



VANIK COUNCIL(UK)

Living Organ Donation - "Give a Gift"

Final Report 2017-2019

1. Aims and objectives

So many Hindus and Jains suffer from high blood pressure and diabetes, the chances of developing kidney failure in our community is high.

The drop in the number of living kidney donations and transplants over the last few years is becoming a major concern.

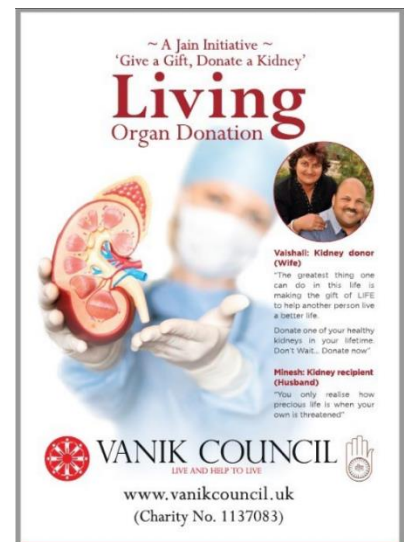
Within the Jain community, organ donation, particularly with kidneys is on the decrease.

Statistics provided by NHS Blood and Transplant in their 2015/16 report indicate that there were 5189 patients waiting for a kidney transplant in the UK and 944 (18%) were from Asian background.

There were only 98 organ donors from the Asian community; 71 were live donors and 27 were donors after death and the numbers of donors are going down.

In view of the above, the main aim of our project which started in 2017 was to make Hindus and Jains aware of the need to donate an organ with emphasis on individuals within our community to come forward.

The Jain/Hindu community, in general, has been reluctant to come forward or openly discuss matters relating to organ donation. Our aim at inception has been to help our community come out of this shell thus help individuals and their families to better understand and endeavour to remove the fear that currently appears to exist. Our community will, as a result, be better informed and we hope this project will provide sufficient information to allow them to come forward, discuss amongst friends and families and consider donating a kidney.



2. Activities Undertaken

The following tasks were undertaken –

Leaflet: a leaflet was designed and produced to help our community answer key questions on living organ donation. Following completion of the leaflet, it was circulated to all community members on our data base (2000 plus families) and we further distributed the printed copies of the leaflets to those attending events organised by our affiliated organisations and at the events we arranged.

Diet leaflet: Vanik Council also published a leaflet titled 'Guidance on reducing Potassium (K) content for Gujarati vegetarian diet' - The leaflet was distributed at events that we held and is also published on our website.

Conferences: In order to raise awareness directly with our community, we arranged a number of conferences through which we could promote living organ donation. During 2017-2018 we held four events and in 2018-2019, we held conferences in Manchester, Leicester, Crawley and in North West London. During these events, we invited a GPs,



Living Donor Coordinator, kidney surgeon/consultant, Dietician (targeted to vegetarians), NBTAs Honorary President and community leaders. The presentations/stories from donors/recipients were followed with a Question and Answer session.

Follow-Up: Following events that were held, we arranged follow-up sessions for those members who wanted more information. Senior LDCs were invited to explain the process and answer their questions.

Videos: As part of this project, we also produced a Video for whoever was interested in donating a kidney. Our expectation was that this could be used by friends, families to generally promote living organ donation within our community. The final videos that we produced included members from NBTAs/Vanik Council who provided a brief summary of the project, medical professionals who provided details on Living organ donation, interviews with recipients and donors who have been through this process and Jain leaders who gave an insight from a religious perspective. These videos were provided to NBTAs and NHSBT for uploading it onto their websites. We have also uploaded it onto the Vanik Council website. In total two videos were produced, one which is around 22 minutes and a shortened version, about 5 mins. At events held during 2018-2019, the videos were also shown to those who attended.



Links to videos are detailed below.

[Living Organ Donation Short](#)

[Living Organ Donation Long](#)



3. Management

Throughout the Project, regular meetings were held to plan, review, monitor and track progress of activities that we had undertaken. Considerable effort from volunteers within Vanik Council and affiliated organisations ensured the success of both projects.

- Leaflet – The generation of the leaflet required considerable effort to ensure answers to key questions were provided. This involved research on the internet, reviewing of material that existed, interviewing people and obtaining approval for the accuracy of the leaflet.



