

## You can register your intention at Japan Organ Transplant Network website.

### Register now to make your intention clear!

You can now register on-line and on your mobile phone.

After you register, a registration card with your ID will be issued. Once you complete your registration, the card will be used to confirm your intention concerning organ donor transplants.

Website:

<http://www.jotnw.or.jp>

Mobile site:



<http://www.jotnw.or.jp/m>



Please contact us if you have any questions about organ transplantation.

**JOTNW** Japan Organ Transplant Network (JOT)

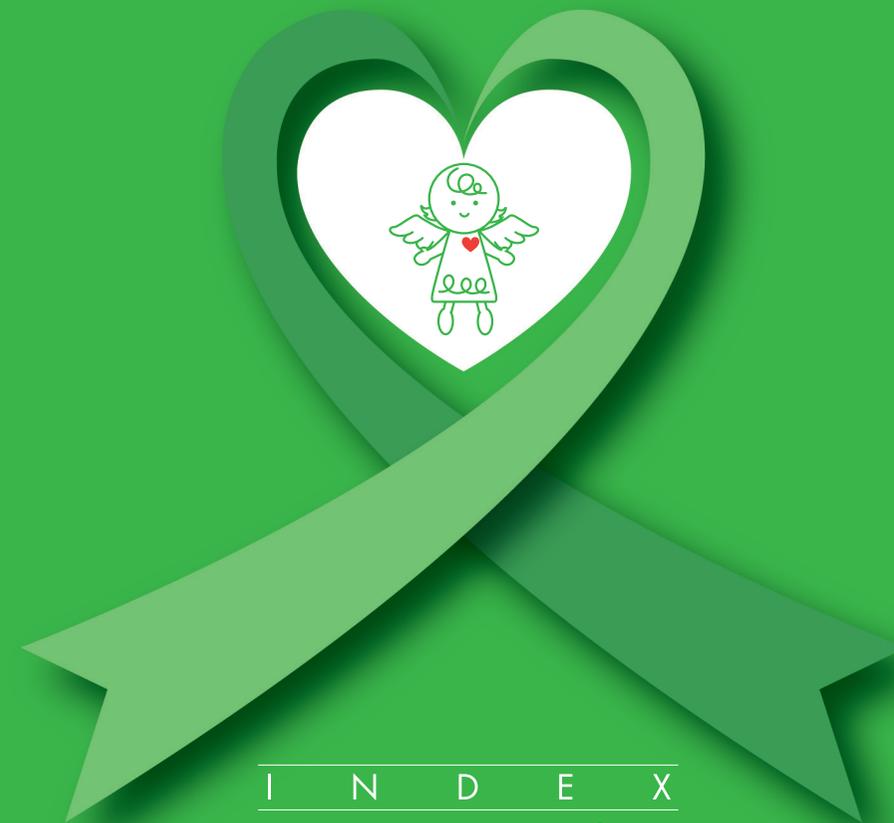
Address: Bansui Bldg., 3<sup>rd</sup> floor, 1-5-16 Toranomon, Minato-ku, Tokyo 105-0001, Japan

Phone: **0120-78-1069** (toll-free) From mobile phones: **03-3502-2071**

Organ transplant  Search  Organ transplant Search - Additional information is available at <http://www.jotnw.or.jp>

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## The Gift of Life



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**JOTNW** Japan Organ Transplant Network



## What is an organ transplant?

Organ transplantation is a medical procedure which involves replacing a failing organ, such as a heart or liver, with a healthy one from a **donor**. This procedure allows the patient who receives the transplant, or **recipient**, to return to health and improve their quality of life. There are two types of organ transplants: **transplants from living donors**, which involve the donation of partial organs, such as a lung, liver or kidney, typically from a family member; and, **transplants from deceased donors**, which involve organ donations from individuals following brain death and donations of kidneys and corneas following cardiac death (refer to pages 3 and 4, bottom).

In many countries brain death is treated as equivalent to clinical death and it is common in such cases for their organs to be donated. In Japan, however, very few organs are donated in such circumstances and as a result living donors remain the greatest source of organ donations. Transplants from living donors, however, entail risks for the donor in terms of surgery as well as increasing the burden on the donor's family.

After receiving a transplant recipients must continue to take immunosuppressants, drugs that suppress the bodies reaction to the transplant that would otherwise result in the new organ being rejected. Aside from this, however, recipients are able to go to school or resume work and lead a relatively normal life. Recipients value their health highly and are extremely grateful to the donors and their families.



