

Rosalyn Harris

[REDACTED]

[REDACTED]

Dear Standing Committee for Human Services,

Organ donation and transplants have become a very important factor in my family's life, because of a rare genetic factor many of our lives have been changed and will continue to be changed. Growing up my own family was relatively healthy and I hadn't experienced anyone at a young age who suffered with no hope of getting better. Things were about to change as my husband's family was about to experience many losses. I have put together a timeline of events to help explain our story and its relevance to organ donation.

1. 1988. My husband's uncle a young man of 47 was diagnosed with Acute Leukemia. At this time there were no treatments available. He passed away a few months later at the age 48. He was more like a brother to my husband and I than an uncle as we spent a lot of time together. Watching him get sicker and sicker was horrible.

2. 1991. My husband's youngest brother was always tired and cold and had no energy but we all just teased him about being lazy not understanding what it actually was. When he was 20 after many Doctor Appointments they finally figured out he had Aplastic Anemia where the red blood cells do not reproduce normally. Blood transfusions could help but the best option was a bone marrow transplant. So my husband and his 3 other brothers and his one sister started

having blood work and DNA testing done in Saskatoon. It was found that my husband had the best match. He and his brother had to go to Vancouver to have the bone marrow transplant done as it was not available here in Saskatchewan. It was Dec 1992 and my husband and I had just had our 3rd child in August and I was left to run our other children to their sporting events and look after the farm that we did together with my mother and father in law, who of course were in Vancouver. The bone marrow transplant was a success, for a while things were looking so good. The transplant had worked and he was up and walking around the halls and feeling quite well. Unfortunately my brother in law had a huge ulcer in his stomach and bleed to death in February 1993 still in Vancouver hospital.

3. 1995. My sister in law is pregnant with her second child and they diagnose her with Aplastic Anemia. They watched her carefully until her daughter was born. Both baby and mom seemed to be fine and my sister in law seemed healthy after and her blood returned to normal.

4. 2003. My father in law had retired from work and was planning on spending lots of time with his wife at their cabin. All winter he was sick with Pneumonia and never seemed to get rid of his cough. He was eventually diagnosed with Pulmonary Fibrosis, a lung disease that has no cure and no drugs that will help it. He had to start on oxygen 24/7. His only hope for life was a Double Lung Transplant. He went to Edmonton and did his fit program so he could become part of the waiting list for lungs. They even thought they would do a heart and lung transplant, if a donor became available. He fought hard to be able to be alive when some organs became

available but he passed in July of 2004 at age 67 at RUH. He in return was able to donate his corneas and some tissue.

5. During this time frame our niece that was born to my sister in law, that had Aplastic Anemia while pregnant, was going to the doctor. The doctors found she had a small hole in heart and had surgery for that. But as she grew older she was still feeling sick. Her parents got her to start seeing the doctors in Edmonton. She was going 2 to 3 times a year, doing many tests each time. Finally as she got to be 16 or so they decided she had Aplastic Anemia. She started to do genetic testing and comparing her to her grandfather and her uncle and found that they all have Dyskeratosis Congenita (DKC), a genetic factor disease of the bone marrow which also effects breathing. So this meant that Pulmonary Fibrosis and Aplastic Anemia were related diseases. At 21, she is still fairly healthy but watches what she does. She is working and attending university.

6. 2013. My sister in law gets bronchitis and cannot get rid of her cough. She starts testing and finds out in August, she has an aggressive form of Pulmonary Fibrosis and nothing will help but a lung transplant. Here we go again. It progressed rapidly, it wasn't before long she was on oxygen 24/7 and got weak and very sick. At the end of February 2014, she was in RUH and they decided to send her to Edmonton to hopefully get a transplant. When she left RUH she had to be put on an Ecmo machine to keep her alive. She was sedated and lived on the Ecmo machine until March 25 when it had been decided she would have no hope of surviving a transplant. So instead she was taken off life support and became an organ donor herself. She

saved 4 lives by her donating her organs!! She was 48. From that my brother in law started an awareness program called the Karen Pilon Organ Donor Awareness Foundation. This is to try to help get people to understand the need to be a donor as well as encouraging others to make their wishes known to as many family and close friends as possible.

7. At the same time my sister in law was going through this our family friend who was 54 was in Edmonton waiting for a lung transplant also. He was diagnosed with a different rare disease. He did receive a lung transplant in July of 2014. His lung transplant worked but his kidneys failed and he was hoping to get a kidney transplant but he passed in 2015.

8. 2016. One of my husband's brothers was diagnosed with Pulmonary Fibrosis!! Only thing to save his life is a lung transplant!!!

9. In 2014, my son and his uncle (the newest diagnosed) decided we needed to raise more awareness about the need for organ donation. Our family has started an annual 3D archery shoot on our family farm. We have hosted "Shoot for the Vitals" for 3 years now and each year we are getting the message out to more people! We donate the money we raise to people and families that are in medical need, as we know the how wonderful it is to receive so much kindness in a long journey.

My story is a long one and I have no idea if this is the last of our need for organ donation but my husband's family has been involved with it since 1992 and we all plan on being organ

donors if it can happen. It is so very important and can change a whole family's life!

Out of this public consultation, I hope that Saskatchewan can become leaders in implementing the "Opt Out" program instead of our current "Opt In" system. That is a huge undertaking and will take some time but we can start with an online provincial registry for people wanting to be organ donors. Making sure that it is easily accessible to doctors at the time of a person's death, to see their wishes for organ and tissue donation fulfilled.

Thank you,

Rosalyn Harris