



## January 2020 newsletter

### Introduction

A very happy and healthy new year to everyone! 2019 has been a remarkable year for promoting organ donation in our communities. 2020 will be remembered as a milestone year because opt out will be implemented in England from Spring 2020, and in Scotland from Autumn 2020.

We are most grateful to everyone for their amazing work in 2019. Lord Jitesh Gadhia's support and encouragement has been invaluable. It has also been great pleasure to work with Millie Banerjee, Chair of NHS Blood and Transplant (NHSBT) and Betsy Bassis, Chief Executive of NHSBT and her staff in 2019. Thank you to everyone for their support and commitment.



*Kirit Modi, Millie Banerjee and Lord Gadhia at the JHOD event in Parliament from 2019.*

## Plans for 2020

JHOD is ready to build on its work in 2020. The JHOD Steering Group of twenty members has ambitious plans to welcome the change in law to opt out. We are planning to participate in a **Welcome Event** nearer the time of the change in law in England. We will be working with NHSBT and the National BAME Transplant Alliance (NBTA) in arranging this.

Our support for work in the Hindu and Jain community will increase, particularly among the five major Hindu and Jain projects, which have received funding from NHSBT. We will help refresh the Hindu and Jain sections on organ donation on the NHSBT website, update the NHSBT faith leaflets on Hinduism (the blue leaflet) and increase our media profile, particularly in the social media space. If you wish to offer your help with these plans, or wish to join the JHOD Steering Group, please contact Kirit Modi ([kiritmodi1@hotmail.com](mailto:kiritmodi1@hotmail.com)). We welcome new faces and ideas!

Let us take every opportunity to explain the change in law amongst the community in 2020. The response from our communities to opt out has been mostly positive. With your support, we can ensure the message goes out far and wide that, Hindus and Jains welcome the change in law and will register to donate their organs after death in order to help save lives.

NHSBT has started advertising the change in law on TV in England. A link to the advert is below:

<https://www.youtube.com/watch?v=MP1rgHYyTi0>

Please share this widely through your contacts, including via social media etc.

## Major funded projects in 2020

We know that many Hindu and Jain groups have plans in 2020 to explain the change in law and promote organ donation. For example, celebrations to mark the 25<sup>th</sup> anniversary of the BAPS Hindu Mandir in Neasden will take place in 2020, whilst Pujya Mahant Swami will be in the UK. BAPS are planning to arrange events promoting organ donation at a number of events.

In Leicester, a major event to celebrate Holi will take place on 21 March 2020 and Jalaram Mandir in Leicester are planning to promote organ donation at this event. Vanik Council UK are planning a series of event to explain the change in law. Lots of events organised by community groups will take place in 2020. Please do contact Kirit Modi if you need any help. We will be delighted to work with you.

We are very pleased that five major Hindu and Jain projects have been funded by NHSBT in 2020. Each of these projects will include a number of activities taking place throughout the year. The organisations selected are:

- **Jalaram Mandir**, Leicester, led by Mr Pramodbhai Thakkar and Mr Bharat Patel
- **Vanik Council UK**, led by Mr Manharbhai Mehta
- **Jain Network**, led by Dr Natubhai Shah
- **Oshwal Association UK**, led by Mr Aswinbhai Shah
- **Veerayatan UK**, led by Mr Bakul Shah

If you would like further details, please contact the organisation directly. A press release announcing the overall funding to 26 BAME projects was issued in December 2019 and is available via the link below:

<https://www.organdonation.nhs.uk/get-involved/news/projects-in-england-and-wales-win-funding-to-promote-organ-donation-among-bame-communities/>

## **Living Transplant Initiative (LTI)**

The final report of a three year work on increasing living kidney donation in BAME groups was published by the National BAME Transplant Alliance (NBTA) and NHSBT. It includes details of excellent work done by the Vanik Council UK, BAPS Charities and SAHA in our communities. Videos and leaflets on living kidney donation from a Hindu and Jain perspective were produced and are now available for use nationally. Work on living kidney donation aimed at our communities continues and is now led by two hospitals in London; the Royal Free and Hammersmith Hospitals.

