



Donors urgently needed from, and for, the South Asian or Black communities



The gap between the supply and demand for organs continues to be a concern. Although we have had recent success in boosting organ donation numbers by 50% in the United Kingdom over the last five years, it remains unclear whether the increase in quantity will mean a decrease in quality. In addition it has been disappointing to recognize the failure to adequately boost organ donation rates from members of the Black, Asian and Minority Ethnic (BAME) community. This is an important concern as individuals from the BAME community constitute 10.8% of the population in the United Kingdom, but are over-represented on organ waiting lists (24.0%) and under-represented on the Organ Donor Register (ODR) (3.5% where ethnicity known). From actual organ donors, only 4.2% of donors are from BAME backgrounds.

Respectively for donation after brain death). All these factors contribute to the BAME community having longer waiting times for an organ due to biological differences between ethnic groups.

Why are BAME individuals reluctant to donate organs? Many cite concerns relating to distrust of the health service, religious and/or socio-cultural issues, family pressures etc. However those same concerns do not materialise when receiving organ transplants. The rationale that someone can be fundamentally opposed to donation but reciprocally be receptive to receipt is flawed – one cannot, and should not, exist without the other. Therefore we need to do more to understand what the obstacles in donating are and plan strategies to overcome them. There are some positives with regards to BAME organ donation - living donation from

Relatives of BAME individuals are also less likely to give consent for organ donation from loved ones who have died in appropriate circumstances (30.3% versus 68.5% res-

BAME individuals has significantly increased and a few BAME individuals are also coming forward as altruistic kidney donors.

In an attempt to boost organ donation from BAME communities the National BSME Transplantation Alliance (NBTA) has been set up under the auspices of the Department of Health to unite different groups, charities and societies to join forces in efforts to bridge this divide. The NBTA is working closely with NHS Blood and Transplant and Government bodies to provide support, advice and strategies to boost organ (and stem cell) donation from members of BAME communities. This will have benefit for the entire waiting list but BAME individuals in particular.

Adnan Sharif, Consultant Nephrologist, Queen Elizabeth Hospital, Birmingham

Adnan Sharif plays a key role in nationwide efforts to encourage more Black and Asian donors. He sits on the All Party Parliamentary Kidney Group and is also a member of the South Asian Health Foundation. Give a Kidney is pleased to welcome Adnan Sharif on to its Steering Committee. He will be talking about organ donation issues amongst the BAME population at our Annual Conference on 18 January.



Be Inspired...

Give a Kidney's AGM & Conference will be held on Saturday 18th January 2014, 9.30am - 3.45pm at the DoubleTree by Hilton London West End, Southampton Row, London WC1B 4BH.

Following brief AGM business, there will be a review of the charity's progress and challenges, forthcoming activities and discussions for 2014 and beyond.

Paul Gibbs, Consultant Vascular and Renal Transplant Surgeon at Portsmouth Hospitals NHS Trust will explain how cross-matching works, and give an insight into how priorities are decided on the kidney transplant waiting list.

Adnan Sharif will highlight organ donation issues amongst the BAME population, so if you feel a little more educated by his article on this page, come and meet him and find out more.

There'll be plenty of time for discussion on topics that interest or concern you in a session facilitated by GP and Altruistic Donor Paul van den Bosch, and as always, one of the great things about get-togethers such as these is to network and meet like-minded people. Go on. Be inspired.

Please get tweeting!

Help us campaign and share information on Twitter and Facebook:



twitter.com/Giveakidney



www.facebook.com (search for Give a Kidney then click on logo)

"What counts in life is not the mere fact that we have lived. It is what difference we have made to the lives of others that will determine the significance of the life we lead." Nelson Mandela

Di Franks gives help and support for people thinking of donation, via her website www.LivingKidneyDonation.co.uk

The charity Give a Kidney had not yet been founded, so it started off really as an informative website for potential donors to understand a bit more what it's like to donate a kidney to a stranger. When I donated I found it a very lonely experience, at times a bit scary not knowing what lay ahead! I wanted other donors to be able to enjoy their experience as much as possible and to know what to expect, not just from the evaluation tests – but emotionally. And I felt only one type of person could actually fill that role – someone who had already donated.

I didn't really think anyone would actually find my website, but I just felt I was doing my 'bit' in helping others should anyone come across it. But since starting it four years ago it's become a huge success - people from around the world either post on it or get in touch with me via the contact



page wanting support or information, knowing that I've been through the process – something their family and friends, however supportive, can't completely empathise with. I probably get around 120 emails a week and in total there have been over 425,000 visits to the website - so I must be doing some good. ☺

I get tremendous pleasure and satisfaction from supporting people. Give a

Kidney also has a scheme where altruistic donors can help people considering donating to a stranger, whereas my blog is for anybody interested or affected by living kidney donation, not just altruistic donors. Some are donating to family/friends, others to strangers and some are from abroad. But I am closely involved with the Give a Kidney charity and wholeheartedly support what they do.

