

## Adnan Sharif nominated for Nobel Peace Prize

Dr Adnan Sharif, a kidney consultant at the Queen Elizabeth Hospital Birmingham, who is also an active supporter of the work of Give a Kidney and member of its Steering Committee, has been nominated for the prestigious Nobel Peace Prize alongside colleagues at QEH for his work with the international organisation Doctors Against Forced Organ Harvesting (DAFOH), set up ten years ago to fight unethical organ transplants around the world.

Dr Sharif, who sits on the Board of Directors for DAFOH, was delighted at the news.

He says: "I hope this recognition fuels interest in the work of DAFOH and draws urgent attention to the issue of unethical organ transplant activity, which unfortunately continues to the present day in places like China."

Dr Sharif has represented DAFOH in Parliamentary meetings in Westminster and in talks with the World Medical Association and several global transplantation organisations. He was also part of a delegation that travelled to Geneva in 2013 to hand in a petition, signed by 1.5 million signatories, asking the United Nations Human Rights Commissioner to investigate claims of forced organ procurement from executed prisoners in China.

The winner of the Prize will be announced in October.

## Give a Kidney's new Chair: Bob Wiggins

I am absolutely delighted to become the Chair of Trustees for Give a Kidney. The inspiration and dedication of those working tirelessly to raise awareness of living kidney donation compels me to want to do far more than I had initially planned.



I pay tribute to Chris Burns-Cox, my predecessor, for successfully steering Give a Kidney through its early years, building strong foundations on which we can continue to build momentum towards our ultimate goal: "No waiting for a transplant for want of a kidney"

These foundations include becoming a widely recognised and credible voice amongst healthcare professionals and the wider transplant community; building a critical mass of supporters and

members; and increasing the number of donations by establishing an effective media presence generating increased awareness and through our information and signposting service for prospective donors.

These strong foundations provide a firm base on which to grow by challenging the healthcare community to provide consistently high standards of service for prospective donors, mobilising our membership to engage in their local communities and support national engagement initiatives (see the Ambassadors' programme below) and building collaborative relationships and joint programmes with other related charities and interest groups.

I relish the challenge ahead and look forward to meeting as many Give a Kidney members and supporters as possible.

## Launch of Ambassador Programme, Saturday 25th June in York

Give a Kidney Ambassadors are people who are willing to help us increase public awareness of non-directed living kidney donation. This might be by engaging with the media, giving a presentation to a local group, manning a stand at a local event, fundraising – or all of the above and more.

On Saturday 25th June, Give a Kidney is launching an Ambassador Programme at Kings Manor, Exhibition Square, York YO1 7EP. The day will begin at 10.00am, with talks from 10.30am and will close at 4.00pm.

Experience has shown that the majority of those who have given a kidney altruistically have done so after hearing - usually on the radio or in a newspaper - about someone else doing just that. As this has become less of an

unusual thing to do, we must work harder to find ways of getting people's individual stories out into the public domain and engaging with our local communities. We will look at latest research around motivation and the importance of Give a Kidney's credibility within the transplant community.

Attendees of this event in York will hear what we are setting out to achieve with the Programme and how it will operate. They will see updated presentations and learn how to access the latest resources and information on non-directed living kidney donation. Some people with practice of giving talks on the subject will share their experiences, with ideas on how to make contact with your local groups and events, tips on making an

engaging presentation and how to answer those frequently asked questions at the end.

Professor Derek Manas, President of the British Transplantation Society, will talk on 'The importance of links between charities and healthcare professionals', and Give a Kidney will provide advice on the best way to approach local media, how to write to your local MP and much more.

The day will also present an opportunity for altruistic donors to get together at a venue that may be more accessible for some than our London AGM venue.

If you would like to be a part of this, please register to attend at [www.eventbrite.co.uk](http://www.eventbrite.co.uk) and look for 'Give a Kidney Ambassador Programme launch'.

## Former GP and donor helps Give a Kidney



We are very grateful to Giles Smith, who has agreed to take over the task of responding to queries that come in through the Give a Kidney website during

the months that Paul van den Bosch is working abroad. Like Paul, Giles is a retired GP and altruistic kidney donor (in 2010), so well placed to understand the breadth and complexity of queries the charity receives.

