

Seasonal greetings from Give a Kidney



Notice of AGM and election of Trustees

As a registered charity, we need up to ten Trustees, who are automatically members of the Steering Committee. Currently we have seven Trustees: John Fletcher, Paul Gibbs, Sanjiv Gohil, Gill Owens, Sara Stacey, Paul van den Bosch and Bob Wiggins. All have put themselves forward for re-election.

Non-Trustee advisers on the Steering Committee are: Lisa Burnapp, advisor representing NHS Blood and Transplant; Suzanna den Dulk, the charity's Administrator; David Lee, Economics Adviser with CH2M Hill; Adnan Sharif, consultant nephrologist, Queen Elizabeth Hospital, Birmingham; and Jan Shorrock, the charity's Executive Officer.

The Charity needs a breadth of skills and experience across its Trustees, who meet every six to eight weeks. A candidate who has fundraising and / or financial experience would be particularly welcome.

If you or anyone you know would be interested in joining the Charity as a Trustee or a member of the Steering Committee, please request a nomination form from Suzanna den Dulk at the above address or by email to info@giveakidney.org. The completed nomination form will need to arrive by 11th January 2019. A final list of nominations will be circulated with a postal ballot form prior to the AGM.

Give a Kidney Annual Conference 2019

Saturday 23 March 2019 from 09:30am at the offices of CZWG Architects, 17 Bowling Green Lane, London EC1R 0QB

We hope to see many of you at the 2019 Annual Conference. More details will follow in the new year, but in the meantime please mark the date on your calendar! You can book through Eventbrite:

<https://www.eventbrite.co.uk/o/give-a-kidney-ones-enough-4114500293>

Preceding the conference will be a short Annual General Meeting, when the Trustees will present the annual report and accounts to members, report on the charity's activities for the year and discuss plans for 2019 and beyond. We will also confirm the election of Trustees for 2019.



EAST MEETS WEST

15 March 2019, 6.30pm-11.30pm, Swindon

This popular event celebrates World Kidney Day and raises funds for Give a Kidney.

Tickets include a three-course authentic Punjabi hot buffet, Bhangra, Bollywood and Western Music and a well-priced bar!

Tickets £15 Adult; £7.50 5-14yrs; under 5s free.

07771 556185 eastmeetswestgak@gmail.com

Put the date in your diary now as it's always a sell-out!

WORLD KIDNEY DAY : 14 MARCH 2019



In 2019, World Kidney Day sets out to raise awareness of the high and increasing burden of kidney diseases worldwide and the need for strategies for the prevention and management of kidney diseases. *Kidney Health for Everyone Everywhere* calls for universal health coverage (UHC) for prevention and early treatment of kidney disease.



Please let us know if you're doing anything to mark this day.

Directed Altruistic Donation - using social media to find a living kidney donor

The British Transplantation Society recently held a symposium to address the topic of directed altruistic donation, whereby kidney patients on the transplant wait list use a public campaign (usually on social media) to find a suitable living kidney. It was a fascinating day with inspirational and informative speakers and workshops, generating a healthy debate amongst all those attending.

Whilst Give a Kidney encourages debate on such issues it adopts a neutral view, notwithstanding that the issues can be relevant and important to the Charity and its members.

The use of social media in this way is likely to rise, increasingly blurring the line between directed and non-directed living donation. This gives rise to many practical and/or ethical issues compared to directed or non-directed living donation - including the following:

Accessibility. Only patients who are social media savvy, or have access to family and friends who are, are able to launch a social media campaign.

Selection criteria. Those coming forward in response to a social media campaign are motivated by factors other than clinical need - the primary factor used in allocating non-directed organs. This creates a form of 'beauty contest'.

Incentives. Directed altruistic donation has an increased risk of the recipient making, and the donor accepting, a financial reward for the donation - placing an additional burden on the assessment process.

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Celebrating a special birthday

The 'Squeezed Oranges', are a group of six non-directed donors, formed by Nicholas Crace and Judi McGetrick. Both had given a kidney to someone

they didn't know ... Judi in her late 60s and Nicholas in his early 80s. They were put in touch with each other by their Transplant Co-ordinator. Over the next few months they met more donors and the group grew to include Sue Dadswell, Lesley Clayton, Cherry Williams and Trish Bailey. They were each inspired to donate for different reasons, but with the common desire to make a big difference to someone's life who was less fortunate.

The Squeezed Oranges gave Nicholas Crace a party in October, to celebrate his 90th birthday, with a superb cake pictured here. ITV Meridian News covered the event, and you can see it by going to ITV Meridian News South and searching for 'Special birthday party.'

