



15 Years of Connecting People to Life

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# MEDIA TOOLKIT

*Updated February 2020*



**AMERICAN  
TRANSPLANT  
FOUNDATION**

15 Years of Connecting People to Life

AMERICANTRANSPLANTFOUNDATION.ORG

## WHO



American Transplant Foundation was founded 15 years ago by Steve Farber, Heidi Heltzel and Dr. Laurence Chan. After struggling with kidney problems when he was a toddler, Steve became founder of a successful law firm. His success did not help him when, at age sixty, his kidneys began to fail for the second time. After facing many obstacles throughout his transplant journey, Steve was given the gift of life from his eldest son Gregg.

Steve's difficult transplant journey inspired him to help families navigate difficult organ transplant issues and the challenges that come with it. He wants to work towards new legislation to create better policy around transplantation in America. It is only when the gap between the need for organs and their supply is eliminated will Steve Farber's journey be complete.

## WHY



## WHAT



American Transplant Foundation (ATF)'s mission is to save lives by reducing the growing list of women, men, and children who are waiting for a transplant. We do this by maximizing living organ donation, which is the most effective way to fulfill our mission. ATF provides a three-tiered approach with educational, emotional, and financial support for living donors, transplant patients, and their families across the country, with a specific focus on Colorado.



ATF is a grassroots organization that does not receive any funding from the government nor organ recovery fees and relies on individual and community donations. We believe that simply increasing awareness of living donation is not enough. There needs to be educational, emotional, and financial services in place to support living donors before, during, after the surgery. **We make our impact by:**

### CREATING COMMUNITY

ATF strives to be inclusive and treat everyone with empathy and compassion. We value and engage volunteers and supporters to collectively move the organization towards the mission.

### AWARENESS AND INSPIRATION

ATF is inspired because we believe in what we are doing and who we are serving. By raising awareness of our mission programs, we help more people receive lifesaving transplants.

### MISSION FOCUSED FUNDRAISING

ATF continuously shares our mission through all fundraising events to inspire and educate our partners.

### INNOVATION AND IMPROVEMENT

ATF strives to be the premier national organization addressing the shortage of organs for transplant through increasing awareness of living donation while providing lifesaving support to transplant patients in need.



# ATF Core Programs

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## **1+1=LIFE Mentorship Program**

Free peer mentoring in 12 languages for anyone who needs help during their transplant journey.

## **Patient Assistance Program**

Lifesaving assistance for the most vulnerable transplant patients across the nation. By offering grants to living donors, American Transplant Foundation is able to remove financial barriers from giving the Gift of Life.

## **Potential Living Donor Database**

The first of its kind. It fills a gap in the system by providing a mechanism for those interested in saving a life to register and learn more about the specific steps to take in order to become living donor.

## **Patient Advocacy**

American Transplant Foundation goes beyond awareness by successfully advocating for living donors' and transplant recipients' rights on the state and federal level. We proudly led the passage of two new laws in 2018 & 2019.

# Impact Stories

## Sasha Adler-Turk, Living Donor, Patient Assistance Grant Recipient



Sasha donated a kidney through a donor chain to benefit the love of her life in April 2018. The couple had been struggling financially due to her partner, Chad's inability to work. While it can sometimes be difficult to donate a kidney, Sasha said the decision to donate was easy. While Sasha was not a match for Chad, her decision to donate made it possible for a five-person chain to take place. They are now both doing very well and are very grateful for Chad's second chance at life!

The grant that Sasha received from American Transplant Foundation allowed her to heal without having to worry about how they would make ends meet while they were both in recovery.

## Travis Atwood, Living Donor, 1+1 Mentorship Program Mentee



Travis knew that during his journey on this Earth that he wanted to give back someday somehow. After finding out about living organ donation, Travis asked himself, "What kind of community, state, country, and world do I want to live in? He answered, "I want to live where people care about the people around them". Travis then made the decision to donate one of his Kidneys, and taking part in helping someone get their life back.

Travis is thankful for his experience with the American Transplant Foundations 1+1=LIFE mentorship program. All his questions were answered by his mentor, and they helped his transplant process run smoothly and comfortably.

# The Journalist's Guide to Living Donation

## Myths and Facts

### Donating a kidney is a dangerous procedure and extremely painful.



Most donors only spend 1-4 nights in the hospital and are able to return to work in 2-3 weeks. The risk of complications from a donation is low, but as with any major surgery there are risks involved. Most donors say that seeing their recipient's improved health after transplant more than outweighs the pain and inconvenience of donating. The American Transplant Foundation's trained Mentors can provide specific support and guidance as well as share about their personal journeys as living donors if you or someone you know is considering living donation.

### Out-of-pocket expenses for the donor will be too high.



It is the recipient's insurance policy that covers the transplant and transplant-related follow-up. Lost wages and medical treatment post-transplant are NOT covered by recipient's insurance. The American Transplant Foundation can provide financial assistance to donors to help cover lost wages.

### Donating a kidney reduces the donor's life expectancy.



Donating a kidney does not reduce the living donor's life expectancy. As living kidney donors must undergo rigorous health checks, they tend to be healthier and outlive the average person.

### Surgery will affect the donor's ability to have children.



There is no evidence to support that kidney donation impacts the ability to have children. Donors should be open and upfront about their donation when consulting obstetricians or gynecologists.

### No one will volunteer to be a donor, especially for a stranger.



Since the first successful donation in 1954, over 150,000 people have become living donors, with an average of 7,300 happening annually. Also, 1 in 4 of these donors aren't biologically

related to the recipient. If your family members/friends are not a match, they can still save your life through paired exchange programs.

