

DONOR FAMILY RESOURCE GUIDE



Dear Donor Family,

On behalf of Donor Network West, we want to offer our sincerest condolences for your loss. We know this is a difficult time for you and your family and want to offer our support during this time.

We also want to thank you for your generosity. The gift that your loved one has given is the greatest gift they could give. It is a selfless gift that will impact the lives of those who receive their gift in a tremendous way and give hope to the more than 100,000 people who are still waiting.

As you continue to grieve for the loss of your loved one, we hope that this booklet will provide you with answers to some of your questions, additional information about the organ and tissue donation process, and opportunities to help cherish the memory of your loved one.

With deepest sympathy,

Donor Network West





This is our story...

No parent ever imagines that they will find themselves in a hospital room being told that there is no hope for their child. But for us, there was the chance to give hope. If we donated our son Matthew's organs and tissues, it would save someone's life.

In the years since our son left us, we have found some peace in knowing that he became a hero through his gifts. He saved and improved the lives of others. Nothing will ever take away the pain of losing him, but we have found peace in knowing that he continues to live on through others. Our hearts are lifted knowing that Matthew is a hero.

~ Zona and Jose

ABOUT ORGAN, EYE AND TISSUE DONATION FOR TRANSPLANTATION

For the countless patients on the national transplant waiting list, receiving the gift of life through organ donation is the only hope for a healthy, productive life – or life at all in some cases. As the number of patients who could benefit from transplantation continues to grow, more donations are needed.

Nationally, more than 100,000 people are waiting for a life-saving organ transplant. Sadly, approximately 20 people die each day waiting.

The impact of one organ and tissue donor is extraordinary. One donor can save up to 8 lives through organ donation and heal another 75 others through tissue donation. In addition to the benefit donation provides to recipients, it also provides a sense of comfort to donor families, knowing that the memory of their loved one lives on through their recipient. In fact, according to a national survey of donor family members, nearly all say they would choose donation if faced with the decision again.

THE BENEFITS OF DONATION

The decision to donate life is one of the most powerful decisions a person can make and the benefits are overwhelming.

- **Bone and tendon** are used to help restore function, prevent limb amputation and replace tendons and ligaments lost due to cancer, trauma, joint disease, or arthritis.
- **Cornea** transplantation helps restore vision.
- **Heart** transplantation helps improve the quality of life and extend the lifespan of people with heart failure.
- **Heart valve** transplantation helps restore normal blood flow, prolongs life and helps preserve the function of the heart muscle.
- **Intestinal** transplantation allows recipients to eat and digest food normally rather than through tubes and chemical support.
- **Kidney** transplantation allows the recipient to live a life free from dialysis treatments.
- **Liver** transplantation helps save the life of individuals with liver failure.
- **Lung** transplantation helps people with severe lung disease breathe easier and resume physical activity.
- **Pancreas** transplantation helps restore normal insulin production and improve blood sugar control in people with diabetes, increasing their quality of life.
- **Skin** is used to help patients who have lost skin due to infections, burns, and wounds and for breast reconstruction after a mastectomy.

AUTHORIZATION FOR DONATION

The decision to become an organ and/or tissue donor is the greatest gift you can give. It is a person's final wish that we at Donor Network West respect and honor. When a loved one is lost, Donor Network West works with their family to make sure that the opportunity for donation is offered to those eligible and facilitated for those who choose and are medically suitable to give the gift of life.

There are two types of authorization for donation, First Person Authorization and Donation Authorized by the Patient's Family.

First Person Authorization

For those persons who have registered to become an organ and/or tissue donor prior to their death, this is referred to as "First Person Authorization."

Under the California and Nevada Uniform Anatomical Gift Acts (UAGA), if a person is medically suitable for donation and knowledge of the donor's legal declaration of an anatomical gift is known, California and Nevada law consider this declaration authorization to proceed with donation. Upon determination by Donor Network West that a declaration of gift is valid, no further approval is required from the patient, patient's next of kin, or patient's agent in order to proceed with the donation of organs and/or tissue.

In this case, the family will be given a copy of the Document of Gift form, which informs the family that their loved one is a registered donor, along with proper documentation of the gift.

