



Blood and Transplant

Media Release

For immediate release

Hindu and Jain communities show support for organ donation this Diwali

A special message on organ donation is being sent by Hindu and Jain community leaders and patients during this year's Diwali festival.

The Hindu and Jain communities have shown their positive support for organ donation and welcome the introduction of the change in the law which comes into force next year in England and Scotland.

Kirit Modi, Chair of the Jain and Hindu organ donation (JHOD) steering group said: "I am delighted that Hindu and Jain community leaders, donor families and patients are sending powerful messages about organ donation this Diwali. We are also launching a [Diwali video](#) which consists of an amazing story from Shivum and Shyamal Kakkad about their father recently donating his organs when he passed away. I urge everyone celebrating Diwali this year to think about organ donation and help save lives."

In 2018/19, there were 149 Asian organ donors in the UK; 83 were living kidney donors and there were more Asian deceased donors than ever before, with 56 people giving the gift of life after death.

But there were still 1006 people from Asian backgrounds waiting for an organ transplant. This shows the urgent need for more Asian organ donors. Most Asian patients receive transplants from white donors, but in reality, for many



the best blood and tissue match would come from a donor of the same ethnic background, meaning a better outcome for the patient.

Millie Banerjee, Chair of NHS Blood and Transplant said: “Diwali is a time of kindness and reflection where we acknowledge the good deeds done for others. Hindus believe in sewa – selfless service – and what better selfless service than donating your organs after death to someone in need of a transplant? Every day across the UK someone dies waiting for a lifesaving organ transplant and people from BAME backgrounds wait longer than white patients for a kidney transplant, the most transplanted organ. Often the best match comes from a person of the same ethnicity so I would encourage everyone this Diwali to consider organ donation and speak to their families about their decision to be a donor.”

While being an organ donor is down to individual choice, it is concerning that the majority of people who have recorded an ‘opt out’ decision are BAME*. Given that the best transplant outcome is often from being matched with someone of the same ethnic origin, this could further impact patients in need of organ transplants from their community. Many have voiced concerns over the process itself, or whether their faith or beliefs will be respected, so NHS Blood and Transplant is encouraging people to find out more about the organ donation process and about the position of their faith or belief system on organ donation.

Lord Jitesh Gadhia supports the work done to encourage Hindus and Jains to find out more about organ donation, make a decision and share their decision with their families. He said:



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“Diwali is a time to celebrate the victory of good over evil and the rise of a new dawn. This year also marks the 150th birth anniversary of Mahatma Gandhi. His commitment to humanity is encapsulated by two powerful quotes: *‘To give pleasure to a single heart by a single act is better than a thousand heads bowing in prayer’* and *‘There are two days in the year that we cannot do anything – yesterday and tomorrow.’* So, this Diwali, I would urge everyone to follow Gandhiji’s inspirational words and sign up today to organ donation and give the ultimate gift of life.”

From spring 2020 in England and Autumn 2020 in Scotland, everyone will be considered as having agreed to donate their own organs when they die unless they record a decision not to donate or are in one of the excluded groups. This system was introduced in Wales in December 2015 and in Jersey in July this year.

Families will still always be involved in organ donation, so it is vital that they know what your choice is. Anyone who has also registered as an organ donor and made it clear that their faith must be considered as part of the organ donation process will have that decision honoured.

In the lead up to the change in law, NHS Blood and Transplant is urging families across England to talk and share their decision. If the time comes, families find the organ donation conversation much easier if they already know what their relative wanted.

Hindu and Jain communities are actively involved in explaining the change in law and have developed [special videos](#) and leaflets aimed at their communities.



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Find out more and register your decision by visiting NHS Organ Donor Register at www.organdonation.nhs.uk and share your decision with your family.

Ends

- For additional information please contact Pam Pye at NHS Blood and Transplant by calling 0151 268 7205 or emailing pam.pye@nhsbt.nhs.uk or Kirit Modi at the National BAME Transplant Alliance kiritmodi1@hotmail.com. Alternatively, call the NHSBT press office on 01923 367 600 or email pressoffice@nhsbt.nhs.uk
- For urgent out of hours enquiries please call: 0117 969 2444

*In 2018/19 2% of those registering as a donor and providing their ethnicity when doing so, told us they were of an Indian background, compared to 6.9% of those opting out.

Notes to editors

- NHS Blood and Transplant is a joint England and Wales Special Health Authority. We provide the blood donation service for England and the organ donation service for the UK. We also provide donated tissues, stem cells and cord blood. We are an essential part of the NHS, saving and improving lives through public donation.
- It is quick and easy to join the NHS Organ Donor Register. Call 0300 123 23 23 or visit www.organdonation.nhs.uk
- Families are always involved in organ donation discussions. You can make things easier for your family by telling them you want to donate.
- Every day across the UK someone dies waiting for an organ transplant



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- Anyone can join the NHS Organ Donor Register, age and medical conditions are not necessarily a barrier to donation.
- One donor can save or transform up to nine lives through organ donation and save and transforms even more by donating tissue.