A big thank you from Give a Kidney

Give a Kidney has benefitted from a generous donation of £5000 from The Toureen Group, after its Managing Director, Denis Nolan, heard about the work of the charity at a living donation event earlier this year and, subsequently, met with Executive Officer Jan Shorrock and Chair Bob Wiggins. The company has also supported some additional training for the Give a Kidney team, which will help us to target potential donors more effectively with the right messaging.

The Toureen Group is a long-established construction group with award-winning, specialist, in-house divisions, delivering high quality projects for a wide range of prestigious clients.

We are enormously grateful to The Toureen Group for both their support and for this very generous contribution which will be used directly towards our mission of 'no waiting for a transplant for want of a kidney'.

Since January, 52 people have donated as a non-directed donor (NDD), taking the overall total to 687. By the end of the year, that figure will be close to 700, given that 18 NDDs were included in the October matching run of the UK Living Kidney Sharing Scheme (UKLKSS) - the highest number to date in a single run. Of those, 16 were matched in a chain and will go ahead in December and January so they are not included in the latest statistics. It is worth noting that the October matching run was the largest in the history of the scheme with 85 transplants identified, of which 43 (51%) were within a chain triggered by a NDD. Some of you may have seen the feature article in the Guardian 'Weekend' magazine on 10th November in which the journalist, Rachel Williams, beautifully illustrated the contribution that non-directed donation makes to patients waiting for a transplant.

The on-line 'Expression of Interest'

form for NDDs at www.organdonation.nhs.uk/livingdonation/ was launched in early October and is beginning to embed. It is early days, but we are already seeing referrals coming through. If you are talking to potential volunteers, do encourage them to go to the website for further information and register their interest at the transplant centre of their choice using the on-line form.

Finally, a note of thanks to all of you for your on-going support and engagement. We have developed some exciting plans for next year as part of the LDKT 2020 Strategy implementation and I look forward to discussing those with you at the Give a Kidney AGM and working with you to bring them to fruition.

In the meantime, a very happy and healthy festive season to you all!

Lisa Burnapp
Lead Nurse - Living Donation
NHS Blood and Transplant



GIFTED ORGANS: celebrating the gift of life through music...

The Gifted Organs Choir and Band is available to pre-order on i-tunes and Amazon from 9th December and is officially released on 21st December 2018.

The Gifted Organs Choir and Band is a unique pop group made up with transplantees, waiting list patients, living donors and people with life limiting conditions.

"*Tomorrow*" is an original song by James Tottle and Julian Kay recorded in Monmouth, Wales. Listen to this moving song here:

<https://www.youtube.com/watch?v=5jz1v-CM1bU>

www.facebook.com/giftedorgans

Gabhru Panjab De (GPD) Bhangra Dancers raise £7000 for Give a Kidney

Give a Kidney was one of the charities championed at an event organised by GPD Bhangra Dancers in West Bronwich on 17 November. At their 30th anniversary Dinner & Dance Ball they raised a total of £21,000 which was split between three charities.

Aki Sandhu, GPD Manager, said: "We are absolutely thrilled by the amount that was raised.

This would not have become reality without the huge commitment and active contribution from our sponsors, partners, donors and guests who attended the Ball. We pulled out all the stops to make it an amazing evening for all our guests".

"Our three named charities are very close to GPD hearts, as we all have had family members with MS, needing a kidney and/or with mental health illness."

There was a champagne reception, a five-course meal with wine and live performances by Gabhru Panjab De Dancers, singers JK, King Premi Johal, Jaswinder Jassi, DJ Paul Nagra. The



event was sold out and attended by 850 guests and celebrities from the UK Bhangra industry.

This year GPD Bhangra Dancers were awarded 'Best Wedding Entertainment Award' and also received an award for 'Outstanding Contribution to the Industry' at this year's Midlands Asian Wedding Awards. GPD also won 1st place for the 'Choreographed/Stylized Adults Dance Group Competition' at Llangollen International Musical Eisteddfod, Wales 2018, putting Bhangra and West Midlands on the international map!

Sanjiv Gohil, one of the Trustees of Give a Kidney, attended the event. He applauded the organisers, saying: "We are incredibly grateful to GPD Bhangra Dancers for their support of Give a Kidney at this event. It was a truly wonderful and memorable night and an amount like this makes a huge difference to a small charity like ours. Thanks to the help and generosity of everyone who supported

the event, this will take us a step closer to achieving our vision of 'no waiting for a transplant for want of a kidney', helping us to raise awareness of the fact that any healthy adult in the UK can donate one of their kidneys to someone very ill on the transplant waiting list."

