

CITIZEN CHARTER

NATIONAL ORGAN AND TISSUE TRANSPLANT ORGANIZATION (NOTTO)

INTRODUCTION

The Transplantation of Human Organs Bill having been passed by both the Houses of Parliament received the assent of President on 8th July, 1994. It came on the Statute Book as the Transplantation of Human Organs Act, 1994 (42 of 1994). By section 3 of the Transplantation of Human Organs (Amendment) Act, 2011 (16 of 2011) the nomenclature of the Act has been amended. Now it stands as TRANSPLANTATION OF HUMAN ORGANS AND TISSUES ACT 1994 (42 of 1994) (Came into force in the States of Goa, Himachal Pradesh and Maharashtra and all the Union Territories on 4-2-1995 and in other States which adopt this Act on the date of such adoption).

In exercise of the powers conferred by section 13C of the Transplantation of Human Organs and Tissues Act, 1994 (42 of 1994), the Central Government has notified the National Human Organs and Tissues Removal and Storage Network, with its Headquarter at New Delhi having jurisdiction over the whole of India. Further, National Organ and Tissue Transplant Organization (NOTTO) the apex level organization has been established at New Delhi under Dte.GHS, MoHFW, GoI to carry out the functions of aforesaid National Human Organs and Tissues Removal and Storage network, and maintaining a national registry of donors and recipients of human organs and tissues.

The office of NOTTO is located at 4th and 5th Floor of National Institute of Pathology (ICMR) Building in Safdarjung Hospital Campus New Delhi. It has following two divisions:

- National Human Organ and Tissue Removal and Storage Network
- National Biomaterial Centre

MANDATE

As mentioned above, NOTTO has been given mandate as follows –

- Setting up National and Regional Network
- Setting up and maintaining National Registry
- NOTTO at Apex level with 5 ROTTOS and SOTTOS in each state
- Establish an efficient system for organ procurement and distribution from donor hospitals till transplant hospitals/storage centres (in case of tissues).
- Ensure transparency and equity in organ donation, sharing and distribution
- Donated Organ is a national resource.
- Establishment of National level Tissue Bank to fulfill the demands of tissue transplantation through activities for procurement, storage and fulfil distribution of biomaterials including training and setting standards SOP in tissue banking and tissue transplantation.

SERVICE/ACTIVITIES

NOTTO would function as apex centre for All India activities of coordination and networking for procurement and distribution of Organs and Tissues and registry of Organs and Tissues Donation and Transplantation in the country and establishment of National Biomaterial

Centre (National Tissue Bank) in the country to fulfill the demands of tissue transplantation including activities for procurement, storage and fulfil distribution of biomaterials. The main thrust & objective of establishing National Biomaterial Centre is to fill up the gap between 'Demand' and 'Supply' as well as 'Quality Assurance' in the availability of various tissues.

NATIONAL NETWORK DIVISION

National Network division of NOTTO would function as apex centre for All India activities of coordination and networking for procurement and distribution of Organs and Tissues and registry of Organs and Tissues Donation and Transplantation in the country. The following activities would be undertaken to facilitate Organ Transplantation in the safest way in shortest possible time and to collect data to develop and publish National Registry: -

At National Level

- Lay down policy guidelines and protocols for various functions.
- Network with similar regional and state level organizations.
- All registry data from States and Regions would be compiled and published.
- Creating awareness, promotion of organ donation and transplantation activities.
- Co-ordination from procurement of organs and tissues to transplantation when organ is allocated outside the region.
- Dissemination of information to all concerned organizations, hospitals and individuals.

- Monitoring of transplantation activities in the Regions and States and maintaining data-bank in this regard.
- To assist in data management for organ transplant surveillance & organ transplant and Organ Donor registry.
- Consultancy support on the legal and non-legal aspects of donation and transplantation.
- Coordinate and Organize trainings for various cadre of workers.

For Delhi and NCR

NOTTO is also mandated to establish the nodal networking agency for Delhi and shall network for Procurement Allocation and Distribution of Organs and Tissues in Delhi. In addition, NOTTO is also performing similar work for NCR area because of practical feasibility.

- Maintaining the waiting list of terminally ill patients requiring transplants.
- Networking with transplant centres, retrieval centres and tissue banks.
- Co-ordination for all activities required for procurement of organs and tissues including medico legal aspects.
- Matching of recipients with donors.
- Allocation, Transportation, Storage and Distribution of Organs and Tissues within Delhi and National Capital Territory region.
- Post-transplant patients & living donor follow-up for assessment of graft rejection, survival rates etc.
- Awareness, Advocacy and Training workshops and other activities for promotion of organ donation.

