

# Organ donation – “attitude and awareness among undergraduates and postgraduates of North-East India”

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## ABSTRACT

**Background:** Organ donation is defined as “When a person allows an organ of theirs to be removed, legally, either by consent while the donor is alive or after death with the assent of the next of kin.” Common transplantations after organ donations include kidney, heart, liver, pancreas, intestines, lungs, bones, bone marrow, skin, and cornea. Although some organs such as kidney and tissues like part of the liver, pancreas, lungs, and intestines can be donated while the donor is alive, most of the donations occur only after the donor’s death. In India, the legislative foundation for brain death and organ donation was officially established, under Transplantation of Human Organs Act, 1994 amended in 2011. It provided a much-needed legal and transparent system for organ donation. India’s organ donation rate (ODR) stands at an abysmal 0.34 per million populations (PMP) when compared with donation rate of 36 PMP in countries like Spain. While in the rest of the country, states like Tamil Nadu, Maharashtra, Andhra Pradesh, and Gujarat have made efforts to ramp up their ODR, by facilitating public and private health sector activities, such vision is still a far cry for the states in the North-Eastern part of India. **Materials and Methods:** This study on awareness of organ donation was conducted in one of the premiere educational institutes at Guwahati. A predesigned performa (questionnaire) was used to collect data from 360 individual, of which 180 participants were undergraduate students and 180 participants were faculties having postgraduate degree. **Results:** The results show that 79.17% (285) of participants were aware about organ donation, and out of all participants, families of only three have donated organ in the past 5 years. A total number of 12 (3.33%) participants have signed up for organ donation. A significant portion of the study population (12.5%) opined that there might be some religious beliefs which are preventing certain strata of local population from donating or accepting organs. More than half (186) (51.67%) of the study group opined that there is lack of awareness among people which may be one of the reasons for low rates of organ donation. **Conclusion:** Organ donation programs are at a very primordial stage in India and are almost negligible in its North-Eastern region. It is high time for the policy makers and other stake holders of a global giant like India to understand the magnitude of the benefits from these programs. Making tangible policies that are reflected nationally, emphasizing attention to both the organ donors and recipients, is the need of the hour.

**Keywords:** Awareness, North-East India, organ donation, religion

## Introduction

Organ donation is when a person allows an organ of theirs to be removed, legally, either by consent while the donor is alive or after death with the assent of the next of kin. Common transplantations include kidneys, heart, liver, pancreas, intestines,

lungs, bones, bone marrow, skin, and corneas. Some organs and tissues can be donated by living donors, such as a kidney or part of the liver, part of the pancreas, part of the lungs, or part of the intestines. Even though possible while living, most donations occur only after the donor’s death.<sup>[1]</sup> A significant number of deaths due to organ failure can be prevented by timely donation and transplantation of organs. However, when it comes to India, the country is beset with a monumental deficit of organs available

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for transplants. India's organ donation rate (ODR) stands at an abysmal 0.34 per million populations (PMP), while countries like Spain are having a donation rate of 36 PMP.<sup>[2]</sup> In 1994, the legislative foundation for brain death and organ donation, amended in 2011, was officially established in India, under Transplantation of Human Organs Act (THOA).<sup>[3]</sup> It provided a much-needed legal and transparent system for organ donation. Yet again in 2015, the health ministry in India announced a policy mechanism to facilitate cadaver organ donation to further address institutional roadblocks.<sup>[2]</sup>

### Brain death and organ donation

It has been quite a long time now that the deceased organ donation/brain death has been popularized worldwide. Maintenance of circulation and respiration becomes possible with the advent of mechanical ventilator and other sophisticated instruments, even if the person's brain is damaged irreversibly. These are known as brain-stem death persons or beating cadavers.<sup>[4]</sup> Organs can be harvested or retrieved from them for transplantation. Harvesting organs for transplantation purposes from such persons is known as *cadaver transplantation*. Recently, determination of brain death has assumed importance for two reasons:

- Counseling relatives of the deceased for organs' donation
- Timely declaration of brain death can reduce prolonged unnecessary hospital stay and cut short hospital bills.