Donation Authorized by the Patient's Family

With more than 100,000 people waiting for a lifesaving organ transplant across the United States, the need is great. As such, every hospital is required by law to notify the organ procurement organization federally designated for their region about every potential donor at the time of death. For those individuals who have not already registered as an organ and/or tissue donor, their next of kin must make that decision for them. Our Donor Network West team will reach out to the next of kin to seek authorization for donation. The next of kin will need to sign an authorization form and a copy of the form will be provided to them. Following the next of kin's authorization, Donor Network West will begin the donation process.

"I feel blessed with two donated corneas because the higher power knew I needed to see my two babies at the same time. The generosity of my donors and their families gave me back my independence. I can now chase after my very active twins and watch them grow up. I am forever grateful."

Dr. Maisha Gray-Diggs
Double Cornea Recipient

pictured with twins Maya and William



FREQUENTLY ASKED QUESTIONS ABOUT DONATION

If my loved one is a registered donor or I am authorizing for donation, will the doctors still try to save my loved one's life?

Yes. The number one priority of health professionals is to save the life of their patient. The organ and tissue donation process does not begin until after all efforts to save the life of their patient have been exhausted and the patient has legally been declared dead. There are legal guidelines around how death is declared. It is required that the physician who declares the patient's death is not involved, in any way, with the recovery of organs and tissues or the transplant teams.

Are all families approached about the opportunity of organ and tissue donation?

While there is great need, not everyone qualifies to be a donor. In fact, less than one percent of all deaths meet the specific medical criteria to be a donor. If however, your loved one meets the medical criteria to be a donor, Donor Network West will make sure to offer the opportunity of organ and tissue donation to you so that your loved one can leave a legacy through the gift of life and help save and heal the lives of the thousands of people waiting.

Are there any religious conflicts to donation?

No. All major religions support organ and tissue donation as a generous act of charity. If you have additional questions regarding your specific religion, please consult with your personal religious advisor.

Does organ and tissue donation delay funeral arrangements?

Donor Network West works closely with more than 500 funeral homes and mortuary services to return your loved one to your family in a timely manner. Organ and tissue donation should not interfere with or delay funeral arrangements and does not prevent open casket services.

Will my family be charged for the cost of the donation?

No. Costs associated with recovering organs and tissue for transplantation and research are the responsibility of Donor Network West.

How long does the organ and tissue donation process take?

The length of time of the organ and tissue donation process can vary due to several factors including what organs or tissue are being recovered, recovery team schedules, operating room availability and the family's needs. Donor Network West makes every possible effort to ensure a timely recovery process, however, the average organ donor recovery can take between 24 and 48 hours. Donor Network West staff will remain on site throughout the recovery and work with your family to fulfill your needs as best as possible.

Should I stay at the hospital during the donation process?

The decision is entirely up to you if you want to remain at the hospital during the donation process. Some families like to visit the bedside a final time before the process begins and then decide to go home to be with other family members. Should there be anything you need during the donation process, please be sure to let your Donor Network West staff member know your wishes.

Who will receive my loved one's donated organs and tissues?

Recipients are selected according to medical criteria and urgency of need. The United Network for Organ Sharing (UNOS) maintains a centralized computer network that matches donated organs to transplant candidates. The matching criteria was developed by the transplant community to save as many lives as possible and provide recipients with the best possible chance for long-term survival. Unlike organs, donated tissue is often preserved after recovery until an appropriate transplant recipient is matched.

BRAIN DEATH Q&A

What does brain death mean?

Brain death, also known as death based on the absence of all neurologic function, is a legal definition of death. It occurs in patients who have suffered a severe injury to the brain. As a result of the injury, the brain swells and obstructs its own blood supply, causing brain tissue to die and permanent loss of brain function. Brain death is permanent and irreversible. However, the vital organs, such as the heart, lungs, liver, pancreas and kidneys can be kept functioning by artificial or mechanical support.

What causes brain death?

There are many causes of brain death. Brain death can occur from illness or accidental injury. Some causes of brain death include head trauma from motor vehicle, all-terrain vehicle and snowmobile accidents, falls, gunshot wounds, hemorrhages from aneurysms and strokes, high blood pressure, heart attack, brain infection, brain tumors, medication overdoses, drowning, and poisoning.

How does a physician determine brain death?

