

# Like Life

## Organ Donation Marketing and Campaigns Bulletin

11th Edition – February 2018

## Introduction

We're already one month into 2018, but we wanted to wish you a Happy New Year. We hope that you are looking forward to the year ahead.

This edition of the bulletin focuses on our current London campaign 'Words Save Lives' as well as the launch of the Government's consultation into an opt out organ donation system in England. We will also be sharing key awareness dates coming up this year that you can get involved with so we can continue working together to save and improve even more lives.

This bulletin is not only a fantastic opportunity for us to let you know what we're working on and our plans for the year ahead to support organ donation. It is also a chance for you all to share with others how you have promoted organ donation in your local community. Let others use your ideas as inspiration!

We'd love to hear from you with your stories or pictures of promotional activity so please get in touch with us via [marketing.comms@nhsbt.nhs.uk](mailto:marketing.comms@nhsbt.nhs.uk).

**The Marketing and Campaigns team, NHS Blood and Transplant**

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# 'Words Save Lives' campaign



In early January, we launched our 'Words Save Lives' campaign to encourage London residents to get talking about organ donation with those closest to them.

There are currently 1,336 people in London on the transplant waiting list, which means one in five people waiting for an organ transplant live in our capital city.

Six in ten people waiting in London are from black or Asian communities. As the most ethnically diverse population in the UK we could make a significant difference by stimulating conversations and increasing support for organ donation from all communities.

A key part of the campaign is a range of films we have developed, which highlight how it feels to be waiting for a transplant, the extraordinary difference organ donors make and the comfort organ donation can bring to grieving families. The films are available along with digital campaign assets on the [Promoting Donation Hub](#). Please share them online to spread the word across the country and help raise awareness.

One of those people waiting for a transplant is 30-year-old Londoner Jessica Harris, who features in our 'Waiting for Kevin' film. Jessica is waiting for a kidney transplant and is currently reliant on dialysis three times a week. The quirky title for the film comes from her naming the kidney she is waiting for, as a way of reducing the fear she feels about the process.

She says: "I think of Kevin as like a little pet I'm waiting for, rather than an organ!

"I was diagnosed with diabetes at the age of 13 and since then my life has always been about going back and forth to hospital. A life on dialysis isn't fun.

"I'm hoping that this transplant will mean that I can get back out there – work, travel, just do what normal 30-year-olds do."

A reluctance to talk about organ donation is contributing to a deadly shortage of organs and leaving families to make a difficult decision when someone they love dies. Many people do not understand why they need to share their donation decision with their family.

We need to make sure that every potential donor who wants to donate is not prevented from doing so due to a lack of awareness. Help us to get London talking.



*Jessica Harris who features in our 'Waiting for Kevin' film*

## Organ donation in the media



*Darren and Nicola Newnes and their children, Ellie and George.*

Nicola Newnes, a mum of two from Basildon in Essex, appeared on The One Show on 24th January to reveal how the show inspired her husband to save lives. A piece about organ donation they watched prompted her and her husband, Darren, to talk about the subject and he made clear he'd be happy to donate. He then went on to save five lives when he died.

Two months after the programme that got them talking, Darren unexpectedly collapsed and died following complications from a cyst on the brain, and Nicola told nurses he wanted to donate. Darren's heart, lungs, kidney, pancreas and liver went to people desperately in need of transplants. 50-year-old Nicola said: "We'd had a conversation a few months before he died while we were watching TV.

"There was an appeal on The One Show for more people to become donors and I just asked him if he'd do it if anything happened and he said, 'of course I would'.

"He helped give five people a chance at a new start in life and that's brilliant. I'm so proud of him."

Nicola and Darren's story was featured on The One Show in support of NHS Blood and Transplant's 'Words Save Lives' campaign. During the show there was a 251% rise in the number of people visiting the organ donation website compared to the same day the previous week. There was also 3,367 sign ups compared to just 200 during the same time the previous week.

