

News from Give a Kidney Scotland

After the excitement generated by the tenth anniversary of the first Scottish altruistic donations this summer, and Ray Duffy's climb of the Old Man of Hoy by night (see page 2), Give a Kidney Scotland congratulated themselves on all the publicity that had ensued.

At its last meeting in Edinburgh, Jen Lumsdaine and Linda White from the NHS were welcomed. Jen gave details of a Scottish survey of 50 directed and 50 'altruistic' donors. Amongst the latter, 61% had found out about the possibility of donating from the media and the rest were almost equally divided between recipient, hospital/GP, and family/friends. 84% of donors had also been blood donors. These results highlighted the importance of explaining to patients in renal failure the possibilities provided by living donation. An information pack has now been provided for GP's and other health professionals.

Linda, who is the NHS Policy Manager,

is fully occupied in preparing for the 'opt out' system of donations (see page 3). An extensive publicity campaign is being instituted to raise awareness of the Act for twelve months and this will emphasise to all faith groups and others that individuals retain the right to opt out.

Last but not least, we need to thank Colin McLachlan who has been a fantastically efficient and creative secretary since our group began. He will be greatly missed but we have a very able replacement, John Farquhar, who has been a great fount of good ideas including his 'Talk to a Donor' plan. This aims to create an arrangement whereby potential donors could be given the phone number of someone who has already donated, with a view to providing information and support. As a sometime Samaritan John is well aware of the possible pitfalls of this scheme but we all hope he can get it off the ground.

John Fletcher



Seasonal greetings

to all our members
and supporters
from Give a Kidney

Annual Conference 2020

Saturday 21st March at Guy's Hospital in London

The Give a Kidney Annual Conference is the charity's main event of the year. It's a great opportunity to discuss all things related to non-directed living kidney donation. The day will include a brief AGM where we cover all the necessary charity business.

The Annual Conference is always a popular event with non-directed donors as well as those with an interest in this area. It's a chance to meet other donors and healthcare professionals, to learn more about the work and plans of the charity and its partners at NHS Blood and Transplant, hear what the latest research around non-directed donation is telling us, and to discuss and debate hot (and sometimes controversial!) topics.

These discussions will inform Give a Kidney's work and help ensure we continue to be as effective as possible at raising awareness and ultimately raising living donor numbers, so that we can achieve our goal of *no waiting for a transplant for want of a kidney*.

There's also time to socialise over lunch, make some new friends and find out about other people's experiences. It's a friendly, informal event and everyone with an interest in the subject is most welcome. The full agenda and speaker list will be announced nearer the date.



Attendees at the 2019 Annual Conference

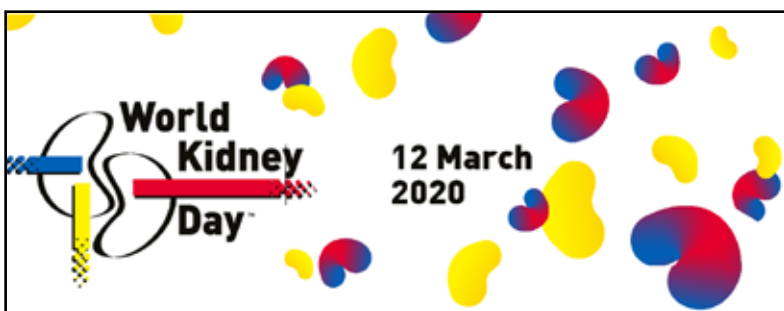
Lunch is provided free of charge, but donations to help us cover the cost of the event and refreshments are gratefully received via Virgin Money Giving.

West London Kidney Patients' Association's

Kidney
PATIENT
EXPO 2020

Wed 4 March,
10.30am-4.00pm

This is a free informative event for all things related to being a kidney patient, providing an opportunity to learn more about kidney failure and how to manage and thrive with the changes it brings. Learn about diet, fitness, holidays, insurance, treatment options and much more – and it's a great chance for networking. See www.eventbrite.co.uk for more information and to book.



Get involved on World Kidney Day

As in previous years, World Kidney Day aims to draw public attention to the importance of maintaining a healthy lifestyle to help protect the kidneys, the risks for developing kidney disease and the impact it has on patients.

