciding that not only were we a perfect clinical match but psychologically too. She was right and it's wonderful to share the obvious joy with which Dave lives his life.

It was wonderful to share our reminiscences about the op and our stay in hospital and for my partner to hear them from Dave who I talk about often, and to hear from Di how their lives have changed.

We will keep in touch and I look forward to celebrating the tenth anniversary and hopefully many more.

*Chris Kendall*

## Raising awareness - doing your own thing

The 2014 YouGov survey results showed a small increase in general awareness of non-directed living kidney donation since the previous survey in 2011. Whereas this is welcome it is also a clear indication that we still have a lot to do, and individual members and supporters can do a lot to spread the word.

Your local paper is a good place to start: approach them to see if they would be interested in an article about Give a Kidney from a local person, be you a donor, recipient, relative or a supporter. Also, keep an eye on your local papers for any article or letter relating to organ transplantation to which you could respond with a letter to the editor. If you belong to a club or association or can find out about any in your area that have occasional speakers, you could consider offering to talk to them about Give a Kidney. Remember, you are not looking specifically for potential donors but to raise general awareness of, to get people talking about and to help people understand non-directed living donation. It's important to stick to the aims and objectives of Give a Kidney and never venture into giving medical opinions – if faced with a difficult question that you can't answer, always make a note of the question and the questioner.

You can then contact someone in Give a Kidney to get the information you need and get back to the questioner. If you are not used to talking to groups of people, don't be afraid to try; local groups are usually small and informal, there's even a chance you might recognise a friendly face in the audience.

In my experience it has worked well to make it clear that you are not asking for a speaker's fee but that any voluntary donation to Give a Kidney would be welcome. Additionally you could ask for your travel costs.

Give a Kidney can help you prepare for your talk as we have developed a PowerPoint presentation, accompanied by full speaker's notes, which are updated regularly and available to anyone who needs it. If you'd like a copy or more information about giving a talk please get in touch at davidhemmings6@btinternet.com.

Jan Shorrock (jan@glowlife.co.uk), our PR Officer, would be more than happy to help you with an article for the local paper, if necessary.

Once you have got the hang of this you can then move on to local radio and television, I look forward to seeing some of you shortly on the One Show!

Good luck.

*David Hemmings*

## Transplant Links

Sharing knowledge and skills in developing countries



In terms of the history of kidney transplants, 'non directed' or 'altruistic' kidney donation is a relatively new concept, and not practised in most of the countries of the world. Directed donations from living donors – ie from a family member or friend – are much more common.

In developing countries, living donors are the major source of transplantable kidneys due to insufficient legislation and infrastructure to increase the deceased donor pool. Kidney failure often goes undiagnosed and untreated; kidney patients face many obstacles including lack of access to dialysis facilities and transplantation centres, quality and safety issues, and exploitation associated with 'transplant tourism'.

Transplant Links (TLC), was set up in 2006 by a group of UK doctors with backgrounds in kidney transplantation who wanted to share their skills in countries where they are badly needed. It became a registered charity (non-religious and non-political) a year later, and relies on charitable donations and the services of volunteer doctors and nurses giving their time and expertise.

TLC only supports living kidney donations within families, often from parent to child. As well as carrying out living kidney transplants, they offer teaching and advice, sharing knowledge with local medical teams, helping them to develop skills to run their own life saving transplant programmes so that they can become sustainable in the long term.

The doctors at the host hospital are mentored throughout the operation by the TLC team, and afterwards the patient's progress is closely monitored by both the Transplant Links and the hospital doctors. TLC remain in contact after they have returned to the UK, and continue to maintain long-term links.

A part of the process is to invite families of children with kidney failure to ask the visiting TLC team questions and raise any concerns re. the transplantation procedure. It's hoped this will encourage more people to come forward and donate kidneys to their loved one.

[www.transplantlinks.org](http://www.transplantlinks.org)



## Home thoughts from a transplant unit

When I got in touch with the transplant unit at Queen Alexandra Hospital, Portsmouth, to enquire whether I might be acceptable as a kidney donor, I little knew what a momentous year would follow.

As a patient you learn to accept that the overworked NHS cannot give individuals more than ten minutes each; not so the Portsmouth renal unit. When attending for an appointment I would ask: "How long have I got?", and the answer always came back: "As long as you want". This was very impressive, and helped to make us donors feel wanted and part of the enterprise.

I found that a remedy that medics had used with success in the past had come back into fashion. It is nearly always efficacious, though some people find it difficult to administer, and it has no side effects. It is also cheap. Its generic name is ... kindness, but it is also known as friendliness, sympathy, patience and consideration. It is extraordinarily effective, and speeds up the healing process.

