




#shareyourspace

www.giveakidney.org

 info@giveakidney.org

 @GiveaKidney

 /give-a-kidney

Give a Kidney is a charity registered in England and Wales (1143576) and in Scotland (SC045767)

Hello everyone!



Welcome to our first formal printable PDF newsletter in a year! We have tried to keep in touch with everyone through our social media, website and through Mailchimp. However, it's nice to be back 'in print' so to speak!

The timing is fortuitous as last week was Organ Donation week. To celebrate this, 'In Your Area' shared a new story every day as part of our new partnership with them. Read more about the partnership below.

November marks the 10th anniversary of our official launch event. As many of you will already be aware, we were hoping to hold a celebratory event on the 6th of November. Unfortunately that is not going to be possible for various reasons. We appreciate how disappointing this news will be for many. We were already planning to do a winter webinar series and are now thinking of doing a series of video shorts / webinars 'In Conversation With' in lieu of the event.

We are also hopeful that we will be able to organise at least one face to face event next year, and maybe even a series of shorter and less formal events at various locations around the UK. This will allow us all the chance to meet and re-establish those all so important social connections again.

As Vera Lynn said, "we'll meet again". Until then, take care, stay safe and thanks for all your help and support over what has been for many people, for a variety of reasons, a very challenging 18 months.

Bob Wiggins, Chair of Trustees

Improving the Living Donor Process - working with NHSBT & transplant professionals

Supporting transplant professionals

This year has seen Give a Kidney involvement in a number of initiatives to support the development of transplant professionals and to ensure the donor voice is heard.

Earlier this year our Executive Officer, Jan Shorrock, presented at the UK Living Donor Network, made up of transplant professionals and charitable organisations with an interest in living donation, where she spoke about the impact of non-directed donors and also the challenge, for some, of accessing emotional support pre- and post-donation.

Shortly after this, Jan was also invited to share her experiences as a donor on the Hesperis Course run by the European Society for Organ Transplantation (ESOT). Hesperis is a unique course on organ transplantation, providing a training platform for individuals who are entering the field and who wish to further their career. The course was attended by participants from across Europe, including from countries where non-directed donation is not legal. Jan's presentation offered participants a chance to hear first-hand from a donor. As well as sharing her own experience, she aimed to offer a challenge to the participants who may have little experience or awareness of living donation within their own countries.

A further new initiative this Autumn will be a Give a Kidney presence in the induction training for new living donor coordinators. Jan has been gathering thoughts from other donors about their experiences and what made a positive and less positive impact on their donation journey, and these collated comments will help to inform her presentation.

Thanks to Lisa Burnapp (NHSBT Clinical Lead, Living Donation) for the invitation and for facilitating Give a Kidney's involvement.

NHSBT Thank You Materials

Give a Kidney, and in particular Trustee Sanjiv Gohil and tireless GaK supporter and volunteer Celia Kent, has worked with NHSBT to create a range of resources to help recipients who wish to thank their donors. This initiative formally launched at the beginning of this month and links to various resources can be found below.

The new webpage can be found via: www.nhsbt.nhs.uk/writing-to-your-living-donor. The main 'Dear Living Donor' film featuring Sanjiv and Celia can be found here - <https://youtu.be/-Wrf8GC9QJw> and is part of a new playlist from NHS Organ Donation.

Printed materials have also been sent to each Transplant Centre to include in discharge packs for recipients of living donor kidneys. Packs of the daisy chain cards for coordinators to send to donors as a thank you have also been sent. Coordinators can then re-order more copies of these materials at any time. Many thanks to Celia and Sanjiv for their input into this.


Blood and Transplant

It's your choice whether you write to your living donor. We are here to support you through the process.

Find out more at nhsbt.nhs.uk/writing-to-your-living-donor



Meet the Team

It's been a time of change, not only globally but also within the Give a Kidney team, you can read more about these changes below.

Goodbye to John and Suzanna

John Fletcher stepped down as a trustee earlier this year but continues to be an active supporter of Give a Kidney, you can read more about his brush with fame on page 3! We would like to take this opportunity to thank John for all he has done and continues to do for Give a Kidney.



We also waved a sad goodbye to our Administrator, Suzanna den Dulk, this spring. Many of you will know Suzanna, who had been with Give a Kidney for more than eight years. She was instrumental in keeping us organised, efficient and helping us move forward. She was a wonderful asset to the charity and will be greatly missed, but we hope she will stay in touch and remain a friend of the charity. Thank you Suzanna!