Giles qualified in 1971 from Birmingham University, becoming a member of the Royal College of Physicians in 1973. He went on to become a GP in Thetford, Norfolk, for 31 years, during which time he started and chaired an Asthma Group, a branch of the British Heart Foundation and also St Nicholas's Hospice Group.

He chaired the Surgery Patients Association and sat on the Local Medical Committee. He was the first in the UK to set up a Healthy Heart Day, when all Thetford patients were screened for diabetes, blood pressure and cholesterol. He was also Medical Officer to Camvac Ltd as well as Riddlesworth Hall School, then President of the Medical Officers of Schools Association.

He helped to start, then chaired The Thetford Society, helped start the Charles Burrell Museum, sat on the CAB Committee and started a weekly surgery in two villages (Elveden and Barnham), where he was Churchwarden.

In 1986 he moved to Sapiston in Suffolk, restoring a large, listed barn. He was Parish Councilor there for three years, helping to start and then chaired The Euston Rural Pastimes Event, raising funds for charities, including the St Nicholas Hospice. He was Chair of the Blackbourne Tree Group, volunteered at Pakenham Water Mill and chaired Thelnetham Windmill. Giles is a Trustee for Artheads, a music and art centre for those in recovery.

He has completed four London Marathons, run the Great North and Great South Runs, cycled from Land's End to John O'Groats and from Northern France to Santiago del Compostella, all the while raising funds for charity.

Giles lives with his wife, Claire, a retired community gynecologist. They have a son, a daughter and five grandchildren.

We are delighted to have his invaluable experience and support.



Give a Kidney supporter, Jasie Rai, once again hosted an annual fundraiser 'East Meets West 2' in Swindon in March, raising more than £2500 for Give a Kidney.



The event was a sell-out with all 250 tickets being snapped up by those wanting to enjoy an evening of floor-filling tunes from Bhangra to Bollywood and a delicious hot Punjabi buffet.

In addition to the sum of over £2,500 raised with the event, we hope for further matched funding from Barclays Bank, thanks to the fundraising support of Charanjit Dhaliwas of Barclays' West Swindon Branch.

Jasie has only one kidney herself having had one removed. She has a pyeloplasty on the remaining kidney and may eventually need a kidney transplant.

She said: "East Meets West has just happened by accident! I am truly overwhelmed by the support and donations from local businesses, friends and family, who have taken it from strength-to-strength. It's a fun event for all, bringing people and East/West cultures, food and music together for

a great cause and becoming more and more popular. We've already set a date for our 2017 event!"

The event was kindly supported by the following generous local businesses:

Asset Guardian Company, Castles Estate Agents, CentraHeat,

Corin Design, Exploreworld, Francis George Solicitor Advocate, Ideal Displays, Kam's Motor Clinic, MLL Print and Digital, Mortgage Advice Bureau, Switch on Computers, Thermographic Consultancy Limited, The Sales and Marketing Hub Limited and Utility Warehouse, as well as others who supported the raffle and auction with prizes.



A big thank you once again to everybody who supported the event, and to Jasie for all her hard work and energy in making it such a huge success.

## AGM outcomes

The charity held its fifth AGM on Saturday 30th January, with almost 50 guests gathering in London. The AGM business was wrapped up in the first hour and both the Chair's report and the 2015 annual accounts can now be found on our website, on the 'About us' tab at the top of the page.

Guests heard from a number of medical professionals involved in the transplantation process, including Isobel Gordon, a Living Donor Coordinator at Guy's; Stephen Potts, Consultant in Transplant Psychiatry in Edinburgh; and Emma Massey, Clinical Psychologist at ErasmusMC University, Rotterdam, giving an insight into why living donor numbers in the Netherlands are highest in Europe. We also heard from the BOUnD study group on their ongoing national assessment, over five years, of altruistic kidney donation. Paul van den Bosch reported on the most frequent queries coming in through the charity website, with his responses. Feedback from attendees has been very positive, with altruistic donors in particular enjoying the opportunity to meet others who had gone through the process.

## Encouraging donors in Scotland

Almost a year ago the Renal Transplant Unit in Edinburgh organised a massive meeting in Dynamic Earth - a Scottish venue resembling the Millennium Dome. Speakers from the Unit as well as altruistic donors and recipients spoke to an audience of about 200 interested parties. I met Chris Jones there and we discussed what we felt was the predicament facing the NHS in trying to encourage more altruistic kidney donors. There are very clear dilemmas for the NHS in being seen to go out and canvass for volunteers yet, we felt, this was something that we two who had previously donated could promote with a clear conscience. Since then we have had many meetings and have tentatively evolved a programme for 2016 – the tenth anniversary of it becoming legal to donate to a stranger.