In India, THOA, 1994 amended in 2011 regulates the removal, storage, and transplantation of human organs/tissues for therapeutic purposes and prevents the commercial dealings of human organs.<sup>[3]</sup>

### Organ donation in India

Data from 2015 show that as against the demand for 1.75 lakhs of kidney transplants, there were only 5000 transplants done. Similarly, of 50,000 people dying of end-stage liver disease, only 1000 got their liver transplanted. Statistics are distressingly poor in case of transplantation of heart or lung.<sup>[2]</sup> Transplant rates for cornea are 1 in 25,000 when compared with 1 in 199 and 1 in 14,000 for the United States and Brazil, respectively.<sup>[5]</sup>

Only 0.08% of Indians donate their organs when compared with 70%–80% of Spaniards and Belgians.<sup>[6]</sup> About 0.5 million people in India die every year due to nonavailability of organs.<sup>[7]</sup>

There are two systems for organ donation practiced worldwide, the *family consent system* and the *presumed consent system*. Countries like the United States, United Kingdom, Germany, and Netherlands follow *family consent system* where people sign up as organ donors, and their family's consent is required. ODR in these countries averages between 10 and 30 PMP. The more aggressive *presumed consent system* is adopted by countries like Singapore, Belgium, and Spain. This system permits organ donation by default unless the donor has explicitly opposed it during his or her lifetime.

This system does not require family's consent. It is seen that the ODR in countries adopting presumed consent is double than the countries who have adopted family consent, averaging between 20 and 40 PMP.<sup>[7]</sup> Inspired by this outcome, the doctors of All India Institute of Medical Sciences, New Delhi, have recently suggested starting "Presumed Consent" in India too, especially in cases of accidental fatalities.<sup>[8]</sup>

### State-wise organ donation status in India

Organ donation from deceased donors is slowly gaining momentum in India. In the year 2000, MOHAN Foundation took the lead in setting up an organ sharing network, the *Indian Network for Organ Sharing* in the state of Tamil Nadu. This network facilitated the retrieval of 1033 organs and tissues.<sup>[9]</sup>

Many other states are also following Tamil Nadu with robust "Deceased organ donation and transplantation program." According to 2014 data, Puducherry has got highest ODR in India with 10.4 organ donation PMP, followed by Chandigarh with an ODR of 5.7 PMP.<sup>[9]</sup> In terms of number of deceased organ donors, Tamil Nadu holds the number one spot with 136 donations during that year.<sup>[9]</sup> Programs such as "Jeevandan" in Andhra Pradesh<sup>[10]</sup> and "Zonal Transplant Coordination Center" in Maharashtra<sup>[11]</sup> are already working for facilitating organ transplantation in these states. MOHAN Foundation has been spearheading efforts in Delhi NCR (National Capital Region) and Chandigarh with encouraging results. Kerala government has set up "Mrithasanjeevani" and the Kerala Network for Organ Sharing,<sup>[12]</sup> which have been running successfully since 2012. The Government of Rajasthan initiated the movement on organ donation with the setting up of the Rajasthan Network for Organ Sharing.<sup>[13]</sup> They have successfully retrieved 12 organs (liver and kidney) from five deceased donor within a period of 7 months since its inception in December 2014.

### Scenario of organ donation North-Eastern part of India

Organ transplantations were being performed in a few occasions in North-Eastern India, but the numbers are very nominal to talk about. Although a few local nongovernment organizations (NGOs) are being reported to be working toward generating awareness for organ donation, overall administrative negligence which can be summed up to lack of basic infrastructure, lack of trained individuals, and lack of government approved centers is probably putting the issue of organ donation to a state of dire straits in this region. It must be noteworthy to mention here that nothing substantial has been heard from the authorities of any of the seven North-Eastern states for adapting policies to facilitate organ donation till now. Thus, hundreds of patients still have to leave this region for transplantation every year. Raising awareness of organ donation in the present healthcare scenario in North-East India emerges as a challenge where even the basic health facilities are a far cry.

### Aims and objectives

1. To determine awareness and knowledge of educated [undergraduate (UG) students and postgraduate (PG) degree holders] population toward organ donation
2. To find out factors impeding the organ donation program in this part of the country
3. To observe differences between findings of UG students and PG degree holders (faculty).