Welcome to Lou and Annabel



We're extremely pleased to welcome Lou Devine to the Give a Kidney Team. Lou is a PR and social media consultant who will be working with us over the coming months to increase our social media presence and to help us reach a wider audience.



In addition, trying to fill some rather large shoes left by Suzanna, is Annabel Bennett who has joined us as the new Administrative & Marketing Officer. Annabel has a very varied CV including more than 15 years spent in office, operations and project management. She will be working very closely not only with Lou and Jan Shorrock but also with Treasurer Sanjiv Gohil as she takes on some of the finance functions for the charity.

We are excited to welcome our new team members and hope this additional capacity we have will allow us to reach even more potential, current and past donors.

'In Your Area' Collaboration

This summer saw the launch of an exciting new partnership with the online news platform In Your Area.

In Your Area aggregates all the latest news for your local area from news sites, blogs and social networks, as well as creating its own content. It currently has more than two million active registered users.

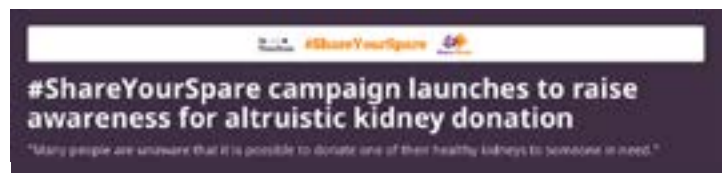
Over the coming months, In Your Area will be sharing stories about kidney patients, kidney donors and transplant professionals nationally and locally, aiming to raise awareness of living kidney donation with the Give a Kidney logo and link and the hashtag #ShareYourSpare.

Kerigh Palmer, community content curator for In Your Area, who is helping lead the campaign, said: "We are delighted to be working alongside Give a Kidney on our #ShareYourSpare campaign to raise awareness of organ donation and transplantation.

"Many people are still unaware that they can become organ donors whilst they are still alive and through our campaign we hope to encourage people to consider becoming a non-directed life-saving organ donor."

Living kidney donor Celia Kent is generously supporting Give a Kidney to help create stories and has already interviewed a number of our supporters and colleagues. A big thank you to Celia for her support, to Kerigh for her energy and passion for this project and to everyone who has been interviewed so far. If you would like to share your story through In Your Area, please do get in touch.

You can read the launch story here: <https://www.inyourarea.co.uk/news/shareyourspare-campaign-to-raise-awareness-for-altruistic-kidney-donation/>



Opportunities...

Give a Kidney is looking for new trustees

As you will have seen from our 'Meet the Team' section above, John Fletcher recently stepped down as a trustee. In addition, our constitution allows for more trustees, and as all our trustees are very busy people with day jobs alongside their trustee responsibilities it would be nice if we could share the workload a bit more.

We are especially keen to hear from people with lived experience of living kidney donation, whether this is as donors, transplant professionals or as recipients of kidney transplants. Indeed we are particularly keen to have a kidney recipient on our board.

To find out more and to request a job pack, please email info@giveakidney.org

Social Media volunteers

We are also advertising on various sites for a social media volunteer / volunteers. This is a great entry level opportunity for someone to work with and have training from Lou Devine, a highly experienced digital social media and PR consultant and former sports journalist. We hope to run training sessions on scheduling platforms, web design and SEO (search engine optimization), and graphics tools. You do not need to have worked in the field before but if you are familiar with a variety of social media platforms that would be great. If you are looking to get into communications, PR and / or marketing this opportunity could be for you.

We are especially keen to talk to people from marginalised communities who may be finding it difficult to break into this field. You only need to give few hours a week so this could be done alongside a paid job or studies. For more information, email info@giveakidney.org

Give a Kidney features on Radio 4's Ramblings with Clare Balding

Despite having to go ahead with very reduced numbers due to Covid (originally, we were hoping this could be a group walk with 15-20 ramblers) Sarah Lundie, Chris Jones and John Fletcher managed to join Clare Balding for an episode of the popular Radio 4 programme 'Ramblings' back in August.

They had a warm almost windless but slightly overcast day for their walk at Auchtermuchty. Setting off from Reediehill Deer Farm (map reference 209132) they were able to watch the red deer being fed, including the very rare white red deer. All the deer from Reediehill are sold for breeding and there is especially strong demand for the unusual white red deer with several new parks recently set up.

Leaving the farm, they headed south and uphill to the trig point at the top of Pitlour Hill marking 274 metres above sea level. This provided distant views, looking south to the Bass Rock in the Firth of Forth and, northwards, to Dundee on the Tay. Closer and to the south east was the spread of the Lomond hills and Loch Leven with the castle on its island made famous by the dramatic night time escape from imprisonment of Mary Queen of Scots.

