

C- 18018/06/2022-MS /FTS.8198055
Government of India
Ministry of Health & Family Welfare
Directorate General of Health Services
(Medical General Section)

Nirman Bhavan, New Delhi
Dated: 10th February 2023

OFFICE MEMORANDUM

Subject:- Minutes of Meeting held on 09.01.2023 regarding issuance of uniform guidelines for registration process and criteria of registration for living/ deceased donor organ transplant (DDOT) and proper implementation of Transplantation of Human Organs and Tissues Act (THOTA) 1994 and rules thereunder.

Sir,

I am directed to enclose herewith the minutes of Meeting held on 09.01.2023 at Nirman Bhawan, New Delhi via hybrid mode under the Chairmanship of Prof. Atul Goel, DGHS on the above subject for your information and necessary action.

2. Further, all concerned are requested to submit the action taken report to this Directorate within a period of one week from the date of receipt the communication.

Encl: Minutes of the meeting.



(Dr. Anil Kumar)
Addl. DDG (AK)
Dte.GHS.
011-23061806

To,

All the participants.

Copy to for information

1. PSO to DGHS
2. PS to Addl. Secretary (VHZ), MoHFW
3. PS to Advisor (Cost), MoHFW
4. PS to DS(MS), MoHFW
5. Dr. Sumana Arora, Senior Consultant, NITI Ayog.

Minutes of the Meeting

A meeting was organised through **hybrid mode on 9th January 2023** under the **chairman ship of Prof. (Dr.) Atul Goel, DGHS at Resource Centre, Room No: 442, 4th Floor, Nirman Bhavan.**

Agenda

Regarding issuance of uniform guidelines for registration process and criteria of registration for living/ deceased donor organ transplant (DDOT) and proper implementation of Transplantation of Human Organs and Tissues Act (THOTA) 1994 and rules thereunder.

The list of participants is as under:

1. Dr. Anil Kumar, Additional DDG,Dte.GHS
2. Dr. Krishan Kumar, Director NOTTO
3. Dr. Ashok Kumar Meena, CMO (NFSG), Dte.GHS
4. Dr. Shiny Pradhan, CMO (NFSG), NOTTO
5. Dr. Archana Kumari, Consultant Coordination, NOTTO
6. Representatives of ROTTOs-Mumbai, Kolkata, Chandigarh, Chennai, Guwahati/SOTTO-Odisha, Madhya Pradesh, Haryana, Kerala, Jharkhand, Telangana, Jammu & Kashmir, Goa, Karnataka, Gujarat, Bihar
7. DHS or Representatives of all States where ROTTO and SOTTO are not existing

Dr Anil Kumar informed about the background of the meeting that a writ petition was filed by 'Gift of Life Adventure Foundation' (Petitioner- Ms. Mohini Priya, AOR) against Union of India and others in the Hon'ble Supreme Court of India regarding the grievance about the requirement of obtaining a domicile certificate for registering for cadaver organ transplantation, imposed by some States. The Hon'ble Supreme Court vide its order dated 5th December, 2022 has permitted the petitioner to submit a representation to Secretary, Union MOHFW for examination of the matter and to take policy decision on the appropriate course to action to be adopted to remedy the grievance expeditiously. He further informed that the petitioner has submitted its representation on 12th December 2022 to the Ministry, which has already been circulated to all participants.

After discussions and deliberations, following decisions were taken/ action points recommended:

Regarding Points raised by the petitioner in her representation.

1. Arbitrary requirement for a Domicile Certificate

Recently Hon'ble High Court ofGujarat has ordered to discontinue the requirement for a domicile certificate for registering the patients requiring deceased donor organ for their transplant. However, it is noted that similar requirement of domicile certificate is in practice in few other states also, which is contrary to the provisions of THOTA-1994 and rules thereunder.

It is noted that as per the law the patient requiring deceased donor organ for transplant (DDOT) can seek treatment from any registered transplant hospital in the country and his/her request will be got registered by the transplant hospital with NOTTO registry for inclusion in the waiting list. A unique ID will be provided by NOTTO to each of these patients. The patient will be counted as the patient of the State where the concerned transplant hospital is located. The patient has the option to change the transplant hospital within or outside the

State after initial registration however, the unique ID and priority in the waiting list will remain the same.

Decision:

- **Remove the condition for domicile requirement, wherever it is there.**
- **NOTTO Registration is mandatory for any Organ/ Tissue transplantation**
- **Daily Data of transplantation of Organ/ Tissues to be shared with SOTTO/ROTO/NOTTO.**

Action:

Letter would be sent to all States from DGHS/Secretary/ Hon'ble HFM level

2. Unnecessary Organ Wastage- The petitioner has mentioned that there is a lack of consistent rules and regulations in States leading to organ wastage.

A powerpoint presentation on NOTTO allocation criteria was made by Dr. Anil Kumar, wherein it was noted that in the criteria for registration of patient, upper age limit has been kept as 65 years in the current guidelines. It was discussed that since the criteria already contains additional points for lesser age difference between the donor and recipient, so it is not fair to put age restrictions for registering patients for DDOT. Such an age restriction also violates the fundamental Right to Life under Constitution of India.

It was also discussed though 708 retrieval/Transplantation Centres have been registered with NOTTO only few centres are actively doing retrieval/transplantation activity. Most of the hospitals apply for retrieval/Transplantation licence to gain status of super speciality Hospital as it gives them better status and higher CGHS rates. More so they get approval for PG seats to impart training in transplantation.