The day highlights the importance of preventing the onset and progression of kidney disease and the theme this year will be *Kidney Health for Everyone, Everywhere – from Prevention to Detection and Equitable Access to Care*.

You can help by organising an activity or event to draw public attention to the importance of kidney health and the risks of kidney disease. Use the World Kidney Day website to help publicise your event, use #worldkidneyday in all your tweets and Facebook posts for readers and supporters to follow your event, and share your photos from the day.

Download World Kidney Day campaign materials for web or print, or order a Support Pack for your awareness event from the World Kidney Day website: www.worldkidneyday.co.uk

Gravely ill toddler who needs kidney, saved by transplant from NHS radiographer

With time running out for their sick daughter Anaya, parents Joety and Amrik Kandola from Newcastle launched a desperate last-ditch appeal for a kidney donor to save her life. Just as all hope seemed lost, NHS radiographer and mum of two, Surinder Sapal, answered the couple's Facebook plea offering to donate one of her organs to the two-year-old and tests showed she was a tissue match for Anaya. Nine months later the kidney transplant took place, pulling the toddler back from the brink and a life on dialysis. She is now thriving.

Joety said: "If she did not have this transplant I don't think she would have made it. Time was running out. She didn't have any energy, wasn't sleeping, she couldn't walk, constantly vomiting. For Surinder to come into our lives and share her kidney was phenomenal. Anaya is our little miracle."

Two year old Anaya had been born prematurely with a chronic disease that led to enlarged kidneys, which had to be removed when she was weeks old. With the couple having been ruled out as a match for their daughter, Surinder was one of 34 who offered to help.

When she spotted the facebook appeal she thought:

'What if it was my child and I was unable to help?' She considered her gift of a kidney as just "one mother helping another".

"It was amazing seeing this person with a piece of me inside her thriving", she said. "They told me I am part of their family. I class her as a third daughter."

Taken from a story covered by the BBC and Mirror, 15 December

Di Frank wins award for helping aspiring kidney donors



Di Franks, from Swindon, donated a kidney to a stranger at a time when it was quite a new concept. Through her website www.livingkidneydonation.co.uk, she supports many others going through the process, and Give a Kidney has presented her with a beautiful award designed by Jo Vincent Glass to recognize her work.

Diane said: "Having donated my kidney back in 2010 I felt I wanted to do more to help people. Being one of the early non-directed donors I found the whole experience rather isolating, with no-one to talk to who could understand the emotions I was going through, or to find out about procedures etc.

"I didn't want other donors to feel the same, so I set up my blog, and soon people started contacting me, thanking me for sharing my experience. As many of them went through the donation process they would tell me how nothing was a surprise as they knew exactly what to expect, not just physically but emotionally as well."

"Getting the award from Give a Kidney was amazing and so unexpected. To learn the news that my help has spread far and wide and being acknowledged is awesome! It means so much to me to know I am really making a difference."

Donor Ray Duffy's epic climb



The Old Man of Hoy is a 449-foot (137m) sea stack on Hoy, one of the Orkney Isles, and in September, non-directed kidney donor, Ray Duffy, and two friends, Glenn Gordon and Neil Busby, succeeded in their night ascent of the iconic stack. In doing so, they raised almost £5000 to support Give a Kidney and we are very grateful to him and all the team for taking on this epic challenge. Ray's story was picked up by media around the world as far away as India, Australia and the USA, and continues to raise awareness for living kidney donation and show that donating a kidney does not preclude someone from living a full and healthy life. Ray has now set his sights set on El Capitan in California.

Thank you to each and every one of you.

As we approach the end of another year, I am delighted to report that numbers of non-directed donors look set to exceed expectations this year. Currently, 92 people have donated since January in comparison with 64 for 2018 and it is likely that there will be one or two more donations before Christmas. Even allowing for the variations we saw in last year's figures because of the quarterly ups and downs created by 'chain' activity, this is the first increase in actual donors since 2015 and the number of transplants achieved in the kidney sharing scheme this year is at an all time high. More and more people are making contact through the on-line expression of interest form

and looking at the information on the www.organdonation.nhs.uk/become-a-living-donor/ website. Early in the New Year, we will be adding further factsheets and refreshing the appearance of these pages so that it is easier for people to find the information they need. Huge thanks to my colleagues Jen Lumsdaine and Julie Glen in Scotland and to Jan Shorrock for their work on the new factsheets.

