

## Original Research Article

# How to motivate people for donor eyes with active support and participation of NGOs

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### ABSTRACT

**Background:** Corneal diseases are among the major causes of vision loss and blindness in the world today, after cataract and glaucoma. In India, it is estimated that there are approximately 6.8 million people who have vision less than 6/60 in at least one eye due to corneal diseases. On an average, the country needs 200,000 corneas in a year, and only 44,806 are collected. Therefore, creating awareness amongst the masses and encouraging them to pledge their eyes for donation is critical. We utilized the help of local voluntary, social, and religious organizations for the implementation of the awareness and motivation program.

**Methods:** Authors utilized the help of local voluntary, social, and religious organizations for the selection of sites, local publicity, arrangement and mobilization of people and other infrastructure. Schools, colleges, clubs, organizations, trade union offices, public functions, etc were utilized for the arrangement of this awareness and motivation camps.

**Results:** As a result of the eye donation awareness and motivation programs we got 1035 eyes in the past 12 years. Starting with 24 eyes in the first year rising to 126eyes in the 12th year. 64% of the eyes received were utilized for keratoplasty and 36% were used for research purposes.

**Conclusions:** Our experiences has convinced us the important role of social and religious organization and its leaders in spreading the message of eye donation among people. These organizations have an active role in creating awareness and motivation of eye donation to clear the backlog of corneal blindness in India.

**Keywords:** Corneal blindness, Eye donation, Social organizations

### INTRODUCTION

Blindness is an important symptom of many eye disorders. Eye diseases affecting the cornea are a major cause of blindness worldwide. In some areas of Africa as much as 90% of all blindness is a direct result of corneal pathology. Corneal disease resulting in corneal scarring is also a common cause of unilateral and bilateral blindness in children and young adults. In high-risk groups in some parts of Africa and Asia, the incidence of childhood cornea-related visual loss is 20-times higher than in

industrialized countries. The importance of corneal disease as a major cause of blindness in the world today remains second only to cataract, but its epidemiology encompasses a wide variety of infectious and inflammatory eye diseases. The prevalence of corneal blindness varies from country to country depending on many factors, such as availability and general standards of eye care. Blindness is one of the major health problem especially in developing countries like India where it leads to loss of many man hours. Blindness continues to

be one of the major public health problems in developing countries.<sup>1</sup>

According to the World Health Organization, corneal diseases are among the major causes of vision loss and blindness in the world today, after cataract and glaucoma. In India, it is estimated that there are approximately 6.8 million people who have vision less than 6/60 in at least one eye due to corneal diseases; of these, about a million have bilateral involvement. It is expected that the number of individuals with unilateral corneal blindness in India will increase to 10.6 million by 2020. According to the National Programme for Control of Blindness (NPCB) estimate, there are currently 120,000 corneal blind persons in the country. According to this estimate there is addition of 25,000-30,000 corneal blindness cases every year in the country. The burden of corneal disease in this country is reflected by the fact that 90% of the global cases of ocular trauma and corneal ulceration leading to corneal blindness occur in developing countries.<sup>2</sup>

On an average, the country needs 200,000 corneas in a year, and only 44,806 are collected. Out of these, only 46% (20,632 eyes) are utilized for sight restoration as the other 54% do not meet the standards for transplantation. As a result, the patient line-up and wait to get a corneal transplant keeps getting longer with each passing day. Furthermore, the cost of cornea transplant in addition to unavailability for corneas makes it practically impossible for underprivileged people to access these medical remedies. Therefore, creating awareness amongst the masses and encouraging them to pledge their eyes for donation is critical.<sup>3</sup>

To face the problem of shortage of good donor eyes, in 2005 Jubilee Mission Medical College and Research Institute (JMMC and RI), Thrissur, Kerala started the eye donation motivation programme with the help of social, religious and voluntary organizations in and around our hospital. By the eye donation awareness and motivation programme we were able to procure 1035 donor eyes during the last 12 years (2005- 2016).

## METHODS

The task of motivation and actually procuring the eyes require a lot of efforts and dedication. Collection of signed eye donation forms (pledge cards) has a limited impact on actual procurement but is helpful in creating some awareness among people regarding eye donation.