NATIONAL BIOMATERIAL CENTRE (NATIONAL TISSUE BANK)

The Transplantation of Human Organs (Amendment) Act 2011 has included the component of tissue donation and registration of tissue Banks. It becomes imperative under the changed circumstances to establish National level Tissue Bank to fulfill the demands of tissue transplantation including activities for procurement, storage and fulfil distribution of biomaterials. The main thrust & objective of establishing the centre is to fill up the gap between 'Demand' and 'Supply' as well as 'Quality Assurance' in the availability of various tissues.

The centre will take care of the standardization of processes, procedures, procurement, storage and distribution including prescribing guidelines, quality and training aspects of following Tissue allografts: -

Bone and bone products e.g. deep-frozen bone allograft, freeze dried bone allograft, dowel allograft, AAA Bone, Duramater, facialata, fresh frozen human amniotic membrane, high temperature treated board cadaveric joints like knees, hips and shoulders, cadaveric cranium bone graft, loose bone fragment, different types of bovine allograft, used in orthodontics

- Skin graft
- Cornea
- Heart valves and vessels
- Other tissues shall be gradually included.

Activities

- Coordination for tissue procurement and distribution
- Donor Tissue Screening
- Removal of Tissues and Storage

- Preservations of Tissue
- Laboratory screening of Tissues
- Tissue Tracking
- Sterilization
- Records maintenance, Data Protection and Confidentiality
- Quality Management in tissues
- Patient Information on tissues
- Development of Guidelines, Protocols and Standard Operating Procedures
- Trainings
- Assisting as per requirement in registration of other Tissue Banks.

ELIGIBILITY CRITERIA AND PROCEDURE TO OBTAIN THE SERVICE

- In case of living donation – individual of age 18 years or above, must be of sound mind and capable of providing informed consent.
- In case of deceased donation – donation can happen at any age
- Consent by the next of kin as per national regulation.
- The donor must be medically assessed and cleared for donation by NOTTO registered transplant centres/Hospitals.
- Potential Recipient who is suffering from organ failure disease must be registered in National Registry of NOTTO through with NOTTO authorized Transplant Centres / Hospital and must fulfill all criteria prescribed by medical board/committee for registration for transplantation.

WHERE AND HOW TO REGISTER FOR RECEIVING ORGAN FOR TRANSPLANTATION, FROM A DECEASED DONOR

Potential Recipient of any age may contact NOTTO registered Transplant Centres / Hospitals anywhere in the country. There is no requirement of any state domicile and there is no fee for registration.

The treating hospital will advise and register the patient with NOTTO registry for transplant. Every patient is given a unique NOTTO ID after registration.

For list of NOTTO registered Transplant Centres/Hospitals please visit website i.e www.notto.mohfw.gov.in or contact NOTTO Helpline - 1800-11-4770 (24X7days)

TIME-FRAME FOR SERVICE

As per provision of THOTA 1994 and rules thereunder. Further executive orders/guidelines issued by Ministry of Health & Family Welfare/NOTTO, GoI shall also be followed.

Information on Organ & Tissue donation and transplantation, Counselling (virtual and physical for walk in patients/attendants) and coordination through helpline tollfree 1800-11-4770 is provided round the clock (24x7).

LIST OF REQUIRED DOCUMENTS

As per provision of THOTA 1994 and rules thereunder. Further executive orders/guidelines issued by Ministry of Health & Family Welfare/NOTTO, GoI shall also be followed.

GRIEVANCE REDRESSAL AND CONTACT DETAILS:

In order to sort resolution for any queries or complaints/ grievance or to get in touch with the officials one can contact on NOTTO Helpline, visit NOTTO website, send an email or visit NOTTO office on below mentioned details:

- NOTTO Helpline - 1800-11-4770 (24X7days)

- Feedback link on Website:

<https://notto.mohfw.gov.in/feedback.htm>

- Email: dir@notto.nic.in

- Address:

The Director NOTTO

4th & 5th Floor, National Institute of Pathology Building

Safdarjung Hospital Campus, New Delhi-110029

- NOTTO Office Location:

<https://maps.app.goo.gl/suDi4PFX3Y4AeMx6A>