



HUS

23/28

Tabled by Chair

Date Sept 12, 2016

Hello, my name is Cheryl Olson. Thank you for giving me the opportunity to speak to you today and share a few ideas on organ donor awareness. I am *thrilled* to see this being discussed and a plan being formed to improve donation rates within Saskatchewan. I will begin by telling you a little about myself and how awareness saved my life. Like most people in the general public, I was ignorant and always thought organ transplants were needed due to a birth defect or poor lifestyle choices. That all changed when I had flu like symptoms in 1999. I was 31 years old, a wife and mother of two young children ages 3 and 6. A virus attacked my body and nearly killed me a couple of times. I ended up in the hospital with triple pneumonia in both of my lungs and a 50/50 chance of surviving. I tell people that for the next 48 hours or so, it was like 'trying to breathe while running a marathon I had never trained for'. Each breath was a painful struggle. As the hours passed, it became obvious I was going to make it. Then a few days later we hit the second brick wall. My platelet levels dropped dangerously low and they thought I might have leukemia. Plans were made to do a spinal tap, but before they did, they gave me a transfusion and thankfully, that cured the issue. Not long after that, it was discovered that my legs were full of blood clots along with one in my liver and one in my heart. I was treated with blood thinners and once again we breathed a sigh of relief that I was ok. After two weeks in the hospital I was allowed to return home. Unfortunately, the virus wasn't done with me yet. After two weeks at home, I was back in the hospital with heart failure. The virus had settled in my heart and destroyed it and my husband was told that many people in my situation do not survive. Within two months of first getting sick, I was on life support in Edmonton with less than 24 hours left before my husband was going to be faced with the decision to let me go or simply be told by the doctors that I was too far gone to survive a heart transplant. This is where awareness comes into the picture. My story was covered heavily in the media with headlines like, "Young wife and mother needs heart transplant to survive". It was the lead story on news broadcasts across Canada. It was front page material in many newspapers and my family and doctors were interviewed. My story was front and centre and hard to miss. A young man named Adam, was watching television with his mother when the news came on. They talked about me and my desperate need for a heart. When the story was over, Adam turned to his mom and said, "Wow, don't you wish you could do something to help them?". Two days later he was involved in a fatal accident that left him brain dead. He was 21 years old. When his mother was approached about donating his organs, she said "Yes, as long as that young mother gets his heart.". Of course they couldn't guarantee

that, but because of the media getting my story out there for people to hear and because of what Adam said, she agreed to organ donation. After 133 hours on life support, my family's prayers were answered and I received a new heart. I wish I could say that Adam's heart and I were still getting along fine all these years later, but I can't. We had a great eight years together before I started having problems. I found myself being told I needed a second transplant due to chronic rejection. Those are not the words a transplant recipient ever wants to hear! Shortly after my nine year anniversary with Adam's heart, my second miracle took place and I received a heart from a beautiful sixteen year old girl named Lyndsey on October 15th, 2008. Over the years, I have been the subject of a few mini documentary type programs and I've done public speaking, radio programs and interviews about organ and tissue donation (and I'll even be on the back of city busses this October), so I am here today to speak on behalf of myself and every recipient I know personally, or in my online groups, and to share the ideas that are often discussed within our community.

I will start with one important demographic that we should strive to inspire and that is our youth. We have a captive audience every day that they are in school. I understand that they are underage for registering without parental consent, but they are the future of our province and our country and if we can get them talking about organ donation, then over time it will become mainstream within our society. I will also point out that both of my donor's were young and had not given much, if any, thought to organ donation. So how do we get our youth talking about it? We go to the schools. For example, we set up a program that involves recipients and a representative from the transplant program who go and speak to a grade nine health or science class one day each semester. I feel a classroom environment would be preferred over an auditorium setting as it would encourage questions and dialogue. Every student who comes into that classroom that day will hear a recipient's story and can take home an information sheet that they can go over with their families. The information sheet can address many of the questions and myths surrounding organ and tissue donation. It gets the discussion happening and ultimately, hopefully, everyone's personal wishes will be known by the time they go to bed that night.

