

A cup half full? Update on Give a Kidney's progress over the last five years

In the last newsletter I referred to the incredible success achieved over the past five years as a charity. I have had the privilege of meeting a number of the original founders over the past months and some would argue that we haven't yet made the impact we sought. The levels of non-directed living donation have indeed declined since the exponential growth we saw up until March 2014 and we are still trying to understand the reasons for this. For my part I see our cup as half full, but focused on filling it to the brim as soon as possible.

Whilst we would all wish to move further faster, we must acknowledge that firstly, we are a very young charity, and to influence change we needed to establish credibility within the media and among healthcare professionals. This has been one of our greatest successes. Secondly, nothing would be achieved without the considerable commitment Suzanna and Jan continue to devote to Give a Kidney beyond their contracted time and the substantial time given freely by very busy

committee members and those that support the committee such as Viv. Nevertheless we have limited financial and people resources, and it is a testament to all involved that we have achieved so much so quickly. Thirdly, we have seized wherever possible the media opportunities available, battling the increasing trend of the national press to be only interested in groundbreaking stories of living donation. Our efforts to promote living donation in the media will continue, as evidenced by the success of the recent 500th donor campaign. We are also looking to build on local press opportunities through the Ambassador Programme. Fourthly, with all of the above as a basis we are investing considerable time and effort in forging stronger and more fruitful relationships with other related charities - and most notably with NHSBT.

NHSBT's mandate is set by Ministers and the Department of Health. In terms of organ donation, NHSBT is working to increase both the number of people on the organ

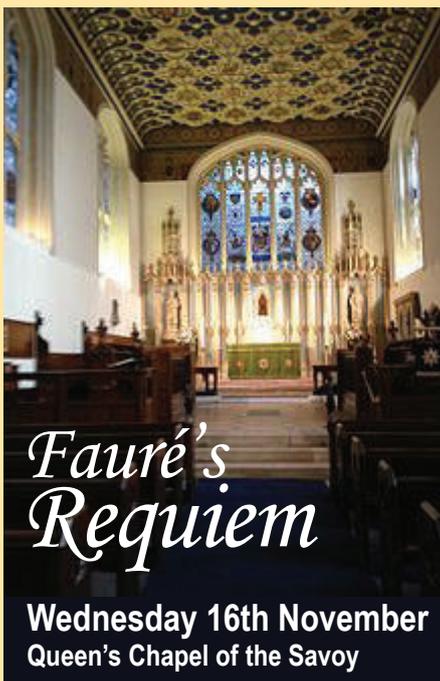
donor register and the number of deceased organs available for transplant. You will have

seen their campaign promoting families to "have the conversation". It's acknowledged that, rightly or wrongly, living donation has not been a priority but this is now becoming a much more prominent feature of their work. In a meeting with Sally Johnson, Director of Organ Donation and Transplantation, we agreed a number of groundbreaking initiatives which are already in hand - see Lisa Burnapp's NHSBT update on page 7.

Our credibility and influence is further evidenced by the increasing requests for sessions on living donation at major conferences such as the recent NHSBT Organ Donation and Transplantation Congress and at the opening ceremony and plenary sessions of the ESOT/EDTCO European Organ Donation Congress in Barcelona. Further upcoming invitations for Give a Kidney to present include meetings and conferences organised by Polycystic Kidney Disease Charity, Human Tissue Authority, British Transplantation Society and European Society for Organ Transplantation (ESOT). This engagement helps to place non-directed living kidney donation into the mainstream of organ transplantation instead of a fringe activity.

We have much to do and we will require greater financial and people resources to achieve it. However on this, the occasion of our 5th anniversary, I would once again like to pay tribute to all the founders, Trustees, members and supporters of Give a Kidney - one's enough for the success achieved and the excellent foundations in place to forge ahead to our ultimate goal - "no waiting for a transplant for want of a kidney"

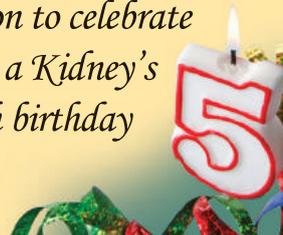
Bob Wiggins, Chair



Worcester College Oxford Chapel Choir will sing in the beautiful Queen's Chapel of the Savoy, as part of the Brandenburg Choral Festival of London.

Apply for tickets by emailing giveakidneyoffice@gmail.com or book via www.brandenburg.org.uk/give-a-kidney
Our charity will benefit from half of our ticket sales plus any donations, so we do hope you and your friends will be able to join us.

