



ORGAN AND TISSUE DONATION IN SASKATCHEWAN
Public Hearing
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Submitted by:

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Attention: Rob Park
Committee Clerk Standing Committee on Human Services
RE: Public Hearings on Organ and Tissue Donation in Saskatchewan

Dear Mr. Park,

Thank you for the opportunity to provide a submission and present to The Legislative Assembly's Standing Committee on Human Services as to how the Government of Saskatchewan can increase the rate of organ donation and improve the effectiveness of the organ and tissue donation program in Saskatchewan.

For the people in our province suffering from severe lung disease, having a lung transplant may be their last and only option to survive.

Lung transplant surgeries are considered when:

- a severe lung condition is continuing to progress and when all other available treatments and medications are no longer helping;
- the individual's life expectancy is in the range of one to two years without the lung transplant; and
- the procedure could result in a better quality of life.¹

Lung disease affects one in five Canadians and several of those lung diseases may lead to the need for a lung transplant.² In fact every 15 minutes someone dies of lung disease in our country.³ The most common diseases for which lung transplant surgery is done include pulmonary fibrosis, chronic obstructive pulmonary disease (COPD), which includes chronic bronchitis and emphysema, and cystic fibrosis.¹

Advances in treatment have made lung transplant possible for a greater number of patients. However, the demand and waitlist for donor organs are growing at a much faster rate than current organ donation rates and unfortunately diseases like COPD are also on the rise. One Canadian dies every hour from COPD.³ This disease is currently the fourth leading cause of death in both men and women, soon to be the third.⁴ COPD is also the leading cause of hospitalization among seniors in our province.³ From 2005-2014 the number of patients on the waiting list and the number of lung transplants performed steadily increased by 52%.⁵ In 2014, 226 lung transplants were performed in our country but 300 people remained on the waitlist and 70 people died while waiting for a transplant.⁶ In 2015 four Saskatchewan residents had lung transplants and ten remained on the wait list.¹³ The need for more organ transplantations will only increase in the future as the population ages.

The other two most common reasons a lung transplant is performed are for those with pulmonary fibrosis or cystic fibrosis.¹ The unfortunate reality is that many of these patients will die waiting for a lung transplant and those with cystic fibrosis often die quite young. Cystic fibrosis is the most common fatal genetic disease affecting Canadian children and young adults. It is an inherited disease that causes abnormally thick and sticky mucus to be produced in the lungs. The mucus blocks the airways in the lung and becomes infected with bacteria very easily. This can lead to life-threatening lung infections and progressive and severe lung damage.

Pulmonary fibrosis is a disease where the lungs lose their ability to transfer oxygen to the bloodstream, causing shortness of breath and vital organs being deprived of the necessary oxygen to survive. The cause in many cases is idiopathic or unknown. In some risk factors such as environmental exposures, genetics, connective tissue diseases, certain medications and smoking

may be identified. In many cases, pulmonary fibrosis is a fatal condition with no cure and no available alternative treatments have been shown to prolong survival, other than lung transplantations. The disease course is often rapid with distressing symptoms of shortness of breath and cough. Sadly, among patients with idiopathic pulmonary fibrosis, 50% of patients will die within two to three years of their diagnosis ¹²

The number of transplants done each year depends entirely upon the number of donor lungs that become available and the systems in place to support these procedures and patients. Canada's donation rate is less than half of that of the best performing countries, and has plateaued over the last decade.⁹ Within Canada, Saskatchewan has one of the lowest donation rates. An average of 4 patients in Saskatchewan receive a lung transplant each year which represents approximately a third to one half of the patients in this province who are actively listed. Although medical care pre- and post-transplant is done in Saskatchewan, no lung transplant surgeries are done here and all patients needing this lifesaving procedure must travel out of province.¹¹

The process of being listed for and receiving a lung transplant is fraught with enormous stress and uncertainty for patients and their loved ones. Patients ask themselves, 'will I survive long enough to receive a transplant? Will an appropriate donor ever become available? Can I afford the costs of travel, medications, and time away from work?' The costs are not only financial, but also emotional and psychological.