Cutting down from a beautiful ancient wood of mature Scots pine and beech know colloquially as the Woods of Arkady, they skirted around the ruined old cottage of Nochnarie and across meadows to walk through a peaceful mossy track amongst sitka spruce trees planted about seventy years ago, known as Pitmedden Forest. They emerged opposite the ruined cottage at Broom Hill known as Lady Miller's. Renowned as the site of a drinking house, and no doubt illicit still,

it lies beside the road along which cattle were driven from Perth south towards the ferries on the Forth. They walked along that old drove road south east to look across at the deer farm before joining the track up to the farm in time for lunch.

There was lots of discussion about living kidney donation thanks to non-directed donors John and Chris and also Living Donor Coordinator Sarah. Thanks to you all for creating such an interesting and informative programme.

The episode is now available on BBC Sounds here - <https://www.bbc.co.uk/programmes/m000zcbm>, along with links to our website and the deer farm's website if you'd like to find out more.



Presenter Clare Balding (centre) chats with Sarah Lundie, John Fletcher and Chris Jones

Give a Kidney on BBC and ITV evening news

Jan Shorrock, our executive officer, has been in much demand lately and has recently appeared on both ITV and BBC television channels. On 27th August she appeared on ITV Border evening news in a piece about a couple in the kidney sharing scheme, and on 3rd September she appeared on BBC North West Tonight to contribute to a piece on the possible impacts of Covid on kidney transplants.

Back in March Jan also appeared in two episodes of the Kidney Warrior podcast, firstly to talk about her own experience as a non-directed living kidney donor and in another episode to talk about the work of Give a Kidney – listen to the podcasts here:

<https://youtu.be/YgPx7uMEsZc> – the work of Give A Kidney

https://youtu.be/b7_AQMZMgsM – Jan's story



Send us a birthday video

We will be creating lots of new social media, website and marketing content for our 10th birthday and we would very much like you to send us a video. Firstly, to wish Give a Kidney a Happy Birthday but also to thank those who have supported you in your kidney journey whether that's your family, colleagues, a particular NHS team, the person who donated a kidney to you or someone else entirely. They don't have to be very long, a minute or two is fine and ideally they would be filmed in landscape. Thanks to those of you who have already sent your videos in – they are brilliant.

You can send your video to us at info@giveakidney.org. If it's too large to send you can use a site like WeTransfer to upload for free or get in touch and we'll help you to get it to us. By sending us a video you are agreeing we can use it on any of our social media channels, website etc and that you are happy for us to edit it as necessary.

One 2020 webinar which was very well attended was our 'Ask the Experts' session back in November last year, and we thought it would be good to add a regular Q&A section to our newsletter.



Our team of wonderful clinical Trustees will answer two or three of your questions each time. They will obviously have to be non-urgent questions and couldn't be specific questions relating to your personal circumstances. All questions would, of course, be anonymised. If you think this is something you would like to see, please submit your questions to info@giveakidney.org

Here are our first questions, with answers, below:

Q Does donating affect your life expectancy?

A living donor's life expectancy should not be affected because of the donation itself, provided that the donor is carefully evaluated and any actual or potential risks to health identified and carefully considered. This risk assessment is always done in discussion with the donor. Donors will also be regularly followed up post donation and this will continue throughout their lives.

Q When was the last time someone healthy died while donating a kidney?

The UK incidence of death due to donation or close to the time of it is 1:3000 donors (approx. 1 in 3 years as we perform c. 1000 living donations each year). No surgery is risk-free but every effort is made to mitigate the risk during donor assessment to prevent unforeseen and devastating complications like this.

Q If a donor later goes on to develop chronic kidney disease and needs a transplant, do they get any special treatment on the kidney transplant waitlist?

This is rare but, in the UK, any living donor who donates and subsequently needs a transplant is prioritised for transplantation. This doesn't mean they go to the top of the list because high priority recipients will always be considered first but they would be prioritised above recipients in their own 'tier'/with a similar immunological risk profile on the waiting list.

Fundraising

Of course, one of the biggest ways you can help is by helping us raise money. Just to do the work we currently do costs us around £25,000 a year, if we want to do more, we need more funds! We are so grateful to everyone who donates and raises funds for us, including our regular supporters who have been a real godsend during Covid.

Giving sites and platforms

There are many ways you can help. With Christmas coming up why not sign up to one of these sites so that when you buy from them, a % of your purchase comes to us: Amazon Smile - <https://smile.amazon.co.uk> or Give As You Live: <https://www.giveasyoulive.com> If you are selling on eBay: <https://www.ebay.co.uk> or Thrift: <https://thrift.plus> - please remember you can choose to give a percentage of your sale to us.