The choral concert will be preceded by a *reception to celebrate Give a Kidney's 5th birthday*



To celebrate Give a Kidney's fifth year of campaigning, this eight-page special edition highlights many of our achievements over half a decade.

2011

On 25 March 2011, the new Charity's constitution was signed by Annabel Ferriman as Chair and fellow Trustees, Chris Burns-Cox, Paul Gibbs, Gareth Jones, Paul van den Bosch and Sara Stacey.

The first YouGov survey was commissioned by the Charity on 22-24 August.

The new Charity website went live on 28 October.

The Give a Kidney press launch, held on 1 November, was a great success!

2012

Johan Stegers, from Uckfield, became the 100th person in the UK to give a kidney to a stranger.

A conference on 16 June at BMA House in London was attended by 65 people. The same day, a beautiful film was created of brief interviews with donors and recipients, masterminded and financed by Annabel Ferriman and Fred Kavalier, was posted on the Charity's website.

Many references to living kidney donation - usually mentioning the Give a Kidney website - appeared in magazines and the national and local press, and featured on radio and television programmes or news.

The Charity commented on the NHSBT paper on reimbursement of expenses of living kidney donors; lectures were given to South West Urological Surgeons and to University of Bristol Community Medicine/ Medical Ethics Department; members attended the All Party Parliamentary Group on the situation on transplants in the black and minority ethnic communities.

2013

In April, the HTA announced updated guidelines for directed altruistic donations.

Also in April, a Mayo Clinic poll showed that half of Americans would consider donating a kidney to a stranger. 84% of respondents said they would be very or somewhat likely to consider donating a kidney or a portion of their liver to a close friend or family member in need, and an astounding 49% said they would be very or somewhat likely to consider donating a kidney to someone they have never met.

In September Sanjiv Gohil took over as Treasurer of Give a Kidney, Adnan Sharif joined the Steering Committee and Jan Shorrock was recruited as the Charity's PR Officer.

Media coverage throughout the year increased: in March, David Rang took part in a documentary for Danish TV, discussing altruistic kidney donation; the April issue of *The Scottish Farmer* carried an article on John Fletcher's donor story; in April, Maggie Harris appeared on BBC Breakfast with Lisa Burnapp to talk about her donation, interviewed by Charlie Stayt and Louise Minchin; Sanjiv Gohil was interviewed by Huw Edwards on the BBC News Channel, talking about his donation; BBC Radio 4's *More or Less* discussion was on altruistic kidney donation; in June Paul and Teresa van den Bosch appeared on *The One Show* to talk about Teresa's recent donation, Paul having done so four years previously; Bob Wiggins raised over £4,000 online for Give a Kidney through JustGiving.com, by asking people to sponsor him for donating a kidney; in July, there was a feature in the

2014

Daily Telegraph about John Carlisle, Sheffield's first altruistic donor; Bob Wiggins and Di Franks featured on Sky News; in October Roger and Andrew Corke were on a BBC R4 Broadcasting House programme and in the *Mail on Sunday*; Jan Shorrock was featured in a double page spread in *North West Evening Mail*; and in December Matilda Mitchell featured in the *University of Edinburgh Journal*.

Wonderful fundraisers included Liz & Phil Hughes who completed the Cheltenham half-marathon raising almost £1000 for Give a Kidney in recognition of Liz's sister Maggie, who received a kidney from an altruistic donor and Jasie Rai's fundraising night raised almost £3,000 for the charity.

In January, Theresa Dobson was on ITV News (Anglia), Jan Shorrock featured in a three page article in *Lancashire Life* magazine and in a full page piece in *Top Sante* magazine; Sanjiv Gohil and Paul van den Bosch were filmed for a Ukrainian current affairs programme; Paul van den Bosch and Teresa Dobson were filmed for ITV Anglia. In February there was a piece in *The Independent* and good local coverage from the 250th campaign; in March Metro newspaper and ITV both featured Clare Bolitho and Marion Pattinson; in May Judith Becker's article in *Woman and Home* (circulation 350,000) also resulted in a donation of £500 from IPC Media; Tom Cledwyn was interviewed on Sky TV News; in June there was a double page spread on Jan Shorrock and Rachel Leah in *My Weekly*; a £10,000 cheque was received from The Robertson Trust to add to over £5,000 raised by Paul Dooley's event in April; Nicholas Crace featured on The Jeremy Vine Show, BBC Radio 2 and in *The Daily Express*; in August there was a six page article on altruistic kidney donors in the *Observer* magazine, a front page photo and whole page article on altruistic donation in the *Saturday*

Telegraph featuring Claire Ramsden; Chris Burns-Cox and his recipient Michael Benton were interviewed for a substantial piece on BBC Radio 5 Live; in September a full page in *Essentials* magazine featured Claire Ramsden; in October Judith Becker's article in *Women and Home* was re-published in *Bon Marche* magazine; in December, filming was completed by BBC Scotland of a documentary about organ donation and the journeys of two non-directed donors (broadcast in 2015).