Amongst other personal stories relating to the three charities, Sandie Shoker shared the story of Anaya, a 22-month old girl with a rare genetic condition called ARPKD who is in urgent need of a kidney transplant. Some guests were moved to immediately register themselves on the NHS Organ Donation Register.

Getting Loud for Kidneys:

Zandria's philosophy to be happier, healthier and live longer with kidney failure

In the last edition of this newsletter, Zandria Richards described what it was like to discover she had kidney failure, and how she coped with that knowledge. Here she explains in more depth her thoughts on living with this debilitating disease and, conversely, how it has actually helped her own personal development.

A couple of years ago she set up #kidneyclever on Instagram, as a medium not only for self expression but encouraging and supporting others with kidney failure.

Zandria believes recipients should shout out and publicise their predicament, be proactive, not just wait for a donor but search for a donor.

She herself has tried several approaches ranging from wearing an 'I need a kidney' T shirt around town, asking people to ring if they could help, and putting adverts in Tesco and on Gum Tree! The Tesco advert was interesting: Zandria had included some strips for people to take home so they could ring her ... all the strips were taken, but then silence. This did at least prove that there



was some interest, even if nothing came of it. After that, she paid for a Facebook advert. 6-8000 people potentially saw it and as a result, nine people offered to donate a kidney but nobody followed through or explained why. She felt it was harder to pick up afterwards from this crushing disappointment. In her rush of hope following the initial response, she had even entertained the thought of having 'spare' kidneys that could help other patients too. She wrote another Instagram post on what the searching for kidneys by a patient doesn't tell you: the emotional roller-coaster that 'getting loud for kidneys' can provoke - and that it's important to recognise that doing it on

your own has its own drawbacks.

The experience didn't dampen her spirits for long though. Two friends have since come forward as potential donors and if they aren't a match, they are willing to go into a donor pool to possibly start a donor chain - which could include Zandria. If it happened, this would be her third kidney transplant, with a lessening chance of success because of increased antibodies - which raises another area of complexity: when someone has kidney failure, other things can start to go wrong too, so medication can be complex and one is having to adapt constantly to new situations. However, Zandria feels this has actually benefited her ... made her more flexible in other areas of her life too.

Positivity seems to be her middle name. "I believe I got kidney failure for a reason", Zandria says. "I have the wherewithal and personality to shout out about it, and I'm free to express myself. After all, I'm qualified to shout about it and who knows? - it might help other people look at the whole thing differently. Focus on the positive. Wake up in the morning and decide to embrace life."

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NHS resources. Social media campaigns can create an influx of potential donors, placing an excessive burden on transplant centres. This can be both inefficient and ineffective, resulting in an adverse effect on processing other living donors.

Positive aspects of directed altruistic campaigns include an overall reduction to the transplant wait list, raising general awareness of living donation and a potential for converting some respondents to become non-directed donors. Regardless, it was accepted that the use of social media campaigns will increase and the practical implications - and how best to mitigate adverse aspects - should be considered.

An argument was made for developing a toolkit and support to those wishing to launch a social media campaign. This toolkit would address key aspects such as: safeguarding the patient and their personal information; incorporating best practice for formulating an effective campaign; ensuring accurate and appropriate information is given; and including a process to pre-screen

out unsuitable donors such as respondents from the developing world looking for payment (usually the overwhelming majority of respondents), incompatible blood groups, etc. for example.

Who would be responsible for developing the toolkit and working with patients who wished to use it needs to be considered further. Clearly the NHS should assist with the development of a toolkit, but they do not have the resources to implement it. This would need to be done by others.

We anticipate a working party made up of healthcare professionals and kidney patient groups being set up to pursue this further. It is in the best interests of all those who are unfortunate enough to find themselves in need of a kidney transplant that social media campaigns are effective and efficient. In the meantime Give a Kidney will continue its work towards raising awareness, supporting donors and influencing change to achieve our vision of "no waiting for a transplant for want of a kidney".

HAVE YOU SEEN...?

The excellent Guardian piece about a donor chain - see <https://www.theguardian.com/society/2018/nov/10/one-day-six-operations-three-kidneys-organ-donor-chain-brought-together>

Also, An engaging little video from Canada: **David got a kidney** - but with a message that transfers across the globe. If you're reading this on-line, just click on the link below.

<https://www.youtube.com/watch?v=sMEd0q61CDE>

Contact us

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