As less centre are actively doing retrieval/transplantation activity this leads to Poor utilization of organs at the local level and Organs/ tissues needs to be transported outside the city/state/region hence resulting in wastage or higher cost.

As they are not doing or doing minimal, retrieval/Transplantation activity this results in inadequate training in retrieval/transplantation.

As being registered as super speciality Hospital they charge higher rates results in loss to the exchequer.

Decision:

- **To rectify the ambiguity and remove the age restriction. Thus, patients requiring DDOT, of any age without any upper limit will be permitted to register all over the country in the waiting list registry.**
- **Minimal monthly/ Annual Targets to be fixed to continue as retrieval/ Transplant centre. Licence to be reviewed annually rather than after every 5 years.**

Action:

DGHS /Secretary to amend the existing Transplantation rules in consultation with NOTTO

3. Lack of Functional Centralized Registry-Director NOTTO informed that a registry was being worked out in consultation with National Health Authority (NHA). In the recent meeting with NITI Ayog it was advised by Secretary Health that as NHA is taking too long to develop NOTTO Real Time Website proposal may be invited from C-Dac, which is under consideration.

Decision:

To discuss the issue with NHA and the other possible alternatives

Action:

A meeting with NHA to be convened under the chairmanship of DGHS to take the decision

4. Delay in obtaining No Objection Certificate and Lack of Clarification of the Rules-It was informed that as of now there is no provision for NOC requirement under THOTA-1994 and Rules 2014. However, following 7 States: Andhra Pradesh, Telangana, Karnataka, Uttarakhand, Mizoram, Meghalaya and Tripura, have not yet adopted amended act and rules. The aforesaid 7 States may be seeking for NOC as per old rules of 2008. As per the current rules, the verification is required to be done by the local tehsildar or his superior officer of the area to establish the identity and domicile status of donor and recipient. Such a verification is required only in those outside state cases, where the donor is not a near relative of the recipient.

Decision:

Requesting states who have not yet adopted THOTA amendment 2011 and Rules 2014, for Adoption of THOTA amendment 2011 and Rules 2014 at the earliest and to other Stats/UTs regarding No requirement of NOCs.

Action:

To write letters from Secretary MOHFW/ Hon'ble HFM to the aforementioned states for adoption of THOTA amendment 2011 and Rules 2014 at the earliest and to other Stats/UTs regarding No requirement of NOCs.

Other Issues Discussed and decisions taken and/or action points recommended

1. It was decided that in case of spousal living donor, marriage certificate will be made mandatory.

Action:

DGHS /Secretary to amend the existing Transplantation rules in consultation with NOTTO

2. It was noted that some states namely Maharashtra (Rs. 5000-10000), Telangana (Rs. 5000), and Gujarat (Rs. 5000), Kerala are charging for registration fee for registering the patients for DDOT which is not as per the THOTA rules 2014. It was decided that States should not charge any fee for registering the patients and all such expenditure involved are provided under NOTP.

Action:

A letter in this regard from the level of DGHS/ Secretary MoHFW/ Hon'ble HFM will be sent to the States.

3. All ROTTOs and SOTTOs were requested to provide list of hospitals which are officially training doctors in organ/ tissue retrieval and transplant.

Action:

Director NOTTO to ask all the ROTTOs to provide the list

4. NOTTO will provide facility for registration of NGOs working in the field of organ donation/ transplantation, transplant coordinators working all over the country and training hospitals on their website.

Action:

Director NOTTO

5. Director NOTTO informed that some states have not provided data for living donor transplants namely Tamil Nadu, Karnataka, Telangana etc. DGHS directed that all States should provide living donor transplant data also along with the diseased donor transplant data on daily basis. All ROTTOs and SOTTOs will ensure collection of this data from the concerned authorities of the State and sending the same to NOTTO for compiling in the central registry. It will be desirable if all data can be uploaded on NOTTO web portal.

Action:

A letter to be sent to the States from the appropriate level in this regard.

6. Director ROTTO and SOTTO Mumbai, Dr. Sujata Patwardhan, pointed out that in Maharashtra there is a society by the name of ZTCC which allocates organs city wise and there are 4 ZTCCs which are functional at Mumbai, Pune, Aurangabad and Nagpur they do allocation in respective cities, in the rest of the areas allocation is done by SOTTO. Though all the ZTCCs are allocating organs in transparent and fair way, maintaining the records and sharing the data with SOTTO/ROTTTO/NOTTO, it is creating confusion in the scope of work between SOTTO and ZTCCs.

Action:

A meeting under the chairmanship of DGHS/ Secretary/Hon'ble HFM level with the respective officers of the State of Maharashtra to resolve the issue

7. Director NOTTO raised one issue where the allocation of paired organs was not done as per NOTTO allocation policy (giving one organ from paired organs in general pool) by giving recent example of donation at SMS hospital where both the kidneys are used by the hospital.

Action: A letter in this regard to be sent by DGHS to the Director SMS medical college and Vice Chancellor of Rajasthan University of Medical/Health Sciences to abide by the allocation criteria strictly.

8. All ROTTOs and SOTTOs were requested to examine the allocation criteria for different organs and cornea as available on the NOTTO Website and send the inputs/ comments within 15 days to Director NOTTO. Thereafter, a meeting will be organized by NOTTO, involving States, ROTTO and SOTTO, Experts and other stakeholders to finalize the uniform organ allocation guidelines for the whole country.

Action:

Director NOTTO to finalize uniform organ/Tissue specific allocation criteria's in consultation with all stake holders to come up with "ONE NATION ONE POLICY".

The meeting ended with a vote of thanks to the chair and participants.