In August, the Charity's second YouGov poll published its results, revealing progress made over the past three years.

In October, Jan Shorrock represented Give a Kidney at the European Donation Congress in Budapest.

In December, funding for BOUnD, a significant new research project into non-directed donation was confirmed - Give a Kidney was represented on the steering group by David Hemmings and Jan Shorrock.

Press coverage: in January Lauren Storer featured on the front page of *Westmorland Gazette* and in *The Daily Mirror*; in February Give a Kidney is 'Charity of the Week' in *The Week* magazine and Claire Bolitho and Marion Pattinson featured in *The Daily Mail*. In July, *Transplant Tales* focused on Give a Kidney members Paul and Kenny Dooley, aired on BBC Scotland; in August there was an article on Joanne Ewing in *The Telegraph*. In September Bob Wiggins and his recipient featured in *The Sunday Telegraph* and *Sky News*. In October Chris Burns-Cox and his recipient Mike Benton featured on Channel 5 News and a 'Gift of Life' documentary was aired on Channel 5; Lisa Burnapp and kidney donor, Trish, were on R4's iPM. In November John Gilmour was featured in the *Sunday Post* and *BBC Radio Scotland Newsdrive*.

In December The Sun carried an article about Alex Brown.

Throughout the year, Give a Kidney participated in the Management Group of the BOUnD study, a five year prospective study into the Benefits and Outcomes of Unspecified Donation.

In March, Give a Kidney joined the LDKT 2020 Strategy Implementation Group to support NHSBT in delivering its Living Donation Strategy to 2020; Give a Kidney was represented at the National Donation and Trans-plantation Congress in Coventry; in June, Give a Kidney participated in a meeting with NHSBT and UK charities to plan for Transplant Week.

In October Give a Kidney representatives met with Dutch counterparts in Amsterdam to discuss how to increase numbers of non-directed kidney donation in The Netherlands, the UK and the rest of Europe.

February saw the first 1,000 copies of Give a Kidney's new charity information leaflet printed.

In May, Roger Corke and Bob Wiggins joined Give a Kidney's Board of Trustees.

In June, Give a Kidney's new website - designed by Curious Road Design and built by JFA Systems - went live, and the Charity received its 1,000th 'like' on Facebook.

Also in June, Give a Kidney representatives met with James Newcombe, the Bishop of Carlisle, and Rev. Brendan McCarthy to discuss the inclusion of information about living donation in the Church's Flesh and Blood campaign.

'Give a Kidney - one's enough' is registered as a charity in Scotland, with Scottish charity no. SC045767.

It was agreed that NHSBT materials about altruistic kidney donation

could be included in blood donor clinics UK-wide

Bob Wiggins took over as Chair at the first meeting following the AGM in January AGM. In April, Chris Burns-Cox's presentation at ELPAT in Rome was very well received.

A meeting was held in York on 25 June to launch the Ambassador Programme. Over 30 members gathered to discuss how best to raise awareness of non-directed living kidney donation and support the aims of the Charity.

Real Stories, featuring, Julie Hughes and David Evans, was aired on ITV, with positive feedback. There was a follow up story in *The Sunday Telegraph* on 21 August.

Over 18 months, Paul Dixon has signed up 6,000 people to the Organ Donor Register and campaigned for living donation. The press in the Merseyside area celebrated this success.

With the 500th non-directed altruistic kidney donation having taken place in July, a joint Give a Kidney / NHSBT press release went out on 21 September to announce this momentous occasion, and supporters were asked to share their story with local media. The campaign generated an enormous amount of coverage throughout the UK as well as a good deal of interest on social media (see page 7).

In September, NHSBT made a commitment that at least one of its key campaigns for 2017 would focus on living donation.

'Give a Kidney Scotland' signed a Memorandum of Understanding: it is now affiliated to the Charity, sharing aims and objectives, rather than a separate organisation.