A copy of the final LTI report is available directly below:

<https://www.nbta-uk.org.uk/resources/reports/living-transplant-initiative-final-report-published/>

## Showcasing successful work in our communities

We are delighted to share details of some of the work done in the community. Some examples are set out below. We encourage everyone to send us details of their work so that we can share and celebrate it widely.

### 1. Jalaram Mandir, Leicester, 2<sup>nd</sup> November 2019



#### Jalaram Bapa's Temple in Leicester Promotes Organ Donation

On 2<sup>nd</sup> November 2019, the eve of Jalaram Jayanti (Pujya Jalaram Bapa's birthday) a packed audience of over 450 people found out about the change in law on Organ Donation in England (Opt Out) and fully supported the change. They listened to a presentation given by Mr Kirit Modi, Chair of JHOD (Jain and Hindu Organ Donation Steering Group) on the details of the change, the reasons for the change and how the Hindu community can help save lives by registering to become organ donors. This important information was broadcast live to thousands in the UK (and abroad) by Aastha television and is available on You Tube.

<https://www.youtube.com/watch?v=vRLDgE8E3ic&feature=youtu.be>



Mr Pramod Thakkar, Chair of the Trustee Board at Jalaram Charitable Trust spoke of the events carried out across the year, including marking the World Kidney Day in March 2019, a lecture on Hindu Religion and Organ Donation by Pujya Shree Giri Bapu and printing the donation message in 10000 panchangs (religious calendars).

In his message to the Hindu community locally and nationally he said:

“I say Ang Daan (Organ Donation) is a part of Seva in which every Hindu should participate. May I urge all Hindus to the call for organ donation? Come join us in this service to mankind.”

Around a 1000 people of Asian background are waiting for an organ transplant in UK and in 2018/19 there were 56 organ donors after death and 83 living kidney donors in the UK, some of whom in Leicester, were inspired by devotees of Jalaram Bapa. There is a desperate need for more organ donors from the Asian community.

Bharat Patel who was waiting for a kidney from the register, eventually received a kidney from a living donor, Avril Patel in 2008, who has been doing amazing work to promote organ donation over many years said:

*“I felt like a little baby being born again with a brand-new life ahead of me. Never could I even dream that such a change in a human lifestyle could ever be possible. Ten years on, my donated kidney is working absolutely fine and functions the same as when first transplanted. Transplantation works.”*

A recent survey of people from Indian heritage in the UK showed that, 48% would definitely donate or consider donating organs after death, 42% had not decided and 10% would not donate their organs. Hinduism supports organ donation and many Hindu faith leaders have publicly supported organ donation.

Prafula Modi, Committee Member and Chair of Bal Vikas requested the audience to make a voluntary pledge by raising their left hand and repeating the following words:

*“On the eve of Jalaram Jayanti, I take a sankalp and make this solemn pledge that I will donate my organs for the benefit of others after my death. I will sign the organ donor register today to this effect and will also make my wishes known to my family so that when the situation arises my family will duly respect my wishes and decision.”*

The pledge was taken by an overwhelming majority of the audience. Jalaram Charitable Trust has secured funding from NHSBT recently to continue its excellent work on organ donation under its slogan *Jalaram Bapa leads the way on Hindu Organ Donation*. The key message from the event was to encourage all Hindus to make a decision on organ donation, to register their decision and to inform their family members about their decision in order to help save lives. A number of events will take place over the next 12 months. It is very easy to register your decision - you can obtain a registration link by emailing: [kidneytrust24@yahoo.co.uk](mailto:kidneytrust24@yahoo.co.uk)

## 2. Shri Vallabh Nidhi, UK, Saturday 14<sup>th</sup> September 2019

Shri Vallabh Nidhi UK (SVNUK) organised a special event at the Wembley Sanatan Mandir, Gokaldham Centre on Saturday 14<sup>th</sup> September 2019. The event was organized to explain the upcoming Spring 2020 change in law for Organ Donation, and to encourage the Hindu Community in and around the Wembley area to actively support organ donation. The event was supported by the Jain & Hindu Organ Donation (JHOD) Team and NHSBT.

Around 210 people attended including many dignitaries and leaders from other local communities, Brent Council and the media. His Worshipful the Mayor of Brent Cllr. Ernest Ezeajughi, the Leader of the Council Cllr. Mohammed Butt, Cllr. Trupti Sangani and the First Secretary (Trade) of the Indian High Commission Mr Rahul Nangare were amongst those who attended. Leaders of the Narayan Sewa Sanstha, Maa Krupa Foundation and the Bhatia Community also attended.

