Advocating for Donor Decisions

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 their care team.

In the final stretch of the meeting, she prepares the donors for their care team.

“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.

“If 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.

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.

“If 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.