## Chapter 2

## MOTIVATION FOR EYE DONATION

#### Motivation – A Difficult Task

The task of motivating and actually procuring the eye donations in adequate numbers requires a lot more efforts and dedication than other similar missions like say, collecting the blood donation. In a single blood-donation camp, it may be possible to collect a large number of blood bottles but such is not the case with eye donations. The instances of voluntary organizations starting an eye bank with enthusiasm and then becoming defunct are common. Thus, while we have over 150 eye banks, the active eye banks collecting at least 100 pairs of eyes a year in the entire country established formally, may number just between 30 and 40. [See Appendix 'F' (I) for the list of Eye Banks in Mumbail.

# Collecting Pledge - cards - A limited Impact on Actual Procurement

Many voluntary service organizations organize drives to collect pledge-cards in large numbers. In fact it is the author's common experience that most of them feel that by organising a camp aimed at collecting a certain number of pledges of eye donation and inviting some celebrities for getting their pledges (more for publicity sake) they have done their utmost to support the cause of eye donation. While such pledge cards may be helpful in creating awareness in favour of eye donation, their effectiveness in getting the actual eye donations is in reality questionable. Usually, so much time elapses between the filling up of such a card and the occurrence of actual death of the pledger that in due course many people even forget having ever filled up such a card. A pledge for eye donation from a young person of (say) 25 years of age may not have any significant meaning for the eye bank if his/her death were to take place 40 to 50 years later. The cards have to be stored in the eye banks for a long time and as the contact is lost over a period of time, the pledge may not be of any practical value. It may be mentioned that even to store the large quantity of pledge eards collected over a period of time becomes a vexed problem for many a eye bank owing to the paucity of storage space.

<sup>&</sup>lt;sup>1</sup> It is still a common practice in our country to call Eye Donation Centres as Eye Banks

#### Donor Cards

Instead of pledge cards being collected by the eye banks, the more purposeful approach would be to distribute Donor Cards (see Specimen on page 17), which could be filled up by the person wishing to donate eyes after his death. Such a card can remain with the person himself. An ideal Donor Card should contain two parts, one of which can be handed over to the nearest relative who will remain aware of the wish of the Donor. This will carry weight as it is actually the next of the kin of the deceased who will be the decision maker for fulfilling the wish of the deceased. The deceased himself beyond expressing his wish cannot play any active role due to obvious reasons as the entire process of donating eyes actually takes place only after his death.

## Role of a Family Physician

The family doctor can also play a very active role in the eye donation. He generally enjoys the confidence of the patient and his being in constant touch with the family of the deceased when the actual death takes place can be of great value in strengthening the motivation in favour of eye donations. On most occasions, especially when the death takes place at home, which is very common in our country, the family physician is the first one to announce the occurrence of death.

One of the most effective ways to generate the necessary motivation and create an awareness on a large scale in the matter of eye donation would be to display a well-designed poster on eye donation (mentioning, inter-alia, the tel. numbers of local eye banks) in general practitioner's dispensary. The continuous exposure of this message to the patients and the medical practitioner himself would create the necessary impact in favour of the eye donation in the long run.

#### Financial Assistance

The grant of some financial assistance to the nearest relative or legal heirs of the deceased donor, especially among the economically weaker sections of the population would also help in providing the necessary incentive in favour of eye donation. However, this is a controversial topic and generally not encouraged. Rather than providing the assistance in cash, the assistance may be provided in the form of defraying the burial or cremation expenses.

## Listing of Eye Bank Phone Numbers

The Dept. of Tele-communications of Central Government has given instructions to allot a four digit no. 1919 for eye donation centres. Many eye donation centres / eye banks in several cities have procured this number, making it easier for the people to remember it. Where there are more than one eye donation centres or eye banks in a city, it is

necessary that they must coordinate amongst themselves for allotment of this number to avoid any controversy or rivalry among themselves. The area and distance that can be reached by each eye donation centre can be identified by these centres in mutual coordination.

## Appeal through Religious Heads

An appeal by the religious heads especially in a country like ours where the religious heads have a large following can go a long way in motivating the people in favour of eye donation. A formal dialogue with these religious heads needs to be established giving them the basic information on the subject and impressing upon them the vital need for procuring a large number of corneas for the benefit of the blind. This is because once these religious heads are sufficiently motivated, they can play a lead role in encouraging eye donations on a larger scale.

