

Introduction by Bob Wiggins

Welcome to this our latest newsletter at a time when there is a great deal of activity. 2016 is proving to be a significant year of progress for Give a Kidney across many fronts as we build on the strong foundations built up over the past five years. Many aspects of this activity are highlighted in this newsletter: our Ambassador Programme launch, the Give a Kidney Scotland Chapter, the upcoming announcement about the 500th non-directed living donor, Lisa's update from NHSBT and the invitations to present at major conferences indicating our continued rising profile amongst the medical community at home and abroad.



Additionally we are making considerable progress at the highest levels within NHSBT to increase emphasis of the benefits and awareness of non-directed living donation. This in combination with a programme of engagement with other notable charities and organisations to explore common ground and initiatives we can take to influence change within the NHS and with the public at large.

All of this while continuing with our existing work, which is yielding excellent results – the recent ITV *Real Choices* programme being a shining example. National media pieces such as this will remain a strong focus of our efforts, but is now complemented by the local focus of our Ambassador Programme.

With a much wider remit of planned activity we now need to focus on the need for sustainable financing of Give a Kidney. We will need to become more organised regarding fundraising and with regular income to support annual running costs, allowing the ad-hoc large one-off donations to fund specific projects.

Our Steering Committee is working hard to drive forward the pace of progress toward our goal of “no waiting for a transplant for want of a kidney” and I would like to pay tribute to each existing and former member of this group and the many individuals that support it on a regular basis.

Give a Kidney launches Ambassador Programme

On 25th June in York, Give a Kidney launched its Ambassador Programme for those willing to help increase public awareness of non-directed living kidney donation. Ambassadors will play a key role in helping the charity to meet its objectives in this regard, as well as encouraging their local communities to raise funds and representing the Charity at local events and functions.

Following a welcome by Give a Kidney's Chair, Bob Wiggins, Lisa Burnapp talked about NHSBT's close relationship with Give a Kidney. She explained that NHSBT funds the donation process, ie. organ allocation and matching, not the actual transplants – adding that State funding for promoting non-directed altruistic kidney donation (NDD) is minimal.

This fact was reiterated by Prof. Derek Manas, Director of the Institute of Transplantation, who proposed targeting politicians to increase awareness of the economic benefits of transplants vs dialysis – because it is NHS England who is responsible for all specialist commissioning in England, holding the purse strings in this regard. Prof. Manas talked about the importance

of links between charities and the NHS and signposted participants to useful websites such as Involve, commenting that public and patient involvement is crucial to research.

Three seasoned volunteer speakers for Give a Kidney, David Hemmings, Gill Owen and John Fletcher, described how they went about it, finding potential audiences and tapping into key dates such as National Transplant Week, and demonstrating how just one talk can have a ripple effect resulting in several lives being transformed for the better. It was suggested that experienced speakers might add their profile to www.speakezee.org

Jan Shorrock, Give a Kidney's Executive Officer, is planning some publicity around the tenth anniversary of the first donation in the UK. The date could also be marked in various transplant units around the country.

Other issues were also aired, such as the formation of regional groups of Give a Kidney supporters where there is an appetite to meet other donors, and the inclusion of testimonials on the website from family members which might be helpful to potential donors.



Time to celebrate the 500th non-directed donation?



At the time of writing we are eagerly awaiting news that the 500th non-directed altruistic donation has taken place. We'll be celebrating this in collaboration with NHSBT later this summer, (once the donor and recipient have had a bit of time to recover!) with a press and social media campaign and we'd like to invite you to get involved.

As part of the campaign we've created some signs reading '500 UK people have donated a kidney to someone they don't know. I gave, could you? #ShareYourSpare' and a similar sign for recipients.

We'd like to invite you to print off the sign or request that we send one through the post and ask a friend to take a good quality photo of you holding it up and send the photo to us. We'd really love to show the diversity of our donors, so if you have a job which requires a uniform or special tools, it would be great if you could wear this (eg if you are a doctor, please wear a stethoscope, if you are a fireman, please wear a uniform etc).