Authors have started the programme of eye donation by motivation of public with the help of Eye Bank Association of Kerala which is affiliated to Eye Bank Association of India (EBAI) during 2005-2006. JMMC and RI is an institutional member of EBAI. EBAI is a national organization acting as a resource center for all eye banks and organizations involved in the eye donation movement. The main objectives of EBAI are to increase

collection of eyes, introduce uniform standards in eye banks all over the country and to educate public about eye donation and prevention of corneal blindness. Over the past few years EBAI has been receiving support from all quarters.

Authors utilized the help of local voluntary, social, and religious organizations for the implementation of the programme. The team consist of a project coordinator, corneal surgeons of our hospital, social worker, publication officer, technicians and projector, video, photography and driver of eye bank vehicle. The help of social, religious and voluntary organizations was used for selection of sites, local publicity, arrangement and mobilization of people and other infrastructure. Schools, colleges, clubs, organizations, trade union offices, public functions, etc. were utilized for the arrangement of this awareness and motivation camps. Newspaper, all India radio, doordarsan, public announcements, notices etc. were used for giving publicity regarding the programs. The program included seminars, study classes, discussions, symposium, question and answer section, lectures and utilized slides, video, films and distributed booklets, posters, eye donation forms etc. Figure 1 shows an awareness program conducted by our hospital.



**Figure 1: Eye donation awareness program conducted by our hospital in association with Lions club.**

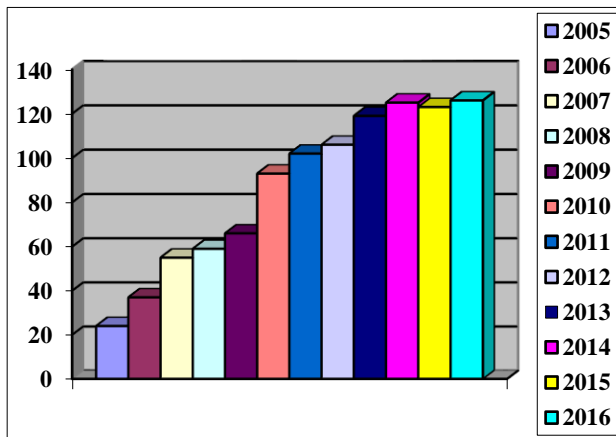
Clubs like Rotary, Lions, Y's Mens, Junior Chamber religious and church services organizations (Catholic Youth Movement, Vincent De Paul Society, Christian Life Community, Muslim Education Society etc.) came forward for the formation of local 'eye donation forum'. Eye donation forums included small groups of motivated and dedicated people of the above organizations in each locality. Many such groups were created in the community. Their functions include selection of sites for awareness classes, local publicity and infrastructure, arrangement and mobilization of people, follow up of motivation services, collecting pledge forms, persuading the relatives at the time of death and inform the eye bank immediately after death of a donor.

**RESULTS**

As a result of the eye donation awareness and motivation programs we got 1035 eyes in the past 12 years. Starting with 24 eyes in the first year rising to 126 eyes in the 12<sup>th</sup> year (Table 1). The male female ratio was 52:48 and age of donors varied from 06 years to 95 years. Maximum donors were between 60-70 years group. There is gradual increase in the number of eyes obtained for eye donation from 2005. Only 24 eye donations in 2005 which improved to 126 by 2016, due to various motivation programs (Figure 2). In 2005 only 16 were utilized for corneal transplantation, which increased to 87 in 2016.

**Table 1: Number of eyes obtained and utilized for KP and research.**

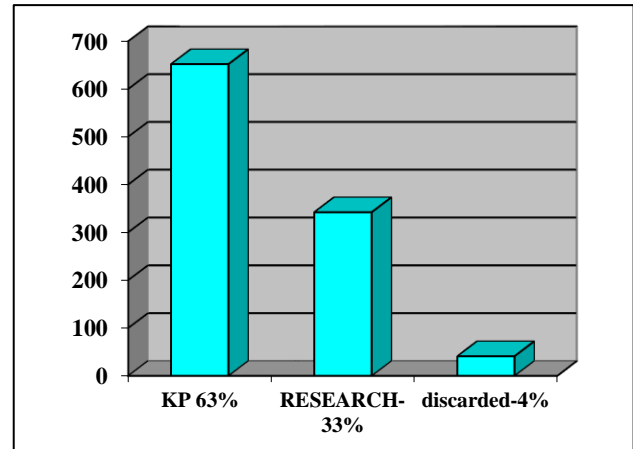
Year	Male	Female	Total	For KP	others
2005	20	4	24	16	8
2006	22	15	37	27	10
2007	21	34	55	35	20
2008	20	39	59	28	31
2009	25	41	66	39	27
2010	45	48	93	62	31
2011	63	39	102	74	28
2012	51	55	106	55	51
2013	58	61	119	69	50
2014	68	57	125	78	47
2015	70	53	123	85	38
2016	74	52	126	87	39
Total	538	497	1035	652	383



