7. SUMMARY

Over last ten years there has been increased incidence of patients of vital organ failures. This had led to increased demand for organ transplants. However for a transplant surgery to benefit the patient in organ failure there has to be an available organ that can be transplanted. Such organs are obtained by process of organ donation.

Organs by organ donation can be obtained from 3 categories of donors, namely living donor, brain dead donor and cardiac dead donor.

Many countries have high organ donation rates ranging between 35 to 45 persons per million population which means 35 to 45 people in every 1 million people become organ donors in these countries. However India has an organ donation rate of 0.5 per million population. Here too some states have a higher organ donation rates than others. There are various factors responsible for these differences in organ donation rates, within India and in the world.

The present study was undertaken to research into the challenges that affect organ donation in Pune Revenue division of the state of Maharashtra. Through the research the study would attempt to provide possible solutions to combat these challenges and provide strategies to raise organ donation rates in this region.

The study targeted three populations who are involved in organ donation, namely the general population of the region, the medical care professionals working in this region and the related patients and their relatives.

Part I consisted of 2225 persons of variable age, sex, religion, education, marital status etc living in the Pune Revenue division of Maharashtra in the cities of Pune, Karad, Kolhapur, Solapur and Sangli-Miraj region. Each of the selected cities had their own sanctioned transplant center/ centers and /or had NTORCs. The responses of the people to a questionnaire were analyzed to study their knowledge and attitude towards organ donation.

Part II consisted of 2 parts. Part II A consisted of 393 medical care professionals consisting of doctors, nurses, social workers and organ transplant coordinators and other hospital personnel who deal with patients in relation to organ donation and transplant activities in above mentioned cities. The responses of this study group to a questionnaire
were analyzed to study their knowledge and attitude towards organ donation. Part II B was a qualitative study and consisted of interviews with various doctors and OTCs involved in organ donation and transplant activities. These interviews helped to find out the challenges that are faced by these medical care professionals in relation to organ donation and ways to solve these challenges through their experiences or suggestions.

Part III consisted of interviews with patients and their relatives on waiting list, patients who had received an organ transplant, live organ donors and their relatives and relatives of brain dead organ donors. Through these interviews the study attempted to bring out the challenges faced by the patient and their relatives while on the waiting list and then the changes in their life after the transplant surgery. It attempted to find out the thought process of the living organ donor and any challenges faced by them. Through the relatives of brain dead donors the study attempted to reveal the thought process of the relatives of the brain dead donor and the reasons for finally agreeing to organ donation.

The analysis of Part I of the research revealed that people of Pune revenue division of Maharashtra had high level of awareness regarding the concept of organ donation. The awareness was higher in younger age group and was found directly proportional to education levels of the respondents. Newspapers and television were the most common sources of information regarding organ donation. Doctors, hospitals and discussions with family members were specially mentioned as sources of knowledge. Internet was noted as a new source emerging in recent times. People were aware of living organ donor and the cardiac dead organ donor, but awareness levels regarding the brain dead category of donor were very poor. Awareness regarding brain death and its key features was also not satisfactory. Highest percentage of the respondents were aware of eye donation followed by kidney and heart donation. All awareness levels regarding the organs that could be donated needed to be raised further by awareness programmes. Large percentage of the respondents was unaware that in case the donor had not signed the donor card to pledge his organs, the family members of the donor could take this decision on behalf of the donor. 58.7% of the respondents were willing to be organ donors and 16% wanted to discuss with their family before taking the decision. The commonest reason for wishing to be an organ donor was a wish to help others live a longer and healthier life. Many respondents mentioned conditional organ donation. Highest percentage of respondents wanted to donate to an unknown individual and very few to a friend. 35.1% of the
respondents who were against organ donation feared being cut open or mutilated during the process and 18.7% feared that their donated organs would be misused. 14.5% of those willing to be organ donors were unwilling to sign the donor card. Almost 45% of the respondents felt that the donors should be financially compensated.

Analysis of questionnaire in part II A revealed that there was high level of awareness regarding organ donation among the medical care professionals. Many received their information regarding organ donation from medical school, newspapers and television. Many medical care professionals were aware regarding the categories of organ donors. Knowledge regarding brain dead organ donor was higher among the doctors than the nursing respondents. Only around 50% of doctors and nurses were ready to accept the brain dead person with a beating heart as dead and only 26.5% believed that a brain dead person was legally dead. Medical care professionals had high levels of awareness regarding the organs that could be donated. Many respondents clearly stated that they felt a need for educational sessions on organ donation which could be held either in undergraduate medical education years or throughout their medical career. 64.4% of the respondents were willing to be organ donors. Maximum respondents wanted to donate to an unknown individual. Out of those who were willing to be organ donors, 20% were unwilling to sign the donor card. More than 50% were aware of the legislation governing organ donation. Highest percentage of respondents favored some incentive to the donor or donor family.

Part II B and Part III were qualitative studies. Findings in Part II B revealed that the Intensivist, OTC, physician, neurologists as well as ICU nurses, all dealt with the brain dead patient and his/her relatives at the level of ICU. Almost all felt the need for higher education and awareness regarding organ donation and specifically regarding brain dead donor. This lack of awareness made the counseling for organ donation from a brain dead patient a very difficult task. All also felt that there were too many forms to be filled up and a lot of procedural delay involved. This took up precious time away from the patient himself/ herself and also from other patients in the ICU. The hepatologists and liver transplant surgeons felt that the finances involved in liver transplant surgery needed government intervention by way of starting liver transplant programmes in government hospitals so as to bring the benefits of this surgery to the masses. The urologists and nephrologists felt reluctance to carry out live donor kidney transplant surgeries due to the
fear of getting caught unawares in some organ trade scam. The forensic medicine specialists and many other participant doctors felt need for education sessions on organ donation. The neurologists felt pressurized to declare brain death.

Findings in Part III revealed that life is a great struggle for patient on the waiting list. The physical ailment of the disease coupled with the severe pressure of financial burden cripples the patient’s and their family members’ lives. After transplant life becomes worth living and many were very grateful to this second chance at life. Many of the recipients were in favor of providing some form of incentive to the donor or the family of the donor. India has close family ties and this could be seen in the number of live organ donors available for each of the patients from within the family itself. However the morbidity and mortality associated with the live liver donation made most patients unwilling to go for live liver transplant, preferring to wait for a cadaver organ. The family members of the brain dead donor found solace in the fact that their family member could be kept alive inside somebody else through organ donation and transplant. This and the giving nature of the persons they had lost motivated them to take this decision of organ donation.