

Connecting People to Life®



American Transplant Foundation

The American Transplant Foundation (ATF) is the only nonprofit in the state of Colorado that provides educational, emotional, and financial support for living donors, transplant recipients, and their families.



Our Mission

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.



Our Belief

We believe no one should die while waiting for a lifesaving transplant.



Three Tiers of Support

We proactively reduce the transplant waiting list by enabling living donation through educational, financial, and emotional support.

11 Years of Impact in Colorado

- **Piloted the first national mentorship program** in Colorado in 2014 for patients and their families. It is now available in all 50 states and in 8 languages.
- Worked with **Colorado Department of Revenue** to include a **donor registry form** in the State income tax booklet.
- **Ran legislation to create a Donate Life specialty license plate** in Colorado in coordination with our partner, Donor Alliance.
- **510** Colorado families helped during the holidays over the course of the past 6 years through our Tree of Life program.
- **\$271,555** raised by our 54 Young Professionals Group Members in Colorado since the group's inception in 2011. They are stewards of our Patient Assistance Program and make all grant decisions.
- **Currently 61 transplant Mentors** and **38 transplant Mentees** providing/receiving emotional support and guidance in Colorado during their transplant journeys.
- **Conduct 15-20 outreach events** per year.
- With every patient we take off the transplant waiting list, **Medicare saves over \$500,000** over the course of 10 years.
- **\$11.62 million** in economic impact created thanks to the Foundation's work over the past three years.



The NEED in Colorado

- **97%** of Coloradans on the waiting list (2,478) are waiting for a kidney or liver –organs that can be donated by a living person.
- **The number of people on the waiting list on Colorado has increased by 50%** over the past 10 years compared to the national 25.6% increase.
- **The average 5-year survival rate for those who receive a kidney from a living donor is 86%** compared to 79% from a deceased donor and 35% for those on dialysis.
- Despite millions of dollars spent on educational programs, the **number of registered donors has only increased by 3% over the last 5 years** and 9% over the last 10 years.
- The 16.5% increase in organ recovery rates by Donor Alliance over the last 10 years is **not enough to address the transplant crisis in Colorado.**
- **If 1 of every 3,000** Coloradans donated a kidney, we could eliminate the kidney waiting list.

Patient Assistance Program - provides lifesaving monetary assistance to the most vulnerable transplant patients in our country. By offering grants to living donors and transplant recipients, the Foundation makes sure those giving the Gift of Life *won't miss a beat* during recovery. We are proud to be the only national nonprofit that provides emergency financial assistance to transplant patients **regardless of their legal status. ATF supports potential living donors by covering their mortgage/rent and other vital living expenses during recovery up to \$1,000.**



Miguel, a Colorado resident donated to his wife, Maria. Miguel worried he would not be able to financially support his wife and two daughters while both of them were recovering. ATF paid for Miguel's mortgage in order to help him save his wife's life in 2016!

"We are so thankful for everything you've done for our family and other families. Don't stop giving! You are a blessing." – Miguel

Potential Living Donor Database – **this program is the first of its kind.** It identifies those interested in becoming a living donor and gives them the opportunity to learn who needs a transplant. It seeks to fill a gap in the system by providing a free program for potential donors to learn about living donation from a trained Mentor- someone who has gone through the process and give them the resources and guidance they need to save a life.

1+1= LIFE Mentorship Program – helps to save patients' lives across the state of Colorado and beyond. 1+1=LIFE offers free, person-to-person mentoring. Since the program's inception in 2014, eight Coloradans facing extreme difficulties in finding a living donor, were removed from the transplant waiting list and 38 are currently being mentored.

Your support truly makes a difference in the lives of Coloradans.

Thank you for caring.

January 23, 2017

Stephen Crider

Boulder, Colorado

Testimony in support of House Bill 17-1027 – Emily Maureen Ellen Keyes Organ and Tissue Donation Awareness Fund's Section 2 Review-Potential Amendment

Mr. Chair Pabon, Members of the Committee –

Thank you for the opportunity to present to you today. My name is Steve Crider, representing the American Transplant Foundation, and I am here to ask you to expand the uses of the Emily Maureen Ellen Keyes Organ and Tissue Donation Awareness Fund to include Living Donation Support and to recommend the American Transplant Foundation as a partner with the Donor Alliance in order to accomplish this.

