

Jason case study and donor family stories

One Life...Many Gifts is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

This cover features the Gift of Life Donor Quilt, which originated with the London Transplant Gift of Life Association.

To view the complete quilt and read the donor stories, visit www.lhsc.on.ca/waystogive/motp/shareyourstory/donorquilt.htm

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Donor Family Stories – An Introduction

You have been reading about organ and tissue donation and about recipients whose lives have been saved by receiving the gift of life. Each year, over 600 people in this province receive organ transplants. This is wonderful news for those recipients and their families. What also needs to be highlighted is that their lives were saved because of the generosity of families who, during the most difficult time in their lives, made the decision to donate their loved ones' organs.

This section will introduce you to some of the families who gave the 'gift of life' to help you approach organ and tissue donation from another perspective. You will see how in the midst of their grief, the White, Morrison-Weir, Therien and Castillo families are comforted by the fact that their loved ones provided life to others.

But first, you will be introduced to the Edwards family who struggled with the decision to donate their son's organs and tissues because they didn't have enough

information on which to base their decision. This case study will allow you to explore some of the issues surrounding how to balance the desire of an individual wishing to be a donor and the feelings of a grieving family

A signed donor card and a conflicted family: The Edwards Family Case Study

The following is a true story, but the names have been changed.

Mr. and Mrs. Edwards had just finished their evening meal when the telephone rang. It was the local hospital advising them that their 19-year-old son, Jason, had just arrived by ambulance at the Emergency Department. The hospital staff requested that they come to the hospital immediately.

Once they arrived at the hospital, a nurse informed them that Jason had fallen from a ladder in the course of his work. Unfortunately, he had chosen not to wear his hard hat, and he sustained a very serious head injury. His parents were asked to wait until further tests were completed, at which time the doctor could provide more details. Over the next 24 hours, Jason's condition steadily deteriorated despite all the life-support measures he was receiving in the Intensive Care Unit. His parents waited by his side, hoping to see their son's eyes open again.

After 48 hours, the doctor explained that Jason's prognosis looked hopeless. The medical tests determined that the swelling of his brain from the trauma had reached an extreme degree. After more tests were completed, the doctor and social worker spoke with Mr. and Mrs. Edwards. They were informed that Jason was brain dead and that the ventilator that was artificially maintaining his breathing would be stopped.

Before the ventilator was discontinued, his parents were asked to consider donating Jason's organs and tissues for transplantation. The doctor explained that Jason could be a donor and his heart, two kidneys, two lungs, liver, pancreas, and small bowel could save the lives of eight people. His corneas could give sight to two people, and his other tissues could help countless patients suffering from burns and bone cancer. Hospital staff had found a signed donor card in Jason's wallet.

Jason's parents were hesitant to give consent because they had never discussed donation with their son and they were uncertain if donation was approved by their faith. They wanted to consult with their faith leader, and hear his perspective before they consented to donation. The hospital staff were waiting to follow their instructions, even though they were aware of Jason's signed donor card.

The Steering Committee acknowledges the contribution of the Multi-Organ Transplant Program, London Health Sciences Centre in developing the original curriculum "Organ & Tissue Donation and Transplantation Health and Physical Education," published in 2001, which included this case study.

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Over
to You...

Discussion and Debate

Jason had signed a donor card and the hospital staff found it in his wallet. Yet, his parents, when asked about whether Jason could donate his organs and tissues, are considering saying 'no' because they do not know whether their religion supports donation. It is not something that they had ever discussed, either at home or at their place of worship.

In a group of three or four, discuss the following questions and write down on a piece of flip chart paper five to ten points you feel represent the opinions of all of your group's members.

- Are there any circumstances in which a donor card should not be followed? For example, should a family be able to override a signed donor card?
- What rights should families have with respect to the body of a relative who has died?
- Assuming there is a signed donor card, should hospital staff be required to request consent for donation from the next of kin? If yes, why? If no, why not?

Remember, not everyone in the group will agree – just write down what your group feels are the most important points to consider.

Once you have finished writing down your points, put your flip chart paper at the front of the class and appoint one person from your group to summarize and present the key ideas from your discussion.

Once all the groups in the class have presented their summaries, read the document "Balancing the Wishes of Individuals and Families" which outlines what the law says about these questions and what happens in actual practice in Ontario.

With this added information, work with a partner to prepare a position either for or against allowing families to override the signed donor card of a loved one. Debate your position with two students who hold the opposing view.

Jason's parents had concerns about whether their religion supported organ and tissue donation. You may wish to refer to the document "Religious Perspectives" in the "Religious and Ethical Perspectives" booklet to learn about the beliefs and viewpoints of various faith groups.

Balancing the wishes of individuals and families

According to the Trillium Gift of Life Network Act, a person who is at least 16 years old may consent to donating his or her organs and tissues either a) in writing (registering through OHIP or signing a donor card) or b) orally in the presence of at least two witnesses during the person's last illness. Upon the death of the individual, this consent "is binding and is full authority" for proceeding – this means that legally, a hospital could proceed with organ and tissue donation if there is registry documentation or a signed donor card. Again, no consent from any other person is legally required. Generally, our society believes in the autonomy of people making their own decisions in all areas of their lives, including death.

