

# Gerard Marinaccio

## *“How Organ Rules Made Cancer the Best Thing to Ever Happen to Me”*

Ten years ago, I was in the midst of a battle with a deadly form of liver disease known as cryptogenic cirrhosis when my doctors decided my only chance of survival was to receive a liver transplant. I was placed on the transplant waiting list and given an estimated wait time of two years, even though my cirrhosis meant that I might be dead in only one. The prospect of fighting such a debilitating disease with my failing liver was daunting – and to be honest, I didn’t have much hope I could make it.

Until I got the best news of my life: I was diagnosed with liver cancer.

Of course, logically, this doesn’t make much sense. Cancer is a terrible disease that claims the lives of millions of Americans every year, but in my case, the diagnosis actually improved my odds of survival. The cancer helped raise my MELD score – a metric used to determine the relative severity of a patient’s liver disease – to a point where my wait time for a liver donation was reduced from two years to three months. In October 2006, thanks to my cancer, I was given a liver and have been able to resume my life. While being diagnosed with cancer should never be a cause for celebration, the current rules governing organ transplants made this backwards notion a reality.

Before my cancer diagnosis, my MELD score stood at 38, which is already relatively high – but in New York and many other states, demand far outstrips supply for organs. That’s largely because medical urgency is not the most important factor in determining how organs are distributed across the country. Instead, the greatest importance is placed on the geographic proximity of the donor to the potential recipient, meaning that a sicker person in New York could wait months, even years, longer for an organ than someone in another area.

As you can imagine, that explanation is incredibly frustrating to a patient waiting on a life-saving transplant. In my case, the seriousness of my disease led some to suggest that I uproot my family, my career, my entire life, and move to an area where my MELD score would give me a better chance of receiving a liver. In transplant support groups, I would regularly hear stories of patients in places like Florida receiving transplants with MELD scores of 15 – patients who were ostensibly less than half as sick as I was.

I remember feeling desperate and helpless, but most of all frustrated. Here I lived in one of America’s premier cities, with high-tech hospitals and world-class doctors at my disposal, yet my only chance to receive an organ was to move to an area where people with illnesses far less severe than mine received transplants long before I ever would. How could that be fair?

Fortunately, policymakers are becoming aware of this untenable status quo and working on solutions to address it. Today, the White House is holding a Summit on organ donation to highlight different initiatives geared towards increasing organ donation and shortening the time patients must wait to receive their transplants. It provides the ideal forum for stakeholders and advocates to discuss the long overdue improvements needed to fix the current approach for organ distribution and hopefully encourage correcting the geographic disparities that endanger the lives of patients across the country.

In fact, the United Network for Organ Sharing – a nonprofit that helps manage the rules governing organ distribution – is considering a reform proposal that would address many of the problems facing the present system. Experts on UNOS' Liver Committee have estimated that these reforms would save more than 500 lives over five years, while saving hundreds-of-millions of dollars in pre-transplant care. As someone who has experienced the injustice of waiting for an organ only because of my zip code, these improvements to the current system cannot come soon enough.

For me, being diagnosed with cancer was like hitting the lottery – and life-saving a transplant was my prize. Until our organ distribution system is fixed, more patients will be hoping they could be so lucky.

*Gerard Marinaccio, a construction project manager in New York, received a life-saving organ transplant in October 2006.*