



Jain and Hindu Organ Donation Steering Group (JHOD)

January 2019 update

Introduction:

You will be pleased to hear of the progress that has been made in the Organ Donation campaign since Autumn 2018. Following the meeting in Parliament hosted by Lord Jitesh Gadhia on 12 September 2018 and the Workshop held in partnership with NHSBT on 2 November 2018, we have established the national Jain and Hindu Organ Donation Steering Group (JHOD).



There was extensive interest shown in volunteering to join the Steering Group, and members took part in its first teleconference meeting on 18 December 2018 and 29 January 2019. The Terms of Reference and a strategy was finalised for the Steering Group. Both are set out below.

The hard work starts now and we hope that work on organ donation within our community can increase significantly. A number of Hindu and Jain projects were successful in securing funding from NHSBT to undertake projects. These details are set out below. We have also provided a calendar of future events that are currently scheduled, which you will be updated about accordingly. If you are planning any events, then we would encourage you to inform Kirit Modi (kiritmodi1@hotmail.com) about them, so that we can publicise them and offer support, if needed.

Calendar of events for the upcoming months:

(please note this is not a full itinerary and you will be kept updated as the calendar develops)

17 February 2019: Vanik Council UK: Conference on Living Kidney Donation in Colindale

10 March 2019: Vanik Council UK: Conference on organ donation in Crawley

17 March 2019: Vanik Council UK: Conference on organ donation in Leicester

24 February 2019: SAHA: Conference on living donation in Leicester

16 March 2019: SAHA: World Kidney Day organ donation event in Leicester

For information of events organised by the Vanik Council UK, please contact Manharbhai Mehta (Manhar.mehta@vanikcouncil.uk) and for the SAHA events, please contact Kirit Mistry (kiritmistry2@gmail.com).

A number of groups submitted bids to NHSBT for funding to promote organ donation within our communities and 6 were successful. These projects will finish in June 2019 and we anticipate that further opportunities for bidding for funding will be available after that. We will of course, publicise these and encourage and support more groups to submit bids in the future. The successful projects and the contact details of the 6 project leaders are set out below.

1. BAPS Swaminarayan Sanstha, UK : Prof Sejal Saglani
ssaglani@yahoo.co.uk
2. Indian Association Oldham: Shashi Mohandas
Shashi_m@msn.com
3. Lightseekers Ltd, Leicester: Kajal Nisha Patel
kajal@kajalpatel.com
4. Santosh Community Centre, Leicester: Kirit Mistry
kiritmistry2@gmail.com
5. Sewa Day: Kartik Dave

kartikdave@hotmail.co.uk

6. Vanik Council UK : Manharbhai Mehta

Manhar.mehta@vanilcouncil.uk

Videos and other resources

A number of videos on organ donation, which are from a Hindu or Jain perspective, have been produced and links to them are set out below.

<https://www.youtube.com/watch?v=zYaQV3levU> - Ari Video

https://www.youtube.com/watch?v=0-7K56iVG_I - Deceased organ donation in Hindu community

<https://www.youtube.com/watch?v=wwAYdVS4ytk> - Hindu community living organ donation

<https://www.youtube.com/watch?v=vNA0K5FSMBw> -Video on conference on living organ donation

<https://www.youtube.com/watch?v=tzOlar4KIOo> - Vanik Council video

A number of leaflets aimed at our communities are also available. Some of the links can be found below.

http://londonmandir.baps.org/images/2017/10/LivingOrganDonation_leaflet.pdf

<http://londonmandir.baps.org/forthcoming-events/living-organ-donation>

NHSBT has a range of leaflets and other resources which can be requested, the contact is: Marketing.Comms@nhsbt.nhs.uk

Deemed consent in England

Legislation on deemed consent (opt out) is with the House of Lords at Committee Stage (1.2.19) at present and it is anticipated that this will become law by April this year; subject to Brexit not making this difficult!

The plan is to publicise the changes extensively and the implementation is due to take place in 2020.

Jain and Hindu Organ Donation Strategy: 2019-2021

Vision: No one should die waiting for an organ transplant in the UK.

Aim: To significantly increase the number of Hindu and Jain organ donors, both living and after death.

