Keynote Speech by Senator Vivienne Poy

The Ultimate Gift

Laurier Club of Manitoba
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Good afternoon ladies and gentlemen:

First of all, I would like to thank Brenda St. Clair for inviting me here today. I will speak on a topic that is of interest to many, and that is - organ transplantation. I will tell you about my own experience last year as a kidney donor to our son. Don't worry, you won't get any gory details because you just had your lunch!

Like many developed countries, Canada is struggling with too few organ donors and a growing number on the recipient waiting lists. In Ontario alone, more than 1,800 Ontarians are on the transplant list at any given time, and of these, over 75% are in need of a kidney. On average, every 3 days, one of them dies.

The need for organs is so great that you often hear of "transplant tourism" to developing countries. This is particularly prevalent for kidney transplants. Since we are born with 2 kidneys, it is presumed, in poor countries, that one of them can be sold to help with family finances. We also hear horror stories about kidneys being stolen from people who are anaesthetized and have one kidney removed without their knowledge or consent.

There is a black market for organs, and the traffickers and the middlemen make a lot of money out of others' pain and suffering. Those who sell their kidneys are paid very little, and one doubts whether they are properly tested as suitable donors, and have any post-operative management. The bulk of the profit is made by the doctors, the hospitals and the traffickers. It really bothers me to think that some human lives are worth less than others.

Buying organs for transplantation is illegal in Canada, but Canadians, like citizens of many developed countries, go abroad to have transplant surgery, at a price, and on their return, Canada's healthcare system is responsible for them post-operatively. So, where there is demand, there is supply.

I recently read in the *South China Morning Post* about an island in the Philippines that is nick-named “kidney island” because so many of their teenage boys have sold their kidneys. There was a photo of them all lined up showing their removal scars. This shows that the kidney-for-sale trade is thriving, so the Department of Health in the Philippines imposed a ban.

However, then I read that foreigners would go as far as marrying the donor for his or her organ. The headline read “Where there’s a will, there’s a kidney.” Manila’s ban on the sale of organs to foreigners is no match for marriages sealed with a donation.

Please do keep in mind that the Philippines is but one of many developing countries with this type of organ trade. In China, I believe the biggest problem is the use of executed prisoners’ organs for hospitals that do transplants for profit. “It’s definitely not a proper source for organ transplants,” said Huang Jiefu, China’s vice minister of health. He admits that up to two thirds of the country’s organ donations come from executed prisoners, and has urged an overhaul of the system.

I first learnt about this topic in the early eighties from our second son who had, by then, lost his kidney function. He was very upset to learn about the trade in organs, and told me that he would rather die than to go to another country to buy a kidney. He really believed, and still does, in our socialized healthcare system, and has said, time and again, that it is only fair to go on a transplant waiting list like everyone else. And I certainly agree with him.

This son started having problems with his kidney function when he was eleven years old. At that time, medical knowledge was such that the doctors couldn’t save his kidneys. It was then that I learnt how important our kidneys are to our general health. And even though he was an independent child, and always insisted on dealing with the doctors himself, I was the one who drove him to see the doctors, and I was always there when help was needed. I spent a lot of time in hospitals with him, and I worried. For close to thirty years, I lived under a lot of stress. However, through his suffering over the years, both of us have become stronger.

When his kidneys were near the end stage, I spoke to his doctor to offer one of mine for transplant, and the doctor said “no”, because, at that time, the waiting time for a kidney was not long, and he said there were many available. I also believe transplantation from live donors was not done as frequently as it is now, and perhaps the protocol was also not as well developed.

Within a short time, a kidney became available from a small child who died. I remember being called at home early one morning, and I woke our son to tell him. But, his nephrologist believed that the kidney would be too small for our son, and that we would be better off waiting for a larger one. Today, the medical community knows that a small organ will grow within the body of a recipient, but the doctors didn’t know that then.

Within a matter of months, another kidney was available. The operation went on for 7 hours, and we found out afterwards that it was a leaky kidney, which had to be mended during the transplant. That operation caused a lot of post-operative problems. It never worked well, causing high blood pressure among many other symptoms, and our son was on a lot of anti-rejection drugs that had terrible side effects.

Despite all his medical problems, and lengthy hospitalizations, he made up for lost time during the summer months, and didn’t fall behind his classmates. Being a very gregarious boy, he not only did well with his schoolwork, he also involved himself in a lot of extracurricular activities in his school. The kidney lasted for about 8 years, and saw him through high school and into university, as well as starting his own advertising business. He went to Ryerson University for Radio and Television Arts, and lived downtown, close to the Toronto General Hospital.

There are different kinds of organ donation, as many in our audience probably know. The one our son had at the time was cadaveric, which means it’s from a person who died and the organ is donated by his or her family. This was the norm 30 years ago.