### Kaho Fujita who received a heart transplant



Prior to entering elementary school, Kaho was diagnosed with dilated cardiomyopathy. Two years later she travelled to the U.S. to receive a heart transplant.

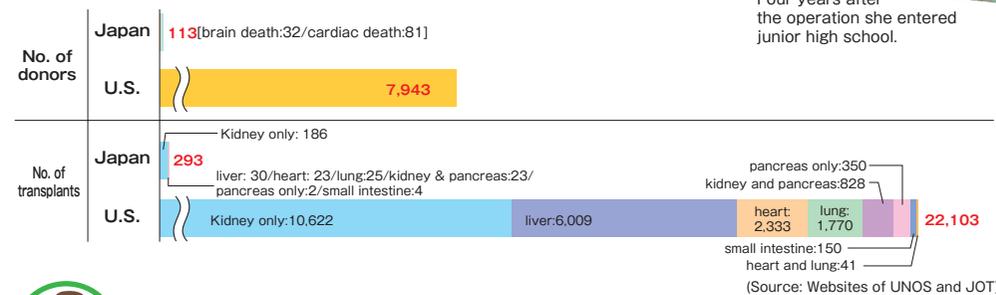


Only two months after surgery she was able to run around.



Four years after the operation she entered junior high school.

### Number of deceased donors and transplants in Japan and the U.S. (2010)



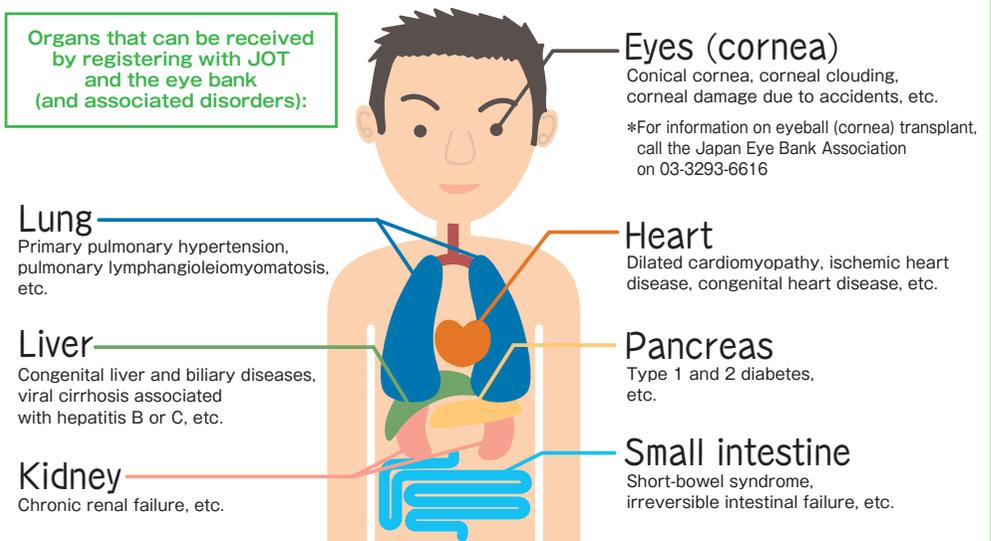
While the U.S. has twice as many people as Japan, it performs 100 times more transplants!



## How many patients need a transplant?

In order for our bodies to work properly we rely on many different organs, such as the heart, lungs, liver and kidneys. However, for many people these organs do not function properly, whether due to injury, disease or for other reasons. As many as 13,000 patients are currently registered with **Japan Organ Transplant Network**, or JOT, and are on a waiting list to receive an organ transplant. In addition, approximately 3,000 patients are awaiting corneal transplants.

Organs that can be received by registering with JOT and the eye bank (and associated disorders):



### Number of patients registered to date, summary of patient outcomes and current waiting list data (January 31, 2012)

|  | Heart | Lung | Liver | Kidney | Pancreas | Small Intestine | Eyes (cornea)                                 |
|--|-------|------|-------|--------|----------|-----------------|---|
| Number of patients registered to date    | 199   | 184  | 407   | 12,523 | 198      | 3               |   |
| <i>Summary of patient outcomes:</i>      |       |      |       |        |          |                 |   |
| Received transplant from deceased donor  | 123   | 127  | 139   | 2,873  | 122      | 12              |   |
| Cancelled their registration             | 17    | 5    | 134   | 15,439 | 25       | 0               |   |
| Died                                     | 175   | 235  | 536   | 2,797  | 35       | 0               |   |
| Received transplant from live-donor      | —     | 32   | 239   | 2,048  | 5        | 0               |   |
| Travelled overseas to receive transplant | 41    | 2    | 30    | —      | 0        | 0               |   |
| Others: unknown                          | 0     | 0    | 0     | 17     | 0        | 0               |   |
| Number of patients awaiting transplants  | 555   | 585  | 1,485 | 35,697 | 385      | 15              | 2,518<br>(No. of patient as of Aug. 31, 2011) |