My next suggestion is one that I think is kind of fun. Let me start by telling you a little personal story. About a month prior to getting sick back in 1999, my husband and I attended a Roughriders luncheon where the then coach, Cal Murphy, was speaking. In case you weren't aware, Cal Murphy was a heart transplant recipient. He started his speech by introducing a young man in the audience who was a kidney recipient that he met in London, Ontario during his recovery. He encouraged everyone there to consider being a donor and to talk about it with their families. Sometime within the next week or so, my husband brought it up and we talked about it. It wasn't a lengthy conversation. We both expressed our decision, that we were willing to donate and then we agreed we would do the same for the our kids. Little did we know that we were about to embark on our own transplant journey and that my life would be saved by organ donation. End of story and back to the fun idea. Saskatchewan is full of crazy, diehard Rider's fans. A partnership with them for an awareness campaign would be fantastic! I do remember seeing a billboard a few years back with a player encouraging organ donation, but I never saw or heard anything else. This *could* be huge! Involve volunteers at games to hand out information and talk to people. If we're lucky enough to get a provincial registry, then get an autographed jersey, get people to sign up at games and put their name in for a draw. Get high profile players involved in commercials that would air during the games. I'm sure there are many other ideas to be had. And while we're on the subject of commercials, I'd like to encourage you to make commercials without the Rider's, too. Make them pull on the heartstrings instead of just a bunch of words encouraging people to consider donation. People's emotions need to be tugged at in order for them to remember something and respond to it.

At the request of a personal friend, I'm going to take a moment to touch on one aspect of awareness that is often overlooked. It is rare that living donation is talked about. She said it would be great if you could "unscarify" (her word, not mine) the topic so more people would consider it. This friend's husband is in need of a kidney and she is hoping to be a match. She has mentioned that she can't find much information about what to expect for the living donor. People need to know that they can donate kidneys, lobes from lungs and portions of their liver. They also need to have a clear understanding of how that will affect them in every aspect.

Another area that we should focus on is the hospitals and medical staff. Before moving out of the city, I was a part of a Saskatoon transplant support group. From time to time we would arrange to go to hospitals and speak to the nurses and doctors most likely to be dealing with patients with severe injuries. We called these events “Thanks for the Asking”. We put a face on the world of organ transplants by sharing our stories with them and thanking them for doing what they do every day. We encouraged them to make sure they don’t let any possible donor opportunities be missed so that every possible life can be saved. Within Saskatchewan we have many rural medical facilities. How equipped are they to identify potential donors and keep them viable until they can be transported to a larger facility? Perhaps this is a matter that could be addressed at the Saskatchewan Medical Association’s annual meeting? Another avenue to explore would be following the example of Ontario. Two years ago they put a spotlight on the issue of organ donation and began to report hospital statistics regarding the notification of potential donors to the Trillium Gift of Life Network. TGLN handles both the waiting list for those in need of a transplant AND the provincial registry of those willing to be a donor. It should be noted that people are asked about their wishes when they renew their driver’s licenses, but they also have the option of going online and signing up there, as well. According to the president and CEO of TGLN, the numbers have been going up since then these programs have been put in place. Ontario now has a 94% provincial average of reporting. Meaning that 94% of the time when there is a donor situation, the TGLN is contacted, however, that does not mean that a donation happened in each of those situations. I couldn’t find what Saskatchewan’s reporting average is, but since we have the lowest rate of donations, I assume we are lower than that. What I did find were the number of donations from 2015. In 2015, there were 10 multi-organ donors and 45 cornea donors in Saskatchewan. Those are low number. We MUST shine our own spotlight here at home by posting hospital stats on reporting possible donations and by educating hospital staff.

At this point I’m going to change things up a bit and move away from awareness to another option that could help increase organ donations. In discussions with other transplant recipients and related individuals, a prevalent theme I hear is that we need to have a provincial online registry where people can register themselves as willing donors. Every province has a different system for indicating one’s wishes when it comes to donation. Alberta, BC, Manitoba and Ontario all have a provincial online registry. Why don’t we? How can that be done? Here are

a few ideas: Develop a website where people can go to sign up. The only problem with this is that it demands action on the part of an individual IF they even hear about it and that type of thing usually ends up in the "I'll do it later" category and is then forgotten about. For example, British Columbia has 1,021,635 registered donors, but their population is 4,683,100.

Obviously, they either aren't hearing about it or they aren't taking action. So how do we get around that problem and still have a useful registry? One possible solution is to require everyone that does a transaction through SGI to answer one simple question, yes or no to organ donation. If they answer yes, then that information could be sent to Sask Health or directly to the Saskatchewan Transplant Program and entered into a registry that is updated daily.

Another option could be to include a line on the Saskatchewan tax return forms. It's not rocket science, but either method would be efficient. I should add here that having a provincial registry would create excellent opportunities for volunteers (probably mostly recipients) to get out into the community by attending functions and getting people to sign up if they haven't already. Believe me when I say that the transplant community is willing to get involved!