A physician conducts medical tests to make the diagnosis of brain death. Tests include a clinical examination to show that your loved one has no brain reflexes and cannot breathe on their own. Other testing may include an apnea test, blood flow test or an EEG (Electroencephalogram). These tests may be done to confirm the absence of blood flow or brain activity.

Your loved one may exhibit spinal activity or reflexes, such as twitching or muscle contractions. Spinal reflexes are caused by electrical impulses that remain in the spinal column. These reflexes are possible even after brain death.

Is there anything else that can be done after brain death?

Everything that can be done to save your loved one's life is done before brain death is declared. After the diagnosis of brain death is made, there is no chance of recovery.

If my loved one is brain dead, why does their heart continue to beat?

The heart has the ability to beat independently of the brain as long as it has oxygen. The ventilator provides enough oxygen to keep the heart beating for several hours. Without ventilator support, the heart will eventually stop.

Why must the ventilator be kept on after a person is declared brain dead?

The ventilator is needed to provide oxygen to the vital organs. Without oxygen, the organs would stop functioning and would not be viable for transplant.

Does our loved one feel any pain or suffer after brain death is declared?

No. When a patient is declared brain dead, they are deceased and cannot feel pain or experience any suffering.

Is it possible that our loved one is just in a coma?

No. People who are brain dead are not in a coma. A patient in a coma continues to have brain activity and function. When brain death occurs, all brain function stops and there is no chance of recovery.

CIRCULATORY DEATH Q&A

What does circulatory death mean?

Circulatory death occurs when the heart stops beating.

What does donation after circulatory death (DCD) mean?

Donation after circulatory death means that after the heart has stopped beating and death is pronounced by a physician, organs and tissues may be recovered and offered for transplant.

Who can be a DCD donor?

A patient who has a severe neurological injury such as a stroke, bleeding into the brain, trauma or suffocation may be a DCD donor. Patients who have amyotrophic lateral sclerosis, or ALS, as well as patients with spinal cord injuries, may also be DCD donors. With these kinds of serious injuries, the brain is too damaged to recover but continues to have minimal function. However, the patient will not survive without ventilator support.

What is ventilator support?

A ventilator is a machine that “breathes” for a patient when the patient is not able to breathe on his or her own. Ventilators, sometimes called respirators, are common in hospitals and provide oxygen to the lungs through a tube that is placed in the patient’s throat. When the brain is too damaged to recover, it can’t instruct the lungs to keep breathing or the heart to keep beating. In order to sustain life, the patient needs ventilator support.

What is the situation that leads up to a DCD donation?

Once the hospital medical team has determined that the patient will not survive or have any meaningful improvement, even with ongoing care and ventilator support, a family may elect to discontinue or forgo further medical intervention. This careful decision includes withdrawal of support, or removing the ventilator, allowing death to occur naturally.

What happens once the family decides to withdraw ventilator support?

After the family makes the decision to stop ventilator support, they will be guided through some end-of-life decisions, including decisions about organ and tissue donation.

Donor Network West, which is responsible for helping with organ donation and transplantation, will be notified. A Donor Network West coordinator will examine the patient and work with the hospital staff to determine if the patient is suitable to be a donor. If the patient can be a donor, the coordinator will speak with the family about organ and tissue donation.

What happens before the ventilator is discontinued?

Until the time of death, the patient remains under the care of the hospital physician and medical team. All comfort measures are maintained and compassionate care is continued. The patient will continue to receive pain medication and other treatments, as directed by the attending physician. If the family chooses, they may be able to remain present and follow rituals that are important for end of life, such as prayers, music or inviting those close to the patient to be present.

What happens next?

Once the ventilator support has been removed and the heart stops beating, a physician from the hospital will declare death. After the declaration of death by the patient's physician, a five-minute period is observed and death is confirmed. At this point, the patient will be prepared for surgery. A separate team of physicians and professionals will perform the organ recovery. After the surgical procedure, the organs will be provided for transplant.



Penelope's story

The fact that Penelope is alive today proves that the power to save a life touches people of all sizes!

Penelope, who lives in San Jose, California, had biliary atresia — the most common lethal liver disease in infants. In 2016, she underwent the Kasai procedure to prevent further damage to her liver before she was placed on the transplant waitlist. Thankfully, she received a liver after eight days.

