

## JHOD NEWSLETTER MAY 2020

### 1. Introduction

We hope you and your family members are well. We are going through challenging times and many Hindu and Jain groups have risen to the challenge by supporting others through amazing acts of kindness, generosity and humanity.

We reached a very important milestone for organ donation in England on 20 May with the introduction of the opt out arrangements.



Kirit Modi, Millie Banerjee, Lord Jitesh Gadhia

Clearly, we have to wait until we are over the pandemic before the full impact of the change will be realised. However, we welcome the law and will continue with our work in getting the information among the Hindu and Jain communities, despite the limitations of coronavirus.

We are delighted that Hindu and Jain groups have found innovative ways of engaging virtually with members of our community. The work being done by the five Hindu and Jain groups funded by NHSBT continues. We are currently working with NHSBT on arrangements for the next round of funding and

the bidding arrangements and will share this information as soon as it is available.

We are seeking your help, and ways in which you may be able to help, as individuals or community leaders, are set out in paragraphs 4 and 5 below.

## **2. JHOD Zoom event and press release**

We were delighted to arrange the Zoom meeting in partnership with NHSBT on 15 May 2020. Many thanks to everyone for your support and for the excellent discussion afterwards. We are most grateful to Lord Jitesh Gadhia and Millie Banerjee, Chair of NHS Blood and Transplant (NHSBT) Board and her team for their support once again. In particular, we are most grateful to Andrea Ttofa from NHSBT who has worked closely with us since the establishment of JHOD. Andrea is leaving NHSBT and our best wishes to her for the future. The agenda for the meeting included:

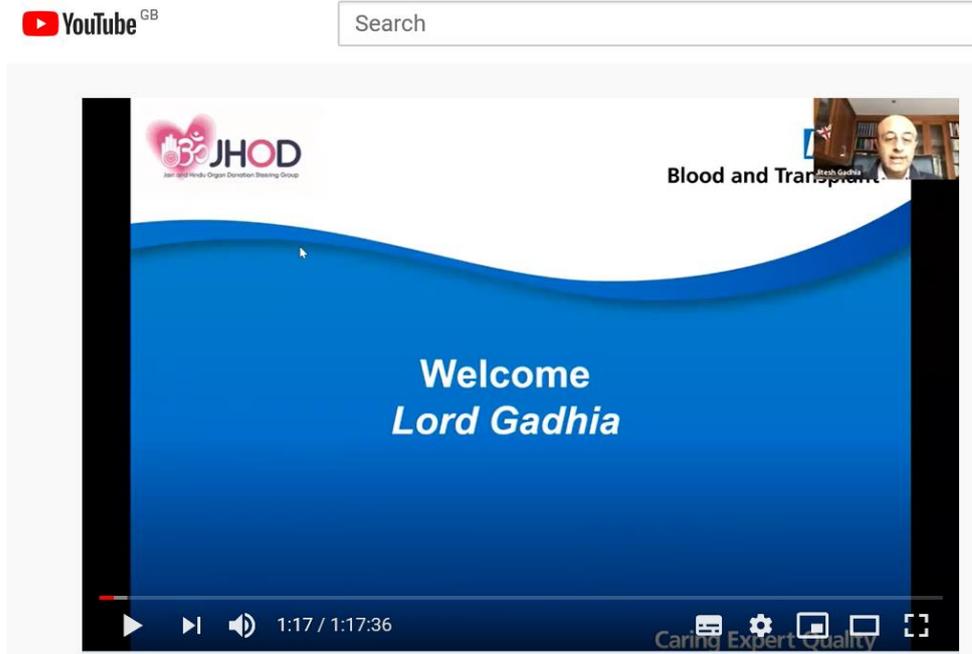
*Welcome: Lord Jitesh Gadhia*

*Introduction: Millie Banerjee, Chair, NHSBT Board*

*Overview of the impact of COVID-19 on organ donation and transplantation and how we move to recovery: Anthony Clarkson  
Director of organ donation and transplantation and Dale Gardiner,  
National Clinical Lead for organ donation*

*Update on the move to an opt out system in England: Claire Williment, Head of Legislation Implementation Programme*

*Issues affecting BAME communities and how Hindu and Jain communities can help: Kirit Modi, Chair, JHOD Steering Group*



The latest information on organ donation in the context of COVID-19 was presented at this meeting. A recording of the meeting is now available for everyone via YouTube:

<https://youtu.be/fbZGrAM18v4>

### **3. Welcoming the change in law in England**

We were delighted to welcome the change in law on 20 May 2020 and issued a press release. We would be grateful if you would circulate it. The press release has been included in the email attachments.

An article on organ donation was written by Aditi Khanna from the Press Trust India following her attendance at the Zoom meeting and it is available at:

## England's new opt-out organ donation law comes into force



By Aditi Khanna

London, May 20 (PTI) A new law which means all adults in England will now 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 an excluded category, comes into force on Wednesday.

