



Fresh impetus needed to promote organ donation.

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A fresh impetus to promoting organ donation in England was discussed at a well-attended meeting chaired by Lord Jitesh Gadhia held in Parliament on 6 September 2023. The meeting was organised by the Jain and Hindu Organ Alliance (JHOD) and attended by a wide range of community organisations and other stakeholders.

The speakers included Lord Jitesh Gadhia, Neil O'Brien MP, Under Secretary of State for Primary Care and Public health, Rt Hon Shailesh Vara MP, Sarah Olney MP and JHOD's Patron Navin Kundra and Chair, Kirit Modi.

Neil O'Brien MP said: "He hugely appreciated the work done by ethnic minority community groups in promoting organ donation within their communities and thanked Lord Gadhia for arranging the meeting. He highlighted the importance of registering to donate organ after death because their families overwhelmingly consent to donation when a specially trained nurse has the conversation in the hospital. He said there was a long way to go, and he will carefully consider the outcomes from the meeting."

Covid has had a significant impact on organ donation activity and there are now considerably more patients waiting for an organ transplant than before the pandemic (5699 in 2019/20 compared to 6959 in 2022/23). The impact of the change in law to an opt out system, implemented since May 2020 in England, has so far been limited and the consent rate i.e., the percentage of families who give consent to a loved one donating their organs after death in the UK, reduced from 68% in 2019/20 to 62% in 2022/23.

Lord Jitesh Gadhia said: "Organ donation continues to have a disproportionate impact on the lives of ethnic minority communities, especially those from South Asia. Hundreds of members of our community die each year waiting for an organ. We expected that the change in law to an opt out system would help address this important healthcare inequality. Unfortunately, the pandemic has set us back and instead increased waiting lists. With the support of community members and organisations, I hope we can redouble our efforts to increase consent rates and give fresh impetus to tackling this important issue. The shortfall in organ donation is within our hands to resolve, and we should grasp the opportunity to save more lives."

Dr Paul Boadu, on behalf of the evaluation team led by the London School of Hygiene and Tropical Medicine reported that there was little or no evidence that the opt out law contributed to increasing consent rates in England. He added that it is likely to have made matters more complex and confusing for staff and families of the deceased.

Kirit Modi, MBE, Chair of JHOD explained the impact on ethnic minority communities at the meeting. The number of patients from ethnic minority backgrounds waiting for an organ transplant increased from 1,826 in March 2020 to 2,237 in March 2023. At the same time, the numbers of donors from ethnic minority background decreased: from 112 in 108 for donors after death and from 159 to 130 for living kidney donors.

He said: "We face a significant challenge in recovering from the impact of Covid on organ donation and transplantation and in meeting the ambitions of the change in law in England. A new approach to promoting organ donation, which highlights the importance of individuals registering to donate their organs after death and clarifies the opt out law, should be developed urgently by the NHS by working in partnership with ethnic minority groups such as JHOD. In addition, longer term funding should be allocated by NHS Blood and Transplant to support ethnic minority groups in spreading the message within their communities.

Navin Kundra, singer, songwriter, entertainer, and Patron of JHOD said:

"I'm extremely proud to become a patron for this wonderful charity because raising organ donation awareness is something that I'm really passionate about. Ultimately, it's about turning death into a Gift of Life and it's a selfless act that is truly life changing. I look forward to using my influence as a singer, songwriter and entertainer to bring more awareness of the incredible work and powerful message of JHOD to a wider audience so that registering to become an organ donor and not opting out are conscious decisions that are discussed with families and proactively pursued, particularly among the new generations."

Rt Hon Shailesh Vara MP said.

"The subject of organ donation is hugely important, especially in terms of understanding the legal position following the passing of the new legislation in 2019. I am very pleased to be co-hosting this event with Lord Gadhia, as it provides an opportunity to discuss the issue further so that there is greater awareness of the law change and ultimately, we can seek to save more lives."

A number of speakers talked about key Hindu and Jain values of "daan" and "sewa" which support organ donation and the encouragement we get from our religious leaders to donate organs to help save lives.

Lord Gadhia welcomed Navin Kundra, as a new Patron of JHOD, to the meeting and said it was very important to involve young people in discussing organ donation.

-Ends-

NOTES:

1. Dr Paul Boadu shared the following implications from the evaluation of the impact of the change in law in England at the meeting.
 - So far, there is little or no evidence that the 2019 Act has contributed to increasing consent rates and is likely to have made matters more complex and confusing for staff and families of the deceased.
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 - There is scope to simplify consent processes even without further legislative change.
 - Some of these findings are likely to be the result of the cautious approach to publicizing the law change, plus the disruptions caused by COVID-19.
 - There remains a need for higher profile and more targeted publicity campaigns directed to subgroups of the population, especially those from minority groups, to try to shift their ambivalence or negativity towards deceased organ donation.