

Hello

My name is Twyla Harris, my father Carmen Harris and my mother Rosalyn Harris. We would like to begin by thanking you for holding public hearings on organ donation.

We would like to take the time, today, to tell you our family story and what we are hoping to achieve with a Organ Donation program in Saskatchewan. We will present ideas such as, but not limited to, an online registry, education, promotions, living organ donations, and an opt-out program.

In 1988 my Uncle, Gordon Harris, at the age of 47 was diagnosed with Acute Leukemia. At that time there were no treatments for this disease; it is now commonly treated with a stem cell transplant. My Uncle Gordon passed away two days before Twyla's third birthday in July, at the age of only 48. Uncle Gordon was loving, supportive and dedicated to his nephews and nieces. He was never married and had no children of his own. He had instead chosen to devote his life to caring for his mother, as his father and my Grandfather, Sidney Harris had passed away in 1968 from emphysema.

My youngest brother, Wendell Harris, was always tired and cold. He never really had any energy. We all thought he was just lazy, and whined a lot so we called him wimpy; even the nieces and nephews would call him "Uncle Wimpy". We had no idea that there was something else going on. In 1991, when he was only 20, we found out what was actually happening. He was diagnosed with Aplastic Anemia, after many medical appointments. For those that may be unaware, Aplastic Anemia is a disease that affects your red blood cells, not allowing them to reproduce normally. Wendell was given two options: blood transfusions, which would only

work for short periods of time; or, a Bone Marrow Transplant. Wendell, along with my parents, decided that a Bone Marrow Transplant was the route to go. All of my siblings and I started the process, having blood work and DNA testing done here, in Saskatoon, to see if any of us matched.

Once we were all tested, including our children, I was the best match. I travelled with Wendell, and our parents, to Vancouver in December 1992, as bone marrow transplants were not available at that time in Saskatchewan. While I was away in Vancouver, my wife, Rosalyn was home by herself, taking care of our three young children, as well as the farm. The Bone Marrow Transplant was a success, and Wendell was doing well, he was up walking around and moving. Despite this, Wendell sadly developed an ulcer in his stomach, which ruptured. He ended up passing away from internal bleeding in February of 1993, while being treated, at Vancouver General Hospital.

My Grandfather, Clarence Harris, had spent years working for the RM of Shellbrook. When he at long last decided to retire, it was so that he could enjoy his cabin with his wife Opal.

Grandpa had been sick with pneumonia and never seemed to be able to lose his cough. He went back to the doctor many times and tried many different medications. After multiple tests, they found that he had Pulmonary Fibrosis. Pulmonary Fibrosis is a disease of the lungs, and it tragically has no cure. Grandpa very quickly, went on oxygen 24/7. He was told his only option was a Double Lung Transplant. Grandpa and Grandma ended up travelling to Edmonton to complete the FIT program, which was required in order to be placed on the waitlist for a lung transplant. After Grandpa finished the FIT program, they returned home. After only a short time, Grandpa got very sick, and ended up in the Royal University Hospital in Saskatoon. My

Grandpa never came home. He passed away on my 19th birthday, in July of 2004. My Grandpa was 67 when he passed away, but was able to donate his corneas, as well as some tissue to help others who were in need.

In 2013 my Auntie, Karen Pilon, had gotten bronchitis and it just kept coming back. Her doctors weren't quite sure what was going on, since none of the medication and treatments were working. They did some testing, and realized that Auntie Karen had the same disease as her father Clarence, Pulmonary Fibrosis. Auntie's illness progressed very quickly. She too was on 24/7 oxygen, and in need of a Double Lung Transplant. In February of 2014, she ended up in ICU at Royal University Hospital. Auntie was not getting better. They decided to send her to Edmonton with the hope to give her a better chance for a transplant. In order to send her, and keep her alive, they needed to put her on an Ecmo machine. Once she was in Edmonton, they kept her on the Ecmo machine and sedated her. She stayed like that until it was decided, even if she received a transplant, she would not survive. On March 25th of that same year, my Uncle Clarence made the difficult decision to take his wife off of life support, so she could become a donor herself. Auntie Karen was able to donate her liver, kidneys and pancreas. Auntie Karen saved 4 lives that day.

Following Auntie's death her husband, Clarence, with both the Harris and Pilon families, started the Karen Pilon Organ Donor Awareness Foundation. Through this project, Clarence has been able to raise funds, and help support other families who are going through similar things. Along with raising funds, the foundation has also spent many hours creating ways to promote organ donation. One particularly successful promotion was billboards across Prince Albert displaying stories of individuals who either received, donated or passed while waiting for the organs they

needed. Clarence and the family have also attended events like Transplant Trot, local parades, Prince Albert SPCA Golf Tournament, and Shoot for the Vitals. Recently, we started selling T-shirts and green bracelets. This year, the Prince Albert Exhibition Finished 4-H Beef Show and Sale chose the Karen Pilon Organ Donor Awareness Foundation as their charity of choice, allowing the foundation to receive the funds from the sale of the Charity Steer.

The Charity steer, this year, was supplied by the Wild Rose 4-H Beef Club. This is the club that Auntie's children, and all of her nieces and nephews, have been a part of for over 22 years. The Charity Steer was cared for and trained by my own family, on our farm. The Charity Steer ended up bringing in \$27,150.00. This money was put towards the purchasing of an Ecmo Machine, for the University Hospital in Edmonton. This is the machine that kept my Auntie alive, what helped get her safely to Edmonton.