Objectives:

- 1) Develop resources (videos, leaflets etc) to explain deemed consent from a Hindu and Jain perspective
- 2) Hold events to explain deemed consent in all areas with significant Hindu/Jain communities in England (Temples, Derasars, professional groups, student groups etc.)
- 3) Obtain public support for deemed consent from Hindu and Jain: Faith leaders, community leaders, patients, organ donors/families, celebrities, politicians
- 4) 4) Communicate key messages using social media, newspapers, radio, TV, etc.

Targets:

Results of a recent survey published by NHSBT shows that 24% of Indians have talked about organ donation, 63% have not and the rest don't know.

In 2017/18, there were 106 Asian organ donors in the UK; 69 were living kidney donors and 37 donated organs after death.

The first target as stated below relates to having conversations about organ donation. The other two targets are about increasing registrations to the Organ Donor Register and the actual number of people who donate organs. NHSBT are currently not monitoring data by religion and we will need their help in measuring the progress against the following three targets, which are intentionally set at a high level because we want to bring changes quickly.

Target 1: Increase the percentage of Hindus and Jains who have had a conversation about organ donation to 40% by 2021

Target 2: Increase registrations on ODR from Hindus and Jains to 12,000 by 2020/21

Target 3: Increase Hindu and Jain donors: 51 deceased and 101 living kidney donors by 2020/21

Plan of implementation:

Hindu plan:

The first priority will be to produce videos and a leaflet on deemed consent from a Hindu perspective by June 2019. The development of the video will be led by Dr Neil Soneji from BAPS and the leaflet by Pramodbhai Thakkar from Jalaram Mandir in Leicester. Funding for producing these resources will be sought from NHSBT. Three videos will be produced; two short ones and one longer one. One of the short videos will be aimed at younger people and the other being a more general viewing. The longer video will provide an opportunity to explain deemed consent from different perspectives: donor family, recipient, medical, faith, community leader etc. The videos will be produced in 5 languages

(English, Gujarati, Hindi, Punjabi and Tamil), in audio form and with subtitles. We will give further consideration to other languages such as Kannada, Malayalam and Bengali. The leaflet will also include different perspectives and its developments will be linked to the production of the videos.

We have established contacts with a wide range of Hindu and Jain groups nationally. All members of the Steering Group will encourage and support these identified groups to promote organ donation and explain deemed consent, as appropriate, through their communities, starting from June 2019. Members of the Steering Group will use their contacts to seek public support from opinion formers in the Hindu community and publicise these in the media, including social media.

Finally, there will be a plan to communicate the key messages surrounding deemed consent to the Hindu community, which will be complementary to the plans developed by NHSBT.

Jain plan:

Work on the Jain plan has started and Manharbhai Mehta from the Vanik Council UK is coordinating this. The plan is to produce three videos; two short and one longer as well as including the Jain perspective in leaflets.

Jain and Hindu Organ Donation Steering Group - Terms of Reference:

Purpose: To provide leadership on organ donation, as a matter of pressing need and encouraging action within the Hindu and Jain communities across the UK.

Role:

1. To develop and publish the Hindu and Jain strategy to increase organ donation in the UK, in the context of the introduction of deemed consent in England.
2. To develop, support and monitor a plan of implementation of the above strategy.
3. To seek funding from NHSBT and others for delivering the implementation plan.
4. To encourage and offer practical support to all Hindu and Jain groups in promoting organ donation.
5. To publish a diary of events and activities organised by Hindu and Jain groups and distribute it widely.
6. To develop specific resources (videos, leaflets etc.) to explain deemed consent from a Hindu and Jain perspective.
7. To obtain public support for deemed consent from influential Hindus and Jains, patients, donor families, faith leaders etc.
8. To communicate the messages about deemed consent effectively by using social media, newspapers, radio, TV etc.
9. To identify spokespersons from the Hindu and Jain communities, including faith leaders, who can promote the messages about deemed consent to the media.

To report regularly to the wider group facilitated by Lord Gadhia in regards to progress made and our successes as a Steering Group, as well as further calls of action.

