

Give a Kidney AGM & Conference 2016

Saturday 30th January

**at the DoubleTree by Hilton London - West End
92 Southampton Row, London WC1B 4BH**

Including presentation of the annual report and accounts to members, a report on the charity's activities for the year and an open discussion of plans for 2016 and beyond.

**All are welcome! Book your place via our website
or by emailing giveakidneyoffice@gmail.com**



January 2015 conference



*Seasonal
Greetings to all
Give a Kidney
members and
supporters*



THANK YOU CHRIS

As Chris Burns-Cox steps down as Chair, Paul van den Bosch pays tribute to his contribution to Give a Kidney

We all have two ages. There is a chronological age recorded on our birth certificates and there is a natural age which remains the same throughout our lives. Chris is and has always been a teenager with the best that that brings. He fizzes with enthusiasm and new ideas. He believes passionately that things can be different and better and questions why they are not. It was his meeting with Annabel Ferriman which sparked off Give a Kidney and it is very much down to his energy and vision that we have come so far.

He has been a wonderful chair for Give a Kidney and although stepping down from this role we look forward to working with him for many years to come.

Developments in The Netherlands

This October, a small delegation from Give a Kidney travelled to the Netherlands to meet up with colleagues from the Erasmus Medical Centre in Rotterdam. Rotterdam has a very impressive track record for living kidney donation, and is home to one of the largest living donation programmes in Europe. The centre has a particular interest in non-directed donation. Together with some non-directed altruistic donors, it is looking to establish a charity similar to Give a Kidney in the Netherlands.

The purpose of the meeting was to start learning from each other's experience and look at opportunities to work collaboratively for a greater impact. The Dutch were represented by Dr Willem Weimar, Professor of Internal Medicine and Chair of the Dutch Transplantation Foundation; Willij Zuidema, a living donor co-ordinator; nephrologist Dr Jacqueline van de Wetering,



Dr Emma Massey, a clinical psychologist; and Henk Smid and Jannes van Everdingen, two non-directed donors. Give a Kidney was represented by Lisa Burnapp, Lead Nurse for Living Donation, NHSBT; Paul Gibbs, transplant surgeon and trustee of Give a Kidney; Paul van den Bosch, GP and trustee of Give a Kidney and Chris Burns-Cox and Jan Shorrock, our Chair and PR Officer.

Delegates were able to talk through

what has worked particularly well, share information and best practice, examine some of the issues we all face and also discuss some of the key 'hot topics'.

As a direct result of the meeting, Give a Kidney will be working with its Dutch colleagues to jointly present a session at the European Society for Organ Transplantation Congress, a major European conference in Barcelona next year. The congress is attended by several hundred transplant professionals from across the world. We hope that by working more closely together we can start to demonstrate to other countries the significant benefits of introducing a non-directed donation programme, as there are still very few countries running a programme like those in the UK and Netherlands.

Against all odds



Photo: Andrew Cawley / DC Thomson

John Gilmour, a 48 year old father-of-three from Largs, North Ayrshire, decided to donate one of his kidneys while watching a moving piece about kidney donation on the TV programme *Surprise Surprise*: instantly, he knew that's what he wanted to do.

He recalls: "[shortly after] I went to see the donor team in Glasgow, and from that moment I had the overwhelming feeling that this was the reason I was here. I knew this was something I had to do." He believes he was afforded a "second chance in life", saying "I'm just so happy that I could help and that someone, somewhere, is living a happy and healthy life with their family. That keeps my soul content."

He's even had a tattoo that marks the kidney transplant, which includes the living donor symbol for strength and hope for life.

John is no stranger to altruistically-motivated deeds: for several years he has been a supporter of Spirit Aid, a charity run by actor David Hayman which raises money for a food programme in Malawi which now

feeds more than 1,000 young people a day. Among other things, John helps organise an annual fundraising comedy night for the charity, collecting auction items from sports clubs and personalities.

John has also completed half-marathons for Spirit Aid, but while running on Bute in 2009 he collapsed, suffering two devastating brain haemorrhages and would most likely have died but fortune was on his side: he was tended to quickly by firemen who were out because it was Guy Fawkes night - then airlifted, in a critical condition, to the Southern General Hospital, Glasgow. He underwent two major operations, and rehabilitation took more than two years.