From spring 2020, all adults in England will be considered to have consented 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. Adults covered by the change will still have a choice whether they want to be an organ donor and their families will still be involved before organ donation goes ahead.

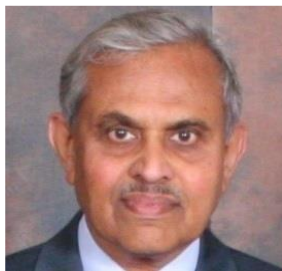
Diwali Messages from Community Leaders:

Yatin Dawada, President, Lohana Community North London (LCNL)



“On this auspicious occasion of Diwali, I wish you and your family a very Happy Diwali and a prosperous Hindu New Year 2076 from the LCNL. Diwali is a festival of new beginnings and the triumph of good over evil, and light over darkness. As we mark the most important festival of the year for Hindus, why not consider organ donation to brighten up someone’s life.”

Manhar Mehta, Chairman, Vanik Council UK



“On this auspicious occasion of Diwali, my appeal to the Jain Community is to “give a gift and pledge for organ donation after death to save someone’s life.”

Bharat Patel, Organ Donor Lead, Jalaram Charitable Trust, Leicester



“With blessings of Pujya Jalaram Bapa, I wish everyone a happy Diwali and prosperous New Year. In the UK there is a desperate need for BAME organs, where they form thirty one percent of the waiting list.

Only one percent are registered donors. This is not acceptable. Societies need to respond and you can do something special this Diwali by joining the register. Remember you may need an organ one day.”

Prafula Shah, Living Kidney Donor and Secretary, Bhakti Mandal UK



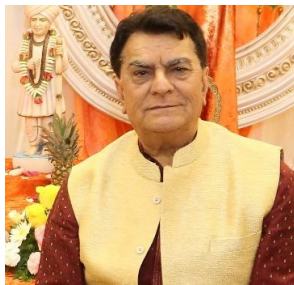
“Diwali is a time to celebrate and spread light. This Diwali – let’s ‘light up a life’ by registering to become an organ donor. This will bring rays of hope to those waiting for transplants.”

Pramod Thakkar, Chairman and Trustee, **Jalaram Charitable Trust**, Leicester



“On the auspicious occasion of Diwali & New Year my message is to follow “Puja Jalaram Bapa’s” preaching’s of serving fellow human beings by taking part in ang daan (organ donation). Join the NHS Organ Donor Register. Donating an organ is the ultimate gift mankind can give to a fellow human being.”

Narendra Thakrar, Executive Chairman, **Shri Vallabh Nidhi UK (SVNUK)**



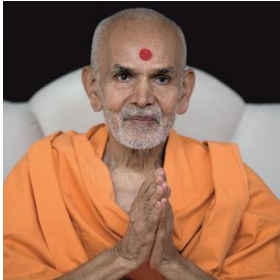
“Diwali is not only a time to share joy and happiness amongst our friends and family, it is also a time to reflect on how blessed we are and give thought to those less fortunate than ourselves.

We at SVNUK would like to wish you all a Happy Diwali and urge all our community members to lift the taboo and help raise awareness and support for organ donation.

This Diwali, join the NHS Organ Donation Register and give the gift of life to someone who is in need of your help.”

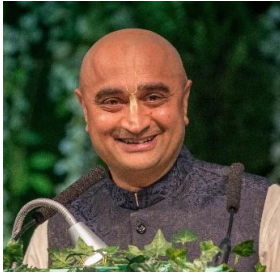
Diwali Messages from Religious Leaders:

Sadhu Yogvivekdas, Head of BAPS Shri Swaminarayan Mandir, London



"Diwali is a time of joyous festivities, and as Pramukh Swami Maharaj taught, what better way to find joy than in helping others! Please join the NHS Organ Donation Register."

Nila Madhav Das, ISKCON, Bhaktivedanta Manor, Hare Krishna Temple, Watford



"The giving of charity is very much instilled within our culture. "Anga daan" (donation of organs) is indeed the one of the highest form of daan one can give. Support the deemed consent campaign!! Hare Krsna."

Mahendrabhai Pandya, Chief Priest, Jalaram Mandir, Leicester



"During the festive season of Diwali this year we have to learn to serve fellow human beings. By registering on the NHS Organ Donor Register and becoming an organ donor you can give a new lease of life to someone by giving them a second chance in life to live their lives. Blessings from Pujya Jalaram Bapa."