For example, a will is drawn up to make plans for a person's eventual death, and an organ donor card is similar. It is a legal document and, in a court of law, could be upheld. Therefore, it could be argued that hospitals and health-care workers should abide by the wishes of the deceased when there are clear, written instructions to proceed.

However, the law also states that after death, the body becomes the property of the next of kin. And the next of kin are making all the decisions regarding the after-life care of the deceased. For example, if no funeral arrangements have been made, the family is responsible for these arrangements. Some would say it only makes sense that organ donation be part of this decision-making.

In practice, hospital staff always discuss with the next of kin of potential donors their feelings regarding donation and what their loved one would have wanted. Out of respect for grieving families, they are asked to provide the final consent. They are the ones who must live with the memories of their loved one. Therefore, it can be argued that it is important that the family participates in the process and feels comfortable about donating the organs and tissues for transplantation. Generally, when the next of kin are aware of the deceased person's wishes, they want to honour those wishes. It is important, therefore, for people to discuss their wishes with their family and ask them to implement those wishes following death. Your family needs to know what your wishes are because, in practice, hospital staff will seek consent from the next of kin and they will not remove organs without their consent.

Sandrine's Gift

The last time her mother spoke to her 11 year old daughter, Sandrine was on a telephone as they checked in after a few days apart. It was the May long weekend of 1999 and Sandrine was staying with neighbours for the weekend while her mother, Diane, was away on business. When Diane called to say goodnight, Sandrine declared happily that she had just had "the best day of her life." She and her friend Rachel had been to the Art Gallery .The day had turned magical with the purchase of a red cellophane fortune telling fish and a table for two with Rachel at the restaurant they had gone to with Rachel's family that evening. Diane remembers smiling into the phone and assuring her daughter that "there would be many, many more good days" in her future.

Sandrine was a happy morning person and loved to greet the day by dancing as she prepared to leave for school. She was always ahead of schedule and often was ready to go before the school bus arrived. On the Tuesday morning after her chat with her mother about her "good day", she waited for her bus longer than usual. Just as she was about to give up and take her neighbour's offer of a ride to school, the bus appeared and she climbed on to join her friends.

Less than five minutes later, a large truck slammed into the bus and the world tumbled into chaos for Sandrine and her classmates as children cried out in pain and others like Sandrine fell into unconsciousness. Soon, Sandrine was lying on the ground covered in a blanket as whirling helicopters lifted her injured classmates

to medical help. Sandrine was placed, unaware of her surroundings, into an ambulance which sped her to the Children's Hospital of Eastern Ontario (CHEO).

Meanwhile, Diane, in another city, was making a presentation when she was interrupted to take an emergency call. It was the CEO of CHEO telling her that Sandrine had been severely injured and that Diane should come right away. Before she boarded the flight for the trip back to Ottawa, after battling airline schedules and desperate to see her daughter, Diane tried to get information about Sandrine's condition. With the help of an airline employee, she heard the bitter truth in a call she made to the hospital where the doctor told her the dreadful news that Sandrine had been the worst casualty and that she had severe brain damage with a very slight chance of survival. The seconds suddenly became hours as Diane made her way to the dying Sandrine accompanied on the flight by a solicitous airline employee. When the plane landed, after what seemed to be an interminable time, there was a police car and one of Diane's friends waiting to rush her to the hospital and to Sandrine's side. This was not unfamiliar territory for Diane who had recently cared for her husband as he reached the final stages of terminal cancer. Once again, the family would face tragic loss and heart wrenching grief.

When Diane saw Sandrine lying in her ICU bed, she was initially lulled into the expectation that Sandrine would awake from the deep sleep she appeared to be in. There were no bruises and no scratches and Sandrine seemed to be resting. However, when Diane asked the nurse the tough question "Do you think she will survive?" and the nurse responded with a look of great compassion, Diane began the painful process of facing the inevitable. The possibility of organ donation crossed her mind.

"It is the only right thing to do"

Sandrine's brother Kenny who was 16 at the time of this terrible accident was away at the National Sports School in Calgary. He too had undergone huge loss, as Diane and Sandrine had, with the passing of his father. One more time, he would be called upon to deal with sorrow almost beyond bearing. Diane made the phone call that got Kenny on a plane back to Ottawa to join his mother in a decision about the gift of life: "Sandrine is in a coma and has severe brain injury."

Kenny arrived at the hospital at 11:30 that night and by 9:00 the next morning Diane and Kenny understood that Sandrine was not going to wake up and that there was no function left in her brain. So, when the doctor asked about organ donation, Diane and Kenny were as ready as they could be for the question. In Kenny's words: "It is the only right thing to do" and Diane agreed.

It took 12 hours to find the right matches and during that time Sandrine's family and friends surrounded her bed and her mother told her that it was alright to go and be with her Dad. And so the pain of one family gave hope and life to the loved ones of several other families: Sandrine's heart and lung went to a 34 year old woman; her kidney went to two teenagers, her liver to an 8 month old baby and her eyes to two elderly people.

The 34 year old mother was able to express her gratitude for her new chance at life directly to Sandrine's family. There was an article in Chatelaine about Sandrine's tragic death and her gift to others. The woman who received the heart and lungs figured out from the timing described in the story that she was the recipient of Sandrine's heart and lungs and called Chatelaine. Prior to her transplant she had been dreaming about a doll in a pink dress, perhaps a premonition of the little girl who would change her life through the generosity of a grieving family.