# Opt out consultation launched

As you will be aware the Government's consultation into an opt out organ donation system was launched in December, and will continue until early March. According to the Department of Health the response so far has been excellent, with more than 10,000 people completing the online [survey](#).

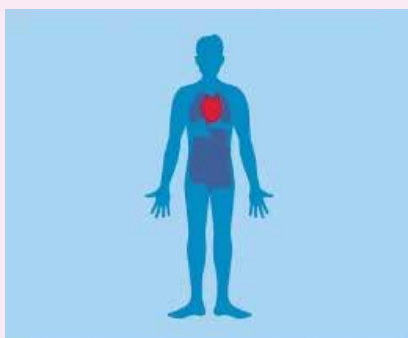
Many of you will have attended a recent Regional Collaborative meeting with a workshop on the consultation, and thanks for your participation come from Sally Johnson, Paul Murphy and Claire Williment. The outcome of the sessions at the collaboratives are being collated now to form part of NHS Blood and Transplant's formal response. A summary will be shared in due course.

Whether you attended a collaborative or not it's important that your views are heard. Many NHS and NHS Blood and Transplant employees have taken part in the consultation already which is very positive, and the Department of Health are looking to ensure there is high representation from the organ donation community. Do remember to have your say whether as a team or individual, and share the consultation link with family and friends to complete before time runs out on March 6th.

We are using the period of the consultation as an opportunity to encourage people to **join the national conversation**; we think that regardless of how the Government moves forward in implementing an opt out system in England people will still need to be talking to their families to ensure their decision is supported. In addition, we often see people are unsure of how to join the Organ Donor Register, or why it's important to talk to their family so we have been working on some educational content in the form of [animations and infographics](#) which we hope will help people understand how organ donation works.

Please feel free to share these with your local Communications teams and wider stakeholders, to keep the national conversation going during this important period for organ donation. We hope to continually provide additional content to help us work together to increase consent rates and the number of lives saved and improved by organ and tissue donation.

The video animations and infographics are available from the [Promoting Donation Hub](#). Download and share them to help promote organ donation.



Video

Organ donation Basics

**1. Intro**

*Why should I become an organ donor?*



Video

Organ donation Basics

**2. Sign up**

*How can I become an organ donor?*



Video

Organ donation Basics

**3. The donation process**

*How does organ donation work?*



# UK's first heart transplant – 50th Anniversary

On 3rd May 2018 we will be celebrating the 50th Anniversary of the UK's first heart transplant. Since the first operation in 1968, around 7,000 people are recorded as having received heart transplants in the UK. For most patients on the heart transplant waiting list, all other medical options have been exhausted, and a donated organ is their only hope.

In December 2017, we featured an article highlighting the number of people spending Christmas on the heart transplant waiting list, including real-life stories of people from three different perspectives.

Personal stories are extremely powerful for encouraging people to become organ donors. If you are aware of any appropriate stories from heart donors or recipients that could work at a local level to promote organ donation and coincide with the 50th anniversary then please contact the press office team at [story@nhsbt.nhs.uk](mailto:story@nhsbt.nhs.uk).

NHSBT's full press release about the UK heart transplant waiting list can be viewed [online](#).

## Teaching resources

The recent launch of the consultation into organ donation in England has sparked significant interest and debate about organ donation. We want to seize this opportunity to get everyone talking about organ donation. We need your support to encourage schools in your area to use our [free teaching resources](#) to educate 11-16-year-olds (key stage 3 and 4 students) about organ and tissue donation so they feel empowered to discuss the topic with their family and friends.

If you know any secondary school teachers please share the resources with them or download our [template letter](#) and send to schools in your local area to encourage them to introduce organ and tissue donation lessons.

We are always keen to hear feedback so we can continually improve our resources further. So, if you have shared the resources with teachers please encourage them to take a moment to complete our short online [survey](#).

Together we can help save even more lives.



# New adaptations of the 'Giving the Gift of Life' booklet



We have been working on creating two new adaptations of the 'Giving the Gift of Life' booklet we introduced last summer for hospitals to use in critical care family areas.