16 November marks the Charity's 5th birthday celebration at a reception followed by a choral concert.

Finance and Fundraising

Give a Kidney's work over the past five years has only been possible by the financial generosity of a handful of private benefactors combined in equal measure with the many individuals that have fundraised on behalf of the charity.

Our income and expenditure has proven to be lumpy but overall maintaining our reserves until recently. Over the past year or so we have had to draw on them due to reduced income to fund operating costs, as well as taking on additional activities. Our costs are made up primarily of admin costs allowing us to function effectively; PR costs supporting our all-important messages across all types of traditional and digital media; disseminating information via newsletters and meetings; and travel costs - the latter two allowing us to keep all our supporters up to date, whether they are past donors, future donors, or within the transplant healthcare community. As one would expect, we try to keep all costs to a minimum. We are looking at publishing the newsletter in digital format only and a large portion of the travel costs are picked up by the individuals concerned or by the organisers of meetings and conferences.

During the course of 2016, as income has been shown to dip,

fundraising has attracted a much greater focus. In order to accomplish the activities planned to raise awareness, influence change and support past and future non-directed living donors, we will need to ensure that we have both greater and more stable income. So we are hoping to try a number of avenues to increase our financial sustainability. Among these we are looking to other charitable organisations that would be interested in supporting our work, as well as private industry such as the pharmaceutical companies. We are organising our own fundraising events such as the classical concert on 16 November at the Queens Chapel of the Savoy.

Finally, we are looking to redefine how our members and supporters can financially support the charity. We are not happy with the lack of clarity regarding membership fees and how they are managed. Members and supporters willing to support the charity financially can help by setting up a monthly standing order in an amount they feel is appropriate to them. This will negate the need to remember how to go about paying fees and help with the Charity's cash flow. Please contact giveakidneyoffice@gmail.com to ask for our account details.

We hope we can look forward to your continuing support.

Give a Kidney AGM & CONFERENCE Saturday 25th March 2017

at the offices of CZWG Architects,
17 Bowling Green Lane, EC1R 0QB
(a short walk from Farringdon tube station)

Please put the date in your diary.

Kidney
Disease &
Obesity
9 March 2017



With over 600 million adults in the UK now classed as 'obese', a factor which increases the risk of developing Chronic Kidney Disease (CKD) or end-stage renal disease (ESRD), the theme for World Kidney Day in 2017 is Kidney Disease and Obesity. The campaign will promote a greater understanding of the links between the two and ways in which people can change their lifestyles.

People who are overweight or obese have two to seven times more chance of developing ESRD (and other serious medical complications) compared to those of normal weight and obesity may lead to CKD indirectly by increasing type 2 diabetes.

All these factors contribute significantly to overall poor health and increasingly high annual medical costs in the UK.

TRANSPLANT SPORTS

Next year, the World Transplant Games are being held in Malaga, Spain, from 25 June to 2 July 2017. For the first time, there will be sporting events for living donors and donor families in the following categories: 100m, long jump, ball throw; 5km and 50m freestyle swimming. There is an overall points-based award for the 'best living donor and donor family member'. Would you like to join the Team and represent Great Britain and Northern Ireland?

The cost per athlete will be circa £1500, which includes full registration, flight, seven nights full board in a 4-star hotel and transport in Malaga, plus kit, insurance, training costs etc. There are no guarantees that funds will be available for individuals, so you may have to raise the full total yourself. There could be a



reduced registration package which does not include accommodation or food but this will be confirmed later, and you'll need to add the costs of getting to the training meets in Warwick (between 18 March and 14 May 2017) to the amount you raise.

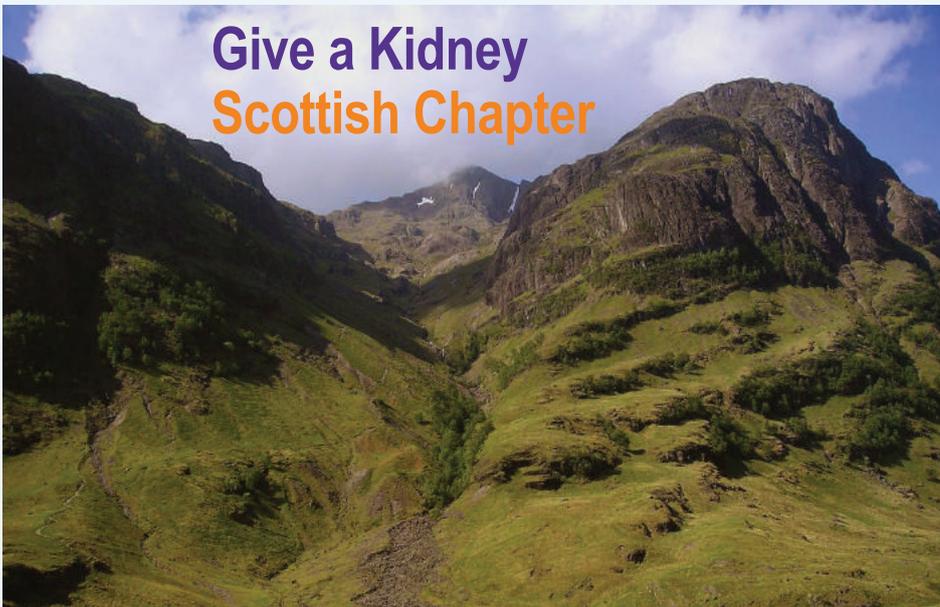
To be part of the Great Britain team, it is important that you remain fit, regularly train in your chosen sport, and attend at least one of the team training meets.