One of Diane's friends who belonged to a group called "Babes in Broadcast" came to the hospital that fateful morning to comfort Diane and Kenny. They decided they wanted to do something in Sandrine's memory and the result was a hugely successful two week campaign that raised over \$350,000 in kind to publicize the importance of organ and tissue donation. That was the beginning of a passionate commitment that is still central to Diane's life. In her words, "It feels like this is what I am supposed to do. If I stopped being a champion for organ and tissue donation, I would feel as if Sandrine was dying all over again."

May 26th, 2009 marks the 10th anniversary of Sandrine's death. Her family and her friends will gather in Ottawa to celebrate her life and her gifts to others. Many of her classmates of a decade ago have joined Sandrine's Wall on Facebook. They remember her and the difference she has made to so many lives. The evening before Sandrine died she happily told her mother that she had had "the best day of her life." Because of her, several others have many days, months and years they would have been denied without her gifts.

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over to you...

Email /Text Message

Sandrine's brother Kenny has faced tragedy in his family twice. Imagine how he must have felt when he got his mother's phone call and had to rush home to Ottawa to find his sister near death. With a partner, discuss all the things that must have been going through his mind. Then write a text message in Kenny's voice to his best friend in which Kenny shares his fears and his feelings about what he will face in Ottawa when he joins his mother at Sandrine's bedside.

Design a Poster/Brochure

Sandrine's family has organized a celebration of the 10th anniversary of Sandrine's death and her gift of life to others. Working with a small group and using information from the story, design a poster or a brochure which would invite people to attend the celebration and promote organ and tissue donation. Include some of the scientific facts about why Sandrine was able to be a donor and the reasons why her family thought it was the "right thing to do." Use illustrations and graphics to make your poster or brochure persuasive and encouraging.

Loving his family more than life itself: The White Family Story

"Hi, and welcome. My name is Jaynel White. When I prepared this speech, I was 15 years old, in grade 10, at Laurier – a London, Ontario, high school. Now, I am 18.

Two years ago, I lived in a family of four. I had my mom, my dad, my brother and myself. For 15 years, my mom and dad looked after us. We had each other; even if we were mad or upset, we were always there for each other. For 15 years, I had it all.

In 2005, winter came as it had every other year, but this time there was nothing that could keep my wonderful family protected from the howling winter winds. It was a season that changed our lives forever. Statistics show that every three days a person dies while waiting for organ transplantation. Today, I am part of a family of three – my mom, my brother and I. We are living proof to that fact.

In the first few weeks of December, my dad had been feeling under the weather. He went to the hospital, came home and then had to go back again. That was our first sign that something was definitely not right. He was not allowed to come home for Christmas, another omen that there was a big problem. Still, we were all together and we were laughing and hugging each other, telling Dad it would not be long before he got out and could come home. A week passed, then another few days. The hospital called my mom; then she asked to speak with us.

As she was talking, I fell deeper and deeper into what felt like a black hole. My legs wobbled and my head was spinning. My dad needed a heart transplant operation. So many thoughts started to run through my mind: 'What if a heart doesn't become available? What if my dad does get a heart, and then his body rejects it? My biggest fear, however, was what if I never get to dance with my father at my wedding?'

After hearing the news, I turned to look at my dad. I saw a look on his face that I will never forget. I saw courage and strength and, more importantly, a sense of hope. My dad's oldest sister had received a heart transplant and she survived. I know we were all thinking the same thing. As that memory ran through our minds, it gave a feeling of strength to everyone in the family. We were confident that everything was going to be all right.

The holidays passed, and we all began to get back to our daily routines – at school and at work. By then, winter had really settled in. It was at this time, that we hit a snag.

My dad took a turn for the worse; he had to be airlifted to the University of Ottawa Heart Institute. After being resuscitated three times in London, the flight – followed by immediate surgery – was a last resort. The surgeons kept him alive by implanting a LVAD, a left ventricle assist device. Just as the name suggests, the LVAD helped support his heart by assisting with the pumping action. Without it, he would have died. I will always be grateful for that extra chance, and time, my dad was given.

After the surgery, my dad was told he had to stay in Ottawa until a donor heart

became available. Waiting and worrying became part of our daily life. Although it was hard on all our family and friends, it was really difficult for my brother, my mother and I. We had to leave Dad in Ottawa, alone. My brother and I returned to London, to a home where we felt incomplete and saddened. Every night we would call our dad, just to talk. We would tell him about our day, what was on our minds and how we felt about various things. The distance between us did not stop us from being a family. When we went on our first trip back to Ottawa, my big, brave dad began to cry when we walked into the room. We all began to cry – and started hugging him and kissing him and telling him how good it was to see him.

In the hospital, we had little goodies to eat and games to play. We watched TV, shared dinner, and – even though the hospital was the last place we wanted to be – we all were still together as a family and that's what made it count. The day we had to leave the hospital in Ottawa was a hard day. Again, we cried, but this time we did not shed tears of joy. There was a deep sadness in our teardrops. As we all gave our hugs and kisses goodbye, my dad's eyes still shone with strength. At home in London, I could not sleep. I felt incomplete and, above all, depressed. I missed my dad even more than before; it was so hard to see him and then have to leave. I prayed to anyone that was listening, asking them to give him back the life he once had – the life he deserved.