Penelope was lucky. Some people wait months or years hoping for their transplant. Sadly, some do not receive one in time. Her Gift of Life allows her to ride her bike often and enjoy her two favorite things: pizza and ice cream!

THE DONATION PROCESS

Before the donation process can begin, a declaration of death must be made and authorization must be obtained.

Evaluation of Donor

The first step of the process is the evaluation of the donor. The organ recovery coordinator evaluates the function of the organs and tissues through laboratory and diagnostics tests to identify what can be donated. During this time, your loved one will remain on a ventilator and be supported with fluids and medications to keep oxygen and blood flowing to the organs.

Identify Recipients

Following the evaluation of the donor, Donor Network West contacts the United Network of Organ Sharing, commonly referred to as UNOS, to match the organs to the most appropriate recipients through a national computer network. The recipient for each organ must be located before the surgical procedure begins due to the limited amount of time organs are viable between recovery and transplant.

Recovery

Organs and/or tissues are surgically removed in an operating room. The donor is treated with the same dignity and respect that would be given to any patient undergoing an operation. Incisions are closed and the donor is reconstructed to aid the funeral director in preparation for viewing or burial.

Release of the Donor

The donor may be released to the medical examiner (ME) or to the funeral home. The ME's office is located in a facility separate from the hospital. The ME determines whether an autopsy will be required, as well as the length of time the donor will remain at the ME's office. The donation process does not affect this time duration. For example, if your loved one dies during the weekend, the ME may not release your loved one to the funeral home until Tuesday. Once the ME has completed his or her review, the donor is then released to the funeral home.

"I'm grateful to be here today because of the selfless act of my kidney donor. I am in my third year of my fourth kidney transplant. Because of my kidney transplant, I have been able to graduate from college, get married, and start a family. In turn, today I'm proudly able to see my son in his second year of college at UC Berkeley."

Sonny
Transplant Recipient



DONATION OUTCOME INFORMATION

Approximately six weeks following the donation of your loved one, Donor Network West will send a letter confirming which organs and/or tissues were recovered and provide general information about each of the recipients of your loved one's vital organs (kidneys, liver, pancreas, intestine, heart and lungs). The names and location of the recipients are kept confidential.

Information about tissue recipients is often unavailable due to the fact that more than 75 people can receive the tissue over the course of several months and even years. However, should you have additional questions regarding your loved one's tissue donation, please contact the Donor Network West Aftercare team.

"I never thought something like this would happen to him. It wasn't at birth that he needed a liver transplant. It happened within months. It is such a blessing! I just want to say thank you to Lorenzo's donor family for saving my son's life."

**Melissa - Mother
of Pediatric Transplant Recipient**



DONOR NETWORK WEST AFTERCARE PROGRAM

Donors and their families make generous decisions that save and heal the lives of recipients every single day and inspire their communities to donate life. We thank you for your generosity. The gifts that you and your loved ones have given impact the lives of those who receive them in a tremendous way, and give hope to the thousands who are still waiting.

At Donor Network West, we aim to provide the highest level of service and support to our donor families. In the Aftercare program, we keep in touch with you for at least one year after the passing of your loved one. Our goal is to provide you with support in order to facilitate your healing process. Our services are designed to help meet the needs of those who consider organ and tissue donation following the loss of a loved one. We offer support through regular contact with our professional bereavement staff.

Our support services include:

- Emotional support
- Crisis management
- Referrals to community support groups, counseling, or other appropriate resources
- Literature on grief and bereavement specifically designed to meet family or individual needs
- Update on the status of recipients
- Bi-annual Donor Family Newsletter
- Personalized set of memorial cards
- Annual Donor Family Ceremony

Additionally, we facilitate correspondence between you and the recipients and provide referrals for grief support.

This can be a very difficult time, and we are here to assist you every step of the way.

DONOR NETWORK WEST DONOR FAMILY EVENTS & PROGRAMS

Donor Family Ceremony

Each year, Donor Network West honors the past year's organ, eye and tissue donors for their gift of life with special private receptions. The Donor Family Ceremonies are held in the spring in Pleasanton and Fresno, California and Reno, Nevada to accommodate the donor families throughout our service area and provide each donor family the opportunity to join with other donor families to celebrate the lives of their loved ones.