Why am I in favor? I've been a supporter of the Foundation for 8 years.... It is CO based....it helps bring Living Organ Donors to CO patients and even others in need across our country. The Foundation believes that no one should die while awaiting an organ transplant, which is very personal for me as my daughter, Kelsey, now 27, was diagnosed with kidney failure at age 17. After 13 surgeries and 3 kidney transplants, ALL from altruistic Living Donors, we were devastated when she lost her last donated organ in 2015. I've woken up many times at 3am and wondered where her next lifesaving kidney would come from...if this would be her last day with our family...just like 1000's of other CO families – There are **2,472** patients on the waiting list TODAY for a kidney or liver!

Thankfully, the Foundation was there to support our family. They are grassroots experts when it comes to living donation because they work with families like mine every day. Some good news, it was a donated rotating Mile High Outdoor billboard in Monument that inspired Nathan Toci, a stranger and her living donor to save my daughter's life. The plea for a Living Donor rotated and was shown for 8 seconds...a virtual 1 in a million chance the perfect match to save my daughter's life would be seen by Nathan and he would step forward. Think about the thousands of other patients that are looking for their Match...to save THEIR Lives.

I understand the issues surrounding organ donation very well as I've been intimately involved with it the past 10 years. I recognize the importance of deceased donation, but truly believe that Living Donation is the answer to this health crisis in Colorado. If just **one out of every 3,000** Coloradans donated an organ, we could eliminate the waiting list tomorrow. I know the American Transplant Foundation is the right organization to help make this a reality. For every month we do not invest in Living Donation awareness through this Fund, we lose lives.

Please consider using this Fund to support living donation awareness and the American Transplant Foundation as Donor Alliance's partner in using it to save lives. Thank you for your time and consideration.

January 23, 2017

Helen Drexler

President and CEO

Delta Dental of Colorado

**Testimony in support of House Bill 17-1027 – Emily Maureen Ellen Keyes
Organ and Tissue Donation Awareness Fund’s Section 2 Review – Potential
Amendment**

Good afternoon elected officials and House Finance committee members.

My name is Helen Drexler. I am President and CEO for Delta Dental of Colorado. However, I am not here in any official capacity nor do my remarks in any way reflect opinions of Delta Dental of Colorado. These prepared comments are my own personal opinions on this important topic.

I recently moved back to Colorado. When I went to get my driver’s license, I was asked this very question about my willingness to donate \$1.00 for a fund to raise awareness for organ donation. I said, no, and then explained that I wanted to donate \$100.00 instead. Yes, I definitely caught the employee at the DMV off guard. I then explained that my son had Stage 5 Kidney Disease and he was on the national registry awaiting a kidney. I am here today to support the renewal of this legislation but to also ask you to consider expanding the use of this fund to include living donation awareness. While this fund has raised over \$3 million for organ donor awareness, the wait list in CO has increased by 50% vs. 25% increase nationally. My son Gary was one of those individuals added to that list in 2016.

I can tell you first-hand how challenging it is to be the mother of a young man undergoing dialysis treatment 3 days a week, waiting to get news on whether he will receive a kidney transplant. I’m happy to report that my son did receive a new kidney just a week and a half ago at the University of Colorado hospital at Anschutz through live organ donation and I’m happy to report that he is doing very well. There is a critical need for all Coloradans to understand the importance of organ donation. I would love for every person with a driver’s license to have a heart on their license. Unfortunately though, the current approach that uses deceased donor kidneys for transplantation is not keeping up with the need. The best alternative is to ALSO promote living kidney donation.

In my son’s case, thankfully, we did not have to wait for a cadaver kidney to be available. His kidney came through live organ donation. His donor will forever be a hero in my eyes. Without funding to raise awareness of the benefits of being an organ donor, we will lose opportunities to save lives. And we must raise awareness for both live organ

donation as well as willingness to state you are an organ donor on your license. Without a live donor willing to donate a kidney to my son, we would likely have waited 5 to 6 years before he received kidney through the national transplant registry. In his case we were able to find a donor in just 4 months. Finding that live organ and getting him transplanted sooner gives him a much better chance of successful transplant and reduced his risk of rejection. This is a quote from Charlie Miller, American Society of Transplant Surgeons President. He says,

“A living donor transplant is a higher quality kidney replacement than a cadaveric donor kidney, and both are better for the patient than dialysis. Living donor kidneys last twice as long – 15 to 20 years – compared to 7-10 years for cadaveric kidneys.”