Today, the number of cadaveric donors in Canada lags behind many developed countries, especially when there is an increasing demand for organ transplants. This is partly because Canadians are living longer, and we have improved emergency care in hospitals, as well as better safety standards and therefore less accidental deaths. You see, a large number of organs that are suitable for donations are from accident victims. The key to increasing our donor numbers is awareness and education, so that the small number of eligible cadaveric donors will have a chance to donate.

We have all read in the papers about the CEO of Apple, Steve Jobs. For a while, everyone was wondering what was going to happen to the company because he seemed so unwell, and it was feared that his health was affecting the stocks at Apple. Then, recently, in the Sept. 10 *Globe & Mail* in the Business Report section, I read that Apple's CEO returned from a liver transplant to unveil the new product lineup and a new strategy for the company. In that press conference, it was his appeal for organ donors that caused a stir. He said, "I now have the liver of a mid-20s person who died in a car crash. I wouldn't be here without such generosity. I hope all of us can be as generous and become organ donors."

Every country has its own policy in regard to cadaveric organ donation, and so does every province in Canada. From the information that I have, B.C., Ontario and Nova Scotia have had registries since the mid 1990s. The one in Nova Scotia has the lovely name of "Legacy of Life," and Ontario has an awareness and promotional programme for our youth called "One Life Many Gifts." Of those who registered themselves as willing donors upon their deaths, very few are actually eligible as cadaveric donors.

Unlike countries such as Spain or Singapore, Canada does not have what is known as "presumed consent." Despite the registration by willing donors, our family members and loved ones are always asked, at the time of death, whether organs from the deceased can be removed for transplantation.

A national registry would not necessarily work well in Canada because of our geography. Tissues and organs cannot survive long distance transportation.

When our son lost his first transplant after 8 years he went back on dialysis. At that time, the protocol was that a patient had to wait 5 years before going back on the transplant list because the body had to get rid of the antibodies completely, and a period of five years was deemed appropriate. I believe the medical community thinks differently now.

During that time, our son had expanded his advertising and PR business. He also got married. Within the first year of his marriage, the five-year waiting period was up, and he was back on the transplant list. Within a very short time - I remember it was Easter weekend while his wife was away visiting her mother in B.C. - he was called by the hospital because they had a donor kidney for him from a car accident victim. We went to the hospital while he checked himself in, and phoned his wife to let her know.

This kidney was a very good match, and initially, it worked very well. Unfortunately, it only lasted 4 years due to the fact that his original disease again attacked this kidney. In the meantime, he and his wife had a daughter, and then, unfortunately, their marriage started to fall apart.

Up to that point, there had been a number of different diagnoses for his condition. By the time he lost the second kidney, it was determined that he had Focal Sclerosis, which had made his body reject his native kidneys, as well as the 2 transplants.

He went back on dialysis, and this time, he had his own machine in his bedroom, which he looked after himself. The dialysis was done during his sleep. As an entrepreneur, he needed a maximum amount of time to work, and people outside of the family didn’t know he had kidney decease because this young man thrived on adrenaline.

In the meantime, he had another health issue that I won’t go into, except it meant he had to wait a lot longer than the usual 5 years to be ready for another transplant. By that time, his body tissues were already degenerating from too many years of dialysis, and his bones were becoming hollow. When he was told he was ready to be back on the waiting list for another transplant, he was asked to bring a family member with him to see his nephrologist. Being always very careful not to intrude because he is an adult, I was only too happy when he called to give me the good news, and I offered to go with him to his appointment. That was the day, in the doctor’s office, that I offered one of my kidneys to him.

You may wonder why I offered myself as a live donor, and did not let him wait on the transplant list. By that time, 2 ½ years ago, the waiting time on the transplant list had lengthened to between 15 to 17years. These numbers vary depending how lucky a patient is. Our son had been having accidents, snapping the tendons in both legs with the slightest fall because of the years of dialysis he had had. As a mother, I wasn’t going to have him wait any longer. It was a matter of whether he would let me give him one of my kidneys. Well, I am very glad he accepted, after giving it some thought.

We then went through numerous tests that went on for about a year. Our medical teams in Canada are very careful in screening donors. They make sure that the donors are in perfect health by checking every function of the body. I have never had such a thorough check up in my life! I became very sensitive to those in poor countries who have to sell their organs to make money. I know they would never have the tests that I had to make sure they are in good health.

Well, thankfully, our son and I were a very good match. This is not a given just because we are from the same family. He and I had discussed that, if we were not a good match, I would be willing to switch with someone else if another live donor’s kidney would be a match for him.

At this time, I want to mention an improvement in medical science, called Plasmapforesis, which treats the disease our son had that destroyed his native kidneys. Because of this important medical development, our timing was good. I remember the conversation we had at the Toronto hospital, when he said that he would do anything to keep the new transplant even if it meant being plugged into a machine at a regular interval in the hospital.