**Figure 2: Number of eye donations in each year.**

The common cause of death was old age, cerebrovascular accidents, cardiac problems, malignancy, renal failure etc. The time of enucleation after death varied from 30 minutes to 6 hours; average 2 hours. We have collected 3ml of blood from all cases for investigations and screening. 4% of eyes were discarded after screening and blood investigations. 63% of the eyes received were utilized for keratoplasty and 33% were used for research

purposes (Figure 3). Of the keratoplasties, 72% were for optical / visual purposes and 28% for therapeutic purposes to maintain the integrity of eye ball.



**Figure 3: Number of eyes used for KP and research.**

**DISCUSSION**

Though India require 200,000 corneas per year we are getting only about 44,806 corneas. This points out to the lack of active functioning eye banks in India and inadequate education and motivation of people. The requirement of donor cornea is increasing every year. Awareness among general population is crucial in improving eye donation rates.

In a cross-sectional study conducted at Rural Health and Training Centre (RHTC) in Pondicherry 80.6% subjects were aware about eye donation.<sup>4</sup> Education and occupation had significant association with awareness. Main source of information about eye donation was television (65.2%). Although the awareness is good in this population, the quantum of people pledged is very low. To make the dream of converting the awareness into pledging and procurement of eyes, the knowledge and motivation about eye donation is highly required.<sup>4</sup>

In a study by Rock D1 et al, factors limiting corneal donation at the University Hospital Tübingen were investigated.<sup>5</sup> They retrospectively studied all hospital deaths from January 2012 to December 2015, considering each deceased patient as a potential corneal donor. During this period an ophthalmic resident managed corneal donor procurement on a full-time basis. Various factors limiting corneal donation were examined. Among the 3412 deaths, 2937 (86.1%) displayed nonfulfillment of corneal donation. Consent for corneal donation was obtained in 475 cases (13.9%). The mean annual corneal donation rate was 13.9 donors per 100 deaths (range: 11.2-17.8). The leading causes of nonfulfillment of corneal donations were refusal to donate (49.8%, 1698 cases) and medical contraindications (23.6%, 805 cases). Their study showed refusal to donate is the most important factor limiting corneal donation. It seems that

increasing the knowledge of people about corneal donation through public education and media are necessary to address the corneal shortage.<sup>5</sup>

Some are interested only to sign the eye donation forms but has failed to follow up. The eye donation pledge has a role in creating awareness about eye donation among people. Among pledge card holders only 4% are above 60 yrs of age; 64% are between 15-40 yrs age and we have to wait for 20-50 years to materialize their pledge. In a study by Gogate B et al, they stated that what is needed is a catalyst to convert this intention to donate eyes into a deed.<sup>6</sup> The first few hours after a person's death are most traumatic to his/her relatives. If someone would seriously suggest them the benefits of eye banking at that time many would be willing. In the present study local eye donation forum acts as the catalyst. They work hard to motivate the relatives at the time of death.

The present study shows that involvement of various social and religious bodies is very useful in the motivation and follow up programs. The activities of local eye donation forums within the community helped to increase eye donation rates about ten-fold in this community.

Future strategy for eye donation includes education work, formation of eye information centres, hospital cornea retrieval programs, proper training of corneal surgeons and strengthening the functions of Eye Bank Association of India. The Govt. of India have a definite program for setting up of eye bank in voluntary and government sector under the national program for the control of blindness (NPCB). Authors experiences have convinced us the important role of social and religious organization and its leaders in spreading the message of eye donation among people. These organizations have an active role in creating awareness and motivation of eye donation to clear the backlog of corneal blindness in India.

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