The summer after my Auntie passed, my Brother Tyler Harris had an idea for a fundraiser. Tyler, along with my Uncle Ralph Harris, came up with the plan for "Shoot for the Vitals". Shoot for the Vitals started July 2014, and began as a Skeet and 3D archery shooting competition. The Harris family has now successfully held this event for 3 years in a row, on our family farm near Prince Albert. This year, we decided to only have the 3D Archery Shoot. Over the three years, we have been able to financially support several individuals from the Shellbrook and Prince Albert areas, as well as the Karen Pilon Organ Donor Awareness Foundation. Our number of participants has risen every year, and continues to grow. By doing this, our family was able to financially help a very close family friend, Rick Galloway. Rick was diagnosed with a lung disease at the same time as my Auntie, and also required a Double Lung Transplant. Rick was lucky

enough to receive his lungs, in July 2014, but sadly his kidneys started to fail and would require a Kidney transplant. Rick passed away last year, in August 2015.

This past March my brother, Ralph Harris, was also diagnosed with Pulmonary Fibrosis. He is currently undergoing doctors care in Saskatoon doing CT Scans, blood work, chest xrays and breathing tests every 3 months, to see how fast the disease is advancing. But we all know a lung transplant is his only option. He is currently waiting to start his FIT program and be placed on the transplant list.

As you can see, organ donation is a huge part of our lives. It has affected us in many ways. While all of this has been happening, we have found out that the cause for our family having these many issues is that some of us are carriers of a genetic factor disease called Dyskeratosis Congenita (DKC). DKC is a disease of the bone marrow that affects your breathing system, showing that Aplastic Anemia and Pulmonary Fibrosis are all linked.

Now that you have heard our story we would like to explain to you what we would like to see happen within Saskatchewan in order to increase organ donation.

The first thing we propose is creation of an online registry for organ donors. This online registry would be created and maintained by the Provincial Government. It would be developed for use in all Saskatchewan Hospitals. This registry would take the legal and decision making burden off of family, at least to some extent. It would work alongside the signed card and sticker on the health card. With this we ask that the Provincial Government push the Federal Government to adopt and put into law Bill C-223 Canadian Organ Donor Registry Act. In conjunction with the standup of a registry, the public would require an awareness campaign on considerations for

folks to speak with their families about their wishes, to describe the types of organs and tissues that can be donated, and the types of living organ donations that are possible. We would like to see the creation of this online registry to follow the registries already in operation in Ontario, British Columbia and Alberta.

Next we would like organ donation to be added to the Grade 8 health or science curriculum. Topics of instruction would be options of donations, myths and facts and the different systems across Canada and the world. This would allow for organ donation to be considered at an earlier age and permit youth to have the discussion with their families. Speaking with many youth, most are unaware of organ donation and surrounding considerations. Education at a younger age will help with the discussion and help raise the number of organ donors.

The province of Saskatchewan currently has a promotion happening now called Offer Hope. I personally do not feel that it is in any way effective. As a family that is heavily involved with promoting organ donation we have hardly ever seen a commercial or poster anywhere. I have repeatedly spoken with coworkers and friends about the Offer Hope Campaign and none have been aware of it. In order to fully educate the public and to increase the number of organ donations, the reach and focus of the advertising campaign needs to be broader. The advertising needs to promote organ donation by teaching facts and sharing information.

Stories are important but must associate with facts and a call to action. There needs to be an ask coming from an awareness campaign, which ties in with the online registry. The promotions need to be shared on all platforms, social media, print, television and radio. We see a generally expanded purpose for the Saskatchewan Transplant Program. They should be attending events and promoting organ donation. It would be great to have them attend events

that are about raising awareness on organ donation and at public events like Broadway Street Fair, Regina Mosaic and Exhibitions.

I recently decided to look into Living Organ Donation and the process is frustrating and takes an extended period of time. Even seeking out information required speaking to four different organizations, which still did not yield the information I needed. This process needs to be easier, both to obtain information and to start the process. A webpage that has a clear outline of the process and who to contact would be exceptionally helpful. I also reached out to my insurance provider to find out what coverage I could get if I chose to do this and I found out that I would only get short term disability. I would not receive coverage of travel and treatment. If I was required to travel to Edmonton, my travel, meals and hospital room would not be covered under my benefits. This puts a very large roadblock up for anyone who would like to do a living organ donation. Increasing information and promotions would help to increase the number of transplants for those who require kidney and liver transplants, which will in turn lower the number of individuals who will require dialysis and other treatments.

Finally, while all of the above is happening we would like the Provincial Government to start public consultations to move the province to an Opt-out Program. This is presumed consent unless the individual has declared their intention to not donate their organs. Additionally, the current barriers to gay men being able to donate organs, tissue and blood need to be changed and removed, as these barriers are not based on actual science but on behavioural practices. They are discriminatory in nature. By implementing opt-out and removing the barriers set against gay men we can increase the number of organ donors available. This will help reduce the number of trips to Alberta for treatments and testing. With over 80% of Canadian

population saying they would donate their organs, this is an idea that could be overwhelmingly supported by a majority of the population. This would make Saskatchewan leaders in organ donation in North America.

Thank you for allowing us to present our views and story to you. We hope that you will take all of this into consideration and are willing to continue to work on major improvements to our organ donation system.

QUESTIONS

Thank you for your questions and your time. It is greatly appreciated. We look forward to working with this committee in the future and are excited to hear what we will be doing in the future.