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.

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

Website: [https://www.jotnw.or.jp/](https://www.jotnw.or.jp/)

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- What is an organ transplant? 
- How many patients need a transplant? 
- The intentions of both donors and their families are important
- What is cardiac death, brain death and a vegetative state?
- What can I do to help?
- What has changed with amendments to the law?
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 body’s 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 live 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.

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

<table>
<thead>
<tr>
<th></th>
<th>Number of donors</th>
<th>Number of transplants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Japan</td>
<td>11,934 brain death/32 cardiac death 81</td>
<td>Kidney only: 166</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Liver: 30 heart, 25 lung, 25 kidney &amp; pancreas</td>
</tr>
<tr>
<td>U.S.</td>
<td>7,943</td>
<td>Kidney only: 10,622</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Liver: 6,009 pancreatic only: 5190, kidney and pancreas: 63</td>
</tr>
</tbody>
</table>

Four years after the operation she entered junior high school.

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

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):

- **Eyes (cornea)**: Corneal cornea, corneal clauding, corneal damage due to accidents, etc.
- **Lung**: Primary pulmonary hypertension, pulmonary lobar pneumonia, etc.
- **Liver**: Congenital liver and biliary diseases, viral cirrhosis associated with hepatitis B or C, etc.
- **Kidney**: Chronic renal failure, etc.
- **Heart**: Dilated cardiomyopathy, ischemic heart disease, congenital heart disease, etc.
- **Pancreas**: Type 1 and 2 diabetes, etc.
- **Small intestine**: Short-bowel syndrome, irreversible intestinal failure, etc.

Number of patients registered to date, summary of patient outcomes and current waiting list data

(January 31, 2012)

<table>
<thead>
<tr>
<th></th>
<th>Heart</th>
<th>Lung</th>
<th>Liver</th>
<th>Kidney</th>
<th>Pancreas</th>
<th>Small Intestine</th>
<th>Eyes (cornea)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients registered to date</td>
<td>199</td>
<td>184</td>
<td>407</td>
<td>12,523</td>
<td>198</td>
<td>3</td>
<td></td>
</tr>
</tbody>
</table>

Summary of patient outcomes:

- **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

<table>
<thead>
<tr>
<th>Number of patients awaiting transplant</th>
<th>555</th>
<th>585</th>
<th>1,485</th>
<th>35,697</th>
<th>385</th>
<th>15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of patients (as of Aug. 31, 2011)</td>
<td>2,518</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The latest data are available at [http://www.jotnw.or.jp](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

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.

4. Selecting patients to receive a transplant

To receive a transplant it is necessary for a patient to be already registered with the Japan 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.

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.

In order for an organ to be donated following brain death, a legally validated 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. 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).

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

- Normal brain: Full brain function
- Brain death: Parts which have lost their function
- Vegetative state: Brainstem, cerebral cortex

Legal diagnosis of brain death

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

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.
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 following cardiac death.
3. I will not donate my organs.

If you choose 1 or 2, the donor organ procurement medical team (DOPM) will be notified of your decision and organ donation will be considered.

Specify which organs you do not want to donate.

If you choose 1 or 2, but would like to exclude any organs, place an (X) over the organ(s) in question.

Fill out the special comments section.

a) Donation of Tissues
   If you choose 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 “heart, “cardiac valves,” “blood vessels,” “bone,” etc.

b) Designating family members as priority donors and recipients for organ donations
   If you wish to designate family members as priority donor recipients, write “Priority family” in this section. (See the back cover of this booklet for more details.)

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 or driver’s license

Example of written declaration section on a health insurance card

Example of written declaration section on a driver’s license

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:

1. 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.
2. Any designated family member(s) (spouse*, children** or parents**) will need to be currently registered in order to be eligible.
3. 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

- The laws regarding organ donation apply to organs eligible for transplants, regardless of whether they are from living or deceased donors. It may not be possible to utilise the organ of a deceased person for transplanting.
- Even if you have designated a family member as a priority recipient, this will not affect your intention concerning all family members, including itself.
- If you stipulate only one family member, even if it is the individual aged over 15 years old, it will not be possible to donate your organs to other individuals, whether family members or not.

To prevent possible eligibility issues regarding organ donations to the deceased’s family, the 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.

The Gift of Life