## Materials and Methods

Guwahati, the gateway to North-East India, is the largest city in this region, serving a population of around 1 million. This study was conducted in one of the premiere educational institutes of Guwahati. A predesigned questionnaire was used to collect data from 360 individuals with  $n = 360$ , 180 UG students, and 180 faculties having PG degree. Data collected were analyzed using Microsoft Excel, which were tabulated and figured accordingly. Comparison between findings was analyzed using Chi-square test ( $\chi^2$ ) test, and  $P$  value was calculated.  $P$  value  $<0.005$  was regarded as significant.

## Results and Observation

### Awareness about organ donation

The results showed that 285 (79.17%) subjects were completely aware about organ donation, 60 (16.67%) were partially aware, and 15 subjects were totally unaware about organ donation. Comparison between UG students and PG degree holders showed significant difference; data show that all UG students were either partially or completely aware about organ donation, whereas 8.33% (15) of PG degree holders are completely unaware about it [Table 1].

### Family members donating organ in the past 5 years

Family member of only three subjects (UG students) had donated organ in the past 5 years.

### Response about organs which can be donated

Most of the subjects, 297 (82.5%) of 360, believed that only eye (cornea) and kidney are the organs available for donation. About one-third people, 129 (35.83%), knew about liver and heart transplantation. Only few, 42 (11.67%), were aware about donation of organs such as lungs, pancreas, and intestine. The results showed significant difference between findings of UG students and PG degree holders [Table 2].

### Ideal organ donor and response of participants

More than one-third, 38.33% (138) subjects, knew that organ can be donated both during life and after death, whereas most of them were uncertain about it. This finding also shows significant difference between both study groups [Table 3].

### Participants signing up for organ donation

Of the total study participants, it was observed that only 12 (3.33%) individuals had signed up for organ donation programs. Among them, nine (5%) were PG degree holders. This finding was not statistically significant with

$P$  value 0.078 when compared between UG and PG study groups.

### Interest in becoming an organ donor

More than half of the participants, 205 (57%), were willing to become a potential donor [Figure 1]. This finding also shows significant difference between the study groups ( $P = 0.0014$ ), with UG students showing more interest in becoming a potential donor.

### Awareness about beating heart donor

**Table 1: Awareness about organ donation among undergraduate students and postgraduate degree holders**

	UG (%)	PG (%)	Total (%)	$\chi^2$ (P)
Yes	153 (85.00)	132 (73.33)	285 (79.17)	17.147 (0.0002)
Partially aware	27 (15.00)	33 (18.33)	60 (16.67)	
Not aware	0 (0.00)	15 (8.33)	15 (4.17)	

UG: Undergraduate; PG: Postgraduate

**Table 2: Response about various organs that can be donated**

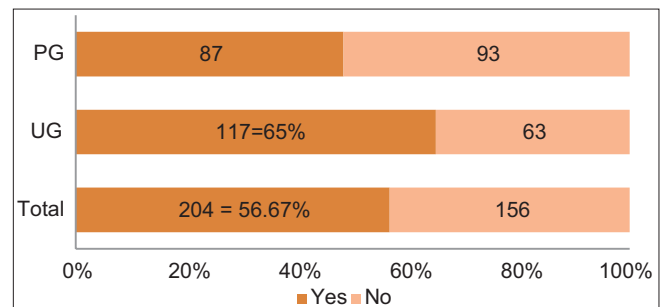
	UG (%)	PG (%)	Total (%)	$\chi^2$ (P)
Eye	147 (81.67)	150 (83.33)	297 (82.50)	19.528 (0.0067)
Kidney	144 (80.00)	135 (75.00)	279 (77.50)	
Liver	42 (23.33)	87 (48.33)	129 (35.83)	
Heart	57 (31.67)	72 (40.00)	129 (35.83)	
Lung	9 (5.00)	12 (6.67)	21 (5.83)	
Pancreas	12 (6.67)	15 (8.33)	27 (7.50)	
Intestine	3 (1.67)	3 (1.67)	6 (1.67)	
All	27 (15.00)	15 (8.33)	42 (11.67)	

