

# Like Life

## Organ Donation Marketing and Campaigns Bulletin

Spring Edition – April 2019

## Introduction

Welcome to the 1st edition of the Like Life Bulletin of 2019! It is only April and yet there is so much to update you on and share the great work of the wider team over the last few months.

Due to the change around the law in England, Organ Donation is a hot topic right now. This bulletin aims to update you on the latest information, and the campaign we're launching soon. We'll also be sharing some fantastic events that have taken place and give you an update on the ongoing schemes running to promote organ donation.

As ever, we'd love to hear from you with your stories or pictures of promotional activity. Let others use your ideas as inspiration 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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# Change in the law around organ donation in England gets closer

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You will no doubt be aware by now that the law around organ donation is set to change in England.

From spring 2020, all adults in England will be considered to have agreed to be an organ donor when they die unless they had recorded a decision not to donate or are in one of the [excluded groups](#).

This is commonly referred to as an 'opt out' system. You may also hear it referred to as '[Max and Keira's Law](#)'.

These changes aim to increase the number of donated organs that save and improve the lives of those in need of a transplant.

The Organ Donation 'deemed consent' Bill progressed smoothly through the House of Commons and House of Lords and received Royal Assent on Friday 15th March. Royal Assent turns a Bill into an Act of Parliament or law.

To make sure we prepare operationally for the new system and that people in England are aware of the changes and the choices they can make, the 'opt out' system won't be implemented until spring 2020.

Later this month we will be launching a public information campaign in England to inform people about the changes and the choices available to them.

Organ donation is an act of great generosity, and people will still have a choice whether or not they want to donate under the new system, and families – who provide vital information – will still be approached before organ donation goes ahead.

Any change like this can be confusing to people and you may have seen or heard some 'fake news' yourselves about the planned changes. Some you may have come across are:

- The 'opt out' system is already in place
- The Government is taking control of people's organs
- Families will be ignored once the system changes.

Public trust is absolutely crucial. So, it is really important that everybody in the organ donation and transplantation community works together to get across accurate information about the new law around organ donation.

Many of the commonly asked questions are answered on our website, so please take some time to familiarise yourselves with the key information about the changes.

The following two pages are probably the best places to start:

- <https://www.organdonation.nhs.uk/opt-out/>
- <https://www.organdonation.nhs.uk/opt-out-faq/>

We will have information leaflets and campaign resources such as posters available for after the campaign launch, and we will provide you with further information about the campaign as soon as it's available.

The law around organ donation is also changing in Scotland, the Channel Islands and Isle of Man. There are no plans to change the system in Northern Ireland.

To find out more about the situation elsewhere across the UK, Channel Islands, and Isle of Man, visit: [www.organdonation.nhs.uk/uk-laws](http://www.organdonation.nhs.uk/uk-laws)

## NHS Blood and Transplant collaborates with the Greater London Authority (GLA) at London City Hall to promote donation.

On Thursday 7th February NHS Blood and Transplant ran a promoting donation event at London City Hall in partnership with the Greater London Authority. Through this event we aimed to raise awareness of the health inequalities that exist in all forms of donation including organ donation and gain the support of key health figures across the capital such as Mayor of London, Sadiq Khan.

We need to increase the number of organ donors who come from black, Asian, mixed race and minority ethnic backgrounds. People from black and Asian communities are more likely to develop high blood pressure, diabetes and certain forms of hepatitis than white people. This makes them more likely to need a transplant. Three in ten (31%) of people waiting for a transplant across the UK are from a black, Asian or minority ethnic background.

Unfortunately, people from these communities are likely to wait longer for an organ transplant with those waiting for a kidney transplant typically waiting six months longer than white people. Over a third of people (35%) waiting for a kidney are from these backgrounds.



Mayor of London, Sadiq Khan attended the event and spoke to our organ donor ambassadors Jay and Sina Patel and Prafula Shah, who ran the organ donation stand on the day. For more information, see the article on the organ donation Ambassador programme (Page 9).

Prafula Shah said - "It was really great that City Hall staff and London local government supported the fantastic work being done by so many organisations and the Mayor was really interested in learning more about organ donation within London and challenges faced by some communities."

The event was attended by many other prominent figures including Dr Onkar Sahota, the Chair of the London Assembly Health Committee; London Assembly Members, London MPs Helen Hayes (Dulwich and West Norwood) and Neil Coyle (Bermondsey and Old Southwark) and Councillors and Chief Executives from the surrounding London Boroughs.