Our rationale is that out there amongst any group of people there exists a number of folk who if they only knew of the possibilities would be driven to donate. We both felt that of all those we had met who wished to donate, the overwhelming majority had such a strong belief in what they were doing that wild horses would not deter them. We reasoned therefore that our little campaign should have the single straightforward objective of raising awareness amongst the general public of the possibilities for donating kidneys to strangers.

We also felt that our goal, which we saw as a vital hook to encourage media interest, should be to sign up a number of would be donors equal to the number of those in Scotland waiting for a kidney. We think this notional target is ambitious but realistic.

As soon as we began to discuss this we were overwhelmed by Scottish donors eager to help and we write now to ask if there are any recipients or donors who would be interested in joining us. If so perhaps they could e-mail either myself or Chris, please: [tjohn.fletcher@virgin.net](mailto:tjohn.fletcher@virgin.net) or [Chris@chrisjones.biz](mailto:Chris@chrisjones.biz). We'll be working closely with Give a Kidney going forward to help raise awareness of non-directed altruistic kidney donation.

*John Fletcher*



At the Wessex Renal Association 50th Anniversary Dinner last Autumn at the Portsmouth Guildhall. Left to right: Richard Pitman, Cherry Williams, Judi McGetrick and Nicholas Crace – all altruistic kidney donors.

### Exciting ways you can help raise vital funds and awareness

Give a Kidney has been very fortunate so far, with donations received from a variety of sources, in particular some big fundraisers. However if it is to continue to fund awareness-raising activities and other methods of increasing altruistic donor numbers, a more regular source of income must be found. Any help from our members will be very gratefully received!

In particular, for those of you who are working:

- If your employer selects a 'Charity of the Year', please let us know how and when we can apply
- If it is more informal in its approach to charity, could you organise a bake sale / sweepstake / raffle / quiz in your workplace to raise funds for the charity?
- If you are willing to do some fundraising, you may find that your company offers 'matched funding', where they match what employees raise
- This is also a really good opportunity to raise awareness of altruistic kidney donation

There are plenty of fundraising opportunities outside the workplace too! Have you considered taking on a challenge such as running one of the many marathons, half marathons, 10k or 5k runs that take place around the country? Simply create an online fundraising page on [www.justgiving.com](http://www.justgiving.com) email the link to colleagues and friends and you will be amazed by how generously people give.

If you have a bit more time and would prefer something overseas, there are some exciting challenges around the

world. We have partnered with Classic Tours who organise a wide range of charity challenges, including cycling in South Africa in September this year, Arctic dog sledding in Sweden in January 2017 and climbing Kilimanjaro in September 2017. You'll be amazed by what you can achieve.

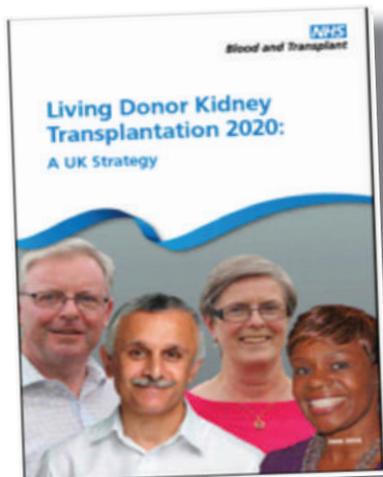
Suzanna will be happy to provide any fundraising materials you might find useful, including sponsorship forms, information leaflets, t-shirts and more! Please email [giveakidneyoffice@gmail.com](mailto:giveakidneyoffice@gmail.com) to let her know what you have planned.

We are in the process of signing up with ebay so that, if you have a clear out and sell those things you no longer want or need, a percentage (or all - your choice) of the sale price can go directly to Give a Kidney.

We've also signed up with Giveacar.co.uk, so if you have an old car you no longer need, they'll collect it from anywhere in the UK free of charge, then either sell or scrap it, giving the proceeds to the charity of your choice. New Chair, Bob Wiggins, was the first to do this for Give a Kidney by scrapping his motor bike!