You can donate through Just Giving, which allows you to set up a regular donation.

<https://www.justgiving.com/giveakidney> - or you can also give a one-off donation via CAF:

<https://www.cafonline.org/my-personal-giving/start-giving/donate-now>

Note to Virgin Money Giving users. We have been using Virgin Money Giving but they have emailed us to let us know they will be closing as of the 30th November 2021. More information here - <https://uk.virginmoneygiving.com/giving/important-update-about-vmg/> Therefore if you currently have a regular donation through them or were planning to do a fundraiser through them, you will need to set up one of the alternatives above. Otherwise, you can email info@giveakidney.org so we can pass on our bank details for you to donate direct to us if you prefer. We do hope you will continue to choose to support us.

We will be setting up at least one more site this winter as Virgin Giving closes and plan to review the platforms we currently use as part of a wider finance and fundraising review. We will be in touch with more information as we have it.

10th Anniversary Fundraisers

We're also asking you to consider doing ten things to raise money for the charity. This could be as simple as:

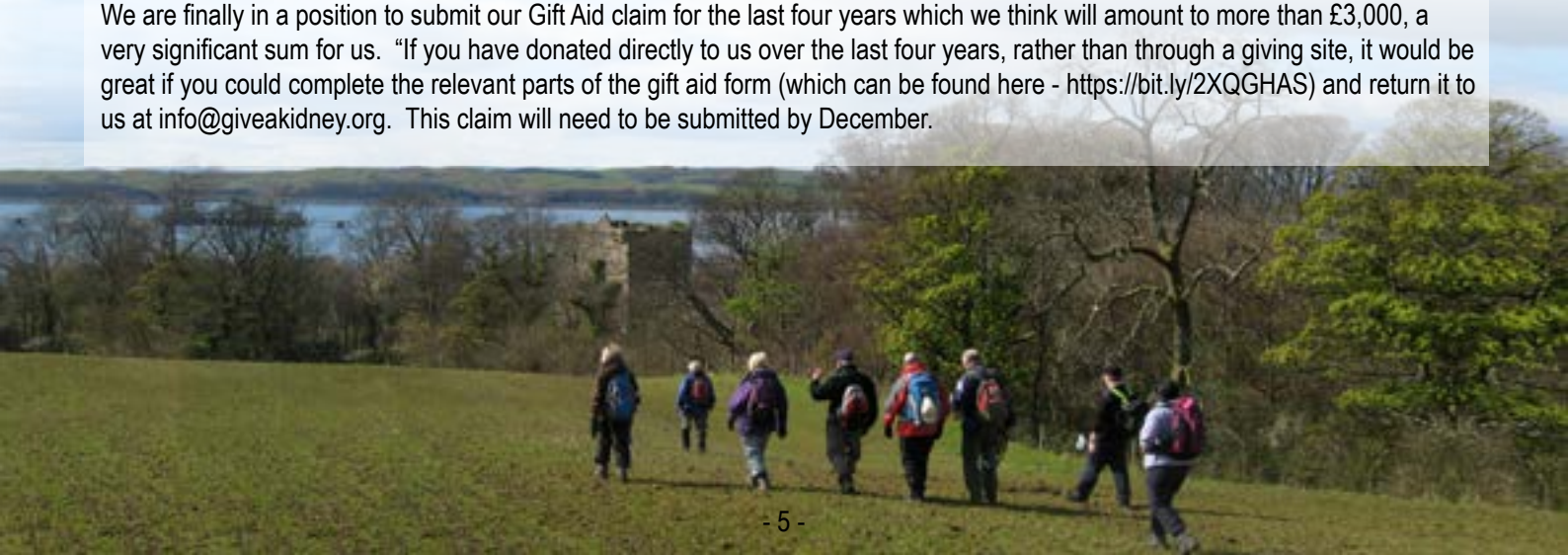
- Getting sponsored to...run ten miles, walk ten hills, do ten days of...
- Introducing ten friends to the charity and getting them to sign up for one or all of the schemes mentioned above
- Donating ten pounds
- Volunteering ten hours of your time to help us fundraise or promote ourselves on social media or provide your professional expertise in some other way
- Get ten of your Facebook friends to set up a Facebook fundraiser for us.