<https://www.outlookindia.com/newscroll/englands-new-optout-organ-donation-law-comes-into-force/1840518>

### 4. How can we help at present?

We have a very good opportunity to share information about organ donation at present; firstly because the law has now changed and secondly because we have more time to think about helping each other during this pandemic. We know of plans some communities have put in place. Jalaram Mandir in Leicester and Oshwal Association UK are developing short plays to explain the change in law and promote organ donation, Vanik Council UK is planning ways in which the change in law can be explained through virtual meetings, Veerayatan UK, Shrimad Rajchandra Mission UK and Shishukunj UK are planning how to explain organ donation to young people. We will, of course, plan how we can highlight the change in law nationally during Paryushan and Diwali this year. We are requesting you to do what you can and have listed some ideas for you to consider.

#### Individual action:

- We should encourage everyone to talk about the change in law with our closely family members, register our decision

on the NHSBT website [www.organdonation.nhs.uk](http://www.organdonation.nhs.uk) or by phoning 0330 303 2094, share the decision with our close family members and help save lives.

- We should use our WhatsApp contacts and social media to share videos on organ donation which are available from the Hindu and Jain playlists; see details below.

### Community Action:

- Consider covering the change in law via a virtual meeting (using Zoom, for example). Set aside part of the time in a religious or other virtual meeting (Jain network



recently arranged a very successful event using Zoom and BAPS Swaminarayan Mandir in Neasden used its webinar to inform thousands of people about the change in law). JHOD can offer support by providing speakers, videos etc.

- In your planning to celebrate Paryushan or Diwali, consider how the change in law can be included.
- If you post newsletters to members of your community, then include an article on the change in law and send out hard copies of the NHSBT leaflet for registering as an organ donor.
- Use your website or social media to send out information about the change in law and how to register to donate online.

- Invite your community leaders, religious leaders and celebrities from your community to publicly support organ donation
- Consider bidding for the next round of funding from NHSBT, to be announced later on this year.

## **5. We are seeking your help**

We are delighted that we now have a number of Hindu and Jain personal stories from donor families (close family members of those who have donated organs after death), patients waiting for an organ transplant and transplant recipients. We have worked in partnership with NHSBT in producing videos of their stories (see lists below). We are looking for more such examples, particularly of donor families. If you know of anyone who may be interested in sharing their story, please let us know.

Secondly, JHOD is planning to develop a website so that we can pull together all information in one place and readily share the latest information extensively. We are seeking help in setting up our website.

Kirit Modi will be delighted to hear from you if you are able to help with these requests. His contact details are [kiritmodi1@hotmail.com](mailto:kiritmodi1@hotmail.com) or phone 07929 778440.

## 6. Resources available

We have easy access to a wide range of resources. These include leaflets and videos.

**Leaflets:** Special leaflets on the change in law from a Hindu and Jain perspective are available. The Hindu leaflet is available from NHSBT and the Jain leaflet from Manharbhai Mehta ([manharmehta@gmail.com](mailto:manharmehta@gmail.com)). You can order NHSBT leaflets and other resources through their website [www.nhsbtleaflets.co.uk](http://www.nhsbtleaflets.co.uk)



The link to the Hindu leaflet is

<https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/16471/hindu-communities-organ-donation-after-death.pdf>

The link to the Jain leaflet is

<https://nhsbtdeb.blob.core.windows.net/umbraco-assets-corp/16472/jain-initiative-organ-donation.pdf>



# A Jain Initiative

*'Give a Gift, Give an Organ'*  
- Pass it On



Following the death of 19-year-old Kurran Mehta in a car crash in Sept 2018, his mother chose to donate most of his organs to give the chance of life to other people.

## Hindu religious leaflet on organ donation from NHSBT

We have worked closely with NHSBT to update the Hindu religious leaflet on organ donation. We are most grateful to our religious leaders for their continued guidance and support for organ donation. The link to the new leaflet is attached in the email.

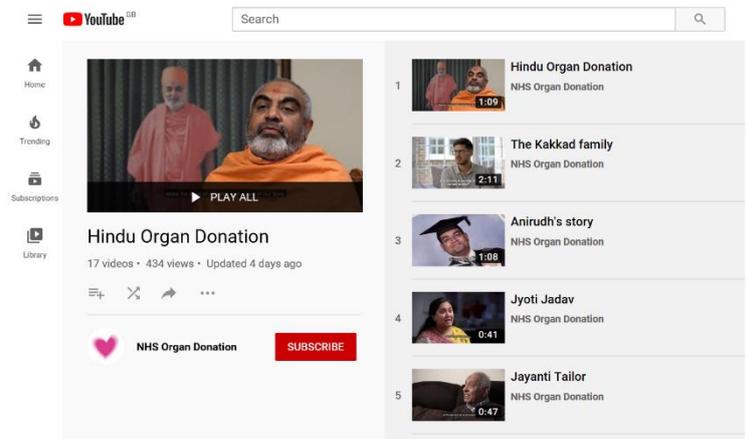


Hard copies of the leaflet can be requested from NHSBT in a few weeks through their website [www.nhsbtleaflets.co.uk](http://www.nhsbtleaflets.co.uk) . If you need large quantities, please contact [leaflets@nhsbt.nhs.uk](mailto:leaflets@nhsbt.nhs.uk)

**Videos:** We have several videos which are on the Hindu and Jain playlists.

The Hindu playlist includes the following.