UG: Undergraduate; PG: Postgraduate

**Table 3: Response about who can actually donate organs**

	UG (%)	PG (%)	Total (%)	$\chi^2$ (P)
Alive and after death	66 (36.67)	72 (40.00)	138 (38.33)	38.777 (<0.0001)
After death	6 (3.33)	39 (21.67)	45 (12.50)	
Fit and healthy	42 (23.33)	36 (20.00)	78 (21.67)	
No idea	21 (11.67)	12 (6.67)	33 (9.17)	
Only young	6 (3.33)	0 (0.00)	6 (1.67)	
Multiple factors	39 (21.67)	21 (11.67)	60 (16.67)	

UG: Undergraduate; PG: Postgraduate



**Figure 1: Person interested in becoming organ donor**

Almost 56% (201) participants were unaware about beating heart donor (or brain death) [Figure 2]. Both UG and PG groups do not show any significant difference regarding their perception with a *P* value of 0.3395.

### Role of religion in donating or accepting organs

About 45 (12.5%) of the participants from the study population believed that religious beliefs do prevent individuals from donating or accepting organs; however, 113 participants (31.37%) were doubtful about it. The differences in the two groups in this regard were not significant statistically [Table 4].

### Reason behind a poor level of organ donation

About 186 (51.67%) of participants opined that lack of awareness among common people was the prime factor responsible for such sparse state of organ donation in this part of India. Both study groups showed significant difference regarding their views about this low level of organ donation [Table 5].

## Discussion

Even though a very few articles were available for evaluation, the findings of our study can be compared with a survey published in the popular Indian English Daily, the Times of India (TOI), which conducted a survey for organ donation in eight major cities of the country.<sup>[14]</sup> High level of awareness or consciousness is

usually associated with a higher rate of organ donation. A good percentage of study population, 79.17% (285), was aware about organ donation, and 15 (4.17%) were completely unaware about it. The TOI survey reported a higher rate of awareness (94%) than our study. The reasons may be a difference in level of both education and social awareness between the two populations.

While carrying out a research at Andhra Medical College, Deepthi *et al.* found that 97.6% of students were aware about organ donation, 87% could tell the definition, and 56.9% show complete knowledge about every aspect of organ donation.<sup>[15]</sup> Sucharitha *et al.*<sup>[16]</sup> in their study observed that 77% of the participants strongly approve organ donation. This study was conducted in the state of Tamil Nadu, which is the forerunner of organ donation in India. It reported a better result with participants of their study claimed to have had a history of organ donation in the family (6.6%). In our study, the majority of the participants (90.6%) agreed that organ donation should also be promoted. With the level of awareness being comparable (79.17%) with the studies conducted by TOI (94%) and Deepthi *et al.* (97.6%), the rate of organ donation was much better with Deepthi (6.6%) when compared with our study (0.83%).

Lack of infrastructure, higher cost of transplantation, and dearth of facilitating organizations are the probable reasons for the poor state of organ donation in North-East India. Voluntary organ donation after brain death necessitates an organ bank for harvesting of retrieved organs. Till now, no such bank is established in the entire North-Eastern part of India. NGOs and people working on promotion of organ donation must compel government on such issues. Only after establishment of such facilities, we can think about intensifying the movement on cadaver organ donation.

People of almost entire Indian subcontinent still believe that the eye and kidney are the only organs available for donation. Almost 80% participants of our study were aware about eye (82.5%) and kidney (77.5%) donation. Few of them knew about donations of liver (35.83%) and heart (35.83%). Only 11.67% believed that most of the organs can be donated. Similar results were reflected in the TOI survey, according to which 91%, 87%, 63%, and 38% participants know about donation of organs such as eye, kidney, heart, and liver, respectively. In contrary to our study, the TOI survey got a worse response (7%) when participants were enquired about possible donation of almost all organs. Compared with our study and the TOI survey, Deepthi *et al.* got better results where 26% of students correctly named the organs available for donation. Saleem *et al.* in their study at Karachi, Pakistan, also found a similar result; 26.2% of participants of their study knew about multiple-organ transplantation.<sup>[17]</sup> Almost similar to our study, 66.2% of study population of Saleem *et al.* and 95.4% of participants of A. Soubhanneyaz *et al.*<sup>[18]</sup> were aware about kidney donation programs.