The latest data are available at <http://www.jotnw.or.jp>



## The intentions of both donors and their families are important.

**1 Explanation from a transplant coordinator**

In cases where a donor has either previously expressed their intention to donate an organ or no clear intention exists, the family can request further information before making a final decision. In such cases, the doctor in charge would contact a transplant coordinator and arrange for them to visit the hospital and answer any questions.



**2 The family reaches a decision**

After meeting the transplant coordinator, a step that can be declined at any stage, family members discuss the matter thoroughly and make a decision on whether to proceed with the organ donation or not.



**3 Diagnosis and pronouncement of brain death (this applies only to organ donations following brain death).**

If the family decides to proceed, a diagnosis of the donor will be performed. Diagnosis and pronouncement of brain death is a rigorous procedure, conducted in strict compliance with the law. Time of death is pronounced upon a second diagnosis of brain death. The family can request to witness the process of the diagnosis and pronouncement of brain death.

 For donations of organs such as kidneys and eyes following cardiac death a legal diagnosis of brain death is not required.

Following amendments to the law, it has become possible to designate family members as priority organ recipients (effective from January 2010). In addition, transplants are now possible from brain death donors (including children under the age of 15) whether a clear intention to donate an organ was previously expressed or not (effective from July 2010).

Organ donations following brain death or cardiac death are possible whether a donor's intention has previously been stated or not, provided the family gives consent. It is therefore important to discuss your wishes concerning donating organs with your family and to convey your intentions clearly.

**4 Selecting patients to receive a transplant**

To receive a transplant it is necessary for a patient to be already registered with the Japan Organ Transplant Network, or JOT. Recipients are selected based on a fair selection process using medical criteria to ensure selection of the most suitable recipient.



**5 Removal and transport of the organ**

Once the recipient is selected, the organ is surgically removed from the donor and is transported to the medical facility where the organ will be transplanted.





Donations of organs following brain death can be conducted at any **hospital capable of carrying out advanced emergency medical procedures.**

 Donations of organs following cardiac death can be conducted at any **hospital equipped with an operating room.** Of special note are cases involving donations from minors under the age of 18. Since it is not possible to accept organ donations from victims of child abuse, strict procedures have been put in place and specific protocols must be observed.



## What is cardiac death, brain death and a vegetative state?

The following symptoms are seen to indicate **cardiac death**: (a) stoppage of the heart, (b) stoppage of breathing, and (c) dilated pupils (indicating a loss of brain function). Advances in Medical technology, however, have seen the development of artificial respirators and other similar devices. This has led to cases where even though brain functions have stopped and cardiac death would otherwise have occurred, it has become possible to maintain breathing and pump the heart through artificial means. This condition is referred to as **brain death**. Less than 1% of people who have died as a result of accident or stroke have suffered brain death. There is no chance of recovery, regardless of the medical treatment administered and in most cases the heart stops functioning within several days (although in some cases it has taken longer). Many countries consider brain death as equivalent to clinical death.

On October 16, 1997 the **Organ Transplant Law** was enacted in Japan. As a result, brain death was recognised as equivalent to clinical death for the purposes of organ donation. This compares to a **vegetative state**, in which a person may have no consciousness and appear to be in a condition akin to brain death, but still maintain brainstem function and spontaneous respiration. As there is also a possibility of recovery it is treated as distinct from brain death.

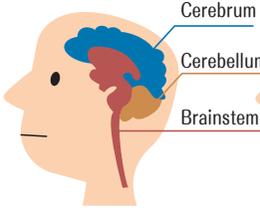


Even after this law was enacted, however, brain death is only recognised as equivalent to clinical death in cases where organ donations are involved.

## Examples of a normal brain, brain death, and a vegetative state:

**Examples of:**

**A normal brain**



**Brain death**



**Example of a vegetative state**



Parts which have lost their function

## Legal diagnosis of brain death

In order for an organ to be donated following brain death, a legally stipulated test is required. This test is called the legal diagnosis of brain death.