### Not all religions support living donation.



All major religions in the U.S. support living and deceased organ donation.

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## FAQs

### What is organ and tissue donation?

- There are two types of organ donation: **deceased** donation and **living** donation.
  - **Deceased** organ, eye, or tissue donation is the process of recovering organs or tissue at the time of the donor's death for transplantation to save another's life.
  - **Living organ donation** occurs when a healthy person donates a kidney or part of the liver, lung, intestine, pancreas, or bone marrow to save another's life.

### Who can donate an organ?

Living donor candidates should be:

- In good physical and mental health
- At least 18 years old
- Be willing to donate: No one should feel that they **MUST** donate



- Be well informed: A good donor candidate has a solid grasp of the risks, benefits, and potential outcomes, both good and bad, for both the donor and recipient
- Have a good support system

## Which organs can be transplanted from living donors?

- Kidney – most common type of living donation.
- Liver – individuals can donate a segment of the liver, which has the ability to regenerate and regain full function
- In very rare cases, individuals can also donate portions of their lungs, intestine, pancreas, heart, or uterus.

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## Organ Donation in Colorado FAQs

### What is the current situation in Colorado?

While the waitlist in Colorado has decreased by 23.8% from 2018, there are still 1,648 Coloradans in need of a transplant.

The number of Coloradans in need of a kidney is 1,379 people. Last year, 119 Coloradans died while waiting for a kidney, an organ that could have been safely donated by a living person with little risk to their health (a serious complication rate of less than 1%).



## How can we best address the critical shortage of kidneys in Colorado?

### 1,648 Coloradans are Waiting for a Lifesaving Transplant



With millions of dollars spent on educational materials and awareness, donor registration for deceased donation has only increased 9% over the past 13 years.

Since 83% of Coloradans on the list are waiting for kidneys, **focusing on live kidney donation seems to be the only immediate solution** for maximizing transplantation in our state.

Even with minimal awareness campaigns, last year in our region, **124 living donors saved lives compared to 159 deceased donors**. Imagine how many more potential live kidney donors would step forward if there was more education and awareness. If just 1 out of every 3,500 Coloradans donated a kidney, the kidney waiting list would be eliminated.

### Who addresses living donation in Colorado?

The American Transplant Foundation (ATF) is the only nonprofit in the state of Colorado that provides three tiers of support for living donors, transplant recipients, and their families. We proactively reduce the transplant wait list by enabling living donation through educational, emotional, and financial support.

Coloradans who participate in the Foundation's 1+1=LIFE mentorship program can receive help either finding a living donor or becoming a living donor, increasing the number of transplants that take place. Additionally, living donor's who qualify for our Patient Assistance program may receive financial assistance for lost wages that occur during donation.

Donor Alliance is an organ procurement organization and our valued partner. It is not focused on living donation and doesn't offer specific programs for living donors. It refers living donors or people who are in need of a living donor to ATF.

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## Policy Change

American Transplant Foundation has also led the efforts for better legislation in order to protect the rights of living donors and transplant recipients. As of January 2020, two bills ATF fought to get passed have taken effect: Colorado [Living Donor Insurance Act](#) and [Living Donor Support Act](#).

### [Living Donor Insurance Act](#)

This bill **prohibits discrimination of living donors** from insurance providers (health, life, disability income, and long-term care insurance). It states that these providers **may not deny coverage or increase premiums** based on living donor status.

### [Living Donor Support Act](#)

This bill supports living donors by allowing them to take **a leave of absence for the purpose of their organ donation**. Employers can claim an income tax credit equal to 35% of their expenses incurred from:

- Paying an employee during his/her leave of absence, equivalent to 10 working days or hourly equivalent; and
- Temporary employee replacement costs, if applicable.

## Organ Donation in Colorado: 2006-2020

	2006	2019	% Change
Percentage of population that are registered donors	60%	69%	+9%
Number of residents who died while on the wait list	99	119	+17%
Number of residents who died while waiting for a kidney	42	60	+30%
Number of deceased organ donors	98	162	+40%
Total number of residents waiting for a lifesaving organ	1,700	1660	-3%
Number of residents in need	970	1,381	+30%

# ATF IMPACT IN COLORADO

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ACTIVE 1+1 LIFE  
MENTORS IN  
COLORADO

COLORADANS  
WHO'VE JOINED  
OUR POTENTIAL  
LIVING DONOR  
DATABASE

105

\$754,675

TOTAL FUNDS  
DONATED AS OF  
JAN, 2020

PATIENTS  
SUPPORTED  
THROUGH OUR  
PATIENT  
ASSISTANCE  
PROGRAM

1,380

SOURCE: AMERICAN TRANSPLANT FOUNDATION

of a kidney transplant			
Number of kidneys transplanted	243	372	+35%
Number of living kidney donors	104	124	+17%
Number of living liver donors	4	30	+87%
Number of undirected unrelated living donors (donation to stranger)	2	21	+91%

Sources: UNOS, Donor Alliance's fact sheets for 2016 and 2007

## What are the benefits of living donation?

In 2014, the American Society of Transplantation stated that living kidney donor transplantation is the **best option** for most kidney transplant candidates. It is critical that more Coloradans have access to it. The average 5-year survival rate for those who receive a kidney from a living donor is 85% compared to 72% from a deceased donor and 35% for those on dialysis.

There are tremendous economic benefits for live kidney donation as it eliminates substantial “transplant acquisition fees” charged to hospitals by organ procurement organizations which are ultimately paid by Medicare/Medicaid and other insurance plans. On average, for each transplanted patient taken off dialysis, Medicare saves over \$500,000 over the course of 10 years.





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