Two weeks later, my prayers were answered. We received the news we had been waiting for: a heart was available and they were checking to see if it was a suitable match for my dad. I felt that my family's dreams were coming true. I phoned my mom; I could hear the hope and the happiness in her voice. That day was the first real smile I gave to myself and to everyone else since my dad was first admitted to the hospital.

Initial elation turned to anxious waiting. Minutes turned to hours, and then even more hours. In our hearts and minds we knew, without being told, that this heart was not right for my dad. That night, I cried. I cried for my mom. I cried for my brother, but most of all I cried for my dad because that night, when I spoke to him, I could hear him crying. It killed me inside.

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A week later, we returned to Ottawa for my mom's birthday. Even though we were all still upset about the not-for-Dad heart, his smile filled us with happiness. We found out that there had been another potential heart, but it did not even make the preliminary prep stage. That's when I created our own motto – 'Third time's a charm.'

Then came the March break. We went to Ottawa, and ran straight to my dad. We played cards together, watched movies, talked about sports, goofed off and ate together. We were having fun. I felt we were making him feel at home again; he was happy. On our last night, we went to an Ottawa Senators game. We called our dad at the hospital and let him know that the Sens had scored a winning goal when there were just seven seconds left in the game. He was thrilled. I didn't know it at the time,

but those precious minutes I had with my dad on the phone would be the last time I heard my dad's voice. My whole world was about to come crashing down, on me, and on my loved ones.

On March 15th, we were awakened by a phone call from the hospital. They told my mom she was needed at the hospital. My brother and I waited, and waited and waited. Four hours passed. My mom came back to the hotel. Her face was pale; her body was tense. She could barely speak. I'll never forget what she told us. Early that morning, my dad had a severe seizure, causing massive brain haemorrhaging. His brain cells were destroyed and internal pressure was pushing down on his brain stem, damaging it so much the doctors could do nothing. My dad was dying.

I was numb. The information didn't really hit me - at first. Then everything came flooding into my mind. My dad wouldn't be there for my prom or for my graduation from high school. He wouldn't be there for my birthdays or for Christmas. What hurt me the most was that I would never walk down the aisle and dance with my father on my wedding day. My dream was shattered.

My mom asked us if we wanted to see Dad one last time. I said I did. The two minutes it took to drive to the hospital felt like two hours. When we got there and went to his room, I felt as though I was rooted to the hospital floor. There I was, face to face with my dad. My strong, courageous dad who was hooked to tubes, and unconscious. That image will haunt me forever. He was so lifeless, so thin. This was not my dad. As my mom left the room, she gave me a chance to speak with him. They say that people who are unconscious can sometimes hear you when you speak to them. I told my father how proud I was of him and how we all loved him more than anything and he was always going to be my daddy and I was always going to be his little girl. Before I left the room, my last words were a promise: 'One day, when we will meet again, and on that day, we'll share our father/daughter dance at last.'

That night was the longest night of my life. I went to the hospital at noon and did not leave until seven. When the family was all together, my mom asked if my dad could be an organ donor. She knew that is what he wanted if anything happened to him. We all agreed. My grandparents and other members of the family waited at the hospital until my dad was taken off life support. At 2.00 a.m., on March 16th, my mom called my brother and me to let us know: 'We are saying our last goodbyes.'

My dad's organs were helping six people, and he could ultimately help up to 15 people.

My dad was dead. All I could do was to choke out a noise; she understood my cracked voice. I never really did get to sleep that night. None of us did. I knew that all of us, especially my mom, lost a piece of ourselves. I cried for most of the night, holding my dad's picture close to me.

A few weeks after my dad's passing, we found out some news that would change our lives. My dad's organs were helping six people, and he could ultimately help up to 15 people. As our family sits and grieves today, others are rejoicing and celebrating a new organ, a new life for someone in their family. A stranger's

happiness was possible, thanks to my dad.

Throughout my life, my dad was more than just a father figure in my life. He was my coach, my mentor and my friend. I will never forget the courage he showed us as he tried to fight in a world that was between life and death. My dad is my hero. Words cannot say how proud I am to be Dave White's daughter.

Today, I write this for you as a student, a teenager, a friend and a daughter. My dad taught me so much in life. My dad showed his loved ones how precious life is, and demonstrated that you can never take anything for granted. He loved my mom more than anyone could love another person, and he loved my brother and me more than life itself.

My message to you today is that you should tell people you love that you love them. Always do what you think is right and never give up. My dad never did.

Today, I am asking you to talk to your family and tell them your wishes after you are gone. Talk to your family about organ donations. By signing your donor card, you can give life to someone with very little hope. By signing your card, you can help someone who is very discouraged regain hope again. My dad talked to my family about his wishes, and because of it, strangers have shared two years more with their loved ones.

Today, you can choose to make a difference.

Choose to take the lead.

Choose to be a hero.

As I share my story with you, I ask you one simple question: 'Can you give life?' The answer is just as simple: 'Yes.'"

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Susan Morrison-Weir's journey from loss and grief to new love and restored hope

Susan Morrison is a volunteer for the Trillium Gift of Life Network, and is a board member of the Sarnia Organ Donor Awareness (SODA) group. When she gives talks about becoming a donor family, she never starts with a discussion of the death of her husband: "I am not here to talk about death. I am here to speak about life." And she does.