Narendrabhai Thakrar, Chairman of SVNUK, welcomed everyone and said that we should all be proud to actively support this life saving project. He thanked Kiritbhai Modi, Chair of JHOD Steering Group for his support of the event, and that he was looking forward to seeing his presentation.



We were pleased to have Shivum Kakkad and his mother Jaiminiben attend. Shivum shared his experience, as his father passed away recently, with the family donating his organs. SVNUK honoured both mother and son for their **gift of life** to others from their sad loss.

A presentation was given by Kirit Modi on Organ Donation and was elaborated mainly in Gujarati to suit the audience. The change of law from Spring 2020, important statistics, the need for more donors and the main concerns of the Hindu Community about organ donation were all addressed. A short video clip was shown with leaders from various Hindu temples across the UK who supported organ donation and explained the rationale behind this.

Questions were asked at the start, as to how many attendees knew about the change of law, how many had already signed up for organ donation and how many had discussed the subject of organ donation with their families. The same questions were asked at the end and the results were very gratifying! The majority understood the new law change; seventeen people were already registered, and fourteen new people registered on the day. A further 51 people said they would sign up later after the discussion.

### 3. Shree Kutch Satsang Swaminarayan Temple, East London, 24 August 2019



Shree Kutch Satsang Swaminarayan Temple - East London, organised an Organ Donation and Transplantation awareness event, attended by around 500 people on Saturday 24th August 2019, on the occasion of the 32nd annual Patotsav ceremony of the Temple. The aim of the event was to raise awareness about the change in law in England among Hindus and to provide practical guidance on improving organ donation rates among the Hindu Community.

Kirit Modi, Chair of the Jain and Hindu Organ Donation (JHOD) Steering Group, emphasised the urgent need to register individual decisions by adults on organ donation and help save lives. He explained how Hindu communities could avail of the growing number of resources to improve education and awareness on organ donation. Shanti Priya Swami from the Bhuj Temple in India endorsed the initiative taken and hailed all the devotees to join this good cause and explained how organ donation is a selfless form of 'daan' (charity) which allows one to give the gift of life and is fully endorsed by the Hindu scriptures. Kirit Suhagiya, a lead volunteer from SKS Swaminarayan Temple, further reinforced the message of giving selflessly and emphasised that organ donation should be considered by all Hindus. Eastham MP Steven Timms was also present and he thanked the temple for taking this initiative and explaining this important information to community members. This event was well attended and received positive feedback from volunteers and devotees.

#### 4. Param Shakti Peeth of UK, October 2019



As a trustee of Param Shakti Peeth of UK (PSP of UK), I was delighted to promote JHOD Organ Donation initiative at the Depala Community Navratri Garba. The event was hosted by Hari Om Arts and Cultural Association and facilitated by the Depala brothers at the Hindu Cultural Society in Finchley.

I had requested Secretary of State for Environment, Food and Rural Affairs, Theresa Villiers MP and Cllr. Roberto Weeden to come along to the event and I'm happy to report that they not only actively participated in raas garbha, but also gave huge support to the JHOD organ donation initiative. Speaking about Organ Donation. Theresa said that we cannot put off an important decision such as this, we must all have conversations about this issue. On behalf of PSP of UK and JHOD, I informed every one of the change in law from Spring 2020. I requested the attentive audience to, 'go home, think about it over the weekend, have conversations with the family and register for organ donation.'

Roberto said that it's not an easy decision, but one we must all make. Young and old participants of raas garbha expressed positive attitude to signing up, through registration forms received.

I wish to thank Sejalben for providing me with the Hindu specific *Pass it On* leaflets and Geraldine Parker for providing the Organ Donation registration leaflets, banners, organ donation cards and some freebies.

I have learnt that talking individually to people has a huge impact and also photos can speak a thousand words. As learning goes on, so must our efforts go on.

#### Dr Harshaben Jani





## 5. Hindu Students, October 2019



A Navratri event organised by the National Hindu Students Forum (NHSF) in October 2019. Over 1100 students attended and had the opportunity to find out about organ donation.

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