For more information on the Games, visit www.wtgmálaga2017.com. If you're interested in taking part and/or need info on fundraising, please contact Lynne Holt on lholt@home.3b.co.uk or 07900014344 for a registration form.

If you're not ready for world-class sport, why not take part in the British Transplant Games which will be held in North Lanarkshire, 27 - 30 July?

Staged annually since 1978, the Games aim to demonstrate the benefits of transplantation, encouraging transplant patients to regain fitness, and increase public awareness of the need for more people to join the NHS Organ Donation Register and discuss their wishes with their families. They also seek to thank donor families for their gift of life.

Give a Kidney Scottish Chapter



Following discussions at the York meeting organised by Give a Kidney we had a well attended meeting in Edinburgh on 29 August. Bob Wiggins and Jan Shorrock had travelled north on behalf of Give a Kidney and after discussion it was agreed that our informal Scottish group of donors – now numbering about twenty - should become formally attached to the charity as Give a Kidney Scotland, or GaKS.

It was clear that we share the same objectives as Give a Kidney - ultimately seeking to raise awareness of the opportunities provided by non-directed live kidney donation to achieve a situation in which nobody need wait to receive a kidney. Connected to this aspiration we need to collaborate with the clinical community within the NHS, provide accurate information when called upon by the media and also to meet and liaise with potential donors.

As had been the theme of the York meeting, this connection with those thinking about donating a kidney to a stranger requires informed 'Ambassadorship' which must be diplomatic, objective and not overly enthusiastic. The risks need stating as do the emotional rewards.

I think that I can speak for other members of GaKS in saying that we believe that Scotland can provide an ideal 'test-bed' as a consequence of its small population, good communications and self-pride, for the objectives which we share with Give a Kidney. We would like to be able to say that sometime in the future Scotland has no waiting list for kidneys and perhaps Scotland could become the first nation in the UK - or perhaps even globally! - to achieve that.

Of course, this would be rather illusory since kidneys do not respect borders, but it is a noble aspiration.

As for the actual mechanics of connecting to Give a Kidney, GaKS will benefit from a regular column in the newsletter - of which this is therefore the first. We hope to have a space on the Give a Kidney website and to benefit from shared development of Ambassadorial resources, shared Public Relations, etc etc. And, of course, we in turn must encourage members to subscribe to Give a Kidney.

Our active Secretary, Colin McLachlan, has agreed to liaise with Jan Shorrock to produce guidelines for those working as 'Buddies' with prospective donors. These would be in accord with the principles of Give a Kidney which include a clear avoidance of any suggestion of active recruitment of potential donors, nor any attempt ever to match donors with recipients nor to suggest that any particular individual is especially well suited to become a donor. These principles are now a part of the formal GaKS Memorandum of Understanding agreed with Give a Kidney and jointly signed by representatives of both bodies.

Amongst other topics discussed at this meeting was a general airing of the degree to which donors and recipients should be put in touch. In particular, the extent to which donors might be entitled to information about the recipient's age, sex, region and progress in recovery.

It was felt that GaKS could assist in many ways in the meetings being held by NHS but it was stressed that it might take time before NHS Transplant Co-

ordinators could build up trust with us, and that in the meantime we should all do our best to develop links with the Coordinators.

There was discussion about the then forthcoming 500th donation and related publicity as well as the plans for celebration of the 10th anniversary of the first non-directed donor in July 2017.