- Events – Arrangements of events to Promote Living Organ Donation on a large scale takes a lot of organisation including promotion to attract large numbers from our community . This is non-trivial and took considerable effort and time from many individuals. Planning the event including identifying and gathering key speakers who could provide the information takes considerable time and effort to arrange. In order to plan these events, numerous meetings and discussions took place prior to the events.
- Video – Numerous meetings were held to discuss the content of the video. As part of the video plans to interview key speakers , recipients and Donors has to be coordinated with interviews being convened at convenient times for the participants. Following completion of the video, considerable time was spent on editing the content to ensure maximum effectiveness.
- Coordination – Organising events away from London needed considerable effort particularly with monitoring and continued guidance to ensure success. There were a number of challenges that had to be overcome particularly with arrangements of speakers and scheduling of the day's itinerary.

4. What worked well

- Participation of community members to events that we organised. For one of the events that we organised, more than 250 people attended.
- Awareness of the project through circulation of the leaflet to over 2000 families
- Participation of key medical professionals at our events.
- Participation of Donors and Recipients including heart-warming stories at our events.
- Excellent Question and Answers sessions from community members at events.
- Completion of feedback forms with positive results.
- Positive interest in community members expressing an interest in living donation
- Positive feedback on event organisation of events.
- Three Kidney donations from living Donors due to our campaign.
- Positive feedback from those who attended the conferences

5. Evaluation

Considerable effort and time was devoted by Vanik Council executive committee members, Volunteers, Medical professionals, Donors , Recipients and many others. In terms of finance, the amount of budget that we spend far exceeded the budget that was allocated, however the results from the promotion and interest shown from our community has made this a very worthwhile project to be involved with.



My Klrit Modi has been instrumental in providing us guidance and support through both projects. Vanik Council is indebted for this continued support.

6. The main challenges

- Attracting community members has been difficult, however with great determination, we exceeded our expectations.
- Video – producing the video has consumed a lot of time and effort. In particular interviewing all involved in the video took a lot of preparation.
- Event arrangements and preparation has taken a lot longer than envisaged.
- Schedule of events has had to be carefully organised to ensure maximum effectiveness.
- Invitations to key speakers and confirmation to attend events was time consuming.
- Leaflet generation consumed a lot more time to ensure accuracy and also for it to be useful for the future.
- Attendance at follow-up sessions was poor
- Individuals who showed an interest in donating at the conferences, failed to pursue.
- Difficulties in coordinating with affiliated organisations where executives from Vanik Council are not based.

7. Summary of Conferences

Summary 2017-2019

	Venue	Date	Attendance	Expressing Interest
2017-2018	Navat Vadil Mandal	May-17	160	No Forms
	Navnat Vadil Kenra	Jun-17	190	26
	Follow Up Sattavisgam	Aug-17	15	N/A
	Navnat Centre	Oct-17	250	50
	Follow Up Sattavisgam	Dec-17	10	N/A
	Follow Up Sattavisgam	Feb-18	35	N/A
	Sattavisgam	Mar-18	100	20
	Total 2017-2018		760	96
2018-2019	Manchester	Oct-18	160	124
	London	Feb-19	106	39
	Crawley	Mar-19	150	26
	Leicester	Mar-19	150	34
		Total 2018-2019		566
	Total 2017-2019		1326	319

Summary of Targets v Actuals

		Target	Actual
2017-2018	Number of People Interested	10	96
	Number of People Assessed	5 to 6	4
	Number of People Suitable	1 or 2	2
	Number of Live Donation	2
2018-2019	Number of People Interested	45	138
	Number of People Assessed	7	5
	Number of People Suitable	2 or 3	1
	Number of Live Donation	1
	People offering live donation but recipients waiting for results of assessments	4

8. Conclusion

In summary, Vanik Council exceeded expectations on a number of fronts –

- Attendees at events exceeded expectations
- Good response in completion of feedback forms.
- Number of people who came forward to being assessed.
- As a result of the promotion, it was remarkable that three members of our community donated their kidneys
- During 2018-2019, we found at least one person at every event



who as a result of our promotion had come forward to donate an organ, however, could not continue due to issues with the assessment.