It may be noted that even in Islamic countries where the activity of eye donation was practically non-existent, the situation is changing rapidly and the maulavis, who had preferred to remain silent on the issue in the past, have now changed their stand in favour of eye donation. In fact, the religious heads in Egypt, Saudi Arabia, Jordan, Pakistan etc. have passed 'Fatavas' in support of the eye donation. Let us hope that the maulavis in our country also would follow suit and the Muslim community, which has uptill now remained aloof in this field, would actively participate in the drive for eye donation.

## Pledge-cards Attached to Driving Licences or Identity Cards

In countries like the U.S.A, almost every adult has a driving licence and many attach their eye donation pledge cards to this licence. In a country where every family owns a vehicle and where the automobile accidents take a heavy toll of life, such a pledge greatly facilitates eye donation. Such pledges can also be included in the identity cards issued to the employees by the employers of large organizations or other agencies. Even the credit card can be modified so as to provide for some space for recording the pledge for eye donation. In large metropolitan cities like Bombay, where a substantial number of people hold season tickets for travel by suburban trains, the identity cards issued to them by railway authorities can provide for the required space for recording their pledge for eye donation.

#### Success of Sri Lanka

It will be of interest to note that the eye donation campaign in our tiny neighbouring country viz; Sri Lanka has proved to be so successful that besides catering to its own requirements, the eye balls are sent by it to several other countries in Asia and Africa. Over the last 35 years, the Sri Lankan Eye Donation Society has flown over 40,000 eye balls to nearly 135 cities in the various countries of the world. The Buddhist

religious leaders have played a vital role in Sri Lanka by including the message of eye donation as a part of their preaching.

#### Promotional Literature

The distribution of promotional literature containing the basic information on the subject with an appeal for eye donation is apt to play an important role in the motivational campaign in favour of eye donation. Such promotional literature can be distributed amongst the relatives of patients in major hospitals. In fact, copies of the literature can be kept at the reception counter in the hospital and also given to the relatives at the time of registration of the patient concerned in order to generate the necessary initial tempo in favour of eye donation. Sponsorship can be obtained from voluntary charitable organizations for meeting the cost of printing such literature.

## Appreciating the Donors and Their Family Members

The posthumous appreciation of the donor and his / her family members by the concerned eye bank and social organizations can go a long way in stimulating the eye donation activity.

The issuance of a Certificate or Letter of Appreciation (see page 19 for specimen) and giving due publicity concerning the noble act of eye donation on the part of the deceased donor would substantially contribute in motivating the members of the public at large.

In Mumbai where the local Gujarati newspapers do not charge for insertion of any announcement pertaining to news of death in the regular obituary column, there is also a tradition of highlighting the mention of eye donation made by the deceased. In fact, one of the leading newspapers (Janmabhoomi) even publishes a photograph of the deceased without any extra cost. Such a thing has helped the cause of Eye Donation in a big way in the Gujarati community which has always provided the majority of Eye Donations in Mumbai. If the newspapers of other languages also sponsor the cause in a similar manner this can certainly spread the message among the readers of other communities.

The Arpan Eye Bank, which has been one of the most successful eye banks in Mumbai, has till now, retrieved 6648 eye balls since it started functioning in the year 1986. Its area of functioning is restricted to Ghatkopar, a suburb of Mumbai having a population of about 7-8 lakhs, majority of which is from Gujarati community. Their present rate of collection is about 50 eye balls per month. It has found a novel way of spreading the message of eye donation. Apart from meeting the family members of the deceased donor and conveying them in person the deep appreciation for their act of donating the eyes of the deceased relative, one of the Trustees attends the condolence-cum-prayer meeting in respect of every such donor at which a grateful mention is made about the noble gesture of eye donation exhibited by the deceased and his family members and the Certificate of Appreciation given by

the Eye Bank is also displayed at this meeting. In this meeting, an appeal is also made for promoting the cause of eye donation in general. It may be mentioned that the whole atmosphere prevailing at such a meeting is highly conducive for the voluntary pledging of donation of eyes since the audience is generally receptive to the inspiring message for eye donation for benefiting the suffering blind humanity in general. It may be mentioned that such motivational efforts gradually but steadily produce the desired results in the long run as has been the experience of the Arpan Eye Bank. There is another social organisation, Tarun Mitra Mandal in Mumbai which organises retrieval of corneas from various places in Mumbai city and suburbs through its network of social workers, has retrieved uptill now 5066 eye balls since it started its activity in 1997.