Still an enthusiastic runner, John was a Glasgow Commonwealth Games baton carrier in 2014. Since his brush with death, John's life has gone through major changes. He and his wife Claire have become busy foster carers and have adopted Keira, who is now six.

John has exchanged brief letters with the person who received his kidney but doesn't know who they are and has never spoken to them in person.

He is now looking to help publicise the work of Give a Kidney, which celebrates the fact that more than 400 people in the UK have now donated a kidney to someone they do not know, changing lives for the better, and saving the NHS approximately £20,000 per year over the cost of dialysis.

SAVE THE DATE

THURSDAY 10 MARCH 2016



World Kidney Day is on Thursday, 10th March 2016. It's an opportunity for you to organise an activity or event to help spread the message of Give a Kidney. 2016 is of particular note in terms of our charity: on 1st September it will be a decade since the Human Tissue Act set up a new authority, the Human Tissue Authority (HTA), to regulate all uses of human tissue, including organ transplantation, and it was decided that non-directed donations to strangers should be allowed. Give a Kidney also celebrates its 5th birthday next year.

World Kidney Day UK is led by the Kidney Charities Together Group, comprising five leading kidney charities including Kidney Research and the National Kidney Foundation.

For ideas on how you can get involved, see the World Kidney Day website at www.worldkidneyday.co.uk (you can register your interest by emailing info@worldkidneyday.co.uk) - or visit our own website for inspiration: www.giveakidney.org

Final Fling!

Final Fling is a website bringing together an on-line community of people who embrace life whilst accepting the inevitability of death.

In their own words, "Final Fling is for people who like to be in control of life and death decisions. Know your options. Make choices. Leave instructions. Stay in charge. Right till the end. And in the meantime, live life to the full."

It offers free Life Planning Tools to record wishes, securely store and share legal and financial documents with a trusted 'Keyholder' as well as a Memory Box for passing on keepsakes, life stories, precious family photos and home movies.

Final Fling is an excellent and informative website, awarded the Good Funeral Guide for Most Outstanding Contribution to Understanding Death, 2012 (the year it launched) and finalist in 2013 and 2014.

Recently, Final Fling featured an article on Chris Burns-Cox, co-founder of Give a Kidney and a kidney donor himself:

"Six years ago I read in a newspaper that a GP from Surrey had given a kidney to a stranger as 'it was the most useful thing I could do'," says Chris. "I thought about this and in 2010 I followed his example at Southmead Hospital, the Bristol Transplant Unit.

"Three years later I received a message via the Transplant Co-ordinator from a man who wanted to celebrate the third birthday of his new kidney. He thought it was time he bought me a beer. (Very good it was too!) Before the transplant, he'd had six years of failing health on dialysis. He had been expecting to fade away. The transplant changed his life. He was now extremely fit.

"Later in 2010 I found other altruists - people who'd discovered that giving really is better than receiving - and together we

formed Give a Kidney."

There are over 5,000 UK patients with chronic kidney failure in need, sometimes desperate, and up to 300 die every year for lack of a kidney.

Any healthy UK citizen can offer to give a kidney through the NHS to someone in dire need. Age is no barrier to donation. Last year an 85 year old lady from Preston decided she was fed up with knitting and watching the TV. She gave a kidney to a complete stranger via Liverpool Transplant Unit and was back home well very quickly.

"Even some people with chronic, severe illnesses have given a kidney as they wanted to do something useful with what was left of their lives. In Holland five people did this in one centre: two with Huntington's disease, two with brain tumours and one with emphysema. All donated successfully and were so pleased they had done it." www.finalfling.com

Rugby superstar Jonah Lomu dies at age 40

18th November marked the death of Jonah Lomu, the great New Zealand rugby union player who died at the age of just 40, reportedly from a heart attack. He had seemed in good health on his visit to the UK for the Rugby World Cup this autumn, but the All Blacks star was suffering from nephrotic syndrome.

