

NHS

Royal Free London
NHS Foundation Trust



Gift of life project

Targeted support to patients on
living kidney donation: 2022/23

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Blood and Transplant

Introduction

The Gift of Life project was led by the Royal Free Hospital (RF) and the Jain and Hindu Organ Donation Alliance (JHOD) and funded by NHS Blood and Transplant (NHSBT) in 2022/23. The main purpose of the project was to provide 1 to 1 support to a targeted group of Hindu/Jain and Black patients waiting for a kidney transplant at the RF. This support was provided by appointing two part time Outreach Workers from the same ethnic backgrounds by the Hospital. A project Team led by Fiona Sharples, Lead Nurse Renal Transplant, RF, and Kirit Modi, MBE, Chair of JHOD, was established and met virtually each month. The Seventh Day Adventist Church (SDAC) was invited to join the project and Edith Samambwa, Health Ministries Director, Seventh Day Adventist Church (SDAC), joined the Project Team. In addition, JHOD and the SDAC arranged events in the community to raise awareness about living kidney donation and transplantation. David Myers and Nii Plange, President and Chair of the RF Kidney Patients Association were active members of the Project Team. The Project Team reviewed the information provided by the RF to patients and family members considering living kidney donation and transplantation at the RF and produced a new Resource Pack.

The project started in April 2022. The two Outreach Worker posts were eventually advertised, and appointments were made. Rekha Parekh was appointed as the Hindu/Jain Outreach Worker. Unfortunately, the Black Outreach Worker resigned because of personal reasons, and it was not possible to replace her in time.

Rekha Parekh was given a list of Hindu/Jain patient on the kidney transplant list and eventually 19 patients were identified within the target group. She contacted them by phone, WhatsApp and face to face meetings: 76 phone calls were made, 114 WhatsApp messages and 4 face to face meetings took place.

2 patients from the 19 had potential living donors and these were referred to the Living Donation Team at the RF by Rekha Parekh.

9 patients did not want to accept a live kidney from a family member and were waiting for a kidney from a deceased donor.

Gift of Life



Living Kidney Donation

Additional support for Hindu, Jain and Black patients

Your opportunity to explore the benefits of Living Kidney Donation even if you don't have a matching donor

The Royal Free Hospital Trust Renal Unit provides personalized assistance to Hindu, Jain, and Black patients with chronic or end-stage kidney disease.

The unit has two dedicated Outreach Workers, Rekha Parekh and Daniel Arthur, who offer an array of support services, including information on living kidney donation and transplantation.

The Outreach Workers offer culturally specific resources and ongoing guidance on finding potential living donors.

Patients can benefit from one-to-one support through phone, email, zoom, or during routine clinical appointments.

This initiative, funded by NHS Blood and Transplant (NHSBT) until March 2024, is part of a project led by the Royal Free Hospital renal team and JHOD.

For more information, please contact rekha.parekh@nhs.net.



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6 patients had tried to find a living kidney donor from the family but could not find anyone.

1 patient had already had a kidney transplant.

1 patient had a daughter who was a potential donor but she had diabetes and he was not happy with the risk of her daughter donating a kidney.

1 patient did not wish to be contacted again and gave no reason for this decision.

Overall, the one-to-one contacts provided valuable insight into the views of the 19 patients. The contacts were not face to face and we plan to arrange face to face meetings with patients in the future.

Resource Pack

The leaflets include “Your opportunity to explore the benefits of Living Kidney Donation even if you don’t have a matching donor”, a leaflet that explains “Kidney Transplantation remains, for those suitable patients, the best option for replacing the function of failed kidneys”, “Could I be a living kidney donor”, “A Jain initiative – Living Kidney Donation” and BAPS - “Making Possible a Gift of Life”.

We have also produced leaflets providing details of short videos talking about living organ donation and transplantation individually for the Jain, Hindu and Black communities. The videos feature many personal stories.

There are references for many short videos that cover cultural topics in living kidney transplantation, long term health for organ donors and practical themes of value to be talked about.

300 hard copies of the pack were printed and distributed to targeted groups of patients from the Hindu / Jain and Black backgrounds. The rest will be used by renal nurses to give to patients considering living kidney transplantation.

Hindu Community event

This event was arranged at the BAPS Swaminarayan Hindu Temple in Chigwell on 26 February 2023 in partnership with Prof Sejal Saglani and Dr Neil Soneji from BAPS and JHOD to increase awareness of living kidney donation and transplantation. 395 people attended; it was chaired by Dr Niraj Barot (BAPS) and speakers included Prof Reza Motallebzadeh (Transplant Surgeon, RF), Prafula Shah (Secretary of JHOD and living kidney donor), Rekha Parekh, Dasharath Patel (kidney recipient) and Kirit Modi. A video in which His Holiness Mahant Swami Maharaj, Spiritual Head of BAPS, speaks in support of organ donation was shown (Living Organ Donation and Transplantation for Hindu Communities - YouTube). Three questions were asked by the Chair before and after the event and the analysis was as follows:

1. Do you support organ donation after death?
Before: 152 After: 270
2. Does Hinduism support organ donation?
Before: 138 After 395
3. Do you support living kidney donation?
Before: 48 After 270.

This analysis proves the effectiveness of community events within the Hindu community when these are led by members of the community and held at community locations. Kirit Modi, Chair of JHOD said:



“I was delighted at outcomes from this event; we had a large attendance, the mixture of speakers was good, the content was targeted at the audience known well by the planning group and we all had a delicious vegetarian meal! It was a pleasure to work with colleagues from BAPS again. We need to do more to increase awareness on living kidney donation among the Hindu and Jain communities in the UK and JHOD is looking forward to working in partnership with Hospitals and community groups in doing so. Please contact us if you are interested; see contact details below.”