At the time of the campaign (PLEASE not before!) we'll be inviting you to do the following:

1. Share your picture through your social media channels
2. Issue it to your local press along with a standardised press release that you can personalise to help encourage local press coverage
3. Allow us and our partners (at NHSBT, other charities etc) to share your photos through our networks to encourage others to spread the word.

You'll already have received an email about this, but if you have not already been in touch and would like to take part, please contact Jan on jan@glowlife.co.uk

Many thanks – it really is a milestone worth celebrating.

Jan Shorrock

When Julie met Dave

Julie from County Down in Northern Ireland is a living kidney donor. In a 'Real Stories' documentary for ITV, she explained why she chose to donate her kidney to a stranger in need, and the programme followed her as she met her recipient Dave for the first time. Julie's surgeon, Tim Brown and Dave's nephrologist, Adnan Sharif, also spoke about what it means to donate a kidney. View at: www.itv.com/.../2016-0.../real-stories-kidney-transplant/



Been a donor?

What tips can you give that might help other donors, or what did you wish you'd done?

In the next issue we will be running a feature on top tips to help you pre- and post-donation; the personal things that medical staff didn't (and couldn't) prepare you for. Please see contact details at the foot of Page 4. We look forward to hearing from you!

Give a Kidney Scottish Chapter

At the recent meeting of Give a Kidney in the very beautiful surroundings of King's Manor in York, the first moves to create local groups of supporters were made. There was already a party of some seven or eight Scots who had travelled south and they agreed to form the first of those regional clans.

In fact this was the culmination of about 12 months of networking in Scotland.

As a result of a meeting organised by NHS Scotland last year, Chris Jones and I gently started talking to other donors in Scotland and soon found ourselves buoyed up by their energy and enthusiasm. So far we have had just a few meetings in a pub and others at the renal unit in Edinburgh, but some newspaper articles have already emerged as well as occasional talks to Rotarians and others and we are hoping for much more. We have also offered a 'buddy' service through the NHS to anyone wishing to donate.

In the meantime the renal unit in Edinburgh has independently started to hold regular get togethers of staff as well as future and present donors and recipients. These have taken place in Edinburgh and Dundee.

Our initial proposals hinged around the development of a group of donors

plus some recipients that could help us with events, media stories, talks to big and small groups of people and assist in talking to prospective donors. We felt that in Scotland the numbers were small enough for us to be able to achieve some ambitious goals, with the single over-riding objective of simply 'raising awareness' so that everyone in Scotland is aware that the gift of a kidney to a stranger is



Left to right: Bob wiggins, Chris Jones, Matilda Hall, Tracey Jolliffe, Kate Douglas, Alan Wallet and John Fletcher

a realistic and possible act open to all who are healthy, and one which will bring benefits to the donor too.

Our Scottish group was further enthused when Bob Wiggins, Jan Shorrock and Chris Burns-Cox came up from Give a Kidney in England to see if we could help each other. This has now provided the basis for the formation in York of what may be called the Scottish Chapter of Give a Kidney. We are all motivated by the same objectives and are eager to get cracking.

John Fletcher

Firstly, a big 'thank you' to Give a Kidney – we are about to celebrate a milestone in anonymous donation that we could not have foreseen ten years ago. Although the number of people volunteering to donate fell again last year, the impact that every donation makes has increased. Every time a non-directed donor 'unlocks' a chain of transplants, up to three people end their wait for a kidney. Almost 150 people received a kidney transplant through the UK Living Kidney Sharing Schemes last year – 50% more than the previous year – and 'chains' are a big part of the story. Our aim is to encourage every non-directed donor to think 'chain first' to make the most of these opportunities.

Living donation now has a distinct brand, with new information on the NHSBT website at <https://www.organdonation.nhs.uk/about-donation/living-donation/> Particular thanks to Jan Shorrock, who worked with me to ensure that the views

of donors, recipients and professionals are properly reflected in the information we provide.