During the day a blood donation session was held and 30 people donated, all of whom were new donors including the Mayor of London, Sadiq Khan. Around 65 'What's Your Blood Type' tests took place throughout the day which help to identify a person's blood type.



*Jay and Sina Patel with the Mayor of London, Sadiq Khan and Prafula Shah*

# Stratford-upon-Avon donor town project

On 24 January a launch was held to mark the beginning of a year-long organ donation campaign by TV celebrity chef and personality Sally Bee. Sally, who lives in Stratford-upon-Avon is a heart patient with a very rare condition called spontaneous coronary artery dissection (SCAD.) She has survived five heart attacks and is a passionate ambassador for organ donation. She set up the campaign with the aim of harnessing the town's community to promote, support and save lives through organ donation.

The campaign, called 'The Donor Town Project' aims to increase the number of people who make their donation decision known to their loved ones and sign the NHS Organ Donor Register. It's hoped that after 12 months the title of 'Donor Town' will be passed on to a different town, and Stratford's project team will support the future town by sharing their knowledge and experience.

The campaign is calling upon schools, businesses and organisations based in Stratford to get involved, by displaying posters in shop windows, sharing information and starting conversations about organ donation. The website [www.donortownproject.uk](http://www.donortownproject.uk) has useful action packs to download. Since the launch they've signed up their first 'ambassador' business, a radio station and a school. The town council are on board, local groups and community leaders too.





# The Paediatric and Neonatal Deceased Donation Strategy

NHS Blood and Transplant's first ever Paediatric and Neonatal Deceased Donation Strategy launched in early March.

The number of child organ donors has stayed the same over the last decade and the plan aims to increase the number of donors to help save more lives, because some children are relying on younger donors for the transplant they need.

More than 45 media outlets covered the launch of the [strategy](#), including national broadcast and print press, with a media reach of nearly 70 million.

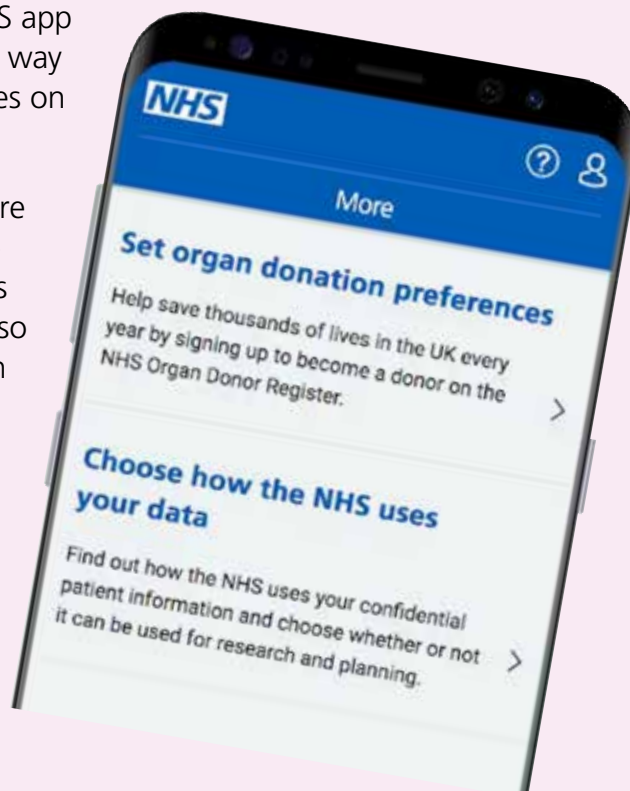
The plan was presented to clinicians at the joint British Transplantation Society and NHS Blood and Transplant Congress later the same week. We will be working together with hospitals to implement the recommendations of the strategy over the coming months and years.

## NHS App

NHS Digital and NHS England launched a free NHS app at the end of 2018, providing a simple and secure way for patients to access a range of healthcare services on their smartphone or tablet.

The new NHS app will give patients safe and secure access to their GP record. As well as being able to make GP appointments, order repeat prescriptions and manage long-term conditions, patients will also be able to state their preferences relating to organ donation and end of life care. The early version of the app is available through the App store or Google Play. The app is being rolled out to GP surgeries across England over the summer.