Practical issues, working methods and future meetings:

1. All members of the Steering Group are volunteers and there is no budget to support the work, at present. However, we will explore the possibility of seeking funding from NHSBT and others to undertake our work.
2. Most the work of the Steering Group will be done through teleconferences, phone and e-mail. We aim to have a teleconference every six weeks, in the first instance.
3. It was also agreed that the Steering Group would regularly review its scope of work to ensure it is taking into account the latest developments surrounding organ donation.

Membership:

Kirit Modi (Chair)
Ravi Bhanot
Bharti Bhikha
Nemubhai Chandaria
Manharbhai Mehta
Kirit Mistry
Jay and Sina Patel
Akshaya Rajangam
Sejal Saglani
Prafula Shah
Satya Sharma
Neil Soneji
Meera Thakkar
Pramod Thakkar
Dr Harsha Jani
Dristi Mae
Nilesh Shah

Sonoo Malkani

Biographies of Steering Group Members

Ravi Bhanot - JP MRPharmS RSA



Some of Ravi's community roles include being Chair of Sewa Week Organization, Committee Member of Diwali in London and Committee Member of the Ilford Vhp Hindu Centre.

Part of Ravi's responsibilities are leading certain community events such as co-ordinating NHS organ and blood donorship events in East London and Essex in the BME (black minority ethnic) communities. Ravi plays an active role in educating, encouraging, recruiting people from the BME group to come forward to give blood and organ donorship.

In 2017, Ravi played a valuable role in increasing blood donation from the BME in Essex by 50%. One of the main targets of Sewa Week Organization is to increase blood donation from the BME communities from a national 3% donating to 10% in the next three years in East London and Essex.

Bharti Bhikha



Bharti Bhikha is Managing Director of Zinc Communications Ltd, part of a group plc and leaders in factual entertainment, educational programming and digital content producers. Bharti's agency specialises in creating pro social communications strategies and behaviour change campaigns for corporates, charities and government department with a purpose to drive positive change and deliver social impact through education and corporate engagement

Bharti has over 20 years extensive experience working with organisations developing award winning sustainable campaigns that will engage, educate and inspire audiences to deliver a positive change. Campaigns include; supporting Governments targets on reducing the number of child road casualties in the UK, increasing awareness and uptake amongst young people of the Government's HPV vaccination programme, promoting issues around mobility, social & diversity inclusion, and many more. She also volunteers within her community supporting them with their communications and

actively engaging young people to encourage on the importance of organ donation and how it can save lives!

Nemu Chandaria OBE



Nemu Chandaria OBE is currently Chairman of The Institute of Jainology and a Trustee of Indian Gymkhana at Osterley. He serves as a Coordinator for OneJAIN and was a formerly Chairman of the Board of Trustees of the Oshwal Association of the UK. Nemubhai is also a trustee of the International Sacred Literature Trust and is a recipient of Jain Ratna award from the Prime Minister of India as well as Her Majesty the Queen for services to the Jain community in the form of the Order of the British Empire.

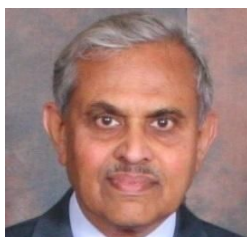
Dr Harsha Jani



After completion of PhD in Neuroscience, pursued further research with the Medical Research Council. Interests include application of genomics in therapeutic medicine. Dr Jani is married with one son.

Dr Jani undertakes social and community work with SEWA U.K. She recently articulated a nationwide parliament outreach programs for Hindu Youth. Dr Jani serves as trustee of Param Shakti Peeth of U.K. a registered charity, working for projects of public benefit in the U.K. and creating global awareness of the practice of foeticide and infanticide in India and resettlement of disenfranchised women and children. Dr Jani is a keen sports enthusiast and traveller.

Manhar Mehta



Manhar Mehta is a professional engineer and has Master's degree in Industrial Management. He is the coordinator of the NHSBT's Living Organ Donation project 2017-2019 for raising awareness of Kidney diseases and need of donation of live organs within Jain community. The project has successfully achieved the planned objectives and milestones set at the inception of the project.