I am also pleased to let you know that a Donor Reported Experience Measure (DREM) will be launched in January via NHSBT. The DREM has been developed with support from colleagues at the University of Hertfordshire. Thanks are owed to many for making this happen but

I would particularly like to acknowledge Jan Shorrock at Give a Kidney and Fiona Loud at Kidney Care UK for their key roles in keeping us all on track from both a donor and recipient perspective.

The development of a new 'Post 2020' Strategy for organ donation and transplantation is advancing well. A document is currently being drafted, which will be out for comment in January.

Finally, thank you all for your fantastic contribution to making a difference to so many lives. Have a very Happy Christmas and I look forward to continuing to work with you in the coming year.

Latest reports and statistics are available at: www.odt.nhs.uk/statistics-and-reports/

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From Spring 2020 the law around organ donation in England is changing



PASS IT ON

In Spring 2020 the opt-out system for organ donors will come into force in England: it presumes that all adults of 18 and over agree to donate their organs after their death **unless they have stated otherwise**. Excluded from this system are those under the age of 18, people who lack the mental capacity to understand the new arrangements and take the necessary action, visitors to England and those not living here voluntarily, and people who have lived in England for less than a year before their death.

A similar opt-out, or 'deemed consent' system has been operating in Wales since December 2015 and legislation was passed in July 2019 in Scotland. The Northern Ireland Assembly decided in 2016 to keep their opt-in laws, meaning organ and tissue will not be donated by default.

It is a sensitive subject and the debates leading to this decision have understandably been contentious. Historically, donations were based on the principle of intentionally choosing to make a gift, as opposed to the default position. It was argued that organ removal without the expressed wish of

the deceased could be distressing and ambiguous for his or her family, which - given that family members can withdraw consent on behalf of their loved ones - might lead to a higher risk of refusal.

But the arguments for introducing the new system were compelling: despite the efforts of NHSBT, the number of people whose lives could be saved by a transplant is rising more rapidly than the number of willing donors. More than 6,500 people in the UK need a transplant, but although the donor consent rate in the UK has risen in the last few years, only about 3,500 transplants are carried out per annum. This is compounded by family opposition: in the last five years, NHS figures show that the families of 505 registered donors refused donation, which resulted in around 1,200 people missing out on potentially life-saving transplants.

Clearly then, it's imperative that discussions with family members take place whilst the potential donors are still living, especially since the opt-out system will not take into account the deceased person's preference unless they have

expressly stated their wish on the Organ Donor Register not to donate, which of course is their right.

Just 5% of organ donors last year were from Black and Asian communities. In a bid to address this discrepancy, the new opt-out scheme will also include a new system to record an individual's faith and ensure the NHS consults religious leaders or family members on any traditions that need to be respected.

The more people are aware of these changes, the less it can be argued that people's values and rights are being eroded. So please pass this on.

Give a Kidney's fundraising platform is now *Virgin Money Giving* as they have dropped their joining fee for new charities for a limited period. There is a 2% fee on donations, but donors have the option to pay that on behalf of the charity.

Give a Kidney thank all those who have donated to date.



Acknowledgements

Give a Kidney would like to acknowledge those who give their time and services to the charity. For example:

The charity's Steering Committee has met at CZW Architects for three years now. They kindly provide a sandwich lunch too. AND they have hosted our past three Annual Conferences free of charge. This represents a huge financial saving for the charity, particularly as the office is in Central London. Sadly they plan to move to smaller premises and so won't be able to do this in future.

The Edinburgh Hilton has also kindly donated a room for Give a Kidney Scotland meetings to take place. Similarly, Guy's Hospital have provided meeting facilities for London meetings.

Curious Road designed our fabulous website, which is hosted by Jim Fatah - he has done so since the charity launched in 2011 and we are very grateful for this valuable resource.