- Hindu long video on the change in law in English and, with subtitles, in Gujarati, Hindi, Punjabi and Tamil.
- Hindu short video on change in law in English and, with subtitles, in Gujarati, Hindi, Punjabi and Tamil.
- Kakkad family short videos on their story and the Diwali 2019 message
- Aari Patel short video
- Anirudh Patel short video
- Jyoti Jadav short video
- Jayanti Tailor short video



The Hindu playlist can be found here

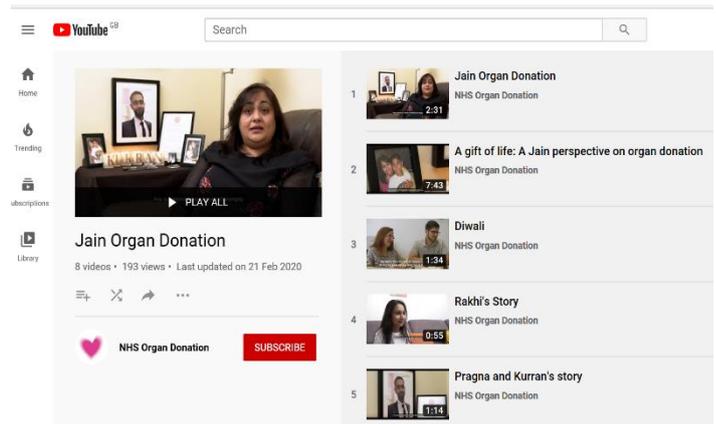
<https://www.youtube.com/playlist?list=PLjI4wHu2TagN2GI4vIcO5qvVldklxsF73>

The Jain playlist includes the following.

- Jain long video on change in law in English and, with subtitles, in Gujarati.
- Jain short video on change in law in English
- Pragna Mehta-Patel short video
- Bharati Shah short video

- Jaswant and Kalpana Doshi short video
- Rakhi Shah short video.

The Jain playlist can be found here



[https://www.youtube.com/playlist?list=PLjl4wHu2TagOmDO R-8D90Z8\\_gNApfGxza](https://www.youtube.com/playlist?list=PLjl4wHu2TagOmDO R-8D90Z8_gNApfGxza)

## Change in law explained in Gujarati

A video on the change in law in Gujarati was produced by the Jalaram Mandir in Leicester and shown live on Aastha TV. The link is at:

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

South Asian Health Action (SAHA) recently produced a short video to explain the change in law in different languages. The link is at:

<https://youtu.be/yg1haSIJBfQ>

## 7. JHOD support group during coronavirus

We are very pleased that a JHOD support group has been established since the beginning of May to have confidential chats with transplants recipients, patients on dialysis and those

waiting for an organ transplant. We have already supported several people and would be grateful if you would publicise this service using the flyer below.



#Stay safe

We are a small voluntary support group of kidney transplant recipients, dialysis patient and living kidney donors from Hindu and Jain backgrounds. We are pleased to offer support and share our coronavirus experiences with others who may find it helpful by telephone on a voluntary basis. We speak *English and Gujarati*. This support group has been established by the Jain and Hindu Organ Donation Steering Group (JHOD).

- We will follow the following principles:
- We will not advise on any medical issues
  - We will keep the information shared with us strictly confidential
  - We will listen carefully and sympathetically
  - We will share our experiences of coronavirus
  - We will signpost guidance for kidney patients published by the NHS or hospitals
  - We will seek feedback from you to help improve this service

Our contact details are set out below. Please feel free to call us at times indicated below.

Bharat Patel	Kidney transplant recipient	07730 985 071	10am - 8pm everyday
Prafula Shah	Living kidney donor	07789 874 228	6pm - 8pm everyday
Kirit Modi	Kidney transplant recipient	07929 778 440	10am - 4pm everyday
Dishna Hirani	Living kidney donor	07956 539 559	10am - 6pm weekdays
Rakhi Shah	Dialysis patient	07767 457 614	10am – 5pm weekdays

If you have any general queries about this initiative, please contact:  
Kirit Modi | [kiritmodi1@hotmail.com](mailto:kiritmodi1@hotmail.com)

🐦 @JHOD\_uk  
📌 #jhodsaveslives

## 8. Request from NHSBT

We are very pleased to forward the following request from NHSBT to you.

*“Do you receive emails from NHS Blood and Transplant? As a key voice in the BAME/faith community, NHSBT would like to keep in contact with you to keep you informed about their initiatives and any information relevant to you or the community you support. Please email [Marketing.Comms@nhsbt.nhs.uk](mailto:Marketing.Comms@nhsbt.nhs.uk) if you’d like to be added to the mailing list.*

*Please note that NHSBT holds your contact information alongside your faith and ethnicity (if this information is provided) in our database. NHSBT appreciates that information on faith and ethnicity is sensitive personal data. The reason NHSBT holds faith and ethnicity information alongside your contact details is so they can tailor the information, opportunities or new materials that are sent to you. NHSBT is committed to respecting your privacy rights and will always store your information securely and confidentially”.*

**Best wishes and stay safe.**