*NHS App with Organ Donation links*



# Living donation activity

Working with our colleagues in Scotland, Northern Ireland and Wales we ran a week of activity from Monday 11th – Sunday 17th March to promote living donation as a UK-wide initiative, to encourage people to consider donating a kidney during their lifetime to transform someone's life. World Kidney Day was also recognised as part of this week on Thursday 14th March.

The week itself was a huge success and saw lots of great content being shared across social media and in the media. Several living donors and recipients shared their personal experiences to help drive home the positive impact living donation can have on transforming the lives of people waiting for a life-saving kidney transplant.

We arranged a social media takeover, posting a number of real-life stories, videos and myth busting posts to encourage people to find out more about living donation. We achieved strong and positive press coverage, both print and online, across the UK.

Our initial national media story focussed on celebrating the imminent 1,000th living donation transplant to take place as part of the UK Living Kidney Sharing Scheme, which was reached in time for World Kidney Day. The story was covered by Mail Online, Channel 5 and ITV news, in addition to several regional media outlets across the UK.



We also received significant support from our charity and healthcare stakeholders who helped us spread the word by sharing our living donation content and key messages across their own channels. Stakeholders including Birmingham City Council, Cumbria Country Council, Imperial NHS Hospital, Give a Kidney charity and Kidney Research UK contributed to 123 social media posts about living donation, with a combined reach of 430,000 users. Members of Parliament including Rupa Huq, Julie Elliot and Mims Davies also posted about living donation on their Twitter pages during the week.

We need your support to continue spreading the word about living organ donation to encourage more people to consider becoming a living donor. We have lots of information available on our website [here](#), including downloadable social media graphics, videos and posters, which you can use directly on your own channels to help us spread the word!

An NHSBT funded initiative to support engagement with living kidney donation with a focus on communities that do not typically engage with this type of donation will be launched this month. Watch this space for further updates. For more information contact [Lisa.burnapp@nhsbt.nhs.uk](mailto:Lisa.burnapp@nhsbt.nhs.uk)

## Viewers watch live kidney transplant

Hundreds of thousands of viewers of Channel 5's Bafta-nominated Operation Live watched in awe as Eugene McDanart received a life-transforming kidney from his father Daniel on Tuesday 8th April.

Viewers watched the highly skilled transplant team at the Royal London in Whitechapel perform the operation.

The televised surgery saw Daniel's kidney transplanted into his son. In advance of the live operation, Consultant transplant surgeon Rajesh Sivaprakasam told the Evening Standard that he hoped the broadcast would demystify the surgery, educate viewers about the impact of kidney failure and increase organ donations.

Melissa Thermidor, social media manager at NHS Blood and Transplant said: "It was great seeing such a positive reaction on social media during the broadcast of Eugene's operation. On the evening of the programme, more than 250 people posted on twitter about #OperationLive and there were more than 400 visits to the living donation pages on our website. This demonstrates what a positive reaction the programme had, and we hope many people inspired by the programme will find out what's involved in living kidney donation."





# Organ Donation Ambassador Programme

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NHS Blood and Transplant has launched a new, national Organ Donation Ambassador Programme aiming to empower volunteers to deliver impactful messaging about organ donation across UK communities. The organ donation ambassadors are donor family members, transplant recipients, living donors, patients awaiting a transplant, or other passionate individuals trained to present on the subject of organ donation. They help individuals join the NHS Organ Donor Register and encourage vital family conversations on the subject.

The programme was piloted in the Midlands and London with 30 organ donation ambassadors coming on board to help promote organ donation and transplantation. Every volunteer attends an all-day workshop to receive training on key messages, managing promotional stands and talks, and how to effectively engage with the public on the sensitive subject of donation.

During the programme's pilots, from August to October 2018, ambassadors volunteered approximately 165 hours at 31 promotional activities in the two regions. These volunteers reported more than 1,500 meaningful conversations with members of the public and more than 700 instances where the person they spoke with understood and committed to having a donation conversation with their family. There were also approximately 500 sign ups to the NHS Organ Donor Register at these events.

Alongside statistics, key messages, and calls-to-action, the most powerful aspect of the programme are the stories and experiences that each ambassador shares:

- Debra received a double lung transplant and relishes in her new lease on life.
- Prafula donated a kidney on behalf of her niece through the Kidney Sharing Scheme.
- Maz received a life-changing kidney transplant allowing him to come off of dialysis
- Jay and Sina Patel, who's loving son Aari tragically died at 3½ years old and went on to donate 7 organs, saving the lives of others.