He was diagnosed with this rare kidney complaint in 1995, at the peak of his career. He underwent dialysis five times a week, until he had a kidney transplant in July 2004. The organ was donated by radio presenter Grant Kereama; Grant was a guest of Jonah Lomu at Government House in Wellington where Lomu received an award for services to rugby. Grant's kidney served Lomu for seven and a half years, allowing Lomu to make a surprise return to the game less than a year later, going on to play in New Zealand's first division and then for Wales. But in 2011, Lomu's body rejected the replacement kidney and



the disease took over once again. He was on the waiting list for a second kidney when he died.

Give a Kidney pays tribute to this remarkable man who, despite an unpromising start in life, and setbacks due to major illness, still managed to play on the world rugby stage: testament to the difference a transplant can make to a life.

Note: The launch of Live Kidney Donor Transplantation Aotearoa took place in Auckland, New Zealand in March 2014, which was formed to inform, promote and facilitate the concept of live kidney donation in New Zealand. See www.kidneydonor.org.nz/

Kidney recipient and golfer Shoky Visram supports Give a Kidney



Shoky Visram (centre) with Steve Davies

Shoky Visram received a kidney from his daughter, Sheena in 2013. He recently became Captain of the Seniors at Stock Brook Golf Club in Essex, where former snooker champion Steve Davies is Club President.

Shoky Visram's inauguration lunch on 18th November was attended by Suzanna den Dulk, Give a Kidney's administrator and Giles Smith, a retired doctor and altruistic kidney donor - where they also met Sheena and Shoky's wife, Nazeera.

Give a Kidney is the chosen charity for the seniors section of the Golf Club, and Giles gave a talk on the aims and work of the charity.

"60 is the new middle age", claims study

People may need to rethink what they believe is 'old' - as researchers have suggested that 60 is the new middle age.

The claim is made by Dr Sergei Scherbov, the world population programme deputy director at the International Institute for Applied Systems Analysis in Austria. He worked on a study of future population projections for Europe up to the year 2050, led by Professor Warren Sanderson of Stony Brook University in the United States.

Two hundred years ago, a 60-year-old would have been a very old person. With people living longer, healthier lives, age should not just be a number we reach but a reflection of the life we lead, according to the study.

Prof Sanderson said: "The onset of old age is important because it is often used as an indicator of increased disability and dependence, and decreased labour force participation."

Lisa Harris, head of communications at Saga, claimed that 'middle age' is most certainly a state of mind. "Retirement is no longer a cliff edge decision where we stop working purely because we've celebrated a birthday. Instead we change the way we work - often with the goal of achieving a more rewarding work-life balance that allows us to feel valued in the workforce for both the skills and experience we have to offer.

"It also gives us the opportunity to travel, take part in hobbies, volunteer and generally have a bit of fun too. It's not just about living long but ageing well!"

Give a Kidney would also argue that this is a time to reflect on what can be done, rather than what cannot be done... like giving a precious, life-saving gift such as a kidney?

Abridged from Lifestyle on-line magazine, April 2015

You're never too old to donate says 70-year-old organ donor



Trish Bailey was called "brave and generous" by friends after agreeing to give away one of her kidneys to someone on the NHS waiting list earlier this year. She doesn't consider herself a Good Samaritan as she and her late husband John both wanted their bodies to be used for science or transplants. But Trish - one of eight pensionable donors who recently met up to share stories - hopes her act will encourage other people to carry a donor card at the very least. She said: "I want people to know it's not difficult and you don't have to be young and fit. It's easy to donate and change someone's life."

Trish was given the all-clear to donate after going through a series of tests, scans and interviews at the renal transplant unit at Queen Alexandra Hospital. Her left kidney was removed in a three-hour operation and blue-lighted to the recipient, who may never know the identity of the donor.

"If you know the life of someone who's on kidney dialysis and see the change it makes when they get a kidney, you would understand," she added.

Petersfield Post, 16 October 2015

FAITH

and organ donation

Some people are not sure whether their religion would prevent them from agreeing to donate their organs after their death – yet all the major religions in the UK support the principles of organ donation and transplantation.