Over the past few years I have become good friends with some of my correspondents, and I love that. I'm blown away when I get an email thanking me for my site. When the time comes for someone to donate and I mark the date off in my diary ... it is like I am donating all over again ☺ - I feel such excitement for them. Then comes the long awaited email telling me they have now donated! Little did I know when I donated three years ago that my website would also inspire a few others to do the same.

Grand National Charity Flat Race: The Crabbies Challenge Aintree, 5th April

Plans are well under way for a Charity Flat Race on Grand National Day organised by retired British jump jockey and altruistic kidney donor Richard Pitman.

It is the 50th anniversary of The Injured Jockey's Fund so that charity will take main stage, but it's an opportunity to highlight Give a Kidney, as one of the celebrity riders will be singer-songwriter kidney recipient Charlotte Gordon Cumming, who herself

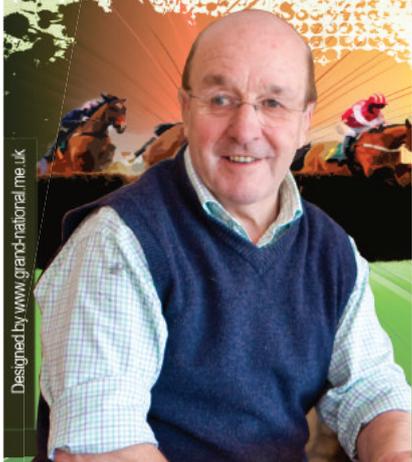
has raised funds for Give a Kidney and is the wife of our Patron, author Nicholas Evans. Charlotte is well on the way to race riding fitness under the strict guidance of local trainer Jimmy Frost who, as a jockey, won the Grand National on *Little Polveir*.

Other riders in the race include high profile names such as breast cancer survivor Judy Halewood, Chairwoman of Halewood International and Nick Skelton,

the Olympic three day event rider who broke his neck a few years ago. Surviving that, he still holds the British Show Jumping High Jump record, which he set in 1978.

The race will be one and a half furlongs on the flat as the first race of the Grand National day and will be televised live on Channel 4 with an anticipated 11 million live viewers and 600 million worldwide.

The Grand National



How Rupert Maclaren's pause for thought ended by saving a life

I have always carried a donor card as far back as I can remember but always considered that this was all I would need to do and it was to be something for other people to deal with after my death. Also, due to an avid interest in tattoos and piercings since the age of 19, I had never given blood, platelets or bone marrow either.

In mid 2011, I found a lump one morning and decided that I should have it checked out. My GP didn't seem too concerned, but sent me for an ultrasound scan just to be sure. There was nothing to worry about but part of the process also included a scan of my kidneys (the first of many) and for the first time I saw that I had two very healthy ones. It was also the first time I heard that this was not always the case with some people being born with only one.

One evening a few months later, my wife handed me an article on the BBC website detailing the launch of a new

charity – *Give a Kidney - one's enough!* I read the article, then I re-read it. I had never heard about altruistic donation before and there was something about it that just made complete sense to me. It may have been the idea that I could make a real difference to someone else's life by simply giving away something I knew I had two of. It may have been that as a wine merchant I couldn't contemplate living on only 500ml of liquid a day! Either way, I could not get rid of the thought that should I or my kids ever need a kidney in the future, how could I, in all good conscience, accept one if I hadn't even tried to see if I could donate.

I spent the next few days reading anything I could find about the subject on the internet including the wonderful blog by Di Franks which answered many of my questions and concerns. After a conversation with my wife, I called my local Donation Centre and a date was arranged to go for an initial assessment. Everything went very smoothly and after five months I was given the all clear and matched up with a recipient.

I was in hospital for four days and whilst I was a little sore after the op, it was by no

means any worse than having a tattoo done. It was however not helped by the chap in the bed next to me who had received a kidney a few days earlier who spent the entire time trying to make me laugh!

A few months later, I received a letter from my donor and their family and although I was warned it would be quite an emotional read, it still brought me to tears. I had never tried to imagine who my recipient was in case things didn't work out and now the full force of what it meant to them was brought home. I have

“[the operation] was no worse than having a tattoo done”

not replied to the letters but know that someone out there is now able to do things I take for granted every day.

Whilst I still don't talk about it too openly, prior to my donation I had only told a handful of people about it - my wife and children, my mother and stepfather, the HR and line managers at work. All were massively supportive even if they found the concept hard to grasp to start with; I couldn't have done it without them and I still feel that part of my donation belongs to them.

I look back now and apart from marrying my wife and having my kids, this was the best thing I have ever done and if I could, I would do it all over again.

The charity can now receive donations by text. Can you please help spread the word and ask people to support?

Text LIFE11 £10 / £5 / £4 to 70070
to donate to Give a Kidney and make a difference today.