Donor Memorial Quilts

Creating a quilt square is another way to honor the legacy of your loved one. Each year we create donor memorial quilts out of the quilt squares provided by donor families. These donor memorial quilts honor and remember those who have given the gift of life. Each square is unique and personal. Some have pictures, others sayings. All together, they represent the lives of all those who have been so generous. We continuously collect memories from donor families to create more donor memorial quilts. Once we receive 25 squares, we sew them together into a quilt and they are displayed in our offices as well as at special events.



Erik's story

Erika Preciado of Ceres, California was not even four years old when her father, Erik Gustavo Sandoval Preciado, was killed during a botched car theft incident in 2007. In 2019, Erika listened to his heart beat in the chest of Ramiro Cruz, who received Erik's donated heart and traveled over 200 miles – from Bakersfield to Modesto - to meet the donor family.

During the meeting, Erika's grandmother and Erik's mother - Julie Sandoval - shared that her son had told her that, if anything ever happened to him, he wanted to be an organ donor. "It's OK, mija," Julie said to comfort her granddaughter, who began to cry as she heard the rhythm of Erik's, now Ramiro's heart.

"Erik made this possible with his natural-born unselfishness and giving heart", says Julie. Erik will always be remembered as the one who gave hope to people in great need.

WRITING TO RECIPIENTS

Donor Network West supports and encourages written correspondence between donor families and transplant recipients. While writing to a recipient is a personal choice, it can also prove to be very rewarding and comforting. Recipients often express appreciation for letters or cards that they receive from donor families. Any decision you make regarding whether or not to correspond with your loved one's recipient will be respected by Donor Network West.

Initially all correspondence is completely anonymous and identities are kept confidential. Donor families and transplant recipients correspond to share information about themselves and their loved one.

Here are some general guidelines to help if you would like to write to your transplant recipients:

Provide General Information

- Keep identities anonymous and confidential. Avoid including any last names, street addresses, city names, phone numbers or the hospital where your loved one died.
- You may want to include your name, your loved one's first name only, as well as information about their age, sex, job, and hobbies or interests.
- You may also include photos if you would like, however, be sure that there is no confidential information.

Closing Your Letter

- Identify your relationship to the donor, for example, donor's mom, donor's spouse, etc.
- Sign your first name only

Sending your Card or Letter

- On a separate piece of paper, write your full name, address, phone number and the name and date of death of your loved one.
- Place the sheet of paper along with the card or letter in an envelope.
- Mail the envelope to:

Family Services

Donor Network West

12667 Alcosta Blvd., Ste. 500

San Ramon, CA 94583

If you wish to send your correspondence electronically, please email your letter and accompanying information to: aftercare@dnwest.org

What happens when Donor Network West receives my card or letter?

Donor Network West evaluates each letter for content. When the correspondence has been accepted, our Family Services Department will forward the letter to the recipient's transplant center. After the transplant center reviews the letter, they will either forward it to the recipient or send it back to Donor Network West with an explanation of why they were unable to forward the correspondence. We will notify you if your correspondence is unable to be forwarded, and provide you with an explanation.

Will I receive a response from my loved one's recipient?

Through the years, Donor Network West has discovered that some transplant recipients may send a letter or card to you in response, while others may choose not to write. Like your decision to write, this is their personal decision. If you do not hear from the recipients, we urge you not to take this silence personally. We find that many transplant recipients are hesitant to respond because they feel overwhelmed by your generosity and their emotion hinders their ability to express their full gratitude in writing.

Can I meet the transplant recipient?

Many transplant recipients and donor families ask if they will ever be able to have personal contact. We have found that after a period of anonymous correspondence, the desire to meet is often expressed by one or both parties. If there is no extenuating circumstances and both sides express a desire to meet, Donor Network West will, with the permission of both parties, facilitate the exchange of personal information. Donor Network West hosts several meetings between donor families and recipients each year.

"I have seen the joy that organ and tissue donation brings to families who receive the lives of their loved ones back. It helps me to know that my husband, Rob was a registered donor and gave the ultimate gift."

Debbie - Donor Wife
pictured with her son, Colin



COMMEMORATING YOUR LOVED ONE'S LEGACY

There are many ways to honor the memory of your loved one.