What else? Good progress has been made with getting information about living donation into blood donation centres; publicity and living donation awareness campaigns are planned for this year and options for developing an on-line registration system for non-directed donors are being explored. More next time. Collaboration with Give a Kidney in all these ventures is absolutely key.

Finally, I am delighted that Bob Wiggins has accepted an invitation to speak at NHSBT's Organ Donation Congress on 20th September. Bob will be speaking in the inaugural session on living donation and I have no doubt that he will be a great ambassador for the charity and non-directed donation.

*Lisa Burnapp
Lead Nurse- Living Donation*



Give a Kidney Gains International Profile

Give a Kidney's success over the past five years has generated considerable interest among the clinical community, both in the UK and abroad. Our credibility and unique perspective, being primarily made up of non-directed donors, has resulted in us being asked to attend, participate and/or present at a number of international meetings and events. We believe increasing awareness and understanding of non-directed donation across what is increasingly a global community of clinical professionals is helpful to our cause.

Give a Kidney was asked to make a presentation at the April ELPAT conference in Rome. ELPAT (Ethical, Legal & Psychological Aspects in Transplantation), is a section of the European Society for Organ Transplantation (ESOT). Chris Burns-Cox eloquently spoke about how a charity such as Give a Kidney and its membership can make a real impact on non-directed living donation. The directness and passion with which Chris delivered his message made a significant and positive impression – so much so he has been invited back for a much longer presentation at the main ESOT Congress next year.

Separately, Give a Kidney accepted

an invitation by the American charity National Kidney Register to attend their New York symposium last May. The symposium focused on donor chains through maximising the number of living organ transplants triggered by a single non-directed donor, dealing with the problems that long chains can create and enhancing the matching process for better outcomes for patients. NKR are at the vanguard of the kidney pairing process in the US, albeit a very different system of organ allocation to our own. They actively pursue compatible directed donor pairs to enter into the donor chains to achieve better matches and longer chains and have recently introduced the concept of "Advanced Living Kidney Donation" where for example a grandparent of a child with kidney disease not yet requiring a transplant, can donate their kidney into the non-directed pool and receive a "voucher" for their grandchild entitling them to rise to the top of the wait list should the time come that they require a transplant.

There are a number of other speaker engagements at future events which we will report on at that time.

Bob Wiggins

Save the date...

We're delighted to announce that we are partnering with the Brandenburg Choral Festival of London with a special Fauré Requiem Concert, being held on the evening of Weds 16 November at the Queen's Chapel of the Savoy, London. It will mark a very special date for the charity - and half the ticket income will be donated to Give a Kidney. For tickets (£18, or £5 for children), contact giveakidneyoffice@gmail.com - please consider bringing a group of friends!



The 2016 British Transplant Games were held in Liverpool on 28-31 July.

Give a Kidney didn't have a team taking part this year but supporters marched in the opening ceremony (see photo below) and had a stall in the marketplace.

Give a Kidney joined with a group of charities during the Transplant Games to promote the '**Donation Conversation**' campaign, encouraging people to talk to their families about their wishes for organ donation, and to increase the family consent rate from 57% to 80%. The campaign was launched on Friday 29 July at the British Transplant Games, with speakers from Transplant Sport, BKPA, the Anthony Nolan Trust and others.

Simultaneously, Facebook posts and tweets promoting "Have the #DonationConversation – 1 organ donor can transform the lives of up to 9 people" were sent via Thunderclap, a crowdspeaking platform using social networks that allows a single message to be mass-shared, flash mob-style, so it gets noticed!



Surgeon Paul Gibbs is director of the Transplant Programme at Queen Alexandra Hospital in Portsmouth and a trustee of Give a Kidney

What was your earliest ambition?

From an early age I was interested in the past and in understanding where we started. I wanted to go and dig up a T rex in Montana.

Who was your biggest inspiration?