Running with a purpose

Last year, my sister Maggie had a life changing event when she received a kidney, donated by a live donor, who, for whatever reason, wanted to donate one of his/her kidneys to a complete stranger. As a family, we cannot thank that selfless person enough and feel immensely grateful for the opportunity of a better quality of life for Maggie.

My husband Phil and I wanted to do something to promote the work of live donation, or 'altruistic' donation as it's officially known. Running a half marathon seemed the perfect way to raise some funds for the nationwide charity Give a Kidney which works to this end. Every year, the number of people coming forward to donate increases and Give a Kidney's work is central to this.

So we ran the Cheltenham Half Marathon on Sunday 15th September, and it went brilliantly. I had a few sticky moments leading up to the race when I wasn't sure I'd be on



the start line, yet both my husband Phil and I were there, ran together, and finished in under two hours, which was our target!

Maggie was in the good hands of surgeon Paul Gibbs from Portsmouth Hospital. It hasn't been an easy recovery, and the anonymous donor might have

experienced challenges in their healing process too. But she now has the potential to completely turn her life around, when previously, dialysis three times a week and the stress of living with kidney disease for a working person in their 40's was the day-to-day reality. She's doing well and has booked to go away on holiday in January - enjoying life like she hasn't been able to for a few years.

With Gift Aid, the total we've raised is nearly £900, and we will continue to promote our success in the hope of raising even more. Every bit helps! You can visit our JustGiving page at: www.justgiving.com/Liz-Hughes2

Liz Hughes

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has.”

Margaret Mead



About fifty people attended a festive summer party hosted by altruistic donor Nicholas Crace in Hampshire. Here, transplant surgeon Sam Dutta from Queen Alexandra Hospital, Portsmouth, gives a speech to an audience which included a dozen donors, of whom six were altruistic, five gave to their spouse, and one father to his daughter. Tadley Concert Brass band entertained.

Thoughts from one donor...

Give a Kidney New Zealand was set up in June this year, inspired by our own charity. It seems the reasons altruistic donors give for wanting to donate one of their kidneys to a stranger is as universal as it is different from person to person. As NZ donor Dana Morgan succinctly put it: "The doctors really make you seriously think about it. 'Why are you doing this?' It's the oddest question. I shook my head and said 'why would I not?' Give me some reasons other than fear."

And fear was something she had to deal with leading up to the operation, she said.

"What if something happens to me? What if something happens to my family and they need a kidney?"

"You've got to be wired in a certain way to even consider something like this. We all have slightly different ways of thinking, but we've advanced enough as a society to where we don't necessarily categorise someone like me wanting to do something like this as 'nuts'. Just as different, and thank goodness.

"How else are other people going to have the opportunity to even consider something like this unless there are people that go through it, and pop out the other end and say it's alright?"

Would you buy one?



Give a Kidney has a number of resources that you can use for campaigning activities. Contact Suzanna den Dulk (suzannadendulk@googlemail.com) if you would like pin badges, wristbands and t-shirts at a modest price. A big **thank you** to Castle Embroidery in Kendal (www.castle-embroidery.co.uk/) for producing the T-shirts at cost price.

Thankyou Bristol

The parishioners of Cotham in Bristol donated £416 to Give a Kidney after a static display was there throughout August. Thank you Cothamites - you will never know what your gift has achieved but it helps us to keep informing the public and saving lives.

Steering group: notes from the last meeting

- The Give a Kidney website has recorded about 2,000 visits per month, 80% of these being new visitors and nearly all from the UK. All agreed this shows that it is a very useful resource.
- Consideration would be given to alternating the annual conference/ AGM between London and another location in the UK eg. Birmingham.
- Of the 242 Altruistic Donors so far, 19 have triggered a chain, which is a very positive story.
- Members should be encouraged to visit the website regularly to keep up to date with recent news on altruistic donation, and any who are signed up to Facebook and Twitter to share information with other users as much as possible.

Useful Web Links...

Our website, with lots of useful information for anyone considering altruistic kidney donation
www.giveakidney.org

For more information about living donation in the UK, go to the NHS Blood and Transplant website:
www.organdonation.nhs.uk

For a UK patients' forum, including personal accounts of giving a kidney to a stranger, go to:
www.livingkidneydonation.co.uk

For a donor and recipient support network based in the UK, go to:
www.transplantsupportnetwork.org.uk

For details of a living donor network in the United States, go to:
www.livingkidneydonorsnetwork.org
 New Zealand has its own organisation to support altruistic kidney donation. Their website is:
www.giveakidney.co.nz

To access professional UK guidelines for living donor kidney transplantation go to the British Transplantation Society:
www.bts.org.uk

Give a Kidney is a member of Transplant 2013, a coalition of patient groups, clinical organisations, and industry representing the combined voice of the organ donation and transplantation community:
www.transplant2013.org.uk

Other useful links:

National Kidney Federation
www.kidney.org.uk
 British Kidney Patients Association
www.britishkidney-pa.co.uk
 Human Tissue Authority
www.hta.gov.uk

Contact us

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