Seventh Day Adventist Church event

Nothing creates common ground and fosters good feelings as much as food and music. Particularly more so within the African and African Caribbean communities. It is with this in mind that the afternoon black community Living Kidney Transplant Donor (LKTD) event on the 1st of April 2023 began with a healthy plant-based lunch for all the guests and a lively gospel music session. Members of the Edmonton Seventh Day Adventist church and community visitors attended the event hosted by LKTD project team which was aimed at increasing awareness of living kidney transplantation and donation in the African/African Caribbean community.

The event was attended by over 100 people from the church and community some of whom had heard the event advertised on the Adventist Radio Station during a podcast recorded the previous Sunday by Edith Samambwa the LKTD project SDA church representative and Nii Plange the chairperson of the Royal Free Kidney Patient Association.

Undoubtedly, the most impactful part of the session was hearing from the five recipients who had received life changing kidney donations. Sharing their traumatic journeys of kidney failure, dialysis, and the anxious wait for a donor, they captivated the audience as they told



their deeply moving stories. Their stories emphasized the prevalence of kidney disease and vulnerabilities in the African and African Caribbean community.

Recipients sharing their journey were: N’ii Plange MBE Chairperson of RFKPA (Royal Free Kidney Patient Association); Funmi Lawal, London Kidney Association Patient Representative; Andy Peynado, Douglas Davis and Makada Brown-Dako.

Presenting at the event was Cynthia Davis, a nurse with a speciality in nephrology. Cynthia had been part of the pioneering work done in the early 2000s by the first London African Kidney Association. Cynthia shared vital statistics and demographic information related to kidney health among black Africans and Caribbean. Davis emphasised the need to continue building awareness to help mitigate organ donation barriers, including issues of trust, cultural and religious myths, misinformation, and access to relevant health information.

Sharon Platt- Mcdonald, the SDA church Health Director in the British Isles and one of the guest speakers highlighted the cultural disparities that impact and inhibit donors from black communities. “Identifying specific faith groups and their beliefs and practice around organ donation provides an opportunity for culturally relevant and most importantly culturally sensitive messaging’ she stated.

It was great to have the support of Rekha Parekh, the LKTD outreach worker for the Asian community who gave an overview of the Living Kidney Transplant Donor (LKTD) project and shared the experiences of donors and recipients in the Asian community and some of the transferable lessons that Black communities can embrace.

Reflecting on the numerous comments about the programme, Edith Samambwa stated that “The responses were very positive and showed that it was a much-needed event. We had requests from guests visiting from other areas of London to bring the event to their local communities. It was a revelation to most of the guests that a person could live with one kidney and that as much as the recipients could survive with one kidney should they decide to donate. It was apparent that greater awareness is needed in the community, and it is our intention to run more community awareness events in the next Project Cycle.

Conclusion

This innovative project has been successful overall, and we have learnt a lot which is helping the second year of the project. We are hoping to secure further funding from NHSBT to continue this project in 2023/24.

The key successes have been:

- The one-to-one contacts with the 19 patients resulting in two referrals to the kidney transplant team of potential living donors. However, the limitations of phone and WhatsApp contacts have been recognised and in the second year all targeted patients will have an initial face to face meeting; followed by subsequent contacts which work best for the patients.
- The targeted patients were those on the transplant waiting list and many had already decided that transplantation was not their preferred option for a variety of reasons. In the second year, we are targeting patients who attend the low clearance clinics and believe most of them have probably not made final decisions on their preferred pathway.
- Rekha Parekh used her knowledge of the surnames to identify the Hindu and Jain patients from the list provided to her. The quality of the information by ethnicity and religion held by the Hospital needs to be reviewed. However, this is an issue for the Hospital and not covered by this project.
- The monthly virtual meetings of the Project Team, and the amazing time and commitment of many project team members given on a voluntary basis. However, attendance by some members has been patchy.
- The development of the specific Recourse Pack for patients and their families considering treatment options. Hard copies will be printed so that they can be used by the targeted patients and other patients at the Hospital.
- The training of living donation champions. We plan to work with the Peer Support Service at the Hospital in the second year of the project.

The key challenges have been:

- The poor service by the Finance and HR teams at the Hospital. This matter has been raised at a senior level within the Renal Department. JHOD has taken over the financial responsibility for the second year of the project to resolve part of the problem, but the HR issues continue to be challenging.
- The overall amount of funding available from NHSBT is not sufficient to undertake this project without the significant voluntary efforts of the members of the Project Team. NHSBT should review this for the future.

LIVING KIDNEY DONATION & TRANSPLANTATION

IN JAIN & HINDU COMMUNITIES

A forum to raise awareness
about the need and importance
of living organ donation



SPEAKERS

Mr Reza Motallebzadeh: Transplant Surgeon, Royal Free Hospital
Kirit Modi MBE: Chair of Jain & Hindu Organ Donation (JHOD) Alliance
Prafula Shah: Living Kidney Donor, Secretary of JHOD
Dashrath Patel: Kidney Recipient and BAPS Volunteer
Rekha Parekh: Hindu/Jain Outreach Worker at the Royal Free Hospital
Vishal Barot: BAPS Volunteer
**Key messages from HH Mahant Swami Maharaj
and Pujya Yogvivekdas Swami**



Sunday 26 February 2023



4.00pm to 5.00pm
Followed by dinner



BAPS Shri Swaminarayan Mandir,
Mandir Lane,
Chigwell IG7 6ED
Free car parking available



Please register using this link: tiny.cc/LivingKidneyConference

This conference is funded by NHS Blood and Transplant through the Community Investment Scheme

SCAN ME



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For further information about this project, please contact:

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or

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Further information about JHOD is available from www.jhod.org.uk