Finally, the charity is indebted to all those who have generously signed up to give on a monthly or annual basis. This regular giving allows the charity to plan ahead, knowing that it has income it can rely on. Just let Suzanna know that you'd like to do this by emailing [giveakidneyoffice@gmail.com](mailto:giveakidneyoffice@gmail.com) and she can send the appropriate details.

The main priority for the LDKT 2020 Strategy Implementation Group in 2015 was to understand and address the shortfall in the numbers of living donor kidney transplants



in comparison with what we hoped could be achieved. With the help of colleagues across the UK, we have identified some of the barriers to living donation and put plans in place to resolve these during the next year. We have also worked with commissioners and Health Departments to ensure that future funding arrangements support the UK programme. One of the highlights of last year was the increase in the number of transplants that were made possible through the sharing schemes. Although the overall number of altruistic donations fell in 2015, the introduction of long altruistic donor chains (three transplants triggered by one donation) in April meant that more transplants were made possible from each donation - 54 transplants from 21 donors, with more donors being matched in a long chain each time. Now that there are fewer delays and more certainty about timing of donation within the schemes, we are seeing more donors 'opting in' to a chain. This year there will be a focus on engaging with patients, families and the public to ensure that people know about all the options for living kidney donation and the difference it can make to people's lives. New information resources, improved messaging and focused media campaigns to encourage people to volunteer are all part of the plan. I would like to take this opportunity to thank all Give a Kidney friends and colleagues for your support and commitment in helping us to deliver this important Strategy.

Lisa Burnapp

Lead Nurse Living Donation NHS Blood & Transplant

### National Transplant Week to be known as Organ Donation Week

NHSBT recently announced that following discussions and feedback from stakeholders and the public, National Transplant Week will now be known as Organ Donation Week. This year's Organ Donation Week will take place between Monday 5th and Sunday 11th September 2016.

Since 2009, National Transplant Week has provided an opportunity for the organ donation and transplant community to promote organ donation nationally and locally, focusing on promoting the importance of people discussing their organ donation decision with their families. We will continue this aim again this September while highlighting the importance of organ donation and celebrating those who have saved lives.

### Recent research update...

Dr Pippa Bailey, a nephrologist in Bristol, has been researching transplant candidate attitudes to non-directed 'altruistic' live-donor kidney transplants.

It might be assumed that all transplant candidates would be willing to receive a non-directed live donor transplant. However, not all study interviewees were. Some patients described feeling unworthy of an 'altruistic' live-donor transplant, while others described feeling responsible for the risks to a non-directed donor, and suggested that declining such an offer would prevent the donor from donating. In addition, some patients were fearful of acquiring an unknown donor's characteristics.

Interviewees who were willing to receive a non-directed live-donor transplant, described recognising the benefits of a live-donor transplant over a deceased-donor transplant, and saw this as a way of protecting friends and family members from the potential risks of donation.

The study highlights that receipt of a non-directed 'altruistic' transplant might be a more complex decision than donation.

Findings are published in 'Better the donor you know? A qualitative study of renal patients' views on 'altruistic' live-donor kidney transplantation'.

<http://www.sciencedirect.com/science/article/pii/S0277953615303002>

As part of a master's dissertation at the London School of Economics, Elizabeth Vossen explored the motivations and experiences of altruistic kidney donors.

In-depth interviews were held with six individuals and six major themes of donor motivations and experiences were found.\*

#### Motivations

1. Helping: All stated their desire to help as a major motivating factor. Helping included moral responsibility (they

should), self efficacy (they could), empathy, social capital (the donor's desire to live in a society where, if they needed help, they would receive it).

2. Donation as a response: Individuals chose to become donors in response to their view of the state of the world, their privileged position in society, and how they wanted to see themselves.
3. Risk and reason: Donors displayed a thoughtful approach where negative outcomes of donation were minimized. Rather than a sense of carelessness, donors' decision-making processes showed a comfort with assuming risk.

#### Experiences

4. Surprising reactions: Donors considered their decision private. Most were surprised by the adverse reactions they invariably received.
5. Telling antecedents: Two aspects were common
  - a. All had been dedicated blood donors.
  - b. The decision to become a donor began on hearing someone else's story about kidney donation.
6. Barriers to kidney donation included lack of public awareness and taking time off work.

\* The results cannot be generalised to the general population.

Researcher note: Thanks to all who participated. This research has not been shared widely, but we hope to make it available on the Give A Kidney website soon.

### Contact us

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