His activities and initiatives include:

- *Established a Jain organisation "Jain Samaj Leicester" in 1973*
- *Served on the executive of the Vanik Council since 1978, and Chairman since 1995.*
- *Established Jain spiritual care system in hospitals across the UK. His efforts led the NHS to recognise "Jainism" as a faith option for patients.*
- *Runs a course, 'Fundamentals of Jainism'*
- *Represents the Jain community on the NHS Healthcare Chaplaincy Multi-Faith Group for many years, served as the Group's Chairman from 2009-11.*

For his service to the Jain community, he has been presented the "OneJain Lifetime Achievement" award at the house of commons by Lord Bourne on the 28th Mar 2018.

Kirit Mistry



Kirit is the Chair and founder of South Asian Health Action Charity, and Co-chair National BAME Transplant Alliance (NBTA). He has developed Hindus, Sikhs and Muslims Embrace Organ Donation Awareness Campaign and South Asian Faith and Community Ambassadors project.

He also is the Co-Chair of East Midlands Patients, Public and Involvement Senate and has significant paid and voluntary sector experience both as a patient and community activist in research and health

services. He has particular experience and passion in delivery of equality and diversity particularly Black and Minority Ethnic communities. He is a type 2 Diabetic and has set up Leicestershire's South Asian Diabetes group a peer-led support group.

Kirit Modi (Chair)



Kirit is a kidney transplant recipient. He has been involved in promoting organ donation and supporting kidney patients for many years, since his retirement as an education officer. He is active within the National Kidney Federation (NKF), has been its Chairman and now has an honorary position with the charity. He is a founding member of NBTA (National BAME Transplant Alliance), has been its Co-chair and now is its Honorary President. He is currently leading the Living Transplant Initiative on behalf of NBTA, an innovative initiative funded by NHSBT, to increase living kidney donors from BAME communities. He is Chair of the Lister Area Kidney Patients Association. Kirit has frequently spoken to the All Party Parliamentary Kidney Group to highlight concerns about organ donation within BAME communities. Kirit received a Points of Light award from the Prime Minister for his work on organ donation in 2018.

Jay and Sina Patel



Sina and Jay are first generation British Hindus of Gujarati origin, whose parents were born in East Africa and India. Sina works as a Clinical Analyst for Guys & St Thomas' NHS Trust and Jay works as an Investment Banker at Deutsche Bank in the city.

The couple have been married for almost 20 years and are proud parents of three wonderful children - Aari and twin girls lyla and Asha.

Both became involved in organ donation following the loss of their 3-year-old son Aari in 2016. The couple both made the decision to donate Aari's organs, which went on to help two other children who are both still doing well today.

Sina and Jay are NHSBT London Ambassadors for Organ Donation which involves working for the NHS as volunteers to promote organ donation. Aari's story has also been part of a government campaign to promote organ donations across the BAME communities. Sina and Jay hope to continue promoting this vital cause and hope Aari's story will make a difference within all communities.

Akshaya Rajangam



Akshaya Rajangam is a fourth year Medical student studying in King's College London. She is an international student from Singapore and has resided in London for the last 5 years.

She currently serves as one of the National General Secretaries of National Hindu Students' Forum (NHSF (UK)), the largest Hindu student organisation outside of India. NHSF (UK), founded in 1991, aims to provide a platform for students to engage in promoting, protecting, preserving and practising Hindu Dharma through various events, initiatives and campaigns at a local and National level. The National Donation Month campaign has been a key initiative where students from across 45 universities have come together to raise awareness and registering for blood, organ and stem cell donations. Akshaya has a career interest in surgery and has published and presented clinical research in the field of urology and ENT.

Akshaya is also passionate about Bharatnatyam (Indian classical dance) and holds a diploma with a title award from Singapore Indian Fine Arts Society (SIFAS). Her other interests include painting and reading.

Professor Sejal Saglani



Sejal Saglani is Professor of Paediatric Respiratory Medicine at Imperial College and The Royal Brompton Hospital, London. She is a volunteer for BAPS Swaminarayan Sanstha with Headquarters at the Hindu Temple in Neasden, London. She is Co-Chair of the BAPS Healthcare Team. One of the key objectives of BAPS Healthcare team is to serve the community by improving Health and Wellness. As such, they are actively engaged in projects that raise awareness of key health issues pertinent to the local Hindu community. Their health awareness activities have focussed on educating the local

community and devotees that attend the Neasden temple and all other BAPS centres in the UK. Events are undertaken in a culturally sensitive way, taking into account lifestyle and preferred language. BAPS has promoted living and deceased organ donation awareness among the South Asian and Hindu community since 2011.