We are translating the book into seven different languages, with versions in Urdu, Arabic and Gujarati soon to be the first completed. Versions in Punjabi, Somali, Bengali and Polish will follow later. These versions will be available as downloadable PDFs that can be printed locally. We hope they will be a useful resource for specialist nurses to make available in family rooms in hospitals with a diverse patient population. They could also

be shared directly with families who have been approached but want more information about donation and transplantation.

Additionally, we have created a printed version of the original 'Giving the Gift of Life' booklet that will be more appropriate for use at promotional events.

It's now available to order [online](#) (item code OLC284). You can order one copy for use at promotional events, for example, when you have a stand and you want to have something available people can flick through to see the benefits of organ donation and transplantation.

We hope you will find these resources useful. For more information please contact [marketing.comms@nhsbt.nhs.uk](mailto:marketing.comms@nhsbt.nhs.uk).

## Celebrating five years of the Order of St John UK Award for Organ Donation

More than 4,000 families have accepted a posthumous honour for their loved one since the introduction of the Order of St John UK Award for Organ Donation in 2013.

Families can choose to accept the honour on behalf of the donor either in person at a special ceremony or by post.

Since the award was set up, we have seen an increasing proportion of families choose to attend one of the Order of St John award ceremonies taking place across the UK.

Many families who receive an award wish to promote their loved one's donation and that they have received the honour on behalf of their family member. This media coverage is important to normalising donation and showing the pride many donor families feel when a loved one has saved and transformed lives.

Each year colleagues across NHS Blood and Transplant and staff and volunteers at the Order of St John work incredibly hard to ensure that the award ceremonies run smoothly. Thank you for making the awards so special to so many families.



*Tom Wilson's sister, Philippa, and Mum, Lisa, accepting the Order of St John Award on his behalf in 2016*

## Donor family Gold Heart Pin badges



Organ donors save and improve thousands of lives and offer hope to all those on the Transplant Waiting List. The support of the donor's family is an act of altruism which takes place without reward or recognition. While the gift made by the organ donor themselves has quite rightly been recognised through the posthumous Order of St John Award for Organ Donation the generosity of the donor family until now received no such acknowledgement.

From February 2018, all families who agree to organ donation will now receive a new Gold Heart Pin, to acknowledge and thank donor families for their unique role in saving lives.

The pin was inspired by the Gold Star Pin awarded in the USA to families who have lost a loved one in the service of the nation. These 'Gold Star Families' are respected and honoured for their sacrifice and are proud to wear their pins. The ambition is that over time the Gold Heart Pin will become recognised in the UK and that donor families will wear their pins with pride as recognition of their part in saving lives. Specialist Nurses – Organ Donation will be offering the Pins to the close family of their organ donors; the pins will then be sent out accompanied by a certificate of thanks hand signed by Anthony Clarkson, the Chief Nurse for Organ Donation and Transplantation at NHSBT. The Gold Heart pins use the stylised heart design we all know as the symbol of organ donation and the pink pin all supporters wear; however the Gold Pin is slightly larger to reflect the greater role of the wearer in supporting organ donation.

Nothing can ever truly thank a donor family for their decision to support organ donation. If over time the Gold Heart Pin is seen as an indicator that the wearer has made the selfless decision to help their relative donate then it can perhaps give these extraordinary people the recognition they so richly deserve. In doing so it will hopefully inspire others to consider organ donation and share their donation decision, offering even more hope to those who wait for a transplant.

## Look out for our partnership with [Moonpig.com](https://moonpig.com)

We're really excited that we're working with [Moonpig.com](https://moonpig.com) on a series of limited edition Valentine's cards to help people share their decision to be an organ donor with their loved ones.

Valentine's is a great time for people to tell their partner that they love them. But thanks to this initiative, it could also be a great opportunity for people to tell their partners that they want to save lives as an organ donor.

In addition to the limited edition cards, [Moonpig.com](https://moonpig.com) will be encouraging people to sign up to the NHS Organ Donor Register.