"In 1983, at the age of 15, I was introduced to an 18-year-old, William Dale Morrison. Mine was an unlikely encounter; my boyfriend at the time introduced me to Bill - he was so skinny that his pants hung from his hips. He was wearing a velour pullover and corduroy pants. He was desperately, and unsuccessfully, trying to grow a moustache. Bill thought that I, Susan May Kitchenmaster, was good-looking.

After a few months of being best friends, Bill gave me a white carnation, tipped in baby blue. Although he had borrowed it from the restaurant where he worked, it became our special flower. I was in Grade 11; he was in Grade 13 and we were inseparable.

Within the year, Bill asked me to marry him. Although we declared our intentions when I was only 16, we were engaged four years before we married. May 14, 1988, became our wedding day. We waited a full five years to start a family. To celebrate the good news, which I learned on Valentine's Day, we had Chinese food and I made personal fortune cookies (the message inside announced the good news) with white carnations, tinted blue. Our son, William David Alexander, arrived in 1995, followed by Victoria May in 1997. As far as I was concerned, they were our little miracles. We had a perfect family.

Our picture postcard life was shattered in 1998. Bill was rushed to the Emergency Department, in cardiac arrest. He was on a ventilator, unconscious, but I know he could hear because his heart rate increased when I spoke. A floor nurse noticed that Bill's pupils were not equally dilated, a serious concern because it indicated swelling of the brain. A CAT scan revealed that Bill's brain was bleeding. While I was contacting Bill's family, the doctor came to see me. He told me that Bill had suffered a subarachnoid haemorrhage (a spontaneous bleeding of the membrane surrounding the brain) and was exhibiting signs of neurological death. The prognosis was grim.

The idea of organ and tissue donation had not entered my mind. However, when the doctor mentioned the possibility, something about it seemed right. Both Bill's parents and I agreed to donate his organs if he were declared neurologically deceased. Following further testing, Bill's death was confirmed. The transplant team was able to retrieve his heart, lungs, liver, kidneys, corneas and bones.

On the day of Bill's funeral, the Eye Bank of Toronto called to let me know they had two recipients for Bill's corneas. I was elated. I spent the morning celebrating my husband's life. Now I had one more reason to celebrate – for someone else's life.

My husband is gone, but it gives me great joy to know that other people have been able to benefit. It gives Bill's seemingly senseless death some meaning. I have received two letters from recipients. They are precious to me because I know that when my children read them, they are proud of their father in life, and in death.

My life has changed dramatically since my husband died. I continue to grieve for my best friend, my husband and the father of my children. There were also the early struggles of being a single parent with two small children, children who did not understand why their father was no longer with us. Although I took my children to see their father at the funeral home, they were too young to know what it meant. They saw their father in the open casket, and just assumed he was coming home. He wasn't, but how do you discuss death with two children under the age of three?

There wasn't any language to explain it, even to myself. The next few years were

difficult. After spending all day in an insurance adjuster's office, it wasn't easy to come home and start a second solitary job. What made it particularly difficult was that everything, right down to what we ate, changed. My husband was a meat and potatoes kind of guy. The children wanted kiddie food, and I just wanted to sit down to any kind of meal with my husband. Instead, I looked at an empty chair.

Some days, it was just the tiniest incident that upset me. At Christmas, we always sent out family cards. Everyone has a certain way of signing family cards, but after Bill's death, I didn't know where to place our names. It sounds so trivial, but seeing the space where his name would ordinarily be made me feel his absence even more acutely.

Life does work in very mysterious ways. My neighbours across the street had a nephew, a man I worked with as a teenager. As a single person, with no children of his own, Andy was very much affected by the loss our family was suffering. Andy came to my house to help out and fix things around the house. Sometimes, I cooked dinner as a thank you. Gradually, Andy made his romantic feelings known and we started to pursue a relationship.

I didn't meet somebody new; I met somebody old. I don't know if Andy knew what he was getting into, but I am now Sue Morrison-Weir. We have been married for four years, and happily so. The children have both accepted Andy; they say that they have two daddies - Bill, their daddy in heaven, and Andy, the daddy who lives with us now. The children are content: Alexander is in sea cadets and Victoria loves to perform in school and church plays, along with her regular participation in GEMS, a Christian girls' club that awards badges for various accomplishments. Both are straight A students.

Of course, you never really get over the loss of a spouse. I had been with Bill since I was a teenager. I didn't know a world that he didn't inhabit. When he died, I felt as though I didn't know who I was or where I belonged. I had a hole in my life. Every little aspect of my life changed. I had to create a brand-new universe, which I have done. Now, my melancholy appears in moments. I try and concentrate on sharing wonderful memories with our children, keeping Bill alive in our hearts and minds.

I must say that I continue to be saddened by the very low levels of organ and tissue donation in Ontario and across Canada. We have some of the best doctors and medical technology in the world, and yet we do not have enough donors. You have the power to change the statistics. You can make a real difference. Speak with your parents over dinner. Let them know what you have learned about organ and tissue donation. Having everyone in your family understand the options, and choosing to be a donor, could save many lives and improve the lives of countless others.