Because of our journey, my family is now actively involved with the American Transplant Foundation, headquartered in Denver, CO. They are actively working in the space of living donation and they understand how to raise awareness about living donation. They helped my family connect with other family members who had been through organ donation and provided advocacy and mentorship throughout the process which was invaluable to us and to our donor family.

Again, thank you for your time, and I want to reiterate that these opinions are my own personal opinions and do not reflect an official opinion by Delta Dental of Colorado.

January 23, 2017

Anastasia Darwish

Executive Director

American Transplant Foundation

Mr. Chairman and Members of the Committee:

My name is Anastasia Darwish and I am Executive Director of the American Transplant Foundation, a national organization founded and based in Colorado which provides critical assistance to organ transplant recipients and living donors.

We are pleased to offer our testimony on House Bill 17-1027 – **Emily Maureen Ellen Keyes Organ and Tissue Donation Awareness Fund**.

Donor Alliance has been our valued partner since the American Transplant Foundation was founded 11 years ago and we shared with them our ideas for this fund in advance.

We greatly respect Donor Alliance's lifesaving work and we believe we can save many more lives in Colorado by working together more effectively and finding a consensus related to the change of this bill. This testimony is about a very specific aspect of the bill **(Section 2)** related to the **Emily Maureen Ellen Keyes Organ and Tissue Donation Awareness Fund**. We believe Section 2 of the Bill needs to be reviewed and potentially amended.

The statute that was approved in 2007 specified the distribution of all available money from the fund to be transferred to Donor Alliance to be used on organ and tissue donation education. Donor Alliance has been utilizing the fund on education programs related to deceased donor donation.

We believe this needs to be reviewed in order to expand the effectiveness of organ donation in Colorado and address the current shortage of organs available for transplantation, especially the critical shortage of kidneys available for transplantation in our state. To achieve this, funding of living donation education is required.

Donor Alliance 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 us.

The good news is that expanding funding to the education of living donors – which would help greatly expand the number of kidneys available for transplant -- will not put the education about deceased donation at risk at all. Indeed, we believe that the **\$30,000 the fund generates monthly** is more than sufficient to accomplish both worthwhile education goals.

Why is this expansion of the education mission so critical?

Despite the millions of dollars allocated through the Fund to promote organ registry and increase deceased donation, more Coloradans died last year waiting for organs than in 2006 – the year the Fund was established. (130 in 2016 vs. 99 in 2006). *Please see table 1 in your handouts.* When you look at this data, it is obvious that the situation in our State has become significantly worse over the last decade.

Yes, Colorado has one of the highest rates for organ registration, but the state's waiting list is growing much faster than the national list. Since the Fund has been established, organ registration rates increased by **9 percent in Colorado**, but the wait list has increased by almost 50 percent while the national list has grown by **25.5 percent**. The state's population increase alone doesn't justify this difference.

Let's look at the situation with kidney donation. **74 percent** of people who are on the list need kidneys to survive. Last year, **163** kidneys from deceased donors were transplanted. The number of Coloradans who currently need kidneys is **1881**.

At this rate, someone will might need to wait up to 11.5 years to receive a kidney from a deceased donor in Colorado. Chances are they not going to make it.

This is why we at the American Transplant Foundation are so passionate about educating men and women about living donation.

The fact is that You can safely donate a kidney to save someone's life. The complications rate for this procedure is less than 1 percent.

Since 74 percent of Coloradans on the wait list are waiting for kidneys, focusing on live kidney donation seems to be the only solution to significantly reduce the long and life-threatening kidney wait list in CO.

Even with minimal awareness campaigns, last year in our region **111** people received kidneys from living donors versus **163** Coloradans who were saved by receiving a kidney from deceased donors.

Imagine how many more potential live kidney donors could step forward if there was more education and awareness!

Donor Alliance and the American Transplant Foundation share the same mission - to save lives through transplantation. At ATF, we believe that maximizing living donations while taking care of living donors is the most efficient way to accomplish this mission. *Please see handout for more statistics on living donation and our work.*

In 2014, the American Society of Transplantation stated that living kidney donor transplantation is the best option for most kidney transplant candidates.