There have been a very good number of media mentions of kidney donations recently in Scotland especially arising from the 500th donation campaign organised throughout Britain by Give a Kidney's Executive Officer Jan Shorrock. It is becoming very clear that there is a remarkable cluster of donors in Fife which seems to fly in the face of the regular abusive comment that you need 'a lang spoon to sup wi' a Fifer'. Several scientists have tendered grant applications to investigate environmental factors that might explain this cluster.

Chris Jones had a great article in *The Guardian* as part of a series of organ donation stories. Colin featured on Motors TV with his ShareyourSpare (kidney not tyre).

If anyone in Scotland is planning to contact the local media, please speak to our PR czar, Dorothy Fenwick (dorothy@djfenwick.co.uk) first.

As a good instance of the use of social media Rodger Webster has done a great job of promoting the Share Your Spare campaign on Facebook – try this link: www.facebook.com/rodger.webster.1

Tracy Joliffe is planning a stand-up comedy routine based on kidney donation, and would welcome any funny stories you can contribute. Contact colin@acme-properties.co.uk who can put you in touch.

Kate Douglas tells us that she has lined up several speaking appointments with local groups. Pam Dippie reports that she will be taking part in The Glasgow Bridges Walk on 9 October, in support of Kidney Research UK.

On the more academic side there is a fascinating TED talk. On www.ted.com search for 'Abigail Marsh: Why some people are more altruistic than others'.

There is also a highly relevant paper in the British Medical Journal which you can reach with this link: <http://www.bmj.com/content/354/bmj.i4746>.

John Fletcher

CANADIAN DONOR'S UK INSPIRATION

Non directed donors can never know the effect that their donation may have on others, and how every bit of publicity can be significant in unforeseen ways. In this heartwarming story, donor Eileen Zheng tells what influenced her big decision.

Although 5,000 miles away and with an age difference of 60 years, a Canadian woman found inspiration in an 88-year-old Brit.

In 2015 Canadian Eileen Zheng, 28, of Vancouver, decided to give one of her kidneys to her mother, who was dying of kidney disease, and for whom a transplant was the only remedy. It was an easy decision for her to make. But she then had to go through the long testing process, to see if her kidney would be a match for her mother, and to ensure that she was fit enough to go through major surgery. At the same time she had a growing and understandable apprehension about what the operation would entail.

"I knew it would be OK"

While going through this process she saw by chance a BBC news item featuring Nicholas Crace, of Overton, Hampshire, then 83, who had donated one of his kidneys to a stranger in 2012, and wrote to him:

"After going through the testing stages and coming back with only good results, I saw your video. It gave me courage and changed my apprehension on the entire process. I saw how you mowed your lawn.



Eileen Zheng, having completed her amazing bike ride, with her mother Wei Zhang

I saw how healthy and happy you looked, and I knew that moment, it will be OK."

Before she underwent the three-hour operation she watched the video a second and third time. "It gave me some sense of peace and courage. You made me feel that everything was going to be fine".

Both kidneys removed

Eileen said that it took years for her to convince her 60-year-old mother to take one of her kidneys, as her mother was concerned for her daughter's health. "Instead, she chose to be on dialysis for

over half a decade; in the end she had no choice because both her kidneys had to be removed and her health was quickly deteriorating, so she had to say yes"

The transplant was a complete success, and both Eileen and her mother are doing better than ever. "My mother ... I've never in my life seen her with so much energy and colour. It changed her life and everyone's around her."

Cross-country bike ride

Eileen then decided to undertake a 4,700 mile bicycle ride across Canada to raise awareness of organ and tissue donation. She completed her amazing 112-day journey in September, returning to her Vancouver home having raised nearly £13,000 pounds in the process for the Canadian Transplant Association.

"Today," she wrote, "Just like you, my mother and I are doing better than ever. This has enriched my life, and I can see how it can change people as human beings. That one decision to save or improve the quality of a life. You are amazing in my eyes, and I can't thank you enough for doing what you did. You probably gave many people the courage to become organ donors without knowing it."

Calling all Give a Kidney Ambassadors

As you are probably aware, in June this year we held our first Ambassador's day - a day to get to understand the charity better and for us to discuss between us the shape of the Ambassador Programme. We're at the beginning of this programme and we need your help with its development. Eleven of you have already signed up formally as Ambassadors and we hope more will follow suit. We know that many others of you continue to support informally and are grateful for all you do to help.

As well as the Scottish Chapter of Give a Kidney, other informal regional groups are starting to think about how they can work together to support us in raising awareness. Celia Kent is hosting a North London Group meeting on 14 November, a chance to meet other

people interested in raising awareness and discuss possibilities. Big thanks to Celia for her work and to everyone who is getting involved in some way. Please let us know if you would like more information on the North London meeting and we can put you in touch with Celia.