The details on this initiative are still under wraps so keep it to yourselves. But keep an eye out on the [Moonpig.com](https://moonpig.com) website in the days leading up to Valentine's so you can order your card for someone special. And obviously, please help promote the initiative through your own social channels after it launches **on 7th Feb. But until then, please don't tell anybody about it and obviously don't mention it on social media as we don't want to jeopardise the launch.**

Thanks [Moonpig.com](https://moonpig.com) for helping to save lives!

moonpig





# Promoting organ donation throughout the year

We are aware that many of you hold promotional events for organ donation throughout the year. Promotional events are a fantastic way to reach out to the local community, encourage people to register and talk about organ donation.

We would encourage you to consider awareness days when planning your events and ways in which you can link in with the local media. An example of this is World Kidney Day which takes place on 8th March 2018. It's a great idea to promote organ donation when there is increased noise around the subject.

Here are some examples of previous articles in the press that have been driven at a local area to promote organ donation during awareness days/weeks; [World Sight Day 2017](#) and [World Kidney Day 2017](#).

If you're planning activity in your local area, you can find some tips and guidance on our [Promoting Donation Hub](#) or for specific queries please contact us via [marketing.comms@nhsbt.nhs.uk](mailto:marketing.comms@nhsbt.nhs.uk).

Remember we also have content focussing on certain awareness days including videos and stories on our social media channels that you can share to help spread the word!

## Here are some key awareness days/weeks for your diaries:

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**8th March**

**World kidney day**  
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**19th March**

**Mother's day**  
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**3rd May**

**50th anniversary of the UK's first heart transplant**  
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**14th – 20th May**

**Dying matters awareness week**  
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**17th June**

**Father's day**  
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**5th July**

**NHS 70 – Celebrating 70 years of the NHS**  
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**1st September**

**World letter writing day**

.....  
**3rd – 9th September**

**Organ donation week**  
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**29th September**

**World heart day**  
.....

**12th October**

**World sight day**  
.....

**28th October**

**Make a difference day**  
.....

**11th – 18th November**

**Interfaith week**  
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**14th November**

**World diabetes day**  
.....

**15th November**

**World COPD day**



# Save the date – Organ Donation Week 2018

We are delighted to announce that our annual Organ Donation Week campaign will be running from **3rd – 9th September 2018** so please make a note in your diaries.

We will be in touch with updates once we have confirmed the theme of the campaign and how you can get involved.

In the meantime, if you have any ideas for this year's campaign to get people talking about organ donation, we would love to hear from you so please get in touch with us via [marketing.comms@nhsbt.nhs.uk](mailto:marketing.comms@nhsbt.nhs.uk).



## Organ donation conversations on the rise



Since the launch of the Behaviour Change Strategy for organ donation, we have carried out a survey twice a year to review public attitudes and actions towards organ donation.

The survey is nationally representative of residents in England so reflects the different demographics within the country.

For the first time since we launched the strategy and the survey, we have seen a positive shift in the percentage of the population who have had a conversation about organ donation against the baseline survey (44%). In the latest survey 47.5% of people told us that they have had a conversation about organ donation. We hope that this is a sign that the work we are

all doing in the organ donation community to emphasise the importance of people talking about donation is starting to have an influence.

We would like to thank you for the contribution you have made to encouraging conversations, by taking part in campaigns, Organ Donation Week activity, working with your local Trust communications teams and the media, and supporting and running local campaigns and events. This collaborative work is really helping to make a difference and ultimately contributing to saving lives.

# Get in touch and who's who:

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Please get in touch with us to let us know about any activity that is taking place in your area. Any information received from you, or the Communications leads in your hospitals will help us work more closely together and share the magnificent work that is being done to promote organ donation.

**For further information relating to this bulletin or if you have anything to contribute to the next bulletin please contact [marketing.comms@nhsbt.nhs.uk](mailto:marketing.comms@nhsbt.nhs.uk).**

The members of the national Organ Donation Campaigns team are listed below.



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