I read once that you shouldn't cry when the sun doesn't shine because your tears won't let you see the stars. Some days I do cry, but I can still see my stars - our beautiful children and the wonderful memories of the time I spent with Bill. Through my first husband's life, and his death, other people have been given a second chance at life. In my darkest days, these are the stars that shine.

if sarah beth had to die, we are glad this happened: The Sarah Beth Therien Story

Most parents are proud of their children, and have been known to brag a little about their virtues. Emile Therien, the father of Sarah Beth, is no exception. He cannot say enough about his beloved daughter: "She is a vibrant, wonderful daughter - a sister, aunt, cousin, niece, granddaughter, mentor and confidante to many people." Of course, Emile doesn't leave out his son, Chris, who lives in New Jersey and is retired as a hockey player with the Philadelphia Flyers. He even jokes that he and his wife, Beth, shouldn't have stopped procreating after two children; they should have kept on going, all the way up to five.

Therien's focus, however, is on the young woman who died, his young 32-year-old daughter. There was absolutely nothing to suggest that Sarah Beth was in any kind of medical trouble. She was healthy, active, always on the go. There were no signs or symptoms of any illness. Then, out of nowhere, Sarah Beth experienced sudden cardiac arrest.

Sarah Beth was rushed to the Ottawa General Hospital and, for almost an entire week, the doctors and nurses in the Intensive Care Unit struggled to bring Sarah Beth out of her comatose state. Nothing worked. Finally, the doctors spoke with the family about withdrawing life support.

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It is at this point that Emile Therien's voice crackles and his breathing becomes laboured. He is remembering the horrible week of sitting by Sarah Beth's bedside, along with his wife and son - praying continuously for her recovery, speaking with her, telling her how much she was loved.

The Theriens knew that people who appear unconscious often hear what is being said to them, and they all wanted Sarah Beth to know they were there, pulling for her.

Pausing for a moment, Therien then shares the highly unlikely coincidence that occurred just a few days before his daughter died. "Sarah Beth was taking something out of her purse just as everyone was going out together. She stopped, looked at her driver's licence and then said: 'I just want to let you know, in case something ever happens to me, that this (pointing to her donor card) is what I would want to happen.'" Emile and Beth are just as startled

in 2008 as they were the day Sarah Beth expressed her wishes in 2006, surprised that an organ donation conversation would happen - out of the blue - so soon before she died. At the time, neither Emile nor Beth gave the passing comment a second thought.

Now, in the Intensive Care Unit, Sarah Beth's wishes came back very vividly. The Theriens had to become a donor family. Although the Canadian Council for Donation and Transplantation approved of Donation after Cardiac Death (DCD) in September 2005, the health-care team was initially a little reticent; Canada had not

performed organ recovery after a cardiac death in recent times. Emile Therien is not a man to be contradicted: "I am not," he says clearly, "just another pretty face." Although he laughs as he refers to his boyish good looks, he was a man on a very definite mission: he was determined to honour his daughter's decision to be a donor. Without going into details, Therien proudly affirms that he had to be a "little aggressive" in getting things moving.

Finally, the hospital agreed. Therien concedes that it was a very tense time when Dr. Joe Pagliarello and his Intensive Care Unit team were present at Sarah Beth's bedside and confirmed cardiac death. It was only then that the surgical team, led by Dr. John Mahoney, recovered the organs from his daughter, and gave them to waiting patients. However, when the word came that everything had gone well, and that the transplants were successful, "there were tears of joy. We felt so happy. We thanked Sarah Beth; we thanked God and we thanked the organ transplant team. We learned almost immediately that her kidneys had been given to two patients, both of whom are still living today."

In the middle of very trying and tragic times in the Theriens' lives, both parents are consoled by the knowledge that several other lives were saved by Sarah Beth's generosity. Emile and Beth's experience with Trillium Gift of Life Network (TGLN) has been, in their words, "a very powerful and rewarding relationship."

Today, Emile Therien is a very active volunteer for TGLN. He knows how difficult it is for a family to grieve the loss of a beloved family member and make a fairly quick decision about organ donation. He also remembers the family needed assurance that the withdrawal of life support was appropriate, and that organ donation would not be in violation of their Christian faith, a faith that influences and guides their lives: "We know that Sarah Beth is in the hands of God."

What distresses Therien is that Canadians seem to have a very limited understanding of organ and tissue donation: "Few people are well informed about the process of becoming an organ donor, and many people are simply not comfortable about discussing the issue with their families and friends. People assume that signing their driver's licence or a donor card will be enough. It is also very important that families be advised of one's wish to donate. Without question, public education and public awareness are critical. The need for donors is great. Advocates and the medical community can help, but all Canadians have to become foot soldiers for this very important public health concern. I know teenagers do not believe in mortality but, at the end of the day, we all die. So it is important that they become organ donors if the situation presents itself. They can save other people's lives. Organ and tissue donation really is the gift of life."

Manuel and Cecilia Castillo are eager to share their teenaged son Manny's greatest passion. "He loved sports, especially football and rugby; these two sports meant everything to him." In May 2007, Manny was playing a junior rugby game at his high school, Lorne Park, in Mississauga. During the game, Manny suffered severe head injuries. Although he was rushed immediately to the Hospital for Sick Children, the doctors could not save his life. The very talented, hugely popular, beloved son of the Castillo family died.