Real Life Stories on Organ Donation:

Shivum Kakkad, Son of an Organ Donor

An Inspirational Story of Organ Donation with the Passing Away of a Beloved

"It was about 6.30 in the morning on a bank holiday earlier this year, where my mother woke up to dad gasping for his life. First thinking he was snoring, then realising he couldn't breathe, she called for me, as I ran in to find my dad taking his last breath.

He had been to a concert the night before, singing away with his friends and having a great time. He had walked the dog and went to sleep as normal, but that one morning changed all our lives in an instant. I administered CPR and within minutes the paramedics were there, but it was a long time before they could get his heart going again.

Once at the hospital doctors couldn't tell immediately what had happened. It wasn't a heart attack or a stroke and there wasn't a clear reason. Dad was only 63, healthy, his arteries clear, heart healthy, brain healthy, fit and active. This was a man who never smoked, hadn't drank alcohol in 30 years, was vegetarian and loved sports. Initially doctors wanted to get him on a path to recovery before investigating further, but things went wrong when trying to take him off life support – it seemed that he was unable to support himself.

After some days and doctors doing everything they could, what had happened started to become clear. There was a blood clot in dad's heart, and on that morning the clot was in the wrong place at the wrong time and dad suffered a cardiac arrest. When using the defibrillator to start his heart again, the clot broke down and travelled up to his brain when his blood started flowing again – this led to him suffering hundreds of tiny strokes throughout his brain. This left him with no chance to survive.

For us as a family, it was the most surreal and difficult time we have ever been through – your lives are turned upside down in an instant. We didn't even have a chance to speak to him. It was heart breaking and it was hard to understand – nothing made sense, there was no reason for this, and we had nothing to blame. But it seems the only thing that did make sense to us was, organ donation.

When the doctors sat us down to give us the news that there were no options left, we raised the topic of organ donation ourselves. Some of us in the family are already on the register and so when the time came, we had the conversation amongst ourselves without hesitation. Dad was not on the register and we had not had a conversation as a family before, but it was the person he was, his faith and beliefs that made us feel we had made the right decision.

We are Hindu, he would visit the temple every Sunday, go to festivals and volunteer and provide support at community events. In fact, only in February this year Dad went to India to help support a charity in giving free cataracts operations for children. He believed in Seva Daan, he believed in giving and supporting those that needed it. Most of all he believed in just being a good person. Organ donation was his last and most giving act and we could not be prouder of what he has done. Through his donation, a man in his 60s and a woman in her 50s have received kidneys, both of which were waiting for over a year, and it will have dramatically changed their lives. He also donated his corneas, some tissue and blood vessels – all that will go on to help more people.

The specialist nurseries were amazing throughout and give you so much support before, during and after. There is no pressure, no stress and everything is up to you as a family. It really is an incredible system that put us at the centre of it and made us feel in control.

I really encourage you all to go back and have this conversation with your families, friends and colleagues. Our community needs support in making a change – in helping to save people's lives. No faith, no religion and no community are against it, but in the end it's a personal choice, so have your say, talk to people and make a change."



Kurran Mehta – Organ Donor Saving Four Lives

The mother of 19 year-old Kurran, Pragna Mehta-Patel, fulfilled his wishes by donating his organs following a fatal car accident. He saved multiple lives with the gifts he gave and has inspired many others to sign up to save lives.

Kurran was always a giver and signed up for organ donation when he applied for his provisional driving licence. His mum did try to change his mind as she felt he was too young to sign up to donate his organs. However, when the unthinkable happened, out of this unimaginable tragedy, something positive happened as Kurran's gifts helped save four lives.

Now, his mum Pragna is helping to raise awareness of organ donation within the Asian community to help others live better lives.



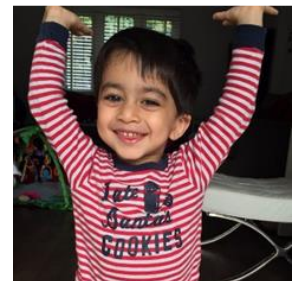
Aari Patel, Organ Donor of Seven Organs - Saving the Lives of Two Children

Aari Patel sadly died in 2016 when he was three, following an accident at home. Aari's parents Sina and Jay Patel made the decision to donate his organs which saved the lives of two children – a boy and a girl – who were in dire need of a transplant.

"If Aari couldn't be helped any further, Sina and I felt strongly that we wanted Aari to help others. We did not want another family to suffer losing their child or loved ones

As parents we are proud of Aari, we never tire of talking about him. Too many people say no to donation because they think their faith prevents it.

There are myths and misunderstandings. We must talk more about the subject with those we love, family and friends, young and old. If more people in our communities supported organ donation, more lives in our communities would be saved." **Thoughts of Jay and Sina Patel, Father and Mother of Aari Patel**



Rohit Shah, Organ Donor

Rohit Shah, a father of four young children, died from a fatal heart attack in his early 50s. He had discussed the idea of organ donation with his wife Bharati and his children previously and so they were aware of his wishes.