The 5 -year survival rate for patients who received a kidney from a deceased donor is **79 percent**; but for patients who received a kidney from a living donor – **86 percent**. (Source - SRTR -- Scientific Registry of Transplant Recipients)

This is the best treatment option for the End Stage Kidney Disease (ESRD) and it is critical that more Coloradans have access to it. Also there are tremendous economic benefits for live donation - as it eliminates substantial "transplant acquisition fees" charged to hospitals by Donor Alliance and 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 (*Data Sources: National Kidney Foundation, American Transplant Foundation*).

We believe transparency and engaging stakeholders in decisions that affect so many lives in the state is key and will pursue the opportunity to engage stakeholders in the discussion about how the Fund can be restructured.

I'll end with one final statistic - **If just 1 out of every 3,000** Coloradans donated a kidney, we could eliminate the waiting list for kidneys in our state and save 100 precious lives annually. (*Data Sources: United States Census Bureau and United Network Organ Sharing*).

Thank you for your time and attention.

Table 1. Organ Donation in Colorado and Wyoming: 2006-2016

	2006	2016	Increase	Notes
Percentage of registered donors in Colorado only	60	69	9%	
Number of residents who died while on the wait list	99	130	31.3%	
Number of residents who died while waiting for a kidney	42	97	131%	
Number of selfless donors in CO and WY whose organs were recovered by Donor Alliance	115	134	16.5%	FY15 data
Total number of residents waiting for a lifesaving organ	1,700	2,542	49.5%	
Number of residents in need of a kidney transplant	970	1881	94%	
Number of kidneys recovered and transplanted	87	126	44.8%	
Percentage of residents taken off the wait list after receiving a kidney from a deceased donor	8.9	6.7	-2.2%	
Percentage of residents in need of a kidney compared to all other organs combined	57	74	17%	

Sources: Donor Alliance's fact sheets for 2016 and 2007 (copies available); UNOS

Note: Data is reported for CO and WY combined; separate data for CO or WY is not available

Table 2. Living Organ Donation in Colorado and Wyoming & ATF Programs: 2006-2016

	2006	FY16 only
Number of living kidney donors total*	104	111
Number of undirected unrelated living donors (donation to complete stranger)*	2	5
Number of residents taken off the wait list with the help of ATF's 1+1=LIFE mentorship program	n/a	8
Number of 1+1=LIFE mentors in Colorado	n/a	61
Number of active 1+1=LIFE mentees in Colorado	n/a	38
Number of Coloradans who expressed interest in becoming living donors through ATF's Potential Living Donor Database	n/a	57
% ratio of applications for financial assistance funded vs. denied	n/a	80:20
Number of families assisted with financial support through Patient Assistance Program	n/a	49

*Source: UNOS

Notes: 1+1=LIFE Mentorship Program established in 2014; Patient Assistance Fund established in 2011; all funding decisions are being made by volunteers.

Table 3. The Need for Living Donation Education

Finding	Reference
75% of transplant patients felt inappropriately educated about living donation	Walterman, AD. 2006. Living Donation Decision making: recipient's concerns and educational needs. National Center for Biotechnology Information. https://www.ncbi.nlm.nih.gov/pubmed/16676669
As many as 80,000 patients may be eligible for kidney transplant, but are not on the waiting list	Schold, J.D. et al. 2008. The overlapping risk profile between dialysis patients listed and not listed for renal transplantation. American Journal of Transplantation, 8: 58-68. http://files.givewell.org/files/labs/grants/Schold%20et%20al%202007.pdf
Randomized controlled trials demonstrated that home visit education programs increased the number of living donor inquiries (18%), evaluation (25.5%), and living donations (22%) compared to clinic-based education.	Rodrigue, J.R. et al. 2006. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. American Journal of Transplantation. http://onlinelibrary.wiley.com/doi/10.1111/j.1600-6143.2006.01623.x/full
One-on-one interventions improved the living donation knowledge, reduced concerns, and increased beneficiaries' willingness to talk to others about living donation.	Rodrigue, J.R. et al. 2006. Increasing live donor kidney transplantation: a randomized controlled trial of a home-based educational intervention. American Journal of Transplantation. http://onlinelibrary.wiley.com/doi/10.1111/j.1600-6143.2006.01623.x/full