Manny's parents were devastated. Manny was just starting his life, and now it had ended. Cecilia, his mother, spontaneously volunteered Manny's heart so that it could be transplanted into a person who needed it. Nobody approached the family or suggested that they should donate organs. Cecilia took less than five minutes to make her offer; for her, the heart is the most important organ. It is the centre of the body and "I loved my son with all my heart." It was a logical emotional choice since she felt it represented the essence of what made her son unique. Shortly after her initial decision, the doctor who was looking after their son suggested that they speak with a person from the Trillium Gift of Life Network. "There was no pressure placed on us at all. We could choose. If we decided to say no, there was no problem with that choice. After reflecting on it, we decided to donate all of Manny's organs. They took his liver, heart, both kidneys, his pancreas and lungs." Because the names of organ donor families are kept confidential, recipients are allowed to write letters to Trillium Gift of Life Network; notes and cards that are then anonymously passed on to the donor families. The Castillos know that five people's lives have been transformed by their compassionate generosity. They have received letters from four of the recipients and, as far as the Castillos know, everyone is still alive after their transplant.

In speaking with Mr. Castillo, it is clear that the death of his son remains an open wound. He says that his wife, Cecilia, is comforted because "she knows that her son is still alive, alive in other people. She's happy with that." Both Manuel and Cecilia say they are also comforted by the legacy their son has provided to others through his death and his gift of organ donation. "Manny doesn't have the chance to choose the life he wanted, but now all his friends and schoolmates have the opportunity to choose the lives they want in their future. We hope they all make smart choices in their lives and be part of the legacy that Manny left to them. We know that after Manny died, several of them signed their donor cards and it's good to know that if younger people are inspired to sign their donor cards and share their donation wishes with their families, they can provide a lesson to their parents and encourage other adults to do the same."

At Trillium Gift of Life Network, staff speak about the gift of life. At a time in their lives when their most precious gift was taken from them, the Castillos still found it within their hearts to give that gift of life to strangers. Without stating it directly, it is clear that Mr. Castillo hopes that everyone will become a donor so that other lives can be saved as well.

over to you...

A. Journal Entry

Imagine you are one of Jason Edwards' parents or Jaynel White. Write an entry in your journal which describes how you felt and what you considered when deciding about donating Jason's or Dave's organs and tissues. Discuss your entry with another student who wrote about the same family.

B. "What If" Activities

You have now read stories of families who, during their darkest hours, made the decision to donate their loved one's organs and tissue so that others could be saved. In the case of Jaynel White's family – they made the decision to donate Dave's organs even when he died waiting for his own life-saving organ transplant. They saw through their own grief and frustration and made the decision to give others what Dave himself did not receive. In the case of Jason, he had signed his donor card, but had not informed his family.

As you have read, family members are the ones who ultimately consent to donating a loved one's organs and that decision is made easier when they know what their loved one wanted. Write down answers to the following scenarios and then check with your family at home to see if your assumptions were correct.

- If your family had to decide whether to donate your organs and tissue, what would they decide? Would their decision match your donation wishes?
- If you were asked to consent to donating a parent's organs and tissues, what would you decide? Do you know what your parents' wishes are? Think about other members of your immediate family. Do you know their wishes?

Write a statement to explain why it is so important for people to discuss their donation wishes with their families.

C. Create a Poster

Bill Morrison's life was rich and full. Not only did he create a powerful relationship with his wife, Susan, but he fathered two children, Alexander and Victoria. In death, Bill created even more life – for the people who received his organs and his tissues. Part of Susan's healing came from the knowledge that two blind people could see because of her decision to be a donor family. Now, in her work as an advocate for increased organ donation, Susan is part of a competition that is held each spring in Sarnia. Starting in the fall, high-school students are asked to prepare an art piece about organ and tissue donation – using oils, pens, and fine art coloured pencils, crayons or markers.

Judges – art teachers and local artists – choose the winners. A cash prize is given to the person who creates the most compelling visual request for organ donation. Sometimes, contestants include words in their posters: Organ Donation. Talk About It or The Gift of Life. Pass it On. The next step is the re-creation of the artworks into placemats, mats that are distributed and used in all the Lambton County restaurants each April. Each time someone sits down for a meal, he or she is invited to become a donor. Good idea. You can replicate the same organ donation campaign in your community, using the title of this curriculum "One Life...Many Gifts" for your promotional materials. Approach local eateries, and ask if they will use the placemats you create for one or two months. If you get agreement,

speak to the art teachers in your school, and see if they would assign the artwork as a class project. Or just do it yourselves; there is no necessary reason for the work to be done in an art class. This could be part of your community service volunteer hours.

D. Write a Slogan

Think of a slogan, a saying or an encouragement that could be placed on a button to promote organ donation. With the appropriate consents and permission, sell the buttons on a cost-recovery basis in the school cafeteria, in your local mall or in a hugely popular place where people like to gather. Your goal is not to make a profit; you are helping to spread the word that everyone can make a difference to the number of organs available for patients on waiting lists all over the province. If a profit is made, donate any funds to an organization dedicated to organ and tissue health, such as The Kidney Foundation of Canada, The Canadian Liver Foundation, The Heart and Stroke Foundation or the Canadian Lung Association.

E. Letter to the Editor

Emile Therien continues his commitment to the issue of organ and tissue donation by writing Letters to the Editor of various newspapers, and by preparing editorial comments for the Opinion Pages of Ontario publications. He also gives lectures to conferences and to small groups that want additional information. Write a Letter to the Editor, in which you capture the importance of communicating your donation wishes to your loved ones. Be sure to make your message and letter as powerful and concise as possible.

