

19. The Committee deliberated upon the feasibility of establishment and setting up organ procurement organizations with Data Bank to encourage organ donations; to achieve objectives of THOA Act and THOA Rules and to facilitate the implementation of schemes for the purposes of dissemination of information on the availability of organs for transplantation. In examining this aspect, the Committee also deliberated upon the steps which may spread the awareness with regard to the organ donations, especially from cases of brainstem death. As integral part of the above discussion, the Committee also examined the feasibility of creation of a Fund to generate awareness, educate public and encourage organ donation through various methods including but not limited to provisions for social security.

20. The committee took note of the fact that at present there exists an organization by the name of Organ Retrieval and Banking Organisation (ORBO) at All India Institute of Medical Sciences (AIIMS). It is a national level facility set up by the Government of India to facilitate transplant program in the country with a view to encourage organ donations, fair and equitable distribution of organs available in the organ bank and optimum utilization of human organs. It is accordingly recommended that the infrastructure, scope and ambit of ORBO activities should be enlarged and the Central Government should create 5 Regional Centres/Units of ORBO to cover Northern, Southern, Eastern, Western and Central Regions of the country. All persons desirous of availing cadaver organs through ORBO must get themselves registered for priority by paying such reasonable registration fees as may be fixed by the Central Government or ORBO. Such Regional Units may in turn have one State Unit covering each State following within the jurisdiction of the Regional Unit. The policy decision and the functioning guidelines of all Regional Units and State Units should be governed by the Central Agency of ORBO in order to keep uniformity of procedures, guidelines, infrastructure and functional norms in all Units in relation to human organ transplant.

21. All Units of ORBO should have provision for preserving all types of preservable human organs so as to keep them transplantable within the period of their shelf-life. The storage/preservations units should be built, equipmentalised and installed as per the contemporary international standards and on adequate mechanism and infrastructure should be made available to each such unit, to facilitate storage/ preservation of donated human organs, which may be received from different sources and under different programs. Technically qualified staff must be employed to regulate the storage/ preservation program function and persons of adequate seniority and high integrity should be employed to control and supervise such activities keeping in view the sensitivity and significance of this entire exercise and also to monitor effective check to prevent any commercial factors creeping into.

22. The Committee is of the considered view that it is extremely important to educate and sensitise public; generate general awareness and remove doubts and misgivings by undertaking nationwide massive publicity campaign using all types of mass-media to promote cadaver organ donation. To be specific, the Committee makes the following recommendations:-

I. CADAVER DONORS

A. (1) A national organ transplant program with special emphasis to promote cadaver donations, is recommended. The program should focus on the following:-

a) Develop a focussed information, education and Communication (IEC) strategy to create awareness about organ transplantation and cadaver donations.

b) Involve Religious leaders and NGOs to sensitize the community about cadaver donations.

c) School curriculum may include certain information about organ donation to bring awareness amongst youth.

d) Get short films made to be frequently shown in electronic visual media highlighting the desirability and virtuosity of the cadaver donations. Some larger duration, inspiring and enlightening documentary films should also be got made to achieve above objective.

(2) Every hospital should make it mandatory for the ICU/Treating Medical staff request relatives of brain dead patients for organ donation. A record of all brain dead patients and that the next of kin who are approached should be kept.

(3) More Hospitals with adequate ICU facilities and availability of specialists to diagnose brain death be recognised as cadaver donor organ harvesting centers.

(4) Retrieval of organs from non heart beating patients should be permissible after consent of the next of kin is taken. This may serve as a valuable source of organs.

(5) Adequate facilities/Professional Fee to doctors who certify brain death.

(6) The Hospitals/centers in transplantation activity be advised to have a post of a Co-coordinator in the ICU (who may be a doctor or a senior nursing staff member) independent of the Transplant Team, who is trained in the communication skills and who can liaison between the treating physician and the relatives of the potential brain-death donor and the ORBO. Such coordinator should possess skills to communicate with the relatives and friends of the patient with a view to explain to them the merits of cadaver organ donation and who possesses adequate

knowledge to remove their doubts and answer their queries with regard to the procedure involved in transplantation activity.

(7) It should be mandatory to report all brain dead potential donors to a central agency (like ORBO).

(8) Organs should be considered a national resource and established guidelines & mechanism be used to allot cadaver organs equitably & fairly and ordinarily on the basis of priority of registration.

B. Incentives for the family of Cadaver Organ Donor

(1) Preferred status in organ transplantation waiting list if the next of kin of the brain dead donor requires organ transplantation in future.

(2) Appreciation letter/award by the State/local Government. Certificate of appreciation by State/local Government with an identity card endorsing his eligibility to obtain and avail various benefits recommended here. The card may prominently display a motivating slogan such as "Thank you for saving a life".

(3) Life long cost incentives such as discounts and partially free treatment in certain specified types of ailments, to be offered by the concerned hospital at their discretion, which can be availed in other branches if any as well of the concerned hospital.

(4) Comprehensive health care scheme for the spouse or one child or the parents of the deceased to be evolved by the Central Government/ State Government as the case may be.

(5) 0% concession in 2nd Class by Indian Railways for the spouse or one child or parents of the cadaver donor.

II. LIVE DONORS

A: Promote Swap Operations: Swap operations that is to say that two different willing but incompatible 'near relative' donors (vis-à-vis their intended related recipient) are permitted to donate their organs in exchange without any commercial interest and only due to the reason that despite willingness, their organ was not found medically compatible for their intended recipients. This would greatly help patients who have 'near relatives' willing to donate but

incompatible for their recipient. Swap operations may be considered by authorization committee on case to case basis and as per the existing THOA Act and rules.

B: Benefits for Live Donors

- (1) Comprehensive health care scheme may be evolved by the Government.
- (2) Life long free renal/liver checkup, follow-up and care in hospital, (including its other branches, if any), where organ donation has taken place.
- (3) To secure the donor against mortality risk due to organ donation related reasons, a customized Life Insurance policy of Rs. 2 Lakhs for 3 years with one time premium to be paid by Recipient.
- (4) Certificate of appreciation to all live donors by State/local Government with an identity card endorsing his eligibility to obtain and avail various benefits recommended here. The card should prominently display a slogan such as “Thank you for saving a life”.
- (5) Compensation for any expenses / loss of income incurred as specified in Section 2 (k) of the THOA Act.
- (6) 50% concession in 2nd Class by Indian Railways.

Those donors who do not wish to avail of any or all of above incentives may waive their entitlement in writing before the Authorisation Committee.

23. In order to create public awareness and educate common-man about organ transplant and organ donation, intensive use of print and electronic media should be undertaken under the supervision of ORBO. Additionally the altruistic virtues of organ donation must also be highlighted in the promotion campaigns with provision for registration with ORBO for altruistic cadaver donations.