

THE AMERICAN TRANSPLANT FOUNDATION

Connecting and Collaborating to Save Lives *By Jan Mazotti*

Just weeks ago, at a book signing and speaking event in Los Angeles, Steve Farber, a lawyer, power broker, and philanthropic leader, met a young woman named Caitlin. This woman, just 20 years old was in need of a kidney. She had luckily been given a kidney just six years prior by her father, but it had failed and Caitlin was facing a nine year wait to get another one. Nine years is the wait in California for a kidney or liver. Already on dialysis for two years, she would have to be on dialysis for another seven, if her body could hold out that long. Farber asked her how she was coping with everything and she said, "not well, but you just deal with it." Struck by her candor and bravery, Farber introduced Caitlin to the crowd before beginning his talk. He shared her story while reminding the crowd that 18 people die every day waiting for a kidney or liver. That's 6,500 people a year. He said, "It's needless...these deaths."

About an hour later, Caitlin and her mother came back over to talk to Farber. Caitlin was sobbing, Farber reacted by saying, "I hope I didn't say something that caused you to feel this way. What is wrong?" Caitlin, through her tears, looked at Farber and said, "It is because of what you said."

Caitlin pointed out a woman across the room and told Farber that they had a discussion and had talked briefly about blood types and that she had agreed to be her donor. They were going to visit the doctor in coming weeks. If all goes well, Caitlin's life will be saved!

Born and raised in Colorado, Steve Farber has been called the most powerful man in Denver – credited with bringing the Democratic National Convention there in 2008. As a child, Farber experienced kidney failure and spent extensive time at the Children's Hospital. He says he remembers it vividly, even today.

Then in 2003, some 40 years later, Farber experienced kidney failure again. This time, without a transplant Farber would die. He explored



Steve Farber

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various options before settling on a live donation from his son, Gregg in May 2004.

I had the extreme honor of visiting with Mr. Farber about one of his new passions, the American Transplant Foundation, and why he chose to create it. He talked about the substantial issues surrounding transplantation, why he wrote the book *On the List: Fixing America's Failing Organ Transplant System* with Harlan Abrahams and what's next on his agenda.

Why is there a need for the American Transplant Foundation (ATF)? How is it different than other non-profits addressing transplant issues?

I was sitting with a priest during this journey to deal with my spirituality and I realized that if I got through this ordeal, there was a lot more for me to do. I knew if I got through the ordeal and God let me stay on this earth there were some other things that I had committed to do. One of them was establishing the Foundation. Before I established the Foundation, I did some due diligence to find out who was around and doing what job. What I found was that nobody was around that could simplify the complexities for me. Forming the Foundation and trying to get the word out to create a greater awareness about transplantation is a big part of it. And then after an article that ran in the *Denver Post* I received a lot of letters and emails that were thankful for my openness, especially concerning my family and personal issues. That's when I decided to write the book. I wish I would have had a roadmap to get through this thing when I was going through it - I didn't know anyone who'd had a transplant. Maybe I could serve as a roadmap, dealing with the physical and medical issues, as well as the emotional issues. It's tough to conceive and deal with all the things that are put before you.

There were organizations like the Donor Alliance, the organ procurement organization, doing a wonderful job at recovering organs and matching them with their recipients. They have certainly created awareness around organ and tissue transplantation.



But what often gets lost is that there are more than 104,000 people in the United States waiting for a life-saving organ transplant. One person being an organ and tissue donor can save 8 lives and impact the quality of another 100. The impact would be unbelievable if everyone registered and shared their desire to give the gift of life by becoming an organ donor.

One of the things we did at the ATF was going to the Department of Revenue with a plan. We said, "What if everyone who submits a state tax return in Colorado could sign up to be an organ donor?" That's when we knew that we were going to the legislature and lobby if

needed. But it wasn't needed. One week later, the Director of the Department of Revenue called me and said, "It's done." We have also created an Endowed Chair at the University of Colorado Hospital in transplantation.

Just like anything else, unless you continue to communicate with the community it slows down. The real goal of the ATF is awareness – getting patients and their families to the right sources, to talk to them ourselves, to be the connector of resources. "Generally it costs upwards of \$125,000 for procedures and we've had so many people call and say, 'I don't have insurance.' We try to direct them to the right spot," said Farber.

How is the American Transplant Foundation trying to change policy issues to tighten the gap between organ supply and demand? In your opinion, what are the most pressing legislative/policy issues?

There are so many. For starters, the Foundation has lobbied against the Family Veto law. We changed one word in the statute and now the wishes of the deceased donor, not their family, must be respected.

Additionally, we have been approached by different State legislators regarding the

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introduction of various pieces of legislation that would promote organ and tissue donation. One such example is "Opt Out" legislation, which would presume that all Colorado residents are donors unless they opt out of the donor program. But it's unclear if such a measure would pass because it's difficult for some people to accept the concept of opting out of a program instead of opting in. A number of European countries have already implemented opt out programs.