- The following criteria are used:
1. Deep coma
  2. Dilated and fixed pupils
  3. Loss of brain stem reflex
  4. Flat brain waves
  5. Loss of spontaneous respiration.
- These five criteria are checked twice, following an interval of 6 hours or more (in the case of children aged from 12 weeks after birth to six years, an interval of 24 hours or more is required).



Donating an organ entails no costs, but donors or their families receive no recompense either. It is purely an act of goodwill.



## What can I do to help?

While we are all destined to die, we can make a significant difference to other people's lives by allowing our organs to be transplanted. This is an important decision that requires careful and serious consideration. **It is imperative to discuss the issue thoroughly with your family and communicate your intentions clearly. This includes any decision not to donate your organs.** The quality of any medical treatment you receive will not vary according to your decision.

From March 2007 it has become possible to register your will to donate or not using your mobile phone or computer, via the Internet. After registering, a Registration Card declaring your intention will be issued to you. When you register, your intentions will be readily accessible and can be more readily confirmed. For details on how to register, please refer to the back cover of this booklet.



### How to fill out the new Organ Donation Decision Card

**(Please circle either 1, 2 or 3)**

- 1. I will donate my organs for transplantation following brain death or cardiac death.**
- 2. I will donate my organs for transplantation only following cardiac death.**
- 3. I will not donate my organs.**

(If you choose 1 or 2, and have an organ you do not wish to donate place an X over it)  
Heart Lung Liver Kidney Pancreas Small Intestine Eyes

Special comment : \_\_\_\_\_ )

Date signed : \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_  
(Month) (Day) (Year)

Donor's signature : \_\_\_\_\_

Signature of a family member : \_\_\_\_\_



Organ Donation Decision Cards are available at prefectural and municipal government offices, public health centres, driver's license testing centres, police stations and some convenience stores throughout Japan.

- STEP 1 Declare your intention.**  
Circle the number that best matches your intention
- STEP 2 Specify which organs you do not want to donate.**  
If you circled 1 or 2, but would like to exclude any organs, place an X over the organ(s) in question.
- STEP 3 Fill out the special comments section.**  
a) *Donation of tissues*  
If you circled 1 or 2, and agree to donate tissues as well, such as skin, cardiac valves, blood vessels, bones, etc. you should write "All tissues" or stipulate which tissues you are willing to donate for example, "skin", "cardiac valve", "blood vessel" or "bone", etc.  
b) *Designating family members as priority recipients for organ donations*  
If you wish to designate family members as priority donor recipients, write "Prioritise family" in this section (read the page on the right for further details).
- STEP 4 Sign your name, etc.**  
Please sign your name and write the date. If possible, have a member of your family who is aware of your declaration sign his/her name, to confirm the fact.

### Example of written declaration section on a health insurance card and driver's license



If you register by mobile phone or on the Internet, a registration card showing your intention will be sent to you. (See the back cover for more details).



## What has changed with amendments to the law?

### Since January 17, 2010 it has become possible to designate family members as priority organ recipients.



To donate organs to family members it is necessary to meet all three of the following requirements:

- In addition to declaring their intention to donate organs, the individual (aged over 15) should put in writing their wish to prioritise family members as organ recipients.
  - Any designated family member(s) (spouse\*, children\*\* or parents\*\*) will need to be currently registered in order to be eligible.
  - Medical requirements (e.g. compatibility) need to be met.
- \* This refers to legally recognised spouses who have submitted their marriage notifications, but does not include those in *de facto* relationships.  
\*\* In addition to biological parents and children, this extends to foster/adopted children and parents in special adoptive relationships recognised by law.

### Important points when designating family members as priority organ recipients

If there are no family members eligible for a transplant due to medical or other reasons, the organ/s will be offered to other individuals.

If you designate a family member as a priority recipient, this will be taken to reflect your intention concerning all family members, including said recipient.

If you stipulate only one recipient, such as "I want to donate my organs only to XX" then it will not be possible to donate your organs to other individuals, whether family members or not.

To prevent possible suicides aimed at donating organs to family members, priority donations to the deceased's family will not be possible in suicide cases.

### Since July 17, 2010 it has been possible for people under the age of 15 to donate their organs following brain death



Following amendments to the law, organ donations are possible whether a donor's intention has been clearly stated or not, provided the family gives its consent. This change has allowed children under the age of 15 to be eligible donors following brain death.



This will significantly expand the opportunities for small children to receive transplants.