Prafula Shah



Change communications specialist working with a range of central/local government and public sector clients. Prafula has held several senior positions in UK PR companies before setting up Aawaz Communications and currently working as a freelance consultant.

Successfully delivered communications campaigns for organisations including Royal Mail Group, Network Rail and The Metropolitan Police Services as well as a number of central government departments and local authorities including Brent, leading on the marketing and communications for the Wembley regeneration project.

Prafula donated a kidney in March 2018 through the national kidney sharing scheme so that her niece Shakti could get a kidney transplant, which took place at the Royal Free Hospital in London.

Prafula serves as a London organ donation Ambassador for NHSBT and committee member of RFHKPA. As a trustee of the Jain Network and chair of Bhakti Mandal London, Prafula has worked with the Jain community for many years.

Satya Sharma



Satya has been interested in Organ donation for three decades. Satya was awarded an MBE in 2010 for designing innovative programmes for promoting OD 2010. He is the founder Chair of POD (Promoting organ donation group) 2012-18 and also chaired the steering group to arrange MOU between Mohan Foundation India and NHSBT 2015, as well as Co-Chair of the implementation group of the aforementioned 2015 onwards. Satya has been an Ambassador for NHSBT since 2018.

Dr Neil Soneji



Dr Neil Soneji is a Consultant Radiologist at the Imperial College Healthcare NHS Trust but also an active volunteer in the Healthcare Team at the BAPS Swaminarayan Temple, Neasden London. As a team of volunteers he has been actively involved in various projects promoting the message of Organ Donation in the Hindu Community since 2012. This has included organising conferences, awareness drives and the production of educational videos and leaflets focussing on both living and deceased organ donation. Events have taken place across the country both within Temples and at external venues with different charities, Temples and co-volunteers also supportive of this good cause. He hopes to continue to spread the message and educate about the new opt-out legislation within the Hindu Community as part of this Steering Group.

Meera Thakkar



A graduate from Bristol University with a Degree in Business; Meera began her career in Private Health Care as a Project Manager for General Health Care Group. Having a stern interest in Global Healthcare, specifically the fast emerging market in India, Meera decided to uproot and move to Mumbai to take on a role as Business Development Consultant for the well-known Diagnostic Testing Centre , NM Medical, Pan India.

Heading projects in Radiology Archiving Systems, International Medical Reporting and in-depth research into International Pathology Testing; she decided to take a break from the corporate world and move back to join the 25-year-old family business; the First Asian Vegetarian Care Home In London- Meera Nursing Home In North West London. Currently a Business Owner; with her experience in Health Care, Meera Assists her Father, Pramod Bhai Thakkar; in various Charitable and Social Projects in the UK, India & Africa.

Pramodbhai Thakkar



Pramodbhai is a Health Care Consultant in the UK and an International Project & Export Consultant for Africa/Asia. He is the Ex Director of Meera Nursing Home, the first vegetarian care home in North West London. Pramodbhai is also an ex member of Board of Governors of Oxford Centre for Hindu Studies.

He has also previously been a consultant and trustee Of Vaishnav Sangh UK and negotiated, purchased and project managed the refurbishment of a Haveli in Leicester. He has been instrumental in negotiating purchase & arranging loan finance of strategic community Centre in London for £4m.

Pramodbhai serves as Chairman and trustee of Jalaram Charitable Trust Leicester since its inception in 1982. He also chaired and project managed the design and construction of the first Jalaram Bapa's Temple in the UK at the cost of £1m between 1992 and 1995 and Jalaram Community Centre built in 2016 £0.5m. The new community centre is designed in such an iconic way that the total complex along with the existing temple is known as "Bapa's gateway to Leicester". Pramodbhai also supports local research charities, the homeless, and participates in multi-cultural activities.