Donor Memory Cards

If you wish to honor your loved one with a memory card, Donor Network West can provide you and your family with a set of 50 memory cards to be distributed at the funeral or memorial service. Memory cards are a visual reminder that recognize and honor your loved one for being a donor.

Honoring Your Loved One in an Obituary

The memory of your loved one will live on each day in the recipients whose lives were forever changed by your loved one's gift of life. You have several opportunities to pay tribute to their selfless act and honor their legacy of love and generosity.

Donor families may wish to have their loved one's gift of life recognized formally in an obituary. This is a wonderful way for family to honor and remember their loved one and will help spread awareness about donation to save lives.

If you wish to recognize your loved one's final act of heroism, here are some sample phrases you may use:

- [Name] gave in death, as he/she gave in life. He/She was a [type of donor] donor.
- [Name] was a [type of donor] donor.
- [Name]'s final act was to give the gift of life through organ and/or tissue donation.
- [Name]'s spirit will live on in the many lives he/she blessed through organ and/or tissue donation.

MOMENT OF HONOR

To honor your loved one's heroic decision to save lives through organ and tissue donation, a designated officiant can read a short tribute in recognition of your loved one and their decision to donate during the memorial service.

Each year the lives of thousands of men, women and children are saved or greatly improved through the miracle of transplantation. The true heroes behind this miracle are organ and tissue donors, and their families, who make generous decisions to save and heal lives. Words cannot possibly express the gratitude of those whose lives have been enriched.

Today we pause to honor the life of [Name]. As we reflect upon [Name]'s life, we acknowledge that his/her final act was to give the most precious gift anyone could give, the gift of life through organ and/or tissue donation. May we find hope in the renewed life brought by this final, selfless act.



Angelo's story

When Angelo Marcoccia was born prematurely he only had a 50% chance of survival. His grandmother wanted to name him 'Angelo' because she thought he might become an angel soon. Angelo became an angel when he suffered a critical head injury while working in 2020. Those who knew him personally remember him for his loving heart and genuine kindness.

Angelo was able to gift both of his kidneys to two women, both waiting over a decade for this once-in-a-lifetime match. A gift that was truly heaven-sent to those who were at the end of the line for hope. He will always be remembered for his giving nature in life and in death, even by those who never got a chance to meet him.

"Angelo was so generous and he gave to the very end. He is still giving even now. There is still him. There is still life," says Katherine Marcoccia, Angelo's wife of 25 years.

IN MEMORIAM

As a donor family you may wish to organize memorial contributions to honor your loved one in lieu of flowers. Memorial donations can be directed to Donor Network West using the information below.

- Checks may be made payable to: Donor Network West
- Credit Cards are accepted by visiting:
www.DonorNetworkWest.org/contributions

Donor Network West asks that you indicate who your contribution is in memory of by writing your loved one's name on the check in the memorandum line. An acknowledgement of all the memorial gifts will be sent to you.

Below are suggested phrases for sharing information about the memorial contributions:

- In keeping with [Name]'s loving and generous spirit, it was his/her decision to donate life so others may live. In lieu of flowers, memorial contributions may be made in [Name]'s name to Donor Network West, 12667 Alcosta Blvd., Ste. 500, San Ramon, CA 94583.
- [Name] gave the gift of life through organ and/or tissue donation. In lieu of flowers, memorial contributions may be made in [Name]'s name to Donor Network West.

FINAL THOUGHTS

The time following the death of a loved one may be filled with a sense of numbness and anxiety. Yet many decisions must be made during this stressful time. We hope the information in this brochure was helpful to you during this difficult time.

While there will be ups and downs, remember to breathe. Take time to be alone and with others you trust and can talk to. Allow yourself to accept expressions of caring from others. And, make sure to replenish yourself by allowing yourself more of the things you needed before. Things will continue to get better as time passes, but in this moment just take small steps and slowly this difficult time will become a little bit easier.

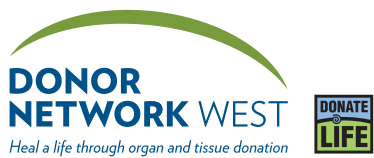
Please contact us at any time. We are here to help.

aftercare@dnwest.org | 888.570.9400

There is no wrong or right way to grieve...there is only your way.







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