



HUS 29/28

Tabled by Chair

Date Sept 13, 2016

I thank the committee for allowing me to speak today.

I believe the organ donation hearings are very important and that there is great potential here in directing the future of organ donation in Saskatchewan.

My name is Sherry Duncan Paterson.

At the age of 34 within 6 weeks of the birth of my second daughter I was diagnosed with Primary Pulmonary Hypertension. At that time, 24 years ago there were no drugs or treatments to extend my life and the only way to save my life was to undergo a heart double lung transplant. Within weeks of being diagnosed I was accepted and placed on a transplant waiting list in London, Ontario which at that time was a leading centre for transplantation.

This diagnosis was a devastating shock to myself, my husband and all our family members. I had just given birth and was told I was dying. It was a very surreal experience. The pregnancy and the disease had exasperated my body. My health rapidly declined with regular hospital visits stays for heart failure symptoms. To walk into my house required that I walk up a landing of 3 steps. This was like climbing a mountain with my failing lungs. My health declined to the point where I could no longer pick up my newborn daughter and I would cry. I was blue.

I have a rare blood type and although placed on an emergency waiting list I was told I was 3rd on the list. All I could do is wait and things looked very bleak. My chance of surviving was dependent on a chain of events and ultimately a gift of organ donation from a grieving family.

I was one of the lucky ones. I only waited 5 months until I got a call in the middle of the night to come to London. I was so shocked that I initially told the transplant coordinator that I was feeling a bit better. After hanging up my husband said call back right now and tell them you're coming. We went by air ambulance and on July 21, 1992 I received my heart double lung transplant. When I woke up afterwards my husband said the sweetest words to me I've ever heard which were 'you are sooo pink'.

One of my goals during rehab after the transplant was to be able to hold my baby when I was reunited with her, so the physiotherapist along with Cal Murphy's wife who was there with Cal as he was rehabbing, had me carry weights up and down the hallway with a homedrawn picture of a baby taped onto them. I met my goal and when I was reunited with my baby who I had not seen for 2 1/2 months I was easily able to hold her and hug her. Out of such a situation I must say came some of the most wonderful moments of my life.

The transplant world was a much different place 24 years ago when I started this journey:

I had to carry a beeper with me at all times in case a transplant became available.

It was not uncommon for people to move from their home provinces to wait near the transplant centre to receive the specialized care they needed at great personal and family expense. Some even moved in hope that somehow being close to the center would increase their chances of transplant.

Hospital stays were long after transplantation. I broke a record at the time for the shortest post surgery stay of 45 days.

Every transplanted person was given almost the same drug regime due to limited transplant drugs.

Transplanted people were encouraged to wear surgical masks when in public.

Many transplants and especially lungs were told not to go back to work for fear of infection.

The Saskatchewan Transplant Program had just started and had either 2 or 3 staff.

In Saskatchewan there were few support groups and resources to help with adjustment after transplant.

In Saskatchewan in general Doctor's awareness of the specialized needs of people with transplants with suppressed immune systems was lacking. I had a couple of hospitalizations here in the early years

where doctors tried to take me off my immunosuppressant drugs. I learned quickly to become my own best advocate.

Organ donation rates were low then and not keeping up with demand.

Now 24 years later I look back and many things have changed at a lot. If I were to develop my disease now I would be treated with new drugs that would extend my life putting transplant off for years.

The science of transplantation and variety of drug treatment regimes has increased dramatically since I was first transplanted and I have only benefitted from it.

I would most likely be referred to Edmonton for transplant but have a lot of assistance from the staff at the Saskatchewan Transplant Program in terms of preparation and resources and follow up.

I could seek out other recipients to talk to through social media and many other groups.

I would be encouraged to return and thrive at work. I would have a specialized transplant physician following me in Saskatoon saving me travel costs and expenses and addressing my needs.

The only thing I really haven't seen improve in my 24 years are low organ donation rates.

I do really like the word 'culture' that has been used by other presenters. I like to think that I have seen an improvement in general public acceptance of organ donation over the years. There is always room for continuing awareness campaigns and public education to develop this culture.

I support school programs in schools. There are inroads being made. Two members of the Canadian Transplant Association – Saskatchewan Branch who are retired principles in collaboration with Dr. Mozer and members of the Catholic school system have just gotten approval to teach organ donation to high school students and have developed a curriculum. It is called One Life Many Gifts. The curriculum will be written and taught in Grades 10/11 Christian ethics for every school in Saskatchewan. This is a huge accomplishment.

I have been over the years been involved quite a bit in promoting organ donation. One opportunity I had was to go to intensive care staff coffee breaks in St. Pauls and RUH hospitals in Saskatoon to share my story and simply say 'thank you for asking'. Many of them have seen patients come through very ill waiting for transplant and never learn of their outcomes. They told us to see thriving healthy people that received transplants really impacted them.

I am an advocate for presumed consent in Saskatchewan and Canada. I know that many families who haven't been affected by transplant do not really think about it until faced with a tragic event. I feel that presumed consent takes some of the burden off of a family faced with making a decision about their loved ones organs.

But procuring organs is only as good as the culture of the system that does it.

Potential donors are lost in Saskatchewan.

Before attending the hearings in Saskatoon yesterday I wanted to advocate for more training within the health system and at the university levels.

I came upon a very in depth written paper titled 'Organ and Tissue Donation in Canadian Undergraduate Medical Education' which has a comprehensive well written description on training students at the pre-clinical stage of education.

In Spain donor rates shot up when critical-care specialists where specially trained. They found success was largely about approach-with a very good trained doctor who could detect potential donors and approach the family. (Interview with Rafael Malisonz, Director of the Spanish

National Transplant Organization by the Toronto Star Sept 30/13 when he was presenting at the Toronto General Hospital).

When I heard the presentations by the Saskatchewan Transplant Program and Dr. Fenton who are in the system I felt a lot of what they had to say made a lot of sense. Given that a mandatory referral system is implemented in Saskatchewan, trained donor physicians can gradually train teams in all the health regions in Saskatchewan that have an intensive care unit. I would envision these teams consisting of doctors, nurses, nurse practitioners and social workers depending on the community and the health region.

In the training sessions I see input from individual donor families and recipients to illustrate the actual outcomes for people that have been through this so that health care professionals can see and meet the real people affected by this and dispel myths.

The cost effective recommendation that they have to hire donor physicians to train other professionals across the province would have many positive ripple effects.

I urge you to seriously consider the recommendations of the Saskatchewan Transplant Program and Dr. Fenton.

In conclusion, I am here today to honor the gift of transplant. I am alive but through a chain of events and ultimately a gift of organ donation from a grieving family.

I only wish for the chain of events to result in better outcomes and increases in organ donation.

I have the privilege now to say I am one of or the longest surviving heart double lung transplants in Canada. What has that meant? I am a living example that transplant works.

More importantly to me that means that not only did I get to hold my baby again – it means that I got to love that baby and nurture her. I got to be a mother to my two wonderful daughters and watch them grow up. Two years ago I got to hold another baby, my beautiful 1st granddaughter. I held her with ease and tears of joy dripping down my still pink cheeks.