The new Ambassador section of the website with information and resources is now live and available to the Ambassadors for their use.

We hope to run further Ambassador days in future, but in the meantime, please let us know if you need any more information or have suggestions of what you need in order that we can better support you to raise awareness.

Thanks to everyone who has expressed a willingness to be involved.



Celia Kent, one of the Give a Kidney Ambassadors

Implementation of the living donor kidney transplantation 2020 strategy continues at a pace. This summer, NHSBT published a new portfolio of website information for donors and recipients on living donation at www.organdonation.nhs.uk/about-donation/living-donation/. Some information will also be available in printed format, including the long-awaited leaflet on non-directed donation. I am working with colleagues to make this available through the online ordering system and on blood donation sessions. We are also working with 'Transplant TV' to produce some short films about living donor kidney transplantation, which will be launched early next year.

This year the emphasis is on public and professional engagement in delivering the strategy. This includes publicity and awareness campaigns to encourage non-directed donation - starting with the 500th milestone and extending into next year, as well as projects that focus closer to home on family and friend donation, particularly within black and Asian communities. All of this has been achieved through collaboration with patient groups and individuals who worked alongside us.

For the first time this year, NHSBT published a centre specific report for living donor kidney transplantation, available at: [http://www.odt.nhs.uk/pdf/annual_report_on_living_donor_kidney_](http://www.odt.nhs.uk/pdf/annual_report_on_living_donor_kidney_transplantation_2016.pdf)

[transplantation_2016.pdf](http://www.odt.nhs.uk/pdf/annual_report_on_living_donor_kidney_transplantation_2016.pdf) to enable individual transplant centres to review and benchmark their own performance against other UK centres. Under the Chairmanship of Dr. Aisling Courtney from Belfast, the LDKT 2020 implementation group has been using this data to share learning and best practice with colleagues in face to face meetings across the UK so that we can work together to achieve the '2020 vision'. The kidney transplant Peer Review process, led by NHS England, is also underway and some of you will have been involved as reviewers. It will report early next year, identifying examples of best practice and areas for improvement.

Finally, NHSBT held its annual Organ Donation Congress on 20-21 September at Warwick University with a session dedicated to living donation. Once again Bob rose to the occasion, contributing a personal perspective in which he highlighted the potential of non-directed donation as a 'gamechanger' in the future of living kidney donation.

Thank you to all of you - Bob, Jan, the steering committee and everyone who gets involved with this all important work. Together we achieve so much more.

Lisa Burnapp
Lead Nurse - Living Donation



Distinguished surgeon Sam Dutta thanked by kidney donors



Earlier this year seven altruistic donors, former patients of leading transplant surgeon Sam Dutta (2nd left, above), met to give him a farewell dinner before he leaves Portsmouth to take up a senior consultant position at Nottingham City Hospital.

Mr. Dutta came to Queen Alexandra Hospital, Portsmouth, in March 2008, and set up the hospital's laparoscopic kidney donation service. Since then he has carried out the operation 150 times. As a pioneer in kidney transplants, Dutta has been the joint lead for the Blood Group Incompatible Transplantation Service at the hospital, and performed the first kidney transplant at Queen Alexandra's where the donor and recipient had different blood groups.

At the dinner Nicholas Crace, who donated a kidney four years ago, presented Mr. Dutta with a Victorian print of Portsmouth from the group. "To the world", he said, "you may be just a surgeon, but to your patients and to a multitude of kidney sufferers you are a hero."

Jan Shorrock, Give a Kidney's Executive Officer, who worked so hard on the '500th donor' campaign was delighted with the results...

Give a Kidney worked very closely with NHSBT's press team on the 500th Donor campaign and were delighted to see them take a very proactive approach to living donation: They not only managed the national press angles but they also featured the campaign in their social media and on their website, which had the '500 donations' as its header on the organ donor registry page. A number of other partners also shared information about the campaign on their websites or social media including the Human Tissue Authority, The British Kidney Patient Association, The Department for Health, Live Life, Give Life and a number of the transplant units.

Overall the media response was excellent given the resources available

and it's hoped there will be other similar opportunities in 2017 with even more press outlets committing to run articles.

There was national coverage in the Times, Independent, Mail, Mirror, Star and Guardian as well as BBC Radio 2,4,5, Channel 5 News and Sky TV. We also achieved a good number of TV features on ITV and BBC regional news TV programmes and regional BBC radio, including the lead story in some instance, as well as a significant amount of local and regional print media coverage, including a number of front pages.