Should someone be fortunate enough to receive a transplant, the process can be expensive.

Although the cost for the surgery itself is covered, there are many other costs to consider. There are currently only five hospitals in all of Canada that perform lung transplants. There are no centres

located in Saskatchewan, forcing all of our province's transplant recipients and donors to go out of province, typically to the University of Alberta Hospital in Edmonton. Costs for travel, accommodation and food for the patient along with their support person must all be considered. Presently, through charitable organizations such as the Kinsmen Foundations and Telemiracle travel, accommodation and food may be covered for the transplant recipient. There are also costs for support people (a mandatory requirement). The core immunosuppressant medications post-transplant are covered but there is a gap in coverage for medications needed to treat side effects from the anti-rejection drugs, medical monitoring equipment, the cost of ongoing bills at home such as a mortgage and utilities, loss in salary for both the organ recipient and their support person while accompanying the patient undergoing the transplant, child care and kennel costs for pets, etc. Those who receive a transplant along with their support person are required to live near the transplant center in Edmonton for a week-long assessment phase, a 4-6 week pre-transplant physiotherapy program and a minimum of 3 months post-surgery. During the first year post-transplant the majority of medical care is done in Edmonton with frequent trips between home and there.

A Patient's Perspective:

Nicole Nelson's Story, Double Lung Transplant Recipient

Nicole Nelson was told she had pulmonary fibrosis at just 18 years old. With a long-standing family history of an inherited form of pulmonary fibrosis, Nicole has lost 16 of her family members already to the disease.

Because of her family history, Nicole was diagnosed in the early stages of the disease with few symptoms. However, in 2013 she noticed a rapid decline. In February of that year she caught a cold that she couldn't seem to get over. She had a dry cough and shortness of breath and she found

herself avoiding stairs, parking close to doors because walking far distances and activities that once seemed effortless were leaving her breathless.

Later that year she was admitted into the hospital and put on oxygen. It was then that she was referred to the Saskatchewan Transplant Clinic. The process involved multiple appointments and tests such as blood work, pulmonary function tests, bone density tests, CT, chest x-rays, an echo, and ECGs to name a few.

In January 2014 Nicole had met the criteria to join the pre-transplant program at the University of Alberta Hospital in Edmonton. She attended a 6 week pre-transplant physiotherapy program which required her and a support person to move to Edmonton during that time. Unfortunately due to financial reasons, Nicole and her family could not afford to do this. In order to have another chance at life, she was forced to go on her own and every weekend a different support person (whether it be her husband, an in-law, friend, or other family members) came to see her and help her with the assessments, physiotherapy, occupational therapy, and educational classes about the transplant. The hospital and clinic were a fair distance apart, and Nicole's lack of endurance and breath made this trek challenging. She relied heavily on her support person to push her in a wheelchair to help her get to her many appointments.

After the 6 week program in Edmonton, Nicole returned home to Saskatoon to await 'the call'. During that time she carried her cell phone with her everywhere she went and did her best to stay active and strong for the possibility of upcoming surgery. She managed to stay positive by spending time with friends and family and also doing her best to promote and explain the importance of organ and tissue donation.

In July 2014 Nicole received her life saving call. She and her husband took an air ambulance to Edmonton where they both remained for another 3 months in order to recover from the transplant. They applied for assistance from Telemiracle and were able to stay in a condo that had reduced fees for transplant patients through the Good Hearts Program in Edmonton. Nicole's husband also applied for compassionate care which gave them limited funds.

Today, Nicole describes receiving a donation as “a very humbling and expensive process.” She feels that the best way to increase the rate of organ donation is to increase the province's awareness about the importance of organ donation. She says, “in Saskatchewan, having one's family advocate for us is vital. Everyone should have conversations with their families because ultimately the families are the ones who make those lifesaving decisions.” It is Nicole's hope that organ and tissue donation will become a normal conversation among all families and those wanting to donate their organs and/or tissue have their intentions met. She also wants to see greater efforts among the health care system be taken to ensure health care providers are ready to respond to all donation opportunities and make the most of every suitable organ.