## Hospital Retrieval Programme:-

 The motivational efforts for eye donation could produce very effective results if carried out on a sustained basis in large hospitals especially in wards like ICUs where death rate is much higher than that in other wards<sup>1</sup>.

## A Three Pronged Strategy on the following lines is suggested :-

- (a) Distribution of basic information and knowledge about eye donation disseminated in simple question-answer form in English, Hindi and Regional language(s).
- (b) Posters on eye donation to be displayed at all public places especially the waiting areas. Sponsorship for expenses incurred can be supported by local service organisations such as Rotary Clubs, Lions Clubs etc. (See last cover page for various types of posters published from time to time by different organisations).
- (c) Motivational efforts by the Hospital management and social workers. This is a delicate task & can be planned in the following manner:
- The first contact with the ailing patient or his / her relations must only be an informal one without even an implied

<sup>&</sup>lt;sup>1</sup> In the course of my long association with the cause, I have suggested to individuals and voluntary service organisations to actively involve themselves in a hospital retrieval programme rather than concentrate or divert their energy or resources on organising camps to collect pledge cards which as mentioned earlier on most occasions is more of a publicity oriented programme. Recently, one such organisation, Rotary Club of Bombay Hills (South) has vigorously initiated such programmes in K.E.M., Bombay and Nanavati Hospitals in Mumbai.

suggestion for eye donation but only with an intention to enquire about the health of the patient.

- (ii) The nursing staff including the Head Matron in places such as I.C.U.'s where mortality rate is the highest must be duly motivated about the imperative need for eye donation. They should be briefed on the subject during the course of workshops/short seminars/talks by the representatives of eye banks from time to time.
- (iii) When the actual death of the patient takes places, the nursing staff would be required to play the key role as they would be in day to day touch with the relatives of the deceased and the request/suggestion for eye donation made by them to the relatives could play a very positive role in persuading the relatives to agree to donate the deceased's eyes.
- (iv) The next in line should be the management staff/social workers who have already established the necessary contact with the relatives when the patient is hospitalised.
- (v) The last important link would be the R.M.O./person issuing the death certificate who would be required to make a request for eye donation, if not done already.
- (vi) The momentum for eye donation could be further sustained by suitably displaying the names of eye donors ('Donors of the Month') at prominent places coupled with the reassuring words of appreciation by the Hospital Management Staff and also the issuance of a suitable certificate by the concerned eye bank to the relatives of the deceased.
- (vii) Awards can also be instituted for being given to the best social worker/nursing staff and others who have facilitated an appreciable number of eye donations coupled with the expression of appreciation by way of bestowing an honour on them in public.

The data collected from the hospitals which have initiated hospital retrieval programme indicates encouraging results. If taken up properly, it is possible to reach a retrieval figure of 20 to 25% of total deaths taking place in the hospital through proper motivational efforts within a period of 3 to 5 years. This is evident from the statistics collected in hospitals or nursing homes (having I.C.U.s facilities) where such programmes have been initiated as will be observed in the following tables.

TABLE I
HINDUJA HOSPITAL – CORNEA RETRIEVAL PROGRAMME

Year	No. of eye donations received	
1995	16	
1996	60	
1997	119	
1998	135	
1999	163 170 164	
2000		
2001		
2002	136	

## TABLE II

# ARPAN EYE BANK (MUMBAI) \* HOSPITAL CORNEA RETRIEVAL PROGRAMME

Name of ICU	No. of Monitored Cots	Admission	Death No. (% adm)	Eye Calls No. (% Death)
Ashirwad	9	3535	278 (7.86%)	87 (31,29%)
Hindu Sabha	8	NA	NA	46 (NA)
Varun	6	1225	136 (11.1%)	20 (14.7%)
Average	7.66	2030	207 (8.7%)	51 (24.6%)

- No. of patients admitted is generally 100 per LC.U. monitored cots
- 2. International death rate in ICU-8-10% of Admissions
- 3. Average no. of eye donations received is 20-25% of deaths

## Feedback from successful transplant donees:

The feedback from successful transplant donees plays an important role in any motivational campaign. The restoration of vision and the overall change in the life of the corneally blind persons due to successful corneal transplant should be published and should be displayed at eye donation centres. Such persons should also be called in person in programmes involving motivation campaigns. The narration of change in their lives before and after the transplant helps a great deal and clears doubts in the minds of the audience about the success of corneal transplant operation and has a much greater and lasting impact. A specimen Question and Answer is shown on page 18.