Once it was confirmed that he would not survive the heart attack, his family talked about organ donation with the medical team dealing with his case. Their questions were answered clearly and the process of organ donation was explained to them, including washing and dressing the body and the final funeral rites. His family were fearful but able to make a decision to donate his organs based on clear information given to them at the hospital.

His final journey was a traditional Hindu/Jain funeral with full rites and although the family miss him very much, they know his act of kindness has saved lives – his kidneys, lungs and corneas were donated.

Jyoti Jadhav, Patient with Kidney Failure - Waiting for an Organ Donation

“I’m on a journey now with kidney failure. Being a kidney patient is an experience I wish I was not going through. Being fatigued, and not being able to function like a normal person is hard. It is daunting and it seems like a long wait for a donor to help me save my life.

However, with the new law in April 2020 ‘Max and Keira’s law’ will help save lives of people in need of a new organ. I hope this Diwali there is someone out there that would give a gift of life to a person who is in need of an organ donation. This will not only save lives, but to help live life to the fullest. I hope one day my wish can come true and I can do what others can do. I will look forward to going back to work and being strong again. Wishing you all a Happy Diwali and New Year.”



Rakhi Shah, Patient with Kidney Failure – Waiting for an Organ Donation

“I have been suffering from Lupus since the age of 29. This has scarred my kidneys. Currently I am at stage 5 kidney failure and have now had to start Dialysis, which means I am tied to a machine few days a week. This has adversely affected my quality of life and I’ve had to cut down my working hours.

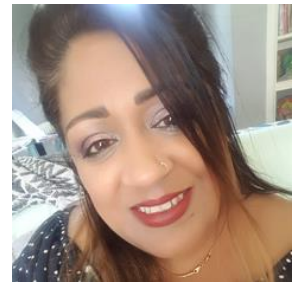
I am on the UK donor waiting list - finding a match has proved challenging. My husband and cousins have come forward to donate but are not a direct match and so we’ve also joined the UK kidney sharing scheme. I very much hope to find a donor soon.”



Hansa Solanki, Renal Patient, Leicester – Waiting for an Organ Donation

“In 2011, I was given shocking news that one of my kidneys was not working and the other kidney had scarring on it. Over the years I kept falling ill with constant severe infections, which left me very poorly and indeed spending long periods in hospitals, requiring constant treatment. Due to this, my kidney function kept going lower and lower, leaving me in a state where I was practically incapable of doing anything. In 2017, I fell ill again, being hospitalised for 3 months, a time during which my kidney function deteriorated so much such, that I had no choice but to start dialysis. This was the end of my life and beginning a new life as a renal patient having to dialyse 3 times a week, 4 hours each time with severe fluid and food restrictions possibly for the rest of my life.

I have now accepted dialysis as a routine and have become mentally strong, managing my life style still being able to go out. Unfortunately for me, I am not on the waiting list as my weight needs to be considerably reduced and I am currently awaiting gastric band surgery and I pray to God that one day I will be able to get a kidney and be able to live my life normally like others.”



Jayantilal Bhikha, Recipient of an Organ Donation

“Our father, Jayantilal, has always been the patriarch of the family, so being diagnosed with advanced cirrhosis of the liver, and given just a 20% chance of survival without a transplant, was a huge shock.

The impact on the family was tremendous, particularly as he wasn't a heavy 'drinker'. In fact, his cirrhosis was the result of having colitis for several years. Conversations about being a donor recipient were difficult, more so as we had made plans to celebrate his 60th birthday on a cruise which had to be cancelled.

Both from fear and cultural belief Dad's initial response was to refuse a transplant, saying 'it's in God's hands', but after consultation, and with reassurance from the fantastic hospital staff, he agreed and was put on the waiting list.

But there was a problem; due to the lack of Asian registered donors he could be waiting 6 months or even 2 years! Fortunately, Dad was lucky and within 4 weeks a match was found. The operation was successful and now, 15 years on, Dad is like a new man; cycling daily, gardening and volunteering at St Luke's.

*I cannot overstate how important it is that Asian people embrace organ donation.” **Thoughts of Bharti Bhikha, daughter of Jayantilal Bhikha***



Anirudh Patel, Recipient of an Organ Donation

“My life was transformed when I was a teenager and received a kidney donation that took me off dialysis. During my time on dialysis, it was difficult to focus on studies and have a normal social life.

Each day would start with finishing overnight dialysis and feeling exhausted, but I was ready to battle through the day. This enduring ordeal impacted my studies, but I managed to get through education luckily with a transplant that was offered to me over 10 years ago. This Diwali, please take a few minutes to register your decision to donate and talk to family and friends. You could also change someone's life, and give them the chance to live happily, and have a normal existence.”