We have estimated that the media campaign has had a combined reach of around 18 million people who will have heard, read or viewed a piece about the

500 DONORS AND COUNTING!

#shareyourspare

campaign so we're delighted. Hundreds of thousands more will have been exposed to the messages via social media or online.

Following a recent meeting with Give a Kidney, NHSBT has now made a commitment to have at least one of its key campaigns for 2017 focus on living donation which is fantastic news and a real step forward. We'll be spending some time with its Communications team between now and then to ensure all our key messages are shared on this and a number of other future initiatives - so watch this space!

Thank you to everyone who participated in the 500th donation campaign. It couldn't have been achieved without your help. We are sure it will encourage others to consider if they could Share Their Spare!

Top Tips for donors

Please let us have any tips of your own and we will collate them with these below and add them to our website among other useful information for prospective donors.

Well before your operation

Be prepared to be patient! The process can feel painfully slow at times as it involves lots of different units and lots of coordination by the teams who are always very busy. Please also remember that the thorough checking process is in place to protect you and to ensure that the risks to your health are acceptably small. Don't be afraid to ask about the time-scale at the beginning of the process so you have a realistic idea of what to expect, and if you're worried that it's gone quiet, do check in with your co-ordinator to find out what's going on.

Be aware that although you think this is a great idea, your friends and family may not agree. It's not unusual for loved-ones to be concerned. They would likely be concerned if you were having an operation that you did need, let alone one you do not need. You may have been thinking this through for some time, but it may come as a shock to them the first time you speak with them about it. Although you may find the level of risk acceptable, other people may have a different perspective on this. All units will welcome key family members to join you for tests or discussions with your healthcare team, so feel free to get them involved in the process as much as you wish to and it may also be helpful to share some of the NHSBT resources around living donation with your loved ones.

Remember that at Give a Kidney we can match you with a 'buddy' - someone who has been through the process and who can share their experience with you. They can't give you medical advice and every person is different, but they can talk to you about how it was for them in a way that many healthcare professionals cannot. If you would like to talk to someone who has been through the process, please get in touch.

Shortly before your operation

Take some throat sweets into hospital. Some people find that their throat can feel sore and scratchy after surgery. Sucking on boiled sweets or throat sweets can help.

Bring a couple of pillows for the journey home. If you are travelling home by car, it can be useful to take a pillow to sit on and one to hold against your abdomen so the seat belt doesn't press against your wound. You are likely to still feel tender around that area and the pillows can help soften the jolts from the bumps in the road.

Take everything down from high shelves (difficult to stretch) and pre-cook some meals if you can't get assistance.

It will be hard to wield hoovers etc for a while after your op - so prepare for that in advance - cut yourself some slack!

After your operation

For women: maternity tights might feel more comfortable than regular tights - and big pants!

Wear loose clothing until you feel comfortable with jeans, belts, etc.

In the Media



Peter Pope

As well as the extensive coverage through the 500th campaign which is featured elsewhere in this newsletter, Nicholas Evans, who helped establish Give a Kidney, and Peter Pope, a non-directed donor, also featured in an inspiring piece on BBC World Service which has been heard around the world.

The Why Factor asks why we do the unusual and extraordinary things we do. In this special episode on organ donation, Nicholas Evans and his daughter Lauren, who donated a kidney to him, talk about their experiences of organ donation and transplantation. Peter Pope, whose daughter, Louisa, a talented artist and musician tragically passed away at the age of 16, talks about the decision to donate Louisa's organs to help others as well as his own decision to donate a kidney as a non-directed donor many years later.

You can listen to the piece online at: www.bbc.co.uk/programmes/p04bygvv or search for BBC The Why Factor.

We have a number of other pieces in development or discussion with journalists and are already starting to plan our next campaigns. We will be supporting NHSBT's work on a campaign around living donation in February 2017 and in Summer 2017 we will be celebrating, together with partners, the next big milestone - the 10th anniversary of the first non-directed donation. The first donor has agreed to be involved with publicity to mark this special date, as has the surgeon who undertook her surgery. It will be an opportunity to reflect on how far we have travelled in the last 10 years, recognise the donors and healthcare teams who have made the programme possible and to renew a call for others to consider donating.

We continue to work with other charity partners and will be attending a meeting later in November to discuss where we go following the successful 'Donation Conversation' campaign earlier this year.

Contact us

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