<sup>&</sup>lt;sup>\*</sup> Data provided by Dr. Prakash Katakia, Ex-Hon. Secretary of EBAI and also a family physician actively involved in enucleation activity on behalf of Arpan Eye Bank. It may be mentioned that all the above 3 LC.Us are situated in Ghatkopar. The results in the table are based on 3-year average of the statistics collected.

## EVE DONOR CARD thereby give my consent to denote my eyes after my death for the purpose of Transplantation or Medical Education or Research Sex : Male/Female lei No . Donor Signature Witness Witness Carry this part of your card with you COORDINATION & RESEARCH K.B.H. Bachaveli Haspital, 56/60, Jehangir Merwanji Street, Neur KEM Hospital, Parel, Mumbai - 400 012. INDIA

fel.: 91-22-2416 2929/2416 4342 Telefox , 91-22-2416 #869 E-mail: eherr@vsnl.com Website : http://www.eyebankrrc.org

Remember Phone 1919 (24 Hours) for Eye Danation

### SPONSORED By

BHAICHAND M. MEHTA CHARITABLE TRUST

B-145/146, Mittal Tower, Nariman Point, Mumbai - 400 021.

Tel: 2202 8532 / 8658 / 2283 2770 mail\_mehtagroup@thgemerald.com

This portion of Donor Card be handed over to your nearest relative. I have pledged to donate my eyes after my death for the purpose of Fransplantation or Medical Education or Research, Kindly respect my wishes. Donor Name . ..... Date : Bonor Signature : Wilness Witness:

ter Eye Donations become your Family Tradition

- in the event of death
- (1) Keep death certificate ready.
- (2) Contact nearest eye bank as soon as possible.(3) Switch off fan. If possible, switch on AC.
- (4) Close the eyelids & put wet cotton on the lids.
- (5) Put two pillows beneath the donor.

Remember Phone 1919 (24 Hours) for Eye Donation

EYE BANK COORDINATION & RESEARCH CENTRE K.B.H. Bachoonli Hospital, 56/60, Jehangir Matwanji Street, Near KEM Haspital, Poref, Mumbai - 400 012, INDIA. Jel. : 91 22-2416 2929 / 2416 4342 \* Jelofax : 91 22 2416 BB69 E-mail : phere@vsnl.com \* Website : http://www.evebunkerc.org

## (Specimen of Patient Feed-back Form used at Eye Bank Coordination & Research Centre, Mumbai)

Name :	Affix Photo	Affix Photograph Here	
Age:	Before Surgery	After Surgery	
Address/Tel:			
	1		

Please help us serve the corneally blind by answering the following questions. Your answers are extremely valuable to us and will help us to improve many lives.

- 1. Since when did you suffer from eye problems? Mention the Year
- What was the condition of the eyes before the operation (Tick ONE Only) Very bad / bad / fair / good / very good / extremely good
- Were you able to do daily routine work before the operation? Yes / No
- How do you feel after the operation? (Tick ONE only)
   Depressed / Unhappy / Happy / Very Happy / Extremely happy
- What changes have come into your daily routine work after the operation? Do you feel better now? Write in short.
- Will you recommend other patients like you to undergo this operation? Yes / No Reasons:
- Are you satisfied with post operative treatment? Yes / No. Any suggestions
- Did you know that sometimes your body rejects another cornea?
   Yes / No.
- Do you know the symptoms when your body begins to reject the new cornea? Yes / No Please contact your doctor as soon as possible if you feel there is an eye problem or if you notice something unusual.
- 10. Did you know that there are many tests done before a cornea can be transplanted? Yes / No

12. Are you willing to help others like you and contribute to this noble cause? Yes / No How will you do so? (few words)
Specimen Certificate issued to the donor's family
We hereby recognise the valuable and humanitarian services rendered
by Shri/Smt
(Next of Kin)
of the late Shri/Smt
by Donating eyes of the deceased. It is the best and the most Precious Gift one can give to the cause of humanity, so that the less fortunate Blind Brothers and Sisters can enjoy the beautiful world.
God may bestow eternal peace on the departed soul.
ISSUED ON:
(The other side of the certificate can contain the translated version in

the concerned vernacular language).

 Did you know that skilled technicians work round the clock to provide high quality cornea for patients like you? Yes / No