My uncle, John: a consultant anaesthetist who took me to his hospital when I was about nine. He showed me an operating theatre, and it was so exciting. That was where I wanted to be, and surgery was how I was going to do it.

What was the worst mistake in your career?

Leaving the operating theatre ten minutes too soon when a colleague was taking out a live donor kidney.

What was your best career move?

Taking a 'stand alone' renal transplant job (one that isn't part of a rotation) in Cardiff, to be closer to a girlfriend. I'd never considered it before then.

Bevan or Lansley: Who has been the best and the worst Health Secretary?

After Bevan, it's never been the same. We need someone to be honest. We can't fund the NHS with an ageing population who have increasing expectations.

Who is the person you would most like to thank, and why?

Simon Darke, a retired vascular surgeon from Bournemouth. He wanted me to convince him that I had what it takes. He challenged me just when I needed it most.

To whom would you most like to apologise

The patients and families who have had a bad outcome from surgery. I'm relieved to say that it hasn't been many, but it's still been more than I would've wished.

If you were given £1m what would you spend it on?

A bolt-hole in southern Spain and a Porsche GT3 to get me there.

Where are or were you happiest

Outdoors with nature, hilltop hiking, mountain top skiing, or surfing.

What single unheralded change has made the most difference in your field?

The Human Tissue Act 2004. That Act made it possible for people to donate a kidney to a stranger – what is called altruistic, or non-directed, donation. This year will see the 500th altruistic kidney donor: that's 500 heroes, right there.

Do you support doctor assisted suicide?

Absolutely. I believe in alleviating suffering.

What book should every doctor read?

Anything by Atul Gawande. He has such a refreshing way of looking at the medical world we live and work in.

What poem, song or passage of prose would you like at your funeral?

I'd have to follow my friend, "Always look on the Bright Side of Life!"

What is your pet hate?

People who live in the past. Learn from it, and move on.

Do you have any regrets about becoming a doctor?

Sometimes I do, on those dark days. Fortunately, there aren't too many of them.

If you weren't in your present position what would you be doing instead?

Running a beach bar somewhere sunnier than Portsmouth.

Ref: *BMJ* 2016, 353;12500

Thank you to Sandrine Bradbury from Swindon who recently ran the Warwick Marathon, raising £130 for Give a Kidney.

A better understanding of rare kidney diseases through RADAR

The Rare Disease Registry (RADAR) is a vital new tool in the fight against kidney disease. Funding from Kidney Research UK of £590,000 made it possible to establish RADAR, in partnership with the British Kidney Patients' Association.

Some kidney diseases are so rare that very little is known about them. Medical teams in their separate hospitals don't come across enough patients with these conditions to build up a deep understanding of the disease.

RADAR offers hope for such people. The registry consists of a database that pulls together detailed information about all of the patients fighting rare kidney diseases in the UK, enabling collaboration and knowledge sharing between medical professionals and patients. For each condition, there is a Rare Disease Group within the registry, which is a source of expertise for patients and renal units everywhere.

The registry also makes it possible to gather together many blood samples from people with rare diseases – something that would otherwise be impossible. A recent research project by Professor Tim Goodship at Newcastle University included samples from membranoproliferative glomerulonephritis Type 2 (MPGN) patients, gathered from RADAR. Professor Goodship was looking for an abnormality in one part of the immune system, and he found this abnormality in 22% of the patients' samples.

This finding points the way to a potential new treatment for 22% of people with MPGN. It may be possible to inhibit this part of their immune system and dramatically slow the destructive power of the condition. This could increase the life of their kidneys by years.

The registry is already a vital tool in the pursuit of new treatments for rare diseases, but the database is still in its infancy, and Kidney Research UK urgently need funds to continue developing RADAR so that medical teams can have access to better information, and so patients might have a brighter future.

Ref: *Kidney Research UK*

Contact us

Give a Kidney - one's enough,
PO Box 65885, London N7 1BR
giveakidney@gmail.com

www.giveakidney.org