Each ambassador has a powerful story to tell, and experiences that drive passionate advocacy for living and deceased organ donation and transplantation.

The active Ambassadors now support requests for talks on organ donation and promotional tables at events, in addition to playing a key role in other grassroots marketing efforts, campaigns, and NHS Blood and Transplant initiatives. The programme will be further rolled out across the UK in 2019 and 2020, beginning with the northern regions of England, and then proceeding through the rest of the country before the programme will be adapted to run in other countries as needed.



If you are interested in updates on future recruitment for the organ donation ambassador programme, please email [Ambassadors.ODT@nhsbt.nhs.uk](mailto:Ambassadors.ODT@nhsbt.nhs.uk) to express your interest and include the region of the country in which you live so we can inform you when the programme is coming to your area. Interested in requesting an ambassador to give a talk or host a promotional stand?

If you are in the London or midlands regions you can now email your request to [Ambassadors.ODT@nhsbt.nhs.uk](mailto:Ambassadors.ODT@nhsbt.nhs.uk).



*Organ donation ambassadors Bharat and Avril Patel at a recruitment event*

# Promoting organ donation in BAME and faith communities

In September 2018, NHS Blood and Transplant invited organisations from across England and Wales to apply for funding to carry out projects to promote deceased organ donation within black, Asian and minority ethnic communities.

This BAME Community Investment Scheme is an important element of the Government's BAME campaign led by NHS Blood and Transplant. As you are probably aware there have been repeated calls from organisations and in external reviews for NHS Blood and Transplant to fund grassroots engagement work. We hope that community-driven projects will help break down barriers towards organ donation after death among black, Asian and minority ethnic communities.



*Successful applicants with advisors at the launch day in December 2018*

We received 40 applications for funding from across England and Wales and an independent judging panel assessed them. This panel consisted of colleagues from the Department of Health and Social Care, the Welsh Government, NHS Blood and Transplant, the National BAME Transplant Alliance, clinical staff, a donor family and recipients.

The panel agreed to fund 25 different projects. These cover a range of geographic areas as well as faiths. Organisations representing Jain, Sikh, Hindu, Muslim, Swahili, black and Asian Christians, black African and Caribbean and multi-faith groups were among the successful bidders from a field of 40 applications.

The organisations are now preparing to launch their projects which will reach people across London, the midlands and the north west of England, as well as in Cardiff, Bristol, Leeds and Newcastle.

The projects vary and include awareness events and workshops, outreach activity at community and faith gatherings, information leaflets, videos and films, and online and social media campaigns.

The organisations leading the projects are supported by advisors from the judging panel and will evaluate their work after the projects have finished in the summer. This insight will help understanding around the different approaches that can be taken to break down barriers towards organ donation.

## How can SNODs help?

We have already been in touch with those of you who have a funded project in your area and may be asked to help provide information on organ donation process, linking up with donor families or members of the wider organ donation or transplant team or to attend community events. If you have any further questions or concerns regarding the scheme or the projects within your region, please email [community.funding@nhsbt.nhs.uk](mailto:community.funding@nhsbt.nhs.uk).

## Inspiring more black, Asian and minority ethnic donors

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As part of the Government's campaign to increase the number of donors for organ donation who come from black and Asian backgrounds, we have recently run a burst of advertising to encourage and inspire more people to consider and discuss organ donation.

From the 18th February until 30th March, we ran four different videos on Facebook and Instagram that aimed to emotionally engage people through real life stories and normalise donation through hearing from people who support organ donation. The real life stories include Aari, Hilaria and Anaya, all of which can be found on our [You Tube channel](#).

At the same time, we ran adverts on digital radio (DAX) and specific radio stations that have a high proportion of BAME listeners (Capital Xtra, Sunrise, Lyca, Dilse and Panjab).

We have also sponsored a podcast, Romesh Ranganathan's, Hip Hop Saved My Life. The advert trails were recorded by the podcast host which means although they used our key messaging, they spoke to the audience in a way that is more likely to resonate especially as they are considered a trusted voice by the listeners.

You can find out more about the campaign [here](#).



# Get in touch and who's who:

Please get in touch with us to let us know about any activity that is taking place in your area. Or share a [Spotlight story](#). 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).**

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