Since this was elective surgery, we also had to book a time suitable for both of us, and we both have very busy schedules. We were able to determine that March last year would be best for both of us. The beginning of the month was best for me because I had a very heavy schedule from the end of April on, and I was told that it would take 6 weeks to regain my strength. It worked out well, and I was on the go again by the end of April, travelling all over Canada.

At the beginning of last year, I received a disturbing call from the nephrologist who was on the transplant team, letting me know that he was hesitant about my donation, because, he saw something blurred on the film of the smaller kidney that the doctors had chosen for the donation. To make a long story short, I insisted on having an arterial gram done to determine the state of that kidney. So I went to the Toronto hospital for the procedure. The arterial gram showed that the kidney was in good shape.

Of all things, the weekend before surgery, our son had a cold and spiked a fever. If it had lasted, the surgery would have had to be cancelled.

Fortunately, two days later, he was fine. I was attending many public events right up to the day of surgery, and very few people knew that I was going into hospital.

I want to add that it was comforting to know that the surgeon who performed both surgeries, is not only a very experienced transplant surgeon, he is also an old friend. It really helped.

On a very early snowy March morning, my husband drove me down to the hospital for surgery, while our son's friends insisted on taking him down from his house. I learnt that morning from our surgeon that I was the one to be pushed into the OR first to have my kidney removed, and after the OR is cleaned, our son would be brought in for the transplant. This, of course, is the ideal scenario because the organ is fresh, and there is no time lag in transportation. Statistically, an organ from a live donor has a much better and longer survival time than a cadaveric organ.

Being an organized person, I had arranged to have 2 good friends and my husband stay over in the hospital with me on 8 hourly shifts. Our son had his two brothers, and his girl friend there for him at all times, even though he was in ICU. I have spent enough time in hospitals to know that it is always best to have someone close to take care of your needs.

Was I afraid? No. Was it painful afterwards? Yes. But considering what our son had endured throughout his life, what I experienced was nothing. After surgery, he was in ICU, and I was brought back to my room. My friend took me in a wheelchair to see him on my second day after surgery. On the third day, all the tubes that were connected to my body were removed, and I was allowed to go home. It was so much better to recover at home.

While our son was still in hospital, he was booked for 10 treatments of Plasmaphoresis at the Princess Margaret Hospital. He only had 8 treatments, and the disease that destroyed his kidneys in the past disappeared! And so far, there is no sign of it reappearing. In other words, today, anyone who has the disease our son had would no longer have to suffer as he did. What marvelous advances we have in medical science! And I must say, our timing was good!

Today, our son's health has greatly improved. Yes, he does have to be on anti-rejection medication the rest of his life, but he is on a very low dosage. He is able to live a normal life like all of us, and is able to go out of town for more than one night without having to arrange for dialysis in a strange place. Within a matter of months, he told me he was able to do 100 push-ups, while before the surgery, he could barely do 10!

It was really special to me when he told me that I had not only given him a new life, but had given our granddaughters a new Dad as well. The first thing he did last June when his daughters got out of school was to pick them up straight from school to the airport and they flew to the Bahamas. What a marvelous surprise it was for our granddaughters!! And since then, he has the energy to do so much with them, and they now have so many more opportunities to get to know each other well.

Transplantation with organs from living donors is nothing new, but it is getting much more common in recent years. I have been told that with kidney transplants, it is about 50%. Just because a person would like to donate an organ or tissue to a relative or friend does not necessarily mean that they are well matched. For that reason, on February 12 this year, the Canadian Blood Services publicly launched the Living Donor Paired Exchange Registry to facilitate kidney donations among live donors. The more pairs who register, the greater the chances of finding compatible matches.

Many of our audience here would have read about Lisa Sayer in the recent *Globe & Mail*. Lisa decided one day that she wanted to donate one of her kidneys to whoever needed it. What she didn't know was that she was going to make Canadian medical history. The Canadian Blood Services database made it possible for living donors who were incompatible with their intended recipients to register their blood and tissue type and donate to a stranger, and in return, their intended recipients would receive organs from strangers with the correct blood and tissue match. This was what our son and I had discussed if we had not been a good match.

On June 24 this year, medical history was made, when Lisa became the domino who precipitated a chain of transplantations in four operating rooms across Canada, saving the lives of four recipients. It is an act like this that makes me proud to be a Canadian.

In closing, I want to stress that I am not asking everyone here to be live donors. I do ask that, for those who wish to donate their organs when they pass away, please make sure your family and loved ones know of your intention, because they are the ones who will be making the ultimate decisions.

One more thing I wish to add. A few months ago, our son suffered from a viral attack, and his nephrologist had to lower his immunosuppressive drugs in order for his body to fight off the virus. He told me at the time, that, if it had not been for my kidney, which is such a close match to him, he could have lost this new transplant. I said to him that I was glad I could do something useful, and he said, “Mom, you have done a lot more than that.” As a mother, that felt really good!