There are other national movements in the U.S. and there are many competing theories – the Free Market Camp, the Human Rights Camp... Senator Arlen Specter has tried to enact legislation that has been referred to as the Economic Approach. Currently, "valuable consideration," which is the exchange of either money or goods and services from one person to another for the donation of an organ, is prohibited. It's a felony. Specter, through his Economic Approach, wants to give States the right to create incentives that will encourage organ donation by allowing the provision of



Photo by Joshua Duplechian – Rich Clarkson & Associates

Steve Farber, Colorado Governor Bill Ritter and Heidi Hehzel at the Crosby, Stills and Nash benefit concert.

benefits, such as health insurance for living donors or burial costs for deceased donors. If you put a system like this into effect there will be a greater impact on the health and welfare of the whole community.

With more transplants you have more patients coming off dialysis, returning to work and contributing to the local economy. At the same time it saves the state money through various state funded programs. So why not do this? We need incentives to encourage people to become either living or deceased donors.

Today, Medicare limits the coverage of immunosuppressants for many transplant patients to three years. If Medicare covered the drugs for the life of the patient the government would actually save money in the long run. When Medicare stops covering the drugs, many people either reduce or stop taking them because they can't afford them. Then they go into rejection and all of a sudden they're back on dialysis again waiting for another transplant. That's our medical system.

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Photo by Joshua Duplechian – Rich Clarkson & Associates

Team Transplant cycles the 2009 Elephant Rock Ride.

We've ask federal legislators, as they craft this new health care reform, that they extend the drug program for the rest of a transplant patient's life. It's been received very well. It's really about what the free market is going to drive. It comes down to fundamental fairness and equity issues.

(He laughs...) I feel like I've had more than a hand in it, I've had a kidney too.

It sounds like you considered transplant tourism and then backed off. Why?

I had the ability to fly to a foreign country and get a black market organ. So many others don't. But when it was all presented and after talking to a lawyer, who had gone to Turkey, for a kidney that the more I explored it - it was illegal. The moral issues, paying somebody money, so that they could put food on the table by buying an organ from them, just didn't sit well with me. And then the movie *Midnight Express* kept going through my mind.

Just two weeks before I was scheduled to go to Turkey, I ran into a doctor friend at the Blue Bonnet restaurant. He said from across the restaurant that I looked terrible. I sarcastically said thank you. He said, "Wouldn't it be a shame if you died when your son is a match?" I just sat there.

After dinner I went home and called my son and said, "Are you still there for me?" He said okay and we decided we'd do it in the next two weeks, but he said, 'just don't tell mom.' I laughed and said don't worry about it. It was ironic because the tables were turned. My son was now giving his father the gift of life.

You've said that one of your important life lessons was your willingness to be the beneficiary of change, but not prepared to be the agent for it. How have you taken that lesson and incorporated it into your endeavors? How do you see yourself changing the world?

I never forget what my mother said (and she told me constantly) about when I was a



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baby and the miracle of my life. Even though I was only 18 months old at the time, I remember the measles ward. About 6 years ago I received a call from a lady and she asked if I was the Farber boy brought in to the hospital in 1944. I said, "It depends. Who are you?" She said, "If you are that baby I was your nurse." So we went for dinner - she was 85 years old - and she remembered my mother bringing me in to the hospital and telling her there was no hope - it was just a matter of time.

We have to know how much we really can change. It's been said in the Talmud that if everybody saved a life, you could save mankind. Each of us can contribute in some way and if we're looking to contribute in the greatest way then being an organ and tissue donor is it.

It's like setting goals - you have to know you can reach and achieve them. If you can, then you have some impact on making it a better world. When you accomplish one goal, then you can set the next one and make it a little loftier. That's business to me. The 10 year plans - I've never been one for that. That's the way I view my impact on the world.

Does collaboration play a role in building the Foundation and the other activities you pursue? How?

Collaboration is the key! A lot of what we set out to do can't be done alone. You've got to have partners and adventurers. If you try to isolate yourself, you lose. It's also a way to test your ideas because nobody has a monopoly on solutions. The beauty of partnerships is that you can sit down with a few people and get their ideas. When you bring in other people and you have a collaborative effort, you're going to get to where you want to get a lot faster.

You've said that "a continuous search for why I'm here and what I really am intended to do" is what defines you. Why are you here and what were you intended to do?

Even when you're on a path, maybe the wrong path, you have to recognize it. I was a pre-med major at the University of Colorado - Boulder. During my senior year I wondered if I would waste four more years of my life if I didn't want to be a doctor. That day, I went to Boulder and asked my advisor if I could get into law school. The next day I picked up an application, applied to take the LSAT, and really never looked back. So maybe it was my destiny to save more lives through the Foundation than if I had become a doctor.

You have to find something you are passionate about. If you don't, you are not going to be very successful at it. Every community requires leadership and the older I get the less energy I have. My vision is focused on what's going to occur and on the younger people who are going to make a difference.

To learn more about organ and tissue donation visit <http://www.americantransplantfoundation.org/>.

