

Advocating for Donor Decisions

Story by Katelyn Blough
Photo by Mark Bolster

On an average day, 750,000 people trek through Grand Central Station in New York City. This hub gathers commuters from 67 different train tracks and routes them to their destination.

Your body has a similar hub, but it comes in a smaller package. Weighing in at 3.5 pounds, your liver collects everything you eat and drink and repackages it for your body's use or elimination — your body's personal Grand Central Station.

The problem is, not all livers can handle the body's constant traffic, and each year 1,400 people die waiting for a life-saving liver on the transplant waitlist.

UPMC's Living-Donor Liver Transplant program is making strides to combat those numbers by allowing donors to give a portion of their healthy liver to a recipient, freeing them from the race against the clock. One of the busiest programs in the country, our surgeons perform 20 to 25 living-donor transplants every year.

"We have one of the most recognized programs in the country, both for adult and pediatric patients, and have been performing this procedure routinely for the last 15 years," said **Abhinav Humar, MD**, chief of transplantation, UPMC, and clinical leader of the Living-Donor Liver Transplant program.

Jennifer Steel, PhD, associate professor of surgery, psychiatry, and psychology

Jennifer Steel is UPMC's living-donor advocate. In simple terms, her job is to help donors recognize the personal risks of donation, make sure they don't feel pressured to donate, and remain a neutral part of the care team throughout the transplant process.

But in many ways, Jennifer is a humble pioneer. She is soft-spoken, and her inviting demeanor is that of an old friend you haven't seen in a while. It's surprising, really, for someone who has paved the pathway for such a remarkable program.

There were few guidelines established for advocates when they became a requirement for transplant programs in 2007, and Jennifer took the reins. Her team has conducted research on advocate qualifications, training, and continuing education to establish best practices for advocates all across the country — far from an easy feat.

And that's only a small part of her job. When someone wants to become a living donor at UPMC, they encounter several stops along their train route. They're in good hands, of course, because Jennifer and her dedicated team are their conductors. After an initial phone screening, they meet with Jennifer who assesses their situation:

- Why did they come forward to donate?
- How long have they known the recipient?
- Have they ever had any problems with surgeries?
- Do they have a history of depression or anxiety?

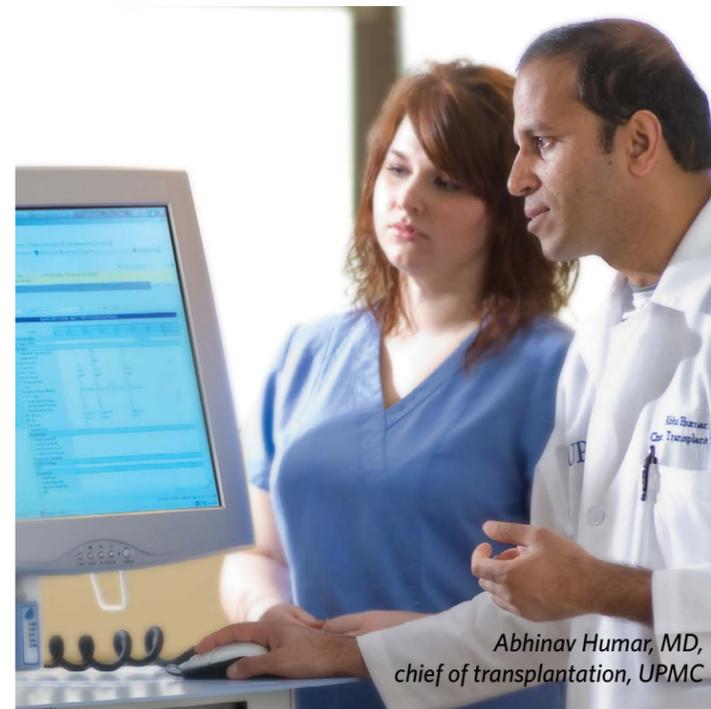
Those are a few of the many questions she uses to compile a report that identifies any psychosocial, medical, and financial risks to the donor. Eventually, she approves or declines them at a selection committee meeting.

"I have to choose whether to protect the person [from possible risks] or advocate for their wishes. So sometimes balancing that is difficult, but I usually try to fall in line with what the donor wants. I'm here to support them in their decision, and help them make an informed choice after I express my concerns," Jennifer said optimistically.

In the final stretch of the meeting, she prepares the donors for the rest of their evaluation process. The next several stops on their train route? Meetings with hepatologists, surgeons, social workers, nurses, nutritionists, ethicists, and anyone else on their care team.

It's a lot of responsibility, but Jennifer finds it rewarding.

"It's emotional, even for me, to see people making these selfless choices and undergoing the risk of surgery to help somebody else. It's rewarding to see people who love and care so much about others," she said with a smile.



*Abhinav Humar, MD,
chief of transplantation, UPMC*

Just as Jennifer set the standards for advocates all across the country with her research, the Living-Donor Liver Transplant program at UPMC has played an integral part in sharing knowledge and data with other programs nationwide.

"We've been involved in consortiums with other medical centers that are doing the same kinds of surgeries so we can better understand the risk to donors, as well as find ways to increase their safety," Dr. Humar explained. "Each center only has a few living donors every year, so it helps to have a forum where we can bring all our information together."

UPMC's high-volume program translates to increased skills in our surgeons and high success rates. The program is not only viable for the recipient because it eliminates a wait, but it also offers them the added benefit of receiving a transplant before their liver disease progresses to a severe state, improving long-term outcomes for patients.

"Patients who receive transplants in the standard way — from deceased donors — have to wait until they're at the top of the waitlist. Essentially, that means being the sickest in the group. The best time for transplantation is when patients are in a relatively healthy state where their bodies are able to tolerate a major surgical procedure," said Dr. Humar.

And luckily for the donor, the liver is the only organ with the unique ability to regenerate itself. So while the part of the liver that was removed will not grow back, what is left of their liver will grow to its original size.

"I think very few people are aware that you can donate part of your liver, but it has an amazing ripple effect. If someone helps their loved one by donating part of their liver, it also helps a stranger because another person is off the waitlist and a deceased donor's liver is now available," said Jennifer.

[Learn more about the UPMC Living-Donor Liver Transplant program, including how you can become a donor, at UPMC.com/PALivingDonor.](https://www.upmc.com/PALivingDonor)