A Patient's Perspective:

Charlotte L'Oste-Brown, Resident on the Lung Transplant Waitlist

Charlotte L'Oste has always led an active, busy life. The mother of two, coached softball, sat on the local school board while owning and operating a 15,000 square foot greenhouse in her hometown of Hazemore, Saskatchewan. In 2003 she was diagnosed with the terminal disease pulmonary fibrosis. Charlotte gradually stopped doing anything physical like cutting the grass, lifting objects, performing quick movements and enjoyable hobbies such as curling and dancing. As her disease progressed, she also had to give up her two-story home and her greenhouse. She now lives in room

and board housing closer to medical services in Regina.

In the summer of 2014 her oxygen saturation dropped to 38% (normal is 98%) because of an infection and the thick smoke around Regina from forest fires at the time. Charlotte's condition was serious and she was hospitalized. She was put through rigorous testing to determine if a lung transplant would be possible and later Charlotte was sent to Edmonton for her 6 week pre-operation physiotherapy program. She has now been listed for transplant since December 1, 2015. Charlotte has to take immunosuppressants for her illness while she waits in hope of her life saving call. Each day she lives with caution and her greatest enemy, other than the pulmonary fibrosis itself, is infection. She describes the past few years as daunting, frustrating and stressful. She is attached to a 50 foot hose and has to go everywhere with oxygen. She goes to bed every night hoping she will make it through without choking. Then she starts each day wondering if today will be the day she gets her second chance at life. She often feels that she has been sent home from Edmonton to simply cope with death.

To keep moving forward Charlotte relies on her support system. She has also embraced an advocate role and actively seeks opportunities to educate and inform the public about organ and tissue donation by sharing her story. She believes her story will have an impact because she is not a pamphlet in the mail, but a "real person". A real person not waiting for someone to die, but rather "a woman who has no other choice but to wait for someone that has made the choice to give the gift of life." She encourages everyone to "talk to their family about their wishes to become an organ donor today because people waiting may not have tomorrow."

Recommendations:

Increase Organ Donation Rates

- The current process for organ and tissue donations allows the ability for the next of kin to override a donor sticker on a health card. While some do attach an organ donor sticker to their health cards, what matters most is that people are actually able to fulfill their intention to become donors upon their deaths. Stronger public education and awareness campaigns are required to ensure more Saskatchewan residents not only speak to their families about their wishes to be an organ and tissue donor, but that their commitments to be one are carried out. We recommend funds be allocated towards a robust organ and tissue donation campaign that debunks common myths and focuses on the essential need for all Saskatchewan residents to warrant that their intentions regarding organ and tissue donations are met. It is our goal that becoming an organ and tissue donor is no longer a rare occurrence, but rather a norm Saskatchewan residents are accustomed to. This will not only save more lives but absolve loved ones from making such an important decision themselves when an immediate response is required during such a distressing time.
- Ensuring that the system is ready to respond to all donation opportunities, and guaranteeing that the most is made of every potential donor organ by allocating necessary resources and appropriate management to understand and explore the medical and logistical reasons why donors/potential donors are missed in our province.
- Allotting funds to train and empower physicians, surgeons, and other health practitioners to do their part in identifying and referring potential donors. Allowing a complete culture shift within a patient –focused care system to ensure every member of the treatment team is aware of which patients may qualify to be organ and tissue donors.

- Allocating funds specifically to support medical management of potential organ donors.

Increase Accessibility of Essential Services for Recipients and their Support Systems

- Ensuring adequate and affordable housing accommodations are available close to treatment centers regardless of patient socioeconomic status.
- Safeguarding funding to support both the transplant recipient and their required support person for the additional costs they incur (loss of salaries when in Edmonton, out of province accommodations, support for continuous everyday cost of living in Saskatchewan including utility bills, mortgages, child care, pet kennels while out of province and absent from the workforce).

Thank you for this opportunity and for considering our recommendations.



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It's a matter of life and breath.

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