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PRESENTATION
TO THE

STANDING COMMITTEE ON HUMAN SERVICES

“PUBLIC HEARINGS ON ORGAN AND TISSUE DONATION”

Saskatoon, Saskatchewan

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Good afternoon. I would like to thank the committee for the opportunity to address you this afternoon.

I will start by giving you a very short background on my personal transplant journey. In 2002 I was diagnosed with Liver Carcinoid, a fairly rare form of liver cancer. Surgery and various treatments followed, but the only true option for a cure and a chance at life was a liver transplant. I was listed for transplant at the University of Alberta early in May of 2006 and got my call a month later, receiving my new liver on June 4, 2006. I adapted very well to my new liver and was out of the hospital in a week and returned home to stay within a month. I celebrated my 10 year anniversary about 3 months ago.

I think we have a great opportunity as a Province to lead the way with regards to improving the rate of organs available for transplant. As you know our record in Canada is very poor overall and is absolutely abysmal in Saskatchewan. I don't believe that Saskatchewan people oppose organ donation, on the contrary, Saskatchewan people are generous and caring in nature and are always willing to do the right thing.

Our current system of placing an 'organ donor' sticker on our health card is just not working as indicated by the low donation rate in Saskatchewan. At the time of an accident or donation opportunity it is often overlooked and neither the family nor the health care professionals think to check. This is very understandable given the level of stress and distress at a time such as this. Consideration for organ donation often comes after it is too late.

Part of the problem in Saskatchewan is that many of the accidents that might result in organs being made available for transplant occur in rural Saskatchewan. I think it would be fair to say that most rural hospitals are not trained or equipped to deal with families regarding organ donation at the time of the death or pending death of a loved one. In our major cities we have health care professionals who are better equipped to deal with families at such a time, but given the very low number of organs made available for transplant, it is obvious that even in our major centres the message may not be getting through.

Most families, given the opportunity, would like to see something positive arise from the death of a loved one. A good friend of ours lost his life in an accident less than a year ago and his wife told me a number of months later that the possibility of donating her husbands' organs was never discussed and she wished that they would have had the opportunity to do so. It should also be noted that he did have his donor sticker on his health card – in the chaos surrounding the accident it was never considered. As noted earlier, it would have allowed something positive to occur from a tragic event.

This past January we all witnessed the senseless tragedy involving the Jordan Van de Vorst family when their entire family were lost due to a drunk driver in an accident just north of Saskatoon. This must have been an unbelievably terrible nightmare for their surviving families but 2 very important positive events evolved from this accident: Firstly, as many as 32 lives may have been saved through the donation of organs so graciously provided by the Van de Vorst families. Jordan Van de Vorst's father, Lou Van de Vorst went to great lengths to thank the organ donation team in Saskatoon and noted the importance of

making some good evolve from a tragedy such as this. Secondly, due to the magnitude of this accident and the media attention to it, there has been a significant increase in the awareness of the importance and value of organ donation. As a result of this terrible loss, more people are understanding and appreciating the benefits of the “Opt Out” system for organ donation. Hopefully the Van de Vorst families will find some solace in these 2 positive outcomes.

Organ transplantation works! There is no question as to the benefits surrounding organ donation and organ transplantation. As I noted earlier, I received my new liver in 2006. In June of 2011, the University of Alberta Liver Transplant team celebrated the 1,000th liver transplant carried out at the U. of A. To commemorate the event, a celebration was held and concluded with a large banquet. A significant number of liver recipients and their families returned to Edmonton and attended the function. The benefits to the organ recipient is obvious – a second chance at life and the opportunity to continue as productive members of society. But it is also important to look at the effect it has on other family members and friends. I remember very well talking with many people that evening and seeing the gratitude in the eyes of the family members who still had their dad, their mother, their brother or sister, their grandpa, in their lives. What value do you put on this? On a personal note I lost my brother to cancer in 1990. Without the option of transplant, my mother, who is now 100 years old, would have had to endure seeing another son laid to rest.

The event in Edmonton was very uplifting. Every liver recipient had their “liver transplant number” shown on their name tag. I was number 883. During the evening a number of recipients spoke including #3 who had received her liver in 1989. A that time there were many more challenges involved with the

surgery and she spent most of a year in the hospital before becoming stabilized. Over the years the drugs have improved greatly and the procedure has been improved dramatically. At this point in time the success rate is very good with survival at 5 years in the range of 78 out of 100. This figure is specific to liver transplantation.

Considering all organs, at any given time in Canada there will be approx. 4,500 people on the waiting list waiting for organ transplantation. Of these, about 25% will die while waiting for an organ to become available. **These deaths need not occur!** The weak link in the whole process is the shortage of donor organs and this is a problem which could easily be rectified by initiating the 'Opt Out' system for organ donors.

We realize that there are some groups who for religious, cultural or personal reasons are not in favour of organ donation and it is very important that we respect their views. In light of this there should be an easily accessible method of opting out of the system if you do not wish to have your organs used for transplant after your passing. Hopefully this would address the concerns of those not wishing to make their organs available.

I am very passionate about the benefits of organ donation and the transplant process and over the past 10 years have had the opportunity to speak to several thousand people to promote organ donation. I am sure the large majority of people support the idea and would wish their organs to be used after their death, but unfortunately they rarely do, in large part to the reasons we have discussed above. This can be remedied!

In my mind there is no downside to moving to an “Opt Out” system:

- Significantly more organs available for transplant.
 - Many more lives saved.
- Pressure removed from families having to make the decision at time of death as the decision has already been made by their loved one by the fact that they had not opted out.
- Health care professionals not required to counsel families with regards to possible organ donation at highly stressful time for both these professionals and the family involved.
- Provision of an easy method in place for those wishing to opt out.

These are but a few of the benefits involved if we move to an ‘Opt Out’ system. As I noted at the beginning of my presentation, we have a great opportunity before us to lead in the area of organ donation and organ transplantation. A vast majority of Saskatchewan residents, if taken the time to consider organ donation, would certainly agree to become a donor.

I never speak about organ donation without publicly thanking my donor family who made the decision to have their son’s organs donated after a very bad accident back in 2006. There are six of us alive today because they chose to make that decision and I hope that knowledge has brought some comfort to my donor family over the past 10 years. In that 10 years I have seen my daughters happily married and bring 6 more grandchildren into our family for a total of 7. I have retired and am enjoying life to the max – this would not have happened were it not for the gift of life that they so generously provided to not only me, but also to my family. Thank You!

I will conclude by asking that every resident of this province ask themselves this one simple question: "If my son or daughter, mother or father, brother or sister, grandchild or grandparent, were on the transplant list, would I support the "Opt Out" system?" I think the answer is clear!

Thank you for your time this afternoon. I strongly urge you to recommend the initiation of the "Opt Out" system for the residents of our province – it's the right thing to do!