Who can actually donate organ; during life, after brain death, or only young and healthy individuals? In response to this question,

**Table 4: Role of religion in organ donation**

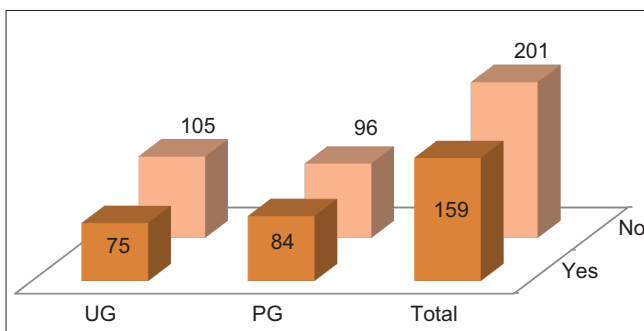
	UG (%)	PG (%)	Total (%)	$\chi^2$ (P)
Yes	18 (10.00)	27 (15.00)	45 (12.50)	3.235 (0.1984)
No	108 (60.00)	93 (51.67)	201 (55.83)	
Doubtful	54 (30.00)	60 (33.33)	114 (31.67)	

UG: Undergraduate; PG: Postgraduate

**Table 5: Reasons for infancy level of organ donation**

	UG (%)	PG (%)	Total (%)	$\chi^2$ (P)
Lack of awareness	87 (48.33)	99 (55.00)	186 (51.67)	18.362 (0.004)
Lack of facilities	33 (18.33)	15 (8.33)	48 (13.33)	
Very few people working on OD	27 (15.00)	12 (6.67)	39 (10.83)	
Multiple factors	33 (18.33)	54 (30.00)	87 (24.17)	

OD: Organ donation; UG: Undergraduate; PG: Postgraduate



**Figure 2: Awareness about beating heart donor**

38.33% of participants of our study say that it can be donated both during and after life. Another 12.5% believe that organ can only be donated after death. Just like our study, in the TOI survey, 46% individuals were aware that organ can be donated both during life and after death. In contrary to our study, they found a higher response (45%) regarding only deceased organ donation. In Sucharitha *et al.*, 11.3% of participants were aware that organ donation can be done both while living and after death.<sup>[16]</sup> Regarding age of the donor, 19.2% of participants of Sucharitha *et al.* and 47.2% of Deepthi *et al.* opined that the donor can be of any age. In a study conducted by Sahu RK *et al.*<sup>[19]</sup> on 342 participants, they found that 218 (63.7%) participants thought that organ can only be donated by living persons, while 4.09% were aware that organ can be retrieved from both living and cadaver. About 50% of participants (50.1%) of Saleem *et al.* say that organ for donation can come from cadavers, while 36.5% knew about living organ donation.<sup>[17]</sup> In this study, 23% responded that organs can be donated both during life and after death.

Only 12 (3.33%) of 360 participants have signed up for organ donation till now. This finding is almost consistent with the TOI survey, where barely 5% finally took the step to register as organ donors. Sahu *et al.* reported a better scenario; 10.6% participants of this study have already signed up the organ donation form (89.4% have not filled up any pledge on organ/body donation). A collective approach with political and administrative will with sensitization campaigns in print/electronic/social media and active involvement of stakeholders from health sectors including doctors might help increase the number of people signing for these organ donation programs.

More than half participants of our study (57%) are interested in becoming a potential donor. Similarly, 53.5% of participants of Sucharitha *et al.* responded positively to pledge their organs for donation after death. Deepthi *et al.* found that about 50% of students are willing to donate their own organs and 61% show willingness to donate their family member's organs after their death. A better response is obtained in the TOI survey with 69% participants nodding their head for potential organ donation. In contrary to these studies, Sahu *et al.* observed that only 44.1% of participants are keen to donate their body for organ donation after death. Abdulrahman Soubhanneyaz *et al.* in their study conducted in Saudi Arabia found that 73.5% of participants are interested in becoming an organ donor.<sup>[18]</sup> About 62.3% of participants of Saleem *et al.* were seen motivated to donate their organs. A study from Nigeria shows a poor response, where only 30% respondents expressed their willingness to donate their organs.<sup>[20]</sup> Better results were shown in studies from Ohio<sup>[21]</sup> and Brazil<sup>[22]</sup> with 96% and 87% participants, respectively, showing willingness to donate. Almost similar to our study, 57.9% of study population of Hamed *et al.* was willing to donate their organs.<sup>[23]</sup> H. Schauenburg and A. Hildebrandt conducted a study catering citizens of Germany and Spain on *Public Knowledge and Attitudes on Organ Donation*. They found that 17.71% of participants were seriously thinking (much thought)