10th Anniversary Auction

We are also holding an online auction for the charity as part of our 10th anniversary celebrations. The auction will feature a new item each week which will be available to bid on for a week. We already have an afternoon tea with Lady Edith from Downton Abbey, a one-of-a-kind sculpture, a 'money can't buy' weekend away and a signed Arsenal shirt, but we still need more items. We were hoping to have at least 10 (do you see the theme here?), so if you, or a friend or family member, have a 'money can't buy' item that you could donate to the charity such as a weekend away somewhere, a celebrity connection who might be able to sign or donate something, then we'd love to hear from you! Look out for auction details on our social media platforms and we will also email a newsflash when the first item goes live.

Gift Aid – Important news for donors who donate directly to our bank account

We are finally in a position to submit our Gift Aid claim for the last four years which we think will amount to more than £3,000, a very significant sum for us. "If you have donated directly to us over the last four years, rather than through a giving site, it would be great if you could complete the relevant parts of the gift aid form (which can be found here - <https://bit.ly/2XQGHAS>) and return it to us at info@giveakidney.org. This claim will need to be submitted by December.



Do let us know if you undertake any activity for us, so we can share on social media and we may be able to let your local press know as well. Two people who have already stepped up to raise funds for us this year are Chris Luck and Bonnie Venter ... read more about them and their efforts here.

Once again, we know how much many of you already do for the charity, and we want to say a huge thank you to everyone who has supported us over what has been a very challenging period for the charitable sector and much of the population.

Chris's selfless act raises thousands for Give a Kidney

Earlier this year Chris Luck donated one of his kidneys to his friend Steph. Steph has polycystic kidney disease and needed a kidney transplant to live. As part of his journey, he and Steph learned a lot about kidney donation and wanted to share their story and also raise some money for Give a Kidney. They raised the incredible amount of £5667.23 including Gift Aid. Give a Kidney is extremely grateful for this significant boost to its funds. We are also pleased to report that Chris, Steph and Barry (his kidney!) are all doing well.



Bonnie Venter's story

Bonnie's interest in organ donation and transplantation has been going strong for almost a decade now. It has led her to write her PhD thesis on the relationship between the living kidney donation pathway and the laws and regulations guiding this process in the UK. So, in essence, how the law plays a role in deciding who is allowed (or not allowed) to act as a living kidney donor.

A specific part of the process she is interested in is the mental health assessment of prospective donors. As part of her research, she is conducting interviews with living kidney donors, health care professionals and individuals who are involved with the drafting of organ donation and transplantation policies or laws.

If you would like to learn more about her project or participate, you can do so by heading to <https://woven.blogs.bristol.ac.uk> or contacting her at bonnie.venter@bristol.ac.uk

During her recent conversations Bonnie found it interesting to learn that not everybody is aware of non-directed kidney donation or the change it can make to someone's life. Whilst she understands



that not everyone is eligible to donate, or might not even agree with the concept of non-directed donation, she feels it is important for us as a society to have a better understanding of non-directed living donation.

Bonnie believes that promoting organ donation has always been about the conversation. Her experiences suggest that improved awareness and understanding of non-directed living donation could assist potential donors when making their decision to donate. Additionally, increased awareness and education might also help family members and loved ones to gain

a better understanding of why someone would decide to become a donor.

Her interviews led her to volunteering to run a half marathon on 25th September to raise funds for Give a Kidney to help them create awareness of non-directed living kidney donation. Bonnie successfully completed the half marathon on Saturday - congratulations Bonnie!

If it is possible, she would be grateful if you could support her cause with a financial donation to help her reach her goal of raising £500. Her Just Giving page will be open until the end of October so there's still time to give: <https://www.justgiving.com/fundraising/bonnie-venter> But if a financial contribution is a bit tricky at the moment, you can also follow her progress on Twitter @TheOrganOgress (<https://twitter.com/TheOrganOgress>) or Strava (<https://www.strava.com/athletes/27167411>). On both platforms, she will be sharing some facts about living kidney donation that you can share to help to stimulate further conversation and awareness.

Winter Webinars

Look out for our winter webinar series coming soon which we hope will feature 'The Science of Transplantation' webinar with Deborah Pritchard, a Consultant Clinical Scientist working at the Transplant Laboratories at the Welsh Blood Service (Cardiff) and Southmead Hospital (Bristol) which we had to reschedule earlier this year, plus another expert Q&A and some 'In Conversation With' looking back at the last ten years of living kidney donation and discussing what the next ten years might hold in store. We will also be relaunching our YouTube channel very shortly and will have all of the 2020/21 winter webinars on there as well as lots more exciting content.

Give a Kidney - one's enough, 20 Corbyn Street, London N4 3BZ. Email: info@giveakidney.org www.giveakidney.org

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Got any ideas for future articles or news you'd like to share? Please send copy to info@giveakidney.org by 31 December 2021