

Good After Noon

Thank-you ...panel....for allowing Sherry and myself here today for me to present my story on how detrimental it is to have a registry set up.

I am waiting because I have a terminal disease called Pulmonary Fibrosis There is no cure.

A transplant is the only option.

My story —

I was living on a mixed farm operation....raising to energetic daughters

I coached ball and was active on the school board and in the community.

I got the disease in 2003. The conditions of the disease did not bother to much in the first few years.

I gradually gave up physical jobs. I owned and operated a 15,000 sq ft green house for 18 years. So that had to go in the first year. Cutting grass. I don't remember the last time I ran. Lifting, quick movements....dancing. I gave up curling next.

Till now today I do nothing other then exercise. Yoga and strengthening to keep my upper body in shape.

I have downsized to a room and board situation.....

from maintaining a 2 acre yard and 1300 sq foot, 2 story home.

My career changed to an advertising consultant for Prairies North Magazine of Sask. I work out of my home..

Honestly I took everything in my stride, with a lot of inner frustration, but I did what I was told to do.

The changes happened gradually.

My oxygen went from 100% to 68 % over that 12 year period

Now in 2014 my oxygen went down to about 38% over nite practically because of a infection and that is when the appointments started to get me on the lung transplant list

Oh I was so happy.....not realizing the wait ahead

I have been to Edmonton for my 6 week Pre OP Nov 2015

I got a place to stay

I have funds in order. For a 3month stay with a 24 hour caregiver groceries for 2.....pay my rent in Regina.

I have been on the TOP of the list since Dec 1 2015.

Now I am just downright angry.

I have jumped every hoop possible to survive this far. I was told when I got diagnosed that 7 out of 10 people die with in 10 years. So I needed to look after myself till the need for a organ transplant was a option.

I have done that

In the last 2 years I find it very daunting/frustrated that I am attached to a 50ft hose and have to go every where on oxygen. It is extremely stressful.

Not to mention that I go out in my health condition advocating for the gift of life.

This doesn't even make scence. Why hasn't something been done before this?????

4500 people approx. died last year waiting for organs.

33% or 2 out of every 6

I go to bed every nite hoping I get up in the morning and haven't chocked thru the nite. Then I start my day waiting for the call and at the same time expected to have a bright cherry outlook on the future and carry on. REALLY

Honestly, when one comes out of the Pre Op...one is at the top of ones game so to speak. Physically pre pared and mentally. A great program.

BUT

Then one is sent home to wait and continue looking after ones self.....9 months later .I totally feel like I have been sent home to LEARN HOW TO COPE WITH DEATH.

I have a great support system that recognize that I need to get out and they make sure I do. I am very fortunate to have my support people call me regularly.

So in doing public speaking engagements :

This is what I hear....Oh you mean that little piece of paper that comes with your drivers license and that little red sticker.

Oh ya I have it on my desk...ya I need to fill that out some time my response is.." Yes if you want to be an organ donor and give someone the gift of life... do it today people waiting for organs may not have tomorrow."

People are not filling out the card now or even putting the sticker on the card.....and that is not time a time consuming task .....Obviously it is .....less then 1% of people in Sask donate

So in trying to decide what type of system there needs to be.....I hear well we need to have people just go on -line.

My question then is.....

So would people actually go on -line and take the time. I don't think so.

People totally able to use a computer are the same ones not putting the sticker on their hospitalization cards

Taking note that people that are not donating in this province are over 65 years because they do not believe that the elderly are able to donate organs.

So are they computer savvy?

I was at a independent living condo place last week, approx. 200 residents...I was greeted at the door by a lady that said.... The reason there are not very many people here is we are to old to donate our organs..

I said to her "well I am here to let you know how valuable each and every one of you are."

I am happy that my dr and a representative of the Canadian Transplant Assoc. encouraged me to advocate the need for education in this area . The advocating for donor awareness will in fact be never ending.

Advocating and in desperate need.... like my self is tireing and very emotional at times

I keep on going and doing because

**Right now I believe that people like me waiting, make a impact because we are not a pamphlet coming in the mailbox . We are real.**

**We, people that can need to be out there educating now.**

I admit I don't know what the answer is to a successful/efficient registry to get this province on board.

But I am sure budget talks will come into effect.

One needs to think about the cost of people waiting for organs and I will refer to my situation:

The longer I wait the more help I need.

The longer I wait then I like most will need to quit work. I cannot do a physical job at all.

I sell advertising out of my home and at that it is getting to much to apply the mental work involved.

I need to have income as I am single , so then I apply for any services available to me.....just the stress of the paper work jeopardizes my mental health.

And realistically...there isn't enough funds available for me to quit my job anyway. I would be better off to take a cut in pay.

Then I may need care.

Then extra meds and hospital visits.

The bills just keep adding up.

Now that all these things have happened..... now I am no longer a productive member of society. THIS COSTS BIG TIME

So how much are those 4000 plus people worth that died waiting in their beds... and approximately 200 children.

I don't think budget should enter the picture

I have stories of people that have their life savings waiting.

I for sure feel that in planning a registry..... people that are wanting to give the gift of life **have to have a easy way to be able to give that gift of life**

**I hear several people in my travels wanting a opt out program. Given my current status in desperate need , I am tending to think that way as well.....HOWEVER**

**... the more I speak with people I hear other ideas as well**

If I was asked if I wanted to give the gift of life as often as I was asked for my next of kin and confirm my address at:

dr's office or the hospital

eye dr's say to me....tell people we need eyes. Eyes are the least donated organ.

Banking



trying to retrieve my Sask tell account password

So maybe we need businesses like this to get involved

Along with pharmacies

We have in this province so many business that are in touch on a daily basis with people able to ask the question and just have to tick off one more box.

Then the information could be transferred into our health system where administration is already in place

.I think that would cover a lot of demographics.

I am praying for a quick efficient outcome on educating the Sask people or a registry or both .

Several transplant people waiting don't have till tomorrow.

Should you want any further information about my story. It is on line and I brought a couple of copies

My story is in the PINK magazine July issue on line

It is in Prairies North on line [www.prairiesnorth.com](http://www.prairiesnorth.com)

As we speak the Carlyle Observer has just done a interview they did on me for this weeks paper for out on that SE corner of the province

On behalf of Sherry and my self I thank you for your time.

I felt it is important for the panel to hear stories of what the wait is like and how just hard - it is extremely difficult & can actually become debilitating & there is suicide then become a option for some.

Charlette L. St. Brown

Sherry