and 54.5% were somewhat thinking to donate organs.<sup>[24]</sup> Lack of sensitization, family refusal, and fear of mutilation of the body after death are a few possible factors responsible for not getting enough organ donors from this part of the country. Cumbersome official paper works or insufficient knowledge about the procedure might be some of the other pertinent factors.

Our study shows that 44.17% of participants were aware about beating heart donor (brain-stem death). Compared with this, very less percentage (11.7%) of participants from Hamed *et al.* were aware about brain-stem death. With such a good level of awareness about beating heart donor, a better status of organ donation in North-Eastern India can be expected. Nongovernment agencies along with medico organizations must work together to sensitize common people about the concept of brain death and organ donation. We can expect a more number of potential donors from North-Eastern part of India, once people are fully sensitized.

Religion does prevent someone from donating or accepting organs; 12.5% participants have opined like that and 31.37% are doubtful about it. Similarly, 12% of students of Deepthi *et al.* think religion as possible barrier. Sahu *et al.* and the TOI survey found almost equal results in this regard with 5.5% and 5% of responses. In Suchiritha ST *et al.*, 64.3% individuals mentioned that their religion allows organ donation. Just like the TOI survey, 5% participants of Abdulrahman Soubhanneyaz *et al.* believe that religion is an important factor in donating organs. In Saleem *et al.*, almost 30% (29.6) of participants say that before donating any organ they would consider religion of the recipient. Hamed *et al.* found religious prohibition as a cause of refusal to donate organs in 19% of participants.

About 52% of participants of our study think that lack of awareness among common people is the factor responsible for such poor state of organ donation in this part of India. Whereas 95.9% of participants of Deepthi *et al.* thought that there is need to create awareness in the public to promote organ donation. Sensitization of common people and involvement of different agencies and media are a must to do to for a better outcome.

### Limitations of the study

1. The study carried out in one of the premiere educational institutes of Guwahati might not exactly be representing the scenario of organ donation in India, but it is definitely highlighting a few important factors that need to be addressed at this point of time
2. A bigger sample size would reflect a better picture of the research issue.

### Conclusion

With a rate of about 10 transplants per year, Gauhati Medical College and Hospital is one of the leading institutes in

North-East India catering organ transplant procedures.<sup>[25]</sup> Such low rates in the region make North-East India lag much far behind the rest of the country in organ donation and transplantation programs. Be it lack of resources in the form of medical facilities and expertise or lack of awareness due to negligible promotion in the public domain, this miserable state of affair is unacceptable and should be attended by the authorities in precedence. While recently it was seen that efforts are being made by some NGOs for creating awareness toward organ donation,<sup>[26,27]</sup> such programs need more participation from the learned section of the society. This is where the healthcare providers can contribute in a significant way through mass education. Thus, apart from revealing the perception of the educated strata of our society toward organ donation, this study also attempts to make efforts for raising awareness of the same.

Even though provisions for organ donation are available under regulations provided by the government in this part of the country, a more organized and proactive approach by the policy makers is need of the hour.

### Implications to the policy makers for organ donation

1. Establishment of organ banks with facilitating speedy transport and harvesting of organs
2. Promotion of the concept of brain death, mandatory declaration of brain death, and henceforth promotion of organ donation among the common people
3. Minimal charges for organ donation (retrieval) and transplantation
4. Offering incentives in the form of educational and financial support to dependent children of donors
5. Implementation of “presumed consent” for harvesting organs in cases of accidental deaths
6. Convenient and donor-friendly official paper works.

### Implications to nongovernmental stakeholders

1. The NGOs along with healthcare providers should start awareness programs on organ donation in a more intensive way, involving print/social and electronic media.

There is a long way to traverse, but there is still hope to achieve what we seek.

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### Conflicts of interest

There are no conflicts of interest.

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