

NGO Conclave

NGOs 5th Collaborative Conclave for Organ Donation

Sunayana Singh
ORGAN India, Delhi, India



Ms. Sunayana Singh
Chief Executive Officer
Organ India

The 5th Collaborative Conclave on Organ Donation for NGOs and government bodies took place on August 4, 2024 at the India Habitat Centre in New Delhi. ORGAN India, Parashar Foundation, under the aegis of National Organ & Tissue Transplant Organization (NOTTO), organised this annual event, where national, regional, and non-government stakeholders convened under one umbrella to discuss critical issues, challenges, and potential solutions within the organ donation ecosystem. The

Conclave saw participation from 16 NGOs and key stakeholders, including NOTTO, ROTTO North, ROTTO/SOTTO West, SOTTO MP, SOTTO J&K, ZTCC Pune, the Appropriate Authority of Rajasthan, Vidhi Center for Legal Policy as well as members of India's Transplant Sports Team.

The Conclave was inaugurated by the Chief Guest, Prof. (Dr.) Atul Goel, Director General of Health Services, MoHFW, GOI, who stressed that NGOs must put a lot more focus on prevention of organ failure as there will never be enough organs to meet the demand.

The NGOs present were ORGAN India (Delhi), MOHAN Foundation (pan India), Zuble Foundation (Assam), Shine India Foundation (Rajasthan), Donate Life (Gujarat), Kidney Warriors Foundation (Maharashtra), Kidney Patient Welfare Foundation (Rajasthan), Barasat Samajik Pratishthan (West Bengal), Bengal Organ Donation Society (West Bengal), Dadhichi Deh Daan Society (Delhi), MFJCF (Rajasthan), Kiran Foundation (Karnataka), Komal New Life Foundation (Maharashtra), Rebirth Foundation (Tamil Nadu), Shatayu (Gujarat), Bhartiya Jan Sangh (Delhi). Each NGO presented its work, highlighted unique activities that could serve as models for other organizations, and shared the challenges they face in the field. The Conclave included the following panel discussions:

1. Advisory Committees & the Role of NGOs in Aiding NOTTO, ROTTO, SOTTO.
2. Pan India Body Donation - Facilitating Body Donation through NGOs.
3. Transplant Games in India & Abroad - Promoting Health and Raising Awareness.



Discussion groups were formed which focused on technology, process, and legal reforms to establish a more transparent National Policy on Organ Donation and Transplantation. Below are some of the key recommendations:

1. One Nation, One Policy: Issues and Challenges
 - The government shall bear the cost of transporting organs across states to ensure equitable allocation.
 - States adopting NOTTO's guidelines to standardize organ allocation.
 - Recognize and motivate NTORCs to promote organ donation.
 - Donor families should be honoured, and organ donors / transplant recipients should serve as brand ambassadors to promote post-transplant health and inspire others.
2. Amendments to the Law: Living Donor Protection Act
 - Hospitals must update registries, with penalties and license suspensions for violators.
 - Guidelines for authorizing committees and transplant hospital donations should be set by NOTTO, with a minimum number of donations required for license renewal.
3. Community Participation and Social Mobilization
 - NGOs and government should collaborate on donor family felicitation and support.
 - Donor families could receive benefits like government jobs, health insurance, or education for children.
 - Public and medical awareness campaigns are crucial for promoting organ donation.
 - NOTTO should issue advisories to verify NGOs in each state to facilitate easier collaboration and outreach.
4. NGO Roles and Responsibilities
 - NGOs should maintain ethics, confidentiality, and compliance with laws, and collaborate with the government.
 - Correct information dissemination, staff training, and support for donors/recipients should be prioritized.
 - NGO credibility endorsed by NOTTO/ROTTOT/SOTTO
5. Health Insurance for Donors and Recipients
 - IRDA should create favourable insurance products for donors and recipients.
 - Expand coverage to all organ transplants, like Ayushman scheme.
 - Living donors should receive insurance as they are medically fit when donating.
6. Successes and Challenges from New States
 - Dialogue with state governments is lacking in the Northeast region, and NGOs struggle with credibility for community education programs, especially among tribal communities with strong cultural beliefs regarding the deceased.

Corresponding Author: Dr. Sunil Shroff,
MOHAN Foundation, Chennai, Tamil Nadu, India
Email: shroff@mohanfoundation.org

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