Now, I have shared with you some ideas about awareness on a provincial level, so please bear with me while I go outside of the provincial box for this next point I'm going to make. It is a point that is the on the top of the list for things recipients would like to see happen and the only way it will happen is if we educate the lawmakers. Recently, bill C-233, asking for a national registry to be developed, was quietly voted down by a margin of 171 against to 131 in favour, in what appears to be a partisan decision. A ruling that most definitely will affect many lives. They're "logic" for voting it down is that the Canadian Blood Services is currently involved with the organ transplant program and they feel that that is good enough. Well guess what? It isn't. Don't get me wrong, what they do is excellent, but the registries they oversee do not include a registry of those willing to donate. As one MP said regarding bill C-233, "In principle, it appeared to me something we should send to committee," said Toronto's Beaches-East York MP Nathaniel Erskine-Smith. "The idea of the bill was to improve organ donations in Canada and hopefully increase organ donations. That is a worthy goal. Whether that mechanism is the right one, I have no idea, but it deserved further study." Thanks to that vote, it will not receive further study. I realize this was on the national level, not provincial, but I'm going to speak about it anyway because the goal here is to raise awareness AND

increase donations, which is what we feel a national registry would do. And let's face it, the need for an organ donation does not know provincial boundaries. At the very least, this province and this country needs a national registry of willing donors, but I will take this one step further and suggest that what this country really needs is to follow the example of many other countries and develop a presumed consent or "opt-out" program. Canada has one of the worst donation rates in the developed world. Statistics have shown that 80 to 90% of Canadians would be willing to donate, but many of them don't take the steps to indicate their wishes. With an "opt-out" program, you better believe that those opposed to donating will take action to add their names on the "Do not Donate" list. According to a 2014 report by the International Registry in Organ Donation and Transplantation, Canada had approximately 16.5 deceased donors per million population, trailing way behind world-leader Spain at nearly 36. Spain instigated presumed consent in 1979...1979! **That is 37 years ago!** Another example is Belgium, who passed their law in 1986. They had two similar transplant centers – one in Leuven and one in Antwerp. Leuven switched to presumed consent with the passage of the law and in three years, its donation rate climbed from 15 to 40 donors per million, while Antwerp did not change its policy and only maintained previous levels. In Austria, presumed consent became law in 1982, and by 1990, the rates of donation had quadrupled, to the point where the number of patients awaiting kidneys nearly equaled the number of kidney transplants performed. I think you get the picture. Saskatchewan's leaders need to follow in the footsteps of the honourable Tommy Douglas, who led Canada in the development of a national healthcare program, and push for what is best for not only our province, but the entire country. I feel that there is no reason why Saskatchewan can't be a leader on this subject. Can the opt-out program begin within one province? Well, according to the words Health Minister Jane Philpott used when defending the death of Bill C-233, organ donation is a matter that is, quote "under provincial jurisdiction", so that tells me that we can consider forming any kind of provincial program we feel is best for our province. Let's take this presumed consent or "opt-out" option to a more emotional level for a moment and think about the families who, while in the middle of one of the most devastating moments of their lives, are approached about donating the organs of their loved one. Imagine, if you can, being asked to make a rational decision while experiencing that kind of grief and shock that comes from being told your loved one is gone. Neither of my donor's had indicated their wishes regarding organ donation, other than what Adam said to his mother, so my very LIFE hung in the balance as

doctor's waited for these devastated families to say "yes" or "no". Presumed consent would do away with the need for that difficult conversation. Even if we don't have presumed consent, a registry of some kind would take the weight of the decision off of the family. I truly feel that our society is ready for presumed consent. If you want to test that theory, get a discussion started on social media. We have seen time and time again that social media gets people talking about issues and makes things happen. In the meantime, we need to put people in front of the lawmakers that can tell their story and explain what organ donation has done for them. We need to put people in front of the lawmakers that can share their story of sitting and watching their wife, husband, child or parent die because they didn't receive an organ in time. I, personally, would fully embrace the opportunity to share my entire story and my passion on this subject and then challenge any person in that room to explain to me why they would not support presumed consent or at the very least, a national registry of willing donors. I dare say that they couldn't look me in the eye and do it.

Organ donation not only saved my life, it saved my family. It kept us whole. It kept a wife and mother in the home. So far, I have had an extra seventeen years of life. During those years I have watched my son learn to ride a bike and listened to my daughter sing. I have made school lunches, attended school plays and parent/teacher conferences. I have been there for first crushes and first heartbreaks. I have posed with Mickey Mouse alongside my family. I have proudly and gratefully watched as both of my children graduated high school. I have wrapped Christmas gifts and baked birthday cakes. My kids who were 3 and 6 when this journey started are now 20 and 23 and I've celebrated 26 years of wonderful marriage with my husband. I have made memories and I look forward to making many, many more!

So to you, the committee, I beg you and challenge you to be aggressive with your plans for organ and tissue donor awareness within our province and within our country. You have the power to make change. A power many of us wish we had. On behalf of every person on a waiting list right now and every recipient that might be told their transplanted organ is failing, please use your power wisely and as though the life of someone you love is depending on it.

Thank you for your time.