All those who make connections locally and speak to groups about altruistic kidney donation. Also those who have been willing to share their personal stories in other ways, for example through interviews and articles in the press. You help raise awareness of altruistic kidney donation and explain why it's such a good idea to be a living kidney donor.

Graham Healy has very kindly compiled our accounts for the past three years, so that we can submit them to the Charity Commission and the OSCR (the Scottish version).

Finally and most importantly, Viv Calderbank of topicaldesign.co.uk has produced all the artwork we have ever needed for information leaflets, letterhead, banners, posters, sponsorship forms... the list goes on. We are extremely fortunate to have this wonderful resource which has saved us many thousands of pounds over the past 8+ years.

Bob Wiggins, Chair, Give a Kidney

Are you kidney aware?

FACT 1 Kidney disease is common, can affect anyone but is treatable for some people if recognised early

FACT 2 An estimated 60,000 people in the UK die prematurely due to kidney disease every year

FACT 3 Uncontrolled diabetes or high blood pressure are the biggest causes of kidney failure

FACT 4 Right now, around 64,000 people in the UK are being treated for kidney failure; without dialysis or a transplant, it is fatal

FACT 5 People from black, Asian or minority ethnic (BAME) backgrounds are more likely to progress faster towards kidney failure

FACT 6 4,820 people are waiting for a kidney, yet only around 3,300 transplants are carried out each year

FACT 7 Acute kidney injury (AKI) affects one in five people admitted to hospital as an emergency. It is a sudden drop in kidney function due to serious illness and may be more deadly than a heart attack

FACT 8 More women have kidney disease, yet more men start dialysis

KIDNEY HEALTH FOR EVERYONE EVERYWHERE

14th MARCH 2019

Two sporting events for kidney charities

Cardiff 5K – Race For Victory 2020 - Saturday 9 May, 7pm in aid of Kidney Wales.

The Jurassic Coast Challenge 2020: walk, jog, or run the iconic Dorset coastline, in aid of Kidney Cancer UK.

For more information and to register, see:

www.kidneywales.cymru

www.kcuk.org.uk/event/

Nicolas Crace: my scar

A hundred years ago veterans of Britain's overseas military adventures had to be discouraged from showing reluctant acquaintances operation scars across their abdomen. This habit is less common now, perhaps because more patients survive their operation, so that a hospital scar confers little more status than an MBE. Now I've got one - a scar that is - supplied free to me by the NHS.

Now that I have the scar I take little real pride in it, but its acquisition has widened my experience, which was small, of nurses, surgeons, anaesthetists, hospital food, the things that can happen to the helpless, trusting and simple, how very much the nursing sisters know, and how much they have still to learn.

Hospital days start early. To acquire my scar I was woken at 6.15 and after a shower I was wheeled in a procession to the operating theatre. It felt like a royal progress, and I had to restrain myself from bowing to curious onlookers. The operating



theatre itself was like a cavernous underground garage, but the staff there was welcoming, and I was introduced to each of them. Surgical masks are no longer de rigeur for laparoscopic (keyhole) operations, their effectiveness lasting for a bare three minutes, which reduces the drama and sense of occasion, but does lead to greater informality and lack of tension.

I had been told that NHS patients cannot hope to read or write in hospital. But within a day I was sitting up and reading Anthony Powell's *A Dance to the Music of Time*, and beginning to feel that this life, after all, was good enough for however long it might take to finish this remarkable and mammoth work.

The occasional endearing NHS incompetence lightened life. Another kidney donor's procession to the operating theatre one morning was abruptly halted at the last moment. What had happened to stop the proceedings? Had the recipient been

taken ill? Had the surgeon been held up? No. Someone had turned off the hospital ice-making machine the night before, so there was no ice to encase the kidney on its onward journey. A quick visit to Tesco put this right.

I used to look upon myself as a relatively unemotional person, but I was moved by the things that I saw and some of the people that I encountered in hospital. The amazing and genuine dedication of the staff was inspiring. I remember signing on to join the NHS seventy years ago when I was a squaddy in East Africa. I have never regretted it.

In 2013 Nicholas Crace was the 103rd altruistic kidney donor, at the age of 83.

Contact us

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