It is important that people from all backgrounds donate organs, as there is a much better success rate when transplants are carried out within the same ethnic group. Black and Asian people are three times as likely to need a kidney transplant as white people, so there is an even greater need for more black and Asian donors.

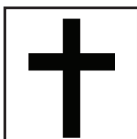
Buddhism and organ donation

There are no injunctions in Buddhism for or against organ donation. The death process of an individual is viewed as a very important time that should be treated with the greatest care and respect. Because the definition of the moment of death varies in different Buddhist traditions there are differing views as to the acceptability of organ transplantation. The needs and wishes of the dying person must not be compromised by the wish to save a life, and each decision will depend on individual circumstances. Central to Buddhism is a wish to relieve suffering and there may be circumstances where organ donation may be seen as an act of generosity. Where it is truly the wish of the dying person, it would be seen in that light.



Christianity and organ donation

The Christian faith is based upon the revelation of God in the life of Jesus Christ. Throughout his life Jesus taught people to love one another. It seems in keeping with this that Christians consider organ donation as a genuine act of love and a way of following Jesus' example. This act of love then becomes part of a Christian discipleship or faith journey that is motivated by compassion to help someone else and demonstrates a sense of social responsibility. Sacrifice and helping others are consistent themes in Christianity, which teaches the principle of seeking to do for others what you hope others would do for you, and Christians should be encouraged to help others in need. Discussing organ donation with family and friends is a responsible and thoughtful act.



How to give a kidney...

Here we go. Three easy steps:

- 1 Look up the charity's website to find out more.
- 2 Contact your nearest transplant unit for a visit and chat with the Living Kidney Donor Co-ordinator.
- 3 Do it. Whatever age and stage you're at. You will never regret it, and it may just be the best thing you ever do. More than 450 others have done and haven't looked back.

Each donation of a kidney to a stranger can enable and trigger **two or three more kidney transplants** – and each transplant that takes a person off kidney dialysis saves the NHS more than £20,000 a year.



Hinduism and organ donation

There are many references that support the concept of organ donation in Hindu scripture. Daan is the original word in Sanskrit for donation, meaning selfless giving in the list of the ten Niyamas (virtuous acts). Life after death is a strong belief of Hindus and is an ongoing process of rebirth. The law of karma decides which way the soul will go in the next life. Organ donation is an integral part of the Hindu way of life, as guided by the Vedas. That which sustains is accepted and promoted as Dharma (righteous living). Scientific treatises form an important part of the Vedas – Sage Charaka deals with internal medicine while Sage Sushruta includes features of organ and limb transplants.



Islam and organ donation

In 1995 The Muslim Law (Shariah) Council UK issued a fatwa (religious opinion) on organ donation. The council resolved to support organ transplantation as a means of alleviating pain or saving life on the basis of the rules of the Shariah. Muslims may carry donor cards, and the next of kin of a dead person, in the absence of a card or an expressed wish to donate their organs, may give permission to obtain organs from the body to save other people's lives. Normally, violating the human body, whether living or dead, is forbidden in Islam – but the Shariah believes this can be overruled when saving another person's life: al-darurat tubih al-mahzurat (necessities overrule prohibition). However, there is also a significant number of Muslim scholars who believe that organ donation is not permissible and individual Muslims



should make a decision according to their understanding of the Shariah.

Judaism and organ donation

In principle, Judaism supports and encourages organ donation in order to save lives (pikuach nefesh). This principle can sometimes override the strong objections to any unnecessary interference with the body after death, and the requirement for immediate burial of the complete body. As all cases are different, Jewish law requires consultation with a competent Rabbinic authority before consent is granted.



Sikhism and organ donation

Sikh philosophy and teachings place great emphasis on the importance of giving and putting others before oneself. It also stresses the importance of performing noble deeds and there are many examples of selfless giving and sacrifice in Sikh teachings by the ten Gurus and other Sikhs. Sikhs believe life after death is a continuous cycle of rebirth but the physical body is not needed in this cycle – a person's soul is their real essence. The last act of giving and helping others through organ donation is both consistent with, and in the spirit of, Sikh teachings.



For further information, see 'Organ donation and religious perspectives', a leaflet produced by NHS Blood and Transplant.

Contact us

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