F. Write an Autobiographical or Biographical Article

On October 6, 2006, the Globe and Mail published Emile Therien's summary of his daughter's life in a section called Lives Lived. Read the description of his daughter's time on earth on the next page of this booklet. Then, prepare a Lives Lived for yourself, or for someone you know and care about. What would you say about the life you have lived, so far? Use the same format as the one utilized by The Globe and Mail.

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The Globe and Mail

Sarah Beth Therien Friday, October 6, 2006

Emile Therien, Beth Therien, Christopher Therien and Diana Therien Daughter, sister, aunt, niece, granddaughter, sister-in-law.

Born Nov. 1, 1973 in Ottawa. Died June 17 of cardiac arrest, aged 32.

Sarah Beth, a long-time employee of the Canada Safety Council, was often the person behind Elmer the Safety Elephant. In the massive mascot costume, she waved and danced, thrilling children who came to the Santa Claus parade and other community events. From babysitter training to motorcycle training to instructor certification, she certainly made a difference in the lives of those she worked to keep healthy and safe.

When new immigrants opened a hairdressing business in the neighbourhood, Sarah Beth was one of the first customers. She recommended it to others, and the owners credit her with helping them succeed in their new life in Canada.

Sarah Beth couldn't resist giving money to street people, but was also very astute in her personal finances. Her many kindnesses started at a young age. When she was in Grade 7, one of her friends was hospitalized for almost a year with a serious health problem. Every day, Sarah went to visit and encourage her. That young friend - now a mother happily married with two children - recently confided that if it were not for Sarah Beth, her young life probably would have ended.

Sarah Beth lived in a multiethnic, multicultural area in Ottawa. She often referred to that neighbourhood as "our little United Nations." She prided herself in knowing almost everyone. She boasted that the makeup of her neighbourhood represented the very future of Canada, making a great country that much greater.

In a twist of fate, just a week before she became gravely ill, Sarah Beth watched a documentary on organ donation. The program moved her to tell us: "Just so you know, I've signed a card." Organ donation can be difficult to discuss for a young, vibrant and healthy person. But she made it very clear: "If I'm gone, I want someone else to live." Who could have known how important this conversation was to be.

The family very much wanted to honour Sarah Beth's wishes to become an organ donor after the brief, sudden illness that placed her on life support. We approached an ICU nurse at the Ottawa Hospital and were told that brain death was the only criterion for organ donation.

Before making the independent decision to withdraw life support, we approached the health-care team about Sarah Beth's wishes to become an organ donor. The compassionate health-care team at the Ottawa Hospital and Trillium Gift of Life Network were determined to do their best to fulfill Sarah Beth's wish: She was always one to make things happen and they wanted to do the same for her. In this situation, donation after cardiac death (DCD) was the only option to make Sarah Beth's wish possible.

The work done to meet Sarah Beth's wish helped change the protocol and make DCD acceptable. DCD marks a new era for organ donation in Canada with the potential to increase donations by 25 per cent across the country. Shortly after her death, two people received her organs. They are now on their way to full recovery.

In many ways Sarah Beth was just an ordinary person. Sarah Beth loved hockey. She was a devout Philadelphia Flyers fan but she was never reluctant to rip them when they lost. She was obsessed with neatness and having a dust-free house. She loved to entertain and cook, to try any dish that was new or different. She never sought the spotlight; for her, helping other people was its own reward. Her final act of goodness was to give two people (and many more in the future) the chance to live healthy, full lives.

Emile and Beth are Sarah Beth's parents;

Christopher, her brother and Diana her sister-in-law.

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One Life...Many Gifts is a curriculum resource to educate senior secondary school students about the vital importance of organ and tissue donation and transplantation. It brings to life the drama, generosity and the life-saving promise of donation and transplantation.

Funding for this project has been provided by the provincial Ministry of Education and the Ministry of Health and Long-Term Care. This project would not have been possible without their support or the generosity of an anonymous Ontario resident whose contribution ensures that students in the province understand the life-saving promise of organ and tissue donation and transplantation. The Steering Committee sincerely thanks all of our supporters. The development of this curriculum has been co-sponsored and coordinated by the Trillium Gift of Life Network, the Multi-Organ Transplant Program at London Health Sciences Centre and The Kidney Foundation of Canada.

Educating secondary school students and their families about the need for organ and tissue donation and the success of transplantation was originally initiated in the London region in 2000. With funding received from The Kidney Foundation of Canada, the Multi-Organ Transplant Program at London Health Sciences Centre had the vision to develop a unit of study, One Life...Many Gifts, working with both the Thames Valley District School Board and the London Catholic District School Board. The original program was used in Healthy Active Living Education, Grade 11, Open (PPL30) in Ontario's curriculum. The curriculum resource before you builds on the vision and foundation provided by this original program and the Steering Committee gratefully acknowledges the dedication and pioneering effort of all those involved in the original program.

This curriculum is dedicated to the many Ontarians who have given the gift of life through the donation of organs and tissue and to the many others who will in the future.

For more information on the One Life...Many Gifts curriculum program please contact the Director of Communications, Trillium Gift of Life Network at 1-800-263-2833 or visit: www.onelifemanygifts.ca

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