I certainly did not expect that in the process I would make so many friends outside the hospital. The group of altruistic donors, self-named Squeezed Oranges, came together naturally, and meets from time to time to talk over old times and to discuss how to increase the flow of kidney donors. And why Squeezed Oranges? During our work-up to the operation we became in the eyes of the hospital (and sometimes, alas, to ourselves) Important People. But after the surgeons have done their work, we have to accept that we are no longer significant to the NHS, with no greater value than a squeezed orange. But squeezed oranges have a value - as compost. And from this putrefying mass, who knows, will emerge a new crop of oranges to be harvested.

Blood donations, donor cards and now kidney donations have all become accepted parts of the nation's fabric. In the last nine years living donor transplantation has developed from an exceptional event into a routine clinical practice across the UK. I was privileged to be part of its development.

Nicholas Crace

## From father to daughter...

*Last year you wrote a to-do list on your Facebook page. One of the items was "donate a kidney". I wasn't sure if you were serious but, knowing you as I do, I should have known immediately that you were. Then at Christmas you told us you were planning to become an altruistic donor, giving a kidney to a stranger on the transplant waiting list. I don't think you will ever meet the recipient or know his or her identity.*

*I am proud to say that we have never tried to dissuade you, although we did suggest that you delay until after you have had children. We know that the risks are small, that donors live, on average, longer than the rest of us. But we are your parents. Worrying about you is part of the job description. I am not proud to say that I hoped the NHS would reject you as a donor.*

*Over the past nine months, we have felt a slow-growing fear, as you passed all the medical and psychological tests. At the same time, our admiration for you has grown as you pursue this goal.*

*Last weekend we happened to be sitting next to you when the email arrived to confirm the date of your operation. You were elated. You explained the process by which someone would be given the priceless gift of your kidney.*

*Your mum and I have spent the time since then feeling raw and tearful, leaning on each other for comfort.*

*I thought of my mum and how she would have reacted. I was glad that she's not around to worry but sad that she is not here to give me a comforting hug.*

*On Thursday, completely by chance, I met a lovely man whose wife had given him a kidney. He sat patiently while I fought back tears and told him about you. I showed him your photograph and told him, as best I could, how proud and how worried I am.*

*He told me how the kidney had transformed his life and that six weeks after the transplant they were out walking the fells together. He said I should be very proud of you and that you are doing a wonderful thing.*

*Now the operation is four days away. Your mum and I talk about it - and our feelings - every day. She will be with you at the hospital while I wait anxiously and look after home, dog and son, 300 miles away. You will be coming home to us to recover.*

*I am so proud of you that it hurts. I know the risks are low and that you are probably safer in the operating theatre than on the journey home. But for once I struggle to take a rational view. I spend much of my day feeling close to tears. I feel foolish - after all, you're the one having the operation.*

*But this is not just about fear. I know that it will have a permanent effect on you as well as the lucky recipient. However, it's such a momentous event, such a big, wonderful thing you are doing, provoking such strong feelings of love, admiration and compassion, that it has changed other people too.*

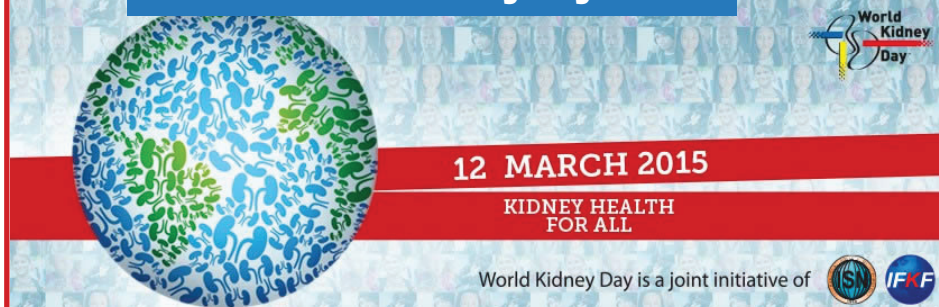
*With all my love and all my fingers crossed,*

*Your dad*



[written in 2014]

## WORLD KIDNEY DAY 2015

[www.worldkidneyday.co.uk](http://www.worldkidneyday.co.uk)



**12 MARCH 2015**  
KIDNEY HEALTH  
FOR ALL

World Kidney Day is a joint initiative of  

## Becoming an altruistic kidney donor

If you are considering donating a kidney, or would like to talk to someone for further information, contact the Living Donor Co-ordinator Nursing Team at your closest kidney transplant centre (locate them on [www.nhsbt.nhs.uk](http://www.nhsbt.nhs.uk)) or get in touch with us at [giveakidney@gmail.com](mailto:giveakidney@gmail.com) and visit [www.giveakidney.org](http://www.giveakidney.org)



**THE ANONYMOUS GIFT**  
ALTRUISTIC KIDNEY DONATION  
An open information evening at  
Dynamic Earth, Edinburgh  
Thurs 30th April 18.00-20.00

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## Contact us

Give a Kidney - one's enough,  
PO Box 65885, London N7 1BR  
[giveakidney@gmail.com](mailto:giveakidney@gmail.com)  
[www.giveakidney.org](http://www.giveakidney.org)